# How is person-centred care understood and implemented in practice?

# A literature review

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# Acknowledgements

# Contents

# Part 1: Summary of the evidence from a quality improvement perspective

## What we did

The multi-faceted and evolving nature of person-centred care means that evidence continues to emerge that supports how best to achieve this in practice. In this summary produced by the Evidence and Evaluation for Improvement Team we highlight evidence supporting person-centred care from a quality improvement perspective. In part 2, the breadth and depth of the literature relevant to person-centred care is reviewed including the approaches associated with current key initiatives being implemented in Scotland.

## What we found

### Defining person-centred care

Since person-centred care is context dependent and multi-dimensional it can be defined in different ways ([Box 1](#) - Examples of person-centred care definitions). There are also a variety of connected terms and meanings in the literature relating to person-centred care including patient-centred, client-centred, and relationship-centred amongst others.

In the context of healthcare, person-centred care recognises that optimal care is centred on a person's needs, preferences and values in the context of their lives rather than only their symptoms and diagnosis as a patient.[1] The Healthcare Quality Strategy for NHS Scotland describes the ambition for person-centred care as involving "mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision making".[2: p.7]

While definitions of person-centred care vary, common principles have been developed to support shared understanding of what person-centred care means and looks like in practice, such as the Health Foundation's framework which includes offering coordinated and personal care and support, and supporting people to recognise and develop their own abilities.[3] In addition to common principles, person-centred care can be understood as involving different models and strategies which include shared decision making, self-management support, care planning, and co-production.

The development of person-centred approaches has evolved across different fields such as self-management in chronic care and co-production of services in mental health. Therefore, person-centered care overlaps with other areas of practice including patient and public engagement and co-production of services.

There are different ways in which person-centred care as a process and outcome can be viewed and implemented in practice. From an ethical and philosophical position of personhood, person-centred care emphasises the needs and rights of the person, in the whole context of their personal lives and social circumstances, not just that within the healthcare setting. This requires recognition of what matters outwith the provision of healthcare and clinical encounters if person-centred outcomes are to be achieved in partnership with healthcare practitioners. Entwhistle and Watt (2013)[4] make a particular case for a capabilities approach in practice.

> **Box 1. Examples of person-centred care definitions**
>
> The US Institute of Medicine's 'quality chasm' report defines person-centred care as "providing care that is respectful of and responsive to individual patient preferences, needs, and cultural values and ensuring that patient values guide all clinical decisions"[5: p.6]
>
> The Health Foundation identifies person-centred care as where "health and social care professionals work collaboratively with people who use services. Person-centred care supports people to develop the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own health and health care."[6: p.4]

## What person-centred initiatives are supported by the evidence?

There are a range of approaches by which patients and professionals engage to enact the principles of person-centred care.[7] Those being broadly implemented in Scotland which have also been evaluated include shared decision making, self-management support, person-centred care planning and personal outcomes approaches. Other key approaches in Scotland, where evidence is emerging, includes those that are community led and asset-based and those based on participation and involvement of people using services in the co-design of quality improvement such as Experience-based Co-design (EBCD).

**Experience Based Co-design** involves gathering experiences from people who use services and staff who deliver them through in-depth interviewing, observations and group discussions to identify emotionally significant points and create a short edited film that provides a basis for understanding how people experience a service.[8] Staff are then brought together with people who use the service to explore improvement opportunities and implement solutions to these. There is some evidence of improvement in people's self-management and physical and mental health from using co-design methods.[9]

**Shared decision making** involves supporting people to be active partners in decisions about their care and treatment. There is emerging evidence including at systematic review level that shared decision making can improve self-care behaviour and adherence with treatment, however evidence of clinical or health service outcomes is reported as limited and requires further research.[10]

**Self-management support** is an approach for people with long-term conditions where they are supported to manage their health and wellbeing in active partnership with health care professionals.[11] There is evidence reported to suggest that self-management can improve symptoms and clinical outcomes although this varies depending on the type of approach and condition.[11, 5] A whole system and shared responsibility approach has been identified as necessary for enabling self-management. House of Care is an example of this approach where commissioning and planning embeds self-management support within services and ensures a range of support is available in addition to medical care.

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**Box 2. 'What matters to you?' enabling person-centred care practice in Scotland**

There are other focused initiatives which are said to represent enablers for person-centred care in Scotland. 'What matters to you?' is a Scotland-wide campaign to encourage and support meaningful conversations between people who provide health and social care and the people, families and carers who receive such care. Key aims include engaging with individuals using NHS services as people, and supporting genuinely shared decision-making.

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**Personalised care planning** involves a conversation, or series of conversations, between a person (often with one or more long term conditions) and a practitioner, possibly involving family too, whereby they jointly agree on goals and actions to improve health and wellbeing.[12] There is some evidence that personalised care planning can lead to improvements in health outcomes including physical health, psychological health, self-management capabilities and self-care activities.[12]

**Personal outcomes approaches** aim to engage with people who need care or support to identify what matters to them, building on their capabilities in informing decisions.[13] The quality of the interaction can itself contribute to improved outcomes.[14] Effectiveness is partly determined by whether an organisational approach is adopted.[15-16] Personal outcomes underpin [Self-Directed Support legislation](#) in Scotland.

The evidence base for person-centred care approaches such as shared decision-making and self-management support is understood to be still emerging with methodological issues being a key contributor to the limitations of current research and the variability of evidence reported.[5] The effectiveness of approaches like self-management also depend on how they are conceptualised, planned and implemented.[11]

A capabilities approach is discussed in the literature as being important for orientating self-management support so that it accommodates more fully what matters to people and what helps them to live well.[4] New models of how self-management can be implemented include House of Care. A key component of this model is commissioning and planning that embeds self-management within a range services that enables support for people beyond only medical care and that includes voluntary and community support.[11]

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**Box 3. What evidence is there in relation to key person centred care approaches?**

**Shared decision making**
- supporting people to share in decision making can improve their satisfaction with care, self-confidence and the extent to which they stick with treatment
- impact on clinical outcomes and health service use is more limited so far with more longitudinal research needed

**Self-management**
- self-management as an enabling approach for people with long-term conditions to be active partners can improve symptoms and clinical outcomes although this varies depending on the type of approach and what condition is being managed
- self-management requires a whole system and shared responsibility approach to how services are planned, commissioned and delivered with House of Care being a model for this approach

**Personalised care planning**
- involving a conversation or series of conversation between a person and a practitioner whereby goals and actions are jointly agreed
- shows evidence of improvements in health outcomes including self-management capabilities, self-care and adherence to medications

**Personal outcomes approaches**
- a focus on personal outcomes supports relational approaches to care and support for people
- there is some evidence of improved decision making from the approach and improvement in short-term outcomes for people

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## How is person-centred care implemented?

There are a range of factors identified in the literature for how implementation of person-centred care can be facilitated (Box 4). A key barrier to implementation discussed in the literature is that of practitioners and managers believing that they are already doing person-centred care when this may not be the case.[4] It is clear however that team working and person-centred relationships can support the shared understanding of what person-centred care involves and how it should be put into practice.

