Improving Health Literacy

Identifying barriers and facilitators to people's ability to obtain health information, and the development and evaluation of an intervention to improve health literacy

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Takk!

Dette prosjektet har vært en fantastisk reise å få være med på, kanskje særlig på grunn av alle de jeg har fått lov til å dele den med. Først og fremst vil jeg gjerne få rette en stor takk til mine veiledere Sølvi Helseth og Arild Bjørndal for deres ro, optimisme og visdom. Jeg har følt meg svært privilegert som har hatt dere som veiledere. Jeg er også svært takknemlig for at Stein Danielsen og Elin Opheim ble en del av dette prosjektet. "Sunn skepsis" hadde ikke blitt det samme uten dere! Jeg har satt enormt pris på vårt samarbeid, både faglig og sosial.

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List of papers

Austvoll-Dahlgren, A. and Helseth, S. What informs parents' decision-making about childhood vaccinations? Journal of Advanced Nursing, 66(11), 2421–2430.

Austvoll-Dahlgren, A. and Helseth, S. Public health nurses' barriers and facilitators to the use of research in consultations about childhood vaccinations. Scandinavian Journal of Caring Sciences 15 DEC 2011.

Austvoll-Dahlgren, A. Falk, RS. and Helseth, S. Cognitive factors predicting intentions to search for health information: an application of the Theory of Planned Behaviour. Submitted with revisions 18.01.2012 to Health Information and Libraries Journal.

Austvoll-Dahlgren, A. Danielsen, SO. Opheim, E. Bjørndal, A. Reinar, LM.,Flottorp, SA. Oxman, AD. and Helseth, S. A complex intervention: tailoring a web portal to improve user health literacy skills. Submitted 14.02.2012 to Health Information and Libraries Journal.

Austvoll-Dahlgren, A. Bjørndal, A.Odgaard-Jensen, J. and Helseth, S. Evaluation of a web portal for improving public access to evidence-based health information and health literacy skills: a pragmatic trial. Submitted with revisions 15.02.2012 to PLoS ONE.

Norsk sammendrag

Brukermedvirkning i helsetjenesten et kjerneelement i kunnskapsbasert praksis og en rettighet i følge pasientrettighetsloven. Nyere forskning viser at brukere både kan og vil involveres i beslutninger om helse. Effektiv deltakelse er avhengig av at brukerne har tilgang til pålitelig helseinformasjon samt kunnskaper og ferdigheter for å tilegne seg denne informasjon. Slike kunnskaper og ferdigheter er også definert som *helserelatert kompetanse* (health literacy). Dessverre er ikke forskningsbasert informasjon lett tilgjengelig, og mange har ikke tilstrekkelig helserelatert kompetanse til å dra nytte av slik informasjon. Det finnes ulike måter å bedre tilgangen til pålitelig informasjon for folk flest, blant annet at forskere oppsummerer forskning på en forståelig måte, nettbaserte søkemotorer som filtrerer ut upålitelig informasjon, at nettsteder og andre former for brukerinformasjon blir kvalitetssikret og merket, samt brukeropplæring i helserelatert kompetanse.

Selv om alle disse tiltakene er viktige, er det kun den siste fremgangsmåten som utstyrer brukerne med kunnskap og egenskaper på tvers av kilder, kontekst og tema. Dette området er av stor interesse internasjonalt, og karakteriseres av metodeutvikling og tverrfaglighet. Til nå har det vært lite forskning på tiltak som retter seg mot helserelatert kompetanse knyttet til det å oppsøke og kritisk vurdere helseinformasjon. I denne avhandlingen beskriver jeg hvordan vi gikk frem for å utvikle og evaluere et slikt tiltak, nettportalen 'Sunn skepsis' (www.sunnskepsis.no). Prosjektet er en kompleks intervensjon i tre faser: i første fase utforsket vi hva som hindrer og fremmer brukere i å tilegne seg pålitelig informasjon, i den andre fasen utviklet vi nettportalen med et brukerperspektiv og hvor forskningsbaserte strategier ble utformet for å møte disse hindrene, og i den siste fasen ble denne nettportalen evaluert.

Abstract

Background

User participation is a core element of evidence based practice and an important contributor to user autonomy and health. However, effective participation is dependent on user access to reliable health information as well as the necessary knowledge and skills to obtain such information. Research has found that evidence based information is not readily available to the public and that many users have poor health literacy skills.

Objective

The overall goal of this project was: to improve people's health literacy skills related to obtaining health information through an intervention to target key identified barriers and facilitators, and to evaluate this effort.

Method

This project was conducted in three phases. In the first phase, we used qualitative interviews, a questionnaire study and literature searches to identify barriers and facilitators to obtaining health information. In the second phase, we developed a web portal intervention to address the important identified barriers using a choice of evidence based strategies. In the final phase, we evaluated the web portal.

Results

Three main barriers were identified as areas for improvement: the inability of users to understand and critically appraise health information, the inability to exchange information in consultations, and not knowing where to find reliable and relevant health information. The design of the web portal was grounded in the conceptual framework of shared decision making and evidence based practice. It included three main strategies to address the identified barriers: an introduction to research methods and ways to find evidence-based health information efficiently, an introduction to critical appraisal and a checklist, and information about patients' participation rights in decision making (the section included a decision aid for consultations). When testing the web portal during the pragmatic trial we found improvements in users' positive beliefs about searching. In addition, the web portal was regarded as a relevant tool by users.

Conclusion

The web portal was developed in a transparent and systematic way, based on feedback from our target audiences. Open access was provided to the tools included in the web portal: healthcare users could utilise these independently or in consultations with health professionals.

Although providing access to such resources may be important in itself, future educational efforts should consider including this web portal in more intensive interventions. These interventions may include, for example, organised courses targeting patients or patient representatives, educational programmes in schools, or the use of the web portal during consultations with health professionals.

Introduction

The involvement of healthcare users (hereafter referred to as users) is a core element of evidence based practice (1). This has been nationally and internationally affirmed through legislation such as the Norwegian Patients' Rights Act, and in international declarations such as those issued by the World Health Organization (WHO) (2-4). The rationale for advocating participation is rooted in ethical principles in respect for patient rights and autonomy (2, 5) as well as pragmatic arguments based on research showing that participation may be important for user satisfaction with care, improving the exchange of information, reducing decisional conflict, and improving knowledge (6, 7). Recent arguments have also highlighted the importance of participation and public involvement as a duty and a responsibility, and as necessary for managing care in ways that meet the current challenges in healthcare effectively (5).

Effective participation is dependent on users being given the opportunity to be involved in consultations with health professionals, having access to reliable health information (6), and the necessary health literacy skills to obtain, evaluate and act upon such information (8). However, evidence suggests that people are less involved in decision making than they would like to be, and that their communication with health professionals and sharing of information may be sub-optimal (9-11). Moreover, evidence based information is not readily available to the public (12-16), and studies have found that many users have limited health literacy skills (17, 18). Consequently, people are often poorly equipped either to participate in decision-making or to make informed decisions in which they have confidence. There is therefore a need for interventions that facilitate peoples' access to reliable health information and their ability to use this information, and these efforts should be evaluated in order to inform practice (6, 17, 19, 20).

Improving users health literacy skills is by the WHO described as the main outcome of health education (2) and a central priority at the EU level advocated by the European Patients Forum (umbrella organisation of pan-European patient organisations) (21).

Based on these arguments and research findings, we decided to develop a resource that could be made freely available to the Norwegian public and that would target users of healthcare with the purpose of improving health literacy skills related to obtaining health information. The aim was to do this through an intervention targeting key identified barriers and facilitators, and to evaluate this effort. In this thesis, I describe the rationale, development and evaluation of this intervention; a web portal we named 'Healthy Scepticism' (Sunn skepsis).

Models, arenas and differences in participation

Numerous models and terminologies have been used to describe clinical decision making (5, 10, 22). The discourse on participation often relates to consultations and decision making about healthcare, such as treatment or screening options (7). In this context, participation is generally categorised into three main decision making models, namely: provider-led, user-led and shared decision making (5). These models occur across a 'locus of control' spectrum and reflect, to a large extent, when different paradigms were preferred at different times (7).

The provider-led model is a traditional, paternalistic and prescriptive model in which the provider decides and the user consents or adheres (5). Critics of this model suggest that it does not foster self-care and efficacy, but encourages passivity instead (5). Evidence suggests that this communication style does not facilitate the exchange of information, which may be important for

treatment and patient safety (7). It may also foster unrealistic patient demands for healthcare by increasing dependency on health professionals, and by not emphasising self-management. This in turn may lead to frustration and dissatisfaction among patients as well as health professionals (5).

In the second model of participation, namely user-led decision making, the user decides and the providers deliver the information (5). This model, based on the libertarian principles of consumerist market mechanisms, was prominent in the early 1980s and developed as a response to the dominant provider-led model of the time (5, 23). A perhaps obvious criticism of this model is that it may generate an unnecessary demand for healthcare. Another shortcoming of this model is that it encourages user demand while failing to emphasise shared responsibilities (5).

The third model of participation acknowledges the shortcomings of the first two. Often referred to as the 'shared decision making' or 'partnership' model, it is now the predominantly accepted and advocated approach (5, 7, 9). In it, both parties share information and responsibility, and decisions are made together (5). It should be noted that the terminology of *shared decision-making* is often used interchangeably with *patient-centred care* (5, 7). In addition to emphasising shared roles and responsibilities, this approach adapts the focus of a humanistic biopsychological perspective upon the individual, rather than focusing upon the disease itself (as would be done within a more biomedical perspective) (7). Although this third model is not perfect (if such perfection exists), it is considered preferable to the first two described above because both user and healthcare provider perspectives are respected, and the model acknowledges that both parties have valuable knowledge and preferences to bring to the table (5).

It is important to recognise that participation in health is not restricted to consultations. In fact, most health activities take place in everyday life. On the individual level (from a preventive

and health promoting perspective), participation includes how we choose to live our life and how we act on health messages (8). The focus on participation outside of healthcare settings is particularly important considering the increased number of people living and coping with incurable or chronic disease (24). These diseases require active engagement from individuals in order for them to master their everyday life, keep up with treatment regimes, manoeuvre their way through the healthcare system, and to manage the enormous volume of health information they are exposed to (8, 24). Furthermore, participation also takes place on a system level in the form of performance assessments of health services and engagement in public health discourse (6, 8, 25).

Age is often found to be an important factor shaping differences in participation both inside and outside the consultation setting (9, 26-29). Younger people are typically seen to be more active (26-28) and more likely to prefer a shared decision making model, whereas the elderly may prefer a more traditional provider-led model (9). This variation can be explained by differences in generational culture, but also by educational and practical issues, such as the degree of familiarity with the use of new information technologies (5, 9, 27, 29, 30). The latter factor is associated with what is known as the 'digital divide' (6), which is expected to diminish over time as more people of all ages become familiar with such technologies (29).

Evidence based information is not readily available

Acknowledging users' rights to participate and their key role in evidence base practice (1, 3, 4) means that user access to reliable health information is a necessity for effective participation

and informed decision making (6). As a result of the emergence of new information technologies, health information previously in the exclusive domain of professionals is now also widely available to the public and many people actively search for it (26-29). Mass media and particularly social media are becoming important sources of health information (25, 28). When people use the internet for health research purposes, most search for information about a specific illness, treatment or therapy (28, 29). In a cross-sectional study in Norway, over 90% of the respondents were reported to have read about health or illness issues online (28). Furthermore, the percentage of people using the internet for health-related purposes in Norway has been estimated to be 67% (2007) (28). Despite the importance of new information technologies, many people still rate family and friends and health professionals as their most important sources of health information (27-29), and evidence suggests that other sources are used to complement traditional channels of information (25, 28).

Having practice based on the best available evidence is a national and international priority (1, 31, 32). However, the information that people are presented with, or depend on, may not be evidence based. Through mass media, the public is exposed to a wide range of treatment alternatives, claims about health risks, and advice about how to promote good health. Many of these reports are incomplete, biased or not based on research (12, 15, 16). Furthermore, although advice from family and friends may provide support, it is likely to be based on anecdotes and personal experiences rather than systematic research. Health professionals have a vital role in providing users with information, but studies have found that evidence based practice and shared decision making have not always been adopted (11, 33-35), and that the quality of patient information varies (6, 13, 14).

