

**SPECIAL ISSUE "ISDM 2017 -**

**"Implementation of Patient-Centred Care - The way forward with Shared Decision Making"**

**Title:**

Status report from Norway: Implementation of patient involvement in Norwegian health care

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Wordcount: 20120

**Abstract:**

Norway has traditionally high standards regarding civil rights particularly emphasizing equal access to societal resources including health care. This background and the health care system's centralized national organization make it perfectly suited for implementation of shared decision making (SDM). In recent years, great efforts have been made by policy-makers, regional health authorities and not least the patients to facilitate a process of change in health communication culture. SDM is currently even given highest priority in health care strategies on all system levels. SDM has been structurally implemented, e.g. by including corresponding guidance in the standard patient pathways. Moreover, SDM is established as an element of service on the national health portal hosting a constantly increasing number of decision aids. Essentially the Norwegian Knowledge Center for Health Services contributes by searching and providing information for use in decision aids. Implementation is now being rolled out unit by unit for a list of medical problems as a series production of SDM using decision aids and health professional training. Importantly, production of SDM begins and succeeds as a soundly structured communication with both clinical environments and patients. However, as communication training has not been implemented before now, there are no data demonstrating sufficient realization of SDM in current health care. Beyond making reasonable use of scientific achievements, the Norwegian movement's secret of success is the simultaneous commitment of all actors of the health system to a common idea.

**Zusammenfassung**

Die norwegischen Bürgerrechte legen traditionell viel Gewicht auf gleichberechtigten Zugang zu sozialen und insbesondere Gesundheitsleistungen. Im Zusammenspiel mit der zentralisierten Organisation des norwegischen Gesundheitswesens bietet dies perfekte Voraussetzungen für die Implementierung einer Kultur der Patientenbeteiligung an den eigenen Entscheidungen (PEF). In den vergangenen Jahren wurden seitens der Politik, der regionalen Gesundheitsbehörden und nicht zuletzt der Patienten große Anstrengungen zur Veränderung der gesundheitsbezogenen Kommunikation unternommen. Auf allen Systemniveaus rangiert PEF unter den wichtigsten Strategiezielen. Strukturell ist PEF bereits explizit und fest implementiert, z.B. in den klinischen Standardpatientenpfaden oder als ständig wachsendes Angebot von Entscheidungshilfen auf der nationalen Gesundheitsplattform. Das Norwegische Institut für Evidenz im Gesundheitswesen trägt mit systematischer Informationsbeschaffung essentiell zur Produktion von Entscheidungshilfen bei. Unter Anwendung von Entscheidungshilfen und Trainings von Gesundheitsberufen wird die Implementierung entlang einer Liste mit medizinischen Problemstellungen nun im Sinne einer Serienproduktion Einheit für Einheit ausgeweitet. Der Erfolg der Produktion von PEF steht und fällt dabei mit der Einbeziehung der medizinischen Milieus und der Patienten. Da allerdings die Trainings erst jetzt systematisch eingeführt werden, wäre es falsch zu behaupten, dass PEF schon richtig in der klinischen Praxis angekommen ist. Eine Stärke des norwegischen Vorgehens ist die konsequente Orientierung an der wissenschaftlichen Evidenz. Darüber hinaus stellt das gleichzeitige Engagement aller Akteure im Gesundheitswesen für die gemeinsame Idee das Erfolgsgeheimnis der Norwegischen Bewegung dar.

**Keywords:**

Shared decision making, patient participation, Norway, evidence based medicine, implementation, knowledge translation

**Schlüsselworte**

Partizipative Entscheidungsfindung, Patientenbeteiligung, Norwegen, Evidenzbasierte Medizin, Implementierung

## **The Norwegian Health nation**

In Norway, healthcare is governed and financed nationally. The total health expenditure of about 9% of the Gross Domestic Product is at about the average for OECD countries but ranks in terms of absolute per capita expenditure among the highest. Social security is financed through national and municipal taxes and covers public retirement funds, sick leave payment, and reimbursement of extra health care costs for some patient groups. [1]. Primary care is provided in 426 municipalities [2] as the “regular general practitioner (GP) scheme”. People, register with one GP, who is also functioning as the gatekeeper to specialist treatment [1,3]. The four state-owned *Regional Health Authorities (RHAs)* are responsible for specialist somatic and psychiatric care.

