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# What Works to Support and Promote Shared Decision Making: A synthesis of recent evidence



**HEALTH AND SOCIAL CARE**



# **What Works to Support and Promote Shared Decision Making: A synthesis of recent evidence**

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## **Executive Summary**

Realistic Medicine puts the person receiving care at the centre of decision-making and creates a personalised approach to their treatment and care. This summary highlights some practical tools, skills and attitudes that can foster and facilitate greater engagement in Shared Decision Making (SDM) and draws on international academic and policy literature with a focus on relevance to Scotland. The objectives of this research were to identify:

- What we know about shared decision-making in Scotland?
- What are the existing barriers to further uptake of SDM in clinical consultations?
- What can be done to encourage greater engagement of SDM in Scotland?

## **What is Shared Decision-making?**

SDM decisions are made utilising both the medical knowledge of the clinician and the personal preferences of the patient. SDM 'represents an important shift in the roles of both patients and clinicians' moving away from 'the doctor knows best' approach with unilateral information transfer, towards more active participation from patients, and support from professionals as curators of information.

## **What do we already know about SDM in Scotland?**

SDM is a key feature of Realistic Medicine, as set out in the Chief Medical Officer's recent Annual Reports (2014/15-2016/17). This evidence review suggests that most patients are keen to receive more information about their healthcare and participate in SDM, and the majority of clinicians are keen to provide this information. However, there was not a dominant patient view on what information would help them to make healthcare decisions, although there was a general preference to be given this information face-to-face. Shifting the culture toward shared decision making will mean shifting the balance of communication in consultations to encourage the exchange of knowledge and information between patients and their healthcare professionals.

## **Barriers**

The literature highlights several barriers to greater engagement with SDM, namely:

### Knowledge barriers:

- Lack of (clinician) knowledge on how to carry out SDM;
- Clinician concern that SDM may mean they appear unknowledgeable to patients;
- Clinician belief that they are already doing SDM;
- Clinician concern on how to respond to patients who disagree with them;
- Lower patient health literacy could lead to difficulties in making decisions.

### Expectations

- Patient concern that participating in SDM may lead to bad or no treatment from clinician;
- Lack of belief (patient and clinician) that SDM will happen;
- Inconsistencies between how clinicians and patients understand ‘a shared decision’;
- Lack of time to participate in SDM;
- Clinician’s assumptions of patient preferences.

### Meaningful conversation

- Lack of recognition of patient-clinician SDM power dynamics;
- Concern that environment is not receptive to SDM and difficult conversations;
- Lack of trust/ familiarity between patient and clinician.

### **What are the key conditions of an SDM process?**

The recent evidence identified a number of key conditions to facilitate SDM:

- Trusting relationships between patient-clinicians supported by organisational practice and culture;
- Recognition of power imbalances between patient-clinicians;
- Patients viewed as active participants in their healthcare;
- A policy climate that appreciates the importance of SDM.

### **Effective tools, skills and attitudes for SDM**

The recent evidence on SDM identified a number of tools, skills and attitudes that can encourage greater SDM engagement. A single example will not be effective in all contexts, but a change in attitudes may be the catalyst as ‘skills trump tools, and attitudes trump skills’ (Joseph-Williams, et al., 2017, p. 2). Key findings are:

<b>Level</b>	<b>Tools</b>	<b>Skills</b>	<b>Attitudes</b>
<b>Individual appointment</b>	In-consultation decision aids; recording consultations	Enhancing communication skills of clinicians	Ensuring SDM receptiveness/ awareness of clinicians/ patients
<b>Board</b>	Identify SDM readiness of local teams; more efficient practices	Training in SDM throughout clinician career	Promotion of SDM through clinical and patient champions
<b>System</b>	Tools to measure SDM successes; education to raise awareness	Communicating SDM benefits	Leading by example

## **Conclusions**

Clinicians and patients are generally receptive to SDM but the wider system tends to focus on efficiencies (e.g. reducing waiting lists) and this can make practising shared decision-making difficult. The perceived barriers to SDM highlight uncertainties from patients and clinicians around participating in SDM, as many believe they are already doing it or do not attempt it. Training is needed for more effective communication skills (e.g. role-plays on effective SDM). This report identifies several key conditions that need to be present to foster and facilitate SDM and there is a lack of evidence on how to measure and evaluate SDM effectively. Better evaluation of SDM might encourage greater engagement by demonstrating its value and how best to participate in SDM.

## **Recommendations**

The following recommendations require consideration from policymakers, as well as relevant stakeholders at a local and national level:

- Implementation of tools to measure and evaluate the impact of SDM (e.g. patient and clinician satisfaction, and statistics on waste and variation);
- Creation of a training programme to improve communication skills of clinicians on how to conduct meaningful conversations;
- More training and education (for patients, clinicians and boards) to raise awareness of how SDM can be practised (and to highlight the evidence that SDM does not have to add more time to consultations);
- More public training and education campaigns on how best to discuss: 'what matters to you'; patient preferences; and promote better 'continuity of care';
- Easy access up-to-date information on benefits/ risks of various treatments, and improved access to information on patient preferences.
- Identify what information would best help patients make healthcare decisions;
- Promotion of clinical, and system level (e.g. national-level stakeholders and CMO) SDM champions to promote and foster attitudes that are receptive of SDM;
- Creation, and maintenance, of a culture that appreciates the importance of SDM. e.g. suite of complementary policies related to SDM and person-centred care.

## **1. Introduction**

Realistic Medicine puts the person receiving care at the centre of decision making and creates a personalised approach. Changing our style to shared decisions and enabling people to make informed choices about their care, based on what matters most to them, are priorities for Realistic Medicine. This report provides a synthesis of the evidence on shared decision making (SDM):

- Section 1 outlines the methodological approach and evidence base;
- Section 2 defines SDM and what is currently known about SDM in Scotland;
- Section 3 highlights the barriers to further uptake;
- Section 4 highlights practical tools, skills, attitudes and conditions to encourage greater SDM in clinical consultations; and,
- Section 5 provides some conclusions and recommended next steps.

### **1.1 Aims**

This report synthesises evidence on SDM applicable to Scotland from the last 5-10 years with the aim of highlighting some practical tools, skills and behaviours that can encourage greater engagement in SDM. The objectives of the review were to identify:

- What we know about shared decision making in Scotland
- What are the existing barriers to further uptake of SDM in clinical consultations?
- What can be done to encourage greater engagement of SDM in clinical consultations in Scotland?

### **1.2 Methodology and search strategy**

Literature searches were conducted using a range of databases and search terms. Although the primary interest was in evidence from Scotland, a wider geographic search was carried out to capture other relevant evidence. Larger scale systematic reviews and meta-analyses on SDM were the focus, rather than smaller scale single condition studies, however some smaller scale studies were included when they specifically concerned the views of patients, clinicians, or the barriers and facilitators of SDM, or if they were of particular relevance to Scotland. Specifically 76 journal articles and policy reports were used as evidence within this report, along with supporting material from several relevant websites. More details on the search strategy and evidence base and gaps can be found in Annexes 1 and 2.

Overall, the review of the evidence identified a lack of studies on evaluating the impacts of SDM, and on the wider impacts of SDM (i.e. over and above the patient-clinician relationship), and difficulties in envisioning what an SDM process could look like in practice. As such, suggestions for further research are:

- Conduct further research into how best to measure the impact of SDM (in terms of: patient and clinician satisfaction; and reducing waste and variation);

- Raise awareness of the SDM process (in practice) and its benefits to patients, clinicians and national-level stakeholders;
- Gain a better understanding of the role of issues such as trust and power within SDM encounters.

## 2. Defining Shared Decision Making

This section provides some discussion on what SDM is and the associated practical benefits.

SDM ‘represents an important shift in the roles of both patients and clinicians’ (Elwyn, et al., 2017, p. 1). Although there is no agreed definition of SDM, common themes are:

- ‘Stressing the importance of the people we care for and support, and professionals working in partnership, making decisions based on the best clinical evidence, making sure that people are fully informed about risks and benefits, and combining this information with the person’s values and preferences’ ([Realising Realistic Medicine report, 2017](#)) to enable a more person-centred approach to care, and better informed consent processes.
- Within SDM, decisions are made by simultaneously utilising the expert medical knowledge of the clinician with the expert knowledge of the patient (Halpern, 2018), in terms of their values and preferences and ‘what matters most to them?’, rather than ‘what is the matter with them?’
- The principles of SDM are accepted in theory by many patients, clinicians and policy-makers alike (Gulbrandsen, et al., 2016; Elwyn, et al., 2016). However, its practical application is more inconsistent.

Elwyn et al (2017) propose that it is the lack of an agreed set of steps to describe the approach which has led to inconsistencies in uptake to date. Nevertheless, numerous authors (Elwyn, et al., 2017; Coulter & Collins, 2011; Makoul & Clayman, 2006) have conducted research on the key features of an SDM process, as summarised in Table 1. These features combine essential and ideal elements.

