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



Statusbericht aus Norwegen: Implementierung von Patientenbeteiligung im norwegischen Gesundheitswesen

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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.

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ZUSAMMENFASSUNG

Die norwegischen Bürgerrechte legen traditionell viel Gewicht auf den gleichberechtigten Zugang zu sozialen und insbesondere zu Gesundheitsleistungen. Im Zusammenspiel mit der zentralisierten Organisation des norwegischen Gesundheitswesens bietet dies perfekte Voraussetzungen für die Implementierung einer Kultur der partizipativen Entscheidungsfindung (PEF). In den vergangenen Jahren wurden seitens der Politik, der regionalen Gesundheitsbehörden und nicht zuletzt der Patienten große Anstrengungen im Hinblick auf eine Veränderung der gesundheitsbezogenen Kommunikation unternommen. Auf allen Systemebenen rangiert PEF unter den wichtigsten Strategiezielen. Strukturell ist PEF bereits explizit und fest implementiert, z. B. in den klinischen Standard-Patientenpfaden oder im Rahmen des ständig wachsenden Angebots von Entscheidungshilfen auf der nationalen Gesundheitsplattform. Das norwegische Institut für Evidenz im Gesundheitswesen trägt mit systematischer Informationsbeschaffung wesentlich zur Erstellung von Entscheidungshilfen bei.

Unter Anwendung von Entscheidungshilfen und Schulungen von medizinischem Fachpersonal wird die Implementierung für eine Reihe von medizinischen Problemstellungen nun im Sinne einer Serienproduktion Einheit für Einheit ausgeweitet. Der Erfolg von PEF steht und fällt dabei mit der Einbeziehung der jeweiligen klinischen Bereiche und der Patienten. Da die Kommunikationstrainings allerdings 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.

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 also functions as the gatekeeper to specialist treatment [1,3]. The four state-owned *Regional Health Authorities (RHAs)* are responsible for specialist somatic and psychiatric care (A list of abbreviations is provided in table 1).

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 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 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 administered separately) of the Norwegian health system is still causing limitations regarding quality of care. Part of the problem is an absence of continuity at the junction between specialist and municipal health care. The e-Health vision “*One Citizen – One Record*” aims 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 pre-conditions 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].

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