Work by the Health Foundation on 'co-creating health' in relation to self-management emphasises the need for a whole system and health economy approach that aligns with the holistic principles of providing person-centred care rather than fragmented, 'working across secondary, community and primary care services (and the third sector and local authority where appropriate)'.[17:p.8] A whole system approach to how services are improved is also identified as being important for better understanding and resolving of tensions between person-centred care and issues relating to resource pressures and inequality of access to services.

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**Box 4. Organisational facilitators of person-centred care**

A range of facilitators identified in the literature for how person-centred care can be implemented in an organization are as follows:

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

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**How is person-centred care measured?**

There are different reasons for and approaches to measuring person-centred care. A review of person-centred measurement identifies that approaches can either be broad in focus such as assessing the quality of person-centred care as part of services or focus on specific components of how person-centred care is applied in practice such as the effectiveness of shared decision making.[11]

The most common measurement approach is the use of structured surveys, with less structured approaches including the use of interviews and observation. However, there is a lack of agreement about which approaches are most appropriate or meaningful to use and which aspects of person-centred care should be the focus.[18] System measures have been identified as having been prioritised with quantitative surveys being a key tool. However, these have been shown to be unreliable in terms of capturing people's personal perspectives and needs.[19]

There is agreement that different forms of measurement and evidence are required to appropriately evaluate the complex nature of person-centred care. This also requires consensus around the intended outcomes of person-centred care including the importance of outcomes that matter to people personally and that result directly from person-centred interactions; such as feeling understood, respected and listened to.[20] Few approaches have been found that are driven by patient or service user perspectives despite this being a key principle of person-centred care.

Thus a combination of methods and tools are understood as being required to measure what matters for people personally, as well as what matters for organisations and systems.[11]

## Conclusion

The evidence in this summary identifies how person-centred care as a model or approach underpins improving quality. This includes the use of particular approaches such as personal outcomes to engage with people who need care or support and to build on their capabilities.

From an implementation perspective, person-centred care aligns with a whole system approach. Recent policy developments in Scotland support the central role of person-centred principles for improving quality. This more recently includes the Independent Review of Adult Social Care[21] which states that "it is vital that we amplify the voice of lived experience at every level in our redesign. We have a duty to co-produce our new system with the people who it is designed to support, both individually and collectively." Translating these principles of person-centred care for a whole system approach will be important as these policy developments move forward.

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# Part 2: Person-centred care literature review

## Introduction

This review of literature on the theme of person-centred care was commissioned by Healthcare Improvement Scotland in November 2018.

The specification for work included a review of evidence around person-centred culture and capabilities and their impact on delivering person-centred care, as well as a range of interventions and approaches that could evidence improved clinical, social and personal outcomes.

## Methodology

In our initial discussions about the review, we agreed to undertake a scoping review, which is described by Mays, Roberts and Popay (2001, p194) as aiming "to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially where an area is complex..."

Early discussion also confirmed the need to adopt a pragmatic approach to the review, with a focus on informing practical implementation in Scotland. It was agreed that the review should consider debates about definitions of person-centred care, before going on to consider what the benefits are, what is known about implementation in general, a comparison of key initiatives currently being implemented in Scotland, and challenges and strategies with measurement.

We scoped relevant literature over a period of two months, paying particular attention to:

1) Existing recent reviews of relevant literature including international examples

2) Evidence based reports from key national and international agencies including the Healthcare Foundation and the Picker Institute

3) Previous work by the reviewer which included a review of person-centred initiatives in Scotland, person-centred care and dementia and person-centred care and recovery in mental health

4) Following this initial review of influential and/or particularly relevant texts, we used key search terms consistent with the following themes:

- Definitions of person-centred care
- Person-centred culture and capabilities
- Measurement of person-centred care

In addition, once we identified key initiatives being implemented in Scotland, which were supported by evidence, we searched for relevant evidence, and with the focus on pragmatism, additional texts which support implementation.

Brevity was a priority, given that one of the most frequently identified barriers to achieving person-centred care is time. Each of the following sections includes a brief conclusion, summarising the key arguments made, and includes references, so that each section can be read as a standalone report.

# Findings

## Defining person-centred care

### Person or patient

In reviewing relevant literature, it quickly becomes apparent that definitions have changed over time and that there is a range of similar terms used including patient-centred care, client-centred care, person-centred care, and relationship-centred care amongst others (de Silva 2014, Harding et al 2015). Person-centred care is also by nature highly individualised and context-dependent, making unilateral declarations of its practical application difficult (Matthews et al 2018). While reference to person rather than patient centred care has become established as a way of signaling that the focus is on the human being rather than their symptoms or diagnosis (de Silva 2014, Paparella 2016) the term patient-centered still prevails. We will consider this latter dimension in more detail first.

The term person-centred care is widely identified as having its origins in the work of Carl Rogers (1961) and client-centred psychotherapy. Client-centred is a less frequently used term now in counselling terms, with emphasis on the person being viewed as an expert on themselves. While Rogerian therapy has tended to be practised with adults who are cognitively intact, its wider influence has been enormously influential on thinking about therapeutic relationships and emotional difficulties (Brooker 2003).

There is considerable ethical and philosophical discussion in the literature about what it means to be treated as a person. Colleagues in Sweden emphasise that person-centered care highlights the importance of knowing the person – as a human being with reason, will, feelings, and needs – in order to engage them as an active partner in his/her care and treatment (Ekman et al 2011). This type of definition also understands the clinician as a person, as demonstrated in the following statement from the field of medicine:

"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" (Miles and Mezzich 2011, p74)

## Compatability with evidence-based approaches

Concern is identified that person-centred care can be at odds with evidence-based approaches, which stem from the evidence-based medicine movement and which tend to focus on evidence at population level rather than what matters to individuals. Such evidence-based approaches have developed in parallel with development of the person-centred practice movement. While in theory, these two paradigms should be able to find ways to develop in tandem, tensions continue between their respective advocates in practice. While there is considerable support across sectors for the inclusion of formal research evidence in decision-making, debate centres around the forms of evidence prioritised by traditional evidence-based approaches and their assumptions about what useful knowledge is and whose knowledge counts.

The principle concern about this type of evidence-based approach is its technical rational orientation towards the 'hierarchy of evidence' (Webb 2001). The hierarchy of evidence was developed by the Canadian Task Force on Preventive Health Care, was also adopted by the US Preventive Services Task Force and gives precedence to biomedical perspectives and experimental methods, while qualitative evidence and the voices of practitioners and people using services tend to be muted, with implications for how decisions are made, and in whose interests. Some have argued the tensions are now resolved:

"Fortunately, that debate has been laid to rest; proponents of evidence-based medicine now accept that a good outcome must be defined in terms of what is meaningful and valuable to the individual patient" (Epstein and Street 2011, p100).

