The Strategy Unit.

Person-Centred Intelligence (PCI)

Stakeholder perspectives

Ipsos

Ipsos MORI

About this guide

- This guide forms part of the Strategy Unit and Ipsos MORI's series about person-centred intelligence.
- This guide presents stakeholder perspectives on person-centred care and person-centred intelligence, with a particular focus on the factors that impact implementation.
- 18 interviews were conducted with a range of stakeholders working in/with the NHS (full list in appendix A) regarding Person-Centred Intelligence (PCI).
- The aim of the interviews was to explore expert opinions and real-life use of PCI to inform practical guidance and recommendations for making decisions around selection, implementation and use of person-centred measures (the interview topic guide can be found in appendix B).

Contents

Summary of key findings

- Person-centred care is ***care that focuses on the individual and what matters to them, taking into consideration the perspectives of staff and carers.***
- The importance of person-centred intelligence can be recognised on three perspectives:
  - **Individual level** - mainly used to support clinical practice such as the clinician-patient consultation.
  - **Organisational level** - enables performance measurement undertaken by providers or commissioners.
  - **System level** – is mainly used for policy, regulation and research / evaluation activities.
- There are ***three core principles*** to consider when selecting the right measure;

What does the '**PERSON**' want

What is the **PURPOSE** of the data

What are the current national **PRIORITIES**

- When implementing person-centred intelligence it is important to **consider how data is collected, by who, the expertise required to interpret data** and **financing** / **incentivising** measures.
- Challenges to address collecting and using data include; **buy-in and engagement with stakeholders and organisations, burden of measurements on staff and system and utilisation of findings.**
- **Evaluation should be embedded** into the implementation of person-centred intelligence.

Person-centred care is …

**Most commonly occurring words used by stakeholders when asked to describe their understanding of person-centred care*

What is Person-Centred Care?

Person-centred care was broadly described as: ***care that focuses on the individual and what matters to them, taking into consideration the perspectives of staff and carers.***

Stakeholders identified the following as the key features of person-centred care:

- Meeting the **needs and priorities of the person** rather than the needs of the system and it's professionals, by balancing what's realistically possible (by the system) with what is most valued (by the person).
- The **person is at the centre of the planning process** by recognising and developing their knowledge, skills and confidence through shared decision-making to **develop a sense of agency**.
- **Holistic** in addressing all needs, including: physical and mental health and taking into account social value and personal circumstances.
- Manifests an approach that affords people **dignity, compassion and respect.**
- A **responsive system delivering coordinated and personalised care** with an interdisciplinary approach where everything comes together around the person.
- **Includes asking carers and staff what matters to them**

'Person' - there's a strong push to use 'person' instead of 'patient' to foster a more holistic and inclusive approach.

Other terms – Terms such as; *person-centred care, patient centred care, precision care, individualised care and personalisation,* were used interchangeably, as well as there being a variation in stakeholder's understanding of each.

There is a general consensus of the importance of having a shared understanding of person-centred care.

Why measure person-centred care?

Stakeholders were in agreement that:

"What's measured is what counts"

*The term **'person-centred intelligence'** (PCI) is used to describe any data that focuses on the needs of people rather than systems and organisations and involves them in the process of deciding what to measure and how. It is based on the concepts that underpin person-centred care (as described in the main guide).*

Stakeholders largely agreed the term 'person-centred intelligence' was **relevant**, with the caution that there needs to be a shared definition adopted by all.

Stakeholders suggest that measuring person-centred care enables the **identification, monitoring and management of the principles that make up the delivery of person-centred care**.

The importance of such measures is discussed in more detail on the following slide, which considers the importance from three perspectives:

- **Individual level** - mainly used to support clinical practice, such as the clinician-patient consultation.
- **Organisational level** - enables performance measurement undertaken by providers or commissioners.
- **System level** – is mainly used for policy, regulation and research / evaluation activities

Why is person-centred intelligence important?

