Measuring patient activation: the utility of the Patient Activation Measure within a UK context - results from four exemplar studies and potential future applications

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Abbreviations

FEV_1	Forced expiratory volume in 1 second
MRC Score	Medical Research Council Dyspnoea score

Keywords: patient activation; self-management; long term conditions

Accepted refereed manuscript of: Roberts NJ, Kidd L, Dougall N, Patel IS, McNarry S & Nixon C (2016) Measuring patient activation: the utility of the Patient Activation Measure within a UK context - results from four exemplar studies and potential future applications. *Patient Education and Counseling*, 99 (10), pp. 1739-1746. DOI: https://doi.org/10.1016/j.pec.2016.05.006

Abstract

Objective: Patient activation can be measured using the Patient Activation Measure (PAM) developed by Hibbard et al, however, little is known about the uses of the PAM in research and in practice. This study aims to explore its differing utility in four UK exemplar sites.

Methods : Data from four exemplars in a range of health settings with people living with long-term conditions (i.e. stroke or COPD) were evaluated. PAM scores were described and explored in relation to clinical and sociodemographic variables and outcome measures.

Results: PAM scores illustrated that most with COPD or stroke reported PAM levels of 3 or 4, indicating that they are engaging, but may need help to sustain their scores. The exemplars illustrate the utility of, and potential issues involved in, using PAM as a process/outcome measure to predict activation and the effectiveness of interventions, and as a tool to inform tailoring of targeted interventions.

Conclusions: The PAM tool has been shown to be useful as an outcome measure, a screening tool to tailor education, or a quality indicator for delivery of care.

Practice implications: However good demographic and patient history are needed to substantiate PAM scores. Further work is needed to monitor PAM prospectively.

Background

It is widely acknowledged that healthcare systems in the UK and worldwide are facing profound challenges. [1] In the UK, the English National Health Service (NHS) five year forward view[2] states that due to an increasingly ageing population, [3] the increasing prevalence of multiple long-term conditions [4,5] and the limits to the available financial resources new models of care are needed to face the demands of the current population. Globally, there have been moves towards a culture of patient engagement and self-care with an expectation that systems will be redesigned to be more patient-centred, based on needs, priorities and experiences where decision making and care planning is in partnership between patients and professionals, [6-8] such as the House of Care model. [9] The house of Care model is a coordinated delivery system for personalised care and support planning across multiple partners and sectors.

Measuring the quality and effectiveness of person-centred care, however, has its challenges. [1] A wide variety of PROMS (Patient Reported Outcomes Measures) and PREMS (Patient Reported Experience Measures) exist to measure service performance and quality indicators, or patient outcomes such as quality of life and self-management. [10,11] There is, however, no one 'right' way, and a general lack of clarity about what we mean by 'person-centred care' [12] in order to start unpicking its components. One area receiving growing attention across the UK's NHS in relation to person-centred long-term condition management is the concept of patient activation and its measurement as an indicator of quality and effectiveness, but also as a tool to tailor and stratify the delivery of care or people at risk of poor self-management.

Patient activation or readiness to self-manage measures individuals' understanding of their role in managing their health and their willingness and ability to take independent actions and decisions to manage their health and healthcare, [13,14] either self-directed or facilitated (but not driven) by professionals and/or peers. Hibbard *et al* suggests that patient activation provides a better understanding of why some patients engage fully with their health and others do not. [12] Operationally, patient activation, can be measured by the Patient Activation Measure (PAM) , a 13-item scale developed by Hibbard et al, [15,16] designed to assess an individual's knowledge, skill, and confidence with respect to managing his/her health. The score ranges from 0-100, and determines how 'activated' a person is, as one of four stages (Level 1-4, where 1 is least activated, Figure 1). International evidence demonstrates it has been used as an outcome to evaluate a vast array of self-management interventions [17, 18] across different long-term conditions and, different counties and cultures. [19-23] with some studies showing improvement in activation scores after interventions. [20,21,23] Studies have also shown that increases in patient activation are associated with a range of positive health outcomes, including reduction in body mass index, reduced blood glucose levels, reduced blood pressure and reduced cholesterol,[24-27] and positive health behaviours with regards to decision making, health information seeking, engagement in health behaviour and lifestyle changes, uptake of preventative health care, and self-management. [15,16,28]

It has been reported that the PAM can be used as: i) a process or outcome measure to determine the clinical or sociodemographic characteristics that may predict level of activation in order to improve patient engagement and health outcomes, with increases in activation being either an endpoint or a tool with which to improve other health outcomes, ii) a tool to inform tailoring of targeted interventions, by assessing an individuals' capacity for self-management and enabling the type and amount of support required by the individual to be targeted towards this and, iii) an outcome measure in evaluating the performance and effectiveness of healthcare systems and interventions, by undertaking before and after evaluations of the person's level of activation (also summarised in Table 1). [29] Recently, NHS England policy[1] has begun to advocate the use of the PAM as a 'vital sign' in addressing the challenge of providing high quality, person-centred, sustainable and cost effective long-term condition support. To date, the PAM has been more frequently used elsewhere in the World and evidence to support this policy direction in the UK and its effectiveness and appropriateness within a UK, long-term condition management context has yet to emerge and be disseminated at a national and international scale. In particular, we know little about how activated. (or not) populations with different long-term conditions across the UK are, how this changes over time and whether there clinical and sociodemographic factors can predict activation levels and changes in these. We also know little about the utility of the PAM in helping to tailor the type and amount of self-management support individuals receive and its effectiveness as an outcome measure to determine the effectiveness of the interventions and services that we offer. In this paper, we draw on evidence from four exemplar studies (two prospective studies and two secondary analyses) in which the utility of the PAM within a UK context in patients with long term conditions (in these examples, COPD or stroke) was explored. This paper is amongst the first to report on the utility of the PAM within a UK context, ahead of the evidence from NHS England and the Health Foundation's pilot and evaluation sites.