Table 1: Key elements of a Shared Decision Making process

Essential elements	Ideal elements
Define/ explain problem	Unbiased information
Present options	Define roles (desire for involvement)
Discuss pros/cons (benefits/risks/costs)	Present evidence
Patient values/preferences	Mutual agreement
Discuss patient ability/self-efficacy	Involvement of family or other companions
Doctor knowledge/recommendations	Option and decision discussions in different appointments
Check/clarify understanding	Active listening



Make or explicitly defer decision	
Arrange follow-up	

Adapted from (Elwyn, et al., 2017; Coulter & Collins, 2011; Makoul & Clayman, 2006)

The key features above are not necessarily meant to act as a step-by-step guide, but rather a starting point through which patients and clinicians can better identify whether or not they are actively participating in SDM encounters and processes. Furthermore, each patient and clinician will have their own style of SDM.

Several authors have offered strategies for undertaking an SDM process/ conversation such as presenting surgical outcomes in terms of best, worst and most likely case (Fisher, et al., 2018), or promoting the ‘three talk model’ (Elwyn, et al., 2017) comprising three stages: team talk, option talk and decision talk. A key feature of any SDM strategy is allowing the process of decision making to take place over multiple encounters where possible (to encourage a trusting relationship between patient and clinician).

This new style of healthcare decision making has a number of practical benefits: it recognises the right for patients to be involved in their own healthcare decisions; it focuses on treatments and options with more beneficial outcomes (Légaré, et al., 2018; Shafir & Rosenthal, 2012); and it may reduce unwarranted variation in practices. These issues are outlined in more detail at Annex 3.

## 2.1 Current context of Shared Decision Making in Scotland

This section provides an overview of the current context for SDM in Scotland. The Chief Medical Officer’s (CMO) vision is that: ‘By 2025, everyone who provides healthcare in Scotland will demonstrate their professionalism through the approaches, behaviours and attitudes of Realistic Medicine’ (Realising Realistic Medicine, 2017). SDM is one of the key features of Realistic Medicine as set out in the CMO’s last three Annual Reports (2016, 2017, 2018). Realistic Medicine incorporates six interlinked key features:

- Building a Personalised approach to Care;
- Changing our style to Shared Decision Making;
- Reducing harm and waste;
- Reducing unwarranted variation in practice and outcomes;
- Managing risk better;
- Become Improvers and Innovators;

Realistic Medicine recognises that a ‘one-size fits all’ approach to healthcare is not the most effective outlook for either the patient or NHS. By recognising the role of patient preferences towards certain treatments (or no treatment) it is argued that there will be less wasted treatment, as patients receive ‘the care they need, and no less, and the care they want, and no more’ (Mulley, et al., 2012, p. 2).



The need for more person-centred approaches to care (and reducing the focus on the one-size fits all approach) were evidenced from a range of statistics from patient experience

surveys and health literacy studies and supported by recent Scottish frameworks and action plans (GauN Yersel, 2008; House of Care, 2014; Making it Easier, 2017). For instance, 40-80% of information received in consultations is either forgotten or misunderstood by patients (Kessels, 2003) and the rate of information retention reduces as age increases (Kessels, 2003). Furthermore, 43% of English working age adults struggle to understand instructions to calculate a childhood paracetamol dose (Making it Easy, 2014), which flags the importance of dialogue in the clinician-patient relationship. The 2018 Health and Social Care Standards are person centred and based on inclusion in decisions about care and support.

The work on the Scottish burden of disease has highlighted that different geographical areas have specific 'burdens of disease' and as such different priorities in terms of current and future healthcare planning (ScotPHO, 2016). As such, a more efficient means to undertaking health and social care and the associated decisions is warranted, and Realistic Medicine (and SDM) aims to offer this, whereby the preferences of the patient are accepted and understood by the healthcare professional.<sup>1</sup> Scottish Government undertook two activities in Autumn 2018 to gain a better understanding of the existing views of, and desires for, SDM: a Citizen's Jury - gathering the views of the public; and a 'Realistic Medicine' survey gathering the views of healthcare professionals.

The Citizen's Jury<sup>2</sup> met over 3 days around the question of 'What should Shared Decision Making look like, and what needs to be done for this to happen?'. This took place between October and November 2018. The jury was enacted by 24 members of the public (from a range of backgrounds – to be representative of the wider community) and comprised of a series of activities including small group discussions, presentations from stakeholders and formulation of policy recommendations. The jury recommendations were focused around: informing, educating and preparing patients to ask questions; creating a culture and support for shared decision making; how appointments are organised; training for professionals and advocacy (Scottish Health Council, 2019).

The Realistic Medicine survey<sup>3</sup> was disseminated through a variety of channels to gather the views of Health and Social Care practitioners on their understandings of, and future priorities for, Realistic Medicine. Almost 2500 responses were gathered between September and October 2018. Around half of these were from doctors and the remainder from other healthcare professionals. The survey results highlighted that the biggest barriers to making changes and improvements aligned to Realistic Medicine (and SDM) were seen as: insufficient staff time; lack of formal training; and lack of local leadership. The survey also called for the building of a more personalised approach to health care and wider public engagement to improve understanding of Realistic Medicine (and thus SDM). This discussion highlights the importance of SDM. The following section highlights the recent work 'on the ground' in Scotland.

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<sup>1</sup> Shared decision making is also fundamental to the delivery of social care which uses self-directed support to allow people to choose how their care is delivered.

<sup>2</sup> A Citizens Jury brings together a diverse group of 12-25 members of the public (usually randomly selected). Their task is to work through an issue, share ideas, explore options and create recommendations. The jury was the first of its kind in Scottish health and social care.

<sup>3</sup> A summary of the Realistic Medicine survey results will be included in the Chief Medical Officer's Annual report 2018-19, with a fuller version to be provided on the Realistic Medicine website <https://realisticmedicine.scot/>

## 2.2 What do we already know about SDM in Scotland?

This section highlights what we already know about SDM in Scotland in terms of patient and clinician views and practices.

### Views of Patients

Recent views of patients in Scotland around SDM have been gathered through three main sources – the [Scottish Care and Experience Surveys \(2018\)](#)<sup>4</sup>, the [Citizen's Panel](#)<sup>5</sup> responses, and the [General Medical Council's \(GMC\) report on attitudes to consent and decision making](#)<sup>6</sup>. The key findings are:

#### Satisfaction with care:

- Patients were generally positive about the care they have received through their GP practice (83%) ([Health and Care Experience Survey, 2018](#));
- 76% of patients felt that being listened to and given sufficient time to speak to their GP were key for 'good consultations' ([Health and Care Experience Survey, 2018](#));
- Patients reported positive results in feeling comfortable asking a doctor about treatment risks and benefits (87%), but fewer respondents have actually asked such questions (54%) ([Citizens Panel 2, 2017](#));
- Clinicians should demonstrate a friendly demeanour and active listening, use simple language and display information in a range of formats ([GMC, 2018](#)).
- Improvements could be made around how well patients are kept informed within A&E and post-hospital care ([Inpatient Experience Survey, 2018](#));

#### Relationship with doctors/ clinicians:

- Still a 'doctor knows best' culture within Scotland - many respondents (41%) would feel uncomfortable asking to speak to another doctor (i.e. for a 2nd opinion) ([Health and Care Experience Survey, 2018](#));
- Yet in another survey, 35% would be comfortable asking to speak to another doctor, 71% would be comfortable asking to be referred to a specialist ([Citizens Panel 3, 2017](#));
- Most patients wanted information via face-to-face consultations with their doctor (or nurse) ([Health and Care Experience Survey, 2018](#));

#### Relationship with other healthcare professionals:

- There is a desire for stronger relationships between healthcare professionals and patient ([Health and Care Experience Survey, 2018](#));

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<sup>4</sup> National suite of surveys covering: Health and Social Care Experience; Inpatient Experience; Maternity Care; and, Cancer Patient Experience. They provide local and national information on the quality of health and care services from the user perspective.

<sup>5</sup> The Our Voice Citizen's Panel is a large demographically representative group of citizens used to assess public opinions on specific issues, including in 2016, SDM. 44% of panel members (541) responded to this particular survey.

