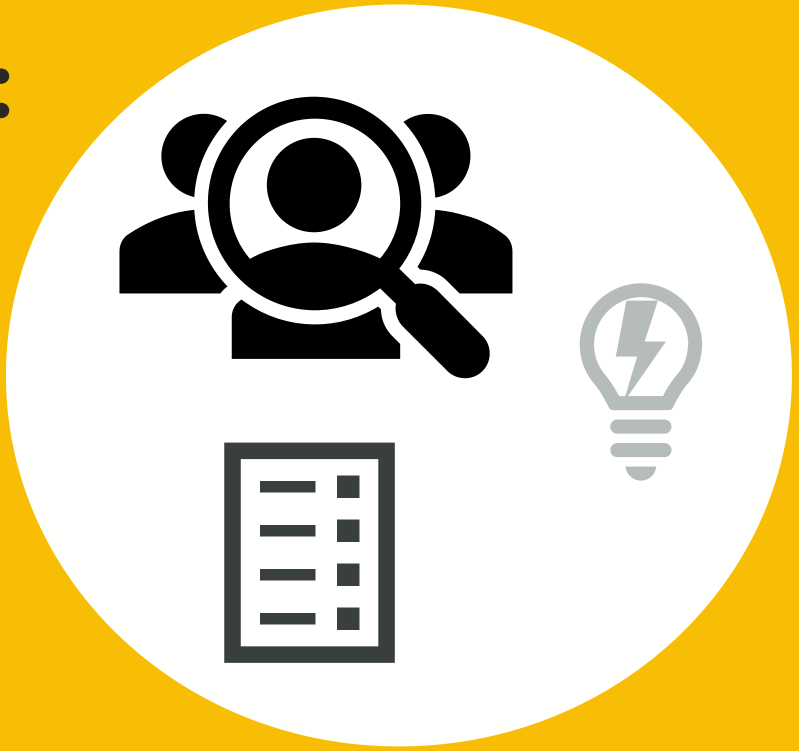
Person-centred intelligence: Person-reported measures



The Strategy Unit and Ipsos MORI

About this guide

- This guide forms part of The Strategy Unit and Ipsos MORI’s series about person-centred intelligence.
- It outlines the concept of ‘person-reported measures’. Having worked through this guide, readers should have an understanding of the main subtypes of person-reported measures, how they can be used and some of the key challenges to implementation.

Contents

Introduction to person-centred measures

Person reported measures are…
…self-reported measures completed by patients, carers or staff via questionnaires and surveys that measure outcomes and experiences.

They provide insight into the impact health care services and interventions have *from the perspective of individuals.*

- **Patient reported measures** are the most commonly used measures. There are many established tools to obtain data concerning outcomes (PROMS), and experience (PREMS).
- **There are emerging measures for carer and staff**, demonstrating the importance of the all-encompassing definition of person-centred care.
- **Most research measuring person-centred care have been conducted in a hospital context,** but an increasing amount of research is exploring person-centred care in primary care and community services.
- **There are thousands of person centred measures available.** Not all measures will cover all aspects of person-centred care, so a combination of measures might be needed to achieve a purpose.

Surveys and questionnaires are not the only method for measuring person-centred care. Other methods include:

- Interviews
- Discussion / focus groups
- Observing interactions

These methods can provide more in-depth information, however analysis is less likely to provide generalisable information for making decisions about wider populations or service changes.

Surveys provide information that may be generalised more easily to wider groups.

Other methods such as in-depth discursive interviews or discussion groups can explore the quantitative findings and the reasons underlying them in more detail, and can be a useful addition to further develop action plans.

Outcome measures

In this context, outcome measures are…
…the subjective perspective of the impact of an intervention on an individual's health status (impairment), functional status (disability) and quality of life (well-being).

They are typically gathered through standardised validated surveys known as patient reported outcome measures (PROMs).

There are two main types of outcome measures:

1. **Generic –** which can be used across different groups or conditions and/or across different settings. The broadest instruments can be used at a population level; or
2. **Condition-specific –** developed for and focusing on outcomes relevant to a particular condition, e.g. people with a particular long-term condition, such as diabetes.

e.g. EQ-5D: Five questions seeking information that best describes the patient's health that day, covering mobility, self care, usual activities, pain/discomfort, anxiety/depression.

e.g. Oxford Hip Score: Twelve questions about how the patient has been over the previous 4 weeks covering pain (4 items), mobility (3 items), and activities (5 items).

