

**UNIVERSITY of
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**Improving accessibility to cervical cancer screening for individuals with intellectual disabilities in
Scotland: Exploring barriers, facilitators and the acceptability of future HPV self-sampling**

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ABSTRACT

Background: Cervical cancer is the fourth most common cancer in women around the world, with an estimated 660,000 newly identified cases in 2022 (WHO, 2024). A group where cervical cancer screening attendance has consistently been the lowest at around 30% is those with intellectual disabilities (ID). Screening for cervical cancer in Scotland checks for high-risk Human Papillomavirus (HPV) and cervical cell changes to enable early detection and prevention. HPV self-sampling could provide an easier and more accessible opportunity for women with ID to screen for cervical cancer. The objective of this study was to gain an understanding of the barriers, facilitators and acceptability of future HPV self-sampling from the perspective of healthcare professionals (HCP) and those with an ID across Scotland.

Methods: A mixed methods design was utilised. An online survey was used for HCPs; themes from qualitative data were analysed using a social constructionist thematic analysis (TA). Quantitative data was analysed using descriptive and correlational analysis. Focus groups explored the views of those with ID. Recordings were transcribed and reflexive TA used to analyse data.

Results: A total of 107 participants across Scotland took part in the survey. Most participants were female (94.4%), with 61.7% working in urban locations and 38.3% in rural locations. Participants with greater knowledge of self-sampling were more likely to think it was a good idea. Those with increased knowledge of self-sampling were more likely to think that self-sampling should be promoted. Zero participants thought that it should not be promoted. Thematic analysis resulted in 4 themes and 2 subthemes, including *“self-sampling could provide autonomy and choice for the public”* and *“insufficient thought could lead to self-sampling increasing health inequities”*. HCP completed story completion tasks and identified groups where self-sampling could be advantageous or disadvantageous. A total of 13 participants took part in focus groups. Participants were female (n=12; 11 women with ID, 1 carer) and male (n=1 carer). Thematic analysis resulted in 5 themes and 6 subthemes, including *“power imbalance leading to loss of control and uninformed consent”* and *“self-sampling could be a powerful tool to regain control and reduce feelings of vulnerability”*. Participants considered self-sampling a positive initiative which could overcome many barriers to screening providing that the needs of patients were considered within its implementation.

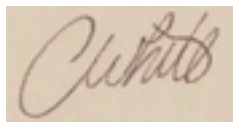
Conclusion: This study evidenced significant support for self-sampling from both HCP and women with ID in Scotland. Self-sampling could significantly advance health equity goals while improving healthcare outcomes.

DECLARATION

I declare that, except where explicit reference is made to the contribution of others, this thesis embodies the results of my own research and was composed by me.

This thesis has not been submitted for any other degree at the University of Stirling or any other institution.

Signature:

A handwritten signature in brown ink on a light beige background. The signature is cursive and appears to read 'C White'.

Printed name: Catherine White

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LIST OF ACRONYMS AND ABBREVIATIONS

CCSP	Cervical Cancer Screening Pathway
CFIR	Consolidated Framework for Implementation Research
HBM	Health Belief Model
HCP	Healthcare Professional(s)
HIS	Health Improvement Scotland
HPV	Human Papilloma Virus
ID	Intellectual Disabilities
JCVI	Joint Committee on Vaccination and Immunisation
NHS	National Health Service
PHS	Public Health Scotland
QIS	Quality Improvement Scotland
SCCSP	Scottish Cervical Cancer Screening Programme
SCCRS	Scottish Cervical Call Recall System
SG	Scottish Government
TA	Thematic Analysis
TFA	Theoretical Framework of Acceptability
TPB	Theory of Planned Behaviour
NSC	UK National Screening Committee
WHO	World Health Organisation
WPwC	Women and People with a Cervix

CHAPTER 1

INTRODUCTION

Cervical cancer (CC) is the fourth most common cancer in women and people with a cervix (WPwC) around the world, with an estimated 660,000 new cases identified in 2022 (World Health Organization (WHO), 2024). The WHO's (2020) global strategy for CC elimination prioritises screening, which has been shown to reduce mortality rates by 41-92% among attendees across Europe (Jansen et al., 2020). Screening is provided free at point of access through the National Health Service within the UK, testing for high-risk Human Papillomavirus (HPV) and cell changes.

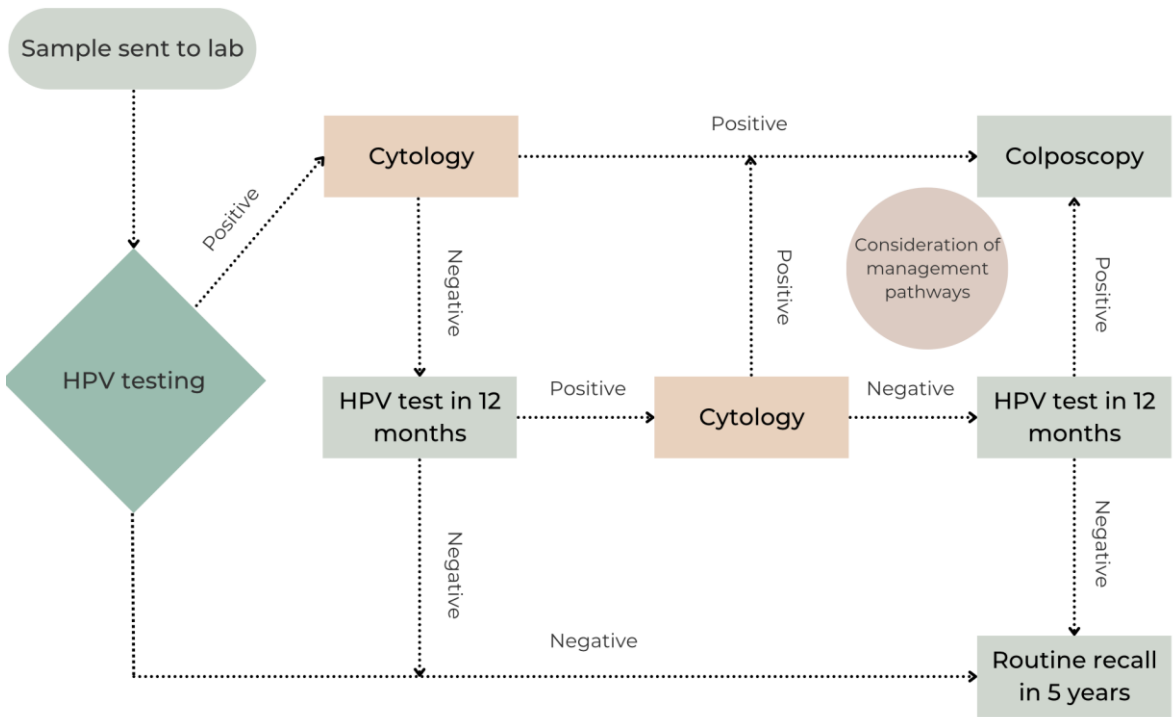
HPV, a sexually transmitted infection, is the main cause of nearly all CCs (Jemal et al., 2010), with an estimated 99.8% of cases in the UK caused by HPV (Brown et al., 2018). The WHO reports that nearly all sexually active people will be infected at some time in their lives (WHO, 2024). While typically asymptomatic (NHS, 2022), persistent HPV infection can lead to cancerous cell development over 15-20 years, with progression accelerated by factors including early pregnancy, HIV presence, and smoking (WHO, 2024). Significant health inequities exist, with 94% of CC deaths in 2022 occurring in low and middle-income countries (WHO, 2024).

Scotland utilises the electronic Scottish Cervical Call Recall System (SCCRS) to manage screening invitations and follow-up investigation (HIS, 2024). Recipients arrange to attend screening, usually at their GP practice; appointments typically take 10 minutes, with patients lying on a bed whilst the clinician inserts a speculum (a tube-shaped instrument) into their vagina, using a small brush to take a cell sample from their cervix. Samples are sent to the laboratory (Figure 1), where they are tested for HPV. Patients are informed of results via letter and if negative, they will be invited for screening again in 5 years. If positive, cytology then checks whether abnormal cells are present; if so, patients are invited to a further examination - colposcopy - which takes a closer look at their cervix.

Recent data indicates a 0.7% decrease in screening uptake (68.7% attendance) in Scotland in 2021/22 (PHS, 2023). Health inequalities consistently impact engagement with the Scottish Cervical Cancer Screening Programme (SCCSP) (HIS, 2024). Public Health Scotland (PHS; 2022b) advises that annual disease burdens are predicted to increase by 21% between 2019 and 2043, with two-thirds of this due to a rise in conditions including cancers (PHS, 2022).

PHS leads a variety of initiatives to **prevent** disease, **promote** health and **prolong** health in Scotland. The Scottish Government aims to address these disparities through initiatives like the Scottish Equity in Screening Strategy 2023-26 (SG, 2023) and the forthcoming Population Health Framework (SG, 2024a; Figure 2).

FIGURE 1.
Current cervical cancer screening pathway in Scotland



Engagement with health-harming behaviours including smoking, a known risk factor for CC (Cancer Research, 2023a), differs depending on the individual’s environment and socioeconomic status. Social determinants significantly influence health outcomes, exemplified by the 25% smoking prevalence in Scotland's most deprived areas—18% higher than in least deprived areas—with corresponding threefold higher lung cancer rates (ASH Scotland, 2024). While healthcare access is crucial, it accounts for only 20% of individual wellbeing, with socioeconomic factors, environment, and health behaviours comprising the remaining 80% (Institute for Clinical Systems Improvement, 2014; see Figure 3).

FIGURE 2.
The Population Health Framework’s Prevention Focussed System (SG, 2024a)

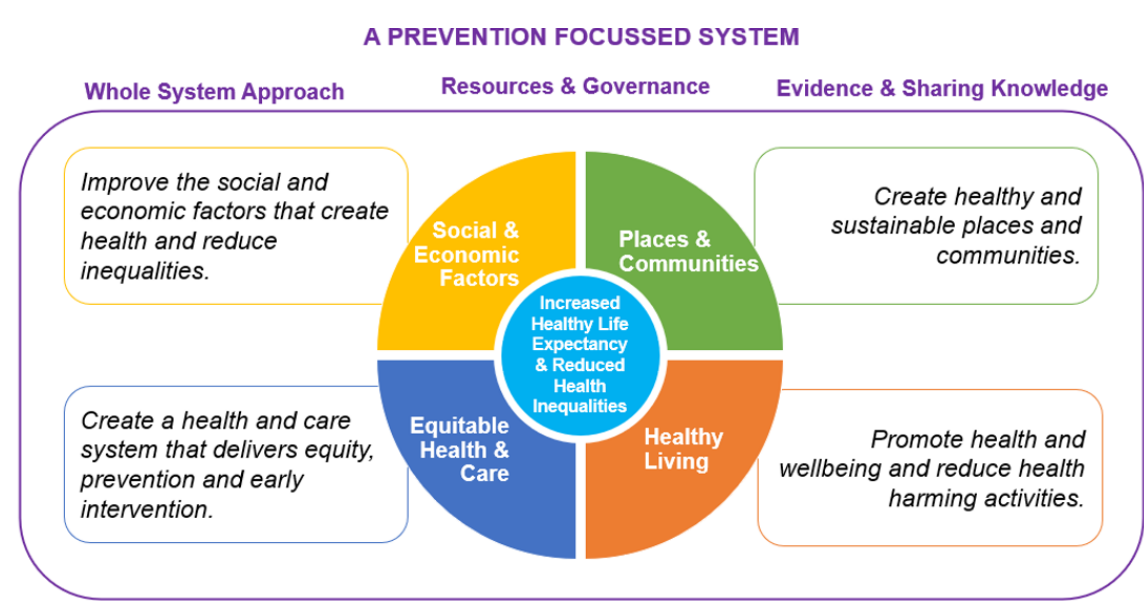
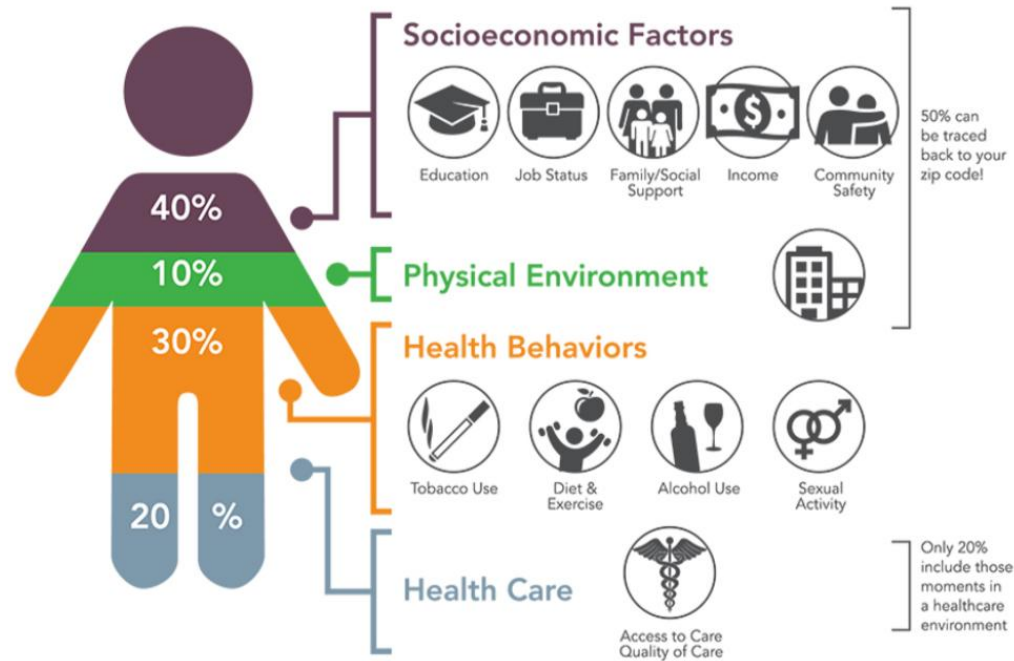


FIGURE 3.
Factors which impact health and quality of life (Institute for Clinical Systems Improvement, 2014).



1.1 HISTORY OF CERVICAL CANCER SCREENING IN SCOTLAND

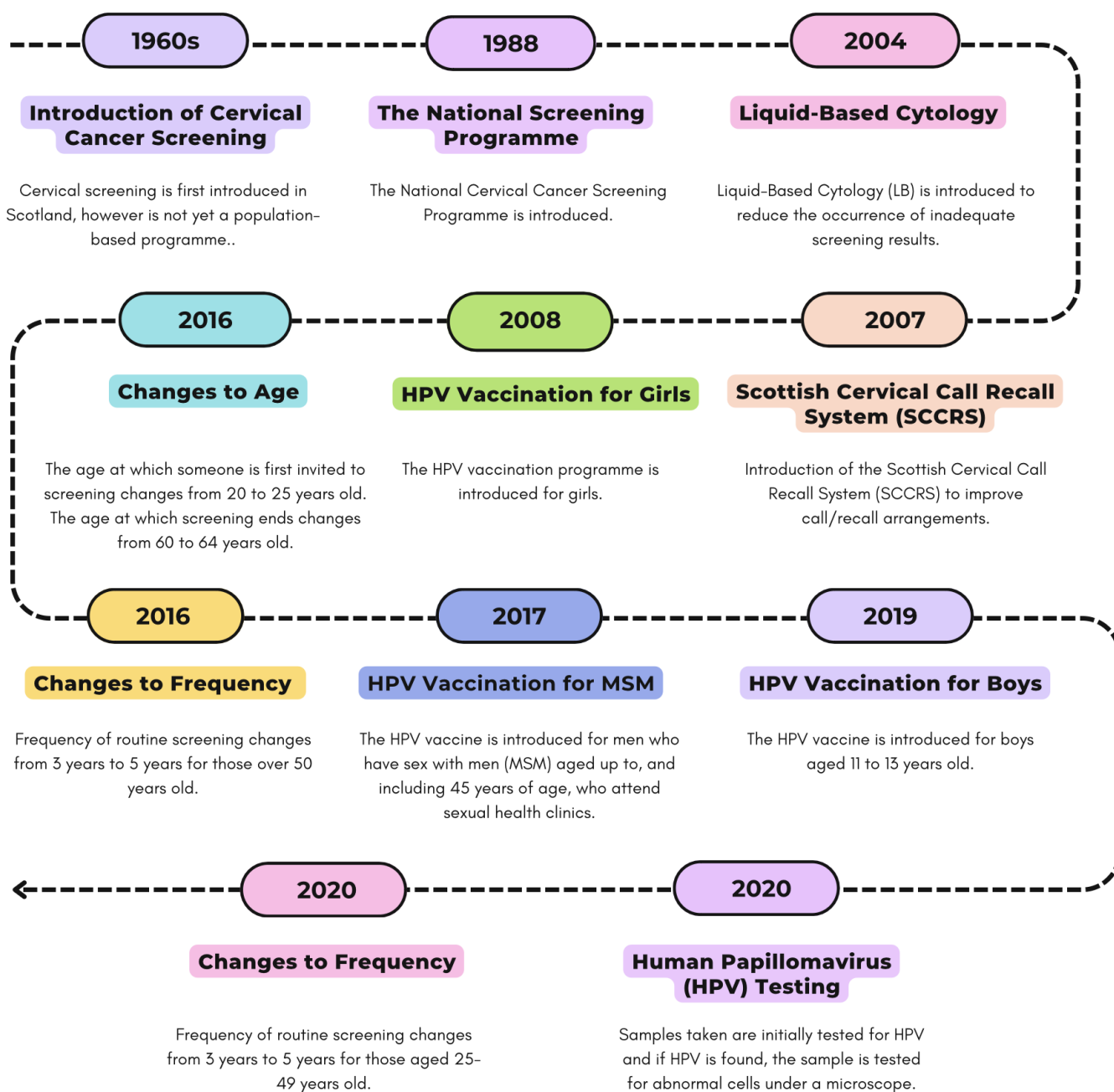
CC screening programmes were introduced in Scotland in the 1960s as a means of taking a preventative approach to health (Figure 4). Pilot trials began across the UK, however this was hampered by clinician shortages and inconsistent funding, preventing immediate population-wide coverage (Robson-Mainwaring, 2020). Over the next couple of decades, public awareness campaigns were developed while government funding continued to be sporadic. While evidence of effectiveness remained limited, Aberdeen's early programme demonstrated reduced mortality rates (Macgregor & Baird, 1963). Following a pivotal Lancet editorial highlighting increasing CC deaths, the SCCSP was established in the 1980s, offering triennial screening to women aged 20-60 years old (Robson-Mainwaring, 2020). This yielded significant results, with CC incidence decreasing by 47.7% between 1986 and 2005 (SG, 2008).

Following relatively slow progress, the 2000s saw a surge in changes to the SCCSP. In 2004, Liquid-Based Cytology was introduced to reduce inadequate test results and thereby the number of women needing to repeat their test. Following the NHS QIS 'Standard for Cervical Screening' stating that 80% of test results should be received within 4 weeks, the SCCRS was introduced in 2007.

The SCCRS aimed to improve call/recall of patients and to enable more efficient reporting of results (SG, 2008). This system allowed NHS boards to ensure they were meeting standards and to see whether changes needed to be made. NHS Scotland includes 14 territorial boards, 8 special boards and a public health body (Figure 5). Territorial boards are responsible for the health of their local population, and special boards support them by providing various specialist and national services. Each board works together with other bodies to fulfil the Scottish Government's outcomes and standards, including that of the Standards for Cervical Screening.

FIGURE 4.

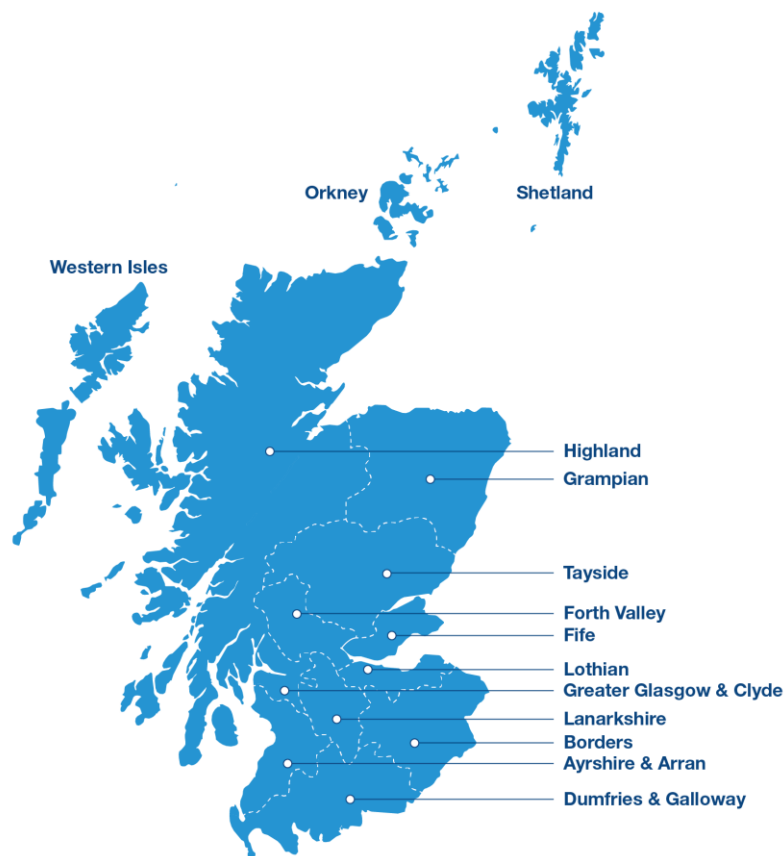
Timeline of changes to the cervical cancer screening pathway



In 2008, the HPV vaccination programme was introduced in Scotland. The vaccine protects against many types of HPV which can cause cancer but not all, therefore cervical screening is still required. This was offered to the routine cohort of S1 female pupils (aged 11-13 years old), alongside a ‘catch-up’ cohort of girls aged 13-17 years old.

FIGURE 5.

Map of NHS boards (NHS Scotland, 2022)



Following recommendations in 2017 from the Joint Committee on Vaccination and Immunisation (JCVI), the programme expanded to include men who have sex with men (up to age 45) and boys aged 11-13 years (JCVI, 2018).

Over the 2010s, various changes were made to the age range and frequency of screening. In 2016, the age was increased from 20 to 25 years old and was extended from 60 to 64 years old following recommendations by the UK National Screening Committee (NSC) (SG, 2016). This followed a review which concluded that those over 60 were still at risk. It was also concluded that it was not effective to screen those under 25 due to CC being very rare in this group; the review concluded it would cause more harm to screen due to high numbers of women unnecessarily receiving treatment, leading to complications that could affect them if they were to become pregnant (NSC, 2024). Frequency was changed to every 5 years in those over 50 due to this providing the same level of protection. In 2020, the

frequency was changed for those aged 25-49 years old, bringing this in-line with those over 50 years old. This was due to recommendations from the NSC, who advised that 5yearly screening would pick up any changes in time due to HPV taking many years to develop into cancer (PHS, 2022). Whilst England and Northern Ireland continue to offer 3-yearly testing for those aged 25-49 years old, Scotland and Wales subsequently updated their guidelines (Figure 6; data from Cancer Research (2023b)). Screening for those testing positive for HPV continues to occur yearly.

FIGURE 6.
Cervical cancer screening across the UK

CERVICAL SCREENING	SCOTLAND	WALES	NORTHERN IRELAND	ENGLAND
Age	25 to 64 years old			
Frequency	Routine: Every 5 years HPV-positive: Every year		25-49 years old: Every 3 years 50-64 years old: Every 5 years HPV-positive: Every year	
Test	Primary test: HPV screening If HPV-positive: Liquid Based Cytology			
Coverage	2021-22: 69%	2021-22: 70%	2022-23: 70%	2022-23: 69%

In 2020, HPV testing became the primary screening test in Scotland, due to its increased sensitivity and effectiveness in identifying those at risk of cancer (PHS, 2022a). Primary HPV screening, along with self-sampling, are recommended within WHO guidelines and in guidance from the International Agency for Research on Cancer (WHO, 2022; Bouvard et al., 2021). Previous cytology screening had become less effective due to the success of the vaccination programme, where no new CC cases have occurred in fully vaccinated individuals who received the vaccine at age 12-13 (PHS, 2024). The move to HPV primary testing is projected to prevent approximately 487 cervical cancers annually in the UK (Castanon et al., 2017), however, research indicates a need for enhanced public education about HPV and its relationship with CC (McBride et al., 2020).

1.2 HPV SELF-SAMPLING

HPV screening provides the opportunity for self-sampling, currently being considered for roll-out in Scotland. Self-sampling allows individuals to take the swab themselves at home, offering comparable diagnostic accuracy to clinic-based samples while potentially addressing established barriers to screening attendance, including logistical challenges and personal concerns such as negative past experiences and procedural discomfort (Arbyn et al., 2018; Robb, 2021). By eliminating speculum examination, self-sampling has demonstrated increased participation among non-attenders (Gok et al., 2012; Chorley et al., 2016).

In March 2024, a petition was lodged with the Scottish Parliament calling on the Scottish Government to introduce self-sampling as a means of eliminating CC (SG, 2024b). The government committed to reviewing NSC recommendations, including findings from Dumfries and Galloway's research on uptake in non-attenders (Wedisinghe et al., 2022). YouScreen, a study piloting self-sampling in areas of London with non-attenders, was one of the first steps towards self-sampling being rolled-out across the UK (NHS North Central London Cancer Alliance, n.d.). This demonstrated significant success, particularly with opportunistic delivery (n=6061, 65.5% completion rate) compared to tests delivered via mail (n=2777, 12.9%) (Lim et al., 2024). Opportunistically provided samples were considered substantially more efficient, acceptable and cost-effective. It increased non-attender screening by 22% monthly, notably reaching underserved populations - defined as marginalised groups of people with zero or limited access to resources - including ethnic minorities (64%) and those from deprived areas (60%) (Lim et al., 2024). YouScreen supported individuals to participate who had not previously attended including transgender men, individuals with intellectual difficulties and those with trauma.

The HPVvalidate study corroborated these findings. Results demonstrated that 75% of participants found the kit "excellent" to use, with 85% stating they would like the choice of self-sampling in future (Waller et al., 2024). Four self-collection workflows met validation requirements and could therefore be considered for further exploration for use with the public (Mathews et al., 2024). Further research observed that the specificity of self-sampling was comparable to clinician-taken samples, identifying some positive results in men who have sex with men exclusively (Ni et al., 2023).

Self-sampling is successfully available as an option in approximately 17 countries, either for everyone (e.g., Albania and Kenya) or specifically for those underserved (e.g., Australia and Finland) (Serrano et al., 2022). In some countries, the kit is provided via mail or opportunistically in-clinic; in other areas this is facilitated by a healthcare professional in clinic or at home (Australian Government, n.d.). While Australian stakeholders report enthusiasm for its potential, implementation challenges include insufficient healthcare provider information and laboratory processing capacity (Zammit et al., 2022). Serrano et al. (2022) agree that implementation is challenging, with success requiring comprehensive guidance, efficient sample transportation, and robust follow-up processes (Hawkes et al., 2020).

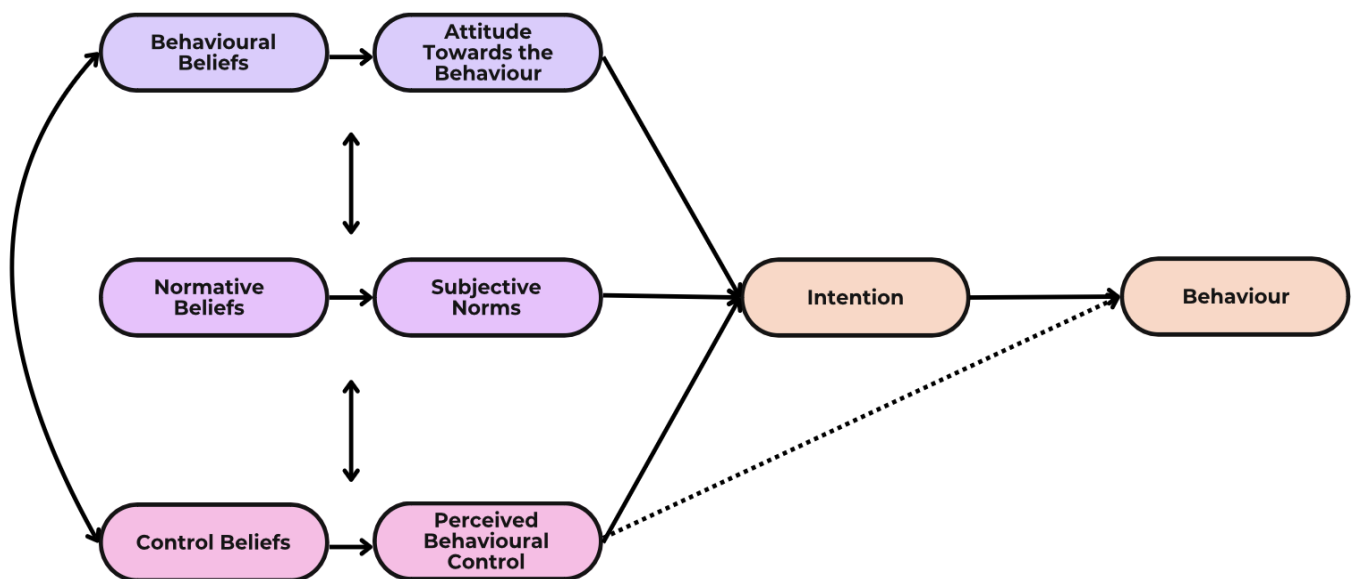
Multiple systematic reviews confirm high acceptability of self-sampling, particularly regarding convenience and privacy (Kamath et al., 2021; Nishimura et al., 2021). A meta-analysis of 33 studies demonstrated increased engagement through mail-out or when clinicians delivered kits directly to their door (Yeh et al., 2019). Integration with clinical systems could facilitate opportunistic offering to non-attenders during routine GP visits (Lim et al., 2024). Lim et al. noted self-sampling's potential to overcome barriers to screening, emphasising its potential to increase engagement in underserved patients.

1.3 SCREENING AS A HEALTH BEHAVIOUR

Engagement in cancer screening can be understood through behaviours and cognitions, within the context of social determinants of health and environmental factors. For screening to have a significant impact on incidence, uptake must be optimal. Understanding factors involved in health-related decision-making is vital to describe and predict engagement with screening. Theoretical frameworks are one such way we can understand determinants that may impact engagement. The Theory of Planned Behaviour (TPB; Ajzen, 1991) posits that screening engagement is determined by attitudes, subjective norms, and perceived behavioural control (Figure 7). TPB-based interventions have demonstrated efficacy in increasing cervical screening participation (Dsouza et al., 2021). Research indicates however, that due to cognitive and social functioning impairments, individuals with ID may experience lower understanding of screening benefits and greater distress, potentially impacting engagement (Parish et al., 2008).

FIGURE 7.

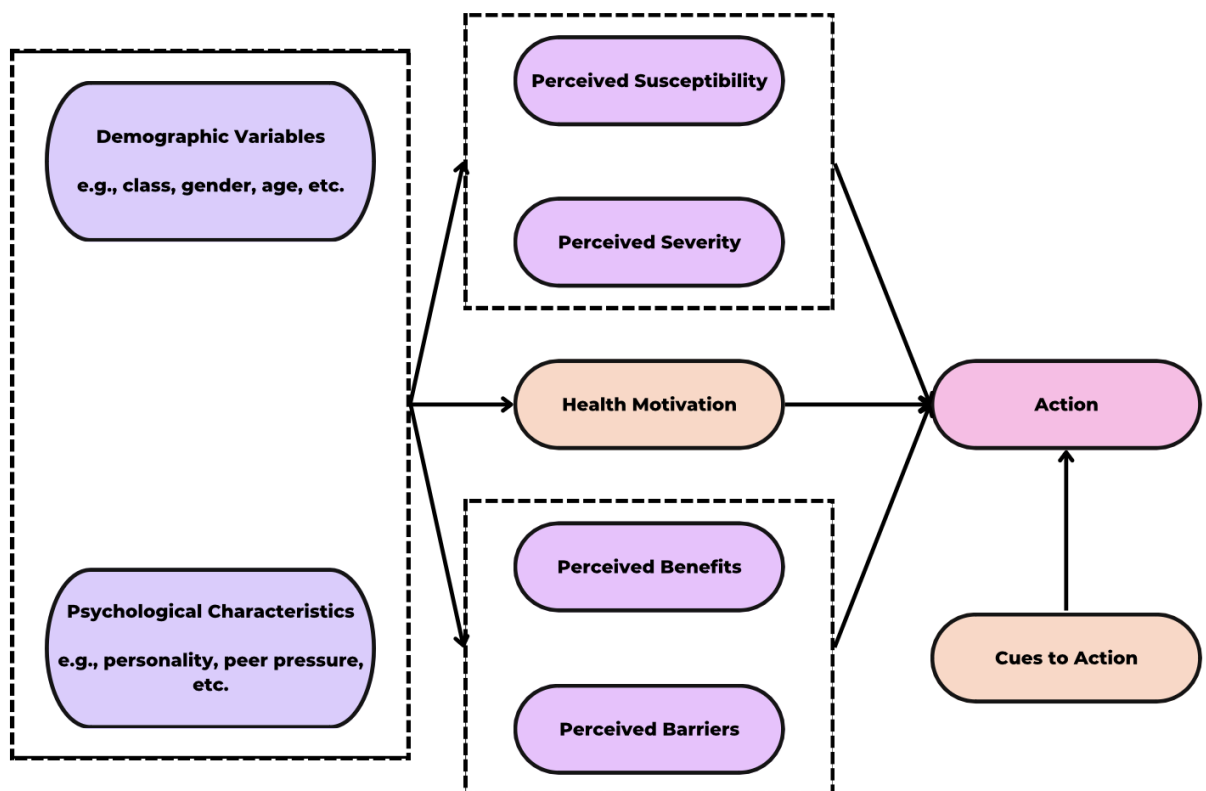
Theory of Planned Behaviour (Ajzen, 1991)



The Health Belief Model (Janz & Becker, 1984; Figure 8) is another framework for understanding behaviour (Belay et al., 2023). This describes and predicts engagement considering how individuals perceive health threats (risk of CC), with the expectation that demographic variables and psychological characteristics influence motivation to engage. Other constructs which influence motivation to engage in protective health actions include perceived fear of the severity of a disease (e.g., negative consequences of getting CC including health and economic difficulties); beliefs about susceptibility (e.g., those who believe they are at high risk of CC are more likely to attend screening); perceived benefits (e.g., beliefs about positive outcomes associated with screening); and perceived barriers (e.g., beliefs about obstacles to screening). This model helps us to understand factors which impact each construct, either increasing or decreasing motivation to attend screening. Demographic variables - gender, age, class, - and psychological characteristics, are generally static variables. Perceptions, however, are constructs which can be targeted. Recent UK data reveals limited public understanding, with 77.6% of 1,930 women demonstrating an awareness of HPV, but a much lower 12.2% comprehending the screening procedure (Waller et al., 2024). Strong awareness campaigns need to educate around the risks, benefits and importance of screening to support informed decision-making.