<sup>6</sup> Research conducted with 100 people across UK to gather views to update the current consent and SDM guidelines (published 2008). Qualitative research was undertaken with samples from particular groups (e.g. gypsy-travellers, people with limited mental capacity)

- Considering healthcare professionals other than doctors, patients felt most comfortable asking a nurse about treatment/care options (91%), and less comfortable asking social care professionals (65%) and counsellors/ support staff (65%). Patients cited level of knowledge/ training as reasons ([Citizens Panel 3, 2017](#));

#### Decision Making

- No common suggestions for the type of information that would help with SDM;
- People generally feel it is not always warranted or possible to involve patients in decision making e.g. due to certain characteristics or circumstances ([GMC, 2018](#));
- Some patients may prefer to leave the decision making to the Healthcare Professional;
- Other groups wanted more involvement in decisions (i.e. patients with limited English);

#### Views of Healthcare Professionals

There has been little research and studies conducted on clinicians' views of SDM in Scotland to date and thus this section will draw on broader UK and international findings which may be illustrative of the Scottish perspective. Specifically these are the [GMC report on Doctors attitudes to consent and shared decision making](#)<sup>7</sup> (2017) and findings from wider academic literature. The key findings are:

- There is familiarity with broad SDM principles and willing adherence to varying degrees ([GMC, 2017](#));
- Clinicians were most likely to inform patients of their choices rather than any other aspect of SDM (Kunneman, et al., 2016);
- Attitudes towards the degree of when and how SDM should take place is varied (Frerichs, et al., 2016);
- There is less familiarity with individualising SDM conversations ([GMC, 2017](#));
- Clinicians' perceived lack of time to understand individual patients' needs/wants, capacity and expectations ([GMC, 2017](#));
- Clinicians were concerned around how to explain complex information in a way that patients will understand it when there is a lack of good current evidence of the risks and benefits of some treatments ([GMC, 2017](#));
- The biggest barriers of further implementation of SDM by healthcare professionals are: time constraints; lack of applicability due to patient characteristics; and, lack of applicability due to the clinical setting (Gravel, et al., 2006);
- Most studies predominantly only concern the views of doctors. Further studies should be conducted on other healthcare professionals' views (Forcino, et al., 2018).

### 2.3 Summary

Overall, there appears to be a consensus across many of the views of clinicians and patients. The majority of patients are keen to receive more information about their healthcare, and

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<sup>7</sup> The new draft GMC consent guidelines are currently under review. New guidelines are due to be published in 2019.

the majority of clinicians are eager to identify the best ways to obtain and provide such information. However, there was a not a single dominant view from patients on the type of information that would help them to make such decisions around their healthcare. Thus there may be a need to conduct research into what this information could look like.

### 3. Barriers

The literature around SDM (Carter & Martin, 2018; Coulter, 2006; Elwyn, et al., 2016; Legare & Thompson-Leduc, 2014; Legare, et al., 2008) highlights a number of barriers preventing greater engagement with, and uptake of SDM within clinical consultations, which may explain why SDM is not part of everyday medical practice (Gulbrandsen, et al., 2016).

The barriers may be actual or perceived, and have been grouped within three overarching categories: barriers surrounding knowledge; around expectations; and around the meaningful conversation. Solutions require a mix of individual, board and system level changes (see Section 4 for examples). Each barrier will now be discussed in more detail.

#### 3.1 Knowledge

Both clinicians and patients reported a number of barriers concerning knowledge. For clinicians current knowledge barriers include a lack of knowledge of how to carry out an SDM process (Legare & Thompson-Leduc, 2014), often manifested in the (often incorrect) belief of clinicians that they are 'already doing SDM'. In reality, there may be a focus only on particular aspects (i.e. providing information to patients).

Another clinician-cited knowledge barrier was highlighted by Joseph-Williams et al (2014), whereby clinicians (particularly less experienced clinicians) can worry that asking patients for their views and preferences may reduce a patient's trust in their skills as a clinician.

A common barrier for clinicians was difficulties responding to patients who disagree with a recommendation (Zeuner, et al., 2014). However, evidence suggests that generally patients would prefer to be asked for their views and any lack of trust would more likely arise from poorly communicated information, or a poor evidence base to draw from (i.e. inconsistent access to information of the risks and benefits of certain treatments). This can be improved through additional training and creation of a better evidence base (Joseph-Williams, et al., 2017).

Furthermore, increased uncertainty may occur by raising patients' awareness of additional options with uncertain outcomes in terms of risks and benefits (Gulbrandsen, et al., 2016). However this again can stem from poorly communicated information, or poorly executed SDM processes, but may be a particular concern for patients with lower health literacy.

Low health literacy is the main knowledge barrier for some patients. Generally, patients with lower levels of health literacy:

- have poorer health status and self-reported health;
- are less able to communicate with health professionals;
- wait until they are sicker before going to the doctor;
- have an increased risk of developing multiple health problems; and,
- are less likely to engage with health promotions such as flu vaccines and breast screenings. ([Making it easy, 2014](#))

Low health literacy will remain a barrier towards greater SDM unless changes can be made to make active participation in healthcare easier. Calls for health and social care services to do more to support better health literacy and numeracy are often promoted as solutions to these barriers through the use of simple language and providing information in various forms (Coulter & Collins, 2011).

### **3.2 Expectations**

There appears to be a mismatch of expectations of healthcare services between patients, clinicians and wider healthcare systems which has created a number of barriers (Joseph-Williams, et al., 2014; Zeuner, et al., 2014; Fisher, et al., 2018). Some patients have the expectation that instigating a process of SDM (i.e. more active involvement in decisions) may lead to poorer treatment from their clinician (i.e. because the clinician may feel the patient has disrespected their knowledge or role) (Zeuner, et al., 2014). This expectation may stem from the paternalistic healthcare model in which 'doctors knows best'.

Meanwhile some patients and clinicians both reported they do not pursue SDM because they do not believe it will actually happen. This may be connected to self-efficacy (one's belief in one's ability to succeed at a task) (Legare & Thompson-Leduc, 2014).

Furthermore, there can be inconsistencies between how patients and clinicians conceive of and understand 'a shared decision', a decision in general (Leppin, et al., 2014), or the most appropriate style of SDM for each situation (Fisher, et al., 2018).

Perhaps the most frequently cited reason for the lack of SDM uptake by clinicians remains the lack of time in consultations (Joseph-Williams, et al., 2014), with the expectation that SDM discussions will add to an already pressured 10 minute consultation (Legare & Thompson-Leduc, 2014). However much literature exists to show that often SDM can reduce the length of time per patient overall in terms of more targeted follow up appointments and discussions (Legare & Thompson-Leduc, 2014), especially if the patients are given information beforehand and come to their appointment prepared. For example, Butow et al (1995) found that on average patients spoke for only 24% of a consultation and asked 5.6 questions on average, which took up less than 0.1% of the total consultation time. In comparison clinicians spoke for 44% of the consultation time on average, and only 5% of this time was spent answering patient questions.

In addition, SDM should not be expected to always occur within a single consultation (Elwyn, et al., 2017). SDM is about exchanging information in a more useful and accessible way, e.g. personalised to the patient in terms of their preferences. It is argued that 'any change that is proposed for the busy clinical context is always assumed to add more time to the consultation' (Legare & Thompson-Leduc, 2014, p. 283), when in actual fact no evidence has yet been produced to support this claim. A Cochrane systematic review highlighted research on ten decision aids specifically embedded in interventions that measured consultation lengths and the majority of studies found that there was no statistically significant change in consultation length (Stacey, et al., 2014). Furthermore some of the decision aids reduced indecision in participants overall, had a positive effect on patient-

clinician communication, and reduced the number of decisions for major invasive surgery, in favour of more conservative decision options (Stacey, et al., 2014).

Some patients (e.g. often older generations) can feel pressured to cut appointments short if the waiting room is busy (as they don't want to waste valuable clinician time) (Bastiaens, et al., 2007). Giving clinicians and patients the right tools, skills and conditions for undertaking SDM, away from pressurised targets and waiting lists, may alleviate this barrier.

Finally misaligned expectations around patient preferences can also be a barrier. Lack of easy access to robust evidence of certain treatments, as well as a perceived lack of time to assess patient preferences can lead clinicians to have incorrect assumptions over what matter most to their patients (Mulley, et al., 2012; Zeuner, et al., 2014). For instance Lee et al (2010) highlighted research in which clinicians believed that 71% of patients with breast cancer consider keeping their breast as a top priority, when in reality the figure was only 7%. This highlights the importance of understanding patient preferences, and also reducing waste through lowering the incidence of unwarranted treatments and having more meaningful conversations.

### **3.3 Meaningful conversation**

An effective SDM process requires meaningful conversations between patient and healthcare professional to determine the preferences of the patient (Elwyn, et al., 2017). A number of factors can act as barriers to these conversations, namely: unrecognised power imbalances, lack of trust and familiarity; and lack of self-belief.

SDM requires a change, at least to some degree, in the power dynamics between patient and clinician from the traditional paternalistic healthcare model (Fisher, et al., 2018). This transfer of power needs to be recognised by both clinician and patient to enable an SDM process to take place. Nevertheless the balance of power is still held by the healthcare professional, given that, along with the diagnosis and prognosis information they hold, these SDM processes often take place in environments that are more familiar to the healthcare professional (i.e. GP surgery/ hospital) (Joseph-Williams, et al., 2014). These environments are often not attune to meaningful conversations. Physical barriers such as desks and computers (Joseph-Williams, et al., 2014) may be a hindrance to trust building and may reinforce the power imbalance between patient and clinician.

