



**National Strategies
for Implementing
Shared Decision Making**

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Contents

1	Executive summary	5
2	Acknowledgements	5
3	Declaration of interests	5
4	Introduction	6
4.1	What is shared decision making?	6
4.2	When is it appropriate?	6
4.3	How can it be encouraged?	7
5	Methods	8
6	Implementation strategies	9
6.1	Clinicians' attitudes	9
6.2	A framework for facilitating system-wide implementation of SDM	10
7	Leadership and culture	12
7.1	Policy bodies	12
7.2	Professional organisations	15
7.3	Patient groups	16
8	National infrastructure	17
8.1	Training	17
8.2	Tools	18
8.3	Campaigns	21
9	Supporting local practice	22
9.1	Demonstration	22
9.2	Measurement	24
9.3	Coordination and support	27
10	Recommendations for Germany	29

11	Appendix: country summaries	30
11.1	Australia	30
11.2	Canada	33
11.3	Denmark	36
11.4	Germany	38
11.5	Netherlands	41
11.6	Norway.....	44
11.7	Taiwan	47
11.8	United Kingdom	50
11.9	United States of America.....	54
12	References	58
	Author	65
	Imprint.....	66

1 Executive summary

Shared decision making involves clinicians and patients working together to select appropriate care, based on clinical evidence and the patient's informed preferences.

Despite strong political, ethical and evidential support for this approach, it has been slow to enter the mainstream of medical practice.

Greater progress has been made in some countries than others. This study examined the state of SDM implementation in nine leading countries (Australia, Canada, Denmark, Germany, the Netherlands, Norway, Taiwan, UK and USA) with a view to identifying best practice and developing proposals for a system-wide strategy to promote wider use of SDM.

A framework for a system-wide SDM implementation strategy is proposed, involving policy, professional and patient leadership, development of basic infrastructure, including training, tools and public campaigns, with practical support and learning from demonstration projects, standardised measurement and feedback, together with practical support and coordination of implementation efforts. The framework offers a checklist of activities that may prove useful, but it is not intended as a universal blueprint - local adaptation is always necessary.

The report includes example of initiatives that have been adopted in various countries. Further details of the current state of SDM implementation in each of the nine countries is included in the appendix.

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3 Declaration of interests

Angela Coulter has been involved in researching shared decision making since the mid-1980s and has published more than 100 papers, articles, reports, books and book chapters on the topic. From 2009 to 2015 she provided paid consultancy support to the not-for-profit Informed Medical Decisions Foundation of Boston, USA. She has also acted as an advisor on patient engagement and shared decision making to a number of national and international public bodies, professional and patient organisations.

4 Introduction

4.1 What is shared decision making?

Shared decision making (SDM) is a process in which clinicians (doctors, nurses, therapists and other health professionals) and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences (1). It involves the provision of evidence-based information about options, outcomes and uncertainties (often, but not always, assisted by the use of patient decision aids (PDAs)), together with decision support counselling and a systematic approach to recording and implementing patients' preferences (2).

Recommended more than 30 years ago by a US Presidential Commission (3), SDM was seen as a means of reforming doctor-patient communications and making informed consent more meaningful. It is based on the premise that clinicians and patients bring different, but equally important forms of expertise to the decision-making process. The clinician's expertise is based on knowledge of the diagnosis, likely prognosis, treatment and support options and the range of possible outcomes; the patient knows about the impact of the condition on their daily life, and their personal attitude to risk, values and preferences (1). Good quality decisions draw on both types of expertise, involving patients and clinicians in a collaborative process to determine the best course of action.

4.2 When is it appropriate?

SDM is appropriate for people facing major treatment decisions when there is more than one feasible option, for decisions about screening tests and preventive strategies, for diagnostic decisions, for maternity care choices, for setting goals and developing action plans in relation to long-term conditions, for advance care planning for mental health problems, and for end-of-life care.

Much of the research into SDM has focused on single, discrete decisions about major treatments, but SDM is also recommended for helping people with long-term conditions who may need to make multiple health decisions over a long period. Personalised care planning, used in chronic disease management to identify and discuss problems related to the patient's condition and develop a plan for managing these, is SDM by another name (4). In other words, it involves a collaborative conversation or series of conversations in which a patient and a clinician jointly agree goals and actions for managing the patient's condition. The attitudes and skills required are the same as those involved in SDM for acute conditions.

SDM is viewed as an ethical imperative that respects the patient's right to autonomy, but also recognises their right to delegate decisions if they wish to. Sensitive listening and excellent communication skills are required, as well as a commitment to share information, communicate risks, clarify preferences and reach decisions collaboratively (5).

Low health literacy need not be a bar to involvement in decisions. Indeed, there is some evidence that people from disadvantaged groups achieve greater benefit from SDM than those with higher literacy, education and socioeconomic status (6). Interventions that are specially tailored to the needs of these groups are more effective than those that aren't. This includes well-designed, well-illustrated PDAs and excellent communication skills to prepare people for making shared decisions. Extra preparation may also help, including question prompts and decision coaching prior to clinical consultations (7, 8).

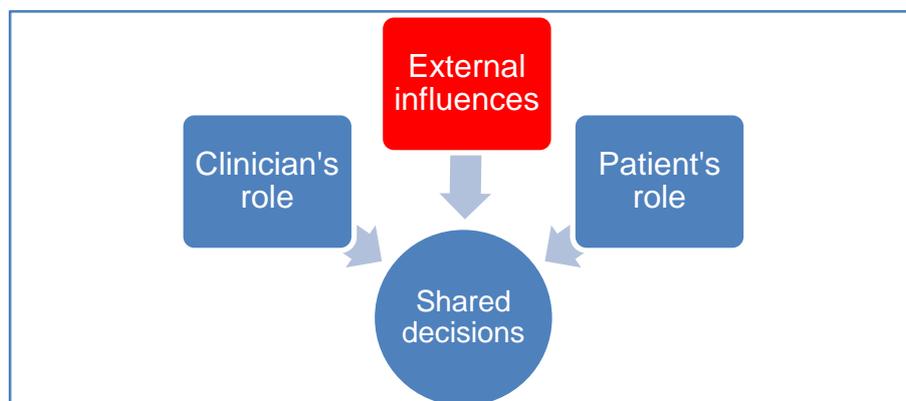
SDM supported by PDAs has been shown to increase patients' knowledge and ability to participate actively, improving the quality and appropriateness of clinical decision making (9, 10). Cost reduction is an occasional

welcome side-effect of SDM, since informed patients often want to avoid invasive procedures if there are viable alternatives (9).

4.3 How can it be encouraged?

There is an extensive body of research into SDM, most of which is focused on the clinical interactions between patients and clinicians. Those interactions are not the main focus of this report. Instead we are specifically interested in the external influences on what happens in clinical interactions. By external factors, we mean the policies, infrastructure and practical support that can strengthen or inhibit the process of incorporating SDM into mainstream care (figure 1).

Figure 1: Factors that influence implementation of shared decision making



SDM draws together two of the major goals of modern healthcare – evidence-based medicine and person-centred care – into a pinnacle of excellence that many aspire to (11). However, despite its many advantages, uptake of SDM into mainstream care has been slow and highly variable, both within and between countries.

Most people want to be involved in decisions about their care, but their opportunities to do so are often thwarted by clinicians unwilling, or unable, to cede control (12, 13). It is quite common for doctors to do most of the talking, seeing themselves as information providers, instead of listening to patients and responding to their concerns (14). Others believe they do practice SDM, when in fact they don't, or think their patients don't want it, when they do (15). It is true that some patients, used to a more paternalistic style, are surprised when they are expected to play an active role in decisions about their care. They may need preparation for this role, and encouragement, but the essential point is that it is a *shared* process, not a delegation of responsibility to the patient.

Policymakers can do much to encourage and support SDM implementation at a national or more local level, by understanding and removing barriers, aligning incentives and providing support for practitioners. This report looks at what is currently happening in those countries that are leading the way in the effort to incorporate SDM into the mainstream of clinical practice.

5 Methods

To achieve better understanding of the factors that help to improve uptake of SDM, the Bertelsmann Foundation commissioned this study to look at the state of SDM implementation in selected countries, with a view to identifying and sharing good practice.

Our starting point was a special issue of ZEFQ, the Journal of Evidence and Quality in Healthcare, that included chapters on international accomplishments in shared decision making in 22 countries (16). Nine of these chapters described relatively advanced implementation strategies, so we focused on these:

- Australia (17)
- Canada (18)
- Denmark (19)
- Germany (20)
- Netherlands (21)
- Norway (22)
- Taiwan (23)
- UK (24)
- USA (25)

By focusing on these nine countries, we certainly do not mean to imply that nothing important is happening elsewhere. On the contrary, the ZEFQ special issue described interesting initiatives in many parts of the world, but time constraints necessitated restricting our attentions to those countries where SDM appears to be more established on national policy agendas.

The study included several components. We began by organising a workshop at the 2017 International Shared Decision Making (ISDM) conference in Lyon, France, to test our understanding of the essential elements of national strategies for implementing SDM. The workshop was attended by more than 20 participants from Argentina, Australia, Canada, China, Denmark, Germany, Israel, Netherlands, Norway, Spain, UK and USA, and useful information was shared and discussed.

Chapters in the ZEFQ special issue, published in June 2017 to coincide with the ISDM conference, were then carefully reviewed to identify key points and information gaps, together with other relevant literature on SDM implementation. This generated a list of questions about the situation in each country which was sent to interviewees prior to the interview.

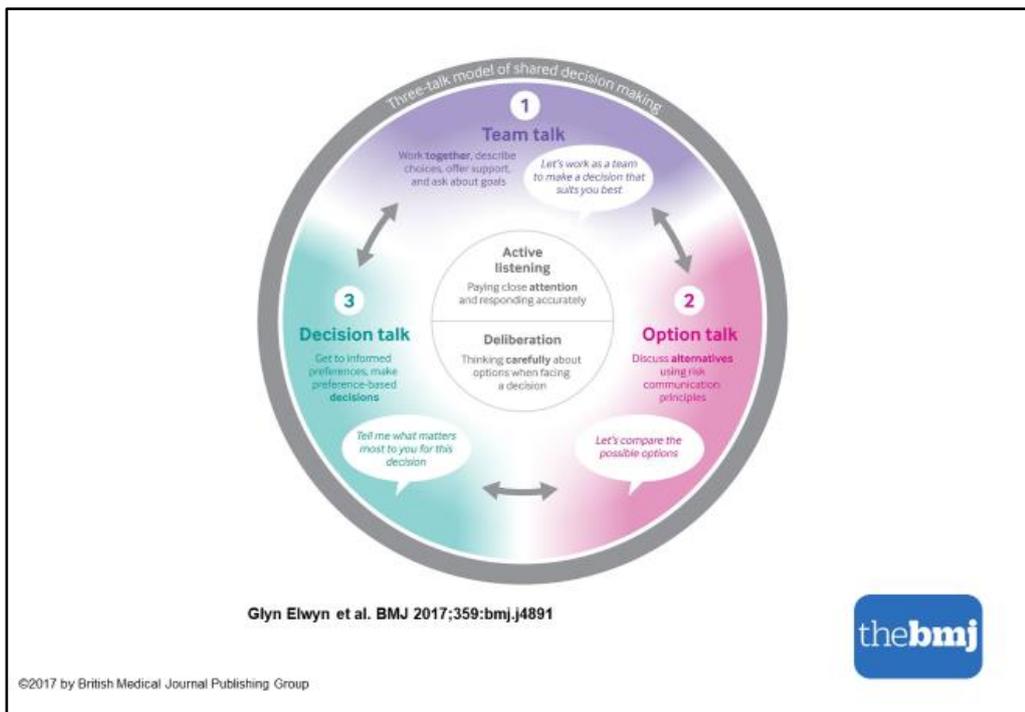
Following this, Skype or phone interviews were organised with at least one author of each of the nine selected country chapters to obtain more context and detail. The interviews were supplemented with additional information gathered from web searches and publications, with the assistance of Google Translate where necessary. Interviewees were invited to check the country summaries produced after each interview.

6 Implementation strategies

6.1 Clinicians' attitudes

Shared decision making implies a fundamental change in the way clinicians view their roles, from seeing themselves as the sole arbiter on what is best for patients, to a more collaborative approach. This often means modifying long-held attitudes and beliefs. An SDM conversation has been described as a 'three-talk model' (figure 2) (26).

Figure 2: The three-talk model of shared decision making



Making this change can be hard for clinicians trained to see themselves as experts. Many barriers, real or perceived, inhibit the change. Studies of doctors' attitudes to implementing SDM have found that lack of time is the most commonly reported barrier (27). Some doctors are uncomfortable about relinquishing their role as sole decision-maker, while others are unwilling to admit to uncertainty about the best option, perhaps fearing that this would undermine patients' confidence in them. And some patients may feel ill-equipped to participate in decisions about their care.

Cultural change is possible, however, and there are signs that positive attitudes towards SDM are beginning to dominate among both clinicians and patients, but many barriers remain (28). Some clinicians believe they already practice SDM, while patients' reports indicate a lack of involvement. Others assume, often mistakenly, that their patients don't want it or couldn't cope with it. Lack of support, lack of tools, rigidity of clinical guidelines, complex work schedules and competing priorities are additional reasons given for resisting exhortations to adopt SDM (15, 29). These objections are often described as myths or misconceptions, but they must be taken seriously and dealt with, if the benefits are to be realised (30).

We use the shorthand '*national*' implementation strategy to refer to any system-wide initiative, be it national, regional or across an accountable care organisation. We acknowledge that responsibility for healthcare is devolved to regional authorities in some countries and the degree to which this occurs varies from country to country. For example, states in Australia and the USA, and Canadian provinces, probably have more scope for autonomous

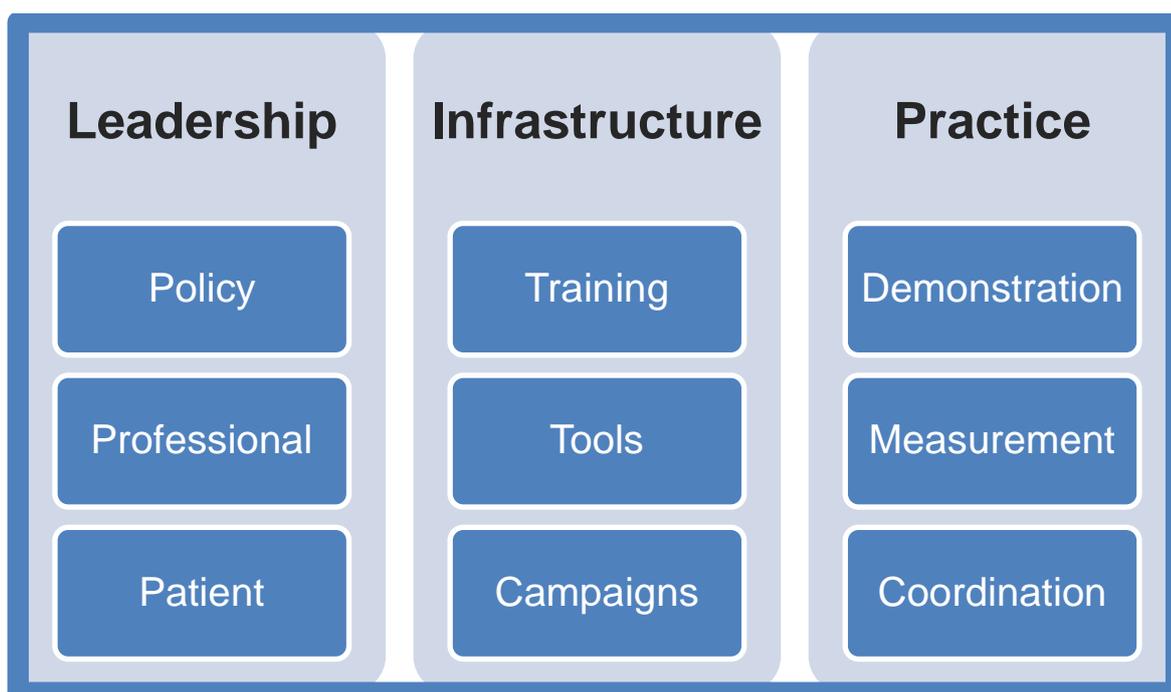
decision making than regional authorities in Denmark, Germany, the Netherlands, Norway, Taiwan and the UK, where health policy is somewhat more centralised, or where the payers, including health insurers, exert a considerable amount of influence over what happens. Even in the most decentralised systems there is scope for federal activity, and many 'national' implementation strategies can be applied at a regional level also.

