

Seen but not heard: An exploration of the care journeys and experiences of children, their parents and CAMHS (Child and Adolescent Mental Health Services) practitioners after children are referred to CAMHS for reasons of suicidality.

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#### Gratitude

For me life is a journey and I try not to focus on the destination but enjoy the adventures and people along the way. I feel incredibly lucky to have had so many people in my corner supporting me along the way during my PhD. And although in danger of this being longer and more sentimental than an Oscars speech it is only because of the support of those around me that I have managed to achieve a finished thesis.

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I am completely indebted to all the friends and fellow mums who have had my back through this, looking after the boys, listening to me go on about how much I have to do, and encouraging me every step of the way. I can't tell you how much I appreciate it.

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#### Abstract

Suicide is the leading cause of death amongst children and young people in the UK. Children seeking help with suicidality are generally referred to Child and Adolescent Mental Health Services (CAMHS) for assessment and treatment. However, CAMHS across the UK are unable to meet the demand for their services. Little is known about how many children are referred for suicidality, or what happens to these children after they have been referred to CAMHS.

This mixed methods thesis sought to explore the journey of care for children referred to CAMHS for suicidality; capturing how this is experienced by the children, alongside the views of their parents and CAMHS practitioners. It endeavoured to provide insight as to what the children, parents and practitioners would find helpful.

The study comprised four main phases:

- 1. Literature reviews
- 2. A retrospective cohort study conducted in two different CAMHS in Scotland
- 3. A series of 27 qualitative interviews with children referred for suicidality, parents and practitioners working in CAMHS.
- 4. Overall narrative synthesis.

The retrospective cohort study found approximately one quarter of all referrals were for children presenting with suicidality, and the outcome of these referrals varied greatly between services. The qualitative interviews found most children and parents felt let down by CAMHS, and the service did not meet their needs even when they were seen. Staff were under pressure to deliver short interventions using a prescribed approach. Children, parents, and practitioners all prioritised the relationship with the child above the intervention approach.

The thesis goes beyond describing what happens, to present an overall interpretation: even when children who are suicidal were seen by CAMHS they did not feel heard. This was found to reflect not only the current CAMHS systems, but a dominant discourse that denies childhood suicidality in favour of a dialogue around distress.

# Definitions

The literature review phase identified that this field of research is complicated by variable use of definitions for behaviours associated with suicide (1), and the age range attributed to the terms adolescent and young people (2,3). For the purposes of clarity this study will employ the following definitions:

- Suicidal behaviour: Any form of self-harming behaviour motivated by suicidal intent. It may have a fatal or non-fatal outcome.
- Suicidal ideation: Having thoughts about suicide, which may include planning suicide.
- Suicidality: A term of reference that includes both suicidal behaviour and ideation.
- Self-harm: Any behaviour that causes self-injury, with and without suicidal intent.
   Most people who self-injure do not intend die and differentiate between self-harming and suicidal behaviours.
- Child: Anyone under the age of 18yrs.
- Young people: This term is used in the information leaflets etc. for children because older children may not identify themselves as children and will prefer the term young people. However, the study is only concerned with those under age 18 years, and the terms child or children are used throughout to refer to the population of concern.

#### Abbreviations

- AC Attention control
- ANOVA- Analysis of Variance
- ASD Autistic Spectrum Disorder
- CAMHS Child and Adolescent Mental Health Service
- **CBT-** Cognitive Behavioural Therapy
- CINAHL Cumulative Index to Nursing & Allied Health (electronic database)
- **CR-** Critical Realism
- cRCT cluster RCT
- CYP Children and Young People
- DataSTORRE- Stirling Online Repository for Research Data
- DBT Dialectical Behaviour Therapy
- DSH Deliberate self-harm
- EUC Enhanced usual care
- FET Fishers Exact Test
- **GDPR General Data Protection Regulation**
- GRADE Grading of Recommendations, Assessment, Development and Evaluation
- MBT Mentalisation Behaviour therapy
- **MI-** Motivational Interviewing
- NHS National Health Service
- NR Not reported
- NSSI Non-suicidal self-injury
- RCT Randomised Control Trial

SA – Suicide attempt

SH – Self-harm

SI – Suicidal ideation

- qRCT quasi–Randomised Control Trial
- UC Usual Care
- UNCRC United Nations Convention on the Rights of the Child
- UK United Kingdom
- WHO World Health Organization
- YP Young People
- Yrs. years

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# **Chapter 1: Introduction**

You do not have to look far to read or hear reports that the numbers of children who are thinking about, attempting, and dying by suicide are increasing. It has become a commonplace news story (4–7), the subject of investigative journalism (8–16), the outcry of children's charities (17–19), an issue highlighted by academic researchers (20,21) and government bodies (22–26). National statistics reveal the numbers of suicides amongst those under 25 yrs. has been continually rising since 2017, with a marked 22% rise in the year 2018 (24). Childline (a UK wide telephone counselling service for children) report that 67 children a day called their helpline in 2018/19 for help with suicidal feelings, and there was an 87% increase (from 2015/16) in calls from children under 11 yrs. seeking help with suicidal thoughts and behaviours (18). The problem is a global issue (27,28), as well as within the UK. Notably Scotland is reported to have the highest rate of suicides amongst children in the UK<sup>1</sup> (29).

However, alongside these worrying statistics and commentaries, we are told that child and adolescent mental health services (CAMHS) are *'not fit for purpose'* (30). In the UK 20-25% of referrals are rejected (31,32), and some children have to wait over a year to be seen (32,33). The number of these referrals that were made for children who are suicidal is unknown.

Before returning to academia to start this PhD I had spent my adult working life (almost 20 years) with children and young people who were often suicidal in front line services. I began working with young homeless people, and then female survivors of child sexual abuse, before setting up and delivering a service under Choose Life<sup>2</sup> for children aged 12-18 yrs., who were suicidal and / or self-harming. I went on to manage small therapeutic children's homes for children who had experienced multiple and complex trauma. I then managed the children's service at a Women's Aid Centre, before taking up post as a children's advocacy worker with ASSIST (Advocacy, Support, Safety, Information, Services Together)<sup>3</sup>.

<sup>&</sup>lt;sup>1</sup> Scotland has the highest rate of deaths by suicide across all age groups (24,496)

<sup>&</sup>lt;sup>2</sup> Choose Life was the Scottish Governments' national strategy and action plan to reduce suicide (575) (ref).

<sup>&</sup>lt;sup>3</sup> ASSIST is an independent advocacy service that works in partnership with the police, social work, and Glasgow Sheriff Court - Domestic Abuse Court.

Many of the children I worked with thought about and attempted suicide. Sadly, some went on to end their lives. I have countless stories I could share but choose not to, as they are not mine to tell.

Suffice to say that many of these children struggled to or were unable to access mental health support when they needed it. Referrals to CAMHS were often rejected with children and families left struggling and unsure where to turn. Children who were seen by CAMHS often did not engage with their workers, reporting experiences of a clinical and judgemental approach which they did not find helpful. Bearing witness to this process over a period of nearly twenty years and across four different health board areas, with very little change, I wanted to be able to find a feasible, alternative solution.

As many feminist academics before me have purported, the personal is political. The experiences of the children I worked with have shaped my experience and fuelled my quest to understand and address the problems they encountered. Suicide in children is a highly emotive subject, and I did not undertake this study lightly or because it was *interesting*. I was fully aware of how painful it is for children experiencing suicidal thoughts and behaviour, and the devastation and sorrow a child dying by suicide brings.

Although I knew from my experience what was often the plight of children referred to CAMHS for suicidality, there seemed to be very little academic research in this area. I identified a need to evidence what happens to children who present with suicidality after they are referred to CAMHS. Not only did I want to explore what their care journey looked like, but also how this was experienced by the children, and what the views of their families and the practitioners working in CAMHS were.

I was fortunate enough to be introduced to and taken on by my supervisor, Professor Margaret Maxwell, and with her support was successful in my application for an ESRC scholarship to fund this study and realise my ambition. The hope being that I could affect change in policy and practice through research.

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# **Chapter 2: Literature Review**

## **INTRODUCTION TO PHASE 1.**

The aim of this chapter is to bring together and present the literature reviews conducted in Phase 1. The findings of this review process identified many gaps in knowledge which directed the development of the specific aims of this study and methodological approach (Ch. 3). What is presented here is by no means testimony to all the available literature, but rather a focused attempt to contextualise this study, within what is already known, and unknown about children's experiences of CAMHS after being referred for reasons of suicidality.

The chapter is divided into three main sections demarcated by review method. It begins with a narrative literature review which broadly encapsulates what is known about child and adolescent mental health services approach to dealing with children who experience suicidality. This includes a brief history of CAMHS, child psychiatry, and psychology, as well as what is known about current referral rates in Scotland for children identified as suicidal. It moves on to consider what the research literature says about childhood suicidality, providing a brief description and critique of two main differing approaches: psychological and sociological. A summary of the qualitative literature pertaining to the views and experiences of children referred to CAMHS for suicidality, their parents and the practitioners working with them is then provided. The specific gaps identified across these reviews, were the lack of knowledge about how many children were being referred to CAMHS for suicidality, and the paucity of qualitative studies addressing the views and experiences of children, parents, and practitioners regarding their care and treatment by CAMHS. In essence, very little was found to be known about what happened to children after they were referred to CAMHS for suicidality.

Before proceeding with the development of the research study which would seek to explore what happened, it was important to consider what should happen (Part two: Policy addressing suicidality in children and young people: an international scoping review.). Little is known about how policy addresses suicidality in children and young people. Therefore, understanding how services are underpinned by policy in this area was explored with an international scoping review (34). The scoping review found policy documents offer little direction beyond suggesting children who present as suicidal are referred to CAMHS for assessment. Thus, mapping the processing of these referrals was also identified as knowledge this thesis could provide.

It was also important to understand what services could or should be delivering in terms of evidence-based treatments for suicidality in children. Many systematic reviews had already been conducted in this field, but this evidence had not been brought together with a specific focus on indicated interventions. The final section of the chapter (Part Three: Treatments and interventions for suicidality in children and young people: an overview of reviews) presents an overview of reviews, which found no high-quality evidence to support the effectiveness of any particular intervention in addressing suicidality in children. With no known successful treatments, it was vital for the study to capture what was helpful to the children and families using CAMHS for reasons of suicidality, and the practitioners' views on this. This could be a helpful first step towards developing more child-oriented suicide prevention interventions in the future.

The chapter concludes that despite the breadth of literature presented, there are still many gaps in knowledge concerning what happens to suicidal children referred to CAMHS, what the children (and parents/guardians) think of their experiences of being referred to CAHMS, and what CAMHS staff views are of dealing with suicidal children. This thesis seeks to specifically consider what happens to children who present with suicidality after they have been referred to CAMHS, and how this is experienced by the children, their parents and the practitioners who work within CAMHS.

## PART ONE: NARRATIVE REVIEW

#### Introduction

This part of the literature review was conducted non-systematically, although CINAHL, Medline, Scopus, and Web of Science were searched using broad base terms for papers relating to the various topic areas. Google, Google scholar, and key government and charity organisation websites such as UK GOV; Scottish Government; WHO; The Mental Health Foundation and Young Minds were also used to help identify literature.

#### Brief history of CAMHS (Child and Adolescent Mental Health Services)

Although CAMHS in the UK has been the focus of many government reports and task forces in recent years (31,35–39) little has been written about the history of CAMHS. Providing a full history of the development of CAMHS through legislative reform and societal changes is beyond the scope of this thesis; however, it is important to put in context the current provision and role of CAMHS.

Child and adolescent mental health services are a relatively recent establishment. Child psychiatry did not exist before the 19<sup>th</sup> century, and its development was intertwined with changing conceptions of childhood, and theories of child development. Previous beliefs about madness being genetically inherited were challenged as developmental psychology emerged post World War 1 (40–43).

Before the second world war mental health support for children was delivered in multidisciplinary child guidance clinics by individuals initially interested in helping children avoid juvenile incarceration (43). Following the second world war, and with the advent of the NHS (1948) these clinics had grown in an ad-hoc fashion (assisted by a grant from the Commonwealth fund), into a network of around 300 clinics across England and Wales (43). They were generally comprised of social workers, doctors, psychologists, and some psychiatrists working collaboratively with schools and other agencies. However, there were reported tensions between the different professions (43).

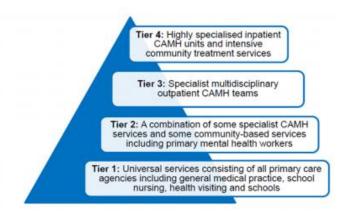
Although there were guidance clinics in Scotland, they were reported to be different from those in England as they tended to be led by psychologists as opposed to psychiatrists.

Psychiatrists in Scotland remained primarily hospital based until the 60's and 70's and there were very few dedicated to working with children (44). Although reportedly different (44), they were also disorganised and relied upon individual and local commitment (45).

Globally, psychiatrists from the time of the early child guidance clinics onwards, developed questionnaires to measure intelligence, and specific symptoms such as depression<sup>4</sup>. After World War 2, the World Health Organisation published the ICD 6 (International Classification of Diseases) (1949) (46) which contained classifications of mental disorders for the first time. The first *'Diagnostic and statistical manual of mental disorders (DSM-I)*' was published in 1952 (47). During the 1960's and 70's focus shifted from questionnaires to diagnostic interviews in an effort to improve the trustworthiness of psychiatric diagnosis (43). The DSM-III published in 1980 was the first version to include childhood disorders (47).

It was not until the publication of the Health Advisory Service report 'Together We Stand' (1995) (48) that formalised community child mental health services were established in the UK, based on the tier system we now know (45,49). The tier system stratifies access to mental health support services based upon the child's presenting condition. Specialist mental health services (tiers three and four) are reserved for children with *"severe, complex or persistent disorders"* (Burton, 2014; 3(13)). Tiers one and two are universal and preventative services delivered by a range of professional and not necessarily mental health workers (see Figure 1).

Figure 1: CAMHS Tier System



1. Scottish Government Mental Health Strategy 2017-27 (50)

<sup>&</sup>lt;sup>4</sup> For example, the Brent – Simon test (1905) was one of the first tests to measure mental age; the Wechesler Intelligence Test for children (1949) and questionnaires pioneered by Stanley Hall and Willam Haley followed (43)

Developments within child psychiatry, and psychology, and the growth of CAMHS<sup>5</sup> coincided with the development of conceptions of childhood as a period of innocence and children in need of protection (51,52). Throughout the 1990's and early 2000's important legislative changes and programs of investment into CAMHS continued, prioritising child and adolescent mental health (49). A legislative framework concerned with child welfare was evolving simultaneously (49). This was not unique to the UK; reports and guidance from the World Health Organisation (53–55), global and European children's charities and organisations (56,57) have continually called for improved provision and access to mental health services for children and contributed to the growth of child and adolescent mental health.

As the fields of child psychiatry and psychology have grown, an ever-expanding range of conditions in children have been recognised (58,59). This has not been without its challenges (60)<sup>6</sup>. The impetus to classify disorders continued to gain momentum from the DSM -111 onwards (60). The most recent version of the DSM- V (61) adopts a life span approach with disorders being organised around the age they may develop (62), and the specific chapter for disorders likely to develop in child and adolescence removed (61).

Child and Adolescent Mental health services, like other health provisions are also increasingly expected to utilise evidenced based practice (49,63,64). The World Health Organisation provides global guidance on a range of health issues covering the lifespan including mental health and wellbeing, for example, the WHO Mental Health Gap Action Programme (mhGAP) intervention guide which has a section dedicated to Child & Adolescent Mental & Behavioural Disorders (65). In the UK NICE publish good practice guidelines and recommended interventions for children that clinicians are advised to implement, on everything from depression (66) and ADHD (Attention Deficit Hyper-Activity Disorder) (67) to psychosis (68). The UK and Scottish Government also commission their own research to review the evidence and provide practice guidance (69–72). The result being child and adolescent mental health interventions are becoming increasingly more prescribed.

<sup>&</sup>lt;sup>5</sup> Sociologists have identified the social construction of childhood throughout the 20<sup>th</sup> century and considered this in relation to emerging theories of child development etc.

<sup>&</sup>lt;sup>6</sup> For example, during the 1960's-70's alternative views of mental health evolved, the conditions of mental health asylums were exposed and some psychiatric diagnosis were found to be unreliable. (61)

Demand for CAMHS services has continued to grow; the umbrella of child and adolescent mental health steadily widening (35). As a result, they are currently under immense pressure, with demand for their services exceeding capacity (32,33,39,73). One in five referrals to CAMHS in Scotland are rejected (31), in England one in four are rejected (74). Waiting times can be in excess of a year (32,33). There have been reports describing them as the 'Cinderella service', underfunded in relation to physical health services (75,76). Various reports and reviews have been actioned to consider the problem (31,39,71,77,78), although delivery of services and investment varies across as well as within the different countries that comprise the United Kingdom.

CAMHS in Scotland continues to operate the tier system and remain positioned as a specialist service, funded by the NHS. However, there has also been an increase in mental health support services in schools, and a continued shift in focus towards prevention, and early interventions (37,39). Recent reports suggest a re-design of mental health services will follow, making them more accessible with community based 'one-stop' service provision (37,39). This has yet to be realised and attempts to better manage referrals to CAMHS have had little impact so far. Referral numbers continue to grow, and although waiting times generally have decreased, children in some places (9/14 health boards) are still waiting more than a year to access CAMHS (79,80).

#### CAMHS Data

There is a paucity of reliable data from CAMHS generally, and in Scotland the lack of available information was identified as barrier to service re-design (81). Information Services Division (ISD) in Scotland collects CAMHS data from each health board (national workforce and performance data) which is limited to referral numbers and waiting times. Recent routine reports on waiting times indicate health boards are working to improve the accuracy of the data they provide to ISD (33). However, waiting times for CAHMS services across Scotland continue to be reported as excessively long. Information is still not routinely collected pertaining to the reason for referral. Therefore, the number of children who have been referred to CAMHS for reasons of suicidality and subsequently placed on a waiting list is undetermined.

In 2017, as a direct recommendation made in the 'National Mental Health Strategy' (82), ISD and SAMH (Scottish Association for Mental Health) were commissioned by the Scottish Government to conduct an audit of rejected referrals to CAMHS (31). ISD collected quantitative information from seven participating health boards (7/14) about referrals they had received and processed over one month (February 2018), whilst SAMH conducted an online survey, focus groups and telephone interviews with young people, parents and carers, GPs, and teachers. They found that 20% of all referrals to CAMHS were rejected. As part of the audit data set ISD requested information from the participating health boards about the reason a young person had been referred. They found there to be inconsistencies between the information provided by the boards, and that provided by children and families as to why a referral had been made. The data from the health boards showed 0.4% of referrals to have been made because of suicidal ideation, and 1.4% following self-harm, whilst suicidal ideation was one of the most cited reason for referrals being made by the patients and families, revealing potential discrepancy in the figures provided. The investigators themselves also query the reliability of the data they were provided (31). Whilst this audit provides valuable insight into the referral process overall and the extent of the problem in relation to rejected referrals from CAMHS, it does not adequately address the issue of quantifying the numbers of children who are suicidal or provide insight into the pathways of care they experience thereafter.

Also following the recommendation made in the 'National Mental Health Strategy', 2017 (82), in response to increased number of referrals to CAMHS (22% from 2013/14 – 2017/18) and increased waiting times on access to CAMHS, the Scottish Government commissioned a national audit of CAMHS services (81). Reporting on the efficacy of the delivery and funding of CAMHS across Scotland, they used mixed methods: utilising ISD routinely collected data alongside interviews and focus groups with patients and their parents / carers, senior staff, front-line staff, NHS managers and government representatives. Mental health support services were not found to be easily accessible to children and young people, with different services and protocols in place in different areas. This audit found there were large inconsistencies and variations in the funding, organisation, and delivery of CAMHS services across the country. They reported it was not possible to accurately quantify local health board spending on CAMHS services, and that existing data on CAMHS outcomes was deficient. Audit

Scotland described CAMHS as being under increasing pressure, with higher numbers of referrals and increasing waiting times.

Despite these recent audits (31,81) it remains uncertain how many children are referred to CAMHS for reasons of suicidality, and what their care pathways look like. Issues reported in relation to the reliability of the data provided to the auditors, alongside concerns about the pressures that CAMHS are under informed the decision in this thesis to undertake data collection in person, as it was not otherwise available. Screening the referrals independently for suicidality in two sites also allowed suspected inaccuracies in reporting to be clarified (See Chapter 4).

#### Childhood suicidality.

As was stated in the introduction the numbers of children who think about suicide, attempt to take their own lives, and indeed end their lives by suicide is said to be increasing. This has been identified globally, as well as within the UK (83–85).

As might be expected the numbers of children ending their life by suicide has varied over time, as well as between cultures. There is evidence to suggest the numbers of children ending their lives by suicide in the 16<sup>th</sup> century was higher than amongst the adult population (86). Another study in the USA showed that the rate of 15-24-year old's dying by suicide between 1900 and 1955 was on par with the rest of the population but started to rise thereafter (87).

Until the Suicide Act of 1961 (88), suicide was a criminal act, and consequently there were ramifications for deaths recorded as suicides amongst adults as well as children. Additionally, it had long been propagated to be a moral sin (89). Suicide was associated with stigma and shame (90), and as such, deaths by suicide amongst children were often concealed (91).

It is widely accepted that statistics may not accurately portray the extent of the problem. Under-reporting through classifying deaths as accidents, misadventure, or undetermined events, has been historically common (92). Sociologists (as discussed below) have long argued about the interpretative nature of statistics, and in particular suicide statistics (91,93,94).

The 'proof' required to evidence a death as suicide, and what can be classified as death by suicide has changed over time. Most recently there has been a change in the classification of

suicide to include undetermined deaths. The world health assembly adopted the ICD 10 in 1990 (95); these changes were implemented in Scotland until 2011 (25,96). The changes meant deaths by drug abuse / intoxication were now categorised as self-poisoning and classified as an undetermined death. (A newer version (the ICD 11 (97)) has since been adopted and will come into force in 2022; it continues to include unintentional deaths as verdicts of probable suicide).

Statistics on the numbers of child suicide deaths have not always been reported consistently or accurately (91,92,98,99). As described above, clearer guidelines exist today that attempt to overcome the under-reporting of suicides (ICD-10 (58)). However, even within the UK this is interpreted and implemented differently. For example, in England, although suicides for children age 10 years upwards are reported, only undetermined deaths in those over 15yrs of age are counted as suicide (24).

"Deaths from an event of undetermined intent in 10- to- 14-year-olds are not included in these suicide statistics, because although for older teenagers and adults we assume that in these deaths the harm was self-inflicted, for younger children it is not clear whether this assumption is appropriate." (ONS 2021, (24))

In Scotland, there are two reporting bodies (Scottish Suicide Information Database (ScotSID), and National Records Scotland (NRS)), both reporting the number of suicides in children differently.

"The number of 'probable suicide' deaths included in ScotSID differs slightly from the number published by National Records of Scotland (NRS). While both are based on the year in which a death is registered, this release of ScotSID uses the new coding rules (see Coding rules in Glossary). Additionally, unlike NRS, ScotSID excludes deaths of children aged less than 5 years. This is on the basis that deaths in this age group are more likely to be due to accidents or assault, and highly unlikely to be actual suicides. There were six such cases for deaths registered in the period 2011-2018. Finally, NRS includes non-Scottish residents in its analyses, but this release of ScotSID excludes this group." (ISD 2020, 70)

The compilation of statistics relating to the number of children who die by suicide remains bound up in values and attitudes. For many there remains a disbelief that children can understand what suicide really means (100). From this position, their death may then be interpreted as accidental. Opinion on this varies. The seminal study by Mishara, 1999 (101) is often used as a benchmark in relation to the age that a child can conceivably understand what suicide means, citing aged 8. However, the WHO (with many nations following suit) only record self-inflicted deaths in individuals aged 10yrs and over, without providing a rationale for this. The youngest child suicide recorded in the USA was a child aged 6yrs in Florida (102).

Although sociologists and historians have explored shifting patterns of numbers more fully, and societal attitudes to suicide more generally (89,103), there is a paucity of literature exploring childhood suicidality with the same approach. A recent study applying Rodgers ecological model to the concept of child suicide, explored different approaches to the topic within academic literature (104). However, this analysis was limited to published research. Overall, the construction of knowledge and representation of childhood suicidality is not static, nor limited to the academic domain and is an area requiring further research.

# Psychological theories of suicide

Psychological research has come to dominate the field of suicidology in recent times; developing theoretical frameworks to explain suicidal thoughts and behaviours as well as interventions to treat suicidality. Although in the main concerned with adult populations, psychologists have also attempted to use these approaches with children and adolescents. The overview of reviews included within this chapter describes these treatments and reveals there is no evidence for the effectiveness of any psychological treatment with childhood suicidality. The table below illustrates recent theoretical frameworks proposed by psychologists, some of which have recently been tested upon adolescents but with limited success (105).

First Author, Year	Theory	Description of main concepts	
Beck, 1967; 1974 (106)	Hopelessness	People suffering from depression have a reduced ability to feel optimistic about their future. An increased sense of hopelessness was found to be associated with more serious suicidal intent.	

#### Table 1: Psychological Theoretical Frameworks of Suicide

Shneidman, 1985; 1995 (107)	Psychache	Psychache is the term Shneidman uses to describe unbearable psychological pain that leads to suicide. Shneidman refers to people having different pain thresholds. Suicide is seen as a way out of intolerable pain, the individual cannot see any other possibility other than death.	
Joiner, 2005 (108)	The Interpersonal Theory of Suicide	Thwarted belonginess together with perceived burdensomeness can result in the acquired capacity for suicide (ACS). The capacity for suicide refers to an increased pain threshold and lowered fear of death.	Idea to action theories
O'Connor, 2011; 2018 (109)	Integrated Volitional Model (IVM)	<ol> <li>Three phases:         <ol> <li>Pre-motivational phase – biopsychosocial vulnerability factors and triggering life events / circumstances forming the background to suicidal thoughts</li> <li>Motivational phase – main drivers of suicidal ideation are defeat and entrapment.</li> <li>Volitational phase – individual moves from thoughts to action</li> </ol> </li> </ol>	
Klonksy, 2015 (110)	The three-step theory (3ST)	<ol> <li>Pain (psychological) and Hopelessness give rise to suicidal thoughts.</li> <li>Connectedness – to people / job / place /purpose. Without connections leads to strong suicidal ideation.</li> </ol>	
		<ul> <li>3) Capacity – disposition, acquired capacity, and practical means leads to suicidal behaviour.</li> </ul>	

Although these models may be helpful in considering some of the thoughts preceding suicide, none were developed specifically for children. There is evidence to suggest that the risk factors, and behaviours of children who are suicidal are different from older adolescents, and adults (111).

Psychological theories of child development have historically associated childhood suicide with abnormal development, although there has been a shift within this lens to identifying

factors that predict suicide in children (20,104,112,113). The overall concern for psychologists is to determine the cognitive cause of suicidal thoughts and behaviour within an individual.

Psychiatrists and psychologists have invested many years of research trying to predict suicide and identify categorical risk factors (114). Multiple questionnaires and tools have been developed and are used to assess an individual's risk of suicide (115), including some specifically for children (116). However, there is currently no evidence to suggest any risk assessment tool is effective (114,117,118). Additionally, a recent study found evidence to show that suicide in children and young people often happens without warning and in the absence of known risk factors (119).

## Sociology of suicide in children

As noted above, sociological literature concerned specifically with suicide in children is sparse, with few authors concentrating on this specific population (120,121). However, sociology has a long history of exploring the social causes and meaning of suicide more generally. There have been many reviews of this literature, with most contemporary authors concerned with their position in relation to their Sociological 'grandfathers' (103,122–124).

Durkheim, 1897 (93), although widely criticised now for his positivist approach, first used the topic of suicide to establish the need and usefulness of Sociology. He used suicide rates to show differences between societies, and social class groups within a society. Although a very simplified summation; Durkheim argued risk of suicide was related to social regulation, and the social structures of a society. He advocated that social structures and regulation offered some protection against suicide, whilst over regulation was identified as a causal factor (93). Social integration was argued to be equally potent in offering protection, or if lacking, escalating risk (103).

Douglas, 1967 (94) adopting a more Weberian approach (125,126) was concerned with the meaning of suicide, both within cultures and societies and as a social act (127). In his critique of Durkheim's theory (93) (which had been adopted and re-branded by many including the Chicago School 1920's – 50s (122,127), he brought into question the validity of suicide rates and use of statistics.

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Critical of both Durkheim, 1897 (93) and Douglas 1967 (94), adopting a social constructionist position Atkinson 1978 (91) considered how deaths became categorised as suicide. His investigations revealed the subjective nature of coroner reports and challenged over-reliance on statistical knowledge (103).

The discipline of sociology houses many different positions (128) and therefore many ways of approaching Suicide research (122–124). However, sociologists primary concern has been to consider suicide within the context of social, cultural, and economic factors, and to question its representation and conception within society. Differences between social and ethnic groups, genders, cultures, religions, and social classes, are explored and used to advocate against individualised, medicalised and illness-based approaches. Arguments of social constructionism, challenge what is known about suicide and how it is viewed (121,129).

Most recently, critical suicidologists, often adopting a post-structuralist position, continue to challenge the elitism of medical and psychological research in this field (130–132). These authors highlight the dominance of a bio-medical discourse in relation to suicide which pathologises it, locating the problem within the individual (130,133). Similar arguments emerged within the anti-psychiatry movement of the 70's (134), and among sociologists of mental health and illness more generally (135). Critical suicidologists also identify a publication bias within the literature toward quantitative research (136–138), and have sought not only to challenge this, but to develop networks of support for like-minded researchers (139).

Critics have suggested critical suicidologists have merely established themselves in opposition to the dominant sectors of suicide research (psychology and psychiatry) (103,127,140). It is proposed that such duality is unhelpful and does not support the development of new understandings of suicide that utilise all available knowledge. There are arguments for multidisciplinary working, and the promotion of both qualitative and quantitative knowledge, and for medical (psychiatry), psychological and sociological research studies to add to the existing knowledge base and research landscape (137,138). These views fit more comfortably with my own critical realist position which is discussed in full in Ch 3.

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#### **Qualitative Literature**

Identifying qualitative literature is recognised generally as often being problematic. Study titles are often metaphoric and not specific to the issue, thus not easily identifiable in database searches, and qualitative studies frequently remain in the domain of the grey or unpublished literature (141). There are multiple methods for searching and synthesising qualitative literature, and their application a research study in itself (142). Having conducted a meta-ethnography focusing upon the views and experiences of suicidal children and young people of mental health support services (143), immediately prior to starting this PhD, I was fully aware of the demands of the process. I was also aware that studies involving children who have been or are suicidal are uncommon. Perhaps not least because of the ethical challenges involved in accessing this vulnerable and hard to reach population (131,144). Preliminary searches for literature on parents and practitioners' viewpoints revealed a similar gap in qualitative research in this area. This informed my decision to briefly summarise the findings of my meta-ethnography, alongside the slim literature identified pertaining to parents and practitioners' perspectives and focus on addressing this gap in primary research rather than conducting further full evidence synthesises for studies involving parent and practitioners.

The meta-ethnography I conducted for my masters dissertation, focusing upon the views and experiences of suicidal children and young people of mental health support services found only 4 studies that met the inclusion criteria (143). Common reasons for exclusion were - the sample population was mostly adults, or it was the wrong topic / methodology. A systematic approach to searching the literature was used, and although I had believed a large literature base to exist, a paucity of research was identified pertaining to children (under 18 years).

The meta-ethnography (143) found that children and young people (CYP) do not know what mental health services are available and find them difficult to access. Additionally, CYP who are seen by mental health services want to be taken seriously but often do not feel listened to by practitioners. A potential silence around suicide was identified, both within conversations between practitioners and CYP, and within the academic literature itself. There was an absence of references to suicide even within papers identified as pertaining to this issue. It was suggested that use of the term 'self-harm' to include 'suicidal behaviours' may be contributing to this silence as it removed the term 'suicide' from the discourse.

Although full systematic searching of the literature was not conducted for studies which consider the views and experiences of the parents of children who present to mental health services for reasons of suicidality, preliminary searches using combinations of broad base search terms such as "suicide", "parents", "children", "views", "perspectives", "experiences", "CAMHS", "mental health support services" etc. (Google, Google scholar, Medline, CINAHL, Web of Science) indicated there is a lack of published research in this area also. Of the literature that was identified very few studies were of parents whose children had been specifically suicidal (15,145,146) whilst others included parents of children for whom deliberate self-harm (which included suicidal behaviour) was the presenting issue (147–150). There was also appeared to be a body of literature exploring the experiences and perspectives of parents of children using mental health services more generally (151–153)

The few studies identified, suggested parents of children who think about or attempt suicide need help to understand and support their child (145) and there is a lack of information and advice available to them (146,149). These studies show that parents often feel isolated, unsure of how best to care for their child at home and keep them safe from suicide (15,146,148,150).

Although the literature presented similar themes, it had been conducted in a variety of settings and was not particular to the UK. (South Africa n=1 (145); Ireland n=2 (148,149); USA = 2 (15,146); Denmark n=1 (150). One study reported a sampling bias, with all the parents interviewed being female (145), although gender and ethnicity was unreported in most (15,146,148–150). The age range of the children varied, one study included adults up to 34 yrs. (150) but was unspecified in n=2 studies (15,145). No quality assessment of these studies was conducted however reporting appeared to be poor.

Again, although a full systematic literature review was not conducted for studies pertaining to the perspective of practitioners working with children who present as suicidal, from the preliminary searches conducted, this also appears to be an under-researched area. Similar to the non-systematic search strategy described above combinations of broad-based terms ("practitioners", "CAMHS", "workers", "children", "suicide", "views", "perspective", etc.)

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were used to search platforms such as Google and Google Scholar, as well as databases like Medline, CINAHL, and Web of Science.

A meta-synthesis by Lachal et al. (154) (identified during the meta-ethnography search) included only six studies concerned with practitioners views of working with children or young people who are or have been suicidal (155–160); three of which were papers by the same author from the same study (155–157). The others were only loosely relevant to this thesis: one was concerned with how practitioners engaged with the parents of potentially suicidal adolescents (159); one explored psychology students in Ghana's attitudes towards suicide more generally (158); and one was an evaluation of an Applied Suicide Intervention Skills Training Program (ASSIST) as utilised by public health nurses working with adolescents (160). The synthesis by Lachal et al. (154) presented that the child's desire to die was '*incomprehensible*' to professionals, and this prevented them from being able to empathise with the child / young person.

Only a few qualitative studies specific to the views of practitioners who work with children or young people presenting as suicidal were identified (155–157,161,162). However, most were by the same author (Anderson et al 2000; 2003; 2005; 2007 (155–157,161). In general, the studies identified seemed to focus upon practitioners' attitudes towards children and young people who are suicidal, as opposed to their experiences of trying to support them. Medical staff were found to associate suicidal behaviour with mental illness, or as a '*cry for help*' (161), and in general suicidal behaviours were stigmatised (163).

Overall, the paucity of literature on children's, parents, and practitioners' views points to the need for more primary research in this area and will be a focus of this PhD study.

This narrative literature review identified many areas where further research could be beneficial. However, the priority areas for this thesis were to provide new knowledge about children being referred to CAMHS for suicidality and what happens to them thereafter, and to explore their perspectives of what happens as well as parents, and practitioner's views. Before proceeding with methodological considerations and the development of a study design it was important to investigate what should happen, and if there were any recommended treatment approaches that were found to be most effective. Thus, the remainder of this chapter is dedicated to presenting the reports of a scoping review of international policy documents and an overview of systematic reviews of treatments and interventions for childhood suicidality.

# PART TWO: POLICY ADDRESSING SUICIDALITY IN CHILDREN AND YOUNG PEOPLE: AN INTERNATIONAL SCOPING REVIEW.

International and government policies establish the context for the direction of resources for the development and delivery of services. Health policy provides a future vision (internationally, nationally or regionally), sets priorities, and can include an action plan to achieve specific health related objectives (164). Public policies reflect international or national commitment and ambitions to address specific issues, but can vary in whether, and how they translate or relate to practice and whether there is a mandate for action.

Many countries commonly address the health needs of children and young people separately to adults, with discrete policy and service provision, although definitions of what age range constitutes being a child, adolescent or young person varies greatly (165). However, with most suicide prevention and mental health strategies now taking a universal approach, there is the potential for the specific needs of children and young people to become lost.

Fortune and Clarkstone (38) highlight the gulf that can often exist between suicide prevention policy and practice. They argue that although policy documents in New Zealand state that every-one who is suicidal should be assessed by a trained mental health professional, services are not adequately resourced to meet the demand. This is not unique to New Zealand, or to suicide prevention policy. The overall political context and policy agenda needs to be analysed in greater depth in order to make sense of the meaning conveyed within policy documents, and attributed to them (166).

Little is known about how policy addresses suicidality in children and young people. Preliminary searches of review databases (Cochrane, DARE, JBI, and the Campbell Collection), found there had not been a review of worldwide policy in relation to children and young people who are suicidal. Reviews to date have focused upon the effectiveness of prevention and intervention strategies (167,168). Although generating valuable knowledge on the evidence base for interventions, they do not consider the policies behind such strategies and how this shapes their focus and direction.

Mapping key policy documents world-wide and identifying how they address the treatment and care needs of suicidal children and young people will support an understanding of what policy documents should happen in the treatment and care of children who present as suicidal. It will highlight best practice for how policy can influence the resourcing of services; change practice; and identify any gaps in policy provision for this vulnerable population. This knowledge will support countries who wish to develop new policies or further develop existing policies that address suicidality in children and young people.

The review question, objectives, search strategy, and inclusion criteria were specified in advance and documented in a published protocol (169). Although I carried out the research tasks, and wrote the final report, this review was conducted with support from my supervisors to ensure rigor (see methods below) and was published (34) (Appendix 1: Copy of published policy scoping review).

#### Objective:

To map key policy documents worldwide and establish how they address the treatment and care needs of children and young people who are suicidal.

#### Methods

#### Inclusion Criteria:

#### Population

The key characteristics of the population were age and suicidality, neither of which have agreed universal definitions. As mentioned in the introduction the authors recognise the disparity between the needs of children and young adults. Youth suicide research publications often tend to focus on older adolescents and young adults. Whilst appreciating the complex challenges, including transition from child to adult services faced by 16-25-year-olds, this thesis is concerned specifically with a Scottish school aged population (children under 18 years). On this basis it was agreed to adopt a definition of a child as anyone under the age of 18 years, in line with: The Children (Scotland) Act 1995 (170), and the UNCRC (United Nations Convention of the Rights of the Child, 1998) (171). Policies solely about populations aged over 18 years were excluded, however policies that cover the lifespan were included.

Suicidal behaviour is defined as acts of self-harm that result in death, as well as those with a non-fatal outcome. Non-suicidal self-injury is a term used to describe self-harming behaviour where there is no intent to die. This is most commonly used in the USA and became a discrete

diagnostic category in the DSM V (172). However, in the UK and some other European countries definitions of self-harm are now also often used to include all non-fatal self-harming behaviours regardless of intent, and can include behaviour that may also be described as attempted suicide (173). As this review is concerned with identifying relevant policies for children who are suicidal (had attempted to end their own life or were thinking about suicide), it was agreed not to use the term self-harm as a search term.

#### Concept

Suicide prevention activities can be divided into three domains: universal activities which are aimed at everybody, including public health education programmes; selected or targeted interventions that aim to reduce the risk amongst specific high-risk groups; and indicated interventions that may include treatments and are aimed solely at individuals presenting with suicidal behaviour. This review is solely concerned with identifying policy in relation to indicated activities, aimed at children (under 18 years of age) who are suicidal.

#### Context

Identified policy documents were assessed for direct relevance to Scotland and the UK, or relevant to the context and population of the UK. Policies relating to indigenous populations such as the Sami populations in Norway, Sweden and Finland, were consequently excluded (174); but generic policies in post-industrial nations with developed economies such as Australia, and New Zealand were included (175,176).

#### Types of Sources

Suicide prevention, like much health care policy, does not sit within clearly defined and labelled singular policy documents. As well as national suicide prevention strategies, there are more generic mental health strategies or frameworks, and national guidelines such as those published by the National Institute of Clinical Excellence (NICE) in the UK, which may contain specific references to indicated intervention approaches. Mapping policy requires a recognition of the variety of formats in which relevant documents may be found. Local government agencies and organisations also have their own individual policies and procedures; however, these should reflect the national approach. It was agreed that for the purposes of this review, policy documents would include: policies, policy guidance, strategies,

codes of conduct, national service frameworks, national practice guidance, and white and green papers (177). Reviews of policy documents centred on children who are suicidal were also eligible for inclusion as they contribute to the development of what is known in this area.

Given that the review aimed to map the present policy context, and most strategies are updated within a ten-year period, it was agreed to exclude any policy document or review published prior to 2000. Only those available as English Language versions were included.

#### Search Strategy

Key words to be used as search terms (Table 2) were generated from the review question (169). Preliminary searches assisted in the refinement of these terms, and the identification of the most appropriate databases, platforms, and websites. These terms were then amended for each of the databases and the exact terms, including any MESH terms and subject headings used recorded. (Available at

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6830632/bin/bmjopen-2019-030699supp001.pdf )

Concept	Keywords							
Children and Young People (5-	Child*; "young people"; youth; adolesc*; teen*;							
18yrs)	paediatric							
Suicide	Suicide; suicidal;							
Policy	Policy; Procedure; Guidance; Strategy							
LIMITS	English Language; Published after 2000.							

Four databases (CINAHL; Medline; Psych info; The Cochrane Database of Systematic reviews) and the websites of the following key government, statutory and non-statutory agencies were searched, focusing on post-industrial nations with developed economies in order to identify those with most applicability to the UK: - for example, WHO; UNICEF, UK Government; Scottish Government; ScotPHO; NICE (UK National Institute of Health Care Excellence); National Office of Suicide Prevention (Ireland); Ministry of Health NZ; Australian Government Website; and the Mental Health Commission Canada. Google, and Google Scholar were also

used to identify other policy documents and any relevant grey literature. Leading experts in the field were consulted via email (e.g., Scottish Government, World Health Organisation) and were asked if there were any relevant policies we should consider including, and about the availability of international policies in English language.

All results were screened by title and abstract or executive summary by LG, with MM and ED screening a sample of 20%. Policy documents and articles were all screened in full by LG, and another sample of 20% was independently screened by MM and ED for inclusion. Disagreements were resolved by discussion, with the third reviewer acting as mediator.

## Method of the report

This review employed scoping review methodology to systematically identify relevant key policy documents following a pre-established search strategy and published protocol (169). Scoping review methodology and guidance first outlined by Arskey & O'Malley (178) and further developed by Levac, (179), and the Joanna Briggs Institute (180) were used to inform the methodological process. The scoping review method was chosen as it allows for the synthesis of different types of study design. Thus, lending itself to the incorporation of different policy document formats (policies, policy guidance, strategies, codes of conduct, national service frameworks, national practice guidance, and white and green papers (177)) as well as any relevant existing published policy reviews. Suicidology of children and young people is a newly emerging, highly sensitive and complex area of research, therefore well suited to scoping review methods (178). The review is reported in line with the new PRISMA extension for Scoping Reviews (181). Patients and the public were not consulted as part of this scoping review as it was not appropriate or applicable.

There were 43 records retrieved from Psych-info, 193 from CINAHL, 12 from Medline and 49 from the Cochrane database of systematic reviews. After removing duplicates there was a total of 297 records to be screened by title and abstract. Separate Excel spreadsheets were set up to catalogue the lists of references from each of the databases. After screening these results by title and abstract (completed in full by me with a second reviewer independently screening for validity) all 8 records to be screened in full text were found on CINAHL, although 2 were also found in duplicate on Psychinfo. Reasons for rejection of records included wrong topic, not in English, and published before 2000.

After screening the 8 articles identified by searching the databases (cross validated by a second reviewer) only 2 met the inclusion criteria (182,183). Five were rejected as they were not policy documents about children and young people who were suicidal, and although one seemed relevant in its references to the New Zealand suicide prevention strategy (38), it was neither a policy document, nor a review of policy.

Internet searching was an iterative process, using keywords to search worldwide government, statutory and non-statutory agencies websites, with 39 potentially relevant policy documents identified. Although it is common practice in systematic reviews to screen the references of included documents for other potentially relevant papers, this occurred intuitively throughout the identification of policy documents, with one referencing others within a country. Policy documents were only included for screening if by their title and description they seemed potentially relevant.

The World Health Organisation (WHO) Mindbank database houses links to member states National Suicide Prevention Strategies, however, many were unavailable in English. The WHO mental health policy and services representative was contacted to request contact details of policy authors or country specific contacts to enquire about English language versions. From these enquiries an English language brochure outlining the content of the Swedish Suicide Prevention Strategy (known to be innovative for its zero suicide target) was obtained but we were unable to access the full document (184). Although it was recognised that not every worldwide policy relating to CYP who were suicidal could be sourced, it was important to try and include all Scottish and UK wide relevant policies. A request to the Scottish Government asking them to detail policies that should be included in the review, identified one further policy that had not been considered (185) , and this together with a related practice guide (186) were included for screening.

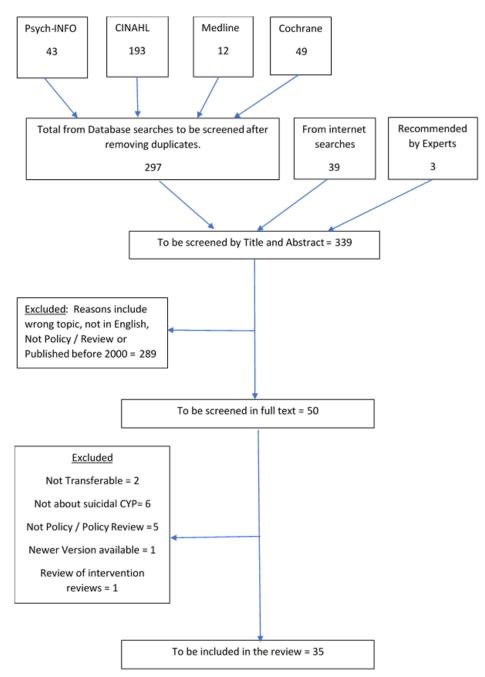
Screening of the 42 full text documents was completed in full by the first reviewer (LG), with second reviewers each reviewing 5 independently (ED; MM), meaning a total of 25% was cross - validated. A meeting was then held to discuss the policy screening process, and to agree decisions about inclusion and exclusion. There were 32 policy documents that met the inclusion criteria. Reasons for exclusion were - the document did not relate to or mention child suicidality; was not transferable to the UK or Scottish setting; was a review of systematic of document reviews; а newer version the is now available

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(<u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6830632/#SP2</u>). Together with the 3 published miscellaneous reviews / reports (187–189), there was a total of 35 documents identified to be included – shown in the PRISMA diagram below (190).

## Results

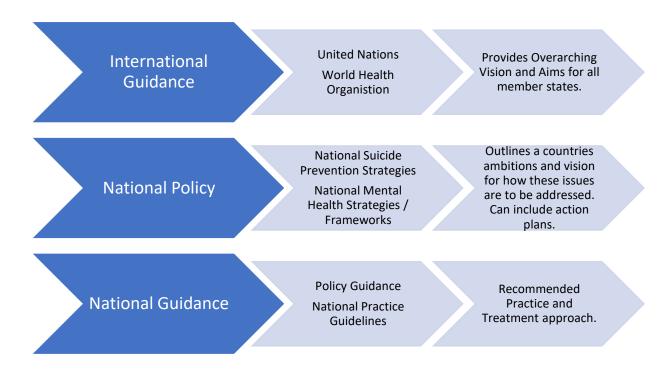
Figure 2: PRISMA Diagram (190)



The 35 included policy documents, ranged from: international guidance provided by the United Nations and World Health Organisation (65,191–193); national suicide prevention

strategies (176,184,194–201); mental health strategies (82,202–206); and frameworks (77,207–210); to national practice guidelines detailing how children and young people who are suicidal should be assessed and treated (173,183,211–214). The organisation and classification of these documents is illustrated in Figure 3 below; providing language with which to describe the policy landscape.

Figure 3: Classification of Included Policy Documents



I completed data extraction using a predefined template (see

<u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6830632/#SP3</u>) to collate key information about each of the documents including its aims and objectives, and how it related to the review question. A second reviewer independently extracted data for a sample of 25%. All three reviewers then met to discuss the process, and outcomes. There was some variation in the verbatim content extracted. This was regarded as a reflection of – (1) the size of the policy documents, and (2) because there were so few direct references to suicidal children, other content that could be interpreted as applicable but did not specifically mention suicide was also extracted from some to give context. The data extracted from each of the included policy documents were then tabulated (Appendix 2: Table mapping included policy documents) categorised first by policy type, and then alphabetically by the country.

#### International Guidance

The UN 2030 Agenda for sustainable development (191) details the goals and action plan that all countries in the United Nations have agreed to deliver. Although it does not specifically mention suicidal children and young people, reducing mortality by non-communicable illness (Goal 3.4) means that reducing suicide, which as a leading cause of death, must be a priority.

The WHO 'Mental health action plan 2013 -20' (215), set a target that all countries should work towards reducing suicide rates by 10% by 2020. It recommended that countries adopt a life-course approach to mental health, reflecting an understanding of the impact of key stages in people's lives upon health outcomes across their life span (216,217). It promotes that countries create national policies and strategies to tackle suicide prevention prioritising at risk groups including "youth". However, other than the identification of "youth" as a priority group it does not provide any other guidance on how countries should address suicidal children and young people specifically.

Two other included documents published by the WHO (65,193), although also identifying suicidal children and young people as a priority group, similarly do not go beyond this in terms of how their needs should be addressed. The WHO 'Mental Health Gap Action Programme (mhGAP) intervention guide' provides generic guidance relating to interventions for all persons aged 10yrs and over who are suicidal, suggests suicide should be included within an assessment, and advises that if young people feel suicidal they should talk to someone they trust and return to mental health support services (65). No rationale is provided as to why 10 years of age has been selected. It does not differentiate between the assessment and treatment approach for suicidal children, and adults. Clarification on this point was sought from the WHO, but no response was received.

#### National policy

The World Health Organisation recommends that countries should develop suicide prevention and mental health strategies (192,193). Ten suicide prevention strategies were included in this review (176,184,194–201), five national mental health strategies and a young person's friendly version of the Canadian mental health policy (82,202–206). As recommended by the WHO (192) the suicide prevention strategies adopt a universal and life-course approach. They generally provide demographic background information on suicides

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within their country and establish why it is a priority area. The policy documents describe their government's approach to tackling suicide by detailing lists of aims, objectives and recommendations. Most strategies recognise that children and young people are a priority group for universal and targeted suicide prevention activities (for example, universal whole school-based suicide prevention programmes and generic school counselling services). However, they do not differentiate between the indicated assessment and treatment offered to adults and that available to children who are suicidal. Some strategies made no reference to suicidal children and young people (176,194,200), including the Scottish 'Suicide Prevention Strategy 2013-2016' (200). Few mentions of therapeutic interventions specifically for children and young people who are suicidal are made in the strategies. The Irish strategy includes statements recommending that there should be early intervention, and 'enhanced support' available (197). The New Zealand draft consultation document (198) contains suggestions that training teachers to talk to children who are suicidal, and having direct links between schools and psychologists will improve access to support for CYP who are suicidal. Notably New Zealand previously had a suicide prevention strategy directed specifically at 'youth' suicide (218), but they have since adopted a universal policy covering the life course (176). Similarly, other countries such as the USA previously had a strategy document that contained detailed objectives directly related to children and young people (youth) (219) and has moved towards a much more generic approach (199).

National mental health strategies were also found to take a life course approach and were concerned with mental health promotion, supporting positive mental health and well-being and service delivery for those who experience mental ill health. The ten national mental health strategies included in the review incorporate references to discrete service provision for children and young people. Beyond generic school-based approaches to promoting positive mental health and well-being, there was also a focus on early intervention and easier access to child and adolescent mental health services.

Although most strategies refer to suicide as being a priority area in mental health provision; the Irish national mental health strategy (205) is the only one that specifically mentions suicidal children and young people. Within a section dedicated to child and adolescent mental health under a heading 'Suicide and Deliberate Self-Harm' (205), it has recommendations that all children who present with self-harm should be assessed by the child and adolescent mental

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health team, and if appropriate receive treatment. It contains statements recognising adolescence as being a period of increased risk of suicide, and notably conveys that service provision should be the same across the whole country.

The Canadian 'Mental Health Strategy: A Youth Perspective' (203) was produced to allow the document to be more accessible and relevant to young people. Although it does not provide specific recommendations in relation to the treatment and care of children who are suicidal, it urges that mental health services should be more accessible to all and highlights the Thunder Bay Youth Suicide Prevention Task Force as an example. This task force comprised of 30 organisations working collectively to provide an immediate response.

The UK government policy 'No Health without mental health' (204) highlights the high incidence of self-harm amongst young people providing as an example that "10–13% of 15–16-year-olds have self-harmed in their lifetime". It includes a suggestion that all workers who are in contact with children and young people should be aware of the issues surrounding this, and sets reducing the numbers of people of all ages who harm themselves as a target. However, the document does not contain a definition of self-harm in the glossary, and it is unclear if this suggestion includes those who attempt suicide. The policy contains no specific references to children and young people who are suicidal.

The Scottish Government 'Mental Health Strategy 2017-2027' (82) has a dedicated section to addressing the mental health needs of children and young people. However, there is no reference to children and young people who are suicidal. In relation to suicide, the strategy includes a statement that suicide prevention remains a government priority that will be dealt with separately (the Scottish Government's 'Suicide Prevention National Action Plan' (22), which was published following conclusion of the scoping review search – see discussion).

Child and adolescent mental health services are delivered separately from adult services in many countries; consequently, there are distinct policies articulating a country's vision and aims for children and young people's mental health. There are five such policy documents (77,207,209,210,220) included in this review, entitled as frameworks. The term 'frameworks' suggests they provide guidance for local authorities and those commissioning and delivering services; in the UK it also denotes that they define standards of care. These frameworks include an outline of goals to prioritise and promote the mental health and well-being of

children and young people, and to deliver accessible services. None, however, specifically address children and young people who are suicidal. Although containing recommendations for improving access to services and crisis support which could be applicable to children and young people who are thinking about or have attempted suicide, this is not explicitly mentioned.

#### **National Guidance**

Another category of documents included in the review were national clinical guidance. These documents contain evidence-based recommendations for good practice. Although it is not compulsory to follow guidelines, organisations and clinicians must be aware of them and potentially justify their decision making should they choose to not implement them. Included clinical guidelines were: the UK NICE (Institute for Clinical Excellence) 'Guidelines for Self-Harm in over 8's: short term management and prevention of recurrence' (173), Self-Harm in over 8's long term management and prevention of recurrence (213), the New Zealand document: 'The Assessment and Management of People at Risk of Suicide' (212), the United States Preventative Task Force recommendations (183), and the American Academy of Paediatrics Guidance (214). The Irish 'National Standard Operating Procedure for CAMHS' (221) was also included in this category, because it was a national document and specifically addressed the treatment and care needs of suicidal children and young people. However, it was different to the other documents in this category because its implementation is compulsory.

The UK NICE guidelines for 'Self-Harm in over 8's: short term management and prevention of recurrence' (173), apply to everyone over 8 years of age who presents following an incidence of self-harm, defining this as any act of self-harm regardless of intent. Therefore, these guidelines are applicable to anyone over 8 years who has attempted suicide; although, it does not differentiate between the behaviours (with or without suicidal intent) in relation to treatment. They cover the immediate period following a presentation of self-harm (48hrs). The guidelines contain recommendations that all children and young people who have self-harmed are admitted to hospital overnight in a paediatric ward (including adolescents aged over 14yrs of age, if this is their preference) and they should be assessed by a specialist in child and adolescent mental health. This assessment should be the same as that for adults but also include a holistic assessment of their family situation, education etc. The only direct

mention of suicide is that it is listed as a factor to be assessed. In the document that follows from NICE, Self-Harm in over 8s long term management and prevention of recurrence (213), the same definition of self-harm (to include self-harming behaviours with suicidal intent) is provided, and although suicidal intent is mentioned in relation to assessing risk, it also warns against using risk assessment tools to assess suicide risk. This reflects the lack of evidence for their effectiveness (222,223). In the final recommendations section under 'Access to Services' (213), it states children and young people who self-harm should be able to access all therapies and treatments available from Child and Adolescent Mental Health Services.

The New Zealand guidelines (212) are explicitly in relation to managing (all) people at risk of suicide. This document includes statements that all persons who are suicidal should be taken seriously and has a section dedicated to the treatment of children and adolescents. It includes recommendations that risk assessment of suicidal children and young people should be conducted by someone trained in working with them, and that they should draw on information from the people around the child such as family and teachers etc. as well as the child or young person themselves. In the background information provided in the document it is stated that New Zealand has one of the highest rates of suicide amongst young people.

The USA document 'Screening for Suicide Risk in Adolescents, Adults, and Older Adults in Primary Care: U.S. Preventive Services Task Force Recommendation Statement' (183) includes a statement reflecting that there is no evidence to support any particular treatment or intervention for adolescents at risk of suicide, and not enough evidence to support assessment tools. The American Academy of Paediatrics however, publish very specific guidance for the treatment of adolescents presenting to primary healthcare following a suicide attempt or presenting with suicidal ideation (182).

The 'National Standard Operating Procedure (SOP) for CAMHS' in Ireland (221) was unique in that it specifically included standards of expected care and treatment for children and young people who are suicidal across Ireland. It contained a statement that CAMHS would accept referrals for children and young people where there are suicidal behaviours, and intent. Similarly, to what was found within the other frameworks for child and adolescent mental health that were included in the review, this document (221) also included general statements about service provision that could be applied to children and young people who are suicidal, for example, references to children and young people who need an immediate response, however the term suicidal is not specifically used.

Beyond the policy documents included (international policies, national policies, and national frameworks), there were very few other reports or reviews that were identified as relevant to the review question. The report 'Responding to Self-Harm in Scotland' (188), is the report from the national self-harm working group and recognises that most people who self-harm do not intend to die. It includes a statement that young people are more likely to self-harm. One of its key recommendations is that there are clear referral pathways developed for people who self-harm, but it does not suggest what this might be, and is not specific to, or does not differentiate, between child and adult populations. A report commissioned in New Zealand to review the evidence on improving the outcomes for adolescents transitioning to adult services has a chapter dedicated to youth suicide (189) which aims to provide an overview of the issue and prevention strategies. This chapter includes a description of how its national suicide prevention strategy and each of its goals applies to young people. The author concludes that the actions from the strategy can be applied to young people, albeit they are not specific to this population.

#### Discussion

This scoping review sought to answer the question: how does policy address the treatment and care needs of children and young people who were suicidal? A total of 33 policy documents and two reports were included. However, overall, they offer little in relation to specific policy guidance for addressing suicidality in children and young people. Suicide prevention strategies recognise that children and young people are a priority population. The focus of these strategies is primarily upon universal prevention approaches for children and young people, such as whole school-based mental health and well-being education programmes, or generic counselling services. Both national mental health strategies across the lifespan, and national frameworks for children and young people's mental health, provide a blueprint for delivering services that are accessible to children and young people who need them, when they need them. However, they do not specifically mention the population of children who are suicidal clearly enough to establish explicitly the care and treatment that they should be provided with. They also do not guarantee that the strategies or frameworks are delivered.

The national guidelines included within this review contain suggestions that CYP who are selfharming, or are suicidal, should be assessed by a child and adolescent mental health practitioner, and referred to CAMHS for treatment and therapeutic interventions. However, the included national frameworks for child and adolescent mental health barely reference children and young people who are suicidal.

Recent research has found that even when there are national clinical guidelines recommending practice in relation to suicide intervention and treatment, clinical staff teams are not always aware of these, and implementation varies (224). This strengthens the case for countries adopting a model, like that in Ireland, where implementing the 'Child and Adolescent Mental Health Services SOP' (221) is compulsory, and goes beyond guidelines for recommended practice.

One of the reasons for the identified paucity of policy direction in providing interventions and treatments for children and young people who are suicidal, is perhaps the lack of evidence for the effectiveness of any particular treatment approach (225,226). Carol Bacchi (227,228) suggests, policy documents articulate and create societal problems by naming and defining them, and it could be that by not specifically naming childhood suicidality the 'problem' is denied or at least not acknowledged to exist. This could be because as the overview of reviews that follows shows, there is no straightforward, evidenced based treatment that can be offered to individuals. The current climate of evidence-based policy, emerging from evidenced based medicine does not support alternative understandings (229). The underlying societal issues faced by suicidal children such as poverty, abuse, bullying, and inequality could be considered to reflect society's structural, economic, and institutional systems, presenting a challenge to this regimen of policy making.

It could also be argued that the function of policy is not to address the treatment and care needs of specific populations but provide a future vision and action plan to achieve this, and which can be interpreted and disseminated within a local context. However, the lack of dialogue around children and young people who are suicidal within the documents reviewed highlights a gap in policy provision for this population. The review of the New Zealand 'Suicide

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Prevention Strategy' (189) demonstrated that the generic goals set out in the strategy could be applicable to young people; however, this was not obviously apparent from the document itself. This may be true for other national suicide prevention strategies and national mental health strategies. However, by not being explicit about their relevance to children and young people who are suicidal, it could mean that the needs of this population are overlooked by the local government agencies charged with interpreting, implementing, and resourcing them. It may also lead to large variations in terms of service design and delivery across different local authorities.

#### Limitations

This is the first scoping review to consider how policy addresses the needs of children and young people who are suicidal and provides unique insight into this policy domain. However, the lack of methodological guidance for conducting policy reviews made this challenging. Whist recognising some of this study's limitations, every effort was made to be explicit in the methodology and conduct the review with rigour. Additionally, the lack of any previous description of the suicidality policy landscape for children and young people, made identifying and sourcing relevant documents complex. The systematic searching of primarily journal-based databases returned very few relevant documents. Searching government websites for terms such as: "child", and "young people", and "suicide", was also problematic because many of the key documents include little direct references to children and young people who are suicidal. The search for policy documents was more intuitive than anticipated, in part due to the paucity of research in this area. One of the key findings was that there is a gap in policy specifically addressing this population, but this gap also contributed to the difficulty in finding relevant policies to be included.

The identification of Ireland's 'Standard operating procedure for CAMHS' (221) suggests there may be clear protocols for child and adolescent mental health services, and practitioners available in other countries. However, these documents tend to vary between organisations and local authorities / states and were excluded from this review because they were not national. Further exploration of these local policies, or purposive searching for other international CAMHS protocols should be considered within any future policy research in this area.

Although not a prerequisite in a scoping review, triangulating screening, and data extraction, helped to identify there is little policy dialogue about indicated suicide prevention strategies for children. This lack of specific reference to the care needs and pathways for suicidal children meant the documents were open to subjective interpretation. For example, although parts of policies could be interpreted as being applicable to this population of children and young people, in attempting to extract verbatim the text that addressed them reviewers struggled to identify significant relevance.

As the review was limited to English language many suicide prevention policies had to be excluded, including those of the Nordic Nations who are known to have advanced mental health and suicide action plans, as they could not be translated. These countries may make their policies available in English in the future as they have with 'Plan for suicide prevention among the sàmi people in Norway, Sweden, and Finland' (174) and they could then be included in a future review.

The policy landscape is constantly changing and evolving. Two highly relevant documents were published following completion of the systematic literature search. The Scottish Government published an updated Suicide Prevention Strategy (230), which contains acknowledgments that 'children and young people require a specific focus'. Recommendations within the policy document itself remain largely at a universal prevention level, for example training teachers. The strategy clearly includes a recommendation that all children should have access to crisis support when they need it, and that it is the governments' intention to "transform" child and adolescent mental health services, having appointed a children and young people's mental health task force. However, it also contains a statement suggesting that suicide rates in children are falling, which is contrary to reports from other sources which suggest that they are increasing (231), and that rates in Scotland are higher than other parts of the UK (29).

Another key document published latterly was the UK wide 'Self-harm and Suicide Competence Framework children and young people' (69). This document is intended to outline the key competencies required of professionals working with children and young people who self-harm or are suicidal. Identifying the knowledge and skills of those who support children who self-harm or are suicidal requires different competencies to those who work with adults is undoubtedly a positive development. Within the document, it is

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emphasised a person-centered approach should be taken towards CYP who have self-harmed or are suicidal, and they are treated with compassion and respect. It contains acknowledgement of the challenges in assessing suicide risk: scales and risk assessment tools have a low prediction value; and there remains a lack of evidence base for any effective interventions. However, it goes on to promote the use of Dialectical Behavioral Therapy (DBT) and Mentalisation Behavioral Therapy (MBT) as specific interventions for use by mental health professionals based on the identification of positive effect in single trials of DBT and MBT (79; 27). This is then followed by a statement warning that the generalisability of these approaches is unknown.

Overall, the report conveys the complexity involved in understanding the needs of children who self-harm and are suicidal and is a welcome guide to practitioners and service providers, concerned with the supervision and training needs of their workforce. However, it remains within the realm of recommendations, its application is not compulsory, and it highlights the paucity of evidence to support effective treatment models for this vulnerable population.

#### Implications for future research

This review highlights the need for further research in several areas. It establishes a need for more robustly defined policy review methodology, as well as a deeper exploration of the potential gap in policy provision for suicidal children and young people.

Although scoping review methodology lends itself well to policy review, ensuring that the search strategy and identification of policy documents is reliable is complicated by variation in document formats, and titles that do not describe the issue in focus. This presents similar issues to those found when trying to identify qualitative literature for the purposes of review synthesis (232,233), and learning from developments in the field of qualitative evidence review could support development of more robust policy review methodology.

Application of discourse analysis or interpretative policy analysis (234) may help to understand the meaning of the policy dialogue, as policy can in and of itself support the construction of, or denial of social issues (235). Consideration of how the problem of childhood suicidality is represented in policy documents could provide valuable insight (228) into the politics of addressing this highly sensitive subject, and the needs of these children. However, this type of intensive empirical analysis is beyond the scope of this thesis. This scoping review was conducted to establish how policy shapes and informs service provision and was not intended to involve this level of analysis.

Additionally, widening the inclusion criteria in future reviews to include more local policies would provide further knowledge on how national policy is interpreted and applied at a local level. Exploring whether there are variations in interpretation locally, and if in fact the specific needs of suicidal children and young people do get lost in translation is a knowledge gap that needs addressed.

## Implications for policy and practice

Policy documents need to be written in such a way that they are careful not to exclude people and are therefore often very generic. Taking a lifespan approach to mental health policy and suicide prevention strategies supports the holistic understanding that mental health is not just about the absence of illness. Mental ill health, periods of distress and suicidality are all fluid concepts that can touch all our lives at different points. The aim of these strategies is for governments to explicate their commitment to addressing these issues, and to supporting people of all ages who are affected by them. However, this review suggests that by not specifically naming suicidal children and young people as a group that should have immediate access to services or supports, and what this might look like, there lies a danger that generic policy statements are too open to interpretation. This could have implications for the local funding, commissioning and delivery of child and adolescent mental health services. Policy makers should clarify their ambitions for how the treatment and care needs of suicidal children and young people should be addressed in future policy documents. A briefing paper was sent to the WHO and Scottish Government following publication of this review (Appendix 3: Briefing Paper), which may be used to inform policy direction.

This review provides practitioners with an overview of the international and national policy context within which they work, informing their practice and providing key knowledge. It may support their understanding of practice guidelines in relation to children and young people who are suicidal and equip them with a reference resource from which to draw upon.

## Conclusion

This scoping review mapped key policy documents worldwide and established how they addressed the treatment and care needs of children and young people who are suicidal. Categorising these documents by; International Policy, National Policy and National Guidance, revealed that despite the assertion that children and young people are a priority target population within policy documents, their content mainly promotes the use of universal prevention strategies, and does not specifically address the treatment and care of children and young people who are suicidal. This highlights a potential gap in policy that could lead to the needs of this very vulnerable group being overlooked, and varying interpretations of how they should be provided for. National guidelines (in the UK, and New Zealand) (173,212), and Ireland's SOP for CAMHS (211) contain recommendations that children and young people who are considered to be at risk of suicide are assessed by a child and adolescent mental health practitioner, however, stop short of recommending treatments and interventions beyond this.

Overall, this scoping review established that children who present as suicidal should be referred to CAMHS for assessment and treatment. What happens or should happen beyond the referral to CAMHS remains unknown and is the focus of this thesis. The following section of this chapter first seeks to review if there are any known effective treatments that CAMHS practitioners could provide to address childhood suicidality.

