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EXECUTIVE SUMMARY

Demographic shifts, technological advancements and global economic pressures have exerted a great burden on our health and social care system. This, combined with changes in our health care commissioning and provider landscape, and the ongoing poor experiences and outcomes of care for the most vulnerable, is necessitating significant changes in how we organise services and work with individual patients. Services are striving forward to improve in spite of the uncertainty about how to achieve such complex multifaceted change. The NHS and associated care services cannot achieve such lasting and meaningful change alone, for this to be achieved we require collaborative action that brings together different sectors of society and enhances the role of the citizen. This will require, at the very least, partnership working that involves NHS services, social care organisations, and research groups, alongside other non-government organisations, coming together in the spirit of co-production with citizens to meet these challenges.

This work supports the commissioning, implementation and development of person centred coordinated care (P3C) using Metrics, Measures, and Insights. It is aimed at commissioners, practitioners, researchers, and patients. This short guide is part of a portfolio of intelligence consisting of a detailed guidance document and an online compendium of patient reported measures that provide a gateway to what we currently understand as the core ingredients of P3C. It also outlines how to assess if the core processes for P3C are being delivered and the extent to which they are supporting change through the use of metrics, measures, and insights. The focus on patient reported measures highlights the importance of placing the patient voice at the heart of service redesign and provides tools to examine how these can be used to improve the experiences and outcomes for people with long-term conditions, multimorbidity (i.e. two or more long term conditions), and those at the End of their Life (EoL). Collaborative action, with patients as equal partners provides the best opportunity to create a system that prioritises person centred coordinated care.

ACKNOWLEDGEMENTS

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INTRODUCTION

This guide provides a brief overview of the measurement of Person Centred Coordinated Care (P3C). Its aim is to support the commissioning, implementation, and evaluation of P3C for people living with long-term conditions (LTCs), multimorbidity (i.e. multiple long term conditions (MLTCs)), and those at the end of life (EOL) by using metrics, measures, and insights. Aligned with NICE guidelines on [Multimorbidity: clinical assessment and management](#) (2016) this guide is supported by:

- [A detailed reference guide](#)
- An online compendium of patient reported measures (PRMs) (<http://p3c.org.uk/>).

Why this is Important to Commissioners

Around one in four of the population have multimorbidity (defined as two or more LTCs)¹. This rises to two thirds for those aged 65 years or over². Multimorbidity is becoming the norm. People with multimorbidity commonly experience a reduced quality of life, a higher risk of premature death, complications due to multiple medication use, and high rates of unplanned care³. Despite this, the commissioning and delivery of care for people is still often built around commissioning for individual conditions and does not always give enough consideration to the impact of multiple conditions, and their treatments, upon a person's quality of life. This results in fragmentation of care across many different specialities and services. Person Centred Coordinated Care (P3C) may be the way forward to address this problem (refer **Box 1** for short definition of P3C and section [3.1. of the detailed guide](#) for the extended definition of P3C). This guide outlines an approach to use metrics, measures and insights in commissioning such P3C services.

Box 1: Short definition of P3C

Care that is guided by and organised effectively around the needs and preferences of the individual.

¹ <https://www.nice.org.uk/guidance/NG56/documents/draft-guideline>

² [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(12\)60240-2.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(12)60240-2.pdf)

³ http://www.bmj.com/content/bmj/suppl/2016/09/21/bmj.i4843.DC1/farc050916.w2_default.pdf

Approach and Relationship between this Guide and the Online Compendium

This work has been produced with commissioners, patients, professionals, and academics to provide a gateway of support primarily for commissioners, but also for professionals and researchers, to begin to develop and implement P3C through co-design.

This guide attempts to distil current theory and practice on the measurement of P3C to provide a foundation to support commissioning of P3C (Level 3 in **Figure 1**). There are a plethora of policy documents highlighting the need for new models of P3C, but a paucity of guidance on ‘how to’ make this happen. We have attempted to provide clear and actionable guidance for commissioners and delivery organisations to plan, design, and evaluate P3C, constructed around three sections:

- Where to start
- What to change
- How to change

The online compendium, available at www.p3c.org.uk, is a repository of Patient Reported Measures (PRMs) that was developed to support this guide. PRMs are measures (predominantly questionnaires) that probe individual patient perspectives, or the perspective of carers and family members, on a range of health and social care related experiences and outcomes. These might include changes in symptoms, health status or health-related Quality of Life (hrQoL), or experiences of care. This body of work consists of thousands of instruments that can be categorised into an increasingly complex family of related tools. To help make sense of the vast array of tools available and to support this guidance, we have designed and built the aforementioned compendium of PRMs that could be used to support, measure, and evaluate P3C for people with long term conditions, multimorbidity and those at the EoL. As this is an emerging area, this guide will have a relatively short shelf life but the online compendium of PRMs is designed to provide an updated user-friendly repository of these tools, including useful “help” information and links to further resources.

