The Health Policy Partnership

The state of play in person-centred care:

A pragmatic review of how person-centred care is defined, applied and measured, featuring selected key contributors and case studies across the field.

Full report

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LIST OF INTERVIEWEES

The authors would like to give their considerable thanks all those key figures who agreed to be interviewed, and cited, within this report – all of whom gave the benefit of often lifelong experience and knowledge of the field. This report would not have been possible without them.

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PART 1: INTRODUCTION

i.   About this report

In April 2014 the Health Foundation commissioned the Health Policy Partnership to undertake an international Environment Scan in person-centred care. The Health Foundation wanted to find out who was doing what in person-centred care, what different people mean by the term, and where this important global discussion might be going.

The Health Policy partnership set out to build a global picture of key contributors involved in person-centred care – (e.g. researchers, coordinators and implementers acting as focal catalysts for change) – and to create an overarching picture of the 'state of play' in research, implementation and measurement of person-centred care, looking also at the future direction and gap analysis of each of these fields, and highlighting key work, barriers and opportunities to progress.

The synthesis report and catalogue of key contributors

The Health Policy Partnership provided two major outputs from an international environment scan in person-centred care: a research synthesis (this document) and a catalogue of key contributors, including several organisational profiles. These resources are intended to reinforce each other and be used in parallel.

- More information on research methodology is contained in the **Appendix.**
- To view the accompanying catalogue of key contributors, see the Health Foundation website http://personcentredcare.health.org.uk/around-the-world

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ii.   Working definition of person-centred care

It is a common observation in other research that there is no single definition of person-centred care, and that person-centredness in health and care is a multidimensional concept[1] that can mean many different things to many people.

This research drew on earlier work sponsored by the Health Foundation to help create a working definition of person-centred care (see below). This definition was used to inform the research protocol (featured in the **Appendix**.)

Four key principles of person-centred care[2]

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

Collins A. Measuring what really matters. The Health Foundation, London, 2014.

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Furthermore, the following additional principles were adopted as helpful further clarification of person-centred healthcare:

- Patients are partners in their own health and health care, and the person should be the focus of health care, not their illnesses or conditions.
- A person-centred healthcare system is one that supports people to make informed decisions about and successfully manage their own health and care, including choosing when to let others act on their behalf, and one that delivers care responsive to people's individual abilities, preferences, lifestyles and goals.
- Achieving a person-centred system requires a change in behaviour and mindset from patients and clinicians, supported by a system that puts patients at its heart.

Early research established that other terms such as 'patient-centred care', and 'patient and family-centred care' were likely to help identify supportive and aligned work, as were terms that referred to specific models, instruments or principles that are fundamental to person-centred care, such as 'shared decision making', 'self-management support' and 'patient engagement'. A full list of these aligned terms is available in the Research Protocol, in the **Appendix.**

iii.   How to use this document

This synthesis report is intended to be read alongside the accompanying catalogue of key contributors on the Health Foundation website (see above). The aim of the synthesis report is to assist readers to orientate themselves across a diverse and evolving field in which terminology can be unclear or even at times contentious (e.g. the overlap with related terms such as 'patient-centred care' or 'patient engagement'), where context is often vital (e.g. setting, disease, country, sector) and where ongoing debate is a vital lens through which to understand existing work in the field (e.g. the feasibility and value of measurement in person-centred practice).

The overview of person-centred care provides an introduction, overview of context, conceptual groupings and strategic research issues, and the **practical themes** sections summarise key findings across seven practical themes in implementation and measurement. .

Key summaries are included at the front of every section, and the sections on implementation and measurement come with an overarching context at the front, including key definitions and assessments of progress so far. These are mirrored by a digest of barriers and opportunities at the end.

The seven practical themes all follow a set template:

- a key summary ('essential knowledge')
- definitions ('what does it mean')
- value and role within the debate on person-centred care ('why is this important')
- an assessment of the state of play ('progress so far')
- supporting information in the form of a shortlist of relevant key contributors; and
- Selected key reading identified by the international environment sca

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PART 2: SUMMARY OF FINDINGS

In 2014 the Health Foundation commissioned the Health Policy Partnership to undertake an international environment scan in person-centred care. The Health Policy partnership set out to build a global picture of key contributors involved in person-centred care – (e.g. researchers, coordinators and implementers from all backgrounds acting as focal catalysts for change) – and to create an overarching picture of the 'state of play' in research, implementation of measurement of person-centred care, looking also at the future direction and gap analysis of each of these fields, and highlighting key work, barriers and opportunities to progress.

Key findings are summarised below.

a) Preface - reflections from the authors

This report aims to provide a clearer and more comprehensive picture of the different schools of thought and ongoing associated activities around the world. Our research was able to identify a number of common themes that arise in the literature or in discussions with key commentators. It also identifies some key contributors to the field of person-centred care around the world.

A substantial international body of work currently exists; much of it is ranged across a heterogeneous and evolving community of person-centred care, with complex synergy between person-centred care and other associated terms (e.g. patient-centred care, patient- and family-centred care, shared decision making, patient engagement and patient empowerment), each of these also heterogeneous terms, each of these also evolving.

Despite a great deal of common ground on person-centred care in the UK and around the world there are also many different views, assumptions and nuances that cannot be reconciled, some of which we explore later in this report. Given the environment described above, establishing a definitive and shared agenda for research, implementation and measurement *across the entirety* of concepts and models that are commonly associated within person-centred care has not been possible within the scope of this work. Meta-reviews and position statements (rightly) reflect individual or organisational understandings of person-centred care and must be interpreted carefully; the findings of one may not automatically be accepted or valued by all key contributors, depending on the assumptions and values underpinning each author's values set.

Inevitably there has been a cut-off point, and we end this current phase of work mindful that we simply have not been able to connect with every key contributor who would doubtless have added further richness and insight. This report cannot aim to replace the dedicated focus offered elsewhere, for example in meta-reviews or strategic position statements, on associated topics such as shared decision making, self-management support, health literacy or others. While focal to the mission of person-centred care, this depth cannot be reproduced in this report without extending it by several orders of magnitude. We do not claim therefore that this report is a comprehensive one,

although we did set out to listen and learn from commentators across a wide variety of backgrounds and specialisms.

Beyond our decision to include research and commentary on the grounds of relevance and compatibility to the Health Foundation's own definition of person-centred care (see above), we have not set out to evaluate or judge. The exclusion of any material from this report is not necessarily a rejection of its value. We were mindful that within this 'close family' each key contributor we spoke to conveyed a deep personal calling (and often the dedication of a lifetime of work) to better understand and promote the interests of the person, patient and fellow citizen. Indeed, much of the variation in values, definitions and practices reflects the unique context of a given country, region, disease group (or groups), or setting of care.

Person-centred care is a rich and evolving discussion, which belongs to many commentators, and of course, to all people, and patients. Doubtless then, each reader will continue to reach their own conclusions as to how and why 'person-centred care' has value, what its essential elements are, and they wish to absorb, reflect, or reject from this work.

We hope our report is a useful catalyst to this important process, but we recognise from the very beginning that understanding person-centred health care is (and may always be) an individual journey.

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b) 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. [3] 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,[4,5] 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 emphasising personhood** – i.e. care practices rooted in a philosophy of people as 'purposeful, thinking, feeling, emotional, reflective, relational, responsive to meaning',[6] where patients 'are known as persons in the context of their own social worlds, listened to, informed, and respected.'[7] This underpinned by a fundamental principle that healthcare must accept a person as an end in themselves, not a means.[8]

- **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.[9]

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c) 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.[10,11] Cancer care has pioneered many examples of how to integrate communication and shared decision making into person-centred practice,[12] but self-management support in the field appears to be underdeveloped.[13]

There are many other notably strengths across the broad field of person-centred care, for example, family involvement in paediatric care, and self-management in chronic disease, 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.[14,15] [16] For example, the relevance and transferability of measurement models across different disease areas is unclear.[11 17 18] Equally, interpretation and application of models in a multidisciplinary environment may be challenging.[16]

➤ **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[4 19] and on delivery and measurement.[18]

The lack of conceptual clarity and clear definitions in the research may also impede the replication of successful innovations in care, [20] and the further isolation of cause and effect,[15 14 20 21] which may be important in securing commitment from policy makers.[22]

➤ **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.[14]

Many measurement tools have been designed for research – and may need adaptation for mainstream use.[11] Yet policy makers will demand proof of outcomes, and likely, 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.[11]

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d) Progress in implementation and measurement

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

➢ **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 [23,24]

The 'patient-based care challenge' in New South Wales involves 26 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.

➢ **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 Kingdom[25]

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.

➢ **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 Kingdom [26]

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.

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> ➤ **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), Sweden[27]

The GPCC has developed 3 routines for listening, which acts as a foundation for person-led care planning. Outcomes include shortened hospital stays and improved functional performance.

> ➤ **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, USA [28-30]

The VHA's Patient Aligned Care Team is a major programme that aim to provide a 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.

> ➤ **Measurement is a critical test for person-centred care**

Many key commentators believe the routine measurement of person-centred care is a vital enabler for consistent mainstream implementation. Patient satisfaction, patient experience, and patient reported outcome measures (PROMs) have been a major performance focus in recent years,[31] although the limitations of such data to measure person-centredness are increasingly being exposed.

Case study: International Alliance of Patients' Organizations (IAPO)[32]

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

> ➤ **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)[33]

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

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PART 3: AN OVERVIEW OF PERSON-CENTRED CARE

(a)   An international community of person-centred practice

i.   Key findings

- **Person-centred provokes a fundamental questioning of the essence of healthcare**, its meaning and the purpose of health systems -
- **A multidimensional concept** – person-centred care is understood in many different ways by many different people, and a diverse global community of key contributors has emerged.
- **Person-centred care is part of a holistic paradigm** – virtually all key contributors agree that healthcare is currently too inflexible, episodic, and fragmented, and fails to see beyond a disease focus to engage with psychological and social determinants of health and wellbeing.
- **There is a broad, multidisciplinary community of key contributors working in person-centred care.** Key commentators debate and align with other more specific qualities of person-centredness, with different groupings on conceptual lines and also practical methods of delivery.
- **Context has shaped person-centredness in different settings and areas of care** – diversity in definitions and emphases may reflect the different needs of different populations and healthcare settings.
- **Some disciplines and care groups have been particularly fertile ground for distinct aspects of person-centred best practice** (e.g. communication and shared decision making in cancer and fertility treatment, care planning and self-management support in long-term conditions, preservation of personhood in dementia care, family involvement in paediatric care, and patient and service user co-production of services in mental health).
- **Person-centred care does not always translate** – person-centred care is not always understood or valued equally across different countries, languages and cultures.

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ii.   A movement, a community, a trend, or none of the above? Making sense of the phenomenon of person-centred care

"The good physician treats the disease; the great physician treats the patient with the disease"

Sir William Osler (1849-1919)

There is a long tradition of efforts to improve the humanity, comprehensiveness and effectiveness of healthcare practices that extends back over many centuries. Person-centred care is a relatively modern incarnation of these efforts, and is a term that provokes, inspires and brings minds together today. It has succeeded in rallying countless people across the world to a more humanist, holistic and sustainable agenda for change in healthcare.

Person centred care has won influential champions within governments and health care systems. Policy makers around the world have encapsulated an aspiration for person-centred care and similar models at the highest level, and person-centred practices are arguably dominant in some areas and settings of care. However the phrase has not passed without challenge by those who find its meaning unclear, or who see greater value and clarity in other conceptual models and phrases.

iii.   Person-centred provokes a fundamental questioning of the essence of healthcare, its meaning and the purpose of health systems

Person-centred care is arguably one of the seminal topics in health policy today. The term provokes a broad, substantive and multidimensional debate on the meaning of healthcare and the purpose of health systems – e.g. what they are for, how they should work, how patients (or citizens) would each expect to experience care and support.

For most of its proponents, the term defines the progressive debate on quality and sustainability in healthcare. It has won and held hearts and minds around the world, been adopted into formal policy and guidance in many countries and fields, and still retains considerable currency.

As discussed further below, significant recognition has been awarded to person-centred care and associated terms (particularly patient-centred care) in high level policy in many countries, certainly the UK, USA, Australia, regions of Canada,[4,8] as well as Denmark,[34] the Netherlands[35] and others, and has been summarised as having 'made it to centre stage in discussions of quality'.[8]

iv.   Person-centred care – a multidimensional concept

"Thus, person-centredness encompasses multiple meanings that cannot be summed up under one notion. In other words, it is a multidimensional concept. What is more, person-centredness not only covers several ideas, each of these ideas can be (and has been) interpreted in a variety of ways." [1]

Leplege A, Gzil F, Cammelli M, et al. Person-centredness: conceptual and historical perspectives. Disability & Rehabilitation 2007;29(20-21):1555-65.

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> *"It is not possible to produce a simple map of person-centred care – or to give a simple answer to what it is. Person-centred care is not a dismantled jigsaw puzzle – the pieces will not (line up neatly and) fit together as one."*
>
> Prof Alan Cribb, King's College London, United Kingdom

That person-centred care is understood in many different ways by many different people is a point raised in many leading reports and materials [1 14 36 37] By definition, the term is often considered to be equivalent to 'care that is centred on the person',[38 3] or care of the 'whole person',[7] yet behind these truisms lies almost immediate complexity and divergence. How, for example, are we to understand a person, and to apply this seemingly abstract concept to healthcare? Do we hold in our minds a classical definition of personhood, or a bio-psycho-social 'whole person' model, or both? What does 'centred' mean in this instance – and what degree of orientation or alignment does it suggest, what is feasible and possible, and who decides? What is a meaningful package of care and support, and how does this change across different conditions and populations? As is commonly noted, few would argue against person-centredness, (or argue for doctor-centred care for example),[39] but such debates may rapidly flush out quite different underlying assumptions and values.

v. Part of a holistic paradigm of care

> *"There is a raging debate about these terms (person-centred care, patient-centred care, patient- and family-centred care, patient experience, and patient and family engagement). It could be positive, it could bring us together, but could drive us apart."*
>
> Beverley H Johnson, Institute for Patient- and Family-Centered Care, USA

Any analysis of person-centred care must navigate a quite heterogeneous body of literature and commentary and innovative practice. Not all that is arguably person-centred is necessarily labelled as such – and naive and tokenistic usages of the phrase are reported to be commonplace.[40,41] Most notably, the conceptual phenomenon of person-centred care clearly overlaps, draws from and is co-evolving alongside other similar groupings (for example those grouped by the terms patient engagement, empowerment, patient-centred care, relationship-centred care, client-centred care or patient- and family-centred care, or co-production, consumer and community engagement).

Similarly, these terms may themselves also be best understood as complex phenomena, and multidimensional concepts, lacking single definitions and subject to continual debate, evolution and revalidation.[16 42-45]

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vi.   A community of many movements and groupings

> *"We are championing a perspective on person-centred care – there is no one definition, but among colleagues there is a discernible school of thought. Colleagues take a very international perspective – we are informed by work in the USA, UK, Europe, and beyond – international trends form a large part of this perspective."*
>
> Dr William Levack, University of Otago, New Zealand

This review asked if person-centred care was a recognisable movement for change. Although the term appears in a vast amount of literature, this alone would not justify seeing it as a cohesive and defined whole.[46] Currently, it is difficult to evidence any single movement that encapsulates everything to do with person-centred care, but within this broad phenomenon of person-centre care is arguably a diffuse community sharing a holistic paradigm,[14] interwoven with schools of thought, networks and subgroups.[47 48]

The relationship between person-centred care and other terms is not straightforward. Some key contributors and policy papers embrace commonality between a range of terms.[4 11 14 49 50] Others affirm distinctions, noting for example that behind the seemingly like terms lie quite different values and histories.[16 45]

Strong and potentially opposing political and ethical views can come into play when comparing similar terms. For example, 'client-centred care' may have connotations of market liberalism to some, and therefore be a source of concern – i.e. that treating patients as clients or consumers may be contrary to care and therefore the true mission of 'person-centredness'.[38 51-54] Alternatively the term 'client' may be a neutral and acceptable term in some professions (such as occupational therapy).[37]

> *"We need a 'careful and kind' system – we must differentiate 'patient-centred care' from the current corrupt mission to see patients as the 'centre' of the healthcare economy and market."*
>
> Dr Victor Montori, Mayo Clinic, USA

An example of one such issue is the difference in nomenclature between 'patient' and 'person'. Upholding the term 'person' is held by some to be an important principle in the fight against enduring medical paternalism and the corruption of medical ethics,[55-57] or the qualities of the person may be upheld as critical to the ethics and goals of a given area of care, such as in dementia,[11] people living in residential care and nursing homes,[58] or the very practice of ethical healthcare itself.[59-61]

Finally, to other key contributors the whole debate may be regarded as one of nomenclature[19] or as an unproductive semantic distraction.[46 55 62] The proliferation of related terms is to others confusing and unhelpful.[63]

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vii.   Context has shaped person-centredness in different settings and areas of care to date

*"There are notable differences in how different healthcare professionals view person-centred care. For example, occupational therapists **have** to engage with the person – it is not possible to operate through a bio-medical model alone."*

Prof Nicky Britten, University of Exeter Medical School, United Kingdom

"In mental health, earlier terms of 're-ablement' and 'rehabilitation' have been overtaken by 'recovery' – this acknowledges the role of the individual, their identity, and the importance of real lives. Professional competency is about both technical skills and personal qualities. My experience of the acute sector is that the mindset is still very different."

Susan Morris, Macmillan Cancer Support Wales, United Kingdom

Many of the different values and properties within schools of thought in person-centred care are rooted in context – i.e. the explicit and possibly implicit assumptions of what it stands for (or against) in the minds of each commentator, organisation or network.

Plurality in the field reflects a number of interwoven lineages of theory and practice of person-centred care,[1] with discernible histories but significant cross-fertilisation. In this fashion, communication and shared decision making is a leading area of person-centred practice in cancer[12] and fertility treatment.[64] Other areas have their own marked themes in person-centredness – family and patient engagement in children's and adult healthcare,[65] personal goal setting in rehabilitation,[48] recovery, self-efficacy, and patient and service user co-production of services in mental health, [66-69] self-management in diabetes, and so on. In dementia, person-centred care is a central framework for best practice,[10] albeit shaped around the imperative of preserving personhood against the effects of dementia[11] and the challenge of communication between care professional and person.[70] Person-centred care models for older people may stress self-care alongside support for housing and tenancy, social engagement, and mobility.[71]

Special focus: Person-centred care in dementia - National Institute for Clinical Excellence, UK

"There is broad consensus that the principles of person-centred care underpin good practice in the field of dementia care and they are reflected in many of the recommendations made in the guideline. The principles assert:

- the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
- the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
- the importance of the perspective of the person with dementia
- the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being

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The [fifth] principle emphasises the imperative in dementia care to consider the needs of carers, whether family and friends or paid care-workers, and to consider ways of supporting and enhancing their input to the person with dementia."

Dementia: supporting people with dementia and their carers in health and social care
NICE guidelines [CG42]. NICE, 2006.

https://www.nice.org.uk/guidance/cg42

Groupings and patterns are also discernible across contexts such as geographies[16][72] the settings of care (e.g. acute or community)[11] and sectors (e.g. patient advocates, clinicians, academics).[1][5] For example the term 'patient-centred care' may be more commonly associated with the acute and hospital setting,[11] whereas 'client-centred care' is more prominent in the North American residential and nursing home setting.[16]

"Expectations regarding person-centredness may vary, depending on the setting. In residential and nursing home care we're talking about people who live there, so quality of life is key. You wouldn't necessarily think about quality of life in a hospital, you would think about quality of care."

Prof Sheryl Zimmerman, University of North Carolina, USA

Different emphases are also visible by sector and contexts. As noted later, significant differences exist in the research achievements to date across different areas of disease. In the medical sphere person-centredness may be thought of as a reconnection with traditional values, or even a process of co-empowerment of the clinician, who has been forced from ethics and practices of the past by the advance of care protocols, capacity demands, growing social and economic gulf between physicians and patients, and the steady delegation and specialisation of care.[38][51][53][73] In particular, the focus of evidence-based medicine often without taking account of individual preferences is cited as a major factor in the loss of person-centredness in the medical profession – i.e. the erosion of skills and qualities of human connection, trust, and decision making in the context of the patient's life and individual characteristics.[53][74]

"Evidence-based medicine has become the dominant framework in medical practice. But people forget that research alone doesn't tell you what is best for a given patient with their own preferences and in their own context. Conversations have often been insufficient, lacked context, and made a lot of assumptions about patients' needs. How can we create better conversations, better decisions based on evidence? Clinicians should bring the evidence to a conversation with the patients, and then deliberate and decide together."

Dr Victor Montori, Mayo Clinic, USA

Equality of access to healthcare is a notable theme in medical organisations active at the global level,[38] as is the inclusion of a population-level focus lifestyle within people-centred health.[75] Patient

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involvement in health policy at the strategic level may be upheld as an important domain of person-centredness.[21] Within the disability and patient and service user rights movement, person-centred models may emphasise the social inclusion or the social model of disability (i.e. how services and society stop disabled people being equal and having control over their own lives) and self-directed support models, including planning or controlling personal budgets, and more prominent discussions about perceptions of risk.[1 5 51 76]

viii. An Anglo bias? 'Person-centred care' does not always translate

> *"Person-centred care is arguably a Western notion – to focus on structuring healthcare around individuals. In other cultures the individual is not necessarily the best or only focus for healthcare, and instead family wellbeing or community wellbeing might be considered more important."*
>
> Dr William Levack, University of Otago, New Zealand

Another important context is that of language and culture. A major review in patient engagement noted that the meaning of the term was heavily dependent on the cultural context of the country or community, including social norms, regulations, beliefs, and social determinants of health.[44]

Country-specific nuances are clear in the meaning ascribed to person-centred care. In the UK, for example, several key policy reports connect the value and purpose of person-centred care (and closely related terms) as important corrective measures in light of recent national care scandals.[77 78] In the US, leadership is more visible at the level of the healthcare provider, reflecting a more market-oriented system where the levers for reform are considered to rest to a greater degree at the organisational level.[79] In one European former communist country, person-centredness is reported to be understood in contrast to Soviet-era dogma, centralism and the subordination of the individual, and its proponents see an embrace of intellectual openness and liberal Western values therein.[80] Resource limitations and expediency may also be a factor in low and middle income countries, particularly with regards to patient information, self-management support and family and carer involvement.[81] For example, one interviewee reported that in Africa it is the norm for a family member (usually mother or grandmother) to stay and provide personal care to a child that has been admitted to hospital. Reportedly, therapeutic education to enable mothers to care for their children with tracheotomies at home are safely completed within just six weeks after insertion of the tracheotomy, whereas in the UK it can often take more than a year to prepare to discharge a child with similarly complex needs.[81]

The meaning ascribed to person-centred care may be readily compatible across countries with a closer shared language, heritage and values (e.g. the UK and Australia),[38] or within Western Europe and English-speaking countries. Certainly, 'person-centred care' does not always translate in a recognised or meaningful way into another language, context or culture.[62 60]

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"In some settings, European and other, many cultural and generational factors mitigate against practical operationalisaton of the concept. This is especially evident in societies that are strongly hierarchical and/or patriarchal. Patient-centred care simply doesn't often fit well in the daily repertoire of practitioners indoctrinated within such patriarchal societies and healthcare systems."

Prof Richard Osborne, Deakin University, Australia

In the Netherlands and Norway for example, key commentators report the term translates well and acceptance for the resulting phrase is growing.[70] [51] However, in Germany the leading equivalent term –'*Patientenorientierung*' – is reported to carry quite different connotations to how most people understand person-centred care (i.e. it imparts much less challenge to traditional paternalistic values).[82] In the Netherlands, where person-centred care may only recently have come to prominence, organisations who adopt the phrase may consider themselves front runners,[51] and person-centred care may still on occasion be labelled a 'foreign' (i.e. Anglo) concept, of questionable relevance.[52] Certainly, person-centred care and other similar terms (notably patient-centred care) appear to enjoy much greater adoption into high level policy in English speaking countries,[8] [19] [4] and meta-reviews on topics such as shared decision making may still reveal the majority of studies originating in English-speaking countries.[83]

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ix.   Selected key reading identified by the international environment scan:

- Bright FA, Kayes NM, Worrall L, et al. A conceptual review of engagement in healthcare and rehabilitation. Disability & Rehabilitation 2014(0):1-12.
- Brookman C, et al. Client-Centred Care in the Canadian Home and Community Sector: A Review of Key Concepts. Final Report, Saint Elizabeth 2011.
- Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Affairs 2013;32(2):223-31.
- Epstein RM, Street RL. The values and value of patient-centered care. The Annals of Family Medicine 2011;9(2):100-03.
- Edgman-Levitan S, Brady C. Partnering with patients, families, and Communities for health: a global imperative: Report of the patients and family engagement working group. World Innovation Summit for Health (WISH). 2013. www.wish-qatar.org/app/media/380
- Härter M, van der Weijden T, Elwyn G. Policy and practice developments in the implementation of shared decision making: an international perspective. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen 2011;105(4):229-33.
- Kitson A, Marshall A, Bassett K, et al. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. Journal of Advanced Nursing 2013;69 (1):4-15.
  http://www.ncbi.nlm.nih.gov/pubmed/22709336
- Leplege A, Gzil F, Cammelli M, et al. Person-centredness: conceptual and historical perspectives. Disability & Rehabilitation 2007;29(20-21):1555-65.
- McCance T, McCormack B, Dewing J. An exploration of person-centredness in practice. OJIN: The Online Journal of Issues in Nursing 2011;16(2).
- Miles A, Asbridge JE. Clarifying the concepts, epistemology and lexicon of person-centeredness: an essential pre-requisite for the effective operationalization of PCH within modern healthcare systems. European Journal for Person Centered Healthcare 2014;2(1):1-15.
- Olsson LE, Jakobsson Ung E, Swedberg K, et al. Efficacy of person-centred care as an intervention in controlled trials – a systematic review. Journal of clinical nursing 2013;22(3-4):456-65.
- Scholl I, Zill JM, Härter M, et al. An Integrative Model of Patient-Centeredness – A Systematic Review and Concept Analysis. PloS one 2014;9(9):e107828.

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(b) Key groupings and concepts in person-centred care

i. Key findings

There are shared concepts within the community of person-centred care:

- **Common ground** – key commentators often use the literal definition of ''care that is centred on the person' as a point of departure. Humanitarian principles of mutual respect and individuality are present in some form in all models, as is the relationship between health and wellbeing.
- **Shared concepts and origins with other models and terms** many key contributors draw from, and are active in, a wider family of terms such as patient-centred care, patient- and family-centred care and patient engagement.
- **Different emphases and schools of thought** – commentators give different *emphasis and priority* to different qualities of person-centred care. **These are not mutually exclusive**, but include:

    - **An overarching grouping of concepts** – person-centred care gathers a number of distinct concepts and practices and makes better sense of them as a coherent whole, e.g. shared-decision making, care planning, information, or patient engagement, among others.
    - **Personhood and anti-reductionism** – healthcare professionals using an existential and philosophical understanding of personhood to better engage with the patient, address their unique needs, and align with the patient's own values and aspirations.
    - **Partnership, mutualism, co-production** – an understanding that through partnership, mutual respect and self-knowledge, medical expertise can combine with patient self-knowledge for maximum benefit.

ii. Common ground

> "Understanding the term simplistically and literally, person-centeredness is all about putting patients first, at the center of health and social care, that is respectful and responsive to individual patient preferences, needs and values."[84]
>
> Hudon C, Fortin M, Haggerty JL, et al. Measuring patients' perceptions of patient-centered care: a systematic review of tools for family medicine. The Annals of Family Medicine 2011;**9**(2):155-64.

