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

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33 **Abbreviations**

34 FEV₁ Forced expiratory volume in 1 second

35 MRC Score Medical Research Council Dyspnoea score

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

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1 **Abstract**

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

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

8

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

13

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

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

1 Background

2 It is widely acknowledged that healthcare systems in the UK and worldwide are facing profound
3 challenges.¹ In the UK, the English National Health Service (NHS) five year forward view² states that due
4 to an increasingly ageing population,³ the increasing prevalence of multiple long-term conditions^{4,5} and
5 the limits to the available financial resources new models of care are needed to face the demands of the
6 current population. Globally, there have been moves towards a culture of patient engagement and self-
7 care with an expectation that systems will be redesigned to be more patient-centred, based on needs,
8 priorities and experiences where decision making and care planning is in partnership between patients and
9 professionals,⁶⁻⁸ such as the House of Care model.⁹ The house of Care model is a coordinated delivery
10 system for personalised care and support planning across multiple partners and sectors.

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

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

1 It has been reported that the PAM can be used as: i) a process or outcome measure to determine the
2 clinical or sociodemographic characteristics that may predict level of activation in order to improve patient
3 engagement and health outcomes, with increases in activation being either an endpoint or a tool with
4 which to improve other health outcomes, ii) a tool to inform tailoring of targeted interventions, by
5 assessing an individuals' capacity for self-management and enabling the type and amount of support
6 required by the individual to be targeted towards this and, iii) an outcome measure in evaluating the
7 performance and effectiveness of healthcare systems and interventions, by undertaking before and after
8 evaluations of the person's level of activation (also summarised in Table 1).²⁹ Recently, NHS England policy¹
9 has begun to advocate the use of the PAM as a 'vital sign' in addressing the challenge of providing high
10 quality, person-centred, sustainable and cost effective long-term condition support. To date, the PAM has
11 been more frequently used elsewhere in the World and evidence to support this policy direction in the UK
12 and its effectiveness and appropriateness within a UK, long-term condition management context has yet to
13 emerge and be disseminated at a national and international scale. In particular, we know little about how
14 activated. (or not) populations with different long-term conditions across the UK are, how this changes
15 over time and whether there clinical and sociodemographic factors can predict activation levels and
16 changes in these. We also know little about the utility of the PAM in helping to tailor the type and amount
17 of self-management support individuals receive and its effectiveness as an outcome measure to determine
18 the effectiveness of the interventions and services that we offer. In this paper, we draw on evidence from
19 four exemplar studies (two prospective studies and two secondary analyses) in which the utility of the PAM
20 within a UK context in patients with long term conditions (in these examples, COPD or stroke) was
21 explored. This paper is amongst the first to report on the utility of the PAM within a UK context, ahead of
22 the evidence from NHS England and the Health Foundation's pilot and evaluation sites.

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1 **Methods**

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

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

13

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

20

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

28 Exemplar 3 – This retrospective review of routine care in a pulmonary rehabilitation centre (2013-2014).

29 The pulmonary rehabilitation (PR) programme was an “opt-in” twice weekly 6 week self-management
30 programme for patients with an individualised exercise programme and education component. The PAM
31 measure was used as a group outcome measure administered anonymously pre-PR, post-PR, 6mth and 12
32 mths. Patients were unmatched ‘events’.

33

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

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

6 Data analysis

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

13

14 Ethical approval

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16 Exemplar 1 and 4 obtained ethical approval from NHS ethics Committees (ref: 12/YH/0234) and (ref
17 12/WS/0103). For Exemplar 2 and 3 approval was sought from R&D in each NHS Board and ethical approval
18 was given by the SHLS ethics committee at Glasgow Caledonian University.

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1 Results

2 Table 2 summarises the characteristics and data from the four exemplars including two prospective studies
3 and two retrospective secondary analyses of data previously collected from a Co-Creating Health site, and
4 routine data from community care. The PAM tool was used differently in each exemplar (Table 2),
5 corresponding with the reported applications in the literature²⁹ Table 2 shows the findings from each
6 individual exemplar.

