



## Introduction

This quick guide provides an overview of how to use [metrics, measures and insights](#) to develop and evaluate [Person Centred Coordinated Care](#) (P3C) for people living with Long Term Conditions (LTCs), Multiple Long Term Conditions (MLTCs) (also referred as multimorbidity) and those who are approaching the End of their Life (EoL). It is also designed as a navigational tool to be used along with the [detailed guide](#) and an online compendium of patient reported measures (PRMs) (<http://p3c.org.uk/>).

[Person centred coordinated care](#) is co-created between an individual, their support network, and their professionals. It is an approach to care and support that places an emphasis on understanding the relationship between an individual and their resources and capabilities, whether these are psycho-social resources, or those within their wider environment. Importantly, this approach to care and support strives to be responsive and coordinated across all sectors including community and local resources (i.e. third sector). Interventions and service delivery changes that seek to improve P3C are often complex and require multiple changes in both service configuration and the behaviours of practitioners and professionals. Engagement and partnership working with an individual and their support or familial network is critically important.

Aimed at commissioners and service delivery organisations, this comprehensive tool kit provides a supportive mechanism for understanding, developing and evaluating P3C initiatives, in particular, those that are being implemented to support the vision of reformed and integrated public services set out in the [5 Year Forward View](#) (5YFV). These initiatives aim for public services to work alongside communities, social networks and the voluntary sector to support people living with LTCs or a disability to live well with choice and control at EoL decisions. A number of national programmes (the [Integrated Personal Commissioning programme](#), the work of the [Vanguards](#) and of the [Realising the Value](#) consortium) are attempting to embed person and community-centred approaches to deliver this vision. These programmes of work need to be locally commissioned in order for them to grow and to meet the complex regional demands of the health economy; potentially contributing more nuanced and responsive models of P3C.

For P3C to be commissioned, delivered and improved we need to understand the essential core components required for delivery, as well as how to measure multilevel processes and impact from the perspective that matters most – that of people living with LTCs, multimorbidity, and those approaching the EoL. There is also an important requirement to measure both the process and the impact of delivering new models of care from the perspective of the staff who are core to the delivery model, in addition to characterising and understanding the organisational changes in the process towards P3C. However, the evaluation and measurement of P3C is technically immature, leading to inconsistent and haphazard implementation.

This tool kit provides a practical guide towards a shared understanding for the commissioning, implementation and evaluation of P3C through the use of metrics, measures and insights (see [section 3.3](#) of the detailed guide for explanation of these terms). This will allow:

- **Commissioners** to develop a suite of measures that can be used to commission for person centred outcomes at an individual and population level
- **Providers** to measure the impact of their interventions, supporting continuous improvement of services and embedding 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 type of metrics, measures and insights are most suitable for a particular purpose. This guide was developed as part of a portfolio of work commissioned by NHSE. It builds on the work of the Programme South West Peninsula CLAHRC (Collaboration for Leadership in Applied Health and Care) ([PenCLAHRC](#)) and the South West Academic Health Science Network ([SWAHSN](#)) collaborative programme to develop conceptual clarity, theory and evidence to support services to develop P3C.

The portfolio of work commissioned by NHSE includes: a) a rapid synthesis of the evidence for the use of measures to inform P3C<sup>1</sup>, b) active stakeholder engagement through workshops and primary data collection, and c) the production of an online compendium of P3C measures with guidance on their person centeredness and their psychometric properties (<http://p3c.org.uk/>). The compendium also highlights a defined number of measures which are most suitable for routine data capture in NHS or social care settings (i.e. shorter instruments with practical utility). The full guidance document also provides a set of implementation case studies (5.9), detail on how individuals with LTCs perceive P3C (5.8) and guidance on how and why to measure staff experiences and organisational change (6.5).

## Delivering Person Centred Coordinated Care: From Principles to Actions

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 is perceived to be the answer but is hampered by confusion, rhetoric and a mixed evidence base. Furthermore, the organisational composition and configuration of services in the UK is highly variable with only some forming part of newly arranged Integrated Care Organisations (ICOs). This effectively means that a large number of health, social care and community organisations which are unlikely to ever be fully integrated, will need to find a new way of working that attempts to counter the fragmented system that so many people continue to experience. Person Centred Coordinated Care (P3C) is emerging as a potential way in which to achieve better outcomes for individuals and provide more responsive and holistic care and support whilst linking a range of statutory and non-statutory services to reduce waste and duplication. P3C can be described as: ***‘Care and support that is guided by and organised effectively around the needs and preferences of individuals.’***