As mentioned previously, there is no single definition for person-centred care. However, common themes emerge across leading models. As per the meaning of the term 'person-centred', in all models huge value is attached to establishing the person as the primary focus of care – that is to say, that the person is elevated above other beliefs and values considered to be a distraction from, or in opposition to, the true ethical focus of humanist medicine and care.[7] The principles of respect, dignity, patient expertise, patient engagement, patient empowerment, coordinated and comprehensive care, and recognition of health and wellbeing as interdependent factors are present at some level in all leading models. [4 14 61 74 85 86]

iii. Beyond the literal meaning, person-centred care is also commonly upheld as what it is against, as much as what it is for.[4 38 61]

That is to say its leading proponents find grave fault with the 'status quo', (e.g. medical paternalism; reductionist medical approaches; objectification of the individual and human distance between professional and patient; inflexible and/or fragmented care modelled to the immediate convenience of the service provider; and a focus on illness and disease to the neglect of the whole person as a spiritual, bio-psycho-social entity).[1 11 36 75 78 84 74]

iv. Shared concepts and origins with other models and terms

In navigating the literature on person-centred care, it is helpful to note that most key contributors draw on definitions and research from the wider holistic paradigm of similar models and principles such as patient-centred care, client-centred care, and patient engagement. Commonality is perhaps most upheld between person-centred care and 'patient-centred care', which has been stated by key commentators as having meaningful dynamics,[56] similarity in philosophy and practice,[11 87] a shared fundamental approach to care,[4] an important and complementary focus [49 52] and shared origins.[14]

> "The concept of person-centred care has its roots within a holistic paradigm, which suggests that people need to be seen in their bio-psychosocial entity and draws medical attention to patients' personal identities. Person-centred care is intended to personalise care, or to compensate for our inability to predict and adapt care to exceptions from the medical norm."[14]
>
> Olsson LE, Jakobsson Ung E, Swedberg K, et al. Efficacy of person-centred care as an intervention in controlled trials – a systematic review. Journal of Clinical Nursing 2013;22(3-4):456-65.

Accordingly, it is helpful to reference some of the most prominent literature in patient-centred care, for example the US Institute of Medicine's (IOM) 2001 definition, which has been widely recognised as a conceptual foundation for how many people understand person-centred care today.

Special focus: Definition of patient-centred care – US Institute of Medicine (IOM) 2001[88]

"Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care."

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v. Different emphases and schools of thought within person-centred care

"Each organisation has to find its own way of implementing person-centred care given its history, strengths and weaknesses – there is worth in multiple voices that create an ever more noticeable chorus."

Dr Dominick Frosch, Gordon and Betty Moore Foundation, USA

Beyond these commonalities, richness and depth are discernible upon closer inspection of different models of person-centred care. It is important to note that conceptual 'schools of thought' within person-centred care **do not neatly divide, and are not mutually exclusive**. Rather, different commentators will draw from some or all of these themes and typically give different *emphasis and priority* to different qualities of person-centredness.

vi. Person-centred care as an overarching grouping of concepts

"It is helpful to think of patient-centred care as representing a collection of components (e.g. health literacy, shared decision making, communication). [Prof Ron] Epstein called patient-centred care a moral framework, and this is important, but having done this, if you want to teach or evaluate it, you need to be able to break it down."

Prof Phyllis Butow, University of Sydney, Australia

One of the primary ways key contributors emphasise and construct person-centred care is as an overarching grouping of concepts – a conceptual and organisational superstructure through which a variety of sub-themes, mechanisms and specialisms (like attitudes, behaviours etc.) in healthcare come together and represent a coherent and more meaningful whole.[5 39 41 47 55 60 82] This will usually span the health and care setting, and may extend into care and services outside of the traditional medical sphere (housing, financial support, social interaction), family and friends[45 89] or equally interventions to assist with issues 'outside' of health such as lifestyle and behavioural change.[58 75]

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In this theme, person-centred care is both an outcome (i.e. something that can be achieved for people) and a process (i.e. a method of delivering care and support) that can be realised by combined application of a range of different contributing concepts and mechanisms; for example, shared decision making (SDM), self-management support (SMS), patient–professional communication, health literacy, patient engagement, care planning, and integrated or comprehensive care. [41][47][82][5] Some key commentators active in these various 'contributing' fields have also embraced this relationship (i.e. that empowerment, engagement and shared decision making contribute towards 'person-' or 'patient-centred care').[21][44]

> *"Individual approaches such as shared decision making or specific patient information are useful and important, but person-centred care can integrate these fields and give focus and direction to each composite part. This would make the comprehensive care model clearer to patients and clinicians, with the ultimate goal of improving care."*
>
> Prof Martin Härter, University Medical Centre Hamburg-Eppendorf, Germany
>
> *"It makes sense to think of person-centred care as made up of different 'pillars' and components, for example shared decision making, self-management support, PROMS, patient information, health literacy, patient- and family-centred care, and communication between patients and professionals, although in the past these have often felt like separate tribes."*
>
> Dr Alf Collins, GP, United Kingdom

Person-centred, coordinated care: the service user perspective[5] (National Voices 2013)

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This theme of person-centredness as an overarching paradigm appears to draw from and continue in the tradition of patient-centred care (and other models), where leading definitions have emphasised domains. (See, for example, the diagram above, from UK patient group National Voices.)

One of the most influential models in this vein has been the Picker Institute and Commonwealth Fund model, which traces its origins back to research in the 1980s, and was highly influential in shaping the Institute of Medicine 2001 definition of patient-centred care. The Picker Institute and Commonwealth Fund proposed eight core domains of patient-centredness:[90]

- The respect for patient values and preferences
- Emotional support
- Physical comfort
- Information, communication and education
- Continuity and transition
- Coordination of care
- The involvement of family and friends; and
- Access to care.

A significant range of models have arisen since. A 2014 meta-review captured 15 dimensions of patient-centredness in the literature, which are proposed as interrelated rather than being independent from one another; 'for example, the essential characteristics of the clinician influence the clinician–patient relationship; patient involvement in care is not possible without patient information; emotional support requires good clinician–patient communication; and communication is foundational to build a supportive relationship'.[4]

An integrative model of patient-centredness[4] (Scholl 2014)
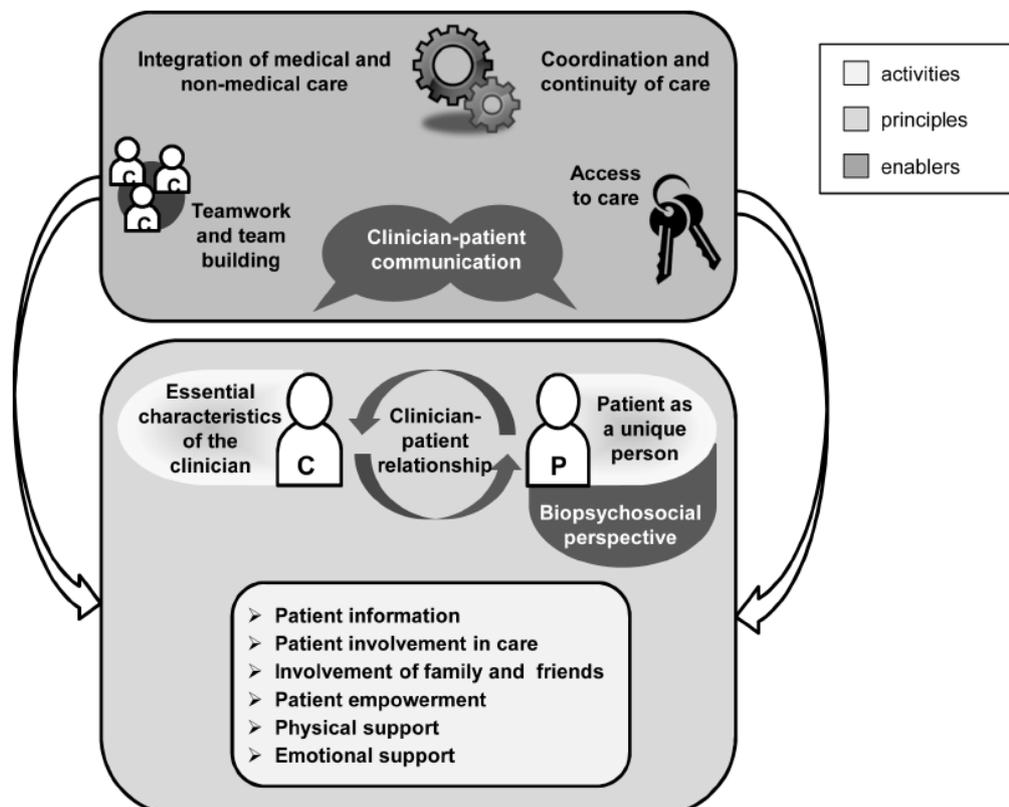
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vii.   Personhood and anti-reductionism

"Person-centred care is a big step change – it's not just a latest iteration of system adaption or tools to implement. We are only a patient (i.e. a disease) for a very small amount of the time, but we are a person all the time. I'm not sure other models such as shared decision making have always had that focus to the same degree."

Prof Nicky Britten, University of Exeter Medical School, United Kingdom

*"Person-centredness is built on a classical philosophical framework of personhood – not a care perspective – that lack of recognition is the problem – the reason why the policy response to person-centred care is so incoherent. It is helpful to think about the components of person-centred care (e.g. SDM, SMS, health literacy, engagement, etc) and these are vital to operationalising person-centred care, but **only** if the particular philosophy of personhood is enshrined in those approaches/models."*

Prof Brendan McCormack, Queen Margaret University, Scotland, United Kingdom

Another notable theme of person-centred care places emphasis on a philosophical understanding of personhood – i.e. where patients 'are known as persons in the context of their own social worlds, listened to, informed, respected, and involved in their care – and their wishes are honoured (but not mindlessly enacted) during their healthcare journey'.[8]

"The promotion of the person as a fundamental ethical imperative is based on the Kantian proclamation that a person must never be taken as a means but as an end in itself."

Mezzich JE, Appleyard JE, Botbol M, et al. Ethics in Person Centered Medicine: Conceptual Place and Ongoing Developments The Journal of Person-Centred Medicine 2013;3(4):255-57.

The quality of personhood in this model pervades (in theory) every dimension and setting of medicine and care, and emphases the unique value that a deep understanding of personhood brings to the clinician, the person/patient, and indeed to the healthcare system and wider society. One recent example of this is the definition of person-centred care adopted by the International College of Person-Centred Medicine, which describes person-centred care as a 'medicine of the person, for the person, by the person and with the person'.[86]

"A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational, human individual always in action, responsive to meaning, and whose life in all spheres points both outward and inward. Virtually all of a person's actions – volitional, habitual, instinctual, or automatic – are based on meanings… all persons have a spiritual life – a transcendent dimension that reaches beyond them."[6]

Cassell EJ. The person in medicine. International Journal of Integrated Care 2010;10.

Personhood in this vein may also be understood as an anti-reductionist position, a counterbalance to evidence-based medicine (EBM). EBM is perceived by some key commenters to have diluted clinical skills at the level of individual communication and decision making,[41] or even to have corrupted and dehumanised modern medical practice.[74]

> "The notion of person-centred care represents antireductionism. It asserts that patients are people and should not be reduced to their disease alone, but rather that their subjectivity, integration within a given environment, their strengths, their future plans and their rights should also be taken into account."[1]
>
> Leplege A, Gzil F, Cammelli M, et al. Person-centredness: conceptual and historical perspectives. Disability & Rehabilitation 2007;29(20-21):1555-65.

Personhood also emphasises the needs and nature of the person outside the healthcare setting, that is to say, it emphasises the assets and attributes of an individual who is a person first and foremost, locating that person in their individual past and future,[80][74] their family, community and culture, reflecting the observation that one is a person all the time, and a patient very little of the time.[67] For example, key commentators Professor Brendan McCormack and colleagues provided a theoretical account of the key aspects of person-centred gerontological nursing as 'being in relation (social relationships); being in a social world (biography and relationships); being in place (environmental conditions); and being with self (individual values)'.[91]

In this theme, Le Plege's seminal 2007 paper on rehabilitation and person-centred care summarised the qualities of person centred care as follows:

(a) Person-centredness means addressing the person's specific and holistic properties
(b) Person-centredness means addressing the person's difficulties in everyday life
(c) Person-centredness means the person as an expert: participation and empowerment
(d) Person-centredness means respecting the person 'behind' the impairment or the disease.

> "Our use [of the term 'person-centred care'] derives not from personal style or aesthetic preference, but rather from a philosophical understanding of personhood… all persons have a past, a history and a future and that both are therefore part of the person who lives and presents. The concept of the person within the context of the clinical encounter is, then, altogether more richly and vividly descriptive than that of patient and recognises that there are two individuals within the clinical encounter, the person of the patient and the person of the clinician."[74]
>
> Miles A, Mezzich J. The care of the patient and the soul of the clinic: person-centered medicine as an emergent model of modern clinical practice. International Journal of Person Centered Medicine 2011;1(2):207-22.

As such both person-centredness (and sometimes patient-centred care) may be upheld as rooted in humanistic psychology, and in particular that of psychologist Carl Rogers and psychiatrist George Engel.[1][36][87] For key contributors in this mould, personhood can be understood as having deep philosophical, ethical and legal ramifications that are not necessarily present in a traditional 'care' perspective.[56][60][92] This may also include quite tangible notions of personhood – i.e. that a person is legally responsible for his or her own acts and behaviours, and therefore can assume responsibility and give consent to decisions in healthcare much more readily than a 'patient'.[1]

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> *"There are a wide variety of opinions on person-centred care in rehabilitation, but in the Auckland University of Technology we're against a tick box mentality on this – person-centred care connects psychological, emotional, physical aspects of health and wellbeing. Person-centred care is about recognising people are psychological and social beings."*
>
> Prof Paula Kersten and Prof Kathryn McPherson, AUT, New Zealand

For example, a more recent model of person-centeredness co-developed with patients in the UK was built around the expectation of individual space. This personal space was both emotional (e.g. being acknowledged as a unique, equal, respected, whole person; and being heeded) as well as physical (e.g. having an unrushed visit) and temporal, (being given sufficient time to tell their story). When these fundamental human needs were unmet, patients reported the immediate experience was feeling 'invisible, unheard, and overlooked',[93] arguably the opposite of being a person.

viii.   Partnership, mutualism, co-production

> *"Why do we use the word 'person'? Because this reflects our core philosophy and ethics. Mutuality, respect, listening to others – these are core principles. Other practitioners may say they 'do' person-centred care but really this is a vision for coordination – listening, understanding or the valuing of personhood are not systematically implemented in daily practice."*
>
> Prof Inger Ekman, University of Gothenburg, Sweden

In another theme, person-centredness emphasises the critical importance of inter-dependence, trust and mutuality between patient and professional. This may be expressed through terms such as co-production,[54] trust,[80] partnerships and relationship,[39] 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,[9] in which ultimately patient and professional strive to reach 'a state of shared information, shared deliberation, and shared mind'.[8] In this model, it may be primarily *through* partnership and mutual recognition that person-centred qualities such as dignity and empowerment arise.[52] Some highly influential commentators have shaped their definitions of person-centred care in this fashion. For example, one of the key criteria for inclusion into a leading synthesis review of person-centred care from Gothenburg University was the extent to which patients were viewed as genuine partners in the study interventions.[14]

> "Healing relationships are more than sources of information and expertise; they also provide emotional support, guidance, and understanding. These relationships can help patients adjust better to their illnesses, perhaps partially by increasing social support, by providing early recognition of symptoms and emotional responsiveness, and by attenuating the effects of uncertainty."[94]

> Epstein RM, Fiscella K, Lesser CS, et al. Why the nation needs a policy push on patient-centered health care. Health Affairs 2010;29(8):1489-95.

Far more so than other themes within person-centred care*,* this theme may give emphasis to the care professional as a person *themselves* (i.e. an individual with self-knowledge, assets, limitations, and humanity)*,* and see value in a clinician achieving a deep knowledge of himself or herself, their ethics, values and attributes. [74][95][96][9] Thus person-centred care can also liberate the healthcare professional from the 'drudgery, cognitive overload and exhaustion' of 'productivity driven, assembly line medicine', and allow the healthcare professional and patient to each meet each other as a *person*,[8][9] enabled to challenge the status quo together.[52]

> *"Doctors don't want to be robots that only follow guidelines – they want to be a person too."*
>
> Prof Jan Kremer, Radboud University Medical Centre, the Netherlands

Co-production therefore is an opportunity for medical knowledge to combine with principles and skills such as shared deliberation, human connection, mutual respect and deep dialogue to achieve person-centred care, while avoiding paternalistic, formulaic or obstructive behaviours.[97] An interesting model in this theme has developed as part of the 'personalisation' agenda in the UK – see below – with the added dimension of different levels of 'expertise' being recognised between clinical decisions and those of wellbeing and life circumstances.[68]

Key contributors in this theme are also more likely to uphold the value of clinical expertise, and the concern that person-centred care (or indeed related terms) has in the past been misunderstood with consumerism and unethical practice (for example, concerns about overtreatment for cancer patients, or an absence of mature dialogue when making marginal treatment calls).[92] There may be a far more open question as to what levels of control over decision making may be desired by both the healthcare professional and patient, or a belief that clinicians have a right to challenge the patients views where this is likely to optimise treatment.[94]

Seemingly, this assertion of mutual alignment and symbiosis is more visible in key contributors in person-centred care from an academic or healthcare professional background.[8][92][98] It is noticeably less visible in position statements from patient advocacy groups and government policy position papers, where the terminology instead may emphasise patient control, autonomy and the need for respect for patients' values.[5][99]

Special focus: the Person-Centred Practice Framework – University of Ulster, United Kingdom

Ulster University's Person-centred Practice Research Centre (PcPRC) is the home of the Person-centred Practice Framework, a highly influential contribution developed by Prof Brendan McCormack and Prof Tanya McCance, where person-centred practice is defined as an approach that is established through the formation and fostering of healthful relationships between all care providers, patients and others significant to them.

http://www.science.ulster.ac.uk/inhr/pcp/

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ix.   Selected key reading identified by the international environment scan:

➢ **Person-centred care as an overarching grouping of concepts**

- IAPO. What is Patient-Centred Healthcare? A Review of Definitions and Principles. International Alliance of Patients' Organisations 2007
- Kitson A, Marshall A, Bassett K, et al. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. Journal of Advanced Nursing 2013;69 (1):4-15.
- Luxford K, et al. Patient Centred Care: Improving Quality and Safety through Partnerships with Patients and Consumers. ACSQH, 2011.
- National Voices: A Narrative for Person-Centred Coordinated Care. Think Local Act Personal. NHS, 2013.
- Scholl I, Zill JM, Härter M, et al. An Integrative Model of Patient-Centeredness – A Systematic Review and Concept Analysis. PloS one 2014;9(9):e107828.

➢ **Personhood and philosophical approaches**

- Leplege A, Gzil F, Cammelli M, et al. Person-centredness: conceptual and historical perspectives. Disability & Rehabilitation 2007;29(20-21):1555-65.
- Epstein RM. Realizing Engel's Biopsychosocial Vision: Resilience, Compassion, and Quality of Care. The International Journal of Psychiatry in Medicine 2014;47(4):275-87.
- Leplege A, Gzil F, Cammelli M, et al. Person-centredness: conceptual and historical perspectives. Disability & Rehabilitation 2007;29(20-21):1555-65.
- McCance T, McCormack B, Dewing J. An exploration of person-centredness in practice. OJIN: The Online Journal of Issues in Nursing 2011;16(2).
- Miles A, Asbridge JE. Clarifying the concepts, epistemology and lexicon of person-centeredness: an essential pre-requisite for the effective operationalization of PCH within modern healthcare systems. European Journal for Person Centered Healthcare 2014;2(1):1-15.
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(c)   Overarching research issues; definitions and evidence of impact

i.   Key findings

- **Conceptualisation and definitions** – overall, many aspects of person-centred care lack common definitions and understanding grounded in research. This is a potentially a barrier to understanding if person-centred care is effective, and how we apply it consistently.
- **Need for better linkage and comparability between research 'hotspots'** – person-centredness is more established in some fields than others, but siloed activity may mean barriers to the diffusion of evidence and good practice, and divergent meanings.
- **Impact of person-centred care is promising, but needs further research** – behind some evidence of effectiveness there are still questions about what really counts as 'success', and which aspects of person-centred practice can consistently deliver demonstrably improved care.
- **Person-centred care drives non-clinical outcomes, but do they matter?** There are different assumptions about what consitutes success, for example, whether improved patient experience and self-management skills are valued alongside clinical outcomes.
- **Need for further clarity on cause and effect** – it is common to test a suite of personalised interventions at the same time, making it hard to know which specific interventions are effective.
- **Greater patient involvement in research** – patient involvement in helping to shape research priorities is still too rare, meaning that researchers may not be asking the right questions.
- **Research gaps identified in the leading literature** – across the recent literature, researchers have identified a list of key unknowns, which are summarised below.

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i.   **Conceptualisation and definition of person-centred care**

Key commentators report considerable ongoing conceptual challenges in person-centred care. A leading 2010 review of the evidence for person-centred care concluded that although there is an important body of opinion papers and (non-systematic) reviews, all person-related aspects remain insufficiently defined and researched.[100] This is reinforced by similar findings in associated terms such as 'patient-centred care',[4 15 19 21 72] 'client centred care'[16] and 'patient empowerment' (see below).[22]

> *"The Society´s work in researching and building a consensus on person-centered care reveals considerable confusion in terms. In order to define what person-centered care is, we need first to define what a person is – there are major bioethical disagreements on this point. Are we a person from the moment of conception? Or do we become a person at a specific point during the typical nine months of pregnancy? And after birth, when do we cease to be a person? On brain death? Or when cognitive function declines to a specific point as in, for example, advanced dementia? Such questions are vital since if we can classify and declassify a human individual as having or not having personhood, we make ourselves masters of their future in our hands."*
>
> Prof Andrew Miles, European Society for Person Centered Healthcare

Conceptual challenges appear to be more than merely a theoretical or semantic distraction, at least for most key commentators. 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[4 19] and delivery and measurement.[18] The lack of common definitions may also be a barrier in professional education.[82] A major UK parliamentary report notes that patient empowerment is a difficult concept to quantify and compare, making it hard to say clearly where best practice lies, and how it has been achieved.[22]

This has not stopped several attempts at compiling comparative definitions, for example a significant report by the Australian Commission on Safety and Quality in Heath Care on 'patient-centred care' has produced list of definitions of associated terms, including 'person-centred care', 'consumer-focused care', 'shared decision making' and so on.[49]

ii.   **Need for better linkage and comparability between research 'hotspots'**

Despite the absence of an overarching definition for person-centred care, some models of person-centred theory and practice are in fact well established in different conditions (e.g. dementia),[11 87 101] professions (e.g. nursing)[87] and settings (e.g. residential and nursing home care).[58] Different components of person-centred care are also well established in a variety of different areas, for example communication in oncology,[12] shared decision making in fertility[51] and self-management in

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mental health.[20] The different emphases on person-centredness in different areas appear to reflect the fact that a person's overall experience of living with illness is significantly shaped by the nature of their specific dominant disease.[102] In recent years, progress may reflect an appetite among researchers and innovators to avoid entanglement in conceptual ambiguities, and instead to push ahead with tangible interventions in distinct areas (such as communication).[4]

While this is encouraging, the limitations of conducting research on person-centredness within separate fields appears to be siloed development activity within disciplines [14] and a lack of common meaning and measures as a result. [15][16] For example, the relevance and transferability of measurement models across different disease areas is unclear.[11][17][18] Interpretation and application of different models in a multidisciplinary environment therefore may be challenging.[16] (As an example, this research noted that literature on children and family-centred care is seemingly absent from mainstream established commentary on person-centred care, despite being a major area of research and good practice in itself.) A map of innovative and experimental strengths may, from the perspective of consistent, mainstream implementation, be read in reverse as a roster of gaps and weaknesses. For example, shared decision making and communication may be better developed in cancer, but self-management support underdeveloped.[13] And while the dominant focus in the literature on self-management is on managing chronic disease, defining the concept and clarifying its use in palliative care remains largely unresolved to date.[103] As another example, efforts to test and embed shared decision making in the emergency setting appear rare.[104]

Special focus: person-centred care across the whole pathway

A recent study at the Gothenburg Centre for Person-centred Care (GPCC) has tested a person-centred care approach across settings, following patients from the hospital through discharge and into the community setting.

Fors A, Ekman I, Taft C, Björkelund C, Frid K, Larsson M, et al. Person-centred care after acute coronary syndrome, from hospital to primary care – a randomised controlled trial. *Int J Cardiol.* 2015 May 6;187:693-9
http://www.ncbi.nlm.nih.gov/pubmed/25919754

Even within each setting or professional discipline the challenge of collating and synthesising evidence on person-centred care is made more complex by the multidimensional nature of person-centred care *within* that setting. That is to say that different studies use different interventions in different combinations, (e.g. patient–clinician communication, shared decision making, or self-management support). For example, a review of self-management models among people with severe mental illness found promising evidence of application, but noted that the substantial variation in study design, types of training and examined outcomes weakened conclusions about the comparative effectiveness of existing studies as a whole.[20] The authors of a major review of patient-centred care interventions concluded that the primary limitation was an inability to combine the results of varied interventions, surveys and outcome measures across studies.[15]

The cause–effect pathway from intervention through to outcome may be difficult to collate across studies where the multifaceted package of care interventions and organisational changes to accompany it may vary considerably.[14][20][21] Different interventions may be also be insufficiently described and lacking in transparency, and potentially not reproducible.[15]

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Comparison and collation of international research has been noted by key commentators as a prerequisite for a large-scale implementation of patient-centredness into health care.[19] Yet this may be currently obstructed to varying degrees across linguistic barriers. For example, a major review of current research projects on patient-centredness in Germany noted competition between the two major comparable German terms '*patientenorientierung*' (literal translation 'patient orientation') and '*patientenzentrierung*' (literal translation 'patient-centredness'), and highlighted the risk of confusion this creates in searching for and drawing from equivalent work across the international field.[19]

iii.   Impact of person-centred care is promising, but needs further research

Many studies and reports discuss the effectiveness of person-centred care, however without a single definition or framework, authors can only express the relative success of the different interventions and measures that have been chosen to represent person-centred care. Interpreting the diversity of findings on the impact of person-centred care and related terms is not a straightforward task.

One of the most recent meta-reviews in the field is from the Gothenburg Centre for Person-Centred Care (GPCC) at Gothenburg University. The review notes the difficulties in establishing clear results, but summarises that person-centred models seem to improve care, (even for objective endpoints, including HbA1c, BMI, cost of care and length of hospital stay), but still concludes that more carefully designed studies still need to be performed.[14]

A promising recent study in heart failure from the GPCC has demonstrated that a combined person-centred approach in the inpatient setting shortened hospital stay and maintained functional performance without increasing risk for readmission or jeopardising patients' health-related quality of life.[27] The model incorporated multidisciplinary teamwork and staff-led improvement strategies, formal listening, documenting of patient narratives and wishes, shared decision making, and strategies to engage and activate the patient in their own care.

