

The
Strategy
Unit.

Patient-centred intelligence: Glossary of terms



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 focuses specifically on the terminology associated with person-centred care and person-centred measures – providing definitions of frequently used terms and links to relevant source material that is likely to be of interest to the reader.

Glossary

Always events: *Aspects of the patient's experience that should occur when patients, service users, their family members and carers, interact with health care professionals and the health care delivery system. The Always Events Framework developed by the Institute for Healthcare Improvement (IHI) provides a strategy to help health care providers, in partnership with patients, care partners, and service users, to identify, develop, and achieve reliability in person- and family-centered care delivery processes.*

Accountable Care Organisation: An organisational form in which a group of providers agree to take responsibility for providing all care for a given population for a defined period of time under a contractual arrangement with a commissioner. Providers are held accountable for achieving a set of pre-agreed quality outcomes within a given budget or expenditure target.

Biopsychosocial: *A model of care that recognises social, psychological and environmental influences on health, as well as biological factors.*

Chronic Care Model (CCM): *An organizational approach to caring for people with chronic disease in a primary care setting. The system is population-based and creates practical, supportive, evidence-based interactions between an informed, activated patient and a prepared, proactive practice team.*

Comprehensive Personalised Care Model: *A model designed by NHS England that helps to establish a whole-population approach to supporting people of all ages and their carers to manage their physical and mental health and wellbeing, build community resilience, and make informed decisions and choices when their health changes.*

Condition-specific measure: *A measure designed to measure the experiences of patients with particular conditions, or healthcare settings.*

Co-design: Involves the patients in the design process and works with them to understand their met and unmet needs. A shift from the traditional design process where the health care team is independently coming up with ideas for problems.

Glossary

Co-production: Co-production refers to the contribution of service users to the provision of services. Co-production requires users to be experts in their own circumstances and capable of making decisions, while professionals must move from being fixers to facilitators.

Experience-based co-design (EBCD): Experience-based co-design (EBCD) was designed for and with the NHS to allow people – both patients and staff – to tell stories about their experiences with the hope of improving services and wellbeing. EBCD involves patients and staff working together to design what the future of that service will look like.

Experience measures: Experience can cover both objective experiences and subjective experiences.

Generic measure: A measure which can be used across different groups or conditions and across different settings.

Health: A resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities.

Health literacy: A term used to describe people's ability to understand, access and use health information and services. It is increasingly being viewed as a framework for understanding how competent organisations are at enabling and responding to the needs of the people they serve. When understood in this way, it is a key component of person-centred care as it ensures that care is personalised to the needs of each individual.

Holistic care: Focuses on the whole person when evaluating their health status – not just the illness. Physical, psychological, spiritual and social needs are all considered.

Glossary

House of care (HoC): *A framework for a coordinated service model that enables patients with long-term conditions (LTCs) and clinicians to work together to determine and shape the support needed to enable them to live well with their condition.*

I Statements: *National Voices' 'I statement' publications describe what person-centred, coordinated care should feel like, from the perspectives of people receiving care and their families. They are first-person statements which focus on the feelings and beliefs of the speaker; in this case the person accessing a service. The statements are present-tense and aspirational. They describe a situation in which care is always based upon what matters most to the person receiving it.*

Integrated Care: *An approach to an individual's care that aims to address fragmentation in patient services and enable better co-ordinated care and continuity of care to improve patient experience and achieve greater efficiency of health delivery systems.*

Integrated Care System (ICS): *An ICS was formerly referred to as an accountable care system (ACS), until NHS England and NHS Improvement renamed them in the 2018/19 planning guidance. An ICS is an advanced version of an STP. Unlike the STP process – where all areas of the country produced plans according to a nationally mandated timetable – the introduction of ICSs will be a gradual process, with areas only being selected when their local system is considered to be advanced enough. In June 2017, 10 areas were selected by NHS England as the 'first wave' of ICSs. In addition to working together more closely, organisations within an ICS (both commissioners and providers) also take collective responsibility, often in partnership with local authorities, for resources (funding, workforce, estates, technology, information) and population health, either on the STP footprint or, a smaller, sub-STP footprint.*

Logic model: *A graphic which represents the theory of how an intervention produces its outcomes. It represents, in a simplified way, a hypothesis or 'theory of change' about how an intervention works.*

Glossary

NHS Vanguard: Individual organisations and health and social care partnerships that were chosen by NHS England in 2015 to develop models to support the improvement and integration of services, with the aim of transforming how care is delivered locally.

Objective experiences: Focus on specific aspects of the processes of care e.g. were you offered a care plan.

Outcomes-based commissioning: An approach to commissioning health care that is based on the combination of five components: (1) use of outcomes; (2) a population approach; (3) use of metrics and learning; (4) payments and incentives; and (5) coordinated delivery. Rather than an individual intervention, it is one part of a broader approach to transforming a whole health care system. It is closely linked to the concept of accountable care organisations (ACOs).

Outcome measures: Subjective perspective of the impact of an intervention on an individual's health status (impairment), functional status (disability) and quality of life (well-being).

Person centred coordinated care (P3C): Similar to person centred care, but emphasising the importance of coordinating care between (and across) services. This is especially salient for people with long-term health conditions, who often receive care and treatment from numerous services – including health and/or social care.

