

Evidence:

Helping people share decision making

A review of evidence considering whether shared decision making is worthwhile

June 2012



Identify Innovate Demonstrate Encourage

This research was commissioned and funded by the Health Foundation to help identify where and how improvements in healthcare quality can be made. The views expressed in this report do not necessarily represent the views of the Health Foundation.

This research was managed by:

Darshan Patel, Research and Development Manager
The Health Foundation

darshan.patel@health.org.uk
020 7257 8000

Author
Debra Da Silva

Organisation
The Evidence Centre

Contact
debra@evidencecentre.com

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Evidence: Helping people share decisions
is published by the Health Foundation,
90 Long Acre, London WC2E 9RA

ISBN 978-1-906461-40-9

Health Foundation commentary

With roots in the disability rights movement, the phrase ‘nothing about me without me’ became the clarion call of professionals and patients alike at the Salzburg Global Seminar in 1998. Their vision was a shift in healthcare from ‘biomedicine’ to ‘infomedicine’, in which people and professionals worked in partnership, contributing equally in every stage of the health and care journey.

A few years later, Derek Wanless* recommended that, in order to cope with rising demand and costs, the NHS should move to ensure that all patients were ‘fully engaged’ in managing their health status and healthcare.

Successive governments have promoted this approach. It is reflected in Scotland’s mutuality agenda giving patients rights to involvement in their care. In England it has been manifested most recently in the rhetoric of ‘no decision about me without me’ and given a legislative footing in the Health and Social Care Act 2012, which places new duties on the NHS to promote the involvement of patients in decisions about their treatment and care.

Yet, if we are seeing an emerging consensus between professionals, patients and politicians, we are not yet seeing a shared agenda for achieving this vision. For many, such as those who met in the Salzburg Global Seminar, shared decision making is a philosophy as well as a way of doing things. Central to it is the belief that patients have a vital role in the decision making process; that their values and self-determination need to be considered equally alongside scientific knowledge.

Thus, shared decision making is necessary because I, and only I, in the context of my life, my relationships and my capabilities, can decide what will best meet my needs from the choices available to me. For others, shared decision making is justified on the basis of its consequences. It is an approach to be promoted only if and in those circumstances where it has wider system benefits, for example, lower costs.

Whether we embrace shared decision making because of the ethical imperative or because of wider benefits, a common factor is that shared decision making reduces unwarranted variation – that is variation driven by provider preference rather than the variation warranted by personal preferences or clinical circumstance. Evidence-based clinical guidelines address the issue of clinical circumstance, but leave unaddressed the tools and mechanisms to incorporate people’s different values and informed preferences into decisions. It is our beliefs that determine when and how we, as clinicians, researchers, managers or commissioners, take those preferences into account.

Helping people share decisions brings together the evidence of the impact of shared decision making on the quality of healthcare as defined by the Institute of Medicine’s six dimensions of quality: safe, effective, timely, patient-centred, efficient and equitable care. It provides an up-to-date single reference point for the state of current knowledge about how shared decision making improves patients’ knowledge and understanding of risk

*Securing Our Future Health: Taking a Long-Term View, Final Report, Derek Wanless, April 2002

and their experience and comfort with decisions; whether this can improve outcomes; and whether it may lead to a more effective allocation of resources. An important conclusion in the current climate is the recognition that it would be misleading to promote shared decision making as a panacea for the financial challenges facing the NHS.

In drawing together the evidence on shared decision making, *Helping people share decisions* highlights gaps in current knowledge, such as the long term cost-effectiveness of shared decision making if, for example, treatment decisions are deferred. There is also little evidence on how it can impact on domains of quality such as equity and patient safety. This lack of evidence does not mean that there is no relationship or benefit, but that there is currently insufficient research to draw conclusions. One of the striking findings in this review is that there is no common definition of shared decision making in the studies, creating significant challenges in understanding and replicating benefits and drawing conclusions across multiple studies.

This evidence review also clearly demonstrates that putting shared decision making into practice will not be achieved through policy statements: active steps to change the behaviour of both healthcare professionals and patients are central to its successful delivery. In concert with *Helping people help themselves*, the Health Foundation's May 2011 review of the evidence on supporting self-management, this review highlights the need for approaches that support patients to have the confidence, information and support to participate in decisions about their health and healthcare.

The two sites taking part in our MAGIC (Making Good Decisions in Collaboration) improvement programme, Newcastle and Cardiff, are developing and testing practical methods of putting shared decision making into practice in a variety of conditions across primary and secondary care, focusing on changing behaviour alongside developing and using decision making tools. This work will offer a much needed contribution to the evidence base on implementation.

The knowledge and insight into effective shared decision making is increasing. However, it is clear that further action is required. Research funders could help by commissioning high-quality research on the long term benefits and risks of shared decision making, its short and long term impact on healthcare resources and the best strategies to embed and implement it. They also have a key role to play in ensuring that definitions and reporting are clear and comprehensive, so that the interventions and approaches can be adopted and the results replicated.

Health Education England can ensure training at undergraduate and postgraduate level, and throughout professional development to enhance clinical skills in supporting people to take decisions about their health and healthcare. Commissioners and providers can ensure that programmes that support people to develop their health literacy, and have the confidence to act as equal partners in their care and treatment, are embedded in local care patient pathways. The NHS Commissioning Board, both in its role as setting the framework for local commissioning and as a commissioner itself, can lead the way to developing robust and meaningful measures of patient participation in decision making.

Through our own work, and in partnership with others, we will continue to inform the debate and to promote a shift in relationships so that the Wanless vision of a 'fully engaged' patient, in which patients are active partners in their care, becomes the norm rather than the exception.

Adrian Sieff
Assistant Director
The Health Foundation

Contents

Executive summary	iv
Chapter 1: What is shared decision making?	1
Chapter 2: Does shared decision making work?	9
Chapter 3: Tools to support implementation	14
Chapter 4: Facilitators and barriers	23
Chapter 5: Issues that need more attention	34
References	39
Appendix 1: Review methods	67

Executive summary

Health services in the UK are increasingly focused on partnership, respect and helping people take control and responsibility for their health. This rapid review describes how shared decision making can improve people's engagement in healthcare and help build patient-centred services.

What is shared decision making?

This review focuses specifically on shared decision making whereby patients and professionals work in partnership to make decisions about care when there is more than one good way forward. Research suggests that this requires patients and professionals to be informed, motivated and engaged.

Shared decision making is both a philosophy and a process. It requires a partnership between patients and professionals, working together to select tests, treatments and support packages based on patient preferences, clinician experience and research evidence. This often necessitates a shift in the perceived roles of patients and professionals, the provision of evidence-based information about options, outcomes and uncertainties, and support and feedback to ensure that patients and professionals are actively engaged.

Surveys and observations have found that shared decision making is often talked or written about but is less common in day-to-day clinical practice. While clinicians may believe that they implement shared decision making, the evidence does not always support this.

In this sister publication to our review about self-management support, *Helping people help themselves*, we examine research about the impacts of shared decision making and the factors that may facilitate it or act as barriers.

Eighteen bibliographic databases were searched for material available as of mid-November 2011 and 465 studies were included.

Does sharing decisions work?

Research from the UK and other countries suggests that strategies to enhance shared decision making can improve:

- people's knowledge about their condition and treatment options
- people's involvement in their care
- people's satisfaction with care
- people's self-confidence in their own knowledge and self-care skills
- professionals' communication with patients.

There is some evidence that helping people to share in decision making can have benefits for those using services and their families. There is also emerging evidence, from mainly observational and small scale studies, that supporting people to share in decision making can improve their satisfaction with care and the extent to which they concord with treatment. Some believe that this may in turn have follow-on impacts for symptoms and clinical outcomes, though research about these impacts is sparse.

Although some studies suggest that shared decision making reduces the use of health services, evidence is mixed and not yet generalisable. Rather than significantly reducing healthcare use, the evidence implies that patterns of service use may be more likely to change as a result of shared decision making.

However, the lack of evidence related to clinical outcomes and resource use does not signal a lack of effect. It merely means that as yet little high-quality longitudinal research is available.

An implication from the literature is that helping people become active participants in decisions about their care has the potential to alleviate pressure on health and social services, but implementing one-off interventions or small-scale tools is unlikely to make a significant impact on the overall health of the population or on the sustainability of health and social care systems. Supporting shared decision making is not a panacea for all the financial and capacity issues in the health system. Despite this, shared decision making may have most impact when implemented as part of wider initiatives to improve care through educating practitioners, supporting self-management, applying best evidence, and using technology and organisational partnerships effectively.

What do we need to do to support shared decisions?

A wide range of initiatives have been tested to implement shared decision making at scale. Initiatives can be categorised along a continuum, with passive information provision at one end and initiatives that actively seek to support patients at the other (see Figure 1).

Strategies that have been tested include:

- skills training for professionals
- decision aids for patients
- strategies to activate patients
- measuring the extent of shared decision making
- providing feedback and prompts for clinicians.

A number of studies have found benefits from decision aids, training clinicians, educating patients and action plans, but other research about these initiatives has not found favourable impacts. The varying findings may be because interventions to help people share in decision making differ considerably in their aims, approach, content, delivery, duration and target group.

Research suggests that information provision and patient-held records alone are unlikely to be sufficient to motivate ongoing shared decision making. Instead, more active support from professionals is needed. Evidence implies that active support for both patients and professionals is needed to enable true partnerships. For this reason, decision aids and access to records alone are unlikely to be as effective as multifaceted strategies. All of these strategies could be seen as pieces of a jigsaw, which may work well together to form a more complete picture.

Studies have found that key facilitators to support shared decision making include strong leadership, changing patient and professional roles, motivated patients and professionals and appropriate infrastructure. This implies that a fundamental shift is needed in the way that both patients and professionals view their roles and, therefore, the culture and infrastructure of health services will be as important as the motivation and attitudes of patients and professionals.



Figure 1: Continuum of strategies to support shared decision making

Studies have concluded that barriers to shared decision making at scale include a paternalistic healthcare culture, attitudes of patients and professionals, a perceived lack of time in consultations and failure to address the systems issues that constrain clinicians from shared decision making.

What else do we need to know?

A great deal has been written about shared decision making, yet there is still much to learn about how to make it happen consistently and effectively within real life frontline healthcare settings. Numerous studies are currently underway including tests of decision support tools, evaluations of training for professionals, studies of how policy, guidance and frameworks may be important and examinations of how shared decision making works in practice. However, ongoing studies are generally not focusing on the impact of shared decisions on patients' physical wellbeing and on resource use within health and social care. Impacts are assumed rather than being tested.

Major gaps in knowledge and issues in need of further attention include understanding how to develop new relationships and partnerships between patients and professionals, learning how to engage clinicians and transmit the attitudes and skills they need to help patients share decisions, and the best tools and strategies to embed shared decision making in routine practice.

As there is no agreed definition of shared decision making it remains challenging to extrapolate generalisable lessons. However, the existing evidence base does allow us to draw various conclusions about next steps in moving forward with the concept and practice of shared decision making. For instance, it may be important for patients, professionals and policy makers to have a joint understanding of shared decision making, including whether this involves real power for patients or whether it is merely about gaining approval from patients for suggestions made by clinicians.

Practical strategies to support shared decision making in routine practice are needed, including easy-to-use decision support tools.

Better measures and metrics would also be useful to provide clinical and managerial healthcare leaders and individual clinicians with information about how well shared decision making is being achieved within their organisations and services.

Another core component is supporting clinicians to help people share in decisions. This includes developing the competencies and skills that clinicians need to help patients and changing the way that patients and practitioners see their roles to create more of a partnership approach. It may also be important to consider how to minimise feelings of risk and fears of litigation among professionals, especially if patients ultimately make decisions that clinicians might not initially concord with.

Research suggests that shared decision making can impact on how people think, feel and act. The challenge is to explore the best ways to support shared decision making and to help patients, clinicians and healthcare managers make this a reality. A number of innovative strategies are being tested to support behaviour change in the UK. Rigorous evaluation of these programmes and wide dissemination of learning will enhance knowledge in this area considerably.

Chapter 1

What is shared decision making?

1.1 Introduction

Engaging people in their health and care is a key component of developing a healthcare system of the highest possible quality; one that is safe, effective, person centred, timely, efficient and equitable.¹

Health services are facing significant challenges.² The population is growing in size and age, medical advances mean that people are living longer and there are often many treatment options to choose from.³ Over the past decade there has been an increasing focus in the UK and around the world on supporting people to be involved in decisions about their care.⁴⁻⁷ There is a move away from a paternalistic model where clinicians ‘do things to’ and make decisions for patients towards helping people to take more control of their health and care.⁸ Politically this is currently expressed as ‘no decision about me without me’.⁹⁻¹⁰

Many strategies have been tested to help people share in decisions about their care with varying success, including providing accessible information, decision support aids, information prescriptions and communication skills training for patients and professionals.¹¹⁻¹²

This review compiles evidence about helping patients and professionals share in decisions and the impact this may have on domains of quality such as people’s involvement, satisfaction, clinical outcomes and health service use. It also examines research about the most effective strategies to support shared decision making. It is a sister publication to our review *Helping people help themselves* which examined the evidence about supporting self-management.

The review does not aim to be exhaustive but instead provides a rapid and easy-to-use compilation of evidence. In total, 465 studies were identified from 18 bibliographic databases in mid-November 2011. This field is developing rapidly and a great deal of new research is published regularly. Appendix 1 describes the methodology and how best to interpret the evidence presented in this review.

This chapter defines shared decision making, explores how it is measured and considers the extent to which decisions are currently shared within healthcare. The subsequent chapters examine the impacts of shared decision making on patient experience, clinical outcomes and service use and consider interventions that have been used to help people share in decision making. This allows us to draw conclusions about facilitators and barriers to shared decision making and areas in need of further exploration.

1.2 What is shared decision making?

The term shared decision making has been used to describe many aspects of patient involvement in their health and care, including access to personal health records, personal health budgets, care planning and decision aids.¹³ This review focuses specifically on shared decision making whereby patients and professionals work in partnership to make decisions about treatment and care when there is more than one good way forward. This requires patients and professionals to be informed, motivated and engaged.¹⁴

*Shared decision making is a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.*¹⁵

Supporting people to be active participants in their care may have important implications for patient satisfaction, the extent to which people concord with treatment, relationships between patients and professionals and long-term health outcomes.¹⁶ Such patient activation is increasingly important given financial challenges in healthcare and the imperative to make best use of limited staffing and service capacity. Fully involving patients in their care and in decisions about their care is one component of this.¹⁷

The term 'shared decision making' first gained popularity in the late 1990s in the USA.¹⁸ Some suggest that shared decision making requires that:

*at least two participants, the clinician and patient be involved; that both parties share information; that both parties take steps to build a consensus about the preferred treatment; and that an agreement is reached on the treatment to implement.*¹⁹

This assumes that patients and professionals must ultimately agree on the decisions being made, but others have argued that agreeing to disagree about a course of action is also acceptable within shared decision making.²⁰

Shared decision making is appropriate in any situation when there is more than one reasonable course of action and where no specific option is best for everyone.²¹ This situation is common in healthcare.²² The patient's attitudes towards benefits and risks are an important consideration in such decisions.²³

One of the most common reasons for people's dissatisfaction with health services is not being properly informed about their illness and the options for treatment.²⁴⁻²⁵ Many patients may want more information and a greater say in their care.²⁶⁻²⁹ Recognising this, shared decision making focuses on supporting patients to be involved as active partners with professionals in clarifying acceptable options and choosing a preferred course of care.³⁰

Shared decision making is one component of broader initiatives for patient-centred care so there are some overlaps in the philosophies, ideals and tools used. Similar to supporting self-management, we suggest that shared decision making can be seen as having two broad components: the philosophy of partnership and the tools used to support this.

