Twenty-one years of the International Shared Decision Making Conference: lessons learnt and future priorities

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The first International Shared Decision Making (ISDM) Conference took place in Oxford (UK), 2001. It was attended by 120 motivated people who saw the potential of shared decision making (SDM) to lead to safer and more effective healthcare. Two years later in Swansea (UK), the conference book opened with this foreword: 'In a few decades, the fact that we did not involve patients in the design of services and their delivery, at population and individual level, will look peculiar' (GE and AE).

Fortunately, after 21 years of the ISDM conferences, this prediction was correct. Patient involvement is not yet universal, it does not happen all the time, and there is room for improvement; but we have witnessed a paradigm shift internationally in healthcare delivery towards person-centred models. It is now more peculiar when patient involvement is not attempted or resisted, than when it is attempted or encouraged. Figure 1 summarises the ISDM conference history within this paradigm shift in healthcare, where our collective research increasingly focuses on filling gaps in scientific knowledge found in the person-centred care model, and less on changing hearts and minds about the value of the approach. However, it is important to note that the pace of change in research and clinical practice is not always the same; the reality is that important challenges to routine implementation remain.

In this article, we describe what we have learnt during the 21 years of the ISDM conference, present SDM research and implementation priorities, and future challenges—what do we need to do more of so that the benefits of SDM can be realised for more people?

What have we learnt?

One of the first questions we often get asked is 'what can we do today that will help us to do more SDM in our organisation?'. When the first ISDM conference took place in 2001, 73 publications in PubMed used the term 'shared decision making' in the title or abstract. Over 20 years on, 2300 publications used this term in 2022, and there are over 13 000 results in total. It is an excellent and diverse evidence base on which to draw. During the 21 years of the ISDM conferences, some themes have been consistently covered and we now know a lot about 'what will work'. The 21 country updates that were published in a special issue of The Journal of Evidence and Quality in Healthcare in June 2022 (volume 171)[1] also provide a good summary of what has been working well and supporting progress in embedding SDM in routine practice internationally.

During the conference history, various theoretical models have been developed that capture both the essential and desirable elements of the SDM process.[2–6] Emphasis various between models on certain tasks, but all provide useful, evidence-based frameworks and checklists for teaching and implementing SDM. The effectiveness of patient decision aids to support SDM is also clear. A Cochrane review brings together evidence from 105 studies involving 31 043 people, focusing on 50 different decisions.[7] Regardless of format, patient decision aids consistently demonstrate benefits to patients including feeling more knowledgeable, informed and clearer about personal values; importantly, there are no adverse effects on health outcomes or satisfaction. We have also learnt a lot about how to develop patient decision aids. The International Patient Decision Aids Standards Collaboration[8] (established 2003) has led the field in establishing evidence-informed frameworks and criteria for enhancing the quality and effectiveness of patient decision aids. They published their 2.0 Evidence Update in October 2021; a collection of papers that present standards for developing, evaluating and implementing patient decision aids.[9] The standards have also been used internationally to inform country-level/region-level frameworks and certification processes (see reference 10 for UK example).

Various measurement tools have been developed to capture the SDM process and outcomes.[11] This includes patient-reported measures that capture patient's experience of the decision making process,[12 13] observational measures, where trained assessors rate the observable aspects of a consultation,[14] measures that focus on things that influence the SDM process, for example, control preferences,[15] and measures that focus on patient's attitudes, feelings and values.[16 17] Syntheses of implementation attempts have also identified several key factors that play an important role in supporting routine implementation of SDM and patient decision aids,[18 19] including leadership and coordination, training and education, redesigning care pathways, enabling patients to participate in SDM, policy-level support, sustainable patient decision aid resources, guidelines that promote SDM and incentives (financial and non-financial).

