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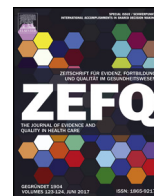
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Special Issue / Schwerpunkt

## Shared decision making, a buzz-word in the Netherlands, the pace quickens towards nationwide implementation. . .



*Partizipative Entscheidungsfindung – auch in den Niederlanden ein Schlagwort: Das Tempo der landesweiten Implementierung zieht an . . .*

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### ABSTRACT

Currently, shared decision making (SDM) is on the agenda among target patient representative groups, policy makers and professional bodies. Although the International Conference for Shared Decision Making (ISDM) 2011 generated a positive boost, hesitation was also felt among Dutch clinicians, who are challenged by many new tasks. No hesitation is seen among the majority of patients, opting mostly for the SDM model. We haven't reached these patients' needs fully yet, given disappointing research data on patients' experiences and professional behaviour.

There is plenty of room for improvement in daily practice, for which many best practices are being designed and increasingly implemented, such as national campaigns to empower patients, central governance of patient decision aids that are developed along clinical practice guidelines, postgraduate training, collaborative learning and system changes, and merging goal setting and SDM in complex care. This is explicitly supported by the Dutch government, the Ministry of Health, patient groups, professional bodies and health insurers. The culture shift in the minds and hearts of patients and clinicians has started but is still ongoing. Enthusiasm for this way of working could be undermined if SDM is defined and implemented in a simplistic, dogmatic manner leading to irresponsible transferring of the professionals' uncertainty, responsibility, and decisional stress to patients.

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### ZUSAMMENFASSUNG

Das Thema partizipative Entscheidungsfindung im Gesundheitswesen steht aktuell auf der Tagesordnung von Patientenverbänden, politischen Entscheidungsträgern und Berufsverbänden. Auch wenn die *International Conference for Shared Decision Making* (ISDM) 2011 ausgesprochen positive Resonanz fand, so war unter den niederländischen Ärzten, auf die jetzt viele neue Aufgaben zukommen, diesbezüglich doch auch eine gewisse Zurückhaltung zu beobachten. Patienten haben grundsätzlich Interesse

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## Patientenbeteiligung medizinische Entscheidungshilfen Implementierung

und befürworten eine partizipative Entscheidungsfindung (PEF) zumeist. Doch wie die enttäuschenden Forschungsergebnisse in Bezug auf die Erfahrungen von Patienten und das Verhalten von medizinischem Fachpersonal belegen, werden wir den Bedürfnissen der Patienten noch nicht vollkommen gerecht.

Es gibt noch viel Spielraum für Verbesserungen, auch wenn schon viele exzellente Modellinterventionen entwickelt und bereits in die tägliche Praxis implementiert worden sind. Beispiele dafür sind nationale Initiativen zum Empowerment von Patienten, die zentrale Steuerung von Entscheidungshilfen für Patienten, die zusammen mit klinischen Leitlinien entwickelt wurden, Weiterbildungsangebote, gemeinschaftliches Lernen, die dafür erforderlichen Systemveränderungen und die Zusammenführung von individuellen Gesundheitszielen und partizipativer Entscheidungsfindung in komplexen Versorgungssituationen. Diese Initiativen werden von verschiedenen politischen und sozialen Trägern unterstützt, u. a. von der niederländischen Regierung, vom Gesundheitsministerium, von Patientenorganisationen und -gruppen, Berufsverbänden sowie Krankenversicherern. Die Notwendigkeit einer Kulturveränderung im niederländischen Gesundheitswesen hat Eingang ins Bewusstsein und die Herzen von Patienten und Fachpersonal gefunden, muss sich aber noch weiter entwickeln. Die Begeisterung für ein solches Vorgehen könnte einen Dämpfer erhalten, wenn partizipative Entscheidungsfindung vereinfacht und dogmatisch definiert und umgesetzt würde, was zur Folge hätte, dass Unsicherheit, Verantwortung und Entscheidungslast auf Seiten des Fachpersonals in unverantwortlicher Weise auf die Patienten übergingen.