The process of shared decision making may include:³¹

- identifying and clarifying the issue
- identifying potential solutions
- discussing options and uncertainties
- providing information about the potential benefits, harms and uncertainties of each option
- checking that patients and professionals have a joint understanding
- gaining feedback and reactions
- agreeing a course of action
- implementing the chosen treatment
- arranging follow-up
- evaluating outcomes and assessing next steps.

However, whatever process is followed, a defining characteristic of shared decision making involves fostering a real partnership, whereby the health professional is seen as an expert on the effectiveness and potential benefits and harms of treatment options and the patient is viewed as an expert on themselves, their circumstances, attitudes to illness and risk, values, preferences and the extent to which treatment options might fit within their lifestyle.³² Both parties need to be willing and able to share information and accept responsibility for joint decision making.³³

Although the potential benefits of shared decision making have been espoused in policy and research throughout the Western world, there is no universally accepted definition of this concept.^{34–35} A systematic review of 76 studies found that several definitions of shared decision making have been proposed but that they are not used consistently in research.³⁶ The reviewers found that terms such as ‘informed decision making’ are also sometimes used as if they are synonymous with shared decision making. Only about one-third of the studies in the review cited standard definitions. More than a quarter of the studies did not provide or cite any definition of shared decision making or used the term in a different way from usual definitions.³⁷

Another systematic review of 418 articles about shared decision making found that around two-fifths included a conceptual definition. The 161 different definitions used 31 separate concepts to define shared decision making, most commonly ‘patient preferences’ and ‘options’. Few articles explicitly recognised and integrated previous work. There was no standard definition of shared decision making.³⁸

Another systematic review of literature published between 2000 and 2009 identified 147 publications about shared decision making by German researchers alone. The reviewers found that the definitions used varied widely, as did the tools used to measure shared decision making. There was little research about the theoretical foundations and ethical implications of shared decision making.³⁹

Thus, there appears to be no universally used definition of shared decision making. Furthermore, research suggests that there may be different conceptualisations among patients and professionals about what shared decision making means and the extent to which it is occurring.^{40–46}

For example, interviews with patients, public representatives, health professionals and health service managers in Norway explored differences in the definition of patient involvement and shared decision making. All groups believed that patient involvement was founded on mutual respect and undertaken through dialogue, but patients and professionals assigned varying levels of importance to different components. Respect was imperative for patients, but more implicit for professionals. Both patients and professionals worried that the other party wanted to make sole decisions.⁴⁷

Similarly, interviews with parents of children with attention deficit hyperactivity disorder (ADHD) and doctors in the USA found that parents described shared decision making as a partnership between equals, with doctors providing medical expertise and the family contributing in-depth knowledge about the child. In contrast, doctors understood shared decision making as a means to encourage families to accept the clinicians’ preferred treatment.⁴⁸

The studies included in this review also use a variety of definitions which means that it is difficult and perhaps unwise to make comparisons between studies.

1.3 How is shared decision making measured?

The main ways that researchers have measured whether decisions are being shared include:⁴⁹

- asking patients whether they have been involved in decisions
- asking clinicians whether they have involved patients in decisions
- examining patient records for evidence of shared decision making
- asking clinicians for feedback about what they would do in hypothetical situations
- observing encounters between clinicians or trainees and simulated patients
- observing encounters between patients and clinicians or audio or video taping consultations and watching them later.

There are issues with all of these methods. For instance, case note review cannot accurately ascertain whether decisions were truly shared, observation may be intrusive and labour intensive and patient and professional reports of the quality and quantity of shared decision making have been found to differ from those of independent observers.⁵⁰

To increase the reliability of measures, structured tools have been developed. For example, often when encounters are observed, scales and proformas are used to count the number of times certain actions occur or the level of involvement evident.⁵¹

An assessment tool known as the Observing Patient Involvement in Decision Making (OPTION) scale has been developed to measure the extent to which professionals involve patients in decision making. OPTION measures 12 behaviours on a scale of 0% to 100%, whereby high scores signal greater shared decision making.⁵²⁻⁵⁴ A dyadic version of the instrument has been developed so that the tool can be completed by both clinicians and patients after a consultation.⁵⁵⁻⁵⁶ The tool has been translated into many languages, including Dutch, Chinese, French, German, Spanish and Italian.⁵⁷⁻⁵⁸

The Shared Decision Making Questionnaire has also been found to be a useful tool and has been tested mainly in Europe.⁵⁹⁻⁶⁰

Other tools to measure communication preferences and the extent of shared decision making have been validated in a number of countries.⁶¹⁻⁶³ This includes scales and checklists developed for people with certain conditions such as cancer⁶⁴⁻⁶⁸ and specific demographic traits⁶⁹ as well as more generic tools designed to measure shared decision making in any healthcare context.⁷⁰⁻⁷⁵

New instruments to measure the process, outcomes and contextual factors in shared decision making are being developed. A systematic review published in 2011 found eight scales that have undergone detailed psychometric testing, 11 new psychometrically tested instruments and nine unpublished tools. The reported reliability of most scales was good, but they differed in the extent to which they had been validated. Most of the newer tools measure shared decision making processes from a dyadic approach, assessing both the patient's and the clinician's perspective. An increasing number of tools are being tested in languages other than English.⁷⁶

Other reviews have identified between 11 and 18 tools and scales designed to measure shared decision making. Most focus on patients' preferences for information and participation and their views about decisional conflict, self-efficacy and the decision-making process.⁷⁷⁻⁷⁸

Assessment instruments have also been developed to measure regrets about healthcare decision making. However, a systematic review of 32 articles about the development, validation and implementation of measures of decision regret found that tools are somewhat simplistic and fail to capture decision-making concepts robustly.⁷⁹

Thus, we can conclude that a wide variety of methods and tools have been used to measure shared decision making but that there are pros and cons with each method and each method may measure slightly different things.

1.4 Is shared decision making occurring?

Global studies suggest that some patients want to be more involved in decisions about their care.⁸⁰⁻⁸³ However, shared decision making may not be taking place as often as possible in clinical practice.⁸⁴⁻⁸⁵ A Cochrane review concluded that:

Shared decision making is a process by which a healthcare choice is made jointly by the practitioner and the patient and is said to be the crux of patient centred care. Policy makers perceive shared decision making as desirable because of its potential to a) reduce overuse of options not clearly associated with benefits for all (e.g. prostate cancer screening); b) enhance the use of options clearly associated with benefits for the vast majority (e.g. cardiovascular risk factor management); c) reduce unwarranted healthcare practice variations; d) foster the sustainability of the healthcare system; and e) promote the right of patients to be involved in decisions concerning their health. Despite this potential, shared decision making has not yet been widely adopted in clinical practice.⁸⁶

This section describes how patients, professionals and policy makers may express support for shared decision making,⁸⁷⁻⁸⁹ but such approaches may not yet be routinely implemented in the UK and elsewhere.⁹⁰⁻⁹²

The policy context: UK and beyond

In England, both the current and the previous government emphasised the importance of involving patients in decisions about their care as a way of supporting self-management and repositioning the focus and responsibility for wellbeing away from acute services and towards individual patients and

families.⁹³⁻⁹⁴ Documents such as *Our health, our care, our say, Equity and excellence* and the 2011 Health and Social Care Bill all contain references to supporting patient involvement and control over decision making and care.⁹⁵⁻⁹⁷ Similar policy directives are available in Scotland and Wales.⁹⁸⁻⁹⁹ The NHS Constitution emphasises patients' right to be involved in decisions and this is reinforced in the standards set by professional regulators.¹⁰⁰

Governments in England, Scotland and Wales have invested heavily in patient information initiatives and a limited number of decision aids are freely available on public websites.¹⁰¹

Studies about shared decision making in the UK are largely being undertaken by a select number of higher educational institutes and specialist research centres in partnership with NHS organisations.¹⁰²

Other countries throughout Europe are also exploring the potential of shared decision making. In Switzerland, national policies are focusing on strengthening patient rights and patient involvement in healthcare decisions. There is no national programme promoting shared decision making but a small number of decision support tools have been developed and implemented widely.¹⁰³ Swiss doctors generally acknowledge that shared decision making is important, but patient–doctor relationships still tend to be hierarchical. Training initiatives for medical students have been established to address this.¹⁰⁴

Germany has introduced legislation to standardise the rights and responsibilities of patients and professionals. This includes the right to informed decisions, comprehensive information for patients and decisions based on partnerships between patients and professionals.¹⁰⁵ Shared decision making training programmes have been implemented for professionals and a number of decision support tools have been tested, largely by health insurance providers.¹⁰⁶ The German government and other public institutions are funding research into shared decision making and decision support tools.¹⁰⁷⁻¹⁰⁸

France also has legislation promoting greater patient information and participation in the decision-making process, but implementation has been slow.¹⁰⁹ There is some evidence that patients and professionals have different definitions of shared decision making and that there may be some

reluctance to embrace the concept fully.¹¹⁰ There are localised research projects about patient decision aids, but little at national level.¹¹¹⁻¹¹²

In Spain, the past two decades have seen a growing recognition of the importance of considering patients' values and preferences in healthcare decisions.¹¹³ Decision aids are being funded nationally by health technology assessment agencies, but Spain's national health service has yet to routinely incorporate reforms in law that recognise shared decision making and decision aids as a key component of healthcare services and professional curricula.¹¹⁴ Most patients and professionals are not familiar with a patient's right to be kept informed and participate in their own healthcare decisions.¹¹⁵

Over the past five years the Dutch healthcare system has been reformed to be more patient oriented and driven by patient demand.¹¹⁶ A platform for shared decision making was launched in 2011.¹¹⁷ A government healthcare internet portal for patients includes 16 patient decision aids, but healthcare professionals receive limited training in shared decision making.

Research projects about shared decision making are underway throughout the Netherlands, but there is limited national coordination of the research agenda.¹¹⁸⁻¹¹⁹

In Italy, the national health plan and many regional and local health authorities have recognised the importance of patient participation in healthcare decisions at the macro, meso and micro level of decision making. However, implementation remains at an early stage in Italy.¹²⁰ Demonstration projects have found positive outcomes and suggested that particular attention should be dedicated to the most disadvantaged groups of the population. There is also a focus on involving patient organisations and adopting approaches that take context into account.¹²¹

In the USA, shared decision making has become an important part of health policy and is viewed as a way of improving effectiveness and reducing costs.¹²² Recent federal healthcare reform legislation includes several provisions related to shared decision making and patient decision support. Several states have passed or are considering legislation that incorporates shared decision making as an essential element of healthcare.¹²³

Research about shared decision making in the USA is funded by a range of public and private organisations and non-profit, for profit, academic and government organisations are developing decision support tools for people with various conditions. Some tools are publicly available and others are provided by patients' health insurance companies and healthcare professionals.¹²⁴ Numerous studies and demonstration projects are underway to evaluate how to incorporate shared decision making and decision aids into routine clinical care.¹²⁵

In Canada, approaches to shared decision making vary widely.¹²⁶ Canada has 14 health insurance plans at various administrative levels. Shared decision making initiatives are taking place to a varying extent within these different pockets of the country. In the most advanced province, the local government is introducing patient decision aids into certain surgical specialties. There is a public inventory of decision aids ranked according to international standards and free guides and toolkits have been developed for patients and professionals.¹²⁷ Canada's main health research funding agency is sponsoring several projects.¹²⁸

Developments are also underway further afield. In Australia there is support for shared decision making in recent guidelines and policy documents and the concept is strongly endorsed by consumer organisations. However, there is no clear overarching policy framework and little by way of implementation. Some health research and consumer organisation websites include decision support tools but their use is not widespread.¹²⁹⁻¹³⁰

In Chile, health reform and policy documents have strengthened interest in shared decision making. Research has been undertaken largely by one academic institution. This research has highlighted that people in Chile have a desire to participate in health decisions and that professionals can be trained to enhance their skills in this area.¹³¹ Little has been done nationally to roll out these findings and decision support tools and coaching interventions are limited largely to people with diabetes.¹³²

In Brazil, shared decision making is not routinely implemented in clinical practice but the first steps have been taken towards research and tool development. This has been associated with movements against a dictatorship era and the introduction of a medical ethical code.¹³³

In Israel, laws have been set up focused on informed consent and patients' right to information but there are few formal shared decision making initiatives or programmes to promote this concept to professionals or the public.¹³⁴ Government support of research related to shared decision making is minimal and there is no national programme to develop decision aids. However, there is an increasing awareness of shared decision making due to greater patient litigation, the incorporation of communication skills training into medical curricula and awareness raising campaigns by the largest national health insurance plan.¹³⁵

Many other countries are also prioritising shared decision making in policy and research, and this section has provided only a small snapshot.

From policy to practice

Although shared decision making is often discussed in policy and planning documents,¹³⁶ the extent to which it is occurring in practice is less certain. Some research suggests that patients are generally happy with communication and decision making in healthcare,¹³⁷ but far more research suggests that currently there is minimal sharing of decisions in primary care and hospital consultations,¹³⁸⁻¹³⁹ even though doctors and nurses often say that shared decision making is important and believe that they are actively involving patients.¹⁴⁰⁻¹⁴³ This is true in many countries throughout the world.

