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How To Use Metrics, Measures & Insights To Commission Person Centred Coordinated Care: A Guide for Commissioners.

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NHSE

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METRICS FOR PERSON-CENTRED CARE

The use of person-centred measures to improve the quality of care for people with long-term conditions, multiple long-term conditions, and those at the end of their life: synthesis of the evidence.

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About the team

We are a team of academic researchers and commissioners based in the South West and led from Plymouth University. We are supported by the South West Peninsula CLAHRC (Collaboration for Leadership in Applied Health Research and Care) and the South-West Academic Health Science Network (SWAHSN) to develop theory and support innovation for PCCC through a consistent formative evaluation framework (the PCCC Programme). Through a process of critical examination of policy material and key literature we have moved away from the notion of ‘integrated care’, instead framing our theoretical base around two key concepts that are critical for the individual receiving care: person centred and coordinated care (PCCC).

We are currently working collaboratively with the Health Foundation, the Department of Health, NHS England and the Coalition for Collaborative Care. We are evaluating Pioneer, Vanguard and local PCCC sites (e.g. Exeter, Somerset: Test and Learn, SPQS, Torbay: Pioneer, ICO, Kernow: Living Well), and our team includes three clinicians, together providing us with a breadth of hands-on experience of working with services.

About the work

This synthesis is the initial output of a work package commissioned by NHSE in January 2016. The aim of the project is to produce a portfolio of intelligence on the use of measures for improving person centred care for people with long term conditions, multiple long term conditions and those at the end of their life. The final report contains (1) this synthesis (2) a focused compendium of evaluated PCC measures and (3) a commissioner's guide, including implementation stories from institutions that are currently using person-centred care metrics (such as PROMs etc.) in practice to improve care, in addition to guidance about how to select and use such measures. Both the compendium and the commissioner's guide will be informed by patient and commissioner stakeholder engagement workshops.

Box 1 - some common abbreviations in this work.

Box 1: acronyms

LTC	Long-Term Condition
mLTC	Multiple Long Term Conditions
EoL	End of Life (i.e. palliative care)
PCC	Person Centred Care
PRM	Person Reported Measure – any measure from a patient's perspective, whether it is measuring an experience or an outcome
PROM	Patient Reported Outcome Measure
PREM	Patient Reported Experience Measure
PCC-PRM	A PRM that measures some aspect of Person Centred Care
OBC	Outcomes Based Commissioning
QoL	Quality of Life. Often measured by a PRM
HRQoL	Health Related Quality of Life
CCM	Chronic Care Model
CDSMP	Chronic Disease Self-Management Program

Executive summary

The aim of this work was to provide a rapid appraisal of the evidence for the use of Patient Reported Measures (PRMs) to improve the care for those with Long Term Conditions (LTCs), Multiple LTCs (MLTCs) and those at the end of their life (EoL). To achieve this in a short period of time (7.5 weeks) we conducted a rapid and pragmatic narrative synthesis of the available evidence. This involved a two-tiered search-strategy beginning with an initial scoping stage followed by targeted searches (see methods). In total, around 2800 documents (both grey and academic literature) were scanned with 480 relevant documents utilised to inform this evidence synthesis. We set out to answer the following two questions posed by NHSE in the project specification document:

- 1) Is there evidence to suggest that PRMs lead to improvements in the outcomes and experiences of care for people with LTCs, MLTCs and those at the end of their life?
- 2) For whom, and in which service contexts do PCC metrics provide the most benefit?

In answer to the above questions, we found evidence from a number of systematic reviews that Person-Centred Care (PCC) metrics have improved the quality of care in a number of ways. Firstly, as a tool in academic studies that have established interventions which incorporate aspects of PCC (such as the Chronic Care Model (CCM)) and Chronic Disease Self-Management Programmes (CDSMP). Secondly, as an intervention tool with feedback in clinical practice to support aspects of PCC – for examples, where PRMs are used to screen for mental health issues, establish the severity of psychiatric symptoms for stratification of management, monitor for side effects in cancer treatment, or supporting self-management of chronic conditions.

The strongest evidence for benefit has been demonstrated for oncology (followed by psychiatry), where PRMs are now well integrated into services. Palliative care appears to be overcoming implementation challenges. There is a sparse literature on non-cancer LTCs, although evidence is encouraging when aggregated. There is very sparse evidence concerning mLTCs. The section below highlights our key findings and conclusions.

Key Findings:

- The evidence base for the use of PCC metrics to improve care for the above groups is of a complex, fragmented and disparate nature. Furthermore, when assessing scientific studies or clinical interventions that utilise PCC metrics, it is often impossible to disentangle the exact contribution of an individual measure – i.e. they are components of wider systems aimed at improving care.
- We make the logical assumption that for PCC metrics to improve care, then the information derived from a patient/person reported measures (PRMs) has to generate **actionable feedback**. This feedback can operate in a variety of ways - from feedback of individual patient data during a clinical interaction through to aggregated data to inform research or management (see figure 1 of the main text).
- **The “classic” use of PRMs is as an evaluation tool in research studies.** A variety of PRMs (including some specifically designed to measure components of person centred care “PCC-PRMs”) have become an integral component of the researcher’s toolkit, and have helped establish the evidence for PCC interventions.
 - **It is within this context that there is the most robust evidence, including a number of recent authoritative reviews.** Whilst PRMs and PCC-PRMs may not have formed part of the intervention, they have helped establish the evidence for person-centred healthcare and for interventions that improve patient relevant outcomes¹.
 - For example, PCC-PRMs have been utilised to establish various benefits of patient activation and self-management programs (such as the Chronic Care Model) for a variety of chronic conditions²⁻⁴ (including diabetes⁵, cancer⁶, depression⁷), population groups (older people^{8,9,10}) and clinical settings¹¹⁻¹⁴.
- **PRMs have “evolved” from their classic usage into intervention tools in routine clinical practice.** Here, they can be used for diagnosis and monitoring,

but can also act as components of PCC interventions themselves, where it has been established that feedback of PRM data to clinicians and “feed-forward” to patients can improve aspects of PCC such as shared decision making and self-management:

- Early systematic reviews on this level of clinical feedback were compromised by serious methodological issues¹⁵⁻¹⁷, but other reviews (especially more recent publications) have revealed that routine use of PRMs can result in a better quality of care¹⁸⁻²⁰.
 - This has the greatest effect on proximal outcomes, such as PCC or processes of care. There is strong evidence that feedback of PRMs can lead to improvements in: patient-provider communication²¹⁻²⁴, shared decision making, patient satisfaction, experience of care and clinical processes of care^{17-20,25-27}.
 - Routine clinical use of PRMs in this way has a smaller effect on downstream outcomes (such as health outcomes), where the impact becomes equivocal^{16,17}.
 - PRMs have now been well integrated into oncology services, and it is in this context that there is the strongest evidence of their advantages^{19,21}, followed by psychiatry²⁸⁻³⁰.
 - PRMs are increasingly being utilised in palliative care³¹, where idiosyncratic challenges such as impaired cognition and awareness of patients has necessitated the development of proxy-outcome measures (completed by professionals or family)^{32,33}. A recent systematic review found strong evidence for an impact of PRM feedback on processes of care including better symptom recognition, more discussion of quality of life, and increased referrals¹⁸. However, most of the data was from oncology settings, and more research is needed from other contexts.
 - There is sporadic but encouraging evidence from other LTC contexts (e.g. non-oncological/psychiatric)^{16,17,20,34,35}.
- **Finally, there are emerging developments of PRMs, including ePRO/ePRM systems and system-level feedback.** Here, it is hoped that transformative technologies will streamline the use of PRM data – not just in clinical practice and at home, but also for researchers, managers and commissioners.

- There is an increased use of PRM data for system level feedback - including a number of national initiatives; as monitoring tools in schemes such as the Vanguards and Better Care Funds (BCFs); in addition to a policy drive for Outcomes-Based Commissioning (OBC).
- We found little to no evidence that system-level feedback has led to improvements in the quality of care^{15,19,35,36}.
- We found evidence of the growing use of increasingly sophisticated eHealth solutions such as online portals, telehealth and monitoring applications etc. These systems often integrate PRMs seamlessly with other patient-related information. Initial evidence encourages the further development of technological solutions.
- Formalised feedback and computerised technological solutions may improve the outcomes of interventions^{29,37}, with some LTC population groups making sophisticated use of ePRM systems to self-manage, with good evidence of benefits. The best documented of these has been the US-based website, PatientsLikeMe.com.
- Within a clinical context, ePRM systems have been successfully implemented in (for example) US oncology³⁸ and European rheumatology contexts³⁹ as a component of sophisticated networks that can simultaneously provide feedback in various directions.

Conclusions:

- Clarity and guidance is required to help support the appropriate use of PRMs for routine practice. This should include both when and how to measure processes and outcomes, with the right approach for each. For example, experience measures (i.e. Patient Reported Experience Measures (PREMs)) generally measure processes of care and how individuals experience services

or interventions. In contrast, outcomes (i.e. Patient Reported Outcome Measures (PROMs)) tend to measure the subjective perspective of the impact of an intervention on an individual's health or wellbeing status. Both are often necessary, and the measures used should logically reflect the service or intervention being delivered and be chosen in concert with delivery teams and patients.

- The future development of PRMs is on a trajectory that will incorporate the increasingly sophisticated use of technology. This is beginning to unlock the potential for rapid and user-friendly feedback in multiple directions: to patients, clinicians, researchers and healthcare providers. It is likely that aggregated data from these PRMs will have more utility for improving care than current nationwide schemes. However, it will require a flexible and interoperable technological infrastructure that allows the data to be vertically integrated, such that feedback can operate at multiple levels, allowing synergies can be leveraged.
 - Of particular note within the UK context, one example is the QTool ePRO system. This has been developed for use in NHS organisations, can link to the Electronic Health Register (HER) and the data can be used for research and auditing. This is being utilised by the Leeds and Yorkshire Cancer Network, where it is being evaluated by Yorkshire & Humber AHSN.

- The literature on PCC metrics in the context of multimorbidities is sparse. Methodological problems may be overcome by the usage of more nuanced constructs that are designed to suit the specific purposes of the research, which should overcome some of the existing barriers^{40,41}. Furthermore, many generic PRMs that measure aspects of health or health-related quality of life have shortcomings in the context of LTCs and mLTCs, as a single tool is often not valid over such a wide range of outcomes.

- These challenges may be addressed by developments in the underlying statistical construction of PRMs. Computerised adaptive testing (CAT) and item

banking can optimise shorter PRMs that retain good performance against traditional measures⁴²⁻⁴⁴. Of particular note is the NIH-backed PROMIS scheme⁴⁴. This project is compiling a core set of questions to assess the most common dimensions of patient-relevant outcomes for the widest possible range of chronic diseases.

- Further tools that could be utilised in the situation of LTCs/mLTCs include “individualised PROs” iPROs (which are tailored to the specific needs of the patient^{45,46}) and metrics that specifically measure aspects of person-centred care such as activation and self-management. Such measures could be utilised in a suite of tools alongside CATs.
- The combination of generic ePRO software running CAT-based PRMs is likely to be a potent force in the future, particularly for challenging contexts such as system-wide monitoring of mLTCs. Such systems are capable of overcoming many of the existing barriers (most notably, they can be sensitive across a range of conditions without being overly long/burdensome to clinician or patient), and offer the best hope for ambitions of “whole systems outcomes”. These are developments that should be monitored closely.
- The achievement of “whole system” PRM feedback (i.e. simultaneous feedback in multiple directions) will require further research, along with the development of associated methodologies. Such investigations will need to assess the impact and optimisation of feedback in various directions. In particular, there has been very little research on the use of aggregated data for quality improvements (to clinicians, teams, managers and commissioners), and a key question is how to feedback information so that it maximizes interpretability and actionability. Such studies will need to determine whether the presence of issues such as gaming and biases contaminate data, assess whether such programs are cost-effective, whether they misdirect the focus of care and whether they are overly burdensome for clinicians, patients and administrators.

Introduction

Over the course of the 20th century, ageing populations dramatically increased, with the number of people over 40 more than trebling⁴⁷. This demographic shift has dramatically altered health service use (including community care) towards ageing individuals with LTCs, often several at the same time: around 40% of the UK population have a LTC; somewhere between a quarter and a half of patients have multimorbidities (and the number is rising)⁴⁸; LTCs account for 78% of GP appointments⁴⁹ and 70% of inpatient bed days⁵⁰. Not surprisingly, LTCs have been called “the greatest challenge facing health systems around the world today”⁵¹.

