UNIVERSITY OF LEEDS

This is a repository copy of *A Patient Reported Experience Measure (PREM) for use by older people in community services*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/88491/

Version: Accepted Version

Article:

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

A Patient Reported Experience Measure (PREM) for use by older people in community services

E A Teale[1], JB Young[1]

[1]Academic Unit of Elderly Care and Rehabilitation, Bradford Institute for Health Research, Bradford, West Yorkshire, UK

Abstract:

Background:

Intermediate care (IC) services operate between health and social care and are an essential component of integrated care for older people. Patient Reported Experience Measures (PREMs) offer an objective measure of user experience, and a practical way to measure person-centred, integrated care in IC settings.

Objective:

To describe the development of PREMs suitable for use in IC services, and to examine their feasibility, acceptability and scaling properties.

Setting:

131 bed-based and 143 home-based or re-ablement IC services in England.

Methods:

PREMs for each of home- and bed-based IC services were developed through consensus. These were incorporated into the 2013 NAIC and distributed to 50 consecutive users of each bed-based and 250 users of each home-based service. Return rates and patterns of missing data were examined. Scaling properties of the PREMs were examined with Mokken anaylsis.

Results:

1832 responses were received from users of bed-based, and 4627 from home-based services (return rates 28% and 13% respectively). Missing data were infrequent. Mokken analysis of completed bed-based PREMs (1398) revealed 8 items measuring the same construct and forming a medium strength

(Loevinger H 0.44) scale with acceptable reliability (ρ = 0.76). Analysis of completed home-based PREMs (3392 records) revealed a medium-strength scale of 12 items (Loevinger H 0.41) with acceptable reliability (ρ=0.81).

Conclusions:

The two PREMs offer a method to evaluate user experience of both bed- and home-based IC services. Each scale measures a single construct with moderate scaling properties, allowing summation of scores to give an overall measure of experience.

Key Words: Intermediate Care, Audit, Patient Reported Experience, Item Response Theory

Word Count: 2,359

Key Points:

- IC-PREMs offer an objective measure of user experience of Intermediate Care services
- The IC-PREM may identify areas for service development to improve the delivery of intermediate care
- Individual item scores from the IC-PREMs may be summed to provide an overall user-experience score

3

-

Introduction:

Health and care services internationally are planning and implementing services to address the increasing proportion of older people within populations. Developing and improving community services is a central component of this response and intermediate care is a generic term that describes an important grouping of similar services providing "care closer to home" for older people. Key functions of intermediate care services are to provide an alternative for emergency hospital admission, to expedite timely discharge from hospital and, through a short period of intensive support, prevent admission to long term institutional care. As these services operate between secondary and primary care within the NHS, and between the NHS and local government, it is important that separate clinical governance structures are in place to monitor the quality and safety of services. In England, this has been addressed in part through the National Audit of Intermediate Care[1]. It was considered important in the audit design to include information obtained directly from service users. One type of measure considered was to use a service satisfaction questionnaire. However, this approach has been criticised as lacking rigor and providing false reassurance of service quality as service users typically report high levels of satisfaction but may have received poor care[2]. On the other hand, Patient Reported Experience Measures (PREMs) are considered more objective as the questions are designed to encourage the user to describe their actual experience of the care received [3]. Effective intermediate care services are considered an essential mechanism for improving the integration of health and care services for older people[4] and improving outcomes for the health and care system as a whole. Integrated care has been defined as care that is "person centred and co-ordinated" [5]. Service users are in the strongest position to comment on this practical definition of integration and PREMs have therefore been included as one of five key metrics to assess integration nationally in England [6]. This paper describes the development of PREMs

suitable for use in intermediate care community services. The main findings from the IC-PREMs are

reported in the 2013 National Audit of Intermediate Care report[1]. We present data describing the

feasibility and acceptability of the measures, examine the extent to which the PREM items may be

converted to a numerical score (the scaling properties of the questionnaires), and offer suggestions

for future improvements.