For instance, observation of 212 general practice consultations in England and follow-up interviews with patients found that decisions were generally doctor led, even those that did not involve medical treatments. Some doctors were significantly better than others at meeting different patients' preferences about their decision-making role.¹⁴⁴

Elsewhere in England, interviews examined how practice nurses approached decisions about asthma inhaler choice and long-term inhaler use. Despite holding positive views about shared decision making, nurses reported limited shared decision making in practice. Patients were only offered an

opportunity to share in decisions about which inhaler to use, based on the nurse's preselected recommendations. Nurses thought that giving patients a 'choice' of devices would improve adherence. The researchers concluded that there is a discrepancy between nurses' understanding of shared decision making and the wider policy framework. Shared decision making was used as a tool to support the nurses' agenda, rather than as a partnership between patients and nurses.¹⁴⁵

Researchers in Germany observed the extent to which general practitioners (GPs) involved overweight people in decisions about their care using recorded consultations. There was minimal implementation of shared decision making.¹⁴⁶

In Sweden, a survey of 156 elderly people in hospital found that one-quarter were not asked for their opinion or encouraged to share in decision making, one-quarter had less participation than they would have preferred, one-third had their exact preferred level of participation, and 15% had more responsibility than they would have preferred. Most people wanted to be given more information and involvement without having to ask.¹⁴⁷

Investigators in Norway found that elderly people tended to trust health professionals, but some felt powerless and were afraid of what might happen if they refused to follow instructions from professionals. They thought that professionals 'owned' knowledge and decided what patients needed to know. But patients wanted dialogue about the future and struggled to be involved in decision making.¹⁴⁸

Interviews with people recently diagnosed with lung cancer in Belgium found that patients who preferred the doctor to make decisions or those who preferred to make the decision themselves often achieved this, while those who wanted to share decisions and have some involvement often did not feel that this occurred. The majority of people did not feel well informed about decisions, let alone involved in making them.¹⁴⁹

Researchers in Australia found that GPs tended to adopt the role of persuader rather than informer when speaking to parents about vaccinations for children. They did not implement shared decision making in practice.¹⁵⁰

Shared decision making may be seen as acceptable in some clinical contexts but not in others. For example, in Australia around six out of 10 health professionals and patient advocates supported the general concept of shared decision making in breast cancer but less than one-third of surgeons, doctors and radiation oncologists supported involving women in multidisciplinary treatment planning meetings. Nurses and patient advocates were more likely to be positive.¹⁵¹

A study with simulated patients in the USA found that medical students tended to encourage shared decision making in most of their consultations to some extent, particularly regarding medical interventions. In fact, students took around 90% of opportunities available to encourage shared decisions, though this was in an artificial observed environment. Good communication skills alone were not enough to ensure that trainees and clinicians supported shared decision making.¹⁵²

A survey of cancer doctors in Canada found that only 58% had heard the term shared decision making and 29% said that they were aware of its meaning.¹⁵³

Some studies have quantified the extent of shared decision making more precisely.^{154,155} For instance, researchers in Canada used the OPTION scale to rate 12 shared decision making behaviours among 152 GPs and family medicine residents and their patients, where higher scores were associated with better shared decision making. The overall average score was just 24%, with average scores ranging from 4% to 37% for each of the 12 behaviours. This suggests that shared decision making was not well integrated into routine practice.¹⁵⁶

In the Netherlands, videos of consultations between cancer doctors and their patients found that clinicians infrequently offered patients a choice or explored the pros and cons of different options. Patients were offered a choice or actively asked to participate in decisions in about 40% of cases.¹⁵⁷

Researchers in the USA examined 44 primary care visits among people with long-term conditions. They found that shared decision activities occurred in 61% of the visits. Decision aids were not used in any visit even though 34% of visits included topics where peer-validated decision aids were freely available.¹⁵⁸

Other observations in US primary care found that 50% of decisions were shared to some extent.¹⁵⁹ Another US study of lifestyle modifications in people with psychiatric disabilities found that decisions were shared between patients and practitioners in 44% of routine consultations where lifestyle behaviours were discussed. In this study shared decision making was defined as sharing information and options about behaviour by either or both practitioner and client and affirmation of a decision by both. This is a rather passive definition of shared decision making, but shows that some involvement in decisions is feasible even within short routine consultations.¹⁶⁰

Some have postulated that there is a spectrum of pressure applied in 'shared decisions'. In other words, not only is the frequency of shared decision making limited but so too is the amount of 'sharing' and partnership involved. For instance, audio recordings of 92 psychiatry consultations in the UK found 'pressured shared decisions' at one end of the spectrum, which are characterised by an escalating cycle of pressure and resistance to conform to a decision preferred by either the patient or the clinician. In the middle were directed decisions, where the patient cooperates with being diplomatically steered by the professional. At the other extreme were open decisions where the patient was encouraged to decide, with little or no pressure. Few decisions were truly shared by both patients and clinicians.¹⁶¹

Many other studies have explored the proportion of decisions that are shared between patients and professionals. The aim of this review is not to derive the proportion of decisions that are shared, but rather to emphasise that research suggests that the proportion of decisions that are shared is relatively low. The mismatch between policy rhetoric and practice may be due to differences in how shared decision making is defined. For instance, professionals may define sharing decisions as providing information or giving patients an opportunity to comment on the decisions that the clinician is making.¹⁶² The low uptake of shared decision making may also be due to professionals not having the skills or the time to fully involve patients as equal partners in care.¹⁶³ Other facilitators and barriers are explored overleaf.

1.5 Summary

Literature suggests that shared decision making involves proactive engagement of patients and professionals working in partnership to share information, consider the pros and cons of different options and make a joint decision.¹⁶⁴ Shared decision making is feasible wherever there is no one best evidence-based course of action. Patients are viewed as experts about their own health, values and lifestyle and professionals are viewed as experts about treatment options and potential risks and benefits.¹⁶⁵

While a substantial amount of policy and research focuses on shared decision making, there is not one universally accepted definition.¹⁶⁶ Patients and professionals may also define the term quite differently and believe that the concept has different objectives.¹⁶⁷

In developed countries the concept of shared decision making is promoted in high-level policy and seen as a crucial component of patient-centred care.¹⁶⁸⁻¹⁶⁹ Health professionals generally say that they support shared decision making, but surveys and observational studies in numerous contexts suggest that there is a mismatch between policy directives, professionals' reports and the extent of shared decision making in practice.¹⁷⁰⁻¹⁷¹

There is significant scope to increase the proportion of decisions that are shared between patients and professionals.¹⁷²⁻¹⁷³ The next chapter explores why it may be worthwhile to do so.

Chapter 2

Does shared decision making work?

This chapter describes evidence about the impact of shared decision making on the six US Institute of Medicine domains of quality: patient-centred experience, effectiveness, efficiency, timeliness, equity and safety.¹⁷⁴ In some instances, few studies have examined the impacts in these areas, but each aspect of quality is examined for completeness.

It is important when interpreting these findings to appreciate that the effects of different interventions and types of shared decision making may vary. When reading this chapter it is important to bear in mind that interventions to encourage shared decision making vary considerably in their aims, approach, content, delivery, duration and target group as well as in terms of the health economies in which they are implemented.¹⁷⁵ It would therefore be misleading to consider 'shared decision making initiatives' as an integrated whole.

2.1 Impact on patient-centred experience

Patient satisfaction

People who participate in decisions and who are given an explanation of their health problems are more likely to be satisfied with their care.¹⁷⁶

A number of studies suggest that shared decision making improves patient satisfaction with health services and with their involvement in care.¹⁷⁷⁻¹⁸³

For instance, a systematic review of 108 studies found that shared decision making was associated with improved patient satisfaction.¹⁸⁴

Another literature review found that shared decision making had a positive effect on patient satisfaction and had more impact than gender, education or the number of healthcare visits.¹⁸⁵

Similarly, a national study of more than 1,000 people with major depression in the USA found that shared decision making improved patient satisfaction.¹⁸⁶

Research about the impact of shared decision making on patient experience tends to focus on the value of specific tools or techniques, such as aids to help patients and professionals communicate more effectively or structured checklists to support the decision-making process.¹⁸⁷

Descriptions about various tools are provided in the next chapter but, in general, research suggests that tools to encourage shared decision making can help patients feel more engaged in decisions and this increases satisfaction with care.¹⁸⁸⁻¹⁹¹

Strategies to involve partners and family members in decision making have also been found to improve satisfaction with care¹⁹² as have initiatives to train professionals.¹⁹³

But not all research is positive.¹⁹⁴ A large randomised trial in Germany found that a structured patient decision support tool for cardiovascular prevention in primary care did not significantly improve satisfaction among patients or doctors. The investigators concluded that better ways to measure the impact of shared decision making are needed, rather than focusing predominantly on patient satisfaction and experience.¹⁹⁵

Another randomised trial in Germany found that using a decision aid for women with suspected breast cancer improved knowledge but did not increase patient satisfaction, decrease conflicts when making decisions, or influence treatment uptake.¹⁹⁶

A randomised trial in Norway tested a computerised decision support system for people with cancer. Patients scheduled for an outpatient visit used the system on a tablet computer to report their symptoms and preferences prior to their consultation. This was then used to generate a report for use in subsequent consultations. There were no differences in patient satisfaction compared to usual care.¹⁹⁷

Communicating about the risks as well as the benefits of different options is an important component of shared decision making. In Wales, researchers explored how doctors communicate uncertainty about treatments and the impact of this on women's decisions and satisfaction with decisions about breast cancer. When doctors talked about uncertainty this reduced women's involvement in, and satisfaction with, the decisions made, but the researchers suggested that in the long term involving patients in decisions might help them tolerate uncertainty. In the short term, however, this component of shared decision making may reduce patient satisfaction.¹⁹⁸

Drawing on the available evidence, we can conclude that while shared decision making has often been found to improve patient satisfaction with care, this is not the case in all research.

Self-confidence

How people think and feel about their health can have a significant impact on their behaviours and outcomes.¹⁹⁹⁻²⁰⁴

Studies suggest that irrespective of preferences for involvement, patients are more confident in decisions in which they perceived they were involved.²⁰⁵

There is evidence that improved self-efficacy or self-confidence about health behaviours is correlated with improved clinical outcomes.²⁰⁶⁻²¹⁴ Correspondingly, some studies have examined the impact of shared decision making on self-efficacy as a proxy for other outcomes. For instance, in the Netherlands, clinicians at three addiction treatment

centres were randomly assigned to encourage shared decision making or to provide care as usual. Shared decision making was associated with an increase in patient autonomy and confidence in independent behaviour.²¹⁵

A number of other studies have suggested improvements in decision-making confidence, particularly from decision aids.²¹⁶ However, the best strategies to encourage self-efficacy remain uncertain.²¹⁷

2.2 Impact on effectiveness

While research generally supports the impact of shared decision making on patient satisfaction and experience,²¹⁸ findings are not conclusive about the impact on clinical outcomes.

For instance, a systematic review of 11 randomised trials comparing shared decision making interventions with usual care found mixed results regarding satisfaction, treatment adherence and health status. Five of the studies found that shared decision making had no impact, one found no short-term effects but positive longer-term impacts, and five trials reported some positive effect on outcome measures, including in mental health.²¹⁹

More positively, feedback from professionals suggests that patients may be more likely to adhere to treatment if they are involved in decisions about their care. For instance, dieticians in Canada reported that people were much more likely to follow through with treatments and actions if decisions were mutually agreed.²²⁰

A randomised trial in the USA also found that shared decisions between people with asthma and clinicians resulted in greater adherence to treatment and better clinical outcomes such as quality of life, symptom control and lung function over a two-year period.²²¹

There may also be some more direct impacts on health outcomes. A trial in the Netherlands found that structured shared decision-making sessions supported drug users to reduce problematic behaviours. This was associated with improved clinical outcomes.²²²

Another example is a survey of 212 people with diabetes in the USA which found that blood pressure control was influenced by a shared decision making style and proactive communication with doctors about self-monitoring and blood pressure results.²²³

A randomised trial in the USA found that patient involvement in decisions improved the quality of care and reduced the symptoms of depression over an 18-month period.²²⁴

Research has also explored the benefits of specific tools and strategies to improve shared decision making, rather than just the decision making style in general. For instance, a goal-setting intervention to improve shared decision making among people with diabetes in the USA was associated with trends towards improved blood glucose control and weight.²²⁵

A trial in Germany compared usual care versus a 20-minute decision aid and a brochure prior to a planning consultation for women with newly diagnosed breast cancer. One year on, those who received shared decision support had better long-term body image outcomes and coping strategies.²²⁶

But other research has been less favourable. A Cochrane review of shared decision making in mental health identified two relevant studies. One study found that shared decision making improved patient satisfaction, the other did not. There was no evidence of improvements in adherence to treatment, clinical outcomes or hospital readmission rates.²²⁷

In Germany, a randomised trial found that people with high blood pressure whose clinicians were trained in shared decision making did not have better clinical outcomes than those who received usual care.^{228–229} Other trials of training health professionals in Germany found similar results for people with a variety of different conditions.^{230–232}

A randomised trial in the USA assessed the impact of a decision aid on perceived risk of heart attacks and medication adherence among people with diabetes. The decision aid improved knowledge but there was no difference in medication adherence or clinical outcomes at three or six months.²³³

Another US trial of a decision aid for people with diabetes found improved knowledge and involvement in decision making about diabetes medications. However, at six-month follow-up there was no difference from usual care in medication use or blood glucose control.²³⁴

A randomised trial of a DVD decision aid for people with heart disease in Canada found no differences in satisfaction or health outcomes after six months compared to those receiving usual care.²³⁵

Another trial in Canada examined the impact of a decision aid for people with atrial fibrillation. There was a short-term improvement in the appropriateness of medication use among people using the decision aid, but this did not last.²³⁶

A randomised trial of training GPs in shared decision making in Wales found no impact on patient outcomes at one-month follow-up, but this may be too short a follow-up period.²³⁷

To summarise, some research has found improved adherence to treatment recommendations when patients are encouraged to play an active role in decision making, though these studies tend to focus on clinician-reported behaviours. There is less conclusive evidence about the impacts of shared decision making on clinical outcomes.

It may be difficult to measure impacts on clinical outcomes, especially because shared decision making may have long-term downstream impacts rather than effects on symptoms that can be easily and quickly measured.²³⁸ Few studies include long enough follow-up periods to allow conclusions to be drawn about longer-term clinical outcomes.^{239–243} This is reinforced by a study in the Netherlands of two assessment sessions followed by individualised treatment information for women at high risk of developing breast cancer. A randomised trial found that this shared decision making approach had no effect in the short term. In the longer term, however, the shared decision making sessions were associated with better general health and less depression.²⁴⁴

2.3 Impact on resource use

There is mixed evidence about the impact of shared decision making or specific decision making tools and techniques on healthcare resource use and cost effectiveness.

Few studies report on the cost of interventions to support shared decision making. An exception is a study of the cost of training GPs in shared decision making in Wales. Training cost £1,218 per practitioner which equated to an increase of £2.89 in the cost of each consultation. Training in shared decision making influenced some prescribing, but did not affect the probability of investigations, referrals or follow-up GP visits. The investigators therefore concluded that unless training has a major influence on consultation length, it is unlikely to have any major impacts on cost.²⁴⁵

There is mixed evidence about the impact of shared decision making on consultation length.²⁴⁶ Some studies suggest that shared decision making is feasible within the usual timespan of consultations,²⁴⁷ but others have found that shared decision making takes more time than 'traditional' care.²⁴⁸

On one hand, doctors and nurses participating in a trial of a decision aid for people considering colorectal cancer screening reported that the tool complemented their usual approach and saved time. The time saved was not quantified or costed.²⁴⁹

However, on the other hand, a study in England examined computer-based decision aids for reducing the risk of stroke in older people with atrial fibrillation. Decision aids significantly prolonged GP consultations. The authors concluded that decision aids may not lead to more 'sharing' in treatment decision making and that they may take too long to use in routine primary care.²⁵⁰

Another example is a training programme for doctors in Germany which was associated with improved consultation behaviours. However, shared decision making was found to be time consuming and needed to be implemented over the course of more than one consultation.²⁵¹

A limited number of studies have directly examined the relationship between shared decision making and the cost of care or quantity of service use. For example, a randomised trial with more than 600 people in the USA

found that shared decisions between adults with asthma and clinicians resulted in reduced health service use over a one-year period.²⁵²

In the Netherlands, a blood loss chart was used to help women with problematic blood loss from the uterus decide on appropriate treatments. Using the chart resulted in a 50% reduction in retreatments within one year. Although an extra clinic visit was needed to use the chart for shared decision making, the costs were offset by lower overall treatment costs and more favourable cost per quality adjusted life year gained.²⁵³

Other evidence about the cost effectiveness of shared decision making is indirect. For example, a randomised trial in Canada found that training GPs in shared decision making reduced the proportion of people with respiratory symptoms who decided to use antibiotics immediately after consulting their doctor. This is important because it may reduce medication bills and also complications and follow-on care arising from unnecessary use of antibiotics.²⁵⁴⁻²⁵⁵ Other studies have found similar reductions in unnecessary medication use.²⁵⁶

A randomised trial in the USA examined the impact of a decision aid with individualised risk information for women with breast cancer. The tool resulted in fewer women with tumours of low severity choosing adjuvant treatment, thus saving resources.²⁵⁷

However, other research is not as favourable. Most such studies evaluate the effects of specific tools to support shared decision making rather than the concept and practice of shared decision making itself.

