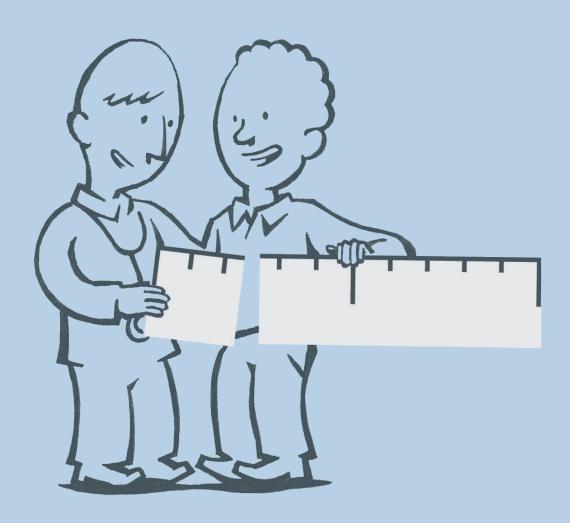


Helping measure person-centred care

A review of evidence about commonly used approaches and tools used to help measure person-centred care



Evidence review

This research was commissioned and funded by the Health Foundation to help identify where and how improvements in healthcare quality can be made. This research was managed by:

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A spreadsheet listing 160 of the most commonly researched measurement tools accompanies this review. Download the spreadsheet from: www.health.org.uk/helpingmeasurepcc

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Key points

This rapid review signposts to research about commonly used approaches and tools to help measure person-centred care. It aims to showcase the many tools available for those working in policy and practice.

What is person-centred care?

A person-centred health system is one that supports people to make informed decisions about, and to successfully manage, their own health and care, able to make informed decisions and choose when to invite others to act on their behalf. This requires healthcare services to work in partnership to deliver care responsive to people's individual abilities, preferences, lifestyles and goals.

Many strategies have been tested to help people be more central to their care. Robust measurement is needed to understand the extent to which care is person-centred and to help differentiate worthwhile initiatives. This rapid review summarises themes from more than 23,000 studies about measuring person-centred care or its components. Specific examples from 921 studies are included. To source the material, two reviewers independently searched five bibliographic databases and screened more than 200,000 studies.

What is measured?

There is no universally agreed definition of person-centred care in the empirical literature. Approaches to measuring person-centred care attempt to measure either the holistic concept or specific subcomponents such as communication or shared decision making (see Table 1).

Studies of person-centred care tend to focus on one of four main issues:

- examining how patients or professionals define the components of person-centred care (definitions)
- examining the type of care that patients want or professionals' attitudes and values (preferences)
- examining the extent to which care feels personcentred (experiences)
- examining what happens as a result of personcentred care (outcomes).

How is it measured?

The three most commonly researched ways to measure person-centred care are:

- surveys and interviews with people using health services
- surveys of clinicians
- observation of clinical encounters.

A wide variety of unnamed surveys have been developed to measure specific initiatives. There are also an increasing number of named and validated tools for measuring person-centred care holistically as well as its specific components. The most commonly reported tools for measuring person-centred care are the Individualised Care Scale, the Measure of Processes of Care and the Person-centred Care Assessment Tool.

To date, the largest proportion of studies about personcentred 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. Nursing homes have also taken part in research.

Published research tends to have been undertaken by academic researchers, often working in partnership with health service teams as part of improvement initiatives or one-off research projects. Less has been published about how clinical teams or health organisations routinely measure person-centred care as part of clinical practice.

Implications for the future

The key messages from this review are as follows.

- A large number of tools are available to measure person-centred care, but there is no agreement about which tools are most worthwhile.
- There is no 'silver bullet' or best measure that covers all aspects of person-centred care.

- It is a priority to understand what 'person-centred' means. Until we know what we want to achieve, it is difficult to know the most appropriate way to measure it.
- Combining a range of methods and tools is likely to provide the most robust measure of person-centred care. Patient surveys could be used routinely in practice, with results as part of quality scorecards alongside indicators of safety and cost. Surveys alone do not provide the full picture about person-centred
- care so these could be coupled with interviews with patients and clinicians or observation of clinical encounters, perhaps annually.
- Local testing is needed to examine the usefulness
 of tools in the UK. Although many tools have been
 widely written about, this does not mean they are of
 good quality or useful for the UK context but there
 is a good foundation to begin from.

Table 1: Examples of approaches used to measure person-centred care and its components

Concept	Commonly researched measurement approaches	Most commonly researched structured tools
1. Holistic concept of p	erson-centred care	
Person-centred care / patient-centred care / individualised care / family-centred care	 Surveys with professionals Surveys with patients Interviews with patients Interviews with professionals Focus groups Observation Interviews with family Review of patient notes 	 Individualised Care Scale (ICS) Measure of Processes of Care (MOPC) Person-centred Care Assessment Tool (P-CAT) Person-centred Climate Questionnaire (PCCQ)
2. Examples of subcom	ponents of person-centred care	
Patient satisfaction / experience of care	 Surveys with patients Interviews with patients Focus groups Surveys with family Interviews with family 	 Consumer Assessment of Healthcare Providers and Systems Hospital Survey (CAHPS) Patient Assessment of Chronic Illness Care (PACIC)
Patient engagement / activation	 Surveys with patients Surveys with professionals	• Patient Activation Measure (PAM)
Empathy / compassion / dignity	Surveys with patientsSurveys with professionalsSimulations / observationInterviews	 Jefferson Scale of Physician Empathy (JSPE) Consultation and Relational Empathy Scale (CARE)
3. Examples of behavio	ours supporting person-centred care	
Person-centred communication	ObservationSurveys with patientsSurveys with professionals	Wide range of tools, including the Doctors' Interpersonal Communication survey; no single tool most commonly researched
Extent to which professionals support self-management	Surveys with patientsSurveys with professionals	Wide range of tools, including the Resources and Support for Chronic Illness Self-management Scale; no single tool most commonly researched
Shared decision making	Surveys with patientsSurveys with professionalsObservation	Decisional Conflict Scale (DCS)OPTION scale

Note: The subcomponents of person-centred care are examples only. Many more components have been identified in the empirical literature.

A spreadsheet listing 160 of the most commonly researched measurement tools is available for download at www.health.org.uk/helpingmeasurepcc. This 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.

Part 1: Overarching themes

Part 1 summarises broad themes in the literature and is designed for those who want to gain a quick overview of important ideas and frequently used tools.

Chapter 1:

Setting the scene

Person-centred, individualised, personalised, patient-centred, family-centred, patient-centric and many other terms have been used to signal a change in how health services engage with people. This review summarises research about measuring the extent to which care is person-centred.

Scope and objectives of the review

This review aims to help those interested in measuring person-centred care by signposting to published research about commonly used approaches and tools.

The review is organised into two parts. Part 1 summarises broad themes in the literature and is designed for those who want to gain a quick overview of important ideas and frequently used tools. Part 2 provides examples of empirical studies about these approaches and tools and is designed for those who want to delve into more depth about different methods.

A spreadsheet listing 160 of the most commonly researched measurement tools is available for download at www.health.org.uk/helpingmeasurepcc. This 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.

Three key questions guided the review:

- How is person-centred care being measured in healthcare (for example, is it measured through observation, routine datasets, validated survey tools and so on)?
- What types of measures are used (for instance, process measures or outcome measures)?
- Why and by whom is measurement taking place (for example, is it in the context of academic research, in a clinical setting for assessment, for quality improvement purposes and so on, and what types of organisations are doing it)?

In addition to briefly summarising trends in how, what and why person-centred care is measured, the review also examined which measures of person-centred care are often being used alongside one another; which other aspects of healthcare are being measured alongside measures of person-centred care; any limitations of the current measures for person-centred care; and any lessons for developing and implementing future measures of person-centred care.

The term 'person-centred' is used throughout the review for consistency, even though individual studies may have used other terms.

Studies included in this review

The review summarises themes from more than 23,000 studies about measuring person-centred care or its components. Specific examples from 921 studies are included. To source the material, two reviewers independently searched five bibliographic databases and screened more than 200,000 studies. The search process, inclusion criteria and things to bear in mind when reading the review are included in Appendix 1.

In total, 503 studies focused on person-centred care as a broad holistic concept (55%) and 418 examined ways to measure specific components of person-centred care, such as shared decision making or communication (45%).

Of the studies included as examples, 12% were from the UK, 26% were from other parts of Europe, 47% were from North America and 14% were from elsewhere, predominantly Australia and Asia (see Table 2 overleaf).

Most studies were non-experimental research designs, such as cross-sectional or before-and-after surveys (59%) and interviews/focus groups (15%). A small number used observation (6%), multi-method case studies (5%) or other approaches (8%) (see Table 3 overleaf). In addition, 72 systematic reviews on related topics were included (8%).^{1–72}

In order to make the review as readable and relevant as possible, when summarising commonly used tools the reviewers selected the top six most frequently recurring subcomponents of person-centred care to focus on, in addition to holistic measures. The six components were: experience of care; dignity and compassion; patient activation and engagement; personcentred communication; shared decision making; and supporting self-management. These components are prevalent in the policy literature, as well as in the empirical literature. It is important to note though that this selection process means that not all research about how subcomponents of person-centred care are measured is summarised.

What is person-centred care?

Person-centred care is a philosophy that sees patients as equal partners in planning, developing and assessing care to make sure it is most appropriate for their needs. This involves patients and their families being at the heart of all decisions. Services are reorientated to be user-focused, to promote control, independence and autonomy for the patient and the carers and family, to provide choice and be based on a collaborative team philosophy. It takes service users' needs and views into account and builds relationships with family members.⁷³

Key components of person-centred care include compassion, dignity and respect. These may be demonstrated via shared decision making, supporting self-management and proactive communication. Person-centred care can occur on an individual basis, whereby patients engage clinicians in decisions about their health and care, or a collective group basis whereby the public are involved in decisions about the design and delivery of services.

Table 2: Characteristics of included studies

	Person- centred care	Components of person- centred care	Total no.
UK	55	60	115
Europe	157	80	237
North America	211	223	434
Other	80	55	135
Total no.	503	418	921

Person-centred care is not about simply giving patients whatever they want, nor about merely providing information. It is about considering patients' preferences, values, family situations, social circumstances and lifestyles; seeing people as individuals and then working together to develop appropriate solutions. 74-76 In other words, person-centred care is about co-production rather than consumerism.

Why is this important?

Policy context

Over the last decade there has been an increasing focus on supporting people to be more involved in their care and in tailoring services around the needs of individuals.^{77,78}

UK health services are facing significant challenges, with a population increasing in size and age, people living longer with multiple conditions and severe financial constraints in the health system. ^{79,80} It is recognised that person-centred care can help to improve outcomes and reduce the burden on health services, ^{81–83} so policy papers and legislation emphasise strengthening the voice of patients ^{84–87} and moving away from a paternalistic model where clinicians 'do things to' people in favour of greater interaction. ^{88–90}

Engaging people in their health and care is now recognised as a key component of developing healthcare of the highest quality. 91–94 The US Institute of Medicine's definition of quality in healthcare, which is widely used throughout the world, includes person-centred care as one of the six pillars for high quality care. 95 Care that is respectful, compassionate and responsive to individuals is prioritised as a key indicator of quality and an essential component to strive for when improving healthcare systems.

Table 3: Study designs of included research

	Person- centred care	Components of person- centred care	Total no.
Reviews	40	32	72
Tools/ surveys	271	268	539
Interviews/ focus groups	97	45	142
Observing	11	42	53
Case study	37	7	44
Other	47	24	71
Total no.	503	418	921

The Institute of Medicine prioritises six dimensions of patient-centredness as crucial to providing quality healthcare. These are: 1) being respectful to patients' values, preferences, and expressed needs; 2) being coordinated and integrated; 3) providing information, communication and education; 4) ensuring physical comfort; 5) providing emotional support and relieving fear and anxiety; and 6) involving family and friends.⁹⁶

Traditionally health services were structured so as to provide care to the majority. People were expected to fit in with routines and practices that service providers felt were most appropriate. Thus decisions about the type and quantity of services offered and how they were provided may have been made based on operational, feasibility, resource and other provider-centred issues. In contrast, in order to be person-centred, services must be more flexible to meet people's needs in a manner that is best for them. This involves working in partnership with patients and their families to identify the best way to provide their care.

Person-centred approaches to care are not particularly novel. Such concepts have been discussed in fields such as social care, mental health services, learning disabilities and services for people with dementia for about a quarter of a century. 98–102 What is more novel is that this philosophy is now central to UK health policy and is built into National Service Frameworks, monitoring requirements and legislation in all four countries of the UK.

For instance, the NHS constitution in England has person-centred care as one of its seven core principles:

'The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services.' 103

Much progress has been made. In the UK, the 'personalisation agenda' emphasises autonomy, dignity and privacy as demonstrated by the focus on single sex hospital wards, promoting more empathy in end-of-life care and supporting personal budgets for health and social care. These trends are evident in other parts of the world too.¹⁰⁴ Other initiatives include self-management education programmes, patient decision aids and ways to measure patient experience in real time, among many others. ^{105–107}

Much remains to be done to promote a truly personcentred health system – and to measure the extent to which this is happening. In order to understand which strategies are most effective and the extent to which care is person-centred, robust measurement approaches are needed.

