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**THE BEHAVIOURAL ASPECTS OF SHARED DECISION  
MAKING**

by

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A doctoral thesis submitted in the partial fulfilment for the degree of  
Doctor of Philosophy

in the

Behavioural Science Group

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# Contents

|  |             |
|--|-------------|
| <b>Contents .....</b>  | <b>i</b>    |
| <b>List of Tables.....</b>   | <b>iv</b>   |
| <b>List of Figures .....</b>   | <b>v</b>    |
| <b>Acknowledgements .....</b>  | <b>vi</b>   |
| <b>Declaration of Authorship .....</b>   | <b>vii</b>  |
| <b>Abstract .....</b>  | <b>viii</b> |
| <b>Chapter 1 Introduction.....</b>   | <b>1</b>    |
| Rise of shared decision making.....  | 2           |
| Contributions of the thesis.....   | 4           |
| <b>Chapter 2 Literature Review .....</b>   | <b>8</b>    |
| Models of shared decision making.....  | 8           |
| Developments in shared decision making .....   | 11          |
| Political setting .....  | 11          |
| Organisational setting .....   | 13          |
| Social setting .....   | 16          |
| Current gaps in the literature .....   | 19          |
| <b>Chapter 3 A systematic review and an agent-centric model of shared decision making.....</b> | <b>22</b>   |
| Methods .....  | 24          |
| Search strategy.....   | 24          |
| Thematic analysis.....   | 26          |
| Model development.....   | 26          |
| Findings from the review.....  | 26          |
| Decision agents.....   | 26          |
| Decision process .....   | 31          |
| Decision Context .....   | 35          |
| Summary of the review .....  | 37          |
| An agent-centric model of shared decision making .....   | 38          |
| Decision Context .....   | 39          |

|  |           |
|--|-----------|
| Pre-decision Phase .....   | 40        |
| Decision Making Phase .....  | 41        |
| Post-decision Phase.....   | 43        |
| Discussion and conclusion.....   | 43        |
| Implications for theory and practice .....                                   | 44        |
| Conclusions .....  | 46        |
| <b>Chapter 4 Advice giving in shared decision making.....</b>                | <b>48</b> |
| Literature review .....  | 49        |
| Expert advice .....  | 49        |
| Anxiety.....   | 51        |
| Prostate screening advice and patient anxiety.....                           | 51        |
| Methods .....  | 53        |
| Materials .....  | 53        |
| Measures and variables.....  | 53        |
| Procedure .....  | 55        |
| Participants .....   | 55        |
| Manipulation checks.....   | 57        |
| Statistical analyses.....  | 57        |
| Results.....   | 58        |
| Overview of results.....   | 58        |
| Screening decision making .....  | 58        |
| Mediation analyses (Recommend against screening).....                        | 59        |
| Mediation analyses (Recommend for screening) .....                           | 61        |
| Discussion .....   | 62        |
| Study limitations .....  | 65        |
| Conclusions .....  | 66        |
| <b>Chapter 5 Shared decision making for person-centred social care .....</b> | <b>67</b> |
| Background .....   | 68        |
| Shared decision making in social care .....                                  | 70        |
| The COM-B framework.....   | 75        |
| Capability .....   | 75        |
| Opportunity .....  | 78        |
| Motivation.....  | 81        |

|  |            |
|--|------------|
| Behaviour .....  | 86         |
| Discussion .....   | 91         |
| Impact model of shared decision making .....             | 91         |
| Additional moderators.....                               | 93         |
| Social support network .....                             | 94         |
| Policymaking .....                                       | 95         |
| Limitations .....  | 97         |
| Conclusions.....   | 97         |
| <b>Chapter 6 General discussion and conclusion .....</b> | <b>99</b>  |
| Confusion about control.....                             | 100        |
| Authentic shared decision making.....                    | 102        |
| Culture .....  | 105        |
| Organisational culture.....                              | 105        |
| National culture.....                                    | 106        |
| Overall conclusions.....                                 | 107        |
| <b>References.....</b>                                   | <b>110</b> |
| <b>Appendix A .....</b>                                  | <b>131</b> |
| <b>Appendix B.....</b>                                   | <b>154</b> |

# List of Tables

|   |    |
|---|----|
| Table 1. Overview of included articles.....                             | 25 |
| Table 2. Overview of domains and themes.....                            | 27 |
| Table 3. Summary characteristics of the sample.....                     | 56 |
| Table 4. Means, standard deviations, and correlations of variables..... | 58 |

# List of Figures

|  |    |
|--|----|
| Figure 1. PRISMA flowchart.....  | 24 |
| Figure 2. An agent-centric model of shared decision making.....                  | 39 |
| Figure 3 Expertise and activities in person-centred social care.....             | 73 |
| Figure 4 Impact of shared decision making (SDM) on person-centred social care... | 92 |

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# Declaration of Authorship

The work done in this dissertation was performed wholly during my candidature for the degree of Doctor of Philosophy at this University. Chapter 3 was co-authored with Sebastiano Massaro and Ivo Vlaev. The experiment in Chapter 4 was designed with suggestions from Daniel Read, Sebastiano Massaro, and Ivo Vlaev. The objective and scope of the review paper in Chapter 5 were co-defined by Which? and Warwick Business School. The rest of the material provided in this dissertation represents my own work.

An early version of Chapter 3 has appeared as a conference proceeding at the 2017 Academy of Management Conference. An early version of Chapter 5 has been published as a policy report by Which? in 2018 and is available online as a preprint.

This dissertation has not been submitted for a degree at any other University.

# Abstract

Shared decision making (SDM), a paradigm in which healthcare practitioners and lay people collaborate to make informed and person-centred decisions, has been increasingly advocated in health policy and practice. Despite widespread interest and efforts to embed SDM into routine care, recent research suggest that it is still rarely observed in practice, and that its health outcomes are often mixed.

In this dissertation, I argue that the extant SDM literature has mostly overlooked the behavioural aspects that govern professional-patient collaboration in clinical decision making. To enrich knowledge on the process of sharing in decision making, the role of bounded rationality should be better accounted for. This will enable researchers to understand the complexities involved in a dyadic interaction and the ways in which they contribute to informed and person-centred decision outcomes.

Across three essays, I address the main research questions of: Why is there significant variation in how decision makers implement SDM? What are the behavioural aspects that shape SDM? And, how do behavioural influences affect person-centred care? The first essay reviews the behavioural aspects that underpin SDM and advances an agent-centric model that elucidates the bounded rational nature through which decision agents make person-centred decisions. The second essay supports this model by empirically investigating the ways in which emotion and advice-giving affect SDM. I show that emotion plays a crucial role in shaping patients' judgment and decision making, with implications for person-centred care. The third piece proposes SDM as a promising framework for enabling person-centred social care and establishes its behavioural dimensions. Overall, this dissertation advances knowledge on the bounded rational nature of social interactions and the ways in which behavioural influences shape informed and person-centred care.

# Chapter 1

## Introduction

Most lay individuals facing a serious health decision are prone to being under-or over-influenced by their healthcare professional. Imagine an intensive care patient who is suffering from a rapidly progressing illness (e.g., malignant cancer) and has a small but real chance of surviving if he or she undergoes a medical intervention (e.g., radiotherapy). The patient feels that there has been enough pain already and asks for palliative care only. By chance, the patient is assigned to one of three hypothetical healthcare professionals. Doctor A downplays supportive care, highlights the benefits of maximising one's chances of survival, and convinces the patient to have the medical intervention without ever considering the patient's own preferences. Doctor B communicates the options and evidence available, assesses the patient's preferences, and decides together that palliative care is the best overall option. Doctor C ensures that the patient understands the options and evidence available and accedes to the patient's request of having palliative care without sharing any professional input.

Data from several surveys and observational studies indicate that the dominant mode of decision making may still reflect that of Doctor A, or the paternalistic approach (Floyd J, Gerstein & Barry 2013; Couët, Desroches, Robitaille, Vaillancourt, Leblanc, Turcotte, et al. 2015). This is despite widening interest over the last few decades to promote patient involvement in decision making, culminating in many political, legislative and practical changes (Spatz, Elwyn, Moulton, Volk & Frosch 2017; Coulter, Edwards, Entwistle, Kramer, Nye, Thomson, et al. 2017). More professionals

are trained in shared or person-centred decision making, an approach that reflects Doctor B's communication style, than ever before. However, some professionals like Doctor C have gone to the extent of autonomous decision making in which they withhold their experience and have patients decide almost independently (Quill & Brody 1996).

Why is there such variation in how people share decision making?

Doctor A took full control of a critical decision by making a crucial assumption that a patient's best interest would be to maximise his or her chances of survival. Doctor C allowed the patient to take full control of the decision, but at the expense of sharing expert opinion. On the other hand, Doctor B shared decision control with the patient, but only after engaging in an intense discussion about the implications of the decision and sharing the belief that palliative care was the best overall choice. Compared to the first two approaches, shared decision making was able to integrate both perspectives, the professional's as well as the patient's, and produce an informed decision that respects individuals' preferences (Epstein & Gramling 2013). Clearly, moving paternalistic and autonomous decision making styles to a more central position in which both professionals and lay individuals can share decision making requires decision makers to overcome a number of behavioural issues. Hence, the first step is to know what these are. The second is to address them. Both these steps may be challenging, but they are necessary for enabling person-centred care. The aim of this thesis is to tackle these gaps in the context of health and social care.

## **Rise of shared decision making**

Rising interest in shared decision making is the result of several changing trends. Informed consent, now legally and ethically recognised as a patient right, appears to involve at least a minimum of shared decision making in the form of basic patient comprehension and approval to any clinical intervention (Appelbaum, Lidz & Meisel 1987; General Medical Council 1998). Furthermore, the principle of informed choice, requiring the disclosure of treatment options and the evidence behind them, has been

ratified by several governments worldwide, including Canada, Australia, the United States (US), and the United Kingdom (UK) (Woolf, Chan, Harris, Sheridan, Braddock Iii, Kaplan, et al. 2005; Marteau, Dormandy & Michie 2001).

At the same time, there is a growing consumer rights movement in healthcare. Here, calls for greater patient involvement in clinical decision making have transcended beyond informed consent to encompass broader concepts, such as patient autonomy and control (Kilbride & Joffe 2018). Shared decision making has become a means for rebalancing the traditional power asymmetry that exists between professionals and patients. The argument is that by empowering people with more information, more autonomy, and more control in clinical decisions, they would be able to exert more influence on their own wellbeing (Charles, Gafni & Whelan 1997).

A third factor is the evolving nature of medical practice. Up until a few decades ago, most major clinical decisions were made exclusively by healthcare professionals. They were made paternalistically; mostly based on beneficent intent, but without much discussion with patients. At that time, such an approach offered some benefits. It spared patients and their families from unnecessary distress over interventions that had little hope (Rosenbaum 2015; Rosenbaum 2014; Quill & Brody 1996). However, in recent times, rapid advances in biomedicine have led to an explosion of treatment options, which has greatly exacerbated the complexity faced by healthcare professionals in determining a proper option on behalf of a patient (Mulley, Trimble & Elwyn 2012; Holman & Lorig 2000). Moreover, the prevalence of comorbidities has risen dramatically over the past few decades; professionals today usually manage multiple chronic illnesses, rather than cure a specific disease (Mulley, Trimble & Elwyn 2012). These complex conditions often require long-term attention and continuous monitoring, where optimal care may depend on the quality of professional-patient relationship (Holman & Lorig 2000). Hence, in many domains of medicine, effective management of complex illnesses works best when both professionals and patients can have a say in decision making.

Finally, providing care that is person-centred, or respectful of individuals' needs, preferences, and values, is an increasingly important quality dimension in many modern healthcare systems (Scholl, Zill, Härter & Dirmaier 2014). Shared or person-centred decision making may not only improve quality of care, but also control for unwarranted practice variations. Early indications of this came from research on small area variations, where medical interventions for the same disease varied significantly and which could not be explained by differences in the health status of the population (Roos 1984; Chassin, Brook, Park, Keeseey, Fink, Kosecoff, et al. 1986; Leape, Hilborne, Park, Bernstein, Kamberg, Sherwood, et al. 1993). Thus, patient preferences in decision making were thought to be an underlying factor and accounting for them in practice could help reduce over-and/or under-utilisation of resources.

## **Contributions of the thesis**

Shared decision making is an increasingly attractive framework for enabling person-centred care. Yet, there is substantial variation in how individuals share decision making with one another. The aim of this thesis is to advance understanding on the reasons behind such patterns of behaviours. In so doing, this thesis will not only contribute knowledge on the process of sharing decision making, but also the ways in which interventions may improve its process and outcomes. This thesis focuses at the micro-level where there are multiple options available and the best option requires value judgment from the recipient of care. This thesis does not discuss in detail macro-level economic constraints, such as payment methods and costs of care, in determining how shared decision making unfolds in practice (e.g., whether patients can afford certain treatments).

This thesis begins with a general literature review of the political, organisational and social context in which shared decision making occurs in (Chapter 2). It will discuss recent trends and developments as well as highlight existing gaps in knowledge. This is followed by three separate papers, each with a specific research question. Together,

they contribute knowledge on the socially complex nature through which decision makers share decision making. This thesis argues that extant conceptions of shared decision making are relatively static and grounded on rational behaviour, which overlook the bounded rational nature of decision making and the behavioural influences that affect effective collaboration. Further understanding on these issues can greatly improve the ways in which shared decision making is effectively and equitably implemented across the board in health and social care.

The first paper (Chapter 3) systematically reviews the latest research on shared decision making to identify the core dimensions of enacting effective person-centred care. Building on these findings, this paper proposes an agent-centric framework of shared decision making—one that accounts for the various behavioural influences that shape informed and person-centred decision making. The paper elucidates the process of sharing decision making and establishes its various barriers and facilitators. In so doing, this paper contributes knowledge on the bounded and dyadic nature through which professionals and patients make person-centred decisions.

The second paper (Chapter 4) is an empirical piece about the role and ways in which expert opinion and patient emotion influences the extent to which decisions are consistent with a patient's own preferences. In particular, the paper distinguishes two types of advice (i.e., advice for informed choice versus treatment recommendation), and investigates how expert advice and patient anxiety interact to predict prostate screening decisions—a medically recognised preference-sensitive scenario in which the quality of shared or person-centred decision making depends largely on whether the outcomes reflect a person's autonomous preferences. In so doing, this paper advances empirical understanding on the specific ways in which behavioural influences (i.e., advice and emotion) affect shared decision making and person-centred care.

The third paper (Chapter 5) is a policy-oriented piece on person-centred social care. The paper discusses the importance of advance care planning in light of the recent emphasis on individual empowerment and uses a behavioural framework—the

competence, opportunity, motivation, and behaviour (i.e., COMB) model—to analyse the implementation of shared or person-centred decision making in social care. The paper critiques which dimensions are most in play at different stages of shared decision making. In so doing, this paper provides a behavioural model for future policy analysis regarding general public behaviour and extends knowledge on shared decision making by highlighting the interaction between recipients of care (i.e., elderly) and their social support network (e.g., friends, family, caregivers).

The final chapter (Chapter 6) summarises the main contributions of this thesis to the shared decision making literature, draws out key topics of interest where debate continues, and suggests future research directions for enriching insights on shared decision making. Altogether, this thesis advances current understanding on shared decision making in several ways:

- It presents shared decision making as a process of mutual influence involving two (or more) bounded rational decision agents, as opposed to static conceptions where professionals and patients are assumed to be fully rational agents in clinical encounters.
- It establishes the active ingredients that shape the ways in which professionals and lay individuals come to an “informed” and “person-centred” decision.
- It empirically demonstrates the mechanisms through which behavioural influences such as expert advice and personal emotion influence shared or person-centred decision making, thereby contributing knowledge on its dyadic and behavioural nature.
- It highlights the multi-faceted nature of sharing decision making in health and social care and provides an analytical tool for studying and implementing future policies concerning public behaviour.

In summary, shared decision making is a social interaction involving multiple bounded rational agents. Effective shared decision making produces person-centred care only when those directly and indirectly involved, including professionals, lay



individuals, social support networks, organisations, and policymakers, recognise and address a range of behavioural influences in their interactions.

## Chapter 2

# Literature Review

There are several roles that a healthcare professional and a lay individual (i.e., any recipient of care) can play in clinical decision making. These have traditionally been conceptualised as a spectrum. At one end is paternalism, in which the professional makes decisions based on medical expertise, without considering a lay person's preferences. At the other end is autonomous decision making, in which the professional fully informs the lay individual by explaining all options and their implications so that he or she can make an informed decision based on personal preferences. The middle of the spectrum is generally shared decision making, in which a professional and a lay person jointly exchange information about options and preferences before deciding together (Charles, Gafni & Whelan 1997; Charles, Gafni & Whelan 1999). Because the gulf between paternalism and autonomous decision making is arguably wide and varied, various interpretations of shared decision making have emerged in the literature.

### Models of shared decision making

The concept of shared decision making in healthcare originated from the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982). The study was commissioned to examine the potential ramifications, challenges and opportunities in relation to the growing emphasis placed on informed consent in medical practice. This seminal article framed shared decision making as a process based on mutual respect and partnership. It argued that

patient preferences play a legitimate role in the determination of a rightful option, especially when there are no objective medical criteria to ascertain the impact of a medical intervention on a person's wellbeing. Although this article set the political, legal and ethical precedence for many works to follow, it did not specify the core characteristics of shared decision making, or how professionals and patients may enact this process.

In an attempt to address this conceptual gap, Charles et al. (1997; 1999) outlined four basic principles for shared decision making to occur: (a) an involvement of at least two agents—a professional and a patient; (b) both parties make attempts to participate in decision making; (c) an information exchange occurs in which professionals present available treatments and explain their likely consequences, and patients describe their preferences, goals and values; and (d) a treatment decision that they can both agree to. In proposing these defining characteristics, Charles et al. (1997; 1999) recognised some practical challenges with shared decision making. For example, there may be ethically complex treatment discussions in which professionals cannot agree to certain option(s) on professional, medical, or religious grounds. The authors suggested that professionals refer patients to other professionals who might be more comfortable with sharing such decisions. This not only highlights the importance of the decision context in determining *when* shared decision making is appropriate, but also the fact that decision makers may take evasive actions to avoid such discussions in the first instance. Clearly, a more comprehensive understanding on what these issues are is important for enacting effective shared decision making.

On the other hand, Towle and Godolphin (1999) proposed a framework for teaching and learning shared decision making. They believed that effective shared decision making arises when professionals and patients acquire a set of necessary competencies, including the ability to engage in open communication, resolve conflicts and decide in an informed manner. The framework is a useful checklist for assessing a person's readiness to engage in shared decision making, but offers little

insight on how these dimensions influence person-centred decision making once the interaction begins.

Acknowledging how heterogeneously shared decision making is defined in healthcare, Makoul and Clayman (2006) performed a systematic literature review to develop an integrated definition. Through a survey of 161 articles with conceptual definitions of shared decision making, the authors came to define it as a continuum with professionals leading the discussion and making the decision on one end, and patients leading the discussion and making the decision on the other end. The authors believed that shared decision making occurs at the midpoint where professionals and patients share equally in deliberation and decision making.

Thus far, most models of shared decision making have sought to distinguish itself from paternalism and autonomous decision making, without paying much attention to the collaborative process. To overcome this limitation, Elwyn et al. (Elwyn, Frosch, Thomson, Joseph-Williams, Lloyd, Kinnersley, et al. 2012) developed a prescriptive model for implementing shared decision making in clinical practice, which consists of three phases: 1) choice talk, where professionals inform patients about the opportunity to make a decision; 2) option talk, where professionals present clinical evidence and elicit patients' preferences; and 3) decision talk, where professionals and patients make a joint decision. The model casts shared decision making as a deliberative process and acknowledges key activities that are necessary for bringing about person-centred outcomes. However, the model serves more as an instructional guideline for healthcare professionals to follow and adhere to, rather than understand the factors that contribute to effective shared decision making. As such, there is limited insight on the potential barriers and facilitators to implementation.

Two observations can be made from extant conceptualizations of shared decision making. Firstly, they assume that the process involves at least two rational parties who are fully capable, willing and motivated to collaborate in the clinical encounter. Secondly, these models posit that effective shared decision making arises when decision makers enact severable key communicative behaviours, such as sharing

information and eliciting patient preferences. Although these works have advanced understanding on the construct of shared decision making, they generally do not explain why significant variation in practice exists or how the process affects person-centred outcomes.

## **Developments in shared decision making**

Such is the interest in shared decision making that research on this subject has proliferated in recent times. A survey of 15 high impact medical journals between 1996 and 2011 revealed an exponential growth in the number of publications containing the term “shared decision making” in their abstract or full text (Blanc, Collet, Auer, Fischer, Locatelli, Iriarte, et al. 2014). This number grew from 49 in 1996 to 155 in 2011, indicating widening research and development in the area. The following sub-sections detail the key political, organisational and social developments that have come to cement the importance of shared decision making in health and social care.

### **Political setting**

In 2011, the then Secretary of State of Health, Andrew Lansley, articulated the UK government’s vision of placing patients’ needs, values and preferences at the centre of clinical decision making, in the White Paper titled ‘No decision about me without me’ (Department of Health 2012). The document outlined the importance for the NHS to harness the information revolution and increase choice and control for patients and the public. It called on the NHS to: enplace shared decision making as the norm in most clinical decisions, a position shared by the General Medical Council (2008); give patients any choice of provider, GP practice, and treatment wherever relevant (i.e., reasonable mental capacity to consent); promote personalised care that is consistent with individuals’ health and care needs; and ensure that everyone benefits from person-centred care. However, the government’s White Paper (Department of Health 2012) also acknowledged some challenges in giving lay individuals a more active role in clinical decision making. For one, there were no clear quality standards

at that time to monitor the implementation of shared decision making, and consequently the National Institute for Health and Care Excellence (NICE) was tasked with developing these. Secondly, there was a lack of incentives for quality improvement, especially since the payment system in the NHS (or rather, lack thereof) limited the ability of funders and providers to improve outcomes. Hence, while this seminal report sparked a major revolution in how healthcare providers and professionals approached lay individuals in clinical decision making, it offered little guidance on what it meant for those involved or how such processes could be improved (Coulter & Collins 2011).

More recently, the UK government released a Green Paper in July 2019 with a focus on proactive, predictive and personalised prevention before care needs escalate (Department of Health and Social Care 2019). This came at the back of another reform known as the 2014 Care Act, which saw major changes in how social care was organised and delivered to the general public (Department of Health and Social Care 2014b). In particular, people were given more information, more choice, and more autonomy in deciding how best to meet their own social care needs. Nevertheless, these reforms also changed the traditional processes that people were familiar with when dealing with their care needs (Bottery 2019). For example, unlike the NHS where healthcare is free at the point of use, most people today are expected to make a significant financial contribution towards their own social care, for which they may not be prepared to do so when the need arises (Behavioural Insights Team 2017). Hence, for people to receive the care they want, advance planning and shared decision making may be important for promoting person-centred social care.

In the US, emphasis on shared decision making emerged with the introduction of the 2010 Patient Protection and Affordable Care Act (now known as Affordable Care Act) (US House of Representatives 2010). It authorised a Shared Decision Making Program to support patients in collaborating with their healthcare professional to make informed decisions based on clinical evidence and individual needs, values and preferences (Frosch, Moulton, Wexler, Holmes-Rovner, Volk & Levin 2011). The program focused on the development and dissemination of informational

interventions (or decision aids) to help decision makers understand their options, which has sparked major interest in the design, certification, and use of decision aids to support shared decision making in clinical encounters (Braddock 2010; Oshima Lee & Emanuel 2013). The creation of the International Patient Decision Aid Standards (IPDAS) for example, assesses the quality and effectiveness of each decision aid in promoting unbiased and informed decision making, and is kept up-to-date by a panel of international medical experts from various medical specialties (Volk, Llewellyn-Thomas, Stacey & Elwyn 2013). In addition, several states in the US have incorporated the use of shared decision making and decision aids in their vision of healthcare. For example, Washington, Vermont, and Minnesota, have made legislative changes to formally test the effectiveness of shared decision making and decision aids in improving quality and reducing costs of care (Frosch et al. 2011).

Similar reforms in recognition of shared decision making can be found in many other high-quality healthcare systems around the world, including Germany, Canada and Australia (Légaré, Stacey, Forest & Coutu 2011; Härter, Müller, Dirmaier, Donner-Banzhoff, Bieber & Eich 2011; McCaffery, Smith, Shepherd, Sze, Dhillon, Jansen, et al. 2011). Together, these political developments highlight the promise of shared decision making in elevating standards of care and containing rising healthcare costs.

### **Organisational setting**

Early efforts to embed shared decision making into routine practice in the NHS began even before the UK government made policy changes to recognise its accruing benefits. The Health Foundation, a major proponent of shared decision making, founded the 'Making Good Decisions in Collaboration' or MAGIC program in 2010 (The Health Foundation 2010). The program involved researchers and frontline health professionals from Newcastle and Cardiff, and their priority was to develop, test, and share best practices in shared decision making. The program placed special emphasis on medical education, professional workshops and training, information campaigns, and the development of decision aids (Coulter 2010; Lloyd, Joseph-Williams, Edwards, Rix & Elwyn 2013). One success from the program was the

creation of a fast and frugal decision aid, known as Option Grids, to communicate key information about available treatment options and their risks, harms and benefits to a lay patient (Elwyn, Lloyd, Joseph-Williams, Cording, Thomson, Durand, et al. 2013). Interviews with participating clinicians suggest that the use of Option Grids signals a professional's respect for patient autonomy and is a symbolic gesture of their intent to share power with patients (Elwyn et al. 2013). There are now over three dozen Option Grids for different medical decisions (The Dartmouth Institute 2017).

Decision aids to support shared decision making have become a mainstay in the NHS. An early Cochrane systematic review of 55 trials indicated that patients who used these tools became more informed and active in decision making (O'Connor, Bennett, Stacey, Barry, Col, Eden, et al. 2009). Moreover, there was some evidence to suggest that well-informed patients were not only more likely to adhere to treatment regimens, but also more likely to select conservative treatments or less invasive surgeries. In some cases, decision aids and decision support from clinicians were able to reduce elective surgeries by up to 25%, representing a significant cost saving for the NHS if shared decision making could occur before patient consent to common elective surgeries (O'Connor et al. 2009).

The accruing benefits of shared decision making had attracted considerable attention from health authorities who were hoping to widen its implementation across the NHS. In 2010, NHS Direct piloted three web-based decision aids for patients with either prostate cancer, osteoarthritis, or prostatic hypertrophy (Coulter, Edwards, Elwyn & Thomson 2011). Eight NHS sites were selected and patients scheduled for specialist advice for these medical conditions were asked to view the web-based decision aid before they attended their appointment so that they can participate in decision making more effectively. Those patients without Internet access were given a telephone number instead, to reach information advisers at NHS Direct who would offer the same information that was available online. In this way, patients could receive the information they needed before the clinical encounter.



However, implementing shared decision making is not without its challenges. Professionals often claim that there is insufficient time to fully involve patients in every medical decision, contradicting organisational objectives, and that shared decision making already occurs (Légaré, Ratté, Gravel & Graham 2008; Gravel, Légaré & Graham 2006). According to NICE, the mean of three patient-reported experience measures of having ‘better information and more choice’ in the NHS (scale 0-100) exhibited a fairly flat and stable trend over the last decade, rising from a score of 66.8 in 2009/10 to 67.3 in 2018/19 (NHS 2019). In the US, a nationally representative survey of 2718 respondents aged 40 or older with experience of discussing one or more of 10 common medical decisions with a healthcare professional, revealed substantial variation in patient involvement; conversations about the pros and cons of tests were often imbalanced, and patient input was rarely sought in three decisions (37.3%-42.7%) (Floyd J, Gerstein & Barry 2013). Similarly, a systematic review of 33 observational studies conducted between 2001 and 2012, and most of which in North America, pointed to low levels of shared decision making in clinical practice ( $M=23$ ,  $SD=14$ ; scale 0-100) (Couët et al. 2015). Hence, while organisations may have made significant strides in developing tools to support informed decision making, little is known on how to create the conditions under which professionals and patients espouse shared decision making as routine practice. Achieving this will likely require multiple approaches, including an organisational culture that views and supports shared decision making as the norm, and the mastery of basic decision making and communication skills, among others. The list is likely to be exhaustive and more research is needed to consolidate the drivers and barriers of effective shared decision making.

