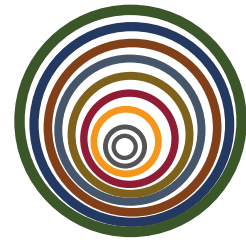


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PCVBHC

Person-Centred Value-Based Health Care

A report analysing the approaches to bringing together Value-Based Health Care, Person-Centred Health Care and Population Equity

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Please note, wherever possible throughout this report, we refer to “people receiving care” rather than “patients”.



Executive Summary

Background

Value-Based Health Care (VBHC) and Person-Centred Health Care (PeCHC) are important approaches to health care which aim to improve the outcomes that matter to people. VBHC seeks to do this by organising care around patients with a specific condition or common needs, standardising outcome measurement (using clinical and patient-reported outcomes) and cost measurement, using this data to perform comparisons and learning from those with better outcomes and the same or lower costs. PeCHC takes a more individualistic view that relates to the context, goals and preferences of a single person. PeCHC also enables meaningful involvement of people receiving care in health service design and health system strengthening. When considering the implementation of both of these approaches to health care delivery, we realise how little we know about the preferences and goals of people receiving care, and the extent to which we have met them and achieved the desired outcome. Additionally, as the cost of health care continues to rise inexorably around the world, we seek assurance that our investment in health is, indeed, meeting the needs of people equitably.

Objective

This report aims to assess the opportunities in developing health care systems that centre on the individual patient preference in determining high quality health care, while enabling the management of limited population health care budgets.

Methodology

In order to achieve the objective, we brought together an international Community of Experts (CoE) to work through a structured methodology. The work of the CoE was supported by a pragmatic review of the literature and input from an Industry Advisory Panel (IAP), representing pharmaceutical and medical technology companies.



Top level recommendations

1. Through Shared Decision Making, clinicians and a person receiving care must work together to understand the goals of that person, and then use these goals to determine the outcomes that matter and the processes and structures that are applied to achieve these.
2. People receiving care must be involved, through established methodologies, in all aspects of health care system policy and strategy development, pathway design, and throughout the life cycle of the development of medicines and technologies.
3. Due to finite resources, it is not possible to provide every person with their preference all of the time. When making decisions about resource allocation, systems must be transparent about the methodology that underpins the decision making. Clinical teams must then work with the available services, products and resources to best determine how to meet the goals of individuals.

Introduction

Value-Based Health Care

Over the past 100 years there have been dramatic improvements in life expectancy, with the global average life expectancy more than doubling. (1) However, we have made significantly less progress in understanding the extent to which people are enjoying the health outcomes that matter to them, in both health and disease. The Organisation for Economic Co-operation and Development (OECD) predicted in November 2019 that over the next 15 years health spending would increase by more than GDP growth in most OECD countries, averaging an annual growth rate of 2.7%. (2) Yet, despite rising expenditure, we have limited understanding around the extent to which the money we invest in health and well-being is achieving what matters to people.

Recognising these challenges has contributed to the development and adoption of the concept of Value-Based Health Care (VBHC). (3, 4)

VBHC is based on the premise that we need to systematically measure the outcomes that matter to people and relate these outcomes to the cost that it takes to achieve them. Value should be measured around diseases, conditions, symptoms (e.g. breathlessness), characteristics (e.g. multi-morbidity) or population groups (e.g. overall adult health), not focusing on institutions, specialties or technologies but instead focusing on the person. (4, 5) The goal is high value care – that is the best health outcomes for every unit of currency that is spent. The VBHC framework then encourages comparison of the value achieved between peers in the same and different health care systems, with the aim of learning and knowledge translation – all with the goal of improving value. (4) This enables us to focus on allocative value at the population level, allocating resources to achieve maximal value. It also enables us to consider personal value, focusing on the outcomes that matter most to people at the individual level. (6) VBHC aims to increase both effectiveness (outcomes) and efficiency (low monetary and treatment burden).

It is an inescapable truth that as the health needs and expectations of the world's population grow and as the number of medical interventions made possible increase, demands for expenditure in health care are outstripping the availability of funds. If we accept that resources are finite, then we accept that choices will have to be made about where and how those resources are deployed. This reinforces the need to focus on high value activity. Many other initiatives such as Choosing Wisely (7), Too Much Medicine (8), Prudent Healthcare (9), Realistic Medicine (10), The Essential Project (11) support in part or in whole the principles that underpin VBHC. There is much to be done to reduce low value care and release resources to improve care elsewhere in

the pathway. To achieve value across a pathway we must optimise prevention, early diagnosis, intervention, self-management, and the switch from active disease management to active symptom management and better palliative care at the end of life.

A question remains around how we incentivise or nudge health care systems towards a focus on high value activity across the whole pathway for people at risk of, or living with a health condition or with a common set of needs. Optimum financing for value is hotly debated and beyond the scope of this report – the impact of bundled payments or allocative efficiency on VBHC delivery warrants further research.

VBHC at odds with individualised care?

Donabedian describes quality measurement in health care as the consideration of structures, processes and outcomes (see Table 1). (12) Health care systems, often through national and international guidelines, have sought to standardise structures and processes of care and with the concept of VBHC increasing our focus on outcomes, we are in the process of standardising outcomes measurement. (13, 14) In line with standardised measurement, we have also developed standardised definitions of success, which are typically high scores in the metrics that are captured. For example, in cancer care, we measure 5-year survival and the goal is to achieve the greatest proportion of people surviving 5 years or more.

Definitions

| | |
|-------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Structure | The settings in which care takes place. For example, the facilities and equipment, the qualifications of staff. (12) |
| Process | The process of care itself, determining whether what is known to be “good” care has been applied. For example, (i) the application of evidence-based guidelines, (ii) technical competence in the performance of diagnostic and therapeutic procedures. (12) |
| Outcome | A milestone, consequence or endpoint that matters to a person. |
| Experience | What the process of receiving care feels like for the patient, their family and carers. (15) |

Table 1: Definitions (Part 1).

We do not currently standardise around individualisation. Therefore, in its current form, standardisation means that the structures, processes and outcomes that we capture, and their associated standardised definitions of success, will not always reflect what matters to the person at that particular point in time. Thus, it follows that standardised measures and standardised definitions of success do not necessarily align with the goals or preferences of individual people. For example, when faced with the trade-offs that result from making different choices about their treatment, an 85-year-old person with cancer may decide that their primary focus is on prioritising their quality of life over their length of life. If this ability to exercise preference is not reflected in how providers are measured and assessed, then this could create a tension which might encourage a movement away from focusing on what matters most to individuals. This tension might be further exacerbated by benchmarking efforts. (16) Additionally, people receiving care may prefer certain processes or structures, irrespective of the effect that that choice might have on the outcome. This becomes an even greater challenge when we are paying for the achievement of predefined outcomes, incentivising a system and partners to the system, like life science companies, to focus on specific outcomes, even if they are not what an individual desires or prioritises. (17) As such, VBHC may well lack alignment with Person-Centred Health Care (PeCHC).

Person-Centred Health Care

The concept of Patient-Centred Health Care originated in response to previous prevailing illness- and doctor-oriented care. Illness-oriented care was perceived as limited, focusing only on biological aspects of illness, unable to capture patients' unique context and experiences with their illness. (18, 19)

As Don Berwick proposed during his time on the Institute of Medicine's (IoM) Committee that was charged with writing the report *Crossing the Quality Chasm*, patient-centredness is: "The experience of transparency, individualisation, recognition, respect, dignity, and choice (to the extent the informed, individual patient desires it) in all matters, without exception, related to one's person, circumstances, and relationships in health care." (20)

Dimensions to patient-centredness that have been mentioned in the literature over the past 12 years include: (i) shared decision making, (ii) acknowledgement of the person as a unique person, obtaining their perspective, (iii) a holistic view, considering all aspects of life, (iv) respectful communication and building a therapeutic alliance, (v) co-ordinated and integrated care, (vi) qualities of clinicians like empathy and self-awareness. (21)

Person-Centred Health Care (PeCHC) is an evolution from the concept of

Patient-Centred Health Care, where the focus is less on a patient in the sick role but more on an individual with an illness.

