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## Shared decision-making in the Netherlands

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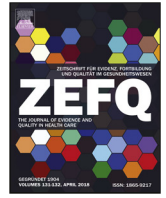
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## Shared decision-making in the Netherlands: Progress is made, but not for all. Time to become inclusive to patients



*Partizipative Entscheidungsfindung in den Niederlanden: Es gibt Fortschritte, aber nicht für alle – Zeit, die Patienten zu beteiligen*

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### ABSTRACT

Dutch initiatives targeting shared decision-making (SDM) are still growing, supported by the government, the Federation of Patients' Organisations, professional bodies and healthcare insurers. The large majority of patients prefers the SDM model. The Dutch are working hard to realise improvement in the application of SDM in daily clinical practice, resulting in glimpses of success with objectified improvement on observed behavior. Nevertheless, the culture shift is still ongoing. Large-scale uptake of SDM behavior is still a challenge. We haven't yet fully reached the patients' needs, given disappointing research data on patients' experiences and professional behavior. In all Dutch implementation projects, early adopters, believers or higher-educated persons have been overrepresented, while patients with limited health literacy have been underrepresented. This is a huge problem as 25% of the Dutch adult population have limited health literacy.

To further enhance SDM there are issues to be addressed: We need to make physicians conscious about their limited application of SDM in daily practice, especially regarding preference and decision talk. We need to reward clinicians for the extra work that comes with SDM. We need to be inclusive to patients with limited health literacy, who are less often actually involved in decision-making and at the same time more likely to regret their chosen treatment compared to patients with higher health literacy.

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### ZUSAMMENFASSUNG

Die Zahl der niederländischen Initiativen zu partizipativer Entscheidungsfindung (PEF) nimmt stetig zu. Unterstützung erfahren diese Initiativen von der Regierung, von der Vereinigung der Patientenorganisationen, von Berufsverbänden und Krankenversicherern. Die große Mehrheit der Patienten bevorzugt das PEF-Modell. Die Niederländer arbeiten hart an einer besseren Umsetzung von PEF im klinischen Alltag, und erste Erfolge zeigen sich an objektivierten Verbesserungen im beobachteten

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**Schlüsselwörter:**

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 Implementierung

Verhalten. Und dennoch: Der Kulturwandel dauert noch an. Die Aneignung von PEF-Verhalten auf breiter Basis stellt nach wie vor eine Herausforderung dar. Angesichts der enttäuschenden Daten zu Patientenerfahrungen und ärztlichem Verhalten ist es noch nicht vollständig gelungen, den Bedürfnissen von Patienten gerecht zu werden. In allen niederländischen Implementierungsprojekten sind die Innovationsfreudigen, die Überzeugten oder besser Gebildeten überrepräsentiert, während Patienten mit begrenzter Gesundheitskompetenz bislang nur schwach vertreten sind. Das ist ein Riesenproblem, da 25% der erwachsenen Bevölkerung in den Niederlanden über eine nur begrenzte Gesundheitskompetenz verfügen.

Um PEF weiter auszubauen, müssen folgende Probleme angegangen werden: Wir müssen den Ärztinnen und Ärzten bewusst machen, dass sie PEF im Praxisalltag nur unzureichend umsetzen; dies betrifft vor allem die Phasen von Konsultationsgesprächen, in denen es um Präferenzen und Entscheidungen geht. Wir müssen die mit PEF verbundene zusätzliche Arbeit von Ärztinnen und Ärzten vergüten. Wir müssen dafür sorgen, dass Patienten mit begrenzter Gesundheitskompetenz, die in die medizinische Entscheidungsfindung tatsächlich seltener einbezogen sind und gleichzeitig die von ihnen gewählte Behandlung eher bereuen als Patienten mit höherer Gesundheitskompetenz, besser eingebunden werden.

## Introduction

During the last decade, the narratives on shared decision-making (SDM) have been changing in the Netherlands. Currently, the active verb “*samen beslissen*” [to decide together], initiated by the *Netherlands Patients Federations*, is most frequently used. An overview of SDM-narratives showed that a unified view on what SDM is, is still lacking [1]. We keep working on the definition of SDM. In this paper, we use the terms ‘choice talk, option talk, preference talk, and decision talk’ to refer to the four steps as shown in [Figure 1](#).

Since January 2020 SDM is explicitly mentioned as a prerequisite during doctor-patient encounters in the Dutch law on the medical treatment agreement (WGBO). The healthcare professional has the legal duty to introduce the option of abstaining from a medical intervention, and to explore the patient’s preferences [2].