However some patients (e.g. some older people) will not be willing to participate in SDM to the same degree due to long-term acceptance of and familiarity with, the 'doctor knows best' outlook for their healthcare (Bastiaens, et al., 2007). As such clinicians need to be more aware of the preferences of the patient in relation to their desire for involvement in SDM.

SDM also necessitates that the patient trusts their clinician to engage in a discussion about their preferences. The issues of power and trust are dependent to an extent on the way in which information is offered and retained (e.g. clinicians need to carefully consider when to provide certain information and through which means) (Gulbrandsen, et al., 2016; Joseph-Williams, et al., 2014). The SDM literature (e.g. (Legare, et al., 2008)) highlights that concern



exists for some clinicians around how to effectively begin an SDM discussion, particularly in times when the discussion may concern end-of-life options. Difficulties may arise when trying to elicit preferences from patients as 'what matters to you' is not easy to answer (Jacobsen, et al., 2018). This barrier can lead some clinicians being more likely to suggest a treatment that they are more comfortable performing (even if it may not match with the patient's preferences) (Mulley, et al., 2012). Furthermore clinicians may find it difficult to 'hide' biases they have toward particular treatments, which may almost subconsciously appear through use of a particular tone, or time given to discussing each option (Joseph-Williams, et al., 2014). This may damage trust and deter patients from further SDM.

A final barrier concerning difficulties around enacting meaningful conversation relates to a lack of familiarity between the healthcare professional and patient. Whilst SDM remains a relatively new means of healthcare delivery greater importance is placed on trust and familiarity between clinician and patient. Thus having appointments with different clinicians, can be a perceived barrier to SDM as then extra, already pressurised, consultation time is spent retelling medical/ treatment history (Joseph-Williams, et al., 2014). This is a particular issue for patients with longer term or chronic conditions who have more contact with healthcare professionals. Chronic conditions affect over 15 million people in the UK, particularly as we age, and recent research highlighted that 42% of the population have at least one chronic condition (Coulter, et al., 2013).

In terms of specific examples, Beaver et al (2005) conducted a qualitative study into the preferences for SDM of patients undergoing treatment for colorectal cancer, concluding that trust in their clinician and continuity of care were important factors in their likelihood to participate in SDM. Furthermore Belcher et al. (2006) found that older people were more likely to participate in their own medical decision making if they trusted their clinician.

### **3.4 Summary**

Overall, the barriers around knowledge, expectations and the meaningful conversation require a mix of individual, board and system level solutions. There is a lack of understanding (patient and clinician) of what the SDM process could look like in practice, and some barriers related to the legacy of paternalistic healthcare (e.g. 'I'm already doing it', or 'it's disrespectful to my clinician'). Raising public and clinician awareness of 'SDM in practice' may subsequently help with other barriers such as lower health literacy, the importance of key conditions (e.g. trust and power imbalances) and misaligned expectations of preferences between patient and clinician. Some examples of solutions to these barriers are presented in Section 4.

#### 4. What works in encouraging greater engagement of SDM in clinical consultations?

Encouraging greater engagement of SDM in clinical consultations will require a culture change above all else. It will require culture changes at multiple levels (e.g. clinicians, their organisations and patients) and as such it is a complex task (Stiggelbout, et al., 2015). This section highlights ways in which such change might be supported. This comprises a discussion of the key conditions that encourage SDM, in terms of effective tools, skills and attitudes. Some examples of good practice case studies are also provided.

##### 4.1 What are the key conditions of an SDM process?

This section highlights the key conditions that need to be present to ensure good quality SDM can occur. Recognition of, and achieving, these conditions will also act as solutions to several of the barriers mentioned in Section 3. Some need to be present before any process of SDM can begin (e.g. trusting relationship; recognition of power imbalances; patients as active rather than passive healthcare participants) but others will emerge through good patient and clinician acceptance, and use, of SDM.

As Fisher et al (2018, p. 9) highlight, ‘patient readiness to engage in SDM is related to their knowledge, emotional state, and power balance with their clinician’ and once these things are in place the other conditions should soon follow. Table 2 summarises these key conditions, noting the sources and the availability and strength of the evidence (i.e. based on number of studies and type of studies). It will be important to keep these conditions in mind when considering the implications of, and current evidence for, interventions.

Table 2: Key conditions to enable an SDM process

<b>Condition</b>	<b>Source</b>	<b>Availability &amp; Strength of evidence<sup>8</sup></b>
Trusting relationship between patient, clinician and healthcare system	(Fisher, et al., 2018) (Carter & Martin, 2018) (Gulbrandsen, et al., 2016)	Discussed in several qualitative studies as key. Draws on a range of other studies, including systematic reviews
Recognition of power imbalances between patient, clinician and healthcare system	(Coulter, et al., 2011) (Fisher, et al., 2018) (Joseph-Williams, et al., 2014)	Discussed in several qualitative studies as key, including large scale studies and systematic reviews
Patients viewed as active rather than passive participants in their healthcare	(Fisher, et al., 2018) (Walach & Loughlin, 2018) (Joseph-Williams, et al., 2017)	Discussed to a degree in several studies but often the existence of this condition appears to be assumed rather than explicitly discussed

<sup>8</sup> This column is based on the author’s assessment of the availability and strength of the evidence in terms of numbers of studies that mention the condition and scales of studies, and if the studies were conceptual or based on primary data.

Policy climate that appreciates the importance of SDM	(Coulter, et al., 2011) (Gravel, et al., 2006) (Joseph-Williams, et al., 2017)	Discussed to a degree in several studies including a systematic review, but often the existence of this condition appears to be assumed rather than explicitly discussed
Patient acceptance of, and desire to participate in, SDM (i.e. some older patients may not accept SDM as tolerant of paternalistic model)	(Coulter, et al., 2011) (Fisher, et al., 2018) (Leppin, et al., 2014) (Shay & Lafata, 2015)	Discussed to a degree in several studies but often the existence of this condition appears to be assumed rather than explicitly discussed
Patient's understanding of the decision options	(Coulter, et al., 2011) (Fisher, et al., 2018)	Widely discussed in a range of studies, including a systematic review
Availability of decision support information and tools	(Coulter, et al., 2011) (Elwyn, et al., 2017)	Discussed to a degree in several studies – both qualitative and quantitative studies which draw on several other examples.
Patient and clinical champions of SDM at Board level	(Coulter, et al., 2011)	Discussed conceptually in a systematic review
Evidence base of benefits and risks of treatments and options accessible to all clinicians	(Coulter, et al., 2011)	Discussed to a degree in several studies, including a systematic review, but often the existence of this condition appears to be assumed rather than explicitly discussed
Clinicians acceptance of, and desire to participate in, SDM	(Gravel, et al., 2006)	Discussed to a degree in several studies but often the existence of this condition appears to be assumed rather than explicitly discussed

These conditions involve a range of Individual, NHS Board and System level actions but much of the evidence (Carter & Martin, 2018; Coulter, et al., 2011; Elwyn, et al., 2016; Coulter, et al., 2011; Jacobsen, et al., 2018) has shown that the culmination of these should create the right conditions to enable SDM, and normalise it as the main method for healthcare decision making in Scotland. Furthermore, lack of many of these conditions were presented as barriers in Section 3. The first four conditions are foundational, and were most widely and strongly evidenced. They are discussed below in terms of how they can be put in place.

### Trusting relationships

Trust is of upmost importance to SDM processes as it requires the development of a new relationship between patient and clinician (and the wider system), with potentially more vulnerability. Trusting relationships can be encouraged in a number of ways.

- The time spent within an appointment on the meaningful conversation could be increased, by raising awareness of the importance of the meaningful conversation,

and promoting a style of appointment which provides the patient with more space and time to discuss their preferences. This requires a change from current practices in which clinicians tend to speak for most of the appointment (Legare, et al., 2008).

- Encouraging clinicians (through training) to recognise when SDM might be appropriate and well-received, whilst simultaneously training patients in having the self-belief to undertake it and even ask for it. Research has shown that currently patients are more likely to participate in SDM processes for more minor decisions (Fisher, et al., 2018) and the level of SDM may depend on level of familiarity (e.g. level of trust). For instance, a patient may be happy to engage with their GP about a prostate cancer screening, but not happy to engage with the oncologist about treatment decisions shortly after diagnosis (Fisher, et al., 2018).
- According to Gulbrandsen (2016, p. 1507) a trusting relationship has two parts: ‘trust in the power of medicine to reduce risk, and trust in the belief that physicians in general are benevolent’. One way to encourage the trust in medicine is ensuring accurate and easily accessible information on the risks and benefits of treatments. Thus a trusting relationship can be encouraged in a number of ways, and each of these relate to (clinicians and patients) having a better recognition of the (changing) power imbalances related to SDM.
- Poor continuity of care can be a barrier to building trusting relationships, due to the involvement of too many clinicians in a patient’s care or a lack of consistency of clinicians during a course of treatment (Joseph-Williams, et al., 2014). Efforts should be made to try to ensure better practices for continuity of care. Patients could be empowered to take a more active role in their healthcare by having a say in who is involved in their treatment and building therapeutic relationships with their clinicians (and vice versa) (Freeman & Hughes, 2010).
- Better recognition that the power imbalances may differ across different patient groups, for instance older people often tend to relinquish all power to the doctor (Bastiaens, et al., 2007). Thus there needs to be additional training to raise awareness of the potential specific concerns of particular groups.