Across the wider literature however, considerable questions remain as to the degree to which person-centred interventions improve outcomes relative to traditional ones,[100] and similarly for related models such as patient-centred care.[15] For example, an international meta-review of enhanced patient participation in oncology consultations noted insufficient evidence for an effect on psychological wellbeing, physical wellbeing and consultation duration.[83] However, a major review by the Commonwealth Fund of patient engagement in 11 countries found that engaged patients reported receiving higher quality care, fewer errors, and more positive views of the health system.[105]

Where significant benefits have been found, it may relate to specific elements of person-centred care. For example, there is broad supportive evidence that shared decision making improves patients' knowledge and experiences, healthcare utilisation, health status and behaviour[106][107] and self–management.[20,108,107] Self-management has also been shown to improve patient satisfaction and experience.[109] However, some inconsistencies remain across these elements of person-centred care, and their contribution in achieving person-centred care as a concept remains unclear, just as there is variation in definitions of what person-centred care is itself.[15]

One of the leading disease areas in person-centred care is dementia. Several studies have demonstrated tangible benefits of person-centred care, for example, strong evidence of reduced

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agitation,[110] as well as other evidence of reduced discomfort and aggression among people with dementia, reduction of neuroleptic medication without worsening symptoms as well as positive changes in staff behaviour such as gentleness and use of verbal support.[11]

There is some promising evidence in children- and family-centred care. Patient-centred approaches in children with asthma, for example, have been shown to deliver positive outcomes specific to emergency room visits, hospitalisations, unscheduled primary care provider visits and missed school days when asthma care plans are individualised and when an educational component is incorporated.[111]

Multidisciplinary approaches to patient-centredness in the US have shown significant evidence of impact, including higher performance on measures of clinical quality, lower staff burnout, lower hospitalisation rates, and lower emergency department use.[112]

iv.   Person-centred care drives non-clinical outcomes, but do they matter?

Encouraging as these findings are, there are often different assumptions at play as to what person-centred care is expected to achieve, and within this, which outcomes are most valued.

Typically, clinical outcomes and reduced economic indicators such as emergency or hospital service usage remain a holy grail, although so-called 'softer' outcomes such as patient engagement, patient satisfaction and staff satisfaction may be increasingly viewed as important outcomes in their own right. For example, in the US and Canada, where some hospitals are publically reporting their patient satisfaction scores.

Thus there may be different assessments within different meta-reviews or evidence summaries, depending on how valued non-clinical outcomes are by each observer. This may in part reflect the degree to which patient behaviours and self-motivation are recognisably intertwined with quality of clinical care and outcomes. For example, motivational interviewing appears effective at improving health outcomes in treating addictions, but less so in diabetes, asthma, high blood pressure and heart disease, but is nonetheless effective overall at driving lifestyle change outcomes and psychological outcomes.[113]

Or similarly, major reviews into decision aids[114][115] and patient-centred approaches in clinical consultations[21] provide some encouraging results for improving knowledge, risk perception and patient activation, however the effects on patient satisfaction, health behaviour and health status remain unclear still for both.[21][115] Decision aids have been shown to reduce the choice of discretionary surgery and appear to have a positive effect on patient–practitioner communication, but their effects on adherence, cost-effectiveness, and use with developing and/or lower literacy populations remain unclear.[114]

Just as the criteria for selecting outcomes have (rightly) changed in the past, it is possible that patient experience may be awarded further recognition as a quality indicator as the positive associations between health, wellbeing, service use, satisfaction and enabling processes such as self-management become clearer.[15] Another area where positive associations would seem likely to be increasingly valued is staff satisfaction, for example in light of strategic, health system challenges such as workforce retention. A recent systematic review of evidence found that person-centred care is reported to have a positive impact on staff job satisfaction, staff capacity to meet the needs of patients and better levels of staff autonomy and empowerment.[116]

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v.   Research gaps

This research found several immediate research priorities going forward through the recommendations of leading studies in the field. This ranges from conceptual work on overarching definitions of person-centred care, through to evidencing the impact and value of different interventions in different settings. These are listed below.

Overarching research issues:

Conceptual definitions

"Part of the mixed results regarding outcomes of patient-centered care could be explained by the variation in the definition of the concept which may constitute a barrier to the implementation of patient-centered care into routine clinical practice. Recently, efforts have been made to disentangle conceptual ambiguities by focusing on specific aspects (e.g. patient-centered communication or ethical considerations) or disease-specific dimensions (e.g. cancer care). However, a comprehensive and systematic analysis of existing conceptual definitions is lacking."[4]

Scholl I, Zill JM, Härter M, et al. An Integrative Model of Patient-Centeredness – A Systematic Review and Concept Analysis. PloS one 2014;**9**(9):e107828.

Evidence of effectiveness

"[A call for] the generation of more empirical evidence (as well as evidence deriving from the qualitative exploration of the subjective experience of illness by the patient) to illustrate the superiority of person-centered care approaches – both in terms of their clinical outcomes and the costs of those clinical outcomes."[73]

Miles A, Asbridge JE. On the need for transformational leadership in the delivery of person-centered clinical practice within 21st Century healthcare systems. European Journal for Person Centered Healthcare 2014;2(3):261-64.

Hope, flourishing and thriving

"Other areas of fruitful exploration [in person-centred care] Include concepts of hope, flourishing and thriving."[117]

McCormack B. Guest Editorial - The Person-centred Practice Research International Community of Practice. International Practice Development Journal 2012;**2**(1).

Measurement and patient involvement in measurement

"Few well-defined and coherent system level indicators were found during the literature review. These also highlighted an uneven spread of indicators... with a large number of indicators for access and support, and information, fewer for choice and empowerment and respect, and only two

initiatives mentioned indicators for patient involvement in policy-making. The majority of the literature discussed in the results did not demonstrate patient involvement in the development of these indicators."[32]

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IAPO. Patient-Centred Healthcare Indicators Review: International Alliance of Patient Organisations, 2012.

Models of care:

Shared decision making

"More studies on interventions to increase shared decision making need to include comprehensive reports on the interventions' impacts on health care processes and patient outcomes – as well as their potentially unintended effects – in a variety of clinical situations."[106]

Légaré F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. Health Affairs 2013;32(2):276-84.

Decision aids

"Effects on adherence, patient–practitioner communication, cost-effectiveness, and use with developing and/or lower literacy populations remain unclear, as does the degree of detail that decision aids need in order to have positive effects on attributes of the decision or decision-making process."[114]

Stacey D, Bennett C, Barry M, et al. Decision aids for people facing health treatment or screening decisions (Review). In: Collaboration TC, ed. The Cochrane Library, 2011.

Communication and 'shared mind'

"Although individual behaviors have been the subject of communication research, the process of alignment rarely has been studied."[12]

Epstein RM. Patient-centered Communication in Cancer Care: Promoting Healing and Reducing Suffering: National Cancer Institute, US Department of Health and Human Services, National Institutes of Health, 2010.

Electronic health records

"Personal health records with greater focus and interoperability between clinical teams, patients and their home care-givers must be given a priority for research and development… there is an urgent need to invest in high quality PHR research for patients with chronic diseases."[118]

Wells S, Rozenblum R, Park A, et al. Personal health records for patients with chronic disease: A major opportunity. Applied Clinical Informatics 2014;5(2):416.

Web-based support

"Person-centred web-based support is a new area and few studies focus on how web-based interventions can contribute to the development of person-centred care."[119]

Josefsson U, Berg M, Koinberg I, et al. Person-centred web-based support-development through a Swedish multi-case study. BMC Medical Informatics and Decision Making 2013;13(1):119.

IT support for self-management of chronic illness

"[Study concluded on] the need for more well designed trials to test the efficacy of these interventions, particularly head-to-head comparisons with similar programmes delivered by healthcare professionals. Future research should also assess the costs of these interventions and their use in older adults."[120]

McDermott M, While A. Maximizing the healthcare environment: A systematic review exploring the potential of computer technology to promote self-management of chronic illness in healthcare settings. Patient Education and Counseling 2013;92(1):13–22.

"EHealth and mHealth are rapidly developing areas of today's health care, however, there is a lack of knowledge of what is required to create accessible and functional person-centered information systems tailored to users' needs."[121]

Ekman I. Care4ourselves (C4) – Person-centered information and communication technology (ICT) support to people with chronic heart failure and/or chronic obstructive pulmonary disease – A randomized, controlled study. 2015. http://gpcc.gu.se/english/research/current/care4ourselves

By care group or population:

Children

"Few studies have focused on interventions to support children's participation in decisions about their health. More research is needed to determine effective methods for supporting children's health decision making."[122]

Feenstra B, Boland L, Lawson ML, et al. Interventions to support children's engagement in health-related decisions: a systematic review. BMC Pediatrics 2014;14(1):109.

Disadvantaged groups

"[The] impact [shared decision making models] on disadvantaged groups, who concurrently experience the highest burden of disease, have never been investigated in a systematic manner."[123]

Durand M-A, Carpenter L, Dolan H, et al. Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. PloS one 2014;9(4):e94670.

Caregivers

"Relatively little is known about the effect that giving person-centred care has on caregivers…. Further study is required to expand and to support these tentative conclusions."[124]

Pol-Grevelink A, Jukema J, Smits C. Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. International Journal of Geriatric Psychiatry 2012;27(3):219–29.

By disease area:

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Diabetes

"Little research has been done to try to understand how patient-centred care is understood and practised by healthcare professionals specialising in patients with diabetes."[125]

Boström E, Isaksson U, Lundman B, et al. Interaction between diabetes specialist nurses and patients during group sessions about self-management in type 2 diabetes. Patient Education and Counseling 2014;94(2):187-92.

Severe mental illness

"Self-management of health care, a strategy considered an integral aspect of typical care, has been infrequently included in interventions for people with severe mental illness. Future work is needed to determine what elements of training or skills lead to the most salient changes [in SMS.]"[20]

Kelly EL, Fenwick KM, Barr N, et al. A Systematic Review of Self-Management Health Care Models for Individuals With Serious Mental Illnesses. Psychiatric Services 2014;65(11):1300-10.

Cancer

"Most papers on pain management in cancer focused on treatment induced by the professional caregiver or on the active involvement of the patient, and not on the combination of both."[126]

Boveldt N, Vernooij-Dassen M, Leppink I, et al. Patient empowerment in cancer pain management: an integrative literature review. Psycho-Oncology 2014;**23**(11):1203-11.

By setting:

Inpatient setting

"There are considerable gaps in knowledge regarding patient engagement in the hospital setting and inconsistent use of terminology regarding patient engagement overall. Research on inpatient engagement technologies has been limited, especially concerning the impact on health outcomes and cost effectiveness."[127]

Prey JE, Woollen J, Wilcox L, et al. Patient engagement in the inpatient setting: a systematic review. Journal of the American Medical Informatics Association 2014;21(4):742-50.

A major Cochrane review into person-centred care planning suggests that leading studies in personalised care planning are dominated by the primary care or community settings, with few being located in hospital clinics.[128]

Coulter A, Entwistle VA, Eccles A, et al. Personalised care planning for adults with chronic or long-term health conditions. The Cochrane Library, 2015.

Emergency care

"Many decisions in the emergency department (ED) may benefit from patient involvement, even though this setting has been considered least conducive to shared decision making… future work is needed to develop and test additional SDM interventions in the ED and to identify contextual barriers and facilitators to implementation in practice."[104]

Flynn D, Knoedler MA, Hess EP, et al. Engaging Patients in Health Care Decisions in the Emergency Department Through Shared Decision-making: A Systematic Review. Academic Emergency Medicine 2012;19(8):959-67.

Residential and nursing home care

"Frail older people who are considering movement into residential aged care or returning home following a hospital admission often face complex and difficult decisions. Despite research interest in this area, a recent Cochrane review was unable to identify any studies of interventions to support decision making in this group that met the experimental or quasi-experimental study design criteria."[129]

Gravolin M, Rowell K, de Groot J. Interventions to support the decision-making process for older people facing the possibility of long-term residential care. The Cochrane Library, 2007.

Other topics:

"… Research into workplace cultures is still highly underdeveloped and whilst there is rhetoric of empowerment, it is increasingly recognised that top-down driven models of organisational development have little if any impact on how practitioners experience their work environment."[117]

McCormack B. Guest Editorial - The Person-centred Practice Research International Community of Practice. International Practice Development Journal 2 (1). http://www.fons.org/library/journal.aspx

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vi.   Some of the key contributors in research identified by the international environment scan

> **Sweden, Gothenburg University, GPCC – multidisciplinary research in person-centred care**

The Centre for Person-centred Care (the GPCC) is an interdisciplinary research centre for the study of person-centred care in long-term illness. The centre's overall aim is to systematically and comprehensively investigate person-centred care from the perspectives of the person, the healthcare professional, and the healthcare organisation. At present, the centre is coordinating 10 large studies in these areas and over 60 published studies have already originated from the GPCC.

In particular, the GPCC has worked to research the effectiveness of person-centred care in several controlled studies, using powered samples, many of which have been published in high impact journals. Three key recent examples of this considerable portfolio of work are featured below (see 'key reading' for this section).

http://gpcc.gu.se/english

> **United States, The Patient-Centered Outcomes Research Institute (PCORI) – patient involvement in research**

PCORI is a non-profit, nongovernmental organisation located in Washington, DC, authorised by Congress via the US Patient Protection and Affordable Care Act of 2010. Specifically PCORI's goal is to lead clinical effectiveness research based on a Patient-Centered Outcomes Research (PCOR) model – i.e. to understand the issues *most relevant to patients* and to research models of care that deliver them effectively.

PCORI state they are 'the largest single research funder that has clinical effectiveness research as its main focus, and we incorporate patients and other stakeholders throughout the process more consistently and intensively than others have before'.

http://www.pcori.org/

> **Europe – The European Society for Person Centered Healthcare – the Lexicon and Dictionary of Person-Centred Care**

In 2014, the ESPCH called for the construction and publication of a Lexicon and Dictionary of Terms for Person Centered Healthcare. The intention is to produce both in a constituent chapter of the Society's forthcoming seminal textbook: *Person-centered Healthcare: How to Practise and Teach PCH*.[73]

http://www.pchealthcare.org.uk/about-espch/about-european-society-person-centered-healthcare

> **Germany, the Federal Ministry of Education and Research – patient-centred research programme**

The German Federal Ministry of Education and Research, together with several associations from the health insurance sector, launched a large research priority programme on patient-centredness and chronic diseases. This ongoing research programme started in 2007 and has a total funding volume

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of over €20 million for 77 research projects. The programme focuses on three main topics in relation to patient-centredness: research on patient information, efficient training programmes for chronically ill patients, and patient-centred design of care.[19]

> **Germany, Hamburg Eppendorf University, Institute and Outpatient Clinic of Medical Psychology, Medical University Centre**

Hamburg Eppendorf University is leading the research of a new integrative model on patient-centredness that systematically takes into account the broad variety of definitions and models found in the international research literature. The model is to be used to identify gaps in the measurement of patient-centredness and promote greater international comparability of research results.[19]

http://www.uke.de/institute/medizinische-psychologie/

> **International College of Person-Centred Medicine**

The International College of Person-centered Medicine (ICPCM) is a not-for-profit educational, research, and advocacy organisation. The ICPCM's activities include studies and research projects to explore, validate, and extend person-centred care. It works to disseminate the principles and practice of person-centred medicine, including via the publication of International Journal of Person Centred Medicine, and via conferences and other scientific meetings, including an annual conferences on person-centred medicine in Geneva. It is also active in clinical guidelines, educational programmes, and many other supporting fields.

see: http://personcenteredmedicine.org/

> **International Community of Practice for Person-centred Practice (ICOP)**

The International Community of Practice for Person-centred Practice (ICOP) is a partnership of academic clinical centres around the world. The focus of the ICOP is to build a programme of research and practice development between the parties with the intention of advancing knowledge, skills and expertise in person-centred practice, practice development and research (with a particular focus on practitioner research). The ICOP supports the person-centredness framework as developed by Brendan McCormack and Tanya McCance (2013).

> **The International Alliance of Patients' Organizations (IAPO)**

IAPO is a global network representing patients of all nationalities around the world. It is one of the few international patient organisations to have developed a definition of 'patient-based care', which it launched in 2006.

IAPO has held a series of biannual conferences on different aspects of patient-centred care, for example 2008 (key theme: making patient centred care a reality), 2010 (patient engagement), and 2012 (indicators of progress and success in patient-centred care).

In 2014, IAPO co-signed the 2014 Geneva Declaration of People and Person-centered Integrated Health Care for All, led by the International College of Person-centered Medicine.

www.iapo.org.uk

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vii.   Selected key reading identified by the international environment scan

General

- All-Party Parliamentary Groups on Global Health; Patient empowerment: for better quality, more sustainable health services globally: A report by the All-Party Parliamentary Groups on Global Health; HIV/AIDs; Population, Development and Reproductive Health; Global Tuberculosis; and Patient and Public Involvement in Health and Social Care, 2014.
- Luxford K, et al. Patient Centred Care: Improving Quality and Safety through Partnerships with Patients and Consumers. ACSQH, 2011.
- Miles A, Asbridge JE. On the need for transformational leadership in the delivery of person-centered clinical practice within 21st Century healthcare systems. European Journal for Person Centered Healthcare 2014;2(3):261-64.
- Royen PV, Beyer M, Chevallier P. The research agenda for general practice/family medicine and primary health care in Europe. Part 3. Results: person-centred care, comprehensive and holistic approach. European Journal of General Practice 2010;16(2):113-19.
- Scholl I, Zill JM, Härter M, et al. An Integrative Model of Patient-Centeredness – A Systematic Review and Concept Analysis. PloS one 2014;9(9):e107828.

Evidence of effectiveness

- Coulter A, Entwistle VA, Eccles A, et al. Personalised care planning for adults with chronic or long-term health conditions. The Cochrane Library, 2015.
- Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. BMJ 2007;335:24
- Dwamena F, Holmes-Rovner M, Gaulden CM, et al. Interventions for providers to promote a patient-centred approach in clinical consultations. The Cochrane Library, 2012.
- Ekman I, Wolf A, Olsson LE, Swedberg K. Effects of person-centred care in patients with chronic heart failure: The PCC-HF study. GPCC 2012.
- Fenlon D, Foster C. Self-Management Support: A Review of the Evidence. Southampton: University of Southampton 2009.
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PART 4: IMPLEMENTATION

a) Section summary

Context:

- There is a broad consensus that the challenge of establishing person-centred care in the mainstream is a substantial one.
- In terms of progress, there is a tangible and growing presence of person-centred care in healthcare policy, and in research increasing evidence of effectiveness and 'proof of concept' across a number of areas of person-centred practice.
- However, across the breadth of commentary available, the implementation of person-centred approaches in the mainstream lags a considerable way behind the policy aspirations.

Practical theme: Organisational development and culture change

Key commentators place an enormous emphasis on organisational development, and healthcare environments and culture as an immense factor in the routine implementation of person-centred care.

- Several organisational change models have been developed to assess person-centredness and lead change.
- Models of accreditation aim to embed person-centred practice by setting demanding standards for organisational development and care may make an effective contribution.
- The United States in particular has been a site of significant activity in this field, with many supportive resources and organisational development processes aimed at healthcare providers interested in driving change.
- Overall, progress in *achieving* organisational and culture change in support of person-centred care is uncertain, but excellence seems rare.

Practical theme: Professional skills, education and training

- The formal education and training of healthcare professionals is an essential element of moving healthcare systems towards person-centred care.
- Practising person-centred care requires a rounded mix of skills and values, not all of which may be sufficiently represented in the current healthcare workforce.
- Medical training in particular receives the most critique, the consensus being that traditional medical education can objectify patients and instil an enduring human distance between physician and patient.
- The role of professional education in driving person-centred care enjoys significant proof of concept, with several key contributors leading effective models at all stages of professional development.

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- Progress in professional education appears mixed, with very significant gaps to be covered and distance left to travel, and in particular, communication and shared decision making skills.

Practical theme: Professional ethics and values

- Facilitating a deeper understanding and connection with personal ethics and values is an emerging area of professional and organisational development.
- For some key commentators, encouraging a deep understanding of person-centredness among healthcare professionals is the *definitive* implementation challenge – all other models are likely to fail without each individual having time to reflect, absorb and internalise what person-centred care really means, *to them, and to others*.
- Some initiatives in this field suggest a valuable contribution to enabling person-centred practice, for example in remaining resilient in pressurised care environments.
- Progress is difficult to ascertain, but approaches have achieved considerable traction in the US, the UK, and more widely in nursing.

Practical theme: Communication, shared decision making, co-production and self-management

- At the heart of many models of person-centred care is the principle of partnership, exchange of knowledge, and the co-production of care and health outcomes between care professional and patient.
- There are several major strands of work that are arguably interwoven; structured listening, communication, shared decision making (SDM), self-management support (SMS), and care planning and goal setting.
- Few commentators believe any of these models are satisfactorily embedded in everyday healthcare practice, however health policy however does appear increasingly supportive in many Western countries, for example, in the US, UK and Canada.

Practical theme: Integrated care, coordinated care, and health IT

- 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 of integrated and coordinated care.
- Despite mass implementation of integrated models, and in particularly the Patient-Centred Medical Home (PCHM) in the US (and associated models), research and key commentators suggest a relatively early stage of development, with some promising results but more consistent evidence of impact needed, as well as clearer models of optimal practice.
- Health information technology (HIT) has formed a significant part of integrated approaches, and has included the use of computerised (and often internet-based) data management for patient registries, performance reporting, tools for organising clinical data, test and referral tracking, and electronic prescribing.
- While the potential of IT to support person-centred approaches is promising, research and practical models of implementation appear to be in their infancy.

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Barriers, opportunities and next steps

- There is enduring confusion among healthcare management and care professionals as to what person-centred care really means. This confusion can result in superficial, naive and opportunistic uses of the term and active resistance among healthcare professionals. It may also give rise to claims that professionals 'already do' person-centred care, despite clear evidence to the contrary.
- The implementation challenge will require a whole system response, for example formal education and training for healthcare professionals, but also efforts to connect and explore with deeper meanings of 'personhood', ethical and personal values within each healthcare professional, while simultaneously tackling competing pressures.
- Experience suggests that reconnecting with professional and personal values can be successful in challenging current norms and practices, and refocusing on the patient and their needs.
- However, embedding person-centred practice is likely to mean frank discussions about realities of everyday care and perceptions of conflicting demands on care professionals, for example capacity issues, or expectations that care professionals distribute time and resources equitably.
- While person-centred care may be particularly important and beneficial to vulnerable and disadvantaged populations, implementers must consider how to avoid further exacerbating inequalities, and anticipate a variety of different needs, assets, values, and barriers to participation.

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b) Implementation: useful context

i.   Overview

As needs little explanation, implementation of the principles, values and models of person-centred care into mainstream healthcare is without question the focal challenge and debate within the community of person-centred care.

What is implementation?

There is no single definition, however a major review in the field adopted the following definition: 'the constellation of processes intended to get an intervention into use within an organisation' and '… the critical gateway between an organisational decision to adopt an intervention and the routine use of that intervention, i.e., the transition period in which targeted stakeholders become increasingly skilful, consistent and committed in their use of an intervention.'[130]

Elwyn G, Scholl I, Tietbohl C, et al. 'Many miles to go… ': a systematic review of the implementation of patient decision support interventions into routine clinical practice. BMC Medical Informatics and Decision Making 2013;13(Suppl 2):S14.

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ii.   Progress so far/state of play

"People in most developed countries believe in person-centred care in theory, but still have a very paternalistic approach to medical practice."

Dr. Angela Coulter, Nuffield Department of Population Heath, University of Oxford, United Kingdom

"For both shared decision-making and support for self-management moving from principle to practice requires a combination of vision (reorienting our sense of what healthcare is about and for) and small practical stepping stones that enable organisations and individuals to make discernible progress in the direction."

Prof. Alan Cribb, King's College London, United Kingdom

While key commentators report varying assessments of actual progress and implementation to date, there is a broad consensus that the challenge of establishing person-centred care in the mainstream is a substantial one. Whatever promise is seen to reside in theoretical or conceptual development, whatever value is attached to a growing 'face validity of the concept', and an emerging body of evidence and experimental models of care, and whatever reported political

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movement there is for change, a clear sense arises of the need for much greater efforts to drive more practical, consistent and mainstream application.[14 61 73 78 89 93 131-133]

Assessing global progress is not straightforward. Few studies have attempted to map the implementation of 'person-centred care' across whole systems, in depth, and interested observers must piece together an overall picture from a variety of sources.

While pragmatic, this approach has some limitations. Mapping exercises in other fields (e.g. see 'patient empowerment' below) are likely to be a good indication of progress, but are not the whole picture. Different commentators inevitably base state of play assessments on different combinations of these associated concepts and delivery components.

Similarly, research and policy commentaries on implementation of person-centredness and other related models may reflect different *criteria* for what really counts as progress, e.g. whether operationalising a self-management model counts as a desirable outcome in itself, or whether patient experience and health outcomes must also improve before person-centredness is judged to have been achieved.[21 44 132-134]

Broadly, however, it is clear that across the breadth of commentary and research available, the implementation of person-centred approaches lags behind policy aspirations, and behind conceptual research.[49 132 135 117] Much of the research so far has focused on the issue of conceptual definitions of 'person-centred care' and 'person-centredness', with significantly less effort given over the application of these models in different settings.[60 73]

The numerous research gaps identified in **Part One** can also be reasonably interpreted as an one indicator of progress in implementation, i.e. that there are many missing pieces of person-centredness by disease area, setting and care population, with much work still be to done.

Person-centred care is a whole system challenge. Understandably, key commentators note the solutions required to establish person-centred care as a dominant model for healthcare are broad,[136] given the industrial scale of healthcare.[55] To some leading commentators, person-centred care is nothing less than a 'revolution' in current practice.[8]

Certainly, earlier work by the Health Foundation on 'co-creating health' has emphasised the whole-system challenge, requiring a 'whole health economy approach, working across secondary, community and primary care services (and the third sector and local authority where appropriate); and across all long-term conditions'.[137]

iii. Recognition in policy

"There has been more change in the last five years than the previous twenty. Prior to 2010 we felt like fighters fighting the 'good fight' – this all changed with the passage of the Affordable Care Act, which moved the discussion of patient and family engagement to the centre stage, and gave much greater momentum towards patient- and family-centred care."

Dr Dominick Frosch, Gordon and Betty Moore Foundation, USA

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One indication of (and arguably, a prerequisite for) the implementation of person-centred care is its presence in health policy. Key commentators and position papers affirm the increasing visibility of person-centred care (or associated terms) in policy documents, particularly (but not exclusively) in English-speaking countries.[4 49]

United States

Most notably, in the United States the uptake of patient-centred care and partnerships with patients and families into organisational policy and consciousness is reported to have increased dramatically in the wake the seminal Institute of Medicine report in 2001,[8 65] and has since made it into federal policy (most notably the 2010 Patient Protection and Affordable Care Act).[138] The range of organisations featuring person-centred care in high level policy and standards manuals includes the Commission on Accreditation of Rehabilitation Facilities (CARF), The National Center for Assisted Living and the American College of Health Care Administrators.[40] The US National Association of Long Term Care Administrator Boards also recently included person-centred care in its study exam guides for both assisted living and nursing home administrators.[40]

> "Patient-centered care [in the US] has now made it to center stage in discussions of quality. Enshrined by the Institute of Medicine's 'quality chasm' report as 1 of 6 key elements of high-quality care, health care institutions, health planners, congressional representatives, and hospital public relations departments now include the phrase in their lexicons. Insurance payments are increasingly linked to the provision of patient-centered care."[8]
>
> Epstein RM, Street RL. The values and value of patient-centered care. The Annals of Family Medicine 2011;9(2):100-03.

