

**The
Strategy
Unit.**

Patient-centred intelligence: Useful resources



The Strategy Unit and Ipsos MORI



Ipsos MORI



About this guide

- This guide forms part of the Strategy Unit and Ipsos MORI's series about person-centred intelligence.
- It links to and describes useful resources spanning person-centred care and person-centred measures, which have informed our work in this area.



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Overviews of Person-Centred Care (PCC)

[A Narrative for Person-Centred Coordinated Care \(National Voices, 2013\)](#): This narrative describes what good quality integrated care looks like, from the point of view of anyone who needs access to multiple services over time. Created with the help of Think Local Act Personal (TLAP), and working with service users, carers, charities, commissioners and professionals, it was adopted as a national definition for integrated care by all the system leading bodies in England, including the Department of Health in a [national 'Shared commitment' document](#).

[Person-centred care made simple \(Health Foundation 2014\)](#):

This guide seeks to provide a quick overview of person-centred care. It is written for anyone interested in health and health care, including health care professionals and those who use the NHS.

[Overview of person-centred care? \(Health Foundation\)](#):

Overview of person-centred care covering: What PCC is; Why PCC is important; Components of PCC; and How to implement PCC.

Current Person-Centred Care Policy

NHS Long Term Plan (NHS England, 2019): Person-centred care is a key part of the plan. There is a recognition that there needs to be a 'fundamental shift in how we work alongside patients and individuals to deliver more person-centred care, recognising the importance of 'what matters to someone' is not just 'what's the matter with someone'.

Universal Personalised Care: Implementing the Comprehensive Mode1 (NHS England, 2019): This document is the action plan for the rolling out of personalised care across England. It sets out how NHS England plan to achieve personalised care benefitting up to 2.5 million by 2023/24.

Person-Centred Care Commissioning guidance

[Personalised Care: Finance, Commissioning and Contracting Handbook \(NHS England, 2019\)](#): This guide aims to provide finance, commissioning and contracting staff with the information required to implement personalised care locally. It will enable staff to understand what the expansion of the programme means for their areas of work; what specialist support is available to facilitate the expansion; and what the impact may be on current processes and local contracting arrangements.

[Involving people in their own health and care \(NHS England, 2017\): Statutory guidance for clinical commissioning groups and NHS England \(2017\)](#): This guidance will help Clinical Commissioning Groups (CCGs) and NHS England to involve people in their own health and care in a meaningful way. It demonstrates the importance of involving people, their carers and families, to improve individuals' health and wellbeing outcomes and the efficiency and effectiveness of health services. It also explains how CCGs and NHS England can meet their legal duties.

[Commissioning person centred end of life care A toolkit for health and social care \(NHS England, 2016\)](#): A toolkit containing a range of practical resources to support those involved in commissioning for person centred end of life care.

[Six principles for engaging people and communities: Putting them into practice \(National Voices, 2016\)](#): The six principles set out the basis of good person-centred, community-focused health and care. This document sets out why the principles are important, and offers case studies and key questions to help local leaders put them into practice.

[Six principles for engaging people and communities: definitions, evaluation and measurement \(National Voices, 2016\)](#): Contains information and suggestions to help organisations and planners to understand and measure the impact of engaging with local people and communities.

[How to Use Metrics, Measures &C Insights to Commission Person Centred Coordinated Care \(PenCLAHRC, 2017\)](#): 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.

[PFCC: Patient and Family-Centred Care toolkit \(The Point of Care Foundation\)](#): A step-by-step guide to improving processes of care and staff-patient interactions. It offers a simple way for organisations to show their commitment to patients' experience while also motivating the staff who deliver that care.

Useful Frameworks of Person-Centred Care

Integrated commissioning for better outcomes :A commissioning framework (Local Government Association, 2018): Integrated commissioning for better outcomes: (ICBO) is designed to support continuous improvement in integrated commissioning and service re-design. The framework covers four areas: building the foundations; taking a person-centred, place-based and outcomes-focused approach; shaping provision to support people, places and populations; and continuously raising the ambition.

Framework on integrated, people-centred health services (WHO, 2016): Sets out a vision of a future in which all people have access to health services that are provided in a way that are coordinated around their needs, respects their preferences, and are safe, effective, timely, affordable, and of acceptable quality. It has been developed as a universal vision and can be adapted to all countries whether high, medium or low income, with mature or fragile health systems.