Part of the reported variation in shared decision making may be due to measurement issues. According to Barr and Elwyn (2016), two threats to validity confront these measures—they assume that clinical encounters possess one discrete “decision point” and that people necessarily recognise them. Such challenges may be greater in some medical contexts, such as chronic diseases, preventive care or mental health where the effective control of illnesses rests on a series of low-intensity decisions (e.g.,

planning). As a result, some researchers have advocated for quality indicators that examine relevant aspects of patients' experience, such as the degree of deliberation, gains in knowledge, and the attainment of skills in shared decision making (Coulter, Edwards, Elwyn & Thomson 2011; Coulter & Collins 2011). This not only posits that decision makers have different attitudes and capabilities in shared decision making, but that they can also acquire these 'ingredients' to participate more effectively. Hence, more knowledge on these dimensions may be crucial for promoting high-quality shared decision making interactions.

### **Social setting**

Shared decision making brings together two different but equally important forms of expertise to clinical decision making: the professional who has expertise on medical diagnosis, treatment alternatives, and their likely implications based on population evidence; and the patient who is knowledgeable about the experience of illness, impact of care on their daily lives, attitudes to risk, values, and preferences (Coulter 2010).

Shared decision making occurs when professionals and patients are able to fully exchange these forms of expertise with one another (Charles, Gafni & Whelan 1997; Charles, Gafni & Whelan 1999). A rigorous conversation about the risks, harms and benefits of treatment options, including inaction (or active surveillance), is an important part of gaining informed consent to medical interventions (General Medical Council 2008). It not only demonstrates mutual acknowledgement and respect for the expertise that decision makers possess, but also helps to reduce the informational and power asymmetry that hampers the transfer of expertise necessary for bringing about person-centred decisions (Scholl, Zill, Härter & Dirmaier 2014; Mulley, Trimble & Elwyn 2012).

There are several reasons to support these normative behaviours in shared decision making. One view is that professionals are generally poor at predicting patients' needs and preferences (Sevdalis & Harvey 2006). Early evidence for this can be found in discussions about end-of-life care, under which advance directives legally bind

professionals to the fulfilment of a patient's wish(es) in a period of health or mental decline. Two surveys of professionals' and their patients' preferences for end-of-life care showed poor levels of agreement between the two parties (Gramelspacher, Zhou, Hanna & Tierney 1997; Fischer, Tulskey, Rose, Siminoff & Arnold 1998). In one case, 78 doctors and their 831 patients revealed significant differences between what doctors wanted for their patient and what patients wanted for themselves if the latter were to become terminally ill, with doctors wanting less treatment in five of six available treatment options (e.g., hospitalisation, intensive care, resuscitation) (Gramelspacher, Zhou, Hanna & Tierney 1997). Likewise, Bruera et al. (2002) surveyed 57 breast cancer physician and patient dyads regarding patients' preferred decision making role (i.e., active, shared or passive) in treatment discussions. The researchers found that fewer than half of all cases (n=24 or 42%) were able to achieve concordance, meaning that professionals were generally poor at predicting patients' preferences for involvement in decision making.

What these studies demonstrate is that there are considerable differences between what patients want and what professionals believe patients want. This is described as a preference misdiagnosis (Mulley, Trimble & Elwyn 2012). In so far that shared decision making leads to better outcomes in patients, a preference misdiagnosis may erroneously hamper treatment and recovery, and thus highlights the crucial nature of involving patients in decision making.

Another view is that patients can learn to be more discerning consumers in health and social care (Sepucha & Mulley 2009). Research have shown that lay individuals<sup>1</sup> frequently overweight the likely benefits and underweight the likely harms of treatments (Treadwell & Lenert 1999; Rasiel, Weinfurt & Schulman 2005; Verhoef, de Haan & Van Daal 1994). Such inaccurate assessments may lead patients to select options that they might not have if they were otherwise informed and objective in decision making. Moreover, promoting informed decision making in collaboration

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<sup>1</sup> Similar patterns of behaviour can be found in clinicians (Eeckhoudt, Lebrun & Saily 1985)

with professionals frequently improves decision knowledge, confidence, satisfaction, and adherence to regimens in patients<sup>2</sup> (Clayman, Bylund, Chewning & Makoul 2016).

Yet, full disclosure of information and complete involvement of patients in decision making are in sharp contrast to the traditional approach in medical practice, wherein the professional is usually the only recognised expert who makes decisions *for* rather than *with* a lay individual (Coulter 2010). Recalibrating the traditional power and informational asymmetry that has come to define professional-patient interactions presents several unique challenges. Professionals commonly claim that they support or that they are already engaging in shared decision making, but studies have shown that their attitudes are not always consistent with their approach in practice (Pieterse, Baas-Thijssen, Marijnen & Stiggelbout 2008; Boivin, Légaré & Gagnon 2008; Shepherd, Tattersall & Butow 2007)—they rarely disclose all treatment options, present all available evidence, discuss pros and cons in a balanced manner, or elicit patient preferences (Couët et al. 2015). In addition, consistent annual reports by the Care Quality Commission in the UK have stated that members of the public demand more information, more choice, and more control in matters concerning their own welfare (Care Quality Commission 2010; Care Quality Commission 2011; Care Quality Commission 2012). Yet, patients typically assume a passive stance by default in clinical encounters (Deber, Kraetschmer, Urowitz & Sharpe 2007; Deber, Kraetschmer & Irvine 1996). Moreover, the link between preference-concordance and clinical outcomes is somewhat tenuous (Kashaf & McGill 2015; Shay & Lafata 2015) and questions about how shared decision making leads to better health outcomes remains largely unanswered.

Clearly, significant challenges to the implementation of shared decision making exist. These are usually multi-faceted, affecting both professionals and patients with the potential to change over time depending on how the interaction unfolds in practice.

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<sup>2</sup> Taking medical prescriptions as planned, leading to better control of chronic illnesses like (high) blood pressure and asthma.

Given the importance of person-centred care, more insight into the black box of shared decision making is necessary to understand the process through which decision makers can foster decisions that are informed and centred on individuals' preferences.

## **Current gaps in the literature**

Shared decision making is a promising model for protecting and enhancing the health of the population, and may even help to curb rising health care costs. Effective shared decision making arises when professionals and lay individuals fully exchange their expertise to make informed and person-centred decisions. To promote this, extant research has placed considerable emphasis on informed decision making, or the development of tools, measures, and techniques for fostering the full exchange of expertise between decision makers. Yet, in focusing on rational behaviour, much of the present literature has overlooked issue of bounded rationality (Simon, 1955) in hampering effective decision making. Like most human decision makers, professionals and patients are bounded rational agents with limited cognitive capacities and a limited amount of time to make 'rational' decisions, and are thus prone to a host behavioural influences (e.g., heuristics, biases, emotion) (Gigerenzer & Selten 2001; Kahneman 2011). The role of competence, emotion, social bias, and situational influences in shaping how shared decision making unfolds are important aspects to account for, especially in a dyadic interaction where behaviours have interdependent consequences. A better conceptualisation of these issues will enrich understanding on current practice variations as well as highlight areas where practical interventions are likely to promote effective shared decision making.

A related point is that current conceptualisations of shared decision making offer a fairly static and normative view of how professionals and patients *should* behave in clinical encounters. Early works (Charles, Gafni & Whelan 1997; Towle & Godolphin 1999; Makoul & Clayman 2006) generally aimed to define and distinguish different forms of clinical decision making between professionals and patients, without paying

much attention to the development of the process or how it may produce better outcomes. Elwyn and colleagues' (2012) model for clinical practice is a good attempt at filling this gap. It outlines the key steps that a professional must undertake in shared decision making but only reveals half the picture necessary for bringing about effective collaborations. The patient's role in shared decision making is otherwise missing. Given the equally important form of expertise that recipients of care have, a better acknowledgement of their role and influence in shared decision making is essential for conceptualising the ways in which the process achieves person-centred care.

The largely rational basis for shared decision making opens some interesting questions about the role of other behavioural influences in shared decision making. For example, strict communication models of shared decision making do not include the role of emotion and emotional support (Makoul & Clayman 2006; Towle & Godolphin 1999). Some even discourage professionals from sharing any recommendation at all (Quill & Brody 1996; Emanuel & Emanuel 1992). Nevertheless, patients often want some guidance from their professional and not doing so could induce significant distress in the patient as well as conflict in the professional worried about influencing patients' autonomous preferences (Stevenson, Barry, Britten, Barber & Bradley 2000; Elwyn, Edwards & Kinnersley 1999).

These behavioural issues raise some important concerns about the effects of advice and emotion in shared decision making. For example, Botti et al. (2009) investigated the interplay between patient autonomy and negative affect by studying how patients and their doctors make 'tragic choices' in the clinical setting. In highly aversive situations, such as ending an infant's life support, patients usually experienced significantly higher levels of negative affect when choices were made personally than externally (i.e., physician decides). Interestingly, these negative feelings did not appear to deter patients from involvement; they generally expressed a desire to be informed and were unwilling to defer decision making to their doctors (Botti, Orfali & Iyengar 2009). This finding suggests that the relationship between autonomy and emotion may be highly complex, but leaves questions about their

mechanisms largely unanswered. More knowledge on the interplay between expert advice and emotion in professional-patient interactions may help researchers understand if and the ways in which they affect person-centred care.

Finally, the concept of shared decision making has traditionally involved a professional and a patient with the aim of enabling person-centred care. The recent emphasis on increasing information, choice, and autonomy to promote person-centred social care opens a new dimension in shared decision making research, which has thus far only considered healthcare professionals and patients in a clinical encounter. By contrast, those who require social care products and services in the later part of their lives regularly engage their friends and family in decision making. Results from the British Household Panel Survey and Understanding Society between the years 1991-2018 show that about 65% of adults in the UK had provided care for someone in their life (Institute for Social and Economic Research 2018). Furthermore, the NHS Information Centre Survey for Carers in Households (2010) reports that about 75% of all carers care for their parents, parents-in-law, spouse, partner, or friend. Though shared decision making has the potential to advance person-centred social care, not much is known on how it could contribute towards this. This demands a thorough analysis of the public's reaction to recent policy changes, which would help in the identification of key gaps and areas where shared decision making may address.

Altogether, this thesis aims to give a better appreciation of the behavioural factors that shape shared decision making and in so doing, contribute knowledge on the range of issues that contribute to person-centred outcomes. The focus of this thesis is intentionally narrow on the health and social care context. However, the implications of this work will bear relevance for research in different disciplines and domains. This is especially true for any interpersonal situation involving a more proficient decision maker (e.g., knowledgeable, skilled, composed) and a lay person who is more knowledgeable about personal preferences, needs and values.

## Chapter 3

# **A systematic review and an agent-centric model of shared decision making**

Shared decision making (SDM) is widely advocated in clinical practice. SDM is mandated in several high-quality healthcare systems around the world (e.g., the US and UK), and embedded in many clinical screening and treatment guidelines. In these, clinicians are typically expected to share decision making with patients so that care is provided in an evidence-based and person-centred manner. Although various conceptions of SDM exist, its core elements generally includes an outline of different clinical options, an explanation of harms, benefits and risks involved, and the elicitation of patients' values and preferences (Charles, Gafni & Whelan 1999; Makoul & Clayman 2006; Elwyn et al. 2012). These steps are intended to respect the autonomy of patients and support beneficence as patient involvement in decision making is often associated with positive decisional (e.g., knowledge), psychosocial (e.g., satisfaction) and behavioural outcomes (e.g., treatment adherence) (Clayman, Bylund, Chewning & Makoul 2016; Shay & Lafata 2015). Therefore, SDM has the potential to safeguard and improve the health of the population.

Despite this, SDM is still rarely observed in practice; clinicians seldom explore patients' concerns, present all available options and evidence, or emphasize the need for a decision to be made (Couët et al. 2015). A poorly executed SDM process may lead patients to choices that are inconsistent with their own preferences, thereby



undermining the principles of person-centred care and the quality of SDM. It may also explain why SDM is weakly associated with positive health outcomes (Shay & Lafata 2015).

Why is there such significant variation in shared decision making?

There is usually a multitude of reasons for this. Some are contextual in nature and thus bounded to a given situation or environment (e.g., life-saving interventions in medical emergencies) (Friedberg, Van Busum, Wexler, Bowen & Schneider 2013). Others can be attributed to the different sorts of biases that colour decision makers' attitudes, preferences and motivation in SDM. These biases are not made with maleficent intent. Rather, they are systematic errors or misconceptions that can affect effective SDM across the board.

How do these behavioural influences shape the ways in which shared decision making unfolds?

Addressing these questions are important for several reasons. Normative models of SDM overlook the antecedents of effective professional-patient collaboration in decision making. Elucidating the range of issues that govern such processes will enrich understanding on the potential barriers and facilitators of SDM, as well as how they affect the unfolding process. Furthermore, a more dynamic framework linking these behavioural influences to desirable SDM outcomes is necessary for appreciating the ways in which policymakers and researchers can promote person-centred care.

In this chapter, I address these questions by systematically reviewing the current SDM literature and subsequently, developing an agent-centric model for enabling person-centred care. The review suggests that in focusing on shared decisions, current research have mostly overlooked the complex *collaborative process of sharing* decision making. Several factors pertaining to decision makers, the decision making process, and the decision context can shape the ways in which SDM unfolds. Building on these findings, the essay advances an agent-centric model of SDM that incorporates these behavioural aspects and maps their influence on the development

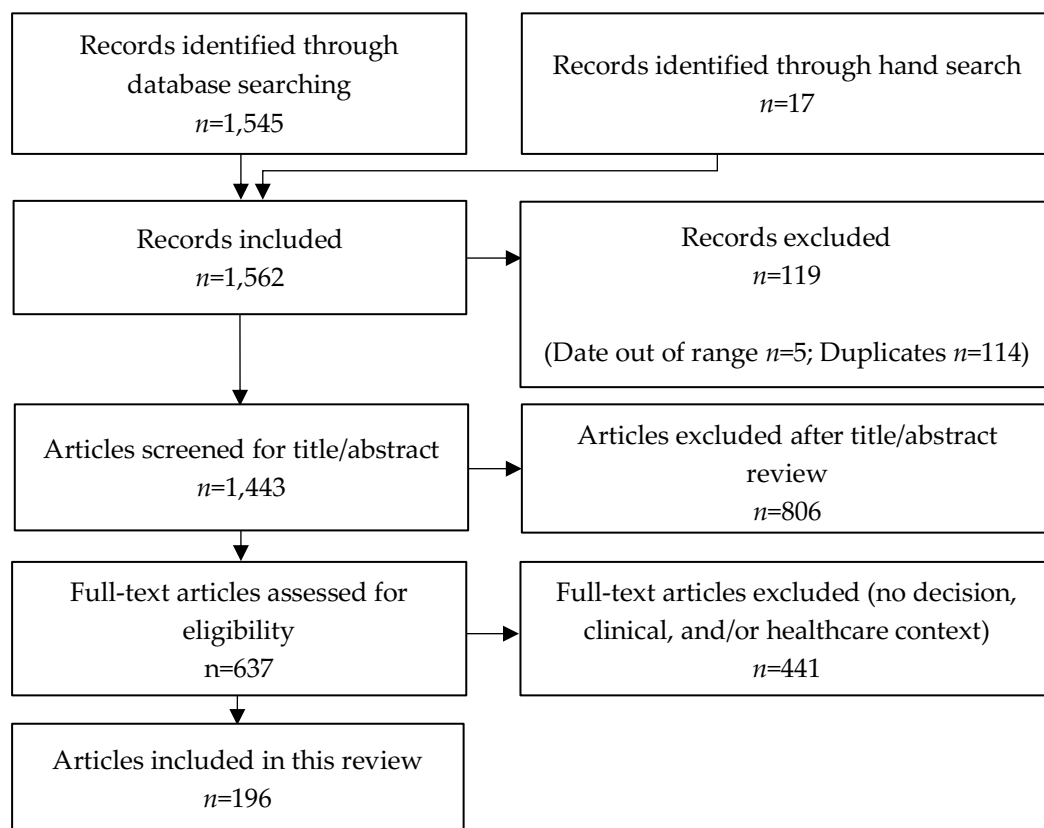
of preferences. And in so doing, the model accounts for how professionals and patients can engage in effective decision making. Finally, this chapter discusses the implications and limitations of this work and offers suggestions for future research.

## Methods

### Search strategy

A systematic search for articles and reviews on the databases PsycINFO, Web of Knowledge, PubMed, and Scopus, was conducted according to PRISMA guidelines. Titles and abstracts were searched for terms such as “shared decision making,” “informed choice,” “patient participation,” and/or “patient involvement.” These terms represented core, unambiguous and widely agreed principles of SDM. Only peer-reviewed articles published in English during the years 2010–2017 were included. Figure 1 describes the overall search process.

**Figure 1.** PRISMA flowchart



My initial search returned 1443 unique citations. Titles and abstracts were independently screened to exclude study protocols, commentaries, and articles without an explicit decision context. This yielded 637 articles with a concordance rate of 72% between two assessors. In a subsequent stage, full-text articles related to shared decision making in theory and/or practice, and professional-patient communication in decision making were independently assessed for inclusion. This resulted in a final selection of 196 articles representing a rich body of evidence associated with the participatory encounter, with a concordance rate of 81% between two assessors. The final pool of papers varied significantly with respect to research aim, design, analysis, and context as evidenced Table 1 (for a complete list, see Appendix A).

**Table 1.** Overview of included articles

| Study                | Data Collection  | Analysis  | Decision Context   |
|----------------------|--|---|--|
| Qualitative<br>N=68  | Interviews; focus groups; observation (e.g., direct and/or taped)                    | Decision analysis coding system for oncology; observing patient involvement in decision making (OPTION); Delphi method                        | Medical treatments; screening; surgery; therapy; encouraging behavior (e.g., participation in decision making, prevention, health promotion); illness management |
| Quantitative<br>N=82 | Surveys (e.g., cross-sectional, longitudinal); experiments (e.g., randomized trials) | Questionnaires (e.g., control preferences scale, autonomy preference index, decisional conflict scale, preparation for decision making scale) | Similar to qualitative studies with an emphasis on ascertaining patients' preferences for involvement and medical options  |
| Mixed Methods<br>N=8 | Mostly survey-observation or survey-interview research designs                       | Combination of the above  | Primary care; screening; behavioral management (e.g., diabetes, smoking, elderly support)  |
| Reviews<br>N=32      | Conceptual, narrative and systematic reviews   | Systematic search strategy or unstructured  | Aggregates information on: SDM conceptualization; preferences and involvement behaviors; barriers and facilitators of SDM  |
| Perspectives<br>N=6  | Not applicable   | Not applicable  | Provides theoretical and ethical insights  |

## **Thematic analysis**

A thematic analysis was performed to identify emerging topics and patterns among these articles. Following Braun and Clarke's (2006) guidelines, key concepts were coded, abstracted, and aggregated into a coherent list of themes. Three distinguishable domains emerged from the review, one associated with decision agents (i.e., professional, patient), one with the decision making process, and the last with the decision context.

## **Model development**

Building on my review, I integrated extant knowledge on SDM with insights from behavioural science to advance an agent-centric model of effective collaboration in decision making. The model considers three fundamental stages that are common in most clinical encounters: pre-decision; decision making; and post-decision. The conceptual model distils various behavioural influences (e.g., cognitive, emotional and social biases) and maps their influence on the development of SDM. In so doing, the model not only highlights the potential pitfalls in SDM, but also provides a theory-driven framework from which to develop and test new interventions.

## **Findings from the review**

The retrieved literature on SDM covered a spectrum of situations, ranging from relatively simple decisions (e.g., routine medication) to complex scenarios (e.g., multidisciplinary teams), and from discrete (e.g., screening) to continuous management (e.g., active prevention, illness control). Table 2 summarizes the list of themes.

### **Decision agents**

Healthcare professionals and patients usually enter a clinical encounter with different expectations and beliefs, both of which can powerfully shape how SDM unfolds afterwards. The analysis of literature revealed four main themes: competence, attitudes and preferences, emotion, and contextual issues.

**Table 2.** Overview of domains and themes

| Domains          | Themes                    | Sub-themes   |
|------------------|---------------------------|--|
| Decision agents  | Competence                | Professional decision making and communication skills <ul style="list-style-type: none"> <li>• Technical knowledge and expertise</li> <li>• Objective reasoning and judgment</li> <li>• Respect and empathy</li> <li>• Educate, engage and empower people</li> </ul> Patient decision making skills <ul style="list-style-type: none"> <li>• Literacy and numeracy</li> <li>• Objective reasoning and judgment</li> </ul>  |
|                  |                           | Attitudes Professional attitudes <ul style="list-style-type: none"> <li>• Higher when professionals have greater trust in patients</li> <li>• Ethical concerns when involving “less capable” people</li> </ul> Patient attitudes <ul style="list-style-type: none"> <li>• Conceive involvement and decision making as different</li> <li>• Misconceptions</li> </ul>   |
|                  | Emotional influences      | Professional reactions to people’s emotions <ul style="list-style-type: none"> <li>• Understanding, empathizing, and addressing concerns</li> <li>• Providing socio-emotional support</li> </ul> Professional coping and regulation <ul style="list-style-type: none"> <li>• Limit self-disclosure or withdraw</li> <li>• Expressions affect observing parties</li> </ul> Patient emotions <ul style="list-style-type: none"> <li>• Feelings of anxiety and distress</li> <li>• Want comfort, understanding and sense of safety</li> </ul> |
|                  |                           |  |
| Decision process | Open communication        | Professional-patient relationship <ul style="list-style-type: none"> <li>• (Perceived) power-imbalance</li> <li>• Communication tone</li> </ul>  |
|                  | Rational evaluation       | Communicative and social biases <ul style="list-style-type: none"> <li>• Information exchange</li> <li>• Objective weighting and incorporating preferences</li> <li>• Use of decision aids</li> </ul>  |
|                  | Responsibility            | Sharing responsibility and control <ul style="list-style-type: none"> <li>• Information grants greater responsibility and control</li> <li>• Preferences for information and control change as the discussion unfolds</li> </ul>   |
| Decision context | Policy and organisational | Policy <ul style="list-style-type: none"> <li>• Legislative changes</li> </ul> Organizational and Professional level <ul style="list-style-type: none"> <li>• Institutional norms, rules, measures, and incentives</li> <li>• Alignment between bureaucratic and participation outcomes</li> </ul>   |
|                  |                           |  |
|                  | Time                      | Availability of time <ul style="list-style-type: none"> <li>• Urgency</li> <li>• Nature of the decision</li> </ul>   |
|                  | Professional boundaries   | Professional identity<br>Interprofessional work  |

**Competence.** Proficiency in executing various decisional and communication-related activities is crucial in SDM. Medical training and curriculum often require healthcare professionals to have the relevant technical expertise, medical knowledge, the ability to make objective judgements (Bernabeo & Holmboe 2013) and communicate effectively with patients, including being respectful, understanding, and unbiased when presenting information (Levinson, Lesser & Epstein 2010).

Research suggests that all these competencies are desirable for enacting effective SDM. For example, a study of 292 surgeons from 60 countries showed that surgeons with high levels of numeracy were about 4 times more likely to support patient involvement in treatment decision making (Garcia-Retamero, Wicki, Cokely & Hanson 2014). While this study indicates that professionals' own decision making competencies may influence their willingness to share decision making, the sample was dominated by males (82%) and non-native English speakers (85%) from mainly the trauma department (67%). Hence, more research is necessary to establish its generalizability and to understand if there are any moderating factors (e.g., language barriers).

The healthcare literature is rich with programs and interventions that aim to improve the communication skills of healthcare professionals. A systematic review of 39 studies, most of which developed in the West (e.g., US, UK, Canada, Germany; 90%), found that professionals in the intervention group (i.e., SDM) frequently recorded higher levels of SDM than those in the control group (i.e., usual care) (Légaré, Stacey, Turcotte, Cossi, Kryworuchko, Graham, et al. 2014). However, these studies tend to differ in their own programs and approach to improvement. For example, Hoffmann et al. (2014) engaged 107 medical students and randomly assigned them to either a control or intervention group. Those who underwent the intervention, which comprised of a one-hour tutorial, a pre-recorded modelled role-play, and a critique session, displayed significantly more SDM-related behaviours in role-plays with other student, than those in the control group. Although these interventions show that improvements to communication skills may promote effective SDM, they rarely capture or demonstrate their impact on health outcomes.

For patients, effective participation often rests on their ability to assimilate information, share valuable input, articulate their own preferences and make appropriate trade-offs (Bernabeo & Holmboe 2013). Research suggests that literacy, numeracy and decision making capacity (whether someone suffers from cognitive impairment) are important dimensions of informed decision making (Smith, Simpson, Trevena & McCaffery 2014; Petrova, Garcia-Retamero & Cokely 2015). In a probabilistic national survey comprising of participants from Germany (n=117) and the United States (n=117), people with poor numeracy skills wanted less involvement in decision making whereas those with high numeracy skills were satisfied with the current role (Galesic & Garcia-Retamero 2011). Furthermore, the study found that Americans were generally more active than Germans, which represents only a handful of studies examining cross-cultural preferences for SDM.

**Attitudes.** Healthcare professionals have different levels of support towards SDM. A systematic review of 43 studies, consisting mainly of American, Canadian and European-based research (70%), revealed a higher level of professional support for SDM when there is a perceived dependence on patients for joint outcomes (e.g., chronic illness management), or in situations of clinical equipoise where the relative benefits and harms of options are not so clear-cut (Pollard, Bansback & Bryan 2015). Additionally, professional support is greater when patients appear to be informed, capable, and motivated to participate. The findings of this review are interesting in that it analyses both qualitative and quantitative research in reaching a general position of SDM among healthcare professionals. More importantly, it demonstrates that professionals' motivation to share decision making requires judgment calls about the decision context and the perceived benefits of sharing with patients.

Chewning et al. (2012) conducted a similar systematic review to establish patients' preferences for involvement in treatment decision making. Across 115 studies, patients' preferences for a shared role increased from 50% of the studies before 2000 to 71% of the studies from 2000 and later, suggesting that patients increasingly want an active role in their medical decisions. Although the study observed some differences in involvement based on the type of decision (e.g., cancer treatment,

invasive procedure, chronic conditions) and the type of measure used, the review did not provide any data about the country of origins or the sizes of the sample contained in each study. Hence, it is difficult to determine the generalizability of the results.

Qualitative investigations about patients' role in SDM provides some nuance to the findings above. The concept of involvement appears to be a difficult one to explain according to patients. They tend to view complex medical decisions as two distinctive parts: "problem solving" (i.e., deliberating over the right treatment) followed by "decision making" (i.e., deciding on the most attractive bundle of outcomes), and while they may want some influence over the final decision, they may not want to be involved during problem solving (Mira, Guilabert, Pérez-Jover & Lorenzo 2014; Moreau, Carol, Dedienne, Dupraz, Perdrix, Lainé, et al. 2012). Patients' preferences for involvement may therefore depend on which phase of decision making they are involved in, though more empirical research is necessary to disentangle these constructs in SDM.

**Emotion.** Professional-patient interactions involve emotions, which can affect how people communicate and interpret information during decision making (Epstein & Street 2011). Such is their importance that emotional (or relational) skills training are evident in contemporary SDM training programmes (Légaré, Moumjid-Ferdjaoui, Drolet, Stacey, Härter, Bastian, et al. 2013).