Australia

In Australia patient-centredness is one of the three core principles of the Australian Safety and Quality Framework for Health Care, which was endorsed in 2010.[4] The 2008 National Health and Hospitals Reform Commission has recommended 'people- and family-centred care' as the first principle for guiding the delivery of healthcare.[50]

Canada

In Canada, person- and patient-centred care is reported to be a prominent aspect of policy in some regions,[41 139] where for example patient-centred care formed part of the current Saskatchewan administration's electoral platform.[41]

Germany

In Germany patient information and shared decision making are embedded in social health insurance programs.[106] The Federal Ministry of Education and Research, together with the pension and health insurance schemes, has established a large research programme on patient-centredness and chronic diseases.[19]

Denmark

In Denmark, the Danish Regions are in the process of implementing IOM's six measures of quality as a means of ensuring higher quality standards in healthcare.[34] Patient-centred care is reported to have been adopted as a policy priority by the Dutch government.[35]

United Kingdom

In the UK, NHS England has interpreted its statutory duty to drive the better integration of care as 'care which is centred around the whole person; coordinated around the needs of patients, families and carers and feels more "joined up" to the individual'.[140] NHS England and the UK Department of health have led a significant personalisation agenda, working across health and social care to test models of care planning, self-management support and personal budgets, and to encapsulate good practice in official policy and guidance.[5] In Sweden the care professionals union Vårdförbundet has made a statement of intent to 'flip' the whole system over to person-centred care.[141]

Global policy

At the global level, the World Health Organisation (WHO) has embraced the terminology of 'people-centred health',[75] and reportedly, in 2006 the OECD adopted the concept of 'patient-centredness' or 'responsiveness' as one of three dimensions of healthcare quality.[142] The empowerment of service users and carers is one of the priorities of the Helsinki Declaration and the European Pact for Mental Health. It is also stressed in the WHO MH Action Plan for Europe.[143]

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c) Practical theme: organisational development and culture change

ESSENTIAL KNOWLEDGE:

There has been a very considerable focus on working environments and care settings and the degree to which organisations and groups foster person-centred practice. This reflects the very substantial impact organisational culture, peer support and day-to-day workloads can have on person-centred practice, and the difficulties faced by isolated practitioners in an unsupportive practice

i. What does it mean?

Organisational development (OD) means many things to different people. The NHS leadership Academy defines OD as involving management, leaders and staff working together to develop their organisation to ensure it can meet the needs of patients and service users in the most effective ways possible.[144]

Leadership and organisational development is also about understanding context and culture, and being able to lead and champion change at many different levels.[95][96][144] According to the Veterans Association in the USA, organisational culture is 'a set of values, expectations, formal and informal practices, and behaviours that define the unique corporate environment. Culture is deeply ingrained in the fabric of organisational life; it determines how the organisation conducts its business, treats its employees, evaluates its leaders, serves its customers, and handles productivity and performance'.[145]

ii. Why is this important?

"Establishing patient- and family-centred care requires a long-term commitment. It entails transforming the organisational culture. This approach to care is a journey, not a destination – one that requires continual exploration and evaluation of new ways to collaborate with patients and families."[146]

Institute for Patient- and Family-Centred Care (IPFCC). Advancing the Practice of Patient- and Family-Centered Care in Hospitals: How to Get Started. 2011.

Key commentators place an enormous emphasis on organisational development, healthcare environments and culture as an immense factor in the routine implementation of person-centred care – i.e. that it is supportive organisational climates (or organisational change) that often reflect the fundamental difference between achieving person-centred care or not.[40][90][98][136][146][147] or where individual or spontaneous practices become the established norm.[98] For example, supportive health

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care environments are noted as an important facilitator for effective communication, alongside the knowledge, skills, and motivation on the part of both clinician and patient.[12]

> *"Only culture change can bring about true transformation – but to do so we need to understand what culture is. It is behaviour – based on experience and incentives – which tells you that we need to address both of these factors if real change is going to happen. It is very hard to make a real change unless you are totally 'in'."*
>
> Dr Tracy Gaudet, US Department of Veterans Affairs, Veterans Health Administration, USA
>
> *"One of the mistakes we've made is not to recognise how big patient-centred care is. We need strategies that change cultures – and at the same time we need to induce behaviour change, through incentives and concrete tools – where clear expectations can be stated about usage and implementation."*
>
> Dr Dominick Frosch, Gordon and Betty Moore Foundation, USA

This reflects several decades of experience that top down or compartmentalised approaches to person-centred care will fail without efforts to change underlying cultures and processes within healthcare organisations,[40] and may be perceived as irrelevant by staff.[147] Similarly, efforts to drive new behaviours through needs analysis and performance measurement alone may fail without cultures that value people, innovation, and teamwork. [90] Thus for some key commentators, implementing person-centredness is viewed as a comprehensive and ongoing process of transforming the culture and operation of an organisation or care setting.[25 40 96 90]

iii. What progress has been made?

Progress in organisational and culture change for person-centred care is hard to ascertain, although organisational change in support of person-centredness seems to enjoy considerable proof of concept. In the United States, Canada and the UK, in particular, numerous studies and reports have attempted to identify the common attributes of successful person-centred organisations and working environments. For example, a study of leading US healthcare providers of patient-centred care has outlined the common organisational attributes of high performing organisations, (see Luxford 2011 below), which includes cultural and organisational factors as well as other mechanisms such as measurement and feedback on performance.

Special focus: Common attributes of leading implementers of patient centred care (hospitals)[90]

1. Strong, committed senior leadership
2. Communication of strategic vision
3. Engagement of patients and families
4. Sustained focus on employee satisfaction
5. Regular measurement and feedback reporting
6. Adequate resourcing for care delivery redesign

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7. Building staff capacity to support delivering patient-centred care
8. Accountability and incentives
9. Culture strongly supportive of change and learning

Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. International Journal for Quality in Health Care, 2011.

The United States in particular has been a site of significant activity in this field, with very many 'how-to' guides and supportive resources aimed at healthcare organisations interested in leading change,[146] in particular led by the Veterans Health Administration, Planetree, the Joint Commission, and the Institute of Patient- and Family-Centred care (see below). The 'Culture Change' movement in the North American residential and nursing home sector in support of person-centred practice is also reported to be very significant.[58] The importance of organisation development and culture change to deliver person-centred models of care has also been affirmed in the UK, for example via the 'Year of Care' programme, an integrated, multidisciplinary person-centred model for long-term conditions, and also in Australia, for example via the 'Patient-based care challenge' (see below).

The accreditation of organisational achievement in person-centred practice is also an emerging theme. In this vein, several non-statutory models have arisen which set demanding standards for organisations, management, and organisational processes to reinforce and embed person-centred practice. In the USA, Planetree's recognition programme has been taken up by over 500 organisations to date.[148] North American residential care providers hoping for accreditation to the widely recognised 'Green House' model must abide by key organisational elements, emphasising, among other things, staff empowerment.[58] In Australia, a national discussion paper on patient-centred care was followed by organisational accreditation standards on partnering with patients, which allows benchmarking of health services nationally.[149]

Nonetheless, progress in *achieving* organisational and culture change overall is uncertain, but excellence seems rare. In major position papers such as the US Veterans Association 2014 Blueprint, the main narrative gives prominence to overall progress being unsatisfactory to date.[145] It is notable, for example, that Planetree's recognition programme has only ever given four gold awards in its history.[148] Even leading authors of major organisational change models in person-centred practice are unequivocal as to the scale of the remaining challenges.[117]

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iv.   Some of the key contributors in organisation development identified by the international environment scan

> **United States – Planetree accreditation and organisational change management in healthcare**

Planetree provide an accreditation scheme that demonstrates if healthcare organisations have fulfilled their aspiration for patient-centred care. Awards are given following an assessment of 66 different criteria, with patient focus groups closely involved in the judging process. For example, one criterion is whether or not patients are able to access, view and comment on their own record. Reportedly, of 500 organisations that Planetree have worked with, only four have received the award.[148]

http://planetree.org/approach/

> **Canada – 'Culture Change' – the Alzheimer Society of Canada**

In 2008, the Alzheimer Society of Canada embarked on a 'Culture Change' initiative focusing on the needs of people with dementia living in long-term care homes. The culmination of their first phase of work was the publication in 2011 of guidelines for person-centred care for people with dementia in care homes. This was followed in 2014 with PC-PEARLS – a series of information sheets based around seven key elements on how to begin and sustain culture change in long-term care.

The guidelines can be viewed here:
www.alzheimer.ca/~/media/Files/national/Culture-change/culture_change_framework_e.pdf

PC-PEARLS can be viewed here:
www.alzheimer.ca/~/media/Files/national/Culture-change/PCPEARLS_full_e.pdf

> **Australia – the Clinical Excellence Commission (CEC): patient-based care challenge**

The CEC has issued a 'patient-based care challenge' (also known as 'The Challenge') to district healthcare services in New South Wales. The challenge involves 26 improvement strategies in nine key domains, each chosen following a review of the literature and in collaboration with an advisory panel of patients, clinicians, managers and policy makers. The competitive approach was deliberately chosen to reflect the difficulties of making system-wide changes. The domains span leadership, patient and family engagement, supporting a learning organisational culture, a focus on the work environment and accountability, among others.[23,24]

http://www.cec.health.nsw.gov.au/programs/partnering-with-patients/patient-based-care-challenge

> **United States, Gordon and Betty Moore Foundation – The Patient and Family Engagement Roadmap**

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The Gordon and Betty Moore Foundation have provided a roadmap aiming to consolidate best practice in patient engagement – from the level of care decision making all the way to organisational strategy and leadership. The roadmap proposes five practical actions each organisation can take, each informed by a consensus of 60 advisers, drawn from international key commentators, clinicians, researchers, patient advocates, employers, insurers, federal policy makers, federal and private funders.

www.patientfamilyengagement.org/vision

> **United States, Institute for Patient- and Family-Centered Care (IPFCC)**

The IPFCC have provided a guide for healthcare organisations, *Advancing the practice of patient- and family-centered care in hospitals, how to get started*. This includes practical advice for starting new partnerships with patients, and an assessment tool to help take stock of current practice, and also another to measure the current perceptions of staff and management. It also involves an eight-step process for leading organisational change, e.g. starting with early scoping work, appointing advisers, and moving through to initial assessments, action planning, delivering new models of care and support services, and monitoring and evaluating change.[146]

http://www.ipfcc.org/pdf/getting_started.pdf

> **United States, Veterans Health Association – the Blueprint for Excellence**

The relationship of culture to positive outcomes - the organizational 'health chain'

The Veterans Health Administration has pledged itself to comprehensive organisational change in support of patient and patient- and family-centered care via the 'Blueprint for Excellence'.

http://www.va.gov/HEALTH/docs/VHA_Blueprint_for_Excellence.pdf

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v.   Selected key reading identified by the international environment scan

- Hahtela N, Paavilainen E, McCormack B, Slater P, Helminen M and Suominen T. Influence of workplace culture on nursing sensitive nurse outcomes in municipal primary health care. Journal of Nursing Management 2015;23(7):931-939
- Institute for Patient- and Family-Centred Care (IPFCC). Advancing the Practice of Patient- and Family-Centered Care in Hospitals: How to Get Started. 2011.
- Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. International Journal for Quality in Health Care, 2011.
- McCance T, McCormack B, Dewing J. An exploration of person-centredness in practice. OJIN: The Online Journal of Issues in Nursing 2011;16(2).
- McCormack B, et al. Creating places that flourish – the essential role of the gerontological nurse: University of Ulster, 2010.
- McCormack B. Guest Editorial - The Person-centred Practice Research International Community of Practice. International Practice Development Journal 2012;**2**(1).

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d) Practical theme: professional skills, education and training

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ESSENTIAL KNOWLEDGE:

The formal education and training of healthcare professionals is an essential element of moving healthcare systems towards person-centred care. Practising person-centred care requires a rounded mix of skills and values, not all of which may be present in everyday clinical practice, or formal training and education of healthcare professionals.

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i. What does it mean?

Professional education usually relates to formal education required to qualify as a care practitioner, or to maintain professional competency, for example for professionals such as doctors, nurses, and healthcare assistants.

Informal training and professional development may also be provided by healthcare providers or similar host organisations, or via professional or other groups. For example in the case of person-centred care this might be focus on processes such as shared decision making, care planning, multidisciplinary working, or data collation.

ii. Why is this important?

"We have an opportunity to advance the practice of person- and family-centred care by more fully integrating its core concepts in all levels of education for healthcare professionals across disciplines, and by involving patient and family faculty in these educational programmes."

Beverley H Johnson, Institute for Patient- and Family-Centered Care, USA

"The biggest challenge is changing the mindset of healthcare professionals. This will require changes to professional education, training and supervision."

Dr. Angela Coulter, Nuffield Department of Population Heath, University of Oxford, United Kingdom

"Clinicians' attitudes, understanding, and practice of person-centred care are a major barrier. It is easier to morph attitudes of medical students in the training stage, than changing more ingrained attitudes when in practice, even at the early residency stage."

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Many key commentators in person-centred care raise the issue of formal education and training of care professionals as a major barrier, and opportunity, for implementing person-centred care.[38 44] [52 80 90 137 141 150] At the heart of this issue is the very significant challenge that person-centred care presents to the modern healthcare professional, and the likelihood that without training and professional development, few clinicians may be able overcome system deficits, and the pressures and competing demands of everyday practice. For example, a review of nursing competencies in person-centred care highlighted the leadership qualities required to lead their teams and shape environments (see below).[151]

"To practise in a person-centred way, [nurses] must work through others on their team to ensure that staff truly relate to their residents, tailor approaches based on the remaining abilities of the residents and manipulate environments to match the competence of the individual, while focusing on residents' personhood… competencies of registered nurses to deliver person-centred care include leadership, facilitation, clinical excellence and critical thinking skills."

Gilton KS, Heath H, Chu CH, et al. Moving the agenda forward: a person-centred framework in long-term care. International Journal of Older People Nursing 2012;**7**(4):303-09.

Professional training is a subject of some discussion, with concerns that medical and nursing students are poorly supported to uphold personal values of empathy and compassion in the face of many pressures of everyday care settings, or to help avoid human 'distance' between patient and professionals when faced with such pressures.[56 92] For example, in nursing, even where students are aware of the concepts, principles and professional values of person-centred care from early on, they may yet be preoccupied by learning about what nurses 'do', rather than how patients experience care.[150]

Training and education in person-centred approaches may actually provide an opportunity to improve professional satisfaction. Key contributors describe modern medicine becoming increasingly procedural and fragmented between specialisms and sub-specialisms,[51 55] as well as being 'robotic' and mentally and morally exhausting.[8]

Communication and shared decision making skills are reported to be a major challenge for healthcare professionals,[44] both in terms of the lack of specific training currently offered,[82] and the inherent complexity of values clarification or preference elicitation.[106] The teaching and assessment of interpersonal skills also appears a current deficit.[8]

Misunderstanding and even active resistance among qualified health care professionals is also a notable theme in the literature.[44 75 132] Research suggests paternalistic mindsets are not easily overcome, and may still endure below the surface even after training, for example, a belief that shared decision making models should be vetted in advance by the clinician's judgement of patients' 'best interests'.[152] Person-centred care may also be confused with a wide range of associated terms, for example patient 'empowerment',[132] decision making,[106] self-management, information sharing,[153 154] and relationship-centred care.[60]

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iii.   What progress has been made?

Progress in professional education appears mixed. Globally, at least one major study concludes that 'patient-centredness is increasingly being advocated and incorporated into the training of healthcare providers',[21] and this upward trajectory (at least) is echoed in other national level reports, who may nonetheless also simultaneously highlight the very significant gaps to be covered and distance left to travel,[49,] (and in particular, communication and shared decision making skills).[82 113]

The role of professional training has also been clearly demonstrated. Mature models in this field are available, as well as a number of impactful case studies. For example, a study of leading organisations in patient-centred care in the USA demonstrated that retraining and remodelling the workforce for 'mission commitment' was a core focus.[90] Workforce capacity building techniques reported by such organisations included training in communication skills, patient-centred care values, customer service and leadership skills and using specific patient feedback in individual staff development.[90] Multidisciplinary team training has also been a successful area of innovation.[155]

A key message to emerge from a Health Foundation research synthesis of shared management support was the importance of training whole teams together – i.e. clinicians, healthcare professionals and other support staff. Team training helped to generate momentum, through a common understanding and awareness of available tools and ways of working, and also promoted a supportive environment or culture in the workplace.[137] The study also noted that a range of approaches is needed in order to accommodate different learning styles, the time people have available, the geography of health communities and resources available. These included action learning sets; refresher courses; buddying; one to one support; e-learning; clinical supervision; and supportive systems and processes.[137]

iv.   Some of the key contributors in professional education and training identified by the international environment scan

> **United Kingdom, Scotland, NHS Education Scotland – Person-Centred Health and Care Collaborative**

The Person-Centred Health and Care Collaborative have developed an education, training and workforce development delivery plan to support the Person-Centred Portfolio (a range of improvement initiatives backed by NHS Scotland). They are involved in other areas of interest including self-directed support and self-management.[156]

http://www.healthcareimprovementscotland.org/our_work/person-centred_care/person-centred_collaborative.aspx

> **The Netherlands, Radboud University Medical Centre – patient involvement in medical training**

Radboud University now includes patients in setting their medical bachelor degree curriculum – lecturers report they now see their curriculum differently as a result of the patient being involved. According to Professor Jan Kremer, 'our medical students are coached by patients and patients sit on the committees designing our new curriculum to inform concepts, context, and complexity'.[51]

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> ➢ **Ireland, The Older Persons National Practice Development Programme**

A national two-year professional development programme for nurses and care workers took place in Ireland between 2007-2009, influenced by Professor Brendan McCormack's work (then at the University of Ulster) leading the Person-Centred Practice Framework, and in particular a focus on the attributes of the care worker. The programme was evaluated using the Person-Centred Care (PCCI) and Nursing Indices (PCNI) among other tools, and noted a significant positive culture change and a reduction in examples of poor practice.[25]

> ➢ **Canada, Université Laval – Better Training For Better Collaboration,**

The Université Laval developed the theoretical and practical basis required for healthcare professionals to work more collaboratively to ensure effective patient-centred practice. An evaluation of the programme found that although the implementation of an inter-faculty training curriculum on inter-professional collaborative practice is challenging in many ways, it offers a true opportunity to prepare future health professionals for contemporary patient-centred practice.[155]

> ➢ **United States, Veterans Health Administration – Centers of Excellence in Primary Care Education**

The VA is testing models for training students in Patient-Centered Medical Home practices – integrated care models that represent focal part of the VA's delivery model for patient-centred care. The VA's Office of Academic Affiliations has established five 'Academic Centers of Excellence' for primary care education, each developing training and integrated practice models. The selected sites are Seattle, Boise, San Francisco, Cleveland and Connecticut.

http://www.va.gov/oaa/coepce/

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e) Practical theme: professional ethics and values

ESSENTIAL KNOWLEDGE

Facilitating a deeper understanding and connection with personal ethics and values is an emerging area of professional development. This is closely aligned with conceptual models of person-centred care focusing on a philosophical, spiritual and individual understanding of 'personhood'. Reportedly, training courses in this field have been popular and successful in enabling staff to practice person-centred approaches in everyday care settings, even in difficult pressurised environments.

i.   What does it mean?

There are many definitions of ethics and values, including those specific to medicine and healthcare. However in the context of person-centred care, discussions with key contributors indicated that ethics for health professionals were considered to encompass an individual's own affiliation to principles of humanity, empathy, duty, responsibility and morality – in essence, a powerful and internal psychological framework to which each person holds themselves ultimately to account, and to which each person's own sense of identity and 'self' is intrinsically linked.

Training, group counselling and discussion sessions may typically aim to support healthcare professionals to find personal 'space' and to (re)connect with internal values. They may also suggest accessible mental cues for rapid recollection when required. The goal, therefore, is to establish confidence and psychological resilience to help professionals achieve person-centred practice in the demanding realities of the healthcare setting.

ii.   Why is this important?

"Personhood is lived – definitions do not create person-centred cultures – you need reflection and experience of the self, team, and patients. Person-centre care cannot be reduced to a checklist – it needs to be more conceptual, deeper – we need to look beyond simplistic choices."

Brendan McCormack, Queen Margaret University, Scotland, United Kingdom

A growing aspect of the conceptual development of person-centred care overall has been a focus on the importance of values, ethics, self-motivation and a deeper individual and spiritual understanding of person-centredness among professionals,[59][60][92] as compared to an instrumental approach (see Part One). Such models affirm person-centredness as something than can *only* be practised when the relevant philosophy, values and self-knowledge are internalised within each health care professional, and ideally, where this is further supported within a shared and humanitarian culture of care.

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> *"People need to come to PCC themselves, and not be told they are wrong. Individual motivation is very important and powerful to explore – for example recalling why someone became a cardiologist or nurse in the first place. When we do this we get a joined up person on the inside – it creates an internal dialogue which can be expressed in the group and shared by the group."*
>
> Michael Paterson, Joining the Dots, Scotland, United Kingdom
>
> *"Most clinicians want to be person centred, but in practice they struggle in the face of pressures, tasks, and schedules. Person-centred care is not about doing more – it is about doing things differently, it permeates all areas of care. There are tools to enhance person-centredness, but the main challenge is to get people to think about their approach in everyday care."*
>
> Anne Marie Mork Rokstad, Norwegian National Advisory Unit on Ageing and Health, Norway

A major review of patient engagement notes that initiatives often challenge healthcare professionals as they attempt to navigate a variety of conflicting issues in their practice,[45] i.e. that barriers are not simply related to culture or capacities, they are also related to internal values. Care professionals may experience ethical tensions where the compatibility of 'person-centredness' with resource pressures and equity of access is not well articulated or understood.[48]

iii. What progress has been made?

This research was not able to ascertain an overall state of play regarding research or application. It is clear, however, that personal development for person-centredness based on ethical and values-based approaches has achieved considerable traction in the US and UK,[59] and more widely in nursing, in line with key contributor Professor Brendan McCormack and former colleagues at the University of Ulster.[25]

More than 375 organisations in US have implemented Schwarz Rounds (structured opportunities for staff from all disciplines to reflect on the emotional aspects of their work and person-centred practice), and 120 trusts and hospices in the UK have also done so.[157]

A leading hub of individual self-knowledge and ethical practice in person-centred care in the UK is the Values-Based Reflective Practice (VBRP) which is reported to be in wide use in the NHS in Scotland (see below).[59] Typically, a participating hospital might run introductory sessions followed up by regular reflection sessions for staff. Recent research evidence suggests very high suitability in the healthcare setting, even in the middle of multidisciplinary or team decision making, and that regularly reflecting 'on action' fostered an enhanced ability to reflect 'in action', i.e. in the clinical moment.[59]

The two main tools of VBRP – NAVVY and MAP (see below) – appear to be flexible, and from its initial conceptualisation and application in NHS chaplaincy, VBRP has spread to nursing, medicine and other professions, even prisons, and been used in other applications such as design and

planning of healthcare architecture.[59] Measurement shows that both NAVVY and MAP tools improve morale and satisfaction, make for better patient handover, and improve communication.[59]

> iv. **Some of the key contributors in professional ethics and values identified by the international environment scan**

> ➢ **United Kingdom (Scotland), NHS Education for Scotland – Values-Based Reflective Practice (VBRP)**

VBRP is a structured programme which equips health and social care staff to facilitate values-based reflection in their local professional setting. The programme originated among NHS chaplains who often had very little training and opportunity to reflect on personal values and their application in day-to-day practice in the face of working pressures. VBRP is based on liberation philosophy and theology – specifically the recognition that no situation is neutral – and empowers people to weigh up the values and ethics of care operative in any given situation. Following a one-year pilot, VBRP spread to other professions and is now widely used across health and social care in Scotland.

The VBRP initiative was conceived and designed by Michael Paterson and Ewan Kelly. The facilitators training course is accredited by the Institute of Pastoral Supervision and Reflective Practice (www.ipsrp.org.uk).

'NAVVY', one of the tools to support VBRP, consists of five questions that can be used to reflect and affirm personhood and person-centred care in every day practice:

1. **Needs:** Whose needs were met/left unmet?
2. **Abilities**: What does this tell us about my/our abilities or capabilities?
3. **Voice:** Whose voice was heard/ignored in decisions or actions?
4. **Values:** What was valued, undervalued, overvalued in this situation?
5. **You:** What does this say about you/me/us?

www.vbrp.scot.nhs.uk

www.ipsrp.org.uk

> ➢ **United States, the Schwartz Centre for Compassionate Healthcare – Schwarz Rounds**

Schwartz Center Rounds are a tool being used by many health and care providers to help improve the culture of their organisation. In offering Schwartz Rounds to their staff, healthcare organisations provide a structured opportunity for staff from all disciplines to discuss and reflect on the social and emotional issues they face in their work and in caring for patients and families. The Rounds operate on the premise that healthcare professionals and staff are better able to make personal connections with patients and colleagues when they have greater insight into their own responses and feelings.

In the UK, support and training for Schwarz Rounds is provided by the Point of Care Foundation, an independent UK charity working to improve patients' experience of care and increase support for the staff who work with them.

In the US see: http://www.theschwartzcenter.org/supporting-caregivers/schwartz-center-rounds/

In the UK see: http://www.pointofcarefoundation.org.uk/Schwartz-Rounds/

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➢ **United Kingdom (Scotland), NHS Institute for Innovation and Improvement - Releasing Time to Care programme**

Releasing Time to Care (RTC) is a programme developed by the NHS Institute for Innovation and Improvement. According to Fiona Cook, programme lead within Healthcare Improvement Scotland, 'it's about stopping what you're doing and taking a look around you… RTC Is also about realising that you don't need permission to pause and think twice about particular behaviours or aspects of your working environment. As we describe it, you always have permission to pause. Reflection is a key aspect of this work and it's important for people to stand back at times and try to look at things differently.'

The programme reportedly uses change management approaches to help NHS staff examine a range of existing systems and processes within their healthcare settings and to encourage them to view these systems and processes through a different perspective. Teams are empowered to make positive changes, eliminating waste and inefficiencies, releasing more time to provide direct patient care. According to the project leads, RTC can be used by frontline NHS employees of all kinds, including healthcare assistants and GPs.

A 2012 report by the NHS Institute for Innovation and Improvement included the main findings and themes of the Releasing Time to Care Programme across NHS Scotland and made recommendations for the ongoing implementation, spread and sustainability of the programme's work.

http://www.healthcareimprovementscotland.org/our_work/person-centred_care/releasing_time_to_care.aspx

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f) Practical theme: communication, shared decision making, co-production and self-management

ESSENTIAL KNOWLEDGE:

At the heart of many models of person-centred care is the principle of respect, partnership, and the co-production of care and health outcomes between care professional and patient. There are several strands that are arguably interwoven; listening, healing relationships, communication, shared decision making (SDM), self-management support, (SMS) care planning and goal setting, each of which are arguably practical models underpinned by deeper concepts, interdependent to each other.

i. What does it mean?

There are a range of associated concepts and delivery models that are arguably very closely related aspects of effective communication and partnership between patient and professionals. There are many terms, however some of the most common ones are given below.

Shared decision making has been defined an interpersonal, interdependent process in which the healthcare provider and the patient relate to and influence each other as they collaborate in making decisions about the patient's healthcare.[106] It may be particularly rewarding where clinical situations have a two or more acceptable courses of action, for example, a patient electing to have a mastectomy or lumpectomy in early breast cancer, where the evidence for long-term outcomes is comparable.[113]

"Shared decision making is patient specific, and it relies on the medical evidence, the provider's clinical expertise, and the unique attributes of the patient and his or her family. For example, cultural factors are important, as are factors that affect patient–clinician interactions, such as mutual trust and language concordance or discordance between patient and healthcare provider."[106]

Légaré F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. Health Affairs 2013;32(2):276-84.

