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The Right PREM™: Rasch analysis of a new patient reported experience measure for use by older people in hospital

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Abstract

Healthcare rights exist to protect older people from harm and to empower older people to participate in their care with independence, choice and control. Multiple investigations revealing abuse provide evidence that older people's rights are being breached. Older people must have the opportunity to report on their experience of care against their rights. The Right PREM™ is a new instrument designed to measure older people's experience of care against their healthcare rights. The objective of this cross-sectional validation study was to assess the psychometric properties of a new instrument to measure the experience of care consistent with the healthcare rights of older people in the hospital setting. Data were collected from older people who were current hospital inpatients of medical wards in four South Australian metropolitan hospitals. The Rasch model was used to assess the psychometric properties of the patient version of The Right PREM™. The analysis was performed using the Winsteps® software program. Two hundred older patients completed the 50-item questionnaire. During the process of analysis, four items were removed as they did not fit the model and a further 11 items were removed due to high residual correlations. The final 23 items had a Person Separation Index of 2.23, a Person Separation Reliability Coefficient 0.83, an Item Separation Index of 7.70 and an Item Separation Reliability Coefficient of 0.98. Rasch analysis of the patient version of The Right PREM™, based on a robust sample, demonstrated this new instrument is psychometrically sound and warrants ongoing development.

Keywords

Healthcare rights, hospital, Patient Reported Experience Measure, older people, psychometrics, questionnaire, Rasch measurement

Introduction

Australia, along with most other countries, is experiencing a rapid ageing of the population.¹ As a proportion of the population, older people, particularly those aged 80 and over, have higher rates of overnight hospital admissions.¹ Providing care to older people is now core business for hospitals. Knowledge of the hazards of hospitalisation for older people is not new.² Many older people have multiple morbidities, including cognitive impairment, placing them at a greater risk of harm.³ Internationally, human and healthcare rights have been developed to protect people from harm.⁴

In 2019, the Charter of Healthcare Rights was revised in Australia.⁵ Providing care consistent with these rights should reduce the risk of harm. Safeguarding vulnerable people, reliant on others for care, requires the implementation of many different strategies.⁶ These strategies must include asking the person to report their experience of care. Recognition of the importance of this strategy is reflected in the growing international interest in Patient Reported Experience Measures (PREMs).⁷ Our

research brings together these two important aspects of safeguarding: using PREMs to understand the translation of healthcare rights into practice.

There are many reasons older people in hospital are unable to complete a PREM; the development of a Carer Reported Experience Measure (The Right CREM™) was an essential part of this research study; the findings of The Right CREM™ will be the subject of a separate paper.

Study rationale

In the past decade, there has been great advancement in the development of Patient Reported Outcome Measures (PROMs), mostly disease-specific measures designed to examine health outcomes.⁸ The development of PREMs has not kept pace with the development of PROMs.⁷ Measuring 'experience' can be more elusive than measuring an 'outcome,' such as recovery from a specific type of surgery. In the same way a generic outcome measure would not reveal as much as a disease-specific PROM, a generic measure of patient experience is less likely to reveal as much as a PREM developed specifically for that patient group.

The Australian Hospital Patient Experience Question Set (AHPEQS)⁹ has a vital role as the national generic PREM. The items must be broad to accommodate the needs of all adult patients. A generic PREM might not meet the specific needs of older people.

The Right PREMTM evolved from the concept of dignity in care. In 2006, in response to horrific revelations of abuse of older people in care, the 10 Principles of Dignity in Care were used to undergird the United Kingdom's

Dignity Campaign. Dignity is core to human and healthcare rights.¹⁰ The 10 Principles of Dignity in Care were used as the conceptual framework for the development of The Right PREMTM. The 10 Principles were examined for content in common with the 2019 revision of the Australian Charter of Healthcare Rights⁵ and the close alignment in core content between them was discovered (Table 1 lists the 10 Principles in the left column matched to the seven constructs of the Australian Charter of Healthcare Rights in the right column).

Table 1. The 10 Principles of Dignity in Care (left) and the Australian Charter of Healthcare Rights (right)

10 Principles of Dignity in Care ⁵¹	Australian Charter of Healthcare Rights ⁵
Aligns with Principle 5 'Needs and wants'	Access - Healthcare services and treatment that meets my needs
Principle 1. Zero tolerance of all forms of abuse.	Safety - Receive safe and high-quality health care that meets national standards - Be cared for in an environment that is safe and makes me feel safe
Principle 2. Support people with the same respect you would want for yourself or a member of your family. Principle 3. Treat each person as an individual by offering a personalised service.	Respect - Be treated as an individual, and with dignity and respect - Have my culture, identity, beliefs and choices recognized and respected
Principle 4. Enable people to maintain the maximum possible level of independence, choice and control.	Partnership - Ask questions and be involved in open and honest communication, make decisions with my healthcare provider, to the extent that I choose and am able to.
Principle 5. Listen to and support people to express their needs and wants.	Information - Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent. - Receive information about services, waiting times and costs. - Be given assistance, when I need it, to help me to understand and use health information. - Access my health information. - Be told is something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe.
Principle 6. Respect people's privacy.	Privacy - Have my personal privacy respected and have information about me and my health kept secure and confidential.
Principle 7. Ensure people feel able to complain without fear of retribution.	Give feedback - Provide feedback or make a complaint without it affecting the way I am treated, have my concerns addressed in a transparent and timely way, and share my experience and participate to improve the quality of care and health services.
Principle 8. Engage with family members and carers as care partners.	As per Partnership above - Include the people that I want in planning and decision-making.
Principle 9. Assist people to maintain confidence and a positive self-esteem.	Aligns with the Charter's construct of 'Respect'
Principle 10. Act to alleviate people's loneliness and isolation.	Aligns with the Charter's construct of 'Respect'

Three important reasons are given for shifting the language of the PREM we have developed from ‘dignity’ to ‘rights’: First, the alignment of core content between the 10 Principles and the seven constructs of the Australian Charter of Healthcare Rights (Table 1); second, to avoid being embroiled in the fluctuating fashions in terminology for care (‘patient-centred,’ ‘person-centred,’ ‘relationship-centred,’ ‘individualised’ and ‘compassionate’ and ‘dignity’ are the most common); third, to promote the unquestionable message of ‘Rights.’ There is only one definition of the Australian Charter of Healthcare Rights.⁵ The content of the Charter is openly accessible to all; it is written in plain English and available in other languages.⁵ Use of the term ‘Rights’ is consistent with the shift in language being used to promote care of people with cognitive impairment.¹¹ To promote health literacy, there should be a shift away from bureaucratic and poorly defined terms such ‘person-centred’ care¹² and a shift toward the consumer empowering message of Rights contained in the Charter.

