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Trevena, Lyndal J.; Shepherd, Heather L.; Bonner, Carissa; Jansen, Jesse; Cust, Anne E; Leask, Julie; Shadbolt, Narelle; Del Mar, Chris; McCaffery, Kirsten J; Hoffmann, Tammy

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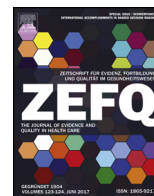
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Shared decision making in Australia in 2017



Partizipative Entscheidungsfindung in Australien im Jahr 2017

Lyndal Trevena^{a,*}, Heather L Shepherd^b, Carissa Bonner^a, Jesse Jansen^c, Anne E Cust^d, Julie Leask^e, Narelle Shadbolt^f, Chris Del Mar^g, Kirsten McCaffery^h, Tammy Hoffmann^g^a ASK-GP Centre of Research Excellence, Sydney School of Public Health, University of Sydney, NSW, Australia^b ASK-GP Centre of Research Excellence, CeMPED, School of Public Health, The University of Sydney, PoCoG, School of Psychology, The University of Sydney, Australia^c Wisser Healthcare, ASK-GP Centre of Research Excellence, Sydney School of Public Health, The University of Sydney, NSW, Australia^d ASK-GP Centre of Research Excellence, Sydney School of Public Health, The University of Sydney, NSW, Australia^e ASK-GP Centre of Research Excellence, Sydney School of Public Health, the University of Sydney, NSW, 2006, Australia, Sydney School of Nursing, the University of Sydney, NSW, Australia^f ASK-GP Centre of Research Excellence, Sydney Medical School, University of Sydney, NSW, Australia^g ASK-GP Centre for Research Excellence, Centre for Research in Evidence-Based Practice, Bond University, Gold Coast, QLD, Australia^h CeMPED, Wisser Healthcare, ASK-GP Centre of Research Excellence, Sydney School of Public Health, The University of Sydney, NSW, Australia

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ABSTRACT

Shared decision making (SDM) is now firmly established within national clinical standards for accrediting hospitals, day procedure services, public dental services and medical education in Australia, with plans to align general practice, aged care and disability service. Implementation of these standards and training of health professionals is a key challenge for the Australian health sector at this time. Consumer involvement in health research, policy and clinical service governance has also increased, with a major focus on encouraging patients to ask questions during their clinical care. Tools to support shared decision making are increasingly used but there is a need for more systemic approaches to their development, cultural adaptation and implementation. Sustainable solutions to ensure tools are kept up-to-date with the best available evidence will be important for the future.

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ZUSAMMENFASSUNG

Partizipative Entscheidungsfindung (PEF) ist in Australien mittlerweile fest in den nationalen klinischen Standards für die Akkreditierung von Krankenhäusern, Tageskliniken und öffentlichen Zahnarztpraxen sowie in der medizinischen Ausbildung verankert; und es bestehen Pläne, diese auf allgemeinmedizinische Praxen, Alten- und Behinderteneinrichtungen auszuweiten. Die Implementierung dieser Standards und die entsprechende Ausbildung von Gesundheitsfachkräften stellen für den australischen Gesundheitssektor derzeit eine der wichtigsten Herausforderungen dar. Die Einbindung der Konsumenten in Gesundheitsforschung, Gesundheitspolitik und Steuerung der klinischen Leistungserbringung hat ebenfalls zugenommen, wobei der Schwerpunkt darauf liegt, Patienten zu ermutigen, im Rahmen ihrer medizinischen Versorgung Fragen zu stellen. Immer häufiger werden Instrumente zur Unterstützung partizipativer Entscheidungsfindung genutzt, ihre Entwicklung, ihre kulturelle Adaptation und Implementierung erfordern jedoch stärker systemisch ausgerichtete Ansätze. Für die Zukunft wird es nötig sein, nachhaltige Lösungen zu entwickeln, um zu gewährleisten, dass diese Entscheidungshilfen auf der Grundlage der besten verfügbaren Evidenz ständig aktualisiert werden.

