

**The Pros and Cons of PROMs and PREMs**  
**26 November 2018**  
**Short Oral Presentation Abstracts**

**PROMs/PREMs for Quality Assurance and Benchmarking**

## Patient Assessment of Chronic Illness Care in Type 2 Diabetes

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Introduction/Background	Before using patient perspectives to evaluate whether established chronic care services are delivered to an agreed standard consistently and whether clients with chronic disease receive quality integrated multidisciplinary care across services, settings and time to optimise healthcare outcomes, evidence is required on how well existing instruments measure the quality of chronic illness care and factors influencing patient assessment of chronic care. Thus, we examined: psychometric characteristics of the Patient Assessment of Chronic Illness Care (PACIC) instrument; patient factors associating with PACIC; and the impact of patient-assessed quality of care on health-related outcomes over two years.
Methods	Data were obtained from a prospective cohort study of patients with type 2 diabetes in Queensland, from 2008 to 2010 (N=3,761; N=3,209; and N=3,040 respectively). Participants completed the 20-item PACIC, 13-item Patient Activation Measure (PAM), EQ-5D-3L, and reported glycaemic control. Construct validity of the PACIC over three years was assessed using exploratory factor analysis, and reliability using Spearman-Brown coefficient. Associations between PACIC and other variables were examined using logistic regression, Analysis of Variance, and an inverse probability weighted Poisson regression with a log-link function.
Results	A one-factor structure was deemed optimal for PACIC, with high internal consistency and moderate agreement within the scales over time. Patient activation was positively associated with the median PACIC score. The interaction effects of the PACIC and PAM on glycaemic control and EQ VAS were observed. No association was found with EQ-5D index.
Conclusions/Policy Implications	PACIC is a reliable, valid and reproducible instrument for assessment of chronic care, and we recommend its use as a single scale. PAM and PACIC should be considered together in the interpretation of patient care assessment: interpreting PACIC scores within strata of PAM. Better patient-assessed chronic care received consistently over time may facilitate achievement of better glycaemic control and positively affect health status in patients with low activation.

# Developing Quality Indicators in Community Aged Care: Role of Social Engagement and Quality of Life Instruments

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Introduction/Background	<p>The Australian aged care sector is undergoing significant reform as our Government responds to the challenges associated with an ageing population. As part of these reforms, the National Aged Care Quality Indicator Program was developed to measure aspects of service provision that contribute to aged care quality in residential aged care. Quality outcome measures have not been rolled out in community aged care.</p> <p>Our aim is to assess the integration of two Patient Reported Outcome Measures (PROMs) into routine community aged care assessments in terms of their (i) acceptability, accessibility and relevance for clients and staff; (ii) ability to shape discussions around care planning and service provision; and (iii) usefulness in monitoring client trajectories over time.</p>
Methods	<p>Community aged care staff completed the Australian Community Participation Questionnaire (ACPQ) and ICEpop CAPability Measure for Older Adults (ICECAP-O) tools with 957 older adults. Focus groups with staff and clients were conducted to obtain feedback on usefulness of the PROMs. Data on social participation and quality of life were integrated with data on service provision, demographics and other key outcomes within the provider's care management system.</p>
Results	<p>Mean age of clients completing the PROMs was 83.4 years (SD 8.1) and 72.9% were female. Most clients (93.4%) participated in at least one social participation domain and over 50% were in the top quartile. Clients with high care needs had the lowest levels of participation and wellbeing. The tools were found to be acceptable by both clients and staff, were useful in obtaining additional information to guide care planning and valued for measuring longitudinal changes.</p>
Conclusions/Policy Implications	<p>This study has identified valid, useful, psychosocial PROMs for use in community aged care. Integrating PROMs into client management systems allows for real time monitoring of unmet needs and a mechanism to capture how PROMs influence trajectories of service provision and other client outcomes.</p>

# PROMs and PREMs in Clinical Quality Registries for melanoma care

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**Introduction/Background** Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) are tools used to assess a patient's health condition or experience of healthcare which come directly from the patient, without interpretation from clinicians or other healthcare professionals. In the treatment of cutaneous melanoma, these tools can provide valuable insight into patient needs and may be used for quality assurance and benchmarking. However they are not routinely utilised in Australia.