The argument of these authors might be considered optimistic in terms of the positioning of the person's perspective in relation to evidence-based medicine, but the argument to achieve a better balance between the two is well made. The following provides an example of how this might look in practice:

"Research evidence is necessary but insufficient for making patient care decisions. An effective but toxic chemotherapeutic regimen is the treatment one patient with cancer can and will take, another patient can take but will not, and yet another patient could not take even if wanted. Careful attention to the bio-psychosocial context of patients and to their informed preferences when crafting treatments requires expertise and practical wisdom. This represents the optimal practice of evidence-based medicine" (Montori et al 2013).

Moving beyond the need to blend evidence-based approaches with person-centred approaches, there is also a need to consider integrated understandings of how persons are treated by health services.

**Integrated understandings**

It is notable that there is very little focus on person-centred care as a fully integrated concept; that is, literature tends to focus on health or social care rather than both. One recent relevant commentary on person-centred care in Scotland included both health and social care (Barrie and Miller 2017). Although given time limitations, this review has focused almost entirely on health literature, as it is widely acknowledged that achieving person-centred care within health, with its own diversity of services, settings and specialisms, presents considerable challenges (Harding et al 2015, Pelzang 2010).

Pelzang (2010) describes the tendency towards role division and fragmentation of care within 'discontinuous' healthcare systems, in which people are handed over from one set of personnel to another in new venues of care. This encourages a narrow, task-specific view of illness rather than engagement with the whole person (Pelzang 2010).  In this context, there is increased international focus on person-centred AND integrated care in recent years, not least by the WHO's *Global strategy on integrated people-centred health services 2016-2026* (WHO 2016), to be reviewed in the next section on *why* person-centred care, and which encourages a wider focus on the social determinants of health.

Diversity is also present in the evidence, with distinct professional literatures for person-centred occupational therapy (Hammell 2013) medicine (Mezzich, Appleyard and Cluzet 2017) and nursing (McCormack 2001) to name a few.

# Conclusion

We opened this review by considering definitions, acknowledging that there is considerable diversity in definitions of person-centred care. This is not unusual in the complex and messy world of human services, where multiple perspectives, disciplines, policy drivers and interests collide or combine.

In considering definitions, we started with thinking about the fundamental issue of whether we are talking about patients or people, with most key voices on person-centred care making a clear case for the need to think about people in holistic terms rather than about diagnoses or symptoms primarily. Associated with this, we considered key tensions between evidence-based medicine and person-centred care, with key voices again promoting the need to ensure the person (and their voice) is not lost in clinical encounters, whilst acknowledging that scientific evidence has a place.

These tensions extend into considerations of maintaining personhood, autonomy and capabilities when individual cognitive abilities are reduced, referring to the specific case of dementia, where evidence supports the value of relational practice supporting individual dignity and comfort. While there is no single definition, there is reasonable agreement about the principles of person-centred care, and a few examples are included here as a possible basis from which to discuss approaches to implementation.

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# Why deliver person-centred care?

## A global agenda

In their "Global strategy on integrated people-centred health services 2016-2026", the World Health Organisation (WHO) called for a paradigm shift in the way health services are funded, managed and delivered. To achieve this, the document set out a global strategy on integrated people-centred health services as follows:

"Developing more integrated people-centred care systems has the potential to generate significant benefits to the health and health care of all people, including improved access to care, improved health and clinical outcomes, better health literacy and self-care, increased satisfaction with care, improved job satisfaction, improved efficiency of services, and reduced overall costs" (WHO 2016, p10).

Part of this global agenda is the 'Vienna Recommendations on Health Promoting Hospitals', in which the World Health Organisation (1997) recognised the participatory role people need to play to improve both quality and efficiency of healthcare (Alharbi et al 2014). Writing from a Swedish perspective, Alharbi et al (2014) note that their healthcare system shares features with the UK model in being at least historically largely publicly funded and designed to collectivise and standardise services. While standardisation has a place, particularly with regard to proven surgical procedures for example, there is always scope for person-centred care, particularly with complex long-term conditions.

Overburdened health care systems are not prepared to meet demographic challenges, and require reform to realign traditional acute-care clinical practices and organisations to accommodate illness management as central to care and treatment. As we set out in the definitions section, people are often required to navigate through fragmented health care systems and adapt to the customs and processes of health care organisations and professionals, rather than receiving care responsive to their needs, preferences and values. As an alternative, person-centred care is widely advocated both as a key component of effective illness management (Ekman et al 2011) and as part of an integrated approach to care (WHO 2016).

The literature covers diverse reasons for person centred care. In addition to the global concerns about sustainability of healthy systems, underpinning philosophical and ethical values are promoted as reasons for doing this, and there are also the associated outcomes. We consider the philosophical/ethical perspective first.

## Philosophical and ethical reasons for person-centred care

Given the previous discussion on definitions which highlighted the various interpretations of person-centred care, it also makes sense that different reasons are given in the literature for carrying out person-cented care.  First, returning to more philosophical or ethical orientations as introduced in the last section, person-centered care is considered to be an approach to care

which is 'the right thing to do'. This links to humanism being identified as the essence of medicine in the definitions section (Mezzich, Appleyard and Cluzet 2017).

The ethical imperative for person-centred care is clearly highlighted in the definitions section, with emphasis on the need for people to be "treated as persons." Entwhistle and Watt (2013) make a particular case to use insights from the capabilities approach to render person-centered care applicable to diverse individuals and situations. These authors argue that excessive concentration on the 'rolling out' of particular processes and on narrow clinical outcomes can lead to an instrumental approach unlikely to achieve the culture change required. Instead they argue for respectful and compassionate encounters, which acknowledge people's social context, and respond to the capabilities of each individual in endeavours to support autonomy (Entwhistle and Watt 2013). We now turn to consider diverse outcomes associated with person-centred care, which include a variety of types of outcome.

## Outcomes of person-centred care

While a commitment to the philosophical/ethical underpinnings of person-centred care is fundamental to its effective practice, there is also a substantial body of evidence which explores associated outcomes. We approach the evidence base for person-centred care with some qualifications in mind. First, we cannot cover the entire evidence base here, but touch on diverse aspects to provide an overview of the types of outcome that are considered. Second, we note that caution is required in considering particular types of outcome, or in narrowing the focus to system generated outcomes at the expense of capability outcomes or outcomes prioritised by people, and therefore aim to acknowledge these different outcomes. Third it is not within the scope of this review to comprehensively assess the evidence relating to efficacy of person-centred care approaches. However, touching on different types of outcomes associated with person-centred care can help with attempts to clarify the intended purpose of person-centred care:

"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'" (Harding, Wait and Scrutton 2015, p10)

Despite the fact that definitions of person-centred care and its concomitant measurement are complex and hard to pin down, evidence of benefits is widely reported, whilst still tentative at times. Identified benefits include being better able to manage complex chronic conditions, seeking appropriate assistance, experiencing reduced anxiety and stress, and having shorter hospitalisations (Balik et al, 2011). People are also more likely to adhere to their treatment plans and choose less invasive and costly treatments if receiving person-centered care (de Silva, 2014; Stanhope et al 2013). To take the example of mental health services, effective person-centred care has been found to increase engagement in therapeutic and psychiatric treatment, improve medication adherence, client reports of wellbeing and reduce symptom severity, based on a number of studies reviewed by Matthews et al (2018).