Potential to improve healthcare quality

Another reason why it is important to be able to measure person-centred care is its potential to improve healthcare systems' processes and outcomes. The possible benefits of person-centred care have been espoused in policy and research throughout the Western world. For example, a systematic review examined the efficacy of person-centred care in 11 randomised controlled trials or quasi-experimental studies. Person-centred care interventions were found to lead to improvements in 8 out of 11 studies (73%). 110

Another systematic review of 30 randomised trials found that most person-centred care interventions for people with long-term conditions included attempts to educate patients or prompt them about how to manage a health consultation. Other common interventions involved training professionals to deliver empowering care. There were some promising findings in terms of patient satisfaction and perceived quality of care.¹¹¹

Another review of studies investigating the relationship between measures of patient-centred consulting and outcomes in primary care found links between personcentred doctor behaviour and selected patient health outcomes.¹¹²

A systematic review of 43 randomised trials assessed the effects of interventions targeting healthcare professionals to promote person-centred care in clinical consultations. Training interventions generally had positive effects on consultation processes such as clarifying patients' concerns and beliefs; communicating about treatment options; levels of empathy; and patients' perception of providers' attentiveness to them and their concerns.¹¹³

Another systematic review included seven studies of job satisfaction for professionals delivering person-centred care in nursing homes. Person-centred care had some positive effects on general job satisfaction, job demands, emotional exhaustion and personal accomplishment among professionals.114

These reviews suggest the potential for positive outcomes from person-centred care. However a recurring theme is an emphasis on the relatively low quality of the evidence base, and the equivocal nature of evidence relating to the benefits of person-centred care. 115 It is difficult to make generalisable statements from a field that is so diverse and means different things to different people. This reinforces the importance of robust and repeated measures of person-centred care, so that health services can better understand the benefits of this approach and the extent to which it is being implemented.

Unpacking the term 'person-centred care'

There was no universally accepted definition of personcentred care in the empirical literature.

'Person-centredness is recognised as a multidimensional concept. The complexity of the concept contributes to the challenge of articulating its shared meaning and describing how it can be applied in practice.'116

Although this review did not aim to provide a definitive description of person-centred care, trends in how the term is used in the empirical literature are reported here for completeness.

Where definitions or principles were provided in empirical studies, these tended to have been developed by academics, health professionals or policy makers. An important finding is that patients have generally not been involved in defining what person-centred healthcare means.

Terminology

There are some variations in the terminology used in various parts of the world or in different disciplines. These differences are important because they may impact on what is included within specific measures of person-centred care.

Many studies using the term 'person-centred care' focused on care for older people, those with dementia, those using mental health services or those nearing the end of life. 117-135 The holistic term 136 person-centred care may be slightly more common in literature from the UK and other parts of Europe^{137,138} compared to North America. 139-141

The term 'patient-centred care' was more commonly used than person-centred care, and tended to cover a much wider range of disease areas (rather than predominantly older people and mental healthcare). 142,143 This term has been commonly used in North America, as well as in the UK and Europe. 144-147 However the definitions vary widely.

For instance, in the US the term 'patient-centred' is often associated with the 'patient-centred medical home' model. This is similar to the UK approach in that primary care is responsible for prevention and continuity of care for a defined population of patients, while acting as a gatekeeper to secondary care. 148-168

The term 'family-centred' was most commonly used with regard to children's services, 169-193 and has also been used in older people's services. 194-196

'Individualised' or 'humanised' care was often used in nursing, but has also begun to be used in other fields, particularly in the US. 197-204

The terms 'patient centric' and 'user centred' tended to be found in studies relating to technology development.205

The notion of 'client-centred practice' or 'whole person care' was sometimes used in social care, mental health and allied professions. 206,207

Many of these terms were used interchangeably or to represent very similar principles. However, the terms were often used with the assumption that readers know what they mean, rather than providing a definition.

Components of person-centred care

Regardless of the exact terminology used, some research saw 'person-centred care' as a broad concept with many different components. Terms such as 'person-centred', 'patient-centred', 'family-centred', 'individualised' and 'personalised' were used. The concept may include many different subcomponents, but often these were not defined precisely.²⁰⁸

The second type of relevant research focuses on specific subcomponents or activities within person-centred care. This included shared decision making, supporting self-management, patient activation and person-centred communication, among many others.

The subcomponents of person-centred care included in broad definitions or studied separately could be broken down into two broad categories for analytic purposes: specific activities or behaviours (such as supporting self-management) and broader concepts such as dignity and empathy, which may be displayed through specific behaviours but are also more intangible. 209-212

For example, a review identified 60 studies about the core elements of person-centred care in the health policy, medical and nursing literature. There were few common definitions across the literature, but three core themes emerged: patient participation and involvement; the relationship between the patient and the healthcare professional; and the context where care is delivered. Different professional groups tended to emphasise varying elements within these themes, which may influence how the concept is measured.²¹³

Another systematic review of 32 articles explored the dimensions of person-centred primary care for people with long-term conditions. Six main components emerged: starting from the patient's situation; legitimising the illness experience; acknowledging the patient's expertise; offering realistic hope; developing an ongoing partnership; and providing advocacy for the patient to help negotiate the healthcare system. This is a more task-focused conceptualisation and reinforces that the definition of person-centred care varies widely.²¹⁴ This is important because the way person-centred care is defined may influence how it is measured.

There were many other similar studies and reviews seeking to define the concept of person-centred care.^{215–232}

The principles of person-centred care that recurred in the empirical literature included: 233-246

- getting to know the patient as a person and recognising their individuality and specificity
- taking a holistic approach to assessing needs and providing care (which may include families and recognising social and environmental factors as part of a bio-psychosocial perspective)
- seeing the patient as an expert about their own health and care

- recognising autonomy and thus sharing power and responsibility, including enablement and activation in decisions about care
- ensuring that services are accessible, flexible to individual needs and easy to navigate
- coordination of services into an integrated pathway that views the whole experience of care from the patient's point of view and strives for continuity
- ensuring that the physical, cultural and psychosocial environment of health services is conducive to person-centred care
- having supportive staff who are well trained in communication and engagement and strive to put patients at the centre of their care.

Partnership and mutual respect were key to most conceptualisations of person-centred care. 247-254

'The overriding message is that personcentred care is about a collaborative and respectful partnership between the service provider and user. The service provider respects the contribution the service user can make to their own health, such as their values, goals, past experience, and knowledge of their own health needs, and the service user respects the contribution the service provider can make, including their professional expertise and knowledge, information about the options available to the service user, and their values and experience.'255

'Patient- and family-centred care is premised on the belief that patients, families, and healthcare providers who are empowered and engaged throughout the healthcare system are integral components, with each vital to the delivery of quality and safe care.'256

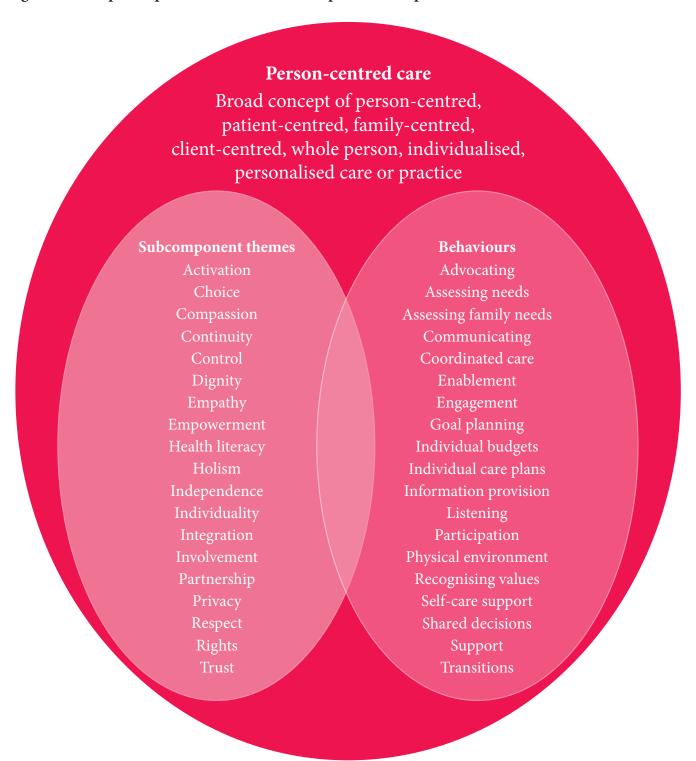
Despite these commonalities, there remained differences in opinion about whether person-centred care encompassed everything that a health system does to improve the patient's experience of care (such as providing safe and effective treatment), or whether

it focused primarily on practices that are designed to directly involve the patient and their family in their own healthcare.²⁵⁷

There were also some gaps in the definitions used, with words such as 'empowerment' and 'enablement' being used frequently in policy and descriptive articles, but not so commonly in the empirical literature seeking to measure person-centred care.

To conclude this chapter, Figure 1 provides a visual representation of how the overarching definitions and specific concepts and subcomponents of personcentred care may fit together. This breakdown emerged based on key themes extracted from the empirical literature, illustrating the holistic concept made up of subcategories including intangible components and specific behaviours.

Figure 1: Examples of person-centred care concepts in the empirical literature



Chapter 2:

Measuring person-centred care

This chapter summarises who measures person-centred care; why, where, when and what is measured; and how.

Who measures person-centred care?

There are thousands of studies measuring personcentred care so it is not surprising that the rationale, timing and researcher type vary considerably within studies. However, it is possible to draw out some broad trends. This chapter summarises key themes emerging from the evidence in more than 23,000 studies.

In practice, many groups may be interested in measuring person-centred care, including patient groups, clinicians, managers, service planners, commissioners, quality assessors, regulators, policy makers and researchers. However, not all of these groups publish their findings. The published empirical literature was most commonly undertaken by academic teams from universities and other learning institutions. This was not solely theoretical in nature, and was often conducted in partnership with health services teams, perhaps in the context of learning how to improve services. However, much less has been published about how person-centred care is measured by those working day-to-day in clinical practice.

Why is person-centred care measured?

The reason why person-centred care is being measured is important as this may influence the type of measurement approaches and tools used.

There were many different reasons that person-centred care is measured, but the three most common were:

- to assess the quality of service provision
- to measure the benefits of a specific improvement initiative
- to gauge whether people's needs and preferences are being addressed.

Little research about measuring person-centred care focused on assessing the impact of interventions at a population level in order to allocate resources or gaining insight into the relationships between processes. Most studies focused on assessing the impact of interventions at an individual level in order to tailor care more appropriately.

Where is person-centred care measured?

About two thirds of published research about measuring person-centred care to date has taken place in a hospital context, although more recently there has been a trend towards exploration of this concept in primary and community care. Nursing homes and other specialist care centres have also received some attention.

Part 2 describes examples of individual studies undertaken in different contexts.

What is measured?

The review found that studies sought to measure four main features of person-centred care. These were:

- definitions: examining how patients or professionals defined the components of person-centred care^{258–263}
- preferences: examining the type of care the patients wanted or the attitudes and values of health professionals^{264–278}
- experiences: examining the extent to which care was person-centred (such as examining patient views about care they have received)²⁷⁹⁻²⁹³
- outcomes: examining the impact of person-centred care (for example, implementing an initiative to improve person-centred communication and assessing the effects of this on patient experience).^{294–318}

Studies may measure either the broad holistic concept of person-centred care or specific subcomponents. Examples are described in the 'commonly used measures' section on the following pages.

Much of the published empirical literature focused on processes or experiences, such as the extent to which self-management or shared decision making was supported, the level of communication and involvement of patients within a specific encounter, or overall patient or professional perceptions of person-centred care. 319-330

The outcomes resulting from person-centred care were less commonly measured than processes, although more recently studies have begun to explore this. 331-345 The movement towards patient-reported outcomes measures (PROMs) could be seen to be part of this, however this approach tends to use system-centric outcome measures, rather than those that may be of most importance to patients and families. A systematic review found that there are no psychometrically rigorous PROMs developed with cancer patients that capture all dimensions of person-centred care.346

Throughout the empirical literature, the outcomes of person-centred care tended to be measured using data about satisfaction, quality of life, functional status or health service use. In other words, person-centred care was sometimes seen as a mechanism by which other outcomes may be achieved and those outcomes were measured using other sources, not person-centred care tools.

When is person-centred care measured?

The four aspects of definitions, preferences, experiences and outcomes of person-centred care map broadly onto a care pathway or continuum (see Figure 2). For instance, studies looking at definitions of personcentred care tended to take place before an episode of care was provided, whereas studies focusing on experiences of care occurred during or after the care episode. It is acknowledged that the care pathway is not linear or episodic, especially for people with ongoing care needs such as those with long-term conditions. The point being made is that different measures of person-centred care are conducted at varying points in a person's care continuum.

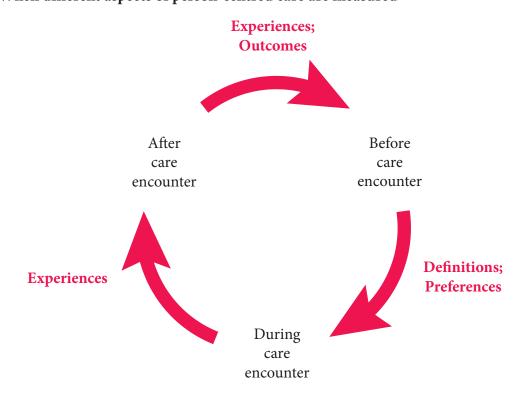
How is person-centred care measured?