“Long-term disorders are the main challenge facing health-care systems worldwide, but health systems are largely configured for individual diseases rather than multimorbidity... Our findings challenge the single-disease framework by which most health care, medical research, and medical education is configured.” – Barnett et al. (2012)⁴⁸

These conditions often require complex and personalised treatment solutions that are both responsive and empowering⁵¹. The assertion of Hippocrates that “It is more important to know what sort of person has a disease than to know what sort of disease a person has” may have got side-lined by the biomedical emphasis of the 19th and 20th centuries, but once again, it seems more relevant than ever. But how do you embed person-centred care into healthcare organisations that have now evolved to be largely driven by systems and processes⁵²?

“Traditional approaches to care delivery, such as medical models, which adopt a paternalistic approach to service design and delivery, often result in tension between the aims and priorities of healthcare professionals and those of patients” – Lawrence & Kinn (2012)⁵³.

Worse still, the problem is compounded by the context of tightening budgets and fiscal austerity – at a time when around 70% of health and social care budgets are allocated to LTCs⁵⁰. Whilst the need for healthcare professionals to incorporate “biopsychosocial” models into their workflow was recognised as early as the 1970s⁵⁴, it wasn’t until the new millennium – when the demographic and economic forces collided – that healthcare policy began to reflect the new reality.

In the year 2000, the NHS Plan began highlighting the need for personalisation and coordination⁵⁵. In 2001, the Institute of Medicine published its globally influential work “A New Health System for the 21st Century”. One of its core aims was a patient-centred system to drive forward improvements in health care quality⁵⁶, and since then, healthcare policy documents have shifted in tone, increasingly emphasising person-centred approaches. The 2002 Wanless report “Securing our future health: taking a long-term view” focused on enablement and empowerment, with patients being described as partners in care⁵⁷. In 2006, the Department of Health white paper, ‘*Our health, our care, our say*’⁵⁸, laid out the agenda for increased integration of social and healthcare services.

“Society is changing and so too are people’s needs. Our population is getting older, chronic conditions are increasing and becoming more complex, and we need to do more to prevent ill-health and support people to live as independently as possible. The importance of listening cannot be underestimated in facing these and other challenges... Genuinely patient-centred care can happen only if we listen to the people who use these services.” - Department of Health (2006)⁵⁸

The notion of person-centeredness took centre-stage in 2008 where ‘*Putting People First*’ began to define the actual practicalities of the approach – co-production, personal care plans, personal budgets, and integrated care⁵⁹. In the same year, Lord Darzi’s ‘*Next Stage Review*’ strove towards improved quality through individual choice and empowerment⁶⁰. Locally-led, patient-centred care was top of the agenda, with the assurance that the NHS will “for the first time... systematically measure and publish information about the quality of care from the frontline up. Measures will

include patients' own views on the success of their treatment and the quality of their experiences.”

The 2010, *Equity and Excellence: Liberating the NHS*⁶¹ further emphasised quality and patient involvement in decision making, and committed to increase the use of Patient Reported Outcome Measures (PROMs) as a means of providing information about “how patients feel”.

DEFINING PERSON-CENTRED CARE

The concept of *person-centeredness* is multi-dimensional and complex – it has a meaning that is subjective, context-sensitive and it often intersects other concepts such as co-ordinated or integrated care. This lack of agreement has – for some years – been viewed as one of the key barriers in the development of successful PCC⁵³. In fact, a large body of both theoretical and empirical literature attempts to define and understand the concept⁶². Whilst PCC may continue to evade a singular universal definition, there is an emerging consensus of the core domains required for PCC^{62–64}. In 2013 a coalition of charities (National Voices) worked with service users to develop a narrative for PCC, encapsulated in a set of 38 “I” statements⁶⁵. These are grouped into six headings (box 2).

The “I” statements are proving to be a coherent framework and structural definition of PCC that is applicable to a broad range of contexts. For instance, our own attempts at mapping both the “I” statements and the Year of Care model⁶⁶ into broad domains of PCC⁶⁷ arrived at essentially identical conclusions to an independently conducted expert-evaluation project⁶³.

Whilst some publications continue to re-iterate that “the field would benefit from a consensus definition ... to clarify how to operationalize a PCC approach”⁶⁸, and concept-reviews of PCC have arrived at a broader and more nuanced definition of PCC comprising 15 dimensions⁶², other researchers are finally beginning to argue that there is a “broad agreement on what it is”⁶⁹.

Box 2: broad domains of the “I” Statements

- Goals/outcomes
- Communication
- Information
- Decision making
- Care Planning
- Transitions

These various components of PCC approaches are particularly relevant to the challenges posed by LTCs and mLTCs - individuals in these population groups spend more than 99% of their lives managing the conditions themselves⁷⁰ and are likely to have highly individualised priorities and goals that will benefit from personalised approaches to medicine. Those that are empowered to self-manage effectively and are “activated” are more likely to adopt healthy behaviours and have better health outcomes and care experience⁷¹.

Methods overview

The full methodology and search strategies of this review are detailed in appendix 1.

This work is a rapid synthesis using a narrative review approach⁷². A two-tiered strategy was utilised. First, an initial scoping stage involved searches for reviews on PRMs and PCC, expert local knowledge, and focused trawls of the grey literature (see appendix for details).

Papers were categorised along several dimensions:

- 1) Direction of feedback (e.g. to researcher, clinician, patient, or system level) – see box 3 and figure 1.
- 2) Condition category (e.g. LTCs; mLTCs, EoL).
- 3) Evidence type (e.g. grey literature; peer-reviewed; systematic review; Cochrane review; narrative review etc.)

This was followed by a second phase of structured searches, which focused on components of the literature that had poor coverage from the first stage (particularly mLTCs and palliative care). In total, around 2800 documents were scanned with 480 relevant documents included in a database of relevant literature, all of which were utilised to inform this evidence synthesis.

Box 3: Pro feedback for improving care

Without feedback, PRM data cannot improve the quality of care. Feedback can operate in a variety of directions:

Level 1: Research (aggregated data)

- Treatment outcomes in a trial
- As an evaluation tool in trials for PCC interventions

Level 2: Clinical practice (individual data)

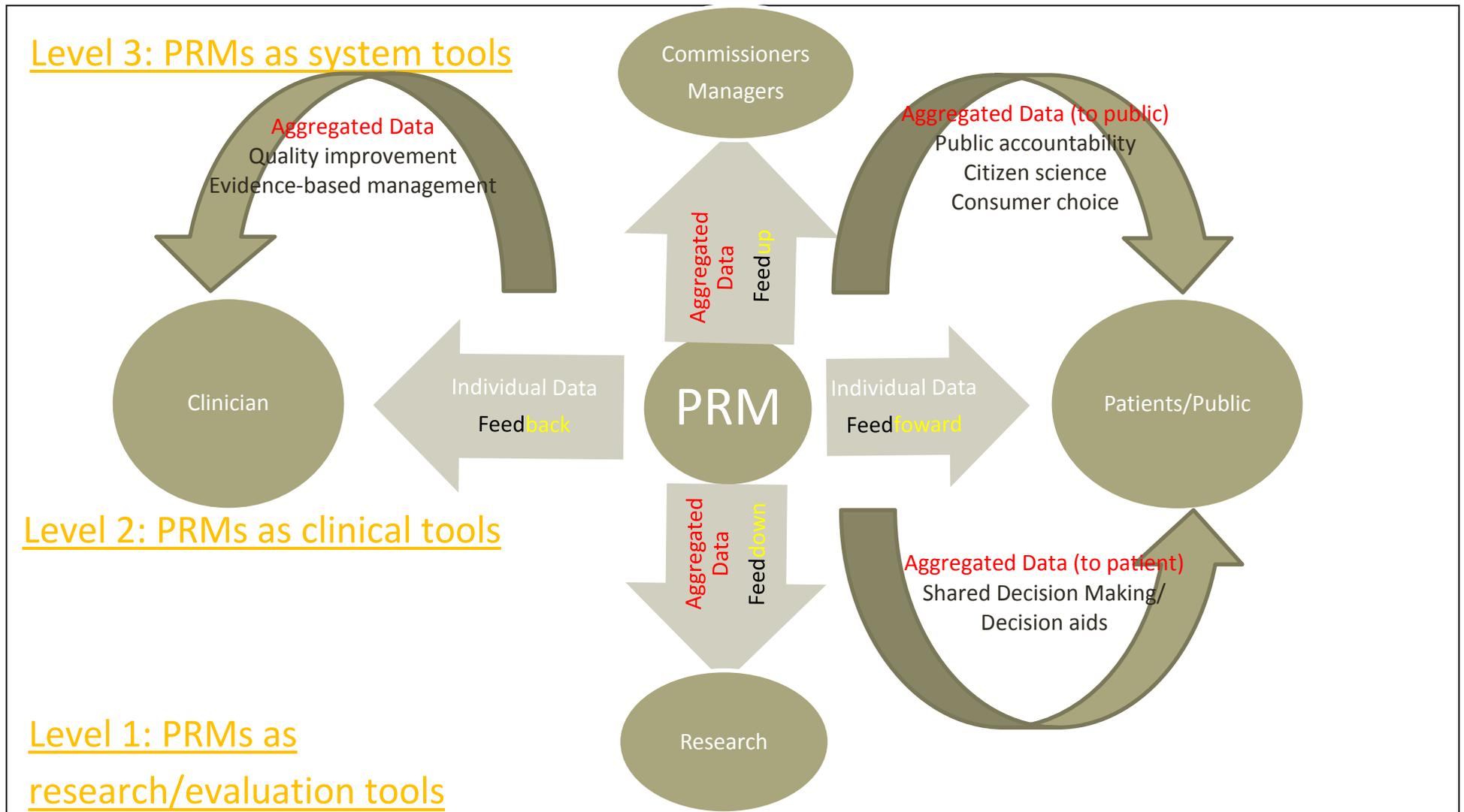
- Feedback can be to clinician and/or patient
- PCC metrics can be used for:
 - Supporting decision making in the diagnostic process:
 - Screening
 - Diagnosis
 - Supporting decision making for treatment (medical/surgical)
 - Informing risk stratification and prognosis (identification of vulnerable patients and those “at risk”)
 - Supporting prioritisation and goal setting
 - Facilitating monitoring of:
 - Health status
 - Response to treatment/management
 - Improving communication
 - Self-management support
 - Shared decision making
 - Personalised care planning

Level 3a: Healthcare providers (aggregated data)

- Benchmarking.
- Audits/quality improvement
- Commissioning/sub-contracting

We found that feedback of PRM data can operate in several directions (see box 3 and figure 1). The following results section of this document is structured according to this simplified schema of how PRMs – and their uses - have evolved within medical systems, with each of the three results sections highlighting the evidence for three distinct “levels” of PRMs to promote patient centred care – 1) as evaluation tools 2) as intervention tools and 3) for system-level feedback.

Figure 1: multi-directional use of PRM data. The diagram is necessarily an oversimplification, and only illustrative examples are given. For more detail, refer to box 3.



Results 1: Patient-reported measures: evaluation tools for person-centred care

Patient Reported Outcome Measures (PROMs) were initially designed as evaluation instruments for academic studies such as Randomised Control Trials (RCTs). The growing family of PRMs expanded to cover aspects of PCCs, where they have been useful tools in establishing the evidence for various PCC interventions.

Whilst PROMS evolved from earlier measures (such as patient satisfaction) that proved to be methodologically problematic, well-validated PROMs have been established to be as reliable as clinical measures such as diastolic blood pressure or blood glucose⁷³. Historically, the PROMs movement has been largely driven by researchers³⁹, generating a vast battery of tools (by the year 2000 there were over 1275 PROMs⁷⁴ - estimates are now entirely unknown). They can be broadly classified along three dimensions (box 4).