While we have learnt a lot about these things over 21 years, there is always more work and innovation to do. We also need to recognise the

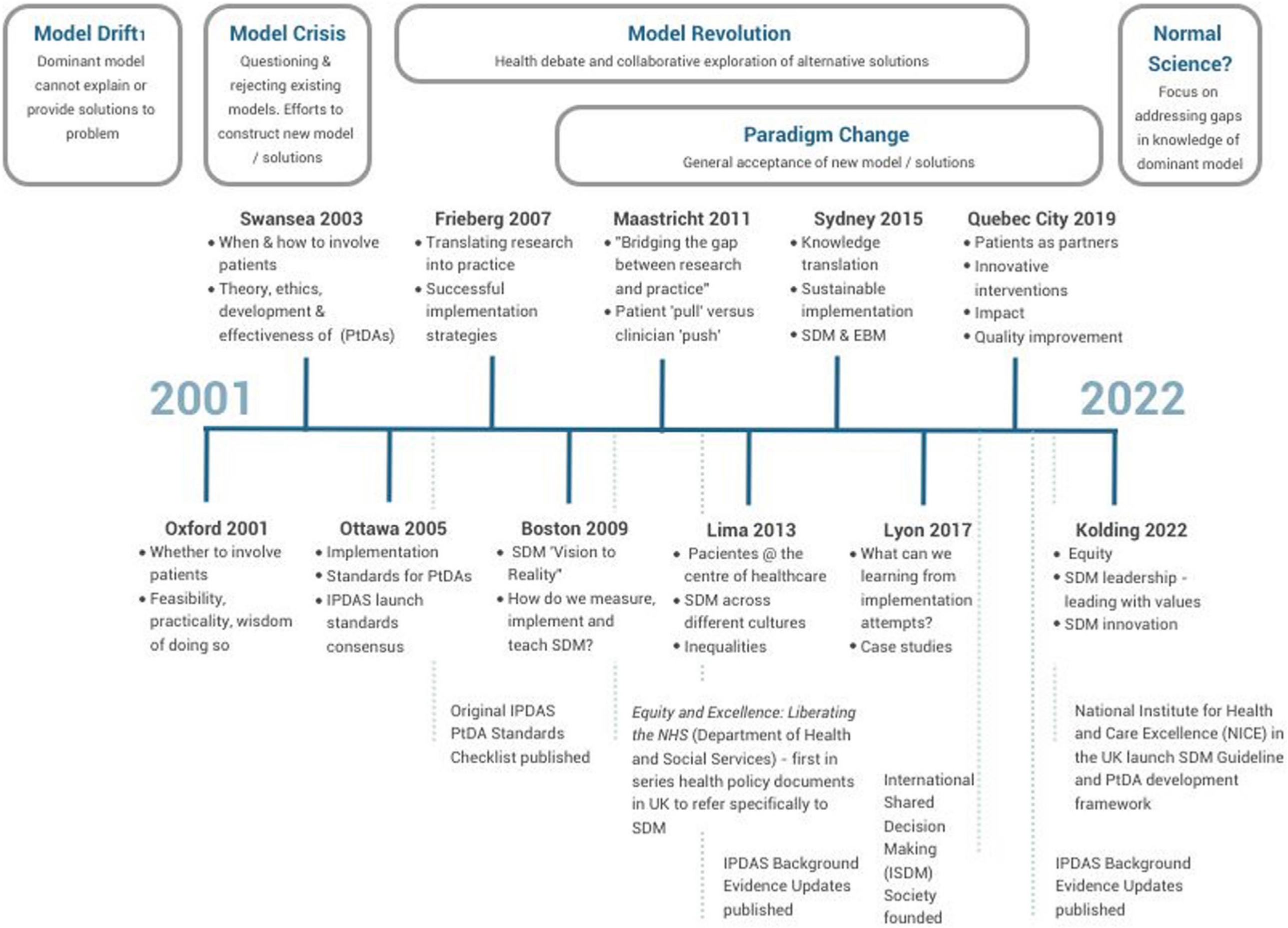

Figure 1 The 21-year history of the ISDM conference. Kuhn, 2012.[27] EBM, evidence-based medicine; IPDAS, International Patient Decision Aids Standards; NHS, National Health Service; SDM, shared decision making; PtDA, Patient Decision Aids.

remaining gap between knowing what works and realising this in routine clinical practice. We also know that these will not be universal, and more work is needed to work out how they work for different groups and in different settings. But we know enough about them and their effectiveness that they can be used to improve SDM—and if we do these things, we can be more certain that patients are more involved in decision making than when they are not used.

