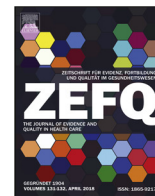




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## Implementing shared decision-making in UK: Progress 2017–2022



## Implementierung von partizipativer Entscheidungsfindung in Großbritannien: Fortschritte in den Jahren 2017 bis 2022

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## ABSTRACT

Shared decision making has been on the policy agenda in the UK for at least twelve years, but it lacked a comprehensive approach to delivery. That has changed over the past five years, and we can now see significant progress across all aspects of a comprehensive approach, including leadership at policy, professional and patient levels; infrastructure developments, including the provision of training, tools and campaigns; and practice improvements, such as demonstrations, measurement and coordination. All these initiatives were necessary, but the last, central coordination, would appear to be key to success.

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## ZUSAMMENFASSUNG

In Großbritannien steht partizipative Entscheidungsfindung schon seit mindestens zwölf Jahren auf der politischen Agenda, es fehlte jedoch an einem umfassenden Umsetzungskonzept. Das hat sich in den vergangenen fünf Jahren geändert, sodass wir inzwischen in allen Bereichen dieses umfassenden Konzepts erhebliche Fortschritte verzeichnen können: Dazu zählen Führung auf der Ebene von Politik, Gesundheitsfachkräften und Patienten, Infrastrukturentwicklungen (darunter die Bereitstellung von Schulungsmaßnahmen, Instrumenten und Kampagnen) und Verbesserungen in der Praxis wie beispielsweise Demonstrationsprojekte sowie Erfassungs- und Koordinierungsaktivitäten. Alle diese Initiativen waren notwendig; der Schlüssel zum Erfolg scheint allerdings in der letzten, zentralen Koordination zu liegen.

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**Introduction**

Shared decision making (SDM) has been on the policy agenda for the UK NHS (National Health Service) since 2010 [1]. Since that time UK patients have been informed that they 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 such involvement, including information about test and treatment options and the benefits and risks of each [2–5].

Spelling out people’s rights to participate in decisions about their healthcare is an important step, but it is insufficient to ensure decisions are shared in practice. Experience in the UK and many other countries has shown that this is much more challenging [6,7]. However, the past five years have seen an increased emphasis on SDM implementation that is at last generating results, marking a significant step forward since we last reviewed progress in 2017 [8].

The NHS was established in 1948, funded out of general taxation 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. This has resulted in some policy differences among the UK nations, including their approaches to shared decision making (SDM). Taxes continue to be raised centrally, however, and funding is channelled to the devolved nations from the UK Treasury, with larger per capita allocations for Scotland, Wales and Northern Ireland than for England.

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 (inpatients and outpatients), community care (including home nursing and other out-of-hospital services), and mental health care. These services are mostly free at the point of use, but co-payments are levied for dental care and optometry and medicines for adults under 60 (in England only). 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.

This brief outline of the current situation in the UK follows a framework designed to encapsulate the full range of strategies that

could be adopted to implement SDM across a health system [9]. This covers leadership by policymakers, professional and patient organisations; infrastructure, including training, tools and campaigns; and practice, including demonstrations, measurement and coordination.

**Leadership**

*Policy*

In 2015 the landmark ‘Montgomery’ 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 associated risks, including those most pertinent to the particular patient, to enable them to make informed decisions when giving or withholding consent to treatment [10]. This led to an intensification of activity in favour of SDM, the effects of which are only now becoming apparent.

In 2019, NHS England and Improvement, the body that sets the priorities and direction of the NHS in England, launched a new comprehensive strategy named *Universal Personalised Care* aiming to give patients greater control over the way their care is planned and delivered, based on what matters to them and their individual strengths, needs and preferences [11].

Figure 1 included six components: shared decision making, personalised care and support planning, enabling choice of provider, social prescribing, supported self-management, and personal health budgets. The objectives of this approach were to help people manage their physical and mental health and wellbeing, to build community resilience, to make informed decisions and choices when in need of medical care, and to build knowledge, skills and confidence amongst those with more complex conditions, by giving them more choice and control over their care.