The earlier described definition and dimensions of patient-centredness show great overlap with aspects of PeCHC. However, the goals of the two concepts differ whereby in Patient-Centred Health Care it typically revolves around functional aspects, such as reducing burden of disease and in PeCHC it is about understanding what matters to people and what they value in their lives. (19) Indeed, in Patient Centred Health Care the focus is mainly on a functional life, but in PeCHC on a meaningful life. (19, 22, 23)

PeCHC principles encourage meaningful involvement of the person receiving care in the design of care delivery, for example through experience-based co-design.

Population equity

All health care systems have finite resources which must be allocated to different health conditions and to different population groups, whether defined demographically and/or socially and/or economically and/or geographically. Value judgements on equity must be stated explicitly and transparently. We must understand how personal preference and goal setting at the micro level and the allocation of resource at the meso and macro levels interact (definitions in Table 2). Clearly, in the context of finite resources, it is not possible for everyone to get exactly what they want, when they want it.

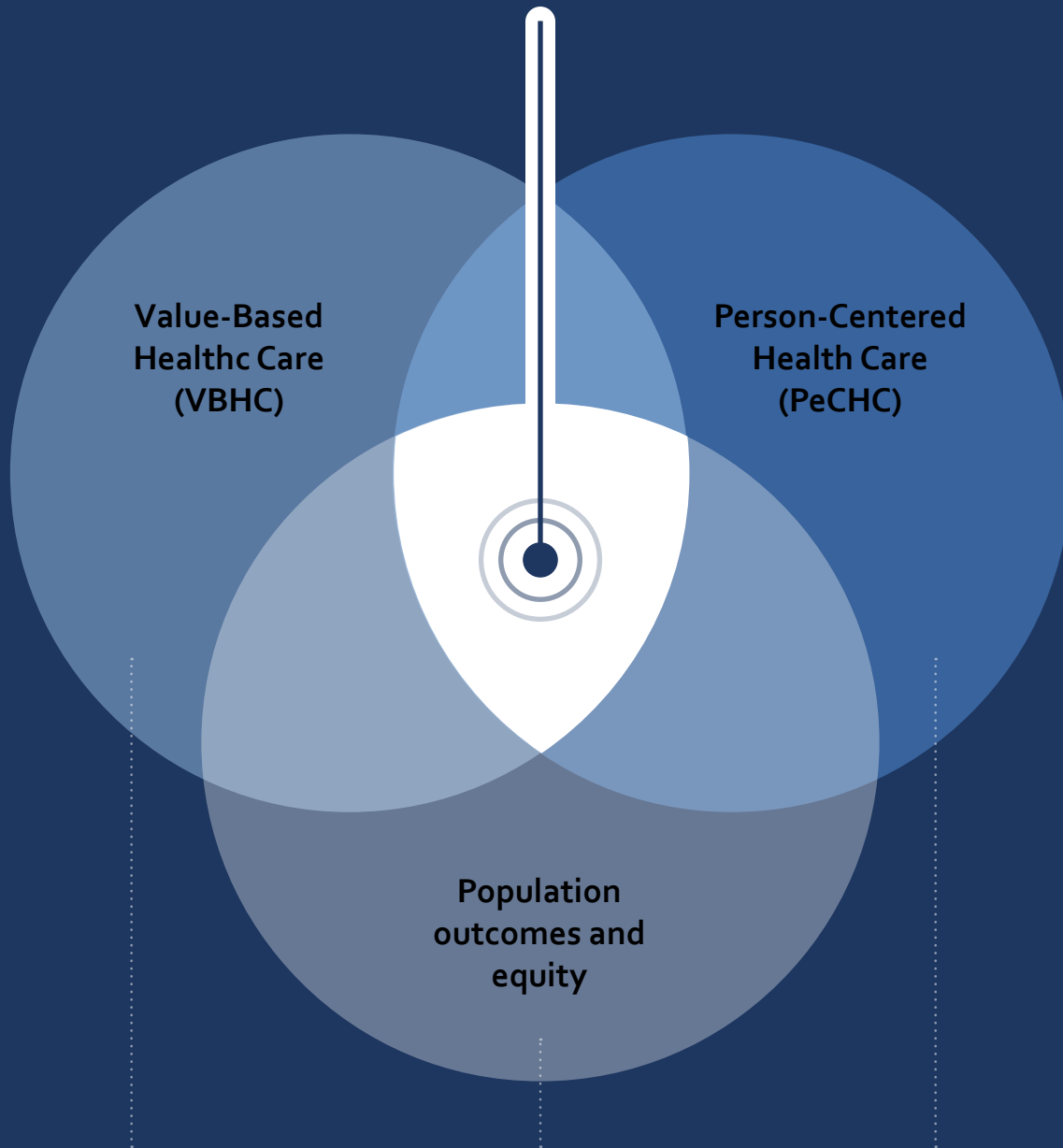
Definitions

| | |
|--------------|----------------------------------------------------------------------------------------------------------------------|
| Micro | The settings in which care takes place. For example, the facilities and equipment, the qualifications of staff. (12) |
| Meso | Interaction at the level of the institution, hospital, care pathway(s). |
| Macro | Population health outcomes and the associated regulatory, policy and financial decision making in health care. (24) |

Table 2: Definitions (Part 2).

The original aim of VBHC was to put the person with a specific condition at the centre and to focus on achieving the outcomes that matter to them at the lowest possible cost. The implementation of VBHC risks jeopardising the focus on the person. PeCHC supports putting the person at the centre of health care but does not stress measurement, evaluation and improvement. In both VBHC and PeCHC, there is a lack of recognition that resources are finite and therefore, it is not possible for everyone to have everything they want. Indeed, Figure 1 illustrates the point that if we only consider the individual in a Person-Centred and Value-Based Health Care system, then we will neglect the needs of others in the population. This may particularly discriminate against certain sections of society, already vulnerable to exclusion, or against less influential sections of health care. Therefore, there is a need (see Figure 1) to bring together VBHC, PeCHC and population equity. We have termed this concept Person-Centred Value-Based Health Care (PCVBHC).

How do we reach this point?



Value-Based Health Care (VBHC)

- Achieving the best outcomes with the available resources for individual conditions.
- Unwarranted variation, waste and harm.
- Quality Improvement.
- New models of care.

Population outcomes and equity

- The greatest quantum of health gained for the whole population.
- Issues of equity, affordability and sustainability.

Person-Centered Health Care (PeCHC)

- Shared goal setting and decision making.
- What matters to me?

Figure 1: Bringing together VBHC, PeCHC and population equity.

3.0

Methodology

The methodology consisted of eight steps, outlined below. The process was managed by a Project Team (Appendix 4).

Step 1 Through a preliminary, exploratory literature search, common ground and tensions between VBHC, PeCHC and population equity were examined. This resulted in a short report, providing background knowledge to VBHC, PeCHC and population equity, covering tensions between the principles and identifying possibilities for alignment.

Simultaneously, an international Community of Experts (CoE) representing key stakeholder groups was formed (Appendix 2). Experienced patient advocates were a central part of the CoE. Input from individual pharmaceutical and medical technology companies was considered and brought in by a separate Industry Advisory Panel (IAP) (Appendix 3).

A structured approach was used to select the CoE and IAP.



Approach to bringing together the CoE:

- The key stakeholder groups were identified by the Project Team.
- A formal stakeholder mapping was then conducted, identifying target CoE members within each stakeholder group. The targets were identified based on (i) knowledge of the Project Team, (ii) a review of key literature in the field of PeCHC and VBHC, (iii) a review of speakers at key international conferences including the International Consortium for Health Outcomes Measurement (ICHOM) and the International Society for Pharmacoeconomics and Outcomes Research (ISPOR).
- The Project Team then took a decision as to which target members would be contacted first. Letters were distributed from the Co-Chairs and the Project Lead and an introductory video call arranged.
- It was decided to keep the number of CoE members at 20 or below in order to optimise the effectiveness of the virtual meetings. Ultimately, the PCVBHC Community consisted of 19 members.
- The representative from the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the representative with a history of working at the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK, were invited to chair the IAP.