Self-management or **self-management support** is typically associated with long-term conditions, and may involve a complicated range of tasks, requiring confidence and skill. This may include taking medicines properly, monitoring symptoms, adopting or maintaining healthy lifestyles, managing emotions, solving practical problems, knowing when and how to seek medical advice or community support, and coping with the impact of the condition(s) on their daily lives. At the heart of the model is an informed, active patient, supported by a well prepared, proactive primary care team, working together to develop and implement a personalised care plan.[128]

Personalised care planning aims to provide support from health professionals that is tailored to the needs of individual patients. Such support recognises patients' concerns, and helps them become more able to manage their own health. Personalised care planning is a conversation, or series of conversations, between a patient and a clinician when they jointly agree on goals and actions for managing the patient's health problems.[128] According to the Veterans Health Administration 'care plans must link people and resources to work effectively across time and location to achieve care goals… quality [is] measured in terms of patient-tailored goals'.[145]

Listening has been upheld as formal mechanism to uphold genuine co-production, personalisation and 'shared mind' between patient and professional, in contrast with tokenistic, spontaneous or 'instrumental' approaches to consultation.[92] Rather than being merely a passive, organic interaction between care professional and patient, listening has been framed in leading models (and by leading commentators) as a structured and planned activity, for example being called 'optimal' listening.[92]

Co-production has been called 'a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities.'[69] It is may be understood to mean partnership between patient and healthcare professionals in terms of immediate care processes and outcomes (e.g. self-management support or shared decision making) as well as patient or service use involvement in the design of services, or in strategic policy making.

> "As with all communication encounters, the clinical consultation is jointly constructed by the participants as they weave together communicative actions to create the conversation. How one participant communicates will affect the communication of the other." [12]
>
> Epstein R, Street L. Patient-centered Communication in Cancer Care: Promoting Healing and Reducing Suffering: National Cancer Institute, US Department of Health and Human Services, National Institutes of Health, 2007.

Communication - although there is no single definition of communication between patients and health care professionals, leading commentators have been defined communication as encompassing the exchange of information, the management of uncertainty and emotions, and the building of relationships between the patient and professional.[158] Communication may also be taken to assume support for patients' self-management and shared decision making.[158]

ii.   Why is this important?

> "Care planning is central in coordinated care. This requires a rounded set of skills [for healthcare professionals], not just the 'communication skills' now included in medical education, and which are still oriented toward getting across what the doctor needs to say about clinical issues."[159]
>
> National Voices. Integrated care: what do patients, service users and carers want? 2012.

Care planning, shared decision making and self-management support are arguably the focal mechanisms by which patient and professional interact and engage to deliver person-centred care.

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For these to be meaningful, both patient and professional must experience trust, mutual respect, and work to ensure effective exchange of their relevant knowledge and expertise – typically for the clinician, knowledge of the diagnosis, prognosis, treatment options, and the range of possible outcomes, and for patients the impact of a condition on their daily life, their personal values, preferences and attitude to risk, and any issues in adhering to treatments and behaviours.[128]

Broadly, there is good evidence that when such meaningful relationships occur, shared decision making and person-centred care planning can deliver significant results – such as better adherence to medications and improved chronic disease control, without incurring higher costs.[12][94] There is also reasonable evidence that personalised care planning leads to improvements in physical health, psychological health, self-management capabilities and self-care activities.[128]

Listening and communication have received a considerable amount of attention as both pre-requisites for processes such as shared decision making and care planning being meaningful (and person centred), as well as contributing to person-centred care in their own right.[61][160][161] It has been asserted that it is through listening and patient story telling that a patient's true narrative emerges, revealing the individual's attributes, circumstances, needs, and aspirations, and from there the opportunity for the patient and healthcare professional to establish a 'healing relationship' and respond.[12][61][161]

iii.   What progress has been made?

Key commentators are clear that neither shared decision making, care planning, listening or patient-clinician communication are sufficiently established in everyday healthcare practice.[94][22][44][92][162] For example, only half of English patients in hospital say they are involved in decisions about their care as much as they would like – a figure that has shown no improvement over the last decade.[132]

Interpersonal communication has been called 'a process of mutual influence',[12] and clearly processes such as shared decision making are unlikely to add much value if either party is reluctant or unable to participate.[128] Unfortunately, current practice in modern medicine is widely regarded as insufficient – for example, archetypal chronic care management programmes have been criticised for lacking genuine dialogue with the patient.[61] Evidence suggests that clinicians often do not take patients' perspectives into account; or at least, it appears common for them to promote specific treatments rather than consider patients' preferences during decision-making processes.[113]

The policy aspiration however does appear increasingly supportive, for example, the 2010 Affordable Care Act in the US explicitly promotes shared decision making (SDM) and the use of decision support interventions. The UK and Canada at least are also known to have included SDM in formal policy, and other countries are reported to be alert to the benefits and are considering policy developments in this area.[163]

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> *"Many healthcare professionals express concerns that having a dialogue with patients, sharing information in a mutually beneficial manner is too time intensive... they fear that there isn't time to listen to patients. Research has shown just the opposite; when professionals respectfully elicit goals and priorities from the patient, care can be more time- and cost-efficient."*
>
> Beverley H Johnson, Institute for Patient- and Family-Centered Care, USA

As noted elsewhere in this document, shared decision making, self-management support and care planning may have reasonable footholds in other areas of care (see Part One). Listening however appears to be relatively under-recognised in policy and emerging practice. This may change – study models of listening have been trialled in Sweden since 2010 in a range of settings including patients with very acute needs in internal medicine clinics,[27] with impressive results that have attracted the attention of several key contributors interviewed as part of this work. Listening has been upheld in a national policy position paper in the UK (NHS Wales) (Personal correspondence S. Williams), and featured in high profile healthcare organisational reform in the Netherlands.[160]

> "'Listening' must be a planned activity, built into the structures of NHS Wales organisations to ensure it happens. Ultimately, becoming a listening organisation will ensure healthcare remains focused on the people being cared for. It will help staff see patients as people, first and foremost, and will lead to a healthier relationship between those who care and those being cared for."[78]
>
> Williams A, et al. The Listening Organisation: Ensuring care is person centred in NHS Wales. Improving Healthcare White Paper Series – No11. Wales, 2013.

a) **Some of the key contributors in communication, shared decision making, co-production and self-management**

➢ **United Kingdom, Think Local Act Personal – Personal Budgets**

Think Local Act Personal – a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support – have been developing personal budgets in social care with the support and involvement of the UK Department of Health, and more recently in partnership with NHS England to deliver personal health budgets.

As of 2015, approximately 70,000 people in England have a personal budget and 3,000 a personal health budget. Rather than simply being a payment mechanism, budgets come with a package of support interventions comprising multidisciplinary care planning, personalised goal setting and monitoring and evaluation of personal outcomes.

Following a pilot phase, personal health budgets are to be extended beyond NHS Continuing Care to people who have high levels of need, such as people with learning disabilities or autism, people who make ongoing use of mental health services, people with long-term conditions who end up accessing acute services more; and people who need high cost, longer-term rehabilitation e.g. people with an acquired brain injury, spinal injury or mental health recovery.

http://www.england.nhs.uk/healthbudgets/understanding/rollout/

http://www.thinklocalactpersonal.org.uk/

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➢ **The Netherlands, Radboud University Hospital's Listening Officer**

Radboud University Hospital have appointed a listening officer. The role featured in an online article for the BMJ in 2014. The officer's job is to listen to patients, carers and family members and 'find out what worries them, how illness disrupts their lives, what they want to know about, and the things they don't share with doctors'.[160]

➢ **United States, Dartmouth College – The Dartmouth Center for Health Care Delivery Science**

Dartmouth College are widely renowned as one of the key contributors to Interdisciplinary research in shared decision making, user-centred design of patient decision support interventions and the integration of these into routine health care, patient/provider communication and patient decision support technologies.

Professor Glyn Elwyn and colleagues have developed an influential model for shared decision making, framed around key stages of choice talk, option talk and decision talk, where the clinician supports deliberation throughout the process. [163] Among their numerous other outputs, Dartmouth are leading the development and publication of a repository of knowledge on patients' information and decision support needs for key clinical decisions.

http://www.dartmouth.edu/~cecs/about.html

➢ **Sweden, University of Gothenburg Centre for Person-Centred Care (GPCC) - 3 routines for listening**

The GPCC has worked on how listening is turned into a condensed narrative with the patent, including goals, which is then signed as a 'contract'. It has defined person-centred care through three key routines.[61] The model is specifically adapted for everyday clinical practice and is broken down into three routines – routine 1: initiating the partnership: patient narratives; routine 2: working the partnership: shared decision making; and routine 3: safeguarding the partnership: documenting the narrative.

The approach has been tested in significant proof-of-concept study in chronic and worsening heart failure patients in the acute setting. When applied to the processes of shared decision making and care and discharge planning, the approach was found to shorten hospital stay and maintain functional performance.

http://gpcc.gu.se/english

➢ **Centre for Medical Psychology & Evidence-based Decision-making, (CeMPED), and the Sydney Health Decision Group, Sydney University, Australia**

CeMPED is a network of researchers interested in patient-centred care, which conducts research in the areas of doctor–patient communication and shared decision making (SDM) in oncology cancer screening, primary care and secondary care, heart disease, palliative care, immunisation, pregnancy and depression. Primary activities to date have been in cancer. It combines the two very active existing research groups within the University: the Medical Psychology Research Unit (MPRU) and the Shared Decision Making Hub. Its research strengths lie in the themes of vulnerable groups

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(including low literacy groups, rural groups, ageing, carers and cultural and linguistically diverse background (CALD) groups. The research focus of CeMPED can be viewed here:

http://www.psych.usyd.edu.au/cemped/

The Sydney Health Decision Group hosts a very substantial suite of resources to support patient decision making:

http://sydney.edu.au/medicine/public-health/shdg/completed/consumer.php

A further and also substantial list of ongoing work is available here:

http://sydney.edu.au/medicine/public-health/shdg/current/consumer.php

> **United Kingdom (Scotland), Aberdeen University and partners – Good Goals in children's services**

Good Goals has been the first large-scale programme of research in the UK in children's services to seek evidence-based approaches to implementing family-centred care. The work has been acknowledged by NHS Advancing Healthcare Awards in 2010, and the programme currently has several NHS organisations signed up for the next stage of the work that focuses on implementing family-centred goal setting in children's services and its effects on children's and families' empowerment, health and wellbeing. The work to date has been within children's services, however, it is expected that the intervention will have relevance across community allied health services in general.

See: http://www.abdn.ac.uk/hsru/research/delivery/organisation/caseload-management/

> **United Kingdom – Northumbria Healthcare NHS Foundation Trust – Year of Care Partnerships**

'Year of Care' is an NHS-based organisation that is dedicated to driving improvement in the care of long-term conditions using care planning to shape services which involve people in their own care, provide a more personalised approach and which support self-management.

The partnership was established to build on the learning and expertise of the earlier Year of Care programme. The national training and support team is now based in Northumbria Healthcare NHS Foundation Trust.

Year of Care Partnerships have developed a 'gold standard' approach to support organisations who want to embed care planning and support for self-management systematically, using the Year of Care whole system approach. This is focused on culture change, care delivery and the development of care planning skills within the workforce which in turn support self-management and coordinated care.

http://www.yearofcare.co.uk/

> **Canada – Université Laval – The Canada Research Chair in Implementation of Shared Decision Making in Primary Care**

The Canada Research Chair in Implementation of Shared Decision Making in Primary Care team has produced a number of useful documents on shared decision making. These include scientific

publications, articles for the general public, conferences, presentations and decision aids. Relevant publications and resources can be found here:

http://www.decision.chaire.fmed.ulaval.ca/en/tool-box/

The mission of the Chair, Dr France Légaré, is to provide health professionals and their patients with the necessary skills to promote shared decision making throughout the healthcare continuum.

Research by Dr Légaré aims at (a) gaining a better understanding of the needs of professionals delivering primary health care and encouraging professionals to practise shared decision making; (b) developing the tools needed to apply this new professional technique; (c) developing effective strategies for introducing those tools; and (d) assessing the impact of the tools.

See mission of the Chair here: http://www.decision.chaire.fmed.ulaval.ca/en/the-chair/mission/

> **Norway and the United Kingdom - The Norwegian Knowledge Centre for the Health Services & University of Dundee – the DECIDE project**

The Norwegian Knowledge Centre for the Health Services & University of Dundee, Scotland, are joint leaders of the DECIDE project on how to communicate evidence to clinicians and patients for shared decision making

By developing and evaluating targeted dissemination strategies, DECIDE aims to increase the use of evidence-based interventions in a sustainable way and to reduce the use of interventions where benefits are uncertain. Project deliverables include research into: decision aids that promote shared decision making; and developing and disseminating patient versions of clinical practice guidelines. Project partners for the DECIDE project come from 12 different organisations.

see: http://www.decide-collaboration.eu/project-partners,
and: http://www.decide-collaboration.eu/tools-decision-making-and-dissemination-under-development

e Breathe Easy Programme delivers a pioneering training programme enabling mothers to care for their children with tracheotomies. Children whose care givers have completed the programme can now be safely discharged just six weeks after insertion of the tracheotomy, and are then cared for by their family at home, whereas in the UK it can often take more than a year to prepare to discharge a child with similarly complex needs.[81] According to Natasha North, Research Programme Director for the Child Nurse Practice Development Programme at the University of Cape Town, 'they are demonstrating truly impressive results… they embody a belief in the capacity of mothers and children, and an inherently empowering approach, which encapsulate very powerfully the essence of person-centred care.'

http://www.bbc.co.uk/news/health-32164237

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b) Selected key reading identified by the international environment scan

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- Légaré F, Thompson-Leduc P. Twelve myths about shared decision making. Patient education and counseling 2014;96(3):281-86.
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- Slay J, Stephens L. Co-production in mental health - A literature review: New Economics Foundation, MIND, 2013.

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g) Practical theme: integrated care, coordinated care, and health IT

i.   What does this mean?

'Integration' and 'coordination' in the context of healthcare has been the subject of a great deal of conceptual research and efforts at implementation, and very many definitions exist.[164]

A leading synthesis of research identified the four following aspects of integrated working:

Special focus: the four main types of integration in healthcare[165]

Functional: integration of key support functions and activities, such as financial management, strategic planning and human resource management;

Organisational: for example, creation of networks, mergers, contracting;

Professional: for example, joint working, group practices, contracting or strategic alliances of healthcare professionals within and between institutions and organisations;

Clinical: integration of the different components of clinical processes, such as coordination of care services for individual healthcare service users or care pathways.

From: Nolte E, Pitchforth E. What is the evidence on the economic impacts of integrated care? European Observatory on Health Systems and Policies, WHO, 2014.

Other key factors and variable are frequently cited, however some leading definitions have affirmed the needs and perspective of the patients as the dominant principles of integrated and coordinated care.[5] [166] [167] [168]

Health information technology (HIT) has formed a significant part of integrated approaches, and has included the use of computerised (and often internet-based) data management for patient registries, performance reporting, tools for organising clinical data, test and referral tracking, and electronic prescribing.[8]

HIT has been defined as 'the application of information processing involving both computer hardware and software that deals with the storage, retrieval, sharing, and use of healthcare information, data, and knowledge for communication and decision making'.[169] It may encompass a variety of electronic tools including electronic and personal health records, patient registries, mobile health applications and remote monitoring devices.[169]

ii.   Why is this important?

"Investments in infrastructure (increasing accessibility, use of non-physician staff, quality metrics for index conditions, and systems for coordinating care) and information technology (IT) applications… are important in fostering environments that enable accessible, coordinated, and responsive care."[8]

Epstein RM, Street RL. The values and value of patient-centered care. The Annals of Family Medicine 2011;**9**(2):100-03.

Integrated and coordinated models of care are commonly flagged by key contributors as important delivery models for person-centred care, i.e. that professional, technical and organisational alignment is intrinsically linked to the ability of individual practitioners to achieve person centredness.[8 141 142 170]

Care coordination was affirmed by the US Institute of Medicine's 2001 report 'Crossing the quality chasm – a new health system for the 21st Century', a seminal influence in both patient-centred care and person-centred care. Since then coordination, continuity and multidisciplinary working have featured centrally in many conceptual definition of patient- and person-centred care models,[4] including those closely developed with patients.[5 93] This includes that of National Voices (see below), whose maxim of 'person-centred, coordinated care' has been adopted by NHS England.

The National Voices definition for person-centred, coordinated care

"I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me."[5]

National Voices. A Narrative for Person-Centred Coordinated Care. In: Voices N, ed. Think Local Act Personal. NHSE, 2013.

Research syntheses from successful integrated care models in the last two decades provide familiar messages to those of person-centred care, emphasising the importance of collaborative cultures, team working, individual participation and self-management, use of guidelines/pathways to promote best practice, information sharing, decision support systems, and shared leadership at all levels of the healthcare system and across whole communities.[171]

Health information technology has received considerable attention as an enabler for person-centred care, and in particular, key commentators have highlighted the opportunities presented by IT systems to gather a variety of functions such as care records, decision aids, and tools for self-management support into a practical framework for delivery supportive of person-centred approaches.[8 106] Information sharing was highlighted by a major policy review in the UK as a practical barrier to 'whole person care'.[28]

"Lack of interoperability as an impediment to whole person care… was an important theme highlighted within our consultation process – and is something which is recognised nationally as a central priority for the health and care system. It is also something which is essential for the development of integrated health and care records available across multiple care providers."[28]

Oldham J. One Person, One Team, One System. Report of the Independent Commission on Whole Person Care for the Labour Party, 2014.

Considerable synergies have been established between HIT and person-centred care. One of the leading research summaries has mapped a considerable degree of overlap (see below).

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Synergy between principles of effective collaborative care and health information technology[169]
(from Bauer 2014)

Clinical Processes or Tasks	Health IT Capabilities
Patient education Patient engagement and activation Self-management support Shared decision-making to negotiate a care plan Effective coordination and collaboration among providers and patients	Education and self-management tools are delivered in multimedia format through the internet, mobile web, and mobile health apps and are accessible to patients at any time and from any location Patient medical records are accessible though patient portals Communication between patients and providers is facilitated through secure email Care plan and key patient outcomes relevant to the care plan are visible and can be shared effectively across providers and with patients

Perhaps more fundamentally than the practical applications of HIT to person-centred practice, some key commentators uphold person-centred care and the IT revolution as interlinked – part of the same phenomenon where increasing public access to information and expertise engineers a shift in patient expectations and power.[51][57]

"The incredible advances in IT over the past two decades have enabled one of the greatest paradigm shifts in health information and power in the history of mankind – this being the transfer from the provider and scholars to the people. More than anything else, an increasingly informed and empowered population is driving the evolution to person-centric care and person-centric system reform."

Dr Vaughan Glover, Canadian Association for Person-Centered Healthcare, Canada

iii.   What progress has been made

Integrated care models

Efforts to lead integrated care models in the last decade are many and varied, and cannot be summarised here. Broadly, however, summary research messages give a not unfamiliar assessment of the evidence of effectiveness to that of person-centred models, for example that that integrated care models are generally accepted to have a positive effect on the quality of care, health outcomes and patient satisfaction, but evidence of cost impact is less established.[165]

However, there is encouraging progress in delivering integrated and coordinated care models that are closely linked to 'person-centred' approaches, although as noted elsewhere, many models are still considered innovative. One of the largest single fields of activity has been the Patient-Centered Medical Home (PCMH), a model of working that arose in children's care in the United States in the 1970s, which has since spread as an organisational principle into other disease areas, most notably chronic disease and combined psycho-social-health approaches.[148] The PCMH has been adopted by

77

the Veterans Health Administration in the United States as the Patient Aligned Care Team (PACT), greatly contributing to the extent of implementation.[136] According to key commentators both PACT and the PCMH are still models undergoing evolution, dealing for example with mainstream implementation issues such as reimbursement[148] and the need to embed cultural change, with a greater focus on care that is personalised, proactive and person driven.[136]

> "Patient Aligned Care Teams (PACT) are one of the leading examples of efforts to implement the shift to person-centred care. The groundwork is in place; first phase was restructuring how we do primary care, but there has been no paradigm shift yet. The same opportunity exists for failure or success – we could end up with the same doctor-based model, **or** we could drive a paradigm shift – the difference is whether or not we drive culture change at the same time."
>
> Dr Tracy Gaudet, US Department of Veterans Affairs, Veterans Health Administration, United States

The evidence however is promising, including higher performance on measures of clinical quality, lower staff burnout, lower hospitalisation rates, and lower emergency department use. [29]

Information technology

> "Health IT should not be viewed as an end in itself. Rather, it should be used to reinforce healing relationships, continuity, and shared mind. Patient-oriented information systems should give the clinician easy access to information about the patient's family and other contextual data; provide space to document the patient's treatment preferences; and not distract the clinician with burdensome documentation for administrative and billing purposes."[8]
>
> Epstein RM, Street RL. The values and value of patient-centered care. The Annals of Family Medicine 2011;9(2):100-03.

Online care records are also a demonstrable area of activity, with key commentators noting significant efforts to provide access to medical records via the internet.[44] This is most apparent in the United States, as a result of the mass adoption of online care records, most prominently by the Veterans Health Administration and Kaiser Permanente, both major US health insurers and providers. Reportedly, there were over 1.3 million registered users in 2011 of My HealtheVet, the VA's online healthcare record and data portal, and 1.8 million users of Kaiser Permanente's 'My Health Manager' electronic care record.[28] The US Federal Government has also instigated incentives in support of patient access to their health information.[118] More than a mere issue of applied technology, this trend is reported as driving a cultural shift towards transparency that is changing the dynamics of care.[57][136]

Whereas availability is widespread and growing, the development and sophistication of e-health records appears to be at a relatively early stage of development. For example, targeted support for patients with chronic diseases seems to be rare.[118]

There is some emerging commentary on how e-health records can be supportive of person-centred approaches. For example, a survey of leading adopters of e-health records with high patient satisfaction emphasised the importance of allowing (and even prioritising) patient-generated data, and combining e-health records with secure messaging.[118] As yet, however, the direction of future

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research is unclear, and in urgent need of orientation to the major progressive issues in healthcare.[118]

Web and IT-based interventions in support of person-centred care appear promising, but relatively few studies are reported in the field.[120] One review of computer-based patient self-management programmes suggests the majority of studies are taking place in the USA, with interventions being delivered by healthcare professionals either in groups or to individuals, and including techniques beyond the provision of information (such as creating action plans).[120] Another review of e-health records again provides tentative conclusions only, but suggests promising approaches include individualised features, such as personally tailored advice and feedback, and interventions that are part of larger health management programmes that include clinicians.[119]

iv.   Some of the key contributors in integrated and coordinated care, and health IT

➢ **United Kingdom, King's Fund**

The King's Fund is an independent charity working to improve health and healthcare in England. The Kings Fund have sponsored a variety of research, literature and supporting resources in the field of integrated care, including practical support tools for healthcare management and policy makers. See

http://www.kingsfund.org.uk/topics/integrated-care

➢ **United States, The Agency for Healthcare Research and Quality (AHRQ)**

ARHQ's mission is to produce evidence to make healthcare safer, higher quality, more accessible, equitable and affordable, and to work within the US Department of Health and Human Services and with other partners to make sure that the evidence is understood and used.

AHRQ provides a major resource for research on the Patient Centred Medical Home (PCMH), with supporting resources across the five key domains on the PCMH, as well as other supporting resources on topics such as workforce and financing.

http://www.pcmh.ahrq.gov/page/tools-resources

This is accompanied by a range of materials such as highlights for policy makers, patients, best practice examples, as well as strategic research contributions (i.e. methodologies and research approaches).

http://www.pcmh.ahrq.gov/page/patient-centered-care

http://www.pcmh.ahrq.gov/page/evidence-and-evaluation

➢ **United States, Veterans Health Administration - the Patient Aligned Care Team (PACT), and e-health records**

The Patient Aligned Care Team (PACT) is the cornerstone of current VHA transformation initiatives intended to transform the way Veterans receive their care. It aims to transform care by providing patient-driven, proactive, personalised, team-based care oriented toward wellness and disease prevention.

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http://www.va.gov/health/services/primarycare/pact/

VHA E-Health records – the VHA has developed a comprehensive, integrated electronic health record available across all its providers. Since 2003 this system has also been linked to a personal health record – My HealtheVet – allowing users to access their own their electronic record, while also accessing a variety of other sources of information to support co-management and informed decision making. Users are also invited to use My HealtheVet to contribute their own information, to record and track personal health measurements, and set personal health goals.

The Blue Button is a function that allows users to download and store information from the My HealtheVet system. The programme was developed by the US Veterans Administration; it was subsequently made available to other healthcare organisations. As of October 2013, more than 500 organisations in the US have publicly made one of two pledges for data holders; the pledge is to 'make it easier for individuals and their caregivers to have secure, timely, and electronic access to their health information' and to 'encourage individuals to use this information to improve their health and their care'; and for non-data holders, the pledge is to 'engage and empower individuals to be partners in their health through information technology'.[28]

See: www.healthit.gov/patients-families/pledge-info

> **United Kingdom, Patient View - online medical records**

PatientView allows patients in certain specialities and locations secure access to results from their healthcare records to look up test results and info about their disease and its treatment. It began as a Renal (kidney) project, and now covers 90% of UK renal units as of 2015. Other conditions are now covered in some other locations, such as heart failure, inflammatory bowel disease and diabetes.

http://rixg.org/patientview2/

> **Canada, the Canadian Association for People Centred Health (CAPCH) - The Connected Health and Wellness Project (CHWP)**

The CHWP is a collaboration of 19 public, private and academic partners and affiliates who share a common vision to drive a more people-centred approach to healthcare delivery and enhance lifelong wellness though a focus on improved access to trusted health information, health coaching and technology. The project has two major goals:

(a) to create components of the 'Connected Wellness Platform' (CWP): a cloud-based software system to allow patients, their family, friends and professional care teams to collaboratively manage health and wellness through the use of innovative applications and the delivery of healthcare services; and

(b) to build an educational platform for healthcare professionals that will be foundational for the emergence of future standards and practice competencies in the health coach profession, which will integrate the CWP into practice in health promotion, disease prevention and chronic disease management.

At $37M, the Connected Health and Wellness Project (CHWP) was the single largest healthcare project funded by the Economic Development Agency for Southern Ontario.

www.chwp.com

➢ **Canada, The Change Foundation**

The Change Foundation is an independent healthcare think tank, intent on changing the debate, the practice and the healthcare experience in Ontario. It has led several key reports into patient-centred integrated approaches, including:

(2011) Winning Conditions to Improve Patient Care: Integrated Healthcare in Ontario. www.changefoundation.ca/site/wp-content/.../WinningConditionsFinal.pdf

(2010) Integration of Care: Summary Report analysing the responses of all provider groups. http://www.changefoundation.ca/library/summary-report-integration-of-care-perspectives-of-home-and-community-providers/

➢ **Sweden, the Gothenburg Centre for Person-Centred Care (GPCC) - Care4ourselves project (C4)**

The GPCC is testing a range of person-centred information and communication technology (ICT) support to people with chronic heart failure and/or chronic obstructive pulmonary disease.

C4 has the overall aim to develop and evaluate person-centred Information and communications technology (ICT) support, comprising information giving, education and support for people with CHF and/or COPD and their carers. The effect on people's confidence and self-efficacy in disease management, disease specific hospital readmission and the usefulness and quality of the person-centred support will be evaluated.