Health literacy: a public health issue

There are many ways to improve people's access to reliable health information. Such initiatives include the synthesis and tailoring of evidence based information to individuals by experts (36), automated systems for filtering information online (37), publisher's codes of conduct and the standardisation of initiatives amongst those who publish information (such as the HONcode) (38); and users' own development of their skills through education (8, 39). Although all of these types of interventions are important and may contribute to improving access to health information, it is only the latter that prepares people to understand the facts that are presented to them, interpret what these facts are based on, and decide whether they are actually applicable to a range of health issues and settings (8).

Contemporary healthcare is complex and demands insight as well as the ability to navigate these systems. For users, participation in decision making is not only dependent on access to valid information, but also on the ability to interpret, understand and act upon such information. These are what are often referred to as *health literacy skills* (19). Health literacy as a field of clinical and scientific interest is fairly new but is rooted in many disciplines and is of interest to many, including health professionals and health psychologists, health services researchers and health educators, (8). The term 'health literacy' was used for the first time in 1974 (40) and since then many attempts have been made to define and refine the concept (8, 19, 40-42). The discourse is still very much alive and evolving, and the aims, content and scope of health literacy are still being sketched out.

Health literacy as a field of interest has its roots in two approaches that are somewhat different in their aims and scope (19). The first approach, referred to as a risk model or as

'medical literacy', sees limited health literacy as a risk factor that should be addressed in a clinical setting (19, 40). The focus of studies rooted in this tradition is typically on the ability of users to read, understand and act on information relevant to healthcare settings. This includes, for example, being able to read and understand package labels, the ability to self-manage disease, adhere to health advice, share decision making, and seek information (19, 40). A commonly used definition of health literacy, according to those who subscribe to this approach is:

'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' p32, (43).

According to this approach, the term 'health literacy' describes individual literacy capacities as *mediating* factors predicting health (19). One criticism of this approach is that it is too narrow in scope and individually-oriented and does not include broader social, ecological and systemic perspectives of health and wellbeing (41). Another concern is that this definition does not necessarily incorporate healthy individuals or those health decisions that are made outside clinical settings (40, 41). A broader definition of health literacy has therefore been proposed in which health literacy is seen as an 'asset' and as an end outcome that is critical to empowerment (19). Health literacy according to this approach is not only advocated to optimise health outcomes and cost effectiveness, but also for ethical reasons by facilitating equal access to healthcare, autonomy and the right to citizenship (2, 5, 19, 40, 44-47). This broader understanding of health literacy forms the backdrop of this project and is the position increasingly being adopted by governmental and international organisations. The WHO, for example (2), states:

'Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' p10, (2)

Further, the WHO states:

'Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment' p10, (2).

These definitions show that health literacy is also seen as a preventive and health promoting initiative, which includes a broader societal perspective. Further, they take into account the importance of system knowledge as well as recognising the implications of health literacy on public health (8, 24, 44). Through health literacy, people are enabled to take control of their own life and health, including the personal, social and environmental determinants of their health (19, 40, 41, 44).

This understanding of health literacy is particularly important given the prevalence of preventable chronic diseases, including those affecting young people (24). But it is also an understanding that is important to helping to solve public health issues associated with patients who have *already* become sick. Chronically ill patients are more likely to have contact with health systems and are also required to manage their illness on daily basis in many ways. Such activities have been found to be dependent on levels of health literacy competency (17).

Furthermore, improving peoples' knowledge and skills is seen as a key element of sustainable health and healthcare, and a facilitator of successful policy implementation through shared information, responsibility and accountability (5, 41, 48).

What do health literacy skills really entail?

Health literacy has been defined and conceptualised in many different ways. Earlier definitions developed by researchers and policymakers, for example, tend to focus on the basic reading, writing and numeracy skills needed for decision making in healthcare – often referred to as *functional* or *fundamental literacy* skills (8, 44). Functional health literacy is important and forms the basis for developing other skills, as well as the ability to participate in individual decision making and within society. But reading and writing alone do not address current challenges in public health and clinical care, and an awareness of this has led to greater emphasis on the importance of more advanced critical and social skills (8, 40-42, 44). It for this reason that the conceptualisation of health literacy formulated by Zarcadoolas and colleagues was adopted in this project (8). According to this perspective, a person who is health literate '*is able to use health concepts and information generatively—applying information to novel situations and to participate in the ongoing public and private dialogues about health, medicine, scientific knowledge and cultural beliefs'* p196, (49).

This model of understanding effectively adapts the public health literacy perspective and contains four central domains: fundamental literacy, science literacy, civic literacy, and cultural literacy (see Figure 1) (8). Importantly, these domains include – and are dependent on – several

specific interdependent and overlapping skills and knowledge. For example, functional literacy may be a prerequisite for civic literacy, such as the ability to participate in public debates. On the other hand, the skills that a person has in one domain may also help to compensate for their having inadequate skills in another (8).

A multi-dimensional model of health literacy	
Fundamental literacy	Reading, writing, speaking and working with numbers
Science literacy	Skills and abilities for understanding and using (the process of) science and technology, including: • Knowledge of fundamental scientific concepts • Ability to comprehend technical complexity • An understanding of technology • An understanding of scientific uncertainty and that change in accepted science is possible
Civic literacy	Skills and abilities that enables citizens to become aware of public issues, participate in critical dialogue about them and become involved in the decision making process, including: • Media literacy • Knowledge about civic and governmental systems and processes • Knowledge of power, inequity and other hierarchical relationships • Knowledge that the behaviour and choices of the individual affect others in larger community and society
Cultural literacy	Skills and abilities to recognice understand and use collective beliefs, customs, worldview and social identity of diverse individuals.

Figure 1. A multi-dimensional model of health literacy by Zarcadoolas and colleagues (8)

Health literacy and associated outcomes

The relationship between health literacy and health (although generally only measuring functional literacy skills) has been evaluated in many studies, and the findings indicate that low health literacy levels are associated with poorer health, increased healthcare utilisation, inappropriate drug use, and a low uptake of disease prevention services (such as vaccination) (17, 18). Health literacy has also been found to be a stronger predictor of health status than age, income, employment status, education level and ethnicity (6). Such outcomes may have serious consequences for individuals, but people's health literacy skills may also be important on a systemic level. Many health systems face major challenges including increases in healthcare expenses and the need to prioritise issues (5, 8). One such issue is the development of new and costly treatments and screening programmes, which require limited resources to be prioritised in appropriate ways in the face of difficult ethical and socio-economic considerations. Public engagement – and appropriate health literacy skills among the public – can help to facilitate sustainable healthcare systems by that users have insight into the ingredients of such decision making.

It is therefore concerning that levels of health literacy skills have often been found to be suboptimal (6, 18). Lower health literacy levels have been found to be more prevalent among lower socioeconomic groups, ethnic minorities, the elderly and those with chronic conditions or disabilities (6, 50, 51). These associations may also be the reasons why the improvement of public health literacy is seen as integral to reducing health inequalities (6).

It should be noted that research exploring the prevalence of health literacy skills has been limited in two ways: firstly, most studies have been conducted in the United States of America

(USA) and it is difficult therefore to estimate the health literacy level in other contexts such as Norway or Europe (6). Secondly, health literacy has not always been measured consistently and most studies until now have primarily evaluated functional skills (52). The European Health Literacy Survey (HLS-EU) aims to bridge these knowledge gaps by initiating the development of a tool to measure health literacy in Europe and by conducting a cross-sectional Europe-based study (53). The project, funded by the European Union, is hosted by Maastricht University and is a collaborative effort involving eight partner countries (53). The results from this study, following evaluations conducted in Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain, are expected to be published in early 2012 (53).

Tools for mapping all relevant health literacy domains may not yet be available but studies have explored important aspects of health literacy. These include: that people rely on sources that are not necessarily evidence based and use sub- optimal critera to evaluate the information they find (13, 27, 54, 55); do not have insight into the ingredients of decision making about treatments (such as screening for breast cancer and childhood vaccination) including principles and processes of medical and health related research (56-60). Furthermore, studies have explored people's understanding of healthcare policy, such as the reasons for policy switches between using branded or generic drugs, or the rationales for preventive policies. These studies suggest that people may think that information is withheld or that implementation of a drug policy is solely driven by cost-concerns without consideration of safety and efficacy (56, 58, 61, 62). The results of these studies have highlighted the great potential for improving health literacy and point to the fact that people's health literacy skills are poor in terms of one or more of the four domains defined by Zarcadoolas and colleagues (8).

Previous interventions targeting health literacy

Presently, most interventions have been developed to improve the functional literacy of patients. Such interventions have adopted a medical literacy approach and have been limited to evaluating the abilities of patients to read, use numbers and the impacts of this on context-specific health behaviour such as adherence to treatment regimes (6, 17, 18). But advice based on reviews of the health literacy literature and studies of conceptual development have extended this focus to include recommendations about the development of initiatives that target critical and interactive skills. This focus goes beyond functional literacy to include a public health perspective (6, 8, 17, 18). Further interventions are needed that target 'generic' health literacy skills, and which are not restricted to a specific health decision or illness (63). Only a few studies have been done in this area, targeting skills such as science literacy and critical appraisal of health information (39, 64).

The field of research related to user-directed interventions to enable health literacy skills is in rapid development. Such interventions can be broadly divided into three main categories: written information, alternative format resources (such as health informatics), and mass media interventions (6). These main categories are not necessarily exclusive, and interventions can include one, two, or all of them. Evidence suggest that interactive solutions, such as websites, may be more effective educational strategies, and have been associated with improved knowledge, high user satisfaction, and beneficial effects on self efficacy and health behaviours (6, 65-67).

Complex problems may require complex interventions

The methodological development of research on change and quality improvement is an important and expanding new field of research (68, 69). Such research is often complex given the many potential intervention points and components (68). Methodologists and health services researchers argue that it is unrealistic to expect that one simple improvement measure would be enough to solve all problems, and that research questions are best addressed by what are often referred to as *complex interventions* (68). These are characterised by several interacting components and use multiple research methods, including both qualitative and quantitative designs (68, 69). Moreover, the complexity of these interventions may also include variations in the number and complexity of behaviours studied, the inclusion of heterogeneous target groups, and the measurement of a range of different outcomes (69, 70). The purpose of complex interventions is usually to optimise patient care and improve health and life quality, but it is also to develop sustainable strategies that work in practice, not just in the laboratory (69, 70). This multi-disciplinary field draws upon knowledge and methodologies within epidemiology, the social sciences, educational sciences, organisation and management science, and economics (68).

Several methodological frameworks for complex interventions exist and a single optimal one has yet to be found. However, there are guiding rules that have been advocated by methodologists (69, 70). For instance, an explorative yet systematic and transparent approach is encouraged when designing complex interventions (69, 70). A complex intervention is also generally defined as including several steps or phases (although these may not necessarily follow in a linear sequence) (69, 70). The model by van Boekhoven and colleagues (2004) provides a transparent overview of the phases they included and was used to inform the overall design of

this project. These phases are: the identification and analysis of the problem, the development of intervention, piloting/feasibility testing, and implementation and evaluation (see Figure 2) (70).

Central to the problem formulation phase is the identification of important barriers and facilitators to change (68-71). This can be done through literature searches, the involvement of target group representatives or other stakeholders, and by conducting qualitative and quantitative explorative studies (68-70, 72). An intervention can then be tailored to address such barriers and facilitators through the choice of the form of intervention delivery and its content. In many cases, more facilitators and barriers are identified than it is possible to address within a single intervention, and choices need to be made about which ones to prioritise (70). These choices depend on their perceived importance, changeability, and a consideration of practical issues such as the resources available (70).

Complex interventions may be evaluated using several designs. However, depending on the actual research question, some designs may be better suited than others (73). Whereas qualitative designs and cross-sectional studies may be useful tools for feasibility or process evaluations, experimental designs – and, more specifically, randomised controlled trials – are best suited and introduce less risk of bias when the effects of the interventions are evaluated (69, 73).