What Person Centred Coordinated Care Means to Individuals with Long Term Conditions and Multimorbidity

A number of initiatives have explored what patients' desire from their Healthcare⁴. These have been incorporated into current models of P3C. Involving patients meaningfully in the spirit of co-design is essential to P3C, both at an individual clinical level and also in the redesign and commissioning of services. This work was informed and shaped by patients through workshops and as well as through public and lay membership in our project steering group.

For the individuals that took part in our workshops, P3C means:

- professionals and services recognised the individual over and above their condition(s) and also recognised them as experts in their own right
- a way to deliver bespoke and coordinated care and support, and provide choice to the individual and their support network
- interactions with practitioners and professionals that are always caring and respectful
- being listened to and being able to relay their concerns was incredibly important, as was having their complaints taken seriously
- good communication and information sharing
- humanising care that offered a route to dignity and equality for patients

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.

⁴ Most notably the work of National Voices | Statement Narratives, NHSE PCOMs project, House of Care/Year of Care, Health Foundation, Coalition for Collaborative Care, Nuffield Trust, Realising the Value Consortium etc.

What we mean by ‘Metrics, Measures and Insights’

The term ‘metrics’ is often used as an umbrella term to describe:

(a) routinely collected health service data that can be used for the purposes of audit or evaluation to monitor health or social care processes (e.g. number of care planning appointments, emergency attendances) or,

(b) data captured from the perspective of an individual using a PRM. This can include Patient Reported Outcome Measure (PROMS) data that probes 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 Health Related Quality of Life (HRQoL) and Health Status measures. Measures that focus on experiences of person centred care or components of it can be referred to as P3C measures⁵.

Table 1 provides examples of the range of metrics that can be used for monitoring the implementation (or not) of P3C.

Qualitative insights (although outside the scope of this work) are another important component of measurement and are commonly garnered through talking to people using interviews or focus groups.

Table 1: Examples of the range of metrics that can be used to monitor the implementation (or not) of P3C

Type of Metric	Examples	What does it tell us?	Level of Use
Routine data e.g. service utilisation and activity 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
Processes of care data	Number of personalised care plans, multidisciplinary team meetings	How services change their processes as they implement PCC	“ “
Individually reported measures	Client Generated Index, SF-36, PAM, howRyou, P3C-PEQ	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 some measures.
Organisational measures	P3C-OCT	An organisational perspective, organisational readiness	At practice and organisational levels, with potential to aggregate

⁵ De Silva (2014) Measuring What Matters. <http://www.health.org.uk/sites/health/files/HelpingMeasurePersonCentredCare.pdf>

SECTION 1: WHERE TO START

People that Benefit from the P3C Approach

This document focuses on people with long term conditions (LTCs), multimorbidity (i.e. two or more LTCs), and people who are approaching the end of their life (EoL). However, the approaches in this document apply equally to people for whom any of the following apply:

- they find it difficult to manage their treatments or day-to-day activities
- they receive care and support from multiple services and need additional services
- they have both long-term physical and mental health conditions
- they have frailty or falls
- they frequently seek unplanned or emergency care
- they are prescribed multiple regular medicines.

Start Small

Services are facing redesign challenges to better meet the needs of a shifting demographic and to create efficiencies in times of increasing financial restrictions. Integrated care or approaches that strive to be person centred and coordinated are perceived to be the answer but can be hampered by confusion, rhetoric, and a mixed evidence base. As such it can be helpful to change small areas where care is particularly fragmented and focus on improvement activities that aim to improve the outcomes and experiences for patients. This guide (and the [detailed reference guide](#)) provides a starting block to think about where you can begin to make changes and how you can assess if they are working. For example, understanding what you can learn from metrics will help target areas for improvement. The next section focuses on where you can begin to make changes to improve P3C.