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**Methods** A systematic review of PROM/PREM collection in routine care and Clinical Quality Registries involving patients treated for cutaneous melanoma was conducted. We searched MEDLINE, PreMEDLINE, Embase, PsychInfo, Cochrane Database, TUFTS CEA, and Google Scholar databases from inception to Jan 2018. Excluded were studies that did not identify patient-reported outcomes (e.g. clinician reported), and studies where PROMs/PREMs were collected solely for research purposes.

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**Results** The search strategy identified 749 studies. The full text of 255 articles was independently reviewed following exclusion of articles from title and abstract screening using Covidence software. A total of 12 studies met the inclusion criteria. Four registries collected PROMs or PREMs for melanoma patients: the Dutch Melanoma Treatment Registry; the PROFILES Registry (Patient-Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship); the Adelphi Real

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World Disease Specific Programme (Melanoma); and the Cancer Experience Registry. Seven PROMs were featured: EORTC EQ-5D, FACT-G, FACT-M, RUQ-M, EORTC QLQ-C30, FAS, HADS; and one PREM: QLQ-INFO25. The purpose of collection included clinical auditing, increasing the transparency of melanoma care, providing insights into real-world cost-effectiveness and creating a platform for research.

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**Conclusions/Policy Implications** This study provides viable examples of PROM and PREM collection in large-scale registries, used for a variety of purposes. It identifies specific instruments currently utilised in melanoma care, which may be valuable to integrate into the new Australian Melanoma Clinical Outcomes Registry, (MelCOR).

# Patient experience matters, so what are PREMs actually measuring?

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Introduction/Background	Patient experience is a critical differentiator of healthcare quality and is becoming increasingly more important in value-based performance and purchasing. In order to ensure that users of patient-reported experience measures (PREMs) are selecting the most appropriate instrument for their evaluation purposes, it is important to understand the key domains of patient-reported experiences. Thus the aim of this systematic review was to report on the key domains of patient-reported experiences according to how it has been measured by PREMs to date, and secondly to understand whether the key domains differ according to the healthcare context (e.g. care setting).
Methods	The following databases were searched: Medline, CINAHL and Scopus. No date restrictions were applied. PREMs were only included in the thematic analysis if they were designed to be completed by the individual receiving care and had established validity and reliability. PREMs were excluded from the thematic analysis if they only presented items as item labels (incomplete items), only a portion of items were published, or items were written in a way that they encouraged satisfaction-based answers (e.g. How would you rate...).
Results	Eighty-eight PREMs with some degree of established validity and reliability were identified, of which 59 were included in the thematic analysis. A total of 1,345 items were extracted from the 59 PREMs, resulting in the identification of 8 major themes and 37 sub-themes of patient-reported experience. The eight major themes were: (i) communication, (ii) personable care, (iii) quality, (iv) integration, (v) involvement, (vi) accessibility, (vii) environment and facilities, and (viii) suffering. 'Accessibility' was significantly more likely to be captured in PREMs designed for primary care services than other care settings. The presence of domains did not differ significantly over time.
Conclusions/Policy Implications	Some major themes of patient-reported experiences appear to be more important in some healthcare contexts than others. Users of PREMs need to be considerate of whether the PREM they intend to utilise captures all relevant aspects of the patient-reported experience, in conjunction with other important considerations, such as the appropriateness of the instrument to their local context and patient population, and the instruments established validity and reliability.