Approach to bringing together the IAP:

- The key companies were identified that have a history in industry leadership with regard to VBHC and PeCHC. This was based on insight from the Co-Chairs of the IAP.
- The IAP Co-Chairs then assigned names to each of the target companies.
- The IAP Co-Chairs then decided which targets would be contacted first. Letters were distributed from the Co-Chairs and the Project Lead and an introductory video call arranged.
- The IAP consisted of 10 members.

- Step 2**
Meeting 1 of the CoE
- In preparation, the short report was shared with the CoE. The meeting focused on discussing the questions raised in the short report and exploring themes brought up by members of the CoE. This meeting concluded that there are opportunities to align VBHC, PeCHC and population equity.
- Step 3**
Meeting 1 of the IAP
- The short report was shared with the IAP and as above, the meeting focused on discussing questions raised in the short report and exploring themes brought up by members of the IAP. This feedback was fed into the second meeting of the CoE.
- Step 4**
Meeting 2 of the CoE
- This meeting focused on co-designing project questions that needed to be answered in order to understand how to achieve PCVBHC. These questions have formed the basis for this report and reflect the chapters in this report.
- Step 5:**
Literature review
- The answers to these questions and recommendations stated in this report are supported, as much as possible, by evidence retrieved from a literature review. For this literature review: (i) we translated the broad project questions into multiple research questions and (ii) we searched MEDLINE for all relevant empirical literature concerning these research questions (Appendix 5). The answers to the questions and recommendations are also based on the expert opinions of the CoE.
- Step 6:**
Drafting the report
- The Project Lead drafted the report, which underwent three rounds of review by each member of the Project Team.
- Step 7:**
Report review by the CoE
- The report was then reviewed by the CoE and they provided structured input via a standardised template. The input was consolidated and discussed at the third CoE virtual meeting, where consensus was sought on the changes to make. Additionally, during this meeting, the recommendations were finalised.
- Step 8:**
Report review by the IAP
- The report was then circulated to the IAP and they also provided structured feedback via the standardised template. The feedback was consolidated and reviewed at the second IAP virtual meeting, where consensus was sought on the recommended changes.
- Step 9:**
Final review by the CoE
- The final version of the report was circulated to the CoE in advance of the fourth virtual CoE meeting (this included the changes that were recommended by the IAP). At this fourth meeting, agreement was sought for the inclusion of the recommended changes from the IAP and any further changes were agreed. Approval was also sought to publish the report.

4.0

Inputs: what information do we need to collect in a PCVBHC system and why?

Background

Despite the increased emphasis on measuring what matters to people, the reality is that the outcomes, processes and structures that we measure are often not responsive to the goals and preferences of individuals. Indeed, discussions around goals of care are not routinely integrated into patient care. (25-29) Further, we know that physicians frequently make inaccurate judgements about patient values and preferences. (30) For example, among patients with chronic kidney disease receiving dialysis, 61% regretted initiating dialysis; 52% reported that dialysis was chosen only because it was the physician's wish. (31) This can be a particular problem in ethnic minority communities which typically experience poorer communication with health care providers and less involvement in treatment decisions. (32) Measurement must reflect personal goals and preferences, otherwise it is impossible to know whether we are actually achieving the outcomes and following the structures and processes that matter to individuals. At the different health care levels (micro, meso and macro), this could mean collecting variable 'inputs', with inputs defined as: a data point, both qualitative and quantitative, that gives information, supporting the process of determining what matters to the person and the extent to which that has been achieved.

Micro level

Goals and preferences

At the micro level, we are concerned with the individual and working with them to achieve their goals. Goals assist the development of individualised care plans and they support people receiving care in maintaining a sense of purpose and control. (33) Goal setting also increases the involvement of people receiving care in the decision-making process. (34)

Measurement must be simple and meaningful for the individual. Simple tools and questions can be used to support the goal elicitation and recording process. (35) In one study looking at Aortic Stenosis, the authors simply

asked the question “what do you hope to accomplish by having your valve replaced?” and responses were recorded in an internally protected spreadsheet. (36)

Patient Reported Outcome Measures (PROMs)

Definition: “These are tools measuring outcomes that matter to patients, more specifically reflecting patients’ or caregivers’ perspective on the impact of the condition on their lives and how illness is experienced (for example, ‘can I now climb my stairs?’, rather than ‘has my spirometry improved?’).” (37)

PROMs can support the goal of incorporating perceptions of the health of people receiving care into dialogues with health care professionals. (38) Indeed, they can support shared decision making. (38) In Low and Middle Income Countries (LMIC), it is possible to successfully use PROMs through the use of mobile phones. (39) PROMs can support people receiving care and clinicians with monitoring outcomes (including symptom burden) over time, helping to inform treatment decisions, (40, 41) but they have also been shown to sometimes impair rather than enhance communication between people receiving care and health professionals. Standardised PROM tools might enable outcome comparison given their uniformity but may not always be sufficiently sensitive to reflect what matters to the individual person. (42) An important part of shared decision making is the determination of preferred personal health outcomes and it may be questioned whether PROMs support this process. (43) It seems plausible that these drawbacks to PROMs can be overcome through goal elicitation. (44)

Clinical outcomes

Clinical outcomes are outcomes reported by clinical team members, for example: complications of treatment. They are important as they contribute to a wider suite of outcomes that holistically reflect what matters most to people receiving care. However, as stated earlier, if they are used as quality indicators, or even as financial incentives, and do not reflect what matters to individuals, we will not achieve value for that individual.

Outcomes collected via administrative data

These would include outcomes like mortality, readmission, length of stay, which can be captured via health systems’ administrative records.

Processes and Structures

Processes and structures (as defined in Table 1) reflect the approaches taken for care and treatment delivery. They are typically aligned to evidence-based standards which can be part of local, regional, national and international guidelines. Evidence-based care processes and structures are an important mechanism for increasing the likelihood that the desired outcomes are achieved. Care processes and structures in themselves may be important to patients as well. A patient may well be willing to trade outcomes for a more comfortable or convenient process, for example.

Patient Reported Experience Measures (PREMs)

PREMs capture people's experience of care. Experience is a core condition, reflecting the values of a particular health care system.

Patient characteristics

Patient characteristics including demographic factors and pre-existing medical conditions support the case mix adjustment required to perform meaningful comparisons at the meso and macro levels.

Meso level

Inputs at the meso level consist of aggregated micro level data – this means all individual level data is brought together to give a meso level perspective. This could be data at the level of health conditions (for example, lung cancer) and/or aggregated health condition level data (for example, cancer). Resource data is also important at the meso level, where some of the allocation and investment decisions are taken. Specifically:

- Aggregated, outcomes data (outcomes from administrative data, clinical outcomes, PROMs): this would give an overall picture of the outcomes being achieved at the level of the organisation or pathway – both the average and variations in outcomes. For example, in the National Health Service (NHS) in Wales, UK, the system is organised around seven integrated health boards. A dashboard has been developed for many conditions, with one example being lung cancer, which provides meso level outcomes data (health board level data) for clinical and management teams to use. (45) This has not yet been extended for use by patients to support their decisions around the services they would like to use.
- Aggregated case mix variables: these are important to understand the profile of the population, in order to perform case mix adjustment to enable comparison of outcomes between teams.
- Aggregated process, structure and resource data: this enables stratification of the outcomes data into groups that reflect the different processes and structures used. It also enables assessment of the resources consumed in relation to the different outcomes achieved and the different processes and structures used.
- Aggregated PREMs: Given that experience is a core condition, reflecting the values of a particular health care system, capturing PREMs at the individual level enable their aggregation to understand the extent to which the core condition is being achieved.