Problem/target for improvement

Problem analysis
- Describe problems in quantifiable measures of quality of life, health and quality of care
- Describe barriers and facilitators, both personal and in the external
- Describe target population in terms of subgroups, stages of change

Design of intervention
- Specify intervention objectives
  - State expected changes in behaviour and external
  - Specify performance objectives
  - Specify barriers and facilitators
  - Create matrices of intervention objectives
- Select methods and strategies
  - Brainstorm on methods
  - Translate methods into practical strategies
  - Organise methods and strategies at each level
- Design the programme
  - Operationalise strategies into plans, considering implementers and sites
  - Develop design documents
  - Produce programme materials

Pretest
- Testing materials – readability and usefulness of materials
- Pilot test   – acceptability for target population
- (Randomised) trial – understanding of messages
                     – coherence of programme
                     – feasibility of time schedule
                     – effectiveness of programme

Adoption and implementation
- Write implementation plan
- Implementation

Evaluation
- Write evaluation plan with effect measures and process measures
- Evaluate

Adjustment

Figure 2. Model describing phases of complex interventions by van Boekhoven and colleagues (70)

Parents' decision making as a case

Although the target group of the intervention developed in this project was the public in general (and all health decisions), decision making by parents was used as the case for this thesis. There were several reasons for this. At this life stage, parents typically have many questions about treating and preventing health problems. They are also healthcare users with the highest number of health visits per year, both for themselves (a mean number of visits per year of 4.6), and for their children (mean number of visits of 3) (74). Parents, generally being young, are also statistically more likely to search for health information online (28). Furthermore, parents are faced with a range of health issues to consider. One such issue is deciding about child vaccination, and this was chosen as the particular focus in this project. We assumed that when we examined the issue of decision making it would be easier for participants if the discussion related to a concrete decision. Moreover, decision making about vaccination is complex and reflects many of the changes in contemporary healthcare discussed earlier in the Introduction of this thesis. For example, childhood vaccination has been a topic for discussion in the media for many years, and numerous strong and often conflicting opinions about both important benefits and serious side-effects have been expressed in the public debate (15, 58, 75-77). Finally, given that vaccination is voluntary in Norway, this option was seen as a health decision that the majority of the population would need to make.

Aims

The overall goal of this project was to improve people's health literacy skills related to obtaining health information through an intervention targeting key identified barriers and facilitators, and to evaluate this effort. This objective was addressed using both quantitative and qualitative methods, and included three phases (see also Figure 3):

Phase 1: Analysing the problem and identifying barriers and facilitators to change

a. Firstly, we conducted qualitative interviews with parents and public health nurses in order to:

- Explore decision making related to a common case (childhood vaccination) and what informed such decisions, and to

- Identify perceived barriers and facilitators to obtaining information so that these could inform the development of a questionnaire to further explore them and enable them be targeted by the intervention. These findings are presented in Paper I and II.

b. Secondly, we developed and conducted a questionnaire study based on the findings of the previous qualitative study, supplemented by a literature search in order to:

- Identify important predictors associated with intention to search for health information so that these could be targeted by the intervention (Phase 2), and to

- Provide a tool that we could use to evaluate the effects of the web portal in the randomised controlled trial (Phase 3). These findings are presented in Paper III.

Phase 2: Designing the intervention

In the second phase of the project, we developed a web portal, integrating the lessons from the web portal pre-studies with findings from a literature search. The purpose of this phase was to:

- Tailor the web portal in a transparent and systematic way, so that it addressed key barriers to obtaining reliable health information using evidence based strategies. This development is presented in Paper IV.

Phase 3: Evaluating the intervention

The final phase of the project included an evaluation of the web portal in a pragmatic randomised controlled trial. The purpose of this was to:

- Evaluate the effects of the web portal intervention compared to no intervention in a real life setting. These findings are presented in Paper V.

As Figure 3 shows, we also planned for user testing which would involve potential members of our target groups. Given the size of this project, this work was not lead by me but by a Masters student in Clinical Nursing Science, Stein Ove Danielsen, at the Oslo University College, who was invited to prepare and conduct this user testing work. This work was undertaken as a part of his masters thesis and is therefore not included in this dissertation (78). However, the findings of his study were important for the development of the web portal, and the methods and main results are therefore briefly referenced in this dissertation, with the permission of Stein Ove Danielsen.
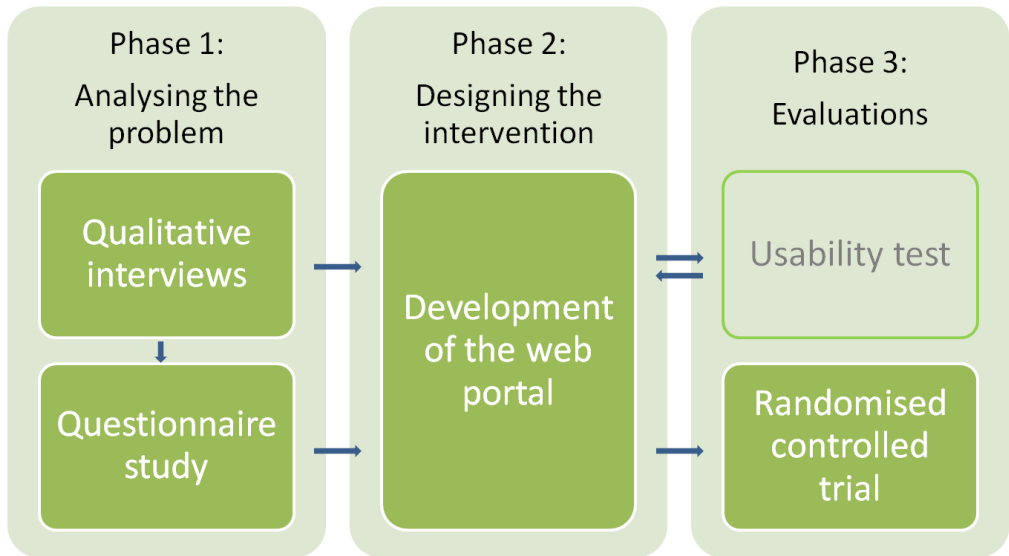
Figure 3. Project outline showing the three phases

Methods

Analysing the problem and identifying barriers and facilitators to change

When planning an intervention, the use of qualitative studies is highly recommended for exploring concerns that really matter to users (72, 79). Using a grounded theory approach and semi-structured individual and focus group interviews, we explored the decision making about childhood vaccination made by parents of pre-school children and by public health nurses. In this study we aimed to identify perceived barriers and facilitators to obtaining health information (80-83). Grounded theory has been found to be particularly well-suited when research is explorative, and is a systematic yet flexible approach for '*learning about the worlds we study*', and is *'a method of constructing theory grounded in the data itself'* p10,(80).

Parents and public health nurses were recruited from the same maternal and child health centres. Three districts in a major Norwegian city were chosen using strategic sampling to represent diverse socio-economic backgrounds. These included one maternal and child health centre on the west side, one on the east side, and one in the city centre which serves a mixed population. Parents of pre-school children who had made a decision about childhood vaccination within the previous three months were invited to participate, and a total of 10 parents was included. We aimed strategically in our initial recruiting to include those characteristics previously identified as influencing the studied behaviour (i.e. information retrieval), such as age, sex and education (27, 84).

The public health nurses were recruited using pragmatic convenience sampling; all the public health nurses who volunteered – a total of 16 – were included. The interviews were led by

me, assisted by a nursing student who was the interview secretary, and the sessions were taped and transcribed as part of the analysis process. Data were coded 'incident by incident' so that key concepts could be identified, and the analysis was performed continuously (80). In the final stage of the analysis we created a chart based on the principles of axial coding to explore connections between the categories (80). To complement the grounded theory approach, we drew also on framework analysis when managing the data (85). To improve the credibility of the reading and interpretation of the data, this was done independently by me and an additional researcher who was trained as a public health nurse. The interview guide included general topics relating to what had informed the decision to vaccinate, as well as the facilitators and barriers to searching for health information (see Appendix 1 for a copy of the interview guides).

The use of evidence based theory may be useful for tailoring interventions, providing the development process with structure and transparancy (86, 87). We developed and conducted a questionnaire study, based on the theory of planned behaviour (TPB), to explore which cognitive factors predict the independent search for health information outside consultations (79, 88). The TPB is a rigorously tested and widely used social cognition model (79, 89-91) and previous studies have used the TPB model to explore behavioural intentions across a range of health related behaviours and professional practice (92-98). The TPB model has also been applied successfully in the tailoring and evaluation of interventions (79, 92, 98-100).

The questionnaire was developed based on an operationalisation of the Theory of Planned Behavior Manual by Francis and colleagues, that provided us with pragmatic and evidence based guidelines throughout the development process (79). According to the TPB model, three variables influence behavioural intentions, namely: attitudes towards the behaviour, subjective

norms, and perceived behavioural control (79, 88). These variables are measured using both *direct* and *indirect* measures. Whereas direct measures describe respondents' overall assessment, indirect measures probe the underlying specific beliefs and outcome evaluations associated with these overall assessments (79). Standardised items were used to measure intention to search and direct measures of variables, as recommended by the TPB manual. Items describing indirect measures were created based on beliefs identified in the qualitative study described above and through a literature search (79). The application of the TPB questionnaire was intended to explore, identify and evaluate beliefs associated with the search for information related to an intervention to improve specific domains of health literacy. This aim was also reflected in the choice of the specific beliefs included in the questionnaire. Consequently, the specific beliefs chosen were (changeable) factors related to domains of health literacy (with the exception of subjective norm).

The questionnaire was tested twice on two samples. The first sample was taken from the general population. A sample of 100 men and 100 women was drawn from three separate districts of Oslo, the capital city of Norway (these were the same district divisions used in the qualitative study described above). In order to include those who were most likely to have internet access, we decided to exclude people over the age of 65. The questionnaire was administered by post and included a pre-stamped envelope. One reminder letter was sent, and a lottery for a small gift certificate (value 750 NOK) was held as this has been shown to improve response rates (101). The second sample consisted of parents. The questionnaires were administered face-to-face at the local maternal and child health centre and associated shopping centre in a district of Oslo and we aimed to include 80 respondents. All data were entered according to the manual guidelines for the SPSS statistical program, and the items were recoded (79). Datasets were explored to identify

missing and illogical values (79). New composite scores were created for intention, direct and indirect measurements and descriptive analysis was done to describe the background characteristics and the distributions of the measures (79). The questionnaire was tested for internal consistency by calculating inter-correlations between theoretically-related constructs, and by using multiple regression analysis. This was done by exploring: a) the internal structure (reliability) of the items measuring the same construct of intention to search, as well as the homogeneity of direct measures (where Cronbach's Alphas values above 0.6 were considered to be indicators of acceptable consistency) (79), b) the nomological network proposed by the TPB model (by computing simple bivariate correlations using Pearson R between the mean composite scores of the direct, indirect, and intention to search measures) (89), and c) the relationship between indirect and direct measures through a multiple regression analysis in which the mean composite score of the indirect measures for each construct were the independent variables and the corresponding mean composite direct measure were the dependent variables (79).

Finally, we tested the overall potential of the questionnaire for predicting intention to search, and identified the predictive strength of each direct measure, by performing a multiple regression analysis in which the three mean composite scores of each direct measure (attitude, subjective norm, and perceived behavioural control) were the independent variables, and the mean composite score of intention to search measures was the dependent variable (79).

Designing the intervention

Decisions related to the content and main focus of our intervention, namely which specific health literacy skills to improve, were informed by the pre-studies described above as well as a review of existing literature identified through literature searches (102-104). The findings from these suggested several areas of improvement related to all the identified domains of health literacy: functional literacy (numeracy), science literacy, civic literacy (system and roles) and cultural literacy (the understanding of concepts related to decision making about healthcare). These were grouped into three key barriers related to obtaining information. Following this, potential targets for intervention were identified and these are briefly described below.

Barrier 1: The inability to understand and critically appraise health information

We identified the inability to understand and critically appraise health information as a key barrier to obtaining information (102, 103). Understanding research information and the quality criteria for assessing health information is essential, and studies have found that people may not effectively check the accuracy of health information they find, may overrate the trustworthyness of such information, and have poor understanding of health and medical related research (13, 25, 27, 54, 60, 105). In particular, concepts such as 'randomisation', 'risk', 'uncertainty', 'causality' and 'applicability' need to be addressed (56, 57, 59, 60, 105-109).

