

Project report

The Integration of Peer Competence in Public E-Health Information resources

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NST-report: 05-2006
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ISBN: 82-92092-72-2
Date: 2006-07-01
Number of pages: 29
Keywords: Peer knowledge, health information, user participation, universal design

Summary: Medical, technical, pedagogical, and social scientific presumptions for integrating peer knowledge in electronic health information resources have been described and analyzed during this feasibility study. Building on the client organizations' own conceptualizations of peer competence and of self help, we have described a main project aiming at specifying practical routines for integrating peer knowledge into public e-health information and learning resources.

This feasibility study has been carried out in close collaboration with voluntary sector in North Norway and the Learning and Coping Centre (LMS) at The University Hospital North Norway (UNN). Professional medical knowledge and peer competence are by the voluntary organizations regarded as complementary and mutually enforcing resources in health information systems. According to the clients, the professional medical community pay at present only restricted attention to peer knowledge in their information routines towards patients and their families- even if The learning and coping center at UNN seems to make an exception in this respect.

According to our cooperation partners in voluntary sector, chronically ill and disabled clients have a keen interest in experience exchange among peers. Peer competence is regarded as a community resource which may be drawn upon in all prevention, treatment and rehabilitation, and constitutes the foundation of self help and local coping. We have compared two strategies for health information distribution- "the expert model" and the "self-empowering model", and analyzed their application in the context of e-health. We suggest a dialog-oriented approach to e-health service production, both during planning and implementation of specific services (at an organizational level) - as well as when it comes to the content delivery.

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Preface

This feasibility study was carried out at the Norwegian Centre for Telemedicine in 2005. Six man-months were funded by Helse Nord in order to clarify how peer knowledge may be integrated within public e-health services. At The Norwegian Centre for Telemedicine (NST), The eHealth Consumer Program works continuously with questions concerning clients' application of e-health services and client participation within e-health service production. In the context of this feasibility study, we have collaborated closely with The Association of Heart and Lung Patients Region North (LHL)¹, The Norwegian Association of Disabled Region North (NHF)² and The Norwegian Association of Blind and Partially Sighted People Troms county (NBf)³. The close contact with voluntary sector secures NST updated information on internet use among the voluntary organizations in general, and about their members' use of electronic health information more specifically. Know-how about the organizations own use of ICT for member contact and for information distribution, as well as for organizational development becomes available through close collaboration with voluntary sector, and such knowledge seems to be of fundamental importance for an understanding of how peer knowledge may best be fitted into public health information resources.

Two concrete projects, "The Eczema School" (carried out by the Learning and Coping Centre at the University Hospital North Norway (UNN)) and "Reparere" of Intermedia, the University of Oslo have contributed significantly to the information basis of this feasibility study.

I am indebted to my colleagues at NST for providing me an external eye on my manuscript, and to my informants and friends in voluntary sector for offering me practical orientation in the field, guidance and encouragement.

The populations' estimated need for health information as well as the design of information resources will probably be decisively influenced by the underpinning conceptualizations of health. It is an underlying premise for this study that the clients themselves possess knowledge and skills which may be drawn upon in all prevention, treatment and rehabilitation. Patient empowerment and well organized self help units are taken to be essential for efficient public health care, and hence a dialogue-oriented model for health information design will be suggested. Here's a little story which I stumbled upon among my informants, and which illustrates fairly well what this study is all about:

"People affected by specific diagnoses meet many unexpected challenges. They might need to work towards a mastering of their practical, psychological and social situation. To master a situation includes both an emotional mastering and a practical mastering of problems and challenges. There are several topics on which they will need information and guidance, for instance about the illness, how it effects their daily life, how to manage and plan the daily life, and what kind of measures and precautions should be taken. Patients are in a situation where they need information.

¹ The Norwegian translation is: Landsforeningen for hjerte- og lungesyke, region Nord

² The Norwegian translation is: Norges Handicapforbund Region Nord

³ The Norwegian translation is: Norges Blindforbund Troms.

Other people's experiences and personal situation can be a source of information for helping them with their new challenges.

A person who experiences a turn in life needs to make reflections about the new life situation. The conversation is an activity with great potential in peer work. The peer conversation gives the patient an opportunity to present what he or she goes through. By explaining the problems one can gain new insight into and understanding of ones situation. This can give an opportunity to think of alternatives”
(Adopted from a lecture given by Knut Ellingsen in 2002.).

Tromsø, February 2006.

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1 Approaching the field

1.1 Health information and peer knowledge

This feasibility study has focused on alternative work procedures for integrating peer knowledge in public ICT-based information- and learning resources for patients and the chronically ill as well as their families/close persons. These work procedures aim at specifying how peer competence may be collected, adapted, integrated and presented as supplements to professional medical information in e-health services. A main project has been described, which emphasizes social scientific, pedagogical and technological questions concerning the integration of peer competence in e-health resources, and which addresses the need for an empirical basis for such integration. We suggest that the empirical basis for the integration of peer competence in public e-health services should be a study of how peer knowledge is generated and maintained within specific organizations of disabled and chronically ill.

The goals of the main project are to concretize how peer competence is generated and maintained among members in specific voluntary organizations in North Norway, and to show how disabled and chronically ill persons own know-how and coping strategies may be fitted into ICT-based public health information systems.

The peer networks of voluntary organizations are a basis for self help activities and coping, and represent a community resource which may be drawn upon in all rehabilitation- and convalescence processes carried out by the public health sector. The "users perspectives" and the users own strategies for symptom management in local contexts constitute an important supplement to professional medical knowledge. At present there is no exact methodology available to feed peer competence back into public health information systems and professional health organizations - and in the main project we will evaluate the concrete alternatives at hand.