### **Recognition of power imbalances**

Recognition of these common power imbalances are important to ensure SDM can occur and again there are a number of ways in which they can be handled, related to clinician training and changes in attitudes. SDM denotes changes to the roles played by patients and clinicians and each requires additional training, such as:

- Health Board officials could undergo training on ‘SDM in practice’ (Gulbrandsen, et al., 2016), so they can highlight good practice within their boards.
- ‘The balance of medical knowledge and social power in the provider–patient relationship is nearly always tipped toward physicians’ (Makoul & Clayman, 2006, p. 307). Training for clinicians on how to undertake their new role as a curators is needed (Gulbrandsen, et al., 2016). This role comprises presenting information on

the potential benefits and risks of treatments in as neutral a way as possible (e.g. clinician should not present an option as preferential without considering the preferences of the patient).

- To best recognise power imbalances patients need to be confident to undertake their role as more active patients, facilitated through national campaigns and education.
- The power imbalances may also be more apparent depending on age, ethnicity or certain conditions (Bastiaens, et al., 2007; Belcher, et al., 2006; Peek, et al., 2009). As such there may be a role for advocates to ensure particular power imbalances do not negatively impact on the SDM processes, and ensure patients of all circumstances are actively involved in their healthcare when desired (Coulter & Collins, 2011).

### **Patients viewed as active rather than passive participants in their healthcare**

The popular and pervasive view of the patient as a passive recipient of healthcare held by some patients and clinicians (emerging from the model of paternalism) needs to be altered to one in which the patient is more active in their healthcare decisions (Walach & Loughlin, 2018). This active role is generally welcomed by patients who desire greater involvement in decision making, with often better outcomes (Legare & Thompson-Leduc, 2014; Hack, et al., 2006; Hibbard & Greene, 2013). However there also needs to be a recognition that certain groups of patients may not desire a more active role. For example, older people are often wary of SDM as they are used to 'doctor knows best'.

Although assurances need to be made to determine if the choice of a more passive role is actually a preference, or related to low self-efficacy (Legare, et al., 2011). Research has highlighted that even patients with lower levels of self-efficacy still want to be involved in the discussions about their care (Makoul & Clayman, 2006), even if they cannot be involved in the decisions per se.

Recognition also needs to be maintained that certain groups of patients may need additional support to effectively self-manage and become more active participants in their healthcare (through various support tools and training) (Belcher, et al., 2006). The ability to self-manage conditions is particularly important for empowering patients with longer term conditions (Lhussier, et al., 2013). Changes are needed to encourage the idea of the active patient wherever it is possible, and welcomed by the patients. Thus there needs to be effective person-centred care policies (and supportive clinicians) in place to support patients with longer-term care to participative as actively as possible in their healthcare

### **Policy climate that appreciates the importance of SDM**

Policy-makers have a vital role to play in promoting the importance of SDM through simultaneously ensuring healthcare systems facilitate good SDM (e.g. person-centred approaches to healthcare) and empowering patients and clinicians to accept and promote SDM. To date, Scotland has undertaken some activities that highlight a policy climate appreciative of SDM, namely:

- The drive towards Realistic Medicine by the CMO demonstrates its focus on SDM.

- An interest in gathering the views of clinicians and patients (e.g. Realistic Medicine Survey, Citizen’s Jury) and a commitment to carefully consider and reply to each of the emerging recommendations strengthened this focus further.
- The move towards a more person-centred healthcare system (e.g. House of Care).
- The promotion of supporting self-management of health (aided by technology and better understanding of contributing lifestyle factors) also shows appreciation for some key SDM aspects (e.g. involving the patient more in their own healthcare).

There are also some other activities that could strengthen this focus in Scotland further:

- Measuring quality and efficiency of healthcare systems based on person-centred measures (e.g. patient and clinician wellbeing) rather than only targets such as waiting times/ lists.
- A greater focus on SDM as a spectrum (Makoul & Clayman, 2006) in which people in different contexts with different characteristics and circumstances can, and feel able to, participate in SDM at a level at which they (and their clinicians and families) are receptive to.
- Moving towards healthcare systems which are proactive rather than reactive. The Chronic Care model (Coulter, et al., 2013) highlighted that healthcare systems tend to be reactive (responding to patients when they are sick) rather than proactive (promoting and supporting patients to self-manage their healthcare). Coulter et al (2013) called for the overturn of this to better support patients with longer-term conditions (who spend the majority of their time self-managing their conditions).

These conditions are foundational. The other conditions can emerge once the foundations are firm. Effective tools, skills and attitudes may help encourage the other conditions.

#### **4.2 Effective tools, skills and attitudes for SDM**

This section provides an illustration of some key tools, skills and attitudes that have been effective in promoting SDM at different levels. Relative strengths and weaknesses are also considered, as no activity can improve SDM in all contexts (Joseph-Williams, et al., 2017).

There needs to be recognition that different clinicians and patients will have various motivations for participating in SDM ([MAGIC programme evaluation, 2013](#)). In fact changing attitudes may well be the most effective activity, and thus if they can be changed then the associated tools and skills will be more likely to succeed. This was highlighted as a key learning point from the MAGIC programme whereby ‘skills trump tools, and attitudes trump skills’ (Joseph-Williams, et al., 2017, p. 2).

The categorisation into individual appointment, board and system level is an adaptation of categorisations in the literature and has been informed by the stakeholder discussions and the earlier sections of this report.

## Individual appointment level

### *Tools:*

The literature highlighted a number of tools that either had been effective in promoting SDM or were considered to be potentially effective, for the individual patient or clinician. Decision aids (e.g. Option Grids and Brief Decision Aids) are effective facilitators for initiating an SDM process due to being simple to use and effectively promoting consistent practices across clinical teams and patients, ([MAGIC programme evaluation, 2013](#)), particularly in-consultation aids (Joseph-Williams, et al., 2017).

However a wide range of decision aids are needed to recognise varying levels of health literacy and self-efficacy, and they do not necessarily prepare the patient for SDM in terms of prior groundwork (Joseph-Williams, et al., 2014). Additionally, although there has been little evaluation carried out to date, numerous authors (Elwyn & Buckman, 2015; Tsulukidze, et al., 2014) suggested recording consultations may be effective for encouraging SDM as it allows patients a precise record of the conversations, and thus greater ability to reflect on options and participate in meaningful conversations. Thus these tools can help to create more meaningful conversations and improve the knowledge of clinicians and patients.

### *Skills:*

Similarly, effective communication skills (for example practiced through role-play) will enable patients and clinicians to have more meaningful conversations through managing their expectations and improving their level of knowledge. Better communication skills within SDM will raise the confidence of less experienced clinicians, and manage the expectations of more experienced clinicians who may feel SDM is too time consuming. As identified in the evaluation of the MAGIC programme ([MAGIC programme evaluation, 2013](#)), better communication skills were recommended to improve future SDM uptake, as MAGIC found it difficult to engage more senior clinicians who felt they lacked the time to participate in SDM, which may also connect to changes in attitudes.

### *Attitudes:*

Fostering good attitudes to SDM is key. In their evaluation of the MAGIC programme, Joseph-Williams et al (2017, p. 3) recommended that ‘we need to change attitudes to reflect this [importance of patient and clinician knowledge], so that patients are not seen as “non-compliant” if they have a different opinion and clinicians are not seen as overly paternalistic if they are listening to the patients preferences and considering this in a recommended treatment plan’. To achieve this attitude change the key conditions of Section 4.1 provide some helpful discussions as the findings here highlighted the importance of trust, recognition of long-standing imbalance of power and empowering patients and clinicians to participate in SDM. Changing individual attitudes will also help to manage the expectations of all those involved in SDM.

## Board level

### *Tools:*

There are numerous tools that can be promoted at NHS Board level. Boards (rather than individuals) have more control over tools that can improve the efficiency of the health services and as such the potential for SDM. Research has highlighted that assessing the baseline of local teams (e.g. their motivations and readiness to engage with SDM) may result in more tailored and thus more effective approaches to SDM implementation ([MAGIC programme evaluation, 2013](#)). Additionally the creation of better digital databases of the risks and benefits of treatment options (including multiple chronic conditions, and more evidence on the lack of benefits of certain treatments) for clinicians (Coulter, et al., 2013) would be helpful in reducing the lack of knowledge and enabling more meaningful conversations. This also relates to the utilisation of a tool on sharing available evidence (including patient experience where possible) on the practical benefits of SDM to clinicians, patients and their outcomes, as well as improving access to patient records across different health and social care departments to improve the continuity of care.