Barrier 2: The inability to exchange information in consultations

A second major barrier to obtaining information is the inability of users to exchange information which is important to their decision making during consultations with health professionals (102). Consultations are an important arena for health information exchange. However, studies have found that these exchanges are often sub-optimal (9-11, 20, 102, 104). Often users are unaware of their rights, what to ask their provider and may not be able to remember what they have been told (9, 10, 20, 102).

Barrier 3: Not knowing where to find reliable and relevant information

The third major barrier we identified to obtaining health information is the inability of users to know *where* and *how* to find reliable and relevant information (102, 103). Specifically, users feel overwhelmed and frustrated by the vast amount of information available and unsure about who or what they should trust (27, 110). Furthermore, evidence based information is not readily available to the public (12-14, 16). As a result, user searches for health information may be haphazard and rely on general online searching engines (26, 28), or advice from family and friends, news sites or discussion forums that may potentially contain information of poor scientific quality (12-16, 111).

Our web portal was therefore tailored to address these three key barriers to obtaining information and below we describe the decisions taken and strategies used to address these barriers.

The choice of a web portal as the intervention delivery approach was based on our reviews of related literature which indicated that web-based interventions may be more sustainable and more effective than conventional information strategies (6, 65, 66). The target audience of our web portal was the general public and our aim was to provide an easily accessible resource for lay people searching for health information that they could either use independently or during consultations with health professionals. We chose a design template for the web portal that met recommended accessibility standards (112) and presented the content in compliance with the standards recommended by Health On the Net Foundation's 'Code of Conduct for Medical and Health Web Sites (HONcode)' (38).

Furthermore, we sought to root the development of the content within the conceptual frameworks of shared decision making and evidence-based practice (1, 5, 113). This meant that we aimed to: encourage active user involvement; promote the importance of basing decisions on the best available evidence; and to include content that could facilitate skills and the development of knowledge (rather than adherence to any specific regime). The content was presented using mixed media, real-life examples, plain language, and the provision of information in small and 'digestible' quantities (6, 20, 114-116).

Although the purpose of the web portal was educational, a key objective was also to develop an easy-access point to practical tools and evidence. We therefore organised the content in the form of a set of tools. We decided to have three facilitators – or toolsets – to address each of the three main barriers to obtaining information, and these are briefly described below:

Toolset 1: Improving critical appraisal skills

We provided an introduction to the basic research methods of medical- and health-related research (8, 113, 117-121). We also searched systematically in the literature for checklists that would enable users to critically appraise health information by addressing key quality domains (122, 123). For a checklist to be included in the web portal, it had to be generic and applicable to all settings and preferably evaluated for construct validity and inter-observer reliability. All the references identified were read both by a fellow researcher and by me, and all the potentially relevant tools were retrieved. The final selection was done by me and reviewed by the fellow researcher. Studies that have aimed to improve users understanding of research and critical appraisal skills is scarce, but suggest that such efforts are feasible, may improve knowledge and confidence and are perceived as useful by users (39, 64, 124). Standardised tools such as checklists used for critical appraisal may produce ratings that are similar to that of professionals and assist the user in selecting information (125).

Toolset 2: Enabling exchange of health information

We decided to include basic information about the rights of patients to participate in decision making (3). In addition, we included information about what decision making related to treatment or screening options entails (113, 117, 118, 126). We also searched systematically in the literature for checklists or decision aids that could be used in consultations. Decision aids have been found to be effective tools for improving peoples' knowledge of health options, their

expectations of possible benefits and harms, their ability to make decisions consistent with their informed values, and increasing participation in decision making (127).

To be included, the tools had to be generic and applicable to all types of consultations. The purpose of the tool also had to be to provide information about the condition of the users and the options available, to help to people clarify their values, and to help them to share their values with their health provider and others (128). The final selection was done by me and reviewed by my fellow researcher.

Toolset 3: Improved access to reliable research-based sources of health information

We aimed to improve access to reliable sources of health information by providing direct access to medical- and health-related research databases. The key criteria for selecting databases were: that the information should be based on empirical research, that the databases should reflect different study types and levels of synthesis, rely on explicit and systematic criteria (if reviews of summaries of research), and be freely available to the Norwegian public. The final database selection was done jointly through a discussion in the project group and in consideration of the above criteria. Furthermore, we decided to build this toolset section using the guidelines for evidence based practice, adapted to a lay audience by us (1, 113).

Evaluating the intervention

Evaluation should be a central element in the planning of all interventions (69, 70). Important foci for such evaluations include feedback about user experiences and about relevance (69, 70). Throughout the development process, the project protocol, the selection of the tools, and the final portal itself were presented to an advisory group for peer review and professional feedback. In addition, usability testing was conducted through a qualitative evaluation in which a mixed group of 17 people (including representatives from patient organisations as well as healthy users), were invited to evaluate and comment upon their user-experiences of the web portal. This evaluation was based Morvilles Honeycomb model (78). This model, a useful instrument frequently applied to measurements of user experiences of websites, encompasses seven domains to assess whether a website is: accessible, usable, credible, valuable, findable, desirable, and useful (78, 112). In specific analysis, the domain 'findable' was not tested because the web portal had not yet been made official. Based on feedback from the advisory group and the user representatives, the web portal was updated and finalised before it was evaluated in a randomised controlled trial.

In order to evaluate the effects of the web portal in a real life setting, we chose a randomised controlled parallel design with a simple randomisation procedure. We wanted to include typical target-group users for the web portal in the study's participant sample. In addition, we wished to increase the probability that the portal would be used by participants in association with their visits to health professionals during the trial. Parents with children under the age of 4-years were therefore targeted, as they were highly likely to search for health information and to

have contact with the health services (28, 74). Similarly, the issue of vaccination was selected given that it is a very relevant topic for this particular group.

Based on a power-analysis, we estimated that a sample size of approximately 140 people was needed. Information about the study was distributed at maternity and child health centres and through online advertisements and social media. Those who were interested and wished to participate were directed to a recruitment web page. Here, people received information about the study and were asked for their consent to participate and to fill in an online questionnaire that enabled inclusion criteria screening. People were excluded if anyone else in their household was already participating in the study (to ensure that the participants were blinded and to protect against potential sample contamination), and if they did not have children aged <4-years. Parents were allocated to receive either access to the portal or no intervention, and assigned three tasks to perform over a three-week period. These tasks were: a searching task in which parents were asked to formulate a question about a health issue and to find information related to this question; a critical appraisal task about online swine flu vaccination information; and reporting on perceptions about participation related to independent search for health information and overall activation.

All the information was delivered online and data were collected using an online questionnaire system. The study was single blinded in that participants were not informed about which study group they would be allocated to. We planned to collect data from March to the end of June 2011. The main outcomes were: beliefs about searching for health information and overall activation (participation), use of research-based information, and the development of critical appraisal skills. In addition, we also wanted to obtain feedback from the participants

regarding their satisfaction with the web portal. Participation was measured using our previously developed TPB questionnaire and the patient activation measure (PAM) (129). The use of evidence based information was measured by calculating the relative risk between groups in terms of their use of research, and critical skills were measured using the DISCERN tool (125). Satisfaction with the portal was measured using Morvilles Honeycomb criteria (112) .

All analyses were performed using available cases, but based on the principle of intention to treat (ITT) (i.e. all participants were analysed in the group to which they were randomly assigned). Given the opportunity that this trial offered in terms of further testing the utility of the TPB questionnaire, we decided therefore to test the internal reliability of the item measuring intention and direct measures. We also tested the relationship between the mean composite scores of these measures (the nomological network) for the responses of the whole sample in the same way as was done in Paper III. Data were treated anonymously and ethical approval was granted by the Norwegian Social Science Data Services (NSD) and the Regional Committees for Medical and Health Research Ethics (REK), Norway. The trial was registered at ClinicalTrials.gov under the identification number NCT01266798.

Results

Decision making by parents, and barriers and facilitators to obtaining information

In the qualitative study, we found that parental decision making about childhood vaccination was based on both trust and common sense. 'Being positive towards vaccination' and 'being decided' were found to be main barriers to participation and obtaining information. Other factors were own 'abilities' and 'capacity'. Consequently the parents were found to have had little involvement in the decision making, and in influencing the information obtained during consultation and their own searching behaviour. Parents suggested that their searches for information would be facilitated if public health nurses were able to recommend reliable internet sites to those who wanted information beyond what had been given during consultations.

Although the level of parents' involvement in decision making was low, they had significant expectations of public health nurses and the nurses were seen as their most important source of information. Parents emphasized the public health nurses' crucial role. However, the public health nurses were found to inform to facilitate vaccinations and not an informed decision in itself. Thus, potentially leaving those who where positive towards vaccinations less informed than those being more critical. The public health nurses were also not necessarily considered by the parents to be balanced in the way they provided information, and were perceived as being biased towards the positive effects of vaccination. There was also confusion about the discrepancy between the information presented by public health nurses and what the parents had

learned through media reports or stories from family and friends, particularly with regard to the potential harms associated with vaccination.

Issues related to the small amount of parental involvement included parents reporting that they had little knowledge about the diseases and about vaccination. Furthermore, some expressed low levels of confidence about the decision they had made and uncertainty about their rights and responsibilities in decision making.

The public health nurses only occasionally looked up extra information in their work related to childhood vaccinations and this information rarely included research. Instead, the most important sources of information the nurses consulted about vaccination were the Norwegian national guidelines and other information issued by Norwegian National Institute of Public Health. They also consulted peers, superiors, other health personnel, referred to their own professional experience, textbooks, mass media reports, the internet, and the information from the pharmaceutical industry. The public health nurses stressed the importance of providing the best possible quality care and reliable research was considered central to this. Three main facilitators to the use of research were identified during the focus groups: being able to base practice on solid knowledge, the belief that the use of research was important for professional development and necessary, and the need to meet parental demand for extra information. Despite these facilitators, the nurses were reluctant to do so. The main three barriers identified that prevented them from doing so were: a belief that searching for research findings and using them was 'not part of their role'; and their perceived 'limited critical appraisal skills' and 'capacity'. Thus, research was seen as something that should be managed centrally and quality-approved by a higher authority.

In the questionnaire study we quantified some of the findings from the qualitative study. The response rate to our questionnaire was low, with only 16% (n=30) in the mixed population sample and 43% (n=45) in the parent sample. The distribution of age and sex in the mixed population was evenly distributed. In the parent sample, females and people in the age category 31-40 were overrepresented. In both samples, those with higher education were also overrepresented.

In the reliability analysis of the items measuring each direct measure respectively, one item (measuring perceived behavioural control) was found to be very poorly inter-item correlated with the other items which described the same construct across both samples, and was therefore subsequently deleted. The Cronbach's Alpha for the remaining items ranged from satisfactory (0.66) to very good (0.98) across the samples. When examining the theoretical relationship between variables (nomological network), the mean composite scores of direct measures and intention were found to be positively and significantly correlated with intention to search, with the exception of subjective norm which was not found to be significant. Inter-correlations were also found between the direct measures, where subjective norm and perceived behavioural control correlated with attitude. Five single items measuring indirect measures, which were found to be very poorly inter-item correlated with their corresponding direct measure, were deleted. The remaining items and mean composite indirect measures had positive and significant correlations with their corresponding direct measures, with the exception of perceived behavioural control in the parent cohort, which was only borderline significant (p=0.07). The association between the mean composite indirect measures and intention to search followed the same pattern as the direct measures. In the regression analysis, the composite indirect measures in the mixed and parent samples explained 53% and 48% of the variance in direct attitude, 25% and

12% of the direct subjective norm, and 20% and 8% in the direct perceived behavioural control components respectively. The final questionnaire contained 31 items as well as a set of demographic background questions (see Appendix 2 for a copy of the questionnaire, items 1-20).

