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Expert Commentary

What is the state of the art in person-centred care?

An **Expert Commentary** brokered by the Sax Institute for the Australian Commission on Safety and Quality in Health Care. April 2016.

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This report was prepared by:

Sue Lukersmith, Carmen Huckel Schneider, Luis Salvador-Carulla, Joachim Sturmberg, Andrew Wilson and James Gillespie.

June 2016

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Suggested Citation:

Lukersmith S, Huckel Schneider C, Salvador-Carulla L, Sturmberg J, Wilson A, Gillespie J. What is the state of the art in person-centred care? An Expert Commentary brokered by the Sax Institute (www.saxinstitute.org.au) for the Australian Commission on Safety and Quality in Health Care, 2016.

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Contents

1 Executive summary

The terms patient, person, people centred are all found in the literature. In this commentary we have used the term person- and people-centred healthcare (PPCHC) as it is inclusive. PPCHC has been at the heart of recent attempts to improve the quality and responsiveness of the health system. It requires a major shift from established modes of clinical and administrative practice, making individuals, with their complex needs and preferences, the drivers of healthcare.

PPCHC is a whole philosophy and culture of care that drives a complex healthcare system. It includes a range of key characteristics including a holistic perspective of health, functioning and wellbeing, shared decision-making, empowerment and co-production of care, integrated care, context and complexity. We can learn from countries and sub-systems that have adopted a PPCHC approach. However, each country context is different. Australia will need to develop its own strategies and roadmap in moving towards person- and people-centred healthcare.

This expert commentary has been commissioned by the Australian Commission for Safety and Quality in Healthcare (ACSQHC) and the Sax Institute to contribute to a series of consultation and discussion papers on its future vision for the Australian healthcare system. The commentary team has been engaged to offer independent expertise and experience to prepare this plain English commentary. The document provides a policy and research perspective, rather than operational.

Literature capture

There has been significant interest and development of person- and people-centred healthcare (PPCHC) concepts over the past 6–7 years. There is now a considerable body of broad reviews and consensus statements from global and other leading health organisations. These, as well as literature known to the authors provided our starting point. We then hand searched references of this known literature, conducted a grey literature search of websites of national and international agencies, and performed a targeted search of literature in the *Medline* database related specifically to the utility of information and communication technology for PPCHC to capture most recent literature in this emerging sub-field.

These papers were then drawn on to inform the following commentary, distinguished from a traditional systematic review in that:

1. Database searches served to complement review team knowledge of seminal papers
2. Papers found were not subject to a systematic quality appraisal process, rather
3. Expert knowledge was sought to appraise the evidence in light of the questions posed by the commissioning agency.

Eleven experts from the field of PPCHC with both academic and policy backgrounds accepted the invitation to comment and offer insights on an initial draft of the paper as a ‘consultation group’. All responses were then gathered and considered in a revision of the paper.

This commentary is structured around specific questions posed by the ACSQHC in the commissioning brief as follows:

Question 1: How has the concept of person-centred care changed?

Key points:

- The Alma-Ata Declaration in 1978 provided the conceptual ground for the development of the population health approach to person-centred healthcare
- Reactions to the Alma-Ata Declaration were mixed and PPCHC-related concepts have faced several barriers including: financial and governance structures favouring centralised healthcare, perceptions that community-based health was second rate to quality and reductionist approaches in evidence based medicine (EBM)
- Three developments, partly as lessons learnt from the mixed reactions to the Alma-Ata declaration and other barriers, have been key markers of more recent developments in PPCHC:
    1. There has been a growing international consensus on what constitutes PPCHC, as well as its benefits for whole populations
    2. It has become increasingly clear that PPCHC requires a whole system perspective
    3. The conceptualisation of a holistic approach to health has advanced substantially, to include multiple components such as health status, experience of health, positive health, health and environmental determinants as contributory factors and personal characteristics, among others
- On the basis of these developments, we can now conceptualise PPCHC as being comprised of four key characteristics:
    1. A holistic approach based on the internationally accepted biopsychosocial model. This model is now codified in the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) but is still being developed and supplemented by new taxonomies of sets of health-related factors
    2. Empowerment of the person based on human rights. This attribute of PPCHC emphasises equality, needs-based care, and the involvement of people in their own healthcare and decisions
    3. Integrated care and universal access – whereby integration has developed beyond coordination and collaboration between services for the person (vertical integration) to inclusion, participation and community care, engaging the person and assessing personal factors such as quality of life and planning for solutions
    4. Complexity and context dependence – while there is no single model of PPCHC because each context is different, there can be a common framework.

Question 2: What are the key characteristics of approaches to implement and advance person-centred care?

Key Points:

- The cornerstone for enabling PPCHC is grouped under co-production of care, shared knowledge and decision-making, and includes co-design of changes to improve the safety, quality and outcomes of healthcare. Expressions of shared knowledge and decision-making that contribute to this key facilitator for PPCHC include:
    - A sentinel approach to life-long healthcare
    - The expert patient, self-management and peer support
    - Locally relevant person-centred primary and community care
    - Investment in information communications technology development
    - Inter-sector interaction, collaboration and partnerships.

- The promotion of shared values and goals in the health system that embody the characteristics of PPCHC will enable system change and break down barriers. Broader health system strategies that might contribute include:
    - Long-term commitment to shared values and goals
    - Promoting of use of broader sources of knowledge
    - New methods of analysis, performance monitoring and measurement for accessibility, transparency and meaning to users
    - Healthcare workforce and education.

Question 3: Has the experience of healthcare (as reported by healthcare consumers) become more person-centred?

Key points:

- The experience of healthcare as reported by consumers has significantly increased in the last decade. However, internationally, formal methods of identification and measurement of PPCHC have lagged behind advocacy and analysis

- Measuring whether the experience of healthcare is person-centred, and the progress towards principles of person-centred over time is complex. The problems in measurement arise from the interaction among and between the system components and the PPCHC characteristics. As PPCHC is context specific and change occurs at each system level, measuring the experience of PPCHC must occur at the nano, micro, meso and macro system levels to develop a deep understanding of the variations and progress towards PPCHC within the whole system

- While there has been progress in some areas of measurement, particularly at the nano and micro level, more work needs to be done to accurately measure healthcare experience at the macro and meso levels. Typically, current standard measures of outcomes in health systems focus on, and provide information about the service and experience of healthcare, but do not usually measure the person's perception of their own health and the outcomes (health experience) nor health determinants. For this reason, while standard measures are progressing in the right direction, they are not seen as adequate measures of the PPCHC characteristics

- There are examples of measures that have been used to examine PPCHC, at nano, micro, meso and macro system levels. Measures at the nano to meso levels include those examining assessment, planning, intervention and monitoring, discontinuation and review. PPCHC measures at the meso and macro system level examine person and people feedback loops, models and pathways, policy and funding systems and integration cross sector care

- Generally, the literature provides insufficient detail or the scope of measures used, and considering the differences in terminology and levels of measures (patient, person and people; system levels). A detailed scoping study would better establish the range of measures at each level of the system, and may attempt to identify the components of PPCHC that are/are not measured

- To advance a comprehensive PPCHC, there needs to be multiple measures which focus on the components of PPCHC including: the six domains of integrated care (clinical, professional, organisational, system, functional and normative integration), all system levels, person and population focused perspectives of their own care and broader health in a holistic sense.

Question 4: Drawing on contexts comparative with the Australian healthcare system, which approaches to person-centred care have shown the strongest positive impact on consumer's experience of care?

Key points

- Numerous examples of change at different system levels towards a PPCHC model have been implemented in healthcare systems comparable to Australia

- Not all attempts at system change necessarily embody the key characteristics properties of PPCHC holism, empowerment, integration and complexity.

- Facilitators identified in the examples include:
    - Engagement with the person and people, shared management and decisions around healthcare services
    - Strong government and clinical leadership
    - The integrated information systems and care pathways
    - Inter-sector collaborations
    - Focus on patient empowerment

- The context dependency of documented approaches, as well as the diversity of approach, and the cautions that must be taken in evaluating outcomes from complex, multi-faceted change programs makes it difficult to draw conclusions on strongest/weakest approaches to achieve PPCHC. However, what is evident from examples found in the literature is a lack of broad, whole system approaches

- A comprehensive road map to move towards PPCHC needs to come from complex adaptive systems perspective, with clear knowledge and understanding of local context and involves bottom up and top down strategies and shared values.

2 Introduction

This expert commentary has been commissioned by the Australian Commission for Safety and Quality in Health Care (ACSQHC) and the Sax Institute to contribute to a series of consultation and discussion papers on its future vision for the Australian healthcare system.

The commissioning brief outlines the Commission's intent to commence a project aiming to support the creation of a person-centred healthcare system for Australia. The commentary team has been engaged to offer independent expertise and experience to prepare this plain English commentary.

This commentary is structured around specific questions posed by the ACSQHC in the commissioning brief as follows:

- Section 1. We begin by defining the dual concepts of person-centred healthcare (PCHC) and the broader person- and people-centred healthcare (PPCHC), which we will then refer to throughout the commentary. We then approach the Commission's first question of interest: How has the concept of person-centred care changed?
- Section 2. We address the characteristics and facilitators of people and person-centred health care in response to the Commission's second question of interest: What are the key characteristics of approaches to implement and advance person-centred care?
- Section 3. We examine how consumer experiences of person- and people-centred healthcare can be tested by relevant measures and ask whether: Over time, has the experience of healthcare (as reported by healthcare consumers) become more person-centred?
- Section 4. We look at key strategies that have had impact in moving towards person-centred healthcare in response to the question: Drawing on contexts comparative with the Australian healthcare system, which approaches to person-centred care have shown the strongest positive impact on consumer's experience of care?

Approach

Person- and people-centred healthcare (PPCHC) is not merely a clinical concept. It is a whole philosophy and culture of care that drives a complex healthcare system. It includes a range of concepts including a holistic perspective of health, functioning and wellbeing, shared decision-making and empowerment, co-produced and integrated care, context and complexity. While we can learn from countries and sub-systems that have adopted a PPCHC approach the importance of context means that Australia will need to develop its own strategies and roadmap in moving towards person- and people-centred healthcare.

As the concepts are complex at the person and system levels, we scaffold the concepts through the document. We provide commentary on the meaning of PPCHC, describe its key characteristics and provide examples of tools to assess person-centredness at the nano, micro, meso and macro levels of care. We also provide examples of PPCHC systems using a systems thinking approach.

Literature capture

There has been significant interest and development of person- and people-centred healthcare concepts over the past decade. The World Health Organization's 2008 World Health Report entitled 'Primary Health Care: Now More than Ever'[1] invigorated the broader person- and people-centred healthcare movement. There is now a considerable body of broad reviews and consensus statements from global and other leading health organisations. These provide our starting point:

- Consensus statements
    - Six international consensus declarations from the International College of Person-centred Medicine (ICPCM) particularly the 2014 Geneva Declaration on Person- and People-centred Integrated Health Care for All[2]
    - The Salzburg statement on shared decision-making which calls on healthcare practitioners to consider the role patients can and should play in their healthcare decisions.[3]

- International Organisation reports which reflect on the concepts of PPCHC, review and synthesise the evidence including:
    - The WHO People-centred and integrated health services overview of the evidence on the benefits that people-centred and integrated care can bring to people, communities and countries that presents a number of case studies (July 2015)[4]
    - The WHO "Roadmap : Strengthening people-centred health systems in the WHO European Region: A Framework for Action" (2013)[5] and the recently launched online knowledge platform 'IntegratedCare4people'[6]
    - The Health Foundation/ Health Policy Partnership Report provides an 'environment scan' in person-centred care (Harding et al, 'The State of Play in Person-centred care' report ; December 2015)[7]
    - The WHO background briefing document to the executive board of WHO on the framework on integrated, people-centred health services[8]
    - Making progress in people-centred care: country experiences and lessons learnt.[9]

- Systematic reviews
    - Mockford et al (2012)[10]
    - McMillan et al (2013)[11]
    - Rathert et al (2013)[12]
    - Dwamena et al (2012)[13]
    - Milton et al (2011)[14]

- Earlier reviews completed by Australian public agencies
    - Commission on Safety and Quality in Health Care (2011)[15]
    - New South Wales Ageing Disability and Home Care (ADAHC) (2008)[16]

- Recent policy papers by Australian agencies
    - Ernst and Young, Wentwest and Menzies Centre for Health Policy, model for person-centred home – December 2015.[17]

This paper was commissioned as an expert commentary rather than a systematic review of literature, so we began by capturing key messages in literature known to the authors. We then hand searched references of this known literature using a snowballing method to expand the scope of references and search for specific exemplars of PPCHC. We also conducted a grey literature search of websites of national and international

agencies, including WHO, International Foundation for Integrated Care (IFIC) and the Health Foundation. This collection of papers was supplemented by a targeted search of literature in the *Medline* database related specifically to the utility of information and communication technology for PPCHC to capture most recent literature in this emerging sub-field.