The *Directorate of Health (DH)*, a specialized agency under the *Ministry*, issues clinical guidelines, houses the *National System for the Managed Introduction of New Health Technologies*, coordinates 18 patient ombudsmen, and administers a national strategy for health information technology. Here is the interface with the *Directorate of eHealth NDE*. In collaboration with stakeholders, the *NDE* drives the national e-health priorities facilitating development of e-Health solutions. The *Division for Health Services in the Norwegian Institute of Public Health (NIPH)* works with quality indicators, patient safety, and national patient experience surveys and produces evidence syntheses to be applied by the *DH* to guidelines, making policy, and decisions about new technologies [1,3].

Healthcare in Norway is a constitutional right – expected to provide services equitably across all phases of life and regardless of socioeconomic status, ethnicity, and area of residence. The focus in health care policy has, however, shifted over time from a focus on equality in the 1970s over cost containment, efficiency and decentralization in the 80s and 90s to, recently, patient empowerment. Norwegian strategies and priorities of the health care are widely steered by political values conveyed by the *National Health and Hospital Plans: 2016-2019* lists “empowering the patient” as the first of seven goals [4].

Besides the common challenges, such as the rapidly ageing population, health care in Norway faces some of specific problems. The 5.2 million citizens are unevenly spread over a big country, which stretches over 2000 kilometers from south to north with a 25 000 kilometer coastline and thousands of islands and mountains. Together with a rough climate, these conditions bring logistical challenges for the provision of health care. Not surprisingly, Norway still struggles to ensure geographical and social equity in access to health care [1].

Despite a couple of reforms, the semi-decentralized organization (primary and specialist care administrated separately) of the Norwegian health system is still causing limitations regarding quality of care. Part of the problem is lacking continuity at the junction between specialist and municipal health care. The e-Health vision “*One Citizen – One Record*” is shaped aiming at accelerating collaboration between health care providers. Every resident is allotted a unique personal identification number, which is used in primary care and for hospitals’ medical records [1, 3].

## **Efforts made on the systems macro level to strengthen patient involvement**

The partly centralized structure of the Norwegian health services, the anchoring of democratic thinking and equality in the society, and its manageable size seem to provide optimal preconditions for implementation of shared decision making (SDM). Although Norway was amongst the last countries jumping onto the SDM bandwagon, the current dynamic of incorporating SDM into health care is impressive making it likely that Norway will be amongst the first to fully implement the communication culture of the active and informed patient. This development has been prepared by efforts made on the macro-level of the health care system and from three points of view.

Firstly, the users have a strong voice in the Norwegian health care system. Over the last couple of years both patient/user organizations and user committees from the *RHAs*, and at local trusts have been promoting SDM, e.g. by writing chronicles and by implementing SDM in their strategies [5-8]. The patient/user voice not only represents a party to be taken into account when decisions are made

on health policy issues but has also, in many cases, been the driving force to achieve important innovations in the patient's health care. It was therefore no coincidence that the Norwegian term for SDM, *samvalg*, was coined by a patient representative [9]. The word turned out to be usable and easily found its way into the main health policy agenda of the Ministry.

Secondly, considerable efforts have been made in the legislation. The debate over patient rights began in the 1970s [10]. The key legal act governing patient rights in Norway is the 1999 *Patients' Rights Act*, which has been amended several times to further strengthen patient rights [11]. The act can be divided into three groups of patient rights: 1. the resident's rights to become a patient, in particular accessibility of healthcare and the patient's entitlement to health care; 2. The patient's procedural right to participate in treatment choices, be informed and make his or her own medical decisions; 3. procedural rights referring to eventually demand review, reversal and correction of decisions made by health professionals [10].

