# (Un)organizing equal collaboration between users and professionals: on management of patient education in Norway

Roar Stokken Cand.Pol.*†

*Faculty of Social Sciences and Technology Management, Norwegian University of Science and Technology, Trondheim, Norway and †Researcher, Patient Education Resource Centre, Sunnmøre Hospital Trust, Volda, Norway

## Abstract

**Background** This is an article about how patient education is managed in Norway, but it also addresses a matter of broader relevance that of how an organization imbued with a request for rational choices is able to take on board a contradictory ideology. In Norway, patient education under the auspice of hospitals is to be conducted as an equal collaboration between users and professionals, posing challenges to the ethos of rationally justified choices within the hospital sector. This calls for an exploration of how the organization copes with the contradictory demands.

**Methods** A theoretical approach on the basis of theories from Scandinavian institutional theory and science and technology studies, informed by documents, interviews and experiences from national, regional and local levels in Norway.

**Discussion** The field of patient education is divided into three decoupled domains: one at management level, one at the practical level, and in the middle a domain that acts as an interface between management and practice. This interface mediates the relationship between ideas and practice, without making overt the fact that ideas might not be possible to put into practice and that practice might not reflect ideas.

**Conclusions** The decoupling of practice and management allows patient education as equal collaboration between users and professionals to thrive as an idea, not subjugated by practical challenges. Thus, it can exist as a guiding star that both management and practitioners can attune to, but this situation might now be threatened by the demand for quality assurance in the field.

## Introduction

In Norway, patient education should render users' and professionals' knowledge equal in the planning, delivery and evaluation of educative initiatives, even though this might contradict with a strong ethos within modern health care: the demand for justified choices on a rational basis. Obviously, it can be argued that listening to users is rational, but as we will see, there are

some tangles down the loom, tangles that left me with a question: *What enables hospitals to take on board equality between users and professionals when it challenges the ethos of justified choices on a rational basis?*

To answer this question, this article discusses how patient education came into being and is organized in Norway. The discussion is undertaken on a theoretical basis informed by documents, interviews and experiences from national, regional and local levels. At regional and local levels, material has mainly been acquired from Central Norway.

Theories from Scandinavian institutional theory are used to understand the contradictions between policy and practice at a macrolevel. Theories from science and technology studies (STS) are used to understand the mechanisms at microlevel. Together, these two sets of theories provide input to understand how the organization can cope with contradictory demands at the mesolevel, which at present has received meagre attention in research literature.

In the text below, we first have a look at patient education in the context of Norwegian policy. We then look more closely at the imbued difference between professionals' and users' knowledge before we consider how the demand for patient education as equal collaboration between users and professionals came into being. Against this background, we investigate the status for patient education in the health-care sector today before we on this basis evaluate the contemporary trend towards the quality assurance of patient education and what that might lead to.

## Patient education in the context of Norwegian policy

Patient education became legislated[1] in Norway in 1999 as one of the four main tasks of hospitals, along with treatment, research and the education of health professionals. The Norwegian health-care system is financed through general taxes and provides universal coverage, and the free market plays an insignificant role. (In 2009, 99% of all hospital stays were publicly funded.) Thus, patient education under the auspice of hospitals in practice has the entire Norwegian population as its target group.

Guidelines[2–5] require patient education to be planned, delivered and evaluated in equal collaboration between users and professionals. This is at the heart of contemporary policies,[6–10] which adhere to the idea of helping people to help themselves, and conceives the health-care system as a partner for the patient. The ideas are also in accordance with the Norwegian welfare model, which is built upon egalitarian values and positive rights given to the citizens. Furthermore, patient education as equal collaboration between users and professionals is in accordance with the demand for user involvement at all levels of the health-care system,[1,4,8,11] a mandate evolved to realign services around those they serve in co-operation with them, rather than simply on their behalf.