## Introduction

Among Dutch government and policy makers a loud buzz is heard around Shared Decision Making (SDM). This buzz has inspired many professionals in daily care. But talking about SDM is not the same as acting according to SDM models. The question is whether the pace quickens towards nationwide implementation.

Researchers had been using direct translations from the English language discourse on SDM, such as “*gedeelde besluitvorming*”, but the *Dutch Federation of Patients' Organisations* has successfully propagated to use the active verb “*samen beslissen*” [making decisions together].

This paper is structured along the following themes: 1) background information on the Dutch healthcare system and a short overview of SDM in the Netherlands, 2) best practices at the national, regional, and local level(s). We summarise the current state of affairs in the Netherlands, and apologise for not mentioning valuable initiatives that we were not aware of or had to leave out due to space limitations.

## The Dutch healthcare system

The Netherlands has an inclusive healthcare system for its 17 million inhabitants. The *Health Insurance Act* from 2006 introduced regulated competition among healthcare providers and among explicitly not-for-profit healthcare insurers. All residents have to choose a health insurance provider, and all health insurers are obliged to cover a basic package of healthcare for every resident, without any restrictions on acceptance. Patients have a freedom of choosing their community-based physician, but once enlisted in a primary care the GP is the gatekeeper for secondary care specialists. In long-term care, patients receive a personalized budget – a voucher – to negotiate with providers about care arrangements and price. The new version of the *Law on the Medical Treatment Agreement* from 1995 is in the final stage of formalisation. It obliges healthcare professionals to inform the patient on pros and cons of the proposed medical option, and gives patients the right to access to their personal medical record. Unauthorized translation: *The healthcare provider clearly informs the patient, tailored to the patient's comprehensive ability, and discusses the proposed investigations, treatment, and health status. The healthcare provider additionally asks whether the patient wishes to receive information in writing, by electronic means, or otherwise, and, if desired, provides this information to the patient, unless this provision of this information cannot reasonably be expected from the provider.*

The Netherlands score number 1 on the *Euro Health Consumer Index* 2016, but are in the top of European countries with the highest costs per capita spent on healthcare [1]. The high quality may be due to 24/7 accessibility to primary care centres. A threat to healthcare accessibility is the individual risk for out-of-pocket costs up to €385 for co-payments for referral to secondary care, and for certain diagnostic exams and pharmaceuticals. This can be increased on voluntary basis, to lower insurance premiums. In 2013, 22% of patients skipped needed healthcare at least once due to high out-of-pocket costs [2]. The number 1 score on the Euro Health Consumer Index made the authors of the report speculate that “*the Dutch healthcare operative decisions are taken, to an unusually high degree, by medical professionals with patient co-participation*” [1]. There is indeed a strong patient participation movement in the Netherlands, at least at the macro and meso levels. Patient representatives are increasingly involved in setting national research agendas, developing clinical practice guidelines, making coverage decisions by the *Dutch Council of Health Insurances*, and advising hospital boards. But what about the micro-level of the clinical encounter? In 2011 we reported that patient participation at the micro level (SDM) in the Netherlands was not yet ready for nationwide implementation, despite some progress in the previous years. There was a need for concerted action on educating professionals, empowering patients, and making high-quality patient decision aids publicly accessible [3].

