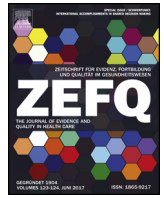




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Special Issue / Schwerpunkt

Implementing shared decision making in Denmark: First steps and future focus areas

*Die Implementierung von partizipativer Entscheidungsfindung in Dänemark: erste Schritte und künftige Schwerpunkte*Karina Dahl Steffensen^{1,2,3,*}, Vibe Hjelholt Baker⁴, Mette Marianne Vinter⁵¹ Centre for Shared Decision Making, Lillebaelt Hospital, Vejle, Denmark² Department of Oncology, Vejle, Lillebaelt Hospital, Vejle, Denmark³ Institute of Regional Health Research, University of Southern Denmark, Odense, Denmark⁴ Knowledge Centre for User Involvement (ViBIS), Copenhagen, Denmark⁵ The Danish Cancer Society, Copenhagen, Denmark

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ABSTRACT

What about the political climate?

Although there is no explicit description of patient involvement in Danish legislation, patient-centred care is on the political agenda in Denmark. It is integrated as one of eight new national indicators of quality in health care, as well as in the most recent national plan for cancer treatment.

What about tools for patient decision support?

Development of evidence-based patient decision aids (PDAs) are still at an early stage in Denmark, but recent national and private funding has helped push the field forward. Furthermore, a few stakeholders have started working more systematically with developing and testing PDAs in clinical settings.

What about implementation?

There is growing interest among Danish health care professionals, but SDM is still far from standard practice in Denmark. Although some courses in SDM and use of PDAs now exist, few health care professionals have received systematic training, and there is little knowledge about implementation and sustainability of SDM in daily clinical practice.

What does the future look like for SDM in Denmark?

Future progress will depend on the extent to which SDM is systematically integrated in the daily routines of health care professionals and in patient trajectories across treatment courses. The Danish health care system needs to invest further in training and to start addressing the challenges on the organisational and system level, which affect implementation.

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ZUSAMMENFASSUNG

Wie steht es mit dem politischen Klima?

Obwohl die Patientenbeteiligung in der dänischen Gesetzgebung nicht explizit niedergelegt ist, steht die patientenorientierte Versorgung in Dänemark auf der politischen Agenda. Sie ist integraler Bestandteil der acht neuen nationalen Indikatoren für Qualität im Gesundheitswesen sowie des aktuellen Nationalen Krebsbehandlungsplans.

Wie steht es mit Tools für die Unterstützung von Patientenentscheidungen?

Die Entwicklung von evidenzbasierten Entscheidungshilfen für Patienten befindet sich in Dänemark noch im Anfangsstadium, aber aktuelle staatliche und private Fördermittel haben dazu beigetragen, den Prozess voranzutreiben. Darüber hinaus haben verschiedene Interessenvertreter damit begonnen, systematischer an der Entwicklung und Testung von Entscheidungshilfen für Patienten im klinischen Bereich zu arbeiten.

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Wie steht es mit der Umsetzung?

Medizinische Fachkräfte in Dänemark zeigen zwar ein zunehmendes Interesse, aber partizipative Entscheidungsfindung (PEF) ist noch längst kein fester Bestandteil im Praxisalltag. Obwohl bereits einige Kurse in PEF und dem Einsatz von Entscheidungshilfen für Patienten angeboten werden, haben nur wenige medizinische Fachkräfte eine systematische Ausbildung erhalten, und es liegen auch kaum Kenntnisse über die Umsetzung und Nachhaltigkeit von PEF im Klinikalltag vor.

Wie sieht die Zukunft von PEF in Dänemark aus?

Der künftige Fortschritt wird davon abhängen, in welchem Ausmaß PEF systematisch in die täglichen Routinen des Gesundheitspersonals und in die Überweisungswege der Patienten integriert wird. Das dänische Gesundheitssystem muss weiter in die Ausbildung investieren und anfangen, die Herausforderungen, welche die Implementierung von PEF betreffen, auf Organisations- und Systemebene in Angriff zu nehmen.