6.2 A framework for facilitating system-wide implementation of SDM

What are the best means of encouraging the types of behaviour change that will be required if SDM is to become the norm? Various theories have been developed to explain the social psychology of SDM and the mechanisms involved, but these don't really point to what can be done at a system level (31-35).¹ Reviews of behaviour change strategies underline the importance of having a clear theory or framework to guide actions (30), but few theories focus on whole system change and we found none that had been applied to national SDM implementation.

Any strategy for integrating SDM into mainstream practice must take multiple factors into account (37). Building on a previous study of European experience with SDM (38), and informed by theories of behaviour change (39, 40), we created a framework incorporating the main external factors that can support system-wide uptake of SDM (figure 3).

Figure 3: Framework for national implementation of shared decision making



This framework is informed by, but considerably simpler than the well-known Behaviour Change Wheel, which encompasses a more comprehensive list of policy levers, intervention functions and external factors (38). The authors of the behaviour change wheel point to the fact that people's capability, motivation and opportunity to

¹ A scoping review of organizational and system-level factors influencing the implementation of shared decision making was published after this report had been written. It focused on published studies only, mostly from the US, and highlighted similar characteristics to those listed in the framework above. 36. Scholl I, LaRussa A, Hahlweg P, Kobrin S, Elwyn G. Organizational- and system-level characteristics that influence implementation of shared decision-making and strategies to address them - a scoping review. *Implementation science* : IS. 2018;13(1):40.

adopt or change a specific behaviour can be influenced by a wide range of possible interventions. The comprehensive nature of their model makes it too complex for our purpose, but its general approach is helpful for identifying the types of interventions that should be considered when developing a system-wide strategy to implement SDM.

Our framework categorises various activities to promote SDM implementation that are currently being undertaken in the countries we reviewed. It is not intended as an explanatory model, nor is it a universal blueprint, but rather a checklist for use by those wishing to facilitate wider uptake of SDM. We have grouped the various facilitatory factors under three headings – leadership, infrastructure and practice, the details of which are explained in the next section of this report.

Our framework was also informed by ideas from behavioural economics on how to encourage behaviour change (39). The EAST approach offers four useful principles:

- 1) make it **E**asy - harnessing the power of defaults, limiting the amount of effort required, and simplifying messages.
- 2) make it **A**tttractive - drawing attention to the desired behaviour and ensuring that incentives are aligned.
- 3) make it **S**ocial – using the power of social relationships and networks and encouraging commitment.
- 4) make it **T**imely – prompting people when they are most receptive, focusing on immediate costs and benefits, identifying barriers to action and developing specific plans to address them (39).

Thus, an implementation strategy should take account of existing human and financial resources, workflows, clinical pathways and time pressures to work out how to incorporate SDM without disrupting these. It should include the provision of simple tools and reminders to make it as easy as possible to implement. It should consider incentives for clinicians and patients to participate, including possible rewards and sanctions, strengthening these where necessary. It should engage professional and patient networks and build on their leadership capacity, encouraging them to commit to specific activities. And it should be opportunistic, linking the desired shift to existing goals and policies, demonstrating how SDM aligns with other current issues that people care about.

The situation in each of the nine countries is outlined in the country summaries in the Appendix to this report, categorised under the headings listed in figure 3, and supported by web links and references. The next section of the report summarises each of the policies, activities or interventions adopted in one or more of the nine countries, together with brief examples of how and where they are being implemented.

It is important to be aware of likely biases in the accounts of SDM initiatives cited below and the country overviews from which they were drawn. They were mostly derived from articles, reports and websites produced by various actors in the field, or described by individual interviewees, all of whom were engaged in SDM implementation to some degree. These are not dispassionate accounts of rigorously conducted research, nor is it reasonable to think that any individual could have a complete picture of everything that is happening in his/her country in relation to SDM implementation. For these reasons, the examples may provide an overly optimistic picture of the current state of play in each of the countries, but this should not detract from their value as a source of useful ideas. The demand for greater patient and public involvement and a more personalised system of care is growing ever stronger and this is a fast-moving field. There is much to be gained from sharing examples of what health systems can do to satisfy these expectations.

7 Leadership and culture

7.1 Policy bodies

National implementation strategies require effective leadership underpinned by supportive policies and enabling legislation. Leadership is key to creating a culture that is receptive to new ideas and new ways of working. Policy leadership may come from the health ministry, other government departments, or from non-governmental organisations. This type of leadership was clearly an important factor in several of the countries that are leading the way in SDM implementation (figure 4):

Figure 4: Political leadership and policies

Actors	Activities
Ministries	Setting goals and priorities Ministerial speeches Hosting national and international conferences Incorporating SDM into national plans (e.g. cancer plans) Funding for research and development Financial incentives to practice SDM
Parliament/legislators and law courts	Patients' rights laws and charters Legal judgements
Health technology assessment agencies and producers of clinical guidelines	Evidence reviews and summaries Development of patient decision aids Support for SDM in clinical guidelines
Quality improvement agencies, accreditation bodies and organisational regulators	Incorporating SDM into good practice standards Educational materials Inspection and measurement

Ministerial interest and leadership can help to create a supportive climate for SDM implementation, especially when governments and other policy bodies provide support in the form of dedicated funds. Examples of countries where this has made a significant impact include Germany, the Netherlands and Taiwan.

- There has been high level support for person-centred care in Germany from the Federal Ministry of Health, the Federal Ministry of Education and Research, and several other policy bodies. The Ministry of Health provided the first funds for research into SDM in 2001-5. Following that a large research programme was launched in 2008 involving different ministries, insurance companies and the German statutory pension scheme. This provided more than €20 million to fund around 70 research projects on patient involvement in care.
- There is strong commitment to SDM from the Ministry of Health in the Netherlands. Through the Healthcare Institute, the Ministry of Health has provided grants of €5 million for five years to improve transparency and patient-centredness, including SDM, leading to several implementation projects. The Netherlands Organisation for Health Research and Development has also provided funds for this purpose.

- The Taiwan Ministry of Health and Welfare is strongly committed to patient safety, evidence-based medicine and patient-centred care and SDM is seen as an important aspect of both. National implementation of SDM was launched in 2015 following a pilot study in 10 hospitals, together with a series of specialist consultations and consensus meetings, involving patient groups, professional organisations, the Joint Commission of Taiwan and Taiwan Medical Association. The resulting implementation plan involved multiple coordinated approaches.

While health ministers usually stress ethical reasons for encouraging SDM – ‘the right thing to do’ (11), they often hope that it will also be an effective means of cost-containment, leading to the holy grail of high quality care at lower cost. While it is reasonable to expect SDM to lead to a return-on-investment expressed in terms of greater value for patients, it has not been shown to reduce costs. There is some evidence that patients do tend to opt for less invasive interventions when given clear information about treatment options (9, 41) and doctors sometimes see this as an advantage too (42), but over-emphasis of this potential side-effect of SDM can risk alienating clinicians and patients. SDM should not be seen as a means of rationing access to healthcare, or as a tool for cost reduction.

National implementation strategies often begin by focusing on specific clinical topics or conditions. Incorporating SDM into national clinical plans, especially national cancer plans, has been a feature in several countries, including Denmark, Germany, and Norway.

- The fourth version of the Danish Cancer Plan, published in 2016, included a strong focus on SDM, supported by government funds of 22 million DKK (€2 million) to implement the policy and develop PDAs for cancer patients.
- The latest update of the German cancer plan aims to improve the quality of patient information, to involve patients actively in making decisions about their care, and to implement SDM in clinical practice. There is also a commitment to provide balanced and unbiased information on the benefits and harms of cancer screening programmes. Funds have been made available to study how best to achieve these goals.
- The Norwegian Directorate of Health has introduced 28 cancer patient pathways and SDM has been incorporated into these.

Many cancer plans are aimed at achieving faster, more efficient care for patients. This is clearly beneficial in most cases, but it can pose challenges for SDM if fast-tracking leaves insufficient time for patients to consider their options.

National cancer plans are fashionable now in many countries, but this type of approach to system-wide disease planning rarely extends to other conditions. Nevertheless, some priority topics are being tackled in several countries and promotion of SDM has been a feature of these initiatives. One such example is management of musculoskeletal conditions:

- NHS England has provided funding and support for a network of ten organisations to introduce SDM into musculoskeletal care pathways. They are helped to develop detailed action plans and timelines and are encouraged to identify clinical and patient champions, to organise training workshops, to use quality-assured information materials and decision aids, and to monitor and report on their progress.

7.1.1 Financial incentives

As well requiring new skills, SDM consultations may take a little longer to accomplish. This should not be a major problem – a systematic review (9) found that use of PDAs led to a median increase in consultation length of 2.6 minutes – but it can act as a disincentive. To counter this, financial incentives have been introduced in the Netherlands and the USA to encourage clinicians to practice SDM.

- The Netherlands Ministry of Health has announced the provision of a specific registration code to finance the extra time needed for SDM consultations.
- In 2017 the US Centers for Medicare and Medicaid Services (CMS) introduced plans to test two new types of payment incentive – the SDM model (where decision support is provided within clinical encounters) and the Direct Decision Support (DDS) model (where it is provided outside the clinical care setting).

The SDM model was later shelved due to lack of interest from Accountable Care Organisations. The DDS model is still in place however, and once fully rolled out it should provide decision support to a significant majority of the Medicare fee-for-service population with heart disease, hip or knee osteoarthritis, herniated disc, prostate cancer, and benign prostatic hyperplasia.

Provision of dedicated funding streams for SDM research and development have been very important in stimulating implementation. Much of the initial impetus for SDM came from academic researchers, and ready availability of funds enabled them to extend their efforts into evaluating various implementation strategies. This has been an important feature of SDM developments in Australia, Canada, Denmark, Germany, Netherlands, Norway and USA.

Payment methods could act as a disincentive to practising SDM, for example if clinicians paid on a fee-for-service basis are concerned that their income will be reduced if patients refuse certain treatments. We found no evidence that this is occurring in any of the countries reviewed here, but it may be an under-reported barrier requiring the attention of policymakers if it becomes apparent.

7.1.2 Patients' rights

Patients' rights laws or charters are ubiquitous in most developed countries nowadays. Each of the nine countries in our study benefits from legislation or charters clarifying patients' rights, including the right to be given information about treatment options and the right to make decisions about these. While this is an important part of the legislative framework, often these rights are not well publicised and compliance is not effectively monitored. There is much that could be done to strengthen this aspect of public policy.

- One example of an important development in this regard occurred in the UK recently, when a patient's complaint about lack of information on treatment options reached the Supreme Court, and their judgement set a new standard for informed consent that amounts to a legal requirement for SDM (42).

7.1.3 Clinical guidance and quality standards

There are moves afoot in several countries to link SDM to work on health technology assessment and clinical guidelines. Interesting initiatives include development of PDAs by health technology assessment agencies, such as IQWiG in Germany and NICE in England, linked to clinical guidelines.

- The Institute for Quality and Efficiency in Healthcare (IQWiG) in Germany, an independent, non-governmental, not-for-profit foundation that carries out health technology assessments, provides evidence-based health information for patients and public, including some PDAs (e.g. on cancer screening) on its national portal.
- The National Institute for Health and Care Excellence (NICE), which produces evidence-based guidance for the NHS in the UK, has published several quality standards underlining the need for SDM, is developing PDAs to go alongside some of its clinical guidelines, and is working on the production of a guideline on the uses and effects of SDM.

Alignment with guideline producers makes good sense, since both clinical guidelines and PDAs draw on the same evidence base, so developing both together may prove more efficient (43). It may also encourage greater awareness of, and trust in these tools among clinicians.

Quality improvement agencies, accreditation bodies and organisational regulators can reinforce the importance of SDM through their quality standards and inspections, and many are beginning to do so.

- A good example is the Australian Commission on Safety and Quality in Healthcare (ACSQHC), whose accreditation standards include a requirement to demonstrate partnership with patients at individual, service and system levels, and to promote SDM.

7.2 Professional organisations

Professional leadership is key to shaping the culture of care and organisations and specialty societies can do much to persuade their constituents and members that SDM is a standard of practice that they should aspire to. Professional associations tend to be quite conservative in their approach, but we found several examples of professional initiatives to promote SDM, listed in figure 5.

Figure 5: Professional leadership

Actors	Activities
Professional regulators	Codes of conduct Training standards
Medical colleges and specialty societies	Curriculum design Clinical guidelines Collaboration with patient organisations Campaigns, e.g. Choosing Wisely Ambassadors and change agents

Our review of nine countries found an encouraging number of professional organisations supporting wider use of SDM.

- Professional regulators, such as the Australian Medical Council and the UK's General Medical Council state clearly in their codes of conduct that doctors should work in partnership with patients, providing the information they need to make decisions about their care. Since these organisations are also responsible for setting training standards, that ought to mean that SDM skills are incorporated into medical curricula, but as we note below, this type of training has not been universally implemented as yet.

7.2.1 Specialty societies

Sentiments of support for SDM also appear in the professional ethical codes of the Royal Australian College of General Practitioners, the College of Family Physicians of Canada and numerous American specialty societies, but such statements, though welcome, are not likely to make much impact unless they are accompanied by practical actions. Some specialty societies have gone beyond simply publishing codes, taking specific actions to ensure they are implemented.

- The Danish Association of Junior Doctors has launched a programme to train doctors as 'ambassadors' or change agents to promote SDM to their colleagues.
- The German Association of Scientific Medical Societies is facilitating SDM through the production of patient information materials.
- Three organisations in the Netherlands – the Federation of Medical Specialties, the College of General Practitioners, and the Dutch Federation of Patients Organisations – have launched a public website containing evidence-based information and PDAs to complement their clinical guidelines.
- The UK's Academy of Medical Royal Colleges is promoting SDM through its Choosing Wisely campaign, a key goal of which is to encourage better conversations between patients and doctors. Choosing Wisely has been adopted in more than 20 countries worldwide, and several of these, including Australia, Canada and the USA, are actively promoting patient involvement.
- Also in the UK, the Royal College of General Practitioners is working with other organisations to promote SDM for people with chronic or long-term conditions by involving them in goal-setting and action-planning.
- Various medical organizations in the US have highlighted the need for SDM in their clinical guidelines and some of these have developed or endorsed PDAs.

7.3 Patient groups

While patient organisations play an active role in promoting person-centred care at national, regional and organisational levels in most of the countries we looked at, these groups have not generally been at the forefront of moves to implement SDM. However, a few trailblazers have demonstrated the potential impact of their role as advocates for involvement in treatment decisions (figure 6). This is important, not just because of their political influence, but also because it can help to instil confidence among their members that it is acceptable to ask questions and express their views on treatment options.

Figure 6: Patient leadership

Actors	Activities
General patient/consumer organisations and 'umbrella' groups	Advocacy campaigns Designing and advising on implementation projects Evidence summaries Collaborative projects Surveys
Disease-focused patient organisations	Helping to design PDAs and other materials Involvement in research and evaluation Information and publicity

- Danish Patients, an umbrella organisation for 83 patient associations, and its knowledge centre subsidiary, Vibis, played a leading role in the development of SDM in Denmark. They have actively campaigned for it, informed their members about it, and are currently involved in helping to deliver an SDM implementation programme in Aarhus hospital. They are also working with the Danish Association of Junior Doctors to help develop their SDM ambassadors programme.
- The Dutch Federation of Patient Organisations has also actively campaigned for SDM. They were responsible for finding a suitable term to describe it in Dutch, '*samen beslissen*' – making decisions together, thus solving the problem of how to translate the term from English since Dutch has no exact equivalent.
- National Voices, a coalition of 140 charities based in the UK, is also an effective advocate for SDM. Their Narrative for Person-Centred Coordinated Care (44), has been influential at national and local policy levels. They have also produced summaries of the evidence for person-centred care, including SDM, and have used overviews of national patient survey data to draw attention to slow progress in rolling out SDM (45).

The groups whose activities are described above have a broad focus, but single-issue patient groups and individuals concerned with specific conditions can also play a useful role. Many developers of patient information materials and PDAs enlist patient representatives to help develop and test these tools, and patient organisations then publicise these to their members. Cancer patient organisations played an active role in several of the countries we looked at, but it was mainly a supportive rather than leading role.

8 National infrastructure

8.1 Training

Any strategy for SDM implementation should include a training component for clinical staff. Ideally such courses should teach theory and concepts, provide opportunities to observe SDM in practice, and give students ample time to test their skills and obtain feedback on these. SDM involves a great deal more than simply giving information, so it is highly unlikely that all this can be achieved in a single session without additional reinforcement (26, 46-49) (figure 7).