Outcome measures can also be categorised by domains they measure, such as:

- **Physical function**
- **Symptoms**
- **Psychological well-being**
- **Social well-being**
- **Cognitive functioning**
- **Quality of life (QoL)**
- **Health related quality of life (HRQoL)**

Experience measures

In this context, experience measures can cover both *objective experiences* and *subjective experiences*…

- *Objective experiences* of care, focus on specific aspects of the processes of care e.g. were you offered a care plan. Objective experience are gathered through standardised validated surveys known as patient reported experience measures (PREMs).
- *Subjective experiences* of care focus on whether a patient's expectations about a health encounter were met e.g. how satisfied are you with the opening hours. Patient satisfaction is commonly captured via the use of satisfaction surveys.

There are two main types of experience measures:

1. **Generic –** which can be used across different groups or conditions and/or across different settings. The broadest instruments can be used at a population level; or

e.g. IntegRATE**:** A brief 4 question generic patient-reported measure of integration in health care delivery.

2. **Condition-specific –** developed for and focusing on outcomes relevant to a particular condition, e.g. people with a particular long-term condition such as diabetes.

e.g. Patient Assessment of Care for Chronic Conditions (PACIC)**:** A well-established tool for measuring patient experience of chronic illness care and is applicable to many settings consisting of 20 items.

Experience measures can also be categorised by domains they measure, such as:

- **Patient engagement**
- **Person-centred communication**
- **Support with self-management**
- **Patient empowerment and activation**
- **Shared decision-making**
- **Coordinated care**
- **Goal setting and tailoring**

Development of carer and staff measures

Carer and staff reported measures differ from tools that use carers or staff as a proxy respondent…
…instead they focus on the individual carer or staff member as a person.

Capturing staff experience is starting to gain more attention at national level…

- For example, recent evaluations of the national new care model vanguard programme have demonstrated a commitment to capturing staff perspective.
- Many vanguards have chosen to add the dimension staff experience alongside patient experience, population outcomes and cost effectiveness, in what is referenced a move from the triple aim of health to the quadruple aim (or triple aim plus one).
- The quadruple aim is increasingly being promoted in the UK and internationally.

"Family involvement appears to remain marginal to the practice and measurement of person-centred care." (National Voices, 2017)

"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. (Lloyd et al., 2018)

- **There are a small number of self-reported measurements available for carers.**
- **The recent NHS Long-Term Plan proposes the creation of an 'integration index',** developed jointly with patients groups and the voluntary sector.
- It will measure the extent to which the local health service and its partners are genuinely providing joined up, personalised and anticipatory care. This will take into account patients', carers' and the public's point of view.

Potential uses of person-reported measures

Uses of person-reported measures can be broadly subdivided into three main groups, which relate to the level at which they are used:

Supporting clinical practice (individual level)

Performance measurement (organisational level)

National regulation and evaluation (system level)

It is important to take into account the level at which the underlying purpose is focussed – as this will determine the type of measurement required:

- Purposes at the *individual level require* ***individual level data***
- Purposes at the *organisation level and system level require* ***aggregated level data*** *– so some form of standardisation in collection is essential*

Potential uses at individual, organisation and system level are listed on the following slide – subdivided according to features in common.

Potential uses of person-reported measures

1. Individual level –
Focused on supporting clinical practice.

1.1 Clinical decision-making
- Decision-making for screening / diagnosis / treatment
- Monitoring disease progression and response to treatment
- Communication - provider to provider
- Risk stratification and care pathway allocation

1.2 Promoting person-centred care
- Communication - patient to healthcare practitioner
- Supporting prioritisation and goal setting
- Self-management support
- Shared-decision making
- Personalised care planning

2. Organisational level –
Focused on performance measurement

2.1 Provider quality improvement
- Continuous professional development/revalidation
- Identification of problems - stimulating audit and research
- Stimulating local service improvement
- Monitoring patient-reported adverse events
- Benchmarking with other providers
- Public reporting - informing provider choice
- Enhancing the calculation of healthcare productivity

2.2 Commissioner
- Performance monitoring
- Risk stratification
- Selective contracting
- Contracting e.g. outcome-based commissioning