Within person-centred care, there are bodies of evidence associated with particular approaches (see section 4). For example, there is evidence of benefits to people and families through helping people to share in decision-making. There is also emerging evidence that supporting people to share in decision making can improve their satisfaction with care, self-confidence and the extent to which they stick with treatment. Research on whether this may in turn have impacts on symptoms and clinical outcomes is limited so far with more longitudinal research needed (da Silva 2012). Da Silva's review cautiously concludes that helping people become active participants in decisions about their care can potentially alleviate pressure on services, but, reflecting the perspective of Entwhistle and Watt (2013) above, one-off interventions or tools are unlikely to make a significant impact on population health or the sustainability of systems.

There can be a tendency to separate out non-clinical and clinical outcomes in research about both shared decision-making and person-centred care in general and it is argued that the person's experience should be further recognised as an indication of quality alongside health and wellbeing and so on (Harding et al 2015).  A range of studies link health and wellbeing benefits to the experience people have in interacting with health care personnel.  Harding et al (2015) reviewing studies relating to effective care planning, shared decision making and self-management support, note the requirement for both people and professionals to experience trust and mutual respect, and exchange their relevant knowledge and expertise, to achieve good outcomes. The practitioner brings knowledge of the diagnosis, prognosis, treatment options, and possible outcomes, and the person brings knowledge of the impact of a condition on their daily life, their personal values, preferences and attitude to risk, and any issues in adhering to treatments. The relational aspects of such interventions are found to contribute to significant results including adherence to medications and improved chronic disease control, without necessarily incurring higher costs (Epstein and Street 2007, Epstein et al 2010).

Coulter et al (2015) in reporting results of their systematic review, found that personalised care planning is a promising approach that offers the potential to provide effective help to patients, leading to better health outcomes, with more research needed.

To take an example from Sweden, Alharbi et al (2014) note that when people felt listened to and had their own perceptions noted, this created trust. People felt secure knowing healthcare professionals had listened to them and that their concerns had been taken seriously. People spontaneously expressed that they felt that staff saw them as people and did not solely focus on their disease. It was also stated that not every ailment or aspect of a person's illness needed to be addressed or resolved for open listening to be perceived as a positive encounter. The fact that staff had a wider understanding of the person's situation provided peace of mind. There was an increased sense of personal responsibility and a stronger basis for a continuing relationship with healthcare providers (Alharbi et al 2014).

**Why an integrated person-centred approach?**

Referring back to the global agenda around person-centred care, this increasingly makes an explicit link between person-centredness and the integration of care (WHO 2016).  In the definitions section we discussed concerns in the literature about fragmentation of care within 'discontinuous' healthcare systems, in which people can fall between the cracks. This tendency towards division encourages a task-specific view of illness rather than the holistic approach required for overall health and wellbeing. Avoiding fragmentation and ensuring genuine person-centredness not only requires a multi-agency approach (Fox and Reeves 2015, Harding 2014) but an understanding of the tensions created by medical hierarchies, and requires greater equity within health systems to avoid further inequity for people using the services.

Further debate and discussion around the professional hierarchies that exist in health care, the power that comes with knowledge and expertise, and the impact of this on inter-professional practice are required in order to provide care that equitably addresses the needs of patients (Fox and Reeves 2015, p117)

# Conclusion

The case for person-centred care is compelling. This is now a global agenda, whereby the sustainability of services is linked to the need to implement not only person-centred, but integrated care, at scale.

The two main types of reason given are firstly the philosophical and ethical reasons, in that this is the right thing to do, to treat individuals in need of health care with humanity, dignity and respect and to treat them as whole persons not as conditions.  Secondly, there is evidence of improved outcomes, despite the various definitions in operation and the challenges for measurement.

Reported outcomes are diverse and include improved health, wellbeing and quality of life for people and families and improved effectiveness and efficiency for services. There is some evidence that much of this can be achieved without incurring additional cost. However, the potential for improved outcomes needs to be considered in tandem with philosophical and ethical considerations, and the case for responding to each person in their social context, paying attention to their personal capabilities, regardless of age or cognitive ability. Further consideration is given to the developing evidence base in the measurement section.

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# Person-centred initiatives

Following from the section on how to deliver person-centred care, including evidence about what is known to work in general, this section considers selected key evidence-based initiatives associated with person-centred care.  The criteria for inclusion were as follows:

- Initiatives which are already being implemented broadly in Scotland
- Supported by a strong evidence base
- Supported by guidance on implementation

## Shared decision-making

The phrase shared decision-making was first used in 1972 by Veatch, in his paper on models for ethical medicine. Where the previous ethical model had thrived on the moral principles of doing no harm to the patient, Veatch added patients' freedom and dignity, as well as justice, emphasising fairness and equality among individuals. The origins of shared decision-making can be traced back to the concept of informed consent, underpinned by values such as autonomy and respect for people (Ahmad et al (2014).

There is interest in finding a middle ground between more paternalistic approaches whereby the practitioner makes the decisions, and what is described as the informed model, where the person decides. Principles have developed to support shared decision-making which include that information provided should be unbiased, the person's perspective should be considered, the relative merits of different options discussed and that ideally a mutually agreed position is reached (Ahmad et al 2014).  More recent definitions variously emphasise the relational nature of decision-making, a concern with what is achieved, and the importance of documenting and acting upon the decision reached (Legare and Witteman, 2013)

Research has found that key facilitators to support shared decision making include strong leadership, motivated people and professionals and appropriate infrastructure. Therefore, the culture and infrastructure of health services are as important as the motivation and attitudes of people and professionals (da Silva 2012). Evidence also implies that active support for both people and professionals is needed to enable true partnerships. In practical terms.

Elwyn et al (2012) propose a model of how to do shared decision making based on choice, option and decision talk. Their relational model supports a process of deliberation, and proposes that decisions should be influenced by exploring and respecting 'what matters most' to people, which also depends on them developing informed preferences. The aim is not just to provide information, but also to elicit information from the person about what treatment options might mean with regard to personal circumstances linking to wellbeing and quality of life.

The model acknowledges that the person may want to discuss their options with others before making a decision, and that it may be an iterative process. There is concern to maintain balance within the clinical encounter, with some cautioning against over emphasis on framing people as

autonomous decision-makers and inhibiting professionals from going beyond information giving for fear of steering individual preferences (Cribb and Entwhistle 2011).

