

The state of play in person-centred care:

A pragmatic review of how person-centred care is defined, applied and measured.



Report summary

Ed Harding, Suzanne Wait, and Jonathan Scrutton

To read the full report see
<http://www.healthpolicypartnership.com/person-centred-care/>

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Why this report

Person-centred care is perhaps one of the most influential global discussions in modern healthcare. It is very much alive as an area of practice, theory, and research, and many organisations include it in their mission statements. Person-centred care also has a considerable presence within government policy across Europe and the English speaking world.

Few people would argue against person-centred care, but what does it really stand for, and why do we need it today? Certainly, terminology can be confusing, with a multiplicity of terms used to denote person-centred care. Good practice models have often been developed within the confines of their particular areas (e.g. by setting, disease, country, and sector). There is also significant ongoing debate as to many fundamental principles, such as conceptual definitions, or whether person-centred care can, or should, be measured. Yet there is promising evidence that many aspects of person-centred care are improving people's lives and making healthcare delivery more effective.

Most people agree on one key thing – healthcare today is rarely person-centred. Despite a great deal of progress, much of modern medicine and care is inflexible, episodic, and fragmented, and fails to see beyond a disease focus to engage holistically with the psychological or social dimensions of health and wellbeing. Person-centredness may be a real and achievable need in modern healthcare, but unfortunately it remains the exception rather than the rule.

But if person-centred care is to be achieved more equitably and consistently, several key questions need urgent attention. For example, what are the critical values and practices that differentiate person-centredness from normal care? What forms has person-centred care taken in different fields, and what common terms and practices may be applied across whole health care systems, if any? What lessons have we learned so far, and what are the barriers and opportunities we must address?

In response to some of these questions, the Health Foundation commissioned an international environment scan to build an overarching picture of the 'state of play' in person-centred care, to assess ongoing research, measurement and implementation in the field. The primary aim of this research was to identify some of the key contributions to the evolving field of person-centred care and to gain a better understanding of where this global discussion is going. This research resulted in two main outputs – a synthesis report ('The state of play in person-centred care'), and a directory of key organisations active in person-centred care. **A summary of findings from the report is included here.**

To view the full report, see

<http://www.healthpolicypartnership.com/person-centred-care/>

**To view the directory of key organisations
active in person-centred care see**

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About the research

The international environment scan was conducted in 2014-2015 as a pragmatic review of the scientific and policy literature in person-centred care, supported by an international call for information and interviews with 40 recognised figures in the field drawn from Australia, Germany, Canada, the Netherlands, New Zealand, South Africa, Sweden, the UK, and the USA. For a fuller description of the methods used and key findings from the research, please see the full report.

This summary was written by Ed Harding and Suzanne Wait, (The Health Policy Partnership) and Jonathan Scrutton, (The International Longevity Centre UK). Please note the views contained within this summary represent those of the authors and do not necessarily represent the views of the Health Foundation.

What is person-centred care?

There is no established global definition of person-centred care.¹⁻⁴ It is a multidimensional concept⁴ that can mean many different things to many people. We used a working definition as a guiding basis for our research (see below).

Four key principles of person-centred care⁵

Principle 1

Being person-centred means affording people dignity, respect and compassion

Principle 2

Being person-centred means offering coordinated care, support or treatment

Principle 3

Being person-centred means offering personalised care, support or treatment

Principle 4

Being person-centred means being enabling

Why person-centred care?

A range of other terms is often used to refer to similar principles and activities, for example 'patient-centred care', or 'personalisation'. In this research, we used the word 'person' in order to emphasise a holistic approach to care, that takes into account the whole person – not a narrow focus on their condition or symptoms but also their preferences, wellbeing and wider social and cultural background.⁶

However, much useful and aligned work exists under other terms, (as above) and we used the word 'patient' where it was helpful to refer to a person using or in need of healthcare.

Key findings – a diverse and evolving community of practice

There is some common ground in global definitions of person-centred care, but much richness and diversity as well.

Key commentators often use the literal definition of ‘care that is centred on the person’ as a point of departure.⁷ Humanitarian principles of mutual respect and individuality are also present in some form in all models, as is a recognition of the interdependency between health and wellbeing.

How do people understand person-centred care differently?

Around the world, key commentators give different *emphasis and priority* to different qualities of person-centred care. **These are not mutually exclusive**, but three key conceptual pillars emerged from the research:

Person-centred care as an overarching grouping of concepts

– i.e. that person-centred care is a coherent, holistic package of activities, principles, and enablers,^{8,9} designed to focus care on patient’s needs and circumstances. For example, this includes shared decision-making, self-management support, patient information, care planning, and integrated care, as well as better communication between healthcare professionals and patients.