# Development of patient experience domains and benchmark levels for NSW Key Performance Indicators

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Introduction/Background	The historic NSW patient experience KPIs needed to be updated to address issues of data stability, appropriateness and benchmark levels to identify underperforming organisations.
Methods	<p>BHI undertook factor analysis of the Adult Admitted Patient Survey (~28,000 respondents) to identify topic domains for reporting. Consultation with stakeholders identified a subset of domains to use as KPIs. Analyses using more than 56,000 adult admitted patients from 2015 and 2016 was conducted to assess reliability, construct and concurrent validity of proposed measures and the reliability of quarterly measures for smaller LHDs and vulnerable populations. Benchmarks were determined through analysis of 2015 and 2016 quarterly distribution of the proposed KPIs, followed by consultation with stakeholders.</p>
Results	<p>BHI identified three measures that provide a broad assessment of some of the most important elements of patient experience:</p> <ul style="list-style-type: none"><li>• Overall patient experience index (four questions)</li><li>• Patient engagement index (six questions)</li><li>• Respect and dignity (single question score).</li></ul> <p>The index scores demonstrated good internal reliability at NSW level (Cronbach's Alpha = 0.87 and 0.77 respectively) and showed high concurrent validity when compared to the existing KPI (<math>r = 0.79</math> and <math>0.83</math>). However, both indices are more reliable and stable estimates of performance than the current KPI. Factor analysis identified the respect and dignity question as being a key component in more than half the domains. Consultation supported that the questions that comprised these indices were seen as highly pertinent to patient-centred care and were demonstrated as having high importance to patients in literature.</p> <p>Benchmarks were established at 8.5 for 'performing' for the index scores and 9.5 for the respect and dignity question</p>
Conclusions/Policy Implications	Establishment of new KPIs requires robust evidence and engagement with users. Benchmarks for acceptable levels of performance can be supported but should be periodically reviewed.

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# Creating intelligence from patient experience: just a Qlik away?

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Introduction/Background	Metro North Hospital and Health Service (MNHHS) provides public cancer care to its 960,000 population at six locations in northern Brisbane. A consumer-influenced cancer patient experience survey (CPES) was adopted in 2016 and garners around 600 responses annually. The survey comprises 57 questions, each with up to six response options. Previously, CPES data was analysed centrally by the MNHHS cancer safety and quality team using Microsoft® Excel pivot tables and charts, then provided in static form to hospital-based committees for analysis and action plan development.
Methods	Data was extracted from the existing CPES database and loaded into the Qlik® data visualisation platform. Questions were grouped into domains. Filtering options reflecting important patient and service attributes were developed. A variable colour-coding regimen was adopted to reflect relative response favourability for each question and domain. Work was overseen by the MNHHS cancer clinical advisory group and undertaken by an in-house analytics team.
Results	The resulting CPES dashboard is now used across MNHHS to identify patient experience achievements and challenges. The dashboard facilitates iterative, local analysis of CPES results. It enriches CPES data by enabling harnessing of tacit information available only at the hospital level (and not centrally) to better understand factors at play in patient-reported experience results and to tailor reforms accordingly.
Conclusions/Policy Implications	Appropriate software, technical capability and analytical skills are vital to transforming patient-reported experience data into intelligence capable of identifying outliers, refining services and recognising success. The growing volume and variation in patients' experiences, scale of data collections and decentralised service models mean that relying on static summary statistics without facilitating dynamic stakeholder inquiry are unlikely to drive optimal improvements. Our application of tools and techniques to CPES data is equally relevant to patient-reported outcomes, with its multitude of response influences and emerging data collection scale and investment.

# Towards systematic monitoring of the experiences of care of Aboriginal and Torres Strait Islander people with cancer: Phase One

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Introduction/Background	Disparities in cancer outcomes amongst Indigenous Australians reflect a pattern of reduced access to and engagement with health services. A growing emphasis on patient-centred care has increased efforts to measure patient experiences, but it is unclear whether existing approaches: a) assess the most critical aspects of care that shape the experiences of Indigenous people with cancer; and b) facilitate the engagement and participation of Indigenous people with the measurement of care experiences.
Methods	Semi-structured interviews and focus groups were used to elicit stakeholders' views on priorities for measuring the cancer care experiences of Indigenous cancer patients and on the acceptability of various methods for capturing such information. Participants included Indigenous people affected by cancer (n=17), health professionals (n=26) and individuals in both groups (n=5). Recruitment occurred through a national web-based network and through four cancer services in urban and regional areas in three jurisdictions across Australia.
Results	Several aspects of cancer care were identified as critical in shaping Indigenous patients' experiences. Key themes included: feeling safe in the system; importance of Indigenous staff; barriers to care; the role of family and friends; effective communication and education; and coordination of care and transition between services. Participants expressed support for a face-to-face interview with a trusted person as the most appropriate means of collecting cancer care experience information.
Conclusions/Policy Implications	While existing experience measurement tools would partially capture some important aspects of care, other critical areas would likely be missed. Appropriate tools and approaches, developed by and with Indigenous people, are urgently needed to determine the extent to which health services are meeting the needs of Indigenous people with cancer, and to identify areas for action to improve these services.