Yet, empirical knowledge about the role and the ways in which emotion influences patient-reported outcomes remains relatively sparse. Some rare exceptions have shown that clinician's reactions to scientific ambiguity can affect patients' self-reported experiences of care, including satisfaction and confidence (Politi & Légaré 2010; Politi, Clark, Ombao, Dizon & Elwyn 2011). While these studies add knowledge on the dyadic role of emotion in social interactions such as SDM, the findings are somewhat limited to the experiences of 75 patients in a single Breast Health Center in Rhode Island.

A stronger set of evidence about the role of emotion in SDM can be found in a systematic review of 27 articles on clinician communication in cancer treatment (De



Vries, de Roten, Meystre, Passchier, Despland & Stiefel 2014). The authors linked clinician displays of empathy and anxiety to patient-reported levels of confidence, distress, and satisfaction in cancer decisions. Taken together, these few studies indicate that emotions have a central role to play in SDM. Much more remains to be explored. For example, current research does not explain why and how emotion influences decision making—only that it affects psychosocial outcomes. Future research exploring the intersection of emotion and SDM may shed light on the ways in which emotion promotes or hinders person-centred care.

### **Decision process**

The second domain emerging from the literature review considers four participatory themes associated with the deliberative process: open communication, rational evaluation, and responsibility.

**Open communication.** A respectful and egalitarian environment facilitates SDM. Research suggests that most patients are unable, rather than unwilling to participate in decision making and this is mainly due to a perceived power-imbalance in professional-patient relationships (Joseph-Williams, Edwards & Elwyn 2014). Several qualitative studies have been highly informative on this topic. Aasen, Kvangarsnes and Heggen (2012) interviewed 11 elderly patients with end-stage renal disease in Norway and found two dominant discourses, one related to the healthcare team's power and control over knowledge and the perceived reprisals it may attract from failing to follow instructions, and the other related to patients' struggle for SDM due to deterioration in health. Similarly, Frosch et al. (2012) conducted six focus groups with 48 people from the San Francisco Bay Area and found some common misconceptions about a patient's role in treatment decision making. Specifically, people believe that there is a need to be a "good," passive patient, and that doctors see questioning as a sign of distrust or as a challenge against their medical authority. Together, these studies highlight the potential barriers for genuine communication to arise. Whether people are generally healthy or nearing the end of life, they tend to hold similar (misinformed) views about their role in SDM.

Yet, a perceived power-imbalance in clinician-patient interactions may be exacerbated by other factors, such as differences in ethnicity, culture, gender, and socio-economic class (Joseph-Williams, Elwyn & Edwards 2014). For example, a study on the perspectives of African-American patients in SDM revealed that perceived differences in race, between a doctor and patient, frequently hindered open communication (Peek, Odoms-Young, Quinn, Gorawara-Bhat, Wilson & Chin 2010). One respondent from the study said *"The thing that gets to me is when a doctor comes in the room and acts like, because I am black, that I am not smart enough to understand the test that he took or what's going on with the results of the test he took"* (Peek et al. 2010, p.7). Such findings, which are common in the few studies that examine inter-cultural differences (for a review, see Mead *et al.*, 2013), suggest that the motivational barriers confronting certain patient groups may be greater and professionals should be more sensitive and respectful of such perceived differences. Clinicians who do not apportion sufficient time to help such patients get the best out of SDM may mistake a patient's lack of interest or reluctance to participate as a preference for paternalism.

To promote meaningful discussions, professionals may adopt an open and collaborative communication style and avoid the use of authoritarian language or tone (Frosch, May, Rendle, Tietbohl & Elwyn 2012). They could use a three-step practical model, comprising choice talk, option talk, and decision talk, to facilitate patient-centred communication (Elwyn et al. 2012). Other formal interventions, like the Ask 3 Questions campaign where patients are encouraged to ask questions, share their preferences, and know about their options, have been shown to promote patient involvement in decision making (Shepherd, Barratt, Jones, Bateson, Carey, Trevena, et al. 2016). However, the study relied on a before-and-after experimental design which generally suffers from a demand-effect. Moreover, it did not provide any objective decision or clinical outcomes, other patients' intentions to recommend and use such questions in future health encounters. Hence, while such communication interventions may promote active patient involvement in decision making, there is still limited understanding on the specific aspects (e.g., trust, confidence, conflict, partnership) and extent to which they improve SDM.

**Rational evaluation.** Optimal SDM happens when clinicians and patients have the best available evidence and are able to objectively weight the benefits, risks and harms of each option to make a joint decision (Elwyn & Miron-Shatz 2010), though this does not necessarily imply an equal distribution of responsibility (Stiggelbout, Van Der Weijden, De Wit, Frosch, Légaré, Montori, et al. 2012). Findings from over a hundred randomised trials indicate that patients' preference for involvement usually changes, towards a more active role, as they become more knowledgeable and confident about their decision (Stacey, Légaré, Lewis, Barry, Bennett, Eden, et al. 2017). Yet, little is known if and how professionals' own preferences for sharing develops over the course of the clinical encounter. Further research in this area may be important for understanding the adoption of SDM among healthcare professionals.

Decisions aids have become a cornerstone in SDM. Decision aids are tools that provide structure to conversations and facilitate the communication of complex information in a clear, concise, and comprehensible manner, with the aim of encouraging informed and unbiased decisions (Volk, Llewellyn-Thomas, Stacey & Elwyn 2013). Studies show that unaided discussions are rarely comprehensive enough and that the use of decision aids nearly always improved patients' decision knowledge, confidence and satisfaction (for a review, see Stacey *et al.*, 2017). Furthermore, a meta-analysis of seven randomized trials found no association between patient socio-demographic characteristics and decision aid outcomes (Coylewright, Branda, Inselman, Shah, Hess, LeBlanc, et al. 2014), indicating that patients from different ages and backgrounds were equally likely to benefit from involvement in decision making. These pieces of evidence challenge the common perception among healthcare professionals that sharing decision making may be less beneficial for certain population groups (e.g., poorer economic class, less educated, ethnic minority) (Légaré & Witteman 2013).

**Responsibility.** As patients learn more about their own condition and the options before them, they will usually feel more empowered to make a proper decision. Consequently, a more active role in decision making often means assuming more

control and responsibility for the outcomes of a decision (Fumagalli, Radaelli, Lettieri, Bertele' & Masella 2015; Castro, Van Regenmortel, Vanhaecht, Sermeus & Van Hecke 2016). However, several qualitative studies show that taking on more decision control and responsibility can be emotionally challenging for the lay patient. For example, an interview with children aged 7-16 (n=20) diagnosed with cancer indicated that they may have different preferences about their role and responsibility in decision making (Coyne, Amory, Kiernan & Gibson 2014). One participant said, *"Well I usually don't like making big decisions because I don't really feel like it's my place"* and another stated, *"It's not like the parents are getting it, it's you. So you should be able to have a say in it"* (Coyne, Amory, Kiernan & Gibson 2014, p.276). Indeed, patients' trust in carers (including friends and family) may be an influential determinant of their involvement in decision making. In Peek and colleagues' (2013) study, relying on focus groups (n=27) and interviews (n=24) with diabetic patients, some participants recounted how trust in their doctors motivated sharing, while other participants retreated into passivity and deferred judgment to their attending physician owing to a greater sense of safety. Together, these studies offer some insights on the intertwined nature of involvement and responsibility, and illustrate that a patient's preference for information and control in decision making may change as a function of their experience in care. Future research exploring the conditions under which individuals prefer one and not the other may shed light on how these constructs differ.

Healthcare professionals may experience a conflict of responsibilities themselves. Mendick and colleagues' (2010) interview with 20 recently diagnosed breast cancer patients and their doctors in a NHS unit revealed some interesting insights. When the evidence was clear, healthcare professionals would frequently recommend treatments as if they had already been decided on (e.g., *"in that situation you always, always have to have radiotherapy"*) and withhold other viable options that offered little benefit (i.e., low survival rate), thereby respecting beneficence (Mendick, Young, Holcombe & Salmon 2010, p.1906). When the evidence was unclear however, they would usually offer more choice to patients and use 'we' (i.e., multidisciplinary team)

instead of 'I' in discussions, perhaps as a manoeuvre to respect patient autonomy. These qualitative findings overlap those from experimental research in other domains, including general practice (Portnoy, Han, Ferrer, Klein & Clauser 2013), prostate cancer (Dillard, Couper & Zikmund-Fisher 2010), and bowel cancer (Dalton, Golin, Esserman, Pignone, Pathman & Lewis 2015). This hints that why professionals approach shared decision making the way they do, may depend largely on how professionals view and understand their own set of beliefs and values.

## **Decision Context**

The decision context considers structural factors that can affect the equitable and effective implementation of SDM across the board.

**Policy and organizational factors.** Policy changes to recognize and encourage SDM is evident in many high-quality healthcare systems worldwide. The Patient-Centered Outcomes Research Institute, established through the 2010 US Affordable Care Act, has allocated millions of dollars to help fund interventions that promote SDM, including the development of patient decision aids (Frosch et al. 2011). In a more direct way, the Centers for Medicare and Medicaid Services, specified SDM as necessary for the reimbursement of several medical procedures (e.g., lung cancer screening), acknowledging that fully informed patients may choose differently (Spatz, Elwyn, Moulton, Volk & Frosch 2017). In the UK, the National Institute for Health and Clinical Excellence has published quality standards regarding the implementation of SDM in the NHS and in a watershed moment, the Supreme Court in 2015 has made SDM a legal imperative in the country (Coulter et al. 2017). The practical implication is that people with full mental capacity must be properly informed about their options in treatment decision making, and thus illustrates the ways in which SDM is politically and legally-bounded.

An organizational culture that regards SDM as usual care can motivate clinicians to implement it (Joseph-Williams, Lloyd, Edwards, Stobbart, Tomson, Macphail, et al. 2017). Although various SDM interventions have surfaced in recent years, ranging from clinical practice guidelines to incentives, and training programs to tools (Légaré,

Adekpedjou, Stacey, Turcotte, Kryworuchko, Graham, et al. 2018) few have properly studied their impact on healthcare processes and clinical outcomes. Some rare exceptions have shown that SDM can help lower healthcare costs (Hibbard & Greene 2013) and that preference-concordance in treatment decision making may improve patients' management of chronic illness (Wilson, Strub, Buist, Knowles, Lavori, Lapidus, et al. 2010). Given the importance of SDM in enabling person-centred care, more data is needed for clinicians to understand the wider implications and perhaps, unintended consequences of SDM. Amidst this paucity of evidence, a better alignment between organizational objectives and the outcomes SDM aims to promote is likely to engender greater commitment in clinicians.

**Time.** Time, or a lack thereof, is the most commonly cited barrier to implementation in SDM (Légaré & Witteman 2013; Joseph-Williams et al. 2017; Friedberg, Van Busum, Wexler, Bowen & Schneider 2013). Any proposed changes that may prolong the busy clinical encounter is likely to be met with resistance from clinicians. However, there is little evidence to suggest that SDM takes significantly longer to complete than usual care. In a recent systematic review of 22 SDM interventions that included data on consultation lengths, five studies reported that SDM took a longer time than usual care, whereas 17 studies found no statistically significant difference in duration (Légaré et al. 2018). Thus, SDM has a variable effect on consultation length. A more critical examination on what contexts and what aspects in SDM are associated with longer, shorter or no impact on duration may be vital for identifying areas for introducing process change.

**Professional boundaries.** Clinicians have different roles and responsibilities in the provision of care, and these will usually affect their approach to SDM (Joseph-Williams, Elwyn & Edwards 2014). For example, Beitinger et al.'s (2014) review noted that patient participation was less observed in mental health than in general medicine and that physicians were more likely to discuss the pros and cons of each option, while pharmacists and therapists tended to focus on meeting patients' care needs. Research on these practical differences have become a matter of priority in healthcare systems seeking to deliver high-quality integrated care (Chong, Aslani & Chen 2013;

Stacey, Légaré, Pouliot, Kryworuchko & Dunn 2010; Légaré, Stacey, Brière, Fraser, Desroches, Dumont, et al. 2013). A mixed method investigation on delivering interprofessional SDM in the context of home-based care, surfaced some operational considerations (Légaré, Stacey, Brière, Robitaille, Lord, Desroches, et al. 2014). Relying on focus groups, interviews with eight managers, and a survey of 272 healthcare professionals based in Quebec City, Canada, the researchers found that poor team cohesion, confusion about responsibilities, and high staff turnover were major barriers for implementing SDM. These findings stress the need to go beyond traditional clinician-patient dyads in determining what other socio-technical factors (e.g., diversity in expertise, team size) may affect optimal care. As multi-disciplinary teams and integrated care become increasingly common concepts, so must researchers and practitioners know the conditions under which interprofessional SDM leads to better care outcomes.

### **Summary of the review**

The first half of this chapter reviewed the current clinical evidence on SDM and systematized knowledge on the behavioural factors that govern open collaboration and informed decision making. A methodical search strategy and a thematic analysis led to the development of three overarching domains: decision agents; decision process; and decision context. These domains encompass the most recent and prevalent research on professional-patient collaboration in decision making.

The review uncovered several areas of strengths and gaps in the present SDM literature. The rhetoric around patient involvement in decision making is widely supported by both providers and recipients of care. While there is strong evidence to support more (rather than less) patient involvement in decision making, the exact process and ways in which SDM produces better outcomes, other than improvements to decision making and quality of care, remains vague. More research is needed to conceptualize the antecedents of effective collaboration and their links to improved outcomes, which would offer opportunities for empirical testing.

Relatedly, extant conceptualisations of SDM have tended to focus on its outcome (i.e., what makes a shared decision), rather than its process (i.e., how professionals and patients can collaborate meaningfully to make person-centred decisions) which this review finds to be a highly complex and multifaceted interaction. Contrary to static conceptions of SDM, where professionals are simply expected to elicit patients' preferences, preferences are contingent, mutable and co-constructed in practice. Sharing decision making is thus a process of mutual influence and both professionals and patients are responsible for the way in which it unfolds.

This brings the review to the next point. Effective SDM first requires professionals and patients to have the necessary competencies, the right attitudes about it, and a rational mind. And even so, how decision agents communicate and process information in clinical encounters matters. There was ample evidence from the review to suggest that informational or involvement needs were separate constructs from decision control and responsibility. When patients express a preference for involvement, they rarely anticipate how learning complex information would come to affect them. An effective SDM process should therefore be about empowering patients to make an informed decision, even if one chooses to defer decision making to a professional. This is what distinguishes shared decision from SDM.

Finally, how practically professionals and patients can achieve effective SDM routinely depends on a number of structural factors—issues that are mainly beyond the direct control of decision agents. Thus, the aim might be to respond and optimize the ways in which SDM can be implemented effectively. Process redesign, including the use of modern technologies and the Internet, may provide some way forward.

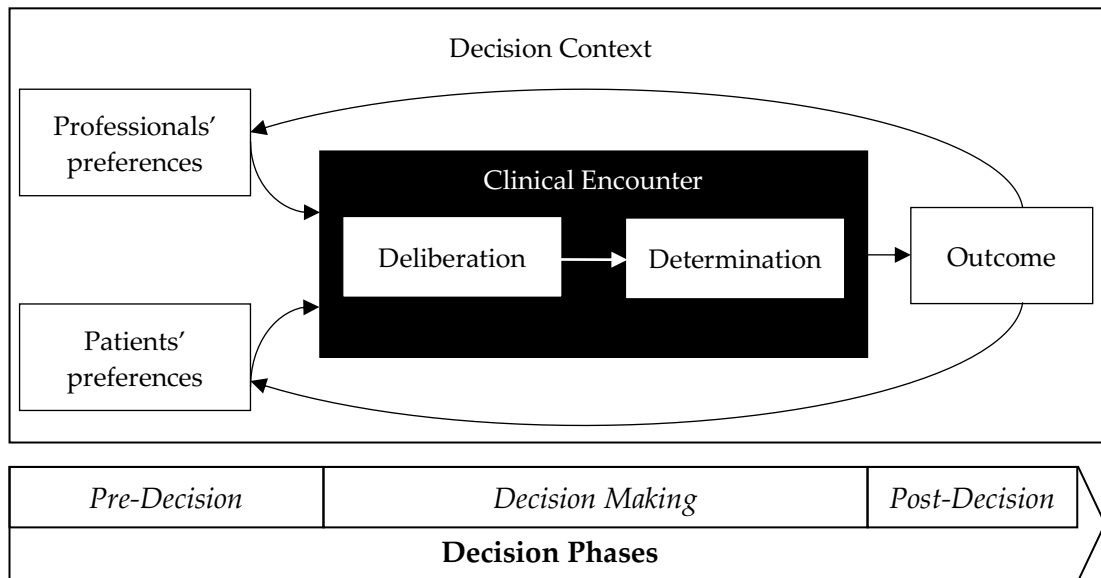
## **An agent-centric model of shared decision making**

To expand the current confines of normative conceptions, this chapter leverages on the review to redefine shared decision making as a social interaction involving bounded rational agents (Simon 1955; Kahneman 2011; Gigerenzer & Selten 2001). It advances a model, shown in Figure 2, that accounts for the behavioural aspects



reviewed before as well as their influence on the construction of preferences (Slovic 1995), thereby linking effective shared decision making to desirable outcomes.

**Figure 2.** An agent-centric model of shared decision making



This agent-centric model maps out the flow of various cognitive, emotional and social biases in shaping the extent to which shared decision making is implemented in an open, unbiased and informed manner. It recognizes the social nature through which professionals and patients collaborate to reach an informed decision. The model is contextually-bounded and captures three main stages in SDM: (a) pre-decision; (b) decision making; and (c) post-decision.

### Decision Context

The practicality of SDM rests on several structural factors that lie largely beyond the direct control of professionals and patients. The importance of policy-and legislative-related changes in shaping how professionals and patient collaborate can be seen in light of the Affordable Care Act which has appropriated 10 billion US dollars to experiment innovative service delivery models, including the payment of healthcare providers to use decision aids in their communication with patients (Frosch et al. 2011). These reforms can radically change the public's perception of their role in clinical encounters, as well as how healthcare institutions organize and allocate

resources to enable such processes. Organizational culture, aligned objectives, and ample training and resources are necessary for professionals to commit to SDM. Moreover, online decision support and process redesign (e.g., having nurses or receptionists prepare patients for SDM) may free up precious time in the clinical encounter for professionals to share decision making.

Nevertheless, situational variables like time pressure and the complexity of illnesses may impact how realistically involved and informed patients can be in clinical encounters. Likewise, professional identity and the type of illness may well influence how SDM is conceived in practice. This means that any assessments of its outcomes will have to depend on the nature of the decision.

### **Pre-decision Phase**

Before the clinical encounter, professionals and patients usually enter a clinical encounter with preconceived preferences that are misinformed for various reasons. Patients may assume a passive position by default out of a fear of being labelled difficult, whereas professionals may automatically adopt a paternalistic stance when dealing with certain patient groups. Such erroneous beliefs can limit space for genuine collaboration to occur.

The clinical encounter begins when professionals and patients establish first contact. Here, professionals have the opportunity to clarify misconceptions, explain to patients that their preferences matter, and invite them to share in decision making. This preparatory step is crucial for removing any preconceived biases that professionals and patients may have about collaborating in healthcare decisions. For example, professionals may learn of a patient's desire for more information and control in decision making through effective preparation, than if they were to simply assume patients' preferences based on their socio-economic or educational background alone. More importantly, preparation demonstrates a professional's genuine attempt to share decision making. It helps to resolve the inherent power imbalance in professional-patient relationships and to establish patients' "true" initial preferences in SDM.

On that note, initial preferences play a critical role in SDM; the clinical encounter is less likely to invite change when decision agents arrive with strong, coherent preferences over the role they wish to play or the decisions they wish to make. Consequently, some decision agents may be more confident, capable, and motivated to collaborate, whereas others may require more attention, patience, and encouragement. This applies to both professionals and patients.

### **Decision Making Phase**

The next stage of our model disentangles “deliberation,” which concerns the process leading up to an informed decision from “determination,” which is about the integration of preferences and values to determine the overall best option.

**Deliberation.** Deliberation is a process in which decision agents can reflect carefully on a matter, evaluate the harms and benefits of alternatives and aim to arrive at a decision based on facts and values (Elwyn & Miron-Shatz 2010). Three behavioural issues are of note here: knowledge, competence and emotion.

During deliberation, both decision agents will exchange information to form an overall mental picture of the situation (Epstein & Street 2011). Professionals will normally present a diagnosis, an array of alternatives, and a balanced set of evidence concerning each alternative. Patients will commonly respond by sharing their needs, preferences and values. An active discussion allows both decision agents to build a shared understanding of the situation based on what information is (or not) disclosed and how it is framed (Epstein & Gramling 2013). An agent’s knowledge is therefore bounded in SDM.

Decision-related competencies influence how readily and capably decision agents can perform in SDM. A non-exhaustive list includes skills such as numeracy, literacy and communication. As reviewed earlier, professionals and patients with poorer proficiencies in these areas may shun SDM. This implies that inter-individual differences in competencies may account for some variation in attitudes, motivation and behaviours in clinical encounters.

Related to decision knowledge and competence is the role of emotion in hampering objective reasoning. Decisions in healthcare are often affect-laden and can invite feelings of sadness, distress and anxiety in people. Since emotion has cognitive (e.g., perception of risk), motivational (e.g., self-efficacy) and social (e.g., receptivity to advice) properties (Forgas 1995; Lazarus 1991; Gino, Brooks & Schweitzer 2012), an agent's ability to regulate personal emotions may influence objective reasoning in decision making (Gross & Levenson 1997; Gross 1998). From a dyadic perspective, providing relational support may also be crucial for motivating SDM (Dizon, Politi & Back 2013).

**Determination.** Having deliberated about the situation, determination is about incorporating preferences and values to ascertain a proper option. Two behavioural issues, responsibility and method of input, are relevant here.

Professionals typically have reservations about giving patients complete control in decision making. This could be due to their professional responsibility to act in the best interest of their patients (e.g., less educated and literate), or a responsibility to society by giving patients only what is deserved (e.g., cost-effective medication). On the other hand, patients may want some engagement and information in SDM, but not necessarily the responsibility associated with a final decision (Degner & Sloan 1992; Deber, Kraetschmer & Irvine 1996). Moreover, rational decision making is cognitively demanding (Gigerenzer, Todd & ABC Research Group. 1999). Patients may wish to trade decision making accuracy and effort for greater emotional comfort (Payne 1976; Muramatsu & Hanoch 2005) by sharing or deferring decision authority to professionals. It is thus necessary to reconsider if patients want some involvement in decision making at all, especially after deliberation but before choice determination.

The final step considers how best to incorporate decision agents' preferences and values to arrive at a collective decision. To properly account for these issues, professionals and patients can use transparent and systematic techniques, such as multi-criteria decision analysis, to valuate, rank, and identify the most attractive

option altogether (Dowie, Kjer Kaltoft, Salkeld & Cunich 2015; Rapaport, Leshno & Fink 2014). Through an open negotiation process on whether decision agents wish to take equal or different responsibility for a decision, it is possible to adjust for each party's weight of influence on the overall decision (Nutt, King & Phillips 2010). Although the final decision may differ from initial expectations, everyone's interests are broadly accommodated in an equitable, accountable, and legitimate way.

### **Post-decision Phase**

SDM outcomes are generally difficult to measure. This in part stems from the heterogeneous ways in which the concept has been defined. While some focus on its process (e.g., whether key behaviours are observed), others tend to focus on its outcome (e.g., perception of involvement, decisional conflict) (Scholl, Koelewijn-van Loon, Sepucha, Elwyn, Légaré, Härter, et al. 2011). Moreover, given the generally prolonged nature of treatment and recovery in medicine, the benefits of engaging in SDM may not always be immediately clear.

Though some questions remain, positive SDM outcomes (e.g., decision, psychosocial, health) are likely to enhance a patient's perception of having been involved and improve a professional's evaluation of whether patient involvement was worthwhile. Successful experiences are likely to foster a genuine partnership and a deep sense of trust, thereby motivating greater collaboration in future encounters. Conversely, negative outcomes may deter future collaboration, especially for the same professional-patient dyad. SDM outcomes are therefore learned experiences. The present experience and outcomes of SDM will shape a decision agent's (preconceived) preferences in a future visit, which is depicted as a feedback loop in the model.

## **Discussion and conclusion**

Shared decision making is a promising model for safeguarding and improving the health of the population. Yet, its implementation has been poor and its outcomes

outcomes often mixed. This chapter argued that the principal reason for this gap was due to the static and rational nature in which SDM had been conceived: they had overlooked the *process of sharing* decision making, which is key for enacting person-centred decisions and care.

To provide insights on the behavioural factors that hamper effective SDM, this work systematically reviewed the healthcare literature and synthesized its active ingredients. These were mostly dyadic in nature and could affect the ways in which SDM unfolded in an open, informed and unbiased manner. This work then advanced an agent-centric model that recognised the development of preferences as a bounded rational and dyadic process. The model outlined three sequential stages in SDM and highlighted its fluid nature, with implications on informed and patient-centred care.

### **Implications for theory and practice**

This article has several theoretical implications. It puts forward the behavioural issues that underpin open collaboration and informed decision making. These influences operate at the personal and interpersonal level, and evolve with how professional-patient interactions develop over time. Thus, two conditions will usually need satisfying for effective SDM to arise. First, decision agents should be willing and motivated to participate in healthcare decisions, even if they may not want to share decision making control. Second, decision agents should communicate and process all information thoroughly and objectively so that they can construct preferences in an unbiased manner. These assumptions distinguish deliberation from determination in SDM and is consistent with our review that patients perceive complex medical decision making as two separate parts. Furthermore, information search and rational computation apply a cognitive cost (Payne 1976; Schwartz, Ward, Monterosso, Lyubomirsky, White & Lehman 2002). Patients may wish to compromise effort and accuracy for greater emotional comfort by deferring choice determination to professionals. Additionally, it emphasizes the importance of being “adequately” and objectively informed first, before choice-making happens. The subsequent phase being a negotiation of decision control and responsibility.

However, it is unclear if professionals and patients can ever be completely motivated to participate or perfectly rational during SDM. Owing to time constraints, bureaucratic pressures, the nature of illnesses and decision maker's limited cognitive capacities, it is perhaps more important to maximize the chances of effective SDM rather than arrive at shared decisions. Put differently, given that SDM promotes desirable outcomes in people, policymakers and professionals have a moral responsibility to promote its effective implementation across the board, with adaptations to individual patients and situations, rather than simply withhold it because it may take more time. Only then can SDM equitably and effectively achieve person-centred care.

This article has several practical implications. Given that each theme is a potential behavioural lever, this work presents a wide array of strategies for promoting SDM. These include competency assessments and training prior to the clinical encounter, a checklist of questions and misconceptions to clarify with patients, decision support interventions, and SDM training for professionals. Additionally, the distinction between deliberation and determination enables professionals to find new ways of "outsourcing" the former to processes outside the clinical encounter, thereby freeing precious clinical time for developing meaningful partnerships and facilitating choice determination. For example, patients who are curious about their own condition may refer to online informational aids to begin deliberation. For less complex illnesses, professionals and patients may arrange to have a video call over the Internet to determine a proper option, followed by the posting of drugs and medication. The distinction between deliberation and determination also creates two new functionally separate processes in SDM, each of which could be assessed separately. For example, deliberation could be measured by simple comprehension checks to assess knowledge, whereas determination could be measured by how preference-concordant patients feel about their final decision.

This work opens several opportunities for future research. Researchers can develop common standards for assessing the content, quality, and format of information presentation as these are frequently overlooked in current assessments of SDM.