Common research approaches

The main research methods that studies have used to measure person-centred care included the following, in order of frequency.

- Asking clinicians about the extent to which care is person-centred. 347-349 This usually took the form of surveys, often in paper form (most of which were unnamed bespoke surveys designed for particular programmes).

Figure 2: When different aspects of person-centred care are measured



- Asking patients (and to a lesser extent families) about the extent to which care is person-centred. 350-352 Surveys completed by patients were the second most common measurement method, usually in paper form (including validated surveys and bespoke surveys designed for particular programmes). Surveys were used for examining 'person-centred care' at a broad level as well as specific components and activities such as shared decision making. They can take a variety of formats including short postcards, paper forms, online forms and survey kiosks. Interviews and focus groups with patients, family members and professionals were less commonly used but still evident.
- Observing clinical encounters, either with real patients or simulated patients in person or via recording, or asking clinicians for feedback about what they would do in hypothetical situations.^{353–358} This approach was particularly common for measuring communication or shared decision making.
- Examining patient records or other routinely collected data for evidence of person-centred care (and sometimes comparing with other data or observations).³⁵⁹

As outlined previously in Figure 1, for analytical purposes the concept of person-centred care can be divided into three main spheres: the broad holistic concept of person-centred care, specific behaviours related to person-centred care and less tangible subcomponents. Table 4 overleaf lists the research methods used most commonly in published studies to measure each of these three spheres.

Part 2 provides more detail about the measurement approaches most commonly used, including examples of studies using each of these approaches.

Commonly used measures

Surveys and structured (observation) tools were the most widely reported research method overall, but the specific tools used vary in both scope and content. There were a multitude of unnamed surveys, designed bespoke for use within a specific project or research study. Named tools that have been validated in some way were also increasingly used.

Table 5 on pages 15–19 lists examples of named validated surveys and structured scales that have been used to measure the broad concept of person-centred care and some of its components. This provides a flavour of the large number of tools available, rather than aiming to be an exhaustive list.

The table first lists 1) tools used to measure the holistic concept of person-centred care. It then provides examples of tools used to measure some of the components of person-centred care divided into: 2) concepts such as patient experience, activation and empathy; and 3) behaviours that might support personcentred care such as self-management support, shared decision making and person-centred communication.

Only tools used to measure the holistic concept of person-centred care or the six subcomponents selected for illustrative purposes for this review are included. The six subcomponents of patient experience, dignity, activation, self-management support, shared decision making and communication were selected because these are the most commonly recurring subthemes, and these concepts are also prevalent in government policy throughout all four countries of the UK.

Part 2 contains examples of how the most frequently used tools have been applied in research.

It is important to emphasise that just because a tool is mentioned here does not mean that it is being recommended. The aim is to illustrate the wide range of named and validated tools reported in the published empirical literature.

Table 4: Examples of research methods used to measure person-centred care

Concept	Common research methods, in order of frequency		
1. Holistic concept of person-centred care			
Person-centred care / patient-centred care / individualised care / family-centred care	 Surveys with professionals Surveys with patients Interviews with patients Interviews with professionals Focus groups Observation Interviews with family Review of patient notes 		
2. Selected subcomponents of person-centred	d care		
Patient satisfaction / experience of care	 Surveys with patients Interviews with patients Focus groups Surveys with family Interviews with family 		
Patient engagement / involvement / activation	Surveys with patientsSurveys with professionals		
Empathy / compassion / dignity	 Surveys with patients Surveys with professionals Simulations / observation Interviews 		
3. Behaviours supporting person-centred care			
Person-centred communication	ObservationSurveys with patientsSurveys with professionals		
Extent to which professionals support self-management	Surveys with patientsSurveys with professionals		
Extent to which professionals support shared decision making	Surveys with patientsSurveys with professionals		

Note: Only selected examples of the subcomponents listed in Figure 1 are included here, for illustrative purposes.

Table 5: Selected examples of validated tools used to measure person-centred care

Concept	Definition	Examples of named tools
1. Holistic conce	pt of person-centred care	
Person-centred care / patient-centred care / individualised care	Person-centred care aims to ensure a person is an equal partner in their healthcare. Each of the tools measuring person-centred care as a holistic concept defines the term in a slightly different way, but recurring themes include respect and holism, power and empowerment, personalisation, choice and autonomy, empathy and compassion.	Client-Centred Care Questionnaire (CCCQ) 160-362 Client Generated Index 363 Components of Primary Care Index 364-371 Consumer Quality Index (CQ-index) 372-366 ENDOCARE questionnaire (ECQ) (endometriosis) 387,388 Family-Centred Care Scale 189 Individual Care Instrument (ICI) 360 Individualised Care Scale (ICS-patient version) 391-803 Measure of Processes of Care (MPOC) 464-412 Patient-centred Inpatient Scale (P-CIS) 413 Patient-centred Outcomes Questionnaire 184-419 Patient-centred Outcomes Questionnaire 184-419 Patient Perception of Patient-Centredness (PPPC) 436 Personal Identity Threat Survey 27 Personal Identity Threat Survey 27 Person-centred Climate Questionnaire (PCQ-patient version) 228 Primary Care Assessment Survey (PACS) 139-346 Primary Care Assessment Tool (P-CAT) 437-446 Youth Friendly Health Services Questionnaire (YFHS-WHO+) 447 For professionals Artefact of Culture Change Tool 488 Barriers to Providing Family-Centred Care 489 Benchmarking Person-centred Care 489 Benchmarking Person-centred Care 489 Benchmarking Person-centred Care 489 CARES observational tool 481 Davis Observation Code 483-483 Dementia Care Mapping (specific codes) 484-487 Family-Centred Care Questionnaire 488 Family-Centred Care Self-Assessment Inventory 489 Individualised Care Inventory 479 Measure of Processes of Care for Service Providers 487-4176 Patient-centred Care Scale 477 Patient-Family-Centred Care Survey 479 Person-centred Care Assessment Tool (P-CAT) 479-485 Person-centred Care Assessment Fool (P-CAT) 489-489 Person-centred Care of older people with cognitive impairment in acute care scale (POPAC) 486-487 Person-centred Staff survey 489 Personhood in Dementia Questionnaire 489 Personhood of Dementia Questionnaire 489 Personhood of Dementia Questionnaire 489 Personhood of Dementia Questionnaire 489

Definition

Examples of named tools

2. Selected subcomponents of person-centred care

Patient satisfaction / experience of care Patient experience relates to how patients perceive healthcare services and activities, including satisfaction with the care received. Many of the tools ask patients to report on what happened / their experiences or ask them to rate the extent to which they were satisfied with care. Some tools also examine perceived continuity of care.

Primary / community care

- Ambulatory Care Experiences Survey⁵⁰⁴
- Consultation Satisfaction Questionnaire (CSQ)⁵⁰⁵
- Consumer Assessment of Healthcare Providers and Systems (CAHPS)⁵⁰⁶⁻⁵¹¹
- General Practice Assessment Survey (GPAS / GPAQ)^{512,513}
- General Practice Patient Survey England^{514–516}
- Improving Practice Questionnaire (IPQ)⁵¹⁷
- Medical Interview Satisfaction Scale (MISS-21)⁵¹⁸
- National Research Corporation Picker Paediatric Inpatient Survey (NRC Picker)⁵¹⁹
- Partners for Change Outcome Management System (PCOMS)⁵²⁰
- Patient Experience Questionnaire (PEQ)⁵²¹
- Patient Satisfaction Questionnaire (PSQ)⁵²²
- Survey of Healthcare Experiences of Patients (SHEP)⁵²³
- Tucker Culturally Sensitive Health Care Clinic Environment Inventory - Patient Form⁵²⁴
- Other primary and community care surveys^{525–549}

Hospital care

- American Board of Internal Medicine (ABIM-10)⁵⁵⁰
- Baker and Taylor Measurement Scale⁵⁵¹
- Client Satisfaction Survey⁵⁵²
- Consumer Assessment of Healthcare Providers and Systems Hospital Survey (CAHPS Hospital)^{553–559}
- Euro Health Consumer Index⁵⁶⁰
- Global Rating Scale⁵⁶¹
- Hong Kong Inpatient Experience Questionnaire⁵⁶²
- Inpatient Consumer Survey (ICS)⁵⁶³
- Inpatient Experience Survey⁵⁶⁴
- Irish National Perception of Quality of Care Survey 565
- Newcastle Satisfaction with Nursing Scale^{566,567}
- NHS National Adult Inpatient Survey^{568,569}
- Parents' Perceptions of Continuity Scale⁵⁷⁰
- Patient's Assessment of Quality Scale⁵⁷¹
- Patient Evaluation of Emotional Care during Hospitalisation (PEECH)⁵⁷²
- Patient Measure of Safety (PMOS)⁵⁷³
- Patient Satisfaction Scale^{574,575}
- Picker Patient Experience Questionnaire (PPE-15)^{576,577}
- Quality from the Patient's Perspective Questionnaire (QPP)⁵⁷⁸
- Quality of Discharge Teaching Scale (QDTS)⁵⁷⁹
- Questionnaire for satisfaction of hospitalised (QSH) patients⁵⁸⁰
- UK General Medical Council Patient Questionnaire⁵⁸¹
- Views on Inpatient Care (VOICE)⁵⁸²
- Other hospital surveys^{583–611}

Concept	Definition	Examples of named tools	
2. Selected subco	omponents of person-centred care	care (continued)	
Patient engagement / involvement	Patient engagement relates to the extent to which people feel	 Specific services and conditions Cardiovascular population scale⁶¹² Patient Assessment of Chronic Illness Care (PACIC)⁶¹³⁻⁶²⁰ Anticoagulant services, ⁶²¹ children's services, ⁶²² chiropractic care, ⁶²³ dentistry, ⁶²⁴⁻⁶²⁶ genetic counselling, ⁶²⁷ long-term care, ⁶²⁸ major injury care, ⁶²⁹ mental health, ⁶³⁰⁻⁶³⁴ nursing, ⁶³⁵⁻⁶³⁸ obesity, ⁶³⁹ occupational health, ^{640,641} out of hours, ^{642,643} outpatient services, ⁶⁴⁴ pain management, ^{645,646} pharmacy, ⁶⁴⁷⁻⁶⁵⁶ physical therapy, ⁶⁵⁷⁻⁶⁶⁴ prison health services, ⁶⁶⁵ radiotherapy, ⁶⁶⁶ rheumatology, ^{667,668} screening and tests, ⁶⁶⁹⁻⁶⁷² sexual health, ⁶⁷³⁻⁶⁷⁵ substance abuse services, ⁶⁷⁶ surgery, ⁶⁷⁷⁻⁶⁸⁹ telecare, ^{690,691} transgender services, ⁶⁹² women's services and maternity, ⁶⁹³⁻⁶⁹⁶ and specific conditions ⁶⁹⁷⁻⁷³⁰ Other broad experience and 'quality' measures⁷³¹⁻⁷³⁶ Other surveys about continuity of care⁷³⁷⁻⁷⁴³ Carers Caregiver Evaluation of Quality of End-of-Life Care (CEQUEL)⁷⁴⁴ Carer Experience Scale⁷⁴⁵ Carer Hospital Satisfaction Questionnaire (Carer HospSat)⁷⁴⁶ Stroke Carer Experience Questionnaire (SCEQ) ⁷⁴⁷ Other surveys for carers of people with specific conditions ^{748,749} Clinician Support for Patient Activation Measure (CS-PAM)⁷⁵⁰ Consultation Quality Index (CQI / CQI-2)⁷⁵¹ 	
/ activation	part of the care process, such as the level of active participation. A number of tools in this category measure staff perceptions of the extent to which care empowers patients.	 Family Empowerment Scale⁷⁵² Organisational Values Questionnaire (for staff)⁷⁵³⁻⁷⁵⁵ Patient Activation Measure (PAM)⁷⁵⁶⁻⁷⁸² Patient Activation Measure for Customer Quality⁷⁸³ Patient Empowerment Scale^{784,785} Patient Enablement Instrument⁷⁸⁶ Patient Participation in Rehabilitation Questionnaire⁷⁸⁷ Patient Participation Scale⁷⁸⁸ Shared Care Instrument^{789,790} 	
Empathy / compassion / dignity	Dignity involves ensuring people know they are worthy of respect. Tools often focus on the extent to which professionals exhibit empathy or compassion, which is the capacity to recognise and respond to the emotions and feelings of others.	 Caring Behaviours Inventory⁷⁹¹ Caring Behaviour Measurement⁷⁹² Compassion Scale⁷⁹³ Consultation and Relational Empathy Scale (CARE)⁷⁹⁴⁻⁷⁹⁹ Elderly Resident-Perceived Caring Scale (EPCS)⁸⁰⁰ Emotional Intimacy Scale⁸⁰¹ Empathy Quotient (EQ)^{802,803} Hogan Empathy Scale⁸⁰⁴ Interpersonal Reactivity Index (IRI)^{805,806} Jefferson Scale of (Physician) Empathy (JSE)⁸⁰⁷⁻⁸²¹ Patient Dignity Inventory (PDI)⁸²²⁻⁸²⁵ Toronto Empathy Questionnaire⁸²⁶ 	

Definition

Examples of named tools

3. Behaviours supporting person-centred care

Person-centred communication

Tools measuring personcentred communication explore the extent to which patients are active and involved in discussions; whether professionals encourage patients and families to express their needs, preferences and concerns; whether professionals monopolise the conversation and the extent to which patients feel engaged and valued. Tools are available to assess both patient and staff views of person-centred communication and associated behaviours.