7 Exemplar 1

8 40 COPD patients participated in this prospective study (20 males mean age 68 SD±9.4, median PAM score
9 56.4, IQR 27.1; FEV₁55.5%; MRC score =3.0±0.90; 12 current smokers). 60% had mild/moderate COPD,
10 50% had severe/very severe COPD [27]. In total there had been 23 self-reported respiratory hospital
11 admissions and 87 self-reported exacerbations in the last 12 months. Most were attending for pulmonary
12 rehabilitation (n=20), routine clinic appointment (n=16), or maintenance classes (n=4). Those attending PR
13 had a significantly higher PAM score compared to those attending clinic appointments (median 67.25 IQR
14 28.3, vs median 52.9, IQR 10; p=0.023, Figure 2a) . There were no significant differences between PAM
15 Scores and disease severity (mild/moderate vs severe/very severe, (Mann Whitney p=0.389). Multiple
16 regression analysis using the PAM score identified three variables which gave the best model fit to predict
17 PAM score, these included COPD severity, gender and exacerbation frequency (some missing data).
18 Statistical assumptions of linearity, independence of errors, homoscedasticity, normality of residuals were
19 met. Only one variable, exacerbation frequency was statistically significant in the prediction, p<0.05.

21 Exemplar 2

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

30 Exemplar 3

31 This retrospective analysis included PAM data from 231 individuals attending PR at three time points:
32 baseline (n=128), 6 mths (n=65), and 12 mths (n=38). During the same time-period 274 individuals
33 attended PR and 188 completed 6 mth and 147 had a 12 mth follow-up. Median baseline score pre-
34 pulmonary rehabilitation were 56.4 (IQR 14.8), at 6 and 12 months post rehabilitation the scores were
35 63.2(IQR 14.4) and 63.2 (IQR20.1), respectively. There were significant differences between baseline and
36 six months (p<0.001), and baseline and 12 months (p<0.001, Figure 2c).

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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 elsewhere³² 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.

1 **Discussion and Conclusion**

2 Discussion

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

17

18 This is the first report, to our knowledge, that presents information on current PAM levels within a UK
19 population of people with long-term conditions. What we have shown here is some of the pitfalls of using
20 tools for service evaluation and research. Some of the key issues are lack of access to clinical data in
21 routine datasets, incomplete data and small datasets and the unreliability of repeated measures. There are
22 often time issues around adding extra detail to routine measures and of using data for multiple purposes.
23 We acknowledge that the data is limited in its generalisability and that our interpretations must be treated
24 with caution given their methodological limitations. In these exemplars the majority of people with COPD
25 and stroke in our studies reported PAM levels of 3 or 4, indicating that are engaging in self-management
26 but may require different types of support to sustain this at different times in their journey. These scores
27 are similar to a telephone survey by Ellins et al,³³ who found in the UK, scores of 59.43 (stage 3) with nearly
28 60% of those sampled reaching this stage (n=3000). Previous evidence on PAM suggests that variables such
29 as gender, age and disease severity are important predictors of PAM scores and theoretically, their
30 engagement in self-management.³⁴⁻³⁷ Although data indicated few associations, this is likely because the
31 studies were significantly underpowered. To our knowledge, exacerbation frequency has not previously
32 been investigated in association with PAM and self-management skills for those with COPD. Further
33 research is clearly needed to validate this finding in datasets which are optimally powered to detect such
34 differences. Understanding baseline PAM levels can enable health professionals to tailor their care,
35 education and treatment to suit individuals' level of engagement or readiness. This may include screening
36 prior to pulmonary rehab to delay or advance referral or to tailor learning materials for educational