# PART THREE: TREATMENTS AND INTERVENTIONS FOR SUICIDALITY IN CHILDREN AND YOUNG PEOPLE: AN OVERVIEW OF REVIEWS

Treatment addressing suicidality in children is a rapidly developing research area with research trials testing an ever-expanding range of interventions. Several interventions are described in the literature including psychotherapy, cognitive behavioural therapy (CBT), dialectical behavioural therapy (DBT), mentalisation based therapy (MBT), group therapy, family therapy, outreach and community-based programs, on-line and computer-based applications, psycho-education, and creative distal methods.

There is a need to determine which treatments are most effective in addressing suicidality amongst children and young people. Numerous systematic reviews have attempted to critically appraise and pool the available evidence. However, many have focused upon a specific intervention approach (e.g. CBT (236), or family interventions (237)), or interventions delivered in particular settings (e.g. schools (238)). A rapid evidence knowledge synthesis was published using an overview (systematic review of reviews) methodology which sought to explore the effectiveness of school-based prevention and treatment studies, and non-school based prevention studies in children and young people (with one or more suicide attempts) (168). Their review was mostly focused on prevention policies and programs. Since the publication of the synthesis by Bennett et al (168) (last search May 2012), there has been substantial research in this field, and a more up-to-date overview is overdue in order to support the development of policy, clinical guidelines and evidenced based treatment approaches to address the needs of suicidal children (239). Furthermore, there has been significant methodological improvement in the conduct and reporting of overviews (240,241).

This overview aims to systematically identify, appraise, and synthesise the evidence for the effectiveness of interventions used to address suicidality in children, establishing any gaps in knowledge or gaps in the quality of evidence for these treatments. The overview will build on the earlier work of Bennett (168) but focuses specifically upon indicated intervention activities relevant to suicide in a younger population (i.e. children and young people aged between 8-18 years) across *all* settings. That is, it seeks to identify effective treatments for children who present as suicidal and has more relevance to supporting evidenced-based treatments for children and young people accessing mental health services. Thus, identifying

what treatment / interventions are available to children accessing support from CAMHS for suicidality, and what best practice in this area may be.

This overview was conducted independently by me as part of this PhD thesis, with support and expert guidance from supervisors, a specialist in statistics (CB) and an expert in 'overviews of reviews' methodology (PC). The support of these experts ensured the trustworthiness and reliability of the review. I conceived the idea for the review, led in its design, conducted, and wrote the first draft and subsequent revisions. Based on feedback from the other authors, the paper has been submitted for publication, and following further revisions it is anticipated it will be published in the autumn of 2021. The input from MM, ED, CB, and PC is detailed further in the methods section below.

## Methods

#### Design

This overview (review of systematic reviews) was conducted using established Cochrane guidance specific to reviews of reviews (240) alongside the recommendations of Hunt et al (239), and the findings of Pollock et al (242). The search criteria and a plan for analysis was determined in a protocol registered with PROSPERO (CRD42018089168).

### Criteria for considering reviews

Only high-quality, up to date (published within the last 10 years) reviews meeting predetermined criteria were considered for inclusion in the overview. Table 3 details the inclusion and exclusion criteria that was developed as follows.

The population of concern was defined as children aged 8-18yrs who were suicidal (reflecting legislation (170,243), UK national guidance (213,244) and the population of concern for this thesis). Recognising the variation in application of different age ranges to refer to children and young people (165), it was agreed not to exclude reviews that included studies of populations exceeding the target age of our population (8-18 years), if most of their sample was aged 8-18 years, or where the reviews addressed this child / adolescent population and related studies separately. Similarly, reviews that addressed the effectiveness of interventions in relation to self-harm were included if their definition of self-harm included suicidal behaviour, but reviews primarily concerned with non-suicidal self-injury were

excluded. Suicidality can often be symptomatic of other diagnosable mental health conditions such as psychosis. Reviews primarily addressing specific conditions other than suicidality were excluded.

This review used a definition of suicidal behaviour as 'any act of self-harm intended to end ones' life which can result in both a fatal and non-fatal outcome. Suicidal ideation refers to thinking about ending ones' life and can include planning suicidal behaviour. Self-harm is defined as any act of self-poisoning or self-injury, that may or may not be intended to end ones' life; it can include suicidal behaviour, however most people who self-harm do not intend to end their lives and use self-harm as a means of coping with over whelming distress. Eligible reviews had to include suicidal behaviour, and or suicidal ideation as an outcome measure for their included studies. Although this is an overview of the effectiveness of treatments / interventions, to ensure included review evidence was not arbitrarily limited, reviews that contained all study designs were considered.

As stated previously suicide prevention activity can be categorised as universal, selective, or indicated<sup>7</sup>. This overview only included reviews of indicated activities; that is reviews of any treatments or interventions that were provided to relieve or address suicidal behaviours or ideation in an individual presenting with suicidality.

Although there are differences in the precise definitions of 'treatments' and 'interventions' these terms are often used interchangeably within the literature, therefore reviews using either term was included. The treatment of children who are suicidal is not limited to clinical settings - reviews of treatments / interventions delivered in any context (school / home / outpatient etc.) were included. This overview was conducted in the UK, to inform this thesis and therefore only reviews relevant and applicable to the UK context were included.

<sup>&</sup>lt;sup>7</sup> Universal prevention strategies are aimed at the whole population indiscriminately; selective interventions are targeted at specific groups of individuals who may be considered high risk; indicated interventions are delivered only to individuals presenting as suicidal.

#### **Table 3: Selection Criteria**

Inclusion	Exclusion
About children less than 18yrs and over 8yrs.	Mostly about a population less than 8yrs old.
About suicide; suicidal behaviors (attempts) and suicidal ideation	Mostly about a population over 18yrs old.
Uses a definition of self-harm to include suicidal behavior.	Solely about Non-Suicidal Self Injury.
	About treating another illness e.g. psychosis, eating disorders, depression.
Any treatments / interventions that are provided to relieve or address suicidal behaviors and or ideation presenting in an individual Children and Young People	Solely concerned with prevention activities.
Reviews of treatments / interventions that could be transferable to Scotland, assessed using five -point criteria (245)	Reviews concentrating upon treatments / interventions in developing countries or specific indigenous populations.
Reviews of treatments / interventions in any setting.	Published before 2008

### Search Methods for identification of reviews

The search strategy comprised two distinct phases. Firstly, databases known to house high quality systematic reviews (Cochrane database for systematic reviews, CDSR, DARE, HTA, JBI and the Campbell Collection) were searched using broad base text terms "suicide" and "suicidal" during February 2018. The search was limited to reviews and English language, but no other limits were applied at this stage. A total of 134 reviews were then screened by title and abstract using the inclusion / exclusion criteria above (LG/ED/MM), with disagreements resolved through discussion. References of identified reviews were checked for other reviews.

A meeting between LG, MM, and ED (February 2018) agreed the parameters of the phase 2 search strategy based on the findings of preliminary searching in phase 1 and agreed detailed search terms (Table 4). Since the Database of Abstracts of Reviews of Effects (DARE) had not been updated since 2015, five other databases known also to house health related systematic reviews (CINAHL, Medline, Psychinfo, Science Direct, and Web of Science) were searched using these search terms, limited by date (2014 onwards to capture those that would not

have been added to DARE), and English language. These search terms (Table 4) were also used to search the review databases searched in phase 1 again to ensure no review had been missed. (Full mesh terms used available in dataSTORRE <u>http://hdl.handle.net/11667/175</u>.)

Table 4: Search Terms

CONCEPT	KEYWORDS
CHILDREN AND YOUNG PEOPLE (5-18YRS)	Child*; "young people"; youth; adolesc*; teen*; paediatric
SUICIDE	Suicide; suicidal; self-harm; self-injury
TREATMENT / INTERVENTION	Treatment*; Intervention*
REVIEW	Systematic review; review
LIMITS	English Language Years: 2014-2018 inclusive

## Methodological quality assessment of reviews

Two independent reviewers (LG, CB) assessed the methodological quality of the reviews using the Risk of Bias in Systematic Review (ROBIS) tool (246). Reviews were judged based on their (a) relevance (b) identifying areas of concern in the conduct of the review and (c) any potential risk of bias. A specifically designed data extraction form was created in Excel following a recommended guidance toolkit (247). Disagreements were resolved using consensus meetings.

Quality of the individual studies within the included reviews were not reassessed and the review authors' original quality assessment was extracted where possible.

Quality of evidence within included reviews

Quality of the evidence synthesised within each review was assessed: data from the relevant analyses and forest plots which presented data for suicidality in children and young people was systematically extracted and judged using the GRADE approach (Grading of Recommendations Assessment, Development and Evaluation) (248). This evidence was downgraded based on five factors:

• Risk of bias (e.g. due to poor study design or conduct) (249)

- Imprecision of results (i.e. wide confidence intervals) (250)
- Indirectness (i.e. variations in participants, interventions, comparisons and outcomes) (251)
- Inconsistency of results (e.g. a large I<sup>2</sup>) (252)
- Publication bias (253)

## Data Extraction and Management

One overview author (LG) extracted the following data using predefined templates.

- At the level of the review: First review author and year; Aims; Definition of suicide and self-harm; number and type of studies included; participants; interventions; comparators; methodological assessment; and key findings.
- At the trial level (as reported within the review): Review; Study ID (First author; Year); Overlap; type of intervention; study design; country; setting; participants; comorbidity; intervention name; procedures; mode of delivery; who delivered the intervention; intervention regime; control; outcome measures; time frame; key findings; data source (review).

This data was then cross-checked by another review author (CB, PC, ED). Any disagreement was resolved by discussion between the review team involving a third reviewer as required. The studies extracted from the reviews were organised and coded in a separate excel spreadsheet (available in DataSTORRE <u>http://hdl.handle.net/11667/175</u>. ) which allowed for the identification of overlapping studies (available in DataSTORRE <u>http://hdl.handle.net/11667/175</u>. )

## Data Synthesis

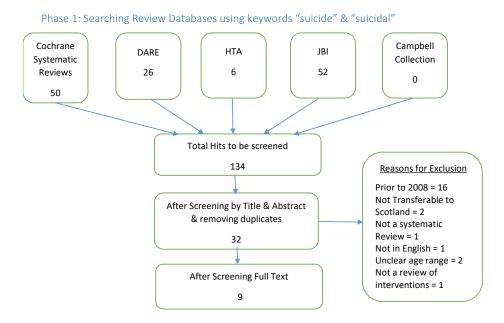
Tabular and narrative synthesis of the reviews was completed; Led by LG, supported by PC and CB and verified by MM and ED. Data relating to statistical outcomes and meta-analysis conducted within the reviews were GRADED accordingly where appropriate (Conducted by PC, verified by LG and CB).

## Results

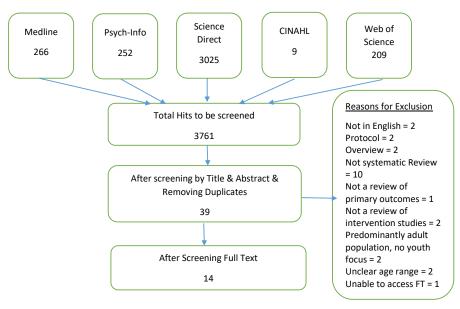
## **Results of the Search**

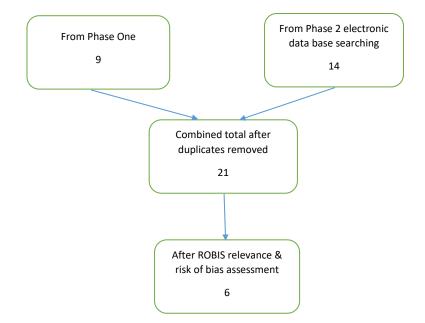
There were 3895 potential records identified, of which 71 full text papers were retrieved. We excluded 50 of these papers with reasons provided, and a total of 21 met the selection criteria (236,238,262–271,254,272,255–261) (See Figure 4 below).

#### Figure 4: PRISMA Diagram (190)



Phase 2: Searching data bases using keywords & individual mesh terms etc.





Combined Results from Phase 1 & 2 after screening in full text:

Two reviewers (LG and CB) independently assessed the 21 review papers using ROBIS (246) (See Figure 5). Of these 15/21 were excluded as the reviews were judged to be at high or unclear risk of bias (237,259,277–279,260,267,268,271,273–276), and were not included in any further analysis. The record of judgements for each of these reviews is available at (available in dataSTORRE <u>http://hdl.handle.net/11667/175</u>.). The remaining 6/21 reviews were assessed as high quality, and suitable for inclusion in this overview (236,255,257,262,265,266). Table 5 summarises the key characteristics of the included reviews (236,255,257,262,265,266).

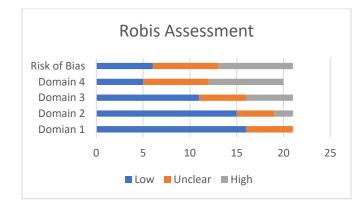


Figure 5: ROBIS Summary Graph

**1**. Domain 4 reports findings from only 20 reviews as Perry et al (269) included only one study in their review, therefore questions relating to the quality assessment of synthesis were irrelevant.

#### Description of included reviews.

The included systematic reviews were conducted between 2010-2016 (236,255,257,262,265,266). Three of the reviews included meta-analyses (236,262,266); the remaining reviews were narrative syntheses (255,257,265).

Four reviews focussed on psycho-social interventions (236,262,265,266). One review explored the accuracy of screening instruments for treatment of suicidal populations (266) and the remaining review considered interventions initiated in emergency departments (265).

Suicidality was defined in 4/6 reviews (236,255,257,262). The remaining two reviews did not provide a definition of suicidal behaviour or self-harm.

The total sample size of the studies included in each review varied from 718 (265) to 10654 (255). Individual study sample sizes ranged from 9 (257) to 4133 (255). Three reviews reported that study samples were predominantly female (255,262,265). Gender is unreported in three reviews (236,257,266). Ethnicity was unreported in all reviews (236,255,257,262,265,266). The reviews varied in terms of the numbers of trials they included from 11 (262) – 56 (266), although only 15/56 trials in this review (266) were solely focused on child / adolescent populations. The review with largest number of trials with a child / adolescent population (n=28) was by Calear et al. 2016 (255).

Five reviews (236,255,257,265,266) focused primarily on suicidal behaviour as an outcome measure, one (262) was interested in treatments for self-harm in children – defining self-harm as any intentional act of self-injury regardless of intent.

An overview of the review characteristics is provided in Table 5 below.

#### Table 5: Review Characteristics 8

Review ID First Author (Year)	Aim	Review authors definition of suicide and self-harm ("quotes")	Number and type of intervention studies.	Participants	Interventions	Comparators (UC/ no treatment?)	Methodological assessment (as assessed by the review authors) [Data –Pooled within meta- analyses?] (Y/N)	Key Findings
Calear (2015) (255)	"To identify RCTs of psychosocial interventions for youth suicide in school, community and healthcare settings, with the aim of identifying what types of interventions can be effective in these settings	"suicidal behaviour (self-harm, ideation, attempt and completion) " "self-harm may not involve suicidal intent" Calear et al. (2015:468)	28 studies; RCTs (n=24); follow up of cRCT (n= 1); more than 2 arms (n=3). *authors report on 32 comparisons	n=10,654 (sample size ranged from 30 - 4133). Mean age of participants ranged from 12.9 to 22 years. Percentage of male participants in each trial ranged from 10 to 82 %	Face to face (n=27/32); Distal (n=3); face to face + telephone (n=2). Individual (n= 12/32); individual + parent / family (n = 7/32); family therapy (n= 4/32); group (n= 6/32); individual and	TAU (n=22); AC (n=1); waiting list (n=4); parallel treatments with no control (n=1).	Risk of bias tool – not reported GRADE [No]	Just over half of included studies reported positive effect on SI; SA; or self-harm. Follow up period influenced likelihood of positive effect: SI at short term follow up; SA longer term; lengthier follow up/ large sample less likely to find effect sustained. Trials found to be most effective were for "indicated populations" (those

<sup>&</sup>lt;sup>8</sup> Abbreviations: RCT – randomised controlled trials; qRCT – quasi RCT; cRCT – cluster RCT; TAU – treatment as usual; AC – attention control; UC – Usual Care; EUC – enhanced usual care; NR – not reported; SI – Suicidal ideation; SA – Suicide attempt; SH – Self-harm; DSH – Deliberate self-harm; CBT – Cognitive behavioural therapy; DBT – Dialectical Behavioural Therapy; MBT – mentalisation based therapy; MI – Motivational Interviewing

and where future research efforts should be directed."	69%; depres or DSF 25%; univer 6%. Austra (n=4); (n=1); Norwa (n=1); Taiwa	6, n = $(n=2/32)$ ; parent only (n=1/32) CBT (n=2/28); CBT + family (n=3) DBT + family (n=1/28); MBT + family (n=1/28); rsal = problem- solving therapy Alia (n=1/28); Iran psychotherapy (n=1/28); problem- solving therapy (n=1/28); problem- solving therapy (n=1/28); MI + Turkey group UK (n=2/28); MI + USA parent	already identified as being suicidal). Outcomes varied with delivery mode with positive effects for: Individual interventions on suicidal ideation; group and family interventions on suicide attempts; combined individual and family support on suicidal ideation and suicidal behaviour. 27/28 studies reported a positive or null effect – suggesting no adverse effects of psycho-social interventions for youth suicide. Different types of interventions delivered in a range of settings can be effective. They suggest that this supports further development of multi- modal interventions.
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					contact (n=3/28); psycho- education (n=3/28);			
Devenish (2016) (257)	"to determine whether psychological interventions aimed to prevent and/or treat depression in adolescents can also reduce suicidality." Devenish et al (2016:726)	"Suicide behaviour consists of death by suicide (self- inflicted and intentional killing of oneself), suicide attempts (self- injurious behaviour with the intent to cause death) and suicidal ideation (persistent, serious thoughts of suicide). we refer to all these features with the term	16 studies: RCT (n=4); RCT with more than 2 arms (n=6); Cluster RCT (n=1); Pilot Open Trial (n=2); Non RCT (n=1); Non RCT with more than 2 arms (n=1); Quasi- experimental study with 1 condition (n=1).	n=3,226 (range 9- 1030). Aged = 11-19 yrs. Gender & ethnicity = NR. Recruitment criteria = Depression 3 studies excluded participants assessed as high risk of suicide. Country = NR.	Face to Face (n=16). Individual (n=6); Family (n=4); individual + family (n=2); group (n=2); group prevention (n=4). (NB: n≠16 as some trials had more than one arm) CBT (n=4); CBT + family (n=2); psychotherapy (n=2); family therapy (n=2); MI+ group (n=2); psych- ed (n=3).	TAU (n=4); parallel treatments with no control (n=7); N/A (n=4); No treatment (n=1).	GRADE	Psychological depression interventions shown to be as effective as other treatment options. Little to no between group differences. Trials for CBT did not show that CBT was more effective than control treatments, except in one trial that compared CBT with fluoxetine medication (March et al 2009). In the majority of studies suicidality is shown to reduce (pre- post treatment). Lack of waiting list control groups, or no treatment controls, it may be there is a natural resolution of symptoms over time.

	suicidality (Maurisic, 2004)" Devenish et al (2016:727)						Not enough evidence to support any specific psychological intervention.
Hawton"Identify all(2015)RCT's of(262)psychosocialinterventions,pharmacological agents, ornaturalproducts forSH in childrenandadolescents,and conductmeta-analyses(wherepossible) tocompare theeffects ofspecifictreatmentswithcomparisontypes oftreatment(e.g.treatment asusual oralternative	"The term 'self-harm' is used to describe all intentional acts of self- poisoning (such as overdoses) or self-injury (such as self- cutting), irrespective of degree of suicidal intent or other types of motivation (Hawton 2003). Thus, it includes acts intended to result in death ('attempted	11 studies; RCT (n=10); Cluster RCT (n=1).	n= 1,126 (Sample size ranged from 29- 366). Age = $\leq 18$ yrs.; Mean age = 15.3 (0.5 SD). Female = 80.6% Ethnicity = NR. UK (n=5); Norway(n=1) ; Australia (n=1): New Zealand (n=1); USA(n=3). Recruit criteria: Any number of SH episodes within 6	Face to face (n=10) (face to face + telephone support (n=2/10)); remote contact (n=1). Individual (n=2); individual + family (n=4); individual + family (n=4); individual + family + group (n=1); group (n=3); remote contact (n=1). Individual CBT (n=1); interventions for patients with multiple episodes of SH or emerging personality problems	TAU (n=10); AC (n=1).	GRADE	Limited but positive evidence for DBT-A, and Mentalisation therapy in reducing SH; each based on single trials. A single cluster trial for a comprehensive therapeutic assessment prior to treatment found it increased engagement with treatment. No positive effect was found on reduction in SH episodes. There was no evidence found to support positive effect of group therapy; one group therapy trial (Hazel 2009) reported a breach of confidentiality

	pharmacologic al treatment) for children and adolescents who SH." (Hawton et al 2015: 1).	suicide'), those without suicidal intent (for example, to communicat e distress, to temporarily reduce unpleasant feelings), and those with mixed motivation (Hjelmeland 2002; Scoliers2009) ." (Hawton et al 2015: 6).		months prior to commencem ent of trial; 1/11 - Depression / BPD and DSH.	(n=3) (DBT (n=2/3); MBT (n=1/3); Group based psychotherapy (n=3); therapeutic assessment (n=1); compliance enhancement (n=1); home- based family interventions (n=1); remote contact interventions (n=1).			highlighting a potential for harm. No evidence of positive effect on reducing episodes of SH for trials of compliance enhancement, CBT based psychotherapy, home-based family interventions, or the provision of an emergency cards. There was no strong evidence base for any intervention.
Newton (2010) (265)	" evaluate the effectiveness of interventions for paediatric patients with suicide related behaviour in emergency department (ED) visits."	Not reported.	10 studies: 7 RCT (n=7) qRCT (n=3)	Sample size 3,818 (range 31-1867). Age = 10-85 yrs. (5/10 studies included participants ≥19)	Face to face (n=10) (face to face + telephone n=1/10). Individual (n=6); individual + family (n=1); hospitalisation (n=1);	TAU (n=6); AC (n=1); EUC (n=1); Parallel treatment with no control (n=1); no treatment (n=1);	Jadad 5 –point scale; Schultz et al (1995) guidelines were used to assess concealment of allocation. Quasi- experimental studies were assessed using Downs and	Emergency department discharge planning service increased the number of sessions attended following discharge. 3 studies for transition interventions showed reduced suicide related hospital visits, reduced risk of suicide, and

	(Newton et al 2010:649).			female =72 % (range 54% - 100%). Ethnicity =NR USA (n=6), Belgium (n=1), Ireland (n=1), International -including sites in Brazil, India, Sri Lanka, and China (n=1). Recruitment criteria: suicide related presentation to the emergency department.	outreach (n=1); NR = 1. ED intervention (n=1); Post ED interventions – direct ED enrolment (n=6); ED + post ED (n=3) CBT (n=2); CBT + family (n=1); Brief Intervention and Contact (n=1); Enhanced compliance (n=2); Hospitalisation (n=1); Outreach (n=2); Skills training (n=1).		Black (1998) methodological criteria. NO	increased treatment completion. No high-quality research evidence to suggest that the quality of clinical care can be improved by specialist emergency department team. Interventions that began before discharge from the emergency department and continue following discharge show positive effect on suicide related outcomes, and treatment adherence.
O'Connor (2013) (266)	"To review the accuracy of screening instruments and the	Not reported.	15/56 studies for adolescents.	Total sample size for 15 /56 studies =	Face to face (n=14); computer assisted assessment	NR	Pre-defined design specific criteria by USPSTF - supplemented	Trials addressing screening in adolescence did not perform well.

efficacy and safety of screening fo treatment o suicide risk i general populations and settings relevant to primary care (O'Connor e al 2013; 741	RCT with more tha arms (n=	n=2); 39-615). =1); Age = 12- 24yrs	done with clinician (n=1). Individual (n=8); individual + family (n=1); individual + parent (n=1); individual +parent + family (n=1); group (n=3); individual + group (n=1). Screening Instruments (n=2); psychotherapy (n=12); EUC = (1).		by the Quality Assessment Accuracy studies tool; all papers were rated: good, fair, or poor. They excluded poor quality trials. YES	There is little research evidence available in screening adolescents. Psychotherapy did not reduce repeat suicide attempts in adolescents. The trials included in this review did not show positive treatment effect on suicidality in adolescence. Results in adolescents did not rule out the possibility of harm with some forms of psychotherapy (increased suicide attempts). Samples were high risk populations, may not be transferable to populations identified in primary care settings.
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Tarrier (2012)	"to systematically review studies that evaluated a CBT or a treatment that contains cognitive- behavioural methods as a substantial part of that treatment, in an attempt to reduce suicide behaviour." Tarrier et al (2012:79).	"We define suicide behaviour as including completed suicides, suicide attempts, suicide intent and/or plans, and suicide ideation." (Tarrier et al 2008;79).	7 / 28 studies had adolescent populations. RCT (n=4); Feasibility (Pilot) RCT (n=1); Non- randomised CT (n=1); RCT with more than 2 arms (n=1).	For 7 studies pertaining to adolescent populations: total sample population is 1,215 (range 39-439). Age = ≤ 24 Gender = NR Ethnicity = NR UK (n=1); USA (n=5); Israel (n=1).	Face to face (n=7) Individual (n=2); individual + parent (n=1); group (n=2); NR (n=2) CBT (n=5); DBT (n=2).	TAU (n=4); AC (n=1); Parallel treatment with no control (n=1); None (n=1).	CTAM (clinical Trials Assessment Measure). YES	The included trials did not show that CBT had a positive effect on suicide behaviour. Variation in trial authors definitions of adolescence meant one study described as adolescent population had an upper age limit of 24yrs. However, when the population was primarily adolescent age then CBT was not shown to have positive effect on suicidal behaviour. Overall, there was little evidence to draw upon for adolescent

Description of the studies reported within the included reviews

The six included reviews collectively reported data from 87 intervention studies; of which 29 studies were included in more than one review. The overlap in studies across reviews is summarised in a table available in DataSTORRE <u>http://hdl.handle.net/11667/175</u>.

Once duplicated studies were removed, 58 unique studies were found to be reported across the six reviews (a table of study characteristics is available in DataSTORRE <a href="http://hdl.handle.net/11667/175">http://hdl.handle.net/11667/175</a>).

The majority of studies employed a randomised controlled trial (RCT) design (n= 46/58) (280,281,290–299,282,300–309,283,310–316,284–289) (317–324) (325). The remaining 12 studies as described by review authors were:

- Quasi-experimental (n=3) ((326–328)
- Non-randomised control studies (n= 1) (329)
- Non-randomised control trial with more than one arm (n=1) (330)
- Cohort study (n=2) (331,332)
- Pilot Open trials (Pre and Post) (n=2) (333,334)
- Open trial with one condition (n=1) (335)
- Cluster RCT (n=2) (267,336)

Most of the included studies as reported within the reviews were conducted in the USA (n=21/58)(282,283,310,319-321,323-

325,327,329,337,287,338,288,289,291,293,300,301,309), followed by the U.K (n=8) (267,286,296,297,308,313,315,316,339)<sup>9</sup> and Australia (n=5) (305–307,340,341). Individual trials were included from Belgium (314); Canada (326); Finland (331); Iran (280); Ireland (303); Israel (302); New Zealand (285); Norway (342); Taiwan (312), and Turkey (290). One trial was conducted in more than one country (294). The geographical region was not reported for 13 studies (295,311,336,343,344,317,318,322,328,330,332,333,335).

<sup>&</sup>lt;sup>9</sup> The included citation for Ougrin et al. 2013 (339) is a follow up paper on the original study Ougrin et al. 2011 (267)

### Participants and Intervention Setting.

Many of the trials included with the reviews (58%; n=33) only included, or had within their sample participants with recognised co-morbid conditions such as depression (n=25) (267,282,310,313–315,318,319,323–

326,283,327,328,332,336,337,339,287,293,294,300,302,303,307) personality disorder traits (n=4) (308,329,340,342), psychosis (n=2) (338,345), conduct / behavioural disorders (n= 4) (296,297,316,341), unspecified psychiatric disorders or conditions (n=5) (285,286,301,340,342) or alcohol / substance use (n=3) (291,341,342). For 25 trials no comorbidity was reported or was unreported / unclear within the reviews (DataSTORRE http://hdl.handle.net/11667/175).

The most commonly reported intervention setting was in schools (n=13) (282,283,328,332,336,290,302,312,318–320,323,324), followed by clinical outpatient settings (n= 11) (285,289,342,295,296,305,316,326,331,333,341) academic (University) settings (n=1) (293); home based (n=2) (297,314), community outreach programs (n=3) (287,300,301), in-patient settings (n=5) (280,286,291,325,334), emergency departments (n=2) (281,310); emergency departments with follow on support (n=2) (294,327), other hospital settings (n=2) (267,315); and by distal communication (n=1) (307). The settings was unreported by review authors for (n=16) studies (288,303,329,330,335,338,340,343,306,308,309,311,313,317,321,322).

### Comparisons

The most used comparison group was TAU (Treatment as usual) (n=30) (267,285,301,305–310,312,316,319,286,323,325,326,329,337–

339,341,342,346,287,347,288,291,294,296,297,300). Other comparisons included enhanced usual care (n=2) (288,342); a referral to an alternative community provider (288); standard emergency room care + a SNAP (abbreviation not defined within review) therapy referral (327); attention control (n=1) (289); waiting lists (n=4) (280,282,283,290); pharmacological treatment and / or a combination of medication plus psychological intervention (n=5) (295,321,322,330,343). Trials for C-CARE (a brief interview–Counsellors CARE) (n=4) involved combinations of testing the effectiveness of C-CARE plus CAST (Coping and Support Training), and P-CARE (Parent sessions) (319,320,323,324). aimed at individuals and / or families (n=2)

(311,317). Other combinations of alternative treatment programs aimed at individuals and / or families (n=2) (311,317). Other reported controls were the screening of a generalised health advice video (n=1) (293); hospital inpatient (n=1)(338); home discharge from hospital (n=1)(315). For the remaining studies control was unreported (n=1) (340); no alternative treatment / control (n=2) (278,302); N/A (n=6) (328,331–335).

#### Types of treatments and interventions addressing suicidality in CYP

Most trials were for individual treatments / interventions (n=15) (289,290,331,332,340,343,346,294,295,306,310,312,325,326,330), followed by individual treatments complimented by a family / parent component (n=12) (267,280,327,339,342,288,291,308,311,317,320–322). An individual intervention alongside a peer support / skills group (n=5) (285,318,319,323,324); group setting (n=10) (282,283,296,309,316,328,333,334,336,341). Other formats included outreach (n=4) (287,300,301,347), family based work (n=5) (281,297,305,335,338) and remote contact / alternative delivery method (n=3) (286,293,307). Mode of delivery was unreported unclear in three trials (n=3) (302,303,329).

For most trials, the length of the intervention was unreported. However, from the information available in the reviews they ranged from a single day to 12 months. There was a large amount of variation across the trials in the number of sessions that were delivered: 1 session (n=3)  $(267,293,318,339)^{10}$ ; 1 session + 6 outpatient appointments (n=1) (327); 1 sessions + TC follow up support sessions (n=1) (310); 1 individual session + 13 group sessions (n=2) (323,324); 2 sessions (n=3) (282,283,347); 5 sessions (n=2) (281,303); 7 sessions (n=1) (346); 9 follow up contacts (n=1) (294); 12 sessions (n=6) (280,295,302,312,335,343); 12 postcards (n=1) (307); 10-14 sessions (n=1) (289); 14 sessions (n=1)(325); 12-16 weeks followed by 2-4 booster sessions (n=1) (317); 19 sessions (n=1) (342); 24 sessions (n=1) (284); 26 sessions (n=1) (285); up to 34 sessions (n=1) (296) and 64 sessions (n=1) (308). The number of sessions was reported as varied (n=7) (296,298,300,301,316,338), and in 2 of these trials (298,316) sessions were reported to have continued until the YP wanted them to end. The number of sessions was unreported for 5 trials (287,315,326,328,336).

<sup>&</sup>lt;sup>10</sup> The included citation for Ougrin et al. 2013 (339) is a follow up paper on the original study Ougrin et al. 2011 (267)

Interventions were delivered by a variety of professionals including clinicians (n=5) (267,280,281,308,331,339), therapists (n=8)(285,288,290,291,296,338,342,346), counsellors (n=1)(312); nurse and/or counsellor and/or social worker (n=4) (319,320,323,324); psychiatrist and psychiatric nurse (n=2)(316,326); nurse (n=1) (347); psychologist (n=2) (309,345); medical doctor (n=1)(286); social work (n=1) (297); teacher (n=2) (282,283); researchers / post-docs (n=4) (293,305,307,310); lay-person (n=2) (300,301). Who delivered the intervention was not reported or was unclear for 23/58 trials (DataSTORRE http://hdl.handle.net/11667/175.). Training or resources required to deliver the intervention was not reported in any of the included reviews.

Interventions were categorised according to descriptions provided by the review authors. These are not discrete categories and some overlap. For example, a group or family intervention may also have been based on CBT. There were no trials solely for pharmaceutical interventions included in any of the reviews, although as mentioned above five multi-modal trials had anti-depressant medications as a treatment arm (295,321,322,330,343).

- Cognitive Behavioural Therapy (CBT) (n=14)
   (280,281,321,322,326,343,289,291,295,302,306,311,313,317); 5/14 involved some family component to treatment (280,289,291,311,317). 1/11 was an enhanced compliance intervention (281).
- Dialectical behavioural therapy (DBT) (n=4) (285,325,329,342) 3/4 also reported a family component to the intervention (285,329,342). The procedure was unclearly reported (257) for 1/4 trials (325).
- Mentalisation based therapy (MBT) (n=1) (308); This included a family component as well as individual treatment.
- Family therapy / Family component (n=15)
   (280,281,317,329,335,338,342,285,288,289,291,297,305,308,310); 6 /15 were based on CBT principles (280,281,289,291,311,317); 3 /15 were DBT interventions
   (285,329,342); 1/15 was MTB (308); 2/15 were attachment based (288,335); 1/15 was a home based problem solving approach (297); 1/15 was for multi-systemic family therapy (338) and 1/15 was a parent psycho-education program (305).

• Group Therapy / peer support (n=14)

(282,283,328,330,333,334,336,296,298,309,316,318,319,323,324); 3/14 were for CBT based group therapy (298,333,334); 3/14 were for peer support groups alongside motivational interviewing (319,323,324); 2/14 were described as developmental group psychotherapy(296,316); 1/14 was a Psycho-education, problem solving and experiential affective support group (309) and 5/14 were for psycho-education group work (282,283,318,328,336)

- Psychotherapy (n=2)(312,330).
- Psycho-dynamic or interpersonal therapy (n=1) (340).
- Motivational interviewing (n=4); 3/4 delivered a peer support / skills training group. alongside individual support (319,323,324); 1/4 tested a parent intervention alongside individual support (320).
- Assessment / screening tools (n=3) (267,331,332,339).
- Enhanced Compliance (initiated in the ED) (n=3) (281,310,327) 1/3 was based on CBT principles (281).
- Brief intervention (n=1) (294)
- Remote contact interventions (crisis cards; postcards) (n=2) (286,307)
- Alternative delivery method (video) (n=1) (293).
- Non-specific problem solving / emotional support / liaison (n=6) (287,290,300,301,303,347); 4/6 were delivered on an outreach basis trials (287,300,301,347)
- Hospitalisation (n=1) (315)

### Outcomes

There was large variation between trials in terms of not only what they measured but how they measured suicide related outcomes. For example, suicidal ideation was measured in 32/58 trials using seven different measurement tools (280,282,297,299–301,304,307,309,312,316,319,283,320,321,323,324,330,333–

335,341,343,285,345,288,289,291,293,295,296) including: Beck Scale for Suicidal Ideation (SSI) (n= 2) (288,319); Suicidal ideation questionnaire – JR (n=3) (289,335,343); Suicidal ideation questionnaire (n=2) (297,330); Brief Suicide Risk Behaviour Scale (n=1) (312); Item 13 of Children's depression rating scale – Revised (CDRS – R) (n=1) (334); CDSR – R (n=1) (333); K-SADS- PL (items on suicidal thoughts and ideation) (n=1) (295). How the outcome suicidal ideation was measured was not reported in 20 studies (280,282,304,306,307,309,316,320,323,324,328,341,283,290,291,293,296,299–301).

Other outcome measures related to suicide and the tools used to capture them were reported as follows:

- Suicide attempts were measured in 19/58

   (281,282,319,320,323,324,326,327,329,345,283,287,288,291,299–301,309):

   Presentation at A&E following a suicide attempt (n=1) (288); Repeat hospitalisation

   (n=1) (326), however, in most the tool was unreported (n=16)
   (281,282,320,323,324,327,329,345,283,287,291,299–301,309,319).
- Repeated deliberate self-harm: (n=16)
   (267,284,310,315,316,320,340,341,346,285,286,289,296,297,303,307,308); tool NR
   (n= 5) (303,307,320,346); Self-Report (n=7) (285,289,296,297,310,316,341); Repeat
   presentation at hospital (n=2) (267,315); Clinical notes (n=1) (286); Risk Taking and
   Self-Harm Inventory (n=1) (308).
- Para suicidal behaviour (n=1) (325)
- Suicidality (n=4)(305,317,318,322); HSQ (High School Questionnaire) (n=1) (318); rated by the clinician and SIQ -JR (suicide ideation questionnaire junior) (n=1) (317); K-SADS-PL (n=1) (322); tool NR (n=1) (305).
- Tools reported without a note of precise behaviour (n=2): Six items of MFQ (Moods and Feelings Questionnaire) (n=1) (278); Suicide severity rating scale (n=1) (311).
- Suicidal behaviour (n=1) tool NR (302)

• Death by suicide (n=1) (although this was measured for all studies it was reported as the key outcome measure by review authors (265) for Fleischmann et al (294).

#### **Risk of Harm**

Two reviews warn of the potential for harm to be caused by group therapy interventions. O'Connor et al. (2013) (255), identify an increase in episodes of self-harm being shown in a third of their included psychotherapy trials for adolescents, and particularly in group therapy settings. The Cochrane review of self-harm interventions (262) identified one trial (298) where specific harm was caused by a young person sharing another's information.

### Assessment of methodological quality of included studies.

Methodological quality assessment was conducted in all the included reviews, however the tools used to assess the quality of included studies varied across reviews. Three reviews (255,257,262) used the Cochrane Risk of Bias tool (348); however the number of criteria applied varied (ranged from four (255) to eight (262)). The Risk of Bias (348) as judged by review authors was extracted from each of these reviews (available in DataSTORRE <a href="http://hdl.handle.net/11667/175">http://hdl.handle.net/11667/175</a>.). Interestingly, quality appraisal as judged by the review authors differed for 7/8 studies where there was overlap of included studies.

The remaining reviews used a variety of other quality measurement tools (e.g. Jadad (349) and Downs and Black (350) in Newton (2010) (265); Clinical trials assessment measure (351) in Tarrier (236), and USPTF Quality criteria and Quality Assessment of Diagnostic accuracy Studies tool in O'Connor (266)). Due to unclear reporting of the judgements made by review authors data relating to quality assessment could not be extracted from these reviews.

#### Quality of evidence within included reviews

Three reviews reported meta-analyses (236,262,266). However, due to unclear reporting of the studies included within their analysis data could not be extracted from the review by Tarrier et al (236). Pooled data were available for 20 comparisons reported within two reviews (262,266). The pooled data alongside the GRADE judgement is summarised in a table, available in DataSTORRE <a href="http://hdl.handle.net/11667/175">http://hdl.handle.net/11667/175</a>. No high-quality evidence was identified, and one comparison was judged as providing moderate quality evidence. The remaining data was judged as low or very low quality.

Only 2/20 comparisons found evidence of benefit for the following interventions:

- Mentalisation therapy for patients with multiple episodes of self-harm or emerging personality problems compared with treatment as usual (or other routine management) on repetition of self-harm (Moderate quality evidence) (308).
- Dialectical behaviour therapy for patients with multiple episodes of self-harm or emerging personality problems compared with treatment as usual (or other routine management) on suicidal ideation (Low quality evidence) (342).

### Discussion

### **Main Findings**

This overview identified six high quality reviews that included 58 studies (18900 participants) that were conducted over 25 years. Most participants were female, who were also diagnosed with other co-morbid conditions (e.g., depression, personality disorder, substance misuse). Ethnicity, along with other factors such as socio-economic status was not reported within the reviews.

A wide range of interventions were described; most were described as psycho-social interventions and were mainly delivered in schools or outpatient settings. Interventions were delivered by people in a wide range of clinical (e.g., therapists, nurses, doctors) and nonclinical roles (e.g., social workers, teachers, lay people). The expertise, background and any specific training given to intervention providers to deliver the intervention was poorly reported across all reviews. Interventions were predominantly delivered face to face either individually, with their family, or within a group. However, there were some interventions that involved telephone or other distal contact methods. The duration and frequency of sessions for intervention studies was also widely variable with some consisting of one-off individual contacts (267,286,293,339) and others sustaining weekly sessions up to a year(308).

It was difficult to draw any conclusions about the methodological quality of trials within the reviews as each review had employed different criteria, and tools to assess the trials. Only one review excluded trials judged to be low quality (266). However, our overview found no high-quality GRADE evidence. Only one comparison was judged as moderate-quality GRADE

evidence (308). This was based on a single trial (n=77 participants) in which mentalisation behaviour therapy was delivered by a mental health worker to the individual (and their family) in 64 sessions over a year. The primary outcome measure reported was repeat deliberate selfharm. Although recognising the links between self-harm and suicide (231) they are arguably different. Therefore, while there was evidence of benefit for repeated self-harm, it cannot be concluded that this intervention has a significant effect upon suicidal behaviour. The remaining 19 comparisons were all judged as low or very low-quality evidence.

#### Interpretation of the main findings and gaps in knowledge

This overview has highlighted an important gap in the evidence-base regarding the lack of high-quality evidence for suicidality in children. Only one study judged as low GRADE showed evidence of benefit for dialectical behaviour therapy in patients with multiple episodes of self-harm or emerging personality problems compared with treatment as usual (or other routine management) on suicidal ideation. Although most trials of talking therapies seemed to show a positive effect upon suicidal ideation and suicide attempts (pre and post), very few trials were able to evidence between group differences. This may be reflective of most studies using active control groups as offering suicidal children no treatment would be unethical. While regression to the mean must be considered as a possible explanation for most interventions having positive effect (pre and post), it may also suggest, as argued by Calear et al. (255), that the benefit may lie in talking to someone, regardless of the intervention model.

The findings of this overview concur with and build upon the previous overview by Bennett et al (168). Despite being able to include more up to date reviews, there remains a gap in evidence for the effectiveness of interventions to help children who seek help with suicidal thoughts and behaviour. This overview offered further insight into this research gap by grading the quality of the evidence available and concentrating more specifically upon the effectiveness of indicated interventions.

Research in this area continues to be hampered by the considerable heterogeneity related to participants, interventions, and outcome measures. This overview found a lack of studies including younger children (≤16yrs). Additionally, the participants in the different included reviews were predominantly female and therefore evidence for interventions that are acceptable to, or effective for boys remains unknown. Ethnicity was unreported at the level

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of the review, creating a gap in knowledge as to whether there are any differences in an intervention's acceptability or efficacy by ethnic group. In addition, more than half of the included participants reported in the reviews had a recognised mental health condition. A recent report In the UK showed the majority of children and young people who end their life by suicide have no diagnosed mental illness, or contact with mental health services prior to their death (29). Thus, the generalisability of the findings from these studies presents a challenge, and may not be transferable to a wider primary care population (308).

The interventions reported across the trials were diverse. They varied not only in terms of their psychological or therapeutic approach, but also in the treatment setting, duration and who delivered the treatment. For example, CBT interventions range from one hour delivered by a medical doctor in an emergency department to a course of treatment delivered over weeks and months in an outpatient context. There was also inconsistency in terminology (i.e.) between what constitutes self-harm, and attempted suicide further complicating attempts to identify effectiveness for suicide interventions. Self-harm although increasing the risk of suicide (231,352) is not always a suicide attempt, and in fact for many it helps them to cope (353). It could be misleading to infer those interventions that reduce repeat episodes of self-harming behaviour are effective in treating suicidality. For example, self-harm is more commonly identified in females whilst most children and young people who die by suicide are male (29). Interventions that are shown to be effective for female repeat self-harmers, may not be acceptable or effective for suicidal males.

Review authors report differences in outcome measures and definitions (suicidal behaviour / self-harm and adolescents / young people) make comparisons and synthesis difficult. The numbers of children who die by suicide will never be a suitable outcome measure due to the low frequency of these events. Repeat attempts and suicidal ideation will remain the closest indicators, however these measures rely upon self-reporting and help-seeking by participants. This overview found that trialists employ a broad range of outcome measures, but that there were differences in effect between these. For example, some studies found significant differences in suicidal ideation but not suicide attempts and vice versa (table of study characteristics available in DataSTORRE <a href="http://hdl.handle.net/11667/175">http://hdl.handle.net/11667/175</a>.), indicating that the outcome measures used matters. Furthermore, the variety of different tools used to report the same outcome varied substantially.

Without an agreed core outcome set, not only do studies report upon a wide variety of outcomes, but the way that these outcomes are measured (self-report, questionnaires, repeat presentations at hospital etc.) also widely differed.

#### Strengths and Limitations

This overview of reviews was conducted using a robust methodological approach and applying stringent criteria. Consequently, it presents a credible overview of the current evidence base of interventions to address suicidality in children. Although by only including reviews which were assessed as low risk of bias, there may be interventions not captured (such as technological innovations) it increases the reliability of the findings.

Equally with a time lag between completing the review and publication there may be more up to date reviews that were not considered for inclusion. However, although there are forever new studies and systematic reviews being published, there remains a gap in the evidence base for interventions that benefit children who are suicidal. This overview provides valuable insight into the gaps in knowledge and quality of evidence (at a specific point in time (2018)) that can be used as a platform to inform future research.

An unavoidable limitation of the overview was the level of reporting within the included systematic reviews, that made data extraction, and the grading of the evidence challenging. Trialists may have reported more details, but these were not reflected within the reviews. This is an issue identified in other overview of reviews, and an inherent part of the process (245)

### Recommendations for future research

This overview identified three key areas for future research beyond the scope of this thesis:

Firstly, researchers developing new interventions must consider their acceptability to children and young people, and especially boys who are or have been suicidal. There is also a need for more studies aimed at younger children, and particularly children and young people who present as suicidal but do not have co-morbid conditions. It would also be beneficial to consider the acceptability of research studies to black and ethnic minority children, and to actively seek their participation. Secondly, reporting of interventions studies could be improved by review authors providing clearer descriptions of trials. Utilising a reporting mechanism such as the TIDieR guidance (354) would support more consistent information being recorded about the intervention, e.g. who delivered it, the training and tools needed to deliver it, how it was delivered etc. Researchers should also report upon ethnicity and the socio-economic and cultural context both at the level of the trial, and within any future systematic reviews. Development of a framework for categorising interventions would also support more consistent reporting by review authors seeking to appraise and synthesise a range of approaches.

Improved consistency in terminology, such as definitions of suicidal behaviour and self -harm, would provide greater clarity as to the effectiveness of interventions upon suicidality for children and young people. Development of an agreed core-outcome set is fundamental to addressing the challenges heterogeneity in outcome measures creates in attempting to establish a reliable evidence base for interventions in this field.

### Conclusion

In summary, this overview found six high quality systematic reviews of interventions for children and young people who are suicidal. The current evidence base highlights a lack of high-quality evidence to support the effectiveness of any treatment or intervention for children and young people who are suicidal. The research is limited by the heterogeneity in participants, interventions, and outcomes. There is a need to develop an agreed core outcome set that is specific to suicidal ideation and behaviours in children and young people to support improving the quality of the evidence. This will also help to avoid research waste as many studies included within these reviews fail to meet the standard required for implementation.

These findings add weight to the need for the thesis that follows. With no evidenced based treatment approach for child suicidality identified it remains unclear what interventions CAMHS offer children referred for suicidality or how this is experienced by those receiving and delivering this support.

### CHAPTER CONCLUSION

The purpose of this chapter was to provide the context for this thesis. The narrative review, scoping review and overview of reviews reveal that childhood suicidality is a relatively new field of research and multiple gaps in knowledge and areas for future research were identified. This thesis seeks to address some of them.

The numbers of children experiencing suicidality are reported to be increasing (84,355). We know from the literature that policy documents suggest all children who present as suicidal should be referred to CAMHS for assessment, and yet CAMHS is overwhelmed by referrals. The data presently available does not provide a clear picture of the number of referrals to CAMHS for children who are suicidal, or what happens to these children thereafter. It has also been identified that at present there is no evidence to support the use of any suicide risk assessment tools, or any interventions. There is a dearth of qualitative research studies in this area, and yet capturing the views of children, parents and practitioners is vital if mental health support services are to be able to effectively meet the needs of children presenting with suicidality.

The following chapter presents the rationale behind the methodology, and the study design of this thesis, which seeks to address these gaps in knowledge. The Cohort study which follows outlines what happens to the referrals for suicidal children in two different health board areas. Qualitative evidence from a series of interview studies then informs us as to the experiences that children presenting with suicidality and their parents have following a referral to CAMHS. This experience is couched alongside the perspective of the practitioners working in CAMHS who treat children who are referred for suicidality. The findings from the various component parts of the thesis will then be brought together to present an overall picture of what happens to children who are referred to CAMHS for reasons of suicidality and how this is experienced to inform future policy and service delivery.

# **Chapter 3: Methodology and Study Design**

### Introduction

This chapter provides an overview of the methodology and study design, including a detailed description of and justification for the distinct research methods used. It begins by explaining the overall research paradigm of the thesis. It is then explained how data collection and analysis methods were selected to best answer the research questions and reflect both the epistemological and theoretical position of the author. This will be contextualised within the contemporary literature on mixed methods, which will provide an understanding of how these methods dovetail together (356,357) to present an overall picture of the experiences and pathways of care for children who are suicidal after they have been referred to CAMHS.

Overall, this is a sequential mixed methods PhD study (using both qualitative and quantitative research methods). It is the first study to document both quantitative and qualitative evidence in relation to children who are suicidal and what happens after they are referred to CAMHS.

### METHODOLOGY

It is well documented that the methodological approach chosen by researchers to address their research question is influenced by their philosophical beliefs, values, experiences, and training (358,359). It can also be argued that the construction of the research question itself is also influenced by the researchers desire to work within a desired paradigm (360). Some of the tensions around positivist and realist ideas versus social constructionism and interpretivism were noted in the narrative literature review (Ch. 2), however, what is presented here is an explanation and reflection upon my own methodological position.

Ontology refers to the study of reality, and at opposing ends of this continuum there is realism, and idealism or relativism. Realists advocate there exists pure truth and an objective reality, whilst at the opposite end an idealist would purport there is no such thing as reality, only interpretations. Quantitative methodologies are often associated with realism, and the idea that there is a truth or reality that exists that can be measured and quantified. Qualitative methodology has traditionally been assigned the position of the idealist / naturalist, being

concerned more with understanding the meaning attached to experience, and individuals' interpretations of what it might mean. Although this description is overly simplistic it illustrates the crux of why many researchers argue that quantitative and qualitative methodologies cannot be reconciled (360).

However, there exists along this ontological continuum a range of subtleties, and understandings of what reality is and the degrees to which it may be constructed. There are varying realist positions: naive realism considers the world to exist independently of interpretation; critical realism (a phrase first coined by Bhaskar (361)) supports the view that an independent reality exists, but accepts that multiple realities may also exist; subtle realism advocates that although an independent reality exists we can only know our own interpretation of it; and analytic realism focuses on the reality of the individuals lived experience (362). Many naturalists' positions have now endorsed the emergence of the constructivist epistemology. Constructivism allows for the acceptance of some degree of critical realism, but advocates social realities are constructed (363). Pragmatism supports a critical realist position, and accepts there are multiple views of reality, and ways of knowing the world. Pragmatists reject the dualism that is often presented in ontological and epistemological debates in favour of valuing ideas by their usefulness (364).

Epistemology refers to theories of knowledge, and how knowledge is acquired. A range of views on this exist, also sitting along a continuum from positivism, to interpretivism. Epistemological realism purports that reality can be known objectively (365). This positivist scientific approach to establish "truth" has been the dominant research doctrine, and from this perspective, attempts to classify and categorise the social world using scientific methods have prevailed (359). However, many social scientists, and qualitative researchers reject the scientific approach and are concerned with how people, and social structures create knowledge and interpret meaning (366).

Philosophical debate concerning the nature of reality, and knowledge have a long history (367). Much has been and continues to be written on the subject. A full rehearsal of these arguments is beyond the scope of this thesis, however acknowledging my own position is vital as it informs my methodological decision making.

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As stated in the introduction (Ch. 1), I return to academic research as a mature student having spent my career working in various capacities and roles with children and young people. This research study is borne out of my experience of working with children who presented as suicidal. This front-line experience also informed and embedded my commitment to emancipatory approaches, namely feminism and children's rights.

My undergraduate degree was in Sociology, and theories of social constructionism and critical realism are akin to my quest to understand social meanings and realities. The critical realist approach to understanding the social construction of mental illness has supported my exploration of this theoretical model, as well as work in the field (368,369). I accepted that people experienced mental ill health, knowing, and working with people who were troubled by auditory and visual hallucinations, depression, anxiety, paranoia, psychosis, etc. However, what this meant to the individual and those around them invariably differed. Studies such as that by Rosenhan, 1973 (370) where eight individuals pretending to experience symptoms of auditory hallucinations are detained, highlighted that expert knowledge of mental illness is fallible. Considering some of these ideas about the social construction of mental illness, led me to question how knowledge about suicide and suicidality in children is created and what meaning it holds. Accepting the realist position that children do consider, attempt, and die by suicide. And yet simultaneously understanding that this reality, what it means to different people, and the role they play in creating this knowledge is variable. For example, what is understood to be suicidal behaviour or 'counted' as a child suicide is highly variable and depends on who has influence over the process and perhaps their own underlying beliefs about child suicide. Such views and ideas can also change over time.

The French post-structural philosopher Michel Foucault (371), provides a theoretical framework that informs my thinking about knowledge and discourse. Much of the philosophical debate around discourse prior to Foucault had been concerned with linguistics, and semiotics (372,373). Foucault's (371) concern was with power and knowledge and discourse. He conceptualised discourse as socially produced knowledge, legitimised by the power of institutions and social structures. His work highlighted that knowledge is not fixed, and how what we know to be true at a specific point in time may not be true in the future or past. He also recognised that what may be held as true in one social context or society may not be in another. Much of Foucault's work was concerned with showing how knowledge is a

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productive entity that changes over time. His works on 'Madness and Civilisation' (374), the 'Birth of the Clinic' (375), 'Discipline and Punish' (376), and 'The History of Sexuality' (377) providing tangible examples of the complexity and power of discourse, and particularly in the fields of mental illness and health.

Although the purpose of this thesis is not to conduct a Foucauldian discourse analysis of the topic, his theories inform the investigation. They support a depth to the analysis and substantive theory, without constraining it. Foucault himself never intended his ideas to be constrictive and presented them for interpretation *"What I say ought to be taken as 'propositions', 'game openings' where those who may be interested are invited to join in;..."(Foucault, 1991; 74* (378)), thus allowing for further development of these idea through application.

Pragmatism is often associated with the application of mixed methods, but this can often deny any philosophical affiliations or considerations and is presented simplistically as selecting the methods best suited to the question. There have been recent arguments to reinstate pragmatism as a philosophical discipline in its own right (379). However, without disregarding the depth of this position, it is enough to acknowledge here the value in adopting an attitude that pays credence to action, and getting the job done. Overall, adopting an applied health sciences approach to this study, and focusing upon the research questions meant that a systematic and methodological approach was used.

### METHODS

### Mixed Methods

Mixed methods research (using both qualitative and quantitative research methods within a single study) is arguably relatively new and remains a largely contested approach. Some argue it is the third paradigm (358), not bound by the constriction of traditional positivist (Quantitative) and naturalist (Qualitative) approaches, it allows researchers to choose the research method that will best answer the research question (380). There is much debate about epistemological issues and paradigm wars, but most mixed methods researchers advocate it is grounded in 'pragmatism' and also suited to emancipatory / transformative

research (380). These conceptual frameworks encompass the driving forces associated with my choice of research methods.

As discussed in chapter. 2, the field of Suicidology has been dominated by quantitative research and there have been calls to recognise the value and contribution of qualitative research in furthering the academic acumen in this field (136). Equally these views have been criticised for rejecting the validity and contribution of quantitative research (381).

Both quantitative and qualitative approaches offer a range of different research methods. Albeit researchers may choose to position themselves at opposing ends of the positivist – interpretivist spectrum, the methods themselves can be used together to provide a greater understanding of complex societal issues. Mixed methods allow research questions to be answered more fully, whereas a single methodology alone would not provide the depth or scope of information required (357).

The mixed methodology can reflect a critical realist (CR) approach (361,382). Critical Realism drives the objectives of this study: capturing the objective reality for children who are suicidal and referred to CAMHS (the number of children referred, who was assessed, who was entered into a treatment pathway etc.), alongside the subjective experiences of these children and those who shape and influence responses to them (their parents / carers and the CAMHS practitioners), demanding a mixed methods approach. These methods fit together like pieces of the same jigsaw puzzle to provide a more complete picture of the research phenomena: what happens to children and young people who are referred to CAMHS for suicidality?

There are many mixed method study designs, and efforts to categorise these continue to evolve, with authors attempting to advance understandings of the field, and demystify the ever-increasing amounts of jargon. Tashakorri and Teddlie, 2015 (383) provide three main typologies: mixed method, mixed model, and multi method. (These are then defined and redefined by others in the field (384–386)). *Mixed methods* denote the use of both qualitative and quantitative research methods and includes both *mixed method* and *mixed model* research. *Mixed method* research uses both quantitative and qualitative research methods, which can be sequential in design, or parallel (convergent). *Mixed Model* research uses multiple research uses multiple to a particular paradigm - either qualitative or

quantitative (380,383). Other authors such as Morse, 2003 (384), argue the main difference between *multi-model research* and *mixed method research* is that with multi – model research there is no dependency between the findings of entirely separate research studies. Morse, 2003 (384) also advocates that the theoretical drive of a research project will determine the direction of the research and which methodology will be more dominant. Suggesting inductive reasoning is associated with exploratory research and qualitative methods, whilst deductive reasoning implies the testing of a hypothesis, and quantitative methods.

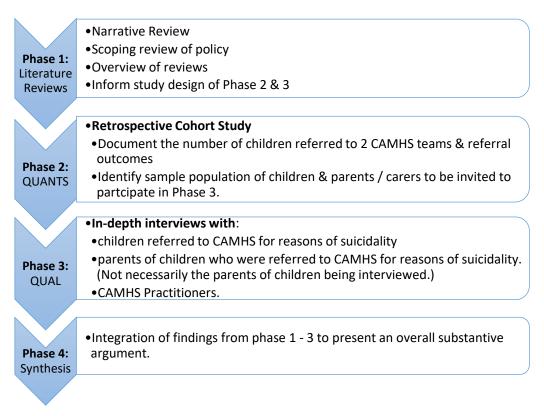
The theoretical drive of this study is inductive - exploratory. Literature reviews were completed to establish what is known regarding current policy and practice. The findings from these reviews (Ch. 2), informed the development of the stages that follow. Quantitative methods were used to establish base line evidence of the numbers of children being referred to CAMHS for reasons of suicidality and the outcomes of these referrals, before using qualitative interviews to explore what this means to them, and those supporting their care (parent / carers & CAMHS practitioners). To find out about the experiences of the children and parents who accessed the services investigated in the cohort study, the sample population of children, and parents / carers to be interviewed had to be identified from the data sources used for the quantitative study. Therefore, this is a sequential mixed method study. It does not fit neatly into Creswell's (358) description of explanatory sequential (starts with a quantitative study, follows with qualitative study to explain the findings of the quantitative) or exploratory (starts with qualitative study, followed by a quantitative study to test a hypothesis generated by the qualitative findings). Neither method is prioritised, both are needed equally to address the research questions, and through the theoretically informed narrative synthesis were brought together to produce new insight.

### Overall Study Design

This study comprised four phases. The literature reviews in phase 1 (Ch. 2) informed the identification of the specific knowledge gaps to be addressed in phases 2 & 3. Phase 2 was concerned with quantifying the number of children referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality in two different health boards, over a sixmonth period. Thus, identifying the sample population for phase 3. It also shows the referral outcomes for these children and explored potential relationships between demographic

indicators (such as age) with the referral outcomes. In phase 3 a series of qualitative interviews captured the perspective of children referred for suicidality, as well as the views of their parents / carers and CAMHS practitioners. The findings of these different phases were analysed separately before being brought together through a narrative synthesis – phase 4 (Ch. 8).

Figure 6: Study Outline



# **Research Sites**

Identifying CAMHS teams to participate in the study was initiated by contacting the service managers and lead practitioners of several CAMHS teams in Scotland. I initially approached four CAMHS services via existing contacts and recommendations. Two teams, from two very different geographical regions and health boards were immediately supportive of the study and agreed to participate (Site A and B). The support of these two clinical service managers allowed this research study to be realised. Although it would have been preferable to include a third more urban site, efforts to secure this were unsuccessful within the timescales of the PhD (See Ch.9).

The CAMHS services that participated in the study are referred to throughout as Site A and Site B. Although it may be apparent to those with local knowledge of Scotland where they are situated, in reading the narrative of the thesis overall, and within any subsequent publications, this further protects the confidentiality of the practitioner participants.

## PHASE TWO: RETROSPECTIVE CHOHORT STUDY

### Objectives:

- To quantify the numbers of children referred to two different CAMHS services in Scotland over a six-month period for reasons of suicidality and document the outcome of these referrals.
- 2) To document descriptive information about the identified sample population, age, gender, family composition, and any identified underlying issues, etc. as well as information about the person making the referral.
- To explore any potential relationship between demographic indicators and referral outcome.
- 4) To identify the sampling framework for the qualitative study (Phase 3).

### Data Source: CAMHS patient referrals

Information regarding the number of children who are referred primarily for reasons of suicidality is not routinely available (See Ch. 2). This information can only be identified from the initial referral letter and / or completed form sent to the CAMHS service. These referral forms and letters were identified as the data source for this study, as they provided access to the components of the sample population (14). To be able to access the data I had to position myself within the CAMHS service and extract data from individual referral forms in person. To do this a research passport, full PVG, honorary contract with the NHS, NHS REC approval and Caldicott Guardian approval was needed. (Please see ethics and governance below, and Appendix 4: Ethical Approvals).

Data was collected from referrals made over a period of six months to have a large enough sample from which to identify any potential referral patterns, as well as participants for the qualitative study in phase 3. Although the numbers of children referred for suicidality during this period may not be large, every CAMHS referral made during this time had to be reviewed to identify these individual records. To allow for some comparison between the referrals received by the different CAMHS teams – the same time frame was used: January –June 2019. (Although differences between the services, and context of the sample population limit their comparability.)

#### Variables

The data extracted reflected the objectives of the retrospective cohort study, and variables were specified in advance (Appendix 5: Retrospective cohort study variables). The name and address of identified individuals, alongside the name and address of their parents / carers was needed to provide a sampling framework for Phase 3. Reasons for referral, referral outcomes and anonymised demographic data was extracted to provide descriptive statistics for the sample population as well as explore the potential relationship between demographic indicators and referral outcomes. For example, the Scottish Index of Multiple Deprivation (SIMD) 2016 version<sup>11</sup> was used to calculate a deprivation score for each child referred for reasons of suicidality. The SIMD tool ranks geographical data zones (based on postcodes) by their level of deprivation. Decile rankings are achieved by combining data from 7 domains of deprivation measured: income, employment, health, education, access, crime, and housing.

#### Data extraction

I extracted the data in person, from within the CAMHS sites, according to the study protocol.

Extracting data to count frequencies from a qualitative source is not straightforward. Some degree of interpretation inevitably occurs. In this instance the presence of certain words in the referral document dictated whether categories were indicated. For example, 'suicidal thoughts' or 'been thinking about suicide' etc. However, the richness of the qualitative data in undeniably lost during this process, and issues of dubiety occurred as referral information was sometimes unclear or scant (See Ch. 4).

<sup>&</sup>lt;sup>11</sup> The SIMD 2020 version was released following data collection.

Furthermore, variables such as referral outcome were not clearly defined within the individual records and narrative data was used to ascertain what happened to the referral. (e.g., whether the individual was offered a face-to-face assessment, added to a waiting list etc.). It is important to note that categories were defined by me, based upon the information available, and were not necessarily categories employed by the CAMHS teams, although they were based on the data available. Pulling data into categories meant that simple terms like 'closed' were used to describe a collection of possible occurrences that could be counted as such. For example, 'closed' was used to indicate the case was closed because the person did not attend appointment they were offered, attended one and did not engage thereafter, was not offered further treatment, or attended for treatment and this has ended. The back story as to why the case was closed was lost through the process of anonymising and categorising the data. For additional clarity categories that define a range of situations are outlined in Appendix 5: Retrospective cohort study variables

A coding diary was kept throughout the process, which allowed for decisions to be tracked and to ensure consistency. Categories were discussed, agreed, and collapsed as necessary in consultation with supervisors ED, and MM. Categories such as 'other' were collapsed during the analysis process as numbers in these groups would have been so low, they may have compromised individual confidentiality.

#### Data Storage & Handling

Personal data was stored in an excel spreadsheet on a password protected NHS computer. It was only accessed within the designated secure office space at the NHS sites, in clear sight of approved NHS staff who ensured that data accessed was appropriate. It was only accessible to myself, and the CAMHS administrator responsible for sending invitations on my behalf (see phase 3 below).

Anonymised demographic data was stored in an SPSS file on a password protected and encrypted University of Stirling computer. It was then transferred to an individual password protected and encrypted University of Stirling Research Drive. It was intended that data would only be accessed from a password protected University of Stirling computer, located within the NMAPH – Research unit, University of Stirling. Following COVID lockdown restrictions, it was necessary to access the research drive via VPN (Virtual Private Network) on a password protected University of Stirling laptop. Access was shared with my supervisors, Margaret Maxwell, and Edward Duncan, as well as Dr Catherine Best, as the named statistician who verified data analysis.

A data management plan was created with the support of the University of Stirling data management officer. Considering the sensitive nature of this data, substantial attention was given to data protection and governance issues (see Study Specific Governance Approvals). A data protection impact assessment was completed and approved by my supervisor Margaret Maxwell, as well as the University of Stirling data protection team.

#### Analysis

A full study protocol and data analysis plan was written prior to data collection commencing, which was subject to internal (University of Stirling) and external (CAMHS (Child and adolescent mental health service) service managers, NHS REC (research ethics committee, R&D (Research and Development), NRS (NHS Research Scotland) and Caldicott Guardian) review (Appendix 4: Ethical Approvals).

Data analysis was conducted independently, with Catherine Best (NMAHP-RU statistician) verifying process and results. Descriptive statistics were produced summarising the characteristics of the children referred and referral outcomes. Continuous variables were summarised as mean and standard deviation, or median and Inter quartile range (IQR) as appropriate. Categorical variables were summarised as frequencies. Chi Squared analysis and Fishers exact tests were used to examine relationships between categorical variables. Fisher's exact test was employed when small cells sizes meant that Chi Square tests were not appropriate. One-way ANOVAs were used to examine if continuous variables such as age at referral were associated with referral outcome.

### PHASE 3: QUALITATIVE INTERVIEWS

**Objectives:** 

 Interview children who have been referred to CAMHS because they have been thinking about or have attempted suicide, to explore their views about their care journey.  Interview the parents / carers of children referred to CAMHS, and CAMHS practitioners to explore their perspective.

Qualitative research methods is an umbrella term for a whole range of interpretative research tools often considered to reflect the epistemological beliefs of the individual researchers (128,387), but which strive to reveal or give voice to the experience / perspective / reality of the population of interest. The distinction between qualitative / quantitative methodologies does not wholly reflect the nuance, differences and intellectual battles that play out between different qualitative researchers. Qualitative enquiry ranges from naturalist (purely observational) to constructivist and attempts to categorise these approaches continue to evolve (388). Qualitative approaches include but are not limited to ethnography, phenomenology, narrative enquiry, grounded theory approaches, discourse and discursive analysis, and participatory action research (387,389). The boundaries between paradigms are much more fluid in recent years (390), and consequently researchers choose to use various and sometimes overlapping methodological approaches that best fit their own epistemological, and theoretical position. Academic research studies are also often funded a set amount of money for specific periods of time and do not allow for more traditional sampling methods such as those used in grounded theory. Researchers often need to make pragmatic choices about research methods that will allow them to gather the data they need with the resources available.

