

This document provides practical guidance on how and why to use metrics, measures and insights to commission, evaluate and improve processes and outcomes in Person Centred Coordinated Care (P3C) for people living with long-term conditions, multiple long term conditions (i.e. multimorbidity) or at the end of their life.



How to Use Metrics, Measures & Insights to Commission Person Centred Coordinated Care

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ABOUT THIS WORK

This work was commissioned by NHSE Long Term Conditions Team as part of a wider project to provide a portfolio of intelligence on the use of Metrics for Person Centred Coordinated Care (P3C) for people with Long Term Conditions, Multiple Long Term Conditions and those at the End of their life. A team of researchers led by Dr Helen Lloyd at the South West Peninsula CLAHRC (PenCLAHRC) commenced work in January 2016. A set of linked deliverables included: 1) rapid evidence scan to synthesise the evidence for the use of patient reported measures (PRMs) to improve care for the target groups, 2) primary research to collect implementation stories from a variety of settings to explore the use of PRMs, 3) stakeholder engagement with patient groups to explore their views on the use of PRMs, 4) a survey to capture the experiences and views of commissioners, 5) the production of an online compendium of measures which assesses core P3C measures in relation to principles of person centeredness and their psychometric properties for use with the three population groups described earlier and 6) a guide to support commissioners and delivery organisations to develop P3C.

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ACKNOWLEDGEMENTS

The P3C Metrics team would like to thank all the patients, commissioners, researchers and academics who contributed to this piece of work. The P3C metrics team would also like to extend warm thanks to the NHSE steering group team who provided a critical eye and worked in a collaborative and supportive manner to ensure the successful delivery of this piece of work.

This research was supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care South West Peninsula at the Royal Devon and Exeter NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

1. WHAT COMMISSIONERS WANT TO KNOW: THE PURPOSE OF THIS GUIDANCE

Many policy documents highlight the need for new models of Person Centred Coordinated Care (P3C), but there is a paucity of clear, actionable guidance for commissioners and delivery organisations on how to 1) deliver P3C and 2) evaluate whether changes in care delivery achieve the desired outcomes. Clear and tangible guidance is necessary to provide a bridge from the philosophical principles of P3C to real-world commissioning and delivery. This guide is therefore a starting point for commissioners and delivery organisations to align their efforts to achieve P3C. Through engagement with commissioners and building on the ongoing collaboration that the South West Peninsula CLAHRC (PenCLAHRC) and the South West Academic Health Science Network (SWAHSN) have set up to link research to practice, the following core questions have been identified that commissioners have in relation to implementing and assessing P3C:

- 1) Is there a co-designed framework in place to assess the implementation of P3C, i.e. have patients and relevant stakeholders been involved in the choice of metrics (process and monitoring data, measures and qualitative approaches)?
- 2) Is the framework - wherever possible and desirable - co-delivered?
- 3) Does the measurement framework include:
 - Social determinants, inequity and inequality?
 - Health literacy?
 - Activation or potential to self-manage?
 - Experience of care and support?
- 4) Does the framework measure if the system is treating people as individuals in a holistic and personalised manner?
 - Do people share decisions and plan care with their professional teams?
 - Do professionals ask about patient preferences (both treatment preferences and outcome preferences/goals)?
- 5) Does the measurement framework monitor if the system enables people to feel in control of their treatment and care?
 - Are those individuals at low levels of activation or confidence to self-manage being supported to develop the knowledge, skills and confidence to manage their health and wellbeing?

- Are people truly planning their own care and support?
- 6) Does the framework provide evidence that the system is co-ordinating its activities around the person and their carers/family?
- 7) Does the framework detect whether the system is creating a change in psychosocial wellbeing in addition to improvements in physical health?
- 8) Does the framework provide a mechanism for detecting if the system is identifying and supporting carers?
- 9) Does the framework record or detect if community assets are being deployed, including peers, social networks, and the voluntary sector?
- 10) Does the framework record how the system signposts to support people to engage with their communities?

This guidance attempts to address some of the above issues and provide examples of how the above can be developed, measured and refined.

1.1. The Purpose of this Guidance and How to Use it

Aligned with NICE guidelines on [Multimorbidity: clinical assessment and management](#) (2016) this document provides a practical guide to progress a shared understanding, and the implementation and commissioning of P3C through the use of metrics, measures and insights for Long-Term Conditions (LTCs), Multiple Long-Term Conditions (MLTCs) (also termed as multimorbidity) and for those at the End of their Life (EoL). This will allow:

- **Commissioners** to develop a suite of measures that can be used to commission person centred outcomes at an individual and population level
- **Providers** to measure the impact of their interventions, supporting continuous improvement of services and to embed measurement of person centeredness into the clinical encounter
- **Patients and their support network** to challenge what their local services can deliver and provide them with an understanding of the role that they play within this partnership

In addition, this guidance will highlight which types of metrics, measures and insights are most suitable for a particular purpose and provide a succinct narrative of what we know about how P3C measures work to influence quality improvement and resultant service level utilisation.

This guidance could be used in a number of ways, but it is designed to be used in conjunction with the linked P3C compendium (<http://p3c.org.uk/>) (See [section 1.2](#) below). A [short navigation overview guide](#) at the beginning of this document has been developed with hyperlinks to different sections throughout this substantially longer and more detailed document. The contents section of this guide also hyperlinks to other places in the document that provide, for example, details of examples of the experiences of professionals using measures for developing and evaluating P3C (see [section 5.5](#)), as well as guidance on how and why to measure staff and organisational change.

1.2. A Compendium of Patient Reported Measures for Person Centred Coordinated Care


There are an increasing number of measures that have been designed to evaluate a variety of healthcare outcomes and experiences from the patient perspective, or from the perspective of carers and family members. This body of work consists of literally thousands of instruments that can be categorised into an increasingly complex family of related tools. To help make sense of this vast array of data and to support this commissioner's guide, we have designed and built an online compendium of patient-reported measures (PRMs) that could be used to support, measure, and evaluate Person Centred care within the target conditions. We have included some tools that can be completed by family members where patient report is hindered by an aspect of illness, such as those at the end of their life. Necessarily, such a compendium includes a large number of designated "Person Centred care patient-reported measures" (PCC-PRMs), which measure domains such as communication, self-management and patient activation. However, we did not limit the scope of the compendium to these measures, and have also included Quality of Life (QoL) and health-related QoL (hrQoL) measures, as domains such as mental and social health are often important features in the delivery and evaluation of P3C.

A detailed methodology for how we identified, categorised, mapped and shortlisted these measures is presented as Appendix 1. In brief, we scoped a number of sources (including existing databases, compendiums and academic literature) to identify PRMs. This identified several hundred candidate measures that were available. Next we pragmatically excluded a large number of measures (e.g. too long; very specific tools; measuring flawed constructs such as satisfaction). We then mapped the remaining measures according to the "I" statement domains, allowing us to produce a series of shortlists:

- 1) A shortlist of *generic person centred coordinated care measures* (“P3C-PRMs”).
- 2) A series of shortlists of P3C-PRMs that target *specific domains of person centred care*, such as empowerment/activations, shared-decision making etc.
- 3) A series of shortlists according to *disease-specific categories* that relate to the target conditions of this project. In addition to P3C-PRMs for these conditions, we supplemented these shortlists with Quality of Life (QoL) measures.

We have made our data publicly available (<http://p3c.org.uk/>). This includes a “database” of unselected/unsorted P3C measures in addition to our more refined “shortlists” of selected example measures in various categories (<http://p3c.org.uk/shortlist>). Whilst the shortlists are the main launching point for the information, the website is fully searchable and filterable, aiding the selection of candidate PRMs in a variety of contexts (e.g. [Figure 1](#)). Each PRM contains a variety of associated information such as links to the academic reference, links to the website of the developer, and even a link to a copy of the questionnaire (where available). For our non-excluded P3C measures, we also have full mapping data available in graphical format. When systematic reviews of psychometric properties were available for measures, we have included an indication of these results as a graphical “traffic light” system. The website is designed to be a user-friendly gateway for PRMs, including useful “help” information and links to further resources. It is aimed to be a gateway to the often confusing and disparate world of PRMs, and is a tool that is designed to be of utility to a range of stakeholders, from naïve users through to specialised academics.

Figure 1: An example search from for P3C measures specifically for Diabetes


**MEASURES FOR PERSON
CENTRED COORDINATED CARE**

[HOME](#)
[ABOUT](#)
[SHORTLIST](#)
[FULL DATABASE](#)
[OTHER RESOURCES](#)
[CONTACT](#)

Broad Concept
 Person Centred Coordinated Care

Main Concept Measured
 Select to filter

Type Of Measure
 Select to filter

Respondent
 Patients

Country Developed In
 Select to filter

Target Condition
 Select to filter



Target Age
 Select to filter

Show 10 entries

Abbreviated Name	Full Name	Items	Short Description	Broad Concept	Action
C-DEPS	Chinese Diabetes Empowerment Process Scale	15		Person Centred Coordinated Care	View Detail
DCP	Diabetes Care Profile	8	the DCP is a standardized instrument for assessing social and psychological factors related to diabetes and its treatment	Person Centred Coordinated Care	View Detail
DESv1	Diabetes Empowerment Scale version 1	28		Person Centred Coordinated Care	View Detail
DESv2	Diabetes Empowerment Scale version 2 (Chinese)	20		Person Centred Coordinated Care	View Detail
DESv3	Diabetes Empowerment Scale version 3 (Swedish)	23		Person Centred Coordinated Care	View Detail
DIAB-Q	Diabetes Intention, Attitude, and Behavior Questionnaire	17	a brief questionnaire to measure physical activity, dietary control, maintenance of a healthy weight, and psychological antecedents	Person Centred Coordinated Care	View Detail
MARS	Medication Adherence Report Scale	5	Medication taking in diabetes	Person Centred Coordinated Care	View Detail
MMAS-8	Morisky Medication Adherence Scale Adherence Scale	4	Medication taking in diabetes	Person Centred Coordinated Care	View Detail
SDSCA	Summary of Diabetes Self-Care Activities	12	A multidimensional tool for the assessment of self-management in diabetes	Person Centred Coordinated Care	View Detail
Abbreviated Name	Full Name	Items	Short Description	Broad Concept	Action

Showing 1 to 9 of 9 entries

Previous
 1
 Next

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2. WHY IS PERSON CENTRED COORDINATED CARE IMPORTANT?

Individuals with complex bio-psychosocial needs often receive fragmented and uncoordinated care from the NHS and social care system. Older individuals considered as 'frail' and those with high impact multi-morbidity are particularly affected, and consequently suffer poorer outcomes and experiences than those with less complex needs. The cost of care for these individuals is high - not solely financial, but also in the impact on practitioner morale and patient safety.

The millennium call for Personalisation and Coordination in the NHS¹ was brought into a sharp refocus following the publication of the Francis report, which hastened calls for a 'new humanism' for the NHS. Furthermore, the aging demographic with increasing multi morbidity reignited policy and practice to "see the individual". However, advances in medicine, increasing specialisation with a single disease focus, and the dominance of pharmaceutical-led research over the past fifty years, have led to less consideration of the interaction of social and psychological factors with health and illness in the clinical practice settings. These divergent trends in medicine, health and social care set the context for our whole-person approach to integration.

Systems not supporting bio-psycho-social models of care can cause problems for both practitioners (who want to care for patients well), and individuals (who are often left dissatisfied and unhappy with the process). Many have suggested that in order to achieve less bewildering and more coherent care, the support provided by the NHS, social care and associated community services need to be more person centred and coordinated. They need to be focused around the needs of the individual and their family and be responsive to an individual's strengths and existing networks/resources.

Person Centred Coordinated Care (P3C) is perceived as a way of achieving better outcomes for individuals with complex health and social care needs and addressing the demands our health and support systems are facing. Crucially, it is now also perceived as a way in which to improve the efficiency of health and care economies. This perception is based upon the assumption that seeing the 'whole person' will help professionals and

¹ <https://www.gov.uk/government/publications/personalised-health-and-care-2020/using-data-and-technology-to-transform-outcomes-for-patients-and-citizens>,
<https://www.england.nhs.uk/wp-content/uploads/2014/08/no-assumps-mh.pdf>,
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf

services organise care more efficiently, and this will almost certainly necessitate some degree of enhanced care co-ordination. In turn, this will frequently require the restructuring of teams and organisations.

3. SHARED DEFINITIONS, A COMMON UNDERSTANDING AND CONCEPTUAL CLARITY

3.1. Person Centred Coordinated Care (P3C)

Person Centred Coordinated Care, referred by the acronym P3C, is the conjunction of three concepts that represent the current state of thinking in the development of better care and support within our health and social care system. This tripartite definition stresses (i) the importance of person centred care: the co-creation of care between an individual patient, their support network and his or her professional(s), with (ii) an emphasis on understanding the relationship between an individual and their capabilities and resources, whether these are psycho-social resources, or those within the wider environment. Importantly, this definition also acknowledges that care and support provided to the individual should (iii) strive to be responsive and coordinated, across all sectors and include engagement with the third sector, irrespective of organisational structures and configurations. Each element of the definition is supported by core principles which inform a number of sub domains. These will be described in detail in [chapter 5](#) where they will be linked to components of service delivery. The following box provides a breakdown of the three elements of the current definition of P3C:

Person Centred Care	The co-creation of care between the patient, their family and informal carers, and health professionals. This definition is becoming widely used by many international organizations and the WHO ² and has been translated into a proven approach and used at the Gothenburg University Centre for Person Centred Care (GPCC). Person centred care strives to see an individual as bio-psycho-social whole, as a person and not an illness or a collection of conditions.
Capabilities & Resources	Psycho-social and environmental resources are non-clinical and have a community focus. This is commonly being referred to as 'Community-centred approaches' that complement other types of interventions that focus more on individual care and behaviour change or on developing sustainable environments. These approaches acknowledge the importance of social capital for health and wellbeing to flourish. ³
Coordinated Care	Coordinated care is the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the

² The King's Fund. at <http://www.kingsfund.org.uk/blog/2014/11/power-people/>), Health Foundation. at <http://www.health.org.uk/theme/person-centred-care/>), Moore Foundation. at <http://patientfamilyengagement.org/>), Richards T. Listen to patients first. Bmj 2014;349:g5765.

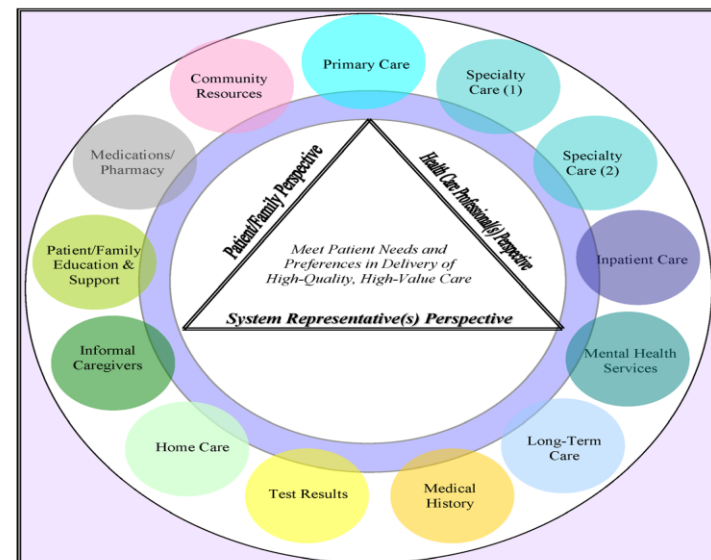
³ Public Health England & National Health Service England (2015). A guide to community-centred approaches for health and wellbeing Full report. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417515/A_guide_to_community-centred_approaches_for_health_and_wellbeing_full_report.pdf

exchange of information among participants responsible for different aspects of care⁴. From a person or family perspective, coordinated care is any activity that helps ensure that the individual's needs and preferences for health services and information sharing across people, functions, and sites are met over time⁵.

In short, we define P3C as 'Care that is guided by and organised effectively around the needs and preferences of individuals'. The following quote describes the 'ethics' of Person Centeredness and the diagram below right taken with permission from the Agency for Health Research and Quality (AHRQ) illustrates a pictorial definition care coordination ([Figure 2](#)):

An approach to practice, established through the formation and fostering of healthful relationships between all care providers, people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures that foster continuous approaches to practice development. (McCormack's 2010).

Figure 2: A pictorial definition of care coordination:



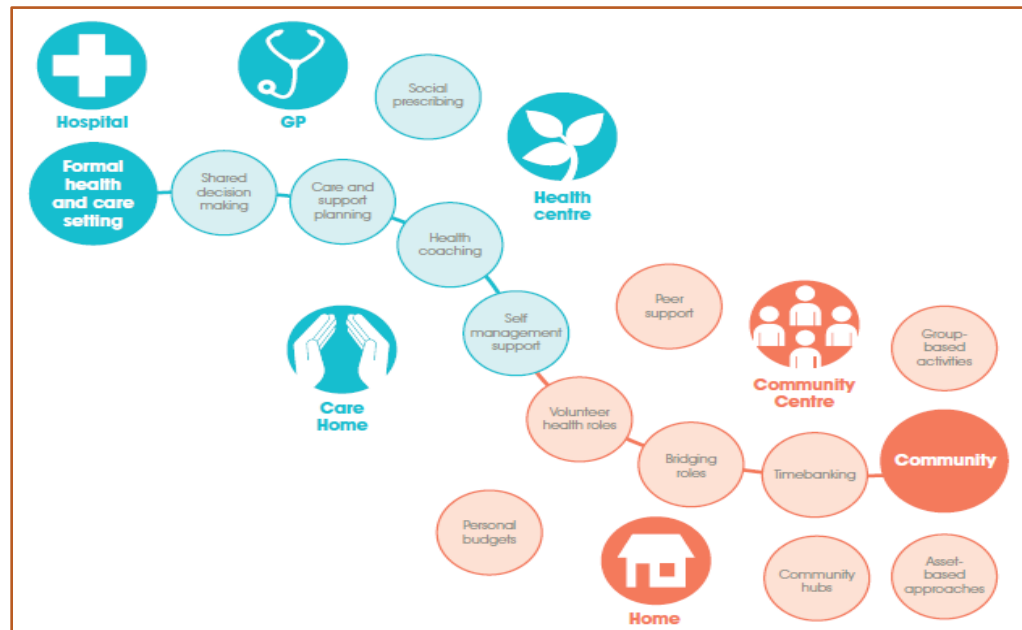
⁴ Agency for Health Care Research and Quality (AHRQ): Care Coordination Measures Atlas: <http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html>

⁵ Agency for Health Care Research and Quality (AHRQ): Adapted from information published by the National Quality Forum. Link as above

Person centeredness and coordination of care occupy a symbiotic relationship in the forming of “healthful” (defined in [section 4.3](#)) behaviours, relationships, and more healthful cultures. Emerging thinking and evidence suggests that healthful cultures form both a context of the development of person centeredness and coordination of care, and are also enhanced by the practice of these (McCormack B and McCance T, 2016). For example, effective coordination is dependent on professional communication and team work based on an understanding a person’s needs and preferences, which in turn is built upon by trust, mutual respect and understanding through partnership working with a person. If the core of person centred care is the co-creation of care between individuals, their families and care partners based on the ethics described above, then the central goal (within the triangle above) of care coordination (blue ring) is to deliver that co-created plan of care by bridging gaps (white spaces) along the care pathway by a variety of different activities and processes.

Community centred care links both person centred care and coordination to community resources and a range of activities that help people to look after themselves and increase their personal resources (also a principle of P3C). Community centred care also has the potential to provide opportunities for individuals to have meaningful relationships and work collaboratively with professionals (who also develop their professional resources) as depicted in [Figure 3](#). We acknowledge that P3C is reliant on coordination across service boundaries, and also recognises the potential role of community resources (however defined) in supporting health and wellbeing and self-management.

Figure 3: Community Centred Care



3.2. What Person Centred Coordinated Care Means to Individuals with LTCS and MLTCS

A number of influential policy documents have formed a narrative of what service users expect from care and support services⁶. These have been incorporated and used extensively to guide the policy landscape towards P3C (e.g. National Voices 'I Statement Narratives'). Regional work within the PenCLAHRC also produced principles for person centred care that resonate with the 'I statement narratives'. Involving patients consistently and meaningfully in the spirit of co-design is essential to P3C and as such several workshops were conducted with patients with LTCs and MLTCs to inform this work. These workshops focused on their understanding of the meaning of P3C and their views on the use of PRMs for improving care and support.

For the individuals that took part in our workshops, P3C meant that professionals and services recognised the **person more than their condition(s) and also recognised them as an expert in their own right**. They perceived P3C as a way to deliver bespoke care and support and **provide choice to the individual and their support network**. They felt strongly that interactions with practitioners and professionals **should always be caring and respectful and that this was core to P3C**. They felt that **being listened to and being able to relay their concerns was incredibly important, as was having their complaints taken seriously**.

Person Centred Coordinated Care was felt to embody humanising care that offered a route to dignity and equality and facilitated working within a partnership and as part of a team.

Essentially, P3C was felt to exemplify **humanising care that offered a route to dignity and equality** and facilitated working within a partnership and as part of a team. **Information, coordination and communication** were viewed as necessary for P3C to work well.

⁶ Most notably the work of National Voices I Statement Narratives, NHSE PCOMs project, House of Care/Year of Care, Health Foundation, Coalition for Collaborative Care, Nuffield Trust, Realising the Value Consortium etc.

3.3. Metrics, Measures and Insights

The term ‘metrics’ is often used as an umbrella term to describe a) routinely collected service data or data collected for evaluation purposes to monitor health or social care processes e.g. number of care plans (sometimes referred to as enabler metrics) and service utilisation such as GP attendance etc. (sometimes referred to as activity data), and also b) data captured from the perspective of an individual using a patient report measure (PRM). This latter category includes Patient Reported Outcome Measures (PROMs) that probe an individual’s perception of outcomes of treatment or illness, and Patient Reported Experience Measures (PREMs) that probe an individual’s experiences of care. This category also includes HRQoL and Health Status measures. Staff or family reported measures capture experiences of delivering or receiving care. There is also another emerging subcategory of PRMs that can be considered as P3C measures⁷. These measures can be categorised as person centred or community centred⁸ because they probe a core component of P3C or they seek to measure the extent to which this is being delivered and how the individuals experience it. [Table 1](#) provides examples of different types of metrics and their characteristics.

Table 1: Examples of Measures and Metrics

Type of Metric	Examples	What does it tell us?	Level of Use
Service utilisation and pathway data	Length of GP appointment, frequency of A&E attendance, mortality rates	How services are utilised by an individual and/or groups of individuals	At individual level and aggregated to organisation and system levels
Activity process data	Number of personalised care plans, multidisciplinary team meetings	How services change their processes as they implement P3C	“ “
Individually (patient, staff or family) reported measures	Client Generated Index, SF-36, PAM, howRyou, P3C-EQ	An individual’s perspective or experience of care/treatment received and/or the resultant outcomes, illness or symptom experiences, health status, wellbeing etc.	At individual level in all cases, with the potential to aggregate to organisational and system level with all but a few measures.
Organisational measures	P3C-OCT	An organisational perspective, organisational readiness	At practice and organisational levels, with potential to aggregate

⁷ De Silva (2014) Measuring What Matters

⁸ Realising the Value

Some PRMs can act as an intervention, in addition to collecting an individual's experience or perspective. When implemented in this way they can be directly used to support care planning or support the delivery of P3C. E.g. using individualised measures that include goal setting or those which focus on ability to self-manage. Other PRMS lend themselves more readily to being aggregated beyond their immediate clinical function. Such measures are usually PROMs which are designed to measure outcomes from the perspective of the individual at a population level.

Insights defined within this guide refer to data that is gathered qualitatively or garnered from social media, patient opinion or other relatively unstructured mechanisms.

4. DELIVERING PERSON CENTRED COORDINATED CARE: CO-DESIGN, COLLABORATION, PRINCIPLES & ACTIONS FOR HEALTHFUL CULTURES

4.1. Co-design and Collaboration

Implementing P3C is not straightforward, it is a complex and multi-faceted intervention that requires support and action at all levels of health, social care and associated community organisations. The PenCLAHRC and the SWAHSN have developed a collaborative approach to support development of P3C across Somerset, Devon and Cornwall through an interlinked programme of service redesign, evaluation, and research. This type of collaboration is core to realising the vision of the 5 Year Forward View (5YFV) and can only be achieved through stakeholder engagement, where it is possible to learn about grass roots challenges, define evaluation needs and create learning opportunities to understand practice based evidence. The PenCLAHRC and SWAHSN have built a whole system approach to metrics that takes into account the outcomes of importance to patients, practitioners and health systems. This work has produced a core linked evaluation framework with a selection of metrics alongside the use of qualitative interviews and observational data. Results of analysis are fed-back locally, improving practice. However, data is also used for research purposes to generate theory and evidence which can help drive further improvements in P3C. There are similar collaborations in place, or being established, with comparable organisations across the UK. Working with academic partners, patient representative groups and provider organisations will enhance the potential for effective measurement and evaluation systems which support the delivery of P3C.

