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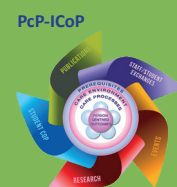
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CRITICAL REVIEW OF LITERATURE

Review of developments in person-centred healthcare

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Abstract

In recent years, there has been a shift in orientation towards person-centredness as part of a global move towards humanising and centralising the person within healthcare. Person-centredness, underpinned by robust philosophical and theoretical concepts, has an increasingly solid footprint in policy and practice, but research and education lag behind. This article considers the emergence of person-centredness, including person-centred care, and how it is positioned in healthcare policy around the world, while recognising a dominant philosophical positioning in Western philosophy, concepts and theories. Second, the evolution of person-centred healthcare over the past five years is reviewed. Published evidence of person-centred healthcare developments is drawn on, as well as information gathered from key stakeholders who engaged with the partner organisations in an Erasmus+ project to develop a European person-centred healthcare curriculum framework.

Five themes are identified, which underpin the literature and stakeholder perspectives:

- Policy development for transformation
- Participatory strategies for public engagement
- Healthcare integration and coordination strategies
- Frameworks for practice
- Process and outcome measurement

These themes reflect the World Health Organization's global perspective on people-centred and integrated healthcare, and give some indication of development priorities as person-centred healthcare systems continue to be developed.

Keywords: Person-centredness, person-centred integrated care, global developments, service user narratives

Introduction

Recent years have seen a significant increase in focus on person-centredness in healthcare (Ward et al., 2018). Person-centred healthcare is an approach to healthcare delivery that includes placing the beliefs and values of service users at the centre of decision making. In doing this, healthcare practitioners need to be able to work compassionately with healthcare service users as actively engaged partners in care. There is a global evidence base showing the benefits of this approach to healthcare delivery at individual, unit and systems levels. Person-centredness is underpinned by philosophical and theoretical constructs and may transcend any one worldview, philosophical perspective or theory. It also frames all aspects of healthcare delivery, from the macro-perspective of policy and organisational practices to the micro-perspective of compassionate, person-to-person interaction and experience of healthcare (whether as professional or care receiver/partner). Person-centredness has historically been influenced by various discourses. These include: discourses on rights-based approaches; a move from the authoritarian position of biomedicine to the democratisation of psycho-social care; and an increasing acknowledgement that care experience is a key indicator of good healthcare that can shift focus away from quantitative outputs such as service performance indicators, cost savings, or disease-orientated (symptom-managed) care (Phelan et al., 2017). As such, person-centred care is recognised as a core competency in the healthcare workforce (World Health Organization, 2005; Nursing and Midwifery Council, 2018).

Person-centredness is an important pillar of high-quality healthcare (Institute of Medicine, 2001) and has a solid theoretical base with distinct principles, methodologies and measurement approaches (van Dulmen et al., 2017). Furthermore, it has been linked to staff wellbeing and job satisfaction (van der Meer et al., 2018), as well as improved standards in quality and safety, enhanced quality of life and higher satisfaction with care (Rathert et al., 2013; Teeling et al., 2020). In essence, person-centredness pivots on the humanising of healthcare delivery (McCormack et al., 2015) and prioritises the individual person rather than the anonymous collective or the tasks of care. Similar developments can be seen in the integration of person-centred frameworks into healthcare higher education (Cook et al., 2018).

Background

Person-centredness in context

The move from biomedical approaches towards those broadly termed as psycho-social is significant in contemporary healthcare. Historically, healthcare professionals underwent theoretical and practical training to provide traditional knowledge, skills and competencies that validated their respective qualifications, but were generally focused on providing support for biomedical approaches.

Various sociological perspectives have described the loss of personhood within healthcare. Goffman for example, when observing 'total institutions', describes how, in places such as psychiatric hospitals or prisons, the social environment can diminish identity and 'it can be difficult to be a person' (Goffman, 1967, p 91). The person is subject to a case record of 'facts' that show how the patient is sick, thus the individual fades into standardisation (Goffman 1961). Parsons (1951) examined the rights and responsibilities of those who are sick through 'sanctioned deviance', which proposed that the individual is not only physically sick but assumes a social role.' Those who are ill are obliged to accept the clinical intrusion of healthcare examination and treatment; their autonomy is removed and they are absented from choice and preference in care under the authority of medicine's disciplinary knowledge (Parsons, 1951; Varul, 2010). This is what Charmaz (1983, p 168) describes as the 'loss of self', which ultimately undermines the legitimacy of personhood. This loss is further epitomised by Foucault (1973), who argued that the 'clinical gaze' positioned 'patients' as objects to be examined, giving professionals power to validate paternalistic health activities. As medicine (and other healthcare professions) increasingly specialised, the 'body' was repeatedly fractured into discrete, often systems-based components, which were the fundamental focus of examination, surveillance and treatment. Within these disempowering knowledge-power discourses, the patient assumed the role of a docile body, accepting the authority of healthcare professionals, who traditionally focused on signs, symptoms

and management: that is, forms of absolute knowledge. Thus, healthcare professionals legitimately exercised the governance of people in care through their control of knowledge and the body, while people became subjects of their power-knowledge positions. This control and paternalistic approach has been considered an important factor in negating the person's own agenda (McCormack et al., 2017).

The development of professional priorities and practices is no longer accepted as absolute knowledge, in Foucauldian terms. In addition, care must not be looked at in isolation from broader social, economic and legal/cultural developments: for example, patriarchy, gender, diversities and human or citizen's rights. Indeed, it is now broadly accepted that effective healthcare is more than clinical or efficient evidence-based interventions (Institute of Medicine, 2001). Over time, the power-control scenario has changed, driven by two major catalysts. First, there has been a move away from the absolutism of biological knowledge, combined with a growing acceptance of the social and personal construction of knowledge, and experience becoming recognised as inherently central (Todres et al., 2009). This involves consideration of humans as persons, situated in their own lived culture, time, places and relationships. In this context, person-centredness is relational in that it manifests in compassionate care relationships, and the care provider is concerned about what the service user as a person wants, their perspective on their own health and the meaningful outcomes in their health journey. Person-centred healthcare recognises individuals have full lives and are not just the illness or presenting health issue (Lariviere, 2019). Person-centred care is important because it is founded on scaffolding care around the context of the person's life world and directed by his/her will, preferences, values and beliefs. As such, advantages are demonstrated in outcomes such as shorter hospital stays, maintenance of functional ability and better health-related quality of life (Ekman et al. 2012); improved long-term quality of life, care costs and care outcomes (Wynia et al., 2018) as well as co-creating healthcare around what people want (Phelan et al., 2017). The value of person-centred care lies in building healthful partnerships where decisions are based on the person's right to make independent, informed choices, free from paternalism, undue influence or discrimination (Phelan and Rickard-Clarke, 2020). Essentially, it involves meaningful engagement, often supported through professional expectations; for example, the Irish Department of Health (Department of Health, 2019a) promotes standards of nursing and midwifery as compassion, care and commitment, while similar standards are promoted in other countries (Royal College of Nursing, 2013) and by other professions (Irish Medical Council, 2019). Such attributes are explicit within person-centred care frameworks (see Kitwood, 1997; McCormack and McCance, 2017; Centre for Person Centred Care, 2017).

Such sense-making across different worldviews call for intuitive and reflexive healthcare professionals, whose range of knowledge and skills includes a refined ability to communicate compassionately beyond traditional boundaries, with a focus on building trusting, helping relationships (Naldemirci et al., 2020). At the core of this is a deeply held, values-based commitment to persons and personhood (McCormack and McCance, 2017; Dewing, 2019). The voices of powerful healthcare professions are being superseded by individual preference, values and beliefs – not an easy transformation and one that is not yet complete. The hegemonic culture in healthcare has been challenged, particularly in relation to people's involvement in co-creating their care, having their voice authentically heard and negotiating positive risk. Healthcare professionals need to facilitate active engagement and partnership, regardless of a person's capacity to make decisions or choices (Dewing, 2009; Harraldsdottir et al., 2019). This points to the need to know the person and what matters to them (their past, their family, their faith, their choices or their preferences for the future), as well as the need for organisational structures, processes and cultures that enable practitioners to work in these ways.

