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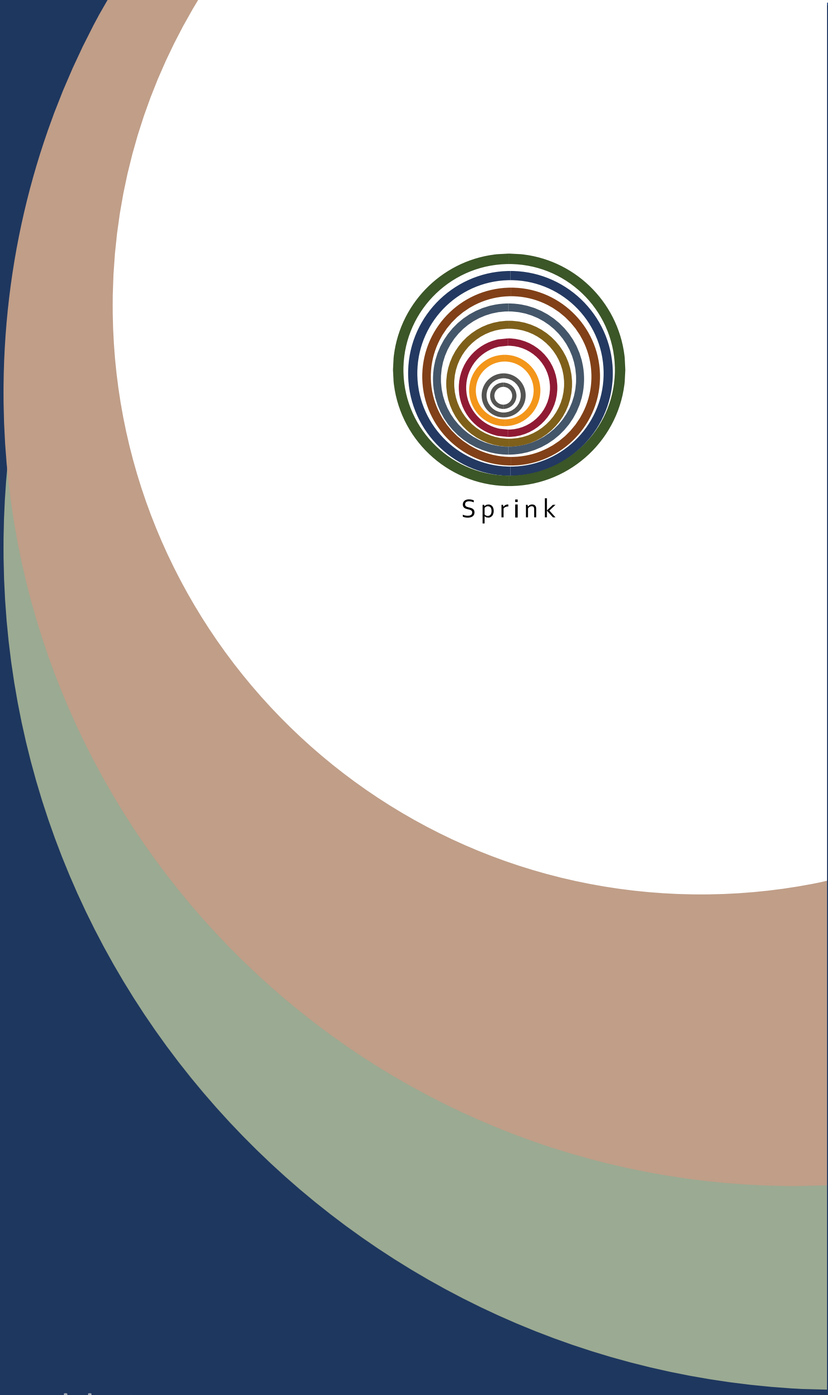

Sprink

Person-Centred Value-Based Health Care

Enabling people accessing care and their clinicians to collaborate in a shared goal-setting and decision making process to align care to personal values, goals and preferences.

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Industry Advisory Panel

The Industry Advisory Panel provided valuable input into the research and development of this Report; however, the authors had the ultimate responsibility for its final approval to mitigate any perceived or actual bias.

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Please note: Industry Advisory Panel affiliations are provided in Appendix III.

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We all recognise that the authors are each individual leaders in this field and have contributed, over many years, a tremendous amount of thinking, practical insight and usable tools, to the fields of goal setting, understanding preferences and shared decision making. We hope this Report shines a light on much of this work to raise awareness among stakeholders around the world. We also hope that, together, we have been able to provide some novel analysis which will help with practically understanding the values, goals and preferences of people accessing care.

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About Sprink

Sprink is an organisation that focuses on supporting people to achieve the outcomes that matter to them sustainably.

In order to achieve this vision, we focus on two areas: (i) Person-Centred Value-Based Health Care (PCVBHC) and (ii) the creation of Healthy Food Environments (HFE) in health care systems and wider society.

Sprink is organised into four divisions.

- **Division 1.** Global Centres of Excellence in PCVBHC and HFE. These have a membership structure and focus on developing open-access research, delivering virtual education programmes and convening conferences around the world.
- **Division 2.** This focuses on using Sprink's structured methodologies to develop and implement value-based public private partnerships between health care systems and life science companies (including pharmaceutical companies, medical technology companies and food companies).
- **Division 3.** This focuses on delivering commissioned qualitative research, bespoke education programmes and decarbonisation of food services.
- **Division 4.** This focuses on developing novel technology, with a focus on personalisation. We have recently launched a novel PCVBHC technology which enables the capture, measurement and aggregation of people's values, goals and preferences.

Sprink has many different ways of collaborating with organisations. If you are interested to find out more, please email enqiries@sprink.co.uk

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Prioritising personalised care in health care: A balancing act of measurement and compassion

Our intention with this Report is not only to provide guidance on eliciting and using personal values, goals and preferences but also to emphasise the significance of measuring their achievement. This data is crucial for understanding patients' priorities, guiding best practices, shaping policy development, driving research, and optimising resource allocation within health care.

However, amidst our focus on practicality and measurement we must not lose sight of the essence of health care: caring for people. We are turning away from the industrialisation of health care, recognising that the overemphasis on efficiency can sometimes hinder our ability to provide personalised, careful and kind care.

“When we speak of ‘kind’ care, we're not just referring to being nice; rather, it signifies our commitment to respecting our patients' goals and priorities in life. Illness interrupts lives, and our aim is to provide care that is minimally disruptive and tailored to individual needs”. –Professor Victor Montori, Mayo Clinic.

The primary focus remains on care itself, with the ultimate goal of enhancing the care provided to individuals. It is essential to remember that measuring what is important to people shouldn't dehumanise care but rather equip health care systems with the tools and skills to better care for others.

1.0 Introduction

The challenges facing health care systems around the world are well understood – in summary: growing demand, constrained financial resources and a workforce crisis. If high quality health care that supports people to live the lives they want to live is to be provided, we need to rethink the relationship between people and the services that provide their care.

Value-Based Health Care (VBHC) aims to sustainably improve the outcomes that matter to people by organising care around individuals with a specific condition, standardising outcome and cost measurement, and then using this data to monitor and compare performance within and between organisations, with the aim of stimulating learning and improvement. In VBHC, value is defined as the achievement of the best possible outcomes for individuals at the lowest possible cost.[1]

Person-Centred Health Care (PeCHC) is about focusing on the needs of individuals. Dimensions of person-centredness that have been described in the literature include: (1) shared decision making, (2) acknowledging each person as a unique individual, (3) care professionals developing a holistic view, considering all aspects of life of the person, (4) respectful communication and building a therapeutic alliance, (5) co-ordinated and integrated care, and (6) qualities of clinicians such as empathy and self-awareness. PeCHC principles also encourage meaningful involvement of the individual in the design of care delivery.[2,3]

All health care systems have finite resources which must be equitably allocated to different health conditions and to different population groups. Value judgements on equity must be stated explicitly and transparently. Aggregated goals and preferences at the micro level must inform resource allocation decisions at the meso and macro levels. Once choices have been made on the allocation of resources, it is then for individuals and their clinicians to decide how best to meet their personal values, goals and preferences within the envelope of resources available.

This is the essence of Person-Centred Value-Based Health Care (PCVBHC): linking personal values, goals and preferences in PeCHC with the principle of standardised measurement and benchmarking in VBHC, underpinned by the equitable allocation of finite resources.

As a first step in achieving PCVBHC, we need to understand how we can enable people accessing care and their clinicians to collaborate in a shared goal-setting and decision-making process to align care to people's personal values, goals and preferences. The initial perception of personalising care can seem overwhelming and resource-intensive. This Report is strategically crafted with the explicit objective of dissecting this apparent complexity and transforming it into tangible, actionable opportunities for implementation. Rather than viewing personalisation as a daunting challenge, the Report seeks to provide a comprehensive roadmap that organisations and clinicians can follow to effectively integrate personalised care into their practices.

*(1) Please note, wherever possible throughout this Report, we refer to "people accessing care" rather than "patients".

*(2) Please note, throughout this Report, the word "clinician" applies to any clinician who works one-on-one with people accessing care, diagnosing or treating conditions.

2.0 Call for action

PCVBHC represents an evolution, bringing together three concepts: Value-Based Health Care, Person-Centred Health Care and Health Equity. At the core of this evolution is the true empowerment of individuals accessing care, with a focus on working collaboratively with their clinicians, to develop personalised care plans. We must move away from a one-size-fits-all approach in health care – both in delivery and in measurement of quality and effectiveness – to systems that respect and incorporate the uniqueness of each person's needs and aspirations.

The alliance between the individual accessing care and the Clinician(s) must focus on developing a shared understanding of personal values, goals and preferences. This is the only way that we can truly understand value in health care. Through understanding this data at the micro level, we can then begin to aggregate it to inform decisions at the meso and macro levels.

As a first step, we invite all stakeholders to digest this Report and to begin to develop a focus on understanding the personal values, goals and preferences of people accessing care and then using this data to guide the care that is provided.

How to get started

Use this practical Report as a comprehensive resource hub, offering knowledge, tools, resources, and information designed to guide and empower both individuals accessing care and clinicians in initiating and navigating the collaborative care journey.

Together, let's champion a health care paradigm where collaboration, personalisation, and shared decision making are not just ideals but everyday realities.

3.0

Methodology summary

The methodology for this project consisted of ten steps, managed by the Project Lead. The detailed methodology can be found in Appendix I. This methodology ensured a structured and collaborative approach to producing the final Policy Report.

Methodological steps

Step 1: Community of Experts and Industry Advisory Panel selection.

An international, multi-stakeholder Community of Experts (CoE) was assembled (Appendix II). Experienced patient advocates were a central part of the CoE. Input from individual pharmaceutical and medical technology companies was obtained via a separate Industry Advisory Panel (IAP) (Appendix III).

Step 2: First meeting with CoE and IAP.

Separate virtual meetings were held with the CoE and IAP to identify themes that would shape the project questions.

Step 3: Second meeting with CoE and IAP.

Additional virtual meetings were conducted with the CoE and IAP to co-design specific project questions.

Step 4: Finalisation of project questions.

The project questions were finalised by the CoE Chair, IAP Chair, Project Lead and Research Fellow.

Step 5: Pragmatic literature review.

The Research Fellow conducted independent searches for each project question, limited to literature reviews in MEDLINE OvidSP and EMBASE OvidSP from 2000 to 2023.

Step 6: Grey literature review.

Grey literature searches were conducted using specific keywords and filters, followed by title and content reviews.

Step 7: Individual interviews with CoE and IAP.

Virtual interviews were conducted with CoE and IAP members, recorded, transcribed, and thematically analysed.

Step 8: Drafting the Report.

The Project Lead drafted the Report, incorporating findings from the literature reviews and interviews. It was reviewed by the CoE and IAP Chairs.

Step 9: CoE and IAP feedback on draft Report.

The draft Report was circulated to all CoE and IAP members for structured feedback, which was summarised and discussed in joint meetings to achieve consensus on edits.

Step 10: Final review by CoE.

After incorporating the agreed edits, a final version of the Report was circulated to the CoE for a final review and agreement to publish the Policy Report.

4.0

Results

4.1 Definitions of personal values, goals and preferences

The evidence emphasises the importance of tailoring health care to individual personal values, goals and preferences as a vital component of high-quality health care. This supports people to develop the knowledge, skills and confidence they need to more effectively manage their own health and health care.[4] However, current health care systems predominantly operate under a disease-oriented paradigm, whereby treatment plans target underlying disease mechanisms with the goal of improving disease-related outcomes. This may not adequately address people's personal values, goals and preferences. By shifting the focus from "what's the matter with the person accessing care?" to "what matters to the person accessing care," clinicians can create processes that actively seek and meet people's personal values, goals and preferences.[5]

However, there is no consensus on the definition of the terms "personal values", "goals" and "preferences" and they are often used interchangeably. Therefore, we have developed proposed definitions as described below.

I. Personal values

Personal values are what drive our decision making in life, they are the basis for our beliefs and actions; they bring meaning to our lives. Personal values can often be categorised, for example: (1) relationships and connections, (2) sense of productivity and enjoyment in life, (3) autonomy and functioning. Some people also consider health values to be a key category. Whether or not people are aware of it, each person lives their everyday lives by a set of personal values that influence their actions and behaviours. Personal values have been formed through childhood, families, relationships, education, culture and religion and tend to remain stable over time. Hence, a 'one size fits all' approach does not work when it comes to providing personalised care and support aligned to people's personal values.

A study focusing on people's values in health care identified three main categories: values related to the person and their personal context, values related to the characteristics of Clinicians, and values related to the interaction between the person and the professional. Examples include uniqueness, autonomy, compassion, professionalism, responsiveness, partnership, and empowerment.[6]

Proposed definition of personal values

Personal values are what drive us, acting as the basis for our beliefs and bringing meaning to our lives. Personal values tend to remain stable over time.

II. Goals

When people accessing care embark on a therapeutic journey, it is frequently the case that their goals are neither expressed nor solicited (by clinicians). While clinicians may feel that they can approximate individual goals informally, prior studies demonstrate that clinicians and health care systems tend to misjudge what people accessing care believe is important for their treatment and recovery. Therefore, goal-oriented care emphasises the need of a shift towards individuals setting their own goals.[7,8]

Goal-oriented care can be understood as a multifaceted, dynamic, and iterative process. This process is characterised by three stages: (1) goal elicitation, (2) goal setting and (3) goal evaluation. Goal elicitation builds a relationship between the person and the health care provider, with time and space to discuss and work towards the person's agenda. The goal-setting stage serves as a mechanism to embrace people's social context and to work together to agree on realistic goals. When this process is comprehensive, goal setting should support people, as far as possible, to continue doing what matters most to them. Goal setting can be broken down into sub-goals, to make them easier to achieve and measure (for example: I want to walk two blocks without shortness of breath). The third stage is goal evaluation, which assesses the extent to which goals have been met. During the evaluation stage, goals can be redefined and adjusted. Possible reasons to adjust goals might be that goals were unrealistic or no longer relevant to the person's situation. Goals tend to vary with life and health changes. They assist the development of individualised care plans and support people receiving care to maintain a sense of purpose and control. Goal setting also increases the involvement of people receiving care in the decision-making process. To support goal setting, people receiving care must be informed about their health condition, its likely trajectory, their prognosis, treatment options and the associated benefits and risks.

Therefore, goal-oriented care becomes a reflective process, ensuring that goals are continually assessed and adjusted as necessary.

There are two main types of goals:

- **Overarching goals:** these reflect the broader aspects of life that matter to a person, resulting in a broad description of a goal. For example: I want to live in my own home for as long as possible.
- **Sub-goals:** overarching goals can sometimes be difficult to work with and therefore, are frequently broken down into a series of sub-goals, which when taken together, support achieving the overarching goal. Sub-goals should be SMART – specific, measurable, actionable, realistic and time-bound. For example: I need to be able to get out of a chair without falling over.[9,10].

Proposed definition of goals

Goals reflect a desired end state that is typically consistent with an individual's underlying personal values. There are overarching goals and sub-goals, with sub-goals supporting achievement of an over-arching goal. Goals should be SMART: specific, measurable, actionable, realistic and time-bound.

Example

This example illustrates how goals can be used in practice, emphasising the interplay between overarching goals and sub-goals, within the context of managing long-term conditions. Dr. Patel, the primary care physician, collaborates with Ms. Rodriguez, a person dealing with multiple long-term conditions, including diabetes, high blood pressure, and osteoarthritis.