Preference is at the heart of PCVBHC. However, health care systems still need designing so that patients can choose from the processes and

structures that are available. Therefore, in creating PCVBHC systems, people receiving care should be directly involved in the design of care delivery pathways, services and tools. Inputs could come from a variety of sources, including:

- Active involvement in the design of pathways, services and tools. This can be through a variety of approaches including surveys, discrete choice experiments, interviews and, with more impact, action research approaches like experience-based co-design. (46-53) It is also possible to develop broader citizen science studies. (54) People receiving care and health care professionals should engage in continuous dialogue and sharing of experiences and preferences. (55)
- Ethnography, consisting of observation and interviews, to understand the perspectives of people receiving care on the processes that are used and the extent to which they are low value or high value. (56, 57)

Macro level

At the macro level, we would use aggregated meso level data to give a view of entire system level performance. As with the meso level, resource data is also important at the macro level, where allocation and investment decisions are taken. This would be organised in a similar way to the meso level, specifically:

- Aggregated case mix variables: these would enable comparison between different organisations and services across the whole system.
- The presentation of the aggregated data would be built as a pyramid:
 - Meso level data for all aspects of the system to enable comparison between systems/services. This consists of structure, process, outcome and resource data.
 - Aggregated meso level data to give an aggregated view of the entire system. This would consist of (i) health condition level data (e.g. lung cancer), (ii) aggregated health condition level data (e.g. cancer) and (iii) overall population data, aggregating data across population segments (e.g. quality of life). Again, this would consist of structure, process, outcome and resource data.

Building on the person-centred pathway design at the meso level, it is possible to have a person-centred approach to health system design and strengthening and inclusive health policy at the macro level. This is through the collective efforts and inputs of patient organisations and cooperation across stakeholders.

We must also continue with the role of meaningful patient engagement in the life cycle of medicines and technologies, which is increasingly recognised by industry, regulators and authorities. This spans research prioritisation, clinical trial design, early dialogue with regulators and HTA experts, through to approval, pharmacovigilance, Real World Evidence and disinvestment, with the overarching objective of ensuring innovation reflects the needs and goals of patients and leads to better outcomes.

5.0

Using the inputs

Micro level

Health systems need to capture goals and link the goals to outcomes, processes and structures. It is then possible to use the data to help individuals and their care teams to monitor progress towards the goals and to identify areas that need attention.

To support goal setting, people receiving care must be informed about their health condition, its likely trajectory and their prognosis, treatment options and the associated benefits and risks and the uncertainty in evidence. (33, 58) Supporting health literacy is vitally important to enable effective co-production and shared decision making. Additionally, health care professionals must be trained in shared decision making and goal setting, understanding for example the importance of encouraging the expression of preferences, while checking for understanding and agreement about decisions and having awareness of the impact of language. (58, 59) There must also be sufficient investment to ensure sufficient time is allocated to do this properly. This represents a culture shift for both health care teams and people receiving care. (60) We have developed a simple framework (Figure 2), for use at the micro level, to support systems with their transition to a PCVBHC approach.

To inform people receiving care about their prognosis and options available, we need to understand the outcomes we are achieving for groups of people with similar needs, but then translate these to the individual's goals and preferences. If addressing the defined need using aggregated outcomes from previous patients is discordant with the individual's goals and preferences, then addressing it cannot be valuable from either the societal or individual perspective.

It follows that the structure and process of care must enable the exercise of preference at key points in the pathway. Once such preferences are exercised it is then possible to focus on standardisation and efficiency.

A framework to support the transition to PCVBHC

Training and Education for people with health conditions and for health care professionals

- All health care professionals and all people with health conditions should be educated in the principles and practice of shared decision making, goal setting and outcomes measurement.
- For health care professionals, this is the responsibility of universities, employers and postgraduate education structures.
- For people with health conditions, this is the responsibility of partnership working between patient advocacy groups and health care providers.

Goal Setting in practice

- Development of goals following the SMART principles – specific, measurable, achievable, realistic/relevant, timed.
- Use of simple questions to elicit goals. See examples at the bottom of this diagram.¹
- Self-management booklets/ decision aids shared with patients in advance of the meeting.
- Goals reviewed regularly, with frequency of reviews defined by each individual person and their health care team.
- Goals should be recorded in the health record, with copies available for all members of the team to see whenever they wish. An example approach is included later in this section.

Standardised Outcomes Measurements

- Suite of standardised outcome measures which, through shared decision making, are mapped to the goals that have been identified. As a first step, we would encourage health systems to use the work of ICHOM² and PROMIS³.
- In cases where people do not want to set goals, then it would be possible to focus on the complete Core Outcome Set from an organisation like ICHOM.

Standardised process and structure measurement

- Suite of standardised process and structure data, which (as with outcomes measurement) through shared decision making, are linked to the goals that patients have set. This may be explicit e.g. a goal that specifies a particular process or structure, or it may be in the knowledge that a particular process will support achieving another goal.

Health care systems slowly transition to a PCVBHC approach, starting with single health conditions

Figure 2: A framework to support the transition to PCVBHC.

1 Simple questions to elicit goals:

- When you think about the future, what are your expectations for your health?
- What are your most important goals given your medical condition? (61)

2 ICHOM: International Consortium for Health Outcomes Measurement. See: www.ichom.org

3 PROMIS: Patient Reported Outcomes Measurement Information System. See: www.healthmeasures.net



This approach moves us away from telling people which outcomes, processes and structures matter to asking individuals what they want from their care.

It also recognises that trade-off decisions may be necessary during the care process and so getting the best outcome is neither always possible nor desirable.

We are still able to maintain the standardisation of data, which will help enable comparisons to support learning and improvement.



Case Study 1

Goal setting and outcomes measurement for Diabetes in the Netherlands (62)

Background

The Dutch Diabetes Federation developed a 4-step consultation model to put patient centred care into practice. The model is aimed at general practitioners, internal medicine specialists, practice nurses and diabetes specialist nurses.

Model

In preparing for the consultation, patients were asked to consider these four questions:

1. Do you have health problems?
2. Do you want to solve your health problems?
3. How do you want to do that?
4. What kind of support do you need?

Step 1 Broad ranging discussion on factors that influence goals, treatment options and professional support.

Step 2 Shared decision making, working together to set personal and health related goals.

Step 3 Shared decision making, discussing treatment options to reach the goals.

Step 4 Shared decision making, to determine the professional support needed to achieve the goals.

Conclusions

A nationwide implementation study was performed across 47 general practices and 6 hospital outpatient settings. 72% of all of the conversations could be performed in less than 25 minutes. 74% of all patients prepared the consultation at home. 94.4% reported being involved in making decisions about their treatment goals.

Figure 3: Case Study 1

Case Study 2

Shared Decision Making in Prostate Cancer (63)

Background

The American Urological Association, the National Comprehensive Cancer Network in the US and the European Association of Urology recommend shared decision making and eliciting patient preferences when choosing treatment for localised prostate cancer. Current approaches result in inadequate decision quality. This particular case study looked at a novel approach to shared decision making.

Model

Patients completed a web-based application called WiserCare. WiserCare provides education, preference measurement (around goals and desired outcomes) and personalised decision analysis. WiserCare then generates an individualised report, ranking treatment options according to their fit. Patients complete the application either at home or in the clinic waiting room and the reports are filed in the medical record to support shared decision making.

Comparison was made between the WiserCare group and the normal care group. Significantly more people in the WiserCare group (88%) strongly agreed that they felt more included in the treatment decision (57% in the normal care group; $p=0.01$). A range of preferences were seen but of note, 35% of patients did not include longevity in their top three preferences and recovery time was the least common concern.

WiserCare effectively decreased decision conflict. It also seems that WiserCare supports both a higher quality decision making process and a resultant higher quality decision.

Conclusions

Using shared decision making and providing adequate support to patients to engage in the shared decision making process (education, opportunities for recording goals and preferences) results in decisions that are aligned with what patients want.

Meso level

We need to ensure we develop cultures across our health care systems that focus on using data to support quality assurance and continual improvement. If the data is used as a stick, with punishments in place for poor performance, then engagement is likely to fall.