For patients

- Communication Assessment Tool (CAT)827,828
- Components of Primary Care Index (CPCI)⁸²⁹
- Consultation Satisfaction Questionnaire⁸³⁰
- Dialogue consultation satisfaction questionnaire⁸³¹
- Doctors' Interpersonal Skills Questionnaire (DISQ)832-834
- Emotional Tone Rating Scale⁸³⁵
- EUROPEP^{836,837}
- Health Care Communication Questionnaire (HCCQ)838
- Health Information Wants Questionnaire⁸³⁹
- Interpersonal Processes of Care Survey^{840,841}
- Medical Expenditure Panel Survey (MEPS)⁸⁴²
- Paediatric Asthma Control and Communication Instrument (PACCI)⁸⁴³
- Patient Approach and Views toward Healthcare Communication Scale (PAV-COM)⁸⁴⁴
- Patient-Doctor Interaction Scale (PDIS)⁸⁴⁵
- Patient Feedback on Consultation Skills (PFC)846,847
- Patient-Health Care Provider Communication Scale (PHCPCS)⁸⁴⁸
- Physician-Patient Communication Behaviours Scale⁸⁴⁹
- Primary Care Assessment Survey (PCAS)850
- Perceived Involvement in Care Scale^{851,852}
- Quality of End-of-life Communication Scale⁸⁵³
- QUOTE-questionnaires (Quality Of care Through the patients' Eyes)⁸⁵⁴

For professionals

- 4 Habits Coding Scheme⁸⁵⁵
- Affective Communication Questionnaire (ACQ)⁸⁵⁶
- Communication Skills Attitude Scale (CSAS)857
- Communicator Styles Measure (CSM)⁸⁵⁸
- Effective Listening and Interactive Communication Scale (ELICS)⁸⁵⁹
- Explicit Professional Oral Communication (EPOC)⁸⁶⁰
- Interpersonal Communication Assessment Scale (ICAS)861
- MAAS History-taking and Advice Checklist GP (MAAS-GP)⁸⁶²
- Measure of Patient-Centred Communication (MPCC)863,864
- Medical Communications Behaviour System⁸⁶⁵
- Nurse Quality of Communication with Patient Questionnaire (NQCPQ)⁸⁶⁶
- Nursing Activities for Communication With Families⁸⁶⁷
- Patient-Practitioner Orientation Scale (for staff)^{868–873}
- Person-Centred Communication Coding System (PCCCS)⁸⁷⁴
- Role Category Questionnaire (RCQ)⁸⁷⁵
- Roter Interaction Analysis System for rating consultations (RIAS)^{876,877}
- Siminoff Communication Content and Affect Programme (SCCAP)⁸⁷⁸
- Work Observation Method by Activity Timing (WOMBAT)⁸⁷⁹

Concept	Definition	Examples of named tools
3. Behaviours supporting person-centred care (continued)		
Supporting self-management	Self-management is about the decisions and behaviours that patients undertake to care for themselves. Some tools measure self-management itself but are not included here. Tools measuring self-management support are the focus. This is the encouragement that professionals provide to help patients understand their central role in managing their condition and making decisions.	 Assessment Chronic Illness Care (ACIC)^{880,881} Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management (PCRS)⁸⁸² Practices in Self-management Support⁸⁸³ Resources and Support for Chronic Illness Self-management Scale^{884,885}
Supporting shared decision making	Shared decision-making involves patients and professionals communicating about potential care options, and professionals supporting patients to consider the possible consequences of options and the evidence available before arriving at informed preferences.	 CollaboRATE⁸⁸⁶ Control Preferences Scale^{887,888} Decision-making Involvement Scale⁸⁸⁹ Decision Self-Efficacy Scale⁸⁹⁰ Decisional Balance for Patient Choice in Substance Abuse Treatment⁸⁹¹ Decisional Conflict Scale^{892–901} Informed Decision Making tool^{902,903} OPTION (single and paired versions)^{904–909} Physician Trust in the Patient⁹¹⁰ Shared Decision Making - Meeting its concept's Assumptions (SDM(MASS))⁹¹¹ Shared Decision Making Questionnaire^{912,913} Shared Decision-Making Inventory⁹¹⁴ SURE scale^{915,916} Other scales^{917–919}

Note: The list above provides examples of the most commonly mentioned validated tools in the empirical literature, but does not aim to be comprehensive. Only the illustrative subcomponents selected for more detailed review are included.

Visit www.health.org.uk/helpingmeasurepcc to download a searchable spreadsheet listing the most commonly researched measurement tools.

Table 5 lists more than 200 survey tools for measuring person-centred care. The following sections briefly highlight the most frequently written about tools for measuring person-centred care as a holistic concept and the most frequently used tools for measuring specific subcomponents.

Common surveys about the holistic concept of person-centred care

The most commonly cited validated surveys for measuring the broad concept of person-centred care holistically in the empirical literature were the:

- Individualised Care Scale
- Measure of Processes of Care
- Person-centred Care Assessment Tool
- Person-centred Climate Questionnaire.

The Individualised Care Scale focuses on health professionals' ability to respond to patients' individual needs in hospital. It is available as a version for patients and as a version for professionals (usually nurses). It has been applied in both Europe and the US and found to be valid and reliable.

The Measure of Processes of Care tool is usually completed by family members of children using rehabilitation or hospital services. There is also a version for professionals. It has been used around the world in countries such as Australia, North America and South Africa.

The Person-centred Care Assessment Tool is targeted at professionals. It was developed as a self-reporting assessment scale for nurses. It has been tested in hospitals and residential units for older people in Europe and other parts of the world and found to be valid and reliable. 920 It has 13 items, though has been adapted and added to in some studies.

The Person-centred Climate Questionnaire is available as a version for patients and as a version for professionals. It has been tested predominantly in Scandinavia and Australia and found to be valid and reliable for exploring the extent to which hospital and long-term residential care for older people is person-centred.

Part 2 provides examples of studies using each of these validated surveys.

A wide range of other survey tools are available, as listed in Table 5. Although the four above are most commonly used in published research about the holistic concept of person-centred care, this does not mean they are of better quality or more appropriate or applicable for the NHS. Few studies have compared the merits of different measures and reviews have acknowledged the limited quality of some of the tools available.⁹²¹

Common surveys of components of person-centred care

Structured tools were also available to measure specific subcomponents of person-centred care. For instance, the Consumer Assessment of Healthcare Providers and Systems surveys and the Patient Assessment of Chronic Illness Care tool were popular for measuring patient experience, particularly in the US.

- With regards to patient engagement and activation, the Patient Activation Measure was most commonly written about. The Patient-Practitioner Orientation Scale and the Organisational Values Questionnaire were two other commonly used tools. These seek feedback about the extent to which professionals believe the care they provide empowers patients.
- For measuring empathy and compassion, the two most commonly used tools were the Jefferson Scale of Physician Empathy and the Consultation and Relational Empathy Scale.
- Studies have used a wide range of structured observation checklists and survey tools to measure person-centred communication and there is not one tool that stands out as being most commonly used. The Doctors' Interpersonal Skills Questionnaire was one example, and many other examples are listed in Table 5.
- There were three main generic validated scales for measuring the extent to which professionals support self-management: the Resources and Support for Chronic Illness Self-management Scale; Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management; and Practices in Self-management Support. There were also many tools measuring the extent to which patients self-manage but these were outside the scope of the review.
- For shared decision making, the two most commonly mentioned tools were the Decisional Conflict Scale and the OPTION scale. Many other tools are also available, again as listed in Table 5.

Examples of studies using each of these commonly mentioned tools are given in Part 2, which provides more of a flavour of how the tools have been applied in practice.

There are more than 200 named and validated tools available, but there is insufficient evidence to recommend one survey tool over another, largely because comparisons

are rare. Furthermore, the choice of survey tool depends on the context (hospital, primary care, nursing home or rehabilitation); whether patients, staff or both are the target; the preferred length or number of survey items; and whether the focus is on the broad concept of personcentred care or a narrower subcomponent.

Measures reported alongside person-centred care

A number of different measures of person-centred care were often used alongside one another. It is difficult to generalise about measures that were commonly used together because this varied widely according to the scope of the study.

Studies focused on the broad concept of personcentred care often used bespoke tools that included a range of components such as communication style, perceived involvement in consultations and satisfaction with care. Some studies also measured the degree of self-management support or shared decision making, although these were more likely to be measured in research focusing particularly on these concepts alone.

Many measurement approaches for person-centred care were generic, and able to be used across care settings for people with a range of conditions. Other tools were targeted towards a certain care setting (such as hospitals or nursing homes) or tailored towards the needs of a particular patient group. For example, a systematic review identified three stroke-specific patient-centred care outcome measures: the Subjective Index of Physical and Social Outcomes, the Stroke Impact Scale and the Communication Outcome after Stroke scale. These scales all included similar themes, namely meaningfulness and relevance, quality and communication. 922

Another review examined instruments for measuring person- and family-centred children's healthcare. Valid and reliable instruments for measuring patient/ family experience of care that are often used together in this context included the Consumer Assessment of Healthcare Providers and Systems tools (CAHPS), Promoting Healthy Development Survey (PHDS), Young Adult Health Care Survey (YAHCS), and the National Research Corporation Picker Paediatric Inpatient Survey (NRC Picker). All of these tools are largely US based. 923

Other aspects of healthcare were also commonly measured alongside person-centred care. Again it is difficult to generalise about the types of measures used together because the metrics included varied widely depending on the focus of the individual study.

It was common for person-centred care to be one of a number of measures within studies which also examined health service usage, quality of life and patient and staff experience/satisfaction with care. 924,925

For instance, university researchers in the UK examined whether a 'whole systems' approach to self-management improved outcomes. Nineteen hospitals took part in a randomised trial. Consultants from intervention sites received training in person-centred care, provided their patients with a self-help guidebook and encouraged patients to prepare a self-management plan. Surveys and in-depth qualitative interviews were used to measure patients' and consultants' experiences and routinely collected data was used to explore service use. In addition to person-centred care, the outcomes measured included rates of outpatient consultation, quality of life, acceptability to patients, health service resource use and cost-effectiveness. ⁹²⁶

Another example comes from the US where university researchers explored the relationship between patient activation, health literacy and health outcomes. Almost 700 patients completed structured scales including the Patient Activation Measure (PAM), the Test of Functional Health Literacy in Adults (TOFHLA), the SF-36 physical health subscale and Patient Reported Outcomes Measurement Information Service (PROMIS) subscales. There was a small relationship between health literacy and patient activation, and both health literacy and activation were correlated with health outcomes. 927 This is one example of the complex mix of surveys and tools used within research and illustrates the difficulty of drawing conclusions about tools commonly used together.

These few examples serve to highlight that a broad range of tools may be used together, and that it is difficult to isolate one or two tools that are most commonly applied.

Sometimes a single measure of person-centred care was used, such as interviews or a survey tool, and then this data is combined with other information about processes or patient outcomes.

Structured survey and observational tools have been listed in some detail in this chapter because they are commonly used to measure person-centred care. However, this does not mean that these tools should be prioritised over other possible approaches. As outlined in the next chapter, there are limitations with survey approaches, so these tools may be best viewed as one of a suite of approaches to understand and measure person-centred care.

Chapter 3:

Thinking about the future

Prioritising person-centred care requires a clear commitment to implementation and measurement. This chapter examines things to consider when applying the research evidence in practice.

There are many positive and useful examples of how studies have used interviews, observation, surveys and routinely collected data to measure person-centred care (as described in more detail in Part 2). In providing examples of available research, it is clear that there are also some issues to bear in mind. This chapter describes things to consider when applying the evidence in practice and planning how best to improve current measures of person-centred care. The aim is to highlight issues that those measuring person-centred care at the frontline or in system steward roles may need to consider when selecting the most appropriate approach for local contexts.

Improving the usefulness of evidence for practice

Defining person-centred care

A number of things could be done to enhance the definition and measurement of person-centred care in practice. For example, person-centred care was defined quite broadly and potentially differently in various countries, contexts and care environments – and this has implications for how the concept is measured.

A decade ago the King's Fund interviewed representatives from health organisations, regulatory bodies, educational institutions, patient and user groups, consumer organisations, Royal Colleges and other professional bodies to explore how person-centred care was understood by stakeholders in the UK. It was reported that person-centred care covered a range of activities, from patient involvement in individual care through to public involvement in health policy decisions.

It was suggested that government policy had made person-centred care a priority, but did not clarify exactly what this term meant. This resulted in health professionals, educators, managers and patient representatives all developing different understandings to reflect their own backgrounds and roles. 928 These findings are perhaps equally valid today, and supported by more recent research outlining the difficulties defining person-centred care and the multitude of perspectives about this issue. 929,930

It is therefore not surprising that many studies did not clearly define the concept of person-centred care, or used varying definitions. This means that studies were not comparing 'like with like.'