Figure 7: Shared decision making skills and competencies

Training levels	Learning objectives
Pre-registration Post-registration Continuing professional development E-learning	Relational competencies: <ul style="list-style-type: none"> • Developing a partnership and building trust • Non-directive interviewing • Active listening • Empathising • Assessing health literacy and mental capacity • Using plain language • Awareness of patients' information needs • Communicating relevant information • Cultural competence • Negotiation skills • Ethical issues Risk communication competencies: <ul style="list-style-type: none"> • Explaining that a decision needs to be made • Listing treatment options • Explaining and discussing prognosis, probabilities, risks and uncertainties • Communicating benefits and harms • Using PDAs • Eliciting preferences • Collaborative goal-setting and action planning • Making decisions together

8.1.1 Communication skills

While most medical and nursing students receive some communication skills training, it is often at a fairly basic level, and does not usually include SDM. A systematic approach to embedding SDM training into regular undergraduate, postgraduate, or professional courses is rare. Many SDM training courses are one-off initiatives, developed in isolation and not evaluated. Frequently they lack structured assessments, aside from one or two multiple choice questions in a final exam. There is no common agreement on the most appropriate stage of training to introduce these skills, nor how and when they should be reinforced.

Despite these problems, our country reviews indicated a growing demand from clinicians, at various stages of their professional development, for SDM training and increasing numbers of bespoke courses are now being offered. An inventory of SDM training programmes developed at Laval University in Quebec, Canada, listed more than 100 initiatives up to 2013 and many more have been developed since then. There is an increasing number

of online courses, intended to support self-study or as an adjunct to a classroom-based course. These may be very helpful for showing people what is involved, but they are no substitute for real-life practice.

8.1.2 Training initiatives

We noted a number of interesting examples of training initiatives.

- The Australian Commission on Safety and Quality in Health Care (ACSQHC) and the Royal Australian College of General Practitioners have developed an open-access e-learning course.
- The Ottawa Hospital Institute in Canada has developed a range of training materials that are now being widely used around the world
- The Vejle Hospital in Denmark has incorporated SDM training into its three-day mandatory training programme for all staff
- At the University of Hamburg in Germany every medical student receives SDM training in the fourth semester and this is assessed with a specially-designed Objective Structured Clinical Examination (OSCE)
- Maastricht University in the Netherlands has developed a list of 20 core competencies for SDM and assessment tools, including taped consultations, are under development.
- In Norway, the Ministry of Health has introduced mandatory postgraduate training in communication skills and SDM
- In Taiwan SDM training courses are being offered to staff in more than 40 hospitals
- In the UK, training workshops developed as part of the MAGIC (Making Good decisions In Collaboration) SDM demonstration programme are now being provided for clinicians in a range of medical specialties
- The US Agency for Health Research and Quality's SHARE training programme is rolling out its five-steps approach to SDM skills, including train-the-trainers courses.

8.2 Tools

8.2.1 Question prompts

The simplest SDM tools are question prompts designed to encourage patients to ask questions and providers to be ready to answer them. An Australian trial tested the use of three questions asked by simulated patients during GP consultations (Figure 8). Use of these questions improved the amount of information provided by the GPs and led to increased participation by the patients (50). There is little evidence on whether ordinary (non-simulated) patients are willing to ask such questions, but the idea has caught on and is now incorporated in campaigns across Australia and many other countries, including Denmark, Norway, UK and USA (see below for details of campaigns).

Figure 8: Ask, Share, Know – three questions

- | |
|--|
| <ol style="list-style-type: none"> 1. What are my options (including watch and wait)? 2. What are the possible benefits and harms of those options? 3. How likely are each of the benefits and harms to happen to me? |
|--|

8.2.2 Patient decision aids

Situations where there is a simple choice between treatment or no treatment are relatively rare. At most clinical decision points there are a number of alternatives, including different types of intervention or different interventions of the same type (e.g. different drugs), or various support packages, preventive strategies, or lifestyle changes, in addition to the option of watchful waiting or doing nothing.

Patients who want to participate in decisions about their care need access to well-designed, comprehensible information about their condition(s) and the options for dealing with it. This must be based on reliable research

evidence wherever possible, outlining likely outcomes and knowledge gaps in a clear, comprehensible and unbiased manner.

PDA's are designed to prepare patients to participate in shared decisions with clinicians - to supplement clinical discussions, not to supplant them. Ranging from simple leaflets to more detailed booklets, videos, and web-tools, PDA's provide information on treatment or management options, and often include tools to help users clarify their preferences in preparation for making a decision. Unlike clinical guidelines, which are often derived from the same evidence base, PDA's do not tell people what to do and do not make recommendations. They are preparation tools or conversation aids, designed to support collaborative decision making with a clinician.

PDA's have been extensively researched – a Cochrane systematic review looking at the effectiveness of these tools identified 105 randomised controlled trials, and concluded that their use leads to improvements in people's knowledge, improves their understanding of risks, and helps them be clear about what matters most to them, leading to more appropriate treatment (9). Patients who use these tools are clearer about the decisions they need to make, more willing and able to participate, and they tend to be less likely to choose elective surgery over other alternatives. The meta-analysis found a small increase in consultation length of 2.6 minutes when PDA's were used, but the total time spent in an episode of care may be the same or possibly shorter.

Some PDA's are intended for use as conversation guides within clinical consultations, while others are designed for the patient to review at home, either before or after a clinical discussion. There is no evidence on which works best, but there does seem to be a general move towards the development of briefer tools and away from those that require considerable investment to develop and disseminate.

Decision aids are not essential for SDM but they can be very useful, especially for decisions involving more than two options or those where the patient needs to absorb and understand complex evidence.

PDA's were under development in each of the countries in our study. There were several particularly interesting initiatives.

- In Australia, the *Ask, Share, Know* GP network, a collaboration between Bond University and the University of Sydney, has been established to test and translate resources to improve uptake of evidence-based practice and SDM. They produce evidence summaries and PDA's to help GPs manage a variety of conditions.
- In Canada, the Ottawa Hospital Research Institute's global A-Z Inventory of PDA's provides links to a large number of PDA's covering nearly 150 different conditions.
- Laval University in Canada produces the Decision Box, an evidence-based summary of the most important benefits and harms of a health care intervention. The clinician version of the Decision Box prepares healthcare professionals to translate evidence to patients. The patient version aims to support discussions between patients, their healthcare providers and their family members.
- The Centre for Shared Decision Making at Vejle Hospital in Denmark is working with the Design School Kolding to develop a Danish platform for PDA's. This takes the form of a generic template that can be populated with relevant data for a variety of different decisions. The design and content of the PDA's are being carefully tested with patients in different demonstration projects within the hospital. They are carefully designed to meet the IPDAS criteria.
- IQWiG in Germany, which is developing its national portal for patient information, is planning to include a central register of PDA's. They also hope to introduce a more coordinated approach to the development of these tools. It is intended that the national portal will include an assessment of the quality of PDA's.
- A Dutch website, Med-Decs, provides links to PDA's developed in the Netherlands and internationally covering 22 disease areas.
- PDA's developed by the University Hospital of North Norway have been published on the My Treatment Choices website and this will shortly be incorporated into the national health information portal, Health Norway.
- Another Norwegian website, DECIDE Treatment, currently being developed by a team from the University of Oslo, aims to support shared decision making and care planning for people with long-term

conditions to self-manage their health. This platform has been designed for use with multiple clinical topics and includes tools called Health Helpers to support a variety of decisions.

- MAGICapp is a tool for developing and publishing structured electronic guidelines, evidence summaries and PDAs developed by a team based at the University of Oslo in Norway, in collaboration with a number of international organisations and research groups. It is early days yet, but it holds out the possibility of automated development of PDAs alongside clinical guidelines.
- In 2016 the Ministry of Health in Taiwan invited medical associations to suggest priority topics for the development of PDAs and 22 themes were suggested. A total of 174 tools were developed by hospital staff covering most of the 22 themes plus several others. An expert committee was established to review these against IPDAS criteria, leading to the approval of 57 PDAs for wider dissemination. These were then uploaded onto a national SDM platform for use by medical care providers across the country.
- A number of organisations in the UK have developed PDAs for use in the NHS, including NHS England, which has funded and approved 52 PDAs, NICE, and the Health Foundation's MAGIC (making good decisions in collaboration) programme. These are all freely available on various websites, and the NICE website now carries links to 77 PDAs.
- Many US-based organisations have developed PDAs, including researchers, companies (both for-profit and not-for-profit), health care providers, professional societies, insurers, and government agencies. Examples include AHRQ, EBSCO Health, Health Dialog, Healthwise, and Mayo Clinic.

8.2.3 Quality assurance

It is important that PDAs are developed carefully and their content is reliable and tested with patients. The International Patient Decision Aid Standards (IPDAS) collaboration has developed a list of quality criteria and a checklist for assessing these (51-54). IPDAS is widely used by PDA developers and is increasingly used to assess the quality of PDAs prior to including them on an electronic register or portal. IPDAS includes 40 quality criteria but the basic characteristics are shown in figure 9:

Figure 9: Essential elements of a patient decision aid (53)

- | |
|--|
| <ul style="list-style-type: none"> • Describes the health condition or problem (treatment, procedure or investigation) • States the decision that needs to be considered • Describes the options available • Describes the positive features (benefits or advantages) of each option • Describes the negative features (harms, side-effects or disadvantages) of each option • Describes what it is like to experience the consequences of the options (physical, psychological, social) |
|--|

IPDAS is being proposed as the basis for PDA certification schemes in the US, and is influencing developments in Australia, Canada, Denmark, Germany, the Netherlands, Norway, Taiwan and the UK.

8.2.4 Decision aid development and maintenance

PDA development is a very important step towards implementing SDM, but provision of these tools is not sufficient on its own. This obvious point has sometimes been missed in projects focusing on tools exclusively, without providing training and support to ensure they are used appropriately (55).

Many PDAs have been developed by academics for use in research studies, with no plan as to how they will be disseminated and used after the study has ended (56). Few of these study-generated PDAs are supported by institutions that have the capacity and resources to regularly review them and ensure they are kept up-to-date; some are hard to find due to lack of national portals or expensive to purchase; dissemination often relies on the publication of academic papers and other ad hoc means; and there have been few attempts to incorporate PDAs into electronic medical record systems to ensure they are always available when needed.

A potential solution is to make PDA development and/or maintenance the responsibility of established institutions, such as those responsible for producing national clinical guidelines, for example the Institute for Quality and Efficiency in Health Care (IQWiG) in Germany, or the National Institute for Health and Care Excellence (NICE) in the

UK. These organisations are now beginning to develop their roles in relation to SDM, and this type of solution seems likely to emerge in other countries before long.

8.3 Campaigns

Social marketing campaigns form a key part of many implementation strategies, so it is not surprising that these have featured in several countries' efforts to promote SDM. Social marketing has been defined as "*the adaptation of commercial marketing technologies to programs designed to influence the voluntary behavior of target audiences to improve their personal welfare and that of the society of which they are a part*" (57). Many of these campaigns are focused on preparing patients to play an active role in decisions about their care.

- In Australia the ACSQHC partnered with HealthDirect Australia, the national public health portal, to develop and promote a Question Builder to encourage patients to ask relevant questions about their health problems and treatment in specific settings.
- Choosing Wisely Canada aims to reduce unnecessary care by promoting better conversations between patients and clinicians. It's *More is not always better* campaign uses advertising techniques to encourage patients to talk to doctors about when they might need a particular test or treatment and when they don't.
- Hello Healthcare, a cooperation between Danish Foundation TrygFonden and the Danish Society for Patient Safety, developed a tool *Just Ask* – a small booklet of questions other patients have found helpful in their care, such as, "Could you please explain it another way?" "Is there an alternative?" and "Could my wife be present during rounds?"
- The Dutch Federation of Patients' Organisations and the Federation of Medical Specialties launched a national campaign entitled *Improved Care Starts with a Good Conversation* to build awareness of SDM among both patients and clinicians. They also launched an *Ask 3 Questions* campaign that is used in approximately half of all Dutch hospitals.
- A national campaign was launched in Taiwan to encourage medical and healthcare organisations to practice SDM and to promote the use and development of PDAs. Videos were produced to promote SDM to healthcare professionals and patients. Available in two dialects (Taiwanese and Hakka) in addition to Mandarin Chinese, the public version encourages patients to consider what matters most to them and to communicate their expectations to doctors. The professional version provides information about SDM, including the differences between SDM, informed consent and health education, PDAs, and how the process can be implemented.
- Those involved in the MAGIC programme in the UK wanted to raise patients' awareness of SDM and change their expectations about how they might share decisions with clinicians. They involved patient representatives in the design and content of social marketing materials, which included flyers, handouts, pens, posters, videos and 'sticky' notes. Clinical teams used the MAGIC materials in their clinics and waiting rooms and handed out flyers to patients. 61% of clinicians who participated in the evaluation of the MAGIC programme reported that their patients were more likely to ask questions as a result of the campaign (58). It is also likely that the materials provided helpful reminders to clinicians to be ready to answer patients' questions.
- In October 2017 the US National Quality Forum, in partnership with 20 professional and patient organisations, issued a national call to action for all individuals and organizations that provide, receive, pay for, and make policies for healthcare to embrace and integrate shared decision making into clinical practice as a standard of person-centred care.

9 Supporting local practice

9.1 Demonstration

Practical demonstrations can be a good way to persuade skeptical people that SDM can be implemented in the real world. It can also be the best way to identify practical problems and means of overcoming them. However, the lessons are not likely to be learnt unless the demonstrations are carefully evaluated, allowing participants and intended beneficiaries an opportunity to reflect on what they have achieved and what they might have done differently.

Establishing a successful demonstration requires careful planning. The Health Foundation, instigator, funder and evaluator of numerous demonstration projects in the UK and elsewhere, lists ten challenges that should be considered and planned for (59) (figure 11).

Figure 11: Planning a shared decision-making demonstration project

Challenges	Possible solutions for SDM implementation
Convincing people that there is a problem	Many doctors think they already practice SDM – role play or videos of consultations can be used to convince them that this is not the case.
Convincing people that the solution chosen is the right one	There is a common assumption that patients do not want to be involved in choosing treatments, so this misperception must be dispelled.
Getting data collection and monitoring systems right	There is no consensus on the best way to measure SDM, so measures must be selected carefully.
Excess ambitions and ‘projectness’	Embedding SDM into clinical workflows takes time. It may be best to focus on a relatively discrete area or single specialty and get that right rather than trying to spread SDM across a whole system.
The organizational context, culture and capabilities	Staff may not understand their role in SDM implementation and what it involves. Help them to see it in relation to the wider goals of the organization.
Tribalism and lack of staff engagement	Ensure that clinicians review and approve any materials given to their patients. Clarify people’s roles in relation to SDM – for example who will distribute PDAs, who will provide decision coaching, administrative support, and so on.
Leadership	Offer train-the-trainers workshops in SDM skills and ensure that clinical leaders are well-supported.

Balancing carrots and sticks – harnessing commitment through incentives and potential sanctions	Intrinsic motivation may not be sufficient. Enlist senior executives and professional bodies to provide encouragement and sanctions, where necessary.
Securing sustainability	Keep it simple. Identify future funding sources, if necessary, and mobilise other mechanisms to embed SDM into routine practice (e.g. computer prompts).
Considering the side-effects of change.	Be vigilant about detecting unintended consequences and deal with them when they arise, for example if SDM consultations are taking too long, offer preparation before the consultation.

The importance of taking time to engage all staff, clinicians and administrators, adapting workflows where necessary, and applying constant evaluation and iterative improvements cannot be overestimated. Projects that do this are much more likely to achieve their goals than those that do not (15, 40, 60-64).