### *Skills:*

Research has shown healthcare professionals need to be encouraged and supported in their new roles as curators of various forms of information and knowledge (Gulbrandsen, et al., 2016). This requires additional and more extensive training which could be best offered at board level. According to Zeuner et al (2014), ensuring more extensive training of clinicians both pre- and post- licensure can help to increase their SDM skills. Training via simulations and role plays should be offered at Board level to create more opportunities to see consistent forms of 'SDM in practice' ([MAGIC programme evaluation, 2013](#)), (e.g. see case study in Section 4.3). Fisher et al (2018, p. 7) have called for clinicians to be equipped 'with the skills to engage patients in SDM when patients are willing, and to use other strategies to achieve a patient-centred decision when patients prefer not to participate in SDM', including not making assumptions about a patient's preferences - this could be most effectively implemented at Board level by way of training and education campaigns, and help to reduce the barriers around the meaningful conversation.

### *Attitudes:*

Attitudes at the board level can have a big impact on the subsequent attitudes of individual clinicians and patients in terms of if they feel valued, and confident enough to participate in SDM (Joseph-Williams, et al., 2017). The MAGIC programme implemented changes in two boards in England and Wales and the evaluation highlighted the importance of embedding SDM through creation of the right leadership, culture and behaviours – much of which can be implemented at board level.

Boards need to promote the best version of SDM (e.g. a process rather than a single occurrence) , and decisions are made at a time that is appropriate for the patient. Boards should encourage patient and clinician SDM champions to demonstrate 'visible organisational buy-in and support' (Joseph-Williams, et al., 2017, p. 3), ensure confidence for undertaking SDM, and reduce the barriers around knowledge and expectations.



## System level

### *Tools:*

System level tools refer to those that are implemented at the national level. Much of the literature and evaluations call for greater evidence of the success and benefits of SDM, by way of measurement tools ([Engaging Patients in Patient Safety, 2016](#)). Evaluation is one method which involves ‘systematically assessing an initiative’s design, implementation, and results to learn or influence decisions [and] it requires collecting and analyzing information about the program’s activities, characteristics, and outcomes ([Engaging Patients in Patient Safety, 2016](#)). Specifically they could be in a range of forms such as scorecards or fuller toolkits ([CEPPP Evaluation Toolkits](#); [Scottish Health Council Participation Toolkit, 2014](#)).

Having better tools to measure SDM (in terms of person-centred care benefits and cost-effectiveness) will give more weight to the process of SDM and create more pressure for further promotion and acceptance across Scotland. In tandem there is a call for more education to raise awareness of the benefits of SDM, what an SDM process would look like ‘in practice’, and how patients, clinicians and boards can best ‘train for’ their new roles. ([Engaging Patients in Patient Safety, 2016](#)). These tools could reduce disbelief that SDM will happen and increase the evidence base around the concept.

### *Skills:*

Skills to enhance system level engagement with SDM are similar to those at the appointment and board level in terms of better communication skills. These include promoting the benefits of SDM and ensuring buy-in of senior officials, patients and clinicians ([Engaging Patients in Patient Safety, 2016](#); [MAGIC programme evaluation, 2013](#)), and could reduce disbelief that SDM will happen, and create more realistic expectations of SDM.

### *Attitudes:*

Recommendations from the literature for changing system level attitudes begins with leading by example, and promoting the importance of SDM and active patients throughout society. Within Scotland one way in which this has been enacted is through the CMO’s drive for Realistic Medicine. Policy-makers play an important role in changing the expectations of patients, clinics and organisations that SDM will actually happen. Recommended ways to achieve this are the use of local facilitators (clinical peers with relevant knowledge, experience and enthusiasm) to support others who are implementing SDM and to get buy-in from senior leaders, managers and commissioners ([MAGIC programme evaluation, 2013](#)).

Overall, a mixture of these tools and skills will be needed to facilitate SDM, prompted by a change in attitudes at each level. The table below summarises the examples in this section, and the case studies in the following section highlight some practical examples where some of these tools, skills and attitudes have been successfully put into practice.

Table 3: Summary of effective tools, skills and attitudes for greater SDM

Level	Tools	Skills	Attitudes
<b>Individual appointment</b>	In-consultation decision aids; recording consultations	Enhancing communication skills of clinicians	Ensuring receptiveness and awareness of clinicians and patients to SDM
<b>Board</b>	Identifying baseline SDM readiness and motivation of local teams; more efficient practices	Training in SDM throughout clinician career	Promotion of SDM through clinical and patient champions
<b>System</b>	Tools to measure SDM successes; raising awareness through education	Communicating benefits of SDM effectively	Leading by example

### 4.3 Case study examples

In this section some exemplar case studies are highlighted. These emphasise the impact that particular changes can have on encouraging greater SDM in terms of raising public awareness, use of navigator tools and role playing, and through devising a new framework for the ‘person’ in their healthcare. These represent changes at the Individual, Board and System level and although often context specific, provide suggestions for good practice.

#### Case Study: Raising Public Awareness through a range of audio-visual tools

Location: Newcastle, Northumbria and Cardiff Health Boards/ Foundations

Level: Board Level

This work was carried out within the Health Foundation’s MAGIC (Making good decisions in collaborations) programme (Joseph-Williams, et al., 2017). MAGIC (2010-2013) aimed to demonstrate SDM can ‘feasibly, affordably and sustainably become a core characteristic of routine clinical care’ and build practical and transferable knowledge of how to increase SDM engagement. Newcastle and Cardiff were used as case study sites. An evaluation<sup>9</sup> of the study ([MAGIC programme evaluation, 2013](#)), found that using a range of audio-visual tools was beneficial to promoting the aims and values of SDM across the case study areas. These tools included ‘What is SDM’ and ‘Ask 3 Questions’, whereby patients were encouraged to ask clinicians about their treatment/care: 1) What are my options; 2) What are the possible benefits/risks; and 3) How can we make a decision together that is right for me.

The Ask 3 questions campaigns was promoted across surgeries in the form of posters, leaflets, and DVDs played in surgery waiting rooms. A survey on their effectiveness was sent

<sup>9</sup> MAGIC was conducted over three years across ten clinical teams from different Health boards across Cardiff and Northumbria. The Health Foundation conducted an independent evaluation of the MAGIC programme investigating the motivations of uptake of SDM, the barriers to further implementation and the role of systems in implementing SDM.

to participating surgeries, with 54% of respondents saying the SDM DVDs had been extremely or somewhat important/ valuable. 64% of respondents believed the posters had been extremely or somewhat important/ valuable in helping them to implement SDM.

Evidence of impact: Several authors (Lloyd, et al., 2013; Legare & Thompson-Leduc, 2014) have spoken of the need for a culture change whereby SDM is accepted as the future direction for health care decision-making. Raising awareness further is a step in the right direction. Research has shown (Joseph-Williams, et al., 2017) that obtaining public acceptance of, and desire for, an issue is often the most effective means to change. Thus it is the role of government and policy to support and encourage such engagement (Elwyn, et al., 2016). The MAGIC evaluation considered these to be effective means in delivering and embedding SDM in clinical settings, however there are nevertheless some additional issues to consider (Scottish Health Council, 2014). The techniques require buy-in from patients, clinicians and senior officials, patients may be reluctant to ask questions in their appointments due to limited time (making it difficult for the healthcare professional to gauge understanding), and the tools may be difficult for those with lower health literacy. However, hopefully this evidence will empower patients and clinicians to participate.

### **Case study: Shared Decision Making simulations and role-plays**

Location: NHS Lothian, NHS Borders, NHS Lanarkshire

Level: Board

One of the main barriers to increased uptake of SDM is that some clinicians incorrectly perceive they are already delivering SDM. The MAGIC evaluation ([MAGIC programme evaluation, 2013](#)), found that demonstrating good quality SDM through role-play was a good means to challenge this clinician complacency. Within Scotland these role-play demonstration workshops (simulations) are carried out by 'Effective Communication for Healthcare' (EC4H) entitled 'Shared Decision Making and Informed Consent: Realistic Medicine in practice'. In these workshops healthcare professionals are guided through good quality SDM practices facilitated by senior clinicians in the form of role-plays. The simulated scenarios are suggested by the participants and they work together in small groups to identify appropriate words and mannerisms to enable quality SDM in each situation.

The workshops allow consultants to practice different styles of SDM within a safe and constructive environment. The workshops delve more deeply into the question of 'what matters to you'. Recognising that this is a large and difficult question to answer, suggestions are offered on how to make these conversations more manageable and meaningful.

Evidence of impact: As these workshops have only recently taken place there is not yet any published evaluation on their impact on the practices of participants. However anecdotally, feedback (in the form of end of workshop feedback forms) from prior workshops has been very positive, with most participants valuing the experience of learning with and from people from different disciplines and backgrounds. After the workshop, participants felt more confident to: communicate the benefits and risks of treatment in a balanced way with patients; manage patients and families unrealistic expectations of treatment and outcomes

after the workshop; use decision aids to support their SDM practice; and, help patients to understand clinical outcomes of their treatment and gaining consent for treatment. Some participants appreciated being able to have a safe environment where they could be open and honest and others valued the opportunity to test different communication skills.