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

3
4 The data identified that those who attended routine clinics only and those who hadn't yet engaged with a
5 Pulmonary Rehabilitation (PR) or self-management programme (exemplar 1), typically lacked confidence to
6 engage in self-management and were not yet 'active self-managers'. However following engagement with
7 a pulmonary rehabilitation or self-management programme, scores were generally higher at Level 3 or 4,
8 which may demonstrate increased confidence after the self-management or pulmonary rehabilitation.
9 Data from participants following stroke (exemplar 4) had very high PAM Scores, higher than the COPD
10 patients, this may be in part because of the acute nature of a stroke event, compared with the gradual
11 development of COPD for example, or because of the intensive treatment and rehabilitation that people
12 would have received shortly after the stroke event. Although it is not possible to determine a causal link,
13 the data - taken collectively – suggests that PAM could be used to stratify and identify who may benefit
14 most from, and engage with, programmes for PR and self-management. Our data also identifies that PAM
15 can be used as a useful outcome measure to evaluate the effectiveness of existing services and
16 interventions (exemplars 2 and 3). However, Brewster et al¹² caution that increases in PAM scores are
17 likely to be more demonstrable in those who were low to begin with; which is comparable with some of
18 the international evidence. We also echo the concerns of Brewster et al¹² who acknowledge that increases
19 in PAM scores may not necessarily be the best indicator of an effective, and more importantly, person-
20 centred service or intervention and that maintaining PAM score, rather than increasing it, may be a positive
21 outcome. Indeed, our data indicated that the initial peak in PAM scores seen after PR and self-
22 management programmes were not sustained over time (Exemplar 2). Further research is needed to
23 explore this and to understand how PAM levels change and how they can best be sustained over time with
24 timely and appropriate models of follow up.

25
26 The fourth exemplar specifically explored the feasibility and acceptability of using PAM as a basis for
27 guiding the provision of tailored self-management support for stroke survivors.³² Tailored coaching is not
28 widely used as yet in the UK and there is little published evidence on this although it does hold potential
29 and is of growing interest to researchers, practitioners, service providers and commissioners given the
30 need to be more cost effective with resource use. This data illustrated that although PAM was useful for
31 gauging PAM levels across a group of stroke survivors, some found it challenging to complete and the
32 stroke nurses delivering the intervention reported that it did not enable tailoring of appropriate care and
33 support. Thus, further research is needed to understand more about whether the PAM translates
34 sufficiently to a UK population, and indeed groups of people with specific long-term conditions, and
35 whether the elements of the PAM are specific enough to capture the outcomes that are most important to
36 these groups in relation to their self-management.

1

2 Conclusions

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

11 Practice implications

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

16

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1 References

2

- 3 1. De Silva D. Helping measure person-centred care: A review of evidence about commonly used
4 approaches and tools used to help measure person-centred care. *London: Health Foundation*. 2014
- 5 2. England, NHS. Five year forward view. *London: HM Government*. 2014
- 6 3. Barnett K, Mercer SW, Norbury M, WattG, WykeS, Guthrie B. Epidemiology of multimorbidity and
7 implications for health care, research, and medical education: a cross-sectional study. *The Lancet*
8 2012; **380**:37-43.
- 9 4. Berzins K, Reilly S, Abell J, Hughes J and D Challis. UK self-care support initiatives for older patients
10 with long term conditions: a review. *Chronic Illn*2009;**5**: 56–72.
- 11 5. Scottish Government. Improving health and wellbeing of people with long term conditions in Scotland:
12 An action plan. Edinburgh 2009
- 13 6. De Silva D. Evidence: Helping people help themselves: A review of the evidence considering whether
14 it is worthwhile to support self-management. *London: Health Foundation* 2011.
- 15 7. Coulter A, Roberts S, Dixon A. Delivering better services for people with long-term conditions: building
16 the house of care. London: *The King’s Fund*. 2013
- 17 8. De Silva D. Helping people share decision making. London: *Health Foundation*. 2012
- 18 9. Coulter A., Roberts S, & Dixon A. Delivering better services for people with long-term conditions:
19 building the house of care. *The Kings Fund* 2013
- 20 10. De Silva D. Measuring patient experience. *London: The Health Foundation*. 2013
- 21 11. Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr A J. The routine use of patient reported outcome
22 measures in healthcare settings. *BMJ* 2010;**340** c186(2a.)
- 23 12. Brewster J, Ramcharan P. Enabling and supporting person-centred approaches *Learning*
24 *Disability* 2005; **491**.
- 25 13. Hibbard JH, Cunningham P. How Engaged Are Consumers in Their Health and HealthCare, and Why
26 Does it Matter? Center for Studying Health Systems Change Research Brief October 2008.
27 <http://www.hschange.com/CONTENT/1019/>
- 28 14. Greene J. Hibbard JH. Why does patient activation matter? An examination of the relationships
29 between patient activation and health-related outcomes. *Journal of General Internal Medicine* 2012;
30 **27.5**: 520-526.
- 31 15. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM):
32 conceptualizing and measuring activation in patients and consumers. *Health Serv Res.* 2004; **39**:1005-
33 1026.
- 34 16. Hibbard JH, Mahoney E, Stockard J, Tusler M. Development and testing of a short form of the Patient
35 Activation Measure (PAM). *Health Serv Res.* 2005;**40**:1918-1930.
- 36 17. Adams S, Goler NC, Sanna RS, Boccio M, Bellamy DJ, Brown SD, Neugebauer RS, Ferrara A, Wiley DM,
37 Schmittdiel JA. Patient Satisfaction and Perceived Success with a Telephonic Health Coaching Program:

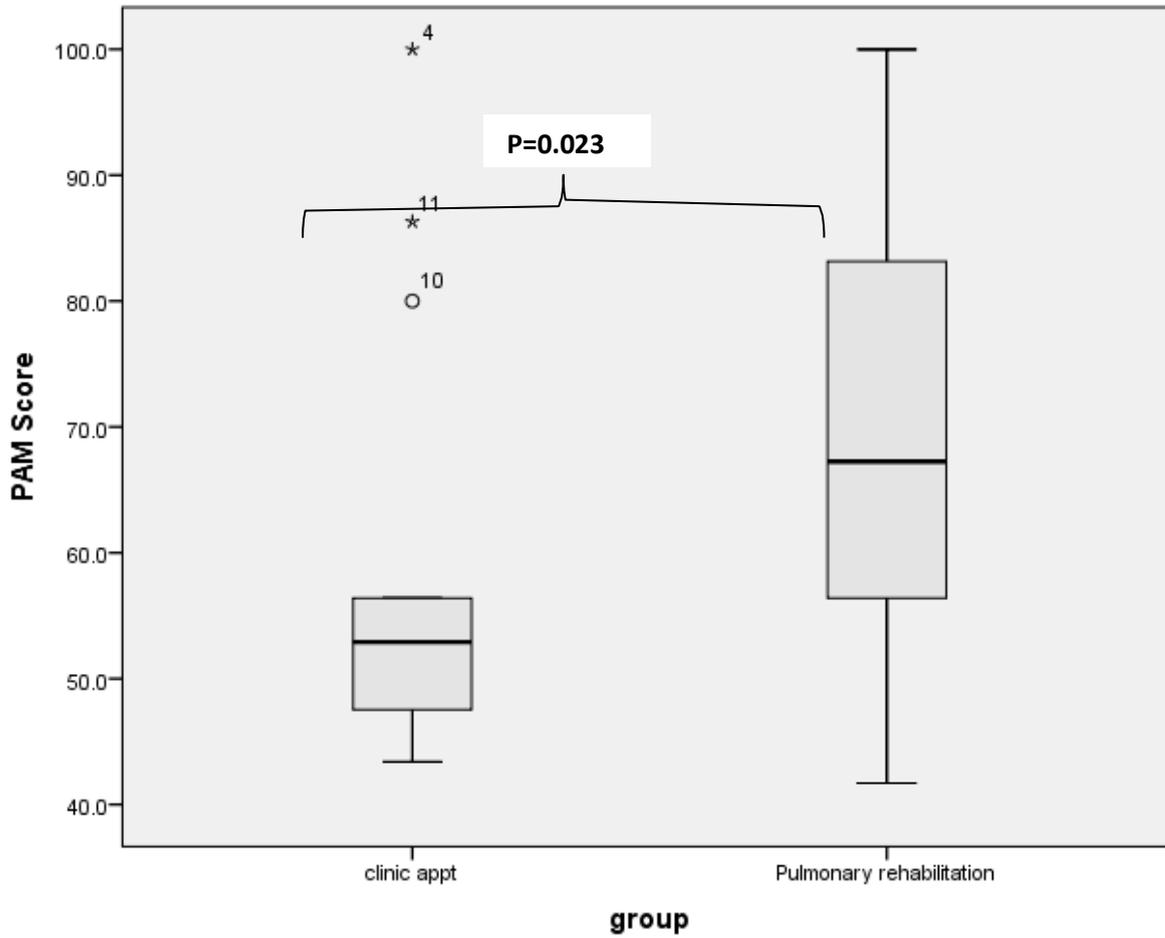
- 1 The Natural Experiments for Translation in Diabetes (NEXT---D) Study. *Prev Chronic Dis* 2013;
2 **10**:130116
- 3 18. Deen D, Lu WH, Rothstein D, Santana L, Gold MR. Asking questions: The effect of a brief intervention in
4 community health centers on patient activation. *Patient Education and Counseling* 2011; **84**:257-60
- 5 19. Richmond group of charities, King's fund. From vision to action: Making patient-centred care a reality.
6 2012 [www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Richmond-group-from-vision-to-](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Richmond-group-from-vision-to-action-april-2012-1.pdf)
7 [action-april-2012-1.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Richmond-group-from-vision-to-action-april-2012-1.pdf)
- 8 20. Shane-McWhorter L, McAdam-Marx C, Lenert L, Petersen M, Woolsey S ; Coursey JM, Whittaker TC,
9 Hyer C; LaMarche D; Carroll P, Chuy L Pharmacist-provided diabetes management and education via
10 a telemonitoring program *J Am Pharm Assoc* 2015; **55**:516-526.
- 11 21. Ehde DM, Elzea J, Verrall AM, Gibbons LE, Smith A, Amtmann D. Efficacy of A Telephone-Delivered
12 Self-Management Intervention For Persons With Multiple Sclerosis: a Randomized Controlled Trial
13 With a One-Year Follow-Up *Arch Phys Med Rehabil.* 2015; **96**:1945-1958
- 14 22. Juul L, Andersen V J, Arnoldsen J, Maindal H T. Effectiveness of a brief theory-based health promotion
15 intervention among adults at high risk of type 2 diabetes: One-year results from a randomised trial in a
16 community setting. *Primary care diabetes* 2015 in press
- 17 23. Turner AP, Anderson J K, Wallace L M, Kennedy-Williams P. Evaluation of a self-management
18 programme for patients with chronic obstructive pulmonary disease. *Chronic respiratory disease*
19 2014, 1479972314539979.
- 20 24. Remmers C, Hibbard J, Mosen DM, Wagenfield M, Hoyer RE, Jones C.. Is patient activation associated
21 with future health outcomes and healthcare utilization among patients with diabetes? *The Journal of*
22 *ambulatory care management* 2009; **32**: 320-327.
- 23 25. Rogvi S, Tapagerl, Almdal TP, Schiøtz, ML, Willaing I. Patient factors and glycaemic control-
24 associations and explanatory power. *Diabetic Medicine* 2012; **29**: e382-e389.
- 25 26. Skolasky RL, Mackenzie E.J, Wegener ST, Riley LH.. Patient activation and functional recovery in
26 persons undergoing spine surgery. *The Journal of Bone & Joint Surgery* 2011; **93**: 1665-1671.
- 27 27. Terry PE, Fowles J B, Harvey L. Employee engagement factors that affect enrollment compared with
28 retention in two coaching programs—the ACTIVATE study. *Population Health Management* 2010;
29 **13.3**: 115-122.
- 30 28. Hibbard J H., Mahoney ER, Stock R, Tusler M.. Do Increases in Patient Activation Result in Improved
31 Self-Management Behaviors? *Health services research* 2007; **42**: 1443-1463.
- 32 29. Hibbard JH, Gilbert H.. Supporting people to manage their health: an introduction to patient activation.
33 *London The Health Foundation* 2014
- 34 30. Wallace, L. *Co-creating health: Evaluation of the first phase*. The Health Foundation, 2012.
- 35 31. NHS Ayrshire and Arran Local evaluation for Co-creating health
36 http://www.health.org.uk/sites/default/files/CoCreatingHealth_NHSAyrshireArran_evaluation.pdf
37 http://www.health.org.uk/sites/default/files/CoCreatingHealth_NHSAyrshireArran_evaluation.pdf
(accessed 4 November 2015)