We have trademarked this new instrument The Right PREM™ for the purpose of using the name in the development of a suite of measurement tools and resources, not for the purpose of charging for use of the tool. The process of item development for The Right PREM™ has been published separately.¹³

Where PROMs have advanced the use of ‘modern’ methods of psychometric analysis, using techniques such as the Rasch method, PREMs have been slow to shift from the use of the traditional methods of ‘classical test theory’ (CTT).¹⁴ An extensive literature exists describing the debate between the use of ‘traditional’ versus ‘modern’ methods of analysis in instrument development.^{14–16} At the heart of the debate is the criticism that the methods used in CTT, which include factor analysis and Cronbach’s alpha, are based on inaccurate assumptions. These assumptions, that the data can be analysed with techniques suitable for interval level data and that responses can be summed into a total score, are sources of criticism of CTT.¹⁴ Rasch analysis is a method for constructing, from categorical responses (i.e., Likert scales), linear systems within which item difficulty and person ability can be measured unambiguously.¹⁷

The subject of this paper is the further development and psychometric evaluation, using Rasch analysis, of a new instrument, which was shaped by the 10 Principles of Dignity in Care and the Australian Charter of Healthcare Rights, which has been given the name The Right PREM™.

Study aims

The aim of the study was to assess the unidimensionality, construct validity and internal reliability of the patient version of The Right PREM™ using Rasch analysis.

Methods

Item generation and response format

A 57 person Delphi panel of consumers, clinicians and academics gained consensus on the 69-items and the response format to be used in a pilot test of the questionnaire; this process is reported in detail elsewhere.¹³ The pilot study was undertaken in a major metropolitan hospital in South Australia, where 32 inpatients and 20 carers participated in a cognitive interview while completing the questionnaire. The questionnaire was reduced from 69 to 50 items following the feedback on content and face validity provided by participants, which guided item revision and removal.

The questionnaire

The 50-item questionnaire was administered in paper (hard copy) format. The questionnaire was printed in large font (14 for text and 18 for headings) to enable ease of reading by older people.

The response format of ‘Never,’ ‘Rarely,’ ‘Sometimes,’ ‘Often’ and ‘Always’ (NRSOA) was used as they are simple and easy to understand, but also because there are few options for “frequency” type responses.¹⁸ Thirty-one (of the 50 items) only included the response categories NRSOA. Six items (3.4, 3.5, 8.1, 8.2, 8.3 and 8.4) included NRSOA and ‘Not Applicable’ (N/A). One item (4.4) included NRSOA and ‘Unsure’. Five items (1.2, 1.5, 3.2, 5.5 and 8.5) included NRSOA and an additional response category unique to that item. Seven items (4.5, 7.2, 7.3, 7.4, 7.5, 10.4 and 10.5) had non-scalable response options (i.e., Yes, No, Unsure). Full details of the 50 items and their response categories are provided in the Supplementary Material (Appendix S1).

Design

The Right PREM™ was developed in three stages: 1) the Delphi panel developed the item pool,¹³ which was 2) tested in a pilot study, and 3) this paper reports on a cross-sectional validation study, using data from the 50-item questionnaire, which was completed by older hospital inpatients.

The STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) checklist¹⁹ was used to demonstrate the quality of the study design (Appendix - STROBE Checklist).

Participants and setting

Inclusion and exclusion criteria

Eligible participants were current inpatients admitted to medical wards of four South Australian metropolitan hospitals. The inclusion criteria for patient participants were age 65 and over (50 for Aboriginal and Torres Strait Islander people), willing and able to give informed consent to participate in the study or who had a carer who could legally give consent on their behalf.

The ward Shift Co-ordinator and the patient's direct care nurse were consulted as to which patients could be approached and whether the individual had capacity to provide consent. This was assessed by the researcher during the process of gaining consent and as the participant completed the questionnaire. Patients who did not speak English were eligible for inclusion, with specific funding obtained to cover the cost of interpreters.

The research excluded people who were unable to give consent and who did not have a carer who could legally give consent on their behalf. Patients requiring Personal Protective Equipment precautions²⁰ were excluded. The study also excluded patients who were in the last days of life.

Ethical considerations

Ethical approval for the study was granted by the Central Adelaide Local Health Network Ethics Committee (HREC/17/TQEH/91) with reciprocal approval from the Southern Adelaide Local Health Network's Ethics Committee. Participants were required to read the Participant Information and Consent Form and sign the consent. The consent form was co-signed by the researcher and participants were provided with a photocopy of the signed consent form.

Sample size

Linacre (2002)²¹ proposes at least 10 observations per response category for polytomous models (i.e., models with more than two response categories) and notes a sample size of 50 would be a minimum requirement for polytomies, ranging upward to 500 for studies requiring robust confidence due to high stake outcomes. A sample size of 150 is required to have 99% confidence that no item calibration would be more than $\pm 1/2$ logit away from its stable value.²² Based on Linacre's evidence, the target sample size for this study was 150 patients.

Data Collection

Data collection process

Data collection took place from October 2018 to February 2019. Prior to commencing data collection at each site, meetings were scheduled with Clinical Directors and Nurse Managers of each participating ward to brief them on the research and the data collection process and make

opportunities available for in-service education to ward staff to explain the research study.

Once data collection commenced, the lead author (LH) was present on the allocated wards, in the participating hospitals, to recruit, consent, facilitate administration of, and collect the questionnaires from participants. On each data collection day, LH would introduce herself to the Shift Co-ordinator/Team Leader of each participating ward and ask them to consider which patients might be suitable to undertake the questionnaire. The Shift-Co-ordinator/Team Leader would provide a patient list and note which patients might be suitable and which patients should not be approached.

The author (LH) would then circulate through wards and locate the nurse looking after the patients identified by the Shift Co-ordinator/Team Leader. If the nurse felt it was appropriate to speak with the patient, the nurse would check with the patient, and, if the patient agreed, the nurse would then introduce LH to the patient. The author (LH) would go through the Research Project Information Sheet with the patient and, if they agreed to participate, would obtain their consent.

The author (LH) would hand the paper questionnaire to each participant and collect the questionnaire when the participant had completed the questionnaire. LH offered to sit with the participant, if they wanted, while they completed the questionnaire. LH explained she was happy to help explain any aspect of the questionnaire, but she was clear her role was not to have any part in determining the response to the items.

Data analysis

The role of quantitative data analysis in instrument development is to assess the unidimensionality (does it measure a single construct), validity (does it measure what it is intended to measure) and reliability (does it measure consistently) of the data collected from the sample of participants who have completed the questionnaire.²³ The challenge in measuring experience of care is the requirement to measure the construct of healthcare rights (known as the latent variable), because of the difficulty in measuring the experience of care consistent with healthcare rights directly.²⁴ Rasch analysis was used to assess unidimensionality, construct validity and internal reliability.

In addition to the Rasch analysis, basic descriptive statistics were analysed, including the floor and ceiling effects.

Rasch analysis

Rasch analysis is a method for constructing, from categorical responses (i.e., Likert scales), linear systems within which item difficulty and person ability can be

measured unambiguously.¹⁷ This is achieved by positioning persons (completed questionnaires) and items (questions of the questionnaire) on a logit scale (log-odds unit), which represents the log odds ratio of the probability a person will select a particular response option of an item over 1- the same probability.¹⁵ Through logarithmic transformation, Rasch analysis transforms ordinal categorical data into interval level data.

Rasch analysis was undertaken using the Rating Scale Model (RSM).²⁵ The justification for using the RSM was based on the fact that the response categories for the items used in the analysis all shared the same rating scale ('Never,' 'Rarely,' 'Sometimes,' 'Often,' 'Always').