Introduction to Australia, its health system and a health snapshot

Australia currently has a population of approximately 24.2 million people [1]. Australians enjoy one of the highest life

* Corresponding Author: Professor Lyndal Trevena, Room 321b, Edward Ford Building (A27), University of Sydney, NSW 2006 Australia.
E-mail: lyndal.trevena@sydney.edu.au (L. Trevena).

expectancies in the world with males born between 2012 and 2014 expecting to live until 80.3 years and for females, until 84.4 years [2]. Coronary heart disease remains the leading cause of death, accounting for 13% all deaths in 2013. Cancer is the leading cause of disease-burden followed by cardiovascular disease, mental and substance abuse disorders, musculoskeletal disease and injury. However, 63% of Australian adults (11.2 million people) were overweight or obese in 2014–15 with 5 million of these being obese. Aboriginal and Torres Strait Islander peoples in Australia continue to have lower life expectancy and much higher rates of diabetes, kidney disease, heart disease and injury. Over half of Australians have very poor or marginal health literacy, meaning they have inadequate skills to meaningfully engage in health care and shared decision making (SDM), and this has been linked to worse chronic disease outcomes [3]. Australia spends about 9.4% of Gross Domestic Product (GDP) on health, in line with the average health expenditure of 9.3% for OECD countries [2].

Healthcare costs in Australia are funded by a mix of government, private health insurance and consumer out-of-pocket expenses. The *Australian Government's Medicare system* provides a safety net to ensure access to essential healthcare. General Practitioners (GPs) and other members of the primary health care team (community nurses, pharmacists, allied health, dentists etc.) are usually the first point of contact with over 80% of all Australians seeing a GP at least once per year. Most medical and some allied health services are funded by a fee-for-service system called the *Medicare Benefits Schedule (MBS)*. Most essential medication is subsidised by the *Pharmaceutical Benefits Scheme (PBS)*. These systems are administered by the national Australian Government, whilst hospital care is administered by the seven State and Territory governments. These different jurisdictions have relevance to the complexity of SDM implementation in policy and practice.

Australian policy developments in shared decision making

Since our 2011 manuscript, the interest in SDM in Australia has increased and this is evident from the incorporation into policy, or discussion about, SDM by a number of national and state organisations. For example, the *Australian Commission on Safety and Quality in Health Care (ACSQHC)*, who lead and coordinate national improvements in safety and quality in health care, hosted national symposiums about SDM in 2013 and 2014 to which representatives from stakeholder health organisations were invited. In conjunction with the ACSQHC and the *National Health and Medical Research Council (NHMRC)*, SDM researchers also hosted Australia's inaugural symposium on SDM Research, with a view to encouraging collaboration and raising awareness of SDM among Australian clinicians and health organisations. An 'awareness-raising' article resulting from this was published in the centenary issue of the *Medical Journal of Australia* [4].

The ACSQHC have also extended their earlier work [5] by developing several programs in SDM, Health Literacy and Partnering with Consumers. In 2017 they plan to release the second version of the *Australian 'National Safety and Quality Health Services Standards'* and by 2019, all health services will be assessed against these standards for accreditation [6]. The evolution of "*Standard Two: Partnering with Consumers*" in the 2012 version to the new version in 2017 is shown in [Table 1](#) and demonstrates a clear shift towards patients being more actively involved in their own care if that is their preference.

The draft version of the new standards go further to explicitly mandate that "health services have processes for clinicians to partner with patients and/or their substitute decision maker to plan, communicate, set goals and make decisions about the current and future care". These standards apply for accreditation of all public and private hospitals, day procedure services and public dental

Box 1: Key components of the Australian Charter of Healthcare Rights

Access: I have the right to health care
Safety: I have a right to receive safe and high quality care
Respect: I have a right to be shown respect, dignity and consideration
Communication: I have a right to be informed about services, treatment, options and costs in a clear and open way
Participation: I have a right to be included in decisions and choices about my care
Privacy: I have a right to privacy and confidentiality of my personal information
Comment: I have a right to comment on my care and to have my concerns addressed

services in Australia. There has also been a change to begin aligning general practice, aged care and disability service accreditation with this same framework and process. The *Royal Australian College of General Practitioners (RACGP)* states that patients have the right to make informed decisions about their health and that "the clinical team must demonstrate how they provide information to their patients about the purpose, importance, benefits and possible costs of proposed investigations, referrals or treatments." ACSQHC has also established an Expert Advisory Committee to provide oversight and advice on the development of safety and quality strategies, tools and resources for primary care. The committee includes representation from audiology, podiatry, nursing, dentistry, psychology, consumers, pharmacy, optometry and general practice. This process of wider consultation will occur from mid-2017.

Further documentation of the right of patients to be informed and involved in their healthcare is supported by the requirement for all health organisations in Australia to have an easily accessible version of the "Australian Charter of Healthcare Rights". This Charter comprises seven core components (See [Box 1](#)).