Meanwhile the other UK nations were also proceeding with plans to enable patients to play a more active role in their care. As part of its *Realistic Medicine* strategy, the Scottish Government organised a Citizen’s Jury on SDM to learn more about people’s priorities and this led to a comprehensive plan of action focused on enabling SDM and patient empowerment through various

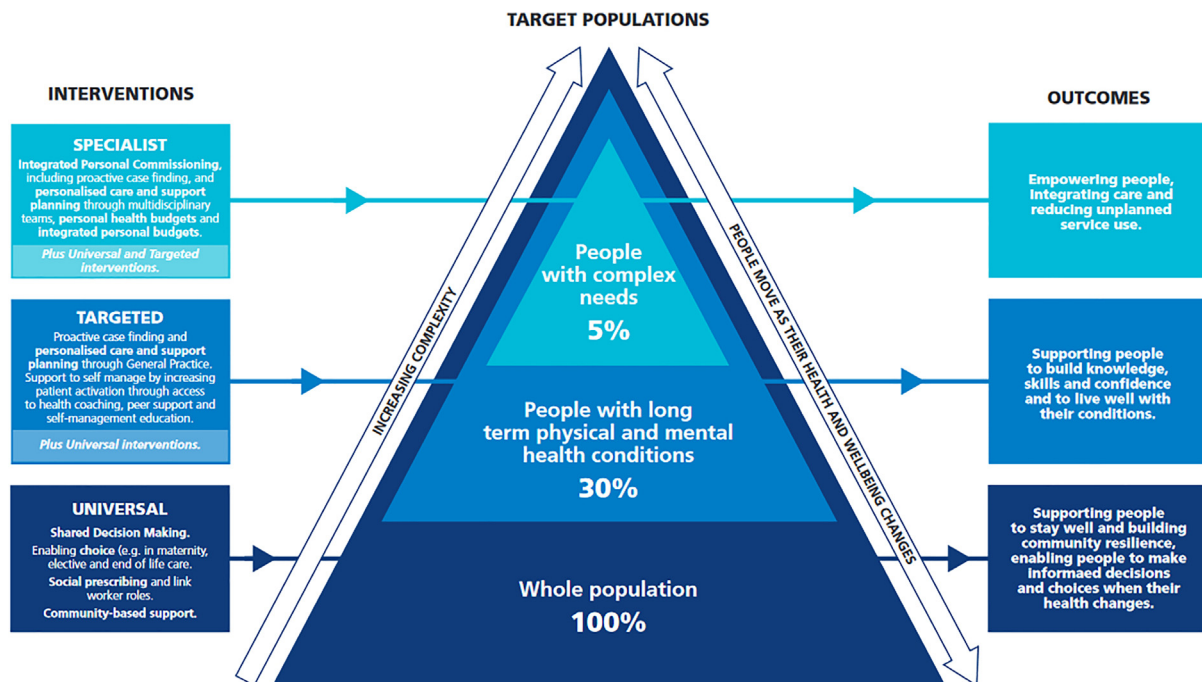


Fig. 1. Comprehensive model of personalised care.

means, including training, resources and funding [12,13]; and the Welsh government's *Value in Health* strategy emphasises the fundamental importance of person-centred care as a means to improve health outcomes and includes the goal of embedding SDM into clinical practice through training for clinicians [14]. Progress has been slower in Northern Ireland, probably due its unique arrangements for government by power-sharing, but the Northern Ireland Public Health Agency recently launched a set of shared decision making tools and guidance designed to achieve the same ends, though apparently without specific funding or coordinated support [15].

### Professional

Many of the professional bodies and some patient organisations have UK-wide coverage, while others focus on the individual nations. Professional leadership was strengthened in 2020 when the General Medical Council, the regulatory body for all UK doctors, updated its guidance on seeking informed consent, explicitly linking it to SDM and underlining its fundamental relationship to good medical practice. Doctors were advised that they should try to find out what matters to patients so they can share relevant information about the benefits and harms of proposed treatment or management options and reasonable alternatives, including the option to take no action [16].

At the same time, several other key national institutions were developing initiatives to promote wider uptake of SDM, in particular the National Institute for Health and Care Excellence (NICE), an influential organisation amongst clinicians both nationally and internationally, which has a long history of support for SDM. In June 2021, NICE published guidance, accompanied by an online learning package, showing how SDM can be incorporated into mainstream care in all healthcare settings, including how to embed it at an organisational level, how to support clinicians to put it into practice, how to ensure the quality of patient decision aids, and how to communicate the risks, benefits and likely consequences of treatments [17]. The publication of this guidance sent an important signal to the wider health and care system about policy expectations. It also signalled to patients that the 'how' of care delivery is as important as the 'what'. The guidance was warmly welcomed by patient groups, some of which contributed to its development [18].