- 1 32. Kidd L, Lawrence M, Booth J, Rowat A and Russell S Development and evaluation of a nurse-led,
2 tailored stroke self-management intervention. *BMC Health Services Research* 2015 (in press)
- 3 33. Ellins, J, Coulter A. How engaged are people in their health care? Findings of a national
4 telephone survey. *The Health Foundation* 2005.
- 5 34. Cameron J, Worrall-Carter L, Riegel B, Lo SK, Stewart S Testing a model of patient characteristics,
6 psychologic status, and cognitive function as predictors of self-care in persons with chronic heart
7 failure. *Heart Lung* 2009; **38**: 410–418.
- 8 35. Rose M, Fliege H, Hildebrandt M, Schirop T, Klapp B F. The network of psychological variables in
9 patients with diabetes and their importance for quality of life and metabolic control. *Diabetes*
10 *Care* 2002; **25**: 35-42.
- 11 36. Connelly CE. An empirical study of a model of self-care in chronic illness. *Clinical Nurse Specialist*
12 1993; **7** : 247-253.
- 13 37. Disler RT, Gallagher RD, Davidson PM Factors influencing self-management in chronic obstructive
14 pulmonary disease: an integrative review. *Int J Nurs Stud* 2012; **49**: 230–242.
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Figure 1 Description of the Hibbard's four stages of the Patient Activation Framework ¹⁵