The Danish healthcare system

Denmark is a high-income Northern European country divided into five regions with a total population of 5.7 million people. The five regions are joined together in the *Association of Danish Regions* and the regional authorities are responsible for funding and administering hospital care in Denmark, as well as coordinating care between hospitals and the primary care sector (general practitioners and various health services offered by local municipalities). The Danish healthcare system is financed through income tax and based on the principle that all citizens must have free and equal access to healthcare – regardless of economic status, relation to the labour market or personal insurance situation. A number of councils and boards refer to the *Ministry of Health*, including the *Danish Health Board*, which has overall responsibility for information, prevention and treatment in the Danish health care system.

Legislation and political climate

The principle of informed consent was introduced into the Danish health care legislation in the middle of the 20th century. The *Danish Health Act* states that the patient must receive complete information about their treatment and explicitly consent to receive it, but so far, no further legislative efforts have been made to strengthen involvement of patients and relatives in treatment decisions.

However, in the last few years, patient-centred care has been put on the national political agenda, including the use of *Patient Reported Outcomes* (PRO) and *Patient Decision Aids* (PDAs) [1]. This national political ambition has now permeated the regional policy level; the *Association of Danish Regions* is now collaborating with patient organizations and other relevant stakeholders to strengthen user involvement in the health care sector [2]. The Danish government and the *Association of Danish Regions* have recently launched eight national quality indicators to monitor quality and progress in the health care sector [3], of which one is involvement of patients and family members in treatment and care.

Furthermore, a new national cancer plan – *Cancer Plan IV - The Patients' Cancer Plan* – launched by the government and the *Ministry of Health* has a strong focus on user involvement, shared decision-making (SDM) and development of PDAs as means to ensure patient-centred cancer care [4].

The increased political focus on user involvement in health care in general and SDM in particular is due to a relatively new realization amongst decision makers that patients want to participate in making decisions about their own care, as documented by recent national surveys [5]. Another factor is the prevalent perception of SDM as a means to counter future challenges of rising medicine and treatment costs due to demographic changes and an increase in the number of patients with (multiple) chronic diseases. For instance, the *Ministry of Health* recently asked the *Danish*

Knowledge Centre for User Involvement in Health Care (ViBIS) to synthesize the evidence for SDM in decisions regarding medical treatments with drugs (as opposed to surgery or other medical interventions) in order to assess the potential medical and/or economical effect of introducing SDM systematically into such decisions [6].

Awareness of the importance of better collaboration between patient and provider is thus constantly growing, prompting a call for more evidence-based methods to ensure both efficient and patient-centred treatment across hospital units and health care sectors.

Patient and public involvement

However, political decision makers are not the only stakeholders in Denmark calling for a more patient-centred health care system. The latest national patient survey conducted in 2016 included more than 250.000 patients from various hospital departments, who were invited to provide feedback on their experiences during hospital visits [5]. The survey documents that up to half of the patients experience poor communication with health professionals about the risks and benefits of various treatment options. This apparent 'room for improvement' has been used by several patient organisations to lobby for greater user involvement in treatment decisions. For example, *Danish Patients* – an umbrella organisation representing 20 different patient organisations with a total of 880.000 members – states that '*All institutions in health care should be lawfully obligated to systematically involve patients and family members. Involvement of patients in their own care should be done systematically by developing a system and culture, in which patients' knowledge is considered an important and necessary part of the decision processes concerning their treatment and care*' [7]. Along the same line, a recent survey was carried out among 6.000 Danish patients [8], which showed that the majority of respondents (75%) wanted to participate more in decisions about their treatment and care. Responding to this result, the chairperson for the *Organisation of Patient Safety* commented that '*it is central to accommodate this wish, so that patients can contribute to correct and safe treatment – every time*' [9].