Overall, roleplaying is beneficial to SDM as it offers opportunity to learn the processes and skills of SDM in an context that is safe and positive. Zeuner et al (2014) have taken this idea one step further suggesting the use of simulation centres, which currently used for improving general clinical skills, to practice SDM communication skills. One aspect to be aware of is health literacy, and steps should be taken within these simulations to ensure that as many people as possible can benefit from the impacts of this training.

#### **4.4 Summary**

This section has highlighted some practical examples from recent evidence on encouraging greater engagement in SDM. Implementing any of these changes requires some societal and cultural level changes, which are of course not easy to carry out. Nevertheless steps are being taken to further SDM, particularly in Scotland. To further this progress SDM needs to be accepted at each level (individual, board and system) in terms of the right attitudes and facilitated by numerous tools, through clinical and patient champions, a good digital database of the risks and benefits of treatments, and continued and consistent training and education of patients, clinicians and senior officials on the importance of SDM and how the process can work in reality. By having the right attitudes at system level to encourage the right attitudes at all other levels the success of SDM as the normal means of healthcare delivery in Scotland will become more likely. This can be strengthened further through encouraging the key conditions, effective means to measure the successes of SDM and improving the communication skills of clinicians and patients when discussing 'what matters to you'.

## 5. Conclusions and next steps

In conclusion, this report aimed to identify the existing barriers to further uptake of SDM, along with what can be done to encourage greater engagement of SDM, in clinical consultations in Scotland by way of a synthesis of the recent academic and policy literature.

The report highlights that there is an increasing drive in Scotland towards Realistic Medicine and SDM. In terms of the barriers to greater engagement, the existing evidence highlighted a multitude of perceived and actual barriers, within the areas of knowledge, expectations and around ‘the meaningful conversation’. Many of these barriers mapped onto the key conditions that were identified as necessary for an SDM process to be enacted. These key conditions were discussed at length in Section 4 and may be the most important finding of this report.

Further studies into these key conditions could be conducted to further emphasise their importance and impact. Additionally, this report has highlighted a range of tools, skills and attitudes that can, and in some cases have been implemented to, encourage greater SDM engagement in Scotland.

Overall, changes in attitudes at each level, and ensuring existence of the key conditions provide the best examples for encouraging greater SDM. However, there also needs to be greater recognition that involvement in an SDM process is not necessarily merely accepted or not. It can be ‘a state and not a trait’ (Fisher, et al., 2018, p. 6) and level of involvement may depend on the seriousness of the decision, or who the encounter is with.

Finally, the table below summarises the main issues and solutions suggested in this report.

Table 4: Summary of main issues and suggestions solutions identified in this report

Issue	Suggested solutions
SDM creates new patient-clinician power dynamics	Raise clinician awareness ‘SDM in practice’; training on communication skills e.g. role-plays; raising public awareness of the new power dynamics; Raise awareness that some patients (e.g. older people) may not welcome SDM
Lack of trust/ familiarity between patient/ clinician	Ensure continuity of care where possible; Highlight statistics on consultation time use to encourage clinicians to give patients more time to talk; Implement evaluation tools to measure SDM impact and increase the evidence base
Clinicians feel they are ‘already doing SDM’	Raise clinician awareness of ‘SDM in practice’; Communication skills training e.g. role-plays; Contact with SDM champions
Low knowledge of ‘SDM in practice’	Raise clinician awareness of ‘SDM in practice’; Communication skills training e.g. role-plays; Contact with SDM champions
Lack of time to undertake SDM	Raise awareness of evidence highlighting that SDM (and use of decision aids) does not have to make consultations longer; Highlight statistics on consultation time use to encourage clinicians to give patients more time to talk
Misaligned views of	More public training/ education campaigns on how best to

patient preferences	discuss 'what matters to you', patient preferences; Clinician database with up-to-date benefits/risks for treatments
Fear that undertaking SDM could lead to no/bad treatment from clinician	Raise public awareness of SDM to increase confidence of public in the process; Implement evaluation tools to measure SDM impact and increase the evidence base
Poor environment/ surroundings for SDM	Conduct further research on impact of surroundings on SDM through patient surveys/ piloting different 'SDM environments' (e.g. removing barriers such as desks and computers)
Issues around low patient health literacy	More public training/ education campaigns on how best to discuss 'what matters to you', patient preferences; Clinician training (role-plays) on how to conduct SDM with people with lower health literacy (e.g. use of clear/ simple language)
Lack of belief that SDM will happen	Promote SDM at national level e.g. promotion by CMO and Board level stakeholders; Implement evaluation tools to measure SDM impact and increase the evidence base

## 5.1 Recommendations

The following recommendations require consideration from policymakers, as well as relevant stakeholders at a local and national level:

- Implementation of tools to measure and evaluate the impact of SDM (e.g. patient and clinician satisfaction, and statistics on waste and variation);
- Creation of a training programme to improve communication skills of clinicians on how to conduct meaningful conversations;
- More training and education (for patients, clinicians and boards) to raise awareness of how SDM can be practised (and to highlight the evidence that SDM does not have to add more time to consultations);
- More public training and education campaigns on how best to discuss: 'what matters to you'; patient preferences; and promote better 'continuity of care';
- Easy access up-to-date information on benefits/ risks of various treatments, and improved access to information on patient preferences.
- Identify what information would best help patients make healthcare decisions;
- Promotion of clinical, and system level (e.g. national-level stakeholders and CMO) SDM champions to promote and foster attitudes that are receptive of SDM;
- Creation, and maintenance, of a culture that appreciates the importance of SDM. e.g. suite of complementary policies related to SDM and person-centred care.

In terms of future and further research, this report provides four suggestions:

1. There are still gaps over how best to measure to impact of SDM, an issue that is frequently mentioned in the literature (Legare & Thompson-Leduc, 2014),. Additional research could subsequently give it more weight in policy contexts (and provide a framework for the first Policy Recommendation) and raise the public awareness further, especially if a common set of validated measures were identified.
2. The role of the key conditions (Gulbrandsen, et al., 2016) and surrounding environment (Joseph-Williams, et al., 2014) to help or hinder an SDM process.
3. Obtaining a better understanding of what makes a patient and clinician label a decision as 'shared', as research has highlighted some inconsistencies between the views of the two groups (Leppin, et al., 2014; Shay & Lafata, 2015).
4. Research on why certain treatments become less popular after an SDM process, to gain a better understandings of patient preferences and outcomes, as patients tend to choose less treatments as they become more informed (Mulley, et al., 2012).

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## **7. Annexes**

### **7.1 Annex 1: Search Strategy**

Literature searches were conducted using a range of databases (Knowledge and Evidence, science direct, scopus, pubmed) and search terms ('Shared Decision Making'; 'patient support'; 'person-centred care'; 'supported-decision making'; 'advocacy'; 'patient involvement'). Although the primary interest was in evidence from Scotland, a wider geographic search was carried out to capture other relevant evidence. Additional references were obtained from google searches, and discussions with subject matter experts<sup>10</sup> (particularly references for reports and policy material).

Larger scale systematic reviews and meta-analyses on SDM were the focus, rather than smaller scale single condition studies, however some smaller scale studies were included when they specifically concerned the views of patients, clinicians, or the barriers and facilitators of SDM, or if they were of particular relevance to Scotland.

Initial searching identified a large number of articles. This was sifted to 150 (more relevant) articles which were used to inform and guide the report's framework. They were sifted through a review of their titles and abstracts to gauge relevance to the report aim and objectives, geographical coverage and scale of the study (meta-analysis or systematic reviews were preferred). Specifically 76 journal articles and policy reports were used as evidence within this report, along with supporting material from several relevant websites.

### **7.2 Annex 2: Overview of evidence base and gaps**

The evidence used in this report comprises studies predominantly from UK, USA and Canada. Several studies are theoretical or conceptual, or drawing on qualitative primary data, whilst many of the remaining studies are systematic reviews or meta-analyses which mainly comprise of quantitative data (to quantify the degree to which SDM taking place, its impact, or frequency of cited barriers), as well as some meta-analysis of qualitative studies.

The majority of the articles in this report are qualitative in nature because the report's aims and objectives are centred on perceptions and experiences of SDM (subject matter more aligned to qualitative research). A few studies represent findings from national or international studies (Coulter, 2006; Bastiaens, et al., 2007), while the theoretical or conceptual studies tend to focus on wider issues such as system level impacts (Elwyn, et al., 2016; Legare & Thompson-Leduc, 2014). In terms of specific patient groups, literature was identified on older people (Belcher, et al., 2006), young adults (Joseph-Williams, et al., 2014), and the particular roles of the patient and clinician when the patient has particular needs or conditions (e.g. mental health issues, dementia) (Bhatt, et al., 2018).