'Despite its popularity, this concept has often been criticised for lacking a unified definition and operationalised measurement... Patient-centredness is a multifaceted construct with no single theory that can sufficiently define the whole concept.'931

Teams may need to carefully consider how to define person-centred care so that it is meaningful and practical.

Some commentators have suggested that the model of person-centred care in official government policies is somewhat rhetorical⁹³² and equates to a 'consumerbased' model rather than a psychosocial approach. In this view, 'official' versions of person-centred care focus predominantly on offering service users more choice and promoting independence rather than emphasising partnership and a compassionate, respectful model of care. For example, an analysis of minimum standards for residential care for older people in Ireland found that a consumer-driven model of person-centred care

was pre-eminent. Residential healthcare was portrayed as a hotel-like service with residents as discerning consumers. Yet, this philosophy may be unsuitable for severely unwell people and older people with limited capacity to make key choices for themselves.⁹³³

There are many examples of where person-centred care terminology has been used as a 'buzzword' 934,935 and there is perhaps a need to more fully define the concept to assist with robust measurement. Yet this is more easily said than done. The concept of person-centred care is very broad and has many subcomponents, which means that the tools used also vary widely.

Involving patients and carers

In examining approaches to measure person-centred care, some tensions emerge between an 'ideal' approach and what is happening in practice.

An important tension is the extent to which patients are involved in developing approaches and tools and the extent to which the tools measure concepts of importance to patients.

The concept of person-centred care puts patients at the heart of their health and care, yet few approaches to measuring person-centred care have been driven by patients or built on aspects identified by patients as being most crucial.936 It could be argued that in refining measurement approaches or selecting tools for future improvement initiatives, patients and families need to be placed first in terms of what is measured. At present system measures may be prioritised. For example, improvement initiatives may focus on measuring outcomes such as reducing emergency department visits, but a more person-centred approach to measurement may need to identify whether this outcome is important to patients – or whether issues such as access, continuity and empathy are of higher priority. In other words, if care is to be person-centred, then the primary measures of healthcare quality used might also usefully be person-centred.

When designing a measurement system, it is important that teams take time to consider the principles and outcomes that it is essential to achieve. If patients are to be placed at the heart of health systems, then it may be necessary to understand patient priorities and preferences, and to design measurement systems to ensure these priorities are being met.

But this is not solely about prioritising patient references. Some studies of person-centred care focus on preferences, yet researchers from the UK found this might be problematic because patients reported changing their preferences, and the reasons underlying these preferences, over time. People generally prioritised the things they were currently doing and perhaps overlooked other options or the potential way things could be.⁹³⁷

Thus rather than relying on simplistic or readily available measures, it may be important to define what the system is fundamentally trying to achieve before focusing on how to measure it.

Things to consider when selecting measurement approaches

Research methods for measuring person-centred care can be categorised according to the depth of information they provide and the extent to which they collect information that may be generalisable to a wider population. For instance, while interviews and focus groups can provide in-depth information, this may be less generalisable for making decisions about wider populations or service changes. On the other hand, surveys provide information that may be generalised more easily to wider groups, but the type of data collected is usually at surface level.

Referring back to the four aspects of person-centred care (definitions, preferences, experiences and outcomes), studies interested in definitions tended to be more likely to use qualitative methods such as interviews and focus groups, where more detailed information and probing is possible. Research about preferences and experiences used either qualitative or quantitative methods, or combinations of both. Studies of outcomes tended to use more structured survey tools.

There are potential issues with all of these methods. For instance, patient and professional reports of the quality and quantity of person-centred care and its components have been found to differ from those of independent observers. 938 Observation may be intrusive and labour intensive, whereas reviewing patient records cannot accurately ascertain whether care was truly personcentred retrospectively.

To increase the reliability of measures, structured tools have been developed⁹³⁹ and an increasing number of teams have begun using more than one method to triangulate data about person-centred care.

It is not possible to make a definitive recommendation about the most effective research method, but the method used may impact on the findings. For instance, a team in the US examined whether the mechanism for distributing surveys influenced the results. Over a 17-month period, all families of babies discharged from the neonatal intensive care unit at one hospital were surveyed after discharge with two parallel surveys, one posted and one by telephone. The response rate was 94% by telephone and 29% by post. Three out of the five questions yielded significantly different answers in posted and telephone responses.940

Elsewhere in the US, a randomised trial compared patient satisfaction results gained from a survey that was either handed out in primary care or posted. Surveys that were handed out at the practice yielded higher satisfaction scores than posted surveys. The response rate was higher with handed out surveys than with mailed surveys, but handed out surveys were returned with more questions left unanswered and fewer written comments.⁹⁴¹ Thus health service teams may need to weigh up the number of responses gained versus the quality of the feedback when selecting an appropriate method.

Health services selecting an approach to measure person-centred care may also need to weigh up the importance of depth versus generalisability, or to combine approaches to gain a mixture of both. Other important trade-offs include the cost to various parties, the time incurred by different parties, the extent to which methods can be implemented as part of routine practice or require specific targeted data collection and whether specialist personnel are needed.

Selecting appropriate tools

Another issue to bear in mind is that many of the existing surveys and structured tools focus on one-off measures of interventions or episodes of care. With an increasing number of people living with longterm conditions, it may be important to consider how measurement can examine processes and care over time.

There are also tensions between the use of individual measures versus measures of wider population outcomes. Similarly, some measures are designed for improvement purposes whereas others focus on outcomes. There is no right or wrong way to measure person-centred care and it is not possible to define what makes a good measure until there is some clarity about what teams are trying to achieve. The important point is that this issue is more complex than simply attempting to choose a single tool or measurement approach.

Context and purpose need to be considered when designing and implementing measurement strategies. It is important that tools are used in the clinical context

and level of the system that they were designed for. For instance, simple evaluation or improvement tools are not designed for use by policy makers and high level population tools are not usually designed to drive improvement.

Knowing the pitfalls of surveys

In the empirical literature there has been a focus on survey instruments. Observation has been used to a limited extent in studies of communication and consultation styles, but there is little triangulation of data gained via surveys from patients, surveys from professionals, observation and routinely collected datasets.

Although surveys are commonly used to measure person-centred care and patient experience, it is important to bear in mind potential issues with this approach. For example, a qualitative interview study in 10 general practices in England investigated how 37 professionals perceived and used patient feedback from a national survey. Although some professionals reported making changes to their practice in response to the survey data, many expressed doubts about the credibility of the results. There were particular concerns about practical aspects of the survey such as the response rate and representativeness of the sample. Professionals also felt that the survey provided insufficient detail to facilitate change and failed to address some important issues.942

This reinforces that although professionals generally have positive attitudes towards patient feedback, survey data may not always be seen as the most appropriate or objective way to collect this. This may be a barrier to using patient-reported data to implement changes to practice.

Another issue with surveys is that they may not capture differences according to demographics or socioeconomic characteristics, and they may be more likely to be completed by patients or staff who are well educated, find it easy to express their thoughts in writing and have specific age and ethnic traits. 943

Furthermore, the content of validated surveys may not cover some important aspects of person-centred care. University researchers from Canada assessed the extent to which validated instruments for assessing primary care included attributes that were important from a patient perspective. A team identified 24 person-centred attributes and explored the extent to which 13 validated tools included these components. Accessibility, relational continuity, interpersonal

communication, management continuity, respectfulness and technical quality of clinical care were widely covered in the tools. However, advocacy, management of clinical information, comprehensiveness of services, cultural sensitivity, family-centred care, whole-person care and equity were poorly covered. The researchers concluded that validated instruments to evaluate care quality from the patient perspective omit many important attributes.⁹⁴⁴

It is well known that the measurement approach chosen may affect the outcome in research generally, and this also holds true for measures of person-centred care. University researchers from the UK compared the relative value of surveys versus detailed patient narratives for exploring patient experiences and identifying priorities for change. Thirteen patients described their experiences of care using narrative interviews and 82 took part in a postal survey. The datasets were analysed separately and then compared to determine whether similar priorities for improvement were identified. Each method prioritised slightly different areas. The priorities identified by the narrative interviews often related to 'relational' aspects of patient experience whereas those identified within the survey typically related to more 'functional' aspects and were not always sufficiently detailed to identify specific improvement actions. The researchers concluded that surveys may be useful as a screening tool to identify potential problems in person-centred care, but do not provide sufficient detail about what needs to be done to improve services. It was recommended that surveys be used as preliminary tools, with better use of open-ended comments, followed by in-depth qualitative interviews and analysis to capture the multifaceted nature of patient experience.945

Recognising the need for triangulation

The empirical evidence suggests that there is no single 'silver bullet' for measuring person-centred care.

There is not an agreed or standardised mechanism for measurement.

Many measures of the components of personcentred care are available. Individual tools may focus on a narrow range of issues, such as activation, communication or self-management support, whereas the concept of person-centred care includes all of these variables. This may mean that more than one tool is needed, requiring careful selection and triangulation of measures. 946

Learning points

To conclude Part 1, the review suggests the following learning points about measuring person-centred care in practice.

- Before considering how to measure person-centred care, teams may want to invest time in defining this term and its components fully. Having a clear definition would help health service teams know what they are aiming for, and would make measurement easier.
- There is already a wealth of tools available, so an important next step may be to test their feasibility and usefulness in a UK context. This would help develop a suite of tools that could be recommended for measuring person-centred care and its components in a standardised and comparable manner. This review has not assessed the quality of the tools, only listed their existence. An important next step may be to assess the quality and applicability of some of the most common tools.
- There is no agreement about the most effective measures to use. It is likely that different tools may be more appropriate for some contexts or some subcomponents of person-centred care. Combining a range of methods and tools is likely to provide the most robust measure of person-centred care. The concept of person-centred care is complex and multifaceted so measurement strategies need to reflect this. Rather than promoting one or two tools, it may be worthwhile considering how approaches to triangulating information from patients, professionals and routinely collected data could be built into a balanced scorecard and how these measures could be promoted so they are routinely used alongside measures of patient safety and efficiency.
- There is no 'silver bullet' or best measure that covers all aspects of person-centred care, but the evidence suggests 10 'top tips' to consider when selecting approaches for use locally (see Box 1 overleaf).

Person-centred care is fundamental to transforming health services. In order to assess the extent to which care is person-centred, robust measurement approaches are needed. While there is much left to do to better understand how to measure person-centred care, a great deal of work has already been undertaken and there is a solid foundation upon which to build. Many research methods and structured tools have been widely used, which means that health service teams, researchers and policy makers have a wealth of existing material to draw on when planning how to measure person-centred care locally.

Box 1: Things to consider when selecting a measurement approach

- 1. Develop a clear local definition of person-centred care to help shape what needs to be measured.
- 2. Think about why it is important for you to measure person-centred care and how the information will be used because this will shape the measurement approach chosen.
- 3. Think about how approaches can be combined to provide both depth and generalisability. This may include both qualitative and more quantitative material.
- 4. Consider whether it is important to ask everyone using services or only a sample to provide feedback. The most appropriate sample will depend on why the information is being collected.
- 5. Consider the best time to collect feedback. Sometimes it is helpful to collect feedback immediately after using services, when experiences are fresh in people's minds. At other times it may be more helpful to allow some time to pass so people can reflect back. Using a combination of immediate and follow-up feedback could be worthwhile.
- 6. It is important to allocate enough time and resources to plan, implement, analyse and use measures of person-centred care. Pilot testing is sometimes overlooked or only done on a small scale but allocating enough time at the outset to plan and test methods is worthwhile, particularly if these will be used for many years to monitor change over time.
- 7. In order to make positive change, appropriate infrastructure is needed at an organisational level to analyse and use information about person-centred care.
- 8. Consider how the end result needs to be presented for various audiences as this may shape how data is collected.
- 9. Make sure patients, carers, managers and clinicians are all comfortable with why data is being collected and how it will be used.
- 10. Person-centred care measures are one component of a broader framework of measurement so all the approaches need to work well together, without excessive burden for patients or staff.

Part 2: Examples of measuring person-centred care

Part 2 provides examples of studies measuring person-centred healthcare to give a flavour of the evidence available.

Chapter 4:

Measurement approaches

This chapter signposts to studies about collecting feedback from patients, clinicians, observation and record review.

Part 1 provided an overview of the broad themes in literature about measuring person-centred care. Part 2 summarises the findings of some of the individual studies from which these themes were drawn. The aim is to signpost readers to empirical evidence.

Collecting feedback from patients and families

Surveys

The most commonly researched measure of personcentred care involved structured surveys of clinicians and patients.

Examples of the variety of named and validated surveys are provided in the next chapter, but this section provides brief examples of how patient surveys have been used to measure person-centred care or its components in general terms.

Measuring person-centred care holistically

Surveys were the most commonly used approach to measure person-centred care from the patient's perspective, either during routine practice or, more commonly, as part of one-off studies. 947-957

For example, university researchers in Australia tested whether a survey tool developed in the UK could be transferred to other populations. The survey included 20 scales and space to provide additional open-ended comments. Patients discharged from a sub-acute setting over a six-month period were sent a postal survey and a prepaid envelope. The response rate was 54%. The tool was found to be useful and suggested several areas for improvement. 958

Other university researchers from Australia used a touch screen computer to survey 344 people with cancer about their perceptions of person-centred care. Participants were drawn from four hospitals and asked to comment on eight domains of person-centred care, including information and communication, emotional and spiritual support, management of physical symptoms and involving friends and family.⁹⁵⁹

University researchers in the US assessed the feasibility of using an electronic survey embedded on a mobile device to assess person-centred care provided to older people by hospital nurses. The electronic format was found to be feasible for administering a validated tool. It took older people about 30 minutes to complete. 960

There were a multitude of other examples of using surveys, either validated named tools or bespoke surveys, to measure person-centred care – though the exact content of the tools varied widely. 961–963 These studies illustrate that surveys can be undertaken using a variety of different administration methods and at various stages in the patient journey, including before, during and after receiving care.