4.2. From Principles to Actions for P3C:

Despite the fact that there is widespread consensus on the need to move away from a depersonalised, bio-medical model, a lack of guidance means that P3C is rarely delivered in a consistent manner. The lack of tangible guidance relates in part to difficulties in translating and understanding how to promote and support the cultural change required for P3C and the barriers that might place constraints on the development of this process. This is because some of the core principles of P3C are existential, they are a way of being, i.e. being respectful; having dignity; understanding personal nuances. Ways of being are sometimes hard to translate into actions and behaviours, as often these are viewed as personality types or communication styles. P3C is an approach to practice that is built from fostering “healthful” relationships between all care providers, people, and those important to them. These types of relationships foster the accomplishment of health in the broadest sense including social, emotional, and physical health gains. Respect for the individual and their right to self-determination are also core principles of P3C, in addition to an emphasis on mutual respect and understanding in settings which value continuous practice development (McCormack, 2010).

The practice of how to 'do' Person Centred Care (PCC) is being established, evidenced and documented, most consistently and most practically by the work of Ekman and colleagues⁹ at the Gothenburg Centre for Person Centred Care (GPCC). Ekman and colleagues have established and tested three PCC routines based around the following key activities:

- 1) Establish the individual's narrative by active listening/appreciative enquiry**
- 2) Agree and formulate a plan together based on shared decision making and the preferences of the individual: working the partnership**
- 3) Safeguard this contract by documenting it in a co-created care or support plan**

For those with complexity of need there is also a 4th routine that should be emphasised and practiced across the systems and organisations involved in care and support for individuals:

- 4) An agreement to act in conjunction with other professionals (to coordinate the care plan)**

The above four routines provide a practice framework to achieve P3C. An orientation towards 'healthful' relationships as emphasised by McCormack provides a context and a culture that practice behaviour towards P3C can be supported and realised. Alongside putting interventions in place and ensuring ongoing contact, progress needs to be evaluated and plans collaboratively reworked. The P3C routines above provide a mechanism for experiential learning for both the practitioner and the individual with whom they work. Such experiences provide opportunities for new ways of thinking, reflecting, and working, to redefine care roles and relationships.

Within the UK, the House of Care (HoC) model (<https://www.england.nhs.uk/house-of-care/>) has been developed with the aim of designing a partnership delivery model focused on coordinated services, encompassing all people with LTC's and assigning an active role for patients. It was established based on an understanding of the needs of people with LTC's, and a departure from a disease focused reactive system toward one that was focused on a pre-emptive, holistic view of the person. The goal is to drive a whole system approach, based on the understanding that the model

⁹ [HTTP://WWW.NCBI.NLM.NIH.GOV/PUBMED/21764386](http://www.ncbi.nlm.nih.gov/pubmed/21764386): EKMAN I1, SWEDBERG K, TAFT C, LINDSETH A, NORBERG A, BRINK E, CARLSSON J, DAHLIN-IVANOFF S, JOHANSSON IL, KJELLGREN K, LIDÉN E, ÖHLÉN J, OLSSON LE, ROSÉN H, RYDMARK M, SUNNERHAGEN KS. PERSON-CENTERED CARE--READY FOR PRIME TIME. EUR J CARDIOVASC NURS. 2011 DEC;10(4):248-51. DOI: 10.1016/J.EJCNURSE.2011.06.008. EPUB 2011 JUL 20.

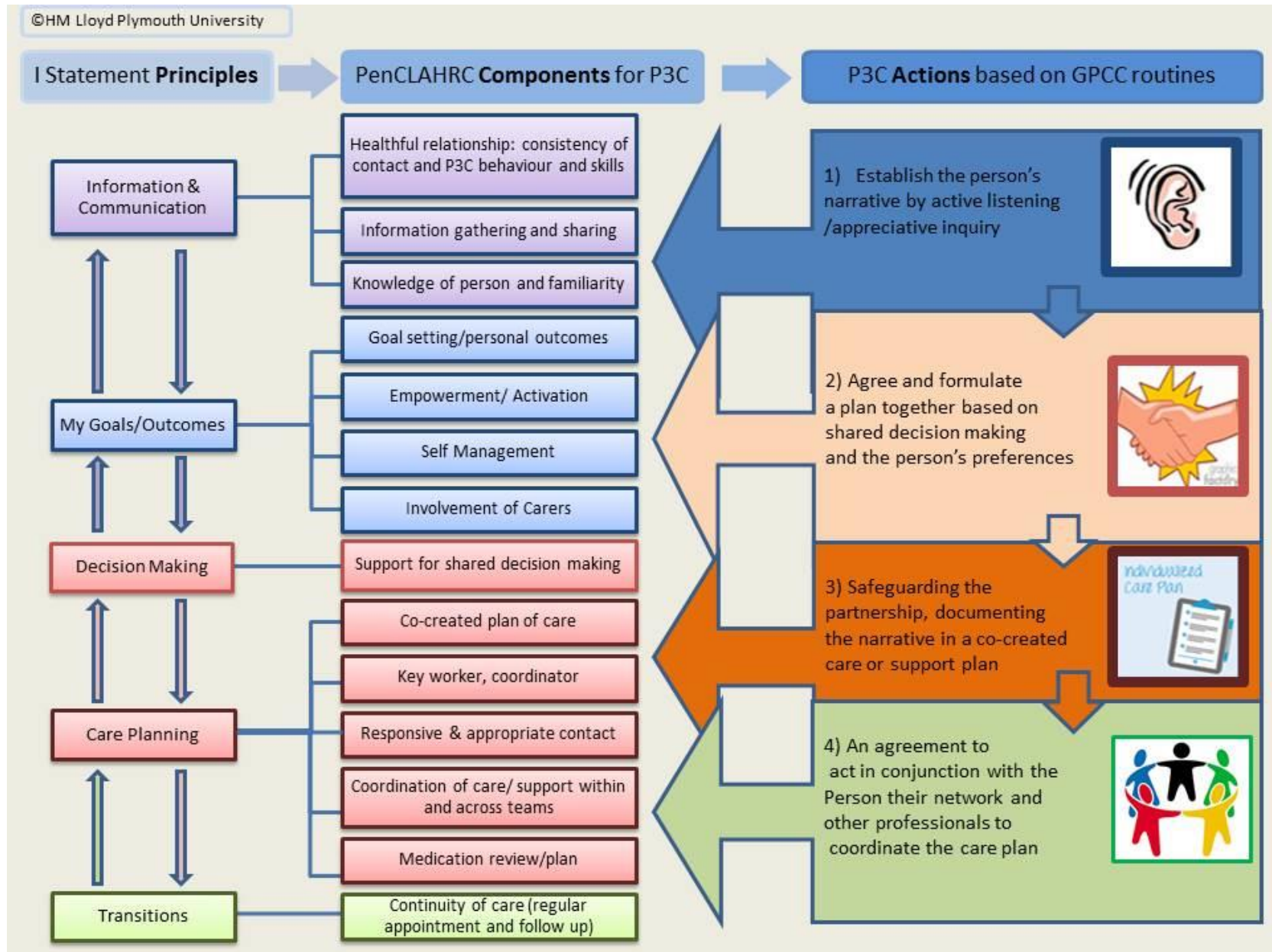
is interdependent, and all components are needed in order to sustain implementation. Much like the GPCC routines above, personalised care planning is also core to the HoC model. Whilst the model provides a comprehensive summary of the various aspects of P3C and provides signposting to how these may be achieved, there are few navigational tools to guide and monitor implementation at the clinical/person interface. There is therefore uncertainty about how best to implement and achieve P3C as well as about what good P3C ‘looks like’ in terms of the exact configuration of components required to achieve it in any given context.

Whilst there is a broad consensus that P3C is the “right thing to do”, there is continued ambiguity over the exact configuration and implementation in different settings. This lack of clarity makes evaluation an absolute necessity, laying the foundations for evidence-based progress in the future. The core ethics and routines outlined for P3C above provide guidance for the type of actions and behaviours that individuals and teams need to embrace to deliver P3C, irrespective of the type of organisation. Importantly however, P3C should result in a positive change in how care is experienced, improved population health (through better outcomes for individuals), and improved service efficiency, thus mapping well to the triple aim of modern health care: 1) improving the patient experience of care (including quality and experience), 2) improving the health of population, and 3) reducing the per capita cost of health care (<http://www.ihi.org/engage/initiatives/tripleaim/pages/default.aspx>). P3C also has the potential to contribute to improved staff experience and health, thus constituting what Bodenheimer calls the Quadruple aim¹⁰.

Work by the PenCLAHRC and the SWAHSN has furthered understanding of P3C by identifying principal components from the HoC framework, evidence scans, and results of systematic reviews. These were then mapped to the National Voices ‘I Statement Narratives’ and the GPCC routines, adding a fourth routine to the process, as described in the following diagram: [Figure 4](#) provides an indication of how principles and components can be actioned into processes to create P3C. What the diagram does not depict are the supporting organisational processes required for these to be achieved. These will be covered in [section 4.4](#), where each routine (and its constituent components) is defined according to how they can be measured and further developed.

¹⁰ [From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider](#) Thomas Bodenheimer, MD and Christine Sinsky, MD. Ann Fam Med 2014vol. 12 no. 6 573-57

Figure 4: I statements, principal components and P3C routines



4.3. Healthful Cultures: A Context and an Outcome of P3C

Emerging thinking and evidence suggests that healthful cultures form both a context of the development of P3C and are also enhanced by the practice of P3C. Organisations that strive to be 'healthful' are those in which:

'Decision-making is shared, staff relationships are collaborative, leadership is transformational, innovative practices are supported and is the ultimate outcome for teams working to develop a workplace that is person-centred. This is a key factor in the delivery of Person Centred care and the extent to which the environment supports and maintains Person Centred principles has been shown to be critical to Person Centred practice' (McCormack B and McCance T, 2016:pp)

McCormack et al (2016) have moved away from the term 'therapeutic cultures'¹¹ to reflect the broader focus of their conceptualisation of 'Person Centred Care' on living a positive life, embracing all dimensions of our being. They argue that the term 'therapeutic' has been used to reflect the positive nature of expected outcomes associated with a 'health' benefit, and thus may now not accurately reflect the potential outcomes for all who are engaged in the care process. Importantly they also argue that this 'broader notion of health is more relevant from the perspective of staff where a healthful culture is one in which they are supported and enabled to deliver Person Centred care in line with their values', pointing out that being able to deliver Person Centred care has benefits for staff, enhances retention and job satisfaction (Kings Fund 2010). Emphasising the support needs of professionals and any impact upon their work experience is a core feature of P3C and will also be important to measure in the development towards P3C.

In the next section we focus on each of the 4 routines outlined in the preceding section, discussing each in detail. The components required for their operationalisation are defined, along with the expected outcomes that will reveal that implementation has been successful. The following section presents the ways in which these processes and activities can be measured, assessed and supported by organisations.

¹¹ For examples those which provide facilitative healing orientated encounters or relationships in health settings towards a health gain or outcome

4.4. Implementing P3C Routines

Routine 1) Initiating the Partnership: Establish the person's narrative by active listening/appreciative inquiry:



Care and support cannot be person centred or coordinated well without embracing both the ethic and the practice of 'healthful' relationships in the workplace (see previous section). However, through experiential learning and reflexive practice, the ethics and the practice will develop alongside one another if the right support is in place. Following training, the development of experiential learning towards person centred care can begin, with the process and methods of learning about the person, their story, and what matters most to them in relation to their life, health and wellbeing, and the conditions in which they live. This type of holistic knowledge, which considers a person as a bio-psycho-social whole can only be gained by having a different conversation and interaction within a clinical or support encounter through eliciting a person's narrative. The We-Implement PCC¹² consortium, a multi-centre research group consisting of experts in PCC, describe the personal narrative and its value in establishing PCC as follows:

'The sick person's account of his/her illness, symptoms, and their impact on her/his life. It captures the person's experience in an everyday context, in contrast to medical narratives that reflect the process of diagnosing and treating the disease. The person's narrative constitutes the starting point for P3C and lays the ground for a partnership in care. The mere invitation to relate a narrative sends a message to the individual that his/her experiences, feelings, beliefs, and preferences are important considerations. The elicitation of a personal narrative creates a shifting point from the disease to the person with the illness (needs and resources). The narrating of the person's story is a therapeutically central act in many health practices, because finding the words to describe the disorder and its attendant worries gives shape to and control over the chaos of illness'.

These types of conversations should be focused on building a narrative picture of a person, asking an individual to tell their story, highlighting what is important to them, enabling a dialogue to take place about how care and support can help achieve their goals. At this stage, relevant carers or supporters will also be involved in care planning. This approach is similar to qualitative research methods, where the respondent is encouraged to use their own language and tell their story with minimal interference. Providing the respondent with a space to tell their story allows the interviewer to build knowledge of the individual, seeing the world through their eyes and creating an empathic understanding with the individual. Researchers - and

¹² PCC is defined as Person Centred Care, often shorthand for Person Centred Coordinated Care. The origins of the PCC consortium project began in hospital care in Sweden where coordination in that context was less of a problem. P3C emphasises the forth 'C', that of Coordination across the care and support sectors.

increasingly health and social care practitioners - are using guided probes in this type of a conversation, ensuring that a range of health and psychosocial issues are covered during these conversations.

There are a number of approaches that can aid the elicitation of a person centred narrative during care and support interactions. An Appreciative inquiry (AI) approach is particularly well suited as it is an approach that helps recognise a person's abilities and strengths rather than their deficits or problems. It is an approach that helps people move towards their most positive potential with a personalised care or support plan as an outcome. It also attempts to set out how change will happen. AI treats all individuals as equal partners, focuses on developing the strengths already present, and helps all involved in the process to feel appreciated, valued and important. AI helps practitioners connect, learn, and agree ways forward, supporting individuals or teams to embed new behaviour and lasting change. It has been used extensively in organisational change and most recently in health change interventions. This approach fits very well with the definitions of P3C outlined in earlier sections.

The process of eliciting a person's narrative can result in the following outcomes (although it may take multiple encounters for these to be achieved):

- Enhanced Person Centred (PC) (holistic) knowledge about the person
- Enhanced information and knowledge for the person and their carers or supporters
- Enhanced communication between practitioner and the person
- Enhanced PC communication and empathy from the practitioner
- A healthful relationship and enhanced trust and familiarity
- Enhanced job satisfaction
- Feelings of value and respect
- Information about what matters to the person and their goals and outcomes - The beginning of a PC partnership

A consistency of contact with the same practitioner will enhance these outcomes in people with LTCs, MLTCs and those at the end of their life.

Routine 2) Agree and formulate a plan together, based on shared-decision making and the preferences of the person: working the partnership



The second important step or routine that follows the elicitation of a personal narrative within the care or support encounter is the formulation and agreement of a plan which is based on shared-decision making and the preferences of the individual.

This step is incredibly important in developing the partnership between individuals and professionals, and in setting the tone for the resultant care and relationships. It is also an opportunity to actively encourage the individual to think and plan with the professional and to agree mutually defined steps and goals that care and support professionals can work towards in partnership with the individual and their support network, to achieve better outcomes. A co-created care and support plan will be informed by the knowledge of the person that the professional has gained through routine one (described above) as the elicitation of the personal narrative. The professional can use notes that they have taken to reflect on, and clarify, important contextual or other information that the individual communicated during routine one. Some individuals may struggle to articulate or conceptualise goals, and it is here that the professional can encourage this process by referring to key issues or topics that the individual may have talked about during routine one. Using structured prompts during this interaction might be helpful to facilitate the elicitation of preferences of treatment and goals or outcomes. Some good care plans have these prompts embedded in the document for ease. Importantly, the appearance, length, and language of the care and support plan should be patient-friendly and in a format that is appropriate for that individual. Supporting the individual in this way will contribute to active listening and provide a basis of support for empowerment for the individual. The value of routine two 'Working the Partnership' can be described as follows:

'Despite the availability of effective and safe treatments in long-term conditions (e.g., diabetes, chronic heart failure, hypertension) many patients do not achieve recommended target doses or optimal care. Given the progressive nature of long-term diseases and the need for extensive illness management, it is important that professionals and patients (often including relatives) develop a partnership to achieve commonly agreed goals. During care and support planning, the care team, including the patient, should evaluate all aspects of management, taking into account treatment options that are suited to the patient's lifestyle, preferences, beliefs, previous experiences, values, and health issues.'

Narrative communication, involving sharing experiences and learning from each other, puts the concept of partnership into practice. Telling and listening is a way of creating a common understanding of the illness experience, which, together with signs of disease,

gives the professional a good basis for discussing and planning care and treatment with the patient¹⁴. Indeed, PCC starts with partnership building and includes shared information, mutual understanding of treatment goals, shared deliberation about options how to reach these goals, and ultimately shared decision making.' (We-Implement PCC consortium)

During routine two, the professional and the individual will understand the individual's capacity to self-manage, and how this can be improved or supported. Some delivery teams use Patient Activation Measures (PAMs) to assess this potential for self-management, further possible utility to influence care planning and aid goal setting. However, this is not the only method for doing this. Whatever method is used, the reason for the procedure (i.e. as a tool to inform self-management, rather than merely a measurement) should be clearly articulated to the individual. Clinical Commissioning Groups using the PAM need to ensure that there are processes in place to feed results back to practice, and that the information is used to inform care and not merely to elicit a benchmarking score.

During routine two (working the partnership), the professional can also explore the needs of carers or supporters. A carer's assessment or referral could also be arranged as part of this process. This routine also provides an opportunity for the emerging partnership to decide how the individual wishes his or her family to be involved in the planning of care and support, and how this information is conveyed in the personalised care plan. It provides a further space to explore what is important to the individual through the agreement of the plan, increasing the flow of information to and from the professional and the individual. Through the enactment and embodiment of this routine, further opportunities are created to provide a greater sense of holistic knowledge about the person, and a person-centred narrative picture of the individual for embedding in the personalised care plan. Realising the potential of an individual and the beginning of a healthful relationship are key outcomes of this routine and will only be achieved if shared decision-making is supported and embraced.

The development of the partnership and the co-created plan will depend upon the degree to which the individual feels valued and listened to – communication & shared decision making are the fundamental cornerstones.

Working the partnership in this way through agreeing and formulating a plan together based on shared decision making and the preferences of the individual, if supported and developed well, could result in the following outcomes (although these may take more than one encounter to achieve):

- Individual feelings of empowerment
- Level of potential activation
- An understanding of the potential of the individual to self-manage their condition(s)
- Preferences for the involvement of carers, family, support network
- Shared decision-making
- Increased flow of information and communication (to foster a healthful relationship)
- Key issues and identified goals or outcomes – recorded and ready for developing into a personalised care plan
- An enhanced sense of knowledge about the individual and what matters to them
- Development of trust and healthful relationship
- Plan for carer assessment or referral

Routine 3) Safeguarding the Partnership: Documenting the narrative in a co-created care or support plan



Depending on the service or delivery organisation, the exact form or template used to record the preferences and goals and the narrative information may vary. However, at a very minimum this plan should include the following elements:

- Identified short-medium-long term goals that are most important to the individual whether these be social, medical, clinical, psychological, functional, environmental etc.
- Information about side effects of medication and a list of all current medications
- Potential barriers and facilitators to the achievement of goals and outcomes
- First steps and clarification of next steps to achieve goals and outcomes
- Escalation and de-escalation plans
- Any plans for the support or assessment of carers
- Preferences of mode of contact and interaction between professionals and the individual and their family
- An agreement that the above will be inserted in a personalised care plan that will be developed and provided back to the individual

There appears to be great variability in the extent to which personalised care plans are developed and shared with individuals, so much so that there are few patient reported measures that capture this process. However, as part of the GPCC routines, it is considered as the evidence-based cornerstone of their model. The importance of this mechanism in safeguarding the partnership and facilitating continuity of care is described:

‘Documenting patient preferences, beliefs, and values, as well as preferred involvement in care and treatment decision-making and the outcomes of the decision-making process in patient records gives legitimacy to patient perspectives, makes the patient–provider interplay transparent, and facilitates continuity in care. The registration of such information must be considered equally mandatory as clinical and lab findings.’

Another important feature of the care plan document is the potential for it to also facilitate the coordination of care when multiple professionals and services are involved in the care and support of a person. The care plan document should be accessible to the person or held by them with the potential for the individual to amend and change the document. The degree to which this document is digitised will again depend on the service, but at the very least a paper version should be available to the core members of the partnership. New technology could be explored with individuals who are able to use it. This could include applications suitable for mobile phones or other electronic devices such as tablets or computers. Regardless of the mode of delivery it should be user-friendly and contain information of use to the individual, or else it will be an ineffective cog in the routines necessary for the delivery of P3C.

Safeguarding the partnership by using a personalised care and support plan could help facilitate the following outcomes:

- A co-created and person centred care plan
- Identification of a key person coordinating care for the individual
- Information about who to contact at what point (i.e. nominated key worker and relevant professionals)
- Facilitation of responsive and appropriate care (i.e. based on list of elements defined above)
- Better coordination of care (based on facilitation of responsive and appropriate care, knowledge of person, who to contact when and who is involved in care and support)
- Facilitation of continuity of care (i.e. maintaining person centred quality of care over time by providing a portal/mode of transmission of PC knowledge about the person, and thus encouraging promotion of PC behaviour & communication)
- A referral or assessment for carers or supporters

The documentation of the narrative gives legitimacy to the patient perspective with the potential to facilitate responsive and appropriate care, coordination of care and continuity of care.

Respondents who participated in a workshop to help inform this work endorsed the use of personalised care plans, but few, if any, reported having one themselves. The workshop participants felt that care plans provided a mechanism for patients and service users **to feel more in control of their care and support**. They also felt that care plans should interact with technology (i.e. applications for smart phones etc.), require collective buy-in from across the professions involved in care and support, and hold the potential to enhance care coordination and continuity of care. **There was a consensus among the group that care plans should include social goals and needs and they should include as a minimum:**

- **A person(s) to contact for the appropriate purpose (i.e. who to contact in a crisis or for routine queries), and a backup contact if initial contact is unavailable**
- **Medication information and dates for reviews**
- **Forward planning**

Routine 4) An agreement to act in conjunction with the person, their network and other professionals to coordinate the care plan



For individuals with LTCs, MLTCs and those with complex needs, fragmentation and poor coordination occurs most often when care and support need to be sourced from across the health service, third sector and social care boundaries. Schisms in care and support also manifest between health sectors such as General Practice, community nursing, mental health services and acute hospitals. A key issue that is most apparent is the failure to achieve – and make coherent for the individual – key clinical functions, such as preventing and responding to urgent care needs, rational management of multiple long-term conditions (polypharmacy, self-care), and support to promote social goals along with mental and physical wellbeing. There is much uncertainty about how to coordinate care well for these patient groups. However, efforts to organise the delivery of care using new models in the UK are starting to tackle these issues. Some organisations are setting up specific pathways and local multi-agency teams. Others are joining together delivery and commissioning organisations and setting out on joint ventures. The Integrated Person Commissioning programme (IPC) as a critical part of the 5YFV will attempt to put individuals in control of commissioning their services to meet their needs with support from organisations. Furthermore, linking coordination with community and non-statutory organisations will help to support more community centred care, provide the potential to build community and individual assets, and importantly, operationalise the ethic of helping people fulfil their potential by supporting resilience and self-management. It will be some time before we know which configuration or organisational structure is most conducive to P3C and in which contexts these models are likely to thrive. In the meantime, we need to promote and support coordination both across sectors and within sectors to improve P3C in existing settings.

The agreement to act in conjunction with the individual and their network, and other professionals across health, social care and community boundaries to coordinate care and support, creates a first step in this process. It must begin with the individual and keep them at the heart of the coordination. This role will often be allocated to professional key workers or care coordinators within statutory and some non-statutory services. However, this role may also be taken on by a carer or family member, or indeed a professional from a social care organisation. Building PC knowledge of the person and what is important to them through the first three routines will help create a framework for coordination and facilitate the knowledge-building and actions that will aid the personalised care plan. However, asking professionals to coordinate care across an often fragmented system is no easy task and will depend on positive risk taking, assertiveness, good communication skills, enhanced organisation skills, insistence, training and an increased

knowledge of the range of services available. Next, this knowledge will need to be linked to coordination action plans that link back to the individual, involving them in the decision making process. Professionals will also need to efficiently interoperate. There are mechanisms that will support this process, such as shared IT systems, existing agreements and relationships between organisations, multidisciplinary team meetings and social prescribing models, in addition to professional support for the continuing development of coordination skills.