Dr Patel: Good morning, Ms Rodriguez. I understand you have been managing several long-term conditions. Today, I thought we could work together to understand your goals that we can collaboratively work towards.

Ms Rodriguez: This sounds great. I must say, it is challenging. I have been dealing with these conditions for a while now, and it feels like a constant juggling act. I just want to be able to live independently and enjoy my life again. *[An overarching goal.]*

After some back-and-forth discussion.

Dr Patel: Ms Rodriguez, based on our discussion, it seems managing your blood sugar levels and being able to walk to the shops and the café are key priorities. How about we set some measurable goals together?

Ms Rodriguez: That sounds good. I'd like to see more stable blood sugar levels and be able to walk to the shops and the café down the road each day. *[Sub-goals.]*

Dr Patel: Excellent. Let's establish specific targets for your blood sugar levels and work on a plan together that enables you to get to the shops and café. We will take it one step at a time.

Over time Dr Patel and Ms Rodriguez monitor progress and where necessary make adjustments to the goals and plan for achieving the goals.

Dr Patel: Ms Rodriguez, it has been a month since we set your goals. How have you been feeling, and have you noticed any changes?

Ms Rodriguez: I have been monitoring my blood sugar levels, and they seem more stable. However, I am still not getting out to the shops because my joints are too painful.

Dr Patel: Thank you for sharing that. It is important for us to reassess and make adjustments as needed. Let's look at how we can reduce the pain and perhaps consider consulting with a rheumatologist for specialised input on managing your arthritis. As we navigate through these long-term conditions, I want you to feel comfortable reaching out whenever you encounter challenges or changes in your health. We are partners in managing your health and well-being.

III. Preferences

Preferences are health care interventions or therapies a person wants or does not want and should support achievement of their goals.

The Ottawa Decision Support Framework defines preferences as the favoured option identified through a collaborative process between the clinician and individual. It acknowledges that in many health care situations, there may be multiple appropriate care options without a clear consensus on superiority between options. Preferences are influenced by individual informed attitudes towards the positive and negative characteristics of each care option.[11] Preferences are also influenced by past experiences and the consequences of previous decisions. An individual's positive and negative experiences are linked to the extent to which their expectations and preferences are met, emphasising the importance of treating people as individuals with specific needs.[12]

Personal values and beliefs affect health care-seeking behaviour and people's preferences to accept specific treatments. For example, in the context of religion, preferences may reflect anticipated rewards in the afterlife, or the possibility of miracles.[13] Spiritual beliefs and practices are sources of comfort, coping, and support. Religious prohibitions at end of life may result in preferences against certain medical interventions.[14]

Individuals may also have distinct preferences for where they receive care, whether it is in a traditional hospital, a community health centre, or their own home. This may be influenced by factors such as the perceived atmosphere, convenience, and accessibility of the chosen care setting.

While the value of understanding and acting on personal preferences in health care is well recognised, implementation presents a challenge to clinicians and individuals alike. To imagine what a future state of health might be like and to determine the desirability of that future state is a complex cognitive task. Attempting to do so under the stressful circumstance of the clinical encounter can burden the person to an even greater degree. The fragmented, time-limited nature of much of health care delivery often leaves little opportunity to conduct the interpersonal exploration needed to elicit and utilise individuals' preferences.

Proposed definition of preferences

Care that people are willing and able to do or to receive that is aligned to their values and that supports them in achieving their goals.

Table 1. Summary of definitions with supporting examples

	Definition	Examples
Personal values	Personal values are what drive us, acting as the basis for our beliefs and bringing meaning to our lives. Personal values tend to remain stable over time.	• I value family life and personal independence/self-reliance. • I value giving back to society, for example through volunteering.
Goals	Goals reflect a desired end state that is typically consistent with an individual's underlying personal values. There are overarching goals and sub-goals, with sub-goals supporting achievement of an over-arching goal. Goals should be SMART: specific, measurable, actionable, realistic and time-bound.	• *Overarching goal:* I want to be fully independent and not dependent on others to do the activities that are important to me. • *Sub-goals:* I want to be able to continue to work and to be able to walk my dog in the park each day.
Preferences	Preferences refer to the care that people are willing and able to do or to receive that is aligned to their values and that supports them in achieving their goals.	• I don't want to have surgery because there is a risk that it will stop me from being able to walk...and walking my dog each day in the park is something I don't want to risk losing.

4.2 Specific approaches at the micro level enabling people accessing care and their clinicians to elicit and use personal values, goals, and preferences

We will outline practical approaches to enable people accessing care and their clinical teams to elicit and use personal values, goals and preferences.

I. Building on our current approach to clinical practice

Much progress has been made over the past twenty years in personalising approaches to health care. However, this has often focused on obtaining preferences for decisions about specific interventions and procedures. Although important, this is not sufficient. We now need to build on these conversations, to understand people's personal values and goals as well as their preferences. This will support guiding individuals on the extent to which their decisions around specific interventions will or will not align with their personal values and goals.

To have a conversation about personal values, goals and preferences, it is essential to assess the understanding that people have about their condition(s). Those with a lower level of understanding may need more time and support to develop a greater understanding. It is also important to determine the extent to which people want to engage in a discussion about their personal values, goals and preferences. Franz Ingelfinger, a former editor of the New England Journal of Medicine, related most eloquently in a 1980 Special Article, that when diagnosed with cancer and flooded with options, he was in agony, craving for an authoritarian decision.[15] Therefore, personalising approaches to care and treatment is not sufficient; we must also personalise the consultation process itself so that the approach for each person is different, depending on their level of understanding and their desire to engage in discussions about their personal values, goals and preferences. Indeed, understanding people's personal values, goals and preferences, should be part of a genuine, authentic desire from clinicians to understand an individual's overall context and personal situation.

Eliciting and using personal values, goals and preferences is an ongoing and iterative process. People's needs, desires, capacities, capabilities and personal or medical situations frequently change and therefore, care plans must be flexible and modified as necessary. Ultimately, care plans must be designed for 'this person' rather than 'people like this'. For many, this represents a clear departure from a conventional consultation.

Carers can also serve as important partners in understanding and using individual personal values, goals, and preferences. They can serve as advocates for the person accessing care, ensuring that clinicians are aware of their personal values, goals, and preferences.[16] Carers can also contribute valuable information about the individual's history, preferences, and daily life, enhancing the overall understanding of their needs. However, respecting individual autonomy is paramount.[16] Carers should be attuned to individual values, goals and preferences, ensuring that the person accessing care retains control over their health care choices.[17]

Recently, an international and interdisciplinary group of people accessing care, caregivers, clinicians, scholars, health care designers, and policy makers published the 'Making Care Fit Manifesto'.[18] The principles in this manifesto should be at the forefront of the minds of all Clinicians. This manifesto describes that to make care fit, it should be: (1) maximally responsive to people's unique situation, reflecting each person's personal and medical backstory, and life circumstances; (2) maximally supportive of individual priorities, placing people's needs and wishes in the foreground, accounting for and supporting their capacity to cope, adapt and thrive and congruent with each person accessing care's personal values and their goals for life, well-being and health care; (3) minimally disruptive of people's lives, understanding that care contributes to how life is lived or aimed to be lived and that people have a finite and varying capacity to prevent disruption, to cope and to adapt and (4) minimally disruptive of people's loved ones and social networks.

Therefore, to make care fit, people and clinicians need to collaborate using person-sensitive communication, tailoring both the content and the manner of their conversation to the person's needs, abilities and to the situation. Care is built through equal person–clinician relationships, mutual respect, willingness to accept each other's contributions, empathy, humanity and dignity.

A case study

The surgical options for the treatment of early-stage breast cancer usually include mastectomy (complete removal of the breast) or lumpectomy (breast-sparing surgery with a local excision of the tumour). A series of clinical trials have shown that the impact on survival is about the same for both approaches, but the other outcomes are quite different. The consequences for women who choose mastectomy include the loss of the breast and, for some, using a prosthesis or undergoing reconstructive surgery. For women who choose breast-sparing surgery, the consequences can include having radiation and living with the risk of local recurrence, which will require further surgery. Which treatment a woman chooses should depend on her own personal values and informed goals and preferences, rather than simply relying on her physician's opinion about what they believe would be best.[19]

II. Shared Decision Making

Shared Decision Making (SDM) is a collaborative process through which a clinician supports a person to reach a decision about their treatment that is right for them, based on their personal values, goals and preferences.[20,21] This includes an informed choice to have no treatment or not changing what they are currently doing. Different models have been developed to guide the practice of SDM. The Community of Experts highlighted four models for inclusion in this Report: (1) Three-Talk Model, (2) Implement-SDM model, (3) The Ottawa Decision Framework, and (4) Purposeful SDM.[22,23,24] It is important to note that the model preference may vary among clinicians and organisations. The choice may depend on factors such as the specific health care context, the training and familiarity of clinicians with the model, and the needs and preferences of the patient population served. Ultimately, the goal is to ensure active collaboration between people accessing care and clinicians.

It has been recommended that to support the SDM process, clinicians need to:

1. **Provide information:** Clinicians need to understand what people already know, and whether it is correct. People place different levels of importance on the outcomes associated with different options and have different preferences about the processes and paths that lead to these outcomes. If people are not informed, they will be unable to assess 'what is important to them', and so establish informed preferences. The first task of SDM is to ensure that individuals are not making decisions when insufficiently informed about key issues.

2. **Support deliberation:** To support people to become aware of choice, understand their options (within the constraints of the disease and their co-morbidities, what diagnostics and treatments are available and what the system can support) and have time and support to consider what matters most to them. This may require more than one clinical contact (not necessarily face to face) and may require the use of decision support aids. Some people may feel surprised and unsettled by the offer of options and uncertainty about what might be best. Some people may initially decline the decisional responsibility role and be wary about participating in decision making.[25]

3. **Integration of personal values, goals, and preferences:** By weaving together people's personal values, goals and preferences, health care decisions become more tailored, person-centric, and reflective of the unique needs and desires of the individual involved. This integration ensures that the decision-making process is a collaborative journey aligned with the individual's vision for their health and well-being.

Description of models for Shared Decision Making

1. Three-Talk Model[26]

The 'Three Talk Model' (Figure 2) suggests key steps for SDM in clinical practice, namely: Team Talk, Option Talk and Decision Talk, where the clinician supports deliberation throughout the process.

- **Team Talk**. Refers to the step of explaining the intention to collaborate and support deliberation.

- **Option Talk**. Refers to providing more detailed information about options and working together to compare alternatives.

- **Decision Talk**. Refers to eliciting preferences and deciding on the course of action.

This model highlights three interconnected steps in establishing a person-clinician relationship: the provision of information by the clinician regarding the nature of the problem and available options, person inquiry about their preferences, and integration of informed preferences into the decision-making process.

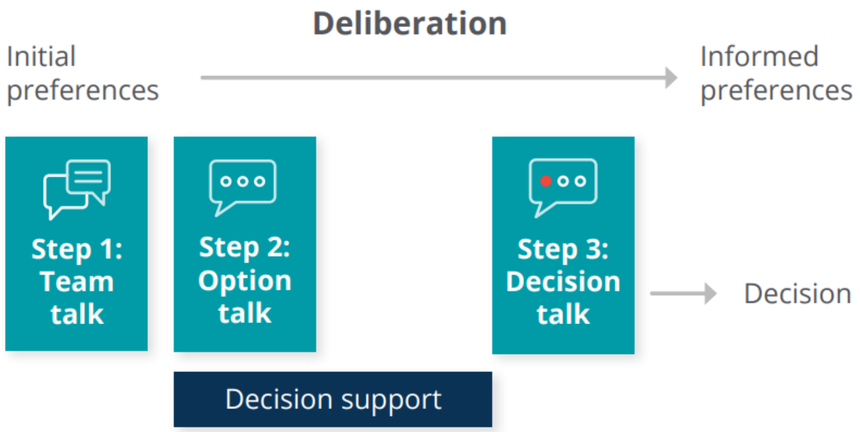


Figure 2: The Three Talk Model[27]

Traditional models of SDM have not explicitly included consideration of people's personal values and goals, which are of course central to informing preferences. Professor Alf Collins, formerly the Clinical Director, Personalised Care Group at NHS England, advocates adding an extra step to the Three Talk Model - a step that comes after Team Talk, called Goal Talk. This is where people can then describe their personal values and goals. For example: "Have you had chance to think about what you would like to achieve as a result of managing your...?", "What would you like to be able to do as a result of managing your...?"

The Three-Talk Model is a valuable framework for SDM. For example, The Health Foundation, along with NHS Wales and NHS England, applied this approach during the implementation of the three-year [MAGIC (Making Good Decisions in Collaboration) programme]().[28] One potential limitation is its linear approach, which does not seem to capture the dynamic nature of decision-making in health care and therefore, the need to frequently revisit and review decisions that have been taken at earlier points in time.[29]

2. Implement-SDM model[30]

This model reflects the distributed nature of the SDM process, spanning across time, individuals, and various health care settings. The model acknowledges the multi-staged and complex nature of many decisions, challenging the notion that SDM is solely about 'decisions.' Instead, it emphasises that SDM may be more accurately characterised as facilitating 'support and planning' for the subsequent steps in an individual's health care journey.

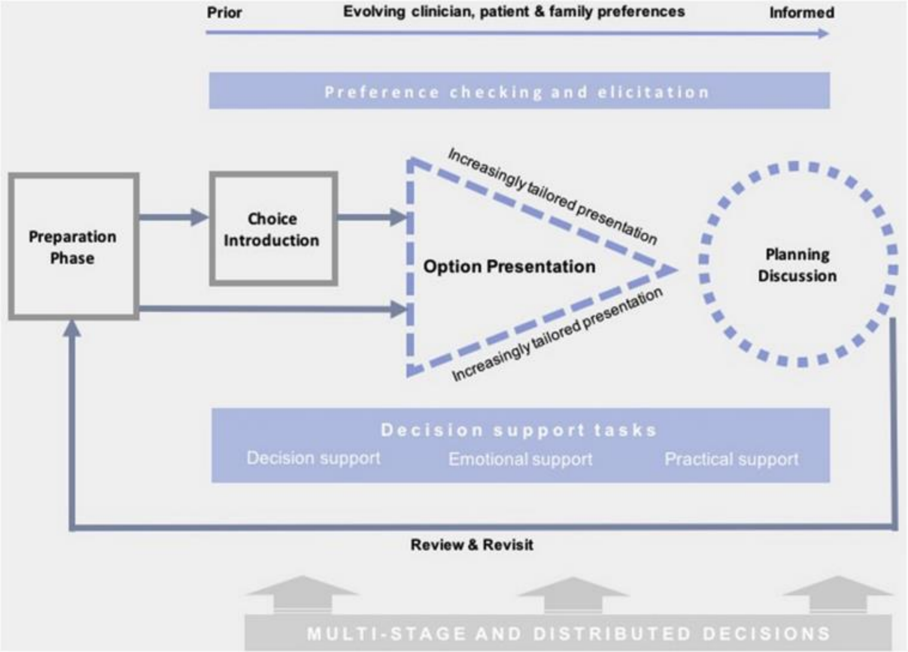


Figure 3: Implement-SDM model[31]

While this model acknowledges the complexity of decision-making processes, its detailed nature might make it challenging to implement in certain settings, particularly those with limited resources or time constraints. Additionally, while the emphasis on 'support and planning' is a strength, it might lead to a relative underemphasis on the content of decisions.