Methods:

Intermediate care services are heterogeneous but can be broadly divided into bed-based (for

example community hospitals) and home-based (for example hospital-at-home) services. To reflect

these sub-types of intermediate care, two PREMs were developed.

Development of the PREMs

The two intermediate care PREMs (IC-PREMs) were developed by a Delphi consensus process

performed by email with a panel of intermediate care experts (the National Audit of Intermediate

Care (NAIC) Steering Group); a panel of intermediate care practitioners (NAIC Participant Reference

Group); a patient and public group (co-ordinated by the Patients' Association); and representation

from the Picker Institute.

Forty-one questions from the 2008 Picker Adult Inpatient Survey bank of 80 questions had face

validity for bed- or home-based intermediate care services[7]. These questions had therefore all

previously satisfied cognitive and acceptability testing procedures. These were circulated to the

consensus group (29 people) with instructions to identify items felt relevant to each of home- or

bed-based intermediate care settings. Suggestions for new questions to cover aspects of

intermediate care not encompassed by existing items were requested at this stage. Sixteen

responses resulted in two long-lists of questions: including suggestions for novel questions, there

were 45 candidate questions for bed-based services, and 40 for home-based services. In the second round, the two long-lists of questions were re-circulated to the panels with instructions to identify the 20 most relevant questions for each of the two IC-PREMs. Fifteen responses were obtained. From these responses, the fifteen questions most frequently identified as relevant were extracted and formed the IC-PREMs (figure 1). Wording of the questions was modified to create 'I' statements in line with the recommendations of National Voices [5]. The questionnaires were sent to Patients' Association Ambassadors and five recent users of intermediate care services for comments and feedback. Feedback regarding language, layout, font and clarification of content were incorporated into the final questionnaires. The final versions of the PREMs were field tested in three sites prior to adoption in the audit, and are provided as an online supplement [ONLINE SUPPLEMENT]

IC-PREM testing

The IC-PREMs were incorporated into the 2013 NAIC [1]. Approximately half of the NHS in England registered to participate in the audit (92 commissioners; 202 provider organisations; 535 intermediate care services) and included separate organisational and service user components. The service user audit occurred between May and August 2013. For bed-based intermediate care services, the IC-PREM was included as part of the service user questionnaire pack. At discharge, the IC-PREM (bed-based) was detached and handed to 50 consecutive bed-based service users from each participating service. Recipients were provided with a pre-paid envelope to return the completed PREM questionnaire. For the participating home-based intermediate care services (including both social care re-ablement and health care hospital-at-home services), service managers were sent 250 PREM questionnaires and pre-paid envelopes to distribute to service-users at discharge from their service. A barcode linked the PREM form to the service, but the PREM forms contained no identifiers of individual service users. As PREM returns were anonymous and results

used for service evaluation/improvement, ethical approval from a research ethics committee was not sought.

Analysis

The bed-based and the home-based PREM were considered separately. The questions each had between 2, 3 or 4 response categories but the responses were summarised to provide a dichotomous 'problem score', the approach suggested by the Picker Europe[8]. Using this scoring method, user responses indicating that care could have been improved are coded as a 'problem' (e.g. where an aspect of care did not occur, occurred sometimes, or where there was poor experience of care). In contrast, where good care was always received, where particular aspects of care were not applicable, or where poor care was never experienced, were coded as 'no problem' and ascribed a score of '1'. Higher scores indicate a better report of care experience, with lower scores highlighting areas for service improvement.

Acceptability and feasibility of the two IC-PREMs were assessed by return rates and the volumes and patterns of missing data. Scalability of the IC-PREMs was explored with Mokken analysis (non-parametric item response theory (NIRT) [9]). For these analyses, "don't know" responses were coded missing. Records with missing responses were excluded for the purposes of the Mokken scaling analyses. In order for a set of questions to form a meaningful scale, they must all measure the same underlying construct – the latent trait, in this case user-experience. This property of a set of questions is called unidimensionality and is assessed through calculation of Loevinger H statistics[10]. An item Loevinger H coefficient (H_i) greater than 0.3 suggests the item should be retained in the scale, providing it makes clinical sense. Stepwise item selection algorithms using the *mokken* package in R freeware were used for this procedure[11]. A summary Loevinger H co

efficient for the overall scale (H) was also calculated: 0.3-0.4 indicates a weak scale, 0.4-0.5 is moderate and >0.5, a strong scale.