For example, in Germany people with schizophrenia received a decision aid about medication choices and a planning talk with a doctor. Shared decision making was not associated with improved long-term medication compliance or readmissions to hospital compared to a control group receiving usual care.²⁵⁸

A randomised trial in Finland evaluated the effects of a decision aid for more than 500 women with heavy menstruation. A booklet explaining the condition and treatment options was posted to patients before their first hospital outpatient appointment. The decision aid improved treatment, but there were no marked differences from usual care in health outcomes, satisfaction with treatment, or costs.²⁵⁹

2.4 Impact on timeliness

The review identified no studies that examined the extent to which shared decision making impacts on the timeliness of care provided as a primary outcome.

2.5 Impact on equity

Few studies have examined the extent to which shared decision making impacts on equity in healthcare.

In the USA, black and Hispanic people have been found to be less likely to share decision making than white people²⁶⁰⁻²⁶² and this may contribute to poorer healthcare and health disparities.²⁶³ However, good quality studies have not directly investigated whether initiatives to strengthen shared decision making also improve equity and access to health services and reduce health disparities.

2.6 Impact on safety

Few studies have examined the extent to which shared decision making impacts on patient safety. Those that do exist tend to focus on the potential for enhancing safety by reducing reliance on unnecessary medications or reducing adverse effects rather than decreasing the rate of healthcare errors.²⁶⁴⁻²⁶⁵

2.7 Summary

Despite a great deal being hypothesised about the benefits of shared decision making, there is relatively limited robust research available. There is evidence that shared decision making improves satisfaction with care,²⁶⁶ but little research about safety, timeliness or equity. There are mixed findings about clinical outcomes and resource use. Some studies have very favourable findings,²⁶⁷⁻²⁶⁸ but others show no difference from usual care.²⁶⁹⁻²⁷¹

The mixed nature of the evidence base implies that shared decision making may be most effective when used as part of a broader ethos of care. A review found that patients who engage in collaborative care, share decision making with professionals and self-manage their conditions have improved health outcomes. Shared decision making was just one component of improving health outcomes and may not have this impact if used alone.²⁷²

Chapter 3

Tools to support implementation

Various tools and techniques have been tested to encourage shared decision making. This chapter summarises approaches targeting patients, professionals and the wider healthcare system.

3.1 Tools targeting patients

A variety of approaches have been researched to help patients share decision making. These can be conceptualised on a continuum with more passive information sharing approaches at one end and more active planning and support at the other – see Figure 1. Approaches are summarised in this chapter beginning with more passive strategies.

Printed and electronic information

Providing information about people's conditions and the options for managing them is an important aspect of supporting shared decision making.²⁷³ Information can be provided using leaflets, websites, email, text messages, electronic forums, by telephone and in person individually or in groups.^{274–275}

A great deal has been written about different ways to provide healthcare information to support shared decision making or self-management.²⁷⁶ Much of the literature sees sharing in decisions as one component of supporting self-management.^{277–278}

There is some evidence that written motivational leaflets or letters can help people feel more confident to raise their concerns and discuss their symptoms,²⁷⁹ but there is sparse evidence that such methods improve decisions, self-management behaviours or clinical outcomes.²⁸⁰

Reviews and studies suggest that printed information can improve knowledge,^{281–283} but may not impact on behaviour when used alone.^{284–285}

However, findings are mixed. Some trials suggest that posted educational materials are as effective for improving symptoms and self-efficacy as group education sessions.²⁸⁶ There is also evidence that combining written information with lectures or other educational activities can be more effective than written information alone for supporting self-management and shared decision making.²⁸⁷

Some studies suggest that targeting and personalising information is more effective than standardised materials.^{288–291} Most of these studies focus on the impacts of written information on self-management and self-efficacy. Shared decision making may be one component of this, but is not usually the sole outcome examined.

A novel approach was used at one psychiatric medication clinic in the USA. The waiting area was converted into a peer run 'decision support centre' featuring a user-friendly computer programme that helped patients with severe mental disorders create a one-page report for use during the consultation. The intervention was well used and well regarded by patients and professionals. It reportedly improved efficiency during consultations and empowered patients to become more involved in making decisions about their care.²⁹²

Information prescriptions are gaining popularity. In England, the Department of Health has developed an initiative whereby everyone with a long-term condition or social care need is supposed to be

offered an ‘information prescription’ to help guide people to relevant and reliable sources of information and help them feel more in control of their care.²⁹³ Information prescriptions may contain details about people’s conditions and treatments, benefits, support groups and local health, social care and other services. As yet there has been limited evaluation about whether information prescriptions can include, or act as, decision aids, but work in this area is ongoing.²⁹⁴

Various technologies have also been used to provide information to support shared decision making including text messages, computer programmes and DVDs.²⁹⁵ These technologies tend to have similar outcomes to written information materials: they may increase knowledge, but their impact on longer-term patient activation and clinical outcomes is uncertain.²⁹⁶

Patient-held and electronic records

Another strategy to increase people’s involvement in healthcare processes and decision making is providing people with access to, and more control over, their care records. Sometimes people are given their medical records to keep and bring to each consultation, which is known as patient-held records. Another approach is to allow online access. There is some evidence that this is welcomed by patients.²⁹⁷

It has been suggested that giving people access to their health records can be a driver to enable people to take more control over their health and manage their care more effectively.²⁹⁸ Patient-held records might also be a lever for improving the quality of care.^{299–301}

Some suggest that giving people access to their records electronically may benefit both patients and GP practices.³⁰² Being able to view their medical records from anywhere at any time may help people feel more in charge of their health and improve relationships between patients and the GP practice.^{303–306}

A randomised trial in the USA provided patient records online to people with heart failure. After one year, those who had access to their records online were more likely to adhere to treatment, but there were no differences in self-efficacy or satisfaction with care.³⁰⁷ This suggests that

patient-held records and electronic access may have some benefits, but they do not necessarily help people share in decision making.

Although this approach is gaining popularity, a number of reviews and trials suggest that patient-held records and access to electronic records have limited effects on shared decision making and self-management behaviours.^{308–309} The evidence is too mixed to suggest that patient-held records are a useful enabler for shared decision making.

Thus, based on the evidence, we conclude that encouraging patients to have control over their health records may be useful but not sufficient to shift the balance of power within consultations. In this view, access to, and control over, care records needs to be seen in the context of a changing relationship between healthcare providers and patients.^{310–311} The value of patient-held records is therefore not simply about access to information – it is a component of changing the broader model of care.³¹²

Traditionally, the provision of health information may focus on a paternalistic model of care whereby the ‘doctor knows best’ and where information is for clinicians to use in determining what patients should do.³¹³ To encourage shared decision making, patient records may need to shift from being a passive archive for recording information towards being an active tool for supporting both the patient and the clinical team.³¹⁴

Decision aids for patients

Decision aids have been developed to encourage patients to be actively involved in decision making. These take a variety of forms including online applications and computer programs, DVDs, games, worksheets and leaflets.

*Decision aids based on the philosophy of shared decision making are designed to help patients make informed choices among diagnostic or treatment options by delivering evidence based information on options and outcomes.*³¹⁵

A great deal of research has been undertaken about decision aids of many forms.^{316–343}

For example, ‘decision boards’ have been designed to help clinicians present options and include patients in decision making. They often comprise clinical information, different treatment options and description of potential benefits and side effects. Patients are encouraged to select what they think are the three worst side effects and are then informed of the probability that these will occur. Tests in Brazil found that tools like these can work well to improve patients’ knowledge and participation.³⁴⁴

A randomised trial in the USA tested a decision board to encourage shared decision making in dentistry. The decision board included treatment alternatives, benefits, risks, prognosis and costs of procedures such as root canals and tooth extractions. The group using the decision board had better knowledge but no change in satisfaction or anxiety compared to usual care.³⁴⁵

Another example is ‘outcome wheels’. These have been used immediately following stroke to display information simply and help patients and their families share in making informed decisions in a time sensitive manner. The tools visually display outcomes and the role of chance in a ‘spin the wheel’ manner.³⁴⁶

Games and interactive activities have also been tested. In the USA, men with prostate cancer were invited to play an interactive ‘game’ to assist with decision making. Focus groups and a survey found that the game was a useful and appropriate decision tool which helped to increase awareness of the pros and cons of treatment and generated questions for patients to ask clinicians.³⁴⁷

Although offered in different formats, many decision aids have characteristics in common, including providing facts about the condition, options and outcomes; helping patients clarify their values and what matters to them most; and helping people think through the pros and cons of different options so that they can make informed choices.³⁴⁸

Systematic reviews and studies suggest that evidence-based decision aids can improve patients’ knowledge, ensure a better understanding of treatment options and help people more accurately perceive the benefits and risks of different options.^{349–363}

For instance, a literature review found that multimedia decision aids or support systems can improve the quality of decision making in terms of enhancing knowledge, reducing decisional conflict, and customising education and coaching for people with cancer.³⁶⁴

Another systematic review of 23 randomised trials found that people with cancer using decision aids were more likely to participate in decision making and achieve higher-quality decisions.³⁶⁵

Another systematic review of 11 studies found that decision aids improved knowledge, involvement in decisions and satisfaction with the decision-making process among women with breast cancer. Decision aids were well received by clinicians and patients and were feasible to use in routine practice.³⁶⁶

In the USA, a computerised decision aid was used to help women with breast cancer make decisions about reconstructive surgery. Those who used the computer learning module reported having a greater role in choosing the type of reconstruction, said that more reconstructive options were offered to them and were more satisfied with the amount of information they were provided with.³⁶⁷

Research suggests that decision aids can be useful when weighing up the benefits and harms of different treatments or screening options,^{368–372} when considering symptom management and the most appropriate level of care^{373–374} and when managing long-term care in a manner informed by patient values.^{375–376}

A randomised trial in the USA tested an interactive computer-based decision aid for cancer screening. In total, 665 people of average risk were allocated to receive the decision aid alone, the decision aid plus a personalised risk assessment or usual care. The decision aid was used just prior to a scheduled primary care visit. Those receiving the decision aid alone or with a risk assessment had better knowledge and were more likely to make a decision about screening tests. However, professionals only complied with patient preferences in six out of 10 cases. The researchers concluded that decision aids can help patients identify their preferences but their overall effectiveness depends on the extent to which professionals are willing to discuss and take on board patients’ views.³⁷⁷

The benefits of decision aids may also depend on how they are disseminated. A comparison of distributing video decision aids for prostate cancer using four methods found that automatically mailing decision aids to all appropriate patients improved uptake of screening but also led to ineligible patients receiving decision aids. Non-automatic distribution strategies led to low rates of receipt. The researchers concluded that automatically distributing decision aids is more effective than relying on clinicians to give material to people.³⁷⁸

Most studies of decision aids focus on people with a relatively narrow range of conditions.³⁷⁹ Research is not universally positive and there is still a lot to learn about how to implement decision aids.³⁸⁰ For instance, a trial of a decision aid for people with multiple sclerosis found improved knowledge but no impact on the roles adopted in consultations or the choices made. The researchers concluded that providing patients with balanced information and decision aids may not be sufficient to alter the decision-making process.³⁸¹

However, despite these caveats, the totality of evidence suggests that, when used as part of a broader support intervention, decision aids help to increase patient involvement in decision making and enhance patients' confidence in the process.^{382–383}

There are studies suggesting that decision aids in many different formats have benefits, however, few studies compare different types of decision aids or consider which might work best in various contexts or for certain audiences. An exception is a US study comparing a standard brochure versus a video decision aid about cancer screening in 13 primary care practices serving racially and ethnically diverse patients in economically disadvantaged neighbourhoods. The video decision aid increased knowledge but made people more likely to want to make the decision themselves rather than in partnership with their doctor.³⁸⁴

Some suggest that decision aids are best when accompanied by training of clinicians.³⁸⁵ An example of this is a set of decision aids developed for people with suspected stable coronary artery disease being asked to make decisions about operations and interventions. Decision aids were implemented alongside Grand Rounds, training

in communication skills and clinical evidence for professionals, a patient group visit and a scheduled discussion between patients and professionals.³⁸⁶

Decision aids may work better for some groups than others. For instance, a US study examined the reach and impact of five decision aids distributed to 549 women with breast cancer. Decision aids were associated with increased knowledge and decreased conflict or uncertainty about decisions. Improvements were most likely among those who knew less at the outset, those who were uncertain about their choices and women from minority ethnic groups.³⁸⁷

Similarly, a randomised trial in the USA found that a CD-ROM decision aid for women at high risk of breast cancer was most effective among those who were initially undecided about how to manage their breast cancer risk. Within this group, the decision aid led to an increased likelihood of reaching a management decision, decreased decisional uncertainty and increased satisfaction. Among women who had an idea about their treatment options from the outset, the decision aid had no impact on knowledge or satisfaction.³⁸⁸

It might be hypothesised that providing people with information about various options could be overwhelming or lead to uncertainties. However, research does not suggest that using decision aids makes people more nervous, anxious or uncertain about their care.^{389–394} Some studies have found that decision aids can increase anxiety in the short term, but this does not usually last for a significant amount of time.³⁹⁵

Instead, such tools may encourage patients and their family members to take more responsibility for their care, help people feel more in control, encourage health professionals to follow recommended care protocols and have some impacts on quality of life.³⁹⁶

A randomised trial of a decision aid for people with diabetes found that the tool even improved patients' trust of healthcare professionals by increasing knowledge and involvement in decisions and reducing uncertainty.³⁹⁷

But reviews and studies of decision aids suggest that such aids generally affect attitudes and knowledge rather than behaviours.^{398–401}

An exception is in behaviours related to screening tests for cancer and other conditions. Here, there is some evidence that decision aids may influence behaviours such as either increasing or decreasing screening for cancer or genetic conditions.^{402–407}

There is no evidence that decision aids increase patient demand for expensive or inappropriate treatments. In fact, decision aids may support more cost-effective care if they help patients choose less expensive treatments, or can be cost neutral.⁴⁰⁸

One study found that decision aids were associated with significant reductions in the rate of elective surgery, with no adverse effects on patient satisfaction or health outcomes.⁴⁰⁹

There are mixed findings about whether decision aids increase the duration of consultations.^{410–411} For instance, in Belgium a decision aid was tested for men with prostate cancer. The decision aid helped men become more active partners in decision making. Men were more likely to discuss issues with their family, were better prepared for consultations with their doctors, asked more questions and were better able to make choices. The decision aid improved the quality of the consultation and usually resulted in a treatment decision agreed upon by both parties. However, sometimes consultations were more time consuming.⁴¹²

Action plans

A proactive care plan or action plan is a document collaboratively designed by service users and professionals covering issues, interventions and review processes.⁴¹³ Action plans may include both goal setting and planning how to achieve these goals.^{414–415} Although action plans are not always positioned as a tool to support shared decision making, these have sometimes been used as tools to actively engage people in decisions. If constructed appropriately, action plans involve patients and professionals discussing and agreeing on a course of action. Thus they can be key tools for facilitating shared decision making.