“Many PROMs are sponsored by the pharmaceutical industry, in line with Food and Drug Administration guidelines, to support label claims for the added value of their medicines to improve symptom relief or quality of life. Some claim that an unintended consequence of this has been the development of a “cottage industry” of companies developing measures with the needs of pharmaceutical sponsors primarily in mind. Furthermore the sharing of such tools may be restricted through licensing because the measurements are considered to offer a competitive advantage.” - Wicks (2015)⁷⁵

Box 4: the three dimensions of patient reported measures

- 1) **Population Group** e.g.
 - **Disease-specific Vs generic:** this is the most fundamental division of PRMs
 - **Age**
 - **Language/culture**

- 2) **Construct** (i.e. the focus of enquiry) e.g.
 - **Health**
 - **Symptoms** More frequently **disease-specific** measures
 - **Physical/mental/social function**
 - **Health status**
 - **HRQoL**
 - **QoL**
 - **Well-being (mental)** More frequently **generic** measures
 - **Experiences of health care**
 - **Activation**
 - **Person centredness**

- 3) **The measurement model** (i.e. the underlying statistical properties of the model)
 - **Psychometric.** The most common model; uses the sum (possibly weighted) of responses
 - **Clinimetric.** E.g. ranked against other individuals in a trial
 - **Econometric.** Preference based measures, useful for calculating quality-adjusted life years (QALYs)

PROMs have evolved into a broad family of highly versatile tools (box 5), which have been adopted in a variety of contexts, with differing goals and differing feedback mechanisms (box 2). For example, experience measures (i.e. Patient Reported Experience Measures (PREMs)) generally measure processes of care and how individuals experience services or interventions. In contrast, outcomes (i.e. Patient Reported Outcome Measures (PROMs)) tend to measure the subjective perspective of the impact of an intervention on an individual’s health or wellbeing status. Both are often necessary, and the measures used should logically reflect the service or intervention being delivered and be chosen in concert with delivery teams and patients. In this document, we use the term “PRM” as a broad umbrella term for the whole family.

Box 5: Patient reported measures

PRM	A very broad umbrella term that we use for any measurement of aspects of a patient's health status or experience that comes directly from the patient.
PRO	An umbrella term used by the FDA for any measurement of aspects of a patient's health status that comes directly from the patient.
PROM	Patient Reported Outcome Measure – a focus on the outcomes of illness, treatment or care. Usually used interchangeably with PRO in UK.
PREM	Patient Reported Experience Measure. Focus more specifically on a patient's experience of illness. For example, may have PCC aspects on the humanity of care such as being treated with dignity or being kept waiting.
PROXY	A measure completed by a proxy individual (such as carer) at times when the patient may be unable to complete the tool. Particularly relevant to areas such as paediatrics and palliative care.
iPROs	Individualised PROs ⁷⁶ such as the Person Generated Index ⁴⁶ allow patients to modify the content or scoring system, prioritising the symptoms to address ⁴⁵ . Such patient empowerment is particularly salient to complex scenarios such as mLTCs ⁷⁷ . However, there are disadvantages of such measures that include increased burden (for researcher, clinician, administrator and patient), methodological/analytical complexities ^{77,78} and problems with aggregation and “their most important role may be in ... a consultation process” ⁷⁶ .
PCOM	Person Centred Outcome Measure is a term that has been used in different contexts, most commonly as another term for a PROM that measures QoL/HRQoL ^{18,79} .
PCC-PRM	A PRM that measures domain(s) of PCC, such as communication or goal-planning.
ePRO/ePROM	A PROM delivered through a technological interface such as computer, phone or tablet device. It often refers to an integrated technological solution that can aggregate system level data for use by researches and managers.

Naturally, the growing scope of PRMs has extended into the measurement of PCC. At face value, such metrics might appear to resolve the dilemma of promoting person-centred care within the procedurally-driven world of biomedicine. However, progress has been hampered by challenges that are inherited when trying to combine person-centred care with the PRMs movement - the problem of the vast number of PRMs becomes amplified by the lack of conceptual clarity over defining person-centred care. A recent review of metrics for PCC identified 23,746 publications as relevant to PCC metrics, with a total of 921 studies being selected for the review⁸⁰. There are more than 200 named and validated tools available for PCC alone*.

'it is not possible to define what makes a good measure until there is some clarity about what teams are trying to achieve. Context and purpose therefore need to be considered when designing and implementing measurement strategies.' – De Silva (2014)⁸⁰.

Comparisons between the various measures are rare and usually inappropriate due to the heterogeneous nature of the tools, and there is insufficient evidence to recommend one survey tool over another⁸⁰. Instead, the choice of tool depends on a range of factors – the context (hospital, primary care, nursing home or rehabilitation); whether patients, staff or both are the target; the preferred length or number of survey items; and whether the focus is on the broad concept of PCC or a narrower subcomponent (such as communication or shared decision making)⁸⁰. A further key consideration is the timing of data collection – e.g. are the PRMs collected during, before or after a clinical encounter (such issues will be more fully explored in the later “commissioners guide” work package). See table 1 for some examples of commonly used measures and their uses.

* A spreadsheet listing 160 of the most commonly researched PCC measurement tools (as of March 2014) is available for download: <http://www.health.org.uk/publication/helping-measure-person-centred-care>⁸¹.

Table 1: Some common PCC-PRMs

Concept	Examples of Commonly Used Measures
Broad PCC	Individualised Care Scale (ICS) Measure of Processes of Care (MOPC)
	Person-Centred Climate Questionnaire (PCCQ)
Patient Experience/Satisfaction	Consumer Assessment of Healthcare Providers and Systems Hospital Survey (CAHPS) Patient Assessment of Chronic Illness Care (PACIC) ⁸²
Patient Activation	Patient Activation Measure (PAM)
Empathy	Jefferson Scale of Physician Empathy (JSPE) Consultation and Relational Empathy Scale (CARE)
Communication	Components of Primary Care Assessment Tool (PCAT - patient version); no single tool most commonly used
Self-Management	Resources and Support for Chronic Illness Self-management Scale; no single measure most commonly used Lorig/Stanford scales
Shared Decision Making	Decisional Conflict Scale (DCS) OPTION scale
Stroke Specific	Subjective Index of Physical and Social Outcomes (SIPSO) Communication Outcome after Stroke scale (COAST)
Cancer Specific	Patient Satisfaction with Cancer-related Care scale (PSCC)
Cardiac	Swedish Cardiac Self-Efficacy Scale (S-CSES)
Diabetes	Diabetes-specific Illness Representations Questionnaire (DIRQ)

SUMMARY OF RESULTS: PRMS AS EVALUATION TOOLS

Patient-reported measures have been a fundamental part of the researchers' toolkit for studies that evaluate PCC interventions. This has often included purpose-designed PCC measures and QoL/HRQoL PRMs (sometimes referred to as PCOMs). It is within this "classic" context – as an evaluation tool - that there is the most robust and substantial evidence for the use of PRMs to improve the quality of care for a wide range of health conditions. They have helped drive innovation and quality improvements in PCC healthcare, including the widespread adoption of approaches such as self-management and patient activation in chronic conditions - one of the underpinning principles of chronic disease management in the UK and a continuing policy aim⁸³.

Within this context, one of the most widely discussed approaches is the Chronic Care Model (CCM), which emphasises a PCC approach that empowers the person to manage medication, maintain life roles, manage negative emotions, increase self-efficacy to deal with disease related problems and establishes a productive interaction with healthcare professionals⁸⁴. The model has been well-established in meta-analyses to improve processes of care and outcomes⁸⁵, and is implemented in over 1000 healthcare organizations worldwide⁸⁶.

A battery of PRMs and PCC-related metrics have been fundamental tools in assessing the evidence for CCM and other PCC interventions, with recent authoritative reviews (see table 2) revealing that over half of PCC intervention studies have utilised some form of PRM for evaluation. For self-management interventions, a previous systematic review³ revealed that the majority of studies utilised the well-validated Lorig/Stanford scales when measuring self-efficacy and health behaviour/attitude⁸⁷, with many studies using the RAND 36-item survey for health status and Quality of Life. In box 6, we discuss some real-world examples of PCC interventions, and the role that PRMs have played.

Box 6: PCC in practice: Chronic Disease Self-Management Programme (CDSMP)

In Ireland, the CDSMP was introduced in the North West region under the title 'Quality of Life Programme'- a CCM-derived educational/empowerment intervention programme for a range of chronic disease¹¹. An academic evaluation was conducted by University of Ulster, which utilised PCC components of the Lorig/Stanford scales that include communication and self-efficacy, in addition to PRM measures of illness/well-being. The study established the success of the intervention, revealing a significant and marked improvements in self-efficacy, quality of life, health behaviour and health status (in addition to many other self-reported disease specific outcomes), and a non-significant improvement of communication with doctors. Such findings have been replicated in other contexts. In the USA, a 2-year CDSMP program for patients with a wide range of chronic disease revealed reduced health distress and self-efficacy (Lorig/Stanford scales), although there were no significant changes in other outcomes⁸⁸

PCC in Practice: Expert Patients Programme & DESMOND

A UK initiative, the Expert Patients Programme, is a lay-led version of the CDSMP for chronic condition self-management. An RCT evaluation revealed improvements in self-efficacy, control and quality of life of the individual, although there was no reduction in hospital utilisation^{12,89}. Extension of the CDSMP program for Bangladeshi adults with chronic disease revealed improvements in self-efficacy, self-management behaviour, and reduced depression scores, although communication and healthcare use were not significantly different between the two groups⁹⁰.

In Contrast, the DESMOND educational and self-management intervention for diabetes has been established as having a non-significant impact on the self-management of diabetes but a sustained improvement in some illness beliefs^{13,14}.

Table 2. Systematic reviews of PCC interventions, with research-level feedback of PRM data to inform PCC practice

Title	Evidence type	Condition group	No. Of Studies that used a PRM for evaluating the intervention	Intervention	Results	Measures Used
Smith et al., 2016 ⁹¹	Cochrane Review	Multimorbidity	14/18 studies used a PRM	Mostly chronic care model (CCM)	Tendency to improve prescribing and medication adherence.	SF36, PACIC, PAM, HRQOL-14 etc.
Lawrence and Kinn, 2012 ⁵³	Systematic Review	Stroke	2/4 studies used a PRM	Family-centred rehabilitation	Both studies showed improve functioning	Occupational Self-Assessment (OSA-36); Quality from the Patients Perspective; customised.
Dwamena et al., 2012 ⁹²	Cochrane Review	18 of 43 studies on LTCs	14/18 studies used a PRM	PCC training	Fairly strong evidence of improved consultation process.	SF-36 or General Health Questionnaire-12 (GHQ-12) etc.
Olsson et al., 2013 ⁹³	Systematic Review	9 of 11 studies on LTCs	5/9 studies uses a PRM	patient/practitioner partnership	The results suggest that person-centred care may lead to significant improvements	SF-36; Patients satisfaction of care; Patients Perception of Quality of Care etc.
Coulter et al., 2015 ⁵¹	Cochrane Review	LTCs	10/19 studies used a PRM	Chronic care model (CCM)	Probably reduced depression, improved self-management and small improvements in physical health	SF-36, SF-12, EQ-5D, Stanford self efficacy, PAM, and disease specific measures
Lin et al., 2014 ⁹⁴	Systematic Review	Metabolic syndrome	3/5 studies used a PRM	Lifestyle-modification programs	positive effects on some metabolic risks and on quality of life	SF-36, EQ-5D etc.

Such studies have revealed that PCC interventions improve the consultation process for a number of measures including communication, empathy and patient perceptions^{92,93}, although a tendency for equivocal results is revealed as the outcomes measured become more distal – e.g. from patient satisfaction/patient experience, to behaviour and finally health status (which has the most mixed results)⁹². Complex interventions - involving both patient and practitioner – showed the greatest health benefits⁹².

Beyond the context of evaluating PCC interventions, there has also been broader research successes derived from using PCC metrics for the study of LTCs. For instance, they have been used to establish that the overall health profiles of cancer survivors are broadly similar to those with serious LTCs⁹⁵⁻⁹⁷ and that cancer survivors who also report a chronic illness are in poorer health still⁹⁵. This has led to the suggestion that such populations should be re-classified as LTCs, with a subsequent emphasis on long term care^{98,99}.