Overall, the mean intention to search was high in both samples: 4.9 for the mixed population (SD=1.86) and 5.4 (SD=1.09) for the parent sample (range from 1 to 7). In both samples, the intention to search was higher for those with college or university education. The assessments of the mean direct measures for the mixed population and parent samples respectively were: 5.4 (SD 1.5) and 5.6 (SD 1.3) for attitudes, 3.3 (SD 1.3) and 3.6 (SD 1.5) for subjective norm, and finally 4.7 (1.6), and 5.2 (1.2) for perceived behavioural control (ranged from 1 to 7). For indirect measures, the mean assessments of the composite scores for the mixed population and parent samples respectively were: 45.0 (SD 25.6) and 40.3 (SD 26.3) of a possible -84 to + 84 for attitude, 13.9 (SD 18.4) and 14.3 (SD 17.5) of a possible -63 to +63 for subjective norm, and -12.6 (SD 23.6) and -3.0 (SD 19.8) of a possible -63 to +63 for perceived behavioural control.

The direct measures of overall prediction of intention to search accounted for 47% of the variance in behavioural intentions in the parent sample and 55% in the mixed population respectively. The strongest positive predictor of intention to search was perceived behavioural control in the mixed population sample (β=.66, p=.00), followed by attitudes β=.38, p=.09. In the parents sample, the strongest predictors were attitudes (β= .51, p=.00), followed by perceived behavioural control .15, p= .25. In both samples, subjective norm had a negative predictive effect, with β=-.08, p=71 in the mixed population sample, and β=-.25, p=.01 in the parent sample.

Choice of intervention delivery and content

The portal was developed based on á priori design principles and published on the site www.sunnskepsis.no. It met the recommended standards for website accessibility and was in compliance with the HONcode (38). Overall, the portal content was illustrated using practical examples that people could relate to. The content was presented in ways that encouraged users to adopt an active role in decision making and encouraged them to see that decisions about healthcare should be informed by the best available, current, valid, and relevant evidence. Central to the design of the structure of the web portal were three sets of tools, each presented in an easily accessible and logically structured way. These are briefly described below:

Results Toolset 1: Improving critical appraisal skills

General introductions to research methodology, research ethics, and applicability of research findings were provided throughout the portal (8, 113, 117-121). In our search for critical appraisal tools, only one tool met all our inclusion criteria (125) and this – the Norwegian version of DISCERN – was included both as a printable checklist and as an interactive tool (130).

Results Toolset 2: Enabling exchange of health information

We provided an introduction to decision making about treatment and screening and described the right to participate in decision making (3, 113, 117, 118, 126). In our search for checklists or decision aids, we only identified two tools that met our criteria (118, 131). We

included the tool developed by Irwig and colleagues and this was translated into Norwegian and

adapted to the web portal with the permission of the authors (118). Because the decision aid did

not include an item related to user health conditions/diagnosis, it was further supplemented using

IPDASI criteria (128).

Results Toolset 3: Improved access to reliable sources of health information

We developed a toolset which was based on the steps of evidence based practice (1, 113).

These steps were adapted for the lay public to facilitate direct access to research-based

information and to provide a path through the information retrieval process. This was done by

giving an introduction to problem formulation and the corresponding study design(s), a

description of each database, and tips on easy search strategies and how to assess the relevance of

the information (113). We also described different levels of synthesis (113, 132).

Usability and effectiveness of the web portal

The feedback from the advisory group proved valuable for the quality assurance of our

project. Furthermore, the results from the usability testing with members of our potential target

groups were encouraging: the overall rating of the web portal was in keeping with optimal

estimates for a beta-version of a website (approximately 70%) (78). The summary of the ratings

per usability category from the interviews is presented in Appendix 3. In general, all the

suggestions made led to changes. In cases where the feedback was not taken into account, this

was because the proposals conflicted with the intention of the web portal to improve health

literacy skills or because the suggestions were not technically possible. These suggestions are explored in more detail in Appendix 4 which provides a summary of the suggested changes and the final solutions chosen.

The final web portal was evaluated in a randomised controlled trial. A total of 100 participants signed up for the study. Of these, four did not meet the inclusion criteria. The remaining 96 were included in the study: 47 were randomised to the intervention group and 49 to the control group. The overall response rates for the intervention group and control group were 60% (n=28) and 80% (n=39) respectively. There was a small but borderline statistically significant (p<0.06) difference between the intervention and control group in terms of loss to follow-up: more were seen to drop out of the intervention group. Background characteristics were similar across those who participated in one or more of tasks, but the mean level of education was slightly higher in the control group.

An overview of the ingredients of the intervention and the variables hypothesised to influence the study's outcomes is provided in Table 1. This describes the specific health literacy domain that each of these variables is thought to touch upon. In the table, I also describe which instruments were used to measure each domain.

In the searching task, two research-based sources were identified in the intervention group, and one in the control group. The relative risk was 2.8 (CI 0.3-29.2) (p=0.39) favouring the intervention group. In the critical appraisal task, the mean rating of the information was 2.41 (SD 0.80) by the intervention group and 2.44 (SD 1.02) by the control. The mean difference was -0.03 (p=0.904) favouring the intervention group.

The overall activation (PAM) score was 66.5 in the intervention group and 61.9 in the control group (possible range 1-100 with better indicated by higher), and the mean difference was 4.61 (p=0.20) in favour of the intervention group.

In the reporting of respondent beliefs associated with searching, a statistically significant difference of 0.63 was found for direct assessment of attitude: 0.6 (p=0.03) in favour of the intervention group. The mean the differences for the direct assessment of subjective norm (-0.2; p=0.49) and perceived behavioural control (0.41; p=0.15), as well as the indirect measures, were not statistically significant. The direct measurement of attitude was the most important positive predictor of intention (B=0.51; p<0.002), whereas the predictive strength of direct measures of subjective norm and perceived behaviour control were -0.15 (p=0.25) and -0.06 (p=0.72) respectively.

The internal consistency (Cronbach's Alpha) of the TPB questionnaire's main components (intention and direct measures) for the complete sample ranged from 0.64 to 0.90. The inter-correlations between theoretically-related constructs was consistent with previous testings (see Appendix 5)

The mean respondent usefulness rating of the web portal was 4.71 (SD 1.11), the mean usability rating was 4.14 (SD 0.97), and the mean credibility rating was 4.75 (SD 0.93) (possible range 1-7).

Barriers identified in pre-studies and literature search	Facilitators/content of intervention	Health literacy domains	Evaluated in pragmatic trial
All	Shared decision making (promoting an active role) and evidence based practice as conceptual framework (promoting evidence based decisions)	Civic literacy (system and relationships) Science literacy	TPB *(attitude and subjective norms associated with search) PAM**
Inability to understand and critically appraise health information	Improving critical appraisal skills *Introduction to scientific concepts and (checklist for) evaluating trustworthiness of health information*	Science literacy *Examples: Validity, uncertainty, causality* Functional literacy (numeracy) *Example: Understanding risk* Civic literacy (media literacy) *Examples: How research and scientific discourse are presented in the media*	Searching task Critical appraisal task TPB (perceived behavioural control and attitudes towards search)
Not knowing where to find reliable and relevant information	Improved access to reliable research based sources of health information *Introduction to searching for evidence based information (adapted EBP-model)*	Science literacy *Examples: Basic study designs and assessment of relevance* Civic literacy (media literacy) *Examples: Search strategies, publication types and sources*	Searching task TPB (perceived behavioural control and attitudes towards search)
Inability to exchange information in consultations	Enabling exchange of health information *Introduction to clinical decision making and checklist for the consultation*	Science literacy Civic literacy (system and relationships) Cultural literacy (understanding of concepts used in decision making about health care)	PAM

*Theory of planned behaviour **Patient activation measure

Table 1. Overview of the intervention components, corresponding health literacy domains hypothesised targeted and measurements to evaluate these

Discussion

This project contributes new knowledge to several areas. Although the included sub-studies are part of a greater whole – the purpose of which was to improve health literacy skills related to obtain health information – these should also be seen as independent studies describing specific areas related to decision making by the users of healthcare.

Previous research exploring decision making and participation related to childhood vaccination has generally targeted attitudes towards vaccination or adopted a provider-led decision making perspective. It has also focused on issues of adherence and sub-optimal vaccination coverage. Although these issues may be important, such studies provide little information about those who *do* decide to vaccinate, the decision making process itself, what informs the decision, and the barriers and facilitators to obtaining information. Furthermore, although several studies have explored the use of evidence based practice by health providers and the barriers associated with this, few – if any – have focused on public health nurses. Public health nurses are key mediators and moderators of health information in the community. Their practice covers a wide range of health topics and is vital for the general public at key life stages. Our study of parents and public health nurses therefore contributes new knowledge to these areas by identifying areas of improvement in order to facilitate informed decision making and potentially identifying targets for intervention.

Although health professionals are an important source of health information, independent searches for such information by health users are an important part of participation. Being updated on the latest health information is a precondition for effective participation both in

consultations and in public debate, as well as for the management of personal health. Other studies describing searches for health information have generally focused on personal characteristics and sources of health information. To our knowledge few, if any, studies have explored the cognitive factors that predict intention to search. By doing so, our cross-sectional study expands the body of research describing searching behaviour. Moreover, the instruments available for measuring health literacy skills are few and generally focus on reading and numeracy skills (functional literacy). The TPB questionnaire thus also provides a new way of mapping and evaluating specific domains of health literacy related to search.

The development of interventions is often unsystematic and poorly reported. An important part of this project was to identify and integrate user needs and preferences with the evidence from the research literature in the development of our intervention. This was done in a systematic and transparent way within a conceptual and theoretical framework. Although online resources have been created in other international settings, no such resource is available in Norwegian. The web portal is therefore a unique resource for improving not only public access to evidence based health information, but also for providing practical tools that can be used independently by users or in consultations with health professionals.

In the randomised controlled trial, we sought to evaluate the extent to which the web portal could improve the use of evidence based information and health literacy skills in a real life setting. The study also provided knowledge about the perceived relevance of the web portal by potential users. This information was valuable given that the purpose of the web portal and the concepts that it introduced would be novel to most users. The methodological considerations of these studies and our findings, and their implications, are discussed below.

Methodological considerations

In the first phase of this project we conducted qualitative interviews with parents and public health nurses using a grounded theory design. Grounded theory has been criticised for being reductionist and even quantitative in its approach, but the method has both objectivist *and* constructionist roots (80). Later methodologists, such as Charmaz (80), integrated these perspectives, adopting systematic, explicit and rigorous objectivist principles while acknowledging the subjectivity involved in the data collection process and analysis (80). In grounded theory, as in much of qualitative research, the researcher is not seen as independent to the research process. Instead, a researcher's discipline, background, and guiding empirical interest form the backdrop of the research and serve as points of departure (80). Consequently, findings (and theory developed from data) are not deterministic explanations offered to us as exact pictures of the world, but are seen as interpretative and explorative (80). In our study, the interdisciplinarity of the research team added different perspectives and viewpoints to the study about, for example, theoretical knowledge and clinical experience. The scope of the study and design of the interview guides and analysis were further influenced by the fact that the study aimed to inform the development of the TPB questionnaire and the web portal, targeting health literacy skills within the theoretical and conceptual framework of both shared decision making and evidence based practice.

The data were collected through individual and focus group interviews all of which were held at maternity and child health centres. Using these sites for the interviews may have had potential benefits (such as providing a familiar environment for users), but may also have had disadvantages. It was important that is was made clear to the parents that the moderators of the

study were not associated with the centres in any way. We were also explicit in explaining that the public health nurses would not have access to the raw data, so that this would allow parents to speak freely. For the public health nurses, the fact that the interview group included representatives from the management may potentially have moderated their responses. Although, our specific goal was to facilitate and balance the discussion in such a way that no one would be allowed to dominate the discussion, some participants may have adopted more conservative points of view.

The theory of planned behaviour informed the development and testing of the questionnaire. (79). An issue related to the measurement properties of the questionnaire was that the TPB is social cognition model, and therefore assumes that behaviour can be explained by primarily cognitive processes (89). In other words, it is what could be termed a 'complete' model of behaviour – all other possible factors are theorised to influence behaviour indirectly through these TPB components (89). A criticism which has been raised towards the TPB and which may be a limitation to our study is that the model assumes that all behaviour is rational (89). Thus, it may overlook other relevant factors such as for example affective or emotional variables which in the TPB are considered only as background variables mediating the TPB components (89). This assumption may therefore be a limitation to our study (89).