The methods used to collect study data for analysis are driven by the intellectual position of the researcher and practical considerations, as much as by the research questions. Methods for qualitative data collection include participant observation, focus groups, interviews, arts-based methods, and participatory / collaborative methods. These data collection techniques and tools can be used and understood in a variety of different ways depending upon the standpoint of the researcher.

Methods are chosen not only to reflect the theoretical position of the researcher; their selection is often also about ensuring the research is unbiased and conducted using a rigorous methodology. Researchers want to know they are producing research that will be taken seriously (391), editors want to publish research of a high standard, and funders want to ensure they make sound investments (392).

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A range of tools and criteria have been developed to measure quality in qualitative research however, this remains a highly contested area. There have been attempts to apply criteria traditionally used to judge quantitative studies such as validity, and reliability. Validity refers to how well the research did what it set out to do, and reliability - how replicable the study and results are (393). Many qualitative researchers reject the use of quantitative criteria as inappropriate given the wide range of different approaches housed under the qualitative research umbrella (394).

Reliability, credibility, and trustworthiness, first suggested as more appropriate terminology by Guba and Lincoln (395,396), have become widely accepted terms used to judge and describe how well a qualitative study was conducted (397). There is an ever-expanding range of new criteria and checklists being developed with which to specifically appraise qualitative research (CASP (Critical Appraisal Skills Programme)(398), CORE-Q (Consolidated criteria for reporting qualitative research)(399), STROBE(400) (401)). However, as noted by Sandelowski, (401) and Hammersly, (394) there remains an element of judgement / personal bias / personal taste in their application.

Techniques such as member checking (asking participants to validate interview transcripts), triangulation (the use of more than one approach, to corroborate findings), and analytic induction also offer researcher's practical opportunities to improve the trustworthiness of their study (391,392).

Overall, the issue of quality in qualitative research remains unresolved for many authors and there continues to be a vast amount of literature attempting to offer solutions. However, given the diversity of positions it is unlikely a resolution incorporating all viewpoints will be found. Arguably responsibility for how well a study is conducted and reported lies with the researcher regardless of their position (397).

Through the transparent reporting of the study design, selection of methods, how the study was conducted, data analysed, and interpretations made, this study was developed and realised using a rigorous approach. Consideration of issues in relation to the quality of the study are made throughout the thesis, and specifically further addressed in the discussion and limitations (Ch 9).

One to one semi-structured interviews were chosen for this study, because they were felt to provide the most appropriate form of data to answer the research questions, as well as promote the safety and confidentiality of the participants. Alongside these pragmatic justifications, interviews were chosen as they allow participants voices to be heard (402), reflecting a children's rights-based approach, and feminist position (403). Feminist theories have often been associated with 'giving voice' to those who are often denied a voice, those who may be considered disempowered, and whose experiences are often under researched (404). The 'voices' of all participant groups within this study could be considered under researched.

Qualitative interviews also support a phenomenological approach concerned with the individuals lived experience (405) which can also then be interpreted according to theoretical understandings and beliefs about how the meaning attached to these experiences is constructed (406).

"The qualitative research interview attempts to understand the world from the subjects' points of view, to unfold the meaning of their experiences, to uncover their lived world prior to scientific explanations.... At the same time, however, the term subject indicates that people are subject to discourses, power relations, and ideologies that are not of their own making but that nonetheless affect and perhaps constitute what they talk about and how." (Kvale and Brinkmann; 2015:3(407))

Semi-structured interviews allowed participants more opportunity to talk about issues most relevant or important to them (than would have been the case in a structured interview), whilst also providing the researcher the opportunity to ask questions relating specifically to the research questions (this would be less so with unstructured interviews) (408). Given the sensitive nature of the discussion topic, semi-structured interviews also supported the development of rapport and trust required, as well as providing margins to support safe boundaries around the conversation (see ethics below). The one-to-one interview was preferable to a focus group format as focus groups would not have assured the anonymity of participants and could have compromised their safety (409). Topic guides were created for all interview cohorts reflecting the research questions (Appendix 6: Interview topic guides).

In essence, interviews are a conversation between individuals. The dialogue between the interviewer and participant serves to co-produce new knowledge (410). However, conversations in the context of a research interview are subject to pronounced power differentials, are directed rather than free forming, and require significant reflexivity on the part of the researcher in relation to their presentation and interpretation of what is said (411). My previous experience of working with children, and the families of children who were suicidal provided me with some 'insider' status (412) that facilitated establishing trust and rapport with participants within the interviews more readily. I was perhaps more relaxed and confident asking children and parents questions about their experiences of suicidality and help seeking than I may have been without prior knowledge and experience. Likewise, in interviews with practitioners my prior experience equipped me with an understanding of their position. However, new to the role of researcher I also had to be mindful of my role as an 'outsider' (412), maintaining different boundaries and not falling into a supporting and directing role with children. Although my stance may not be considered neutral given the previous experience I brought to the interviews, I was aware of and reflected upon this throughout. I also note that what is presented here is one interpretation and there may be others. (This insider / outsider status is also referred to in the introduction (Ch 1) as well as the discussion and limitations chapter (Ch 9)).

#### Qualitative Data Analysis Method

There is a vast range of methods used by qualitative researchers to analyse their data, reflecting their beliefs and attitudes, but which also recognise the individual interpretation of researchers. Commonly used approaches within applied health research are framework analysis (413) and content (414) or thematic analysis (415). Although framework analysis is both inductive and deductive, originating from policy research - it is most suited to research projects which have specific lines of enquiry that can be used as a priori headings (413). Albeit this can be useful in helping to organise data, I was concerned using such an approach could limit my ability to appreciate the richness of the data, and nuanced undertones that may convey the experience and subjectivity of the individuals being interviewed. Thematic analysis as purported by Braun & Clark (415) is a-theoretical providing flexibility in its application. The method they outline supports the creativity of the qualitative researcher in identifying

themes and patterns from their data set. However, I wanted to go beyond describing the data, and consider what is said, and unsaid, and what this might mean overall.

While Interpretative Phenomenological Analysis (IPA) and narrative analysis were appealing because they have a stronger focus upon the subjective meaning of what the interview participants are saying, neither reflected the depth of analysis or level of creativity with which I wished to approach the data. IPA, which has philosophical roots in theories of phenomenology and hermeneutics (405), at its most simplistic level can be described as attempting to understand the meaning of an individual's experience to them. The focus remains upon the "phenomenon", and although some argue it can fit with narrative and discourse analysis, it often remains descriptive of an individual's experience.

Narrative analysis is concerned with how individuals structure their stories and uses a constructionist approach to consider the creation of an identity (416,417). However, although I wished to explore the identification of individuals as suicidal, I also wanted to compare experiences and discourses within and between the different groups of people I interviewed, and to locate these within the broader social context.

Discourse analysis, concerned with how words both spoken and written, are productive and not just descriptive (418), has become a popular approach to qualitative interview analysis. Broadly speaking there are two different camps of discourse analysis: conversational analysis or discursive analysis; and Foucauldian discourse analysis.

Discursive analysis has foundations in linguistics, with philosophical forefathers such as Saussure (419). These ideas have been developed to provide a model for conversational analysis widely used in psychology (420,421). This approach focuses upon the subject position and interpretative repertoire as revealed through the words used. Although mindful of the value in viewing conversations as productive, this micro level detailed analysis does not take account of broader social structures, or indeed what is unsaid. The meta-ethnography conducted exploring the views and experiences suicidal children have of mental health support services highlight's that power can lie within what is unspoken (143).

Foucauldian discourse analysis is generally considered to be a more macro-level approach to textual analysis. Examining discourse through this lens reveals the construction of knowledge and power. It goes beyond the immediate situation to also consider historical subject

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positions, and how discourses change over time. Foucault articulates the power that lies within what is said, and what remains unspoken (422,423).

"To this theme is connected another according to which all manifest discourse is secretly based on an "already said"; and that this "already said" is not merely a phrase that has already been written, but a "never-said", an incorporeal discourse, a voice as silent as a breath, a writing that is merely the hollow of its own mark. It is supposed therefore that everything that is formulated in discourse was already articulated in that semi-silence that precedes it, which continues to run obstinately beneath it, but which uncovers and silences. The manifest discourse therefore is really no more than the repressive presence of what it does not say; and this 'not said' is a hollow that undermines from within all that is said." (Foucault, 1989:27 (423)).

Foucault does not detail "how" to do discourse analysis (424), and most Foucauldian informed analysis draws upon written textual formats such as newspapers, policy documents, research literature to show the fluidity of the concept being considered. Bonnor and Bacchi (425) recently applied their interpretation of Foucauldian discourse analysis to interviews conducted with female cyclists. They set out to identify within the interviews "what is said" about an "object" (bike) and "subject" (cyclist). Their study helps explain and express the concepts of Foucauldian knowledge creation and subjectation. However, following this method prescriptively may mean other potentially emerging themes between interviews and participants could be missed, and would not allow for consideration of what is unspoken.

Although recognising the strengths and limitations in many different analytic approaches to analysing interview data, Charmaz' (426) 'Constructivist Grounded Theory' offers an approach that recognises the existence of multiple realities, and the role of the researcher in constructing an interpretation of those presented by the participants. It also allows for the researcher's theoretical position to be recognised, and fluidity in data collection as it is informed by and evolves from the analysis (426). This method was helpful in that it acknowledged interviews are not all conducted in the same way, and as I conducted more interviews, I could ask more pertinent questions, and test out ideas that emerged from a previous interview. Memo writing is encouraged alongside data collection as it can help to inform the development of early codes and is something I made full advantage of. Being able to stand back from the data and critique it as ideas emerged supported the development of thought upon which final codes and theory are based.

Crucially, constructivist grounded theory also appreciates the importance of discourse (426), and thus exploring interview data from a position informed by Foucauldian discourse analysis could be realised.

#### Sample

Constructivist grounded theory, although allowing more flexibility and creativity than its methodological predecessor Grounded Theory (427) still purports 'theoretical sampling'. This is where the researcher continues to conduct interviews until they reach 'saturation'. That is, until they feel confident that no new categories of interest are emerging from the interview data. Although theoretical saturation is the most coveted way of deciding sample size, for many it is not feasible due to practical constraints (428).

Although there are many different views upon how many interviews are enough, six in depth interviews has been suggested by Guest, 2013 as 'The magic number' (429). The rationale being that the majority of coding, even in much larger sample populations occurs within the first six interviews, and is also supported by the recommendations of others (429). This suggestion is of course qualified by reference to the homogeneity of the sample population, and richness of the interview data. Qualitative research is by nature different from quantitative, and it is arguably inappropriate to apply to the same processes to sampling (430). It is suggested that questions about generalisability be replaced with concern for validity (430). The number of participants is believed to be less important than the richness of the data, and whether the interviews are *'informationally representative'* (431). Debate upon the ideal qualitative sample size continues, however it is broadly accepted that judgements need to be made by researchers (429,431). A recent systematic review of sample sizes in qualitative studies found that reporting of sample size was often lacking, or unclear (432). As is often the case with qualitative methods debates much depends upon the epistemological position of the researcher as much as external constraints such as funding requirements etc.

Working within the strict NHS ethics and governance conditions, and within the parameters of PhD timescales and resources, it was necessary to specify in advance approximate numbers

of individuals to be interviewed. Pragmatic considerations about what was achievable with the resources available, influenced decision-making around sample size. As I had decided to interview three different groups of participants: children, parents, and practitioners; I anticipated the sample size for each group would be small. However, including these different perspectives would provide a richer and more full understanding of the research topic. Recruiting participants directly from the sites where the cohort study was conducted meant that although it could be suggested the sample is not representative of all children, parents or practitioners, they were *"informationally representative"* (431) of the experience of children and parents referred to CAMHS in these areas for reasons of suicidality, and the practitioners that work with them. It was anticipated the data from these interviews would provide a snapshot of the experiences of the population of concern.

In the study protocol approximate targets for purposive sample populations across the two sites were provided as illustrated below (Table 6). It was decided to try and include more child participants given the potential for diversity of age ranges, and the central importance of their experience to the thesis. Although the sample population was purposive in that only people meeting specific criteria were invited to participate, it was also convenience sampling as any child or parent who opted in was offered an interview.

Sample Population	Approx. Target	Ideal Strata	Inclusion / Exclusion Criteria
Children	N=12	N=6 from Site A, and N=6	Inclusion:
		from Site B.	8-18yrs of age
			Male or Female
		N=6 who had received	Referred to CAMHS for
		treatment from CAMHS.	reasons of suicidality
		N=6 who had been	Exclusion Criteria
		rejected or were still	Under 8yrs of age or over
		waiting on treatment.	18yrs of age.
			Primary reason for referral
		N=6 males	to CAMHS was something
			other than suicidality.
		N=6 females.	Hospitalised as an in-
			patient.
Parents / Carers	N=9	A mix of parents,	Inclusion Criteria:
		stepparents, foster	Parents, kinship carers,
		parents, kinship carers,	foster carers, allocated

#### Table 6: Summary of proposed sample

		and residential carers would be preferable. A mix of genders would also be preferred.	residential children home worker. Child was referred to CAMHS for reasons of suicidality. <u>Exclusion Criteria:</u> Not the parent / guardian of the child. Child was referred to CAMHS primarily for reasons other than suicidality. Known to have been bereaved by the loss of their child to suicide. (This applied to sending invitations only and any parent who disclosed bereavement by suicide and wished to participate was
Practitioners	N=9	Could include consultant psychiatrists, specialist nurse therapists, and child psychologists.	supported to do so).Inclusion CriteriaWorks as a practitionerwithin one of the CAMHSservices involved in thestudy.Assesses and supportschildren who are referred toCAMHS for reasons ofsuicidality.Exclusion CriteriaDoes not have a job rolethat involves assessing andtreating children forsuicidality.Works out with the CAMHSservices involved in thestudy.

# Coding

Interview transcripts were initially grouped by participants (children, parents, practitioners), and coded line by line in Nvivo 11. Further focused codes were developed following an iterative process of constant comparison, and reflection and the creation of concept maps. Standing back from the data and using story-line analysis helped to explain the process and refine these focused codes and grounded theory *'into a digestible format'* (433). Birks and Mills (433) describe storyline as an analytic tool that can help to explain the abstract concepts and process of a grounded theory. Theoretical coding emerged from this process, reflecting the wider knowledge accrued through the research journey, analysing and identify relationships between codes (426). Thus, the findings from my research interviews go beyond describing what was said, to offer theoretical insight, initially for each subset of interviews and then for the thesis overall.

#### **Ethical Considerations**

Ethical principles inform us how we should act, and research ethics guide our actions throughout the research process, ensuring participants and especially vulnerable groups are protected from harm (434). Ethical considerations should not be a one-off event before a study begins, but fluid and responsive throughout the study's life cycle (435). The pioneering works of Beauchamp and Childress, 1979; 2013 (436), outlines four main ethical principles that continue to permeate all principle-based ethics. These four principles of autonomy, beneficence, non-maleficence, and justice can be identified in most ethical research guidelines (The Belmont Report, 1979 (437); ESRC guidelines, 2017 (438), The Research Ethics Guidebook, 2018 (439), Ethical Research Involving Children (ERIC) (440)). These principles are believed to be universal. Autonomy refers to independence and freedom to act. In research terms, individuals' participation must not be coerced, they must be fully informed, and must have the capacity to understand and give active consent if they wish to. Beneficence conveys that the research should help others. Non-Maleficence means do no harm; akin to the medical code of ethics and generally means that no harm should come to research participants (436).

These principles were not intended to be absolute and have been elaborated to provide further clarity in relation to good practice in published guidebooks and guidelines across the globe. For example, the ESRC Framework for Research Ethics, lists six principles; ensure quality and integrity of your research; seek informed consent; respect the confidentiality and anonymity of your research respondents; ensure participants participate voluntarily; avoid harm to your participants; and research should be independent and impartial (441).

How research principles are interpreted and applied depends on the beliefs of the researcher. Their world view influences what they identify as ethical issues (442). Ethical models of thinking and reasoning can support our understanding of this vast philosophical landscape, (Deontological, Utilitarian, Virtues, Feminist, etc. (436,442), however it remains predominantly reflective of the individual and societal moral perspective.

Governance refers to legal obligations and requirements and varies locally. However, local policy embodies, international guidelines, and principles such as The Nuremberg Code 1947 (443), and The Declaration of Helsinki (World Medical Association, 1964. 1989, 2013 (444)); which arose in response to abusive practices in medical research such as those in Nazi Germany where people were ultimately murdered in the name of research (445). The main principles of the Declaration of Helsinki are reflective of treating participants as individuals, respecting their rights, seeking informed consent, and not causing harm. It also states researchers must have training in Ethics and outlines vulnerable groups that require additional ethical consideration (444).

No definitive legislative requirements governing research ethics currently exists (446). The legislation that researchers must abide by depends upon the country, community, and population within which research is being conducted. Legislation and documents identified as relevant to the ethical considerations to be made for this study are as follows:

- Data Protection Act (2018) (447)– this relates to access to information, as well as data storage and handling, outlining the principles of General Data Protection Regulation.
- Mental Capacity Act (2005) (448)– provides guidance on capacity to give informed consent.
- The Age of Legal Capacity (Scotland) Act (1991) (449) (This does not pertain solely to medical procedures but also covers agreements & transactions.)
- Gillick Competence and Fraser Guidelines (1985) (450) Although related specifically to the case of Victoria Gillick has become widely used to assess the competence of a child to make their own decisions.
- Children's Scotland Act (1995) (170)– States that children can give consent providing the child is knowledgeable and mature enough to form an opinion. This is also relevant along with Children and Young Peoples Scotland Act (2014) (451), in relation to child protection. It infers that if the researcher becomes aware of

information that suggests a child is at risk or in danger then they have a duty to share this with the relevant protective agencies.

- United Nations Convention of the Rights of the Child (1998) (UNCRC) (171)– specifically articulates children's right to be researched, and to be safe.
- Declaration of Helsinki (World Medical Association, 1964. 1989, 2013) (444)

### Ethical Research with Children

Children are a vulnerable group fundamentally because adults have power over them (452). Doing research with children is understandably subject to high levels of ethical scrutiny. Researching children's lives and experiences is often avoided, and the issues faced by especially vulnerable children (such as those who have attempted suicide) left unaddressed (453). The historical background of children being harmed, and even killed through medical research (445,454) adds weight to the need for rigor in consideration of ethical issues, and tight governance procedures in research involving children. More recent depictions of children as autonomous agents (51), supported by the children rights agenda, promotes the position that children should be consulted in research, that they have a right to be heard, listened to, and consulted on matters that affect them (455,456). The UNCRC, became enshrined by law in Scotland and the UK (The Children (Scotland) Act (1995) (170); Children and Young Peoples (Scotland) Act 2014 (451); The Children (Scotland) Act (2020) (457); The Children's Act (1998; 2004) (458,459). This has supported these high international ethical standards within local legislation.

There is evidence to show the benefits to children who participate in research, and this includes groups of vulnerable children for whom the research process gives power to their voice, validates their experience, and allows them to be heard (453,460). Children who are suicidal are deemed to be especially vulnerable and are often excluded from research trials for fear of risk (257,262). However, there is an emerging body of evidence suggesting that contrary to concerns that being involved in research may cause harm to participants, the experience of being involved in qualitative research for suicidal young people can have a positive impact on their well-being (144,461–463). A recent literature review found there to be no evidence to support the most prominent fear that by talking to participants about

suicide it will make them more vulnerable to suicide; in fact, they found it may help to improve mental health (144).

Weighing up the benefits of taking part in research with any risk of harm informed the study design process. The risk benefit conundrum is reflected throughout international regulations such as the Declaration of Helsiniki (444), and those from the European Commission, 2013 (464). A study exploring issues identified by researchers who conduct research with suicidal populations concluded that although stringent informed consent, and risk assessment measures need to be in place, 'Ethical research with people who might be suicidal is not greatly different to good research generally.' (Lakeman & Fitzgerald, 2009: 16 (465)).

A literature review of ethical issues in research with children identified contemporary issues to be: informed consent, protection of children, anonymity and confidentiality, and payment of participants (292). This international review was commissioned by the Child Watch International Research Network, a collaborator with Ethical Research Involving Children Project (ERIC). ERIC have produced a charter, and guidelines for good practice (440) that was used to support considering the ethical concerns for this study.

#### Informed Consent

How and by whom children are invited to take part in research studies is important within the context of informed consent. Concerns of coercion can arise if a therapist or teacher asks them, as children may agree to try and please them or be too afraid to say no because of the future consequences (466). The same may also be true if the parent or guardian is first made aware of the research study, and the child is made to feel that they should or should not participate, depending upon the adult's viewpoint. Confidentiality also needed to be considered at this early stage as giving them information leaflets etc. to take home stating they are invited to take part in a research study about suicide and mental health support services, had the potential to compromise them in front of parents, siblings, or peers.

In line with General Data Protection Regulation (GDPR) (447) I was unable to contact the child / young person directly and relied upon CAMHS administration staff to make initial contact; sending a letter and information pack (a participant information leaflet, a postcard with an URL code linking them to the website, and a USB card with a copy of the animation (Appendix 7-9) on my behalf.

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For consent to be informed, it must be freely given, and the child must fully understand what they are consenting to by participating. This means that information about the study, and what is expected of participants is conveyed to the children in a format accessible to them and that they can understand. There are guidelines (467,468) on creating health research participant information leaflets for children and young people, and research which suggests that using visual imagery and multi-media formats can improve acceptability and comprehension of the information presented to children (469–471).

Aware of the importance of informed consent in research with children, and keen to involve children and young people in every stage of the research study I worked to identify a group of young people who could create a short animation to explain the informed consent process to potential participants. Allowing young people to design, and word the content of the animation would make the complex information about what would be involved in participating more meaningful and accessible to children and young people.

After several unsuccessful attempts to engage local colleges and art groups, I met with the creative learning manager at the MacRobert Arts Centre (which is based within the University of Stirling campus) who was keen to collaborate on such a project. The MacRobert Arts Centre ran a film crew class for teenagers that they identified as a group who could take this forward. Firstly, I met with their tutor to discuss the idea, before presenting it to the young people themselves. They were happy to take it forward and welcomed the opportunity to contribute to a real-life research project.

The group were provided a brief, detailing the information the animation must contain. Thereafter they worked with their film tutor to create an original and highly innovate animation over the course of a term. The film was launched at a special event within the MacRobert Arts Centre film house to an audience of invited guests. It was introduced by a key-note speaker from Children in Scotland who spoke about children's rights and the importance of involving children in research and followed by a panel discussion. The animation was well received. Additionally, I was awarded a runner – up prize of £500, at the Scottish Graduate School of Social Sciences Impact Awards 2019. Two of the young people also co-presented a key-note session on collaborative working and the process of creating the animation at a conference on Children and Young Peoples Mental Health and Well-Being at the University of Stirling in September 2019.

Recognising that children and young people are shown to engage more with multi-media and on-line information sources (469), a web-page for the study was created (<u>https://is-there-anybody-out-there.com/</u>). It housed all the relevant information pertaining to the study from the participant information sheets, along with the animation itself. It also included a contact form, so that interested parties or potential participants could make direct contact. This was used by two participants who did not want to share their participation with their parents.

A postcard (Appendix 9), depicting a still image from the animation, with a QR (Quick Response) code link to the webpage was also created to provide a discrete source of information about the study to potential participants, who may not want to retain a full information sheet. This postcard was amended to include a reminder notice and sent to potential participants who had not responded to an initial invitation two weeks after. It was then further amended to include a note of thanks and was given to participants within their 'Thank You' pack which also contained a list of local supports. The consistency of the use of the image from the animation worked like 'branding' and supported the recognisability of study artefacts (472).

Participant information leaflets were designed to be accessible and used a combination of simple statements and graphics. These were reviewed by the children and young person's resource worker at 'See Me' (a Scottish mental health stigma charity), and had an overall readability FLESCH score B, with A being a score of very easy to read (473). Appreciating that the literacy levels of the children would be variable – keeping the language simple with graphics to support it allowed the information to be more accessible to all. The language remained neutral and child person friendly.

After receiving an invitation<sup>12</sup> children had to initiate contact with me directly if they were interested in participating the study. Contact could be made by telephone, email, text message, or via the webpage. Invitations were titrated (sent out twenty at a time), to avoid over recruitment as there could have been a potential for harm to be caused if I had rejected a child who wanted to participate because the target sample size had been reached (440). However, recruitment was very slow in Site A. Following discussions with supervisor's it was agreed to send out invitations in batches of 40 in Site B.

<sup>&</sup>lt;sup>12</sup> Letter, information leaflet, postcard with QR code, and a USB credit card flash drive with the animation on it

The Children's (Scotland) Act (1995) (170) and Children and Young People (Scotland) Act (2014) (451) state children can give informed consent if they have the capacity to do so. Gillick competence (450) and was allows that used to ascertain that children over age 12 did not need parental approval to participate, although this was also encouraged. Parents / guardians were informed about the study at the same time as the child / young person as an information pack and invitation to participate was sent to them simultaneously. If the child was over 12 years of age and preferred not to inform their parents, they were interested in participating, their right to privacy was respected but, they were also encouraged to identify a safe adult e.g., teacher or CAMHS worker (if they are involved with CAMHS) they were happy to share this intention with. Where children were too young to give consent (under 12 years), parental consent was to be sought.

Checks were built into the consent process to ensure that participants understood they could withdraw consent at any point, without consequences. Firstly, at initial contact they were made aware that by agreeing to meet to discuss the research they did not have to go ahead with an interview. Prior to the interview, their right to withdraw consent was explained again. Following the interview, the researcher also checked with the participant they were happy with the interview and for their data to be used.

All the children who participated were invited to watch the animation, as well as reading through the information sheet to go over issues such as confidentiality and how their data would be used prior to the interview. If they wished to proceed with the interview participants were then asked to sign a consent form, parental consent form, and child assent form as appropriate.

#### Safety Concerns

Over-riding all ethical concerns is the premise that participating in the research study should not cause participant's harm. As has been mentioned already, this applies to issues of confidentiality and informed consent as well as the physical and emotional safety of the individuals. It also requires consideration of the researcher's personal safety.

Interviews were conducted at agreed safe locations; within the CAMHS service, at the person's home, or an agreed community venue. I established there were always other identified safe adults in the vicinity of where an interview was taking place and children were

only interviewed at home if the parents were aware and present within the house. Measures were taken to protect my own safety such as carrying a mobile telephone, using the Skyguard SOS system (474) and always notifying a colleague / supervisor of my whereabouts.

Following lockdown restrictions put in place March 2020 it was necessary to conduct a few final pre-arranged interviews via Skype, as meeting in person was prohibited. These interviews were conducted with the child and parents having had several discussions with me beforehand to ensure they fully understood the consent process, what was expected in relation to their participation.

There was a risk that children / parents and practitioners participating in interviews could become distressed during the interview, or immediately after. Distress protocols were created for each group of participants (Appendix 10) (475), that included creating emotional safety plans with people prior to the interview starting, as well as clear actions to be taken should there be a disclosure of a child protection nature, and or an expression of suicidal intent. At the end of the interview, participants were given an information sheet of local resources and national helplines and encouraged to identify a person they would speak to if they were upset. My experience of supporting children and young people who have been suicidal, and their families, equipped me with the knowledge and understanding to ensure that my responses were appropriate and informed. Children were invited to bring along a parent, sibling, friend, or other safe person, although many did not wish to. A range of participatory methods were offered to participants – play-doh, stress relief toys, colouring sheets, to help them relax and allow them to choose how they wished to engage.

## Token of Thanks

Paying children to take part in research could be considered coercion, but good practice would be to offer a token of thanks afterwards (292,476). By offering to pay for travelling expenses and giving all participants a £10 voucher following the interview, it demonstrated respect, valuing their time and contribution to the study.

The young people who created the animation were also presented with vouchers for cinema tickets at the launch event, and those who presented at the conference were given vouchers as a token of thanks.

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## Study Specific Governance Approvals

All researchers must apply for ethical approval from a Research Ethics Committee (REC) prior to starting their studies (440). Scrutiny by the REC can help to ensure that ethical standards and principles are embedded within the research design. Given the complexity of the research and governance application systems, advice regarding this process was sought from:

- My supervisors,
- Staff within the Nursing Midwifery and Allied Health Professions Research Unit who are experienced in completing IRAS and PBPP applications.
- An NHS ethics committee member
- An NHS research ethics & governance manager
- eDRIS (e- data research and innovation service) who provided information and support to researchers looking to apply to the Public Benefit and Privacy Panel for Health and Social Care.

I also met with the service managers, and clinical leads of four CAMHS services, as well as a child and adolescent psychiatrist. This was in line with the one of the top suggested recommendations from ethics committee members for good practice in ethical research involving people who are suicidal – *'Consult with the ethics committee, experienced researchers, support agencies, and potential participants'* (465).

In the first instance, an application was made for this study to the University of Stirling NHS, Invasive or Clinical Research Ethics committee. Following some minor amendments approval was granted to make an Integrated Research Application System application (IRAS) to the NHS research ethics committee and seek Research and Development (R&D) approval (Appendix 4). This application was made centrally online as a single application and was reviewed by NHS Grampian REC in February 2019. My principal supervisor and I telephoned into the meeting. The study was awarded conditional approval subject to some minor amendments such as, the inclusion of distress protocols for interviews (Appendix 10). Formal NHS REC approval was granted in March 2019 (Appendix 4).

A further application was then made to the NHS Scotland Public Benefit and Privacy Panel (PBPP) for Health and Social Care for access to public health data contained within the initial referral documents sent to CAMHS, as this required Caldicott guardian approval. The PBPP provide a centralised governance process for the consideration of requests for access to NHS Scotland data to benefit the public for purposes other than direct care. The application to the

PBPP was to be made on the grounds that Caldicott guardian approval was needed for more than one health board, and this was a centralised system. Prior to making the application an enquiry form was submitted to establish this was an appropriate application, and I attended PBPP training. It was advised this was an appropriate PBPP application and that it be submitted following NHS REC approval.

The PBPP in Scotland operate a system whereby they allocate a worker to review each application prior to submitting it to the panel. These systems have become so overwhelmed with applications that there was a waiting list for applicants to be allocated a worker. This process incurred nearly two months of delays, awaiting review of the application. Following review, I was advised that given the sensitivity of the topic, and vulnerability of the patient population they believed the application would most likely be escalated to tier 2 and possibly tier 3 for approval, and at the earliest this would not be completed until the end of September 2019. They suggested as there were only two health boards involved, individual Caldicott approval could be sought from each Board. They also advised that, even if the application were approved by the PBPP, it would still need approval from the individual Caldicott Guardians, and therefore this would seem the most straightforward route. The application to the panel was withdrawn, individual Caldicott guardian applications were made, and approval was granted.

The researcher already held a full PVG which was transferred to the University of Stirling. An application was made for a research passport with full occupational health checks undertaken by NHS Fife on behalf of the University of Stirling prior to the commencement of data collection. Applications were also made for honorary contracts with both NHS boards.

A further review process, which had not been anticipated, but which caused further delays to starting data collection, was an NHS research and development internal audit and review process. NHS Research Scotland conduct this study wide review on behalf of local boards to help their decision making regarding whether to grant NHS R&D permission, by reviewing all supporting documentation such as participant information sheets, and insurance documents etc. The host NHS organisation retains the power to grant NHS R&D permission. This review process was triggered by a request by R&D in the health board for Site B in March 2019 and took until the end of July 2019 to complete.

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### Involving Children and Young people in Research

As stated, not only is it good practice to involve children and young people in research, but it reflects children's rights (477,478). Considering where, how, and when to involve them depends on the motivation of individual researchers and the nature of the study. There has been recent examples of research studies that involve children from the proposal stage and as co-researchers, collaborating fully throughout the study, or indeed action research projects that empower the young people to conduct and take ownership of the study completely (479,480). Concerns remain that predominantly children's participation in research often remains tokenistic (481). However, for children and young people's involvement to be meaningful, it must also be relevant, appropriate and something they will benefit from (482).

Given this PhD was an ESRC funded studentship, the proposal and study design were generated by me, with the support of my supervisors. I tried to consider ways in which to involve young people throughout the study design lifecycle. Although appreciating the value in having children and young people co-create research, given the sensitivity of my topic, vulnerability of participants, and lack of wider support structures I did not seek to specifically recruit young people with experience of suicidality to collaborate on research tasks. I approached pre-existing groups of children and young people to ask for their input – thus support structures for these young people were already in place and their involvement in the research project was not connected to their position in the group or access to support. The specific tasks identified that young people could be invited to assist with were of themselves contained projects:

- 1. An animation to support the informed consent process.
- 2. Review of participant information leaflets and interview topic guides.
- 3. Writing a lay summary report of the findings. (It had been anticipated that a work placement could have been offered to senior high school students through a local school however, COVID restrictions have prevented this thus far).

### Synthesis

Integrating the results of mixed-method studies is crucial for the study to be viewed as a whole, and not separate projects. O' Cathain et al, 2010 (483) describe three approaches to the synthesis of different methods within the same research project: triangulation, following

a thread, and a mixed method matrix. They state triangulation within the context of mixed methods conveys the use of different methods being used to study the same phenomenon to get a fuller picture, with the findings of each component part of the study being compared for similarities and differences. Following a thread – they suggest occurs at the analysis stage – where themes that cut across the different elements of the studies can be identified. Other authors have similarly looked to existing mixed methods studies to consider their approach to integrating findings (360).

Mixed method authors seem to present these different models of integration as though they are not complementary, and that researchers must choose between them. I would suggest these different ways of integrating mixed method studies can in fact work together, and that I employed triangulation, following a thread, constructivist grounded theory and Foucauldian discourse analysis to my overall integration of the different study phases.

The synthesis of the component parts of this PhD study is explicated through narrative (Ch. 8). Arriving at this was an iterative process, bearing resemblance to Charmaz' (426) descriptions of constructivist grounded theory; as the study progressed the phases were no longer distinct entities but interacted with one another and informed the development of each. For example, the interviews with staff were conducted following completion of the literature reviews which allowed the opportunity to ask questions that had arose from their findings. Through memo writing, not just in the qualitative data phase, but throughout the PhD, this encouraged reflection, constant comparison and checking of themes and ideas. *'Following a thread'* therefore occurred throughout, and by applying a Foucauldian discourse analysis lens to the findings of each component part the overall picture could be considered – in a fashion not dis-similar to triangulation.

Recent authors (484,485) have advocated for a return to the use of theory to consider and interpret the findings of qualitative research studies, arguing that much health and social research is becoming a-theoretical. Using and generating theory is certainly not a new idea. Good research of any discipline should be grounded in theory, but not stuck in it or constrained by it. The findings of the thesis are considered within a sociological and Foucauldian context, whilst also bringing the component parts together to present my own analysis, interpretation, and overarching theory. It is important to note however, that although I may be 'thinking with theory' (485), this does not extend to such abstract

discussions that the outcomes of this study bear no relevance to the people involved. The thesis remains grounded in critical realism, with a principal aim of trying to understand better what is going on for suicidal children and young people who are referred to CAMHS, so that it may inform future development and delivery of services.

### Conclusion

This chapter describes and justifies my methodological position and the use of a mixed method approach. It also shows how this applied health research study utilises theory to provide a deeper understanding not only of what the care journeys and experiences of children who are suicidal and referred to CAMHS are, but what this means: to the children and young people, their parents, and carers, and the CAMHS practitioners, within the wider contemporary context.

This study design was developed by me and is unique to this study. Other researchers may have approached the issue differently and interpreted the findings in a different way. Acknowledging this and being both reflexive and transparent in reporting provides an understanding of how conclusions were reached.

The findings presented in the next chapter (Ch. 4) provide the base line statistics of how many children were referred to CAMHS teams in Site A and B for reasons of suicidality between January and June 2019. Descriptive statistics for this population and the referral outcomes are provided. The analysis of potential relationships between demographic indicators, and outcomes are also explored. The following three chapters (Ch. 5, 6 and 7) presents the data and analysis of the qualitative interviews, before bringing these findings together (Ch. 8). A discussion of these findings within the context of the literature, and consideration of the study's strengths and limitations, alongside implications for future research is provided in Chapter 9.

# **Chapter 4: Retrospective Cohort Study**

## **INTRODUCTION**

This chapter reports the findings of phase 2 of this thesis: a retrospective cohort study documenting the numbers of children referred to CAMHS for suicidality, and the outcomes of these referrals in two Scottish CAMHS teams. Following a prescribed protocol as described in Chapter 3, data was independently extracted from all referrals made to CAMHS in Site A and B between Jan – June 2019 inclusive. Data collection took place between August and December 2019. In Site A referrals were stored in paper-based files, while Site B used electronic patient records with original referral forms being uploaded as PDF documents. The data was anonymised at the point of entry to an SPSS file.

### AIMS:

1) Quantify the numbers of children referred to two different CAMHS services in Scotland over a six-month period for reasons of suicidality and document the outcome of these referrals.

2) Provide descriptive demographic information about the identified sample population: age, gender, family composition, etc.

3) Explore whether there is any potential relationship between reason for referral, referral source and demographic indicators with referral outcomes.

4) Identify the sampling framework for the qualitative study (Phase 3).

Findings are primarily reported using tables, charts, and graphs as appropriate. The findings are then summarised and process diagrams mapping the journey of care for children after they have been referred to CAMHS for suicidality in these two sites presented.

A full discussion of these findings in the context of the thesis, as well as consideration of the study's strengths and limitations follows in Ch. 8.

This chapter concludes that this customised retrospective cohort study shows there is a high number of children being referred to CAMHs for reasons of suicidality, and there is variation both within and between services in terms of assessment, referral outcomes and care pathways for these children.

So many statistics chapters in mixed method studies begin with the quote made famous by Mark Twain '*Lies, damned lies, and statistics*' (Anon). This is testament to the interpretative nature of numbers which are often presented as a pure and objective truth. Quantitative researchers traditionally hail from a positivist position, however, as is discussed in full in chapter 3, the statistics presented here are reflective of a critical realist position. Identifying referrals for children who were suicidal from individual records was both a complex and arduous task, given the inconsistencies in recording practices and variation in referral information provided. There is an unavoidable element of interpretation, and construction as the qualitative referral information and record of first contact is deciphered and coded. This may have been approached differently by another researcher, what is presented here is a transparent report of the findings employing the pre-defined protocol set out in Chapter 3. I proactively engaged in reflexivity and memo-writing, discussing, and verifying with supervisors throughout.

## RESULTS

## Base Line and Demographic Data

### Number of Referrals & Reason for Referral

In Site A, a total of 397 referrals were screened. This was the total number of referrals received by CAMHS at Site A between January and June 2019. This comprised: referrals that were accepted and put on the waiting list (n=161); rejected referrals (n=209); and direct tier four referrals (usually accessed by presentation at A&E (n=27). These categories reflect how referrals were organised within CAMHS at Site A. The total number of children identified as being referred to CAMHS because of concerns about suicidality (between Jan – June 2019) was 104, which was 26% of all referrals reviewed. Table 7 overleaf shows reason for referral was broken down as follows:

#### Table 7: Reason for referral (Site A)

	Number	Percent
Ideation	40	38.5
Attempt	8	7.7
Ideation & Previous suicidal behaviour and / or self-harm.	46	44.2
Attempt & Previous suicidal behaviour and / or self-harm.	10	9.6
Total	104	100

\*suicidal behaviour can include thinking about suicide, researching and / or planning a suicide, sending, or writing suicide notes, or previous attempts.

\*self-harm in this context includes all acts of self-harm regardless of intent and if noted by the referrer alongside suicidality was recorded because previous self-harm is known to increase future risk of suicide.

The total number of referrals screened in Site B was 762. This was the total number of referrals made to CAMHS across Site B between Jan – June 2019, that were directed to the following services: Suicide and Self-harm team (n=131), East (n=226), West (n=294), specific services for children who are looked after and accommodated, and for children who have experienced child sexual abuse (111). This included all referrals to these specific teams during this period, reflecting how referrals were organised. The total number of children identified as having been referred to CAMHS because they were experiencing suicidality between Jan – June 2019 was 180. This was 24% of 762 children referrals screened <sup>13</sup>. Table 8 overleaf shows a breakdown of the reason for referral as identified for those referred primarily for suicidality.

<sup>&</sup>lt;sup>13</sup> The actual number of children referred to CAMHS in Site B overall, would also include those referred for ASD assessments, the learning disabilities team, and psychological services and would be much higher. These referrals were not included or screened, on the advice of the data managers as these are not considered core CAMHS services, and the primary reason for their referral would not have been suicide.

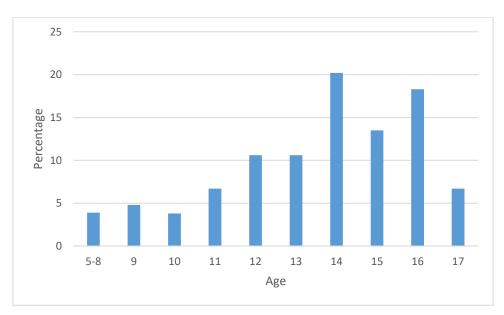
#### Table 8: Reason for Referral (Site B)

	Number	Percent
Ideation	73	40.6
Attempt	12	6.7
Ideation & Previous suicidal behaviour and / or self-harm.	58	32.2
Attempt & Previous suicidal behaviour and / or self-harm.	37	20.6
Total	180	

## Gender & Age

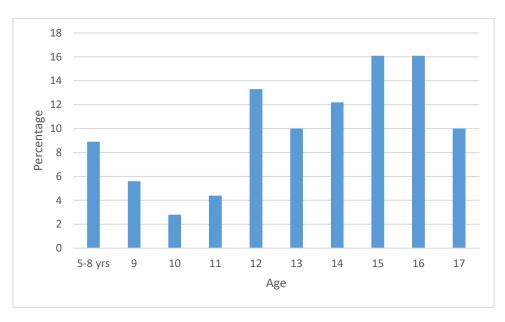
Of the children referred for suicidality to Site A; 42 (40.3%) were boys, 62 (59.7%) were girls. Their age at the point of referral ranged from 5 - 17. The mean age was 13.5, with a standard deviation of 2.52; Thirty percent of children were aged 12 and below. There was 1 missing data unit for age – therefore these statistics depicted in Figure 7 below represent 103 referrals.





\* Children aged 5-8 years are grouped together in line with ISD statistical reporting guidelines which state that numbers less than 4 should not be reported for personal data that may be potentially identifiable (486)

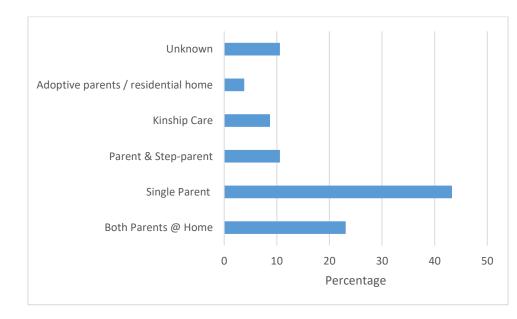
In Site B, 76 (42.2 %) of children identified were male, 104 (57.8%) were female. Age ranged from 5 to 17 years, with a mean age of 13.28, and a standard deviation of 2.96. Thirty-five percent of children were aged 12 and under. This is presented in Figure 8 below.





\* Children aged 5-8 years are grouped together in line with ISD statistical reporting guidelines which state that numbers less than 4 should not be reported as participants may be identifiable (486).

## Family Composition



#### Figure 9: Family Composition (Site A)

\*Unknown means there was no mention of the child / young person's family circumstances in the referral information.

As is shown in Figure 9 above most children referred for suicidality in Site A were found to live at home with at least one of their parents (77%), with the majority being single parent families. However, family composition was not described in 10% of the referrals. Similarly, Figure 10 shows in Site B most children lived with at least one of their parents (76.2%), however, in contrast to Site A, most children had both parents at home. Less than 5% of referrals lacked any information about family composition in Site B.

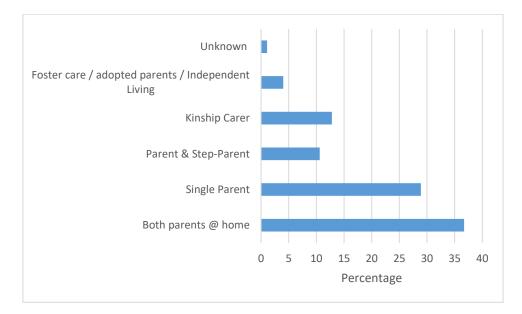


Figure 10: Family Composition (Site B)

\*Unknown means there was no mention of the child / young person's family circumstances in the referral information.

### SIMD (Scottish Index of Multiple Deprivation) data

For each child in the dataset (those identified as being referred for reasons of suicidality) I calculated a deprivation score based on the Scottish Index of Multiple Deprivation (SIMD) 2016 version (the 2020 coding was released following data collection). The SIMD tool is an official tool that ranks Scottish geographical data zones by their level of deprivation, on a scale of one to ten. One indicates that an area is within the most deprived 10%, whilst 10 equates to an area being within the least deprived 10%. These decile rankings are achieved by combining data from 7 domains of deprivation measured: income, employment, health, education, access, crime, and housing.

Postcode data was missing for 17.3% of referrals for suicidality in Site A. The spread of postcode decile for the remaining 86 individuals identified as having been referred for

suicidality is illustrated in Figure 11 below. This is compared to the SIMD data for the region in the discussion which follows.

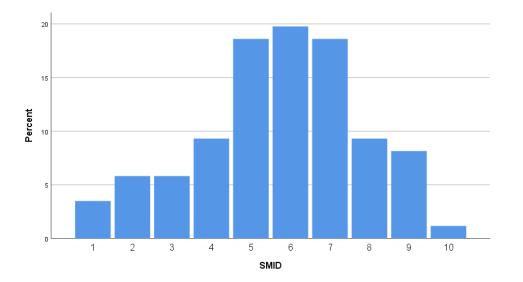


Figure 11: SIMD data (Site A)

The SIMD data from the postcodes of the children referred to Site B illustrated in Figure 12 below showed that there was a high proportion living in the second most deprived areas (based on SIMD ranking) and fewer referrals were living in the more affluent areas.

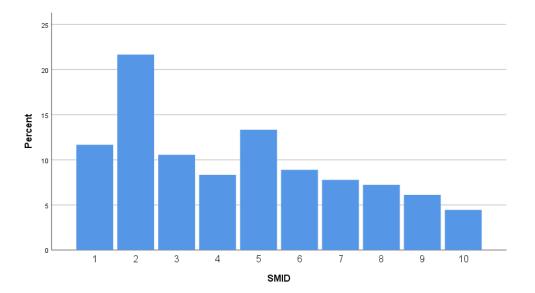


Figure 12:SIMD data (Site B)

## Source of Referral

Overall, as is shown in Figure 13 below 65% of referrals for children presenting with suicidality in site A were made by medical professionals, with 51% of these being GP referrals. The second largest source of referral were teachers (29.8%). Similarly, as can be seen in Figure 14 below, most referrals to Site B for children who were suicidal came from medical professionals (77.8%) but with higher numbers of referrals from 'other doctor or healthcare professionals and A&E than in Site A. Site B had fewer referrals from teachers (22.2%) than Site A, but a higher number of referrals from other sources (15.6%).

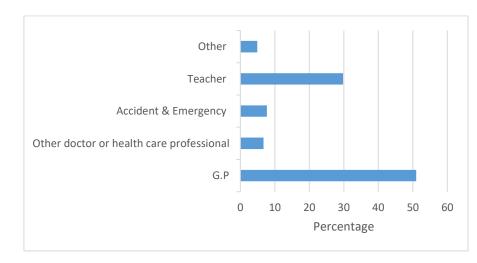


Figure 13: Occupation of Referrer (Site A)

\*Other includes school nurse, social worker, other support organisation and parents.

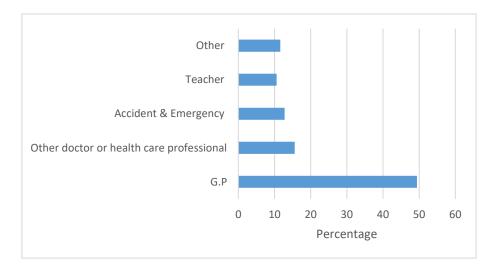


Figure 14: Occupation of Referrer (Site B)

\*Other includes school nurse, social worker, other support organisation, another adult and parent.

## Assessment

When a child is referred to CAMHs in Site A, they may or may not be offered a face-to-face assessment by a CAMHS worker, before their referral is rejected, redirected, or added to the waiting list etc. The chart below (Figure 15) shows that most (69%) of children referred to CAMHS for suicidality in Site A were not offered a face-to-face assessment. (The practitioner screening the referrals may in some instances provide a telephone consultation with the person making the referral).

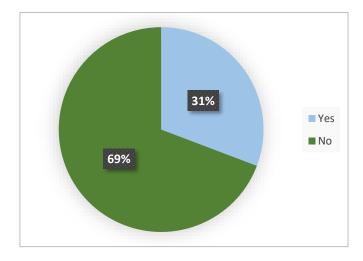


Figure 15: Offered an Assessment (Site A)

\*assessment refers to a face-to-face appointment with a CAMHS clinician. It does not account for background work e.g., information gathering etc. to support the screening process.

Whilst Figure 16 shows in Site B, most children identified as having been referred for suicidality were offered a face-to-face assessment (82%).

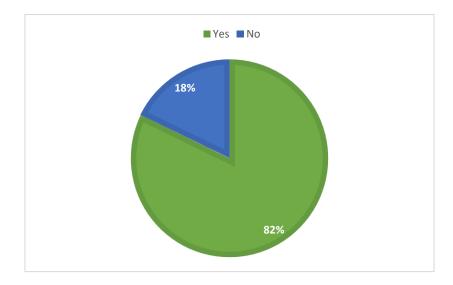
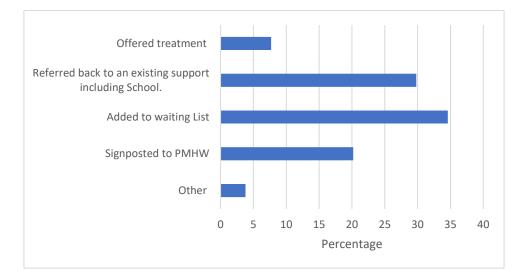


Figure 16: Offered an Assessment (Site B)

## **Referral Outcome**

The referral outcome documents the decision that was made immediately following referral and / or assessment in relation to whether the person was offered a service with CAMHS or not. As is noted in Ch. 3 it is important to be mindful that the categories used to define variables were assigned by me at the point of data extraction, as this information was not readily available and had to be identified from the narrative within patient records. Definitions of categories that were not straightforward are provided in Appendix 5: Retrospective cohort study variables. Figure 17 below shows that less than 10% of children were offered treatment straight away, and although 34.6% were added to the waiting list, most referrals were not accepted (57.6%).

#### Figure 17: Referral Outcome (Site A)

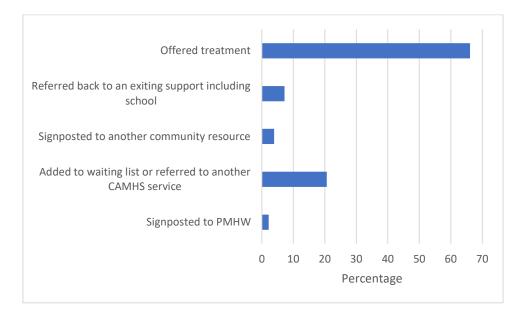


\*Other includes hospitalised; referred to adult services; referred to a community support service.

\*PMHW = Primary Mental Health Worker.

In contrast, Figure 18 shows most children (66.1%) in Site B were offered treatment. One fifth (20.5%) of referrals were either added to a waiting list or referred to another CAMHS service such as primary care psychology, and 13.3% were signposted or re-directed.

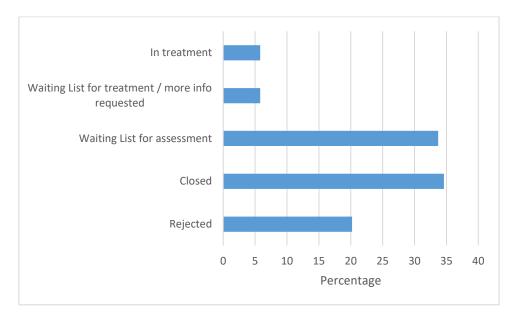
#### Figure 18: Referral Outcome (Site B)



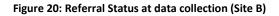
## Status of referral at the point of data collection

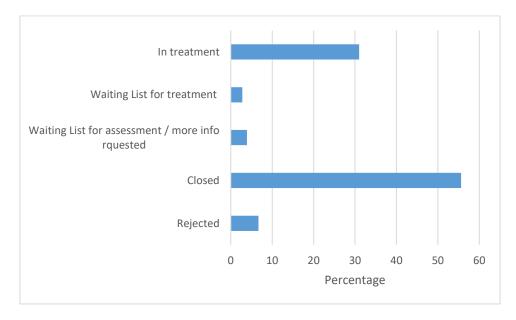
Data was collected over several months in chronological order of when the referrals were made, meaning that approximately six months had passed since the initial referral. Recording the status of the referral at the point of data collection allows a snapshot of how referrals progressed through the system, and how many were still awaiting assessments or treatment. The two sites were found to process referrals quite differently and this is reflected in the different scope of the categories used for the different sites. In Site B most children were offered an assessment upon referral, whereas in Site A (as can be seen in Figure 19) many were put on a waiting list without being assessed or following an assessment (for example if they had been admitted to hospital), were added to a waiting list for treatment.

#### Figure 19: Status of referral at data collection (Site A)



\*Closed may mean that the person did not attend appointment they were offered, attended one and did not engage thereafter, was not offered further treatment, or attended for treatment and this has ended.



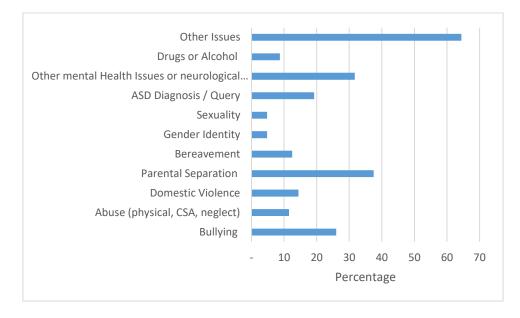


In Site B data collection also took place approximately six months following the initial referral being made. Consistent with the finding that most children were offered an assessment in Site B, Figure 20 above shows most cases had been closed (55.5%) (following assessment and or treatment), or the child was now in treatment (31%).

### Underlying issues

Underlying issues identified within the initial referral information or the first contact with the CAHMS service. Each child may have had more than one issue reported. Figure 21 below shows that in Site A parental separation, other mental health issues or neurological condition, bullying, and ASD were the most mentioned.

#### Figure 21: Underlying Issues (Site A)

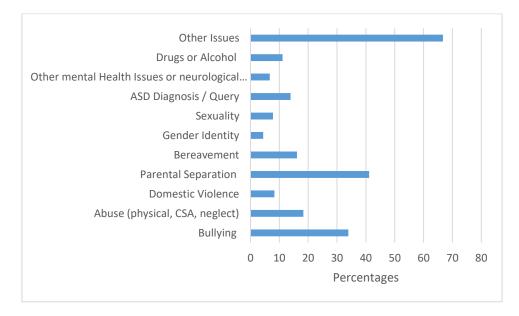


\*Other mental health issues or neurological conditions included depression, low mood, anxiety, voice hearing, eating disorders and learning disabilities.

\*Other included young carer, parent / sibling with terminal illness, sibling with disability or additional support needs, parental addiction, victim of crime, parental criminality & parent in prison, homeless, contact with an abusive parent, bereaved specifically by suicide, siblings looked after and accommodated, acting out violent behaviour.

As is shown in Figure 22, in Site B the issues most reported for children were parental separation (41.1%) and bullying (33.9%), followed by abuse (18.3%) and bereavement (16.1%).

#### Figure 22: Underlying Issues (Site B)



\*Other mental health issues or neurological conditions included depression, low mood, anxiety, voice hearing, eating disorders and learning disabilities.

\*Other included young carer, parent / sibling with terminal illness, sibling with disability or additional support needs, parental addiction, victim of crime, parental criminality and or parent in prison, homeless, contact with an abusive parent, bereaved specifically by suicide, siblings looked after and accommodated, acting out violent behaviour.

## Exploration of associations between demographic indicators & outcomes

### **Reason for referral & assessment**

Cross tabulation and Chi Squared tests were conducted to explore if there was any relationship between reason for referral and assessment. Although the numbers of children who had attempted suicide both with and without previous suicidal behaviour was much lower than the number of children referred for suicidal ideation, they were more likely to be offered an assessment. As is shown in Table 9, in Site A the Chi Squared result was significant:  $X^2$  (3 degrees of freedom, n = 104) = 14.01, p=.003. However, 2 cells (25%) had a count of less than 5, therefore a Fishers Exact Test (FET) was used to confirm there was a relationship (p=.003 FET).

			Reason for referral			
			ideation	attempt	ideation + history	attempt + history
Offered	YES	Count	8	6	12	6
assessment		% within Reason for referral	20.0%	75.0%	26.1%	60.0%
		% of Total	7.7%	5.8%	11.5%	5.8%
	NO	Count	32	#	34	#
		% within Reason for referral	80.0%	25.0%	73.9%	40.0%
		% of Total	30.8%	1.9%	32.7%	3.8%
Total		Count	40	8	46	10
		% within Reason for referral	100.0%	100.0%	100.0%	100.0%
		% of Total	38.5%	7.7%	44.2%	9.6%

\*History = previous suicidal behaviour and or self-harm

Similarly, in Site B, an FET found there may be a relationship between reason for referral and assessment (p=.010 FET), as there were slightly higher numbers of children offered an assessment following a suicide attempt (with and without previous behaviour) (Table 10). However, overall, most children in Site B were offered an assessment (see Figure 16 above).

### Table 10: Reason for Referral & Offered Assessment Crosstab (Site B)

			Reason for referral			
					ideation	attempt
	_		ideation	attempt	+ history	+ history
Offered	YES	Count	52	10	51	35
Assessment		% within Reason for	71.2%	83.3%	87.9%	94.6%
		referral				
	NO	Count	21	#	7	#
		% within Reason for	28.8%	16.7%	12.1%	5.4%
		referral				
Total		Count	73	12	58	37
		% within Reason for	100.0%	100.0%	100.0%	100.0%
		referral				

## Reason for Referral & Referral Outcome

Unfortunately, it was not possible to with this data set to determine whether there was any association between the reason that a child had been referred, and the outcome of the referral for either site. Cross tabulation of these variables using the data from Site A, produced a contingency table with 70% of cells (n=14) containing a value of less than 5. The same cross tabulation with the data form Site B resulted in a 68.5% of cells with a count of less than 5. Categories had been collapsed as far as was conceptually feasible.

## Referral Source & Assessment

Five cells in the contingency table below (Table 11) for Site A have a value <5, therefore an FET was chosen over Chi Square. The results (p<0.001, FET) indicating there may be a relationship between the source of the referral and whether the child was offered an assessment. Over 85% of referrals from A&E were assessed although the overall number of referrals was less than 10. Whilst over 85% of G.P referrals were not assessed, albeit the greatest number of referrals received were from GPs.

			ASSESSM	ENT
			YES	NO
Source	G. P	Count	6	47
of		% within Referral Source	11.3%	88.7%
Referral	Accident &	Count	7	#
	Emergency Doctor	% within Referral Source	87.5%	12.5%
	Other doctor or	Count	#	#
	health professional	% within Referral Source	42.9%	57.1%
	Teacher	Count	15	16
		% within Referral Source	48.4%	51.6%
	Other	Count	#	#
		% within Referral Source	20.0%	80.0%
Total		Count	32	72
		% within Referral Source	30.8%	69.2%
		% of Total	30.8%	69.2%

### Table 11: Referral Source & Assessment (Site A)

\*Other includes school nurse, social worker, and other support organisation.

\* # = (n<5).

Table 12 presents the number and % of children offered an assessment by source of referral for Site B. This shows that most children, from whatever route of referral, were offered an assessment. However, there are some differences, for example, all children and young people referred by A & E were assessed, whereas less than 70% of referrals from teachers were assessed (Four cells (40%) had a count <5, p=.022 FET).

			Offe	ered
			Asses	sment
	-		Yes	No
Referral	G. P	Count	74	15
Source		% within Occupation of	83.1%	16.9%
		referrer		
	Other Doctor or	Count	20	8
	health	% within Occupation of	71.4%	28.6%
	professional	referrer		
	A&E	Count	23	0
		% within Occupation of	100.0%	0.0%
		referrer		
	Teacher	Count	13	6
		% within Occupation of	68.4%	31.6%
		referrer		
	Other	Count	18	#
		% within Occupation of	90.0%	10.0%
		referrer		
Total		Count	148	31
		% within Occupation of	82.7%	17.3%
		referrer		

Table 12: Referral Source & Assessment (Site B)

## Referral Source & Referral Outcome

Exploring the relationship between the referral source and referral outcome (in Site A) with FET showed a potential relationship (p=.028). However, 79% of cells (n=19) in the crosstab contingency table for these variables had a value of less than 5, suggesting that these results should be interpreted with caution. This was echoed in Site B, where in the contingency table for the occupation of referrer and referral outcome 68% of cells have a value of less than 5. A relationship between these variables with this data could not be determined. Combining categories further would have meant they were no longer meaningful, for example all 'health

care professionals' would not have indicated their different roles or the settings within which they worked.

## Age & Referral Outcome

Analysis of any relationship between age at referral and assessment was not possible because age is a continuous variable and assessment had only two categories. However, a one-way ANOVA indicated a statistically significant difference between age and referral outcome (F (4,98) = 3.536, P=.010). The table of means below shows that younger children were more likely to be referred to an existing support or onto a primary mental health worker.

### Table 13: Age & Referral Outcome (Site A)

Outcome of referral	Mean Age	N	Std. Deviation
Signposted to PMHW	12.70	20	2.716
Added to waiting List	13.92	36	1.962
Other	14.86	7	1.676
Referred back to an existing support including school	12.75	32	2.896
Offered treatment	15.50	8	1.512
Total	13.50	103	2.524

A one-way ANOVA also showed that there was a statistically significant difference between the age of children and their referral outcomes (F (12,167) = 2.964, p<.001) in Site B. From the table of means below it appears children offered treatment are older than for other referral outcomes.

Table 14: Age & Referral Outcome (Site B)

Outcome of referral	Mean	Ν	Std. Deviation
Signposted to PMHW	11.50	4	4.796
Added to waiting List or referred to another service within CAMHS	11.78	37	3.128
Signposted to other community resource	11.86	7	4.100
Referred back to an existing support including school	11.69	13	3.376
Offered treatment	14.06	119	2.423
Total	13.28	180	2.958

## Age & Reason for Referral

The table (Table 15) of comparison of mean ages within reason for referral for Site A showed that the average age of children having attempted suicide and having attempted suicide with a history of suicidal behaviour was slightly higher than for the ideation categories. A one-way ANOVA showed a statistically significant relationship between reason for referral and age (F (3,99) =4.283, p=0.007).

Table 15: Reason for Referral & Age

			Std. Error of
Reason for referral	Mean	Ν	Mean
Ideation	12.49	39	.42
Attempt	14.50	8	1.00
Ideation + previous suicidal	13.89	46	.34
behaviour and or self-harm			
Attempt + previous suicidal	14.90	10	.48
behaviour and or self-harm			
Total	13.50	103	.25

A one-way ANOVA, also showed in Site B the relationship between the age of a child for each reason for referral category was statistically significant (F (3,176) =2.990, p=.032). Table 16 showing mean age of referral and the associated standard errors for each referral category suggests that children with a history of previous suicidal behaviour or self-harm tended to be older than those presenting with a first suicide attempt or ideation.

Table 16: Age & Reason for Referral (Site	B)
---	----

Age @ Referral				
			Std. Error of	
Reason for referral	Mean	N	Mean	
ideation	12.85	73	.391	
attempt	11.67	12	1.1	
ideation + previous suicidal behaviour and or self-harm	13.64	58	.26	
attempt + previous suicidal behaviour and or self-harm	14.08	37	.47	
Total	13.28	180	.22	

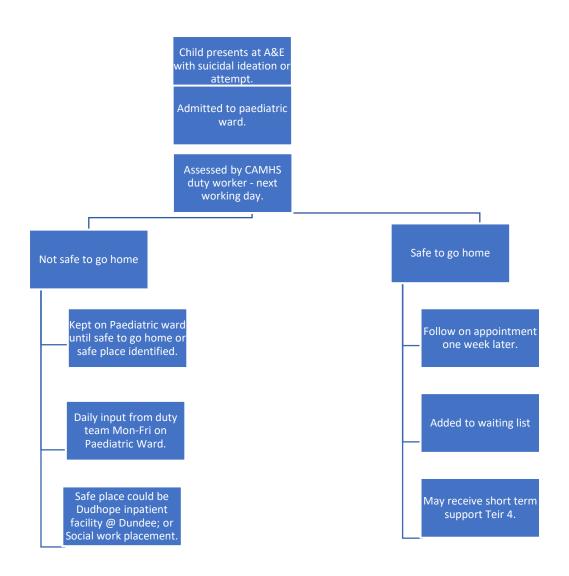
## SUMMARY OF MAIN FINDINGS

Approximately 25% of all referrals to CAMHS over a six-month period in both regions were for children presenting with suicidality (26% (n=104) in Site A and 24% (n=180) in Site B). The assessment and outcome of these referrals varied between the health boards. In Site A, 31% of children referred were offered an assessment appointment, compared with 82% of children in Site B.

Referral outcomes for this cohort in Site A indicated that 7.7% were offered treatment, 34.6% were added to the waiting list, 20.2% were signposted to primary mental health workers, and 36.5% of children were referred to other agencies, school or back to the referring agency for support. In Site B 47.8% of children referred for suicidality were provided and engaged in treatment, 18.3% of young people were offered treatment but did not engage or attend their appointment, 13.3% were added to the waiting list, 2.2% were signposted to primary mental health workers, 7.2% referred on to a different CAMHS service (e.g., psychology), 11.2% were referred to other agencies, school or back to the referring agency for support.

Through the process of data collection, it was possible to map the journeys of care made by children in the two sites following their referral to CAMHS. This is depicted in Figure 23, Figure 24, Figure 25, and Figure 26, that follow.

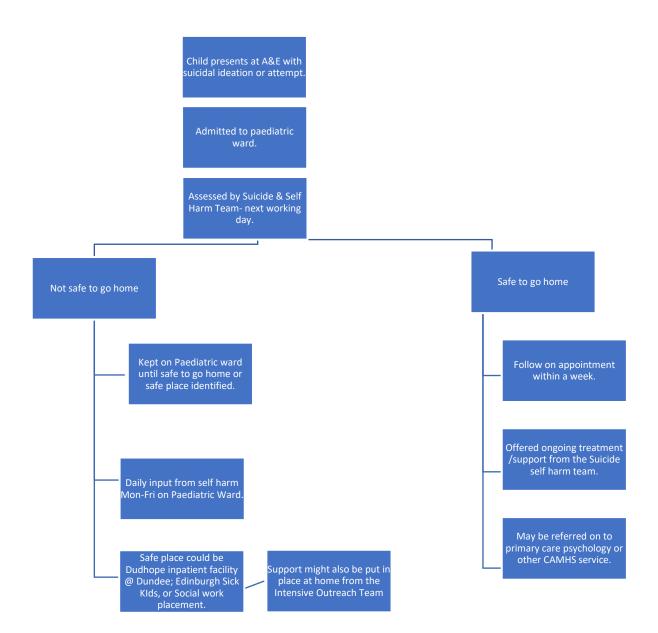
#### Figure 23: Referral pathway for child presenting at A&E (Site A)



#### Figure 24: Referral pathway for referrals from other sources (Site A)



#### Figure 25: Referral Pathways for referrals from A & E (Site B)



#### Figure 26: Referral Pathways for Referrals from other sources (Site B)



The reason for referral (whether they had been (thinking about suicide, attempted suicide, or had a history of suicidal behaviour) may have had a bearing on whether children were offered an assessment in Site A and Site B, with children who had been referred following a suicide attempt being offered an assessment more often than those referred for ideation. In both areas, children were also more likely to be offered an assessment if they had been referred directly from accident and emergency at the hospital, than from any other referral source, although in Site B most children were offered an assessment regardless of referral source, or reason for referral.