In practice, the most frequently used argument for patient education as collaboration between users and professionals is that their knowledge are complimentary and that user involvement contributes to the provision of services that are less cut off from their context.[12,13] Justification of user involvement in health care is also predicated on a number of other foundations. It can for instance provide legitimacy through accountability to taxpayers, voters and consumers[14] and has been connected to concepts like post-modernism,[15] consumerism[14] and new public management.[16] Thus, user involvement also concerns the redistribution of power between health care and individuals/society, challenging the dominance of health-care expertise. But user involvement and patient education also relate to concepts such as active citizenship, empowerment and auto nomous, self-sustaining and smart patients.

All in all, patient education and the underlying ethos of equality between users' and professionals' knowledge reflect contemporary policies well and receive wide support among users, professionals and politicians – even though they can be challenging to put into practice. Three dilemmas that professionals experience when equality is to be rendered between users and

professionals have been identified at one of the local hospitals from which material has been acquired.[17] These are expressed as the dilemmas of *payment*, *knowledge* and *collaboration*.

Despite being in accordance with policies, it might seem hypocritical to demand equality between users and professionals when it both contradicts the demand for rationally justified choices within the hospital sector and meets challenges when put into practice, and this could well be the case. It is probably not only in the Dutch context that users are considered as equal in policy while not being equal in practice.[18] But acting contradictorily and hypocritically is not only a bad thing.

The public sector in a democratic society must be accountable to the population as a whole, where contradictory demands are more the rule than an exception. In the free market, hospitals divide the 'market' between each other through specialization. This cannot be done when health care is provided by the state alone. But, by embedding contradictory demands into how the organization solves tasks, hospitals can reflect inconsistencies in the population through 'producing' inconsistencies between practice and ideologies and thereby (strangely enough?) increasing legitimacy.[19] Hence, despite potential contradictions, providing legitimacy to both rationally justified choices on an evidence-based foundation and an amalgamation of users' and professionals' knowledge is in some sense rational.

Brunsson[19] labels such embedded contradictions as *organized hypocrisy*.[19] The ability to embed contradictions is achieved through decoupling ideas from practice[20,21] and is not understood as a reprehensible way of acting, but an efficient way of gaining legitimacy. As such, organized hypocrisy reflects a democratic society where no one gets it all and many get at least something. This is accomplished by providing one group with decisions they desire, another group with what they desire in terms of what one plans to do and a third group with desired actions. Thus, equality between users and professionals can thrive as an ethos to be decided upon and talked about without causing prob-lems to the organization, even if it meets challenges when attempts are made to put it into action.

This lack of the need for a direct link between idea and practice can explain the fact that the demand for equality is translated into guidelines, despite it being hard to put onto practice. To investigate how the organization actually copes with these contradictory demands, we ought to look into the nature of the contradiction. In the text that follows, we mainly focus upon the challenge inherent in the diversity between users' and professionals' knowledge.

## Users' and professionals' knowledges

In Borkman's[22] seminal article on knowledge in mutual aid groups, she outlines the difference between the knowledge of users and professionals. Professionals' knowledge is found to be general and developed, applied and transmitted by an established and specialized occupation, while users' knowledge is *experiential*. This denotes that it is context-bound and learned through personal experience with a phenomenon, rather than acquired by discursive reasoning, observation or reflection on information provided. Hence, professionals' knowledge is by nature universal, while users' experiential knowledge is context-bound.

The universal and context-independent nature of professional knowledge makes it possible for patients to develop expertise in professional terms.[23] On the contrary, the professional is prevented from accessing experiential knowledge directly, owing to it being tightly bound to personal experience. However, a professional can develop experiential knowledge first hand; an oncologist will develop experiential knowledge of cancer, if she gets cancer herself. But she can also embed accounts from experiential knowledge in her professional knowledge, but these embedded accounts are by definition not experiential knowledge.