# Measuring client experience in aged care services

Catherine Joyce

Benetas

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**Introduction/Background** While patient experience measures have become standard in health services, client experience measurement in aged care is relatively under-developed, with no standard measurement tools or approaches. We developed and implemented a client experience survey which aimed to better understand client experiences for quality monitoring and improvement.

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**Methods** A client experience survey was conducted across all Benetas Home Care (HC) and residential aged care services in late 2017. All eligible clients (n=1562) and contactable relatives (n=1641) were invited to take part. A customised tool was developed, to measure five domains of quality: Dignity, autonomy & choice; Staff interactions; Personal & clinical care; Lifestyle & support services; and Service environment. The survey tool included 24-32 rating questions and an open-ended question. It was administered through phone and face-to-face interview with clients, and self-completion by relatives.

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**Results** 1374 people responded to the survey, including 518 HC clients (49% response rate [RR]), 318 residential clients (63% RR), and 513 relatives (31% RR). Strongly positive results were observed for foundation aspects of quality, including: Staff treating clients with respect; Respect for privacy; and feeling safe. A wealth of information about potential areas of improvement was generated through both the quantitative and qualitative questions, for example being asked what's important to you; and food quality. Findings were reported back to service managers and appropriate improvement actions incorporated into local Quality Improvement Plans.

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**Conclusions/Policy Implications** The policy context and the new aged care standards place increased emphasis on consumer perspectives. Client experience measurement in aged care can help to illuminate client voice and drive person-centred approaches, increasing quality of care.

Undertaking client experience surveys in aged care is feasible, if resource-intensive, and can generate valuable information for quality improvement. Systems to 'close the loop' to ensure data are used to drive changes are just as important as the data.

## Using the iPOS-Renal to ensure optimum symptom management in dialysis patients

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Introduction/Background	The symptom burden of patients with end stage kidney disease on dialysis has been well documented world-wide. To ensure that patients with distressing symptoms are appropriately referred to the Renal Supportive Care (RSC) service, we established an automatic referral process based upon IPOS-Renal results.
Methods	Since 2014, 6 monthly symptom surveys (POS-S-Renal (2014-2015) and IPOS-Renal (2015-2017)) have been distributed to all dialysis patients as part of usual clinical practice. Hospital haemodialysis (HD) patients complete their surveys while in hospital, and home therapy patients (Peritoneal dialysis (PD) and Home HD (HHD)) are sent their surveys via mail. Nephrologists are informed of their patients' results, highlighting those with severe or overwhelming symptoms.
Results	Surveying the symptoms of dialysis patients since 2014 allowed those with high symptom burden to be flagged to their nephrologist. However, nephrologists were uncertain they had addressed such symptoms in the midst of busy dialysis clinics. Subsequently, nephrologists suggested automatic referral of patients with severe/overwhelming symptoms to the RSC service. In the latest survey (April 2017), 65% of dialysis patients responded. Of these, 38% (54) reported at least one symptom as severe or overwhelming (an average of 3 severe/overwhelming symptoms per patient, range 1-12).
Conclusions/Policy Implications	Evaluating symptom burden in dialysis patients is no guarantee that appropriate treatment will ensue. Appropriate referral to the RSC service should ensure this. Further evaluation is required to assess whether this change in process has been beneficial for these patients.