Person-centred care as partnership

– i.e. the importance of recognising inter-dependency between patient and professional, and therefore the value of trust and mutuality. This may be expressed through various terms such as co-production, trust, partnerships and relationships, but at its heart is a recognition that optimal health outcomes must (and can only be) achieved by symbiosis and the sharing of knowledge and expertise within a healing relationship, or therapeutic alliance.¹³

Person-centred care emphasising personhood

– i.e. care practices rooted in a philosophy of people as ‘purposeful, thinking, feeling, emotional, reflective, relational, responsive to meaning’,¹⁰ where patients ‘are known as persons in the context of their own social worlds, listened to, informed, and respected.’¹¹ This underpinned by a fundamental principle that healthcare must accept a person as an end in themselves, not a means.¹²

The state of play in person-centred care

Person-centred care has evolved differently in different fields

There is huge diversity in best practice models, and an enormous opportunity for different fields of activity to learn from each other. For example, dementia has provided many leading practice models and measures that aim to uphold personhood.^{14,15} Cancer care has pioneered many examples of how to integrate communication and shared decision making into person-centred practice,¹⁶ but self-management support in the field appears to be underdeveloped.¹⁷ Alternatively whilst the dominant focus of self-management to date has been on managing chronic disease, defining the concept and clarifying its use in palliative care remains largely unresolved to date.¹⁸

There are many other notable strengths across the broad field of person-centred care, for example, family involvement in paediatric care, and patient and service user co-production of services in mental health.

However, a result of this diversity has been that innovation and research are often fragmented.^{3,19,20} For example, the relevance and transferability of measurement models across different disease areas is unclear.^{15 21 22} Equally, interpretation and application of models in a multidisciplinary environment may be challenging.²⁰

The lack of common definitions across fields may hinder implementation

Conceptual debates are still ongoing as to what constitutes person-centred care. Although sometimes complex, these are likely to be more than just a distraction from hands-on implementation and delivery challenges. For example, synthesis reviews of the literature identify lack of accepted common definitions to be one of the major barriers to the aggregation of research on effectiveness^{8 23} and on delivery and measurement.²²

The lack of conceptual clarity and clear definitions in the research may also impede the replication of successful innovations in care,²⁴ and the further isolation of cause and effect,^{19 3 24 25} which may be important in securing commitment from policy makers.²⁶

After an era of successful experimentation, mainstream implementation remains a challenge

The impact of person-centred care is promising, and there is significant proof of concept. But further research is needed to establish which aspects work consistently in the mainstream.³

Many measurement tools have been designed for research – and may need adaptation for everyday use.¹⁵ Yet policy makers will demand proof of outcomes, and likely, routine measures of success. Across disciplines, there are often different assumptions as to what person-centred care is expected to achieve – for example, whether improvements to patient experience or self-management skills are to be valued, or whether bio-medical outcomes and cost savings are to remain a ‘holy grail’.

Patients must shape the fundamental assumptions behind research and innovation – i.e. by defining from first principles what the problems are with existing models of care, what counts as success, and whether interventions are likely to improve ‘person-centredness’. Yet patient involvement in defining research priorities – and measurement tools – is too rare.¹⁵

Progress in implementation and measurement

As part of our research, we tried to identify key areas of activity in the implementation and measurement of person-centred care. A short summary is offered below.

1 Organisational development is a powerful tool to embrace person-centred care in practice

Peer behaviours and workplace cultures are a major factor in whether initiatives translate from aspiration into established practice. Several models have been developed to assess workplaces and organisations, and to lead change in support of more person-centred working environments.

CASE STUDY

The Clinical Excellence Commission (CEC), Australia^{27,28}

The 'patient-based care challenge' in New South Wales involves²⁶ improvement strategies in nine key domains of organisational improvement, spanning patient and family engagement, leadership, a learning organisational culture, a focus on the work environment and accountability.

2 Formal education and training are needed to equip the workforce for person-centred care

Practising person-centred care can be demanding, and requires a rounded mix of skills and expertise, which the current healthcare workforce may be lacking. For example, there is a consensus that medical training must provide better communication and shared decision making skills to students.

CASE STUDY

Person-centred Practice Research Centre, University of Ulster, United Kingdom²⁹

The Person-Centred Practice Framework is a widely recognised approach to workforce development which has been tested in many countries and settings. It is supported by standardised measures such as the Person-Centred Caring Index (PCCI), also developed at Ulster.



3 Support for professional ethics and values is vital - not just a 'nice to have'

Activating individual ethics and values in support of person-centred care is an emerging area of practice. Leading models offer guided group discussions and time for personal reflection, often to explore and identify individual motivations, aspirations, and to support psychological resilience, even in pressurised care environments.

CASE STUDY

Joining the Dots, Scotland, United Kingdom³⁰

Values-Based Reflective Practice is a structured programme based on liberation philosophy and theology, which aims to equip health and social care staff to practice person-centred approaches in their everyday care settings. The model is now widely used across health and social care in Scotland.

4 Communication, shared decision-making, co-production and self-management are some of the most operationalised components of person-centred care

At the heart of many models of person-centred care is the principle of partnership and exchange of knowledge between care professional and patient. There are several major strands of work in this vein, including structured listening, communication, shared decision making, self-management support, and care planning and goal setting.

CASE STUDY

The Gothenburg Centre for Person-centred Care (GPCC), Sweden³¹

The GPCC has developed a highly successful approach in heart failure based around 3 routines for listening, which acts as a foundation for shared decision making and person-led care planning. Promising outcomes include shortened hospital stays and improved functional performance.