A health economic analysis will evaluate if person-centred care is more cost-effective compared to conventional care for patients with CHF and/or COPD.

http://gpcc.gu.se/english/research/current/care4ourselves

v. Selected key reading identified by the international environment scan

- Josefsson U, Berg M, Koinberg I, et al. Person-centred web-based support-development through a Swedish multi-case study. BMC medical informatics and decision making 2013;13(1):119.
- McDermott MS, While AE. Maximizing the healthcare environment: A systematic review exploring the potential of computer technology to promote self-management of chronic illness in healthcare settings (2013). http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0055385/
- Bauer AM, Thielke SM, Katon W, Areán P. Aligning health information technologies with effective service delivery models to improve chronic disease care. (2014). http://www.ncbi.nlm.nih.gov/pubmed/24963895
- NHS Confederation and LGA. 'All together now…' Making integration happen. http://nhsconfed.org/resources/2014/07/all-together-now
- Oldham J. One Person, One Team, One System. Report of the Independent Commission on Whole Person Care for the Labour Party, 2014.
- ● Wells S et al. Personal Health Records for Patients with Chronic Disease. Appl Clin Inform 2014;5:416-429.

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h) Implementation - barriers, opportunities and next steps

i. The 'whole system' challenge of implementation

A noted earlier, despite energy and movement at policy level, and a range of best practice, key commentators report slow progress in implementation, and a range of barriers currently obstructing greater movement.[44] The solutions required to establish person-centred care as a dominant model for healthcare are as broad perhaps as the barriers described to date. Certainly, earlier work by the Health Foundation on 'co-creating health' has emphasised the **whole-system challenge**, requiring a 'whole health economy approach, working across secondary, community and primary care services (and the third sector and local authority where appropriate); and across all long-term conditions'.[137]

> *"[Person-centred care] requires that mindsets must change – we still view the system as being about large hospitals, but community and residential care settings are really the major theatres for care now. The structure is shifting, but the mindset has stayed the same."*
>
> Lisbeth Löpare-Johansson, Vårdförbundet, Sweden

Organisations and individual care professionals face many obstacles in delivering person-centred care. Broadly, commentators note that behind the policy aspiration, healthcare remains largely dominated by scientific breakthroughs in care, by political priorities and financial pressures, or by adherence to internal policies and protocols that may not be driven by the interests of the patient.[78] For example, institutional long-term care may be a difficult environment for person-centredness to flourish as long as the organisational focus is primarily task oriented, driven in turn by a focus on efficiency and payment models.[40] As explored below, those quality and performance measures that do exist remain focused on clinical outcomes and such factors as the avoidance of adverse events, to the detriment of more person-centred outcomes such as quality of life or wellbeing,[28 40 172] a reality that deeply frames the everyday professional mind set in turn.[151] Where there are real debates on healthcare reform, these may be dominated by other priorities such as efficiencies and care scandals.[135]

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> *"We need strategies that change cultures – and at the same time we need to induce behaviour change, through incentives, concrete tools, organisational strategies that deliver – where clear expectations can be stated about usage and implementation. It is very easy to talk about culture change – and very hard to do it."*
>
> Dr Dominick Frosch, Gordon and Betty Moore Foundation, USA
>
> *"Individual physicians may try to work ethically, but time and incentives may not be aligned. Throughput and units of care are still what is measured and rewarded in Australia."*
>
> Prof Phyllis Butow, University Of Sydney, Australia

Some key commentators noted the links between person-centred care and the broader, unresolved challenge of restructuring health systems from the acute to the community setting,[141] or from structuring workforces to shift from a doctor-centric model to a team-centric model where there is optimisation of scope of practice for all provider stakeholders.[57]

ii.   The need for leadership at strategic and organisational level

> *"Leadership – we need individuals with credibility who can articulate how and why it matters. We'd like to think everything is evidence based – but it's not that simple – we have (and need) people on the inside."*
>
> Prof Paula Kersten and Prof Kathryn McPherson, AUT, New Zealand
>
> *"To be a leader in person-centred care is a very complex task – you have to be able to support staff on a daily basis, to enable them to use their own resources, to individualise support for care staff themselves."*
>
> Anne Marie Mork Rokstad, Norwegian National Advisory Unit on Ageing and Health, Norway

Unsurprisingly, many commentators note the requirement for strong and supportive leadership at all levels, for example the national and macro level,[141] [153] [154] organisational level,[90] and in professional bodies and societies.[38]

As explored earlier, organisational change is complex and demanding. Leaders from all sectors will need impressive qualities,[73] [70] and be willing to go beyond their current skills and comfort zones. For example, one key contributor cited concern that senior management in healthcare organisations and residential care homes tend to be drawn more from professionals in administration, management and economics, and as such may be distanced from professional development and the day-to-day delivery challenge of care 'on the front line'.[70]

The role of engaged patients in the strategic and organisation level of system design has also been a highly visible theme. The WHO has framed people-centred healthcare systems as a cornerstone of its own strategic objectives for sustainable health systems ('Health 2020'), where 'patients should become active partners in improving the safety, quality and efficiency of health service delivery.'

Patient engagement in Europe has been led prominently in Europe by the European Patient's Forum, for whom two of the five key patient engagement domains relate to strategic involvement in healthcare design (see below).

Special focus: the European Patient's Forum 'Patient's prescribe E5' campaign[173]

"*Patients prescribe E5 for sustainable health systems*" is the tagline for a major EPF campaign to demonstrate that patients are active people who can, if supported and according to their individual capabilities and situation, make a difference for the sustainability of healthcare systems, and be part of the strategic and organisational response to driving more person-centred care.

According to the EPF, the five "E" of Empowerment stand for:

- Education: patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.
- Expertise: patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.
- Equality: patients need support to become equal partners with health professionals in the management of their condition.
- Experience: individual patients work with patient organisations to represent them, and channel their experience and collective voice.
- Engagement: patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services

http://www.eu-patient.eu/campaign/PatientsprescribE/

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iii.   Confusion still to be tackled at the level of management

"We've by no means come to grips with what we really mean by person-centred care or patient-centred care – a lot of organisations may have these terms in their mission statement, but actually do very little – with low levels of effort to translate philosophy into practice."

Prof Phyllis Butow, University Of Sydney, Australia

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> *"The term is used rather lightly – despite the talk, implementation of person-centred care is rather limited, everyone hopes it is an easy simple thing, but when you actually drill down, it is unclear what people mean by it, people are still hoping for easy wins."*
>
> Prof Paula Kersten and Prof Kathryn McPherson, AUT, New Zealand
>
> *"[The term] patient-centred care is widely used, but not always by those who share the patient's best interests. It is about arrogance and naivety, not understanding that there is more to the term than they realise. There is still value in the term patient-centred care – but important to recognise the patient's best interests are hard to decide without the patient being involved."*
>
> Dr Victor Montori, Mayo Clinic, USA

One of the main reasons put forward by key commentators to explain the gulf between policy and practice is endemic confusion at the management level as to what person-centred care (and related terms) really mean. In the absence of deeper understanding, competing system incentives and demands may drive superficial, naive and opportunistic uses of the term.[39 41 46 52 53 60] For example, with the US hospital sector, the terms 'person-centred care' and 'patient-centred care' are reported to commonly misappropriated for enhanced residential amenities and aesthetic services (e.g. comfort gadgets, greenery and greeters).[97 170]

> *"At the policy making and management level there has been a failure to see the burden that implementation represents to health care providers – not just the burdens of changing care protocols, or the specific behavioural adaptations these entail, but the burdens of having to forge new identities and relationships, and to manage the dilemmas these create."*
>
> Prof Alan Cribb, King's College London, United Kingdom

Measurement is likely to be a contributing factor. Boards of healthcare organisations will certainly require information on the patient experience and measures of person-centredness, yet in the UK at least such discussions may still be in their infancy, with 'everyday' organisational metrics still dominated by finance and performance.[78] As noted later (see the section on 'Measurement'), reliable indicators across the full spectrum person-centred care are lacking. The lack of deeper organisational alignment with person-centredness is perhaps not surprising if, as noted earlier, management mindsets typically value the measurement (and reimbursement) of tasks over all else.[40]

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iv.   Winning hearts and minds at the level of practice

> *"In cancer, we see many health care professionals saying 'we already do person-centred care' – but actually they don't. If you want to challenge this you have to get practical and tangible. In Wales for example each cancer patient should get a care plan, which means a 30-45 minute conversation at least, covering different dimensions of care, which has to be written up and shared with the patient. The Wales Cancer Patient experience surveys showed that only 20% of patients answered positively to the question 'were you offered a care plan, and did you receive a copy?' We used this to open up a conversation about what wasn't working and how we could move forwards."*
>
> Susan Morris, Macmillan Cancer Support, Wales, United Kingdom

Winning the hearts and minds of care professionals has been a major area of discussion. Some key contributors report this has been very possible, but involves persistence, appeals to the core values of care professionals, an explanation of how terminology around 'person-centredness' adds value, and fundamentally, a focus on the experience and outcomes for the patient.[66 90 136] For example, one key commentator recounted overcoming resistance from care professionals to a scheme to boost patient safety by extending visitor hours for friends and family. A productive strategy in countering this opposition was to re-analyse the policy of restricted opening hours in light of professional values and first principles of care, asking questions from first principles such as 'why do we do it?', and 'who benefits from this?'[149]

> *"Nobody comes to work in the clinical setting to do a bad job – healthcare professionals want to make lives better, to help people. Spend time appealing to their original values for working in healthcare – to energise and empower health care professionals to drive change – and make sure their views form part of this transforming work."*
>
> Dr Karen Luxford, Clinical Excellence Commission, Australia

Another reported barrier is the perception of conflicting demands on care professionals, implying that awareness raising and efforts to secure 'buy-in' may have their limits without more fundamental discussions. A well established objection from professionals is that person-centred approaches place unsustainable demands on capacity.[45 61 82 106 132,] Certainly, the combination of poor understanding of person-centred care with workload pressures creates particularly significant barriers.[78 174] As noted above, practising person-centred care may severely test healthcare professionals as they provide care amid a variety of parallel demands to manage a complex and expensive healthcare system and generate valid evidence for research.[45] It may also be necessary to prepare clinicians to use 'standard' models of person-centred care flexibly, anticipating unusual patient characteristics and unique clinical situations.[106]

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> *"Many healthcare professionals express concerns that having a dialogue with patients, and sharing information in a mutually beneficial manner is too time intensive... they fear that there isn't time to listen to patients. Research has shown just the opposite; when professionals respectfully elicit goals and priorities from the patient, care can be more time- and cost-efficient."*
>
> Prof Alan Cribb, King's College London, United Kingdom

Another significant issue may be concern that 'person-centredness' implies more demanding rather than more independent patients,[132] and unrestricted access, i.e. 'giving the patient what they want', and that clinicians have other moral obligations; to ensure equitable access to care, and appropriate use of societal resources,[48] as well as clinical safety.

> *"Person-centred care is not our only moral obligation – fair sharing of resources is also important. We should question, for example, the pursuit of small gains based on personal whim, if these required a high level of cost. Person-centred care rubs up against other moral responsibilities as a clinician – such as being just when sharing out services to a community of people. It is best if we identify and address these tensions, rather than pretend they don't exist. Education we provide on this is popular, because many care professionals experience [these pressures] and feel they are not doing a good job, despite their own commitment to the principles of person-centred care."*
>
> Dr William Levack, University Of Otago, New Zealand

Unfortunately, misunderstanding is a notable theme among healthcare professionals.[44 125,132] As mentioned previously, person-centred care may be confused with a wide range of associated terms, for example decision making,[106] self-management, information sharing,[153 154] and relationship-centred care.[60] Most commonly, person-centred care is considered as being equivalent to compassion (i.e. 'being nice to people')[60 152] or may be rejected as unhelpful and duplicative (i.e. 'we do it already').[41 61 66 67]

> *"It is blatant that person-centred care is not properly understood across healthcare professionals – it is not just about being nice to people."*
>
> Prof Brendan McCormack, Queen Margaret University, Scotland, United Kingdom

Whether justified or not, professional resistance may also be driven by perceptions of withdrawn or lessened expertise, the inconvenience of changing routines and beliefs that patient-centred care is difficult.[125]

> "In planning our studies we had anticipated that the staff at the hospital departments where the studies are being performed would be sceptical to the merits of person-centred care. We found instead that they considered person-centred care to be a self-evident and important facet of care. In

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fact, our major challenge was not in persuading them to practise person-centred care, but rather in convincing them that they were not practising person-centred care – at least not consistently or systematically."[61]

Ekman I, Swedberg K, Taft C, et al. Person-centered care – Ready for prime time. European Journal of Cardiovascular Nursing 2011;10(4):248-51.

Where they exist, such misunderstandings pose a considerable risk by underestimating the challenges of applying person-centred approaches, which includes the diversity of situations that a care professional must be ready for, and the varying psychosocial, cultural and medical implications they must navigate. For example, shared decision making in end-of-life care may pose very different demands from counselling a patient with a long-term health condition or providing advice about preventative care.[113] One apparently helpful strategy has been following and documenting usual care to identify visible departures from person-centredness that can be well evidenced.[61] For example, Macmillan Cancer Support in Wales documented the low proportion of cancer patients being offered care plans, and successfully challenged attitudes by presenting this to care professionals who had previously asserted that person-centred care was normal practice.[66]

As noted above, even early stage training may not wholly establish supportive mindsets, suggesting that enhanced efforts to help students internalise, reflect on and gain confidence in person-centred approaches may be necessary, such as targeted support from mentors.[150]

v.   Patient activation and health literacy

Work in patient activation and health literacy measures has been both at the level of developing indicators of quality and outcomes, (see 'Measurement' section below) as well as in support of shared decision making and self-management support at the individual level.

Both patient activation and health literacy are associated with a range of health outcomes, for example lower activation may explain some aspects of unmet needs for medical care and lower adherence to treatment.[175] Major reviews of health literacy affirm the linkage with higher prevalence of conditions such as diabetes and heart failure, lower accessing of healthcare, poorer self-management skills.[176]

One such initiative to marry activation and literacy to patient engagement and person-centred approaches has been the DECIDE intervention (see below) a package of support to help patients learn to ask questions effectively and participate in health care decisions. DECIDE appears to contribute to enhanced patient activation and self-management, underlining the potential for such models to support person-centredness, but for this further evidence will be needed. Early studies suggest, at the least, the importance of securing close professional support for such initiatives.[175]

Special focus: the DECIDE Intervention – US National Institute of Health

DECIDE is a bilingual, manualised intervention that teaches patients to (1) identify decisions regarding their behavioural healthcare, (2) generate and refine questions for their healthcare professionals regarding these decisions, and (3) promote interactions with healthcare professionals that allow for patient needs to be shared and addressed. DECIDE consists of three training sessions that balance didactic presentation with opportunities for participation, role-play and reflection.

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4311517/pdf/nihms653342.pdf

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vi.   Diverse, vulnerable and disadvantaged groups

> *"We tend to talk to those who are very literate, able and want more power, but people come from a wide spectrum. We need more sensitive models that reflect this."*
>
> Susan Morris, Macmillan Cancer Support, Wales, UK

Amongst academic and clinical key contributors, a notable theme is the degree to which 'person-centredness' (and by extension, models of shared decision making, self-management, patient engagement and goal setting) was applicable in different settings, and what adaptation and specialisation might be necessary across specialisms and populations. [37 44 66 139]

> "Equally, person-centred care cannot operate in a context that does not take into account the social structures and interpersonal elements that affect the lives of service users, carers and practitioners… practitioners also have to understand how person-centred practice takes into account elements such as class, culture, ethnicity, age, gender and sexuality. Anti-discriminatory practice is therefore crucial in providing a context that underpins a number of the challenges for practitioners."[37]
>
> Koubel G, Bungay H. The Challenge of Person-Centred Care: An Interprofessional Perspective. Basingstoke: Palgrave Macmillan, 2009.

Certainly, there is an acknowledgment that person-centred care may be particularly important and beneficial to vulnerable and disadvantaged populations,[106] but also that the mainstream application of some aspects of person-centred care may inadvertently have the *opposite* effect – that is, to further exacerbate inequalities if such models do not fully anticipate a variety of different needs, assets, values and barriers to participation.[37] The UK Equality and Human Rights Commission saw fit to raise serious concerns about the impact of personalisation (i.e. self-directed care and support) on minority and disadvantaged groups.[177]

Research suggests the rationale for this should not be dismissed. For example, poverty is strongly associated with lack of resources, information and knowledge, as well as distrust of the health care system.[178] Vulnerable patient populations – such as older people, immigrants, people with less education in general, and those with lower numeracy – report less interest in shared decision making than other groups of patients.[106] Meaningful shared decision making certainly requires all parties involved to understand the best available medical evidence relevant to the decision, a goal which may be complicated by varying levels of health literacy among patients,[8 106] or reduced access to the internet.[8] Other relevant factors known to influence the quality of communication and shared decision making between clinicians and patients include trust in physician, race/ethnicity, education level, employment status, depression and language barriers.[179]

If health IT becomes a major delivery mechanism for more person-centred support, as would seem likely, it will need to consider the needs of minority populations, as well as those with limited English proficiency and low literacy.[8]

Special focus: the Centre for Medical Psychology & Evidence-based Decision-making: University of Sydney Australia

CeMPED has focused a great deal of research on two themes, both of which have a focus on vulnerable groups (including low literacy groups, rural groups, ageing, carers and cultural and linguistically diverse background (CALD) groups. It combines two existing research groups within the University; the Medical Psychology Research Unit (MPRU) and the Shared Decision Making Hub.

The centre is a network of researchers interested in patient-centred care, who conduct research in the areas of doctor–patient communication and shared decision making (SDM) in oncology cancer screening, primary care and secondary care, heart disease, palliative care, immunisation, pregnancy and depression. Primary activities to date have been in cancer. The centre hosts the 'Sydney Health Decision Group' – a collaboration to support evidence-based decision making at the level of the consumer, clinician and policymaker. Its focus to date has been the development of tools and methods to support health decisions in the field of cancer screening and treatment.

http://www.psych.usyd.edu.au/cemped/

A suite of resources in shared decision making and patient support aids is available here:

http://sydney.edu.au/medicine/public-health/shdg/completed/consumer.php

vii.   Key reading identified by the international environment scan

- Berkman et al 2011. Health literacy interventions and outcomes. An updated systematic review. Agency for Healthcare Research and Quality.
- CEAL. Person-centred Care in Assisted Living: An Informational Guide. 2010
- Edgman-Levitan S, Brady C. Partnering with patients, families, and communities for health: a global imperative: Report of the Patients and Family Engagement Working Group, 2013. World Innovation Summit for Health, 2013. www.wish-qatar.org/app/media/380
- Equality and Human Rights Commission. Personalisation in the reform of social care: key messages. UK: 2012.
- Légaré F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. Health affairs 2013;32(2):276-84.
- Kaur JS. How should we "empower" cancer patients? Cancer 2014;120(20):3108-10.
- Koubel G, Bungay H. The Challenge of Person-Centred Care: An Interprofessional Perspective. Basingstoke: Palgrave Macmillan, 2009.

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PART 5: PRACTICAL THEMES - MEASUREMENT

a) Section summary

Context

- The majority of key contributors interviewed consider measurement to be vitally important in person-centred care as it ensures that the work is relevant, beneficial to the healthcare system, and receives support from funders and policy makers.
- The solicitation and inclusion of self-reported data can also help to promote person-centred approaches in a variety of ways – it can be a major part of collaboration and co-production between patient and professional.
- However, a number of practical and ethical concerns arise, including: an apparent lack of validated models for measurement; doubts over the transferability of models; a reliance on proxy measures of person-centredness to ascertain 'success'; uncertain psycho-metric instruments; and the absence of the patient voice in outcomes measured.
- There is also disagreement on which measures most succinctly measure person-centred care, mirroring the differences in opinion in how to define person-centred care itself.

Practical theme 6: standardised self-reported data

- Standardised self-reported data (e.g. qualitative data) has been an important area of activity in measuring person-centred care in recent years.
- Common models include patient satisfaction, patient experience, and patient reported outcome measures (PROMS). While efforts have had some successes, (for example in better identifying poor performers) there are concerns as to limitations in the reliability and relevance of data generated in such models, and their potential overuse.
- Many commentators are aware of the need to deepen qualitative feedback and to combine and balance it against other measures.

Practical theme 7: person-led outcomes and measures

- Moving away from standardised (and often clinically) measures is upheld as an important priority in person-centred care, not least due to the strong and growing evidence that what really matters varies enormously across settings, areas of care and different individuals.
- The art and science, however, of more personalised outcomes, and how they are set and monitored, is relatively new, and a great deal of commentary and research is concerned with the experimental and 'proof of concept' stage.

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Barriers, opportunities and next steps

- Research suggests very different perspectives between healthcare professionals on what indicators are helpful measures of quality. These are likely to need exposing and reconciling if measurement of person-centred care is to function well.
- The linkage of measurement to financial incentives for person-centred care seems rare, however any measurement (reimbursed or otherwise) is likely to encounter the issue of perverse incentives and how to avoid them.
- There may be fundamental challenges in applying scientific evaluation methods to quality paradigms defined by individuality and subjectivity.
- There appear to be practical limits to measurement, including measurement 'overload' and capacity issues among clinicians and management, highlighting the need for quick and practical measurement in the everyday care setting.
- Those tools that exist have mostly been designed for research – i.e. to evidence the benefits of an intervention – and therefore may be challenging for mainstream use.
- It appears to be rare to involve patients in design and validation of measurement tools.
- Where measures have been developed, research suggests these may be quite specific to an area or setting of care, for example dementia, and it remains difficult to benchmark tools (or their findings) across disciplines.
- Whole system measures of person-centredness appear to be lacking. There are also gaps in indicators for patient choice, empowerment and respect, and for patient involvement in policy-making.
- Gaps in the current research on measurement include the involvement of family and friends, empowerment, partnerships and co-production, self-identity and the linkage of person-centred care with safety.

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b) Useful context

KEY KNOWLEDGE:

Measurement of person-centred care and its related fields is a major area of research, implementation and discussion. Similarly to other key areas of work within the field, the debate on measurement operates at many levels which link back to the different views on what constitutes 'person-centredness', and from there, the practicality, relevance and need for measurement instruments.

The art and science of measuring person-centred care is the centre of very considerable debate. This reflects both the technical, organisational and implementation challenge of measurement in person-centred care,[16 48 51] concerns as to the 'double-edged sword' of measurement and the risk of perverse incentives or opportunities for gaming,[80] and more fundamental concerns as to the core values of person-centredness and how appropriate measurement is to that mission.[60]

For some, 'measuring' the complexities of person-centred care is best made sense of as a human narrative, with limited value attributed to standardised metrics of the patient experience, and emphasis instead on human connection and co-production between healthcare professional and patient.

Current research methods and tools in 'measurement' span a range of different purposes, for example, supporting system performance analysis (i.e. 'macro' measures) or tools to assist in organisational development (e.g. assessments of working environment in support of culture change and improvement). Patient satisfaction and experience data are likely to feature in any of the above, alongside a range of other data, for example staff experience or other process measures.

At the level of the patient and clinician, there is a blurry line between individual goal setting and measurement. Many established models of care planning and shared decision involve self-reported experience of symptoms, functioning, or quality of life, the result of which may be aggregated up into system measures.[18 48] Clinicians may also use other forms of measurement in support of decision making, such as health literacy or patient activation.

i. The value of measurement

"Measurement is crucial. It sends a signal that we care about person-centred care, that it is urgent, that it is a first order problem."

Dr. Dominic Frosch, Gordon and Betty Moore Foundation, USA

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> *"Traumatic brain Injury is often marked by problems with change in self-identity. We don't know if this can be meaningfully measured and evaluated, but yet it is absolutely key to the person-centred care in this field."*
>
> Dr William Levack, University of Otago, New Zealand
>
> *"There is a tendency to want to measure person-centred care – but it is an esoteric concept, it is existential, care is based on respect. We should stop measuring satisfaction – and start measuring outcomes – using a lot of patient and staff stories".*
>
> Professor Brendan McCormack, Queen Margaret University, Scotland, United Kingdom

A position adopted by a majority of key contributors in person-centred care is that 'you get what you measure' – i.e. that within modern resource-pressured, accreditation-heavy and performance-driven healthcare systems to pass unmeasured and unevidenced is to be invisible, or at best peripheral.[39 52 56 79 92 133 136 141 153 154]

> *"Most governments have limited resources, and need evidence to justify investment to embed self-management support or shared decision making skills training in medical education."*
>
> Prof Ron Epstein, University of Rochester Medical Center, USA
>
> *"We have a business model based on interventions and economic reward – where is the business model for person-centred care? For example, in cancer, there is no payment incentive for making good shared decisions, or for coaching patients."*
>
> Prof Jan Kremer, Radboud University Nijmegen Medical Centre, the Netherlands
>
> *"Unless we're able to measure person-centred care in a realistic and practical way so that it's possible to get feedback to managers and clinicians, then this approach is going to remain a pipedream."*
>
> Prof Glyn Elwyn, Dartmouth College, USA

Among several key commentators there is a marked sense of urgency to test and improve the measurement of person-centred care as it progresses from proof-of-concept stage into the mainstream, i.e. that reliable measures of quality are key to securing the compliance of the wider health system with person-centredness,[49 51 97] to achieve parity of esteem with established medical indicators,[141] and to help drive and improve care at the front line.[48]

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ii.   Progress so far/state of play

The history of progress so far is a mixed one, with most key commentators describing unsatisfactory progress to date, and a 'long way to go' until the consistent and meaningful measurement of person-centred care and its outcomes are in the mainstream.[8 11 151 172 180 181] Significant improvement activities based on patient feedback appear to have been rare.[31] Encouragingly, at least, patient experience data is now routinely gathered in some countries, for example the US, however this is not without limitations, as explored below.[8]

Current performance assessment and outcomes measures are reported to be dominated by clinical outcomes, the avoidance of adverse events, or process-driven measures to the detriment of health and wellbeing outcomes, and quality of life.[28 40 149 151 172] Even in leading fields such as dementia, the emergence of empirical measures of person-centredness appears to be relatively recent and still experimental.[11]

Significant challenges are noted in the literature and by key commentators – not least that:

- Researchers are only beginning to model pathways through which patient-centred care behaviours contribute to better outcomes.[8]
- 'Soft' data such as patient experience, quality of life and self-efficacy have a way to go until they enjoy parity of esteem with 'hard' data – i.e. clinical outcomes such as survival, or service outcomes such as readmission.[56 153 154]
- There has been a relatively narrow focus to date on measurement in the patient–physician interaction, to the exclusion of other aspects of care and outcomes.[39]
- Definitions of person-centred care and measuring person-centred care have been somewhat 'chicken and egg' – i.e. the traditional approach to defining quality has lacked the necessary concepts of patient- or person-centred care because there are no widely accepted indicators or criteria to determine patient-centredness in healthcare.[49] As such, there is a reliance on proxy measures of person-centredness.[11]
- Literature reviews suggest that although measurement tools seem to draw on similar conceptual principles and care ethos, this is rarely explicit in the tool presentation and this makes it difficult to ascertain the conceptual comparability of the tools.[11]
- Generally, there is a still an absence of the patient voice in defining which outcomes are meaningful and which can be measured.[11 18 55 67 136 159 170 182 32]
- A review of measurement tools in the field of dementia, at least, found that only a minority had incorporated substantive literature reviews in their design and research phases,[11] suggesting that attempts to ground new measurement tools in existing research and best practice may often be half-hearted.
- There is a shortage of validated models for measurement in many critical areas, for example primary care,[100] and even in disease areas considered to be leaders in person-centred care, for example dementia.[11]
- Whole system measures of person-centredness appear to be lacking.[32]
- There can be different assumptions between models as to their hierarchy of processes and outcomes, for example whether patient experience falls under person-centredness, or vice versa.[63] The implications of this do not appear well understood.

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- The relevance and transferability of measurement models across different areas of care need to be clarified.[11 17 18]

iii.   Navigating the debate on measurement: key issues to consider

> "Consider a situation in which a patient is satisfied with physician's listening skills, yet her chronic disease control worsens. Has patient-centred care been accomplished?"[8]
>
> Epstein RM, Street RL. The values and value of patient-centered care. The Annals of Family Medicine 2011;9(2):100-03.