Agreeing to act in conjunction with others (professionals from a range of organisations, the individual, and their networks) will help to develop coordination if this is centred on a personalised care plan. Importantly, coordination and continuity of care are interrelated and need to work based on person centred principles if unwarranted admissions and duplication of efforts are to be avoided. If professionals and individuals are supported by their organisations, the following outcomes may be achieved:

- Increased potential for self-management and asset-building through the optimisation of care and support and through coordination with non-statutory or community organisations
- Operationalisation of shared decision-making leading to development of healthful cultures of practice
- The development of responsive and appropriate on-going care leading to the avoidance of duplication and unwarranted reliance on secondary and acute care
- Increased continuity of care
- Better management of transitions leading to the avoidance of duplication, avoidance of delays and unwarranted reliance on secondary and acute care
- Enhanced spread of person-centred knowledge of the person
- The spread and development of healthful relationships through enhanced contact with other professionals
- Coordination of support and assessment of carer or supporter needs

Coordinating the personalised care plan will demonstrate shared decision-making, develop responsive and appropriate care and enhance the spread of person-centred knowledge and healthful relationships.

4.5. Person-Centred End of Life Care

The routines above and many of the principles and components listed in the previous section also apply to person centred End of Life care. End of Life (EoL) is defined by the GMC as when a person is likely to die within the next 12 months, and this includes people whose death is imminent. A very helpful toolkit has been produced by NHSE for commissioning for Person Centred End of Life Care (<https://www.england.nhs.uk/wp-content/uploads/2016/04/nhsiq-comms-eolc-tlkit-.pdf>) which outlines the ambitions for palliative and EoL care and the foundations required to achieve them. These are described in the box below:

Ambitions	Foundations
1. Each person is seen as an individual	I. Personalised care planning
2. Each person gets fair access to care	II. Shared records
3. Maximising comfort and wellbeing	III. Evidence and information
4. Care is coordinated	IV. Involving, supporting and caring for those important to the person
5. All staff are prepared to care	V. Education and training
6. Each community is prepared to help	VI. 24/7 access
	VII. Co-design
	VIII. Leadership

The ambitions and foundations listed above that have not been discussed in relation to the previous section (i.e. fair access to care, education and training, and leadership) are also important to P3C more generally and for people with LTCs and MLTCs. They will be discussed in the following sections as facilitative factors in the implementation of P3C.

4.6. More than the Sum of their Parts: Impact on Population Health, Wellbeing and Service Efficiency

In addition to the short- and medium-term outcomes and improved processes described above, if the four routines are implemented, developed and supported, it is possible that people with LTCs and MLTCs will improve in relation to self-reported perceptions of health and wellbeing, perhaps even Quality of Life and contentment. For people at the end of their life and their loved ones, feeling appreciated, respected, and in control of life during those critical stages may become a routine experience rather than an aspiration. Moreover, it may also be possible that that health and social care systems may become more efficient, particularly if coordination improves alongside payment and commissioning systems. These outcomes may take time to develop; working to understand how progress is being made and actively supporting practitioners will be more productive than simply benchmarking progress or performance-managing. Furthermore, practitioners and delivery teams need to believe in and understand why they are being asked to work differently. Before the measurement, monitoring, and further development of these routines and resultant practice, changes first need to be established. Furthermore, it will be crucial to communicate to individual patients early in this process that measurement and assessment are necessary to develop practice and to help tailor support to their needs. This will immediately signal to all parties – patients and practitioners - that co-design of delivery is a necessity. This needs to be honoured from delivery-level interactions right through to system level monitoring and up to quality improvement activities. The following section outlines some of the methods that can be used to iteratively develop these routines and measure short-, medium- and long-term processes and outcomes.

5. METRICS, MEASURES AND INSIGHTS: CREATING CHANGE & ONGOING IMPROVEMENT FOR P3C USING EVALUATION METHODOLOGY

5.1. Developing and Monitoring P3C: the prerequisites

To implement the four P3C routines and create the 'healthful' culture discussed previously, the organisations involved need to have the following in place. These prerequisites will also ensure sustained change.

5.1.1. Staff Training, Briefing and Support

Staff training should precede the inception of P3C interventions or service changes, whether this is Year of Care Training (<http://www.yearofcare.co.uk/training-and-support>) or other training programmes. Training and development opportunities need to be continuous and be incorporated into current roles through learning sets and PDSA cycles of improvement. At a minimum, training for self-management support and care planning will be crucial to the delivery of P3C. Delivery management teams and CCG staff responsible for development and training also need to ensure that delivery teams understand the process and methods for measuring activity (the evaluation framework). These transitions will be more fluid if the system has been co-designed with leaders from delivery teams, as they will already be familiar with the framework and how to embed in with academic partners. Team-based workshops, exploring methods for assessment, in addition to involving patients and carers, will also help development and measurement processes. One example would be the implementation of agreed Read Codes for the clinical system to identify which individuals should be recruited to an intervention; it might be necessary to work with local commissioning support units. Importantly, upon clarification of the framework of the design (such as appropriate time for data collection points), all those involved need to be consulted, ensuring that they understand the value of measurement and assessment. Prior communication of the PDSA cycle ensures that teams know what to expect and enable them to feel part of the process. Plans for the feedback to patients will also need to be discussed with patient representatives to decide how this can be best operationalised.

5.1.2. Prerequisite Characteristics of Staff & the Care Environment

McCormack and McCance (2010)¹³ highlight the prerequisite characteristics of nurses required for person-centred care, which could be applied to a range of Health Care Professionals. They suggest that practitioners should be:

- a) Professionally competent: *possess the knowledge and skills to make decisions and prioritise care (including physical and technical aspects of care)*
- b) Possess developed interpersonal skills: *the ability to communicate at a variety of levels*
- c) Be committed to their job: *dedication to provide the best care for the patient*
- e) Hold clarity of beliefs and values: *those that are linked to moral and ethical codes which align with P3C, such as taking into account peoples preferences and views, the right to self-determination etc.*
- f) Know themselves: *linked to the above and related that knowledge of self and how we function will help understanding and helping others.*

Helping staff to become competent in P3C and increase their interpersonal skills may have positive effects on how committed they feel to their job, provide enhanced recognition of beliefs and values, and improve self-awareness and knowledge of self. However, the care environment itself is the underlying substrate for P3C, and staff will only be supported to thrive if the care environment is flexible. This will involve attending to the workplace culture and ethos and ensuring that P3C values are well-known and articulated at an organisational level. It will also involve ensuring that there is an appropriate skill mix of professionals required for P3C and that they work together to support shared decision making, both between staff and between staff-patient dyads. This will facilitate power-sharing between staff, and effective relationships will provide a basis for confidence, innovation and risk taking. The physical environment where people work should also be considered and attuned to P3C values (i.e. accessible, welcoming, functional and empowering)¹⁹.

¹³

https://www.google.co.uk/imgres?imgurl=http://t0.gstatic.com/images%3Fq%3Dtbn:ANd9GcQOzGcP4LgNNG9wFOGbCBIsBFc3_UbgEPe6tZWEfkdJLEqScfbd&imgrefurl=http://books.google.com/books/about/Person_centred_Nursing.html%3Fid%3DxAsJwGcFH8QC%26source%3Dkp_cover&h=900&w=635&tbnid=JLuGP8ihb7IEIM:&tbnh=160&tbnw=112&usq=__b5oslgAu_tRoJzqwxL_EnuEB2vM=&vet=10ahUKEwi50-qXhuHTAhUJCcAKHfb7BNMQ_B0IfDAK..i&docid=NFEFaOhuYm-6OM&itg=1&sa=X&ved=0ahUKEwi50-qXhuHTAhUJCcAKHfb7BNMQ_B0IfDAK

5.1.3. Champions and Leaders for P3C

Champions and leaders for P3C at various levels within the organisation are a necessary precondition for change. When service developments go “live”, professionals and patients are often confronted with change and can subsequently struggle with systemic barriers and organisational pressures. At these times, it is often P3C champions and leaders that can provide the momentum and steer. A role for P3C champions and leaders that is often not realised is that of evaluation lead or link person to academic partners. Many commissioning organisations fail to invest in the skills required to understand evaluation and data driven improvement, even though many individuals with these skills are present in related organisations, such as commissioning support units. Partnering with local CLAHRCs, AHSN's and academic organisations will provide support in this area. Some of the CLAHRCs (for example) provide workshops that aim to increase the understanding of evidence in health and social care sectors (see: <http://clahrc-west.nihr.ac.uk/training-and-capacity-building/clahrc-west-courses/critical-appraisal-for-healthcare-professionals/>). See also the Courses <http://www.clahrc-norththames.nihr.ac.uk/clahrc-academy-short-training-courses/> offered recently by NIHR CLAHRC North Thames to service leaders on the purposes of and approaches to evaluation. Losing leadership is one of the factors frequently implicated in the failure of interventions. P3C leaders should be employed in the same capacity as any role – not as personal champions, but instead as vital (but replaceable) employees. This will facilitate cultural change and the upskilling of existing employees. Having several key people within the organisation take on this role will ensure that leadership continues even if one member leaves. Individuals who take on this role could have designated roles to link P3C initiatives with Sustainability and Transformation Plans (STPs) (see: <https://www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/stp/>) which will become increasingly important to deliver the 5YFV.

5.1.4. Knowing Your Population and Identifying People for P3C

Understanding the needs of your LTC/MLTC and EoL populations will be important for deciding how P3C will be planned and implemented. There are national tools that can be used to support this process for local use. The NHS Atlas of Variation in Healthcare provides information on activity and outcomes in relation to investment for whole population needs (see: <http://fingertips.phe.org.uk/profile/atlas-of-variation>). Similarly, NHS England operates a LTC dashboard that provides comparative data on a range of outcomes and prevalence information on LTCs

(<http://ccgtools.england.nhs.uk/lcdashboard/flash/atlas.html>). Other useful documents and websites include the Public Health Older Peoples Wellbeing Atlas (<http://www.apho.org.uk/resource/item.aspx?RID=120576>) and the following commissioning guide for specialist palliative care (<http://www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf>).

How people are identified as those which could most benefit from P3C is something that services and commissioning groups can find challenging. Whilst P3C should be an aspiration for all members of society, those with the most complex needs will benefit the most from such approaches and should be prioritised. Several risk stratification methods are available, but many of these are insensitive to identifying those most at risk of decline and subsequent hospital admissions. For example an influential publication by Roland and Abel (<http://www.bmj.com/content/345/bmj.e6017>) revealed that focusing on the top 0.5% - 1% highest risk patients offers a relatively small opportunity to reduce emergency admissions. The subject of risk stratification and case finding was well covered by NHSE in a document that provides helpful links, an overview of current methods and some important considerations when selecting and using these tools (see <https://www.england.nhs.uk/wp-content/uploads/2015/01/2015-01-20-CFRS-v0.14-FINAL.pdf>). In practice, it is important to use a variety of tools for P3C stratification, ensuring that local intelligence and service information is used. Approaches based purely on algorithmic or computerised programmes have limitations that will omit relevant portions of the population. They must be complemented by cross-sector and team-working, which can help address equity of access issues and the inverse care law (those with the greatest need for care are the least likely to receive it)¹⁴, particularly if such case finding approaches are used in conjunction with population intelligence.

5.1.5. Information Technology & P3C Plans

A lack of integrated technology across health and social care sectors and the lack of shared electronic patient records remain significant barriers to P3C. However, progress has been made with the Summary Care Record (SCR) in some localities with ambulance trusts, community pharmacy and General Practice utilisation sharing access (see link for more information <http://systems.hscic.gov.uk/scr>). An early case study evaluation revealed that

¹⁴ The Inverse Care Law, Tudor Hart, Julian, The Lancet, Volume 297, Issue 7696, 405 – 412.

use of the SCR prevented medicine mistakes, though adoption and implementation were challenging.¹⁵ However, a Person Centred Care Plan is quite different from the SCR. Although an SCR is clearly very necessary for individuals who require P3C, a more detailed care plan as described in [section 4.4](#) is necessary to ensure that person-centred information is transmitted across sectors. This is a key mechanism in ensuring that coordination is facilitated. There are inherent problems with making sure that this type of information is kept up-to-date and shared across all sectors in an electronic format. Providing a copy of a personalised care plan to individuals and their families to “hold and own” and be something that can accompany them as they journey through the health and social care organisations is one obvious intermediate solution. Moreover, some organisations have now achieved an electronic P3C plan that is interoperable across sectors. A notable example is the Patient Knows Best platform used in South Somerset (see <https://www.patientsknowbest.com/>). This system is designed to help empower patients and families and share important P3C information for better care for the patient. A good paper template is being used by Hampshire County Council (http://www3.hants.gov.uk/pact_care_form_sign.pdf). There are many other examples of P3C care plans. The primary consideration is that it is meaningful and sensible to patients. It should include the information outlined in [section 4.4](#) as a minimum, and there should be the option for a paper copy.

5.1.6. Organisational Agreements

To ensure coordination of services it will be necessary to form organisational agreements. This will involve public, private, voluntary, and community sector organisations. Agreements will vary in formality and legal standing. For example, organisations can work with the public sector according to:

- informal arrangements which may outline protocols only at operational level
- grant agreements
- memorandums of understanding
- legally binding contracts, including service level agreements

The above options may be used in combination and vary in the degree to which they are legally binding, but if a public body wants to procure a service, a contract is best practice (see <https://knowhownonprofit.org/organisation/collaboration/working-collaboratively/joint-working-for-public->

¹⁵ Greenhalgh Trisha, Stramer Katja, Bratan Tanja, Byrne Emma, Russell Jill, Potts Henry W Et Al. Adoption And Non-Adoption Of A Shared Electronic Summary Record In England: A Mixed-Method Case Study Bmj 2010; 340 :C3111

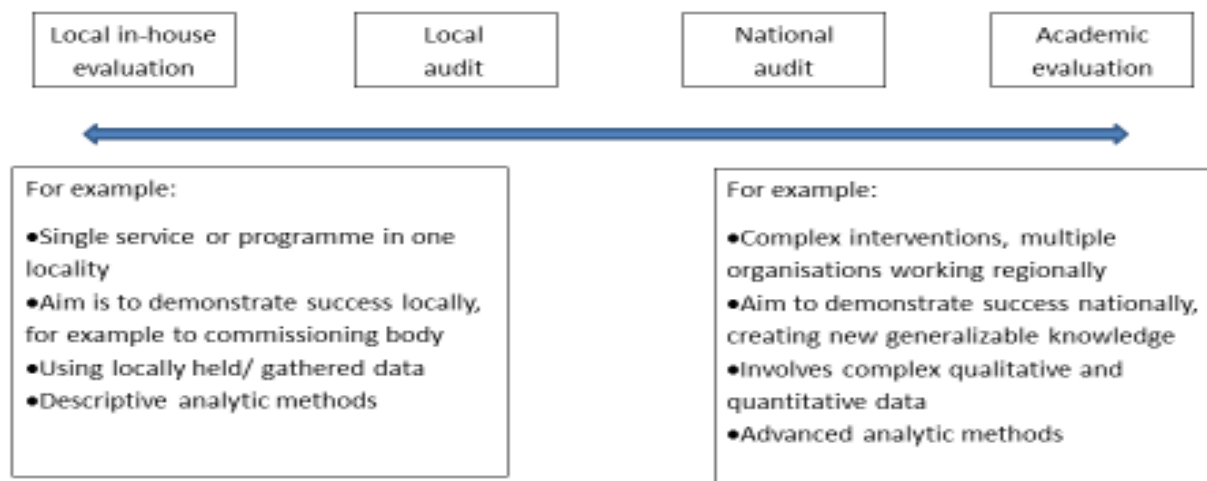
[service-delivery-ncvo](#)). If organisational agreements are not in place, this can provide a significant barrier to implementing P3C as it threatens multidisciplinary working by preventing cross-sector representation. Subsequently any agreement to act in partnership to coordinate the care plan will suffer.

5.2. Evaluation Frameworks

Finding non-invasive and efficient mechanisms for understanding if P3C is working will ensure the ongoing development and continued funding of P3C interventions. An [evaluation framework](#) will be necessary to organise how this can be achieved. The evaluation framework or the type of measurement that is adopted to help develop any P3C intervention will depend on the scale of change being implemented (i.e. a single-level service change or more extensive system-wide change). The diagram below produced by NIHR CLAHRC North Thames displays the evaluation continuum ([Figure 5](#) see Mears et al <http://www.hsj.co.uk/comment/why-the-nhs-must-evaluate-complex-service-changes/5089761.fullarticle>).

It is also likely, given the complex nature of P3C, that evaluation frameworks will consist of more than one type of data collection process across

FIGURE 5: Approaches: appropriate evaluation



NIHR CLAHRC NORTH THAMES © UCL

multiple levels (i.e. from individual patient data to aggregated data) representing the right end of the above diagram.

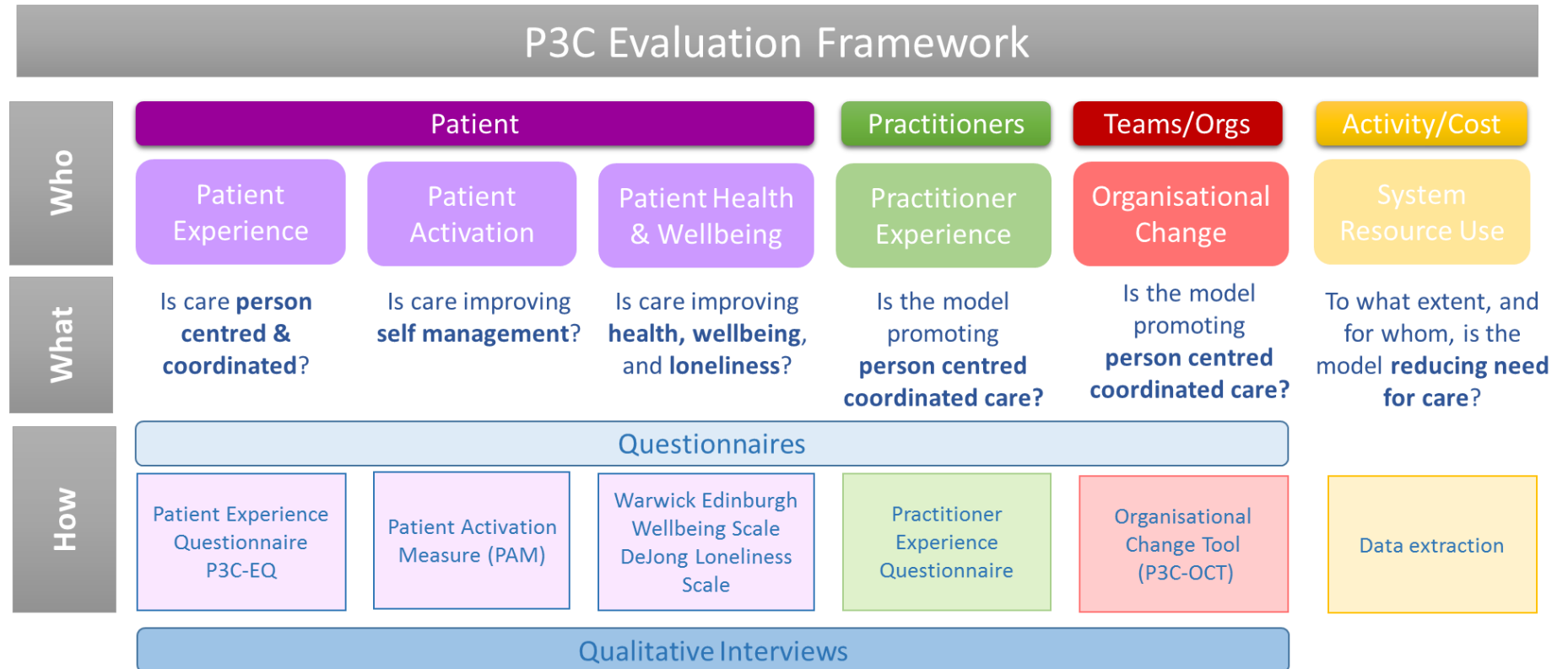
The feedback of data collected as part of the evaluation will be key to the iterative development of the delivery model, following adjustments made using [Plan-Do-Study-Act](http://www.ihl.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx) (PDSA: <http://www.ihl.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx>) cycles or similar processes. Logic models are a graphical representation of the theory of change of an intervention. They can be usefully used alongside evaluation frameworks and are a good way to communicate the theory of change and underlying assumptions of P3C interventions. They also provide a useful planning tool to guide what processes, resources, and activities are required to implement P3C and what anticipated outcomes might follow if implementation is successful. Used together, evaluation frameworks, logic models, and improvement cycles provide a necessary formative approach to the development of P3C.

A well-planned evaluation framework will provide a process to think about the Aims, Outcomes, Measures, Data Collection, and Analysis of the data and the reporting of the findings. It will also allow for the development and critical questioning that should precede the development of the intervention and outline how the evaluation will help to inform the intervention model.

The following example (see Figure 7) is of a mixed method multi-level evaluation measurement framework developed by the PenCLAHRC to guide a consistent framework for P3C service evaluations across the region. It shows the ways that different types of data can be collected to assess and develop P3C. It illustrates the complex nature of P3C, where multiple simultaneous activities, outcomes, and processes could be captured through multilevel and mixed methods data. Importantly, it illustrates a **core minimum data set** built around the quadruple aims¹⁶ (**Improved Patient Experience, Improved Population Health, Improved Efficiency and Improved Staff Experience**). As outlined previously, measurement should be built upon to ensure that the outcomes and changes in activities and processes are adequately captured. The Better Care Fund document 'How to understand and measure impact' provides further advice and detail on the importance of evaluation frameworks (<https://www.england.nhs.uk/wp-content/uploads/2015/06/bcf-user-guide-04.pdf.pdf>).

¹⁶ Bodheimer : <http://www.annfammed.org/content/12/6/573.full>

Figure 7: An example evaluation framework for P3C: Quadruple aim

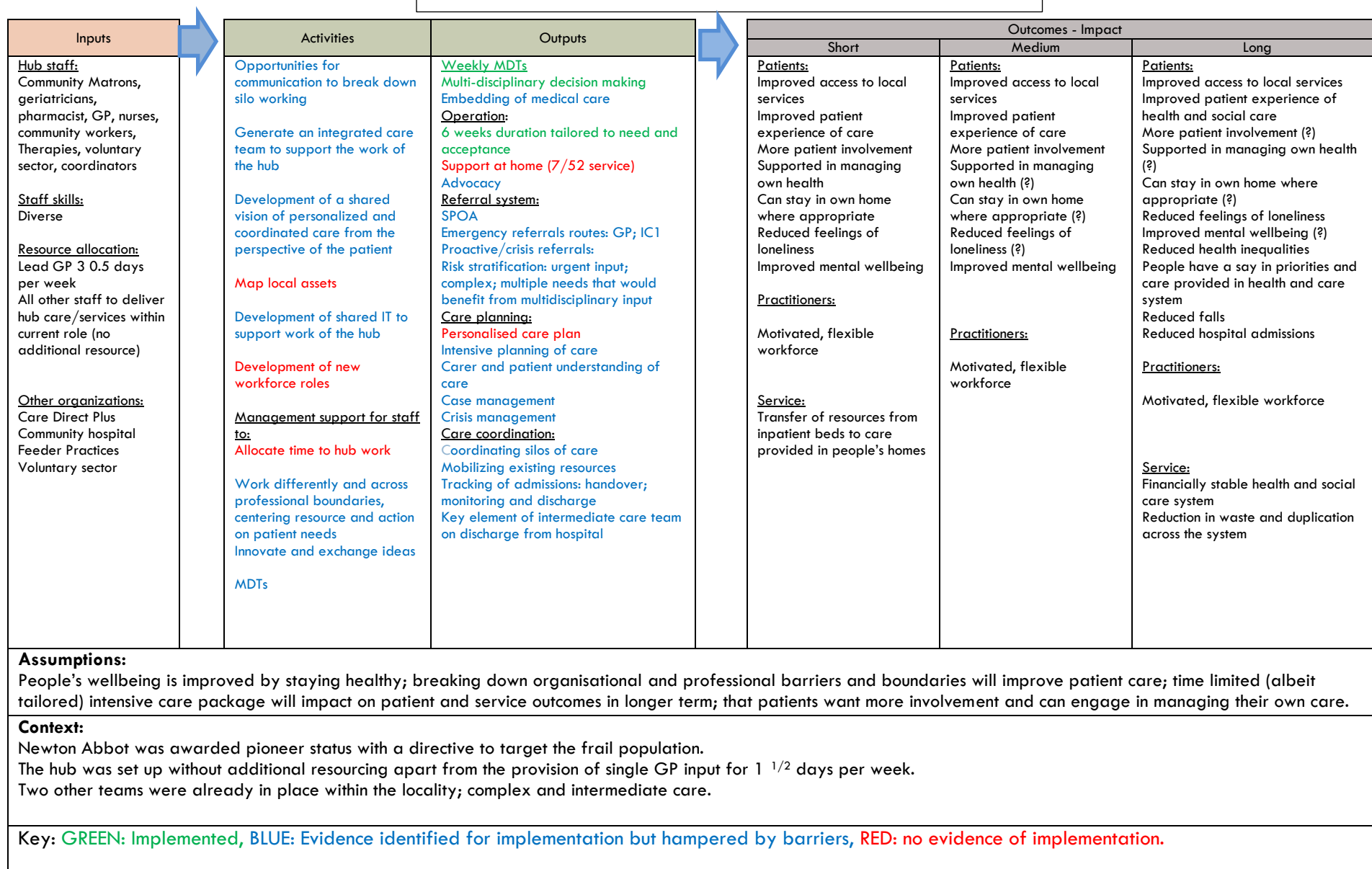


5.3. Logic Models

Logic models have been described well elsewhere <https://www.wkkf.org/resource-directory/resource/2006/02/wk-kellogg-foundation-logic-model-development-guide> and are not covered in detail here. However, it is worth emphasising the important functions of a logic model (LM). Firstly, LMs help plan how an intervention is going to be delivered. They provide a way to plan what is required in terms of resources (people, technology) to deliver what kind of activities (interventions), and they also provide a means to explore how activities create mechanisms to achieve outputs (e.g. improved efficiency of health and wellbeing). An often overlooked function of logic models is the potential to identify where stakeholders have differing understandings of the intended intervention. Logic models are not silver bullets, and care should be taken that they are not over-emphasised at the expense of advanced planning for service change. This guide has focused on establishing the routines required for P3C and how to develop them using formative evaluation. Logic models form a part of this process; used in isolation they are unlikely to be helpful.