ICT-based communication arenas may promote personal coping, self help and serve as adapted and qualified learning opportunities in convalescence after acute illness or in connection with a chronic disease and habilitation/rehabilitation. If patients' and chronically ill's self management is to be enhanced, it is important to present peer competence and professional knowledge as complementary and mutually enforcing resources.

This feasibility study aims at knowledge production regarding the formation and maintenance of peer competence, and the development of methodologies for collecting, adapting and presenting peer knowledge which may be reused and refined in concrete ICT-based communication- and information services for users with chronic conditions and/or multiple handicaps where cross-organizational and multidisciplinary coordination and client participation are important elements.

The right to information, the right to be consulted and the right to opt for service producer or hospital are secured for the patient in Norwegian Health Legislation (Department of Health Affairs 1999a, 1999b). At the same time as more is expected from the service producers, participation by the clients themselves is requested in the health sector. Knowledge and information which take into consideration personal, cultural and situational conditions in the client corps is at present regarded as decisive for effective self-management and coping locally.

1.2 Summary

Medical, technical, pedagogical, and social scientific presumptions for integrating peer knowledge in electronic health information resources have been described and analyzed during this feasibility study. Building on the client organizations' own conceptualizations of peer competence and of self help, we have described a main project aiming at specifying practical routines for integrating peer knowledge into public e-health information and learning resources.

This feasibility study has been carried out in close collaboration with voluntary sector in North Norway and the learning and coping Centre at The University Hospital North Norway (UNN). Professional medical knowledge and peer competence are by the voluntary organizations regarded as complementary and mutually enforcing resources in health information systems. According to the clients, the professional medical community pay at present only restricted attention to peer knowledge in their information routines towards patients and their families- even if The learning and coping center at UNN seems to make an exception in this respect. According to our cooperation partners in voluntary sector, chronically ill and disabled clients have a keen interest in experience exchange among peers. Peer competence is regarded as a community resource which may be drawn upon in all prevention, treatment and rehabilitation, and constitutes the foundation of self help and local coping.

We have compared two strategies for health information distribution- "the expert model" and the "self-empowering model", and analyzed their application in the context of e-health. We suggest a dialog-oriented approach to e-health service production, both during planning and implementation of specific services (at an organizational level)- as well as when it comes to the content delivery.

Two example e-health projects were selected for closer inspection during the feasibility study- the Eczema School on the net (UNN's Learning and Coping Center) and Reparere by Intermedia. Both of these projects apply a "top-down model" for content distribution, and may be said to be emphasizing professional medical knowledge at the expense of peer knowledge. The focus on general accessibility has been strengthened though during the implementation of these information resources.

The use of ICT among members in voluntary sector is at present restricted, but recently the organizations have started to use data tools for organizational development, seminars and member contact. All of our cooperation partners have home sites on the internet, but these pages are currently seldom used actively for health information purposes.

2 Peer knowledge and self help

2.1 Conceptualizing peer competence

Peer competence among disabled and chronically ill persons is about coping with specific symptoms and about self help in local communities. The experience based peer knowledge is acquired and maintained within peer networks, and hence voluntary organizations represent an important community resource. The Norwegian self help Forum writes about self help on their internet site (www.selvhjelp.no):

``Self help means to get a grip on ones own opportunities and to actively locate own resources. Self help means to become a responsible actor in ones own life, and to steer life in

the direction of own preferences. Self help means to initialize a process aiming at becoming an active participant in own life rather than remaining a passive receiver of external help".

The Norwegian formulations are cited below:

"Selvhjelp er å ta tak i egne muligheter, finne fram til egne ressurser, ta ansvar for livet sitt og selv styre det i den retning en ønsker. Selvhjelp er å sette i gang en prosess, fra passiv mottaker til aktiv deltaker i eget liv."

We refer to the underlying competence in self help processes as "peer competence". The peer knowledge is context- and process oriented, and may be said to cover the areas of a) symptom handling b) psychosocial relations c) activities of daily life and d) physical activity and life style. "Problem descriptions" about disease management and rehabilitation within the peer corps often differs from the professional ones in that the clients' own accounts have to take into consideration relations with the local community . The clients own descriptions of personal situation have to embrace a whole life totality. Peer competence and professional knowledge about diagnostics, treatment and rehabilitation/coping are supplementary resources within self help activities. E-health systems may contribute significantly to the establishment and maintenance of peer knowledge by 1. facilitate a strengthening of peer2peer communication in dispersed symptom units, 2. by offering new virtual meeting places between professional medical competence and client experiences and 3. by providing the client corps updated and adjusted professional health information.

E-health systems may contribute significantly to the strengthening of all aspects of experience-based peer knowledge by offering voluntary sector new opportunities of communication, and also, these systems may provide new meeting places between peer knowledge and professional medical competence. Responsibility for personal health relies heavily on access to updated health information, and ICT-based information systems may play a key role to solve this task.

In the main project, we will apply a concept of peer knowledge as suggested by "Norsk Selvhjelpsforum".