Despite this strong legal emphasis on SDM we still need concerted action to keep the SDM buzz ongoing, as a quality assurance system with a valid and acceptable performance indicator is lacking [4].

## Background of the Dutch healthcare system

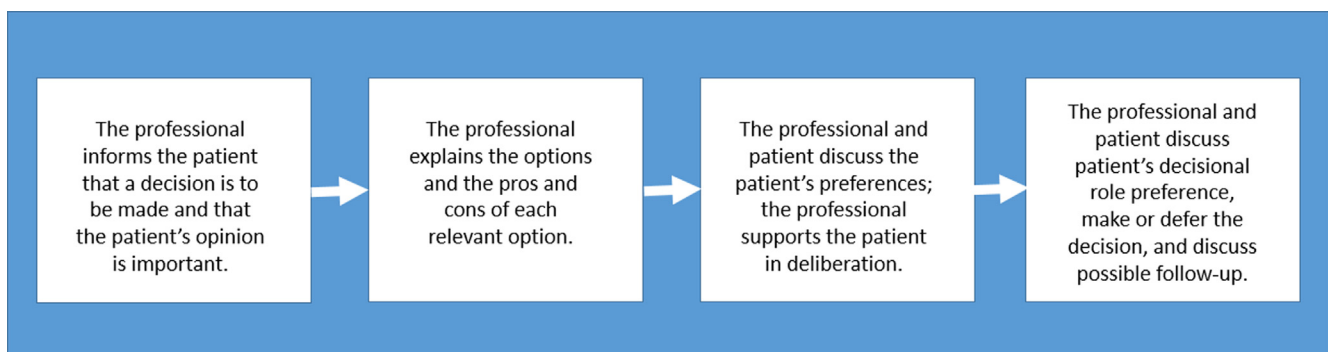
Healthcare in the Netherlands is mainly financed through compulsory health insurance contributions from citizens, with additional funds from general taxation. The not-for-profit health insurance providers provide coverage for all types of care. Most hospitals are independent not-for-profit organisations. All citizens have to choose a health insurance provider, and health insurers are obliged to cover a basic package of healthcare for every citizen, without any restrictions on acceptance. Patients are free to choose their general practitioner (GP), who provides 24/7 access to primary care. The GP is the gatekeeper for secondary care specialists. The citizen

may be faced with a deductible of €385 for care other than that of the GP. This amount can be increased on voluntary basis, to lower insurance premiums. For individuals receiving long-term care outside of the hospital, a personalized budget – a voucher – is available to negotiate with providers about care arrangements and price.

There is strong commitment to SDM from the *Ministry of Health* inspired by its critical reflection on how evidence based practice guidelines had been applied so far in practice as “cookbook medicine”, leaving relatively little room for a tailor-made approach to individual patient care. As an added benefit, the government hoped that encouraging SDM would lead to lower costs. There is a strong patient participation movement in the Netherlands 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.

## State of the art of SDM in the Netherlands

The Netherlands has made progress in promoting SDM, benefiting from strong ministerial leadership and good collaboration between patient and professional bodies. Currently, SDM is set high on the agenda among target patient representative groups, professional bodies, educators, and policy makers. Many best practices are being designed and increasingly implemented, such as national campaigns to empower patients, the development of patient decision aids in conjunction with clinical practice guidelines, postgraduate training, collaborative learning and system changes. There has been impressive progress in some clinical areas, in particular mental health care, primary care, maternity care, and long-term and palliative care [5]. Much attention is now given to getting SDM embedded into hospital specialties.



**Figure 1.** The structure of the SDM conversation [3].

### Issues and concerns at the policy and educational levels

Along with the new WGBO law, the *Ministry of Health* has tried to support extra time needed for SDM during consultations per 1 January 2018. The healthcare insurance companies have defined that extra time for SDM can be registered by using a certain code in the declaration system. ‘Extra time’ is defined by minimally twice the standard consultation time, which may take the format of an additional consultation with a physician or nurse. In practice, however, this code does not seem to function. The clinicians cannot clearly pinpoint the doubling of consultation time, as SDM is often distributed over various consultations during the clinical pathway. So far, the code has not led to financial rewards of SDM.

Although developers of clinical practice guidelines are becoming increasingly aware of the need to acknowledge preference-sensitivity in their recommendations, current Dutch guidelines do not sufficiently phrase this in their recommendations [6]. In addition, clinicians experience information overload, which is not addressed effectively by developing numerous unclearly defined knowledge tools. We found 67 different tool types, such as guidelines, protocols, clinical pathways and patient decision aids (PtDA), available to Dutch clinicians and patients [7].