The different application of related concepts and terms across countries and healthcare systems has highlighted the need to standardise language between stakeholders (Santana et al., 2018). For example, for at least 20 years there has been an increase in the application of the humanistic concept of 'centredness' to healthcare practice situations. While person-centredness has become a well-used term globally, it is often used interchangeably with other terms such as 'woman-centredness' (Leap, 2009),

'child-centredness' (Ford et al., 2018), 'family-centredness' (Isaacs, 2020), 'client-centredness' (Ranner et al., 2016) and 'patient-centredness' (Eklund et al., 2019). This has led to confusion among many commentators, and a perception that person-centredness is poorly defined, non-specific and overly generalised (Dewing and McCormack, 2017). In their review of person-centred care, Harding et al. (2015) identified three fundamental concepts, which are not mutually exclusive. These are:

1. Person-centred care as an overarching grouping of concepts, which include care based on shared decision making, care planning, integrated care, patient information and self-management support
2. Person-centred care emphasising personhood: people being immersed in their own context and a person as a discrete human being
3. Person-centred care as partnership: care imbued with mutuality, trust, collaboration, and a therapeutic relationship

While Harding and colleagues adopt the narrow focus of 'care' in their review, their conceptualisation is helpful in raising the need to consider the deeper aspects of personhood necessary for person-centred healthcare to go beyond a series of tasks, processes and procedures. Although the origins of person-centredness can be seen as firmly rooted in a humanising care perspective, over the past 10 years in particular there has been increased recognition of the need to adopt a broader, inclusive and systems-wide perspective. This influence has been captured in work by the World Health Organization and its 'people-centred and integrated health systems' strategy (World Health Organization, 2016a), and by others who have argued for person-centredness to be applied to all persons – as all persons have personhood – and thus reject a prioritised approach (for example, that the personhood of service users is more important than that of staff) (Buetow, 2016; McCormack and McCance, 2017). This more inclusive approach has enabled the principles of person-centredness to be applied in a variety of healthcare contexts such as in education (Feo et al., 2017; McCormack and Dewing, 2019), embracing other concepts that are necessary for the development of person-centredness, such as flourishing (McCormack and Titchen, 2014; Phelan et al., 2017), leadership (Reeve, 2018; Cardiff et al., 2018; Lynch et al., 2018; Kuluski and Guilcher, 2019), collaborations within and across settings (Lloyd et al., 2017; Reeve, 2018), and culture (Michael, 2016; Kuluski and Guilcher, 2019). A dominant focus of much of the published literature is person-centred care, but achieving person-centred care is limited without person-centred cultures that enable all persons to flourish in healthcare organisations (McCormack et al., 2015). Thus, this article is framed by the definition of person-centredness given by McCormack et al. (2015, p 3):

'...an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.'

As would be expected, this definition is continually evolving: it is acknowledged that variations of it exist, and that it is adapted according to specific contexts and work foci that prevail in them.

Review methodology

This article represents one stage of a large funded project that is developing the first pan-European Person-centred Healthcare Curriculum Framework. This project is being undertaken by a partnership of six universities in the UK, Ireland, the Netherlands, Norway and Slovenia, and focuses on designing an international curriculum framework for educating person-centred practitioners. The first stage of this work, outlined here, is a review of global developments in person-centred healthcare, building on previous reviews undertaken by Harding et al. (2015), which specifically focused on global developments in person-centred care, and McCormack et al. (2015), which examined person-centredness as a core concept in healthcare policy and practice. A three-stage approach was applied

to carry out this review. The first step was to revisit the work of Harding et al. (2015) and McCormack et al. (2015), considering their key foci and findings. A literature search was then undertaken, between January 2016 and April 2020, using the keywords person-centred* AND person cent* AND person-cent* healthcare in the contexts of policy and strategy. The search was limited to policy and strategy because the focus of this review is person-centred healthcare developments at a national level, rather than specific developments in, for example, services. Thus, it is acknowledged that a myriad of quality improvements in individual organisations and practice settings focused on specific practice developments were excluded as beyond the scope of our review. The CINAHL, PubMed and Embase databases were searched (see Figure 1), resulting in 14 papers for inclusion (see Table 1).

Figure 1: Prisma flowchart (adapted from Moher et al. 2005)