3. The Ottawa Decision Framework[32]

The Ottawa Decision Support Framework (ODSF) conceptualises the assistance required by patients, families, and their practitioners when facing 'difficult' decisions involving multiple options whose features are valued differently. This framework guides practitioners and researchers in assessing participants' decisional needs, delivering decision support interventions, and evaluating the impact of these interventions on decisional outcomes. One essential component of the ODSF is that it emphasises the use of decision aids to support people accessing care in making informed choices. Another crucial aspect is the clarification of decision-making roles. The ODSF outlines the roles of both the clinician and the individual accessing care, emphasising shared responsibility and active participation in the decision-making process. The framework also emphasises incorporating the individual's situation, encouraging clinicians to take into account the person’s health status, lifestyle, and social context when making decisions, recognising that choices may vary based on individual circumstances.[33]

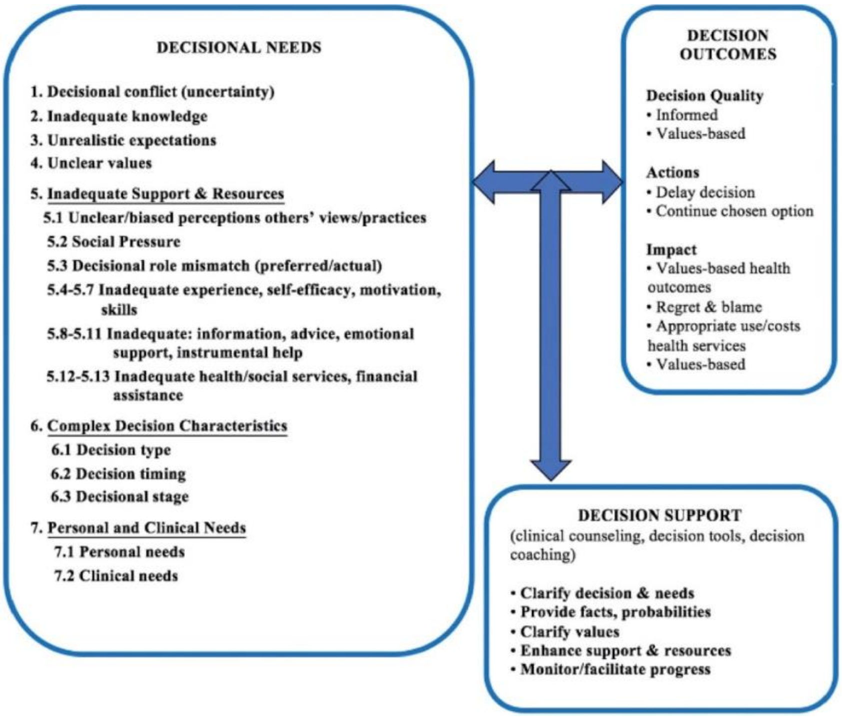


Figure 4: The Ottawa Decision Support Framework[34]

While the Ottawa Decision Support Framework (ODSF) is a valuable tool for promoting SDM, it is important to recognise some limitations associated with its application.[35] The ODSF may be perceived as complex and resource-intensive. This could limit its feasibility in busy clinical settings. The ODSF also primarily focuses on cognitive aspects of decision-making (for example: an individual that investigates every available treatment for their condition, evaluating potential side effects, considering the impact on their daily life, and assessing how well each option aligns with their personal values, goals and preferences)[36] and may not adequately address emotional factors (for example: fear, hope, anxiety) that can influence the decision-making process. Emotions may impact the effectiveness of SDM. Despite these limitations, the ODSF remains a valuable guide, and its application can be enhanced by considering and addressing these challenges in different health care contexts.

4. Purposeful SDM

Purposeful SDM represents a problem-centred viewpoint on SDM. In this context, the goal of SDM is to construct care that effectively addresses the medical, practical, emotional, and existential aspects of each individual's problems.[37] Purposeful SDM shifts away from viewing people's involvement in care as the sole reason for employing SDM. Instead, it positions individual and clinician collaboration as a means to address care-related challenges. Purposeful SDM suggests four forms of

SDM, each tailored to address a specific problematic situation: (1) evaluating treatment alternatives (for example: a person with type 2 diabetes engages in a discussion with their clinician regarding the addition of a second-line medication for their condition. The clinician involves the individual in the decision-making process, presenting various medication options. Collaboratively, they consider the pros and cons, preferences, and ultimately make a shared decision).[38] (2) Navigating intra- or interpersonal conflicts (for example: an individual is initially hesitant about taking an antidepressant, due to perceptions of weakness, discusses his internal conflict with his clinician. The man, realising the impact of his worsening depression on his relationship with his wife, undergoes a shift in perspective. He acknowledges that he doesn't perceive others taking medications as weak. This realisation leads to a decision, made in collaboration with the clinician, to initiate an antidepressant).[39] (3) Problem-solving multiple competing demands (for example: a woman, previously managing well-controlled diabetes and other long-term conditions, faces health challenges as she takes on the role of caregiver for her spouse undergoing cancer treatment. Unable to cook at home due to her spouse's sensitivity to cooking smells, she resorts to cheap fast-food options. Financial constraints prevent her from affording her current insulin regimen, and stress affects her sleep and work. The woman and clinician engage in collaborative problem-solving, exploring options such as eating at a friend's house, considering alternate caregivers, or switching to a more affordable insulin type. Together, they develop a comprehensive plan to address her health and lifestyle challenges.[40] (4) Developing existential insight (for example: during a conversation between a primary care clinician, an elderly woman undergoing dialysis for end-stage renal disease, and her daughter, the emotional toll of life-diminishing dialysis is revealed. Together, they come to a mutual understanding that it may be appropriate to discontinue dialysis and instead explore palliative approaches. The decision is made to transition to these supportive and comfort-focused measures).[41] In practical terms, purposeful SDM requires clinicians and individuals to jointly discover real-time information, establish a conducive way of communication, consider the human aspect of their conversation, define the purpose and method of joint decision-making, and identify the human values guiding their collaboration.[42] These elements must be identified, drawn out, shaped, and integrated seamlessly into everyday patient-clinician conversations to ensure a coherent and appropriate response.[43]

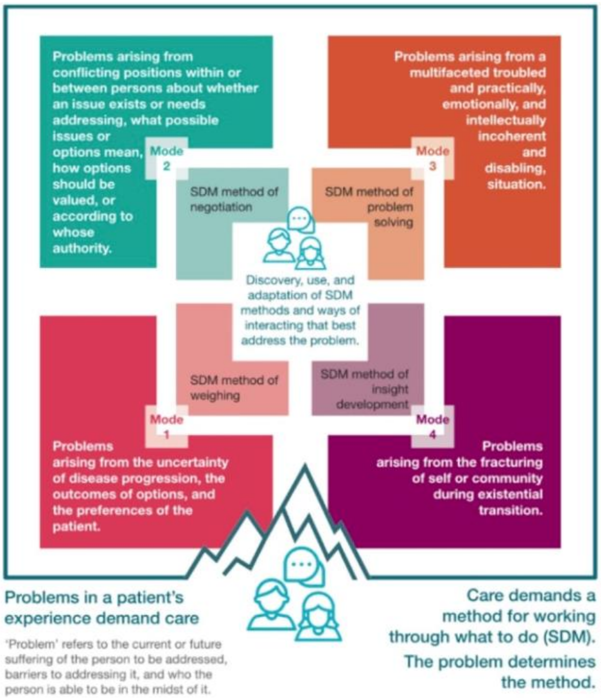


Figure 5: Purposeful SDM[44]

A limitation of the Purposeful SDM model is that embedding it into routine clinical practice may face practical challenges in those systems that are unable to accommodate the depth of exploration and collaboration advocated by the model.

The complexity of SDM scenarios becomes particularly pronounced in cases involving long-term or multiple health conditions. We have identified six key factors that contribute to this complexity.[45,46]

Factors that contribute to the complexity of SDM

1. **Multifaceted decision landscape**: Long-term conditions often involve a multitude of decisions over time. These decisions can range from treatment choices to lifestyle modifications, creating a complex decision landscape that requires ongoing attention.

2. **Dynamic nature of health conditions:** Health conditions can evolve, and their management may require adjustments over time. This dynamic nature introduces additional layers of complexity as decisions need to be revisited and adapted based on changes in health status.

3. **Cumulative impact of multiple conditions:** Individuals with multiple health conditions may face decisions that interact and compound one another. The combined effects and potential interactions of different conditions can complicate decision-making processes.

4. **Uncertainty and unpredictability:** Long-term conditions often come with a degree of uncertainty, and predicting the course of an illness over an extended period can be challenging. Decision-making in the face of uncertainty adds another layer of complexity.

5. **Treatment burden:** The management of multiple conditions may involve a significant treatment burden, including medication regimens, appointments, and lifestyle modifications. Decisions need to consider the overall burden on the person accessing care's life and well-being.

6. **Interdisciplinary collaboration**: Co-ordinating care and decision-making across different health care specialties becomes crucial. The involvement of multiple clinicians requires effective communication and collaboration to ensure a comprehensive and coherent approach.

Example: Making Good Decisions in Collaboration

Health Foundation MAGIC Programme[47]

Despite 40 years of research and substantial policy support, the integration of SDM into routine practice has progressed at a slow pace.[48,49,50,51] In 2010, the Health Foundation in the UK initiated the 3-year MAGIC (Making Good Decisions in Collaboration) programme. The purpose of this programme was to design, test, and determine the most effective methods for integrating SDM into routine primary and secondary care through the application of quality improvement methods. Interventions were employed including workshops, the development of decision support tools, patient activation campaigns, and feedback mechanisms.[52] These interventions took place in different clinical areas at Cardiff and Vale University Health Board in Wales and Newcastle upon Tyne Hospitals NHS Foundation Trust and Northumbria Health care NHS Foundation Trust in England.[53]

The MAGIC Programme identified key challenges in implementing SDM and proposed practical solutions, including:[54] (1) Interactive skills workshops: conducting workshops involving clinical scenarios and role play with actors or other participants, (2) Development of brief tools to support SDM in practice, (3) Patient activation and preparation: creating in each hospital a dedicated panel of individuals and public representatives to guide the development and testing of interventions, (4) Measurement: employing measures that directly impact practice e.g. decision quality measure for breast cancer, and (5) Securing organisational buy-in/senior level support: through initiatives including identifying SDM as an organisational priority, and dedicating an executive board member to collaborate with the implementation team.

Overcoming the complexity: A step-by-step guide

We have developed a proposed step-by-step guide for eliciting people's personal values, goals, and preferences (Table 2). We have based this guide off the Three-Talk Model. While the content of these conversations may vary based on circumstances, the approach remains consistent. Clinicians are encouraged to modify the suggested wording to align with their communication style and meet the individual needs and preferences of those accessing care.

Table 2. Step-by-step guide for eliciting the personal values, goals and preferences of people accessing care

Steps	Suggested starters
Team Talk from the Three Talk Model	• I believe that managing your health is a partnership. Let's work together to figure out the best approach to your care. It's important to me that we find a plan that fits your personal goals and lifestyle. How do you feel about discussing the options available to address your condition? • Confirm that this is what the person wants – does this sound okay? Or would you prefer a different approach to working together? • Is there anyone you rely on to help you make important decisions?
Understanding	• Could you tell me a little bit about your illness and how it might impact your life? • Do you have any thoughts about what lies ahead with your treatment and overall health?
Information	• Could you tell me how much you want to know about your condition? • How do you prefer to receive information about your health care decisions (e.g., in-person discussions, written materials, digital communication)? • How involved would you like to be in the decision-making process regarding your health care? • Are there decisions where you would like the health care team to take the lead, or do you prefer to lead discussions? • Are there specific health care decisions where you believe collaboration with family members or carers is particularly important?
Personal values	• Could you tell me a little bit more about you and your background? • What is important to you in your life and health?

Goals	• Have you had chance to think about what you would like to achieve as a result of managing your...? • What do you want to achieve/be able to do as a result of managing your...? • As you look forward, are there particular things that you really want to achieve? Are there any future life events that are particularly important for you? • When you think about the future, what do you worry about? • Given what you have told me and what I know about your illness, it sounds like [insert what you've heard, e.g., "increase physical activity for improved cardiovascular health", "quit smoking for improved respiratory health" or "effectively manage chronic pain …"] is important to you now. Have I understood your goals of care correctly? Please note: o You might need to (1) identify and agree to multiple goals of care, particularly for people with complex health care needs, or life-limiting illnesses, (2) break up overarching medium- or long-term goals into smaller sub-goals and set timeframes to help people feel like they are making progress. o It is important to frame goals as achieving a positive, rather than avoiding a negative, outcome. o Not all goals may be attainable for an individual, but understanding people's goals can be helpful to guide them to make decisions that best align with those goals.
Preferences: Option Talk and Decision Talk from the Three Talk Model	• Using the three-talk SDM model:[55] o Describe options in greater detail, often by integrating the use of patient decision aids. o Openly discuss the risks, benefits and consequences of each preference option (making sure the person knows this includes choosing no treatment, or no change to what they are currently doing), clarify what the person hopes to gain from a treatment and set aside enough time to answer questions. o Move towards making a decision, supporting people to express their preferences. o Note that individuals might express a preference for no intervention. Clinicians should respect and accept this decision.
Personalised care plans	• Through SDM, develop personalised care plans that reflect the integrated personal values, goals and preferences. This may involve tailoring treatment plans, lifestyle recommendations, and self-management strategies to suit the individual's unique needs. • To facilitate the adoption of the NICE guideline on SDM, Keele University and NICE have collaborated to create a free online learning package. Designed for Clinicians, the package aims to empower professionals with the necessary skills and knowledge for conducting high-quality shared decision-making discussions with their care recipients.

Follow up	- Remind the person that the team of clinicians is always available to discuss their goals and preferences. They can change their mind about a decision they have made at any time. - The medical records should describe and reflect the person accessing care's stated values, goals, and preferences. - Revisit the discussion regularly, especially if the person accessing care's health status changes.

The Professional Record Standards Body (PRSB) is a UK-based organisation dedicated to developing standards for health and social care records. Its primary goal is to enhance the quality, uniformity, and compatibility of health and care records across diverse care environments. An illustrative instance of a standard record developed by the PRSB, and pertinent to this Report, is the Personalised Care and Support Plan Standard.

4.3 Eliciting and using personal values, goals, and preferences for all aspects of health care

The suitability of specific approaches that enable individuals accessing care and their clinicians to elicit and use personal values, goals, and preferences vary depending on the clinical context (for example: acute conditions versus long-term conditions; single conditions versus multiple conditions) and the type of decision-making (for example: one-time decisions versus the ability to revisit choices over time).[56] Additionally, the approach can be influenced by factors such as the level of personal risk associated with a particular decision, with studies suggesting that eliciting and using personal values, goals and preferences may be more feasible for decisions with lower personal risk, such as those involving minor adjustments to medication.[57] However, despite this, eliciting personal values, goals and preferences is especially important in high-risk situations and clinicians should work together with individuals to address their unique needs and circumstances.

I. Long-term conditions

Long-term conditions often involve (1) care and treatment over extended periods of time, (2) people accessing care and clinicians building close therapeutic relationships, and (3) people's active involvement in management.[58]

For people with a single long-term condition, the approach outlined earlier in this Report can usually be used to successfully understand and revisit personal values, goals and preferences and to use such data to guide treatment and management decisions.

Increasingly, people have multiple long-term conditions. In these cases, people frequently face numerous - and often conflicting - treatment choices. Health care teams and people accessing care must take a holistic perspective, seeking to understand personal values and overarching goals, which can then guide treatment preferences. Indeed, decision prioritisation needs a stepwise and individualised approach: (1) First, there must be a discussion that considers the person's goals so that any care provided aligns with these. In an examination of the goals of older adults with high blood pressure and risk of falls, half of the participants identified reducing the risk of cardiovascular events as more important than reducing their combined risk of fall injuries or medication symptoms, whereas the other half of the participants identified the opposite priorities.[59] (2) Once realistic and achievable goals have been collaboratively decided, the conversation can shift to determining how the goals may best be attained i.e. care preferences. This typically entails exploring treatment options, weighing the benefits and risks of each option, and assessing their practicality and feasibility. Additionally, long-term conditions often come with changing needs over time so continuous monitoring and reassessment allows for the adaptation of care plans to evolving goals, preferences and health status. Patient Priorities Care (PCC) is an evidence-based approach providing a systematic and reliable method for ascertaining individual's personal values, goals and preferences as recommended for SDM.[60,61,62] This approach is especially relevant in situations where individuals have multiple long-term conditions, interact with multiple clinicians, or feel overwhelmed by their current care strategy.[63] PCC has developed various freely accessible resources to assist individuals accessing care and clinicians in integrating PCC into their practices. These resources include a set of three interactive online training modules designed for clinicians and a self-directed web-based goals and preferences identification tool called "My Health Priorities".[64] This tool will be described further in section 4.6.