# RESPONSE: Validating a symptom screening tool for Australian children with cancer

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Introduction/Background	In Australia, there are no standard tools used to routinely assess symptoms associated with cancer and cancer treatment in children 0-18 years, yet young people experience a significant number of symptoms. The associated distress can lead to poor treatment adherence, increased hospitalisation and compromised quality-of-life.
Methods	This project is using a co-design process to develop a system for remote symptom monitoring and delivery of tailored and personalised self-management advice for children and adolescents (8-18 years) with cancer. We are currently validating an Australian translation of a 15 item Symptom Screening Tool in Paediatrics (SSPedi). This tool, developed in Canada, measures patient reported experience of distress from symptoms experienced during cancer treatment. Input was obtained from an Australian expert clinical group to modify SSPedi wording. Cognitive interviewing was completed with 10 children (9-16 years) using 'think aloud' techniques. Probing was used to evaluate understanding of individual items and of the response scale. We used a five point Likert scale (1=very hard to 5= very easy) to rate child's ease with completing the SSPedi and a four point Likert scale (1= completely incorrect to 4=completely correct) to rate the child's understanding of the scale.
Results	Despite the tool being developed in English, there were a number of changes required for translation to Australian English. The mean difficulty for completing all items on the modified SSPedi was 3.3 (mean of individual item range 2.8 to 3.6). The items most difficult for children to complete were symptoms of tingly or numb hand and feet (mean 2.8) and diarrhoea (mean 3.2). Despite children reporting difficulty with completing items, they were able to correctly understand items and the response scale (mean all items 3.8, mean of individual item range 3.6-4.0).
Conclusions/Policy Implications	Validation of the SSPedi tool for the Australian population is the first step in our aim to improve symptom control for children with cancer.

# Assessing the impact of crusted scabies on quality of life in Indigenous communities in the Northern Territory: a pilot study

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**Introduction/Background** The quality of life (QoL) for patients with Crusted Scabies (CS) is unknown, and it is unknown how QoL is impacted over the different stages of disease. In addition, existing QoL measures are not culturally and linguistically appropriate for populations most at risk of CS.

A pilot study is being conducted to test and develop instruments to assess the QoL of people who have experienced CS in the Northern Territory. Our instruments aim to quantify the impact of CS on the various dimensions of QoL including everyday activities and relationships.

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**Methods** The pilot study consists of three phases

1. Pre-measurement:
  - a. Systematic review of existing QoL studies in scabies and/or CS
  - b. Focus group with Indigenous researchers explore whether questions from three existing QoL questionnaires reflect aspects that are important to people with CS, are sufficiently easy to answer and culturally appropriate approach.
2. Incorporating the pre-measurement results, conduct repeated measurement of QoL in 100 individuals
3. Analysis and refinement of a QoL instrument suitable for use in Indigenous populations

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**Results** The systematic review identified 3 QoL studies performed in scabies patients, none of which compared the QoL of patients with CS and simple scabies. All used the Dermatology Life Quality Index (DLQI), or modified versions.

The focus group revealed that the questionnaire needs to be administered by people experienced with working with Indigenous communities, being mindful of gender and poison relationships and local language expertise. Interviewers should be trained and questions asked as part of a conversation. The order and phrasing of questions should be allowed to vary, sufficient time provided and visual aids to assist understanding.

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**Conclusions/Policy Implications** Questions from the complete EQ-5D, the DLQI and the ASCOT were selected. Stick figures will be used to communicate the concept the question is about, and smileys will represent the various answer options.