SDM demonstration projects are currently under way in Australia, Canada, Denmark, Germany, the Netherlands, Norway, Taiwan, UK, and USA. The following examples are particularly noteworthy:

- Vejle Hospital, part of the Lillebaelt Hospital organisation in Denmark, launched an ambitious programme in 2012 to further develop the hospital into a patient-centred, modern and highly specialised cancer hospital with a primary focus on patients' and relatives needs and preferences. To support this work they set up a Centre for Shared Decision Making. The Centre is the result of a collaboration between various clinical departments, the Danish Cancer Society and the University of Southern Denmark, with the aim of developing and evaluating tools, training programmes and implementation projects across the hospital. Prior to establishing the project the team visited various SDM demonstration sites in Canada, UK and USA to learn from best practice elsewhere, and an international advisory group regularly reviews their progress.
- The Northern Norway regional health authority financed the development of a portal hosting PDAs and guidance on implementation led by a team at the University Hospital of Northern Norway in Tromsø. The team has also developed a comprehensive implementation framework. Organised as a virtual production site, the DA Factory is developing a systematic approach to SDM implementation which is now being replicated in Kiel in Germany.
- Participants in Taiwan's national SDM programme have included 23 academic medical centres, 63 metropolitan hospitals, and 79 local community hospitals. Together these 165 institutions have trained more than 17,300 health professionals, and reached more than 100,000 people through their campaign materials, health education activities and social media.
- MAGIC was the UK's largest SDM demonstration project to date. It was funded by the Health Foundation and led by academic teams at Cardiff and Newcastle universities (58). Clinical teams from a variety of services (primary care, breast cancer care, obstetrics, urology and ear, nose and throat) took part, including 270 doctors, nurses and NHS managers. Activities included skills development and engagement, guidance on developing, adapting and implementing PDAs, facilitation and peer support for clinical teams, patient forums and the Ask 3 Questions campaign. The programme helped to consolidate learning about the key implementation challenges and how these can be overcome (15).
- In the US, the Informed Medical Decisions Foundation (previously known as the Foundation for Informed Medical Decision Making) was founded in 1989 and worked for over two decades to advance evidence-based SDM through research, policy, clinical models and patient decision support. Their medical editors and clinical advisors came from prestigious academic medical centres and research groups. They established a network of about 30 demonstration sites around the USA, with a learning collaborative dedicated to embedding SDM in routine clinical care in a variety of settings (11, 62). The Foundation merged with Healthwise in 2014. The research work now continues as the Informed Medical Decisions Program, based at Massachusetts General Hospital, with core funding from Healthwise.

These demonstration projects reflect the increasing maturity of the field, which has progressed from an exclusive focus on PDAs to an awareness that SDM is a complex intervention requiring a sophisticated approach to implementation and evaluation. Pooling the learning from the current international batch of demonstration projects would help to put SDM implementation on an even firmer footing.

9.2 Measurement

9.2.1 Specially-designed measures

The ability to measure the extent to which SDM has occurred is crucial for identifying training needs, for audit and feedback on the quality of consultations, and for evaluating tools, campaigns and demonstration projects. Ideally, measures for routine use should be brief, easy to administer, simple to analyse and carefully tested for validity and reliability. Where possible they should cover the main elements of SDM, though this presupposes agreement on what these are (65).

Various instruments have been developed to assess the presence or absence of SDM. These broadly fall into two types: patient reports and observer tools (66, 67). Patients' descriptions of their experience of clinical decisions are usually gathered via structured self-completion surveys, although more qualitative methods – interviews and focus groups – can also be used. Observer tools are structured templates for analysing clinical conversations or recordings (audio, video or typed transcript) of conversations. Some commonly-used instruments are listed in figure 12.

Figure 12: Selected instruments for measuring shared decision making

Name	Design	Content	Languages
Patient surveys			
CollaboRATE (68-73)	Brief, post-consultation questionnaire; 3 items - 0-9 rating scale	Explanation of the health issue; elicitation of patient's preferences; integration of patient's preferences.	English, Danish, Spanish, Swedish
Decisional Conflict Scale (74-91) Also low literacy version of DCS, and Decisional Regret Scale	17 items - 5 response options	Personal perceptions of uncertainty; modifiable factors; effective decision making.	Chinese, Danish, English, French, German, Italian, Japanese, Spanish
Decision Quality Instruments (92-97)	Versions for back pain, breast cancer, cardiology, colon cancer, mental health, hip and knee osteoarthritis, prostate screening and treatment, menopause	Decision-specific knowledge; decision-specific goals; involvement in decision making.	English, Spanish

SDM-Q-9 (98-101) Physicians version also available SDM-Q-doc	9-items, 6 response options	Doctor explained decision, options, pros and cons; discussed preferences; supported decision making process.	Arabic, Czech, Danish, Dutch, English, Filipino, French, German, Hebrew, Italian, Japanese, Korean, Mandarin Chinese, Malay, Norwegian, Persian, Portuguese, Romanian, Spanish, Thai, Turkish
SURE (74, 86) A screening instrument for decisional conflict	4 items - yes/no responses	Sure of best choice; understand information; risk-benefit ratio; encouragement.	English, French
Patient experience surveys	Single items within longer patient surveys	Selected questions, for example “were you involved as much as you wanted to be in decisions about your care?”	Various
Observer tools			
MAPPIN'SDM (102-104)	9 items – 5 ratings	Rates interactions between doctor, patient and observer.	English, German, Norwegian
Observer Option-5 Instrument (105-108) Also 12-item version and dyadic version	5 items – 5 ratings	Clinician explains options; provides support and reassurance; gives information or checks understanding; elicits preferences; integrates preferences.	Dutch, English

There is no consensus on which of these instruments is best. While brief patient-reported measures may appeal to policymakers, many of these have strong ceiling effects that limit their discriminatory power. Ceiling effects occur when a high proportion of respondents give the best possible ratings, even when there are observed variations in their experience of SDM. This may be because they have low expectations of involvement or because patients tend to be grateful for the care they receive and unwilling to criticise clinicians. Mode effects can also be an issue. This is when the mode of data collection affects the results due to ‘social desirability bias’. For example, telephone surveys tend to yield more positive results than mail or web surveys, so a comparison of data collected in these different ways may be unreliable.

Observer methods can yield richer data on what goes on in consultations, but they rely on patients and clinicians agreeing to allow a recorder into the intimate setting of a consultation room, and analysis of the data requires

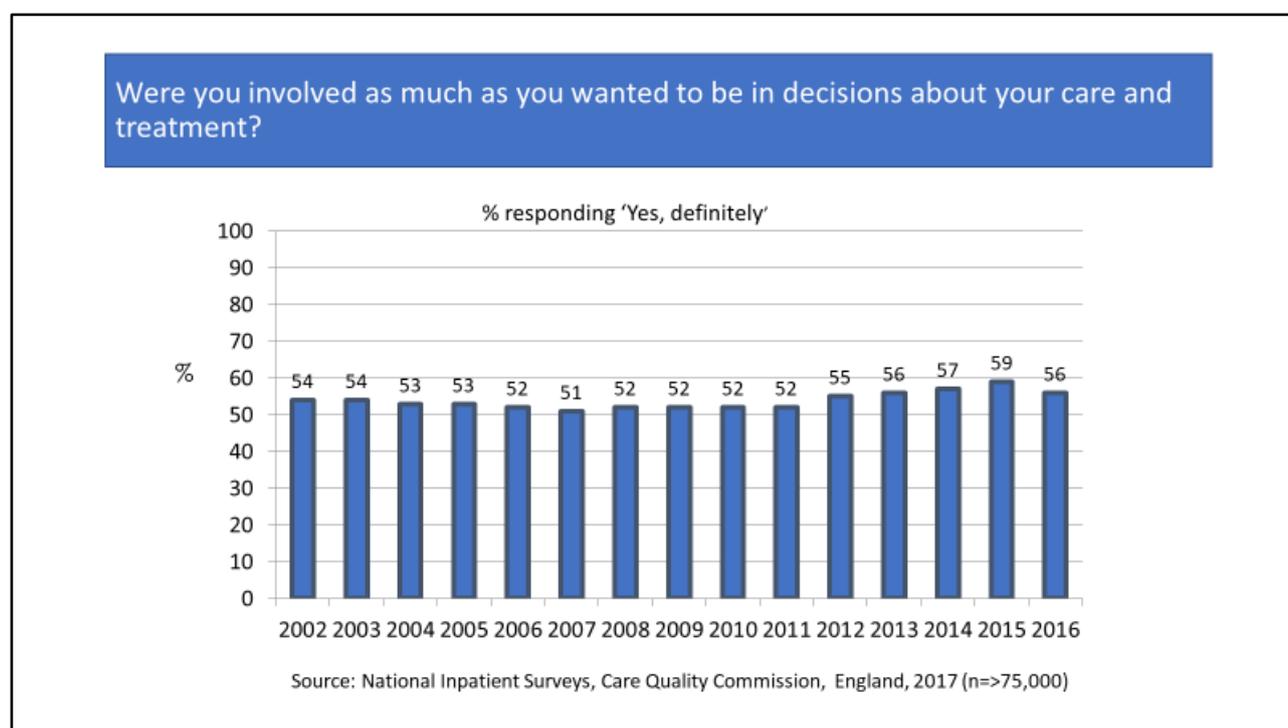
special training and is time-consuming and expensive. These methods are unlikely to be used much outside of research settings.

Another method that is used in some countries is to record the number of patients who are given access to PDAs to inform their decisions. This type of measure is relatively simple to collect, but it presupposes that there are sufficient PDAs available covering all relevant topics, and this is rarely the case. Also, as we have seen, SDM can be carried out effectively without the use of PDAs, so this would produce only a partial measure of the extent of SDM practice.

9.2.2 Patient experience surveys

Many countries and regional authorities carry out regular patient experience surveys to gain feedback on a variety of healthcare quality issues. In some cases these include relevant questions that can be used to give an indication of patients' views on the extent to which they were involved in decisions about their care; for example figure 13 shows results from a single question in the NHS national inpatient survey for England which has been running annually since 2002.

Figure 13: Trends in response to a single 'involvement' question in NHS inpatient surveys in England



Interpreting single questions in cross-sectional surveys like this is challenging because people's responses may be affected by their expectations of involvement which could change over time. Nevertheless, the results from these large-scale postal surveys, completed by more than 75,000 respondents each year, and carried out at a time when patient involvement was a policy priority, are a clear demonstration of how hard it can be to make an impact on mainstream practice of SDM. However, an analysis of the Medical Expenditure Survey in the US, which includes seven questions of relevance to SDM found encouraging improvements between 2002 and 2014, although socio-economic disparities persisted throughout the period (109).

Apart from these general patient surveys, routine measurement of SDM is rare as yet, and usually confined to specific studies or demonstration projects. For example, Vejle Hospital in Denmark is testing the use of CollaborATE, the Decisional Regret Scale and a Decision Quality Instrument for herniated disc; the SDM-Q-9 questionnaire has been widely used in Germany, the Netherlands, and several other countries; MAPPIN'SDM is

used in Germany and Norway; in the UK the MAGIC project used adapted versions of the Decision Quality Instruments, while the AQuA programme used a balanced score care including both SURE and CollaboRATE; Observer Option has been used in the USA and several other countries.

9.3 Coordination and support

9.3.1 Fragmented development

In most countries work on SDM was initiated by academics, with an early focus on the development of PDAs funded from 'soft money' fixed term grants. Interest in more comprehensive implementation strategies began to grow when it became clear that these information and values clarification tools were insufficient on their own to change the culture of care. Since then, as we have seen, a number of other players began to get involved and a variety of initiatives were introduced in all the nine countries we have looked at.

However, in most of these countries efforts to promote SDM have developed in an ad hoc and uncoordinated manner. This makes it hard for anyone interested, for example provider organisations or clinicians, to know where to go to find support for implementing SDM in their organisations. It limits opportunities to learn from others' experiences and leads to wasted effort and resources.

Similarly, the development of PDAs proceeded in a largely uncoordinated fashion, led by the interests of the developers rather than any clear set of national priorities. Development of a good quality PtDA is a complex task, involving identifying decision points, reviewing evidence, development of a prototype, testing with patients and clinicians, and evaluating its use in real-life settings (56). Given the vast number of clinical decisions where there is more than one feasible option and where patients should be involved, it makes little sense to duplicate efforts, yet this is a common problem.

9.3.2 National coordination

There are several ways in which establishing a national coordination centre, or network of centres, could be useful (figure 14).

Figure 14: Potential roles for a national SDM coordination centre

Strategy development	Convening stakeholder meetings to agree priorities and develop an implementation plan, liaising with politicians, policy organisations and funding bodies.
Education and training	Developing core competencies for SDM, mapping training opportunities, encouraging the development of new training courses, shaping curricula, designing assessments, promoting shared learning.
Tools	Coordinating the development of PDAs, producing a central register, quality assuring PDAs, hosting these on a national portal, linking them to clinical guidelines, ensuring they are kept up-to-date, establishing a certification scheme, liaising with suppliers to build PDAs and SDM prompts into electronic medical record systems.
Campaigns	Organising conferences, designing social marketing campaigns, developing and distributing materials, liaising with patient and professional organisations.

Demonstrations	Mapping, supporting and evaluating demonstration projects, summarising and disseminating the learning from these, encouraging replication.
Measurement	Developing or selecting appropriate measurement instruments, monitoring the state of SDM nationally, providing feedback and publishing regular reports.

9.3.3 Collaborations

We found no examples of comprehensive national coordination centres along these lines, but several countries are taking important steps towards a more coordinated model.

- The Netherlands has benefited from strong ministerial interest, coupled with generous funding, enabling the development of infrastructural support. However, it currently lacks institutional support for the development and updating of PDAs.
- Norway has also made great strides in a relatively short space of time, encouraged and funded by the Ministry of Health. They have developed interesting tools, communications training and demonstrations, but there is no central institution responsible for coordinating these as yet. The Ministry of Health has established a process for approving PDAs, based on IPDAS criteria, and they will be placed on a national portal.
- The UK has a longer history of working on SDM, but their efforts remained fragmented and uncoordinated until 2015 when the National Institute for Health and Clinical Excellence (NICE), working together with NHS England, convened a group that has developed into a loose coordinating mechanism known as the NICE SDM Collaborative (110). This involves a large number of organisations committed to taking forward various actions to promote wider roll-out of SDM. As part of this initiative, NICE has recently announced their intention to develop clinical guidance on SDM, and NHS England has launched a new SDM demonstration project focused on musculoskeletal conditions.
- Taiwan comes closest to having a well-coordinated approach. Top down leadership by the Ministry of Health and Welfare and the Joint Commission for Taiwan has been responsible for rapid progress towards nationwide SDM implementation. Helped by the fact that they entered the field relatively late, Taiwan was able to learn from experience in other countries and avoid repeating their mistakes. SDM initiatives around Taiwan are coordinated by the Joint Commission, assisted by a single online resource to provide support, and a system for quality assuring locally-developed PDAs. A national system of Q-codes make it easy to prescribe PDAs. The Joint Commission keeps tabs on developments around the country and uses conferences, workshops and competitive awards to incentivise local hospitals and encourage sharing of good practices. Campaign materials are developed centrally and available for use by local leaders, as are training materials and workshops.

10 Recommendations for Germany

SDM implementation in Germany benefits from a relatively high level of ministerial commitment and funding, several internationally-respected academic groups with an interest in the topic, and professional and non-governmental involvement from a range of organisations. There is considerable experience of developing and evaluating PDAs and a national portal for hosting these is under development. Some interesting training initiatives have taken place, several demonstration sites exist, and there are locally developed measurement tools. However, these initiatives have emerged in an ad hoc manner, with little coordination.

Consideration should be given to establishing a national SDM resource centre (or series of linked centres) with the following objectives:

1. Map current activities in SDM implementation and draft a national implementation strategy for wide consultation and adoption by stakeholder organisations
1. Agree priorities and secure commitments to action on SDM from policy, professional and patient stakeholders
2. Ensure that every clinical student (in medicine, nursing, and allied health professions) receives appropriate training in SDM skills and their performance is assessed
3. Map existing PDAs, establish a register, and agree a list of priority clinical topics for further development
4. Agree quality criteria for assessing PDAs and establish a mechanism for keeping these up-to-date, perhaps linked to the development of clinical guidelines
5. Design and deliver social marketing campaigns aimed at promoting SDM to professionals, patients and the public
6. Support the development of and evaluation of SDM demonstration sites and establish a means of sharing the learning from these
7. Design a set of routine measures of SDM practice and encourage payers and provider organisations to implement these and publish the results
8. Liaise with funding bodies to agree on priorities for further research and development
9. Offer practical support to local initiatives focused on SDM implementation.

11 Appendix: country summaries

These summaries do not claim to be comprehensive accounts of all SDM-related activities in these countries. I owe a deep debt of gratitude to the people who helped me gather the information, including all the authors of the ZEFQ special issue. However, the study relied on a fairly small number of interviews, supplemented by email communications, web searches and literature reviews, so it is always possible that some relevant initiatives may have been missed.