“With recent improvements in the early detection, diagnosis, and treatment of cancer, people with cancer are living longer, and their cancer may be managed as a chronic illness. Cancer as a chronic illness places new demands on patients and families to manage their own care, and it challenges old paradigms that oncology's work is done after treatment.” – McCorkle et al. (2011)⁶

In summary, there is a growing body of evidence supporting the use of PCC approaches¹, with a substantial proportion of these studies using feedback from PRMs, PCC-PRMs or PCOMs to establish various benefits of self-management programs (particularly the Chronic Care Model) for:

- Routine clinical settings¹¹⁻¹⁴.
- A wide variety of chronic conditions – where 18 of 27 CCM studies demonstrated reduced health care costs or lower use of health care services^{2,3,100}.
- Cancer – where “self-management is critical across all the phases of the cancer care continuum”⁶.
- Older people with chronic conditions – where they “may lead to small, short-term improvements in participants' self-efficacy, self-rated health, cognitive symptom management”⁸⁻¹⁰.
- Arthritis – where the “[small] functional gains that can be achieved in a growing older adult population translate into a larger effect overall”¹⁰¹.

- Diabetes - where self-management improves HbA1C levels, self-efficacy, and empowerment^{5,8,102}.
- Hypertension and heart disease^{8,102}.
- Depression^{7,102}.

“UK and US policy supports person centred care and shared decision making, and the World Health Organization champions it. We know it improves the quality of care and promotes appropriate use of services. There is broad agreement on what it is, and guidance on how to deliver it. The challenge remains one of overcoming “system” inertia and paternalism.” - Richards et al. (2015)⁶⁹

Results 2: Patient-reported measures: intervention tools for person-centred care

The US Food & Drug Administration (FDA) defined a PRO as an umbrella term for all the various quantitative tools that measure “any aspect of a patient’s health status that comes directly from the patient (i.e., without the interpretation of the patient’s responses by a physician or anyone else)”¹⁰³.

This broad definition emphasises the notion that at a fundamental level, all PRMs can be defined as person-centred tools - whilst the “construct” (the focus of enquiry) might be unrelated to PCC, the very act of asking questions is inherently person-centred. In some contexts, even the most disease-specific constructs can efficiently tap the issues that matter most to the patient, but with none of the unnecessary burden of extra questions. If this information is effectively fed back to the practitioner, the patient - or ideally both - then it can often form a central component of a PCC intervention.

An increasing number of studies have involved PRMs in this central role, as a component of intervention. In other instances, PRMs can be simultaneously acting as both an *intervention* and an *evaluation*.

There have now been a number of systematic reviews on the use of feedback and “feed-forward”[†] within the clinical context. These are summarised below, although many of the nuances are lost in such a uniform review, with the underlying schemes being highly heterogeneous. They vary in terms of the instruments used; the mechanism of feedback; the nature of training; the outcomes measured; even a lack of consensus how the intervention actually works^{15,17,45}. Furthermore, the interventions themselves are often highly complex¹⁰⁵, and PRMs may only be one aspect. With regard to the outcome assessed by an intervention, these can vary from the proximal (e.g. clinician-patient communication or shared-decision making), through the intermediate (e.g. self-management and patient experience), to the distal – e.g. health outcomes (including quality of life)¹⁵. Logically, studies are more likely to observe an impact on proximal outcomes, and these may be a more realistic goal.

[†]A term occasionally used for patient-directed feedback¹⁰⁴

PRACTITIONER/PATIENT FEEDBACK OF PRMS: GENERIC REVIEWS

The findings of early systematic reviews were severely compromised by serious methodological issues of the underlying publications^{15,17,45‡}. However, later systematic reviews – particularly in oncology and psychiatry (discussed in detail below) - have found a series of mixed but encouraging findings (see table 3 for details).

These reviews revealed that:

- The routine use of PRM feedback in a variety of contexts (often LTCs) can result in a better quality of care^{18–20}.
- The greatest effect is on proximal outcomes such as PCC or process of care, with strong evidence of improvements in processes of care (including patient-provider communication and shared decision making), patient satisfaction, and experience of care^{17–20,25–27}. These findings have been replicated in reviews in a variety of contexts, including cancer^{19,21}, palliative care¹⁸ and LTCs^{17,20}.
- Routine clinical use of PROs has a smaller effect on distal outcomes (such as health outcomes), where the impact becomes more equivocal^{17–20,25–27}.
- One systematic review (currently being updated) reported that routine use of PROs had an impact on process of care in 65% of studies. In contrast, only 47% of studies had an impact on outcomes of care^{16,17}.
- Systematic reviews of the impact of PRM interventions on outcomes (as measured by PROMs) range from 0 (oncology)²¹; 36% (psychiatry)²⁵; 41% (non-specific patient population)³⁵ and 60% (psychiatry)¹⁰⁶.
- In non-psychiatric LTC populations, there is little evidence for the use of PROs for screening³⁵.
- There are concerns by clinicians that PRMs can be burdensome for routine use. However, these barriers may be overcome by increasingly sophisticated technological solutions¹⁰⁷.

‡The statistical analysis did not correspond with the unit of allocation i.e. patients were analysed as if they were the units of randomisation when, in fact, it was clinicians or groups of clinicians that were randomised.

- The effect of intervention may be strongest when there is both feedback and feedforward within a formalised feedback mechanism²⁹. For example, feedback/forward of OQ-45 scores in a psychiatric clinic prior to each visit¹⁰⁸.
- Computerised support tool software and frequency of feedback are also related to positive therapeutic outcomes²⁹ - for example, as a signal alarm tool in psychotherapy¹⁰⁹.

Table 3. Reviews of PCC interventions with clinical feedback/forward.

Title	Evidence type	Feedback	No. of studies	Condition group	Results
Greenhalgh and Meadows, 1999 ³⁴	Review	Clinicians	13	5 LTCs; 1 elderly patients	Increases the detection of psychological and, to a lesser extent, functional problems. Little evidence to suggest their use substantially changed patient management or improved patient outcomes.
Marshall et al., 2006 ²⁰	Structured review	Clinicians/Patients	38	13 mental health; 5 cancer; 4 chronic illness; 3 older people	Feedback of PROMs to health care providers appears to have a substantial impact on some processes of care; the impact on patient health status is less consistent.
Greenhalgh, 2009 ¹⁵	Narrative Review	To clinicians for multiple purposes	?	Mixed	As screening/monitoring tools - can improve detection particularly in psychiatric problems although a much smaller impact on clinical management; less evidence for promoting PCC, but the best evidence is for improved communication.
J. M. Valderas et al., 2008 ¹⁷ ; with update - Valderas, 2010 ¹⁶	Systematic review	Clinicians	34	14 mental health and 6 other LTCs	Impact on 65 % of studies measuring process of care and 47 % of studies measuring outcomes of care.
Gonçalves Bradley et al., 2012 ¹⁰⁷	Systematic review of qualitative studies	Clinicians	8	Unknown; conference abstract only	PROs could be considered as an indicator of patient-centeredness and good quality of care; barriers can be overcome via technology.
Boyce and Browne, 2013 ³⁵	Narrative Review	As screening tool; as patient management tool; as performance tool	16 for patient level feedback	15 on LTCs	41 % of studies found a positive effect; best evidence for PROMs as a management tool in an outpatient setting on a specialised patient population. In contrast, there was weak evidence supporting with the use of PROMs as a screening tool.
Lockett et al., 2009 ²¹	Review	Clinicians/Patients	6	Oncology	Impact on communication but effect on patient outcomes was limited.

Metrics for PCC

Alsaleh, 2013 ²²	Systematic	Clinicians/Patients	6	Oncology	The routine use of such tools in the outpatient settings for improving patient outcome or satisfaction cannot be recommended.
Howell et al., 2015 ²³	Scoping	Clinicians	30	Oncology	PROs enable earlier detection of symptoms and may improve communication between clinicians and patients.
Kotronoulas et al., 2014 ²⁴	Systematic	Clinicians/Patients	24	Oncology	Increase the frequency of discussion of patient outcomes during consultation, associated in some studies with increased supportive care measures, improved symptom control and better patient satisfaction.
Gilbert et al., 2015 ³⁷	Narrative	Clinicians/Patients + system level	7	Oncology	The routine collection and feedback of PROs was found to improve care for patients at both an individual level, through improved communication and management of symptoms, and at an organizational level, by enabling aggregation of data to compare performance.
Chen et al., 2013 ¹⁹	Systematic	Clinicians/Patients + system level	27	Oncology	Strong evidence that the PROs improved patient-provider communication and patient satisfaction. There was also growing evidence that it improved the monitoring of treatment response and the detection of unrecognised problems.
Espallargues et al., 2000 ²⁵	Systematic	Clinicians	21	Psychiatry	55% finding a significant improvement in at least one process indicator and 36% detecting significant improvements in outcome.
Gilbody et al., 2001 ¹⁰⁶	Systematic	Clinicians	9	Psychiatry	Increased recognition but no impact on patient management or outcomes.
Gilbody et al., 2002 ¹¹⁰	Systematic	Clinicians	9	Psychiatry	Little impact on recognition, outcomes or clinical decision-making.

Metrics for PCC

Knaup et al., 2009 ²⁸	Systematic	Clinicians/Patients	12 (1 old age)	Psychiatry	Feeding back outcome showed a small, but significant positive short-term effect.
Krägeloh et al., 2015 ²⁹	Scoping	Clinicians/Patients	27	Psychiatry	Nine of 11 studies with formalised feedback reported significant effects of intervention.
Etkind et al., 2015 ¹⁸	Systematic	Clinicians/Patients	13	Palliative Care	There was strong evidence for an impact of PCOMs (e.g. QoL PROs) feedback on processes of care including better symptom recognition, more discussion of quality of life, and increased referrals based on PCOMs reporting.

The specialties of oncology and psychiatry – with the advantages of a stable clinical environment – have pioneered the use of PRMs for formalised feedback in routine clinical settings, where they are now well integrated into services. It is in these disciplines that there is the most advanced, sophisticated, and most robust evidence for their use (see table 3).

It should be noted that PRMs can act as both *evaluation* and *intervention* tools - sometimes, even performing both roles simultaneously. The prime example for this is the Patient Activation Measure, which is discussed in box 7.

Box 7: PCC in Practice: Dual-use metrics for evaluation and intervention – the Patient Activation Measure (PAM)

The distinction of PRMs as evaluation tools versus intervention tools is an oversimplification. Many tools can be used for both purposes, often at the same time - especially measures for PCC such as the PACIC.

A prime example is the well-validated PAM, a tool measures how engaged a person is with their healthcare and assessing their knowledge, skill and confidence for self-management¹¹¹. It has been used in a variety of guises:

1) As an evaluation tool – often for educational interventions such as the Chronic Disease Self-Management Program. Studies have revealed that patients can have significantly higher PAM scores at the end of programs⁹, are subsequently more likely to use decision aids¹¹² and show improvements in knowledge and behaviour¹¹³.

2) As a targeted intervention to increase Patient Activation - health coaching and educational classes have specifically aimed to increase PAM¹¹³. Higher PAM scores have been associated with improved QoL^{9,114}, experience of care^{115,116}, adherence to treatment^{117,118}, reduced symptoms¹¹⁹ and reduced hospital admissions¹²⁰. A common finding is that patients who begin with the lowest activation scores typically benefit from the highest increases in their scores^{9,113,121}, although they may require more support¹¹².

3) For population segmentation to target interventions - examples include using PAM to allocate the correct strategy for recurrent urinary tract infections (self-management versus frequent appointments)¹²²; scheduling mammogram appointments according to activation level¹¹⁶; or to tailor the level of support for patients as they transfer to home from hospital¹²³. Grouping patients by disease burden and activation level has the potential to create a more efficient allocation of resources.

PRACTITIONER/PATIENT FEEDBACK OF PRMS IN ONCOLOGY

Within oncology, the use of PRMs is well-established, and there is clear evidence that they are being routinely utilised to deliver high-quality care. This clinical context has allowed a small number PRMs to be widely used for monitoring purposes (e.g. EORTC-QLQ30).