In both regions there appeared to be a relationship between the age of the child and the reason for referral, although the nature of this relationship differed. In Site A the age of the children having attempted suicide seemed to be higher than those presenting with suicidal ideation. Whilst in Site B the data suggested that older children were more likely to have a history of previous suicidal behaviour than those being referred following a first attempt or suicidal ideation.

In both services, the age of referral also seemed to have a similar relationship with the referral outcome - older children were more likely to be offered treatment.

Demographic information from both areas indicated that in general, the underlying issues identified in referrals, family composition and age range of these sample populations were similar.

## CONCLUSIONS

This study shows despite differences in geography and context, suicidality in children is a factor in approximately a quarter of all referrals to these two CAMHS, and there are vast differences in how these referrals are processed and responded to. There is little difference in the issues being identified by referrers, the age range of children, and the behaviours they present and yet there were very different outcomes, and pathways of care.

The data presented here is novel and will provide a vital source of information to decision makers and service providers in their consideration of service structures and allocation of resources. The following three chapters of the thesis seek to understand what this means to the people working within the service, and the children and families seeking support from CAMHS for suicidality. This is followed by a summary and synthesis of the study findings overall. The findings of this cohort chapter are explored and situated within the context of the literature in the Discussion chapter (Ch.9), alongside consideration of the other component parts of the thesis. Including its strengths and limitations. Recommendations for policy, practice and future are also made here, before presenting the final conclusions.

# Introduction to Phase Three (Ch. 5-7)

The following three chapters present the findings from a series of interviews with practitioners, parents, and children who were referred to CAMHS for reasons of suicidality. Using a constructivist grounded theory approach (426), the data from each group of interviews was coded line by line, and focused codes emerged from these early codes which then informed the development of an over-arching substantive argument. Standing back from the data and using story-line analysis helped to explain the process and refine these focused codes and grounded theory into a *"digestible"* format (433). The findings from each sample population are reported distinctly as separate chapters before bringing them together in chapter 8.

The data from these interviews informs the thesis on several levels. Firstly, it speaks to the process; that is how children who present to CAMHS with suicidality are assessed and supported. Secondly, it informs us of the views and experiences the participants have of this process. Finally, it supports the development of an overall substantive argument that offers an explanation of what has been found and presented.

The overall synthesis is based not only upon the findings of the qualitative chapters, but also the retrospective cohort study, and preceding literature reviews. Using Charmaz' constructivist grounded theory approach (426), and thinking with theory (485), the findings are both cumulative and considered.

Although already noted in my acknowledgments, I cannot express enough my appreciation to all participants, for their time, humility, and candour. Without their contributions this study would not have been realised. At this juncture it is particularly important to stress that although the data presented reveals gaps in service provision for children who experience suicidality, the commitment, endeavour, and motivation of individual CAMHS practitioners is not in question. The findings, and interpretations that follow, point more to systemic issues and a dominant discourse that proffers children are not 'really' suicidal.

# **Chapter 5: Qualitative findings from staff interviews**

## INTRODUCTION

This chapter presents the analysis and findings from eleven in-depth interviews with CAMHS practitioners based in two different Scottish health boards. The aim of this section was to explore the experience and perspective of CAMHS practitioners working with suicidal children. Their views about working with children who are suicidal will help to create an overall picture of the pathways of care and experiences of these children after they have been referred to CAMHS. Other research studies in Scotland with a focus on CAMHS have not considered or included the practitioners voice (31); however, their knowledge could be instrumental in identifying gaps, and challenges as well as furthering our understanding of what works, and what children who are suicidal need from mental health services. As was identified in the literature review (Ch. 2) CAMHS often receive criticism and are reported to be failing children (30,31,39,71,77), but consideration must be given to the experience of the over stretched practitioners on the ground trying to deliver services with limited resources.

Whilst on a pragmatic level the interview data can be used to describe how the staff work with children who are referred for suicidality, and their views on this, conducting an analysis informed by constructivist grounded theory (426) (see Ch. 3) also allowed for the development of a substantive theory. This goes beyond merely describing the data to present a new argument and explanation of what is being said in the interviews. This chapter argues that CAMHS practitioners attempt to regulate and manage the risk and social taboo of childhood suicidality by normalising suicidality. However, staff were simultaneously found to hold conflicting views as they also recognise there are children who want to, attempt to, and do end their life by suicide. Staff expressed that children who are suicidal need a flexible, person centred approach and value a worker who establishes a positive relationship with them and "actually listens".

The overall argument presented emerged from three theoretical themes which express the foundations on which it is based: (1) expert assessment of the great unknown (2) diffusing danger with an alternative discourse (3) imposing order on the intuitive and flexible practitioner. These themes house several sub-themes which help to express the tension

between what is expected of CAMHS workers, and the processes they should follow, alongside what they do in practice and believe works best.

Before presenting the analysis of the data, a brief outline of the sample population and dataset is provided. This is followed by Table 17 which provides a summary of the substantive argument, themes and sub-themes and shows how they fit together.

### Sample Population and Dataset

Eleven CAMHS Practitioners were interviewed between August – November 2019; six worked in Site A and five in Site B. Three were male, all interviewees were white. The occupations of the staff interviewed included mental health nurses, psychologists, a psychiatrist, lead mental health nurses, and the head of CAMHS services for each area. The data extracts that are included below do not reference the individuals job role or research site as this could have deemed them identifiable. The differing structures and leadership of the two CAMHS services meant there was a higher proportion of psychologists interviewed in Site A and a higher numbers of mental health nurses in the other Site B. The interviews took place within the participant's workplace, for most this was within the CAMHS service offices; one participant in Site B was based within a community health centre.

As was discussed in the methods chapter (Ch. 3) interviews were analysed collectively. However, the difference in context between the two regions was apparent in the data. The staff's views and language reflected the different structures they worked within. For example, in Site B where there currently exists a suicide and self-harm team, children referred for suicidality were identified by all staff there as being a '*priority*' and were seen by this specific team. In Site A, children who were referred from the paediatric ward following a suicide attempt would be assessed by their tier 4 outreach team, however, all other children referred for suicidality were either rejected or added to a waiting list before being seen by either CAMHS nurses or psychologists. The impact of these differences is considered further in the discussion (Ch. 9), but it is important to note here that although analysis took place, attitudinal differences were often context specific.

#### Table 17: Summary of practitioner themes

Substantive	The eventory dependent for the second for	
Theory:	The system doesn't facilitate staff to listen.	Although Child and Adolescent Mental Health Services can be viewed as attempting to provide social regulation of the suicidal child through a) imposing a linear and systematic approach b) employing a discourse of distress that neutralises risk and denies suicidality, it is also a site of resistance and knowledge transformation. Staff are frustrated by the constraints of the system they work within, and express the need for a flexible, person centred approach, that prioritises the relationship between the worker and the child / young person beyond any prescribed model.
Theme 1:	Expert assessment of the great unknown.	This theme explains how although a large part of the CAMHS practitioners job involves assessing children and young people who present as suicidal, there is no specific model or tool used for this. Furthermore, the staff convey that the risk of suicide cannot be quantified. A descriptive model of the decision-making process around risk assessment is presented.
Subtheme 1:	Risk assessment – <i>"it's our job"</i>	The staff spoke about how a large part of their role is to risk assess children and young people who have attempted or are thinking about suicide. This is an expectation of professionals referring to CAMHS as well as the families of children being referred.
Subtheme 2:	No prescribed tool	How risk is assessed varies between individual workers depending upon their training and background, and there is no specific tool they must use.
Subtheme 3:	"You don't know and that's the reality"	Despite the time and energy that goes into risk assessment, the staff express that the risk of suicide remains unknown; it is unpredictable.
Subtheme 4:	The suicide risk assessment process – a descriptive representation.	This sub-theme describes and presents the process of suicide risk assessment by CAMHS that emerged from the interview data. It was possible to identify the drivers of the risk assessment process, as well as goals / desirable outcomes.
Theme 2:	Diffusing danger with an alternative discourse.	This theme explores how staff frame and interpret children's expressions of being suicidal by re-conceptualizing them as

		distressed and not suicidal. Although this alternative narrative supports their efforts to manage and normalise the risk of suicide, staff also accept there are some children who do want to die, and they fear may go on to end their lives.
Sub-theme 1	"I don't necessarily see them as suicidal kids"	Many of the staff expressed a belief that most of the children who were referred to CAMHS for suicidality were not suicidal. There was also a suggestion that some referrers used the word "suicide" to escalate a referral.
Sub-theme 2	A discourse of distress	The staff interviewed explained that rather than see children as suicidal they viewed them as "distressed". By reframing suicidality with this alternative narrative, they normalised what is being presented and abate the fear and risk around it; for the young person and their family, the people around the young person and the CAMHS worker themselves.
Sub-theme 3	The dichotomy: <i>"you've got the</i> ones who genuinely do feel [suicidal]"	Although the staff spoke about providing alternative narratives and understandings of children's expressions of suicidality, they also recognised there were children who "genuinely" wanted to die, and some who did end their life by suicide. Staff identified children they feared would go on to kill themselves, and how they were left holding this worry.
Theme 3	Imposing order on the intuitive and flexible practice.	Staff identified how their practice was constrained by institutional demands, and attempts to organise, and systematise their work. However, this is not how most of them wanted to, or did work. They had found children who were suicidal needed a flexible and intuitive approach, and above all valued a positive supportive relationship with someone who listens.
Sub-theme 1	"the system is broken"	Although a few staff members spoke positively about the tier system as it supported streaming referrals- others felt it was a "broken" and outdated model, that caused children to get stuck or lost in the system.
Sub-theme 2	Pushed for time	The staff understood that due to the number of referrals and waiting times for CAMHS there was a pressure to keep interventions as short as possible to improve the flow of people through the service. However, they believed it often

		took time to build rapport and get to know a child or young person before they would open up, and they needed to have the flexibility to offer longer term interventions when they were needed.
Sub-theme 3	Formulaic Approaches	They also described attempts to introduce standardised and prescribed 'off the shelf' approaches to be used with all children who presented as suicidal. Staff found these often-put children and young people off engaging, and that an open, needs led approach was much more successful.
Sub-theme 4	Clinical locations	Capacity dictated that in the main children attend clinics and hospital settings for appointments. However, the staff interviewed understood this was less than ideal and spoke of the benefit of being able to provide an outreach service that could offer flexibility and choice in the location of appointments.
Sub-theme 5	The relationship is key	Overall, the staff expressed that the relationship the practitioner had with the child or young person was key to the success of any intervention, beyond the model they used.

# EXPERT ASSESSMENT OF THE GREAT UNKNOWN

# Risk assessment - "it's our job"

Children who have attempted or are thinking about suicide are referred to child and adolescent mental health services in the first instance for an assessment. People referring suicidal children to CAMHS (e.g., A&E staff, hospital consultants, G. P's, primary mental health workers, social work services, teachers etc.), alongside family, expect they will be provided an assessment of risk. Policies within external agencies such social work, as well as CAMHS themselves affirm that children who are suicidal should be assessed by CAMHS.

So if they're classed as an emergency we would see them, so like the overdoses and that in hospital, the policy is that they should be admitted if they've taken an overdose or a serious self-harm risk, or suicidal, they should be admitted to a general ward or the observation unit in A&E and they then have to phone by ten o'clock the next day and we will see them that day, that morning usually. We try our best to get there as quick as possible and see them on the ward that day. If it's a referral from a GP they're usually classed, there's routine referrals, priority routine which is mainly the self-harm referrals, and the urgent ones obviously if it's suicide. We try and see them within as quickly as possible. (S2)

...I get phone calls from GPs, from social workers, guidance staff, teaching staff; they all phone in and ask for advice on duty if they have a suicidal person with them. (S1)

...and the purpose of that assessment will be I suppose getting a more kinda specialist assessment of what that young person's risk presents with, (S5)

CAMHS workers accept this is part of their job. It is something they are believed to be '*expert*' in, and others look to them to impart advice and to know what to do.

...because that's what we're here for, you know, if it wasn't for these young people we wouldn't have a job, you know, (S3)

...but I just think it's part of the job and it's what you need to do...(S4)

The children being referred also expect CAMHS workers to be skilled and knowledgeable in assessing suicidality.

## No Prescribed Tool

Although assessing risk of suicide is a core component of a CAMHS practitioners job role, there is no formalised risk assessment process and staff all approach this differently. The staff spoke of how their approach often reflected their own background and training.

Because the way that a psychologist will do an assessment is very different from what I'll do in an assessment, but we'll come to the same conclusion. We've got very different training. I'll come in very medically minded modelled and look at safety planning, crisis planning and recovery focused. This is very generalised, psychologists will look at the whole picture and go into the whole thing and come up with a formulation and 'how do we get there, what are we doing there and how we get out of it?' where I'd be coming in 'how are you here, why are you here, how are you doing it, how are we getting you home and how do we make it safe?' [...] Yeah, still the same goal and we would go about it probably very differently. But that's good because we don't want to all be the same. (S6)

Although there were pro-formas available to them most of the staff interviewed did not use these in practice. They identified reporting templates as requiring information that could be used as a guide, but there was no specific, systematic tool used to assess suicide risk.

We have a risk assessment pro forma here that we occasionally would use in terms of planning things forward, we put together a safety plan, there's a couple of templates kicking about for that. I tend not to have a specific tick box structure or criteria for things because I think, well, I'm not aware of particularly good evidence that they can change the outcomes, so I think it's as much about assessing that individual's situation and the risk, ...but we don't have a structured tool that we would use every time...(S11)

There is risk assessment tools out there. The one we've got here is not a risk assessment, it's very medical minded, it's malnutrition, suicide, there's nothing that pulls it out and I think a lot of that is pulled out in the assessment that we do. (S6)

There's a screening sheet that is used, it can help people make decisions. So within that there are certain criteria that young people would have to meet to meet the threshold for CAMHS; one of those criteria talks about level of risk and safety, but as far as tools go that's as far as it would go, the rest is really just sitting down and having a conversation amongst the clinicians who are doing the screening to think about the risk factors within the referral letter and having a think about how quickly do we need to respond.(S1)

The staff described their assessments and interventions as being be-spoke, tailored to the individual child / young person.

I think it is just so different, so individual to each child and each family what they're going to need. (S10)

I guess it just is a needs led basis, it's not a, like, do the same thing for them all, it'll be different depending on the need and the risk. (S4)

# "You don't know and that's the reality"

Although the staff spoke of how much energy and effort goes into assessing a child / young person's risk of suicide, they were open about the fact that the risk of suicide remains largely unknown.

I think psychiatry or mental health puts a lot on risk or ability to assess then manage when actually the evidence would say we're pretty bad at doing that in a reliable way and we're bad at predicting human behaviour cause human behaviour is pretty unpredictable. (S11)

You don't know and that's the reality. And there are people who kinda slip through the net who have been in hospital, have taken major overdoses and have refused to stay, especially young people who have kinda got lost in the system. (S2)

Staff describe how sometimes the children who present with less severe injuries or have taken a less lethal overdose in an attempt to end their life are more at risk than those who present after what might be deemed a "serious" attempt.

Yeah. So they're maybe in hospital cause they've taken three Paracetamol but there's a major issue there for them, whereas you might get somebody that's taken 40 and it's been, I don't know, a breakup with a boyfriend or something and then things have got fixed out and everything's okay again, so you would think the 40 is a more serious one but the two or three might be the more serious one. [...] ...it's not always about the amount and what they've taken, again it goes back to the story and what's going on in their life. (S2)

So it's quite difficult to determine if it's somebody's first presentation which way you think that's going to go. (S11)

The staff express that suicide is often unpredictable. In this excerpt below the staff member links impulsiveness and suicidal behaviour, highlighting the possibility that children and young people could often accidentally kill themselves.

The most difficult ones to hold are the kids that you know are very impulsive, yeah, so if you have kids that are in an environment that is not very contained and is not very caring and nurturing and you can't fix it as a CAMHS worker, and you can't even ask the social worker to just sort that out, those kids on a very impulsive basis all of a sudden can feel highly suicidal and they might do a very serious attempt and they, by accident almost, kill themselves. They try to just give a very strong message but they feel they need to up the ante because nobody's fixing their problem. [...] But the danger is always in that moment when that distress rises and they can take an impulsive decision that the only way is to go out. Some kids could potentially take such a high overdose that it could work. But in that sense that's not any different from an adult; ... (S7)

Most staff accepted and worked from the position they never categorically knew who was most at risk of death by suicide. This uncertainty was identified as being an inherent part of their job.

No but I suppose that's where we need to try and recognise that there are and will be unknowns [...] ...we always need to keep an open mind that we don't know what we don't know (S11)

Yeah, yeah and it doesn't... it doesn't mean nothing but it's fairly... there's only so much you can glean from it and we know that people who say they're going to complete the suicide or express thoughts of self-harm are more likely than whoever that hasn't to do that but we can't put a time point on that so you can only work as best you can within that. (S11)

This person (S11) sums up this sentiment that the risk of suicide cannot be quantified or predicted. They work with what is being presented, accepting the limitations of any assessment they do.

# The suicide risk assessment process

Overall, the interview data suggests the risk assessment of children who are suicidal is a descriptive process, driven by a complex interplay of factors inherent to the individual conducting the assessment (e.g., job role, experience, training), as well as those which are often intangible and fluid such as intuition, heuristics, and bias. The diagram overleaf (Figure 27) shows the goals of the process as identified by staff, are to normalise / reduce the risk, create a safety plan, and send the child home; after assessing the capacity of the parents to

keep the child / young person safe, and identifying any underlying issues. The data supporting the development of this illustration is presented in Appendix 11: Data supporting CAMHS Risk assessment process.

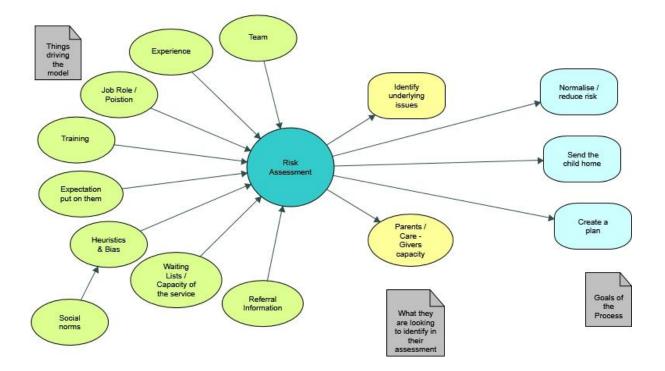


Figure 27: CAMHS suicide risk assessment process

# DIFFUSING DANGER WITH AN ALTERNATIVE DISCOURSE

"...I don't necessarily see them as suicidal kids ... "

Many of the staff related that although children had been referred for suicidality, they questioned whether this was how the child / young person was feeling.

I suppose I don't necessarily see them as suicidal kids is the main thing [laugh]. (S5) I think a lot, [...], a lot of the referrals probably do say 'self-harm, suicidal ideation' and then when you actually assess them, when you look at it I wouldn't be particularly worried about suicidal ideation. When you get into it and you assess it and you use the right language and you ask more questions and be curious and wondering, I don't get anxious when I read that. (S6) We are very aware that if... we are fairly used to hearing that kids say 'oh I want to die', I'm not saying that that becomes normal but I think we hear it so often that we know that most kids don't really want to die and most kids don't really want to kill themselves. (S7)

There were suggestions from some participants that referrers used the term "suicide" to escalate the referral and avoid lengthy waiting lists for access to CAMHS services.

I think referrers also know keywords to put into a referral in order to get a quick assessment. So, the self-harm service would say this, a lot of the kids that they see urgently don't require an urgent intervention. (S5)

... we do get referrals in that are classed as urgent referrals, but then actually when you speak to the parent or to the young person themselves it's not always as urgent as what it initially comes across. They still get seen but it's like you kinda then know they don't need to be seen right there and then. (S2)

... a lot of the referrals probably do say 'self-harm, suicidal ideation' and then when you actually assess them, when you look at it I wouldn't be particularly worried about suicidal ideation. (S6)

Referrers have often requested an urgent assessment as they are concerned about the child or young person being at risk of suicide. However, the CAMHS workers present a different point of view and suggest suicidality may not be the issue for most of them.

# A discourse of distress

The staff spoke of how they reframe the child / young person's suicidality and provide an alternative narrative. The language around the child's feelings and behaviour was changed from being about '*suicide*' to a '*symptom of distress*'.

I worry that we get caught up in the suicidality as the problem when actually it's just a symptom of the distress and the issues, and we need to understand that. (S11)

I guess if self-harm and suicidality is the core issue I would always do an assessment because my thoughts would be that's not the core issue, that's your symptom of distress somewhere. (S8) ...the way we look at it it's not so much that we call them suicidal children, these are children in distress, and we need to decide where that level of distress sits and where are they best held, (S7)

So, it's your ultimate way of expressing distress ... (S7)

...even thoughts of ending it sometimes are more about taking away distress rather than ending life, you know, (S1)

Altering the dialogue around the child / young person's behaviour reduces some of the anxiety and fear attributed with suicidal behaviour.

So, what you start to realise is when we get kids in, like, almost daily, yeah, talking about suicide, we do know that what they're really expressing is not wanting to die. So, if you start to recognise that the expression of wanting to die is more a message of distress, ...(S7)

When you get into it and you assess it and you use the right language [...] you recognise that that young person's really, really struggling and they want things to change and they want things to stop and it's about communicating that level of distress that they're at... (S6)

Do I really believe he wants to die? No. He wants to be in a better situation with his mum and dad and he wants to learn to handle his levels of distress better cause he feels distressed about his own distress and what he does when he's so distressed. So, there is something about the narrative around why kids feel the way they feel and being able to get to them in a way I think is really, really important because I don't think they really want to die. (S7)

Although the staff still identify that the child / young person may need support to deal with what is causing their distress, this support is not considered to be needed as urgently as presented. Risk of death by suicide is no longer the focus. The dialogue around distress seems to be more acceptable, and less scary.

"...sounds really scary but it's just distressed behaviour" (S8)

The dichotomy: "you've got the ones who genuinely do feel [suicidal]"

I would try and normalise the experience ...(S8)

Although the staff interviewed spoke about "normalising" the child or young person's behaviour by reconceptualizing it, they were also acutely aware that the risk of suicide remained for some children.

...and then you've got the ones who genuinely do feel [suicidal] (S4)

...she's a risk of suicide (S3)

They understood that in amongst these referrals there were children who did want to die, and some may even go on to end their lives.

I think she'll kill herself. (S9)

...those kids on a very impulsive basis all of a sudden can feel highly suicidal and they might do a very serious attempt and they, by accident almost, kill themselves. (S7)

There's a bit of a sense of as long as we're keeping her alive until something in her or her family system can shift, but those ones are tricky. (S11)

The emotional burden of working with children at risk of suicide was ever-present.

*Well the most challenging thing for me would be that they kill themselves I think cause that's horrible. (S9)* 

Staff in Site B spoke of being reassured that the systems they had in place meant children who were identified as being suicidal would be seen quickly.

Even though things have changed we've maintained a priority status for young people who present with self-harming or suicidal thoughts, so we continue to class them as a priority, so I'm pleased about that. (S1)

Whilst staff in Site A worried that children referred because they had been thinking about or attempted suicide might be kept on a waiting list.

What is shocking for me is that if somebody is presenting with suicidal ideation that they're left on a waiting list, I think that's shocking, I think it's disgusting. I don't

know how that is dealt with. I'm sure clearly if they had suicidal intent those ones that were left, say, for eight months they would be dead I suppose, could be, but suicidal ideation isn't just about does this person want to die right now, it's about what is the meaning for them of thinking like that on a daily basis and the withdrawal of hope, ... (S9)

I think what is difficult sometimes is when you see a young person you know that they are on the wait list to be seen but then the waiting time can be an issue. So, the girl last week I saw that will be assessed, I'm not sure how long of a wait they're going to have, but they have been made aware that the duty call system is in place if they need it. I suppose my fear or what is difficult as a clinician to think about is that she may end up presenting on the ward again before she's actually seen for assessment here and that is difficult to think of that. (S10)

The interview data shows that although the staff are instrumental in reframing the risk of suicide, they also identified there were children at risk of death by suicide who needed urgent access to support.

# IMPOSING ORDER ON THE INTUITIVE AND FLEXIBLE PRACTICE.

# "...the system is broken"

I think tiers are the biggest waste of time. I think we should be way more fluid, in and out, which I don't think we are. (S6)

Some staff expressed a real frustration with the structure and organisation of CAMHS. They felt it created barriers and prevented children from being able to access the support needed easily.

I think people do get stuck: what's Tier 2, what's Tier 3? I think we don't get stuck 3 to 4 and that's because we're in this building together, I think we have good working relationships and it's easier where our Tier 2 service is not part of CAMHS, that is part of CAMHS, it sits with the council so I think that barriers there. Social work and health are different, they're just different training, different breed and I think we sit with different hats on so it's very difficult to step up and step down, it doesn't feel as easy, it doesn't feel fluid (S6)

Other staff liked the tier system as it helped to manage the number of referrals coming in, supported specialisms and the role of CAMHS workers as expert professionals.

I like the idea of things being tiered, you know, rather than just everything being fired up to a really specialist service because the idea of things being tiered in some way fits with that idea of us learning to tolerate and manage distress, and keep it at a level that fits [laugh] rather than having blue lights flashing every time, you know, there's a bit of anxiety or worry around. (S1)

...ideally we don't want everyone coming into Tier 3/Tier 4 which is a specialist service, we can't have all children that raise suicidal ideation to come into that team cause a lot of those kids, basically kids when they say 'I want to die' most kids don't want to die. (S7)

I don't necessarily think that the direct access should be with us because we are a Tier 3 service and for a lot of years, part of the problem that we got into was we accepted everybody and we're not commissioned for that, we're not resourced for that. (S5)

There were differences of opinion though, and some staff were even conflicted within themselves. There were suggestions that workers at a tier 2 level would not be qualified or experienced enough to assess and support children at risk of suicide.

No, no I think that'd be... yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. (S5)

Whilst others believed that with support and training there was no reason primary mental health workers could not perform this role and may be better placed to do so.

Well as I understand it, cause I was going to say that in the main primary mental health workers wouldn't see people who might have suicide as part of their presentation or suicidality, they would always refer up to Tier 3 which I think is bizarre, you know, and it may be that they don't think that they're trained enough to cope with it but, I mean, a lot of them are art therapists, a lot of them are psychotherapists, a lot of them are ex-nurses, social workers, of course they're skilled but it's something that says in the hierarchy of the referral process 'this is what's seen here, this is what's seen there and this is what's seen there' rather than 'can this be managed in our service?' and the closer you are to the kid would seem better to me, but they just didn't have the staff. There are more staff here than there ever were in primary mental health workers so that might be the wrong way round [laugh] might lose my job for saying that! (S9)

...whoever's able to talk about it rather than needing Tier 3 or specialist CAMHS input cause I think some of the stuff we do sometimes is not particularly highfaluting or clever. (S11)

One of the flaws identified was children being passed between workers and teams as referrals are escalated.

Yeah because how frustrating is it for a family when they see their young person so distressed, so distraught, voicing suicidal ideation, cutting themselves and thinking where do you go and getting battered from pillar to post, it must be horrendous. (S6)

Overall, there was a sense from all the staff interviewed that the system was overwhelmed with referrals, and that the present structure was not working.

...the system is broken. The system is definitely broken. (S7)

# **Pushed for Time**

Both staff teams spoke about feeling under pressure to deliver short interventions to try and reduce waiting lists. However, this was uncomfortable for them as they did not believe it was helpful or supportive of the children's engagement.

I've had young people in here who've said that 'I've told my story ten times and nobody's...' I think the biggest part of it is being able to stick with them and that's difficult in this day and age because it's all about so many sessions with people. [...] Obviously we've got to watch our numbers. (S2) But there might be, yeah from higher up, yeah. [Interviewer: ...there might be an expectation that that's what you would do?] Yeah. [...] Three or four sessions yeah. (S2)

...well this is how they're thinking of it, is that you do your basic risk assessment and then maybe do two or three appointments and to me that's not therapeutic. (S3)

...what worries me is that because there is lack of capacity there's a real drive to get throughputs so that you get a quick flow through the system, kids being seen and I think the worst thing that could happen is that we base what we offer on what looks good on the service. (S7)

The staff spoke about how children needed time to get to know their worker and establish trust before they could begin to identify or work on any underlying issues.

It can take a long time just to build up that trust and get to know somebody before you can find out about any of the issues to be honest with you, it can take a while. And that's how sometimes I think this kinda do two or three sessions thing [sigh], I think it's really, it doesn't work, it's so hard. (S2)

We're getting more cases that are longer term work, lots of attachment problems, these are not cases that are just simple anxiety that we work our way through, these are cases that are developmental problems plus trauma plus neglect and it all comes into CAMHS to then be worked with, but that is not like a six session kinda model that these kids need. (S7)

For most kids that we see at the level of distress that they express, six sessions just starts with the therapy just actually making a relationship with them, sometimes just can take six sessions or more. (S7)

...there will be kids that won't be ready at whatever point to disclose and for that we need to be welcoming enough as a service that with time we would hope that you can offer and engage people to build up trust. (S11)

It's so hard because you lose the person. I always think if they come in and you're kinda saying to them right from the start 'we've got three sessions to do bla, bla, bla'. [...] It's like you're putting a barrier up sometimes before you start. (S2)

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Although most interventions were described as only lasting a matter of weeks, many of the staff identified children they had worked with long-term as this was what had been needed. In the main their managers had supported them with this, however, there was concern that the pressure to deliver short-term interventions may erode their ability to do this.

I would say on average it's probably about eight sessions I think... but there's some real exceptions within that as well. So sometimes people come once and they don't come back, other times we've had people on our caseload for two or three years because there's just been ongoing difficulties and concern around risk, so there's some real exceptions to that eight-session average. (S1)

...it's not too bad because we can kind of figure out the ones that need that wee bit extra and we've all got people on our caseload that we've had for quite a long time depending on what the issues are and what you're working with, but I've got young people that have been with me probably for months and months. (S2)

Just depends. Some patients are seen for a few months and I've got a couple of patients that I think I've seen since I started two years ago, but them I'm not seeing as often because there is improvements. (S4)

It was quite tricky cause we actually did a piece of work over a number of years which meant in terms of resources for the department I had to have a very good rationale why I didn't discharge her, but for me that didn't fit with our attachment based formulation which was if I discharge her it's another rupture, it's another rejection, it's not helpful. (S8)

This staff member articulates how in some cases short-term interventions may do more harm than good, inviting a child into a therapeutic space and then not seeing the work through with them.

So I'm not saying we should see everyone long term, what I do hope is that we'll never be in a situation where we determine what a child gets by what the service can offer instead of being able to assess what the child needs, because I think we're on a really downward spiral because what we're then doing is we sacrifice quality over quantity [...]. The pressure is there because there's constant pressure of getting kids through quickly because that will improve your flow and it will deal with your demand, but at the same time if I get particular kids in and I think 'well if I offer you six sessions that might actually be damaging' because if these kids have always been rejected and part of their problem is being rejected and not being heard, if I let them come in and actually don't even have the time to sit down with them and actually get to know them they will just have a negative experience on top of all the other ones that you've already had. I'm better not seeing them. (S7)

Although there is pressure on staff to deliver short-term interventions, the interview data shows that staff feel this is often unhelpful and they exercise a lot more flexibility in terms of timescales where they can.

## Formulaic approaches

In an effort to regulate the content and length of the intervention both teams had been asked to introduce a prescribed CBT group work intervention which is packaged as a distress tolerance model (The Decider (487)). In Site A they had tried referring all children who had presented to hospital following a suicide attempt to a 'decider skills group', whilst in Site B, the suicide and self-harm team staff were being asked to use the model in their one-to-one sessions with children.

It was suggested that the ourselves, the self-harm team and the intensive therapy team all go on it because there's some look at reforming or revamping the self-harm team and it was looked at whether the decider skills would allow us to do shorter pieces of work with young people rather than the sometimes prolonged pieces of work. (S3)

We did do decider skills, have you heard of that? [...] Yeah, we did try to set up a group where everybody who presented on the ward would automatically be put onto the group but it wasn't really taken up by the young people. (S6)

The staff described the implementation of the 'decider skills program' as having been executed from the top down. And although they attended the training and delivered it as requested, they did not find that the children engaged with the program.

...we were very solution focused and now we've all been trained apart from one of the team in decider skills. (S1)

Despite efforts by staff to adopt a prescribed approach they found that most children did not find this helpful, and neither did they.

Basically it seems to be that that's what our consultants have decided that decider skills is to be used for is your really personality disorders, and they've maybe been given a diagnosis but they've also got trauma. But as I said I've tried, I've got two that you could really say are personality disorders and then they both looked at me going 'not doing that'. (S3)

For some reason it just wasn't ... we didn't have much take up on it, ...(S6)

...we used to run the decider skills workshop and that was a chance for young people to develop skills after they have an admission to the ward for deliberate self-harm, ...but it was actually the uptake of those groups for some reason it just wasn't happening. (S10)

Staff spoke about how the children presented with their own issues that required them to engage with them as individuals.

They've got their own agenda. ... And you might go with an agenda of what you're going to work on but it's the young people that set it, and kind of lead the appointments in lots of ways, which can be challenging at times cause you might want them on one track and they're on another, but you go with what they want. (S2)

There was also recognition that generic anxiety management programs did not support the children to address the specific difficulties in their lives.

I'm thinking but what about these kids that are sitting here and are so distressed, there is so much rubbish happening to kids that a little bit of anxiety management is almost patronising. It's dismissing the high level of dysfunction that is in families, high level of dysfunction that is happening within actually the systems around children, ... (S7)

# **Clinical locations**

The staff spoke about how in the main they were expected to meet with children within clinical offices and hospital-based environments. They understood this was to enable them to see as many children as possible. However, as is noted by this participant (S2) below, these locations were not always accessible or child friendly.

...especially the young lads, you could get more information from a young person playing a game of pool than what you can get sitting in a clinical environment with them, but then you wouldn't be able to see so many people so it's quite hard. (S2)

It's a doctor's room basically. [...] It's not a therapeutic space I would've said. [...] And a lot of the young people that come in here will say 'I was really, really nervous coming along, really anxious coming along'. (S2)

So if you're given appointments up at xxxxx you're in the grounds of the psychiatric hospital and a lot of people don't attend because of that, so there's the stigma bit. (S2)

One person remembered a time when they were able to provide more of an outreach service, meeting with young people in school, at home or in the community. They recognised the child felt more relaxed and was able to be more open with the worker than they are in a clinical environment.

When you go into people's houses you tend to find out a lot more. I'm not saying that we never do that, like, we would still do that but it's a very, very odd occasion now that I would do that. (S2)

Another member of staff spoke about trying to maintain the flexibility in their schedule to offer appointments in school, but how this was not always feasible.

I go to four high schools and I tend to try and allocate a time each week to go there but it doesn't always work out that way. (S3)

The vast rural geography of Site A means that home visits and community appointments are not practical.

...we also recognise that we're the xxxxxx, my patch is double the size of Belgium [laugh] so when you think about it in that sense, and then if we have urgents, like, one of my girls is,[ XXXXXX] girl out in the community is the back of beyond, she's xxxxx, that takes a nurse all day to get there, see the patient, do that and then come back. That's one girl or nurse I've lost all day and if she needs that twice a week it's a big, big resource. (S6)

The current model supports an outreach clinic in a few remote areas, but most people need to attend appointments at a centralised clinical location that can be hundred miles from where they live.

Can you imagine being so distressed that you take an overdose then you receive treatment and then you get bundled in an ambulance, drove three hours up the road, put into another strange ward and then wait for somebody to come and talk to you. 'What happened?', 'right okay we'll let you go home', an hour of safety planning, they've to go back in the car and drive three hours back down the road, it's soul destroying, it's just not okay. (S6)

...I've had people come from xxxx and xxxx and I've had young people arrive and they're exhausted just from the journey before they get here so for them to sit in an hour-long appointment sometimes has been too much. (S10)

Staff appreciate that expecting children to travel such long distances to attend appointments is not helpful, and yet for children and young people who are suicidal this may be the only option made available to them. Although 'near me' appointments (via NHS video link) have been tried, this staff member articulates why it would not be their preference given the sensitivity of the issues and potential for suicidal behaviour.

We do try to do Near Me or Attend Anywhere type appointments too through the computer but that's... I personally wouldn't feel as comfortable with that setup when you've got someone who's high risk, you'd always want to make sure you had someone at the other end managing that. [...] I only work with my young people when I've had a number of appointments with them face to face before I would do that kind of therapy over those kinds of appointments. People who are risky I wouldn't be as comfortable with ...(S10) For children thinking about or attempting suicide in remote or rural areas access to CAMHS remains an issue.

Overall, staff in both locations would prefer to offer children and young people face to face appointments in a place that was more comfortable and convenient for them.

## The relationship is key

The staff interviewed all approached working with the child / young person differently.

The morals within which people work within vary and that to be honest is probably more informed by the training that they've had rather than lots of consideration about the evidence base, cause as far as I know the evidence base isn't fantastic anyway, so it's probably more informed by the clinician's past training; so that could be CBT, it could be solution focused, it could be some of the psychologists do interpersonal therapy, so they would be the main approaches I think... (S1)

This varied not only according to their training and job role, but also how the young person presented.

...and then it's about I guess using whatever model you bring in a way that suits the young person that's sitting in front of you really. (S1)

It there again very much depends on the individual. (S10)

Despite having different professional backgrounds and employing different approaches, all the staff interviewed stressed the importance of listening to the child / young person and establishing a positive rapport and relationship with them.

My own personal view is I think there's always a task involved in engaging young people and making them feel comfortable and listened to, and valued and heard and that's the first job regardless of the model, and if you don't do those things whatever model you're using goes out the window, ... (S1)

...it's about listening to their story and I sometimes don't think people have time to do that nowadays. Maybe I'm just old school, I don't know. [...] And they just need somebody to listen and support them and help them through it and help them to come to terms with it. So, it kinda takes you away from what you think your work is, or what other people might think your work is. (S2)

... if you make it too pro forma driven then the outcomes don't change and I think you can miss the relationship, so I think a lot of the time yeah it's about trying to establish the relationship, ... (S11)

Personally, I think it's the relationship that you have with the young person, the therapy counts but you've also got to have a therapeutic relationship. If you don't the young person's not going to buy into whatever therapy you're doing. [...] I think so. Their engagement is the most important part of the therapy. If a young person's not engaged with you there's no point them coming along to the appointment cause they're just going to sit there or they're going to vote with their feet and not come at all. [...] (S3)

The staff related that the children and young people valued being listened to and having the opportunity to talk through their worries / problems.

I think it's if you make them feel valued and listened to, ... [...] I think my experience is especially with the suicidal kids is they need to feel that they're being listened to, you know, how many times do we use 'oh it's attention seeking, they're just attention seeking' and it's a real struggle for us as therapists to try and break that barrier of no it's not attention seeking, these kids are really struggling and more and more. (S3)

...give them a sense that somebody's actually listening to them, that often negates that sense of hopelessness. (S7)

One member of staff spoke of how astute the children were, and how they could tell if someone genuinely cared, or was going through the motions.

...and I always remember when I worked in the adolescent unit one of the kids said to me 'you know the staff that want to be here XXXX and you know the staff that are here because they get paid' and I went 'oh why?' 'because the smile reaches your eyes, it doesn't reach the ones that don't want to be here' and I kinda hang onto that that you've got to want to do this. (S3) It was evident from the interview data staff believed it was the person, and their ability to listen and form a positive relationship with the child or young person that was essential for the intervention to be beneficial.

It works well because of the people we've got rather than the model that we've got. (S5)

You need to be human. You need to be... I always take it back to what if that was me sitting, what if that was my mum sitting, what if that was my child and I think once you put that compassion in there and you're not being a twat and not being the know it all I think it just breaks down all the barriers. I don't care what you do in the room, if you don't start building that relationship you've got nothing. So I think you come across as human first, that kinda care and compassionate. That's a big thing with the nurses anyway with their conduct, the code of conduct, but I think if you don't have a human, and there's a lot of people who are not, who are very kinda regimented and modelled. (S6)

### SUBSTANTIVE THEORY: THE SYSTEM DOESN'T FACILIATE STAFF TO LISTEN.

Overall, Child and Adolescent Mental Health Services can be viewed as attempting to provide social regulation of the suicidal child through a) imposing a linear and systematic approach, and b) employing a discourse of distress that neutralises risk and denies suicidality. However, it is also a site of resistance and knowledge transformation. Staff are frustrated by the constraints of the system they work within, and express the need for a flexible, person centred approach, that prioritises the relationship between the worker and the child / young person beyond any prescribed model.

## CONCLUSION

This chapter presented the findings from the practitioner interviews. The themes (expert assessment of the unknown, diffusing danger with an alternative discourse, and imposing order on the flexible and intuitive practitioner) describe and explain how children are assessed and managed by CAMHS, and how staff perceive their work with these children. The overall substantive argument suggests that although staff know what children who are suicidal need, their work is constrained by the over-riding systematic and process driven approach of Child and Adolescent Mental Health Services.

The following chapter goes on to present the findings from the interviews with parents, before presenting the experience and perspective of the children themselves. The findings from the thesis overall are then synthesised in Ch 8 to provide an over-arching substantive theory.

# **Chapter 6: Qualitative findings from parent interviews**

# INTRODUCTION

This chapter presents the findings of the qualitative interview study involving parents of children who had attempted or been thinking about suicide and were referred to CAMHS. This part of the study aimed to explore the experiences and perspectives of parents in relation to their child's experience after they had been referred to CAMHS. Seven parents were interviewed and the transcripts analysed using a constructivist grounded theory approach (426). This enabled the identification of three main themes: 'From the side lines', 'we need help' and 'Who helped and what we need'. Bringing these themes together allowed for the emergence of an overall substantive theme: marginalised parents. (An overview of these themes is presented in Table 18 below).

It will be argued that CAMHS approach to suicidal children and their families' positions parents out-with their intervention, thus failing to recognise or meet the parents need for support. Furthermore, it disables them from having a voice within the process or recognising how parents might be able to be part of the process for supporting for their child. The implications of this finding are that children are placed at further risk of suicide as parents are left unequipped to deal with the demands of parenting a suicidal child and are unlikely to seek future mental health support for their child from CAMHS.

As was outlined in Ch. 3, there has been very little qualitative research studies involving specifically parents of children who have attempted or been thinking about suicide. This novel study provides key messages for practitioners, and service providers as well as academic researchers. Within the context of the thesis, it also supports a more complete understanding of the children's experience of seeking help from CAMH'S for suicidality.

The chapter begins by describing the sample group. The structure of theoretical themes and sub themes is then presented in Table 18, before they are explained in full. The substantive argument is then expressed more fully and situated within the preceding analysis.

## Sample Population & Dataset

The participants were all parents of children referred to CAMHS because their child had attempted or been thinking about suicide. As discussed in the methods chapter (Ch. 3), these parents self-selected and 4 / 7 interviews were conducted face to face within the participant's home, whilst the others had to be conducted via skype due to COVID -19 lockdown restrictions. Two parents were interviewed together as they were married, cohabiting, and raising their children together. Two parents were interviewed with their child present, all other interviews were conducted with the parents alone.

Only one participant was male, all were white. Two participants lived within the health board area of Site A, five participants within health board area for Site B. The referral for the child of one parent in Site A had been rejected, whilst one had been assessed but had been on the waiting list for treatment from CAMHS for a year. The children of all parents within Site B had been assessed and had accessed a service from CAMHS. Three of the children had been referred to CAMHS following a presentation at Accident and Emergency following a suicide attempt. All other referrals were made by the child's G.P. All their children either had plans to end their life or had made a suicide attempt.

Substantive theory:	Marginalised Parents	Through non-engagement of parents in the mental health support and treatment of the child who presents as suicidal, parents are disenfranchised, and rendered powerless in their quest for help and support from CAMHS.
Theme 1:	From the side-lines	This theme captures the parent's impressions and experience of their child going to CAMHS for suicidality.
Sub-theme 1:	"on the periphery"	Parents were side-lined by CAMHS and did not feel involved or consulted about their child's treatment.
Sub-theme 2:	"scratching the surface"	Parents were unconvinced that the workers had really got to know their child, or that the intervention had been beneficial to them.
Sub-theme 3:	Abrupt endings.	Parents spoke of their children being discharged from the service often without warning, or them feeling they were ready. They were not consulted about this or provided an opportunity to discuss it.

#### Table 18: Summary of parent interview themes

Sub-theme 4:	"CAMHS left me"	Parents felt both they and their child were
		abandoned by CAMHS with no follow on
		or alternative supports provided.
Sub-theme 5:	It wasn't personal	The parents believed their child's poor
		experience of CAMHS reflected how under
		pressure the service was. They also
		reasoned that the lack of communication
		with them was borne out of policies
		regarding confidentiality.
Theme 2:	"we need help"	Parents identified their own need for help
		and support to parent their suicidal child.
Sub-theme 1:	Parenting on eggshells	Parents articulated the impact that their
		child's suicidality had on their ability to set
		boundaries, and their need for support
		and guidance that wasn't made available.
Sub-theme 2:	Living in fear	Although the suicidal crisis that had
	Ũ	initiated the referral to CAMHS had passed
		many of the parents remained terrified
		that their child would end their life.
Sub-theme 3:	The risk is real	Parents were all aware of the risk factors
		for suicide their children were facing or
		had experience of. For example, identity
		issues, bullying, sexual assault, and having
		known someone who ended their life.
Theme 3:	Who helped, and what we	This theme captures the people and things
	need.	that parents felt did help their child, as
		well as what / who, if anything, helped or
		would have helped them as parents.
Sub-theme 1:	The relationship and not the	Parents identified the people who had
	professional that helped	helped their child had listened to them
	their child.	and engaged with them on their level.
Sub-theme 2:	What we needed	This relates to sources of support that
		parents had found for themselves, as well
		as resources they would have found
		helpful.

# FROM THE SIDE-LINES

# "...on the periphery"

The parents interviewed generally reported they were not involved in their child's treatment or appointments at CAMH'S. They often took their child to their appointments, but in the main workers did not invite them to participate in the sessions, update them after or ask for their opinion. No not really no, they didn't really talk to us. [...] And then, yeah, I think she had about three appointments, nobody ever spoke to us at all. (P1)

...so we went up, initially we were just going once a week, she was going to speak to somebody and during they sessions obviously I wasn't present at all, I just used to wait outside with my daughter. She'd go in, she'd be in for 45 minutes approximately and come out and we'd go home. (P3)

I've never once had a conversation with CAMHS about xxxxx, not once. Not once. I just took her to the appointment and brought her home. (P3)

I never had any input with any professional on my own. (P5)

Although parents spoke about respecting their child's right to have time to speak to their worker alone, they shared a frustration that there were things they needed to say that were important, but no-one ever asked or offered them the opportunity.

...that wasn't opened up for me particularly, but they were very much focused on communicating with xxxxx so a lot of my concerns and things weren't really imparted, and I don't think they ever really were imparted,[...] But at no point was I asked to disclose information that maybe xxxxx wouldn't want to hear, does that make sense, because I think he was so vulnerable some of the stuff that I was seeing and wanted to say I didn't necessarily want him to hear and I was very much told that I wasn't to have a conversation that I wouldn't repeat to him, and not in an unkind way but I just felt that, you know, they were treating him very much as an adult and he should have everything disclosed, where I felt at that point that he was very much a child because his behaviour was not rational. (P7)

Parents also spoke of having questions they needed to ask but were never given an opportunity.

No which is very hard because obviously, it's not so much I needed to know what was being said, it was more like I needed to know how to talk to her at home, you know, what we could be doing. It's very difficult. (P1)

Parents who were invited to join at the end of their child's session expressed they felt this was almost tokenistic and lacked any real engagement with them or their child.

I think initially no but then after a certain length of time at the end you get asked in, but to very little effect, it's a wee summary of what the conversation that they had. ...it was so obvious the lack of a relationship that hadn't been built up. (P6)

There was a sense in the conversations with parents they did not want to interfere or overstep. They wanted their child to get the help and support they needed and were getting a clear message from CAMHS that this did not involve them. They had to trust the worker knew best.

...yeah, you kind of think you're putting your trust in them that that's the way they do it, that's the best way to do it. (P5)

Backing off to let the "professional" do their job, seemed to be what was expected of them. And yet the parents recognised what might have been most helpful to them and their child would have been to support their child to speak to them.

So it's not just looking after them in isolation but it's allowing to bring the people together more as well, so a sort of... I think they do need their own space but I think there also should be a family element to it because that way it sort of heals that feeling of separation really, that feeling that you are on your own within your family sort of thing. I mean, I know everyone's situation's different and there are people who genuinely maybe are on their own and talking to their parents is dangerous in some way, but a lot of the time that isn't the case, it's more you feel isolated but you don't need to be sort of thing... (P1)

Only one parent spoke about participating throughout the assessment appointment with their child. In this instance it was the only appointment the child had with CAMHS, and in contrast with all the other participants they were never seen independently from their parent. In the main, parents did not feel that CAMHS workers engaged with them in any meaningful way. For the parent of the child who was rejected without being seen this typified lack of consultation with parents.

It felt like people weren't taking on our concerns, you know, as a parent I know my child really well and I know when something's really not right and, you know, you don't

go to GPs and you don't ask for help if there's not anything wrong, and it felt like we weren't being listened to almost. (P2)

In the main parents described being outside of appointments, and held at a distance by CAMHS workers.

...we feel that we inevitably are kind of placed on the periphery... (P6)

# Scratching the surface

Presenting as being well 'on the surface' was something a lot of parents spoke about their child doing. This caused concern to parents as they worried people might presume they were okay, when they knew they were not.

Oh aye definitely, people could not believe, my own family, her teachers could not believe, friends of mine who's children went through the primary school with her and still see her now cannot believe, cannot believe the mental health issues that she has, and they always say to me 'what, she's so confident?' I'm like 'she's not'. Outwardly, appearance wise cause that's her barrier, that's 'I'll appear to be confident; I'll do all of this to my face' but inside she's not. (P3)

...he's very good at coming across as together and socially strong, he puts on a very good front, he's got some good outdoor coping strategies, but they tend to come indoors when nobody else is around (P7)

Because she would be low but then the next day...(P5) [She'd be singing in her room.P6] ...you'd hear her up in her room singing, you know, along to something on her computer singing away, and we're like that's not the idea that you have of someone who's going to take their own life.(P5)

xxxxx can put up a massive screen when she's okay and everybody's like 'there's nothing wrong with her' and then I see her in the house and I know there's something wrong, ...(P4)

Most parents were unconvinced CAMHS workers had gotten to know what was really going on for their child under the surface. I just would question the person's commitment, you know, full commitment to it and I think that's very important talking about suicidal people that are just 15 years old, it's really important how you engage with them and you build that relationship with them because otherwise you're just going to be scratching the surface and you're going to be missing out what's going on in the background, maybe hearing all the answers that you want to hear but then if you just approached it in another way you might hear something completely different which requires action. (P6)

One parent reported a worker demonstrating little appreciation of their family circumstance, and the sensitivity of the situation.

I think it was the CAMHS person who came in and basically, cause my ex-husband didn't know about some things that had happened and obviously I think xxxxx had obviously said something to them and told them about some things, and then the CAMHS person sort of blurted that out in front of him, so it was the first time he knew about, and so it was all very awkward cause there was me and xxxxx and I was having to go 'yeah I knew about that' cause xxxxx had asked me not to tell him and, yeah. So that was kind of our first thing with CAMHS ... [...] Yeah it just felt a bit sort of like they don't really know what they're doing and they don't understand how these things work, you know, like teenagers and parents and what they know and what parents might, you know, sort of... (P1)

This incident could have resulted in causing the child further distress as their father had not known about events leading up to the suicide attempt. Had the CAMHS worker had more knowledge of the wider circumstances and family dynamics this situation could have been avoided.

Other parents reported it was apparent to them the worker did not have a good rapport with their child or engage with them well.

...it's not that the person that did it was in any way horrible or anything like that, there was just a lack of an effective relationship. (P6)

The perceived lack of understanding and engagement left many parents feeling let down and they would not seek help from CAMHS in the future.

I think because she had such a bad experience that in my opinion, she might tell you different but I doubt it, 'what's the point mum?'...'What's the point because they'll see me twice, two/three times, see/say that I'm okay and then send me home? [...] For me CAMHS is a no go and I would be very, very reluctant to take her back and I think she would be, you'll know by chatting to her later, I think she would be very reluctant because I don't think she felt they were any use at all to be honest with you. (P3)

Parents would have valued someone taking the time to get to know their child, and what was troubling them. Although one parent did report that their child got along well with their worker, this was an exception.

...he ended up with the right counsellor who he felt he trusted, and I think he spoke very openly and honestly to him. (p7)

Most felt their child's case was opened and closed without much therapeutic intervention in between, and without affording them the opportunity to discuss their child's case. Parent descriptions of their child accessing or attempting to access support from CAMHS suggested they felt that they and their child were processed through a system rather than being dealt with or met as individuals.

The whole system's a let-down to be honest with you, if you're under the age of 16 there's no help, there's nothing, there's no help for parents, the help for them is minimal, minimal. (P3)

Parents felt let down by the service they had hoped was going to help their child, and them to support their child at home.

## Abrupt endings

With very little or no conversation between the parent and CAMHS worker (for those whose child had been seen by CAMHS), they often found their child had been discharged from the service without advanced warning or planning. A few parents spoke about their child presenting well on one occasion and subsequently being told by their worker they were fine and did not need to come any-more.

... and on this particular occasion when we went she was having a particularly good mental health day, she was feeling quite positive, I think she'd had a good result at the school, a good pass on a test and things like that so her mood was up. We went to CAMHS and they seen an increase in her mood and discharged her that day. [...] Fair enough they had seen an improvement in her mood, had I seen an improvement? Not particularly but my opinion wasn't taken into account. They didn't speak to me, they didn't tell me they had discharged her. [...] No, no. She just came out and said 'that's it, I don't need to go back anymore' and that was that. (P3)

...after those three appointments they said 'oh no, that's it, she doesn't need us anymore' and then she just started getting really bad again, like, really sad and saying she was thinking about doing it, suicide all the time, and at that point I think she was thinking more about cutting herself rather than taking tablets. (P1)

Parents expressed that although they recognised their children had presented more positively to their workers, this was not reflective of their overall mental health and suicidality remained a concern. However, parents were not consulted about the discharge of their child from the service and were not afforded the opportunity to discuss it.

There was no discussion about why she didn't have to go back, what they were feeling or anything like that, there was no after discussion about anything for confidentiality reasons. I wasn't asking for any confidential information but I would've liked to have known on what they were basing discharging her on, was it because she was alright that day or had they seen an improvement before and this was another improvement? So then she was discharged. (P3)

One parent related their child being discharged was communicated publicly in the reception area where there was no space for any questions, or discussion.

As I say, I would sit and wait in the waiting room doing my [work] and after xxxx went in with the lady, [...], I hadn't met this lady before, and she came out with xxxx into the area where I was standing, I wasn't invited in, they actually came out to where I was standing and she said that she didn't think that they would make another appointment but she'd given xxxx literature and a card that she could get in contact with her...I mean, there was no receptionist there but there was actually people finishing their work, [...]... came out and got into his car and said hello to me as he went past as I was standing talking to the nurse, you know. So no there was no privacy but the nature of what she was saying to me, I don't know, there was nothing really. (P5)

The interview data suggests parents were often not afforded any privacy or confidentiality by CAMHS workers, in contrast to their children. This lack of safe space for a conversation to take place with a parent prevented parents from questioning the workers decision to discharge their child.

# "CAMHS left me ... "

Following what had been described as an impersonal and often abrupt ending, parents spoke of feeling left with no follow-on or alternative support.

I felt it was effective, but I felt it was then taken away with no proper support afterwards, [...] ...while he was being seen actually his behaviour changed enough that I was okay, I felt confident that he had somebody to go to, that that person was providing him with that resource that I obviously wasn't giving him, but when it left, when things went wrong he had nowhere to go and I had nowhere to go. (P7)

This parent reported their child had had a positive experience with CAMHS, but following their child being discharged they were left to try and organise supports for their child all over again. There had been no communication between CAMHS and other agencies such as school and there was no follow on supports in place. They expressed feeling abandoned.

So CAMHS left me, they did a really good job and then they just took it away, you know, it's like building a house and then not properly finishing it off and having nobody to come back and fix the little cracks that appear, so I had to battle with the school to try and put something back in place of which xxxxx was very resistant because, because it hadn't been in place already I was interfering again, so that was quite hard. (P7)

Although some parents were told to get back in touch if they needed, most would not. Feeling the door was being shut on them, they often felt that going through the process again would be pointless. I wouldn't even bother with CAMHS because it's... my personal experience has been awful with them, absolutely awful. (P3)

I honestly, I do get very concerned partly because they don't give you any structure of where you can go or how you can seek help, you almost have to go back to the beginning again if you have concerns and you're going through the whole process of waiting,...(P7)

Not all the children of the parents interviewed had had a service from CAMHS, and similarly there seemed to be a lack of alternative resources made available. After a year of waiting for a service from CAMHS with no interim support this parent described being left to cope with a child for whom suicidality remained an issue.

I notice her behaviour, you know, I know recently her mood's been low again and I haven't been saying it too much to her but I'm aware of it and that worries me, you know, I still feel like we're out on a limb, we're on our own trying to deal with this. (P2)

They had been told they would receive primary mental health worker support while they were waiting, but this had not materialised. The parent spoke of being ricocheted between her G.P, CAMHS and school requesting help for their child.

I feel like just everything gets passed on and we're going round in circles. [...] It's just like nobody's taking real ownership, ... (P2)

Another parent of a child who was rejected from CAMHS speaks to the disappointment and horror of not even being offered an assessment, after having been assured by their G.P a CAMHS referral was the best option.

They just sent a letter out to say, I can't remember the exact wording but it was just like the words to me read, like, 'you're not eligible for the help, you're not serious enough for us to be able to help you' that kinda impression I got from it. I just screwed it up and chucked it in the bin! [...] Just feel really let down and wonder what it is that a child has to do to be classed as urgent or important enough for the service essentially? I know everybody's short staffed or underfunded but how d'you filter that, how d'you say that kid can get our service but that kid isn't, and I wonder if she'd maybe ended up in hospital with slit wrists or an overdose then maybe we would've gotten help but that potentially could be too late by that point. But just felt really let down and didn't know where else to turn really. (P2)

With no contact from CAMHS other than a rejection letter, this family were provided with no mental health assessment or support. They went on to access a social work-based support service via school, but this was unrelated to the CAMHS referral.

# It wasn't personal

Although the parents expressed different levels of anger, disappointment, and frustration with CAMHS, they did not blame the individual workers. The dialogue used by parents in relation to their poor experience of CAMHS reflected a perception that the service was too busy and under-resourced.

I mean, it's probably a funding thing or something, but it's just not really there. There aren't enough people, there isn't enough resources (P1)

I just think CAMHS... they're underfunded, they are under resourced, they don't have the staff. Mental health is an epidemic just now, like, bairns as young as eight, d'you know what I mean, ... (P3)

The pressure on CAMHS was offered as a reason for the service being unable to meet their child's needs.

I know everybody's short staffed or underfunded ... (P2)

I know they don't have the staff, I work in the hospital, I get it, we're all struggling for staff, d'you know what I mean, I get it, but I think more... what's the word, like more... more input definitely... (P3)

Beliefs about the service being so overwhelmed were also provided as a reason by parents for not complaining. They believed it would have been futile.

No never complained, no. I should've but I never did. (P2)

I presume you could've done but you just wouldn't have been confident of getting much help, you know, the response, you know, is just that kind of like, you know, you feel like you're just getting a shrug and like 'no, well we can't, there's not enough people, it's too busy, too many people need us' sort of thing. (P1)

Parents also expressed a belief that the lack of communication with them was because of patient confidentiality.

Yeah, my feeling is in the modern world when you have a situation like this and someone's at the centre of it, what age was xxxx at the time, was she 16 at the time? [...] 15, but still in the modern world they have the rights to their own privacy about what they reveal and whatever, I think people are kinda caught in the middle there and it's almost we feel that we inevitably are kind of placed on the periphery because we're not really the party that's got the difficulty. I can see the way the modern world functions in relation to people having difficulties that it's quite easy to squeeze other people out that are at the end of things, that's how I feel about it, and I don't really know if I have an answer to that. (P6)

It's all about confidentiality, they wouldn't speak to me about anything. They never told me how to keep her safe, anybody I could contact if anything was to happen, nothing like that, absolutely nothing, nothing at all. (P3)

Confidentiality for these parents meant that they had no idea what happened in the sessions, how their child was viewed or what treatment they were engaging with. They were relegated to the role of taxi driver and relied on their child to relay how beneficial or engaging their appointments had been.

Because of confidentiality and things like that I don't know what they were doing, I don't know what they were discussing. I'm very big on her having her own privacy and what she wants to talk about, but it would've been... I didn't know how she was truly feeling. She would tell me but is that how she was truly feeling? Did she go into more depth with CAMHS? But again it comes down to confidentiality, they'll not divulge anything she has said unless she has indicated that she's going to harm herself and then they would say to me 'listen she's at risk of such and such, this is what we're going to do' but aye it's a hard one. (P3) As this quote captures, the belief that there was no communication with them as a parent due to confidentiality was a barrier to them challenging this or pressing workers for answers.

#### "WE NEED HELP"

#### Parenting on eggshells

All the parents interviewed spoke about the challenges parenting a child who had either attempted or been thinking about suicide. Fear that they may choose to end their life or do something impulsive created a situation where they felt as if they were walking on eggshells around their child. Parents were scared to impose boundaries they believed they would have otherwise set.

Well yeah cause you don't know what you're supposed to do and when you've got a child who's already actually attempted suicide then that's always hanging over you, you're always worried about upsetting them and, you know, when you've got a teenager and they're constantly pushing the boundaries and you're, like, trying to set boundaries but you're always worried about what the reaction is going to be, you know, as a parent you could really do with some support, somebody to tell you how you're meant to handle those situations because it becomes very difficult. When she's saying 'I want to come home from school because I feel really anxious and really sad and I really feel like I might hurt myself' and you're like 'well, okay come home' you know, but then you're also think 'but no but you need to stay in school because it's important'. (P1)

Yeah, so my partner always says to me 'you let her get away with murder' but it's a fear factor. I let her get away with murder because sometimes I think if I tell her no is she going to go and cut herself, if I don't get her something is she going to go and cut herself? And then my partner will say 'yeah but she's being manipulative because she knows that mum's going to get her something' because I've got the fear that she'll then go and do something. I never say no to her, never, for the fear that she'll go, and she wouldn't, I don't think she would and I don't think she thinks like that but parenting her is hard because you don't know, and she'll tell you I always say the wrong thing to her, I always say the wrong thing, and she'll say to me 'oh you don't understand' and I'm like 'well I try to understand, help me understand then if I'm not understanding' 'oh you don't get it, I'll speak to my dad' know what I mean, so it is hard to parent, you're always walking on eggshells and that's what I say to them, you're always walking on eggshells. (P3)

Absolutely, I give in an awful lot more than I would do based on the fact that I don't know whether a threat is him being a teenager trying to get at me or whether he walks out that door and climbs up, we live right next to a railway line, whether he would just climb up onto the railway line. (P7)

Parents spoke about second guessing themselves, trying to say the right thing, and trying not to say the wrong thing. They worried about making the right choices in their approach to dealing with their child's behaviour, but also the impact that treating them differently would have on their behaviour long term.

Yeah that does terrify me so I tend to back down which probably doesn't help him because he gets away with things that I wouldn't let my other son get away with because I don't have any of those concerns with my younger son. (P7)

The parents interviewed were open about the challenges they faced, and the absence of any support being made available for them to deal with this.

But there's no support for parents. [...] There's no support... [Interviewer: For parents?] ...no, none whatsoever, none whatsoever, unless you research it yourself, which I have done. (P3)

I think yeah xxxx wasn't let down by the service but I do feel sometimes that I didn't get any resources for me as a parent. (P7)

It was clear from the interview data that parents wanted and needed advice and support that was not forthcoming.

Well yeah 'cause obviously I didn't know what you're supposed to do in that situation... I think, yes, parents need some support or some guidance... (P7)

...when she first went back, so I went in for the first one then and they gave us... they gave her a list of numbers but yeah that was focused for her, there wasn't any sort of

thing of like 'well these are the people who support the people around you' sort of thing. And you're just told the Samaritans and all this kind of stuff, and you're like well actually what you need is somebody to be able to talk to, people who actually understand the caring side, not the I'm in crisis, I'm the person in crisis, although I suppose there's times where you feel like you are now in crisis yourself sort of thing! (P1)

They never told me how to keep her safe, anybody I could contact if anything was to happen, nothing like that, absolutely nothing, nothing at all. (P3)

One parent spoke about how although the worker had said they would call to discuss things with them privately, this never transpired.

She did say she was going to contact me to give me some support and that never happened, and I didn't chase it up because when I hear how sort of short CAMHS are at getting things, (P7)

And yet they all spoke about how they themselves needed help to know how to handle the situation, and best support their child.

I mean, it's very much, yeah, obviously her pain and her, yeah, how she feels about the world regardless of how it is, is what's important and that's what needs looking after but it is important to, like, have the people around her understanding what's happening so that they can support her because obviously you only have your appointment with CAMHS or whoever once a week at most and the rest of the time [laugh] they're not there! (P1)

Participants expressed that although their child needed support with their thinking and behaviour, their suicidality impacted upon the whole family, and yet they did not feel that this was acknowledged.

...I was just at that desperate point where I was saying to the doctor 'look, what do we do, we need help, somebody needs to help me 'cause I don't know what to do?' and also with her aggression in the house and obviously xxxxx and xxxxx are younger, they were seeing it, which was then having an effect on xxxxx especially cause he wears his heart on his sleeve, so at points he hated her because she was making me cry or, d'you know, so it was having a massive effect on the entire household (P2)

...maybe it's just not properly understood that when somebody has a problem then it's not just them, it's everybody, cause you're expecting other people to be their carers, they're not in a medical institute or anything, so everyone around them has to understand how to look after them as well, you know, it's not just that person and especially when they're a child. (P1)

#### Living with fear ...

Knowing their child had attempted to take their own life or been thinking about suicide terrified parents. Many remained frightened that suicide was still a possibility.

...threatening to take his life and he was doing things like climbing out the window in front of me, so I moved his bedroom from upstairs to downstairs so that he couldn't do that, when he went out the door I didn't know what he was going to do because he was so... I don't know, I couldn't read his emotions, he became so angry that just glazed over, just so locked down and I eventually took him to the doctors 'cause I thought I'm scared because I have no understanding of what's going on in his head and he was doing things that I felt were putting him at risk, and it wasn't normal teenage behaviour. [...] So for me there was a lot of stuff and I think I, at that point, started to react in fear as well, ... (P7)

No, no and because of our location, I don't know if she talked to you about that, because we live almost on the doorstep of the railway line, right there, I think that made it more urgent as well because, you know, it would only take, what, half a minute to get to the railway from where we are ... (P5)

...think even as a family we're still, I mean, I'm anxious about xxxxx and you know, she's still got points when her mood's low and then sometimes I worry that, you know, if I... not... I don't want to add to her distress, I don't want to put pressure about school, you know, if that makes sense, I don't want her to feel like she's got no way out again. (P4) Fear of suicide was driving their worry, and parenting. Although some time had passed since the initial attempt or disclosure of suicidality, they remained fearful suicide was still something their child would consider.

I think by that time xxxx had moved away from that, it wasn't so much the crisis but as you say we were worried that it could dip into that again because we had no idea that that's where she was at then, the danger is how are we going to know next time? (P5)

...my attitude from the very beginning was that if what this is, is a sort of para-suicide event then para-suicide I know from years ago when I was studying it was associated with a greater likelihood of successful suicide in the end, so what may seem like a dabbling and something that someone's not going to follow through on is a big warning sign [inaudible 00:50:31] So how I feel about it and my gauging of how she feels I chose to mistrust and just go with take this seriously. (P6)

Am I 100% convinced that she would do something? Aye and no. When her mood's really low aye I do, but it's just trying to find that balance of will she, know what I mean, it's hard to tell. (P3)

What worried them was not knowing, not categorically being able to tell whether their child would again think about or try to kill themselves. Every parent's biggest fear being they would find them dead.

*I live in fear that I'm going to find her dead... that she's going to do something daft and there's going to be no coming back from it. (P3)* 

#### The risk is real

Although some parents had spoken about how their child did not tell them everything, they were all able to identify underlying issues and sources of stress in their lives including: bereavement, relationship breakdowns, bullying, and gender identity issues.