SDM priorities

Ahead of the ISDM conference in 2022, a brief online survey was used to capture what conference attendees (including academics, clinicians, policy-makers and patients) felt the key priorities in SDM research and implementation were. A total of 103 free-text priority research questions were submitted from 10 countries and grouped into themes (see table 1) and ranked, before being presented back during the keynote speech delivered by Joseph-Williams in Kolding (2022). The top five ranked priorities identified were: (1) measurement and outcomes, (2) sustainable implementation, (3) SDM as a core competency, (4) supporting underserved groups and (5) and digital transformations. We cross-checked these priorities against areas identified as requiring more work in the 21 country updates.[1] Each of the top five priorities identified by the survey was also referenced across these updates as areas of priority.

Moving forward and key challenges

Bringing progress and priorities together, we propose three key challenges for SDM research and implementation moving forward (see table 2). These are not all-encompassing, and we plan to replicate the international priority-setting exercise on a large scale in the next year, but we believe these represent important areas of focus.

Routine measurement of distributed care

Measurement is reported as one of the most challenging aspects of SDM. A quarter of the survey priorities proposed by the ISDM community focused on some element of measurement, and routine measurement was a consistent challenge reported in the country updates.[1] This does not mean that we do not have any good or reliable measurement tools. There are some validated examples of patient-reported[12 13 15 16] and observer instruments[14] that can show whether SDM took place in an encounter, the quality of the interaction, or the outcomes.

The challenge arises when we adopt an exclusively linear approach to measuring SDM for all healthcare contexts, for all patients and all decisions. Sometimes, there is a clear pathway for decision making: the patient receives a diagnosis, they are presented with discrete and, sometimes, irreversible treatment options by one professional, they are supported to make the decision, they undergo the treatment and then they are asked to reflect on that process of deciding on the treatment they chose.

Table 1 Top five SDM research and implementation priorities identified

Top priority area	Example questions/evidence needs
1. Measurement and outcomes	▶ How do we define a successful SDM process when there is no set time point for decision-making? ▶ What are the longer-term outcomes for patients of experiencing SDM? ▶ How can we balance having short and simple measures with capturing all parts of the construct? ▶ How does SDM affect clinical outcomes? ▶ How can we capture the resource use of SDM (economic evaluations)? ▶ How can we improve the timing of measurement (when is the optimal time across different settings and conditions?) ▶ How can we improve the relevance (eg, how can we link the measure to a specific decision point and specific healthcare professional/team or capture the complex and distributed nature of decision making?)
2. Sustainable implementation	▶ How can we guarantee sustainability of SDM in clinical encounters? ▶ How can we improve synergy between SDM and guidelines? ▶ How can we support interprofessional promotion of SDM? ▶ What are the most efficient approaches to implementing SDM? ▶ How can we use technology to improve the amount, quality, measurement and sustainability of SDM?
3. SDM as a core competency	▶ How can we sustainably teach SDM skills to our health and care workforce? ▶ Which undergraduate training programmes for healthcare professionals best support sustainable SDM skills? ▶ What are the core competencies of SDM across different settings? ▶ How can we use data to develop learning systems to drive continual improvement?
4. Supporting underserved groups	▶ How can we empower disadvantaged groups to participate in SDM? ▶ How can we be more inclusive and support those with lower levels of health literacy? ▶ How can SDM be implemented in an equitable way? ▶ How do we move away from the one-size-fits-all approach and recognise the unique needs of different individuals and groups? ▶ What are the additional barriers we need to overcome before we invite patients from underserved groups to become involved? ▶ What are the unique support needs of different groups?
5. Digital transformation	▶ What new challenges and opportunities does remote care present for SDM? ▶ How can we harness data-driven SDM? ▶ How can we use SDM data to drive real-time improvement? ▶ How can we use digital innovations to update patient decision aid evidence? ▶ How can we harness artificial intelligence for SDM measurement? ▶ What are the barriers to using digital recordings/artificial intelligence to capture the medical encounter? ▶ How we can support patients to use these systems in a way that results in benefits for them and the SDM process. ▶ What unique opportunities and challenges do remote consultations bring to SDM?