- A consistent finding is that PRMs improve communication between patient and practitioner²¹⁻²⁴. This is supported by qualitative evidence, where explicit feedforward during consultation has been shown to provide an opportunity for the patient to clarify and further elaborate on the side effects of chemotherapy and make decisions about support¹²⁴.
- Additionally, some recent & large systematic reviews find evidence that there is increased supportive care measures, improved symptom control and better patient satisfaction²⁴, monitoring of treatment response and the detection of unrecognised problems¹⁹. However, there is negligible impact on health outcomes^{19,24}.
- Whilst some studies have reported clinically significant impacts on Health-Related Quality of Life (HRQoL)¹²⁵, one recent systematic review concluded that routine administration of questionnaires in medical oncology outpatient clinics is currently “hardly justified”²².
- Recent reviews identified that PROs were now successfully being used at an organizational level by enabling aggregation of data to compare performance³⁷. This is contrary to slightly earlier publications¹⁹, suggesting that technological development is currently being pioneered within oncology.

PRACTITIONER/PATIENT FEEDBACK OF PRMS IN PSYCHIATRY

The relatively advanced use of PRMs within the field of psychiatry has its roots in psychotherapy, where the routine use of PRM feedback has been well established for two decades or more¹²⁶, and a 2006 meta-analysis revealed that formalised feedback of patient progress reduced deterioration by 4% to 8%, increased positive outcomes and reduced the average cost of treatment per patient¹²⁷. Other studies have revealed that it leads to faster recoveries and is twice as likely to achieve a clinically significant improvement¹²⁸.

Two short tools that have emerged from psychotherapy and deployed in a psychiatric context are the Outcome Rating Scale (ORS, a HRQoL measure) and the Session Rating Scale (SRS, a PCC

measure)¹²⁹, where they have produced small but significant improvement on mental health outcomes²⁸. Furthermore, the ORS/SRS are now utilised within the context of the UK's Improving Access to Psychological Therapies programme (IAPT – see box 8)^{130,131}.

- In contrast to non-psychiatric contexts³⁵, PRMs are more promising for screening in psychiatry^{15,20,132}, although this may have little impact on subsequent clinical practice^{34,106,133}.
- The evidence is weaker as monitoring tools¹⁵.
- Feedback on perceived health status to health professionals has an effect on the process of care²⁵.
- Whilst early reviews found the effect on outcomes equivocal^{25,106,110}, more recent (and larger) systematic reviews have found small, but significant evidence on therapeutic outcomes²⁹ and short-term effects on mental health outcomes²⁸.

See box 8 for a discussion of IAPT, where a number of PRMs have now been routinely integrated into psychological therapy services.

Box 8: PCC in Practice: Improving Access to Psychological Therapies programme (IAPT)

The IAPT was implemented in 2008, overhauling the management and treatment of psychological therapies in the UK, and making it mandatory for practitioners to use and record PRMs at every encounter with patients¹³⁴. It has been a pioneer for the emerging health-care strategy of combining health-care treatment with data collection and dissemination. For adults, this includes a battery of standard assessment measures that are used at every session, including:

- Patient Health Questionnaire (for depression - PHQ-9)
- Work and Social Adjustment Scale (WSAS)
- Additionally, condition-specific measures e.g. IESR (for PTSD)

Completed at the end of treatment:

- IAPT patient choice and experience questionnaire

Data is inputted into IAPTUS – either by clinician or patient (even at home). The software has user-friendly aggregated data-analytic packages available for service managers.

Furthermore, the data collected from the child & young person CYP (CYP IAPT) are centrally collated by the child and adolescent mental health service (CAMHD) Outcomes Research Consortium (CORC)¹³⁵, with the dataset being utilised for evaluation of PROMs within this psychiatric context¹³⁶ amongst numerous other research applications¹³⁷.

PRACTITIONER/PATIENT FEEDBACK OF PRMS IN PALLIATIVE CARE

- PRMs are increasingly being utilised in palliative care³¹, although their uptake and development is behind other specialities such as cancer and psychiatry.
- This context has idiosyncratic challenges. For instance, impaired cognition and awareness of patients necessitates the frequent use of a proxy to complete the outcome measures (e.g. completed by professionals or family)^{32,138–140}. A large body of research is being conducted on aspects concerning the barriers and facilitators of PRM use in this context³³, and the integration of outcome measurement into routine practice is proving challenging³³.

- A recent systematic review found “strong evidence for an effect of PCOMs feedback [particularly HRQoL measures] on processes of health care that allows more responsive and holistic care”¹⁸, in particular better symptom recognition, more discussion of quality of life, and increased referrals. There was evidence of improved emotional and psychological patient outcomes but no effect on overall quality of life or symptom burden¹⁸. Such findings have been replicated in the context of childhood advanced cancer¹⁴¹.
- However, most of the data was from oncology settings, and more research is needed from other contexts¹⁸.

PRACTITIONER/PATIENT FEEDBACK OF PRMS: OTHER LTCS AND MLTCS

Much of the evidence for PRMs for the management of non-cancer LTCs are at a much earlier stage of implementation, and the majority of the evidence from the above reviews is derived from oncology. A recent study highlighted a number of implementation difficulties (particularly response rate and follow-up timeframes) that need to be overcome prior to the widespread adoption of PRMs in primary care for LTCs¹⁴². Nonetheless, studies have found that PRM use can improve the quality of care in a range of LTCs. For instance, a US-based study has established that the Patient Assessment of Chronic Illness Care (PACIC) scale (a PCC metric) was positively associated with self-management, patient-rated health and quality of life in adults with a variety of chronic conditions (diabetes, chronic pain, heart failure, asthma and CAD)².

With regard to individuals with multimorbidity, we discovered very little evidence for how PRMs influence the quality of care. Whilst the above studies would likely have contained significant numbers of individuals with multimorbidity⁴⁸, there are unresolved methodological issues with the classification of mLTCs (as they are highly variable) which continue to limit progress⁴¹. Future research that adopts more nuanced constructs (such as ‘complex multimorbidity’⁴¹) that are designed to suit the specific research purposes should overcome some of the existing barriers⁴⁰.

Results 3: Emerging themes: system-level feedback & ePROs

Converging forces are driving the usage of PRMs on a future trajectory where it is hoped that they can put the patients' voice at the heart of health services (see figure 1 on p17). First, it is thought that system-level aggregation of PRM data could improve healthcare services – for instance, by informing service design and commissioning¹⁴³. Second, transformative technology is beginning to unlock PRM data to realise these ambitions, allowing the simultaneous use of data to be efficiently leveraged by several parties – the clinicians, patients, researchers, managers and commissioners. This section first explores the evidence of how aggregated PRM data is being utilised by national and local schemes, followed by an overview the state-of-play in the deployment of technological ePRO solutions.

EVIDENCE FOR SYSTEM-LEVEL FEEDBACK

The use of PRMs for system-level aggregation is a relatively new concept, and a review of PRMs in cancer stated that the evidence was non-existent for effective quality improvement, increased transparency, accountability, public reporting and better health care system performance¹⁹, confirming earlier reviews¹⁵. A further systematic review discovered only one study with group-level feedback³⁵, with this study finding no intervention effect¹⁴⁴.

“The infrastructure and established processes also must ensure that the most vulnerable (e.g., elderly, those with learning difficulties or dementia) who are just as likely to benefit from healthcare improvements are not excluded when PRO data are collected.” – Black et al. (2015)³⁶

Nonetheless, a variety of national and local programs in the UK are now routinely implementing PRM data as system-level monitoring tools, often targeting patient groups such as older adults or those with LTCs with the explicit goal of incorporating PCC approaches into clinical practice. As discussed in further detail below, many of these schemes are often at early or pilot stages (e.g. such as the Vanguard and Better Care Fund); have been hampered by implementational

challenges (e.g. incentivisation of a PRO for depression under the Quality and Outcomes Framework); often with a lack of agreement about what core outcome measures might be appropriate for new models of care. Despite these issues, some schemes – such as mandatory PROs for surgical procedures – have at least established that PRMs can be routinely collected and provide meaningful data.

Often, large-scale national surveys (see below) are implemented to address the needs of policymakers – particularly targeting accountability and transparency¹⁴⁵. However, it has been argued that there is a “chasm” between the views of senior managers and clinicians at the front line¹⁴⁶. Traditional methods have been criticised for survey length, being too generic and not focused at those who could most benefit from improvements in care, infrequent sampling frequency, slow feedback and failure to use results to improve care¹⁴⁷. Furthermore, these schemes have come under criticism for methodological problems and the difficulty of effectively using the data to actually improve care^{147–150}.

QOF depression PRO

Standardised PRO measures⁵ were implemented for the evaluation of depression severity within primary care in 2006 as part of the GP pay-for-performance scheme, the Quality and Outcomes Framework (QOF)¹⁵². Whilst patients were generally positive about the questionnaire as a ‘tangible measure’ of their condition^{153,154,155}, the PRO was criticised by clinicians and researchers for a series of implementational difficulties. It was deemed intrusive¹⁵⁵, burdensome^{150,155}, and the lack of formal training¹⁵⁰ compromised both validity¹⁵⁵ and limited the occurrence of patient feedback for shared decision making and treatment choice¹⁵⁴. Incentivisation of these PROs under the QOF scheme was stopped in 2013¹⁵⁶.

NHS Friends and Family Test / NHS Choices Reviews

The NHS Friends and Family Test (FFT)¹⁵⁷ – a single, global question of patient experience – has been criticised for statistical and methodological issues that render it unsuitable as a comparator across organisations or as a basis for incentive payments¹⁴⁸. In fact, research has suggested that aggregated or composite scores from existing quality scores (rather than global

⁵ Patient Health Questionnaire [PHQ-9], Beck Depression Inventory Second Edition [BDI-II], and Hospital and Anxiety Depression Scale [HADS]),¹⁵¹

healthcare ratings) may have several advantages (higher validity and greater ability to detect differences)¹⁵⁸.

However, such schemes are designed with the explicit goal of enabling consumer choice. Evidence from both the NHS choices review (an internet review of NHS services, where 3/5 questions cover dimensions of PCC) and a US equivalent suggest that they can provide a good indication of the quality of health services, as measured by patient experiences, mortality and patient safety rates^{159–161}. Nonetheless, one criticism is that many patients – particularly those most at need – are not in a position to make choices concerning service providers. Furthermore, even if targeted to individuals with LTCs, MLTCs and those at the end of their life, the friends and family test will simply not capture the issues of importance in relation to the complexity of care that these individuals' require.

“Unsolicited web-based patient ratings of their care, though potentially prone to many biases, are correlated with survey measures of patient experience. They may be useful tools for patients when choosing healthcare providers and for clinicians to improve the quality of their services.” - Greaves et al. (2012)¹⁵⁹

Routine PROMs in the NHS

The national PROMs programme** collects data for all NHS patients undergoing one of four elective surgical procedures (hip replacement, knee replacement, varicose vein, and groin hernia surgery), both before and some months after surgery^{162,163}. This programme has a specific focus on aggregated data for comparison of providers.

Prior to the scheme, there was little evidence that feedback from such system-level schemes could be used to improve quality^{19,35}, and the scheme has served as a template for understanding the feasibility, feedback and implementation of routine PRM collection and feedback. Early publications on the NHS scheme argued that the aggregated data had utility to determine differences between providers, between sub-groups of patients and changes over time¹⁶³, with the data being used to establish that there was no evidence of inappropriate surgery¹⁶⁴. It has been established that the PROM/PREM utilised measured different aspects of

** EQ-5D and EQ-VAS alongside condition-specific instruments – Oxford Hip Score; Oxford Knee Score; Aberdeen Varicose Vein Questionnaire.

patient domains of quality¹⁶⁵, and that a higher level of communication and trust was most strongly associated with outcomes - a higher experience score (of about 1.5 on a 10-point scale) was associated with about 30% less likelihood of the patient reporting a complication¹⁶⁵. The scheme has achieved modest recruitment rates, with demographic influences that do not confound analysis^{166,167}. The data has been utilised for benchmarking across hospitals, with the data aggregated in a format suitable for presentation to the general public¹⁶⁸. Whilst there is no general evidence that hospitals with lower resource use have worse health outcomes, there is unexplained variation amongst hospitals. This suggests that there is room for improvement among hospitals in both their utilisation of resources and patient outcomes and that the data is meaningful for directing attention towards under-performing hospitals¹⁶⁸.