SECTION 2: WHAT TO CHANGE

Core Issues to Person Centred Coordinated Care

Through engagement with commissioners and building on the ongoing collaboration that the South West Peninsula CLAHRC⁶ (PenCLAHRC) and South West Academic Health Sciences Network⁷ (SWAHSN), the following core issues will be important to commissioners planning to implement P3C interventions:

- 1) Is there a co-designed evaluation 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 (are there collaborations to support implementation and evaluation, i.e. academics, peer support groups, involvement of the voluntary sector alongside statutory services)?
- 3) Does the measurement and implementation framework include tools to assess;
 - social determinants, inequity and inequality?
 - health literacy?
 - 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? In particular,
 - 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?

⁶ The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South West Peninsula <http://clahrc-peninsula.nihr.ac.uk/>

⁷ <http://www.swahsn.com/>

- 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?

The above questions are a good starting place to consider how to implement P3C approaches. The emphasis on co-design is crucial to engage patients, staff, and partnership organisations in the selection of measures to encourage ownership and use patient preferences to drive change.

Establishing benchmarks for activity for certain outcomes and processes will be important to understand your starting position, but it will also be necessary to focus development activity and training in those areas to ensure that changes occur at an intensity that permit detection through the use of metrics. In order to observe change towards P3C outcomes it can be helpful to think of the four core routines that structure P3C service delivery. These are the things that professionals need to do as routine and areas that services need to support in order for P3C to be achieved. These are:

- 1) **R1: Establish individual patient narratives (understand their story) by active listening/appreciative enquiry**
- 2) **R2: Create a partnership with the patient by agreeing and formulating a plan together based on shared decision making and the preferences of the individual**
- 3) **R2: Safeguard the plan by documenting it in a co-created care or support document(s) or other such mechanisms**
- 4) **R4: Agree to act in conjunction with the individual patient, their family and other professionals to coordinate care based on the co-designed plan**

The above routines have been established, evidenced, and documented through the work of Ekman and colleagues at the Gothenburg Centre for Person Centred Care⁸ and the PenCLAHRC⁹ (see section [4.4 detailed guide](#) for more information on the four P3C routines).

Measurement and Development

Listening to and Being Informed by Patients and Professionals: Co-design

The workshops that we conducted to inform this guide explored what patients felt about the ways in which their experiences of health and care support could be used to improve service delivery. We have summarised this in the bullet points below but would advise that commissioners and providers strive to understand the preferences of their local patient groups to ensure the success of measurement and development systems.

Patients that we spoke to felt that:

- the purpose and use of data should be clear
- multiple methods were preferable for collecting feedback from patients about services and that this would optimise response rates
- questionnaires were more suited to national and regional impact (feed up and feed back to services)
- 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!
- their views needed to be listened to and acted upon
- should include people who are hard to reach
- qualitative interviews could be helpful but needed some structure to avoid them being influenced by the relationship between the patient and practitioner

⁸ <https://www.ncbi.nlm.nih.gov/pubmed/21764386>

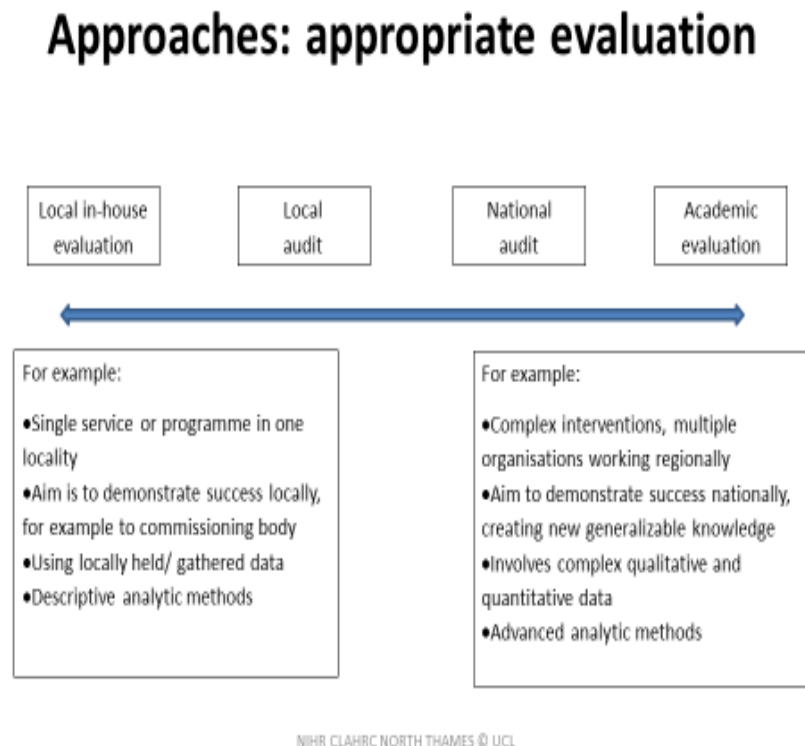
⁹ <http://clahrc-peninsula.nihr.ac.uk/research/person-centred-coordinated-care-p3c>