These papers were then drawn on to inform the following commentary, distinguished from a traditional systematic review in that:

1. Database searches served to compliment review team knowledge of seminal papers
2. Papers found were not subject to a systematic quality appraisal process, rather
3. Expert knowledge was sought to appraise the evidence in light of the questions posed by the commissioning agency.

A comprehensive list of websites searched for grey literature, as well as search terms for the Medline search, are listed in Appendix 1.

Expert consultation

Eleven experts from the field of PPCHC accepted the invitation and provided comment and insights on an initial draft of the paper as a 'consultation group'. Invitations to participate in the consultation group were sent to leading scholars in the field, with both academic and policy backgrounds. Several invitees either did not respond, or did not have the time to review.

The consultation group was asked to respond to an earlier draft of this commentary, and was asked specific questions in relation to the commentary paper:

1. Bearing in mind the page limit, do you see any critical information gaps in what we have provided concerning the development and current perspective of person- and people-centred healthcare?
2. Are there characteristics or facilitators that we have not mentioned, that in your opinion should be mentioned?
3. Do you know of any additional examples (or categories) of tools and methods to measure experience of person-centred care, at any level of the system?
4. Considering the key characteristics we have identified, do you have any case examples of approaches to advancing PPCHC that have shown a strong impact?

All responses were then gathered and considered in the final paper. The comments provided by expert reviewers in the body of their emails or letter format are provided in a supplementary document.

3 Section 1

How has the concept of person-centred care changed?

Premise

That major and informative conceptual shifts have occurred in the definition and understanding of person-centred care, e.g. since the declaration of Alma-Ata in 1978.

Interpretation for expert commentary

Outline how person-centred and people-centred health care is conceptualised now and indicate key historical contributions to it.

Key points

- Patient-centred, person-centred and people-centred care are all terms found in the literature and each relates to a different system level
- Person- and people-centred healthcare (PPCHC) is a whole philosophy of care that considers health status, the person's experience, the environment, social determinants and personal factors
- The Alma-Ata Declaration in 1978 provided the conceptual ground for the development of the public health approach to person-centred healthcare
- Reactions to the Alma-Ata Declaration were mixed for a number of historical and political reasons and the concepts relevant to PPCHC have faced several barriers including: financial and governance structures favouring centralised healthcare, perceptions that community-based health was of second-rate quality and reductionist approaches in evidence based medicine (EBM)
- Three developments have been key to progress in adoption of PPCHC
- There has been a growing international consensus on what constitutes PPCHC, and its benefits for whole populations
- It has become increasingly clear that PPCHC requires a whole system perspective. The application of person-centred care in pockets of healthcare has not led to a substantive paradigm shift at the macro level
- The conceptualisation of a holistic approach to health has advanced to include multiple components such as health status, experience of health, positive health, health and environmental determinants as contributory factors and personal characteristics among others
- From these developments, we can now conceptualise PPCHC as comprising four key characteristics
- At system level key characteristics of PPCHC are:

- A holistic approach based on the biopsychosocial model, which finds structure in the WHO International Classification of Functioning, Disability and Health is still being developed and supplemented by new taxonomies of health-related factors
- Empowerment of the person based on human rights. This characteristic of PPCHC emphasises equity, needs-based care, and the involvement of people in their own healthcare and decisions
- Complexity and context dependency – while there is no single model of PPCHC because each context is different, but there is a common framework
- Integrated care and universal access – does not just refer to coordination between services but goes beyond this to refer to the person's inclusion, community care and their participation, engaging the person and assessing personal factors such as quality of life and planning for solutions at the patient and person level.

Person- and people-centred healthcare (PPCHC) - definitions

The aim of PPCHC is to engage and empower persons in the management of their individual care; and the promotion, prevention and planning at the system level, equity, quality, efficiency and ethics of the care and health system. The anticipated benefits and outcomes of PPCHC is that all people are able to access high-quality health services that meet their needs and preferences for improved health of populations.[2, 8, 18] The international development and progress towards PPCHC provide valuable information and lessons learnt, but confirm the benefits of PPCHC.[4, 7, 9] Person- and people-centred healthcare (PPCHC) is an umbrella term that encompasses a whole philosophy or culture of care, a way of thinking and understanding the experiences of people, and acting accordingly.

In the literature the terms 'person-centred', 'patient-centred' and 'people-centred' are all found and sometimes used interchangeably without distinction. The development of a taxonomy of the terms in PPCHC would provide a common language and assist with policy and planning and analysis. In this commentary we adopt the following:

- Patient-centred care is generally applied at the level of the individual who is a service user and already within the healthcare system

- Person-centred healthcare refers to both non-patients and patients or groups who have health related needs in terms of being at risk, and require protective or preventative interventions as individuals or groups.

Person-centred healthcare sees the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health at the centre of care, rather than a set of conditions or diagnoses.[18]

It is guided by the ethical principle of respect for the autonomy, dignity and responsibility of each person. It considers the person (and their family) as the expert on their own context and situation. Accordingly, healthcare is organised on the basis of *need* rather than around disease-specific service silos.

- People-centred refers to the population and macro level of health services organised around health needs and expectations of people rather than diseases; and includes analysis of outcomes, policy development, planning and funding. People-centred care consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health

systems that respond to their needs and preferences in humane and holistic ways. It also requires that people have the education and support they need to make decisions and participate in their own care.[18]

As a core value of a health system and whole philosophy of care, **PPCHC** requires a commitment to measurable goals to improve equity for populations (particularly for vulnerable populations such as older persons, people with disabilities, or multi-morbidity). It is built on measurement and continuous improvement of the experience of health service users, to benefit for the person, the community and the health services.

PPCHC considers health status, the person's experience, the environment and social determinants and personal factors. The whole person refers to the person, their health condition and his/her context.[18, 19] In this sense, some authors prefer person-centred ***health***care rather than person-centred care. 'Health' encompasses the whole system and the person's experience, not just the immediate care received (i.e. interventions). For the remainder of this commentary, we continue to use the term person- and people-centred healthcare.

In the literature there is also the term personalised medicine. Personalised medicine relates to the biomedical model of healthcare involving technologies tailored to every individual's genomic profile. Although recently expanded in precision medicine to the interactions of multiple genetically regulated processes for each person, it focuses on the body function, body structure and biological part of health only (refer to the glossary). As such, personalised medicine is not addressed in this paper.

Figure 1 shows the relationship between patient-, person- and people-centred healthcare at the levels of the system.

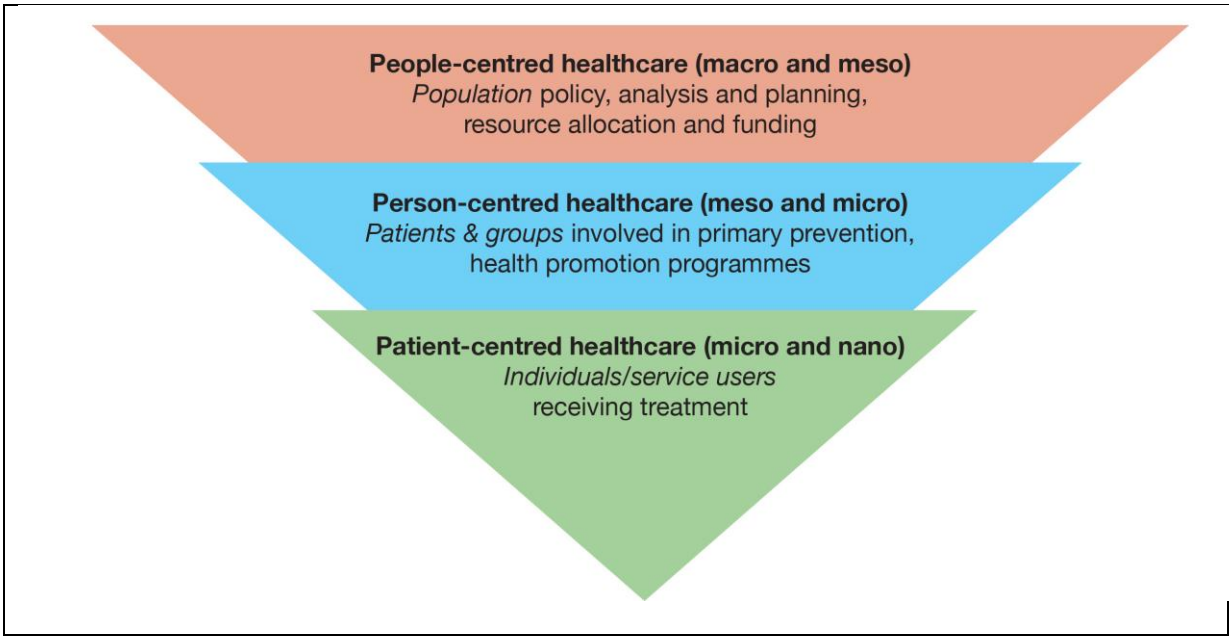

Figure 1: The relationship between people-, person- and patient-centred healthcare and system levels.

The development of the concepts of PPCHC

Response to Alma-Ata

The Alma-Ata Declaration in 1978 provided the conceptual ground for the development of the public health approach to person-centred healthcare (PCHC). Recent reviews by authors of this commentary detail the Alma-Ata Declaration and the history of the formal adoption of the primary healthcare model as the key means to provide comprehensive, equitable, and affordable healthcare services to all people in order to redress the existing inequalities in health within and among countries.

The international response to the Alma-Ata Declaration throughout the 1980s and 1990s was mixed for a number of sometimes contradictory historical reasons[20] including:

1. Adoption of a 'selective' primary healthcare approach
2. Financial and governance structures favouring centralised healthcare
3. Marketisation – a fashion for market, or quasi-market, forms of healthcare provision
4. Reinvigoration of a disease-focused approach triggered by epidemics such as HIV
5. Surge in medical technology and a consequent reductionist disease focus
6. Cost containment and managerialism translating into too much reduction of variability in clinical management (recognising that in some developing countries, there has been a reduction in variability and a matrix of care resulted in healthcare improvements).

These historical barriers to the broader adoption of PPCHC elements as envisaged in the Alma-Ata Declaration are expanded upon in Appendix 2.

Several other parallel developments in clinical practice that spanned the period before and after the Alma-Ata Declaration acted as enablers and barriers to person-centred care. The notable movements toward person-centredness were:

- The design of a humanistic approach to medical practice and in psychotherapy[7, 19, 21-23]
- The introduction of the concept of personhood and recovery to the psycho-social rehabilitation field and "The Need-adaptive Assessment and Treatment" approach developed[19]
- Development person-centred models in other areas of healthcare such as family practice with the patient-centred clinical method[24], and the total person approach in nursing[25] and the two-body practice in occupational therapy[26]
- The patients also responded to the disease-specific approaches by establishing a number of patient organisations to advocate for patient voices to be heard, involvement of patients in their own care, and equity in healthcare. Some of these organisations are Planetree and the Institute for patient- and family-centred care (formerly Picker Institute) (United States), Patient's Association (United Kingdom), International Alliance of Patients' Organizations Institute (International)[27-29]
- The publicity and attention of the harm done to patients also gave rise to the safety and quality movement in healthcare. Internationally, governments responded with the establishment of organisations such as the Australian Commission for Safety and Quality Health Care (ACSQHC) (Australia), the National Institute for Health and Care Excellence (NICE) (United Kingdom), Agency for Healthcare Research and Quality (AHRQ) (United States), Health Quality and Safety Commission

(HQSC) (New Zealand). These organisations have helped to establish systems such as informed consent, reporting standards.

One of the most notable barriers to the broad adoption of PPCHC in clinical practice has been the reductionist approaches found in evidence based medicine (EBM). While early in the evolution of EBM, patient preferences and choices were included, the current interpretation has resulted in a steady decline in the status and use of key components of PPCHC, such as expert-knowledge, observational data and patient's narratives, experiences, choices and aspirations. PPCHC has built a philosophy of care and recognises the need for changes to practice to empower the person through engagement in decisions, building a broad understanding of health beyond the disease and impairment, and requiring a rigorous systematic understanding of the context and forms of integration of care.

Recent perspectives of PPCHC

Three developments, partly as lessons learnt from the mixed reactions to the Alma-Ata Declaration and other barriers listed above, have been key markers of more recent developments in PPCHC:

1. There has been a growing international consensus on what constitutes PPCHC, as well as its benefits for whole populations
2. It has become increasingly clear that PPCHC requires a whole system perspective
3. The conceptualisation of a holistic approach to health has advanced substantially to include multiple components such as health status, experience of health, positive health, health and environmental determinants as contributory factors, and personal characteristics.