# Are generic PROMS valid for clinical care? A psychometric assessment

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Introduction/Background	The use of PROMs in clinical settings is becoming widespread, and there is a proliferation of PROMs specific to certain conditions. However, there are many 'generic' instruments designed for use across conditions. These PROMs could have a role in clinical care whilst allowing for comparisons across areas. The aim is to use psychometric methods to test the performance of three generic instruments across different conditions, and inform their potential use in clinical settings.
Methods	Data was collected online from 402 people in Australia reporting different conditions including depression, diabetes, arthritis and severe pain. The sample completed three generic health PROMs (EQ-5D-5L, SF-36, PROMIS-29) as part of a wider battery. We assessed their sensitivity to different conditions, and investigated the relationship between them using correlations, and item response patterns. We also used item response theory to examine which measures exhibited differential item functioning across condition severity groups.
Results	The results suggest that the physical health dimensions of three PROMs are sensitive to differences in the level of severity across the condition groups included. The same is the case for the dimensions focused on mental health and vitality for the depression group. Correlations between the PROMs range from moderate to high meaning that there is overlap in what they measure. There is evidence of differential item functioning, meaning that some items are more relevant for certain conditions.
Conclusions/Policy Implications	The sensitivity of the PROMs suggests that they could be used alongside more condition specific instruments to guide clinical care. They could also be used to feedback information to patients, with the bonus of being able to compare this information across conditions and populations. Further work is needed to establish the widespread use of PROMs in clinical settings, and information from psychometric analysis can help inform which PROMS should be used in which settings.

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# PROMPT-Care eHealth decision-support system: PROMs informing service delivery and self-management

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Introduction/Background	Routine assessment and clinical utilisation of patient-reported outcome measures (PROMs) can lead to improved patient wellbeing and survival outcomes, but clinical integration remains challenging. We developed PROMPT-Care to support electronic PROMs capture in the oncology setting and utilise that information to a) support real-time patient-centred care, and b) empower patients to self-manage their cancer related concerns. It is the first Australian system to achieve full electronic integration into hospital oncology information systems (OIS).
Methods	We developed PROMPT-Care with clinical (n=38) and technical (n=23) input, and demonstrated feasibility and acceptability (Phase 1; n=35 cancer patients, n=5 oncology staff). In a pragmatic controlled implementation trial, patients (currently receiving or scheduled to receive cancer care at four NSW cancer centres) completed PROMPT-Care assessments online approximately monthly, via an emailed link. To facilitate clinical care, PROMs are presented as summary reports, accessed in real-time and used by the medical staff to address “red flag” issues. Furthermore, if the patient’s scores on any PROMs breach a predefined threshold on two consecutive assessments, an email alert is generated for review and action by a designated team of nurse care coordinators.
Results	In the implementation trial (Phase 2) 439 patients completed 2650+ PROMPT-Care assessments. Patients reported that PROMPT-Care facilitated communication and increased recognition and acknowledgment of their concerns. Oncology staff have indicated that the PROMPT-Care system is a useful screening tool which allows them to identify specific issues to raise with the patient during consultations, with the specific clinical feedback reports allowing them to adequately prepare for the upcoming consultation.
Conclusions/Policy Implications	Evaluation will inform the system impact on health service utilisation and utility as an alternative model of ongoing supportive care. Implement as business as usual (Phase 3) will include tailored cancer follow-up care informed by PROMs.

Funding: Cancer Institute NSW, Bupa Health Foundation

# Understanding Patient Reported Outcome Measures and the 3 P Dynamic in Australia: Patients, Payers and Providers

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Introduction/Background	<p><b>Aim</b></p> <p>This paper discusses proposed research to understand why and how Australian Patients, Payers and Providers within the private healthcare system are currently using the PROMS data and metrics.</p> <p><b>Background</b></p> <p>The current status of PROMs collection in the Australian healthcare sector is not as advanced as other countries (e.g. England Netherlands, United States and Sweden). There is a high degree of interest across the sector (both private and public) to collect PROMs to improve patient quality and safety (Williams, 2016). However, there is no consistent or mandatory collection across Australia, collection appears to be selective and differs between hospitals and clinicians. For the Australian private healthcare system, which espouses the patient centricity as core distinctive value, there is a coherent and robust rationale for the collection of PROMS . However, there is limited evidence as to how the Australian private healthcare system and policymakers can and will use PROMS data to improve patient-centred care and patient outcomes.</p>
Methods	<p>This study will be one of the first Australian studies to investigate the use of PROMS and how clinicians and payers expect to use PROMs in the private health care sector. Using mixed methods approach the study will also investigate patient understanding of PROM results and and the barriers to implementation and use in the private health care sector.</p>
Results	<p>Results to be published in the near future</p>
Conclusions/Policy Implications	<p>There is no current information on how private providers and payers view PROMs as a quality improvement tool, as a basis for value-based payment models nor on their willingness to make their PROMS data publicly available. This research seeks to develop a framework within the private healthcare system.</p>