Analysis and decision making should focus on the extent to which the goals of individuals have been met. This is possible by presenting the standardised outcome, process and structure data, which would be aligned with the goals of individuals. By definition, processes and structure have to service many people and not a single individual. Therefore, it is impossible to personalise every process such that they align with everyone's individual goals. This is why it is important to use established methodologies to receive input from people receiving care into the design of pathways, services and tools. Consequently, it is necessary to understand the goals of individuals and to align those to the greatest extent possible with the structures and processes available.

Therefore, we should follow these steps when using the data:

1. The data should be presented in an aggregated balanced scorecard, which enables an organisational/system view, showing the risk adjusted outcome, process, structure and resource data. It would be possible to view the impact of different processes and structures on the outcomes achieved.
2. The scorecard should be updated as close to real time as possible and should be available for all teams to view and use. It should be used by clinical teams in their quality improvement initiatives, supporting the development of hypotheses for how they can improve the outcomes that matter to people. The scorecard should then be used to observe the impact of their interventions and indeed determine whether outcomes have actually improved. The scorecard should also be used by leadership and management teams to support identification of areas that require extra help and intervention, to support their investment decisions and to support their communication with external stakeholders.

Additionally, the data should be used to support allocative value. (64) We should be taking decisions whereby we invest resources to achieve the greatest value for each unit of currency invested. We can develop hypotheses around how we achieve allocative value and balanced scorecards can then visualise the extent to which allocative value has been achieved and how this varies between teams.

Meso and macro levels

At both the meso and macro levels, we need to take decisions around the products, skills and services that will be procured. Procurement increasingly aims to link payment with the outcomes achieved. This therefore strongly incentivises the achievement of particular outcomes and underscores the need to ensure that products are targeted at the appropriate patients, as defined by their goals.

Real World Data (RWD) allows new technologies to be introduced in a risk managed way. A life-cycle approach to performance data, using RWD, offers benefits to all and could lower the cost of introducing technologies to markets, whilst enhancing rates of adoption of successful interventions. Equally, less successful ones can be modified or withdrawn in a timely manner. Success must be defined by the impact that the product or service has on specific outcomes, relative to its costs. Indeed, from the perspective of medicines, in order to deliver the highest value care, we must gain a better understanding of the true impact of medicines after adoption, given the limitations of randomised controlled trials and the frequent paucity of generalisable evidence available for health technology appraisals.

A policy decision is typically taken on whether the cost-effectiveness of an intervention is acceptable. If it is, then the procurement of the intervention or programme can take place. In such reimbursement decisions it is the public that pays, and therefore consensus is that outcomes are valued by members of the general public, often using classification systems such as the EQ-5D. (65) Since the public may have different priorities from those of patients, it is not unthinkable that policy decisions based on cost-effectiveness are different from those in PCVBHC. Further research is needed to explore how to bring the principles of PCVBHC and cost effectiveness analysis together. (66)

Ultimately, through determining the goals and therefore, the outcomes, processes and structures that matter to individuals, clinicians must then target medicines and technologies appropriately. It is then acceptable to consider linking remuneration to the achievement of those outcomes and delivery of the agreed processes and structures.

As highlighted throughout this report, in a world of finite resources there will always be decisions to be made about allocation of those resources. A focus on the individual's right to pursue a specific outcome is acceptable but a focus on a specific treatment in order to achieve a specific outcome may be in tension with the health system's responsibilities to improve population outcomes equitably. It is necessary to disaggregate choices about the allocation of pooled societal resources and understanding the goals and preferences of individuals. We need to understand the goals of individuals and clinicians must work to try and achieve those goals. Policy makers and system leaders must make defensible choices about the allocation of pooled

societal resources and they must be explicit and transparent about the values that guide those choices. It is then for patients and clinicians to work together, within the envelope of allocated resources, to figure out how best to achieve the goals. Clearly, the more an individual's values align with those values, the greater the alignment between person-centred and value-based health care decisions should be.

Macro level

At the macro level, the presentation of the outcome, process, structure and resource data would enable comparison between the different parts of the system, which would be important for learning and improvement, accountability, management and resource allocation. This has been achieved by the NHS in Wales through the development of national balanced scorecards for a range of conditions across the spectrum of chronic disease and cancer. It would also be possible to have a view of entire system level performance which could help with comparing performance to other health care systems and countries.

The development of policy and the design and evolution of health care systems should benefit from the systematic and structured input of patient organisations.

6.0

Bringing this all together

Micro level

At the micro level, we focus on individual people receiving care and, through shared decision making, seek to understand their goals. We then link their goals to standardised metrics – outcomes, processes and structures. The metrics for processes and structures reflect what is possible for a given system. We also collect data on individual patient characteristics (demographics and pre-existing medical conditions).

This approach enables personalisation and standardisation to be brought together.

Meso level

At the meso level, care pathways and services are co-designed with people receiving care. Aggregated standardised micro level data ensures a continued focus on what matters most to individuals. Combining this with data on resources used, supports quality improvement, guideline development, resource allocation and Real World Evidence generation to support assessment of the effectiveness of medicines and technologies.

At both the meso and macro levels policy makers and health care system leaders have a duty to improve population outcomes equitably and must transparently state the values and decision-making criteria that underpin resource allocation decisions.

Macro level

At the macro level, partnerships with patient organisations support the development of health care policy and health care system design. Aggregated data (outcome, process, structure and resource) is used to support comparison between services across an entire system and to understand whole system performance.

At all levels we are focusing on what matters most to people. This is because the standardised outcome, process and structure data reflects the goals of individuals.

7.0

What are the implications for implementation?

Implementing PCVBHC requires that we reflect on core conditions and constraints, and search for facilitators and enablers. Issues of costs and resources will also need to be addressed and we will need to identify areas where further research is required.

Core conditions

In creating a PCVBHC system, there are certain core conditions that need to be present. These include a commitment to:

- The importance of individual autonomy in determining goals of care.
- The meaningful involvement of people receiving care in health care system and service design and health policy.
- Equity between different population groups, in the context of finite resources.
- Integrity of professionals and integrity of people receiving care.
- Continual learning, development and support of people receiving care and professionals.
- A focus on the patient experience.

Equity

All health care systems have finite resources and therefore, it is not possible to achieve everyone's goals and to follow everyone's preference.

Therefore, at the macro level, health care systems need to decide how much money they are going to invest, whether in particular health conditions or in particular organisations, and the outcomes they expect for such investment. According to the principles of PCVBHC, we are aiming to achieve the outcomes, processes and structures that matter most to individuals. Depending on the system, at the meso and/or macro levels, leaders need to decide in which products and services they will invest to make this happen. These decisions need to be informed by Cost Effectiveness Analysis (CEA) and based on the principles of equity. As stated earlier, value judgements on

equity must be stated explicitly and transparently. This can be supported by approaches that enable extensive participation by members of the general population. (67) Clinical teams at the level of individual people then need to decide how to achieve the goals of people receiving care, within the envelope of the funded services and products.

Key enablers

System design

Organisational and system leaders need to consider the change in approach that could be required so that PCVBHC can be achieved. Most importantly, it needs to be sustainable and therefore, must not increase the workload for clinicians. For example, it may be necessary to:

- Restructure consultations, with longer initial consultations for goal setting and the dedication of specific team members to the goal setting process
- Introduce more remote monitoring using PROMs
- Use data dashboards to support decision making

Systems might also establish mechanisms to verify that the processes being followed to determine goals and to collect and use data are rigorous, honest and efficient. This could be achieved through independent audit. In the spirit of PCVBHC, the audit methodology and results should be transparent and could be reported to the health system regulator who could have the authority to act if problems are identified.

Alignment

The strategy for an entire organisation and/or system must be underpinned by a clear vision and framework. PCVBHC aims to provide that vision and framework. The different teams that make up the organisation and their respective strategies for achieving PCVBHC must then be aligned – this is particularly the case for the patient engagement strategy, digital strategy, clinical strategy, financial strategy and procurement strategy. This requires a trusted collaboration between clinicians, operational leaders, finance leaders, procurement leaders, digital leaders and patient representatives.