The Winsteps® software program (Linacre, J. M. 2019, version 4.4.5) was used to perform the Rasch analysis.²⁶ A 'valid' questionnaire should demonstrate unidimensionality, meaning the instrument measures a single underlying construct (the latent variable) and each item 'fits' the underlying construct.²⁷ To determine if the data fit the Rasch model, an assessment was made of:

- i. **Category Threshold Order:** A 'threshold' represents the transition between response options. It occurs when the likelihood of endorsing one category becomes the same as the likelihood of endorsing the next category.²⁴ If persons completing the questionnaire do not use the full range of response categories, this can cause disordered thresholds. Items with disordered thresholds might misfit the unidimensional model.
- ii. **Person Separation Index (PSI) / Person Separation Reliability Coefficient (PSRC):** To fit the Rasch model, the PSI should be > 2.0 and the PSRC > 0.8 .²⁸ These results would indicate that the item distribution is adequate to reliably generate person hierarchy, that the persons have a wide range of abilities and the persons could be grouped into different strata of the latent construct they have experienced.
- iii. **Item Separation Index (ISI) / Item Separation Reliability Coefficient (ISRC):** To fit the Rasch model, the ISI should be > 3.0 and the ISRC > 0.90 .²⁸ These results would indicate that the person distribution is adequate to reliably generate item hierarchy and that the items have a wide range of difficulties.
- iv. **Fit Statistics:** The Rasch model fit statistics report how well the observed data correspond to the measure estimates. Two 'fit statistics' were assessed; the 'Infit' which is more sensitive to the pattern of responses to items targeted to the person and the 'Outfit' which is more sensitive to responses to items with difficulty far from a person's ability.¹⁵ Fit statistics between 0.6 MnSq and 1.4 MnSq are considered optimal for rating scales such as Likert

response categories.²⁹ Items with fit statistics outside of acceptable parameters were considered for removal from the instrument.

- v. **Response Dependency:** Local independence is a requirement of the Rasch model, it is achieved when items are only correlated through the latent trait the instrument is measuring.³⁰ The assumption of local independence can be violated through response dependency, which can occur when the item response on one item influences the response on another, because, for example, the items are similar in content and response categories.³⁰ The Yen's Q_3 test statistic, calculated by the average of all standardized residual item correlations (SRIC) and then add 0.2³⁰, was used to detect response dependency. Item pair SRICs greater than the calculated Yen's Q_3 test statistic of 0.18 were reviewed and one item in each pair assessed for removal from the instrument.
- vi. **Principal Components Analysis of the Residuals (PCAOR)** is used to assess dimensionality.²⁷ Residuals are the differences between observed data and the model estimates (expected data).²⁷ For a unidimensional measure, most of the variance should be explained by the principal factor (construct). The observed raw variance explained by the first factor should approximate the expected.³¹ Items clustered together with factor loadings for residuals significantly higher than zero (i.e., > 0.40) might indicate multidimensionality.³² The eigen value is used to explain systematic variance.³³ It is the patterns (rather than the size) of the loadings that are important.³²
- vii. **Targeting** demonstrates how well the item-difficulty matches the person-ability. Optimally, there should be a match of persons to items, including a balance of easy and difficult items. Gaps along the item measurement continuum indicate gaps in the measurement continuum. An instrument that has perfect targeting would have a difference between the person mean and item mean of 0. An instrument with a difference between the person and items means of more than 1 logit indicates poor targeting.⁴
- viii. **Differential Item Functioning (DIF)**, or item bias, occurs when subgroups of people with comparable levels of ability respond differently to an item, which implies a response to some characteristic other than item 'difficulty'.¹⁵ Differential item functioning was examined across gender, age (65 to 79 years versus ≥ 80) and length of hospital stay prior to completing the questionnaire (1 to 5 days versus 6+ days). Differential item functioning was measured by the DIF Contrast in Winsteps³⁵, using the following parameters as a guide: 1) it is optimal for all items to have DIF < 0.50 logits, 2) it is acceptable if some items are between 0.5 and 1.0 logits, and 3) it is unacceptable to have more than one item with DIF > 1.0 logits.³⁴

Preparation of the data for analysis

Prior to undertaking the Rasch analysis, seven (of the 50 items) included in the questionnaire were removed as all their response category options were non-scalable (i.e., a response category other than NRSOA, leaving 43 items (Figure 1).

There was very little missing data as a result of participants not responding to an item(s). Across 43 items there were

only 63 (0.7%) missing responses (Table 2). There were thirteen items that included one non-scalable response category (i.e., NRSOA plus ‘Not Applicable’ (N/A)). The response category (i.e., ‘N/A’) was treated as missing data. For four of these 13 items the majority of respondents selected the non-scalable response category, which created excessive missing data (>55% of all responses for the item), which required removal of those four items from the analysis (Figure 1).

Figure 1. Tracking item changes through the Rasch analyses

Table 2. Response category totals

	Missing	Never	Rarely	Sometimes	Often	Always	Additional Response *	Total
Totals	63	525	312	896	1,476	4,142	1,186	8,600
%	0.7%	6.1%	3.6%	10.4%	17.2%	48.2%	13.8%	100%

Results

A total of 200 participants completed the patient version of the questionnaire. The participants were 52% female and 48% male. A greater proportion of the females were aged ≥ 80 years ($n = 64$; 62%) compared to males ($n = 45$; 47%). On average patient participants were 81 years of age (standard deviation 8.4 years). One hundred and seventeen (58%) of patient participants had been in hospital for between one and five days and 83 (42%) of patient participants had been in hospital for 6 or more days, when they completed the questionnaire. All participants spoke English.

Item removal and retention was guided by the findings of each step of the Rasch analysis, supplemented by 'expert' judgement, to maintain content validity. Results of the analysis are summarised in Table 3 and detailed below. Rasch analysis was undertaken on 39 items (Figure 1). The category probability curves were disordered for all 39 items. This finding was not surprising given the underutilised response category of 'Rarely' which was

selected by less than 10 people for three quarters (74%) of the items, as well as the substantial ceiling effect (Table 2). Collapsing the 'Never' and 'Rarely' response categories restored order for all items. The 39 items, with ordered thresholds, had a PSI (PSRC) of 2.71 (0.88) and ISI (ISRC) of 4.94 (0.96).