FIGURE 8.

The Health Belief Model (Janz & Becker, 1984)

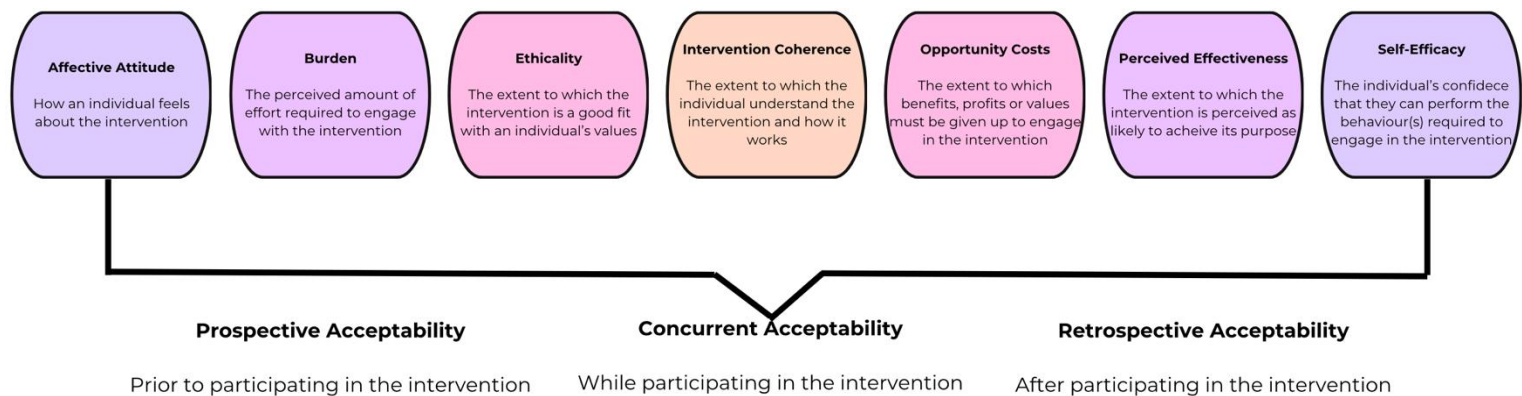


For novel initiatives like self-sampling, acceptability must be evaluated. Sekhon et al. (2017) explain that this is a complex concept which incorporates attitudes, anticipated burden, beliefs around effectiveness and ethicality. The Theoretical Framework of Acceptability (TFA; Sekhon et al., 2017; Figure 9) is a structured means of assessing whether a health initiative is acceptable to those receiving or delivering this, through exploration of their cognitive and emotional responses. With self-sampling, individual decisions should be based on informed choice and therefore reflect beliefs and attitudes. This means that people have the right to decline to participate in screening as they have autonomy to exercise choice over what happens to their body (Parker et al., 2017). The difficulty lies - particularly when considering people with ID and potential low health literacy – with ensuring this decision is made with *informed* consent. Health literacy is the ability to access, understand and assess health information to make judgments and decisions about one's health (Sorenson et al., 2012). A systematic review by Kobayashi et al. (2016) highlighted the extent of this as a public health challenge, where between one-third and one-half of individuals in the European Union demonstrated low health literacy. This impacts ability to process health information and take appropriate action (Paillaud et al., 2025). It is therefore vital to consider methods of improving health literacy in patients, to increase acceptability around self-sampling and

empower individuals to make decisions about their health. Using the TFA for both patients and HCPs could support decisionmakers to make changes which would enhance acceptability of self-sampling in both groups.

FIGURE 9.

The Theoretical Framework of Acceptability (Sekhon et al., 2017)



1.4 SCREENING ATTENDANCE IN THOSE WITH INTELLECTUAL DISABILITIES

A group where CC screening attendance has consistently been the lowest is those with IDs (Ward et al., 2024). An ID is defined as significant deficits in cognitive, functional and adaptive skills, usually observed where an individual's IQ is <70 (Shogren & Turnbull, 2010). There are an estimated 1.5 million people with an ID in the UK (Mencap, 2020). Individuals with ID experience significant inequalities, resulting in a premature mortality gap of ~20 years (O'Leary et al., 2018). In Scotland, CC screening attendance among eligible individuals with ID is approximately 30% (Jo's Cervical Cancer Trust, 2020), significantly below both the general population attendance rate of 69% and the WHO's recommended minimum target of 70% for achieving positive mortality outcomes (WHO, 2021b). Data comparing those with ID to the general population shows a clear trend of higher cancer deaths despite an often-lower comparable incidence rate across cancer types (Ward et al., 2024). Research has consistently highlighted lower attendance in cancer screening in this group which may also impact on cancer statistics, with cases underdiagnosed and underreported (McCowan et al., 2019).

A recent systematic review by Power et al. (2024) noted that, in order for the WHO's global strategy of cervical cancer elimination to be successful, elimination must also be achieved for underrepresented groups, including people with an ID. Power et al. highlight that, despite people

with ID demonstrating unique risk factors for CC, there has been little focus on the barriers and facilitators to screening for this group. Multiple barriers to screening attendance have been identified across the literature for people with ID, including comprehension difficulties with invitation letters, insufficient appointment duration, physical discomfort, attitudes of professionals, and inadequate resource accessibility (Watts, 2008; Gribben & Bell, 2010; Doherty et al., 2020; Jo's Cervical Cancer Trust, 2020). Power et al. also highlight additional barriers within their review including insufficient time to prepare for screening and lack of confidence in HCP in relation to communicating with those with ID. Misconceptions of HCPs have previously resulted in inappropriate removal of women from screening programmes based on assumptions about sexual activity or undisclosed trauma history. This is particularly concerning given that women with ID experience sexual assault at twice the rate of the general population, with 5% reporting such incidents between 2018-2020 (Office for National Statistics, 2021).

The Scottish Government's 2020 Screening Inequalities Fund prioritises improving accessibility for individuals with ID, building upon initiatives established through the 'Keys to Life' learning disability strategy (SG, 2019). Although research remains limited, a comprehensive study of 16,767 individuals in Korea revealed that those with disabilities were more likely to receive late-stage CC diagnoses, receive lower levels of treatment and face higher mortality rates compared to individuals without disabilities (Choi et al., 2021). Findings underscore the critical importance of developing and adapting screening programmes, offering modalities like self-sampling to reduce health inequities.

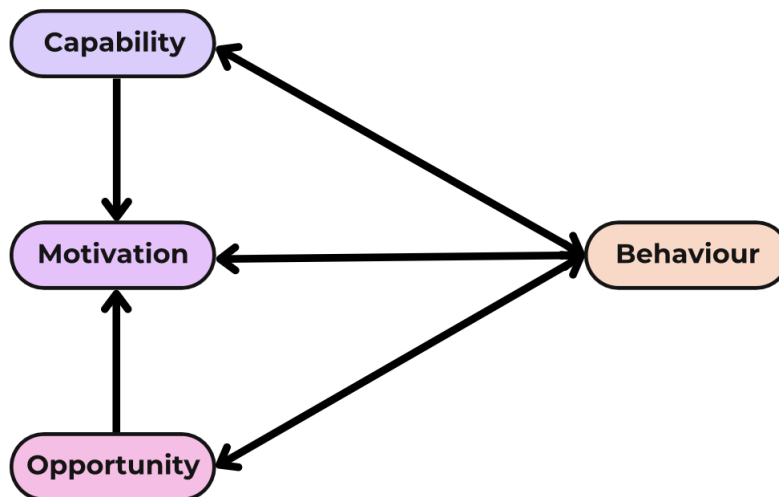
1.5 HPV SELF-SAMPLING AND INTELLECTUAL DISABILITIES

Choice could be the key to achieving the WHO's goal of global elimination of CC. Jo's Cervical Cancer Trust (2019), the UK's leading CC charity prior to their closure after two decades in 2024, proposed that self-sampling could enhance accessibility for women with disabilities. They specifically emphasised the need for additional research to determine optimal implementation strategies to support engagement. YouScreen demonstrated comprehensive accessibility considerations in their patient-facing materials employing co-development approaches and providing multilingual resources, including written and pictorial information, alongside dedicated helpline support (Lim et al., 2024). Their methodology incorporated various engagement strategies, such as primer letters, online campaigns, and pre-paid return envelopes. All materials considered the COM-B model (Michie, 2011), aiming to increase both capability (*providing specific written instructions*)

and opportunity (*providing a pre-paid envelope to post back*) thereby potentially increasing participant motivation to complete screening procedures (Figure 10).

FIGURE 10.

COM-B Model of Behaviour Change (Michie, 2011)



HCPs across Scotland must develop a thorough understanding of the specific needs and requirements of individuals with ID to ensure equitable access to self-sampling options. Mencap (2017) outlines several practical approaches to enhance equality for individuals with ID, including staff training programmes, extended appointment durations, accessible resources, and jargon-free communication incorporating visual aids where appropriate. Additionally, comprehensive and accessible information regarding what happens after screening should be provided, encompassing result communication methods, interpretation guidance, and timeframes.

1.6 REFLEXIVITY

I am a Trainee Health Psychologist, who worked full-time within NHS mental health services as I fulfilled each competency on the professional doctorate. Conducting the initial stages of this research whilst working in the NHS provided me with an understanding of the structure and inner workings of the organisation and provided access to contacts to support with survey recruitment. My role also provided experience of working with young people with ID and increased motivation to explore ways to improve accessibility of services for this group. My training and experience supported with running focus groups, communicating effectively and building rapport. During this

project, I moved into a new role as a Senior Policy Coordinator for an alcohol advocacy charity. This enabled me to consider research from a policy perspective, understanding the work required to enable change, alongside the complexities of decision-making within government.

I have a personal interest in this topic due to being female with personal experience of attending CC screening in Scotland. I have a close friend who was diagnosed with CC at a later stage who recognised that fear had prevented her from attending screening earlier. My perspective as a Trainee Health Psychologist considers that engagement in public health interventions and cancer screening can be understood through behaviours and cognitions, which are influenced by the social determinants of health and other relevant factors. I am aware that imposing one's own beliefs and perceptions on the research process is an inherent aspect of qualitative research; it does not aim to be free from bias but to instead be transparent and accountable. Qualitative research acknowledges the subjectivity of the researcher and I therefore engaged in reflexivity throughout the research process to examine my positionality. I reflected on how my background, beliefs and experiences may have shaped the study design, process and analysis within a reflective diary. This was discussed within supervision; during the refinement of codes and themes, my supervisor challenged and queried decisions made, allowing me to consider final codes and themes with greater objectivity while not losing the unique lens that my own perspective brings.

1.7 THE CURRENT STUDY

Understanding the perspectives of both HCPs and individuals with ID across Scotland regarding self-sampling is essential, as their engagement and acceptance will be crucial to the initiative's success. This investigation is particularly timely following YouScreen, as the UK approaches a potential nationwide implementation of self-sampling, which has been specifically identified as a strategic component in Scotland's efforts to address screening uptake disparities (SG, 2023). This research aims to provide comprehensive insights into barriers to screening attendance and to increase awareness among HCPs at each stage of the CCSP. Gathering perspectives from individuals with ID regarding the self-sampling kit prior to its implementation could yield valuable insights for optimising accessibility. The study followed the timeline outlined in Figure 11. This project is publicly available on Open Science Framework: <https://osf.io/uzchp/>

This research has five overarching aims:

1. Gain insight into healthcare professionals' views in Scotland on the introduction of HPV self-sampling,
2. Gain insight into healthcare professionals' views on the barriers and facilitators to accessing self-sampling,
3. Understand healthcare professionals' views and opinions on how self-sampling may be advantageous or disadvantageous,
4. Understand the views and opinions of individuals with intellectual disabilities on the self-sampling kit,
5. Gain insight into the views of individuals with intellectual disabilities on the barriers and facilitators to using self-sampling and accessing cervical screening.

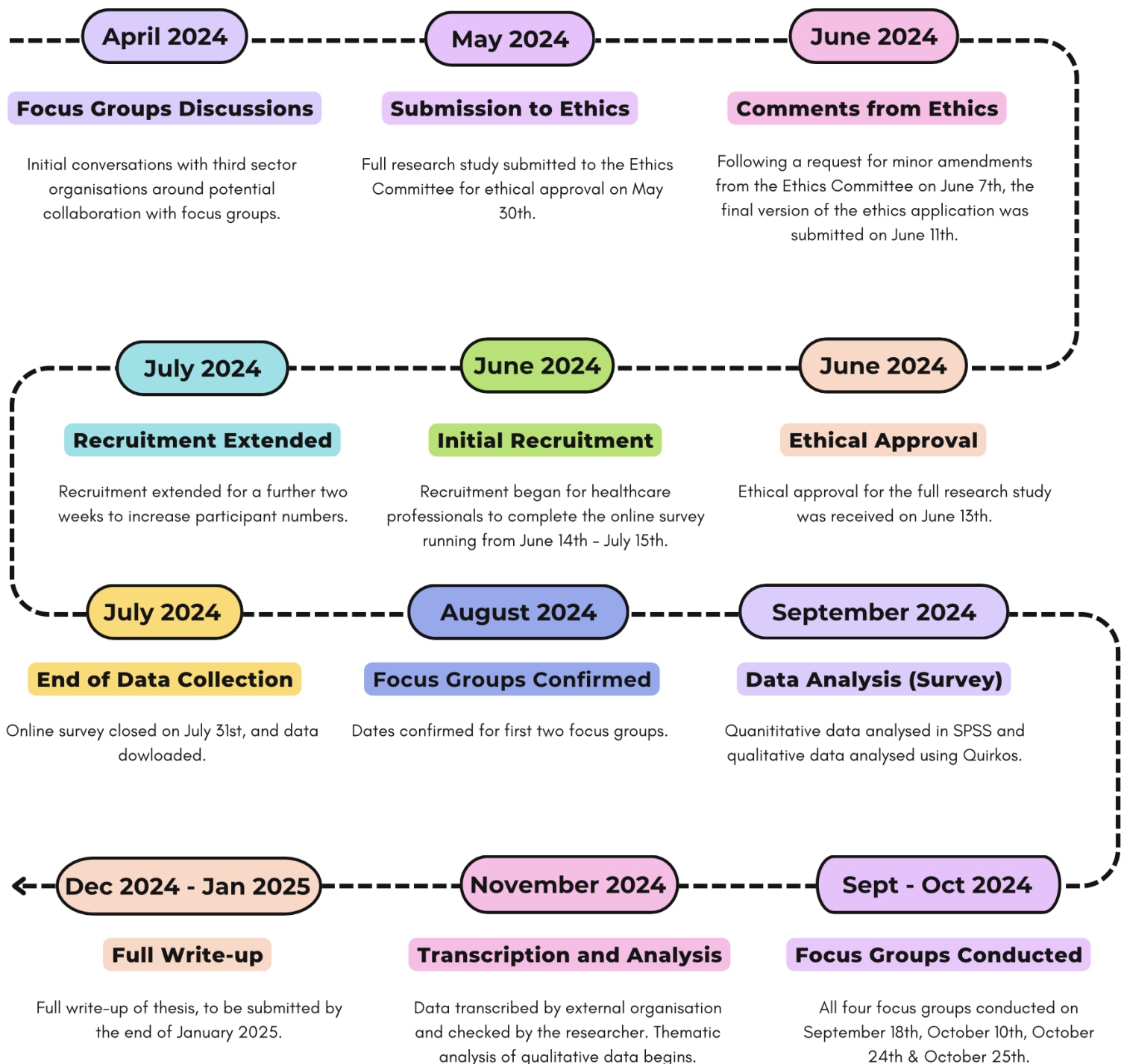
1.8 RESEARCH QUESTIONS

Throughout this thesis, the following two questions will be answered:

1. What are the views of healthcare professionals involved in a patient-facing role in the cervical cancer screening pathway in Scotland around HPV self-sampling for the public and those with intellectual disabilities (including knowledge, advantages/disadvantages, barriers/facilitators)?
2. What are the views of those with an intellectual disability who have a cervix in Scotland and who are eligible for screening, around cervical cancer screening and HPV self-sampling (including views on the presentation of the sampling kit itself)?

FIGURE 11.

Research Timeline



1.9 STRUCTURE OF THESIS

This thesis examines cervical cancer screening and self-sampling among individuals with intellectual disabilities in Scotland through two empirical studies. The research is structured as follows:

- Chapter 2 presents a comprehensive analysis of an online survey conducted among HCPs working in patient-facing roles within Scotland's CCSP. This encompasses the methodological approach, survey findings, and a detailed discussion of results.
- Chapter 3 details the qualitative investigation conducted through focus groups with individuals with ID. This includes the methodological framework, analysis of focus group data, and discussion of themes.
- Chapter 4 synthesises findings from both studies, examining implications of the HCPs survey and focus group investigations. This concluding chapter addresses study limitations and proposes directions for future research.

CHAPTER 2

STUDY 1: SURVEY OF HEALTHCARE PROFESSIONALS

2.1 INTRODUCTION

HCPs play a pivotal role in reducing cancer incidence and mortality through their essential function in patient education and cervical screening promotion (Abdallah et al., 2016). Insufficient professional education regarding CC can result in suboptimal patient care and information dissemination (Li et al., 2023). The COM-B model (Michie, 2011) demonstrates that enhanced capability correlates with increased behavioural motivation; HCPs who feel competent in providing screening guidance are more likely to engage in patient education, thereby improving patient understanding (Drivenes et al., 2019).

Health advice from professionals often has greater validity due to messenger credibility, with the public demonstrating increased attention to information from perceived credible sources (Biswas et al., 2006). Biswas et al. emphasise that expert endorsement enhances public acceptance, underscoring the potential influence of HCPs in facilitating self-sampling acceptance. Nelson-Brantley and Ford (2017) note however, that approximately two-thirds of healthcare changes fail due to factors including staff demotivation, inadequate communication, and concurrent change implementation. The 2010s brought a lot of change within the CC screening programme, as illustrated in Figure 4 (Chapter 1), adding to the existing demands on primary care staff. The COVID19 pandemic further intensified workplace pressures, significantly affecting staff wellbeing. A 2020 UK health workforce survey revealed that over half of participants reported mental health impacts, with 20% considering leaving the public health sector (Thomas & Quilter-Pinner, 2020). It is therefore essential that any changes implemented going forward take this into consideration to reduce the chances of overwhelming staff and to encourage buy-in.

Understanding HCP perspectives on effective practices and implementation requirements is therefore crucial for successful self-sampling roll-out. While research examining HCP views on self-sampling has been conducted in England through YouScreen (Lim et al., 2024), this study represents the first exploration of clinician perspectives across Scotland. Given the distinct differences between Scottish and English CC screening programmes, regional perspectives may vary, with Scottish HCPs potentially holding unique concerns and beliefs.

Understanding their receptiveness to, and acceptance of, self-sampling implementation is therefore essential.

This study employed a mixed methods approach, utilising an online survey to examine HCP knowledge and opinions. Qualitative data was analysed using social constructionist thematic analysis to explore features, similarities and variation between responses. Following ethical approval being granted, HCPs who worked in a patient-facing role on the CCSP in Scotland were recruited. This chapter will describe methods used, findings of the research and discussion of results.

2.2 METHODOLOGY

2.2.1 RESEARCH DESIGN AND ETHICAL APPROVAL

The following question was addressed:

What are the views of healthcare professionals involved in a patient-facing role in the cervical cancer screening pathway in Scotland around HPV self-sampling for the public and those with intellectual disabilities (including knowledge levels, advantages/disadvantages, barriers/facilitators)?

An anonymous online survey was developed that incorporated the collection of quantitative and qualitative data. This format was chosen to allow for a greater number of responses to be gathered and collected across Scotland, including rural and remote locations. This examined current knowledge and awareness levels around self-sampling; it explored attitudes and beliefs relating to advantages/disadvantages, barriers/facilitators and what information would be required prior to its introduction. Secondary analysis explored differences across groups, including duration of time in role and whether participants were based in an urban or rural location. The final two questions utilised a story completion approach, a flexible approach grounded in a social constructionist framework and used to discover hidden unconscious meanings behind stories written by participants (Clarke et al., 2017). These specific questions introduced the beginning of two scenarios (see 2.2.3), where participants were required to describe what they would do next.

This study aims to understand the beliefs and needs of HCPs prior to a roll-out of self-sampling, and to detail what they believe could lead to success in terms of increasing CC screening numbers.

Ethical approval was granted by The University of Stirling NHS, Invasive or Clinical Research Committee (NICR) (Reference Number: NICR 2024 17404 13777; 13.06.24) (Appendix 1).

2.2.2 PARTICIPANTS AND RECRUITMENT

An a priori G*Power 3.1 (Faul et al., 2007) calculation was conducted to establish required participant numbers. A power calculation based on an Independent Means T-Test specified a minimum sample size of 102. This would detect a medium effect size (0.5) of the group with experience of working with those with intellectual disabilities on the outcome relating to knowledge of YouScreen, with a power of 0.8 and alpha set at 0.05. Participants were recruited via the researcher's professional networks at NHS Scotland with individual email invitations (Appendix 5) sent from the researcher to service leads; specialist NHS Gynaecological and Obstetrics teams; GP surgeries (746 surgeries across every health board, plus practice manager contacts for 2 health boards where individual surgery details were unavailable); direct clinical contacts of junior to senior patient-facing practitioners across all 14 NHS Scotland territorial health boards. Invitations to participate were also sent through local service updates by team leads and by liaising with a network of expert practitioners with a special interest in cancer screening and via social media (e.g., LinkedIn). Sexual health clinics who provided cervical screening were also contacted, both via post and email. Principal inclusion and exclusion criteria are highlighted in table 1.

TABLE 1.*Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
• A healthcare professional within NHS Scotland who currently works, or has previously worked, within a patient-facing role as part of the CCSP. • Aged 18 years old and over. • Resident of Scotland. • Able to consent to take part in an online survey.	• Someone who does not currently work, or has not previously worked, within a patient-facing role as part of the CCSP in NHS Scotland. • Aged under 18 years old. • Not resident in Scotland. • Unable to consent to take part in an online survey.

Recruitment began in June 2024. Participants who had a current or previous patient-facing role in CC screening were invited to participate. Data collection initially ran for 4 weeks with 82 responses; following discussion within supervision, this was extended for 2 weeks due to contacts advising that staff were on leave for summer. There was no maximum number of participants set to allow anyone who wished to participate to do so. The study poster (Appendix 6) and link were sent to a total of 1,268 contacts via email and 30 contacts via post by the researcher; a snowball technique was applied to reach as many people as possible, with recipients encouraged to forward the invitation onwards. Between June 14th and July 31st, 2024, a total of 107 HCPs participated.

2.2.3 MEASURES***Online Survey for Healthcare Professionals***

Section 1. Demographics. Participants were asked 7 questions relating to demographics. Multiple-choice questions asked respondents their age, gender and ethnicity, with an open-ended question requesting the first half of the postcode where they worked in their role on the CC screening pathway e.g., EH54. Respondents were asked multiple-choice questions on how long they had worked in this role and whether they worked with people with ID.

Section 2. Knowledge and attitudes. Questions were created by the researcher (see Appendix 2 for full questions), who explored similar surveys conducted with HCPs on cancer screening including the *'National Survey of Primary Care Physicians Cancer Screening Recommendations and Practices: Breast and Cervical Cancer Screening'* (National Cancer Institute, 2006) and *'Personalised Breast Cancer Risk Assessment and Screening Mammogram Questionnaire for Healthcare Professionals'* (Brooks et al., 2021). Additional questions were added, informed by psychological theory and the COM-B model to ensure the research question would be answered (e.g., *What information do you feel that you would need before the introduction of HPV self-sampling in Scotland for the general public?*). Multiple-choice questions (n=4) explored knowledge and understanding of self-sampling, and whether participants felt self-sampling was a good idea and should be promoted. Open-ended questions (n=7) with an automatic character limit for responses of 1,024, were included to gain insight to perceived advantages and disadvantages, barriers and facilitators.

Section 3. Story completion tasks. Respondents were presented with 2 story completion tasks. These aimed to explore how HCPs would approach two scenarios with patients with ID, and to see whether there were any preconceptions when working with individuals with ID. Completion instructions stated: *"The following two tasks provide scenarios which you have been presented with. Please provide a short paragraph, continuing the story based on how you would approach this situation"*. Participants were not provided with a word limit. The pre-determined 'stems' for each question are detailed below:

Story 1.

A 32-year-old female, whom you have not met but know has been diagnosed with an intellectual disability from her patient record, enters your clinic room. You can see that they have not ever attended for a cervical screening appointment. They advise that they have never been in a sexual relationship with a partner and so they do not need to be screened. What would you do next?

Story 2.

A 41-year-old female with an intellectual disability has attended for an appointment with you for a routine medication review. She unexpectedly asks for more information about cervical cancer screening for which she has never attended before. She is unsure if she needs to have a test and feels anxious about the idea of the test itself. What would you do next?

JISC was the selected platform to host the survey as this is the approved survey tool within the NHS. This allowed participants to access and complete the survey following receipt to their work email, rather than needing to access this on a separate device.

2.2.4 STAKEHOLDER INVOLVEMENT

It was important that survey questions were relevant and worded appropriately for the intended audience. PPI input was received, with questions discussed individually with a Specialist Nurse, Nurse Practitioner and Specialty Doctor in NHS Lothian, where they suggested minor amendments relating to concision of one question and adjustment of wording within another, which led to the final set of questions. They then conducted a trial run through the survey to ensure that everything flowed correctly and to gain an average completion time which could be used to inform potential participants of the expected time to complete (17 minutes).

2.2.5 CONSENT AND CONFIDENTIALITY

As participants accessed the survey via the link or QR code, they were presented with an online copy of the Information Sheet (Appendix 3) and Consent Form (Appendix 4). Participants were provided with the contact details of the researcher, their supervisor and an independent faculty member to allow participants to get in touch prior to commencement. All participants were assigned a unique ID code by JISC to enhance confidentiality. Participants were able to return to finish the survey later via a unique link based on their ID code or by returning to the original survey link using the same IP address. All participants were informed that they could withdraw at any time without providing a reason. They could contact the researcher via email to request data be removed prior to data analysis, quoting their participant ID that was provided upon completion/partial completion of the survey; this could also be accessed by returning to the survey link.

Processes for collection and storage of data adhered to the requirements of the Data Protection Act 2018. Data from the survey was downloaded into a password-protected Excel file and individual responses were permanently deleted from JISC. Data was stored in the researcher's university SharePoint folder to which only the researcher and their supervisor have access.

2.2.6 PROCEDURE

The invitation email and study poster were emailed to prospective participants. Three reminder emails were manually sent on weeks 2/4/5 to all contacts by the researcher which led to a spike in participant numbers, however there was at least one completed response each day. For postal contacts, the invitation, study poster and researcher's contact details were sent via first-class post. Recipients were advised to click the link in the email to proceed, where they were presented with the participant information sheet and were provided with the opportunity to contact the researcher with any questions. The study poster included a weblink and QR code to allow ease of access to the survey. Participants clicked 'next' to the online consent form where they acknowledged each statement to confirm they had read and understood these. Once participants agreed to participate, they clicked 'next' which took them into the survey.

Participants could work through the survey in one sitting or return at any point during the 6 weeks. Participants were required to work through each section of the survey in order. Once participants had finished the final section, they were directed to a final screen, thanking them for their time and contribution to this project; the contact details of the researcher, their supervisor and independent contact were provided. At the end of data collection, responses were downloaded to a Microsoft Excel spreadsheet for data cleansing and deleted from JISC.

2.2.7 ANALYSIS

Quantitative data was analysed using SPSS and qualitative data using Quirkos/Microsoft Excel. Descriptive analysis explored the proportion of participants with particular responses. Inferential statistics, tests of associations (Mantel-Haenszel test of trend, Chi-square test), odds ratios, and tests of difference (Jonckheere-Terpstra test, Mann-Whitney U test) were used to determine similarities/differences between:

- Awareness of YouScreen depending on experience of working with ID. This was analysed to explore whether those who have experience of working with ID may be seeking out information about the YouScreen trial, potentially considering self-sampling to be a viable alternative to traditional screening methods for this group.

- Knowledge of self-sampling depending on duration of time in role/whether they worked in rural or urban locations/gender/age. This was analysed to explore whether particular groups were more likely to seek out information about self-sampling and whether knowledge levels were higher in certain groups.
- Beliefs as to whether self-sampling is a good idea depending on duration of time in role/whether they worked in rural or urban locations/gender/age. Linear regression was also used to explore whether knowledge levels predicted if participants thought self-sampling was a good idea.
- Beliefs as to whether self-sampling should be promoted depending on duration of time in role/whether they worked in rural or urban locations/gender/age. This was analysed to explore whether certain groups were more likely to believe that self-sampling should be promoted and to understand which groups may be less likely to say self-sampling should be promoted.

A social constructionist thematic analysis was used for qualitative data (Braun & Clarke, 2006). As described by Clarke et al. (2019), this can provide an understanding of horizontal patterning across the dataset in response to the research question. This approach is exploratory and draws on social constructionist principles, allowing the researcher to identify a pattern within the data while recognising that respondents' descriptions within their responses and stories can be understood through their social context and cultural discourse (Braun & Clarke, 2006). This approach allows for curiosity around how HCPs construct the world around them, placing onus on subjectivity, rather than scientific or theoretical fact. It provides the opportunity to understand how HCPs construct the objects and subjects which they discuss within the context of their professional role, environment and culture. It allows exploration into how HCPs and their professional identities are constructed and positioned within psychological models and frameworks, and the ramifications this has for self-sampling.

Thematic analysis followed the six-step guide as described by Braun & Clarke (2006), with the researcher initially familiarising herself with the data by reading through each category of responses several times. Quirkos was used to organise and facilitate coding. Inductive coding was used to generate codes. Sections of data were labelled during a free coding process by the researcher, recording initial thoughts and reflections. This was initially done for each participant, followed by 'horizontal patterning', where codes were analysed across the dataset in response to the research questions. Following the completion of coding, themes were refined and semantic themes defined, creating a map with colour coding. Latent themes were then refined using the semantic theme map

in Excel. Codes and themes were discussed with the researcher’s supervisor, with revision and refinement leading to the generation of final themes.

2.3 RESULTS

2.3.1 Quantitative Analysis

Demographic Data

Data from 107 participants was collected over a 6-week period between June & July 2024 to answer research question one, with each respondent answering every survey question. Demographic data is available in Table 2. Most participants were female (94.4%, n=101), with remaining participants identifying as male. Most were aged 55-64 years old (n= 49). Due to only one participant being in the 18-24 category, they have been added to the 25-34 category for the remaining analysis, resulting in the 18-34 category. Participants were located across Scotland, with 61.7% (n=66) working in urban locations and 38.3% in rural locations, as classified by the Scottish Government Urban Rural 2-Fold Classification (SG, 2022; Figure 12). A total of 89.7% (n=96) participants currently worked in a patient-facing role on the CC screening pathway.

TABLE 2.
Demographic data

	Frequency	Percentage
AGE RANGE		
18-24 years old	1	0.9
25-34 years old	9	8.4
35-44 years old	22	20.6
45-54 years old	26	24.3
55-64 years old	49	45.8
GENDER		
Woman	101	94.4
Man	6	5.6
ETHNICITY		
Prefer not to say	2	1.9
White: English/Welsh/Scottish/Northern Irish/British	98	91.6

White:Irish	1	0.9
Mixed/Multiple Ethnic Groups	2	1.9
Other White: European	2	1.9
Asian/Asian British: Indian	1	0.9
Asian/Asian British: Chinese	1	0.9

LOCATION

Glasgow	18	16.8
Edinburgh	17	15.9
Isle of South Uist	1	0.9
Tweed	2	1.9
Kilmarnock	6	5.6
Kirkcaldy	1	0.9
Whitburn	1	0.9
Broxburn	1	0.9
Sutherland	1	0.9
East Dunbartonshire	2	1.9
Motherwell	2	1.9
Kilchrenan	1	0.9
Livingston	2	1.9
Outer Hebrides	3	2.8
Pitlochry	1	0.9
Dundee	5	4.7
Dumfries	1	0.9
Dumbarton	1	0.9
Berwickshire	1	0.9
Inverness	3	2.8
Melrose	1	0.9
Aberdeen	12	11.2
Falkirk	13	12.1
Paisley	5	4.7
Highlands and Islands	2	1.9
Aberfeldy	1	0.9
Perth and Kinross	1	0.9

Quantitative data for participants is listed in Table 3. Most had worked in a patient-facing role for over 10 years (54.2%; n=58) with only 3.7% working in this area for <1 year. A large number of participants, 87.9% (n=94), currently worked with individuals with an ID to some extent; a small proportion either had previous experience of working with individuals with an ID (6.5%) or had never done so (5.6%).

FIGURE 12.