SDM, shared decision making.

The reality is that many patients do not make treatment or management decisions in this way. They interact in complex healthcare systems, they see multiple health professionals, these appointments take place across time and location, they often have more than one health issue ongoing at the same time, they involve significant others in their decisions and sometimes they are planning for future decisions and have not yet chosen a treatment or management option.[6] This is especially the case for patients with chronic conditions, who have comorbidity or multimorbidity, and those with rare diseases. There are several challenges for these patients when asked to complete a routine SDM measure: Which decision are they thinking about? Which professional are they being asked to rate? They have not yet decided on a management option as they are planning for longer-term care goals; should they still complete the measure?

Measurement is essential—we need to know if patients are receiving this gold standard of care when they have decisions to make. However, if we are going to do this routinely, we need to understand which patients these measurements work for, in which situations and why—perhaps more importantly, when don't they work? Ultimately, we need to improve the timing (when is the optimal time across different settings and conditions?) and the relevance (how can we link the measure to a specific decision point and specific healthcare professional/team or capture the complex and distributed nature of decision making?)[20] of routinely collected SDM measures. In achieving this, we must also be mindful of the current implementation context, where increasing amounts of data are being collected and we risk overburdening patients and clinicians. We should also recognise the potential of non-routinely collected measures, that could be less

Table 2 Moving forward: key challenges for SDM research and implementation

Key challenge	Summary
Routine measurement of distributed care	How can we better capture SDM when it is distributed across time, people and settings?
Harnessing digital technology	How can we harness the full potential of digital innovations to realise timely, up-to-date, responsive and sustainable SDM?
Promoting equity and supporting underserved groups	How can we make sure we do not exacerbate existing health inequalities and provide equal opportunities for everyone to be partners in their health and care decisions?

burdensome and perhaps more informative for local learning and improvement.

Harnessing digital technology

An area that has significant potential in the SDM field is digital technology. This featured as a top five priority from the survey and was consistently mentioned in the country updates[1] as a way to drive forward SDM implementation. How can we use this technology to improve the amount, quality, measurement and sustainability of SDM? Researchers in this area are already starting to explore the ways in which this technology can be harnessed.[21 22]

This technology has potential to improve care navigation, especially for patients with complex decision-making pathways. Currently, medical records are almost exclusively curated by health professionals. Mobile phones, perhaps integrated with online platforms, could capture both medical information and information about patients' preferences, allowing patients to provide real-time updates as their circumstances change so that the health professional (or the clinical system) can react to this. Further, current healthcare systems do not typically foster continuity in care; patients make decisions across healthcare professionals, location and time. Digital platforms that capture patient-reported information, in addition to medical information, could play a role in fostering this continuity, providing an up-to-date holistic view of the patient to all health professionals accessing their record. The question is how we can support patients to use these systems in a way that results in benefits for them and the SDM process.