# What Matters? Identifying Wellbeing and Quality of life dimensions for Aboriginal and Torres Strait Islander people.

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Introduction/Background	There are significant disparities between Aboriginal and Torres Strait Islander (hereafter, respectfully, Indigenous) and non-Indigenous populations on individual outcomes/factors that are likely to influence quality of life (QOL) and wellbeing. However, these disparities in wellbeing are not currently captured in conventional wellbeing instruments, as they do not include dimensions that are likely to be relevant to Indigenous populations; for example, connection to land, language and spirituality. To develop Patient Report Outcome Measures (PROMs) for Indigenous people across a range of illnesses, we first need to identify wellbeing dimensions relevant to Indigenous people. The objective of the current systematic was to identify these wellbeing domains
Methods	We searched PsycINFO, PubMed, Econlit, CINAHL, Embase, and grey literature using keywords relating to 1) adult Indigenous Australians and 2) QOL and wellbeing. We included qualitative, quantitative, and mixed methods studies, and review papers. We extracted dimensions of QOL and wellbeing identified in the paper, and synthesised the dimensions into broad themes
Results	Synthesis of the search findings revealed several interconnected wellbeing dimensions including: Autonomy, Empowerment and Recognition; Family and Community; Culture, Spirituality and Identity; Country; Education; Basic Needs; Health; Social and Emotional Wellbeing; and Work, Roles and Responsibilities.
Conclusions/Policy Implications	Our findings suggest the need for a tailored wellbeing instrument that includes dimensions relevant to Indigenous populations. Developing such an instrument will ensure meaningful wellbeing measurement for Indigenous Australian people and will contribute to the development of culturally-appropriate PROMs. Moreover, ensuring the instrument can be used in economic evaluations will enable effective translation of research into practice and policy.

# Development of an Indigenous quality of life and wellbeing index – The What Matters study

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Introduction/Background	Aboriginal and Torres Strait Islander Australians continue to experience significant health inequities compared to non-Indigenous Australians, with markedly worse survival, and higher incidence and prevalence of disease, all contributing to disparities in wellbeing and QOL. However, these disparities in wellbeing are not currently captured by existing utility instruments, as they do not include the dimensions of wellbeing relevant and important to Indigenous Australians; nor are they informed by their values and preferences. The aim of this study is to develop such an instrument.
Methods	This project comprises three phases: 1. Identification and exploration of wellbeing domains for Aboriginal and Torres Strait Islander Australians: systematic reviews, focus groups and face to face interviews with Aboriginal and Torres Strait Islander Australians will be conducted to ensure all relevant dimensions of wellbeing are captured. 2. Development and validation of a descriptive system for the instrument: Relevant dimensions from Phase 1, and those from existing MAUIs, will be refined and prioritised using a best-worst scaling (BWS) study. Face to face interviews and pilot testing will be conducted ensure language of the descriptive system is meaningful. 3. Development of a scoring system for the instrument: We will use a best-worst discrete choice experiment (BWS DCE) to determine the value placed on each dimension/level, as has been done for existing MAUIs.
Results	To date we have conducted 27 focus groups with 260 participants and 6 individual interviews. A systematic review of over 80 articles published in both grey literature and peer-reviewed journals revealed nine tightly interconnected wellbeing domains: Autonomy, Empowerment and Recognition; Family and Community; Culture, Spirituality and Identity; Country; Education; Basic Needs; Health; Social and Emotional Wellbeing; and Work, Roles and Responsibilities.
Conclusions/Policy Implications	The final instrument will ensure that health outcomes such as QALYs can meaningfully incorporate the wellbeing for Indigenous Australians, improving transparency and relevance of clinical and health policy decision making.