It should be noted that we did not compare intended behaviour (to search) with actual searching behaviour in the questionnaire study (or in the randomised controlled trial), and we therefore do not know the strength of this relationship. Although the measurement of the relationship between intention and actual participation – or the intervention effects of the web portal on potential increased searching activity – may be of interest in future studies, these was

not the main study objective of this project. Our main objectives and final end points were instead to facilitate skills (which may *enable* participation) but not necessarily to increase participation in itself. This being said, evidence across a range of TPB studies shows intention to be a valid proxy measurement and the relationship to be strong (90, 91)

The low response rate we experienced was a limitation of this study. Unfortunately, this is a challenge common to most questionnaire studies, and a response rate above 50% is usually not achieved (79). The extent to which this may have influenced the results of the questionnaire is unclear. Age and education are the factors most likely to influence searching behaviour (26-29), and the data set of those who chose to respond showed the distribution of age to be even across the age groups. However, people with higher education were overrepresented and this may indicate that people with lower education may have been less likely to respond. In addition, the overrepresentation of people with higher education in the sample may potentially have resulted in an overestimation of the overall score on intention (producing a higher level of intention) to search compared to a more mixed population. Unfortunately, we do not have data to enable us to explore these hypotheses further.

Another potential limitation to our study was that we did not perform a test-retest procedure, which is used as a psychometric method to test for reliability (79). We predicted that recruiting and achieving an adequate response rate would be challenging and therefore decided against asking people to do a retest. However by administrating the questionnaire to two different samples we were able to compare the questionnaire's consistency across them.

In the second phase of the project we developed the intervention. Complex interventions that are tailored to target important barriers to change are considered more likely to be effective

(69, 70). There is, however, no 'gold' standard' for how to develop effective complex interventions. A Cochrane review found that tailored interventions to improve professional practice improved processes of care and patient outcomes, but that there was insufficient evidence to determine the most effective approaches to tailoring, including how to identify barriers and how to select interventions to address identified barriers (133). Our decisions on what barriers to target and the choice of facilitators to address these barriers were based on our judgement of what we considered to be the most important barriers, if there were evidence based strategies available to address those barriers, and what was feasible given the resources available (69, 70). This meant that not all the identified barriers could be addressed, and a selection of barriers was thus made. Consequently, the intervention may not have included all the important factors, but it did include changeable and relevant variables that could help to improve public access to evidence based information and health literacy skills. Despite our efforts, important barriers and facilitators may have been missed or not appropriately addressed.

In the final phase of the project we evaluated the web portal. Its effectiveness was evaluated in a randomised controlled trial of a group of typical users in a real life setting, in what is referred to as a *pragmatic* trial (134, 135). A distinction is often made between explanatory and pragmatic trials. Explanatory trials aim to determine the effects (efficacy) of a precisely-defined intervention on a specific group of people under optimal conditions (134). Although such studies may hold high internal validity and provide important knowledge, the results may have applicability issues (134). Healthcare interventions are often complex in nature and must be addressed accordingly. Pragmatic trials are recommended as a way of achieving this through their measurement of the effects of an intervention in the same setting that the intervention will be implemented and under real-life circumstances (134, 135). Other important criteria for

generalisability are a minimum of exclusion criteria and ensuring that a large degree of freedom

is associated with the intervention (136). It should be noted that although a clear distinction is

often made in the literature between the approaches used in explanatory and pragmatic trials, in

practice they are not dichotomous and should be seen as part of a research continuum (134).

Pragmatic trials are used to inform practice and the methodological choices that are made will

reflect this (134). By using a pragmatic approach, the intention of this study was to maximise the

external validity and thus to ensure generalisability. These advantages must be weighed against

threats against the internal validity introduced by the real life setting (136). These criteria and

considerations were embedded into the design and execution of our trial. All parents with

children under the age of four years were included and participant exposure to the intervention

was flexible: parents were free to respond to the tasks in their own time and at leisure within a

familiar environment. The degree to which we were successful in blinding the parents to the

intervention is unclear, but several measures were introduced to ascertain this making it unlikely

that this influenced the outcomes to a large degree. All participants were informed that they

would receive the portal but at different time points, and standardised and automated

communication and data collection methods were also important measures used. Such systems

also reduced the risk of potential errors as data could be exported directly into Excel and SPSS

for analysis after the trial. This was also logistically beneficial as it provided us with a

time-saving and cost-efficient strategy for managing the study and made it easier to keep track of

response rates and sending out tasks and reminders.

The trial was also limited by the fact that we were not able to recruit as many participants

as intended and because the study also suffered some loss to follow-up. The background

characteristics between participant groups were very similar, except for the level of participant

education, which was somewhat higher in the control group. This may mean that we underestimated the improvements in the intervention group given that education has been found to be partly correlated with health literacy skills (17). It is difficult to speculate about the reasons for the loss to follow-up: the majority of the dropouts gave no reasons for leaving. The fact that the loss to follow-up happened between the time of the first screening questionnaire and the time of the first task may indicate two things: firstly, that the tasks were considered too extensive and, secondly, that people joined the study primarily in order to receive access to the portal. Once they had been access, they may have dropped out before the first task was given.

Capacity, abilities, and the perceived need as barriers

The interviews with parents and public health nurses provided complex data. When we explored the decision making it was evident that the participation of parents as well as public health nurses took the form typical of a traditional provider-led decision making model, but that there was also confusion about roles and expectations. While parents expressed a desire to be involved they were passive at the same time and demanded much of the public health nurses. The public health nurses stressed the right of parents to make a free choice, but were also reported to have given parents the information in a biased way that facilitated vaccination. In other words, their method of informing was characterised by persuasive information delivery in which the main goal was to achieve adherence. In Norway, this form of health communication can be seen in the discourse of public health. For example, an editorial about vaccination against swine flu in the Journal of the Norwegian Medical Association (Tidsskrift for den Norske Legeforening), stated that physicians should not inform patients about *'everything'* (137) – in other words, that

they should not make people aware of all the possible risks. A further example is found in the Childhood Vaccination Handbook for Health Professionals issued by the Norwegian Public Health Institute, which states that '*it must be assumed that [parents] would like vaccination*' (138). A major weakness of such an authoritative and prescriptive decision making model is that it assumes that it correctly knows users preferences and abilities, and also assumes that professionals are competent enough to decide what is appropriate on behalf of users (5, 10, 11). Furthermore, it does not facilitate informed decision making given that information is withheld or tailored to facilitate a specific choice. A systematic review of barriers to shared decision making concluded that one of the main reasons why people are sub-optimally involved in health decisions is that health professionals assume that people are either not willing to participate or not capable of doing so (11). However, the willingness or capacity of people should not be underestimated (5). A large cross-sectional study of peoples perceptions on the responsiveness of health systems and own participation conducted in Germany, Italy, Poland, Slovenia, Spain, Sweden, Switzerland and the United Kingdom (UK), with 8,119 people aged 16-years or over, concluded that patients wished to have a more autonomous role in healthcare (9). When asked which decision making model they preferred, the shared decision making model was the most popular by far, with 51% of the total sample opting for it (9).

The barrier categories we identified to the ability of parents to participate and obtain information were: own capacity, abilities, and being positive towards vaccination and having already decided. The first two categories relate to parents having the opportunity and necessary skills, while the latter category relates to the perceived need of the parents for information associated with the specific health decision. Own capacity such as being overwhelmed and being able to find and assess reliable health information have been identified as common barriers to

searching for health information in general (27, 29). The health decision in itself, according to other studies, may also influence the degree to which people want to be involved (139, 140). We know that many people decide to vaccinate because this is a well-known and accepted treatment in our society, recommended by governmental bodies, and seen as 'the normal thing to do' (also known as the 'bandwagon' effect) (140). Thus, those people who are positive in attitude towards vaccination may perceive less of a need for information than those who are going against 'the establishment'; leaving adherers less informed. Consequently, the fact that people adhere to guidelines does not necessarily imply that they are well-informed.

These identified barriers are not unrelated. Having the necessary abilities may save people time and improve capacity: parents, for example, could more easily navigate the information flow of society and also know *what* to ask public health nurses. A perceived need for information may also be dependent on the ability to evaluate the information available and consequently on making a judgement about whether more information is still needed to make an informed decision. For example, a person with high science literacy may not be satisfied with health advice that is based on personal anecdotes. Furthermore, as was found in this study, knowledge about people's own roles and responsibilities in decision making may also influence their perceived need. It can thus be argued that these barriers are interrelated and that an improvement in one area may lead to improvements in the other domains.

The parents in our study reported that they had little knowledge about vaccination. This lack of knowledge about different vaccines, diseases, how immunisation works, or uncertainty about the effects of vaccination, is evident in other developed countries with high vaccination rates (58, 141, 142). Furthermore, our study showed that decision making is often based on

common sense, trust and personal experiences (140, 141). Although trust and personal experience are important in healthcare, they are an incomplete foundation for informed decision making about treatments. When trust forms the basis of decisions rather than knowledge, people are encouraged to rely solely on health professionals instead of being empowered to think for themselves (5). Decisions based on trust are also easily weakened and may not apply to new treatments (108). Recent examples of controversies related to vaccination, for example, include public debates about vaccination against the human papilloma virus (HPV) and swine flu (H1N1 influenza virus) (137, 143). A study of responses to governmental recommendations related to swine flu in the UK found a general scepticism toward public messages and that people questioned the credibility of such information (144). To a large degree, decision making was found to be informed by people's own beliefs about the disease and how to prevent it and by personal anecdotes from people they knew (144).

Without adequate knowledge and (health literacy) skills, it is nearly impossible for a layperson to critically appraise the information exchanged in such discourses. Instead, the choice about whether to vaccinate or not may be determined by deciding *who* to trust instead of weighing the benefits and harms based on the best available evidence. Interestingly, in vaccination behavioural research, *who* people trust has been found to be one of the characteristics that differentiates vaccinators from non-vaccinators (139, 141). Parents who decides to vaccinate are more likely to trust the government than those who decide not to vaccinate, and who are instead more likely to use alternative providers of health care such as homeopaths (139, 141).

These examples and other research suggest that there are important areas for improvements related to health literacy. Firstly, while evidence based practice and user

involvement may be stressed in policy documents and by researchers, it may still remain
unknown to both users and providers of healthcare, and may not be an integrated part of all
practice (11, 33-35). There is also a need for people to be provided with insight into the elements
of clinical decision making to enable them to find and evaluate health information.

Parent and public health nurse barriers may be similar

Our study identified potential areas for improvement relevant to the practice of public
health nurses. Public health nurses were seen by the parents as their most important source of
health information and parents expressed great confidence in them, emphasising their roles as
counsellors and moderators of health information. Health professionals have a crucial role in
health education and the dissemination of health information, a role that has become perhaps
even more important and challenging in recent years due to the rapid increase of health
information available to the public (7). To keep pace with both the latest developments, and with
knowledge which is important for patient outcomes and good quality healthcare, public health
nurses must be able to integrate the best available research into practice (1, 31, 145). Moreover,
insight into how knowledge is produced and how to evaluate the reliability and applicability of
such information is important to address the information needs of parents. Enabling users to
search for reliable information and being able to discuss such information is an important activity
for health professionals and has been emphasised in studies exploring user information needs
(146, 147). Despite acknowledging the importance of using research, the public health nurses that
participated in our study were reluctant to search independently for such information. The main
reasons for this, in relation to vaccination, were that they did not consider doing so to be part of

their role and thought that such searches could potentially conflict with their mandate. Other reasons were critical appraisal skills and capacity. This indicates that the barriers related to obtaining health information (and the health literacy skills required) may not be so different from the skill and capacity issues of parents which were common barriers to obtaining research. Furthermore, this finding underlines the importance of quality-improvement initiatives targeting public health nurses who should be empowered to use and integrate research in practice, and the need for such initiatives to target the barriers and facilitators to change identified in our study.

Attitude and perceived behavioural control are important predictors of intention to search for health information

To our knowledge this is the first questionnaire to explore the cognitive factors that influence behavioural intentions to search. Based on our analysis, we concluded that the internal structure (reliability) of items measuring intention to search and direct measures were satisfactory, and that the relationships between these variables generally supported the theoretical predispositions of the TPB and previous evidence (79). We also found that the questionnaire's overall predictive strength (of intention to search) was very good and consistent with what has been found in other studies using the TPB (90). Comparing these values with the same reliability and validity tests performed in the RCT study, the utility of the questionnaire was confirmed by the consistency of findings. This indicates that this questionnaire is a reliable tool for mapping and evaluating intention to search and underlying variables.