Map of working locations of 107 survey participants

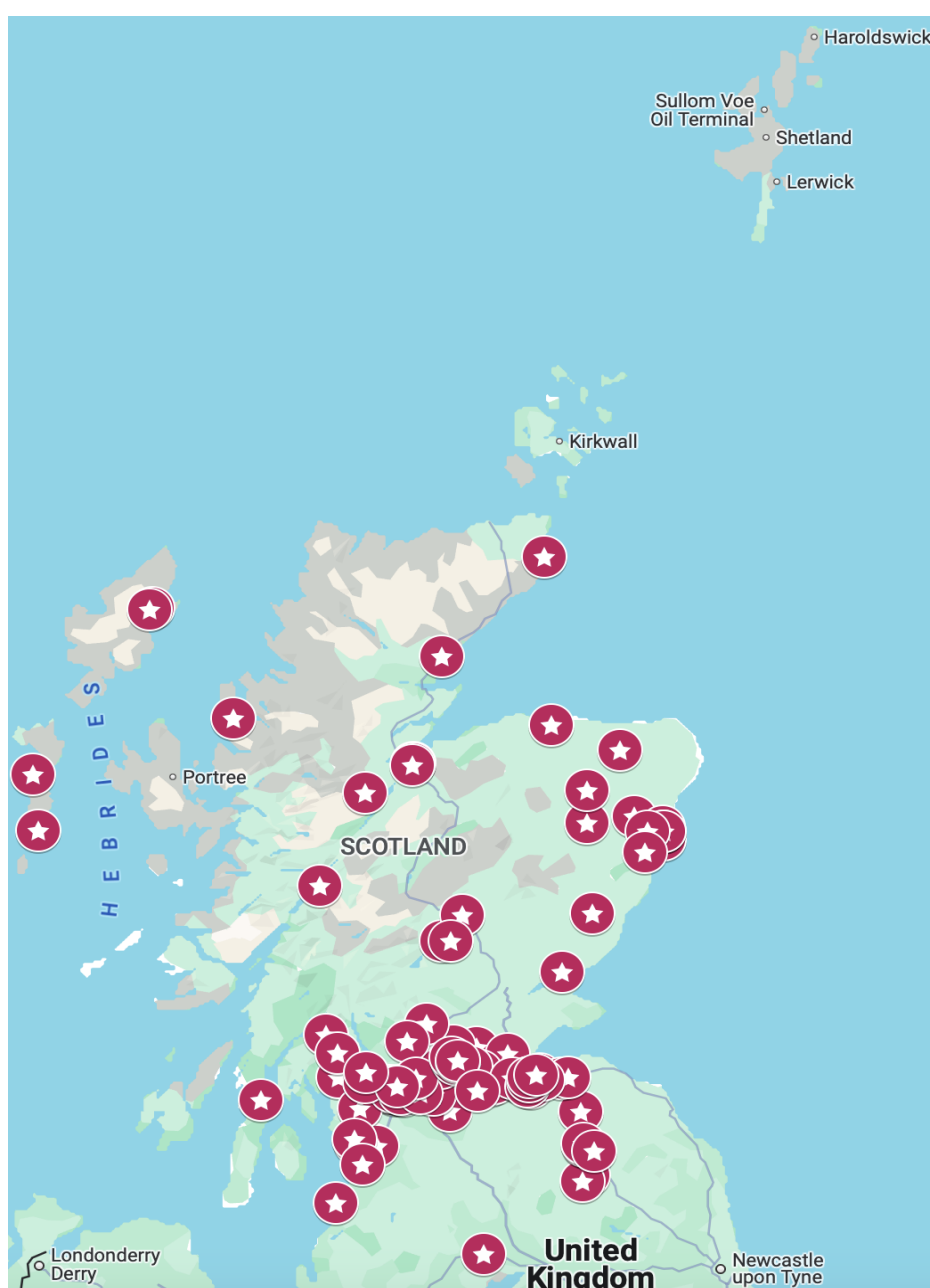


TABLE 3.*Response data for each quantitative survey question*

	Frequency	Percentage
ROLE DURATION		
Up to six months	1	0.9
Over six months, but less than a year	3	2.8
Between one and two years	12	11.2
Between two and three years	6	5.6
Between three and five years	7	6.5
Between five and ten years	20	18.7
Over ten years	58	54.2
EXPERIENCE WORKING WITH INTELLECTUAL DISABILITIES		
No, never	6	5.6
No, but I have previous experience of working with those with intellectual disabilities	7	6.5
Yes in my current role, but not often	83	77.6
Yes, a lot in my current role	11	10.3
AWARENESS OF YOUSCREEN		
Unsure	4	3.7
Yes	59	55.1
No	44	41.1
KNOWLEDGE OF SELF-SAMPLING		
I do not feel like I know anything about self-sampling	11	10.3
I know very little information about self-sampling	16	15.0
I know a little information about self-sampling	31	29.0
I know some information about self-sampling	35	32.7
I know a lot about self-sampling	14	13.1
IS SELF-SAMPLING A GOOD IDEA?		
Unsure	29	27.1
Yes	73	68.2
No	5	4.7
SHOULD SELF-SAMPLING BE PROMOTED?		

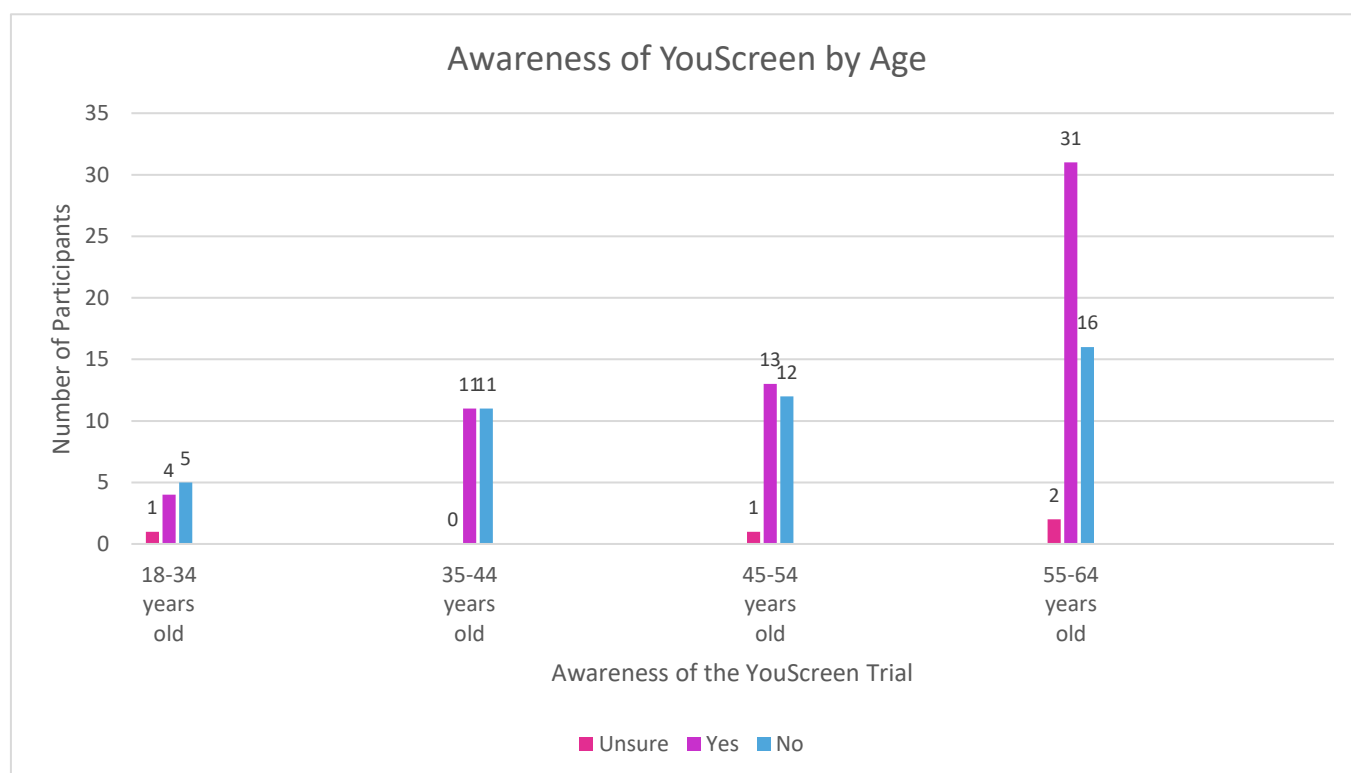
Unsure	29	27.1
Yes	78	72.9
No	0	0.0

Awareness of YouScreen

Awareness of YouScreen was mixed, with 55.1% of participants having heard of this. Most age groups showed similar proportions of participants either knowing or not knowing about YouScreen except for those aged 55-64 years old where 63.27% advised they had heard of this (n= 31; Figure 13). A Mantel-Haenszel test of trend was run to determine whether a linear association existed between awareness of YouScreen and experience with ID. Awareness of YouScreen was rated 'yes' and 'no' (which included the 4 'unsure' responses for the purposes of this analysis); experience with ID was categorised as 'no (never or in a previous role only)' and 'yes (in my current role)'. This did not show a statistically significant linear association between level of awareness and experience with ID, $\chi^2(1) = 2.812$, $p = .094$, $r = -.163$.

FIGURE 13.

Awareness of YouScreen by age

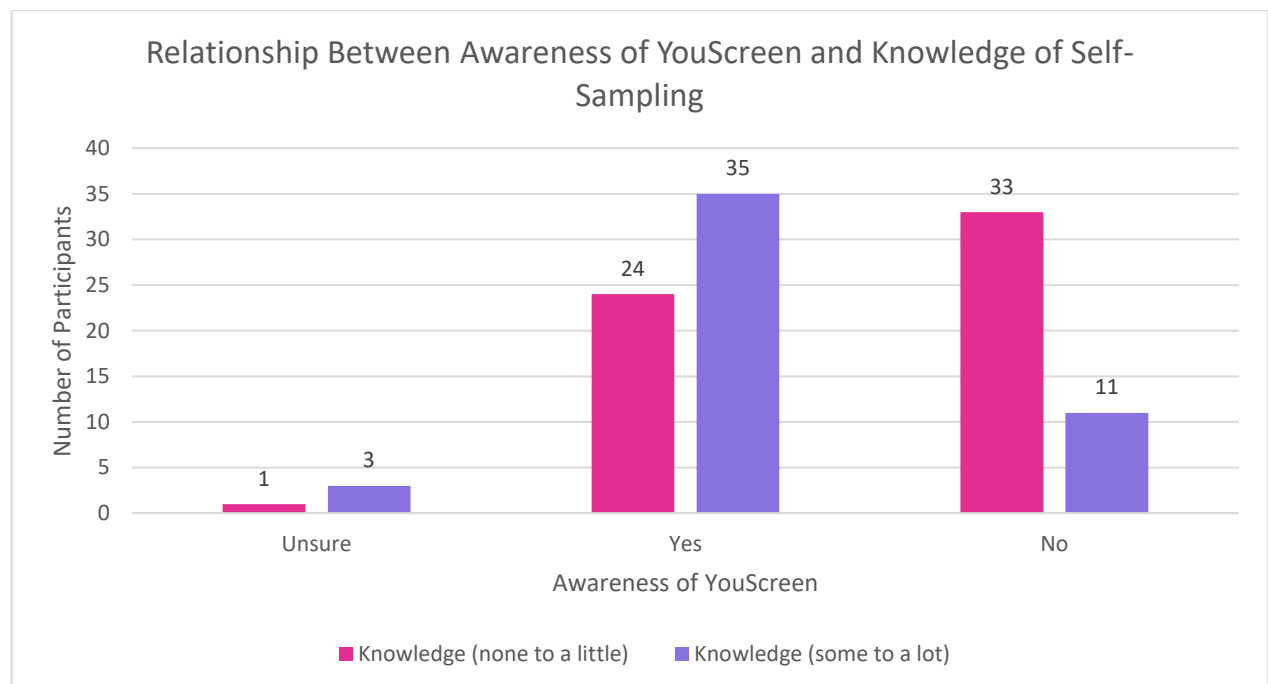


Knowledge of Self-Sampling

YouScreen and Knowledge. Most participants knew “some” (32.7%) or a “little” (29%) information about self-sampling (Table 3). A test of trend was run to determine whether a linear association existed between awareness of YouScreen and knowledge. Awareness of YouScreen was scored as ‘yes’ and ‘no’ (including the 4 ‘unsure’ responses for purposes of this analysis); knowledge of self-sampling was scored “none to a little” and “some to a lot”. This showed a statistically significant linear association between awareness of YouScreen and knowledge of self-sampling, $\chi^2(1) = 9.605$, $p = .002$, $r = .301$ (Figure 14). Higher awareness levels were associated with greater knowledge levels and vice-versa.

FIGURE 14.

Relationship between awareness of YouScreen and knowledge of self-sampling



Age, Gender and Location. Participants most likely to report knowing “some” information were those aged 45-54 years old (38.5%, $n=10$), and 55-64 years old (32.7%, $n=16$; Figure 15). Most of those aged 35-44 years old said they knew “a little” (27.3%, $n=6$) and most 18–34-year-olds said they knew “very little” or “some” information (both 30%, $n=3$). Somers' d was run to determine the association between age and knowledge of self-sampling. There was a weak positive correlation between age and knowledge, but this was not statistically significant ($d = .151$, $p = .084$). It was hypothesised that there would be an increasing monotonic trend in knowledge levels as age

increased. A Jonckheere-Terpstra test determined that there was no statistically significant increasing monotonic trend in median knowledge levels, $p = .081$. Kendall's τ_b between age range and knowledge of self-sampling was significant $r = .143$, $p = .040$.

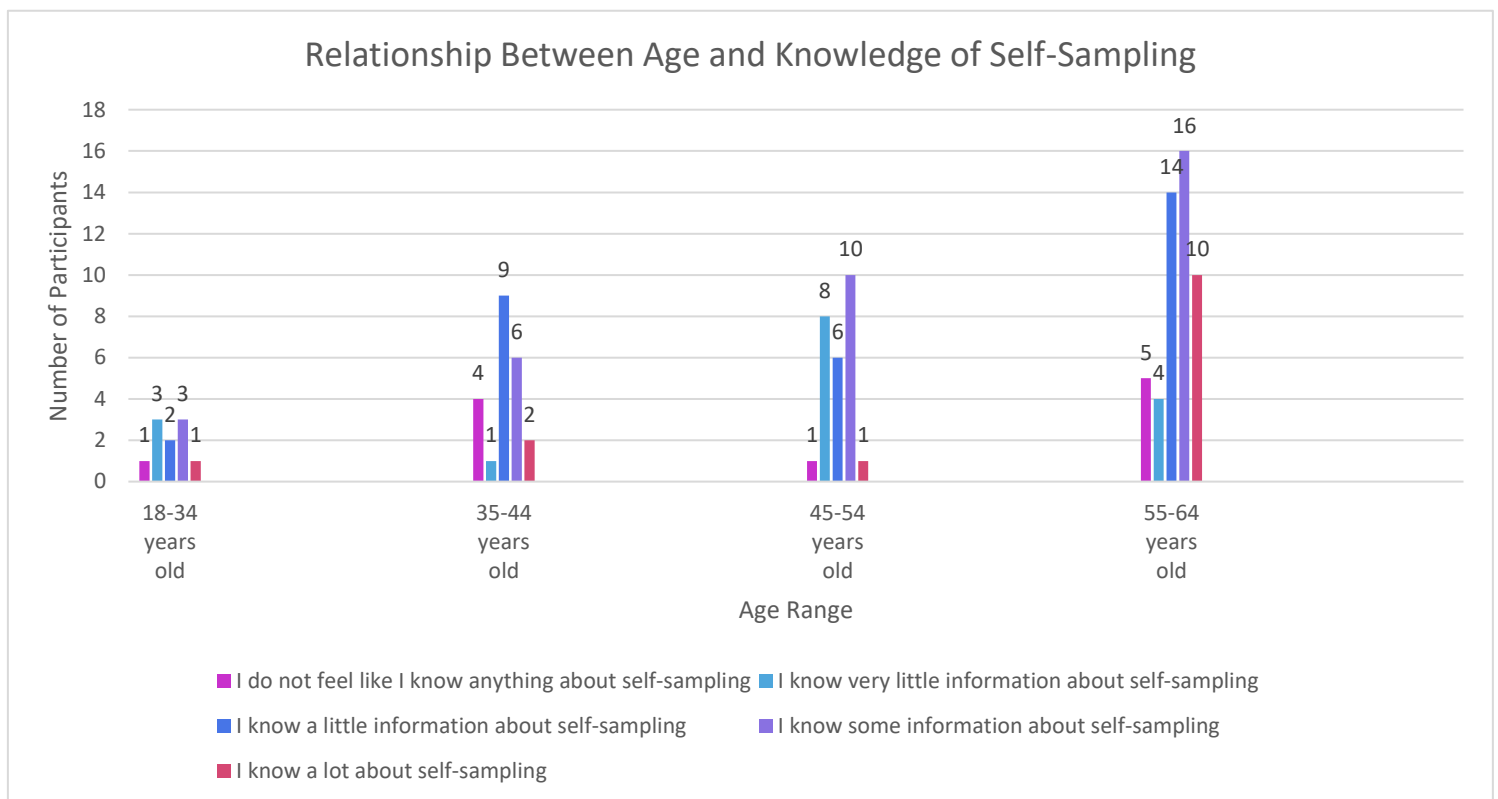
A Mann-Whitney U test was run to determine if there were differences in knowledge levels between genders. Distribution of knowledge levels for males and females were similar, as assessed by visual inspection. Median knowledge levels were not statistically significantly different, $U = 426.50$, $z = 1.730$, $p = .064$.

Differences in knowledge levels between those in rural or urban locations were investigated. Distribution of knowledge levels in rural or urban locations were similar, as assessed by visual inspection. Median knowledge levels were not statistically significantly different, $U = 1396.00$, $z = 0.285$, $p = .776$.

Most of those working within a rural setting said they knew "a little" information about self-sampling (34.1%, $n=14$), whilst most of those working in an urban setting said they knew "some" information (34.8%, $n=23$). The probability of those in a rural location having "none to a little" knowledge was 1.41 times greater rather than the odds of them having "some to a lot" of knowledge. The probability of those in an urban location having "none to a little" knowledge was 1.06 times greater rather than the odds of them having "some to a lot" of knowledge. Those in an urban location were therefore almost twice as likely (1.88) than those in a rural location to report greater knowledge levels.

FIGURE 15.

Relationship between age and knowledge of self-sampling

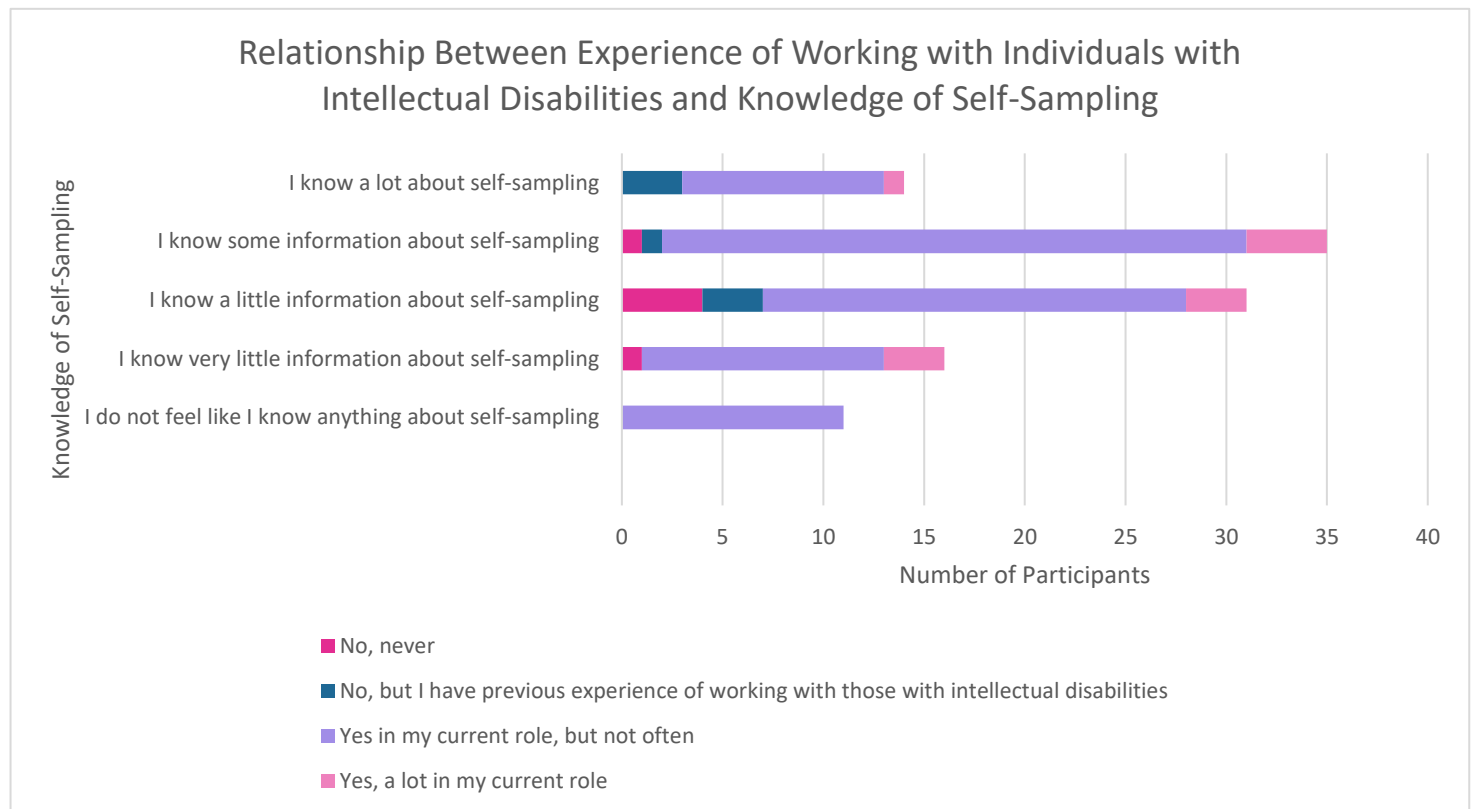


Experience with ID and Role Duration. The only group where some reported to not know anything about self-sampling, were those who had limited experience of working with ID in their current role (n=11; Figure 16). Most participants across groups said they knew “some” information about self-sampling (32.7%), the highest proportion of which often worked with individuals with IDs in their current role (36.4% of this group, n=4), followed by those who worked with individuals with IDs in their role but to a limited extent (34.9% of this group, n=29). Most individuals who stated they knew “a lot” about self-sampling, worked with individuals with ID but to a limited extent.

Those who had worked in a patient-facing role on the CCSP for >3 years were most likely to know “some” information (n=28, 32.9%; Figure 17). Those in post for <3 years were most likely to know “a little” information (n=8, 36.4%). Regardless of role duration, most participants felt that self-sampling should be promoted (72.7% of <3 years; 72.9% of >3 years), with zero participants stating it should not be promoted. A Chi-square test showed that there was a significant relationship between knowledge of self-sampling and whether participants thought self-sampling was a good idea; participants with greater knowledge of self-sampling were more likely to think it was a good idea, $\chi^2(2, N = 107) = 13.65, p = .001$.

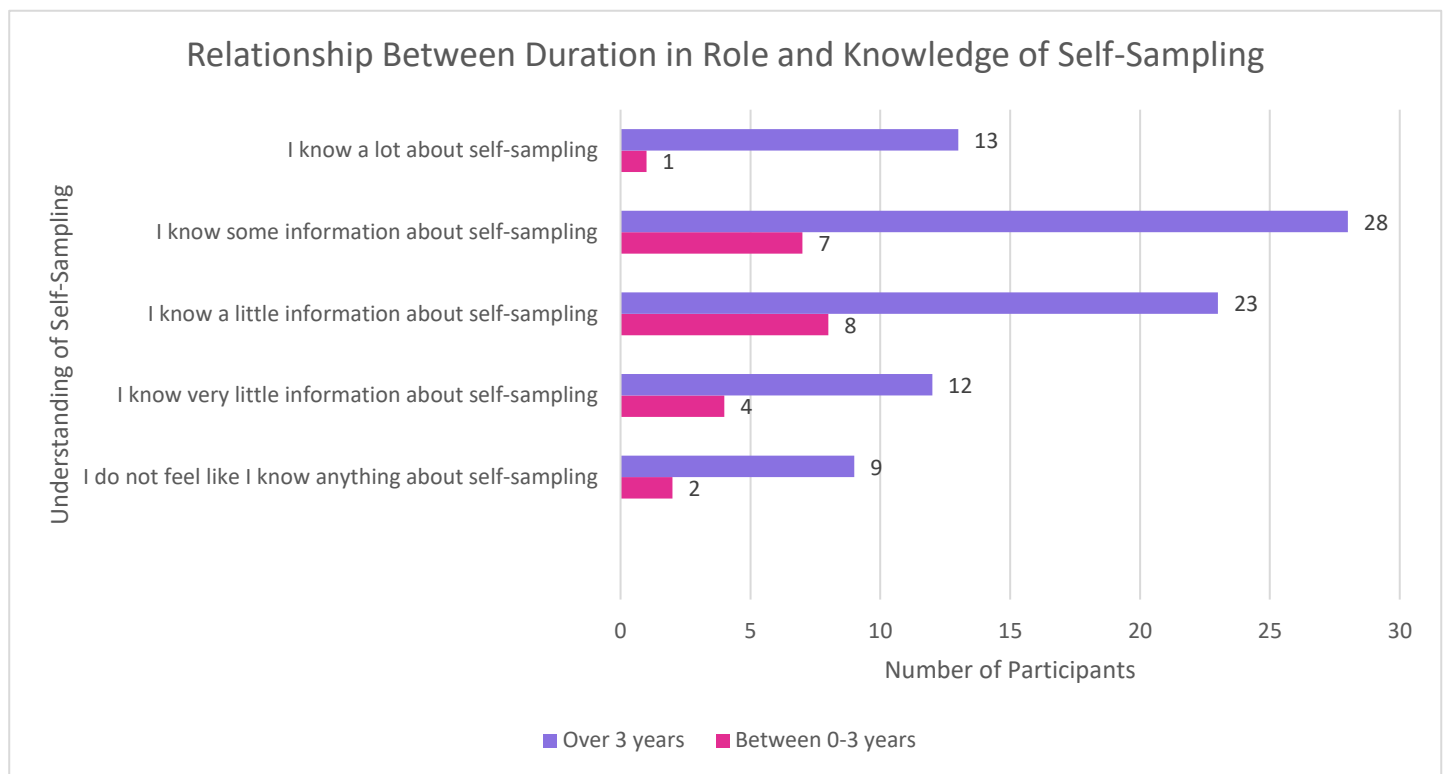
FIGURE 16.

Relationship between experience with IDs and knowledge of self-sampling



Beliefs around Whether Self-Sampling is a Good Idea

Age, Gender and Location. Most participants (68.2%) felt that the introduction of self-sampling was a good idea, followed by 27.1% who stated they were unsure and then 4.7% advising they did not think this was a good idea. This pattern was observed across various conditions (see Table 4) including location and age group. All male participants (n=6) said self-sampling was a good idea. Female responses followed the above pattern of responses with most saying yes (66.3%), followed by those who were unsure (28.7%) and the minority who said no (5%).

FIGURE 17.*Relationship between duration in role and understanding of self-sampling***TABLE 4.***Responses as to whether self-sampling is a good idea across locations and age groups*

Is the introduction of self-sampling a good idea?			
Location and age range	Yes	Unsure	No
Urban Setting	74.2% (n=49)	22.7% (n=15)	3% (n=2)
Rural Setting	58.5% (n=24)	34.1% (n=14)	7.3% (n=3)
18 – 34 years old	60% (n=6)	30% (n=3)	10% (n=1)
35 – 44 years old	63.6% (n=14)	31.8% (n=7)	4.5% (n=1)
45 – 54 years old	76.9% (n=20)	19.2% (n=5)	3.8% (n=1)
55 – 64 years old	67.3% (n=33)	28.6% (n=14)	4.1% (n=2)

The odds of people being more likely to think self-sampling is a good idea for rural versus urban participants is 0.435 (95% CI, 0.177 to 1.065), which was not statistically significant, $X^2(1) = 3.323$, $p = 0.068$. This indicates that those in a rural location experienced a reduction of 56.5% in the odds of thinking self-sampling was a good idea.

Knowledge and Experience. Considering role duration, responses again followed the pattern above, with most thinking this was a good idea and the minority thinking it was not (Table 5). The highest proportion of participants to state that this was a good idea had been in the role >10 years, accounting for 57.5% (n=42) of all participants to provide this response. Those who had current or previous experience of working with ID, also followed this pattern with most thinking self-sampling was a good idea (n=73, 68.2%; see Table 6). Knowledge levels of participants had a statistically significant effect on the prediction of whether participants thought self-sampling was a good idea, Wald $\chi^2(4) = 8.632$, $p=0.071$ (Figure 18).

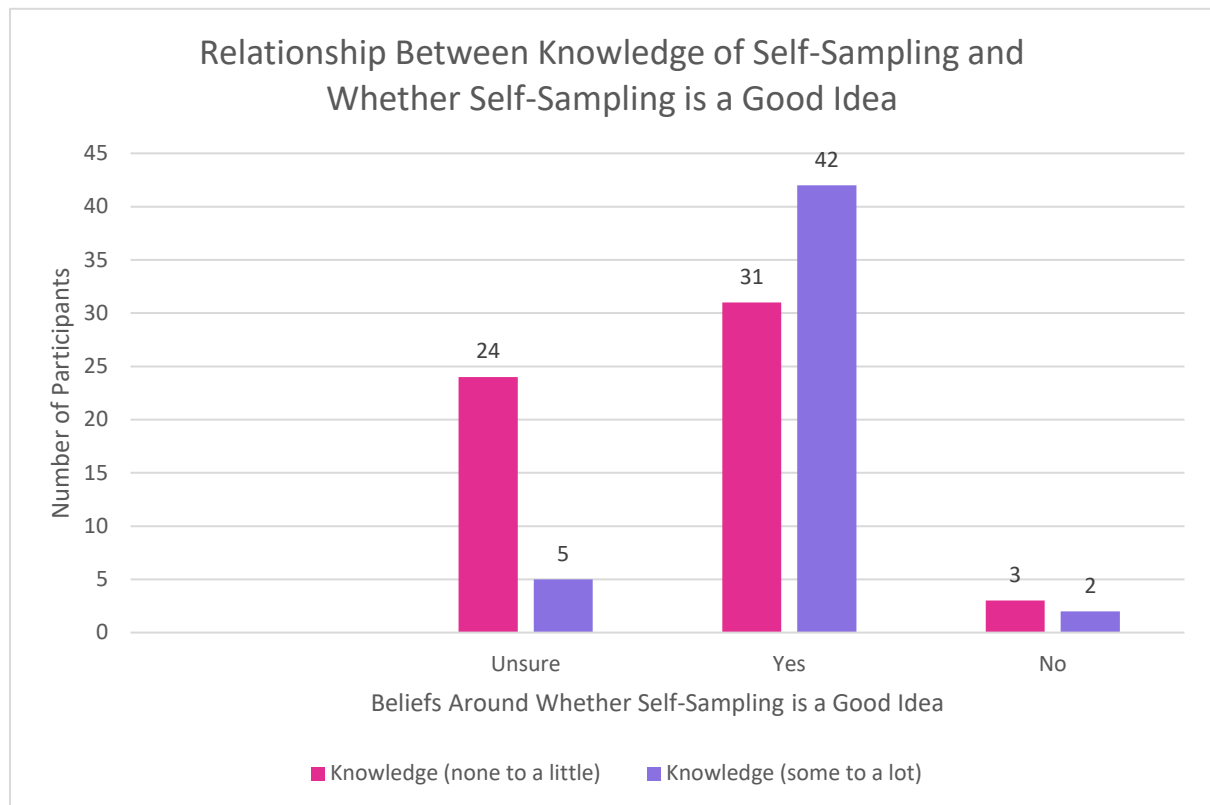
TABLE 5.

Responses as to whether self-sampling is a good idea by role duration

Is the introduction of self-sampling a good idea?				
Duration of		Yes	Unsure	No
time in role	Up to 6 months	100% (n=1)	0% (n=0)	0% (n=0)
	6 months to 1 year	66.7% (n=2)	33.3% (n=1)	0% (n=0)
	Between 1-2 years	58.3% (n=7)	33.3% (n=4)	8.3% (n=1)
	Between 2-3 years	66.7% (n=4)	33.3% (n=2)	0% (n=0)
	Between 3-5 years	71.4% (n=5)	14.3% (n=1)	14.3% (n=1)
	Between 5-10 years	60% (n=12)	35% (n=7)	5% (n=1)
	Over 10 years	72.4% (n=42)	24.1% (n=14)	3.4% (n=2)

FIGURE 18.

Relationship between knowledge of self-sampling and whether self-sampling is a good idea



Beliefs around Whether Self-Sampling Should be Promoted

Age, Gender and Location. A total of 72.9% of participants felt self-sampling should be promoted, with 27.1% unsure and zero participants saying it should not be promoted. Across age groups, most participants said self-sampling should be promoted. 100% of men said it should be promoted, with most women in agreement (71.3%); women were 2.48 times more likely to say that self-sampling should be promoted as opposed to being unsure.

A significant relationship between whether participants worked in a rural or urban setting and whether they thought self-sampling should be promoted was observed, $\chi^2(1, N=107) = 4.78, p=.029$. The probability of those in a rural location thinking that self-sampling should be promoted was 1.56 times greater rather than the odds of them being unsure; the probability of those in an urban location advising that self-sampling should be promoted was much higher at 4.08 times greater rather than the odds of them being unsure. The odds of being more likely to think self-sampling should be promoted for rural versus urban participants is 0.356 (95% CI, 0.145 to 0.871), a statistically significant effect, $\chi^2(1) = 5.116, p = 0.024$. This indicates that those in a rural location

experienced a reduction of 64.4% in the odds of thinking self-sampling should be promoted; 80.3% of participants in urban locations said self-sampling should be promoted, in comparison with 61% of those in rural locations.

TABLE 6.