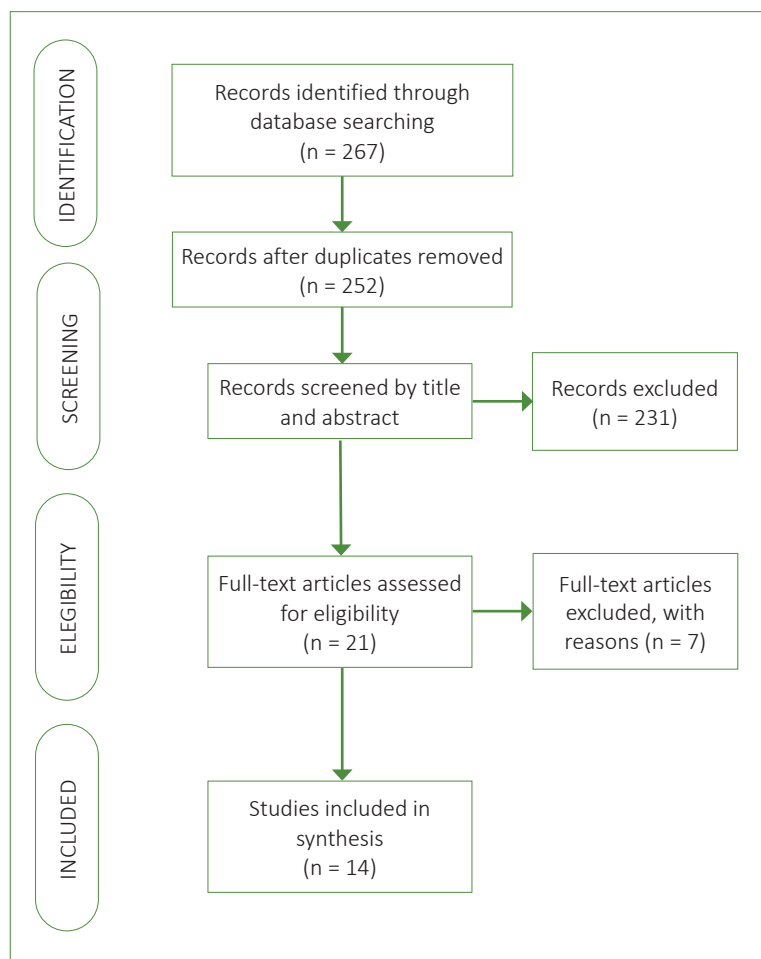


Table 1: Matrix of papers from literature review

	Author/year/country	Type of paper and focus	Methodology/approach	Key arguments/findings	Conclusions
1	Rock and Cross (2020) Australia	Discussion paper. Generally focuses on mental health system reform	Draws on an Institute of Medicine (2006) approach of nano, micro, meso and macrosystems	<ul style="list-style-type: none"> • There is a need to unite population-focused policy directives to the context-bound healthcare needs of individuals in communities • Care plans are not person-centred but based on what works for the 'average' individual • Separate processes needed for selecting what is planned for implementation and implementing what is planned. There is a need for individual and context accommodation 	<ul style="list-style-type: none"> • Responsive health systems need managers to have flexible facilitators to support individual engagement in care • A new model of care is needed linking macro (policy), meso (regional) and micro (care directly experienced). Real-world planning and implementation with contextualised data is needed • Structural inequalities of care should be appreciated and addressed in person-centred care approaches • The full cycle of care should be addressed • Meaningful co-design at a whole-system level should be an 'always' event • Data should be presented in an understandable way • Planning needs clear change processes underpinned by implementation science for person-centred and whole-community contexts • The value of services is with the people, not funders
2	Kuluski and Guilcher (2019) Canada	Discussion paper. Examines three concepts of current healthcare: person-centred care, value-based healthcare and learning health systems	Draws on three concepts: person-centred care, values-based healthcare and learning health systems	<ul style="list-style-type: none"> • Argues for conceptual combination for person-centred learning health system (PC-LHS) • Need to reframe care delivery with a focus on the PC-LHS • Need to collect data that is meaningful and of value to people 	<ul style="list-style-type: none"> • Person-centred care requires funding, leadership and trusting collaborations • Foster an enabling system process to collect data and real-time feedback • Goals need to be aligned with organisational culture and practice and values of providers • Focus on whole-patient journey, with systems to facilitate and integrate across settings (i.e. IT and data-sharing agreements) • Recognise responsibility and accountability of health and social care ministries
3	Bhattacharyya et al. (2019) Canada	Discussion paper. Examines features of traditional and newer methods of healthcare improvement to enhance care and service user experience	Considers methods of service improvement. Uses exemplars of three service improvement/development approaches for person-centred services: process, solution, and user need or problem	<ul style="list-style-type: none"> • Careful review of the focus of service developments for person-centred care is needed • Process: improve existing service • Solution: new service to better meet needs of new/existing customers • User need/outcome: Identification of unmet, unacknowledged needs to be met by new services and new processes 	<ul style="list-style-type: none"> • Application of any revised/new approaches or processes can be implemented under existing policy
4	Kaehne (2018) UK	Discussion paper. Argues the need for service integration from the service user's point of view	Examines how person-centred policy and systems are within models of integrated care	<ul style="list-style-type: none"> • There is a need to look at a service from the patient's perspective • Health systems are constructed in a rationalistic way; identify a problem and apply a rationalistic approach to health systems. Consequently, policy has been directed by rational decision making • Health care delivery needs inter-organisational links, care pathways and governance arrangements built around the service user's preference • Patient experience governed by multiple contingent care perspective 	<ul style="list-style-type: none"> • Care system needs to accommodate the person • Currently, integrated care is defined by what organisations do, not service user experience. The starting point should be service user experience, not organisational dilemmas • The partnership system was suited to a time of adequate resources, while integration reflects austerity • Disparity between patient experience and organised focus equates to major policy and research issues

Table 1: Matrix of papers from literature review (*continued*)

	Author/year/country	Type of paper and focus	Methodology/approach	Key arguments/findings	Conclusions
5	Jones et al. (2018) UK	Research paper. Update and revalidate the Valuing Patients as Individuals Scale for use as a method for patient appraisal of received healthcare	<ul style="list-style-type: none"> Scoping literature review Item and questionnaire development Cognitive testing of questionnaires Exploratory factor analysis 	<ul style="list-style-type: none"> Measures of patient satisfaction have limitations in terms of failing to examine the multifaceted aspects of the experience of receiving care Study focused on developing and validating the updated Valuing Patients as Individuals Scale (uVPAIS) Points to policy move to authentically measure and evaluate patient experiences 	<ul style="list-style-type: none"> Potential for Valuing Patients as Individuals Scale to help meet policy objective of measuring person-centred care Generation of short 10-item scale demonstrated good reliability and validity Recommendations emphasise improving patient experience through measurement of person-centred care, an important point for policy agendas Future research should further development the scale
6	Reeve (2018) UK	Discussion paper. Presents a redesign of primary care to deliver person-centred care	<ul style="list-style-type: none"> Draws on blue sky thinking to propose a 'dangerous model' (Reeves 2016) Proposes a three-tiered, person-centred approach for primary healthcare redesign in general medicine: consultation, practice team organisation and health system 	<ul style="list-style-type: none"> Notes disparity between language of policy and experience of care Consultation: tailor care to the individual, shaping clinical decisions around the life world (individual circumstances and perspective of the person). Rebalance hierarchy of knowledge to put prioritise professional wisdom Practice team: redesign needed to address complexity rather than linearity. Look at who is in the team and how they are working System: design the system with balanced generalist-specialist care. For patients, a life for living, co-construction of care, needs-based living. For clinicians, revised training, restructuring and reprioritising. For the system, redefine best care, expand and sustain expertise 	<ul style="list-style-type: none"> Need to do more than describe a vision Change is coming from new revolutionary group – patients Need to do more than describe a vision – redesign generalised care to focus on meaningful outcomes for service users, revised training and practice organisation and reshaping of systems towards person-centred care in complex interventions There is a need for leadership and collaborations between clinicians and academics
7	Feo et al. (2017) Australia	Research paper Considers development of guidance for person-centred fundamental care by nurses	<ul style="list-style-type: none"> Developed a new methodological approach: historical interpretative synthesis (assess feasibility, interpretative synthesis, generate behaviours) Umbrella review of 12 papers 	<ul style="list-style-type: none"> Uses lens in model of Fundamentals of Care: three dimensions (establishing the relationship, delivering fundamental care and care context) with five relational elements (trust, focus, anticipate, know and evaluate) 	<ul style="list-style-type: none"> Provides practical guidance to deliver person-centred fundamental care Nurse-person relationship fostered throughout care episode (establishment, maintenance and evaluation) Further research is required to test recommendations (face validity, content validity and construct validity) Embed practice recommendations in nursing education and continuous professional development Demonstrates a novel way to distil empirical evidence to create a series of actionable recommendations Recommendations can impact on fulfilling policy recommendations and healthcare reform for fundamental care and person-centred care

Table 1: Matrix of papers from literature review (*continued*)

	Author/year/country	Type of paper and focus	Methodology/approach	Key arguments/findings	Conclusions
8	Sobolewska et al. (2020) Australia	Research paper. Explores how national, state and organisational policies support person-centred care implementation for persons living with chronic conditions	<ul style="list-style-type: none"> Review of online national, state and organisational Queensland Health policies and other documents on person-centred care, chronic care and nurse navigator programme Three national documents and five Queensland documents were identified that referred to person-centred care principles. There was also evidence in organisational documents Content analysis was used to analyse documents 	<ul style="list-style-type: none"> Patient vs government partner at rhetoric level. Identified how shared positions of power are negotiated with uneven power differentials, which include access to funds and resources Analysis of policies found: <ul style="list-style-type: none"> – A context of service user versus the state – Healthcare delivery versus the political agenda. State government has competing agendas. Particular challenges are seen in sustainability within electoral cycles – Organisational policy versus the patient: how can a clinician deliver person-centred care and change the system? 	<ul style="list-style-type: none"> Person-centred care is an expectation – definition, implementation and approaches are elusive in service delivery Policy implementation is system centred and not aligned to person-centred care Funding is a constraint, in terms of out-of-pocket expenses for healthcare being high. Partnership as rhetoric as power differentials exist when operationalising care More stable definitions are needed to measure person-centred care outcomes in the context of the nurse navigator service
9	Lloyd et al. (2017) UK	Research paper. Collaborative action for person-centred co-ordinated care	<ul style="list-style-type: none"> Co-designed collaborative action Uses questionnaires, interviews and data from clinical support units and providers 	<ul style="list-style-type: none"> Health systems are adapting to meet expectations of integration and person-centred care Change needs to occur at multiple levels in organisations, with inbuilt evaluation Collaborative action facilitates transfer and synthesis from local to a wider range of settings Measurements used (i.e. cost of care, patient reported outcomes, patient experience, admission rates) Uses multilevel, multi-perspective measurement examining how, what and who, under patients, practitioners, teams/organisations and activity/cost 	<ul style="list-style-type: none"> Policy drivers and staff turnover can inhibit engagement Sustained support from commissioners and providers is needed
10	Waters and Buchanan (2017) Australia	Literature review. Exploring person-centred concepts in human services	<ul style="list-style-type: none"> Adapted scoping review Thematic analysis of literature 	<ul style="list-style-type: none"> Contexts of the use of the term ‘person-centred care’, terms used in conjunction with the term ‘person-centred’ Characteristics that evidence person-centredness (honouring the person, being in relationship, facilitating participation and engagement, social inclusion/citizenship, experiencing compassionate love, and being strengths/capacity focused, as well as organisational characteristics) 	<ul style="list-style-type: none"> Identified multiple approaches to person-centred care within different philosophical foundations within the literature Regarding policy, person-centred care found to have developed in silos Wide range of interpretations and applications mitigate against common understanding, frameworks, measurement or applications Person-centredness can differ in each policy focus and how it is operationalised Shared understanding is important to avoid diluted understanding, leading to potentially fragmented or ineffective services Person-centredness is not a policy challenge but a value position on which policy and practice are based