## What has happened since 2011?

The ISDM 2011 conference in Maastricht contributed to increased awareness on the urgency and complexity of SDM [4,5]. This was further enhanced by the considerable attention being given to SDM by the governmental advisory board propagating SDM [6] and at the 2014 EACH conference held in Amsterdam [7]. Currently, SDM is on the agenda among target patient representative groups, policy makers and, most importantly, professional bodies. We have clinical opinion leaders making the case for implementation of SDM in the heart of medicine, e.g. by publishing a book on SDM in lay language for both clinicians and patients [8]. Although ISDM 2011 generated a positive boost [9] and professional bodies call for a coaching role of clinicians in their 2025-vision-documents, hesitation was also felt among Dutch clinicians, who are challenged by many new tasks. The value of SDM has been critically questioned in reports and in the two leading medical Dutch journals [10]. Ethical tension is felt by authors who, despite the deliberate indication for SDM in situations of equipoise, fear a dogmatic implementation of SDM for all medical decisions in all

contexts in which patients often feel sick, vulnerable, and dependent, and reflection time is limited [11]. Also, the role of low health literacy in the SDM process is critically addressed [12].

No clear hesitation is seen among patients, with 98% of a national patient panel opting mostly or always for the SDM model [13]. Also, among seriously ill patients a positive attitude was found [14], and patients using *Patient Decision Aids (PtDAs)* were found to choose treatment in accordance with their post-PtDA preference and to a lesser extent to the doctor's preference [15]. Have we reached these patients' needs fully yet? In a survey among lung cancer patients, only 29% of patients reported that two curative treatment options (surgery and radiotherapy) were discussed [16]. In a survey among 732 cancer patients, only just over 50% answered positively on the question "Were you involved in decision-making on the treatment given?" [2,17]. Similarly, if we look at objectified professional behaviour, it does not seem the case yet [18–23]. There is plenty of room for improvement in daily practice, for which many best practices are being designed and increasingly implemented.

## Best Practices

### National level: guidelines, PtDAs, campaigns and research

The *Dutch Ministry of Health* supports and applauds SDM initiatives in the field from an ethical imperative, but a 'choosing wisely' motivation is also explicitly pronounced. 'Choosing Wisely' started in the US in 2012, aiming to avoid wasteful or unnecessary medical tests, treatments, and procedures. Based on Stacey's Cochrane review of PtDA studies showing that patients often choose conservative options, the idea spread quickly that supporting SDM (with PtDAs) would lead to lower costs through "wiser choices". The Ministry of Health called for a culture change, e.g. by financing implementation programs supporting initiatives that target SDM in practice, and by facilitating patient empowerment, e.g. by ensuring that audiotaping the consultation is a patient's right. It also financed the development of a national guidance on quality criteria for the content of patient versions of guidelines and PtDAs, ideally developed in conjunction with clinical practice guidelines (CPGs). The guidance pleads for mutually linked knowledge documents, and national governance on a national patient portal for patient versions of guidelines and PtDAs [24]. Tension like in the USA, where legislation and certification of PtDAs is at stake [25] does not seem to be felt, as so far the Dutch treasure a culture of trust. This guidance fits the already existing national guidance on developing CPGs, which promotes the SDM model as the leading principle in recommendations on preference sensitive decisions. To prevent recommendations in CPGs to be too strongly formulated, the guidance for guideline developers propagates more tolerance towards

uncertainty and equipoise in guideline recommendations, e.g. by applying the GRADE method ([www.gradeworkinggroup.org](http://www.gradeworkinggroup.org)).

There is strong collaboration between the *Dutch Federation of Patients' Organisations*, the *Federation of Medical Specialities*, and the *College of General Practitioners* to implement the mentioned national governance by hosting public available PtDA on national patient portals such as *Thuisarts.nl* and *Zorgkaartnederland.nl*. Two years after the launch of this website with evidence-based patient information and decision aids, GP consultation rate decreased with 12% [26].

PtDAs have been developed in many settings, such as e.g. the field of oncology (screening, treatment and follow-up strategies), elective surgical procedures, cardiovascular diseases, gynaecology and obstetrics, mental healthcare, long term and chronic care (diabetes, asthma, rheumatic and renal diseases), and end-of-life decision making. An exemplary national initiative currently aims to develop PtDAs for use during consultations, the so-called "consultkaarten" [Consultation Cards], inspired by, amongst others, Giguères Decision Boxes [27] and Elwyn's Option Grids [28]. This being a positive trend, the need for national governance is felt strongly, as many initiatives co-exist of collaborations of patient organisations or (subgroups of) professional bodies with small and medium-sized enterprises. This has resulted in an uncoordinated, partly overlapping mixture of publicly and commercially available PtDAs. For example the company that designed web-based PtDAs exploits these in a business model of hospital departments subscribing to receive in-log codes for patients.