There is evidence that action plans or proactive planning may improve self-management behaviours for people with long-term conditions,^{416–421} and this may impact on healthcare resource use.^{422–424} Numerous examples are available. For instance, systematic reviews support

an action plan coupled with self-adjustment of medications and regular medical review for people with asthma.^{425–426}

Electronic care planning systems have been proposed as a mechanism to support both patient and professional decision making and to improve communication, especially in fields with high staff turnover. A randomised trial in the USA tested a community mental health system which allowed patients to build their own care plans electronically during consultations with case managers. Patients who used the electronic system were more likely to recall and adhere to aspects of their care plan, but were no more satisfied with care.⁴²⁷

Whether written or electronic, there are questions about whether action plans and tools to facilitate joint care planning are favoured by patients and professionals⁴²⁸ or directly impact on clinical outcomes.^{429–430}

Evidence about the impact on healthcare resource use is mixed.⁴³¹ While some studies have found that action plans and goal setting can reduce the use of GP and hospital appointments,^{432–433} other reviews and trials have found limited benefits,^{434–435} particularly for those who have been hospitalised.^{436–437}

Studies have attempted to explore why action plans work well sometimes and not at other times, but few firm conclusions are possible. Some studies suggest that action plans are most effective for engaging patients when they are used as one component of a broader programme.^{438–439}

Others have found that action plans work best in primary care rather than in hospital.⁴⁴⁰ This approach may be better as a ‘preventive’ measure or to manage stable conditions rather than for those with the most severe disease or for those who are hospitalised for the first time.⁴⁴¹

An important component of action plans may be joint goal setting.⁴⁴² Jointly setting goals for treatment and care can encourage patients and practitioners to identify their core values and make decisions together. A number of studies have outlined the benefits of goal setting, particularly for people with long-term conditions.^{443–457}

For instance, a trial in the USA found that personalised goal setting as part of a broader self-management support intervention for older women with heart conditions was associated with reduced days in hospital and reduced overall healthcare costs.⁴⁵⁸

Opportunities for patients to receive ongoing support following goal setting may be a key success factor.^{459–465} This follow-up can be undertaken by professionals or can be automated using electronic devices such as computer programmes or text messages.⁴⁶⁶ For example, a small randomised trial found that discussions about goal setting which included proactive follow up by professionals improved the use of community resources, physical activity and adherence to medication.⁴⁶⁷

Other trials have found improved self-care knowledge and behaviours^{468–469} and reduced hospital admissions and days in hospital when proactive follow-up is used.⁴⁷⁰

The best frequency and method for following up goals that patients and professionals have set together remains uncertain. A US trial compared telephone follow-up every month or every three months. There were no significant differences between these follow-up intervals on any clinical outcomes or quality of life.⁴⁷¹ This demonstrates that there is still a lot to learn about the best strategies for supporting shared decision making using goal setting and follow-up approaches.

It is also important to note that most studies of action planning and goal setting are focused on broader self-management outcomes rather than solely shared decision making. Shared decision making is often seen as a tangential outcome in these studies and a proxy for the wider concept of self-management because it is hoped that by sharing in decisions, people will take more responsibility for their health and care.

Communication tools

Good communication is an essential ingredient for shared decision making⁴⁷² but patients and professionals rarely know what makes ‘good communication’.⁴⁷³ Therefore tools have been tested to improve communication processes. In the USA, 180 patients were randomly assigned to standard care or to use a written communication tool to facilitate patient–doctor communication. The tool

improved how patients and doctors perceived communication and input into decisions. Helping patients structure their communication using a written tool helped patients improve the way they described their health concerns, organise their needs and questions and be more proactive.⁴⁷⁴

The World Health Organization has developed a tool to support family planning decisions in developing countries. Tests in Indonesia, Mexico and Nicaragua found that the tool improved the extent to which patients communicated and were involved. It also improved the way professionals communicated with patients, helping them engage people more and provide a better quality and quantity of tailored information.⁴⁷⁵

The difference between these tools and decision aids is that communication tools are specifically focused on improving consultation skills and communication techniques, whereas decision support tools may also have these effects but focus more on supporting patients through the steps needed to ask questions and make informed choices.

Individual education and coaching

Research is beginning to emerge about proactive educational sessions to support shared decisions.⁴⁷⁶ A systematic review of 15 initiatives to promote informed decision making included one-to-one counselling, small group education, strategies targeting professionals, technologies and combinations of these approaches. Individual counselling and group education were found to improve patients’ knowledge about their conditions and the pros and cons of treatments.⁴⁷⁷

‘Decision counselling’ involves one-to-one sessions to provide background information and consider each decision step in a structured manner. A randomised trial compared usual care versus a nurse-led decision counselling session prior to a man’s usual appointment with the GP to discuss prostate cancer screening. One-to-one discussion sessions were associated with improved knowledge and more informed decision making, though men taking part were less likely to be screened compared to the control group.⁴⁷⁸

Similarly, in the Netherlands, drug users were invited to take part in five educational sessions to support shared decision making. A randomised trial found that this approach improved drug use and reduced psychiatric problems.⁴⁷⁹

Some studies are beginning to explore the use of peer counsellors to support shared decision making, particularly in mental health.⁴⁸⁰ However, this research is in its infancy.

Group sessions

This review identified only a small number of studies focused on group sessions or meetings for patients to enhance shared decision making, but initial indications are positive.

For instance, 61 inpatients with schizophrenia or schizoaffective disorder in Germany were randomly assigned to receive training in shared decision making or cognitive training (control condition). Training in shared decision making increased people's desire to take more responsibility in treatment decisions, which continued to six-month follow-up.⁴⁸¹

Researchers in Australia assessed the feasibility and acceptability of involving women diagnosed with breast cancer in multidisciplinary clinic discussions and treatment planning. This was valued by most patients and acceptable to most health professionals. There was no increase in anxiety.⁴⁸²

3.2 Tools targeting professionals

Research suggests that many health professionals may support shared decision making, but need help to implement it in practice.⁴⁸³ A number of studies have tested tools and techniques that professionals can use to better support shared decision making. Most of these focus on training to upskill clinicians in shared decision making.

A Cochrane systematic review of initiatives to improve the adoption of shared decision making by health professionals identified five relevant randomised trials. Three studies took place in primary care and two in specialised ambulatory care. Four of the studies targeted doctors only and one targeted nurses only. Only two of the trials found a significant improvement in shared decision making. The first compared supporting

professionals to use a patient decision tool versus a standard patient information leaflet. The second study compared usual care versus a multifaceted intervention comprising educational materials, an educational meeting and audit and feedback. The reviewers reported that it was not possible to draw firm conclusions about the most effective types of intervention for increasing health professionals' adoption of shared decision making. However, training to develop new skills and attitudes may be important, particularly in tandem with patient-focused interventions such as decision aids.⁴⁸⁴

Approaches to training professionals

In order for patients and professionals to have a more equal role in decisions about care, professionals need a variety of skills. These range from technical communication and interpersonal skills to more fundamental changes in attitudes about the relative roles and expertise of patients and professionals.^{485–486}

A number of formal training approaches have been tested to build skills and overcome resistance to shared decision making among clinicians, including at preregistration stage and as continuing professional development. In fact, a recent international symposium identified 53 training programmes specifically about shared decision making from 14 countries. These programmes varied significantly in scope, duration and approach. The group suggested that more work is needed to develop competencies for shared decision making and to accredit continuing professional development initiatives.⁴⁸⁷

There are likely to be many more informal, ad hoc or localised programmes.^{488–489} For example, a randomised trial in Wales, that involved 20 practices and 747 patients, found that training GPs in shared decision making improved communication and heightened patient involvement in decisions. Listening, providing easy-to-understand information and a greater quantity of information, encouraging shared treatment decisions and longer consultation durations all improved patient experiences.^{490–491}

Doctors had positive attitudes towards shared decision making from the outset and the training did not enhance views about patient involvement. However, it did increase confidence in shared decision making skills.⁴⁹²

The researchers found that doctors who received training in shared decision making reported positive impacts on their consultation style. However, they said that there was limited opportunity to apply their skills and shared decision making tools outside the formal study. GPs were selective about when they felt greater patient involvement was appropriate and feasible, rather than trying to apply shared decision making approaches to most consultations. They attributed this lack of implementation to consumer preferences for low levels of involvement and the limited time available in consultations.⁴⁹³

Examples are available from other countries too. A small randomised trial in Canada found that continuing medical education for GPs about shared decision making helped to reduce the unnecessary use of antibiotics. GPs took part in three three-hour workshops over a four- to six-month period.⁴⁹⁴

Elsewhere in Canada, training for GPs was also found to be feasible and to help GPs change their consultation style.⁴⁹⁵

A randomised trial in the USA tested shared decision making training for hospital doctors treating people with chronic pain. The training involved two one-hour sessions. Those who took part in the training reported better relationships with patients, greater doctor satisfaction with care, better use of time and more appropriate care.⁴⁹⁶

Elsewhere in the USA, a programme was tested to help clinicians involve patients in shared decisions about end-of-life care. The programme included six hours of workshops and two hours of one-to-one interaction between trainers and clinicians. Doctors, medical students, social workers and nurses took part. Evaluations found some improvement in clinicians' skills.⁴⁹⁷

In Germany, a number of voluntary training programmes about shared decision making have been developed for doctors.⁴⁹⁸⁻⁵⁰³ For instance, a study of 150 doctors taking part in an eight-hour programme found improved knowledge and confidence about shared decision making. Experienced, middle aged doctors were more likely to take part in the training, particularly GPs and those with positive attitudes towards shared decision making from the outset.⁵⁰⁴

A trial in Germany found that training doctors in shared decision making was associated with improved patient knowledge about their condition and use of medication.⁵⁰⁵

Another trial in Germany tested training for doctors and a computer-based decision support tool for patients. One group of patients had access to the computer program and gained care from doctors who had received training. Another group had access to the computer program and gained care from doctors who had not been trained and the final group received usual care. The training and the decision aid were both associated with increased involvement in decisions about treatment and better treatment decisions.⁵⁰⁶

A training programme about shared decision making in depression was developed for 20 GPs in Germany. The training included depression-specific components regarding diagnosis, patient information and therapy and general components such as communication and shared decision making skills. Five sessions were run over a six-month period, totalling 20 hours of training. GPs reported that they were able to use the skills learnt in routine practice.⁵⁰⁷

However, elsewhere in Germany, training GPs in shared decision making did not improve the clinical outcomes of patients over a year-long period.⁵⁰⁸

Other studies have found inconclusive results.⁵⁰⁹ The literature leads us to suggest that training tends to be associated with improved skills and knowledge, but not necessarily better outcomes for patients.

For instance, a randomised trial in Germany tested shared decision making training for doctors supporting people with fibromyalgia. All patients received access to a computer-based information package and were treated by a doctor as usual or a doctor trained in shared decision making. The training improved interactions between patients and doctors but did not impact on choices or clinical outcomes.⁵¹⁰

Most published articles about training approaches describe whether the programme improved the knowledge and attitudes of professionals. Some also examine skills and behaviour change. However, few examine the follow-on impacts for interactions with patients, clinical outcomes or value for money.

Most studies do not provide enough details of what was included in the training or what teaching methods were used to allow such programmes to be replicated in other settings.

From the limited information available, it appears that the most successful courses tend to include content to encourage professionals to respect patients' autonomy and use strategies such as skill building workshops, electronic tutorials, familiarisation with decision aids, structured decision support protocols, practice with real or simulated patients and feedback about performance.⁵¹¹⁻⁵¹⁵

Journal articles

Another strategy to support shared decision making involves published articles for professionals.

Researchers in Canada explored whether journal articles for professionals might improve shared decision making. They assessed 30 articles about clinical topics published in five peer-reviewed and non-peer-reviewed medical journals, offered without charge to primary care doctors. The articles tended to focus on describing health conditions and treatment options. Possible harms and methods to help communicate about benefits and harms to patients were almost never described. The researchers concluded that continuing medical education articles may not include the information needed to support shared decision making in clinical practice.⁵¹⁶

Prompts, reminders and guidelines

Prompts and reminder systems to support shared decision making have been tested, with mixed success.⁵¹⁷⁻⁵¹⁹

For instance, in Norway a computer system was developed to remind nurses and doctors to facilitate patient choice among people with cancer. Interviews with nurses and doctors found that the system was well used, especially by nurses. No information was available about the effect on patient outcomes.⁵²⁰

Nurses in Norway also tested a palm top-based decision support tool to help elicit patient preferences for care in hospital. The tool helped to change nursing care to be more consistent with patient preferences.⁵²¹

In Belgium, clinical practice guidelines were used to support shared decision making when introducing assistive devices in home care. Surveys with 116 home care workers and nurses and 140 people with disabilities found that nurses thought that the guidelines increased shared decision making but this effect reduced over time. Patients generally did not think the guidelines had made a difference.⁵²²

3.3 Targeting systems issues

Most interventions target patients or professionals, usually as separate groups. Apart from studies described in other sections, this review did not identify empirical evidence about system or organisational level interventions to support shared decision making.

3.4 Summary

Strategies to increase shared decision making have predominantly targeted patients, although some interventions to support and educate professionals have also been tested. Research suggests that the most effective strategies may include:

- decision aids of various types⁵²³⁻⁵²⁸
- action plans and goal setting⁵²⁹⁻⁵³³
- structured one-to-one or group support for patients⁵³⁴⁻⁵³⁹
- training to enhance the skills of professionals.⁵⁴⁰⁻⁵⁴⁷

For both patients and professionals, the range of initiatives tested lies along a continuum with passive information provision at one end and more active support at the other. There is no clear evidence about which approaches are most effective, but the evidence suggests that proactive strategies may be necessary to sustain change.

Crucially, however, it is important to see these approaches as tools rather than as an end in themselves. The most fundamental requirement to enhance shared decision making may be ensuring that patients and professionals both support and see the value of this.⁵⁴⁸⁻⁵⁴⁹ There is no strong evidence about the best ways to facilitate such an underpinning change in culture and attitudes. Training sessions may play a role, but cannot be relied on alone to facilitate change.⁵⁵⁰

Chapter 4

Facilitators and barriers

In addition to research about specific tools and techniques for implementing shared decision making, studies have also examined factors that may act as facilitators or barriers. This chapter outlines some of the factors that may help or hinder the embedding of shared decision making into everyday care.

4.1 Characteristics of patients

Values and attitudes of patients

The attitudes, opinions, emotional readiness and life experience of patients may influence the extent to which they want to share in decision making or feel comfortable doing so.^{551–554}

For instance, researchers in Canada found that women considering screening for anomalies during pregnancy were more willing to engage in shared decision making if they had positive attitudes, good self-efficacy and if they thought that their GP had a positive attitude.⁵⁵⁵

A systematic review of 40 studies found that interpersonal relationships, preservation of current wellbeing, quality of life, need for control and perceptions of benefits and risks for individual circumstances were all important when people with chronic kidney disease made decisions.⁵⁵⁶

Patients' attitudes and values are likely to interact with the attitudes and behaviours of professionals to influence shared decision making. Research about these interactions is summarised overleaf.