...my mum passed away. So my mum was her go to person so she would chat to my mum about everything and anything ... (P3)

The bullying intensified and there had been threats to kill her, there'd been threats that people were going to come to the house, so there was different various families who

are quite well known that were making threats and it was quite relentless on social media and threats to come to the house and things like that. (P4)

Which is what happened, she had a breakup with her boyfriend and then got a new boyfriend who wasn't very nice and I think that, I mean, without knowing the details of what happened, but I think that's something to do with it, how she felt around that time, maybe communications about her in social media that weren't very nice, we've heard bits about it but not really. (P6)

...when she comes down to you she'll probably present herself as male so this is what I mean about not fitting in. So obviously she was born a girl, she looks like a girl, I call her xxxx, nobody else calls her xxxx, her name's xxxxx to everybody else and she is known as a male to everybody else, including the school. [...] she struggles with who she is, she struggles with her identity, (P3)

Parents recognised that life events and circumstances were often the trigger for their child's suicidality. They also identified additional factors that placed them at an increased risk of suicide. For example, more than one young person had a family history of mental health problems and / or autistic spectrum disorder.

...his father had mental health issues and is diagnosed ADHD, [...] his father has now been diagnosed with ADHD with the ADD component of it and it's been described that xxxxx is very similar in those ways. So when he was little he wouldn't do things like if the dog bit him he wouldn't learn not to go back and poke the dog again, and it wasn't till I had my other son who if he poked the dog and got bitten would never go near the dog again, I suddenly realised that some of xxxxx's behaviours were inappropriate. (P7)

...my sister's just turned 30 and she's only just been diagnosed with bipolar at 30 years old after struggling for god knows how many years, but really struggling since my mum died, hallucinations the whole shebang, so she's been started on a new medication today so see how that goes. But she suffers with her mental health as well, and xxxx sees that, xxxx sees that. She doesn't know that my sister sees my dead mum and that but she knows that her Auntie xxxxx struggles with, knows that. (P3) Moreover, some of the parents spoke about their child knowing someone who had ended their life by suicide, and in more than one instance this was another young person.

...we knew a family who had that experience a year before, a child that had gone through school with xxxx and with our son as well and he had taken his life on the railway line behind our house. ...we also have a family experience of someone taking their life, not someone that xxxx would know particularly well but xxxxx's cousin.... (P5)

...it didn't come much long after my friend's son had, and not due to suicidal tendencies but had a bad trip on drugs, first ever time taking drugs, had walked up onto the railway line and then xxxxx would keep saying 'well that's what I want to do', ... (P7)

The risk of death by suicide was real for these families. Their fear justified. Many continued to worry that unaddressed suicidality would be something that stayed with their child into their future, potentially manifesting as deep-rooted mental health problems and / or increase the likelihood of death by suicide.

...what worries me is that she's also at an age where if she doesn't get the right support at the right time we're going to end up maybe with long term mental health issues, you know, that's my worry. (P4)

...there needs to be something more in depth so you could get to the root of the problem now before she turns 18/19/20 and then the next thing you know she's jumping in front of buses and things like that. (P3)

Parents were left living with these fears, without having them acknowledged or addressed by CAMHS.

#### WHO HELPED, AND WHAT WE NEED

## The relationship not the professional that helped their child

The parents interviewed were able to identify people who in the main had worked out with CAMHS, or indeed were family members, or friends that helped their child; primary mental health workers, social workers, teachers, an art therapist, a private psychologist. They understood that the relationship and rapport these individuals established with their child was key to gaining their child's trust and establishing engagement.

...when she went to the psychologist because I think she felt she was being properly heard so that helped her relax a bit more...(P1)

The first woman that she spoke to was absolutely superb, speaking to the both of us, immediately created a very effective bond with xxxx. (P6)

XXXX was more a friend than I think what xxxxxx looks at, like, a social worker's this person with a suit on whereas xxxx was normal, she was like you and I, she would appear with a hoodie on, jeans, trainers, she'd say the odd swear word, you know, she was quite cool. [...] Totally relatable, ... (P4)

Listening, offering empathy, being personable, and making an effort to get to know the child, were all attributes the parents valued and recognised in the person who helped.

...but I think what'd been good for xxxx is building the relationship with the worker, so that one appointment with xxxxx went okay, (P4)

The frustration for some parents was their children had met someone they could open up to and trust, but then had no follow up appointment or were then passed on to another worker, and the same engagement wasn't there. In this quote below the initial appointment had been with a primary mental health worker and because they were assessed as being appropriate for CAMH's they were then passed on. Perhaps this is indicative of the fact that it was the person rather than their role or profession that was helpful to their child.

The disappointment for me was that it didn't go on with the same person, that was a disappointment for me, and then the second person I didn't find remotely, I went up with xxxx to... [...] ...yeah, and I don't know what xxxxx will say about it but I really was, I just didn't think she, she just lacked empathy. The first one was so good and the second one I thought was so poor in terms of her ability, she just sounded too detached from the whole thing, you know, to the extent that she didn't feel like she was the sort of person that was properly involved in trying to help someone, she just didn't convince which surprised me a lot. (P6)

However, there were parents who expressed that although they had been anxious about a change in worker both within the CAMHS service, and a social work based support service reported this had gone well and their child continued to engage.

...she loved xxxx and then xxxx got a promotion and I was really, really worried ...[...] but she was really lucky to get xxx and xxx's been in, we've had a few meetings with xxx. (P2)

No, the first appointment wasn't ultimately with the counsellor that he saw. I think we saw this lady twice, she was lovely, I can't remember her name, who took us in, had a wee chat, I then left and then was invited back in. [...] ... he ended up with the right counsellor who he felt he trusted, and I think he spoke very openly and honestly to him. (P7)

Some of the workers from services other than CAMHS had been able to offer flexibility in terms of where they saw the child or young person, and they were given a degree of choice around this.

But she would even offer to come out and take her for a coffee, you know, come and just meet her any day of the week. (P2)

Aye. xxxx was quite good during the holidays there, she still met with xxxx on a weekly basis outside the school... (P3)

A few parents noted their child's worker (a social work support worker and an art therapist) had kept in touch with them and initiated contact during school holiday periods. This was something they really valued and demonstrated genuine concern for their child.

...she was away from her support group of friends and particular teachers and things like that, so aye the holidays and things like that make it difficult cause she's not got that, as much as she speaks to me, I think the conversations that she potentially has with her teachers or other adults is more in depth maybe, cause she sees I get upset and I try not to, I try my hardest not to cause I don't want her to feel 'oh my god if I tell my mum she's going to greet' know what I mean, I don't want her to feel like that. (P3)

Holidays, she said 'just you phone me, I'll come down from xxxx and we'll go for a coffee, lunch, whatever and a chat'. [...] She texted throughout the Christmas holidays as well didn't she? [...] She'd say like 'merry Christmas, I hope you had a lovely time, how's your family, what did you get from santa?' you know, that kinda friendly chit chat as well, which is good cause it makes her feel like she's got an adult outside of the

house, cause obviously mum being her mum we don't get on 100% of the time, 99% of the time I'm like 'xxxxx this, xxxxx get your room done, xxxxx do this, xxxxx do that' or whatever, so it's nice for her to have that outside contact that's an adult she feels can help. (P2)

In the main, the parents interviewed wanted someone approachable who would listen to their child and support them with their feelings.

xxxx was more a friend than I think what xxxxx looks at, like, a social worker's this person with a suit on whereas xxxx was normal, she was like you and I, she would appear with a hoodie on, jeans, trainers, she'd say the odd swear word, you know, she was quite cool. [...] Yeah, she was always on your side. 100%. (P2)

I think if xxxxx had had the chance to get to know a worker more, you know, she doesn't want to feel the way she feels, you've said that to me, you want help, you don't like feeling like this and it would've been nice maybe for her to have the time to talk to a worker that was able to do that work with her and to help her with some of her anxiety. (P4)

Making time, and taking their time went a long way to helping establish positive rapport and relationships with the children and young people.

## What we needed

In the absence of professional advice and support from CAMHS, parents sought out their own supports, which relied upon them having connections and positive relationships to draw upon.

No, just I've got my family, like, my partner and I support each other and my mum and my dad both live locally so they would be a good help for an ear to listen while I ranted and raved [laugh],... But yeah had 100% support from them, but professionally nothing at all. (P2)

I've got a friend at work, a colleague at work who's daughter's got issues that xxxx actually is at school with by coincidence, yeah, and has been friends with at certain

times, so I've had conversations with him about, you know, another dad to sort of share your concern. (P6)

I had quite a lot of support when I went looking for it around that and was able to ask for support from people around about me, and I think that made a big difference to me. I think if I hadn't had that I would've felt that I was very much looking on Google, you know, I was told I would get this contact and the GP did say if the problem was worse just to give them a call, but again limited what he was going to be able to do. So I think I didn't get the resources from there but I was quite lucky that I had the resources around about me. (P7)

The quote below shows how challenging it was for a parent having to search the internet for information and support for their child.

...I then went out and sourced my own levels of support; I went onto Mood Café, she was pointed in the direction of Mood Café and things like that by the A&E doctor until her CAMHS appointment comes through but I just went and done all the sourcing of information myself...And it's an absolute minefield 'cause you click on one thing and then the next thing you're diverted to suicide hotlines, know what I mean, so it's hard and I feel sorry for her, being her mum I just want to fix her. (P3)

The participants were keen to express that they understood CAMHS were busy but that had their need for support been acknowledged, signposting to other formats of parental support, such as peer support would have been acceptable.

... I think having someone to speak to in the sense of you wouldn't be looking for anybody to solve anything but all you'd want is just someone that understand how you feel, they might have their own personal experience to share, they might have some meaningful things to refer you to, to go and look at that you felt you were actually getting something from. [...] The other thing I was going to say was if I was in the situation again I think I would probably try and get in touch with more of a self-help group approach that people in the same position as us but have been there and got the t-shirt that can, first of all can relate and understand how you feel and can give you more experienced advice 'cause they've shared it among other parents that have been in the same situation. (P6) I think to know that there's other parents out there that children are suffering from mental health and things like that. You think you're on your own, you think that there's no other bairn going through this, this is just happening to her, this is just happening to me in my life, there's nobody else that this is happening to. So there's not a lot of support groups where parents can chat and maybe such and such's daughter makes you look at your situation and think 'know what, it's actually not that bad, at least she's not trying to harm herself' know what I mean. (P3)

One parent noted that even written information would have been helpful.

...parents need some support or some guidance even if it's in a paper form, ... (P7)

The parents interviewed were looking for understanding and solutions. Many sourced information and support independently of CAMHS, but this often took considerable effort.

I was always making phone calls, I was always making phone calls to the school or dealing with the doctors or dealing with xxxx or xxxxx ... I mean, that situation with the school I had to go and source that myself, I had to go to the school and I had to go to meetings at the school, I had to agree with the school 'can we try this, can we try that?' I had to agree, I had to get them to draft people in, know what I mean, I was doing all the legwork in a situation that for any other person might be overwhelming. (P2)

Getting help for their child was for some a '80.0battle' (P7), and the information and support they needed was not readily available. Those who managed to find the advice and resources they needed, or who felt supported by friends or family still identified a gap in service provision for parents of children who are suicidal.

#### SUBSTANTIVE THEORY: MARGINALISED PARENTS

Together the themes presented above show how through non-engagement of parents in the mental health support and intervention of the child who presents as suicidal, parents are disenfranchised, and rendered powerless in their quest for help and support from CAMHS. Parents are held at a distance and the worker's engagement with them procedural and superficial. They are not afforded opportunities to complain, have a voice, or place demands on the service or worker.

It could be argued that one of the ways parents are discouraged from contacting or appealing to the workers for more support is through dominant discourses: Firstly, the presupposition that CAMHS are underfunded and short staffed, and secondly the inference that honouring a child's right to confidentiality means not sharing any information or communicating with parents.

Parents are subjugated to the role of by-stander. Their need for support and advice largely unrecognised by CAMHS.

The following chapter turns attention the views and experiences of the children and young people themselves.

# Chapter 7: Findings of the qualitative interviews with children

# **INTRODUCTION**

This part of the thesis aimed to explore children's experiences of being referred to CAMHS for suicidality and to present their care journey from their perspective. To my knowledge this is the first qualitative study of suicidal children's views and experiences of mental health services in Scotland. It provides original insight into their perspective, what works and what they feel they need most from a service. This chapter presents the findings from ten semi-structured interviews with children aged (13-17yrs) who had been referred to CAMHS (in either Site A or B) following a suicide attempt or reported suicidal ideation.

The children interviewed all had their own unique story as well as some shared experiences, and as such it is not a linear story, but one of variation. A chronological approach of the children's care journey is used to frame and organise the themes that emerged, so they naturally address the aims of this qualitative study, as well as delving deeper to ascertain what is going on more holistically.

The chapter begins by introducing the participants, and the dataset(s). The data are then described and presented through four focused themes:

- Breaking Point: seeking help for suicidality
- Nothing got resolved: the care experience
- "If you had more choice..." about how, when and where they worked with you.
- The person not the profession who helped.

The complexity of the story is built in layers, with sub-themes expressing the different dimensions of the overall interpretation (see Table 19 below). This is followed by a summary and explanation of the substantive theory to have emerged from this dataset as a whole: children's experiences of CAMHS are conceptualised as 'Seen but not heard'. It is argued that overall, CAMHS do not meet the needs

of suicidal children and young people even when they are seen.

Table 19: Summary of themes fro	om child interviews
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Substantive theory	Seen but not Heard:	CAMHS do not meet the needs of
Substantive theory		suicidal children and young people
		even when they are seen.
Theme 1	Breaking Point: seeking help for	This theme describes the process, and
	suicidality	experience of the children when they
		initially sought help for suicidality and
		were referred to CAMHS.
Sub-theme 1	Suicidal exigency	Captures the crisis that led to the
		initial appointment with the G.P or
		first presentation at hospital for
		suicidality.
Sub-theme 2	Talking about suicide?	Explores how children found these
		early conversations with medical
		professionals about their suicidal
		thoughts and or behaviour.
Sub-theme 3	How did it come to this?	Most of the children spoke about
		trying to manage a range of difficult
		life events and stresses, such as
		bullying, bereavement, being a young
		carer, and domestic abuse. Others
		were unsure of any social / emotional
		triggers but described enduring
		mental health difficulties for some
		time.
Sub-theme 4	Being passed around	Many of the young people describe
		being passed on to different workers,
		sometimes in different roles, having
		to retell their story and make a fresh
		plea for help each time, before being
		allocated a CAMHS worker (if they
		were accepted onto the service).
Theme 2	"Nothing got resolved"	This theme explores what happened
		when they got to CAMHS, and how
		the children experienced this.
Sub-theme 1	Hoping for help	Most of the young people had gone
		to CAMHS hopeful that it would be a
		helpful experience.
Sub-theme 2	"Nothing really happened at	Many of the children reported that
	CAMHS"- frustrated,	attending CAMHS made no difference
	disappointed and let-down	to them. They did not feel it was
		beneficial.
Sub-theme 3	Prescribed approach	Workers were described as using a
		clinical approach, which some felt led
		to them having preconceived ideas
		about what was wrong.

Sub thoma 4	Generic advice	Advice was often found act to be
Sub-theme 4		Advice was often found not to be
		helpful, but rather generic and
		dismissive of the child's painful
Sub theme 5	Popdy or pot	situation.
Sub-theme 5	Ready or not	Children / young people were often
		discharged without warning or
		planning, before they were ready.
		They experienced being discharged
		before they were ready as a rejection
		/ dismissal and this put them off
		seeking help from CAMHS in the
There a D		future.
Theme 3	"If you had more of a choice"	This theme shows how the children
		and young people were given little
		choice: about where they were seen,
		how they communicated with
		workers, or parental involvement.
Sub-theme 1	Location, Location	Although a few were seen within
		school many children described
		having to attend clinical
		environments at locations that were
		inaccessible to them without their
		parents taking them. And in Highland
		CAMHS was too far away for one
		young person to be able to attend.
		There were requests to make the
		location of the appointments more
		flexible, with the option of a non-
		clinical environment.
Sub-theme 2	Get in touch	Generally, the children and young
		people did not feel they would or
		could contact CAMHS. They would
		have preferred different means of
		communication than letters being
		sent to their home address or being
		asked to telephone for support if they
		needed it. Young people reported
		more positively on services offering
		text messaging, and more informal
		communication and appointment
		systems.
Sub-theme 3	Family matters & Confidentiality	Whether parents should know their
		child was seeing CAMHS, or the
		extent they should be involved in
		appointments, was complex and
		varied depending upon the individual
		child's circumstances. The children
		needed their views about this to be
		acknowledged from the outset, in
		order to be able to engage with the
		service. Confidentiality was important

		to all the children and young people. This extended to all areas of interaction with CAMHS and wider services.
Theme 4	The person not the "profession" that helped.	There was a wide range of people the children and young people identified as having helped them. But they all shared common characteristics such as being easy to talk to, listening, believing, and being trustworthy, that were prioritised above the persons position or occupation.

## Sample population & Dataset

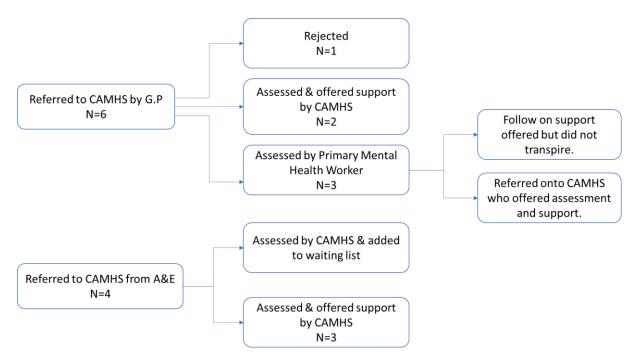
Ten interviews were conducted with participants aged 13-17 years in Site A and B. Interviews took place within the child or young person's home (n=5), community centre (n=1), place of education (n=3) and following the COVID -19 lockdown via skype (n=2). Two of the young people requested their parent be present throughout their face-to-face interview, resulting in these being joint interviews with the parents.

Three of the children lived in Site A, all the other participants lived in Site B. Three of the children lived in single parent households, one lived with a parent and stepparent, the remaining six lived at home with both parents. Nine participants were of school age, seven attended school, one attended a local authority 'alternative to school' provision, and one child did not go to school. One participant was attending University, although they had been in high school at the time of their referral to CAMHS. At the time of interview only one participant was actively involved with CAMHS, and one was on the waiting list.

The children and young people each described or had support from their parent to describe their referral process to CAMHS. This is presented in

Figure 28 and confirms what was found in both the cohort study chapter and staff interviews – children who attend Accident and Emergency (A&E) are assessed by a CAMHS worker either before discharge or within 24 hours (4/10). Children and young people who are referred from their G.P or another source may be rejected without an assessment (2/10) or have an appointment with a primary mental health worker before being referred onto CAMHS (3/10), if at all.

Figure 28: Referral pathway of child participants



# BREAKING POINT: SEEKING HELP FOR SUICIDALITY

## Suicidal exigency

The children interviewed took different journeys in seeking help. Some had gone straight to A&E following a suicide attempt (4/10), others had initially sought help from their G.P. after having attempted suicide or coming close to acting upon a suicide plan.

Yeah so there was one night I was... I was feeling really down and I decided to go for a run and I ran past the train track and I went and stood on it for a bit and then my mum phoned me and it stopped me, she didn't realise that, I didn't tell her. (YP10)

I took some Ibuprofen and Paracetamol. (YP1)

It was definitely, like, planned but then I changed my mind last minute 'cause I just couldn't do it. (YP9)

I took an overdose [...] Well I told her cause I was a bit delirious, I guess. (YP3)

It was like a bit after I kind of attempted. [...] Well I sort of tried but then I was too scared to carry on. (YP8)

I attempted before I went to see him and then had a lot of thoughts about it from then till I went to go see him, and still, like, occurs, it's more... whenever I wake up at really stupid times it happens. [...] It was more an overdose. [...] my sister kinda walked in and stuff before it was too much kinda thing. (YP2)

I had attempted to try and take my own life a little bit and so then I went to the doctors to get referred to CAMHS (YP10)

The children had often been encouraged by people around them (sibling / girlfriend / friend / parent) to attend their G.P to ask for help, others had gone of their own volition, or asked a parent to take them.

...my girlfriend went like 'you need to sort yourself out, you need to go see someone'. So, I went to my GP... (YP4)

She took me to the GP and then she took me in, introduced me and mentioned, not mentioned but said what had happened, well not what had happened but what she wanted, like, CAMHS, ... (YP10)

The children described how hard it had been for them to seek help, many had struggled with suicidal ideation on and off for a long time prior to their first presentation. Going to the G.P was described almost as a last resort, or as indicative of how bad things had got. Fear (either their own or that of their family / friends) of how they were feeling and what they might do, triggered their request for help.

Yeah. I went on my own because I thought things were getting bad. (YP2)

It was something that I'd been thinking about before I went to the doctors, so I knew something was going on with me and I knew that I had to go and speak to someone about it, yeah. (YP9)

For the children who had gone straight to A & E, their initial assessment with a CAMHS worker happened either before or within days of discharge from hospital.

## Talking about suicide

An appointment with the G.P was important as it was ultimately the doctor's decision whether a referral to CAMHS would be made. This relied upon the child being able to

articulate their feelings and tell their G.P they had been thinking about or had attempted suicide. Finding the words, was not always easy. One young person wrote it down and handed their doctor a note, for another it took several appointments before their G.P asked them directly if they were thinking about suicide.

Well I ended up, like, I had it written down and then I gave that to her, and then she read it and then, like, yeah referred me. (YP7)

So I went to my GP, told them briefly about feeling low and they're like 'okay, we'll put you on a year's waiting list' and I was like 'well that's not going to happen', so I went again and I kept basically saying, like, 'I'm getting really bad now' and they kept 'right okay' and it basically got to the point where I was put onto immediate review by the CAMHS. [...] Yeah, I went back to the GP and like, 'I've gotten worse, self-harming, stuff like that' and they're like 'have you ever thought about suicide?' I was like 'yeah all the time'. (YP4)

For some of the young people it was almost a relief to have been asked if they had been thinking about or attempted suicide.

So I went to my GP, Dr X, he kind of, like, asked me a bunch of questions that weren't too close and that and just, like, things about if I'd tried to attempt suicide in the past few weeks to months, and then he kinda got scared and referred me because of it and I guess he kind of hit a nail because it happened ... (YP2)

Suicide is what they had gone to get help with, but without being able to have a conversation about it their referral would not happen.

I wanted them to notice me and be like 'd'you need help?' that's what I wanted, like, in my entire life just someone come along and be like 'I'll save you' that sort of thing, but [inaudible 00:07:03] cause you have to tell people. (YP4)

A few of the children spoke about how their parents did not know about their suicidality when they attended the G.P. This prevented them from being able to be entirely open and honest with the doctor.

... I think I did go with my dad the first time to the doctors and I think because he was there, I didn't really want to say much, ... (YP9)

I think because I was with my mum and, I don't know, just 'cause I didn't really feel like I could talk about it. (YP8)

Having a doctor recognise this and make space for them to talk without their parent was pivotal for one child being able to speak about their suicide attempt.

She took me to the GP and then she took me in, introduced me and mentioned, not mentioned but said what had happened, well not what had happened but what she wanted, like, CAMHS, she was hoping to get a referral to CAMHS, so then the doctor spoke to me individually to see why so he could do the referral and then yeah I got the referral. But mum wasn't in the room at that point when I was speaking to him. (YP10)

Although it took a lot of courage on the part of the child, being able to access services without their parent knowing was important to some of the children and allowed them to speak with someone about feeling suicidal.

I never really spoke to my parents about that yeah again you feel like you're failing them, you didn't want to worry, it's not really nice to tell your parents why you're feeling bad, like, they might feel it's their fault, that sort of thing. (YP4)

Yeah 'cause I refused to take my mum and that, cause then they'd find out and I didn't really want her to find out... (YP2)

Although not the case for all the children, it shows how not only can it be difficult to name feeling suicidal and ask for help, but also how important confidentiality is in accessing support.

#### How did it come to this?

Most of the children spoke about struggling with their mental health, and difficult life experiences for a long time before going for help.

Yeah. I don't really have many memories of this, I've tried blocking them out. The most memories I could ever think of is just being numb. I honestly, I only really felt numb and then I'd feel really sad. I'd have some moments where I'd be happy but those were, like, when I tried distracting myself through going out with pals, doing big things, spending time with my dad, ya-de-yada. There's nothing that really was much of a distraction so most of the days were probably really dark at that time. (YP6)

Just, like, I wasn't in school for ages and I was refusing to speak to anybody especially my mum and that, it's like I was kinda isolating myself in a way. Not the best thing to do [laugh]. (YP2)

Just really, really low. I'd been like that for years and it was just, like, getting to the point where I was, like, getting really rough for myself... (YP4)

The children's feelings of hopelessness stemmed from a variety of causes such as bereavement, bullying, isolation, trauma, family problems including domestic abuse, ill health and being a young carer. These complex and multiple issues contributed heavily to their feelings of suicidality as they struggled to comprehend how to deal with them or believe that things could be different or get better.

...something happened with a boy, there was a sexual assault with a boy and I still went to the same school as him [...] and then all of his mates would always call me a slut or a slag or whatever, and then all my friends, I was in a group of friends and they all basically turned around and said 'I don't want to be friends with a slut' and then they all fell out with me, so I was kind of on my own and it was before I was going out with my boyfriend and I didn't really have many friends, like, I had a couple of friends but they didn't really hang out with me much. So, I was quite lonely and that was kind of it, I was really lonely [laugh]. [...] Yeah I started thinking, like, there's not really any point in being here cause it's boring, I've got no friends, I've got nothing to do, like, I come home and go to my bed, I'll come and have dinner, whatever, and then go straight to my bed and I just don't want to, like, wake up the next morning and have to go to school again and deal with it all again. (YP5)

Honestly, I can't even really remember most of it. It definitely has spurred from my past of, like, being bullied throughout primary school and the bullying was starting to get worse throughout high school and my gran was recently diagnosed with cancer at that time, and I think this was round about the time where she was about to pass away maybe, I'm not quite sure, I can't really remember the time, and that's really mostly it, it's just mental health, bullying and my gran, that kinda made that whole thing tumble down. (YP6) They know 'cause they had to know but, like, I didn't really want them to know cause my mum has mental health issues, she's off work just now so I just didn't really want to worry her too much more. [...] It can be quite hard but I kinda like... I've always got to be there, so I don't really want to get, like, how I'm feeling in the way. (YP8)

Although the situation was individual to each child, their feelings of suicidality had not come from no-where, and often had a backdrop of exceptional difficulties with family or peers.

#### **Being Passed Around**

Following a referral being made to CAMHS by a G.P, the children were generally assessed by a primary mental health worker.

*I first went to see this, I think it's like a guy which would decide where I have to go, ... (YP8)* 

...she just spoke to me about what was going on and if I should get a referral to CAMHS basically, I think she was the step before CAMHS. (YP9)

Some of the children had found these appointments to be positive experiences. They were given the opportunity to speak openly about what was going on for them, and had their feelings validated.

No but at the first, the first nurse I found was really, really good between the doctor and CAMHS [...] I think the first lady that I spoke to I found her really, like, she was listening to me and she was speaking to me about how I could, like, communicate and stuff with my parents and address stuff, like, feel comfortable speaking to them, and she brought my dad in with permission and she kind of explained for me because I was really upset at that point, I mean, when kinda told my dad cause I couldn't, but she was really, really, she was really good at doing that. (YP9)

He was really nice and kinda like give you, like, hope and stuff. [...] I think just cause he kinda like reassured me that it'd be okay and that he was going to do something about it, so like made you think that it's going to get better. (YP8)

Although they accepted that being moved on was part of the process, there was a sense of disappointment conveyed by these children that they had to then go to CAMHS and meet another worker, after having had such a positive experience.

However, this was not every-one's experience. One young person reported their primary mental health worker didn't really talk with them about what was going on for them but asked them to complete a questionnaire, rating their mood and risk of suicide.

...it was more just, like, so there's numbers from one to four, one being a good kind of number to choose and four being really high, don't know why they did it like that but...[...] if it was really high then it's bad and they'd make another appointment. I was up at 37. [...] Out of 40. (YP2)

They were offered another appointment but due to circumstances were unable to attend. They went on to speak about how they fell through the system and were left struggling with on-going suicidality.

...suicide or like killing myself and then I have the urge to self-harm and even, like, during the day I could be smiling, and I'd still have that urge to self-harm and it confuses me because I could be so happy and still want to or, like, feel the need to, [...]

INTERVIEWER: It's in there, in your thoughts.

Yeah. More than it should be.

INTERVIEWER: And the suicidal thoughts do you know where you would go for help now? Do you feel like...

There's not really anybody that's there 24/7 that you can go for help, like, I've got a thing like if I feel like it's going to happen I fall asleep, I put the music on and I go to sleep just because it'll get it off my mind for that time I'm sleeping. And in a sense, it's going to sound really weird, but it's like when you're asleep it's like you're not alive type of thing, [...] Yeah it kinda just feels like it's happening even though it hasn't happened. (YP 2)

Once (if) children were accepted by CAMHS, there were further reports of having to see different workers before being allocated someone to provide treatment. For one young

person this worked in their favour as they were moved onto a worker who they got on well with, and this made for a positive experience.

*I sort of... he... I got on more with, I had lots of things in common with him like sports and stuff like that, yeah. (YP10)* 

However, for others although accepting of these changes, it was something they felt they had little control over, and it perhaps wouldn't have been their choice. Every-time they were given a new worker they had to retell their story and explain why they needed help again.

I didn't like it so much. [...] Maybe it's 'cause she kinda just did the, she had to get to know me and stuff and I had to redo that all again. (YP8)

I've already [inaudible 00:22:33] with these two and I was like, fine, I was comfortable with them and then switching to someone I don't know explaining the situation to them. (YP4)

Most of the children report being "passed on" or having to go back and forth to make their case for help. Waiting for appointments with the next person in the chain and hoping to meet someone who could help them. With one of the children expressing how this process could have been an intolerable situation for some children.

It's wild, yeah. If I was really keen on actually doing, going through, I don't think I would be alive if it was that bad, which is quite brutal [laugh]. (YP9)

While the quote below expresses the exasperation and effort children face accessing help.

... they're like 'right you need to book your own appointment with your GP' booked that and they're like 'right we've got a referral for psychiatry' but you need to do all this, like, you just had to jump through hurdles every time. So, you have to make your phone calls to your GP, then you get your phone call from your psychiatry, you have to make an appointment with them, appointment at your GP and it was all just, like... (YP4)

Overall, this theme (Breaking Point: seeking help for suicidality) presents that at the point of help-seeking the children were overwhelmed by their thoughts of suicide or had already tried to end their life. Many had been struggling with difficult circumstances and their mental health for a long time before reaching this point. Going for help was neither easy nor straightforward. Talking about suicide was often difficult as they had to be able to articulate this to adult professionals who would make decisions based on what the young person said and how well they could (or could not) express themselves. For some, having their parents present in appointments or having to know, prevented their ability to speak out and was therefore a barrier to getting the help they needed. Being 'referred' generally involved multiple appointments often with different people before being granted access to CAMHS if they made it that far.

## "NOTHING GOT RESOLVED"

## Hoping for help

Yeah. I did ask for help 'cause I thought it would, like, help me. (YP6)

Although nervous, the children and young people sought support from CAMHS with hope and an open mind.

I was nervous but glad at the same time to, like, speak to somebody, d'you get me? (YP7)

#### It was good, I was still nervous and stuff. (YP8)

Some reported feeling relieved that they were finally able to speak to someone they believed would be able to help. They were unsure what to expect but hopeful they would now get the help they needed.

Only one child's testimony did not reflect this. They had not wanted to be referred to CAMHS, and spoke of feeling scared to talk to anyone, fearing parental involvement or hospitalisation.

I felt if I said anything or that she'll tell mum or dad or, like, take me to A&E (YP1)

Confidentiality was vital for this child, and they had yet to be assured that it was safe to open up.

#### Yeah, I understood it's confidential but... don't know, I can't trust anyone. (YP1)

For the other children, including those who had been rejected by CAMHS, they had anticipated that this the service would provide the support they needed.

# "Nothing really happened at CAMHS"- frustrated, disappointed and let-down

Although the data suggests the children had attended CAMHS anticipating it would be a helpful experience, many reported they were left disappointed, as it did not help them to address their worries.

It was questions and I personally didn't find it helpful, like, at all to be honest, just not really at all. (YP9)

Nothing really got resolved. I usually just talked about my day. I only went there for like, well, five weeks and then I got, like, told my mood seemed good enough that I could stop going or something like that, I can't remember the real name for it, but yeah. [...] I felt... honestly, I felt like nothing got resolved, like, nothing, you can't really get resolved in one session, but like nothing really happened of it. (YP6)

There was an expression of nothing having changed for them because of going to CAMHS. The word "resolved" being used indicated a quest for solutions that had not been found. They were left no better off than when they started.

Not really no, nothing really happened at CAMHS, I only really talked about my day and then five/six weeks later I got sent off and then that was it and I was back to me in my house and all that. (YP6)

Some reported they did not feel engaged with or understood by their worker. The children spoke about their worries not being taken seriously, dismissed, or missed altogether.

It was just similar to speaking to like a parent, I don't know, it wasn't really... she basically, cause obviously when I was talking about what happened and that, she basically just said it was probably hormones and I just didn't think that was very...

[Interviewer: She told you she thought that it was hormones...]

Yeah.

[Interviewer: ...that was what, that made you take an overdose?]

Yeah, yeah.

[Interviewer: Right okay. And what did you think of that response?]

Well I just thought it wasn't, even if it was the case I didn't think it's the best thing to say.

[Interviwer: No. Did you feel that she understood you?]

No. (YP3)

One child spoke about how although the primary mental health worker had helped them to identify the main underlying issue for them, it was only after having engaged with CAMHS for two separate periods that their worker there recognised this.

xxxxx only really properly picked up on it, like, a few weeks ago but I don't know if she's really, she's gone a bit into it but...(YP8)

Despite hoping they would be allocated someone they could talk to, not all the children found their workers easy to talk to.

She wasn't really the best; she wasn't really a warm character so it was quite difficult to talk to her. (YP3)

Not feeling they could talk to their worker, or supported by them to open up, left the children feeling it was all a bit pointless.

It was even hard to speak to my parents about it never mind someone that I'd never met before, and I understand she's a medical person but it was just the way that she was kinda like a bit careless, like, she didn't really care really, it sounded as if she was just like 'oh you don't seem that serious, okay there you go, over' that was pretty much it. So, I don't think it helped. (YP9)

A few children articulated feeling that the people they encountered did not 'really care'. This extended to professionals in other roles such as G. P's and a primary mental health worker. But, when it came across in their interactions with CAMHS workers, it was experienced as an ultimate disappointment, having believed this person would have been able to help them. For some this compounded belief they were not worthy of help or could not be fixed.

They all do good and they all try their best but sometimes there's just people that can't really be fixed I guess, quote/unquote. (YP6)

Although, most of the data reflected this position of not having made a connection with the CAMHS workers or having been supported to identify and address their issues, there was one child who shared having had a positive experience of their worker. They spoke of feeling they could relate to them, and that the worker recognised and understood their difficulties, even supporting them to talk to their mum.

No, I think it was actually really good, it was very positive. There wasn't really anything that could've improved it really cause I got on really well with the counsellor and we talked about, like, sports and stuff, so at the start off of things he'd start off by just sort of easing me into the conversations by talking about sports, like, the football scores at the weekend and stuff like that, sort of ease me in cause I'd still be anxious to meet, like, even though I'd been going for a while I'd still be anxious the first minutes of the session and then I'd ease back in. (YP10)

There was one other report of a child having a positive session with a CAMHS worker, but unfortunately, they were moved onto to someone else who they didn't feel a connection with. These positive examples will be discussed further in the theme: 'The person not the profession that helped' but it is important to note here, it was very much the exception.

## **Prescribed Approach**

A clinical approach was identified by the children as contributing to them not feeling understood or listened to. This manifested as workers being cold, distant, and applying set ways of working.

She wasn't really the best, she wasn't really a warm character so it was quite difficult to talk to her. (YP3)

The way that she treated me was kind of like... careless and kind of like I was not a person but more like clinical if that makes sense, I was more like my circumstance than an actual person going through that. It was quite uncomfortable, like, awkward, I found it quite... I don't know how to describe it; it was just really... I don't know, I didn't find it helpful. (YP9)

Some of the children reported they felt that their worker wanted to label them. They experienced this as a way of dismissing their worries, providing a medical explanation removed from their social and emotional world.

...when I was talking about what happened and that, she basically just said it was probably hormones and I just didn't think that was very...(YP3)

...with the lady at CAMHS the atmosphere was quite uncomfortable, awkward, I did feel quite intimidated. If I said something and it didn't fit into kind of what her mindset was or what box she wanted to put me in, she kinda didn't act like she cared about my certain situations, so with her I kinda felt as if she wanted me to say, like, she wanted me to say certain things for her to be able to, like, tick me off as having depression or tick me off as, yeah, ... (YP9)

I think she also came from, like, eating disorders and stuff, she fixated a bit more on, like, your weight and things like that. (YP 8)

By concentrating on symptoms, and potential illness, the focus was shifted from difficulties the children were facing at home or in their personal lives, to what was *wrong* with them. This was experienced not only in young people's interactions with CAMHS, but the wider professionals' children consulted for help before they reached CAMHS.

It was more like my doctor told me that I had... I was stressed, that was coming from the stress and then my mental health worker told me that I was cutting because of depression and then people in xxxxx were like maybe it's both, maybe it's anxiety on top and I'm like there's a lot of things, like, I'm getting told a lot of words, like, I understand them, I've gotten to know what every single one means, you know, but like I didn't know which one was the...(YP2).

Although this was not the experience of all the children who were interviewed, when the dialogue around suicidality was reduced to potential medical conditions, the children felt misunderstood. Their own thoughts about what was going on were different to this. However, as a child seeking help from a medical professional, they did not feel able to articulate this.

Well I just thought it wasn't, (YP3)

I think she also came from, like, eating disorders and stuff, she fixated a bit more on, like, your weight and things like that.

[Interviewer: Did she, okay. And was that something that was going on for you at the same time?]

It was a bit but to me it wasn't really that much of a problem. (YP8)

I could probably more stand up for myself and, like, make it known that maybe it's not what they think it is. I don't personally know if it's one or the other but, like, I would say it's definitely not stress. It's gone on for so long. (YP2)

This dissonance often remained unspoken between the child and the worker but contributed to the children feeling their CAMHS worker did not understand or help them.

#### Generic advice.

Many of the strategies and techniques offered to the children by CAMHS would fall under the umbrella term 'self-help'. They described self-harm minimisation advice, distraction and relaxation techniques, and various apps that were recommended. Most children did not find this to be helpful, or in tune with what they needed.

She never really gave me any strategies, she just... the most things she said was, like, how, like, I don't know... she never gave me any, like, phys... she always, basically all she said was if you're feeling that just go, like, go do an activity for, like, 20 minutes, just keep your mind busy. That's basically what she said. (YP3)

The only thing I remember is the woman asked 'what are you using to cut?' and I was like 'a Stanley knife' and they're like 'don't do that' and I was like 'okay' and they're like 'if you're going to cut use, like, a razor, like a pencil sharpener razor'. [...] Or something like that, something like a sharp, sharp razor because if you use that then it's not slicing too deep, you don't need to put too much pressure on so you're not, like, going to slice your arm open and need medical attention, and 'don't slice long and don't slice that way'. (YP4) RES: I think one of them, I think xxxx might have said something I think, I think she said like putting an elastic band round a wrist or something and they told me sites to go to and stuff.

INT: And were the websites helpful?

RES: I never looked at them. (YP8)

Some of the children reported never trying to implement the advice or look at the resources that were suggested. Others felt these were things they would have done by themselves anyway. But, in the main there was an incongruence between what the children needed and the generalised advice they received.

*Like, if you're at a point where you're low you're not really going to concentrate and, like, really anxious. I was really anxious to sit and meditate, like, I think that was a weird one. (YP4)* 

The one coping thing that I can remember her telling me when my dad was in the room, a traffic light system, it was just a bit wishy washy kind of like she said communication was kind of a problem between me and my parents so if I was feeling a certain way I could tell my parents, I could make it easier to say to my parents which I was like 'oh okay, that sounds okay' and then she said that if I'm feeling upset I could say, like, I'm feeling red or I'm feeling okay saying amber or green, I was just like, I don't really understand how that's going to help with communication and stuff between me and my parents, it just wouldn't have helped. (YP9)

The children articulated needing different things. For example, one person had tried multiple on-line resources and found some to be helpful for a while, whilst another clearly stated that this would not be of interest to them.

It was good up until I kind of... just didn't see the point in the app because it stopped kind of helping. (YP2)

I think when I'm at home I just want to be at home, I don't want it to be, like, part of my therapy or whatever. (YP10)

Although there were some reports of advice and self-help strategies being given, overall, the children did not provide positive accounts of their usefulness.

## Ready or not

Most children reported discharge happened before they were ready, and there were several for whom suicidal ideation continued to be an on-going issue. Far from being a collaborate and planned for event, it was often sudden, seemed to come without warning and was experienced as a rejection, or dismissal.

She was just like 'oh I think you've got better, I think you should just, like, go home, you don't really need to come back here' she gave me her phone number. (YP8)

I didn't really want to see her but she said that basically 'cause she thought I was fine to be discharged. [...] I thought 'well I'm not' [laugh]. (YP3)

I only went there for like, well, five weeks and then I got, like, told my mood seemed good enough that I could stop going or something like that, I can't remember the real name for it, but yeah... (YP6)

Some of the participants expressed they were continuing to self-harm, and / or were thinking about suicide at the time of discharge.

A few of the children disclosed they had told their worker they had stopped self-harming or had no plans for suicide to allow the sessions to end as they had not felt they were beneficial.

I just said I stopped cutting and she discharged me.

[Interviewer: And had you?]

For about two weeks.

[Interviewer: Right okay. And did you tell her that so that she didn't come back to see you?]

Yeah.

[Interviewer: Right okay, and what about the suicidal feelings and stuff, was that something that you were able to be honest about?]

No (YP1)

She basically just asked if I'd made plans, like, plans to attempt suicide and well I said no 'cause I didn't actually.

[Interviewer: So, you didn't have any plans, but you were still having thoughts.] Yeah.

[Interviewer:And were they every day or were they, like...?]

I would say pretty much every day. (YP3)

Others, although accepting of the workers decision were hurt and let down, having their case closed before they felt ready.

It's just like demoralising cause I didn't really feel like, like, I'd improved but I wasn't, like, better. (YP8)

Many of the children related that upon discharge they were told to get in touch if they needed to. If they didn't contact CAMHS within this time it was assumed they were 'fine'.

She said until August, if you don't contact me until August we'll kind of like... it wasn't like get rid of your file but it was kind of like... (YP9)

Most said they wouldn't have contacted the worker at this point even if they needed to. Having experienced rejection and not feeling understood, the sentiment of 'what would be the point' was conveyed by the children.

Probably not because I didn't find it helpful. Although maybe if I was quite desperate maybe I would but no I wasn't in that situation, luckily, luckily I wasn't in that situation. (YP9)

[Interviwer: Would you ever go back and seek support from mental health services?]

Not really, I don't really know. (YP6)

Several children were re-referred to CAMHS following a repeat suicide attempt or increased suicidal ideation. Often parents requested the re-referral for them, via the G.P. However, this

was not always the case and in the absence of being able to confide in a parent one child had to find the courage themselves to ask for help a second time.

[Interviewer: Was it easier going for help the next time or was it just as difficult?]

I got in easier but asking was harder. (YP8)

Being discharged and told to get in touch if they needed anything was experienced as a rejection, but also as a communication that they '*should*' be okay. Most did not feel okay at the point of discharge, however, did not challenge this.

# "IF YOU HAD MORE OF A CHOICE"

Location, Location.

Appointments were generally held in hospitals or other clinical locations that the child was invited to attend.

It was in a clinic, well was it a clinic, yeah it was in a clinic the first one, but then when I moved to the guy it was in sort of a building just for CAMHS, it was like just a building for CAMHS yeah. (YP10)

I went to the hospital and I saw them, ... (YP3)

I went to this, like, it's not really a hospital but it's in xxxx. (YP8)

This meant the children needed to be taken to their appointments, as they would have been otherwise inaccessible. Subsequently they had little choice about informing / involving parents.

My mum had to come cause I was under the age of 16, like, she doesn't come in but she has to drop me off cause it's in the middle of nowhere. (YP8)

...yeah he would always take me or my mum would take me in the car (YP9)

My mum took me because at that point I was at xxxxx so I had to be, like, driven. (YP3) One child reported that living rurally meant CAMHS was too far away to be accessible for them. I'd have to go down to xxxxx for their kinda CAMHS situation which would be, like, a long journey and in there for, like, half an hour kinda meeting and then have to travel back home. It'd be long day. (YP2)

This person was hopeful that once they moved to adult services there may be more support available to them, but as a child under 16 yrs. there was a dearth of mental health support services locally.

For those who had seen CAMHS, the space within which the appointments took place were described almost as empty rooms, with a formality to them.

Well I went in and it was basically just a room with three chairs in it, and then I'd to sit down and I would just being a bit awkward [laugh], ... (YP3)

Although the children spoke about how it was difficult to get to these places without their parents taking them, most seemed to accept unquestioningly that this was where the appointments were held. And even though they may have preferred their parent not to be there, most were resigned to the need for parents to know about and transport them to appointments.

Not all the young people wanted their parents to know that they were seeking mental health support, or why.

They know 'cause they had to know but, like, I didn't really want them to know...(YP8) ...I refused to take my mum and that, cause then they'd find out and I didn't really want her to find out ... (YP2)

Autonomy and confidentiality were of the utmost importance to most of the young people interviewed. Asking them to attend appointments at hard-to-reach hospital locations with their parents potentially compromised this from the outset.

Two children from site B spoke about their worker from the suicide and self-harm team coming to see them in school. This was after their initial appointment within the hospital setting, and for one child only happened upon their second time of using the service following a re-referral. Appointments taking place in school did not necessarily mean they were in a more positive environment, or easier to attend. The room provided by one school was akin to a disused storage cupboard, and one of the children was so keen to avoid the appointments they deliberately skipped the classes at the times the worker had told them they would come.

I didn't always go to them, but she'll try and get me out of class so I just maybe missed, don't go to the class (YP9).

This stood out from the other interviews as this child had not wanted CAMHS support. For the other child (YP8) being able to see a worker in school had been pivotal in them being able to access support as they had not wanted their parents to know.

Yeah, cause it also means my parents, like, I think they know now but they didn't know when I first went. (YP8).

Although seeing someone in school was helpful for this child, others stated this would not have been their choice, as it would compromise their confidentiality with peers and teachers.

... just a sort of place that you don't feel judged really, cause sort of in school if you were to talk about it, I don't know, I feel like I'd be judged because people or teachers would know and I wouldn't want them to know cause even though they probably wouldn't be judging me, I'd still be feeling judged. It's just sort of an environment where you don't feel judged is really what I feel is the best sort of thing. (YP10)

The interview data shows the children considered not only the location of the appointment to be important, but the overall environment.

...think in a location that's not in a hospital or something that's like, just the clinical side of it kinda like makes it a bit iffy and uncomfortable, and as soon as you walk into that environment you're going to... your mindset's going to be like 'oh no take me out of here, I don't want to speak about how I feel, I don't want to speak to this new person', but if you're in your own house or your own environment you kind of will feel a bit more comfortable speaking to that person. Like, even now I feel more comfortable speaking to you [laugh]. (YP9).

The data suggest that one of the reasons some children found other services more beneficial was in part due to the flexibility and choice they were able to offer about where appointments took place, and there was a more collaborative dialogue around this.

#### I think if you got to choose more where they, like, met you. (YP3)

Given that even amongst this small sample of children there were a variety of opinions about the best place to meet it would suggest that being given a choice around this would be beneficial.

#### Can we talk?

When the person they identified as having helped had been in a professional role (other than CAMHS practitioner), they had often been flexible about where and when they met and had arranged home visits or took them out for a coffee etc. Some had also taken the time to check up on how the child was when they had not seen them, or during holiday periods.

She was really open. If you had a problem, even if it was like when she was busy doing work, she would stop and she would come and speak to you or she'd take you out of class, take you out in her car and take you for a drive for ten minutes and just get your mind off of it, and then you go back to class and feel better, not fully better but as good as you could which is better than here, ... (YP2)

Feeling their worker was available to them and interested in them helped the child to feel supported and open up.

I've got xxxx number and she texts me quite frequently, like, 'hi, how's things?' 'can I come see you?' (YP 5)

For most of the children being given a choice not just about where they saw their worker but how they would communicate was important.

I'd do it not by letter, like, maybe text or something, so it's, like, confidential there. (YP8)

If I could book appointments online, I think, ... (YP4)

When the onus was on the child to telephone the service or worker this was often too difficult for them to do.

Well with both the private service and with CAMHS they always gave me, like, numbers and stuff but I never really feel comfortable doing that. (YP 3)

#### I just find phone calls they give me quite bad anxiety. (YP4)

Offering a range of means of communication and having the worker lead on this by taking the initiative and contacting the child would better support them to feel they could contact their worker if need be.

## Family Matters & Confidentiality

Most of the children interviewed talked about how they had found it hard to talk to their parents about their suicidality, or what was going on for them. Some remained adamant that they did not want their parents to know. The fear of their parents finding out that they were accessing CAMHS support, was a barrier to them seeking help or confiding in anyone.

Yeah, so my parents actually didn't know that I was quite depressed so it was quite a shock to them, ...(YP9)

I never really spoke to my parents about that yeah again you feel like you're failing them, you didn't want to worry, it's not really nice to tell your parents why you're feeling bad, like, they might feel it's their fault, that sort of thing. (YP4)

Yeah 'cause I refused to take my mum and that, cause then they'd find out and I didn't really want her to find out cause she's going through a lot with her husband,... (YP2)

I felt if I said anything or that she'll tell mum or dad...(YP1)

I think yeah, I kinda wanted it to be confidential rather than telling my parents (YP8)

These children were often dealing with very complex and challenging family circumstances at home, and yet this was not always recognised by services or practitioners. Through the process of seeking help from CAMHS their parents were informed or became involved without their choosing.

They know 'cause they had to know but, like, I didn't really want them to know cause my mum has mental health issues, she's off work just now so I just didn't really want to worry her too much more. [...] (YP8)

One child had expressed to their G.P that they did not want their parent to know, and in this instance a letter was only sent to them and not their parents. However, clearly depending

upon the family situation this letter being sent to their home may still have comprised their confidentiality with their parent.

...it was just a letter to me because my doctor told them that if there was anything to be referred to just send to me not to my mum, cause I told him I didn't want her to know. (YP2)

For some, having their parents present in appointments prevented them from being open or sharing how difficult things were.

A bit, well I can't actually... I think I did go with my dad the first time to the doctors and I think because he was there I didn't really want to say much, ... (YP9)

No cause my mum was there so I couldn't really say anything. (YP2)

I think because I was with my mum and, I don't know, just 'cause I didn't really feel like I could talk about it. (YP8)

Although not all the children's difficulties were located within the home, they wanted to be able to choose what was shared with their parents and have their right to privacy respected. Thus, also acknowledging and creating room to discuss any difficulties there may be in these relationships.

If they were more, like, interactive with you. I guess if they spoke to your parents, like, after each session, just had a wee chat with them cause I used to be like let go and that was it. (YP3)

A few reported they had had positive experiences of primary mental health workers supporting them to share information agreed in advance with parents.

Well one of them kind of spoke to my mum but he was the guy called xxxx I think his name is, and he asked me and we discussed what we were going to say. So my mum knew a bit but not really loads of stuff. (YP8)

I think the first lady that I spoke to I found her really, like, she was listening to me and she was speaking to me about how I could, like, communicate and stuff with my parents and address stuff, like, feel comfortable speaking to them, and she brought my dad in with permission and she kind of explained for me because I was really upset at that point, I mean, when kinda told my dad 'cause I couldn't, but she was really, really, she was really good at doing that. (YP9)

There was also one positive example of a CAMHS worker supporting a child to share agreed information with their parent following the appointment.

So I always don't like my mum being in the session if I'm speaking to someone 'cause she always tries to sort of take over the conversations, cause she's a chatty person and so he, 'cause we'd talked about it a bit, and he'd to get my mum to come in to talk about what we did and stuff, he didn't sort of like stop her but he would sort of try to tell her, well not tell her but talk so she wouldn't be able to talk cause he knew I didn't like that. So, he did that well, but he did talk to my mum and tell mum the stuff that I wanted her to hear, not the stuff that I didn't want her to hear well. (YP10)

Being supported to talk to their parents was a key factor in what made the intervention beneficial for these children. However, this would not have been desirable for all the children interviewed. Others would not have found this helpful and would have rather their parents were not involved at all.

The children's family situations and relationships were complex and diverse, and yet this was not always felt to be understood or reflected in the approach adopted by CAMHS, or the services making referrals to CAMHS. This is bound up within issues of confidentiality that was not always afforded to these children: their parents were informed about a referral being made to CAMHS, parents were invited to attend appointments with their child without their child being consulted, and children often needed to rely upon their parents to take them to appointments due to their geographical location. Overall, regardless of their situation confidentiality was of great importance to the children interviewed.

I'd make it, like, completely confidential... (YP 8)

#### THE PERSON NOT THE PROFESSION THAT HELPED

When the children spoke about the person who had helped them it was clear they identified the person's personal characteristics and how they made them feel beyond their job role or any treatment approach. For most, the individual had not been a CAMHS worker but included a family member, friend, support worker, social worker, or primary mental health worker. My friends were really helpful. My mum and dad were really helpful. (YP3)

Right now I'd go to my dad or my pals online. They're, like, the only people I can really confidently speak to about this stuff. (YP6)

Just my friends and I didn't even speak to my family about it, it was really difficult for me but I have good friends so they were helping me through it and I think I just kinda needed to be alone at that point to think about stuff and kinda process what I was going through at that time 'cause it was really difficult. (YP9)

... my best friend [...] she's been more helpful than the mental health worker that I've got, although she doesn't know anything about mental health [inaudible 00:24:45], but she's just been there through everything with me and she's stood by me even when we weren't close she would still stand by me.(YP2)

When it was a support worker / social worker / primary mental health worker who had helped, the children spoke about how they had made them feel relaxed, and that they could talk to them.

Yeah. Her approach was less clinical if that makes sense, she was less... I don't know how to put it, she was not trying to put me in some kind of category or making me say certain things, that it wasn't as intimidating with her, whereas with the lady at CAMHS the atmosphere was quite uncomfortable, awkward,... (YP9)

I had a social worker called, xxxx was her name, and she was helping me at school, like, she'd come and see me every week and we'd just talk about, like, how I felt and things like that and she was really good,... [...] Yeah, I'd quite often speak about that [suicide and self-harm] with XXXX but we didn't really do much work on it, like, I don't know what type of work you'd do but we didn't really do much work about it, we'd just talk about how I was feeling and if I was feeling better or if I was feeling worse, it was just that type of thing. (YP5)

The person they felt had helped them was identified as trustworthy, and the children felt they could confide in them. They were *"warm"*, *"open"*, *"friendly"* and *"nice"*. They were interested, interested in the child and what was going on for them. They showed compassion and adopted a non-clinical approach. Perhaps above everything they listened.

*I think the first lady that I spoke to I found her really, like, she was listening to me... (YP 9)* 

Well, he was just more warm, like, and also he didn't go full in, like, first day, you know, cause obviously he just warmed into it instead of all of a sudden being, like, really heavy. (YP3)

The child who reported that attending CAMHS had been a beneficial equated this to having had a positive relationship with their worker and being able to get along with them.

... I got on really well with the counsellor and we talked about, like, sports and stuff, so at the start off of things he'd start off by just sort of easing me into the conversations by talking about sports, like, the football scores at the weekend and stuff like that, ...(YP10)

The relationship the worker had with the child outweighed other factors such as their job role.

*Probably xxxxx Team because they're really easy to talk to, depending on who you get but most of them are quite easy to talk to. (YP5)* 

As can be identified in many of the quotes above, the children and young people valued people engaging with them on their level and adopting a non-clinical approach. When asked directly what they would want from a worker their responses conveyed a need for the person to be approachable.

I'd make it, like, completely confidential and make sure nice people are employed as well. [...] Like, friendly and kind I guess. Don't know, I'm trying to think, whatever you'd put with a nice person. (YP9)

Not only did the worker need to be "nice", but to show that they cared. That they cared about the young person and what was going on for them.

Someone to care because not a lot of people do, even though they say they do, like, [inaudible 00:23:41] to actually understand that people. I get a lot of people saying 'I understand how you feel' but they don't and it's like, don't know how to, like, respond to them sometimes. (YP2)

## SUBSTANTIVE THEORY: SEEN BUT NOT HEARD.

Overall CAMHS did not meet the needs or expectations of most of the children and young people interviewed for this study. Only one young person spoke of having been allocated a CAMHS worker who 'got' them and feeling supported with the things they were struggling most with, including talking to their parent. The other children and were either rejected without being seen by CAMHS, or when they were seen, did not feel their worker really saw what they were struggling with or heard what was going on for them.

The children understandably faced barriers in being able to speak openly about what was troubling them, and yet the sessions they described did not support their engagement. They remained clinical and prescriptive, without making space to get to know or listen to what the child or young person needed. The young people did not identify the standard self-help advice they received as very helpful. Discharged before they were ready, young people were left feeling let down by the service they had hoped would help them.

This over-arching theme argues that although the children were processed by CAMHS, in the main those that were seen did not feel heard. The children and young people wanted and needed different things from the service, yet there was little flexibility or choice offered. The lack of a collaborative and supportive relationship left the children feeling their needs had not been met by CAMHS.

This theme is further explored in the following chapter (Ch. 8) which brings together the findings from the other qualitative interview chapters (Ch. 5, Ch. 6) as well as the retrospective cohort study chapter (Ch. 4).

# **Chapter 8: Overall synthesis & substantive theory**

This chapter precedes a full discussion of the thesis, presenting a summary of the key findings from each element of the study, before bringing together the findings of the cohort study (Ch 4), with the qualitative interviews (Ch 5 -7). This allowed not only for these research questions to be answered but for the development of an overall substantive argument: CAMHS 'process' but do not help children who present with suicidality.

This thesis aimed to provide a detailed picture of what happens to children after they are referred to CAMHS for reasons of suicidality. It sought to answer four main research questions:

- 1. What are the current pathways of care for children after they are referred to CAMHS for reasons of suicidality?
- 2. How do children who are referred to CAMHS for suicidality experience their treatment and journey of care?
- 3. What are the perspectives of the parents / carers of the care of children referred to CAMHS for reasons of suicidality and the CAMHS practitioners who assess and treat these children?
- 4. What specific responses and interventions does this research tell us children presenting with suicidal behaviours (including ideation) need?

The study design was developed to address these questions, mapping their journeys of care for all children referred to two different CAMHS teams in Scotland over a six-month period, and using qualitative interviews to explore the experiences and perspectives of the children, their families, and the practitioners delivering child and adolescent mental health services (Ch 3).

The Venn diagram overleaf (Figure 29) helps illustrate where the findings of each of the qualitative chapters overlap, as well as ways in which they differ. This is then followed by a brief synopsis of the main findings of each chapter, establishing links and addressing the specific research questions. Viewing these findings collectively supports the overall interpretation.

#### Figure 29: Venn Diagram of Qualitative Findings

#### Child & Staff sub-theme Child & Parent sub-theme overlap overlap Prescribed Approach Hoping for help Formulaic Approach "scratching the surface" Child themes Location, Location **Breaking Point** Family matters & Nothing Got Resolved Confidentiality **Clinical locations** If I had more choice It wasn't personal

## Staff Themes

Expert Assessment of the great unknown.

Diffusing danger with an alternative discourse.

Imposing order on the intuitive and flexible practice. Parent Themes From the side-lines "we need help" Who helped, and what we need

#### Child & Parent & Staff overlap

Ready or not

Abrupt endings.

"CAMHS left me..."

Pushed for time

The person not the "profession" that helped.

The relationship and not the professional that helped their child.

Relationship is key

#### COHORT STUDY FINDINGS

The cohort study (Ch 4) showed that one quarter of all referrals to CAMHS in both sites were for children who had either attempted or been thinking about suicide, and that one third of these were for children under 12.

The findings indicate that older children in both areas were more likely to be offered treatment. The underlying issues identified by referrers were also similar in both health boards and included a broad range of complex familial and social factors, suggesting that suicidal children are not a homogenous group. This was supported by the interview data from children, staff and parents who all spoke about the difficult and often longstanding issues faced by the children.

There was a vast difference in the numbers of children who were offered assessments and treatment between the Sites reflecting the structural differences between teams. In Site A only 31% were offered an assessment, whilst in Site B, who had a specific suicide and self-harm team were able to provide face to face assessments for 82% of children referred. Similarly, more children in Site B were offered treatment (47.8%), than Site A (7.7%).

It is apparent from the quantitative data that having a specialist team to respond to referrals for suicidality appears to better equip CAMHS in Site B to assess these children and offer some form of intervention.

#### PRACTITIONERS INTERVIEW FINDINGS

Child and Adolescent Mental Health Services can be considered as providing social regulation of the suicidal child through a) imposing a linear and systematic approach b) employing a discourse of distress that neutralises risk and curbs any reference to suicidality. However, it is also a site of resistance and knowledge transformation. Staff are frustrated by the demands upon and constraints of the system they work within. They expressed a need for a flexible, person centred approach, which prioritises the relationship between the worker and the child / young person beyond any prescribed model (Ch 7).

Suicide risk assessment is a key task of the CAMHS practitioner, however, there is no set formalised process which they follow. They each reported approaching it differently, mindful of the fact that the risk of suicide cannot be completely quantified. Decision making around risk assessment is informed by several factors (background, training, experience, team etc.) with the main goals being to identify any underlying issues, create a safety plan and send the child home.

The interview data suggests CAMHS staff reconceptualize children who are referred for suicidality as 'distressed' instead of suicidal. This alternative narrative refocuses attention from the danger of death by suicide to a discourse of 'managing feelings'. Although they suggest most children do not want to die, and are not suicidal, there is a dichotomy presented as they also recognise there are children who are at risk of death by suicide.

There is pressure on staff to deliver short-term interventions using prescribed models such as the 'decider skills'. Staff find this is unhelpful and believe children who are suicidal need a more flexible and intuitive approach, that is needs led, and prioritises building a relationship with the child, getting to know them, and listening to what is going on for them.

#### PARENT INTERVIEW FINDINGS

Marginalised mums and dads: Through non-engagement of parents in the mental health support and treatment of the child who presents as suicidal, parents are disenfranchised, and rendered powerless in their quest for help and support from CAMHS (Ch. 6).

Most parents did not feel that the CAMHS workers had got to know their child, or that using their service had been beneficial to them. Parents also felt their children were discharged too early, without any advanced notice or planning, or consultation with parents. As a result, parents felt abandoned, without any follow on supports or future help-seeking strategies in place.

Parent participants recognised the risk factors for suicide that their child had been exposed to. They lived in fear that their child would die by suicide.

Parents reported they were not consulted or involved in their child's care. They did not feel they received any help from CAMHS. Confidentiality was often used to justify a lack of information sharing with parents. Parents expressed they needed help and support in their own right. They would have liked advice and guidance on how to best help their child, as well as emotional support around their child's suicidality. Most stated peer support would have been acceptable to them.

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Parents were able to identify people and relationships out with CAMHS that were beneficial to their child. They were characterised by someone taking time to listen and get to know their child, being friendly and approachable, and offering flexibility about when and where they met.

#### CHILD INTERVIEW FINDINGS

# Seen but not Heard: CAMHS do not meet the needs of suicidal children and young people even when they are seen (Ch. 7).

Accessing help from CAMHS was not easy or straightforward for the children interviewed. All data sources corroborated that most of the children were dealing with complex and long-standing underlying issues: bullying, family problems, ill health, bereavement etc. and it had taken them a long time before reaching the point of thinking about or attempting suicide. The onus was on the child to vocalise suicidal intent before they could be referred to CAMHS. They often had to repeat their story several times and were passed between professionals before being allocated their own worker assigned to help them. Many children were not seen or allocated to receive treatment from CAMHS.

The children expressed that confidentiality was of great importance to them, and for some this extended to a desire for their parents not to know they were accessing help for suicidality. Some of the systems CAMHS have in place did not afford the children this possibility. For example, letters regarding appointments etc. were posted to the child's parents and to them at their home address. Most children had been offered little choice about where appointments took place, often resulting in parents needing to be involved to transport them to appointments in hard-to-reach clinical locations.

Most of the children interviewed did not find CAMHS helpful. Those that were seen reported not feeling their worker really got know them, and often found them hard to talk to. They did not like the clinical and prescribed approach used by some staff. This finding was echoed in both the parent and staff interviews. Most children were discharged without prior notice or planning and before they perceived they were ready. Children and parents reported that the child was often only starting to engage with the worker when their case was closed. Overall, the children expressed a need to be listened to, by a worker that was friendly, compassionate and took a non-clinical approach. They wanted someone who would spend time getting to know them, and whom they could get along with. They needed time to establish trust, and a longer-term intervention than was provided.

#### INTERPRETATION AND OVERALL THEORETICAL FINDING

Together these findings suggest that CAMHS 'process' but do not meet the needs of children who are referred for suicidality. They are 'Seen but not heard'. They are viewed as 'distressed' and not 'suicidal'. They are offered short-term interventions using prescribed approaches that deny staff the opportunity to get to know or really engage with the child. Children are often discharged before they feel ready and feel let down by CAMHS. Parents are marginalised from this process and most do not feel the support from CAMHS was beneficial to their child. All groups of participants suggest that the relationship between the child and practitioner is more important than their profession, or any specific intervention approach.

The expectation of CAMHS to respond to and assess suicidal children, coupled with pressure to reduce waiting times, results in preventing staff from being able to effectively engage with and support children referred for suicidality. Referrals are managed either by being rejected / placed on a waiting list or offering children such a short-term intervention it fails to allow staff to really connect with the child, facilitate them feeling heard, or address any underlying issues. Children, parents, and staff identified that it was the practitioner's relationship with the child that was most important in helping them, alongside being able to offer more flexibility and longer-term interventions. Current structures and systems for processing referrals in CAMHS do not support the type of needs led, and person-centred approach that children and families find helpful.

Specific responses and interventions needed by children presenting with suicidality.

The following list summarises key suggestions made by the children and parents regarding the type of response that would work best:

Most importantly, children want to be listened to, heard, and taken seriously.

When children seek help from their G.P they want to be asked directly if they have been thinking about suicide.

Children want to be seen by someone (rather than receive a letter of rejection with no followon support).

Children need to be allocated a worker who can stick with them and not be passed around needing to tell their story multiple times.

Confidentiality, discretion, and respect for their family situation / circumstances were important to the children.

Children want the right to choose whether their parents are informed or the extent to which they are involved.

Children need to be supported to talk to their parents if / when they are ready, only if this is appropriate.

Children want flexibility and choice about how they communicate with CAMHS, and where appointments are held.

Workers need to get to know them and prioritise establishing a positive relationship with them.

Children want a non-clinical / prescribed approach.

Children need support to identify and work through underlying issues.

Children want flexibility in the length of the intervention with the option of longer term or continued support.

Children want to be consulted with and plan for discharge from the service.

Appropriate follow on supports and future help seeking strategies need to be in place for children prior to discharge.

#### Parental support needs

Parents want support to be available for themselves, as the parent of a suicidal child.

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Parents want practical information and advice on how to keep their child safe within the home.

Parents want information on available resources and local services.

Parents want emotional support, and validation of their experience – peer support would be acceptable.

Parents want advice on parenting a child at risk of suicide e.g., boundary setting

#### Accessibility to CAMHS in remote rural locations

The findings revealed a stark difference in the accessibility of CAMHS to children living within Site A, and B. Some of the reason for this may (as was mentioned in Ch.4), be due to the differing structure of services within these areas. However, it was also very apparent that there were issues children living within remote rural areas faced that were specific to the geography of the region. One child spoke of being unable to attend CAMHS as it would have been too far away to travel there and back comfortably for an appointment. The data from staff interviews also revealed that they were acutely aware of the challenges for the children, and for the service in trying to meet their needs. One practitioner spoke about being uncomfortable using video link to assess children who were feeling suicidal, whilst another was acutely aware of the time it would take for a staff member to go out to meet the child, and the resource implications for the service. Although the issue of access to appointments was discussed more generally, this study also provides insight into the necessity to consider context when planning and delivering services, and the discernible gap that exists in service provision for children who experience suicidality within Site A.