In the case of decision aids, these tools rather address specific conditions, and are not typically designed for people with multiple conditions. Hence, a more flexible approach to generic tools may be valuable. For example, generic versions of decision-support tools are available, such as the Ottawa Personal Decision Guide – this is a template that prompts the clinician and person to discuss and complete a form with the options, their pros and cons, how much each pro or con matters to the person, available support, further decision-making needs, and next steps.[65]

II. Simple conditions

Using personal values, goals and preferences is not limited by the complexity of the condition and it can be applied for people with simple conditions too. Individuals should be encouraged to actively participate in their care and decision making and voice their personal values, goals and preferences so that treatment plans include them.[66] To achieve this, open and clear communication is essential as simple conditions can still be emotionally distressing for some people accessing care. Ongoing follow up, when possible, will also allow clinicians to make necessary adjustments to the treatment plan to ensure people's goals are achieved.

III. Acute conditions

In the context of acute conditions, using personal values, goals and preferences can be challenging without the context and trust that is often established in the management of long-term conditions.[67] However, every effort should be made to understand people's personal values, goals and preferences even when time is of the essence. When people lack the capacity to be involved in decision making, clinicians must try to contact their relatives, to find out about their personal values, goals and preferences to ensure the best decisions are taken.

Although there is no consensus regarding how to incorporate people's personal values, goals and preferences into acute decision making, the following structure should help support both the clinician and the person accessing care:

- Ensure you understand the clinical problem between the clinician, the person accessing care, and those closest to the individual.
- If possible, elicit the person's personal values and goals.
- Be clear about what treatment options are available and seek to understand the person's preferences.
- Summarise the person's goals and the agreed focus of care, and actual therapy the person will receive.
- Agree the proposed treatment plan and care you will be organising.[68]

Additionally, given the nature of acute conditions and their quick onset, empathy and emotional support are very important when engaging in discussions around the condition and people's personal values, goals and preferences. Acute conditions can evoke strong emotions and anxiety and therefore, where possible, timing discussions appropriately will help ensure that individuals are able to receive information when they are most receptive.

IV. Conditions with a high level of risk

In the context of people with high levels of risk (individuals presenting a risk of mortality or morbidity that is higher than the reference population based on epidemiological data), to the extent individuals desire it, using personal values, goals and preferences is especially important as they often have complex medical needs, and their care can be challenging.[69,70] Thus, a comprehensive assessment is required to understand their medical history, current conditions, and, where desired their individual personal values, goals and preferences. Individuals should be provided with detailed information about their condition(s), treatment options, potential risks, and benefits.[71] Ongoing communication and regular follow ups to discuss their goals are vital as their condition may change rapidly and care plans need to adapt to their evolving needs, goals and preferences.

Example: The Conversation Project

This is a public engagement initiative of the Institute for Health Care Improvement (IHI) that focuses on the importance of advance care planning and discussions about end-of-life care preferences. It encourages individuals to have meaningful conversations with their loved ones and clinicians about their personal values, goals, and preferences for care, especially in the context of palliative and end-of-life care.[72]

4.4 Barriers when trying to elicit and use personal values, goals, and preferences

Certain barriers can limit the extent to which clinicians and people accessing care focus on, understand and act on personal values, goals, and preferences. Identifying and addressing these barriers is crucial for delivering Person-Centred Value-Based Health Care.

I. Cultural barriers

Eliciting and using personal values, goals and preferences depends on high-quality communication between the clinician and the individual. Whether the clinician or the person accessing care, their beliefs, personal values, behaviours, demographical background and traditions that make up an individual's culture can affect the way they communicate and receive information and the way they then use that information to make decisions.[73] When there is a cultural difference between clinicians and people accessing care, it may lead to the wrong assumptions being made, disparate priorities, a lack of shared goals, and ultimately a conflict. However, this conflict may be unspoken and therefore, the clinician may be unaware that such a conflict exists.[74]

Example

A severely ill 80-year-old individual learns that one of her heart valves has stopped working. To survive, she needs surgery to replace the valve. The person has a history of excessive bleeding. This will require doctors to perform blood transfusions during the surgery. However, the person is a devout Jehovah's Witness. According to their religious beliefs and interpretations, the Bible does not allow any type of blood transfusion, so the person accessing care refuses the surgery. The medical team engages the person, their family, and trusted members within the religious community in discussions about the nature of the surgery and the risk that the person might not survive without it. After the person gets all the information and seems to understand all the risks, the medical team respects their choice to forgo the operation.[75]

When it comes to eliciting and using personal values, goals and preferences in cross-cultural encounters, we recommend that:

- Clinicians acknowledge their own cultural beliefs and personal values (including those stemming from the culture of medicine).
- Maintain awareness of potential biases and assumptions.
- Appreciate the complexity of individual and family identities and narratives.
- Practise cultural humility (entering a relationship with another person with the intention of honouring their beliefs, customs, and personal values).
- Understand the moral relevance of culture, and respect individual and family preferences.

Asking about people's beliefs, religion, culture, and demographical background can help clinicians engage individuals so that, together, they can devise treatment plans that are consistent with the person's personal values, goals and preferences. If needed, and it is important for the individual, clinicians can also involve the person's family or support system as they often play a significant role in the person's life and can provide valuable insights.[76,77] Failing to recognise an individual as part of a family can led to an incomplete understanding of people's personal values, goals and preferences.[78]

Example

Dave's health is on the decline. Despite surgery, chemotherapy, radiation, and hormonal treatments, his prostate cancer has metastasised to his bones. Dave's family has remained optimistic, confident, and encouraging; they fully expect him to pursue aggressive treatment. The palliative care clinician discusses alone with Dave his end-of-life wishes. Dave insists on pursuing aggressive care for his prostate cancer, but he also seems exhausted. As the clinician begins to probe deeper into Dave's goals, he confesses that he worries about aggressive treatment, states that it isn't what he wants, expresses that he particularly values his independence and that he fears pain, suffering, impending loss of functioning, and loss of his autonomy. He finally admits that aggressive care seems to him to be excessive but that he doesn't want to let his family down by not "fighting." He fears that his family thinks of hospice and palliative care as capitulating and "giving up".

This case highlights the importance of understanding Dave's personal values, goals and preferences, supporting him so that these are respected and working with him, in a culturally sensitive way, to help his family understand.[79]

II. Linguistic barriers

In the context of linguistic barriers, people may face limitations in fully engaging with information and participating in information exchange due to language constraints. These people may experience challenges in conveying their personal values, goals and preferences effectively to their clinicians.[80] For individuals with linguistic barriers, language interpretation services can be used to facilitate effective communication between people and Clinicians. Providing information in the person's preferred language or using visual aids can also enhance understanding and active participation in decision-making.

III. Barriers for Clinicians

1. **Time constraints:** Busy schedules and heavy workloads can limit the amount of time clinicians have to engage in in-depth discussions about personal values, goals and preferences with each person accessing care. Clinicians can optimise time management by implementing efficient communication strategies, such as agenda setting for appointments, pre-visit planning and using instruments for eliciting personal values, goals and preferences.

2. **Lack of training**: Some clinicians may lack the skills to (1) elicit and use people's personal values, goals and preferences, (2) communicate in a manner that is person-centred and (3) build trust in settings that are culturally diverse. Universities and health care organisations must invest in training programmes that support the development of communication skills, empathetic listening, and the practical application of shared decision-making principles in real clinical settings.

3. **Building trust:** People accessing care may be hesitant to share personal values, goals and preferences with clinicians due to concerns about privacy, fear of judgment, worries about stigmatisation, cultural and communication barriers, a power imbalance in the relationship, and past negative experiences in health care. Additionally, time constraints and a lack of relationship building can hinder the establishment of trust. Yet, trust forms the cornerstone of a robust relationship between an individual and a Clinician. It is crucial for making people feel respected, understood, and actively involved in their care. Moreover, it establishes a sense of comfort for individuals to openly share their personal values, goals, and preferences. The skill of building trust is something that can be acquired and refined through frequent and effective communication, the expression of empathy, and projecting a sense of calmness.[81]

4. **Bias and assumptions:** Clinicians may hold implicit biases or make assumptions about individuals based on their age, gender, race, or other factors, which can influence the care provided and impair both the ability to understand and thus the ability to act on their personal values, goals and preferences.[82] Cultural competency and implicit bias training can help clinicians recognise and address their biases. Implementing strategies like the use of inclusive language and culturally sensitive care can reduce assumptions and enhance care equity.

5. **Emphasis on biomedical model:** The traditional biomedical model of care often focuses on diagnosing and treating medical conditions, sometimes at the expense of addressing individual personal values, goals and preferences and holistic well-being.[83] Organisations can encourage a shift in the organisational culture towards a person-centred approach. Health care organisations can promote holistic care models that consider people's personal values, goals and preferences alongside medical treatment.

6. **Documentation burden**: Extensive documentation requirements can lead to a focus on paperwork over discussions about people's personal values, goals and preferences. Clinicians may feel pressured to complete records rather than engage in meaningful conversations. Streamlining documentation requirements, reducing redundancy, and using technology to simplify record-keeping can free up time for meaningful interactions.

7. **Power dynamics in health care**: Traditionally, the power has been concentrated in the clinician – they have held the knowledge and the keys to access different forms of treatment. As a result, people accessing care have frequently felt disempowered and hesitant to challenge medical recommendations.[84] This imbalance impacts communication, the overall effectiveness of treatment, and therefore, the ultimate value of the care provided. Equalising the power dynamic requires a fundamental cultural shift and an acceptance by clinicians of a change in their role – from the single expert to the partner – and a change in how they are viewed by people accessing care.

8. **Absence of evidence-based medicine information available for discussion:** In health care, where ambiguity exists and where there are often uncertainties around the 'evidence' available and how it relates to a particular context, clinicians may encounter challenges in providing individuals with thorough and reliable information regarding potential risks, benefits, and outcomes tied to specific treatment options. This limitation can impede the individual's ability to make fully informed decisions aligned to their personal values and goals. The inability to provide such evidence may impact people's expectations and satisfaction, as they may perceive a gap in the clinician's ability to offer validated guidance. To address this barrier, clinicians need to navigate conversations with transparency, clearly communicating the limitations in available evidence, and working collaboratively with people accessing care to make decisions that align with their personal values and goals, within the bounds of current knowledge, patient safety and ethical considerations.

IV. Barriers for people accessing care

1. **Limited health literacy:** People with limited health literacy may have greater difficulty in assessing the implications of various treatment options, making it challenging to express their preferences.

2. **Fear or anxiety:** People may experience fear or anxiety related to their condition, treatment options, or the health care system, which can hinder open discussions about personal values, goals and preferences. Clinicians should focus on building a genuinely open, respectful and trusting environment, acknowledging and working together to support them in managing their fears and anxieties.

3. **Hierarchy in health care:** A hierarchical structure in health care can deter open communication, as people may feel hesitant to express their personal values, goals and preferences to authority figures. People can hesitate to participate in their health care, preferring to leave the responsibility to experts, due to a perceived lack of competence.[85] Moreover, clinicians may have reservations about involving people in discussions about personal values, goals and preferences, particularly if they perceive people to be limited in their cognitive and/or communication abilities.

4. **Lack of continuity of care:** The lack of continuity of care refers to the absence of an ongoing relationship between a person and a clinical team or its members. It denotes a situation where clinical care lacks coordination and does not progress seamlessly as the individual transitions between different components of the health care service.[86] From an individual's perspective, this can be a significant barrier in discussions about personal values, goals and preferences. This is principally because it can be very difficult to form a relationship with Clinicians.[87,88] To address this barrier, efforts should focus on enhancing care coordination and fostering an approach that ensures consistency and collaboration among Clinicians, thereby promoting an environment conducive to shared decision making aligned with the individual's personal values, goals and preferences.

5. **Individual's capacity:** A person's capacity, particularly their cognitive and decision-making abilities, can act as a barrier when clinicians seek to elicit and use their personal values, goals, and preferences. For example, people with cognitive impairments, such as dementia or severe mental health conditions, may struggle to express their personal values, goals and preferences coherently. This can impede the Clinician's ability to fully understand and integrate these factors into the decision-making process. People experiencing physical discomfort, pain, fatigue, emotional distress or depression may also have difficulty focusing on discussions about personal values, goals and preferences.[89,90] By recognising and addressing people's capacity as a potential barrier, clinicians can tailor their communication strategies, leverage supportive tools, and involve additional resources to ensure that individual's personal values, goals and preferences are adequately elicited and incorporated into the

decision-making process. An example of additional resources may involve a health care facilitator or patient advocate, who can work alongside the individual and their health care team to facilitate communication, provide education, and ensure that the individual's personal values, goals and preferences are thoroughly understood.

6. **Individual autonomy:** The barriers to eliciting and using personal values, goals, and preferences are closely linked to the existing gap between the idealised model of individual autonomy and the current reality in health care. Challenges in people's access to comprehensive health information and their active engagement in health care decisions contribute to this gap. The transformative potential of artificial intelligence (AI) in addressing these challenges is recognised, as it can provide personalised information and support decision-making.[91,92] However, the lack of a collaborative effort among stakeholders, including health care providers, technologists, policymakers, and people accessing care, hinders the effective integration of AI into health care. To bridge this gap, a unified approach is needed to establish ethical guidelines and standards, ensuring that AI applications empower individuals while aligning with clinician's expertise. Collective action is crucial to realising the full potential of AI in achieving tangible advancements in individual autonomy within the health care system.

7. **Minority or excluded groups:** Health problems often disproportionately affect marginalised or excluded groups (including racial or ethnic minorities, socioeconomically disadvantaged populations or individuals experiencing homelessness) highlighting the importance of understanding and addressing their unique personal values, goals, and preferences.[93,94] Building trust with these communities is essential but challenging due to historical and systemic factors like discrimination and mistrust of health care systems.[95] Eliciting personal values, goals and preferences requires targeted outreach efforts, as individuals from minority communities may not be adequately represented in traditional health care systems and may lack regular care contacts.[96] Culturally competent approaches and community partnerships are crucial for effectively engaging these populations. Addressing structural barriers to health care access, such as transportation and language barriers, is necessary to ensure equitable access to care and to gather comprehensive personal values, goals and preferences.[97]

4.5 Guidelines for information provision for people accessing care to enable informed decisions about personal values, goals, and preferences

There are key principles that underpin information provision for people accessing care, to support conversations around personal values, goals and preferences:

I. Timing

Discussions around personal values, goals and preferences should happen as early and clearly as possible from the moment of diagnosis. People accessing care must have access to appropriate information to ensure an informed discussion. However, ultimately when this information is provided and when these discussions take place is dependent on each individual scenario and should be guided by the readiness of the person accessing care.

II. Accessibility

Clinicians must consider the language needs and communication limitations of everyone to whom they provide care. They must find ways of ensuring that information is accessible to all.[98]

1. **Content:** We have brought together a summary of the guidance around how to present information to people accessing care and their families:

    (a) Three questions can be included in information provided to people in advance of a discussion around personal values and goals, encouraging them to reflect on their responses:

    1. What do you hope to achieve/be able to do as a result of managing your...?
    2. What do you hope will happen as a result of the consultation?
    3. What questions would you like to ask during the consultation?

    (b) When thinking through preferences, it can be helpful for people to have the following questions in mind:

    The ‘Three questions plus one’ approach:

    1. What are my options?
    2. What are the possible benefits and risks of those options?
    3. How likely are the possible benefits and risks of each option to occur?
    4. To what extent does the option help me achieve my goals?[99]

    The ’Four questions plus one’ (BRAN) approach can also be used:

    1. What are the Benefits?

2. What are the Risks?
3. What are the Alternatives?
4. What if I do Nothing?
5. To what extent does the option help me achieve my goals? [100]

(c) When providing information about the disease or about treatment options, use text that is easy to read and inclusive, specifically:
    - Use personal pronouns such as ‘we’ and ‘you’.
    - Do not use frightening language, for example: ‘electrodes will be put on your chest’.
    - If it is difficult to avoid using some medical terminology, such as ‘nuclear medicine’, provide an explanation.
    - Do not confuse people by covering more than one condition in the same leaflet.
    - Try to keep sentences short (in general no more than 15 to 20 words long).
    - Use lower-case letters, where possible, as they are easier to read. Exceptions to this are names and the first letter in a sentence.
    - Try to use bulleted or numbered points to divide up complicated information.
    - Aim for small blocks of text. Try to not use long paragraphs but instead divide them up using headings and new paragraphs.
    - Incorporate plenty of white space as this makes the information easier to read.
    - Use large and bold formatting to emphasise text.
    - Avoid upper case letters, italics and underlining as they make the text more difficult to read.
    - Always try to use a font size of no less than 12 point. [101]

(d) When discussing numerical information:[102]
    - Consider using a mixture of numbers and pictures, for example, numerical rates along with pictograms or icon arrays.
    - Try to use absolute risk rather than relative risk. For example, the risk of an event increases from 1 in 1,000 to 2 in 1,000, rather than the risk of the event doubles.
    - Try to use natural frequencies (for example, 10 in 100) rather than percentages (10%).
    - Make numerical information visual using charts or graphs depending on the nature of the data. For example, the pictograph, which displays numerical information with the use of icons or picture symbols (graphic representations of spoken and written language) to represent data sets.