How to Assess if P3C is Being Delivered and Producing Change – need for evaluation framework

Finding non-invasive and efficient mechanisms for understanding if P3C is working will ensure evaluation and ongoing development of P3C interventions. The intensity of the evaluation will depend on the complexity of the intervention and the capacity of existing relationships within the services and collaborating partners. Additionally, the evaluation framework or the type of measurement that is adopted will depend on the scale of change being implemented (i.e. a single-level service change or more extensive system-wide change). The diagram (**Figure 1**) produced by NIHR CLAHRC North Thames displays the evaluation continuum¹⁰.

An evaluation framework is necessary to organise how change can be achieved, along with logic modelling and plan-do-study-act (PDSA) cycles. 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. PDSA cycles provide a framework for developing, testing, and implementing changes which lead to improvement (see PDSA section of detailed guide). They provide an initial understanding of the intervention and routes to improvement. 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 PDSA cycles or similar processes.

Figure 1: Approaches to Evaluation



¹⁰ Mears et al <http://www.hsj.co.uk/comment/why-the-nhs-must-evaluate-complex-service-changes/5089761.fullarticle>

Used together, evaluation frameworks, logic models, and improvement cycles provide a formative approach to the development of P3C (see [section 5](#) of the detailed guide for more information).

A well-planned and developed 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 allow for the development and critical questioning that should precede the implementation of the intervention, and also support thinking about how the ongoing evaluation will help support the development of the intervention. It is likely, given the complex nature of P3C, that evaluation frameworks will consist of more than one type of data collection process across multiple levels (i.e. from individual patient data to aggregated data), representing the right-hand side of **Figure 1**.

Feedback from patients and staff will guide the essential formative learning and reshaping of the intervention (if needed). This activity honours the principle of co-design, a core concept within P3C. Therefore, evaluation frameworks should include measurement of patient, staff and carer experience. Improvements in Quality of Life and Wellbeing are outcomes that P3C should strive to achieve as intermediate or long term outcomes. Evaluation frameworks should also include organisational process and activity data, to understand how the intervention is impacting on service utilisation and organisational processes, in addition to patient outcomes and experiences. There are several staff and organisational measures that could be used to provide this broader perspective of change (e.g. P3C-OCT is an implementation tool that provides organisations with a coherent approach to monitor progress and support practice development towards P3C). P3C approaches should be used in conjunction with the appropriate routine monitoring of pathophysiological outcomes for people with LTCs, multimorbidity, and those at the EoL, to provide a whole person outcome measurement as well as responsive and appropriate care.

Refer to [section 5](#) of the detailed guide for more information on the logic behind measurement in relation to the core ingredients of P3C, and for examples from researchers and health and social care professionals who are using PRMs. A detailed explanation of how P3C outcomes can be measured from the perspective of individual patients, staff, and organisational process metrics is also covered in this section. The Better Care Fund document 'How to understand and measure impact' provides further advice and detail on the importance of evaluation frameworks¹¹.

¹¹ <https://www.england.nhs.uk/wp-content/uploads/2015/06/bcf-user-guide-04.pdf.pdf>

Use of patient reported measures (PRMs)

The perspective of the patient matters most within P3C and could be obtained/collected through a number of patient reported measures (PRMs). PRMs probe the individual patient perspective, or the perspective of carers and family members, on a range of health and social care related experiences and outcomes. Evidence from a number of systematic reviews suggests that PRMs have improved the quality of care in specific areas and have been used across the health system in a number of ways. Figure 2 (on the following page) describes the ways in which PRM measures could be used across the system for care interactions, evaluation, and service development. Some PRMs can be used to serve several different purposes, resulting in less burden on respondents and resources. For example, the Patient Activation Measure (PAM) can be used to structure care planning conversations, be used to feed forward to patients to support self-management, and also to feed backwards to professionals to support training. The PAM can also be aggregated and used at system level for service planning. Care process measures such as the P3C-EQ or similar can be used for improving practice by feedback to staff through training and at commissioning level for evaluation purposes.