### Patient

Several patient organisations have provided effective national leadership on SDM, including the Patients Association, who made information on SDM available to users of their website and their telephone helpline [19], Mind, the charity for people with mental health problems who encourage patients to ask questions of clinicians and get involved in decision-making [20], and the Patient Information Forum, who have launched a self-accreditation scheme called *PIF-TICK* designed to improve the quality of health information for the public [21].

## Infrastructure

### Training

In 2020 the Personalised Care Institute was established in conjunction with a large number of professional organisations to help embed all components of the comprehensive model of personalised care. Its specific remit was to develop and curate e-learning in personalised care skills, including SDM, and to quality assure training across England [22]. There are currently over 100 e-learning modules and resources accessible from their website

and to date these have been accessed by more than 11,000 clinicians. The institute has developed a curriculum that sets a national standard for training in SDM and describes the capabilities expected of practitioners across three levels, depending on the requirements of their role. As training and development activities are re-established following the disruption of the COVID pandemic, those responsible for training will be able to provide accredited face-to-face courses in SDM and person-centred skills. The ultimate goal is to provide this training for up to 300,000 clinical staff.

In Scotland, the Royal College of Surgeons of Edinburgh has developed a course for surgeons entitled *Informed Consent: Sharing the Decision*, as a direct response to the Supreme Court ruling referred to above. Students learn about the potentially catastrophic and costly consequences of failure to share important surgical decisions, how to discuss options and communicate risk, and how to use decision support tools during and after the clinical encounter [23].

To help organisations ensure that SDM and personalised care are central to their operations and culture, NHS England has developed a peer-leadership development programme to develop the knowledge, skills and confidence of people with lived experience of the health and care system, enabling them to work with other patients and promoting personalised care from the bottom up. This programme has involved 200 peer leaders to date. Working towards a target of 500 peer leaders by the end of 2023/24, it is hoped that this will ensure that patient expertise in SDM will eventually be spread across the health system.

### Tools

Ensuring clinicians and patients have access to high quality decision support tools is an important component of the plan to make SDM 'business as usual'. NICE has developed a number of patient decision aids for use alongside their clinical guidelines, together with a set of standards to enable people using patient decision aids to assess their quality and usefulness [24]. The framework is also intended for use by developers of decision aids, acting as a self-assessment tool. It is similar to the International Patient Decision Aid Standards (IPDAS) framework, but easier to implement in a UK setting.

The number of patient decision aids designed for use in the NHS has been growing. NHS England's plans to tackle the post-pandemic backlog in elective care include the introduction into care pathways of a two-stage shared decision making process enabling a short period of reflection to allow patients time to consider their options. Also relevant are the plans to introduce patient-initiated post-treatment follow-up for some cancers, replacing routine follow-up regimes that confer little or no benefit [25]. To support these initiatives, the Winton Centre for Risk and Evidence Communication at the University of Cambridge has been commissioned to produce a set of 30 decision aids applicable to specific high volume, preference-sensitive decisions. These are being co-produced with patients and their use in clinical pathways will be encouraged. It is hoped to expand the list of digital tools, making them available through an elective care app, currently under production for use in remote consultations [26].

Meanwhile, a patient-focused charity, Versus Arthritis, has worked with academics at Keele University to develop a suite of decision support tools for patients with musculoskeletal conditions [27], and the National Institute for Health Research has recently commissioned studies to develop and test decision aids for breast cancer and maternity care.

### Campaigns

Social marketing campaigns that have been adapted for use in various UK settings have included *Ask 3 Questions*, originally

developed in Australia [28], and BRAN, first developed by members of the National Childbirth Campaign, which encourages patients to ask questions about Benefits, Risks, Alternatives and the option of No treatment (BRAN). The Academy of Medical Royal Colleges has been working with the Patients Association to develop a series of BRAN leaflets, question prompts, brief videos and animations designed to help patients understand these questions and what SDM involves, as part of its *Evidence-Based Interventions* programme [29].