> 60 children out of 100 who take drug A will experience good pain relief.

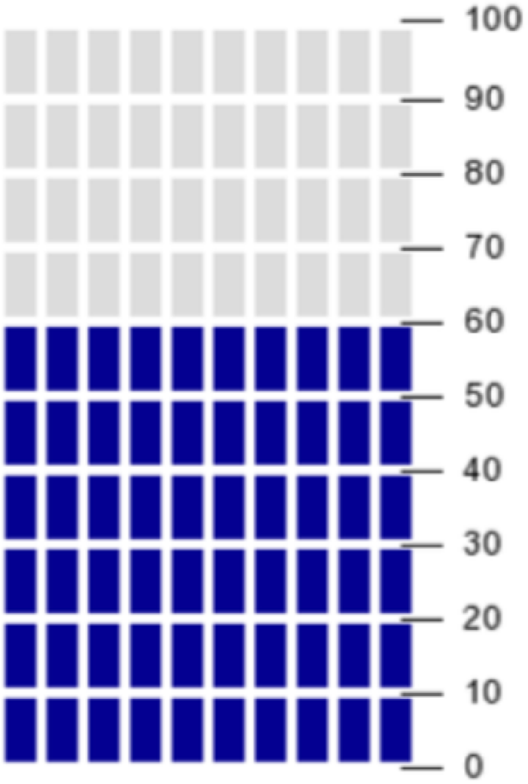


Figure 6: Example of the pictograph format for depicting benefit (pain relief).[103]

(e) Ensure that information provided in different formats and through different channels is all consistent, accurate and up to date. There should be clear lines of ownership accountability and responsibility for maintaining information.[104]

(f) When developing information resources, ask people accessing care to review and co-design the information, for example through patient groups.

Although the principles mentioned above should be used as guidance when developing information resources, it is important to be aware that there are also different factors that shape how information should be adapted depending on age, gender, educational level and cultural background. Specifically:

(a) Age:

- *Children and young adults*: Information should be presented in a simple, age-appropriate manner, using language and visuals that are easy for them to understand.[105] Recognise that children and young adult's personal values, goals and preferences may change as they mature, so it is necessary to revisit them on a regular basis and to adapt support, information and complexity of discussions accordingly.[106] Engage with parents or carers to ensure they comprehend and can support their personal values, goals and preferences.
- *Adults*: It is common in health care to offer information leaflets with different complexity levels to accommodate the unique needs and preferences of individuals. This can be achieved by identifying the specific needs and constraints

of the target population, evaluating the readability of the leaflets to ensure they are comprehensible to the intended audience and conducting a series of consumer tests within the target population, involving multiple rounds of feedback and revisions to enhance the effectiveness and user-friendliness of the leaflets. [107,108]

- *Elderly individuals:* Clinicians should address any sensory issues such as hearing or visual loss, making sure information is accessible to all.[109,110]

(b) Gender:

- Respect individual's gender identity and preferred pronouns:[111] Use gender-neutral language when appropriate.

(c) Educational level:

- Use everyday language: Regardless of the individual's educational level, clinicians should avoid jargon and acronyms and use plain language to make information easier to read.[112] Clinicians should tailor explanations to the person's educational level, ensuring they can understand the information presented.
- Visual aids: Utilise visual aids, diagrams, or models to help discuss complex issues with individuals. These can be especially helpful for people accessing care with lower educational levels.

(d) Learning difficulties:

- "Easy read" versions are simplified versions of written information designed specifically for individuals with learning difficulties or cognitive impairments.[113]
- Language simplification: Simplify the language by using shorter sentences and easier-to-understand words. Avoid abbreviations and acronyms.
- Visual aids: Use visual aids including pictures, symbols, and icons to enhance understanding and reinforce key concepts.
- Highlighting key points: Important information can be emphasised using techniques such as bold text, colour coding, or underlining. This helps individuals to focus on essential details and key messages.

Examples of easy-to-read material are available on Easy Health and NHS England's easy-to-read information.

III. Health Literacy

‘Health literacy’ refers to people having the appropriate skills, knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services.[114] Health literacy is also influenced by services’ engagement of users and provision of clear, accessible information for all. People with higher health literacy levels are potentially empowered in health care consultations as they possess cognitive and social skills that facilitate engagement with information. On the other hand, even people who read well and are comfortable using numbers can face health literacy issues when (1) they aren’t familiar with medical terms or how their bodies work; (2) they have to interpret statistics and evaluate risks and benefits that affect their health and safety; (3) they are diagnosed with a serious illness and are scared and confused; and (4) they have health conditions that require complicated self-care.[115] In the field of shared decision making, low health literacy has most often been positioned as a potential risk factor, and actions in relation to health literacy have tended to be goal-directed, seeking to mitigate the related risks of lower health literacy to achieve improved clinical outcomes.[116] A seminal review of Patient Decision Aids published in 2010 found that they were rarely developed with lower literacy populations in mind, and that measures of health literacy and decision aid readability were rarely Reported.[117]

Research into health literacy and eliciting and using personal values, goals and preferences has largely developed along parallel, but distinct lines. There is little evidence that the concepts and related practice have intersected except in the most functional way, for example, to simplify shared decision making tools by improving readability scores of decision aids.

Health Education England has created the "Health Literacy 'How To' Guide" to outline practical tools and techniques that clinicians can use to assist individuals with low levels of health literacy.

An expanded model which incorporates health literacy concepts and promotes two-tiered intervention methods to improve the targeting and personalisation of communication and support the development of transferable health literacy skills among people accessing cares has been proposed.[118,119] Firstly, simplifying information is necessary but not sufficient to achieve active participation. For people to successfully share their personal values, goals and preferences, they need skills to communicate effectively, to obtain, understand, and share information with clinicians. Individuals also need the cognitive and social skills to express themselves and to contextualise and critically evaluate information to make a decision which aligns with their personal values, goals and preferences. Such an approach often requires more time and can best be delivered in a more structured educational setting. This might be through established Adult Basic Education programmes, schools, or health educational settings like diabetes educator group sessions. Well-designed on-line learning programmes have also been proposed as a platform to support skill-development. Self-management education and peer support are complementary strategies aimed at enhancing health literacy and enabling individuals to participate actively in their health care.[120,121] Self-management education empowers individuals to manage their health conditions and make informed decisions about their care, while considering their personal values, goals, and preferences.[122] Peer support involves individuals with similar health experiences providing mutual encouragement, empathy, and practical assistance to each other. These approaches allow for flexibility in addressing the unique personal values, goals, and preferences of individuals, ultimately promoting more personalised health care engagement.[123,124] The second suggested shift in practice is the integration of health literacy into SDM training programmes for Clinicians.[125] To date, training in health literacy and shared decision making has tended to occur in silos both in initial education and as a part of continuing professional development, with only recent signs of integration. Bringing training together can foster greater appreciation of how efforts to support eliciting and using personal values, goals and preferences need to acknowledge health literacy and recognition of the implications of addressing health literacy on engagement in decision making.

There have been increased efforts to reduce low health literacy “risk” by removing literacy-related barriers in decision aids such as decreasing readability scores, including people of all literacy levels in the development process and alternative formats for decision support, such as Care that Fits Tools and Option Grids™ which generally have less textual information compared with typical decision aids.[126]

When individuals have varying levels of health literacy, goal setting can also be an uncertain interactional space with confusion around (1) understanding what type of conversation is taking place, (2) the roles of the person accessing care and Clinician, and (3) how the individual’s priorities may be configured as goals. To adapt the goal-setting process to the individual's health literacy level, it is important to use the key principles that underpin information provision for people accessing care described above.

4.6 Key existing instruments supporting clinicians and people accessing care to discuss personal values, goals, and preferences

Decision support instruments can help in initiating and structuring a conversation between people accessing care and clinicians with a focus on understanding their personal values, goals and preferences.

I. Instruments to discuss personal values

Helping individuals to express personal values is an ongoing part of clinical care, and likely occurs regularly and informally during clinical discussions. Efforts in the development of value assessment tools to support these discussions in a formal structure have focused on (1) open-ended interviews, (2) check lists or rating scales, and (3) stories and scenarios:

1. **Open-ended interviews**: Open-ended interviews use questions that prompt the beginning of a longer conversation by starting with "why," "how," and "what if"? They encourage a full answer, rather than the simple “yes” or “no” response and the topics covered in these interviews include general attitudes toward health, importance of independence and control, nature of personal relationships, attitudes toward life, illness, dying, and death, religious background and beliefs, attitudes toward living environment, finances, and wishes regrading care.[127,128] One example is the Value History Form developed by the National Personal Values History Project at the University of New Mexico and includes questions such as: (1) What is important to you in your life? (2) What makes life worth living? (3) What activities do you enjoy? (4) What do you fear most? (5) What frightens or upsets you? (6) What importance do family and friends play in your life? (7) How do you expect friends, family and others to support your decisions regarding medical treatment you may need now or in the future? [129]

2. **Check lists and rating scales**: In contrast to the open-ended interview, self-Report tools have been developed that allow a person to endorse or rate the importance of a range of personal values pertaining to health care decisions. These approaches are useful in terms of encouraging individuals to consider the question of personal values, and they allow self-Report on standard questions, easy documentation, and the potential for quantitative analysis. An example of a self-Report tool is The Valued Living Questionnaire (VLQ) which systematically assesses the extent to which individuals regard their personal values and incorporates them into daily actions.[130]

3. **Stories and scenarios:** People accessing care are asked what they would do, given the circumstances represented by specific stories/scenarios, and asked to rewrite the stories based on how they would like to see them end. In this way, an attempt is made to understand the basis upon which the person would consider a range of decisions. Subsequent to discussion about the stories, people are asked to rate the importance of value statements more generally, both as an indicator of current personal values,

and to be used by a proxy in the case of future incompetence; for example: are you more like my father, who worries about cancer and prefers to have every screening test done?

II. Instruments to discuss goals

Helping people accessing care to express goals can be experienced as simultaneously straightforward and challenging, by both individuals and Clinicians. The ‘simplicity’ of goal elicitation is embedded in deep knowledge and skills and in the absence of those, dedicated tools may be helpful:

1. **SMART Goals**: People accessing care and clinicians should reflect setting goals using the SMART approach: A SMART goal is:
    - Specific – a very clear statement of what the person is trying to achieve.
    - Measurable – has a numerical target that can be measured.
    - Achievable – is realistic and attainable in the time allowed.
    - Relevant – is linked to people’s personal values.
    - Time-bound – has a clearly defined timeframe within which the goal should be achieved. [131]

    SMART goal example: To help manage his diabetes, John will walk outside for 15 minutes every day for the next 4 weeks.

2. **CLEVER Goals:** [132] This approach goes beyond the traditional SMART goal framework by considering the individual's unique context and personal factors. It aims to create goals that are more meaningful and achievable for individuals by tailoring them to their unique circumstances and aspirations. CLEVER stands for:

    - *Context:* To consider the specific context in which the individual lives; this involves understanding factors such as environment and culture that may affect the goal. By considering the context, clinicians and people accessing care can set goals that are realistic and attainable within the individual's living situation.
    - *Life-narrative:* To consider the individual's life story and experiences so goals are relevant and meaningful with people’s personal journey and aspirations.
    - *Engagement:* To assess the individual's level of engagement and motivation regarding the goal. Goals are more likely to be achieved if they resonate with the individual's interests and passions.
    - *Personal values:* To consider an individual’s personal values.
    - *Emotions:* To recognise the emotions that the individual associates with the goal. Positive emotions can drive motivation, while understanding negative emotions can help address potential barriers and challenges.
    - *Relevance:* To evaluate the relevance of the goal to the individual's life. Goals should be meaningful and significant to the person, making them more likely to commit to and achieve their objectives.

CLEVER goal example: To help manage his diabetes and in the context of his busy life, John's goal is to establish a consistent fitness routine over the next six months, making it an integral part of his life by engaging in regular home-based workouts and outdoor activities for at least 30 minutes, five days a week. [133]

3. **Goal Finder:**[134] The main aim of this approach is to facilitate meaningful communication between individuals and their clinicians while helping people accessing care identify and prioritise what is important to them in terms of their quality of life. By covering past, present, and future aspects of their lives, Goal Finder can help people accessing care and clinicians gain insights into the individual's experiences and aspirations.

   Specifically:

   - Exploring individual's past: may include questions about the person's life history, experiences, and achievements, helping to identify aspects that are significant and meaningful to them. For example: ask about past accomplishments.
   - Exploring individual's present: may include questions about the person's current state of well-being and quality of life, for example: current interests, daily activities, and sources of satisfaction.
   - Future: may include questions about how individuals envision their future aspirations and goals, for example: what they would like to achieve, and how they see their quality of life improving.

   Goal Finder goal example: To help manage his diabetes, John will incorporate 30 minutes of physical activity into his daily routine. He will also actively participate in local charity events and continue to engage in support group meetings to stay motivated. [135]

4. **Collaborative Goal Setting**: This is a process by which clinicians and people accessing care agree on goals together, establishing SMART goals and linking them to measurement categories: did not achieve it (e.g., blood pressure remains unchanged or increases), did better, (e.g., a slight decrease in blood pressure) or much better (e.g., achieving a significant reduction in blood pressure) to track progress. These categories help both the individual and clinicianassess and compare the person accessing care's actual progress with the desired goals. Collaborative Goal Setting can be measured using Goal Attainment Scaling (GAS), a standardised method to assess and quantify the extent to which individuals achieve specific goals during an intervention and it's particularly valuable when dealing with goals that are not easily quantified using numerical scales.[136] GAS employs a scaling system that assigns numerical personal values to different levels of goal achievement and allows for the conversion of qualitative or subjective progress into quantitative data, enabling comparisons over time.

5. **My Health Priorities:**[137,138] This evidence-based self-directed, web-based goals identification tool assists individuals with multiple long-term conditions in navigating steps to determine concrete, attainable goals grounded in their values—what brings significance, fulfilment, and happiness in their daily life. It also considers preferences regarding health care decisions, such as medication use and frequency of medical visits, and identifies the most troubling health issue and the primary health concern ("One Thing") they wish to address. Users receive a printable and downloadable form based on their input. This tool can be completed virtually, in any setting. By offering to complete “My Health Priorities” either prior to or during their appointments, control is shifted towards the individual, empowering them to pinpoint their health goals without the limitations of clinical time constraints. This enables clinicians to understand the priorities of individuals, facilitating discussions aimed at achieving particular goals within clinical environments. (online) (PDF).

Example: Collaborative Goal Setting

To help manage John's diabetes, John and Dr Smith work together to identify specific goals to improve diabetes management. John expresses his challenges, which include inconsistent blood sugar monitoring and sedentary concerns. Together, they set SMART goals, such as consistent blood sugar checks and incorporating physical activity into his daily routine. They create an action plan that includes consulting an exercise therapist and scheduling regular follow-up appointments for monitoring and feedback.[139,140,141]

III. Instruments to discuss preferences

These instruments include the Autonomy Preference Index, Patient Decision Aids, Option Grid^{TM} , Decision Boxes, Question Prompt Lists, and Care that Fits tools.

1. **The Autonomy Preference Index (API):** A self-administered instrument for measuring individuals' preferences for two identified dimensions of autonomy: their desire to make medical decisions and their desire to be informed.[142] Acknowledging the significance of the preference for involvement in decision-making is crucial in recognising and respecting individual autonomy. People's preferences regarding their level of participation in decisions that affect them can vary widely. Some individuals may prefer a more collaborative or shared decision-making approach, actively engaging in the process, while others may lean towards a more passive or delegated approach, entrusting decisions to others.

