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## European Experience with Shared Decision Making

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### Abstract:

**Background:** Shared decision making (SDM) is frequently advocated but not yet widely implemented in European countries. Experience suggests that various incentives must be in alignment to encourage wider uptake.

**Objectives:** To assess readiness for mainstream implementation of SDM in five European countries.

**Methods:** Qualitative assessment of clinical policies and the availability of various SDM support services in Germany, France, Spain, the Netherlands and the UK.

**Results:** All five countries have research groups working on SDM, patient groups calling for its wider use, and ethical and professional standards indicating its desirability, but apart from a small number of demonstration projects, there is no evidence of a systematic approach to implementation in any of the countries as yet.

**Conclusions:** Greater attention will need to be given to the provision of effective leadership, training and practical support if SDM is to become a regular feature of clinical practice in these countries.

### Keywords:

shared decision making; France; Germany; Spain; Netherlands; UK

### JEL codes:

D7, D8

## European Experience with Shared Decision Making

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### Abstract

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## Background

Shared decision making (SDM) is a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a systematic approach to recording and implementing patient's preferences (1). This has been shown to improve patients' knowledge and ability to participate in decisions about their care, improving the quality of clinical decision-making (2). It also leads to improvements in health outcomes for people with long-term health problems (3). It is appropriate for patients facing major healthcare decisions where there is more than one feasible and evidence-based option, for decisions about screening tests and preventive strategies, and for choosing care and support packages for long-term conditions (4).

SDM has been enthusiastically embraced by patient groups, policy makers, clinicians, researchers and professional societies in several European countries, but it has been slow to filter into mainstream clinical practice (5). Successful implementation depends on aligning incentives for both clinicians and patients, providing training and support, and ensuring that patient information and decision aids are readily accessible via electronic systems to avoid disruption to clinical routines (6).

Experience in various demonstration projects in the US

(<http://www.informedmedicaldecisions.org/shared-decision-making-in-practice/demonstration-sites/>)

and Europe (<http://www.health.org.uk/areas-of-work/topics/person-centred-care/>) leads us

to believe that the following ten factors need to be in place to promote more widespread adoption:

1. Research evidence showing that it can be effective in a specific clinical or local context
2. Medical leadership willing to encourage it
3. Demand for it from patient leaders and organisations
4. Incentives for clinicians to change their practice – ethical, financial, or professional
5. Training for clinical staff in SDM and risk communication skills, plus support and supervision for implementation
6. Availability of good quality patient decision aids (PtDAs)

7. Integration of PtDAs into electronic medical record systems
8. Institutional support for developing and updating PtDAs
9. Certification schemes to assure the quality of PtDAs
10. Validated measures to monitor the extent to which patients feel informed and involved in decisions about their care, plus feedback to enable clinicians to monitor progress.

Recent developments in the USA have pushed SDM higher up the policy agenda (7), but it is not clear if the same is happening in Europe. Two special issues of the German Journal for Evidence and Quality in Health Care in 2007 (8) and 2011 (9) described progress in some European countries in respect of researching and implementing SDM, but this is a fast-moving field. We therefore decided to compare and assess the situation in five European countries in respect of their readiness for SDM in 2015.

## **Objectives**

To assess the policy climate in respect of SDM in five European countries - France, Germany, the Netherlands, Spain and the UK – with reference to ten factors considered necessary for successful implementation.

## **Methods**

The ten factors listed above were used as a checklist against which each author made an independent assessment of the situation in his or her country. We based this qualitative assessment on our knowledge of SDM policy, research and practice. Our qualifications for making the assessments rest on the fact that, as leading academics in this field, we have been researching, teaching and writing about SDM for many years. Each of us has specialised knowledge of SDM policy in our own country and good general knowledge of international developments. As advisors and active players in SDM implementation initiatives we believe we are well-placed to assess progress towards mainstream adoption of SDM in each of the countries.

The independently produced assessments were collated and tabulated by the lead author (AC). All authors contributed to the overview commentary.

## **Results**

Detailed responses are given in Table 1. Below we provide an overview of progress in these European countries in respect of each of the ten factors.