#### CONCLUSIONS

The findings from each part of the study were able to be synthesised to provide an overall picture and understanding of both how CAMHS process referrals for children presenting with suicidality in two distinct CAMHS teams, and how this is experienced by the children, their parents and the practitioners providing the service. This thesis proposes that CAMHS process the children referred for suicidality, but do not meet their needs.

This chapter expressed the complexity and layers of discoveries that contributed to the interpretation that is presented. Not only was it possible to construct a substantive argument from the findings, but also to identify what children who are suicidal most need from a service. Additionally, the data from the parent interviews provides key insight into the support needs of parents.

The following chapter situates these findings within the policy context and in relation to the research literature. It considers the strengths and limitations of the thesis, as well as implications for policy makers, service providers and future research. The final chapter concludes the thesis, drawing together the overall findings and argument, in light of the preceding discussion.

# **Chapter 9: Discussion**

This chapter aims to provide a full discussion of the thesis findings, considering them in relation to pre-existing research literature, and policy context. It also reflects upon the strengths and limitations of the study, before offering recommendations for policy, practice, and future research.

As noted in the previous chapter (Ch. 8) the thesis findings speak to both what happens to children who present with suicidality after they are referred to two separate CAMHS teams in Scotland, and how this is experienced by the children, their parents and the practitioners who deliver this service. Additionally, an overall substantive argument (CAMHS process the children referred for suicidality, but do not meet their needs) was presented.

Reflecting on 'what happens' to children is organised into four key discussion points: (1) The findings of the Cohort study (2) risk assessment and decision making; (3) processing referrals in a system that is overwhelmed; (4) the power of discourse. This is followed by discussion of the views and experiences of the participants and how these, and the overall substantive argument of the thesis, fit with existing evidence and theory. An outline of the strengths and limitations of the thesis is then presented, before identifying implications and recommendations.

The chapter concludes that despite its limitations, this thesis offers new knowledge and insight into what happens when children are referred to CAMHS for suicidality, how this is experienced, and what they would find most helpful from a service. The overarching substantive argument suggests that at present CAMHS process but do not meet the needs of children presenting with suicidality and that a different approach is required.

#### WHAT HAPPENS

#### Findings of the cohort study

The two sites are situated in different parts of Scotland, and not only are the CAMH services operationally distinct from one another, but the local cultural contexts are also different. For example, the population of the geographical region of Site A in June 2019, was 235, 540 whilst in Site B it was 371,910. The number of children aged 0-15 years, in Site A and B was 39,335,

and 64,473 respectively. Whilst these numbers reflected a similar percentage of the locality's overall populations (16.7% and 17.3%), Site A has 39% less children aged 0-15 than Site B (25). This difference in the size of child populations is reflected in the number of children referred to the CAMHS services, with Site A receiving 42% less referrals for children and young people who were suicidal during the data collection period.

The size of the population aged 16-18yrs. is unknown as NRS (National Records Scotland) data is grouped by ages 0-15 yrs., and 16-24yrs. (25). However, it is worth noting that although Site A only accept referrals for young people aged 16-18yrs. if they are still attending school, in Site B they work with all children up to 18yrs. The number of referrals each CAMHS received for children aged 16-18 yrs. who were suicidal was 25% and 26% respectively (Figure 7; Figure 8). This shows that the difference in remit for Site A CAMHS had very little impact on where services referred young people of this age. Or there was a higher proportion of young people aged 16-18 years who were presenting to health services as suicidal in Site A (as we would expect there would also be a number referred to adult services) or higher numbers of children remained in school beyond 16yrs.

The stark difference in the numbers of children offered face to face assessments between these regions, highlights the benefits in Site B having a discrete suicide and self-harm team. Although due to pressure on resources they are moving to a new model of care (see chapter 3), which could adversely affect their ability to respond as quickly to these children in future.

It also re-iterates the geographical challenges faced by CAMHS workers in providing accessible face to face appointments for children living in remote and rural locations in Site A. Although there have been and are ongoing attempts to address this, through the provision of 'near me' appointments (Video Link), and primary mental health workers located within specific regions, these have presented challenges in themselves (see Ch. 5 and 8), and arguably it remains a gap in service provision.

If we consider referrals that were not added to the waiting list or provided treatment as 'rejected' <sup>i14</sup>, then 57.2% of children referred to CAMHS in Site A for suicidality were rejected, compared with 20.6% in Site B. These numbers highlight again the difference between

<sup>&</sup>lt;sup>14</sup> Rejected is the term used by the team conducting the national CAMHS audit (36), although redirected is often a preferred term.

outcomes for children referred to different services. The national CAMHS audit reports that 1 in 5 (20%) of referrals to CAMHS across Scotland are rejected (36). This study shows that whilst the number of rejected referrals for suicidal children in Site B is in keeping with this figure, in Site A they are more than double the reported national average. Neither service reject less referrals for reasons of suicide than the reported national average, which is contrary to belief held by parents that CAMHS only see young people who are suicidal, as was reported in the audit of rejected referrals (31).

The SIMD data shows there was a difference in the proportion of referrals for children from areas of multiple deprivation between Site A and B, with more children in Site B being referred from areas of multiple deprivation. However, this may be reflective of the levels in deprivation across these sites more generally. There are more areas of Site B considered to be amongst the 20% of most deprived areas in Scotland (19% of data zones in Site B are considered in the lowest quintile for deprivation, in Site A this figure is 8%). Whilst there are pockets of areas of deprivation in Site A, poverty of access is a much more prominent issue, with almost half of localities reported as being in the lowest quintile for access (47%) (488,489).

The 2018 audit by SAMH and ISD, of rejected referrals to CAMHS (31) found there were a higher a number of rejected referrals for children from areas of multiple deprivation than more affluent areas, however they were unable to situate this within the context of SIMD data for all CAMHS referrals, as this data is not routinely gathered or available. They suggest that higher numbers of referrals for children to CAMHS from deprived areas would be expected given what is known about the links between poverty and poorer mental health. There could also be a disparity in access to mental health services for children based on social class (490). There are clearly established links between suicide and deprivation (138,491,492). Although postcode data may not provide the whole picture in relation to the adversity experienced by a child it is important their access to mental health support services be considered within a context of social stratification if we are to understand the specific barriers and challenges, they face. For example, means of transport to attend appointments.

In both regions there were slightly higher numbers of referrals for females than males. However, the number of males referred averaged 41% in both regions (40.3% in Site A, and 42.2% in Site B), and was much higher than reported rates of self-harming behaviour amongst boys generally (rates of self-harm have been found to be three times higher for girls than for boys (493)). Given that completed suicide is known to be higher amongst young men and males generally it could be a positive that boys are seeking help with suicidal feelings at a young age (27,85,494–497). However, it also highlights the importance of these children receiving help when they need it, and the opportunity that it is presented to provide an intervention at the point of referral.

The age of children referred to both services ranged from 5-17yrs. Suicidality is generally perceived as an adult problem, and although there is growing recognition that it is an issue for many adolescents and young adults it is not commonly associated with younger children (352,498). This study showed that approximately 1/3 of all referrals for children who were suicidal made to these CAMHS services were aged 12 or younger (30% in Site A; 35% in Site B).

There is much debate upon whether children under the age of 12 fully comprehend suicide (499). Evidence suggests they do present with suicidal ideation, make attempts to end their life, and complete suicide (498,500). There remains a paucity of research studies with very young children around suicide (501). But given the increased numbers of deaths by suicide amongst this population (85,494), it may be harmful to ignore or dismiss young children presenting with suicidality because of a belief that they are too young to fully understand what suicide really means (101).

The underlying issues identified within the referrals in both regions have recognisable similarities. For example, 37.5% of children in Site A, and 41.1 % in Site B noted parental separation. Domestic abuse was reported in 8.3% of referrals in Site B, and 14% in Site A. Child abuse (physical, emotional, sexual or neglect) was mentioned in 12% of referrals in Site A, while the overall rate of child abuse within the referrals in Site B was 18 %, with child sexual abuse specifically mentioned in 10% of identified referrals. This could be because CAMHS in Site B have a dedicated service to support trauma recovery in children who have experienced sexual abuse, encouraging referrers to explicitly mention this.

Parental separation featured in approximately 40% (38% in Site A; 41% in Site B) of all referrals for children who were suicidal, highlighting this is a difficult issue for children not just at the point of separation but also after. It may be this is the case for all referrals to CAMHS and not just the ones identified for suicidality. An accurate number of children having experienced

parental separation across Scotland is not available, however information from the 2011 census tells us that 31% of families with dependent children were lone parent households, 15% were cohabiting, and 54% were married. Of the cohabiting families 29% were stepfamilies, and 8% of married families were stepfamilies (502). This suggests that parental separation across the population of children in Scotland is perhaps not that different from the number of children referred to CAMHS for suicidality. Additionally, as is reported in other research literature (29,352), suicidality in children generally stems from a combination of more than one issue and is not solely attributable to parental separation.

Approximately 20% of all children referred for suicidality either had an ASD diagnosis, or ASD was queried within the referral. We know from the research literature generally that the links between autistic spectrum disorder and suicide have been established (503). Specialist support around suicidality should be made available for children with autism and their families.

Drugs and / or alcohol were only mentioned in 9% of referrals in Site A, and 11.1% in Site B. This supports the findings of other research in this area that suggest that unlike in adult populations there is not a clear association between suicidality and drugs / alcohol in children (29,504,505).

The data sets from Site A and B were different in that other mental health or neurological conditions (Low mood, anxiety, eating disorders, psychosis etc.) were only mentioned in 6.7% of referrals for children presenting with suicidality in Site B compared to 32% in Site A. This could be due to differences in the choice of language used by referrers to describe symptoms and feelings e.g., anxiety and low mood, and warrants further exploration in future studies. It could also be because the existence of the dedicated suicide and self-harm team in Site B means that rightly or wrongly referrers do not feel the need to pathologise mood and anxiety as much as they are more confident that the expression of suicidality alone meets the threshold for CAMHS. Additionally, referrals where the primary reason for referral was related to ASD were not screened in Site B as these were directed to another team. Importantly though these figures show that a sizeable proportion of the referrals in Site A suggest there is a co-occurring presenting mental health issue that may require assessment / treatment / support.

The underlying issues identified in these referrals supports what is already known about risk factors and suicide in children and young people (504). These are issued faced by many young people growing up. However, as was identified in the UK National Confidential Enquiry report, 2017 (29), young people who are suicidal often face multiple challenges, and it may be unhelpful to attempt to compartmentalise support around particular issues for individuals who are actively suicidal.

#### Risk assessment

Policy suggests that children who are suicidal should be assessed by a CAMHS professional. However, there is a lack of specific guidance on assessing childhood suicidality (34). The use of suicide risk assessment scales is discouraged as there is no evidence to support their efficacy and many warn their use could be dangerous (114,117,118,222,223). Practitioner guidelines such as NICE short and long-term management of self-harm in over 8's (173,213) recommend a holistic needs assessment and advise taking into consideration the child's familial circumstances and education.

In the absence of an evidence-based process for the assessment of suicide the finding that staff all conduct this differently is unsurprising. All clinical decision making arguably carries a degree of uncertainty (506). In the field of mental health and illness the role of bias, and the subjective nature of decisions well documented (507).

Much has been written about clinical decision making (508), generally with a focus upon identifying and eliminating or minimising error. Several theories and models have evolved broadly falling into three categories: normative (ideal scenario – usually based on statistics and focused on outcomes), descriptive (focuses upon how judgements are made), and prescriptive (using guidelines etc. to improve practice and reduce errors in decision making) (506).

The findings presented in chapter 5 show that decision making within the context of the suicide risk assessment of children is a descriptive rather than prescriptive process. The descriptive illustration of factors influencing decision making presented in (Ch. 5 (Figure 27)) also resonates with the General Assessment and Decision-Making Model (GDAM) (509) (which was originally developed in the field of social work in relation to decisions about child welfare) in respect to thresholds. The GDAM model breaks down decision making into two

phases 1) assessment – although the case information might be the same, the actions which follow vary because of the individual making the assessment 2) individual and organisational thresholds for action. Their model relates to the amount of information needed for a decision to be made to accommodate a child, and the consequences of thresholds being 'too high' or 'too low', or mismatched thresholds with other professionals (for example with physicians). They suggest thresholds can change in response to policy shifts, organisational issues, workers experience etc.

The role of thresholds in the assessment of childhood suicidality can be recognised within the description of decision-making process around risk assessment presented in chapter 5 (Figure 27). For example, experience of working with suicidal children was identified as informing practice and making staff less reactive to disclosures of suicidality. However, as Carter and Spittal (114), identify experience can incur confirmation bias. For example, the low prevalence of deaths by suicide amongst children can be used to justify decisions not to intervene.

As a previous suicide attempt is the biggest predictor of future suicide (510), and adolescents with previous suicidal thoughts and behaviours are more likely to die from suicide than those in older age groups (511), non-engagement of children who are referred to CAMHS with suicidality means that the opportunity for early intervention is lost.

Additionally, team decision making was found to encompass the assessment process. Team decision making in this sense has the benefit of diffusing the responsibility for deciding a course of action, and therefore accountability should it be the wrong decision. This has the advantage of supporting less experienced members of staff, pulling resources, and ensuring a range of opinions are considered. However, it can also lead to group think, and conformity (512). Less experienced members of staff may be reluctant to challenge ingrained ways of thinking, or indeed thresholds of risk.

Thresholds are also subject to change with the capacity and resources available at any given time. As Lipsky (513) states, services overwhelmed by demand must somehow be rationed. In this respect, it could be that decisions making around risk is often more influenced by factors such as waiting times and capacity than what is presented by the child. This is considered in more detail below, however, it is worth noting here the role played by availability of resources in influencing decision making.

CAMHS are a 'specialist' resource and rely upon the stratification of risk to substantiate decisions about access to the service. It also serves to reinforce their position as experts and professionals with specialist knowledge able to assess the suicidal child and decide upon the best course of action. Although CAMHS are 'experienced' in conducting assessments of suicidal children, this is not an exact science.

#### **Processing referrals**

Child and adolescent mental health services generally are said to be overwhelmed by referrals (39). Recent reports have been concerned with waiting times (32) and the numbers of rejected referrals (31). Interviews with staff showed they were acutely aware of the pressure on their service and that they were unable to meet the needs of all the children being referred. Fortune and Clarkston (38) observe, that policies directing all children who present as suicidal be assessed by CAMHS are unhelpful, as they do not have the capacity to meet this demand.

The findings of this study concur with the suggestion by Lipsky (513), that when demand for services outweighs capacity, ways to ration the service and limit access must be found. *Marginalised parents* and *Imposing order on the flexible and intuitive practitioner*, could be considered strategies for managing interactions with children and their families, and limiting the involvement of CAMHS. Lipsky's description of the impact of an overwhelmed system clearly resonates with the experience of the children, parents and staff that were interviewed.

"Workers may despair of ever catching up or otherwise getting out from the pressing burden of work. They may become insensitive to the human dimensions of the job. Certainly clients will bear the costs of agencies not having the capacity to meet unpredictable demands. Long and unexpected waiting times, broken appointments, short and hurried treatment are all costs that the clients bear from the unpredictable (yet certain to arise) system overload." (Lipsky, 2010; 27(467))

Routinisation of appointments, and the imposition of a prescribed approach, although understandable given the pressure CAMHS are under, erodes the capacity of staff to get to know the child and offer a person-centred service. Thus, resulting in children being **seen but not heard**.

Staff know what children and young people who are suicidal need, but their ability to provide this is compromised by their over-burdened caseload and attempts to systematise their working practice.

This finding is not unique to CAMHS support for suicidal children but has been recognised in health services more generally (514). This recognition that the lack of personal connection with patients adversely affects their engagement and treatment supports the findings of this study. However, to suggest this is a recent development would be misplaced.

Psychiatric services have long been criticised for their application of the bio-medical model, authoritative position, and clinical approach (368,369). Recent authors have argued medicalisation of suicide is the crux of the problem (133,515). However, as is discussed below, CAMHS rhetoric in relation to the suicidality of children does not reflect this.

The problem, as it is presented in government reports (31,39,79)(See Ch 3), and was found in these two case studies, suggests that CAMHS do not have the capacity to meet the needs of the numbers of children being referred. In Site A, most children who are referred for suicidality are not assessed or offered treatment. While in Site B, they have a dedicated team for children and young people who self-harm or are suicidal, and consequently assess 87% of all children referred for suicidality. However, the qualitative data tells us staff here are under pressure to deliver short-term interventions, and children and parents did not feel their needs were met.

Lipsky (513) argues that demand increases in line with service provision; therefore creation of specialist services to extend capacity results in increasing referrals as awareness of the service extends. However, this study did not find this to be the case. Referrals for children who presented as suicidal were approximately one quarter of all CAMHS referrals in both regions, even although one had a specialist suicide and self-harm team.

#### **Discourse of Distress**

The finding that CAMHS reconceptualise suicide as distress could indicate a 'discursive formation' (371). Foucault (371) suggests a discursive formation is 'a group of rules proper to discursive practice'. In other words, what can be said about something.

Foucault was concerned with how institutions produced discourse and administrative practices to regulate social norms. The institution, and subjects working within it being awarded the authority to create knowledge and classify objects. As Foucault (371), argued these objects are not fixed, but fluid and changeable.

CAMHS practitioners, as subjects hold authority awarded to their positions via the institution of child and adolescent psychiatry. These positions (clinical services manager, psychiatrist, mental health nurse, psychologist, and psychotherapist) hold the power to create and define objects of child and adolescent mental health. For example, the transformation of suicidal ideation or intent to a 'state of distress' or 'distress behaviour' is recognisable as a site of object production and problematisation.

Clearly the way suicidality in children is conceptualised and the discourse around this is important, not least for the children seeking help.

Not only is *what is said* significant but who says it, and the subject position they hold is also important. CAMHS practitioners are awarded the status of *expert*. Therefore, if they define suicidal behaviour as distress, and deny that a child is *really* suicidal, it denies them permission to express suicidality or to speak of wanting to die.

"...our experience is largely written for us by the multitude of conflicting discourses of which we are a part." (Phillips & Hardy 2002: 2 (516))

Foucualt (371) was primarily concerned with 'what was said', and 'what could be said', as opposed to 'what this meant' or any causal relationships. However, considering the subject position of the suicidal child, to deny they felt suicidal could result in silencing them, engendering a feeling of not being heard or listened to, and put them off help-seeking in future (517).

Knowledge production and dissemination are vast topics within their own right; there are a range of theoretical positions and a broad literature base beyond the scope of the argument

being made in this thesis. However, it is important to note that knowledge making is not a linear process, there are conflicting discourses, sites of resistance and tension (371). The findings of Ch. 7 identify how on the one hand staff impart a narrative of 'distress', whilst also conceding there are children who they believe to be at risk of suicide. This dichotomy can be understood by the process of subjectation (371,425,518). An individual can be awarded one subject position (e.g., job role of psychiatrist or nurse) but simultaneously hold another (e.g., mother, colleague etc.). Within the research interviews conducted with staff the most prominent position presented was that of a CAMHS practitioner, however, it is also possible to identify from the data other positions and knowledge bases that co-exist.

When we consider this dominant discourse of 'distress' within the context of discourse around childhood suicidality more generally, we can identify further sites of tension and knowledge production. As was mentioned in the introduction (Ch. 1), media reports suggest there is currently a children's mental health crisis and increasing numbers of children are thinking about and attempting suicide (4,6,519,520). This is generally followed by accusations that CAMHS are failing children and young people and are under-resourced (30).

This discourse was identified in the interviews with parents (Ch 6). Parents reported how they understood CAMHS services to be overwhelmed by referrals, and in need of funding. The problem is then *"represented to be"* (227,228) about funding for CAMHS services, and no longer about suicidal children, or the issues causing suicidality.

Research papers (including my own (34,143,521)) in the field nearly all begin by referencing the numbers of lives lost to suicide and restating it as the second leading cause of death in children and young people<sup>15</sup>. Data on the number of children dying by suicide shows they are increasing (24,85), and while overall prevalence remains low in those under 18 years of age, this rises sharply amongst young adults.

Epidemiological data is more often presented as 'fact' (although as was highlighted in Ch. 2 suicide statistics are interpretative and change between contexts and over time) and used to justify policy direction and the distribution of resources including research funding. The call is

<sup>&</sup>lt;sup>15</sup> I have refrained from referencing specific journal articles here as there are too many to include and the decision to select a few would be arbitrary. However, there is an extensive reference list attached to this thesis and the reader will find most of the cited articles to begin in this fashion.

to do more for children and young people's mental health, and to better resource child and adolescent mental health services. As was found in the scoping review of policy (34) (Ch. 2), children and young people's mental health is identified as a priority; however, childhood suicidality is rarely addressed.

Sociological literature has criticised the medicalisation of suicide, and psychological research which presents it as an individual problem within an illness model (130). The findings of this study however show that rather than attempting to medicalise suicidality in children, the dominant discourse is to normalise it, and relocate the needs of these children out with the scope of the medical domain. Suicide in children is de-medicalised (522); perhaps because of the lack of any evidence based treatment programs (Ch. 3), or the lack of capacity within CAMHS more generally, or indeed because suicide is not a medical illness, but usually a response to overwhelming life events or circumstances (29).

Contextual factors and societal issues such as poverty, cultures of bullying, child abuse in all its forms, and family breakdown are recognised suicide risk factors (29,111,231,523,524). However, dominant discourse remains concerned with access to 'treatment' for individuals, rather than addressing these wider contextual issues.

Suicide in relation to children, continues to be for many a 'taboo' topic (525). The construction of childhood as a period of innocence, that should be full of fun, playing and learning etc. (52) is severely challenged by the child who wishes to end their life. Notions of childhood bound up in a protectionist discourse that posit children as vulnerable, and society as dangerous, posing many risks to children (466,526) infer that children thinking about and attempting suicide reflects a failure of society.

Qualitative research has shown that suicide in children is often described as 'unthinkable' and shrouded with fear (154). There remains a silence around suicide in children, within the research literature involving children (143), and policy documents (34), supported by the dominant discourse. As was identified in the literature review phase (Ch2) self-harm is often used as a caveat term to include suicidal behaviour thus reducing the need to specifically use the word suicide (143). Conversations about "self-harm" and "distress" are perhaps less shocking and easier to have. However, the numbers of children thinking about, attempting to, and ending their lives by suicide continues to rise, and by not naming suicidal feelings as

such, these children do not feel heard, do not have their feelings validated, and continue to be at future risk of suicide.

There are recognisable parallels with the child sexual abuse literature. The dangers posed by not naming abusive behaviour with children can mean they struggle to find a safe person to disclose to (527). The experience of child sexual abuse can manifest in many difficult presenting behaviours and have a profound impact upon children and young people's mental health and well-being that extends into adulthood (528,529). Although it does not account for all suicidal behaviour, it is important not to forget the established strong association between child sexual abuse and suicide (530,531). This also adds weight to the need for interventions that allow children to get to know and build trust with a worker over time.

#### PARTICIPANTS VIEWS AND EXPERIENCE

#### **Practitioners Perspectives:**

Although the findings from the practitioners' interview study are mostly addressed in the discussion above (risk assessment; processing referrals and a discourse of distress), the experience and perspective of the practitioners themselves also needs to be considered within the context of other qualitative literature in this field.

Practitioners' attitudes towards suicide have been explored in several studies and have often been found to be problematic, viewing suicidal behaviours as 'attention-seeking' or 'a cry for help' (156), associated with mental illness (161) or normal (162). The doctoral study by Geradi, 2018 (162) identified there was an increased acceptance of suicidal behaviour in children as *normal* as exposure to the behaviour increased. This can be recognised in the findings of this study, where the staff identified their 'experience' as guiding and informing their approach and decision making.

This normalisation of childhood suicidality, although often still contradicted by exceptions, signifies a shift from the previously dominant discourse which associated suicide with mental illness, and in children specifically 'abnormal' development (104), to one where such behaviour is 'normalised. Viewed through this "*normal*" lens, suicidal behaviour provokes a less immediate or reactionary response and perhaps helps the staff to cope with the burden

of risk management they face. Interestingly this contrasts with the dominant discourse for suicidality amongst an adult population which remains associated with mental illness (532).

The identification of the staff's frustrations at the current resourcing of CAMHS and attempts to regulate their work is not something identifiable in other qualitative studies with CAMHS practitioners. Although media reports of individual workers speaking about their concerns can be found (533), as well as a report in the grey literature (534) which speaks to how practitioners feel compromised by the present system. Other recent research into CAMHS in the UK may have consulted with practitioners, however, their input was used to describe what they do, rather than how they experience their work (535). Despite being perceived as the '*experts*' in dealing with children and young people's suicidality, their opinions are rarely sought in service redesign. Practitioners are also expected to implement formal processes and standardised programs without much consideration of their acceptability to staff or indeed their capacity to do so. Instead of increasing consistency, this results in increased informal and ad-hoc approaches (513).

## Parents' perspective:

The findings from this study revealed parents do not feel involved or consulted about their child's treatment and care and this resonates with the findings from other studies involving parents of children who use CAMHS more generally (151–153). When consulted parents consistently report struggling to access information and support for their child.

As was identified in chapter 2, there remains a paucity of literature specifically exploring the views of parents of children who are suicidal in relation to child and adolescent mental health services. However, from the scarce qualitative research that exists, the need for parental advice and support is apparent. One focus group study identified similar issues for parents as those found in this study, namely that: children had endured problems for a long time before their suicide attempt and their parents had struggled to access help for them; parents felt isolated following their child's attempt believing no-one would understand; and associated their behaviour with shame and stigma; and stressed how the individual child's suicidality had a much wider impact on the whole family (150). A previous focus group study conducted in Ireland, which aimed to identify priorities for parents of children who deliberately self-harmed prior to setting up a new support service also identified similar themes to those found

in this thesis. It reported that parents needed information, and support with parenting as well as emotional support to deal with the fear their child may end their life. They also found the group did not feel supported by child and adolescent mental health services (536).

Although these other studies describe the views of parents and establish the need for support for parents, they do not explore the wider context, or why parents believe they are excluded from their child's care. Within the qualitative literature about parents' views of CAMHS more generally, there are references to parents feeling blamed by CAMHS practitioners for their child's mental ill health (151,152). Although parents in this study may have feared being judged this was not something, they reported experiencing. This may have been due to their contact with CAMHS being so limited.

Parents' beliefs that they were excluded from decision making about their children's care due to reasons of confidentiality is not evident in other qualitative studies exploring these issues. However, in this study this finding was pivotal in their acceptance of being positioned outside their child's treatment and care with CAMHS.

Children and young people have a right to confidentiality assured by law (UNCR, Children's Act Scotland etc. (455,537)). However, this remains an ethically and legally complex thing for health care professionals to assess capacity, negotiate and deliver (538–540).

Wider literature on parental views of child confidentiality in a medical context showed parents wanted information shared with them about their child's mental health even if their child did not want this information shared (541). It has also been well documented that many parents are not adequately informed about their child's right to confidentiality (542). Some studies suggest a lack of clarity regarding what confidentiality means for children and young people accessing services leads to confusion both on the part of the practitioner and the parent and can hinder children and young people accessing support from services (542,543).

The parents in this study were clear they were not looking for information on everything their child spoke about with the practitioner, but clearer guidance on how to best support them at home, and information and advice for them in their role as a parent of a suicidal child. As stated, they felt that they needed emotional support separate to their child to help them cope with their child's suicidality.

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Although limited research into the needs of parents whose children have attempted suicide is available, their need for psychological, social, and parenting support has been established (15,145,146,148,149). The parents interviewed for this study suggested that peer support would be helpful. The overview of reviews (Ch. 2) identified only one pilot study for a parent psycho-education group program running simultaneously to support for their child (305). To date there has not been a review of the effectiveness or indeed feasibility of peer support group programmes for parents of suicidal children. There has been some recognition of the benefits of involving parents in the treatment and care of children who are at risk of suicide (544–546). However, as was found in the overview of reviews (Ch 2.) there is no high-quality evidence to support family therapy as an effective intervention. The findings of this PhD study suggests that parents would like support that is independent to that offered to their child. A pilot study in Ireland providing separate support tailored to the needs of parents, found this to be beneficial to the child as well as the parent participants (547). Further research is needed to develop support services or networks specifically for parents of children who present as suicidal.

#### Children's perspective

The findings from the qualitative interviews with children are supported by other qualitative studies in the field (143,154,546,548,549). However, very few other studies specifically included participants who were suicidal, or younger children (under 16 years).

Children's experiences of being passed around and having to re-tell their story repeatedly to access help has been recognised in studies about children accessing mental health services generally (548,549), as well as in studies specifically about children who experienced suicidality (550). The meta-ethnography I conducted immediately prior to starting this thesis (143), identified that children who were suicidal were unable to directly access mental health services without another adult referring them, and this was also found to be true for the children interviewed for this thesis.

Children who are suicidal reporting not feeling listened to or taken seriously by practitioners has been identified repeatedly in the literature (143,154). The importance of the relationship between the practitioner and the child has also been identified in other child and adolescent mental health research (551,552).

Confidentiality was found to be especially important to the children interviewed, and for some crucial to their ability to engage with CAMHS. Some of the children identified current CAMHS practices that do not allow them to retain confidentiality beyond attending their G.P, such as sending letters to their family home, arranging appointments at inaccessible locations that means they need to rely on parents taking them, or indeed having appointments within school. It has been well documented that children are less likely to seek help with sensitive issues unless they can be assured it is confidential (553). Other studies have also shown that children often feel CAMHS do not provide enough information about their rights to confidentiality and what information would be shared for them to have confidence using their services (551).

By situating the findings within the broader children and young people's mental health research literature, as well as the suicide and self-harm literature, it is apparent they are not specific to the context of child and adolescent mental health services in Site A, or B, or indeed Scotland. Studies conducted in Canada (120,546) and other European countries (552), as well as the UK (153,554) all present similar findings. Although perhaps reported differently, the voices of children and young people seem to repeatedly be saying the same things about mental health services: they often feel their needs are not met and would prioritise the relationship with the worker over seeing a particular professional.

This suggests that although children and young people are more involved in mental health research studies (555,556), and more often consulted by service providers (151,557) and policy makers (35,548,558–560), there exists a barrier in relation to implementing their recommendations. A systematic review in this area found there to be no studies that demonstrated a change in practice based on child and adolescent mental health service consultations with children and young people (561). There are many possible explanations as to why this may be the case. Consulting with children and listening to their views is arguably a relatively new phenomenon, and it may be that at present in the field of mental health services this remains tokenistic, despite efforts to improve impact. Qualitative studies with children and young people who have been or are suicidal, generally have small samples, and limited generalisability. It could be the qualitative evidence available is not considered 'good enough' to be used to inform practice guidelines which tends to rely on evidence from RCT's (562,563). Or it may be the current structure of mental health services and resources in place

does not allow practitioners to work in this way. Further research exploring the barriers to implementing what children tell researchers they would like from a service is urgently needed.

#### **OVERALL SUBSTANTIVE THEORY**

The overall argument of the thesis that CAMHS process but do not meet the needs of children who are suicidal emerged from and is built upon the tenants of what has just been presented. There have been many recent criticisms of CAMHS in government reports, the media and academic literature (Ch 2). However, the experience of the child referred for suicidality has never been closely considered, and not in conjunction with the views of the adults (parents and practitioners) providing their care.

As has been identified the data from all groups of participants suggests that the relationship with the worker is more important than their profession or training. The power of the therapeutic relationship has been recognised within the field of adult mental health. The 'Dodo Effect' (a term initially coined by Rosenzweig, 1936 (564)) refers to the suggestion that all psychotherapy treatments are as good as one another. However, none are found to be beneficial unless the practitioner has a positive rapport, and engagement with their patient or client. Smith and Glass, 1977 (565) showed that whilst many psychotherapy treatments had evidence of effectiveness there was no difference in effect between the types of psychotherapy. Other studies have gone on to show that difference in effectiveness is due to the individual therapist delivering treatment (566). As stated by Richard P. Bentall, 2010 (566), the work of Carl Rodgers has been instrumental in understanding the nature and importance of the therapeutic relationship which he (Carl Rodgers) terms the therapeutic alliance (567). Despite the recognition of the importance of the relationship in delivering adult mental health treatments, there has been little attention paid to measuring the therapeutic alliance / connection between practitioners delivering child mental health interventions (568). The focus continues to be upon developing processes and prescribed approaches, neither of which are reported to be helpful to children who are considering or have attempted suicide.

The findings of this study, that suggest a congruent relationship with the practitioner is most important, is supported by the wider literature. It is therefore perhaps surprising that in the two sites considered for this study, service structures do not seem to allow the time and space for practitioners to develop the trusting relationship that children, their parents, and practitioners recognise they most need.

#### **STRENGTHS & LIMITATIONS**

This thesis is the first mixed method study to explore the pathways of care and experiences of children who are suicidal after they are referred to CAMHS, and to include interviews with children, parents, and practitioners. The data collected and presented on the numbers of children presenting as suicidal and the outcomes of their referrals was previously unknown. Although there have been interview studies of children about their experience of mental health services, this is the first to consider specifically the views of suicidal children, alongside those of their parents and the practitioners that provide them with a service. This thesis has synthesised the results and findings of each component of the study to provide an overall picture of the experience suicidal children have of being referred and treated by CAMHS and to identify what they most need form a service. The knowledge generated by this thesis can be used to inform policy, practice, service re-design and development, as well as future research into childhood suicidality.

Methodologically this study was strengthened by involving children and young people from the outset. Collaborating with a group of children from the MacRobert Arts Centre film making group to create the animation grounded the study in child-friendly practices, and generated images and resources that were accessible and captivating for children. The animation was awarded a runner-up prize of £500 at the SGSSS impact awards 2019; and the young people involved delivered a key-note presentation alongside the researcher at an international conference on child mental health and well-being at the University of Stirling, in September 2019.

Managers and CAMHS practitioners were consulted in the early stages of study design to ensure that the study was feasible, and relevant to them. A practitioner stakeholder event was organised, but sadly not attended by those invited due to work commitments. The demands upon their time meant consulting with them prior to finalising the study design was limited to individual meetings and telephone calls. Involving CAMHS practitioners and managers in research requires a flexible and understanding approach.

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Identifying CAMHS teams willing to host the research study was a challenging task. Prior to starting communications with CAMHS, it had been hoped that three or four CAMHS services may be involved, providing a mix of urban and rural locations, and reflecting the diversity of ways in which referrals are processed by different teams. Unfortunately, despite efforts to engage with a large urban site they were unwilling to participate. Data controllers within the NHS ultimately have the power to block research studies. However, in contrast the unwavering support and encouragement throughout the research study from the two host CAMHS teams was outstanding. The service managers in these areas were both clearly committed to trying to improve services for children through informed research. However, it means the findings of this study are based on one rural health board area and one mixed rural/small urban area. The experience of children dwelling in city locations is not represented.

As was outlined in the Cohort study chapter (Ch. 4), data collection in this phase was limited by the availability and accuracy of the data held by CAMHS. Additionally, the requirement of NHS ethics and Caldicott guardian approval to specify variables in advance prohibited the flexibility to respond to the dataset that was found to exist, rather than what was presumed to be there. For example, whilst collecting data in Site B it became apparent that although children may be offered treatment many did not attend appointments.

The study was designed in such a way the sample population of children and parents for the qualitative interview studies was to be sourced from the CAMHS services that agreed to participate in the cohort study. This strengthened the understanding of the context for these interview participants as they could be situated within the overall processing of referrals within these CAMHS services. However, it also added a layer of complexity to the recruitment process as the CAMHS team had to contact potential participants on behalf of the researcher, inviting them to consider participation. Four families made contact to say they had not had a good experience of CAMHS and wanted to decline the opportunity to participate. Three parents were offended that CAMHS had contacted them after the lack of service they had received. After it was explained to parents that CAMHS were doing this on the behalf of the researcher, and the study was not being conducted by CAMHS, two expressed interest in participating, but sadly this was not the case for everyone.

The sample recruited were predominantly from Site B, and therefore responses were bias towards this model of service provision. Two out of three participants from Site A had not received a service, and one was on the waiting list. It could be argued that the voice of the child who had received treatment from CAMHS in Site A was absent. However, as was found in the retrospective cohort study (Ch. 4), most referrals for children who are suicidal in Site A were rejected or added to the waiting list and therefore the children interviewed reflected this experience. All the children and parents from Site B, had been seen by CAMHS.

It could also be suggested there is a negative bias within the parent and child participant's experience, that can be common to samples that opt-in to research about patient experiences (self-selection bias) (569,570). People who are generally satisfied with the service they received may not feel strongly about the need to participate in research interviews. This issue was noted with the sample population recruited to the Rejected Referrals to CAMHS report (36) and is not unique to this study. However, these arguments fall within the realms of methodological debates about the appropriateness of the application of quantitative research quality measures to qualitative studies and are beyond the scope of this thesis (569). It is enough to note here that there may have been other children, and / or parents who held different views or had different experiences than those included within this study. The sample aimed to be inclusive (all children and parents of children identified in the cohort study (Ch. 4) were invited to participate), but arguably cannot be known to be truly representative of opinion.

Overall, the sample populations in the qualitative studies were small. This makes it hard to generalise from the findings. However, recruitment to qualitative studies about childhood suicidality is particularly challenging given the vulnerability of participants and sensitivity of the topic. It is often the case that recruitment numbers fail to meet targets in research studies such as this and can mean researchers having to adapt selection criteria (571), or data collection methods (31). A strength of this study was that despite the challenges in recruiting enough numbers it was possible without altering the study protocol. There are arguments for the use of small samples, especially with hard-to-reach populations such as this (572). Recognition of the richness and quality of the data is suggested to be more important than the number of people participating (431). Additionally, the parent and child participants were predominantly white females. The voices and experience of fathers is not represented in this

sample perhaps reflecting the increased responsibility mothers feel for their children's healthcare (573). This is often the case with research studies in the field of child suicidality as well as children's health research more generally, and an important area for further consideration and development (574). It should also be noted however, that reflexive authors of qualitative research studies do not claim them to be representative of the whole population being researched, and indeed their position is one of subjective interpretivism (120).

Positionality and researcher bias must be considered in any study, and especially qualitative research. From the outset reflexivity was identified as an important part of the research process. My experience of working in the field with children and young people who were suicidal undoubtedly influenced my decision to do this research study and how I viewed the problem (Ch. 1). This experience was communicated to interview participants and perhaps awarded me some *insider* status that supported their ability to identify with me, and share their experiences and views with me as a researcher and *outsider* (412). It could be suggested that this position prevented me from being impartial or truly objective in my analysis. However, it may also have been beneficial in establishing rapport easily with such a hard-to-reach population. It is also worth noting the analysis of the interviews was not conducted in isolation. Transcripts were independently coded by my supervisors and coding frameworks discussed to resolve disagreements. This potential for bias was challenged by them throughout the process, to ensure the findings of this study were grounded in the data.

Despite the recognised limitations of this study, this thesis presents important and novel findings which will inform future policy direction, and service development. Not only does it provide an overall picture of what happens to referrals for children who are suicidal after they are referred to CAMHS, but gives voice to their experiences, and the views of both their parents and the practitioners charged with assessing and helping them.

#### IMPLICATIONS AND RECOMMENDATIONS

For policy

• Following on from the findings of the policy scoping review (34) (Ch. 2), policy documents should specifically refer to children experiencing suicidality to prevent

their treatment needs being overlooked, and ensure they are prioritised by commissioning bodies and service providers.

- Policy makers should be aware that a discourse of distress may lead to a lack of clarity in relation to the specific needs of children who consider or attempt suicide. And as is noted below (recommendations for service providers and practitioners) have detrimental implications for children seeking helping with suicidality.
- Current policy direction which suggests children who are suicidal be assessed by CAMHS should be reconsidered taking account of the following:

1) There are no formalised criteria for determining who is considered suicidal and when suicidal behaviour requires therapeutic intervention.

2) There is no strong high-quality evidence to support the benefit of any specific intervention in addressing childhood suicidality (Ch. 2).

3) CAMHS services are overwhelmed by referrals, and do not appear to have the capacity to offer the high numbers of children being referred an appropriate or helpful response.

• The needs of children who are suicidal are not met by current policy or service provision.

#### For Service Providers and Practitioners

- Children who have attempted or been thinking about suicide want and need to be able to access a service that can offer flexibility in terms of the location and time of appointments; a person-centred approach; workers who have time to get know them; someone to really listen to them; confidentiality; and kindness. Children, parents, and staff agree that the relationship with the child is more important the profession or status of the worker.
- Services should support workers to develop creative and flexible approaches to working with children that support establishing trusting relationships, rather than attempting to impose standardised models and short-term interventions that have no evidence of effectiveness on suicidality in children.
- Discrete service provision for this population has been shown in this study to be successful in ensuring these children are assessed timeously. However, they lack the

resources or capacity to offer children the flexibility of longer-term support should they need it.

- Confidentiality is important to children accessing support for suicidality. CAMHS
  must consider ways in which their processes potentially compromise a child's
  confidentiality and develop ways of working that protect confidentiality. CAMHS
  should explicitly state their position on child confidentiality to children, parents, and
  other agencies such as schools.
- Practitioners should be aware that a discourse of distress may contribute to children not feeling heard and silence their feelings of suicide. This may deter them from future-help seeking and thus place them at future risk of suicide.
- Parents need information and resources on how to best support their child at home.
   Only when it is appropriate CAMHS should also support parents to communicate with their child.
- Parents need independent emotional support to deal with the trauma of having a child who has or is considering ending their life. Peer support groups should be considered.
- CAMHS must be supported to improve the consistency and quality of data collection, including clear, accurate, and consistent referral information.

### For future research

- Researchers may consider in future a discourse analysis of policy documents to explore not only how childhood suicidality is addressed but how it is represented and knowledge about it created within policy documents.
- Researchers should seek to develop the co-production and design of a new service model for and with children seeking help with suicidality. The model should be informed, and led by their preferences for a non-clinical, flexible approach, delivered by workers that have time to, and actually listen to them.
- Future research must also consider the co-design and development of services that are accessible to children living in remote rural locations, as there is an urgent need to address this gap in service provision.

- A similar research study should be conducted in an urban location to explore whether access to services and the experiences of children presenting with suicidality are different.
- Further research is needed to establish the feasibility and acceptability of a parental peer support group.
- Researchers must consult with boys and men, as well as those from Black and ethnic minority communities to ensure future research studies are relevant and acceptable to them as participants.
- With 1/3 of all referrals for suicidal children being made for children aged 12 years and younger, there is a need to better understand and address the needs of these younger children.

### **IMPACT & DISSEMINATION**

As has been mentioned previously two papers have already been published from the thesis (34,169), with a third submitted to a journal publication is anticipated later this year. A policy briefing paper was shared with the WHO and the Scottish Government (Appendix 3: Briefing Paper), and there were many newspaper reports and a radio interview following their publication.

Prior to COVID -19 and the implementation of lockdown restrictions I attended and presented my work at a variety of conferences, forums, and seminars.

- Key-note presentation & Poster: Involving young people to involve children who have been or are suicidal in research: an animation to support informed consent. A three-day conference: Children and Young People's Mental Health and Wellbeing: Communities, families, resilience and resistance, University of Stirling. Sep 2019
- **Presentation and workshop on Ethics and Informed Consent.** Faculty of Education Research Group, University of Dundee.
- Oral Presentation: A Meta-Ethnography: what the qualitative literature tells us about the views and experiences of suicidal children and young people of using mental health support services.
   4<sup>th</sup> Suicide and Self-Harm Early and Mid-Career Researchers' Forum (EMCRF19) June 2019
- ORAL PRESENTION: Is there anybody out there?

Health Behaviour Change Conference, University of Stirling, June 2019

- Pecha kucha Presentation: Data Management Festival of research, University of Stirling, May 2019
- POSTER: Involving young people to involve children who have been or are suicidal in research: an animation to support informed consent. SGSS Collaboration Showcase Event, V&A Dundee, May 2019

Many of the conferences I had planned to attend over the last year were cancelled, however, looking forward I hope to be able to access opportunities to disseminate my work via online forums and conferences.

I have been fortunate enough to have received two awards for work involved with this PhD: Highly commended early career researcher, **University of Stirling Research Culture Award** 2020; Runner up – **Research Impact and Knowledge Exchange Award** 2019, Scottish Graduate School of Social Sciences.

However, perhaps the some of the most meaningful impact so far, could be within the children who created the animation to support the informed consent process, and then presented their work at the Children and Young People's Mental Health and Wellbeing: Communities, families, resilience and resistance, conference. They reported an increase in their confidence and self-esteem that they related to their involvement in the project. Both children who presented at the conference have also gone on to pursue studies and a career in media and film and related that being involved in making the animation for a real-world research study helped them to decide upon this career path.

# Conclusion

This thesis aimed to evidence what happens to children after they are referred to CAMHS for suicidality in Scotland. I aspired to change policy and practice through research, by showing the reality of their care journey.

This thesis was the first study to quantify numbers of children referred for suicidality in Scotland and capture their experiences and journeys of care thereafter. It found that one quarter of all referrals to CAMHS in two different sites in Scotland were for children presenting with suicidality. It showed that many of these children are not being seen by CAMHS, and that those who are, are seen and not heard. Their referrals are being processed but CAMHS do not meet the needs of these children. As is commonly known but all too often overlooked, it found that it was the relationship between the worker and the child that mattered most, above their professional background and any intervention models. Children, parents, and practitioners all agree that a person-centred approach is most helpful to these children, and yet the current system does not support staff to be able to deliver this.

Not only does this thesis provide insight that can inform policy and the development of services, but it contributes to the sociological literature in this field. Recognising the importance and role of discourse in relation to childhood suicidality. If practitioners hear 'apples' when children are talking about 'pears' - 'distress' instead of 'suicide' – there is a danger that children will stop talking about and seeking help for suicidality as they are not being heard.

Many recommendations for policy makers, service providers, practitioners, and researchers have been made throughout the thesis, and within the 'Implications and recommendations' section above. However, perhaps the most important next steps are to work with children and practitioners to develop a new service model that can provide the treatment and care they believe would be most beneficial. An application to the National Institute for Health Research is underway, and I have plans to share the findings of this thesis with the Scottish Government.

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# Appendix

# APPENDIX 1: COPY OF PUBLISHED POLICY SCOPING REVIEW

Objective To map key policy documents worldwide and

establish how they address the treatment and care needs

Design We conducted a scoping review to systematically

PsycINFO; The Cochrane Database of Systematic reviews)

and the websites of key government, statutory and non-

Scholar were used to identify other policy documents and

relevant grey literature. Leading experts were consulted

Eligibility ortheria for selected studies Policies, policy

guidance, strategies, codes of conduct, national service

frameworks, national practice guidance, white and green

papers, and reviews of policy-concerned with indicated suicide prevention approaches for children up to 18years old. Limited by English language and published after 2000. Data extraction and synthesis Data were extracted

categorised as international guidance, national policy and

national guidance, and presented in a table providing a

brief description of the policy, alongside how it specifically

addresses suicidal CYP. Findings were further expressed

Results 35 policy documents were included in the review.

priority population, most do not explicitly address suicidal

CYP. In general, national guidance documents were found

to convey that suicidal children should be assessed by a

child and adolescent mental health practitioner but offer

Conclusion The lack of specific reference within policy

who are suicidal highlights a potential gap in policy

that could lead to the needs of suicidal children being

documents to the treatment and care of needs of children

no clear recommendations beyond this.

Although many recognise CYP as being a high-risk or

using a predetermined template. Second reviewers

independently extracted 25%. Documents were

using narrative synthesis.

statutory agencies were searched. Google and Google

identify relevant key policy documents following a pre-

Data sources Four databases (CINAHL; Medline;

established published protocol.

of children and young people (CYP) who are suicidal.

# Original research Open access BMJ Open Policy addressing suicidality in children and young people: an international scoping review

Lynne Gilmour 🧿 , Margaret Maxwell, Edward Duncan 🕚

To other Gimour L. Maxwell M. Dunean E. Policy addressing suicidality in childron and young people: an international scoing raview. BMJ Open 2019;5:x030699.doi:10.1136/ bmjopen-2019-030699

ABSTRACT

by email.

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# Strengths and limitations of this study

- This is the first scoping review to investigate how policy addresses suicidality in children and young people and provides new knowledge.
- The review authors employed a rigorous and meth-odological approach to the identification, screening and inclusion of policy documents, and following a clearly defined protocol
- There is a lack of clear guidance in relation to how to conduct a systematic review of policy documents, which added complexity to the review process and reporting.
- The lack of specific reference to suicidal children within policy documents made it difficult to identity relevant documents, and there may be some we were unable to identify for inclusion.

which member states agreed to work towards reducing suicide rates by 10% by 2020 Globally, suicide prevention strategies have been established in 28 countries to date.

International and government policies establish the context for the direction of resources for the development and delivery of services. Health policy provides a future vision (internationally, nationally or regionally), sets priorities and can include an action plan to achieve specific health-related objecuves.5 Public policies reflect international or national commitment and ambidons to address specific issues, but can vary in whether, and how they translate or relate to practice and whether there is a mandate for action.

Suicide is a leading cause of death of children and young people (CYP) worldwide, second only to accidental death.4 It is esdmated that as many as one in three children In some countries have considered suicide in the past year.5 Although globally low/ middle-income countries are often identifled as having the highest rates of suicide overall, more economically developed countries report some of the highest rates of BMJ Open: first published as 10.1133/bmjopen-2019-030699 on 28 O dober 2019 .Downloaded from http://bmjopen ï 8 8 Ì ő ã g 18em0 Protected ģ m Burldoo

overlooked, and varying interpretations of appropriate responses and service provision.

RACKGROUND

Suicide is a global health policy priority,

with nearly 800000 lives lost to suicide

annually. Suicide is arguably preventable.

Reducing suicide rates is a target of WHO

Menual Health Action Plan 2015-20201 in

suicide among <sup>67</sup>CYP and in some it is the main cause oF death 📍

It is widely acknowledged that CYP have different needs to adults. A retrospective review of suicides among CYP found that there were even differences between the presenting issues for children under 15 years compared with adolescents (age ranges of adolescents was unspecifled by the authors).

Many countries commonly address the health needs of CVP separately to adults, with discrete policy and service provision, although definitions of what age range constiuues being a child, adolescent or young person varies gready.10 However, with most suicide prevention and mental health strategies now taking a universal approach, there is the potential for the specific needs of CYP to become lost.

Fortune and Clarkson<sup>11</sup> highlight the gulf that can often exist between suicide prevention policy and practice. They argue that although policy documents in New Zealand state that everyone who is suicidal should be assessed by a trained mental health professional, services are not adequately resourced to meet the demand. This is not unique to New Zealand, or to suicide prevention policy. The overall political context and policy agenda needs to be analysed in greater depth in order to make sense of the meaning conveyed within policy documents and auributed to them.12

Linle is known about how policy addresses suicidality in CYP. Preliminary searches of review databases (Cochrane, DARE, [BI and the Campbell Collection) found that there had not been a review of worldwide policy in relation to CYP who are suicidal. Reviews to date have focused on the effectiveness of prevention and intervention strategies.<sup>10 14</sup> Although generating valuable knowledge on the evidence base for interventions, they do not consider the policies behind such strategies and how this shape their focus and direction.

Mapping key policy documents worldwide and idendifying how they address the treatment and care needs of suicidal CYP will: highlight the best practice for how policy can influence the resourcing of services; change practice and identify any gaps in policy provision for this vulnerable population. This knowledge will support countries who wish to develop new policies or further develop existing policies that address suicidality in CYP. The review question, objectives, search strategy and inclusion criteria were specified in advance and documented in a published protocol.15

#### Objective

To map key policy documents worldwide and establish how they address the treatment and care needs of CYP who are suicidal.

#### Inclusion oriteria

## Population

The key characteristics of the population were age and suicidality, neither of which have agreed universal definitions. As mentioned in the introduction, the authors recognise the disparity between the needs of children and young adults. Youth suicide research publications often tend to focus on older adolescents and young adults. While appreciating the complex challenges, including transition from child to adult services faced by 16-25years old, this review informs a larger study, concerned specifically with a Scoutsh school-aged population. On this basis it was agreed to adopt a definition of a child as anyone under the age of 18 years, in line with: The Children (Scotland) Act 1995.10 and the United Nations Convention of the Rights of the Child, 1998. Policies solely about populations aged over 18 years were excluded, however, policies that cover the lifespan were included.

Suicidal behaviour is defined as acts of self-harm that result in death, as well as those with a non-fatal outcome. Non-suicidal self-injury is a term used to describe selfharming behaviour where there is no intent to die. This is most commonly used in the USA and became a discrete diagnostic category in the DSM V (Diagnostic and Statistacal Manual-5).18 However, in the UK and some other European countries, definitions of self-harm are now also often used to include all non-fatal self-harming behaviours regardless of intent, and can include behaviour that may also be described as accompand suicide.19 As this review is concerned with identifying relevant policies for children who are suicidal (had accempted to end their own life or were thinking about suicide), it was agreed not to use the term self-harm as a search term.

#### Concept

Suicide prevention activities can be divided into three domains: universal activities which are aimed at everybody, including public health education programmes; selected or targeted interventions that aim to reduce the risk among specific high-risk groups and indicated interventions that may include treatments and are aimed solely at individuals presenting with suicidal behaviour. This review is solely concerned with identifying policy in relation to indicated activities, aimed at children (under 18 years of age) who are suicidal.

#### Context:

Identified policy documents were assessed for direct relevance to Scodand and the UK, or relevant to the context and population of the UK. Policies relating to indigenous populations, such as the Sami populations in Norway, Sweden and Finland, were consequently excluded<sup>33</sup> but generic policies in postindustrial nations with developed economies such as Australia and New Zealand were included.<sup>21,22</sup>

#### Types of sources

Suicide prevention, like much healthcare policy, does not sit within clearly defined and labelled singular policy documents. As well as national suicide prevention strategtes, there are more generic menual health surategies

Table 1 Search terms	
Concept	Keywords
Children and young people (5–18 years)	Child"; "young people"; youth; adolesc"; teen"; paediatric
Suicide	Suicide; suicidal;
Policy	Policy; Procedure; Guidance; Strategy
Limit search by:	English Language; Published after 2000.

or frameworks, and national guidelines such as those published by the National Institute for Health and Care Excellence (NICE) in the UK, which may contain specific references to indicated intervention approaches. Mapping policy requires a recognition of the variety of formais in which relevant documents may be found. Local government agencies and organisations also have their own individual policies and procedures, however, these should reflect the national approach. It was agreed that for the purposes of this review, policy documents would include: policies, policy guidance, strategies, codes of conduct, national service frameworks, national practice guidance, and white and green papers.28 Reviews of policy documents centred on children who are suicidal were also eligible for inclusion as they contribute to the development of what is known in this area.

Given that the review almed to map the present policy context, and most strategies are updated within a 10-year period, it was agreed to exclude any policy document or review published prior to 2000. Only those available as English Language versions were included.

# Search strategy

Keywords to be used as search terms (table 1) were generated from the review question.<sup>15</sup> Preliminary searches assisted in the refinement of these terms, and the identification of the most appropriate databases, platforms and websites. These terms were then amended for each of the databases and the exact terms, including any MeSH terms and subject headings used recorded (online supplementary file 1).

Four databases (CINAHL; Medline; PsycINFO; The Cochrane Database of Systematic reviews) and the websites of the following key government, statutory and non-statutory agencies were searched, focusing on postindustrial nations with developed economies in order to identify those with most applicability to the UK, for example, WHO; UNICEF, UK Government; Scotdish Government; ScotPHO; UK NICE; National Office of Suicide Prevention (Ireland); Ministry of Health NZ; Australian Government Website and the Mental Health Commission Canada. Google and Google Scholar were also used to identify other policy documents and any relevant grey literature. Leading expens in the field were consulted via email. All results were screened by title and abstract or executive summary by LG, with MM and ED screening a sample of 20%. Policy documents and articles were all screened in full by LG, and another sample of 20% was independently screened by MM and ED for inclusion. Disagreements were resolved by discussion, with the third reviewer acting as mediator.

### Method of the report

This review employed scoping review methodology to systematically identify relevant key policy documents following a pre-established search strategy and published protocol.<sup>10</sup> Scoping review methodology and guidance first outlined by Arksey & O'Malley24 and further developed by Levac,28 and the Joanna Briggs Institute28 were used to inform the methodological process. The scoping review method was chosen as it allows for the synthesis of different opes of sudy design. Thus, lending liself to the incorporation of different policy document formats (policies, policy guidance, strategies, codes of conduct, national service frameworks, national practice guidance, and white and green papers)<sup>28</sup> as well as any relevant existing published policy reviews. Suicidology of CYP is a newly emerging, highly sensitive and complex area of research, therefore well suited to scoping review methods.24 The review is reported in line with the new Preferred Reporting Items for Systematic Reviews and Meiz-Analyses (PRISMA) extension for Scoping Reviews.<sup>27</sup> Patients and the public were not consulted as part of this scoping review as it was not appropriate or applicable.

There were 45 records retrieved from PsycINFO, 195 from CINAHL, 12 from Medline and 49 from the Cochrane database of systematic reviews. After removing duplicates, there was a total of 297 records to be screened by title and abstract. Separate Excel spreadsheets were set up to catalogue the lists of references from each of the databases. After screening these results by title and abstract (completed in full by LG with a second reviewer independently screening for validity), all eight records to be screened in full text were found on CINAHL, although two were also found in duplicate on PsycINFO. Reasons for rejection of records included wrong topic, not in English and published before 2000.

After screening the eight articles identified by searching the databases (cross validated by a second reviewer), only two met the inclusion criteria.<sup>28,29</sup> Five were rejected as they were not policy documents about CYP who were suicidal, and although one seemed relevant in its references to the New Zealand suicide prevention strategy,<sup>11</sup> it was neither a policy document, nor a review of policy.

Internet searching was an iterative process, using keywords to search worldwide government, statutory and non-statutory agencies websites, with 39 potentially relevant policy documents identified. Although it is common practice in systematic reviews to screen the references of included documents for other potentially relevant papers, this occurred intuitively throughout the identification of policy documents, with one referencing others

within a country. Policy documents were only included for screening if by their title and description they seemed potentially relevant.

WHO Mindbank database houses links to member states National Suicide Prevention Strategies, however, many were unavailable in English. WHO menual health policy and services representative was contacted to request contact details of policy authors or country-specific contacts to enquire about English language versions. From these enquiries, an English language brochure oudining the content of the Swedish Suicide Prevention Strategy (known to be innovative for its zero suicide target) was obtained but we were unable to access the full document.<sup>30</sup> Although it was recognised that not every worldwide policy relating to CYP who were suicidal could be sourced, it was important to try and include all Scouish and UK-wide relevant policies. A request to the Scouish Government asking them to detail policies that should be included in the review, identified one further policy that had not been considered,<sup>51</sup> and this together with a related practice guide<sup>52</sup> were included for screening.

Screening of the 42 full-text documents was completed in full by the first reviewer (LG), with second reviewers each reviewing five independently (ED and MM), meaning a total of 25% was cross-validated. A meeting was then held to discuss the policy screening process, and to agree decisions about inclusion and exclusion. A total of 52 policy documents met the inclusion criteria. Reasons for exclusion were: document did not relate to or mention child suicidality, were not transferable to the UK or Scoutsh setting, was a review of systematic reviews; a newer version of the document is now available (online supplementary file 2). Together with the three published miscellaneous reviews/reports,<sup>35–86</sup> there were a total of 55 documents identified to be included—shown in the PRISMA diagram below<sup>50</sup> below (figure 1).

#### Patient and public involvement

No public were involved in this review.

#### RESULTS

The 55 included policy documents, ranged from: international guidance provided by the United Nations and WHO<sup>457-95</sup>; national suicide prevention strategies<sup>12,250,40–47</sup>; mental health strategies<sup>45-56</sup> and frameworks<sup>54-54</sup>; to national practice guidelines detailing how CYP who are suicidal should be assessed and treated.<sup>10,29,59-42</sup> The organisation and classification of these documents are illustrated in figure 2; providing language with which to describe the policy landscape.

Data extraction was completed by LG using a predefined template (online supplementary file 5) to collate key information about each of the documents including its aims and objectives, and how it related to the review question. A second reviewer independently extracted data for a sample of 25%. All three reviewers then met to discuss the process and outcomes. There was some variation in а

the verbatim content extracted. This was regarded as a reflection of—(1) the size of the policy documents, and (2) because there were so few direct references to suicidal children, other content that could be interpreted as applicable but did not specifically mention suicide was also extracted from some to give context. The data extracted from each of the included policy documents were then tabulated (online supplementary file 4), categorised first, by policy type, and then alphabetically by the country.

#### International guidance

The UN 2090 Agenda for sustainable development<sup>30</sup> details the goals and action plan that all countries in the United Nations have agreed to deliver. Although it does not specifically mention suicidal CVP, reducing mortality by non-communicable illness (Coal 3.4) means that reducing suicide, which as a leading cause of death, must be a priority.

WHO mental health action plan 2019–2020<sup>1</sup> set a target that all countries should work towards reducing suicide rates by 10% by 2020. It recommended that countries adopt a life-course approach to mental health, reflecting an understanding of the impact of key stages in people's lives on health outcomes across their life span.<sup>60,104</sup> It promotes that countries create national policies and strategies to tackle suicide prevention prioritising at risk groups including 'youth'. However, other than the identification of 'youth' as a priority group it does not provide any other guidance on how countries should address suicidal CMP specifically.

Two other included documents published by WHO,<sup>4,20</sup> although also identifying suicidal CVP as a priority group, similarly do not go beyond this in terms of how their needs should be addressed. WHO Mental Health Gap Action Programme intervention guide provides generic guidance relating to interventions for all persons aged 10 years and over who are suicidal, suggests suicide should be included within an assessment, and advises that if young people feel suicidal they should talk to someone they trust and return to mental health support services.<sup>30</sup> No rationale is provided as to why 10 years of age has been selected. It does not differentiate between the assessment and treatment approach for suicidal children and adults. Clarification on this point was sought from WHO, but no response was received.

## National policy

WHO recommends that countries should develop suicide prevention and mental health strategies.<sup>4, 28</sup> Ten suicide prevention strategies were included in this review,<sup>22, 50,40-47</sup> five national mental health strategies and a young person's friendly version of the Canadian mental health policy.<sup>46-43</sup> As recommended by WHO,<sup>38</sup> the suicide prevention strategies adopt a universal and lifecourse approach. They generally provide demographic background information on suicides within their country and establish why it is a priority area. The policy documents describe their government's approach to tackling BMJ Open: first published as 10.1138/brijopen-2019-030699 on 28 October 2019. Downloaded from http://brijopen.brij.com/ on April 19, 2021 by guest. Protected by copyright

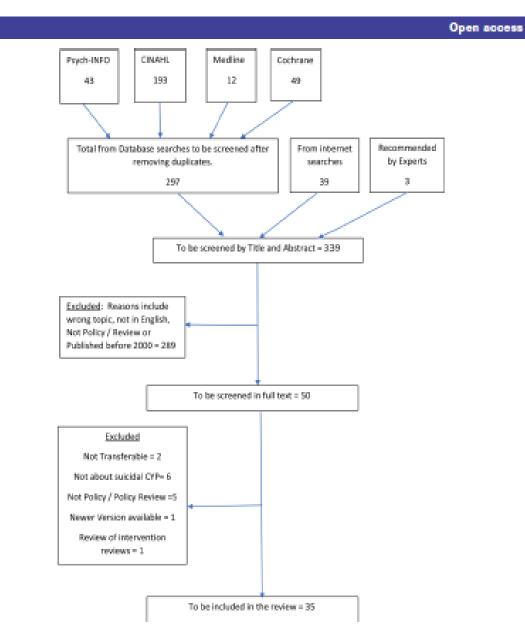


Figure 1 Search results – PRISMA diagram. CYP, children and young people; PRISMA, Preferred Reporting items for Systematic Reviews and Meta-Analyses.

suicide by detailing lists of aims, objectives and recommendations. Most strategies recognise that CYP are a priority group for universal and targeted suicide prevention activities (eg, universal whole school-based suicide prevention programmes and generic school counselling services), however, they do not differentiate between the indicated assessment and treatment offered to adults and that available to children who are suicidal. Some strategies made no reference to suicidal CYP,<sup>12,40,40</sup> including the Scoutsh Suicide Prevention Strategy 2015–2016. Few mentions of therapeutic interventions specifically for CYP who are suicidal are made in the strategies.

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The Irish surategy includes statements recommending that there should be early intervention, and 'enhanced support' available.<sup>40</sup> The New Zealand draft consultation document<sup>44</sup> contains suggestions that training teachers to talk to children who are suicidal, and having direct links between schools and psychologists will improve access to support for CMP who are suicidal. Notably New Zealand previously had a suicide prevention strategy directed specifically at 'youth' suicide,<sup>55</sup> but they have since adopted a universal policy covering the life course.<sup>36</sup> Similarly, other countries such as the USA previously had a strategy document that contained detailed objectives

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Figure 2 Policy categories.

directly related to CYP (youth)<sup>60</sup> and has moved towards a much more generic approach.<sup>40</sup>

National mental health strategies were also found to take a life-course approach and were concerned with mental health promotion, supporting positive mental health and well-being and service delivery for those who experience mental ill health. The 10 national mental health strategies included in the review incorporate references to discrete service provision for GYP. Beyond, generic school-based approaches to promoting positive mental health and well-being, there was also a focus on early intervention and easier access to child and adolescent mental health services.

Although most strategies refer to suicide as being a priority area in mental health provision; the Irish national mental health strategy<sup>51</sup> is the only one that specifically mentions suicidal CAP. Within a section dedicated to child and adolescent mental health under a heading "Suicide and Deliberate Self-Harm",<sup>51</sup> it has recommendations that all children who present with self-harm should be assessed by the child and adolescent mental health team, and if appropriate receive treatment. It contains statements recognising adolescence as being a period of increased risk of suicide, and notably conveys that service provision should be the same across the whole country.

The Canadian Mental Health Strategy: A Youth Perspective<sup>®</sup> was produced to allow the document to be more accessible and relevant to young people. Although it does not provide specific recommendations in relation to the treatment and care of children who are suicidal, it urges that mental health services should be more accessible to all and highlights the Thunder Bay Youth Suicide Prevention Task Force as an example. This task force comprised 90 organisations working collectively to provide an immediate response.

The UK government policy 'No Health without mental health<sup>80</sup> highlights the high incidence of self-harm among young people providing as an example that '10%--15% of 15-16 years old have self-harmed in their lifetime'. It includes a suggestion that all workers who are in contact, with CVP should be aware of the issues surrounding this, and sets reducing the numbers of people of all ages who harm themselves as a target. However, the document does not contain a definition of self-harm in the glossary and it is unclear if this suggestion includes those who attempt suicide. The policy contains no specific references to CVP who are suicidal.

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The Scouish Government Mental Health Strategy 2017– 2027<sup>52</sup> has a dedicated section to addressing the mental health needs of CYP. However, there is no reference to CYP who are suicidal. In relation to suicide, the strategy includes a statement that suicide prevention remains a government priority that will be dealt with separately (the Scouish Government's Suicide Prevention National Action Plan, <sup>60</sup> which was published following conclusion of the scoping review search—see the Discussion section). Child and adolescent mental health services are deliv-

ered separately from adult services in many countries; consequently, there are distinct policies articulating a country's vision and aims for CYP's mental health. There are five such policy documents<sup>54 20-58 68</sup> included in this review, entitled as frameworks. The term 'frameworks' suggest they provide guidance for local authorities and those commissioning and delivering services; in the UK, It also denotes that they define standards of care. These frameworks include an outline of goals to prioritise and promote the mental health and well-being of CYP, and to deliver accessible services. None, however, specifically address CYP who are suicidal. Although containing recommendations for improving access to services and crisis support which could be applicable to CVP who are thinking about or have attempted suicide, this is not explicitly mentioned.

### National guidance

Another category of documents included in the review was national clinical guidance. These documents contain evidence-based recommendations for good practice. Although it is not compulsory to follow guidelines, organisations and clinicians must be aware of them and potendally justify their decision making should they choose to not implement them. Included clinical guidelines were: the UK NICE Guidelines for Self-Harm in over 8s: short term management and prevention of recurrence,19 Self-Harm in over 8s long-term management and prevention of recurrence,54 the New Zealand document: The Assessment and Management of People at Risk of Suicide,<sup>30</sup> the United States Preventative Task Force recommendations' and the American Academy of Paediatrics Guidance.12 The Irish National Standard Operating Procedure for Child and Adolescent Mental Health Service (CAMHS)<sup>5</sup> was also included in this category, because it was a national document and specifically addressed the treatment and care needs of suicidal CAP. However, it was different to the other documents in this category because its implementation is compulsory.