INDIVIDUAL LEVEL

- It can **change clinician behaviour and patient expectations – "***there is a need for tools, devices, ways to shift that interaction and this requires more deliberate measures."*
- It **provides evidence on what is working – "***If evidence shows that it improves workforce satisfaction, decreases workload, reduce number of contacts with the system etc then those practices can be encouraged."*
- **'You can't model everything' so more relevant measures are required** –"*Person-centred care promotes an individualised approach to goal-setting, which sometimes conflict with rigid policies that encourage models but need to realise you can't 'model' everything" for example "If the purpose is to measure outcome not input / process then you have to focus on outcome measures for the individual."*

ORGANISATIONAL LEVEL

- Measuring facilitates a **broader view across a population perspective and helps highlight priorities** - "*What measures is what counts' if you say you have to (measure) you're essentially saying 'this is important'. For example if a deprived area wanted to focus on dealing with health inequalities it would need measures to assess wither the interventions make a dent in the issue".*
- Measures can **inform decision-making** as "*good evidence can be very powerful – commissioners recognise that quality of care is important and measuring this can inform whether they continue an intervention or decommission."*
- Measurements are required to "***satisfy, assess and meet contractual arrangements** with providers."*

SYSTEM LEVEL

- Person-centred care is ***"a feature of good health care** and a **critical indicator of how integrated a health and care system is.** Integration is a key objective in the long-term plan and measures are needed to get an indication of how well ICSs are performing, particularly as the system doesn't pay attention to the stuff it's not measuring."*
- **NHS systems are complex and adaptive** and require accountability on multiple levels – *"everyone needs to recognise what they are accountable for, so there needs to be measures available to do that."*
- Establishing person-centred care is a priority **shared across NHS functions** – "*priority in the Personalised Care movement and its a requirement in audits, such as CQC who assess experience measures and metrics".*

Selecting measures

This section discusses key considerations recognised by interviewees for selecting the right measures

Principles to consider to select the right measure - *The 3 Ps*

Stakeholders suggested **three core principles** to consider when selecting what measure to use…

PERSON

There was resounding view that the first and most fundamental consideration for person-centred care to ask ***"what does the PERSON want."***

The person should be involved in decision making of their needs as a whole, not just restricted to health care. For example; *"the risk currently is to fall short of people's needs by failing to deliver social care, while exceeding their want in delivering high science, high technology medical care.*

PURPOSE

Identify the **PURPOSE** *'what is the data for - what do you do when get the data back, who will be collecting the data and who will be using it"* For example benchmarking, performance management, commissioning, contracting, service improvement etc.

PRIORITIES

PRIORITIES should be in accordance with the national priority areas such as; *"the Long-Term Plan- that's where the money and energy is going to go, so its important that we're not working in isolation".*

"That substitution of a hip replacement or repair of a bannister happens all the time … a frail woman who lives alone, who can't get down five steps to talk to the postman every day will feel less alone and more connected with the world, and will have their life improved dramatically with a bannister that makes her feel comfortable and safe walking those five steps down and up. She does not need a hip replacement that she's likely to get, if it's decision making from the scientifically trained MSK pathway designers. All you need to do is ask questions to elicit what matters."

Deciding on the type of measure to use

Stakeholders mentioned key factors to consider when deciding on the type of measures to use:

Balancing the ‘ideal’ with the ‘pragmatic’	*“In a perfect world start with a blank sheet what would dimensions a measure of person-centred care would cover, what would need to be collected, how would it be collected. Pragmatically - what data do we already have and what can we do or improve what currently exists.”*
Use existing means	Measures *“need to be practical and feasible instrument to apply in the care process and meet the organisational interests.” Data should be* **data simple** yet sufficiently detailed – *“don’t overburden / overload the system with more data collection”.*
Adopt a multi-method approach	*“There’s a lot of hard metrics that get the focus and that are collected (e.g. hospital admissions) but needs to be supplemented with feedback and experience.”*
National measures	There were mixed views on using national measures, whilst acknowledging they were *“important to compare systems… individual has to be given the opportunity to say what is bothering them”.* There were fears that they are “*not actually used to improve services*” and that “there is no national consistency.”
Generic vs specific	Generic measures were considered *“good for comparisons”* but specific measures are *“closest to what you care about and have more privilege to change patient and clinician interaction.“*
Aggregating measures-	*“Each level (individual, organisational, system) needs to know what is being measured at the other levels”* and how that fits with the aims of their measures.
Patient’s role	*“Remember you are not asking the patient to become an expert, you’re asking questions that allows you to gain the benefit of their expertise.”*
Resource required	For example; *“qualitative methods collecting patient experience are more resource intensive”* and there is a *“competitive market of survey providers which runs the risk of it being done as cheaply as possible to fulfil the requirement.”*

Examples of measures

This section presents descriptions and views on examples of measures highlighted by interviewees

Existing measures - Patient

PROMs - Patient Reported Outcome Measures

PROMs was part of a national programme which consisted of validated measures that look at what outcomes are important to patients.