Following these developments, we can say at the present point in time that PPCHC embodies four key characteristics described below. While we recognise that all characteristics of PPCHC are not included here we have maintained a policy and research perspective rather than operational. Necessarily it does not provide detail of operational characteristics such as responsiveness or cultural sensitivity of providers.

Even though person-centredness can be applied to specific aspects of an individual treatment or an organisation of care delivery, the four features described here provide a framework for its conceptualisation and analysis. The first three characteristics (holism, empowerment and complexity) can be regarded as attributes of PPCHC, that is, they are essential or inherent properties of a PPCHC system. The fourth characteristic (integrated care) can be regarded as an extrinsic property. It is possible that PPCHC can occur without integrated care, and integrated care can also be implemented without PPCHC (refer to Question 4 and Table 2). The major core driver for the development of an integrated PPCHC approach within the healthcare system is considered to be the shared values.

Key characteristics

1. Holistic approach based on the biopsychosocial model

The first key characteristic is that PPHC follows a holistic perspective of health. The biomedical and social models are often presented as dichotomous, where the biomedical focuses on the disease, the diagnosis, impairments of the body, with the main concern being the medical treatment and professional help.[30, 31] In contrast, the social model does not define people by the disease or diagnosis, rather the social outcomes of the individual, social integration and participation, human rights and empowerment.[31-33] Neither the biomedical nor the social model considers how the biological, physical, psychological, social, environmental, contextual, personal and cultural factors *interact* with each other to influence health and wellbeing.

Over the past 30 years a biopsychosocial perspective of health has been codified in the WHO International Classification of Functioning, Disability and Health (ICF).[34] The ICF biopsychosocial model perceives health as a function of the complex and dynamic interaction between all the domains of health which are body impairments, limitations of activity, the restriction in social participation and the interaction of these domains with the environment and a person's context.[35] It depicts a complex concept of health where the domains are relational, interactive and interdependent. Context also refers to environmental factors such as personal supports and relationships (including attitudes of others), products and technology, health systems and services, policies and the physical environment. Personal factors (mentioned but not developed in the ICF) include social and demographic indicators such as gender, age, race, education and profession; and lifestyles, habits and other personal characteristics which influence individual functioning.[36, 37]

The ICF biopsychosocial model has been expanded to include sub-domains such as health-related quality of life[38-40], spirituality[41], the ability to adapt and self-manage challenges[42], bio-semiotics, referring to the person's ability to interpret and attach meaning to triggers in their environment[43], meaning in life[44], and cultural interpretations.[7, 45] These sub-domains have resulted in expanded biopsychosocial incorporating spiritual meaning, and cultural health, among others.

The International College of Person-centred Medicine (ICPCM) has produced a matrix of the key *health components* of PPCHC that follow from this holistic approach (health status, experiences of health and contributory factors). The matrix incorporates the positive aspects of health, including wellbeing and recovery, good functioning, satisfaction with life and positive experiences of wellbeing together with determinants or "contributors" to health.[19, 21] This conceptualisation captures core components of the broader person-centred healthcare concepts, including:

- Wellbeing and recovery/disease[46]
- Functioning /disability[47, 48]
- Personal experiences linked to both ill health (suffering, understanding and meaning of illness or satisfaction with the health services) and positive health (aspirations, life satisfaction[49]
- Personal determinants of health, including personal factors (demographic characteristics), lifestyle and general personality traits (e.g. extroversion, neuroticism, self-directedness, cooperativeness and self-transcendence)[50]
- Social determinants of health such as employment, education, violence and discrimination, food and transport and include cultural factors[33, 51], social structures or constructs such as attitudes of others (barriers and facilitators).[32, 52]

2. Empowerment of the person based on human rights

The second characteristic of PPCHC is the empowerment of the person based on human rights. Underpinning the holistic perspective of health are the principles of human rights.[2, 4, 7, 53, 54] Australia has ratified a number of Human Rights conventions that relate to health including the United Nations' Convention on the Rights of Persons with Disabilities, Rights of the Child and the Elimination of all forms of Discrimination Against Women. In the 1960s a strong movement from persons with disability and later people living with diabetes and AIDS gave voice to human rights, empowerment and equity models. The phrase 'nothing about us without us' was coined by disability activists in the 1990s[55] is now adopted by many other interest and populist movements to proactively promote involvement of patients in decisions about their treatment and care and the engagement of people in health systems.

In healthcare practice, communication plays a central role in the empowerment and engagement of the patient, their family and people. Respectful and empathic communication supports engagement of the person as a partner in their care. At the people and population level empowerment means there is communication with people and families, and they are involved in the challenges of safety, quality and goals for better outcomes through co-design and co-production of healthcare. Patient or people engagement will vary across the healthcare system and levels from the nano level, clinical setting/point of care through to the micro, meso and macro level with organisational design, governance and policy making.[56] There is emerging evidence of the impact of positive communications and empowering human interactions among providers[57]; between health provider and the person[58]; and engagement with the patient, family and people. Recent studies identify a positive relationship between communication and engagement with improvements in care coordination, goal setting, patient health outcomes, communication and outreach, a reduction in costs, improvements in safety and quality healthcare, enhanced leadership commitment and provider training.[59-62]

Recently Greenhalgh and colleagues described the major aspects in classical evidence-based medicine that may inadvertently move away from a person-centered approach and devalue the patient and carer agenda.[63] These are:

- Lack of patient input to the research process
- Low status given to experience ('anecdote') in the hierarchy of evidence
- Tendency of clinicians to conflate consulting a patient and use of decision-making tools with person-centred care, when it is only part of the communication
- Limited attention given to power imbalances that suppress the patient's voice
- Over-emphasis on the clinician-patient dyad (overlooking the ongoing work of self-management and the importance of the patient's wider social networks, both online and offline)
- Primary focus on people who seek and obtain care (rather than on the hidden denominator of those who do not seek or cannot access care).

The call for person-centred needs-based care, and the involvement of people in their own healthcare and decisions on services was reinforced in the WHO 'World Report on Disability' (2011). WHO recommends engaging in shared decision-making in matters that concern patients directly whether in health, education, rehabilitation or community living.[64] The recently published 'World Report on Ageing and Health' (2015) also reinforces the need to ensure person-centred, case management and integrated care across the health and social care sectors.[65]

3. Complexity and whole system perspective

The third characteristic at system level follows the paradigm shift embodied in systems thinking approaches and the recognition that change in healthcare requires a whole system perspective.[66, 67] There are examples of development of person-centred care in pockets of healthcare, some of whom are presented as case studies in the WHO's 'Global strategy on integrated people-centred health services 2016–2026.'[18] However, none of these demonstrate a substantive paradigm shift at the macro level. As each context is different, there can be no single model of PPCHC. Moreover, there can be a common framework with different implementation strategies or adaptations at the local level.

PPCHC has to be achieved in health systems that are complex adaptive systems, with multiple interdependent components and relationships between agents, which are non-linear and context dependent. System approaches to implementing PPCHC should occur at both the individual practice level (nano, micro) and organisational and whole system levels (meso and macro). At the nano or person level complexity arises from the interaction of the person's domains of health, and the context of the environmental and personal factors of the person's own context. At the micro, meso and macro system level complexity arises from the relationships between various components of the healthcare system.

PPCHC can only develop with concurrent change from the bottom up (e.g. individuals' understanding of their health) and top-down system levels (e.g. reallocating resources to enable providers to deliver needs-based care). The key learning is that substantive change towards PPCHC will require whole systems and complex adaptive systems thinking to be fit for purpose in the Australian context.

4. Integrated care and universal access

The third key characteristic of integrated care and universal access emerged in the 1960s from the recognition of the connection between integrated and coordinated care and better outcomes. Developments in mental health led the way. The de-institutionalisation of large numbers of people with severe mental health conditions and/ or intellectual disabilities[68, 69] posed new questions around the organisation of care. As the alternative solution to out-of-hospital care, day care and home support services emerged as well as new integrated care programs (e.g. Assertive Community Treatment) and new health-related interventions such as case management. Case management involved the assessment, planning, coordination and referral of people with mental health conditions living in the community to outpatient mental health and other mainstream community services. However, the person was still seen as a passive (and disempowered) recipient of case management rather than an active partner.[70, 71]

Integrated and coordinated care is now known to contribute to improved health outcomes and benefits for both the person and health system.[4] The meaning of integration has developed beyond coordination and collaboration between services (vertical integration with primary, secondary and tertiary healthcare) to recognising and conceptualising inclusion, participation and community care, the need to engage the person, assessing personal factors such as quality of life and planning for solutions.[7] It is recognised that integrated care needs to be accompanied by choice, shared decision-making and community participation.[69, 70, 72]

PPCHC also emphasises horizontal integration of healthcare and inter-sector collaboration across multiple sectors of society through coordinated planning and community-based delivery of services. Primary and community-based care are necessarily critical components for the integration and accessibility of healthcare. The many sectors relevant to the inter-sector collaboration with health include education, social care, employment, housing, transportation, justice, finance, and ecological management.[2]

In 2013 Valentijn and colleagues developed the Rainbow framework of integrated primary care.[73, 74] The Rainbow model identifies six domains of integrated care [clinical, professional, organisational, system, functional (technical) and normative (the cultural and context)] and two guiding principles (person-focused and population-focused) across the micro, meso and macro levels in a system. It articulates the horizontal and vertical integration of care across sectors. People-focused population-based care, such as preventive health programs, lie on the horizontal axis; whereas individual case management, which focuses on individuals and their immediate contexts, lies along the vertical axis.

WHO has accepted that 'People-centred and integrated health services' provide an essential basis for building equity and universal health coverage; and improving the health status and wellbeing of

populations, with due respect for local contexts [4], and specific attention to the social determinants of health.[14, 75] Universal access is a corollary of PPCHC and particularly relevant for vulnerable and at-risk populations.[75] Financial incentives and service reimbursement structures should enable universal access to care, and promote rather than inhibit organisations working together around the needs of the person.[17, 76-78]

The current conceptualisation of PPCHC

We have developed 'An Expanded Model of a PPCHC system' (refer to Figure 2) recognising that a system of PPCHC should be people-centred and integrated. Figure 2 draws on the perspectives of health, and models of care that inform the current conceptualisation of PPCHC.[18, 21, 34, 79] Integration and systems are depicted in the upper segment, the holistic biopsychosocial perspective and key components of health and the health cycle are in the lower segment.

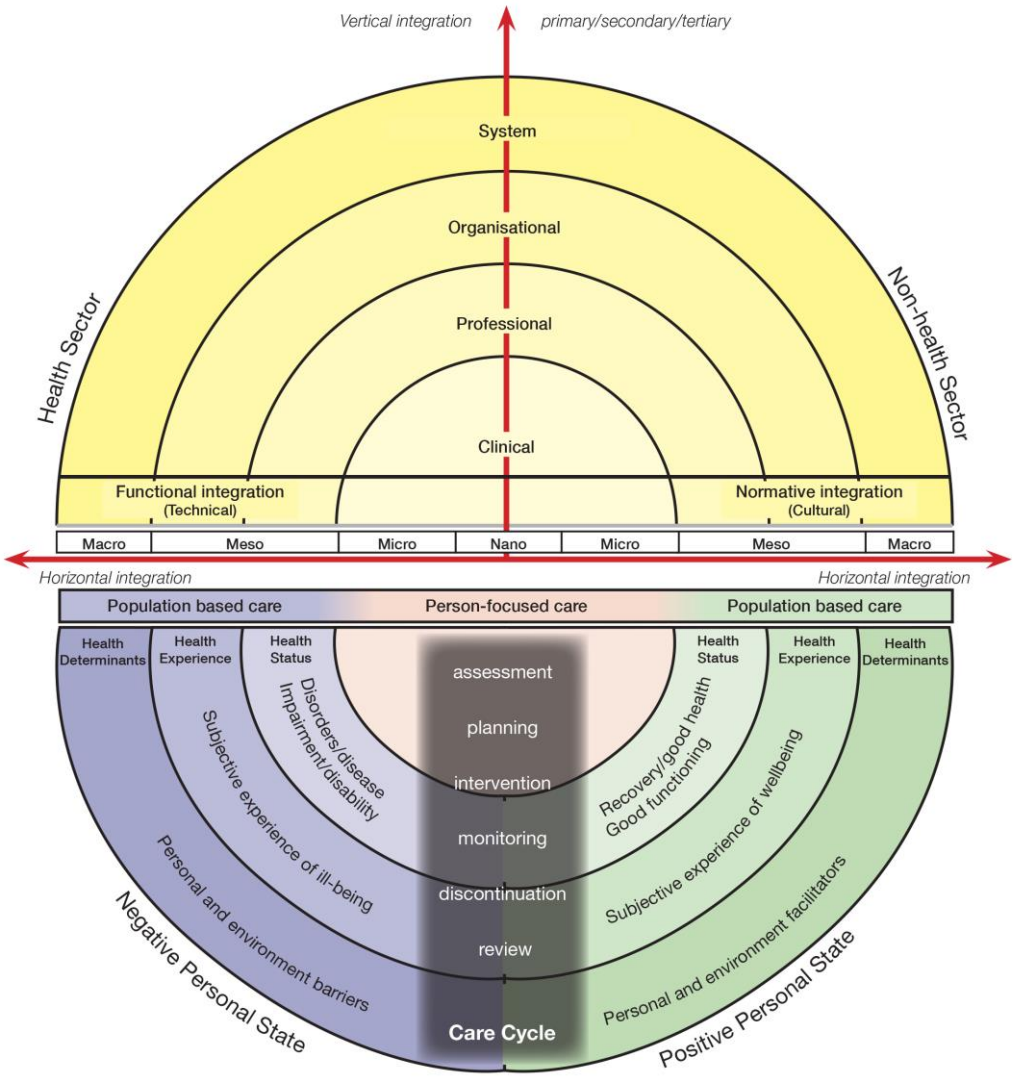

Figure 2: Expanded model of person and people centred integrated health care

Figure 2: Expanded model of person- and people-centred integrated healthcare system.