This questionnaire enabled us to explore further and quantify the findings of the qualitative study of parents and public health nurses, supplemented by findings in the published

literature. The findings of the questionnaire supported the relevance of these identified issues. According to the TPB, by changing the most important predictor(s) *'we can increase the chance that the person will intend to do a desired action and thus increase the chance of the person actually doing it'* p7,(79) . Thus, when developing an intervention, these predictors should be targeted (79). The participants in both samples had high assessments of their direct attitude towards searching, including the indirect measures. Their assessments of direct perceived behavioural control were moderate to high, but the indirect measures they reported showed that certain areas needed improvement. The score for the direct subjective norm for both samples was moderate, and the assessment of indirect measures associated with social pressure was modest. Attitudes and perceived behavioural control were identified as important positive predictors of intention to search. These results are supported by findings from other descriptive cross-sectional studies which describe searches for information by patients and healthy citizens. In these studies, people were reported to have had positive attitudes associated with searching because it provided them with support with their decision making and in consultations with health professionals. It also provided them with comfort and additional knowledge (27, 148, 149). However, barriers to searching for health information, as the data from our questionnaire revealed, include people being unsure if the information is understood properly or feeling overwhelmed, frustrated and confused by the information they find (27, 149). In contrast, the finding from our study in addition to what we know from other studies, social pressure or expectations to search may not be a variable positively predicting search (9, 11, 27, 149-152).

The operationalisation of TPB and the theory itself have received much attention and scientific interest, and are subject to extensive methodological research and development (89, 90, 153). This research is predominantly in two areas: an exploration of additional predictors to

behaviour, and the measurement or conceptualisation issues related to the existing TPB components (intention, attitude, subjective norm and perceived behavioural control) (89, 90, 153). This research has been welcomed by Ajzen, as long as empirical (and theoretical) justifications are made (89). Research on the conceptualisations of the existing TPB components is, to a large extent, focused on the component of the subjective norm. The main reason for this is that it has been found to be a weaker predictor of certain behaviours (90). In part, this has been attributed to measurement issues in previous studies (in which only one item has been used), but also because the construct may not adequately capture the complexity of social influence (90). Our study contributes to this discussion and challenges the TPB model's classical assumption that increased social pressure creates greater behavioural intentions. In our study the subjective norm was found to be poorly correlated with intentions and a non-statistically significant or even negative predictor of intentions. This finding was also reproduced in the randomised controlled trial.

The TPB questionnaire in our study was also developed in order to be used to evaluate the effects of the web portal in the randomised controlled trial. The specific beliefs that were included in the questionnaire were all chosen based on the fact that they were (changeable) factors related to specific health literacy skills (with the exception of subjective norm). Attitudes and perceived behavioural control towards search for health information are constructs that can be directly related to individual, personal health literacy skills. Whereas the perceived behavioural control items (direct and indirect) describes actual perceived skills and feelings of mastering the exercise of searching, the items describing a person's attitude towards searching relate to a person's belief in their own participation and their knowledge about the benefits of doing so. In other words, more health literate people would hypothetically be more likely to have

positive attitudes towards searching, have a higher perceived behavioural control, and thus be more likely to have higher intention to search. In contrast, the subjective norm variable does not relate to an individual's own health literacy – instead, it relates to social pressure from others. However, when evaluating the effects of the intervention – and acknowledging subjective norm as a significant variable found to influence behaviour – the construct provides valuable knowledge about the degree to which the participants perceived the intervention to increase social pressure to search.

Providing an easy access point to evidence and tools

As mentioned earlier in the introduction to this research, many areas for improvement related to health literacy skills have been identified. Our findings and other research have led us to conclude that certain health literacy skills should be targeted specifically in an intervention. In this study, these skills were grouped and organised into three main barrier categories: the inability to understand and critically appraise health information, the inability to exchange information in consultations, and not knowing where to find reliable and relevant information. To address the identified barriers, the content of the intervention was developed within the conceptual frameworks of shared decision making and evidence-based practice (1, 5, 113). To achieve this, three strategies were chosen: providing an introduction to critical appraisal (and an associated checklist); providing information about what decision making about treatment or screening entails (and a decision aid for consultations); and improving access to reliable research-based sources of health information through the provision of an introduction to research methods and providing help with finding evidence-based health information efficiently, based on the principles

of evidence-based practice. These strategies touch upon specific domains of health literacy (8) (see Figure 1 and Table 1), including: the understanding of risk (functional literacy), knowledge of fundamental scientific concepts and processes (science literacy), how and where information is presented (civic literacy), roles and rights (civic literacy), and the understanding of concepts used in decision making about healthcare (cultural literacy). Although other efforts have been made to facilitate Norwegian public access to evidence based information, we do not know of any existing online tool that provides insight into these domains of health literacy. Internationally, there is a longer tradition of research on how to improve health literacy and several tools can be found that address related elements (see www.sunnskepsis.no . Other examples of web based resources include: 'Testing treatments' (www.testingtreatments.org), which focuses on science literacy and the evaluation of the effects of treatments, and 'What are your chances' (www.whatareyourchances.com), which focuses on numeracy and how to understand risk.

Our web portal was developed to target the public in general and to be used independently or in consultations with health professionals. An important question raised in the project group during this process was: 'What separates an intervention targeting the health literacy skills of lay people from an intervention targeting those of health professionals?' As previously discussed, both health professionals and users may be unaccustomed to the principles of evidence based practice and may share the same barriers to obtaining reliable health information. Much of the content included in the web portal may therefore be of equal relevance to users and health professionals alike. However, two main differences were taken into account when developing the web portal. Firstly, not all users may be familiar with medical terminology (and knowledge about medicine). Secondly, users – in contrast to health professionals – are not obliged to adopt

evidence based practice in their lives and have the freedom to choose *not* to be involved in decision making.

Consequently, we made an effort to structure the web portal in a way that would provide easy access to the included resources, but we aimed as well to develop the content in a way that would be relevant to the contexts of users. We achieved this by using as much plain language as possible, except when we used medical- or research methodology-related jargon deliberately with an educational purpose in mind. Real-life examples, such as scenarios or news stories, were used when presenting text, and we only included tools that had been designed with a user-perspective in mind. Issues of access and the targeting of a lay public were also taken into account when developing the section in the web portal that facilitates direct access to research-based information. This section built on the steps included within circle model of evidence based practice, taking the problem formulation phase as our point of departure (113). In this model, problems are defined into six main categories: prevalence, aetiology, diagnostics, effectiveness of treatments, prognosis, and patient or provider attitudes or experiences (113). However, when creating the problem formulation section, we decided to omit the diagnostics category. Although this may be debated, the field of diagnostics is complicated and we decided that this should be done in consultations with a health professional. A more accessible checklist which could be used to appraise the relevance of research was included instead of the critical appraisal checklists typically used by researchers and professionals. However, to accommodate (and encourage) users who might want to learn more, we added a link to these checklists as well.

The web portal was judged as a relevant tool and may improve attitudes in a pragmatic setting

The effectiveness of the web portal was evaluated in a pragmatic trial. When this study was conducted, there was no single available instrument suitable to capture the complete model of health literacy (52) which included not only functional literacy but also science literacy, civic literacy and cultural literacy (8). The outcomes of our study were measured instead using a selection of instruments specifically aimed to evaluate domains of health literacy that our intervention targeted.

Only minor and non-statistically significant differences were found in the searching task and the critical appraisal task. The participants in both groups adopted a sceptical point of view when evaluating the information about swine flu. However, when searching for health information, nearly all parents chose to use information that was not evidence based and without any explicit statement on what the information had been based on. This suggests that the parents may not have had enough time to explore the web portal, and may have preferred to rely on sources with which they were familiar. It also signifies that explicit statements about what health information is based on are not important criteria for parents when validating the sources of information they find. Studies exploring which criteria people base their evaluations on, conclude that people largely assess online information on other criteria such as: the source (the publisher), URL (whether it is commercial or not), funding, the date, and how it is presented (29, 55, 105).

The high respondent score on beliefs related to both search and overall participation illustrates that the parents were generally positive towards participation. This finding is congruent with other research in Europe which has mapped people's willingness to participate (9). We

found an improvement in favour of the intervention group for overall intention and overall activation. Improvements were also found in favour of the intervention group for the variables predicting intention-perceived behavioural control and attitude. However, only the difference in attitude was significant between the two groups, a variable which was also identified as the most important predictor of intention to search in both samples. This may indicate that the web portal may have played a role in raising parent awareness about taking on an active role in health decisions. Subjective norm was rated as moderate and had a weak relationship with intention in both groups. This finding adds weight to our previous research showing that social expectations or pressure did not appear to be an important factor associated with people's intention to search for health information.

The web portal was considered by the participants to have good usability, usefulness and credibility, and this supported the findings from the usability test conducted as part of our research development process (78). Considering that the purpose of the web portal and the concepts introduced were probably novel to most of the parents, this finding is encouraging and we hope will inspire further studies in this area.

Parallel to the randomised controlled trial, the web portal was also tested in an independent study to explore how user representatives evaluated the usefulness of a course in evidence-based practice and critical appraisal (154). I was not personally involved in this study conducted by Elin Opheim, a student from the Masters Degree Programme in Evidence Based Practice at Bergen University College, Norway. At the time the research was undertaken, it was the first study of its kind conducted in Norway (154). The course had three steps: an introduction to evidence based practice, searching for health information (based on the web portal), and

critical appraisal (also based on the web portal) (154). Overall, the course was regarded by the user representatives as very useful and relevant to their role, by giving them attitudes and skills that were important to their work in organisation and representative participation (154). This was specifically because they felt that they were being equipped with a tool – a tool which they saw as already being available to health professionals and official authorities (154). By gaining access to such a resource, the participants felt this would enable them to gain influence, justification and trustworthiness for their views (154). The acknowledgement of their key role and responsibility as representatives for knowledge translation, the provision of access to research, and the ability to evaluate such information were considered by them to be essential as means of quality assurance in meetings they had with members of their organisation (154).

People may not trust in science, and rational decision making may not result in the 'recommended' choice

The conceptual and theoretical perspectives adopted in this project are typical of epidemiology and health services research (86) in that they primarily address cognitive factors such as attitudes, knowledge and skills. The underlying assumption of this study is that people balance advantages and disadvantages in a rational decision making process. From this viewpoint, access to adequate information (and the ability to understand and act upon this information) is seen as crucial to change (86). However, the paradox facing all initiatives built on this assumption is that people may reject science in its entirety and choose to base their decisions on other belief systems about health. This has been found to be the case with regard to the topic of vaccination. Some anti-vaccination groups rely on different bases of knowledge rooted in, for

example, personal anecdotes, philosophy or religion, and these sources of knowledge are often

linked to social networks or communities (15, 155, 156). Such reliance on other knowledge

paradigms has also been associated with distrust in the healthcare system in general (15, 139).

The role of new information technologies may add strength to these kinds of networks,

demonstrating how knowledge is negotiated and shared not only between professionals and users,

but also between users (155). Improving the access people have to evidence based information

and educational initiatives therefore may not be adequate as such information may not be

accepted by its receiver.

Another paradox from a rational decision making perspective is that despite the fact that

people are appropriately informed and health literate, their final decision may not be what is

considered to be the' best option' by health professionals. This was demonstrated in a systematic

review of decision aids (127) which showed that although decision aids increased people's

involvement and improved their knowledge and realistic perception of outcomes, the effects on

adherence were inconclusive (127). Despite this, the improved exchange of health information

and clarification of values may make health behaviour and cognitive processes more explicit and

be a better starting point for the process of care (7).

