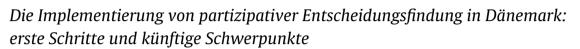
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# Implementing shared decision making in Denmark: First steps and future focus areas



Karina Dahl Steffensen<sup>1,2,3,\*</sup>, Vibe Hjelholt Baker<sup>4</sup>, Mette Marianne Vinter<sup>5</sup>

<sup>1</sup> Centre for Shared Decision Making, Lillebaelt Hospital, Vejle, Denmark

<sup>2</sup> Department of Oncology, Vejle, Lillebaelt Hospital, Vejle, Denmark

<sup>3</sup> Institute of Regional Health Research, University of Southern Denmark, Odense, Denmark

<sup>4</sup> Knowledge Centre for User Involvement (ViBIS), Copenhagen, Denmark

<sup>5</sup> 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.

#### 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.

\* Corresponding author: Karina Dahl Steffensen, MD, PhD, Associate Professor, Director Centre for Shared Decision Making, Institute of Regional Health Research, University of Southern Denmark, Lillebaelt Hospital, Beriderbakken 4, 7100 Vejle, Denmark. E-mail: Karina.Dahl.Steffensen@rsyd.dk (K. Dahl Steffensen).

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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. Download English Version:

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