Person-Centred Care Clinical Guidance

NHS England

[Social prescribing and community-based support Summary guide \(NHS England, 2019\)](#): Social prescribing and community-based support is part of the NHS Long-Term Plan's commitment to make personalised care 'business as usual' across the health and care system. This guide is aimed at people and organisations leading local implementation of social prescribing.

[Shared Decision Making: Summary guide \(NHS England, 2019\)](#): This guide is intended for people leading local implementation of shared decision making.

[Module 1: PAM: implementation - quick guide \(NHS England, 2018\)](#): Patient activation and supported self-management is listed as a key component in rolling out of personalised care. This guide aims to provide practical and operational support to organisations looking to implement the PAM. It focusses on why patient activation is important and what organisations need to consider before implementation. It should be used in the context of a fully integrated approach to personalised care.

[Personalised care and support planning handbook: The journey to person-centred care \(NHS England, 2016\)](#): Sets out what personalised care and support planning is, and how to deliver it.

NICE

[Patient experience in adult NHS services \(NICE, 2019\)](#): Quality standard covering improving the quality of the patient experience for people who use adult NHS services.

[Community engagement: improving health and wellbeing and reducing health inequalities \(NICE, 2016\)](#): Guideline covering community engagement approaches to reduce health inequalities, ensure health and wellbeing initiatives are effective and help local authorities and health bodies meet their statutory obligations.

Skills for Health

[Person-Centred Approaches: A core skills education and training framework \(Skills for Health, 2017\)](#): The framework provides a description of behaviours, knowledge and skills to put a person-centred approach into practice.

Promotion of Person-Centred Care

Innovative models of general practice (The Kings Fund, 2018): This report sets out five attributes that underpin general practice including person-centred, holistic care. The reports warns that models that focus on access at the expense of other attributes may not provide the most effective and comprehensive care for patients.

Supporting people to manage their health: An introduction to patient activation (The Kings Fund, 2014): The paper draws on evidence from the US and UK to describe PAM a patient reported measure used to gauge patient activation.

What is person-centred care and why is it important? (Health Innovation Network South London, 2016): This brief document provides an overview of what person-centred care is and why it is important.

Delivering better services for people with long-term conditions: Building the house of care (The Kings Fund, 2013): This paper describes a co-ordinated service delivery model – the 'house of care' – that aims to deliver proactive, holistic and patient-centred care for people with long-term conditions. It incorporates learning from a number of sites in England that are working to achieve these goals, and makes recommendations on how key stakeholders can work together to improve care for people with long-term conditions.

State of Play of Person-Centred Care

UK

[Person-centred care in 2017: Evidence from service users](#)

[\(National Voices, 2017\)](#): This report attempts to create a snapshot of the extent of person-centred care in the English health and care system, based on how people report their experience of treatment, care and support. This data can be found — in patches — in surveys of patients and service users.

[Is the NHS becoming more person-centred? \(Health Foundation, 2015\)](#)

This overview examines how the NHS in England has performed over this parliament in relation to indicators that reflect person-centred care. It considers a range of measures including: dignity, respect and compassion; patient involvement in decisions; support for self-management and care planning.

[People in control of their own health and care: The state of involvement \(The Kings Fund, 2014\)](#)

This report explores why there has been a lack of progress towards fully involving people in their own health and care despite person centred care being a policy goal of politicians and senior policy-makers in health for at least 20 years.

[Independent evaluation of the feasibility of using the Patient Activation Measure in the NHS in England: Final Report](#)

[\(University of Leicester, 2017\)](#): The evaluators worked alongside a 'learning set' of five Clinical Commissioning Groups and one disease registry as they experimented with using the PAM in different ways and at different levels of scale, across a range of approaches for improving care and supporting self-management.

Internationally

[The state of play in person-centred care: a pragmatic review of how person-centred care is defined, applied and measured, featuring selected key contributors and case studies across the field \(Health Foundation, 2015\)](#)

A comprehensive picture of the state of play in research, implementation and measurement of person-centred care, looking at the future direction and gap analysis of each of these fields, and highlighting key work, barriers and opportunities to progress.

[Use of patient-reported outcome and experience measures in patient care and policy \(KCE, 2018\)](#)

This report explains what PROMs and PREMs are, why they can be relevant to patients, clinicians and policy makers and what the barriers and prerequisites are in case of implementation. The report includes international examples and lessons learned.