11.1 Australia	
Health system	Health care in Australia is provided by both private and government organisations. Central government is responsible for national health policy and for Medicare funding, but hospital administration, community and public health, ambulance, public dental services and mental health programmes are devolved to the seven state and territory governments.
Leadership	
Policy	<p>The Australian Charter of Healthcare Rights was formally adopted by the government in July 2008. It applies to all health settings anywhere in Australia, including public and private hospitals, general practice and other community settings. It specifies patients' rights to be informed about services, treatment options and costs in a clear and open way, and to be included in decisions and choices about their care. Healthcare providers are expected to discuss available treatment options, expected outcomes, success rates and incidence of side effects. They must also inform patients and consumers of their right to refuse treatment or withdraw consent at any time.</p> <p>The Australian Commission on Safety and Quality in Health Care (ACSQHC), a government agency based in Sydney, introduced its national safety and quality health service accreditation standards in 2011 and updated these in November 2017. They include a requirement to partner with patients at individual, service and system levels, and to promote shared decision making. The relevant standard, 'sharing decisions and planning care', states that organisations must have processes in place for clinicians to partner with patients and/or their substitute decision maker (if the patient lacks capacity) to plan, communicate, set goals and make decisions about their current and future care (111). Guidance for hospitals suggests various ways in which this could be achieved, including reviewing patients' information needs, providing PDAs, question prompts and self-management support, and organising communication skills training for staff.</p> <p>To support these goals, the ACSQHC has hosted symposia and launched national programmes on SDM, health literacy and partnering with consumers (17). Their leaflet on Top Tips for Safe Health Care encourages patients to ask questions, find good information, and understand the risks and benefits of treatment options.</p> <p>Meanwhile several state governments are developing strategies to encourage greater uptake of SDM, including Victoria and New South Wales.</p>
Professional	<p>Apart from the patients' rights charter, there are no other legal or financial incentives for medical professionals in Australia to practice SDM, but several professional bodies view it as an ethical and professional standard.</p> <p>The Australian Medical Council's (AMC) code of conduct for doctors, Good Medical Practice, explicitly endorses SDM: '<i>Making decisions about health care is the shared responsibility of the doctor and the patients</i>'. The AMC also sets standards for medical education and assessment, but whether SDM skills are taught or assessed, and if so, how, is left up to individual medical schools and specialty societies.</p>

	<p>The latest edition of the Royal Australian College of General Practitioners (RACGP) standards for GPs states: <i>'Patients have the right to make informed decisions about their health, medical treatments, referrals and procedures. You have a duty to provide information that the patient can understand, and that is tailored to their individual needs'</i> (112).</p>
Patient	<p>Consumers Health Forum of Australia is the leading group representing consumer interests in health care, with member organisations from around Australia. Their mission is to generate consumer-led ideas for a high quality and affordable health system centred on the needs and preferences of consumers. Information on their website does not mention SDM explicitly, but blogs and videos posted there include patients calling for greater involvement in decisions about their care.</p>
Infrastructure	
Training	<p>Despite evidence of growing demand for it, there is as yet no systematic approach to SDM training and no agreement on the core competencies (17). It is up to individual medical schools and specialist societies to decide what to teach and how to teach it. However, the AMC's standards state that medical graduates must learn how to <i>'elicit patients' questions and their views, concerns and preferences, promote rapport, and ensure patients' full understanding of their problem(s); involve patients in decision-making and planning their treatment, including communicating risk and benefits of management options'</i> (17).</p> <p>The University of Sydney, which has a strong Health Decision Group, is planning to expand its teaching and assessment of SDM competencies.</p> <p>The ACSQHC and the RACGP have developed an online training module for doctors on shared decision making and risk communication. The training modules are available to RACGP members and anyone else via the RACGP website. The ACSQHC is also working with a steering group to develop adapted versions of the online module for specialist colleges.</p>
Tools	<p>The Ask, Share, Know GP network, a collaboration between Bond University and The University of Sydney, has been established to test and translate resources to improve uptake of evidence-based practice and SDM. They produce evidence summaries and PDAs to help GPs manage a variety of conditions.</p> <p>Several other PDAs have been developed, but development and updating of these tools has been ad hoc and uncoordinated. Many were developed for specific research projects, and few have been widely disseminated after completion of the study. Exceptions are the PDAs produced by ACSQHC on use of antibiotics, the RACGP's patient decision aid on screening for prostate cancer, and several PDAs developed by the University of Sydney's health decision group.</p> <p>Bupa, the global commercial health insurance company which has an Australian subsidiary, at one time offered PDAs developed by the US company, Health Dialog, but it is not clear if these are still in use in Australia.</p> <p>There are no plans to certify PDAs and as yet little discussion among policymakers on how these might be quality assured. Researchers in the field are aware of the IPDAS standards, but these are not mentioned on the relevant websites.</p>
Campaigns	<p>Since the publication of a landmark trial (113), there has been considerable interest in Australia and further afield in encouraging patients to ask questions about their prognosis and treatment options. More recent Australian trials have underscored the benefits of this, recommending the use of the following questions: <i>'1. What are my options; 2. What are the possible benefits and harms of those options; 3. How likely are each of those benefits and harms to happen to me?'</i> (50, 114, 115). This approach has now been adopted by</p>

	<p>Cancer Council Australia and Choosing Wisely Australia, both of which recommend slightly different questions.</p> <p>The ACSQHC partnered with HealthDirect Australia, the national public health portal, to develop a 'question builder', encouraging patients to ask relevant questions about their health problems and treatment in specific settings.</p>
Practice	
Demonstration	<p>The Health Decision Group at Sydney University is involved in a number of research projects, including local feasibility studies based in general practice and studies of the effects of low health literacy. Together with colleagues at Bond University, they have obtained a 5-year programme grant to develop research and evaluation of SDM initiatives. Their Ask, Share, Know website includes decision aids and question prompts, and they are working with primary health networks in Australia, China and Myanmar.</p> <p>The Agency for Clinical Innovation in New South Wales is currently developing a strategy to implement SDM across the state.</p>
Measurement	<p>There is no direct measurement of the extent to which SDM is occurring across the country and no consensus on appropriate measures, but some work on measurement is under way linked to hospital accreditation programmes in different states, for example Victoria and New South Wales.</p> <p>Practice variations are monitored and published in the Australian Atlas of Healthcare Variations. ACSQHC has explicitly included SDM among their recommended strategies for tackling unwarranted variations.</p> <p>The New South Wales Bureau of Health Information conducts a regular patient survey which includes a question about involvement in decisions. In 2014, 60% of hospital inpatients said they were definitely involved as much as they wanted in decisions about their care, but a quarter of those receiving new medicines were not told about the side-effects.</p>
Coordination	<p>There is no central coordinating function for work on SDM, no central register or national portal for hosting PDAs, and no dedicated funding source for further development of these. The fact that Australia has made progress towards wider use of SDM is due in large part to the efforts of academics and their success in obtaining funds for SDM studies.</p>
Overview	
	<p>The policy climate in Australia is positive for SDM and professionals are becoming interested. There has been some effective national leadership, notably from the ACSQHC, but implementation of SDM has been patchy and largely uncoordinated to date.</p>

11.2 Canada	
Health system	Responsibility for healthcare provision is devolved to the ten provinces and three territories that make up Canada. The provincial and territorial governments are responsible for the management, organization and delivery of care services health, while the federal government sets standards and provides funds through the publicly-funded Medicare system. The federal government also provides services for certain specific groups, including First Nations people and the military.
Leadership	
Policy	<p>Canada has a long history of supporting SDM research, mainly through the Canadian Institutes of Health Research, and two leading Canadian research groups have influenced policy developments and implementation, both nationally and internationally.</p> <p>The Ottawa Patient Decision Aids Research Group began work in 1989 and since then they have launched the Ottawa Decision Support Framework, developed the Ottawa Decision Support tutorial, created a global inventory of PDAs assessed against IPDAS criteria, and led and regularly updated the Cochrane review on the effects of PDAs (9). Their bilingual website, which also includes a generic personal decision guide for use in any situation, attracts large numbers of visitors from around the world and is now available in English, French, Swedish, Dutch, Danish, Spanish, German and Japanese. Prof Dawn Stacey, who leads this work, is the Canada Research Chair in Knowledge Translation to Patients.</p> <p>Prof France Legaré, Canada Research Chair in Shared Decision Making and Knowledge Translation, is based at the Centre for Research on Primary Care and Services at Laval University, Quebec. She leads the Laboratory for the Implementation of Shared Decision Making in Primary Care, led the Cochrane review on interventions for improving the adoption of shared decision making by healthcare professionals (36), and has developed an inventory of programs and training activities dedicated to shared decision making.</p> <p>Saskatchewan, one of the country's smallest and least populous provinces, was the first to develop a strategy for implementing SDM across the province (18, 116). Their Patient First initiative included implementing SDM as one of its main goals.</p>
Professional	<p>The College of Family Physicians of Canada has called for a patient-centred approach to care, stating: <i>"patients, their families, and their personal caregivers should be listened to and respected as active participants in their care decisions and their ongoing care"</i> (117).</p> <p>A number of specialty groups have instituted collaborative research projects in SDM in areas such as elder care, paediatrics, emergency and critical care medicine, cardiology, nutrition, arthritis, occupational therapy, and social care (18).</p> <p>The Canadian Task Force on Preventive Healthcare has a patient engagement strategy for its guidelines programme and is beginning to promote SDM (118) .</p> <p>There are currently no direct legal or financial incentives for clinicians in Canada to practice SDM.</p>
Patient	Patients Canada campaigns for improvements in patients' experience, but SDM has not been a specific focus of their work. While it seems that no Canadian patient organisations have majored on SDM, various individual patient leaders have been prominent in calling for it.

Infrastructure	
Training	<p>SDM training for clinicians is not coordinated across Canada and not specifically assessed in the exams for medical students, residents or specialists. Little is known about the extent to which SDM skills are taught, or who receives such training.</p> <p>The University of Montreal's medical school has initiated a major patient partnership initiative, including a pioneering project to integrate patient-partners into oncology teams, at both clinical and organizational levels.</p> <p>The University of British Columbia's Patient and Community Partnership for Education works to promote a partnership model of client-health professional communication in line with current trends in health care including evidence-based practice, client-centred care and informed and shared decision making.</p> <p>The Ottawa Decision Support tutorial, an online training programme that has been publicly available since 2007, includes a knowledge test that has been completed by 6,500 users to date.</p>
Tools	<p>The Ottawa Hospital Research Institute's global A-Z Inventory of PDAs provides links to a large number of PDAs covering nearly 150 different conditions</p> <p>Laval University produces the decision box, an evidence-based summary of the most important benefits and harms of a health care intervention. The clinician version of the Decision box prepares healthcare professionals to translate evidence to patients, an essential step to evidence-based practice and shared decision making. The patient version is a PDA to support discussion between patients, their health care providers and their family relatives.</p> <p>A US not-for-profit company Healthwise, markets their information products in Canada. These are used in several provinces, including Alberta, British Columbia and Saskatchewan, but the extent to which the SDM elements of their package are used in Canada is not known.</p> <p>Other decision aid producers include academic groups such as the Ottawa Patient Decision Aids Research Group, the Centre for Research and Primary Care Services in Quebec, and the Decision Sciences Programme at the University of British Columbia.</p> <p>Many of the PDAs produced by academic groups were designed for use in specific research studies and are not available for wider use.</p> <p>Health Quality Ontario produces clinical quality standards and is intending to develop patient decision aids to complement these.</p> <p>Apart from Healthwise, there is currently no Canadian organisation dedicated to producing PDAs and keeping them up-to-date.</p>
Campaigns	<p>Choosing Wisely Canada aims to reduce unnecessary care by promoting better conversations between patients and clinicians. It's More is not always better campaign uses advertising techniques to encourage patients to talk to doctors about when they might need a particular test or treatment and when they don't. Many of the priority lists submitted by specialty societies recommend shared decision making. Choosing Wisely Canada also hosts the international secretariat for Choosing Wisely which is promoting patient involvement in decisions about their care (119). They also produce campaign materials, including posters and videos, to encourage patients to ask four questions: <i>Do I really need this test, treatment or procedure? What are the downsides? Are there simpler, safer</i></p>

	<i>options? What happens if I do nothing?</i> But these questions are focused on reducing over-treatment rather than providing balanced information (120).
Practice	
Demonstration	<p>The Saskatchewan Surgical Initiative introduced SDM into specific clinical pathways, including hip and knee replacement, prostate cancer screening, spine and pelvic floor problems (121).</p> <p>Since 2009 the Children's Hospital of Eastern Ontario has implemented a hospital-wide programme to provide paediatric PDAs and training for health professionals (18).</p>
Measurement	<p>In 2015 the Canadian Institute for Health Information (CIHI) launched a pan-Canadian patient experience survey. This includes the following question: <i>Were you involved as much as you wanted to be in decisions about your care and treatment?</i> No results have been published yet, but when they are this may give an indication of the extent to which SDM is practised across Canada.</p> <p>Meanwhile patient surveys have been undertaken in various Canadian provinces revealing shortfalls in SDM practice. For example, a 2016 survey report from Quebec found that only 35% of family physicians claimed to discuss treatment options with their patients, compared to 67% in the UK, and Quebec patients were less likely to feel involved in treatment decisions, with only 60% of those aged over 55 saying they were, compared to 76% in Switzerland (122).</p> <p>The Ministry of Health in Saskatchewan uses the SURE instrument to screen for decisional conflict in surgical pathways as part of their Patient First programme.</p>
Coordination	There is no central coordinating function for work on SDM and no dedicated funding source for further development of these. However, the Ottawa Hospital Research Institute's inventory of PDAs and their other materials play a key role in disseminating learning about SDM, not just in Canada but also internationally.
Overview	
	Much of the impetus to implement SDM in Canada has come from academic groups to date. While some provinces have made progress, there has been no attempt to coordinate initiatives across the country, professional leadership has been relatively weak, patient/public leadership non-existent and there is a lack of infrastructure support. However, change is in the air and the desire for greater involvement in decisions is becoming more apparent.

11.3 Denmark	
Health system	Healthcare in Denmark is funded through taxation and available to all free at the point of use. Local services are administered and coordinated by five regional health authorities.
Leadership	
Policy	<p>The Danish Health Act states that patients must receive complete information about their treatment and give their explicit consent to receive it.</p> <p>The Danish Ministry of Health is actively promoting the use of patient-reported outcomes and PDAs (19). In 2016 they provided funds of 40 million Danish kroner (€4m) to support 28 specific decision support projects at various Danish hospitals and municipalities.</p> <p>The fourth version of the Danish Cancer Plan, published in 2016, included a strong focus on SDM and PDAs. In support of this the government made funding available amounting to 22 million DKK (€2m) for the development of PDAs for cancer patients.</p>
Professional	The Danish Association of Junior Hospital Doctors , in collaboration with the Danish Patients knowledge centre, ViBIS , has launched a programme to train doctors as 'ambassadors' or change agents to spread the word about SDM among their colleagues. To date 62 ambassadors have been trained.
Patient	Danish Patients is an umbrella organization for 83 patient associations in Denmark, representing a total of 885,000 individual members. ViBIS , their knowledge centre for patient involvement in healthcare, has been a strong influence on the development of SDM in Denmark. They are currently working with Aarhus University Hospital to implement a project to roll out SDM and patient involvement across different departments. When the work is completed, in 2018, they plan wider dissemination including PDAs and an implementation manual.
Infrastructure	
Training	<p>SDM is not yet included in medical curricula on a systematic basis, but some medical schools include it as part of communications skills training. The University of Southern Denmark is planning to introduce training on SDM for pre-clinical students from 2018.</p> <p>ViBIS has developed a series of training courses and skills-building workshops in SDM targeted at specific groups of health care professionals, including the junior doctors ambassadors programme mentioned above.</p> <p>In Vejle Hospital a one-day in-service training course for clinicians in how to communicate and do shared decision making with patients has been developed as an add-on to the hospitals existing three-day mandatory course on general patient communication (123).</p> <p>Aarhus University provides a course in patient involvement for medical graduates.</p>
Tools	<p>Few PDAs have been developed and tested in Denmark as yet and translating existing international tools into Danish is not always feasible, so the Centre for Shared Decision Making at Vejle Hospital is working with the Design School at Kolding to develop a Danish platform. This takes the form of a generic template for PDAs that can be populated with relevant data for a variety of different decisions. The design and content of the PDAs are being carefully tested with patients in different demonstration projects within the hospital. The PDAs are carefully designed to meet the IPDAS criteria.</p> <p>In 2012, with the support of Trygfonden and Danish Regions, the Danish Society for Patient Safety instituted the production of a decision support tool – in the form of a video for patients with osteoarthritis of the knee, who are about to make a decision about knee replacement. The video was produced in collaboration with the Department of Orthopaedic</p>