1. **Research evidence:** Studies of SDM implementation and the use and effectiveness of PtDAs have been carried out in each of the five countries. There is now a large body of published literature on the topic and several systematic reviews on SDM effectiveness and implementation, as well as methodological reviews (3, 10-13). These studies have demonstrated the relevance of SDM in a variety of clinical contexts.
2. **Medical leadership:** There is no shortage of individual clinical champions of SDM in each of the five countries (6). However, the major medical and nursing organisations have been slow to give it their whole-hearted support, paying lip service but not yet exerting the full weight of their very considerable influence to ensure that SDM is implemented.
3. **Patient demand:** SDM is supported in patients' rights legislation and patient charters in several countries (14). Many European patient organisations see implementation of SDM as a priority (15). Their voice is increasingly heard in local, national and international policy forums, but their influence has not yet proved strong enough to prompt a concerted effort to implement SDM throughout mainstream clinical practice.
4. **Incentives for clinicians:** SDM is now seen as an ethical and, increasingly, a legal imperative in these countries, backed by professional quality standards and guidelines (16, 17). But there have been no attempts as yet in these European countries to use financial incentives to encourage clinicians to practise SDM.
5. **Training and support:** The picture in respect of SDM skills training is patchy. Various short courses and workshops have been developed and SDM is beginning to be included in basic communication skills training (18). However it is not yet seen as a core component of European medical and nursing education, with the possible exception of Germany where it is now taught and examined in most medical schools (19).
6. **Availability of decision aids:** Here again we see a mixed picture. PtDAs are not absolutely essential for SDM but, by packaging evidence-based information in an accessible form, they certainly make it easier (2). A limited number of decision aids is available in each of the countries. National policymakers are now encouraging the production of PtDAs in each of the

five countries, with most progress to date in the UK, where government funds have supported the development of a core set of publicly available decision aids (20).

7. **Integration into EMRs:** For PtDAs to be widely used they must be readily accessible at appropriate decision points. One way to ensure this is to integrate them into electronic medical records (EMRs). This has been achieved by one of the four main general practice EMR systems accredited for use in the UK <http://www.emis-online.com/>, but we are unaware of any similar primary care initiatives in the other four countries. Patient decision aids are sometimes included in specialty-based electronic systems and several studies are evaluating web-based tools and applications for patients.
8. **Institutional support:** Many PtDAs have been developed as part of individual projects, but development is only one part of the story. They need to be hosted in an accessible place or website, user-tested, promoted, distributed and kept up-to-date (21). None of the five countries has a clear mechanism for doing this at present, though some national bodies, including health ministries, are considering the establishment of some form of institutional support for hosting and updating. There is some interest in linking this function to that of national clinical guideline production under the auspices of organisations such as the Institute for Quality and Efficiency in Health Care (IQWiG) in Germany and the National Institute for Health and Care Excellence (NICE) in the UK (22).
9. **Certification schemes:** Effective implementation of SDM depends on trust in the reliability of the information, which must also be well-designed and user-tested. The International Patient Decision Aids Standards (IPDAS) were developed by an international multi-stakeholder group (23, 24) and there is considerable interest in using these as the basis for certification schemes to assure the quality of PtDAs. No formal certification schemes have been established to date, but discussions are currently under way in each of the five countries.
10. **Measurement and feedback:** Measuring performance in shared decision making and feeding this information back to clinicians is widely agreed to be important for stimulating better practice. A number of patient-reported measures have been developed but there is no consensus on which, if any, are most appropriate for this purpose (25, 26). Some work has been done to translate and test these measures, but no widespread SDM performance monitoring scheme has been established in any of the five countries as yet (12, 27).

## **Discussion**

This study was based on our knowledge of policy developments in each of the countries.

Unfortunately there is no statistical evidence on the penetration of SDM or the wide range of factors contributing to its uptake to validate our impressions. It is always possible that our knowledge is incomplete, but we believe we are well placed to make informed judgements on the extent to which various incentives to practise SDM are in place. In view of our longstanding interest in the topic and extensive networks, we think it unlikely that we have missed any significant developments.

We found evidence of growing interest in SDM in each of the five countries. Academic researchers have led the way, with some strong research groups in each of the five countries and significant numbers of published papers. Patient groups are calling for SDM and many clinicians, health insurance companies and policymakers are very interested. Some guideline groups and professional bodies are promoting SDM, but there is a lack of strong, effective push from professional associations at present. SDM skills training is not yet widespread across Europe.