Technology

While it is possible to use a paper-based approach, technology acts as an enabler and we strongly encourage the use of technology to implement PCVBHC. Dedicated software can support the capture of outcomes in the clinic, in hospital or remotely. Electronic Medical Records (EMRs) and personal digital environments can support the electronic completion and storage of goals and the integration and visualisation of outcome, process

and structure data. Mobile telephones have significant potential in supporting a PCVBHC approach. They have already been shown to enable the completion of outcome questionnaires – an approach that has tremendous potential globally, but particularly in LMICs. (39)

Education

Many health care systems are working to move to a value-based approach; we need to support this continued transition and at the same time embed the principles of PCVBHC. This should be through structured education programmes for patients and professionals, which should include approaches to goal setting and shared decision making.

Getting started

To get started with PCVBHC, the relevant clinical teams need to be trained in the shared decision making and goal setting approaches, and they need to be equipped with the appropriate templates to support record keeping. Reorganisation of clinics may need to take place to ensure that longer appointments are scheduled for the shared decision making and goal setting sessions. This may be supported by the reallocation of resources from follow-up visits to initial goal setting sessions. Moreover, better alignment of decisions with patient preferences and goals will lead to better adherence and may lead to fewer complaints, thereby positively contributing to patient health and potentially saving time for health care professionals. (68, 69)

We also need to collect evidence that this is working. This should be through (i) the short term and long-term collection of outcomes and costs and (ii) understanding perspectives, from people receiving care and professionals working in the system, on this new approach.

Resources

If we are truly to achieve PCVBHC, we need to produce a toolkit of financial incentives to support such activity in health care delivery, whilst accepting that choices will always need to be made about the adoption of medicines, devices and care processes. Decision-making must incentivise:

1. the elimination of 'no value care', i.e. care that is aimed at outcomes that the individual person receiving care does not value.
2. care processes that address systemic inequity in health, health care access and health care outcomes.
3. decision processes that are transparent at micro, meso and macro levels of the health care system.

Finance toolkits must incentivise excellence through:

- Optimising standard processes.
- Reducing variation that does not reflect heterogeneity in patient goals and preferences.
- Avoiding under-provision of treatment that patients value.
- Rewarding sustainable processes and outcomes that matter to patients.

However, finance toolkits must also incentivise investment in support for people receiving care to articulate their goals and preferences for care through:

- Culture.
- Convenience.
- Time.
- Information.
- Avoidance of the harms of over-treatment.

Low and Middle Income Countries

All aspects of this report apply to LMICs. Given the limited legacy systems in place, LMICs are very well positioned to incorporate the principles of PCVBHC as they further develop their universal health care systems. Since the COVID-19 pandemic, health inequality in LMICs has increased. This only reinforces the need to focus on PCVBHC principles. Certain LMIC populations may not be used to expressing their preference in a health care context - as such, priority may need to be given to education of health care professionals, supporting the move away from a paternalistic model to a model focused on PCVBHC.

Social care

This report has not considered the application of PCVBHC to social care. Integration of health and social care is a key global policy objective and so it is the intention that this would form a future piece of work.

8.0

Moving forward

Many health care systems are working to move to a value-based approach; we need to support this continued transition and at the same time embed the principles of PCVBHC. We need to do this at scale.

We include below specific recommendations and ideas for key stakeholder groups. However, our overall recommendation is that all stakeholders should come together and work together to develop a true multi-stakeholder strategy for PCVBHC that sees a shared responsibility for its development and delivery. In line with this, all stakeholders must also align on a consistent approach to communication to ensure that the health care workforce, people receiving care and society at large understand the rationale for PCVBHC and the approaches that underpin it.

People receiving care

PCVBHC provides people receiving care with the opportunity to tailor health care towards their explicit goals. It further equalises the partnership between people receiving care and clinical teams. In order to make this a reality, we recommend:



Local, national and international patient advocacy groups and specialty societies should systematically work together to empower people receiving care through the provision of education and continuous skills development. This should focus on (i) patient activation, (ii) the process of Shared Decision Making, (iii) the process of goal setting and (iv) specific information about their health condition. This should be promoted by national governments and health care systems and it should be part of the formal operating model of patient advocacy groups and specialty societies.

Further efforts should be made to ensure structured involvement of people receiving care in health care service and system design and strengthening, drawing on internationally recognised examples of good practice.

Health care systems

Health care systems need to focus on the outcomes that matter to people – if they do not do this then the resources they are using are potentially wasted. Health care systems also need to embrace digital technology as digital tools are key enablers for PCVBHC. In order to make this a reality, we recommend:



Health care systems should determine how to operationalise PCVBHC in their own context. Such a strategy should consist of:

- The vision for PCVBHC
- Their key goals over the next 5 years to support achieving the vision, which should include their roll-out goals and an assessment of their current PCVBHC status
- Their key activities for achieving the goals, which should include their roll-out strategy
- Key Performance Indicators and a workable approach to evaluation

They should begin the approach in a small part of their system and then gradually scale, rolling out across their system. It should be jointly led by clinicians and people receiving care. The professionals in the area(s) where they begin should be trained in the principles of PCVBHC, shared decision making and goal setting. Clinic lengths should be changed and templates should be prepared whether for use on paper or through technology, enabling the presentation and use of balanced score cards by people receiving care and by professionals at different levels of the system.

All Low and Middle Income Countries should incorporate PCVBHC into their strategic plans for the development and evolution of their universal health care systems.

People receiving care and their clinical teams should be able to view their goals, outcomes, processes and structures to track the extent to which the goals are being achieved, in an individualised balanced scorecard (Figure 5). These should be viewable at any time, from anywhere, whether paper based, part of an Electronic Medical Record or via patient or personal health portals. Indeed, we know that web-based communication aids can support communication and understanding between people receiving care and health care professionals when it comes to goals and preferences. (70)



The scorecard should form part of the consultation to help focus the discussion on areas of unmet need and through shared decision making, co-produce individualised plans for people receiving care.

Collected data should be made available, with appropriate governance and privacy protection, to researchers, including life science companies.

Data privacy should be managed in line with existing data protection standards.

Further specific work is needed to understand the financial mechanisms and wider incentives required at micro, meso and macro levels to address the points raised, taking us towards the 'best fit' between person and population.

Balanced Scorecard

Disease area – Breast Cancer

Goals

Through shared decision making, we define people's goals and list these in the medical record. These would be written as free text, following the SMART principles.

For example:

1. "I want to live a length of life as close to normal for someone who has not had cancer"
2. "I want my breast reconstruction to look normal in my bra"
3. "I want to continue to work full time in my present busy job without debilitating side effects"

There would be a traffic light system next to each goal to show the progress in achieving each goal

Outcomes

Through shared decision making, we would match the goals to standardised outcomes. For illustrative purposes, the outcomes below have been taken from the ICHOM dataset.

Survival: "Overall survival"

Breast-Q

Quality of Life:
EORTC QLQ-C30*

Processes

Through shared decision making, we would match the goals to standardised processes. These would include treatment related processes which would support achieving the desired goals and outcomes. It would also include specific processes that are directly linked to specific goals.

Structures

Through shared decision making, we would match the goals to standardised structures. These would again be used to support achieving the desired goals and outcomes.

The scorecard would enable you to click on the specific outcomes, processes and structures to see the results

* EORTC QLQ-C30: European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire, Core-30. Quality of Life questionnaire for people with cancer.

Figure 5: An example of a micro level balanced scorecard

Payers

Payers in different parts of the world, whether insurance companies, government agencies, development organisations or individuals are increasingly committed to the concept of linking reimbursement to the actual value achieved. This is commonly referred to as value-based procurement. To date, this has typically been through the achievement of predefined outcomes with predefined definitions of success. This has been a positive step away from simply reimbursing based on volume. This needs to evolve to a PCVBHC approach. This is in the interest of payers as it ensures that they are paying for care that patients actually want and it has the potential to attract customers and to reduce claims. In order to make this a reality, we recommend:



Payers should link payment to the standardised outcomes that are being captured (which would reflect the goals of people) and they should agree on definitions of success with patient and provider organisations. Payers should also link payment to processes of care that prioritise the role of patient choice and articulation of goals.