The *Ministry of Health* has announced the use of a specific registration code to finance the extra time that is needed for SDM during consultations per 1 January 2018. Such a code is already in place for extra time needed for communication about advanced care planning and palliative care in the last phase of life. Many governmental efforts are aimed at implementation of SDM, often combined with research. Through the Healthcare Institute the Ministry finances grants on improving transparency and patient-centredness, including SDM, with €5 million per year for 5 years, while the *Netherlands Organisation for Health Research and Development* currently finances around €2 to 3 million distributed over various research calls. The first implementation projects have started, e.g. digital PtDAs platform for SDM in mental healthcare, implementation of SDM in 24 clinical pathways in 12 hospitals, implementation of SDM in stroke care. Within these calls there is a strong movement forward towards patient participation in research: researchers should include patients and patient representatives in the planning and execution of SDM research.

The *Dutch Federation of Patients' Organisations*, launched a national campaign together with the *Federation of Medical Specialities* called "Betere zorg begint met een goed gesprek" [improved care starts with a good conversation], to improve awareness of

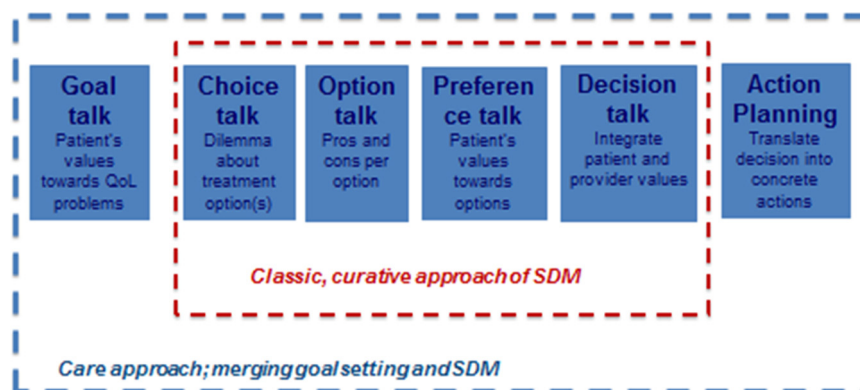


Figure 1. Model for shared decision making in cure and care situations, merging goal setting with SDM (See also Ref. [40]).

SDM among both patients and clinicians (begineengoedgesprek.nl). Secondly, they launched “Ask3Questions” to provoke SDM conversations, based on Shepherd’s work [29]. A strategy was chosen in which both patient organisations and hospitals stimulate patients to ask the three questions. Once a patient has been scheduled

for an appointment at the polyclinic, the patient receives instruction on the three ‘good questions’ by email. It is estimated that almost half of the hospitals are currently working according to “Ask3Questions” to some extent. Implementation in primary care has recently started as well. Thirdly, the *Dutch Federation of Patients’*

**Table 1**  
Overview of best practices on different ecological levels, aimed at specific barriers (H = healthcare professional, P = patient).