Professional and experiential knowledge also relate to two diverse modes of thought.[24] Professional knowledge relates to the *paradigmatic or logico-scientific [mode, which] attempts to*

*fulfill the ideal of a formal, mathematical system of description and explanation,*[25, p. 12] while experiential knowledge relates to the narrative mode of thought and leads *to good stories, gripping drama, believable (though not necessarily 'true') historical accounts.*[25, p. 12] *This also means that the central vehicle for storing and communicating these knowledge types is different.*

The diversity between the knowledge types goes even deeper, because in terms of Habermas[26] professional knowledge belongs to the *system*, while experiential knowledge belongs to the *lifeworld. Systems* are rational and function according to means-end rationality, seeking to optimize what can be counted; this is in contrast to the *lifeworld*, which strives for consensus and loyalty through *communicative action*. Thus, the rationality embedded in professional knowledge seeks to optimize outcome, while the communicative rationale embedded in users' knowledge seeks to optimize mutual understanding. This diversity concerning what is perceived as important also contributes to the fact that the knowledge types are not always easily aligned. Another aspect that contributes to the challenges in rendering equality between users' and professionals' knowledge is the relationship between knowledge and power. The professionals are employed by the system, while the users partake voluntarily on lifeworldly premises. This affects the equality between the two parties, because the professionals are more responsible and granted more power by the system.

In the context of individual treatment, amalgamation of the two knowledge types can be justified as rational through patients' rights to possess control over their own lives. But at system level, the challenges are more demanding because health care is imbued with concepts like evidence-based medicine, evidence-based practice and new public management; concepts highly dependent upon professional knowledge and upon functioning according to means-end rationality.

In sum, the diversity between users' personal, context-bound, narratively stored and voluntarily provided knowledge and health workers' universal and system-bound professional knowledge provided as employed personnel makes the demand for rendering these two types of knowledge equal a rather radical requirement. The reason for this requirement is to be found in the policy process that led to patient education becoming one of four main hospital tasks in Norway.

## Patient education as policy process

Patient education as a legislated hospital task and the national guidelines stating that users and professionals are to be rendered equal are related to one of the major changes in public planning in recent decades: the move from *government* to *governance*. 'Government' refers to the formal structures of authoritative decision making in the modern state, while 'governance' relates to governmental and non-governmental organizations working together in partnerships between sectors and levels.[27] The interplay between these processes is evident in the development of patient education in Norway.

Back in the mid-nineties, users' organizations in general and the Norwegian Diabetes Association in particular (Manager of the National Patient Education Resource Centre, pers. comm.; Minister of Health, pers. comm.; Secretary General of the Norwegian Diabetes Association) fronted patient education in the policy debate. This resulted in the instigation of a governance initiative founded upon a common interest among health professionals, patient organizations and politicians in developing smart patients. This idea suited the government structure well, because the strategy of the newly appointed Minister of Health in 1995 was to 'create' as few patients as possible (Minister of Health, pers. comm.). Hence, smart patients were at the heart of the on-going health-care reforms, allowing for patient education to become easily adopted by policies fed downwards within the publicly owned hospital structure.

The government and the governance processes were carried out in two phases, leading to two generations of documents. The first phase started in the mid-nineties and concerned ideol-

ogy and provided documents[28–30] that established patient education as equal collaboration between lay and professional. This phase culminated in the legislation of patient education as a central hospital function in 1999.[1] The second phase has flourished in the new millennium and concerns implementation and aims at the dissemination of the ideas developed in the first phase.

Distance and diversity between the first and second phase in terms of time, kind of processes and the organizations involved in the process allow for the second phase to take the outcome of the first one for granted. Thus, it has been possible to avoid the problematic nature of equality between users' and professionals' knowledge in the second government-driven phase.

## Embracing a diverse field

The attention brought to patient education from both the government and the governance processes was well received within hospitals in Norway. This boosted the interest in patient education throughout the country, providing practitioners support from management in a way unheard of until then. An important reason was patient education being disseminated as a concept that supports heterogeneity.

To understand how one could support heterogeneity, we turn to STS. Within the framework of STS, Star[31] developed the concept of boundary objects in her influential article about 'The Berkley Museum'. Boundary objects are objects shared between diverse social worlds in stable relationships with each other. At the boundary between these worlds, such objects act as crossing points that let concepts mean different things in the contexts they facilitate communication between.[31,32] This is achieved through a plasticity that absorbs tensions[33] by not connecting perspectives and meanings across the boundary.[34] Boundary objects do not need to be material things that you can hold in your hand, put in your pocket or throw at someone. They can in fact exist only in the world of ideas, such as *democracy*, *love* and *autonomous* or have both concrete and abstract aspects, such as tools, artefacts, techniques and *patient education*.