Methods

Four exemplar data sets which involved the use of the PAM (permission received from Insignia Health (http://www.insigniahealth.com/solutions/patient-activation-measure) were identified and used. The exemplar datasets utilised a variety of approaches, were undertaken in a range of settings and included people living with long-term conditions (i.e. stroke or COPD) (Table 2). The four exemplars used for this report were identified locally from clinical and academic colleagues, all of whom were using the PAM locally, two as part of funded research projects and two as part of service evaluations.

The aims were to explore and describe PAM scores within populations with stroke or COPD, how these changed as a result of interventions and/or how they were associated with clinical and sociodemographic variables and how they were used in real life practice. In reviewing the datasets collectively, it became clear that we could present descriptive evidence to illustrate how the PAM has been used in different ways within a UK context.

Exemplar 1 **-**This was a single-site prospective cross-sectional study (CLCH NHS Trust, London, 2012). A convenience sample of COPD patients attending for clinic or pulmonary rehabilitation appointments were used to maximise recruitment. Participants completed the study measure and gave access to notes for additional information (age, gender, disease severity (MRC Score), spirometry (where available), current smoking status, HADS (Hospital Anxiety and Depression Scale) score, number of hospital admissions and self-reported respiratory disease exacerbations in the previous 12 months).

Exemplar 2 - NHS Ayrshire and Arran (A&A) was a demonstration site for The Health Foundation's Co-Creating Health (CCH) initiative [30,31] which covered four clinical areas (COPD, depression, diabetes and muscoskeletal pain) and aimed to embed self-management support within UK services. The programme was delivered by an expert patient and clinician facilitators, (5 generic and one condition-specific sessions). Patients were identified from disease registers in primary care. The PAM tool was administered pre and post-programme and then at 3, 6 and 12 months post programme. This retrospective analysis focusses on COPD.

Exemplar 3 – This retrospective review of routine care in a pulmonary rehabilitation centre (2013-2014). The pulmonary rehabilitation (PR) programme was an "opt-in" twice weekly 6 week self-management programme for patients with an individualised exercise programme and education component. The PAM measure was used as a group outcome measure administered anonymously pre-PR, post-PR, 6mth and 12 mths. Patients were unmatched 'events'.

Exemplar 4 – This research project explored how the PAM could be used to tailor self-management support intervention for stroke survivors (3 months post stroke) in the community. [32] The intervention consisted of a tailored self-management action plan, incorporating an individualised assessment of stroke survivors'

levels of activation (using the PAM), goal setting and motivational interviewing and the study reported on both stroke survivors'(n=6) and professionals' (n=5) perspectives of the intervention and the use of the PAM to guide the provision of self-management support. In this study, the PAM was not used as an outcome measure but rather a process tool to identify participant's level of activation and align the provision of tailored support towards that based on the underpinning theory.

Data analysis

Descriptive statistics were used in estimating means or medians together with their respective standard deviations or inter-quartile ranges. These were reported using the appropriate summary estimates for all demographic and clinical variables as well as PAM scores for each set of study data. All data were entered into and analysis carried out using SPSS (V.19.0). ANOVA with post hoc Tukey HSD comparisons (Exemplar 3), repeated measures ANOVA with a Greenhouse-Geisser correction (Exemplar 2), multiple regression analysis (Exemplar 1), and Mann Whitney and chi-square tests (Exemplar 1) were undertaken.

Ethical approval

Exemplar 1 and 4 obtained ethical approval from NHS ethics Committees (ref: 12/YH/0234) and (ref 12/WS/0103). For Exemplar 2 and 3 approval was sought from R&D in each NHS Board and ethical approval was given by the SHLS ethics committee at Glasgow Caledonian University.

Results

Table 2 summarises the characteristics and data from the four exemplars including two prospective studies and two retrospective secondary analyses of data previously collected from a Co-Creating Health site, and routine data from community care. The PAM tool was used differently in each exemplar (Table 2), corresponding with the reported applications in the literature[29] Table 2 shows the findings from each individual exemplar.

Exemplar 1

40 COPD patients participated in this prospective study (20 males mean age 68 SD±9.4, median PAM score 56.4, IQR 27.1; $FEV_1$55.5%; MRC score =3.0±0.90; 12 current smokers). 60% had mild/moderate COPD, 50% had severe/very severe COPD [27]. In total there had been 23 self-reported respiratory hospital admissions and 87 self-reported exacerbations in the last 12 months. Most were attending for pulmonary rehabilitation (n=20), routine clinic appointment (n=16), or maintenance classes (n=4). Those attending PR had a significantly higher PAM score compared to those attending clinic appointments (median 67.25 IQR 28.3, vs median 52.9, IQR 10; p=0.023, Figure 2a) . There were no significant differences between PAM Scores and disease severity (mild/moderate vs severe/very severe, (Mann Whitney p=0.389). Multiple regression analysis using the PAM score identified three variables which gave the best model fit to predict PAM score, these included COPD severity, gender and exacerbation frequency (some missing data). Statistical assumptions of linearity, independence of errors, homoscedasticity, normality of residuals were met. Only one variable, exacerbation frequency was statistically significant in the prediction, $p<0.05$.