The following logic model ([Figure 7](#)) was developed for an evaluation of a Pioneer service for older people. This logic model was developed at the beginning of the evaluation and then revisited once data was gathered to help understand which parts of the model had been implemented, which had failed, and which were proving a challenge. Using evidence to interrogate logic models allows for identification of barriers and problems, allowing further optimisation of the model. Data from the organisational change tool (P3C-OCT) was used in this example to interrogate the success of the implementation using a logic model framework. What is apparent in the example provided is that there is a noticeable lack of detail in the “activities” column specifying the development of a shared vision of personalised and coordinated care. A further noticeable feature is the under-resourcing of staff depicted in the ‘inputs’ column. It is also evident from the ‘activities’ and ‘outputs’ columns that very little was implemented fully. Despite positive patient experiences and committed staff, this service later folded. Without the logic model, it would have been difficult to understand why this happened. Had the logic model been developed at the planning stage, with a pilot test and data-generated feedback to follow, timely improvements could have been made to the delivery model, increasing the chances of the service being ultimately successful. Furthermore, this example underscores the critical importance of adequate resourcing for successful P3C interventions.

Figure 8: Logic Model Developed for a Pioneer Evaluation



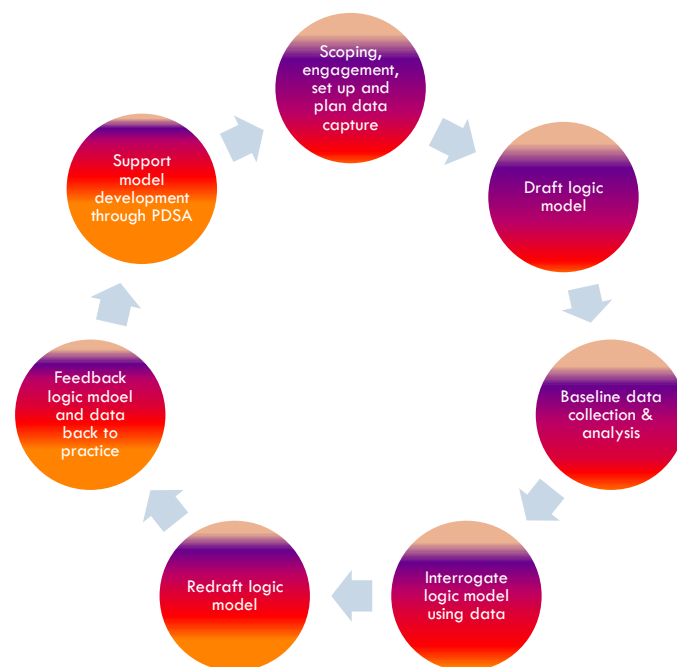
5.4. Plan – Do – Study – Act (PDSA) Cycles for Continuous Improvement

The development and improvement of P3C will be contingent upon the willingness of an organisation to acknowledge uncertainty - especially as approaches to P3C can vary according to local nuances. It will also involve a commitment to formative learning, not just through ‘doing’, but also from the feedback of evaluation data (Data Driven Improvement). There is a long tradition of using these methods within the NHS to improve practice, and good evidence to suggest benefit¹⁷.

The type of learning will vary by organisation. However, it will usually require a “plan-do-study-act” (PDSA) cycle. This could have embedded action learning sets¹⁸ mapped to quality improvement methodology. Action learning sets are particularly suited to P3C. They focus on learning from interactions, thus providing a mechanism to reflect and problem solve. These skills are particularly important for health and social care professionals who are being asked to work in a different way for P3C, where coordination across sector boundaries may be challenging. The adjacent diagram (Figure 9) represents an approach to P-D-S-A cycle that uses logic models and data derived from an evaluation for the development of P3C. The example is used in Somerset to scale out a complex care model for

people with three or more LTCs, with the plan to use similar cycles at 6-month and 12-month follow-up.

Figure 9: An example of a PDSA approach



¹⁷ <http://www.ihl.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx>).

¹⁸ Action Learning Sets are a structured method enabling small groups to address complicated issues by meeting regularly and working collectively. This tool is especially geared to learning and personal development at the professional and managerial levels

5.5. Sampling for Data Collection

Sampling individuals to take part in qualitative interviews or surveys is common in research, where it is often not possible to capture data on a whole population. Qualitative interviews and approaches will always require sampling because they are resource-intensive. In contrast, a service may well decide that using a questionnaire to capture experiences is appropriate for all people experiencing a new service in order to canvass a broad view and adjust positive selection bias (i.e. capturing data on those most motivated). The trade-off between qualitative approaches and more structured questionnaires is between depth vs breadth. Different sampling strategies are required for different forms of data collection.

In general, qualitative approaches are used to understand the “how and why” of whether something is or isn’t working and, as such, it will be necessary to understand this from a range of individual perspectives. Sampling should therefore attempt to provide representation from a range of groups (i.e. males/females, ethnic groups, age ranges, disability and conditions). Services may decide to film or record interactions for quality improvement activities and as such could either sample purposefully, as suggested, or choose to randomly select care contact episodes. Convenience and pragmatism is also likely to play a role in any sampling procedure, which is common in applied health care research and evaluation, where time and resources are limited.

Activity data (service utilisation) can be routinely collected on all those referred to a service if this is made explicit to patients and service users. Furthermore, if data is analysed and anonymised at group level (providing this is not linked to qualitative and questionnaire data) it can capture activity of the whole cohort. However, explicit consent would however be required to link this type of data with questionnaire or qualitative data.

The phasing of data collection will depend on the nature of the intervention. For example, it would be sensible to collect baseline data from all individuals entering a new service. However, if individuals are only in the service for a short amount of time, waiting 6 months to conduct follow-up interviews or send follow-up questionnaires will not provide timely feedback to improve the model. In this scenario, offering exit interviews or questionnaires provides a good way of capturing their experiences whilst memory of the service is still fresh. Furthermore, there is no reason (providing sufficient justification and acceptability from practitioners and patients) that focused data capture on the specifics of delivery shouldn’t be added to this core data set at particular times. For example, if communication or shared decision-making was being targeted, an efficient implementation could involve using the same P3C tool (e.g. a patient reported measure) for both intervention and simultaneous data collection.

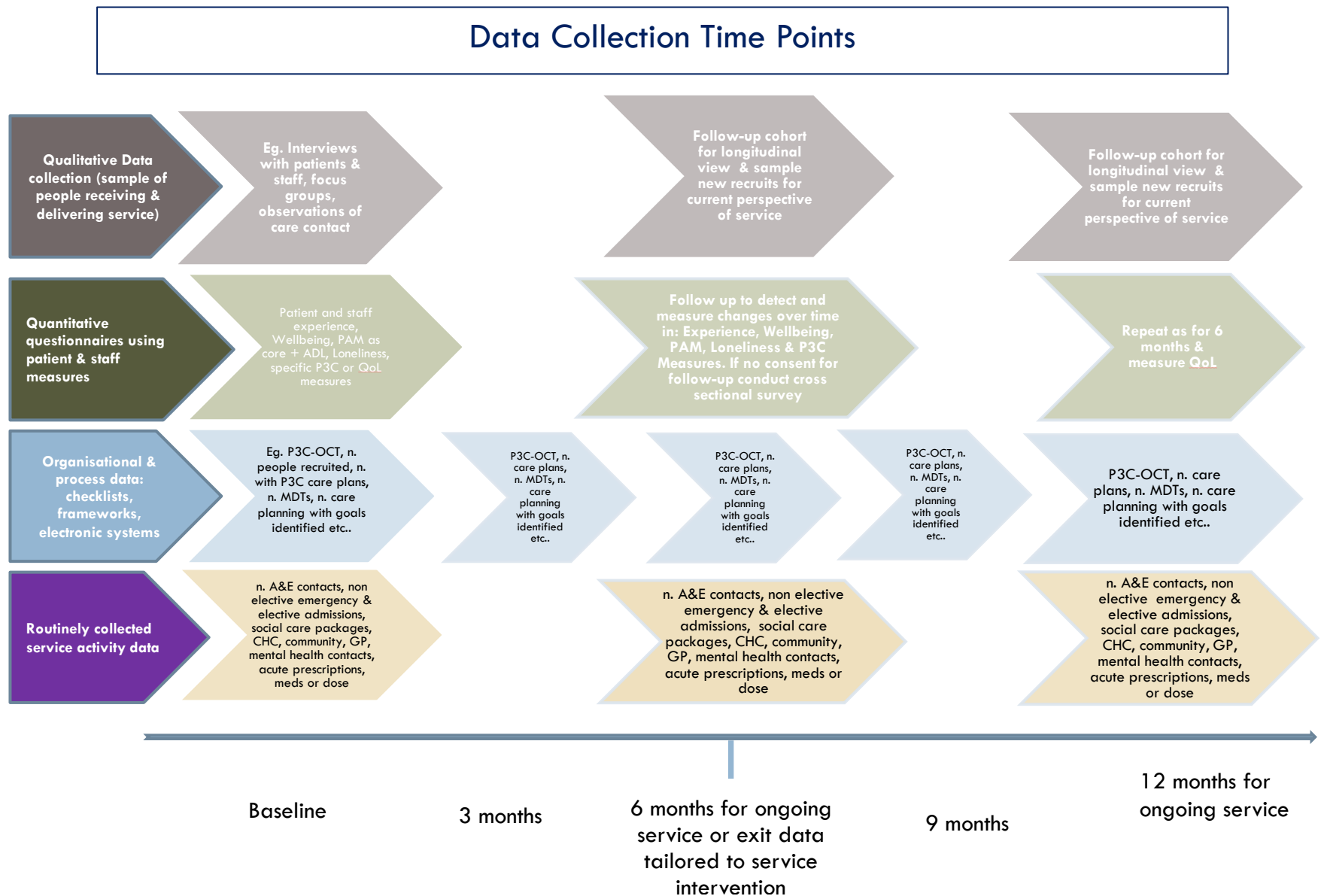
The framework presented as Figure 7 is not intended to be prescriptive, but merely to illustrate what a framework meeting the quadruple aims might look like with a core data set. Most ongoing service change interventions that aim to care and support people with LTCs and MLTCs over time can adopt routine data capture of the minimum core data set described above using the suggested time frames. The phasing of data capture in 6-monthly cycles for this core set has been designed to minimise respondent burden and also provide time for changes to be implemented (see previous [PDSA](#) link), adjusted, and realised throughout the system (see Figure 10).

5.6. Service Utilisation, Linked Data Sets & Matched Cohorts

The potential to link health and social care data sets in order to understand an individual's pathway following exposure to a P3C intervention is finally becoming a realistic possibility. Progress is being made by working through data flow and governance issues. Other developments have included the use of propensity scoring to identify and rationally match cohorts of patients or service users for comparison. Linked data sets (or even unified data sets) allow for a longitudinal exploration of the impact of P3C on service utilisation using time series analysis (see <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4680165/>). This type of analysis will be more powerful if compared to a cohort (tracked by NHS number following explicit consent) of people who are part of a P3C intervention. A useful document provided by the National Institute for Health Research outlines the use of quantitative measures for complex interventions and explores this method in detail¹⁹. The allure of this methodology is the ability to understand the potential impact on a range of services of any given intervention over time. Given the aging nature of people with LTCs and MLTCs, small increases in secondary care use (for example) would naturally be expected. Working to understand trends in the data and other factors influencing service utilisation (i.e. closure of a community hospital, or lack of out of hours GP service) is a necessary endeavour. What is important to emphasise here is that linking data sets across health and social care requires considerable time and resources, and has to take account of the associated logistics, which range from ethics and governance issues to data handling and processing. Working with academic or health science partners will facilitate a robust process. It will help ensure robust operationalisation of the evaluation, linking efforts to capture patient experience and other key outcomes for P3C through qualitative approaches and questionnaire data. The ultimate result is to tell a more nuanced story of how the intervention is being delivered, experienced, and effecting change.

¹⁹ <http://www.journalslibrary.nihr.ac.uk/hsdr/volume-4/issue-16-.V18rN-NbnOk.mailto>

Figure 10: Data collection time points



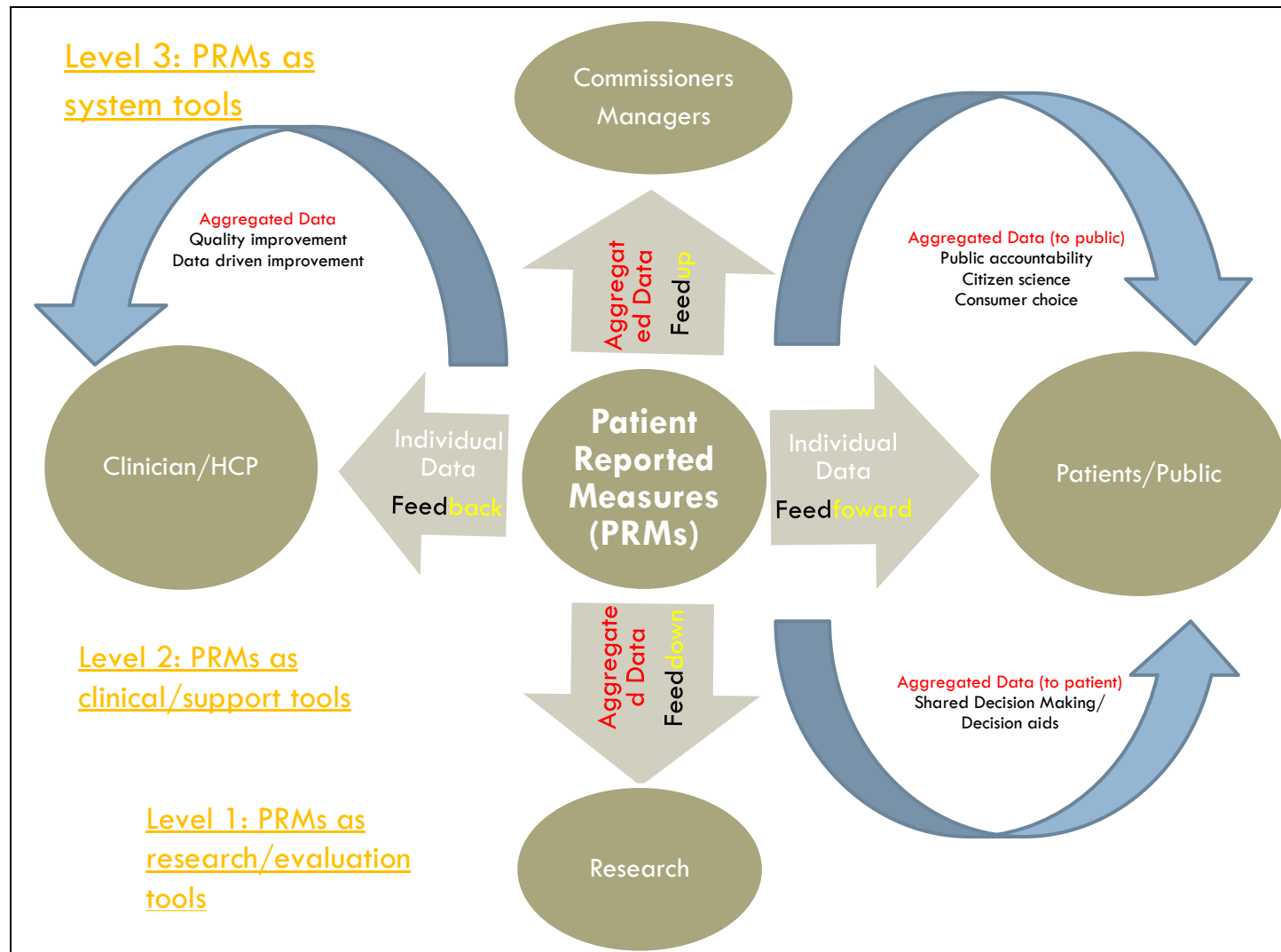
5.7. The Use of Patient Reported Measures to Provide Feedback to Improve Care and Support

Feedback is an essential component of the PDSA cycle and the feedback from the perspective to whom it matters the most (i.e. the patient) is the most crucial. As described previously in [section 3.3](#), patient reported measures (PRMs) are recommended for this.

As part of this work, an evidence scan was conducted to explore the use of PRMs to improve the care for those with LTCs, MLTCs, and those at the EoL. Evidence from a number of systematic reviews suggested that PRMs 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 P3C (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 P3C; for example, 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 support self-management of chronic conditions. The strongest evidence for benefit was demonstrated for oncology (followed by psychiatry), where PRMs are now well integrated into services. Palliative care appears to be overcoming implementation challenges, but the evidence for non-cancer LTCs and MLTCs was sparse. [Figure 10](#) represents the possible ways in which PRM data can be used across the system. It is rare in practice that PRM data is used so effectively, in reality there is more measurement than is necessary and feedback-driven change is rarely actioned. The section below highlights the key findings and conclusions of this work, which should be considered in plans to use PRMs for evaluation and quality improvement for P3C:

*For P3C measures to improve care, the information derived from them must generate **actionable feedback**. This feedback can operate in a variety of ways - from feedback of individual patient data during a clinical or support interaction through to aggregated data to inform management and system improvements (see [Figure 10](#) and box below).*

Figure 11 : Multi-directional use of PRM data



PRMs have “evolved” from their classic usage as research tools into intervention tools in routine clinical practice. Here, they can be used for diagnosis and monitoring but can also act as components of P3C interventions themselves, where it has been established that feedback of PRM data to clinicians and “feed-forward” to patients can improve aspects of P3C, such as shared decision-making and self-management (see boxed text).

PRMs are increasingly being utilised in palliative care, where idiosyncratic challenges, such as impaired cognition and awareness of patients, has necessitated the development of proxy-outcome measures (completed by professionals or family members). 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 referrals²⁰. There is also 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).

PRM 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/Evaluation (aggregated data)

- Treatment outcomes in a trial or complex intervention
- As an evaluation tool in trials for P3C interventions

Level 2: Clinical practice (individual patient 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

²⁰ Etkind, S. N. *et al.* Capture, Transfer, and Feedback of Patient-Centered Outcomes Data in Palliative Care Populations: Does It Make a Difference? A Systematic Review. *J. Pain Symptom Manage.* **49**, 611–624 (2015).

Key Considerations for the Use of PRMS for the Development and Evaluations of P3C:

- 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, patient experience measures (i.e. Patient Reported Experience Measures (PREMs)) generally measure processes of care and how individuals experience services or interventions. In contrast, 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 to be leveraged.
 - Of particular note within the UK context, is the QTool ePRO system. This 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.
- Many generic **PRMs that measure aspects of health or health-related quality of life have shortcomings in the context of MLTCs**, as a single tool is often not valid over such a wide range of outcomes. Use of well selected disease specific measures can be used to augment the core data set if respondent burden is to be minimised.

- Further tools that could be utilised in the situation of LTCs/MLTCs include “individualised Patient Reported Outcomes” iPROs (which are tailored to the specific needs of the patient) and metrics that specifically measure aspects of P3C such as activation and self-management.
- 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 the information so that it maximizes interpretability and actionability.

5.8. The Use of Patient Reported Measures: What Patients and Service Users Think

We conducted a series of several patient workshops to inform this guide. Patients were asked how they would like to provide feedback about their experiences of health and care support. They felt that:

- Multiple methods were preferable for collecting feedback and that this would optimise response rates
- Questionnaires were more suited to national impact (feed up and feed back to services) and that conversations were more suited to local and personal impact (to inform care planning) but this would depend on the intended purpose of the data capture
- Questionnaires need to be clear and not too long!

They emphasised that the purpose of the approach and intended use of the data should be clearly explained. They also questioned if their accounts would be listened to and acted upon. This demonstrates the value in communicating the purpose of data collection and emphasising how important it is to include patients and service users in the development of P3C, clearly showing how feedback has been acted upon. Participants also voiced

concerns over questionnaires in relation to data protection issues and data handling issues. They also articulated important issues in relation to potential response biases. They were concerned that patients who took part in interviews or completed questionnaires would be those most interested in providing feedback (i.e. self-selection bias). One way to overcome this would be to positively sample from those who are harder to reach (and therefore underrepresented in the main sample). When asked about conversations or qualitative interviews, service users felt that these were a good idea, but had concerns that they would depend on individual and practitioner mood, personality and the quality the interpersonal relationship between the patient and the practitioner. A way to mitigate this would be to sample a range of individual and professional dyads.

5.9. The Use of Patient Reported Measures: The Experiences of Professionals

To gain a picture of the different ways in which PRMs are currently being implemented and used to improve care, interviews were conducted with professionals from different international and national settings. Key researchers within this field of work, members of Clinical Commissioning Groups (CCG) who were using PRMs to make improvements in care, and practitioners using these measures at practice level were invited to participate. A total of 13 implementation stories were collected. The key messages that emerged from these interviews are presented below, followed by a table ([Table 2](#)) that summarises information about the aims, methods, and outcomes of the use of PRMS in the different settings covered²¹.

Key Messages

- **Current state of affairs** - While the use of PRMs to drive improvements in care is expanding, this approach is still very much in its infancy within the UK. Consequently, some of the benefits of using PRMs in this way are only just being realised by health-care organisations. This

²¹ All respondents agreed to their names and organisations being listed in this guide.

delay is likely to be due to the lack of feedback-informed change following measurement. However, in some cases, where the value of PRMs has been fully realised, there is a real sense of excitement of what these types of measures can offer.

- **Existing guidance** - The lack of guidance currently available on how to select, implement and translate findings from measures appears to have (and continues to have) a significant role in why the use of such measures has not been adopted more widely.
- **The importance of the pre-implementation planning phase** – Within the various stories told many barriers to implementation were shared. This highlighted the importance of spending a considerable amount of time on the planning phase before implementing measures. Knowledge of the purpose and process of measurement (psychometrics, implementation science, recruitment and sampling) and an understanding of the condition(s) of targeted patients were felt to be advantageous and underpinned the successful use of PRMs.
- **Patients and staff felt a ‘culture shock’** when being asked to start using PRMs as they are often very different to what they have come across before. They can involve new workloads for a range of individuals – patients, clinicians, and managers - and their true value is often opaque. Efforts need to be undertaken before implementing measures to reduce burden and communicate future benefits.
- **Measures being used** - Every CCG that we interviewed stated that they were developing, or wished to develop, their own measures. This was because they felt that existing measures were not capturing what they were specifically interested in and/or they want to create measures that mapped onto the needs of their local population. Patients were given a large role in the development of these measures, and the interviewees were passionate about making sure that these co-designed tools measured what patients considered to be the most important outcomes and experiences.
- **Patient involvement is the ‘gold standard’ to develop PRMs but added significantly to time frames** - for both evaluations and the commissioning processes. Whilst there is often a clear rationale for developing new measures, improved guidance on what measures are currently available (and how to select appropriate measures) would often save resources.
- **Feedback** - A common theme throughout the stories was that a tension exists between wanting (or being encouraged) to use standardised, national measurements that are widely accepted (and which can allow comparisons between organisations), versus the desire to use measures that are sensitive to local issues. Furthermore, the delay in reporting from national surveys was deemed frustrating and detrimental to

initiatives for rapid change. As one interviewee stated, feedback could be enhanced when data from different types of measures are merged and translated into individual organisations' own plans for change. **Sound mechanisms for translating data from P3C PRMs into actionable feedback appear to be lacking, limiting the utility of the data. An aversion to statistically-heavy feedback reports was commonly voiced. More popular types of feedback were web-based dashboards and reports which graphically represented the results.**

- **Pre-consultation “feed-forward” to patients** (mentioned by two international interviewees) involves allowing patients to complete PRMs before a consultation with a health care professional. This process allows practitioners to have early access to important data that can aid decision-making processes within the consultation. Furthermore, it is likely to signal to patients the utility of such measures. If PRMs are going to be utilised, where possible such ‘feed-forward’ systems should be encouraged, providing it is used to aid conversation about important goals and outcomes (rather than replace it).
- **Organisations kept data from PRMs within house** and do not have the opportunity to benefit from sharing data across organisations (with the exception of results from national surveys). This limits the possibilities for specific benchmarking activities. Exploring how PRM data could be used and shared between organisations and governing bodies (such as CCGs) would unlock further value. One practitioner was especially keen to share his organisation’s data with his local CCG, but there was no pathway of communication available which could facilitate this.