The *Federation of Medical Specialists* and the *Federation of Nurses* have launched a set of competencies for SDM [8], echoed in the updated qualifications for the medical educational curriculum. SDM is frequently mentioned in the bachelor and master programs in healthcare [9]. However, in only 24% of the 78 curricula for medical students, nurses and postgraduate medical trainees, SDM was specifically addressed [10].

### Issues and concerns at the level of patient empowerment

Figure 2 shows a stable state of the patients’ subjective experience of SDM (SDM-Q9) in a random sample of health care consumers who were asked to reflect on the most recent consultation with a clinician (n = 1500) [11]. Another source shows more in-depth results: patients (n = 781) visiting a medical specialist in a representative Dutch hospital were asked to indicate their perceived and experienced decision-making roles by means of the Control Preference Scale. It showed room for improvement as 21% of patients preferring SDM did not experience SDM [12].

There has been good progress in producing PtDAs, and there is an increasingly positive attitude towards encounter PtDAs [13], but a national plan for implementation is missing. Available PtDAs are not being systematically used. When used, professionals use PtDAs as easy tools to inform patients, instead of using them for SDM [14]. Even if the focus is on systematic use of PtDA for one specific decision, we face insufficient uptake. In a large implementation study, 33 hospitals aimed to use a prostate cancer PtDA. Overall, PtDA uptake was 40% [15]. Another study in eight hospitals showed more encouraging results, with an implementation rate of 60% [16]. We still have a scattered supply of PtDAs through

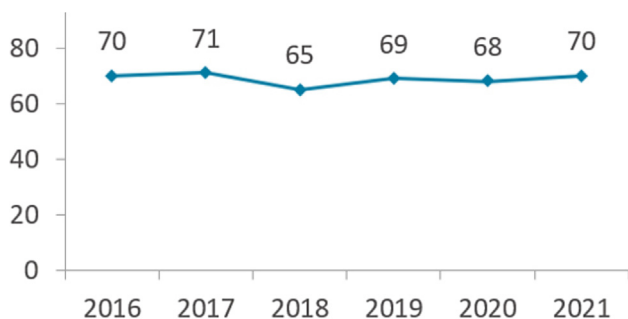


Figure 2. Experience of SDM among a panel of Dutch healthcare consumers [11].

various platforms, some of which are not open access. So far, the stakeholders have not succeeded in choosing one easily accessible patient portal for PtDAs. Finally, a systematic analysis of all, mostly digital, Dutch PtDAs (n = 202) revealed that less than 2% of these PtDAs were truly understandable for patients with limited health literacy [Richter, to be submitted].

The government program *Healthcare Evaluation and Appropriate Care* (Zorg Evaluatie en Gepast Gebruik) may stimulate the use of PtDAs, since for many hospitals these are a way to fulfill requirements for this recently started obligatory program. Another facilitator is the fact that there are two major commercial decision aid developers – Zorgkeuzelab© en Patient+©, that have become well known. Co-creating PtDAs together with the lower educated end users has just started in the Netherlands. We need to realize though, that empowering patients through PtDAs is only part of the solution, since these aids will not be available for all possible decisions, and will not be used by all patients. Moreover, for complex decisions, looking for other solutions remains important, such as using service design to provide patients with a better overview of their care paths and its decision making moments and improve information provision [17].

### Issues and concerns at the level of implementation in routine practice

The findings reported in Figure 2 on patients’ subjective experience of SDM may be looked upon critically if we study objective behavior. Analysis of video-recorded encounters of 781 patients in consultation with 41 specialists from various disciplines showed an overall low level of patient involvement (mean OPTION5 scores 16.8, SD 17.1, scale range 0–100) [18]. The study suggested incompetence in SDM, of which specialists were unaware. This was also found in implementation studies in oncology. Although clinicians often discuss different options with pros and cons, they hardly ever elucidate patient preferences or apply these in reaching a decision [19–20]. A similar concern is SDM in patients presenting complex problems, e.g. due to multimorbidity. Goal setting and prioritizing the main problem to be decided upon together with the patient is not yet widely recognised by clinicians as a core aspect of the SDM approach [21].