Patient activation: Understanding one's role in the care process and having the knowledge, skill, and confidence to manage one's health and health care.

Patient Activation Measure (PAM): The most commonly used measure of patient activation.

Person and family-centred care (PFCC): A method of improving health care quality that changes the perspective of staff delivering care, and helps them reconnect with their values and motivation for working in health care. It is designed to tackle two parallel aspects of health care: processes of care and staff–patient interactions.

Glossary

Personalised care and support planning: A systematic way of ensuring that individuals living with one or more long term condition are supported through proactive conversations, with their clinician or health and care professionals. These conversations should focus on what matters most to that individual (their personal goals) and the support they need to manage their health and wellbeing. It should be a process of sharing information, identifying medical and non-medical support needs, discussing options, contingency planning, setting goals, documenting the discussion (often in the form of a care plan) and monitoring progress through regular review.

Person Centred Care (PCC): A holistic approach that meets the person's needs and priorities before those of the system or its professionals, engages people in their care as fully as possible, and attempts to support people to take decisions and to be as much in control as possible. Also known as patient-centred care, personalisation, individualised care, patient centric and mutuality.

Person Centred Intelligence (PCI): Quantitative data and intelligence measuring person-centred care that is obtained through questionnaires and surveys containing self-reporting measures completed by patients, carers or staff. It goes beyond the measurement of patient-centred activities and seeks to understand if care is truly person-centred captured through feedback from individuals.

Personal health budgets and integrated personal commissioning: A way to improve personal outcomes and experience by giving more choice and control over the care received. They centre on personalised care and support planning and allow people to choose how they prefer to meet their health and wellbeing in personalised ways.

Patient Reported Experience Measure (PREM): Standardised validated surveys used to collect objective experience of a intervention or service from patients.

Glossary

Patient Reported Outcome Measure (PROM):

Standardised validated surveys used to collect subjective perspective of the impact of an intervention on an patient's health status (impairment), functional status (disability) and quality of life (well-being).

Person reported measures: *Self-reported measures completed by patients, carers or staff that measure outcomes and experiences.*

Sampling frame: *The source material, or list from which the sample to be asked to complete the survey will be selected from.*

Quadruple Aim: *Sometimes referenced as the triple aim plus one, this derives from the triple aim, an approach developed in the USA, to describe the ambition to drive improvement across three dimensions of health care: population health, patient experience and cost-effectiveness. The quadruple aim refers to the extension of this approach to incorporate staff/provider experience.*

Records access: *People can use their health records in a number of ways, from checking test results to reminding themselves about what was discussed during an appointment. There is already evidence that people feel more confident and are better able to manage their own health when they have access to their own records. It is a key component of a system of care that is person-centred as it enables people to better manage their own health.*

Schwartz Rounds: *An approach designed to help providers of health and social care develop their organisational culture and support staff by allowing time for staff reflection and sharing insights. They provide a structured forum where all staff, clinical and non-clinical, come together regularly to discuss the emotional and social aspects of working in healthcare. The purpose of Rounds is to understand the challenges and rewards that are intrinsic to providing care, not to solve problems or to focus on the clinical aspects of patient care.*

Glossary

Self-management: *A term given to a range of approaches that aim to enable people living with long term conditions to manage their own health effectively. Self-management recognises individuals as experts in their own lives, having acquired the skills and knowledge to cope as best they can with their long term condition.*

Shared decision making: *Shared decision making is a process in which people who experience a change in their health work together with clinicians to select tests, treatments, management or support packages. This is based on the best available evidence and the individual's informed preferences.*

Social prescribing: *A way of linking patients in primary care with sources of support in the community. It provides GPs with a non-medical referral option that can operate alongside existing treatments to improve health and wellbeing.*

Subjective experiences: *Focus on whether a patient's expectations about a health encounter were met e.g. how satisfied are you with the opening hours.*

Sustainability and transformation partnerships (STPs): *Local 'place-based' partnerships of NHS and local authority organisations introduced in NHS planning guidance published in December 2015 to help implement the changes set out in the Forward View. Forty-four areas of England were identified as the geographical 'footprints' for the STPs. The most advanced local partnerships have been asked to develop 'integrated care systems' (ICSs).*

Target population: *The entire group of people whose views and experiences want to be understood.*

Theory of change: *A comprehensive description and illustration of how and why a desired change is expected to happen in a particular context.*

Value-based healthcare: *Is concerned with maximising value for patients; achieving the best outcomes at the lowest cost. This is achieved by healthcare system moving away from a supply-driven health care system organised around what physicians do and toward a person-centred system organised around what patients need.*

Glossary

Wellbeing: *Is about 'how we are doing' as individuals, communities and as a nation and how sustainable this is for the future. It has been defined as having 10 broad dimensions which have been shown to matter most to people in the UK as identified through a national debate. The dimensions are: the natural environment, personal well-being, our relationships, health, what we do, where we live, personal finance, the economy, education and skills and governance. Personal wellbeing is a particularly important dimension which we define as how satisfied we are with our lives, our sense that what we do in life is worthwhile, our day to day emotional experiences (happiness and anxiety) and our wider mental wellbeing.*