[Table 2](#) presents key details about the implementation stories collected for this piece of work. It shows the variety of ways in which PRMs are being used across different services, highlighting some of the challenges and successes. Following this, [selections of more detailed vignettes](#) are presented.

Table 2: Key details about the implementation stories

Respondent & Organisation	Type of story	Measures used/looked at	Key features	Aims of the measures	Stage of project	Levels of use	Impact of measures	Feedback process
Dr Fliss Murtagh King's College London	Identification of 'best' measures (palliative care)	Integrated Palliative Outcome Scale (IPOS), Views on Care (quality of life), POS-S (symptoms), Edmonton Symptom Assessment tool, Memorial Symptoms Assessment Scale, <i>Views on Care</i>	Capture what is <u>specifically</u> important to palliative care patients Measure needs to be valid, reliable and responsive to change	To inform and improve palliative care and to ensure the patient's voice is heard To help make sure what is being commissioned is what is important to patients	Complete	Individual practice and national	Used to evaluate services, aid commissioning choices and tailor individual care	Patient web-based platform, Practitioner-patient consultations, practitioner team meetings Clinical Commissioning Groups
Dr Richard Harding King's College London	Identification of 'best' measures (cancer) Project examining the use of PROMs for people living with HIV	Various versions of the Palliative Outcome Scale PACE –Patient Assessment Communication Evaluation	Developed a clinical decision tool to accompany PRMs, which supports the use of the measures in routine practice. Measures embedded into electronic medical record, used routinely in practice	To inform and improve palliative care and to ensure the patient voice is heard To help make sure what is being commissioned is what is important to patients	Complete	Used at an individual practice level, nationally and at a global level	Informs Commissioners' choices regarding what services to finance Used to adjust care planning Global measurement tool that allows for international comparisons Informs government tariffs	Multidisciplinary meetings Clinical Commissioning Groups Patient-practitioner consultations
3. Aran Porter The Whole Systems Integrated Care Programme – North West London	Identification of 'best' measures Identification of core set of metrics aligned to outcome domains to provide an aggregated view across the 8 CCGs that form NWL.	GP National survey, professional survey targeted at integrated care teams with members across health, social care and third sector and other existing measures (e.g. Unscheduled admissions). Potential for PAM to be used as PROM to monitor patients' knowledge,	Wanted to primarily focus on existing measures as this allows for a historical baseline to be used Work built upon a number of outputs from various projects and involved a number of different organisations including a strong co-production element with local residents and lay partners.	Wanted to identify a core set of metrics that could be used across several CCGs (at an aggregated level), but which could be used by individual CCGs at a local level to address their areas of interest and fit with their models of care Benchmarking at a local level	Pre-roll-out	Used at a national level and by local Clinical Commissioning Groups	/	/

Respondent & Organisation	Type of story	Measures used/looked at	Key features	Aims of the measures	Stage of project	Levels of use	Impact of measures	Feedback process
		skills and confidence in managing their condition.						
Professor Jenny Billings Kent University	Identification of 'best' measures (integrated care) Using PRMs for service evaluation (Integrated care) Development of framework for evaluation in Kent	Person-Centred Coordinated Care Experiences Questionnaire (P3CEQ) Patient Activation Measure (the PAM) Patient assessment of integrated elderly care (PAIEC) Quality of Life measures	Uses periodic interviews with managers (within services being evaluated) and interviews with carers, alongside the data retrieved from the measures, to inform evaluation Employs implementation science when designing an evaluation. Wanted separate outcome measures for person-centred care and work force, services and build indicators around the achievement of these outcomes	By using these measures at a baseline and post-intervention time point, the evaluation team can determine whether an intervention has led to an improvement in integrated care	Testing	Used at service level and locally by a Clinical Commissioning Group International comparisons of integrated care also being made through use of these measures in a European project (SUSTAIN)	/	Will be feeding back through the use of the Evidence Integration Triangle to stakeholder group and also using their PPI officer to develop best methods of feeding back results. Will publish results in academic outlets. Will report back to Clinical Commissioning Groups.
Phil Wrigley Islington CCG	Using PRMs for service evaluation (Diabetes)	Developed own PROM based on patient devised outcomes	Patients devised their own outcomes; the developed questionnaire was then created, so that it could test specifically whether these patient-devised outcomes were being met	Providers of care will be remunerated based on the achievement of these patient-devised outcomes, as well as clinical ones	Testing measure to be rolled out to (16K) patients with diabetes over next few months	Used at an individual and local level through a Clinical Commissioning Group	/	Patients who were involved in the development of the outcomes and the PROM will be consulted once the service is up and running
Cheryl Davenport Health and Care Integration Leicestershire Country Council	Using PRMs for service evaluation (integrated care)	Outcomes Star (by community development workers) GP Patient Survey (to evaluate integrated care program)	Measures not sensitive enough to capture aspects of care they are particularly interested in	To evaluate and improve care pathways. Want to measure integrated care at a general level, but to also measure whether individual goals are being met	Pilot	Wanted a measure at a programme (organisational) level and at a national level	Improvements already being made	Results reviewed at service level Plans to develop a dashboard that will provide an overview of all services covered by the evaluation

Respondent & Organisation	Type of story	Measures used/looked at	Key features	Aims of the measures	Stage of project	Levels of use	Impact of measures	Feedback process
Marianne Hiley Windsor, Ascot, and Maidenhead Clinical Commissioning Group (CCG)	Using PRMs for service evaluation (domiciliary care)	Using own measures that are based on a model from a recognised provider, with a proven track record in creatively gathering health and social care patient feedback.	Plan to deliver it on a tablet or smart phone when in the roll out phase of the evaluation.	Using measures for outcome focused reappraisal of the domiciliary care programme within their CCG area. Triangulating what patients are saying with what service providers are saying about how the is being delivered.	Pre-testing	At an organisation level and locally through a Clinical Commissioning Group.	Use findings to improve the consistency and quality of the domiciliary service	/
Emma Rowse Living Well Programme, Cornwall	Using PRMs for service evaluation (2+ LTCs or frailty).	Warwick Edinburgh Mental Wellbeing Scale (short version) Have added items from De Jong loneliness scales to the Warwick Edinburgh measure. Reviewed all loneliness measure available at the time (2013) and none were suitable. Looked for person-experience questionnaire but again none were suitable	Uses interviews with service users, alongside data from the measurement tools, to inform the evaluation.	To evaluate the outcomes of a Pioneer Programme by providing baseline and post-intervention scores. Used to monitor the progress of the programme at key milestones.	Complete	Used at an individual level and at a local level through a Clinical Commissioning Group.	Interviewee stated that it was important to evaluate more than just the financial impact of the programme and to be able to demonstrate improvements in wellbeing was critical to the success of the service. However longer-term change can only really be made if the service is commissioned. The interviewee also highlighted that they might have used more newly developed measures if they'd been available at the time e.g. Campaign to end loneliness 3Q tool.	Academic publications National presentations Results fed back to local Clinical Commissioning Group and local partners.

Respondent & Organisation	Type of story	Measures used/looked at	Key features	Aims of the measures	Stage of project	Levels of use	Impact of measures	Feedback process
John Herring Network Manager for Cancer - Greater Manchester, Lancashire and South Cumbria	Using PRMs for service evaluation (cancer)	National Cancer Patient Experience Survey Their own 20 item measure for pancreatic and biliary services in Greater Manchester. Interested in using quality of life measures alongside experience measures in the future, so that clinicians can think about improving lives with and beyond cancer.	When developing their own measure for (biliary and pancreatic cancer) they picked (what they believed to be) the 20 key questions from the existing National Cancer Patient Experience Survey.	It is hoped that by making the measure brief and delivering it through an electronic format (on iPads) they will get a better response rate than National Surveys typically achieve. May also use a peer advocate system, which will help with completion of the questionnaire and could help reduce response bias.	Initial roll out	Patient, commissioner and national level.	The results from the National Cancer Patient Experience Survey are fed into their own data reports that go to commissioners and providers within this area; allowing benchmarking to be done. The interviewee stated that feeding back the data in this way has enabled Greater Manchester to be rated as first or second, nationally, in terms of cancer care.	Future report that details response rate, what the outcomes were and how the results compared to the national questionnaire. In addition to collecting experiences at the end of care, they may also collect data at additional time markers, so that patients can observe their own progression. Patient experience will be a focal point on the new Cancer System Board that is part of the Cancer Vanguard in this area.
Dr Helena Forsberg Karolinska University Hospital, Sweden	Measures used to make improvements in care at a practice level	Partner organisations had existing validated measures that are relevant to their area of care	Organisations have added their own items based on feedback from patients and their own evaluations An electronic system is used that allows patients to respond outside of the clinic	To evaluate poor/good areas of care To stratify and tailor care To inform national evaluations/guides and provide a benchmark for individual organisations	Organisations use these measures on an ongoing basis	Individual, organisational and national	Enhanced patient ability to self-manage Has helped identify dangerous health behaviours Poor performing organisations have visited, and learnt from, high performing organisations	Feed-forward process – patients register their data before they visit with the practitioner, so that their practitioner is better prepared for the visit

Respondent & Organisation	Type of story	Measures used/looked at	Key features	Aims of the measures	Stage of project	Levels of use	Impact of measures	Feedback process
Dr Carolyn Kerrigan Dartmouth Institute, USA	Measures used to make improvements in care at a practice level	Dartmouth uses a vast number of existing measures and measures developed by people within their organisation e.g. Breast Cue and CollaboRATE Uses PROMIS (a measurement system that bundles generic questionnaires)	Measures used need to be validated and available to the public (no licencing fee)	To inform practitioner-patient consultations and make them more efficient by creating a 'feed-forward process' (many history-taking questions collected before the consultation, rather than during it) For risk stratification	Ongoing	Dartmouth works with over 32 different health initiatives (including primary, paediatric, adult and speciality care services)	Results from PRMs inform HCPS' decision re treatment choices e.g. who receives surgery Saves time as history taken in advance facilitates decision-making during the consultation (patient preferences already highlighted) Risk stratification to prevent the escalation of health conditions through a 'health coach' intervention	Feedback given to organisations who are using the measures and occasionally used at a national level
Dr Ollie Hart Sheffield CCG	Measures used to make improvements in care at a practice level (GP-patient)	Patient Activation Measure (PAM)	Wanted a validated, evidence-based measure that could monitor changes in empowerment and activation Financial incentive attached to its use Adjustments made due to use of American terms within the items	To use as a stratification tool by which to tailor individual care To help improve patient activation levels	Implementation	Used at an individual Practice and regional level	'Tuned' practitioners into the issue of activation Has helped trigger important conversations between practitioners and patients	Results discussed between practitioners and patients Results also to be used during discussions about integrated care at meetings with various health organisations in the area

Respondent & Organisation	Type of story	Measures used/looked at	Key features	Aims of the measures	Stage of project	Levels of use	Impact of measures	Feedback process
Dr Stuart Kyle NDDH Hospital, Barnstaple, UK	Measures used to make improvements in care at a practice level (rheumatology)	Health Assessment Questionnaire (condition specific) BASDAI (spinal pain) CQRA – experience Would like to use process metrics (e.g. hospital admissions/length of stay) alongside PRMs to better evidence how they are improving health care in other ways (i.e. saving money).	Used a NHS innovation company (3S) to create the electronic measurement system for them Patients are able to fill out the measure outside of the clinic	To improve the effectiveness of health care service To empower patients by improved access to their outcome measures & help gain a better understanding of their condition Piloting the use of the electronic measurement system to explore whether it could be nationalised, with all data feeding into a central data bank; this would enable national benchmarking and help with case-mixing	Ongoing implementation in progress	Used within their organisation Hope to use the PRM data to open up discussions with CCGs about how to improve management in Practices e.g. to reduce their management of stable patients and increase their management of less engaged patients	Results from PRMs used to justify and maintain expenditure on certain services that patients want e.g. patient education classes Will be considering using a PRM feedback alert system that will highlight any significant negative changes to patient outcomes and experiences scores	Reports generated by free text box responses by patients have been used for staff appraisals The organisation regularly reviews the results from the PRMs Results fed back into individual patients' care plans
Juliette Cosgrove Calderdale & Huddersfield NHS Foundation Trust	Using advanced technology to deliver PRMs (Qtool)	Developed own measure to examine how people want to be involved in decision-making about health care Also uses national surveys, the friends and family test and their own short PROM Uses qualitative interviews alongside PRMs to get more in-depth information	Delivered the measure to patients through Qtool (an electronic delivery system for measures) Developed features such as whether they used passwords so it could be completed at home or a tablet for on-site completion; patients preferred different locations	Qtool used to examine how people prefer to be involved in decision making Other PRMs used but unsure of their value, concerned about whether the people who they should really be targeting may not get asked to complete it Data too often skewed by issues relating to demographics National measures are too broad to allow benchmarking by organisations.	Complete	Organisation	Helped them to identify how best to engage with patients	Plans to publish details about the implementation process and their findings in an academic journal Fed back results to the organisation Uses a 'You said, we did' board to feed back results from other PRMs to patients at hospitals

Implementation stories (vignette1): Identifying 'best' measures for palliative care

Dr Fliss Murtagh: King's College London - Reader and Consultant in Palliative Medicine.

We've been doing a project called the Outcomes Assessment and Complexity Collaborative, and the purpose of this project, over the last three years, has been to implement a set of Person Centred outcome measures into palliative care practice in South East London. Our objectives were to: identify the best measures out there; agree on a core set of outcome measures with the clinical people we're working with; to implement them into practice and at the same time study which is the best way to implement them into practice. We've done the implementation work with nine teams across six organisations, all of which are in South East London, and all of which are providers of specialist palliative care. We've also done two parallel research studies. One has involved qualitative interviews with patients, families, and with professionals, about the acceptability and the impact of using outcome measures in practice. The other piece of research was a feasibility study; to inform a full-scale cluster randomised trial of outcome measures. In addition, we've worked with Hospice UK and developed training resources based on our work, which we then disseminated across the country to providers of palliative care in order to support them in their own implementation of outcome measures.

I would say that the outcome measures are used in three ways:

- 1) One way we ask teams to use the measures is to use them with individual patients to improve care. So we embed the measures into their system and you can press a button in an individual patient record and get a score, a visual representation of the scores over time. And if they are actually high, so if they've got a severe symptom or problem, it registers red. If it's not so bad, it registers orange, and if it's not a problem, it registers green. So you can see very quickly, this problem is still orange or red; and we encourage the team, individually, to look quickly and understand which things are not being addressed. We also use them in our team meetings in this individual patient way, to focus on the things that are not being resolved; so if something is persistent, then it's staying red; we, kind of, have a think about why that's staying there; what can we do to help with this issue; how can we improve things
- 2) The clinical leads and the team managers use the aggregated data for the whole cohort of patients to try and understand what are the things that are systematically being done well, or less well; what are the things that need, perhaps, more resource or less resource? So, for example, one of the teams we are working with in the community has got four different geographical patches, and they discovered that in one area there was a different distribution of some of the issues; and so they've actually shifted some of the resources to help address those issues. So that's using outcomes data on an aggregated level, for a whole cohort of patients.
- 3) People have used it for commissioning and for their Care Quality Commission (CQC) inspections. They want evidence that we are making the right difference for people; so we've found that a lot of the palliative providers have found that their outcomes data, particularly the measure called Views on Care, but also their IPOS data, has been useful to inform their CQC inspection. And also, we've used this aggregated outcomes data with the Commissioners to make business cases for issues that need more resources. So, for example, there were psychological areas that were not improving very well in the outcomes data, so we've been able to try and make a business case for more psychological resources.

Implementation stories (vignette2): Using PRMs for service evaluation

Marianne Hiley: Windsor, Ascot, and Maidenhead Clinical Commissioning Group (CCG)

We have in our area probably the largest number of care homes per rata our relatively small sized population. We've got a population of 150,000, but we've got 48 care homes on our patch, which is a lot. Over the last couple of years or so we've worked really closely with the care home providers to improve the consistency and quality of the services that their healthcare assistance has been providing on a day to day basis. Looking at things like nutrition, falls prevention, skincare, ability to deal with people's behavioural challenges if they have dementia.

We have learnt from that and are now applying a simplified version of it with just half a dozen questions in the context of Short Term Renablement and domiciliary care provision. [In addition], the Better Care Fund has afforded us the opportunity to actually triangulate what patients are saying with what the service provider is saying, and actually correlate that against something which is written down that says this is what we were both trying to do.

[When considering how to measure this, we began by] looking in the market place to see what processes were already available. [We decided to work] with an existing model from a recognised provider, with a proven track record in creatively gathering health and social care patient feedback. [However], we wanted to make sure that just because it sounded attractive to us, it wasn't necessarily an assumption that we were making without consultation, [so], we are going to be trialling it in two different locations – Short Term re-enablement team and domiciliary care provision.

How can the measures lead to an improvement in care for people? - I think that the key is to actually think about outcomes and not deliverables.

We are rationalising service delivery all the time against how do we avoid district nurses actually spending more time with patients than we can afford currently? How do we deliver those services differently per collective groups of people and so on? For me this puts the whole thing on its head and says what outcome can we realistically achieve for this individual and how do we access the information and support that enables them to do that?

That really does put the self-care, the patient's (or the resident's) own responsibility right into the framework to start with. If they don't want to do these things to help themselves, it will not move forward and that won't be for want of good quality services being delivered - if they don't want to engage they won't. Service providers have to engage effectively with patients/service users to help them to help themselves to deliver a shared results and that is what we are looking for through this toolkit.

Implementation stories (vignette3): Using PRMs to make improvements at practice level

Dr Ollie Hart - Sheffield CCG

We are really interested in Person Centred care and markers of how you can help people feel more empowered and engaged, and more in control of managing their own conditions. We've been trying to encourage patients to understand why we ask them certain questions and what relevance it has to their care; we're asking these questions because this is an area that we think's important and it should be important to you too. [By doing this we hope we are] tuning people into the emphasis we place on their role in their own healthcare.

It is quite difficult to monitor change in that arena, so we were looking for a measure that was validated and had some evidence-base behind it, and that had [been used in this sort of] setting [before]. So, after having looked around, the PAM (Patient Activation Measure) appeared to be the most evidence based, pragmatic and usable tool. So, we got engaged in a pilot for NHS England [and during that] we [found] that [it is] functional, it is usable, and so we've continued using it. We have been using it on a practice level to try and tailor our clinical approach and on how our nurses deal with people.

[We are also] planning to use it as a stratification tool for how we organise who sees who. So, [we will consider what type of] experience they may get from certain practitioners, what sort of approach the practitioners use and then what sort of tools the practitioners might use with them. So we've been doing that and we've been feeding into a Person Centred programme on a commissioner level as well.

Dr Stuart Kyle NDDH, Barnstaple- Consultant Rheumatologist

What we thought we needed to do was start collecting data on outcome measures and experience measures in common conditions that we look after, so that we can actually start proving how effective we are at what we're doing. We also wanted to adapt and modify our service according to what the data tells us.

We began by selecting three of our most common conditions. We then thought about which outcome measures and experience measures were validated in those conditions and that were of most clinical use to us. Sometimes this process was very easy for us, but for certain conditions it wasn't.

We also switched to using an electronic method of delivery, rather than paper. We have tablets in the clinic and these tend to be used more for the experience measures, straight after the clinic, but we can now also email patients outcome measure, so that they can do it in the comfort of their own home.

We felt it was important to make the switch to electronic methods, because historically what we've done is we've collected bits of paper and then no one has ever looked at them again. Also, we have started to consider using something like the PAM, as we've got lots of patients and many of them are highly motivated and want to take on responsibility for their disease. They know how to manage it and we need to start managing long-term conditions in rheumatology. Our patients are alive for a long period of time and our waiting lists and our numbers just grow exponentially. So we've got to find ways of safely managing patients on a remote basis.

There is also the possibility that we could use the results from these measures in discussions with CCGs, as we could say 'look we've got cohorts of patients that we know are quite stable and are highly educated. They understand what's required of them, so do we need to see them as frequently as we have been? Let us focus on the patients that aren't terribly engaged and who struggle to understand their conditions'.

Implementing Patient Reported Measures: Barriers and Facilitators

A number of barriers to the successful implementation of PRMs were mentioned in the implementation stories. These ranged from a lack of guidance, the relevancy of tools, stakeholder consensus, measurement as a diversion from care, and factors relating to recruitment, sampling, and the interpretation of results from PRMs (e.g. the effects of case mix). Specific barriers were also reported in relation to dissemination and feedback of the results from PRMs. These ranged from issues with data storage, the time delay between completion, analysis and feedback. These issues are common and can be tackled through: 1) effective collaboration and planning with academic partners such as CLAHRCs and local university groups; 2) involving key stakeholders in the selection and planning of instruments and; 3) ensuring that measurement is not solely a reporting process, but instead has a clear logic model in place for feedback either as an intervention or for improving care. Many of these goals can be achieved by engaging with AHSNs to develop quality improvement cycles or methodologies.

Some key take-home messages in relation to implementing PRMs and using them to improve care are:

- Engage key stakeholders early and ensure that patients, provider staff, commissioning representatives, and academic and support partners are involved
- Decide on PRMs – there are a multitude of available measures (see compendium); only a few are well aligned to probe many of the core domains of P3C
 - Keep it as simple as possible, reduce respondent burden by using concise measures that target multiple domains. Accept that capturing everything is counter-productive, and instead prioritise those experiences and outcomes that are relevant to the target populations
- Plan and communicate the purpose of PRM with stakeholders:
 - Separate care planning PRMs from evaluation/outcome PRMs (there can be overlap but the immediate use will differ)

- Develop strategies for use of dual purpose use (i.e. tools that can be used for care planning and evaluation)
 - Establish what 'good' and 'bad' look like for both purposes outlined above (again with partners and stakeholders)
- Decide on how and who will hold the data, how it is to be shared, and how and to whom feedback will operate
 - Different channels and methods will be required for different audiences
- Designate partners who understands PRMs within the system to help analyse and manage the data
- Plan for quality improvements and synchronise with data collection points

A table of barriers and enablers and the results from the commissioner's survey are presented as Appendix 3 and Appendix 4. These distinguish between barriers that impact the planning and implementation phase of PRM delivery, and those which impact on the dissemination of results and the feedback process. Initials are given after each comment, corresponding to the relevant interviewee. Where possible, facilitative actions that can prevent (or limit) the impact of these barriers is indicated.

6. MEASURES, METRICS AND INSIGHTS: HOW TO ASSESS IF P3C IS BEING DELIVERED AND PRODUCING CHANGE

The table below (Table 3) depicts the domains and processes that could be probed as part of an evaluation framework to assess if 1) P3C routines are being implemented and 2) they are producing changes towards short, medium and long term outcomes. The table presents a mixture of patient reported measures, process and activity data. It provides examples of patient reported measures that are either well used or well-constructed to probe the domain and outcome of interest, or those that provide good coverage to the processes and outcomes that P3C seeks to address²². Each measure is listed in the compendium (<http://p3c.org.uk/>) that was built to accompany this guide. The compendium is an ongoing product that will be developed further to support the measurement of P3C. Where information on each measure has been identified and extracted (i.e. validation and use) it has been added to the compendium, helping commissioners and delivery organisations make decisions about the suitability of the measure.

²² Due to the time frame of this project and the size and complexity of literature pertaining to the psychometric properties of instruments the authors did not perform a psychometric synthesis of measures within the compendium. The authors have however provided links to papers and the impact of each measure where possible. The authors have also mapped each measure to highlight which domains are covered and if the measure is well used.