The UK NICE guidelines for Self-Harm in over 8x shortterm management and prevention of recurrence,<sup>19</sup> apply to everyone over 8 years of age who presents following an incidence of self-harm, defining this as any act of selfharm regardless of intent. Therefore, these guidelines are applicable to anyone over 8 years who has attempted

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suicide; although, it does not differentiate between the behaviours (with or without suicidal intent) in relation to treatment. They cover the immediate period following a presentation of self-harm (48 hours). The guidelines contain recommendations that all CVP who have selfharmed are admitted to hospital overnight in a paediautic ward (including adolescents aged over 14 years of age, if this is their preference) and they should be assessed by a specialist in child and adolescent mental health. This assessment should be the same as that for adults but also include a holistic assessment of their family situation, education. The only direct mention of suicide is that it is listed as a factor to be assessed. In the document that follows from NICE. Self-Harm in over 8s long-term management and prevention of recurrence,<sup>51</sup> the same definition of self-harm (to include self-harming behaviours with suicidal intent) is provided, and although suicidal intent is mendoned in relation to assessing risk, it also warns against using risk assessment tools to assess suicide risk. This reflects the lack of evidence for their effectiveness.2071 In the final recommendations section under 'Access to Services',51 it states CYP who self-harm should be able to access all therapies and treatments available from Child and Adolescent Mental Health Services.

The New Zealand guidelines<sup>50</sup> are explicitly in relation to managing (all) people at risk of suicide. This document includes statements that all persons who are suicidal should be taken seriously and has a section dedicated to the treatment of children and adolescents. It includes recommendations that risk assessment of suicidal GYP should be conducted by someone trained in working with them, and that they should draw on information from the people around the child such as family and teachers as well as the child or young person themselves. In the background, information provided in the document it is stated that New Zealand has one of the highest rates of suicide among young people.

The USA document 'Screening for Suicide Risk in Adolescents, Adults and Older Adults in Primary Care: US Preventive Services Task Force Recommendation Statement<sup>29</sup> includes a statement reflecting that there is no evidence to support any particular treatment or intervention for adolescents at risk of suicide, and not enough evidence to support assessment tools. The American Academy of Paediatrics, however, publishes very specific guidance for the treatment of adolescents presenting to primary healthcare following a suicide attempt or presenting with suicidal ideation.<sup>28</sup>

The National Operating Procedure for CAMHS in Ireland<sup>60</sup> was unique in that it specifically included standards of expected care and treatment for CMP who are suicidal across Ireland. It contained a statement that CAMHS would accept referrals for CMP where there are suicidal behaviours and intent. Similarly, to what was found within the other frameworks for child and adolescent mental health that were included in the review, this document<sup>60</sup> also included general statements about service provision that could be applied to CMP who are suicidal, for example, references to CYP who need an immediate response, however, the term suicidal is not specifically used.

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Beyond the policy documents included (international policies, national policies and national frameworks), there were very few other reports or reviews that were identified as relevant to the review question. Responding to Self-Harm in Scotland<sup>14</sup> is the report from the national self-harm working group and recognises that most people who self-harm do not intend to die. It includes a statement that young people are more likely to self-harm. One of its key recommendations is that there are clear referral pathways developed for people who self-harm, but it does not suggest what this might be, and is not specific to, or does not differentiate, between child and adult populations. A report commissioned in New Zealand to review the evidence on improving the outcomes for adolescents transitioning to adult services has a chapter dedicated to youth suicide,28 which aims to provide an overview of the issue and prevention strategies. This chapter includes a description of how its national suicide prevention strategy and each of its goals applies to young people. The author concludes that the actions from the strategy can be applied to young people, although they are not specific to this population.

# DISCUSSION

This scoping review sought to answer the question: how does policy address the treatment and care needs of GYP who were suicidal? A total of 55 policy documents and Z reports were included. However, overall, they offer little in relation to specific policy guidance for addressing suicidality in CYP. Suicide prevention strategies recognize that CYP are a priority population. However, the focus of these strategies is primarily on universal prevention approaches for CYP, such as whole school-based menual health and well-being education programmes or generic counselling services. Both national mental health strategies across the lifespan, and national frameworks for CYP's mental health, provide a blueprint for delivering services that are accessible to CYP who need them, when they need them. However, they do not specifically mention the population of children who are suicidal clearly enough to establish explicitly the care and treatment that they should be provided with. They also do not guarantee that the strategies or frameworks are delivered.

The national guidelines included within this review contain suggestions that CMP, who are self-harming or are suicidal, should be assessed by a child and adolescent mental health practitioner, and referred to CAMHS for treatment and therapeutic interventions. However, the included national frameworks for child and adolescent mental health barely reference CMP who are suicidal.

Recent research has found that even when there are national dinical guidelines recommending pracdice in relation to suicide intervention and treatment, clinical staff teams are not always aware of these and

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Implementation varies.<sup>72</sup> This strengthens the case for countries adopting a model, like that in Ireland, where implementing the Child and Adolescent Mental Health Services SOP<sup>20</sup> is compulsory, and goes beyond guidelines for recommended practice.

One of the reasons for the identified paucity of policy direction in providing interventions and treatments for CAP who are suicidal is perhaps the lack of evidence for the effectiveness of any particular treatment approach.<sup>7374</sup>

It could also be argued that the function of policy is not to address the treatment and care needs of specific populations, but provide a future vision and action plan to achieve this, which can be interpreted and disseminated within a local context. However, the lack of dialogue around CYP who are suicidal within the documents reviewed highlights a gap in policy provision for this population. The review of the New Zealand Suicide Prevention Strategy\* demonstrated that the generic goals set out in the strategy could be applicable to young people; however, this was not obviously apparent from the document liself. This may be true for other national suicide prevention strategies and national mental health strategies. However, by not being explicit about their relevance to CYP who are suicidal, it could mean that the needs of this population are overlooked by the local government agencies charged with interpreting, implementing and resourcing them. It may also lead to large variations in terms of service design and delivery across different local authorities.

## LIMITATIONS

This is the first scoping review to consider how policy addresses the needs of CYP who are suicidal, and provides unique insight into this policy domain. However, the lack of methodological guidance for conducting policy reviews made this challenging. While we recognise some of this study's limitations, we have tried to be explicit in our methodology and conduct the review with rigour. Additionally, the lack of any previous description of the suicidality policy landscape for CYP, made identifying and sourcing relevant documents complex. The systematic searching of primarily journal-based databases returned very few relevant documents. Searching government websites for terms such as: 'child', and 'young people', and 'suicide', was also problematic because many of the key documents include little direct references to CYP who are suicidal. The search for policy documents was more inulitive than anticipated, in part due to the paucity of research in this area. One of the key findings was that there is a gap in policy specifically addressing this population, but this gap also contributed to the difficulty in finding relevant policies to be included.

The identification of Ireland's standard operating procedure for GAMHS<sup>60</sup> suggests that there may be clear protocols for child and adolescent mental health services, and practitioners available in other countries. However, these documents tend to vary between organisations and local authorities/states and were excluded from this review because they were not national. Further exploration of these local policies, or purposive searching for other international GAMHS protocols should be considered within any future policy research in this area.

Although not a prerequisite in a scoping review, triangulating screening and data extraction helped to identify that there is little policy dialogue about indicated suicide prevention strategies for children. This lack of specific reference to the care needs and pathways for suicidal children meant that the documents were open to subjective interpretation. For example, although parts of policies could be interpreted as being applicable to this population of CMP, in auempting to extract verbadm the text that addressed them reviewers struggled to identify significant relevance.

As the review was limited to English language many of the suicide prevention policies had to be excluded, including those of the Nordic Nations who are known to have advanced mental health and suicide action plans, as they could not be translated. These countries may make their policies available in English in the future as they have with 'Plan for suicide prevention among the Sami people in Norway, Sweden and Finland<sup>20</sup>, and they could then be included in a future review.

The policy landscape is constantly changing and evolving. Two highly relevant documents were published following completion of the systematic literature search. The Scouish Government published an updated Suicide Prevention Strategy,20 which contains acknowledgements that 'CYP require a specific focus'. Recommendations within the policy document itself remain largely at a universal prevention level, for example, training teachers. The strategy clearly includes a recommendation that all children should have access to crisis support when they need it, and that it is the governments' intention to 'transform' child and adolescent mental health services, having appointed a CYP's mental health task force. However, it also contains a statement suggesting that suicide rates in children are falling, which is contrary to reports from other sources which suggest that they are increasing,70 and that rates in Scotland are higher than other parts of the UK." (Recent changes in coding of deaths in line with ICD-10" (International Classification of Diseases - 10) (deaths with undetermined intent are now being recorded as suicide) has had implications on recent suicide rates. Additionally, the Scouish Government does not publish annual suicide rates in populations of children aged under 15 years. They provide a statement that this statistic could be misleadingly high for children in this 'extreme' age group as a higher proportion of deaths are recorded as undetermined.3

Another key document published latterly was the UK-wide Self-harm and Suicide Competence Framework CPP.<sup>70</sup> This document is intended to outline the key competencies required of professionals working with CPP who self-harm or are suicidal. Identifying that the knowledge and skills of those who support children who

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self-harm or are suicidal requires different competencies to those who work with adults is undoubtedly a positive development. Within the document, it is emphasised that a person-centred approach should be taken towards CYP who have self-harmed or are suicidal, and they are treated with compassion and respect. It contains acknowledgement of the challenges in assessing suicide risk: scales and risk assessment tools have a low prediction value; and there remains a lack of evidence base for any effective interventions. However, it goes on to promote the use of dialectical behavioural therapy (DBT) and mentalisation behavioural therapy (MBT) as specific interventions for use by menual health professionals based on the identification of positive effect in single trials of DBT and MBT (79:27). This is then followed by a statement warning that the generalisability of these approaches is unknown.

Overall, the report conveys the complexity involved in understanding the needs of children who self-harm and are suicidal and is a welcome guide to practitioners and service providers, concerned with the supervision and training needs of their workforce. However, it remains within the realm of recommendations, its application is not compulsory, and it highlights the paucity of evidence to support effective treatment models for this vulnerable population.

## IMPLICATIONS FOR FUTURE RESEARCH

This review highlights the need for further research in several areas. It establishes a need for more robusily defined policy review methodology, as well as a deeper exploration of the potential gap in policy provision for suicidal CYP.

Although scoping review methodology lends itself well to policy review, ensuring that the search strategy and identification of policy documents is reliable is complicated by variation in document formats, and titles that do not describe the issue in focus. This presents similar issues to those found when trying to identify qualitative literature for the purposes of review synthesis, 1081 and learning from developments in the field of qualitative evidence review could support development of more robust policy review methodology.

Application of discourse analysis or interpretative policy analysis<sup>42</sup> may help to understand the meaning of the policy dialogue, as policy can in and of itself support the construction of or denial of social issues.10 Consideration of how the problem of childhood suicidality is represented in policy documents could provide valuable insight<sup>54</sup> into the politics of addressing this highly sensitive subject, and the needs of these children.

Additionally, widening the inclusion criteria in future reviews to include more local policies would provide further knowledge on how national policy is interpreted and applied at a local level. Exploring whether there are variations in interpretation locally, and if in fact the specific needs of suicidal CVP do get lost in translation is a knowledge gap that needs addressed.

Policy documents need to be written in such a way that they are careful not to exclude people and are therefore often very generic. Taking a lifespan approach to mental health policy and suicide prevention strategies supports the holistic understanding that mental health is not just about the absence of illness. Mental ill health, periods of distress and suicidality are all fluid concepts that can touch all our lives at different points. The aim of these strategies is for governments to explicate their commitment to addressing these issues, and to supporting people of all ages who are affected by them. However, this review suggests that by not specifically naming suicidal CYP as a group that should have immediate access to services or supports, and what this might look like, there lies a danger that generic policy statements are too open to interpretation. This could have implications for the local funding, commissioning and delivery of child and adolescent mental health services. Policy-makers should clarify their ambidons for how the treatment and care needs of suicidal CAP should be addressed in future policy documents

This review provides practitioners with an overview of the international and national policy context within which they work, informing their practice and providing key knowledge. It may support their understanding of practice guidelines in relation to CYP who are suicidal and equip them with a reference resource from which to draw on

## CONCLUSION

This scoping review mapped key policy documents worldwide and established how they addressed the treatment and care needs of CMP who are suicidal. Categorising these documents by International Policy, National Policy and National Guidance revealed that despite the assertion that CMP are a priority target population within policy documents, their content mainly promotes the use of universal prevention strategies and does not specifically address the treatment and care of CVP who are suicidal. This highlights a potential gap in policy that could lead to the needs of this very vulnerable group being overlooked, and varying interpretations of how they should be provided for. National guidelines (in the UK, and New Zealand)10 60 and Ireland's SOP for CAMHS50 contain recommendations that CVP who are considered to be at risk of suicide are assessed by a child and adolescent menual health practitioner, however, stop short of recommending treatments and interventions beyond this.

Twitter Lynne Gimour Winterpidstudent and Edward Duncan Weasduncan Contributors LG lod this roview and paper, ED and MM contributed to the development of the protocol. LG ran the searches and applied the selection criteria. MM and ED vortiled the selection of documents, independently screening all identified documents by title and abstract, and 50% in tull text. LG completed data antraction, with MM and ED independently extracting data from 25% of included documents. LG mapped the included documents and wrote the first draft of the paper. This was roviewed and commented on by MM and ED. All authors read and approved the final manuscript.

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# APPENDIX 2: TABLE MAPPING INCLUDED POLICY DOCUMENTS

Policy	Country	Author	Document Name	Year	Summary of	How does the policy	How does the policy
Classification	_				Document Purpose	relate to CYP who	address the treatment
						are suicidal?	and care needs of CYP
							who are suicidal?
International	Worldwide	United	Transforming our	2015	Sustainable	Goal 3.4: to reduce	It does not specifically
Guidance.		Nations	world: The 2030		development goals	premature mortality	mention children and
			Agenda for		and action plan	from non-	young people who are
			sustainable		that all countries	communicable	suicidal.
			development		who are members	diseases by one	
					of the united	third.	
					nations have		
					agreed to		
					implement. These		
					goals and actions		
					support working		
					towards a world		
					free from poverty,		
					hunger and		
					inequality, where		
					everyone has equal		
					human rights.		
	Worldwide	WHO	Mental Health	2013	An action plan to	It recognises young	It states that countries
			Action Plan 2013-		provide leadership	people as being a	should develop suicide
			20		and direction in the	priority group in	prevention strategies,
					prevention,	relation to suicide	that give particular
					treatment and care	prevention and	consideration to at risk
					of mental	intervention.	groups – and specifies
					disorders, It aims to		"youth".
					promote the		It speaks to children wi
					human rights of		mental disorders havin

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				persons suffering		access to psycho-social,
				mental ill health,		non-medicalised
				and mental well-		treatments, but does not
				being generally.		provide detail as to
						whether children who
						are suicidal are to be
						considered within this
						group.
Worldwide	WHO	Preventing Suicide	2014	Resource to	It identifies that	Provides a description of
		a Global Imperative		encourage member	suicide is major	generic treatment
				states to develop	health issue for	options that may be
				suicide prevention	young people.	considered helpful for all
				strategies.		persons across the
						lifespan who have
						attempted or are
						thinking about suicide.
						(These are taken from
						the WHO's mhGAP
						Intervention Guide
						(2010)) It notes in
						relation to assessment
						of individuals who
						present as suicidal that
						this should be
						conducted in all person
						aged 10 years and
						above, but does not
						state why this age was
						selected. Otherwise
						there is no specific
						direction regarding the
						care and treatment of

WorldwideWHOmhGAP Intervention Guide for mental, neurological and substance use disorders in non- specialized health settings V22016A model guide of effective and evidence based interventions to bi adapted for local context.It identifies children and adolescents as being a "special population". It does not differentiate between treatment and interventions for children and young people who are suicidal. I Under the heading "2.5 Psychoeducation for emotional problems/disorders including depression in adolescents" (WHO, 2016, pB3) it states that if dev P notices they should talk to someone they trust, and re-attend for mental health support. 2) Within a list a symptoms to assess for, when assessing for moderate to severe derestion in no- specialized healthA model guide of effective and evidence based interventions for children and young people and adults who are suicidal. It offers assessment and intervention guidance which are the same for every- or age. It does not state why age ten is used as a marker.Children and young adolescents" (WHO, 2016, pB3) it states that including depression in adolescents" (WHO, 2016, pB3) it states that including to suicide then they should talk to someone they trust, and re-attend for mental health support. 2) Within a list a symptoms to assess for, when assessing for moderate to severe depression in in							shildren and usung
WorldwideWHOmhGAP Intervention Guide for mental, neurological and substance use disorders in non- specialized health settings V22015A model guide of effective and evidence based adapted for local context.It identifies children and adolescents as being a "special population". It does not differentiate between treatment and interventions for suicide:There is a module dedicated to Child & Adolescent Mental & Behavioural Disorders. Within this module there are two mentions of suicide:1) Under the heading "2.5 Psychoeducation for emotional problems/disorders including depression in adolescents" (WHO, 2016, p 8B) it states that if the YP notices as a marker.1) Under the heading "2.5 Psychoeducation for emotional problems/disorders including depression in adolescents" (WHO, 2016, p 8B) it states that if the YP notices as a marker.							
Intervention Guide for mental, neurological and substance use disorders in non- specialized health settings V2							· ·
for mental, neurological and substance use disorders in non- specialized health settings V2	Worldwide	WHO		2016			
neurological and substance use disorders in non- specialized health settings V2							
substance use disorders in non- specialized health settings V2						being a "special	
disorders in non- specialized health settings V2					interventions to be	• •	
specialized health settings V2			substance use		adapted for local	not differentiate	Within this module there
settings V2 settings V2 children and young people and adults who are suicidal. It offers assessment and intervention guidance which are the same for every- one over ten years of age. It does not state why age ten is used as a marker. 1) Under the heading "2.5 Psychoeducation for emotional problems/disorders including depression in adolescents" (WHO, 2016, p 88) it states that if the VP notices thoughts of suicide then they should talk to someone they trust, and re-attend for mental health support. 2) Within a list a symptoms to assess for, when assessing for moderate to severe			disorders in non-		context.		are two mentions of
people and adults "2.5 Psychoeducation who are suicidal. It offers assessment and intervention guidance which are the same for every- one over ten years of age. It does not state why age ten is used as a marker. (WHO, 2016, p 88) it states that if the YP notices thoughts of suicide then they should talk to someone they trust, and re-attend for mental health support. 2) Within a list a symptoms to assess for, when assessing for moderate to severe			specialized health			and interventions for	
who are suicidal. It offers assessment and intervention guidance which are the same for every- one over ten years of age. It does not state why age ten is used as a marker.			settings V2			children and young	1) Under the heading
offers assessment and intervention guidance which are the same for every- one over ten years of age. It does not state why age ten is used as a marker.						people and adults	"2.5 Psychoeducation
and intervention guidance which are the same for every- one over ten years of age. It does not state why age ten is used as a marker.						who are suicidal. It	for emotional
guidance which are the same for every- one over ten years of age. It does not state why age ten is used as a marker.						offers assessment	problems/disorders
the same for every- one over ten years of age. It does not state why age ten is used as a marker. 2016, p 88) it states that if the YP notices thoughts of suicide then they should talk to someone they trust, and re-attend for mental health support. 2) Writina list a symptoms to assess for, when assessing for moderate to severe						and intervention	including depression in
one over ten years of age. It does not state why age ten is used as a marker.						guidance which are	adolescents" (WHO,
age. It does not state why age ten is used as a marker.						the same for every-	2016, p 88) it states that
why age ten is used as a marker. 2) Within a list a symptoms to assess for, when assessing for moderate to severe						one over ten years of	if the YP notices
as a marker. someone they trust, and re-attend for mental health support. 2) Within a list a symptoms to assess for, when assessing for moderate to severe						age. It does not state	thoughts of suicide then
re-attend for mental health support. 2) Within a list a symptoms to assess for, when assessing for moderate to severe						why age ten is used	they should talk to
health support. 2) Within a list a symptoms to assess for, when assessing for moderate to severe						as a marker.	someone they trust, and
2) Within a list a symptoms to assess for, when assessing for moderate to severe							re-attend for mental
symptoms to assess for, when assessing for moderate to severe							health support.
when assessing for moderate to severe							2) Within a list a
moderate to severe							symptoms to assess for,
							when assessing for
depression in							moderate to severe
							depression in
adolescents.							adolescents.
There is a module							There is a module
detailing the							detailing the
assessment.							
management and follow							,
up for people who might							

							be at high risk of self-
							harming and or suicide.
National	Australia	Department	Life: A Framework	2007	National suicide	This is an over-	Not specific to children
Suicide		of Health	for prevention of		prevention strategy	arching suicide	and young people who
Prevention		and Ageing –	Suicide in Australia		covering the life-	prevention strategy	are suicidal.
Strategies		Australian			span.	and it does not	
		Government.				mention CYP who	
						are suicidal	
						specifically.	
						References to young	
						people include	
						providing support for	
						children who are	
						survivors of	
						childhood abuse, and	
						taking a whole	
						school approach to	
						children's mental	
						health and wellbeing	
						(prevention).	
	England	Department	Preventing suicide	2012	Sets out the	Identifies CYP as a	Mostly refers to
		of Health	in England: A cross-		government's	priority group.	universal and targeted
			government		objectives and	Within a section	prevention approaches;
			outcomes strategy		action plan to	dedicated to CYP the	whole school
			to save lives		reduce suicide	policy gives	approaches etc. and
					rates.	demographic and	generic mental health
						background	provision. It details
						information about	government approaches
						higher at-risk groups	to tackling underlying
						of CYP; those who	issues such as bullying
						have or are being	and child abuse. It does
						bullied, children who	not directly address
							interventions and

Ireland	National Office for Suicide Prevention	Connecting For Life: Ireland's National Strategy to Reduce Suicide 2015-2020	2015	National strategy to prevent suicide. Sets out national vision and action plan.	are looked after and accommodated etc. This policy outlines an action plan for delivering universal, targeted and integrated services for individuals who are suicidal and specifies youth services as being a priority area.	treatments specifically for CYP who are actively suicidal other than stressing that early identification and assessment of at risk children vital. Specifically in relation to interventions for CYP who are suicidal the policy states that there should be "enhanced supports" and "enhanced availability". It recommends early intervention and psychological supports being provided and available to CYP who are at risk of suicide at both the primary care level, and secondary level including CAMHS.
Northern Ireland	Department of Health	Protect Life 2	2016	This document is an update on the previous national suicide prevention strategy and covers the period 2016- 2021. Its sets out five key aims: understanding suicidal behaviour	This strategy covers the lifespan, and includes CYP. It provides demographic information on CYP and suicide and self- harm in NI.	It notes that CYP are not a priority group for suicide prevention as the overall numbers of suicide amongst this population are low. It recognises however, that there has been an increase in the numbers of CYP who die by

				in NI better;		suicide and the high
				improve responses		numbers of CYP who
				to people who are		self-harm. In relation to
				suicidal; prevent		treatments and care of
				suicide; support		CYP who are suicidal the
				recovery; support		strategy states that if
				those bereaved by		those working with CYP
				suicide.		are able to better
						identify risk factors and
						there is easier access to
						CAMHS services this
						would support
						prevention. It also
						outlines the role of
						CHILDLINE in providing
						support and counselling
						to CYP, and Crisis
						Intervention and
						Support Teams to assess
						children who present at
						hospital. It does not
						provide clear direction in
						the treatment and care
						of CYP who are suicidal.
New Zealand	Associate	New Zealand	2006	National Strategy	This document	This document does not
	Minister of	Suicide Prevention		for suicide	replaces the New	specifically address the
	Health	Strategy		prevention.	Zealand Youth	care and treatment
					Suicide Prevention	needs of children and
					Strategy, and moves	young people who are
					to a generic life-span	suicidal. It provides a
					approach, although	review of the literature,
					acknowledges that	the context for suicide
					there may be priority	prevention, and sets

					groups. In a section headed "Issues relating to Age" p19, it states that young people remain a focus as they still have high rates of suicide amongst this population.	seven goals which are applicable across the life span. These goals include improved care for people who are suicidal. Within a section headed "context" it states that although moving to a universal approach, targeted interventions for youth will still be needed.
New Zealand	Associate Minister of Health	A Strategy to Prevent Suicide in New Zealand: A draft public consultation document.	2017	The draft framework for a new National Suicide Prevention Strategy that has three main elements. It outlines a vision (everyone will have a life worth living); a purpose (to reduce the suicide rate); to provide pathways (to increase protective factors and reduce risk).	Young People aged 15-24 are recognised as a target group.	One of the key objectives of the strategy is to recognize and support people in distress and to support people after a suicide attempt or self-harm. Of the prevention activities that are described that may be helpful that pertain specifically to CYP the focus is on improving support in the school setting: supporting teachers to respond to students who are distressed or following a suicide attempt; training

						teachers to talk to students who are distressed or been affected by suicidal behaviour; partnering psychologists and counsellors with schools to improve access to psychological support for CYP.
USA	U.S. Surgeon General and the National Action Alliance for Suicide Prevention	2012 National Strategy for Suicide Prevention: GOALS AND OBJECTIVES FOR ACTION	2012	National Suicide Prevention Strategy which aims to guide suicide prevention activity.	The policy document includes suicide prevention guidance for youth, but is generic in its approach.	The policy outlines demographic information that highlights that suicidal behaviours are more common amongst young people aged 15-24yrs than adult populations. Goal 1 – includes references to school based prevention programs, but not interventions. Goal 5 - refers to the need to develop interventions for all groups of people at risk, and that these should be sensitive to and designed around the different needs of these groups. This is not

Agency of SwedenPROGRAMME FOR Suicide preventionbrochure of the National Strategy, as the actual strategy is not available in English.has nine overall objectives, and states that their overall aim is that no-one should feel suicide is the only option they have. It recognizes young people as being a high risk group".the suicide rate amon the suicide rate amon the suicide rate amon despite a reduction in the overall suicide rate over the last 15/years.Agency of SwedenPROGRAMME FOR Suicide preventionbrochure of the National Strategy, as the actual strategy is not available in English.has nine overall objectives, and states that their overall aim is that no-one should feel suicide is the only option they have. It recognizes young people as being a high risk group".the suicide rate amon to everall suicide rate over the last 15/years.It does not differential between the treatme and care that should if given to CYP who are suicidal, although doe mention under the heading "Improve medical, psychologica and psychosocial initiatives" amongst a list of example initiati							specific to children and young people.
Sweden       Public Health Agency of Sweden       NATIONAL ACTION PROGRAMME FOR Suicide prevention       2008       This is taken form a brochure of the National Strategy, as the actual strategy is not available in English.       The national strategy has nine overall objectives, and states that their overall aim is that no-one should feel suicide is the only option they have. It recognizes young people as being a high risk group".       The brochure states t the suicide rate amon 15-24year olds has remain unchanged, despite a reduction in the overall suicide rat over the last 15years.	Scotland				previous national suicide prevention strategy (The first of which was 2003). A list of commitments and	out the government is committed to reducing suicide and sets out a target of improving responses	children and young
	Sweden	Agency of	PROGRAMME FOR	2008	brochure of the National Strategy, as the actual strategy is not	has nine overall objectives, and states that their overall aim is that no-one should feel suicide is the only option they have. It recognizes young people as being a	remain unchanged, despite a reduction in the overall suicide rate over the last 15years. It does not differentiate between the treatment and care that should be given to CYP who are suicidal, although does mention under the heading "Improve medical, psychological and psychosocial initiatives" amongst a list of example initiatives some with a particular
Government Suicide and Self to prevent suicide. the life span, but background informat	Wales			2015			1

Gilmour L, et al. BMJ Open 2019; 9:e030699. doi: 10.1136/bmjopen-2019-030699

			Harm Prevention		An update on a	identifies that certain	is provided. Strategy
			Strategy for Wales		previous policy.	groups of CYP are	focuses upon universal
			2015-2020			priority: Looked after	school based prevention
						children, Care	programmes and
						leavers, Children and	targeted prevention
						young people in the	activities such as school
						Youth Justice System	based counselling
						Bullied or victimised	services. In relation to
						children and young	CYP who are suicidal it
						people, Survivors of	states that services
						abuse or violence	should be accessible for
						including sexual	those in crisis.
						abuse and domestic	
						violence and children	
						and young people	
						with a background in	
						vulnerability.	
National	CANADA	Mental	Changing	2012	National Mental	This policy	Sets out objectives
Mental		Health	Directions		Health Strategy	recognises suicide as	which include improved
Health		Commission	Changing Lives: The		covering the	being an important	screening and
Strategies.			Mental Health		lifespan.	issue and addresses	assessment for suicide,
_			Strategy for			it directly. It also	and improved access to
			Canada.			recommends CYP are	services. These are
						a priority group.	generic
							recommendations for all
							age groups. In relation to
							children and young
							people specifically it
							states that governments
							should address
							inequality in accessing to
							services psychotherapies

Health Strateg Commission Canada	r Health Strategy Youth written from the	alth Strategy for	and counselling         situation is des         urgent, with far         who do not have         to financial reso         having to wait to         year for treatme         is not specific to         addresses mental         health generally, but         priority. Talks about         access to services         and specialist help         being available to         provision and specialist help         addresses         suicide Prevent         Force (30 organ         working collabo         to prevent suici         provide an immer      <
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	England	HMG/DH	No health without mental health A cross-government mental health outcomes strategy for people of all ages	2011	National Mental Health Strategy across the life span. Aims to address the disparity between how mental health and physical health are treated. Has six main objectives. Aims to mainstream mental health.	Adopts a lifespan approach but identifies CYP as a group with particular needs, and recommends age appropriate services and interventions.	It addresses race and cultural issues in relation to suicide risk for YP: increased risk for Inuit and Metis young people. It refers to organic culturally sensitive initiatives such as The Inuit Tapirit Kanantami National Youth Council, and community health resources that offer programs of support to children and young people at risk of suicide. Gives background demographic information on mental health issues including the numbers of children and young people who have self – harmed. States that all people who come into contact with CYP should be aware of the issues in relation to self-harm, as they do not always attend hospital. States that reducing suicide remains priority
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Ireland	Department of Health	A vision for change	2006	Provides a vision and model for mental health service provision.	This document addresses a wide range of mental health issues and service provision. Within this there is a chapter dedicated to the provision of mental health services for CYP (Ch. 10) and a section dedicated to Suicide Prevention within Ch. 15 on Special Categories. It does not identify CYP as being a priority group.	Reduced numbers of people of all ages harming themselves is set as a measure of success of the strategy. No specific references to CYP who are suicidal. Within Ch.10 it states that all children who present with deliberate self-harm should be assessed by the child and adolescent mental health team, and if appropriate receive treatment. Within this section it also recognises adolescence as being a period of increased risk of suicide.
Scotland	Scottish Government	Mental Health Strategy	2017 - 2020	National Mental Health Strategy covering the life span.	The documents provides a focus on prevention and early intervention for children and young people. It includes actions relating to	It does not specifically address the treatment and care needs of CYP who are suicidal. It states that Suicide and Self-Harm continue to be

	Wales	Welsh Government	Together for Mental Health	2016	Ten year National strategy for Mental Health. Aims to improve the mental health and well- being of people of all ages in Wales adopting a life span approach to policy.	support being available in schools, delivery of CAMHS services, and access to support and services when they are needed. The policy addresses generic mental health needs and provision of mental health support services for CVP. It highlights the need for targeted interventions for those most at risk, and early identification and prevention.	a priority area that will be addressed in a new suicide prevention strategy in 2018. It does not specifically address the treatment and care needs of CYP who are suicidal.
National Frameworks for Children & Adolescent Mental Health	CANADA	Mental Health Commission Canada	Evergreen: A Child and Youth Mental Health Framework for Canada	2010	Framework of values and strategic direction for the provision of mental health services for children and young people.	Policy concerned with promoting mental health and well-being amongst young people, and provision of mental health support services for CYP and families across Canada, but does not specify suicidality.	Does not mention the treatment and care of CYP who are suicidal. Lists recommendations about making services accessible (available in the evenings and weekends, accessible to YP directly, and child / youth centred), including creating "one- stop shops", however

EnglandDepartment of HealthNational Service Framework for Children, Young People and Services. It is the standard for thatemity Services. It is the standard for children and Psychological Wellbeing of Children and Young People, Department of Health and Psychological People, Department for Education and Skills (2004) -National Service 2004This is part of the national framework for standards for standards for child healthThis standard sets out a vision for all Specific to CPP weight and services. It is the standard for children and Psychological out of hours support.The standard is 1 specific to CPP weight and services when they directly refers to CYP who are suicidal out of hours support.EnglandDepartment of Health and Department for Education and Skills (2004) -2004This is part of the national framework for standards for services. It is the services when they directly refers to CYP who are suicidal once in relation to out of hours support.
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England Department Transforming 2017 Green paper Policy update to Recomm	
	he treatment and
	CYP experiencing
of Education Health Provision: A adolescent mental and or in "crisis" distress	or being in crisis
Green Paper health service being able to access could be	e applied to CYP
provision: the the right support who att	empted or are
appointment of when they need it actively	thinking about
mental health leads but does not directly suicide,	but it does not
in each school; refer to suicide. specifica	ally address
creation of support suicidal	CYP. Under a
teams to asses and section	entitled
act as a bridge "Improv	ing Crisis Care"
between school there is	reference to
and CAMHS pilot mo	odels of crisis
services; trial a support	underway, a
four-week waiting new gov	vernment funded
time for CAMHS scheme	called "Beyond
specialist services. Places o	of Safety" for
	of all ages who
are in cr	risis, and the
	sioning of the
develop	ment of generic
and cris	is mental health
pathwar	ys for CYP.
	ific references to
Government of Children and (Due to framework to be of children's mental CYP who	o are suicidal.
Young People: A be used as a guide for and health and well-	
Framework for updated) local authorities being and recognises	
Promotion, and commissioners the role that	
Prevention and of children's everyone in contact	
Care services to guide with CYP have in	
service design and supporting their	
delivery. mental health.	

	Wales	Welsh Government	Together for Children and Young People: Framework for Action.	2015	National Framework for child and adolescent mental health support services.	The framework provides multi agency guidance for the provision of children and young people's mental health and well- being.	It does not specifically address the treatment and care of children and young people who are suicidal. It does state that there should be a specialist CAMHS pathway, and this includes out of hours support for CYP in crisis.
Guidance Documents	Ireland	Health Service Executive & Child and Adolescent Mental Health Service.	Child and Adolescent Mental Health Services Standard Operating Procedure	2015	Provide clear direction for the delivery of CAMHS services across Ireland, to ensure consistent and transparent approach.	This document outlines the standard operating procedures for CAMHS services in Ireland, and the treatment and services that CYP and their families should expect. This includes CYP who are suicidal.	Generic statements about CAMHS services being accessible, and response times especially for situations where there may be a risk to the young person and an immediate response is required could be applicable to CYP where there is a risk of suicide but this is not clearly stated. The treatment of CYP who are suicidal is only specifically addressed in reference to the fact that CAMHS will accept referrals for CYP with "suicidal behaviours and ideation where intent is present" p15, and in terms of risk

						management listing risk of suicide amongst potential risk behaviours within an in-patient unit.
New Zealand	Ministry of Health & New Zealand Guidelines Group	The Assessment and Management of People at Risk of Suicide	2003	These National Guidelines are a resource and guide for clinical staff in emergency departments, and psychiatric services working with people in mental distress who are at high risk of suicide or have attempted suicide.	This document specifically states how all persons who are suicidal should be treated and has a small section referencing the treatment of children and adolescents within it.	These guidelines provide specific recommendations on how to respond to and treat anyone who is suicidal, including children and young people. It states that anyone talking about suicide should be taken seriously. In particular to CYP it states: "Self-harm among children is rare and should be treated very seriouslyThe assessment of suicidal young people should be carried out by a clinician who is skilled in interviewing and working with children and adolescents whenever possibleRisk assessments should draw on information from multiple sources, including the young

	UK	NICE	Self-harm in over 8s: short-term management and prevention of recurrence	2004	Clinical guidelines for the management of self-harm in people over 8yrs in the first 48hrs following the incident of self- harm. These guidelines apply to everyone regardless of whether there is an underlying mental health illness.	The definition of Self-Harm used includes all acts of self-harm regardless of suicidal intent. These guidelines therefore apply to CVP (8-16yrs) who have attempted suicide, although this is not specifically stated.	person, their teachers/guidance counsellors, parents etc." In the section on background information following the guidance it notes that New Zealand has one of the highest rates of suicide amongst young people. It recommends that CYP who have self-harmed are admitted overnight to a paediatric ward (potentially adolescent ward if preferred by those aged 14yrs+), and fully assessed before discharge. The guidelines state that they should be assessed by someone trained and with experience in assessing CYP who have self-harmed. It states that assessment should be the same as for adults but also include holistic assessment of family situation etc. The only direct reference to suicide is contained
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UK	NICE	Self-harm in over 8s: long term management and prevention of recurrence	2004	Guidelines for the long-term psychological treatment and management of self-harm. It aims to improve the quality of care that they receive, and	The definition of Self-Harm used includes all acts of self-harm regardless of suicidal intent. These guidelines therefore apply to CYP (8-16yrs) who have attempted	harmed should be trained, skilled in risk assessment, supervised regularly, and have access to senior support. Family are to be recommended to remove access to means of self-harm in the immediate aftermath of the incident. Under the heading "Risk Assessment" there are two references to suicide, which it states should be assessed in relation to risk (risk of self-harm & past and present suicidal intent). However it warns
						within the generic description of "Assessment"; it is included in a list of factors to be assessed. It goes on to specify that child and adolescent mental health practitioners assessing CYP who have self-

		Under the heading
		"Access to Services" it
		states that children and
		young people who self-
		harm should be able to
		access psychological
		therapies and
		treatments from child
		and adolescent mental
		health services."
		CAMHS workers who are
		working with CYP who
		self-harm should
		consider safeguarding
		procedures, and where
		children are referred to
		CAMHS under
		safeguarding procedures
		then there should be a
		multi-agency approach
		and consideration of
		common sense
		framework.
		Under the heading
		"Primary Care" it
		recommends that
		consideration be given
		to referring CYP who
		present with self-harm
		to CAMHS for specialist
		help. Factors to consider

USA	Chun et al, American Academy of Paediatrics	Evaluation and Management of Children and Adolescents With Acute Mental Health or Behavioral Problems. Part I: Common Clinical Challenges of Patients With Mental Health and/or Behavioral Emergencies	2016	To provide clinical guidance to staff in the USA primarily working in A & E departments, but for all clinicians who work with children with emotional and behavioural problems on dealing with paediatric mental health emergencies. It is not intended to be used as a standard of care and is a recommended practice as opposed to enforced.	This document has a section dedicated to dealing with children who present to the Emergency Department in hospital following a suicide attempt.	are the parent or carers' distress / anxiety. This document provides very specific recommendations on the assessment and care of children where there has been a suicide attempt. This includes medical assessment as well as suggestions for psychological assessment. It states that although there is no recognised effective risk assessment tool for suicide, it lists criteria such as not engaging in safety planning and remaining intent upon dying that if present suggest the child should be admitted to hospital for their own safety. It suggests that otherwise the child might be referred for outpatient treatment and that if this is unavailable or waiting times are long mental home providers (Patient centred care co-
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	USA	Michael L. LeFevre, MD, MSPH, on behalf of the U.S. Preventive Services Task Force*	Screening for Suicide Risk in Adolescents, Adults, and Older Adults in Primary Care: U.S. Preventive Services Task Force Recommendation Statement.	2014	Recommended clinical guidance for primary care settings in relation to the assessment of suicide risk.	Specifically addressed assessing the suicide risk in adolescents.	doctor) are encouraged to provide support in the interim. There is limited evidence for any treatments for adolescents at risk of suicide, and not enough evidence to support the potential benefit or harm of either screening for risk of suicide, or not.
Miscellaneous reports about policy.	Northern Ireland	Dr Jennifer Betts and Dr Janice Thompson	Mental Health in Northern Ireland: Overview, Strategies, Policies, Care Pathways, CAMHS and Barriers to Accessing Services	2017	This paper provides background information on mental health and illness in Northern Ireland (NI) including demographics on Suicide and self- harm. It details the relevant strategies and policies. It describes the care pathway for treating mental health problems, with specific reference to child and adolescent mental health	Reports on recent changes in the delivery of CAMHS services and attempts to make them accessible. Early intervention is highlighted as a priority. Provides an overview of key mental health policies and refers to objectives to reduce the number of people presenting with self-harm, and suicide prevention activity.	Gives demographic information highlighting that suicide and self- harm are issues for young people in Northern Ireland. Not specific to suicide, but it states that a referral care pathway for CAMHS is currently being developed.

				services (CAMHS);		
				discussing barriers		
				to accessing		
				services.		
Scotland	Scottish	Responding to self-	2011	This document is a	This document is a	Provides background
	Government	harm in Scotland:		report from the	recommendation for	information and
		Mapping out the		National Self Harm	policy. It calls for	demographic
		next steps		working group who	improved responses	information on self-
				were tasked with	to people who self-	harm rates in Scotland.
				mapping out the	harm across the life	It states that young
				next stages	span, and recognizes	people are more likely to
				following	that for most people	self-harm. Within the
				publication of the	who self-harm they	proposed objectives for
				Truth Hurts in	do not intend to die.	future actions there are
				2006.		recommendations for
						clear referral pathways
						for all people who self-
						harm but is not specific
						to CYP. The only direct
						references to the
						treatment and care of
						CYP are
						recommendations on
						guidance on
						confidentiality and
						information sharing
						where a child is at risk.
New Zealand	Prime	Improving the	2011	This is a report	Ch. 16 is devoted to	Ch.16 of the report
	Minister's	Transition Reducing		commissioned by	Youth Suicide. It aims	considers how the New
	Chief Science	Social and		the government to	to give an overview	Zealand Suicide
	Advisor – Ch.	Psychological		review the	of the issue and	prevention strategy
	16: Keren	Morbidity During		evidence on how to	prevention	goals apply to young
	Skegg.	Adolescence		improve the	strategies.	people. It takes each

		outcomes for adolescents transitioning to adulthood.	goal in turn and cogitates how it focuses on youth. In conclusion it argues that the strategy involves actions that can be applied to the issues of youth suicide. It also argues that any programmes aimed at young people must be evidence based.
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#### **APPENDIX 3: BRIEFING PAPER**

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# Policy addressing suicidality in children and young people: An international scoping review

Suicide is a global health policy priority. As many as 800,000 lives are lost to suicide annually, in what is arguably a preventable cause of death. The World Health Organisation's Mental Health Action Plan 2013-20sets a target of reducing suicide rates by 10% by 2020, with member states agreeing to work towards this outcome. However, public policies instituted at national level can vary in how they translate this target into practical support.

Suicide is a leading cause of death among children and young people (CYP) workdwide, with an estimated 1 in 3 children in some countries having considered suicide in the past year. Despite acknowledgment that children and young people have different needs to adults, most suicide prevention and mental health strategies take a universal approach, in which the specific needs for children and young people risk becoming lost.

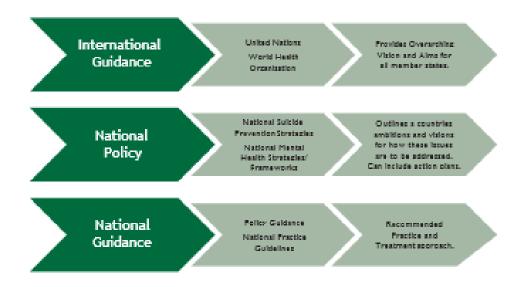
As the WHO's target date of 2020 approaches, this briefing paper summarises a global review of national policy documents, considering how they address the treatment and care needs of suicidal children and young people. In doing so, it highlights best practice for how policy can influence the resourcing of <u>services</u>, <u>and</u> identifies gaps in policy provision for this vulnerable population. The paper aims to support both the WHO and individual countries that wish to develop <u>new, or</u> refine existing policies that address suicidality in children and young people.

### Study

This scoping review considered how policy addresses the treatment and care needs of CYP who are suicidal. A child was defined as anyone under the age of 18 years, in line with the UN Convention on the Rights of the Child. Policies solely targeting populations over the age of 18 were excluded from the analysis, but policies covering individuals of all ages were included.

#### Key findings

- There is a significant policy gap in provision for suicidal children and young people; policy documents offer little specific guidance for addressing suicidality in this vulnerable group.
- While suicide prevention strategies recognise that children and young people are a priority population, most focus primarily on universal prevention approaches or generic counselling services.
- National mental health strategies for children and young people, and individuals of all ages, provide a blueprint for accessible services, but do not explicitly mention for care and treatment for children and young people who are suicidal or at risk of becoming suicidal.
- Not being explicit about provision for children and young people who are suicidal creates a risk that the
  needs of this population are overlooked by those tasked with interpreting, resourcing and
  implementing policies. It may also lead to large variations in terms of service design and delivery across.



#### Fig.1 Categorisation of policy documents

Researchers mapped key policy documents worldwide, considering all papers published in English after 2000. The study analysed 35 documents, categorised as international guidance, national policies, and national practice guidelines. National policies included suicide prevention strategies, mental health strategies and frameworks, whereas national guidelines detailed how those presenting with mental health issues should be assessed and treated. The relationship between these categories of documents is detailed in Figure 1.

#### International guidance

Two international guidance documents were included. The UN 2030 Agencia for sustainable development details the goals and action plan that all countries in the United Nations have agreed to deliver. While the document does not specifically mention suicidal CYP, it does prioritise reducing mortality by non- communicable illness, which incorporates suicide as a leading cause of death.

The WHO mental health action plan 2013–2020 set a target that all countries should work towards reducing suicide rates by 10% by 2020, recommending countries adopt a lifecourse approach to mental health. The plan promotes that countries create national policies and strategies to tackle suicide prevention, prioritising at risk groups including 'youth'.

However, other than the identification of 'youth' as a priority group it does not provide any other guidance on how countries should address suicidal CYP specifically.



WHO seeks to reduce suicide rates by 10% by 2020

## National policy

WHO recommends that countries should develop suicide prevention and mental health <u>strategies</u>. The study surveyed a range of national policy documents, including 10 suicide prevention strategies, five national mental health strategies, and a young person-friendly version of the Canadian mental health policy.

Overall, the documents offer little in relation to specific policy guidance for addressing suicidality in CYP. Suicide prevention strategies recognise that CYP are a priority population. However, the focus of these strategies is primarily on universal prevention approaches for CYP, such as whole school-based mental health and well-being education programmes or generic counselling services.

Both national mental health strategies, and national frameworks for CYP's mental health, provide a blueprint for delivering services that are accessible to CYP who need them, when they need them. However, they do not specifically mention the population of children who are suicidal clearly enough to establish explicitly the care and treatment that they should be provided with. They also do not guarantee that the strategies or frameworks are delivered.

The irish National Mental Health Strategy is the only strategy that specifically mentions suicidal CYP. It goes on to recommend that all CYP who present with self-harm should be assessed by child and adolescent mental health specialists. The strategy recognises adolescence as a period of increased risk of <u>suicide</u>, and recommends that service provision should be uniform across ireland.

### National guidance

A third category of documents considered was national clinical guidance; documents containing evidence-based recommendations for good practice. While not setting out compulsory actions or procedures, clinicians and practitioners should recognise such guidelines and potentially justify their decision making should they choose not to implement them. However, recent research suggests that clinicians are not always aware of guidelines' existence.

The national guidelines included within this review contain suggestions that CYP, who are self-harming or are suicidal, should be assessed by a child and adolescent mental health practitioner, and referred to CAMHS for treatment and therapeutic interventions. However, the included national frameworks for child and adolescent mental health barely reference CYP who are suicidal.

Again, the exception is the Republic of Ireland. The Irish National Standard Operating Procedures for Child and Adolescent Mental Health Service differs from other guidelines in that its implementation is compulsory. Combined with the Irish National Mental Health Strategy, the Republic of Ireland is the strongest example of both headline policy and guidelines for implementation instituting a clear, consistent provision of support for children and young people who are suicidal.

### Analysis

international guidance documents are clear that reducing death by suicide is a global health priority. Despite an acknowledgement that suicidal youth are a priority group, no guidance is provided for how countries should address suicidal youth specifically.

In line with international guidance, countries have developed mental health and suicide prevention strategies, adopting a universal and life-course approach. Many of these do not specifically address the treatment and care of suicidal children and young people. Few countries also specifically address suicide in CYP in guidelines for clinical practice. Therefore, a potential policy gap exists between the global objective of suicide reduction and the pronounced risk of suicide among children and young people. With little in the way of firm guidance, the needs of this vulnerable group risk being overlooked as interpretations of how they should be looked after <u>ware</u>. Even where some countries have specifically

recommended assessment of those at risk of suicide by child and adolescent mental health specialists, little further guidance exists regarding treatments or interventions.

### Implications for policy and practice:

- · General policy statements that do not specifically address the risk of suicidality among children and young people are open to interpretation, and can lead to inconsistency in delivery.
- · Global health organisations may wish to specifically note the increased risk of suicide among children and young people, clarifying their ambitions for how the treatment and care needs of those at risk should be addressed in future policy documents at a national level.
- National governments may wish to consider affording greater attention to the heightened risk of suicide among. children and young people, and encouraging consistent approach to specialist mental health services for those at risk
- · Greater direction at an international level may translate into more detailed policy objectives at a national level, and more consistent guidelines for clinical practice.

### About this research

This briefing is based on research undertaken by

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- Professor Margaret Maxwell Director, Nursing, Midwifery and Allied Health Professions Research Unit, University of Stirling
- Dr Edward Duncan Associate Professor, Nursing, Midwifery and Allied Health Professions Research Unit, University of Stirling

#### If citing this research, please reference the following papers:

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### **APPENDIX 4: ETHICAL APPROVALS**

#### North of Scotland Research Ethics Committee (1) Summerfield House 2 Eday Road Aberdeen

Telephone: 01224 558458 Facsimile: 01224 558600 Email: nosres@nhs.net



18 March 2019

AB15 BRE

Ms Lynne Gilmour NMAHP-RU 13 Scion House Innovation Park University of Stirling STIRLING FK9 4NF

Dear Ms Gilmour

Study title:

is There Anybody Out There? An exploration of the pathways of care and experience of children after they are referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality. REC reference: 19/NS/0031 Protocol number: NVA. 256546 IRAS project ID:

Thank you for your letter of 14 March 2019, responding to the Committee's request for further Information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Lead Reviewer.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

#### Confirmation of ethical opinion

On behalf of the Committee. I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales) NHS permission for research is available in the integrated Research Application System, at <u>www.hra.nhs.uk</u> or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timetrame, they should contact <u>hra.studyregistration@nhs.net</u>. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are compiled with before the start of the study or its initiation at a particular site (as applicable).

#### Ethical review of research sites

#### NHS stes

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [Confirmation of Indemnity]		11 January 2019
Interview schedules or topic guides for participants [interview Topic Guide Practitioners]	3	11 March 2019
Interview schedules or topic guides for participants [interview Topic Guide CYP]	3	11 March 2019
Interview schedules or topic guides for participants [interview Topic Guide Parents]	3	11 March 2019
IRAS Application Form	256546/130 9514/37/74 5	29 January 2019
IRAS Checklist XML [Checklist 18/03/2019]		18 March 2019
Letter from sponsor		03 May 2016
Letters of invitation to participant [Parents/Carers of Children under 12]	1	04 February 2019
Letters of Invitation to participant [Parents/Carers]	2	04 February 2019
Letters of invitation to participant [Children]	2	04 February 2019
Other [University of Stirling Insurance Certificate - Allanz]		07 February 2019
Other [University of Stirling Liability Cover]		30 July 2018
Other [University of Stirling Health and Safety Policy Inc. Lone Working]		07 February 2019"
Other [Screenshot of Contact Form from Webpage 1]		07 February 2019*
Other [Screenshot of Contact Form from Webpage 2]		07 February 2019*
Other [Screenshot from Contact Form from Webpage 3]		07 February 2019*
Other [Local Resource List for Thank You Pack - Children and Young People in Fife]	1	04 February 2019
Other [Local Resource List for Parents/Carers in Fife]	1	04 February 2019
Other [Local Resource List for Children and Young People In Highland]	1	04 February 2019
Other [Local Resource List Parents/Carers in Highland]	1	04 February 2019
Other [References for IRAS Form]	2	04 February 2019
Other [Postcard with UR code]	1	04 February 2019
Other [Reminder Postcard with UR Code]	1	04 February 2019
Other [Second Commation of Funding Letter ]	1	23 January 2019

Other [Letter for parents of child consenting ]	1	04 February 2019
Other [Distress Protocol Children / Young Person ]	1	11 March 2019
Other [Distress Protocol Parent / Carers]	1	11 March 2019
Other [Distress Protocol Practitioners ]	1	11 March 2019
Other [Response Letter]	1	14 March 2019
Participant consent form [Children and Young People aged	2	04 February 2019
12-18 years]		
Participant consent form [Parent/Carer Assent Form for Chile	1 2	04 February 2019
over 12 years		
Participant consent form [Parent/Carer of Child under 12 years]	2	04 February 2019
Participant consent form (Parent/Carer)	2	04 February 2019
Participant consent form (Practitioners)		04 February 2019
	2	
Participant Information sheet (PIS) [Parent of Child U12]	3	13 February 2019
Participant Information sheet (PIS) [Parent/Carer]	6	13 February 2019
Participant Information sheet (PIS) [Child & Young Person PI	-	11 March 2019
Participant Information sheet (PIS) [Parents of child under 12 PIS]	2 4	11 March 2019
Participant Information sheet (PIS) [Practitioners PIS]	5	11 March 2019
Participant Information sheet (PIS) [Parents PIS]	6	11 March 2019
Participant Information sheet (PIS) [Child under 12 PIS]	5	11 March 2019
Referee's report or other scientific critique report [Evidence on Peer Review]	at i	01 February 2019
Research protocol or project proposal [Study Protocol]	3	08 March 2019
Summary CV for Chief Investigator (CI) [Lynne Glimour]		26 November 2018
Summary CV for student [Lynne Gilmour]		26 November 2018
Summary CV for supervisor (student research) [Margaret Maxwell ]		11 January 2019
Summary CV for supervisor (student research) [Edward Duncan]		01 February 2019

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

Reporting requirements

The attached document fAfter ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/guality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <u>https://www.hra.nins.uk/planning-and-improving-research/learning/</u>

19/NS/0031 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

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Professor Nigel Webster Chair

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: Ms Joy Taylor

TEMP009 Version 1 July 2019

Professor Angus Watson Research & Development Director NHS Highland Research & Development Office Centre for Health Science Old Perth Road Inverses IV2 3JH



Tel: 01463 255822 Fax: 01463 255838 E-mail: angus wateon@nhs.net

31<sup>87</sup> July 2019

NHS Highland R&D ID: HIGHLAND 1502 NRSPCC ID: NRS19/256546

Ms. Lynne Gilmour NMAHP-RU 13 Scion House Innovation Park University of Stirling FK9 4NF

Dear Ms. Gilmour

#### Management Approval for Non-Commercial Research

I am pleased to tell you that you now have Management Approval for the research project entitled:

'A mixed methods study of referrals to CAMHS for reasons of suicidality V1.0'

Lacknowledge that:

- The project is sponsored by The University of Stirling.
- · The project has no external funding.
- Ethics approval for the project has been obtained from the North of Scotland REC on 18/03/2019 Research Ethics Committee, (Reference Number: 19/NS/0031)

The following conditions apply:

- The responsibility for monitoring and auditing this project lies with University of Stirling.
- This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the UK Policy Framework for Health and Social Care Research (2018, V3.3 07/11/17, however prior written notice of audit will be given.

 Any researchers coming into NHS Highland for the purposes of carrying out research with patients will require the submission of a Research Passport, percupational Health approval and Letter of Access before starting the study at this

Headquarters: Assynt House, Beechwood Park, INVERNESS JV2 3BW

Interim Chair: Professor Boyd Robertson Chief Executive: Jain Stowart site. Please contact a member of the RD&I Governance team at <u>high-uhb.nhshighlandresearchpassports@nhs.net</u> for further assistance, if this is required.

- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be notified to the NHS Highland R&D Governance team. Please email documents to RD&I Facilitator at <u>High-UHB.RandD@nhs.net</u>.
- You are reminded that all amendments (minor or substantial) to the protocol and associated study documents or to the REC application should be copied to the NHS Highland Research and Development Office to obtain a R&D amendment approval letter. Guidance can be found at https://www.nhsresearchscotland.org.uk/services/permissions-co-ordinatingcentre/permissions
- If applicable, monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month, to Debbie McDonald, Data Manager (<u>debbie.mcdonald@nhs.net</u>). Please guote your RD&I Highland reference number (Highland 1502).
- Please report any other changes in resources used, or staff involved in the project, to the NHS Highland Research and Development Manager, Frances Hines (01463 255822, <u>frances.hines@nhs.net</u>).

Please quote your RD&I Highland reference number (Highland 1502) on all correspondence.

Yours sincerely,

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Frances Hines R&D Manager

Medical Director

Ms Lynne Gilmour NMAHP – RU 13 Scion House Innovation Park University of Stirling STIRLING FK9 4NF Hayfield House Hayfield Road KIRKCALDY KY2 5AH



Don I August 2019 Our Ref 19-010 238348 18:3530031 Enquiries in Atlenn Sell E-most attempell@oks.net Relephone 0183 623623 Est 28940 Bretaite www.selu@o.org

Dear Ms Gilmour

#### Project Title: A mixed methods study of referrals to CAMHS for reasons of suicidality

Thank you for your application to carry out the above project. Your project documentation (detailed below) has been reviewed for resource and financial implications for NHS Fife and I am happy to inform you that NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
Letter for parents of child consenting	1	4 February 2019
Letters of Invitation to Participant : Parents/Carers of Children under 12	1	4 February 2019
Participant Consent Form : Parent/Carer of Child under 12 years	2	4 February 2019
Participant Consent Form – Children & Young People aged 12-18 years	2	4 February 2019
Letters of Invitation to Participant : Parents/Carers	2	4 February 2019
Participant Consent Form : Parent/Carer	2	4 February 2019
Letters of Invitation to Participant : Children	2	4 February 2019
Participant Consent Form : Parent/Carer Assent Form for child over 12 years	2	4 February 2019
Participant Consent Form ; Practitioners	2	4 February 2019
Local Resource List for Thank You Pack – Children and Young People in Fife	1	4 February 2019
Local Resource List for Parents/Carers in Fife	1	4 February 2019
Postcard with UR Code	1	4 February 2019
Reminder Postcard with UR Code	1	4 February 2019
Screenshot of Contact Form from Webpage 1		7 February 2019
Screenshot of Contact Form from Webpage 2		7 February 2019
Screenshot of Contact Form from Webpage 3		7 February 2019
Participant Information Sheet : Parent/Carer	6	13 February 2019
REC provisional favourable opinion letter	15 C	4 March 2019
Protocol	3	8 March 2019

<sup>4</sup> NHS Fife was awarded the Carbon Trust Standard in February 2010 and is the first Scottish NHS Board to achieve this neolade.





# NHS

Fife

Interview Topic Guide Practitioners	3	11 March 2019
Interview Topic Guide Children/Young People	3	11 March 2019
Interview Topic Guide Parents	3	11 March 2019
Distress Protocol Children/Young Person	1	11 March 2019
Distress Protocol Parent/Carers	1	11 March 2019
Distress Protocol Practitioners	1	11 March 2019
Participant Information Sheet - Child & Young Person	5	11 March 2019
Participant Information Sheet : Parent of Child under 12	4	11 March 2019
Participant Information Sheet : Practitioners	5	11 March 2019
Participant Information Sheet : Parents	6	11 March 2019
Participant Information Sheet : Child under 12	5	11 March 2019
IRAS R&D Form REC final favourable opinion letter	5.11	13 March 2019 18 March 2019
Caldicott Guardian Approval Letter		17 June 2019
Study-Wide Governance Report	-	25 July 2019
OID Form	1 1	31 July 2019

The terms of the approval state that you are the Principal Investigator authorised to undertake this study within NHS Fife, with assistance from Lee Cowie, Clinical Service Manager, Child & Adolescent Mental Health Services.

I note that the favourable ethical opinion applies to all NHS sites taking part in the study therefore no separate Site Specific Review is required in this case.

The sponsors for this study are University of Stirling. Please note that it is the responsibility of the Sponsor to ensure that adequate and appropriate insurance is maintained throughout the course of the study.

Details of our participation in studies will be included in annual raturns we are expected to complete as part of our agreement with the Chief Scientist Office. Regular reports of the study require to be submitted. Your first report should be submitted to Dr A Wood, R&D Manager, R&D Department, Queen Margaret Hospital, Whitefield Rd, Dunfermline, KY12 OSU (Amanda wood3@nhs.net) in 12 months time and subsequently at yearly intervals until the work is completed. A Lay Summary will also be required upon completion of the project.

In addition, approval is granted subject to the following conditions:-

All research activity must comply with the standards detailed in the UK Policy Framework for Health and Social Care Research <a href="http://www.ntwresearchscotland.org.uk/uploads/invmce/uk-policyframework-health-social-care-research.pdf">http://www.ntwresearchscotland.org.uk/uploads/invmce/uk-policyframework-health-social-care-research.pdf</a>, health & safety regulations, data protection principles, other appropriate statutory legislation and in accordance with Good Clinical Practice (GCP). Any amendments which may subsequently be made to the study should also be notified to Aleen Yell, R&D Research Coordinator (<u>aleenyeti@nhs.net</u>), as well as the appropriate regulatory authorities. Notification should also be given of any new research team members post approval and/or any changes to the status of the project.

This organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research. You will be required to assist with and provide information in regard to monitoring and study outcomes (including providing recruitment figures to the R&D office as and when required).

As custodian or the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until the destruction of this data.

Permission is only granted for the activities for which a favourable opinion has been given by the REC (and which have been authorised by the MHRA where appropriate).

The research sponsor or the Chief Investigator or local Principal Investigator at a research site may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office (<u>alleenvell@nhs.net</u>) should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

I would like to wish you every success with your study and look forward to receiving a summary of the findings for dissemination once the project is complete.

Yours sincerely

AA

DR CHRIS MCKENNA Medical Director NHS Fife

Cc : Aileen Yell, R&D Research Coordinator, NHS Fife, Queen Margaret Hospital, Dusfermine Lee Covie, CAMHS



#### CALDICOTT APPROVAL FORM FOR USE OF PATIENT IDENTIFIABLE DATA for Health Research, Audit purposes or Service Improvement NHS Highland data only

#### Please return this form to: Christine Robinson, Public Health

Carally sheleting as bigger 700 at a set

Email: christine.robinson7@nhs.net Typewritten applications only please

Public Health, 2<sup>st</sup> Floor, Larch House, Stoneyfield Business Park, Inverness IV2 7PA

#### Project, Programme or Study Title

Is There Anybody out there? An exploration of the pathways of care and experience of children after they are referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality.

#### Name of Applicant: Lynne Glimour

NMAHP – RU, 13 Scion House, University of Stirling Innovation Park, Stirling, FK9 4NF

Tel No 01786 466102

Email address:

Lyg1@stir.ac.uk

Name of organisation receiving data: University of stirling

and their ICO Registration Number:

How long do you	want Caldicott	Guardian	approval fo	r this	work?
Please tick					

1 year	$\gamma'$	2 years	
3 years		5 уеага	

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What patient identifiable information are you looking to use? Please tick all those which apply

CHI Number	NO
Forename	া (Processing Only)
Surname	(Processing Only)
Initials	NO
Date of Birth	NO
Address	4
Postcode	4
Age	At time of Referral
Gender	4
Other: (Please detail)	Parent / Carers name (Processing Only) Parent Carers Address (Processing Only) Ethnicity SMID Index for postcode Month of referral Occupation / Position of Referrer Outcome of Referral Status of Referral Family circumstances Other Issues mentioned in referral – (Builying, child sexual abuse, neglect, domestic violence, parental separation, bereavement etc.)

#### General Description of the Study

Please provide a brief description of the study, including aims, objectives, methods and envisaged benefits to patients or the wider public. In particular, it should be clear whether the study relates to audit and service improvement or research. (Principle 1)

#### 4. Purpose for which data are to be used (Principle 1):

Suicide is a leading cause of death for children and young people, and a public health priority. Children who present as suicidal (having attempted or been thinking about suicide) are generally referred to CAMHS (Child and Adolescent Mental Health Services) for assessment and treatment. Little is known about what happens to them after they are referred to CAMHS, or even how many children this is, as this is presently undocumented.

The data is required as part of a mixed methods sequential PhD study involving: (1) Comprehensive reviews of both the policy context, and intervention research literature. (2) The number of children referred to CAMHS (Child and Adolescent Mental Health Services) (Fife), for reasons of suicidality, over a six month period will be measured. The referral outcomes for these children will be recorded, and any potential relationships between demographic indicators (such as gender, age, and ethnicity) with referral outcomes explored (3) A series of qualitative interviews

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capturing the perspective of children referred for suicidality, as well as the views of parents / carers, and CAMHS practitioners.

Research Questions:

 What are the current pathways of care for children after they are referred to CAMHS for reasons of suicidality (having attempted or considered suicide)?
 How do children who are referred to CAMHS for suicidality experience their treatment and journey of care?

3) What are the perspectives of the parents / carers of children referred to CAMHS for reasons of suicidality and the CAMHS practitioners who assess and treat these children?

This study aims to provide a detailed picture of what happens to children after they are referred to CAMHS for reasons of suicidality.

Objectives:

 Quantify the number of children referred for reasons of suicidality to two different CAMHS teams in Scotland and record the outcome of these referrals.
 Interview children who have been referred to CAMHS because they have been thinking about, or have attempted suicide, to explore the meaning of their care journey for them.

 Investigate the perspectives of the parents / carers of children referred to CAMHS, and CAMHS practitioners by interviewing them.

This study will provide new knowledge: about the numbers of children being referred to CAMHS for reasons of suicidality, what happens to them after they have been referred, and what the children and those involved in their care (parents / carers) feel about this experience. This knowledge will be invaluable to those developing and delivering services and interventions for children who are suicidal, providing a detailed picture of what currently happens, together with the views and experiences of those involved. Fundamentally, this could improve practice, inform the development of effective interventions to better support children who are suicidal, and save lives.

This is a mixed methods sequential study - with four phases. The methodology

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extracted separately to demographic data, to allow a CAMHS administrator to send invitations to participate in Phase 3 of the study.

Data Storage: The names and contact details for patients, and their parents / carers will be extracted separately to demographic data, and stored in an excel spreadsheet on a CAMHS service computer. This data will remain within the CAMHS service at all times. The referral outcome will be recorded to enable purposive sampling.

Anonymised demographic data (fields and justifications listed below (month of referal, occupation / relationship of person making the referral, gender, ethnicity, SMID code, - will be extracted and input along with the referral outcome to SPSS (a statistical software package) on a University of Stirling encrypted laptop and saved to the University of Stirling Research Drive, where it will be held securely, and will only be accessible to named individuals with approval - primary researcher, statistician, two academic researcher supervisors. This will not be linked in any way to participant information.

This file will be stored on an encrypted flash drive, transferred to the University of Stirling research drive via a password protected University of Stirling computer. **Data Analysis:** Descriptive statistics will be produced summarising the characteristics of the young people referred and the referral outcomes - SPSS (a statistical software package) will be used to analyse the anonymised demographic data collected. Continuous variables will be summarised as mean and standard deviation or median and IQR (Inter Quartile Range) as appropriate. Categorical variables will be summarised as frequencies. Logistic regression will be employed to examine which variables predict referral outcome. The effect size will be reported as the odds ratio and associated 95% confidence interval. Missing data will be recorded as such.

#### Please refer also to the full study protocol for detailed study design and methodology.

#### Requirement to use identifiable data (Principle 2)

Please request only the minimum detail required to meet the purpose of the study

No identifiable patient information will be used beyond the identification of the sample population.

The data required to be used for analysis in this study has been minimised e.g age at point of referral instead of D.O.B, and only using their name and address for processing purposes.

Data will be anonymised at the point of data collection. Data that is published will not be linked to any personal identifiers. Where there are multiple data outputs these will be considered to ensure that combinations of data do not risk disclosure, and cell values of 1-4 will not be given in line with the NHS NSS Statistical Disclosure Control Protocol (Version 3), which will be used as a guide in relation to statistical disclosure of sensitive topics.