2.2 Patient empowerment

There is a growing interest in theories of empowerment in health care among Norwegian professional health workers, not least because of the recent emphasis on "user participation" in national health legislation. Patient empowerment may be seen as a way of operationalizing user participation in the health sector (even if the concept's roots in the American civil movement make it quite distinct from the Scandinavian conceptualization of the participatory democracy). However, there is more to the interest in the concept of empowerment than this (Askheim 2003⁴, Ghay 2000). From a professional point of view a need for local symptom management and illness prevention may be emphasized, and this may in turn indicate that mobilizing the clients' own resources is important for successful implementation of health promotion activities. It is an inherent aspect of such lines of reasoning that professional medical competence and peer knowledge are taken to be complementary resources in this respect, and that the patients' own experiences may be extensively drawn on in all prevention, treatment, and rehabilitation. Client knowledge concerns local ways of illness prevention and responsibility

⁴ The norwegian title of O. P. Askheim's book translates into "From normalization to empowerment: ideologies and practises in work with the disabled" "

for personal health. Such knowledge also concerns the tackling of lasting or chronic symptoms within the local environment. For the clients themselves local knowledge and self help build on the sharing of coping strategies among peers.

The concept of empowerment appears to be the process of enabling individuals to take responsibility for personal health - or imparting power from the professional health workers to the patients themselves in questions concerning health management and coping. The ideas of empowerment is often used by professional health workers in illness prevention and health promotion, since the principles of empowerment are about enabling people to increase control over and improve their personal health. Since the meaning of empowerment is "to authorize" and "to enable", this implies shared responsibility between clients and health workers. The ideas of self-responsibility, self-determination, and self-care - together with notions of personal control - are summarized in the concept of empowerment of the individual. It is believed that information technology can help people think and act for themselves by providing them correct and updated information at the right time and at the right place. A positive self-esteem may be created as a consequence, which gives the individual the ability to set and achieve goals, gives a sense of control over their life, and yield a sense of hope for the future.

Empowerment of the care recipient to access and understand details of his or her own health status; to reach knowledge about preventive care and other services on offer, so as to make correct decisions, solve problems etc; to be involved in his/her own process of care and be able to provide input to this process and give feedback about the quality of the services in general; to be in easy contact and perform effective and good communication with relatives and other individuals at the point of care, and to receive prompt and focused support and advice from the care community as a whole, are all expectations to the impact of new ICT-based tools.

Accurate and updated patient information is an important presumption for service production in accord with goals about enhanced patient involvement and life quality.

"Patient participation" in the democratic sense is about patients' influence and feedback concerning the planning and running of health care at an organizational level. It should be noted that patient empowerment and participation do not concern professional medical decision making about diagnostics, treatment, or follow-up: such decisions are the health worker's responsibility.

We have distinguished between two levels in the reasoning about client empowerment and participation in ICT-based health services (Holthe 2004, Holthe et al. 2005). Firstly, empowerment concerns the clients' involvement in service production. Empowerment at this face-to-face level is about interaction or cooperation between the clients/families and professional health workers. The aim of empowerment initiatives is to provide health services which comply with the clients' needs and priorities. Empowerment is also about self help and the incorporation of peer competence in ICT aided health care systems. Empowerment of the clients in this sense implies a focus on illness prevention, health promotion, and the clients' responsibilities for personal health. Empowerment initiatives in the context of e-health mean a strengthening of client-client communication as well as client-staff relations through the application of ICT - and involve electronic distribution of accurate, relevant, and updated health information.

Secondly, empowerment is about client influence on the shaping and running of e-health services at an organizational level. In this context, ICT equipment offers new opportunities for mutual contact between professionals and clients, especially in situations where people live scattered over a vast geographic area like northern Norway. Patient empowerment also relies heavily on a strengthening of

patient/patient communication patterns, since coping strategies are constructed and maintained within peer networks, and because successful patient participation presumes coordinated standpoints within the patient corps. Constructive reasoning about empowerment in health care services probably will have to take into consideration both of these levels for empowerment initiatives.

2.3 What is self help?

Patient empowerment in the context of e-health service production concerns issues about technological innovations, the patients' local coping, as well as medical interventions. Patient involvement, participation, and influence presume technological tools which are generally accessible, and which in itself do not create new communication barriers. Self help and local symptom management rely upon patient/patient information exchange - and ICT can contribute significantly to the organizing of peer networks. Especially in low frequent patient units living dispersed over wide geographic areas.

Here's a little more of K. Ellingsens' outline about self help:

Peer work is an approach for working with and supporting people affected by an illness. Peer work or peer support work is about exchange of experience. It is undertaken on a voluntary basis. This type of work is performed in many self help organizations of people with illnesses.

Peer work is based on the idea that patients, although they have problems, do have some resources. Their resources can be utilized to support other patients, and therefore peer work is a kind of self help work. It is about transfer of personal experience from one person to another. It is organized between people who have similarities in diagnosis and life situation and who are therefore likely to have common interest. Therefore the work takes place between people in equal positions. It is also necessary to recognize that even though there are similarities between their experiences, there are also significant differences.

Peer work can take place either between two people as a one-to-one relation, or in a group of people meeting each other. Peers can support each other both through conversation and activities. Peers can also support each other in pure practical matters. In the early 1990's the Norwegian government recognized the importance of peer work and have since that granted the organizations with official funding. These fundings have made it possible for the organizations to develop and improve the peer work mostly through systematically training.

To day LHL has a variety of peer work activities like discussion groups, visiting service, telephone service, physical exercise programs etc.

The special advantage of peer work is something more than a source of information. The peers understanding of a situation is different from the knowledge of professional health personnel. In contact between peers there can be special advantages in the way a peer will meet another peer, and the way they can talk together about the illness and their situation. Peers are people on an equal footing. Between peers a fellow feeling can be created that gives strength. A feeling of community can support the peers and open up for a new mastering of the situation.