	Barrier	Action
<b>The innovation (SDM and PtDAs)</b>		
H	Unclear concept, lack of uniform language Unattractive concept for biomedically oriented clinicians  Low quality PtDAs	Accredited e-learning for professionals and patients. Deliberately introduction of SDM in the slipstream of personalised medicine, as a Trojan horse. Clinicians, epidemiologists, and SDM researchers investigate the integration of prediction models in a responsible way into PtDAs: from ‘one size fits all’ to tailoring based on medical evidence as well as user preferences. National guidance containing quality criteria. Growing expertise among professionals, patient representatives and Industrial designers.
<b>The users</b>		
H	Negative attitude “My patients are not competent for SDM” Lack of awareness on suboptimal performance “I do perform SDM” (optimistic bias)	Instruction on evidence underlying Ask3Questions campaign. National campaign <a href="http://www.begineengoedgesprek.nl">www.begineengoedgesprek.nl</a> . Training postgraduate clinicians by means of workplace learning. Audit and feedback, peer review, development of measures for feedback, PREMs.
P	Lack of awareness of equipoise, optimistic bias towards (side)effects of medical interventions Lack of knowledge on SDM, low expectations Lack of knowledge on health situation  Overload of information in PtDAs  Too much uncertainty in population-based estimates used in PtDAs Low health literacy	Patient versions of guidelines, PtDAs linked to guidelines. Ask3Questions campaign. Campaign <a href="http://www.begineengoedgesprek.nl">www.begineengoedgesprek.nl</a> . Open access to electronic patient file, which is already organised in some Dutch hospitals. Design of short decision boxes ( <i>Consulkaarten</i> ). Design of personalised PtDAs, including clinical prediction models, with regard to the relevant options given the patient’s profile and preferences. Design of personalised PtDAs with regard to risk estimates (built-in algorithms from clinical prediction models). Graphical representations to enable goals and preference talk based on ICF and Dialogue Model [32].
<b>Direct social context, team level</b>		
H	Lack of role models  Lack of support by team members  Medical-technical focus in MDT  Lack of clear responsibility for SDM	Train the trainer in implementation projects. Courses for postgraduate trainees. Interprofessional education, clear assignment of chair of multidisciplinary teams (MDT), and of case manager. Redesign of MDT meetings with indication setting for PtDA, registration of individualised care plan in electronic patient file, checklist with strategies to enhance patient centredness. Timing of talking about options with PtDA is designed in clinical pathway, with clear task delegation.
P	Fear to be judged as awkward patient  Lack of time for reflection due to high-speed clinical pathway  Lack of support in deliberation at home	Ask3Questions Campaign. Audiotaping the consultation. Downgrading the fast track clinical pathways by time-out conversation with GP ( <i>‘Kiesgerust gesprek’</i> , or by distributing option talk and decision talk over two consultations. The time devoted to the physician–patient encounter of ~10 minutes per patient is a major system barrier. Paradoxically, the smooth clinical pathways in oncology are patient-centred regarding waiting times, but are for some patients experienced as being too fast, hindering critical reflection on difficult decisions. Audiotaping discussion at consultation.
<b>Local or regional organisation</b>		
H	Wrong timing of SDM  Lack of support by management  Lack of feedback on performance  Lack of financial incentives	Delegation of SDM to primary care; instead of referring the patient with gonarthrosis to orthopaedic surgeon the GP discusses the pros and cons of elective knee surgery using a PtDA. Implementation of SDM in 12 hospitals with explicit management support. Hospital directors sign the Salzburg Statement. OPTion5, SDMQ9, Collaborate. Patient federation, professional bodies and insurance companies collaborating to define valid indicators. Insurers negotiate on care contracts based on SDM performance.

Organisations coordinates patient participation in the development of patient decision aids together with scientific associations representing medical specialists.

Much effort also has been spent on *validation of Dutch language versions of measurement instruments* such as Option 5, SDM-Q-9, and Collaborate [30,31] or subscales of regret [32]. Parallel to this, generic quality indicators for patient involvement are being validated by representatives of patients, providers, and insurers. Specific questions are integrated in short *Patient Reported Experience Measurements (PREMs)*, e.g. on hospital care. Patients could answer on 5 points Likert scales (the higher the better) on questions such as "Did the healthcare provider inform you about the pros and cons of the treatment?" (mean score 4.28), "Were you involved in decision making about the treatment by the providers?" (mean score 3.76). In the validation study the PREM was sent within 3 months of hospitalization to over 12500 patients aged >16 years in 17 hospitals. The response rate was low, 35%. If data are gathered of at least 200 patients per hospitals it may have discriminative power for internal and external quality assurance, once adjusted for case mix on gender, age, general health and educational level [33].