Exemplar 2

This retrospective dataset had matched data from 29 patients with COPD attending a self-management programme (Male 15, female 14, mean age 69.5 SD 8.6). Median PAM scores were higher for post programme (compared to baseline) and then dropped at 3mths (baseline PAM Score 55.2 [IQR 17.2]; post programme 71.95 [IQR 23.6], 3 mths 56.4 [IQR 16.4]. Repeated measure ANOVA (GLM) for the overall score shows that there were significant differences between the means at the different time-points (Greenhouse-Geisser [$F(1.976, 53.352)=7.164$, $p=0.002$). Post-hoc analysis shows there were significant differences between baseline and post-programme measurements (p=0.001) (Figure 2b)

Examplar 3

This retrospective analysis included PAM data from 231 individuals attending PR at three time points: baseline (n=128), 6 mths (n=65), and 12 mths (n=38). During the same time-period 274 individuals attended PR and 188 completed 6 mth and 147 had a 12 mth follow-up. Median baseline score pre-pulmonary rehabilitation were 56.4 (IQR 14.8), at 6 and 12 months post rehabilitation the scores were 63.2(IQR 14.4) and 63.2 (IQR20.1), respectively. There were significant differences between baseline and six months ($p<0.001$), and baseline and 12 months ($p<0.001$, Figure 2c).

Exemplar 4

PAM scores were not measured pre and post intervention in this study because the sample was very small and because the PAM was used as a process measure rather than an outcome measure. The median PAM score was 76.4 (IQR 10.93) (Level 4), identifying that they were all 'active self-managers who needed support only in times of stress or illness' (Figure 1). There were no significant differences in PAM Scores when comparing gender and Modified Rankin Scores (level of disability). Despite the quantitative PAM scores, qualitative interviews reflected characteristics associated with lower PAM levels (e.g. Levels 1 and 2, as shown in Figure 1). Perceptions on the use of PAM in this study are reported elsewhere [32] however, briefly, stroke survivors perceived that the PAM had been easy and straightforward to follow but not specific enough to identify their personal abilities and needs i.e. it didn't measure what was most relevant to the participants. The professionals reported concerns that patients may give 'socially desirable' answers rather than a true reflection of their readiness to engage, as demonstrated by the discrepancy between the qualitative and quantitative data, and that the appropriateness of the wording may need reconsidered for a UK audience. They perceived, therefore, that the PAM was less valuable as a tool for tailoring self-management support interventions in this study.

These 4 exemplars demonstrate how PAM can be used in a variety of ways and settings. Closer inspection of Exemplar 2 and 3 where PAM is used as part of service evaluation, PAM is also used as an outcome measure to measure effectiveness of interventions. Both analyses were retrospective, in Exemplar 3 data was anonymised and only examined group effectiveness and in Exemplar 2 the data were individually matched. Clinical data from participants was not available at both sites, and other details are limited around socio-economic variables, disease history etc. At both sites the PAM was used purely to look at change pre and post intervention.

Exemplar 1 used PAM as a process/outcome measure to predict engagement, a different approach from the service evaluations described previously. This research project collected more clinical data with PAM which allowed richer analysis, however the same sample size and lack of repeat data collection makes further analysis difficult. Exemplar 4 used the PAM as part of a mixed methods study, to inform tailoring of targeted interventions.

Discussion and Conclusion

Discussion

The potential use of the Patient Activation Measure as a tool for measuring the effectiveness of, or to aid in the tailoring of, interventions and care delivery is fast becoming of interest across the UK. Existing data on its use, however, largely stems from the USA and therefore we know little about the feasibility and challenge of using the PAM within a UK context. [12] This prompted us to summarise data from four studies, conducted by the authors, using a case study approach to present data on PAM levels across groups of people living in the UK with COPD or stroke, and to illustrate examples of the different ways in which the PAM can be used, as articulated by Hibbard and Gilburt (2014). [29] The data in this report was drawn from different parts of the UK which is valuable since it contextualises its use within the UK's devolved healthcare systems i.e. Scotland and England/Wales and within the UK's current system of routine care and service delivery using two long term conditions. It is also important to see the wide range of approaches and practices used, such as repeated measures after intervention, group responses, matching scores with qualitative data and looking for associations with socio-economic and clinical factors prior to interventions. Using aspects from all of these exemplars can be used to improve delivery of care and tailoring of interventions.

This is the first report, to our knowledge, that presents information on current PAM levels within a UK population of people with long-term conditions. What we have shown here is some of the pitfalls of using tools for service evaluation and research. Some of the key issues are lack of access to clinical data in routine datasets, incomplete data and small datasets and the unreliability of repeated measures. There are often time issues around adding extra detail to routine measures and of using data for multiple purposes. We acknowledge that the data is limited in its generalisability and that our interpretations must be treated with caution given their methodological limitations. In these exemplars he majority of people with COPD and stroke in our studies reported PAM levels of 3 or 4, indicating that are engaging in self-management but may require different types of support to sustain this at different times in their journey. These scores are similar to a telephone survey by Ellins et al, [33] who found in the UK, scores of 59.43 (stage 3) with nearly 60% of those sampled reaching this stage (n=3000). Previous evidence on PAM suggests that variables such as gender, age and disease severity are important predictors of PAM scores and theoretically, their engagement in self-management.[34-37] Although data indicated few associations, this is likely because the studies were significantly underpowered. To our knowledge, exacerbation frequency has not previously been investigated in association with PAM and self -management skills for those with COPD. Further research is clearly needed to validate this finding in datasets which are optimally powered to detect such differences. Understanding baseline PAM levels can enable health professionals to tailor their care, education and treatment to suit individuals' level of engagement or readiness. This may include screening prior to pulmonary rehab to delay or advance referral or to tailor learning materials for educational

programmes. Thus, the findings reported on here help to offer some support for the potential use of PAM, within a UK context, as a tool to identify and stratify those most in need of anticipatory advice or support.