The intention of organizing peer work is that people who have the same type of problem can make use of the resources and experiences they have and help each other. This can be organized and offered to persons who need help, support and guidance from people who have experienced much of the same problems and challenges in trying to cope with and manage their illness. In this way the person seeking support can receive the attention and support of an equal who is not an external "expert".

Peers are people in similar life situations, as I have already mentioned. People who have gone through the illness experience are genuinely experts in their own situation, and common situation and experience make people peers. There are two categories of people affected by an illness who might be seeking help. On the one hand the patients themselves who are suffering from the illness. On the other hand family and close relatives of the patients might be affected and suffer from the situation of having a family member with a serious illness. Both people with the illness and their families can benefit from peer work.

In organized peer work at least one of the persons should have a reasonable longer exposure to the illness and experience in coping with the illness and the related problems. This person can be the peer worker. The peer worker has faced similar problems as the person they are working with, and the peer worker has gone through the feelings, emotions, concerns and worries of the person seeking aid. The peer worker has made reflections about and adapted to the situation. The matured experiences are recognized as resources to be utilized. Therefore the peer worker is expected to approach the problems and peer group situation in a more prepared way than others do. A peer worker can facilitate the process of others by listening to the problems the other person goes through, and to focus on possibilities and resources.

The person seeking aid is a person who needs support, help and guidance from people who have experienced much of the same problems and challenges in trying to cope with and manage their illness and life situation.

Peer work is not a fixed approach, but frames can be developed to secure good and reliable peer work. Demands are made on the peer worker, and the peer worker should also receive support and guidance.

Meetings between people take place somewhere and at a particular time. To bring people together there is a need to create links and networks. People need to know where to go and seek help or to offer support for others. Therefore there is a need to offer a structure where people can be included in activities and can sign up as available peer workers. A patient organization may have the task to organize the practical peer work.

As mentioned, peer work can be organized as conversations or activities. Conversations can be undertaken in the form of group conversations or by paying visits to the help seeking person. The conversation can be connected to other activities. To do activities together can be a valuable entrance for a good conversation. And, it is often the case that the conversation has to spring out of an activity to break ground.

There are several requirements that the peer worker must satisfy. The person should be able to share experiences, to take interest of the help seeking person, to listen to, give attention

and show care for peers. Further, the peer worker must show respect to the person who is getting support, and he or she must not have an attitude of superiority.

Often sensitive issues are raised in a conversation between peers. The person seeking help must be able to feel confidence in the situation when talking about personal things. Therefore a peer worker must be bound by secrecy. The peer workers must always secure anonymity of people with whom they work when discussing with other people. A promise of secrecy can be made in writing and signed by the peer worker. The promise of secrecy must remain in force also after the person has ended his or her support work.

A peer worker might experience challenging situations and need support in his or her work. To secure quality of the work and to support peer workers in their tasks they should receive instructions and guidance. This can be organized as training. A network of peer workers can also be established. It can give an opportunity to exchange personal experiences. As mentioned above, peer workers must always secure anonymity of the person about whom they talk though.

Peer work has its limitations, and the peer worker needs to know his or her limitations. There are areas and subjects, which should not be left to peers, but remain the responsibility of professionals. Information given by peers needs to be of the kind they can give as correct information. There might be aid seeking people who have bigger problems than a peer worker can manage. On the one hand, a peer worker can be worn out. On the other hand, a patient might feel frustrated of not receiving the type of help they will need. In organized peer work it is necessary to make judgments about peers, peer workers and what tasks should be subject to peer work".

New cooperation patterns and the introduction and use of ICT in the health sector as well as more skilled and active patients invite to the establishment of new net based communication and learning arenas in the health sector. Such arenas can supply adapted and qualified health information, opportunities of supervision regarding symptom management, and stimulate to self help in peer networks. A presumption for enhanced self management and personal coping seems to be to provide the users with opportunities of sharing experiences. ICT-based information services may constitute an important supplement to the communication between patients, families and health personnel (Andreassen, Sandaune, Gammon and Hjortdahl 2002, Eng et. al. 1998, Hjortdahl and Guldbrandsen 2000). User adapted information- and communication services for the chronically ill or for persons in convalescence can promote self help, contribute to local symptom handling and the coping with various challenges of everyday life. An important presumption for enhanced self management through the use of e-health services probably is that medical knowledge and peer competence are made accessible as complementary resources in the service production.

Patient involvement in the realization of e-health services implies among other things the incorporation of peer competence and the patients' own coping strategies in the information- and learning resources, and that feedback from the users' organizations is secured while the design of the service still is in progress (Holthe 2004). The last aspect concerns the usability of the user interface and questions concerning universal design of ICT-systems. In this project we primarily concentrate on patient involvement as potential coping resources in convalescence and rehabilitation processes, while the relational aspects of the user/helper meetings (Sigstad 2004) is only of by way interest.

2.4 Two perspectives on health and health information

During the early and mid 1980s the World Health Organization (WHO) worked out their health promotion and disease prevention programs (Conf. the Ottawa-charter of 1986). A new disease panorama had emerged after the defeat of the epidemics. Now the chronic illnesses and disablement, and environmental and life-style diseases constituted the hot-spot of health-care. Based on user participation, decentralization and primary health care, as well as the minimizing of social disparities in symptom distribution, WHO attempted to set a new agenda for health care service production. The WHO recommendations were followed up in Norway by a white paper about health promotion in 1987-88 (Ministry Of Health And Social Affairs, 1987-88).