Table 1: Matrix of papers from literature review (*continued*)

	Author/year/country	Type of paper and focus	Methodology/approach	Key arguments/findings	Conclusions
11	Michael (2016) Australia	Research to develop a diversity conceptual model	<ul style="list-style-type: none"> A multiphase approach using a) literature review and b) organisation consultation, national service provider focus groups and stakeholder interviews Twelve external provider interviews 	<ul style="list-style-type: none"> Notes the imperative from the National Health and Hospitals Reform Commission on aged care and diversity Five themes: <ol style="list-style-type: none"> Acknowledge and consider reason for referral Cultural group identity to be the central diversity characteristic Identification of diversity characteristics common to and shared by older people Focus on research and continuous quality improvements for greater equity in policy Use of client narratives to support the diversity conceptual model 	<ul style="list-style-type: none"> The model is a method of boosting inclusivity, quality improvement and equity in policy Wider consultation and testing is needed Limited by no consumer involvement
12	Tak et al. (2019) South Korea	Research on operators' provision of long-term care for older people in South Korea	<ul style="list-style-type: none"> Phenomenology, with 10 participants 	<ul style="list-style-type: none"> Post-enactment of long-term care insurance legislation in South Korea Four themes: <ol style="list-style-type: none"> Starting as a facilitator Dream of an ideal long-term care facility Struggling desperately in the practical field Obtaining hope by providing care 	<ul style="list-style-type: none"> Difficulties in securing appropriate staff with expertise after policy introduction (lack of education completion and verification of competencies) Experienced negative perceptions of the facilities Need to have positive relationships with communities they are established in Understanding the contextual experience of operators of long-term care may assist policymakers, educators and healthcare providers' decisions on improving services Need for additional information on policy change Flexible policy needed to adapt to local situation Ideal nursing home is a home not a hospital Diagnosis related payment programme needs revision
13	Larson et al. (2019) US/Australia/ Switzerland	Discussion paper. Examines two aspects of person-centred care measurement: patient experience and patient satisfaction	Review of child and maternal health literature to provide guidance on using quality measures effectively and choosing person-centred measures effectively	<ul style="list-style-type: none"> Person-centred approaches are a key in quality care and health systems Intrinsically important: the right to dignity and respect Instrumentally important: improved healthcare use and improved outcomes Measures of person-centred care reflect health system accountability Measures need clarity and precision 	<ul style="list-style-type: none"> Components: patient experience and patient satisfaction Patient experience: process indicator focusing on interpersonal aspects of care. Three domains - effective communication, respect and dignity, and emotional support Patient satisfaction: outcome measure comprising health outcome, patient satisfaction with care and confidence in healthcare system Consider a) both measures have different underlying constructs, choosing measure based on its anticipated use is essential, b) impact on subjectivity in patient's report, c) measures that are tested and validated. Need attention to question phrasing, response choice and questions targeting expectations Recognise patient experience measures can be sensitive to differences in quality care across various settings, environments and populations Ensure construct and content validity Note that patient satisfaction measures may be influenced by changes in care quality, patient demand, values or expectations For policy, measures can account for levels of care quality and how responsive services are to patient expectations

Table 1: Matrix of papers from literature review (*continued*)

	Author/year/country	Type of paper and focus	Methodology/approach	Key arguments/findings	Conclusions
14	Santana et al. (2018) Canada	Conceptual development of a person-centred care conceptual framework	<ul style="list-style-type: none"> • Narrative review of literature applying Donabedian model for healthcare improvement • Supported by facilitated discussion to refine framework 	<ul style="list-style-type: none"> • A lack of integration of person-centred care into healthcare quality improvement • Healthcare systems can be challenged by implementing person-centred care as an integrated experience • Service and role redesign and restructureis needed • Needs to prioritise consumer of care perspective rather than that of healthcare professionals or policymakers 	<ul style="list-style-type: none"> • Framework has three dimensions, each with domains, subdomains and components, based on Donabedian model: <ol style="list-style-type: none"> 1. Structure: healthcare system/organisation focus on system and context of delivery 2. Process: interaction between patients and healthcare providers 3. Outcome: value and outcomes of person-centred care model implementation • Need for policy alignment and cultural shift to person centred care

Finally, information arising from engagement events facilitated by each project partner throughout 2019 and 2020 informed the development of key principles for curriculum design. At these events, an interprofessional stakeholder mapping exercise was undertaken, comprising key partners involved in delivering approved healthcare education programmes with partner institutions. Stakeholders were asked for their views on person-centred healthcare, and their perspectives on its development. A total of 391 stakeholders participated across five of the six partner countries: (Queen Margaret University, Scotland, n=232; University of Maribor, Slovenia, n=24; Ulster University, Northern Ireland, n = 135; Fontys University, the Netherlands, n = 16; and University of Southeastern Norway, n = 7). They represented education commissioners, funding agencies, industry partners, public, private and voluntary interprofessional healthcare providers, regulatory bodies, patient advocacy groups, existing and former students, and faculty. Each of the partner organisations used different methods of engagement (workshops, focus groups, surveys, one-to-one interviews and discussion groups), reflecting the differing number of participants. The information gathered from these stakeholder activities was consolidated into a draft report and shared with project partners and associate partners, who reviewed the content and added specific detail relevant to their country. The report forms the basis of this article, while a second article presents the project partners further development of philosophical and pedagogical principles for a pan-European person-centred curriculum framework (Dickson et al., 2020).

Global perspectives on person-centredness

Since 2009, the World Health Organization has committed to creating a framework putting people at the centre of healthcare (World Health Organization, 2016a, p 2). People-centred health services are described as:

'...an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways. People-centred care requires that people have the education and support they need to make decisions and participate in their own care. It is organised around the health needs and expectations of people rather than diseases.'

The work of the WHO has influenced the development of macro health systems towards a common goal of humanising healthcare by ensuring it is rooted in universal principles of human rights and dignity, non-discrimination, participation and empowerment, access and equity, and a partnership of equals. The WHO's overall vision is for health systems that can be trusted and that are responsive to the needs of persons, communities, and populations in humane and holistic ways. To enable people-centred and integrated health services, it has identified five strategies for local adaptation (World Health Organization, 2016b). These are:

1. Engaging and empowering people and communities to take an active role in their health and health services
2. Strengthening governance and accountability to build legitimacy, transparency and trust, and to achieve results
3. Reorientating the model of care to ensure that care is provided at the right time, in the right place and in the right way, while striving to keep people healthy and free of illness
4. Strengthening the coordination of care across providers, organisations, care settings and beyond the health sector to include social services and others
5. Creating an enabling environment to facilitate transformational change through enhanced leadership and management, information systems, financial incentives and reorientation of the healthcare workforce

McCormack et al. (2015) identified a range of healthcare initiatives globally that respond to the challenge of creating healthcare systems and services that are person-centred. These included particular developments in Australia, New Zealand, the Netherlands, Norway, Sweden, the UK

and Ireland. This range has broadened to include further initiatives, strategies and improvements (McCormack et al., 2015). In this article, the analysis of the published evidence and the information gleaned from the authors' stakeholder engagements has identified five themes underpinning these strategic developments that are consistent with the five strategies for local adaptation identified by the WHO.