	<p>Surgery at Gentofte Hospital and the Department of Orthopaedic Surgery at Aarhus University Hospital. An evaluation confirmed the findings of other studies abroad: The more information patients have about alternative options to surgery, the more they decline the surgical option.</p>
Campaigns	<p>Hello Healthcare, a cooperation between Danish Foundation TrygFonden and the Danish Society for Patient Safety, developed a tool <i>Just Ask</i> – a small booklet of questions other patients have found helpful in their care, such as, “Could you please explain it another way?” “Is there an alternative?” and “Could my wife be present during rounds?”</p> <p>Vejle Hospital is working with the Design School at Kolding to develop question prompts promoted via posters and videos in the hospital waiting rooms.</p>
Practice	
Demonstration	<p>Vejle Hospital, part of the Lillebaelt Hospital organisation, is a cancer and university centre in the Central Denmark Region. In 2012 they launched an ambitious programme to further develop the hospital into a patient-centred, modern and highly specialised cancer hospital with a primary focus on patients’ and relatives’ needs and preferences. To support this work they set up a Centre for Shared Decision Making. The Centre is the result of a collaboration between various clinical departments, the Danish Cancer Society and the University of Southern Denmark, with the aim of developing and evaluating tools, training programmes and implementation projects across the hospital. Prior to establishing the project the team visited various SDM demonstration sites in Canada, UK and USA, and an international advisory group regularly reviews their progress.</p>
Measurement	<p>The Danish Cancer Society conducted two large patient surveys in 2011 and 2013. The 2011 survey found that the majority of patients wanted to make decisions about their treatment in partnership with doctors but a significant proportion did not feel sufficiently involved. The 2013 survey found that the situation had improved slightly, with more patients feeling involved.</p> <p>Vejle Hospital is testing the use of the CollaboRATE questionnaire to measure SDM in clinical care. They are also using a Danish translation of the Decisional Regret Scale and the Decision Quality Worksheet for Herniated Disc developed at Massachusetts General Hospital in Boston.</p> <p>The National Danish Survey of Patient Experiences, organised by the Centre for Patient Experience and Evaluation in the Capital Region of Denmark, includes the following question: <i>To what extent were you involved in the decisions that were to be made regarding your care and treatment?</i> In 2016 between 10% and 27% of patients responded that the staff “not at all” or only “slightly” allowed them to participate in decisions about their treatment and care, and up to half reported poor communication about the benefits and harms of various treatment options.</p>
Coordination	<p>There is as yet no central organisation to coordinate SDM initiatives and no central register of PDAs or national portal to host them. However, Denmark is a small country and there is some informal collaboration between leaders in several hospitals and academic groups.</p>
Overview	
	<p>Efforts to implement SDM in clinical practice in Denmark began only recently, for example the work at Vejle Hospital began in November 2014, but their progress has been impressive. Government funding has provided an important boost. As yet there is no central coordinating function for the work and no central register or national portal for hosting PDAs. Development and spread of SDM is still at an early stage, but strong patient leadership and well-based initiatives in Aarhus and Vejle mean that progress has been fast relative to many other countries.</p>

11.4 Germany	
Health system	German health care is funded by statutory health insurance provided by 'sickness' funds that are used by 86% of the population, while 11% are covered by private health insurance companies. Responsibility for administering the health care system is shared between national (federal) and 16 state (Länder) levels, with decision-making devolved to self-governing bodies.
Leadership	
Policy	<p>There has been high level support for person-centred care from the Federal Ministry of Health, the Federal Ministry of Education and Research, and several other policy bodies (20). The Ministry of Health provided the first funds for research into SDM in 2001-2005. Following that a large research programme was launched in 2008 involving different ministries, insurance companies and the German statutory pension scheme. This provided more than 20 million euros to fund about 70 research projects on patient involvement in care.</p> <p>The right to clear comprehensive information and to make informed decisions is enshrined in the Patients' Rights Law of 2013.</p> <p>The next update of the National Cancer Plan aims to improve the quality of patient information, to involve patients actively in making decisions about their care, and to implement SDM in clinical practice. There is also a commitment to provide balanced and unbiased information on the benefits and harms of cancer screening programmes. Funds have been made available to study how best to achieve these goals.</p> <p>The Institute for Quality and Efficiency in Health Care (IQWiG), an independent, non-governmental, not-for-profit foundation that carries out health technology assessments, provides evidence-based health information for patients and public including some PDAs (e.g. on cancer screening) on its national portal.</p> <p>Several government agencies and independent national bodies have provided funds for SDM research, including the Ministry of Health, the Ministry of Education and Research, German Cancer Aid, the German Pension Fund, the German Research Foundation, health insurers, and several foundations.</p>
Professional	<p>Most medical specialist societies are aware of SDM but haven't yet taken a leadership role. However the Association of Scientific Medical Societies (AWMF), representing 175 specialist societies, actively promotes SDM and several of their member organisations have produced patient information materials linked to clinical guidelines. AMWF also hosts the German Choosing Wisely campaign.</p> <p>The German Network for Evidence-Based Medicine (DNEbM) aims to ensure that all patients and citizens receive healthcare based on best evidence and are able to make informed decisions. It has produced a manual on Good Practice for Health Information.</p> <p>The Agency for Quality in Medicine (AZQ) develops and publishes National Disease Management Guidelines with linked patient guidelines, and reliable and comprehensible information for patients based on evidence reviews and studies of patients' preferences.</p> <p>German Cancer Aid and the German Cancer Societies are financing patient guidelines for most of the oncological entities, developed with methodological support from the Agency for Quality in Medicine (ÄZQ).</p> <p>There are no direct financial incentives for clinicians to practice SDM.</p>
Patient	Patient organisations play an important role in policy development in Germany and many of these, e.g. in cancer and mental health, are well networked with policymakers. They have an influential political role as participating organizations within the Federal Joint

	Committee. Most patient groups have called for greater patient engagement on a broad level, but none is specifically campaigning for SDM.
Infrastructure	
Training	<p>The National Competence-Based Catalogue of Learning Objectives for Undergraduate Medical Education (NKLM) includes SDM and most medical schools in Germany now include some element of training on SDM in their curricula. However, this is not necessarily extensively taught and assessment may be based on only two or three multiple choice questions.</p> <p>Some medical schools have gone further and introduced training in practical skills for SDM. In Hamburg medical school every student receives SDM training in the fourth semester and this is assessed with a specially-designed Objective Structured Clinical Examination (OSCE).</p> <p>Heidelberg medical school also teaches SDM skills in three mandatory modules.</p> <p>Discussions have taken place about extending SDM training to postgraduate training schemes, but there has been little progress to date.</p>
Tools	<p>A number of organisations have developed PDAs including IQWiG, AZQ, Bertelsmann Foundation, the Harding Center for Risk Literacy and various academic groups and health insurance companies (20).</p> <p>IQWiG, which is developing a national portal for patient information, is planning to develop a central register of PDAs on a national portal and they hope to introduce a more coordinated approach to the development of PDAs. As yet there is no independent certification scheme specifically for PDAs in Germany, but the proposed national portal may include an assessment of the quality of these tools.</p> <p>There have been few attempts as yet to integrate PDAs into electronic medical records, but the Arriba-lib project in primary care is one example. This electronic library of PDAs for use in general practice was funded by the Federal Ministry of Education and Research (BMBF) (124-127).</p> <p>PDAs have also been produced for people with mental health problems by the Hamburg Network for Mental Health (128).</p> <p>The Bertelsmann Foundation has developed a 'White List' public portal for PDAs that is evidence-based and regularly updated. This is linked to the foundation's work on medical practice variations, the Healthcare Fact Check or Faktencheck Gesundheit.</p> <p>A task force set up by DNEbM published standards for the development of evidence-based health information, emphasising the need to base it on (a) a systematic literature search, (b) justified selection of evidence, (c) unbiased reporting of relevant results, (d) appropriate factual and linguistic communication of uncertainties, (e) either avoidance of any direct recommendations or a strict division between the reporting of results and recommendations, (f) consideration of current evidence on how to communicate figures, risks and probabilities, and (g) transparent information about the authors and publishers of the information, including funding sources (129).</p>
Campaigns	The Coalition for Patient Safety (APS) provides safety tips and encourages patients to ask questions about their medical care.

Practice	
Demonstration	<p>The University Medical Centre in Hamburg hosts a number of projects designed to embed SDM in clinical practice, including an implementation project in cancer care in conjunction with other medical centres. Most implementation projects, here and elsewhere in Germany, have been established as part of research programmes.</p> <p>A large implementation project has recently been launched in Kiel to replicate an SDM project in Norway. This has been allocated 13.6 million euros from the German Innovation Fund and includes development of PDAs, training in SDM skills, measurement and evaluation.</p>
Measurement	<p>The SDM-Q-9 questionnaire (including versions for both clinicians and patients), which was originally developed in Germany and has now been translated into many other languages, has been used in several projects to determine if SDM occurred. A number of other measures have also been adapted and used but there is no agreement on which is the best instrument.</p> <p>Surveys to determine the extent to which SDM is practised in Germany have painted a mixed picture, ranging from 25% to 80% of patients saying they had an opportunity to participate in decisions about their care (20).</p>
Coordination	<p>A relatively large number of initiatives have taken place in Germany to promote the adoption of SDM, but these efforts have been somewhat fragmented. There is no single coordinating body for SDM implementation and as yet no central register of PDAs, though this is planned.</p>
Overview	
	<p>There has been an impressive amount of investment in SDM and some strong national leadership, generating a great many activities, including training, tools development, measurement and implementation, but these activities have not been very well coordinated to date.</p>

11.5 Netherlands	
Health system	Healthcare in the Netherlands is mainly financed through compulsory health insurance contributions from citizens, with additional funds from general taxation. The not-for-profit sickness funds provide cover for all types of care. Most hospitals are independent not-for-profit organisations. General practitioners act as gatekeeper to specialist care.
Leadership	
Policy	<p>There is strong commitment to SDM from the Ministry of Health led by the previous Minister of Health, partly based on the belief that it is the right way to go for ethical reasons, partly due to critical reflection on how evidence-based medicine had been interpreted in an inflexible way, leaving no role for patients, and also perhaps because of a hope that encouraging 'wiser choices' would lead to lower costs.</p> <p>The latest version of the Dutch Act of Agreement on Medical Treatment (WGBO) requires health professionals to provide information on the benefits and harms of treatment options. It also formalises patients' right to access their medical records and to audiotape consultations.</p> <p>Two major international conferences that took place in the Netherlands – the International Shared Decision Making (ISDM) conference in Maastricht in 2011 and the European Association of Communication in Healthcare (EACH) in Amsterdam in 2014 – led to increased awareness of the importance and complexity of SDM (21).</p> <p>In 2013 the Council for Public Health and Health Care (RVZ) published a report entitled The Participating Patient which called on the government to improve the reliability of, and access to health information that outlined the pros and cons of medical interventions; to develop and implement PDAs; to uphold patients' right to demand an individual care plan; and to reward the effort that care providers make to involve patients in decision-making.</p> <p>Through the Healthcare Institute, the Ministry of Health has provided grants of five million euros for five years to improve transparency and patient-centredness, including SDM, leading to several implementation projects. The Netherlands Organisation for Health Research and Development has also provided funds for this purpose.</p> <p>The Ministry of Health has announced the provision of a specific registration code for use from January 2018 to finance the extra time needed for SDM consultations (21). This should counter the tendency to rush patients into a decision as a result of the strong emphasis on speed and efficiency in redesigned clinical pathways.</p>
Professional	<p>There has been strong collaboration between the Federation of Medical Specialties, the College of General Practitioners and the Dutch Federation of Patients' Organisations. In 2012 the Dutch College of General Practitioners (NHG) launched a public website containing evidence-based information to complement their clinical guidelines, together with PDAs. It has since grown to become one of the most visited health care sites in the Netherlands, and a study has shown that it led to a 12% decline consultations two years after the launch (130).</p> <p>Despite these and other initiatives by various organisations, SDM is not yet universally practised and still meets resistance from some doctors.</p>
Patient	There is strong support for SDM among Dutch patients. The Dutch Federation of Patients' Organisations has actively campaigned for SDM. Since there is no easy way to

	<p>translate the English term into Dutch, they proposed using the active verb ‘<i>samen beslissen</i>’ – making decisions together, and this has been widely adopted (21).</p> <p>Breast cancer organisations are also pushing strongly for SDM.</p>
Infrastructure	
Training	<p>Pre-clinical students in the Netherlands usually receive a basic introduction to SDM, but the way in which this is taught varies between institutions.</p> <p>Maastricht University is working to develop a national set of core competencies for SDM training. A list of 20 competencies has been agreed and assessment tools are being developed. The intention is to use video and/or audio tapes to check on SDM skills. Maastricht University Medical Centre will introduce the new programme for postgraduate trainees in all specialties, starting with family medicine.</p> <p>There is some evidence of locally-developed training programmes in SDM being spread more widely; for example, a programme developed in Leiden University Medical Centre is now being used by a number of implementation projects.</p>
Tools	<p>2011 saw the launch of the Med-Decs website providing links to PDAs developed in the Netherlands and internationally. Its collection now includes PDAs developed for patients in 22 disease areas.</p> <p>The Ministry of Health financed the development of national guidance on quality criteria for patient versions of clinical guidelines and PDAs.</p> <p>The Dutch Federation of Patients’ Organisations and the Federation of Medical Specialties have worked together to develop Consult Cards, brief PDAs covering frequently asked questions about specific treatment options.</p> <p>and they coordinate patient participation in the development of PDAs together with specialty groups (21).</p> <p>The Dutch Cancer Society has developed a portal that includes PDAs for cancer patients.</p> <p>A number of academic groups have developed PDAs including the Amsterdam Medical Centre.</p> <p>There have not yet been any attempts to integrated PDAs into electronic medical records, but Maastricht University Medical Centre has a project that is building in prompts to offer PDAs to breast cancer patients.</p>
Campaigns	<p>The Dutch Federation of Patients’ Organisations and the Federation of Medical Specialties launched a national campaign entitled Improved Care Starts with a Good Conversation to build awareness of SDM among both patients and clinicians. They also launched an <i>Ask 3 Questions</i> campaign that is used in approximately half of all Dutch hospitals.</p> <p>Some healthcare insurers are taking steps to actively promote SDM by including it in hospital contracts, and by promoting the use of <i>Ask 3 Questions</i> materials (21).</p>
Practice	
Demonstration	<p>Initiatives to implement SDM are under way in 12 of the 80 Dutch hospitals and in primary care (21).</p>

Measurement	<p>Dutch versions of SDM measurement instruments such as Option 5, SDM-Q-9, Collaborate, and decisional regret have been produced and validated (21).</p> <p>National patient surveys carried out on behalf of the insurance companies include questions of relevance to SDM including “Did the healthcare provider inform you about the pros and cons of the treatment?”, and “Were you involved in decisions about your treatment?”. Results are available from the survey company on request.</p> <p>The Dutch Consumer Quality Index also includes questions on patient involvement.</p> <p>The Dutch government has granted funds to develop better measures of patient participation and these are currently in development.</p>
Coordination	<p>The Netherlands has a more solid infrastructure to support SDM than exists in many other countries, but they still lack institutional support for the development, updating and evaluation of PDAs.</p> <p>Many PDAs have been developed by both public and commercial bodies, but up to now there has been no coordination of these initiatives and uptake among clinicians seems to have been fairly low (21). The international portal for PDAs, Med-Decs, has both Dutch and English versions making it relatively easy to find these tools.</p> <p>Despite separate development initially, there is growing awareness of the similarities between personalised care planning for people with complex long-term or chronic conditions (goal-setting and action-planning) and SDM (mainly focused on acute conditions and discrete choices), with the aim of promoting ‘positive health’, in line with the WHO definition of health (21).</p>
Overview	
	<p>The Netherlands has made more progress than most countries in promoting and supporting SDM, benefiting from strong ministerial leadership and good collaboration between patient and professional bodies. There has been impressive progress in some clinical areas, in particular mental health care, primary care and long-term care, but getting SDM embedded into hospital specialties has proved challenging.</p>