Traditionally, health information seems to have been strictly symptom-oriented and directed towards individual patients. The medical focus on biological/physiological dysfunctions and treatment has dominated the field - easily leading to a top-down information design where the objectives and the educational processes are preset. Hence, "the expert model" of health information takes the form of a monologue where the patient is not always a self-evident part. The health concept under-pinning such an information strategy may best be characterized by formulations such as "absence of disease" or "absence of biological malfunctioning". The risk is that the information is presented to deaf ears - or that it is mis-apprehended or simply not (fully) understood by its' audience.

During the early 1980s Peter Hjort and others worked out an alternative conceptualization of health (Hjort 1982) based on abilities for functional adaptation. Health becomes a question of physical, cognitive, and mental surplus in peoples' meeting with the local community. According to such lines of reasoning, chronically ill and disabled persons may still be considered healthy as long as they can maintain a bodily and mental surplus in their tackling of local surroundings. Following Hjort's path of argumentation, the concept of "health information" emerges with a much wider content than would be the case when the information is founded on purely biological reasoning.

An emphasis on the meeting between individuals or categories of patients with the local context makes relations between cultural patterns and physical surroundings, working life, organizations etc. important for health considerations. The outcomes of these meetings and the task of coping with them is not fixed or set in advance - and calls for an information strategy based on dialog and conversation with the involved parties. From such a perspective successful health promotion and disease prevention can not be planned or implemented without client participation and involvement. "The self-empowering model" of health information build on responsible and active clients who at least, to some extent, make local coping a personal task. Symptom management, in a strict medical sense of the term, will be an integral part of self-empowering strategies for health information distribution - but the scope will be wider than that of a monologue about physiology. Peer knowledge and self help will be built-in features of a self-empowering strategy, and hence medical competence and peer knowledge will operate as complementary and mutually enforcing resources. The information strategy will be less top-down in orientation than is the case with the expert model, but will rather build on cooperation between voluntary organizations and the public health sector.

3 The feasibility study

3.1 The client organization's perspectives on peer competence as a part of public health information

Client participation and involvement in health care service production is a central concern for NST's eHealth Consumer Program. We have collaborated closely with the voluntary sector in North Norway over

the last years - giving us insight into the organizations' application of ICT for self help activities and for organizational development, as well as details about their members' use of net-based health information. In this feasibility study we have concentrated on information from three organizations: The Norwegian Association of Heart and Lung Patients Region North, The Norwegian Association of Disabled Region North, and The Norwegian Association of Blind and Partially Sighted People Troms county - asking how they use ICT tools for peer work, for member contact and organizational work, and how these tools are applied in relation to e-health services. These three national organizations (the number of members ranging from 6-60 thousand) are organized by county and region. This study concerns the counties of Nordland, Troms, and Finnmark.

When asked about their main activities, the organizations usually characterized their work in terms of "interest policy-making" and "user participation". However, peer work is an integral part of all of the ongoing processes - including specially organized peer-activities such as sports, attending cultural events, and seminars. The request for peer knowledge among the organization's members is by our informants characterized as strong, and concerns topics such as the handling of everyday life, social security benefits and welfare services, public service production on offer as well as available aid tools and their application. Social support between peers is a built-in feature of the on-going activities, and, according to the informants, a main reason for member participation. Our cooperation partners told us that the peer-to-peer knowledge exchange is a presumption for local self-sufficiency among their members, which, among other things, involves the acquiring of a proper language for the description and analysis of personal difficulties and opportunities. We were told that the public health sector only occasionally tried to establish contact with the organizations concerning peer knowledge . Neither tried the medical establishment to develop and maintain systematic routines for the contact with voluntary sector in relation to professionally initiated health information efforts, even if the Learning and Coping center at UNN represents an exception in this respect. Throughout our collaboration with the Learning and Coping Centre at UNN, they tried explicitly to integrate peer competence in their information activities.

In addition to peer competence, the organizations may provide their members with health information in the more restricted sense of the term - for instance in the form of specially designed seminars. However, active health information distribution is not necessarily an important part of the organized peer work. The three organizations with which we discussed peer work emphasized social support and peer-to-peer experience exchange about every day coping as the important part of organized peer work.

Peer meetings in the organizations usually took place on a weekly or monthly basis. It should be fair to state that the organizations gear their activities towards the adult, middle-aged population, while

children/youth and elderly persons are not particularly focused on. There seems to be no organized cooperation with professional health workers in ongoing peer work, although professionals may take part in organized courses or seminars.

All of the three organizations have their own rehabilitation centers, usually equipped with a professional staff of health professionals. Private rehabilitation programs represent an important supplement to public service-production, and hence economic support via national authorities is considerable. All of the organizations provide peer networks which visit, inform, and support hospitalized patients.

ICT does not play an important part in any of the organization's peer-oriented work at present. This is probably due to the age composition of members - most of them are middle-aged people without formal training in the use of ICT. Hence, the bulk of the members may lack the skills and training to operate data equipment efficiently. The use of personal computers among visually impaired persons probably makes an exception. Because of restricted or denied access to regular written materials, the blind and visually impaired is urged to use data equipment extensively, and this may be utilized also for organizational developments as well as peer work. Mailing lists are commonly used for member contact - even if this applies only to a smaller fraction of younger and computer literate persons of the member pool.

All of the organizations have home sites on the Internet, but these sites are general in character and not used for organizational purposes.

The use of net-based health information is restricted among the organizations' members, and the use of such information is probably on line with the rest of the population. If this is the case, 8-10 percent of the organizations' members actively use e-health services. The organizations themselves do not distribute health information in the restricted sense via the net to their members.