Theme 1: Policy development for transformation

Person-centredness is a distinct value-based position on which policy and practice are founded (Michael, 2016), yet its development can be siloed in policy leading to diluted understanding (Waters and Buchanan, 2017). Current health policy is not always translated into the experience of healthcare (Lloyd et al., 2017; Kaehne, 2018). Consequently, there is a need for service reform towards person-centred services rather than system-centred care (Lloyd et al., 2017; Reeve, 2018; Tak et al., 2019; Sobolewska et al., 2020). This policy-versus-reality gap can be exacerbated by a lack of collaboration with relevant stakeholders (Michael, 2016; Tak et al., 2019), fragmented care planning for individuals (Rock and Cross, 2020), a lack of support from healthcare commissioners and providers (Lloyd et al., 2017), as well as an historical lack of integration of person-centredness into healthcare quality improvement (Santana et al., 2018). It is also recognised that policy sustainability of person-centred objectives is difficult over electoral cycles because the priorities of political parties may differ (Sobolewska et al., 2020).

An inherent flaw in policy has been its focus on planning based on the 'average' person, which negates issues such as individual context, structural inequalities, individual care journey cohesiveness and cultural diversity (Michael, 2016; Kaehne, 2018; Rock and Cross, 2020). Integrated care policy is therefore often based on rationalism, which may espouse person-centredness yet is directed by organisations not service users, requiring scope for multiple contingencies (Kaehne, 2018; Santana et al., 2018). True orientation of health policy and health systems to person-centredness demands the use of real-world data (with real-time feedback), based on diverse individual experience (Feo et al., 2017; Kuluski and Guilcher, 2019; Rock and Cross, 2020), with careful reform embedded in particular services' foci (Bhattacharyya et al., 2019), equity and inclusivity (Michael, 2016), as well as value-based healthcare and a dynamic learning environment (Kuluski and Guilcher, 2019).

There is some debate as to whether the implementation of person-centred care requires service redesign and policy redirection, or if existing services can be reoriented towards person-centred processes and practices. For example, Santana et al. (2018) point to the need for role and service redesign as well as a cultural transformation in practice. In the Republic of Ireland, the Department of Health has recently consulted (Department of Health, 2019b) on the need for structural changes to support an integrated model of person-centred care. Similarly, in Northern Ireland, there is a policy aspiration to deliver health and social care underpinned by a model of person-centred care focused on prevention, early intervention, supporting independence and wellbeing, while recognising that this requires significant transformation (Department of Health, 2016). However, Bhattacharyya et al. (2019) argue that reorientation may occur within current policies, and changes may improve current care delivery (process-focused), create a new service to meet needs (solution-focused), or use anticipatory methods to identify unmet and unacknowledged needs. It is also important to target various systems' levels within a socio-ecological approach (Reeve, 2018; Santana et al., 2018; Rock and Cross, 2020). For example, in relation to fostering person-centred reform within general medicine, changes are needed at the levels of the direct consultation encounter, the practice team organisation and the broader health system (Reeve, 2018). Santana et al. (2018) and Rock and Cross (2020) advocate a co-design approach framed around and across context-bound healthcare needs. In nursing, Feo et al. (2017) developed practical guidance to meet policy and healthcare reform objectives. Based on an innovative methodological approach (historical interpretative synthesis), a series of actionable recommendations embedded in practice guidance has been developed to facilitate person-centred fundamental care (Feo et al., 2017) to meet policy agendas.

Overall, it is clear that despite many years of policy reform, there is no coherent approach to the development of person-centred healthcare policy internationally. Differing priorities and a lack of strategies for global health development appear to feed this inconsistency in priority setting and approaches to policy development.

Theme 2: Participatory strategies for public engagement

The analysis has identified an observable growth in the development of participatory strategies to support public engagement in policy formulation. These reflect the ethos of person-centredness through valuing the public voice. For example, following *A Programme for Partnership in Government in Ireland* (Houses of the Oireachtas, 2016), a non-political citizens' assembly reflecting the principles of a deliberative democracy was established with 100 members, stratified for factors such as age and socio-economic group. Its brief was to consider important issues related to the reformulation of policy and legislation and make recommendations to government. These have covered abortion rights, gender equality, climate change, and the opportunities and challenges of ageing. Citizens' assemblies have also been constituted in British Columbia and Ontario in Canada (2006), Poland (2016) and the UK (2019). Within these assemblies and other policy formulations, it is common practice to have public consultations and invite submissions on new policy. As previously noted, the Irish Department of Health held a public consultation on models of integrated person-centred care in 2018 (Department of Health, 2019b), while in the UK, the Department of Health and Social Care hosts consultations on areas of policy, regulations and the NHS Constitution. This reflects an increasing focus on public involvement and engagement in health and social care issues. In Northern Ireland, a practical guide to support the public's participatory engagement using a model of co-production was developed to support the transformation of health and social care provision (Department of Health, 2018).

In Slovenia, a growth in the development of participatory strategies to support public engagement in policy formulation is evident. For example, following the publication of *Implementing the Child Participation Assessment Tool* in Slovenia (Boljka et al., 2019), focus groups with children were held, and the views of these children regarding their rights were collected. The outputs of these focus groups were used to inform the national strategic programme for children for 2020-25 (Boljka et al., 2019).

In line with their move from a 'care state' to a 'participative society', the Dutch Ministry for Public Health, Welfare and Sport (MVWS) launched the 'Supporting Appropriate Service Provision' programme in 2017 (Dutch Ministry for Public Health, Welfare and Sport, 2020). Service users (citizens, patients, significant others) and service providers (ministries, insurance organisations, care organisations and community teams, among others) meet in facilitated action-orientated workshops using complex 'personae' (rather than specific) cases to co-create solutions. These may vary from small, practical solutions implemented by those present, to advice on changes to local or national policy. The programme was initially funded for two years, but its success has led to an extension for a further two years. Additionally, the Netherlands Organisation for Health Research and Development, an independent organisation developing grant programmes on behalf of the MVWS and the Netherlands Organisation for Scientific Research, is increasingly using the criterion of service-user participation in its decision making.

Theme 3: Healthcare integration and coordination strategies

Developments in person-centred healthcare have acknowledged that people generally connect with a complex health system involving many different professionals and various environments. Consistent evidence has demonstrated that care can frequently be fragmented and uncoordinated (Lloyd et al., 2017; Wynia et al., 2020) causing stress to service users (Acton, 2013). Kaehne (2018) argues that policy focus has been linked discreetly with the economy: in times of fiscal surplus, multi-agency partnership was favoured, but more recent austerity is connected with an impetus towards the cost-savings associated with integrated care.

It is necessary to address the entire cycle of an individual's care journey (Rock and Cross 2020) through consolidation of interorganisational links, care pathways, and strategic, collaborative governance agreements (Kuluski and Guilcher, 2019). Consequently, individuals require health and social care journeys that are experienced as cohesive, where they remain the central focus and priority for service delivery. Creating health systems that have robust care coordination has a number of advantages, such as improved collaboration, increased participation, a reduction in hospital admissions and effective discharge between settings (Damery et al., 2016; Lloyd et al., 2017). Comprehensive co-design approaches are important: for example, in a South Korean study (Tak et al., 2019), policy changes in the delivery of long-term care identified care operators struggling to understand and comply with reform, while there was a need to collaborate and create positive relationships with local communities.