Patient demographic characteristics

Demographic characteristics such as age may influence the extent to which people want to share in decisions. For instance, reviews and studies suggest that younger people are more likely than those over 60 to want to take part in decision making,^{557–561} though this is not always the case.^{562–563}

Research suggests that some older people may prefer a more paternalistic or directive style of interaction with clinicians.⁵⁶⁴ In fact, one US study found that about half of older people preferred a passive role in healthcare decision making.⁵⁶⁵

There are examples of this trend from many parts of the world. For example, a study in Switzerland found that two-thirds of people wanted to leave decision making to their doctors. Those who preferred shared decision making were more likely to be younger, better educated and in more discomfort.⁵⁶⁶

Another survey of 1,040 people recently discharged from hospital in Switzerland found that older people and those who were less educated were more likely to think that advice from doctors should not be questioned and that doctors should have control over all healthcare decisions.⁵⁶⁷

A national survey of 999 people with long-term conditions in Australia examined how different relationships between patients and professionals may impact on shared decision making. Patients aged between 18 and 34 years were more likely to have an unhappy relationship with clinicians and were less likely to share in decisions about

their care. Those aged 65 or older were more likely to have, and to be happy with, a paternalistic or clinician-directed relationship.⁵⁶⁸

Another national survey in Lithuania found that younger and more educated people have less trust in the healthcare system and are more motivated to play an active role in healthcare decision making.⁵⁶⁹

However, there is evidence that older people can be engaged in shared decision making with the right type of support and when they trust their clinicians.⁵⁷⁰

Preferences for involvement may not remain stable over time. Researchers in Germany found that people may want to be more involved when they are younger but to change and want more doctor-led decisions as they get older.⁵⁷¹

There are no consistent findings about the impact of gender.⁵⁷²⁻⁵⁷³ A survey of elderly people hospitalised in Sweden found that gender did not influence the extent to which people wanted to be involved in decisions.⁵⁷⁴ But a study in the USA found that men might be more likely to be involved in some healthcare decisions than women.⁵⁷⁵

On the other hand, researchers in the USA compared the perceptions of women and men regarding involvement about decisions in hospital following a heart attack. Younger patients and women placed significantly more value on shared decision making than men. Women were more likely to be dissatisfied with the level of involvement they had.⁵⁷⁶ These findings have been replicated in other studies, care contexts and countries.⁵⁷⁷⁻⁵⁸⁰

A postal survey with more than 2,300 members of the general public in Switzerland found that, on average, people favoured shared or active involvement in medical decisions, but attitudes varied considerably. Those who wanted greater levels of involvement or autonomy were more likely to be women, younger, more highly educated, living alone, reporting good health and have experience in making healthcare decisions.⁵⁸¹

Yet, research in Germany found that although educational background and age influenced the extent to which patients wanted to have some control over treatment decisions, there was no difference between men and women or based on medical or treatment characteristics.⁵⁸²

In England, investigators found that 40% of people wanted to be involved in decisions about heart care. There were no differences in terms of age, gender or ethnicity. Cardiologists were more likely to involve patients in decisions about severe disease.⁵⁸³

The cultural and sociopolitical context of healthcare might be an important facilitator of shared decision making that interacts with patient demographics.⁵⁸⁴ Researchers compared preferences for shared decision making among more than 2,300 people from eastern and western Germany. People in eastern Germany had less preference for shared decision making than those in western Germany, even after controlling for demographic variables. The researchers concluded that cultural values have a significant influence on people's expectations and behaviour in healthcare encounters.⁵⁸⁵

Similarly, comparisons between Japan and the USA have found that Japanese people may be more likely to prioritise autonomous patient decision making compared to US patients who prefer shared decision making. Despite the cultural differences, in both countries people wanted to participate more in decision making.⁵⁸⁶

It is unclear whether there are any ethnic differences in preferences towards shared decision making in healthcare.⁵⁸⁷ Most work in this area is based in the USA, where research suggests that black and Hispanic people are more likely to experience lower quality communication with health professionals and are less likely to share decision making than white people.⁵⁸⁸⁻⁵⁹⁰ This may, in turn, contribute to health disparities.⁵⁹¹

Studies have found that black people in the USA believe that the communication skills and attitudes of professionals can have a significant impact on their involvement in healthcare decisions.⁵⁹² For example, black people report that doctor bias or discrimination and cultural discordance may influence the extent of shared decision making in consultations.⁵⁹³ Doctors might be less likely to share information and more likely to be domineering with black patients. Black people have reported a range of other barriers to shared decision making including mistrust of white doctors, negative attitudes, internalised racism, not being forthcoming with doctors about health information, having greater deference to doctors and being less likely to adhere to treatment regimens.⁵⁹⁴

A study of the barriers and facilitators to shared decision making among black people with diabetes identified imbalances in patient–clinician power that were perceived to be exacerbated by ethnicity, poor health literacy, fear and denial, family experiences, self-efficacy and clinician accessibility and interpersonal skills.⁵⁹⁵

However, a large survey in 17 US states found that ethnicity did not influence whether or not people wanted a shared role in agenda setting, information exchange or decision making. In some instances black patients were more likely to report initiating discussions with their doctors than those from other ethnic groups and black people wanted shared decision making just as much as other patients.⁵⁹⁶

The extent to which these findings are generalisable to ethnic minorities in countries such as England is uncertain.

There is some evidence that professionals may treat minority ethnic groups differently to white people. For example, interviews with obstetricians, GPs and midwives in England found that clinicians thought that involving people in decisions about their care was a key element of their role. But professionals sometimes used cultural differences between patients to justify not involving minority groups as much in shared decision making. Minority ethnic groups were judged by clinicians to be more passive and less rational in decision making.⁵⁹⁷

Similarly, research with immigrants in the Netherlands identified a number of barriers to shared decision making including linguistic issues, patients and clinicians not having similar values about health and illness, not having similar expectations about roles, and patients and doctors having prejudices and speaking to each other in a biased manner.⁵⁹⁸

Education may also play a role, with people with higher formal education often attributed as being more engaged in decision making or wanting to be more engaged.^{599–605}

A study in Canada found that less educated women were less likely to engage in shared decision making, largely because they lacked confidence in their ability to understand information and make decisions.⁶⁰⁶

Feedback from 100 people living in care homes in Canada found that those with higher levels of formal education, a greater number of long-term conditions and greater confidence about the worth of their input tended to prefer more active involvement in decision making.⁶⁰⁷

In Germany, 203 people with schizophrenia or multiple sclerosis were surveyed about whether they wanted to share in decision making about their care. People who were more highly educated, who were not satisfied with their treatment and who thought that they had good decision-making skills were more likely to want to be involved in decision making. People who thought that they had poor capacity to make decisions and those who were less well educated preferred not to participate in decision making.⁶⁰⁸

A survey of people from Germany and the USA found that those with low numeracy often wanted to be more passive in decision making than they currently were. On average, Americans reported being more active than Germans during healthcare decision making and middle-aged participants preferred to be more active compared to both younger and older people. The researchers concluded that shared decision making preferences are related to numeracy skills, country and age.⁶⁰⁹

Other researchers in the USA found that those with low numeracy were often less satisfied with how clinicians communicated, and involved them in decisions, and they were less likely to take up preventive screening opportunities as a result.⁶¹⁰

A study in England found that people with less formal education reported greater levels of benefit from a decision aid, but quantitative analyses found that the intervention provided the greatest benefit in those with higher levels of education. Thus there was a difference between what people perceived and objective data.⁶¹¹

American research has found that people with higher socioeconomic status might be more likely to want, and to experience, shared decision making.⁶¹² Other studies have linked involvement in decision making to employment status.⁶¹³

Analysis of national data in the USA also found that families in poorer health may be less likely to perceive that they are involved in shared decision making.⁶¹⁴

To summarise, there is no clear-cut evidence about whether people from various age, ethnicity, gender, education and socioeconomic groups are more or less likely to desire or to achieve shared decision making, but some demographic differences are likely.

The important point is that patients are not a homogeneous group. Just as each person has different medical conditions and health behaviours, so too do they have differing values and opinions regarding the extent to which they want to be involved in decisions. It is important to recognise these differences, and how they may be shaped by age, gender and ethnicity, so as not to assume that everyone wants the same level of involvement in decision making.^{615–616}

*The engagement of patients in medical decisions might not be susceptible to a 'one size fits all' approach; doctors should instead aim to accommodate the individual patient's desire for autonomy.*⁶¹⁷

Perceived knowledge of patients

The extent to which people have appropriate information or feel knowledgeable may influence whether they feel confident sharing in healthcare decisions.^{618–619} Self-efficacy may play an important role.^{620–621}

Research in Italy found that most people wanted to participate in decision making, but felt that substantial gaps in their knowledge was a barrier. Only a small proportion of patients expressed opinions and questions during consultations and clinicians did not usually facilitate questions or encourage involvement.⁶²²

Similarly, interviews with people in the USA found that a perceived lack of knowledge, low self-efficacy and fear were barriers to older people participating in decisions.⁶²³

Furthermore, the perceived knowledge and capacity of patients affects how healthcare professionals involve them in decision making.^{624–625} Professionals may think that patients have insufficient knowledge to participate in decision making, even if this is not the case or if steps could be taken to mitigate this.

4.2 Characteristics of professionals

Attitudes of professionals

The attitudes and skills of healthcare professionals can have a significant effect on the extent to which people feel engaged and supported.^{626–631} People who feel supported by their doctors and nurses may be more 'activated,' more satisfied and have better outcomes.^{632–634} This suggests that the attitudes and roles of clinicians are essential components of shared decision making.⁶³⁵

Obtaining buy-in from clinicians, particularly doctors, may be one of the greatest challenges in increasing the uptake of shared decision making.⁶³⁶ Buy-in from clinicians may be dependent on professionals recognising that there is a problem or issue and believing that there is an easy and practical solution to that problem.^{637–638}

Professionals need to be convinced that the advantages of shared decision making for patients, themselves and their systems outweigh any perceived disadvantages of changing traditional practices.⁶³⁹ There may be tensions between clinicians' desire to respect patients' preferences while simultaneously applying guidelines and current best practice.⁶⁴⁰

Emotional, cognitive and skill barriers can get in the way.⁶⁴¹ Contextual factors and perceptions of patient readiness can be important here.

*Doctors express differing support of patient involvement in decision making dependent on context, impact and effect that involvement may have. Doctors described meeting patient involvement preferences as a challenge, and needing to identify different characteristics, anxiety levels and levels of understanding to guide them to involve patients in decisions.*⁶⁴²

In other words, professionals' beliefs about the value and ease of shared decision making can be a facilitator or a barrier. For instance, professionals supporting women with early-stage breast cancer in Canada said that they supported shared decision making but felt that their patients would not

understand information or were not ready or willing to participate in treatment decisions.⁶⁴³ There may be biases against certain types of patients, such as those who are older or less educated.⁶⁴⁴

Similarly, a British study investigated the views of orthopaedic surgeons about the potential of decision aids for hip and knee replacement surgery. Most were positive about the concept of shared decision making but none had used decision aids. Surgeons said that they would be likely to use decision aids if there was evidence that they improved patients' understanding, enhanced communication and helped patients clarify what is important to them. However, surgeons said that they would be unlikely to support the use of decision aids if they increased workload, were not kept up to date and if patients disliked them.⁶⁴⁵

Elsewhere in England, online decision support tools are being made available for women facing challenging decisions, such as the choice between mastectomy and breast conservation surgery for breast cancer. Interviews with surgeons, nurses and oncologists from four hospitals and national opinion leaders found that many did not have a working knowledge of decision support tools and were ambivalent or sceptical. Some expressed conflicting opinions: on one hand they noted the potential benefits of decision aids, but at the same time they had reservations about information overload and about content that they considered inappropriate. Many wanted patients only to have access to decision support tools under clinical supervision because they were concerned that these tools might make patients feel anxious and might impinge on the professional's role.⁶⁴⁶

Researchers in the USA surveyed primary care clinicians regarding patient decision aids about colorectal cancer screening. More than six out of 10 thought that decision support tools could increase patient knowledge, help patients identify a preferred screening option, improve the quality of decision making, save time and increase patients' desire to get screened. However, clinicians did not necessarily think that such tools improved the overall quality of care or patient satisfaction. Less than half thought that such tools would be easy to implement in routine practice.⁶⁴⁷

Professionals' demographic characteristics

There is mixed evidence about whether professionals' demographic characteristics influence the extent to which they encourage shared decision making.⁶⁴⁸⁻⁶⁵⁰

Some have found no differences in professionals' attitudes and behaviours based on age, gender or ethnicity. For example, a survey of cancer doctors in Asia, Australia, Canada, Europe and the USA found that 71% believed that patients and family members should be involved in decisions about their treatment. Doctors of different ages, genders, country, specialty or years in practice were no more or less likely to support shared decision making.⁶⁵¹

However, other studies have found that the traits of professionals may impact on shared decision making. A survey of GPs from throughout England found that female doctors and those working in larger practices were more likely to believe it was important to share decisions about referrals for surgery with their patients.⁶⁵²

Similarly, analysis of audio-recorded consultations in Germany found that female GPs were more likely to involve patients in decisions about their care.⁶⁵³ The same has been found among female doctors in Australia.⁶⁵⁴

In contrast, studies in the USA suggest that female doctors and doctors with less clinical experience may be less likely to want to disclose uncertainty about treatments during consultations, which in turn impinges on shared decision making.⁶⁵⁵

In Switzerland, more experienced hospital doctors have been found to be more likely to support shared decision making than newer recruits.⁶⁵⁶

But observation of 287 patient interactions in the USA found that older doctors were least likely to engage in shared decision making.⁶⁵⁷ This corresponds to a survey in Germany which found that younger doctors are more likely to support shared decision making.⁶⁵⁸

4.3 Patient–professional interactions

Dynamic process

Shared decision making is a dynamic process in which patients and doctors influence each other.⁶⁵⁹ The characteristics of patients and professionals may interact to influence the extent of shared decision making.^{660–665}

Research in England found that:

*Participation [in consultations] is seen as being co-determined by patients and professionals, and occurring only through the reciprocal relationships of dialogue and shared decision-making. Not everyone wanted to be involved and the extent to which involvement was desired depended on the contexts of type and seriousness of illness, various personal characteristics and patients' relationships with professionals.*⁶⁶⁶

Interviews with patients in the USA found that five elements were repeatedly described as being essential to enable patient participation in healthcare decisions: patient knowledge, explicit encouragement of patient participation, appreciation of the patient's responsibility to play an active role, awareness of choice, and time.⁶⁶⁷ This emphasises that a dynamic mix of patient, professional and system level characteristics were important.

Similarly, focus groups in France found that patients supported shared decision making, particularly when this was actively promoted by doctors. Facilitating factors included trust, good non-verbal communication and allowing people time to think. Obstacles included perceived inadequate knowledge, problems making requests and fear of knowing.⁶⁶⁸

A survey of 41 GPs and 829 of their patients conducted in Norway found that GPs preferred shared decision making, but to a lesser extent than patients. GPs' attitudes towards shared decision making affected patient satisfaction.⁶⁶⁹

In Canada, researchers found that doctors changed the extent to which they supported shared decision making behaviours according to patient factors, including anxiety.⁶⁷⁰ Other studies have also highlighted patient anxiety as a potential barrier and something that influences clinician behaviour.⁶⁷¹

Further weight is given to the findings of these studies by a meta-analysis examining the interactions between patient and professional characteristics. Professional influences on shared decision making included receptiveness to informed patients and patient centredness. Patient influences were motivation and active appraisal of information before a consultation. Shared influences included differing notions of illness and decision making, role expectations and language.⁶⁷²

Concordance of views

Shared decision making may improve clinicians' satisfaction with the care process and perceived therapeutic alliance.⁶⁷³ However, research suggests that in order to heighten satisfaction and positive outcomes among patients and professionals there needs to be concordance between patient preferences for involvement and clinician behaviour.^{674–675}

There may be important links between the attitudes and behaviours of professionals and what they perceive patients think and want. Investigators in the USA examined how the way 1,500 doctors communicate uncertainties is influenced by their own comfort levels and perceptions of patients' tolerance of uncertainty. Communicating uncertainty about the benefits and harms of different treatment options is a component of shared decision making. The medical specialty of doctors and other demographics predicted their attitudes towards communicating scientific uncertainty.