11.6 Norway	
Health system	Health care in Norway is funded out of taxation and partially de-centralised. The public hospitals are owned by central government but administered by four regional health authorities (RHAs), while primary care is provided in 426 municipalities with GPs acting as gatekeepers to secondary care.
Leadership	
Policy	<p>The Directorate of Health (DH), a specialized agency under the Ministry of Health and Care Services, issues clinical guidelines, coordinates 18 patient ombudsmen, and administers the national strategy for health information technology among other things.</p> <p>Patient empowerment is firmly on the policy agenda - the National Health and Hospital Plan 2016-2019 lists empowering patients as the first of its seven goals (22).</p> <p>The 1999 Patients Rights Act confers on individuals a procedural right to participate in treatment choices, be informed and make his or her own medical decisions.</p> <p>There is strong leadership from the Ministry of Health and in particular from the current Minister, who is very keen on SDM. In 2015 the RHAs were told: <i>“Patients require help to involve themselves more actively in decisions about their own treatment. By use of SDM patients choose in cooperation with health personnel the extent and the way they wish to go. The purpose is to agree on the alternative which best fits the patient’s values.”</i> (22)</p> <p>Two of the four RHAs have funded SDM implementation projects costing about 50 million Norwegian Kroner (€5.2 million).</p> <p>SDM has been incorporated into clinical pathways for cancer recently published by the DH.</p>
Professional	<p>There is considerable interest in SDM among Norwegian doctors but most of the push for implementation has come from the Ministry and from academic groups rather than from specialty societies.</p> <p>The usual barriers to SDM are present in Norway – perceived lack of time, lack of skills, lack of obvious patient demand, and a feeling that they do it already. There are no financial incentives for Norwegian doctors to practise SDM.</p>
Patient	Most Norwegian patient groups are campaigning for greater involvement, but none has specifically shown leadership in relation to SDM.
Infrastructure	
Training	<p>Apart from basic communication skills training, SDM is not taught in any depth in undergraduate medical education, but Norway has now introduced mandatory communication skills training and supervision for doctors during their postgraduate specialist training.</p> <p>The Oslo Communication in Healthcare Education and Research group (OCHER) has been conducting research into SDM skills and how they can be taught. They demonstrated that it is possible to improve specialists’ communication skills with the use of a short (two days) course based on the Four Habits model for clinical consultations developed at Kaiser Permanente in the US - Invest in the Beginning, Elicit the Patient’s Perspective, Demonstrate Empathy, and Invest in the End (131, 132). This study influenced the Ministry’s decision to introduce mandatory postgraduate training. The OCHER team see SDM as the last and most complex habit that doctors must learn. This involves major culture change, so it must be carefully taught and continually reinforced – a long-term project.</p>

	<p>A meta-curriculum for training health personnel in SDM communication, klarfor samvalg (ready to SDM), has been developed by the team in Tromsø. This aims to provide the basis for development of the mandatory postgraduate training in communication skills and SDM.</p>
Tools	<p>The DH has adopted a standard set of quality criteria for PDAs based on IPDAS (22).</p> <p>PDAs developed by the University Hospital of North Norway have been published on the My Treatment Choices website and this will shortly be incorporated into the national health information portal Health Norway.</p> <p>Another website, DECIDE Treatment, currently being developed by a team from the University of Oslo, aims to support shared decision making and care planning for people with long-term conditions to self-manage their health (133). This platform has been designed for use with multiple clinical topics and includes tools called Health Helpers to support a variety of decisions.</p> <p>Oslo University Hospital hosts the Center for Shared Decision Making and Collaborative Care Research, which combines e-health research and innovation with the overall goal to improve shared decision making, illness management, self-management and patient-centered collaborative care. They have a special focus on electronic mechanisms for supporting SDM, aimed at supporting patients, clinicians and carers (133).</p> <p>MAGICapp is a tool for developing and publishing structured electronic guidelines, evidence summaries and PDAs developed by a team based at the University of Oslo in collaboration with a number of international organisations and research groups. It is early days yet, but it holds out the possibility of automated development of PDAs alongside clinical guidelines (43).</p>
Campaigns	<p>The DH has launched a <i>Just Ask</i> programme, based on the Australian <i>Ask Share Know</i> initiative, to encourage patients to ask questions about their treatment.</p>
Practice	
Demonstration	<p>The Northern RHA financed the development of a portal hosting PDAs and implementation strategies led by a team at the University Hospital of Northern Norway in Tromsø. The team at the University Hospital of North Norway has also developed a comprehensive implementation framework. Organised as a virtual production site, the DA_{factory} is developing a systematic approach to SDM implementation which is now being replicated in Kiel in Germany (22).</p> <p>The South-Eastern RHA has funded the development of PDAs, a website, e-learning and implementation support.</p> <p>Three or four years ago the Haraldsplass Deaconess Hospital in Bergen adopted a hospital-wide approach to improving communications with patients which is now showing some effects.</p>
Measurement	<p>A standardised measure of SDM, <i>MAPPIN'SDM</i>, has been translated into Norwegian, validated and used in various local projects (102, 103).</p> <p>PasOpp is a national patient experiences survey run by the Norwegian Institute of Public Health which includes relevant questions.</p> <p>The Consumer Ombudsman carries out regular patient surveys and these may give an indication of the extent to which patients feel they are involved in their care.</p>
Coordination	<p>Norway has seen several interesting initiatives to develop tools, communications training and demonstrations. There is no central institution responsible for coordinating these as yet, or for ensuring they are kept up-to-date, but the Ministry of Health has established a</p>

	<p>process for approving PDAs, based on IPDAS criteria, and they will be placed on a national portal. The strong lead from the Ministry of Health means Norway is well placed to develop a coordinated approach to SDM implementation.</p>
<p>Overview</p>	
	<p>Despite the establishment of several strong initiatives in tools development, communications training and implementation strategies, the impact of these on clinical practice has been relatively minor to date. However, it is early days and Norway is working hard to produce a more comprehensive and better coordinated system for launch in the near future.</p>

11.7 Taiwan	
Health system	Taiwan has a single-payer national health insurance system jointly financed by payroll contributions from employers and employees and government subsidies (23). Healthcare is delivered by a public-private mix of 485 hospitals and 21,845 clinics and administration costs are low. There is no gatekeeping function, consultation rates are high by western standards and visits are short (134). This has led to rising levels of dissatisfaction among patients and burnout among doctors (135, 136).
Leadership	
Policy	<p>The Taiwan Ministry of Health and Welfare (MOHW) is strongly committed to patient safety, evidence-based medicine (EBM) and patient-centred care and SDM is seen as an important aspect of both. A nationwide EBM project was launched in 2002 under the supervision of the MOHW and patient involvement has been a goal of the Taiwan Patient Safety programme since 2004.</p> <p>The 1986 Medical Care Act requires written informed consent from patients before operations and the Physicians Act requires doctors to provide patients with clear, comprehensible information about treatment plans, interventions, medications, prognosis and possible adverse effects.</p> <p>A Patient Self-Determination Act introduced in 2015 guaranteed participation and autonomy, but how this should be done and documented is still being worked out (23).</p> <p>SDM was first mentioned at an EBM conference about three years ago, after which the Ministry decided to launch a programme to promote SDM across Taiwan under the leadership of the Joint Commission of Taiwan (JCT). The JCT receives funds from the MOHW and is responsible for the national hospital accreditation programme. JCT staff studied what was going on in other countries in relation to SDM implementation, before developing a comprehensive plan for Taiwan.</p> <p>National implementation of SDM was launched by MOHW in 2015 following a pilot study in 10 hospitals and a series of specialist consultations and consensus meetings involving patient groups, professional organizations, the Joint Commission of Taiwan (JCT), and Taiwan Medical Association. The final implementation plan involved multiple coordinated approaches.</p>
Professional	Medical and nursing associations and some medical specialty societies were actively involved in developing PDAs. They are generally supportive of the SDM implementation programme.
Patient	Patient-centred care has been a policy priority since 2002 and an annual patient safety week serves to focus attention on this topic. More than 200 patient representatives have been trained and most hospitals involve patient volunteers. Despite this, finding patient representatives to help promote SDM has been somewhat challenging. The Taiwan Association for Family Caregivers has a representative on the steering committee. This person, a media specialist, has played an important role in helping to design campaign materials.
Infrastructure	
Training	Medical students and postgraduate medical trainees receive some training in communication skills, but this tends to be rather basic and does not include SDM. One of the drivers for promoting SDM is the high incidence of disputes between patients and doctors, especially in high risk specialties such as surgery and emergency care. It is hoped that exposure to SDM will help to improve doctor-patient communications.

	<p>The SDM platform includes educational programmes and guidance, as well as the accredited PDAs. It also includes special QR codes so physicians can easily prescribe PDAs for their patients.</p> <p>Hospitals are encouraged to promote SDM to their staff through continuing education courses and clinic meetings. Feedback of results is also stressed. The JCT organises regional and national conferences, including competitions and rewards for the best PDAs and the best implementation methods.</p>
Tools	<p>MOHW and JCT worked with the hospitals to develop PDAs. The development process included identifying patients' questions, specifying the target population, clarifying the treatment options, and comparing the benefits and harms of each option in line with patients' preferences. The prototype PDAs, which included brochures and videos, were tested in a pilot study with 30 patients to check for comprehensibility and usability.</p> <p>In 2016 medical associations were asked to suggest priority topics for the development of PDAs and 22 themes were suggested. Following an invitation to participate, 174 PDAs were developed by hospital staff covering most of the 22 themes plus several others. An expert committee was established to review these against IPDAS criteria, leading to the approval of 57 PDAs for wider dissemination. These were uploaded onto the SDM Platform for use by medical care providers across the country. Those that were not approved were mainly traditional health education materials that did not explicitly recognise and support the patient's role in making decisions about their own care.</p> <p>The PDAs are designed for use in clinical consultations and are currently only accessible to medical staff, not the wider public, though this may change next year. Hospitals are free to design their own systems for distributing PDAs. Some have developed electronic prompts to encourage their use, while others rely on paper-based methods to integrate the PDAs into clinical workflows and document their use.</p> <p>There is no formal certification programme for PDAs at present, but it is hoped that one will be established in the near future.</p>
Campaigns	<p>A Shared Decision Making Campaign was launched to encourage medical and healthcare organisations to practice SDM and to promote the use and development of PDAs. Videos were produced to promote SDM to healthcare professionals and patients. Available in two dialects (Taiwanese and Hakka) in addition to Mandarin Chinese, the public version encourages patients to consider what matters most to them and to communicate their expectations to doctors. The professional version provides information about SDM, including the differences between SDM, informed consent and health education, PDAs, and how the process can be implemented.</p> <p>To encourage participation of hospitals, patients and their families, the JCT worked hard to help hospital integrate SDM into their daily practice, using a variety of campaign materials including videos, posters, online resources, social media, health education activities and good practice awards.</p>
Practice	
Demonstration	<p>Participants in the national SDM programme have included 23 academic medical centres, 63 metropolitan hospitals, and 79 local community hospitals. Together these 165 institutions have trained more than 17,300 health professionals, and reached more than 100,000 people through their campaign materials, health education activities and social media.</p> <p>Feedback on the SDM programme from frontline clinical staff has been largely positive, but several challenges remain: busy work schedules can get in the way, especially in emergency services and outpatient clinics, resources are limited and secure funding not</p>

	<p>yet established, proof of concept including PDAs and skills has yet to be proven in Taiwan, uncertainty about the legal status of SDM makes some physicians sceptical, and cultural expectations of families' role in decision making can cause conflicts.</p>
Measurement	<p>Regular public surveys are conducted which in recent years have shown an improving trend in people's willingness to cooperate with health professionals (23).</p>
Coordination	<p>The SDM programme is jointly coordinated by the MOHW and the JCT. JCT provides consultancy services to hospitals to help them implement SDM. Currently 165 hospitals, about a third of the total in Taiwan, are involved in implementing SDM. They are first invited to identify priority topics, followed by a search for suitable PDAs. They then develop strategies for integrating these into their workflows.</p> <p>Funding for central coordination, training, development and design of the campaign comes from the government, while individual hospitals are responsible for covering their own costs. The JCT's hospital accreditation programme includes SDM implementation as one of the quality criteria, providing an added incentive for hospitals to take part.</p> <p>A survey of 484 medical institutions to identify barriers and facilitators to implementing SDM identified lack of appropriate PDAs, lack of relevant training courses, and lack of familiarity with SDM as the main barriers, while recognition of the positive impact of good doctor-patient communication, agreement on the need to improve care outcomes, and the presence of medical staff with adequate knowledge of SDM were seen as the most important facilitators. These findings will be used to design future implementation strategies.</p> <p>A survey of frontline clinical staff (doctors and nurses) and patients involved in the national SDM programme elicited a very positive response with 86% agreeing that PDAs were useful for patients facing major medical decisions and helped to improve communications.</p>
Overview	
	<p>Taiwan has made astonishing progress towards wide implementation of SDM in a remarkably short space of time. This appears to be due to the strong lead from the MOHW and the JCT.</p> <p>There is recognition that the fast roll-out has caused a few problems, including resistance from some clinicians, patients and families, so the programme leaders plan to spend the next year consolidating the learning, strengthening the campaign, and ensuring the programme is sustainable in the longer term. This will involve persuading the national health insurance system to provide financial support and incentives to practice SDM, as well as developing a system for maintaining and updating PDAs. Collaboration with research institutes will also be needed to evaluate the impact of the programme.</p> <p>Judged on progress to date in Taiwan, the scope and scale of this centrally developed, systematically planned, comprehensive national programme is most impressive.</p>

11.8 United Kingdom	
Health system	<p>Most UK citizens depend on the National Health Service (NHS) for almost all their healthcare needs. Funded out of taxation, the NHS covers primary care, hospital care (in-patients and outpatients), community care (including home nursing and other out-of-hospital services), and mental health care. These services are free at the point of use. Social care for those needing non-medical help due to disabilities or frailty is provided on a means-tested rather than universal basis and is organised and funded locally.</p> <p>The NHS was established in 1948 and run centrally for the whole of the UK by the Department of Health in London until 1999, when responsibility for managing healthcare was devolved to the four nations of England, Scotland, Wales and Northern Ireland (24).</p>
Leadership	
Policy	<p>SDM has been a policy priority for the NHS for several years, building on a long tradition of research into SDM dating back to the early 1990s.</p> <p>The NHS Constitution for England states that people have the right to be involved in planning and making decisions about their health and care and to be given information and support to enable this. Scotland's Charter of Patients' Rights and Responsibilities makes a very similar commitment, and similar rights are guaranteed for patients in Wales. Northern Ireland is the only part of the UK that has seen no government commitment to SDM as yet.</p> <p>The National Institute for Health and Care Excellence (NICE), which produces evidence-based guidance for the NHS, has published several quality standards underlining the need for SDM, is developing PDAs to go alongside some of its clinical guidelines, and is working on the production of a guideline on the uses and effects of SDM (110).</p> <p>NHS England, the body that sets the priorities and direction of the NHS in England, is committed to embedding SDM in its strategic and practical developments. Its Right Care programme includes three goals for its work on SDM – to support SDM through the development of tools and decision coaching, to embed SDM in NHS systems and processes, and to create a receptive culture for SDM.</p> <p>In Scotland the Chief Medical Officer has instituted a programme of work entitled Realistic Medicine, with a strong focus on SDM. The Scottish government's Health Literacy Action Plan aims to make it easier for patients to work in collaboration with clinicians, including SDM, through communication skills training and provision of clear information and other literacy tools (137).</p> <p>In 2015 a landmark ruling by the UK Supreme Court set a new legal standard when the judges decided that patients with full mental capacity must be properly advised about their treatment options and the risks associated with each option so that they can make informed decisions when giving or withholding consent to treatment. In other words, the principles of shared decision making must become the norm.</p>
Professional	<p>The General Medical Council (GMC), the official regulator for doctors across the UK, calls on them to work in partnership with patients, providing the information they need to make decisions about their care. Other regulators, including the Nursing and Midwifery Council have espoused similar principles.</p> <p>The Academy of Medical Royal Colleges, the coordinating body for the UK and Ireland's 24 medical Royal Colleges and Faculties, is promoting SDM through its Choosing Wisely campaign. A key goal of the campaign is to encourage better conversations between patients and doctors. The Choosing Wisely website includes links to patient decision aids where these are available to complement their recommendations.</p>

