

# From words to action: time for Australia to take shared decision making implementation seriously

**W**hy is embedding shared decision making within the Australian health care system essential and urgent? Shared decision making is a process of engagement and partnership between a patient and their clinician that enables a collaborative decision to be made based on the best evidence, individual circumstances, and what matters most to the patient.<sup>1</sup> Patient involvement in making informed health decisions is a fundamental right<sup>2</sup> and is central to safe and quality health care. Shared decision making represents the highest standard of informed consent<sup>3</sup> and is a cornerstone of value-based health care. As well as benefitting individual patients and clinicians, shared decision making also has an important role in addressing unwarranted variations in health care and has the potential to contribute to health system sustainability by reducing the overuse of low-value care (where the benefits do not, or hardly, outweigh the harms) and increasing the uptake of care that is known to be effective but is underutilised.<sup>4,5</sup>

Shared decision making can contribute to achieving the quintuple aim of health care improvement,<sup>6</sup> by improving patient care experiences, informed decision-making, care efficiency, the wellbeing of clinical teams, and contributing towards reducing health inequities.<sup>7-12</sup> However, shared decision making is not widely adopted in practice in Australia and requires urgent scaling up so that more individuals and the health system can benefit from it.

## What has been happening to advance shared decision making in Australia?

In 2013, the inaugural national Shared Decision Making Symposium was hosted by the Centre for Research in Evidence-Based Practice (now the Institute for Evidence-Based Healthcare) at Bond University, in collaboration with the Australian Commission on Safety and Quality in Health Care (ACSQHC). One outcome of the symposium was identifying that clinicians' low awareness of shared decision making, misperceptions about it, and limited training opportunities were among the barriers hindering its implementation in Australia. Following the symposium, we published an article in the *Medical Journal of Australia*<sup>1</sup> (MJA) to increase broad awareness about shared decision making, providing a brief explanation and example of the process, and refuting some of the common misperceptions. To address the barrier of limited training opportunities, the ACSQHC developed an online training module in shared decision making for clinicians (Box 1).

The 2014 MJA article noted that "In the absence of a coordinated national effort, we encourage individual clinicians to begin incorporating shared decision making into their consultations..."<sup>1</sup> In the eleven years

since the article's publication, numerous initiatives led by local champions across Australia have promoted and facilitated implementation of shared decision making. Box 1 lists examples of some of these initiatives. Although this represents some progress, implementation has been ad hoc, mostly driven by individuals or teams championing its implementation, and some initiatives were only funded via research grants<sup>13</sup> or were pilot projects, which limits sustained practice change.

This ad hoc approach to advancing shared decision making uptake in Australia is problematic. Concerns include a duplication of efforts and resource development, limited learning from others' experiences, widely inconsistent resource access with no awareness of or access to resources in many health services, over-reliance on the enthusiasm and advocacy of individual champions, lack of monitoring of impact, and challenges with scalability and sustainability. The only national policy leadership for shared decision making in Australia has come from the ACSQHC. Notably, shared decision making was included in the second edition of the *Australian national safety and quality health service standards*, which was released in 2017.<sup>2</sup> Two of the eight standards include items relating to shared decision making: Standard 2 ("Partnering with consumers") and Standard 5 ("Clinicians working collaboratively to plan and deliver comprehensive care"). Similarly, the second edition of the *Australian charter of healthcare rights*, which was released in 2019, includes explicit reference to the core components of shared decision making.<sup>14</sup>

In general, there is now more visibility about shared decision making and it appears more frequently in health policy documents and on health service websites. However, its inclusion in documents is not sufficient for shared decision making to occur in clinical practice. There must be active large scale implementation strategies and a coordinated and resourced plan to ensure that patients who attend any health service across Australia are offered the opportunity to make collaborative and evidence-informed decisions with their clinician.