## Self-management support

The aspiration to develop people's skills associated with self-management support introduces some similar issues to those raised by shared decision making, with both emphasising a collaborative approach, based on partnership and contributing to person-centred care (Ahmad et al 2014). In supporting self-management, the different types of knowledge and understandings discussed and developed through shared decision making may be drawn upon to try to influence the person's beliefs and understandings and subsequent behaviours and activities. In other words, self-management support can be seen as representing the relational context within which more focused (and episodic) shared decision-making sits (Ahmad et al 2014).

Self-management or self-management support is typically associated with long-term conditions, particularly given that most people living with long term conditions manage on their own or with family support most of the time. This may involve a complicated range of tasks, requiring confidence and skill. The Health Foundation identify that for people with long-term conditions, self-management support means:

• being active partners in determining outcomes that are important to them and how to achieve them, working in collaboration with health care professionals

• being supported to build knowledge, skills, confidence and resilience to manage the impact of their symptoms and limitations so they can live a full and meaningful life

• being enabled to access the support they need within and beyond health services to better manage their own health and wellbeing on an ongoing basis (de longh et al 2014, p7)

Tensions were identified in relation to shared decision-making, in ensuring that people do not feel abandoned to face difficult choices alone on the basis of complex information from services. This tension can be amplified in relation to self-management, where the implications for people's lives are broader and longer term:

To be person-centred demands that health care systems do not allocate people responsibilities that are not aligned with their capabilities for self-management, that health promotion efforts do not undermine trusting relationships, preclude the exercise of patients' self-trust or self-respect and that people's own views of what is good for them are not neglected (Entwistle and Watt, 2013)

Like other aspects of person-centred care, effective self-management support requires whole system changes, from how services are regulated, planned, commissioned and provided, to how health practitioners and people with long-term health conditions work together (de longh et al 2015). The House of Care model depicts shared responsibility across a health care system (commissioners, health care professionals, organisational processes and people with long-term health conditions) to deliver care and support planning, identified as the gateway to identifying

the self-management support needs for people (de longh et al 2015). The House of Care has received considerable support in Scotland.

In practical terms, the Health Foundation report to support self-management describes the cultural shift for both people using services and practitioners and recommends approaches which help people to think about their strengths and abilities, identifying information needs and the changes that people can make in their lives to achieve goals and maintain health and wellbeing.

They recommend tools including collaborative agenda setting for meetings between practitioners and people, and care and support planning (de longh et al 2015). The latter is viewed as contrasting with traditional clinical practice, allowing people to set or negotiate the agenda for the consultation, set their own goals and develop a plan for how these will be achieved and by whom (Ahmad et al 2014).  In some services, there may also be a focus on person-centred planning, which we consider next.

## Person-centred Planning

Personalised care planning involves a conversation, or series of conversations, between a person (often with one or more long term conditions) and a practitioner, possibly involving family too, whereby they jointly agree on goals and actions to improve health and wellbeing (Coulter et al 2015). There is evidence that personalised care planning leads to improvements in physical health, psychological health, self-management capabilities and self-care activities (Coulter et al 2015).

Again in practical terms, a range of tools and approaches is available to support person-centred planning.  NHS England and a consortium known as the Coalition of Collaborative Care produced the personalised care and support planning handbook, setting out a collaborative process between equals, involving discussion of:

- what is important to them, setting goals they want to work towards
- things they can do to live well and stay well (and for some people, dying well)
- what support they need for self-management; agreeing actions they can take for themselves
- what care and support they might need from others and how this can best fit in with the rest of their lives
- what good support looks like to them as an individual
- preparing for the future, including making choices and stating in advance preferences for care at the end of their life (where relevant and appropriate) (NHS England 2016, p11)

Person-centred planning includes significant specific literatures relating to different groups of people, including personal planning for people with learning disabilities and people with dementia. We refer here to recent work on personal planning in mental health services. While this work is from the US, recent collaboration demonstrates marked similarities in the challenges and opportunities for embedding person-centred planning in the US and Scotland (Miller et al 2017).

And while the work relates to a specific sector (mental health and recovery services) the core principles are more broadly relevant. For example, it is identified that in the US context, as in the UK, a key challenge is for mental health agencies to reorient their care systems to a person-centred model while negotiating an ever more demanding environment characterised by greater accountability and reduced funding (Stanhope et al 2013).

Work in the US relating to person-centred planning and recovery includes expanding emphasis on collaboration and transparency, with some agencies now also using a collaborative approach to documentation. Collaborative documentation encourages completion of planning and associated processes during face-to-face sessions. It works to mutual benefit by ensuring that plans genuinely reflect people's values with evidence that this can result in greater engagement with services and higher rates of medication adherence (Stanhope et al 2013).

This counters factors known to contribute to disengagement of people with mental illness including lack of trust in the system, poor alliance with providers, not feeling listened to and lack of opportunity for decision-making (Stanhope et al 2013).  A strong therapeutic alliance is identified as key (Hamovitch et al 2018). Emphasis on collaborative documentation and the therapeutic alliance is highly consistent with work on personal outcomes.

## Personal Outcomes approaches

The aim of a personal outcomes approach is to ensure that people using services and their families are supported to live the best lives possible, building on their own capabilities, and that the outcomes identified by people and families are built into decision-making processes. Work in this area started in the 1990s by the Social Policy Research Unit at York University where Hazel Qureshi and colleagues (1998) emphasised that focusing on outcomes meant a shift from service led priorities to ensuring that what matters to people remained central.  While the language has changed more recently, the types of outcomes considered remain focused on three categories identified by Qureshi et al (1998):

- Maintenance (or quality of life) outcomes such as being as well as possible, seeing people, feeling safe
- Change outcomes including improving confidence and skills, managing symptoms, improving mobility
- Process outcomes such as feeling listened to, valued and respected

More recent work in Scotland over the past fifteen years has continued research and implementation work with the emphasis shifting in the context of integration to include health, supported housing and other services.  The early work was commissioned by the Joint Improvement Team of the Scottish Government (Cook and Miller 2012).  More recently the work is being promoted through a multi-agency national network (Personal Outcomes Network 2016).

The overall focus is on the need to think about people in the context of their life and not just services, and about creative ways of working towards the valued ends identified by people. There is also increasing emphasis on the connection between personal outcomes and community-based resources in addition to formal services, and on the importance of acknowledging the

contribution that people and their families want to make. There are also strong links to the Community Led Support programme being led by the ihub in Scotland.  Personal outcomes also underpin Self-Directed Support legislation in Scotland.

The approach and associated evidence (Miller 2011, Miller and Barrie, 2019) highlight the value of the outcomes focused conversation, particularly in the context of relational practice, as a valuable intervention in itself.  There has also been close attention to how personal outcomes are recorded in documentation including personal plans, and echoing the US work on recovery and person-centred planning, how collaboratively produced plans can help to build trust, restore identity and aid recovery (Miller and Barrie, 2019).