	<p>Several of the medical royal colleges and their specialty societies have been encouraging their members to practice SDM, including the Royal College of Physicians, the Royal College of General Practitioners, the Royal College of Surgeons, the Royal College of Anaesthetists, and the Royal College of Psychiatrists.</p> <p>The Royal College of General Practitioners, NHS England, and the Coalition for Collaborative Care are working together to promote care and support care planning (SDM by another name) for people with long-term (chronic) conditions. This involves eliciting the patient's goals and concerns and together developing an action plan to achieve these. The action plans often go beyond traditional medical services to include identifying support from local community groups and services.</p>
Patient	<p>National Voices, a coalition of 140 charities campaigning for people to be in control of their health and care, has a strong record of campaigning for SDM. Their Narrative for Person-Centred Coordinated Care has been very influential at national and local levels in England. They have also produced snapshot reports that draw attention to slow progress in rolling out SDM (45).</p> <p>Healthwatch is the national champion for people who use health and social care services and several of its local groups have joined campaigns to promote SDM.</p>
Infrastructure	
Training	<p>The GMC is responsible for regulating all stages of doctors' training and professional development in the UK. Medical schools and postgraduate training programmes are expected to ensure that the GMC's principles and standards set out in Good Medical Practice are taught and assessed. These include communication skills and the requirement to work in partnership with patients, sharing the information they need to make decisions about their care. The GMC's Generic Professional Capabilities Framework sets out the behaviours, skills and knowledge that doctors in training should demonstrate, including SDM.</p> <p>In 2017, Health Education England (HEE), which coordinates training for the broader healthcare workforce, commissioned Skills for Health to produce a framework to support person-centred approaches for the health and care workforce, including SDM. HEE also commissioned an e-learning course on SDM.</p> <p>The Health Foundation's MAGIC programme developed various SDM training resources from 2010-2013 that are still available on a mothballed website.</p> <p>The Advancing Quality Alliance (AQuA), based in north west England, offers a range of training and consultancy programmes focused on person-centred care and SDM. They worked with NHS Right Care to train health professionals, engage patients and promote the inclusion of SDM in professional education.</p>
Tools	<p>A number of organisations have developed PDAs intended for use in the NHS, including NHS England, which has funded and approved 52 PDAs, NICE, the Option Grid Collaborative and the Health Foundation's MAGIC (making good decisions in collaboration) programme. These are all freely available on various websites, and the NICE website now carries links to 77 PDAs.</p> <p>The NHS in England has a national portal for patient information called NHS Choices, but it no longer carries links to decision aids.</p> <p>NHS England's Information Standard operates a certification scheme for producers of patient information materials, while NICE accredits developers of clinical guidance. A combination of these approaches has been proposed as the basis of a certification scheme for PDAs, but as yet no funds have been made available to cover the cost of establishing it.</p>

Campaigns	<p>The phrase <i>'Nothing about me, without me'</i>, first used in a healthcare context in a Salzburg Seminar in 1998 (138), was adopted as a campaign slogan during the NHS reforms of 2012. It was later modified to <i>'No decision about me, without me'</i> and widely used by NHS England and the King's Fund, among others, to promote the idea of SDM.</p> <p>Several local sites involved in the MAGIC programme adopted the Ask 3 Questions campaign, originally developed and trialled in Australia. The original three questions were: <i>What are my options? What are the possible benefits and risks of these options? How likely are the benefits and risks of each option to occur?</i> In some sites the final question was modified after consultation with local patients, to <i>How can we make a decision together that is right for me?</i> A range of campaign materials was produced to promote the three questions, including flyers, handouts, pens, posters and other materials.</p> <p>AQuA also used the <i>Ask 3 Questions</i> approach in its work with NHS Right Care, and they produced a short video for use in clinic waiting rooms.</p>
Practice	
Demonstration	<p>MAGIC was a national SDM implementation programme funded by the Health Foundation and led by academic teams at Cardiff and Newcastle universities (58). Clinical teams from a variety of services (primary care, breast cancer care, obstetrics, urology and ear, nose and throat) took part, including 270 doctors, nurses and NHS managers. Activities included skills development and engagement, guidance on developing, adapting and implementing PDAs, facilitation and peer support for clinical teams, patient forums and the Ask 3 Questions campaign. The programme helped to consolidate learning about the key implementation challenges and how these can be overcome (15).</p> <p>NHS England, which has been encouraging SDM implementation through its Right Care programme, has recently announced the establishment of a new demonstration project in one region designed to embed SDM in orthopaedic practice.</p> <p>Year of Care Partnerships is examining how to provide better support for people with long-term conditions by engaging them in developing personalised care and support plans. Demonstration sites are using a model known as the House of Care to help primary care teams adapt their services to the needs of these patients (139).</p> <p>The House of Care model is also being promoted by the Coalition for Collaborative Care which aims to make person-centred collaborative care the norm, especially for people with long-term conditions.</p>
Measurement	<p>There is some experience of using SDM measures in routine NHS care. The AQuA programme used a balanced score card that included a longitudinal survey to assess readiness and engagement in implementation, two patient-reported measures - SURE and CollaboRATE, analysis of routine data to assess impact on system processes and clinical outcomes, and various narrative measures of patients' experience. While there was evidence of improvements in the different sites, some of the measures produced results that were hard to interpret (140).</p> <p>The MAGIC programme also used a variety of measures, including a specially developed generic questionnaire about patients' experience of SDM, and Decision Quality Measures based on the Decision Quality Instruments developed in the US. They also developed an SDM code for use in GP computer systems to allow primary care teams to record that an SDM discussion had taken place (58).</p> <p>A number of clinical teams around the UK are using the Patient Activation Measure (PAM) to monitor people's knowledge, skills and confidence to manage their own health. This is being used both for assessing support needs and to measure outcomes of various interventions, including SDM.</p>

	<p>The Care Quality Commission has run a large national patient experience survey programme since 2002. These surveys show that at least 40% of hospital patients remain less than fully satisfied with opportunities for involvement in decisions about their care.</p>
Coordination	<p>In 2015 NICE convened a meeting for organisations working to promote SDM. Since then the group has expanded, meeting on an annual basis to share experiences and coordinate activities (110). It includes representatives from NHS England, medical organisations, patient groups, academics and people working in quality improvement. In 2016 the various organisations involved in the NICE Shared Decision Making Collaborative committed to various actions and in 2017 they reconvened to review progress. NICE has recently announced its intention to develop a guideline on SDM.</p>
Overview	
	<p>The UK has had a long history of researching and implementing SDM, but these efforts were largely uncoordinated initially and progress was slow. There are signs now that the momentum is increasing with better coordination and growing awareness among clinicians. Effective medical leadership was slow to develop but does now seem to be emerging. However, there is no dedicated funding stream for SDM initiatives and little interest from health ministers in England at present, although policymakers in Scotland appear to be more engaged.</p>

11.9 United States of America	
Health system	The traditional fee-for-service health system in the US has proved very costly and inefficient so various reforms have been attempted over the years. Following the passing of the <i>Patient Protection and Affordable Care Act (ACA)</i> in 2010 efforts are being made to shift to a value-based system known as the triple aim – better health, better care and lower costs (141). The ACA led to the development of Accountable Care Organisations (ACOs) and payment reforms, among other things. SDM is seen as a strategy for advancing the triple aim (25).
Leadership	
Policy	<p>1982 saw the first mention of SDM in a US policy document when the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published its report on making health decisions (3). This included the following statement: <i>'Patients who have the capacity to make decisions about their care must be permitted to do so voluntarily and must have all relevant information regarding their condition and alternative treatments, including possible benefits, risks, costs, other consequences, and significant uncertainties surrounding any of this information.'</i></p> <p>Awareness of widespread practice variations documented in the Dartmouth Atlas led to the identification of preference-sensitive procedures where SDM was felt to be the logical response (142).</p> <p><i>Crossing the Quality Chasm</i>, a major policy report from the Institute of Medicine called for shared decision making in 2001 (143).</p> <p>The ACA included several measures to encourage SDM Implementation (141).</p> <p>The Patient-Centred Outcomes Research Institute (PCORI) was established in 2010 to ensure that patients and the public have information they can use to make decisions that reflect their desired health outcomes. PCORI has made significant funds available for SDM research – to date US\$6,500,000 (€5.5 million) for implementation research and US\$8,400,000 (€7.1 million) to develop measures.</p> <p>In 2017 the Centers for Medicare and Medicaid Services (CMS) introduced plans to test two new types of payment incentive – the SDM model (where decision support is provided within clinical encounters) and the Direct Decision Support (DDS) model (where it is provided outside the clinical care setting), but the SDM model was later shelved due to lack of interest from ACOs. The DDS model is still in place however and once fully rolled out it should provide decision support to a significant majority of the Medicare fee-for-service population with one or more of the following conditions: stable ischaemic heart disease, hip osteoarthritis, knee osteoarthritis, herniated disk or spinal stenosis, clinically localized prostate cancer, and benign prostatic hyperplasia. There are also plans to incorporate measures of patient preferences and shared decision making into a new merit-based incentive program (25).</p> <p>Several US states have established specific initiatives to promote SDM (Maine, Massachusetts, Minnesota, Oregon, Vermont, Wisconsin), and most notably Washington State, which introduced legislation in 2007 offering a higher level of protection in informed consent liability actions when SDM is practised (144). Their definition of SDM includes the use of PDAs, so in 2016 they established a certification process to quality assure and approve these tools.</p>

	<p>The National Quality Forum has developed national standards for accrediting decision aid standards, largely based on the IPDAS criteria, and measurement (145).</p> <p>SDM is seen as a key plank of the Primary Care Medical Home model, including the provision of PDAs.</p> <p>The Agency for Healthcare Research and Quality (AHRQ) has developed PDAs and a structured training programme in SDM skills.</p>
Professional	<p>The American Medical Association has endorsed shared decision making between clinicians and patients, as have a number of other medical organizations including the American Academy of Family Physicians, the American Academy of Orthopaedic Surgeons, the American Association of Colleges of Nursing, the American Association of Colleges of Osteopathic Medicine, the American Association of Colleges of Pharmacy, the American Board of Internal Medicine, the American Cancer Society, the American College of Cardiology, the American College of Physicians, the American Dental Education Association, the American Society of Clinical Oncology, the American Urological Association, the Association of American Medical Colleges, the Association of Schools of Public Health, the High Value Health Collaborative, the Josiah Macy Jr. Foundation, and the US Preventive Services Task Force (144).</p> <p>A survey of a representative sample of US doctors in 2012 found that two-thirds endorsed the notion that '<i>promoting better conversations with patients as a means of lowering healthcare costs</i>'. There was strong agreement that PDAs that include information about costs would be helpful, but most disagreed that promoting SDM should be legislated to contain costs (41).</p>
Patient	<p>The National Partnership for Women and Families has been a strong advocate for SDM, likewise the Society for Participatory Medicine, but patient organisations have not been in the forefront of the push for SDM, coming relatively late to the table.</p>
Infrastructure	
Training	<p>Laval University's Inventory of Shared Decision Making Training Programs for Health Professionals lists several courses developed in the US, but there is no formal requirement to include it in pre-registration or post-registration training for doctors.</p> <p>AHRQ's SHARE training programme is a train-the-trainers course that aims to help participants understand and implement SDM. It covers five steps: 1) seek patient's participation, 2) help your patient explore and compare treatment options, 3) assess your patient's values and preferences, 4) reach a decision with your patient, 5) evaluate your patient's decision.</p> <p>The Society for Medical Decision Making offers a short introductory course in shared decision making and PDAs.</p> <p>Healthwise offers a proprietary online course in SDM for clinicians.</p> <p>Dartmouth Medical School has introduced a course in SDM skills for trainees in their third year Family Medicine Clerkship programme (146).</p>
Tools	<p>Many US-based organisations have developed PDAs, including researchers, companies (both for-profit and not-for-profit), health care providers, professional societies, insurers, and government agencies. Examples include AHRQ, EBSCO Health, Health Dialog, Healthwise, and Mayo Clinic. Some of these aids are proprietary and not freely available.</p> <p>AHRQ has developed a number of PDAs on specific clinical topics as part of their Patient Centered Outcomes Research initiative. They have also produced tools to encourage patients to ask questions about their treatment.</p>

	<p>EBSCO Health has recently taken over responsibility for developing and disseminating Option Grids, brief tools presented in a FAQ format and intended for use in clinical consultations.</p> <p>Health Dialog, a population health management company, now part of the Rite Aid group, offers PDAs with video and evidence-based content, 39 of which were originally produced in collaboration with the Informed Medical Decisions Foundation until it merged with Healthwise.</p> <p>Healthwise, a not-for-profit health information company founded in 1975, has produced the greatest number of PDAs, with 172 listed in the ORHI A-Z inventory. Most of their aids are designed for integration into electronic medical record systems.</p> <p>The Mayo Clinic has developed a number of in-consultation tools to aid clinical discussions that are freely available for non-commercial use. Some of their PDAs are available in Spanish and Chinese languages.</p>
Campaigns	<p>In October 2017 the National Quality Forum, in partnership with 20 professional and patient organisations, issued a national call to action for all individuals and organizations that provide, receive, pay for, and make policies for healthcare to embrace and integrate shared decision making into clinical practice as a standard of person-centred care.</p>
Practice	
Demonstration	<p>The Informed Medical Decisions Foundation (previously known as the Foundation for Informed Medical Decision Making) was founded in 1989 and worked for over two decades to advance evidence-based SDM through research, policy, clinical models and patient decision support. Their medical editors and clinical advisors came from prestigious academic medical centres and research groups. They established a network of about 30 demonstration sites around the USA, with a learning collaborative dedicated to embedding SDM in routine clinical care in a variety of settings (11, 62). The Foundation merged with Healthwise in 2014. The research work now continues as the Informed Medical Decisions Program, based at Massachusetts General Hospital, with core funding from Healthwise.</p> <p>The Center for Shared Decision Making at Dartmouth Hitchcock Medical Center in New Hampshire opened in 1999, the first such centre in the US. It provides decision support counselling and PDAs with a patient support corps of volunteers and staff to answer questions and support patients.</p> <p>The Massachusetts General Hospital, a large academic medical centre with a network of primary care practices and a Harvard teaching hospital in Boston, has been encouraging its physicians to practise SDM since 2005 with support from its Health Decision Sciences Center. During the subsequent 10 years they trained more than 900 health professionals and received more than 28,000 orders for one of about 40 PDAs produced by Health Dialog (63). They have also developed a set of detailed measurement tools, the Decision Quality Instruments.</p> <p>Group Health, a large health care delivery system in Washington State (now part of Kaiser Permanente), introduced SDM in six specialties: orthopaedics, cardiology, urology, women's health, breast cancer, and back care (40, 147). The project established systemwide and clinic-specific processes that facilitated the distribution of approximately 25,000 PDAs by July 2012. Several factors were identified as important for success, including strong support from senior leaders, establishing a system for pre-visit ordering, engaging providers and staff in development of the implementation process, and finding</p>

	<p>ways to address concerns about conditions that were perceived as life-threatening and/or time sensitive.</p> <p>The Mayo Clinic has established a shared decision making resource centre, including PDAs, training programmes, implementation toolkits, and research.</p>
Measurement	<p>The DECISIONS study, a nationally representative population survey, carried out in 2006/7 by the Informed Medical Decisions Foundation and the University of Michigan, found major deficits and variations in patients experience of SDM across the US (148, 149). Providers were unlikely to recommend a 'no treatment' option and few patients reported that providers asked them about their preferences, although this varied widely according to the patient's condition and treatment options.</p> <p>A more recent study, based on analysis of the 2014 Medical Expenditure Panel Survey, found significant improvements in the proportion of patients who reported receiving four components of SDM – joint involvement in decisions, sharing of information, building of consensus, and agreement on treatment (109).</p> <p>As part of its work on developing a certification scheme for PDAs, the National Quality Forum is evaluating SDM measurement tools for endorsement (145).</p> <p>The national Consumer Assessment of Health Plans Surveys (CAHPS) patient surveys include a number of questions of relevance to SDM.</p>
Coordination	<p>There is no central organisation that coordinates work on SDM initiatives and tools, but some commercial organisations with a longstanding interest in this area, e.g. Healthwise, have developed systems for hosting and updating PDAs. The current drive for certification of PDAs appears to be a response to the financial incentives for SDM introduced by CMS. It is possible that this may encourage initiatives to coordinate implementation efforts.</p> <p>It remains to be seen whether the National Quality Forum's initiative will develop into an effective coordination mechanism. Their SDM Action Team plans to release a National Quality Partners Playbook™ in March 2018 highlighting common barriers to implementing SDM in clinical practice.</p>
Overview	
	<p>More work has been done on SDM in the US than in any other country, perhaps not surprisingly given that it was there that the concept and methods were first developed. There is encouraging evidence of progress, but the complexity and fragmentation of the health system, coupled with commercial capture of many improvement mechanisms, still inhibit its incorporation into mainstream care.</p>

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