In the absence of any coordinated efforts to measure shared decision making in clinical practice, we do not yet have reliable and specific health service data about how often patients experience shared decision making during consultations. Questions in patient experience surveys are usually not sensitive enough to provide accurate information about whether shared decision making occurred. Some general indication of Australia's performance comes from an analysis of health system performance in ten countries, where for the domain of care process (which contains two elements relevant to shared decision making: patient engagement and sensitivity to patient preferences),

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## 1 Examples of shared decision making initiatives in Australia

### Examples of shared decision making resources:

- Resource hub (Australian Commission on Safety and Quality in Health Care)
  - ▶ Various clinician-facing resources and six patient decision aids
  - ▶ <https://www.safetyandquality.gov.au/our-work/partnering-consumers/shared-decision-making>
- Finding Your Way (NSW Health, Agency for Clinical Innovation)
  - ▶ A culturally adapted model of shared decision making, created with and for Aboriginal people. Various resources to support implementation
  - ▶ <https://aci.health.nsw.gov.au/shared-decision-making>

### Examples of shared decision making implementation pilot projects:

- Shared decision making about osteoarthritis care (NSW Health, Agency for Clinical Innovation)
  - ▶ Three demonstration sites with patient-facing resources targeting patients with osteoarthritis
  - ▶ <https://aci.health.nsw.gov.au/statewide-programs/lbvc/osteoarthritis-chronic-care-program>
- Shared decision making community of practice (Safer Care Victoria and La Trobe University)
  - ▶ Description and evaluation of implementing a shared decision making community of practice as a learning hub for participating Victorian health services
  - ▶ <https://doi.org/10.26181/23620725.v2>

### Examples of integration of shared decision making into Australian clinical guidelines:

- Shared decision making boxes and patient decision aids (Therapeutic Guidelines)
  - ▶ In various topics within the Antibiotics chapter, shared decision making boxes describe the steps clinicians can follow to engage in shared decision making with their patients. Hyperlinks to existing decision aids to support the conversation are also provided
  - ▶ <https://www.tg.org.au/>
- Australian guideline and calculator for assessing and managing cardiovascular disease risk (Heart Foundation)
  - ▶ In the 2023 guideline, a standard expectation was added to “highlight the importance of balancing professional judgement and expertise with the needs and wishes of people receiving care.” The guideline also contains a recommendation that “a relevant decision aid should be used to support effective risk communication and make informed decisions”, practice points for how to communicate risk, and links to relevant resources
  - ▶ <https://www.cvdcheck.org.au>
  - ▶ <https://www.heartfoundation.org.au/first-nations-heart-health/heart-yarning-tool>

### Examples of shared decision making training opportunities:

- Risk communication module (Australian Commission on Safety and Quality in Health Care)
  - ▶ This self-directed online module (approximately 2 hours) supports clinicians to develop and refine their skills in shared decision making, including communicating the benefits and harms of options
  - ▶ <https://www.safetyandquality.gov.au/our-work/partnering-consumers/shared-decision-making/risk-communication-module>
  - ▶ It was also incorporated into the continuing medical education offerings of some of Australia's specialist medical colleges and has been modified and incorporated into a learning module in the Australian and New Zealand College of Anaesthetists' Diploma of Perioperative Medicine <https://www.anzca.edu.au/education-training/perioperative-medicine-qualification>

### Examples of other initiatives:

- Shared decision making clinics for people facing decisions about major surgery eg, <https://www.petermac.org/patients-and-carers/information-and-resources/shared-decision-making>
- Resources that prompt patients to ask their clinician questions; this can initiate a shared decision making conversation eg, <https://www.healthdirect.gov.au/question-builder>; <https://askshareknow.org.au>

Australia was not considered to be among the high performers.<sup>15</sup> Data from the few small Australian research projects that have specifically measured the extent of shared decision making or gathered clinician or patient self-reported information suggest that levels are low.<sup>16,17</sup> Data on the teaching and assessment of shared decision making in Australian university medicine and health curricula are also lacking and difficult to gather, which hinders the identification of gaps and opportunities for improvement in its teaching.

## What can be done in Australia to advance the large scale implementation of shared decision making?

In our 2014 MJA article, we noted that:

Australia is drastically lagging behind many other countries in all aspects of shared decision making... [and] Australia's health training and delivery organisations need urgently to begin prioritising and planning to make shared decision making a reality in Australia.<sup>1</sup>