Before the requirement for informed consent became mandatory, it was considered the doctor's responsibility to decide which treatment the patient would receive, based on his professional judgment of what he believed to be in the patient's best interest. The new principle of informed consent recognizes the patient as an individual with his own objectives, values and attitudes that must be respected. However, it is still a common misconception among clinicians that SDM is the same as informed consent. Some clinicians have little awareness that SDM also entails consideration of the patient's personal preferences and values. At present, there is no legislation requiring health care professionals to follow the principles of SDM.

Research agenda and key initiatives

The increased political awareness is paralleled by more national and private funding to strengthen patient-centred care, particularly the use of *Patient Reported Outcomes (PRO)* and SDM. In the fall of 2016, the report “Program PRO” was launched by ViBIS with a description of how PRO data could be unfolded in a Danish context [10]. The report outlines a guideline for good practice to implement PRO-data in quality development across all sectors of the Danish health care system.

Also last year, the government set aside 40 million DKK on the national budget to support the development of PDAs. Additionally, 22 million DKK has been earmarked to fund the development and implementation of PDAs specifically for decisions regarding cancer treatment. When they have been tested locally, the plan is to roll them out nationally over the next few years [11].

A few initiatives deserve specific mentioning, and are therefore described in more detail in the following section.

Centre for shared decision making [12]

Vejle Hospital, part of the *Lillebaelt Hospital Organisation*, is a regional hospital and cancer treatment centre in the *Region South Denmark*. In 2012, the hospital launched an ambitious program called ‘*The Patients’ Cancer Hospital*’, as part of a strategic partnership between the hospital and *The Danish Cancer Society*. The *Centre for Shared Decision Making* was launched in November 14 as a result of this program. The main purpose of the centre is to implement SDM in clinical oncological practice through developing, testing and evaluating PDAs. Three overall strategic areas - PDAs, PRO and patient-clinician communication - have been given priority in the recognition that PDAs cannot stand alone when trying to implement SDM across a hospital setting. Currently, only a few Danish-language PDAs are available, and merely translating existing tools into Danish is not always an option; either the tool for the specific decision does not exist or procuring the original PDA may be time-consuming or expensive. Therefore, the centre has developed a Danish platform – a generic template for PDAs, which can be used across all types of cancer treatment decisions.

The centre is currently in the process of developing and testing the feasibility of this platform in different decisions regarding treatment for breast, lung and ovarian cancer, as well as outside the cancer area in a spine-center, where the PDA platform is tested on decisions regarding treatment for herniated disc. The feasibility studies target either diagnostic or treatment choices relevant to specific groups of cancer (and spinal) patients, and are developed specifically for clinical situations where patients and healthcare professionals need support to make important treatment decisions.

The User Involving Hospital

In 2014, ViBIS launched *The User Involving Hospital* in collaboration with Aarhus University Hospital in the Western part of Denmark. The aims of the 4-year project are to 1) increase user involvement and 2) gain experience with large-scale implementation of two methods for user involvement - SDM and user-led health care [13] – in a Danish context. During the first phase of the project, 18 hospital departments have developed and tested initiatives; 7 of which are PDAs for various treatment choices. In the second phase, which started in January 2017, the project will focus on disseminating the experiences gained from working with the two methods to other hospitals in Denmark. As part of this process, ‘implementation manuals’ will be developed, containing concrete tools and strategies to implement SDM and user-led health care in a local organisational context. These manuals will initially be tested

in other hospitals, and eventually made available to all health care institutions wanting to increase user-involvement.

ViBIS training and knowledge dissemination

The *Danish Knowledge Centre for User Involvement in Health Care (ViBIS)* was established in 2011 by *Danish Patients* with economic support from TRYGFonden, a private foundation. Since its establishment, ViBIS has gathered and disseminated knowledge about user involvement, including SDM and PRO, to Danish health care professionals and policy makers in many different ways, including organising national conferences, giving presentations at health care seminars, publishing articles and ‘how to’ manuals and providing consultancy support to develop local user involvement interventions. SDM has been an integral part of all these knowledge dissemination activities from the beginning, but recently it has taken a more central position, due to the increased political focus and professional interest in this method.