In the first governance phase, patient education was a boundary object in terms of being a buzzword and an idea still in its shaping. In the second government phase, it also had the form of a boundary object because the documents governing the hospitals' activity are rather vague and thus allowing for heterogeneity. Typical phrases are the following: 'Patient education is the responsibility of the clinical wards'[4,35] and 'professionals' and users' knowledge should be rendered equal when patient educative initiatives are planned, conducted and evaluated'.[4,5,35]

As a result of patient education being disseminated as a boundary object in both phases, it directed focus towards the *coincident boundaries* of interest in the gain in patients' knowledge. This provided the heterogeneity needed by being a concept into which stakeholders could project their own intentions. As long as one cared for an increase in patients' knowledge, one could attune to it. Thus, the concept could embrace several established traditions in both the first and the second phase, grown from a wide variety of requirements and intentions. In fact, it embraced a range from health professionals intending to increase biomedical health indicators, to users' organizations intending to liberate patients from paternalism. However, the reason for both the governance initiative and legislation to establish patient education as a central hospital function was the wish for further development.

## Patient education resource centres

To support development, a patient education resource centre pilot project was instigated at Aker Hospital by the same stakeholders that made patient education part of the government structure. This pilot also came into being in a governance process, in which equality between users and professionals was the founding ethos. The pilot soon became the *de facto* standard for how hospitals could meet their responsibilities regarding patient education, and today patient

education resource centres are found at almost every Norwegian hospital, committed to the concept of patient education more or less as it was developed in the pilot initiative. On the other hand, the way these centres are organized and solve tasks varies significantly.[12] This variety stems from the idea of 'a patient education resource centre' also being a boundary object plastic enough to be transformed to the local context, thus supporting heterogeneity.

One example of a patient education resource centre instigated in Central Norway in the first phase, when patient education was a buzzword, is at Orkdal Hospital. This centre started as a service initiated by a health worker who on her own initiative had applied for and received funding for one specific educative initiative. This initiative soon grew into a generic patient education resource centre funded by the hospital, on the basis of the increased focus upon patient education in the policy debate. The centre is still run by the unit where the initial initiative was instigated, in parallel to physiotherapy, as was also the case with the project that initiated the process. This sort of development trajectory is rather common for resource centres established in the early days of contemporary patient education. Another example is located in Namsos where a hearing loss resource centre was reorganized into a patient education resource centre, thanks to an initiative from a health professional. In both cases, the instigators became managers of the resource centres.

While the patient education resources instigated in the first phase in the main came into being through bottom-up processes supported by management, the approach in the second phase has been mainly top-down. This offered a higher degree of formal legitimacy to the process and established a stronger formal organizational commitment. This was the case at Sunnmøre Hospital Trust where the resource centre is positioned within the medical support unit, patient education coordinators are established within the wards, and resolutions concerning development and organization are passed by the board of directors. Also among resource centres

instigated in the second phase, there are great variations.[12]

Despite the diversity in terms of the phase of instigation, way of organizing and scope of activity, all centres in Norway attune to the idea of equality between users and professionals as it is disseminated through national guidelines issued by the National Patient Education Resource Centre.

## Standard Method

Following a 4-year pilot phase, the centre at Aker Hospital was designated as a National Patient Education Resource Centre in the year 2000. Taking on their new role, they first attempted to impart course templates and other tools developed for their own use. This was soon discontinued, because these penetrated into neither practice nor understanding (Manager of the National Patient Education Resource Centre, pers. comm.). The tools and templates were simply not flexible enough to fit the heterogenic field embraced in the first phase by the plasticity imbued in 'patient education' and 'patient education resource centres'.

The failure to impart tools and templates was followed by an effort to spread the founding idea of equality between users and professionals. The most important dissemination tool in this process has been *The standard method for quality development of patient education*,[13,36,37] in short *The Standard Method*. The method was imparted as both an ideology[3] and national guidelines[3] and is a mix of quality circles,[38,39] democratic values and the idea of self-help.[24] The core of the standard method is the demand for rendering users and professionals and their knowledge, equal during the whole process of planning, delivery and evaluation of patient educative initiatives.