Eleven years on and there has been disappointingly little progress towards this. The lack of coordinated

and sustainable activity, with little focus on implementation and research funding, means that Australia<sup>18</sup> is lagging behind many other countries (eg, Taiwan, Netherlands, Germany) who have committed to large scale implementation of shared decision making. In such countries, a combination of initiatives that target patients, clinicians, and the health system is typically used. For example, initiatives in the Netherlands include accredited shared decision making e-learning for clinicians; national promotion of the Ask 3 Questions to patients (including emails when a clinic appointment is booked); national governance of patient decision aids, quality criteria for these aids, and integration with guidelines; introduction of a specific billing code to finance the time for shared decision making conversations; legislation that empowers patients, such as the right to audiotape conversations, and that informed consent must cover the right to abstain from treatment; and explicit support and funding from the Dutch government and the ministry of health equivalent.<sup>19,20</sup> There is an increasing evidence base to guide shared decision making implementation, much of it generated in other countries.<sup>21-27</sup>

A national symposium on advancing shared decision making was held in September 2024, hosted by the

## 2 Opportunities to progress the implementation of shared decision making in Australia

### 1. Collate shared decision making resources in one national portal

**Problem:** Resources to support shared decision making, such as patient decision aids, patient question prompts, and clinician training, are scattered across numerous intranet and internet websites, including those of hospitals, state and federal health departments, universities, health organisations, and patient health information sites. This scatter imposes a barrier for Australian clinicians as it impedes them knowing which aids exist and being able to use them with patients. The Australian Commission on Safety and Quality in Health Care hosts a shared decision making hub (Box 1), which includes some training materials and a small number of decision aids, which were developed under the auspices of the Australian Commission on Safety and Quality in Health Care, but these constitute only a very small fraction of the resources that exist and covers only a limited number of conditions.

**Opportunity:** Create a national shared decision making resource portal, ideally government-hosted to ensure sustainability. A priority is to provide a designated portal that contains patient decision aids, developed or adapted for use in Australia. This “one stop shop” would enable clinicians and patients to readily find and use appropriate resources. In recent years, a number of countries have developed their own national portal for patient decision aids (eg, Denmark,<sup>21</sup> Taiwan<sup>22</sup>) to facilitate shared decision making, with some using a standard template or developing patient decision aid standards (<https://www.nice.org.uk/corporate/ecd8>).

**Challenges:** The appropriate organisation to host this portal needs to be chosen, along with concerns such as assessing that patient decision aids and other shared decision making resources meet appropriate quality standards<sup>28</sup> and monitoring them for currency. As it is not feasible for a decision aid to exist for all decisions, a decision aid template that can be used and adapted for specific situations would also be needed.

### 2. Foster awareness and uptake of shared decision making through clinical practice guidelines

**Problem:** Clinical practice guidelines are evidence-based tools that contain recommendations to support decision making. However, the role of a guideline is to *guide* decision making. Recommendations are not a fixed protocol that should always be rigidly followed; the applicability of a recommendation for an individual patient needs to consider the individual's values, preferences, and circumstances and ideally involve a discussion with the person. The limited promotion of shared decision making and inclusion of elements and tools to facilitate it within guidelines is a barrier to increasing clinicians' awareness of the need to collaboratively decide with patients and tailor care according to patient values and preferences.<sup>29,30</sup>

**Opportunity:** The National Health and Medical Research Council (NHMRC) are in the process of updating the 2016 version of their *Procedures and requirements for meeting NHMRC standards for clinical practice guidelines*. In the updated version that was made available for public consultation at the end of 2024,<sup>31</sup> one item relevant to shared decision making (*D.11 Recommendations that emphasise consumer and carer involvement in treatment and care decisions are included where relevant*) has been made mandatory. However, the accompanying “how to do it” section for this item is blank. *NHMRC's guidelines for guidelines handbook*, which provides practical information for guideline developers on how to meet the guideline standards, should be updated to include a module with the details developers need to ensure that the guideline promotes shared decision making. Strategies can include altered recommendation wording, considering how the options and benefit/harm evidence are presented, concurrently developing or providing links to patient decision aids, and indicating recommendations and decisions where shared decision making is likely to be a priority.<sup>32</sup> A number of countries and organisations have incorporated shared decision making principles into their guidelines (UK/NICE, Denmark, Netherlands).<sup>20,33,34</sup>

**Challenges:** Many of the guidelines used by Australian clinicians are not developed in accordance with NHMRC standards and may not incorporate strategies to promote and implement shared decision making, even if such strategies are addressed in improved NHMRC standards.