Item reduction

During the process of Rasch analysis, five items were removed because they had fit statistics outside of the acceptable parameters. Four items were retained, based on the value of their content, as judged by the researchers, despite having fit statistics outside of 'optimal' parameters (Item 3.3, Infit 2.42, Outfit 2.55; Item 4.4, Infit 1.57, Outfit 2.08; Item 8.1 Infit 1.75, Outfit 1.85 and Item 10.1 Infit 1.66, Outfit 1.76). One of these four items (Item 3.3) had fit statistics well outside of 'acceptable' parameters. Retention of Item 3.3 'Staff have asked if I have cultural / religious / spiritual beliefs that are important to me' requires explanation. Upon initial inspection it would appear this item should have been removed due to its misfit, however removal of the item had a detrimental effect on the model (PSI dropped from 2.71 to 2.29 and

Table 3. Results of each step of the Rasch analysis

Measured by	Acceptable parameters	Results
Items (n)	N/A	23
Person Separation Index (Person Separation Reliability Coefficient)	> 2.0 (> 0.80) ¹⁵	2.23 (0.83)
Item Separation Index (Item Separation Reliability Coefficient)	> 3.0 (> 0.90) ¹⁵	7.70 (0.98)
Fit Statistics	Between 0.6 MnSq and 1.4 MnSq ²⁹	5 misfitting items removed
Response Dependency	Q3 0.18	12 items removed
Principal Components Analysis of the Residuals (Raw variance explained by measures)	Observed approximates expected ³¹	Observed 49.2% Expected 50.3%
Principal Components Analysis of the Residuals (Unexplained variance in 1st contrast)	< 3.0 ($< 5\%$)/High ³²	Eigen 2.26 Observed 4.9% Expected 9.8%
Targeting (Difference between the person and items means)	< 1 logit	0.94 logits
DIF Gender	DIF Contrast < 0.5 logits	1 item DIF Contrast > 0.5 logits
DIF Age (65 to 79 versus 80+ years)	DIF Contrast < 0.5 logits	23 Items
DIF LOS (1 to 5 versus 6+ days)	DIF Contrast < 0.5 logits	23 Items

ISI dropped from 6.76 to 5.73). Upon investigation, the likely cause of the misfit was the item was not responding as the model expected. Where all other items had a 'ceiling effect', supporting the highest level of care, Item 3.3 was an outlier, as most people selected the 'Never' response category, which represents the lowest level of care. Twelve items were removed due to high SRIC. A further six items (from three pairs) were retained, based on the value of their content, as judged by the researchers, despite having SRIC above the Yen's Q_3 test statistics of 0.18 (they were Items 1.3 and 9.2 with SRIC of 0.24; Items 4.2 and 5.1 with SRIC of 0.19; Item 5.3 and 7.1 with SRIC of 0.19).

Test of unidimensionality

Based on the PCAOR of the final 23-items instrument (Figure 1), the observed raw variance explained by the measure was 49.2%, which is close to the expected 50.3%. The unexplained variance in the 1st contrast had an eigen value of 2.26, an observed variance of 4.9% and an expected variance of 9.8%; all within acceptable parameters.

Construct validity

The final 23-item instrument was able to demonstrate construct validity, as assessed by the final PSI (PSRC) of 2.23 (0.83), indicating the item distribution is adequate to reliably generate person hierarchy, that the persons (patients) have a wide range of abilities and the persons (patients) could be grouped into different strata of the latent construct they have experienced.

Targeting was not optimal, with many patient participants experiencing more of the latent variable, than the items were able to measure. The difference between the person and items means of the 23-item instrument was 0.94 logits. The 23 items spanned a range from -1.19 to 2.67 logits, which is a reasonably broad range, but only two items (Items 3.3 and 10.1) were in the upper end of the range. The final 23-items included one item with a DIF Contrast > 0.5 (Item 6.4, DIF Contrast -0.76), measuring DIF by gender. The DIF contrast was moderate, but within acceptable parameters and was retained due to its content value.

Internal reliability

The final 23-items were able to demonstrate internal reliability, as assessed by the ISI (ISRC) of 7.70 (0.98), which indicates the person (patient) distribution is adequate to reliably generate item hierarchy and that the items have a wide range of difficulties.

The final 23-items are listed in full in Table 4 (column on the right). The final 23 items are also provided in full against the 10 Principles of Dignity in Care and the Australian Charter of Healthcare Rights in the supplementary material (Appendix S2).

Discussion

This study reports on the assessment of the psychometric properties of The Right PREM™; an instrument developed for use by older people in hospital to measure their experience of care against their healthcare rights. The aims of the study were met, as the instrument was able to demonstrate unidimensionality, construct validity and internal reliability.

Internationally there is interest in Values Based Health Care,⁷ which is healthcare that improves: health outcomes that matter to patients, experiences of receiving care, experiences of providing care and effectiveness and efficiency of care.³⁶ Achieving values-based healthcare requires validated instruments to use as PROMs and PREMs. We developed a PREM to meet the experience of care needs of older people in hospital. We chose to use a 'Rights' based approach, focussing on the seven constructs (Access, Safety, Respect, Partnership, Information, Privacy and Give Feedback) of the Australian Charter of Healthcare Rights.⁵ This shift to 'Rights' separates The Right PREM™ from other patient experience measures developed for older people under the generic terms such as 'person-centred' care.³⁷

There is little overlap between the items included in the 23-items of The Right PREM™ and the generic 12-item Australian Hospital Patient Experience Question Set (used for all adult inpatients), which suggests it is important to have validated instruments available for use by older people in hospital. Across the 23-items of The Right PREM™ there are just two items in common with the 12-item AHPEQS. These two items are about being involved in decisions (Q.5 AHPEQS and Item 4.2 The Right PREM™) and the control of pain (Q. 8 AHPESQ and Item 1.5 of The Right PREM™). The full list of items included in the AHPEQS and The Right PREM™ is provided in Table 4. Noting the original item nomenclature has been retained, despite removal of items, to enable the reader to follow items from the initial item pool through development and in acknowledgement that the items remain 'live' and open to further development as the instrument continues to evolve over further research studies.

All 23 items of The Right PREM™ align with the seven constructs of the Australian Charter of Healthcare Rights. We examine each of the constructs and the relevant items from The Right PREM™.

'Access' is the first construct of the Charter, described as 'Healthcare services and treatment that meets my needs.'²⁵ With the focus on meeting needs, The Right PREM™

Table 4. The 23 Items included in the Right PREM™ (right) and the 12 items included in the AHPEQS (left)

AHPEQS	The Right PREM™
1. My views and concerns were listened to	
2. My individual needs were met	
3. When a need could not be met, staff explained why (applies only if Question 2 was answered negatively)	
4. I felt cared for	
5. I was involved as much as I wanted in making decisions about my treatment and care	Item 4.2 'I have been involved, as much as I wanted to be, in decisions about my care'
6. I was kept informed as much as I wanted about my treatment and care	
7. It was clear to me that staff had communicated with each other about my treatment and care	
8. I received pain relief that met my needs	Item 1.5 'Staff have helped to control my pain'
9. When I was in hospital, I felt confident in the safety of my treatment and care	
10. I experienced unexpected harm or distress as a result of my treatment and care	
11. My harm or distress was discussed with me by staff (applies only if Question 10 was answered in the affirmative)	
12. Overall, the quality of treatment and care I received was (very good, good ...)	
	Item 1.2 'Staff come to see me soon after I press the call bell'
	Item 1.3 'Staff have been rough in the way they provide care'
	Item 2.1 'Staff wear name badges large enough to read'
	Item 2.2 'Staff introduce themselves by telling me their name and role'
	Item 2.4 'Staff have been considerate in how they provide care to me'
	Item 2.5 'My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels...)'
	Item 3.1 'Staff have called me by my preferred name'
	Item 3.3 'Staff have asked if I have cultural / religious / spiritual beliefs that are important to me'
	Item 4.3 'Staff have asked my permission before they provide care'
	Item 4.4 'I believe I can choose to refuse treatment'
	Item 5.1 'I have been given enough time to explain what I need'
	Item 5.3 'Staff have encouraged me to ask questions'
	Item 5.4 'Staff have spoken with me about my care in ways I understand'
	Item 5.5 'Staff have encouraged me to be involved in planning my discharge from hospital'
	Item 6.4 'I feel my privacy is respected when I am using the toilet, bedpan or changing a pad'
	Item 7.1 'Staff have made sure there is an opportunity to talk about any concerns'
	Item 8.1 'Staff have asked me which family, friends or carers I want involved in my care'
	Item 9.2 'Staff have spoken to me as an equal'
	Item 9.4 'I have been supported to maintain my personal appearance'
	Item 10.1 'Staff include me in the bedside discussion at shift handover'
	Item 10.2 'Staff have supported me to stay physically and mentally active'