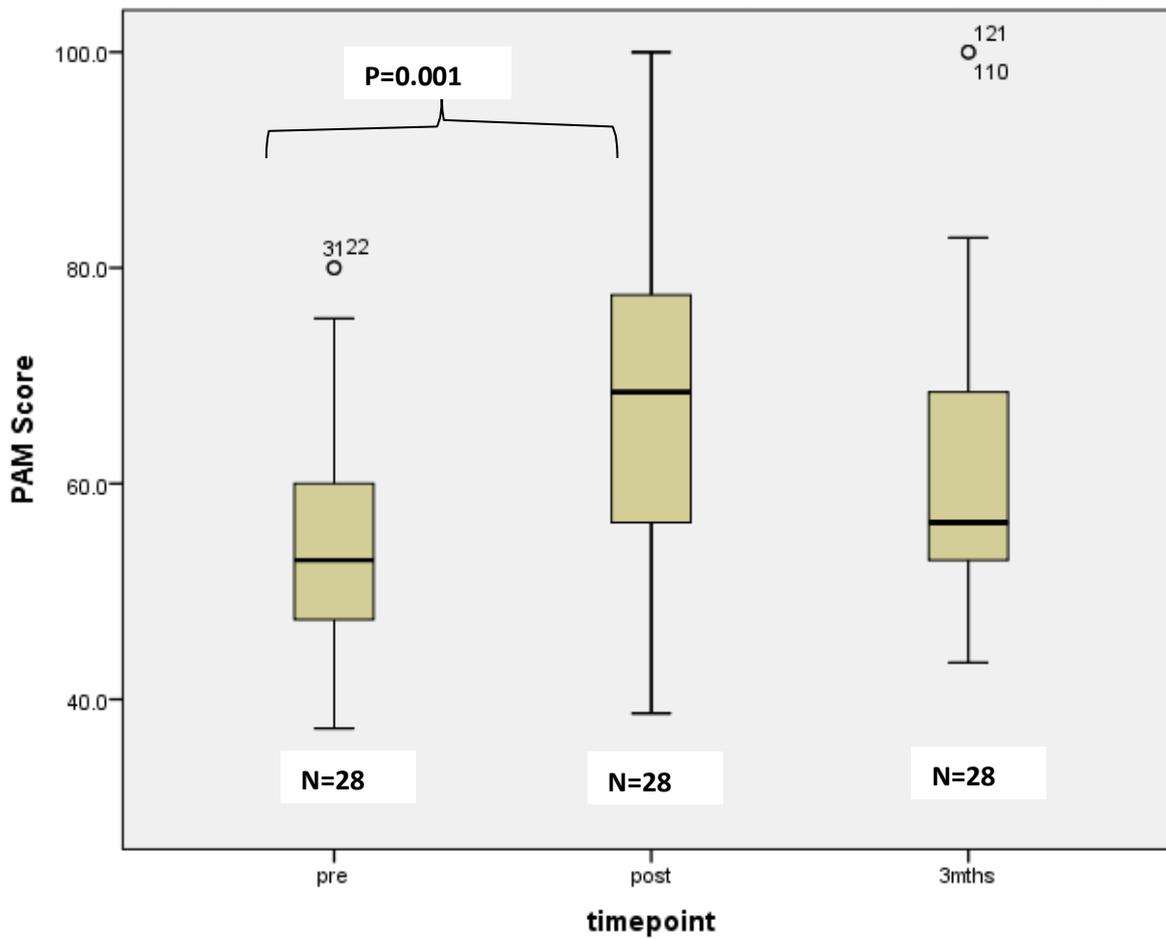
Figure 2a Exemplar 1



O Represents "out" outliers

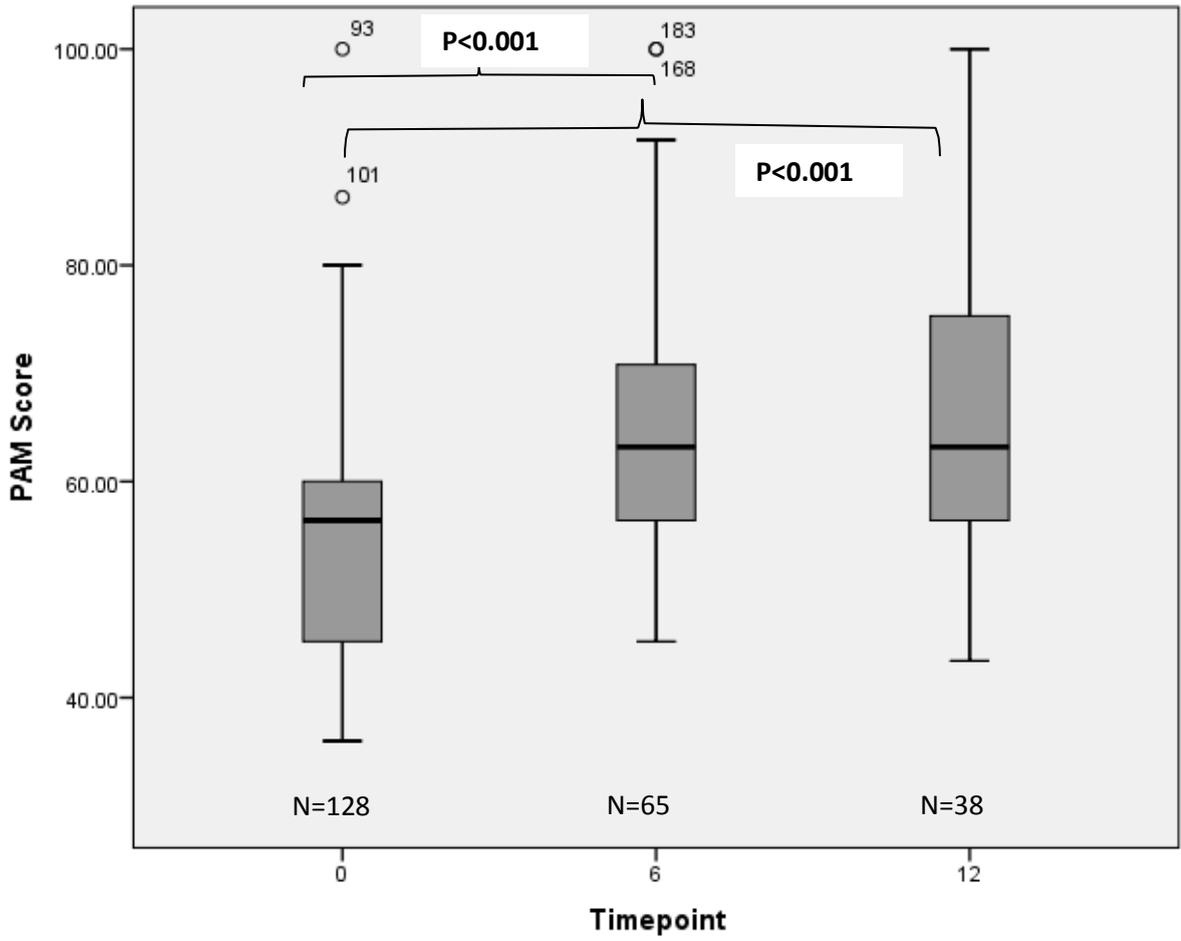
* Represents "far out" outliers

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



○ Represents "out" outliers

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



○ Represents “out” outliers

Table 1 Uses of PAM tool ²⁹

<p>- <i>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.</i></p>
<p>- <i>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,</i></p>
<p>- <i>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</i></p>