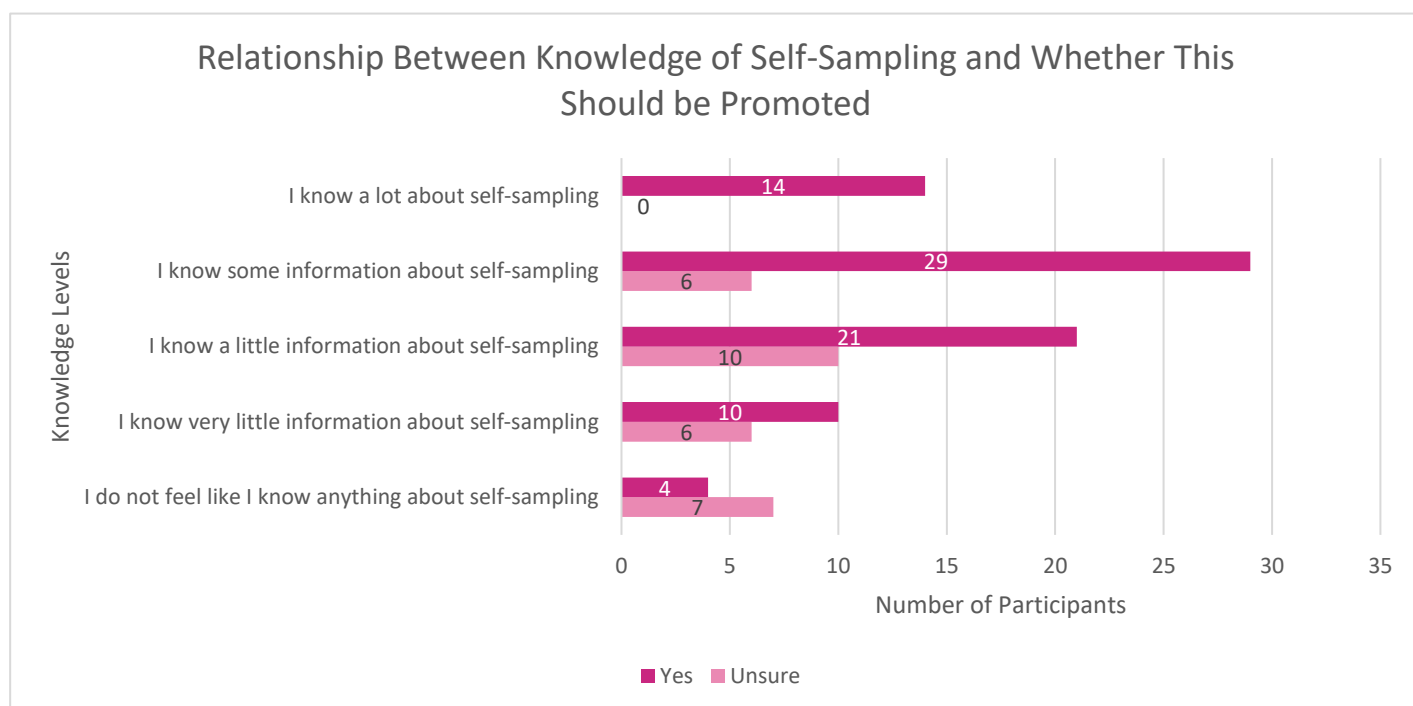
Responses as to whether self-sampling is a good idea by experience with ID

Is the introduction of self-sampling a good idea?				
Experience with		Yes	Unsure	No
intellectual disabilities	None	33.3% (n=2)	66.7% (n=4)	0% (n=0)
	Experience in a previous role	71.4% (n=5)	28.6% (n=2)	0% (n=0)
	Limited experience in current role	71.1% (n=59)	22.9% (n=19)	6% (n=5)
	A lot of experience in current role	63.6% (n=7)	36.4% (n=4)	0% (n=0)

Knowledge and Experience. Those with increased knowledge of self-sampling were more likely to think that it should be promoted, $\chi^2(1, N = 107) = 10.10, p = .001$. A test of trend was run to determine whether a linear association existed between knowledge levels and beliefs around whether self-sampling should be promoted. Knowledge levels were scored from 0 to 4 (from no knowledge to a lot of knowledge around self-sampling) and beliefs as to whether this should be promoted were scored 'no', 'unsure' and 'yes'. This showed a statistically significant linear association between knowledge and beliefs around promotion, $\chi^2(1) = 14.910, p < .001, r = .375$. Higher knowledge levels were associated with a greater belief that self-sampling should be promoted and vice-versa (Figure 19).

FIGURE 19.

Relationship between knowledge of self-sampling and whether this should be promoted

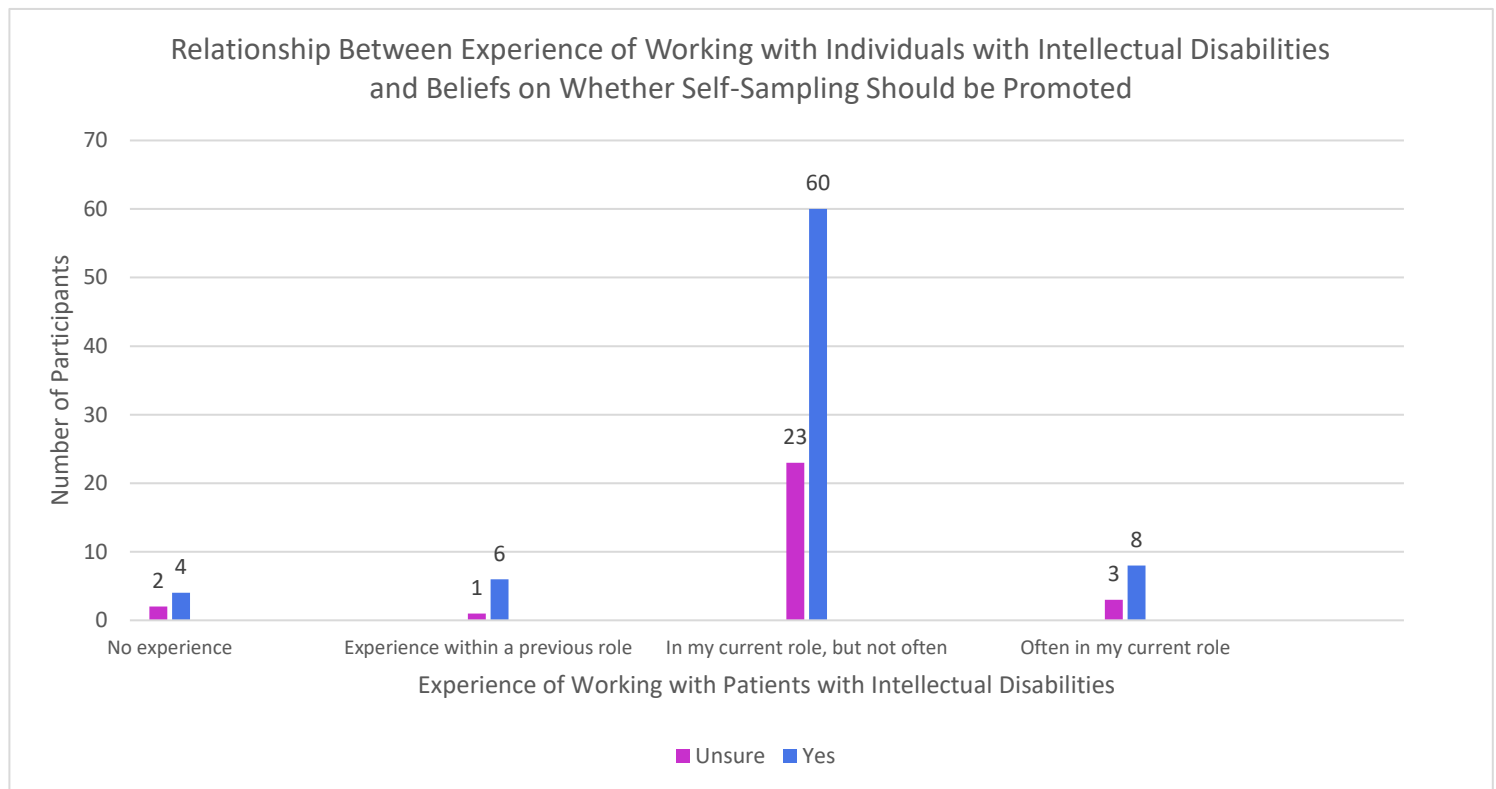


While most participants in both groups said they believed self-sampling should be promoted, a higher proportion of those with “some to a lot” of knowledge of self-sampling were more likely to advise that they felt it should be promoted (n=43, 87.8%) compared to those with “none to a little” knowledge (n=35, 60.3%).

Regardless of duration of time in role, most participants said self-sampling should be promoted. Participants were more likely to state they believed it should be promoted as opposed to being unsure, regardless of whether they had experience of working with individuals with ID or not (Figure 20). Those who did not have previous experience of working with those with ID, however, were also more likely to say this should be promoted (66.7%).

FIGURE 20.

Relationship between experience with ID and whether self-sampling should be promoted



2.3.2 Qualitative Themes

Participants were asked 11 open-ended questions querying what information they would need prior to the introduction of self-sampling and exploring beliefs around advantages/disadvantages and barriers/facilitators of self-sampling (Appendix 2). Responses were integrated into the final dataset for analysis. Following analysis, codes were distilled into themes and subthemes for each category. Extracted quotes for each theme include gender ((M)ale or (F)emale), type of location ((R)ural or (U)rban) and how long they have worked in a patient-facing role on the CCSP. Table 5 provides a summary of the final 4 themes and 2 subthemes. Appendix 7 provides detailed responses for each survey question.

TABLE 7.*Themes and subthemes from the survey of HCP*

Themes	Subthemes
1. Inadequate information would lead to the failure of the self-sampling programme	
2. Self-sampling could provide autonomy and choice for the public.	
3. Need for a systematic implementation framework	
4. Insufficient thought could lead to self-sampling increasing health inequities	1. Insufficient thought around wider issues which could impact engagement with self-sampling may hinder success 2. Concerns around potential abuse in vulnerable populations

1. Inadequate information would lead to the failure of the self-sampling programme

The first theme relates to participants recognising that inadequate information would lead to the failure of self-sampling. Respondents emphasised the importance of understanding the rationale behind the introduction of self-sampling, as well as the benefits, limitations, reliability and acceptability. Respondents requested information about improvements in patient outcomes; this included whether women would be more likely to attend for follow-up if they received an HPV-positive diagnosis. Respondents highlighted that patients would need to be informed of the screening pathway, with expectations communicated with services around changes and anticipated impact i.e., on colposcopy. The importance of education for both professionals and patients was emphasised. Concerns were shared around the practicalities of the test, including insufficient funding. Clear, accessible instructions were highlighted as crucial.

Respondents described the importance of showing that self-sampling was not a cost-cutting exercise, requiring information about its ease of use plus assurance about *“not getting it wrong”*. Evidence should be provided around benefits to engagement and outcomes, including anticipated improvement in *“diagnosis of premalignant disease”*. Participants emphasised the importance of providing information around the screening pathway including *“clear guidance to women that if HPV is detected [they] would have to attend a healthcare provider for follow up treatment”*. Participants highlighted concerns around services becoming increasingly overwhelmed; evidence was requested around *“likely uptake and effect on colposcopy”* and whether women would be more likely to attend for clinician-led screening if they received an HPV-positive diagnosis.

“Is there evidence that self-sampling will encourage positive engagement with cervical screening i.e. if a woman tests positive for HPV high risk will she more likely to go for cervical smear/colposcopy?”

P193, F/U/1-2 years

HCPs advised that education around HPV and CC should be shared more widely with the public as they had observed that knowledge levels were often poor. For patients to therefore understand why they are being asked to test for HPV, they need to receive educational materials at both an individual and national level to support them to understand its role in CC. Such information should also extend to explaining what an HPV-positive result means, which could assist in addressing common misconceptions around causes and that it *“doesn't mean partner [is] cheating on them”*. Participants stated the importance of patients being fully informed, with limitations clearly detailed, ensuring they were aware that, *“without looking at the cervix, it can only exclude HPV not...other abnormalities...I suppose this element of patient care will be missed”*.

Participants expressed worry around patients doing the test incorrectly and potentially receiving a false negative *“which could lead to issues further down the line”*. Participants worried that receiving this false reassurance that everything was fine, or potentially misunderstanding the limits of an HPV test, would lead to participants ignoring physical symptoms or warning signs. They worried that kits might not be used or may be *“spoiled”* due to the testing environment not being controlled, and the cost implications of this.

“I would also worry that patients would not do the test correctly and then be potentially falsely reassured, or would ignore potential warning signs due to reassurance from a negative self test”

P126, F/U/3-5 years

Participants recognised that certain initiatives had failed in the past due to awareness campaigns not reaching their potential. They highlighted that such campaigns should be national and occur prior to the roll-out; they should promote self-sampling in waiting rooms, via various media and social media outlets to educate and provide information on the rationale behind the introduction of this. It was hoped that providing such information using *“good eye-catching posters, links to guides...”* could increase the public's beliefs in their capability to do the test correctly and to understand that self-sampling is being introduced to benefit public health rather than to save government money.

“Good media campaign - not oversimplifying it but clear and stress why the change/ the importance of doing it; Using GP websites/ Facebook pages to promote it directly to patients”

P135, F/R/>10 years

HCPs emphasised that staff must have appropriate training in how to perform self-sampling in order to support patients. They should feel appropriately informed in advance to generate confidence in using new systems/processes, allow sharing of information with patients, and to allow them to provide feedback which could be acted upon prior to the launch. Only one participant said that they would not require any additional information to support patients as *“the responsibility would cease to rest with them”* once self-sampling became available.

“Additional support to primary care staff prior to rolling this programme out to enable them to handle any patient queries; Contact early on in the process with board level public health teams involved in the delivery of the cervical screening programme so they can support other colleagues with the rollout of this at a county level”

P122, F/R/5-10 years

Clear, accessible instructions provided with every kit were recognised as the most important tool. Most highlighted that this should not just contain written information but should also include diagrams, *“pictorial info and QR codes for explanatory videos”* to increase accessibility. HCPs advised that patients could lack confidence to complete self-sampling without clear instructions, with the risk of incorrect samples reducing their chances of attempting this again. Education around self-sampling was suggested across a variety of settings including *“waiting areas, schools, colleges, workplaces”*. Participants shared that this would allow patients to learn alongside their peers and access information in a non-healthcare environment.

Insufficient funding was recognised as a potential barrier, where it would be necessary to ensure *“the supply of tests is consistent and good quality to meet NHS standards”*. Inadequate time to effectively roll out the programme, train professionals and gather feedback were recognised as factors which clinicians felt that the bodies responsible for implementing self-sampling could fail to consider sufficiently.

“Time to effectively roll out a new programme, engaging colleagues at national, board and GP/primary care levels; Make use of a range of community service providers to engage with

all their service users providing information in a range of formats; Producing an engagement 'kit'..."

P122, F/R/5-10 years

Lack of clarity around pathways and lines of responsibility in terms of who would be required to attend to patient queries or follow-up were also highlighted as factors which may cause confusion, frustration and overwhelm.

2. Self-sampling could provide autonomy and choice for the public

The second theme related to self-sampling providing autonomy and choice for patients. Most participants were positive that self-sampling could overcome many barriers to cervical screening for “hard-to-reach” groups and patients considered “defaulters”. Of high importance was the potential for self-sampling to increase autonomy in patients, allowing them to have control over their own health. Respondents discussed the value of self-sampling being less invasive, potentially reducing emotional and physical discomfort. Participants recognised the convenient nature of self-sampling, with this diversifying testing environments. Whilst responses were largely positive towards self-sampling, some reflected that it would remove the benefits of in-person screening, including the opportunity for wellbeing checks, providing health education and visualising the cervix; the latter provoked a great deal of worry that abnormalities could be missed at an early stage.

Many participants believed self-sampling could overcome various barriers to cervical screening. Participants highlighted that this could be a valuable alternative to clinician-led screening, encouraging “defaulters” to participate. This theme emerges strongly in the context of cultural and personal sensitivities. HCPs noted that self-sampling could “reach some ethnic minority communities better” because they would be “able to do without attending practice, don't have to talk about 'taboo' subjects of cancer or genitalia”. Some highlighted that self-sampling could improve uptake and accessibility for “hard-to-reach” groups, where this “may allow them to feel more comfortable to complete the test in the comfort of their own home”.

“Improve the uptake and accessibility to this test for all women but especially those vulnerable women who do not present to us - mental health, previous sexual abuse, previous poor experience etc”

P104, F/U/>10 years

Respondents noted that self-sampling could be “*more accessible and acceptable than the more invasive current speculum examination*”. They recognised the convenience, where participants could complete this at a time and place which suits them, meaning they could receive support from someone they trust.

“Will diversify settings in which testing could occur (e.g. a support worker for someone with learning disability could provide and instruct them...”

P155, M/U/5-10 years

Participants shared that self-sampling could also support patients to have control over their own health. They described that removing the need for a clinician to perform screening could minimise anxiety and “*risk of retraumatising patients*” encouraging “*patients to take their own health into their own hands*”.

They highlighted the importance of this, particularly in patients who had previously experienced domestic or sexual abuse, providing them with control and reducing discomfort. This could reduce potential stigma and fear associated with cervical screening while increasing familiarity with such procedures.

“It would allow people with past sexual abuse to feel in control of testing; I think the privacy aspect is a huge hurdle for people to get past when testing; The tester would probably feel a lot more relaxed obtaining the test”

P199, F/U/2-3 years

While some participants suggested that self-sampling could be done in conjunction with a clinician appointment, some were concerned that this interaction would be lost. This could therefore remove the opportunity for health promotion, sexual education and general advice. A few participants shared that screening appointments often act as an opportunity for a general wellbeing check.

“I find in clinic it's a safe space for a woman to speak freely with myself about any worries they have, we always do a wellness check on if they're feeling safe at home etc. I think this is an important part of the procedure that will be missing”

P150, F/U/6-12 months

This highlighted concerns around “*vulnerable women...who may open up about domestic abuse*” potentially flying under the radar.

3. Need for a systematic implementation framework

The third theme highlighted concerns around how self-sampling will be operationalised. Participants felt positive that self-sampling could ease pressures on services. They highlighted that learning and best practice from existing self-sampling practices have allowed decision-makers to understand what does and does not work which bodes well for HPV self-sampling; as such programmes are viewed as acceptable by many members of the public, it was hoped that this could increase the likelihood of success for HPV self-sampling also. Sufficient information around lines of responsibility and processes to follow was emphasised. The importance of a robust monitoring and evaluation model was stressed, with returned tests monitored, and feedback surveys utilised to ensure adaptations could be made. It was hoped that early indications of a good compliance rate would provide evidence that self-sampling was a positive addition to the CC screening pathway.

Whilst participants recognised some challenges in the early days of the bowel screening programme, they highlighted that “*hopefully we are learning from their experience*”, with decision-makers now aware of what works. They hoped that with the public largely viewing such practices as acceptable, this could increase the likelihood of success for HPV self-sampling.

“It is a similar approach as the bowel screening programme which may be more acceptable and has the potential to increase uptake of the screening programme”

P122, F/R/5-10 years

Participants emphasised the importance of self-sampling being operationalised effectively, relating to areas previously discussed including frequency of testing and lines of responsibility; this extended to such information being presented accessibly to patients, with local teams advised on how to remind patients and encourage participation. They noted that those with health anxiety may not be a suitable group for self-sampling as potential over-testing could maintain and increase these unhelpful thoughts, and clinicians would not have the same opportunity to challenge these beliefs. They explained that the pathway must be clear, detailing timescales, reminder systems and processes around what happens if tests are not returned.

Respondents noted that self-sampling could be more cost-efficient, as it would free up appointments and clinician time for other matters. They wondered how services would become aware if patients

had “defaulted”; if this would be the role of individual practice teams to consider, with completed kits being returned to them prior to testing, or if there would be another means of them being informed if kits were returned directly to the lab.

“If they do not attend for their smears we are aware of this in GP and would encourage them to come when seeing us for other problems- would we be aware if they had not done the self obtained swab?”

P135, F/R/>10 years

Participants queried if a protocol would be provided around how to manage patients who did not attend for follow-up after an HPV-positive diagnosis. Participants anticipated that this could take significant time; some suggested that they would feel uncomfortable with knowing a patient required further investigation or treatment, where nothing was actively being done.

The importance of a robust monitoring and evaluation system was stressed. Participants highlighted that there would need to be effective monitoring of who is eligible for, and who has completed, self-sampling. Ideally kits would be available for opportunistic handout as well as mailout, although patients would need an easy means of updating their address. They would hope to see a good compliance rate to indicate that self-sampling was working.

“Good system for supplying self-test kits to those eligible for screening, monitoring who has completed tests, the results and who is not participating and how non-participation is followed-up”

P192, F/R/1-2 years

Challenges experienced during other screening programmes were highlighted as being valuable in knowing where to anticipate potential “bumps in the road”. Incorporating questions into a public feedback survey could support to understand local trends and where more work may need to be done with specific groups. Surveys exploring the difficulty of the instructions or understanding of the rationale behind self-sampling, were suggested to allow decision-makers to understand if things needed to be modified at an early stage.

4. Insufficient thought could lead to self-sampling increasing health inequities

The final theme explored concerns around self-sampling increasing health inequities. Respondents highlighted concerns about self-sampling increasing stigma and further removing patients from

HCPs. Despite many participants highlighting the ways in which self-sampling could increase accessibility to screening, concerns were raised that it may increase inequalities in certain groups if they were unable to use the kit. It was recognised that some participants may not understand when self-sampling is not enough, despite information and education being provided around this. This could result in them ignoring physical symptoms that could subsequently develop into serious health problems. Concerns were noted around decision-makers not fully considering factors which may impact public or professional engagement with self-sampling. Respondents highlighted that there may be resistance to change from HCPs and patients. Furthermore, participants acknowledged that resistance to change may stem from distrust in the health service, and so this would need to be addressed to increase acceptance from the public. Subthemes included that insufficient thought around wider issues could impact engagement with self-sampling and hinder success, along with concerns around ensuring capacity and informed consent.

Some participants highlighted concerns around self-sampling increasing stigma and further removing patients from HCPs; they recognised that further minimising access to healthcare could increase inequities and promote the idea that gynaecological health is something which should be hidden.

“Makes access to healthcare more remote and acts against normalisation of the discussion of women's health problems which may increase social taboos and reduce attendance for other concerns”

P115, F/U/>10 years

Concerns were raised that self-sampling may increase inequalities in certain groups if they were unable to use the kit. They considered whether those with certain difficulties or impairments may be unable to participate. This emphasised the importance of choice in screening methods, where patients *“shouldn't be prevented from accessing self testing, rather they should have access to alternatives if needed”*.

“Those with a learning disability or any cognitive impairment; Physical disability which may restrict physically being able to sample - offer choice”

P116, F/R/>10 years

It was recognised that some patients may not understand when self-sampling is not enough, despite information and education being provided around this (see theme 1). There were concerns as to whether such patients, who may not attend for other healthcare appointments or have support,

would ignore physical symptoms due to *“being falsely reassured”* following a negative self-sampling result and could subsequently develop serious health problems.

“I worry that non-HPV related cancers would be missed because the cervix isn’t being looked at. These cancers then present later and the treatment is more onerous”

P126, F/U/3-5 years

4.1 Insufficient thought around wider issues which could impact engagement with self-sampling may hinder success

As evident across most themes, there were various worries around decision-makers not fully considering factors which may impact HCPs or patient engagement with self-sampling. Participants highlighted that a main barrier to success would be *“lack of thought about difficult to reach groups”*.

Resistance to change from both professionals and patients was discussed. Respondents highlighted that, particularly due to the large workload in primary care, new initiatives may be met with resistance. They recognised that some professionals may have strong views about maintaining clinician-led screening, and consideration would need to be given on how best to support clinicians and manage resistance. This was also acknowledged as important for patients, who may be resistant to the new initiative or *“who might have always attended for smears”*. Furthermore, participants acknowledged that resistance may stem from distrust in the health service, and so this would need to be addressed to enhance acceptance.

“Need to ensure this is sold as a benefit for patients that will not compromise care, danger that it could be seen as diluting care-doing it on the cheap, cost saving measure rather than a viable alternative to an ‘unneedlessly [SIC]’ invasive element of cervical screening”

P131, F/R/5-10 years

Participants recognised that, if promoted correctly, patients would be able to understand that self-sampling removes the need for an invasive, speculum-based procedure.

4.2 Concerns around potential abuse in vulnerable populations

Concerns were highlighted around the potential for abuse, where vulnerable patients could be forced to do the test.

“If it was forced on someone by a family member or carer and they were traumatised by the experience if not done by a professional experienced in taking swabs (thinking of those with learning disabilities now)”

P115, F/U/>10 years

It was also acknowledged that this could put staff or carers at risk and that it could be helpful to provide guidance around care planning or completing a risk assessment in certain cases.

Self-Sampling: Advantageous and Disadvantageous Groups

HCPs identified numerous population groups for whom self-sampling could prove either advantageous or disadvantageous, with many respondents indicating that self-sampling could benefit most eligible individuals (Table 6). Specific groups identified as potentially benefiting from self-sampling included transgender men, LGBTQ+ community members, housebound patients, individuals disengaged from health services due to previous negative experiences, and those with busy schedules and other commitments. Additional groups included individuals avoiding clinician-led screening due to anxiety or embarrassment, survivors of sexual or domestic violence, those who had not had penetrative sex, individuals facing cultural or religious barriers, remote residents, those with multiple negative screening histories, traveling communities, and individuals experiencing discomfort with speculum examination.

Conversely, HCPs identified several groups for whom self-sampling might be disadvantageous. These included individuals who might struggle to understand instructions or the purpose of the test, those lacking capacity to consent, and individuals with high-risk sexual histories. Additional concerns were raised regarding language barriers or visual impairment, depending on the availability of multilingual and multimodal information resources. Other potentially disadvantaged groups included HPV-positive individuals or those with current symptoms, those with cultural restrictions regarding self-examination, vulnerable individuals who might benefit from clinician wellness checks, those with severe health anxiety prone to over-testing, and individuals without fixed abodes who might face challenges receiving kits or results. A minority of respondents expressed concerns regarding individuals with active substance use disorders or those from lower socioeconomic backgrounds, citing potential health literacy challenges.

HCPs expressed divergent views regarding self-sampling suitability for certain groups. For individuals with physical disabilities, while some highlighted the advantage of avoiding clinic attendance, others

noted potential difficulties with test self-administration. Similar disparities emerged regarding individuals with intellectual difficulties or literacy challenges; while most supported self-sampling as a means to overcome existing screening barriers, some expressed worries around instruction comprehension and proper test execution. Age-related perspectives also varied, with some professionals supporting self-sampling for both older patients (citing lower HPV risk and avoidance of post-menopausal speculum examination) and younger patients (addressing first-screening anxiety). However, others worried about proper test execution among older adults and the potential for younger individuals to develop an aversion to clinician-led screening. Additional concerns included regular attendees potentially foregoing the benefits of clinician-led screening by switching to self-sampling. A small subset of respondents questioned the utility of self-sampling for currently non-engaging individuals.

TABLE 8.

Groups where self-sampling is considered advantageous or disadvantageous to HCP

Groups where self-sampling may be advantageous	Groups where participants would have concerns about introducing self-sampling
• Some participants believed it would be advantageous for most groups. • Women who default due to embarrassment or avoid for various reasons • Elderly patients and those in the older age group where risk of HPV is lower. • Ethnic minorities (do not have to talk about taboo subjects like cancer or genitalia). • Vulnerable women who do not seek healthcare due to mental health or learning difficulties. • Physical disability which limits access to healthcare (mixed opinion from respondents). • Individuals with mental health difficulties, particularly high anxiety levels. • Victims of sexual, physical or domestic abuse. • Intellectual disability (mixed opinion from respondents, but majority say advantageous). • Those who have not been sexually active or have not had penetrative sex. • Those who would struggle to engage due to specific cultural norms or religion. • Transgender individuals and members of the LGBTQ+ community. • Individuals with gender dysphoria. • Housebound patients. • Younger patients who are self-conscious or may be anxious about their first test. • Those who have had previous bad experiences at screening. • Working women, shift workers or those who travel frequently for work. • Post-menopausal women. • Anyone who struggles to attend appointments due to other commitments. • Anyone who struggles to engage with healthcare physically or socially. • Those with no transport links or who live in rural communities. • Those in less populated communities, where all available sample takers are friends/family. • Those who do not access current services (however this would still require a degree of self-motivation)	• People who struggle to understand or follow the instructions, or those who may not understand what the test is for, or what potential results mean. • Those with IDs or learning/literacy difficulties who may struggle to manage or understand how to take the sample correctly. • Those who lack capacity to understand and consent to screening • Individuals from a lower socioeconomic background. • Those who do not currently comply with current screening programmes. • People whose first language is not English (depending on which other languages/formats would be provided) • Those who have had previous abnormalities, have current symptoms or problems, or who have been diagnosed with HPV in the past. • Individuals who have a known riskier sexual health history and who may be at more risk of developing HPV. • Poorly motivated people who do not take an active interest in their health. • Blind people or those with visual impairment (unless adaptations). • People who find touching their own genital area disgusting. • Anyone with physical disabilities or lack of manual dexterity. Some respondents felt carrying out self-sampling would be more manageable than attending an appointment in-person for some physical disabilities e.g., Chronic Fatigue Syndrome. • Vulnerable adults who might benefit from seeing a professional for other reasons e.g., wellbeing checks. • Regular attenders who then switch to self-sampling who subsequently will lose the benefits that come with an in-person appointment. • Individuals with addictions or active substance misuse.

-
- The travelling community.
 - Those who find speculum examination painful or traumatic.
 - Asymptomatic patients and those who have had many negative screening results.
- Older women who may struggle to take the test.
 - People with mental health difficulties who may have extreme health anxiety and therefore may want to test frequently.
 - All groups have potential for concern/risk without visualisation of a cervix.
 - Younger people where they may then feel that clinician-led screening is something to be avoided.
 - Refugees, homeless people or migrants with no fixed address or poor understanding of screening.
 - Patients with HIV.
-

Story completion tasks

All participants completed these tasks, with average response word count for task 1 being 46 (ranging from 4 to 146) and for task 2 being 35 (ranging from 4 to 165). Thematic analysis revealed five key themes (Table 9).

TABLE 9.

Themes resulting from HCP responses to story completion tasks

Themes
1. Consideration should be given to capacity to provide informed consent before any further action
2. Sticking to the original plan versus grabbing the opportunity
3. The patient's views on symptoms and risk of HPV should be central
4. Necessary support and accommodations vary from patient-to-patient
5. Conflicting opinions as to whether screening would still be required

1. Consideration should be given to capacity to provide informed consent before any further action

HCPs consistently emphasised the importance of obtaining informed consent and assessing capacity before proceeding with any screening discussions or procedures. They highlighted the need to explain the procedure using accessible language to ensure the patient could make informed decisions.

"You seek consent to continue and give clear instructions as to what the screening will involve...advise her she can stop the examination/test at any time you agree with her how she will inform you how to stop. Once you were happy she understood what was going to happen you would proceed"

P101, F/R/>10 years

HCPs stressed the importance of confirming that patients were fully informed before making decisions. They noted the importance of exploring *"why she is suddenly asking about it"*, ensuring any sexual activity was consensual and that there was no *"underlying abuse"*.

"The doctor should do their best to answer any queries or concerns during the appointment. If the patient is satisfied with the information and has capacity to consent to a test it could be organised on the day or for another date and materials provided to the patient for further information"

P118, M/R/2-3 years

Participants recognised the importance of addressing patient concerns to ensure patients were fully informed.

2. Sticking to the original plan versus grabbing the opportunity

There were mixed opinions around whether to continue screening discussions within the current appointment or to arrange an additional appointment. Most favoured using the immediate opportunity for health education about cervical screening, though approaches varied. One HCP highlighted the potential risks of delay.

"If a test is wished, to try and do this at this appointment as there could be a chance they may not return if asked to make a further appointment."

P192, F/R/1-2 years

Others advocated for a more measured approach, suggesting follow-up appointments with specialised staff.

"Give her intellectually appropriate resources and make an appointment to come back and speak to a practice Nurse who can explain the procedure"

P101, F/R/>10 years

Some HCPs emphasised the importance of using this opportunity for broader health education.

"...should also have a discussion about contraception as a holistic approach. This means that even if they haven't ever had sex but do in the future, they won't be scared or as apprehensive about the test if they need it."

P199, F/U/2-3 years

Participants recognised that taking the time to provide this information now would enable patients to feel more at ease in future.

3. The patient's views on symptoms and risk of HPV should be central

HCPs highlighted the importance of the patient's views on symptoms and risk being central to decisions made. They advised that they would ascertain the patient's perspectives on cervical screening and their definition of "sexually active". They sought to explore the

patient's sudden interest in screening and whether there were underlying concerns, or if they were “*experiencing symptoms*.” Professionals highlighted the need for comprehensive risk assessment.

“Explain less likely to have cervical changes if not sexually active, but HPV not the only risk factor. Could discuss smoking history/ check weight for example to determine risks”
P204, F/R/>10 years

Some noted the importance of approaching discussions “*sensitively using a trauma informed approach*”. A small number of respondents shared that they would explore other risk factors including smoking, weight, family history and HPV vaccination status. Some recognised the importance of having a potentially difficult conversation with the patient, exploring if there had been any instances of sexual abuse which could have also put them at risk. A small number of participants also wished to question why they had not attended previously.

“Ask her why she is asking now and why she hasn't attended in the past? Has she any symptoms which may be a cause for concern? Has she had sexual contact in the past? It is unlikely that the test will be offered there and then, although if there are symptoms which are a cause for concern the GP should refer on to secondary care coly/gynae services and not take a smear whilst the woman is symptomatic”
P122, F/R/5-10 years

Many participants believed that taking the time to fully assess the patient’s risk of HPV was crucial for informing next steps.

4. Necessary support and accommodations vary from patient-to-patient

HCPs recognised the need for tailored support and accommodations, emphasising the importance of additional time, easy-read materials, and support from trusted individuals. They highlighted the value of building familiarity with the clinician, equipment, and environment.

“I would show them what is used to take the smear test and talk through what will happen. If she would prefer a couple of visits before we take the smear, that can be arranged, to help her build confidence in the process and the health professional”
P122, F/R/5-10 years

Participants considered whether other individuals should join this discussion to support the patient. They advised that they would use *“easy-read material to support the conversation and discussion”*. Some said they would explicitly state that they could stop the procedure at any time and that she could have someone she trusts with her throughout.

“I would invite questions/worries and offer a chaperone. I would show equipment and talk through what happens and reassure that we can stop at anytime”

P124, F/U/3-5 years

A small number of participants advised that, if the participant felt unable to engage in clinician-led screening, they would suggest an HPV test instead.

“If they are very opposed to a proper cervical screening test then they could be offered a test of HPV instead”

P115, F/U/>10 years

This indicated that participants had an understanding of HPV sampling and its value, where this may be preferred by some patients due to its less invasive nature.

5. Conflicting opinions as to whether screening would still be required

There was notable disagreement among HCPs regarding whether screening would be required for patients who had never been sexually active. Some recognised that screening was necessary regardless of sexual activity and they would explain that *“while she is at reduced risk, that it is not no risk”* and would therefore *“encourage her to have screening”*.

“I would explain in simple terms that HPV testing is still required in females who are not in a sexual relationship”

P124, F/U/3-5 years

Many other respondents however said that, if the patient had confirmed that there had never been any sexual activity, there would be no need to screen.

“if they can confirm no penetrative sex or genital to genital contact of any gender would advise Cx smear not required until sexually active”

P184, F/R/>10 years

Some said they would “record that it is inappropriate to screen the patient”, whilst others said they would continue to send screening invitations.

“Advise that they will require screening if they enter a sexual relationship. Continue invitations”

P114, F/U/>10 years

Regardless of whether these participants believed that the patient should be removed from the SCCRS or whether invitations should continue, they stated that they would advise the patient that if she does become sexually active, she should return for screening.

2.4 DISCUSSION

This study employed a mixed methods approach to investigate HCP perspectives on HPV self-sampling within Scotland's CC screening programme. Through social constructionist thematic analysis, this study reveals how professional identities and organisational context shape perspectives on implementation challenges and perceived barriers. The findings revealed several critical insights for national implementation.