Legend. Original item nomenclature has been retained, despite removal of items, to enable the reader to follow items from the initial item pool through development.

includes Item 5.1 'I have been given enough time to explain what I need' and Item 2.5 'My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels...)'. It is this basic care, that should never be inaccessible, that is required of almost all older people in hospital, that if absent or missed, can have profound consequences for both experience and outcomes of hospitalisation.³⁸

Under the Charter's construct of 'Safety', The Right PREM™ includes Item 1.2 'Staff come to see me soon after I press the call bell', Item 1.3 'Staff have been rough in the way they provide care' and Item 1.5 (mentioned above). Once again, 'missed care' including waiting too long for a response to a call bell, can affect both experience and outcomes. An older person may attempt to walk to the toilet unassisted and have a fall causing serious injury.³⁹ Lengthy delays in responding, regardless of cause, can be considered neglectful and, in the extreme, a form of abuse.⁴⁰

Of each of the seven constructs of the Charter, it is 'Respect' which has the greatest prominence in the items retained in The Right PREM™. These include items relating to identification and connection, promoted internationally through campaigns such as 'Hello my name is...' ⁴¹ such as Item 2.1 'Staff wear name badges large enough to read,' Item 2.2 'Staff introduce themselves by telling me their name and role' and Item 3.1 'Staff have called me by my preferred name.' Core to respect, is recognition of the person as an individual, which comes from people using each other's names, but also understanding what is important to them,⁴² such as the content covered in Item 3.3 'Staff have asked if I have cultural / religious / spiritual beliefs that are important to me'.

A number of items under the construct of 'Respect' are about the relationship between staff and the patient, including Item 2.4 'Staff have been considerate in how they provide care to me,' Item 4.3 'Staff have asked my permission before they provide care' and Item 9.2 'Staff have spoken to me as an equal.' Establishing a relationship with the patient is considered core to a positive experience of care.⁴³ The final two items of The Right PREM™ relating to the construct of 'Respect', are in alignment with initiatives such as the internationally acclaimed campaign End PJ Paralysis,⁴⁴ covered by Item 9.4 'I have been supported to maintain my personal appearance' and Item 10.2 'Staff have supported me to stay physically and mentally active.'

The construct of 'Partnership' is covered by a number of diverse items in The Right PREM™, including Item 4.2 'I have been involved, as much as I wanted to be, in decisions about my care' and Item 10.1 'Staff include me in discussions at shift handover.' Item 4.4 'I believe I can

choose to refuse treatment,' taps into the more recent emphasis on asking people to consider and document the care they do and do not want,⁴⁵ which is highly relevant to older people, particularly given over intervention at end of life.⁴⁶ A 'Partnership' requires openness and understanding, seen in Item 5.3 'Staff have encouraged me to ask questions' and Item 5.4 'Staff have spoken with me about my care in ways I understand.' Two further factors are of vital importance to many older people, the first is that the involvement of family, covered by Item 8.1 'Staff have asked me which family, friends or carers I want involved in my care,' the second is that they are well prepared, and involved in, plans for leaving hospital,⁴⁷ as per Item 5.5 'Staff have encouraged me to be involved in planning my discharge from hospital.'

There is just one item in The Right PREM™ which taps into the construct of 'Privacy' at the moment in care when an older person can feel most vulnerable to a breach of privacy,⁴⁸ covered in Item 6.4 'I feel my privacy is respected when I am using the toilet, bedpan or changing a pad.'

In alignment with the shift of health services to promote the making and resolution of comment or complaints at the local level, in the first instance,⁴⁹ the construct of 'Give Feedback' is covered in The Right PREM™ by Item 7.1 'Staff have made sure there is an opportunity to talk about any concerns.'

Providing care to older people that is consistent with the Australian Charter of Healthcare Rights is core business to hospitals. An important way to understand if older people experience care consistent with healthcare rights, is to ask them. The Right PREM™ is a valid measure of the patient's perspective of their experience of care consistent with the Charter of Australian Healthcare Rights.

Strengths and Limitations

Strengths

The 'modern' methods of Rasch theory used in the data analysis are contemporary and rigorous and provide confidence in the results. This method is not yet in common use in the development of PREMs. None of the instruments identified in the literature¹³ used Rasch analysis in the process of psychometric testing.

Rasch analysis was used in preference to the methods of 'classical test theory.' An extensive literature exists describing the debate between the use of 'traditional' versus 'modern' methods of analysis in instrument development.¹⁴⁻¹⁶ At the heart of the debate is the criticism that the methods used in CTT, which include factor analysis and Cronbach's alpha, are based on inaccurate assumptions.

These assumptions stem from the practice of summarising the responses to the questionnaire into a total score. Allowing a summary score assumes the response options are equal distances apart on a scale and that items are of equal value. This assumes the data are on an interval scale. However, data from questionnaires using a Likert scale (i.e., with response categories: 'Never,' 'Rarely,' 'Sometimes,' 'Often,' 'Always') are on an ordinal scale, where the 'distance' between two consecutive unit points on the scale are not uniform and consistent across the entire range of the scale.²³ This assumption results in ordinal level categorical data being treated as interval level data in the analysis.¹⁴ Interval level data are assumed to have parametric data structure: normal distribution, homogeneity (homogeneous groups within the data) and homoscedasticity (equal variance of the residuals).⁵⁰ CTT methods then (inappropriately) employ parametric statistical techniques, including t-tests and analysis of variance, suitable for interval data.⁵⁰

Publication of this research, demonstrating use of Rasch analysis in PREM development, may herald a new direction for the methods of data analysis used in the testing of experience of care instruments. Rasch analysis should and could be used in testing the unidimensionality, content validity and internal reliability of PREMs. Authors who do not use these techniques could rightly be challenged.

Limitations

Recruitment was limited by a number of factors including being able to speak only with the patients identified by the Shift Co-ordinator/Team Leader of each ward. This process was a necessary part of recruitment but had the potential to introduce selection bias. Due to time pressures and interpretation of the request, Shift Co-ordinators/Team Leaders may have used their own inclusion and exclusion criteria for putting forward patients for consideration.

A further limitation was that many patients have advanced dementia and many of those have no 'carer' and many patients had infectious precautions requiring PPE.

A significant limitation of this study was the inability to recruit patients who did not speak English, despite funding being available to enable use of interpreters.

Operationalising the recruitment of older, potentially vulnerable people is challenging, adding the complexity and time to negotiate with staff, including determining if the patient had family who would wish to be consulted on the patient's participation, created obstacles which could not be conquered.