Furthermore, doctors' beliefs about their patients' aversion to ambiguity were important. Doctors who thought that their patients would have negative reactions to ambiguous information were more likely to think that they should decide what is best for their patients and to withhold an intervention that had uncertainty associated with it.⁶⁷⁶

In Germany, more than 400 psychiatrists and surgeons were surveyed about patient behaviours they found helpful and detrimental for shared decision making. When patients searched the internet or were assertive towards the doctor, this sometimes provoked ambivalent or negative attitudes in professionals. The investigators suggested that doctors say that they are open towards the concept of shared decision making during consultations but in reality they do not like to feel challenged. They may become annoyed if patients insist on their preferences and doubt their doctors' recommendations.⁶⁷⁷

Communication style

There is evidence that communication between patients and professionals can help or hinder shared decision making.⁶⁷⁸⁻⁶⁸¹ Interactions between patients and professionals are shaped by the characteristics and attitudes of both parties as well as the culture and infrastructure within which they are operating.⁶⁸²⁻⁶⁸³

A study in Switzerland found that the use of facilitators, open questions and emotional statements by professionals was associated with higher patient involvement.⁶⁸⁴

Researchers in Scotland examined characteristics of interactions between patients and professionals that were more likely to lead to shared decision making in general practice. Facilitators included using first person pronouns during conversations, supporting patients so that they felt their requests were successful, supporting doctors' agendas and reducing their responsibility for decisions made. Perhaps, counter-intuitively, when doctors talked about 'partnership' this tended to invite consensus and acceptance of GPs' views rather than real involvement and debate from patients. Thus the wording used during consultations might influence whether patients are encouraged to share decisions or just agree with decisions being made by professionals.⁶⁸⁵

Similarly, researchers in Israel found that doctors used certain language, syntax and different sources of power to persuade patients to agree with their preferred treatment choice rather than make real shared decisions. The tactics included ways of presenting the illness, treatment and side effects; providing examples from other success or

failure stories; asking for input only about small technical details of little consequence; and using plurals and authority. The investigators suggested that shared decision making may be advocated as a philosophical value, but it is not necessarily implemented in actual communication with patients.⁶⁸⁶

*Shared decision making does not happen with the ease implied by current models and appears to work to maintain a biomedical 'GP as expert' approach rather than one in which the patient is truly involved in partnership... Further research on the impact of conversational activities is likely to benefit our understanding of shared decision making and hence training in and the practice of shared decision making.*⁶⁸⁷

Conflicting priorities and responsibilities may impact on patients' and professionals' communication style. Interviews with GPs and allied health professionals in Australia found that practitioners thought that there was a conflict between professionals' responsibility to deliver evidence-based care and the need to respect patients' right to make decisions. Professionals differed in the emphasis that they placed on 'treating to target' or practising 'personalised care' and this influenced the extent to which they involved patients in decision making. Those preferring to 'treat to target' were more assertive and directive in their approach whereas those who supported 'personalised care' were more accepting of the patient's priorities. 'Treating to target' meant involving patients, where necessary, to tailor care to their needs and abilities, but limiting patient involvement in decisions about the overall agenda. Those more focused on 'personalised care' tended to involve patients to tailor care to patient preferences. Professionals often thought that it was not possible to respect a patient's autonomy while still delivering high-quality evidence-based care.⁶⁸⁸

A study of women with breast cancer in Korea found that women's treatment decisions might be shaped by the information provided by their doctors and that women might request different information from their doctors based on their preferred treatment options.⁶⁸⁹

Support versus prescriptive advice

There is evidence that shared decision making works best when clinicians focus on both providing information and managing emotions and patient views.⁶⁹⁰

In Australia, the cognitive and emotional aspects of shared decision making were analysed in consultations with 55 women with breast cancer. Good information provision and communication predicted patient satisfaction, but good support and picking up on emotional cues affected the extent to which patients felt reassured or anxious. Thus shared decision making is not merely a technical process of going through options and communicating benefits and risks. It is also about taking into account people's feeling and values and providing reassurance and support as needed.⁶⁹¹

Support can also come from family members. There is evidence that patients who are accompanied to consultations and those who have a supportive home environment may be more likely to share decision making.⁶⁹²

Patients' treatment decisions are significantly influenced by professionals' recommendations and the support that clinicians provide during the decision-making process.⁶⁹³ Research suggests that doctors' recommendations can lead people to make decisions that go against what is best and against what they would otherwise prefer.⁶⁹⁴

Researchers in Germany investigated whether doctors' recommendations pulled patients away from their preferred treatment options or whether they supported patients to make informed choices. More than 200 people with schizophrenia or multiple sclerosis were presented with a hypothetical scenario and asked about their preferences. They then received a fictitious clinician's recommendation that was contrary to their preferences and were subsequently asked to make a final choice. 48% of the people with schizophrenia and 26% of those with multiple sclerosis followed the advice of their doctor and chose the treatment option that went against their initial preferences. Patients who followed the doctor's advice were less satisfied with their decision.⁶⁹⁵

Another study found that one-third of elderly people hospitalised in Sweden said that they experienced barriers to shared decision making including the severity of their illness, doctors with different treatment strategies and difficulty understanding medical information. The researchers concluded that professionals are not responsive to patient preferences regarding communication or the patient's participation in decision making and that providing support to make decisions may be just as important as providing information and advice.⁶⁹⁶

Trust

Trust between patients and clinicians has also been identified as a potential facilitator or barrier in a number of countries.⁶⁹⁷⁻⁷⁰⁶

A survey of 606 patients in Canada found that those who had blind trust in their doctors wanted doctor-led decisions, those who did not trust their doctors wanted to make decisions themselves and those who had high, but not excessive, trust supported shared decision making. Trust had a significant influence on preferred role even after controlling for demographic factors such as gender, age and education.⁷⁰⁷

4.4 Characteristics of decisions

Characteristics of treatment decisions may influence how feasible it is to share these decisions between patients and professionals. These characteristics include whether there is a strong evidence base for the most appropriate treatments, the specific illness or condition being considered and the type of treatment being offered.⁷⁰⁸⁻⁷⁰⁹

Is there a solid evidence base for care?

Research has examined whether some types of decisions are more amenable to shared decision making than others. By definition, shared decision making is designed to be used when various options are available and where there is no one best course of action for everyone.⁷¹⁰ Thus, emergency situations and instances where there is just one evidence-based approach may fall outside the scope of shared decision making.

In Canada, researchers found that people followed their doctor's recommendations because they believed that there was no choice of treatments or because there was only one 'best choice'.⁷¹¹ Despite this, interviews with cancer doctors in Australia found that even when there may be a readily perceived 'best' or clear-cut course of action, there was still scope for shared decisions based on the impact of treatment on patients' quality of life and self-image.⁷¹²

Interestingly, a survey of more than 5,300 people recently diagnosed with cancer in the USA assessed if characteristics of the decision influenced patients' roles in decision making, such as evidence about treatment benefits, whether the decision was preference sensitive and treatment modality. Patients thought that they had controlled around two-fifths of decisions, two-fifths were shared and one-fifth were doctor controlled. Shared decisions were more likely when there was good evidence to support a treatment. When evidence was uncertain, patient control was greatest and when there was no evidence for, or evidence against, a treatment, doctor control was greatest. Decisions about treatments for the most serious and advanced cancers were more likely to be controlled by doctors. The research suggested that patients may not want the responsibility of deciding on treatments that will not cure them or where there is no evidence.⁷¹³

Diseases and conditions

People with certain illnesses might want to be more engaged or be more amenable to shared decision making than others.⁷¹⁴ For example, a study in Germany found that people making decisions about solid cancer tumours were more likely to want to share in decisions than those with haematological cancer. The reasons for this are unclear.⁷¹⁵

Alternatively, clinicians may view some conditions as being more amenable to shared decisions than others.⁷¹⁶⁻⁷¹⁷

Interviews with patients, GPs, health managers and researchers in Germany found that shared decision making was considered most important for people with severe illness and long-term conditions. Participants suggested that end-of-life decisions and decisions about prevention should primarily

be made by informed patients rather than through shared decision making. Paternalistic decisions were considered most appropriate in emergency situations and when patients did not want to participate in decision making.⁷¹⁸

Some suggest that in instances where patients are overly stressed, where they do not feel that they have the capacity needed to understand decisions, where there is a lack of supporting information and when people are approaching the end of life it may not be most appropriate to share decision making.⁷¹⁹

In terms of end-of-life care, however, issues may be more a function of the systems and processes used, rather than an inherent problem with the topic area.⁷²⁰⁻⁷²¹ A review of 18 studies found a strong link between shared decision making and having a 'good death'.⁷²² However, a systematic review of 37 articles found that while most people want to participate in end-of-life decisions to some extent, the majority do not achieve their preferred levels of involvement because decisions are delayed and alternative treatment options are seldom discussed.⁷²³

It might be assumed that shared decision making relies on good mental capabilities, but studies with the frail elderly and people with mental health issues, including serious psychiatric conditions, have found that shared decisions are possible, welcomed and can be encouraged.⁷²⁴⁻⁷²⁷ Even people with dementia or schizophrenia can be involved in discussing healthcare options in relation to their values and preferences.⁷²⁸⁻⁷²⁹ Therefore there may not be automatic barriers to this approach based on the topic area or nature of people's conditions.

On the other hand, interviews with people with schizophrenia in Scotland found that most were happy to leave decisions about treatment to clinicians and few sought any role in shared decision making. The researchers emphasised that it should not be assumed that all patients want to take responsibility for their medications and decisions.⁷³⁰

Type of care

The type of care being decided on may act as a facilitator or barrier to shared decision making.⁷³¹

Interviews with primary care clinicians in England suggested that while professionals wanted to be patient centred, they thought that some things were not appropriate for shared decision making. Making decisions about examinations, ordering tests and biomedical aspects of care helped to reinforce the professional identity of practitioners and ‘made them doctors’. These decisions were not felt to be appropriate to share.⁷³²

Researchers in the Netherlands examined whether the type of care to be decided on influenced whether more than 800 people with long-term illnesses and disabilities wanted to have a shared role. Patients attached most importance to shared decision making when occupational healthcare issues were at stake, but they thought that they had relatively low involvement in these decisions.⁷³³

Studies in the USA found that people with severe mental illness wanted to be more involved in decisions about their care. Patients tended to be happy enough with a passive role about general medical care, but wanted to be more actively engaged in decisions about medication and psychiatric care.⁷³⁴

A survey of psychiatrists in Germany found that shared decision making was seen as useful for well informed and compliant people and for those who disliked their medication. Shared decision making was not seen as useful in cases of potentially reduced decisional capacity. Psychosocial topics such as work therapy, future housing and psychotherapy were considered more suitable by clinicians for shared decision making than were medical and legal decisions such as hospitalisation, prescriptions and diagnostic procedures.⁷³⁵

Although it appears that the type of care being discussed may influence the extent to which people want to be involved in decisions and the extent to which professionals believe this is acceptable, there are no clear-cut ‘rules’ about which types of decisions are most appropriate for shared decision making. Furthermore, treatment courses are often a continuous process in which options remain open. It is not a matter of deciding to do one

thing and then ruling out all other alternatives. Sometimes alternatives are tried in succession or simultaneously.⁷³⁶

4.5 Culture and infrastructure

Components of organisational infrastructure and culture that may impact on shared decision making include⁷³⁷⁻⁷⁴⁴:

- policy context⁷⁴⁵
- health service culture⁷⁴⁶
- leadership support⁷⁴⁷
- involving nurses and allied health professionals, not just doctors⁷⁴⁸
- training for professionals⁷⁴⁹⁻⁷⁵¹
- professional attitudes and motivation⁷⁵²⁻⁷⁵⁶
- social support and the opinions of family members⁷⁵⁷⁻⁷⁶⁰
- time⁷⁶¹⁻⁷⁶⁹
- incentives and disincentives⁷⁷⁰
- fears about managing risk, malpractice and litigation⁷⁷¹⁻⁷⁷³
- supportive practice settings and access to care⁷⁷⁴
- availability and appropriateness of supportive tools⁷⁷⁵⁻⁷⁷⁷
- evidence that shared decision making is effective.⁷⁷⁸⁻⁷⁷⁹

A systematic review of 38 studies of health professionals’ views about the barriers and facilitators to shared decision making found that time constraints were the most frequently reported problem, followed by a perception that shared decision making was not appropriate or worthwhile for patients or a particular clinical specialty.

The three most commonly suggested facilitators were motivation among professionals and evidence of positive impacts on the clinical process and on patient outcomes.⁷⁸⁰

Research suggests that implementing strategies to support shared decision making may require changes to infrastructure and have resource implications. Clinicians often stress practical

barriers to shared decision making such as administration and timing.⁷⁸¹ For instance, in Britain a structured decision aid was used to check patients' understanding and treatment preferences in urology, but this involved additional administration. Including the decision aid in existing clinical pathways was not always easy and could involve booking an additional appointment or posting or emailing the tool to patients in advance. This led to more work for nurses and administrative staff.⁷⁸² Systems had to be set up to support the roll out of this decision aid.

The time allocated to consultations may also make a difference.⁷⁸³⁻⁷⁸⁴ Observations in hospital and in primary care suggest that longer consultations are more likely to include shared decision making behaviours⁷⁸⁵ and interviews with professionals suggest insufficient time as a major barrier to shared decision making.⁷⁸⁶⁻⁷⁹⁶

Timing issues may impact on how professionals communicate and whether they use decision aids that could enhance shared decision making.⁷⁹⁷

The structure and complexity of care processes may also have an impact. Interviews with people in the USA found that the expanding number of medications available and multiple doctors prescribing for the same patient were barriers to shared decision making.⁷⁹⁸

Most studies and models of shared decision making do not account for interprofessional work or the need for multiple professionals to interact with patients about their decisions.⁷⁹⁹ Researchers in Scotland found that the dynamics of interprofessional work shaped older patients' participation in decision making about discharge from hospital. Observation and interviews undertaken over a five-month period found that patients and staff had a different understanding about decision making and varying priorities. Care routines centred around assessments and tended to exclude patients from active decision making. The researchers concluded that the organisational context shaped patient and staff interactions and privileged the views of staff over patients and family members.⁸⁰⁰

4.6 Summary

A wide range of factors may act as facilitators or barriers to shared decision making including characteristics of patients and professionals, the assumptions and biases of both parties, the way patients and professionals interact, and the culture and infrastructure of healthcare systems.⁸⁰¹⁻⁸⁰⁷

The totality of evidence implies that showing patients and professionals that shared decision making has benefits and can be implemented relatively easily may be an important driver for change.⁸⁰⁸⁻⁸⁰⁹

From the literature we can surmise that merely making information and decision support tools widely available is unlikely to be sufficient to encourage shared decision making.⁸¹⁰ Instead, it is important that information and tools are accompanied by appropriate support and encouragement to use them.⁸¹¹ Professionals may need to signpost patients to appropriate tools and adapt their practice styles and consultations to provide active support for people wanting to participate in decision making.⁸¹² This requires motivation from individual clinicians as well as a supportive infrastructure and culture in healthcare services, including sufficient time to promote shared decision making.⁸¹³⁻⁸¹⁵ In order to implement shared decision making widely, policy makers and practitioners need to move from talking about this approach towards ensuring that patients and professionals are engaged and have the necessary resources.⁸¹⁶

Chapter 5

Issues that need more attention

Shared decision making aims to support patients to articulate their understanding of their condition and what they want to achieve from treatment, inform patients about their condition and the pros and cons of available treatment options, ensure that patients and clinicians come to a decision based on a mutual understanding of this information and record and implement the decision reached.⁸¹⁷

Research suggests that patients want to be respected, listened to, valued and given honest information and that many want to share in decisions about their care, at least in terms of being involved in discussions.⁸¹⁸⁻⁸²² However people are not always given an opportunity to share in decisions to the extent they wish.⁸²³⁻⁸²⁴

Although there is a debate about how to define shared decision making and how to promote and implement it in day-to-day practice, there is evidence that shared decision making and decision aids can support a patient-centred approach.⁸²⁵

However, there is a lot more to learn about how shared decision making works in practice, which strategies work best and how to implement shared decision making day to day. This chapter briefly explores issues in need of further examination. The points raised have emerged from synthesising the literature, but this chapter provides an informed narrative rather than a listing of research findings.