We also see room for improvement in team decision making. Systematic observations of oncology multidisciplinary team meetings revealed limited use of patient-centred information, such as (age-related) patient characteristics and patient preferences during the decision making process. Decision-making was mostly based on medical technical information [22–23]. Multidisciplinary team members themselves voiced the need for additional patient-centered information during their team meetings and the need for alternative team decision-making strategies e.g. not aiming for consensus on a recommendation of one single option in complex cases [24]. To improve SDM in oncology care paths we have to recognize that decision-making is an unpredictable process with many decision moments, that are often unannounced, which hinders patient participation in decision-making [25].

### Examples of best practices of policy and education, empowerment of patients, and implementation in routine practice.

#### *Policy and educational efforts to implement SDM into the national health care system*

The *Dutch Ministry of Health* is increasingly investing in a parallel boost of value-based health care and SDM. It does so by programming €70 million over the period 2018–2022 to integrate SDM in using patient-reported outcome measures (PROMs) in rou-



tine medical encounters [26]. Patients and professionals were generally positive about using PROMs during medical consultations, although fast largescale implementation is not expected. In practice, clinicians were interested in feedback from PROM results, but hesitated to use it in the consultation. Professionals thought patients should take the initiative in discussing PROMs, whereas patients thought professionals should do so [27].

Grants from the Healthcare Institute to improve transparency and patient-centredness, including SDM, amount to €5 million per year for 5 years. The *Netherlands Organisation for Health Research and Development* finances various research calls on implementation of SDM, e.g. in palliative care and in elderly care. This has e.g. resulted in development of PtDAs that can be used in both primary and secondary care, and made available in a national patient portal *Thuisarts.nl*.

The *Dutch Ministry of Health* also financed the development of a national guidance on quality criteria for the content of patient versions of guidelines and PtDAs [28], the latter based on the existing international IPDAS criteria [ipdas.ohri.ca]. This guidance complements the already existing national guidance on developing guidelines, which promotes the SDM model as the leading principle in recommendations on preference-sensitive decisions. National consensus was reached on a core set of types of knowledge tools that support clinicians and patients in knowledge translation, (shared) decision-making and quality improvement; and to agree on the definitions of these types of tools [29].

There is strong collaboration between the *Netherlands Patients Federations*, professional bodies of clinicians and policy makers to implement SDM. They have agreed in the so-called ‘*hoofdlijnenakkoord*’ (general agreement) to support the implementation of SDM. In 2021, no less than 23 national bodies such as the *Netherlands Patients Federations*, the professional bodies of doctors and nurses, and the healthcare insurers, launched a national campaign “*Begin een goed gesprek*” [Start a good conversation].

A number of educational studies inform us on how to best organise the undergraduate and postgraduate SDM education. It is known that complex skills such as SDM are best learned in a longitudinal fashion with ample practice in an authentic setting, so-called workplace learning. Confrontation with one's own behavior initiates the learning process and should be supported by meaningful feedback through direct observation [30–31]. Training physicians in SDM will only be effective if they are made aware of their limited application of SDM in daily clinical practice. Many Dutch physicians are in the stage of being unconsciously incompetent in SDM, making them unfit to teach SDM to residents and medical students [18]. As a basis for the design of workplace learning for postgraduate training on SDM, national consensus was found on so-called ‘*entrustable professional activities*’ (competences) comprising 18 behavioral SDM indicators [32].

It is important to engage volunteer patients in undergraduate education [33]. At one of our universities patients share their experience with undergraduate students in small group work [34].

#### *Efforts to empower patients*

In many university hospitals, the so-called “three good questions” (what are my options; what are the risks and benefits related to these options; and what does this mean for my situation?) have been implemented to empower patients. Garvelink et al 2019 invited 319 patients to complete a questionnaire, of which 138 patients responded after implementation. One-third (35%) of the respondents remembered to have heard of the “three good questions”. Half of these patients (52%) had used all three questions [35].

To promote SDM for patients with colorectal carcinoma a “time-out consultation” with the GP was organised before start

of treatment. Six topics of discussion were proposed for these consultations: (a) Do I really want to be treated? (b) Is this the right hospital for me? (c) Did I understand all information correctly? (d) What are the consequences of the proposed treatment? (e) Can I continue working? (f) Do I need support at home? The act of making the appointment was left to patients and GPs. This was evaluated in a pre-post questionnaire study, in which 72 patients before and 98 patients after the introduction of the time-out consultation participated. Informing patients about the time-out consultation increased contacts between patients and their GP from 67% to 80%. Especially elderly and palliative care patients seemed to benefit [36].