Responses to the survey were received from professionals across Scotland from both rural and urban locations. Most participants only knew a limited amount of information about self-sampling. They described the most important factors required to make self-sampling a success, including having clear communication and education around self-sampling, the cervical screening pathway, and the role of HPV in CC to both the public and HCPs. They emphasised that careful consideration would need to be given to the operationalisation and evaluation of self-sampling. Participants were generally positive about self-sampling and its potential for overcoming many barriers to screening attendance including providing patients with autonomy, choice and control over their own health.

Some concerns were highlighted however around groups where self-sampling may not be advantageous, and participants recognised that measures would need to be in place to avoid self-sampling potentially increasing health disparities.

This study aimed to understand current knowledge levels around self-sampling, finding that most participants had some familiarity with self-sampling. A higher proportion of participants in urban locations said self-sampling should be promoted, whilst also reporting to know slightly more about self-sampling. Those who worked in rural locations however, were significantly more likely to say self-sampling should be promoted. Importantly, most participants believed that self-sampling should be promoted and, most notably, no participants felt that it should not.

A key finding revealed that participants with greater knowledge of self-sampling were more likely to think it was a good idea and should be promoted. The idea that greater knowledge can increase support for, and confidence in, initiatives in healthcare has been evidenced in the literature; Lucero and Chen (2020) observed that the reinforcement of information through learning led to greater confidence and feelings of competence in HCPs which in turn led to a commitment to engage with new initiatives. The relationship between knowledge and implementation advocacy aligns with established behavioural theory. Drawing on Bandura's (2010) self-efficacy theory and Oyserman and Destin's (2010) identity-based motivation theory, findings suggest that increased knowledge enhances HCP confidence and implementation readiness. This is supported by recent evidence demonstrating that targeted training in behaviour change and communication enhances HCP competence in intervention delivery (Vogt et al., 2023). Given HCPs' central role in patient education and screening guidance (Abdallah et al., 2016), their perceived credibility becomes crucial for public acceptance (Biswas et al., 2006).

The study identified implementation barriers both consistent with previous research and unique to the Scottish healthcare context. While concerns about sample validity and testing environments align with existing literature (Xiong et al., 2022; Mathews et al., 2024), participants highlighted distinctive systemic pressures. Beyond common concerns about staff training and sample accuracy (Harry et al., 2019; Winer et al., 2019), findings reveal unique challenges specific to the Scottish healthcare context. Themes unique to participants in this study include concerns around self-sampling increasing health inequities and that decision-makers must carefully consider the operationalisation, monitoring and evaluation of self-sampling. The implementation context is particularly challenging given current systemic strains. With GP registrations increasing 7% over the last decade and individual caseloads rising 15% since 2013 (British Medical Association, 2024), staff report deteriorating mental health and quality of life (Lamb et al., 2021). Against a backdrop where

only 70% of patients begin cancer treatment within the two-month target (Stiebahl, 2024), concerns around capacity for new initiatives appear well-founded.

A significant contribution emerges in the examination of potential health inequity risks. While previous research highlighted self-sampling's potential to improve access (Xiong et al., 2022), this study reveals complex concerns about unintended consequences. These findings gain particular salience given evidence from Cancer Research UK (2020) showing 33,800 additional cancer cases annually in areas of higher deprivation, with the cost-of-living crisis worsening the situation.

An important finding in the present study was that nearly all participants thought that self-sampling was a good idea. Participants with experience of ID indicated this was a good idea, whilst demonstrating nuanced implementation concerns. This may indicate that, while there is a consensus that self-sampling could be valuable for ID, it is important that implementation challenges for vulnerable populations are considered and that diverse clinical perspectives are incorporated within planning. This extends to other groups, including those with visual impairments or language barriers, though participants identified potential solutions through accessible instructions and materials.

Ensuring that instructions were sufficient was repeatedly highlighted as a key factor in whether self-sampling was a success. An awareness campaign prior to the introduction of self-sampling was emphasised as a must to ensure that the public understood why this change was happening and what to expect. HCPs recognised that work would need to be done to increase public understanding of the link between HPV and CC, to allow them to understand causes and why they were testing for HPV. Misconceptions were evident in the present study, where some HCPs believed that the patient in the story completion task did not need to be screened due to not being sexually active. Li et al.'s (2023) finding that 63% of nurses and 70% of doctors demonstrated prejudice towards patients' sexual partners for their HPV diagnosis suggests that misconceptions and stigma relating to HPV is a widespread issue requiring systematic educational intervention.

Qualitative analysis revealed distinct geographical patterns in concerns and priorities. Urban practitioners showed greater concern about loss of face-to-face contact, while rural practitioners emphasised practical implementation challenges. Both were equally concerned about patient understanding. Rural practitioners emphasised accessibility benefits more,

while urban practitioners focused more on time/convenience benefits. There were similar levels of concern about implementation across both. Similarly, in terms of role duration, more experienced practitioners highlighted worries around sample quality as the top concern, followed by patient understanding and then loss of face-to-face contact. Less experienced practitioners showed slightly different priorities, with greater emphasis on patient understanding and ability to understand what to do. This suggests that implementation strategies may need to be tailored to different healthcare settings, accounting for local service delivery contexts and experience of practitioners.

Participants highlighted the many positives of self-sampling which echoed research by Xiong et al. (2022) who found that its potential to improve uptake in underrepresented groups was viewed as most important by HCPs. There were concerns however, that self-sampling could increase stigma, leading to beliefs that gynaecological care is something to be hidden. Worries around services becoming overwhelmed were echoed throughout. Results from YouScreen indicated that only a small number of women would be expected to test positive for HPV – around 15% - and so this should not overwhelm services. YouScreen demonstrated 90% follow-up attendance for positive results, exceeding the 75% intention rate (Drysdale et al., 2024). This aligns with previous findings of >80% follow-up rates (Lim et al., 2017), suggesting that engagement fears may be overstated. However, participants raised valid concerns about consent and safeguarding, particularly for vulnerable populations.

Findings strongly support the need for a systematic implementation framework. The shift from "hard-to-reach" to "seldom-heard" terminology (Good Governance Institute, 2020) represents an important re-conceptualisation of service engagement responsibility. The Consolidated Framework for Implementation Research (CFIR; Damschroder et al., 2009) offers a promising means of assessing self-sampling in terms of 'items' such as applicability and usability from the perspectives of those both delivering and receiving the intervention. With Scotland varying in terms of local populations, adaptations could be made, guided by this framework while maintaining fidelity. The suggested "self-sampling champions" model from the present study aligns with Horsager's (2024) research on the importance of trusted trainers in reducing resistance and increasing acceptability of self-sampling.

2.4.1 METHODOLOGICAL CHALLENGES

2.4.1.1 Data collection via online survey

An online survey meant the importance of potential participants' contribution to this project was difficult to emphasise via email only, as opposed to having personal and direct contact with individuals. The researcher attempted to overcome this by ensuring the invitation email was concise and highlighted key statistics and information. There was no means of confirming receipt of recruitment information sent via post however this could have been remedied by sending this via recorded mail or conducting follow-up calls. Although we exceeded recommended participant numbers and received responses from across Scotland, carrying out interviews with perhaps a proportion of participants, may have allowed for richer data and supported with recruiting a wider range of participants. There were a much higher number of female participants within the survey which, while this may be indicative of more females working in the area of cervical screening than men, could have impacted on the generalisability of findings. The researcher was in contact with the lead consultant or team leader of most services and so it was hoped that their dissemination of study information to staff would emphasise its importance. It was difficult to know whether team leaders did encourage staff to participate. The use of reminder emails hopefully supported with this, whilst acting as a prompt for individuals to remember to take part within their busy schedule. While participation was consistent throughout and we reached minimum participant numbers, the response rate was low at around 8%. The environment in which individuals participated in the survey was also impossible to control and various factors, such as interruptions, noisy environments, and busy schedules, may have impacted on level of engagement. From analysing responses however, it does not appear that the quality of responses was compromised due to the detailed and considered responses received.

2.4.1.2 Survey design

While the survey included both quantitative and qualitative components, there were no standardised, validated psychometric measures included. This could have been particularly helpful to understand attitudes and belief – potentially using the HPV Testing Attitudes and Beliefs Scale (HTABS; Tatar et al., 2023) - and would have allowed for comparisons to be made with other research. It could have been beneficial to collect data on the specific job roles of participants (e.g., GP, nurse) to allow further comparisons to be made. Rather than solely collecting information on the

participants' total duration of time in role on the cervical cancer screening pathway, it could have been useful to collect information on the specific amount of time that they spend engaging with patients on issues relating to cervical cancer. When considering GPs for example, they may have been in post for a long period of time, however only interact with patients in this capacity on a couple of occasions each month. Alternatively, a nurse who may have been in post for a shorter total duration, may complete cervical cancer screening on a daily basis. An additional measure therefore requesting details of the frequency that participants engage in work relating to the cervical cancer screening pathway (e.g., daily, weekly, monthly, etc.) could have been valuable.

2.4.2 METHODOLOGICAL STRENGTHS

2.4.2.1 Stakeholder engagement

As previously highlighted, the expertise of NHS clinicians including a Specialist Nurse, Nurse Practitioner and Specialty Doctor were utilised during survey design. Their input was invaluable due to their clinical expertise and knowledge relating to the target participant population. This helped to ensure that we overcame potential barriers which participants may have faced in completing the survey, from understanding the survey questions, to ensuring that the time to complete the survey felt feasible for clinicians.

2.4.2.2 Data collection via online survey

While highlighted as a methodological challenge, online surveys were beneficial to ensure that a range of responses from participants across Scotland were received, including those in remote locations. This also provided flexibility, enabling participants to take part at a time and location which suited them, whilst also allowing them to return to complete this. While there were some concerns around whether participants would remember to return to complete the survey, all participants completed this in one sitting. With the NHS being a busy environment, where some boards have introduced bans on staff travelling outside of their usual working location to save funds and focus on clinical need, this approach also allowed individuals the opportunity to participate without needing to take leave, thereby minimising the impact on local services.

2.4.3 CONCLUSION

This study advances understanding of what HCPs believe to be the key factors which could impact the success of self-sampling. Theoretically, it extends our understanding of how professional experience and context shape implementation perspectives. Practically, it identifies specific challenges and potential solutions for Scotland, considering equity and accessibility. The findings suggest that there is support for self-sampling, however, successful implementation requires careful attention to factors including education and support for HCPs; equity and accessibility; systematic implementation frameworks; stakeholder engagement. Having the voices of professionals at the centre of decision-making would allow researchers and decision-makers to understand what is required at a local level, to anticipate potential “bumps in the road” and to problem-solve ways of addressing these which could enable the success of self-sampling.

CHAPTER 3

STUDY 2: FOCUS GROUPS WITH INDIVIDUALS WITH INTELLECTUAL DISABILITIES

3.1 INTRODUCTION

As highlighted in chapter one, there are many reported reasons for CC screening attendance being consistently low in those with ID (Power et al., 2024). Non-attendance has a significant impact on health outcomes for this group, where they are more likely to be diagnosed with CC at a later stage, to receive reduced levels of treatment and have a higher likelihood of mortality compared to those without disabilities (Choi et al., 2021). Jo's Cervical Cancer Trust (2019) suggest that self-sampling could provide an easier and more accessible opportunity for women with disabilities to screen for CC. They suggest that further research needs to be done to find the most feasible and effective way of providing this as an option to such groups of women.

This would be particularly beneficial as we are now approaching a potential UK-wide roll-out of this method, with self-sampling highlighted as a future part of Scotland's strategy to reduce inequalities in screening (SG, 2023). This study aimed to gain a comprehensive understanding of the views and experiences of those with ID and their loved ones around CC screening and self-sampling. It was hoped that this could provide insight into some of the barriers to screening attendance, which could inform education provided to HCP on the CC screening pathway. Gaining an understanding of the views of this group around the self-sampling kit prior to its roll-out could provide valuable information to ensure this kit is accessible, ensuring their voices are at the centre of decisions made.

3.2 METHODOLOGY

3.2.1 RESEARCH DESIGN

Study two addressed the following question:

What are the views of those with an intellectual disability who have a cervix in Scotland and who are eligible for screening, around cervical cancer screening and HPV self-sampling (including presentation of the sampling kit itself)?

To answer this question, four focus groups were arranged with women with ID who attended third sector community groups, and their loved ones. Focus groups were selected following discussion

with Jo's Cervical Cancer Trust who advised this had been an effective means of understanding the views of individuals with ID. They advised that running focus groups within established groups was a supportive means of enabling participants to feel comfortable and able to contribute to discussion. A focus group schedule was developed (see Appendix 8). Data was analysed using reflexive thematic analysis (Braun & Clarke, 2019a). The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to inform how the following section is presented (see Appendix I). Ethical approval was granted in June 2024 (see Appendix 1).

3.2.2 PARTICIPANTS AND RECRUITMENT

We aimed to recruit 12-15 participants over a maximum of 3-4 focus groups. There is mixed opinion around how many focus groups is considered enough for data saturation, or if there is indeed such a thing in this context. Research by Hennink et al. (2019) found that 4 focus groups was sufficient to reach code saturation, where 94% of codes had been identified. Earlier research by Guest et al. (2016) similarly suggested that 3-6 focus groups were enough, with 90% of codes identifiable, indicating that a relatively small number of groups is therefore required to reach saturation. Some researchers disagree with the idea of data saturation in Reflexive TA, with Braun and Clarke (2019b) suggesting that this is not consistent with the value and assumptions of this method. They highlight that meaning is created through interpretation of (not excavated from) data, and so attempting to generate a number of how many 'data items' are required to stop data collection in advance of analysis is not possible. A further concept introduced by Malterud et al. (2015) is that of 'information power' which suggests that the more 'information power' that a sample provides, the fewer 'data items' required and vice versa. For this study, we therefore focused on the number of participants as opposed to the number of groups when considering the appropriate amount of data to collect.

Participant numbers were chosen due to the needs of those with ID, to ensure group sizes were small enough to allow the researcher to have the appropriate time and space to support with communication whilst also being sufficient to allow for rich discussion. Jo's Cervical Cancer Trust suggested a smaller number of participants (4-6 participants) to be most suitable. This is also supported within research by The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disabilities, who advise that 5-6 participants in each group is optimal, as larger numbers may lead to difficulties with engagement (Barrett & Kirk, 2000). Group size was dependent on individual functioning and ability; during recruitment, the appropriate number per group was confirmed with community group leaders who had a good understanding of each

member's abilities. Data collection over 3-4 groups was considered sufficient to gain diversity of views without repetition (Bloor et al., 2011).

The researcher had initially contacted three third sector organisations at the early stages of this project in April 2024, to gauge interest. Following ethical approval, each organisation was contacted again in August 2024, with one confirming that they had capacity to participate. An additional organisation was therefore contacted to ensure an optimal number of participants was reached over a variety of locations. Group leaders presented information sheets to their members to garner interest prior to confirming with the researcher that members would be keen to participate. The researcher offered to discuss the project with potential participants/group leaders prior to the day of the groups, with one group leader agreeing to this in advance. Four focus groups were subsequently arranged with groups based in Falkirk, Alloa and Kirkcaldy. The consent form was provided to group leaders to allow potential participants to familiarise themselves with this and to talk through this with their group leader. They were given at least one week to consider before the researcher got back in touch, with final participant numbers confirmed. Time was allocated at the start of each group to discuss and complete consent forms with participants. Principal inclusion and exclusion criteria are highlighted in table 8. Between September 18th and October 25th, 2024, a total of 11 women with ID and 2 family members participated, with the established group leaders also present in 3 out of 4 focus groups.

TABLE 10.*Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
• A person with a cervix. • Aged between 25 and 64 years old (thereby the recommended age for cervical screening). • Have a diagnosed intellectual disability. • Have capacity to consent (following the British Psychological Society's Capacity to Consent Checklist, see Appendix J). • Resident of Scotland and is part of an established community group (and their carer, if applicable). • May or may not have attended for a CC screening test. • May or may not have, or have had, a CC diagnosis. • Able to travel to an in-person focus group (although there will be an alternative option to conduct these over video call/telephone)	• Someone who does not have a cervix. • Aged under 25 years old, or over 65 years old. • Not resident in Scotland. • Unable to participate in a focus group or interview within the project timeline. • Has a significant or severe impairment which would impact on ability to take part in a focus group or 1:1 interview. • Does not have capacity to consent (following the British Psychological Society's Capacity to Consent Checklist, see Appendix J).

3.2.3 MEASURES

Groups followed the schedule created by the researcher, who facilitated each group (Appendix 8), with cards on display including pictures and concise wording for each topic (Appendix 11). The schedule included components of both the COM-B model and the Theoretical Framework of Acceptability (Sekhon et al., 2017). Participants were provided with individual handouts of the prompt cards. The schedule was sent to group leaders in advance, with a request for feedback to ensure these met the needs of participants; no amendments were required. The schedule split the session into three sections; initially the

facilitator explained the format of the group and prompted discussion around rules for confidentiality. They then completed an icebreaker activity. The second section involved participants discussing their experiences and attitudes towards CC screening. Finally, the self-sampling kit was presented to, and passed around, participants (Figure 21); initial views on the kit were discussed, along with thoughts around barriers/facilitators to completing self-sampling. Additional information was provided verbally around practical aspects of the kit (Table 11).

FIGURE 21.

Example of a self-sampling kit (Royal Australian College of General Practitioners, 2018)



TABLE 11.

Key points covered verbally when explaining HPV self-sampling to participants

Information provided on HPV self-sampling

- An HPV self-sampling kit is a test which lets you complete CC screening by yourself at home. It tests for HPV which can cause CC.
- There has been a recent pilot of self-sampling in London and, following this, it might be available as an option in Scotland.
- It is likely that self-sampling will firstly be offered to those who have not gone to their screening appointment following invitation.
- You would insert the swab, take the sample, and then place this into the test tube. This would then be sent off for testing.
- It is not yet known what instructions would be provided with the kit.
- It is expected that kits will be posted or given to you at the GP to be completed at home, however in some countries like Australia, they also provide the option for this to be done in clinic, with support from a nurse or doctor.
- It is not yet known how any potential reminder systems would work.

3.2.4 STAKEHOLDER INVOLVEMENT

Conversations with third sector organisations confirmed that focus groups would be a suitable and acceptable means of data collection. Information sheets and consent forms were discussed with a Senior Clinical Psychologist in the NHS who was the team lead for the ID pathway; she worked clinically with patients and had designed various documents for this population. She provided feedback on slight wording changes, which were made. Documents were shared with group leaders via email to ensure these were suitable for their members. While the researcher had compiled a draft focus group schedule, this, along with

the picture cards, were shared with community group leaders in advance for input and to confirm that these were appropriate. Measures were available to increase accessibility including materials to allow clients to draw their responses, the opportunity for 1:1 interviews, carers were invited to be involved, and the community group leader was present in an informal role as co-facilitator. The researcher is also 'Talking Mats' informed, a means of effective communication with individuals with ID using symbols and images. Accessible materials were not required, other than prompt cards.

3.2.5 CONSENT AND CONFIDENTIALITY

While confidentiality was not possible, group rules were discussed at the beginning of each group which included information not being shared outside of the room. Transcripts were anonymised by the researcher, with identifiable information including names, locations and clinician names removed, and participants assigned a unique identifier. Names of the third sector groups have been omitted to enhance anonymity. An electronic version of both standard and easy-read versions of the information sheet and consent form (Appendices 12-15) were provided to group leaders in advance of the groups to discuss with potential participants. The researcher also offered to post or deliver these materials in person. On the day of each group, time was allocated beforehand to answer any questions, check participants understood the documents using teach back (participants repeated what had been said in their own words to confirm understanding) and to confirm capacity to consent using the British Psychological Society's Capacity to Consent Checklist (Appendix 10). If written consent was not possible (due to physical/visual impairment), verbal consent would have been noted with the affirming signature of a witness; however, this was not needed. For the two groups which occurred online, consent forms were completed by hand and scanned to the researcher. The same procedure applied to carers.

3.2.6 PROCEDURE

Data collection occurred during September and October 2024. The first two groups occurred in-person at usual group locations, with the final two groups occurring online at request of the group leader/participants. There were 4-5 participants originally expected within the first 3 focus groups, with actual participant numbers in group 1 being 4, and group 3 being 5. Due to some participants in group 2 declining to participate on the day, there was only 1 participant present. For each of these groups the group leader was also present,

contributing to discussion and supporting with conversational flow. A husband carer was interested in contributing and, as both his wife with an ID and her mother were also keen to participate, they formed the final online focus group. Groups ran for 60-90 minutes. The group leaders had received the information sheet and consent form over email around one month beforehand and had talked through these with potential participants, providing paper copies to allow participants to familiarise themselves with the information. The researcher allowed time for casual conversation prior to groups beginning to increase comfortability. Consent forms were completed at the beginning of each group, with a couple of participants in group 1 having completed these beforehand. There was time for questions and the researcher confirmed understanding of each point on the consent form. Following consent, recording began using two encrypted audio recorders. The researcher then followed the schedule (Appendix 8). At the end of the group, there was space for participants to share any additional information. Participants were then provided with a £5 'Love2Shop' voucher as a thank you. Following each group, recordings were uploaded to a secure folder on SharePoint and deleted from the devices. Recordings were transcribed verbatim by an external company, with transcriptions uploaded to the SharePoint folder. The researcher checked each transcript for accuracy and anonymised these (see 3.2.5) prior to analysis.

3.2.7 ANALYSIS

Reflexive thematic analysis was used, with the researcher critically reflecting on how their perspectives and assumptions may influence resulting themes (Braun & Clarke, 2019). It emphasises the central role of the researcher, who engages with the dataset in a reflexive and recursive manner, resulting in a robust analysis. Analysis was inductive and explored themes which arose within groups relating to participant views and experiences. Themes were considered in relation to relevant behaviour change theory. The researcher initially familiarised herself with the data by reading through each transcript several times. Quirkos was used to organise and facilitate coding. Inductive coding was used to generate codes. The researcher added notes to each line of each transcript, recording initial thoughts and reflections. Codes were then analysed horizontally across the dataset in response to the research question. Following completion of coding, themes were refined and semantic themes defined, creating a map with colour coding. Latent themes were then refined using the semantic theme map in Excel. Codes and themes were discussed with the researcher's supervisor, with revision and refinement leading to the generation of final themes.

3.3 RESULTS

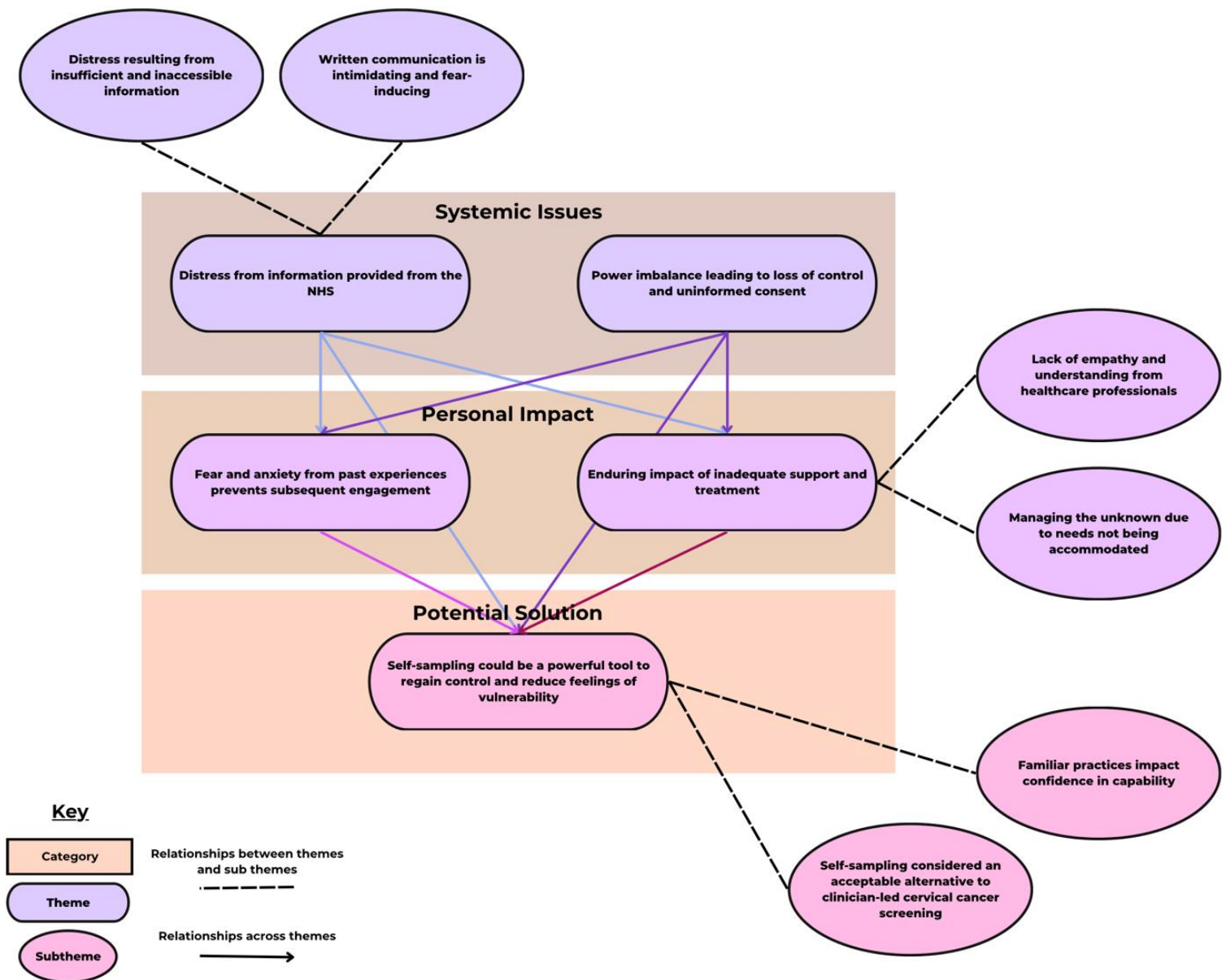
A total of 13 participants took part. Participants were female (n=12; 11 women with ID, 1 carer) and male (n=1 carer). Following analysis, codes were distilled into 5 themes and 6 subthemes; analysis also revealed that themes aligned with 3 categories (Figure 22). Results will be presented utilising these categories, beginning with themes highlighting systemic issues, followed by personal impact and then potential solutions. Extracted verbatim quotes include whether these were provided by the women who attend the support groups or their family members.

1. Distress from information provided from the NHS

Systemic issues were highlighted across groups. A frequent difficulty highlighted by participants related to either not knowing or not being provided with relevant information, and the distress resulting from this. This included feeling inadequately informed about various aspects of the CCSP and relevant timescales. Participants shared uncertainty and misunderstandings relating to HPV. Frustration and anger were shared when recounting instances of HCPs providing false reassurance or information which was not relevant. Written communication was consistently highlighted as a major barrier, with this difficult to understand and inaccessible. Considering self-sampling, participants felt it was important that decision-makers provided information relating to the rationale, reliability and accuracy of the test. Participants discussed the similarities between self-sampling and pre-existing practices. Subthemes identified related to distress from insufficient and inaccessible information, as well as written communication being both intimidating and fear-inducing.

FIGURE 22.

Thematic map of focus group themes and subthemes



1.1 Distress resulting from insufficient and inaccessible information

Significant distress was reported due to poor levels of accessible information being provided. Most participants agreed that the wait for results was one of the most anxiety-provoking elements of screening, often equating a long wait with something being wrong. When no timescale was provided, they noted that some women could “put themselves into so much of a frenzy...it takes longer for them to be able to come back down from it”. Participants noted fear around receiving abnormal results via letter without warning or an HCP present to explain what this means. Some

women emphasised how distressing this could be, particularly when they have pre-existing mental health conditions.

“...obviously I've got anxiety as well so that doesn't really help...you phone up your doctor like, have you heard anything. No, we've not heard anything, don't worry, it'll come soon, and, and it's like, how long's a piece of string...you're sitting there and you're counting the days...”

Woman (FG3)

There was a consensus that communication to the public around the CCSP, and changes to this, was poor. Many reported limited knowledge about HPV and its relationship with CC, often learning about it only upon diagnosis. This lack of information led to misconceptions, with one participant advising their letter claimed, *“HPV can be brought on by stress”*. Uncertainty created additional anxiety. Poor communication around HPV and its symptoms were also seen to induce fear in participants, who expressed dichotomous thinking and expectations of the worst-case scenario.

“And that was all clear and everything was fine. So now...I'm not due another smear test 'til 2025 and, I mean, it is scaring me because at the moment I've had a lot going on down that region of my body. So, yeah, it's, kind of, putting me back to that being back to that basic square one again and I know next year it's coming up and I have to go for this smear test again”

Woman (FG3)

Another participant reported anxiety around suddenly being informed that they no longer need to attend for CC screening, stating *“if I catch it, how am I going to know”*; this comment also illustrates possible misconceptions around transmission of HPV. They described two missed opportunities for information to be provided by HCPs: following hysterectomy and, alongside their letter confirming screening had now stopped. Participants described sharing their fears around screening with their GP, however information provided was not sufficient to assuage fears.

“To put that in, I'd be worried if it makes me bleed, that's what I'm scared of. We've been discussing it, but would anything like that take my virginity?”

Woman (FG3)

There was a frequent desire for HCPs to only provide information which was factual and relevant. Participants shared upset at receiving resources on cancer prior to any diagnosis being made. This led to fear, with participants stating that anticipation of “*hearing the word ‘cancer’*” was enough to prevent them from attending cervical screening. Participants also highlighted the lack of any factual information as being problematic. Inadequate information and poor explanations around medical decisions caused additional worry.

“I was just sent out, oh you'll get a letter in the post saying what we've found...then a letter came, said it was severe CIN 3 and there was no healthy cells in what they removed. So they still left some bad cells in me so then that makes you think, why aren't they getting me back in to take the rest of them out”

Woman (FG2)

The preference for HCPs to keep information factual extended to wishing that they did not provide reassurance without evidence. Accounts were shared of HCPs providing reassurance that everything would be fine following screening, however an abnormal result had unfortunately followed. One participant called this “*the worst part*” of cervical screening and noted that, despite telling HCPs not to do this, they would not listen. Participants wished for HCPs to “*put themselves in the patient's shoes*” and to understand that reassurance provided little help when they still had to wait for an unknown length of time for results to arrive.

1.2 Written communication is intimidating and fear-inducing

Problems relating to written communication received from the NHS were frequently mentioned. Some shared that they would immediately “*put [letters] in the bucket cos they look scary*”, whilst also anticipating they would not be able to understand its content. Written communication emerged as particularly problematic, with NHS letters described as intimidating and anxiety-inducing.

“...I don't know if anybody else feels like the way I feel, but when you see a letter from NHS, my heart rate goes like this” [motions hand quickly on chest]

Woman (FG3)

One carer participant reflected it was often not knowing what to expect which increased anxiety. His wife agreed that she often struggles with the limited information provided on letters. She shared this had led to her “*headbanging*” – a term used for hitting one’s head off of an object due to distress – as she was overwhelmed with the uncertainty of what each appointment was for that week.

“[She] really likes to see what people she’s meeting will look like...and maybe photos of the room she’ll be going to, or even just...more information about what to expect because, I think that’s something a lot of folk struggle with, not knowing what to expect”

Husband (FG4)

Throughout themes, these feelings of distress from managing the unknown due to receiving inadequate accommodations is discussed. Participants highlighted that the first thing that struck them were “*a lot of differences*” between the self-sampling kit and a clinician-based test. This highlighted concerns that self-sampling may not be as reliable and accurate; participants expressed a desire for information to be provided, in an accessible manner, explaining why there are differences and providing reassurance around its effectiveness. They noted that communication around self-sampling “*can’t be really wordy and complex...like other letters*”, with participants aware that common aspects of the screening procedure would be missing with self-sampling.

“At the moment I can speculate, hold on a minute, the doctors have got a speculum, as [group leader] said, they’ve got the big light, your feet are up in stirrups, know what I mean? You’re having to sit a certain way for them to get to where they need to. Well, doing that on your own you can’t do what they’ve done”

Woman (FG2)

This was reiterated by another participant who advised that “*a lot of questions need to be answered*” prior to them feeling assured and able to do the test, demonstrating the levels of mistrust which were evident throughout discussions.

2. Power imbalance leading to loss of control and uninformed consent

A common theme throughout responses related to the perceived power imbalance leading to loss of control and uninformed consent. Examples were shared by participants where they had experienced stigma and blame from HCPs, with others also indicating self-blame

for having HPV. Participants described feeling dismissed and invalidated by HCPs, and shared experiences of when requests to stop or exclamations of pain were ignored. Trust was highlighted as an essential component of CC screening, both in terms of trust with individual clinicians and with the NHS. Discussions raised concerns around power dynamics and informed consent in cervical screening, with barriers to attendance often including fears around not being in control and having a lack of choice.

Participants reported dissatisfaction and uncertainty around whether decisions made were in their best interests, resulting in inadequate patient care. Positive experiences with HCPs were rare, with one participant expressing gratitude for her GP due to her responsiveness and empathy. Some praised self-sampling, with this enabling choice and autonomy. This was welcomed following difficult experiences during clinician-led screening. Women recounted times where, despite clear exclamations of pain and requests to stop, HCPs continued without acknowledging this.

"...and he wouldn't listen to me at all. He put the speculum in...then he put this thing obviously stuck inside me. And I'm going, ow, ow, ow, will you please stop, you're hurting me, I can't do anymore. And he wasn't listening at all"

Woman (FG1)

Participants repeatedly described not feeling listened to. One participant recounted that, despite *"screaming in pain"*, the HCP had told them they could not feel discomfort in this area.

"So my husband obviously came in with me and he sat beside me and I was screaming in pain...it was horrible...And when I screamed cos it was sore, they said, but you don't have pain receptors in there so it isn't sore. And it's like, it is sore"

Woman (FG3)

Participants persistently felt dismissed or invalidated. During discussions, they wondered if this was due to their ID, with HCPs believing they were overly sensitive or that their feelings were not as valid. One participant described feeling like, due to her disability, the GP perhaps did not feel that they needed to provide additional detail around what was happening and why. This therefore presented uncertainty around whether participants were actually providing informed consent.

"...it was like she wasn't listening to me. It was like she'd just thrown me off her list basically, it's not a priority. And then obviously, like, all she was wanting me to do was go and get tests done all the time which, I mean, biopsies all the time to see what was going on down there. And I was like, whoa, we're not doing biopsies, we're not doing tests..."

Woman (FG3)

Throughout accounts, feelings of vulnerability and loss of control were evident. One participant's husband recognised that, while others can communicate verbally, those with ID often struggle with this and rely on non-verbal methods. The fact that non-verbal cues were often ignored by HCPs, however, exacerbates those feelings of being out of control *"especially when it's someone having that power over [her] body"*.