Also, The Standard Method flourishes in the field of patient education as a boundary object, providing various parties with the opportunity to project their own understandings and use their own competence when instigating and conducting patient educative initiatives. This is achieved because The Standard Method concerns the

development process in where partnership with users and users' organizations are crucial, not organizational structure, content or the definition of specific concepts, such as *coping*, *learning*, *equality*, etc. Thus, the understanding of patient education under the national guidelines is allowed to span from being considered as a part of the daily talk on wards (Vice General Manager at Sunnmøre Hospital Trust, pers. comm.) via part of discharge conversation (Ward Manager at Sunnmøre Hospital, pers. comm.) to an extensive learning trajectory, (Secretary General of the Norwegian Diabetes Association, pers. comm.) and from aiming at liberation from paternalism (Manager of the National Patient Education Resource Centre, pers. comm.; Secretary General of the Norwegian Diabetes Association) to enhanced compliance. (Medical Manager at Sunnmøre Hospital Trust, pers. comm.; Vice General Manager at Sunnmøre Hospital Trust, pers. comm.)

Allowing for this wide range of interpretations and practices to coexist has enabled the field to avoid what Toulmin[40] calls *the tyranny of principles* by maintaining a practical focus. One example of how problematic not staying practical can become is the problems that arose when the regional hospital enterprise tried to instigate a *theoretical foundation for patient education in Central Norway*. This document simply became stuck in the process owing to opposition from the local patient education resource centres. This was in contrast to the wide support the preceding action plan received, which is practical in its approach.

The plasticity of the boundary objects can imply that they are without agency,[41] and to the extent they provide stability, it is through the consent of actors on both sides of the boundary.[42] In this case, the consent concerns the underlying ethos of users' knowledge as an important means in patient educative initiatives. Thus, by being a method provided formal legitimacy, standard method has changed patient educative practice over the last decade by providing the legitimacy to increase the involvement of users in the formation, instigation, conduction and evaluation of patient education. Thus, the ethos of equality is allowed to coexist with the ethos of rationally justified choices owing to consent between the actors in the field, but we can still not explain how the organization can cope with the contradiction between these ethos.

## Three domains

Theories of organized hypocrisy can explain why the demand for equality between users and professionals flourishes as an idea while at the same time being problematic to fit to the health-care system. On basis of the same theories, one can understand the field of patient education as three domains: (i) the *domain of decision*, represented by the decision makers, (ii) the *domain of action*, represented by the practitioners, and in the middle between the two: (iii) the *domain of talk*, represented by the patient education resource centres. The relationship between these domains is regulated by the boundary objects in the field, allowing for equality between users' and professionals' knowledge to be interpreted and put into action differently in each of the three domains.

*The domain of decision* sits at the top of the organizational hierarchy and consists of policy makers of various kinds, ranging from politicians to hospital management. This domain takes the outcome of the first phase as granted. It further understands equality between users' and professionals' knowledge as *an idea* that can contribute to increased objective health measures, the patient's quality of life and the efficiency of the health-care sector.[4,28] The management strategy is rationalistic and hierarchical and rests upon the logic whereby decisions are passed on downwards through the sector.

*The domain of action* at the practical level consists of those conducting patient education and is therefore most concerned about good patient educational *practice*. This domain focuses in the main upon horizontal interaction in a governance tradition; this consequently means limited interaction with the governmental structure. A precondition for this is *The Standard Method*, because it concerns the development

process in which partnership with users and users' organizations is crucial, not organizational demands. Thus, equality between users' and professionals' knowledge can be something one practises in a lifeworldly framework even though it means acting like Janus, showing one face when attuning to the health-care system as employed personnel and another face when attuning to user involvement in practice. This is made possible by two diverse sets of logics: one for the system and one for collaboration with users.[17]

*The domain of talk* consists in the main of patient education resource centres and rests in the middle between the domain of decision and the domain of action. This domain aligns the ideas in the *domain of decision* to the practice of the *domain of action* through the boundary objects in the field, thus without making it overt that it might not be possible to put the idea of equality into practice, that practice might contradict with the idea, and without problematizing equality between users and professionals.