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<sup>10</sup> Subject matter experts included: the Realistic Medicine policy team; Person-centred and Participation policy team; Scottish Clinical Leadership Fellow; National Clinical Advisor for Realistic Medicine; Deputy Chief Medical Officer; other clinicians of varying specialities

The evidence in this report appears to be fairly representative of the wider literature on SDM, however the focus here was more on the general barriers to, and facilitators of, better SDM practices. Thus more dedicated research may be warranted on specific patient groups in the future, especially as SDM becomes more commonplace in health decisions, and people continue to live with increasing numbers of chronic conditions (Coulter, et al., 2013).

Although SDM appears a term that is widely discussed, there is no single definition (as highlighted in Section 2). Nevertheless, SDM publications have 'increased exponentially in major medical journals from 1996-2011' (Legare & Thompson-Leduc, 2014, p. 48), and there has been a 611% increase in published articles on SDM between 2003-2013.

Traditionally many publications focussed on the creation, and testing, of decision aids as tools for SDM (Fisher, et al., 2018; Elwyn, et al., 2013; Wyatt, et al., 2014). Recently there has been a shift towards wider consideration of the drivers and impacts of SDM. This comes as decision aids have been increasingly recognised as good facilitators for SDM discussions, but not as evidence of the occurrence of an SDM process per se (Legare, et al., 2008; Edwards, et al., 2004; Montori, 2007). This shift has even lead to discussions around the concept of SDM being too narrow (Elwyn, et al., 2016). Nevertheless, there is a literature gap which could be looked at in future research, in terms of whether decision aid use leads to more SDM.

The focus of studies tends to be on the interaction between patient and clinician rather than on interactions with other healthcare professionals or broader system level factors.

There is increasing amounts of literature on the barriers to SDM (Carter & Martin, 2018; Legare, et al., 2008; Gravel, et al., 2006), however gaps occur in providing effective solutions to these barriers in terms of system level factors (Elwyn, et al., 2016). Literature is also emerging in other fields around Realistic Medicine to raise awareness of the importance of patient preferences (Gawande, 2014), which may highlight the importance of system level factors to a more diverse audience.

The focus on person-centred care, and empowerment of patients has also gained traction in recent years, coinciding with the 'demographic timebomb' (Layzell, et al., 2009). This refers to a combination of overburdened health services, rise in chronic conditions and an increasingly ageing population. There is substantial evidence to emphasise that patients want more involvement in their healthcare decision-making, increased knowledge of their conditions and accurate evidence of risks and benefits and self-management strategies.

Discussions are emerging on the key conditions necessary for SDM to occur, such as trust, and recognition of power imbalances (Fisher, et al., 2018; Elwyn, et al., 2016), and how these can be achieved for both patient and clinician (Halpern, 2018). Relatedly, debates exist in the literature on how to define SDM (Legare & Thompson-Leduc, 2014; Elwyn, et al., 2013) and what an SDM process might look like (Elwyn, et al., 2017; Legare, et al., 2008).

In terms of major conceptual gaps, these remain around discussions of larger scale system and organisational factors (e.g. beyond the individual clinician-patient relationship) as well as some gaps on involvement of SDM with other healthcare professionals (Gravel, et al.,

2006) and on the longer term societal impacts of SDM (Elwyn, et al., 2013). Much of the evidence calls for research into evaluations of SDM processes to enable better measurement of instances of SDM (Legare & Thompson-Leduc, 2014; Shay & Lafata, 2015).

However as Leppin et al (2014, p. 3375) highlight, 'for participants to assess a decision-making process, they must first be able to recognise when they have participated in one'. Furthermore, there has been little research published to assist clinicians and other healthcare professionals in their new roles as 'curators' of evidence and knowledge (Gulbrandsen, et al., 2016), as well as little research on the role of the surrounding environment in promoting or hindering a process of SDM (Joseph-Williams, et al., 2014). Specifically the environment has been identified as a potential barrier for older people (i.e. environments that emphasise the power dynamics i.e. unfamiliar setting, poor access, lack of privacy etc.), but little research has been conducted concerning this issue for other groups (i.e. young adults, those with particular characteristics or circumstances) (Park & Song, 2005). In addition, research is required on effective ways to deal with perceived barriers to SDM such as lack of time (Legare & Thompson-Leduc, 2014; Joseph-Williams, et al., 2014) and clinicians belief that they are already carrying out SDM (Legare & Thompson-Leduc, 2014; Moumjid, et al., 2007; Couet, et al., 2013).

Looking more closely at literature on SDM for different patient groups (i.e. by age or ethnicity) (Joseph-Williams, et al., 2014), a number of specific findings have been identified. Research has shown that older patients can hold the belief of 'the doctor knows' best more strongly than other groups, and their authority should not be questioned (Bastiaens, et al., 2007), making SDM with some older patients difficult. Younger people may lack the authority and self-belief to represent themselves appropriately (Fraenkel & McGraw, 2007).

Although factors such as age and ethnicity cannot be altered (Joseph-Williams, et al., 2014), more research could be carried out on how to alter the existing associated attitudes and prejudices that can make participation in SDM more difficult for particular groups.

There is some literature (Bhatt, et al., 2018) around the role of carers, advocates and patients within SDM (e.g. for patients with dementia), which has identified that a broad spectrum of SDM exists when interacting with patients with dementia. However, there are calls for more research on how to best promote SDM among people with dementia and carers (Miller, et al., 2016). Additionally, more research could be conducted on how to encourage greater involvement of young people in SDM (Fraenkel & McGraw, 2007).

Although much of the literature on SDM has come from wider geographic areas (e.g. UK and USA) there has been some literature produced in Scotland, and lessons can be learnt (with appropriate contextual caveats) from the wider geographic literature. Within Scotland the literature has predominantly emerged from policy and third-sector organisations promoting a focus on person-centred care, strategies for self-management and health literacy (see Section 2 for references). Academic literature in Scotland has mirrored this policy focus, with research on (dis)empowerment through self-management (Roberts, et al., 2015; Munoz, et al., 2014) and digital health technology (Dowd, et al., 2018; Currie, et al., 2015).

Much of this research has been conducted in rural areas (Munoz, 2013; Farmer, et al., 2011) where self-management of health conditions could have a bigger impact on the efficiency of health services, and promote the importance of community. Although there is a lack of academic research specific to Scotland, the overview in this section highlights findings from elsewhere that can be relevant to the Scottish perspective.

Overall, links between SDM and patient health outcomes need further exploration, via longer term and system level studies (Shay & Lafata, 2015; Légaré, et al., 2018).

### **7.3 Annex 3: Benefits of undertaking SDM**

This appendix provides more information on the benefits of undertaking an SDM process.

#### **Gives patients more information**

This is made possible as SDM places the importance of a meaningful conversation at the centre of any interaction between healthcare professional and patient. These conversations are an important part of more active patient involvement (Walach & Loughlin, 2018; Coulter, 2006) which highlight a certain level of trust between patient and clinician (Fisher, et al., 2018; Gulbrandsen, et al., 2016). More active patients could lead to a more sustainable healthcare system (Coulter, 2006) as patients have less reliance on overburdened healthcare services. According to Coulter and Collins (2011), 'where support is offered, patients are more likely to succeed in making health-related changes and to self-manage more effectively', facilitated through meaningful conversations within SDM. This can reduce waste and variation by focusing on treatments and options with more beneficial outcomes (e.g. increasing the quality rather than quantity (at whatever cost) of life).

#### **Focuses on treatments and options with more beneficial outcomes**

SDM recognises that every patient may have different preferences in terms of what is important to them. For instance a ballet dancer may resist an aggressive steroid therapy to control asthma wheezing due to fear of muscle weakness and the clinician is not in a position to tell her the decision is wrong (they are her priorities) (Walach & Loughlin, 2018). The risks and benefits of treatments are particular to the patient and their prognosis (Jacobsen, et al., 2018). SDM encourages more beneficial patient outcomes, and reduce unwarranted waste and variation (created by overtreatment and preference misdiagnosis).

#### **Reduces waste and variation**

Enhancing a shared decision-making process this may encourage a focus on the treatments with more beneficial outcomes for the patient (Coulter, 2006). This could also lead to a reduction in unwarranted treatments, and thus waste. For Mulley et al (2012) this variation in unwarranted treatment and waste as formulated itself through 'the preference misdiagnosis'. Mulley et al (2012) termed this the silent misdiagnosis in which doctors automatically recommend a treatment that they are familiar with, irrespective of the patient preferences. SDM prevents the silent misdiagnosis by creating better informed patients with an understanding of the various treatment (or palliative) options and risks,

and clinicians who have a better idea of the patient preferences. Thus clinicians are better placed to make a recommendation that is better for the patient in terms of their preferences whilst also reducing the unnecessary waste and variation of unwanted treatments. In addition SDM could save money through only carrying out treatments which are requested by fully informed patients (Mulley, et al., 2012). By measuring the instances of preference misdiagnosis the NHS will get a better handle on the costs associated with this, as well as an opportunity to measure SDM, and reduce waste and variation.





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