Thirdly, tremendous political emphasis was placed on the health care system's need to undergo a process of change. Norway has responsible politicians engaged as leading innovators of the health communication culture. In his speech at the national health conference 2016 [12] the health minister, Bent Høie, critically reflected the slogan of *putting the patient at the center*, which recently became widespread in discussions about the Norwegian health care service. He said: "We've got to stop wanting to put patients at the centre." When increasing murmur indicated the audience's astonishment, Høie continued saying "We need to treat patients as equals. A patient isn't someone who just gets put somewhere. We need active patients who decide for themselves." Patient active involvement in decision-making about medical treatment or diagnostics is explicitly and continuously claimed in the government's periodic communications to the parliament (*Stortingsmeldinger*). Of greatest importance to the health sector is the annual assignment document, which provides guidance to the RHAs. The assignment document 2015/16 says e.g.: «*The patients require help to involve themselves more actively into decisions about their own treatment. By use of SDM patients choose in cooperation with health personnel the extent and the way they wish to go. The purpose is to agree on the alternative which best fits the patient's values.*» These lines indicate a clear understanding of and a distinct mandate for SDM. The document from 2017 [13] is even more detailed, using examples, then stating "In addition, there is a need to publish high quality decision aids on *helsenorge.no*". The new Internet portal ([www.helsenorge.no](http://www.helsenorge.no), meaning „healthnorway") contains information on statutory benefits and serves as a guide to the public health-care services. Users have access to several self-service options, such as information on their user-fees, electronic prescriptions and vaccinations or change of GP, and to any kind of patient information.

Meeting the priorities given by the *Ministry*, two of the *RHAs* have in recent years funded research and development on implementation of SDM with more than 50 million Norwegian Kroner (about 5.8 million USD). The *Northern RHA (HN)* financed the development of a platform hosting patient decision aids (PDAs) and corresponding implementation strategies. This work was done by a project group at the *University Hospital of Northern Norway in Tromsø (UNN)*. The *South-Eastern Norway RHA (HSØ)* funded a project at the *Innlandet Hospital trust* commissioned to foster evidence-based medicine which, following recommendations by regional user advocates, was then gradually redefined to support SDM by developing training and decision aids.

### **Actual implementation of patient involvement on the system's meso- and micro-level**

Sustainable establishment of SDM in health care implies a change of culture and therefore needs to reach beyond the macro-level of the health care system and influence corresponding processes on the meso- and the micro-level of the health care system [14]. In Norway, the change of mindset predominantly seems to permeate the entire system starting from the macro-level. In the following, we report measures indicating implementation on the meso-level before we focus on the micro-level.

Indicating structural implementation, SDM has now explicitly become an essential step in each of the standard clinical pathways recently published for cancer diseases by the DH (Directorate for Health).

If the corresponding PDAs are already available, they receive particular emphasis. Work and personnel hitherto funded on the basis of projects for SDM implementation is currently carried over into permanent structures. From 2016, the affiliation of the SDM project funded by HSØ was changed from the local hospital trust to HSØ. Besides SDM related structures, systematic implementation of patient involvement is reflected in provision of or agreement on specific communication quality standards. Commissioned by the ministry and in cooperation with the national experts in the field of SDM the DH has recently passed an agreement on standard quality criteria for patient decision aids. These criteria comply with the international standards [15, 16]. Standards for patient involvement in medical encounters are provided by the *Multifocal APPROach to the sharing IN SDM*, the MAPPIN'SDM inventory [17], which has recently been translated and validated in the Norwegian context [18] and is ready for use for evaluation purposes in the Norwegian health care service. In the latest systematic review, the MAPPIN'SDM is considered the most comprehensive and theoretical well-founded measure of patient involvement [19].

Implementation of SDM is also reflected in the fact that SDM related health services have become part of routine care or have been adjusted to better comply with the needs of evidence based patient information [20]. Central to SDM are the quality and availability of the relevant information to be shared with the residents. The concept of expert recommendations provided by medical guidelines, known as one of the biggest barriers to SDM, is in Norway in a process of revision. Norway is participating in the international research and innovation program MAGIC which has developed *MAGICapp*, a web-based service [21] for effective production, publication and dynamic updating of trustworthy guidelines, evidence summaries and decision aids. The new generation of guidelines is indicating need for choices instead of giving recommendations. Based on a decision of the HD this method is now used for development of national guidelines (example: dementia and gestational diabetes) [21].

PDAs are published by the SDM development group at the UNN on the platform *Mine behandlingsvalg* (Engl.: My treatment choices [22]). The first series of five PDAs (prostate CA low/medium/high risk, pancreas CA, pancreas cyst, and obesity) was launched in autumn 2015. The concept was considered by the DH to be suitable as a prototype for the national health portal [23] and *Mine behandlingsvalg* was encouraged by the recommendation of the national hospital plan to produce more PDAs. On *helsenorge.no* the first PDA was published in autumn 2016. Five additional PDAs are about to move over. Another five will be available in autumn 2017 (Graves', knee /hip arthrosis, breast CA, metastasized prostate CA). Each production involves the respective clinical environment, the patients, and a couple of essential contributors, such as the NIPH providing information generation. The development of *Mine behandlingsvalg* implies conduct of evaluation steps recommended for complex interventions [24].