The University of Plymouth in the UK defined person-centred coordinated care as 'Care that is guided by and organised effectively around the needs and preferences of the individual' (tinyurl.com/plymouth-PCC). Person-centred, coordinated care comprises two concepts: person-centred care and care coordination. Lloyd et al. (2019) suggest these have five core domains: information and communication processes; care planning; care transitions; goals and outcomes; and decision-making. This focus on planning, coordination and shared decision making is consistent with the extensive work undertaken by Ekman and colleagues at the Swedish Centre for Person-centred Healthcare at the University of Gothenburg. The model developed by the team focuses on three key 'practices' by healthcare practitioners that are needed to treat service users and their families as actively engaged partners in care: person-centred assessment, the design of a care plan arising from that assessment, and implementation of the care plan in partnership with service users and their families.

The success of person-centred integrated healthcare is bound within with a number of complex levels and domains. These include the person, clinical and service, community, functional, organisational and systems levels. For sustainable, person-centred integrated healthcare, all the levels must work in synergy because of both their separate functions and their interdependency (Goodwin et al., 2013); such integration not only operates across levels but develops and evolves over time (van Houdt et al., 2013). However, much work remains to be done, particularly in the context of addressing system fragmentation, the lack of continuity of care, siloes in public and private healthcare, and the need for an increase in the use of person-centred coordinated care outcome measures (Sugavanam et al., 2018; Lloyd et al., 2019).

The integration of person-centred principles into healthcare systems is evident in many countries. In England, the NHS has developed person-centred intelligence approaches to measuring healthcare systems. These are concerned with what type of care matters to people, whether systems understand the measures people value, whether systems are supported by resources and leadership, and what structures and disciplines are required to decipher the rationale of decision making. This approach also aims to ensure there is a strategic, systems-based approach to providing the care people want and can be involved in (NHS Strategy Unit, 2020). Other UK initiatives that have focused on horizontal integration of healthcare at the micro-level are: 'Hello, my name is...' (a campaign for more compassionate care in health systems, hellomynameis.org.uk); the *House of Care*, which provides a template service model for people with long-term conditions to work together to co-design care (NHS England, nd.; Coulter et al. 2016); personalised budgets (Health Foundation, 2016); and the 'What Matters to you?' campaign that encourages person-centred conversations focusing on the perspective and life world of the person rather than on 'what is wrong with you?' (Healthcare Improvement Scotland, nd.)

In Scotland, a person-centred approach is considered the 'fourth vital sign' in comprehensive healthcare delivery (Leitch, 2016) and seen as improving an individual's care options, experiences and outcomes. In Northern Ireland, the Public Health Agency engaged with the public to see healthcare through their lens, with the goal of enhancing person-centredness (Public Health Agency, 2014) and further public engagement is in progress to build upon this work. In the Republic of Ireland, recent research has

identified that life story work with people living with dementia helped staff understand the person behind the illness and what was important to them, and positively impacted on how they delivered care (Cooney and O'Shea, 2019).

In Slovenia, there is an increased focus on person-centred healthcare and the recognition that giving a voice to service users is one of the key elements in provision of high-quality healthcare (Nurses and Midwives Association of Slovenia, 2014; Slovenian Government, 2017; European Observatory on Health Systems and Policies/OECD, 2019). The Netherlands has undertaken several initiatives and developed a number of methods to employ service user narratives as an instrument in quality assurance (Cardiff et al., 2011; Sools et al., 2014; Roman et al., 2019).

Another example of coordination for person-centred practice is the healthcare objective of the Victoria State Government in Australia. Here, person-centredness is linked to the Australian Charter of Healthcare Rights (Australian Commission on Safety and Quality in Healthcare, 2019). There is an explicit expectation that care from professionals should be person-centred and respectful, and that people will be actively facilitated to be involved in their care through good communication with professionals within a safe environment (Victorian State Government, 2020).

Within health and social care regulation, the concept of person-centredness is central in many countries. For example, in the Republic of Ireland, the Health Information and Quality Authority (HIQA) has person-centred care and support as a component in all care standards (see hiqa.ie). Similarly, within the main lines of enquiry of the Care Quality Commission in England (cqc.org.uk), person-centred care is key to assessing a service's responsiveness. The Australian Commission on Safety and Quality in Healthcare also links the importance of seeing the person as an individual to safe and valued care (safetyandquality.gov.au).

Theme 4: Frameworks for practice

The development of specific frameworks to capture the essence of persons, personhood and aspects of healthcare processes and outcomes has given rise to both generic and field-specific approaches to care delivery. The field of dementia care probably has the longest tradition of such developments, primarily because of the work of Kitwood (1997) and Brooker (2007). Kitwood was influenced by the central concept of human beings in relationships with each other, and Brooker built on this unfinished work to develop the VIPS (Very Important Persons) Framework. Brooker drew on three constructs: values, individualised perspectives, and positive social psychology, and added the core factors of care environment, systems of care, and direct care in designing the model (Reilly and Houghton, 2019). According to Røsvik et al. (2011), the VIPS model offers a way of translating the concepts of person-centred care into daily care in nursing homes by building a shared base of knowledge and values in the team. These researchers claim, based on their nine-week pilot study, that little organisational change is required, and extra resources are not needed. There is some evidence from their pilot that nursing leadership and organisational support are essential factors in implementation. Likewise, the Senses Framework (Nolan et al., 2006) is intended for older persons' services and is focused on relationships. The Gothenburg Model of Person-Centred Care, developed by Ekman and colleagues and based on three essential practices, has been widely tested in acute care settings. Its ability to improve patient outcomes and resulting impact on service models (such as through cost-effectiveness) has been a notable finding in studies (Ekman et al., 2012; Fors et al., 2016).

In 2018, Santana et al. published a conceptual framework for practising person-centred care, drawing on the Donabedian model for healthcare improvement, and categorising person-centred domains into structure, process, and outcome for healthcare quality improvement. The 'Eight Dimensions Framework for Humanizing Healthcare' (Todres et al., 2009) has applicability in research, practice, and education. This framework focuses on eight philosophical dimensions that must be considered when humanising healthcare services, irrespective of the specific context.

McCormack et al. (2015) argue that frameworks for person-centred healthcare have expanded and broadened their focus to include care experience outcomes. McCormack and McCance's Person-centred Nursing Framework, originally published in 2006 and further developed in 2010, offers a structure for understanding the prerequisites nurses need to be person-centred, the attributes needed in the care environment to sustain person-centredness, and the person-centred processes and outcomes that can reasonably be expected to arise from a person-centred approach. The framework emerged from empirical research and is considered a midrange theory in nursing (McCormack and McCance, 2006; 2016). In 2017, these authors revised and extended their framework to include multi-professional healthcare practice, and published the Person-centred Practice Framework. More recently, both frameworks have been updated (cpcpr.org/resources). These frameworks have also been embedded into research projects and have led to aligned frameworks for educational purposes, such as the Framework for Practice Learning, for integrating person-centredness into healthcare curricula (Cook, 2017). In the Republic of Ireland, an accredited facilitator development programme to foster cultures of person centred care has been delivered since 2016. The programme focuses on staff development to provide competencies to enable and measure person-centred cultures (tinyurl.com/HSE-facilitators). To date, more than 200 staff have engaged with the programme, which is delivered by members of the quality improvement division and office of the nursing and midwifery services division of the Health Service Executive, in partnership with Queen Margaret University, Edinburgh.

In Austria, Mayer and colleagues from the department of nursing science at the University of Vienna have been engaged in practice development work in long-term care since 2014. They have developed a person-centred practice framework for long-term care (PeoPLe), drawing on the Person-centred Practice Framework of McCormack and McCance (2017), contemporary research evidence and original empirical research. The core of this framework is a component called fundamental principles of care, which reflects person-centeredness at the residents' level and from the resident's perspective in terms of desirable conditions and experiences in long-term care. It offers an operationalisation of person-centred practice with older people in long-term care at the level of principle. Mayer and colleagues are also involved in translating measurement tools into German, such as the Person-centred Practice Inventory (PCPI) – Staff (Weis et al., 2020) and service user versions, as well as the Workplace Culture Critical Analysis Tool (WCCAT).