Relatedly, more investigation is needed to establish how informed decision making and preference-concordance leads to better health and operational outcomes. The findings will be important for establishing trade-offs between different public objectives. Finally, the behavioural aspects reviewed in this chapter opens new avenues for studying and improving SDM. An agent-centric model of SDM also suggests that professionals have different attitudes, preferences and motivation towards collaborations in healthcare decisions, and that patients may bring valuable decision-relevant information into the clinical encounter. Consequently, some future behavioural interventions may target a professional's motivation to involve patients, whereas others may seek to improve a patient's decisional competency to make informed decisions.

Nevertheless, there are some limitations to this review. This work only included full-text articles published in peer-reviewed journals in English, and did not assess for publication biases. I mitigated a possible loss of relevant articles by collecting a rich, sizeable sample that was generally concerned with SDM and patient-centred care. Many of the themes included in this study were interrelated and more empirical research may be necessary to establish their relative associations as well as their impact on outcomes of interest. Finally, this review did not consider epidemiological factors (e.g., rarity, contagious nature, rate of progression) that may influence the quality of SDM as illness-specific characteristics may limit the scope and generalizability of our findings. Researchers should consider these issues in addition to our framework in future studies.

## **Conclusions**

The paradigm of SDM has attracted considerable attention in health policy and practice, yet it is rarely observed in clinical practice. This disjointed scenario is mainly due to normative conceptions of SDM that overlook the dynamic nature through which shared decision making unfolds, with implications for patient-centred care. The behavioural factors that hamper open collaboration and informed decision making are thus crucial aspects to account for in SDM.



To address this gap, this chapter reviewed the SDM literature and advanced an agent-centric model that conceptualizes the development of preferences in a dyadic interaction and the behavioural issues that influence this process. This evidence-based model accounts for constraints found in static models of SDM by showcasing the behavioural aspects that govern effective collaboration in decision making. In so doing, it enriches understanding on the socially complex process of sharing decision making and encourages future research to establish its links to desirable outcomes.

## Chapter 4

# Advice giving in shared decision making

In a recent shift from paternalism to patient-centred care, physicians have come to involve patients in clinical decisions more than ever before. Advocates argue from an ethical standpoint that patients have a right to autonomy and self-determination, especially in preference-sensitive situations where patients may be in a better position to evaluate the trade-offs involved (Charles, Gafni & Whelan 1999; Mulley, Trimble & Elwyn 2012; Charles, Gafni & Whelan 1997). Moreover, there is clinical evidence to suggest that patient participation in decision making often improves satisfaction, adherence to regimens, and health outcomes (Clayman, Bylund, Chewning & Makoul 2016; Shay & Lafata 2015). For these reasons, many authorities now expect healthcare experts to share decision making with patients (US House of Representatives 2010; Department of Health 2012).

While significant advances have been made in relation to evidence-based communication (Stacey et al. 2017; Zipkin, Umscheid, Keating, Allen, Aung, Beyth, et al. 2014; Légaré, Turcotte, Stacey, Ratté, Kryworuchko & Graham 2012; Edwards, Naik, Ahmed, Elwyn, Pickles, Hood, et al. 2013), little is still known on the role and influence of expert advice in shared decision making. Some conceptions of shared decision making view advice giving as an essential part of the deliberative process (Makoul & Clayman 2006; Charles, Gafni & Whelan 1999; Elwyn et al. 2012). Others ask if it detracts patients away from their preferred choices, and thus counteracts the principles of patient-centred care (Quill & Brody 1996; Hamann, Kissling & Mendel

2016; Mendel, Traut-Mattausch, Frey, Bu, Berthele, Kissling, et al. 2012; Frongillo, Feibelman, Belkora, Lee & Sepucha 2013).

These issues are particularly relevant in situations where patients may be more susceptible to advice. For example, certain decisions may involve scientific ambiguity where there is limited robust evidence to understand the risks and benefits involved, or when there is clinical equipoise where patients are confronted with more than one medically reasonable option. Under such uncertain circumstances, patients may feel more inclined to listen to the advice of experts, even if doing so is inconsistent with patients' own preferences.

Thus, further research on advice giving is crucial for understanding the reasons why and the ways in which advice shapes patients' choice and experience of care. This study aims to address this gap by investigating the interplay between advice giving and patient anxiety in shared decision making. I examine this in the context of prostate cancer screening, a timely context for advancing knowledge on the ways in which advice and emotion interact to influence choice in a preference-sensitive scenario. In so doing, this paper provides empirical evidence on the dyadic nature of physician-patient communication in shared decision making.

The rest of the chapter is structured as such: It begins with a brief literature review on advice giving and patient anxiety in shared decision making. It then reports the methods and findings of the study. After which, it discusses the implications of the study and concludes by suggesting future areas of research to enrich understanding on shared decision making.

## **Literature review**

### **Expert advice**

Advice giving is a central part of a healthcare expert's work (Elwyn et al. 2012; Makoul & Clayman 2006). In shared decision making, a doctor is expected at the minimum to inform patients about all the possibilities, the risks associated with them

and their implications for care. Presumably, a doctor is expected to present them in a clear, concise and unbiased manner, which is usually facilitated by the use of objective data such as population-based statistics and decision aids. The idea is to encourage informed decision making in patients and empower them to make choices that may be more consistent with their preferences (Elwyn & Miron-Shatz 2010). As such, general advice is usually given in a neutral manner, without impinging on a patient's autonomy (e.g., I would advise you to make your own informed decision).

On the other hand, doctors may give option-specific advice to patients. These tend to carry an expert's values, preferences and experience on which decision option is "better" (Ubel 2015) and is thus more directive in the form of a recommendation (e.g., I would advise choosing treatment A) (Gurmankin, Baron, Hershey & Ubel 2002). Compared to general advice, option-specific advice may be influential in deterring patients from using their own preferences to drive decision making.

These issues are especially important in preference-sensitive situations, where more than one medically reasonable option may exist (Mulley, Trimble & Elwyn 2012). In prostate cancer treatment decisions, Scherr and colleagues (2017) found that patients' treatment choices were based mainly on urologists' recommendations, which were driven by medical factors (e.g., Gleason score) instead of patients' preferences towards the pros and cons of treatment options. Hence, within the framework of shared decision making, the quality of a decision rests largely on whether it reflects a patient's own preferences or not.

Along these lines, researchers have explored how characteristics of a decision maker (e.g., confidence level, disclosure of medical specialty) (Sah, Fagerlin & Ubel 2016; Mendel et al. 2012) and the time in which recommendations are given (i.e., whether it is early on in decision making or at the end) can influence a patient's choice, satisfaction and adherence (Hamann, Kissling & Mendel 2016). However, little is still known about the underlying mechanisms linking option-specific advice giving and decision making in patients.

## **Anxiety**

Spielberger (2010) defines anxiety as a brief and intense emotional feeling that any healthy individual may experience. It is a negative emotion that is commonly associated with fear, nervousness and worry, and which is characterized by high uncertainty and a low control of events (Russell & Barrett 1999; Spielberger 2010). Anxiety is a common emotion in dental care (Gordon, Heimberg, Tellez & Ismail 2013), perioperative surgery (Bailey 2010; Mark 2003), and general consultation (Shimada, Ohira, Hirota, Ikegami, Kondo, Shikino, et al. 2018), and is known to influence information recall, satisfaction with care and health outcomes in patients (van Osch, Sep, van Vliet, van Dulmen & Bensing 2014; Mark 2003).

In the clinical setting, patient anxiety usually arises from being in a risky or uncertain situation (e.g., when there is limited information, scientific ambiguity, or a poor prognosis). Since anxiety is an aversive emotion that can lower an individual's self-confidence (Bandura 1977; Freud 1959) and trigger a need for certainty (Raghunathan & Pham 1999), individuals are motivated to cope with it by seeking help and support from others (Gino, Brooks & Schweitzer 2012). This behavioural coping mechanism enables individuals to regain some level of psychological control and sense of safety. For instance, Gino and colleagues (2012) showed that anxious-induced participants were significantly more receptive to advice than neutral participants, even when the advice was objectively poor. While this study adds knowledge on why and how anxiety may influence an advisee's decision making, it does so in an objective setting (guessing the weight of a person in an incomplete picture). Not much is known on the effects of anxiety on patients' decision making in a preference-sensitive scenario.

## **Prostate screening advice and patient anxiety**

There are different guidelines on whether physicians should recommend for or against prostate cancer screening (i.e., option-specific advice), or simply advocate informed choice (i.e., general advice) (Tikkinen, Dahm, Lytvyn, Heen, Vernooij, Siemieniuk, et al. 2018). Though this will usually depend on a patient's risk factors (e.g., age, family history, race), research has shown that there is still significant

variability in how physicians give advice in prostate cancer screening (Han, Kobrin, Breen, Joseph, Li, Frosch, et al. 2013; Holmes-Rovner, Montgomery, Rovner, Scherer, Whitfield, Kahn, et al. 2015; Floyd J, Gerstein & Barry 2013).

One argument is that in exercising expert judgement, healthcare experts themselves face considerable uncertainty in determining which option is in a patient's best interests and therefore, what advice to give (Politi & Légaré 2010). For example, Dalton and colleagues (2015) found that when physicians were uncertain about the net benefit from screening, they were more likely to advocate for a patient's involvement in decision making than to advice for or advice against screening.

In a dyadic setting, patients may perceive an option-specific advice as an indication of a healthcare expert's confidence in which option is better. A range of psychological studies have shown that advisees tend to use an advisor's confidence level as a good heuristic of competence (Sah, Moore & MacCoun 2013; Snizek & Van Swol 2001; Bonaccio & Dalal 2006). Moreover, clinical studies have shown that advisors' uncertainty can often influence patients' choice and satisfaction (Politi, Clark, Ombao & Légaré 2011; Politi & Légaré 2010). Using general advice for informed choice as a reference point, this study aims to investigate the influence of option-specific advice on patients' decision making as well as uncover its underlying mechanisms. With this in mind, I formulate the following hypotheses:

**H1:** An option-specific advice influences individuals' likelihood of choosing to screen.

**H2:** Individuals' perceptions of confidence in a doctor's advice over which option is better mediates the influence an option-specific advice has on the likelihood of choosing to screen.

Moreover, patient anxiety is a common emotion in prostate cancer screening and treatment decisions (Roth, Rosenfeld, Kornblith, Gibson, Scher, Curley-Smart, et al. 2003; van den Bergh, Essink-Bot, Roobol, Wolters, Schröder, Bangma, et al. 2009). Regulatory guidelines and researchers often cite the worry, emotional burden and

apprehension associated with PSA testing as a factor for consideration in prostate screening decisions (Tikkinen et al. 2018). Anxiety may influence patients' decision making in different ways. It may directly influence a patient's likelihood of screening. Additionally, it may predispose people to the influence of an option-specific advice, resulting in the following hypotheses:

**H3:** Anxiety influences the likelihood of choosing to screen.

**H4:** Anxiety moderates the influence an option-specific advice has on individuals' likelihood of choosing to screen.

The following section explains the details of the experiment. To empirically test the aforementioned hypotheses, the study uses general advice to establish a baseline of preference as to what individuals would do in the absence of an option-specific advice. This enables the study to distinguish between the two types of expert advice.

## **Methods**

### **Materials**

To provide a realistic, preference-sensitive context, I adapted a hypothetical vignette on informed prostate cancer screening decision making (Petrova, Garcia-Retamero & Cokely 2015) and updated it with the latest clinical evidence (Tikkinen et al. 2018). Participants play the role of a 55-year old white male who is in consultation with a doctor on whether to get a PSA test or not. Participants are given the best available evidence there is on prostate cancer screening, including the risks, harms and benefits from having to screen or not, so that they can make an informed choice. The decision aid can be found in Appendix B.

### **Measures and variables**

The main socio-demographic variables included were age, education, employment, country of residence, and prior history with prostate cancer. The main outcome variable was participants' decision to take up screening (0=no, 1=yes).

I measured state anxiety using the State-Trait Anxiety Inventory (STAI) (Marteau & Bekker 1992; Spielberger 2010), which included six items measured on a four-point scale (1=not at all, 4= very much;  $\alpha=.87$ ).

I measured participants' perception of a doctor's confidence using the question "How confident was the doctor in determining which option was best for you?" on a seven-point scale (1=not at all, 7=extremely).

To control for general affect which might influence state anxiety, I asked participants to rate their general feelings over the past one year using the positive affect and negative affect schedule (PANAS) (Watson, Clark & Tellegen 1988). It contained two subscales of 10 items each, one for positive affect (e.g., interested, excited, and determined) and another for negative affect (e.g., distressed, scared, and jittery). Items were measured on a five-point scale (1=very slightly or not at all, 5=extremely). The sum for each subscale was kept separate.

To control for participants' desire to defer decision making to their doctors, I used the control preferences scale (CPS) (Degner, Sloan & Venkatesh 1997). Participants are asked to select one statement that best describes their preferred role in treatment decisions with their doctor from a possible five. These five statements are arranged on a continuum where on one end, participants could prefer to make the decision on their own and on the other end, they could prefer that their doctor makes the decision on his/her own.

Finally, I asked participants if they were to repeat the same scenario again, but this time without any advice from the doctor, what their decision would be (0=I would not get the PSA test, 1=I would get the PSA test).

I included two manipulation checks to ensure that my results are valid. The first asked participants to recall about the screening scenario and what advice was given to them (1= get the PSA test, 2=do not get the PSA test, 3=make your own informed decision). The second asked participants to rate, in relation to their screening



decision, how influential the doctor's advice was in determining whether they got the PSA test or not. This was done on a five-point scale (1=not at all, 5=extremely).

Two attention checks were included to screen out participants who may not be attentively reading the evidence in the decision aid. Participants were asked to identify if a statement was true or false: 1) A PSA test is 100% accurate in detecting the presence of prostate cancer (*False*); and 2) For men, there are more biopsy-related complications from choosing to screen than choosing not to screen (*True*).

## **Procedure**

The study was conducted on the Internet. After providing informed consent, participants read about the hypothetical vignette and prostate cancer decision aid. After completing two attention checks embedded within the decision aid, participants rated their state anxiety (via STAI).

Participants were then randomly allocated to one of three conditions. In the control condition, participants were presented with two options and given a general advice in which "the doctor advises you to make your own informed decision." In the option-specific advice that *supports* screening, "the doctor advises you to get the PSA test," whereas the option-specific advice that is *against* screening states that "the doctor advises you not to get the PSA test." Participants then make their screening decision on whether to get a PSA test or not.

Following which, participants answered about their doctor's perceived level of confidence and completed the PANAS and CPS scales. Participants responded to two manipulation check questions, before ending the survey by filling in some basic demographics. This study has received ethical approval from the Warwick Business School Doctoral Ethics Board.

## **Participants**

A priori power analysis using G\*Power suggested a sample of 143 participants in each condition was required to detect a difference in proportions between two

independent groups, one with 0.50 and another with 0.65, with a power of 0.80. I recruited 451 participants from an online database (Prolific Academic). I included male participants residing in the US or the UK, between the age of 40 and 69 inclusive. Of the 451 participants recruited, 346 (76.72%) successfully passed both attention checks and were retained for analyses. The participants were mainly UK residents (69.65%) with a mean age of 51.18 years (SD=8.57). About one-fifth of the sample (19.70%) had previously consulted a doctor about prostate cancer or experienced prostate cancer screening and treatment first hand. Table 3 summarises the characteristics of the sample.

**Table 3.** Summary characteristics of the sample.

| Variable  | Overall              | Advice Against       | General Advice       | Advice For     |
|---|----------------------|----------------------|----------------------|----------------|
| Sample  | 346                  | 111                  | 117                  | 118            |
| Age   | M=51.18<br>(SD=8.57) | M=51.71<br>(SD=8.38) | M=50.56<br>(SD=7.92) | M=51.30 (9.38) |
| Country of residence                            |                      |                      |                      |                |
| US  | 104 (30.06%)         | 36 (10.40%)          | 31 (8.96%)           | 37 (10.69%)    |
| UK  | 241 (69.65%)         | 75 (21.68%)          | 85 (24.57%)          | 81 (23.41%)    |
| Other   | 1 (0.29%)            | 0 (0%)               | 1 (0.29%)            | 0 (0%)         |
| Education                                       |                      |                      |                      |                |
| High school diploma and below                   | 56(16.18%)           | 15 (4.34%)           | 13 (3.76%)           | 28 (8.09%)     |
| College but no degree                           | 86 (24.86%)          | 27 (7.80%)           | 31 (8.96%)           | 28 (8.09%)     |
| Associate's degree and higher                   | 203 (58.67%)         | 69 (19.94%)          | 72 (20.81%)          | 62 (17.92%)    |
| Other   | 1 (0.29%)            | 0 (0%)               | 1 (0.29%)            | 0 (0%)         |
| Employment                                      |                      |                      |                      |                |
| Employed (full-time)                            | 183 (52.89%)         | 67 (19.36%)          | 62 (17.92%)          | 54 (15.61%)    |
| Employed (part-time)                            | 28 (8.09%)           | 7 (2.02%)            | 14 (4.05%)           | 7 (2.02%)      |
| Unemployed                                      | 23 (6.65%)           | 5 (1.45%)            | 8 (2.31%)            | 10 (2.89%)     |
| Self-employed                                   | 55 (15.90%)          | 16 (4.62%)           | 13 (3.76%)           | 26 (7.51%)     |
| Retired   | 48 (13.87%)          | 15 (4.34%)           | 16 (4.62%)           | 17 (4.91%)     |
| Other   | 9 (2.60%)            | 1 (0.29%)            | 4 (1.16%)            | 4 (1.16%)      |
| Prior exposure or experience of prostate cancer | 68 (19.70%)          | 25 (7.23%)           | 19 (5.49%)           | 24 (6.94%)     |

## **Manipulation checks**

A chi-square test showed that the advice manipulation worked. Across the three conditions, participants were more likely to identify the doctor's advice that they were truly assigned to ( $\chi^2(4)=399.00$ ). Additionally, a t-test showed that option-specific advice had a greater perceived influence on participants' screening decision making than did general advice ( $M_{diff}=.263$ ,  $t(344)=1.986$ ,  $p=.048$ , 95% confidence interval [.003 to .523]). These tests proved that participants recognised the advice that was given and that option-specific advice, either to screen or not to screen, had a greater perceived influence on their own decision. Given these initial findings I use the terms recommend for and against to mean option-specific advice for and against respectively. I refer to general advice as the control condition.

## **Statistical analyses**

To determine if recommendations influenced participants' likelihood of opting for screening, I ran a chi-square test. I also ran an additional chi-square test to understand what participants might choose had they not received any advice at all. These results give a broad overview of participants' screening decisions.

However, recommending for and against screening may impact patients' choice differentially. To investigate the strength of influence recommendations had on participants' likelihood of screening, I conducted two separate sets of analyses—one comparing a recommendation against screening and the control group, and another comparing a recommendation for screening and the control group. In these analyses, I tested if perceived confidence in a doctor mediated the influence recommendations had on choice. In addition, I tested if anxiety moderated the influence of recommendations and if anxiety directly predicted participants' screening decision. All statistical analyses were conducted on SPSS V24. Moderation and mediation analyses were carried out using PROCESS V3.1.

## Results

### Overview of results

The descriptive statistics of the continuous variables included in this study are shown in Table 4. Participants were generally in a more positive than negative state of mind and had moderate levels of decision making control and state anxiety. An ANOVA test showed no significant differences in these variables among my three advice conditions, indicating that participants' screening decision was not biased by the different profiles of people contained in each group.

**Table 4.** Means, standard deviations, and correlations of variables.

| Variable               | Scale | Mean<br>(SD)     | Correlations (exact p-value) |                  |                |                 |   |
|------------------------|-------|------------------|------------------------------|------------------|----------------|-----------------|---|
|                        |       |                  | 1                            | 2                | 3              | 4               | 5 |
| 1. Positive affect     | 10-50 | 32.13<br>(7.40)  | 1                            |                  |                |                 |   |
| 2. Negative affect     | 10-50 | 19.83<br>(7.62)  | -.165**<br>(.002)            | 1                |                |                 |   |
| 3. CPS                 | 1-5   | 2.40<br>(.61)    | .046<br>(.396)               | -.129*<br>(.016) | 1              |                 |   |
| 4. Anxiety             | 20-80 | 36.93<br>(12.51) | -.114*<br>(.035)             | .457**<br>(.000) | .014<br>(.793) | 1               |   |
| 5. Doctor's confidence | 1-7   | 4.95<br>(1.40)   | .032<br>(.548)               | .035<br>(.519)   | .029<br>(.585) | -.073<br>(.177) | 1 |

\*\*p-value < 0.01

\*p-value < 0.05

### Screening decision making

Among the three advice conditions, there was a significant difference in the proportion of participants who opted for screening ( $\chi^2(2)=33.92$ ,  $p=0.000$ ). In the control condition, only 39.3% (46 of 117) decided to screen. However, in the recommend against and for conditions, only 15.3% (17 of 111) and 51.7% (61 of 118) wanted screening respectively.

There was no significant difference in the proportion of participants who would go for screening if they were to repeat the scenario again but receive no expert advice ( $\chi^2(2)=3.92$ ,  $p=.141$ ). In particular, 50.4% (59 of 117) in the control, 37.8% (42 of 111) in the recommend against and 41.5% (49 of 118) in the recommend for conditions would opt for screening in the absence of an expert's advice. This suggests that expert recommendation may not only influence participants' decision making, but also sway them away from their own preferred choice. There is thus evidence to support hypothesis one.

A one way analysis of variance (ANOVA) test on participants' perception of a doctor's confidence in determining which option was best for them revealed a significant difference among the three advice conditions ( $F(2, 343)=21.81$ ,  $p=.000$ ). Post-hoc analyses<sup>3</sup> revealed that participants in the control condition had a much lower rating than those in the recommend against condition ( $M_{diff} = -1.15$  ( $SD=.175$ ),  $p=.000$ , 95% CI [-1.56 to -.73]) and recommend for condition ( $M_{diff} = -.692$  ( $SD=.172$ ),  $p=.000$ , 95% CI [-1.10 to -.29]). Additionally, participants in the recommend against condition had a much higher rating than those in the recommend for condition ( $M_{diff}=.453$  ( $SD=.175$ ),  $p=.027$ , 95% CI [.04 to .86]).

The results indicate that compared to general advice, expert recommendations are perceived to be made by a doctor who is more confident about which option is better for a patient. Furthermore, participants judged a doctor's perceived confidence in recommendation giving differently depending on whether it supported or deterred screening. To investigate if recommendations, perceptions of confidence, and state anxiety influenced participants' likelihood of choosing to screen, two separate sets of mediation analyses were performed.

### **Mediation analyses (Recommend against screening)**

I investigate whether the association between recommending against screening and participants' likelihood of opting for screening was mediated by perceptions of a

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<sup>3</sup> A Tukey test is used.

doctor's confidence in determining which option was better. Both sets of analysis were performed with participants' state anxiety, positive affect, negative affect and CPS as control covariates.

In the first ordinary least squares regression model, a recommendation against screening was significantly related to higher perceived confidence in doctors' advice ( $b=1.12$ ,  $SE=.19$ ,  $p<.001$ , 95% CI [.758 to 1.489]). Anxiety was marginally related to lower perceived confidence in doctors' advice ( $b= -.05$ ,  $SE=.03$ ,  $p<.060$ , 95% CI [-.111 to .002]).

In the second logistic regression model, a recommendation against screening was significantly related to a lower likelihood of screening ( $b= -1.56$ ,  $SE=.36$ ,  $p<.000$ , 95% CI [-2.258 to -.858]). In addition, perceived confidence in a doctor's advice was significantly related to a higher likelihood of screening ( $b=.25$ ,  $SE=.12$ ,  $p=.031$ , 95% CI [.022 to .478]) whereas anxiety was only marginally related to a higher likelihood of screening at the 10% significance level ( $b= .09$ ,  $SE=.05$ ,  $p=.077$ , 95% CI [-.010 to .186]). There was no evidence that anxiety moderated the relationship between the type of advice given and participants' screening decision. Consequently, there is only weak evidence to support hypothesis three but no evidence to support hypothesis four.

The odds of choosing to screen for a recommendation against PSA testing over a general advice was 0.21. In other words, a recommendation against screening would result in a 78.99% decrease in the odds of a person getting a PSA test, compared to an advice for informed choice. In addition, a one unit increase in a person's perception of a doctor's confidence in advice giving increased the odds of having a PSA test by 28.40% and a one unit increment in state anxiety increased the odds of having a PSA test by 9.42%.

The bootstrap confidence intervals<sup>4</sup> derived from 5000 samples suggested that the indirect effect coefficient was significant ( $b= .28$ ,  $SE=.15$ , 95% CI [.019 to .618]), which

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<sup>4</sup> The bootstrapped confidence intervals do not include 0, which means that the true population mean is likely to be different (Baron & Kenny 1986).

supported the hypothesis that the relation between recommending against screening and participant's decision to screen was mediated by perceptions of confidence in a doctor's advice. There is thus evidence to support the second hypothesis.

### **Mediation analyses (Recommend for screening)**

In the first ordinary least squares regression model, a recommendation for screening ( $b=.70$ ,  $SE=.19$ ,  $p<.001$ , 95% CI [.335 to 1.065]) and participants' negative affect was significantly related to higher perceived confidence in doctors' advice ( $b=.03$ ,  $SE=.01$ ,  $p=.036$ , 95% CI [.002 to .059]).

In the second logistic regression model, a recommendation for screening was not related to participants' decision to screen ( $b=.28$ ,  $SE=.29$ ,  $p=.332$ , 95% CI [-.283 to .836]). However, perceived confidence in a doctor's advice ( $b=.44$ ,  $SE=.11$ ,  $p<.000$ , 95% CI [.222 to .661]), anxiety ( $b=.10$ ,  $SE=.04$ ,  $p=.026$ , 95% CI [.012 to .185]), and CPS ( $b=.59$ ,  $SE=.23$ ,  $p=.010$ , 95% CI [.139 to 1.046]) were significantly related to a higher likelihood of screening. Again, anxiety did not moderate the relationship between the type of advice given and participants' screening decision. There is evidence to support hypothesis three, but no evidence to support hypothesis four.

Increments in a person's odds of having a PSA test was 55.27% for a one unit increase in a person's perception of a doctor's confidence in advice giving, 10.52% for a one unit increase in state anxiety, and 80.40% for a one step increase in preference for a doctor to make all treatment decisions (i.e., CPS).

The bootstrap confidence intervals derived from 5000 samples suggested that the indirect effect coefficient was significant ( $b=.31$ ,  $SE=.12$ , 95% CI [.123 to .577]), which supported the hypothesis that the relation between recommending screening and participant's decision to screen was mediated by perceptions of confidence in a doctor's advice. There is thus evidence to support hypothesis two.

## Discussion

Advice giving is a fundamental part of being a healthcare professional and an important aspect in SDM (Quill & Brody 1996; Elwyn et al. 2012). While extant research has demonstrated the ill-effects of advice-giving, particularly how it may counteract the principles of patient-centred care (Gurmankin, Baron, Hershey & Ubel 2002; Mendel et al. 2012), this is the first known investigation into its underlying mechanisms and the role of patients' emotions from a dyadic perspective. There are several interesting results worth mentioning.

Even though participants were told that all best-available evidence had been presented, expert recommendations still had a strong influence in determining whether or not they got a PSA test. More importantly, recommendation giving harbours a real risk of detracting patients away from their own preferences. This is consistent with prior research showing that late recommendations were more influential in steering patients away from their preferred choices, than giving early or no recommendations at all (Hamann, Kissling & Mendel 2016). This suggests that expert recommendations may have a "stickier" effect on patients' preferences than expected.