In collaboration with patient and provider organisations, payers should start small in one health condition and build in a clear mechanism to extract learning to expand to other health conditions in due course. When performing their value assessments, HTA agencies need to take into account the goals, outcomes and preferences of people receiving care.

The health care workforce

PCVBHC supports the health care workforce in working with people to truly achieve what matters to them. This is why most people work in health care. We have only included one recommendation for the health care workforce as we hope all of the other recommendations will enable them to work in a way that is consistent with PCVBHC and indeed their own values.



PCVBHC should be part of the curriculum for continuous professional development for all stakeholders working within and in partnership with health care systems. PCVBHC should also be part of the curriculum at the undergraduate and postgraduate levels of all health care professions. Learned societies, universities, postgraduate education providers and regulators are therefore responsible for making this change.

Life science companies

Definition: for the purposes of this report, life science companies refer to pharmaceutical companies and medical technology companies. Life science companies should continue to develop products that are assessed based on their ability to deliver outcomes that matter to people, not simply biological endpoints. However, it is important that their medicines, technologies and medical products are applied to the right people at the right time to achieve their goals. In order to make this a reality, we recommend:



Companies should continue to increase their meaningful practice of patient engagement in the life cycle of medicines, technologies and medical products – from research prioritisation to the design of randomised control trials to pharmacovigilance, safety monitoring, RWE collection and appropriate disinvestment.

Companies should work with health care systems to develop collaborative approaches that ensure their medicines, technologies and medical products are targeted at the right people receiving care, addressing their desired goals. Companies should work with health care systems to build reimbursement and procurement models that are based around the value delivered.

In line with the recommendations above, companies should also be willing to partner with other life science companies to achieve these objectives. Companies should be seen as partners and not funders.

Academia

Academia must continually evolve the PCVBHC framework and must further understanding of the components that underpin PCVBHC. We therefore recommend that:



Universities develop research programmes to further support the evolution, implementation and evaluation of PCVBHC. Universities support the teaching of PCVBHC approaches.



We encourage all health care systems to adopt the recommendations, frameworks and principles outlined in this report.

In order to support adoption, we would like to accompany and learn from a small number of exemplar projects.

We are actively identifying systems to be exemplars and would encourage any interested organisations/systems to contact the Project Lead.

Moving Fo

A healthcare professional in blue scrubs is assisting a young woman with a walker. The woman is smiling and looking down at the walker. The professional has his hands on her shoulders, providing support. The scene is set in a clinical or hospital environment with a bed and a window in the background.

rward

9.0

Appendix 1: Glossary of Terms

| Word | Definition |
|----------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| EORTC QLQ C-30 | European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire, Core-30. Quality of Life questionnaire for people with cancer. |
| Equity | As defined by the Cambridge Dictionary - the situation in which everyone is treated fairly and equally. |
| Experience | What the process of receiving care feels like for the patient, their family and carers. (15) |
| Macro | Population health outcomes and the associated regulatory, policy and financial decision making in health care. (24) |
| Meso | Interaction at the level of the institution, hospital, care pathway(s). (24) |
| Micro | One-to-one interaction between individuals and their clinical team. (24) |
| Outcome | A milestone, consequence or endpoint that matters to a person. |
| Process | The process of care itself, determining whether what is known to be “good” care has been applied. For example, (i) the application of evidence-based guidelines, (ii) technical competence in the performance of diagnostic and therapeutic procedures. (12) |
| Structure | The settings in which care takes place. For example, the facilities and equipment, the qualifications of staff. (12) |

10.0

Appendix 2: Community of Experts

| Name | Organisation | Location |
|------------------------|---------------------------------------------------------------------------------------|------------------------|
| Thomas Allvin. | European Federation of Pharmaceutical Industries and Associations (EFPIA). | Belgium. |
| Willem Jan Bos. | Leiden University Medical Center (LUMC). | Netherlands. |
| Bruno Bruins. | Previously: Ministry of Health. | Netherlands. |
| António Vaz Carneiro. | University of Lisbon. | Portugal. |
| Alf Collins. | NHS England. | UK. |
| Julie Davey. | Independent patient advocate. | Australia. |
| Toni Dedeu. | World Health Organization. | Denmark. |
| Angie Hamson. | Health Standards Organization (HSO). | Canada. |
| Saranya Loehrer. | Institute for Healthcare Improvement (IHI). | USA. |
| Chris McCabe. | Institute of Health Economics. | Canada. |
| María Navarro. | Hospital Sant Joan de Déu. | Spain. |
| Christobel Saunders. | University of Western Australia. | Australia. |
| Kawaldip Sehmi. | International Alliance of Patients' Organisations (IAPO). | UK. |
| Nicole Spieker. | PharmAccess. | Netherlands and Kenya. |
| Airton Tetelbom Stein. | Federal University of Health Sciences of Porto Alegre and Grupo Hospitalar Conceicao. | Brazil. |
| Sean Tunis. | U.S. Food and Drug Administration (FDA). | USA. |
| Zoe Wainer. | BUPA Australia and New Zealand. | Australia. |
| John Wilkinson. | Previously: Medicines and Healthcare products Regulatory Agency (MHRA). | UK. |
| Adam Wolf. | Danish Regions. | Denmark. |

11.0

Appendix 3: Industry Advisory Panel

| Name | Organisation | Location |
|---------------------|----------------------------------------------------------------------------|--------------|
| Thomas Allvin* | European Federation of Pharmaceutical Industries and Associations (EFPIA). | Belgium. |
| Dineke Amsing. | Dutch Association of Innovative Medicines. | Netherlands. |
| Karin Cerri. | Johnson and Johnson. | Belgium. |
| Kristina Dziekan. | Alcon. | Switzerland. |
| Eszter Kacs Kovics. | Essity. | Hungary. |
| James Kinniburgh. | Boehringer-Ingelheim. | Germany. |
| Etienne Laine. | Roche. | Switzerland. |
| Michele Mestrinaro. | Novartis. | Switzerland. |
| Gabriela Prada. | Medtronic. | USA. |
| Philip Schwab. | Abbvie. | France. |
| Meni Styliadou. | Takeda. | Switzerland. |
| John Wilkinson*. | Previously: Medicines and Healthcare products Regulatory Agency (MHRA). | UK. |

* Co-chairs of the IAP

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Appendix 4: Project Team

| Name | Role | Organisation | Location |
|----------------------|-----------------------------------------------------|-----------------------------------|------------------|
| Nicola Bedlington. | Co-Chair. | Millwater Partners. | Austria. |
| Thomas Kelley. | Project Lead. | Sprink. | UK. |
| Martha Kidanemariam. | Project Team Member and Research Fellow. | Leiden University Medical Center. | The Netherlands. |
| Sally Lewis. | Co-Chair. | NHS Wales. | UK. |
| Anne Stiggelbout. | Project Team Member and Research Fellow Supervisor. | Leiden University Medical Center. | The Netherlands. |

Appendix 5: Literature review, eligibility criteria and search strings

Research question 1:

What is the evidence on patient reported outcomes, preferences and goals (referred to as 'inputs') supporting medical consultations to identify what matters to patients and support decision making?

Research question 2:

What is the evidence on patient reported outcomes, experiences, preferences and goals (referred to as 'inputs') supporting co-creation and management of care pathways and decision making at the meso- and macro level (related to development of guidelines, health technology assessment, cost effectiveness analysis and resource allocation)?

Sub questions:

1. What are the core conditions and/or key-enablers/barriers/implementation strategies described to support the implementation of these inputs?
2. In what way are the answers to questions 1 and 2 different for high-, middle- and low-income countries?
3. To what extent are standardized measures reflective of patient goals and sensitive to changes in patient goals over time?
4. What are the implications of implementation of these inputs in relation to equity and opportunity costs?