*Mine behandlingsvalg* PDAs on *helsenorge.no* will soon be complemented by *DECIDEtreatment*, another approach to web-based PDAs, developed by HSØ and particularly useful for ubiquitous patient involvement and treatment optimization during the entire course of chronic diseases [25]. The tool combines features from chronic health management such as monitoring of symptoms, with common PDA-features on a common platform for patients and healthcare providers. Both on a website and a smartphone-app, support for decisions and follow-up is provided in more than 30 panels representing the patient's state and adherence [25-28].

Based on previous work [29-31] HN and HSØ have cooperatively developed *klar<sub>for</sub>samvalg* (Engl.: ready to SDM), a meta-curriculum for teaching and training health personnel in SDM communication. *klar<sub>for</sub>samvalg* uses didactic means and principles proven efficient to change communication quality which were demonstrated in the *doktormitSDM* training module [30-32]. The curriculum is meant to be adjustable to various needs with regard to health profession, setting or competence level. A couple of applications have already been used and tested [32]. In addition, *klar<sub>for</sub>samvalg* is now in charge of covering the respective SDM related learning objectives of the newly revised specialist medical training, starting in autumn 2017. The corresponding curriculum will include a certification based on

an e-tutorial and analogue training. However, no systematic approach to training medical students' SDM skills has yet been fully implemented in Norway.

Hitherto, there are no data reliably estimating the current SDM performance in the health professional patient communication, the micro-level of health care. Following a recent survey of communication quality in an older sample comprising 380 consultations recorded in the specialized health care, however, MAPPIN'SDM indicated that performance was still poor regarding patient involvement in medical decision making in clinical practice [33]. As training for health personnel has not yet been systematically established, it seems unlikely that communication practice has improved substantially since. Considering the knowledge that PDA alone will not change the culture of communication, *klar\_for\_samvalg* is now about to address this challenge beginning with postgraduate physicians. Results of the current efforts and structural measures cannot be evaluated before communication skills and attitudes regarding patient involvement are developed in clinical practice. [34].

The challenge of coordinating implementation of SDM related health care nationwide is now given particular emphasis. A comprehensive implementation framework for SDM developed by the SDM group at UNN and corresponding to *Mine behandlingsvalg* has been conceived in the form of the DA<sub>factory</sub> [35]. The framework uses generic procedures and is approaching full implementation of patient involvement by fractionating health care into SDM-units defined by medical problems. The same type of units serve as the starting points in the development of PDAs. Organized as a virtual production site, the DA<sub>factory</sub> delivers unit-by-unit SDM-implementation by means of PDAs and additional strategies. These are e.g. health professional training and provision of communication help to patients such as the three question method [36]. Production in the DA<sub>factory</sub> follows a framework of standard strategies, guidelines and particular manuals organized in a system of nine divisions [14]. Analysis of barriers to SDM on several levels and refinement of corresponding strategies to overcome these barriers are part of the production process. Commissioned by the Northern RHA the factory has meanwhile started serial production. The concept has also recently been given priority for funding by the German *Innovationsfonds*. The DA<sub>factory</sub> is used as the model for full scale implementation of SDM in German hospital units [37].

An expert panel has been established at the NDE to supervise new production of decision support on helsenorge.no, in particular with regard to the PDA quality standards and the respective PDA-concepts. Moreover, a national SDM expert council is now about to be founded. It will represent the RHA, the DH, the NDE and national SDM experts and will be responsible for maintenance of the SDM related interventions and coordination of the national implementation concept of SDM.

### **Associated initiatives and research**

Additionally, Norway is hosting many promising initiatives either directly related to SDM but not yet implemented or associated with SDM in a broader context. Here, we provide examples:

The *Patient-Centred Team (PACT)* model has been established as a pilot at two sites of the UNN and the respective municipalities. The purpose of the PACT model is to improve the continuum and quality of care for frail elderly patients and to reduce health care costs. The PACT model is inspired by the Chronic Care Model and focusing on the *informed active patient* and the *pro-active prepared health care team*. Both health management's support and use of information and communication technology are key supporting factors. The PACT pilot is considered feasible and has been found to be effective [38].