## Practice

### Demonstrations

The NICE guidance recommends that healthcare organisations identify senior clinical, non-clinical and patient leaders with responsibility for embedding SDM across all levels of their organisations. Given that this guideline was published while most, if not all, healthcare organisations were struggling with the consequence of the COVID pandemic, the impact of this recommendation has yet to be established.

Meanwhile, certain hospital trusts, primary care organisations and professional bodies have chosen to major on SDM, providing models on which to build. For example, Southampton University Hospital encourages patients to prepare for consultations by writing down questions, thinking about treatment goals, and stressing their rights to be involved in decisions about their care [30]. The Centre for Perioperative Care has produced a range of resources, including short videos, and are offering training courses to their members [31]. And Year of Care Partnerships, who pioneered a model for personalised care and support planning with people with long-term conditions, have been helping groups in primary care and specialist services, for example speech therapy, to implement SDM in their practices [32].

### Measurement

The use of standardised questionnaires (e.g. *CollaboRATE* [33], *SDM-Q9* [34]) to measure patients' experience of SDM is currently being piloted in England on a small scale. Experience to date has shown that these are acceptable tools that have the potential to generate useful results, so their use is being encouraged. In Wales a key goal is to develop data-informed approaches to support SDM by collecting and integrating patient-reported outcome measures (PROMs) into consultations where treatment and management decisions are made.

Patients throughout the UK are regularly asked to complete patient experience surveys that include questions about the extent to which they were involved in decisions about their care as part of more general patient experience surveys [35]. And the Professional Records Standards Body is working on guidance for record-keeping in relation to SDM consultations [36].

An express intention of the NICE guideline on SDM is to stimulate further research. Recent empirical research in the UK has focused on improving understanding of patients' and professionals' views of SDM and observing it in practice [37–39]. There have also been a number of recent studies evaluating decision aids [40–42]. A specific area requiring further research is the development and wider testing of measurement tools that validly capture the complex nature of decisions, the lack of which may act as a constraint on efforts to normalise SDM [43,44].

### Coordination

Many of the initiatives described above were instigated and funded by NHS England, where the team working on personalised

care has a remit to coordinate and support the work, focusing on practical implementation. The team includes clinical speciality advisors in specific areas, including musculoskeletal conditions, cardiovascular disease and prevention, maternity care, respiratory care and long COVID. They work alongside national clinical directors to ensure that SDM, self-management support and social prescribing are incorporated into wider implementation and evaluation strategies for these national programmes.

In Scotland, Healthcare Improvement Scotland and the Health and Social Care Alliance are actively engaged in supporting and promoting person-centred care, including SDM, and in Wales the Welsh Value in Health Centre performs a similar function, working in partnership with universities and healthcare organisations.

## Discussion

Five years ago when we reviewed progress on implementing SDM across the UK [8], we highlighted the need for better coordination and stronger policy, professional and patient leadership. We are pleased to report that this has now been recognised by UK policymakers, with the result that significant improvements have occurred. This success underscores the importance of having an integrated policy covering all aspects of person-centred care, coupled with a clear set of objectives, a dedicated budget, and a coordination centre empowered to lead work across the system.

It is worth noting that the UK approach to date has focused more on carrots than sticks, mostly avoiding measures that have been tried in some other countries, such as individual financial incentives or penalties. An exception to this rule is a mild form of voluntary financial incentive for organisations, known as *Commissioning for Quality and Innovation (CQUIN)*, in which a small proportion of organisational providers' income can be linked to the achievement of quality improvement goals, including personalised care. The latest version is intended to encourage organisations to support clinicians to undergo training in SDM and to use validated tools to evaluate the impact of the training.

That these advances in SDM implementation occurred during the latter part of ten years of economic austerity that significantly weakened the NHS, leaving it facing severe workforce shortages, and in the teeth of the COVID pandemic, is particularly impressive. However, the developments remain fragile and at the mercy of fluctuating funding priorities. Introducing change at a time when the pandemic has caused major disruption to working practices is especially challenging for clinicians. We must not rest easy until SDM is more firmly embedded in professional training and culture and until patients have learnt to be more strident in demanding a role in decision making.

## Conflict of interest

All authors declare that there is no conflict of interest.

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