All these frameworks have strengths and limitations, and offer variable utility for healthcare practice. However, it is the frameworks of McCormack and McCance that have the widest applicability and have been most extensively adopted. They are rooted in rigorously argued philosophical and theoretical foundations, and are transparently situated in person-centredness. The Person-centred Practice Framework has been translated into 10 languages (Dutch, German, Danish, Norwegian, Portuguese, Spanish, Mandarin, Slovenian, Swedish and French) and tested in multiple healthcare contexts, in more than 22 countries. Research and development undertaken with international partners in the UK, Sweden, Norway, Finland, the Netherlands, Spain, Portugal, the Republic of Ireland, Australia, South Africa, the US and Canada has resulted in the development of six evaluation instruments (the Person-centred Nursing Index, the Context Assessment Index, the PCPI [with three versions, for staff, service users and student nurses] and one observation tool, the revised WCCAT-R). Through various implementation studies with these and other international partners, key outcomes from the implementation of person-centred practice have been identified.

Theme 5: Process and outcome measurement

In research related to person-centredness, there are two relevant areas for consideration: first, the increasing emphasis on delivering services and outcome measurement; and second, a transformation in the way research is conducted. Traditionally, care has been defined by what organisations do rather than by service users' experiences (Kaehne, 2018), which exacerbates system fragmentation and perpetuates power hierarchy in healthcare delivery (Sobolewska et al., 2020). In recent years, policy agendas have begun to emphasise improving patient experience (Jones et al., 2018), recognising that

process and outcome measures are fundamentally important in addressing the policy-experience gap (Santana et al., 2018; Jones et al., 2018; Sobolewska et al., 2020), and ensuring quality healthcare systems are underpinned by accountability and responsiveness to service users' expectations (Larson et al., 2019).

Outcome measurement

Research on and evaluations of health systems have increasingly highlighted outcomes-based approaches that focus on service users' evaluation of health and social care. For example, the use of PROMS (Patient Reported Outcomes Measures) and PREMS (Patient Reported Experience Measures) are becoming standard methods of measuring care quality (van Dulmen et al., 2017). The Picker Institute, established in the US in 1986, works with governments, regulators and other organisations to promote person-centredness in policy and practice, develop tools to illuminate patient experiences, and empower staff to improve service delivery. It has created annual service user surveys that assess quality of care (Jenkinson et al., 2002). Such surveys are common in many countries, such as England, Ireland, Scotland, Denmark and New Zealand, and are considered an important aspect in ensuring the person is central to health systems (Health Information and Quality Authority, 2016). These surveys help clarify people's experiences and highlight areas of quality and safety improvement. Sawatzky, however, has critiqued such approaches to outcome measurement and questioned the extent to which they are person-centred (Sawatzky et al., 2012; 2017). At the heart of Sawatzky's position is a critique of approaches to measurement that rely on homogeneous models when, in contrast, person-centredness advocates heterogeneity. He argues for the use of 'latent variable mixture models' that do not treat all persons as consistent in their interpretations of questions about their health status, and that allow for individual difference (Sawatzky et al., 2018). Researchers at the Swedish Centre for Person-centred Care have an established reputation in evaluation of outcomes from the implementation of person-centredness. Using the framework for person-centred care (see above), the team measured patient and staff outcomes arising from the implementation of three essential practices. Research by Ekman and colleagues (2011) shows that when patients are active agents in the development of a care plan, when healthcare teams collaborate to ensure the implementation of the plan, and when evaluation of the impact of the plan is undertaken from the perspective of the patient, then patient and team outcomes can be demonstrated. However, any measures need to be sensitive to quality across and between settings, environments and populations, while acknowledging service demand, values and broad expectations (Sawatzky et al., 2018; Larson et al., 2019).

A significant development has been the emergence of instruments and tools to enable healthcare practitioners and researchers to measure and evaluate person-centredness. In their 2015 publication, McCormack et al. criticised most of these instruments and tools for lacking foundation in person-centred concepts, principles and theories, concluding that most of these instruments were 'proxy measures' of person-centredness. Additionally, most earlier developments in process and outcome measurement focused on person-centred care rather than person-centredness per se – for example, dementia care mapping (tinyurl.com/dementia-mapping) based on Kitwood's (1997) work, and Edvardsson and colleagues' (2011) tool for understanding residents' needs as individual persons (TURNIP).

As indicated above, more than a decade of research into the Person-centred Practice Framework has resulted in the development of six evaluation instruments, with studies identifying key outcomes from the implementation of person-centred practice. Research undertaken in the Republic of Ireland produced seven core attributes of flourishing residential care settings, which have been adopted internationally as a framework of best practice (lenus.ie/handle/10147/190291). Its implementation has resulted in improvements to the care environment, greater resident satisfaction, improved staff wellbeing, a reduction in falls and reduced use of psychotropic medications (Buckley et al., 2014; Shaw et al., 2016; Mekki et al., 2017). In acute care settings, evidence has been produced pointing to better engagement between staff and patients, as well as improved retention of staff with greater job

satisfaction and staff wellbeing (McCormack et al., 2010; Parlour et al., 2014; Hahtela et al., 2014; Laird et al., 2015). In palliative care, the evaluation of systematic practice development programmes has shown improvements in regulator quality indicators, as well as improvements to the quality of the care environment, and better staff communication, development and retention (Yalden and McCormack, 2010; Yalden et al., 2013; McCormack et al., 2017).

Traditional measures of patient satisfaction with care can be limited when evaluating the experience of care as a whole. To address this deficit, Jones et al. (2018) updated the Valuing Patients as Individuals Scale, which can contribute to making person-centred policy a reality for individuals. The 31-item revised scale has demonstrated positive psychometric properties, although the authors recommend further development. More recently, Larson et al., (2019) provided guidance for policymakers and researchers, pointing to a dual function of person-centred approaches in health systems. The experience of person-centredness needs to be intrinsically important (demonstrating dignity and respect), and instrumentally important (improved healthcare use and improved outcomes). Consequently, measuring person-centredness has two inherent, yet distinct, elements: patient experience and patient satisfaction. Patient experience measurement is concerned with process, and has three components: effective communication, dignity and respect, and emotional support. In contrast, patient satisfaction is concerned with health outcomes, patient satisfaction with care, and confidence in the healthcare system itself (Larson et al., 2019).

An international programme of work leading to the development and testing of a set of eight person-centred nursing key performance indicators (KPIs) also offers a mechanism to measure aspects of person-centred practice (Table 2).

Table 2: Nursing key performance indicators (McCance et al., 2012)

1. Consistent delivery of nursing care against identified need
2. The patient's confidence in the knowledge and skills of the nurse
3. The patient's sense of safety while under care of the nurse
4. The patient's involvement in decisions made about his/her nursing care
5. Time spent by nurses with the patient
6. Respect from the nurse for the patient's preference and choice
7. Nurse's support for patients to care for themselves where appropriate
8. Nurse's understanding of what is important to the patient

The eight KPIs are considered novel in the context of the existing evidence base, and differ from other quality indicators generally used. They align to the processes in the Person-centred Nursing Framework (McCormack and McCance, 2010). A set of measurement tools was developed to accompany the KPIs, comprising four data collection methods: a patient survey; an observational tool; patient and family stories; and a review of the patient record undertaken in conjunction with nurse interviews (McCance et al., 2015). These tools, and the KPIs, have been tested through a series of international implementation studies in a range of clinical settings (McCance et al., 2015; McCance and Wilson, 2015; McCance et al., 2016). Findings from these studies confirmed that using the eight KPIs generated evidence of patient experience that facilitated engagement of nurses in developing person-centred practice, contributing to an enhanced care experience.