However, selecting a PRM to suit an intervention is not straightforward due to the vast array of tools available and the variety of domains they cover. This body of work consists of thousands of instruments that can be categorised into an increasingly complex family of related tools. Therefore, selection of a PRM for an intervention is not straightforward and can be confusing and time consuming. To help make sense of the vast array of tools available for this purpose, we undertook an extensive examination and mapping of PRMs and developed an online compendium of PRMs (www.p3c.org.uk). This compendium can be used to support, measure, and evaluate P3C for people with LTCs, multimorbidity, and those at the EoL.

FIGURE 2: The possible ways in which Patient Reported Measures (PRMs) data can be used across the system

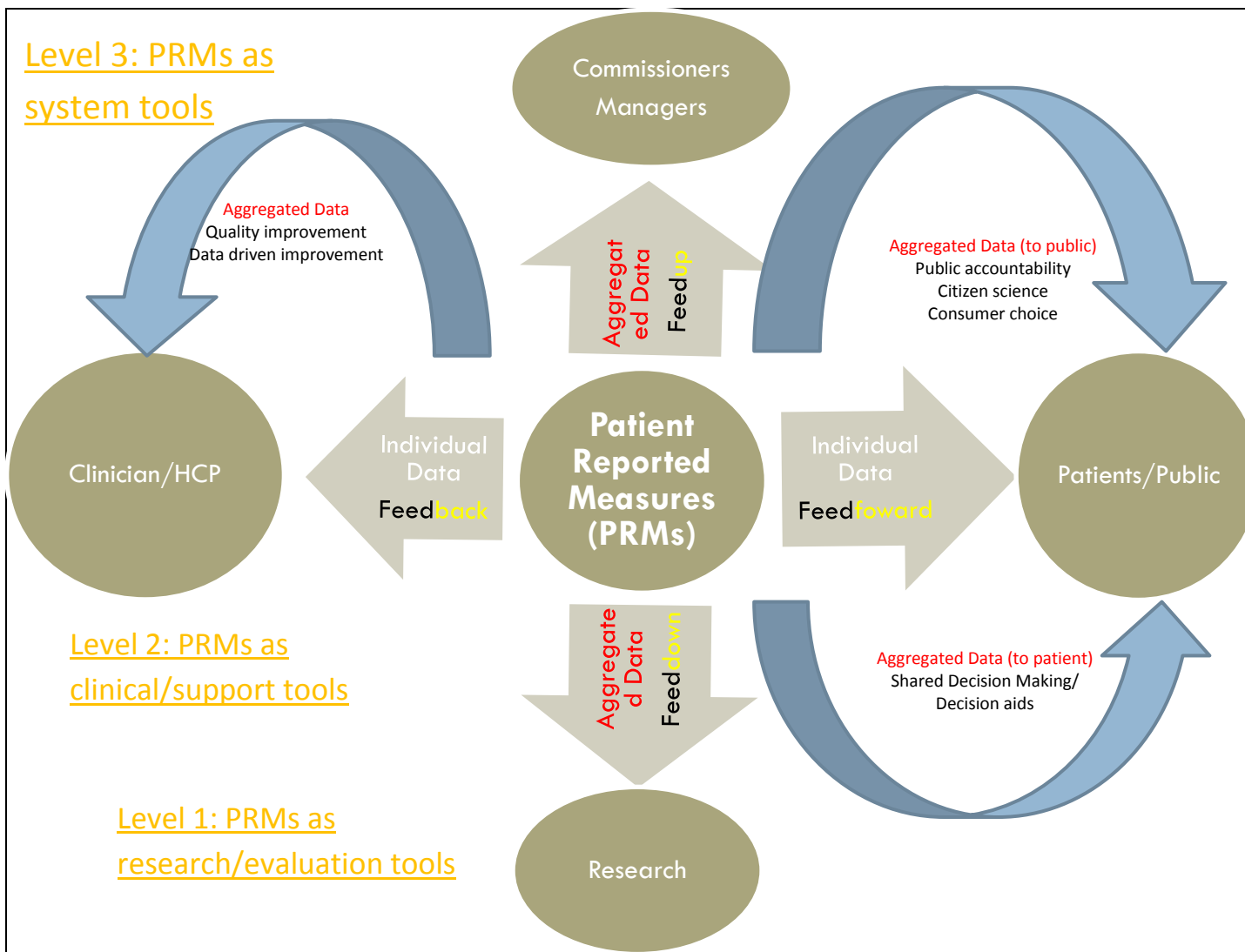


Table 2 depicts the domains and processes that could be probed as part of an evaluation framework to assess (a) if P3C routines are being implemented and (b) if they are producing changes towards short, medium, and long term outcomes. The table presents a mixture of PRMs, process, and activity data. It provides examples of PRMs 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 address (refer to the online compendium at www.p3c.org.uk for more details on each measure).