The data identified that those who attended routine clinics only and those who hadn't yet engaged with a Pulmonary Rehabilitation (PR) or self-management programme (exemplar 1), typically lacked confidence to engage in self-management and were not yet 'active self-managers'. However following engagement with a pulmonary rehabilitation or self-management programme, scores were generally higher at Level 3 or 4, which may demonstrate increased confidence after the self-management or pulmonary rehabilitation. Data from participants following stroke (exemplar 4) had very high PAM Scores, higher than the COPD patients, this may be in part because of the acute nature of a stroke event, compared with the gradual development of COPD for example, or because of the intensive treatment and rehabilitation that people would have received shortly after the stroke event. Although it is not possible to determine a causal link, the data - taken collectively – suggests that PAM could be used to stratify and identify who may benefit most from, and engage with, programmes for PR and self-management. Our data also identifies that PAM can be used as a useful outcome measure to evaluate the effectiveness of existing services and interventions (exemplars 2 and 3). However, Brewster et al [12] caution that increases in PAM scores are likely to be more demonstrable in those who were low to begin with; which is comparable with some of the international evidence. We also echo the concerns of Brewster et al[12] who acknowledge that increases in PAM scores may not necessarily be the best indicator of an effective, and more importantly, person-centred service or intervention and that maintaining PAM score, rather than increasing it, may be a positive outcome. Indeed, our data indicated that the initial peak in PAM scores seen after PR and self-management programmes were not sustained over time (Exemplar 2). Further research is needed to explore this and to understand how PAM levels change and how they can best be sustained over time with timely and appropriate models of follow up.

The fourth exemplar specifically explored the feasibility and acceptability of using PAM as a basis for guiding the provision of tailored self-management support for stroke survivors. [32] Tailored coaching is not widely used as yet in the UK and there is little published evidence on this although it does hold potential and is of growing interest to researchers, practitioners, service providers and commissioners given the need to be more cost effective with resource use. This data illustrated that although PAM was useful for gauging PAM levels across a group of stroke survivors, some found it challenging to complete and the stroke nurses delivering the intervention reported that it did not enable tailoring of appropriate care and support. Thus, further research is needed to understand more about whether the PAM translates sufficiently to a UK population, and indeed groups of people with specific long-term conditions, and whether the elements of the PAM are specific enough to capture the outcomes that are most important to these groups in relation to their self-management.

Conclusions

The data reported on here, has illustrated some examples of the ways in which the PAM could be used within a UK context; as a process/outcome measure to level of predict activation/engagement, as an outcome measure in effectiveness of interventions/services, and as a tool to inform tailoring of interventions. Interest in its roll out across the UK is considerable and has drawn particular support from groups representing patients e.g. National Voices, the International Alliance of Patients' Organisations, as a tool to facilitate the delivery of person-centred care. Our research identifies, however, that there is a wealth of robust research still required to be undertaken in order to fully understand the effectiveness and utility of PAM in a UK context.

Practice implications

The PAM tool is a potential tool which can be used both in research and service evaluation. However the tool should not be used in isolation, and good demographic and patient history details need to be recorded regularly and repeatedly to understand the basis for the PAM scores and the changes that might be evident over time.

Acknowledgements

The Carnegie Trust for the Universities of Scotland provided research funding for the prospective study (Exemplar 1). The Burdett Trust for Nursing provided funding for the stroke exemplar (Exemplar 4). Exemplars 2 and 3 were unfunded.

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Figure 1 Description of the Hibbard's four stages of the Patient Activation Framework [15]