One explanation is that recommendation giving is associated with a greater perceived certainty in a healthcare expert's determination of which option is better for a patient. It mediated the influence recommendations had on patients' likelihood of choosing to screen. However, it is not exactly clear why perceptions of a doctor's confidence were significantly higher in recommendations against screening than in recommendations for screening. Given that a larger proportion of individuals favoured no screening, both in the control condition and when asked to decide again without a doctor's advice, this difference could be down to a person's strength of preference. That is, individuals may have a level of personal confidence and certainty over which option was better. This could also explain why recommendations for screening had no direct influence on the odds of screening.



Another explanation could be an omission bias, where an action producing harm is judged to be worse than an inaction leading to the same degree of harm. The results obtained in this study reflect those found by Gurmankin and colleagues' (2002), in which a recommendation involving action was less influential on participants' vaccination choice than one recommending inaction, when compared to a control group which received no recommendation at all.

On a separate note, state anxiety did not predispose individuals to the recommendations or influence of experts. Nevertheless, it did have a small but positive effect on the odds of screening, meaning that momentary feelings of anxiety may motivate people to take up precautionary screening measures. This has important implications for practice. Worry and uncertainty in the clinical setting is common, and such negative feelings may prompt individuals to seek treatments and options that they may not have otherwise chosen, if they were in a more rational state. Hence, pacifying such emotions may be important in shared decision making. Special attention to how professionals communicate with patients (e.g., remind them that support is available when needed or allowing for more time to pass before deciding) and design their environment (e.g., soothing music in the waiting room) could help to alleviate unnecessary stress and worry. Future research examining how trait anxiety compares with state anxiety in terms of their impact on shared decision making may be useful for identifying particular patient groups or situations where "irrational" decisions are more likely.

It should be noted that in the case of recommendation for screening, individuals' preference for paternalistic decision making had a much larger effect on the odds of screening than even perceptions of a doctor's confidence or state anxiety. Individuals with a higher preference for paternalism risk making their decisions to screen simply because their doctor had recommended it.

This study has several implications for understanding and approaching advice giving in the context of SDM. The present study indicates that there are different types of expert advice that could be given in shared decision making. While some

concern more generally how a patient should behave in decision making (e.g., encourage rational deliberation), others that suggest what a patient ought to decide on (e.g., treatment recommendations) have the potential to detract people away from their own preferences. As such, researchers should be explicit about the type of advice they are referring to in both theory and practice.

Patients on the other hand, appear to view recommendation giving as a confidence heuristic. They believe that by expressing a preference for one option, healthcare experts are communicating their confidence in determining which option is in a person's best interest. Yet such perceptions may not always be true. A physician's advice is often informed by his or her own medical knowledge, clinical guidelines, personal preferences and experience, and not necessarily by a patient's view on the matter (Scherr et al. 2017).

This is not to say that healthcare experts should refrain from expressing any sort of expert judgement in shared decision making. Rather, they should be mindful of their own biases and values as well as a patients' right to self-determination in treatment decision making, especially in preference-sensitive scenarios. Physicians can fulfil the principles of shared decision making by taking the following measures. They can adhere to the "deliberation before determination" rule in shared decision making by separating medical facts from personal expert opinion. Given how "sticky" recommendations can be, physicians should allow patients to decide if they want option-specific advice and if they do want it, explain how such a recommendation was derived.

Alternatively, physicians may only provide recommendations when patients are ambivalent about their options. Physicians could also clarify how certain they are with their recommendation by using a Likert-sort scale (e.g., 1=not at all, 5=extremely). More research is needed to explore how recommendations and strength of patients' preferences interact to predict choice and outcomes.

On a closing note, emotions are an important and common facet in shared decision making. Although this study found no evidence of an interplay between anxiety and

advice giving, there was reason to believe that it influenced patients' screening decision making. Physicians should pay more attention to patients' anxiety in clinical encounters, noting that it may motivate them to seek screening. Future research may consider interventions for alleviating patients' anxiety in screening decision making.

### **Study limitations**

There are limitations to this study. Hypothetical vignette experimental designs raise a number of questions regarding their measures and findings. They can provide controlled comparisons to study participants' reactions, but participants may never have experienced the situation first hand to understand or even anticipate how they might feel in a real clinical encounter. Moreover, the present study placed participants in the shoes of a third person, which may have further diluted the validity of the results. Participants may well act differently when they encounter such difficult circumstances first-hand, a concept known as the "hold-cold" empathy gap (Loewenstein 2005). To bridge this limitation, where participants in a "cold" or calm state find it difficult to fully imagine their own feelings or behaviours in a "hot" state (i.e., confronted with a cancer diagnosis), future research relying on in-depth interviews, focus groups, and observational studies to study cancer decision making may provide richer insights on how patients react to their doctor's advice in practice.

A certain degree of demand-effect, in which participants feel that their choices ought to reflect the information provided (e.g., doctor's advice to take a PSA test) may be present in the study. To mitigate such an effect, future studies could directly manipulate the levels of confidence associated with a recommendation as well as the type of expert involved (e.g., doctor versus a friend). Such a set up would provide a cleaner set of results on the extent to which expert confidence influences advice-taking in people. Other research opportunities could include manipulating expert power (e.g., senior versus junior doctor) and other decision scenarios (e.g., financial advice).

## Conclusions

Shared decision making is a promising framework for safeguarding and improving the health of population, but at the same time a complex and multifaceted process to implement in clinical practice. Past research has shown that expert advice can steer patients away from their preferred options, thus counteracting the principles of patient-centred care. The present study investigated expert advice giving and its influence on patients' screening decision making and contributed insights on its underlying mechanisms. It not only distinguished between general advice and option-specific advice, but also revealed the mediating role of doctors' perceived confidence in explaining the relationship between an advice for informed choice and a recommendation over what option to take. Moreover, the study found a positive relationship between individuals' state anxiety and a decision to screen, indicating that emotions are a relevant and important predictor of choice in shared decision making.

Overall, this study has advanced knowledge on the dyadic and behavioural nature of shared decision making, and how cognition and affect in patients may interact to predict choice. To enrich understanding on the role of expert advice in shared decision making, more research is needed to explore the different sources of influence behind advice giving (e.g., expert emotions, years of experience), and if advice taking hurts (or helps) patient-reported outcomes (e.g., satisfaction, confidence, adherence to treatment regimens). This will contribute knowledge on how best to communicate patients in patient-centred manner.

## Chapter 5

# Shared decision making for person-centred social care

In recent years, the UK government has sought to replace a “one size fits all” approach to care with a person-centred system that caters to individuals’ needs and preferences (Department of Health and Social Care 2014a). More information, more choice, and more autonomy underpin this transformation. Lay individuals are increasingly expected to decide, usually in collaboration with formal caregivers (e.g., social care providers, local authorities), family members, or friends, on how best to meet their own social care needs. As a result, shared decision making—a process in which the public consumer and decision agent(s) from their social support network make decisions that are informed and consistent with consumers’ preferences—has become an increasingly important means for achieving person-centred care.

Nevertheless, the role of shared decision making in social care has never been directly addressed and little is known on how and the ways in which it could support the government’s objective in creating a respectful and responsive social care system. The importance of addressing this lies with two reasons. Firstly, decision making about future care needs is often complex and multifaceted (Carpenter & Yoon 2011; Yoon, Cole & Lee 2009). No one can accurately predict whether they will have care needs or what these may be in the later part of their lives. If they do need it, many will find that unlike healthcare, they will have to financially manage many of these themselves in often challenging circumstances (Behavioural Insights Team 2017). Secondly, a person’s social support network (e.g., formal caregivers, friends, family members)

may render different forms of assistance in helping people to meet their own care needs and is thus an important resource in social care.

To address the question of how shared decision making can contribute to person-centred social care, the current paper applies a behavioural lens to analyse the psychological gaps and opportunities for promoting person-centred decision making and welfare. The paper draws on both peer and non-peer reviewed publications to develop this narrative review, and relies on the popular COM-B ('capability', 'opportunity', 'motivation' and 'behaviour') framework (Michie, van Stralen & West 2011) to guide the classification of themes. The COM-B framework has been used extensively in different disciplines (e.g., psychology, healthcare, management) to study and encourage behaviour change in people. (Michie, West, Sheals & Godinho 2018; Michie, Atkins & West 2014). Hence, the use of this framework shall provide researchers with an analytical toolkit for evaluating future policy implementation concerning human behaviour, such as energy conservation and crime prevention. Altogether, this work sheds light on the behavioural factors that shape person-centred social care and how shared decision making may support this aim.

This paper begins with some background information on the adult social care market and how recent reforms have affected consumer behaviour in this area. In this work, "consumers" refer to both paying and non-paying individuals who use a social care-related good or service for their own needs. This paper focuses on common psychological factors, rather than standard economic factors such as access, affordability, and availability to high-quality services which are mostly structural constraints. Following a brief description of the context, the paper proceeds to review the behavioural issues that underpin person-centred decision making in social care according to the COM-B framework. The paper concludes by discussing the strengths and limitations of the analysis as well as the framework, and suggesting future opportunities for advancing research in social care.

## **Background**

In the UK, about one in 10 older adults will encounter future lifetime costs of over £100,000 in their social care needs (The Health Foundation 2017). About 22% of men and 33% of women aged 65 and over need some form of help with at least one instrumental activity of daily living (e.g., ability to handle finances, prepare food, take medication responsibly), and about 30% of all people use a form of local authority funded social care in their last year of life (Age UK 2018b). These figures are set to grow as the baby boomer generation begins to reach retirement and the life expectancy of the population increases, greatly inflating the demand for social care (The King's Fund 2018).

The importance of planning for future care needs was evident in the 2014 Care Act, which stated that "effective interventions at the right time can stop needs from escalating, and help people maintain their independence for longer" (Department of Health and Social Care 2014b). For example, councils claim that prevention is necessary for them to achieve planned savings in social care (The King's Fund 2018), whereas the National Audit Office (2013) estimated that about 20% of all emergency hospital admissions are for existing issues that could be managed effectively at other levels (e.g., primary and social care) and thus avoided.

To help the general population meet their social care needs, the 2014 Care Act mandated several changes, including the implementation of a person-centred social care system, decentralising social care provision to local authorities, and expanding consumer choice in social care (Department of Health and Social Care 2014b). The intention was to enhance persons' autonomy to choose services based on what they needed and how they felt they could be best cared for, as well as expand the amount of information and services available at the community level. A person-centred decision in social care can therefore be defined as one that is: (1) made under relatively little stress; (2) informed; and (3) consistent with a person's own preferences.

However, getting people to consider their future care needs often proves more difficult than simply giving them more information and services to decide on. A

survey in 2017 showed that about 47 percent of the population wrongly think that social care is free at the point of need and that only 35 percent had made any financial plan for their future care (Ipsos MORI 2017). Furthermore, people tend to differ in when they interact with the social care market. Risk averse and avid planners tend to enter the social care system much earlier (Lusardi & Mitchell 2007), whereas others tend to avoid the subject and only consider their care needs when the situation demands it (Behavioural Insights Team 2017). Unfortunately, the latter often arises in crises when people have limited time and freedom to consider all the information necessary to make a proper decision (Behavioural Insights Team 2017; Which? 2018).

The resulting effect is an increasingly unsustainable social care system in which more adults are struggling with or unable to meet their own care needs. The latest figures from Age UK (2018a) indicate that about 1.4 million older people (or nearly one in seven) do not have access to all the care and support they need, which is an increase of 19% from just two years prior. As the proportion of older adults living with unmet needs increases, so must researchers shift their emphasis in person-centred social care from one that leaves decision making to the devices of the consumer alone to one that fosters shared decision making with formal and informal carers.

### **Shared decision making in social care**

Formal and informal carers play an important role in the provision of social care, especially as an adult consumer begins to age. Formal carers are usually paid professionals who provide social care services on a routine basis (e.g., social workers, nurses, local authorities) who may or not be based in an institutional setting, such as a care home. On the other hand, informal carers are usually the next of kin, family members, relatives, friends or neighbours who are unpaid, and may or may not have prior experience with social care. Both formal and informal carers can share in decision making (e.g., prompt advance planning, scheduling daily activities) and/or contribute directly to a person's wellbeing (e.g., help with household chores, ensure consumer's personal hygiene).



**Formal carers.** To support the aims of person-centred social care, the Care Quality Commission (2017) recommended the following to service providers and professionals: (1) tailoring activities to individuals' likes and interests; (2) fostering supportive staff that actively encourage community engagement; and (3) arranging the environment to promote positive, learning and social experiences. The Shared Lives programme is one good example of how shared decision making between formal caregivers and public consumers can enhance the quality of social care. The Shared Lives programme manages about 11,600 individuals with social care needs (e.g., mental health, assisted living) and has grown by approximately 30% over the span of five years, from 2012 to 2016 (Shared Lives Plus 2017). The scheme matches adults with specific care needs to carers with the appropriate skill set, where 90% of users rated their experience as either 'good' or 'outstanding,' and none reported it as 'inadequate' (Care Quality Commission 2017).

Despite this, there is room for improvement on a national scale. The 2017 Adult Social Care Survey puts overall satisfaction among service users at 64.7 percent (NHS 2017). Only 67.6 percent reported having sufficient choice over the services they have received, while 6.3 percent did not want or need choice (NHS 2017). One confounding issue could be a poor distinction between having the autonomy to choose and having little to choose from (i.e., small choice set), which is known to vary by region (Care Quality Commission 2018). Another issue could be a general lack of awareness or understanding of how the social care system operates until a point of crisis in which options become significantly limited (Behavioural Insights Team 2017; Croucher 2008). The latter of the two issues is the focus of this paper. A more thorough examination of the factors that hinder or facilitate shared decision making may be critical for conceptualising the range of behavioural issues that affect person-centred social care.

**Informal carers.** Informal carers are usually close acquaintances who live in close proximity or share a close relationship with the consumer they care for. Informal carers tend to have shared lived experience, shared understanding of the situation, and shared expectations of the future, which make them highly knowledgeable about

the needs and preferences of those whom they care for (Sudore & Fried 2010). This puts informal carers in a good position to share in decision making as they can help older adults formulate their advance care directives or even serve as surrogate decision makers in end of life care (Song, Ward, Fine, Hanson, Lin, Hladik, et al. 2015; Mullick, Martin & Sallnow 2013).

Informal carers are also a source of relational support. Their presence is often influential in prompting early preparation and planning well before needs escalate, but not much is known about why or how such support may matter. For example, an interview study with 30 family members of patients with dementia to identify the barriers and facilitators of advance planning revealed that planning was mainly triggered by health, living, or financial issues related to a close one, whereas barriers to planning were typically due to ignorance or avoidance on the part of the patient alone (Hirschman, Kapo & Karlawish 2008). Likewise, a randomised trial involving 60 oncology patients and their family surrogates showed that dyads who underwent an advance care planning program were significantly more likely to have matching preferences than those who received standard care and information (Lyon, Jacobs, Briggs, Cheng & Wang 2013). Together, these studies illustrate the pivotal role supporting agents have in enabling person-centred care.

Finally, informal carers can help older adults directly with their personal care needs. According to the Department for Work and Pensions (2017), unpaid carers contribute about £57 billion worth of social care from 2016 to 2017. When adults reach the age of 50, women were likely to spend approximately 5.9 years, and males approximately 4.9 years of their remaining life as unpaid carers (Office for National Statistics 2017), suggesting that adults provide care for others even in the later part of their lives. Hence, on the whole, informal carers offer decisional, relational and direct support to help adult consumers with their social care needs.

Formal and informal carers are a pivotal component in person-centred social care. Notwithstanding economic factors such as variation in access and availability of high-quality social care providers, both types of carers provide the support and

means necessary for adult consumers to receive the care they need and want. Clearly, some these agents tend to bring different sources of expertise to decision making. Conceptualising these aspects may be useful for defining their unique roles in enabling person-centred social care.

**Figure 3** Expertise and activities in person-centred social care.

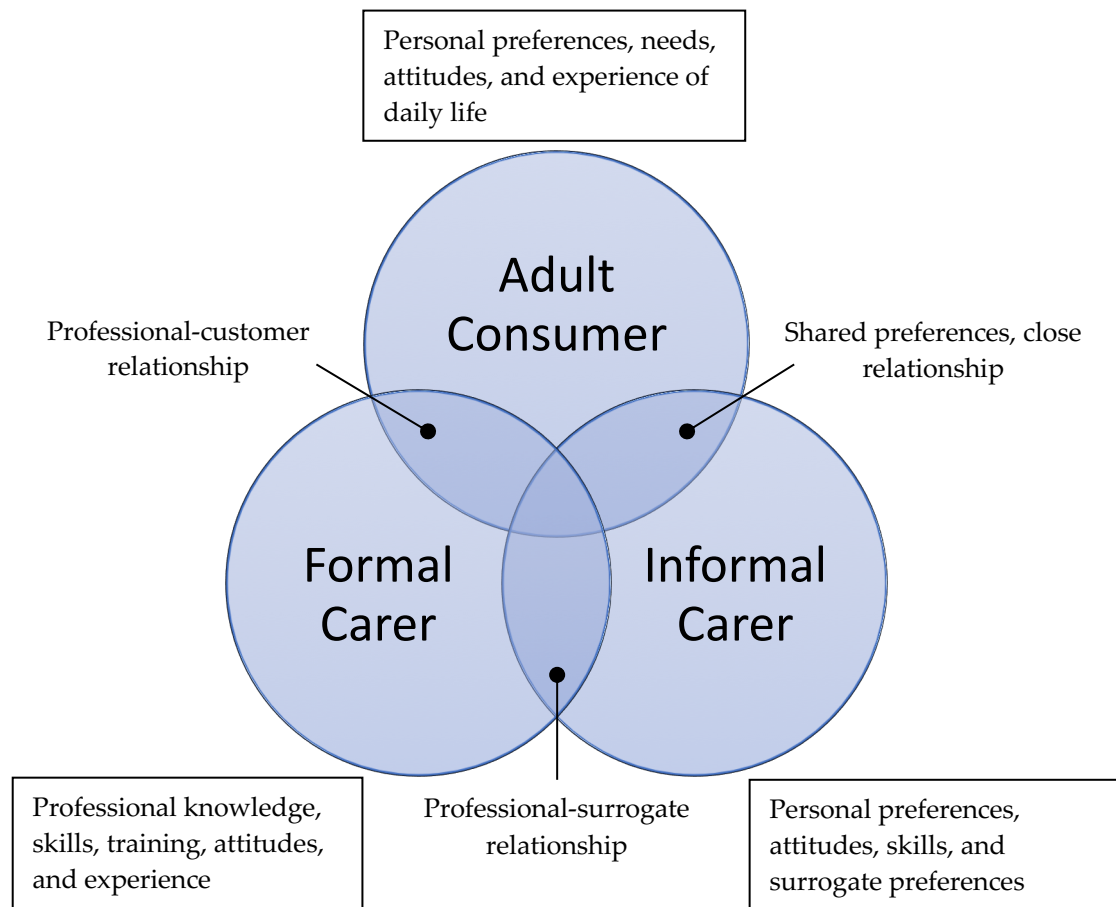


Figure 3 illustrates the different decision agents (in circles) and the types of expertise they have in shared decision making (in boxes). The overlaps between different agents represent the type of relationship they have with each other, with the heart of the Venn diagram being person-centred social care. For example, the adult consumer and informal carer will usually share a close and even familial relationship with one another, thereby allowing them to have relatively concordant preferences in decision making. The adult consumer and formal carer will typically have a formal financial contract between them where the needs of the consumer are fulfilled by the abilities

of the service provider. Some contractual relationships could develop into family-like bonds where mutual trust, understanding and commitment may replace the strict professional-customer relationship, but the first instance is often a customer engagement exercise. Formal and informal carers on the other hand, ensure continuity of care for the adult consumer. In situations where the adult consumer is no longer capable of making informed decisions, the informal carer will usually function as a surrogate decision maker in ensuring that those they care for continue to receive the care they wanted. The heart of the diagram implies that person-centred social care arises when all three parties work in concert to actively provide care and support to an adult consumer. It recognises that in some domains, such as mental health and dementia, specialist medical attention as well as relational support from families are necessary to provide care that is respectful and responsive to individuals' needs.

Planning and decision making about adult social care is often complex and challenging. Figure 3 acknowledges the different, but equally important roles adult consumers, formal carers and informal carers have in shared decision making. However, it does not explain the ways in which the process may help consumers plan, prepare and react to changing circumstances in ways that will allow them to meet their own care needs. To enrich understanding on the factors that hinder or facilitate person-centred social care, the following section reviews key concepts related to consumer decision making in the adult social care market. Since early engagement with the adult social care system is crucial for people to receive the care they want without unnecessary stress, this narrative review shall mainly focus on factors that affect advance care planning. In particular, it relies on the COM-B framework by Michie, van Stralen and West (2011) to identify capability, opportunity, motivation, and behaviour-related issues that promote person-centred social care. The COM-B framework has been used extensively to understand and develop strategies for changing behaviour in people (Michie, West, Sheals & Godinho 2018; Michie, Atkins & West 2014), and is thus a useful toolkit for analysing future policies concerning human behaviour.

## The COM-B framework

The COM-B framework recognises ‘behaviour,’ defined as person-centred decision making in the context of social care<sup>5</sup>, as a system comprising of multiple interacting components, namely ‘capability,’ ‘opportunity’ and ‘motivation.’ The COM-B framework is part of a much larger behaviour change wheel that contains a host of interventions for changing a target behaviour. Both of these have been used extensively in, for example, healthcare to promote healthy eating, physical activity, and smoking cessation in the general population (Michie, West, Sheals & Godinho 2018; Michie, Atkins & West 2014).

Using the COM-B framework to guide the narrative review led to the identification of 10 themes, each of which could affect person-centred decision making in different ways. As a result, these themes also represent areas in which shared decision making may strategically foster person-centred social care.

### Capability

Capability refers to a consumer’s own decisional capacity to engage in planning and decision making about their care needs. The 2005 Mental Capacity Act assumes that individuals have the capacity to decide for themselves, unless established otherwise<sup>6</sup> (Mullick, Martin & Sallnow 2013). Hence, this review shall mainly examine factors that affect person-centred and shared decision making well before consumers lose their mental capacity to decide their personal best interests.

**Knowledge.** Knowledge and awareness about the ways in which social care system operates is usually the first hurdle in getting people to consider their potential care needs. A focus group study into the public’s understanding of social care in the UK

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<sup>5</sup> A person-centred decision in social care can be defined as one that is: (1) made under relatively little stress; (2) informed; and (3) consistent with a consumer’s own preferences (See page 68).

<sup>6</sup> Consists of two tests: a diagnostic test to assess impairment or disturbance in cognitive functioning; and a functional test to determine if individuals can understand, retain, apply, weigh and communicate information related to a decision.

showed that many people do not know what it is, who is responsible for funding and providing it, or how to access it (Mattinson & Knox 2015). A supporting study by the Behavioural Insights Team's research into the care home market showed that people often confuse health and social care, consult their physician instead of their local authority about social care, and feel surprised by the need to pay for their social care needs (Behavioural Insights Team 2017). Some hints of poor public knowledge and experience with the social care system is also evident in the recent 2018 British Social Attitudes (BSA) survey (NatCen Social Research 2019). The BSA survey, which recruited a nationally representative sample of 2926 people between July and October 2018, asked about satisfaction with health and social care, and found a fairly high proportion of 'don't knows' and 'neither satisfied not dissatisfied' related to social care (9% and 31% respectively), compared to GPs (<1% and 13%) and outpatient services (3% and 15%) (NatCen Social Research 2019). This points to a possible problem with participants in forming an opinion about social care.

Government bodies, local authorities and service providers could make people more aware of their entitlement to social care through shared decision making. Educational programmes that provide information and advice to select groups of adults could be one effective means for promoting person-centred decision making in social care. For example, Detering et al. (2010) studied the effects of promoting advance planning on end of life care by randomising 309 legally competent medical inpatients, aged 80 and above, to either a control group (n=155) that underwent usual care or an intervention group (n=154) that received usual care plus information and support about advance planning. After six months, the researchers found that among the patients who had passed away, those randomised to the intervention group were significantly more likely to receive the end of life care they wanted than those in the control group.

In addition, making advance planning seminars available to the public could help individuals understand the importance of preparing ahead of time. Studies show that individuals who attend financial preparation seminars tend to develop a more favourable attitude towards retirement, acquire more knowledge on basic financial planning, engage in financial preparation (Adams & Rau 2011) and contribute more

to their own retirement funding (Bayer, Bernheim & Scholz 1996). Information and advice are thus important components in shared decision making. Sharing more of these may not improve the public's knowledge about planning, but also drive up their commitment towards such actions, thereby increasing the likelihood of having the care they want.

**Competency.** Current social care policy stresses improving public welfare and the efficacy of social care services by encouraging informed consumer decision making. At the same time, planning and decision making about social care involves uncertainty, and many consumers are ill-prepared to understand complex information, manage their care needs, and make rational decisions (Peters, Hibbard, Slovic & Dieckmann 2007).

Literacy, the ability to read, write and understand information, and numeracy, the ability to comprehend and apply numerical concepts, are necessary for forming objective assessments in decision making (Protheroe, Nutbeam & Rowlands 2009; Montori & Rothman 2005). Research across several countries, including the US, Netherlands and Germany, have found that a basic understanding on the principles of saving (e.g., simple versus compound interest) has a direct effect on financial planning and preparation for later life (van Rooij, Lusardi & Alessie 2011; Bucher-Koenen & Lusardi 2011; Lusardi & Mitchell 2014). Closer to social care, a large survey of 784 adults aged 55 to 74 from the Chicago area showed that participants with low literacy had 0.45 times the risk of having an advance directive compared to those with high literacy (Waite, Federman, McCarthy, Sudore, Curtis, Baker, et al. 2013). Put differently, adults with poor literacy were very unlikely to engage in advance planning. An implication of this is that adults with poorer decisional competencies are more at risk of being 'left behind' by recent policy changes.

A competence gap means that certain groups of individuals may require more support in making person-centred decisions in social care, which highlights the relevance of shared decision making. In particular, carers could address this gap by communicating information in ways that are suited to the consumer's level of

competency (McCaffery, Smith & Wolf 2010; McCaffery, Holmes-Rovner, Smith, Rovner, Nutbeam, Clayman, et al. 2013). Carers could use non-technical language, absolute numbers instead of percentages, and graphical diagrams instead of text. Furthermore, clear and concise tables may facilitate comparison between different options with multiple attributes (Elwyn et al. 2013). This suggests that the ways in which third parties share information with consumers may be an influential determinant of social care quality. Despite this, more knowledge is necessary to understand the current state of literacy and numeracy among the general UK population, and if such competencies affect shared decision making in different ways, like desire for involvement, gains in knowledge, and health outcomes. Future research into key competencies of social care decision making may provide further insights into the ways in which they influence consumer behaviour and public welfare.

## **Opportunity**

Opportunity refers to factors beyond the direct control of the consumer that may prompt or make the behaviour possible. The opportunity, or lack thereof, to make a person-centred decision will usually rise and fall depending on the context.

**Health.** Ageing brings significant changes to a person's health status and care needs. It affects both sensory (e.g., vision, hearing, and smell) and physical functions (e.g., motor ability), all of which may progress differently depending on a person's medical condition (e.g., diabetes, dementia) and lifestyle (e.g., exercise, diet, tobacco and alcohol use).

Yet, a consumer's entry and journey through social care does not always unfold in a predetermined manner. For some, the need to make home adaptations to maintain independence may arise when people fear or suffer minor mobility issues. Consumers in these situations are arguably in a good position to make a person-centred decision about their potential care needs. They are legally competent to make their own choices and are in a relatively low-stress state. Consequently, third parties may have little role or say in shared decision making other than to encourage



consumers to consider advance planning. For example, close friends and family members may notice subtle changes in health much earlier than the main consumer would otherwise (Which? 2018) and be able to prompt planning and decision making before care needs begin to escalate dramatically.