Some PtDAs have been developed and tested with local patients in each of the countries, but many of these were developed for research purposes only with no institutional support or plan for wide dissemination. It is still rare for PtDAs to be incorporated into electronic medical record systems and there are no certification procedures in place. Patient questionnaires to measure whether SDM has occurred are under development, but we found no examples of coordinated performance measurement. None of the five countries has adopted a systematic national or regional approach to SDM implementation as yet.

## **Conclusions**

Successful implementation of SDM in Europe will require wider provision of training, support and supervision, and greater availability of PtDAs, ideally integrated into EMRs so they are readily available when needed. There will also need to be organisations capable of developing these and keeping them up-to-date, perhaps linked to the production of clinical guidelines, and certification schemes to quality assure them. Above all, attention needs to be paid to means of incentivising clinicians to change the way they practise so as to engage patients more actively in decisions about their care. The adoption of appropriate performance and outcome measures could play a key role in focusing attention on what needs to change.



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Angela Coulter undertakes part-time paid consultancy for the Informed Medical Decisions Foundation, the research and advocacy division of Healthwise, a not-for-profit company that develops and markets health information and patient decision aids. Trudy van der Weijden is member of the IPDAS steering committee and the Guidelines International Network Public steering committee. These are independent, not-for-profit, non-paid, informal functions on development of quality criteria for patient decision aids and on inventory of patient participation methods in development and implementation of guidelines. Angela Coulter, Martin Härter and Nora Moumjid-Ferdjaoui are also members of the IPDAS steering committee.

We have no other conflicting interests to declare.

Table 1: Assessment of current situation in five European countries

	France	Germany	Netherlands	Spain	UK
Research evidence	A number of SDM studies have been carried out in France since the mid 1990s, mainly in cancer care.	Research consortium (2001-7) funded by the Federal Ministry of Health with 10 SDM demonstration projects; large number of projects funded by the Federal Ministry of Education and Research, health insurance companies, German Pension Fund, German Cancer Aid, Bertelsmann and other foundations (since 2008).	A number of studies in oncology and evaluation of patient decision aids have been conducted in the Netherlands. There has been less focus on changing professional behaviour and implementing SDM in mainstream practice.	Studies of SDM in cancer care, mental health osteoarthritis, diabetes, primary care and some rare diseases have been carried out, including development and evaluation of decision aids, measurement and implementation issues.	Research into SDM started in the early 1990s in the UK and numerous studies have been published since then.
Medical leadership	Medical leaders in oncology (breast cancer) have been promoting SDM for at least two years, and this has occurred more recently in psychiatry, primary care, rheumatology, asthma, and addiction.	SDM is championed by oncologists, GPs, psychiatrists, neurologists, psychologists, medical sociologists and nurses. It is also promoted by the German Network of Evidence-Based Medicine, and the German Agency for Quality in Medicine among others.	Some medical opinion leaders are promoting SDM.	SDM is promoted by medical and nursing leaders in cancer care, psychiatry, endocrinology, trauma care and primary care.	Several medical royal colleges are promoting the concept, notably Royal College of GPs, Royal College of Physicians, Royal College of Psychiatrists and Royal College of Surgeons.
Patient demand	Patient demand led to the Patients' Rights and Quality of the Healthcare system Law adopted in France in March 2002. SDM is mentioned in one article of this law (Art.L.1111-4). SDM is supported by patient associations in cancer and kidney care.	Many self-help organisations are demanding SDM on a continuous basis. Specific pressure comes from the accredited members of self-help organizations within the Federal Committee, the principal institution responsible for health care reimbursement decisions	The Dutch Patient and Consumer Federation is running a demonstration project implementing the Ask 3 Questions campaign in three sites, funded by the Ministry of Health.	SDM is a priority for the Spanish Patient's Forum and for some other patients' associations including GEPAC and FEDER. Called for in some national and international declarations by patient organisations.	SDM is a priority for National Voices, the leading umbrella group for patient organisations in England (with 140 members), and for similar organisations in Scotland, Wales and Northern Ireland. It is also a commitment within the NHS Constitution, a charter for patients and staff.
Incentives for clinicians	The importance of patient partnership is understood by many clinicians as a key component of quality care. No direct financial or professional incentives are in place, but SDM is recommended in	Most professionals understand that SDM is an ethical imperative, but no direct incentives are provided. However, SDM is encouraged in several national clinical guidelines. The "2014 patient's	SDM is encouraged in several national clinical guidelines, with the first guideline just launched (on hernia nucleus pulposus management) with a patient decision aid directly	Most professionals understand that SDM is an ethical imperative, but there are no direct financial or professional incentives to practise it, apart from the fact that SDM is	SDM is embedded in the Good Medical Practice standards published by the General Medical Council, the main professional regulator. A recent legal judgement has clarified and