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# Why is each data field required? (Principle 3)

Identifying or Potentially identifying	Justification
Variable	
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Name	This is solely being used to identify
	potential participants for phase 3 and will
	not be linked in any-way to the demographic data, or removed from the
	demographic data, or removed from the NHS site.
Address	This is solely being used to identify
Action (255)	potential participants for phase 3 and will
	not be inked in any-way to the
	demographic data, or removed from the
	NHS site
Parent / carers name	This is solely being used to identify
	potential participants for phase 3 and will
	not be linked in any-way to the
	demographic data, or removed from the
	NHS site.
Parent / carers address.	This is solely being used to identify
	potential participants for phase 3 and will
	not be linked in any-way to the
	demographic data, or removed from the
	NHS site.
Month of referral	This will help to establish time from point of the referral to treatment. However,
	keeping to the month rather than date
	makes the individual less identifiable.
Occupation / Position of Referrer	This data will not be linked to location, or
Consequences of a consequence of the former	individuals minimising the potential for
	identification. This will be used to establish
	if there is any potential relationship
	between the occupation of the referrer and
	the referral outcome.
Outcome of referral	This relates to whether the patient was
	seen / signposted on / on waiting list etc.
	This information is vital to address the
	research question. It will be anonymised.
Gender	This will be used to explore any gender
	differences in referral outcomes.



Ethnicity	This will be used to describe the sample
	and explore any differences in referral
	outcomes related to ethnicity.
Family circumstances	This will be used to explore any
-	differences in referral outcomes related to
	family circumstances.
Other Issues	This will be used to explore any
	differences in referral outcomes related to
	other issues that were identified by the
	referrer.
SMID code	This is noted to be able to explore whether
	there is any relationship between postcode
	area and referral outcome - not as an
	identifier.

Please note that the small sample size will be taken into account when reporting and as stated above data that is published will not be linked to any personal identifiers. Where there are multiple data outputs these will be considered to ensure that combinations of data do not risk disclosure, and cell values of 1-4 will not be given in line with the NHS NSS statistical Disclosure Control Protocol (Version 3), which will be used as a guide in relation to statistical disclosure of sensitive topics. Please justify the request for using patient identifiable data in your

research study or audit. (Principle 4)

The legal basis for data processing is research in the public interest.

GDPR conditions for processing:

Article 6 condition:

"1(e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller"

Schedule 9 for processing of special category data:

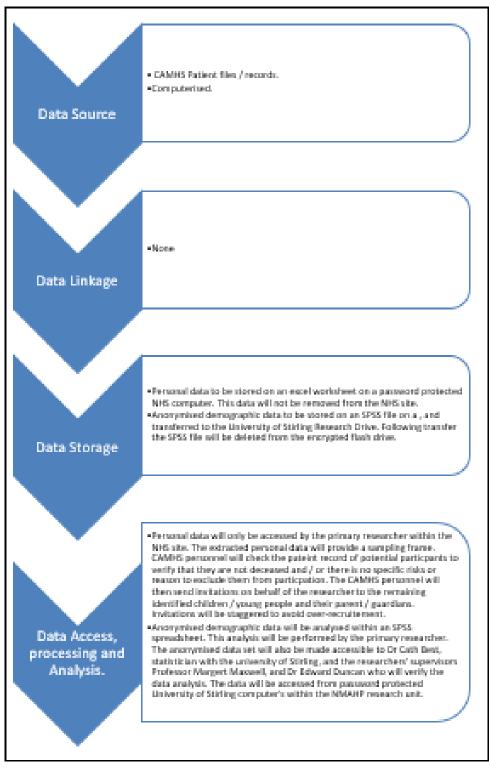
"2()) - the processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject;"

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#### Please provide details of how the data is to be transferred during its storage and destruction. (Principle 5)

A full data management plan is attached.

Anonymised demographic data will be stored in an SPSS file. This file will be saved on a password protected encrypted University of Stirling Laptop. The file will then be securely uploaded to the University of Stirling Research Drive. Data will be transferred to the research drive at a single point – following the completion of data collection.

The University of Stirling research drive is a hybrid, local/cloud, storage solution from Microsoft called StorSimple. This consists of a storage device located in a secure data centre on the Stirling campus which is linked to unlimited cloud storage hosted in Microsoft data centres in Dublin and Amsterdam (with real-time replication of data between the two). Data is initially written to the local storage device but moved transparently to the cloud based on frequency of access by the users. **Data Is encrypted at rest on both local and cloud storage, and at all times whist in transit.** Only the University have access to the encryption keys. Microsoft are responsible for ensuring that the data in their data centres is always available. Backup of the local device is done by the University. Snapshots are taken every evening to cloud storage in Microsoft Azure. Daily snapshots are retained for 28 days and weekly snapshots are retained for 26 weeks. This is detailed in the study data management plan which is written in accordance with the University of Stirling Data Management Policy.

#### Describe the measures in place to protect and use the data securely and confidentially.

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Personal data will only be accessed at a secure location, and will not be removed from the NHS site.

NH 8 Highland - The Phoenix Centre, Raigmore Hospital, Old Perth. Road, Inverness, IV2 3UJ

De-Identified data – University of Stirling -NMAHP – RU, Unit 13 Scion House, University of Stirling Innovation Park, Stirling, FK9 4NF.

Individual accounts will be used to access data both within the NHS sites and at the University of Stirling. Data will not be accessed remotely, or sent via email.

The following security policies/procedures are in place governing access to this physical and technical environment, this includes password protection:

#### NH 8 Highland -

Information Security Policy Data Protection Policy

#### The University of Stirling – Data Protection Policy & Data Protection Guidance Handbook

Relevant sections>

II. Data Security 22 AI University users of personal data must ensure that all personal data they hold is kept securely. They must ensure that it is not disclosed to any unauthorised third party in any form either accidentally or otherwise. Data Security should be undertaken in line with the Information Technology Use Policy, Data Classification and Handling Policy. Links to these policies are provided above and guidance on data security is included in section 4 of the Data Protection Guidance Handbook

viii. Research 40 Data collected for the purposes of research are covered by the GDPR. It is important that staff collecting data for the purpose of research or consultancy incorporate an appropriate lawful basis for processing personal data and provide an appropriate privacy notice to the data subjects. 41 Further information and guidance on data protection and research is provided in section 6 of the Data Protection Guidance Handbook.

# The University of Stirling – Data Protection Guidance Handbook Relevant sections:

6 Research 11 Data Impact Assessments 12 Data Protection by design and default.

Data elacsification and handling policy. All sections are relevant.

### Research Data Management Polloy

Relevant Section 3 Policy

Application Number ...... (for office use only) form amended October 2018



#### Please outline your organisational compliance with legal requirements (Principle 6)

This study has been reviewed by Ethics committees both within the University of Stirling and the NHS:

- University of Stirling NHS, Invasive or Clinical Research (NICR) Ref: NICR (18/19) Paper 009. Approved 16/1/19.
- North of Scotland Research Ethics Committee [1] REC reference: 19/NS/0031; IRAS project ID: 256546. Approved 18/3/19.

NHS Highland – Contact has been made with Dr Wendy Van Reit, Clinical Services manager and Lead Consultant Clinical Psychologist Child & Adolescent Mental Health Services and data controller for CAMHS, who supports the study and is a research study collaborator. Contact has been made with Anne Molver, and Jo Fraser at R&D office in Highland. Highland are the lead R & D team for this study.

The person responsible within the University of Stirling who is not connected to the study research team is Professor Jayne Donaldson, Dean of Health Sciences and Sport – jayne donaldson@stir.ac.uk

A data protection impact assessment has been completed in conjunction with the University of Stirling Data Protection team, and signed off and approved by Professor Margaret Maxwell, academic supervisor of the primary researcher and Director of the NMAHP (Nursing Midwifery and Alied Health Proffessionals Research Unit).



# Please provide details on the type of information to be shared, why and with whom, and also how it will be shared. (Principle 7)

Personal information to be shared by allowing access to CAMHS patient referrals for the primary researcher only. This is for research purposes in the public interest. This will occur within the secure environment of the NHS site. The NHS data controller for this site will provide a safe space for records to be accessed, in clear sight of approved NHS staff who will ensure that data accessed is appropriate.

The primary researcher, Lynne Gilmour has an NHS research passport, and an honorary contract with NHS Highland, and has completed the MRC online Confidentiality & GDPR Quiz. The study has full NHS REC approval – IRAS ID: 256546.

De-identified data will be accessible to the primary researcher, her supervisors and statistician only. This access is to allow for them to support with accurate and rigorous data analysis. They are all subject to the University of Stirling Data Protection Policy, and have completed the MRC on line Confidentiality & GDPR quiz.

# Will the data be transferred outside the European Economic Area at any time?

|--|

No 1

If yes please give reason for transfer out with the EEA.

Please can you give details of the privacy and security measures that are in place (that you are accepting as 'adequate measures' to protect the data by those receiving it (whether in the UK, EU or outside of the EEA) in line with GDPR and associated data protection legislation

Application Number	(for office use only)	12
form amended October 2018		



A data protection impact assessment has been completed in conjuction with the University of Stirling Data Protection team, and signed off and approved by Professor Margaret Maxwell, academic supervisor of the primary researcher and Director of the NMAHP (Nursing Midwifery and Allied Health Proffessionals Research Unit).

Data will not be accessible to anyone other than named researchers (two academic supervisors: Professor Margaret Maxwell, and Associate Professor Dr. Edward Duncan, and one lecturer in statistics, Dr Catherine Best). They all will each have individual password protected accounts, will use the University of Stirling computers, abide by the University of Stiling Data Protection Policy, and have completed MRC training in Confidentiality & GDPR.

Please can you give the details of the process by which the dataset would be de-identified with the identifiers removed and replaced with a study id for the analysis of each dataset.

The extracted data set is comprised of anonymous data, and will not be linked in any way to an individuals identity. There will be no key to re-identify individuals.

Do you have a data governance group? If no, how is that function being managed? If yes, please give details.

No – The University of Stirling has a Data Protection officer, who is supported by a data protection team.

Application Number ...... (for office use only) form amended October 2018

# APPENDIX 5: RETROSPECTIVE COHORT STUDY VARIABLES

Retrospective	Cohort St	udy - T	able	fvariable	to be	extracted.

Variable	Justification for extraction	Storage
Name Address Parent / carers name Parent / carers address.	These data were solely used to identify potential participants for phase 3.	This data was stored in an excel spreadsheet on a password protected NHS computer within the NHS site.
Reason for referral in relation to suicidality	This helped to identify any potential relationship between the presenting suicidal behaviour and referral outcome.	This data was input into an SPSS spreadsheet, on a password protected and encrypted University of Stirling Laptop. It was the transferred to the
Month of referral	This helped to establish the time from point of the referral to treatment. However, keeping to the month rather than date makes the individual less identifiable.	researchers University of Stirling password protected research drive.
Occupation / Position of Referrer	This data was not linked to specific locations, or individuals minimising the potential for identification. This was used to establish if there is any potential relationship between the occupation of the referrer and the referral outcome.	
Outcome of referral	This relates to whether the patient was seen / signposted on / on waiting list etc. This information was vital to address the research question.	
Status of Referral	This information helped to describe the referral outcomes for the children – for example how many were on a waiting list.	
Offered an Assessment	This information was important to show what happened after a referral was made.	

SMID code	This was noted to be able to explore whether there is any relationship between postcode area and referral outcome – not as an identifier.	
Ethnicity	This will be used to explore any differences in referral outcomes related to ethnicity.	
Family circumstances	This was used to explore any differences in referral outcomes related to family circumstances.	
Siblings	This was used to explore any differences in referral outcomes related to family circumstances.	
Other issues identified by the referrer (e.g. Bullying, child sexual abuse, neglect, physical abuse, domestic violence, bereavement, identity, sexuality, ASD (Autism Spectrum Disorder), other mental health issues).	This was used to explore any differences in referral outcomes related to other underlying issues that were identified by the referrer.	

### APPENDIX 6: INTERVIEW TOPIC GUIDES



Is There Anybody out there? An exploration of the pathways of care and experience of children after they are referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality.

V3 11/03/19

## Interview Topic Guide: practitioners

#### INTERVIEW FOCUS

The main purpose of interviewing CAMHS practitioners is to capture their experience of working with children who are suicidal, from their perspective. The interview will encourage them to give their views on the treatment needs of children presenting with suicidality. Topics of interest include:

- Referrals (The number of referrals and the referral process etc.)
- The assessment process.
- What happens next? (Do CAMHS offer these children a service? Do they get signposted on to another service? Etc.). Can they give an anonymised example of a recent case and how it was/is being managed?
- Do they identify anything that is unhelpful or difficult in this process?
- What would be helpful? Or what do they think the best treatment approach would be?
- How do they feel about their experiences of working with these children?

#### SUPPORTING STRUCTURE

- Before the interview starts the researcher will spend time establishing informed consent, using the information leaflet.
- They will introduce the topic of their conversation, and stress that they are interested to hear about the practitioner's perspective as someone who knows about what happens when children are referred to CAMHS because they have attempted or are thinking about suicide. They will explain that there are no right or wrong answers, and stress if they want to take a break at any time they can, and if they do no not want to answer a question they do not have to, and that will be okay.
- The researcher will emphasise they want to know about the help that the suicidal children
  receive from CAMHS or other services, and not with what causes their suicidal thoughts /
  behaviours.
- The interviewer will support the practitioner to identify a person that they might talk to after the interview if they feel worried or upset, acknowledging how difficult this can be for practitioners working with children who may be at risk of suicide within such a pressurised service.
- The researcher will offer the practitioner a drink / snack.

- The researcher has many years of experience of working alongside and of supervising and training practitioners who work with vulnerable children. They will ask open ended questions supporting a conversation around the topic rather than presenting a list of questions. The researcher will also encourage the practitioner to keep conversation to the topic area and maintain safe boundaries.
- When the interview is finished the interviewer will ask the practitioner how they feel about
  what they have spoken about and again ask them to identify the person they might speak with
  should they be worried or upset. They will thank them by offering a voucher, and if there are
  any specific issues that arise suggest follow on support services. The researcher will also ask
  them if they wish to receive a summary of the main findings once the project is finished.

## DISTRESS / DISCLOSURE

If the participant exhibits overwhelming distress or makes a disclosure indicating that they are a
risk to themselves then the researcher will stop the interview and follow the distress protocol
for practitioner's version 1.



Is There Anybody out there? An exploration of the pathways of care and experience of children after they are referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality. V3 11/03/19

## Interview Topic Guide: parents

#### **INTERVIEW FOCUS**

The main purpose of interviewing parents and carers of children who were referred to CAMHS for reasons of suicidality is to capture their experience of what happened after this referral, in their own words, and from their perspective. The interview will encourage them to tell their story chronologically from the point of referral. Topics of interest include:

- When did they first notice that (the YP) was thinking about suicide, and what happened next what did they (or another) do?
- The referral process (Who made the referral? Did they know / consent? Did they wait a long time to be seen?)
- The assessment (Did they go to CAMHS for an assessment? If not, why not? If they did what was this like?)
- What happened next? (Did CAMHS offer their child a service? Did they get signposted on to another service? Etc.). How did they feel about this?
- What helped?
- Was there anything that didn't help or was difficult?
- What would have been helpful or what would make things better?
- How do they feel about their experience?

#### SUPPORTING STRUCTURE

- Before the interview starts the researcher will spend time establishing informed consent, using the animation, information leaflet.
- They will introduce the topic of their conversation, and stress that they are interested to hear
  about the child's story in their own words. They will explain that there are no right or wrong
  answers, and stress if they want to take a break at any time they can, and if they do no not want
  to answer a question they do not have to, and that will be okay.
- The researcher will emphasise they want to know about the help that the child received from CAMHS or other services, and not with what caused their suicidal thoughts / behaviours.
- The interviewer will support the parent / carer to identify a person that they might talk to after the interview if they feel worried or upset, acknowledging how difficult this can be for parents.
- The researcher will offer the parent a drink / snack.

- The researcher has many years of experience of working with the parents and carers of
  vulnerable children and will ask open ended questions supporting a conversation around the
  topic rather than presenting a list of questions. The researcher will also encourage the parent to
  keep conversation to the topic area and maintain safe boundaries.
- When the interview is finished the interviewer will ask the parent / carer how they feel about
  what they have spoken about and again ask them to identify the person they might speak with
  should they be worried or upset. They will thank them by offering a voucher, and a tailored
  "Thank You" pack with contact numbers etc. of local resources. The researcher will also ask
  them if they wish to receive a summary of the main findings once the project is finished.

## DISTRESS / DISCLOSURE

- If the participant exhibits overwhelming distress OR makes a disclosure indicating they are a risk
  to themselves then the researcher will stop the interview and follow the distress protocol for
  parents / carers version 1.
- If the participant makes a disclosure that a child under 18yrs of age is at risk of harm then this
  information will be shared with the most appropriate agency social work / police. The parent /
  carer will be made aware by the researcher that they intend to do this.



Is There Anybody out there? An exploration of the pathways of care and experience of children after they are referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality. V3 11/03/19

## Interview Topic Guide: children / young people

#### INTERVIEW FOCUS

The main purpose of interviewing children who were referred to CAMHS for reasons of suicidality is to capture their experience of what happened after this referral, in their own words, and from their perspective. The interview will encourage them to tell their story chronologically from the point of

referral. Topics of interest include:

- When did they (or someone else) begin to think that something was wrong and that they may need help? What happened next?
- The referral process (Who referred them? Did they know / consent? Did they wait a long time to be seen?)
- The assessment (Did they go to CAMHS for an assessment? If not, why not? If they did what was this like?)
- What happened next? (Did CAMHS offer them a service? Did they get signposted on to another service? Etc.) How did they feel about this?
- What helped?
- · Was there anything that didn't help or was difficult?
- · What would have been helpful or what would make things better?
- · How do they feel about their experience overall? How are they feeling now?

#### SUPPORTING STRUCTURE

· Many older children (11 years +) will not appreciate being referred to as children and the

researcher will use the term young people when and where appropriate.

· Before the interview starts the researcher will spend time establishing informed consent, using

the animation, information leaflet and talking mats.

- They will introduce the topic of their conversation, and stress that they are interested to hear about the child's story in their own words. They will explain that there are no right or wrong answers, and stress if they want to take a break at any time they can, and if they do no not want to answer a question they do not have to, and that will be okay.
- The researcher will emphasise they want to know about the help that the child received from CAMHS or other services, and not with what caused their suicidal thoughts / behaviors'.
- The interviewer will support the child to identify a person that they might talk to after the interview if they feel worried or upset.
- The researcher will offer the child a range of materials that may help them to relax and engage in the conversation (art materials such as colouring sheets, pens and pencils, play-doh, and fidget toys such as tangle sticks).
- The researcher has many years of experience of working with vulnerable children and will ask open ended questions supporting a conversation around the topic rather than presenting a list of questions. The researcher will also encourage the child to keep conversation to the topic area and maintain safe boundaries.
- When the interview is finished the interviewer will ask the child how they feel about what they
  have spoken about and again ask them to identify the person they might speak with should they
  be worried or upset. They will thank them by offering a voucher, and a tailored "Thank You"
  pack with contact numbers etc. of local resources. The researcher will also ask them if they wish
  to receive a summary of the main findings once the project is finished.

## DISTRESS / DISCLOSURE

- If the participant exhibits overwhelming distress OR makes a disclosure indicating they are a risk to themselves then the researcher will stop the interview and follow the distress protocol for children and young people version 1.
- If the participant makes a disclosure that they or another child under 18yrs of age is at risk of harm then this information will be shared with the most appropriate agency – social work / police. The child / young person will be made aware by the researcher that they intend to do this.

## APPENDIX 7: LETTERS OF INVITATION SENT BY CAMHS

IRAS ID: 256546

Version2: Letter to children.

04/02/19

## CAMHS team headed paper

Address, City, Postcode | Telephone | Email

Date Recipient Name Title Address, Postcode

Hello .....,

# An invitation to participate in a research study about children and parent / carers' experiences.

We are writing to you on behalf of Lynne Gilmour, a researcher at the University of Stirling. Lynne would like to invite you to take part in her research study that is looking at what happens to children after they have been referred to CAMHS because they have attempted suicide or were thinking about it. We have sent you an information pack about it, and contact details for the researcher.

The research is not being done by the Child and Adolescent Mental health Team, and if you have any questions you should contact Lynne directly.

Thank you,

#### Name

Is There Anybody out there? An exploration of the pathways of care and experience of children after they are referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality.

# CAMHS team headed paper

Address, City, Postcode | Telephone | Email

#### Date

Recipient Name Title Address, Postcode

#### Dear ......

#### An invitation to participate in an independent research study of children and parent / carers' experiences.

We are writing on behalf of Lynne Gilmour, an independent PhD researcher at the University of Stirling. Lynne would like to invite you and your child to participate in her research study, exploring the pathways of care and experiences of children (and their parents / carers') after they have been referred to CAMHS (child and adolescent mental health team) for reasons of suicidality. We have enclosed an information pack for you and your child to consider, along with the contact details for the researcher.

The research is not being conducted by or for the Child and Adolescent Mental health Team, and if you have any queries you should contact Lynne directly.

Kind Regards,

#### Your Name

Is There Anybody out there? An exploration of the pathways of care and experience of children after they are referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality. IRAS ID 256546

4/2/19

## CAMHS team headed paper

Address, City, Postcode | Telephone | Email

Date

Recipient Name Title Address, Postcode

Dear .....

#### An invitation to participate in an independent research study of children and parent / carers' experiences.

We are writing on behalf of Lynne Gilmour, an independent PhD researcher at the University of Stirling. Lynne would like to invite you to participate in her research study, exploring the pathways of care and experiences of children, and their parents / carers' after they have been referred to CAMHS (child and adolescent mental health team) for reasons of suicidality. We have enclosed an information pack for you to consider, and contact details for the researcher.

The research is not being conducted by or for the Child and Adolescent Mental health Team, and if you have any queries you should contact Lynne directly.

Kind Regards,

Your Name

Is There Anybody out there? An exploration of the pathways of care and experience of children after they are referred to CAMHS (Child and Adolescent Mental Health Services) for reasons of suicidality.

### **APPENDIX 8: PARTICIPANT INFORMATION LEAFLETS**

#### Practitioner's leaflet



# What is the study is about?

Although the number of children who complete suicide remains low, the numbers of children who are thinking about, and attempting suicide is increasing. Addressing suicidality in children is a public health priority.

Children identified as being suicidal are generally referred to Child & Adolescent Mental Health Services (CAMHS) for assessment and treatment. However, little is known about what happens to children after they are referred to CAMHS when they have been thinking about or have attempted suicide. This study wants to find out about their experiences by talking to the children, their parents / carers, and CAMHS practitioners. Presenting the reality of what happens and the views of the children and thase involved in their care could help to show what they most need from a service. (A child is anyone under 18yrs.)

## Why have you been invited to take part?

As a CAMHS practitioner your knowledge and experience of assessing and treating children who have been thinking about or have attempted suicide could provide valuable insight into what works, and what is needed to support this vulnerable population.

# What are you being asked to do?

Lynne would like to meet with you once at your CAMHS office to conduct a short interview of approximately 45 min.

# Do you have to take part?

It is up to you if you decide to participate. You can also change your mind at any time. Lynne will be happy to answer any questions you may have before deciding whether you wish to take part.

## Could there be risks in participating?

Although dealing with children and families for whom suicidality is an issue is part of your job, we also recognise that it can be emotionally challenging. Talking about this aspect of your work may be upsetting. Lynne will talk to you before the interview about who you might go to for support should this happen, and also at the end of the interview.

Children and their parents / carers will be invited to participate in the study separately to you.

## Are there benefits in participating?

By participating in the study you will be contributing to the provision of knowledge that will help to inform policy and service development for children who are suicidal. On a personal level you may appreciate the opportunity to; have your experiences validated, and express your opinions on what works and what is needed to support children who consider or attempt suicide. You will also be

## How will what you say be used?

Anonymised quotes from the interview may be used in writing up the final thesis and journal publications, or in conference presentations. A lay summary reporting the findings will also be made available upon completion of the study and you may request that a



The data from the interview will be typed up by an approved transcriber who fully complies with GDPR.. It will kept strictly confidential. No names or identifiable information will be attached to the interview transcripts. These transcripts will be stored securely on a University of Stirling computer. Following completion of the study anonymised copies of the transcripts will be held for up to 10yrs in the University Of Stirling Research Archive.

#### Parent leaflet



## What is the study is about?

Little is known about what happens to children and young people (under 18 years) after they are referred to Child & Adolescent Mental Health



Services (CAMHS) when they have been thinking about or have attempted suicide. This study wants to find out about their experiences by talking to their parents / carers'. Presenting the reality of what happens and parents views about this could help to show what they most need from a service.

## Why have you been invited to take part?

You are the person who knows most about this! Your views and experience can really help to tell people what children and young people need from services when they feel suicidal.

## What are you being asked to do?

Lynne would like to meet with you, at CAMHS, at home, or in the community, either one to one or with a friend or person you feel safe with, to talk with you about your experience of your child going to CAMHS for help.

## IMPORTANT STUFF

YOU DO NOT NEED TO TAKE PART! It is YOUR choice!

IT'S Okey to change your mind! You can change your mind at any point and neither you or your childs' care or rights will be affected.

Lynns will talk to you before you start to make sure you understand what this is all about.

Lynne will help you to chose someone you might want to talk to after your meeting incase you feel worried or upset.

Lynns only wants to talk about your experience of CAMH5 and services your child may have seen after being referred to CAMHS.

The interview could last 10 min or up to 45 min at the most depending on how much you want to sev.

Lynne will record what you say to make sure she doesn't forget anything on a device with a password.

Your child will be invited to conticipate, in the study take oart even # SSIGNETER TO YOU SHO WAS TO

The words you say will be typed up by an independent transcriber who fully complies with data protection. The written words will be stored on a secure computer at the University of Stirling, but your name will be changed so no one can identify you.

Lynne might use some of these words when she writes her thesis at the end of the project, or in other reports and talks so people can learn from your experiences.

After the study is finished the information about you will be deleted from the computer, but we have to keep copies of what was said in the interview for up to 10 years incese anyone else can use it for other research, or they want to check the research that Lynns did.

As a thank you for giving your valuable time to help with the study all travelling expenses etc. will be paid, and you will receive a small veuchar.



Lynne will not share what you talk about directly with services unless you tell her that a child under 18yrs is in danger or at risk. She has a duty to pass this on to keep children safe from harm.

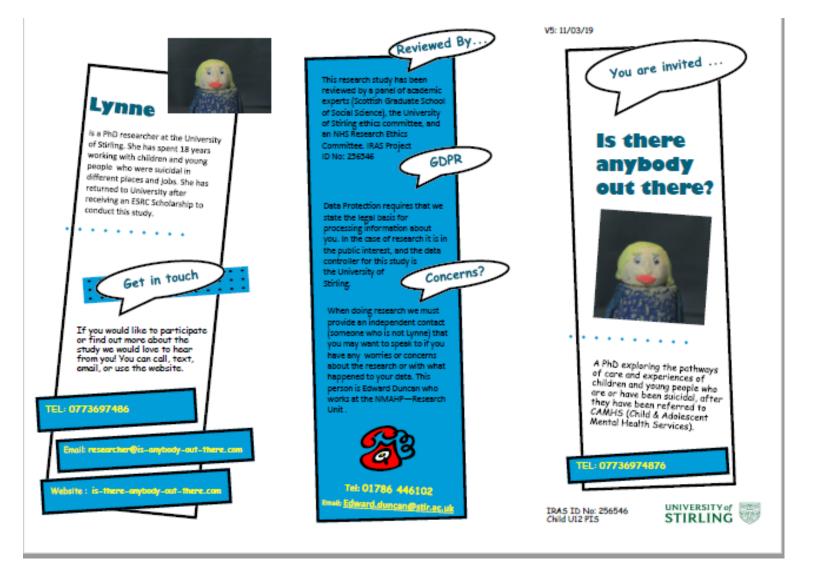
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#### Child under 12yrs leaflet



## What is the study is about?

Little is known about what happens to children or young people (under 18 years of age) after they are referred to Child & Adolescent Mental Health



Services (CAMHS) when they have been thinking about or have attempted suicide. This study wants to find out about their experiences by talking to them. Presenting the reality of what happens and how children feel about this could help to show what they most need from a service.

## Why have you been invited to take part?

You are the person who knows most about this! Your views and experience can really help to tell people what children and young people want from services when they feel suicidal.

# What are you being asked to do?

Lynne would like to meet with you, at CAMHS, or at home, or somewhere else you feel comfortable, either one to one or with a friend or person you feel safe with, to talk with you about your experience of going to CAMHS for help.

## IMPORTANT STUFF

YOU DO NOT NEED TO TAKE PART! No-one will be upset with you in any way if you chose not to. It is YOUR choice!

If you are under 12 years of age we must have your parents permission for you to be able to take part.

IT'S Okay to change your mind You can change your mind at any point and no-one will be upset or angry with you.

Lynns will talk to you before you start to make sure you understand what this is all about.

Lynns will help you to chase someone you might want to talk to after your meeting incase you feel worried or upset.

Lynne only wants to talk about your experience of CAMHS and services you may have seen after being referred to CAMHS,

The interview could last 30 min or up to 45 min at the most depending on how much you want to say.

Lynns will record what you say to make sure she doesn't forget anything on a device with a password.

Your papent or carer will be invited to natticitate in the state second etc and be invited to natticitate in even " you decide not to and yee versa: The words you say will be typed up by an approved transcriber (someone who types up what people say) who fully meets data protection laws. The words will then be stored on a secure computer at the University of Stinling, but your name will be changed se no one will know it was you.



After the study is finished the information about you will be deleted from the computer, but we have to keep copies of what was said in the interview for up to 10 years incase anyone else can use it for othar research, or they want to check the research that Lynne did.

Lynns will thank you for giving your valuable time to help with the study with a small voucher All travelling expenses etc. will be paid.

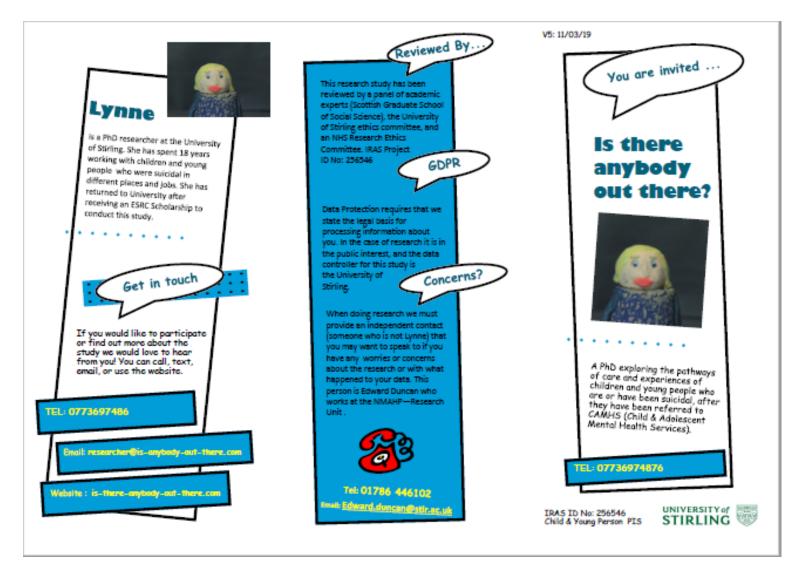


hank 100

Lynne will not share what you talk about directly with services unless you tell her that you or another child under IByrs is in danger or at risk. She has a duty to pass this on to keep children safe from harm.

. . . . . . . . . .

#### Child over 12 years leaflet



## What is the study is about?

Little is known about what happens to children or young people (under 18 years of age) after they are referred to Child & Adolescent Mental Health



Services (CAMHS) when they have been thinking about or have attempted suicide. This study wants to find out about their experiences by talking to them. Presenting the reality of what happens and hav children feel about this could help to show what they most need from a service.

## Why have you been invited to take part?

You are the person who knows most about this! Your views and experience can really help to tell people what children and young people want from services when they feel suicidal.

# What are you being asked to do?

Lynne would like to meet with you, at CAMHS, or at home, or somewhere else you feel comfortable, either one to one or with a friend or person you feel safe with, to talk with you about your experience of going to CAMHS for help.

### IMPORTANT STUFF

YOU DO NOT NEED TO TAKE PART! No-one will be upset with you in any way if you chose not to. It is YOUR choice!

IT'S Okay to change your mind You can change your mind at any point and no-one will be upset or angry with you.

Lynne will talk to you before you start to make sure you understand what this is all about.

Lynne will help you to chase someone you might want to talk to after your meeting incase you feel worried or upset.

Lynne only wants to talk about your experience of CAMHS and services you may have seen after being referred to CAMHS,

The interview could last 10 min or up to 45 min at the most depending on how much you want to say.

Lynns will record what you say to make sure she doesn't forget anything on a device with a password.

Your papent or carer will be invited to participate in the study seturately and can choose to take part even " you decide not to and yee versaThe words you say will be typed up by an approved transcriber (someone who types up what people say) who fully meets data protection laws. The words will then be stored on a secure computer at the University of Stirling, but your name will be changed so no one will know it was you.

Lynne might use some of the words that you say when she writes a big report at the end of the project, or in other reports and talks so people can learn from your experiences.

After the study is finished the information about you will be deleted from the computer, but we have to keep copies of what was said in the interview for up to 10 years incase anyone else can use it for other research, or they want to check the research that Lynne did.

Lynne will thank you for giving your valuable time to help with the study with a small voucher All travelling expenses etc. will be paid.



HOT YOU

Lynne will not share what you talk about directly with services unless you tell her that you or another child under 18yrs is in danger or at risk. She has a duty to pass this on to keep children safe from harm.

..........



## **APPENDIX 9: POSTCARD**



#### Is There Anybody Out There?

A PhD study exploring the pathways of care and experiences of children after they are referred to CAMMS (child and adolescent mental health services) because they have attempted or have been considering suicide.

This is just a wee reminder that you are invited to take part in the research study Is There Anybody Out There? To find out more you can scan the UR code, visit the website https://is-there-anybody-out-there.com/ OR contact Lynne directly by texting 07736974876. We would love to hear from you!

IRAS ID: 256456

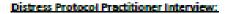
V1 4/2/19

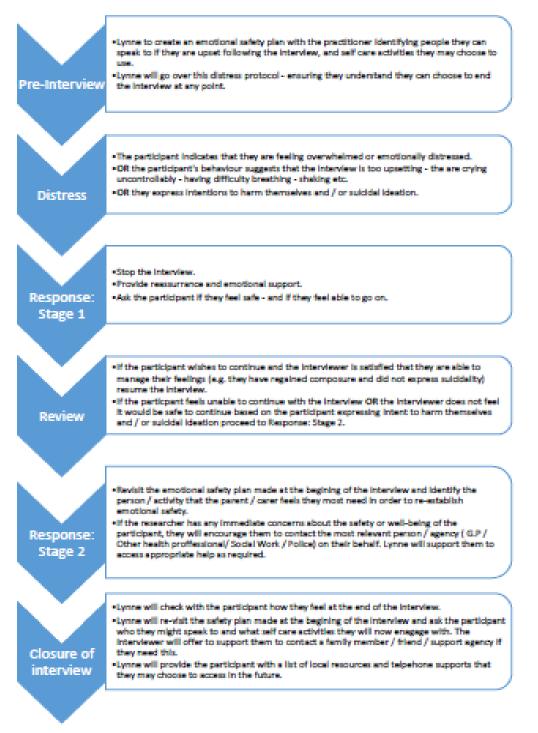


## **APPENDIX 10: DISTRESS PROTOCOLS**

#### IRAS ID: 256546

#### V1:11/03/19

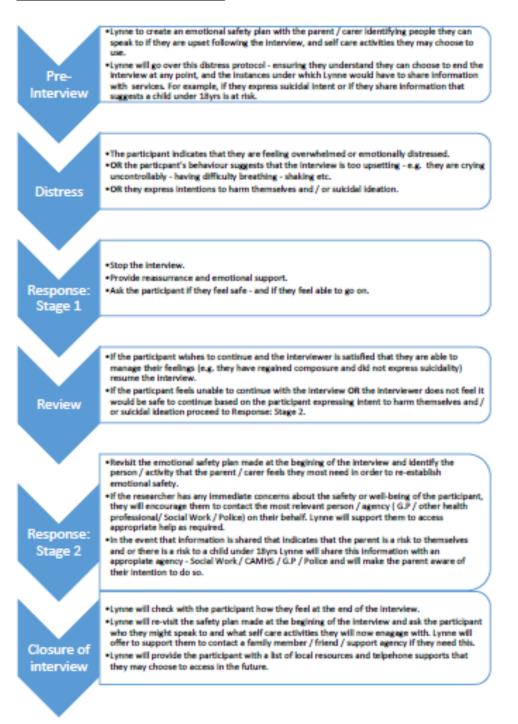




#### IRAS ID: 256546

#### V1: 11/03/19

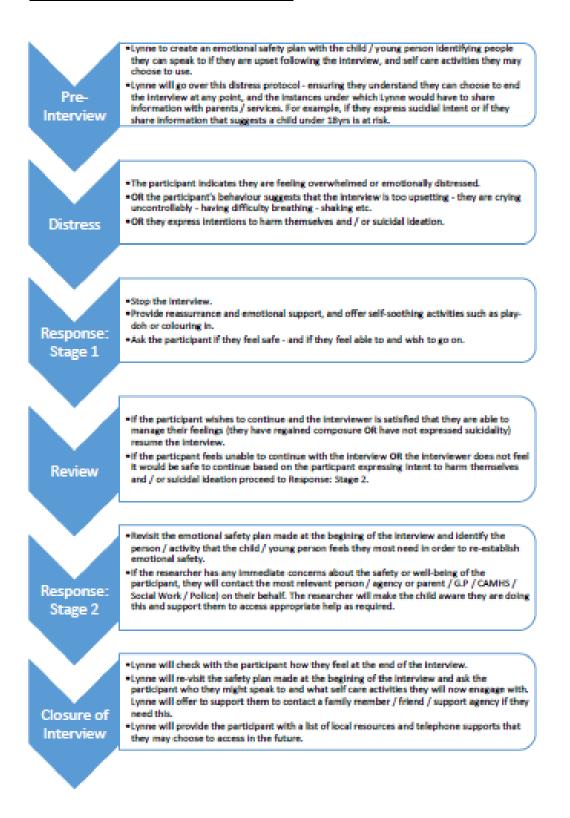
#### Distress Protocol Parent / Carer Interview:



#### IRAS ID: 256546

#### V1:11/03/19

#### Distress Protocol Child / Young Person Interview:



## APPENDIX 11: DATA SUPPORTING CAMHS RISK ASSESSMENT PROCESS

#### Risk Assessment Model

Goal - is a desired outcome from risk assessment the process

Assessment Activity - describes what they actually do within the assessment.

Driver – These are things driving the risk assessment process; informing and influencing decision making.

[		Supportine Data
Goal	"Is this person safe to go home!" or	is this a safe person to let go home!
	remain at home? The staff all aim to	
	he able send the child home from	and we'd be assessing for the mental state
	hospital, or to for them to remain at	examination we would do a template to see if they
	home and avoid a hospital	ware safe to go home
	admission.	were sole to do upone
		If they were on the word I'd be saying right okay, I
		can't go into a whole assessment I'd be saying 'are
		you safe to go home, what is the plan!"
		So only last week there were two young people on the
		ward that had done various things and I needed to do
		some risk assessment with them, think about whether
		or not they would be discharged home
		so it's making sure that we are discharging them
		home and that they can feel safe.
-		
Goal	Normalise / reduce risk	When we go in I think our main role is to try and allay
		that anxiety for them and also for the parents and
		people around them, schools, the education system,
		cause I think once you do that you can then work with the underlying issues. Initially if we go into hospital
		to see somebody and they've taken an overdase
		people around them are scared, like, we've even had
		the school saying they can't go back to school,
		whereas we would say get back to normality as
		quickly as possible. [] That's kinda what our service
		say is to try and get things back to normality, for
		parents not to fuss and change things, try and keep it
		as normal as possible within reason obviously
		depending on what's going on. (S2)
		I would try and normalise the experience so [] So we
		try and normalise it but not hide away from it, (58)
		ar and harmonia report for the analy from to (20)
		Maybe they never come to fruition or nobody ever
		moves into actually harming themselves or leading
		onto sort of thoughts on suicide but I think there's
		something really important about naming that and
		normalising that it's a possibility and we're not going
		to freak out about it and we can work with it, and it's
		safe to talk about, it's okay to talk about. (58)

H	i	i
Goal	Create a Safety Plan	We always go to stock safety planning with the young person and the primary care givers. I actually just had a chat with a young guy this moming who sometimes feels suicidal and talked through safety planning with them.
		what is the plan?" and we would follow up and determine what next. But that initial assessment is what's going on, what's happening, what do I need to do to make this safer?
		if a young person discloses or if a family member or a teacher perhaps raises concerns about risk of self- harm or suicide you would incorporate that into your general assessment with a view to putting together some kind of safety management plan, cause you're obviously wanting to prevent things escalating to a point where a young person has to use more lethal methods of harm. That would be your kind of immediate sort of safety management plan
		what can be tricky of course then is if they disclose something that means they have got a significant level of risk that might be quite immediate. That can be quite stressful as a clinician because you have to then come up with some kind of plan in collaboration with the young person
		And also even if they're older I'll always speak to their parent about safety planning and make them aware cause, like, I always say at the beginning of my assessment as well that everything's confidential but if you tell me anything that I feel you're at risk or anybody else is going to be at risk I need to take the appropriate action, and if they talk about self- harming or suicidal ideation then I always say to them this is something that I really need to speak to your parent or primary care giver. (54)
		They'll put something in place that's going to be able to carry forward that that young person's going to be safe,(53)
Assessment activity	Assessing parental capacity to keep the child / young person safe	Yeah, yeah cause I suppose the young person couldn't guarantee that they could keep themselves safe so you're very much looking to the network around them then and how they keep them safe,
		we'd look at parents, PR responsibility, things like that
		that phone call that I took today on duty that was a mum was saying 'she can't keep herself safe and I can't keep her safe' and it's about empowering that

		mum and saying 'you are keeping her safe, let's lool at what you've done, you've removed all the tablets you've removed all the knives, you'ne talking to her, that communication'. So, it's about empowering them as well to say 'they're telling you this because it's a level of distress that they're at, you can keep them safe, you are keeping them safe'
		she was able to go into a cupboard knowing full w she's a risk of suicide and help herself to two packet of Paracetamol, you know, that should never have been an opportunity for her. I mean, you can't lock everything away, but you can minimise risk. (53)
Assessment Activity	Identify any underlying issues: the staff all expressed this was vitally important, as the underlying issues were the main problems a child /	They've came in initially as self-harmers but self-ha is just what we see on the outside, it's the underlyin issues that are the problem(52)
	young person was facing that was causing them to consider suicide.	I think we do our best to try and figure out why wou a young person be presenting this way and let's see what we can do about it, [S8]
		I'm more focused on finding out what's going on f that young person and what we can change, i.e. what's driving the suicidality, rather than necessaril the suicidality itself because you can keep people so but unless you deal with the underlying difficulty an try and get a sense of that then you're just firefighti all the time. (S11)
		we do the initial assessment for risk to look at where that young person is and often and not self- harm or suicidal thoughts are the symptom of what else is going on for them in that (53)
		Yeah I think so cause we will often, I suppose it's rar that, we end up the kids who have presented from suicidality or suicide attempts they haven't got they're often overnight, you get that occasionally be they report longstanding difficulties (S11)
Driver	Team support and shared decision making: The staff spoke about how they made decisions as a team, and how they looked to colleagues for advice and support with any difficult cases.	There's having a supportive team certainly, having structures in place that helps you manage risk, refle on risk so that you don't feel that you're the whole time carrying a lot of uncertainty or doubt about yo decision making. So having good structures in place around clinical supervision, we used to have group supervision that was very much focused on 'are you making the right decisions around risk!" because those are the things that keep people awake at nigi that keep clinicians awake at night. Making sure w were getting that right as much as possible was rea important. (S1)
		It can be quite difficult at times and we have supervision quite regularly which is really, really go as a team but without that it would be quite a difficult job. (S2)

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	I'm trying to think most of the time if I'm warried or I feel it's difficult I'll ask a psychiatrist to do a joint appointment, or if it's like somebody with eating I'll get the diatician or somebody like that. We also have our supervision and we have case discussions every week, so there's always loads of opportunities to discuss difficult cases or speak to one of your colleagues and say how this is going and 'what d'you think?' cause I think you sometimes don't see the wood for the trees and sometimes a fresh pair of eyes, you know, sometimes you get a bit blinded by it all, especially if it's quite complex, if there's a lot of stuff going on for somebody. It's like going back to the jigsaw and instead of the parents needing to put it together it's like us as the service trying to put everything back together. And we're really lucky in this team cause some people haven't got patients and their doors are usually open so there's always somebody that you could always speak to and generally if you needed just a wee bit of advice or support or just bouncing off somebody. (54)
	So we work very much as a team in making these decisions so, you know, you'd never be left on your own making that decision, you know, you can come back over here from the children's word or phone across. Last week one of my nursing colleagues joined me for one of the assessments as well and that was really helpful. So you're never left solely with the responsibility of that, you're able to talk things through and talk through the different risks and then the different protective factors and make sure you're getting the full picture. So I suppose almost like peer supervision in a way around that and making sure that you're making the right decision at the time for the young person and for their family. But we've a good team here, people are supportive and helpful and that makes a huge difference to my comfort level with doing these types of assessments cause I haven't done them in services previous to this. (510)
	And we're never on our own, I think that's good to remember as well. I don't go over to the ward thinking 'I need to make this decision, you're going home', I can always say 'd'you know what, I'm going to have a think about it' and I can come back here and I can speak to any of my colleagues. And there's not an expectation that I have to make that decision on my own when I'm over there. If at all we're worned or think there's something not quite right here, we can come over and we can speak to any of our colleagues, all our colleagues: psychology, psychiatry, psychological therapies, all our doors are open and we're all very good that way about sharing it and I always say 'share your pain, share your pain'. There's no point being a one woman show or a one

		man show, there's no point at all. Always ask, always
		share, don't be ajraid to ask silly questions because
		that's the one that'll bite you on the burn! (56)
		often the cases that are a bit more risky to hold and that does stress members of staff, yeah. So the way
		2 20 1 I
		we handle this in the team there's a lot of joined working so people are hardly ever left with cases on
		their own. If people do an assessment of this kid they
		often pop into someone else's office and say 'what
		d'you think, is it the right decision, should I send them
		home, is this something that we should've done this
		way or that way?" So I think the support for staff on
		the ground becomes really, really important. (57)
		· · · · · · · · ·
		perhaps somebody will end up being admitted into
		some kind of inpatient setting if it doesn't feel, so that
		obviously as a person, as a clinician and a person feels
		pretty scary, but you generally have a lot of support.
		So I would never then deal with that on a one to one, I
		would probably say to the young person that it would
		be helpful for me to just go check out if there's anything I do need to do or find out what supports we
		have available, check in with usually somebody on the
		outreach Tier 4 team and then we can come up with a
		plan so you're generally not sitting holding that risk
		as an individual. (S8)
Driver	Experience: Most of the staff had	We've got staff who are really skilled who've done it
	been working in mental health for a	for a long time and who could go into a really highly
	long time. Their experience was	charged environment such as an A&E department
	valued, and gave confidence in their	where a young person's maybe been overnight, the
	decision-making.	staff are frought because they're worried, the parents
		are there and they're fraught and they don't know what to do, social work have potentially been pulled
		what to do, social work have botantially been builded
		in and they're wondering what's going to happen and
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there,
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that information with everybody else that's around them
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that information with everybody else that's around them and give them the confidence that this is going to be okay. (53)
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that information with everybody else that's around them and give them the confidence that this is going to be okay. (53) it's scary and I think it's quite scary I think within
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		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that information with everybody else that's around them and give them the confidence that this is going to be okay. (S3) it's scary and I think it's quite scary I think within our service there's a lot of experience within the self- harm service cause we've all been doing it for a long
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		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that information with everybody else that's around them and give them the confidence that this is going to be okay. (53) it's scary and I think it's quite scary I think within our service there's a lot of experience within the self- harm service cause we've all been doing it for a long time, but for other people working with these young folk who are saying they're suicidal it's a scary
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that information with everybody else that's around them and give them the confidence that this is going to be okay. (55) it's scary and I think it's quite scary I think within our service there's a lot of experience within the self- harm service cause we've all been doing it for a long time, but for other people working with these young folk who are saying they're suicidal it's a scary experience and it's hard, it's hard for the young person as well because sometimes you feel like you
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that information with everybody else that's around them and give them the confidence that this is going to be okay. (55) it's scary and I think it's quite scary I think within our service there's a lot of experience within the self- harm service cause we've all been doing it for a long time, but for other people working with these young folk who are saying they're suicidal it's a scary experience and it's hard, it's hard for the young person as well because sometimes you feel like you could be taking more risks with them than maybe what you want to. (52)
		in and they're wondering what's going to happen and the self-harm staff have got the ability to go in there, engage with that young person in a really difficult environment, put things in place that makes them feel contained but most importantly share that information with everybody else that's around them and give them the confidence that this is going to be okay. (55) it's scary and I think it's quite scary I think within our service there's a lot of experience within the self- harm service cause we've all been doing it for a long time, but for other people working with these young folk who are saying they're suicidal it's a scary experience and it's hard, it's hard for the young person as well because sometimes you feel like you could be taking more risks with them than maybe what you want to. (52)
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		of staff, I've got two members of staff who've just joined the team who are adult trained, same as what
		'I'm adult, we're all RMS trained in adults, but then coming into children's service is very different(S6)
		We are very aware that if we are fairly used to hearing that kids say 'oh I want to die', I'm not saying
		that that becomes normal but I think we hear it so
		often(57)
		I've worked for 30 years in adult mental health(59)
		I started off in XXXX in 1998 I think, so I'd worked in XXXX CAMHS before that. Pretty much did that as
		soon as I qualified as a mental health nurse (53)
		I think maybe because I've been nursing for thirty odd years and I've worked in loads of different situations
		and stuff like this, I think cause I've got experience I just know I've got to do it and I do it, whereas I think
		definitely if I was younger or a bit less experienced it might be a kinda harder thing to ask them, (S4)
		And that was in '97,(53)
		worked specifically within the self-harm area for
		probably about 13 years maybe; (51)
Driver	Job Role / Position: The staff	because that's what we're here for, you know, if it
	understood assessing risk of suicide to be part of their job. Their position	wasn't for these young people we wouldn't have a job, you know, (53)
		Jaco Jaco 11001, [20]
	was awarded the status of being qualified or expert enough to make	No, no I think that'd be yeah, no they don't have the
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was accepted that primary mental health	
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was	No, no I think that'd be yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. (53) Well as I understand it, cause I was going to say that
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was accepted that primary mental health	No, no I think that'd be yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. (55) Well as I understand it, cause I was going to say that in the main primary mental health workers wouldn't see people who might have suicide as part of their
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was accepted that primary mental health	No, no I think that'd be yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. (53) Well as I understand it, cause I was going to say that in the main primary mental health workers wouldn't
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was accepted that primary mental health	No, no I think that'd be yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. (S5) Well as I understand it, cause I was going to say that in the main primary mental health workers wouldn't see people who might have suicide as part of their presentation or suicidality, they would always refer
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was accepted that primary mental health	No, no I think that'd be yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. (55) Well as I understand it, cause I was going to say that in the main primary mental health workers wouldn't see people who might have suicide as part of their presentation or suicidality, they would always refer up to Tier 3 (59) I just see it as keeping them safe and it's doing my job, I just think if I can't have that conversation with
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was accepted that primary mental health	No, no I think that'd be yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. [55] Well as I understand it, cause I was going to say that in the main primary mental health workers wouldn't see people who might have suicide as part of their presentation or suicidality, they would always refer up to Tier 3 (59) I just see it as keeping them safe and it's doing my job, I just think if I can't have that conversation with them then who can? (54)
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was accepted that primary mental health	No, no I think that'd be yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. [55] Well as I understand it, cause I was going to say that in the main primary mental health workers wouldn't see people who might have suicide as part of their presentation or suicidality, they would always refer up to Tier 3 (59) I just see it as keeping them safe and it's doing my job, I just think if I can't have that conversation with them then who can? (54) In the health team I'm not part of the duty rota so I'm not as a standard going over and offering deliberate self-harm assessment past suicide attempt, but in my core CAMHS role I was. (58)
	was awarded the status of being qualified or expert enough to make this assessment – whilst it was accepted that primary mental health	No, no I think that'd be yeah, no they don't have the capacity to do that, I don't think they have the skillset to do that. [55] Well as I understand it, cause I was going to say that in the main primary mental health workers wouldn't see people who might have suicide as part of their presentation or suicidality, they would always refer up to Tier 3 (59) I just see it as keeping them safe and it's doing my job, I just think if I can't have that conversation with them then who can? (54) In the health team I'm not part of the duty rota so I'm not as a standard going over and offering deliberate self-harm assessment past suicide attempt, but in my core CAMHS role I was. (58)

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Driver	Training: Many of the staff referred	harming but the risk's much reduced by the time I get them. [] but I think having a team or some practitioners who have got that capacity to do that's a good thing, because if it came to us and we had to respond like that we would end up having to cancel patients on the day and I don't think that's good, cause our diaries are just chock a block, but I think having some sort of crisis response is a good thing. (54) probably more informed by the training that they've
Dinc.	to their specific training as psychologists / psychiatrist / mental health nurses, equipping them to work with suicidal children.	had rather than (S1) We have done kind of training days and things here where (S10)
		So I suppose my psychiatric training. [] the risk, but from my training I suppose I have a pro forma around things that I need or want to know and what I then go on to do with that information, []So we're trained to sit with that risk or unknown (S11)
		they're just different training, different breed and I think [] Because the way that a psychologist will do an assessment is very different from what I'll do an assessment, but we'll come to the same conclusion. We've got very different training. (S6)
		so during my training we would we always been trained up to offer some assessment around risk and psychological intervention around risk working in the core CAMHS part of team, [] it's part of our training [] would ve just been training ten years ago. [] so in my training what was always really, really [] That's what my training tells me to do (S8)
Driver	Expectations: The staff had many expectations placed upon them. Some related to internal procedures that dictated how quickly a child should be assessed etc. Others were more general expectations that other professionals and family members held; namely that CAMHS should see children who were thinking about suicide, and that they would know what to do.	So if they're classed as an emergency we would see them, so like the overdoses and that in hospital, the policy is that they should be admitted if they've taken an overdose or a serious self-harm risk, or suicidal, they should be admitted to a general ward or the observation unit in ASE and they then have to phone by ten o'clock the next day and we will see them that day, that morning usually. We try our best to get there as quick as possible and see them on the ward that day. If it's a referral from a GP they're usually classed, there's routine referrals, priority routine which is mainly the self-harm referrals, and the urgent ones obviously if it's suicide. We try and see them within as quickly as possible. [] Probably dealing with the amount of referrals that come in. If I look it hasn't been quite as bad this last wee while but going further back the amount of referrals that come in and trying to get through them all is quite difficult because you've still got to do all the follow

		up, so if we see somebody in hospital we've got to see them within a week after discharge as well, we've got to do a follow up which is sometimes hard fitting into your diary, so it's juggling and cancelling appointments to fit other people in is probably the biggest challenge. (52)
		I'm on duty today. I get phone calls from GPs, from social workers, guidance staff, teaching staff; they all phone in and ask for advice on duty if they have a suicidal person with them. (S6)
		Mm hmm, so it might be a guidance teacher that'll phone up or a parent because maybe their child's on the waiting list they'll be worried about them or looking for advice. The other week I had a young person who was in care who had got found on one of the local bridges, so it was like 'what do we do?' so
		it's just really kinda advice but we haven't got the capacity, it's just telephone advice. But I think that sometimes maybe is a good thing as well because if there's somebody there really worried about their child or a pupil or whatever then, and sometimes people phone up and we'll go 'Tve got school or social
		work on the phone who say oh we've got this young person and this is what they're saying, are we best referring them to you or are we best referring them to Clued Up or whatever?" Most of the time I'll say put a referral in and then we'll screen them, cause I'd rather do that than they believe maybe not need CAMHS
		and say we've referred them to somewhere else and(54)
		I think in the past what used to happen was when a person would be referred to CAMHS then all of the other services around them would back off and CAMHS would be left to deal with it(S3)
		one of the difficulties is that you come in particularly as a doctor and there's then that
		perception that a doctor is needed or that it is an illness processor that something therapeutic needs to happen when it's not always going to be effective. (\$11)
		I think psychiatry or mental health puts a lot on risk or ability to assess then manage (511)
Driver	Waiting Lists: The staff all felt an emotional burden in relation to the waiting lists and times for CAMHS services. This created a pressure for	The self-harm service I guess has been under pressure at different stages of its journey as it's grown, and it's probably grown sometimes in response to it being overwhelmed but we probably got to the stage
	them to see children quickly, and not hold on to cases for too long so more children could be seen.	where, you know, we're not going to get any more resources so we've had to think about how we manage those numbers in different ways. An example of that would be in the past all referrals for self-harming behaviour and suicidality would go to the self-harm team. Now there's a threshold around

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that because they can't cope with them all, so some of them may not even come to specialist CAMHS,
some of them might go to our generic team
depending on what's the immediate concerns and what's the immediate levels of risk. []And our
working threshold at the moment is, and this is a
temporary thing based on some recent challenges we've had in terms of capacity within the service, but
our working threshold or our working guideline at the
moment is if the initial work is around safety, the initial work is about keeping the young person safe
and working with the system around that then I would go to a self-harm team. (S1)
I suppose my biggest most emotional thing for me
around would be waiting times for young people who are presenting with mental health difficulties. We've talked about if there's a real safety issue they'll be
seen relatively quickly, but there's a lot of young people who present with quite significant mental
health issues but there's not an acute safety concern
so they wait and I think that's a disgrace [laugh] really that we've got young people who are kinda languishing at home, not going to school, presenting
with quite significant mental health problems, but as I
say, because there's not an acute safety issue then they just wait for CAMHS and that can be up to two years sometimes. [S1]
Obviously we've got to watch our numbers. [] I think because there's huge waiting lists I guess
management have to look at stuff like that and think about tackling it and bringing down the waiting lists. (52)
all that happens is that kids who would normally
have been seen within the six weeks are going on our waiting list which is adding to the waiting list. (53)
I think the waiting lists for everything is terrible, it's
really long and I think if you're a young person who's been referred for ASD assessment, I mean, I think at
the moment they're sitting 18 months to two years,
which is awjul. And if it was me or my child I think I would want to know rather than waiting all that time,
but I guess we've got our funding and our teams and it's just what it is at the moment, but I think it must
be horrible to wait that long. And for CAMHS, I don't
know what the ADHD waiting list is but even some of the waits for CAMHS is guite long, but we have got
initiatives in place at the moment to deal with the
longer wait patients, trying to get the waiting lists down. (54)
I think what is difficult sometimes is when you see a
young person you know that they are on the wait list to be seen but then the waiting time can be an issue.

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	So the girl last week I saw that will be assessed, I'm not sure how long of a wait they're going to have, but they have been made aware that the duty call system
	is in place if they need it. I suppose my fear or what is difficult as a clinician to think about is that she may end up presenting on the word again before she's
	octually seen for assessment here and that is difficult to think of that. Obviously we would rather see people sooner and have them assessed and treated
	sooner than that but there's obviously a waiting list as well that we're working through and trying to manage. (S10)
	the hard thing is knowing about wait lists and we would rather see more people, get more people through the doors, get more people discharged but actually when you are doing a piece of work and if there are multiple traumas and thinas, they're not
	people that you're going to be able to see quickly and discharge quickly, so as a psychologist particularly with I suppose trauma cases your numbers can get,
	you can get kind of clogged up with cases and it can be difficult to discharge people and get more new people. So I suppose you're always fighting against those pressures,(S10)
	I suppose we've got a bottleneck in the system whereby somebody will present and then we think 'ah
	you need CPT or IPT or whatever therapy' and as a service our ability to deliver that on the back of it is quite limited because we have people present on the waiting list for all those services who maybe haven't reached the point of suicidality but have a similar mental health need as well. (S11)
	Do they go on our waiting lists? There's a small number again of young people that end up being kept on for a while to contain things before <mark>finaudible</mark> 00:23:23] or because of the high level of clinical need we assist them a bit but generally that's what should happen. (S11)
	I think we would love to do way, way more and I think we're looking at ways to do way more but at the same time I think things are so difficult across the board with so many services and so many resources I think it's very, very difficult and I think it's very challenging. None of us want to say no to anybody. (S6)
	unfortunately our waiting times are pretty long. I think at the moment we're sitting about nine months/ten months or so of waiting time for people that go onto the waiting list. (S7)

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	What I think is a real downfall for us is our waiting list is so long that if you then have a kid that needs not just that crisis management but actually needs to get the therapeutic input, that's where I think we struggle because we have a long waiting list and I can so imagine if my child was in that level of distress and I would hear from a CAMHS team 'I now have to place you on a ten month waiting list' that must be soul destroying. And that's why I don't think the system works. (S7)
	what worries me is that because there is lack of capacity there's a real drive to get throughputs (57)
	my understanding is you may be referred into CAMHS and added to the waiting list if you've got a lot of difficulties and self-harm or suicide risk is part of that, but there's the other part where if you've made a suicide attempt you come in through the DSH rota and you're offered an urgent assessment but that doesn't always necessarily mean you're added to the CAMHS waiting list for intervention. So I guess, I'm hoping it's different but my experience when I worked in core CAMHS was it almost felt like you had to escalate and harm yourself before you would get seen urgently, whereas the young people who would fit our criteria and clearly were distressed but they weren't so distressed that they were ending up on the children's ward, they had to wait. So it almost felt a bit uncomfortable (SB)
	I suppose the frustration is I don't think any of us would feel, I don't know, I'm talking for everyone else now, but I don't think that any of us would feel that we maybe have the resources/the capacity across all services to maybe do that as well as we'd like to, which is a bit sad. (SB)
	What is shocking for me is that if somebody is presenting with suicidal ideation that they're left on a waiting list, I think that's shocking. I think it's disgusting. I don't know how that is dealt with. I'm sure clearly if they had suicidal intent those ones that were left, say, for eight months they would be dead I suppose, could be, but suicidal ideation isn't just about does this person want to die right now, it's about what is the meaning for them of thinking like that on a daily basis and the withdrawal of hope, you know, my view is you need to find some place to hopefully instil hope in somebody so that they don't feel like thinking like that all the time, but there are some people who existentially might. (59)
	I really do think that is a serious, the most concern for me is the fact that someone who presents what suicidal ideation unless it's all been magically sorted

		by an assessment at duty, they get put on a waiting list. (59)
Driver	Heuristics: beliefs held by staff about youth culture, increasing numbers of referrals and children and young people's attitudes to suicide and self and harm all influence their decision making. Additionally, information gleaned from reports / studies was used to try and understand or rationalise current practice.	
		risky than a lot of the girls that we get. (52) And it sounds strange as well but maybe your gut, so that we used to have a consultant who would say 'if you walk away and your gut's telling you you've got it wrong turn back and phone me', (53) high risk kids, like, your looked after kids, there's a lot of them that are suicidal at some stage and their life (53) So we rarely get a young person that presents with a kinda singular issue, there's normally social factors,

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	physical factors as well as emotional and wellbeing
	factors. There's usually family factors in there, there's factors within education, there's issues around
	poverty and the challenges just seem to be
	multiplying around the kids that we're seeing. (53)
	I think it's much more normal for kids to self-harm, I
	think it, you don't want to say it feels a bit like a trend
	at times, I know from my own kids that people don't
	feel ashamed anymore when they have scratches on their arms for example, yeah, there's definitely groups of kids where self-harm is a way of expressing where
	they are. So I think there's probably a trend where
	maybe 30 years ago people might be drinking and smoking and doing all kinds of other stuff. I think self-
	harm has definitely got a place now in expressing
	themselves. I do think that it's probably a higher pressure environment for young people so it wouldn't
	surprise me if levels of anxiety have gone up, but I
	think also I wouldn't dare to say that kids were in
	distress before, I just don't think it was talked about.
	Scotland is not necessarily a very open culture, talking
	about your feelings is not a done thing and luckily that's becoming more of a thing that becomes, so it
	wouldn't surprise me that for a long time a lot of
	problems were masked and that kids were sitting in the classes being really quiet and feeling distressed.
	.So I'm not necessarily saying it's a bad thing but I
	think there is something also, and lots of people talk
	about this, that you know, the odd kid with difficulties
	and feeling distress in adolescence, part of that is actually very normal. We've all feit distressed when
	we were adolescent, yeah, part of being an
	adolescent is that. (57)
	If you see all the kids that are self-harming and then
	all the kids that actually do a suicide attempt, but the
	kids that eventually die from suicide it's one a year if
	that (57)
	It doesn't come from nothing. And I think if we can
	in that sense we do take that very serious because it
	is not normal for kids to think they want to die. I
	don't think it's normal. I have one of my patients,
	he's only nine, it's not normal for a nine-year-old to say 'I think I would be better off dead'. That is not
	normal, yeah, that is not within the limits of 'oh that's
	sort of normal at developmental stages' no, no, no i
	take that very seriously. (57)
	I'm thinking something along the lines of
	intergenerational trauma, I don't know how much
	you know about that, all the ACEs research, you
	probably do, where our young people are maybe more predisposed to mental health vulnerabilities and
	we might have parents or grandparents where
	difficulties in generations before have not been

		addressed or have been addressed but people
		obviously remain struggling for whatever reason and
		that's filtering down, and we have perhaps
		parents/families where their own experiences are
		impacting on their ability to parent in a way that mediates/prevents, sort of breaks the cycle, does that
		mediates/prevents, sort of breaks the cycle, abes that make sense? So I suppose I feel worried that mental
		health presentation in young people is growing and l
		don't know how we stop that because I wonder if a
		lot of it's to do with intergenerational patterns of
		trauma, difficulties, not good enough parenting and
		then you have another generation of young people
		who maybe experience similar difficulties and then
		that will potentially impact on their parenting of their
		children and how do we break the cycle, does that
		make sense." And then I guess I suppose if difficulties
		are very significant that leads to your self-harm and
		suicidality presentations. (58)
		I think that's on the back of some of the guidelines
		that have been released over the years from The
		Royal College as well, the psychiatrists, cause they used to recommend that all young people presenting
		with these behaviours are seen by a specialist CAMHS
		service and that's no longer the case. I think there's
		room for flexibility there so it's really about matching
		some guidelines that are out there as well. (51)
Diver	Referral Information: Assessment /	I suppose we base the decision on a GP referral most
	screening starts before practitioners	of the time, 70% of the time a GP is referring. The
	meet a child. Many referrals are	quality of that referral can range quite broadly and
	rejected or added to a waiting list	out of those 70% of referrals that we get, 1'd say 50%
	without being seen; the information	of them have urgent written on the top so it's very
	provided in the referral is used to inform this decision	hard to determine which ones are urgent because of
	inform this decision.	the risk around that young person or child, or it's urgent because someone has placed a demand on the
		GP that's made them respond in an urgent way. The
		two things aren't necessarily the same which makes it
		hard for services to work out how you put systems in
		place to make sure you're getting the right kids at the
		right time. [] Yeah, and I suppose what we're doing
		just now is we're reliant on the effectiveness and
		accuracy of a GP assessment. We're putting them on
		a waiting list on the back of that. (55)
		I think references also know keywords to put into a
		referral in order to get a quick assessment. So, the
		self-harm service would say this, a lot of the kids that they see urgently don't require an urgent
		intervention. (S3)
		and the second sec
		So sometimes referrals are quite informative and we
		make decisions from them, other times (pauses)
		there's not enough information around and we do
		one or two things then; if we feel we need to find out
1		more information quite quickly we sometimes would
		phone the family, phone the young person to try and oet more information, or the referrer, or if we feel it's

	not something that we need to chase up too urgently we would write back to the referrer and ask them to
	get more information. And if we got a sense that
	there was concern about risk but we needed to find
	out a bit more we would usually contact the referral
	and/or family by phone to try and work out how
	quickly we needed to see the young person. [] but it
	can be very difficult to tell sometimes from referral
	letters and stuff, and I think there's a lot of work
	being done in XXXXX about making sure it's the right
	people that are coming onto our waiting lists now, (51)
	You've got a letter from a GP and it's very, very hard
	to get a hold of GPs to speak to them so you've got a
	few lines from the GP or school or whoever's referring
	and you're kinda going with what's in that letter as to who you see first and how serious it is, so the
	information that you get is really important in kinda
	knowing who you're going to see and how you plan
	out your diary, who you see first yean, difficult. (52)