4 Section 2

What are the key characteristics of approaches to implement and advance PPCHC?

Key points

- Co-production of care, shared knowledge and decision-making is the cornerstone for enabling person- and people-centred healthcare (PPCHC) – where the person has knowledge of their own context, environment and health system. Expressions of shared knowledge and decision-making that contribute to this key facilitator for PPCHC include:
    - A sentinel approach to life-long healthcare
    - The expert patient, self-management and peer support
    - Locally relevant person-centred primary and community care
    - Investment in information communications technology development
- The promotion of shared core values in the health system including vision and mission of PPCHC that embody the characteristics of PPCHC will enable system change and break down barriers. Broader health system strategies that might contribute include:
    - Long-term commitment to shared values
    - Inter-sector interaction, collaboration and partnerships
    - Promoting the use of broader sources of knowledge
    - New methods of analysis, performance monitoring and measurement for accessibility, transparency and meaning to users
    - Healthcare workforce and education.

The organisation of the healthcare system in Australia shows specific characteristics that make it difficult to implement PPCHC. Some of these barriers include: a) fragmentation of the care system at many levels, b) unbalanced care systems with a bias towards hospital-based care, c) specific financing disincentives, d) lack of both community care services and supports; and a population-based approach to care) and lack of accountability, f) the dominant influence of the disease-focused, reductionist approaches on health and medical research clinical practice.

In this section we outline the key 'bottom-up' and 'top-down' facilitators and enablers to advance change towards PPCHC, and remove barriers. The facilitators are divided into two sections for convenience, although many are cross-cutting. The two sections are: (1) shared knowledge and decision-making; and (2) promotion of PPCHC values in the health system.

Co-production of care, shared knowledge and decision-making

Co-production, shared knowledge and decision-making form the cornerstone of facilitating PPCHC. Co-production of healthcare refers to care that is delivered in an equal and reciprocal relationship between professionals and the patient/person, their families and the communities to which they belong (people and

population). Co-production includes partnerships with patients, providers and the community and system to co-design changes to improve the safety, quality and outcomes of health services at the people and population level. Co-production and co-design implies a long-term and meaningful relationship between the person, people, providers and health systems where information, decision-making and service delivery become shared.[18] Shared knowledge and decision-making involves meaningfully engaging the person, and where relevant their family (family-centred) in making decisions concerning their health and care.[80-84] The evidence of the benefits of co-production and shared decision-making is strong and is associated with more appropriate care, better match with patient needs and preferences, a reduction in misdiagnosis, and greater satisfaction and independence.[13, 18, 80]

PPCHC not only demands a shift in thinking about health to a biopsychosocial perspective of health, but also a corresponding shift in the concept of knowledge and sharing of knowledge. Health systems that are disease-focused and arranged around specific diseases, typically adopt a biomedical focus on healthcare that sees patients as passive recipients of health services. In contrast, PPCHC empowers and engages individuals and families by recognising the value of their knowledge as the experts of their own context and the dynamic interaction of these factors in their health outcomes. PPCHC depends on the person having the education and support they need to make decisions and to participate in their own care. This requires a paradigm shift for proactive sharing of knowledge and decisions between the patient and the health professional. As an example, Table 1 shows the consequences of asymmetry of knowledge in the doctor/patient relationship with various healthcare approaches.

Table 1: Matrix of the doctor/patient relationship (adapted from Scambler [85], Habermas [86])

The lower right cell shows how PPCHC should operate with bilateral exchange of knowledge, information and decision-making. An example of what this looks like in practice is provided in Appendix 3 in the planning phase of the healthcare cycle.

Patient	**Health professional**	
Control	Low	High
Low	**External control** *Model* - Managerialism *Relationship*- Deficient *Dynamic*- Neither service user nor health provider has control	**Professional control** *Model* – Authoritarian (Biomedical) *Relationship* – Paternalistic *Dynamic* – Service provider has control
High	**Inverse control** *Model* – Consumeristic *Relationship* – Demand driven (VIP syndrome')[87, 88] *Dynamic* – Service user demands control and makes decisions irrespective of health professional recommendations	**Shared control** *Model* – Person-centred healthcare *Relationship* – Shared decision-making *Dynamic* – Knowledge is shared and decisions made together. The service user has knowledge by experience of their own context (expert experience knowledge) Health professional has expert practice knowledge

We identified four expressions of shared knowledge and decision-making that contribute to this key facilitator for PPCHC.

1. A sentinel approach to a lifelong healthcare cycle

Integrated PPCHC also means that care is provided by the community and in the person's community for their *entire life* and *healthcare cycle*. This lifelong healthcare cycle perspective involves a sentinel approach. For example, a sentinel lifelong approach to attempted suicide would see acute treatment of the effects of attempted suicide as the beginning, not the end point of healthcare. A healthcare cycle involves non-

patients as well as patients, so the person remains engaged in the system of care (health and other sectors) beyond the acute healthcare.

The healthcare cycle involves:

- For the non-patient or person not currently involved in healthcare
    1. Maintaining health
    2. Awareness of vulnerability to a health condition e.g. self-examination for breast cancer
- For the patient involved in healthcare
    3. Initial contact
    4. Diagnosis
    5. Planning and management
    6. Interventions
    7. Monitoring
    8. Discontinuation
    9. Review.

2. The expert patient, self-management and peer support programs

Parallel to shared decision-making and empowerment of individuals and families comes the need to engage people in their own healthcare, to promote choice, living healthy and fulfilling lives, education for self-management. Patient organisations call for greater patient responsibility and advocate for greater involvement of patients in their own care and which will lead to improved quality of life, community- and system-benefits such as cost-effectiveness.[27, 29] This is particularly relevant for people with complex or long-term healthcare needs, including those with chronic conditions, multi-morbidity, those living in disadvantaged communities and older populations. A focus on supporting, educating and enabling people to be partners and involved in the co-production of their own care, should be from a lifelong perspective.[5]

Strategies for patient education, support and empowerment include peer support programs. Evaluation of the effectiveness of peer support programs suggests that there are consistent educational (information), emotional and instrumental benefit.[89-91] There are numerous examples of peer support programs that are a key or complementary healthcare service. A range of examples for different health include: in Australia, the Peers Inspiring Peers for brain injury[92] and CHOICE, the youth mental health services[93]; in Canada the peer support with breastfeeding[90]: diabetes self-management[91] and in the Australia, the Chronic Illness Alliance which aims to build capacity of health based organisations to offer peer support programs to their clients and members.[94]

3. Locally relevant person-centred primary and community care

Primary and community care are key components for universal and accessible care. *Person-centred* primary care is comprehensive care that integrates and coordinates care for all health problems and engages individuals, families and the community.[1, 95] For the person, primary care involves horizontal and vertical integration of lifelong care[73] in their community. Acute services and secondary care need to be closely linked with the system of primary and community care with integration between them. Person-centred primary care has been shown to be the best solution to the major health challenges of case finding, managing and preventing infectious chronic diseases, and is seen to be essential for tackling non-communicable diseases.[95, 96] This change requires a shift from inpatient- and outpatient-based care to person-centred primary care strategies inclusive of ambulatory care[18, 95], such as telehealth/eHealth, health promotion and ill-health prevention strategies. Pivotal to this concept is a single point of care access

(including but not limited to the general practitioner as the point of access), empowerment of patients, reduction of barriers to healthy lifestyles and care that reflects the values of the individual.

Implementing person-centred integrated care means being flexible in different contexts and evaluating impact.[4, 7, 18, 78] Since 2013 there have been international and national efforts to develop a body of knowledge on best practices and frameworks or roadmaps to strengthen health systems towards PPCHC.[5, 97),(98)] The WHO has recently launched an online knowledge platform that aims to consolidate the lessons learnt and best practices on integrated people-centred healthcare, and provide platforms for sharing information on successful models of service delivery.[6] Critical components in the design of context-specific strategies of person-centred care include; knowledge from mapping service availability and workforce capacity; an understanding of the local and country contextual barriers and facilitators and finance analysis.

There are several successful examples of locally adopted approaches to PPCHC. In Cuba, a top down development involves multispecialty community-based polyclinics, plus family doctor and nurse programs that operate countrywide. Approximately 80% of patient health problems and health promotion are managed by the local clinics.[99, 100] In Canada, the BETTER study developed prevention practitioner roles with existing team members in primary care settings. The study demonstrated that comprehensive assessment and planning for treatment was cost effective and enhanced equity for vulnerable populations, specifically on the modifiable risk factors for patients with chronic diseases.[101] In Scotland, a mixed top down and bottom up process has been adopted to develop a patient-focused system.[102]

Knowledge of local priorities and care needs, what and where services exist, along with the gaps in services are key drivers to: planning for and providing services and supports; developing wider networks of providers and inter-sector collaborations. In Spain and other countries in Europe, mapping to create an atlas of services for evidence-informed policy has been successfully done[103, 104] and the process is currently underway in some health districts in mental health in NSW and Queensland.[105] Mapping of other relevant sectors of community-based services is needed for integrated community-based care such as social sector (housing, employment, community programs) and education, to enable population-based health sector planning and inter-sectoral collaborations and partnerships.

4. Investment in information communications technology (ICT) development

At the macro level, investment in information communication technology is critical to support PPCHC. As an example, a trial of the personally controlled eHealth record system commenced in Australia in 2012. The system enables sharing of health information across service providers to promote better care (i.e. provide basic information without the patient having to repeat this to each individual provider, or minimise duplication of tests). The pace of implementation has been slow, at least partly due to a trade off in empowerment, with an 'opt in' versus an 'opt out' system. Now called the My Health Record initiative there have been only 2.5 million registrations out of a population of almost 24 million.[106] Commitment to ICT investment on research and tool development is required for sustainable and up-scaled use of appropriate ICT strategies.

With adequate and sustained investment, ICT can support health service delivery and shared knowledge and decision-making at the meso and micro system levels. The main lines of development in telecare and telemedicine are:

- eHealth – incorporates all types of ICT healthcare solutions relevant to the full life cycle (e.g chronic health conditions)
- Telemedicine – offers support for health practitioners and patients
- Telemonitoring – monitoring vital signs, and video conferencing from home.

Telecare is being used for health promotion, prevention and direct healthcare as well as hybrid models involving ICT and face-to-face healthcare.[107] It is also being used to support healthcare pathways and the coordination of services for older persons who have complex needs through deploying information and communication for coordination of care, self-management, unified health and social sector approaches and better use of resources.[108] ICT for some healthcare is seen as effective in supporting and empowering the person to self-manage care, increase health literacy agnd self-assessment.[109] ICT is particularly relevant for some patient populations in remote or rural communities as well as providing support and guidance to isolated or remote health practitioners.[110-112]

Promotion of PPCHC values in the health system

We have identified five strategies for promoting the shared values in the health system at different levels of organisations, regions, states and government.