Measuring subcomponents of person-centred care

There were an even greater number of examples of using surveys to measure specific components of personcentred care from the patient's perspective. 964-973

The term 'patient experience' was often used simultaneously or interchangeably when referring to person-centred care, or seen as an important component of this broader concept. There were numerous examples of surveying people about their experiences of care and how they communicate with health professionals. 974-977

In the published literature, surveys about specific components of person-centred care were common in both hospital and primary care contexts. One of the most frequent survey administration methods involved handing out surveys during or immediately after service use. This has been found to work well to gain people's immediate impressions of the care they received. There are many other ways to collect survey information including postal^{978,979} and online surveys.^{980–983}

There were few studies comparing the reliability and validity of different survey administration methods. However, a study in Scotland comparing online versus postal approaches for collecting patient-reported experience measures (PREMs) found that almost twice as many people completed the postal version. There were differences in the type of people who chose to complete each type of survey. The online group were younger, in better health and seemed less satisfied with the quality of clinical services. Those completing the postal survey had less negative feedback. 984 On the other hand, a study comparing online versus paper completion of a cancer care survey found similar response rates and patient satisfaction levels. 985

As well as longer surveys, some studies tested simple methods for generating immediate feedback from people about their care. This often took the form of feedback postcards or comment cards. 986,987 For example, in Sweden a hospital tested using a 'tell us' card to help patients report on quality and safety. Patients were asked to write what was most important for them on the cards during the day or just before discharge. This approach asked patients to provide immediate regular feedback about issues relating to their care. The aim was more active participation in an ongoing manner. In wards using the cards, patients were more likely to think they were involved in decisions about their nursing and medical care. 988

Another approach to gaining 'real-time' survey feedback involved using kiosks or electronic devices at the point of care. ⁹⁸⁹ For example, a primary care clinic in the US used electronic touch screen kiosks to obtain patient feedback after their consultation. ⁹⁹⁰ This is similar to the 'friends and family' survey kiosks being set up in UK hospitals.

Some organisations have tried using devices such as hand-held bedside equipment, tablets, text messages, mobile apps or other novel approaches to collate patient feedback, but there have been few empirical studies outlining the relative pros and cons of these approaches.⁹⁹¹

Another novel approach involves using the internet to report on healthcare. P92-998 A review of 21 German and English language doctor rating websites examined the core domains of patient experience and satisfaction. The rating sites included only a small number of domains compared to structured surveys and theoretical frameworks about patient experience, which is one component of person-centred care. The sites tended to ask patients to comment on professional competence and doctor-patient relationships, but there was less exploration of dimensions such as communication skills and information provision, especially on English language websites.

Interviews

Measuring person-centred care holistically

Interviews have been used to measure personcentred care and its components among patients and family members. 1000–1009 This usually occurred on a one-off basis, rather than as part of routine service evaluation. 1010–1018

For example, university researchers from the UK undertook in-depth interviews with 29 older people with potential mental health problems admitted to acute hospitals and their families to assess the extent to which care was person-centred. Interviews were supplemented with 72 hours' worth of ward observations.¹⁰¹⁹

Other university researchers from the UK used semistructured interviews with 17 people with chronic back pain over a one-year period to measure how they defined and experienced person-centred care. 1020

In Sweden, university researchers used a novel approach to assess person-centred care for preschool children with long-term conditions. Skype was used to conduct and record conversations between the child and an online programme facilitator. The conversations were then analysed for patterns related to person-centred care. The children were reportedly able to talk freely about their feelings. 1021

In Australia, a rehabilitation centre used focus groups to collect feedback from 13 recent patients and 11 family members. During the focus groups, two researchers facilitated discussion on any topic that participants considered important to the experience of inpatient rehabilitation. Participants were encouraged to describe their care, needs and preferences. Discussions were audiotaped and transcribed verbatim and field notes

were recorded by hand. Data were analysed and collated into themes. This helped to understand care experiences from the point of view of patients and family members and the data were used to make improvements.¹⁰²²

A small number of studies have examined personcentred care from the point of view of family members or informal carers. Structured surveys have been used, but so too have interviews. For instance, researchers from a nursing school in the US interviewed 16 family members of people with dementia living in nursing homes. Five areas of person-centred care considered important by family members were: providing basic care; ensuring safety and security; creating a sense of belonging and attachment; fostering self-esteem and self-efficacy; and coming to terms with the experience. 1023

Measuring subcomponents of person-centred care

Researchers have also used interviews to measure some of the components of person-centred care such as patient experience or communication. Again, these studies tended to be undertaken by academic researchers on a one-off basis. 1027-1031

Sometimes interviews were used to understand how care could be made more person-centred by focusing on what patients wanted, rather than the care they previously experienced. For instance, university researchers from Iran interviewed patients, family carers and health professionals about the challenges faced by people living with complicated diabetes, chronic heart failure or chronic obstructive pulmonary disease. Patients reported a range of concerns about the quality of encounters with health professionals, including: the need for improved communication and information delivery; wanting reduced waiting times to see professionals; help with self-care; greater recognition among professionals about the need for holistic and continuing care; and including patients and carers in the decision-making process. 1032

There are numerous other examples. The important point is that interviews are a commonly used technique for collecting patient and family feedback, and tend to be undertaken by university researchers as part of specific projects rather than by health professionals during routine care.

Feedback from clinicians

Surveys

Measuring person-centred care holistically

Another common method for measuring personcentred care involves surveying professionals. There were many examples of surveying clinicians and other staff and most of these survey tools were unnamed and not widely validated. 1033–1036

One example is a survey of 392 staff at long-term care facilities in Canada. University researchers surveyed staff after they received training in person-centred and 'relationship-based' care to explore the extent to which they were able to transform their practice. 1037

Medical school researchers from the US compared three short surveys measuring nurses' perspectives of family-centred end-of-life care in intensive care units. Data from 141 critical care nurses were analysed. Person-centred nursing activities fell into two main domains: generic person-centred care and culture-related communication/support. All three surveys were found to work well to provide a consistent, valid picture of nurses' perspectives about family-centred critical care. 1038

Measuring subcomponents of person-centred care

Other staff surveys have examined specific components of person-centred care, such as shared decision making, supporting self-management and communication. 1039–1043 For example, a collaboration between university researchers, community groups and a homecare company in the US developed a 10-item instrument to screen 554 home health aides about the extent to which they provided person-centred care. There was a link between workers' ability to provide person-centred care and their ability to describe others in complex ways (their person-perception skills). 1044

A key component of person-centred care is the ability of professionals to communicate effectively. Many surveys measure professionals' perceptions of relationships or communication. For example, applied university researchers from Canada used staff surveys as part of a quasi-experimental study of improving person-centred communication for people recovering after a stroke. The intervention involved developing an individualised patient communication care plan, a one-day workshop for nursing staff about communication and behavioural

management strategies and a staff support system. Nurses were surveyed about their attitudes and behaviours, and about their perceptions of any improvements in personcentred communication. ¹⁰⁴⁵

Interviews

Interviews with clinicians have been used to measure person-centred care and its components. 1046–1053

Measuring person-centred care holistically

Often interviews of professionals were undertaken by academic researchers on a one-off basis. 1054–1057 For instance, university researchers in Sweden used interviews to explore professionals' perspectives about person-centred mental health care. 1058

Another study compared the perspectives of nursing students and lecturers from universities in Scotland and the Netherlands regarding person-centred care. Data were collected using face-to-face structured interviews. All participants agreed that person-centred care should be incorporated into pre-registration nursing education. 1059

In Ireland, university researchers used semi-structured interviews to examine eight psychiatric nurses' perceptions of the extent to which care for people who self-harm is person-centred.¹⁰⁶⁰

There were many other examples of using interviews to collect information about how staff perceive the concept of person-centred care, the extent to which they believe the care provided is person-centred or barriers to implementation. 1061-1064

Measuring subcomponents of person-centred care

Staff interviews have been used to collect information about specific components of person-centred care. 1065-1068 For instance, in Malaysia, researchers examined patient engagement in shared decision making. Researchers, opinion leaders and representatives from government organisations and patient support groups were interviewed to assess the extent to which patient involvement was incorporated into the medical curriculum, healthcare policies and legislation. 1069

There were also examples of using staff interviews to measure empathy¹⁰⁷⁰ and perceptions about communication.^{1071–1074} In the US, university researchers interviewed seven nurse managers to identify the communication skills needed for cancer

nurses to provide person-centred care. The study suggested that nurses need more training about how to communicate with doctors, patients and family members.¹⁰⁷⁵

Elsewhere in the US, university researchers interviewed 15 doctors about the questions and phrases they use to get to know their patients. Key phrases were grouped into six themes: 1) appreciation of the patient's concerns; 2) personal relationships; 3) hobbies and pleasurable activities; 4) open-ended questions to learn about the patient; 5) work; and 6) the patient's perspective on the patient–doctor relationship. 1076

Observing interactions

A less frequently used approach for measuring personcentred care involves observing encounters between patients and clinicians. This method tended to be used to measure specific components of person-centred care such as communication or shared decision making rather than the broader concept as a whole.

Measuring person-centred care holistically

There were a relatively small number of studies measuring person-centred care using observation. 1077–1080 These tended to be research conducted on a one-off basis, rather than routinely measuring person-centred care over time. 1081

For instance, university researchers in the US examined how person-centred care was defined, shaped and practised by staff members within a long-term care setting for people with dementia. Ethnographic data were collected over an eight-month period using 400 hours of participant observation and interviews with 20 people with dementia and 25 staff members. 1082

Other researchers from a hospital in Australia used observation and qualitative interviews to explore interactions between patients and nurses during medication activities. Sixteen patients and 11 nurses participated. The study explored, on a one-off basis, the extent to which person-centred care was provided. Themes examined included the provision of individualised care, patient participation and barriers to providing person-centred care. While nurses perceived that they were conducting medication activities in a person-centred way, some nurse–patient interactions were centred on routines rather than individualised patient assessment and management. 1083

Structured tools were sometimes used to support observation. For instance, university researchers from the UK assessed the reliability and validity of three observation-based measures of person-centredness in GP consultations. Each tool was applied to the same sample of 55 videotaped GP consultations. The tools had varying levels of inter-rater reliability and validity was relatively low. The researchers concluded that it is important to be cautious when choosing measurement instruments because of differences in how the concept of person-centredness is defined and operationalised. 1084

Another example is a UK hospital that used 'dementia care mapping' as an audit tool in 12 inpatient and day units. This involved mapping the care processes for five patients per unit per day for a four-day period. Routinely collected information as well as observation and discussions were used as part of the audit. The researchers suggested that this approach provided an idea of the quality of care and helped to identify where improvement was necessary. Scores within the tool provided clear signposts to the level of person-centred care and highlighted where staff development may be warranted. This was thought to help identify the overall culture of care and the extent to which each unit adopted a person-centred approach. 1085

Measuring subcomponents of person-centred care

Observation, including audio or video recording, was most common in studies focused on person-centred communication, interactions and shared decision making. 1086-1095

For example, university researchers from the UK suggested that recognising patient cues and concerns is an important part of person-centred care. Five hundred and twenty eight primary care consultations between patients and either nurse prescribers, pharmacist prescribers or GPs were recorded and analysed for the number of cues and concerns raised and the type of response. This measurement approach helped to identify that, while there was no difference in the number of cues or concerns per consultation type, pharmacist prescribers were most likely to respond positively, followed by nurses then GPs. 1096

Observation was often combined with other methods to support the measurement of person-centred care. 1097-1102 For instance, in Denmark a research institute assessed involvement in patient safety using observations from four hospital wards and interviews with 25 people with cancer, 11 hospital doctors, 10 nurses, four general practitioners and two private practising gynaecologists.

The observations and interviews found that patient safety was not a topic of attention for patients or generally present in communication between patients and health professionals. Professionals and patients expressed willingness to engage, but there was no systematic engagement process. 1103

In the US, a medical centre assessed the extent to which doctors were providing 'contextualising care' or person-centred decision making. Selected patients carried concealed audio recorders during consultations. Recordings and medical records were reviewed to assess whether contextual factors, such as an inability to pay for a medication or competing priorities, might undermine an otherwise appropriate care plan. The team developed a coding process to achieve high interrater agreement. 1104

There was some evidence that observation may capture information that people would not remember if surveyed or interviewed. University researchers from the US compared assessing pharmacist communication with patients via either surveys or observation. One pharmacist and 12 patients filling prescriptions were recruited from each of 30 community pharmacies. Each patient-pharmacist interaction was observed and patients were asked to complete a survey when exiting the pharmacy. The survey and the observation tool both included items about pharmacist information provision and questioning behaviours. Both methods had good agreement regarding information provision behaviours, but this was less true for question asking. Surveys were not as good at capturing non-specific questioning behaviours and things that patients did not regard as a serious question.1105

As well as watching real clinical encounters, observation also focused on simulated consultations and role plays. 1106–1112 For instance, university researchers from England used simulated patients to assess the communication skills of community pharmacists. Forty pharmacies were visited by 'mystery shoppers'/simulated patients. Interactions were scored using pre-set criteria. Overall the communication skills of pharmacists were rated highly, although some pharmacists used jargon when explaining complex interactions. 1113

Analysing routine data

The least common approach to measuring personcentred care involved looking at patient records or other routinely collected data. This tended to be done in studies exploring the follow-on outcomes of personcentred care, rather than the care process itself. This approach was often undertaken as one component of a study using multiple methods. 1114,1115

The majority of studies using routinely collected data as a measure of person-centred care aimed to assess the impact of a particular intervention. This included interventions seeking to improve person-centred care as well as the outcomes of interventions that were themselves defined as person-centred.