2. **Patient Decision Aids:** Patient Decision Aids are utilised in clinical settings to support eliciting preferences and to help structure the decision-making process by making treatment, care and support options explicit.[143] They provide evidence-based information about the associated benefits and harms of different options, including doing nothing. For Patient Decision Aids examples please visit Appendix V.

3. **Option Grid^{TM}**: Option grids are brief, easy-to read tools that help people accessing care and clinicians compare health care options. They include evidence-based information about the available options, such as benefits, risks, and potential outcomes. This information is usually presented in a clear, concise, and person-friendly format.[144] For an Option Grid^{TM} example please visit Appendix VI.

4. **Decision Boxes**: These are short clinical summaries that integrate the best available evidence from studies to provide information on different management options. They typically cover medical questions that have no single best answer.[145] For a Decision Box example please visit Appendix VII.

5. **Question Prompt Lists**: simple and inexpensive communication tool used to encourage discussion of a specific condition by clinicians and people accessing care. They comprise of a list of standard questions that encourage the involvement of individuals in preference setting, for example, The Essential Questions Pamphlet and Know Yourself Worksheet designed by The National Coalition for Cancer Survivorship.[146]

6. **Care that Fits Tools:** Developed by Mayo Clinic's Knowledge and Research Unit, these tools facilitate communication and shared decision making between people accessing care and clinicians, aiding in the management of various situations such as medication for diabetes, depression, and cardiovascular risk.

Impact of successfully eliciting and using personal values, goals, and preferences

The effects of successfully eliciting and using personal values, goals and preferences, which is supported through the above approaches and instruments, can be wide-ranging with positive implications for people accessing care, clinicians and wider health care systems.[147,148] Specifically:

1. **Improved individual satisfaction:** When people accessing care are actively involved in their care and their personal values, goals and preferences are respected, they are more likely to be satisfied with their health care experiences. Person-Centred Care is significantly associated with social well-being, physical well-being and satisfaction with care.[149]

2. **People empowerment:** When individuals are involved in decision-making, they feel more empowered to take charge of their health and make choices that align with their personal values.[150]

3. **Better adherence to treatment:** When people accessing care are engaged in setting their own goals and preferences, they are more likely to adhere to prescribed treatments, medications, and lifestyle changes, which can lead to improved health outcomes.[151] As an example: in people with type 2 diabetes mellitus, a study showed significantly greater medical adherence in people whose personal values, goals and preferences were understood compared to the group where personal values, goals and preferences were not elicited. A similar finding was shown in another study that look at breast cancer survivors who began tamoxifen, with those who were engaged in expressing their personal values, goals and preferences, being significantly more likely to still be using the medicine four years after their diagnosis.[152]

4. **Improved individual-clinician communication:** By understanding and considering people's personal values, goals, and preferences, clinicians can establish more effective and open communication. This helps in building trust and rapport.

5. **Reduction in medical errors:** When clinicians are aware of people's personal values, goals and preferences, it helps in avoiding potential misunderstandings or errors in treatment choices, ensuring that the care provided is in line with the individual's wishes.[153]

6. **Optimised resource allocation**: Understanding people's personal values, goals and preferences can help clinicians prioritise interventions and allocate resources more effectively, focusing on what matters most to the individual and optimising the use of health care resources.

Table 3. Summary of key existing instruments that are available to support clinicians and people accessing care to discuss personal values, goals and preferences

Instruments	**Examples**
Instruments to support discussing personal values	- Open-ended interviews. E.g. National Personal values History Project - Check lists and rating scales. E.g. The Valued Living Questionnaire - Stories and scenarios.
Instruments to discuss goals	- SMART Goals. E.g. Dartmouth Health Goals - CLEVER Goals - Goal Finder - Collaborative Goal Setting. E.g. Goal Attainment Scaling - My Health Priorities
Instruments to discuss preferences	- The Autonomy Preference Index - Patient Decision Aids. E.g. Appendix V - Option Grid™. E.g. Appendix VI - Decision Boxes. E.g. Appendix VII - Question Prompt Lists. E.g. The Essential Questions Pamphlet and Know Yourself Worksheet - Care that Fits Tools. E.g. tools

4.7 Organisational support required to enable clinicians and people accessing care to focus on personal values, goals, and preferences and to co-design care plans accordingly

Focusing on personal values, goals and preferences requires a collaborative process through which a clinician works with an individual to reach a decision about their care.

I. Knowledge and skills for clinicians

1. Context – the why?

Key knowledge: Clinicians must understand the theoretical basis of Person-Centred Health Care, Value-Based Health Care and Health Equity. They must also understand the evidence that underpins these approaches and why they matter – for individuals, for health care systems and their sustainability and for wider society.

2. Focusing in on personal values, goals and preferences – the what?

Key knowledge: Clinicians must understand what we mean by personal values, goals and preferences and their importance for both shaping care and informing measurement of quality.

3. Focusing in on personal values, goals and preferences - the how?

Key knowledge and skills: Clinicians must understand and then be able to practice:
- The approaches to eliciting and using personal values, goals and preferences.
- The barriers to eliciting and using personal values, goals and preferences and how to address these barriers.
- The risks associated with eliciting and using personal values, goals and preferences and how to manage these risks.
- The approaches to providing individuals and their families with information and tools that they can use to support deciding and then expressing their personal values, goals and preferences.
- The approaches to supporting people with their actual understanding of information and their ability to then use the information. Two examples are:

1. Teach Back method: This is an effective approach for confirming people's comprehension of information provided. It involves individuals explain, in their own words, what they have learned or what they are supposed to do, rather than simply asking if they understand. This method serves as a way to assess how well information has been conveyed and understood before introducing new details. Clinicians can rephrase information if people are unable to accurately repeat it.[154]

2. Chunk and Check method: This is an approach that can complement tools like Teach Back in ensuring understanding. It involves breaking down complex information into smaller, more manageable portions rather than presenting it all at once. After each "chunk" of information, methods like teach back are used to check for understanding before moving on. This approach encourages individuals to ask questions and seek clarification at appropriate points, rather than holding questions until the end. Chunk and Check is also valuable for structured discussions about a people's personal values, goals, and preferences, where the health care clinician divides the conversation into manageable chunks and checks with the person for their understanding and agreement after each segment.[155]

Underpinning all of the above is an understanding of and ability to practice advanced communication. This is about much more than the words used and it depends on how and when we say things, how we listen, our non-verbal communication and the dynamic judgements we make as communication takes place. An awareness of cultural differences, an understanding of our own individual communication styles and how we are perceived by others is also key. Additionally, trust is the foundation of strong individual-clinician relationships. The ability to build trust can be learned and developed and it is achieved by communicating often and effectively, expressing empathy and projecting calmness.

II. Knowledge and skills of people accessing care

1. Context – the what?

- Key knowledge: People accessing care must understand what we mean by personal values, goals and preferences.

2. Personal values, goals and preferences – the why?

- Key knowledge: People accessing care must understand:
  - Why it is important for us to focus on people's personal values, goals and preferences.
  - Why accessible information and decision support is provided to support people in making decisions.

3. Personal values, goals and preferences – the how?

- Key knowledge and skills: People accessing care must:
  - Know how to express and advocate for their personal values, goals and preferences.
  - Know how to initiate discussions around personal values, goals and preferences.
  - Understand the barriers to expressing and working towards their personal values, goals and preferences and know how to overcome and manage these barriers.
  - Be able to use information contained in information leaflets and the different types of decision aid.
  - Be able to assess different pieces of information and then make a choice.

III. Organisational support

To embed personal values, goals and preferences, health care systems and the organisations that make up health care systems also need to enable it. This can be facilitated by:

1. **High-level leadership commitment:** A senior leader should be accountable and responsible for embedding personal values, goals and preferences across the organisation.

2. **A Patient Director and a Senior Clinician:** These individuals will play a key role in championing the effort to prioritise and address the needs and desires of individuals, and they will work closely with senior leaders to make sure this initiative gains traction and progresses effectively.

3. **Development of a plan:** This should focus on the following steps:
    - Describe the burning platform, clearly and simply – why is this important and why now?
    - Identify where to begin. Ideally starting in two disease areas, where there is enthusiasm from clinical teams.
    - Celebrate successes and share with the wider organisation.
    - Create a plan for gradually extending the work – driven by where there is enthusiasm and a desire to succeed.
    - Bring together the wider organisation to share the progress of the innovators and early adopters, catalysing a wider organisational implementation.

4. **Knowledge and skills:**[156] Organisations should ensure that individuals and key clinical, management and operational staff members have the knowledge and skills to elicit and use personal values, goals and preferences. This could be through:
    - Prioritisation of knowledge sharing and skills training as part of staff induction sessions and/or on-going professional development programmes.
    - Dedicated training for staff and patient groups. It is important to ensure that training is practical (for example, using role play), rather than solely theoretical, so that staff and individuals can put into practice the skills needed to focus on personal values, goals and preferences.
    - Opportunities to develop ‘train-the-trainer’ style workshops for people accessing care and staff.
    - It is important that individuals are empowered. In addition to the training outlined above, this could be through using posters or other media to convey the importance of understanding personal values, goals and preferences, for example: through posters, videos in waiting areas, appointment letters or websites.

5. **Operational planning:**[157] Services need to be organised so that they enable a focus on personal values, goals and preferences. This can be achieved by:
    - Appointment flexibility: ensuring that different appointment lengths are available to (1) ensure longer appointments are available so that adequate time is set aside to discuss people's personal values, goals and preferences and (2) ensure that there is flexibility in appointment length as different people will require different amounts of time to discuss their personal values, goals and preferences.
    - Defining the roles of staff members: within each service, it is important to understand which staff member will have the responsibility for eliciting an individual's personal values, goals and preferences.
    - Communication: once an individual's personal values, goals and preferences have been elicited, there should then be a clear mechanism to communicate this to all other members of the multi-disciplinary team.

6. **Joined up record systems**:[158,159] A Joined-up record system supports the elicitation and use of values, goals, and preferences and SDM by providing clinicians a holistic view of an individual's medical history and current health status. This comprehensive assessment enables clinicians to better understand personal values, goals, and preferences in the context of individual's overall health. A joined-up record system also facilitates communication and information exchange among members of the clinical team, ensuring that they all have access to consistent and up-to-date information about the individual's personal values, goals and preferences. This seamless sharing of information supports care coordination efforts, reduces the likelihood of conflicting recommendations, and promotes a cohesive approach to addressing individual personal values, goals and preferences across care settings.

4.8 Risks associated with people accessing care and their clinicians working together to elicit personal values, goals, and preferences, and management of these risks

1. **Conflict:** Conflict between clinicians and individuals, as an individual's subjective and sometimes informal explanations of health care and illness may clash with the scientific knowledge of Clinicians, leading to disagreements and a lack of acceptance of the decisions made.

2. **Responsibility:** Clinicians often feel ultimately responsible for people's care but can sometimes not recognise that they may lack the competencies required to understand what actually matters most to them.[160]

3. **Decisional conflict and regret:** Decisional conflict involves personal uncertainty about which course of action to take when a choice among competing options involves risk or challenge to people's personal values, goals, and/or preferences. This is directly linked to decisional regret, which is a retrospective emotion experienced when evaluating the outcome of a decision.[161,162]

   These risks can generally be managed through effective communication and building relationships between clinicians and individuals. It is crucial for clinicians to actively listen to individuals, understand their perspectives, and acknowledge their personal values, goals and preferences. Providing people with relevant information in a clear and accessible manner can also empower them to express their personal values, goals and preferences.

4. **Clinical bias:** This refers to both implicit stereotypes and prejudices about certain groups of people.[163] Clinicians are not immune to these biases, which can lead them to unknowingly associate certain demographic groups with negative concepts, like lower competence and decisional capacity. Three potential ways to address clinical bias are (1) perspective-taking, which refers to imagining yourself in the other person's position (seeing things through their eyes) and (2) being on the same team i.e., cultivating a sense that you and the individuals accessing care are on the same team, working toward shared personal values, goals, and preferences.[164] and (3) implicit bias training, which could help clinicians understand and challenge their own biases.

5. **Decisional capacity:** Decisional capacity is a gradient and may vary over time, being affected by disease, medicines and mental state, for example. Therefore, clinicians can benefit from the assistance of time and repeated assessments to establish the threshold at which eliciting personal values, goals, and preferences remains appropriate. It is also clear that profound uncertainty and serious illness can lower decisional capacity. A pulmonologist describes her difficulty in counselling people with incurable lung cancer. She notes that an increasing

number of second-line treatment options are available that can delay cancer progression rather than offer a cure. Sometimes these treatments lead to remission but more commonly they can lead to severe, painful side effects and do not substantially delay progression. However, individual responses to treatments vary and are unpredictable. The inherent uncertainty clouds the decisional capacity and rational comprehension is undermined by fear and emotion.

6. **Personal choice:** There are many people who simply do not desire responsibility for making decisions about their health and prefer clinicians to make decisions on their behalf, especially in times of great need and uncertainty. A way of dealing with this is deferring decisions when they are not urgent and providing enough information so that individuals can reflect in their own time, before meeting again with the Clinician.

7. **Confidence:** Some individuals are reluctant to seek information or discuss it during consultations as they do not want to seem uneducated or appear to be challenging authority. Making people accessing care feel at ease, displaying warmth and demonstrating authenticity, respecting their culture and beliefs and building trust over time can help create the environment that enables people to discuss openly with their Clinicians.

8. **Perceptions:** Many clinicians believe that the care they provide is already person-centred. However, the evidence shows that this is often not the case.[165] There are techniques that can help increase the awareness of clinicians regarding the gap between the care they provide and true Person-Centred Care.[166] These are:
    - For people accessing care, enhance their confidence and ability to engage with clinicians around personal values, goals and preferences.
    - Enable service managers and commissioners to understand how care pathways can support eliciting personal values, goals, and preferences.
    - For people accessing care and key staff members, provide training on personal values, goals, and preferences.

9. **Inequities:** Engaging in discussions around personal values, goals and preferences, intended to empower individuals in their care choices, carries the risk of exacerbating existing disparities. Factors such as information access disparities, communication barriers, cultural and personal beliefs, and health care system disparities can contribute to unequal participation in the decision-making process. There are different ways that this can be addressed:
    - Clinicians should know how to work with people of different levels of health literacy, ensuring that all people accessing care can actively participate in sharing their personal values, goals and preferences.
    - As new decision support tools are developed, they must be developed in such a way that they can be easily understood by everyone, regardless of their level of health literacy.
    - Education materials must be accessible.
    - People accessing care must feel empowered, understanding the importance of expressing their personal values, goals and preferences

during discussions with clinicians and the value the health care system attaches to the dialogue between people accessing care and Clinicians.

- Implementing patient advocacy and support programmes to assist individuals in navigating the health care system. This can include providing advocates or navigators who help individuals understand their options and make informed decisions.
- Clinicians should pay special attention to vulnerable populations, such as those with limited health literacy or limited local language proficiency as these groups may need additional support and resources to ensure equitable care that aligns with each person accessing care's personal values, goals and preferences.
- Clinicians should receive training in cultural competency to understand and respect diverse personal values, goals and preferences. This can improve communication and foster trust between clinicians and people accessing care.

4.9 Case studies demonstrating successful implementation

I. Case 1

Joseph, a 68-year-old man suffers from diabetes, hypertension and chronic obstructive pulmonary disease (COPD). Throughout his entire working life, he was a secondary school teacher. He has been retired for three years now. Even though he is limited by his health conditions, he loves spending time gardening and playing with his grandchildren.

A few years ago, he was a passionate cyclist, but his racing bike has been stored for a long time now. His friends encourage him to cycle with them again on a weekly basis. His wife supports this initiative and argues that this will be beneficial for his social contact. Every month Joseph visits his family doctor for a check-up and in advance of each consultation, he prepares a list of things he wants to discuss. He is fortunate in that he has a strong relationship with his family doctor built on trust and mutual respect.

In his monthly check-up, he suggests his wishes to cycle again with his friends. His doctor hesitates whether this will be possible given his health status. After discussion, they plan that he would join his friends in their weekly cycling trip but only for the first two hours. The group will be asked to adapt their pace and Joseph will make sure that he doesn't return home on his own. The doctor liaises with the cardiologist to adjust the medication scheme according to the increased efforts Joseph will make. The family doctor and Joseph agree to discuss and evaluate the changes after three months, at which point they will also determine if it is possible to increase the biking intensity further. [167]

II. Case 2

Mary is a 40-year-old mother of two young children and has been obese since her childhood.