Some consumers begin planning when they feel or are told that they might be losing their decisional capacity (e.g., dementia) (Mullick, Martin & Sallnow 2013), or when they start to suffer major mobility issues that hinder instrumental daily activities, such as cooking, showering, and housekeeping (Croucher 2008). As consumers age and experience age-related changes, they typically experience some anxiety about their ability to guarantee their personal wellbeing (Steptoe, Deaton & Stone 2015). Shared decision making becomes increasingly relevant to the consumer for several reasons. Firstly, declines in mental and motor functioning increases consumers' dependence on others to manage their personal care needs. Shared decision making enables carers to learn and respect consumers' preferences before they lose their ability to make reasonable choices. Secondly, shared decision making allows others to source for information that will help consumers meet their care needs. An interview study with family carers of 34 older adults who had been admitted to a UK hospital for mental health-related issues revealed the carer's involvement in decision making, in which they actively gathered information, consulted patients about their preferences, and communicated with healthcare professionals about treatment plans to help patients get the care they want (Clissett, Porock, Harwood & Gladman 2013). Thirdly, shared decision making helps to establish a partnership built on trust and understanding between consumers and their carers. This bond gives consumers the necessary confidence and emotional support to confront challenges related to their own care needs (Smith, Juraskova, Butow, Miguel, Lopez, Chang, et al. 2011).

Finally, there are adults who react to unplanned emergencies (e.g., falls). These are among the most complex and challenging forms of entry into the social care system in which consumers will usually have significantly limited time to consider all information and choices in full, or be in calm and composed state of mind to make any rational decision at all (Behavioural Insights Team 2017). In crises, shared

decision making has the greatest potential to enable person-centred social care. Under significant stress and pressure, carers provide crucial informational and emotional support that consumers need to make proper decisions. In addition, carers can deliver care directly by making changes to their home (e.g., installing non-slip mats in the bathroom), lifestyle (e.g., moving in together) and personal finances. For instance, the UK government provides financial allowance to carers supporting someone with disability benefits, if they meet certain conditions, including looking after a disabled person for at least 35 hours a week (Carers UK 2014). In cases of mental incapacitation, consumers may not even have an opportunity to express their preferences and their next of kin is usually their medical proxy. Shared decision making then becomes a professional-surrogate relationship in which a medical proxy would have to make assumptions of the consumer's best interests in delivering person-centred care (Detering, Hancock, Reade & Silvester 2010; Lyon, Jacobs, Briggs, Cheng & Wang 2013).

Overall, it can be said that while good health gives consumers ample time to plan, prepare and even prevent mishaps, poor health generally compels one to satisfy their most immediate care needs with little real choice and freedom to get what they want. The fact that a growing proportion of older adults living are living with unmet needs (Age UK 2018a) seems to suggest that the latter is the more likely and prevalent scenario in society.

**Access and availability of resources.** Recent changes to the 2014 Care Act mean that local authorities are now largely responsible for the provision of information and choice to local residents (Department of Health and Social Care 2014a). This can have a direct influence on consumers' level of awareness and intention to interact with the social care system, such as finding more about what it is, how it works, and the available care options around them. Another implication of decentralisation is that quality and outcomes in social care have become geographically bounded. The Care Quality Commission's 2018 report on the state of health and social care in England attributed variation in the access and availability of services to fragmented organisation, funding and provision of care services (Care Quality Commission

2018). Some consumers living in rural locations had poor transport links and long commutes to make to get the services they wanted, whereas those living in urban regions often enjoyed different forms of services depending on which parts of the city they lived in. For example, about 56% of mental health patients living in London were allocated to a specialist within 50km from their homes, compared to just 7% for patients living in the Midlands (Care Quality Commission 2018). Clearly, the opportunity for consumers to get the services they need or want is largely driven by fiscal policy-related measures (e.g., financial and funding structure, supply management, social care workforce) rather than psychological factors. Consequently, shared decision making has little direct impact on the quality of person-centred social care, especially when the supply of care services is limited to begin with.

## **Motivation**

Motivation is about the processes that energise and direct behaviour.

**Goal clarity.** Planning for a potential decline in health is a challenging and unpleasant process (Croucher 2008). Such thoughts can trigger strong aversive feelings in people and put them off from considering them in the first place (Gross & Levenson 1997). For example, some consumers regard home adaptations, like handrails and ramps, as an attempt to medicalise their own home (Powell, Mackintosh, Bird, Ige, Garrett & Roys 2017). Others tend to regard such changes as an indication that 'help is needed' and therefore, represents a threat to their own self-esteem and dignity (Which? 2018). Because these attitudes and perceptions can be off-putting, having sufficient goal clarity or intention to overcome these negative stereotypes is often necessary for people to consider their potential care needs.

Individuals with a clear intention about what they want are more likely to overcome any psychological barriers and take necessary steps to achieve those ends (Sniehotta, Scholz & Schwarzer 2005). Intention is a motivation to enact a behaviour and an antecedent in many socio-cognitive theories linking behavioural intention and action, including theory of planned behaviour (Ajzen 1991) and protection motivation theory (Maddux & Rogers 1983).

Studies have shown that individuals with a clear goal, a future time perspective (i.e., preference for the long-term view as opposed to focusing on the past or present), and a long-term planning orientation tend to prepare their future finances and contribute more towards their retirement (Jacobs-Lawson & Hershey 2005; Stawski, Hershey & Jacobs-Lawson 2007). Jacobs-Lawson and Hershey (2005) investigated the psychological determinants of retirement planning among 270 middle-aged (M=36.2) working Americans, stratified by geographical region. The researchers found that individuals' knowledge of retirement planning, future time perspective, and financial risk tolerance influenced retirement saving behaviour.<sup>7</sup> These variables interacted with one another, which suggests that goal clarity may be one of several systems (i.e., knowledge and risk preferences) motivating early engagement with the care system. To increase the efficacy of delivering person-centred social care, information and advice (via shared decision making) should target groups of consumers differentially based on these variables. Put differently, given that consumers can be motivated to make advance care plans, carers and the government have a moral responsibility to provide tailored support based on each consumer's traits and competencies, rather than release more information simply because it is necessary for informed decisions. Only then can governments achieve equitable promotion of person-centred social care.

**Time pressure.** Significant time pressure can hamper effective decision making in people. Time pressure is especially relevant in the social care market where decisions are often reactive as opposed to being part of a meticulous plan (Which? 2018; Behavioural Insights Team 2017). In most cases, individuals will come under immense stress and pressure to decide quickly, which limits their ability to consider all available information in determining a proper option (Evans 2008; Kahneman 2011). According to Croucher's (2008) report, a study commissioned by the Communities and Local Government about housing in an ageing society, residents

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<sup>7</sup> 5 items measured on a seven-point Likert scale (1 = strongly disagree, 7 = strongly agree). Items included 'made meaningful contributions to a voluntary retirement savings plan' and 'made a conscious effort to save for retirement.'

can only submit a request for a local authority-funded home adaptation when they develop a need for it, which may eventually arrive too late to be of much use (e.g., 12 months for a stair lift). Hence, the way in which social care is operationalised may explain why people are relatively reactive to their social care needs.

An absence of cognitive load (i.e., stress and pressure) is generally more conducive for rational decision making (Kahneman 2011; Kahneman & Tversky 1982). However, a perceived lack of urgency can similarly demotivate people from advance planning. Researchers explain that people typically discount the importance or value of future choices at different rates, depending on age, self-control, and cost of time spent waiting (Read & Read 2004; Loewenstein, Read & Baumeister 2003; Benzion, Rapoport & Yagil 1989). Hershfield (2011) attributed this discounting behaviour to a lack of physiological connection to a person's future self in which participants placed in a future state or condition, through imagination or simulation, tended to allocate more of their current money to their savings account. While this points to intertemporal decision making as being an individually motivated process, some recent works have begun to explore the influence of others on this. This includes the second (e.g., informal and formal carers) and third parties (e.g., governments and organisations).

Accepting small short-term costs in exchange for larger long-term gains is difficult but predictive of many important life outcomes, including retirement savings and physical wellbeing (Schlam, Wilson, Shoda, Mischel & Ayduk 2013; Laibson, Repetto, Tobacman, Hall, Gale & Akerlof 1998). Yet, delaying gratification also depends on individuals' trust in people to deliver those rewards, especially in shared decision making about potential care needs. Michaelson et al. (2013) investigated the causal role of social trust in delaying gratification and showed that across two experiments, participants (n=250) were less likely to wait for delayed rewards from less reliable personas and perceived trustworthiness predicted the extent to which participants delayed gratification. Consumers' trust in the social care system or carers may therefore affect their own predisposition to plan ahead of time.

Indeed, a study by Henning-Smith and Shippee (2015) appears to highlight individuals' trust in others to provide care for them. In Henning-Smith and Shippee's (2015) analysis of the 2012 National Health Interview Survey conducted in the US, expectations about future care needs and support among adult participants varied by current living arrangement, such that those living with young children were least likely to expect any form of long-term care or support, whereas those living alone felt like they were the most likely to need some form of help in future. This proves that social trust may be a critical dimension in advance planning; consumer beliefs in the ability of their social support network may influence one's motivation to prepare for potential age-related changes. This simultaneously highlights the potential for carers and shared decision making to enable person-centred social care. More empirical studies comparing the met and unmet needs of households with varying living arrangements, and qualitative research on why such patterns of behaviour exists may elucidate the main factors that make shared decision making an attractive model for public consumers in the UK.

**Familiarity.** The performance of certain everyday tasks can become so routine and repetitive that they require little or no conscious effort to execute. Over time, individuals may develop a mental script on how to execute them (e.g., daily commute to the local community centre), and mental schemas for categorizing, comprehending and generalizing issues (e.g., residents from this neighbourhood are nicer) (Reyna & Brainerd 1995). Familiarity may also explain why people overwhelmingly prefer to stay comfortably at home and adjust if need be (e.g., making adaptations), rather than move into other types of sheltered care (Behavioural Insights Team 2017). This also hints at the relatively limited role carers and shared decision making have in influencing familiar consumer activities.

On the other hand, individuals are likely to find the management of novel tasks, such as navigating the complex social care system for the first time, to be especially daunting and challenging. Studies have shown that individuals, especially those older in age, tend to find new technology complicated to learn and use (Nikou 2015; Venkatesh, Thong & Xu 2012). Since learning requires controlled, deliberative

processes where prior knowledge is unlikely to help in a unique task or situation (Johnson & Russo 1984; Wood & Lynch 2002), individuals with lower decision making capacity, competence and motivation may shun complex but necessary matters (e.g., deciding on a care home, getting a mobility aid). Unfamiliar and cognitively-demanding tasks present shared decision making with the unique opportunity to enable person-centred social care. For instance, consistent reports have shown that while social care services may be available in the area, lay consumers do not always know where to go to access them and even if they did, most found the process complicated and confusing (Behavioural Insights Team 2017; Care Quality Commission 2017). More recently, general practitioners and other frontline staff have begun a form of social prescribing in which healthcare professionals would recommend consumers to community services instead of offering only medicalised options (The King's Fund 2017). Social prescribing is an example of how shared decision making can help consumers overcome learning difficulties associated with unfamiliar situations, whilst fostering person-centred outcomes.

In addition, carers can familiarise consumers with the social care system well before care needs develop and alludes to the impact of shared decision making at an earlier stage in life. Webley and Nyhus (2006) investigated the transfer of economic challenges and decisions from one generation to the next by using a Dutch panel survey to compare the attitudes and behaviours of parents with children aged 16 to 21. In their analysis of 1038 individuals, in years 1997, 1998 and 1999, parental approach (e.g., discussing financial issues with children, having a future orientation) to economic issues had a significant influence on children's economic behaviour as well as their economic behaviour in adulthood (Webley & Nyhus 2006). This casts a potentially much larger role for shared decision making to have in social care. Not only does it foster person-centred decision making in unfamiliar situations, shared decision making may also directly shape consumers' exposure, experience and hence, familiarity about the social care system. Carers are therefore a fundamental part of person-centred social care. They provide information and relational support as well as shape the ways in which consumer decision making unfolds, with implications on

when they plan for their care needs and how concordant those options are with their personal preferences.

## **Behaviour**

Behaviour is the amalgamation of capability, opportunity and motivation. In this review on social care, behaviour is defined as a rational decision making process that accounts for consumers' preferences and values. However, because individuals have limited cognitive capacity and attention (Simon 1955; Tversky & Kahneman 1981; Kahneman 2011), several behavioural factors can influence how "rationally" decision making unfolds and knowing more about them will help researchers understand their impact on person-centred social care.

**Cognitive biases.** Researchers have documented a host of biases that affect rational judgment and decision making (Mellers, Schwartz & Cooke 1998) in health care (Blumenthal-Barby & Krieger 2015) and social care (Baicker, Congdon & Mullainathan 2012). Individuals' preferences are usually reference dependent and averse to losses in that there is a common and greater motivation to avoid losses than to secure the same amount of gains (Kahneman & Tversky 1979). For example, consumers in good health may value future losses to illnesses and ageing much more than those who are currently in poor health, thereby predisposing the former to take more precautionary measures, including searching for information and getting a health insurance (Winter, Moss & Hoffman 2009). Similarly, an optimism bias may cause people to underestimate the probability of an adverse event. Older adults may perceive their odds of tripping and needing emergency attention as significantly lower than what objective data may suggest, and which may explain why there is a general reluctance among older adults to move into care homes (Behavioural Insights Team 2017). Such biases can affect objective assessments of care needs and hamper advance planning.

Furthermore, ageing appears to trigger negative stereotypes in people (Dionigi 2015). Ageing stereotypes in Western cultures are primarily negative, depicting later life as a period of ill health, loneliness, and mental and physical decline (Dionigi 2015). One



theory posits that people find ageing a threatening process (Scholl & Sabat 2008). Auman and associates (2005) investigated the relationship between ageing-related stereotypes and anxiety and cardiovascular reactivity by using a mixture of self-reported and physiological measures. In a sample of 122 patients, each randomised to either receive health-related primes (e.g., sickness, helplessness, dependence) or leisure-related primes (e.g., leisure activities), those in the health condition reported significantly higher levels of anxiety and blood pressure than those in the leisure condition. In explaining this phenomenon, Auman et al. (2005) argued that ageing triggers fears of frailty and illness, which discourages people from seeking medical attention before needs begin to develop. Similarly, Levy and colleagues (2000) studied whether stereotypes of ageing might affect decisions about when to die by recruiting a sample of 64 participants, evenly split between old adults (n=22, aged 74 years) and young adults (n=22, aged 25 years). They found that old participants exposed to negative stereotypes frequently declined life-prolonging procedures, while old participants exposed to positive stereotypes often accepted them. No such effect was observed in young adults, which suggests that negative stereotypes about ageing may be particularly detrimental to the health and social care of the elderly.

**Overload.** Research has shown that excessive amounts of information can often overwhelm and deter people from having to decide at all (Jacoby 1984), and even if they do make a decision, many will end up making less optimal choices than if they had lesser information to begin with (Eppler & Mengis 2004; O'Reilly 1980). This paradox, where excessive information paralyses decision making, is known as information overload (Jacoby 1984). Information overload may be particularly disruptive for consumers as they begin to age and lose cognitive capacity (Mata & Nunes 2010; Besedeş, Deck, Sarangi & Shor 2012). Older adults tend to consider fewer pieces of information before making a decision, pay more attention to positive material rather than negative material (Shamaskin, Mikels & Reed 2010), and rely on simpler decision making strategies that may lead to poorer outcomes (e.g., choosing less profitable stocks) (Mata & Nunes 2010). A pure informational approach puts older consumers in an exceptionally vulnerable position. Conversely, shared decision

making may be a useful approach for compensating such declines in mental functioning.

Likewise, having more to choose from is not always better. Individuals confronting two or more options often feel ambivalent about their choices. Research suggest that individuals encountering a large assortment of options are usually less satisfied and less likely to make a choice at all, than those with a smaller choice set (Botti & Iyengar 2006; Iyengar & Lepper 2000; Schwartz et al. 2002)—a phenomenon known as choice overload (Schwartz 2004). A King's Fund report about social care in the UK pointed out that large arrays of care options tend to sow confusion, anxiety and distress in people (Umali, Case & Miller 2016). In the US, a roll out of more than forty Medicare coverage plans reportedly overwhelmed people. Few senior US residents found such "choice" helpful and a majority (about 73%) felt that these plans were "difficult and confusing" to understand (Kaiser Family Foundation 2006). In a more telling experiment of the dangers of choice overload, Hanoch et al. (2009) recruited 192 healthy participants from California, half aged 18 and older, and half aged 65 or older, and randomised assigned them to one of three conditions containing 3, 10 or 20 hypothetical drug plans. The researchers found that old age and a bigger choice set were responsible for fewer correct answers (i.e., deciding on a plan that minimised total annual cost), which raises questions about the ability of older consumers to navigate the wide variety of social care options available in the UK.

**Emotion.** Emotion has cognitive and motivational properties when it comes to good planning and decision making about potential care needs.

*Affective forecasting.* Decisions that impact quality of life outcomes usually requires one to make critical assumptions about how well they can adapt to living with declining health and physical functioning (Winter, Moss & Hoffman 2009). However, people are generally poor at predicting their future emotional state and their ability to overcome adversity, a phenomenon known as affective forecasting (Gilbert, Pinel, Wilson, Blumberg & Wheatley 1998; Gilbert & Ebert 2002). For example, people usually focus on what will change or deteriorate (e.g., growing frail

and dying) rather than on what will stay the same (e.g., ageing is a natural process) or even improve (e.g., more personal time and freedom). Similarly, people often worry that home adaptations would devalue their home (Croucher 2008), even when most prefer to stay than move away anyway (Behavioural Insights Team 2017).

*Hot-cold empathy gap.* People are generally poor at predicting their ability to control visceral forces (e.g., anxiety, anger, hunger, pain) that may influence behaviour and preferences (Loewenstein 1996; Nordgren, van der Pligt & van Harreveld 2008; Ariely 2010), especially when such feelings transcend “hot-cold” emotional states (Loewenstein 2005). According to Loewenstein (2005), people in a ‘cold’ state often fail to fully and accurately appreciate how ‘hot’ states will affect their behaviour and preferences, whereas people in a ‘hot’ state tend to overestimate their ability to manage and control such influences. In the care sector, physical discomfort (e.g., pain), accidents, and emotionally-charged states (e.g., distress) can predispose people to make impulsive decisions (Loewenstein 1996; Van Boven & Loewenstein 2003; Ariely 2010) which they may come to regret later (Zeelenberg & Pieters 2007; Zeelenberg & Beattie 1997). Conversely, planning usually happens in a ‘cold’ state and consumers may delay critical decisions, such as checking out possible care homes and making necessary living arrangements, thinking that they can cope with crises as they come (Croucher 2008). As such, finding ways to bridge the “hot-cold” empathy gap may be instrumental for motivating planning and decision making in social care.

**Facilitating shared decision making.** The bounded rational nature of decision making has major implications for person-centred social care as well as shared decision making. For one, even if consumers had the capability, opportunity and motivation to make decisions about their social care, decision making is usually susceptible to a range of behavioural influences that can hamper or worse, paralyze consumers from making person-centred decisions. This alludes to the importance of shared decision making or rather, the ways in which information and choice could be better presented to consumers. Governments, organisations and carers could leverage on modern information technologies to make information more accessible

to consumers. A review, commissioned by the Agency for Healthcare Research and Quality Effective Health Care Program in the US, examined the use of decision aids for adult advance care planning from the years 1990 to 2014 (Butler, Ratner, McCreedy, Shippee & Kane 2014). The review found that while most studies reported improvements to consumers' clarity of preferences, decision knowledge, and decision confidence, the decision aids found in these interventions tended to differ in terms of format, layout, interactivity as well as proprietary (i.e., whether public consumers have access to such interface). Given the demonstrable benefits of decision aids, third parties could leverage on modern information technology to make information more accessible, comprehensible and customisable (e.g., adding filters for information and choice) to the general masses. This would allow consumers to manage their own cognitive load, based on individual comfort and needs, and through this improve the odds of informed decisions.

In addition, governments and organisations could maximise ease of comparison by mandating the structure and content of decision aids. A quick search on the Internet about the available social care services and most consumers will find such information difficult to extract and apply consistently across different providers. Information about specialist care services, facilities, quality and performance, as well as costs are usually difficult to find or hidden completely from consumers (NHS England 2015). Using a straightforward and standardised format may promote informed decisions. Samanez-Larkin, Wagner, and Knutson (2011) studied the impact of ageing on financial decision making by using neuroimaging techniques. The researchers found that using a simplified format to present critical information reduced the effects of distracting information on participants' decision quality (i.e., optimal financial risk taking), even for those older in age. Research indicate that older adults adapt well to information technology. Information transparency and standardisation are thus key dimensions in person-centred social care and more must be done to foster such practices with existing providers.

Another possibility for shared decision making to promote person-centred social care is through the creation of dedicated services to help consumers navigate the system.

In the UK, several local authorities have developed single points of access which are operated by a team of specialists whom are familiar with the available resources around the region, and are able to assess and match consumers to the most appropriate service, based on needs and preferences (NHS Improvement 2019). Likewise, several NHS trusts have developed coordinator roles, also known as community connectors or care navigators, to refer eligible patients to other forms of community support and services that may better meet their needs (Care Quality Commission 2018). These examples lend support to the growing role carers have in encouraging person-centred social care and thus calls on the government to better recognize and support the expansion of such positions in the existing social care system.

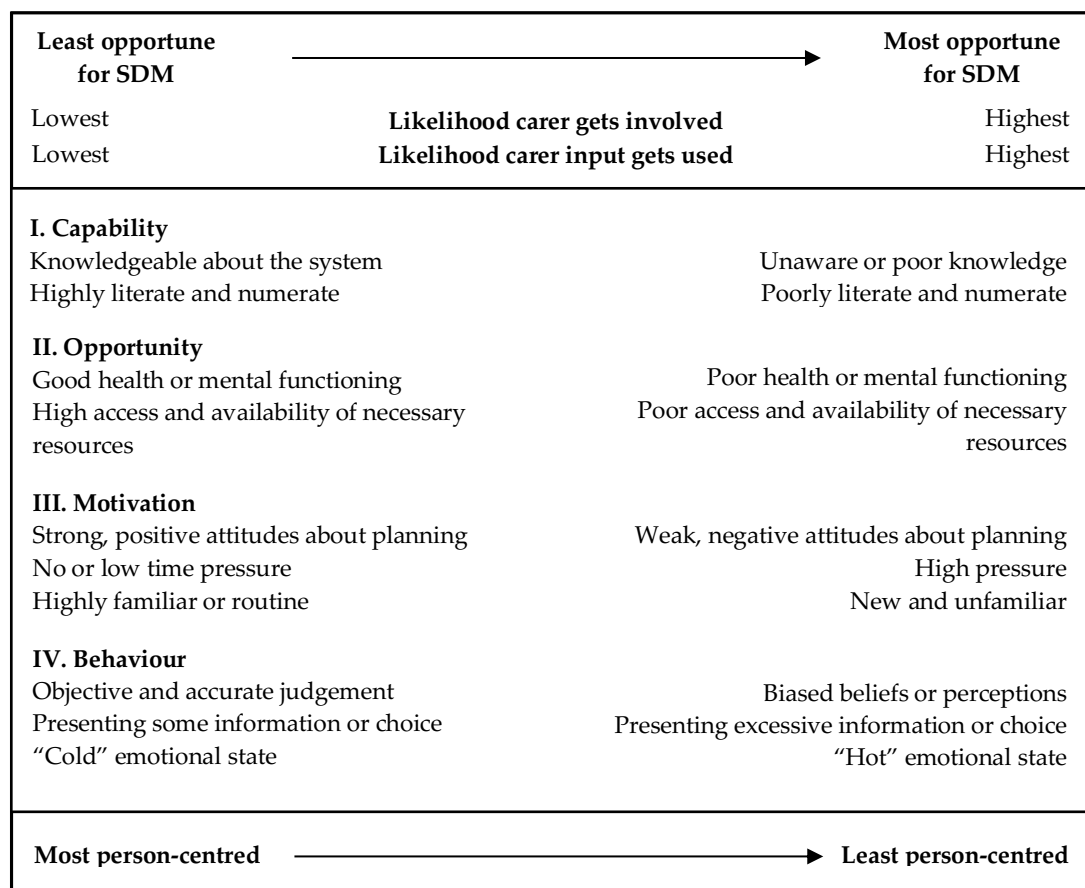
## **Discussion**

Advance planning and informed decision making can help consumers get the care they want well before the onset of a crisis or health decline that impairs their ability to make person-centred decisions. Yet, getting consumers to seriously consider their future care needs is a complex and massive undertaking. It will usually require them to have the necessary capability, opportunity, and motivation for considering such matters. Even then, consumers are subjected to a host of cognitive and affective biases that may undermine rational decision making. For these reasons, shared decision making presents policymakers, caregivers, and consumers with an attractive framework for enacting person-centred social care. As this review finds, informal and formal carers bring precious informational, emotional, and relational value to an otherwise dull and stressful process. Their involvement in decision making nearly always has a positive effect on consumers' ability to make care decisions that are informed and person-centred. However, the impact of shared decision making will likely depend on the consumer's ability to make person-centred decisions at that point in time.

### **Impact model of shared decision making**

Figure 4 conceptualises person-centred social care as a function of shared decision making and its main antecedents. In other words, a consumer's capability, opportunity, motivation, and behaviour affects the likelihood in which shared decision making is necessary to produce person-centred outcomes. The impact model points to some inherent tensions in the present social care system. Conditions that are most beneficial for person-centred social care are also ones that make shared decision making less attractive. Conversely, as a person ages and begins to develop care needs, shared decision making becomes an increasingly important means for enabling respectful and responsive care. As such, how rapidly consumers transition from one extreme to the other is another important dimension of the model.

**Figure 4** Impact of shared decision making (SDM) on person-centred social care.



An impact model of shared decision making recognises person-centred social care as a complex and dynamic process involving multiple factors that may change over

time. The UK government's aim of empowering individuals through more information and choice overlooks how consumers can be encouraged through the decision making process itself, which this review found requires ample decisional and relational support to overcome a range of behavioural barriers. While this implies that efforts to promote quality social care should be broad and multi-pronged, there is little evidence to indicate what or which aspects deserve more attention. Further research combining the use of interviews, focus groups, surveys, and census data could help in the identification of these factors. Even then, researchers will need to weight the benefits against the costs of each intervention as some aspects (e.g., familiarising older adults with the system) may require large and continuous commitment to improve outcomes in social care.

### **Additional moderators**

This review has surfaced several possible moderators of person-centred social care. For example, Western views of ageing are primarily negative (see Cognitive Biases), whereas Asian cultures tend to associate it with more positive concepts such as being health, wealthy and wise (Dionigi 2015). Culture may therefore be a strong psychological barrier in impeding advance planning among Western societies, including those living in the UK. By implication, Asian households may be more open to planning and be financially prepared for their future care needs. More analysis based on census data could reveal important insights on whether such differences exist in the population and if they contribute to health inequalities, like unmet care needs.

Furthermore, several factors allude to the role of perceived psychological safety in motivating advance planning. For example, health deterioration, distrust in family members, and emotional distress may threaten consumers' perceived sense of safety and motivate them to take precautionary measures. Relatedly, emotion regulation may be another important factor in modulating consumers' responses to perceived threats to their wellbeing. Many issues in social care can trigger negative and aversive feelings in people. Studies suggest that individuals who regulate their emotions often

perform better in decision making tasks in that they are able to make more optimal decisions. Consequently, consumers with this proficiency stand to gain most from person-centred social care; they are not only better equipped to make informed decisions, but are also more capable of doing so in times of uncertainty and duress, which makes them a particularly resilient group.