Vital to the division into three domains is the requirement that patient education resource centres act as *boundary organizations*.[41,42] Such organizations attempt to meet the contradictions at the boundary in three ways: (i) they create and use boundary objects; (ii) they involve actors from both sides of the boundary, as well as actors who serve a mediating role; and (iii) they exist at the frontier of the two social worlds with lines of accountability to each. This makes them capable of performing tasks that are useful to both sides while still playing a role that would be difficult or impossible for organizations in either community to play.[41–43]

Through the boundary objects in the field, concepts used in interaction with the other two domains can mean diverse things in diverse contexts. But it is the same actors that perform actions towards both domains, and thus what is experienced in one domain easily influences how one acts in and experiences the other domain.

In the domain of action, the contradiction between the demand for equality between users and professionals, and the demand for rationally justified choices within the hospitals is solved by individuals acting as Janus.[17] The same pattern can be seen concerning how the patient education resource centres undertake their job, where they use two modes of operation: the *assistant mode* towards the domain of practice and the *agent mode* towards the domain of decisions. In this way, they can involve actors from both sides of the boundary on diverse premises and thus allow for two sorts of accountability.

The *assistant mode* is activated when one assist health professionals in the domain of action in conducting patient education. The *agent mode* is activated when the centres act towards the domain of decisions as agents of change in hospital policies and plans. In this mode, organizational units become the target group of the activity, not the individual *per se*, as the case is in assistant mode. Another important difference between the two modes is that while the resource centres in the agent mode subscribe to patient education as *an idea* to be disseminated, in the assistant mode, it is subscribed to *as practice* to be conducted. In this way, the resource centres can keep the idea of equality between users and professionals apart from the challenges that equality between the parties generates in practice. This 'conceals' the practical challenges from the decision makers and hides from the practitioners the problems of making equality between users' and professionals' knowledge fit the system. In this way, patient education as equal collaboration between users and professionals can serve as a beautiful idea, without being subjugated by practical challenges.

## Final discussion

We have established that the field of patient education is governed by plastic concepts that allow both for a great diversity and for the fact that what is intended in one place does not necessarily need to be put into practice in another place. In the domain of decision, equality between users' and professionals' knowledge is an idea that should be implemented; in the domain of action, it is something that is practised, and in the domain of talk, which is an interface between the other two

domains, it is an object attuned to in two diverse ways, dependent upon which domain one is interacting with. Possible contradictions between idea and practice within the domain of talk are concealed by the two modes of operation, allowing for the field neither to be limited to the doable nor to that which is decided upon.

In this way, patient education as equal collaboration between users and professionals can exist as a guiding star to which actors in all three domains can attune, despite practical challenges and the demand for justified choices. The plasticity of the boundary objects in the field seems to be the main reason for the demand for equality between users and professionals having received surprisingly little attention, even though it is a challenge when it comes to practice.[17] Nevertheless, it seems to be hard for those occupying the domain of talk to maintain patient education as both idea and practice. At present, user representation is declining, a process that started already when the pilot at Aker Hospital changed its status to become a national resource centre and users' representation on the Board was reduced from 50% to about 15%. Nowadays, more actors with less knowledge of the policy debate in the governance phase are also enlisted in the initiatives. For the domain of talk, this makes the task of translation from idea to practice more challenging, because both decision makers and practitioners demand more evidence in order to be convinced.[12] In this way, a greater degree of uniformity between patient educational practice and the health-care system is needed now than in the early days. This has led to the instigation of several quality assurance projects throughout the country.

At Sunnmøre Hospital Trust, a project involves a detailed template for use when patient education initiatives are instigated. While the standard method describes a process and leaves the rest to those conducting patient education, the template is much more detailed and calls for descriptions of issues such as intention, target group, aims, responsibility, user involvement, content, etc. Another project has been carried out at Bergen Hospital Trust. This has produced standards that patient educative initiatives should meet in terms of both content and way of organizing. The outcome of both projects regulates patient education to a much stronger degree than standard method. This is a necessity in a quality assurance perspective, where it not is enough to state that both users and professionals should plan, conduct and evaluate and hope for and believe in the manifestation of quality.