### 3. Develop a national shared decision making strategy

**Problem:** Shared decision making is clearly articulated as part of the *National safety and quality health service standards* (NSQHS).<sup>2</sup> It also appears in policy documents and patient-facing resources from all Australian federal, state and territory health departments and services, is described as crucial to the success of the National Medicines Policy, listed as a patient outcome priority in the National Clinical Quality Registry and Virtual Registry Strategy, and stated as a guiding principle and recommendation of various national guidelines. Despite frequent mention of it in health policies, implementation and governance of shared decision making in Australia remains fragmented with no overarching strategy or coordination. This lack of ownership and responsibility for shared decision making implementation is another barrier to the lack of progress towards its uptake. The siloed organisational structure of the Australian Government Department of Health, Disability and Ageing also contributes to the problem. Shared decision making is relevant across numerous aspects of the health system, and while there are brief acknowledgements that shared decision making is important and should occur in documents from multiple programs within the department, no branch or program is tasked with ensuring this occurs.

**Opportunity:** A national shared decision making strategy, underpinned by national policy, is urgently required to support implementation, measurement, and reporting to meet national standards across all jurisdictions, levels, and aspects of health care. To address a similarly broadly relevant issue and recognition of the need for leadership and action by multiple organisations and individuals to achieve improvement, the National Health Literacy Strategy is currently in development, with implications for shared decision making.<sup>35</sup> However, while health literacy is important to shared decision making,<sup>36</sup> the health literacy strategy alone is insufficient to advance shared decision making uptake.

To advance large scale implementation, some countries (eg, the UK) have developed guidance on how to embed shared decision making in everyday health care<sup>33</sup> and other countries (eg, Denmark, Germany) have developed national centres of shared decision making. Others have integrated it into the highest level of all relevant policies and adopted multiple coordinated practical approaches (eg, the Joint Commission of Taiwan and the Ministry of Health and Welfare worked with hospitals to develop locally based decision aids, clinician training, a national awareness campaign, a national portal for the public and clinicians to access aids and resources, and provides help and advice to hospitals to implement shared decision making.<sup>22,37</sup> Australia has experts in the field of shared decision making and the capability to develop a national shared decision making strategy that is informed by the best available evidence. A strategy should be developed collaboratively with patients, clinicians, researchers, educators, policy makers, consumer organisations, and other stakeholders. Patient engagement in designing a national strategy will help to ensure that the recommendations and guidance are inclusive and responsive to the needs of diverse populations and health contexts.

**Challenges:** The development of a national shared decision making strategy requires commitment and support from the federal government and the engagement of many other stakeholders, including patients and families from a range of diverse backgrounds. If such a strategy can be developed, it may be appropriate to leverage the implementation of the national health literacy strategy, albeit with the challenge of recognising that different implementation strategies would be required to embed effective shared decision making into routine clinical care successfully and equitably.

## 2 Continued

### 4. Strengthen implementation and accreditation processes for national standard items relevant to shared decision making

**Problem:** The NSQHS provide a nationally consistent statement on the level of care a patient can expect from health service organisations in Australia, with a primary aim of protecting the public from harm and improving the quality of health services. They cover hospital care and have recently expanded to cover dental, primary and community care, and areas of mental health. As explained earlier, in the second edition of the NSQHS, two standards contain items that explicitly refer to shared decision making. Although it was hoped that this inclusion would lead to widespread adoption of shared decision making within Australian health organisations, this has not eventuated. A key barrier is that the guidance provided within the standards is necessarily high level to suit a wide range of health services, but consequently lacks specific, actionable requirements. Although accreditation processes are used to assess compliance with the standards, it is difficult to judge whether the standards relevant to shared decision making are genuinely achieved by health services. For example, the evidence provided can simply be the existence of policy or training documents about shared decision making. This does not capture whether it actually occurs in practice. A related problem is that there are no requirements or guidance about documenting shared decision making in the clinical record, and the occurrence and appropriateness of this is likely suboptimal.