Artificial intelligence could play an increasing role in data-driven SDM. A key challenge in routine SDM implementation is keeping patient decision aids up to date. How can we harness routinely collected data to develop reactive and 'live' patient decision aid platforms that update themselves, that are linked directly to clinical guidelines, and are directly accessible to patients? Artificial intelligence approaches also have the potential to automate the measurement of SDM during consultations, overcoming the burden of time-consuming observer measurements and issues of timing and relevance associated with patient-reported measurements. Thinking beyond data to support the decision making process, how can we use data to develop learning systems to drive continual improvement? Of course, with innovation often comes some scepticism, and so we need to explore related concerns about privacy issues, the loss of human interaction, and the requirement to access these platforms online.

The COVID-19 pandemic resulted in an accelerated shift to remote healthcare consultations. Some research explored the general benefits and challenges of this approach, but we do not yet know much about the impact of this on SDM. What unique opportunities and challenges do remote consultations bring to SDM? Do the models, training and tools still apply, or do we need to make changes? How can we foster the interpersonal relationship that underpins good SDM through remote care pathways? All the questions related to digital technology should be underpinned by questions about equity.

Promoting equity and supporting underserved groups

One of the most important things we need to do is foster equity, in both our research activities and access to good quality SDM in routine care—how can we ensure every patient has the skills, knowledge and support they need to be able to participate in shared decision making about their health and care?

> Cause they know best, they're the ones with all the training… I know lots of people with low self-esteem and when I was in 'the Valleys' (a socio-economically deprived area of Wales, UK)…well, people just don't feel like they've ever had a choice.
>
> …they were brought up in mining communities, the mines closed, and you talk about human rights and going into hospital, and you must speak up, and you just think **'what's the point, nobody has ever listened to us'**
>
> Participant quote from workshop to discuss views on patient involvement

Even when good quality decision aids are available and health professionals have the knowledge and skills needed to support a shared discussion and decision, many people still find it challenging to speak up. Are we doing enough to support people like the participant in this workshop to take part in SDM? What are the additional barriers we need to overcome before we even invite these patients to become involved? What are the unique support needs of different groups?

Example groups that we need to focus our research efforts on include:

- People with lower levels of literacy and education—for example, do our current decision tools work for these people?
- Ethnoculturally diverse populations—for example, do the westernised models of SDM work in other cultures? How do we support people when the first language is not the same as the health professional?
- People with additional support needs—how do we support people with visual impairments, with limited capacity or those who experience challenges in communication?

Pockets of excellent research are already taking place exploring these issues,[23–25] but are these isolated research activities enough? To ensure equity, we should be moving away from a 'one-size-fits-all' approach in our research and implementation attempts, to always asking questions about equity, and for whom these tools and approaches may not work so well.

Ultimately, we must do everything we can to avoid an 'inverse SDM care law'. Tudor Hart described the 'inverse care law' in 1971,[26] after spending many years working and researching in communities where the patient quoted above lived. It states that those who are most in need of care or services are least able to access and receive it. Unfortunately, more than 50 years later, it is still as prevalent as when first proposed. The real danger of driving forward SDM implementation without considering equity is that those who are in most need of support to take part are least likely to receive it, and they may be left further away from receiving this gold standard of person-centred healthcare that a large proportion of the population will be receiving. SDM tools and approaches are important—but they must not result in greater health inequalities, either access or outcomes. Every SDM report or study should include an equity statement, considering whether their findings can be applied to all.

Conclusion

The field of SDM has come a long way since the first ISDM conference in 2001, and we have learnt a lot from two decades research and implementation attempts. It is no longer about 'making SDM a reality'; it is about making it a reality for every single patient who wants to participate. But, if we want to continue driving forward the adoption of SDM in routine care at pace and demonstrate its benefits, we need to give adequate attention to three key areas of challenge: (1) how can we better capture SDM when it is distributed across time, people and settings?; (2) how can we harness the full potential of digital innovations to realise timely, up-to-date, responsive and sustainable SDM and (3) how can we make sure we do not exacerbate existing health inequalities and provide equal opportunities for everyone to be partners in their health and care decisions?

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