Table 3: Measuring P3C Routines

Possible Outcome by P3C routine	Patient Reported Measures	Process & Activity Metrics
Enhanced person centred knowledge about the person and what matters to them (R1, R2, R3, R4)	Person Centred Coordinated Care Patient Experience Questionnaire (P3C-EQ), Patient Perceptions of Continuity instrument, Relational and Management Continuity Survey in patients with multiple long term conditions, Components of Primary Care Index	n. P3C conversations, record of goals/outcomes elicited and recorded in P3C care plan, IPROs/PCOM completed and recorded as complete on system. Reviews of P3C plans and IPROs/PCOMS. Increased length of appointment times or extra sessions
Enhanced knowledge and information for the person (R1, R2, R3)	P3CEQ, Care Transitions Measure (CTM 15), Instrument on doctor-patient Communication Skills (IDPCHS)	n/a
Enhanced communication between people and practitioners (R1, R2, R3)	P3C-EQ, Four Habits Patient Questionnaire (4HPQ), Communication Assessment Tool, Quality of End of Life Communication Scale	n/a
Enhanced P3C communication and empathy from the practitioners (R1, R2, R3, R4)	Empathy - Jefferson Scale of Patient Perceptions of Physician Empathy (JSSSPE),	n/a
A healthful relationship (enhanced trust and familiarity, shared decision making) (R1, R2, R3,R4)	Scale to measure Therapeutic Relationship (STAP-P) – Condition specific: mental health (also a therapist version). <i>Trust</i> – Patient Perception of Continuity Instrument (2 items explicitly mention trust), Patient Feedback on Consultation Skills (PFC), <i>Shared decision making</i> – Shared Decision Making Questionnaire SDM-Q-9, P3C-EQ	n. P3C care plans with goals recorded
Feelings of value and respect (staff, individuals and carers/family) (R1, R2, R3)	P3C-EQ, <i>Value/Respect (patient)</i> –Communication Assessment Tool (CAT), Doctors Interpersonal Skills Questionnaire (DISQ), Patient Participation in Rehab Questionnaire (PPRQ)	n/a
Identification and agreement of person centred goals and outcomes (R1, R2, R3)	P3C-EQ, Assessment of Care for Chronic Conditions (PACIC), Patient Assessment of Integrated Elderly Care (PAIEC)	n P3C care plans with goals recorded, IPROs/PCOM completed and recorded as complete on system. Reviews of P3C plans and IPROs/PCOMS
Feelings of empowerment (R1, R2, R4)	P3C-EQ, The Health Care Empowerment Questionnaire (HCEQ), Modified Perceived Involvement in Care Scale (MPICS)	n/a
Preference for carer/family/support network involvement (R2, R3)	P3C-EQ, Patient Participation in rehabilitation Questionnaire (PPQ), Picker Patient Experience Questionnaire (PPE-15)	Audit of care plans and systems to identify if involvement and preferences logged, n with preferences specified
Extent of shared decision making (R2, R3,R4)	P3C-EQ, Control Preferences Scale, Shared decision making Questionnaire (SDM-Q-9)	Audit of care plans, n with co-created goals specified

Table 3: Measuring P3C Routines

Possible Outcome by P3C routine	Patient Reported Measures	Process & Activity Metrics
Increase in level of activation or potential to self-manage, Independence (R2, R3)	Patient Activation Measure (PAM), P3C-EQ, Self-Efficacy Scale for chronic disease 6 items scale (SEM-CD -6), Activities of Daily Living (ADL), Oxford Participation and Activities Questionnaire (Ox-PaQ)	n. PAMs completed, score change over time, correlation with service use by score
The beginning of a P3C partnership (R1, R2, R3, R4)	Communication Assessment Tool (CAT), Patient Feedback on Consultation Skills (PFC), Doctors Interpersonal Skills Questionnaire (DISQ), R-Outcomes – HowRwe	n. Person centred care plans
A Co-created P3C care plan (R3)	P3C-EQ, Patient Assessment of Integrated Elderly Care (PAIEC)	n. Person Centred Care Plans
A named key coordinator (R3)	P3C-EQ (Q7), Components of primary care Index, Quality of End of Life care (QEOLC – 10)	n. named coordinators recorded on system for people with LTCs, MLTCs and EoL
Experience of care coordination (R3, R4)	P3C-EQ, Integrate, Relational and management continuity survey in patients with multiple long term conditions, Components of primary care Index	n. of people with shared care plan across teams, n multidisciplinary team meetings, n P3C plans shared across system
Experience of continuity of care (P3C Quality of care over time) (R1, R2, R3,R4)	Changes in scores of selected measures over time, or maintenance of score if good. <i>Continuity of care</i> : Care Transitions Measure (CTM-15), PACIC, PAIEC.	n. and frequency of contact with care coordinator or key person
Carers assessment and care plan	Carer Experience measure (see text below)	n. of carers with needs assessed by routine audit of system, n of carers with care plans
Medication and side effects information (R3,R4)	Medications Side Effects Measure, or Qs from QoL, health status measure, Patient Experience with InPatient care (I-PAHC), Treatment Related Empowerment Scale (TES),	n. medication reviews charted in records and care plans, n. acute prescriptions, n of meds and dose
Better management of transitions (R4)	Care Transitions Measures (CTM-15), The Patient Assessment of Integrated Elderly Care (PAIEC), Assessment of Care for chronic conditions (PACIC),	A reduction (or stabilisation allowing for population demand) in delays in transfer of care between sectors, change in unwarranted readmissions (% of people at home 91 days after discharge), n. shared care plans
Responsive and appropriate on-going care and support (R3, R4)	P3-CEQ (Q9), Care Transitions Measure (CTM-15)	A reduction (or stabilisation allowing for population demand) in unwarranted (non-elective) admissions to acute and general sectors (A&E admissions and attendance), length of stay of admissions.
Increased community assets / links with non-statutory organisations (R4)	Assessment of Care for Chronic Conditions (PACIC), Oxford Activities and Participation Questionnaire (Ox-PaQ)	Increases in social prescribing or referrals to community and non-statutory organisations, n people receiving SP support

6.1. Collecting and Measuring Patient Reported Data

The table above [\(Table 3\)](#) provides examples of the PRMs that probe the outcome domains which are important for the routines described earlier in this document as methods for implementing P3C. Several experience measures stand out as having broad coverage of P3C domains:

- P3C-EQ
- CTM
- PACIC/PAIEC

Despite their broad coverage, these measures are still relatively short. The Person Centred Coordinated Care Experience Questionnaire (P3C-EQ) is an experience measure that probes most domains in 11 questions (with the exception of continuity of care and consistency of care). However, if this measure is used with the same cohort over time, continuity can be explored through the combined construct of the tool.

The Care Transitions Measure (CTM) tool provides good coverage of core domains in 15 items with the exception of single point of contact/key worker and therapeutic relationship (narrower construct than 'healthful' relationship).

The Assessment of Care for Chronic Conditions (PACIC) (20 items) and the version developed for the older population the PAIEC (21 items) do not tap carer involvement, single point of contact/case manager and consistency of contact but do provide good coverage of a high number of important domains. The PACIC is a measure of chronic illness quality of care. It was developed in the US, based on the influential Chronic Care Model (CCM). It has 20 items measuring a number of aspects of care, including patient activation; delivery system design and decision support; goal-setting and tailoring; problem-solving and contextual counselling; follow-up and coordination. It has been extensively used in several countries and has been translated in to many different languages. However, up until 2012, there was little evidence surrounding its performance in UK settings. An evaluation of the psychometric qualities of the PACIC in a large sample of UK patients with long-term conditions sought to address this gap within the literature (Rick et al 2012). This study reported that the PACIC scale had demonstrated potential utility for improving care for long-term conditions, but further

assessment was necessary in order to ascertain why there were low levels of completion and to explore how effective the scale was at predicting outcomes and assessing the effects of interventions.

[Table 3](#) also provides examples of specific measures that can be used to focus on specific domains – such as those that are proving difficult to establish, or those that may be of particular pertinence for a certain context. For example, a diabetes intervention may be targeting self-management, empowerment may be particularly important in severe mental illness, and communication might be deemed important in end-of-life planning. In such situations, generic measures of experience can be augmented with those that are of specific importance for specific groups, or where the emphasis of an intervention is focusing on these areas. The compendium provides information on which domains are covered by measures, with a description and associated link information for each measure.

6.2. Type of Use and Level of Feedback

Some of the measures listed above can be aggregated for feeding results up to commissioners or other professionals to help inform practice and care planning. In addition, they can also be used to feed forward to patients and the public. If these measures are also part of evaluations with academic partners, they can also be used to feed back into the academic literature, if published. Most well-designed measures will be suitable for these purposes, but the power in creating change based on the results will only be as good as the PDSA or other cycles that are informed by this data. Organisational support will be critical. And systems will need to be in place to provide timely feedback (space, time and a method). How data is fed back to patients and staff will need particular thought and planning. For staff feedback this may need to be incorporated into ongoing training and development packages. For feedback to staff and patients in relation to care planning for specific individuals (for example scores of activation or self-management), clear instructions will be required to understand and deliver this information. A process will need to be implemented to monitor if this information is making improvements in the care process and outcomes of focus. This could be achieved via repeated use of the same measure, but could also be explored by asking the individual if this information helps, and recording this in the P3C Plan. Enlisting the help of academic partners will help the process of understanding how measures work and how they help detect changes over time to measure improvement.

Some measures will provide a global summary score, others will provide domain scores, and some may simply require an analysis of frequency counts per response to each question.

6.3. Individualised Measures for Care Planning

Individualised measures, or iPROMs as they are sometimes called, are a category of PRMs that can be used to help plan care and set outcome goals. These measures can be inherently person-centred as they focus on what is important to the individual but are often difficult or impossible to aggregate beyond the level of the patient practitioner interaction. Consequently, the use of these measures as system or population measures is largely impossible.

As part of the work we completed for our compendium we explored some of these measures. We found that overall, the Canadian Occupational Performance Measure²³ (COPM) is deemed reliable and clinically useful for occupational therapist practitioners. It offers a broad focus on occupational performance across a range of areas including self-care, leisure and productivity, and takes into account personal life circumstances. It has been used with a variety of client groups, although there is some evidence that it is not suitable for those with low empowerment/ self-management skills. The Goal Attainment Scaling (GAS)²⁴ was originally used in mental health settings, but has also been undertaken in elderly care settings, as a goal setting facilitator for chronic pain, and in cognitive and amputee rehabilitation. A considerable literature base suggests its usefulness within a person centred decision making process. Although not specific to goal setting, Talking Mats have been used effectively with those

²³ Law, M., Baptiste, S., McColl, M., Opzoomer, A., Polatajko, H., & Pollock, N. (1990). The Canadian Occupational Performance Measure: An Outcome Measure for Occupational Therapy. *Canadian Journal of Occupational Therapy*, 57(2), 82-87. doi:10.1177/000841749005700207

²⁴ Kiresuk, T. J., & Sherman, R. E. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Ment Health J*, 4(6), 443-453. doi:10.1007/bf01530764

with cognitive impairment to facilitate participation in discussions that they may have difficulty in engaging in otherwise²⁵. In addition, we have identified the Patient Generated Index/Modified Patient Generated Index (PGI)²⁶ which although a quality of life measure, allows the individual to select personally relevant areas for improvement through the application of a point scale. Various adaptations have been made to suit a variety of patient groups. It has a well-developed conceptual model, and the modified version in particular is able to detect change. The Measure Yourself Medical Outcome Profile (MYMOP)²⁷ (Paterson, 1996) is an individualised outcome questionnaire. Whilst problem specific, it also includes items on general wellbeing and is relevant across physical, emotional and social symptoms. It is a brief measure and is simple to administer.

6.4. Collecting and Measuring Process and Activity Data and Calculating Costs

Collecting and analysing process data (n. care plans etc., people recruited and discharged, n. P3C conversations) should ideally be conducted fairly frequently (i.e. on a quarterly basis) as specified in [Table 2](#). This will enable rapid response to implementation issues. Mechanisms for the feedback of this data to front line staff and commissioners should be tailored to the audience. Dashboards may be preferable for commissioner groups while simple progress charts or tables may be better suited to dissemination via electronic mail or for discussion at staff meetings. Collecting and analysing this data frequently will allow for the assessment of uptake of intervention and workload distribution (i.e. caseload per keyworker etc.) and the calculation of costs. Process data should also be used to inform PDSA or improvement cycles as described earlier. Creating system Read Codes for

²⁵ Murphy, J., Tester, S., Hubbard, G., Downs, M., & MacDonald, C. (2005). Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats™ as an interview tool. *Health & Social Care in the Community*, 13(2), 95-107. doi:10.1111/j.1365-2524.2005.00528.x

²⁶ Ruta, D. A., Garratt, A. M., Leng, M., Russell, I. T., & MacDonald, L. M. (1994). A new approach to the measurement of quality of life. The Patient-Generated Index. *Med Care*, 32(11), 1109-1126.

²⁷ Paterson, C. (1996). Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey. *BMJ*, 312(7037), 1016-1020.

activities will help facilitate the extraction of this data. For example, specific Read Codes for new individuals on the programme, P3C planning appointments, goals or outcomes, and medication reviews will provide numerical summary data following extraction. The key purpose of extracting process data is to monitor the implementation of P3C routines.

Depending on the context, service use activity data may be slow or fast-responding - it will vary hugely by area, site and intervention. This data should always be interpreted with caution, and analysed alongside other sources of data (i.e. qualitative and questionnaire data). Six-monthly in-depth audits alongside routine monitoring appears to be a sensible compromise. [Table 2](#) and [Table 4](#) describe the type of data that could be collected that links to P3C interventions. However, this type of data is also subject to variation due to a whole range of different factors, not least seasonal and natural variation. Establishing confidence that the data being analysed relates to the cohort under investigation will be one way to ensure that the data set corresponds to activity within the system (see read codes above). Comparing data with a well-matched cohort (see previous section on propensity scoring) will permit an understanding of how variation may influence the data. Increases in activity are often observed when decreases are hoped for i.e. increases in admissions following the inception of an intervention. The data may signal something that should be investigated within the intervention (i.e. people being referred during a crisis) or may be an unrelated confounder. For these reasons, mixed and multi-level data is always recommended.

Costs of the intervention and resultant service utilisation can be calculated on a per-patient basis (units of activity within the system), summed per cohort and then offset against the costs of implementation and delivery (staff, buildings, resources etc.). Calculating resource-use costs can be done in several ways and the information required will need to be extracted from locally available data sets. One approach that could be used involves calculating predefined unit costs; this method is simple to use and provides an approximate expenditure on different activities. More complicated calculations include using real costs and activity to answer more focused questions of efficiency which would, for example, consider the variation between different settings (i.e. between rural and urban sites) ([PIRU, 2014](#)) <http://www.piru.ac.uk/assets/files/IC%20and%20support%20Pioneers-Indicators.pdf>. More sophisticated cost benefits analysis and financial modelling could be considered with sufficient collaboration with academic partners.

6.5. Collecting Staff Experiences & Organisational Data

The work that informed this guide did not set out to assess staff measures for P3C. However, the importance of understanding how staff experience the delivery of P3C is highly important. It is emphasised in McCormack's notion of 'Healthful' cultures as being those which consider the health and wellbeing of staff and their experiences of shared decision making within the organisation that they work in. Staff burnout and satisfaction are also considered important in the work of the Veterans Health Administration in the US in developing the Patient Centred Medical Home (PCMH). This is particularly important in the UK where the pressure on General Practice is high. There are numerous methods to capture the views of Health Care Professionals (HCPs), but few psychometrically validated tools specifically focus on the delivery of P3C. Measuring the delivery of P3C could be achieved by the use of the Person Centred Coordinated Care Practitioner Survey. This measure was modified from the Person Centred Health Care for Older Adults Survey 28* for use in a generic population in the UK by the PenCLAHRC. The Centre for Excellence in Primary Care at the University of San Francisco California uses the Mini Z Burnout as part of their suite of measures to assess the delivery of PCMHs, most specifically those working as part of Patient Aligned Care Teams (PACTs) (see: <https://www.stepsforward.org/modules/physician-burnout-survey>). McCormack et al have developed a measure of staff experience that probes Person Centred Practice and measures the framework that they have developed to facilitate the implementation of P3C (<http://programme.exordo.com/nursingmidwifery2015/delegates/presentation/66/>). The work of R-Outcomes encompasses a suite of measures, including a 4-item staff satisfaction measure and a job confidence score. These measures apply across all health and social care professional groups, and are irrespective of condition or type of care. They minimise respondent burden and provide fast feedback to stakeholders. The Staff HowRWe measure seeks a staff perspective on patients' care and the service provided to them by using the same items given in the patient version of HowRWe. These measures are easy to use and suitable for use by all staff groups, including those whose first language is not English. The results identify trends and allow for comparisons over time (<http://www.r-outcomes.com/>).

Measuring and supporting organisational change can go hand in hand, providing an important but neglected avenue of enquiry that is necessary for the development of P3C. There are a few measures available to do this. Those that do exist provide a mechanism to understand the context and

²⁸ Development and initial testing of the Person Centred Health Care for Older Adults Survey, Briony Dow, Marcia Fearn, Betty Haralambous, Jean Tinney, Keith Hill and Stephen Gibson

setting, and some also provide an ongoing mechanism to measure processes and change towards the development of P3C. Within the PCMH suite of measures The Building Blocks of Primary Care Assessment covers much of the organisational requirements for P3C and is based on the 10 building blocks of high performing primary care (<https://cepc.ucsf.edu/sites/cepc.ucsf.edu/files/Building%20Blocks%20Assessment.pdf>). However, this tool is designed for the US system and as such some cultural specificity may not translate. Instead, an evidence based tool has been developed in the UK by the P3C Programme of work led by the PenCLAHRC. It is specifically designed to address the implementation of P3C, and has been built from the House of Care model and current consensus on what constitutes P3C. The P3C-OCT covers all of the core outcome domains listed in the above table, and also probes activities and interactions between individuals and professionals (Person Centred Care), activities between professionals and other professionals (Coordination), and organisational systems and support processes according to each core domain of P3C below (see Appendix 5 for more details including sub domains):

- My Goals & Outcomes
- Care Planning
- Shared Decision-Making
- Information and communication
- Transitions

This tool provides an organisational perspective of readiness using both objective (reported activity) and subjective (how well an activity is working) ratings²⁹. The P3C-OCT can be used to measure change over time, lending itself to inform PDSA cycles by focusing on defined areas of work. The Context Assessment Index (CAI) is another tool that has been developed to measure the setting or environment where people receive health care and is specifically focused on the development of person centred practice development:

(http://www.science.ulster.ac.uk/inhr/public/pdf/CAI_instrument_pack.pdf).

²⁹ For more information and a copy of the tool contact jane.horrell@plymouth.ac.uk

6.6. Measuring Quality of Life and Wellbeing

Health Related Quality of Life (hrQoL) measures are often used in the delivery of person-centred interventions because seeking to understand an individual's self-perceived quality of life in relation to health issues is arguably inherently person-centred. Quality of life measures provide a comprehensive probe into a person's subjective perception across a range of life domains and are often a very good way to measure population level patient reported outcomes. Many instruments have been developed, ranging from generic instruments to disease specific forms. Currently, there are few generic measures that perform well in measuring hrQoL in people with multiple long term conditions. This has led to the US National Institute for Health's development of the PROMIS System (<http://www.healthmeasures.net/explore-measurement-systems/promis>), an initiative that aims 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.

Many modern UK healthcare initiatives – such as the Better Care Fund, the Vanguard, and the Pioneers – have targeted individuals such as those with LTCs with P3C interventions. These programs often monitor the Quality of Life (QoL) or hrQoL of these patient populations, often with the goal of monitoring the success of these interventions. However, it should be stated that outcomes such as health status and QoL are distal to the interventions, and therefore significant changes in such measures will be less likely than proximal measures, such as tools designed specifically for measuring the experience of processes of P3C. Nonetheless, a further reason for monitoring QoL within P3C approaches might be to tailor care to specific needs, and these tools can also be used as a component of P3C interventions.

Therefore, we have selected a number of QoL measures for inclusion in our compendium of P3C measures. These include both generic measures – such as the SF-36 and EQ-5D – and disease specific QoL instruments for the target conditions of this work. Whilst generic measures are often well-validated across a range of contexts, and may allow aggregation between different patient groups, disease-specific measures will be more sensitive to change between individuals.

Generic QoL Measures

There is a growing interest in the use of PROMS for systematic and routine collection of health status from the patient perspective, with the notion that such data has utility for quality improvement and service evaluation. A recent review aimed to identify the generic QoL PROMS with the best levels of performance and validity for such uses³⁰. Over a variety of criteria (domains captured; psychometric properties; pragmatic considerations), the study produced a final short-list of 8 candidates most suitable for use in primary and community care settings, all of which take between 2-15 minutes to complete.

- Assessment of Quality of Life (AQoL-8D)
- EuroQol EQ-5D-3L
- Health Utilities Index (HUI3)
- Nottingham Health Profile (NHP)
- PROMIS-Global Health Scale (GHS)
- Quality of Well-Being Scale (QWB)
- Short-Form 36 (SF-36)
- World Health Organization Quality of Life Instrument (WHOQoL-BREF)

Overall, the SF-36 had the largest evidence base, was comprehensive, is responsive, has strong content validity, and performed as well or better than other instruments (the SF-36 requires licencing fees outside of research contexts, although the nearly identical RAND-36/RAND-12 are free). The newer PROMIS-GHS was a promising rival, with the advantages of being free, responsive, brief (10 items), well balanced in terms of domain coverage, and good correlation with existing instruments. Other scales were criticised for various shortcomings, such as lack of coverage of mental

³⁰ Bryan et al. 2014: <http://www.longwoods.com/content/24035>

health (HUI3 and QWB), poorer performance in populations with lower burdens of disease (NHP) poor detection of changes in severity of disease (QWB), and limited psychometric data (AQoL-8D).

The NHP may be the most appropriate in populations with major disease burden. The WHOQoL-BREF has the strongest cross-cultural validity (a feature for which it was designed), although the EQ-5D, HUI and SF-36 and SF-12 have also been used in a broad variety of contexts.

There are a range of issues that will govern the use of generic versus disease specific measures. For example, with generic measures the impact of diabetes can be masked by other conditions, or neurological conditions can suffer from floor and ceiling effects. In contrast, disease-specific measures cannot be easily aggregated for comparisons across groups. The compendium that accompanies this guide has attempted to make accessible some of the more well-known QoL measures, with links to further information to aid the decision making process. The advantage of using these measures is that there is often population normative data that can be used to aid benchmarking. Furthermore, many of the contexts in which P3C measures are used (e.g. evaluation of Person Centred interventions) often also measure QoL (De Silva 2014), and some studies have established correlations between person-centeredness and QoL³¹. Therefore, P3C-PRMs and QoL measures often have complementary goals in measuring both the experience and outcomes of P3C interventions. The disease specific categories of shortlists that are included in the accompanying compendium are:

- Diabetes
- Cancer
- Stroke
- Heart Failure
- Neurological disorders
- Older people
- Dementia
- End of Life

³¹ Terada et al 2013, & Brannstrom M, et al. 2014.

Changing HRQOL as a consequence of P3C interventions is an ambitious goal that may take longer to achieve than expected. This is a consequence of the wide range of issues that these measures probe, issues that may be influenced and shaped by factors way beyond the scope of P3C interventions. Careful mapping of intervention components to sub domains of QoL will help understand the logic and assumptions of change within the model. Understanding how other features influence the patterns observed in the data (be that experience or quality of life data) will be important to interpreting the potential impact of the intervention. Case mix is an often neglected but important influencing factor that influences data (i.e. co-morbidities or prior experience). For guidance on how to adjust for case mix influencing variables on your data see: <https://www.gov.uk/government/publications/patient-reported-outcome-measures-proms-in-england-the-case-mix-adjustment-methodology>

Wellbeing and loneliness as sub domains of HRQoL may be more sensitive to change if interventions specifically address these two interrelated issues in people with LTCs, MLTCs and those at the End of Life. Measures that are currently well used to probe these areas are the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) <http://www.experiential-researchers.org/instruments/leijssen/WEMWBS.pdf> and the De Jong Loneliness scale <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2921057/>. Both measures are short and have good data for benchmarking purposes. These two constructs map onto the resources and community centred components of P3C care mentioned in the earlier sections of this guide. The De Jong scale distinguishes between emotional loneliness and social loneliness and is therefore good at highlighting for whom social prescribing, social connectivity, and community connections could be targeted. These measures should be captured in 6 monthly intervals (or less for more intensive interventions). Changes in mean summary scores over time or changes in individual questionnaires can be compared between time points. Measuring HRQoL in 6 monthly or 12 monthly intervals would reduce measurement burden, as some of these instruments can be rather long.

6.7. Using Qualitative Insights to explore if P3C is being Implemented and Achieving Outcomes

Qualitative work is necessary to understand how P3C is working, why there might be barriers and challenges to implementation and how people experience the new models of care. Given the resource implications of qualitative studies, the methods chosen will need to be well matched to the purpose. Focus groups provide the most cost effective form of qualitative study to understand perspectives of patients and staff. Furthermore, they can also be good ways in which to problem solve. Good recording and implementation of the findings will be crucial to developing change as a consequence of this data collection. A further value in focus groups is the opportunity they provide for peer support and connectivity. However, focus groups are not suited to everyone and make some people feel less confident to speak openly.

Observations of practice and context might be very informative to identify areas for improvement and further training and to gain insight into the more nuanced features of P3C delivery. This method might be particularly well suited to exploring the more philosophical and ethical nature of P3C and how practitioners and individuals interact to create P3C.

Guided conversations have the benefit of providing a space to probe in-depth some of the issues that impede or facilitate P3C in a confidential space, allowing respondents to reflect and make sense of their thoughts and feelings. It also provides a way of determining whether people (both patients and staff) understand what is expected of them in relation to being part of a new model of care. These types of conversations are very similar to those which are required to build a narrative picture of someone for P3C interventions. Recording important features of these conversations will provide a means of data for assessing if core aspects of P3C are being delivered (i.e. goal setting, knowledge of person).