**Opportunity:** Considering how evidence of shared decision making practice could be recognised and how accreditation processes could be strengthened to provide accurate information about whether relevant items are truly being met could provide impetus for services to prioritise shared decision making implementation. Countries that have shown greater success in implementing shared decision making have used concrete metrics as quality criteria. For example, in Germany, evidence of shared decision making training by clinicians has been used as a marker of high quality practice if > 80% of clinicians in a clinical department have completed specified training.<sup>38</sup>

Informed consent legislation has provided impetus in some jurisdictions for greater attention to shared decision making.<sup>19</sup> For example, in the Netherlands, informed consent law requires that patients are informed of the right to abstain from treatment (to “wait and see”) and for patient preferences to be explored (and documented) by clinicians.<sup>19</sup> In Australia, informed consent legislation requires that information about the benefits, risks and costs of a treatment is provided to patients in a way that they can understand. However, there is no explicit mention of the need to discuss with the patient their personal preferences, nor the right to “wait and see”. Informed consent is also addressed in the NSQHS (2.04), with it detailing the need to communicate “risks, benefits and alternatives” and “determine patient preferences for treatment”. As with shared decision making, there are similar challenges with accurately capturing the extent to which truly informed consent occurs.

**Challenges:** Appropriate indicators of shared decision making would need to be developed and implemented. Methods and guidance for documenting shared decision making in clinical records are also needed.

Australian Shared Decision Making Network and the Institute for Evidence-Based Healthcare. The symposium included presentations from international and national speakers who have led implementation activities and was attended by researchers, clinician–researchers, and representatives from various state and federal health organisations and departments. Among the topics presented and discussed were the current barriers to shared decision making in Australia, learnings from other countries (particularly about large scale/national level implementation), and practical strategies that could be used to progress uptake (Box 2).

Barriers to the implementation of shared decision making occur at the level of individual patients and clinicians and at the health organisation and system level.<sup>1,39</sup> Patients may face challenges such as low health literacy, cultural expectations, emotional distress, or a lack of confidence in participating. At the clinician level, some of the known barriers include low awareness of and access to shared decision making tools and resources, time constraints, insufficient training, concerns about professional autonomy, limited recognition of the compatibility of shared decision making with clinical practice guidelines, and the misbelief that simply providing a decision aid is enough to facilitate shared decision making.<sup>39,40</sup> System-level barriers to the implementation of shared decision making include limited access to decision aids, misaligned performance incentives, fragmented care, and policy or legal uncertainties.<sup>1,39</sup> The strategies suggested in Box 2 are primarily aimed at helping to mitigate some of these system and clinician-level barriers. However, it is acknowledged that for certain conditions (eg, chronic pain), the complexity of the information and the decision, along with gaps in the evidence, means the shared decision making process

can be more complicated.<sup>41,42</sup> In such situations, addressing barriers needs to include ensuring that a broader atmosphere of care, concern, supportive communication and trust has been established; that goal-setting is incorporated; and there are coordinated efforts across clinical, organisational, and policy domains.

Implementing shared decision making requires a universal approach to ensure equity and access to inclusion in decision making, not just for those with high health literacy and access to care.<sup>43</sup> Adults with lower literacy can use tools to support shared decision making and are willing participants in health decisions.<sup>44</sup> Shared decision making can be most effective in supporting vulnerable populations.<sup>45</sup> In Australia, projects to improve shared decision making in specific communities have been developed<sup>46</sup> and with considered implementation and national support, could avoid widening inequities.

## Conclusion

In Australia, there has been a notable change over the last decade and the term “shared decision making” is now used widely and appears frequently in health policy documents. But this is not enough and is not sufficient to ensure that shared decision making becomes standard practice in Australian health care. Many countries have recognised the importance of actively implementing large scale shared decision making. These international examples provide evidence of the feasibility of bridging the gap between policy and action and provide opportunities for Australia to learn from other countries. Various strategies have been used elsewhere, such as developing national guidance and strategy, establishing a centre focused on implementation,



creating a national portal to provide easy access to shared decision making resources, developing targeted legislation (particularly around informed consent), requiring training and assessing clinician competency in shared decision making, funding implementation research and projects, and promoting shared decision making in guidelines and clinical pathways. Not actively leveraging this knowledge about shared decision making for Australia is a missed opportunity. Australia has been a leader in shared decision making research and policy over the last 20 years; however, we continue to lag behind in clinical practice. Widespread implementation of shared decision making is needed to support safe, high quality, sustainable and patient-centred health care in Australia. This is the right action to take for patients and will help to sustain an increasingly strained health care system. Scaling shared decision making for all in Australia should be a national priority.

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