Each of these moderators offer researchers a new avenue to understand the relationship and inter-relationships different behavioural factors have with one another. More empirical data on these issues is necessary for advancing knowledge on consumer behaviour in social care. Only then can governments and organisations administer targeted and meaningful interventions to promote person-centredness in social care.

### **Social support network**

To achieve person-centred social care, this review has advocated for consumers to share decision making with carers whom are at least equally, if not more rational than the consumer of concern. The quality of social care is thus contingent on the consumer as well the carer's ability to share in decision making. However, the assumption that carers are necessarily more capable or that their involvement leads to improved care outcomes deserves further scrutiny.

For one, bounded rationality implies that carers themselves are subject to the limits of their own cognitive capacity. For example, local authorities usually have trained, qualified and experienced care professionals whose duty is to promote the health and wellbeing of consumers living within a community. Nonetheless, the Care Quality Commission (2018) noted that even professionals working in an area were not always aware about the services available to make referrals in an appropriate and prompt manner. Furthermore, carers and consumers are subject to the effects of groupthink, a dysfunctional behavioural phenomenon in which a group fails to make decisions in a rational manner (Janis 1972). Stoner (1968) found that group decision making frequently led to riskier options than if individuals were to do them independently, prior to discussion, a behaviour that has been repeatedly observed in samples of



different nationalities, ages and sizes (Bateson 1966; Rim 1964; Wallach, Kogan & Bem 1962). This raises questions on whether care professionals are adequately equipped to provide person-centred services and if they should receive specific training on shared decision making.

In addition, socio-cultural factors like the size of families, family norms, family preferences for certain types of care may influence the consumer-centred nature of social care. A comparative study about family carers in six countries, including Germany, Sweden, Greece, Italy, Poland, and the UK, revealed substantial differences in attitudes towards different types of support (Lamura, Dohner & Kofahl 2008). In response to whether information and advice on available help and support services was important to them, 76.6% of UK respondents (n=988) compared to the six-country average of 67.0% (n=5901) claimed that it was necessary. In response to whether help with planning future care was important to them, 60.2% of UK respondents (n=974) compared to the six-country average of 45.5% (n=5869) stated that it was necessary. These findings have ramifications for the organisation of social care. Firstly, UK family carers expect to play an active decision making role in social care and perhaps even more than other European immigrants based in the UK. Secondly, informal carers are important partners in the delivery of social care, though they (as well as consumers) typically have limited influence on the structure or management of care once it is selected. To the extent that formal and informal carers are fundamental for person-centred social care, more research on providing continuous and responsive care may be crucial for understanding how consumers' needs can be actively managed, rather than simply met at the initial phase of consideration (i.e., finding a suitable care service or option).

These issues hint at the possibility that carers, who are crucial for shared decision making, may require their own assessment of COM-B in conceptualising their involvement in person-centred social care. Future research on these aspects may aid in the development of a framework for assessing and improving the quality of carers.

## **Policymaking**

The common rhetoric of giving people more information, more choice and more autonomy in person-centred social care hinges on two assumptions: (1) people know what they want; and (2) people have complete attention and willingness to engage in decision making. Yet, this does not happen with a majority of people as they are bounded rational (Simon 1959; Gigerenzer & Selten 2001; Kahneman 2011; Kahneman & Tversky 1982). For person-centred social care to arise, policymakers and practitioners must take a more proactive stance in helping people overcome the behavioural barriers that impede rational decision making in the first instance.

This paper puts forward a new framework for policy analysis regarding human behaviour. Thus far, most works relying on the COM-B framework have focused on health promotion and behaviour change, without much consideration of the socio-technical aspects involved in decision making. In the case of social care, this is usually a multi-variate problem wherein consumer preferences are contingent on the situation and on beliefs (or misbeliefs) about whether they could be cared for. The latter has special relevance for carers and local authorities, and also introduces a new social dimension into the current COM-B framework. In so doing, this review provides a novel illustration of how COM-B might work in dyadic setting, rather than the more common individual-centred approach to behaviour analysis.

For policymakers, the COM-B framework offers insights into the psychological reactions and factors that shape the effectiveness of policy interventions, especially those concerning human behaviour. This applies to public individuals, businessmen and even civil servants. For example, the UK's Department of Work and Pensions (2018, p.26) has rolled out a program in 254 jobcentres to "provide personalised employment advice and use their knowledge of the local labour markets to match unemployed claimants to suitable job vacancies." The aim was to help claimants overcome barriers, encourage them to begin work, and support their progression at work, aspects where this review may inform policymaking and intervention development. More broadly, the COM-B framework sheds light on the behavioural factors that exist at the citizen-system interface and is thus, a useful addition to the public administration literature. Future research combining the political sciences

with the behavioural sciences may foster evidence-based policymaking and produce more effective interventions.

## **Limitations**

There are some limitations to this paper. Firstly, the narrative review is not based on a systematic search of any specific literature, which makes replication and updating difficult. To mitigate a possible loss of relevant evidence, this paper relied on an established framework in the psychological and behavioural sciences to structure the search. At the same time, the use of the COM-B framework allows future researchers to extend beyond the 10 themes identified in this paper. Secondly, as noted in the review, psychological aspects in decision making are only one side of the equation necessary for promoting person-centred social care. The other concerns the access, availability, costs, and quality of social care services as well as their coordination in providing high-quality care. Whether psychological factors or supply-side factors are more responsible for health and care outcomes in older adults remains an open question, thus demanding further investigation. Thirdly, there is limited understanding on which COM-B factor most predicts advance planning or other consumer-reported outcomes (e.g., satisfaction) in social care. A proper identification could facilitate policy analysis and enable policymakers to develop more refined interventions for improving the quality of person-centred social care.

## **Conclusions**

The public is expected to play an increasingly active role in their own social care. In enabling the general population to do so, considerable emphasis has been placed on giving people more information, more choice, and more autonomy in deciding how they want to be cared for. This implicitly assumes that people *know* what they want—they have clear, coherent preferences. It also assumes that people can *do* what they want—that they have complete focus and willpower to follow through with actions.

However, as this review found, rational planning and decision making in social care are complex and difficult processes. Consumers are often unsure of what they want and reluctant to explore what they may need. And even if they do somehow manage these, most people will find that they lack the necessary attention to rationally evaluate all the information and different options before them. The aversive nature of social care normally deters early planning and preparation. Consequently, most social care decisions are reactive, rather than the result of careful forethought.

These same behavioural barriers are also what makes shared decision making a highly attractive approach for promoting person-centred social care. In particular, this review showed how gaps in consumer's capability, opportunity, motivation and behaviour could be potentially addressed by involving others in decision making. In this respect, the UK government, local authorities, service providers, and family carers all form an invaluable part of a consumer's social support network. They offer not just informational aid, but also relational and functional support for addressing the various behavioural barriers that impede person-centred social care.

The findings from this review raise questions about how effective the UK government's informational strategy is in improving the quality of social care. For consumers to get the care help and support they want, equal if not more emphasis should be paid to how decision making actually unfolds, which usually necessitates (or could at least benefit from) the involvement of carers. Only by recognising both the behavioural factors involved and the promise of shared decision making, can the authorities foster person-centred social care.

## Chapter 6

# General discussion and conclusion

Shared decision making is a promising ideal, but why is it still so rare in health and social care? Across three essays, this dissertation sought to contribute knowledge on the collaborative process through which decision makers make informed and person-centred decisions. It revealed several reasons for the poor state of implementation. One reason is the silent world between professionals and lay individuals: professionals often have control over the communicative process, while patients are normally unaware of how to get involved. The emotional world is another issue: professionals tend to believe that patients are irrational partners in decision making, whereas most patients can learn to be more involved and in control of their decisions. And then there is the rational world: professionals and patients need to acquire a necessary set of competencies to deliberate in an informed manner. Finally, contextual factors, such as a lack of time or poor health status, can put shared decision making out of reach.

The basic building blocks of high quality shared decision making appear to be based on the condition that all decision makers are willing, motivated and competent to collaborate for a common objective. The responsibility of governments and care organisations then, is to create the environment necessary for promoting this condition. Put differently, given that shared decision making has the ability to improve health and social care outcomes, those who organise and deliver care have an ethical responsibility to provide care to all lay individuals and not just those who can most readily understand information or participate in decision making.

On the other hand, the convoluted process of shared decision making exposes the limitations of rational deliberation and the dangers of providing more information and choice without adequately supporting people through decision making. This underscores the need to recognise shared decision making as an inter-dependent, dynamic, and bounded-rational process. As a result, this dissertation has several wider implications for the implementation of person-centred care. The following sections discuss some of these in the grand scheme of things.

## **Confusion about control**

The type of role professionals and patients can adopt in decision making is usually conceived as a unidimensional spectrum, with the paternalistic professional on one end and the autonomous individual on the other. Shared decision making is thought to exist in the middle, where professionals and patients can equally influence decision outcomes. The findings from this dissertation, however, raise some questions about its validity.

Portraying the delicate balance of power in professional-patient relationships as a zero-sum game stokes fear and confusion in people. Professionals who perceive patients as incapable of informed or less willing to participate in decision making may adopt a paternalistic approach. Likewise, patients who learn that they must make a decision may shun the opportunity to know more about their illness and prognosis. In fact, ample studies have shown that decision makers have the capacity to process new information and revise their beliefs or preferences. In Chapter 3's systematic review, professionals randomised to shared decision making interventions often offer more or different choices to patients than those with no exposure to such programmes, presumably indicating that paternalistic professionals are less likely to elicit patients' preferences. And in Chapter 4, the experimental study clearly showed that the receipt of a treatment recommendation significantly influenced participants' autonomous preferences.

Despite all the best intentions and interventions possible, the power balance in professional-patient relationships will almost always be tipped in favour of the professional. The medical world is such that when illness and tragedy strikes, lay individuals will commonly need special care and attention from professionals. This puts patients in a particular position of vulnerability and predisposes them to the influence of professionals. Indeed, a mere label of a medical professional or a patient creates a sort of power disparity between them. This may explain why patients frequently adopt a passive stance by default (see Chapter 3) and why adult consumers fail to search or heed advice on advance care planning until a change in their health status (see Chapter 5).

Is it possible to narrow the power-imbalance then? Records in Bologna dating back to the sixteenth and seventeenth century tell a very different professional-patient relationship. Patients would contractually agree with their doctor to be healed within a set time and for a set amount of money, and a tribunal would settle any broken contracts (Stern & Pomata 1999). This horizontal as opposed to hierarchical professional-patient relationship greatly empowered patients. Today, a similar legal framework can be found in the form of patient lawsuits against doctors for alleged medical malpractices. This number has increased steadily over the past few decades (Mohr 2000). Malpractice suits hand some degree of power and control back to the patient, which could facilitate their involvement in decision making. Unfortunately, the increasingly frequent and exorbitant amounts claimed by patients as plaintiffs have negatively impacted the behaviours of professionals. They have encouraged defensive medicine.

Defensive medicine is the practice of recommending a test or treatment that may not serve the best interest of the patient, but rather to protect the professional against any potential lawsuit from their patient. In a study of 824 US physicians from six specialties most at risk of litigation, 92% reported having ordered tests, performing diagnostic procedures, and referring patients for consultation in clinically unnecessary conditions, whereas 42% reported omitting interventions prone to complications and avoiding patients with more problematic conditions (Studdert,

Mello, Sage, DesRoches, Peugh, Zapert, et al. 2005). Defensive medicine is not only antithetical to person-centred care, but also extremely costly for the healthcare system. One analysis of the US medical liability costs, including defensive medicine, estimated it to be around \$55.6 billion or about 2.4 percent of total annual health expenditure (Mello, Chandra, Gawande & Studdert 2010). A legal approach for balancing the professional-patient relationship is powerful, but it is also highly impractical and may even be detrimental for staff morale and the quality of care in the long-run.

It is likely that any attempt to change the power dynamics in clinical decision making from the extremes of paternalism or autonomy to a more central and equal position (i.e., shared decision making), would obscure the true share of influence each decision maker has in its outcome. Rather than conceive group decision making as a distribution of responsibility, and therefore something to balance, it might be more fruitful to understand the factors that engender authentic shared decision making.

## **Authentic shared decision making**

High-quality shared decision making has traditionally been defined by its rational components. From health care to social care, various stakeholders have recognised the very different, but equally important forms of expertise professionals and patients bring to clinical encounters. As this dissertation found, however, having these forms of expertise are often necessary but insufficient to fully enact person-centred care; how decision makers share information is just as important as having the right information and skills for it. In this regard, authentic shared decision making may be promising ideal to strive for.

Authentic shared decision making emphasises mutual respect in decision making and happens when decision makers are willing, motivated, and able to share their expertise in an open, unfettered manner. Both professionals and patients should be able to meaningfully influence the structure, flow, content, and outcomes in decision making. Authentic shared decision making puts the patient and the medical problem



on equal ground. Professionals and patients are active discussants in this process and while professionals may take the initial lead, they would be mindful of their own opinion and be respectful towards their patient. For example, professionals might explicitly disclose conflicts of interest (e.g., specialty bias). This has been shown, both experimentally and in the field, to increase trust in patients (Sah, Fagerlin & Ubel 2016). Alternatively, a professional might ask “Do you have any concerns that you might want me to know of, or perhaps help to clarify?” or “Why not let’s discuss your initial thoughts or preferences before I tell you more about each option?” Professionals in authentic conversations do not simply relay information. Rather, they are sensitive beings attuned to the feelings, mood and situation of their patients. This enables professionals to navigate difficult topics with tact as well as establish genuine collaboration.

In authentic engagements, social constructs such as trust, honesty, goodwill, a common goal, and shared commitment become key quality dimensions. These constructs put patients at the heart of decision making and are common themes in many qualitative interviews with patients about their involvement in shared decision making (see Chapter 3). These qualities are also commonly found in the context of social care, especially between adult consumers and their family carers (see Chapter 5). Nevertheless, these constructs are rarely assessed or studied in relation to patient- or consumer-associated outcomes. More surveys on this topic may help researchers determine the power each social construct has in explaining key indicators of interest, including satisfaction, behavioural, and clinical outcomes. Such knowledge might be useful for understanding whether it is the feeling of being involved or informed decision making that produces better patient-reported outcomes.

Authentic shared decision making may sound like a radically different approach to standard conceptions, but it is similar to the agent-centric framework proposed in Chapter 3 and many other routine customer engagements (e.g., travel advisor, store assistant, restaurant servers). An authentic approach acknowledges the fundamentally behavioural nature of social decision making and that a number of barriers needs addressing for person-centred care to arise. On the other hand,

customer service interactions resemble authentic patient engagements in that they frequently involve open conversations about what people want and need, rather than begin with a comprehensive list of information on the available products and their attributes. This, however, does not imply that information is any less important than establishing a genuine conversation. Legal and professional obligations still mandate that healthcare professionals obtain informed consent for any medical intervention. Yet, by simply creating a more respectful and egalitarian environment, professionals can gain valuable trust, reduce the perceived power imbalance, and establish rapport in a relatively short time. Professionals and patients would then encounter less communicative barriers in the exchange of unique expertise, which correspondingly facilitates shared decision making and person-centred care.

Authentic shared decision making is a promising ideal, but there are challenges to implementation. For one, authentic engagements serve mainly to create the conditions necessary for facilitating the exchange of expertise between decision makers. What it does not do is address the issue of rational judgment and decision making, which concerns the objective integration of preferences and values to determine an overall best option. Therefore, having the necessary skills and knowledge for informed decision making are just as being able to exchange them in an open and unbiased manner. These are perhaps the core characteristics of high-quality shared decision making.

In addition, authentic shared decision making exposes professionals to potential conflict on three fronts: respect for patient autonomy (i.e., informing and according treatments consistent with patients' preferences); beneficence (i.e., acting in the patient's best interest); and justice (i.e., providing care that is deserved and due). How healthcare professionals understand and balance these principles will shape the information they convey and their approach to decision making. For example, professionals in a welfare state where healthcare is free (e.g., UK) may have reservations about recommending a highly risky medical procedure that is less cost effective than other available interventions. Conversely, professionals in a consumer-oriented healthcare system (e.g., US) may have less concerns about justice, or even

beneficence given the increasingly frequent numbers of malpractice suits. These issues reveal the influential role played by an extraneous variable: culture.

## **Culture**

Shared decision making is a means for managing the power disparity between two experts. Consequently, their interaction is also susceptible to several social influences, one of which is culture. Culture is the amalgamation of rules, norms, beliefs, and habits that over time comes to distinguish the members of one group or group of people from others (Hofstede, Hofstede & Minkov 2010). It can operate on several levels and affect people differently. Consequently, understanding the role of culture in health and social care may provide vital clues on the management of professional-patient relationships in shared decision making.

### **Organisational culture**

Chapter 3 revealed the pivotal role organisational culture has in shaping professionals' motivation to engage in shared decision making. However, this section will elaborate more on how it affects working relationships, instead of professional-patient relationships.

Operations and processes in the provision of care normally involve more types of power imbalances than between professionals and patients. Junior doctors often consult senior doctors for advice on complex medical interventions, nurses often require input from doctors on how to implement certain care plans, and certain medical specialisms may hold a greater level of prestige and authority than others. All of these interactions present researchers with an expanded opportunity to learn about shared decision making among, supposedly, highly rational and knowledgeable experts. Perceived power imbalances can hinder active participation in projects and inter-departmental collaboration, as well as stifle voice against misconduct. Investigations on this shared decision making could be instrumental for

linking climate-related variables (e.g., trust, civility, justice, supervision) to work performance and organisational outcomes (e.g., peer appraisal, efficiency, turnover).

## **National culture**

To date, most extant studies on shared decision making have come from Western health and social care systems (e.g., US, Canada, UK). The social care review in Chapter 5 has hinted at how culture may shape human behaviour, including how they react to concepts and interact with others. Despite this, little is known about the prevalence and attitudes of shared decision making in Eastern or Asian settings (e.g., China, India, Japan).

Asian cultures are relatively collectivistic, in which emphasis is placed on consensus instead of conflict in relationships, and are characterized by a high power distance, one that expects individuals to respect the ladder of authority (Hofstede, Hofstede & Minkov 2010; Jang, Shen, Allen & Zhang 2018; Wang, Zhong & Murnighan 2014). This gives rise to several interesting questions: What perceptions do patients and professionals have in shared decision making? Do patients in Asia prefer less involvement? Is shared decision making more or less common in Asia? What are the barriers and facilitators of shared decision making?

Insights from Asian healthcare systems are valuable for several reasons. If respect for patient autonomy is a fundamental right, then it would be meaningful to understand the state of shared decision making in other parts of the world. Furthermore, evidence and interventions originating from the West may not work as effectively in Asia, especially those that focus only on rational deliberation and much less on the power imbalance in professional-patient relationships. Data from Asian contexts may help researchers refine and improve their interventions. Finally, more knowledge on this front may be beneficial for understanding intercultural dynamics, such as the management of perceived power disparities between decision makers of different ethnicities or nationalities.

## Overall conclusions

Person-centred care is increasingly advocated in many modern, high-quality healthcare systems worldwide. As part of this paradigmatic shift, lay individuals are given more information, more choice and more autonomy in deciding how best they want to be cared for.

Yet, as this dissertation found, people are boundedly rational and this has ramifications for those providing person-centred care as well as those receiving it. The effects of bounded rationality are exacerbated in a dyadic setting where healthcare professionals and lay individuals are increasingly expected to share in decision making. Behavioural influences operating at the individual and interpersonal level can shape the construction of preferences and ultimately, affect the extent to which patients' choice are truly informed and consistent with their own values and preferences. As such, the process of shared decision making can critically influence outcomes in person-centred care.

This dissertation opened several future research avenues for advancing knowledge on shared decision making. First, programs aimed at encouraging informed decision making and person-centred care should pay more attention to how decision makers gather, exchange and process information rather than simply provide more informational resources. Decision aids are just one form of intervention that has been exploited in the shared decision making. Some other opportunities may include decision support for multi-criteria analyses and communication techniques for encouraging collaboration.

Second, shared decision making is a socially complex interaction. More empirical research is needed to enrich understanding on the influence each psycho-social construct has towards self-reported and objective health outcomes. For example, physician trust in patients may be just as important as patient trust in physicians for implementing shared decision making. Similarly, although emotion is a common facet in social interactions, little is still known on their wide-ranging effects on

professionals' and patients' behaviours. Knowing more about the role of emotions in clinical encounters may elucidate the reasons and the ways in which they impede or facilitate authentic shared decision making.

Third, interprofessional work has become increasingly common in the delivery of care. Many aspects of medicine, from general practice to surgery, rely on a diverse set of skills and experience to deliver high-quality care. Future research on interprofessional teamwork may produce new and important insights on the ways in which medical experts assimilate different pieces of information to share in decision making, thereby affecting patients' choice and outcomes. Likewise, patients rarely make decisions alone. Their friends and relatives are a crucial part of the decision making process, helping patients and lay individuals to meet their care needs. They accomplish this either directly as surrogate decision makers and functional helpers, or indirectly by gathering resources and providing valuable relational support. The values and preferences of patients' close ones may thus play a critical role in shared decision making and more research is needed to understand why and in what ways they contribute to care outcomes.

Finally, despite a dearth of evidence linking more patient participation to better outcomes, little is still known on if and the extent to which preference-concordance in shared decision making improves health outcomes. A more thorough examination of this relationship is necessary for political reasons, including the payment and incentivisation of healthcare providers to implement shared decision making. It might also be crucial for practical reasons since few studies have established whether it is information or the feeling of being involved, or both, that improves population welfare. Since emphasis on shared decision making is politically and socially motivated, one could expect cultural differences in the attitudes, preferences, and barriers to implementation across geographic landscapes. This does not mean that shared decision making is less valuable in some parts of the world than others. Rather, it calls on healthcare administrators, professionals and researchers to be more mindful of how medical education, practical interventions, and policies in the extant shared decision making literature may apply to them.

In conclusion, shared decision making is a complex and multifaceted process to effectively implement in practice. It unfolds in a bounded rational manner and involves various behavioural influences that operate subconsciously in clinical encounters. These issues have implications on the extent to which care decisions are “informed” and “person-centred.” Thus, shared decision making is an interesting dyadic interaction deserving of more attention. Future studies into the interplay between different behavioural influences and their effects on self-reported and clinical outcomes may advance meaningful insights on the mechanisms of SDM, enabling policymakers and practitioners to provide for better person-centred care.

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# Appendix A

Table of studies included in the review and their associated characteristics.

| No. | Type of paper | Year | Author(s)               | Decision Agents (Professional) |          |         |         | Decision Agents (Patient) |          |         |         | Decision Process |           |                 |                |
|-----|---------------|------|-------------------------|--------------------------------|----------|---------|---------|---------------------------|----------|---------|---------|------------------|-----------|-----------------|----------------|
|     |               |      |                         | Skills                         | Attitude | Emotion | Context | Skills                    | Attitude | Emotion | Context | Power            | Knowledge | Decision making | Responsibility |
| 1   | Qualitative   | 2010 | de Kort et al.          |                                |          |         |         |                           |          |         |         | X                |           |                 | X              |
| 2   | Qualitative   | 2010 | Mendick et al.          | X                              | X        |         | X       | X                         | X        |         |         | X                | X         |                 | X              |
| 3   | Qualitative   | 2010 | Peek et al.             |                                |          |         |         |                           | X        | X       |         | X                |           |                 |                |
| 4   | Qualitative   | 2010 | Stewart et al.          |                                |          |         |         | X                         | X        | X       | X       |                  |           |                 | X              |
| 5   | Qualitative   | 2010 | Woltmann & Whitley      |                                |          |         |         | X                         | X        | X       | X       | X                | X         |                 | X              |
| 6   | Qualitative   | 2011 | Brinkman et al.         |                                |          |         |         |                           |          |         |         |                  | X         |                 |                |
| 7   | Qualitative   | 2011 | Caldon et al.           |                                |          |         |         |                           |          |         |         |                  |           |                 | X              |
| 8   | Qualitative   | 2011 | Galesic et al.          |                                |          |         |         | X                         |          |         |         |                  |           | X               |                |
| 9   | Qualitative   | 2011 | Müller-Engelmann et al. |                                |          |         | X       |                           |          |         |         |                  |           | X               | X              |
| 10  | Qualitative   | 2011 | Pieterse et al.         | X                              |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 11  | Qualitative   | 2011 | Politi et al.           | X                              |          | X       |         |                           |          | X       |         |                  | X         |                 |                |
| 12  | Qualitative   | 2011 | Robertson et al.        | X                              | X        | X       |         |                           |          |         |         | X                |           |                 | X              |
| 13  | Qualitative   | 2011 | Shepherd et al.         | X                              | X        | X       | X       |                           |          |         |         |                  | X         |                 |                |
| 14  | Qualitative   | 2011 | Smith et al.            | X                              | X        | X       |         | X                         | X        | X       |         | X                |           |                 | X              |
| 15  | Qualitative   | 2011 | Upton et al.            | X                              | X        | X       | X       |                           |          |         |         |                  |           |                 |                |
| 16  | Qualitative   | 2012 | Aasen et al.            |                                |          |         | X       |                           |          |         |         | X                | X         | X               |                |
| 17  | Qualitative   | 2012 | Berger et al.           |                                |          |         | X       |                           |          |         |         | X                | X         |                 | X              |
| 18  | Qualitative   | 2012 | Frosch et al.           |                                |          | X       |         |                           | X        | X       |         | X                |           |                 |                |
| 19  | Qualitative   | 2012 | Giguere et al.          | X                              |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 20  | Qualitative   | 2012 | Koudriavtseva et al.    |                                |          |         |         |                           | X        | X       |         | X                |           |                 | X              |
| 21  | Qualitative   | 2012 | Moreau et al.           |                                |          |         |         | X                         | X        | X       | X       | X                | X         |                 | X              |
| 22  | Qualitative   | 2012 | Quirk et al.            |                                |          |         |         |                           |          |         |         | X                | X         |                 |                |
| 23  | Qualitative   | 2012 | Röing & Holmström       | X                              | X        | X       | X       |                           |          |         |         | X                |           |                 | X              |