For Mokken analysis to be valid, each questionnaire item must meet the assumption of monotonicity: the probability of an individual answering a question positively increases as the amount of the underlying characteristic being measured increases[10]. Thus, if the monotonicity assumption is met, the probability of a service user indicating a good experience of their care for a specific question increases as their overall experience of care increases.

Valid Mokken analysis requires items to be locally independent: answers from previous questions should not influence subsequent responses. This is particularly relevant where 'learning' from questions may occur over the course of a test [10]. The underlying trait of 'experience' should not be influenced in this way and we have therefore assumed local independence of items.

 Providing each question meets monotonicity, unidimensionality and local independence assumptions, a total score for the instrument may be calculated by summing the responses from each question. Crohnbach's alpha is considered to underestimate reliability of scales in NIRT analyses [12]. Having confirmed non-intersection of item characteristic curves, the co-efficient of reliability rho (ρ) was calculated [10]; a cut off value of 0.7 was taken to indicate acceptable reliability of the scale [13]. All analyses were performed using R freeware [11].

Results

Two hundred and two providers of IC services participated in the audit. Table 1 shows the number of services, participants and responses to the PREM questionnaires. Return rates for the bed-based, home based, and re-ablement PREM questionnaires were 28.0%, 12.6% and 13.7% respectively. An overall return rate of 15.3% was achieved (table 1).

Bed Based PREM

Missing data for individual questions were infrequent: fewer than 5% of responses for all questions were missing apart from the question "*the staff that cared for me in this service had been given all the necessary information about my condition or illness by the person who referred me*", where 1.0% of responses were missing and 12.0% '*don't know*'.

After removal of records with absent responses, there were 1398 questionnaires available for Mokken analysis. Eight items have H_i values exceeding 0.3, and these are shown in Table 2. The overall Loevinger H for this scale of 8 items is 0.44 indicating moderate scaling properties. For these 8 items, there is no violation of monotonicity assumptions. The coefficient of reliability (ρ) is 0.76 indicating acceptable reliability [13] (there were no invariant item ordering violations to suggest intersection of item response curves). Response scores from these eight questions may be summed to give a total score out of 8. The remaining items did not form a separate subscale on further analysis, and these items were discarded.

Home based PREM

In common with the bed-based PREM, missing data were infrequent (<6%) apart from the same question relating to *staff* having received *the necessary information from the* referrer for which 1.7% or responses were missing, and 11.4% '*don't know*'.

After removal of incomplete records, 3392 responses remained for analysis. Items with Loevinger H coefficients (H_i) greater than 0.3 are shown in table3. The item *appointment times were convenient* had an H_i of 0.30; removal of this item resulted in improved H_i values for the remaining items in the scale, and the item was therefore excluded. Twelve items were retained in the scale. Monotonicity assumptions for these 12 items were met. The reliability of the scale (ρ) is 0.81 (there were no significant violations of invariant item ordering), and the overall scale H was 0.41 indicating

9

moderate scalability. Individual item response scores for these questions may be summed to give an overall 'experience' score out of 12.

Discussion

Understanding services from a user perspective is critical in the delivery of person-centred, integrated care. Successful rehabilitation should be based on goal directed and individualised care [14]. Person-centred care is therefore especially important in intermediate care services where rehabilitation is a major component of care. The systematic and routine evaluation of person-centred care requires robustly developed assessment tools. The two intermediate care PREMs were developed with these requirements in mind. They utilised existing questions that had undergone prior sense and field testing. Specific question selection involved a consensus process with panels of patients and public, practitioners, managers and academics. The PREMs were developed to be used across a spectrum of intermediate care services for the purposes of local service improvement rather than between service comparisons.