Survey fatigue is real. People want to talk, but not necessarily complete a survey. Additionally, gratitude bias

was evident, with participants discussing poor experiences of care that did not translate through in the scoring of the relevant items in the questionnaire.

Implications for practice

Through a rigorous process of development, involving a broad range of experts and consumers, under the robust framework of the Charter of Australian Healthcare Rights, we have commenced the process of developing The Right PREM™, in the form of a questionnaire. The PREM was designed specifically for older people when they are in hospital. The 23 items in The Right PREM™ are brief, clear, specific and implementable.

These 23 items hold a message that can be used by health services to improve the experience of care for older people. They can be used, as designed, in the form of a questionnaire and they can be used as the foundation of a discussion about experience of care, with those unable to complete a questionnaire. The messages contained in the items can be used in education and training and to guide the implementation of quality improvement activities.

Further research

Further validation of the 23-items of The Right PREM™ is required, four stages are proposed. First, further data collection and analysis based on targeted recruitment of people from diverse communities, including people who do not speak English as their first language, to allow assessment of cross-cultural validity. Second, consideration needs to be given as to how patients requiring care with PPE could be included in the data collection process, as these patients were excluded from the data collection process in this study. Given the Covid-19 pandemic and the increased use of PPE, further research is required to ensure older vulnerable people, further isolated by nature of the PPE requirements, can report on their experience of care. Third, consideration should be given to undertaking test retest assessment of reliability in future research. The value and appropriateness of undertaking test retest must be examined given it is possible a person's experience of care could change within the same day and certainly over a number of days.

Once the instrument has undergone further assessment of validity and reliability, the instrument should be adequately developed to assess its responsiveness, to test the ability to measure change over time. The fourth and final stage of future research would be to consider adapting and validating The Right PREM™ for use with older and/or vulnerable people in aged care and disability settings.

The Right PREM™ aligns with the constructs of the Australian Charter of Healthcare Rights. Future research will also consider its relevance internationally.

Conclusion

Measuring experience of care is difficult. Many instruments are developed to this point and progress no further, thus perpetuating a gap in the research for sound instruments to be filled by yet another instrument that does not reach its potential. A robust instrument cannot be developed to its final form in one research study. The case for a PREM based on health care rights is sound and PREMs specific to older people are urgently required. Based on the promising findings of the psychometric properties of The Right PREM™ in its current state of development, The Right PREM™ will undergo further testing of validity and reliability, including cross-cultural and international validation.

References

1. Australian Institute of Health and Welfare. Australia's Health 2014 Cat. No. AUS 178. In. Canberra 2014.
2. Creditor MC. Hazards of hospitalization of the elderly. *Annals of Internal Medicine*. 1993;118(3):219-223.
3. Australian Institute of Health and Welfare. Dementia care in hospitals: costs and strategies. Cat. no. AGE 72. In. Canberra 2013.
4. World Health Organization. Patients' Rights. <https://www.who.int/genomics/public/patientrights/en/>. Accessed 7 March 2020.
5. Australian Commission on Safety and Quality in Health Care. Australian Charter of Healthcare Rights. www.safetyandquality.com.au. Published 2019. Accessed 2 April 2020.
6. Council of Attorneys-General. National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023. In. Australia 2019.
7. Organization for Economic Cooperation and Development. *Measuring What Matters: The Patient-Reported Indicator Surveys*. 2019.
8. Black N. Patient reported outcome measures may transform healthcare. *BMJ*. 2013;346(7896):19-21.
9. Australian Commission for Safety and Quality in Health Care. Australian Hospital Patient Experience Question Set. <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-hospital-patient-experience-question-set-easy-english>. Published 2020. Accessed 1 March 2020.
10. United Nations. Universal Declaration of Human Rights. <https://www.un.org/en/universal-declaration-human-rights/index.html>. Published 1948. Accessed 30 April 2019.
11. Australian Commission for Safety and Quality in Health Care. My Healthcare Rights - A guide for people with cognitive impairment. www.safetyandquality.gov.au. Accessed 30 July 2020.
12. Sobolewska A, Byrne AL, Harvey CL, et al. Person-centred rhetoric in chronic care: a review of health policies. *Journal of Health Organization and Management*. 2020;34(2):123-143.
13. Heuzenroeder L, Ibrahim F, Khadka J, Woodman R, Kitson A. A Delphi study to identify content for a new questionnaire based on the 10 Principles of Dignity in Care. *J Clin Nurs*. 2020;In press.
14. Boone WJ. Rasch analysis for instrument development: Why, when and how? *CBE - Life Sciences Education*. 2016;15(4):1-7.
15. Bond T, G., Fox CM. *Applying the Rasch Model. Fundamental Measurement in the Human Sciences*. 3rd ed. New York: Routledge; 2015.
16. Massof RW. The measurement of vision disability. *Optometry and Vision Science*. 2002;79(8):516-552.
17. Wright B. Rasch Analysis for Surveys. <https://www.rasch.org/pm/pm4-36.pdf>. Accessed 19 September 2019.
18. McDowell I. *Measuring Health A Guide to Rating Scales and Questionnaires*. 3rd ed. New York: Oxford University Press; 2006.
19. The STROBE Group. STROBE Statement. STrengthening the Reporting of OBservational studies in Epidemiology. www.strobe-statement.org. Accessed 1 September 2020.
20. National Health and Medical Research Council in collaboration with the Australian Commission on Safety and Quality in Healthcare. Australian Guidelines for the Prevention and Control of Infection in Healthcare. <https://www.nhmrc.gov.au/about-us/publications/australian-guidelines-prevention-and-control-infection-healthcare-2010>. Published 2010. Accessed 2 March 2020.
21. Linacre JM. Understanding Rasch measurement: Optimizing rating scale category effectiveness. *Journal of Applied Measurement*. 2002;3(1):85-106.
22. Linacre JM. Sample size and item calibration (or person measure) stability. <https://www.rasch.org/rmt/rmt74m.htm>. Published 1994. Accessed 19 January 2020.
23. Horton MC. *Screening for the risk of self-harm in an adult offender population*: Department of Rehabilitation Medicine, The University of Leeds; 2017.
24. DeVellis RF. *Scale Development Theory and Applications*. 4th ed. Los Angeles: SAGE; 2016.
25. Linacre JM. Comparing and Choosing between Partial Credit Models and Rating Scale Models. <https://www.rasch.org/rmt/rmt143k.htm>. Accessed 19 January 2020.
26. Linacre JM. Winsteps® Rasch measurement computer program. <https://www.winsteps.com/winman/isgroups.htm>. Published 2019. Accessed Version 4.4.5.