Qualitative enquiry can produce a vast amount of rich data, even in applied research and evaluation. There needs to be established plans for how the data will be analysed and used to inform the model being developed. Collecting data that isn't used to create actionable feedback is unethical, costly and a waste of time. Again, working with academic partners will help ensure that the design and operationalisation is optimal for the purposes of evaluation. It is important to remember that data collection should happen as routine for P3C interventions through guided conversations and a secondary analysis of this data will provide a more cost effective way of evaluating interventions on a wider scale than simply carrying out a small number of interviews.

6.8. Creating a Dialogue between Insights, Measures and Metrics: The Value of Mixing Methods in Evaluation of P3C

Understanding how and why complex interventions like P3C work can only be achieved with the use of mixed methods of data collection and by creating a dialogue between the intelligence drawn from each. Whilst measurement data can provide the broad patterns, scope and potential impact of interventions, qualitative insights have the explanatory power to understand the exact causes of failure or success. Numerical data in the form of questionnaire scores may also be subject to bias, and this must be accounted for in relation to certain population groups. This type of data may often exclude those with reading, writing, and comprehension difficulties, and those who are less engaged with services. Understanding how to use different types of data in relation to each other will provide the greatest intelligence for any evaluation of P3C, and both qualitative and quantitative approaches are required. Flexibility will be important to maximise the potential of mixing methods. For example, when interpreting activity that may initially appear worrying, conducting pragmatic interviews with key stakeholders may provide insights into why such trends are occurring (i.e. increases in service use at GP level may be due to increased levels of activation and interest to self-manage, and not because of an increase in crisis contacts). Using interviews to explore if questionnaire data is a true reflection of the patterns observed in summary scores may help provide confidence that questionnaire scales are a true reflection of people's views and experiences.

6.9. Evaluating End of Life Care

Much of the above is concerned with generic principles and approaches to the evaluation of P3C with a particular relevance to people with LTCs and MLTCs. These principles and routines are important for everyone - irrespective of condition or complexity - but for those at the end of their lives, coordination is incredibly important as care and support are delivered from multiple providers. For this group, person-centred coordinated care is also integral for ensuring that people die with dignity, respect, and choice. The Commissioning Person Centred End of Life Care document provides a good overview for reference (<https://www.england.nhs.uk/wp-content/uploads/2016/04/nhsiq-comms-eolc-tlkit-.pdf>) to guide this process. In addition to the outcomes listed in table 4, metrics for the evaluation of end of life care should include the number of P3C plans for those

in palliative care with goals and outcomes specified in relation to preferences for place of death, access to services and choices around medication and resuscitation. Recognising the needs of carers and their role in the process will also be a key point for evaluation (e.g. in carer assessments performed in palliative period).

A Toolkit for the Measurement of End of Life Care has been produced by Teno et al (2001) based at the Picker Institute in the US. This toolkit provides a step-by-step account of how to measure End of Life Care and, despite being slightly dated, it is anchored in the values of P3C (see: <https://nts122.chcr.brown.edu/pcoc/resourceguide/resourceguide.pdf>). The approach consists of a proxy interview with the deceased person's carer or family member, an interview with the General Practitioner and chart reviews to detect activity across the period under observation. The authors argue that a minimum of 30 cases is required to perform the analysis and that this provides a multifaceted and thorough evaluation of the quality of end of life care. This approach was found to be feasible for implementation in a cluster randomised design (see <http://bmcpalliatcare.biomedcentral.com/articles/10.1186/1472-684X-13-36>). The Palliative Care Outcome Scale – (POS) has a suite of related tools for carers, professionals and family members (see <http://p3c.org.uk/shortlist>).

7. SUMMARY

This work was undertaken to help support the commissioning, implementation, and development of person centred coordinated care to improve outcomes for people with long term conditions (LTCS), multiple long term conditions (MLTCS), and those at the End of their Life (EoL). Aimed at commissioners, practitioners, researchers, and patients, this guide provides an overview of what we currently know about the core ingredients of P3C and how to assess if it is being delivered and is working as intended. We have consulted patients and professionals throughout the development of this work. This detailed guide used alongside the accompanying compendium works as a gateway of information for patients, commissioners, professionals and researchers alike, hyperlinks throughout the document help to achieve this. The need for pace and energy for change in how we are currently working with individuals is forcing us to strive forward despite the residual uncertainty about how to achieve such complex multifaceted interventions at a time of limited resources and a shifting demographic. It is with this in mind that we hope that this piece of work has created some clarity about what we currently understand to be Person Centred Coordinated Care and some practical guidance about how to use this knowledge to move us towards a system that provides better care and outcomes for all.

APPENDIX 1: GENERATING A DATABASE AND SHORTLIST OF MEASURES

The structure of the database and shortlist

One deliverable of the project was to generate a “focused compendium of measures for Person Centred Coordinated care” (www.p3c.org.uk). The criteria for this shortlist were informed by discussions with various stakeholders (including the steering group for this project) and our in-depth knowledge of evaluation strategies for Person Centred/Integrated care projects (such as Pioneers and Vanguard). This led us to the decision that such a compendium would have the most utility if it included a range of complementary measures, whereby the most appropriate measures could be selected depending on the context in which they were to be used. Thus, the shortlist is sub-divided into:

- A shortlist of *generic person centred coordinated care measures* (“P3C-PRMs”).
- A series of shortlists of P3C-PRMs that target *specific domains of P3C*, including shortlists for:
 - Goals and outcomes
 - Care planning
 - Transitions
 - Shared decision making
 - Information and communication
- A series of shortlists according to *disease-specific categories* that relate to the target conditions of this project. In addition to P3C-PRMs for these conditions, we supplemented these shortlists with Quality of Life (QoL) measures, as measuring QoL is often part of the delivery of P3C interventions. Furthermore, many of the contexts in which P3C measures are used (e.g. evaluation of P3C interventions) often also measure QoL (De Silva 2014), and some studies have established correlations between person-centeredness and QoL (Terada et al. 2013). Therefore, P3C-PRMs and QoL measures often have complementary goals in measuring both the experience and outcomes of P3C interventions. Our disease specific categories of shortlists include:
 - Diabetes
 - Cancer
 - Psychiatry
 - Stroke
 - Heart Failure
 - Parkinson’s
 - Older people
 - Dementia

- End of Life

Given the complexity of the final deliverable product, generation of the shortlist utilised a nuanced and multi-faceted strategy (see below).

Furthermore, as the shortlisting process involved generating a longer “database” of measures, we decided that it would be useful to present all our data. Thus, we have a long-list “database” of measures, not all of which made the “shortlist”. We have made all this data publicly available, which includes (in addition to many more measures) the full list published by the Health Foundation (De Silva 2014). Given the fact that this full database was drawn from a range of sources, and only a minority of these measures made the shortlist, the full database is uneven in the level of detail about PRMs. Thus, we have:

- A series of shortlists of measures, where we hand-select measures (see above). These have the most detail and most complete information in the database.
- A full database of measures, including all the measures from the Health Foundation spreadsheet (see below). These have the least complete information in the database.
- A series of rejected measures (discovered in literature or other data sources) which due to time constraints were not included in the longer database. These could be added at a later time point.

Identification of relevant measures

The first step in the building of the compendium was the identification of measures. Since two broad categories of measures were being considered, i.e. PRMs targeting P3C (P3C-PRMs) and QoL, complementary strategies were required and several data sources as presented below had to be scrutinised to identify a list of candidate measures. A measure was added to the compendium if it was available in the English language and if it measured the construct of interest (P3C or QoL) for LTCs or EoL. Measures not in English and those that were outcome or symptom measures (e.g. measurement of pain) were rejected.

- (i) Existing compendium/list of measures:

We initiated our search with existing compendiums for the P3C-PRMs due to the high number of tools available. The spreadsheet that accompanied the Health Foundation evidence review, ‘Helping measure person-centred care’, provides details of 160 of the most commonly researched person centred measurement tools (see <http://www.health.org.uk/publication/helping-measure-person-centred-care>) (De Silva 2014). The list was created based on screening more than 200,000 studies published between 2000 and 2013. This freely downloadable document was our starting point and all 160 measures

from this list were selected for the compendium (figure 1). The next resource we considered was the Care Coordination Atlas (CCA) by the Agency for Healthcare Research and Quality, which had 80 measures listed. Of this, 10 new measures that fulfilled our inclusion criteria were added to the compendium (figure 1).

(ii) Literature search:

The database sources (above) were supplemented with measures obtained from the literature, primarily to identify QoL measures. Since QoL measures have been subject to much more rigorous validation and assessment than P3C measures, a review of reviews approach was utilised. Nonetheless, the literature did also identify further P3C-PRMs, and those that passed our screening criteria were also used to supplement the list of P3C-PRMs.

We limited our literature database search to Pubmed. This produced 772 papers for review.

In addition, we also screened the following sources for relevant measures (number of articles obtained from each source is presented within brackets):

- 1) Cosmin Database of references on the “Consensus-based Standards for the selection of health Measurement Instruments” (COSMIN <http://database.cosmin.nl/>) (435 articles).
- 2) Papers that referenced “Terwee criteria” for measurement properties⁷⁰ (422 articles).
- 3) Papers that referenced EMPRO, a tool for the standardized assessment of patient-reported outcome measures⁷¹ (18 articles).
- 4) The Oxford PROMs group systematic reviews of PROMs for long-term conditions⁷² (15 articles)

In total, 1662 articles were obtained from the literature searches, of which 130 were relevant. From these relevant articles, 380 measures were identified, of which 144 new measures fulfilled our inclusion criteria and were added to the compendium (238 rejected) (figure 1).

(iii) Local knowledge and stakeholder engagement:

With several new models of care being commissioned recently, it was important to capture any newly developed measures. This was done through local knowledge and relevant stakeholder engagement. A total of 15 further measures were identified in this manner.

Overall, a total of 328 relevant P3C-PRMs and QoL measures were identified from the above sources and added to the compendium/database (however, our website has additional measures beyond those included in this publication, as it is not a static resource, and also includes some measures represented with multiple versions (figure 1)).

Short listing of P3C-PRMs for mapping

We applied a set of pragmatic inclusion/exclusion criteria to the identified P3C-PRMs in our compendium to produce a short list of P3C-PRMs.

A measure was shortlisted if it was:

- A short measure – less than 20 items (with some pragmatic exceptions): We preferred short measures, as these are necessary to attain satisfactory response rates and reduce responder burden in many situations (especially with our specified target population of MLTCs and EoL).
- A patient reported measure: Measures that are patient-reported not only logically adhere to principles of patient-centred medicine, but evidence also suggests that patient-reported measures are more successful at predicting outcomes than either observations or physicians-reported measures^{75,76}. However, in certain contexts (dementia; EoL) proxy measures (those that can be completed by a family member or professional) are unavoidable, and were therefore retained for shortlisting in these contexts.
- Of utility for our target population (i.e. LTC or EoL).
- Available in full for the purpose of mapping.

A measure was excluded if it was:

- Longer than 20 items
- A satisfaction measure: as explained previously in the introduction, satisfaction measures provide an indication of the process of care and not the experiences of care
- Not a patient reported measure
- A observational tool
- A measure of symptoms
- Not relevant to P3C
- A measure of QoL or Wellbeing or Loneliness or Adherence: Whilst we intended our online compendium/database to include such measures, these were not measures of P3C and were thus excluded.

- An individualised PROM (iPROM): iPROMs allow patients to modify the content or scoring system, prioritising the symptoms to address. Such patient empowerment is particularly salient to complex scenarios such as MLTCs. However, this flexibility means that they cannot be mapped against domains of P3C and hence excluded.
- Unsuitable for the target population (LTCs, EoL)
- Not available in full: Whilst we made best efforts to obtain copies of all target measures (e.g. via references, web searches and contacting authors), for many target measures we could not obtain a copy of the measure, and therefore excluded.

Sixty three P3C-PRMS fulfilled our inclusion/exclusion criteria and were shortlisted for the process of mapping (Figure 1).

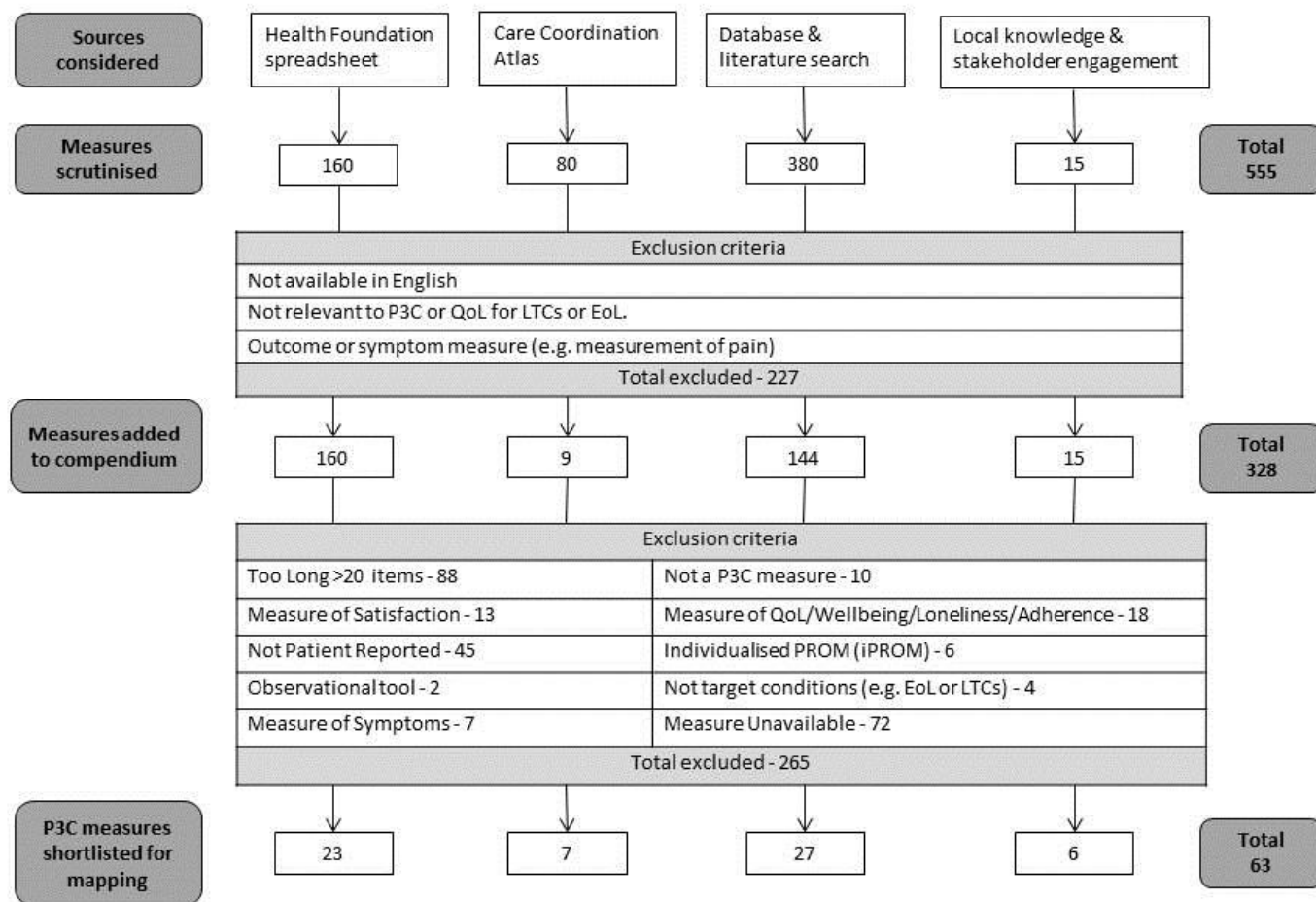


Figure 1: Overview of identification, selection and shortlisting process

Mapping of shortlisted P3C-PRMs

We utilised a mapping procedure that identified how each item on the candidate list of questionnaires corresponded to our model of P3C. This allowed us to construct a map of the questionnaires, allowing us to rapidly identify how various measures corresponded to components/constructs of patient-centred approaches.

Our model of P3C was developed previously through a systematic rigorous process and contains all relevant domains of P3C. It corresponds closely to well-accepted definitions of PCC such as the House of Care³² and the National Voices “I” statements³³. The model utilised includes the following primary domains.

- My goals/outcomes
- Care planning
- Transitions
- Shared decision making
- Information & Communication
- Medication

Two researches (HW and JH) independently assigned each item on the 63 shortlisted questionnaires to the above domains. Any inconsistencies in assignment between the two researchers were cross checked-and reassigned. See figure 2 for example of mapping measures to P3C domains.

³² <https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/house-of-care/>

³³ <http://www.nationalvoices.org.uk/sites/default/files/public/publications/narrative-for-person-centred-coordinated-care.pdf>

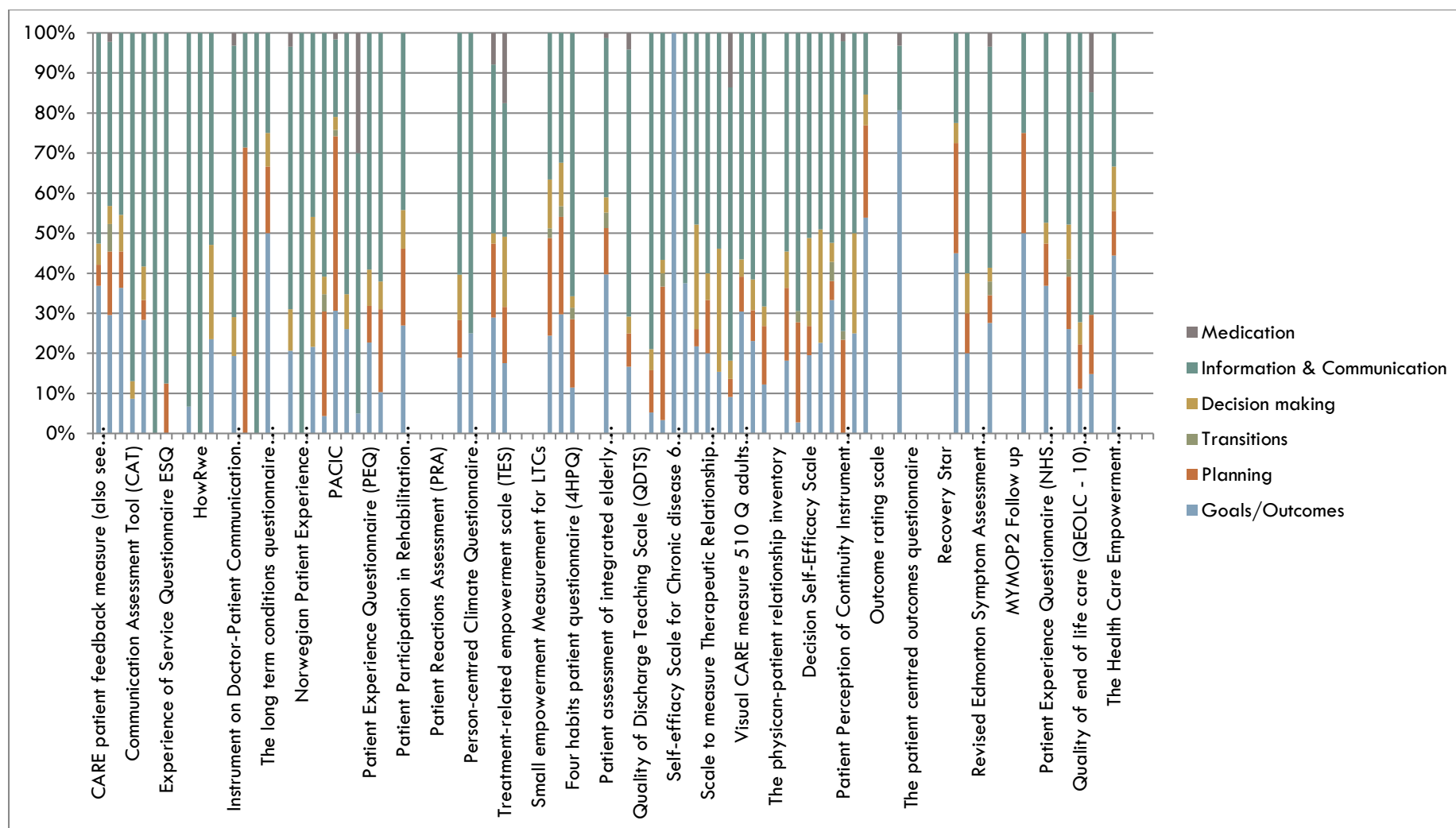


Figure 2: Example of Mapping of Measures to P3C domains

Specific shortlists

In order to simplify categorise and signpost to the key entries in our dataset in an accessible manner, we created further specific shortlists according to (a) domains of P3C and (b) disease specific categories (available on our website www.p3c.org.uk).

The shortlist on the domains of P3C was informed by the mapping process. This provided us with the ability to assign measures into six broad categories of P3C - good generic/overall measures that cover a broad range of outcomes; goals/outcomes; care planning; transitions; decision making; information and communication. As most of these measures were often newly developed or infrequently included within systematic reviews, comparisons could not be made. Therefore we categorised our measures based on a range of pragmatic criteria. Foremost, we utilised our domain map to identify measures that covered each of the six domains of P3C. Furthermore, we also preferred measures that had reasonable psychometric properties, had been co-designed with patients, and had been developed according to recent constructs of P3C. Finally, we also took into account 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).

Our engagement and steering meetings with key stakeholders (e.g. NHS England) informed our disease specific shortlist – diabetes, cancer, psychiatry, stroke, heart failure, Parkinson's, older people, dementia, and end of life. These categories include both measures of P3C that are relevant within this context and measures of QoL that have been well validated within this context. The P3C measures for each category were shortlisted based on the pragmatic criteria described above. For QoL measures, there are generally a small number of well-used and validated measures (e.g. SF-36 and EQ-5D) which are frequently included in systematic reviews. Therefore, these measures were selected on the basis of systematically reviewed psychometric properties.