[Person-centred care in Europe: a cross-country comparison of health system performance, strategies and structures \(Picker Institute, 2016\)](#)

This briefing provides an overview of health systems' performance and strategies in person-centred care across Europe. It focuses on five European countries as exemplars and highlights general learning from them. In each country, the briefing looks at both policy and practice in areas linked to person-centred care, including patient choice, patient information, patient involvement and public satisfaction with the health system.

Understanding Person-centred Measures

[Measuring what really matters: Towards a coherent measurement system to support person-centred care \(Health Foundation, 2014\)](#): This thought paper describes the principles of person-centred care and the activities that a person-centred system should undertake in different contexts. It then describes how to think about constructing measurement systems for use in each of these contexts. The paper also describes the core constituents of person-centredness to demonstrate the steps that could be followed in order to develop a coherent measurement system.

[Helping measure person-centred care: A review of evidence about commonly used approaches and tools used to help measure person-centred care \(Health Foundation, 2014\)](#): The review signposts to research about commonly used approaches and tools to help measure person-centred care. A [spreadsheet](#) listing 160 of the most commonly researched measurement tools accompanies the review. This allows users to search according to the type of tool, who it targets and the main contexts it has been tested in.

[Measuring patient experience \(Health Foundation, 2013\)](#): This evidence scan provides an accessible overview of the range of methods that have been used to measure patient experience, in order to help practitioners, planners and researchers consider the best approaches for their own local improvement initiatives.

[‘What matters to patients’? Developing the evidence base for measuring and improving patient experience \(King’s College London / The King’s Fund, 2011\)](#): This research project for Department of Health and NHS Institute for Innovation & Improvement had three aims: to establish what matters to patients, (particularly in the non-acute sector); to review what NHS organisations in England currently measure in relation to what matters to patients; and provides examples of NHS organisations in England that are using information and insights into patient experience to improve the quality and productivity of health care services.

[Outcomes for mental health services: What really matters? \(The King’s Fund, 2019\)](#): This report examines the pursuit of outcomes by mental health services. Through a series of over 100 conversations with people actively involved in mental health services in England including current and former service users, the report highlights how frameworks for measuring outcomes are often too narrowly focused on clinical outcomes. Whilst recovery-based frameworks are trying to widen this, neither fully captures what really matters to people.

Person-centred Measures for Integrated Care

Developing measures of people's self-reported experiences of integrated care (Picker Institute, 2013): Following on from the report, 'Options appraisal on the measurement of people's experiences of integrated care', the Department of Health commissioned the University of Oxford and Picker Institute Europe to develop a set of measures which can be inserted into existing national collections to measure components of integrated care. The result is a recommended set of 18 questions, a number of which are considered to be usable for national indicator purposes. Space is limited in national surveys, however, so the researchers suggest four questions for use in existing national surveys:

1. Were you involved as much as you wanted to be in decisions about your care and support?
2. Do you know who to contact if you need to ask questions about your condition or treatment?
3. Do you feel this person understands about you and your condition?
4. Do health and social care services help you live the life you want as far as possible?

Developing an integration scorecard: A model for understanding and measuring progress towards health and social care integration (SCIE, 2017): Provides an overarching framework for what good health and social care integration looks like in the form of a logic model. A set of metrics for measuring progress towards this is proposed. (N.B. free MySCIE registration required)

Integrated care and support Pioneers: Indicators for measuring the quality of integrated care Final report (Policy Innovation Research Unit, 2014): The Department of Health commissioned the Policy Innovation Research Unit (PIRU) to provide information on performance indicators using available health and social care data sources, to monitor the progress of integrated care. The indicators were primarily developed for the 'Integrated Pioneers' sites, who also provided feedback on the indicators.

Trusted measures: analytical resources for integrated care (Nuffield Trust, 2018): A toolkit signposting to analytical approaches to integrated care that have been developed at the Nuffield Trust. The toolkit acknowledges while it is a useful starting point, there are still notable gaps in what can be measured using routine data, including staff and patient experience of integration.

Compendiums of Person-centred Measures

Measures for Person Centred Coordinated Care: A [full database](#) of unselected/unsorted P3C measures that is fully searchable and filterable, as well as a "[shortlists](#)" database containing selected example measures in various categories of person centred coordinated care (p3c).