The ACSQHC has also commissioned the *Australian Atlas of Healthcare Variation* [7] which has highlighted variation in antimicrobial prescribing, diagnostic and surgical interventions, psychotropic and mental health treatment, opioid prescription and interventions for chronic disease. The ACSQHC has explicitly identified SDM as a strategy to address unwarranted clinical variation. The Australian specialist colleges have also participated in the Choosing Wisely international movement but as yet there is no explicit inclusion of SDM as a strategy for reducing over-diagnosis and over-treatment.

Patient and public involvement in SDM policy and research

Consumer involvement in policy

The peak body for consumer representation in Australia remains the *Consumers Health Forum*, which has national and state branches. Members of these not-for-profit organisations are actively engaged in policy, advocacy, health service planning and research where possible and these organisations run a range of training programs for their members.

There has been growing interest in citizen's juries as another mechanism for engaging consumers in health decision-making and policy [8]. For example, in the state of Victoria, a jury of 78 Australians met daily for six-weeks to explore evidence and question experts to come up with 20 action points to address the growing problem of obesity in our community.¹ Some of the requests they put forward were for better health ratings on food labels,

¹ <https://www.vichealth.vic.gov.au/programs-and-projects/victorias-citizens-jury-on-obesity>.

Table 1
Evolution of Partnering with Consumers (Standard Two).

2012 Standard Two	2017 Draft Standard Two	Change
<p><i>Health Service Level</i> Consumer partnership in service planning Governance structures are in place to form partnerships with consumers and/or carers Consumer partnership in designing care Consumers and/or carers are supported by the health service organisation to actively participate in the improvement of the patient experience and patient health outcomes Consumer partnership in service measurement and evaluation Consumers and/or carers receive information on the health service organisation's performance and contribute to the ongoing monitoring, measurement and evaluation of performance for continuous quality improvement.</p> <p><i>Individual patient level</i> Elements relevant to shared decision making were included in standards relating to governance, clinical handover, blood and blood products, prevention and management of pressure injuries and prevention and management of falls.</p> <p>Consumers to provide feedback on patient information publications and this to be incorporated. Consideration of patients' capacity to understand health information. Patient information to be provided about infection control, medicines information, blood and blood products, management of pressure sores, and rapid deterioration and escalation of care.</p>	<p><i>Health Service Level</i> Clinical governance and quality Improvement systems to support partnering with consumers Systems are designed and used to support patients, carers, families and consumers to be partners in healthcare planning, design, measurement and evaluation Partnering with consumers in organisational design and governance Consumers are partners in the design and governance of the organisation</p> <p><i>Individual patient level</i> Partnering with patients in their own care Systems that are based on partnering with patients in their own care are used to support the delivery of care. Patients are partners in their own care to the extent that they choose. Health Literacy Health service organisations communicate with patients in a way that supports effective partnerships</p>	<p><i>Health Service Level</i> Continued emphasis on consumer engagement in service governance and design but a distinct shift from consumers being informed about health service performance and design to being partners and co-creators of service design, delivery and quality improvement. The new standards also require training for clinicians in partnering with consumers and monitoring and reporting on the consumer partnership processes.</p> <p><i>Individual patient level</i> A shift from provision of information to consumers in a selected number of areas to being partners in all aspects of healthcare to the extent that patients want to be involved. Similarly a new and overarching requirement for communication that supports and enhances health literacy.</p>

banning junk food and beverage marketing to children, imposing a 20% sugar tax and to establish fast-food exclusions zones around schools, sporting clubs, youth and community centres.

Consumer involvement in research

There has also been a shift towards greater involvement with consumers in designing and reviewing research proposals for grant applications. Furthermore, in 2013 *Australia's National Health and Medical Research Council (NHMRC)* established a *Community and Consumer Advisory Group (CCAG)* to provide high-level strategic advice on health and medical research matters from the consumer and community perspective². In 2016, the Consumers Health Forum and the NHMRC released an update on their *'Statement on Consumer and Community Involvement in Health and Medical Research'*.³ This document provides researchers with a roadmap for the many ways that consumers can be involved in research.

Training for health professionals

There has been increasing interest in SDM training and skills development mainly from health organisations charged with implementing the new standards. Some of the medical specialty colleges have also started to recommend and include training in health communication and SDM but this has not been standardised nor systematised [9]. The *Royal Australian College of General Practitioners (RACGP)*, in conjunction with ACSQHC, has developed an online 'risk communication' module which is available to College members as part of its suite of continuing professional development options but the impact of this has not been evaluated.