In their report on personalised care and support planning NHS England provide examples of personal outcomes in making the case that discussion should be focused on what is being aimed for, from the individual's perspective, and in specific terms what could be working better, be maintained or be avoided:

- To better manage my pain relief so I don't wake up at night
- To stay in my house as long as possible
- To stop taking anti-depressants because I don't like the side-effects
- To learn how to cook healthy meals that the whole family will enjoy
- To have the same person caring for me from 9am-3pm so my parents can go to work and do not need to be at home for staff changeovers
- To meet new people in my local area so I don't have to travel into the centre of town
- To receive end of life care at the hospice close to where my sister lives

(NHS England 2016, p16).

There is also an important distinction in this work in that it considers both outcomes for people using services and outcomes for family carers, recognising that there are shared but also distinct outcomes for each, including for carers having a life outside caring and managing the caring role (Miller 2011).

While further progress is required on the collation and use of data, personal outcomes are seen as responding to concerns about validity of routine outcome measures (Harding et al 2015).

The four initiatives outlined so far are all evidence based and can collectively be described as person-centred approaches, which move progressively from a focus on the clinical encounter, through greater autonomy and wellbeing in self-management of long-term conditions to collaboration and planning based on the person's priorities and valued life goals.

## Co-design/Experience based co-design

Experience Based Co-design (EBCD) is a collaborative, participatory action research approach that aims to improve health care services by enabling people who use services, carers, and staff (ground-level and management) to co-design better services (Larkin et al 2015). The methodology has been developed by Bate and Robert (2008) drawing on knowledge and ideas from design sciences and professions, where the aim of making products or buildings better for the user is

achieved by making the user integral to the design process. The co part of co-design is intended to suggest partnership, with internal staff and users meeting and engaging in dialogue with each other in the quest to improve a product or service (Bate and Robert 2007, 44).

EBCD involves gathering experiences from people using services and staff through in-depth interviewing, observations and group discussions, identifying key 'touch points' (emotionally significant points) and assigning positive or negative feelings. A short edited film is created from people's interviews which is shown to both audiences, conveying in an impactful way how people experience the service. Staff are then brought together with the people involved to explore the findings and to work in small groups to identify and implement activities that will improve the service or the care pathway. The focus is on designing experiences, not processes or systems or just the built environment (Bate and Robert 2006).

A review of EBCD projects reported findings from a survey of respondents about the strengths of the EBCD process in their projects. Of 41 respondents, 37 (90%) said that 'it really engaged patients', 32 (78%) that 'it really engaged staff', 26 (63%) that 'it allowed discussion of difficult topics in a supportive environment, 22 (54%) that 'it led to clear improvement priorities and 21 (51%) that 'it really made a difference to the way we do things around here' (Donatto et al 2014, p28). The review also included survey findings about weaknesses of the EBCD process. Again of 41 respondents, 19 (46%) reported that the project 'took too long', 11 (27%) respondents said that 'it was too complicated', 7 (17%) said 'it cost too much', 11 (27%) said 'staff did not engage with the project' and 2 (5%) respondents said 'patients/carers did not engage with the project' (Donetto et al 2014, p32).

The importance of getting to implementation stage links to the different approaches required for organisational development. An EBCD project can only really be deemed successful if improvements are made, but as with many improvement initiatives, it is repeatedly identified that this requires most support from outside the core project team. A service or organisation may make a commitment to listen to service-users, carers, and staff, but if the organisational will and mechanisms are not available, the project will fail (Larkin et al 2015, Tsianakas et al 2012).

# Conclusion

In this section we have considered some key initiatives associated with person-centred care, which also align with the increasing policy emphasis on Realistic Medicine in Scotland. The principles of realistic medicine relevant to the initiatives discussed here include avoiding unnecessary treatment, combining the expertise of practitioners and people to improve decision-making and achieving outcomes which are both optimal and which matter to people (Calderwood 2017). While the last section considered how to deliver person-centred care in broad terms, in this section we have endeavoured to explore in greater depth the mechanisms and approaches associated with current key initiatives being implemented in Scotland.

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# Implementing person-centred care

## The need for a whole systems approach

Earlier work by the Health Foundation on 'co-creating health' in relation to self-management support emphasised the need for a 'whole health economy approach, working across secondary, community and primary care services (and the third sector and local authority where appropriate)' (Health Foundation 2013, p8). Avoidance of fragmentation is necessary for the holistic and effective approach required to achieve good outcomes for people. There is therefore also emphasis in the literature on the need to engage with all parties involved to effect the change required. Organisational development is seen as a powerful tool to embrace person-centred care in practice (Harding et al 2015) and the need for strong and supportive leadership at all levels is frequently cited (Harding et al 2015).

Further to this, evidence suggests that developing person-centred care is neither a one-off nor linear change event. Because the concept of person-centred care is complex and multidimensional, sustained programmes of culture change are required to embed the principles in everyday practices. In setting out his approach, McCormack (2006) promotes a person-centred nursing framework comprising four constructs – prerequisites, which focus on the attributes of the nurse; the care environment, which focuses on the care context; person-centred processes, which focus on delivering care through a range of activities; and expected outcomes, which are the results of effective person-centred nursing. To deliver person-centred outcomes, account must be taken of the prerequisites and the care environment necessary for providing effective care (McCormack 2006). Although this approach is explicitly related to nursing, the principles are more broadly relevant.

A major review of person-centred engagement notes that initiatives often challenge healthcare professionals as they attempt to navigate conflicting issues in their practice (Carman et al 2013). Care professionals may experience ethical tensions whereby the compatibility of 'person-centredness' with resource pressures and equity of access is not well articulated or understood.

Professional training is an area highlighted for attention, 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 people and professionals when faced with such pressures" (Harding et al 2015, p60). Overall, in working through such tensions, there is consistent reference to the need for organisational and whole systems approaches, within which specific initiatives might make a contribution to achieving sustainable person-centred care.

While we will come back to the topic of measures, it is worth noting here that policy and organisational orientations towards measurement can have a major bearing on approaches to person-centred care and their implementation. Despite significant evidence of the harmful and distorting effects of predominant approaches to performance management, not least from the Francis inquiry (2013), quality and performance measures tend to 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, a reality that deeply frames the everyday professional mind set in turn" (Harding et al 2015, p82)

Following investigation of organisational facilitators and barriers to patient-centered care in US health care institutions renowned for improving the personal care experience, Luxford et al (2011) promote the following principles for organisations wishing to implement person-centred care:

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

These factors may be usefully considered by any organisation as a starting point for implementation.  Before going to consider specific recommendations from different studies, it is worth mentioning the importance and the value of working with teams rather than individual practitioners as a core component of implementation.

## Working as a team

There is much emphasis in the literature on the importance of working with teams. A more democratic and inclusive approach is required to create space for the formation of person-centred relationships (McCormack et al 2010). The following example relates to self-management:

"A whole team approach promoted the development of a common language and a common understanding of key self-management support tools, techniques and concepts, which in turn helped to create an environment or culture within teams that was positive about self-management support" (Health Foundation 2013, p7).