Examples cited

- ***Warwick and Edinburgh Mental Wellbeing Scale-* “***It's ok within a therapeutic intervention, but not so much on the phone. It is good because it measures fundamental importance of subjective importance of wellbeing.”*
- ***R-Outcomes* – “***short, generic measures that are applicable to a wide group of patients (long-term conditions, mental health etc) … they have a good evidence base and have been peer-reviewed and available in paper and electronically and the analysis is done by R-Outcomes. Some clinicians felt that the questions can be too personal for some and as it is commercial requires funding.”*
- ***CollaboRATE and IntegRATE*** – *"can be used for complex needs and for a broad range of conditions, however can often be duplicated across different services or organisations – being burdensome for patients."*

PREMs - Patient Reported Experience Measures

Experience measures look at the individuals experience from their own perspective.

Examples cited

- ***The SUSTAIN study* “***looks at tools that measure person-centred experiences – there is a survey bank of all the different measures."*
- ***PCHC Perceived Control of HealthCare (Dutch)*** – *"gives a sense of autonomy in care, whether you're a part of your care plan, but is top heavy and focussed on service and very broad – do not consider the individual wants."*
- ***InterRAI*** – (European used by Belgium/Finland) looks social, mental and physical needs. *"These focus on individual abilities with checklists e.g. movement measures. They are potentially useful and can be used to make comparisons and knowledge mobilisation, but the drawbacks are that they are incredibly long and complicated – requiring commitment, the reason they work in these countries is because they are mandated by policy so they can be tokenistic."*

Existing measures - Patient

Patient stories / narratives

This type of data enables staff to engage with lived experiences that are considered vital to understanding individual needs.

Satisfaction measures

Satisfaction measures are considered to be a measure of the gap between expectation and experience.

PAM - Patient Activation Measure (more details in our guide to patient activation)

PAM is a tool measuring patient activation in terms on knowledge, skills and confidence of a person.

Success of PAM was considered to be dependent on the use, in terms of timing and the intervention it is linked to.

Examples cited

- ***Health Experiences Research Group Oxford*** – *"are using videos of patient stories alongside quant data to get people to understand the human perspectives."*
- **Public and Patient Involvement panels** are a *"good source for findings people with 'stories' to share."*

Example cited

- ***National GP patient survey -****"measures satisfaction, but they are not nuanced enough to reflect true experience."*

Examples cited

- ***Co-creating health programme*** *(Health Foundation)* learned *"by asking patients to attend a course about their condition, PAM levels actually went down because they realise how little they know about their condition."*
- ***Frome*** found *"by putting in place social prescribing people's activation went up and other indicators measured, demonstrated that unscheduled admissions went down by 18% whilst for the rest of Somerset went up by 29%. It was just so straightforward."*
- ***Dudley*** used PAM for long–term conditions management patients to assess patient activation with a health coaching intervention, and found *"the measure itself became much of the focus rather than using it as a tool to influence clinician-patient interactions."*

Further case studies are in our 'perspectives on patient activation' supplement

Existing measures – Staff and Carers

There were scarce experiences of staff measures and none of the interviewees could provide examples of carers measures. However participants expressed the importance of both.

Some of the **opportunities** described with staff measures, included:

- They are *"much easier to collect and surveys are **easier to administer**"*
- **Good indicators for measuring integration** – *"they address communication, team working and shared knowledge as well as leadership and other relational components"*

Some of the **challenges** mentioned, were:

- Staff surveys are often **dismissed** by saying *'just ask the patient'*
- Staff surveys *"**lack the nuance** required to assess true outcomes, experience and satisfaction of patients"*

Some examples of staff measures cited:

Age UK – are looking at person-centred organisations, which looks at staff and the organisations care for older people and their staff providing the services. They are investigating how staff are recruited, inducted, developed, reviewed and team meetings, including management decisions, away days etc *"the thinking is that person-centred care happens at person-centred organisations – it is more than what happens in 1-to-1 interactions. It's using asset-based logic to assess what do conversations look and feel like for people including staff."*

Co-Creating Health in the Health Foundation - used staff reported measures and found *"if you do start to learn some of these tools and techniques (Health Coaching and Shared Decision Making), it actually makes life better for both staff and patients."*

How to measure

This section discusses factors involved in the implementation of person-centred intelligence, specifically in 'operationalisin'g collection and use of data and evaluation of measures

What are the data and infrastructure requirements?