Patient-Reported Outcomes Measurement Information System (PROMIS): Initiative led by the US National Institute for Health 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. The database can be [filtered](#) to find relevant measures.

Care Coordination Atlas (CCA): List of 80 measures. A Measure Mapping Table exists for each of the three care coordination perspectives—Patient/Family, Health Care Professional(s), and System Representative(s). Measures have been mapped to care coordination domains for three care coordination perspectives using measure numbers. Measure numbers can be looked up in the Index of Measures table. Each individual measure also has a mapping table and is followed by a measure profile designed to provide more detailed information on the measure's purpose, format and data source, perspective, validation and testing, links to outcomes, applications, and key sources.

National Patient and Staff Surveys: NHS England produces and uses a range of different surveys from patients, services users and NHS staff about the care that they receive or provide. This webpage links to survey results published by both NHS England and results published by partner organisations on behalf of NHS England. The webpage also includes links to survey results published by CQC.

Patient-Reported Outcomes Measurement Group: The Patient-Reported Outcomes Measurement Group was developed as part of the National Centre for Health Outcomes Development (NCHOD). Based in the Health Services Research Unit, Nuffield Department of Population Health at the University of Oxford, the group has established a number of important resources focussing on Patient-Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs).

Helping measure person-centred care: The Health Foundation evidence review '[Helping measure person-centred care](#)' links to an accompanying spreadsheet that provides details of 160 of the most commonly researched person centred measurement tools. The list was created based on screening more than 200,000 studies published between 2000 and 2013. The spreadsheet allows users to search according to the type of tool, who it targets and the main contexts it has been tested in. Hyperlinks to the abstracts of examples of research using each tool are also provided.

International Consortium for Health Outcomes Measurement (ICHOM): The purpose is "to transform health care systems worldwide by measuring and reporting patient outcomes in a standardized way." ICHOM organises global teams of physician leaders, outcomes researchers and patient advocates to define Standard Sets of outcomes per medical condition.

Practical guides to measuring impact

[How to... understand and measure impact \(NHS England, 2015\)](#): Developed as part of the Better Care Fund programme this guide is intended to be of practical use to members of Health and Wellbeing Boards (HWBs) including: councils, clinical commissioning groups (CCGs), local Healthwatch and voluntary sector members, representatives of NHS England who sit on HWBs, and additional non-statutory members. This 'How to' guide aims to help local areas to understand and measure the impact of their efforts to integrate services across the provision of health and care.

[The Good Indicators Guide: Understanding how to use and choose indicators \(NHS Institute for Innovation and Improvement and The Association of Public Health Observatories, 2017\)](#): This guide is intended to be a short, practical resource for anyone in any health system who is responsible for using indicators to monitor and improve performance, systems or outcomes.

Other useful resources

[Person-centred care resource centre](#): A resource centre developed by the Health Foundation aimed to help healthcare professionals implement a more person-centred healthcare service, where people are supported to more effectively manage and make informed decisions about their own health and care. (Last updated December 2016).

[Realising the Value: external resources](#): The [Realising the value](#) programme was funded by NHS England and led by Nesta and the Health Foundation. The programme aimed to consolidate what is known about person- and community-centred approaches for health and wellbeing, and make recommendations on how they can have maximum impact. The programme focused on five areas of person-centred and community-based practice: Self-management education; Peer support; Health coaching; Group activities that promote health and well-being; and Asset-based approaches in a health and well-being context. This resource is a selection of practical tools and resources relating to the five focus areas of Realising the Value.

[Evidence for person-centred care](#): National voices have produced a collection of evidence summaries and case studies showing the impact of person-centred care.

[RCGP Person-Centred Care](#): The Royal College of General Practitioners have produced a useful webpage of their resources on person-centred care.

[RCP policy: person-centred care](#): The Royal College of Physicians have produced a useful webpage of their resources on person-centred care.

[QORU publications](#): The Quality and Outcomes of person-centred Care Policy Research Unit (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics and Political Science (LSE). QORU's vision is to improve the quality of health and social care of people with long-term conditions (LTCs), developing and using high quality evidence about need, quality and outcomes of person-centred care.

[Person-Centred Coordinated Care \(P3C\)](#): List of associated papers from the authors of the [Measures for Person Centred Coordinated Care](#) and associated [guide](#).