Initially research about shared decision making tended to focus on acute treatment or screening for cancer, genetic issues or other conditions. However, in recent years there has been more focus on shared decision making in primary care and supporting people with long-term conditions.⁸²⁶

Many researchers in this field meet every two years at an International Shared Decision Making Conference. The Salzburg Statement on Shared Decision Making was also launched in 2011. This postulates that it not only is feasible and appropriate for patients to be involved in decisions about their care, but also an ethical responsibility.⁸²⁷

A great deal has been written about shared decision making and numerous studies are currently underway including tests of decision support tools,⁸²⁸⁻⁸³⁰ evaluations of training for professionals,⁸³¹⁻⁸³⁴ studies of how policy, guidance and frameworks may be important⁸³⁵⁻⁸³⁶ and examinations of how shared decision making works in practice.⁸³⁷⁻⁸⁴² However, much is left to learn.⁸⁴³ Gaps in knowledge include defining shared decision making, understanding how to develop new relationships and partnerships between patients and professionals, learning how to engage clinicians and transmit the attitudes and skills they need to help patients share decisions, and the best tools and strategies to embed shared decision making in routine practice.

5.1 Scope of shared decision making

Defining shared decision making

While the broad principles of shared decision making have been written about extensively, reviews suggest that there is a need for clarity about the fundamental meaning and the underlying purpose of shared decision making.^{844–845} Various definitions of shared decision making are used, illustrating differences of opinion about the purpose of this concept.^{846–847}

It may be important to be clear about whether the aim of shared decision making is about setting out options so that patients can agree with the option recommended by professionals or whether the aim is to empower patients to take responsibility for decisions, using clinicians as a resource for information and support.^{848–850}

Some definitions of shared decision making seem to focus solely on information provision.⁸⁵¹ This follows a traditional biomedical perspective, where collecting ideas, concerns and expectations from the patient aims to help the professional make a better plan for the patient. There is a move away from this approach, towards more actively engaging patients in their own care.⁸⁵² However, while clinicians may believe that they implement shared decision making, the evidence does not always support this.^{853–857} This suggests that there is more work to do to help all parties understand the underlying purpose of shared decision making and the most appropriate techniques to support this.

While it may be easy to say that shared decision making should be more widely implemented, it is important to be clear about what this means and to acknowledge the difficulties with this.^{858–861} It may also be crucial to recognise that true shared decision making may not be what some patients want.⁸⁶² The idea that responsibility for decisions is a fixed entity that can be apportioned between clinicians and patients is also problematic.⁸⁶³

A study in England illustrates these complexities well. Researchers studied treatment decisions about breast cancer by observing consultations and exploring patients' and doctors' perspectives. Twenty consultations were audiotaped and each patient and their surgeon was interviewed separately within a week of the consultation. Surgeons made most decisions for patients and only offered choices where treatment options were clinically equivocal. Thus shared decision making was largely absent. However, patients generally said that they felt that they had ownership of the decisions because surgeons provided justifications for the choices and because patients knew that they could refuse. Furthermore, when asked to make choices and share decisions, patients often lacked trust in their own decisions and usually sought surgeons' recommendations.⁸⁶⁴ Thus merely encouraging patients to be more involved in decisions would not necessarily enhance satisfaction or lead to better outcomes. This suggests that the attitudes and values underlying the principles of shared decision making are perhaps more important than the procedural aspects.

5.2 Implementing shared decision making

Supporting partnership approaches

Research suggests that in order for people to take more responsibility for their health and treatment choices, they need to be equipped with information and support to participate.^{865–868} People must not only be involved in their health but must have influence over their care.^{869–871}

The evidence implies that there is significant overlap between the strategies required to increase self-management and those needed to implement shared healthcare decisions. In particular, both require an integrated approach that supports professionals and patients to move towards a new relationship characterised by collaboration, information sharing, shared goals and an understanding that both parties have an active role to play in improving health outcomes.^{872–874}

A great deal of research has been published about various strategies and tools to encourage shared decision making, sometimes with mixed success.^{875–876} Thus the evidence suggests that rather than focusing on individual tools and techniques, a more fundamental change is needed in the culture of care.⁸⁷⁷

An implication from these studies is that changing the roles of clinicians and patients may have a significant impact on the extent to which shared decision making is accepted and demanded.^{878–882} Clinicians may need to shift from being ‘experts who care for and do to’ patients to ‘enablers who use their expertise to support people to experience optimum health’. Simultaneously, patients may need to shift from being passive recipients of care to taking responsibility for their health and care.^{883–884} The crucial point is that shared decision making requires changes from both patients and professionals, and this is more fundamental than merely providing supportive information and tools.

Little research has explored the barriers and facilitators to fundamental culture change regarding shared decision making. The extent to which the focus should be on policy makers, professionals or patients in moving this agenda forward also remains uncertain.

The role of family members in decision making is similarly unclear, but clinicians and researchers are beginning to acknowledge this as an important area of investigation.^{885–890} Few studies have examined the concept of shared decision making when the patient is a child and those that do tend to focus on involving parents rather than children themselves.⁸⁹¹

Upskilling clinicians

The attitudes and skills of healthcare professionals influence the extent to which people feel engaged and supported.^{892–895} In fact, the views and practices of professionals may be one of the most significant facilitators or barriers to implementing shared decision making.^{896–899}

If people are to be more involved in decisions about their care and more active in keeping themselves well, clinicians may need to be able to communicate information effectively and to consider what level of involvement is appropriate for different

people.^{900–901} Yet, there may still be considerable work to do in this area.^{902–904} Interviews with GPs in 11 European countries found that most GPs thought that involving people in healthcare decisions had positive outcomes but GPs defined patient involvement narrowly, thought it took place solely during consultations and felt that they had limited time to engage with people.⁹⁰⁵

Other studies have identified similar barriers. For instance, research in the UK suggests that clinicians may take a ‘compliance-orientated’ approach and this is unlikely to be helpful.⁹⁰⁶

This suggests that there may be work to do to educate clinicians about the value and scope of supporting shared decision making and the skills they need to achieve this.^{907–913}

A number of strategies have been tested to improve clinician communication strategies and help professionals support self-management and shared decision making.^{914–921} For instance, a randomised trial found that training GPs about risk communication tools and shared decision making for people with long-term conditions could improve prescribing and was unlikely to have major impacts on the cost of care in the UK.⁹²² However, researchers in the UK also found that while GPs appear receptive to patient involvement, training in shared decision making and risk communication did not help them achieve this or improve patient outcomes.⁹²³ This suggests that knowledge is limited about the best strategies to help clinicians support shared decision making.

Supporting clinicians is not only about providing training. There may be some fundamental disincentives to address. Research suggests that professionals may be afraid of truly sharing decisions and moving forward with something that a patient wants which may not be consistent with the clinician’s ideal approach.⁹²⁴ This implies that greater clarity may be needed for health professionals about how to support shared decision making while also remaining confident about their practice. In light of research about professionals’ opinions and frustrations in this regard, regulators, education providers and professional bodies may need to take a view about this issue, especially in the context of an increasingly litigious culture.

5.3 Impact of shared decision making

How does shared decision making work?

A major gap in knowledge is whether and how shared decision making works. Specific tools and techniques may encourage patients and their carers to take more responsibility for their care, help people with long-term conditions feel more in control and improve the overall quality of care by encouraging health professionals to follow recommended care protocols.⁹²⁵ But shared decision making is complex, both conceptually and in terms of implementation.

There is a need to explore in more depth the impacts of shared decision making, rather than merely assuming positive outcomes. This review suggests that impacts on clinical outcomes and resource use are mixed and impacts on safety, timeliness and equity are virtually unknown.

There is also a need to better understand the conflicting and sometimes contradictory research findings. The evidence for shared decision making may be mixed in some cases because a wide range of things are described as ‘shared decision making’. Past reviews have tended to combine initiatives that focus solely on information provision with interventions that more actively target behaviour change and self-efficacy. However, these varying interventions may have different outcomes so combining them could dilute the findings.

Which strategies work best?

There is emerging evidence that helping people to share in decision making about their care can have benefits for people using services and their families, particularly in terms of patient satisfaction.^{926–929} However, this review suggests that the best strategies to support shared decision making remain uncertain. While a number of studies have found benefits from decision support tools, clinician and patient education and action plans, other similar research has not found favourable impacts.^{930–934}

There are a wide range of initiatives to help people share in decision making. These could be categorised along a continuum of interventions, with passive information provision at one end of the scale and training and support initiatives that more actively seek to assist behaviour change and increase self-efficacy at the other end. It remains uncertain which strategies are most effective, alone or in combination.

Interventions to help people share in decision making vary considerably in their aims, approach, content, delivery, duration and target group. The conditions under which interventions work best need further investigation.

People with different demographic and clinical characteristics may require varying approaches to support shared decision making, and certain decisions may be more amendable than others.^{935–941}

Despite these variations and caveats, principles that have been found to work well to support shared decision making include:^{942–946}

- actively supporting people to be involved in decision making
- emphasising options and problem solving
- developing care plans as a partnership between patients and professionals
- setting goals and following up on the extent to which these are achieved over time
- using decision aids rather than merely passive information provision
- providing opportunities to share and learn from others.

The best strategies for implementing these principles remain uncertain.⁹⁴⁷ There is a need for high-quality research and evaluations that focus on building relationships between patients and practitioners and exploring the most effective strategies for encouraging behaviour change.^{948–949}

This review has identified some evidence that the following tools and techniques can encourage shared decision making:

- decision aids
- action plans and goal setting
- training for patients
- training for professionals.

However, the evidence base suggests that while they may have localised benefits, none of these techniques alone are likely to be sustainable or more widely impactful in the long term. Instead, these strategies could be seen as pieces of a jigsaw, which may work well together to form a more complete picture.

The review suggests that information provision and patient-held records alone are unlikely to be sufficient to motivate ongoing shared decision making.^{950–951} The same could be said of decision support tools which, though worthwhile for some people, may have limited long-term impacts if used alone.^{952–954} Active support for both patients and professionals is needed to enable true partnerships.⁹⁵⁵

To really support change in shared decision making, a fundamental shift may be needed in the way both patients and professionals view their roles.^{956–958} In this view, the culture and infrastructure of the health services is as important as the motivation and attitudes of patients and professionals.^{959–961}

Measuring outcomes

There is more work to be done to understand the impact of shared decision making. A systematic review found that studies of decision support interventions apply widely varying outcome measures and instruments. Actual or preferred choice was the most common outcome measured and little attention was paid to clinical outcomes or health service use.⁹⁶²

There is evidence that some patients want to be more involved in decisions and that some practitioners also value this approach.^{963–967} There is also increasing evidence about the feasibility of using tools such as decision aids, action plans, and training and education of various types to encourage shared decision making in routine clinical practice.⁹⁶⁸ Interventions to improve shared decision making have been found to enhance knowledge, involvement in decisions and patient satisfaction and in some cases to improve adherence to treatment.^{969–972} However, good quality evidence about other outcomes is lacking.⁹⁷³

The wider impacts on clinical outcomes, safety and healthcare resource use remain uncertain.^{974–975} While many studies, articles and policy and guidance papers assume that shared decision making improves clinical outcomes and provides value for money, little high-quality research has been undertaken to support this.

Numerous studies are ongoing or planned, but these tend to focus on testing the value of decision support tools or training on increasing involvement in decisions. The actual impact of shared decisions on patients' physical wellbeing and on resource use within health and social care needs investigation.

A number of innovative strategies are being tested to support behaviour change in the UK. Rigorous evaluation of these programmes and wide dissemination of learning will enhance knowledge in this area considerably.

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Appendix 1

Review methods

Methodology

This is a sister publication to the Health Foundation's *Helping people help themselves* review of research about supporting self-management published in 2010.⁹⁷⁶

To compile evidence for this rapid review, two reviewers independently searched bibliographic databases, reference lists of identified articles and the websites of relevant agencies.

The databases included Medline, Embase, ERIC, Science Citation Index, Cochrane Database of Systematic Reviews, Cochrane Controlled Trials Register, DARE, NHS Health Technology Assessment and Economic Assessment databases, NHS Research Register, NHS Evidence, US National Electronic Library for Health, PsychLit, the WHO Library, Agency for Healthcare Research and Quality, Web of Knowledge, Web of Science, Google Scholar and the Health Management Information Consortium.

All databases were searched from 2000 until mid-November 2011 using combinations of words, mesh terms and similes such as shared decision making, patient-provider communication, patient empowerment, involvement, decision aids, family conferences, decisions, self-care, self-efficacy, self-help, self-treatment, self-monitoring, long-term conditions, chronic care, coping skills, behaviour change, care plans and patient-held records.

To be eligible for inclusion, studies had to be:

- empirical research or reviews
- focused on the effects of shared decision making or strategies to improve shared decision making
- published or readily accessible
- available in abstract, journal article, or full report form.

There were no language restrictions.

Unpublished research and evaluations from the Health Foundation were excluded from the review.

More than 40,000 pieces of potentially relevant research were scanned. Those that were most relevant were examined in detail. No formal quality weighting was undertaken, but systematic reviews, randomised trials and large observational studies were prioritised. Where such studies were not available, other research was included.

Data were extracted from all relevant publications using a structured template and studies were grouped according to key questions and outcomes to provide a narrative summary of trends.

In total, 465 studies of relevance were included in the synthesis. In addition, descriptive material was used to provide context.

Review limitations

When interpreting the findings in this report it is important to understand that the review is not exhaustive. It compiles key trends and presents examples of relevant research available at a certain point in time (November 2011), but does not purport to represent every study published about shared decision making.

The focus is on empirical research. Internal evaluations, narratives and descriptive overviews are not included when describing impacts. Articles may have theorised about the importance of shared decision making and potential facilitators and challenges, but these were not eligible for inclusion unless they contained empirical material.

Interventions to support shared decision making vary considerably in their aims, approach, content, delivery, duration and target group. The way shared decision making is defined may also differ. Therefore it would be misleading to refer to initiatives to help people share in decisions as an integrated whole.

Much of the available evidence is sourced from countries with very different healthcare economies and styles of working than the UK so may not be directly comparable.

There is a lack of evidence about the strengths and weaknesses of various approaches and about the implications of using them in routine practice. This lack of evidence does not mean that specific approaches are ineffective or unhelpful, just that little research is available about them.

In most cases there is limited detail within research reports about how interventions were implemented. This means that it is difficult to differentiate the most effective components or strategies, or outline the mechanisms by which supporting shared decision making may work.

The review examined interventions that have been tested to support shared decision making but the conclusions we can draw are limited due to a lack of comparative evidence. Studies tend to describe the benefits of one particular initiative, but not to compare various approaches. This makes it difficult to compare the relative effectiveness or appropriateness of varying approaches.

A lack of evidence or comparisons does not necessarily mean that there is no relationship or benefit, just that there is currently insufficient research to draw conclusions.

Conclusions are further limited because most studies have some methodological difficulties such as being observational, small scale and based at single sites.

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The Health Foundation
90 Long Acre
London WC2E 9RA
T 020 7257 8000
F 020 7257 8001
E info@health.org.uk

Registered charity number: 286967
Registered company number: 1714937

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ISBN 978-1-906461-40-9

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