Participants recalled attending for an appointment and being expected to undergo a procedure which they had no prior knowledge of; for some they were only made aware when lying on the examination table.

"And then what annoyed me was when I saw the big tube, I was like, what were you doing in the first place. He said, I'm going to take a biopsy. You never said biopsy, you said examination. So I was really annoyed with that...so when I managed to finally get my clothes back on, he kept mentioning the coil to me. Now, I don't want the coil either. I actually walked out the room crying"

Woman (FG3)

Such descriptions again raised the question around whether informed consent was sought and received. One participant highlighted the consequences of such experiences, where they felt *"really abused"*. Repeatedly, participants recounted scenarios where they were unaware of what was going to happen to them, including significant surgical procedures.

"I had a phone call from the hospital asking me to go in and I thought, oh that's just another smear test. Nobody told me, they said, didn't your doctor tell you, I was like, no. So, they removed more than half of my cervix, cos it was...and all of that was bad cells, no good cells, so that was worrying"

Woman (FG1)

There were examples of self-blame, where participants had wondered what they may have done wrong to be diagnosed with HPV. Common misconceptions and stigma perhaps added to the belief that they were somehow to blame. Descriptions were shared of HCPs placing blame onto participants for doing something wrong to contract HPV. They blamed participants for “*sleeping around*”, further adding to the stigma associated with the condition.

“And the doctor was telling me it was all my fault I had that and... because I was sleeping around. It's like, I don't sleep around...it stayed with me, that...”

Woman (FG1)

The impact of such statements was clear, where they had stuck with participants many years later. The difficulties described by participants during interactions with the healthcare service indicate problems at a systemic level. It was revealed that this consequently had a significant personal impact.

3. Enduring impact of inadequate support and treatment

The personal impact of insufficient support by HCPs was evidenced in the theme ‘*enduring impact of inadequate support and treatment*’. Participants highlighted the critical importance of appropriate accommodations in enabling screening engagement. Only a small number of participants reported positive experiences with HCPs offering adequate accommodations. Most accounts however, expressed dissatisfaction at experiences to date, with strong beliefs that needs had not been met. This significantly influenced their future screening intentions. Subthemes were identified relating to lack of empathy and understanding from HCPs, along with difficulties managing uncertainty due to needs not being accommodated.

3.1 Lack of empathy and understanding from healthcare professionals

Participants consistently described hesitation in clinical settings, highlighting how their ID often created uncertainty around aspects of appointments, yet they struggled to request accommodations; there was a lack of empathy and understanding from HCPs who did not recognise when patients needed extra support or when they may be uncomfortable.

"I find people with a learning disability don't know what's in front of them as, do I go to this appointment, do I tell people that I'm scared, do I tell the professional if they could be a wee bit gentle..."

Woman (FG2)

Participants emphasised a need for HCPs to recognise the heightened distress experienced by women with ID during gynaecological appointments, noting frequent experiences of low empathy.

"And aye respecting that it'll maybe be more distressing for people with disabilities, so being sensitive to that. Be more gentle and stop if they're showing they're not happy"

Woman (FG4)

This was echoed by many participants who described occasions where both their verbal and nonverbal cues had not been acknowledged or respected.

3.2 Managing the unknown due to needs not being accommodated

With needs not being accommodated, anxiety and distress was communicated due to having to manage the unknown. Participants strongly emphasised the importance of personalised approaches, rejecting *"one size fits all"* solutions. The COVID-19 pandemic particularly highlighted these challenges, where participants *"had to deal with it all on [their] own"*. One striking example involved a domestic violence survivor unexpectedly confronted with two male clinicians, illustrating the critical importance of trauma-informed care. Participants also wished to have control around the location of screening, noting that they wanted this done at home where they *"would be safe"*.

The opportunity to familiarise themselves with procedures and equipment emerged as a crucial accommodation. Many participants described *"petrifying"* experiences of unexpected procedures.

"I mean, I was petrified when she put the [speculum] thing in and she opened the cervix. And then she puts that tube thing in and I'm like, oh where's that going..."

Woman (FG1)

A small number of participants described an HCP taking the time to walk through the procedure. Frequently, women described “*shock*” as the HCP brought out equipment during screening. Even when information was provided, it was often inadequate.

“I remember the first time I went and got it done, I saw her bringing these things out and I'm like...I says, can I ask where- what you're going to do with that? She says that's what I use. I went, oh right”

Women (FG3)

The importance of processing time was highlighted by several participants and carers.

“It's almost like she needs that processing time. So for some people they can hear information, ask questions, then the whatever can happen for the sake of this, your smear test. But for [name] she needs extra time initially to really understand...”

Husband (FG4)

This carer participant highlighted the need for those with an ID to have someone they trust, enabling them to “*go away, speak to us or her friends, and then come back for a second time to do...the procedure or...make a decision*”; a point which was reiterated by other participants.

Several responses around self-sampling highlighted the importance of ensuring accommodations, recognising that additional support was needed. They implored that their views be taken into consideration with self-sampling. Participants highlighted that instructions must meet their needs to increase confidence in capabilities. This included providing easy-read instructions, pictures and videos; some suggested a “*QR code with a video and easy read...cos reading about it is not going to be the same...as watching how to do it*”

“[easy-read instructions] would be best for me cos I've got my dyslexia, so I'm finding it hard to read...if they did wee pictures or a video or something for people like that who haven't got the chance to read obviously big fancy words”

Woman (FG3)

Participants shared concerns around capability to perform the test accurately. They mentioned fear around incorrectly taking the sample and receiving a false negative result,

with one participant stating they would “*still be in [their] head*”, and therefore continue to worry, even if they had received a negative result. Some responses indicated that participants had previously been admonished for doing things incorrectly, which may have impacted confidence levels.

“Aye. I'd be questioning that one, and I'd be...who says I don't get to the right bit and take the right cells, I'm screwing up again...you might not find out you've got, well, I'm not being funny, I've had CIN [abnormal cell changes in the cervix] two, three, four times now...”

Woman (FG2)

Participants consistently highlighted the need for reminders. While some could rely on family members to support with this, responses highlighted that they would easily forget about the kit.

“I'm the type of person, that would probably come through the door, and I would probably put it down, and then forget I'd put it down there. And then I'd be cleaning the house and going through every corner, like, as I do, and it would be, like, oh bugger, that came in weeks ago”

Woman (FG2)

Responses indicated that reminders should be part of the self-sampling process, providing prompts to complete and return the kit.

4. Fear and anxiety from past experiences prevents subsequent engagement

A recurring barrier to engagement with cervical screening were feelings of fear and anxiety relating to past experiences; this had led to ongoing avoidance of CC screening. These related to difficulties with HCPs or with the procedure itself. Whilst participants expressed strong emotions when discussing their own experiences, hearing others' accounts also provoked strong reactions, ranging from anxiety to sadness to anger. Stronger reactions were observed towards HCPs, whom they perceived had acted without empathy or compassion.

It was surmised that women – especially those with an ID – experienced less understanding and, as a result, often received less support. It was highlighted that attending for intimate examinations such as cervical screening, therefore took a lot of courage. Thus, it was even

more disheartening and upsetting for participants to hear about others facing criticism, blame or ignorance from HCPs.

"I think there's less understanding out there for a woman, like especially for us, we've gone through so much and there's less support out there for us... so but when we go out there to get things done like these kind of stuff...I'd be heartbroken the way our doctor spoke to her"
Woman (FG1)

Many described traumatic encounters that created enduring distress. One participant explained that, due to their past experience which involved physical and emotional pain plus feelings of deceit, they felt like they could no longer trust any HCPs.

"It was a horrible experience. And that's why...now next year's obviously going to come up, am I going to this appointment? Well at the moment, no. Because I don't trust anybody anymore now, that's how bad it's getting. I mean, how do you go from that appointment...trusting other people now and, I mean, it's just, it's horrible"
Woman (FG3)

Another participant said they had *"jumped at the chance"* to share their experiences and to feel heard following a traumatic experience.

"...this is why I am absolutely scared and petrified to go to anybody, like, who wants to have a look down there...I'm glad I've come along to this appointment... I was like, I'm going to come and give my side because it is, it's scaring me now because, like, I mean, obviously having gone through that experience just last month there..."
Woman (FG3)

Fear of cancer terminology particularly impacted attendance. One participant noted that past experiences of hearing the word "cancer" from HCPs had prevented her from attending subsequent screening appointments. When she had attended again however, she was met with a lack of understanding from an HCP and subsequently feels hesitant to attend again.

"Don't mention it. If I've not got it, please don't mention it. I mean, this is why I think a lot of people don't go for their screenings, because they're scared...the time I went in, obviously the woman was really nasty to me, the nurse was really nasty to me, she went, what's made you

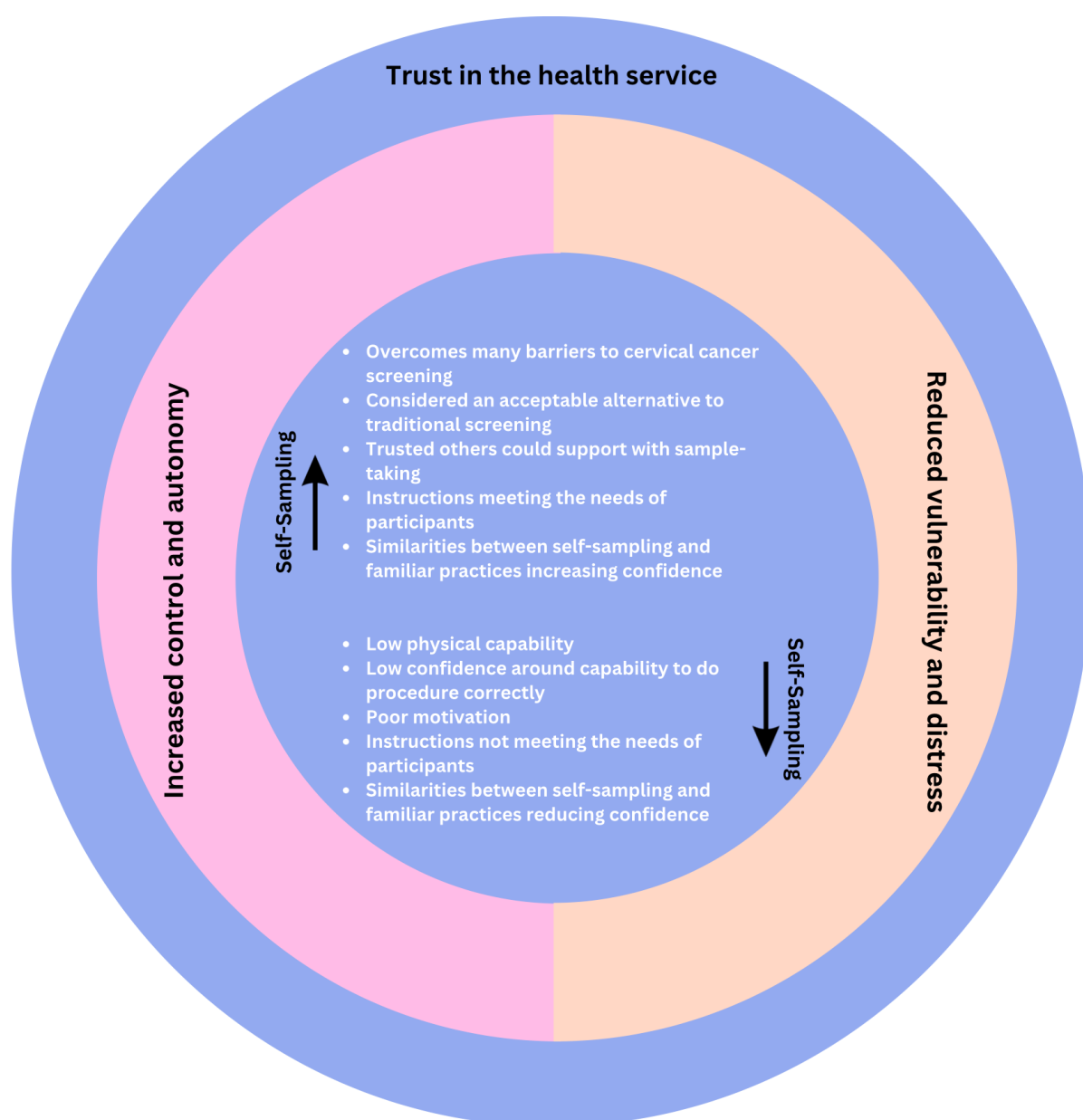
not, like, well you've come in obviously, but what's made you not want to come and I went, sick of hearing the word cancer..."

Woman (FG1)

The repeated mentions of “cancer” alongside HCPs focusing on why participants had missed screening appointments previously, were highlighted by multiple participants as key barriers to engaging with cervical screening. Therefore, while participants had previously stated that they wanted factual information, there was clearly a limit to the extent of what they would like to receive; dichotomous thinking and fear of cancer appeared to lead to participants immediately needing to disengage. Each of the above statements highlight the personal impact of inadequate and insufficient support from HCPs and the NHS, with participants going on to discuss their thoughts around a potential solution.

FIGURE 23.

Schematic of key themes influencing engagement with self-sampling



5. Self-sampling could be a powerful tool to regain control and reduce feelings of vulnerability

Participants were generally positive about the potential for self-sampling to be a solution to overcome barriers to screening, leading to them regaining control and reducing feelings of vulnerability. Throughout groups, participants emphasised that this could be a valuable alternative to clinician-led screening, particularly for those with ID who face unique challenges. Figure 23 summarises the information shared by participants into a schematic of key themes influencing engagement with self-sampling. The inner circle highlights the areas

that participants felt could both increase engagement and likelihood of success (including high acceptability, trusted others supporting with the process and instructions meeting the needs of the group) and those which could hinder success (including low confidence around capability to do the test correctly and poor motivation). The inner rings note the two key overarching benefits of self-sampling for those with ID which are increased control and autonomy, and reduced vulnerability and distress. The outer ring highlights that trust in the health service ultimately impacts the whole process and whether self-sampling can be accepted by this group. Subthemes include that familiar practices increase confidence in capability and that self-sampling is considered an acceptable alternative to clinicianled screening.

Whilst self-sampling was recognised as a way to overcome many barriers to cervical screening, various participants noted that there would still need to be a degree of motivation to both complete and return the test. Participants made various comments about the onus of arranging cervical screening being on the health service rather on them as the individual. Multiple participants advised that they were likely overdue their screening and, while some said they would follow this up, a few said that they would await notification from the NHS as they were *“not going to come chasing”*.

As discussed, loss of control and power in cervical screening was a major barrier to attendance. One of the first things highlighted when discussing self-sampling in each group was the fact that this gave women that power back, thereby eliminating a huge source of anxiety.

“...the minute your adrenaline as I see it, the adrenaline rush goes in, kicks in, get to that doctor surgery, and they give us these [self-sampling kits] at home to the women who have been scared, I think it would ease a lot of pressure”

Woman (FG2)

This participant recognised that self-sampling at home would ease pressure on many WPwC who experience intense levels of anxiety when attending the GP for clinician-led screening. Participants agreed that this could be a positive development for many, where doing the test at home on your own meant that you were *“in charge of it”*. Participants noted that this would remove various obstacles that women can experience including potential sensory and communication issues.

“... so you don’t have to go into, you know how some people might have sensory issues and then communication issues of going into the doctors and then having something like that done...cos that's been taken away”

Woman (FG1)

A couple of participants, however, were wary about why self-sampling was being introduced, with one querying if it was *“because they’ve taken the doctors away”*. This may imply that there are some levels of mistrust as to whether self-sampling is being introduced as a cost-cutting exercise rather than a positive alternative to traditional screening. Focus group discussions also led to participants considering what else would be required to engage with self-sampling. As mentioned, participants identified ways in which self-sampling could overcome barriers around needing to attend at the GP practice and having a clinician-led test. Some participants also noted that being able to complete self-sampling at home meant that loved ones could support them to complete this, most commonly their parent or husband.

5.1 Familiar practices impact confidence in capability

A recurring thread throughout groups, was the similarity between self-sampling and other familiar practices including bowel screening, COVID-19 tests and inserting tampons. For most, this familiarity and reassurance that they had been capable of performing other types of self-sampling led to them feeling more able to complete HPV self-sampling. Others upon hearing these comparisons, noted that this helped them to better understand what would be expected and led to the kit feeling less intimidating.

“But we had to do things ourselves [during COVID] and we got really used to checking”

Woman (FG3)

“I'm thinking it would be like, putting it like, up to the same bit as when you do a tampon. I use tampons”

Woman (FG3)

For others however, these comparisons led to them doubting their ability to engage with self-sampling. Comparisons led to some wondering what additional information would be provided with kits.

“Aye. But to me, getting handed that, I'd be like, mm. Not being funny, the COVID tests you had more than that”

Woman (FG2)

Participants recognised that there were additional items provided with other self-sampling kits including instructions and a return envelope, which were essential in enabling them to complete this.

5.2 Self-sampling considered an acceptable alternative to clinician-led cervical cancer screening

As highlighted, most participants were positive about the idea of self-sampling becoming available. Within each group there were members who had previously refused to attend screening, with some strongly against this at the start of the group. By the end, however, some had changed their minds because of self-sampling, where this had increased their confidence to participate. Within one group, participants joked that *“we'll all put our orders in”*, with the availability of self-sampling making a huge difference to outcomes.

“Yeah. The other thing is it increases the amount of people that do their tests so if it goes in this in our group here, instead of just 50 per cent of us doing it, you've 100 per cent of us do it and then that makes- that'll make a massive difference, won't it...”

Group Leader (FG3)

For one participant who had previously been unable to attend cervical screening, they shared that the self-sampling kit being delivered to their home for completion meant that they could do this with the support of their mother. Another considered the difference that could have been made to lives lost to CC if self-sampling had been available previously.

“But... look how many lives would have been saved if this was available then”

Woman (FG3)

This encapsulates the hope and enthusiasm that participants had for self-sampling being a powerful alternative to traditional screening, allowing people to engage who had previously never felt able to.

3.4 DISCUSSION

This study presents compelling evidence regarding the perspectives of women with ID on CC screening and self-sampling implementation in Scotland. Findings reveal significant systemic barriers within the current CCSP while highlighting self-sampling's potential as a transformative tool for increasing screening accessibility and engagement.

The research demonstrates fundamental inadequacies in the current CCSP's ability to meet the needs of women with ID, particularly regarding communication, appropriate accommodations and information provision. A key finding was the prevalence of dichotomous thinking patterns among participants, consistent with Cooper et al.'s (2018) observations of cognitive rigidity in individuals with ID. This manifested in participants viewing screening as "all bad" and assessing any symptoms as being "back to square one" while being unable to consider the alternative or the potential benefits of screening; a pattern Petrolini et al. (2023) identified as characteristic of ID-related cognitive processing, which must be considered by HCPs.

The relationship between low health literacy and screening engagement difficulties, as previously mentioned by Spadea et al. (2010), appears unchanged over the past decade, suggesting persistent systemic failures in addressing these barriers. This highlights the importance of accessible education within screening utilising frameworks such as the HBM. Previous education programmes utilising the HBM have been successful including the four-session programme by Khalil et al. (2024), which led to significant improvements in knowledge and preventative behaviours relating to prostate cancer screening. Furthermore, Sharifikia et al. (2019) found that women's knowledge in relation to areas such as benefits, barriers and perceived severity of cancer improved following a five-session HBM education programme. A systematic review by Dressler et al. (2021) found that a greater number of perceived barriers to engaging in screening led to a lower comprehension of the potential dangers of getting cancer. The researchers concluded that it is imperative that fear around screening is managed and that perceived barriers are understood to effectively implement screening programmes. Taking this into consideration, decision-makers must obtain an

understanding of the perceived barriers to self-sampling highlighted by participants i.e., poor instructions, no reminders. Educational materials should target the dichotomous thinking in those with ID, raising awareness of susceptibility, severity, and perceived benefits of preventative behaviours.

A systematic review by Lau et al. (2020) found that, in line with the HBM, the more aware one is about their susceptibility and the potential severity of cancer, the more likely they are to participate in preventative behaviours such as screening. It is important that this is managed sensitively as participants in the present study felt strongly that materials on cancer should not be provided unless there was a diagnosis; some stated that fear of hearing the word “cancer” during screening was a barrier to attendance. This aligns with findings from a systematic review from Gil et al. (2023) who identified that those with ID had a “deep fear” around hearing this word, which they suggested could be due to their limited knowledge on the topic. The review also found that carers would often shield those they support from this topic, at times actually preventing individuals from receiving a cancer diagnosis (Flynn et al., 2016). It therefore seems like education is needed for both those with ID and their carers, with consideration given on how to approach the topic of cancer in a factual but sensitive manner. Using the HBM to develop education materials which promote awareness of the benefits of early diagnosis and treatment could support to positively adjust individual beliefs around cervical screening. Dsouza et al.'s (2021) application of the TPB to CC screening also provides valuable insight into potential intervention strategies. Their emphasis on fostering positive attitudes and demonstrating procedural accessibility particularly resonates with our findings regarding the importance of accessibility and control in screening decisions.

A critical finding concerns the inadequacy of current consent practices. Participants' accounts of having their expressions of pain and requests to stop procedures ignored align with the RCGP's (2017) guidance on communication challenges in ID populations. The Learning Disabilities Cancer Strategic Group's (2009) best practice guidelines emphasising the importance of consent via behavioural indicators appear particularly relevant given participants' experiences. Communication strategies around consent should be tailored to the individual; with some participants in the present study sharing that they go non-verbal when in healthcare appointments, it is crucial that HCPs take the time to understand individual needs and follow inclusive practices, to uphold the rights of their patients. This extends to decision-makers ensuring that those with ID provide informed consent to engage

with self-sampling, confirming that they also understand what happens to their sample once returned.

Further adding to the examples of insufficient consent, some participants described not being aware of what procedure they were undergoing until they were on the examination table and presented with equipment. This included one participant who was unaware she was going to have over half of her cervix removed and has since miscarried; she explained being unsure as to whether this was a consequence of that procedure. Participants frequently described the lack of control in screening as being a major barrier. With research suggesting that people with ID may have lower levels of understanding around advantages of screening, with negative affect and beliefs impacting engagement with screening to a greater extent (Parish et al., 2008), the TPB can help us to consider ways in which specific factors can be targeted. Perceived Behavioural Control is a key component of the TPB and is a crucial factor in whether people feel able to attend cancer screening in general (Lawal et al., 2017), and CC specifically (Roncancio et al., 2015). Justifiably, participants in the present study felt vulnerable; while they had initially chosen to attend screening – often with a lot of support from their loved ones – a lack of understanding and time taken to build trust from the HCP, had led them to feel without control as the procedure progressed. This highlights the importance of ensuring ongoing consent, as well as providing sufficient time for processing information and making decisions. Protections are detailed in the United Nations Convention on the Rights of Persons with Disabilities (2006), however a recent review by Dunn et al. (2024) observed that HCPs often do not include patients with ID in decision-making processes and do not follow correct processes around consent. This was recognised by participants in the present study, where they believed that HCPs had made incorrect assumptions around their capacity and desire to make decisions around their health. Evidence from the recent systematic review by Power et al. (2024) confirmed that this is an area which must be considered, where HCPs were stated as believing that those with an ID would not be able to understand information about cancer screening, with most directing any information towards family members or supporters instead. Mirzaei-Alavijeh et al.'s (2024) findings on improving screening uptake by increasing perceived control, combined with Kuper et al.'s (2024) emphasis on "affirmative, active and accessible" consent, provide a framework for improving current practices. Choice and autonomy over screening methods could lead to any abnormalities being identified at an early stage, helping to address inequities and in turn reduce mortality disparities (Tosetti & Kuper, 2023).

The potential of self-sampling to address current barriers appears significant, with findings indicating high acceptability among participants, including those who had previously

declined traditional screening. This aligns with Wedisinghe et al.'s (2022) research showing 97% reengagement intention among defaulters in Dumfries & Galloway when offered self-sampling. Verdoodt et al.'s (2015) findings on increased engagement among underserved populations further support this potential. Many systematic reviews have demonstrated high acceptability, with people most often praising its convenience, accessibility and the elimination of an invasive, and sometimes traumatising, physical procedure (Kamath Mulki & Withers, 2021; Nishimura et al., 2021).

ID occur across a spectrum; needs, abilities and adaptive functioning vary from mild to profound (Office for Health Improvement & Disparities, 2025). It should be considered that even those with a mild ID have a mental age of 9-12 years old, with many going undiagnosed because of their level of functioning. This underscores the need for accessible instructions and for careful consideration of implementation strategies. YouScreen (NHS North Central London Cancer Alliance, n.d.) provides a valuable template for implementation, through its utilisation of the COM-B model within capability-focused messaging used in accessible written and pictorial instructions.

To increase the chances of success, the topic of distrust with the NHS would need to be addressed. While participants were largely positive about the introduction of self-sampling, there were some concerns that this may be a cost-cutting exercise. This lack of trust from those with ID is easily understood when considering recent shortcomings. In 2024, data obtained by the Scottish Labour Party evidenced that, despite being a critical promise following the pandemic, not one Scottish health board had met the target of offering all people with ID an annual health check (STV News, 2024). While it will likely take time to regain trust, promoting the rationale and evidence behind self-sampling could support this group to trust the reasoning behind its introduction.

The potential impact of successful implementation appears substantial. It is believed that one round of self-sampling when aged 40 in those who have defaulted in Australia, could result in 922 fewer cancer diagnoses – with just 3.7 women needing to be treated for pre-cancer to prevent each diagnosis - and 426 fewer deaths from cancer by 84 years of age (Smith et al., 2016). This gains additional significance when considered alongside recent research by Ward et al. (2024) and Herweijer et al. (2023) showing higher cancer mortality rates among women with disabilities. The findings demonstrate strong alignment with the Theoretical Framework of Acceptability (TFA), particularly regarding cognitive and emotional

responses to self-sampling. Participants' positive associations with COVID-19 testing experiences suggest a potential foundation for building confidence in self-sampling capabilities, however more work will be needed to manage the different processes and to ensure participants understand the procedural differences (Boum et al., 2021). With Public Health Scotland (2022b) projecting a 21% increase in annual disease burden in Scotland between 2019 and 2043, the potential impact of successful self-sampling implementation to reduce morbidity and mortality, cannot be overstated.

3.4.1 METHODOLOGICAL CHALLENGES

3.4.1.1 Number of focus group participants

As previously discussed (see 3.2.2), there is mixed opinion around how many focus groups is considered enough for data saturation, or if there is indeed such a thing in this context. Consistent with the literature, we focused on number of participants as opposed to number of groups when considering the appropriate amount of data to collect. The 4 groups within this project provided a great deal of insight and appeared to meet the requirements of 'information power' as discussed within the literature, where participants provided strong dialogue and detailed descriptions of their views and experiences relating to the research question and topic of cervical cancer screening and self-sampling. While the number of groups within this study met the suggested number of participants and provided a great deal of insight into the topics discussed, unfortunately one group only involved one participant due to other expected participants opting not to take part. The inclusion of the group leader still led to an engaging and informative discussion; however, a larger number of participants could have been beneficial.

3.4.1.2 Number of carer participants

Alongside women with ID, their loved ones were also invited to participate. Participants seemed to prefer to have the opportunity to speak to their own experiences and views with most declining to invite their loved ones to join. We therefore only had two carer participants within this study. On reflection, it may have been valuable to have arranged a standalone focus group for carers to ensure both groups had space to share their views. Alternatively, recruiting carers outside of community groups could have been valuable to gather perspectives from both groups of participants.

3.4.2 METHODOLOGICAL STRENGTHS

3.4.2.1 Stakeholder engagement

Participant-facing documents were shared with a clinician who had significant experience of working with, and creating documents for, people with ID. Their suggestions were invaluable due to their expertise and knowledge, ensuring documents were accessible. Individual needs and capabilities can vary significantly, and so sharing these with group leaders in advance of focus groups was valuable to confirm that materials would be appropriate. It is unclear whether leaders discussed materials with group members, which could have enhanced accessibility.

3.4.2.2 Data collection via focus groups in different locations

Third sector organisations with groups in a variety of locations were purposely contacted in the hopes of gaining a representative sample. The offices for each of these groups varied in where they placed on the Scottish Index of Multiple Deprivation 2020. Bases ranged from being within the 10% most deprived, 30% most deprived, and 40% least deprived areas of Scotland, respectively. It was therefore anticipated that participants across different areas, with different backgrounds and experiences of services, would add to the richness of the data. Focus groups were considered an effective means of understanding the experiences of individuals with ID, and running these within established groups was valuable to increase comfortability.

3.4.3 CONCLUSION

This research advances understanding of how self-sampling could transform CC screening accessibility for women with ID in Scotland. The findings suggest that successful implementation, grounded in theoretical frameworks and responsive to user needs, could improve outcomes and healthcare experiences for this underserved population, allowing earlier diagnosis and access to treatment. The integration of participant perspectives with existing theoretical frameworks provides a robust foundation for implementation strategies that could meaningfully address current healthcare inequities.

CHAPTER 4

DISCUSSION

This thesis employed a mixed methods approach to comprehensively examine attitudes and perspectives towards future implementation of HPV self-sampling within Scotland's CC screening programme. Through investigating both HCP perspectives and the lived experiences of women with ID, this research reveals critical insights for national implementation while highlighting the complex interplay between professional practice, systemic barriers, and patient needs.

The Adults with Incapacity Act (2000) provides guidance for HCPs in Scotland around obtaining consent, emphasising that capacity requires the ability to make, communicate, and understand decisions. Focus group findings revealed concerning instances where these principles were not adequately upheld, with attempts to communicate during screening ignored, plus insufficient time and information provided to patients. Both HCPs and patients with ID acknowledged the substantial systemic changes required to address these issues.

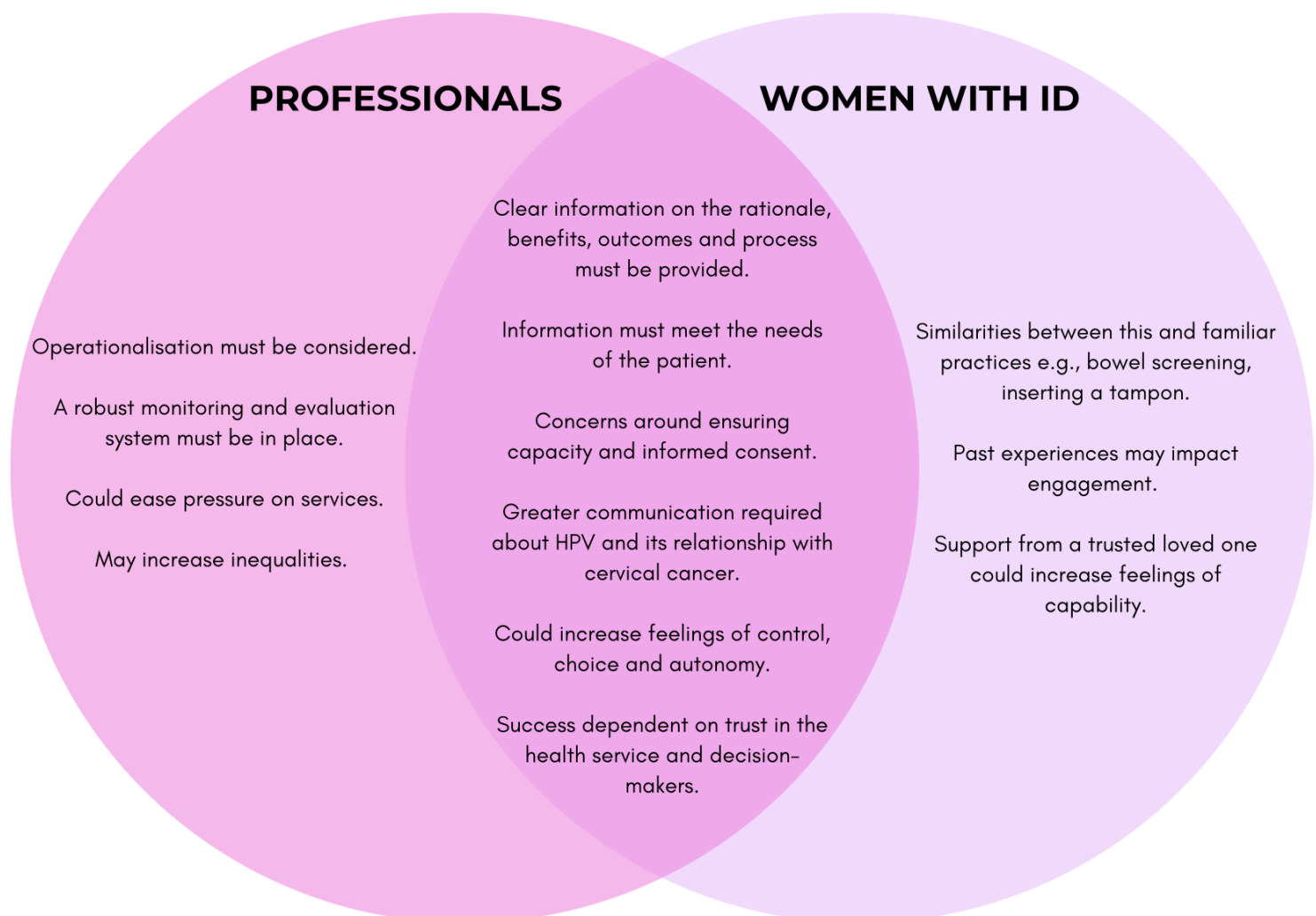
Analysis revealed several overlapping themes between HCPs and patient perspectives regarding successful self-sampling implementation (Figure 24). Both groups emphasised the critical importance of informed consent, data transparency, and accessible information regarding rationale, benefits, and processes. Participants universally recognised self-sampling's potential to enhance patient autonomy while emphasising it should complement rather than replace traditional screening. It was viewed as particularly valuable for certain groups of individuals, such as those with previous negative screening experiences (Table 8; Chapter 2). While both groups appreciated the benefits of self-sampling outside of a clinical setting, HCPs expressed concerns about sample validity in uncontrolled environments.