Table 2: 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 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)	P3C-EQ, 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
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

Table 2: Measuring P3C routines

Possible Outcome by P3C routine	Patient Reported Measures	Process & Activity Metrics
Medication and side effects information (R3,R4)	Medications Side Effects Measure, or Qs from QoI, 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)	P3C-EQ (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

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Implementing Patient Reported Measures: Barriers and Facilitators

Our implementation interviews also engaged key researchers, commissioners from a range of international and national settings who were using PRMs to make improvements in care, and practitioners using measures at practice level. Barriers to the successful implementation of PRMs 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. 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 and the time delay between collection, analysis and feedback of results. 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
- 3) ensuring that measurement is not solely a reporting process, but has a clear logic model in place for feedback as either an intervention or for improving care. Many of these goals can be achieved by engaging with AHSNs to develop quality improvement methodologies

Key messages for improving care by implementing PRMs

- 1) Engage key stakeholders early and ensure that patients, provider staff, commissioning representatives, and academic and support partners are involved
- 2) Decide on PRMs – there are a multitude of available measures (www.p3c.org.uk); 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
- 3) Plan and communicate the purpose of PRMs 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)
- 4) 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
- 5) Designate partners who understand PRMs within the system to help analyse and manage the data
- 6) Plan for quality improvements and synchronise with data collection points

For more detailed information on the barriers and enablers to using PRMS see [appendix 3](#) of the detailed guide.

Important Considerations When Considering the Use of PRMS to Improve and Monitor Care

- **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 healthcare organisations. This 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** – It is important to spend sufficient time planning 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.
- **Culture shock** - Patients and staff can feel 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. Efforts need to be undertaken before implementing measures to reduce burden and communicate future benefits.
- **Measures being used** - Every CCG interviewed stated that they were developing, or wished to develop, their own measures because they felt that existing measures did not capture what they were specifically interested in and/or reflect 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 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.
- **Pre-consultation “feed-forward” to patients** – This involves allowing patients to complete PRMs before a consultation with a health care professional. This process allows practitioners to have early access to information to aid decision-making within the consultation and support conversations about important goals and outcomes (rather than replace them).

- **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.