#### *Efforts to implement SDM in routine practice*

Table 1 describes a list of best practice examples. Four examples have in common that the implementation of SDM was evaluated on choices made and costs. Three of these examples led to significant changes in decisions made and/or cost reductions [37,39,40]. Such impact on decisions made and costs were not seen in the study in primary care, the only one with a robust design for evaluation [38]. The findings on reduced costs have to be interpreted with caution, as quasi-experimental or retrospective designs were used. The last example about implementation of SDM in two local hospitals is at the heart of the current national debate on how to control healthcare costs. In a natural experiment, Bernhoven and Beatrix hospitals, experienced a 13% and 7% reduction of care and thereby turnover, respectively, which seems to be at least partly related to the implementation of SDM [48].

The last four examples of best practices aim at improving the process of SDM, one of which in elderly care and three in oncology.

In these studies referred to so far, early adopters, believers, or highly educated persons were overrepresented, while the patients with limited health literacy (LHL) were underrepresented. In general, patients with LHL are people with a lower educational level and lower social economic status [49]. Health literacy entails people's knowledge, motivation and competence to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life [50]. Patients with LHL experience difficulties in finding information, understanding information in consultations, asking questions and expressing their needs and preferences [51–53].

The option step of SDM is challenging if we try to involve patients with LHL in decision making in the complex reality of daily practice [54]. Verbal labels to describe risk estimates in decision encounters are less helpful to patients with LHL, but still frequently used [55]. The use of graphics may support verbatim and gist understanding in these patients [56]. But, we need to use the appropriate graphs as e.g. infographics of hypothetical cardiovascular risk information had detrimental effects on risk comprehension [57]. Also, preference talk seems challenging for many patients with LHL. Limited health literacy was significantly related to less participation in value clarification exercises with elderly patients with multimorbidity [thesis Pel Littel].

#### **Conclusion and recommendations**

The Dutch initiatives targeting SDM are still growing, supported by the Dutch government, the Federation of Patients' Organisations, professional societies and healthcare insurers [58]. Although we do see glimpses of success measured with objectified improvements on observed behaviour, the culture shift in the minds and hearts of patients and clinicians is still ongoing. As more extrinsic incentives are deployed to stimulate SDM, additional attention is