For instance, one US hospital described how new emergency department systems were set up to optimise person-centred care. Rather than having one senior nurse responsible for all emergency department staff, six patient care managers were added, leading to more distributed leadership. The stated goal was to engage staff in an effort to provide person-centred care. Outcomes were measured using patient and staff satisfaction survey scores and routinely collected data such as walk out rates. This demonstrates that the measures of person-centred care may not be 'direct' and may instead assume that improving certain outcomes (such as access or staff engagement) also lead to greater person-centredness.

This chapter has described examples of studies about different research approaches for measuring personcentred care. Thousands of other examples are available, but the aim is to provide illustrations of the types of material available rather than to summarise every study.

Chapter 5:

Measurement tools

This chapter provides examples of studies about structured tools for measuring person-centred care, particularly survey tools.

A large number of survey tools were available to measure the broad concept of person-centred care. In reviewing available tools, any empirical literature about 'person-centred care' or similes was eligible for assessment, whether or not the study explicitly focused on measurement. The tools used for measurement were then extracted. Table 5 of this review (see pages 15–19) lists the named tools that were identified as most frequently used. In this chapter a small number of examples are described in a little more detail.

The holistic concept of person-centred care

The four most commonly mentioned survey tools in the research about holistic person-centred care were the:

- Individualised Care Scale (patient and professional versions)
- Measure of Processes of Care (patient and professional versions)
- Person-centred Care Assessment Tool (professional version)
- Person-centred Climate Questionnaire (patient and professional versions).

The **Individualised Care Scale (ICS)** focuses on health professionals' ability to respond to patients' individual needs in hospital. It comprises a tool for patients and a separate version for professionals (most commonly nurses). It has been found to be valid and reliable in populations in Europe and North America. For example, 1,126 patients from 27 orthopaedic and trauma inpatient units at 14 hospitals spread across Finland, Greece, Sweden, the UK and the US tested the tool and translated versions. Psychometric evaluation found that the tool was sensitive and easy to use.¹¹¹⁷

The tool has also been used to measure the level of individualised care provided from nurses' point of view. For example, in Finland 544 nurses from three acute hospitals, two psychiatric hospitals and four health centres tested the tool. The survey was found to have good content validity, be easy to administer and able to be completed quickly. Most published research about this tool has been undertaken by one research team.

The Measure of Processes of Care (MPOC) tool focuses on the extent to which care is 'family centred.' A longer 56-item and a shorter 20-item version are available. 1119
It is usually completed by family members of child patients, often children with disabilities or long-term conditions. There is also a version for professionals. It has been used most widely in rehabilitation and long-term care or specialist care facilities and has been tested in many parts of the world. 1120

For example, university researchers from Australia used the tool to understand families' experiences of early childhood intervention services. The tool was used alongside other surveys, including the Family Empowerment Scale, the Family Support Scale and the Parenting Daily Hassles Scale. There were strong relationships between families' ratings of family-centred care and feelings of empowerment.

The Person-centred Care Assessment Tool (P-CAT) was developed as a self-reporting assessment scale for nurses. It has been tested in hospitals and in residential units for older people and found to be valid and reliable. It focuses on measuring the extent to which professionals working in long-term older person's care rate their settings to be person-centred. The survey is a 13-item tool generated from research literature and interviews with professionals, experts in the field, people with dementia and family members. 1123

It has been adapted and added to in some studies and has been tested in both developed and developing countries. It covers the broad areas of individualised care, organisational support and environmental accessibility. 1124

The Person-centred Climate Questionnaire (PCCQ) is available as a version for patients and as a version for professionals. It has been found to be valid and reliable for exploring the extent to which hospital and long-term residential care for older people is person-centred and has been tested predominantly in Scandinavia and Australia. Most studies about this tool have been undertaken by the same large research team.

For instance, university researchers evaluated the psychometric properties of the staff version among 52 Australian hospital professionals. The 14-item questionnaire had high reliability but validity was found to require further evaluation. The researchers concluded that using this tool makes it possible to study associations between person-centredness and different organisational systems, environments, staff characteristics and health and managerial styles. 1125

In Sweden, university researchers tested the patient version of the tool with 544 hospital patients. The 17-item tool covered three broad factors (safety, 'everydayness' and hospitality). The tool has been found to be valid and reliable for assessing the extent to which the climate of hospital environments is personcentred. It reportedly helps to provide descriptions and comparisons of environments, explore the relationships between person-centredness and outcomes and measure the results of improvement interventions. 1126

In addition to these commonly used survey tools for measuring person-centred care, a structured observational tool reported in the literature is the 16-item CARES scale. This has been used in hospitals and nursing homes and found to be a valid and reliable measure of whether person-centred care is being delivered by staff. It has predominantly been used to assess care for older people and people with dementia and is reportedly brief and easy to use. 1127

Patient experience

Although person-centred care is not solely about ensuring people have a good experience of care, in the published literature the term 'patient experience' is sometimes used interchangeably with person-centred care. Much research that describes itself as focusing on person-centred care actually explores patient experience.¹¹²⁸

An evidence scan published by the Health Foundation in 2013 identified 328 empirical studies about measuring patient experience. The findings of all of these studies are not replicated here, but readers are referred to that publication for further detail.

The most common surveys measuring the patient experience component of person-centred care in the empirical literature are the Consumer Assessment of Healthcare Providers and Systems Survey and the Patient Assessment of Chronic Illness Care tool. These are both used predominantly in the US.

The Consumer Assessment of Healthcare Providers and Systems Survey (CAHPS) is available in a version to measure primary care and a version to measure hospital care. Both seek feedback from patients.

The CAHPS tool is often used to measure the success of service improvement initiatives. For instance, a learning collaborative with eight medical groups in the US asked samples of patients to complete a survey before, after and continuously over a 12-month project. Teams were encouraged to set goals for improvement using baseline survey data. The tool helped the teams set goals focused on patient feedback. Team leaders said that receiving frequent survey reports was a powerful stimulus for improvement, but it took time and support to engage clinicians in behaviour change. 1130

The Patient Assessment of Chronic Illness Care (PACIC) tool also focuses on collecting feedback from patients. A version is available for collecting feedback from staff and organisations too (Assessment of Chronic Illness Care). These tools explore the extent to which services provide supportive care for people with long-term conditions, based broadly on components of the 'Chronic Care Model'. PACIC measures aspects such as patient activation; delivery system design and decision support; goal setting and tailoring; problem-solving and contextual counselling; follow-up and coordination.

Longer and shorter versions of the tool are available, and both have been extensively tested. For example, university researchers from the US tested a shorter 11-item survey with 890 people with diabetes. 1131

Hospital researchers from the US examined the relationship between PACIC scores and self-management behaviours, patient ratings of their healthcare and self-reported quality of life. Data from 4,108 people with diabetes, chronic pain, heart failure, asthma or coronary artery disease were analysed. PACIC survey scores were significantly associated with all

measures, meaning that the survey tool may be useful for predicting patient behaviours and outcomes, as well as commenting on the quality of care. 1132

Most studies using this tool are US based but it has been tested in the UK. For instance, people with long-term conditions from 38 general practices completed the tool as part of a longitudinal study. While the survey was generally found to be valid, there were higher rates of missing data using this tool compared to other tools used in the study.¹¹³³

In England, the **General Practice Patient Survey** measures patient experience of care. Studies suggest that although there are associations between clinical quality and measures of patient experience, the two domains are distinct and need separate measures.

Table 5 in Part 1 lists many other validated surveys that have been used to measure patient experience, and several thousand other bespoke or non-validated tools have also been written about.

Empowerment

In terms of patient engagement, empowerment and involvement, the most commonly reported survey tool in the empirical literature is the **Patient Activation**Measure (PAM). This is a 13-item tool that has been used extensively in North America, the UK and other parts of Europe. It has been translated into a number of different languages and found to be valid and reliable for measuring the extent of patient activation in primary care and hospital care. 1137 PAM may help to identify variations in patient self-management knowledge, skills and confidence and these have been linked to differences in health behaviour and outcomes.

Shorter versions have also been used, particularly when measuring the impact on patient activation of a specific improvement initiative. For example, a randomised controlled trial at a US hospital analysed data from 695 patients who completed an adapted, eight-item version of the Patient Activation Measure. Total scores were categorised, using standardised methods, into one of four levels of activation, ranging from highest to lowest. This allowed the researchers to assess whether more highly activated patients had a greater rate of readmissions or service use following discharge. 1138

The **Patient–Practitioner Orientation Scale**^{1139–1143} and the **Organisational Values Questionnaire** were two other commonly used tools. ^{1144,1145} These seek feedback from professionals about the perceived level of patient

interaction and engagement or the extent to which professionals believe the care they provide empowers patients.

For example, academic researchers from Malaysia compared doctors' attitudes toward person-centredness in four different medical settings. Face-to-face interviews used the Patient–Practitioner Orientation Scale. Oncologists were found to have the highest level of person-centeredness, followed by obstetricians and gynaecologists and primary care doctors, with surgeons being the least likely to support patient activation. 1146

In Sweden, university researchers used the Organisational Values Questionnaire to examine the impact of organisational culture on patient uncertainty in five hospital wards during the implementation of a person-centred care initiative. One hundred and seventeen nurses completed the survey and data were compared with patient surveys. The study found that a culture of stability is most effective for promoting person-centred care and improvement.¹¹⁴⁷

Empathy

Empathy, compassion and supporting dignity are emerging as important components of person-centred care. 1148–1150 The review examined studies that specifically investigated ways to measure these concepts. The two most commonly reported tools in this regard were the Jefferson Scale of Physician Empathy and the Consultation and Relational Empathy scale.

The 20-item **Jefferson Scale of Physician Empathy** (**JSPE**) has been widely used, particularly in the US. It has been tested with both fully qualified and student doctors and nurses. For instance, 853 medical students in the UK completed the tool. It was found to be valid and reliable for measuring empathy.¹¹⁵¹

Cultural backgrounds may influence empathy, but the JSPE has been found to work in many contexts. For instance, university researchers in Iran examined the psychometric properties of a translated version of the tool among 181 medical students. There were three key factors measured: compassionate care; perspective taking; and the ability to walk in the patient's shoes. The tool was able to assess any differences in empathy according to gender and years of experience. 1152

The Consultation and Relational Empathy (CARE) scale was designed in the UK and has been validated in a range of other countries. This 10-item scale is used predominantly in primary care consultations. For example, three quarters of the 3,044 patients

attending 26 primary care practices in Scotland who completed the tool thought the CARE measure was very relevant to their consultation, particularly older patients, people with long-standing illness or disability and patients with significant emotional distress. The researchers suggested that a sample size of 50 patients would be sufficient to estimate an average CARE score for an individual GP.¹¹⁵⁶

There are many other tools available. For example, a systematic review identified 20 different empathy measures used in nursing research. There were inconsistencies between tools, which the reviewers attributed to the inherent complexity of measuring empathy and the need to evaluate the rigour of the measures more thoroughly. 1157,1158

Another systematic review examined the reliability and validity of surveys assessing empathy in medical students and doctors. Thirty-six different instruments were identified. Only eight of these tools demonstrated evidence of reliability, internal consistency and validity. Six of these were self-rated measures, one was a patient-rated measure and one was an observer-rated measure. 1159

Communication

There are many thousands of studies about communication styles and interactions between patients and health professionals. The review only examined studies that specifically investigated ways to measure person-centred communication.

Such studies have used a wide range of structured observation checklists and survey tools, and there is not one tool that stands out as being most commonly used to measure person-centred communication.

Table 5 in Part 1 of the review lists the many named tools used, and this section provides a small number of examples. For instance, the **Doctors' Interpersonal** Skills Questionnaire (DISQ) has been used in primary care to assess the communication and interaction skills of general practitioners. 1163 Another example is the Health Care Communication Questionnaire (HCCQ), a self-administered 13-item measure that has been found to have good psychometric properties when used by hospital outpatients. It covers the aspects of problem solving, respect, lack of hostility and non-verbal immediacy. 1164 On the other hand, the Communication Skills Attitude Scale seeks to measure communication behaviours from the point of view of professionals. It was developed in England and has been applied in other countries, most extensively with medical students. 1165

University researchers from Canada examined the extent to which interpersonal communication is captured in validated survey tools that evaluate primary care from the patient's perspective. Interpersonal communication was defined as the professional's ability to elicit and understand patient concerns, to explain healthcare issues and to engage in shared decision making if desired. Components of the following tools were assessed amongst 645 primary care patients: the Primary Care Assessment Survey (PCAS); the Components of Primary Care Index (CPCI); EUROPEP I; and the Interpersonal Processes of Care Survey. The tools were found to measure communication relatively well, though shared decision making was poorly represented. 1166

While it is not possible to state the most commonly used survey tools for measuring person-centred communication, it is possible to draw out common themes in the types of content included. A systematic review of measures of person-centred communication developed an inventory of domains used in tools. The measurement domains could be organised into six categories: exchanging information; fostering healing relationships; recognising and responding to emotions; managing uncertainty; making decisions; and enabling self-management. 1167

Self-management

Supporting self-management is an important aspect of viewing the individual as being at the centre of their own health and care. This involves encouraging people to see themselves as part of the care team, with responsibility for keeping themselves as well as possible and managing their conditions. This is a large topic and many thousands of studies have examined ways to support self-management. The review only examined studies that specifically investigated ways to measure self-management support (not tools measuring the extent of self-management itself).