Undergraduate health students' exposure to SDM teaching and learning is patchy and largely reliant on local champions with expertise to drive this into local curricula. However, the *Australian Medical Council (AMC) standards for accrediting medical schools* now includes the requirement that medical graduates can *"Elicit patients' questions and their views, concerns and preferences, promote rapport, and ensure patients' full understanding of their problem(s); Involve patients in decision-making and planning their treatment, including communicating risk and benefits of management options."* [10]

Current data on the experience of patients in Australia

State based initiatives have also been introduced to capture the experience of patients who have been hospitalised. The *Bureau of Health Information in New South Wales (NSW)* is a board-governed organisation that publishes independent reports about the performance of the NSW public healthcare system. The *NSW Patient Survey Program* asks patients each month about their recent experience with the public healthcare system, which includes questions as part of the NSW Patient Survey Program. Latest available data from the 2014 survey reported that 60% of patients said they were 'definitely' involved in decisions about their care [11].

Tools and resources to support shared decision making

Interest in enhancing the implementation and availability of tools to support SDM in Australia has also gathered momentum over the past six years, although, like many other countries, the development and updating of tools is ad hoc and reactive. One notable example of SDM facilitation has been with PSA screening for prostate cancer and the *Royal Australian College of General Practitioners (RACGP)*. The RACGP guidelines are aligned to an NHMRC-commissioned evidence summary, both of which recommend SDM for asymptomatic men who request a PSA test. As part of this evidence-summary/guideline package, the RACGP also

² (<https://www.nhmrc.gov.au/about/nhmrc-committees/previous-committees-and-advisory-groups/community-and-consumer-advisory-group>).

³ (<https://www.nhmrc.gov.au/guidelines-publications/s01>).

developed a short-form patient decision aid which is one of the most frequently downloaded resources from their website (personal communication). Similarly, the ACSQHC commissioned the development of brief patient decision aids to facilitate SDM about antibiotic prescribing for acute respiratory infections [12]. The latter are currently being evaluated in an NHMRC-funded randomised controlled trial.

Australian researchers have been pioneers in the development and use of generic questions and question prompt lists with this work continuing to evolve over the past six years. The early work in oncology *Question Prompt Lists* [9] has seen a series of these resources published on the NSW Cancer Institute portal. The work on training consumers to ask three questions [13,14] has been extended from the original proof-of-concept trial to a feasibility study that trained patients via a waiting room video and more recently this has been adapted for adults with lower literacy and languages other than English. This latter work has included work with the adult education sector to improve health literacy and has for the first time shown that SDM training increases functional and critical health literacy [15]. The *Australian Government's Health-Direct consumer portal* is currently developing a question builder adapted from the US Agency for Research and Quality in Health Care.

A number of other prominent health organisations direct patients to 'question lists' to guide patients and their families through the types of things it is important to ask when making decisions about their health. Examples of this include the *Cancer Council Australia Questions-to-ask-your-doctor information* [16]⁴ and the National Prescribing Service, who point consumers to *5-questions-to-ask-your-doctor* within their *Choosing Wisely Australia initiative*.⁵ [17] The first national meeting of Choosing Wisely Australia was held in May 2017. Whilst direction towards question asking tools is growing, there is often little information explaining the value of shared decision making and the role question asking has in increasing the opportunity for patients to be involved in decisions about their health.

Future challenges for SDM in Australia

Whilst there has been an exciting shift towards greater patient involvement in healthcare decisions, scaling this up is not an easy task. The implementation of the new National Standards presents both opportunities and challenges. There will be a need for clarification of core competencies in SDM for patients and health professionals as well as meaningful measures of SDM implementation at the service level. There has not been any substantial discussion about certification of patient decision aids or other tools at this stage and there needs to be better familiarity with the *International Patient Decision Aid Standards (IPDAS)*. These standards require that tools are regularly updated and use the best available evidence but mechanisms to ensure the sustainability of this have not yet been considered. Australia is a multi-cultural nation and there is a need to extend the SDM work with adaption of tools for vulnerable population groups. Early research has commenced on SDM with the elderly, lower literacy and patients from non-Western cultural backgrounds. Australia's multicultural population and geographical location within the Asia-Pacific region provides opportunities to extend this work on patient-centred care to lower resource countries. Questions remain about the extent to which SDM or its components and tools can be adopted

in health care decisions where there is strong evidence for one option, such as with vaccination [18], and if so, in which contexts. Further exploration and specificity is required here.

We need to continue to work with our international partners to share resources and ideas to facilitate patient rights and empowerment, and SDM. We look forward to updating this field in the next edition.

Conflict of Interest

None declared.

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