The scheme has therefore provided evidence that the systematic collection of PRM data is feasible at such a large scale and that it provides relevant information about health services delivery. However, it has been criticised that there was little room for inter-provider variation¹⁴⁹, and there does not appear to be evidence to support the notion that increased competition results in improved quality¹⁴⁹. Furthermore, the scheme represents only 1.6% of total hospital activity and it has been argued that routine PROM collection should be extended to other areas of hospital activity – for instance, those areas where there is greater scope for improvement of care, such as emergency admissions to hospital¹⁴⁴. This should first be implemented in those conditions or procedures where existing evidence suggests wide variation in costs and/or other measures of quality¹⁶⁸. Indeed, the program is being considered for people suffering from long-term conditions such as asthma, diabetes and heart failure¹⁶⁸.

“[There is] an obvious gap in the literature on the value of group-level PROMs data as a performance assessment tool. This latter finding highlights a consistent failure by health systems when implementing national policies; resources are invested in policies which are not based on evidence of effectiveness and are not underpinned by a theoretical basis on the mechanisms by which change may occur.” – Boyce & Browne (2013)³⁵

The NHS in England is committed to expanding the use of PROMs, and a Department of Health-funded study recently investigated the potential for using PROMs to enhance the quality of life for people with various long-term conditions (asthma, COPD, diabetes, epilepsy, heart failure and stroke)^{142,169}. The primary conclusions of the study were that the baseline response rates would need to be increased and that longer follow-up periods would be necessary if PROMs are

to be used routinely to monitor outcomes in LTCs, highlighting the implementational nuances that have to be overcome for successful delivery of nationwide PRM initiatives. Furthermore, this pilot study raised questions about the suitability of the EQ-5D to detect changes in LTCs over time¹⁴².

National patient surveys

The national patient survey programme for England conducts annual surveys that include questions about presence of LTCs and dimensions of PCC such as interactions with carers, shared decision making, and support^{††}. However, response rates continue to fall¹⁷⁰ and have drawn criticism that “simple rating or satisfaction questions may not adequately capture the totality of people’s experiences”¹⁷¹. Furthermore, such schemes may not adequately address those with complex health and social needs, with these population groups also liable to introduce response biases into the dataset.

“The NHS has been collecting data on patients’ experience of care for over 10 years but few providers are systematically using the information to improve services.” – Coulter et al. (2014)¹⁴⁵

Pioneers, Vanguard sites and Better Care Fund

In recent years, a number of related UK government-led initiatives have aimed to increase the integration of care with a person-centredness focus, particularly for patient groups whose needs are not well met and for those who contribute a significant cost to healthcare services (such as LTCs and mLTCs). These schemes have included the Integrated Health and Social Care Pioneers, the later Vanguard sites and the Better Care Fund.

The Better Care Fund (BCF) – a pooling of local government and NHS budgets via Health and Wellbeing Boards (HWBs)¹⁷² – aims to integrate services, often with a person-centred approach

^{††} The GP Patient Survey data is available from:

<https://gp-patient.co.uk/>

<https://indicators.ic.nhs.uk/webview/>

The dataset includes PCC aspects of LTCs at a CCG level, such as health-related quality of life for people with long-term conditions.

around older individuals or those with LTCs or at the end of their life. For monitoring of the BCF schemes, in addition to the standardised BCF metrics^{††}, around 75% of the local systems claim to capture and monitor a variety of other patient-reported statistics to help improve care. The use of these statistics was recently reported¹⁷³, revealing that the collection of this data is highly heterogeneous in terms of timeframes (most often annual data) and methods (e.g. from face-to-face, mobile kiosks, mail-outs to local paper surveys). Furthermore, the feedback mechanisms are opaque, with only around 20% of CCGs using this data for issues such as procuring services, strategic planning, monitoring and evaluation, and very few concrete examples of how the data is actually being used to improve the quality of care. Box 9 discusses one of the best documented examples of BCF schemes, the Doncaster Academic Partnership.

Box 9: PCC in Practice: Doncaster Academic Partnership

The Doncaster Academic Partnership involved Doncaster Metropolitan Borough Council working in partnership with Sheffield Hallam University and the University of Sheffield. As part of this scheme, Doncaster is shifting to an Outcomes Based Commissioning (OBC) model, and hopes to reduce hospital usage amongst its ageing population that has high levels of deprivation, poverty, heart disease, stroke and cancer. The scheme has been assessed using nearly 900 questionnaires completed after one year, which included (1) Health Related Quality of Life and (2) subjective well-being¹⁷⁴. This revealed that despite pain/discomfort increasing (which was expected, due to worsening condition of many respondents), there were positive changes in both measures of self-care and wellbeing, most notably in the level of social contact (important for frail elderly).

^{††}These are publicly available via the BCF Atlas: <http://ccgtools.england.nhs.uk/bettercare/flash/atlas.html>
This tool allows Health and Wellbeing Boards (HWBs) to monitor and benchmark their performance against key measures and national performance, with the data including a number of PCC PRM metrics.

OUTCOMES BASED COMMISSIONING

Over the last few years, a further development has seen a shift towards outcome-based commissioning (OCB), an approach to commissioning in healthcare that is rooted in population based outcomes and metrics to co-ordinate delivery and incentivise payments. Such systems are designed to view services from the perspective of the people who use them, rather than from the position of the organisation that provides them. The aim is to keep people healthy in their own homes, shift resources to co-ordinated community services and ultimately to deliver the outcomes that matter to people. Ultimately, it is anticipated that such schemes are likely to make use of PRM data within the commissioning process, either for incentivisation or for benchmarking competing providers.

“More and more people are living with long-term, and often multiple, conditions. Successful care for this group of people is not about providing a cure or a certain number of procedures, but about enabling and supporting them to live as well as possible with their conditions over the long term...Outcomes-based commissioning aims to achieve better outcomes through more integrated, person-centred services and ultimately provide better value for every pound spent on health and care.”- NHS Confederation (2014)¹⁷⁵

The first UK based OCB scheme began in 2011, but there has been a rapid expansion across the country and there are now at least 25 such schemes at some stage of implementation¹⁷⁶. In the UK, musculoskeletal care in Oldham has been cited as a forerunner of some of the elements of an outcomes-based approach. Cost and quality benefits have been reported, but not independently evaluated¹⁷⁵. With domiciliary social-care in Wiltshire, there has seen improvements in the customer experience, but few other observable improvements^{177§§}.

In a European context, the Complex Care Plan of Ribera Salud in Valencia, Spain is a public-private partnership targeting people over 75 years old with chronic conditions. As a component of the patient-centred, integrated planning, a battery of metrics are utilised that include PRMs

^{§§}Neither scheme, however, has yet incorporated PRM data into the commissioning process.

and satisfaction surveys, which are utilised for feedback to both patients and practitioners. Whilst Ribera Salud receives a capitated (per head) payment for its patients, some of these metrics (albeit not PROMS) are also utilised as financial incentives¹⁷⁸. The scheme has reported several improvements, including large and significant reductions in hospital admissions, although the data was not independently evaluated¹⁷⁹.

In the USA, the Accountable Care Organisations (ACOs) incorporate aspects of OBC and have been compared with the NHS Five Year Forward View¹⁸⁰. Initial evaluations have revealed improvements in the quality of patient care (including PCC such as timeliness of care and communication) and lowered overall costs (including chronic care management)^{181,182,183}.

“There is very little evidence of effectiveness and the concept is relatively new in the UK, but there is a general consensus that commissioning services at the individual service user level on the basis of outcomes rather than tasks is a precondition for service change and achieving person-centred care for all service users.” - Billings, & de Weger (2015)¹⁸⁴.

Despite the encouraging early evidence, there have been criticism that these schemes discourage providers from supporting the individuals who are hardest to help and therefore incur the greatest costs¹⁷⁶, a notion supported by an independent analysis¹⁸⁵. Furthermore, they can be hampered by the vast implementation challenges involved - it took 10 years to develop the Oldham partnership into its current form, and calculating the overall programme budget for musculoskeletal care proved particularly complex and time-consuming¹⁸⁶. There are also examples where commissioners and providers have not been able to reach agreement. In Oxfordshire, following objections from two local NHS trusts, the approach was postponed and the CCG accountable officer resigned (although progress has since resumed)¹⁸⁷. Future evaluations of OBC must explore the extent to which the individuals with complex health and social needs are being supported.

“Are commissioners right to see outcomes-based commissioning as the answer to their woes? Tantalisingly, the evidence says ‘maybe’.” – NHS (2015)¹⁷⁶

TECHNOLOGICAL ENABLERS FOR SYSTEM-LEVEL PRMS

The global demographic shifts that are straining healthcare systems are happening at the same time that the world is being transformed by the increasing pace of technologic innovation. Technological “e-health” solutions for managing and monitoring health status and outcomes are becoming more common, increasingly sophisticated and user-friendly¹⁸⁸ at the same time that ever-increasing proportions of the population – including those growing old - are becoming increasingly technically savvy.

Furthermore, such technological solutions streamline the collection, collation, analysis and feedback of PRM data to a variety of stakeholders (see figure 1 on p17)¹⁸⁸. Publications have also argued that ePRO systems – with easy interfaces, timely feedback and tailored information – further contribute to patient empowerment, enhancing self-knowledge, improving self-management and encounters with health care professionals¹⁸⁹. Such systems are now being routinely utilised in a variety of contexts to improve the care for people with LTCs and EoL¹⁸⁹. Furthermore, electronic PROs have been established as equivalent to paper-based versions, with a large majority of participants preferring the electronic formats¹⁹⁰.

The best documented example of an ePRO/eHealth system is the US based PatientsLikeUs.com, which is discussed in box 10. There are other US-based examples. The US primary-care platform HowsYourHealth.org, has been shown to improve quality of care, emotional/social support and health understanding in older patients²⁷ in addition to sustained improvements in those with pain and psychosocial problems when combined with a problem solving intervention³⁰. The ImproveCareNow network are using PRMs to improve results for children with inflammatory bowel disease (IBD) via a range of uses such as population management, pre-visit planning, decision support, promoting self-management, and auditing of care processes for evidence-based improvements. Since establishing the network in 2007, care processes have improved and remission rates have improved from 55% to 77%³⁸. There are now a wide variety of eHealth solutions for IBD (the majority of which rely on PROs), where a recent systematic review established that they can improve self-management, knowledge, disease activity and quality of life¹⁹¹.

The Electronic Self-Report Assessment for Cancer (ESRA-C) combines PRO data with self-care information that has been co-created with patient involvement¹⁹². Two RCTs of the ESRA-C ePRO system have demonstrated its effectiveness in the United States, revealing an increase in discussions of quality of life issues¹⁹³ and a small improvement in symptom distress (SK)¹⁹⁴. Furthermore, a recent US-focused review of ePRO systems in cancer clinical care discovered 33 such systems, highlighting the rapid increase in ePRO systems over recent years¹⁹⁵. These

systems support actionable feedback for multiple clinical activities, including assessment of symptoms and toxicities related to chemotherapy and radiation, postoperative surveillance, and symptom management during palliative care¹⁹⁶. Furthermore, these systems vary markedly with regard to both the focus and features, and these characteristics should determine the choice of ePRO system¹⁹⁵.

Within the European context, the Swedish rheumatology quality registry has integrated PRM usage into standard clinical practice, and is discussed in box 11. A further Swedish innovation is the establishment National Quality Registers for the (optional) reporting of PRO data, where the data has been successfully used for quality improvements in a range of conditions via changes such as protocol optimisation¹⁹⁷. In the UK, a recent RCT investigated the effects of mobile telehealth (self-monitoring via graphical mobile phone applications of HRQoL, depression and anxiety) in patients with diabetes, but did not achieve clinically significant changes in HbA1c. The intervention may, however, have had positive effects on blood pressure and protective effects on some aspects of mental health¹⁹⁸.

“Patients with chronic conditions are increasingly encouraged to self-manage their condition, and digital communities have potential advantages, such as convenience, scalability to large populations, and building a community support network.” – Hixson et al. (2015)¹⁹⁹

Box 10: PCC in Practice: PatientsLikeMe.com

The US website PatientsLikeMe.com is an exemplar for the power of multiple-use ePRO data. It is a tool for patients, researchers, and caregivers that allows users to track and share their data and experiences, make treatment decisions and manage symptoms. Members enter demographic information, longitudinal treatment, symptoms, outcome data, and treatment evaluations using a variety of generic and disease-specific measures which are fed back as longitudinal health profiles and aggregated reports. The platform is inherently person-centred with PRMs at the core of its activities, but extends the concept into the field of social networking, with condition based communities that are primarily for LTCs such as multiple sclerosis, Parkinson's disease, mood conditions, fibromyalgia/chronic fatigue syndrome, and amyotrophic lateral sclerosis.