	some cancer clinical guidelines.	rights law" includes a commitment to SDM in clinical encounters.	integrated in the guideline. There are no direct financial or professional incentives to implement SDM.	recommended in some clinical guidelines.	strengthened the law vis a vis SDM. There are no direct financial incentives, but SDM is recommended in several clinical guidelines.
<b>Training and support</b>	Training is seen as a priority but not yet developed. FREeDOM (an international French-speaking multidisciplinary working group on SDM) is planning training projects.	SDM is taught in most medical schools and is part of the pre-clinical exam. Some medical schools use OSCEs to test students on practical SDM skills. Some training courses have been developed and tested for specialists (GPs, oncologists).	SDM skills training is available on a small scale as a bi-product of research projects, and some academic faculties have (elective) educational modules on SDM in undergraduate or postgraduate courses .	SDM skills are included as a component of some specialist training programmes + many conferences, seminars and short courses. It is now a priority to develop and assess the effectiveness of SDM skills training programmes.	SDM is increasingly included in communications training for medical students. A variety of short training courses are provided for various professional groups.
<b>Availability of decision aids</b>	The National Health Insurance Fund (CNAMTS) and the National Health Authority have both called for PtDAs to be developed. FREeDOM (see above) has highlighted PtDA development as their second most important priority.	About 10 – 15 PtDAs are available for topics such as mammography, breast cancer, prostate cancer screening, HPV vaccination, mental health. Some Option Grids (brief decision aids) are in translation and are being tested.	The Dutch Ministry of Health has launched a call for proposals to develop and host PtDAs.	Web-based information materials are available, e.g. PyDeSalud.com for people with chronic conditions, which includes PtDAs.	There is public access to 36 'Right Care' decision aids funded by the Department of Health, + 18 Option Grids developed by Cardiff University, and 10 Brief Decision Aids developed at Newcastle University.
<b>Integration into EMRs</b>	No	No	No but planned as a component of specific EMR quality assurance projects.	No, but planned as a component of specific research projects.	Yes, via the EMIS general practice clinical record system (patient.co.uk).
<b>Institutional support</b>	No, but discussions have taken place with the French National Cancer Institute to plan the development of a suite of PtDAs for cancer care and prevention. Some SDM projects may be developed in the near future, funded by the Ministry of Health (a call for proposals is currently under discussion).	University and health insurance companies provide some support at present, but the Institute for Quality and Efficiency in Health Care (IQWiG) will probably take more responsibility for the development of PtDAs in the future.	Not yet but may emerge from a Ministry of Health initiative.	The Spanish Ministry of Health and other funders (e.g. a bank and health insurance companies) are supporting some initiatives, but no single institution is responsible for developing and updating PtDAs.	NHS England provides limited support for hosting and updating. The Health Foundation has supported various demonstration projects as part of its MAGIC (Making Good Decisions in Collaboration) programme.
<b>Certification schemes</b>	No formal certification scheme, but some discussions re using the IPDAS criteria	No formal certification scheme but IPDAS is used together with 'Good Practice for Health Information' guide produced by German Network for Evidence-Based Medicine together with IQWiG	No formal certification scheme, but Ministry of Health has issued a call for proposals to develop a Dutch version of IPDAS, together with a guide on how to develop PtDAs	No formal certification scheme, but Spanish Ministry of Health is interested. A Spanish version of the IPDAS standards is in use in some regions.	NHS England runs a certification scheme for patient information (The Information Standard). They have been in discussion with the National Institute for Health and Care Excellence (NICE) about developing a

					specific scheme for PtDAs based on the IPDAS criteria.
<b>Measurement and feedback</b>	Discussions only at this stage.	Measurement tools are being developed and tested, including German adaptations of international instruments	Work is under way to develop and validate Dutch versions of SDM-Q-9, CollaboRATE and OPTION-5 instruments	Work is under way but better measures are needed.	NHS England commissioned and published an overview of validated measures but none has yet been adopted for national use.

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