Table 2

Exemplar 1 -PAM as process/outcome measure to predict activation/engagement				
Study Aim& Setting	Participants	Study Design & Sampling	Methods& Analysis	Results & Limitations
<p>Study aim:</p> <p>To determine PAM levels within COPD populations and to identify associations with clinical and sociodemographic variables</p>	<p>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.</p> <p>Respiratory clinics (n=16) Mean age 66.4 ± 8.9, 8 Females 8 Males , 7 current smokers</p> <p>Pulmonary rehabilitation programmes (n=20) Mean age 66.9±9.9, 12Females 8Males, 5 current smokers</p> <p>Post-pulmonary rehabilitation maintenance classes (n=4) Mean age 70.3±7.1, 4 males, no current smokers</p>	<p>Study design and location: Single site, <u>observational</u> prospective cross sectional study (June-Aug 2012)</p> <p>Central London Community Healthcare NHS Trust (England)</p> <p>Study recruitment: Participants with COPD were identified by the Respiratory Consultant and recruited from three settings using convenience sampling:</p> <ul style="list-style-type: none"> i) respiratory outpatient clinics (hospital-based)/ community respiratory clinics, ii) pulmonary rehabilitation programmes (at multiple locations), or iii) iii) post-pulmonary rehabilitation gym sessions. <p>The consent also requested permission to access the pulmonary rehabilitation and medical notes for additional information.</p> <p>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</p> <p>Study sampling: convenience sampling</p> <p>Ethical approval: Yorkshire & The Humber – Leeds West ethics Committee (ref: 12/YH/0234).</p>	<p>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.</p> <p>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.</p> <p>Mann Whitney statistical tests were used for non-parametric comparisons <u>and chi-square tests for categorical comparisons.</u></p>	<p>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.</p> <p>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)</p>

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].	<p>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</p> <p>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</p> <p>Ethical Approval: NHS Ayrshire and Arran (Scotland), R&D management approval</p>	<p>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.</p> <p>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). <u>Repeated measures ANOVA with a Greenhouse-Geisser correction was undertaken</u></p>	<p>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).</p> <p>Limitations: Small sample size, secondary analysis of retrospective data, no control group, some data not available for all variables for each participant.</p>
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	<p>Study design and location: secondary retrospective analysis of existing, anonymised data collected as part of routine care in a pulmonary rehabilitation centre, NHS Lothian</p> <p>Study recruitment: As part of the rehabilitation programme, participants with COPD were invited to take part in the 6-week programme, twice-weekly</p>	<p>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</p>	<p>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</p>

		<p>self-management programme, comprising individualised exercise programme and education.</p> <p>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.</p> <p>Ethical approval: NHS Lothian, R&D approval obtained)</p>	<p>details of the appointment type (Baseline, 6 months or 12 months) were analysed for this report.</p> <p>Patients were unmatched 'events' and 231 PAM measurements were available in total for analysis from the 274 attendees.</p> <p>n=128 measurements at baseline, n=65 measurements at 6 mths, and n=38 measurements at 12 mths.</p> <p>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</p> <p>Details on age, severity, gender and medical history were not available, all participants had a diagnosis of COPD and were eligible for PR.</p> <p><u>ANOVA with post hoc Tukey HSD comparisons were undertaken.</u></p>	<p>(p<0.001), and baseline and 12 months (p<0.001). Figure 1c shows the PAM scores at the three timepoints.</p> <p>Limitations: secondary analysis of retrospective data, no control group, some data not available for all variables for each participant.</p>
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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 of 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

<p>intervention based on patient activation and tailoring of stroke self-management support.³²</p>	<p>Time since stroke: 1-6mths = 12; 7-12 mths = 8 cognitive impairment (n=12), MRS moderate to mod severe disability (n=10)</p>	<p>Phase 1 (development of intervention)</p> <p>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.</p> <p>Phase 2 involved piloting the self-management intervention (reported elsewhere).³²</p> <p>Ethical approval: 12/WS/0103 West of Scotland Committee 3</p>		<p>characteristics associated with lower PAM levels (e.g. Levels 1 and 2, as shown in Figure 1).</p> <p>Limitations: small sample size, convenience sample, PAM score not assessed following intervention because of short intervention period, sample selection by stroke nurses (possible gatekeeping).</p>
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