While many tools have been used to gauge the extent to which patients feel professionals are supporting self-management, it was not possible to identify one or two most common tools. Table 5 in Part 1 lists the many named tools used.

Examples include the Effective Consumer Scale (EC-17), Practices in Self-management Support¹¹⁷⁵ and Resources and Support for Chronic Illness Self-management Scale. These assess the extent to which either patients or professionals feel that professionals are working in partnership to provide information and support for self-management.

The **Practices in Self-management Support** scale was developed in the UK to measure clinicians' self-reported use of self-management support practices in consultations for people with long-term conditions. The tool has three subscales: clinical self-management support, person-centredness and organisational self-management support. All have been found to have good internal reliability.¹¹⁷⁸

The Resources and Support for Chronic Illness Self-management Scale was developed in the US and includes items about the range of clinical, non-clinical, social and community sources of support available to patients. A study testing the survey with 957 people with diabetes found a good response rate (68%) and validity.¹¹⁷⁹

A number of tools also measured the extent to which patients are self-managing. For example, the 12-item **Partners in Health** survey was developed in Australia to assess the self-management knowledge and behaviours of people with long-term conditions. A test with 294 patients with a range of co-morbid conditions found good internal consistency and validity.¹¹⁸⁰

Interestingly, many of these tools have been developed by applied research centres rather than university departments. Most are still in the initial development and testing stages.

Shared decision making

A great deal has been written about shared decision making, which involves encouraging people to be actively involved in decisions about their health and care. The review only examined studies which specifically investigated ways to measure shared decision making. The two most commonly mentioned tools were the OPTION scale and the Decisional Conflict Scale.

The **Observing Patient Involvement in Decision Making scale (OPTION)** observes and rates 12 behaviours on a scale of 0% to 100%, whereby high scores signal greater shared decision making. 1189–1191

An example of using this tool comes from Peru, where university researchers assessed the extent to which doctors sought to involve patients in decision making by filming all 58 consultations occurring on one day at two different facilities. Two raters independently used a structured scoring system (the 12-item OPTION scale) to quantify the extent to which doctors attempted to involve patients in decision making. The study

concluded that doctors barely sought to involve patients in decision making and that there was no difference between public and private practice.¹¹⁹²

Shorter and adapted versions of the tool are available. For instance, a dyadic version of the instrument has been developed so both clinicians and patients can complete the tool after a consultation. The tool has also been translated into many languages, including Chinese, Dutch, French, German, Italian and Spanish. 1195,1196

The OPTION instrument was developed in Wales. University researchers compared this with the Informed Decision Making tool developed the US. One hundred and twenty-three consultations from six primary care practices in the UK were audiotaped and experts in the use of the two tools rated the recordings. Both instruments performed differently and predicted different 'best' and 'worst' doctors. The researchers concluded that these measures can be useful in identifying shared decision making skills which may be problematic or difficult to integrate into practice and can be used to track changes over time. However they cautioned that this might lead to placing undue value on the aspects of shared decision making that are most easily measured.¹¹⁹⁷

Another tool is the Shared Decision Making Questionnaire, which has been tested mainly in Europe. 1198,1199

There are many other structured tools available for measuring shared decision making. In fact, a systematic review published in 2011 identified eight scales for measuring shared decision making that have undergone detailed psychometric testing, eleven new psychometrically tested instruments and nine unpublished tools. Since this time, other tools have been developed. The reported reliability of most scales was good, but they differed in the extent to which they had been validated. Most of the newer tools measured shared decision making processes using a dyadic approach, assessing both the patient's and the clinician's perspective. 1200

Other reviews have identified between 11 and 18 tools and scales designed to measure shared decision making. Most focus on patients' preferences for information and participation and patients' views about decisional conflict, self-efficacy and the decision making process. 1201,1202

Other tools to measure communication preferences and the extent of shared decision making have been validated in a number of countries. These include scales and checklists developed for people with certain conditions such as cancer and specific demographic traits, as well as more generic tools designed to measure shared decision making in any healthcare context.

Decisional conflict occurs when people feel that they do not know what to do, what their options are or where to look for help. In other words, decisional conflict involves personal uncertainty about which option to choose. It can be a measure of shared decision making and involvement because with good quality interactions and care people will feel less decisional conflict. A number of tools have been used to measure this concept.

For instance, a four-item SURE screening test has been used to understand decisional conflict. This covers the extent to which people feel sure of themselves; the extent to which they understand information; risk-benefit ratios; and encouragement. The tool has been validated in large samples, primarily in North America. 1218,1219

The **Decisional Conflict Scale** is another, longer example. This 16-item tool has been validated in both Western and Eastern countries. 1220,1221 It has also been used to illustrate differences between the perceptions of patients and clinicians following clinical encounters. 1222 This self-administered questionnaire was originally designed to assess decisional conflict in patients but has since been adapted for and tested among health professionals, because decisional conflict as seen by doctors, nurses and other healthcare professionals may be useful in evaluating the quality of shared decision making.

However, it may not be most appropriate to assess the perspectives of the patient and the health professional separately so the scale has been revised to collect information from pairs of patients and professionals.¹²²³

Assessment instruments have also been developed to measure regrets about healthcare decision making but a systematic review of 32 articles about the development, validation and implementation of measures of decision regret found that tools are somewhat simplistic and fail to capture decision making concepts robustly.¹²²⁴

Conclusion

To conclude, Part 2 of this review has summarised common approaches and tools used to measure person-centred care in published empirical literature. It signposts to the range of material available but does not purport to be a practical manual or step-by-step guide to measuring person-centred care. Nor does it contain information about the advantages and limitations of different research techniques more generally.

The overarching message is that no one research method or survey tool is inherently better than another, and that there is a wide range of existing measures for healthcare teams and researchers to try.



Appendix 1:

Methodological approach

This appendix outlines the approach used to identify studies for inclusion in the review.

Inclusion criteria

This rapid review focused on readily available empirical research published in the UK and internationally. It was completed over an eight-week period.

To be eligible for inclusion in the review, material had to:

- be empirical research of any methodological design
- be published in a print or online journal between
 1 January 2000 and 31 October 2013
- include information about person-centred care or one of its components
- be published in English.

There were no geographic restrictions, but the review excluded opinion pieces, grey literature and sources that did not contain empirical research. A number of organisations may have released manuscripts about person-centred care that were not eligible for inclusion because they were published as grey literature rather than a journal article.

Search strategy

The Health Foundation was interested in how any aspects of person-centred care have been measured so this required a broad set of search terms. Combinations of the following terms and similes were used: person-centred care; patient-centred care; individualised care; person-centred climate scale; personalised care; family-centred care; patient centric; user centred; whole person care; person-focused care; measure; measurement; assessing; survey; instrument; tool; collaborative care; personalised care plans; care planning; health literacy; self-efficacy; self-management; self-care; self-help; self-treatment; self-monitoring; home monitoring; self-medication; support; social support; peer support; mutual support; long-term conditions; chronic care; coping skills; quality of life; behaviour change;

telemedicine; telecare; shared decision making; patient-provider communication; communication; patient empowerment; involvement; patient activation; decision aids; family conferences; decisions; patient-held records; dignity; respect; compassion; friends and family; patient activation measure.

Both UK and US English spelling were used in all searches.

Two reviewers independently searched five bibliographic databases comprising Medline/PubMed; Web of Knowledge; Science Direct; the Cochrane Library; and Google Scholar.

Selection

Two reviewers independently identified more than 200,000 articles about person-centred care or its components from the database searches. Based on titles and abstracts, these reviewers identified 23,746 of the most relevant studies for full-text review. Overarching themes from all of these studies are summarised in Part 1.

Reasons for articles not being selected for full-text appraisal included not being empirical research (68%) and not incorporating specific information about the measurement of person-centred care or its components (32%).

The review was undertaken using both broad and refined search techniques. The abstracts were screened of all studies mentioning the general concept of personcentred care, patient-centred care, whole-person care, user-centred care, patient-centric care, family-centred care and similar. In other words, the focus was not solely on studies about the measurement of these concepts, but any empirical research that included these terms. This allowed information about the tools used to measure person-centred care to be drawn out, even when the studies were not specifically about measurement issues.

A more defined search was used to explore how any subcomponents of person-centred care have been measured. Thus studies about components such as self-management, shared decision making, compassion, dignity and so on were screened only if they focused on the measurement of these concepts. This kept the review very much focused on the issue of 'how to measure' subcomponents of person-centred care.

Two reviewers independently read all of the material and categorised articles as being relevant, potentially relevant or not relevant for inclusion as an example in the review. A 'benefit of the doubt' approach was used such that articles of borderline relevance were retained for further screening. Discrepancies were resolved via consensus and reference to a third reviewer if required.

No formal quality appraisal process was used because the review did not seek to exclude studies based on methodological design or quality. Systematic reviews, randomised trials and large observational studies were prioritised. Where such studies were not available, other research was included.

Synthesis

All 23,746 full-text studies were drawn on when considering themes throughout the literature. A total of 921 studies were selected to provide specific examples (see Figure 3 opposite).

Broad findings were extracted using a template. The studies were heterogeneous in terms of their focus, definitions, research design, size and geographic context. Quantitative synthesis was not appropriate and a narrative synthesis was undertaken, grouping the literature according to the type of measurement approach used.

All of the evidence was sourced and compiled systematically, but the review is not a systematic review and does not seek to summarise every study about measuring person-centred care. Instead the aim is to provide examples and draw out overarching themes about the approaches and tools most commonly mentioned in empirical literature.

Interpreting the findings

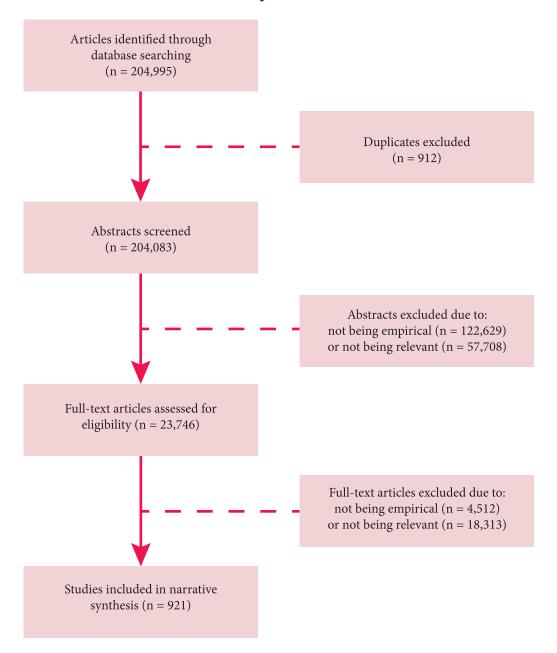
When interpreting the findings of this review it is important to bear in mind several caveats.

 Firstly, the review is not exhaustive. More than 200,000 articles have been published about aspects of person-centred care. The scan presents examples of

- readily available published empirical studies in order to give a flavour of available research, to signpost readers to interesting material and to highlight some of the most commonly mentioned tools.
- There are many descriptions of person-centred care but such descriptions were not eligible for inclusion unless they were based on published empirical research. Grey literature was not included and this means that some examples will have been omitted.
- There may also be approaches being used in practice that are not included because there is little research published about them. If a method or tool is not mentioned this is due to a lack of readily available research rather than any judgement about the relative quality or usefulness of that approach.
- Another important point is that there are relatively few studies providing detail about the tools used.
 Many studies note that a particular survey was used, for example, without outlining the content of the survey.
- As well as issues with the quantity of evidence included, there are also some caveats about the quality of studies. Many of the studies were conducted in single sites, often outside the UK. They also tended to use simple cross-sectional designs. Some of the observational and interview-based studies had small samples. Just because tools or approaches were commonly mentioned in the literature does not mean that they are of good quality. The review did not seek to appraise the quality of the various approaches used.
- Furthermore, there was an overabundance of studies about surveys. A section of the report is devoted to surveys for this reason, but this does not mean that surveys are being put forward as the most appropriate way to measure person-centred care. On the contrary, the review suggests that triangulation of a wider range of methods would be worthwhile.
- There were few studies comparing different methods for measuring person-centred care, so it is not possible to infer that a certain approach or tool is more or less effective than another.

It is useful to keep these points in mind, but there is a wealth of information about measuring person-centred care and this review is one step towards improving understanding of how this can best be done.

Figure 3: Selection of material included in the rapid review



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