**Table 1**  
Efforts to implement SDM in routine practice, list of examples.

Study	Setting and decision at stake	Implementation strategies	Evaluation
<b>Improving the process of SDM aimed at impact on choices made and costs</b>			
The importance of parental counselling approach [37]	Pediatric care regarding palivizumab prescription for respiratory syncytial virus immunization in 198 patients.	Aimed at patients. Only in the first hospital a parental counselling approach was applied. Palivizumab prophylaxis was presented as a preference-sensitive decision including risk communication on treatment burden,	Observational study. The parental counselling approach was related to more conservative choices as compared with a 2 <sup>nd</sup> and 3 <sup>rd</sup> hospital. Prescription rates varied considerably between the three hospitals: 8% (6/64), 89% (32/36) and 99% (97/98).
SDM with patients suffering from non-chronic low back pain [38]	68 GPs and 226 patients	Aimed at physicians. SDM consultations supported with a PtDA. The decision reached was followed by positive reinforcement of the chosen therapy. GPs in the intervention group received two small group training sessions of two and a half hours.	A clustered randomised controlled trial was performed. Although patients in the intervention group reported more involvement in decision-making, no significant differences in any of the clinical outcomes were observed between intervention patients and controls during the follow-up.
Improving SDM in oncological teams [39]	oncological teams and 184 oncogeriatric patients	Aimed at teams. A nurse-led geriatric assessment including preference-talk. The multidisciplinary teams subsequently formulated a treatment proposal based on tumor characteristics, patient preferences, and estimated life expectancy.	For 25% of the patients (46 out of 184), the treatment advice was modified by the oncogeriatric tumor board, mostly to a more conservative intervention, in comparison with the recommendation made in the regular tumor board. There was no significant difference in one-year mortality between the unchanged and modified group. Moreover, the modified group patients had fewer complications (13.3% versus 35.5%) and spent significantly fewer days in hospital (median 5 vs 8.5 days).
The Bernhoven hospital case [40–42]	A local hospital aimed to improve quality of care in general and to decrease healthcare costs, in collaboration with two healthcare insurers.	Aimed at the entire hospital. Key drivers of the strategy were taking time for integrated diagnosis ('first time right diagnosis'), the right care at the right place, and SDM. Various strategies for implementation have been used, such as e.g. PtDAs.	A pre-post evaluation in the surgical outpatient clinic for patients with gallstones or inguinal hernia showed that implementation of PtDAs was associated with high use of the PtDAs (provided to 60% of the patients, of whom 80% used it) and a 12–15% reduced rate of elective operations.
<b>Improving the process of SDM</b>			
Improving the SDM process in elderly care [43]	Two outpatient geriatric clinics, 9 pediatricians, 216 older patients with multiple chronic conditions, 133 caregivers	A training for geriatricians including how to explore personal goals related to quality of life. A preparatory tool for older adults including encouragement to share information about daily and social functioning and exploration of possible goals. The interventions were developed through a process of co-creation.	In a pragmatic trial objective analysis of audiotaped consultations showed significant improvement of 5 out of 7 SDM elements (OPTION-5mcc, adapted from OPTION5), especially with regard to discussing goals.
Improving subjective experience of SDM among oncological patients [44]	Oncology; 20 surgeons recruited 94 patents for inclusion before and after implementation.	Surgeons and nurse specialists treating elderly oncological patients were trained about frailty and geriatric screening (nurses), and in applying SDM (surgeons) in four sessions of 2–3 hours.	Only four surgeons consulted patients (n = 19) before and after (n = 19) training. These were included in the analysis. Subjective patient reported experience, measured by SDM-Q9, changed in the desired direction.
Improving SDM performance in oncology [45]	31 oncologists and 194 patients	A SDM communication skills training, consisting of a reader, two group sessions, a booster session, and a consultation room tool (10 hours). A communication aid for the patient consisting of education on SDM, a question prompt list, and a value clarification exercise.	The oncologists (were randomized to receive the training or no training. The patients were randomized to receive the patient communication aid or not. The oncologist training had a large positive effect on observed SDM measured by audio-recorded consultations (OPTION-12, expressed on a 0–100 scale, improved from 30 to 50).
Improving SDM performance in oncology [46–47]	11 breast cancer teams in 6 hospitals	The SDM implementation program consisting of practical examples, handy cards, interdisciplinary team training and personal and team feedback based on audio-recorded consultations.	Consultations of 139 patients were recorded, resulting in 80 before and 59 recordings after implementation. Mean OPTION-5 scores, expressed on a 0–100 scale, increased from 38 to 53 one year after implementation

needed to nurture the intrinsic motivation of clinicians as this is a success factor for the required behavioral and cultural change.

Enthusiasm for this way of working could be undermined if SDM is implemented in a simplistic manner without making physicians conscious about their limited application of SDM in daily clinical practice, especially regarding preference and decision talk. Further, we need to prevent the paternalistic default model to evolve to the informed patient model ("here is the information on the options, let me know what you have decided"). We also need to extend the work of phrasing recommendations in clinical practice guidelines towards preference-sensitivity, we need to move away

from a reimbursement system that incentivizes interventions to one that incentivizes SDM.

Finally, let us face the biggest challenge. SDM, already being a complex concept, is complicated by the fact that 25% of the Dutch adult population has limited health literacy [59]. We need to be inclusive to patients with LHL. They are more likely to regret their chosen treatment afterwards compared to patients with higher health literacy [53]. Although patients with LHL are motivated for SDM [52], they are less often actually involved in decision-making [60–61]. Clinicians find it difficult to appraise the patient's capacity to be involved in decision-making and therefore often do

not involve patients with LHL to begin with [62], or misinterpret a passive role in the communication as disinterest [51]. At the same time, physicians often overestimate the health literacy of patients, use communication that is too complicated, and do not actively check whether the patient understands the information [63]. It is time to address the elephant in the room and become inclusive to all patients.

### Conflict of interest

None of the authors has financial conflict of interest, except perhaps for Haske van Veenendaal, who is doing a PhD on implementation of SDM and running a consultancy bureau in training in SDM.

### CRedit author statement

All authors' have had an individual contribution in commenting on, in total six, earlier and final versions of the draft paper. Comments were given on how to structure the draft, how to interpret the results of our implementation efforts, or how to formulate the conclusion and recommendations. Most co-authors provided the first author with additional sources and references. All co-authors have approved the revisions made along the comments of the editor.

The first and last author have been working as researchers on the concept and implementation of SDM for decades. The other co-authors represent the important stakeholders in the implementation of SDM in the Netherlands. Therefore, all authors have an intellectual conflict of interest in having this paper published, being believers in or supporters of SDM.

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