Different assumptions and values are often at play behind measurement models and the literature that describes them, and it may not always be possible to reconcile the views of assumptions of key contributors. One major axis is the degree to which key commentators primarily envisage measurement as being a comprehensive and/or system-wide challenge (i.e. a reframing of an unrepresentative performance system with a more 'person-centred' package spanning bio-medical outcomes, processes, quality of life, satisfaction and experience data).

Another grouping is where person-centred care may be seen as more of an individual exercise framed in the care setting around more personalised indicators (e.g. achievement of personal health and wellbeing outcomes) or ethical and values based qualities (e.g. partnership approaches to decision making, the perception of dignity and respect).[11 18 59 60 159]

For example, when reading the literature and resources in this topic it may be helpful to consider:

- What emphasis/assumption there is that measurement is **a macro lever** to drive financial incentives and/or system performance.
- What emphasis/assumption there is of setting and monitoring patient-led outcomes and goals **at the level of the patient–professional relationship** as part of a process of co-production and empowerment of the person.
- That the practical potential and value of measurement is not universally accepted (especially those key contributors emphasising ethical and value-based qualities, such as co-production and personhood).
- What aspects of person-centredness might be impossible (or counter-productive) to measure, or may be held back by other broader ethical and philosophical debates (such as the definition of a 'person' in medicine).
- What particular qualities or outcomes are being measured (e.g. clinical outcomes, quality of life, experience of care), and how these fit within and inform each commentator's vision for person-centredness.
- The extent to which individual self-realisation and patient empowerment feature as quality endpoints in themselves.
- The origin of particular measurement tools (e.g. medical discipline, experimental research or setting of care) and the potential for application in other settings or other disease areas.

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c) Practical theme: standardised self-reported data

> KEY KNOWLEDGE
>
> *Much of the debate on the measurement of person-centred care is concerned with the application in recent years of 'instrumental' or standardised data collation of patient satisfaction and experience data in healthcare. These have achieved some benefits – but the limitations of these models are increasingly clear.*

i.   What does it mean?

Patient feedback on their experiences of healthcare can be captured in many ways (see 'common terms' below). Data may be subjective (e.g. 'did you feel respected') or objective (e.g. 'were you offered a care plan'), general (e.g. 'how satisfied were you with your care') or specific (e.g. 'how satisfied were you with family visiting arrangements). Patients may also provide self-assessment of their health, wellbeing or engagement with their care.

ii.   Why is this important?

The measurement of quality and performance in healthcare is hardly new. However, unlike other aspects of quality, such as efficiency, patient experience is arguably the only way to assess certain constructs that are widely considered to be intrinsic to person-centred care,[8] or to be important goals of person-centred care. For example, **quality of life** measures such as the severity of pain or fatigue experienced by a patient can only reliably be assessed by the patient themselves, and self-report is widely recognised as the gold standard for such assessments.[182] **Patient experience** of the care process is also vital to capture qualities of person-centred care such as dignity, empowerment, enablement and self-realisation.[11]

Anecdotal examples illustrate the point well. For example, one key commentator gave the example of psoriasis, which can cause flaky or scaly skin. A typical goal formulated by healthcare professionals might be a percentage reduction in symptoms, whereas a patient may instead suggest quality of life orientated goals such as being able to shake hands with somebody or wear a T-shirt with no sleeves.[35]

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iii.   What progress has been made?

> *"There has been some progress in the last three years with the larger surveys on patient satisfaction and experience – you can spot with reasonable clarity the bottom 20% of physicians who perform poorly on person-centred care. But it is hard to differentiate between the good and the just OK…"*
>
> Prof Ron Epstein, University of Rochester Medical Center, USA

Patient satisfaction and experience: qualitative self-reported data has dominated much of the research and implementation on the measurement of person-centred care to date.[31 56 153 154]

Standardised models of satisfaction and experience are now part of the mainstream data capture and performance assessment in several countries, for example the Consumer Assessment of Health Plans Study (CAHPS) in the United States.[8 63] Patient experience is also routinely captured and influences reimbursement with the recent introduction of the value-based purchasing (VBP) programme implemented by the Centers for Medicare and Medicaid Services, where experience accounts for 30% of the total score that determines hospital payment. Similar measures are reported to be in development for individual physicians and health systems.[183]

Special focus: some common terms in standardised self-reported data

With acknowledgements to Coulter A, Fitzpatrick R, Cornwell J. (2009) and Millenson ML, Macri J. (2012).

Satisfaction

Patient satisfaction has evolved in part based on consumer marketing techniques developed since the 1980s.[184] Typical patient satisfaction questions might include:[63]

How satisfied are you with the ease of making appointments for check-ups (physical exams, well visits, routine follow-up appointments)?
How satisfied are you with our office's appearance?
How caring is your doctor?

There is no consensus about exactly how patient satisfaction is defined,[31] however it may include satisfaction with health status following treatment (i.e. an outcome), or satisfaction with the way in which care was delivered (e.g. a process). Satisfaction data might typically include any of the personal preferences of the patient, the patient's expectations, and the quality of the care received, and responses may use general evaluation categories (e.g. from 'excellent' to 'poor').[31]

Experience

Typical patient experience questions might include:[63]

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In the last 12 months, when you phoned this doctor's office to get an appointment for care you needed right away, how often did you get an appointment as soon as you thought you needed?
In the last 12 months, when this doctor ordered a blood test, x-ray or other test for you, how often did someone from this doctor's office follow up to give you those results?

Patient experience is likely to include feedback on what actually occurred (for example over a period of time, for a particular care service, or for an episode such as a hospital visit) rather than the patient's evaluation of what occurred.[31] Such questions ask respondents to report whether or not certain processes or events occurred, and what their evaluation of these was.

PROMS

PROMs comprise at least a pair of questionnaires completed by the patient, one before and one after a care intervention. Patients' self-reported health status is assessed through a mixture of generic and condition-specific questions, and may capture health status (impairment), functional status (disability), and health-related quality of life (wellbeing).[31] It is usually necessary to collect detailed information about the patient's clinical status alongside the subjective measures in order to assess the full range of factors that may affect outcome.[31]

Some disease areas are also noted to be ahead in the application and recognition of patient experience data. Examples include prostate cancer treatment, orthopaedics for joint replacement, and physical therapy for pain and physical functioning assessment.[185]

While patient satisfaction data is generally considered to have provided some contribution to measurement and quality, concern about the limitations of patient satisfaction dominated much of the commentary obtained via the interviews conducted as part of this research. Patient satisfaction questionnaires have been considered to be more easily influenced by prior expectations that are a function of age, socioeconomic status or other factors[8 63] and tend to elicit more positive responses than other methods (for example posing factual questions about events and occurrences).[31] The data coming from such measurement exercises may also be difficult to interpret, for example satisfaction surveys generally yield uniformly high average ratings across institutions and thus they provide little insight into strengths and weakness,[31 62] and therefore provide very little practical information to inform improvement opportunities.

Reservations about the risk of misrepresentative data and difficulty of interpreting and responding to patient satisfaction surveys has led to an emphasis on other measures such as **patient experience** which is intended to provide more objective and targeted feedback.[31]

However, there are concerns about the over-reliance on the use of both patient satisfaction and experience data, with the use of instruments often morphing beyond their original design and scope, for example from experimental research into mainstream performance monitoring, or from macro-level organisational performance yardsticks to care professionals.[8]

Patient reported outcome measures (PROMs) are also an area of increasing activity in recent years. PROMS have been designed to offer more rigorous measurement of a range of relevant domains and to better demonstrate cause and effect over time.[31] There are many such models, but a large

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international review in cancer (see key reports below) suggests that PROMS may not yet consistently cover recognisable domains of person-centredness, and that improvements in reliability and internal consistency are still needed.[182] More research in other areas of care would doubtless be useful to build a more representative picture. In any case, despite policy claims, PROMs are no 'magic bullet' on their own and may need to be combined with other measures.

Health literacy and **patient activation** measures have proved successful with care professionals and providers in several countries around the world as a means for assessing individual and community needs, and informing service design (e.g. providing adapted or personalised interventions in response, or reconfiguring and diversifying local health services). Within the field of health literacy, leading contributors have sought to move health literacy from a relatively narrow description focused on literacy and knowledge tests towards a broader measure of personal assets, circumstances and abilities. One of the most prominent models in recent years is the HEiQ and Ophelia tools developed by Deakin University in Australia. The linkage between health-literacy and person-centred care approaches is relatively under-developed in the literature and may be an area of development in future.

> *"PAM is a tool that can help clinicians and clinical teams to be more person centred. Research shows that patient activation is a potent construct and is predictive of costs and outcomes. The studies that use the PAM to predict outcomes highlight the contribution that patients give to these outcomes. Recent studies show that by tailoring support to the patient's level of activation, it is possible to increase activation and improve outcomes. Over 200 published studies show the PAM to be a valid and reliable measure across conditions and for individuals who have no conditions."*
>
> Prof Judith Hibbard, University Of Oregon, USA

Patient activation has been closely linked with person centred-care.[79] The concept is based on the pioneering work of Judith Hibbard and colleagues at the University of Oregon, who led the development of the Patient Activation Measure (PAM).

iv. **Some of the key contributors in standardised self-reported data identified by the international environment scan**

➢ **United States, The Agency for Research in Health and Quality (ARHQ) – Atlas of Indicators and Chartbook**

The US Agency for Research in Health and Quality compiled an 'Atlas' of indicators on coordinated care in 2010. The Atlas provides definitions, a measurement framework and a comprehensive list of measures for specific purposes and contexts – e.g. generic coordination surveys, disease/care pathways, and so on.[180]

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See: http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/

The AHRQ has also created the Person- and Family-Centred Care Chartbook, which is part of a family of documents and tools that support the National Healthcare Quality and Disparities Report (QDR). The QDR includes annual reports to Congress. The Chartbook includes a summary of trends across measures of person-centred care from the QDR and figures illustrating select measures of person-centred care.

http://www.pcmh.ahrq.gov/

> **United Kingdom, The Quality and Outcomes of Person-centred Care Policy Research Unit (QORU),**

QORU is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics and Political Science (LSE), and has been funded by the Department of Health in England (from January 2011 for seven years) to support current government policy in health and social care on achieving outcomes.

See: http://www.qoru.ac.uk/

> **International Alliance of Patients' Organizations (IAPO) - Patient-Centred Healthcare Indicators Review**

IAPO has conducted an international literature review and global stakeholder consultation to identify and assess current initiatives and indicators which aim to measure the patient-centredness of organizations, countries, activities and any other relevant stakeholders. It is part of a larger project to develop a robust set of indicators in order for healthcare service providers to measure how patient-centred they are.

https://www.iapo.org.uk/patient-centred-healthcare

> **United Kingdom - NHS Greater Glasgow and Clyde – PROMs Knowledge Transfer Partnership Project**

NHS Greater Glasgow and Clyde's Person-Centred Health And Care Collaborative Programme Team led a research initiative to see how PROMs questionnaires could be made more accessible and easy to use for groups with low health literacy. Outputs include practical user guide for clinicians and an easy read leaflet to explain the purpose of the PROMs survey to patients.

http://www.healthcareimprovementscotland.org/

> **United States, Prof. Judith Hibbard and the University of Oregon – Patient Activation Measure (PAM)**

The Patient Activation Measure (PAM) is designed to assess a patient's knowledge, skill, and confidence to manage their own health and healthcare. According to its authors, clinicians use the

measure, to 'meet patients where they are', an approach that can translate into starting with smaller steps when focusing on a behavioural change or not overwhelming patients with too much information when working with less activated patients.

The PAM tool was defined by a process of consensus and co-production – including patient focus groups, a literature review, and a national expert panel. There are 10 (or 13) items in the PAM – covering domains such as skills, confidence, knowledge and accessing information.[79]

http://www.insigniahealth.com/

> **Picker Institute Europe**

The Picker Institute is an international charity working across health and social care. Established in 2000, the organisation continues to have a significant impact in the field of person- and family-centred care. The Institute has a rich vein of activity in people's experiences of health and social care, and in working across health and social care systems to support organisations to improve the quality of care. Their work underpins quality measurement in both the USA and the UK with the 'Picker Principles of Care', an internationally renowned quality framework.

http://www.pickereurope.org/working-with-us/measuring-experiences/

> **Australia – Deakin University and Monash University – Health Literacy questionnaires**

The Health Literacy Questionnaire (HLQ) is a comprehensive measure of health literacy, and the starting point for the Ophelia process, a methodology for strategic service planning. It captures fine detail on an individual's health literacy and provides detailed information about what needs to be done to improve systems and services. It is derived from extensive consultation with patients, practitioners and policymakers. The HLQ is currently being used in over 100 projects across the world, including in health promotion and disease management, needs assessment, quality and monitoring.

The HLQ consists of nine domains:
1. Feeling understood and supported by healthcare providers
2. Having sufficient information to manage my health
3. Actively managing my health
4. Social support for health
5. Appraisal of health information
6. Ability to actively engage with healthcare providers
7. Navigating the healthcare system
8. Ability to find good health information
9. Understanding health information well enough to know what to do.

http://www.deakin.edu.au/health/research/phi/health-litracy-questionnaire.php

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v.   Key reading identified by the international environment scan

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d) Practical theme: person-led outcomes

KEY KNOWLEDGE:

For most key commentators, the ultimate goal of person-centred care is to better realise the outcomes that matter to each individual person themselves. Measuring 'success' is therefore extremely problematic without efforts to solicit and record the concerns, priorities and circumstances of each person, and the use of flexible measurement and goal setting instruments to capture, enable and monitor them.

i.   What does it mean?

There is no single definition, however the primary difference from other measures is that patients themselves are able to closely influence the outcomes to be achieved, and the measures that are set to monitor them. Outcomes to be set and measured may relate to aspirations for health, wellbeing, or how care and support services are to operate.

Special focus: a definition of person-led outcomes - Meaningful and Measurable, Scotland

Meaningful and Measurable, a research collaboration in Scotland, have recently defined person-led outcomes as comprising:

Engagement with individuals using services and carers about:
What they want to achieve in life
Assets/strengths they and others bring to achieve this
Extent to which outcomes achieved, what helps and hinders

Recording of information on outcomes:
Recorded qualitatively in language meaningful to the person and that may also be summarised in tick boxes

 Using information for decision making:
 Individual care and support
 Service delivery and improvement
 Planning and commissioning

https://meaningfulandmeasurable.wordpress.com/personal-outcomes/

ii.   Why is this important?

> *"We need to pare down 'one-size-fits-all' healthcare quality measures, and raise goals that are consistent with individual values."*
>
> Dr Dominick Frosch, Gordon and Betty Moore Foundation, USA

The emphasis on setting and measuring outcomes at the individual level has been strengthened by research and key commentators upholding the inherent weaknesses of traditional standardised or clinical outcome measures. Individual priorities and goals are known to be different between patients, and extend beyond a condition or health-specific focus.[147] For example, patient groups may highlight 'non-traditional' goals associated with self-determination and personal identity,[48][139] relational aspects of care and quality of experience across the entire care pathway,[159][34] or individual circumstances such as domestic, social or employment issues[18] and social engagement, mobility, housing and tenancy, and self-care.[159]

> "Ensuring that you are measuring the things that matter most to patients is an essential component of a successful strategy for improving patients' experience."[11]
>
> Edvardsson D, Innes A. Measuring person-centered care: a critical comparative review of published tools. The Gerontologist 2010;50(6):834-46.

Equally relevant to person-centred care, the setting and measuring of individual goals may be a vital part of care planning and decision-making processes between the individual and the care professional.[18][48] The value of obtaining and measuring patient views and other self-reported data is increasingly viewed as a form of indirect care intervention itself, in light of research demonstrating that patients' perceptions of quality of healthcare have been associated with important medical and psychological outcomes, including quality of life, anxiety and depression[182] and that patients' perceptions of quality of care have also been associated with factors that directly affect the effectiveness and efficiency of healthcare, such as the under-utilisation of treatments and mistrust of the medical system.[182]

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iii.   What progress has been made?

> "Being able to set, and be judged by, patient-focused outcomes will be key to the 'next generation' of integrated care approaches."[159]
>
> National Voices. Integrated care: what do patients, service users and carers want? 2012.

As mentioned previously, person-led outcome measures are at the forefront of current research on person-centred care. In the UK at least, there has been a growing commitment over the last 5-10 years to shifting health and social care systems away from an exclusive focus on their own inputs, processes and outputs towards personal outcomes. [186] As a result, practitioners are now expected to engage with individuals about their personal outcomes during assessment and review processes. Increasingly, recorded personal outcomes data is expected to inform, service improvement, service planning and commissioning, and performance management.[186]

Whilst recognised as vital to progress, meaningful person-led outcome measures are as yet widely reported to neither to be readily available, nor very satisfactory, nor widely applied. [11 55 67 136 159 182] The intelligent analysis of personal outcomes data may pose substantial challenges at all levels of healthcare organisations.[186]

A major international review has highlighted a significant deficit of published studies looking at whether or not patients achieved personal goals in care planning,[128] which is of concern for implementation generally. A systematic review of stroke-specific patient-centred outcome measures noted that despite a range of outcome measures available for use in clinical practice, these were generic (i.e. they measured clinical outcomes such as mortality, impairment and disability (activity), and handicap) rather than the specific needs and concerns of individual patients following stroke.[18]

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iv. A selection of key contributors in person-led outcomes identified by the international environment scan

> **United Kingdom, Scotland – Meaningful and Measurable:**

Meaningful and Measurable was a Collaborative Action Research project funded by the Economic and Social Research Council (ESRC), which brought together three academic organisations, eight practice partners and four national stakeholder organisations to develop and test practical approaches to the qualitative and quantitative analysis of personal outcomes data and use of this information for decision making within organisations.

Meaningful and Measurable have published several project briefings covering the following issues:

* a number of commonly encountered misunderstandings concerning the practical applications and implications of qualitative data and qualitative outcomes data

* measurement purpose and limitations in a social context, conceptualising and categorising personal outcomes and the use of scale measures.

* the main uses of collated personal outcomes information identified and facilitated through the project, notably in the areas of practice and service development, service planning and commissioning and using more personalised methods to measure outcomes and gauge performance.

https://meaningfulandmeasurable.wordpress.com/

> **New Zealand, University of Otago, Rehabilitation Teaching and Research Unit**

In rehabilitation, key commentator Dr William Levack has led studies on the conflicts that can arise when applying goal setting in the context of therapy for brain injury. Research has highlighted that care professionals may attempt to influence (and in particular, to dilute) targets where they feel these are unrealistic and likely to not be met, potentially reducing the degree of involvement of the person with the disability in goal setting and treatment planning. Explanatory factors behind this behaviour may include fears of negative performance feedback (whether formally via set measures, or informally via peer perceptions). Dr Levack and colleagues are currently finishing longitudinal studies on brain injury rehabilitation, respiratory rehabilitation, on patient-led development of measures, and on goal setting.[48]

http://www.otago.ac.nz/wellington/study/rehabilitation/

> **New Zealand, Auckland University of Technology, The Centre for Person Centred Research**

The Centre for Person Centred Research (PCR) is a multidisciplinary research centre led by Co-Directors Professor Paula Kersten and Dr Nicola Kayes. The PCR conducts international level research in rehabilitation and disability, with a core focus on 'rethinking rehabilitation' on the premise that

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people matter, and enhancing knowledge in this domain is key to improved outcomes and sustainable health services.

Ongoing longitudinal research in stroke and brain injury rehabilitation led by the Auckland University of Technology (AUT) is expected to reaffirm the enormous variation in patient-led outcomes and the limitations of generalised measures to assess person-centred care.[153] [154]

https://pcrc.aut.ac.nz/

> **Sweden, Gothenburg University, The Centre for Person-Centred Care (GPCC) – MOSAIC study into PROMs**

One of the larger research groups in GPCC is the MOSAIC project, involving researchers from the UK, Turkey and Sweden. MOSAIC aims to improve the precision, interpretability and efficiency of PROM assessments by exploiting potentials offered by item response theory (IRT, here Rasch modelling), item banking and computer adaptive testing (CAT) in order to enhance their utility and thereby increase their application in clinical research and practice. Furthermore, the approach aims to individualise or 'tailor' assessments, and therefore to be suitable for outcome evaluation in person-centred care initiatives.

www.GPCC.gu.se

> **Norway, Umeå University Department of Nursing**

Prof David Edvardsson and Prof Astrid Norberg at Umeå University have led significant work in the measurement and setting of person-led outcomes in dementia. (See key reading section below.)

http://www.omvardnad.umu.se/english/?languageId=1

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

PCORI is an independent non-profit, non-governmental organisation located in Washington, DC. It was authorised by the Unites States Congress in 2010.

PCORI's mandate is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions. Specifically, it funds comparative clinical effectiveness research, or CER, as well as support work that will improve the methods used to conduct such studies.

PCORI began funding research in December 2012. PCORI's emphasis on engaging patients and the broader healthcare community often requires that patients and other stakeholders become integral members of the research process. PCORI's Pipeline to Proposal Awards initiative provides seed money to encourage patients and other stakeholders to partner with researchers to study the issues that are most critical to them.

http://www.pcori.org/

v. Key reading identified by the international environment scan

- Edvardsson D, Innes A. Measuring person-centered care: a critical comparative review of published tools. The Gerontologist 2010;50(6):834-46.
- Lawrence M, Kinn S. Defining and measuring patient-centred care: an example from a mixed-methods systematic review of the stroke literature. Health Expectations 2012;15(3):295-326.
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e) Measurement – barriers, opportunities and next steps

Although measurement remains challenging, many key commentators remain optimistic, and welcome the recent emergence of measures for empirical studies of person-centred care in the literature, even if further application and testing of these tools is needed.[11] Nonetheless, several key challenges emerge.

i. What are we measuring anyway?

> "[Of] several shortcomings of current approaches to measuring patient-centred care, many… result from confusion between its associated philosophy, behaviours, and outcomes."[8]
>
> Epstein RM, Street RL. The values and value of patient-centered care. The Annals of Family Medicine 2011;9(2):100-03.

The debate on measurement will likely continue to be shadowed by broader and possibly quite fundamental issues in terms of what person-centred care is, and whether or not widely accepted definitions can be reached. Leading commentators note that the development of clear measurement domains and instruments has been obstructed by the absence of single and agreed definitions of person-centred care[8 18] a view that is echoed by key commentators across the wider family of the 'holistic paradigm', for example in patient-centred care,[4 19 49] and client-centred care.[16]

ii. Research vs implementation

> "Practice development and practitioner research approaches will be critical to the evolution of this research and development agenda [in models of evaluation], as we increasingly know that the best way to understand person-centredness (and thus to research it) is to do so from an experiential perspective."[117]
>
> McCormack B. Guest Editorial - The Person-centred Practice Research International Community of Practice. International Practice Development Journal 2012;**2**(1).

According to one key study of measurement and care planning tools in dementia, a major issue is that many measurement tools were primarily designed for research – i.e. to evidence the benefits of an intervention – rather than mainstream use, and many have not been used in actual research since the development period.[11] It seems likely therefore that much greater efforts will be needed to develop *and* validate measurement tools able to function in the mainstream, and many existing tools will require their further testing for validity and reliability – even if developed via systematic and rigorous processes.[11] Regardless, when new measures are developed, consistent and whole hearted efforts to ground them in existing research and best practice appears to be needed. [11]

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iii.   Gaps – moving beyond the patient–physician interaction

Other major gaps in established models for measurement are noted as quality of dialogue,[51] self-identity,[48] and broadly those attributes of person-centred care outside of the doctor–patient relationship.[39]

There may also be major gaps in well recognised domains of person-centredness, such as physical comfort, or the involvement of family and friends.[182] Measurement tools linking person-centred care with domains such as patient safety may also be lacking.[181] Empowerment, a concept with a valuable contribution to make to person-centred care, has only rarely been formally assessed and few validated questionnaires to measure it are reported to exist.[17]

A global review led by International Alliance of Patient Organisations (IAPO) noted an uneven spread of indicators in relation to IAPO's five principles of patient-centred healthcare, with a large number of indicators for access and support, and information, and fewer for choice and empowerment and respect. Very few initiatives mentioned indicators for patient involvement in policy-making.[32]

iv.   Reconciling assumptions on quality between patients and professionals

Perhaps most importantly, research suggests very different points of departure between care professionals and patients in terms of perceptions of quality, which are likely to need exposing and reconciling if measurement of person-centred care is to be performed with ethos and commitment. For example, in stroke care research demonstrates that patients may place far greater value than clinicians on day-to-day activities rather than self-care activities, and crucially, the quality of their ability to participate in an activity such as toileting, walking or bathing (i.e. to do it comfortably) not merely the achievement of whether they can do it or not without assistance (i.e. as commonly measured by professionals).[18]

Unfortunately, measurement tools seem to show different degrees of orientation in, and incorporation of, input from patients, carers and clinicians in the design phase [11] The voice of the person with dementia is still absent to a large extent in the available tools, and further work is required on tools that are designed to engage directly with the viewpoints of people with dementia.[11]

A major study in stroke concluded with a research call for comprehensive outcome measures, which facilitate [care professionals'] understanding of priorities and goals of patients with stroke, and how these may change over time.[18] Measures are required that will support healthcare providers in the provision and evaluation of stroke rehabilitation services that patients perceive as effective and meaningful.[18]

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v.   Measurement across whole systems, and across different groups and areas of disease

Where measures have been developed, research suggests these have not been standardised across service providers or jurisdictions,[185] and the different definitions, principles and working demands they serve may be quite specific to an area or setting of care, for example dementia.[11] Accordingly, where tools have been developed, it remains difficult to benchmark them against those developed in other fields, to translate existing tools into different settings[11] or to benchmark service delivery.[49,] Although standardised measures of patient satisfaction such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) are used for performance measurement and payment, research suggests that patients have a complex set of beliefs and expectations about their healthcare, which may not be represented in traditional patient satisfaction measures.[183]

According to a 2012 report by the International Alliance of Patients' Organisation (IAPO), based from an international literature review and global stakeholder consultation, few well-defined and coherent system level indicators currently exist.[32]

vi.   Marrying science and subjectivity, groups and individuals

> *"One of the reasons why person-centred care is so disruptive is that scientific measurement is difficult (e.g. Randomised Control Trials – RCTs). To measure and evaluate it we need process analysis, qualitative research methods. We need groups of people to measure person-centred care, which is of course a contradiction."*
>
> Prof Jan Kremer, Radboud University Nijmegen Medical Centre, the Netherlands

The measurement of personal outcomes may be a difficult compromise between meaningful, personalised and adaptive discussions at the personal level, and the aggregation of standardised data to inform system-level decision making.[172 187] At the least, both quantitative and qualitative indicators will need to be used better in combination if they are to provide a deeper and more accurate measure of person-centredness.[32]

However, key commentators report quite fundamental challenges in applying scientific evaluation methods to quality paradigms defined by individuality and subjectivity,[51] for example that empirical science requires adequate sample sizes, suitable controls and standardised environments,[51 132] whereas person-centred care may often require flexibility, spontaneity and uniqueness.

Another complication noted in person-centred care as a whole is the overlap (and often confusion) between processes, behaviours and outcomes,[8] for example as noted earlier in this paper (see Part One). Thus one key commentator notes of the Consumer Assessment of Health Plans Study (CAHPS) that the hierarchical relationship among terms is very unclear.[63]

Again as noted earlier, (see Part One – Research), establishing cause and effect of person-centred models is made more complex by the simultaneous application of multifaceted interventions in

person-centred care models – such as behaviours (e.g. shared decision making, goal setting), improved access to care professionals (e.g. more regular consultations or monitoring with care professionals) and alternative forms of care (such as self-management or counselling).