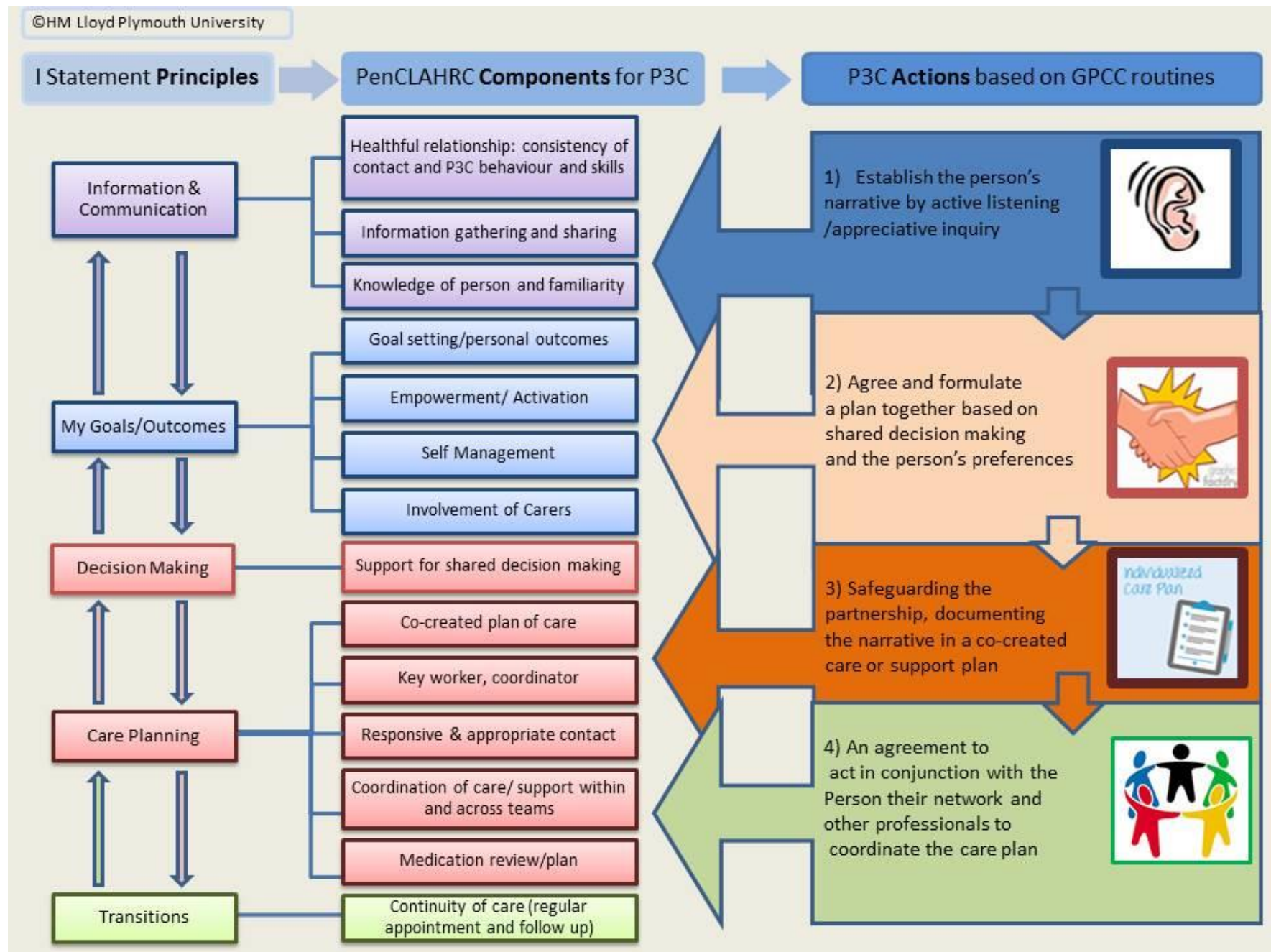
SECTION 3: HOW TO CHANGE: AN EXAMPLE

From Principles to Action

P3C is complex and requires support and action at all levels of health, social care, and associated community organisations. To help to put the principles of P3C and our understanding of it into action, we (PenCLAHRC) developed a model that links the principles of P3C to care process activities and routines (**Error! Reference source not found.**). This model builds on the National Voices I Statements¹², the work of PenCLAHRC and the routines developed by the Gothenburg Centre for Person Centred Care (GPCC). This simplified model depicts how the four routines of person centred coordinated care correspond to care processes. These are shown as PenCLAHRC components in the middle of the diagram. Implementation and changes in these care processes could help develop the routines and create good starting points for small change projects.

¹² <http://www.nationalvoices.org.uk/sites/default/files/public/publications/narrative-for-person-centred-coordinated-care.pdf>

Figure 3: From Principles to Action for P3C



An example of P3C implementation

PenCLAHRC and the SWAHSN have developed a collaborative approach to support the development and implementation of P3C across Somerset, Devon, and Cornwall through an interlinked programme of service redesign, evaluation, and research. It is likely that this type of collaboration will be required to achieve the effective, joined up, and responsive care aspired to in the Five Year Forward View. This is because effective engagement between research and practice facilitates learning and transference of knowledge about the challenges that services face during redesign. Engagement between research and practice also helps define and implement robust evaluation frameworks to understand how organisational practice changes over time. The latter can be used to advance the growing evidence base in this area.