1. Long-term commitment to a shared value

Moving towards PPCHC demands a long-term commitment from all stakeholders. International lessons show that the tendency to centralise administration and funding of integrated care approaches or to create specific pilot or demonstration projects does not necessarily result in sustainable PPCHC change.[5] There needs to be long-term commitment and value placed on PPCHC that is mandated from the top down as well as built from the bottom up. The evidence suggests that piecemeal, pilots and ad hoc approaches have not had a significant impact on enabling change at the scale and pace required to meet future needs.[4, 7, 18, 76, 78] It requires sustained political will and leadership with a top down framework of policy direction, governance structures and incentives that permit 'local action'; creating an enabling environment for bottom up innovation to occur. For example, a recent proposal to develop an Australian person-centred medical home in general practice pointed to a lack of vital information on the business models and structures of general practices.[17]

2. Inter-sector interaction, collaboration and partnerships

Collaborative partnerships are essential to PPCHC for coordination of services between sectors such as health, social, education, employment and others. The health system needs to value inter-sectoral collaboration and partnerships, rather than see them as counter-productive or competing. An Australian Government report describes cross-sector interaction, collaboration and partnerships in the statement:

> *"An ideal, person-centred mental health system would feature more clearly defined pathways between health and mental health. It would recognise the importance of non-health supports such as housing, justice, employment and education, and emphasise cost-effective, community-based care*".[113] p.7

A recent study of integrated care programs in primary care identified factors that enhanced collaboration and integration from policy makers, managers and health professionals' perspectives. Consistent with

previous research, the study confirmed the need for a multilayer commitment from professionals, organisations and system actors to achieve integrated and coordinated care.[74] Professional integration across primary, secondary and tertiary care does not always result in coordinated services. A collaboration based on trust between health sectors with operational or technical (functional) controls is critical, and a common language to understand the respective roles and responsibilities of each should be agreed on.

A challenge in healthcare service management is the level of collaboration, partnering and coalition at all levels of healthcare between state/territory and federally funded services. This is particularly true at the meso and macro levels. A key driver towards a common goal such as PPCHC is bridging. Bridging refers to the 'building partnerships and coalitions between groups or organisations'.[114] If managers could not only administer but also assume a bridging role, they would support the creation of collaborative networks by enhancing and ensuring the flow of information between people and groups. This would facilitate the sharing of ideas of best practice, discover what works, and have examples on how to improve systems and structures. Bridging proactively brings different groups of people and organisations together.

> *"Bridges, brokers and boundary spanners facilitate transactions and the flow of information between people or groups separated or hindered by some gap or barriers. This may be a physical gap such as geographic location, cognitive or cultural gap such as differing disciplines or professions or alternatively, the gap may be that members of one party have no basis on which to trust the other"*[115] p.1

3. New methods of analysis, performance monitoring and measurement for accessibility, transparency and meaning to users

The comparison and measurement of person-centred and integrated care across jurisdictions is a major challenge for health systems research.[116] PPCHC requires new methodological approaches to develop a practical knowledge-base that could be used in implementation and decision-making at multiple levels and by the different agents: the principal (user) and the key stakeholders (clinician, manager, planner). This requires hybrid study designs including pragmatic trials, big data observational studies, cross-design synthesis approaches; combined with collaborative procedures (cooperative analysis between different sector experts such as clinicians and data analysts – Cooperative Analysis) and new tools of analysis usable under conditions of uncertainty (such as Knowledge Discovery from Data which involves extraction of patterns and knowledge from large amounts of data). Design thinking approaches may play a key role in the development of new research in PPCHC.[117]

One of the strongest drivers for health service development is how performance is measured, which directly relates to the values and model of the healthcare.[76] Health services performance is typically measured by process and operational indicators, clinical pathways, effectiveness and cost-effectiveness measures.[118] In contrast PPCHC incorporates other measures such as the patient's health service experience and satisfaction, safety, patient's met and unmet needs, their progress towards person related goals and their perceptions of their quality of life and wellbeing and other patient-reported outcomes.[83]

One of the attributes of the monitoring system should also be access to shared care records so that health providers can improve and respond to people's experiences and outcomes. While these types of measures are increasingly being used, with some indications that the patient reported outcomes are drivers for changes to service delivery[15, 119], there remains a gap between the use of information to change or guide practice.

It is important to use and analyse data to improve its transparency, accountability and accessibility for the potential users. Furthermore, that data capture and analysis includes the ability to disaggregate data by key

groups (e.g. socio-economic, ethnicity, disability, age, gender) to have the capacity to monitor equity and outcomes in line with the values and principles expressed in the United Nations Fundamental Principles of Official Statistics.[120]

4. Promoting a holistic perspective of health and use of broader sources of knowledge

Paradoxically, a major conceptual barrier to reorienting the model of care is the EBM approach to the analysis of scientific knowledge.[121, 122] Traditional randomised controlled trials and meta-analysis of such trials in systematic reviews has limited applicability in the assessment of complex collaborative person-centred care. Evidence on health interventions is translated into clinical guidelines, which in turn guides clinical practice. Increasingly the health workforce is made accountable for practice according to protocols and guidelines. While this has many benefits to the consistency of practice, at present guidelines generally only use clinical research as the main source of knowledge (arising from the EBM approach). The paucity of a PPCHC approach in the development of clinical guidelines means there is a contradictory pull for clinicians to be less flexible and responsive to patient preferences and needs.

There have been calls to adopt a more person-centred approach in clinical guidelines.[123] Some of the changes needed include methods which appraise and use different sources of knowledge beyond clinical trials [124], embrace the person's context and biopsychosocial perspective of health[63, 125], use of patient-reported outcome measures and incorporate shared decision-making. [123, 126] PPCHC oriented guidelines need to consider the individual's risks, preferences and values in the assessment and planning for patients with complex health conditions (e.g. BETTER guidelines in Canada).[127, 128] While there is a stronger focus on including PPCHC principles in clinical guidelines, there is a significant way to go for the majority of guidelines to be enablers of PPCHC rather than a barrier.

5. Health workforce and education

One of the system's challenges in the shift to PPCHC will be a sufficient primary, secondary and tertiary care health professional workforce with the education and knowledge of PPCHC. The lack of training and a consistent approach to health professional education on PPCHC at all levels of education (pre-, postgraduate and lifelong training) is a key barrier to developing a suitable workforce.[15] While health professional education has attempted to keep pace with changes in healthcare, there have been significant challenges.[13, 129, 130] Education is recognised as a major barrier in the Zagreb Declaration on Person-centre Health Professional Education and recommendations.[131] An international commission developed a shared vision and a common strategy for post-secondary education in medicine, nursing and public health which adopted a multi-professional perspective and a systems approach.[132] Targeted training on person-centred health strategies in primary care, including medical specialists such as paediatricians, or nurses practising in community or hospital outpatient settings have been effective in demonstrating change towards PPCHC.[13, 101] However, as recently shown, personal characteristics play a key role in developing a PPCHC approach and the engagement and community support in rural healthcare in Australia.[133]

In particular, a focus and strategies to enhance the primary and community health practitioner workforce and sustainability can be a facilitator of PPHC as these sectors are essential to the accessibility of healthcare. In Australia there is a lack of primary care health professionals in many regional, rural and remote areas of Australia.[134] Internationally there is a need to have more health professional graduates trained in primary care than currently occurs[95, 135] to meet the needs in a person-centred primary- and community-care model.

5 Section 3

Over time, has the experience of healthcare become more person-centred? If so, in what ways and to what extent?

Premise

That the historical journey of person-centred care achievements, known problems, and known drivers (Q1, Q2, Q3) can be tested by evidence from the consumer perspective on relevant measures.

Interpretation for expert commentary

Examine how consumer experiences of person- and people-centred healthcare can be tested by relevant measures. Key points:

- The experience of healthcare as reported by consumers has significantly increased in the last decade. However, internationally, formal methods of identification and measurement of person- and people-centred healthcare (PPCHC) have lagged behind advocacy and analysis.
- Measuring whether the experience of healthcare is person-centred and the progress towards principles of person-centred over time is complex. The problems in measurement arise from the interaction among and between the system components and the PPCHC characteristics. As PPCHC is context specific and change occurs at each system level, measuring the experience of PPCHC must occur at the nano, micro, meso, macro system levels to develop a deep understanding of the variations and progress towards PPCHC within the whole system
- While there has been progress in some areas of measurement, particularly at the nano and micro level, more work needs to be done to accurately measure healthcare experience at the macro and meso levels. Typically, current standard measures of outcomes in health systems focus on, and provide information about the service and experience of healthcare, but do not usually measure the person's perception of their own health and the outcomes (health experience) nor health determinants. For this reason, while standard measures are progressing in the right direction, they are not seen as adequate measures of the PPCHC characteristics
- There are examples of measures that have been used to examine PPCHC, at nano, micro, meso and macros system levels. Measures at the nano to meso levels include those examining assessment, planning, intervention and monitoring, discontinuation and review. PPCHC measures at the meso and macro system level examine person and people feedback loops, models and pathways, policy and funding systems and integration cross-sector care
- Generally, the literature provides insufficient detail or the scope of measures used, and considering the differences in terminology and levels of measures (patient, person and people; system levels). A detailed scoping study would better establish the range of measures at each level of the system, and may attempt to identify the components of PPCHC that are/are not measured

- To advance a comprehensive PPCHC, there needs to be multiple measures which potentially focus on the components of PPCHC including: the six domains of integrated care (clinical, professional, organisational, system, functional and normative integration), all system levels, person and population focuses perspectives of their own care and broader health in a holistic sense.

Internationally, formal methods of identification and measurement of PPCHC have lagged behind advocacy and analysis.[4, 5, 7] Typically, current standard measures of patient experience in health systems focus on, and provide information about the service, and to a limited extent the health status of the person (at the biological level). They do not usually include measures of neither the person's health experience nor health determinants (biopsychosocial, empowerment). For this reason, standard measures are not seen as adequate measures of the PPCHC characteristics (holism, empowerment, complexity and integration).

There are many reported examples in the literature of system (of sub-system) change resulting in care becoming more person-centred, with the use of at least some standardised measure.

We have provided a table of 35 examples of these measures at the nano, micro, macro and meso level of care and across the healthcare cycle in Appendix 4. It does not represent a comprehensive list.

In this section we provide a summary of the examples of measures at the different systems levels (nano, micro, meso, macro). A systematic analysis of the rigour and implementation of these different measures is beyond the scope of this commentary. Generally, however, we have found that the literature provides insufficient detail of measures used to assess the person and people-centredness (e.g. whether the patient survey had questions related to the person and population perspectives of the health experience, participation or health cycle).

Reviews that have considered measures of patient experience at an organisational level[136] and perceptions of patient-centred care in family medicine[129] have highlighted the limitations. A detailed scoping study would better establish the range of measures at the people, person and patient-centred healthcare and system levels, and may attempt to identify the components of PPCHC that are/are not measured.

PPCHC measures developed that are integrated into the healthcare cycle at the nano to meso levels of the system

Assessment and planning:

- Diagnostic schema and tools that purposively include personalised statements or personal narratives from the patient or their representative, plus contextual information about the person's environment and which are incorporated as diagnostic and assessment criteria. There are also examples of self-assessment measures to support self-management and guidance on seeking healthcare [19, 137]. The use of these measures reflects holism, empowerment at the nano and micro levels of the system
- Planning tools for individualised goal setting and care planning in particular for persons with chronic or long-term health conditions, or preferences for healthcare. These tools support the development of a profile and thereby enable care to be contextualised to the person's needs, values and preferences [81, 82]. *The use of these measures reflects the characteristics of holism, empowerment and integration at the nano, micro and in some circumstances the meso levels of the system.*

Intervention and monitoring, discontinuation and review:

- Patient reported outcome measures (PROM) such as surveys, rating scales and self-assessment are measures used at either the intervention and monitoring, discontinuation or review stages of the health cycle. For example, a person's self-rating of wellbeing can reflect a holistic and empowering approach biopsychosocial perspective of health.[138, 139] Wellbeing self-assessment results can provide information at the nano level or can be aggregated to provide information at the micro, meso or macro systems level about what is happening with patients generally. However, it is also sometimes used as a proxy for meso or macro system level measurements
- The limitations of self-reported subjective wellbeing surveys and scales should be considered, in particular with regard to: whether the measure is sensitive the type of change typically achievable through social policy interventions; sensitivity to identify the extent and existence of inequity; and the limitations of making interpersonal comparisons of wellbeing.[140] The latter is particularly relevant for vulnerable populations, and for persons in adverse situations who tend to come to terms with their deprivation because of the need to adjust to their chronic circumstances or the necessity for survival (e.g. persons with a long-term health condition, disability or impairment).[141] *If person-centred in their design and language, PROMs reflect empowerment and holism but often they may be defacto service assessment.*
- Measures such as patient choice of providers, clinician's approaches to shared decision-making for care, self-management eHealth tools and direct funding for care which is controlled and management by the patient (enables choice and control) are provided.[93, 142] *These measures reflect holism, empowerment, to an extent integration at the micro and sometimes the meso level, but generally do not measure complexity.*

PPCHC measures at the meso and macro system level

- Multi-level and multi-method person and people feedback loops to identify issues and drive change have been developed at the macro and meso system level which include methods such as population and individual surveys, focus groups and discussions at patient and stakeholder driven conferences[154,155]

- Models and pathways for chronic diseases have been developed at the clinical (micro), professional and organisational (meso) levels that integrate and continuously embed new knowledge arising from the person's progress (based on patient information – at the individual or aggregated organisational level) into the treatment and systems framework [102]
- Specific policy and funding systems have been developed for funding on the basis of individual assessment of need [(113)] (e.g. Australia with the NDIS, Canada and UK detailed in Appendix 4).
- ICT is being used to as a measure of integrating inter-sector care[(98, 108)]
- Policy and guidance structures which specifically target managers at the micro through to macro level are starting to emerge, although more work needs to be done[(98)]
- There has been recent work on the development of macro and system-wide indicators for specific components of PPCHC, as well as provider performance measures of PPCHC[(143)]

These measures come from an empowering paradigm but also reflect the PPCHC components of integration and contextual complexity.