The experience of measurement so far reveals some challenges to researchers in interpreting inconsistencies between the perceptions of patient and care professionals.[8][18] 'Cognitive dissonance' may also be a limiting factor (i.e. the phenomenon of patients not wanting to 'admit' the doctor they

Where care mapping or goal-setting tools are both interventions and tools to help plan care, as well as to measure success, care may be needed. For example, Dementia Care Mapping (DCM) has been used as an instrument to evaluate the impact of an intervention, to evaluate care, and as both an intervention and measure of outcome. The latter may present problems if the technique/process is the same as the outcome.[11]

vii.   Financial reward, performance and perverse incentives

> *"Measurement is difficult – anything quickly ceases to be a measure once it has become a target."*
>
> Prof. James Appleyard, International College of Person-centred Medicine (ICPCM)
>
> *"Measurement – we must be very careful. Any result can be manipulated, gamed. Ask, how can we get sufficient stakeholder engagement? How do we really know physicians are providing person-centred care? How do we hear the ordinary voice?"*
>
> Michael Paterson, Joining the Dots, Scotland, United Kingdom

Broadly, the linkage of measurement to financial incentives seems rare. For example, as recently as 2012 the payment model of the Veterans Health Administration in the US was not considered supportive of the Patient Aligned Care Team – despite this being a key initiative to provide patient-centred care in the primary care setting, in which the VA is considered a world leader.[30]

Existing payment systems remain dominated by episodic treatment, rewarding activity rather than outcomes,[28][40] let alone person-centred ones. As noted earlier, alternative approaches to care delivery may struggle if they are outside the financial model. For example, in one delivery system, use of the Patient Activation Measure (PAM) was reported to be so successful at reducing hospital admissions that it generated reluctance to use the tool, for fear of lowering revenues further.[79]

Just as with mainstream care, measurement for the purposes of performance analysis or financial reward may raise the issue of perverse incentives. Most simply, providers may be reluctant spend resources collecting data that is not tied to incentives.[187] Key commentators note the mixed history of measurement in other areas, for example the use of the HbA1c threshold in diabetes, which was felt to restrict the freedom of clinicians to apply different judgement calls on quality of life and on risk vs benefit to different populations. Aggressive HbA1c control was rewarded for all patients, despite the opinions of some clinicians that it was often unhelpful and possibly unsafe for older

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people, and particularly those with other co-morbidities, but of more likely value to a younger person.[55]

Overall, while synthesis reviews have established some core quality domains as perceived by patients, it remains unclear how this varies (and might therefore be appropriately weighted) by healthcare setting and disease condition (for example, communication may be potentially more important in outpatient and chronic disease settings vs clinical expertise and quality in the inpatient setting.[183]

> *"Person-centred care is of course needed in contexts such as palliation and intensive care, but measurement is a complex issue, particularly when other family members have to be involved if the patient is incapacitated or unconscious."*
>
> Prof Glyn Elwyn, Dartmouth College, USA

Reassuring then as measurement may seem, the risk of inadvertent harm is a distinct possibility of 'one-size-fits-all' measures. Anecdotal evidence abounds of the danger this poses. For example, one key commentator mentioned a study conducted into person-centred cultures in Norwegian nursing homes, which found (perhaps contrary to expectations) the use of restraint was associated *with* person-centred care models. Behind the seemingly negative association was the ethical policy of those institutions to minimise the unnecessary sedation of patients for the convenience of staff.[60]

viii.   Pragmatic limits to measurement

> *"Measurement must be short and real world, and has to be quick and suitable across conditions and multiple conditions."*
>
> Prof Glyn Elwyn, Dartmouth College, USA
>
> *"Many leaders in healthcare are exhausted by measurement – they feel pressured as it is (e.g. processes of care, targets for nutrition, securing a high quality workforce). Documenting economic and accounting processes draws healthcare organisations away from leading quality of care and professional development. If we're too keen on this it reins in freedom to practise person-centred care, with 'economic prompts' taking up the mind space of healthcare providers."*
>
> Anne Marie Mork Rokstad, Norwegian National Advisory Unit on Ageing and Health, Norway

As noted earlier, managers of healthcare organisations are unlikely to prioritise activities (including data collation) that are not reimbursed, performance assessed or linked to policy priorities.[40] Some

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degree of goodwill is therefore required for measuring and evaluating experimental and models and practices.

Gathering reliable feedback from patients is a sophisticated research task, and healthcare organisations may achieve greater value for money if these exercises were pooled and coordinated.[31] Management will need to engage healthcare professionals in the task of obtaining measurement feedback given their vital role in encouraging patients to participate, or even in recording the data themselves.[31] There are plenty of opportunities to innovate. In the UK for example, several healthcare providers involve volunteers in carrying out on-site patient surveys, with encouraging results.[31]

Staff capacity is another issue in the implementation of measurement – for example one tool (Dementia Care Mapping) is reported to take a minimum of a two-day course to learn about the tool, followed by time-consuming data collection.[11] Other tools may be more streamlined, but have been designed with the intention of research use.[11]

PART 6: REPORT CONCLUSION

Person-centred care as a term evokes considerable debate and energy. It represents, to a majority of those interviewed, a revolutionary agenda, a fundamental questioning of the essence of healthcare, its meaning and the purpose of health systems. Even among more cautious voices, few interviewees doubted its contribution – most acknowledged at the very least that the term has held great value in recent years as a substantial catalyst for change.

As a debate, person-centred care invokes fundamental questions on the meaning of medicine and health care and the very purpose of our health systems to society. The community of person-centred care is led by key contributors with an undoubted sense of mission and purpose. Their views may (rightly) be underpinned by frustration and disappointment at the suffering they have witnessed as result of sometimes impersonal, dehumanised or fragmented care. Unsurprisingly, those who have chosen dedicated years of work to challenging the status quo do not assert their views lightly. Attempts to reconcile world views across the community of person-centred care are frequently called for, but not always universally welcomed when they materialise.

To some, the value of person-centredness to achieving ethical and effective modern healthcare is utterly obvious. To others, person-centredness may be regarded as a new (and even contentious) concept that needs to be carefully vetted just as any other intervention would likely require. Thus very different assumptions and perspectives may surface when healthcare professionals in nursing, psychological rehabilitation, psychiatry, palliative and dementia care attempt to discuss person-centred approaches with colleagues working in a more acute setting or with a more traditional clinical background. There is no good reason why such differences cannot be better recognised at the outset of discussions, or why the complimentary roles of different medical specialties could not be equally valued in their contribution to the whole package of effective, safe and person-centred care. This is the underlying philosophy of multidisciplinary care – and such a shift in attitudes might help to encourage richer and more productive discussions across the whole of the community of medicine and care.

The conceptual divergences within the field of person-centred care came to the fore in our research, and should not be overlooked. The lack of a clear and commonly agreed definition of person-centred care may contribute to limited implementation in some instances.

However, therein lies perhaps one of the greatest questions facing the community of person-centred care – how, and if, such a heterogeneous community of practice is to move forwards as a whole to achieve real improvements in the care individuals receive across the care spectrum. Certainly, there is an increasing expectation that person-centred care has come of age in terms of the policy aspiration, and that if it is to graduate from revolutionary movement to be adopted into the mainstream, it will need to stand up to much greater and sustained scrutiny as a distinct collection of concepts and practices.

As noted earlier, this research aimed to establish a state of play across the domains of research, implementation and measurement. It became clear during the course of this work that such terms

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are hard to distinguish; 'research' arguably defined the vast majority of activity in the field – i.e. few models or measures of person-centred care appear to have been replicated consistently into the mainstream, and even the most recognised and promising concepts and practices are often still being tested. Even those delivery programmes at scale, such as the Patient Centred Medical Home (and related models) in the United States, or the 'Personalisation' agenda in the UK, are often regarded as yet to deliver the whole system 'paradigm shift' of truly person-centred care. In part, this finding may reflect a bias towards academic (and therefore research-driven) sources in the literature searches, calls for information and interviewees for this work, possibly to the detriment of more obvious candidates for implementation, such as healthcare providers, insurers, and national and regional government sources. These contributors seemed harder to identify, lacking the search portals and clearing houses that academic research benefits from, and a much clearer and dedicated map of policy and implementation in such organisations would be a very helpful future development for the community of person-centred care.

Whereas the heterogeneity and experimental nature of the current work on person-centred care is evidently a strength – to which the richness of practice and commentary is testimony – it is at this threshold of entry to the mainstream that the weaknesses of this become much more apparent. If, in the spirit of Alain Le Plege, 'person-centred care' has not already served its useful purpose as a rallying call for those intent on challenging the status quo (i.e. dehumanised, fragmented, inflexible, impersonalised and paternalistic health care), then progression and translation to the mainstream as a recognisable school of thought would seem to require that the relevant lexicon be clarified, *either in humanistic and philosophical terms, or delivery mechanisms, or ideally both.* However favourable policy makers and health system leaders may be to person-centred care simply being 'the right thing to do', they will undoubtedly require clear terms, and a coherent body of evidence and best practice before investing in wide-scale change. As discussed in the report, demonstrating causality requires the aggregation of studies through synthesis and meta-review (often across international settings) and the replication and documentation of results, which itself requires clear terms to compare and pursue evidence. This appears to be a juncture on which person-centred care, as a recognisable community of practice, is standing.

Defining person-centred care therefore seems to be an issue that is unlikely to go away, however blunt, crude or impersonal such exercises may seem. The value of a universal definition of person-centred care as an intellectual exercise and policy goal was often contentious. Definitions were often feared as a reductionist framework, incompatible with the very basic element of person-centred practice, and usually assumed to refer to a service-led, instrumental definition, rather than a humanistic values set, the nurturing of human relationships or a common element of emancipatory practice, for example. Given that some practices and settings of person-centred care are clearly utterly unsuited to either instrumental approaches, measurement or financial reward, yet clearly utterly central to ethical practice (e.g. personal reflection, resilience of individual values and self-knowledge) another language of terms and value may need to be mastered and communicated to policy makers.

Finally, if person-centred care is indeed to enter a period of mainstream implementation and uptake into policy, much greater knowledge exchange will be needed, with a stronger emphasis on lessons learnt in practical delivery and application. The practical experiences of parallel large-scale implementation programmes involving major changes to culture and everyday practice (such as the

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organisational integration of healthcare, patient safety, or healthcare tech and IT programmes) would seem to be a rich vein of wisdom and experience into which the literature on person-centred care rarely draws.

Most areas of care have their natural incubator for different aspects of person-centred practice. Progress in these fields is encouraging and there is much to celebrate. But if proof of concept is increasingly won, much more strategic research is needed to marry up these strengths and weaknesses, to push the boundaries across other elements of care. The community of person-centred care must now work to help ensure the benefits of person-centred practice can spread beyond specific settings and populations for the benefit of all people receiving healthcare, their families, and the healthcare professionals upon whom we rely. There is no time to lose.

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APPENDIX: RESEARCH PROTOCOL

International Environment Scan: person-centred care

Research protocol

March 2014, amended July 2015

1. Introduction and context

This appendix defines the scope of the International Environment Scan on person-centred care (PCC) that the Health Foundation commissioned the Health Policy Partnership to perform in 2014.

The environment scan had a clear task: to deliver a catalogue of key contributors, networks, and a 'state of play' analysis of person-centred care as an evolving movement for change. It was therefore not concerned with:

- Attempting to redefine the Health Foundation's vision and definition of person-centred care
- Cataloguing **all** activity in person-centred care, nor its parallel and inter-related fields
- Identifying **any** key contributor in parallel fields, where they are not relevant to person-centred care.

Our search for information consisted of four research activities:

i) a Google search
ii) a review of the peer-reviewed published literature, using PubMed and Embase
iii) a call for information, emailed to contacts globally via the Health Foundation's e-newsletter and the International Longevity Centre (ILC) network; and
iv) expert interviews.

An intensive desk research phase in March – May '14 informed the design and delivery of the call for information and published literature search, and interview questions. Thereafter the approach was iterative across all areas of activity.

2. Conceptual framework

It was considered vital that this research project adopt clear definitions of PCC. Accordingly, it adopted a core enablement model based closely on that adopted by the Health Foundation in their

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position statement 'Helping to Make Person-Centred Care a Reality' (Collins 2013), where the enablement of the individual to take an active role in their health and health decisions is the primary focus, with models of delivery and provider–patient relationships orientated to achieve this goal.

The four key principles of person-centred care

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

Source: Collins, A. Measuring what really matters. The Health Foundation, London, 2014.

Some other key definitions are reproduced here from recent work sponsored by the Health Foundation:

- [A] *person-centred* health care system [is] one that supports us to make informed decisions, helps us to successfully manage our own health and care, and delivers care with respect for our individual abilities, preferences, lifestyles and goals.
- Patients are *partners in their own health and health care*: the person is the focus of healthcare, not their illnesses or conditions.
- *Health professionals' role* is to support people to determine what they want from their healthcare and to support them to better manage their health, as well as to provide treatment and care in a way that reflects each patient's individual needs and wants.
- Person-centred care *reframes the role of health services* to be one that informs, equips, supports us to manage our health, rather than caring for, determining, directing or telling and in which quality is defined by the people using the health service, their experience and their definition of outcomes.

In shorthand, we referred to this core 'enablement' vision for PCC simply as 'PCC'. We recognised that other related fields of innovation and improvement seek related goals, not least improved patient outcomes, and that person-centred care is a wide term used across a number of areas. These required investigation as some successful enablement approaches to PCC were considered likely to be hidden behind other more dominant nomenclatures. However, the model defined above provided a clear lens for investigation and criteria for inclusion.

3. Objectives:

The purpose of the international environment scan was to establish 'who is doing what' in PCC, the ultimate objective being to inform the Health Foundation's current and future positioning, and research and improvement activities in the field of PCC.

We wished to understand, catalogue and synthesise the following:

a. The main conceptual positions currently adopted by leaders in PCC around the world. Although this project adopted its own conceptual framework, a first step in the scan was to explain how different individuals, networks and organisations were defining PCC (and what

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differences exist in underlying values, methods of delivery, areas of care) and how this fitted into the adopted conceptual framework in (2) above.

b. The activities and leadership in the implementation of PCC concepts into practice, in terms of:
- Research: i.e. advancement of conceptual frameworks, core characteristics and applications of PCC through primary research or secondary analysis
- Development: i.e. the piloting and provision of care and support models
- Implementation: i.e. the roll-out and adaption of existing models at scale
- Measurement: as it relates to all three areas above, i.e. measurement of concepts, how they are implemented in practice, measurement and monitoring of outcomes of PCC, and assessment of the impact of PCC within different contexts.

In the context of this protocol 'leadership' encompassed individuals, networks, and organisations, their activities, visibility of their contribution to the field of PCC, and participation in PCC as movement for change.

4. Key outputs

Synthesis report

- o Global overview of leading stakeholders involved in PCC
- o Thematic analysis of emerging conceptual groupings and themes – how they might be usefully delineated, and what characterises these groupings
- o Identification of future direction and gap analysis – highlighting areas where underdevelopment is likely to constitute a barrier to improvement

Catalogue of leadership of PCC:

- o Excel spreadsheet database following a standard template to allow for easy navigation and data retrieval
- o Word document database providing similar data to the above, (i.e. providing an alternative format to access and reuse data), but with the addition of more 'in depth' profiles of 35-40 selected leading individuals, networks and organisations
- o Organisations to be picked based on them being (a) dominant and relevant models in the field (b) emerging and/or innovative examples of practice of particular note (c) representative of the range of emphases and models in person-centred care

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5. Description of research elements

i. Google search:

Google searches were conducted using key search terms listed in **Table 1** below. Other parameters (type of organisation, year, etc) are also featured below. Terms were entered and followed to 150 results, except where stated otherwise.

All relevant organisations, individuals and networks were entered into a spreadsheet along with relevant contact details, areas of activity/research and country of origin.

Google search parameters, March 2014

- **Target organisations**: those included in our searches were (as per the original Health Foundation Invitation to Tender) academic organisations, healthcare providers, health policy institutes, independent foundations, research and policy think tanks, centres for innovation and improvement, professional bodies/associations, third-sector organisations (including patient groups), private sector organisations (e.g. insurance companies) and formalised or semi-formalised networks. The relative importance of different organisations (e.g. public versus private sector) is likely to vary by country.

- **Information sources** included publicly available documents and sources of information, including institutional/organisational websites, policy reports, policy briefs and communiqués (e.g. from private sector organisations or NGOs), academic working papers, peer-reviewed publications, specialist conference proceedings, professional (healthcare) press publications, bibliographic mapping and Health Foundation research reports and resource centres.

- **Geographical scope**: the UK and a limited, but relevant, additional list of countries of similar economic development to the UK and countries within the EU, namely: EU27 countries, Canada, the United States, Australia, New Zealand, Singapore, South Korea, Japan, Hong Kong and South Africa.

- **Time limits on searches**: for feasibility purposes we limited literature searches to publications dating back to 2007. Although somewhat arbitrary, the belief was that a seven-year period was sufficient for the purposes of this research (i.e. to identify current key contributors). However, sources before this date were identified through our search and included where necessary, for example seminal articles that offered a historical perspective on the evolution of conceptual terms for PCC.

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Table 1: Search terms used in Google, March 2014

Person centred care

Person centred care in health

Patient centred care

Enablement in health
Patient enablement
Service user enablement
Consumer enablement in health

Empowerment in health
Patient empowerment
Engagement in health
Patient engagement

Co-production in health
Patient co-production
Service user co-production
Consumer co-production – 50

Shared decision making in health
Patient shared decision making
Service user shared decision making
Consumer shared decision making in health

Person focused care
Person focused care in health
Patient focused care
Service user focused care
Consumer focused care

Personalisation
Personalisation in health
Patient personalisation
Service user personalisation
Consumer personalisation in health

Individualised care
Individualised care in health
Patient individualised care
Service user individualised care
Consumer individualised care

Recovery in health
Patient recovery – 50
Service user recovery – 50
Consumer recovery in health – 50

Supported self-management in health
Patient supported self-management
Service user supported self-management in health
Consumer supported self-management in health

Health literacy
Patient health literacy
Service user health literacy
Consumer health literacy

Activation in health
Patient activation
Service user activation
Consumer activation in health

Collaborative care
Collaborative care in health – 50
Patient collaborative care – 50
Service user collaborative care – 50
Consumer collaborative care – 50

Patient partnerships
Service user partnerships
Consumer partnerships in health

Involvement in health
Patient involvement – 100
Service user involvement
Consumer involvement in health

Person provider partnerships in health
Patient provider partnerships
Service user provider partnerships
Consumer provider partnerships in health

Re-ablement
Re-ablement in health
Patient re-ablement
Service user re-ablement
Consumer re-ablement in health

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ii. Peer-reviewed literature search:

We focused this stage of the search on PubMed and Embase, with the rationale that these two databases would cover a sufficient proportion of the published literature to constitute a comprehensive but time-efficient method for identifying key academic contributors to person-centred care.

Before conducting the full searches, a shortened version of the search was conducted on PubMed and Embase using core terms from the Google search (e.g. person-centred care, patient-centred care) to develop a methodology appropriate to these search engines. This resulted in two outcomes:

a) a smaller list of search terms, drawn from the larger Google search terms (see **Table 2**)
b) clear criteria for inclusion and exclusion.

Table 2: Search terms used for PubMed and Embase searches

Search term
Person-centred care
Patient-centred care
Patient enablement
Health literacy
Patient empowerment
Patient engagement
Patient self-management
Shared decision making

Exclusion and inclusion criteria:

A summary of exclusion and inclusion criteria is presented below.

❖ **Exclusion criteria**

Below are the criteria which would lead to an abstract being <u>*excluded*</u> from the results. Please note that many serve as examples of more than one exclusion criterion.

- **Outside of scope** – any study published prior to 2007, or based in countries other than those agreed in the research protocol.
- **Incompatibility with core values of person-centred care** – for example, where the subject matter was tangential (such as clinical coordination) or arguably contradictory, such as adherence to medical treatment.
- **Cultural or linguistic adaptation** – as a logical consequence to the above, we also did not include studies which discussed cultural / linguistic adaptations of incompatible or tangential models.

- **A rehearsal of the person-centred 'deficit' in mainstream healthcare** – but without any articulation of a progressive counter-proposal (conceptually or materially).
- **Evidencing causality or concomitance of psychosocial wellbeing and clinical outcome** – being well established, and a fundamental basis for 'person-centred care'.
- **Too clinically specialised** – e.g. literature that did not focus on a prevalent condition or significant care group, or where such findings or conclusions from a specialist setting or condition could not be related to PCC more broadly. Examples **of** prevalent conditions are as (e.g. diabetes, COPD, heart failure, depression, or dementia), significant care groups (e.g. older people, children, mental health), relevant settings (e.g. acute, community) or mainstream professional grouping in healthcare (e.g. primary care, nursing).
- **Small sample size** – a very small sample size and individual personal testimonies were rejected.
- **A lack of conceptual clarity** – impenetrable jargon and use of PCC as a 'buzzword' without any attempt at definition.
- **Mobile and e-health technology solutions** – this was considered a major separate field of research; also there was a tendency of such studies to focus on improved access to traditional care, rather than person-centred care as such. However, some key relevant work did emerge (see Practical Theme 5 in the synthesis report above.)
- **Too specific to national policy** in any given country.
- **Patient experience and patient report outcome measures (PROMs)** – where the patient's role in defining the worth of such measures from first principles seemed poorly articulated.
- **Community and patient engagement in strategic health planning**.
- **Lack of an abstract**.
- **Articles which were comments on other articles**.
- **Articles which focused on complementary and alternative medicine**.

- ❖ **Inclusion criteria**

Results that didn't meet any of the exclusion criteria were analysed to assess their potential to reveal key contributors to PCC by taking into account the following criteria:

- *Remit of the study* – the study length, sample size and the number of institutions involved were taken into account, with larger projects being prioritised.
- *Type of institutions* – studies which involved Europe-wide or worldwide collaborations, and those which included both governmental and academic institutions were prioritised.
- *Number of results* – institutions and individuals which reoccurred more than two times in the results and did not meet any of the exclusion criteria were prioritised in an effort to uncover organisations with portfolios of work in the field as well existing networks.
- *Country of lead institution* – less relevant results were included if they did not meet any of the exclusion criteria, but came from of countries absent from the Google search (in order to give as broad a picture of PCC leaders as possible).

iii.   Call for information

Key text from the original call for information is provided below. The process of issuing the call for information was made up of two parts.

Firstly, the ILC-UK issued a call for information to the members of the ILC Global Alliance (Argentina, Brazil, China, Czech Republic, Dominican Republic, France, India, Israel, Japan, the Netherlands, Singapore, South Africa, USA). A call was also issued to three further organisations who are in the process of becoming ILCs (Australia, Canada, Germany). The call was supported by a short briefing document, highlighting the purpose of the work, and providing brief definition of person-centred care. Despite giving a clear conceptual brief, the respondents were encouraged to send information 'if in doubt'. Respondents were encouraged to follow a simple structure to help ensure the quality and consistency of return information (via three headings of 'Who', 'What' and 'Where') but the format of the return was deliberately open to encourage participation (we offered to accept any email). Reminder emails were sent out at weekly intervals.

The ILC-UK call for information prompted returns across a broad range of countries. ILC Global Alliance members also sent through the contact details of particular individuals who they believed would be able to provide more information for the call. These individuals were contacted and their responses fed into the return results.

Secondly, a call for information was issued via the Health Foundation's website and e-newsletter network, with a reminder send out after three weeks. The call followed a similar format to the ILC-UK led call, however the briefing document received further edits and amends to ensure it was appropriate for the Health Foundation branding. This main call for information prompted a satisfactory number of returns, (approx. 160), with very few invalid responses.

Results from both calls for information were amalgamated into a spreadsheet, and have formed part of our overall analysis for this interim review.

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Extract from call for information

How you can help

We would be grateful to be directed to key contributors working on person-centred care around the world, **and in particular, those leading enablement approaches**. This would include, for example, self-directed support, shared decision making, collaborative care planning, health literacy models or other initiatives with similar aims and principles.

Please note that it does not matter if 'person-centred care' (or its equivalent in other languages) is not a term widely used in your country or area of expertise – if you think a key contributor shares similar values and goals, we'd be very interested to hear about them and their work.

WHO, in your opinion, are the most notable contributors to the development of person-centred care in your country or particular area of expertise? This might include any of the following:

- Individual people
- Academic organisations
- Healthcare providers
- Health policy institutes and think tanks
- Centres for improvement
- Professional bodies/associations
- Patient and third-sector groups
- Private sector organisations
- Formal and semi-formal networks

WHAT are their main current or recent contributions to the development of person-centred care? For example, are they active in any or all of the following ways?

- Research: e.g. advancement of conceptual frameworks, core characteristics and applications of person-centred care through primary research or secondary analysis
- Development and innovation: i.e. the piloting and testing of new person-centred care and support models
- Implementation: i.e. the roll-out and adaption of existing models at scale
- Measurement: as it relates to all three areas above, ie. measurement of concepts, how they are implemented in practice, measurement and monitoring of outcomes of person-centred care, and assessment of the impact of person-centred care within different contexts.

WHERE we can find them – please share any key weblinks, reports, publications and give any relevant names, organisations and contact details.

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iv.   Telephone interviews (main phase Sept to Nov '14)

Between 35-40 in-depth (i.e. 45-minute) telephone interviews took place between September and November '14 to substantiate initial findings in terms of leading organisations and activities.

Key text from the invitation letter and key questions issued prior to each interview is provided below.

The purpose of the interviews was to gain a more in-depth understanding of the state of play on PCC internationally, with a view to identifying the most relevant leaders and activities, as well as the direction of travel of conceptual frameworks and measurement approaches.

With this in mind, each call constituted an invitation to:

- describe the most important leaders and activities in the field of PCC in the interviewee's country or region, and identify the best information sources documenting these
- identify other leaders of PCC for possible approach, as appropriate
- comment on their assessment of the overall 'state of play' in PCC internationally, including existing gaps and barriers to progress
- offer perspectives on evolution of PCC in the UK, if appropriate.

Specialisation of the interview questions by country and also by area of expertise of the interviewee was necessary to maximise the value of each interview. To this end, we adopted a semi-structured interview approach, with core questions common to all interviews yet allowance for variation in the questions posed to each individual as well.

Key extract from invitation to interview – preparatory questions

Questions for interview

Please note you are welcome to respond as an individual, and/or on behalf of an organisation. No comment will be attributed to you without your prior written permission and verification.

1) In your view, how is the term 'person-centred' care understood:
   - in your field of expertise?
   - in any organisation(s) you might represent?

2) What is the particular focus of your work when it comes to person-centred care?
3) How do you view your contribution to person-centred care as a wider concept and movement for change?
4) What are the challenges and priorities going forwards, in terms of establishing person-centred care as a dominant model for healthcare:

   - in your area of expertise?
   - in any organisation(s) you might represent?
   - in your country?
   - globally?

5) What useful or leading examples are you aware of in terms of:

   - conceptual development and clarity in definitions of person-centred care?
   - implementation and delivery?
   - measurement?
   - collaborations and knowledge networks that we should investigate?

In particular, we would appreciate your thoughts on activities that may have evaded us in our largely academic first search phases – namely healthcare providers, government and policy leaders, and industry or commercial leaders, or relatively new international networks and collaborations.

6) In your view, how can this project best add value to the existing commentary and literature on person-centred care?

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6. Data validation

Data validation and review of findings took place via the working group and Health Foundation internal review. As stated above, other key stakeholders were also invited to comment on the pre-final draft (with the agreement and input of the Health Foundation and working group) and will be named as contributors to the report, as appropriate.