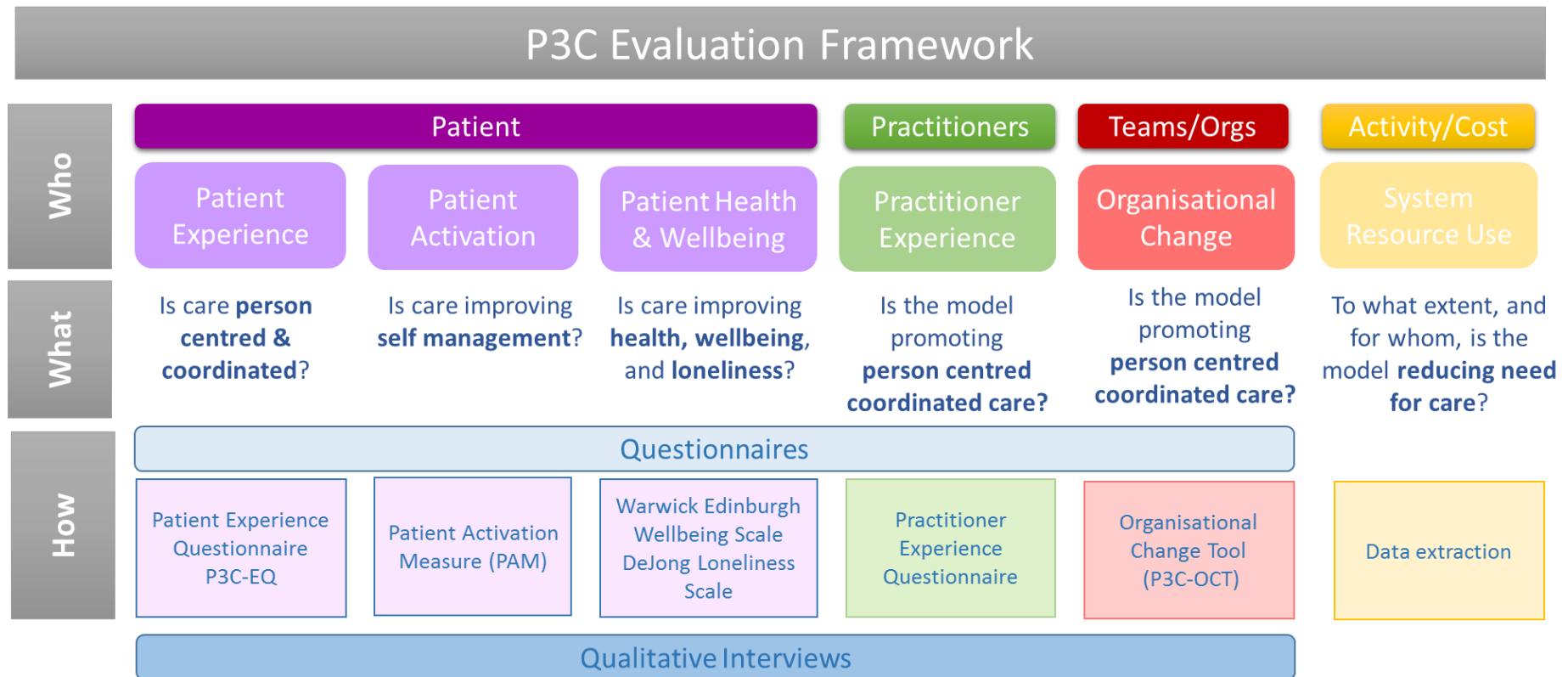
As a result of this type of collaboration PenCLAHRC and SWAHSN have built a whole system approach to metrics that takes into account outcomes of importance to patients, practitioners, and health systems. This work has also produced a core linked evaluation framework with a selection of metrics, alongside the use of qualitative interviews and observational data. The results of analysis are provided as feedback to support local practice improvement. Working with academic partners, patient representative groups, and provider organisations will enhance the potential for measurement and evaluation systems to support the delivery of P3C and measure the right things.

Figure 4) 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 illustrates 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 aims¹³ (**Improved Patient Experience, Improved Population Health, Improved Efficiency, and Improved Staff Experience**). This figure provides an example of the activities that could be implemented and measured to achieve

¹³ Bodheimer : <http://www.annfammed.org/content/12/6/573.full>

P3C and how these relate to the metrics presented earlier in **Table 2**. As outlined in the previous section, measurement should be built upon to ensure that the outcomes and changes in activities and processes are adequately captured.

FIGURE 4: An Example Evaluation Framework for P3C



SUMMARY

This work was undertaken to provide a brief overview of on the measurement of Person Centred Coordinated Care (P3C). Its aim is to support the commissioning, implementation, and evaluation of P3C for people living with long-term conditions (LTCs), multimorbidity (i.e. multiple long term conditions (MLTCs)), and those at the end of life (EOL) by using metrics, measures, and insights. 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. We believe this guide used alongside the accompanying compendium and detailed guidance will work as a gateway of information for patients, commissioners, professionals, and researchers alike.

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. With this in mind, 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 on how to use this knowledge to move us towards a system that provides better care and outcomes for all.

The document was written by Dr Helen Lloyd¹⁴ and was commissioned as a portfolio of work by NHS England in 2016.

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¹⁴ **Person Centred Coordinated Care Programme, South West Peninsula CLAHRC.**

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<https://www.plymouth.ac.uk/research/primarycare/person-centred-coordinated-care>