The examples of measures, show that there has been progress in measuring the experience and outcomes of PPCHC. However, as conceptualised in the model of 'Expanded model of person and people centred integrated care system' in Figure 2 the components which influence PPCHC mean that there is no single or simple way to measure the person's or people's experience of PPCHC. There has been progress and increased use of measures at the nano, micro and meso levels. There have also been some macro level measures identified, but these have yet to be substantively used and evaluated for effectiveness from the perspective of PPCHC. Indeed, our conclusions are affirmed in the December 2015 background document to the WHO Executive Board (provided to us by the expert panel reviewer Dr Montenegro from WHO) the Framework on integrated, people-centred health service.[(8)]

A comprehensive PPCHC system involves multiple measures which potentially focuses on the components of PPCHC including:

- The six domains of integrated care (clinical, professional, organisational, system, functional and normative integration)
- The four main levels of a system: nano, micro, meso and macro levels
- Person- and population-focused perspectives of the experiences of the healthcare cycle and engagement in their own care
- Person- and population-focused perspectives of the health status, experience, environmental and personal determinants and participation.

6 Section 4

Drawing on contexts comparative with the Australian healthcare system, which approaches to person-centred care have shown the strongest positive impact on consumer's experience of care?

Premise

That evidence for desired outcome exists, with key learnings for Australia from international effort.

Interpretation for expert commentary

Identify key strategies likely to have the most impact for change towards person-centred healthcare that should be considered for the Australian context.

Key points

- Numerous examples of change at different system levels towards a person- and people-centred healthcare (PPCHC) model have been implemented in healthcare systems comparable to Australia
- Not all attempts at system change necessarily embody the key characteristics of PPCHC: holism, empowerment, integration and complexity
- Facilitators identified in the provided examples include:
    - Engagement with the person and people, shared management and decisions around healthcare services
    - Strong government and clinical leadership and cross-sector collaborations
    - The integrated information systems and care pathways
    - Inter-sector collaborations
    - Focus on patient empowerment.

The context dependency of documented approaches, as well as the diversity of approach, and the cautions that must be taken in evaluating outcomes from complex, multifaceted change programs makes it difficult to draw conclusions on the strongest/weakest approaches to achieve PPCHC. However, what is evident from examples found in the literature is a lack of broad, whole of system approaches. A comprehensive road map to move towards PPCHC needs to come from complex adaptive systems perspective, with clear knowledge and understanding of local context and involves bottom up and top down strategies and shared values.

There are numerous examples in Australia and internationally of change occurring towards a more PPCHC model. In this section we have selected a cross-section of PPCHC system examples which reflect a range of different countries and that are inclusive of different components as outlined in the Expanded Model of

PPCHC (Figure 2). We have selected examples that are comparative to the Australian healthcare system. The examples were chosen to highlight different aspects at meso and macro levels.

Meso level programs include an indigenous and people-owned primary care example in one catchment area (Alaska, US) and the Geriant model (Noord-Holland, Netherlands). Macro-level programs at state-regional level include the chronic condition and integrated care in Catalonia, Spain and a treatment, rehabilitation and care program for persons who have sustained severe injury in NSW, Australia. The national-level programs include the care provision system for persons with a disability in Australia (National Disability Insurance Agency – NDIA), and a 'Must do with Me' - patient-focused health policy (Scotland).

After a brief description of the PPCHC system example, we then use a systems thinking approach to analyse the presence or absence of the key characteristics referred to in Section 1. The results of this analysis are in Table 2 below. We have undertaken the analysis based on the available information and within the limits of that information.

Meso level programs for PPCHC

Example 1 Indigenous health: Nuka System of Care – Alaska, US

The health service is a meso level health system. The Nuka system of healthcare was started in 1999 following legislative changes to empower Alaskan Indigenous people to take greater control over their health services. The change involved a move from centralised control in Washington D.C. to the local community. The health service, the Southcentral Foundation is a non-profit healthcare organisation that serves a population of approximately 60,000 with an operating budget of $210 million USD.[144, 145] The legislation transferred ownership to the community, which gained a direct role in designing and implementing services. The Nuka System involves the entire healthcare system, including primary, secondary and tertiary care, with a model that has key elements of the patient-centred medical home. Multidisciplinary teams provide integrated health and care services through primary care centres and the community in this health district. Traditional Indigenous Alaskan healing is offered alongside other health services including dental, mother and child programs and elder programs. The care also involves coordination with a range of other services. The health system also drives awareness, prevention and support initiatives such as domestic violence programs, abuse and neglect, smoking weight and nutrition, cancer prevention/support across the population through education, training and community engagement. The community is engaged in the management structure through local advisory groups, use of surveys, focus groups and telephone hotlines to facilitate feedback. The service's mission statement and operational principles emphasise the importance of relationships, working with people (rather than doing to or for), locations and access, outcomes, service financial stability and population-based systems and services. The stated core concepts reinforce person-centredness (e.g. listen, engage, share, dignity, work together etc.). There are annual health summits and conferences for the community.[145, 146] The service has systems in place to respond and act on the feedback. The health service continues to develop collaborations with other local, regional and national partners as gaps in services are identified. The change in outcomes are reported to be improved access to primary care services, improved performance of health services, high customer satisfaction, and 36% reduction in hospital days, 42% reduction in urgent and emergency care services and 58% reduction in visits to specialist's clinics.[144, 145]

Example 2 Geriant for persons with dementia – Noord-Holland province Netherlands

This disease-specific program, developed through a collaboration of nursing homes and public mental health care organisations in the region, commenced in 2000. At the meso level the model involves providing 24/7 community-based health and support service for people with dementia. There is a multi-disciplinary

team of health professionals. A core feature of the model is at the nano and micro level with a case manager who act as the focal point for the client and their informal caregivers, co-ordinating serves from the team and from other network partners including general practitioners, hospitals, home care and welfare organisation. The service users have access to a short stay clinic if more intensive treatment or observation is required. The client's situation is mapped on care dimensions including informal care, client's broader network and home environment. The planning for supports involves the case manager, client and informal caregiver jointly identifying the important challenges, objectives and integrating these into the client's care plan.[147, 148]

Macro level programs for PPCHC

Example 3 Chronic and integrated care in a developed, urban setting – Catalonia, Spain

Following the Health Care Act in 1986, healthcare was devolved to the regions in Spain. Regions have followed different models of care within a common system of universal access funded by taxes, and organised by catchment areas coordinated from the primary care community centres. The governance of the regional systems of health vary greatly ranging from full autonomy in tax collection and pooling such as in the Basque Country, where there is a common regional health service for planning, funding and provision, to a system where taxing and pooling depend mainly from the central government, such as in Catalonia, where the governance and management is fully regional, and planning and funding are separated within the system and provision is made by both public and private providers. In spite of their significant differences in organisation, both the Basque Country and Catalonia have developed highly efficient integrated care systems that are considered exemplars case in Europe.

In 2011 the *"Chronicity Prevention and Care Programme"* was set up in Catalonia. The program identified and implemented key drivers towards a PPCHC for persons with chronic conditions across the health and social systems. The tools to support the change include the macro and meso levels, with chronic and integrated care, policy-driven orientation, introduction of stratification using clinical risk groups, commitment of clinical leadership in the design and implementation of integrated care pathways, shared integrated health information systems, integrative financing and commissioning schemes involving cross-cutting targets among primary and secondary care. At the micro and nano level tools include: a community care orientation for more care at home, self-management and expert patient programs, self-care and personal responsibility for risk factors approaches, health protection, promotion and prevention approaches, rationalising medications, and promoting remote and virtual contacts using the telephone and electronic messaging. Results thus far include a reduction in the rate of emergency and readmission, integrated care pathways for four chronic conditions, and better outcomes in relation to chronic disease control.[149]

Example 4 'My Plan' for severe traumatic injuries (e.g. brain Injury and spinal cord injury) – NSW, Australia

The Lifetime Care and Support Authority in NSW developed a person-centred approach for goal setting, and planning for persons severely injured (e.g. traumatic brain injury, spinal cord injury) in a motor vehicle crash. At the meso level, this state-wide program adopts a person-centred and integrated care approach based on goals generated by the person and their family. At the micro level the person is supported by a community-based planning facilitator (case manager), who works with the funder (Lifetime care) for integrated individualised care as needed, and the multidisciplinary health and social care providers from the public and private sectors, as well as other sectors in education, workplace, housing or others relevant to the person's and social care sector. At the nano level, the planning approach considers the person's goals and context, including formal and informal supports. The person and family contribute to the assessment, planning and monitoring with an emphasis on community participation. Direct funding is being trialled as

an option for those interested to manage their own funding after assessment of capacity and training for this. An annual survey undertaken by the organisation has been used as a stimulus for discussion, plans and actions for organisational change in response to the feedback. The approach was implemented in 2015 and is now being extended to people injured through work-related injuries.[81, 150]

Example 5 'Must do with Me' – Scotland

In Scotland a top down and bottom up process was adopted to develop a patient-focused system following the national health plan launched in December 2000[151]; and the Patient-focussed Booking Implementation Guide in 2006.[102] It includes the patient-focused strategy by the Scottish Health Council and the related program "Must do with me" by Healthcare Improvement Scotland.

According to the Scottish Health Council "*patient-focused NHS* exists for the patient and is designed to meet the needs and wishes of the individual receiving care and treatment".[152] It should therefore:

- Maintain good communications, including listening and talking to patients, the public and communities
- Know about those using the service and understand their needs
- Keep users of the service informed and involved
- Have clear, explicit standards of service
- Maintain politeness and mutual respect
- Have the ability to respond flexibly to an individual's specific needs
- Ensure effective action is taken to improve services
- Talk with service users, the wider public and communities.

Attaining this approach involved the development of a comprehensive normative framework that incorporates the person-centred approach in legislation and policy, the assessment and monitoring of key determinants of health inequalities, strategies to increase empowerment by public partnership forums and patient participation groups, as well as by the development of comprehensive system of assessment that includes ad-hoc organisations and monitoring tools. The 'Monitoring and Evaluation Advisory Group' provides a forum for obtaining advice and input from key stakeholders in order to ensure effective monitoring and evaluation of the Patient Advice and Support Service (PASS). It monitors relevant aspects of service delivery including feedback from service users; identifies and facilitates sharing of areas of good practice and offers recommendations to support future development and continuous improvement. This operational system also includes a standard participation toolkit, eTools such as blogs, social media, content communities, collaborative projects and internet forums, and an advanced e-System to enhance participation, empowerment and sharing patient experiences with the health system (referred to as 'Our Voice').

This overall effort to shift the health system towards PPCHC has been combined with other key initiatives to enhance innovation, increase patient safety and global health in the NHS and to define the drivers of the system [153]. The program recognised that even small change can make a difference to the patient experience. It also aimed to develop inter-sectoral care between health and social care professionals working together and focused the change on three foundational areas: on the health and care experience, person-centred health and care improvement programs, and connecting people and good practice. It also focused on providing the supports to people to develop the knowledge, skills and confidence to engage in shared decision-making and planning and self-management. The five elements of the system promoted to people are 'What matters to you?, Who matters to you?, What information do you need?, Nothing about me without me, and Personalised context'.[154] Education includes online YouTube videos.[155] The progress

towards change and monitoring is undertaken by the Scottish Health Council at the macro level of Scotland, but monitoring how the local boards and councils carry out their responsibilities towards PPCHC and the outcomes achieved is through inequalities assessment, public partnership forums, patient participation groups and an advisory group which involves the public and patients.[156]

Example 6 National Disability Insurance Scheme (NDIS) – Australia

At the macro level in Australia, people with disability led the human rights movement to demand change for a national-based system of adequate funding for support services to meet the needs of people with disability. The movement led to the National Disability Insurance Scheme.[157] The Scheme focuses on person-centred goal setting and planning for supports, choice and control of their own circumstances. The Scheme has been trialled in each state, and is now being rolled out in particular state/regions according to the various state agreements.