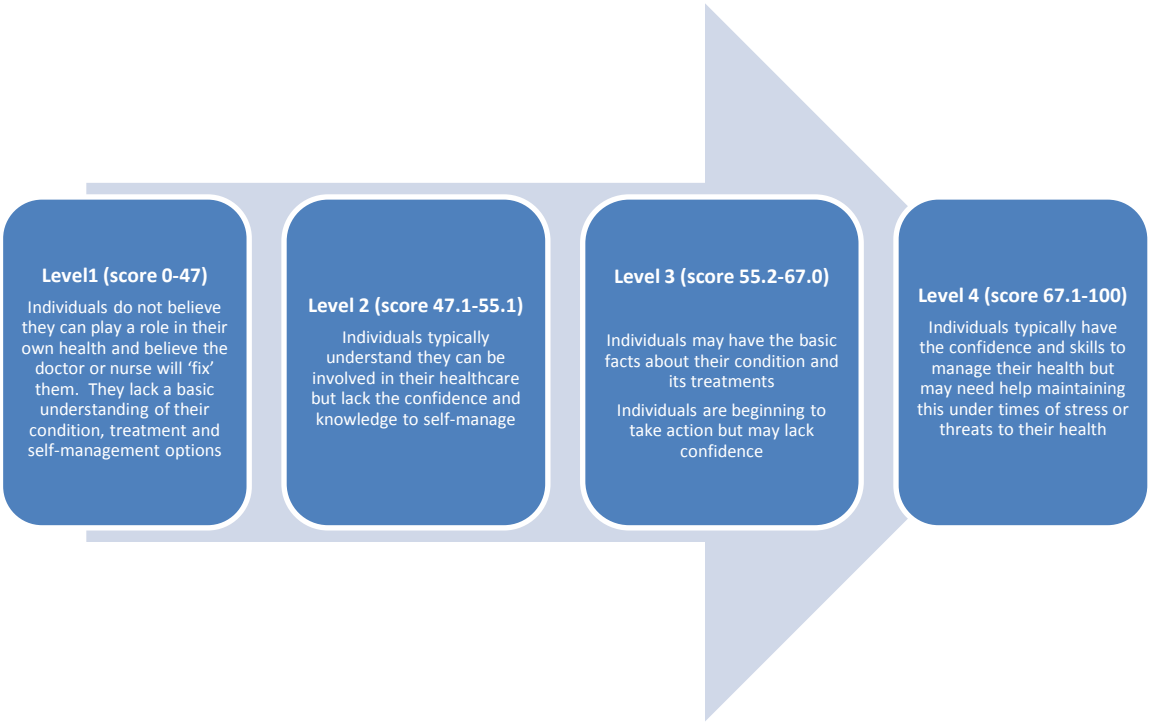
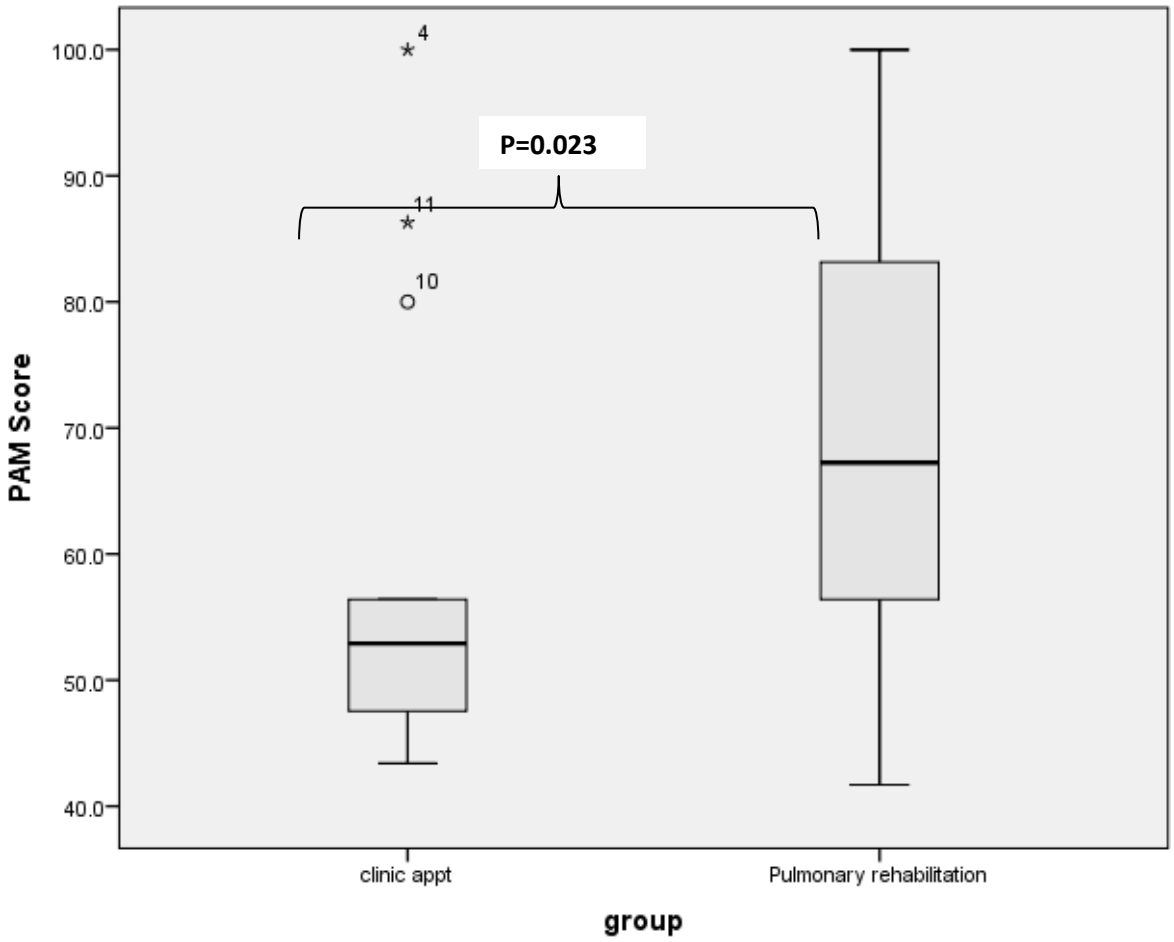