Return rates, acceptability, and scalability were investigated by incorporating the PREMs into the 2013 National Audit of Intermediate Care[1]. This was a large audit involving over 250 services and over 6,000 patients. Return rates for both the bed-based and home-based PREMs were low (28% and 13% respectively), though bed-based return rates were comparable with other national surveys (Friends and Family Test 36.9% [15]). Higher return rates for the bed-based survey may reflect the different distribution methods of the questionnaires: PREMs for bed-based service users were distributed at discharge by hand; home-based service users received their questionnaires by post or by hand. Two hundred and fifty questionnaires were distributed to the manager of each home-based service; the actual number of these questionnaires distributed to users to complete was not

recorded. The seemingly low return rates for the home-based PREM may be explained by fewer than expected users receiving questionnaires to complete. The NAIC was an anonymous survey and demographic information for individual service-users cannot be linked to their PREM responses. Therefore, whether service users completing the PREM were representative of typical users of intermediate care could not be assessed, a possible source of selection bias.

The PREMs were acceptable to users, as reflected in the generally low rates of missing data. The findings also indicated that the IC-PREMs were sensitive to differentiated care experiences. The overall care experience was excellent (>95% of patients reported they had been treated with dignity and respect) but more focussed questions relating to the experience of involvement with decision processes (treatment decisions, discharge planning and goal setting) was weaker. This is an important aspect of person-centred care and the information is highly relevant to professionals and service managers seeking to improve their services. Indeed, patient participation in care planning is increasingly recognised as a key contributor to patient safety and high quality care [16]. Our findings suggest that the IC-PREMS might have utility in informing these types of service improvement decisions.

The IC-PREMs were generally well completed (<6% missing or don't know responses). However, the question "*staff that cared for me in this service had been given all the necessary information about my condition or illness by the person who referred me*" was poorly completed in both bed- and home- based IC-PREMs (12% and 11.4% of respondents reporting "*don't know*" to this question). It is perhaps not surprising that individuals in receipt of a service felt unable to comment on whether information about their condition passed between healthcare professionals was adequate. Re-wording to reflect the service-user's perception of staffs' understanding of their condition may improve acceptability of this item.

Mokken analysis was performed to examine the ordinal scaling properties of the two IC-PREMs. This determined that eight items for the bed-based PREM, and twelve items for the home-based PREM, were related to a single construct of user-experience. Both scales are moderate in terms of their scaling properties, and important modelling assumptions were met. This means it is valid to combine the response scores for these questions to produce an overall service experience score. This could be utilised in the future to facilitate within and between service comparisons. As Mokken analysis is a non-parametric technique, any subsequent statistical analyses of total PREM scores must, in turn, be non-parametric.

Conclusion

Two IC-PREMs have been developed and offer a method routinely to evaluate the delivery of person centred care in home- and bed-based intermediate care settings. For each IC-PREM, Mokken analysis has identified a subgroup of items where scores may be summed to give an overall measure of 'user experience'. The IC-PREMs therefore offer a unique and quantifiable insight into the experience of users of intermediate care services. Our findings suggest that the IC-PREMS might have utility in identifying areas for service development, such as user involvement in treatment decisions, to improve the delivery of co-ordinated and integrated intermediate care.

Table 1 Number of services, participants and responses to the PREM questionnaires

	Number of services	Target number of participants	PREMs returned	Return rate (%)
Bed-based	131	6550	1832	28.0%
Home-based[1]	95	23750	2983	12.6%
Re-ablement	48	12000	1644	13.7%
Overall	274	42300	6459	15.3%

[1] Home based and re-ablement services are considered together for the purposes of the Mokken analysis

Table 2 Loevinger H_i coefficients for Mokken analysis of the bed-based PREM

	Item	H_i[1]
2	Staff have sufficient information	0.45
4	Involvement in goal setting	0.42
7	Questions answered	0.43
8	Confidence in staff	0.49
10	Involved in discharge decisions	0.45
11	Home circumstances considered	0.43
12	Information provided for family	0.41

15	Treated with dignity	0.47
	Overall (H)	0.44

[1] The Loevinger H_i is a measure of unidimensionality: whether or not an item is measuring the underlying trait. 0.3-0.4 indicates a weak scale, 0.4-0.5 is moderate and >0.5, a strong scale.