Before discussing how to deliver person-centred care, we want to first consider a key implementation barrier repeatedly identified across diverse studies. The issue of practitioners and managers believing that they are already doing person-centred care when this may not be the case is widespread and present a significant challenge.

## The problem of not knowing what we don't know

Starting from the position that most health care staff aspire to treat individuals well as persons (Entwhistle and Watt 2013) a key challenge is to find a way to promote greater person-centredness without making practitioners feel that they are being blamed for system ills over which they have limited control. To further complicate matters, it is argued that the more you know, the more you realise it is challenging to do (Entwhistle et al 2018).

Kruger and Dunning developed a theory which asserts that practitioners must know what they are supposed to be doing to accurately report on their success at doing so. Clearly the challenge here is that people don't know what they don't know, with implications for how person-centred practice can be judged. For this reason, those with the lowest levels of knowledge or mastery are most vulnerable to inflating their own levels of proficiency, known as the "Dunning–Kruger Effect" (Matthews et al 2018). Approaches which open up different conversations in practice can be a helpful start.

## Promoting person-centred care

Reviewing a range of studies from different countries identifies some very useful pointers as to the factors that require attention for effective implementation.  Before considering some of these examples it is worth highlighting a key recommendation from recent work by Entwhistle et al (2018) that the ethical tensions inherent in person-centred care need to be better understood and addressed if person-centred care is to be successful (Entwhistle et al 2018). We will return to that theme later.

Based on work in Sweden, Ekman et al (2011) advocate three simple routines to initiate, integrate, and safeguard consistent person-centred practice. The challenge for the provider is to receive the person's self-expression in such a way that confidence is strengthened and resources for healing identified:

- Giving the person the opportunity to present her/himself *as a person* in the form of an illness narrative is the starting point for a collaborative partnership that encourages people to actively contribute to solutions to their problems.
- Following the narrative as the first step, shared decision-making is the second step which builds on the partnership.
- Thirdly, documentation in individual records not only sanctions the value of this information but also contributes to the continuity and transparency of the partnership (Ekman et al 2011).


There are also important pointers on how to navigate some of the complexity involved in balancing the relational practice advocated by many of the authors previously cited on ethical underpinnings of person-centred care with organisational processes. Again from Sweden, Wolf et al (2017) advocate that integrating the person into clinical practice requires a careful balancing act that practitioners as well as people need to reflect on: recognition of the individual as a person (informal aspects) needs to balance the specific practical routines (formal aspects). They caution that the risk could otherwise be that the person becomes a 'tickbox' in a routine, entrenching profession-centred rather than person-centred care (Wolf et al 2017).  This note of caution will be familiar to anyone experienced in implementation.

Core skills required for person-centred care include effective communication and listening, fundamental to the type of therapeutic relationship which Kitson et al (2013) identify as a common theme in their literature review. The therapeutic relationship or alliance is characterised by a trusting and nurturing relationship in which professionals and patients respect each other,

and exchange information to guide the planning, implementation and evaluation of care (Kitson et al 2013).

Writing from an acute care perspective in Australia, Bolster and Manias (2010) argue that person-centred medication activities can be supported through mentorship or more formalised nursing education and practice development programs. They also promote the value of observation in addition to interviews as potentially powerful feedback mechanisms. Another strategy for enhancing practice is discussing literature and reflecting on practice to identify individual and collective learning and development needs (McCormack and McCance, 2006). Coaching is also advocated by Shepherd et al (2014) who emphasise a strengths-based approach in the context of recovery-oriented person-centred care for people using mental health services.

## Inter-professional aspects of person-centred care

We have previously discussed the linking of person-centred care with integrated care in global discourses (WHO 2016) and the need to avoid fragmentation and over medicalisation at the expense of holistic person-centred care. Different professions have developed particular understandings, approaches and literatures relating to person-centred care, which can contribute to inconsistencies (Sidani and Fox 2014).

However, in conducting an interdisciplinary review of the literature, Kitson et al (2014) found consistent key elements of person-centred care:

"What has emerged from the review is that there is more consistency than divergence so we may be in an ideal position to push some of these general principles forward. Perhaps, what is needed is a relatively simple conceptual framework that outlines the main elements of PCC for all parties involved" (Kitson et al 2014, p12)

Further, they identified the need for policy makers to consider how to make person-centred care relevant across disciplines using common language and concepts.

## Inequalities

There is emphasis in the literature on the need to mitigate against amplification of inequalities through implementation of person-centred care (Fox and Reeves 2015). There are risks attached to messaging around person-centred care and equity if it is believed that person-centred care itself is the problem. The problem relates more to confusion with definitions, assumptions and consequent (mis)understandings and it is the selection of associated approaches which needs attention:

"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" (Harding et al 2015, p48)

In considering how to avoid increasing inequalities associated with shared decision making in particular, Entwhistle et al (2018) caution against a narrow focus on patients' knowledge, skills and confidence while neglecting the constraints that social circumstances and relationships can

place on their agency and health.  Instead they advocate a more fluid and dynamic approach, involving various forms of engagement to cultivate autonomy capability in health care.

# Conclusion

While training for practitioners is a key ingredient in supporting person-centred practice, it is not sufficient on its own to achieve the culture change required. Evidence shows that people tend to believe they are being person-centred, whether this is the case or not. This points to the need for additional supports to practice such as coaching, mentorship and practice observations for example. Team approaches are also advocated.

There is consistent emphasis in the literature on the need for an organisational approach to embedding person-centred practice. Systems need to be prepared to support person-centred practice which may require multiple changes. It is not always achievable to resolve all the systemic barriers to person-centred care, such as performance indicators which drive practice in a different direction, or resource limitations. However, the barriers must at least be acknowledged to avoid responsibility being attached to people and/or practitioners, with associated risks of increasing inequalities.

The general view is that there is more consistency than divergence in person centred approaches. A theoretically informed but simple conceptual framework that transcends disciplines is advocated.

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# Measuring person-centred care

In considering the measurement of person-centred care it is important to acknowledge the context of considerable resource pressures on public services caused by demographic changes, financial constraints and accountability for resource allocation. In face of such pressures, there can be a tendency to create a false dichotomy between efficiency and clinical outcomes and so-called softer outcomes, although the latter are gaining traction:

"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" (Harding et al 2015, p37)

Proximal or short-term outcomes which include the person feeling known, respected, involved, listened to, and knowledgeable—are valuable in themselves and can help people manage the distress associated with illness and uncertainty (Epstein and Street 2011, Miller 2011). Closely related are the capability outcomes identified by Entwhistle and Watt (2013) which include valued life goals and autonomy.

While there can be justified concern to avoid an exclusive emphasis on clinical outcomes, there is evidence showing interaction between relational and clinical outcomes, which we explored in the section making the case for why we should deliver person-centred care (Alharbi et al 2014, Coulter et al 2015, Epstein and Street 2007, Epstein et al 2010). Given however, that the impact of communication on health outcomes will usually be indirect, "it is important to understand which proximal outcomes of person-centred care—feeling understood, trust, or motivation for change— might contribute most strongly to improved adherence and self-care" (Epstein and Street 2011, p101).