In developing an implementation plan for person-centred intelligence, the following resource implications were described:

Data collection	**How will data be collected and by who** - what will be the mode of data collection (e.g. phone, post, face to face) and where can patients be accessed in an appropriate and sensitive manner. (e.g. avoid places and times when patients might be anxious).
Support and Expertise	What **support and expertise are needed for data interpretation –**It is vital that this function is *“embedded in the team as they are;1) able to do a lot of the work 2) able to access/motivate people to engage with measures ‘on the ground .”* It might be that this function needs to resourced from elsewhere.
Incentivisation	**Incentivisation of measuring -** Research at Dartmouth University suggests that putting in measures with financial incentives should concentrate on service improvement and impact, "*rather than the activity of the measure being the means for payment …so as not to make the focus the activity, but the change in clinician-patient interaction.”*
Finances	**Additional finances** may be needed if measures have a license fee for usage.

What are the challenges in operationalising data collection and use?

Challenge described	Solution(s) suggested
Organisational buy-in - organisations may not give measurement importance	• **Develop a shared understanding** across the whole organisation around the purpose of measurements. • **Cultural change** is required to make measures a priority; this should include the focus being on service improvement as opposed to performance management and may require external support. Contractual requirements can support prioritisation. • **Shared leadership and shared decision making** - between management and frontline. Leadership should work with management to support frontline staff to "*organise for innovation to create a new kind of team that's designed for learning.*"
Burden of measurement risks overloading the system - efforts focussed on the collection of data can deter from the use of the data for improvement	• **Keep the tools simple and easy to use** • **Allocate appropriate resource and identify efficiencies** - consider what existing measures become redundant or combining activities to ensure smarter working, rather than harder working. • **Training** needs should be identified and appropriate support should be in place for staff to develop "*skills for knowledge translation and mobilisation.*"
Buy-in of stakeholders - *"buy-in is a marker of its success."*	• **Identify key stakeholders** and **champions**, *"to motivate others, who are solution-focussed and working in the same environment as staff."* • **Co-design and co-production** is key. Asking people what they want is the starting point and should be facilitated in the clinician-patient interaction and good **communication** is crucial for this. • **Engage staff** to understand the value of the potential impact on patients – "*there is a deficiency in alignment of scientific/technical training of managers and patient reality.*" • **Patients and carers can be hard to reach -** There needs to be practical considerations about accessibility and understanding.
Staff utilisation of measures – pressures of doing what is right for the system transcending what is right for the person.	• **Close the feedback loop** - the focus to deliver person-centred care is the clinician – patient relationship – and thus i*nformation needs to be given back to the person to* enable change and improvements. • **Ownership** enables individuals to utilise data for improvement in a way that impacts them.

Evaluation should be embedded into the implementation of person-centred intelligence

There was sparse experience of evaluation of person-centred intelligence. Even amongst evaluation experts, it was evident that there was a gap in evaluation in this area. Although measures themselves were used in evaluations of systems, services and interventions, there were no examples of where the use, effectiveness and impact of the measures themselves had been evaluated.

Stakeholders suggested the following elements should be taken into consideration when planning evaluation:

- Evaluation needs to be considered **from the start** and should carry on over time.
- Evaluation should **feed into wider activities**, by identifying; *"what are the gaps, the best measures for these and sometimes that means the 'best of a bad lot' most are pretty awful in terms of person-centred-ness. Commissioners are interested in the value of care of individuals, so the information collected must be usable. This requires continuous monitoring and evaluation."*
- **Evaluation can detract from efforts to improve and innovate** - *"The Achilles' heel of every one of our (large scale) programmes was evaluation and measurement. And the one thing I learned was that you can strangle innovation with measurement."*
- Ensure evaluations are not examining measures **in silo.**
- Embed **evaluation experts** into the intervention, organisation and system of interest.