The standardization these projects bring removes local uncertainties in the information exchanged by forcing descriptions into a form. This reduces the need for plasticity within the domain of talk and transfers the plasticity into the process of filling out the forms and interpreting them. Together with such standardizing tools, the presence of personnel with less knowledge of and commitment to the initial idea of equality between users and professionals reduces the need for consent between the three domains. It is therefore plausible that patient education will be less imbued with the demand for equality between users and professionals in the years to come.

## Acknowledgements

## Funding

## Conflicts of interest

No conflicts of interest.

## References

1 Norwegian Ministry of Health and Social Affairs. *Specialized Health Services Act*. Oslo, Norway: http://www.lovdata.no, 1999.

2 The National Patient Education Resource Centre. *Criteria for Funding [Kriterier for tildeling av midler til forskning og fagutvikling om læring og mestring]*. Oslo, Norway: Nasjonalt kompetansesenter for læring og mestring ved kronisk sjukdom, 2007.

3 The National Patient Education Resource Centre. *Ideology and Method for Self-Management [Ideologi og metode på vei til egenmestring]*. Oslo, Norway: Nasjonalt kompetansesenter for læring og mestring ved kronisk sjukdom, 2005.

4 Central Norway Health Enterprise. *Action Plan for Patient Education [Handlingsplan for pasient og pårørende opplæring]*. Stjørdal, Norway: Helse Midt-Norge, 2004.

5 The National Patient Education Resource Centre. *House Rules for Patient Education Resource Centres [Hustavle for lærings- og mestringssenter]*. Oslo, Norway: Nasjonalt kompetansesenter for læring og mestring ved kronisk sjukdom, 2002.

6 Norwegian Ministry of Health and Care Services. *National Health Plan*. Oslo, Norway: http://www.regjeringen.no, 2007.

7 Norwegian Ministry of Health and Care Services. *National Diabetes Strategy*. Oslo, Norway: http://www.regjeringen.no, 2007.

8 Norwegian Ministry of Health and Care Services. *The Coordination Reform: Proper Treatment – at the Right Place and Right Time*. Oslo, Norway: http://www.regjeringen.no, 2008–2009.

9 Norwegian Ministry of Health and Social Affairs. *Patients' Rights Act*. Oslo, Norway: http://www.lovdata.no, 1999.

10 Norwegian Ministry of Health and Social Affairs. *The Health Personnel Act*. Oslo, Norway: http://www.lovdata.no, 1999.

11 Norwegian Ministry of Health and Care Services. *Health Authorities and Health Trusts Act*. Oslo, Norway: http://www.regjeringen.no, 2001.

12 Steihaug S, Hatling T. *Evaluation of The National Patient Education Resource Centre [Evaluering av Nasjonalt kompetansesenter for læring og mestring ved kronisk sykdom]*. Trondheim, Norway: SINTEF Helse, 2006.

13 Vifladt E, Hopen L. *Health Pedagogics [Helsepedagogikk]*. Oslo, Norway: Nasjonalt kompetansesenter for læring og mestring ved kronisk sjukdom, 2004.

14 Tritter JQ, Koivusalo M, Ollila E, Dorfman P. *Globalisation, Markets and Healthcare Policy: Redrawing the Patient as Consumer*. London, UK: Routledge, 2009.

15 Smith R. The discomfort of patient power. *BMJ*, 2002; **324:** 497–498.

16 Heffernan K. Social work, New Public Management and the language of 'service user'. *British Journal of Social Work*, 2006; **36:** 139–147.

17 Stokken R. Some are more equal than others… On how health workers cope with ideas that seems impossible to practice. *Journal of Risk and Governance*, 2009; **1:** 247–258.

18 van de Bovenkamp HM, Trappenburg MJ, Grit KJ. Patient participation in collective healthcare decision making: the Dutch model. *Health Expectations*, 2010; **13:** 73–85.

19 Brunsson N. *The Organization of Hypocrisy: Talk, Decisions and Actions in Organizations*. Copenhagen, Denmark: Copenhagen Business School Press, 1988/2002.