In the last two years, ViBIS has thus provided a series of courses and skills building workshops specifically about SDM, targeting specific groups of health care professionals. Most notably among these is the ‘SDM Ambassador’ course, developed in collaboration with the Danish Association of Junior Hospital Doctors. The course participants commit to passing on their knowledge about SDM to their colleagues and/or local doctors’ associations after completing the course. These ambassadors will thus help disseminate knowledge amongst doctors about what SDM is, why it is important and how to do it. In 2016, 35 young doctors became *SDM Ambassadors*, and the course is scheduled again later this year with an expectation of a similar number of participants.

ViBIS also currently offers general courses in user involvement methods, consisting of different modules, of which 4 have a specific focus on SDM and PDAs. Health care professionals signing up for the courses then select individually which course modules they want to attend. For the course modules being held during the spring of 2017, 120 health care professionals signed up in total; of these 76 have signed up for modules focused on SDM and PDAs.

Challenges for SDM in Danish health care

Despite growing awareness of SDM, it is still a challenge for a fragmented and highly professionalized health care system, as exists in Denmark, to incorporate a more patient-centred approach to treatment and care. This is partly due to a paradigm shift in the health care system with increased centralization, specialization and standardization of treatment of patients in large hospital units. To ensure timely treatment, waiting lists and fast-track cancer pathways have become mandatory in Danish health care, thus increasing the risk that patients are seen only in terms of their diagnosis – they ‘become their diagnosis’, because they are not given enough time to be treated on their own terms.

At present, SDM is not widely used in clinical practice in Denmark. As described, the need for SDM skills training has been recognised and addressed to some extent. But little attention has been paid to system level factors, which impact the interaction between clinicians and patients - for instance economic incentives favouring short consultations and increased documentation demands on clinicians - and how these can be modified to ensure that SDM becomes part of routine clinical practice. Other challenges are related to integration of SDM into clinical systems and busy workflows, and a lack of strategy for implementation.

Studies suggest that Danish healthcare professionals want to involve patients and family members, and see potential advantages in using SDM, such as increased patient satisfaction, compliance

and reduction of overtreatment [6,14]. However, several challenges (Table 1) need to be more clearly addressed, including:

- Insufficient knowledge about SDM and general communicative skills among health care professionals. Despite strong professional interest, neither user involvement or SDM has become compulsory in the education and training of health care professionals [15]. Currently, a number of initiatives have attempted to address this locally. For instance at Lillebaelt Hospital, where all clinical staff have to complete general communication skills training (a 3-day class), and at Aarhus University, where medical graduates are offered a course in patient involvement. University of Southern Denmark is also planning a teaching course in shared decision making and patient engagement. Introducing SDM systematically in undergraduate and/or post graduate training of all health care professionals would be an important step towards implementing SDM in the Danish health care system.
- Limited awareness among clinicians about how to engage patients in deliberations about medical treatment options; especially when they need to tailor information about health care to various levels of health literacy. Furthermore, for patients it can also require taking on a different mind-set to be able to participate in making critical decisions. If they have not been told in advance that they will be invited to participate in the decision-making, some patients may feel insecure about what they are supposed to contribute with in the decision making and why. Coaching and patient education are well-established methods to address this issue.
- Varying levels of engagement and knowledge of SDM among top management in the health care system, partly due to competing financial and organisational demands. More widespread implementation of SDM requires encouraging hospital managers to take the task on and actively work to make SDM the norm in clinical practice, e.g. by providing SDM skills training and organisational changes to support user involvement.
- Lack of evidence-based Danish-language PDAs. Currently, more than 30 Danish PDAs are being developed with funding from both

the Danish government and some patient organisations. Some of these are translated and adapted from international PDAs, while others are developed to choices where no PDAs currently exist. Most aim to support decision making about treatments provided in hospitals, but a few focus on choices between treatments provided by the primary health care sector, for instance rehabilitation. When these new Danish PDAs are ready to use, it is vital that they are disseminated nationwide and systematically integrated into clinical guidelines and electronic patient records, and that lessons learned from these projects are used to proactively facilitate the development of more and better Danish patient decision aids.