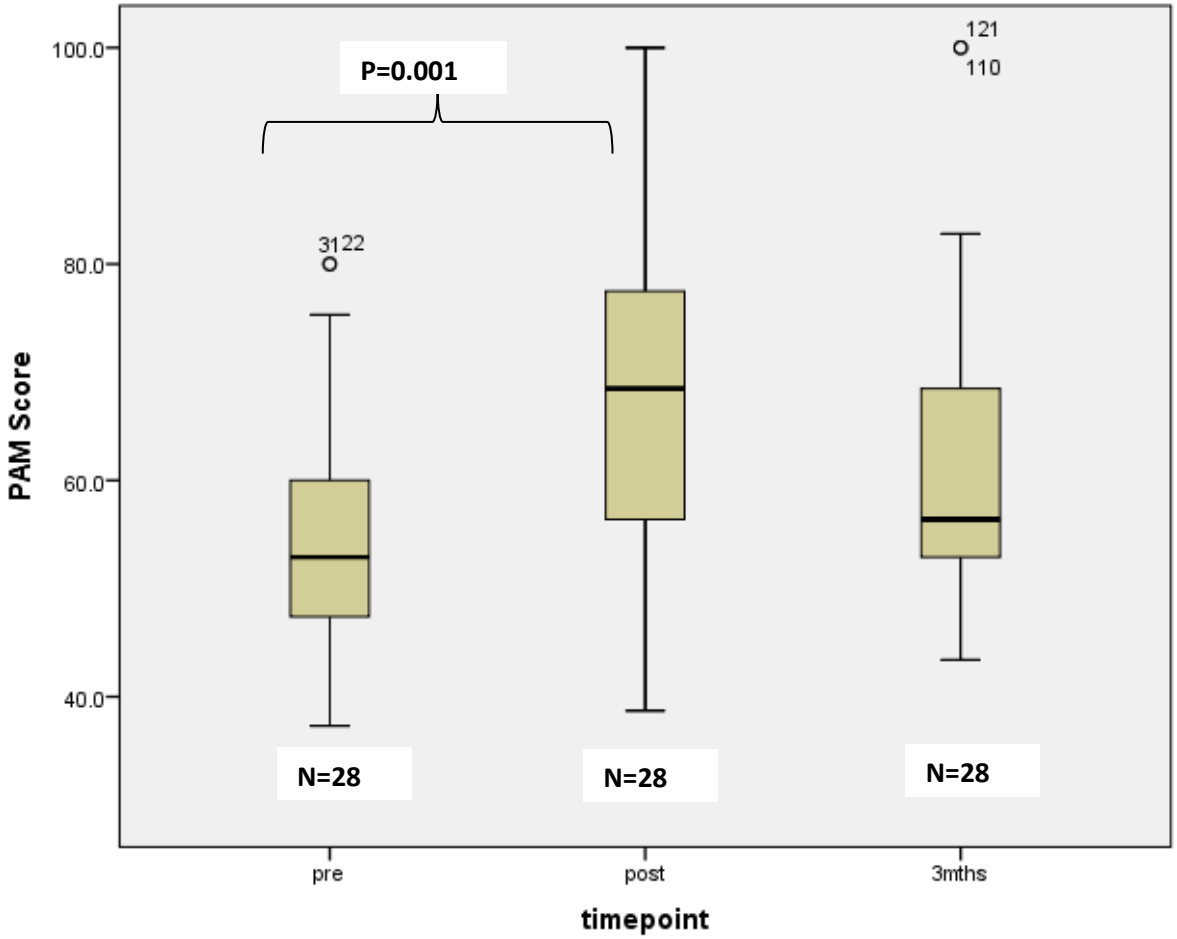
Figure 2a Exemplar 1



O Represents “out” outliers

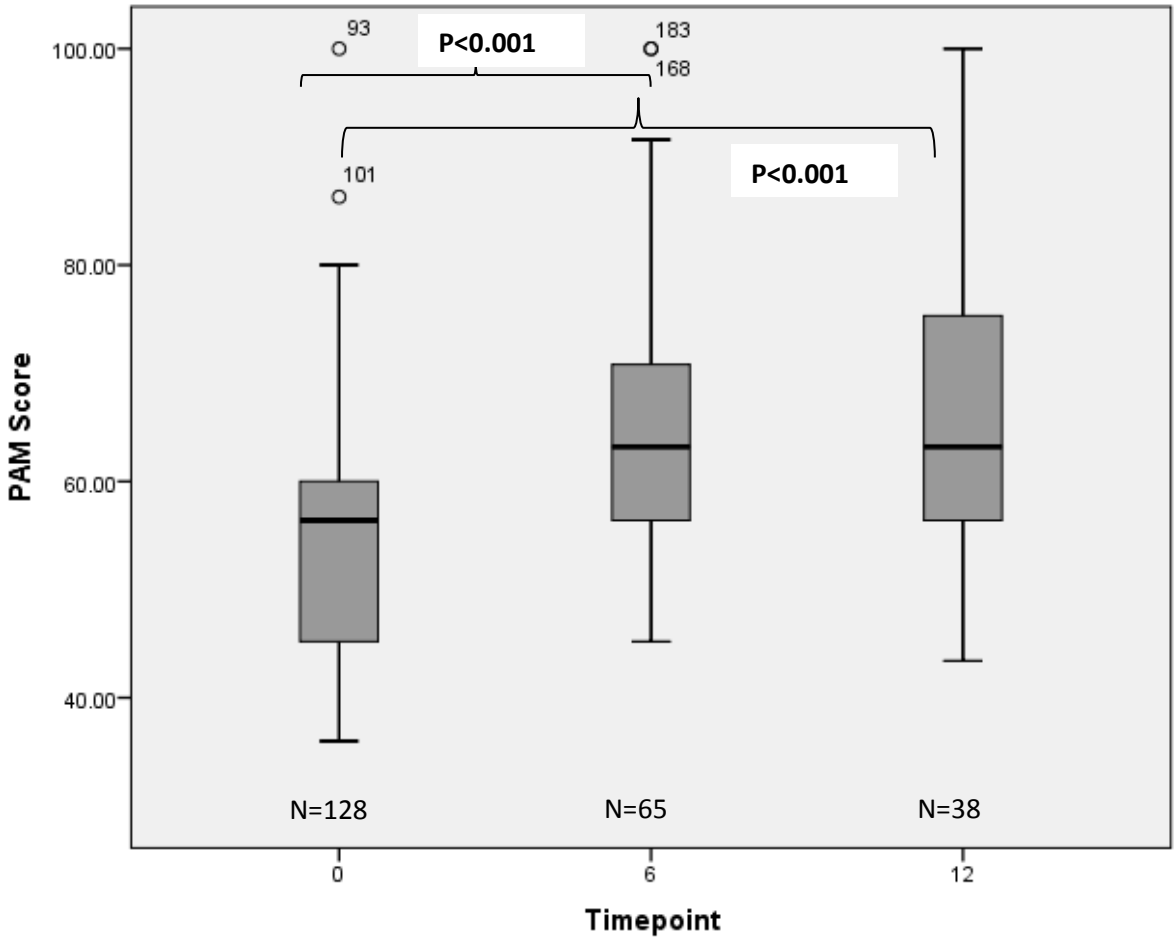
* Represents “far out” outliers

Figure 2b Exemplar 2: PAM Scores before and after a disease-specific self-management programme