During 2002-2004 NST initiated experiments with video conferences in cooperation with The Norwegian Association of Heart and Lung Patients and The Norwegian Association of Disabled Peoples Organizations (FFO). Video conferencing were used for organizational cooperation and for courses, joining together actors at several localities scattered over Northern Norway. Easy access to studio facilities and high-speed network made the experiments successful and clearly pointed out the potential of ICT application in the organizations. Easier member contact, organizational development without extensive travelling budgets and the potential for joining together competence scattered over a vast geographical area make ICT an appealing option for the organizations. During this feasibility study our informants told us explicitly that they wanted to apply ICT for member contact and organizational development as well as for information distribution and for peer work. The main barrier to this approach at present seems according to the informants to be the lack of computer skills among their members. This situation is believed to change though, as younger age classes are recruited as members.

Three relevant perspectives on the incorporation of peer knowledge in e-health systems may be pointed at - the regular organization members' personal viewpoints, the organizations' negotiated standpoints, and professional health workers' perspectives. In this feasibility study we have concentrated on the voluntary sector's perspectives at an organizational level, as this perspective is accounted for by three example organizations. However, to get a full picture of how peer knowledge best may be fitted into e-health information systems, a comparison of perspectives seems essential.

3.2 Example projects

At present no systematic approach in order to incorporate peer competence in ICT-based health services is available. The Learning and Coping Centre at the University Hospital in North Norway (UNN) has started to use ICT as a part of their information strategy.

We have implemented this feasibility study in collaboration with the Learning and Coping Centre at UNN and three of the voluntary organizations in North Norway. We have also cooperated with Intermedia, University of Oslo about one of the example projects. The geographical distances in Nordland, Troms and Finnmark counties make a net-based information and learning system attractive and such net-based services may secure clients in rural areas information services on line with those available for the urban population. Through a selective cooperation with specified voluntary organizations, we aim at specifying the exchange of experience based knowledge in peer networks in a net-based health information system directed to wards these users.

3.2.1 *The Eczema School*

The goal of the Eczema School on the net has been to establish an instructional offer that will be able to accommodate the need for advice and guidance with regards to the treatment of eczema such that young clients feel better. The parents may receive help more promptly and therefore tackle the situation better without having to contact the special services directly.

Because of the great geographic distances in North Norway, such an offer may also save the Health Industry both travel and lodging expenses. The departments of Paediatrics and Dermatology at UNN, together with the LMS have worked out the substantial contents of the project by joint efforts, building on initiatives and ideas suggested by doctor Roald Bolle.

The Learning and Coping Centre at UNN estimate that the eczema-school on the internet will serve as a pilot project that can be used in relation to information about other chronic illnesses.

The internet may provide new opportunities in patient education about eczema. It will be possible to see pictures of eczema in its various stages, as well as different treatments when they are needed.

The Children's section at UNN has, along with the Norwegian Centre for Telemedicine, received resources for a project where they will chart whether direct guidance of the parents of children with topical eczema via the internet leads to the children feeling better or to less frequent doctor visits and hospital stays. The Norwegian Centre for Telemedicine and the Children's section at the UNN completed a feasibility study in the year 2000 that offered guidance via e-mail to four children with topical eczema and their families over a period of four months. The study showed that such an offer was feasible and the parents were satisfied and felt that their children were doing better.

It is desirable to establish a "chain of effort" composed of various offers at different levels where eczema-guidance on the internet and eczema-school on the web will be one of the options.

There has been an increase in the occurrence of topical sicknesses throughout the world. Topical eczema is common among children and the illness is a big challenge for both doctors and parents.

The illness often presents itself in infancy and with repeated eczema outbreaks during childhood, it becomes an extra burden for the clients and their families.

Previously completed studies have shown that education and guidance for parents have positive therapeutic effects. Patients who do not follow their doctor's advice oftentimes experience unsuccessful treatment when it comes to topical eczema. Education through specially-designed eczema-schools has given good treatment results.

Instruction from parents to children with topical eczema is only given to a certain degree when they are at their treatment institution. Clinical experience also shows that the need for information is very large for this group of patients, and that advice given over a prolonged period of time is important. The information has to be repeated and adjusted underway since the sickness is chronic and prone to relapse.

There have been previous eczema-schools for parents of children with eczema at UNN. Because of a shortage of personnel, the school had not been offered until the administration started it up again in 2003. In 2004 four eczema-schools for parents of children with eczema were arranged in cooperation with the Learning and Coping Center. A multi-subject day-class was offered, where treatment of eczema was the focus, along with client contribution about everyday problems, and the presentation of the Association of Asthmatic and Allergic Patients (NAAF).

The strength of the Eczema School on the net seems to be its ability to communicate health information asynchronously to its users, i.e. its ability to overcome the time restrictions between professionals and their clients in face-to-face interactions in medical institutions. During the project development considerable emphasis was put on general accessibility and on involving the clients in all phases of the planning and implementation. A direct communication line with users of the system has been provided through a FAQ-list. From a social scientific point of view though, it may be noted that the client involvement in the project is fairly symptom oriented, and that synchronous communication between clients is not a part of the system. Hence there is a potential for increased feedback from the users to the service providers as well as for direct communication between clients (say for instance through question-answer services or chat rooms).

3.2.2 The Reparere

According to public information, updated and accurate knowledge regarding personal health management and the coping with chronic conditions is in increasing demand in Norway. Patient education and self help support constitute areas of special importance in this respect (Ministry Of Health And Social Affairs, 2001, Directorate Of Health And Social Affairs, 2004, Ministry Of Health And Social Affairs, 1999a and 1999b). This state of affairs is reflected in recently passed health legislation. It is on this background the design and development of the information prototype Reparere is best understood.