- Lack of valid Danish-language outcome measures and measurement instruments to monitor the effect of SDM in clinical practice. Translation of existing international instruments have only just begun, and currently only one, *CollaboRATE* [16–18], is available in Danish, although a few more are underway; the *Decision Quality Worksheet* for herniated disc (DQW-HD v.2.0) [19,20] and the *Decisional Regret Scale* [21] have recently been translated into Danish by the Centre for Shared Decision Making. Being able to monitor the effect of SDM in local clinical practice is crucial to engage clinicians - and hospital managers - in efforts to disseminate and sustain the use of PDAs in clinical practice. The most highly prioritised initiatives in health care are often those which can be measured and for which hospital management will be held officially accountable. The motto “we measure what we value, and we value what we measure” is thus significant when trying to implement SDM in hospital settings. More funding for this work is urgently needed, as well as central coordination of the various initiatives, to avoid multiple translated versions of the same measurement instruments, and ensure that the most valid and useful instruments are translated and validated in a Danish context.

Conclusion

SDM is still at an early stage in Denmark, but national and local initiatives appear promising. Politicians and health care

Table 1
Key implementation challenges for SDM in Denmark.

Challenges	Initiatives	Recommendations
1. Insufficient knowledge about SDM and general communicative skills among health care professionals.	<ul style="list-style-type: none"> • Lillebaelt Hospital: 3 day training course on general communication mandatory for all clinical staff + 1-day add-on course on SDM skills. • Aarhus University: Medical graduates are offered a course in patient involvement. • University of Southern Denmark: Currently planning a course in SDM and patient involvement. 	Introducing SDM systematically in undergraduate and/or postgraduate training of all health care professionals.
2. Limited awareness among clinicians about how to engage patients in deliberations about medical treatment options.	The Danish Society for Patient Safety launches the first national ‘What’s important to you?’ day on June 6 th this year, to help raise public awareness of the importance of patient engagement in treatment deliberations.	Coaching and patient education are well-established methods to address this issue and should be offered systematically in settings where SDM is applied.
3. Varying levels of engagement and knowledge of SDM among top managers of the health care system.	A few regional hospitals have started systematically to initiate organisational changes, starting at the top level, to ensure integration of SDM in clinical practice.	Encouraging top managers in the health care system to take on the task of implementing SDM, e.g. by providing SDM skills training and organisational changes to their employees.
4. Lack of evidence-based Danish-language PDAs.	More than 30 Danish PDAs are currently being developed with funding from the Danish government and patient organisations.	The new Danish PDAs should be disseminated nationwide and systematically integrated into clinical guidelines and electronic patient records.
5. Lack of valid Danish-language outcome measures and measurement instruments to monitor the effect of SDM.	Translated measurement instruments: <ul style="list-style-type: none"> • CollaboRATE • The Decision Quality Worksheet for herniated disc (DQW-HD v.2.0) • The Decisional Regret Scale 	More funding for translation of measurement instruments, as well as central coordination of the various translation initiatives, is urgently needed.

professionals in Denmark perceive SDM as a key element in ensuring high quality patient-centred care, but implementing it in clinical practice is challenging and still has a long way to go. Political intentions like the *National Cancer Plan* and the *Quality Program* are not enough to ensure integration of SDM in everyday clinical practice. This calls for a cultural change in the mind-set of patients, leaders and healthcare professionals. We hope that present and future efforts will ensure a systematic, nationwide approach, which will establish SDM as the norm in Danish healthcare.

Conflict of Interest

None declared.

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