Intersectionality, which considers that parts of a person's identity (e.g., gender, sexuality, disability) are not discrete categories but that they instead "intersect and reflect social structures of oppression and privilege" (Kelly et al., 2021), is an important construct to consider. The analysis from the focus groups generated themes that were likely not just as a result of the participants' intellectual disabilities, but also due to other aspects of their identity, such as gender. We can understand the data in the context of the intersecting elements of the participants' identities, where previous research has also observed that fear and anxiety of past experiences of cancer screening has prevented subsequent engagement and that information provided from the health service is viewed

as inadequate or fear-inducing for women without disabilities (Marques et al., 2023). While there are themes that are common across research into cervical cancer screening in women, there are also themes which appear to be unique to the women with ID and which go beyond some of the common difficulties experienced; difficulties around consent procedures and participants not being actively included in decision-making processes around their health, for example, as well as inadequate consideration of accommodations and non-verbal indicators of distress. When considered in the context of intersectionality, the themes identified and the disparities experienced by participants are the outcome of interconnected aspects of their identity, power relations and social context. Intersectionality enables us to understand how the participants experience cervical cancer screening differently as a result of their identity and unequal power dynamics. Understanding these differences can enable decision-makers to develop more effective policy and processes which could support to tackle the structural disadvantages experienced by this group.

FIGURE 24.

Venn Diagram of key factors relating to the success of self-sampling as identified by participants



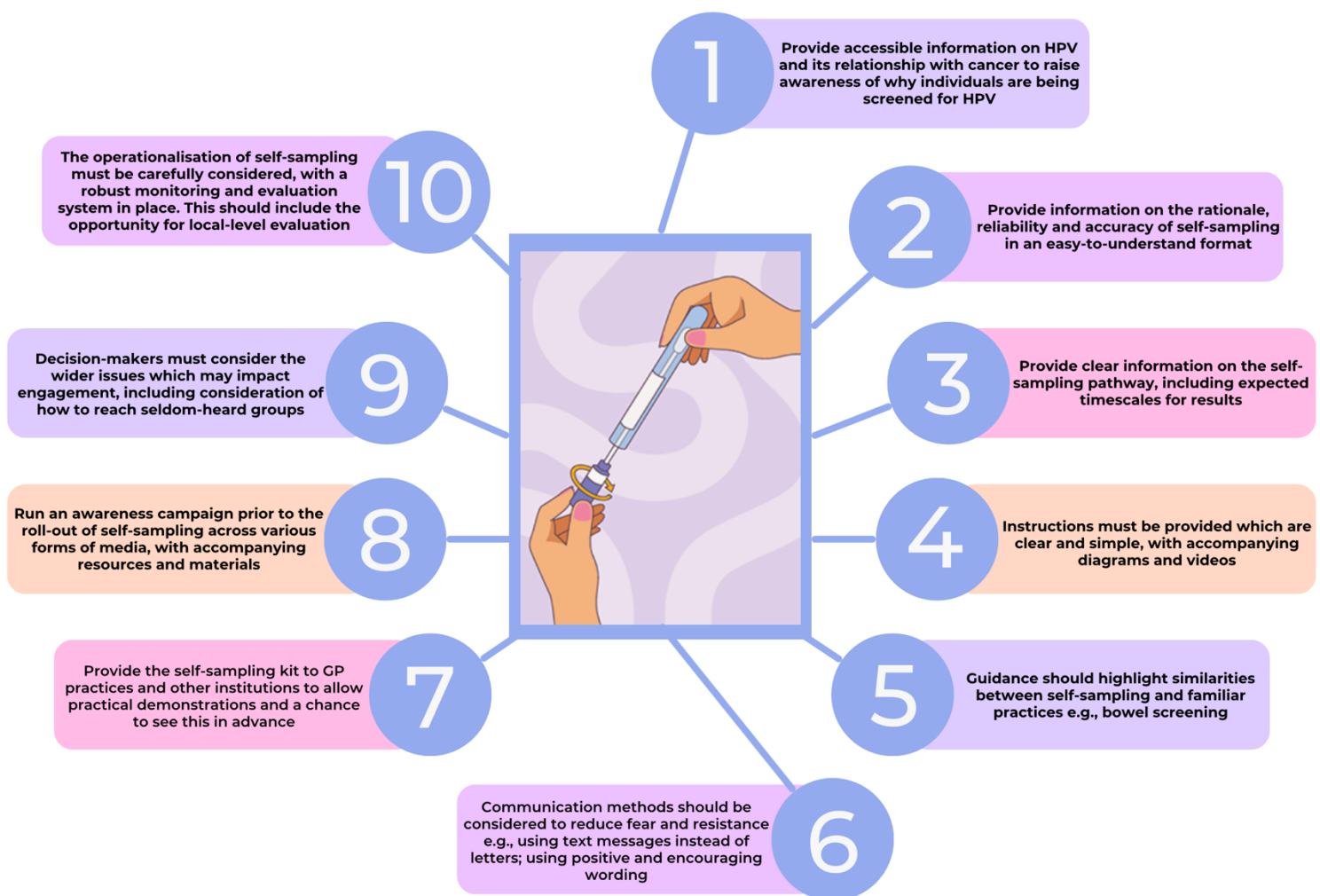
4.1 IMPLICATIONS FOR PRACTICE AND RECOMMENDATIONS

This research revealed significant support for self-sampling from both HCPs and women with ID in Scotland. Currently available in 17 countries worldwide, multiple systematic reviews have confirmed high acceptability, with participants commending its convenience, accessibility and privacy (Kamath et al., 2021; Nishimura et al., 2021). Participants in the present study were positive about the potential of self-sampling in Scotland, recognising this as a powerful means of overcoming barriers in cervical screening, increasing uptake within underrepresented populations. Most HCPs believed that self-sampling should be promoted and, within focus groups, many who had previously felt unable to attend screening believed this could now enable them to engage.

Drawing from the research findings, ten recommendations were developed for the successful implementation of self-sampling in Scotland (Figure 25). These recommendations integrate theoretical frameworks including the COM-B model, HBM, and TPB, while addressing both HCP and patient needs.

FIGURE 25.

Recommendations to enable the successful roll-out of self-sampling in Scotland (centre image by Australian Government (2024))



Implementation requires comprehensive, accessible information materials, available in multiple formats (including Braille and easy-read), and languages. YouScreen (Drysdale et al., 2024) demonstrated the effectiveness of the COM-B model in developing such materials, with participants reporting higher confidence levels compared to similar UK studies. This

success was attributed to specific capability-focused messaging (e.g., *"You can do it"*) integrated across written and pictorial instructions.

Research findings revealed a direct correlation between HCP knowledge and implementation support. Comprehensive training should include sufficient time and materials to build confidence and competence. Educational materials should address care planning for vulnerable population and include guidance on risk assessment procedures. Local teams should receive materials to promote within the community along with a suggested promotional strategy.

Educational materials for the public should be developed using the HBM, focusing on raising awareness of cancer susceptibility and understanding disease severity. They should highlight benefits of screening, emphasising early diagnosis advantages. This approach aligns with Lau et al.'s (2020) findings linking awareness of susceptibility and severity to increased engagement with preventative behaviour. As highlighted, the topic of cancer must be approached sensitively, with education also provided to carers around the importance of timely diagnosis and treatment. A comprehensive pre-implementation awareness campaign should explain the relationship between HPV and CC. It should clarify the rationale for self-sampling, addressing common misconceptions and building public confidence. The campaign should integrate TPB principles (Dsouza et al., 2021), focusing on fostering positive attitudes toward self-sampling, demonstrating procedural accessibility, addressing subjective norms affecting screening decisions (Jalilian & Emdadi, 2011), and building self-efficacy.

Evidence from YouScreen demonstrated higher return rates for opportunistically delivered kits compared to mail-outs, highlighting the importance of effective HCP communication. Implementation should include clear result communication protocols. Text-based reminder systems should be available where preferred; this is in alignment with earlier research by von Wagner et al. (2018) who concluded that reminders were important for increasing attendance at cancer screening. To minimise HCPs' concerns around self-sampling increasing inequities, clear instructions must be provided on who patients should contact if they are unable to use the kit.

Adequate thought must be given to ways of improving opportunity to engage with self-sampling for those with ID. Appointments should be available to discuss and see the kit, where patients can ask questions and have time to process information prior to agreeing to participate. Clear information

should be provided about post-screening processes, including timescales (MENCAP, 2017). The recent systematic review by Power et al. (2024) highlighted that HCPs must receive education and information around giving those with ID an adequate amount of time to prepare for engagement with cervical screening, providing them with the opportunity to process information, increasing predictability with the process and reducing distress. Such person-centred approaches supported with building trust and improving knowledge levels of patients.

Mirzaei-Alavijeh et al. (2024) suggest that supporting people to develop coping responses to potential difficulties in screening, explaining the benefits of receiving results, and using goal-setting can all be effective ways to increase individual sense of control, thereby increasing likelihood of engagement. Information sessions could also be provided outside of a healthcare environment including schools, universities, community groups and workplaces; this could increase accessibility to information and support to address subjective norms.

Careful consideration must be given to the operationalisation of self-sampling to enable it to succeed. Feedback from key stakeholders would enable adaptations to be implemented at an early stage. An evidence-based framework should be utilised, such as the CFIR (Damschroder et al., 2009). This framework considers that there are both core and adaptable elements to an intervention; this means that adjustments could be made to fit the needs of local populations without impacting fidelity. The TFA provides a systematic way of assessing whether self-sampling would be acceptable to those receiving or delivering an intervention, another important factor which must be considered. Self-sampling was considered highly acceptable to the participants within this study, in terms of factors including perceived suitability, convenience and effectiveness. Consideration needs to be given around how to measure and increase acceptability across Scotland. Crucial components include participants feeling positively about this, believing that the burden to complete this is low and that it fits with their values. It also highlights the importance of the intervention being easy-to-understand, effective and of limited cost to the participant, with them feeling confident in their ability to perform this. Consideration must be given around the most effective methods to reach “seldom-heard” groups, including those with disabilities, ethnic minorities, and people living in remote locations, to minimise the risk of increasing inequities. While participants in the present study were relatively independent, future research should explore the acceptability amongst individuals with lower levels of functioning alongside carers of those with ID. Understanding attitudes and beliefs across

these different groups will help to ensure concerns and barriers specific to each group are addressed.

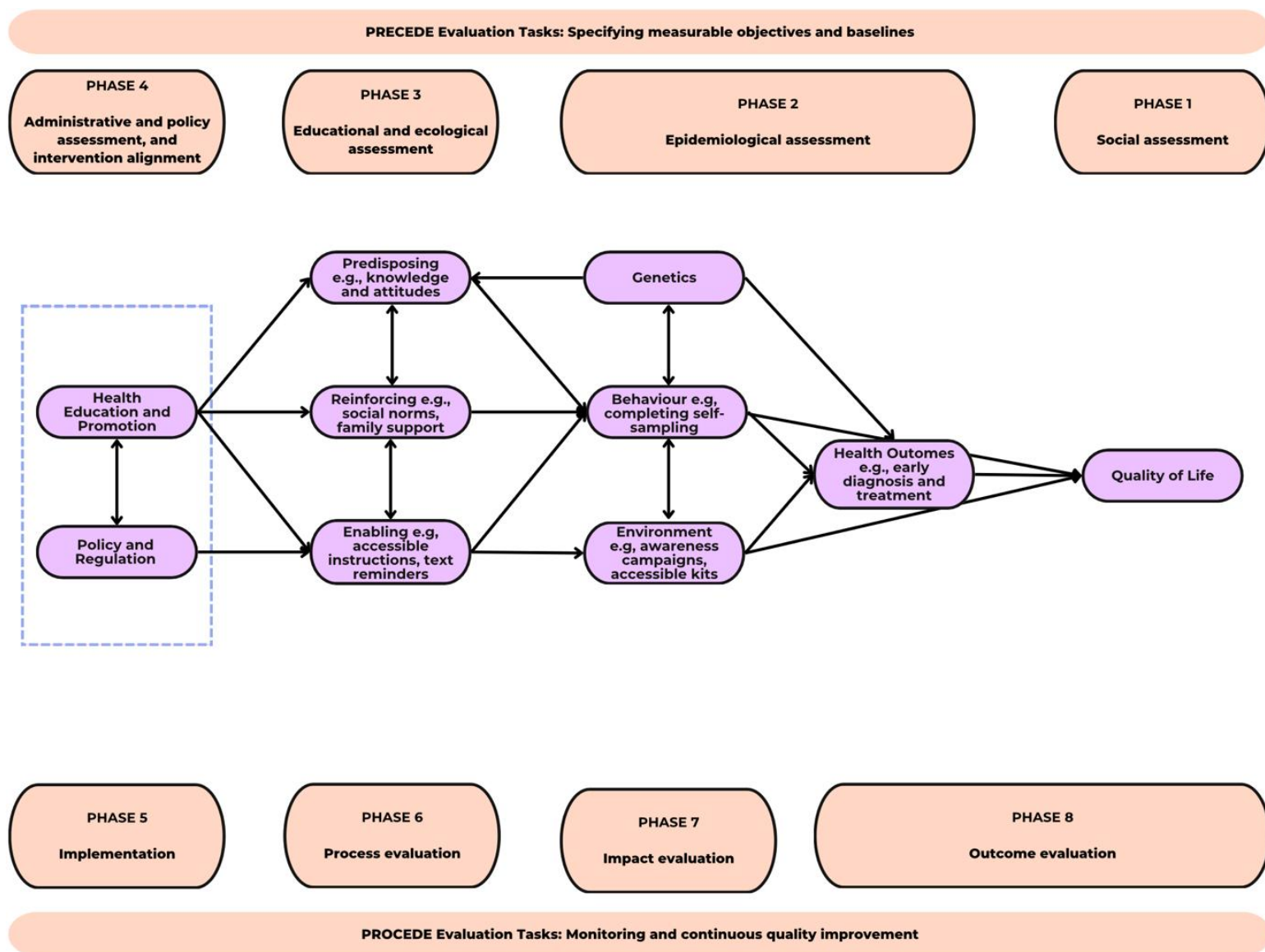
These recommendations provide a starting point for future research. Due to the number of recommendations, intervention mapping using a health promotion model such as PRECEDE-PROCEED (Green & Kreuter, 2005; Figure 26) could be valuable; this would provide a structured approach to planning, implementation and evaluation utilising the communities in which self-sampling is delivered, allowing this to be adjusted to address their specific needs. Future research could utilise a co-production approach, investigating what would be required to enable self-sampling to be a success in individual communities. Trials could be implemented, for example exploring whether:

- Wording informed by the COM-B model to target capability within text reminders could increase self-efficacy and motivation to engage with self-sampling, while reducing fear.
- Educational materials utilising the HBM, promoting the benefits of early diagnosis and treatment of HPV, could increase knowledge levels and successfully get the balance right with providing factual information while not inducing fear and disengagement.
- Training materials for HCPs relating to self-sampling lead to an increase in perceived capability and increase the likelihood that they perform a behaviour, for example, providing opportunistic kits to patients.

The outcomes of such research would help to ensure that self-sampling is a success and that it meets the needs of those receiving and delivering this method of screening.

FIGURE 26.

Intervention mapping for self-sampling using the PRECEDE-PROCEED model



4.2 STRENGTHS AND CONTRIBUTIONS OF THE RESEARCH

This research makes several significant contributions to both theoretical understanding and practical implementation of CC screening innovations in Scotland. The study represents the first comprehensive investigation of HCP perspectives on HPV self-sampling across Scotland. While previous research has examined professional views in England, Scotland's unique healthcare context, organisational structure, and geographical challenges necessitated specific investigation to inform implementation strategies.

A key methodological strength lies in the study's integrated stakeholder approach, examining both HCP perspectives and the lived experiences of women with ID. This dual perspective enabled a nuanced understanding of barriers and facilitators to both self-sampling and traditional cervical screening. Focus groups were held across different locations in Scotland with community group leaders present, enhancing representation while facilitating participant engagement. Notably, this research provided a platform for traditionally marginalised voices; several participants with ID reported this as their first opportunity to contribute to healthcare decision-making processes that directly affect them. Similarly, HCPs expressed the value of pre-implementation consultation, highlighting the importance of stakeholder engagement when introducing new initiatives.

The research's timing is particularly significant, coinciding with the NSC 2024 evidence review and aligning with PHS 2022-25 strategic priorities. With PHS emphasising the creation of an equitable healthcare system and specifically targeting cancer mortality reduction (PHS, 2022b; Figure 27), this research provides timely evidence to inform policy development. The findings are particularly relevant to Scotland's strategic commitment to reducing screening inequalities through self-sampling (PHS, 2022), offering evidence-based insights from key stakeholders invested in the initiative's success.

FIGURE 27.

Public Health Scotland's current strategy (2022b)



4.3 LIMITATIONS

This study has limitations which should be discussed. While participation in the survey of HCP was consistent throughout and minimum participant numbers were reached, the response rate was low at around 8%. There were a much higher number of female respondents. While this could be as a result of more females working within the area of cervical screening than men, this could have impacted on the generalisability of findings. An online survey was utilised as from the researcher's experience of working in the NHS, they were aware that some teams would not allow staff to take time away from their role and to travel to external locations. This would therefore make it difficult for participants to attend an interview. Although the survey therefore provided flexibility, interviews would have potentially allowed for more in-depth responses and for a wider range of participants to be recruited. While the survey was beneficial, it may have been valuable to interview a proportion of respondents – either in-person or over telephone/video call – to add to the richness of the data. While the survey included both quantitative and qualitative components, there were no validated psychometric measures included. Additional data which may have been helpful to collect includes the job role of participants, as well as the specific amount of time that participants spend engaging with patients on issues relating to cervical cancer within their role.

As we did not purposively recruit for carers within focus groups, it could be beneficial for future research to explore their views. Within this study, it was beneficial that participants were able to take part without support. As participants were relatively independent and able to participate on their own, additional research with those who may have lower levels of functioning could be valuable. Additionally, recruitment was extended to participants who had a cervix but did not identify as female. All members of the community groups identified as female; it could have therefore been valuable to explore additional methods of recruiting participants who had an ID and identified as transgender or non-binary. The researcher had initially explored whether there were such community groups, however, there did not appear to be; it could have therefore been useful to independently recruit such participants.

Focus groups were effective in the present study and, arranging these through existing community groups was valuable to ensure participants were comfortable and felt able to share their views. It was difficult to anticipate how many participants would attend on the day however and, for one group, we had only one participant. This did therefore run more like a 1:1 interview; fortunately, this participant was very open and comfortable with discussing their experiences and opinions, and the group leader's contributions enabled this to still flow as a discussion. The women who decided not to attend described feeling apprehensive to discuss cervical screening and were anxious to speak with the researcher whom they were not familiar with. While the researcher had suggested meeting in-person with participants informally beforehand, it could be helpful, particularly when working with participants with ID, to ensure this does occur to increase familiarity.

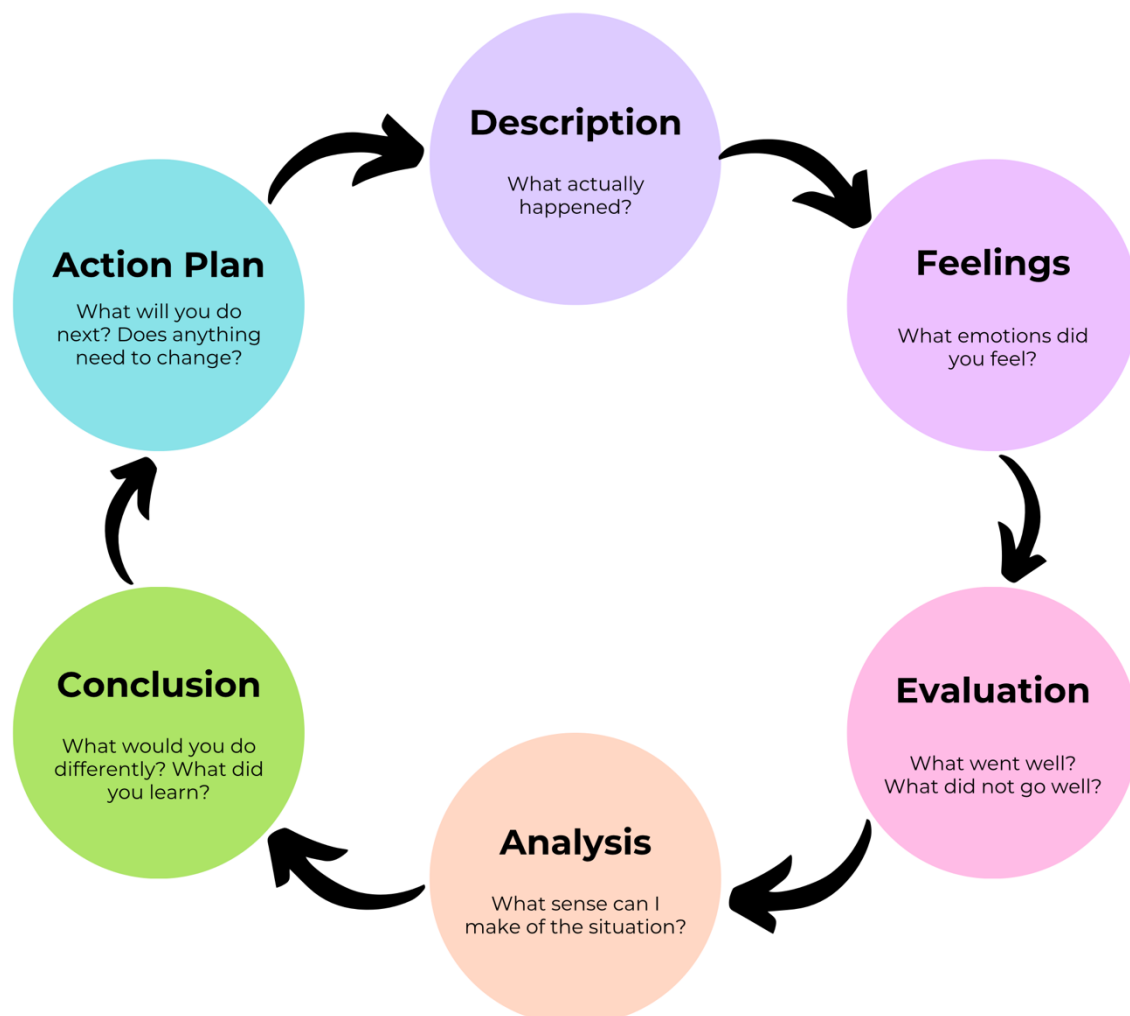
4.4 REFLECTIONS

Utilising Gibbs' Reflective Cycle (1988; Figure 28) as a framework, I critically examined my research journey throughout this project. The research competency evoked mixed emotions - both apprehension and excitement. While previous doctorate competencies had focused on my role within NHS mental health services, this project offered an opportunity to explore my passion for reducing inequalities in cancer screening. Although completing this alongside full-time work was overwhelming at times, my genuine interest in the topic provided crucial motivation throughout the process. It allowed me to develop my understanding of how health psychology can be applied to improve equity of access to screening, and to subsequently lead to improvements in health outcomes.

My initial apprehension stemmed largely from stepping outside my comfort zone into unfamiliar methodological territory. During supervision, I had expressed resistance to qualitative analysis software based on previous frustrating experiences. However, my supervisor's encouragement to explore Quirkos proved worthwhile - although still challenging, it significantly enhanced my analytical capabilities and data organisation. Similarly, using external transcription services while maintaining engagement with the data through reviewing of recordings proved valuable. I was struck by how my initial session notes captured crucial contextual elements - the way a participant's tone or even a slight eye movement could fundamentally alter a comment's meaning.

FIGURE 28.

Gibbs' Reflective Cycle (1988)



I experienced several unexpected emotional responses during this research. Some HCP responses triggered strong reactions, which upon reflection, connected to my own

experiences of feeling dismissed when seeking medical support. This resonated particularly strongly as I began conducting focus groups and listened to participants' experiences. Reading through focus group transcripts often proved emotionally challenging as I revisited the difficult experiences participants had bravely shared. These experiences highlighted the importance of self-care and robust supervision in emotional qualitative research.

My perfectionist tendencies and tendency to second-guess my abilities created additional challenges throughout the doctorate. Regular reflective logs and supervision proved essential in managing this and tracking progress. During focus groups, I maintained brief reflective notes on successes, challenges, and areas for improvement. This helped me observe my growing confidence and decreasing anxiety levels, allowing me to more fully engage with and enjoy the process.

Initially, I worried about talking too much during focus groups, something I know that I do when anxious. Upon listening to recordings however, although I did do this at times initially, I was pleased to see this improve throughout the groups. I think it has been helpful throughout my time as a Trainee Health Psychologist, that I have often listened to recordings of myself delivering interventions or training and subsequently discussed this with my clinical supervisor to identify areas for growth. Although this can be embarrassing, developing an awareness of the things which I can do particularly when anxious, such as needing to fill silences and using filler words, has allowed me to minimise this to ensure I am giving the other person(s) the space to speak. While sometimes uncomfortable, this self-awareness has helped me to become a better practitioner and researcher, creating space for participants to share their experiences.

The gap between my Master's degree and doctorate (~4 years), which I had initially viewed as a potential weakness, proved advantageous. This has helped me to mature and grow as a practitioner and as a person, and I do not think I would have been able to achieve the things I have without having this practical experience in-between. This project has enhanced my passion for working to reduce health inequalities in cancer screening. It has allowed me to further understand the value of research-focused health psychology practice and demonstrated how clinical experience can enhance research capabilities. It has shown me the value of embracing new challenges and maintaining reflective practice throughout the research journey. The emotional and professional challenges encountered have enhanced

both my competence and confidence, while reinforcing the importance of structured reflection and supervision when conducting research.

4.5 CONCLUSION

This thesis provides compelling evidence for the potential of HPV self-sampling within Scotland's CC screening programme, while highlighting critical implementation considerations. The findings reveal strong support from both HCPs and women with ID, suggesting potential for a significant impact on health equity outcomes. This is particularly salient given the documented higher CC mortality rates among women with disabilities; the implementation of self-sampling could therefore have an even greater impact on this historically underserved population.

The research makes several unique contributions to understanding implementation requirements within Scotland's distinct healthcare context. HCPs in Scotland face unique challenges compared to other UK nations, exacerbated by recent changes to the SCCSP and ongoing systemic pressures from the COVID-19 pandemic. Given that healthcare innovations frequently fail during implementation, the research highlights the crucial importance of centring HCP perspectives in implementation planning. Their insights into practical challenges, resource requirements, and potential unintended consequences provide valuable guidance for policy development.

The findings strongly support the need for comprehensive, long-term systemic change to enhance service accessibility and achieve equity in CC morbidity and mortality outcomes. Such change could significantly impact Public Health Scotland's projected disease burden increases, advancing their strategic goal of creating a more equitable healthcare system. The high acceptance levels demonstrated by both HCPs and women with ID indicate significant potential for successful implementation, contingent upon careful consideration of identified success factors. This research provides a framework for implementation that, if done successfully, could support the Scottish Government's goal of reducing screening inequalities. Self-sampling could therefore significantly advance health equity goals while improving healthcare outcomes.

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APPENDICES
APPENDIX 1 – ETHICAL APPROVAL



University of Stirling
Cottrell 3B1
Stirling
FK9 4LA

13/06/2024

Dear Catherine White

Ethics Application Form : Cervical cancer screening uptake in individuals with intellectual disabilities in Scotland: Exploring barriers and facilitators, and the acceptability of future HPV self-sampling

Ethics Reference Number: NICR 2024 17404 13777

Thank you for your submission of the above ethics application. The panel thank-you for your attention to detail.

The ethical approaches of this project have been approved and you can now proceed with your project.

Please note that should any of your proposal change, a further change request submission will be necessary.

If you have any further queries, please do not hesitate to contact the Panel by email to ethics@stir.ac.uk

Yours sincerely,

NHS, Invasive or Clinical Research

APPENDIX 2 - ONLINE SURVEY

Demographics

Please indicate your age range:

Options: 18 to 24 years old

25 to 34 years old

35 to 44 years old

45 to 54 years old

55 to 64 years old

65 years old and over

Prefer not to answer

How would you describe your gender?

Options: Man, Woman, Non-binary, Prefer to self-describe (OPEN), Prefer not to say

Please select from the options below how you would describe your ethnicity, or select 'prefer not to say' at the end:

Options:

White:

1. English/Welsh/Scottish/Northern Irish/British

2. Irish

3. Gypsy or Irish Traveller

4. Any other White background, please describe

Mixed/Multiple ethnic groups:

5. White and Black Caribbean

6. White and Black African

7. White and Asian

8. Any other Mixed/Multiple ethnic background, please describe

Asian/Asian British:

9. Indian

10. Pakistani

11. Bangladeshi

12. Chinese

13. Any other Asian background, please describe

Black/ African/Caribbean/Black British:

14. African

15. Caribbean

16. Any other Black/African/Caribbean background, please describe

Other ethnic group:

17. Arab

18. Any other ethnic group, please describe

Prefer not to say

Do you work in patient-facing role as part of the cervical cancer screening pathway e.g., GP, Nurse, Advanced Practitioner, Specialty Doctor?

Options: Yes, I currently work in this area

I previously worked in this area but do not anymore

No, I have never worked in this area

What is the first half of the postcode for the location in which this position was based e.g., EH54, GL1,

KW15?

Free-text field

How long have you worked within this role? If this is a previous role, how long did you work in this position?

- Options:** up to six months
Over six months, but less than a year
Between one and two years
Between two and three years
Between three and five years
Between five and ten years
Over ten years

Do you work with those with intellectual disabilities?

- Options:** Yes, a lot in my current role
Yes in my current role, but not often
No, but I have previous experience of working with those with intellectual disabilities
No, never

Views on HPV Self-Sampling

Following the YouScreen Trial in England [LINK], it is expected that HPV self-sampling could be rolled-out across the United Kingdom. This would involve a test kit being posted out to those eligible for cervical screening, to allow them to take the swab at home.

Are you aware of the YouScreen trial in England regarding HPV self-sampling?

- Options:** Yes
No
Unsure

Do you feel like you have a good understanding of what HPV self-sampling is?

- Options:** I know a lot about self-sampling
I know some information about self-sampling
I know a little information about self-sampling
I know very little information about self-sampling
I do not feel like I know anything about self-sampling

Do you think self-sampling is a good idea?

- Options:** Yes
No
Unsure

What information do you feel that you would need before the introduction of HPV self-sampling in Scotland for the general public?

Free-text field

Tell me what you think the advantages of introducing HPV self-sampling for the general public could be. Please provide examples where possible.

Free-text field

Tell me what you think the disadvantages of introducing HPV self-sampling for the general public could be. Please provide examples where possible.

Free-text field

Do you think self-sampling should be promoted?

Options: Yes

No

Unsure

What would you say could be the facilitators of a successful roll-out of HPV self-sampling for the general public? Please provide examples where possible from a healthcare professional or patient perspective.

Free-text field

What would you say could be the barriers to a successful introduction of HPV self-sampling for the general public? Please provide examples where possible from a healthcare professional or patient perspective.

Free-text field

Are there any groups in particular where you think that HPV self-sampling could be particularly advantageous?

Free-text field

Are there any groups in particular where you would have concerns about introducing HPV self-sampling?

Free-text field

Case Study Examples

The following two tasks provide scenarios which you have been presented with. Please provide a short paragraph, continuing the story based on how you would approach this situation:

A 32-year-old female, whom you have not met but know has been diagnosed with an intellectual disability from her patient record, enters your clinic room. You can see that they have not ever attended for a cervical screening appointment. They advise that they have never been in a sexual relationship with a partner and so they do not need to be screened. What would you do next?

Free-text field

A 41-year-old female with an intellectual disability has attended for an appointment with their GP for a routine medication review. She unexpectedly asks for more information about cervical cancer screening for which she has never attended before. She is unsure if she needs to have a test and feels anxious about the idea of the test itself. What do you think the doctor should do next?

Free-text field

APPENDIX 3- ONLINE SURVEY - INFORMATION SHEET

Participant Information Sheet – Healthcare Professionals

Project title: Cervical cancer screening uptake in individuals with intellectual disabilities in Scotland: Exploring barriers and facilitators, and the acceptability of future HPV self-sampling.

Principal Investigator: Catherine White, Trainee Health Psychologist.

Address: Faculty of Natural Sciences, University of Stirling, Stirling, FK9 4LA.

You are invited to take part in a study. Please take time to read the following information to decide whether you wish to take part. Please contact us if there is anything that is not clear and if you would like more information.

The purpose of this service evaluation is to explore the views of healthcare professionals across Scotland on cervical cancer screening and HPV self-sampling. It is hoped that this will support to overcome some of the common barriers to cervical cancer screening attendance and to improve health outcomes in those with intellectual disabilities.

1. What does taking part involve?

We are looking to hear from professionals who work in a patient-facing role within the cervical cancer screening pathway in Scotland. You will complete an online evaluation survey including both closed and open-ended questions. You will be asked to describe your opinions of barriers and facilitators to individuals accessing HPV self-sampling, attitudes towards individuals with intellectual disabilities accessing screening, and views on how HPV self-sampling may be advantageous or disadvantageous. There are no right or wrong answers, we are interested in your views.

If you are happy to proceed with the study, please continue down to read and complete the consent form on the next page. By clicking 'next', you confirm that you have read and understood the terms of the consent form. This survey should take around **20 minutes to complete**. You can return to the survey to finish this later via a unique URL which you can access by clicking 'finish later'.

2. Are there any possible risks to taking part?

There are no known risks to participating in this study.

3. Are there any possible benefits to taking part?

You will not benefit directly by taking part in this study; however, your participation will help us to gain an understanding of views and opinions around HPV self-sampling in advance of a UK-wide roll-out from the perspective of healthcare professionals to identify gaps in knowledge or understanding. It is hoped that this will produce findings which could inform the creation of training and educational resources to support professionals to understand the barriers to screening for those with intellectual disabilities, hopefully leading to reduced incidence and mortality rates, and better health outcomes for this group.

We appreciate that taking part in this study will take up your time, however, we are not able to offer any reward at this time.

4. What happens to the data I provide?

The answers you give in the survey will be combined with the answers from all other participants. The survey is completed anonymously as we do not ask for your name at any point. The first half of the postcode of your related place of work is asked for so we can use this to learn more about the area in which each of our participants work during the service evaluation. Once we link your postcode to area information, the postcode is deleted. All remaining data is stored on a secure system (the University uses SharePoint), accessed only by named members of the research team. At the end of the study, once the final report is written, any additional personal data (e.g., age, gender, ethnicity) is deleted and all other data is securely transferred to DataSTORRE, and kept for a minimum of 10 years, as per University guidelines.

5. What is the legal basis for processing my data?

As part of this research study, we will be collecting personal data relating to you (e.g. gender, age, ethnicity). This will be processed in accordance with the General Data Protection Regulation (GDPR). Under GDPR the legal basis for processing your personal data will be public interest/the official authority of the University.

6. Will the research be published?

The results of the study may be published for scientific purposes, but publications will not contain your name or any other personal information that could identify you. If you would like to know the results, please contact the researchers directly (take a note of the contact details at the end of this information). This research will also be publicly available through the university's open access repository (STORRE). This research may also be presented at conferences and through other media outlets. You will not be identifiable in any report/publication.