Consequences, conflict and caution

This section discusses the potential unintended consequences related to person-centred intelligence

Person

- Measures produce data **but patients want changes in the system**; *"Data is powerful, complex, sophisticated, rich and powerful. There's a power in bringing people together to share their experiences as opposed to just the data alone…this triggers change and gives a sense of urgency not just patient survey 'data'"*
- The more needs are identified using these measures *"they may* ***raise expectations of patients/carers, which could exceed what the services are able to offer*** *– services will try to do their best, but the risk will be that the measuring becomes seen as tokenistic – ending up collecting data you can't act on."* However *"some patients prefer to just be treated by the clinician – patient interaction would be different to that of when someone wants to be asked."*

Purpose

- There can be a **conflict of purpose** between improvement and accountability, *"when the primary purpose is explicitly accountability its very difficult to use them for improvement". "In the NHS, data seems to be owned by boards and commissioning bodies, rather than 'front liners', and the problem is it is currently used for accountability and judgment, not improvement. Frontline services are really wary of data and of engaging with it.."*
- **Increased pressure in some parts of the system "***because the care is based on the outcomes rather than the services we want to provide"*. **Measures should not be utilised in isolation** but *"support other elements of care e.g. care plans."*

Priorities

- **Caution needs to be taken with financing and incentivising:**
  - **Personal health budgets can make it…"***hard to unpick from block contracts and thus you could be double paying. E.g. You could be paying community contracts for physio, but then that person has personal health budget, but you have already paid for them."*
  - Emphasis on **Quality and Outcomes Frameworks (QOF)** should not just look at whether an activity has been carried out, but the impact that has had on the person

Appendices

Appendix A: Interview participants

	Role	Organisation
Jo Ellins	Senior Fellow Deputy Director of the BRACE Rapid Evaluation Centre	Health Services Management Centre, University of Birmingham
Jenny Billings	Professor of Applied Health Research Director, Integrated Care Research Unit	Centre for Health Service Studies, University of Kent
Professor Nick Black	Professor of Health Service Research	NHS England PROMs Advisory Group
Philippa Darnton	Associate Director, Insight Locality Account Director – Salisbury/South Wiltshire	Wessex AHSN
Chris Branson	Insight & Feedback Lead	NHS England (Patient insight and feedback unit)
Don Redding	Director of Policy and Partnerships	National Voices
Alf Collins	Clinical Director of Personalised Care Group	NHS England’s Personalised Care Group
Dan Wellings	Senior Fellow	The King's Fund
Usha Boolaky	Assistant Director for Research	The Health Foundation
Jenni Burt	Senior Research Associate	Cambridge Centre for Health Services Research
Muir Gray	Consultant in Public Health Professor Primary Care Health Sciences	Oxford University Hospital NHS Trust University of Oxford
Margaret Mulley	Senior Manager of Global Health Care Delivery	Dartmouth Institute for Health Policy and Clinical Practice
Al Mulley	Managing Director of Global Health Care Delivery Science	Dartmouth Institute for Health Policy and Clinical Practice
Elisabeth Krymalowski	Senior Project Manager: Innovation Programme	Royal College of General Practitioners
Tim Cooper	Director	West Midlands Quality Review Service
Helen Hibbs	Black Country STP SRO	Black Country STP
Andy Williams	Accountable Officer	Sandwell and West Birmingham CCG
Fraser Battye	Principal Consultant	The Strategy Unit
Jill Firth	Consultant Rheumatology Nurse, Director for Service Improvement	Pennine MSK partnership ltd

Appendix B: Topic guide

The purpose of the interviews was to identify the **practicalities involved in the implementation of Person-Centred Intelligence (PCI).**

Interviews were semi-structured and the key questions addressed included:

1. What is your understanding of person-centred care?
2. Why should person-centred care be measured?
3. In your experience / knowledge how are the following used; Patient-reported measures / Staff-reported measures / Carer-reported measures?
4. What are the priority groups/conditions/pathways to focus on for collecting such measures?
5. What are the enablers and challenges of implementing measures of person-centred care?
6. What unintended consequences come from implementing the measures discussed?
7. Describe examples of where you have seen implementation of measures work well or not work well?
8. How do people engage with the implementation of measures?
9. In your opinion, what support do people need to implement these measures?
10. What (if any) other experiences of person-centred measures can you share that may help inform this guide?