Due to her weight, she has a lot of pain in her joints and is short of breath which limits her exercising capacity. Her children are looking forward to playing outside with their mother during the summer holidays. Unfortunately, she is unable to play football or jump on the trampoline because of the pain in her knees. The pain becomes too much for her and after a long hesitation she asks her family doctor for help so that she can play and interact with her children during the summer holidays.

Her family doctor does not explore her personal values, goals and preferences and instead explains that he does not support medication but asks her to first strive for a healthy weight as a solution to relieve the pain. Therefore, he refers her to a diet and exercise management service.

Unfortunately, this is not aligned with Mary's wishes who wanted to start with a short-term solution to be able to play with her children during the summer holidays. In the end, she leaves the consultation room with the referral but ultimately decides not to attend the service.[168]

III. Case 3

The Global Centre of Excellence in PCVBHC is currently developing a collaborative care tool to support the implementation of PCVBHC. The tool enables (1) the capture of people’s personal values, goals and preferences, (2) measurement of the extent to which values and goals are being achieved and (3) aggregation of the data and is scheduled for a trial international Community of Practice to begin using the tool during 2024.

This tool features (1) individual profile and preferences dashboard, (2) secure messaging and virtual consultations, (3) interactive decision support tools, (4) care team collaboration hub where health care team members have access to the individual's profile and can contribute insights and recommendations, ensuring a holistic understanding of the individual's personal values, goals and preferences, (5) goal tracking and progress monitoring and (6) regular surveys and feedback mechanisms.

An example of how this tool can assist Clinicians in eliciting and integrating personal values, goals, and preferences:

John, who has multiple long-term conditions, uses the PCVBHC tool to communicate with his health care team. He updates his profile to reflect his preference for holistic approaches to managing his conditions. During virtual consultations, John and his health care team discuss his values, which include maintaining an active lifestyle and minimising medication side effects. The platform's decision support tools help John explore treatment options aligned with his values, goal and preferences and his care team adjusts his plan accordingly. Regular feedback surveys allow John to express changing preferences, ensuring ongoing collaboration and personalized care.

By fostering continuous communication and collaboration between individuals and their Clinicians, the PCVBHC toll exemplifies a system that actively elicits and integrates personal values, goals, and preferences into the care process, ultimately enhancing the quality of health care delivery.

To obtain additional details about the PCVBHC tool and the trial international Community of Practice, please get in touch with Thomas Kelley via email at t.kelley@sprink.co.uk.

5.0 Conclusion

This Report has focused on how we enable people accessing care and their clinicians to engage in a shared goal-setting and decision-making process to align care to people's personal values, goals, and preferences. This is an essential step in achieving the objectives laid out in the Person-Centred Value-Based Health Care framework, which seeks to harmonise Person-Centred Health Care, Value-Based Health Care and Health Equity.

The findings reveal the importance of empowering both people accessing care and clinicians and at the same time, recognising the associated risks, understanding how to address them, and implementing effective management strategies. By fostering an environment of open communication, active listening, and mutual respect, we can move to a truly personalised model of health care delivery.

Each person is unique, and it is only by understanding their values, goals, and preferences that we are able to deliver inclusive, high value care. Health care systems have finite resources and decisions have to be taken around how to allocate these resources effectively. Such decisions must be informed by aggregated data on people's values, goals and preferences. Once such resource allocation decisions have been taken, it is then for clinicians and people accessing care, to work in collaboration, to determine how best to utilise these resources such that they align with the individual's values, goals and preferences.

As we look forward, we will be announcing a further programme of research which will consider how we begin to aggregate data around values, goals and preferences for use at the meso and macro levels. If you are interested in partnering with us on this research, please contact Dr Andrea Srur (a.srur@sprink.co.uk). We have also launched a Community of Practice and a novel PCVBHC tool to support capturing and aggregating people's personal values, goals and preferences at scale. If this is of interest, please contact Thomas Kelley (t.kelley@sprink.co.uk).

In embracing PCVBHC, we embark on a transformative journey toward a health care system that optimises its allocation and utilisation of finite health care resources, but, above all, is more compassionate, person-focused, and aligned with the personal values, goals and preferences of those it serves.

6.0 Appendix

6.1 Appendix I Research Methodology

The methodology consisted of 10 steps and was managed by the Project Lead. Specifically:

Step 1: Community of Experts and Industry Advisory Panel selection.

- An international, multi-stakeholder Community of Experts (CoE) was assembled (Appendix II). Experienced patient advocates were a central part of the CoE. Input from individual pharmaceutical and medical technology companies was obtained via a separate Industry Advisory Panel (IAP) (Appendix III).

- A structured approach was used to select the CoE and IAP members. Specifically, for the CoE:
    - A Chair of the CoE was appointed.
    - The Chair was selected from the original PCVBHC Community of Experts[169] as an international clinician leader in Person-Centred Health Care and Value-Based Health Care.
    - The Chair was responsible for (1) working with the Project Lead to form the CoE; (2) chairing the CoE video-conference meetings; (3) providing input into the development of materials for CoE virtual meetings; and (4) providing input into the development of the Report and reviewing the final draft Report prior to distribution to the CoE.

- Key stakeholder groups were identified by the Project Lead and Chair. These included patients, caregivers, clinicians, academics and guideline developers.

- A formal stakeholder mapping was then conducted, identifying target members with expertise in goal setting and/or preference elicitation and/or shared decision making and/or Value-Based Health Care. The target members were identified by their membership in the first PCVBHC Community of Experts, peer recommendation and based on expert's overall work and scientific record. The Chair and Project Lead then took a decision as to which target members would be prioritised. The prioritisation was carried out using a ranking methodology weighting expert's overall work experience, scientific record, and current position.

- Letters were distributed from the CoE Chair and Project Lead and an introductory video call arranged.

- Ultimately, the CoE consisted of 18 members.

- Specifically, for the IAP:
    - A Chair of the IAP was appointed.
    - The Chair was selected from the original PCVBHC Community of Experts as an international industry leader in Person-Centred Health Care and Value-Based Health Care with no specific company affiliation.
    - The Chair was responsible for (1) working with the Project Lead to form the IAP, (2) chairing the IAP video-conference meetings; (3) providing input into the development of materials for IAP virtual meetings; and (4) providing input into the development of the Report and reviewing the final draft Report prior to distribution to the IAP.
- Key industry stakeholder groups were identified by the Project Lead and IAP Chair. These included the pharmaceutical and MedTech industry.
- A formal stakeholder mapping was then conducted, identifying target members with expertise in goal setting and/or preference elicitation and/or shared decision making and/or Value-Based Health Care. The target members were identified by their membership in the PCVBHC Community of Practice that has been established by Sprink, peer recommendation and based on expert's overall work. The IAP Chair and Project Lead then took a decision as to which target members would be prioritised. The prioritisation was carried out using a ranking methodology weighting expert's overall work experience, and current position.
- Letters were distributed from the IAP Chair and Project Lead and an introductory video call arranged.
- Ultimately, the IAP consisted of nine members.

Step 2: First meeting with the CoE and IAP.

- A 60-minute virtual meeting was organised with the CoE. Two broad questions were posed to the CoE with the aim of identifying themes that would help to shape the project questions.
- A parallel 60-minute meeting was organised with the IAP, with the same objective and format.

Step 3: Second virtual meeting with the CoE and IAP.

- A 60-minute virtual meeting was organised with the CoE. This focused on co-designing specific project questions that would ultimately answer the overall project objective.
- A parallel 60-minute meeting was organised with the IAP, with the same objective and format.

Step 4: Finalisation of project questions.

- The project questions were finalised by the CoE Chair, IAP Chair, Project Lead and Research Fellow.

Step 5: Pragmatic literature review.

- The Research Fellow conducted two independent searches for each project question. The full search strategies (MEDLINE OvidSP) are outlined in Appendix IV.
- The literature searches were conducted in MEDLINE OvidSP and EMBASE OvidSP.
- The searches were limited to literature reviews (including scoping, narrative and systematic reviews), using the Scottish Intercollegiate Guidelines Network (SIGN) search filters.
- The searches were restricted to articles conducted in adult humans.
- Eligible studies had to be published as full-length articles written in English or Spanish, between 2000 and 2023.

Step 6: Grey Literature review.

- Grey literature is defined as: “information produced by all levels of government, academia, business and industry in electronic and print formats not controlled by commercial publishing.”
- The review was carried out using Google's site limits function to only search government, international and non-governmental organisations and non-departmental public bodies. The search was then performed using specific keywords including “personal values”, “goal setting”, “preferences” and “shared decision making”. A title review was then performed for every result on the first five pages. Results deemed relevant then underwent a further review using the SIFT methodology.[170] This final list of results then underwent a full text review.

Step 7: Individual interviews with the CoE and IAP.

- Virtual interviews were conducted with members of the CoE and IAP.
- Interview guides were prepared and circulated in advance of each interview.
- Interviews were recorded and then subsequently transcribed.
- Interviews were thematically analysed using Nvivo.

Step 8: Drafting the Report.

- The Project Lead drafted the Report addressing each of the project questions, bringing together the findings from the pragmatic literature review, grey literature review and interviews with members of the CoE and IAP.
- The draft Report was then reviewed by the CoE Chair and IAP Chair and their edits were incorporated.

Step 9: CoE and IAP feedback on draft Report.

- The draft Report was circulated to all members of the CoE and IAP and they were asked to provide their structured feedback via a feedback form.
- Their comments were then summarised and discussed at a joint CoE and IAP meeting.
- Two joint meetings were organised to accommodate time zone differences.
- Consensus was sought at these meetings on the edits to be made to the Report.

Step 10: Final review by CoE.

- Following incorporation of the agreed edits from Step 9, a final version of the Report was circulated to the CoE for a final review.
- A fourth (and final) CoE virtual meeting was organised, at which any final requested changes were discussed, and agreement was sought to publish the Report.

6.2 Appendix II Community of Experts

Name	Job title	Organisation	Location
Willem Jan Bos.	Professor in Nephrology (Outcomes of Care).	Leiden University Medical Center.	The Netherlands.
Adrian Edwards.	Professor of General Practice. Co-Director, Division of Population Medicine.	Cardiff University.	Wales, UK.
Ivett Jakab.	President.	Patient advocate.	Hungary.
Natalie Joseph-Williams.	Reader in Improving Patient Care.	Cardiff University.	Wales, UK.
Martha Kidanemariam.	PhD Candidate, Value-Based Health Care.	Leiden University Medical Center.	The Netherlands.
Carl Lander.	Patient representative.	Thrive with Pyruvate Kinase Deficiency Organization.	England,UK.
Richard Lehman.	Honorary Professor of the Shared Understanding of Medicine.	University of Birmingham.	England, UK.
Kirsten McCaffery.	Principal Research Fellow.	Sydney School of Public Health, University of Sydney.	Australia.
Victor Montori.	Robert H. and Susan M. Rewoldt Professor of Medicine.	Mayo Clinic.	USA.
Don Redding.	Formerly, Director of Policy.	Formerly, National Voices.	England, UK.
Emma Rogan.	Project Coordinator.	European Multiple Sclerosis Platform.	Ireland.
James Sanderson.	Director.	Personalised Care at NHS England and NHS Improvement.	England, UK.
Christobel Saunders (Chair).	James Stewart Chair of Surgery.	University of Melbourne.	Australia.
Siân Slade.	Chair.	#NavigatingHealth.	Australia.
Kathryn South.	Head of Person-Centred Care.	Welsh Value in Health Centre.	Wales, UK.
Mary Tinetti.	Gladys Phillips Crofoot Professor of Medicine.	Yale School of Medicine.	USA.
Angelique Weel.	Endowed Professor.	Erasmus School of Health Policy & Management.	The Netherlands.

6.3 Appendix III Industry Advisory Panel

Name	Job title	Organisation	Location
Thomas Allvin (Chair).	Executive Director, Strategy and Health care Systems.	European Federation of Pharmaceutical Industries and Associations (EFPIA).	Belgium.
Sjaak Bloem.	Professor and Associate Director Behavioural Science.	Nyenrode Business University and Janssen-Cilag.	The Netherlands.
Kristina Dziekan.	Non-Executive Board Member.	ONWARD.	Switzerland.
Michele Mestrinaro.	Vice President, Global Head of Policy.	Novartis.	Switzerland.
Thomas Metcalfe.	Head of Health care System Partnerships Cluster, Medical Affairs.	Roche.	Switzerland.
Natalie Pal.	Vice President of Medical Affairs EMEA and North America.	Becton Dickinson.	Switzerland.
Jayant Saha.	Head of Global Business Development - Interventional Radiology.	Siemens Healthineers.	UK.
Vincent Wiersma.	Value-Based Health Care Specialist.	Amgen.	The Netherlands.
John Wilkinson.	Formerly, Director of Devices.	Formerly, Medicines and Health care products Regulatory Agency (MHRA).	UK.

6.4 Appendix IV Data extraction and management

Study selection:

The Research Fellow screened the records retrieved by the searches for inclusion. The selection process was done through Endnote and all the inclusion and exclusion decisions were recorded in the PRISMA flowcharts (Figures 3 and 4). In exploring Question 1, which delves into the definitions of (1) personal values, (2) goals, and (3) preferences the initial search identified a total of 2,154 articles. Four additional records were identified through manual search; after removing the duplicates, there were a total of 1,837 articles for the initial screening by title and abstract. From these, 31 were included for full-text assessment, of which 15 were included for the narrative synthesis. In exploring Question 2, divided into sub questions and targeting the micro level, the emphasis lies in empowering individuals accessing care and their clinicians to elicit and use personal values, goals, and preferences. The preliminary search identified a total of 3,753 articles and nine through manual search; after removing the duplicates, there were a total of 3,252 articles for the initial screening by title and abstract. From these, 50 articles were included for full-text assessment. After full-text assessment, 34 articles were included in the narrative synthesis.

The search terms used during the research process were:

Search strategy = #1 OR (#2 AND #3 AND #4)	
1. Preference elicitation	Preference elicitation [tiab] OR preference clarification* [tiab] OR value elicitation [tiab] OR value clarification* [tiab] OR eliciting preference* [tiab] OR eliciting value* [tiab]
2. Shared decision making	Decision making, shared [MesH] OR ((Decision making [MesH] OR Clinical Decision Making [MesH]) AND shared [tiab]) OR shared decision making [tiab] OR FPI scale* [tiab] OR COMRADE [tiab] OR CollaboRATE [tiab] OR IDM [tiab] OR DSAT [tiab] OR DSAT-10 [tiab] OR observer OPTION [tiab] OR SDM scale* [tiab] OR MAPPIN SDM Inventory [tiab] OR SDM [tiab] OR encounter decision aid* [tiab] OR encounter decision tool* [tiab] OR encounter decision box* [tiab] OR encounter option grid* [tiab] OR decision support* [tiab] OR sharing decision* [tiab] OR share decision* [tiab]
3. Patient engagement/ participation	Patient participation [MesH] OR patient involvement* [tiab] OR patient engagement* [tiab] OR patient participation* [tiab] OR patient empowerment* [tiab] OR patient activation* [tiab] OR involvement of patient* [tiab] OR engagement of patient* [tiab] OR participation of patient* [tiab] OR empowerment of patient* [tiab] OR activation of patient* [tiab]
4. Patient's perspective/context	Patient preference [MesH] OR ((preference* [tiab] OR perspective* [tiab] OR context* [tiab] OR value* [tiab]) AND (patient* [tiab])) OR treatment preference* [tiab]