---

<sup>1</sup> For a copy of the full referenced version of the evidence synthesis contact [james.close@plymouth.ac.uk](mailto:james.close@plymouth.ac.uk)

A recent [Health Policy Partnership](#) document describes the current state of play in Person Centred Care (A term closely related to P3C). This informative document was brought together by international leaders in Person Centred Care in an attempt to create an up-to-date summary definition and to identify core components of the model, demonstrating some international consensus. The work of the National Voices 'I Statement Narratives', Ekman and colleagues at the Gothenburg Centre for Person Centred Care (GPCC), McCormack & McCance and the PenCLAHRC and SWAHSN has informed the following current [extended definition](#) described below (see [section 3.1](#) of the detailed guide for further information).

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 <sup>2</sup> 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. <sup>3</sup>
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 exchange of information among participants responsible for different aspects of care <sup>4</sup> . 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 time <sup>5</sup> .

Promoting a shared understanding is key in this area where a multitude of definitions thrive. Shared understandings will facilitate agreement and coherence about what constitutes P3C across delivery and commissioning levels. These are important first steps towards change in health and social care innovations, but the real challenge will be transforming principles and good intentions into implementable organisational and behavioural change. When implementing P3C, there are core elements that should be considered central to the approach:

<sup>2</sup> 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/.](http://patientfamilyengagement.org/), Richards T. Listen to patients first. *Bmj* 2014;349:g5765.

<sup>3</sup> Public Health England & National Health Service England (2015). A guide to community-centred approaches for health and wellbeing Full report.

<sup>4</sup> 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>

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

- i) Co-design and Collaboration
- ii) Healthful Cultures of Practice
- iii) P3C routines

See sections [4.1](#), [4.3](#), and [4.4](#) of the detailed guide for more information on these core elements. Briefly:

**i) [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. Principles of co-design and collaboration will contribute to the successful implementation of interventions that matter to individuals, will help steer interventions to address the outcomes that they prioritise, and provide opportunities for partnerships with patient representatives and academic partners in addition to service delivery and commissioning organisations. This type of collaboration is central to the delivery of the [5YFV](#) and the [Quadruple Aim](#) and is becoming central to the vision of a reformed health and social care system. The potential of outcomes based commissioning and similar initiatives provide, for example, a route to embedded evaluation or quality improvement using patient experiences to determine capable providers.

**ii) [Healthful Cultures of Practice](#)**

Despite widespread consensus of 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. P3C is an approach to practice that is built from fostering [“healthful”](#) relationships between all care providers, people and those important to them. These cultural features provide a basis for a context conducive to P3C. Healthful 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 that value continuous practice development (McCormack, 2010).

### iii) **P3C Routines**

The work of Ekman and colleagues<sup>6</sup> at the GPCC provides a practical bridge between the philosophical and aspirational notions of Person Centred Care. This has been achieved through extensive research in developing and testing three Person Centred Care routines based around the following key activities:



1) **Establishing an individual's narrative by active listening/appreciative enquiry**



2) **Agreeing and formulating a plan together based on shared decision making and the preferences of the individual: working the partnership**



3) **Safeguarding this contract by documenting it in a co-created care or support plan**

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



4) **An agreement to act in conjunction with other professionals and the individual patient to coordinate the care plan**

The above four routines provide a practice framework to achieve P3C. An orientation towards 'healthful' relationships provides a context and a culture that practice behaviour towards P3C can be supported and realised. The P3C routines 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. For a fuller description and a model depicting how the P3C routines relate

---

<sup>6</sup> [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 I, 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.

to the evidence base and the National Voices 'I Statement Narratives' please see [section 4.4](#) of the detailed guide. For information about how P3C relates to EoL Care please see [section 4.5](#) of the detailed guide.

## Person Centred Coordinated Care (P3C): What Can We Achieve?

The promise of what P3C can deliver for individuals, practitioners, health and social care systems and society at large is tantalising, but there will be some outcomes that will take longer to materialise. We must also move away from expecting impacts and outcomes that P3C will not be able to deliver, and we need to think and plan really carefully for those that it can deliver. Thinking through the logic of P3C interventions and striving to understand how barriers in the system are preventing optimisation will help foster an understanding of what P3C can achieve within given time frames and context settings. Thinking, planning and acting in relation to proximal (near) and distal (far) outcomes and impacts will help set expectations across the system and work in a formative and facilitative way towards implementation. Some of the proximal outcomes that can be expected if the P3C routines are achieved are:

- Enhanced Person Centred knowledge about the person, facilitated by a consistency of contact with the same practitioner
- Enhanced information and knowledge for the person and their carers or supporters
- Enhanced communication between the person and practitioner
- Enhanced Person Centred communication and empathy from the practitioner
- A healthful relationship and enhanced trust and familiarity between individuals and their professionals
- Enhanced role experience for the practitioner
- Feelings of value and respect within an emerging Person Centred partnership
- Information about what matters to the person and their goals and outcomes – fostering the beginning of a P3C partnership
- Feelings of empowerment in individuals
- Understanding the level or potential for activation in patients
- Understanding the potential of individuals to self-manage their condition(s)



- Preferences for the involvement of carers, family and support networks
- Shared decision making within the care partnership and within the organisation
- 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 individuals and what matters to them
- Development of trust and a healthful relationship
- Plan for carer assessment or referral
- A co-created and person centred care plan
- Identification of a key person coordinating care for the individual
- Information about whom to contact and when (i.e. nominated key worker and relevant professionals)
- Facilitation of responsive, appropriate (i.e. based on the list of elements defined above) on-going care leading to the avoidance of duplication and unwarranted reliance on secondary and acute care through better management of transitions and crises
- 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 and increases in continuity of care (i.e. maintaining person centred quality of care over time by providing a portal/mode of transmission of P3C knowledge about the person, and thus encouraging promotion of P3C behaviour & communication)
- Increased potential for self-management and asset-building through the optimisation of care and support and through coordination with non-statutory or community organisations
- The spread and development of healthful relationships through enhanced contact with other professionals

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 (see [section 4.6](#) of the detailed guide). For people at the EoL 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 health and social care systems become more efficient, particularly if coordination improves alongside payment and commissioning systems.

## Person Centred Coordinated Care (P3C): How Do We Know it is Working?

The detailed guidance document below outlines the possible outcomes that could be achieved in the short and long term if P3C is implemented well. Finding non-invasive and efficient mechanisms for understanding if P3C is working will ensure the ongoing development and continued funding of P3C interventions. Through these activities, principles of co-design can be actioned using formative learning and reshaping of the intervention in response to feedback from patients and staff. An [evaluation framework](#) will be necessary to organise how this can be achieved. [Logic modelling](#) and [Plan Do Study Act cycles](#) will provide an understanding of the intervention and routes to improvement, providing evaluation data drives these activities. Importantly, evaluation frameworks should include measurement of patient, staff and carer experience in conjunction with organisational process and activity data to understand how the intervention is impacting on service utilisation and organisational processes.

Improvements in Quality of Life (QoL) and Wellbeing are also outcomes that P3C should strive to achieve as intermediate or long term outcomes (see [6.6](#) of the detailed guide). 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. For more detailed information on evaluation frameworks and methods see [chapter 5](#) of the detailed guide. This section also outlines in some detail the logic behind measurement in relation to what we know are the core ingredients of P3C, whilst also providing examples of implementation experiences from researchers and health and social care professionals who are using patient reported measures in practice. The organisational prerequisites necessary for implementation such as features of the environment, staff and organisational factors, and infrastructural support are highlighted in [5.1](#) of the detailed guide. A detailed explanation of how P3C outcomes can be measured from the perspective of individual patients, staff and organisational process metrics is covered in [chapter 6](#) of the detailed guide.

From the perspective that matters most, that of the patient, there are several experience of care and QoL measures that could be used to assess if P3C is working (see [6.9](#)). Complementary to this are several staff and organisational measures that could be used. This work was informed by the extensive examination and mapping of patient reported measures conducted for the development of the P3C compendium of measures (see <http://p3c.org.uk/>). It is important to emphasise that this work sought specifically to address how P3C can be implemented and further refined through measurement and evaluation. It was not the intention to describe which other clinical routine tests and outcomes should also be considered. P3C approaches should however be used in conjunction with the appropriate routine monitoring of pathophysiological outcomes for people with LTCs, MLTCs and those at the EoL to provide a whole person outcome measurement as well as responsive and appropriate care.

## In Summary

Aimed at commissioners, 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 worked with patients and professionals to develop this work and provided a gateway of information for patients, commissioners, professionals and researchers to begin to develop and implement P3C through co-design. This document does not set out to provide all the answers but attempts to provide some examples and a foundation upon which to base the fundamental changes in how we are currently working with individuals. We are being asked to develop complex multifaceted interventions at a time of limited resources and shifting demographics. With this in mind, we hope that this piece of work has created some clarity, a starting block for 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.