Firstly, the person is assessed as to whether they are eligible. Funding is allocated to the person in the Scheme on the basis of a plan that is developed with the person and, where relevant, the family. The person is assisted with planning for their care by a Local Area Coordinator (LAC) who has a case management role (at the nano and a limited extent at the micro level with the person) but also has a collaboration and community development role at the micro level and involving cross-sector collaboration. However, the person with a disability is responsible for the coordination and collaboration of their own supports and services, which is dependent on the supports being available in the community. There are options for direct funding to enable the person to manage their own funds although the infrastructure and support to develop the skills to achieve the coordination, implementation of care and support and financial management of the funds is still emerging. The NDIS also funds innovative research and development programs for support strategies and tools. The NDIS is still in development. There are narratives about the Scheme enhancing people's lives, as well as narratives about the difficulties for the person – particularly those with complex health conditions – including lack of information, relevant and available services, limited education and support for recipients of the funding.[158]

Table 2: Examples of systems and the presence/absence of PPCHC attributes, properties

Example	Key characteristics				Comments on facilitators
	Holism	**Empower**	**Complex**	**Integrate**	
Meso Level					
Nuka System of Care	+/-	+	+	+	Engagement with the person and people, shared management and decisions around healthcare services
Geriant care model	+	+/-	+/-	+	The program is disease specific which has assisted the collaboration and coordination. However, it has not been translated to the broader population in the region
Macro Level					
Chronic and Integrated Care in Catalonia and Basque Country (Spain)	+/-	+/-	+	+	Strong regional government and clinical leadership and cross-sector collaborations with a focus on chronic care. The integrated information systems and care pathways are also perceived as facilitators. Impact and results of the integrated care strategy are already available but impact of the PPCHC approach is not available yet
'Must do with Me' Scotland	+/-	+	+	+	Strong government and user leadership with a comprehensive strategy focused on patient empowerment and development of assessment tools. Impact and results not available yet
My Plan	+	+	+/-	+	The program involves inter-sector collaborations at the nano and micro level but not meso or macro. It is only available to eligible persons (injury sustained in a motor vehicle crash or at work), although potentially may be used across all states in the planned national injury insurance scheme (NIIS)
NDIS	+/-	+	-	-	The strength of the NDIS is empowerment and enabling. The program is in the implementation phase

As can be seen from these initiatives and examples and lessons learnt, while these may aim to be PPCHC systems they are not necessarily inclusive of all PPCHC characteristics. For example, a system may be integrated vertically across healthcare but not horizontally across health and non-health sectors. It reinforces the need for Australia to develop a road map to move towards PPCHC which comes from a complex adaptive systems perspective, with clear knowledge and understanding of local context and embraces aligned bottom up and top down strategies and shared values.

7 Conclusion

The concepts of person and people-centred healthcare (PPCHC) have evolved over some time. PPCHC is currently in a phase of considerable attention in global as well a national policy practice, as there is significant and recent international consensus and rapidly emerging academic as well as policy literature on the topic.

The concept itself is still advancing. There are gaps including a common international language on person-centred concepts and terms, understanding of the issues of PPCHC in rural and remote contexts, and the standardised tools for the measurement of PPCHC are still in their infancy.

In recent years PPCHC has come to embody

1. Increasing consensus on the benefits of this approach for advancing the health of people
2. Increasingly sophisticated understanding of the many aspects than comprise a holistic view of health
3. The understanding that PPCHC is context dependent and requires a whole of system approach in order to achieve a paradigm shift.

However, there is no simple way to measure the person's or people's experience of PPCHC. Current measurement of a person's experience of health and health care can measure at the nano and micro level. There are emerging measures at the meso and macro level. With exception of the examples provided, these have yet to be tested for effectiveness to pick up PPCHC concepts.

8 Appendices

Appendix 1: Literature capture and expert consultant panel

Websites searched for grey literature

- www.who.int
- www.wpro.who.int/en/
- http://integratedcarefoundation.org/
- www.health.org.uk/
- ADHC
- www.euro.who.int/en/home
- www.apo.org.au
- websites of the organisations in the case examples e.g. the Southcentral Foundation www.southcentralfoundation.com/about-us/ for the Nuka system of healthcare example

Medline search terms

Person-centred*.tw OR people-centred*.tw

AND

Ehealth.mp OR telehealth[MeSH] OR mhealth.mp OR Organizational Innovation[MeSH]. OR Medical Informatics[MeSH]. OR Information Systems[MeSH] OR Medical Records Systems, Computerized/ OR information technology[MeSH]. OR Electronic Health Records[MeSH]. OR Information Services[MeSH].mp

Search limited to 2000 – 2016.

Members of expert consultant panel:

- Robert Cloninger
- Jim Conway
- Catherine Cook
- Jocelyn Cornwell
- Diann Eley
- Eric Emerson
- Susan Frampton
- Karen Luxford
- Juan Enrique Mezzich
- Moira Stewart
- Christine Walker

Appendix 2: History of the development of PPCHC since Alma-Ata

The Alma-Ata declaration took place at a time when it was the norm in both developing and developed countries for the central government to take the pre-eminent role in the provision of health, education and welfare services. The Alma Ata declaration provided a pivotal role in defining the core principles of Primary healthcare – it should be fundamentally person-centred in that it affirms "people have a right and duty to participate individually and collectively in the planning and implementation of their healthcare"[159]. The Alma-Ata declaration promoted a shift from vertical centralised healthcare in large hospitals in major cities, to a horizontal community-based and comprehensive healthcare system involving collaborations with sectors such as education, housing, food, industry/the workplace.

The international response to the Alma-Ata was mixed, where some countries implemented comprehensive community-based PHC[160], others pursued a 'selective primary healthcare' approach which involved a narrowly targeted and vertically controlled, rather than community-based healthcare. By and large, the impact of Alma-Ata on clinical practice in most countries is seen as being low. This is for a number of historical reasons.[20]

1. The selective primary healthcare approach was favoured among key influence policy actors in global health including the Rockefeller Foundation, World Bank and USAID
2. Financial and governance structures of health systems implicitly favoured top down, centralised approaches to healthcare
3. Perceptions of community-based healthcare services being of second-rate quality
4. Notable large-scale health events, such as the HIV epidemic, reinvigorated a disease-focused approach to global health
5. In the last century there was a surge in medical technology and capacity to diagnose and categorise disease, with accompanying treatment specialisation, and reimbursement and research funding.[21],[160-162] Disease was viewed as a separate entity able to be perceived in objective terms (the diagnosis), and considered to be outside the unique characteristics and circumstances of the person.[30, 163] This reductionist disease-focused and increasingly objective approach was appealing to physicians in an increasingly technical healthcare environment. It included the use of an abridged set of symptoms and signs, objective measures for the diagnosis and categorisation of diseases which were consequently incorporated to operational diagnostic systems, prototypical clinical guidelines of interventions and training manuals. This trend was also accompanied by an increasing reliance on laboratory testing, biomarkers, imaging techniques and decision support systems.[121, 163, 164] The disease categories also became linked to the bureaucratic hospital systems and management, specialisations and other social structures such as insurance.[163]
6. A public policy focus on cost containment, health financing and economics and managerialism in healthcare in the 1980s was accompanied by continuous standard monitoring of performance, inputs and outputs, measurable objectives and resource rationing to make the work of health practitioners more transparent through control and surveillance.[121, 165] Even though this approach has translated into reduction of variability in clinical management, it is also related to extreme specialisation and uncontrolled commoditisation and weakening of the doctor–patient relationship.[21, 160, 166]

Appendix 3: What person-centred planning does/does not look like

What the person-centred key messages for planning do/do not look like [167]

DOES look like	DOES NOT look like
Hear, understand and respect the person and their context	
Do you think you need assistance to shower? If so, how would you like to be assisted, and what time is best for you?	You will need assistance in the morning to shower every day (*secondary message: I have professional experience and so know what is best for you*).
Assist the person to utilise their strengths and to build capacity with their supports and the community	
Let's look at your strengths....What do you think you are pretty good at? What are some of your qualities that you are proud of?	You might need help to understand it all, but you have to learn to accept that things are different now and you can't do a lot of things you used to do.
Assist the person to identify and aim for supports that are tailored to their individual needs	
There is a specialist computer skills class for people with disabilities at TAFE. Do you want to go to the specialist class or do you want to go to the mainstream computer class? What support do you think you might need to attend the mainstream class? You could find out from TAFE what support is available for the mainstream class; there may be peer support or a teacher's aide?	It will be better for you to go to the class at TAFE specifically for people with disabilities rather than the mainstream computer class.
Facilitate and promote participant opportunities, rights and responsibilities	
Do you want to return to work? Are there any risks to your return to work? How do you think your fatigue and memory will affect your work? What strategies can you think of that would support you?	You can't return to work now, it is too early and you might make a mistake because of your fatigue and memory problems. If you do, then it could jeopardise your job.
Facilitate and promote progress and review so that supports can be refined	
In six months' time, I will be checking in with you about how you are going with the steps towards your goals. After that we can see what changes to your supports you would like to make.	I will be reviewing your plan in six months. I will write you a letter to tell you what time the appointment will be.

Appendix 4: Examples of PPCHC measures

Type of measure	Example and reference[1]
Measures of PCHC at the nano, micro and meso levels in the healthcare cycle	
Healthcare cycle - Person contributing to diagnosis, monitoring and review	
Multi-dimensional comprehensive diagnostic schema in psychiatry	This diagnostic tool integrates a standardised multiaxial formulation based on PCHC. It includes an idiographic personalised statement allowing clinicians, patients and families to indicate what is unique and most meaningful in the contextualised clinical situation, including positive factors, as well as joint plans for restoration and promotion of health [International](137),(19)
Narrative based medicine	This approach includes the narrative of the person Integrated diagnostic judgments: on the premise that people are not merely an object in the picture (a disease) evidence within the interpreted story. This is an approach suggested by Greenhalgh (168, 169) (which integrates the experiential text, the narrative text, the physical or perceptual text and the instrumental text [UK](168, 169) Integrating the subjective dimensions of the person's mental health into the healthcare requires specific training [International](39)
Self-assessment	Self-assessment to take the first step and preventative healthcare – example for anxiety and depression. The Beyond Blue anxiety checklist [Australian] https://www.beyondblue.org.au/get-support/get-started-now
	For persons with multi-morbidity, the primary care practitioner uses a patient reported outcome measure and individualized measures to take into consideration patient's priorities, their overall health conditions, their goals and expectations [UK](128)

[1] The home country of the example is provided in [brackets]

Type of measure	Example and reference[2]
Measures of PCHC at the nano, micro and meso levels in the healthcare cycle	
Person contributing to the planning (planning, monitoring, termination of services)	
Individualised care planning	The Potku Project aims to improve the healthcare for those with chronic illnesses through individualised care planning and creating a 'citizen profile'. It involves using a broader perspective of health and functioning, self-assessment of how the illness is impacting their lives. Puts the 'patient in the driver's seat' [Finland](128)
Contextualize care to the individual's needs, values and preferences	The My Plan approach for persons with severe injury including traumatic brain injury, spinal cord injury, double amputations, burns and blindness purposively seeks out what is important to the person, asks 'What is important to you' and considers formal and informal supports of the persons' context. [Australia](81)
Family and person-centred practice	Victorian Department of Human Services – An inter-sectoral project developed a suite of seven guides for a range of services providers (educators, support workers, health practitioners) to work in more family-centred ways (adults and children with a disability). [Australia](82)
Planning future care	Advance care directive – A written statement from the person regarding their wishes for their future healthcare. The healthcare system must have processes to enact the wishes in the directive. Identified as a key role for general practitioners with a suite of practice guides and tools for General practitioners. [Australia and Singapore](170),(171)
Person-generated goal setting and planning	A paradigm shift from clinician-developed to person-generated goal planning. The person is supported to set their goals and the health services are the actions to achieve those goals. SMART goals are documented including measurement of goal attainment as a contract between the health providers and the person/family. Various meanings are attached to the acronym SMART depending on the context but typically refer to specific, measurable or meaningful, attainable or achievable, realistic or relevant, and time based [Australia](150)
Shared decision-making	The CHOICE Project developed an innovative shared decision-making and peer support service and adopts a collaborative approach to decision-making, empowering young people to be involved in making decisions about their own care, assisted by peer support workers and an electronic decision aid that facilitates shared decision-making [Australia](93)
	The MAGIC program – making good decisions in collaboration. This program looked at how to embed best practice in shared decision-making with primary care and frontline health professionals including information campaigns, presentations, providing exemplars, information through the intranets of organisations, using blogs and twitter [UK](172)
Facilitator to support planning	Organ donation program – The program involves a comprehensive strategy but critically involves a trained coordinator and adopts a new family approach and care method and training courses [Spain](173)

[2] The home country of the example is provided in [brackets]