*Healthcare insurers*, e.g. CZ Health Care Insurance, take initiatives to actively stimulate SDM. Performance on SDM is explicitly on the agenda in the negotiations with hospitals on care contracts. They also propagate *Ask3Questions* to their clients, and actively collaborate with relevant stakeholders for sustainable implementation of SDM.

An interesting innovation within and between professional bodies is the merging of the SDM and goal setting models, especially in primary, paediatric, elderly, rehabilitation, and mental care, for *patients in need of chronic or complex care*, see figure 1 [34–37]. Also interprofessional teams are opening up towards SDM [38]. The SDM model predominantly seems to have arisen in cure situations in hospital settings, and thus may fall short in more complex care situations. An additional preceding step with shared goal setting – *goal talk* – seems justified. Every time again, for each decision knot the clinician and patient first prioritise the most urgent problems and the patient's goals for quality of life, before decisions are taken on how the problems are to be managed and how the patient's goals are to be reached. Graphical tools have been developed to support goal talk, based on the *WHO International Classification of Functioning, Disability and Health (ICF)*. This resonates with a new perspective on how to define health. It is known in the Netherlands as 'positive health'; the ability to adapt and to self-manage, in the face of social, physical and emotional challenges [39]. The WHO definition of health stemming from 1948 'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' was considered no longer adequate.

According to the authors of these complex care models, the intensity of SDM differs per patient and per context. One could use the metaphor of the DJ mixer with sliding knobs such as a volume fader. Clinicians strive for a patient centred dialog in any consultation, be it on screening, diagnosing, counselling, treating or palliation, with the sliding knobs for SDM being fully open in some (parts of the) consultations, and only slightly in others. In many complex care situations the SDM skills are basically switched on with continuous adjustment of the intensity to the context.

Finally, *training and education* have had an important impetus by local programs being spread to regional and national levels. As an example, a SDM training for residents and their supervisors, developed at the *Leiden University Medical Center*, and the accompanying E-learning for SDM is implemented in various other national initiatives. Most of the implementation activities mentioned above include some form of skills training for clinicians. Coordinated by *Maastricht University* national consensus is currently sought on so-called 'entrustable professional activities' (competences), which

will be used as basis for design of workplace learning for GP trainees on SDM. The *Dutch Platform for SDM*, established at Maastricht ISDM 2011 conference, provides an overview of SDM education at (para)medical curricula.

#### Regional and local level

For reason of comprehensiveness some inspiring best practices at the local and regional levels are only briefly reported in [Table 1](#). [Table 1](#) is summarising the best practices structured along the most relevant barriers for change in the Netherlands.

#### Conclusion and recommendations

There is a growing number of initiatives that really target implementing SDM, such as e.g. central governance of PtDAs, post-graduate training, collaborative learning in 12 of the 80 Dutch hospitals and a national campaign on Ask3Questions. This is explicitly supported by the Dutch government, the Ministry of health, the Federation of Patients' Organisations, professional bodies and health insurers. We believe that combining the efforts and experiences into a 'movement' that intervenes in both behaviour in daily practice (including education) and system factors, will be essential for the success of the implementation of SDM in the following years. The culture shift in the minds and hearts of patients and clinicians has started but is still ongoing. Enthusiasm for this way of working could be undermined if SDM is defined and implemented in a simplistic, dogmatic manner. The question is how much uncertainty professionals and patients can tolerate in our guidelines and dialogues, and how we can prevent the paternalistic default model from evolving into the other extreme, the informed patient model ("here is the information on the options, let me know what you decide"), with irresponsible transferring of the professionals' uncertainty, responsibility, and decisional stress to patients. We cannot do choice and option talk, without goal and preference talk.

#### Conflict of Interest

None declared.

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