O Represents "out" outliers

Figure 2c Exemplar 3: Unmatched PAM Scores before and after pulmonary rehabilitation



O Represents "out" outliers

Table 1 Uses of PAM tool [29]

-	*as a process or outcome measure to determine the clinical or sociodemographic characteristics that may predict level of activation in order to improve patient engagement and health outcomes, with increases in activation being either an endpoint or a tool with which to improve other health outcomes.*
-	*as a tool to inform tailoring of targeted interventions, by assessing an individuals' capacity for self-management and enabling the type and amount of support required by the individual to be targeted towards this and,*
-	*as an outcome measure in evaluating the performance and effectiveness of healthcare systems and interventions, by undertaking before and after evaluations of the person's level of activation*

Table 2

Exemplar 1 -PAM as process/outcome measure to predict activation/engagement				
Study Aim& Setting	**Participants**	**Study Design & Sampling**	**Methods& Analysis**	**Results & Limitations**
Study aim: To determine PAM levels within COPD populations and to identify associations with clinical and sociodemographic variables	40 COPD patients were recruited to this prospective study (20 males mean age 68 SD±9.4, 12 current smokers) with a mean percent predicted Forced Expiratory Volume in one second (FEV1) of 55.5%, and a mean MRC score of 3.0±0.9. 24 had mild/moderate COPD, 16 had severe/very severe COPD. In total there had been 23 self-reported respiratory hospital admissions and 87 self-reported exacerbations in the last 12 months. **Respiratory clinics (n=16)** Mean age 66.4 ± 8.9, 8 Females 8 Males , 7 current smokers **Pulmonary rehabilitation programmes (n=20)** Mean age 66.9±9.9, 12Females 8Males, 5 current smokers **Post-pulmonary rehabilitation maintenance classes (n=4)** Mean age 70.3±7.1, 4 males, no current smokers	**Study design and location:** Single site, observational prospective cross sectional study (June-Aug 2012) Central London Community Healthcare NHS Trust (England) **Study recruitment:** Participants with **COPD** were identified by the Respiratory Consultant and recruited from **three** settings using convenience sampling: i) respiratory outpatient clinics (hospital-based)/ community respiratory clinics, ii) pulmonary rehabilitation programmes (at multiple locations), or iii) iii) post-pulmonary rehabilitation gym sessions. The consent also requested permission to access the pulmonary rehabilitation and medical notes for additional information. Pulmonary rehabilitation [PR, a condition specific supported self-management programme] At this site PR was a rolling programme (with participants attending twice a week for six weeks). Participants had to be aged 18 years and over, able to speak and read English, provide written informed consent and deemed medically fit to participate. No further eligibility criteria such as an upper age limit were put in place. Those attending PR had to fit entry criteria to be eligible to participate **Study sampling**: convenience sampling **Ethical approval:** Yorkshire & The Humber – Leeds West ethics Committee (ref: 12/YH/0234).	Participants completed the PAM tool before or after their appointment. Age, gender, disease severity (MRC Score), spirometry, current smoking status, HADS (Hospital, Anxiety & Depression Scale) score, number of hospital admissions and self-reported respiratory disease exacerbations in previous 12 months) was collated from the medical notes. An exploratory multiple regression analysis was undertaken, with the dependent variable of activation for self-management (adjusted PAM score). COPD severity (MRC score), age, gender, [35] and also included exacerbation frequency, and smoking status were used in the regression analysis using a backward elimination method. Mann Whitney statistical tests were used for non-parametric comparisons and chi-square tests for categorical comparisons.	There was a statistically significant difference in the PAM score between those attending for respiratory clinics (median 52.9, IQR 10)(Level 2) and those attending for pulmonary rehabilitation (median 67.25 IQR 28.3) (Level 3) (p=0.023, Figure 1a). There were no significant differences between PAM Scores and disease severity (mild/moderate versus severe/very severe, (p=0.389). From the exploratory multiple regression analysis three variables were found to provide the best model fit predicting adjusted PAM score. These were COPD classification severity, gender and exacerbation frequency (limited data 27 entries) These three variables did not statistically significantly predict adjusted PAM score, F(3,23) = 2.936, p=.055, adj. R2 = .183, a likely consequence of the low number of subjects. Only one variable, exacerbation frequency was statistically significant in the prediction (associated with lower PAM scores), p<0.05. **Limitations:** Small sample size, convenience sample, single site study, cross sectional so no causal links can be claimed, sample selection by respiratory consultant (possible gatekeeping)