Figure 7: PRISMA flowchart Question 1

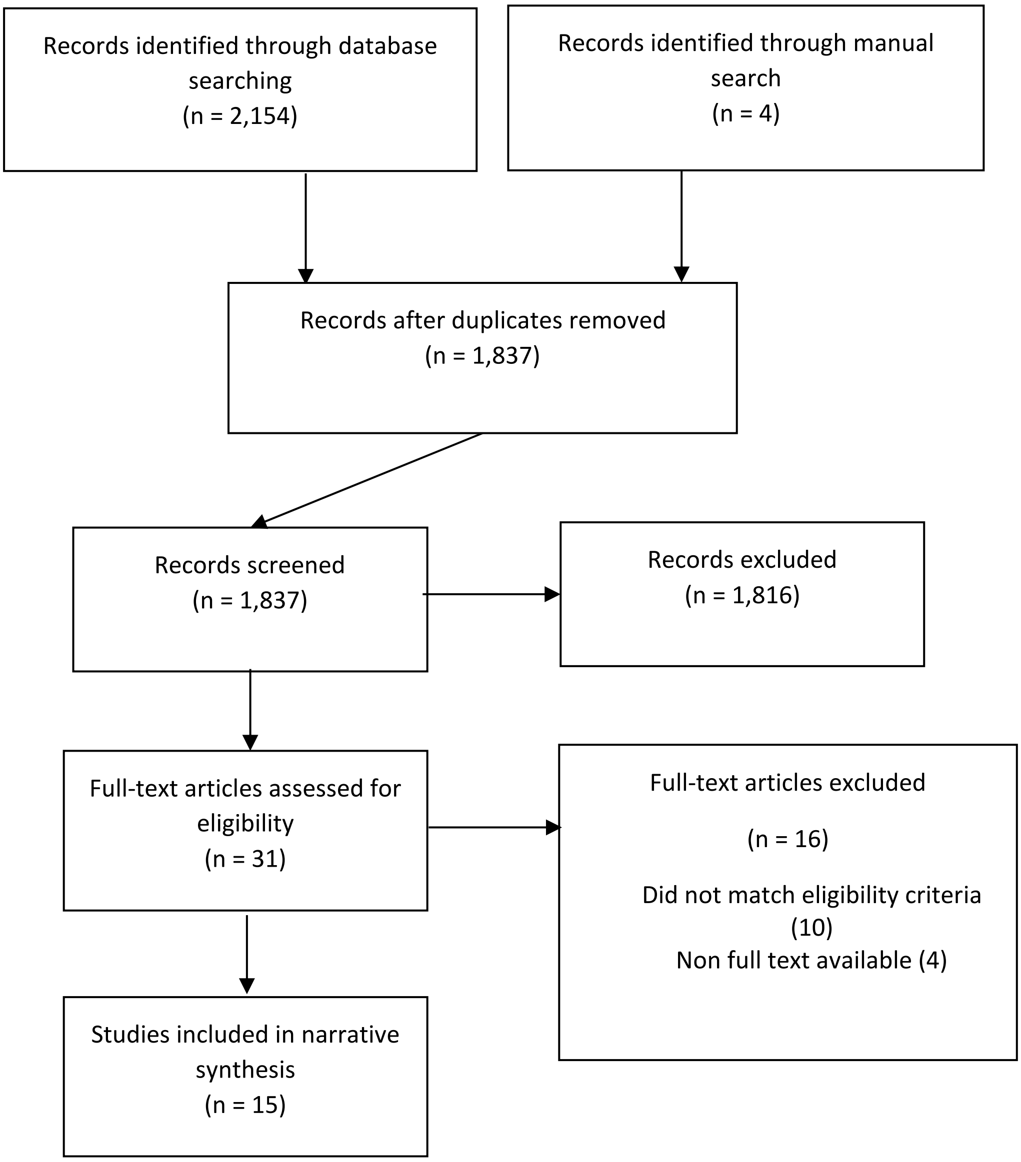
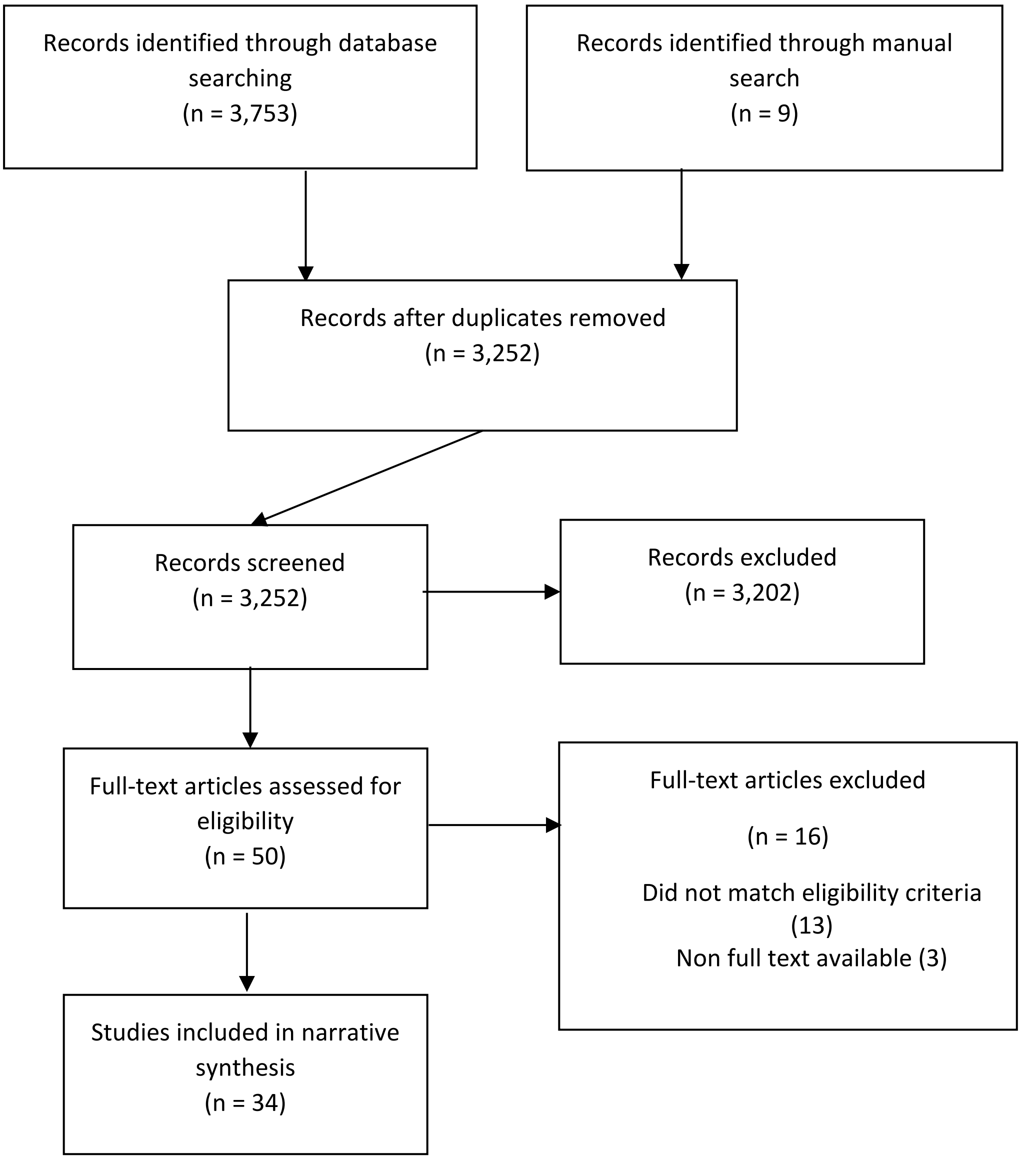


Figure 8: PRISMA flowchart Question 2



6.5 Appendix V Examples of Patient Decision Aids

These tools have been developed by NHS England in accordance with The National Institute for Health and Care Excellence standards framework for shared decision-making support tools.[171]

- Making a decision about carpal tunnel syndrome
- Making a decision about cataracts
- Making a decision about Dupuytren's contracture
- Making a decision about further treatment for atrial fibrillation
- Making a decision about glaucoma
- Making a decision about hip osteoarthritis
- Making a decision about knee osteoarthritis
- Making a decision about recurrent tonsillitis in children and adults
- Making a decision about wet age-related macular degeneration

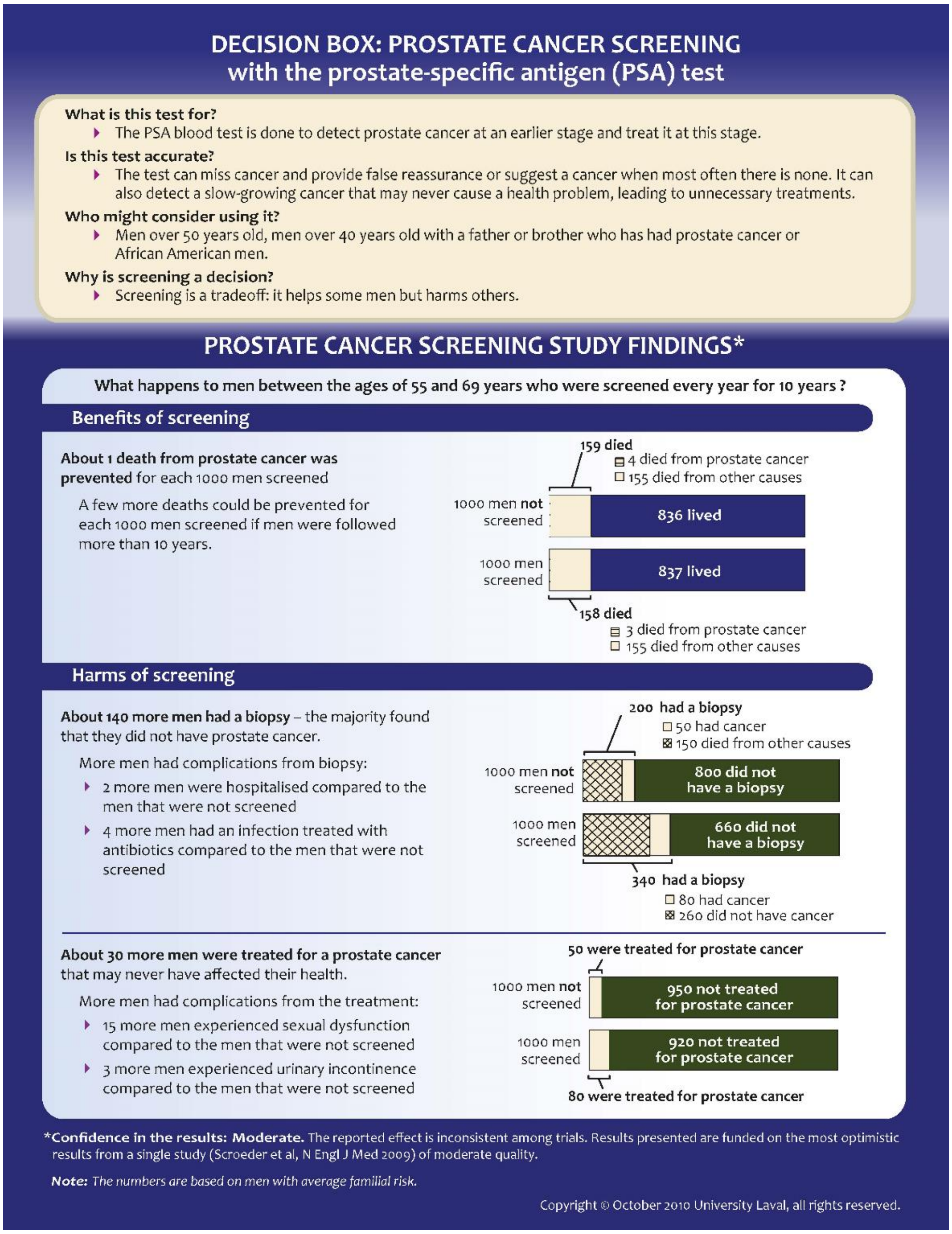
6.6 Appendix VI Example of Option Grid™ for osteoarthritis of the knee in a musculoskeletal clinic [172]

Osteoarthritis of the knee

This grid is designed to help you and your clinician decide how best to manage your knee pain and activity level. The first steps are to become as fit and close to your ideal weight as possible and to consider having physiotherapy. Surgery is normally recommended only after other treatments have been tried.

Frequently asked questions	Painkillers	Joint injections (steroids)	Knee replacement surgery
Will this reduce the pain I have in my knee?	It depends on which tablets are taken. Tablets like ibuprofen are effective for 50 in every 100 people. Over the counter tablets, like paracetamol, including those that have codeine, are also effective.	Some people get good symptomatic relief after an injection, which may include pain relief and/or reduced swelling.	About 90 in every 100 people who have this operation say it leads to relief of most or all of their pain, over time. 10 in every 100 people say it does not lead to significant pain relief.
Will this treatment help improve which activities I can manage to do?	It may. As you get pain relief, you should be able to be more active and this in turn can also help to reduce pain. It helps to take painkillers before doing physical activity.	Yes, usually for up to a month or so. Plan to be more active as a result of the pain relief. Advice from a physiotherapist may help.	Yes, the majority of patients experience improvement in their activity level. However, not everybody sees differences in their ability to walk or climb stairs.
Are there any risks to this treatment?	As with all medications, pain killers have some side effects. For example, codeine often leads to constipation and prolonged use of anti-inflammatory tablets like ibuprofen increases your risk of stomach bleeding.	There is a small risk of frequent injections causing cartilage damage, especially in weight-bearing joints. Allergic reactions and infections due to joint injections are uncommon. You might feel slight pain at the injection site for a few days.	Wound infection needing treatment occurs in 5 in every 100 people. Blood clots in the leg occur in 2 in every 100 people. The risks from surgery increase if you have other conditions, such as heart or lung disease, are a smoker or are overweight.
How long will it take me to feel better after the treatment?	You may start experiencing pain relief within a few days of when you start taking the medication.	Most people who experience relief feel better within the first week or so after the injection	Pain relief is gradual. You will stay in the hospital for around three to five days. Most people walk unaided after 3 months. Full recovery usually takes between 6 and 12 months.
Will I need to have more treatment or surgery?	If things don't get better, talk to your clinician about other treatment options.	Pain relief lasts for up to a month or so. You can only have up to 4 injections per year.	Most knee replacements can last 15 years, many last longer.
What are the outcomes for people with arthritis who have this treatment?	Many people cope well by using medication, being active, and losing weight. Reducing your pain may help you achieve the benefits of exercise.	Some people have good relief by having injections when swelling and pain cause problems.	Surgery is usually considered after other options have been tried. About 80 in every 100 people are satisfied after having a knee replacement. About 20 in every 100 are not satisfied.

6.7 Appendix VII Example of Decision Box in prostate cancer screening



DECISION BOX: PROSTATE CANCER SCREENING
with the prostate-specific antigen (PSA) test

What is this test for?

- The PSA blood test is done to detect prostate cancer at an earlier stage and treat it at this stage.

Is this test accurate?

- The test can miss cancer and provide false reassurance or suggest a cancer when most often there is none. It can also detect a slow-growing cancer that may never cause a health problem, leading to unnecessary treatments.

Who might consider using it?

- Men over 50 years old, men over 40 years old with a father or brother who has had prostate cancer or African American men.

Why is screening a decision?

- Screening is a tradeoff: it helps some men but harms others.

PROSTATE CANCER SCREENING STUDY FINDINGS*

What happens to men between the ages of 55 and 69 years who were screened every year for 10 years ?

Benefits of screening

About 1 death from prostate cancer was prevented for each 1000 men screened

A few more deaths could be prevented for each 1000 men screened if men were followed more than 10 years.

159 died
▤ 4 died from prostate cancer
☐ 155 died from other causes

1000 men **not** screened — 836 lived

1000 men screened — 837 lived

158 died
▤ 3 died from prostate cancer
☐ 155 died from other causes

Harms of screening

About 140 more men had a biopsy – the majority found that they did not have prostate cancer.

More men had complications from biopsy:

- 2 more men were hospitalised compared to the men that were not screened
- 4 more men had an infection treated with antibiotics compared to the men that were not screened

200 had a biopsy
☐ 50 had cancer
▩ 150 died from other causes

1000 men **not** screened — **800 did not have a biopsy**

1000 men screened — **660 did not have a biopsy**

340 had a biopsy
☐ 80 had cancer
▩ 260 did not have cancer

About 30 more men were treated for a prostate cancer that may never have affected their health.

More men had complications from the treatment:

- 15 more men experienced sexual dysfunction compared to the men that were not screened
- 3 more men experienced urinary incontinence compared to the men that were not screened

50 were treated for prostate cancer

1000 men **not** screened — **950 not treated for prostate cancer**

1000 men screened — **920 not treated for prostate cancer**

80 were treated for prostate cancer

***Confidence in the results: Moderate.** The reported effect is inconsistent among trials. Results presented are funded on the most optimistic results from a single study (Scroeder et al, N Engl J Med 2009) of moderate quality.

Note: *The numbers are based on men with average familial risk.*

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