The *Center for SDM and Collaborative Care Research* at the University of Oslo is a research institute with a particular focus on electronic solutions capable of improving SDM, coping, self-management, and patient-centered collaborative care. The center's interdisciplinary team has considerable experience in developing user-centered electronic support systems shown through RCTs to be highly effective in improving health outcomes. By using such measures, patients experience symptomatic

improvement and better coping [39, 40]. To translating interventions into the context of everyday practice the center uses participatory research methods and stakeholder involvement.

In the *SHAREit* project, the authoring and publication platform *MAGICApp* is being used to semi-automatically create decision aids [21], supporting communication of health professionals and patients. Moreover, it is considered a method with the potential to bridge the gap between the approach of patient involvement and the approach of excluding patient from finding treatment recommendations as implied by medical guidelines [21].

## Outlook

In addition to the frequent production of high end PDAs, which now is established, we expect a growing attention to be given to the challenge of communication. Success regarding full implementation of SDM in health care services will need strengthened efforts in training for health professionals and medical trainees. To achieve optimal results, these components require incorporation in the comprehensive implementation concept [41, 36]. Evidence on the efficacy of the entire *DA<sub>factory</sub>* approach will be provided by a cluster-randomized implementation trial, which soon will be initiated. Considerable additional resources are likely to be contributed by the two other RHAs which have been invited to join the ongoing activities to facilitate the change process.

## Conclusions

Norway was amongst the last countries jumping on the SDM bandwagon. Recent dynamics, however, driven by the patient's voice, legislation and honest political will have initiated a broad national movement towards implementation of SDM. Components, already implemented in routine care are evidence based and part of a comprehensive implementation concept. Due to a gap between specialist and municipality healthcare, primary health care has not yet become sufficiently included in this concept. Another major challenge is the establishment of systematic postgraduate training in SDM, which is under way. Resolving these challenges, the Norwegian approach seems likely to achieve full access to SDM in the foreseeable future.

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Tab. 1

	Abbreviation	Explanation
<b>Institutions</b>	DH	Directorate of Health
	NDE	Directorate of E-Health
	Innovationsfonds	Health insurance fund in Germany to improve quality of the structure of the health care system, administered by The Federal Joint Committee (G-BA).
	HN	Helse-Nord = the northern Norwegian Regional Health Authority
	HOD	Helse og Omsorgs Departement = Ministry of Health
	HSØ	Helse Sør-Øst = the south eastern Norwegian Regional Health Authority
	NIPH	Division of Health Services, The Norwegian Institute of Public Health
	OECD	The Organization for Economic Co-operation and Development
	RHA	Regional Health Authority
	Storting	Norwegian Parliament
	UNN	University Hospital of Northern Norway
<b>SDM related achievements</b>	DAfactory	Comprehensive production and implementation concept for SDM by means of decision aids and other SDM related interventions
	DECIDEtreatment	Approach to patient decision aids, covering the entire patient pathway
	doktormitSDM	Minimally invasive SDM training module proven effective for physicians regarding adaption of SDM communication skills
	DAfactory	Comprehensive production and implementation concept for SDM by means of decision aids and other SDM related interventions
	helsenorge.no	The Norwegian national health service web-portal
	Klar for samvalg	"ready to SDM", meta-curriculum for training health personnel in use of SDM
	MAGIC	Making GRADE the Irresistible Choice: research and innovation programme and non-profit initiative to improve the creation, dissemination and dynamic updating of clinical practice guidelines, evidence summaries and decision aids.
	MAPPIN'SDM	The Multifocal APPROach to the 'sharing' IN Shared Decision Making Inventory providing quality standards and measurement scales for patient involvement within medical encounters
	Mine Behandlingsvalg	"My treatment choice", platform hosting patient decision aids, integrated at "helsenorge.no"
	PDA	Patient Decision Aid
	SDM	Shared Decision Making
	ShareIT	SHARing Evidence to Inform Treatment decisions – part of MAGIC project. Encounter tool deriving numerical information for use in medical encounters from medical guidelines

Table 1: The table provides translation and / or definition of the abbreviations used in the article

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