| No. | Type of paper | Year | Author(s)              | Decision Agents (Professional) |          |         |         | Decision Agents (Patient) |          |         |         | Decision Process |           |                 |                |
|-----|---------------|------|------------------------|--------------------------------|----------|---------|---------|---------------------------|----------|---------|---------|------------------|-----------|-----------------|----------------|
|     |               |      |                        | Skills                         | Attitude | Emotion | Context | Skills                    | Attitude | Emotion | Context | Power            | Knowledge | Decision making | Responsibility |
| 24  | Qualitative   | 2012 | Sonntag et al.         | X                              | X        |         |         |                           |          |         |         |                  |           |                 |                |
| 25  | Qualitative   | 2013 | Arcuri et al.          |                                |          |         |         |                           |          |         |         |                  |           |                 | X              |
| 26  | Qualitative   | 2013 | Aubin-Auger et al.     |                                |          |         |         |                           |          |         |         |                  | X         |                 | X              |
| 27  | Qualitative   | 2013 | Caeymaex et al.        |                                |          |         |         | X                         | X        | X       | X       |                  |           |                 | X              |
| 28  | Qualitative   | 2013 | Chhabra et al.         | X                              | X        | X       | X       |                           |          |         |         | X                |           |                 | X              |
| 29  | Qualitative   | 2013 | Chong et al.           |                                |          |         | X       |                           |          |         |         | X                | X         |                 | X              |
| 30  | Qualitative   | 2013 | Chong et al.           | X                              | X        |         | X       |                           |          |         |         | X                | X         | X               | X              |
| 31  | Qualitative   | 2013 | Dierckx et al.         |                                |          |         |         |                           | X        |         |         | X                | X         |                 | X              |
| 32  | Qualitative   | 2013 | Ernst et al.           |                                |          |         | X       | X                         | X        | X       | X       | X                | X         |                 | X              |
| 33  | Qualitative   | 2013 | Lloyd et al.           | X                              | X        | X       | X       |                           |          |         |         |                  | X         | X               | X              |
| 34  | Qualitative   | 2013 | McCabe et al.          | X                              | X        |         | X       |                           |          |         |         |                  |           | X               |                |
| 35  | Qualitative   | 2013 | Mongilardi et al.      |                                |          |         | X       |                           |          |         |         | X                |           |                 |                |
| 36  | Qualitative   | 2013 | O'Brien et al.         | X                              |          |         |         | X                         | X        | X       |         | X                |           |                 | X              |
| 37  | Qualitative   | 2013 | O'Brien et al.         |                                |          |         |         | X                         | X        | X       | X       |                  |           |                 | X              |
| 38  | Qualitative   | 2013 | Peek et al.            |                                |          |         |         | X                         | X        | X       |         | X                | X         |                 |                |
| 39  | Qualitative   | 2013 | Pietrolongo et al.     | X                              |          |         | X       |                           |          |         |         | X                | X         |                 |                |
| 40  | Qualitative   | 2013 | Protheroe et al.       |                                |          |         |         | X                         | X        |         | X       | X                |           |                 | X              |
| 41  | Qualitative   | 2013 | Tiedje et al.          | X                              | X        |         |         |                           |          |         |         |                  | X         | X               | X              |
| 42  | Qualitative   | 2013 | Toerien et al.         |                                | X        |         | X       |                           | X        |         | X       |                  | X         | X               |                |
| 43  | Qualitative   | 2013 | van der Weijden et al. | X                              | X        |         | X       |                           |          |         |         |                  |           | X               |                |
| 44  | Qualitative   | 2013 | Wrede-Sach et al.      |                                |          |         |         | X                         | X        | X       | X       | X                |           |                 | X              |
| 45  | Qualitative   | 2014 | Athale et al.          |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 46  | Qualitative   | 2014 | Beck et al.            |                                | X        |         |         |                           |          | X       |         | X                | X         | X               | X              |
| 47  | Qualitative   | 2014 | Butterworth & Campbell |                                |          |         |         |                           |          | X       |         | X                |           |                 | X              |
| 48  | Qualitative   | 2014 | Coyne et al.           |                                |          |         | X       | X                         | X        | X       | X       | X                |           |                 | X              |
| 49  | Qualitative   | 2014 | Gulbrandsen et al.     | X                              |          | X       |         |                           |          |         |         |                  | X         |                 |                |
| 50  | Qualitative   | 2014 | Hoffmann et al.        | X                              | X        |         |         |                           |          |         |         | X                | X         |                 |                |
| 51  | Qualitative   | 2014 | Jones et al.           |                                | X        |         |         |                           |          |         |         |                  | X         |                 |                |
| 52  | Qualitative   | 2014 | Lam et al.             |                                |          |         | X       |                           |          |         |         |                  |           |                 |                |
| 53  | Qualitative   | 2014 | Matthias et al.        |                                |          |         |         | X                         | X        | X       | X       |                  |           |                 |                |
| 54  | Qualitative   | 2014 | Nota et al.            |                                |          |         |         | X                         | X        | X       | X       | X                | X         |                 | X              |

| No. | Type of paper | Year | Author(s)            | Decision Agents (Professional) |          |         |         | Decision Agents (Patient) |          |         |         | Decision Process |           |                 |                |
|-----|---------------|------|----------------------|--------------------------------|----------|---------|---------|---------------------------|----------|---------|---------|------------------|-----------|-----------------|----------------|
|     |               |      |                      | Skills                         | Attitude | Emotion | Context | Skills                    | Attitude | Emotion | Context | Power            | Knowledge | Decision making | Responsibility |
| 55  | Qualitative   | 2014 | Padgett et al.       |                                |          |         |         | X                         | X        | X       | X       |                  | X         |                 | X              |
| 56  | Qualitative   | 2014 | Rapaport et al.      |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 57  | Qualitative   | 2014 | Salloch et al.       | X                              | X        | X       | X       | X                         | X        | X       |         |                  | X         | X               | X              |
| 58  | Qualitative   | 2014 | Taylor et al.        | X                              | X        | X       | X       | X                         | X        | X       |         | X                |           |                 |                |
| 59  | Qualitative   | 2015 | Chong et al.         |                                |          |         |         |                           |          |         |         |                  |           |                 | X              |
| 60  | Qualitative   | 2015 | De Snoo-Trimp et al. |                                | X        |         |         |                           |          |         |         |                  | X         | X               |                |
| 61  | Qualitative   | 2015 | Eliacin et al.       |                                |          |         |         |                           | X        | X       | X       | X                | X         |                 |                |
| 62  | Qualitative   | 2015 | Hajizadeh et al.     | X                              | X        |         |         |                           | X        | X       | X       |                  |           |                 |                |
| 63  | Qualitative   | 2015 | Morgan et al.        |                                | X        |         |         | X                         | X        |         |         | X                |           |                 | X              |
| 64  | Qualitative   | 2015 | Nilsson et al.       |                                |          |         |         | X                         | X        | X       | X       | X                | X         |                 |                |
| 65  | Qualitative   | 2016 | Hamann et al.        |                                |          |         |         | X                         | X        | X       |         | X                | X         |                 | X              |
| 66  | Qualitative   | 2017 | Brom et al.          |                                |          |         |         |                           |          |         |         |                  | X         |                 |                |
| 67  | Qualitative   | 2017 | Callon et al.        |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 68  | Qualitative   | 2017 | Tamirisa et al.      |                                | X        |         |         |                           | X        |         |         |                  |           | X               | X              |
| 69  | Quantitative  | 2010 | Baars et al.         |                                |          |         |         | X                         | X        |         | X       |                  | X         | X               |                |
| 70  | Quantitative  | 2010 | Burton et al.        |                                |          |         |         |                           |          |         |         | X                |           |                 | X              |
| 71  | Quantitative  | 2010 | Hamann et al.        | X                              |          |         | X       |                           | X        |         |         |                  | X         |                 |                |
| 72  | Quantitative  | 2010 | Keating et al.       |                                |          |         |         |                           | X        | X       | X       |                  | X         | X               |                |
| 73  | Quantitative  | 2010 | Kumar et al.         |                                |          |         |         |                           | X        | X       | X       | X                | X         |                 | X              |
| 74  | Quantitative  | 2010 | Lee et al.           |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 75  | Quantitative  | 2010 | Lee et al.           |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 76  | Quantitative  | 2010 | Patel & Bakken       |                                |          |         |         | X                         | X        | X       | X       | X                | X         | X               |                |
| 77  | Quantitative  | 2010 | Politi & Légaré      | X                              | X        | X       |         |                           |          |         |         |                  |           | X               |                |
| 78  | Quantitative  | 2010 | Ratanawongsa et al.  |                                |          |         |         | X                         |          |         | X       |                  |           |                 |                |
| 79  | Quantitative  | 2010 | Samant et al.        | X                              | X        | X       | X       |                           |          |         |         | X                | X         |                 |                |
| 80  | Quantitative  | 2010 | van Til et al.       | X                              | X        | X       |         | X                         |          |         |         |                  | X         | X               |                |
| 81  | Quantitative  | 2010 | Wilson et al.        | X                              |          |         |         | X                         | X        | X       | X       |                  | X         | X               | X              |
| 82  | Quantitative  | 2011 | De las Cuevas et al. |                                |          |         |         |                           | X        |         |         |                  |           |                 |                |
| 83  | Quantitative  | 2011 | Ernst et al.         |                                |          |         |         |                           | X        | X       | X       |                  |           |                 |                |
| 84  | Quantitative  | 2011 | Ernst et al.         |                                |          |         |         |                           |          |         | X       |                  |           |                 |                |
| 85  | Quantitative  | 2011 | Gong et al.          |                                |          |         |         |                           | X        | X       | X       |                  |           |                 |                |
| 86  | Quantitative  | 2011 | Hamann et al.        | X                              |          |         |         |                           | X        |         |         |                  |           |                 |                |

| No. | Type of paper | Year | Author(s)                   | Decision Agents (Professional) |          |         |         | Decision Agents (Patient) |          |         |         | Decision Process |           |                 |                |
|-----|---------------|------|-----------------------------|--------------------------------|----------|---------|---------|---------------------------|----------|---------|---------|------------------|-----------|-----------------|----------------|
|     |               |      |                             | Skills                         | Attitude | Emotion | Context | Skills                    | Attitude | Emotion | Context | Power            | Knowledge | Decision making | Responsibility |
| 87  | Quantitative  | 2011 | Hamann et al.               |                                |          |         |         | X                         | X        | X       |         |                  | X         |                 | X              |
| 88  | Quantitative  | 2011 | Hamann et al.               |                                |          |         |         | X                         | X        |         |         | X                | X         |                 |                |
| 89  | Quantitative  | 2011 | Joosten et al.              |                                |          |         |         | X                         | X        |         | X       |                  | X         |                 | X              |
| 90  | Quantitative  | 2011 | Légaré et al.               |                                |          |         |         | X                         | X        |         |         |                  |           |                 |                |
| 91  | Quantitative  | 2011 | Légaré et al.               | X                              | X        |         |         |                           |          |         |         |                  | X         |                 |                |
| 92  | Quantitative  | 2011 | Pardon et al.               |                                |          |         |         |                           | X        |         | X       |                  | X         |                 |                |
| 93  | Quantitative  | 2011 | Politi et al.               | X                              |          | X       |         |                           |          |         |         |                  |           | X               |                |
| 94  | Quantitative  | 2011 | van den Brink-Muinen et al. |                                |          |         | X       |                           |          |         |         |                  |           |                 |                |
| 95  | Quantitative  | 2011 | van der Horst et al.        | X                              | X        |         |         |                           |          |         |         |                  |           |                 |                |
| 96  | Quantitative  | 2011 | Zeliadt et al.              |                                |          |         |         |                           |          | X       | X       | X                | X         |                 | X              |
| 97  | Quantitative  | 2012 | Bernhard et al.             |                                |          |         |         |                           |          |         |         | X                | X         |                 |                |
| 98  | Quantitative  | 2012 | De las Cuevas et al.        |                                | X        |         |         |                           | X        |         | X       |                  |           |                 |                |
| 99  | Quantitative  | 2012 | Glass et al.                |                                |          |         |         |                           | X        |         |         | X                | X         |                 |                |
| 100 | Quantitative  | 2012 | Hamann et al.               |                                |          |         |         |                           |          |         |         | X                | X         |                 |                |
| 101 | Quantitative  | 2012 | Körner et al.               | X                              | X        | X       | X       |                           |          |         |         | X                |           |                 |                |
| 102 | Quantitative  | 2012 | Kriston et al.              |                                | X        |         |         |                           | X        |         |         | X                |           |                 |                |
| 103 | Quantitative  | 2012 | Légaré et al.               | X                              | X        |         |         |                           |          |         |         |                  | X         | X               | X              |
| 104 | Quantitative  | 2012 | Mendel et al.               | X                              |          |         |         |                           |          |         |         | X                |           | X               |                |
| 105 | Quantitative  | 2012 | Neeman et al.               |                                |          |         |         |                           |          |         |         | X                | X         | X               |                |
| 106 | Quantitative  | 2012 | Sheridan et al.             |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 107 | Quantitative  | 2013 | Alden et al.                |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 108 | Quantitative  | 2013 | Ashraf et al.               |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 109 | Quantitative  | 2013 | Bozic et al.                |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 110 | Quantitative  | 2013 | Branda et al.               |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 111 | Quantitative  | 2013 | Chawla & Arora              |                                |          |         |         | X                         | X        |         |         | X                |           |                 | X              |
| 112 | Quantitative  | 2013 | Flierler et al.             |                                |          |         |         |                           |          |         |         | X                | X         |                 |                |
| 113 | Quantitative  | 2013 | Fowler et al.               |                                |          |         |         |                           | X        |         | X       |                  | X         |                 |                |
| 114 | Quantitative  | 2013 | Frongillo et al.            |                                |          |         |         |                           |          |         |         |                  |           |                 | X              |
| 115 | Quantitative  | 2013 | Han et al.                  |                                |          |         |         | X                         | X        |         |         |                  | X         | X               |                |
| 116 | Quantitative  | 2013 | Hillyer et al.              |                                | X        | X       | X       |                           |          |         |         | X                | X         | X               |                |
| 117 | Quantitative  | 2013 | Kupke et al.                |                                |          |         |         |                           |          |         |         |                  | X         |                 |                |
| 118 | Quantitative  | 2013 | Landrey et al.              |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |



| No. | Type of paper | Year | Author(s)                 | Decision Agents (Professional) |          |         |         | Decision Agents (Patient) |          |         |         | Decision Process |           |                 |                |
|-----|---------------|------|---------------------------|--------------------------------|----------|---------|---------|---------------------------|----------|---------|---------|------------------|-----------|-----------------|----------------|
|     |               |      |                           | Skills                         | Attitude | Emotion | Context | Skills                    | Attitude | Emotion | Context | Power            | Knowledge | Decision making | Responsibility |
| 119 | Quantitative  | 2013 | Légaré et al.             | X                              | X        |         |         |                           |          |         |         | X                | X         | X               | X              |
| 120 | Quantitative  | 2013 | Müller-Engelmann et al.   |                                |          |         | X       |                           |          |         |         |                  |           |                 |                |
| 121 | Quantitative  | 2013 | Portnoy et al.            | X                              | X        | X       | X       |                           |          |         |         |                  | X         | X               |                |
| 122 | Quantitative  | 2013 | Stein et al.              |                                |          |         |         |                           |          |         |         |                  | X         | X               | X              |
| 123 | Quantitative  | 2013 | van der Krieke et al.     |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 124 | Quantitative  | 2013 | Veroff et al.             |                                |          |         | X       |                           |          |         |         | X                | X         | X               |                |
| 125 | Quantitative  | 2013 | Westermann et al.         | X                              | X        |         | X       |                           |          |         |         | X                | X         | X               |                |
| 126 | Quantitative  | 2013 | Wilkes et al.             | X                              | X        |         | X       | X                         | X        | X       | X       | X                | X         | X               |                |
| 127 | Quantitative  | 2014 | Alden                     |                                |          |         |         |                           |          |         |         | X                | X         |                 | X              |
| 128 | Quantitative  | 2014 | De las Cuevas et al.      |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 129 | Quantitative  | 2014 | De las Cuevas et al.      |                                |          |         |         |                           |          |         |         | X                | X         |                 | X              |
| 130 | Quantitative  | 2014 | Garcia-Retamero et al.    | X                              | X        |         |         |                           |          |         |         |                  |           |                 |                |
| 131 | Quantitative  | 2014 | Miller et al.             | X                              |          |         |         | X                         |          |         |         |                  |           |                 |                |
| 132 | Quantitative  | 2014 | Mira et al.               |                                |          |         | X       | X                         | X        |         | X       | X                | X         | X               | X              |
| 133 | Quantitative  | 2014 | Op den Dries et al.       |                                |          |         |         | X                         | X        |         | X       | X                |           |                 | X              |
| 134 | Quantitative  | 2014 | Park et al.               |                                |          |         |         | X                         | X        |         | X       |                  |           |                 |                |
| 135 | Quantitative  | 2014 | Rätsep et al.             |                                |          |         |         |                           |          |         |         |                  | X         | X               | X              |
| 136 | Quantitative  | 2014 | Rosati et al.             |                                | X        |         |         | X                         | X        |         |         | X                |           |                 | X              |
| 137 | Quantitative  | 2014 | Schroy et al.             |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 138 | Quantitative  | 2014 | Shabason et al.           |                                |          |         |         |                           | X        | X       | X       |                  | X         | X               | X              |
| 139 | Quantitative  | 2014 | Snijders et al.           |                                |          |         |         |                           |          |         |         |                  |           |                 |                |
| 140 | Quantitative  | 2014 | Vaillancourt et al.       |                                | X        |         |         |                           | X        |         |         |                  |           |                 |                |
| 141 | Quantitative  | 2014 | Xie et al.                |                                |          |         |         | X                         | X        |         |         |                  |           |                 |                |
| 142 | Quantitative  | 2015 | Couët et al.              |                                |          |         |         |                           |          |         |         |                  | X         | X               | X              |
| 143 | Quantitative  | 2015 | Hutchinson & Barrie       |                                |          |         |         |                           |          |         |         |                  | X         | X               | X              |
| 144 | Quantitative  | 2015 | LeBlanc et al.            |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 145 | Quantitative  | 2015 | Rood et al.               |                                |          |         |         | X                         | X        | X       | X       |                  |           |                 |                |
| 146 | Quantitative  | 2015 | Tambuyzer & Van Audenhove |                                |          |         |         | X                         | X        |         |         |                  | X         |                 | X              |
| 147 | Quantitative  | 2015 | Varming et al.            | X                              | X        |         |         |                           |          |         |         | X                | X         |                 | X              |
| 148 | Quantitative  | 2016 | Nicolai et al.            | X                              |          | X       |         |                           |          | X       |         | X                | X         | X               | X              |

| No. | Type of paper | Year | Author(s)              | Decision Agents (Professional) |          |         |         | Decision Agents (Patient) |          |         |         | Decision Process |           |                 |                |
|-----|---------------|------|------------------------|--------------------------------|----------|---------|---------|---------------------------|----------|---------|---------|------------------|-----------|-----------------|----------------|
|     |               |      |                        | Skills                         | Attitude | Emotion | Context | Skills                    | Attitude | Emotion | Context | Power            | Knowledge | Decision making | Responsibility |
| 149 | Quantitative  | 2016 | Shepherd et al.        |                                |          |         |         | X                         | X        |         | X       | X                | X         |                 |                |
| 150 | Quantitative  | 2017 | Slomski                |                                |          |         |         | X                         | X        |         |         |                  | X         |                 |                |
| 151 | Mixed         | 2010 | Singh et al.           | X                              | X        | X       | X       | X                         | X        | X       |         | X                | X         |                 |                |
| 152 | Mixed         | 2011 | Claramita et al.       |                                | X        |         |         |                           |          |         |         | X                |           |                 | X              |
| 153 | Mixed         | 2011 | Cooper et al.          | X                              |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 154 | Mixed         | 2011 | Pollock et al.         |                                |          |         |         | X                         | X        | X       | X       |                  | X         |                 |                |
| 155 | Mixed         | 2013 | Légaré et al.          |                                |          | X       | X       |                           |          |         |         | X                | X         |                 |                |
| 156 | Mixed         | 2014 | Légaré et al.          |                                | X        |         | X       |                           |          |         |         | X                | X         |                 |                |
| 157 | Mixed         | 2015 | Kunneman et al.        |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 158 | Mixed         | 2017 | Elwyn et al.           |                                | X        |         | X       |                           | X        |         |         |                  |           | X               |                |
| 159 | Review        | 2010 | Stacey et al.          |                                |          |         | X       |                           |          |         |         | X                | X         |                 |                |
| 160 | Review        | 2011 | Bélangier et al.       | X                              | X        | X       | X       | X                         | X        | X       | X       |                  | X         |                 | X              |
| 161 | Review        | 2011 | Gorini and Pravettoni  | X                              | X        |         |         |                           |          |         |         |                  | X         | X               | X              |
| 162 | Review        | 2012 | Dy & Purnell           | X                              | X        | X       |         | X                         |          | X       |         | X                | X         | X               | X              |
| 163 | Review        | 2012 | Flynn et al.           |                                |          |         |         |                           |          |         |         |                  | X         |                 | X              |
| 164 | Review        | 2012 | Légaré et al.          | X                              | X        |         |         |                           |          |         |         | X                | X         |                 | X              |
| 165 | Review        | 2012 | Slover et al.          |                                |          |         |         |                           |          |         |         | X                | X         | X               |                |
| 166 | Review        | 2012 | Street et al.          | X                              | X        |         | X       | X                         | X        | X       | X       | X                | X         | X               |                |
| 167 | Review        | 2013 | Elwyn et al.           |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 168 | Review        | 2013 | Friedberg et al.       | X                              |          |         |         |                           |          |         |         |                  | X         |                 |                |
| 169 | Review        | 2013 | Kryworuchko et al.     |                                |          |         |         | X                         | X        | X       | X       |                  | X         | X               |                |
| 170 | Review        | 2013 | Légaré & Witteman      |                                | X        |         | X       | X                         |          |         |         |                  |           |                 |                |
| 171 | Review        | 2013 | Mead et al.            | X                              | X        |         |         | X                         | X        | X       | X       | X                | X         | X               |                |
| 172 | Review        | 2013 | Sanders et al.         |                                |          |         |         |                           |          |         |         | X                | X         | X               |                |
| 173 | Review        | 2014 | Beitinger et al.       |                                |          |         |         |                           |          |         |         |                  | X         |                 | X              |
| 174 | Review        | 2014 | De Vries et al.        | X                              | X        | X       |         |                           |          |         |         | X                |           |                 |                |
| 175 | Review        | 2014 | Joseph-Williams et al. |                                |          |         |         | X                         | X        | X       |         |                  | X         | X               | X              |
| 176 | Review        | 2014 | Joseph-Williams et al. |                                |          |         |         | X                         | X        | X       |         | X                |           |                 | X              |
| 177 | Review        | 2014 | Menichetti et al.      | X                              | X        |         |         |                           |          |         |         | X                | X         | X               |                |
| 178 | Review        | 2014 | Nieuwenhuijze et al.   |                                |          | X       | X       |                           |          | X       | X       |                  | X         |                 | X              |

| No. | Type of paper | Year | Author(s)                      | Decision Agents (Professional) |          |         |         | Decision Agents (Patient) |          |         |         | Decision Process |           |                 |                |
|-----|---------------|------|--------------------------------|--------------------------------|----------|---------|---------|---------------------------|----------|---------|---------|------------------|-----------|-----------------|----------------|
|     |               |      |                                | Skills                         | Attitude | Emotion | Context | Skills                    | Attitude | Emotion | Context | Power            | Knowledge | Decision making | Responsibility |
| 179 | Review        | 2014 | Tambuyzer et al.               |                                |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 180 | Review        | 2014 | Thórarinsdóttir & Kristjánsson | X                              | X        | X       | X       | X                         | X        | X       | X       |                  | X         | X               |                |
| 181 | Review        | 2014 | von Arx & Kjær                 |                                |          |         |         |                           | X        |         | X       |                  | X         | X               |                |
| 182 | Review        | 2014 | Wyatt et al.                   | X                              |          |         |         | X                         | X        |         |         |                  |           |                 |                |
| 183 | Review        | 2015 | Blumenthal-Barby & Krieger     | X                              |          |         |         |                           |          |         |         |                  | X         | X               |                |
| 184 | Review        | 2015 | Couët et al.                   |                                |          |         | X       |                           |          |         |         |                  | X         | X               |                |
| 185 | Review        | 2015 | Fumagalli et al.               |                                |          |         |         |                           |          |         |         |                  |           |                 |                |
| 186 | Review        | 2015 | Pollard et al.                 | X                              | X        | X       | X       | X                         |          | X       | X       | X                | X         | X               | X              |
| 187 | Review        | 2015 | Tariman & Szubski              | X                              | X        | X       | X       | X                         | X        | X       |         | X                |           |                 | X              |
| 188 | Review        | 2016 | Castro et al.                  |                                | X        |         | X       | X                         | X        |         | X       | X                | X         |                 | X              |
| 189 | Review        | 2017 | Rose et al.                    | X                              |          |         | X       |                           | X        |         | X       |                  | X         | X               | X              |
| 190 | Review        | 2017 | Stacey et al.                  |                                |          |         |         | X                         | X        | X       |         |                  | X         | X               |                |
| 191 | Perspective   | 2010 | Levinson et al.                | X                              | X        | X       |         |                           |          |         |         | X                |           |                 |                |
| 192 | Perspective   | 2010 | Elwyn & Miron-Shatz            |                                |          |         |         |                           |          |         |         | X                | X         |                 | X              |
| 193 | Perspective   | 2011 | Epstein & Street               |                                | X        |         |         |                           | X        |         |         | X                | X         |                 | X              |
| 194 | Perspective   | 2013 | Christine & Kaldjian           |                                | X        |         |         |                           |          |         |         | X                | X         |                 | X              |
| 195 | Perspective   | 2013 | Dizon et al.                   | X                              | X        | X       |         |                           |          |         |         | X                |           |                 | X              |
| 196 | Perspective   | 2013 | Epstein & Gramling             |                                | X        |         | X       |                           | X        |         | X       | X                | X         |                 | X              |

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# Appendix B

## Background Information

Imagine you are a 55-year-old, white male in consultation with the doctor on whether to take up prostate cancer screening or not. You are a rich, college-educated man with no family history of prostate cancer. To help you make an informed decision, the doctor provides the information below.

### General Information

#### What is prostate cancer?

The prostate is part of the male reproductive system. It is located just below the bladder and in front of the rectum. Prostate cancer is one of the most common types of cancer that affects men.

#### What are the risk factors?

The major risk factors for prostate cancer are: 1) having a family history of prostate cancer; 2) being of African descent; and 3) coming from a poorer socio-economic background. You have none of these.

#### What is prostate cancer screening?

Prostate cancer screening means checking the prostate for cancer before there are signs or symptoms of the disease. A Prostate Specific Antigen (PSA) test\* is performed to detect an elevated level of PSA in the blood.

Although a higher than normal level is indicative of prostate cancer, it may also be due to other factors. Many men have a high PSA level without having cancer (i.e., a false positive result). Conversely, many men with a low PSA level will subsequently be diagnosed with prostate cancer (i.e., a false negative result).

\*For the purposes of this study, please assume that prostate cancer screening (via a PSA test) is administered freely to whoever who wants it.

## Diagnosis and Treatment

### How is prostate cancer diagnosed and treated?

If a PSA level is high, additional tests are usually conducted. A biopsy in which a small piece of tissue is removed from the prostate to detect for cancer cells under a microscope may be performed. If a man is diagnosed with prostate cancer, several treatments are available: 1) Surgery; 2) Radiation therapy; 3) Hormone therapy; and 4) Active surveillance.

However, prostate cancer biopsies and treatments can cause serious side-effects, such as urinary dysfunction, bowel dysfunction, and erectile dysfunction. Tests may also detect small tumours which grow so slowly that they present no symptoms and are unlikely to be life-threatening.

### Making a Decision on Screening

To help you make an informed decision on whether to get a PSA test or not, some final pieces of information are provided below.

### What are the current clinical guidelines on prostate cancer screening?

The advice differs slightly depending on whether you reside in the US or the UK.

| In the US   | In the UK   |
|---|---|
| <p>The United States Preventive Services Task Force (USPSTF) recommends that:</p> <p>For men aged 55 to 69 years, the decision to undergo periodic PSA screening for prostate cancer should be an individual one.</p> | <p>The National Health Service (NHS) states that:</p> <p>For healthy men aged 50 or over, there is an informed choice programme that provides good information on the pros and cons of having a PSA test.</p> |

**What is the evidence concerning no screening versus screening (via a PSA test)?**

The following information is for patients like you, with no major risk factors and no symptoms of prostate cancer.

**Among patients like you**

| Within 10 years...  | <b>No<br/>Screening</b>      | <b>With<br/>Screening</b> |
|---|------------------------------|---------------------------|
| All cause mortality<br>(Death from all causes)                | 129<br>Per 1000              | 128<br>Per 1000           |
|   | 1 fewer with screening       |                           |
| Prostate cancer death<br>(Death from prostate cancer)         | 3<br>Per 1000                | 3<br>Per 1000             |
|   | No difference with screening |                           |
| Incidence of cancer (any stage)<br>(Detected cases of cancer) | 32<br>Per 1000               | 39<br>Per 1000            |
|   | 7 more with screening        |                           |
| Biopsy-related complications                                  |                              | More                      |
| Cancer treatment complications                                |                              | More                      |

**Values and Preferences**

You should consider your own values and preferences in deciding whether to get a PSA screening test or not.