7. Who has reviewed this research project?

This study has been approved by the University of Stirling NHS, Invasive or Clinical Research Committee (NICR) (Ethics application number: NICR 2024 17404 13777).

8. Your rights.

You are free to choose whether or not to take part in this study, and you will not be penalised in any way. You can choose to withdraw your data during or after participation, prior to analysis beginning. You will need to quote your Participant ID Number if you wish to withdraw your data (this will be provided to you upon completion of the survey or when you save your partially completed responses to finish later). If you wish to withdraw, please let Catherine know by email (details below); you do not have to provide any reason for this. You can stop participating at any given time.

9. Contact for further information.

If you have any questions or require additional information about the study and your rights as a participant, you should discuss these with the Principle Researcher, Catherine White (email: cbw1@stir.ac.uk; telephone: 07929 784484). You can also contact Dr Lesley McGregor (Senior Lecturer in Health Psychology & Catherine's supervisor) by email: l.m.mcgregor@stir.ac.uk or telephone: 01786 466 379.

If you would like to complain or have any concerns about how you have been approached or treated during any part of this study, you should do so by contacting the Head of Department of Psychology, Professor Paul Dudchenko (p.a.dudchenko@stir.ac.uk).

Thank you for taking the time to read this information sheet!

APPENDIX 4 - ONLINE SURVEY – CONSENT FORM

Participant Consent Form - Survey

Project title: Cervical cancer screening uptake in individuals with intellectual disabilities in Scotland: Exploring barriers and facilitators, and the acceptability of future HPV self-sampling

Principal Investigator: Catherine White, Trainee Health Psychologist

Please complete this form after you have read the Information Sheet. Prior to progressing to the questionnaire, please read the following and 'tick' each statement to confirm you understand and agree with each point. Click 'next' to then confirm your consent to take part.

If you have any questions arising from the Information Sheet, please ask the researcher before you decide whether to participate.

- I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
- I understand that the project requires me to complete an online service evaluation of the cervical cancer screening pathway in Scotland on JISC, with my responses downloaded to a password-protected Microsoft Excel document and saved in the researcher's secure OneDrive. ☐
- I understand that participation in this study is entirely voluntary, and I can withdraw from the study at any time without giving a reason. ☐
- I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately knowing that my responses will be removed from the dataset prior to analysis beginning when I provide my Participant ID Number which is provided to me upon completion of the survey or when I save my partially completed responses to finish later. ☐
- Anonymised responses will be stored securely. Responses within the JISC Online Survey Tool will be kept until the analysis has been completed and then they will be deleted securely. Downloaded data will be held for a minimum of ten years. ☐
- Anonymised direct quotes can be used in any publications or reports as an outcome of this study. ☐
- Anonymised data may be shared with publishers as part of the publication process. ☐
- I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study. ☐

Comments or concerns during the study: If you have any questions or require additional information about the study and your rights as a participant, you should discuss these with the Principal Researcher, Catherine White (email: cbw1@stir.ac.uk; telephone: 07929 784484). You can also contact Dr Lesley McGregor (Senior Lecturer in Health Psychology & Catherine's supervisor) by email: l.m.mcgregor@stir.ac.uk or telephone: 01786 466 379.

If you would like to complain or have any concerns about how you have been approached or treated during any part of this study, you should do so by contacting the Head of Department of Psychology, Professor Paul Dudchenko (p.a.dudchenko@stir.ac.uk).

Thank you for your interest in taking part in this research.

APPENDIX 5 - ONLINE SURVEY – INVITATION EMAIL

Dear XX

Re. Could you help us to improve access to cervical cancer screening for those with intellectual disabilities across Scotland?

Research from Jo's Cervical Cancer Trust (2020) indicates that only 30% of eligible individuals with

an intellectual disability attend for cervical cancer screening across Scotland, compared to 69% of the general population. Data comparing those with intellectual disabilities to the general population shows a clear trend of higher cancer deaths despite an often lower comparable incidence rate across cancer types (Ward et al., 2024).

I am therefore writing to invite you to help us to improve access to cervical cancer screening for those with intellectual disabilities across Scotland. You can do this by taking part in a short, anonymous survey exploring the views of healthcare professionals in a patient-facing role within the cervical cancer screening pathway across Scotland. This survey should take 15-20 minutes to complete. You don't have to complete this all at once, and you can come back to the survey to finish this at any point prior to the survey closing on **DATE**.

If you would like to take part, please visit the survey at the following link, where the full information sheet and consent form are available: **LINK**

Please contact Catherine White on cbw1@stir.ac.uk if you have any questions.

Many thanks for taking the time to read this invitation.

Yours Sincerely,

Catherine White

Principal Investigator and Trainee Health Psychologist

University of Stirling

APPENDIX 6 - ONLINE SURVEY – RECRUITMENT POSTER



Improving cervical cancer screening across Scotland

A SERVICE EVALUATION

We are interested in hearing healthcare professionals' views around the opportunities and challenges of attending cervical cancer screening and taking part in HPV self-sampling.

If you...

- ✓ are currently, or have been, an NHS Scotland Health Professional in a patient-facing role on the cervical cancer screening pathway.
- ✓ are over 18 years old.

...you could take part in an online survey exploring barriers and facilitators to accessing cervical cancer screening services and views on how HPV self-sampling may be advantageous or disadvantageous to individuals across Scotland.

MORE INFO



SURVEY LINK
<https://tinyurl.com/3jbkxxdf>



If you would like to discuss the research with us, please feel free to contact:

Catherine White (Trainee Health Psychologist) – cbw1@stir.ac.uk

Dr Lesley McGregor (Supervisor) – l.m.mcgregor@stir.ac.uk

APPENDIX 7 - ONLINE SURVEY – DETAILED RESPONSES

Information needed prior to the introduction of self-sampling

- Statistics and rationale that support the recommendation would need to be communicated to make it clear that this is not just a cost-saving exercise by the NHS.
- Data should be provided on the reliability and acceptability of self-sampling to women.
- Data should be provided on the specificity and sensitivity of the test compared to healthcare provider tests. This should include any limitations, information on how many samples need to be discarded and whether self-sampling is evidenced to increase engagement and outcomes.
- Clear guidance must be provided to patients that if HPV was detected, women would need to attend for clinician-led follow-up (however, there were queries around what would happen for patients who did not respond to a request for follow-up and around what follow-up would consist of).
- Clear information around the pathways which each result would then follow would be required, in order to educate patients fully and to ensure staff were informed. This would also need to contain expected timescales for each step.
- Expectations would need to be communicated with services in terms of how many patients would be expected to require follow-up (and subsequent impact on services).
- Patients would need to understand that, like typical screening services, there is an ongoing need to repeat at regular intervals.
- Whether there would be an easy way for patients to change their address to ensure the kit was not undelivered.
- To increase feelings of capability, patients must understand that self-sampling is easy and can be done in conjunction with an appointment.
- Information would need to be given to patients around the importance of screening, and the relationship between HPV and cervical cancer. Similarly, this should provide clarity that the test is only testing for HPV and provide advice on how to recognise other symptoms which would prompt review as other abnormalities which may be detected during clinician examination, cannot be detected.
- Important that clear, concise and short instructions are included for patients, including how to obtain, take and return the test. This should be in appropriate formats (accessible/easy read/different languages). This may include infographics or a video.
- Teams should provide local communications as necessary, including local phone numbers and contacts for patient queries (however there were queries around how this would work in practice and the subsequent impact on services).
- Information would be required to understand eligibility criteria and when it would be advised that people should not self-sample. If someone receives the kit and is unable to use this, clear guidance must be provided around next steps.

- Healthcare providers would need to receive information and education around self-sampling so they can also inform patients accurately. Training time, and potential attendance at an information webinar or study day, would need to be taken into account.
- The roll-out would need to be well-advertised in advance, with a strong national communication and marketing campaign via health websites, YouTube, social media, GP resources and television adverts (noted that awareness campaigns may be difficult due to fewer health improvements/promotions team).
- While the majority of professionals highlighted the need for information to allow them to inform and support patients, one participant noted that no information would be needed as the responsibility would cease to rest with them if self-sampling was rolled-out.
- Clinicians had some queries around this including if individuals would have a choice of doing the self-sampling kit or if they could request to attend for clinician-led screening. They wondered whether there would be an option for the sample to be done in a health care environment. They questioned how the kits would be distributed i.e., GP practice or SCCRS, and if there would be spare kits in GP practices to hand out opportunistically. Clinicians queried how uncompleted tests would be recorded, and who would be responsible with following up with the patient or informing the GP.

Advantages of self-sampling for the general public

- Provides an opportunity to encourage defaulters to participate in screening, increasing accessibility and reducing cancer rates.
- Could improve uptake and accessibility especially for vulnerable and hard-to-reach groups who often do not present at clinician-led screening e.g., those with mental health difficulties, history of sexual abuse, transgender men, housebound patients, minority groups, anyone with previous poor experiences, and those who are not or have never been sexually active.
- Will provide more data around HPV with more opportunity to offer appropriate treatment.
- May reduce the number of those who do not attend due to embarrassment.
- As this is less invasive and more private, it could minimise anxiety, stress and risk of retraumatising those who have experienced previous trauma or had a bad experience. This may increase autonomy, accessibility, feelings of control, familiarity and remove stigma, fear and perceived complexity.
- Experiences and learning from self-sampling in the bowel screening programme provides an example of best practice.
- May be seen as an easier, convenient, time-saving and quicker way to complete screening, rather than needing to wait for an appointment. If patients can post back the sample with ease, i.e., at a normal post box, this may increase uptake.
- More likely to be a pain-free experience and reduces the need for a speculum examination which can cause anxiety.

- Could release more appointments at the GP practice, ease pressure on services and will cause fewer appointments to be lost to non-attendance.
- Will diversify settings in which testing could occur, e.g., a support worker for someone with an ID could provide or instruct them on how to self-take a swab.
- Increases accessibility, for example, as no transport would be required this could enable those on low income, who cannot drive or who have limited access to public transport to access screening at home; those who have trouble engaging socially would not need to do so; those who find it hard to get to an appointment due to work, childcare, geography, or disability; those with cultural or religious differences (may feel it is inappropriate for someone else to touch their genitals, have a language barrier, could feel uncomfortable or embarrassed despite reassurance).

Disadvantages of self-sampling for the general public

- Does not detect other abnormalities or provide HCP with an awareness of other physical, mental health or personal/wellbeing issues.
- Eliminates the opportunity to provide health promotion and sexual education, general health care or contraception advice.
- There are currently doubts and uncertainty about effectiveness and reliability.
- Patients may feel disconnected from HCP and may feel more isolated.
- Patients may not understand the limits of its scope and when attending a clinician is necessary and self-sampling is not enough.
- May lead to over-testing depending on how the test will be operationalised.
- Could result in overuse of staff time, if patients approach the GP with queries or uncertainty around self-sampling.
- Concerns around if the patient declines further testing or does not fully understand the protocol and that they may need to attend for follow-up.
- May be issues around public education if screening could be perceived as less important if participants are told to do this at home or if they do not know what HPV is and think this is not relevant to them.
- Uncertainty around how women would be encouraged to comply, how their health team would know they had defaulted, and if there would be reminders.
- For some groups, there were worries that this could increase inequalities, e.g., patients who are obese may be unable to perform the test; language barriers could cause issues; disabilities may make it difficult to complete the test; potential problems in identifying those with a cervix who identify as male and have a male CHI number. It could also make access to healthcare more remote, increase social taboos or feelings of shame around screening, reduce the normalisation of discussions around women's health and reduce attendance for other health appointments.

- Worries around participants taking the sample incorrectly or not following the instructions. Participants may be falsely reassured if test is done incorrectly or could ignore potential warning signs due to receiving a negative result.
- Waste of sample kits if not used or delivered to the wrong address which could also be costly.
- Concerns around responsibility being placed on carers of individuals or self-sampling potentially being forced upon someone else by a carer or family member.
- Cultural or religious beliefs, or no previous sexual activity, may mean people do not feel comfortable touching their own genitals.
- Unable to control the conditions of the testing venue, and information would be needed as to when samples would be considered “spoiled”.
- Individuals may not be motivated to complete the test or may have the intention to do so but this does not lead to the behaviour. Some may also practice avoidance if they do not feel confident or capable.

Facilitators to enable the success of self-sampling for the general public

- Needs to become embedded in the population; it may be helpful to start with the younger generation who are just starting HPV screening.
- Should be more targeted, focussed on people who have defaulted. It should not be seen as a replacement.
- Ensuring clear instructions for completing the test are provided. This needs to be clear and uncomplicated, with infographics and QR codes with videos. Instructions should be accessible in different languages, braille, adverts in sign languages, and suitable for those with disabilities.
- Providing positive information, emphasising benefits, evidence of uptake and outcomes, ease and convenience, and reassuring this is not a cost saving or reduced benefit exercise. There needs to be publicity and engagement to highlight the importance and ease of the test. Health promotion materials should be eye-catching and widely available.
- Educate members of the public via an awareness campaign across various media formats, explaining that there is a choice, discussing the pros and cons and explaining that this presents a way for people to have ownership and control over their own health. This should raise awareness of HPV, what it does and how to detect it, reducing the current misunderstandings around HPV (and unnecessary fears/stigma of it being an STI).
- Local GP and nurse involvement and backing, with practices providing adequate training to staff and early contact with board-level public health teams to allow them to support colleagues with the roll-out of this across localities. HCP should provide information via their websites and social media pages. Sexual health clinics could promote self-sampling during consultations. Health promotion videos could play in waiting areas.
- Resources should be available for patients in-clinic, and kits should be available for opportunistic handout.

- Observations could be made from other self-sampling screening programs that have been successful. This should support with normalisation and parallels should be highlighted.
- Clear information on what results mean and what is involved at each stage of the pathway (including advice around when clinician-led screening should be arranged) should be clearly communicated, with timescales included. Some respondents queried whether test results could be delivered via online portal or text/email.
- Reminder texts and email prompts should be used. A primer letter sent in advance of the kit could be beneficial.
- Patient reviews and testimonials of the process. Patient surveys should be created to allow views and feedback to be gathered.
- Drop-in clinics should be available to provide information, answer questions and provide kits to all patient groups. Example kits could reduce the fear/uncertainty. It should be clear who patients should contact with any questions about the kit.
- Ease of access, with it being free and easy to return (mail via post box or drop off at GP or pharmacy). The option for a kit to be picked up rather than delivered and, when delivered, this should be in plain packaging to avoid any embarrassment.
- Accurate patient registration details and an easy way to update address details should be provided to ensure the test, results and any follow-up can be communicated.
- Effective monitoring of who has completed tests, the results and defaulters, and how non-participation is followed up
- Provide education in a variety of settings outside of healthcare i.e., school, college, university. Accessible kits could be available at education providers and other community healthcare sites e.g., pharmacy, sexual health clinic.

Barriers to the success of self-sampling for the general public

- Providing inadequate information, education and awareness to patients. Negative information or misinformation could spread via social media. Patients may not trust the test or may be sceptical of why this has been introduced, which could hinder engagement.
- Providing inadequate information, education and awareness to professionals. Professionals need to feel able to answer patient queries. An engagement pack for GPs and clinicians could be helpful to support the roll-out for vulnerable groups.

- The test kit could be ignored, particularly if the patient is not engaged or motivated. Patients may not read the information they receive, or they may perceive that the test is too complicated or time-consuming.
- Inadequate time to effectively roll out a new programme, including time needed to train professionals and ensuring their voices are heard in the process. Professionals also need to understand how to deal with what may be a slow initial uptake.
- Insufficient funding and financial constraints.
- If kits expire or are “spoiled” this may affect the roll-out along with patient confidence in the process.
- Lack of clarity relating to lines of responsibility in terms of who supports with patient queries and who contacts those who have not returned the test.
- Not understanding instructions e.g., poor literacy, materials provided in limited languages and formats.
- Not performing the test correctly, or if patients are unable to perform the swab e.g., for physical, mental or cognitive reasons, or due to a lack of knowledge of the anatomy.
- Not having a clear pathway for patients but also professionals, where it is not clear how this new process will interact with general surveillance of HPV and the rest of the pathway if the result requires further investigation.
- Increasing potential health inequalities, if there is inadequate thought around how to support hard-to-reach groups, if high risk patients are missed, or if certain groups are unable to perform the test e.g., ID, mental health difficulties, physical disabilities.
- Lack of confidence in carrying out the test, with worries around doing this wrong and with the idea of a clinician-led sample being more reliable and providing reassurance.
- Resistance to change from both patients and professionals.
- Concern regarding how patient information is used and shared. It is important to ensure that capacity and consent has been obtained.

APPENDIX 8 - FOCUS GROUP – SCHEDULE

Equipment: Non-encrypted audio recorder, whiteboard/paper, pens, colourful cards for displaying prompts and topic headings, £5 'Love2shop' vouchers for active participants.

Location: Existing Group locations x2.

Time: 60-90 minutes (example timings provided below for a group running 9am-10:30am).

Facilitators: Catherine White (Trainee Health Psychologist), Existing Group Leader.

Participants: Individuals with an intellectual disability who have a cervix, and their carer(s), where applicable.

Agenda

1. Welcome and introductions (8:30am – 9:05am):
 - a. The researcher will be available at the venue 30 minutes before the official start time of the groups, to welcome participants and to support participants to get refreshments (tea, coffee, pastries, biscuits).
 - b. A social stories format will be used to clearly display the plan for the day and order of events. There will be individual versions of this provided to the existing Group Leader in advance of the day, and available to each participant in the group.
 - c. A script will be available for the facilitator to ensure all key points and wording are used to share information and facilitate discussion.
2. One icebreaker (adapted from suggestions for learners with intellectual disabilities by Granata (2014)) (9:05am – 9:15am):
 - a. Favourite Things: Give everyone a piece of paper and have them draw their favourite things. Make this as fun and creative as possible. This can be anything including their favourite TV show, colours, person, food, animal, etc. Share with the group and see if they can find others who like the same thing.
 - b. If I Were an Animal: Go round the room and ask everyone to share with the group what animal they would choose to be or feel that they're most like (can throw a ball of wool while each person remains holding onto a piece of the wool as this is passed amongst participants). Can invite them to give clues to allow others to guess, and to share why this is their favourite/most relatable.
3. Overview, purpose of the group and ground rules (9:15am – 9:25am):
 - a. Overview of the topic of cervical cancer screening
 - b. Purpose of the study
 - c. Purpose of the morning's focus group and activities
 - d. Ground rules (Ground rules will be created as a group and written on a whiteboard at the front of the group. The facilitator will ensure that key rules are included around confidentiality, creating a non-judgmental, safe space, ensuring participants try not to speak over each other and that opinions are respected).
4. Topics for the focus group activity (activity supported by visuals and prompts to aid understanding) (9:25am – 10:15am):
 - a. Barriers and facilitators to accessing cervical cancer screening (10 minutes),

- b. Presentation of HPV self-sampling kit to receive initial thoughts and opinions (10 minutes),
 - c. Barriers and facilitators of HPV self-sampling (15 minutes),
 - d. Discussion of the acceptability of HPV self-sampling within this group (15 minutes).
- 5. Thanks and close (10:15am – 10:30am).

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Please indicate in which section each item has been reported in your manuscript. If you do not feel an item applies to your manuscript, please enter N/A.

For further information about the COREQ guidelines, please see Tong *et al.*, 2017:

<https://doi.org/10.1093/intqhc/mzm042>

No.	Item	Description	Section #
Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	
3.	Occupation	What was their occupation at the time of the study?	
4.	Gender	Was the researcher male or female?	
5.	Experience and training	What experience or training did the researcher have?	
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>E.g. Personal goals, reasons for doing the research</i>	
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>E.g. Bias, assumptions, reasons and interests in the research topic</i>	
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? <i>E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	
Participant selection			
10.	Sampling	How were participants selected? <i>E.g. purposive, convenience, consecutive, snowball</i>	
11.	Method of approach	How were participants approached? <i>E.g. face-to-face, telephone, mail, email</i>	
12.	Sample size	How many participants were in the study?	
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	
Setting			
14.	Setting of data collection	Where was the data collected? <i>E.g. home, clinic, workplace</i>	
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	

16.	Description of sample	What are the important characteristics of the sample? <i>E.g. demographic data, date</i>	
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	
20.	Field notes	Were field notes made during and/or after the interview or focus group?	
21.	Duration	What was the duration of the interviews or focus group?	
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	
25.	Description of the coding tree	Did authors provide a description of the coding tree?	
26.	Derivation of themes	Were themes identified in advance or derived from the data?	
27.	Software	What software, if applicable, was used to manage the data?	
28.	Participant checking	Did participants provide feedback on the findings?	
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>E.g. Participant number</i>	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	
31.	Clarity of major themes	Were major themes clearly presented in the findings?	
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	

When submitting your manuscript via the online submission form, please upload the completed checklist as a Figure/supplementary file.

If you would like this checklist to be included alongside your article, we ask that you upload the completed checklist to an online repository and include the guideline type, name of the repository, DOI and license in the *Data availability* section of your manuscript.

Developed from: Allison Tong, Peter Sainsbury, Jonathan Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *International Journal for Quality in Health Care*, Volume 19, Issue 6, December 2007, Pages 349–357, <https://doi.org/10.1093/intqhc/mzm042>

APPENDIX 10 - THE BRITISH PSYCHOLOGICAL SOCIETY'S CAPACITY TO CONSENT CHECKLIST

Checklist for researchers to decide whether a prospective participant has the capacity to consent to their participation	
Section A – Enabling capacity: Have you made every effort to enable a prospective participant to make the decision themselves to participate or refuse? ☐ Have you used language or methods of communication that the person is most likely to understand? ☐ Have you given sufficient time for the person to think about the project? ☐ Has the person conferred with others who could help explain the project? ☐	
If NO to any item in Section A, return to BPS guidance on enabling decision making. If YES to all items in Section A continue...	
Section B – Diagnostic assessment Is there evidence to demonstrate impairment of mind or brain? ☐ Is there evidence to demonstrate that this is temporary, fluctuating or permanent? ☐ Is there evidence to demonstrate that the impairment affects the person's ability to decide about their participation in research? ☐	
If NO to any item in Section B discuss with Principal Researcher. If yes to all items in Section B, continue...	
Section C – Functional assessment Does the person understand that they can consent or refuse to participate in research? ☐ Does the person understand what the research is about? ☐ Does the person understand and weigh up the benefits and risks of agreeing or refusing to take part? ☐ Has the person communicated their decision to you in any way? ☐	
If YES to any item in Section C, return to BPS guidance on 'enabling decision making'. If NO to the first three items in Section C – the person does not have the capacity to consent to or to refuse to take part in the research project.	
Checklist completed by: Date:	

APPENDIX 11 - FOCUS GROUP – CARDS

Hello!



What was bad about them?
If you have not used them, what
has stopped you?



Do you think using this kit at home is a
good idea?



What will we be doing today?



We will now have a look at the
cervical self-sampling kit.



When do you think using the kit at
home would work well?



If I were an animal...



What are your first thoughts on the kit?
How would you feel if you got this in the
post?



What do you think would be most helpful to
support you to use cervical cancer screening
services?

Is there anything the doctor or nurse could do?



What is important for today's chat
to feel safe?



What would help you to use the kit?



Have you used cervical cancer
screening services?

What was good about them?



What would stop you from using the kit?



Thank
You!

APPENDIX 12 - FOCUS GROUP - INFORMATION SHEET

Participant Information Sheet – Focus Group

Project title: Improving Cervical Cancer Screening across Scotland.

Principal Investigator: Catherine White, Trainee Health Psychologist.

Address: Faculty of Natural Sciences, University of Stirling, Stirling, FK9 4LA.

You are invited to take part in a study. Please take time to read the following information to decide whether you wish to take part. Please contact us if there is anything that is not clear and if you would like more information.

Purpose of this study

Thank you for your interest in participating in a group discussion (focus group). The purpose of this focus group is to explore the views of those with an intellectual disability and their carers (where applicable), on cervical cancer screening and HPV self-sampling. It is hoped that this will provide a comprehensive understanding of barriers and facilitators to accessing cervical cancer screening. This will then support with improving cancer screening services across Scotland.

1. What does taking part involve?

This study is looking to recruit women and transgender men with a diagnosed intellectual disability, who currently access an established community group in Scotland, and their carers where applicable.

You are under no obligation to take part even having made an expression of interest. You will take part in a group discussion (focus group) with other members of your community group. These groups will run for 60-90 minutes, with the first part of these exploring beliefs about barriers and facilitators to accessing cervical cancer screening. In the second part, we will take a look at an HPV self-sampling kit and have a discussion about this, to gain an understanding of initial reactions and

opinions on this. We would explore the views on whether HPV self-sampling would be advantageous or disadvantageous, and what could make this feel more accessible.

The option for this discussion to be conducted within 1:1 interviews will also be available to support all participants to share their views where they may not be comfortable doing so in a group setting.

If you are happy to proceed with the study, please continue down to read and complete the separate consent form, prior to taking part in the focus group.

2. Do I have to take part?

No, you do not have to take part. Participating in this study is voluntary and therefore entirely up to you. If you do decide to take part, but then change your mind before the group discussion begins, you can withdraw your participation without needing to explain to anyone.

If you wish to withdraw from the study during the discussion, again you are free to leave without needing to explain your reasons why. We will use any information you provide to us during the discussion in our analysis, unless you tell us otherwise. However, it should be noted that we will not be able to completely remove your contributions to the discussion up to that point, but instead we can agree to not include direct quotes from you in our final report. This is the same outcome if you chose to withdraw after the group discussion.

If you take part in a one-to-one interview, and decide you want to withdraw from the study during or after the interview, we will discard your interview unless analysis across all group discussions and/or interviews is already in progress. However, if this is the case, we will agree to not use direct quotes from you in our final report and we will remove your interview from further analysis.

3. Are there any potential risks in taking part?

There are no known risks to participating in this study. This study does involve discussion around cancer and experiences of cancer screening which may be distressing. You can choose to take a break or to stop taking part at any point. The researcher will also provide support and will be available at the end of the focus group to speak further.

4. Are there any benefits to taking part?

You will not benefit directly by taking part in this study; however, your participation will help us to gain an understanding of what people think about cervical screening and the possibility of introducing an at-home kit to do this in Scotland. It is hoped that this will produce findings which could inform the creation of materials that touch on barriers and misconceptions which could be provided to individuals with intellectual disabilities and those who support them, allowing them to make an informed decision around cervical cancer screening. This will hopefully lead to better health outcomes for this group. All participants will also be provided with a £5 'Love2shop' voucher as a thank you for your time and contribution.

5. What is the legal basis for processing my data?

Data will be collected and stored in line with the Data Protection Act 2018. This will be processed in accordance with the General Data Protection Regulation (GDPR). Under GDPR the legal basis for processing your personal data will be public interest/the official authority of the University. This is the legal basis on which we are collecting your data and while this allows us to use your data, it also means we have obligations towards you to not seek more information from you than what is essential and necessary for the study and to make sure that you are not identified by the data.

6. What happens to my data?

Your participation and contributions to the discussion will be treated confidentially and anonymously following the group discussion. Due to the nature of a group discussion, your participation cannot be completely confidential and anonymous as you will be meeting the researcher and other participants face-to-face. Audio data will be kept on a password-protected audio recorder. This will be fully transcribed (every word, by every person typed out) by an external, third-party organisation, who have signed a confidentiality statement. The final transcription will have all participant names changed and will be stored on a secure system (the University uses SharePoint), accessed only by named members of the research team. At the end of the study (report completed), the transcriptions are securely moved to DataSTORRE and kept for a minimum of 10 years, as per University guidelines. Signed consent forms will also be kept on this secure system and moved to DataSTORRE at the end of the study to be destroyed after 1 year.

7. Will the research be published?

The results of the study may be published for scientific purposes within a peer reviewed scientific journal. This research may also be presented at conferences and through other media outlets. Publications will not contain your name or any other personal information that could identify you. The University of Stirling is committed to making the outputs of research publicly accessible and supports this commitment through our online open access repository STORRE. This research will be publicly disseminated through our open access repository.

8. Your rights.

You are free to choose whether or not to take part in this study, and you will not be penalised in any way. You have the right to withdraw from this project at any time without giving reasons and without consequences to you (see point 2 above). You also have the right to object to us processing relevant personal data, however, please note that once the data are being analysed and/or results published it will not be possible to remove your data from the study.

9. Will my taking part in this study be kept confidential?

All information about you which is collected during the course of the study shall be kept strictly confidential, with only the research team having access to your data. Any information about you will be anonymised so that you cannot be recognised from it.

10. Who has reviewed this research project?

This study has been approved by the University of Stirling General University Ethics Panel (GUEP) (Ethics application number: NICR 2024 17404 13777).

11. Contact for further information.

If you have any questions or require additional information about the study and your rights as a participant, you should discuss these with the Principal Researcher, Catherine White (email: cbw1@stir.ac.uk; telephone: 07929 784484). You can also contact Dr Lesley McGregor (Senior

Lecturer in Health Psychology & Catherine's supervisor) by email: l.m.mcgregor@stir.ac.uk or telephone: 01786 466 379.

If you would like to complain or have any concerns about how you have been approached or treated during any part of this study, you should do so by contacting the Head of Department of Psychology, Professor Paul Dudchenko (p.a.dudchenko@stir.ac.uk).

Thank you for taking the time to read this information sheet!

APPENDIX 13 - FOCUS GROUP – EASY-READ INFORMATION SHEET

Improving Cervical Cancer Screening across Scotland

Focus Group Information Form

Who is running the study?



My name is Catherine, and I am a student at the University of Stirling. My supervisor is called Lesley.



We are inviting you to take part in a study.

This is an information sheet about the study.

Please read this sheet and ask questions before you decide if you want to take part.

What is the study about?



Everyone is invited to cancer screening in Scotland.

We want to speak to you to make cancer screening better.



We will all work together with other people in your community, as well as carers, staff and the researcher.

We will talk together to understand the problems that you might have in taking part in cervical cancer screening.



What will I do if I take part?

We want to ask you about what it is like to use cervical cancer screening services.

If you have not used cervical cancer screening services, we want to ask you why.

We want to know what was good and what was bad.

We will talk about the cervical self-sampling kit. I will show you what this is on the day.

We would like to ask you some questions about this at a group meeting, called a **Focus Group**.

We would like you to come to **1 group meeting** with other people in your community.

You do not have to tell us anything you do not want to.

The group will last for 1 hour to 1 hour and 30 minutes.

It will happen at a time and place that is good for you.



WEEK





You can ask to speak to the researcher on your own if you would find this easier.



We want to record what you say in the group.

Please only agree to take part if you are happy to be recorded.



Do I have to take part?

No. You do not have to come to a Focus Group. It is your choice.

Taking part, or not, will not change the support you get.



If you decide to take part, you can still change your mind later.

You can leave the Focus Group if you want to.



You do not have to tell us why you want to leave.

If you do leave, we will not include what you have told us before you leave in our results.



If you want to take part, we will ask you to sign a form.

Good things about taking part?



We will use what you tell us to improve cervical cancer screening for people in Scotland.

This will help us to understand what you think is good and bad, so we can make screening easier to attend.

We will give you a £5 'Love2shop' voucher as a thank you for your time.

What if I feel sad in the group?



You might feel sad.

This is OK, and you can leave the group if you want to.

We will ask you what we can do to make you feel comfortable.



What will you do with the results?

We can tell you what we found at the end of our study.

We will share what we find with other people who are interested in our study.

We will not use your name when we tell people what we found.

What happens to my information?

Your information will be kept private and safe.

The University of Stirling may need to check our work. They will keep your information safe.



If you think you, or someone else, is not safe, we will have to tell other people, like a member of your care team, or a family member.

Contact Details:

If you want to come to a group or ask about the study, you can email us. We can also speak over the telephone:



Catherine White (researcher)

cbw1@stir.ac.uk



07929 784484



Dr Lesley McGregor (supervisor)

l.m.mcgregor@stir.ac.uk



01786 466 379

If you are worried about our study and wish to speak to someone independent, you can contact the Head of the Psychology department:



Professor Paul Dudchenko

p.a.dudchenko@stir.ac.uk

APPENDIX 14 - FOCUS GROUP – CONSENT FORM

Participant Consent Form

Project title: Improving Cervical Cancer Screening across Scotland.

Principal Investigator: Catherine White, Trainee Health Psychologist

Name of participant:

Please complete this form after you have read the Information Sheet.

If you have any questions arising from the Information Sheet, please ask the researcher before you decide whether to join in.

Please initial each box to confirm your consent.

Please initial box

I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

I understand that the project requires me to take part in a Focus Group, where my contributions will be audio-recorded and transcribed and will be anonymised within any publications.

☐

I understand that participation in this study is entirely voluntary, and I can withdraw from the study at any time without giving a reason, providing my Participant Number.

☐

I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately knowing that any direct quotes of mine will be removed from the dataset.

☐

Anonymised responses will be stored securely. The audio recording will be kept until the analysis has been completed and then will be deleted securely. Transcribed data will be held for a minimum of seven years.

☐

Anonymised direct quotes can be used in any publications or reports as an outcome of this study.

☐

Anonymised data may be shared with publishers as part of the publication process.

☐

I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

☐

Comments or concerns during the study: If you have any questions or require additional information about the study and your rights as a participant, you should discuss these with the Principle Researcher, Catherine White (email: cbw1@stir.ac.uk; telephone: 07929 784484). You can

also contact Dr Lesley McGregor (Senior Lecturer in Health Psychology & Catherine's supervisor) by email: l.m.mcgregor@stir.ac.uk or telephone: 01786 466 379.

If you would like to complain or have any concerns about how you have been approached or treated during any part of this study, you should do so by contacting the Head of Department of Psychology, Professor Paul Dudchenko (p.a.dudchenko@stir.ac.uk).

Participant's signature

Print name

Date

Thank you for taking part in this research.

Improving Cervical Cancer Screening across Scotland

Focus Group Consent Form



Please initial each box if you agree:



I have been told about this study and have had my questions answered.

☐


I am happy to take part in a group discussion about cancer screening.

☐


I am happy for you to record the audio of our discussions and to take photographs of any creations for the study. I understand you will not use my name.

☐


I understand that the recordings and photographs will be kept safe and secure by the researcher.

☐


I understand that I can stop at any time, without giving any reason and no one will mind.

☐


I understand that if I decide that I no longer want to take part in this study I can let the researcher know and they will not use my answers as long as I say before the analysis starts.

☐


I agree to take part in the study.

☐

Name of Participant

Date

Signature

Name if signing as a witness on behalf of participant for verbal consent:-

Relationship to participant:

Researcher

Date

Signature