27. Brentari E, Golia S. Unidimensionality in the Rasch model: how to detect and interpret. *Statistica*. 2007;3:253-261.
28. Pesudovs K, Burr JM, Harley C, Elliott DB. The development, assessment, and selection of questionnaires. *Optometry and Vision Science*. 2007;84(8):663-674.
29. Linacre JM. Reasonable mean-square fit values. <https://www.rasch.org/rmt/rmt83b.htm>. Published 1994. Accessed 19 January 2020.
30. Christensen KB, Makransky G, Horton M. Critical Values for Yen's Q3: Identification of Local Dependence in the Rasch Model Using Residual Correlations. *Applied Psychological Measurement*. 2017;41(3):178-194.
31. Linacre JM. Rasch and Multidimensionality Winsteps Table 23 Video. In: Winsteps Forum; 2018.
32. Linacre JM. Principal Components Analysis of Residuals. <https://www.winsteps.com/winman/principalcomponents.htm>. Published 2019. Accessed 22 September 2019.
33. Bland M. *An introduction to medical statistics*. 4th ed. Oxford, United Kingdom: Oxford University Press; 2015.
34. Khadka J, McAlinden C, Pesudovs K. Quality assessment of ophthalmic questionnaires: review and recommendations. *Optometry and Vision Science*. 2013;90(8):720-744.
35. Linacre JM. How to run a DIF analysis. <https://www.winsteps.com/winman/difconcepts.htm>. Accessed 2 January 2020.
36. NSW Health. Values based healthcare. NSW Government. <https://www.health.nsw.gov.au/Value/Pages/default.aspx>. Published 2020. Accessed 10 August 2020.
37. Wilberforce M, Challis D, Davies L, Kelly MP, Roberts C, Loynes N. Person-centredness in the care of older adults: a systematic review of questionnaire-based scales and their measurement properties. *BMC Geriatrics*. 2016;16(63):1-12.
38. Muntlin Athlin A, Brovall M, Wengstrom Y, Conroy T, Kitson AL. Descriptions of fundamental care needs in cancer care-An exploratory study. *Journal of Clinical Nursing*. 27(11-12):2322-2332.
39. Hessels AJ, Paliwal M, Weaver SH, Siddiqui D, Wurmser TA. Impact of Patient Safety Culture on Missed Nursing Care and Adverse Patient Events. *Journal of Nursing Care Quality*. 2019;34(4):287-294.
40. Groves A, Thomson D, McKellar D, Procter N. The Oakden Report. Adelaide, South Australia. In: SA Health Department for Health and Ageing 2017:1-152.
41. hello my name is. <https://www.hellomynameis.org.uk/>. Accessed 20 July 2019.
42. Agency for Healthcare Research and Quality. Health Literacy Universal Precautions Toolkit. Consider Culture, Customs and Beliefs. Tool #10, 2nd Edition. <https://www.ahrq.gov/health-literacy/quality-resources/tools/literacy-toolkit/healthlittoolkit2-tool10.html>. Accessed 19 January 2020.
43. Feo R, Donnelly F, Muntlin Athlin A, Jangland E. Providing high-quality fundamental care for patients with acute abdominal pain. *Journal of Health Organization & Management*. 2019;33(1):110-123.
44. End PJ Paralysis. <https://endpiparalysis.org/>. Accessed 22 July 2019.
45. Rhee JJ, Zwar NA, Kemp LA. Uptake and implementation of Advance Care Planning in Australia: findings of key informant interviews. *Australian Health Review*. 2012;36(1):98-104.
46. Hillman K. *Vital Signs. Stories from Intensive Care*. Sydney: NewSouth Publishing; 2009.
47. Bauer M, Fitzgerald L, Haesler E, Manfrin M. Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing*. 2009;18(18):2539-2546.
48. Birrell J. Promoting privacy and dignity for older patients in hospital. *Nursing Standard*. 2006;20(18):41-46.
49. Australian Council for Safety and Quality in Health Care. Complaints Management Handbook for Health Care Services. In: Commonwealth of Australia; 2005.
50. Andrich D. *Rasch Models for Measurement Quantitative Applications in the Social Sciences*. London: Sage; 1988.
51. Dignity in Care UK. Dignity in Care Campaign. <http://www.dignityincare.org.uk/>. Accessed 19 January 2020.

Appendix – S1. The original 50-items of The Right PREM (The final 23-items are not shaded)

Stem: During this hospital admission...

1.1	I have felt safe when staff provide care to me	Never	Rarely	Sometimes	Often	Always					
1.2	Staff come to see me soon after I press the call bell	Never	Rarely	Sometimes	Often	Always	I have not used the call bell				
1.3	Staff have been rough in the way they provide care	Never	Rarely	Sometimes	Often	Always					
1.4	I have had my arms and legs tied down to restrain me	Never	Rarely	Sometimes	Often	Always					
1.5	Staff have helped to control my pain	Never	Rarely	Sometimes	Often	Always	I had no pain				
2.1	Staff wear name badges large enough to read				Never		Rarely		Sometimes	Often	Always
2.2	Staff introduce themselves by telling me their name and role				Never		Rarely		Sometimes	Often	Always
2.3	Staff have been respectful when they speak with me				Never		Rarely		Sometimes	Often	Always
2.4	Staff have been considerate in how they provide care to me				Never		Rarely		Sometimes	Often	Always
2.5	My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels...)				Never		Rarely		Sometimes	Often	Always
3.1	Staff have called me by my preferred name	Never	Rarely	Sometimes	Often	Always					
3.2	I have had access to an interpreter	Never	Rarely	Sometimes	Often	Always	I do not need an interpreter				
3.3	Staff have asked if I have cultural / religious / spiritual beliefs that are important to me	Never	Rarely	Sometimes	Often	Always					
3.4	Staff have provided care consistent with my cultural / religious / spiritual beliefs	Never	Rarely	Sometimes	Often	Always	Not Applicable				
3.5	Staff have respected my sexual identity	Never	Rarely	Sometimes	Often	Always	Not Applicable				
4.1	I have been involved, as much as I wanted to be, in discussions about my care	Never	Rarely	Sometimes	Often	Always					
4.2	I have been involved, as much as I wanted to be, in decisions about my care	Never	Rarely	Sometimes	Often	Always					
4.3	Staff have asked my permission before they provide care	Never	Rarely	Sometimes	Often	Always					
4.4	I believe I can choose to refuse treatment	Never	Rarely	Sometimes	Often	Always	Unsure				
4.5	I have discussed my Advance Care Directive with staff	Yes		No		I do not know what an Advance Care Directive is			I do not have an Advance Care Directive		

Appendix – S1. The original 50-items of The Right PREM (The final 23-items are not shaded) - continued

5.1	I have been given enough time to explain what I need	Never	Rarely	Sometimes	Often	Always	
5.2	Staff provide care that reflects an understanding of my needs (such as my vision, hearing, memory, mobility and dietary needs)	Never	Rarely	Sometimes	Often	Always	
5.3	Staff have encouraged me to ask questions	Never	Rarely	Sometimes	Often	Always	
5.4	Staff have spoken with me about my care in ways I understand	Never	Rarely	Sometimes	Often	Always	
5.5	Staff have encouraged me to be involved in planning my discharge from hospital	Never	Rarely	Sometimes	Often	Always	Discharge has not been discussed
6.1	I have been given privacy when talking about my condition and treatment	Never		Rarely	Sometimes	Often	Always
6.2	I feel my privacy is respected when I am being examined or treated	Never		Rarely	Sometimes	Often	Always
6.3	I feel my privacy is respected when I am having a wash	Never		Rarely	Sometimes	Often	Always
6.4	I feel my privacy is respected when I am using the toilet, bedpan or changing a pad	Never		Rarely	Sometimes	Often	Always
6.5	My personal space is respected	Never		Rarely	Sometimes	Often	Always
7.1	Staff have made sure there is an opportunity to talk about any concerns	Never	Rarely	Sometimes	Often	Always	
7.2	I have felt I could make a complaint if I needed to	No		I'd be reluctant		Yes	
7.3	I believe I could make a complaint without it affecting my care	No		I'd be reluctant		Yes	
7.4	I know who to contact if I have a complaint	No		Unsure		Yes	
7.5	I made a complaint and I was satisfied with the response	Not satisfied with the response		I did not make a complaint		Yes, satisfied with the response	
8.1	Staff have asked me which family, friends or carers I want involved in my care	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.2	My family, friends or carers have been involved in decisions about my care *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.3	Staff include my family, friends or carers in the bedside discussion at shift handover *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.4	Staff responded quickly when my family, friends or carers reported my condition had deteriorated	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.5	Staff arranged access to interpreters to involve family, friends or carers in my care *	Never	Rarely	Sometimes	Often	Always	Interpreter not required