Exemplar 2 - PAM as outcome measure in effectiveness of interventions/services				
Study Aim& Setting	**Participants**	**Study Design & Sampling**	**Methods& Analysis**	**Results & Limitations**
To determine PAM levels within COPD populations and changes in PAM scores before and after self-management intervention	29 COPD patients [Male 15, female 14, mean age 69.5 SD 8.6).	**Study design and location:** secondary retrospective analysis of existing data collected from one demonstration site for The Health Foundation's Co-Creating Health (CCH) programme (2007-2012) (for COPD patients only), Ayrshire and Arran, Scotland.[30] **Study recruitment:** As part of the CCH programme, participants with COPD, were identified from GP registers and invited to attend a self-management programme (consisting of four generic and one disease-specific sessions) (Moving On Together). [31] **Ethical Approval:** NHS Ayrshire and Arran (Scotland), R&D management approval	Participants were asked to complete the PAM before starting the self-management programme (baseline, pre-programme) and then immediately post-programme and at 3, 6 and 12 months post programme. Matched patient data examined at each timepoint. Descriptive statistics were calculated, means, medians together with their respective standard deviations or inter-quartile ranges. Summary estimates were reported for all demographic and clinical variables as well as PAM scores for each time point. All data were entered into and analysis carried out using the software program Statistical Product and Service Solutions (SPSS) (V.19.0). Repeated measures ANOVA with a Greenhouse-Geisser correction was undertaken	Median PAM scores were higher for post programme (compared to baseline) and then dropped at 3mths (baseline PAM Score 55.2 [IQR 17.2] (Level 3); post programme 71.95 [IQR 23.6] (Level 4), 3 mths 56.4 [IQR 16.4] (Level 3). Repeated measure ANOVA (GLM) for the overall score shows that there were overall significant differences between the means at the different time-points (Greenhouse-Geisser [F(1.976, 53.352)=7.164, p=0.002). Post-hoc analysis shows there were significant differences between baseline and post-programme measurements (p=0.001) (Figure 1b). **Limitations:** Small sample size, secondary analysis of retrospective data, no control group, some data not available for all variables for each participant.
Exemplar 3 - PAM as outcome measure in effectiveness of interventions/services				
Study Aim& Setting	**Participants**	**Study Design & Sampling**	**Methods& Analysis**	**Results & Limitations**
To determine PAM levels within COPD populations and changes in PAM scores before and after rehabilitation programme	Patients attending for pulmonary rehabilitation over a 12 month period Jan 2013 to Feb 2014	**Study design and location:** secondary retrospective analysis of existing, anonymised data collected as part of routine care in a pulmonary rehabilitation centre, NHS Lothian **Study recruitment:** As part of the rehabilitation programme, participants with COPD were invited to take part in the 6-week programme, twice-weekly	Participants were asked to complete the PAM before starting the rehabilitation programme and then immediately post-programme and at 6 and 12 months post programme. Anonymised paper copies with	Median baseline score pre-pulmonary rehabilitation were 56.4 (IQR 14.8) (Level 3), at 6 months post rehabilitation the scores were 63.2(IQR 14.4) (upper end of Level 3) and at 12 months the scores were 63.2 (IQR20.1) (upper end of Level 3). There were significant differences between PAM scores at baseline and six months

		self-management programme, comprising individualised exercise programme and education. **Study sampling:** 274 individuals attended PR during this time period approximately 274 individuals attended PR and 188 completed 6 mth and 147 had a 12 mth follow-up. Patients completed the PAM measure anonymously at several timepoints. **Ethical approval:** NHS Lothian, R&D approval obtained)	details of the appointment type (Baseline, 6 months or 12 months) were analysed for this report. Patients were unmatched 'events' and 231 PAM measurements were available in total for analysis from the 274 attendees. n=128 measurements at baseline, n=65 measurements at 6 mths, and n=38 measurements at 12 mths. Each measurement relates to an individual attending the PR programme. Data was collected by the pulmonary rehabilitation team and inputted into a database by the team leader/administrator Details on age, severity, gender and medical history were not available, all participants had a diagnosis of COPD and were eligible for PR. ANOVA with post hoc Tukey HSD comparisons were undertaken.	(p<0.001), and baseline and 12 months (p<0.001). Figure 1c shows the PAM scores at the three timepoints. **Limitations:** secondary analysis of retrospective data, no control group, some data not available for all variables for each participant.
Exemplar 4 - PAM as a tool to inform tailoring of targeted interventions				
Study Aim& Setting	**Participants**	**Study Design & Sampling**	**Methods& Analysis**	**Results & Limitations**
To determine PAM levels within a community stroke population, to develop and evaluate the feasibility and acceptability pf an	20 participants who had had a **stroke** (in previous 12 months) and were living in the community under a stroke nursing team. Male 12, Female 18, mean age 64 SD 11.51	**Study design and location:** Multisite, two phase mixed method study (2013-2014), NHS Scotland (Fife, Lanarkshire, Highland) **Study recruitment and sampling:** Participants identified through the stroke nursing teams and identified to take part in the study, from routine visits and care.	Participants completed the PAM tool prior to a qualitative interview around their self-management needs.	The median PAM score was 76.4 (IQR 10.93) (Level 4). There were no significant differences in PAM Scores when comparing gender and Modified Rankin Scores (level of disability). Despite the quantitative PAM scores, qualitative interviews reflected

intervention based on patient activation and tailoring of stroke self-management support. [32]	Time since stroke: 1-6mths = 12; 7-12 mths = 8 cognitive impairment (n=12), MRS moderate to mod severe disability (n=10)	Phase 1 (development of intervention) Phase 1 involved interviews with patients to identify PAM levels and self-management needs (through qualitative interviews) and development of a self-management intervention. The 'intervention' comprised a 'tailored self-management action plan (in booklet form) created based on PAM score and person-centred goal setting. Phase 2 involved piloting the self-management intervention (reported elsewhere). [32] **Ethical approval:** 12/WS/0103 West of Scotland Committee 3		characteristics associated with lower PAM levels (e.g. Levels 1 and 2, as shown in Figure 1). **Limitations:** small sample size, convenience sample, PAM score not assessed following intervention because of short intervention period, sample selection by stroke nurses (possible gatekeeping).