3. System level
Focused on regulation and evaluation

3.1 Regulation
- Population health monitoring and prioritisation
- System performance monitoring

3.3 Research
- Evaluation tool – policy initiatives
- Effectiveness of treatment outcomes

Challenges to implementation and potential solutions

Challenges	Potential Solutions
Consensus over measurement – Finding a tool that's satisfies all stakeholders (patients, clinicians, commissioners, providers) can be difficult.	• Early stakeholder engagement is encouraged. • The population the measure is to be used with should be involved in deciding what matters to them. • Selection of measures should be coproduced with all stakeholders.
Cost and resource - Time and cost of collection and analysis e.g. staff time, license fees of tools used, third-party costs.	• Use of IT for web-based entry to minimise data collection resource needed. • Coordinate multi-item collection rather than single transactional items. • Prioritising diseases and treatments suitable for self-reported measures. • Consider tools that are freely available.
Respondent engagement - some population groups are difficult to engage e.g. those in poor health, poor literacy, cognitive or developmental limitations, certain ethnic groups, non-English speaking, not IT literate. For some patients being involved in conversations may be a culture shock. Respondents can also experience questionnaire fatigue if they are asked to complete numerous measures.	• Appropriate interviewing to determine intellectual capacity. • Use of assessments by a proxy carer. • Engagement with community leaders for hard to reach groups. • Use of measure that can be translated into other languages. • Consider using different formats e.g. paper and electronic. • Inform patients about what the measurement process entails and why it is being completed. • Professionals should discuss outcomes with patient – patients should feel results being used for their treatment. • Use short measures where possible. • Monitor how many questionnaires individual patients are receiving. • Consider the use of technology to enable easier completion.
Health professional engagement – there can be wide variation ranging from enthusiast to sceptic. Concerns include issues such as: unclear why measures are being used; staff concern over patient resistance; fear of additional work; fear of negative feedback about their work.	• Ensure staff are well trained to deliver the measure and are confident to discuss scores with patients • Guidelines and care protocols may be useful aids. • Data collection can be integrated into electronic care records so data collection becomes less burdensome. • Use of opinion leaders / champions. • Consider the use of incentives. • Identify key stakeholders early on, and help them understand why measures are being collected. • Staff engagement should focus on the benefits of using the measures.

Challenges to implementation and potential solutions

Challenges	Potential Solutions
Risk of negative impact on patient – Completing the measure can have a detrimental effect on some respondents where the questions are negatively framed e.g. 'I have no family support'. After completion of the measure, respondents can become demotivated when the measures are no longer used. Patients accessing results with no explanation can also have a negative impact.	• Tools that use positively framed questions e.g. Warwick Edinburgh Wellbeing measure may be preferred. • 'Aftercare' support should be provided to those that are vulnerable to the possible detrimental effects of completing a measure. • It is important to be transparent about how the measure will be used. • Restrict access to results until a health professional is ready and able to disseminate them in an accessible way to patients.
Attributing outcomes to the quality of care – Variation within the population group (e.g. levels of family support) can affect outcomes. Furthermore, patients might experience a deterioration in their health condition that is unrelated to the intervention or service they are receiving.	• Use a case-mix strategy where subgroups are used depending on their situation e.g. levels of support available.
Sensitivity of measures – Generic measures are sometimes too broad and not sensitive enough to capture information about individualised initiatives and changes achieved.	• If possible, use both generic and specific measures.
Data storage and handling – Measures collected at an organisational level may mean that information is difficult to access at an individual level.	• Establish data sharing agreements before implementing measures.
Feedback format – 'Statistically heavy' formats can be disengaging for those without experience in their interpretation.	• Data should be presented in simple and easy to understand format
Data collection for multiple purposes - e.g. individual level (delivery person-centred care) and organisational level (moving away from activity-based payments towards outcome-payment payments).	• This remains an ongoing challenge which has not yet been sufficiently addressed.

Unintended consequences

Using person centred measures may lead to unintended consequences such as:

Tunnel vision / effort substitution

- By encouraging attention on one priorities through measurement other priorities may be substituted.

Risk of short-term improvement

- If measures focus on areas where the provider already performs well improvements in quality may only be short-term.

Quality improvement activities lifespan

- Activities are likely to cease once the threshold for maximum remuneration has been reached.

Incentives might introduce manipulation or gaming of the data

- Where incentives are used there is a risk of gaming of data when performance indicators are not credible to clinicians but clinicians are incentivised to collect them. This may be difficult to do when the collection of data relies on patients, but it is important to consider if incentives are introduced.

Compromise the patient-provider consultation

- The use of standardised assessment tools risks the health professional focuses on box-ticking, distracting them from listening to patient

Negatively impact multi-disciplinary working

- Without proper planning the addition of more patient-reported data may contribute to, rather than alleviate, confusion in developing effective and shared protocols.

The risk of these unintended consequences may increase where the use of person-centred measures is incentivised or mandated.

Ready to move on?

Person-reported measures

☑ Person-reported measures are self-reported measures which can cover outcomes and experiences.

☑ They are typically thought of as **generic** (which can be used across different groups or conditions and across different settings) or **specific** (designed to measure particular conditions, or healthcare settings).

☑ Patient reported outcomes are the most widely developed measures, but there are emerging measures for carer and staff.

☑ Measures have a range of potential uses at individual, organisation and system level – the level at which your measures sit will determine the type of measurement required.