Table 3 Loevinger H_i coefficients for Mokken analysis of the home-based PREM

	Item	H_i[1]
2	Staff have sufficient information	0.37
3	Aware of goals	0.35
4	Involvement in goal setting	0.39
5	Aware of how to contact staff	0.34
7	Questions answered	0.39
8	Confidence in staff	0.46
10	Involved in decisions to discharge	0.52
11	Given enough notice about discharge	0.47
12	Information provided for family	0.42
13	Requirement for additional equipment discussed	0.36
14	Discussion regarding further services after discharge	0.34
15	Treated with dignity and respect	0.46

	Overall (H)	0.41

[1] The Loevinger H_i is a measure of unidimensionality: whether or not an item is measuring the underlying trait. 0.3-0.4 indicates a weak scale, 0.4-0.5 is moderate and >0.5, a strong scale.

Figure 1: Consensus process for development of PREMs
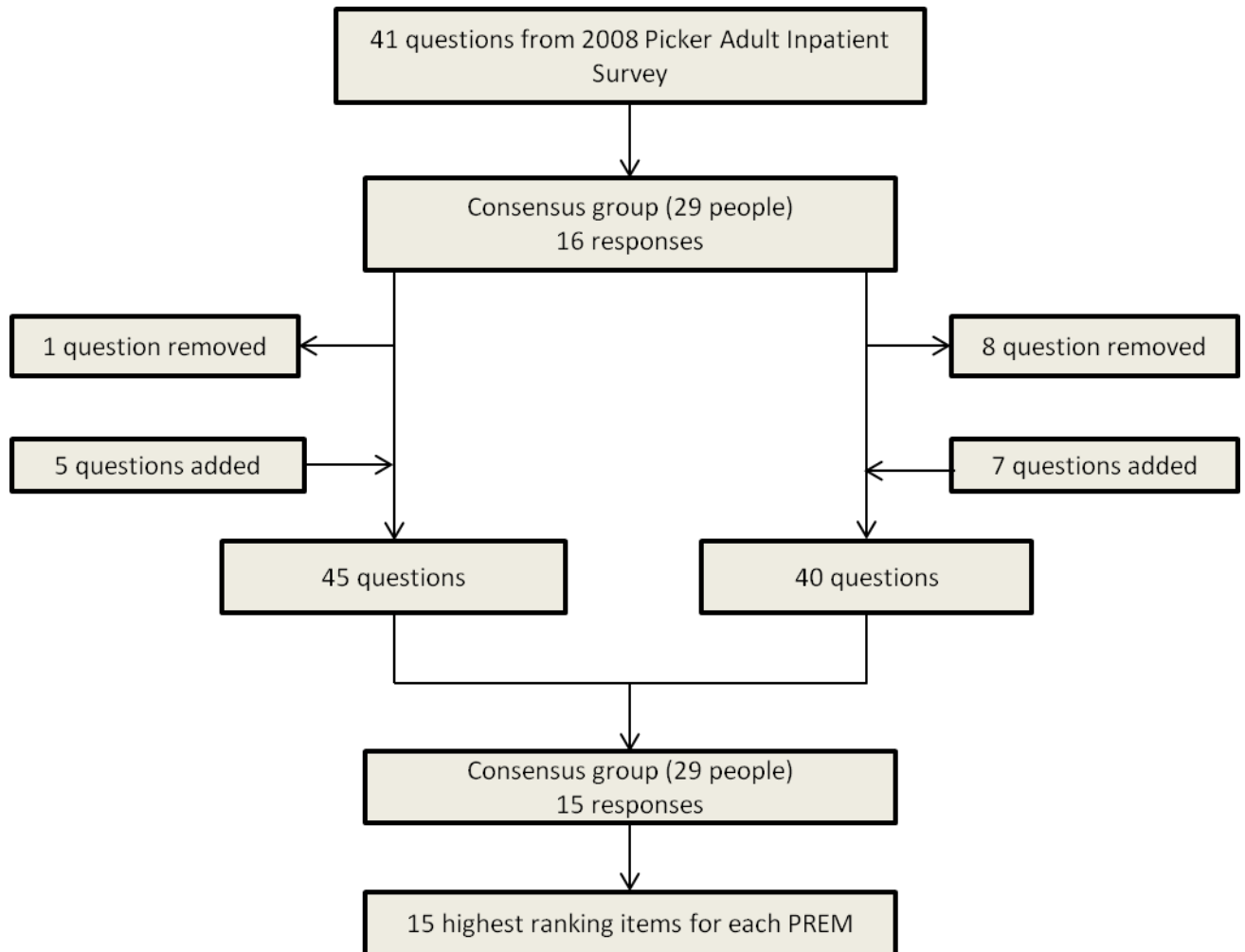
Reference List