We have reflected in earlier sections about the interaction between evidence-based medicine or approaches and person-centred care, noting that while there are tensions between them there is also potential to reconcile aspects of both so that the benefits of person-centred care are better understood and the evidence base of medicine is enriched by improved understanding of what matters to people. A key argument in the literature is that the lack of interaction between evidence and person-centred practice links to continuing complexities and uncertainties around definitions of person-centred care (da Silva 2014).

The lack of conceptual clarity and clear definitions in the research may also impede the replication of successful innovations in care, and the further isolation of cause and effect, which may be important in securing commitment from policy makers (Harding et al 2015, p10).

However, there is also an argument that because person-centred care is complex and multi-faceted, different forms of evidence are required than the still predominantly quantitative approach to measurement and evaluation. Thus some consensus is required about the intended outcomes of person-centred care, or in other words: why do we think that it matters and how do

we know that it is happening and to what effect for people, practitioners, organisations and systems?

And further, what forms of evidence are needed to answer these questions. A focus on common principles can help here.

A further question to consider is at what stage of developing new ways of working do we say that measures can be nailed down. Overall, there can be a tendency to rush to measure before phenomena are properly understood. It is not possible to define what makes a good measure until there is some clarity about what we are trying to achieve. The important point is that this issue is more complex than simply attempting to choose a single tool or measurement approach (da Silva 2014).

It is therefore imperative that the intended use of data is clear from the outset. It is unethical to ask people to comment on their experiences or outcomes if these comments are going to be ignored (Coulter et al 2014). The NHS has been collecting data on peoples' experience of care for many years but few providers are systematically using the information to improve services. Consideration is required to determine how to interpret the results, and put them into practice (Coulter et al 2014). The challenges are summarised as follows:

"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, concerns as to the 'double-edged sword' of measurement and the risk of perverse incentives or opportunities for gaming, and more fundamental concerns as to the core values of person-centredness and how appropriate measurement is to that mission"' (Harding et al 2015, p93)

To take the case of person-centred planning and the purposes of measurement, Smull and Lakin (2002) identify how good intentions with person-centered planning could be derailed when the focus is passing inspection in quality assurance reviews, driven by external criteria. They found that requirements for goals to be measurable and for data to document progress resulted in the recording of goals that were "measurable, but not meaningful" (Smull & Lakin, 2002, p. 383). More recently, Taylor and Taylor (2013) highlighted that identifying pre-determined outcomes could potentially be contradictory to the principles of person-centered planning, since some outcomes may emerge during the planning process itself. Further, excessive requirements for measurement can add to other systemic barriers to effective person-centred care:

"Systems changes that unburden primary care physicians from the drudgery of productivity-driven assembly-line medicine can diminish the cognitive overload and exhaustion that makes medical care anything but caring or patient-centered" (Epstein and Street 2011, p101).

Combining a range of methods and tools is likely to provide the most robust measure of person-centred care. Some argue that patient surveys could be used routinely in practice, with results used as part of quality scorecards alongside indicators of safety and cost (de Silva 2014). However survey measures should also take into account that people often overrate the degree to which they have been informed about and understand their illnesses. This is particularly the case for

people with low literacy, poor English fluency, cognitive impairment, and social disadvantage" (Epstein and Street 2011). Since surveys alone provide a partial picture they could be coupled with interviews and/or observation of clinical encounters (de Silva 2014).

In their extensive review of person-centred care initiatives, Harding et al (2015) note that for most key commentators, the ultimate goal of person-centred care is to better realise the outcomes that matter to each individual person. From this perspective, measurement of 'success' requires solicitation and recording of the concerns, circumstances and outcomes of each person. This in turn requires the use of goal setting approaches flexible enough to capture, enable and monitor these outcomes.

The key difference from other approaches to measurement is that people themselves are able to influence the outcomes to be achieved, requiring an exchange of perspectives between the person, practitioner and family where appropriate (Miller and Barrie 2015) which also represent the measures set to monitor them. With more of a focus on contribution towards outcomes rather than definitive attribution, there is also scope for the person to be acknowledged as contributing to their own outcomes, supporting the individual's capable agency (Miller and Barrie 2015). Outcomes to be set and measured may relate to aspirations for health, wellbeing and wider quality of life (Miller and Barrie 2015). 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 (Plass 2015)

# Conclusion

Measuring, or at least better understanding and evidencing of person-centred care is a work in progress, and this is perhaps inevitable as person-centred care itself continues to evolve conceptually and practically. The overall messages from the literature are that qualitative information is required as well as numbers, which reflects the relational emphasis underpinning person-centred care rather than a more standardised tick-box approach. Socio-economic factors also need to be taken into consideration in improving understanding of effective person-centred care, and this focus is consistent with the increasing public health emphasis associated with Realistic Medicine. There is increasing emphasis on the outcomes important to people as being an essential part of the evidence base with continuing progress on how relevant information can be captured in practice.

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# Conclusion

This review of person-centred care adopted a pragmatic approach, completed within a short time frame and with a particular concern to inform implementation. It also needed to be of relevance in the Scottish context, where Realistic Medicine is a policy priority. The latter is intended to ensure that people are more involved in decisions about their care, and to include all professionals whose roles involve maintenance of health and wellbeing and preventing and treating illness.

Given the continuing development of the person-centred field, attempting a brief review presents some challenges, requiring attempts to navigate through a vast and heterogenous literature to identify predominant trends and themes.  As well as considering evidence about implementation in general, this review has considered key approaches which are already being embedded to varying extents in Scotland.

While debate and discussion continue around the conceptualisation and definition of person-centred care, this is one of several reviews of relevant evidence which concludes that despite the variations, there are core common principles to person-centred care.

A focus on common principles can help to bring different professional and philosophical perspectives closer together, and this should be easily achievable at policy level. Beyond this, there is still a need to acknowledge how ethical tensions manifest in practice, with some way to go before health systems genuinely enable person-centred practice (Entwhistle et al 2018). Amongst these tensions is the requirement to both reduce variation so that people have equitable access to care and treatment, and to receive care that is personalised. Realistic Medicine provides a broad framework highlighting these priorities, but further work is required to clarify how seemingly contradictory features can be reconciled in practice.

The sustainability of health services depends on investing time in relational ways of working, which engage and involve people in decisions about their care and builds on their capabilities. This helps to ensure that interventions, where required, are more likely to achieve the intended outcomes, without necessarily incurring extra cost. Further work is also required to ensure that person-centred care is understood not as an add-on but as fundamental to effective practice. In the face of demographic and socio-economic pressures, the time required for relational and person-centred care can too easily be misconstrued as an unaffordable luxury.

This review has found considerable and encouraging alignment between principles of person-centred care across a range of disciplines and settings, as well as marked similarities between seemingly diverse initiatives. Further work is required on the ground to translate shared principles into whole system approaches which build capabilities and cultures for person-centred care.

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