20 Brunsson N. *Mechanisms of Hope Maintaining the Dream of the Rational Organization*. Malmö, Sweden: Liber, 2006.

21 Brunsson N. Ideas and actions: justification and hypocrisy as alternatives to control. *Accounting, Organizations and Society*, 1993; **18:** 489–506.

22 Borkman TJ. Experiential knowledge: a new concept for the analysis of self-help groups. *The Social Service Review*, 1976; **50:** 445–456.

23 Heldal F, Tjora AH. Making sense of patient expertise. *Social Theory and Health*, 2009; **7:** 1–19.

24 Borkman TJ. *Understanding Self-Help/Mutual Aid: Experiential Learning in the Commons*. New Brunswick, NJ, USA: Rutgers University Press, 1999.

25 Bruner JS. *Actual Minds, Possible Worlds (The Jerusalem-Harvard Lectures)*. London, UK: Harvard University Press, 1986.

26 Habermas J. *The Theory of Communicative Action*. Boston, MA, USA: Beacon Press, 1984.

27 Amdam R. Empowerment planning in regional development. *European Planning Studies*, 2010; **18:** 1805–1819.

28 Norwegian Ministry of Health and Social Affairs. *Proposition to the Odelsting 10 1998–1999: About the Special Care Act*. Oslo, Norway: http://www.regjeringen.no, 1998–1999.

29 Aker Hospital. *Application for Grant: The National Patient Education Resource Centre*. Oslo, Norway: Aker sykehus, 2000.

30 Aker Hospital. *Application for Grant: Patient Education Resource Centre*. Oslo, Norway: Aker sykehus, 1997.

31 Star SL, Griesemer JR. Institutional ecology, 'translations' and boundary objects: amateurs and professionals in Berkeley's Museum of Vertebrate Zoology, 1907–39. *Social Studies of Science*, 1989; **19:** 387–420.

32 Bowker GC, Star SL. *Sorting Things Out: Classification and its Consequences*. Cambridge, MA, USA: MIT Press, 1999.

33 Mol A. *The Body Multiple: Ontology in Medical Practice*. London, UK: Duke University Press, 2002.

34 Wenger E. *Communities of Practice: Learning, Meaning, and Identity*. Cambridge, UK: Cambridge University Press, 1998.

35 Central Norway Health Enterprise. *Regulatory Document 2005 Sunnmøre Hospital Trust [Styringsdokument for 2005 til Helse Sunnmøre HF]*. Stjørdal, Norway: Helse Midt-Norge, 2005.

36 The National Patient Education Resource Centre. *Ideology and Method for Patient Education Resource Centres [Ideologi og metode for Lærings- og mestringssentre]*. Oslo, Norway: Nasjonalt kompetansesenter for læring og mestring ved kronisk sjukdom, 2004.

37 The National Patient Education Resource Centre. *House Rules for Patient Education Resource Centres [Hustavle for Nasjonalt kompetansesenter for læring og mestring ved kronisk sjukdom.]* Oslo, Norway: Nasjonalt kompetansesenter for læring og mestring ved kronisk sjukdom, 2002.

38 Deming WE. *Out of the Crisis: Quality, Productivity and Competitive Position*. Cambridge, UK: Cambridge University Press, 1986.

39 Hopen L, Vifladt E, Rø O. *End Report: Project Quality Across Aker Hospital [Sluttrapport Prosjekt Tverrgående Kvalitet Aker Sykehus]*. Oslo, Norway: Aker sykehus, 1997.

40 Toulmin S. The tyranny of principles. *The Hastings Center Report*, 1981; **11:** 31–38.

41 Frost L, Reich MR, Fujisaki T. A partnership for ivermectin: social worlds and boundary objects. In: Reich MR, (ed.) *Public-Private Partnerships for Public Health*. Cambridge, MA, USA: Harvard Center for Population and Development Studies, 2002.

42 Guston DH. Boundary organisations in environmental policy and science: an introduction. *Science, Technology, and Human Values*, 2001; **26:** 399–408.

43 Guston DH. Stabilizing the boundary between US politics and science: the role of the Office of Technology Transfer as a boundary organisation. *Social Studies of Science*, 1999; **29:** 87–111.