Studies have revealed that social interactions in online communities (such as patientlikeme.com) were significantly associated with the current and future recoveries of patients with mental disorders²⁰⁰, with self-management and self-efficacy in diabetes¹⁹⁹, and a better understanding of disease and increased confidence in diagnosis with LTCs and EoL^{201,202}.

The disease-specific PRMs on PatientsLikeMe have often been co-created between clinicians and patients, with users of the website being involved in developing a plethora of new PRMs for LTCs²⁰³⁻²⁰⁶. In fact, the PatientsLikeMe have established a research platform (openresearchexchange.com) which has the necessary tools and software for researchers to rapidly create, develop and validate new (and permissively licenced) PRMs with substantial patient input^{75,204}. A similar academic initiative, the PCORnet (www.pcornet.org/) scheme is a "patient powered research networks", offering the opportunity for large online registries of patients to contribute to the psychometric development of new PROMs²⁰⁷.

Finally, PatientsLikeMe is also a global online research network that has been described as an "open-participation research platform for the development of patient-centred health outcome measures"²⁰⁰, with numerous research publications using the data to improve the quality of care for people with LTCs and EoL. Most famously, PRMs data from the platform was utilised for patient-led research that revealed that lithium was ineffective for treatment of amyotrophic lateral sclerosis. The work was published in *Nature Biotechnology*, with the findings being confirmed by subsequent clinical trials²⁰⁸. Other examples include evaluations of off-label usage of drugs²⁰⁹; to reveal the high-degree of undiagnosed severe and frequent insomnia as a comorbidity in numerous long-term conditions²¹⁰; that postmenopausal patients reported worse MS disease severity²¹¹; to investigate patient preferences for therapies in multiple sclerosis²¹²; to investigate secondary QOL issues in epilepsy such as concentration, depression, memory and side effects. Data from the website has been used in over 60 research articles²¹³.

“The democratisation of health information, use of social media, rapid growth of networked patient communities, and new technologies have changed the landscape and provide new opportunities to harness the energy and expertise of patients. Clinicians and medical educationalists must catch up. Empowered, engaged e-patients are growing a social movement and spearheading a shift in roles “as profound as women’s liberation,” – Richards et al.(2015)⁶⁹

Whilst the US-based PatientsLikeMe.com (box 10) have expressed an interest in working with the NHS²¹⁴, the integration of social-health networks with government electronic medical registries (EMR) may not be practically feasible. Instead, a number of UK-based schemes are targeted to deliver ePROMs within an NHS context, which are being developed within the pioneering oncological context. Of particular note^{***} is the QTool that has been developed for use in NHS organisations, can link to the Electronic Health Record (EHR), can be used for research and auditing, has been integrated with Leeds and Yorkshire Cancer Network's EHR system, and is currently being independently evaluated³⁷.

Technological improvements in PRMs are not just limited to interface design. Computerised Adaptive Testing (CAT) and item banking^{218,219} are being utilised by (for example) the PROMIS initiative to adjust the level of questions according to the patient’s previous answers²²⁰. Despite the complexity of the underlying CAT algorithms, their administration is straightforward²²¹, enabling an increase in the efficiency of PRMs without impacting their performance^{218,42,221,222}. They have been shown to be acceptable and accurate across diverse populations, including older adults²²², children²²³ and in routine oncology outpatient care^{44,43}. Furthermore, the use of such methods requires smaller sample size to develop measures, which could have particular utility in the context of rare diseases²²⁴.

Machine-learning technologies also hold promise for text-mining and aggregation of the “comments” section of PROMs, where they have been shown to correlate with HRQoL²²⁵. Such approaches could efficiently unlock existing data sources for both benchmarking and to inform future policy and practice.

^{***} Other examples include the private-hospital focused myclinicaloutcomes.com; the UK ePOCs systems which integrates cancer survivors experiences into UK cancer registries^{215 216}; and the CHES software which has been tested within the UK healthcare system²¹⁷.

Finally, the co-existence of competing measures aimed at the same populations has triggered the development of standardised systems for the evaluation of the instruments with the aim of supporting head to head comparisons, such as EMPRO²²⁶, COSMIN²²⁷ and as part of the PROMIS initiative²²⁸.

Box 11: PCC in Practice - the Swedish rheumatology quality registry

The Swedish rheumatology quality registry was established in 1995 and contains data on around 85% of people in Sweden with rheumatoid arthritis. PRMs – including generic and disease specific instruments - are input and tracked via a user-friendly dashboard. The dashboard displays trends and is used to guide treatment, shared decision making, and self-management. This dashboard helps engage and empower patients, increasing their confidence to manage and control their condition, in both the original US context and also in Sweden¹⁰⁴. For the clinician, the system is integrated with other medical data. For the patient, it is integrated with useful information such as the timing of appointments (for routine follow-ups or helping flag urgent care).

An arthritis patient described the system: “Nowadays I work together with my doctor and the computer for every change in my treatment. I can check my disease at home between visits. Before I go to see my doctor I report on and measure my own health. It’s easy; I just click on the screen and enter how I feel now.”³⁹

Clinical outcome measures seem to improve after patients start measuring, reporting, and sharing responsibility for the management of their condition with their physician, with a grey-literature evaluation in one region (Gävle County) reporting that routine use of PROMs improved disease (as measured by C reactive protein)²²⁹.

Conclusions

UK healthcare policy is pushing services in a direction that are more person-centred, with a desire to incorporate the use of PRMs as a patient voice to shape the delivery of services and improve outcomes. Unsurprisingly, there are increasing calls for a generic PRM(s) for long-term conditions that would have widespread applicability across a wide variety of contexts²³⁰. However, there are a number of significant challenges and questions that need to be addressed before such a scheme could be implemented. These are discussed below.

What to measure?

Clarity and guidance is required to help support the appropriate use of PRMs for routine practice. This should include both when and how to measure processes and outcomes, with the right approach for each. Both PROMs (e.g. to measure health and wellbeing) and PREMs (e.g. to measure processes of care and PCC) are often necessary, and the measures used should logically reflect the service or intervention being delivered and be chosen in concert with delivery teams and patients.

A successful PRM has to tap tangible aspects of health that matter to the patient, and should be co-created with all interested parties¹⁵ - including patients, researchers, and now even managers and commissioners. However, a recent review of patient involvement in PROM development discovered that patient involvement had not increased more recently, and concluded that consensus requirements are a necessity²³¹.

At a more fundamental level, there is disagreement about what is appropriate to measure when attempting to use PRMs as a patient-centred tool in long-term conditions. Some authors have argued that disease-specific outcome measures are antithetical to the concept of patient-centredness²³². Others have suggested that generic patient-centred outcome measures may not be the best way forward, where “behaviours and disease-specific measures will remain idiosyncratic”⁹².

Despite such academic disagreements, a recent qualitative study that interviewed a broad range of stakeholders (healthcare, social and charity workers; managers; commissioners) identified widespread support for a measure that would cover traditional domains (quality of life, functioning and social participation) in addition to person-centred domains (in particular empowerment and support from services)²³⁰ – see box 12.

Box 12: Potential domains of a generic PRM for LTCs identified by stakeholders¹⁸⁸

“Traditional” domains:

- Functioning
 - Physical
 - Psychological
 - Social
- Quality of Life

Patient Centred Domains:

- Personalised goals
- Empowerment/self-management
- Access to services/information
- Integrated care
- Impact on carers

Such a definition of a generic measure for LTCs appears to offer a tangible framework for future progress. However, there are fundamental barriers to such a PRM. Standard generic PRMs may not be valid over such a broad range of outcomes, as in many contexts they will not have the ability to discriminate changes over time¹⁴² or between patients (even when measuring only a single disease population)²³³.

mLTCs

Such problems are multiplied with the presence of multiple morbidity, where progress has been hampered by methodological issues of definition. Future research/interventions should utilise more tailored definitions (e.g. “complex multimorbidity”⁴¹) that are suited to the specific context of the research or service intervention⁴⁰.

iPROs

PRM tools that have been designed for group level aggregation may have little relevance (and thus low patient-centredness) at the individual level, and a generic PRM tool for LTCs may be a

particularly blunt instrument. Instead, truly patient-centred care requires the tailoring of measures and interventions to suit the specific needs and priorities of patients and their families⁵³. One solution may instead be the use of individualised PROs (iPROs) that allow patients to modify the content or scoring system, prioritising the symptoms to address^{45,46}. Such patient empowerment is particularly salient to complex scenarios such as mLTCs⁷⁷. However, there are disadvantages of such measures that include increased burden (for researcher, clinician, administrator and patient), methodological/analytical complexities^{77,78} and problems with aggregation that may limit their utility for feedback beyond the consultation process⁷⁶.

Computer Adaptive Testing

An entirely different solution to the challenges of generic PRMs for LTCs is the use of machine learning technologies, which are underpinned by probabilistic (rather than classical) statistics²¹⁹. This allows for the adjustment of questions according to the patient's previous answers, thus asking questions in a more efficient manner²²⁰. This has the benefits of reducing the burden of PRMs in patient groups who might normally be expected to have low response rates. Of particular note is the PROMIS scheme²³⁴, which is backed by the NIH - an organisation with a good history of delivering ambitious, forward-looking projects²³⁵. One of the main objectives of PROMIS is to compile a core set of questions to assess the most common or salient dimensions of patient-relevant outcomes for the widest possible range of chronic disorders and diseases. The project utilises a domain-specific (rather than disease-specific) philosophy, with domains covering aspects fundamental to delivering PCC for LTCs and mLTCs, such as symptoms, physical functioning, participation in activities, social functioning; cognitive-functioning, and emotional status⁴⁴. Such an approach has the power to deliver the nuances required for delivering PCC to patient groups with complex requirements, but without the heavy burden of a lengthy "standard" PRM (and with the subsequent poor response rates). A recent comparison review of generic PROMs in primary and community settings stated that it "warrants serious consideration, especially as it is free to use" (e.g. in comparison to commonly used measures such as EQ-5D and SF-36)²³⁶.

PCC-PRMs for LTCs

One shortcoming of PROMIS is that the current implementation does not include aspects of PCC (such as patient activation, self-management and support from services), which are viewed as important domains for a generic LTC PRM (see box 12)²³⁰. However, the sensitivity issues highlighted above may not be an issue when measuring these domains, and future research should assess the utility of various PCC-PRMs across a range of LTCs and mLTCs. Furthermore, successful monitoring of LTCs in the future may require a battery of the above tools – involving

CATs, iPROs and PCC-PRM, whereby CATs can be utilised to measure the “traditional domains” (quality of life, functioning and social participation) and PCC-PRMs/iPROs can measure person-centred domains (such as empowerment, support and experiences of care).

Whole Systems Outcomes

The majority of stakeholders calling for an LTC-PRM are arguing that such a measure should function simultaneously at both the individual and aggregated level²³⁰. However, commentators have highlighted the tensions that exist between the priorities of healthcare professionals and patients^{53,237}. A recent multinational qualitative study (including UK clinicians and leaders) investigated the use of integrated PRO data. Whilst all parties were supportive of such schemes, there were concerns about the feasibility of integrated PRO data, particularly with the tensions between various stakeholders²³⁸.

Whilst pioneering top-down PRM national initiatives have established the feasibility of such projects, the data has so-far proved to be of questionable utility^{147–150}, with low response rates suggesting that patients have not been engaged in the process as currently implemented^{142,169,170}. Conversely, there is a much greater evidence base for the use of PRMs within clinical practice, especially when formalised feedback mechanisms (often embedded into IT solutions^{29,37}) are in place that generate actionable consequences that directly improve care. Examples would include where PAM feedback - often generated real-time as part of a consultation - is used to determine the clinical strategy for enhancing self-management for engaged patients¹²²; where HRQoL can alert the clinician to side-effects in cancer treatment¹²⁴; where low-activation in diabetes patients can be addressed with educational interventions¹¹²; and where PCC-PRMs are used to alert services when PCC is failing⁶⁷. Furthermore, these proximal (and meaningful) goals are likely to be more successful than evaluating the impact on distal outcomes such as health status.