APPENDIX 2: GLOSSARY – JARGON BUSTER

5YFV - Five year forward view	OBC - Outcome based commissioning
ADL - Activities of daily living	P3C – Person centred coordinated care
AHRQ - Agency for Healthcare Research and Quality	P3C-EQ - Patient centred coordinated care - experience questionnaire
AHSN –Academic Health Science Network	P3C-PRMS – Person centred coordinated care – patients reported measures
AI – Appreciative Inquiry	P3C-OCT – Person centred coordinated care – organisational change tool
CCG - Clinical Commissioning Group	PACIC - The Patient Assessment of Care for Chronic Conditions
CCM - Consultation Care Measure	PAIEC - The Patient Assessment of Integrated Elderly Care
CDSMP - Chronic Disease Self-Management Programme	PAM - The Patient Activation Measure
CQC - Care Quality Commission	PCC – Person Centred Care
CLAHRC - Collaboration for Leadership in Applied Health Research and Care	PCMH - Patient-centred medical home
CTM - Care Transitions Measure	PenCLAHRC - South West Peninsula Collaboration for Leadership in Applied Health Research and Care
DDI – Data Driven Improvement	PDSA - Plan-do-study act cycles
EoL - End of Life	PREMs - Patient reported experience measures
GMC - General Medical Council	PRMs - Patient reported measures
GPCC – Gothenburgh Centre of Person Centred Care	PROMs - Patient reported outcome measures
HoC – House of Care	QoL - Quality of Life
YoC –Year of Care	QTool ePRO – Electronic Patient Reported Outcome
hrQoL - Health-related quality of life	Quadruple Aim - Improving the individual experience of care, improving the health of populations, reducing the per capita cost of healthcare and improving the experience of providing care.
ICO- Integrated Care Organisation	SCR - Summary Care Record
IPC – Intergrated Personal Commissioning	SWAHSN – South West Academic Health Science Network
IPCS - The Interpersonal Processes of Care survey	WHO - World Health Organisation
iPROMs - Individualised patient reported outcome measure(s)	
LM – Logic Model	
LTC - Long term condition	
MLTC - Multiple long term conditions	
NHSE - National Health Service England	

APPENDIX 3: IMPLEMENTING PRMS: BARRIERS AND FACILITATORS

Table 1: Implementing PRMS: Barriers and Facilitators

Type of barrier	Quotes	Related facilitating actions
Lack of guidance	'There is often no support system in place or clear guidance on how to measure health outcomes and experiences' (JB).	<p>Create your own support system by searching out experienced users of the measures you are interested in using.</p> <p>Measures should be accompanied by a suite of support tools to enable people to use it in routine practice, such as a clinical decision tool. Such support tools were created for the palliative care outcome scale (POS) (RH).</p> <p>Our commissioners' guide and compendium will provide support with this process.</p>
Relevancy of using a measurement tool	'Sometimes the experience is so abstract that it can be hard to measure' (JB).	<p>If a standardized measurement is used, then users can be at least sure that they are trying to measure the aspect of care/experience they are focused on in the same way as others have (JB).</p> <p>Need to spend time with stakeholders defining what it is that you will be measuring.</p>
	People can have varying levels of a condition and different resources available to them and they may not always fit into the categories that the scoring system suggests' (OH).	<p>Individualised measures can sometimes be more appropriate in such circumstances.</p> <p>Also, by using interviews, alongside measurement tools, you can get a more personalised understanding about what is important to individual patients and of what they have experienced.</p>
	Real insight is often only retrieved through open questions asked in face to face settings (JC).	<p>One-on-one interviews can provide a valuable and in-depth understanding of an individual's experience and outcomes up to a certain point in time. However, by using PRMs you can easily track changes in outcomes and experiences across a long time frame, establish patterns within an organisation (or at a national level).</p> <p>Furthermore, if you use a range of methods to try and get information about experiences and outcomes of care that you are interested in, then you will be able to make comparisons across the data, identify discrepancies and strengthen your findings.</p>
Stakeholder consensus about tool	<p>'Finding a service experience measure that is understandable, has validity and is acceptable to everyone (e.g. patients, operational staff, commissioners) who is involved with its use can be incredibly difficult' (CD).</p> <p>Health professionals and patients may have contrasting ideas about what it is important to measure. For example, staff may believe patients will be interested in accessibility and waiting times, whereas patients might report that they are concerned about evidence-based medicine and receiving care from experienced and well qualified physicians (HF).</p>	<p>Hold early stakeholder meeting where measures are co-produced (CD).</p> <p>Make sure that service users have the opportunity to give input during the development of, and/or the selection of measures, so that you can make sure that the measures used are measuring what is important to service users and that the language used to express these issues is language that would be used by the service users, not the health care team (CD).</p>
Measurement process delaying/diverting attention from	'Finding a service experience measure that is understandable, has validity and is acceptable to everyone (e.g. patients, operational staff, commissioners) who is involved with its use can be incredibly difficult' (CD).	<p>Hold early stakeholder meeting where measures are co-produced (CD).</p> <p>Make sure that service users have the opportunity to give input during the development of, and/or the selection of measures, so that you can make sure that the measures used are measuring what is important to service users and that the language used to express these issues is language that would be used by the service users, not the health care team (CD).</p>

improvements to care being made	Health professionals and patients may have contrasting ideas about what it is important to measure. For example, staff may believe patients will be interested in accessibility and waiting times, whereas patients might report that they are concerned about evidence-based medicine and receiving care from experienced and well qualified physicians (HF).	
	<p>'Finding a service experience measure that is understandable, has validity and is acceptable to everyone (e.g. patients, operational staff, commissioners) who is involved with its use can be incredibly difficult' (CD).</p> <p>Health professionals and patients may have contrasting ideas about what it is important to measure. For example, staff may believe patients will be interested in accessibility and waiting times, whereas patients might report that they are concerned about evidence-based medicine and receiving care from experienced and well qualified physicians (HF).</p>	<p>Hold early stakeholder meeting where measures are co-produced (CD).</p> <p>Make sure that service users have the opportunity to give input during the development of, and/or the selection of measures, so that you can make sure that the measures used are measuring what is important to service users and that the language used to express these issues is language that would be used by the service users, not the health care team (CD).</p>
	A fixed time interval is often not appropriate for patients in palliative care, as they may be days away from dying (FM).	Rather than using measures over fixed time intervals 'we use a measure called Phase of Illness, which is a way of capturing the context of the current illness. And that, basically, is a way to say whether somebody is stable, unstable, deteriorating, or dying. And we capture the outcome measures in relation to Phase of Illness. So we capture them at the start of a phase and at the end of a phase; and that enables us to understand whether we are able to achieve the best outcome – for example, for all of those people who are in the unstable phase' (FM).
	Initiatives/health care services etc. that you are evaluating though measures can often come to an end before the evaluation (and the measurement phase) has been completed (JB).	<p>It is important that initiatives are given the chance to develop before measurements are done, as improvements take time to kick in. Also, it takes time to pick her right measures. So, there needs to be an awareness that the measurement process takes time. (JB)</p> <p>If you use an implementation science approach, you'll be more likely to have success. Rather than measuring just at before and after time points, measure at a number of juncture points. This is the best way of getting involvement and movement forward, of presenting data and of evaluating it. "[Researchers] need to get in there with the [health care team and] support people's decisions with evidence". (JB) It is important that initiatives are given the chance to develop before measurements are done, as improvements take time to kick in. Also, it takes time to pick her right measures. So, there needs to be awareness that the measurement process takes time. (JB)</p>
Restrictions on use	'The use of a measure can be restricted. There may be a licencing fees or the developers may expect certain requirements to be fulfilled if the measure is used' (CK) (JB).	Often there a number of alternative measures that covers the same outcomes and types of experiences.
Inappropriate question design	Inappropriate wording for certain groups e.g. 'the items within the original Patient Activation Measure were viewed as being too Americanised' (PW) (OH).	Work with the developers to make the items more relevant and fitting with your population group (PW).
	The wording of items within measures could have a detrimental impact on the respondent e.g. I have no family support or I feel sad a lot of the time (ER).	<p>Use measures that use positively framed items such as the Warwick Edinburgh Wellbeing measure (ER).</p> <p>Provide after-care for those who are vulnerable to possible detrimental effects of completing a measure. This may involve signposting them to relevant services and/or providing them with an opportunity to talk with someone immediately after completing the measure.</p>
	Validated measures are good when you want to benchmark results, but questions can become too old and irrelevant to patients (HF).	Check whether measures have been updated and if not, and it is necessary to do so, ask the developers about updating the items.
Sensitivity of measure	'Sometime a condition that requires a disease-specific measure can be inappropriately measured through an 'umbrella'	Develop a measurement tool kit that does allow the measure to be tailored to the individual (MH).

	measure, e.g., palliative care. This may mean that support not tailored to the individual appropriately' (MH).	Use condition specific measures, rather than just generalised ones.
	'Items within national measures can be too broad and not sensitive enough to capture information about individualised initiatives and will therefore not reflect the changes being made' (CD) (JC).	If possible, use a specific evaluation measure alongside the national one (CD).
	In palliative care, family is often the primary source of care for the patient. Consequently, family problems (anxieties) can have a significant impact on the patient. However, family problems, concerns and/or anxieties have been hard to measure in a consistent way because people sometimes don't have family or, instead, they have several family members (FM).	<p>The question of how to measure some aspects of the patient experience (such as family issues) still need to be thought through and tested. Patients need to be involved in this development stage.</p> <p>If an important part of a patient's experience cannot currently be measured through a questionnaire tool, other methods should be used to capture this information, so that it is not simply left unvoiced and un-considered.</p>
	If the measure you are using does not have good psychometric qualities, then you will not be able to detect changes in your data (RH).	Make sure that the measure you are using has good psychometric qualities before using it. Recently, the use of independent psychometric assessments such as COSMIN and EMPRO to evaluate PRMs has become more common. These types of assessments can give the best indication of whether a measure is psychometrically sound.
Factors effecting recruitment and response rate (patient)	'People from certain ethnic backgrounds may be wary of participating' (MH).	<p>Engage with community leaders and with support services that have contact with these communities (MH).</p> <p>Have people that the targeted sample trusts on the recruitment team (MH).</p>
	Multiple languages spoken in one location – need for translated versions of measures (FM).	Use a measure that has translated versions available. Make sure that the questions asked are in their local language and are asked by someone they trust (MH).
	<p>'Culture shock for patients – patients are not used to: being asked to do 'homework' outside of the consultation, be involved in the consultation or to being asked difficult questions that they haven't been asked before' (OH).</p> <p>This may impact on the patient's motivation to complete the measure, as they may not see the point of reporting and view it as only being useful for the health professional' (HF)</p>	<p>Make sure that patients are well informed of what the measurement process entails and why it is needed. Offer support with the completion of these measures when necessary. Convey an awareness and appreciation of the time and effort given by patients who complete these measures.</p> <p>Make sure that improvements to patient care are made in response to the results and that patients are made aware of how the results were used (HF).</p> <p>Make sure someone asks the patient to complete the measure, rather than just having it lying around' (JC).</p> <p>Instead of thinking about what is important to commissioners, or providers, think about what is meaningful to the patient (JH).</p>
	Questionnaire fatigue – Completing measures can be time consuming and burdensome. If a lot of measures are given to the patient they may develop questionnaire fatigue, especially if they are not thanked or told why the results are important (CK).	<p>Use short measures.</p> <p>Monitor how many questionnaires individual patients are receiving.</p> <p>Use one measure, such as the IPOS, that can give them the opportunity to talk about everything, not just certain conditions or issues (FM).</p> <p>Make the completion of measures as easy as possible for the patient. Provide access to the measures via mobile phone, laptop or computer (FM) and enable them to complete it outside of the clinic.</p>

	Technology - If the delivery of the measure becomes electronic then it can introduce a new work flow for the patients (as well as the staff). They may be used to using a paper form and not used to going online. (CK) User interface of the electronic version of the measure may not be user friendly (CK).	Provide different delivery formats and offer support if patients are making a switch to electronic methods. Improve technology, so that access is improved. Use external software agencies for IT support and for sharing patient feedback on the website (CK).
Factors effecting recruitment and response rate (staff)	If the person communicating details about the measure to the respondent is not clear about why it is being given out, and/or appears to be un-engaged with the measurement process, then patients will not be motivated to complete it (HF) (JH).	Make sure that the person delivering the measure is well trained on how to deliver and complete the measure and is enthusiastic about why the measure(s) is being used (JH).
	If the person communicating details about the measure to the respondent is not clear about why it is being given out patients will not be motivated to complete it (HF).	Make sure that the person delivering the measure is well trained and enthusiastic about why the measure(s) is being used.
	Staff resistance due to pre-perception that patient's will resist it themselves (KS).	Offer training or give the responsibility of recruitment to people other than the health care team. Patients have actually enjoyed doing the measure (KS). The measurement system needs to be given time, so that an assessment of how patients react to it can be done properly.
	Staff resistance – view measurement system as extra and unnecessary work (OH) (CK). Health professionals 'are too overwhelmed by existing workloads, so it would be better if they are not responsible for getting patients to complete the measure' (JB).	In order to reduce the burden of the new work flow on the health care team train schedulers to handle the measurement system (CK). Try and make sure that the measurement system integrates easily into a health organisations electronic record system, so that it is less burdensome and so that the information integrates with what data is already being collected (RH). If physicians are responsible for patient participation, then set up face-to-face meetings with practitioners where you can inform them of evidence-based reasons for why it is important for patients to complete the measures, have a strong (research) measurement team presence at the health care site and offer as much support as possible (JB).
	Staff resistance – worried about what feedback they may receive about their work (HF).	Focus on the change and improvement that can be made because of the information retrieved from the measure, rather than on what's gone wrong (HF). Develop good relationships with the healthcare team you are working with (JB). Show evidence of how health care professionals have found the process to be rewarding in other projects. For example, how these measures have opened up communication between health care professionals and patients and have made sure that important questions are asked at every encounter, and in turn improving the assessments that are carried out by the professional (RH).
	Concern whether patients who are experiencing lapses in memory or other cognitive impairments are able to complete the measure and give consent to do so (AP).	Triangulate results from patients, health care practitioners, carers and with standard responses from people with the same condition (MH). Make the decision on a case-by-case basis (AP). While it is best practice to collect outcomes and experiences scores from patients, it is still better to use proxy measures (where carers, family members (or health care professionals can answer the questions on behalf of the patient) rather than no measure, as it is important not to exclude people who are unable to self-report (RH). To combat discrepancies between proxy and self-report measures, staff can receive training on how to best interpret patient behaviours, so that they can act as a good proxy and you can examine what variables influence agreement/disagreement

		<p>between a proxy and a patient score. Once you know what can lead to discrepancies you can adjust the score, so that it these variables are controlled for (RH).</p> <p>Other formats of the measure may be available (or could be made available) that can make self-reporting easier. For example, the talking mats format for PRMs uses a pictorial representation of possible responses, making completion easier for those who are cognitively impaired. A hand scoring system could also be used to help patients who cannot verbalise responses to self-report (RH).</p>
	If you do not want your results about patient experience to be impacted by respondent bias, responses will need to be kept anonymous. This will make it more difficult to collate the data with other sources (CK) and restrict the opportunities for making improvement to individual care.	Reduce bias in other ways e.g. nobody present when the measure completed, enable the patient to complete it outside of the clinic and encourage and explain why truthful responses (even if negative) should be given.
	If you are evaluating a model of care through a measure(s) results may be affected by the variation between patients within your control group and your experimental/intervention group. For example, in a palliative care evaluation you may have a patient who has lung cancer, who is in a lot of pain, has psychological issues and a lack of family support in one group and a patient within in another group that has chronic obstructive disease, very few symptoms and a lot of family support. In this situation the question becomes: did model of care A do well (badly) because it was doing the right (wrong) things or because it had un-complicated (complicated) patients within its group (FM). In effect, you need to adjust for case mix	Use a case mix strategy where you group patients into different groups on the basis of how complicated their situation is and how much (little) support/resources they have available to them (FM).
Sampling issues	If you are using measures within an evaluation of multiple intervention sites, then you need to be conscious of the fact that sample sizes can vary widely across organisations. The sample size can be dependent on individualized initiatives and or whether you are following a care pathway of patients over time or whether you are just measuring a couple of time points. Part of the evaluation process actually involves testing out whether you can use certain measures on the samples you get (JB).	<p>Focus your indicators on the type of patient who is using the initiative you are evaluating through a measure(s). Sometimes it is not helpful to try and do a blanket measurement of the larger populations, because your target sample is so widely dispersed. Instead, focus on what is happening with your focused patient group e.g. Users of integrated care. (JB)</p> <p>Developers of certain measures will offer advice on sampling. (JB)</p>

Table 2: Barriers and Facilitators to the Dissemination and Feedback of PRMS

Type of barrier	Quote	Related Facilitator
Data storage & handling	If a national body administers the measure on your behalf, it may be more difficult to access the information at an individual level. So, there's a tension between where the data originates and where the data should live. Ideally it should be both, it should just be seamless, you should just collect it here and it should be available for anyone who wants to do analysis (CK).	Establish how the data will be shared before implementing the measures. Data sharing agreements can be difficult to establish but once in place make the transfer of data more expedient for future use.
Delay between implementation and receipt of results	If you get results six months after the measures were completed, the patient sample was random, the patients completing the survey may or may not have thought of themselves as having a long-term condition and there may have been different patients answering the questions every year, then it makes comparing the results very difficult. It is also not easy in this situation to attribute improvement or deterioration in results to the integration programme interventions, as opposed to anything else that could have impacted this. Furthermore, if results are not issued for a substantial amount of time limits the opportunity for improvement, especially when you are trying to do a rapid change (CD).	<p>Need to be transparent about the factors that need to be considered when interpreting the results and the limitations of the measure (CD).</p> <p>Develop/use other measures that offer more timely/regular results alongside the measures that are used less frequently (CD) (JK).</p> <p>Using a mix of locally 'owned' measures will help provide faster feedback for quality improvement cycles.</p> <p>Work with national and regional BCF leads to develop more suitable measures which could be used in multiple parts of the country to aid benchmarking (CD).</p>
Accessibility & applicability of the results	Impact of feedback is influenced by how many people understand the findings and how to move forwards (HF).	Merge data sources - If you can merge results from national measures with the quality improvement goals (work) within a specific organisation – and show that they work together to drive improvements this will aid understanding (HF). This level of understanding needs to be fostered at every level of the organisation and at policy level (HF).
	If a patient accesses their results without an explanation being given about them beforehand it can cause confusion and worry (CK).	Restrict patients' exposure to the results from the measures you use until you are ready and able to disseminate them in an accessible way to the patients.
	Can be difficult to feedback to patients who just disappear (HF).	Keep contact records of respondents and involve them in what happens next (feedback and new initiatives to make necessary changes identified by the results).
	When physicians complete the measures, but don't pick up the data and use it, patients can become unmotivated when this is the case: 'why do I do this if you don't use it all. Patients need to feel that that data is being looked after and used'. (HF)	If patients are going to enter a lot of data, then they need to get something back in order to be motivated to use it again. Be transparent about how the data is going to be use and explicitly state how it can support the consultation they are about to have with a health professional (HF).
Feedback format	If the results are delivered in a statically heavy format and the recipient(s) is not very experienced in statistics, then they won't be able to interpret them or share the results with others. (CK)	<p>Give simple overviews of the data, which show trends and give an idea of what might not be a good direction to go in and what might be a good direction. Give different options for how to make changes in care and include graphical representations of the data and a decision support system (HF) (RH).</p> <p>Translate key findings into a web-based dashboard that can be assessed by everyone (staff and patients) and easily understood.</p> <p>The people using the results need to have knowledge of these domains: (1) to improve healthcare you need the specific clinical knowledge about the disease that you are focusing on, including the treatment options, (2) you also need to know how to analyse a system; how to understand variation, to look at data and to see how to move forwards. (HF)</p> <p>Keep it simple – limit the number of questions you use, so that you know what good will look like and you have a really good idea of what the gap between good and bad looks like. If the answer options are related to outcomes that are important to the patients, then the results will be easier to evaluate and sell on the benefits to the individuals and everybody else (MH).</p>

APPENDIX 4: RESULTS FROM THE COMMISSIONERS' SURVEY

Role of respondent	How they are implementing P3C	Evaluation plan?	Type of measures used/to be used, who they target (patient/staff/process) and why they were selected	Why were these measures selected	At what level is (will be) feedback from the measures given	What's working well/problems encountered	Improvements to P3C?	Guidance requested
<p>Clinical Director -</p> <p>Horsham and Mid Sussex</p>	<ul style="list-style-type: none"> - Tailored Health Coaching according to the PAM. - Improving quality of shared decision making in MSK services. - A more person-centred care and support planning approach to Primary Care diabetes. - Community MDT holistic proactive care approach tailored to using the PAM. - A tailored person-centred care approach to Chronic Kidney disease according to the PAM. - A tailored person-centred approach to falls according to the PAM and FRAT. 	Yes	<p>The evaluation is using a variety of measures. They are using the PAM to both tailor the approach as well as evaluate people's knowledge, skills and confidence to self-manage.</p> <p>They are also able to correlate this to their risk of admission stratification score and health cost utilisation. The PAM National CQUIN is being used alongside the person-centred care CQUIN in a meaningful way supported by training by clinicians in coaching and motivational interviewing skills to improve coproduced care and support planning with patients.</p> <p>The SURE score is being utilised as a measure of quality of shared decision making in their integrated community MSK Service. They have agreed to use it in a CQUIN with patient leadership in shaping both the SDM training for clinicians as well as evaluating the outcomes and reflecting on any variation and educational needs for teams.</p> <p>In addition, they are using the Warwick and Edinburgh Mental and Wellbeing Scales and "more meaningful" PROMs such as the MSK-HQ.</p> <p>Using the Docobo risk stratification tool – this measures any number of metrics of healthcare utilisation as well as spend. In addition, it can measure clinical outcomes such as BP, BMI, cholesterol and behaviours, such as smoking.</p> <p>Keen to use the clinician activation measure.</p>	<p>PAM - due to its published evidence base, both as a tailoring tool to improve outcomes as an outcome measure of knowledge, skills and confidence in self-management, which is a priority in both patients' and Commissioners' strategic approach, particularly to management of LTCs.</p> <p>SURE- identified as best measure for SDM two years ago when the service commenced.</p> <p>MSK-HQ – although it's still being validated, the measure stood out as it is the only holistic outcome measure for a host of MSK conditions, rather than being disease specific.</p> <p>Warwick Edinburgh Mental and Wellbeing Scale – decision rested on an NHSE and the description of the measure by the Health Foundation.</p>	<p>Feedback has been national for the Tailored Health Coaching Pilot as part of the NHSE evaluation of the PAM and organisational for the SURE score. MSK-HQ results will be reported at an organisational level and to Arthritis UK.</p>	<p>Problem (patient measures)- using the SURE score in a meaningful way, so that the results can be reflected on by individual clinicians and between teams in MSK service and to inform learning and future improvements in SDM</p>	<p>The tailored aspect of the PAM seems to be delivering improved outcomes and corresponds with increases in both the WEWBS as well as the patient story.</p>	/

Deputy Director of Enterprise – West of England ASHSN	We are the lead organisation within the Diabetes Digital Coach Test Bed consortium project.	Yes.	Using R-Outcome measures (PROMs) to collect both patient and staff experiences and health economic modelling.	Chose these PROMs as they are easy to use and validated.	Will be feeding back to Individuals (patients), Clinical Commissioning Groups and at a national level.	Not using the measures yet.	/	<p>Patient measures - An explanation of how these measures can be helpful.</p> <p>Staff measures – How to use them to show staff that you’ve heard them and that appropriate changes have been discussed with them.</p>
Senior Commissioner – Heywood, Middleton and Rochdale CCG (Greater Manchester)	HMRC CG are implementing P3C in a number of ways including: 1) outcome based commissioned intermediate care services, 2) outcome based commissioned integrated neighbourhood team, 3) outcome based commissioned integrated effective pathways and 4) locality plan for devolution Manchester.	Yes	<p>PROMs (no specific details given).</p> <p>Also, are developing new (staff) outcome measures.</p>	Were selected to be used as part of the contract incentivising in service commissioning.	HMRC CG has a patient experience committee to feedback to patients. Service performance is fed back to a variety of committees. They have also aided the development of national guidance.	<p>Working well – Clinicians and non-clinicians working in the service report high levels of satisfaction working to outcomes, rather than inputs, as it allows them to innovate and delivery P3C.</p> <p>Problem – setting up collection methods and processes takes a long time.</p>	<p>Patient measures – Reduced LOS and an increase in patients rating the services as excellent or very good.</p> <p>Staff measures- Improved engagement with values</p>	Practical how to guides
IPC Lead – Torbay and South Devon NHS Foundation Trust & Regional NHSE IPC team	Through Integrated Personal Commissioning, by adopting a strengths based approach to health and social care.	Yes	<p>Warwick Edinburgh Mental Wellbeing Scale</p> <p>P3CEQ</p> <p>PAM</p> <p>Carer’s Experience tool</p> <p>Practitioner measure tool</p> <p>The South West CSU are supporting the IPC evaluation by collecting this information. It is planned that they will move toward the population level ‘linked data sets’ such as the Somerset symphony’. However, they are awaiting a ‘penetration test’ ordered by</p>	<p>Decision was based on advice from the Academic Health and Science network (AHSN) and the P3C (PenCLAHRC) evaluation team at Plymouth University.</p> <p>The practitioner experience survey is simple and easy to complete.</p>	<p>The Local Trusts evaluation team has a formal reporting structure through which to report progress to the executive team.</p>	<p>Working well (patient measures) - there is an understanding that these measures are evidence based and can support our transformation of healthcare practice.</p> <p>Working well (metrics) – there is accurate data at the patient level. The local ‘performance team’ have developed a process to identify historical patient level usage of the service provided by the integrated health and social care organisation.</p> <p>Problems (patient measures) – Takes a long time - too many forms</p>	<p>Patient measures – A new way of having a ‘guided conversation’ and this being “the way we do things around here” is starting to emerge. However, at present this is only on a small scale.</p> <p>Staff measures – anecdotally, it appears that staff are engaging</p>	/

			their Information Governance team before they go ahead.			<p>Problem (staff measures) – staff often don't see the point of these measures and don't see them as a priority</p> <p>Problem (metrics) – The CSU element takes too long and is onerous - the CPU team cannot get access to GP records easily and the local tem have had to undertake this process and feed into the CSU. This would not be possible on a larger scale.</p>	<p>more fully with P3C approaches.</p> <p>Metrics- a better understanding for staff about what they are aiming for. They anticipate that being able to 'evidence' an improvement as they move along this journey. However, it is still early days.</p>	
Assistant Director of nursing and quality - Bath and North East Somerset.	No	N/A	<p>Not using PRM currently, due to a lack of funding.</p> <p>They did, however, run a small project a couple of years ago within care homes which was successful, but the money was only for a short period.</p>					Any guidance that pulls together all types of PRMs would be helpful.

Key points

- Varied experience and knowledge about PRMs
- Not an extensive amount of reasoning provided for why measures were selected, except in one case
- Problems with implementing PRMs were reported in each case, however some encouraging experiences and outcomes were also described (e.g. people are reacting to and engaging with the measures positively, improved outcomes and P3C behaviours, and the measures are providing strong data).
- While guidance is needed, PRM users may not always be able to clarify what type of guidance is specifically needed. This is perhaps evidenced through the non-specific requests for guidance within the surveys and, despite problems being reported in each of the five surveys, a lack of any type of request for guidance in two of the surveys.

Within each Domain, the OCT asks questions about the following key components of P3C, providing response codes as illustrative ways of achieving that component

My goals

- Goal setting
- Empowerment & Activation
- Self-management
- Carer support

Decision Making

- Involvement in decision making

Care Planning

- The care plan
- Case management
- Single point of contact
- Care coordination (within teams and across teams)

Information & Communication

- Relational continuity
- Information gathering/sharing
- Knowledge of patient/familiarity

Transitions

- Continuity of care

Organisational Process Activities

- Valuing physical & mental health equally
- Proactive case management
- Experience of care
- Longer appointment times
- Staff training
- Supporting people to stay at home