Some studies have used the concept of patient narratives to develop 'I' statements on what people want from integrated and coordinated healthcare. These studies have focused on an inductive way of developing outcomes that are important for service users. The first was undertaken in the UK by

National Voices (Redding, 2013). National Voices is a coalition of charities that support and lobby for person-centred care. Findings were separated into six domains with a total of 38 supporting narratives. These domains were: my goals/outcomes; care planning; communication; information; decision-making (including budgets); and transitions. Similarly, in the Republic of Ireland, the Health Service Executive funded a project to develop patient narratives led by the Irish Platform for Patient Organisations, Science and Industry. A participatory action research approach was used to collect data through 11 focus groups (comprising service users, their caregivers, and patient representative groups) and two surveys. A total of 19 generic 'I' statements were developed spanning three domains – my healthcare experience, care that I am confident in, and my journey through healthcare (Phelan et al. 2017). Both of these initiatives enable healthcare professionals to see how services should be experienced by people who have multiple connections with different healthcare professionals in a variety of settings. Likewise, Michael (2016) prioritises the use of patient narratives in the development of the Diversity Conceptual Model in older person care delivery. The 10,000 voices (Public Health Agency, 2014) and ongoing work (10,000 more voices, 10000morevoices.hscni.net) in Northern Ireland also uses narratives in this way to promote understanding of the person-healthcare service nexus.

In Slovenia, effective communication between health professionals is used as a powerful tool in clinical practice to improve the active participation of service users in care practices. Good communication between healthcare professionals leads to effective troubleshooting, better clinical outcomes, lower costs and higher patient satisfaction (Ministry of Health, 2018). The Patient Rights Act, which defines 14 rights, also aims to provide equal, appropriate, quality and safe treatment based on trust and respect between the service user, doctor and other healthcare professionals (Slovenian Government, 2017).

Transformation in the way research is conducted

The second area of significance in person-centred healthcare research is the transformation in the way research is conducted. Traditionally, research has been a domain of control, where value has been intricately linked to study objectivity through the use of methodologies and methods that privilege the power and control of researchers.

Moving away from the power dynamics of researcher-subject, there have been changes reflected in public and patient engagement and involvement that democratise decision making in research. Van Dulmen et al. (2017) note the need to engage and empower people who use health and social care services in research processes and outputs. Public and patient engagement and involvement is becoming a more frequent requirement of funding for research projects, with such activity often expected from the development of the proposal, through full participation in the research, to its evaluation, dissemination and outputs. This supports the principles of person-centredness by developing meaningful research proposals and projects that are founded on mutuality – researching with, rather than on, service users, and reflecting 'connectivity' (Jacobs et al., 2017) or what McCormack and McCance (2017) term 'informed flexibility'. For example, in 1996 the government-funded programme INVOLVE was established as part of the UK's National Institute for Health Research. INVOLVE's aim is to facilitate active public involvement in health and social care research, providing guidelines on areas such as training and supporting members of the public, and payments and non-monetary methods of recognition. One such document, *UK Standards for Public Involvement in Research* (National Institute for Health Research et al., 2019), includes guidance on communications, governance, impact, working together, support and learning, and inclusive opportunities. A similar development has occurred in the Republic of Ireland, where the Health Research Board and the Irish Research Council have funded a public and patient involvement implementation plan to support with research the active participation of those who use, or have an interest in, health and social care. The collaborative work by Cook (2017) in Northern Ireland is an example of how authentic collaborative research processes can be effective in structuring successful educational approaches that enhance person-centredness through developing the caring attributes of student nurses. A major objective of these projects reflects person-centred

principles in prioritising the views, inputs and perspectives of service users, thus enabling their authentic voices to be heard and responded to.

More recently in the UK, the Health Foundation has launched a £2.1m programme of research, the Common Ambition Programme, to build sustainable change in collaboration with people who use healthcare services (Health Foundation, 2020). Having public and service user engagement and involvement has a major advantage in identifying key issues that researchers may not have recognised but which are important to service users or to those who support them (van Dulmen et al., 2017). In this context, the research participant is an empowered equal partner, or authentic co-researcher, whose voice is valued and whose life world and perspective are integrated into aspects of the research question and process. Another advantage of this approach is that findings more truly reflect the socio-ecological context within which people live, interact and engage in healthful practices.

Drawing on the framework of McCormack and McCance (2017), Titchen et al. (2017) suggest person-centred research should encompass four domains.

- The Person-centred research environment: how do researchers engage with the context and conditions of the research project?
- Prerequisites for person-centredness: from what perspectives (ontological and epistemological), is the researcher coming and what is their motivation? This requires reflexivity on the part of the researcher, who has insight into bias, positionality and the intersubjectivity and self-interrogation of the research process itself (Probst, 2015)
- Person-centred research processes: researcher engagement that continuously fosters person-centred approaches to democratic involvement, participation and authentic equality
- Person-centred research outcomes: the capacity for human growth, wellbeing and flourishing, during and after the research

Research requires a valuing of the plurality of knowledge, with consideration given to the questions asked and the importance ascribed to public and service user involvement (van Dulmen et al., 2017). Despite the growing movement towards research democratisation, challenges remain in divesting researchers of power and challenging the entrenched historical cultures of participants and subjects as passive within research. Nierse (2019) found that including service users in research agenda setting from the outset was relationally empowering as the partnership grew, agendas became more holistic, and themes around values, identity and relationality were formulated.

Person-centred healthcare – where are we now?

In January and February 2020, project partners undertook a series of stakeholder engagement activities in the UK, the Netherlands, Slovenia and Norway. Stakeholders (n=391), including service users, undergraduate and postgraduate students, mentors, educationalists, and service managers and leaders, participated in focus groups. Participants were asked key questions around their understanding of person-centred practice and how they thought it could be made more of a reality. The focus group findings demonstrate that person-centred healthcare systems play a key role in creating conditions for person-centred practices at individual and team levels. In line with the literature, stakeholders recognised the need to embed processes and frameworks of person-centredness within healthcare systems at every level. However, there was a clear theme in the data of ongoing medical dominance and an explicit requirement to realign systems around the needs of persons. For person-centredness to flourish, participants suggested it has to be the norm, with everyone's voice heard and valued. Relationships between all stakeholders within healthcare environments should be characterised by a shared purpose, shared decision making, mutual respect and involvement of all.

Focus group participants highlighted the need for intentional development of individuals and teams as person-centred practitioners within pre- and post-registration programmes. They understood person-centred practitioners as being able to build caring relationships and possessing holistic care

skills. However, participants highlighted that the practice context within which learning takes place was often not supportive of the development needed. They suggested the need for development as emotionally intelligent practitioners able to role-model person-centred practice and to engage in reflective practice.

New findings from this focus group data, not detailed in the existing literature, were the needs for practitioners to be entrepreneurial and to have the ability to challenge practice. Participants believed that, in order to enable this, educators should understand the challenges faced by learners as well as understanding their individual learning needs. Spaces for inquiry that facilitated and encouraged an exploration of theory and practice were seen as conducive to developing person-centredness. Importantly, learning from people's experiences of care was viewed as central to development as a person-centred practitioner. Consequently, it is imperative that space for engagement with the range of frameworks is available in practice. In this special edition, Dickson et al. (2020) further extend this work, demonstrating a framework of developing philosophical and pedagogical principles.

Conclusion

This review of developments in person-centred healthcare has highlighted five themes that dominate the way health systems are developing:

1. Policy development for transformation
2. Participatory strategies for public engagement
3. Healthcare integration and coordination strategies
4. Frameworks for practice
5. Process and outcome measurement

While appreciating that not every country where developments are occurring has been included, nor indeed every national development, the review provides a rich insight into the current 'state of the art' of person-centred healthcare. The stakeholder engagement exercise opens up new avenues for consideration in future healthcare developments, particularly the need for healthcare workers to be entrepreneurial. There are many examples of entrepreneurship among healthcare practitioners, but this has not been so evident in person-centred practices, where the macro-context has a significant influence on the potential for new approaches to healthcare being delivered at scale. Consequently, this review argues that this is a critical issue to be considered in the education of healthcare students, if a comprehensive shift towards person-centredness in healthcare systems is a specific goal within the overall agenda of humanising of healthcare.

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