It is in such contexts that PRMs have the strongest evidence of being valuable instruments for improving the quality of care – e.g. not as performance measures (such as national benchmarking initiatives), but when they are instead performed as a measure of one or more important component of care (e.g. extent of shared decision making) or patient attribute (e.g. level of activation) during a meaningful patient-centred interaction²³⁸. In addition to its immediate utility, aggregation of this clinical-level PRM data (as a process or an outcome) may have several advantages over global healthcare ratings, such as higher validity, greater ability to detect differences¹⁵⁸ and higher response rates. In this way, the exact choice of PRM could be abstracted away from commissioners and health-care organisations, yet the valuable data would still flow upwards.

Despite the logical assumptions that clinical PRM data will have more system-level utility than top-down national initiatives, there is presently little evidence of how system-level feed-up (to clinicians, teams, managers and commissioners) of data can be used to improve the quality of care, and this is an area where future research will need to be directed. Not only will research have to investigate how feedback best operates to maximise interpretability and actionability, but it will also need to develop the framework to assess the challenges and potential negative impacts of such a system.

“more attention needs to be paid to how results are communicated and to the provision of advice as to what action may be taken” - Varagunam et al. (2014)¹⁴⁹.

In particular, unconscious biases (e.g. patients may be influenced by the presence of the clinician) and gaming could contaminate data that is aggregated for secondary purposes. Therefore, interpretation of this data should be considered cautiously. Such issues could limit the utility of PRM data collected during clinical interaction for complex data flows. In contrast, when the use of a measure is primarily used for performance benchmarking, then there is a strong theoretical rationale for measurement being carried outside of the clinical interaction in order to prevent gaming or unconscious bias influencing completion (e.g. patient responses may be influenced by the presence of the clinician).

The simultaneous utilisation of PRM feedback in multiple directions will therefore require nuanced research – along with development of associated methodologies – to fully understand the impact and optimisation of feedback mechanisms²³⁹, and whether issues such as gaming and response biases do contaminate data. Furthermore, such research should fully measure the impact of the downsides and burden of routine PRM collection, and assess whether such programs are cost-effective, whether they misdirect the focus of care and whether they are burdensome in routine clinical practice (for clinicians and/or patients) or in terms of informatics workload. A recent review argued that “this type of operational, process-based research is a key next step in implementing PROs”²⁴⁰.

“More research is required to support PROM cost-benefit in terms of patient safety, clinician burden, and health services usage” - Kotronoulas et al. (2014)²⁴.

Technological enablers

Whilst IT systems are still perceived as another “barrier to progress”²⁴¹, current trends – including the widespread adoption of system standards such as health level 7 (HL7)²⁴² – suggest that we may be reaching an inflection point. A recent review outlined how technology can allow those with chronic conditions to interact directly with health care providers, highlighting the organisational paybacks that can result from the system-level use of this information²⁴³. In Denmark a generic PRO system (WestChronic) has been successfully implemented and used across a broad range of clinical settings, with data being utilised in both clinical practice and for aggregation for both research and quality improvements²⁴⁴. In the UK, the QTool ePRO system has been developed for use in NHS organisations, can link to the Electronic Health Register (EHR) and the data can be used for research and auditing. This is being utilised by the Leeds and Yorkshire Cancer Network, where it is being evaluated by Yorkshire & Humber AHSN. Furthermore, other perceived barriers such as low response rates, administrative burden and “consultation intrusion” are likely to be eroded with the increasing uptake of techniques such as CAT that are enabling questions to be asked in a more efficient and elegant manner.

It is hoped that these various technological developments – such as ePRMs and CAT - will allow the achievement of “Whole System Outcomes”²⁴⁵ – i.e. the experiences that matter most are vertically integrated throughout the system - from the patient, via the clinician, up to individual providers, passed to the researchers, and on to the level of the healthcare system itself. Not only could such a framework unleash cost-saving synergies²³⁸, but it would also have the ability to reconcile one of the fundamental contradictions of modern healthcare: delivery of person-centred care within a metrically-driven system.

“[The NHS] needs to become the first truly democratic, patient-centred healthcare system on the planet. Starting with intelligent transparency, then using it to foster a learning culture to support and empower staff, then embracing technology to give patients real control of their own health and care” – Jeremy Hunt, Secretary of State for Health (2015)

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Appendix: detailed methods

This review aims to provide insights into the use of PRMs to improve care for the target patient groups. It is a rapid synthesis of the literature and as such, it is not an exhaustive and definitive review. The source material used in this review is of a highly heterogeneous nature, and as such it was not logical to employ a traditional systematic approach to assess quality. We did however observe that in general (but not exclusively) the quality of the evidence increased as we moved up through the grey literature, academic literature, reviews and systematic reviews. No attempt has been made to pool or provide statistical meta-data, due to the varied nature of the source material. We are also aware of forthcoming systematic Cochrane reviews that will also contribute to knowledge in this field²⁴⁶.

A two-tiered search strategy was utilised (see figure 2). In the initial scoping stage, we were keen to identify relevant grey literature sources. These are likely to contain examples of how PRM data is being utilised in practice and service settings (as opposed to academic studies) to improve the quality of care for the target groups. A recent publication “The State of Play in Person Centred Care”⁶³ was an authoritative document that listed all key organisations in PCC, in addition to key organisations for the metrics of PCC. We scanned the publications on the websites of these organisations (16 organisations; around 1500 publications), of which 47 were deemed relevant to the evidence synthesis. For academic literature, we used a combination of expert knowledge within the team, in addition to literature scans.

Within the first tier, due to the large body of literature, non-specificity of the search terms, and time constraints, we focused on a “review-of-reviews” approach whereby our searches were primarily for reviews. These reviews were utilised as entry points to pearl-grow the literature database for the review. In total, 480 relevant documents were identified, although not all of these are referenced in this evidence synthesis.

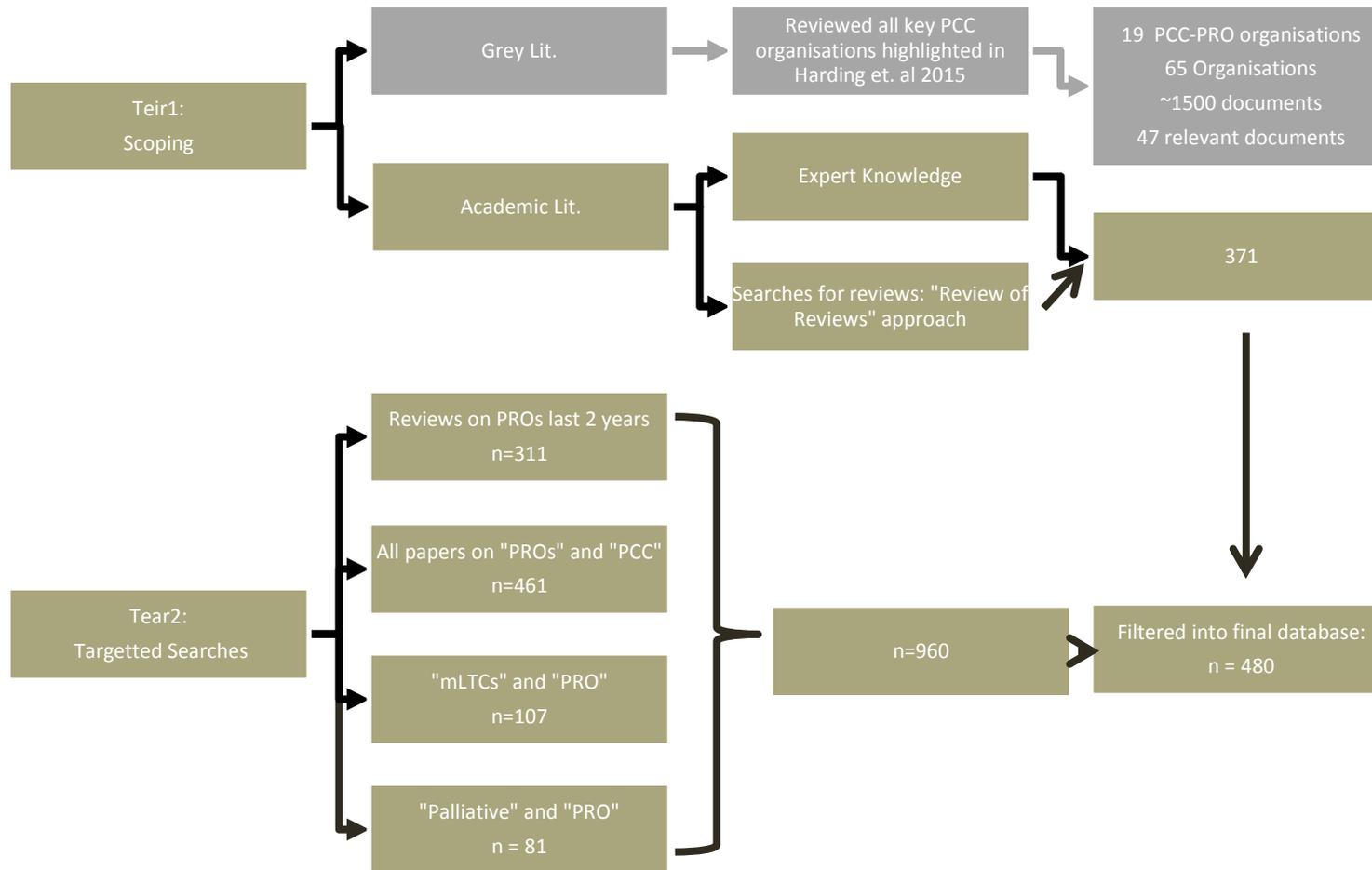


Figure 2: Schematic of two-tiered search methodology.

EXCLUSION/INCLUSION CRITERIA

Papers were automatically excluded according to following criteria:

- 1) Did not include disease specific criteria (e.g. not LTC/EoL)
- 2) Incompatible with core values of PCC (e.g. tangential/contradictory)
- 3) Sample size e.g. case studies
- 4) Lacking conceptual clarity. e.g. buzzword use
- 5) The publications are too specific to national policy of another country
- 6) Articles that are comments on other articles
- 7) Complementary/alternative medicine

CATEGORISATION

Papers were categorised for pre-review according to the following dimensions, allowing interrogation of common themes and findings:

- 1) Direction of feedback (e.g. to researcher, clinician, patient, or system level) – see box 2.
- 2) Condition category (e.g. LTCs; mLTCs, EoL).
- 3) Evidence type (e.g. grey literature; peer-reviewed; systematic review; Cochrane review; narrative review etc.)

After the scoping stage, targeted searches were performed for those areas of the synthesis which had a shortfall of source material.

SEARCH TERMS

Search terms were grouped into domains of interest:

Group 1 (terms for metrics) = (PROM OR "Patient Reported Outcome" OR PREM OR "Patient Reported Experience" OR PCOM OR "Patient Centred Outcome Measure" OR "Patient Centred Outcome Measures")

Group 2 (terms for PCC); an expanded list from ⁶³ = ("Patient Centred" OR "Person Centred" OR "Patient Centered" OR "Person Centered" OR "Patient Co-Ordinated" OR "Patient coordinated" OR "Integrated care" OR "Shared decision" OR "Self Management" OR "Family centred" OR "Family centered" OR "Patient engagement" OR "Patient empowerment" OR "Patient activation" OR "Care Planning" OR "Goal Setting" OR "Client centred" OR "Client centered" OR "Family centred" OR "Family centered" OR "Patient centric" OR "Patient centered" OR "Patient centred")

Searches were limited to PubMed due to time constraints. For the scoping stage, searches were used to supplement local knowledge and the grey literature scan, and were therefore limited to:

- **Group 1 REVIEWS** from the last 2 years
= 311 hits
- **Group 1 + Group 2;** from the last 2 years

= 461 hits

In the second tier, the following targeted searches were performed to discover literature for areas of the review that were not well covered. These were identified PRMs for mLTCs; PRMs for palliative care and PCOMs

- **A search for PRMs for mLTCs:**
Group 1 + (Multiple Long Term Conditions OR “multiple-morbidities” OR “multiple morbidities” OR multimorbidity OR multimorbidities)
= 107 hits
- **A search for PRMs for palliative care:**
Group 1 + (palliative OR “End of Life”)
= 81 hits
- **A search for PCOMs**
("patient centred outcome measure") OR ("patient centered outcome measure")
= 24 hits