Type of measure	Example and reference[3]
Measures of PCHC at the nano, micro and meso levels in the healthcare cycle	
Person perspective of outcomes (patient reported outcome measures (PROM) or person-centred outcome measures (PCO)[4]	
PROMS information resources linked to the biopsychosocial perspective of health	An electronic resource or bank of patient reported outcome measurements. The website includes PROMS for researchers, clinicians and patients [US].[174] All the adult outcome measures were assigned to relevant ICF concepts and the structure of the item banks was described mapped to ICF codes[175]
PROMS for specific health interventions and health status	Patient reported outcomes are frequently used in very different health interventions from rehabilitation and therapy programs[176], surgery[177], for measuring major life changes such as de-institutionalisation and quality of life[178] and for different health conditions [International][179],[180]
Surveys and questionnaires	Health service satisfactions surveys and complaints processes are increasingly used [International].[15, 128, 145, 181-183] These are not necessarily person-centred, and can be service focused. A recent survey and multi-stakeholder meeting sought to address patient and care unmet real needs with digital health apps[184] While surveys asking about satisfaction may reflect the patient's mood it is preferable to survey the patient's experience. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys ask consumers and patients to report on and evaluate their experiences with healthcare (US) https://cahps.ahrq.gov/. Critical is the use of the information from these surveys to drive service and system change
Narrative banks and consumer health forums and social media	The collection and use of personal narratives is a powerful educational tool. In the project Patient voices, the personal narratives and reports of outcomes are placed online (digital storytelling methods) for use for healthcare education and a reflective tool for all stakeholders in healthcare (health practitioners, carers and patients) [UK].[185] Personal narrative banks have been used to inform research, but also by health services e.g educational videos to support, motivate and inspire veterans to better manage their conditions (e.g. comply with medication) as well as educate health providers [US][186] and the Real People, Real Data project [Australia][187]

[3] The home country of the example is provided in [brackets]

[4] Person or Patient reported outcome measures (PROMS) is a method or questionnaire used where the responses are collected from the patient.

Type of measure	Example and reference[5]
Measures of PCHC at the nano, micro and meso levels in the healthcare cycle	
Person sharing the management of their own healthcare – self- management	
Interdependent care – patient and provider	The Buetow model of the 'window mirror' is perceiving the clinician-patient relationship as a window mirror with equal intensity on both sides of the relationship. It involves interdependent and equal moral interests of the patient and clinician in dyadic co-production of care (142)
Opportunities to choose service providers	More recent funding structures enable the person choice and control to select their own service provider. There are a number of examples in the UK, New Zealand and Australia. Choice can only be relevant when the services needed already exist. Measuring whether services are in place to enable choice is important for two emerging Australian systems of My Aged Care and the NDIS
Self-management eHealth tools	mHealth – Self-management tool for mental health using smartphones: The project involved using ICT (smartphones) to enable real-time monitoring of symptoms for designing interventions [Germany](109)
Direct funding	Direct funding refers to funding structures that enables the person to be assessed on need, and then to receive funding to manage their own healthcare and support services including selection of services. In many instances the person can choose either to be the employer of supports e.g attendant and personal support workers or use organisations that already employ the workers they need. These structures exist in a number of countries including Canada http://www.cilt.ca/funding_information.aspx UK http://www.nhs.uk/Conditions/social-care-and-support-guide Australia in terms of supported accommodation https://www.adhc.nsw.gov.au/sp/delivering_disability_services/ and more recently the emerging National Disability Insurance Scheme http://www.ndis.gov.au/participant/self-managing-budgets The principles of direct funding are sound with respect to PCHC, although the processes, assessment of need, structures, assessment of risk and safeguarding have yet to be substantively established
E-health	E-health PPCHC measures can occur across healthcare stakeholders and the healthcare cycle and the lifecycle. Refer to section 2.3

[5] The home country of the example is provided in [brackets]

Type of measure	Example and reference[6]
Measures of PPCHC at the meso and macro system level	
Measuring principle outcome	The Institute for Healthcare Improvement (IHI) has established three strategic organising principles for change. The aims are: improving the individual experience of care, improving the health of populations, and reducing the per capita costs of care for population.(181) While not specifically aiming for PPCHC the Triple Aim initiative has also identified a set of high-level measures including for the individual's experience of care. Measures identified include standard surveys with global questions e.g. on health, experience of service and likelihood to recommend questions for example as well as a patient and family-centred care organisational assessment tool [US](143)
Common methods and core pathways	The Joint Action on Chronic Diseases Project aims to improve management of chronic disease and multi-morbidity by developing a common model including common guidance, methodology and core pathways [Europe](128)
Customer ownership and focus on relationships	South Central in Alaska established the Nuka system of care – established in 1999 is a health system owned and managed by the Alaskan native people and includes behavioural, dental, medical and traditional services and structures supporting service delivery in primary care, outpatient and home settings, residential, health education etc. Performance measurement data include personal interaction with staff, comment cards, special events seeking feedback, surveys, a 24-hour telephone hotline, online form, focus groups and advisory committees(145)
Funding on the basis of need	Direct funding programs and policies (refer to previous section on self-management)
	Development of Policy - Recognition in policy on the need to adopt a PPCHC approach for health services funding change at the system-level and includes a platform on "*person-centred care funded on the basis of need*" *[*Australian] (113) p2.and 7
People reported outcomes – Focus groups and interviews	Population level reporting of patient experience – Exploratory focus groups and in-depth interviews have been used to determine the population level information by person's experiences as social care users [UK](188)
Frameworks for policy makers and managers	Guidelines for managers: The IFIC project – INTEGRATE is developing a framework and benchmarks which will provide policy makers and managers with guidance on how to implement and sustain integrated care initiatives for chronic and age-related conditions in practice. Already there are five cross-cutting themes identified (care process design, IT management, patient involvement, financial flows and health resource management and workforce flows), and international and policy lessons [Europe](98)
Top down stimulating bottom up organisational action	The 'Patient based care challenge' commenced in 2012 driven by a consumer-led advisory panel. It involves stimulating change towards patient-centred healthcare at district level in collaboration with a partnering patient's advisory committee. The districts are challenged with 26 strategies relevant across all healthcare settings to make system-wide change with a competitive aspect infused into the process [NSW Australia](189)

[6] The home country of the example is provided in [brackets]

Type of measure	Example and reference[7]
Measures of PPCHC at the meso and macro system level	
Integrating care	Integrating of pathway knowledge into existing information systems – Organisational semiotics was used to develop integrated clinical pathways rather than paper-based pathways. This project identified the need for care pathways to embed pathway knowledge into treatment processes and information systems. It demonstrated improvements in quality (length of stay, errors) and health services integration when the pathway knowledge was integrated and layered into existing hospital information systems [China](190)
	SMARTCARE uses an open ICT platform to support integrated care pathways for older persons. Individual eCare pathways involve steps described in local care plans, which make use of modern ICT tools to allow health and social care professionals to delivery better care. The project aims to build guidelines and specifications for procuring, organising and implementing the building blocks to integrated care [Europe](108)
Satisfaction with the organisation	Regular surveys by organisations on patient satisfaction conducted by external organisations which directly influences organisational change has occurred in some organisations [Australia(167)
Co-design of changes to improve safety, quality and outcomes of healthcare	PATH Project established in 2013 is a program where patients (seniors) and caregivers are partnered with providers across the community and system to co-design changes to improve healthcare transitions and experiences [Canada] http://www.changefoundation.ca/path-project-archives/
	The People Powered Health Programme (2011–2013) developed by NESTA (Not-for-profit organisation) involving health providers, and patients supported the co-design and delivery of innovative services for people living with long-term health conditions. [UK] http://www.nesta.org.uk/project/people-powered-health
	Patients as Partners in Co-design is a course developed by the Point of Care Foundation, which provides instruction in the co-design improvement method. It teaches how to draw on the experiences of patients, carers and staff to identify where change is needed and design and implement improvements together [UK] http://www.pointofcarefoundation.org.uk/What-We-Do/
Development of system wide indicators	Development of indicators for specific components of PPCHC. The Support Pioneers project developed indicators on the elements of care coordination and integration which included community wellbeing and population health, organisational processes and systems, personal outcomes, resource use/balance of care, service proxies for outcomes, user/carer experience [UK](191)
	Integrated Performance and Incentive Framework (IPIF). This draft framework aims to develop nationally reported system-level measures which include parameters such as the consumer experience, access to healthcare [New Zealand(192)

[7] The home country of the example is provided in [brackets]

Type of measure	Example and reference[8]
Measures of PPCHC at the meso and macro system level	
Service provider and organisation performance measures	Healthcare provider performance in Mental Health: This study investigates the effectiveness of person-centred planning, organisational factors and targeting the service-planning process for people with mental health conditions. The study is measuring person-centred care planning competency of the healthcare service providers (two questionnaires) and organisations (leadership questionnaire readiness for change, recovery self-assessment for administrators and providers) as well as consumer outcomes including employment, housing and forensic involvement status, consumer satisfaction with service, social connectedness, and functioning [US](193)
Measuring the involvement of people in co-design and change	Adopting a people-powered health approach – the Logic model of benefits of people helping people has been described by Mulgan and colleagues. It involves recognising the networks that work to produce outcomes for patients, commissioners, providers and local health authorities [International](194)

[8] The home country of the example is provided in [brackets]

Appendix 5: Glossary of terms

Care coordination: a proactive approach in bringing care professionals and providers together around the needs of service users to ensure that people receive integrated and person-focused care across various settings.[4]

Collaborative care: care that brings together professionals and/or organisations to work in partnership with people to achieve a common purpose.[4]

Co-production: The equal and reciprocal relationship between professionals, people using care services, their families and the communities to which they belong. Co-production implies a long-term relationship between people, providers and health systems where information, decision-making and service delivery become shared.[18]

Empowerment: The process of supporting people and communities to take control of their own health needs resulting, for example, in the uptake of healthier behaviours or the ability to self-manage illnesses.[18]

Functional integration: Refers to the extent to which back-office and support functions are coordinated.[73]

Integrated care services: the management and delivery of health services such that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, through the different levels and sites of care within the health system, and according to their needs throughout the life course.[4]

Inter-sectoral: The inclusion of several sectors, in addition to health[18] e.g. education, housing, social care, transportation, justice, finance.

Macro level: Deals with policy and governance issues.

Meso level: Deals with managing regional health, community, social and infrastructure services.

Micro Level: Deals with local/individual care in the local community.

Nano Level: Describes the personal/organismic health and disease characteristics/functions.[195]

Normative integration: Refers to the extent to which mission, work values etc. are shared within a system.[73]

People-centred care: An approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that respond to their needs and preference in humane and holistic ways. People-centred care also 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.[4]

Person-centred care: care approaches and practices that see the person as a whole with many levels of needs and goals with these needs coming from their own personal social determinants of health.[4]

Personalisation is about enabling people to lead the lives that they choose and achieve the outcomes they want in ways that best suit them. It is important in this process to consider risks, and keeping people safe from harm. However, risks need to be weighed up alongside benefits. Risk should not be an excuse to restrict people's lives.
http://www.thinklocalactpersonal.org.uk/_library/PPF/NCAS/Practical_approaches_to_safeguarding_and_personalisation_12th_Nov_2010_v3_ACC.pdf

Personalised Medicine: Personalised medicine is a newer approach to care delivery tightly attached to the biomedical model of healthcare. It involves new diagnostic and treatment technologies, which are tailored to every individual's genomic profile and biomedical characteristics. As such it focuses on the body function, body structure and biological part of health only[19], and can be misinterpreted as implying unique treatments for the individual.

Precision Medicine: A form of medicine that uses information about a person's genes, proteins, and environment and their interactions to prevent, diagnose and treat disease. The approach proposes to allow healthcare professionals to tailor health treatment to optimise precision of treatment and health outcomes [196]. In cancer, precision medicine uses specific information about a person's tumor to help diagnose, plan treatment, find out how well treatment is working, or make a prognosis.
http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=741769

Recovery: Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's own life as one grows beyond the catastrophic effects of mental illness [197].

Safeguarding is a range of activity aimed at upholding an adult's fundamental right to be safe. Being or feeling unsafe undermines our relationships and self-belief, our ability to participate freely in communities and to contribute to society. Safeguarding is of particular importance to people who, because of their situation or circumstances, are unable to keep themselves safe.
http://www.thinklocalactpersonal.org.uk/_library/PPF/NCAS/Practical_approaches_to_safeguarding_and_personalisation_12th_Nov_2010_v3_ACC.pdf

Whole-system thinking: An approach aimed at perceiving how the things are connected to each other and influence one another within some notion of a whole, and where the parts interact toward a common purpose. Systems thinking is intended to improve the quality of perception of the whole, its parts and the interactions within and between levels.[4]

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