Appendix – S1. The original 50-items of The Right PREM (The final 23-items are not shaded) - continued

9.1	Staff have made me feel welcome	Never	Rarely	Sometimes	Often	Always
9.2	Staff have spoken to me as an equal	Never	Rarely	Sometimes	Often	Always
9.3	I have been given enough opportunity to do what I am capable of doing myself	Never	Rarely	Sometimes	Often	Always
9.4	I have been supported to maintain my personal appearance	Never	Rarely	Sometimes	Often	Always
9.5	Staff took too long to respond when I needed to go to the toilet	Never	Rarely	Sometimes	Often	Always
10.1	Staff include me in the bedside discussion at shift handover	Never	Rarely	Sometimes	Often	Always
10.2	Staff have supported me to stay physically and mentally active	Never	Rarely	Sometimes	Often	Always
10.3	Staff have helped me to find things to do to keep me from being bored	Never	Rarely	Sometimes	Often	Always
10.4	I have been visited by a hospital volunteer	No		Unsure		Yes
10.5	I have had access to an Aboriginal Liaison Officer	No		I am not an Aboriginal person		Yes

* When I wanted these family, friends or carers involved in my care

Appendix - STROBE Checklist

Section	Description
Title and abstract	
	1 (a) commonly used term in the title or the abstract
	1 (b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction	
Background/rationale	2 Explain the scientific background and rationale for the investigation being reported
Objectives	3 State specific objectives, including any prespecified hypotheses
Methods	
Study design	4 Present key elements of study design early in the paper
Setting	5 Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6 Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7 Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8 For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9 Describe any efforts to address potential sources of bias
Study size	10 Explain how the study size was arrived at
Quantitative variables	11 Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12 (a) Describe all statistical methods, including those used to control for confounding
	12 (b) Describe any methods used to examine subgroups and interactions
	12 (c) Explain how missing data were addressed
	12 (d) If applicable, describe analytical methods taking account of sampling strategy
	12 (e) Describe any sensitivity analyses
Results	
Participants	13 (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed.
	13 (b) Give reasons for non-participation at each stage
	13 (c) Consider use of a flow diagram
Descriptive data	14 (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
	14 (b) Indicate number of participants with missing data for each variable of interest
Outcome data	15 Report numbers of outcome events or summary measures
Main results	16 (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
	16 (b) Report category boundaries when continuous variables were categorized
	16 (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time-period
Other analyses	17 Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Appendix - STROBE Checklist - continued

Section	Description
Discussion	
Key results	18 Summarise key results with reference to study objectives
Limitations	19 Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20 Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21 Discuss the generalisability (external validity) of the study results
Other information	
Funding	22 Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

Appendix S2. The 10 Principles of Dignity in Care, the Australian Charter of Healthcare Rights and the 23-items of The Right PREM

10 Principles of Dignity in Care ⁵⁰	Australian Charter of Healthcare Rights ⁵	23-items of The Right PREM
Aligns with Principle 5 'Needs and wants'	Access - Healthcare services and treatment that meets my needs	
Principle 1. Zero tolerance of all forms of abuse.	Safety - Receive safe and high-quality health care that meets national standards - Be cared for in an environment that is safe and makes me feel safe	Item 1.2 'Staff come to see me soon after I press the call bell' Item 1.3 'Staff have been rough in the way they provide care' Item 1.5 'Staff have helped to control my pain'
Principle 2. Support people with the same respect you would want for yourself or a member of your family. Principle 3. Treat each person as an individual by offering a personalised service.	Respect - Be treated as an individual, and with dignity and respect - Have my culture, identity, beliefs and choices recognized and respected	Item 2.1 'Staff wear name badges large enough to read' Item 2.2 'Staff introduce themselves by telling me their name and role' Item 2.4 'Staff have been considerate in how they provide care to me' Item 2.5 'My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels...)' Item 3.1 'Staff have called me by my preferred name' Item 3.3 'Staff have asked if I have cultural / religious / spiritual beliefs that are important to me'
Principle 4. Enable people to maintain the maximum possible level of independence, choice and control.	Partnership - Ask questions and be involved in open and honest communication, make decisions with my healthcare provider, to the extent that I choose and am able to	Item 4.2 'I have been involved, as much as I wanted to be, in decisions about my care' Item 4.3 'Staff have asked my permission before they provide care' Item 4.4 'I believe I can choose to refuse treatment'
Principle 5. Listen to and support people to express their needs and wants.	Information - Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent. - Receive information about services, waiting times and costs. - Be given assistance, when I need it, to help me to understand and use health information. - Access my health information. - Be told is something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe.	Item 5.1 'I have been given enough time to explain what I need' Item 5.3 'Staff have encouraged me to ask questions' Item 5.4 'Staff have spoken with me about my care in ways I understand' Item 5.5 'Staff have encouraged me to be involved in planning my discharge from hospital'

Appendix S2. The 10 Principles of Dignity in Care, the Australian Charter of Healthcare Rights and the 23-items of The Right PREM – Continued

10 Principles of Dignity in Care ⁵⁰	Australian Charter of Healthcare Rights ⁵	23-items of The Right PREM
Principle 6. Respect people's privacy.	Privacy - Have my personal privacy respected and have information about me and my health kept secure and confidential.	Item 6.4 'I feel my privacy is respected when I am using the toilet, bedpan or changing a pad'
Principle 7. Ensure people feel able to complain without fear of retribution.	Give feedback - Provide feedback or make a complaint without it affecting the way I am treated, have my concerns addressed in a transparent and timely way, and share my experience and participate to improve the quality of care and health services.	Item 7.1 'Staff have made sure there is an opportunity to talk about any concerns'
Principle 8. Engage with family members and carers as care partners.	As per Partnership above - Include the people that I want in planning and decision-making.	Item 8.1 'Staff have asked me which family, friends or carers I want involved in my care'
Principle 9. Assist people to maintain confidence and a positive self-esteem.	Aligns with the Charter's construct of ' Respect '	Item 9.2 'Staff have spoken to me as an equal' Item 9.4 'I have been supported to maintain my personal appearance'
Principle 10. Act to alleviate people's loneliness and isolation.	Aligns with the Charter's construct of ' Respect '	Item 10.1 'Staff include me in the bedside discussion at shift handover' Item 10.2 'Staff have supported me to stay physically and mentally active'