Review strategy:

We searched the MEDLINE database using search strings based on text words as described below. These search strings have been drafted in collaboration with a librarian from the Leiden University Medical Center. The research fellow MK or research fellow supervisor AS screened papers to select eligible papers in two rounds, firstly based on title/abstract and secondly the selected papers based on full text documents, assessing criteria as stated below. Lastly, reference lists from selected papers and reviews on the same or related topics, will be examined to identify additional eligible primary papers.

Eligibility criteria:

Eligible study designs/type of publication:

Experimental and quasi-experimental study designs (randomised or non-randomised controlled trials, controlled and uncontrolled pre-post studies and (multiple) interrupted time series). Quantitative descriptive and analytical observational studies (retrospective and prospective cohort studies, case-control and cross-sectional studies, case studies). Qualitative studies. Systematic reviews, meta-analyses, scoping reviews, overview papers, and narrative reviews were used as background references throughout the report. References of reviews will be checked.

Letters to the editors, opinion papers, guidelines, papers on meetings of expert panels and published research protocols of studies not yet completed were excluded.

Papers brought in by community members and not yielded by our MEDLINE search will be considered if fulfilling criteria below.

Inclusion criteria:

- 1) Paper describes implementation and empirical evaluation of at least one of the 'inputs' in a (health) care setting

Exclusion criteria:

- 1) Paper is written in another language than English or Dutch.
- 2) Paper was published prior to 01-01-2000.
- 3) Paper describes implementation and evaluation of 'inputs' in Advance Care Planning.

MEDLINE Search strings

Search string 1

("Patient Reported Outcome Measures"[Mesh] OR "Patient Reported Outcome*" [tw] OR "patient-reported outcome*" [tw] OR "Patient Reported Outcome measure*" [tw] OR "patient-reported outcome measure*" [tw] OR "Patient Outcome Assessment"[Mesh] OR "outcome data" [tw] OR "prom" [tw] OR "proms" [tw] OR "patient reported data" [tw]) AND ("Clinical Decision-Making"[Mesh] OR "Decision Making, Shared"[Mesh] OR "Decision making" [Mesh] OR "Decision Support Techniques"[Mesh] OR "Shared Decision making*" [tw] OR "Shared-decision making*" [tw] OR "SDM" [tw] OR "shared decision*" [tw] OR "shared-decision*" [tw] OR "decision making*" [tw] OR "decision-making*" [tw] OR "medical decision*" [tw] OR "treatment decision*" [tw] OR "clinical decision*" [tw] OR "Person-Centered Psychotherapy"[Mesh] OR "Patient-Centered Care"[Mesh] OR "Patient centered*" [tw] OR "patient centred*" [tw] OR "person centred*" [tw] OR "person centered*" [tw] OR "patient-centred*" [tw] OR "person-centred*" [tw] OR "patient-centered*" [tw] OR "person-centered*" [tw] OR "patient goal*" [tw] OR "patient treatment goal*" [tw] OR "Patient Preference"[Mesh] OR "patient preference*" [tw] OR "outcome preference*" [tw] OR "patient narrative*" [tw] OR "patient reported data" [tw] OR "patient assessment*" [tw] OR "patient input*" [tw]) AND ("Remote Consultation"[Mesh] OR "remote consultation*" [tw] OR "Videoconferencing"[Mesh] OR "Videoconferencing" [tw] OR "video-conference" [tw] OR "videoconferen- ce" [tw] OR "Telephone consultation*" [tw] OR "Teleconsultation*" [tw] OR "medical consultation*" [tw] OR "doctor patient communication*" [tw] OR "doctor-patient communication*" [tw] OR "conversation*" [tw] OR "clinical encounter*" [tw] OR "encounter*" [tw] OR "consultation*" [tw])

Search string 2

("patient goal*[tw] OR "patients goal*[tw] OR "patient treatment goal*[tw] OR "patients treatment goal*[tw] OR "treatment goal*[tw] OR "*care goal*[tw] OR "personalised goal*[tw] OR "personalized goal*[tw] OR "patient narrative*[tw] OR "patient input*[tw] OR "patients input*[tw] OR "Patient Preference"[Mesh] OR "patient preference*[tw] OR "patient outcome preference*[tw] OR "patient treatment preference*[tw] OR "patient value*[tw]) AND ("Clinical Decision-Making"[Mesh] OR "Decision Making, Shared"[Mesh] OR "Decision making"[Mesh] OR "Decision Support Techniques"[Mesh] OR "Shared Decision making*[tw] OR "Shared-decision making*[tw] OR "SDM"[tw] OR "shared decision*[tw] OR "shared-decision*[tw] OR "decision making*[tw] OR "decision-making*[tw] OR "medical decision*[tw] OR "treatment decision*[tw] OR "clinical decision*[tw] OR "Person-Centered Psychotherapy"[Mesh] OR "Patient-Centered Care"[Mesh] OR "Patient centered*[tw] OR "patient centred*[tw] OR "person centred*[tw] OR "person centered*[tw] OR "patient-centred*[tw] OR "person-centred*[tw] OR "patient-centered*[tw] OR "person-centered*[tw] AND ("Remote Consultation"[Mesh] OR "remote consultation*[tw] OR "Videoconferencing"[Mesh] OR "Videoconferencing"[tw] OR "video-conference"[tw] OR "videoconference"[tw] OR "Telephone consultation*[tw] OR "Teleconsultation*[tw] OR "medical consultation*[tw] OR "doctor patient communication*[tw] OR "doctor-patient communication*[tw] OR "conversation*[tw] OR "clinical encounter*[tw] OR "encounter*[tw] OR "consultation*[tw])

Search string 3

("Patient Reported Outcome Measures"[Mesh] OR "Patient Reported Outcome*[tw] OR "patient-reported outcome*[tw] OR "Patient Reported Outcome measure*[tw] OR "patient-reported outcome measure*[tw] OR "Patient Outcome Assessment"[Mesh] OR "outcome data"[tw] OR "prom"[tw] OR "proms"[tw] OR "patient reported data"[tw] OR Patient Reported Experience Measure*[TW] OR PREM*[tw] OR ((patient*[tw] AND (satisfaction*[TW] OR Experience*[TW] OR Opinion*[TW] OR Perspective*[TW])) OR "Patient Preference"[Mesh] OR "patient preference*[tw] OR "patients preference*[tw] OR "patient outcome preference*[tw] OR "patient treatment preference*[tw] OR "patient value*[tw] OR "patient narrative*[tw] OR "patients narrative*[tw] OR "patient input*[tw] OR "patients input*[tw] OR "patient goal*[tw] OR "patients goal*[tw] OR "patient treatment goal*[tw] OR "patients treatment goal*[tw] OR "patient care goal*[tw] OR "patients care goal*[tw] OR "personalised goal*[tw] OR "personalized goal*[tw] AND ((Co-creat*[tw] OR co-design[tw] OR stakeholder participant*[TW] OR Patient participant*[tw] OR "resource allocation"[Mesh] OR "resource allocation*[tw] OR Allocative Efficiency*[TW] OR allocative value[tw] OR "Decision Making, Organizational"[Mesh] OR "healthcare decision making"[tw] OR "healthcare decision-making"[tw]) AND ("Critical Pathways"[Mesh] OR Critical Pathway[TW] OR Clinical Pathway*[TW] OR "carepath*[tw] OR "care path*[tw] OR "IPU"[tw] OR IPus[tw] OR "integrated practice unit*[tw] OR "integrated

care*[tw] OR "collaborative care"[tw] OR "multidisciplinary care"[tw] OR "health technology assessment*[tw] OR "Technology Assessment, Biomedical"[Mesh] OR "HTA"[tw] OR "clinical guideline*[tw] "clinical guideline*[tw] OR "practice guideline*[tw] OR "guideline develop*[tw] OR "Guidelines as Topic"[Mesh] OR "Practice Guidelines as Topic"[Mesh] OR "Benchmarking"[Mesh] OR "benchmark*[tw] OR "outcome compar*[tw] OR "cost-effect*[tw] OR "cost effect*[tw] OR "cost benefit*[tw] OR "Cost-Benefit Analysis"[Mesh] OR "meso-level"[tw] OR "macro-level"[tw]))

14.0

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