1. NHS Benchmarking Network and NAIC Steering Committee. The National Audit of Intermediate Care Report. (2013). Available from: http://www.nhsbenchmarking.nhs.uk/CubeCore/.uploads/icsurvey/NAIC%202013/NAICNationalReport2013.pdf. Accessed 14/4/2014.

2. Coulter A, Fitzpatrick R, and Cornwell J. The King's Fund. The Point of Care. Measures of patients' experience in hospital: purpose, methods and uses. (2009). Available from: http://www.kingsfund.org.uk/sites/files/kf/Point-of-Care-Measures-of-patients-experience-in-hospital-Kings-Fund-July-2009_0.pdf. Accessed 14/4/2014.

3. Whelan PJ, Reddy L, Andrews T. Patient satisfaction rating scales v patient-related outcome and experience measures. The Psychiatrist. 2011; 3532-33.

4. Bennett L and Humphries R. The Kings Fund. Making best use of the Better Care Fund: spending to save? (2014). Available from: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-best-use-of-the-better-care-fund-kingsfund-jan14.pdf. Accessed 14/4/2014.

5. National Voices. Integrated care: what do patients, service users and carers want? (2012). Available from: http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/principles_for_integrated_care_20111021.pdf. Accessed 14/4/2014.

6. NHS England. Developing Plans for the Better Care Fund: Annex to the NHS England Planning Guidance. (2013). Available from: http://www.england.nhs.uk/wp-content/uploads/2013/12/bcf-plann-guid.pdf. Accessed 14/4/2014.

7. The Picker Institute Europe. Adult Inpatient Survey 2013. (2013). Available from: http://www.nhssurveys.org/surveys/705. Accessed 14/4/2014.

8. Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. International Journal for Quality in Health Care. 2002; 14(5):353-358.

9. van Schuur WH. Mokken Scale Analysis: Between the Guttman Scale and Parametric Item Response Theory. Political Analysis. 2003; 11:139-163.

10. Stochl J, Jones PB, Croudace TJ. Mokken scale analysis of mental health and well-being questionnaire item responses: a non-parametric IRT method in empirical research for applied health researchers. BMC Medical Research Methodology. 2012; 12:74 doi:10.1186/1471-2288-12-74

11. R Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing. 2014. Vienna, Austria. http://www.R-project.org.

12. Sitjtsma K and Molenaar IW. Reliability of test scores in nonparametric item response theory. Psychometrika. 1987; 52(1):79-97.

13. Kempen GIJM and Suurmeijer TPBM. The development of a hierarchical polychotomous ADL-IADL scale for noninstitutionalized elders. Gerontologist. 1990; 30(4):497-502.

14. Young J. Caring for Older People: Rehabilitation and Older People. British Medical Journal. 1996; 313:677-681.

15. NHS England Statistical Commentary Friends and Family Test Data (Inpatients, A&E, Maternity) August 2014. Available from http://www.england.nhs.uk/statistics/wp-

content/uploads/sites/2/2013/07/Patient-FFT-Stats-Commentary-August.pdf

Accessed 13/10/2014

16. National Advisory Group on the Safety of Patients in England. A promise to learn - a commitment to act: Improving the safety of patients in England. (2013). Available from:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf. Accessed 14/5/2014.