Anne Moen and coworkers at Intermedia, University of Oslo, describe Reparere as follows: "Using a horizontal prototype approach, Reparere incorporates examples of textual information, video-clips, images and illustrations relevant to different aspects of the recovery trajectory and user's profile. The development of the prototype also includes considerations of security and confidentiality versus flexibility and usability, tailoring and sequencing resources and presentation mindful of principles of universal access". (Moen, Nøvdal and Smørdal 2004).

The description continues: "Using the horizontal prototype approach, Reparere" contains examples of relevant, sequenced information according to a common CABG recovery trajectory, further tailored based on individual user profiles. Adding a communication arena for peer-to-peer support or asynchronous communication with professionals, patients and their families during recovery can further optimize the application (Moen et al.).

In Norway, electronic resources for health management support and for patient-provider consultations are still relatively scarce (Høie 2002). Building on Moen and coworkers, it may be underlined that information systems aiming specifically at supporting and empowering patients and their families during habilitation and recovery imply an extension of current design and development of e-health systems. Reparere is in particular aiming at presenting a simple and consistent user interface, as well as at incorporating knowledge about the user's capacity and literacy.

An Open Source software platform has been chosen for the construction of the information prototype Reparere, where Apache's Cocoon-Lenya is the content management system. According to Moen, the software is further customized to meet the specific challenges in design of the prototype (Moen). The strength of Reparere seems to be its underlying open source software and its emphasis on general accessibility. However, routines for user feedback and the incorporation of peer competence in the prototype are still under consideration.

3.3 Work procedures for the incorporation of peer in ICT-based health information systems

In the LMS project the clients were actively included from the design phase and onwards. The client participants were recruited to the project on advice from their organizations, but had no extensive discussions about the development of the project as the work progressed from design to implementation. As seen from the client organization's point of view, the limited access to skilled representatives may actually hamper their influence on the system design.

The content part of the system was delivered by professional health workers (doctors), and only to a little extent influenced by the client participants. However, both pedagogical and technical topics were discussed extensively during reference group meetings.

Client feedback was provided via an option at the front page of the web course. However, no extensive discussions about the answering service were carried out during reference meetings, and peer supervision of course is a challenge both from a legal and a personal point of view. The Eczema School on the net fits a top-down information design fairly well, and a balanced information content may for instance be achieved through a systematic question/answer-service.

The Reparere project is also based on a top-down information design, attempting to provide sequenced information according to phase in the rehabilitation process - i.e. health information "just-in-time" and "just-in-case". However, routines for client feedback are not implemented yet, and this calls for a substantial client cooperation.

Both the Eczema School on the net and Reparere have put considerable emphasis on general accessibility and the use of open source software application. This increases the projects' potential for platform independent information presentation.

If e-Health services are seen in the extension of conventional health information distribution, the debate about individually oriented versus context oriented information strategies prevails. The individually oriented top-down designs have been heavily criticised for their seemingly lacking abilities to meet with the WHO's request for minimizing social differences in symptom distribution and an extended conceptualization of health. A serious consideration of the WHO's requests suggest a close and continuous collaboration with voluntary sector about health information issues at two levels. At an organizational level the aims, implementation and evaluation of e-Health services should be clarified in cooperation with the public. The clients and their organizations also should contribute actively to the content part of these services.

4 General accessibility

According to our informants, it is important to construct public health information systems which comply with standards for general accessibility. If the systems do not comply with standards for universal design, the risk is that the systems in themselves will constitute efficient communication barriers. Lately principles of universal design have been emphasized also for ICT systems developed for the public sector. In a memorandum from 2005 the Norwegian Ministry of Modernization (MOD) writes: "In a democratic and participatory perspective the demands for universal design of ICT systems are important elements, and these principles must also influence on the choice of standards for interaction in and with the public sector".

In the report "Architecture for electronic interaction in the public sector" from June 2004 the state administration suggests that universal design becomes an integral part of the public IT policies, and as a follow up, a work unit directed by Sigmund Evjen was established in march 2005.

Pragmatically speaking, the principles of universal design ensure that public health information reaches as great a fraction of the target units as possible. "Services must not be designed in a way which excludes certain user units or individual users" MOD writes, and continues: "this also applies for persons with visual, hearing, mobility and/or cognitive difficulties". Universal design in this context means that information and products are to be made accessible as such for (virtually) all (not by means of additional or extra equipment or adaptations conf. the seven principles of universal design by the World Wide Web Consortium). The Web Accessibility Initiative (WAI) specifies requirements for accessibility to public web services - but there may also be a need for similar requirements for other channels (such as local or wide area public and commercial networks). "Functionality for Braille displays and audio presentation of information content must be integrated in all requirement specifications for public bought ICT systems" MOD suggests. In order to secure the development of cost efficient solutions in these areas, the establishment of generalized requirements specifications should be considered.

Using a three layer model for analyzing electronic document handling, the work unit concentrates on exchange and presentation of text information, distinguishing between "formal documents" (communication between the public and private persons) and "general information" on the web. They state: document exchange and presentation touches important policy areas such as universal design, management of intellectual rights, platform independent access to public information, and that the parties of public sector should be able to exchange documents internally without reference to ICT equipment.

Recently, OASIS 2 has published the standard Open Document Format (OpenDocument) version 1.03. This standard, based on XML is regarded by the MOD's work unit as an important future contribution to a common standard for document exchange and presentation. Through the IDABC-program the EU commission has prepared a follow-up of this standard by ISO.