5 Integrated care and health IT can be huge enablers of person-centred care

Some leading definitions of integration and coordination in the context of healthcare have affirmed the needs and perspective of the patients as the dominant organising principles. Health information technology has also formed a significant part of integrated and person-centred approaches, such as via patient registries, shared care records, and self-management support.

CASE STUDY

The Veterans Health Association, USA³²⁻³⁴

The VHA's Patient Aligned Care Team is a major programme that aim to provide proactive, personalised, team-based care oriented toward wellness and disease prevention. The VHA also offer online access to personal health records for millions of people.

6 Measurement is a critical test for person-centred care in the mainstream

Many key commentators believe the routine measurement of person-centred care is a vital enabler for consistent implementation. Patient satisfaction, patient experience, and patient reported outcome measures (PROMs) have been a major performance focus in recent years,³⁵ although the limitations of such data to measure person-centredness are increasingly being exposed.

CASE STUDY

International Alliance of Patients' Organizations (IAPO)³⁶

IAPO is leading international research to identify good practice in measures of patient-centredness to develop a robust set of indicators.

7 We need to develop, and apply, more person-led outcomes and measures

Moving away from standardised measures is an urgent priority in person-centred care, not least due to evidence that what really matters to patients varies enormously across settings, areas of care and different individuals. The art and science of setting and monitoring such outcomes is a relatively new one, and a great deal of research is concerned with the experimental and proof of concept stage.

CASE STUDY

United States, The Patient-Centered Outcomes Research Institute (PCORI)³⁷

PCORI is developing new models of care and measurement that reflect the issues most relevant to patients. Patients help to shape organisational strategy and are consulted at all stages of research.

Conclusions – the barriers and opportunities ahead

Person-centred care is a rich and evolving global discussion. It has been enshrined into formal policy and guidance in many countries and fields, and enjoys considerable influence. However, the implementation of person-centred approaches in the mainstream is still tentative and limited to specific settings or conditions, and lags behind more ambitious policy aspirations.

Across the field, a number of barriers and opportunities were identified which inform the challenges ahead in securing a more person-centred healthcare system, highlights of which are provided below:

- **There is enduring confusion among healthcare management and care professionals as to what person-centred care really means.** This can result in superficial uses of the term, scepticism and active resistance. Whatever models or values are chosen, it will be important to differentiate their unique contribution to good practice.
- **Implementing person-centred care will require a comprehensive and whole system approach,** for example, starting with the formal education and training of healthcare professionals, but also efforts to enable a deeper personal understanding of relevant ethics and values within all staff.
- **Equally, no aspect of this whole system challenge can be done without patients.** Yet it still appears to be rare to fully involve patients in research, measurement, organisational change or professional training.
- **Embedding person-centred practice will require honesty and realism at the organisation and healthcare team level** – meaning frank and mature discussions about the realities of everyday care, conflicting demands on care professionals, delegation and risk.
- **Health inequalities cannot be allowed to grow** – person-centred care may be particularly beneficial to vulnerable and disadvantaged populations, for example, but policy makers must anticipate a variety of different needs, assets, and barriers to participation across whole populations. Also, they must ensure it is not just the most health literate and empowered who benefit.
- **Different perspectives on what counts as success need to be reconciled** (e.g. psychological, ethical, or medical outcomes, or processes measures) if the delivery and measurement of person-centred care is to function well, not least in multi-disciplinary settings.
- **Measures must be carefully chosen, and their limitations acknowledged.** Any incentives can quickly become a double-edged sword, and other supportive strategies such as supporting workplace cultures must not be overlooked. Quick and practical measures may be required in everyday care settings and measurement overload avoided.
- **Person-centred care must benefit more from learning and experience in other fields.** For example numerous barriers and opportunities for delivery have been identified and explored in other related fields in the holistic tradition, such as in patient-centred care, or integrated care.



Read more in the full report and international directory



About the report

The report includes an introduction, summary of findings, and a contextual overview of person-centred care, including key conceptual groupings and strategic research issues.

The main body of the report is organised around seven practical themes in implementation and measurement. Each theme includes:

- Key summaries
- Original quotes from leading stakeholders and excerpts from key literature
- Leading definitions
- Succinct background and context to each issue
- Assessment of the state of play and progress so far
- A shortlist of relevant key contributors and selected key reading

The full report can be read here: www.healthpolicypartnership.com/person-centred-care/

About the directory of key organisations active in person-centred care

The international environment scan identified 64 organisations as key contributors within the field of person-centred care, details of which were captured into a directory, with details such as:

- Overview of activities, networks and key projects
- Mission statements
- Key publications
- Web links

In addition, several enhanced organisational profiles were created. These can all be found in a downloadable spreadsheet here: <http://personcentredcare.health.org.uk/around-the-world>



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The Health Policy Partnership Ltd
5 Chancery Lane, London WC2A 1LG, United Kingdom
Company registered in England and Wales no. 9258848