The work unit suggests the following requirements for document exchange and information formats from the public sector to the Norwegian inhabitants:

1. The document format must be open (non proprietary).
2. Citizens and commercial units must be able to receive documents from the public sector independently of hardware solutions (<http://www.oasis-open.org>, <http://www.oasis-open.org/specs/index.php#opendocumentv1.0.4> , <http://www.openoffice.org/>).
3. The documents should be readable via the most common operating systems.
4. Citizens and commercial units should be able to read the documents independent of presentation software (ie. they should have the opportunity to opt for software solutions independently).
5. The document formats must support the principles of universal design (the format should for example be accessible via a braille display or via audio output).
6. The standard should support character sets covering all official languages in Norway.

The work unit suggests the following time table:

The WAI specifications are accepted as requirements for all public electronic services on the web from 2006.

Within 2006, requirements specification for access to public web information via braille displays or through audio presentation should be worked out.

Within 2008 a general requirement specification for exchange of text information in and with the public sector is put into effect according to the standard suggested by the work unit.

Within 2009 requirements specification for text exchange and presentation in several channels should be worked out.

The Norwegian health information on the web is at present only partly - if at all- influenced by the principles of universal design. If the MOD suggestions for exchange and presentation of ICT-based public information are put into effect (according to the tentative time table), much of the current information systems will have to be reconsidered and at least to some extent redesigned. Even if this might be seen as a formidable task, it will imply a clear strengthening of the communication with a broad public audience. For development of new systems, the requirements suggested by the MOD work unit should be taken into consideration from start on.

5 Conclusions

5.1 The need for health information

A change in disease panorama and mortality rates in N. Norway during the 20. century has altered the populations' need for health information significantly - and currently the emphasis of the public health sector is on environmental and life-style diseases as well as on the chronically ill and disabled. However, the conceptualization of health, chronic illness and disability to a large extent will influence the estimated need for health information.

To the chronically-ill and their organizations, health information is not only about symptom knowledge, treatment and rehabilitation in the strict biological sense - but also about local coping on a daily basis, about illness prevention and about health promotion in the widest sense. According to the clients themselves, their need for health related information includes peer-to-peer experience exchange, knowledge about health service on offer, as well as about social security benefits, civil rights and technical aid equipment and its application.

It should be fair to state that the populations' estimated needs for health information will differ depending on which standpoint the judgement is carried out from. If net-based health information distribution is considered in the extension of conventional information routines, two underlying models for information design may be pointed at: The expert model versus the self-empowerment model. Both of these models may have pros and cons in specific situations - and both should be considered when planning or evaluating concrete e-health resources.

5.2 Health pedagogy

Health information systems should take into consideration the full range of cognitive, intellectual and cultural variability within the population. Principles of universal design should be closely considered. Focusing on e-health resources aiming at disease prevention, health promotion and coping with chronic conditions and disablement, a few additional suggestions may be offered: strict technical approaches to information distribution - i.e. a rationale where goals, implementation and needs are determined prior to interventions and in isolation from the users of the information – are likely to be less successful than dialogue-oriented approaches to health information distribution based on citizen participation. The dialogue-oriented pedagogical approaches have a firm basis in Norwegian society, building on the work of, for instance, Hans Skjervheim and Jon Hellesnes. In e-health resources, as in conventional health information systems, any information is likely to be reinterpreted and reframed by the users of the resources according to their specific life situation, and hence, any specific health information initiative should be planned, implemented and evaluated in close collaboration with the information users.

5.3 A model for integration of peer knowledge

We have so far emphasized medical competence and peer knowledge as complementary and mutually enforcing resources. We suggest that net-based health information initiatives about disease prevention, health promotion and coping with chronic conditions and disablement build upon close collaboration between clients/clients' organizations and professional health workers in all phases of

the initiatives. Such a model may be referred to as a self-empowerment model of health information design and distribution.

Local coping strategies are constructed and maintained in surroundings which, in themselves, may be disease producing, and symptom distributions often tend to be socially skewed. Hence, efficient disease prevention and health promotion presumes accurately tailored target units. We suggest that e-health information resources are planned and implemented in close collaboration with the involved parties at two levels:

- a) Cooperation between service providers and information users at the organizational level secures an adequate determination of information-need in specified target units together with the clients themselves. At this level, qualification and adaption of peer knowledge for use in public health services is a central concern. The Eczema School-Project described earlier in this report may serve as a path-finder in this respect. The project was planned in close collaboration with the target unit's organization, and a reference group consisting of professionals as well as users participated throughout the project. This approach increases the chance for presentation of relevant and accurate client knowledge.

- b) Substantially, the clients themselves are likely to know best where the shoe is pinching. Hence, client participation at the content-level of information may include that the clients themselves have opportunities for feedback to the e-health service, or that the clients and their organizations contribute to content production. Opportunities for client feedback may be provided in the form of "frequently asked question" lists, mailing lists, chat-rooms, or more sophisticated question/answer services. In the latter case, security issues become crucial - and it should be noted that patient mentoring by peers is at present legally uncertain. If possible, direct client contributions to content production will probably increase the resources' ability to communicate with a broad audience. However, such contributions presume active and skilled client organizations, with opportunities for parttaking in e-health resource development from the start on, and long-term cooperation between these organizations and the health authorities.

Patient involvement, participation, and influence presume technological tools which are generally accessible, and which in themselves do not create new communication barriers. Self help and local symptom management relies upon patient-to-patient information exchange - and ICT can contribute significantly to the organization of peer networks. Especially in low-frequency patient units living dispersed over wide geographic areas.

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