Some have expressed concerns about interventions targeting user participation and health literacy

Criticism has been raised about interventions that aim to improve participation and health

literacy skills. Firstly, a concern may be that such interventions can create expectations that

cannot be met, considering that many health professionals may also be unfamiliar with finding,

evaluating and applying research (33-35). Although these concerns may be valid, they are not valid enough reasons to leave users uninformed. Aside from the ethical and legal dimensions of user involvement and education, more-informed patients can also actually play a role in promoting evidence based practice by professionals (157, 158). A second major concern is that better-informed users may increase the demand for healthcare by, for example, through increased consultation length (20, 127, 159). However, evidence regarding such effects is inconclusive (20, 127, 159). Furthermore, the potential costs associated with factors such as potential increases in consultation length may be outweighed by improved user outcomes and more appropriate treatments (20, 159). Findings indicate, for example, that informed users are more likely to choose less risky treatments and adopt a wait-and-see attitude (127). In contrast, misconceptions about generic substitution, the underuse of generic medications, and the increased use of healthcare services have been associated with low literacy levels (17, 62). Thus it can be argued that educating and involving users may in fact result in resources being spent more wisely. The two concerns noted above, it can therefore be argued, are built upon a traditional and outdated view of how information about medical and health related information is transferred, namely that it moves between the professional and user. Today, health information is widely distributed through various communication channels, including between users themselves (25). Acknowledging this, the public must be recognised as key actors in knowledge transfer. Improving health literacy skills is not only important to ensure informed decision making for the individual, but is also vital for knowledge transfer in society as a whole.

Conclusions

In this thesis we examined a tailored intervention informed by qualitative and quantitative pre-studies as well as literature searches. The studies provided us with rich data that enabled us to identify and target barriers and facilitators that were considered important by members of our key audiences. Through a consideration of these barriers, we developed a web portal designed using the conceptual frameworks of shared decision making and evidence based practice. The purpose of doing this was to improve specific domains of health literacy related to obtaining health information.

The effects of the web portal were evaluated in a pragmatic setting on a group of parents. The findings of this study suggest that the web portal may improve positive attitudes towards searching for health information, a variable identified as the most important predictor of intention to search. Furthermore, the relevance of the web portal to users was confirmed.

Implications for practice and further research

Research describing decision making and health behaviour related to vaccination has generally been concerned with reasons for non-adherence. This has largely focused on the attitudes and beliefs associated with vaccination and on satisfaction with the associated services. Recognising health literacy as a public health goal, future studies should instead complement our study by exploring further what informs decision making related to vaccination. Furthermore,

there is very little evidence available which map the knowledge of parents about immunisation in Norway and about health literacy skills. Future research efforts should include large cross-sectional studies to explore this and inform interventions targeting specific information needs.

In this project, emphasis was placed on the identification of the barriers and facilitators associated with obtaining health information. Providing insight into the process, components and intended intervention mechanisms is important for reproducibility and as a way to inform the efforts of other researchers and methodologists within this field (69, 133). Although tailored interventions have been found to be effective, there is no clear evidence on which particular method of tailoring is most appropriate (133). Adopting an explicit conceptual and methodological approach is of particular importance when developing interventions (68, 69), but more evidence is needed on the development of interventions and the potential benefits of tailoring (133).

Overall, the findings in the pragmatic trial were modest and indicated that online resources alone – such as the web portal – may be insufficient to effectively improve health literacy skills. As an element of acknowledging the rights and central role of users in evidence based practice, it is important that resources such as the web portal are made available to enable access to evidence based information and to facilitate health literacy skills through practical tools. In order to ensure a more intensive form of intervention, future research efforts should consider interventions in which the web portal is included in consultations with health providers, as part of evidence-based practice as an integrated part of patient education or, for example, in educational programmes in schools.

References

1.   Dawes M, Summerskill W, Glasziou P, Cartabellotta A, Martin J, Hopayian K, et al. Sicily statement on evidence-based practice. BMC medical education [Internet]. 2005 544887]; 5(1):[1 p.]. Available from:
www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=15634359.
2.   Nutbeam D. Health promotion glossary1998:[36 p.]. Available from:
www.who.int/hpr/NPH/docs/hp_glossary_en.pdf.
3.   Ministry of Health and Care Services. The Norwegian Bill of Patients' Rights. LOV-1999-07-02-63 [Internet]. 1999. Available from: www.lovdata.no/cgi-wift/ldles?doc=/all/nl-20060630-045.html.
4.   Ministry of Health and Care Services. St.meld. nr. 47 (2008-2009).[The Interaction Reform: The right treatment - at the right place - at the right time]2009:[150 p.]. Available from:
www.regjeringen.no/nb/dep/hod/dok/regpubl/stmeld/2008-2009/stmeld-nr-47-2008-2009-.html?id=567201.
5.   Coulter A. The Autonomous patient: ending paternalism in medical care. London: TSO; 2002. 121 p.
6.   Coulter A, Ellins J. Patient-focused interventions: a review of the evidence2006:[277 p.]. Available from: www.pickereurope.org/Filestore/PIE_reports/QQUIP/QEI_Review_AB.pdf.
7.   Taylor K. Paternalism, participation and partnership - the evolution of patient centeredness in the consultation. Patient education and counseling. 2009;74(2):150-5.
8.   Zarcadoolas C, Pleasant A, Greer D. Advancing health literacy: a framework for understanding and action. 1st ed. San Francisco, CA: Jossey-Bass; 2006. 368 p.
9.   Coulter A, Jenkinson C. European patients' views on the responsiveness of health systems and healthcare providers. European Journal of Public Health. 2005;15(4):355-60.
10.   Bugge C, Entwistle V, Watt I. The significance for decision-making of information that is not exchanged by patients and health professionals during consultations. Social science & medicine. 2006;63(8):2065-78.
11.   Legare F, Ratte S, Gravel K, Graham I. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. Patient education and counseling. 2008;73(3):526-35.
12.   Glenton C, Paulsen E, Oxman A. Portals to Wonderland? Health portals lead confusing information about the effects of health care. BMC medical informatics and decision making [Internet]. 2005; 5:7:[8 p.]. Available from: www.biomedcentral.com/content/pdf/1472-6947-5-7.pdf.
13.   Glenton C, Oxman A. The use of evidence by health care user organizations. Health Expectations. 1998;1(1):14-22.
14.   Johansen L, Bjørndal A, Flottorp S, Grøtting T, Oxman A. [Evaluation of health information in newspapers and brochures. What can we believe?]. Tidsskrift for Den norske Legeforening. 1996;116(2):260-4.
15.   Wolfe R, Sharp L, Lipsky M. Content and design attributes of antivaccination web sites. Journal of American Medical Association. 2002;287(24):3245-8.
16.   Hoye S, Hjortdahl P. ["New wonder pill!"--what do Norwegian newspapers write]. Tidsskrift for Den norske Legeforening. 2002;Jun 30;122(17):1671-6.
17.   Berkman N, Sheridan S, Donahue K, Halpern D, Crotty K. Low Health Literacy and Health Outcomes: An Updated Systematic Review. Annals of Internal Medicine. 2011;155(2):97-101.

18.   Sanders L, Federico S, Klass P, Abrams M, Dreyer B. Literacy and child health: a systematic review. Archives of Pediatric & Adolescent Medicine. 2009;163(2):131-40.
19.   Nutbeam D. The evolving concept of health literacy. Social Science and Medicine. 2008;67(12):2072-8.
20.   Detmer D, Singleton P, MacLeod S, Wait S, Taylor M, Ridgwell J. The informed patient: Study Report. Cambridge: University of Cambridge; 2003 March 2003. 53 p.
21.   European Patients Forum. European Patients Forum Annual Report 2010. 2010:[44 p.]. Available from: www.eu-patient.eu/Documents/Publications/AnnualReports/epf-annual-report-2010.pdf.
22.   Moumjid N, Gafni A, Bremond A, Carrere MO. Shared decision making in the medical encounter: Are we all talking about the same thing? Medical Decision Making. 2007;27(5):539-46.
23.   Coulter A. Paternalism or partnership? Patients have grown up-and there's no going back. The British Medical Journal. 1999;319(7212):719-20.
24.   Manganello J. Health literacy and adolescents: a framework and agenda for future research. Health Education Research. 2008;23(5):840-7.
25.   Fox S, Jones S. The Social Life of Health Information. . PEW Internet and American Life Project [Internet]. 2009:[88 p.]. Available from: www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx.
26.   Spadaro R. European union citizens and sources of information about health: Eurobarometer 58.0. 2003:[16 p.]. Available from: www.europa.eu.int/comm/health/ph_information/documents/eb_58_en.pdf.
27.   Fox S. Online health search. PEW Internet and American Life Project [Internet]. 2006:[22 p.]. Available from: www.pewinternet.org/PPF/r/190/report_display.asp.
28.   Wangberg S, Andreassen H, Kummervold P, Wynn R, Sorensen T. Use of the internet for health purposes: trends in Norway 2000-2010. Scandinavian Journal of Caring Sciences. 2009;23(4):691-6.
29.   Pletneva N, Vargas A, Boyer C. Requirements for the general public health search. 2011. Available from: www.hon.ch/Global/pdf/Khresmoi/KHRESMOI_general_public_survey_report.pdf.
30.   Statistics Norway. Use of the Internet, frequency and location of use last 3 months. Percentage of population, by sex, age, education and employment situation. 2nd quarter 2010 Statistics Norway; 2011 [cited 2011 19.05]; Available from: www.ssb.no/english/subjects/10/03/ikthus_en/tab-2010-09-24-04-en.html.
31.   Brownson R, Fielding J, Maylahn C. Evidence-Based Public Health: A Fundamental Concept for Public Health Practice. Annual Review of Public Health. 2009;30:175-201.
32.   The Norwegian Directorate for Health and Social Affairs. ...and it's going to get better! National Strategy for Quality Improvement in health and Social Services (2005-2015). 2005.
33.   Forsetlund L, Bjorndal A. Identifying barriers to the use of research faced by public health physicians in Norway and developing an intervention to reduce them. Journal of health services research & policy. 2002;7(1):10-8.
34.   Treweek S, Flottorp S, Fretheim A, Havelsrud K, Kristoffersen D, Oxman A, et al. [What do general practitioners do to keep themselves up to date?]. Tidsskrift for Den norske Legeforening. 2005;125(3):304-6.
35.   Havelsrud K, Flottorp S, Fretheim A, Kristoffersen D, Oxman A, Treweek S, et al. [How do general practice assistants keep themselves up to date?]. Tidsskrift for Den norske Legeforening. 2005;125(3):307-9.
36.   Glenton C, Santesso N, Rosenbaum S, Nilsen E, Rader T, Ciapponi A, et al. Presenting the results of Cochrane Systematic Reviews to a consumer audience: a qualitative study. Medical Decision Making. 2010;30(5):566-77.

37.   Eysenbach G, Diepgen T. Towards quality management of medical information on the internet: evaluation, labelling, and filtering of information. The British Medical Journal. 1998;317(7171):1496-500.

38.   Health On The Net Foundation (HON). Trustworthy health and medical information:the health on the net intiative. 2010 [cited 2010 30.11.2010]; Available from: www.hon.ch/HONcode/Webmasters/.

39.   Berger B, Steckelberg A, Meyer G, Kasper J, Muhlhauser I. Training of patient and consumer representatives in the basic competencies of evidence-based medicine: a feasibility study. BMC medical education. 2010;10:1-9.

40.   Peerson A, Saunders M. Health literacy revisited: what do we mean and why does it matter? Health promotion international. 2009;24(3):285-96.

41.   Freedman DA, Bess KD, Tucker HA, Boyd DL, Tuchman AM, Wallston KA. Public Health Literacy Defined. American Journal of Preventive Medicine. 2009;36(5):446-51.

42.   Ishikawa H, Yano E. Patient health literacy and participation in the health-care process. Health Expectations. 2008;11(2):113-22.

43.   Nielsen-Bohlman L, Institute of Medicine (U.S.). Committee on Health Literacy. Health literacy: a prescription to end confusion. Washington, D.C.: National Academies Press; 2004. xix, 345 p.

44.   Nutbeam D. Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. Health promotion international. 2000;15(3):259-67.

45.   The Lancet. Taking health literacy seriously. The Lancet. 2005;366(9480):95.

46.   Pirisi A. Low health literacy prevents equal access to care. The Lancet. 2000;356(9244):1828.

47.   Hironaka L, Paasche-Orlow M. The implications of health literacy on patient-provider communication. Archives of Disease in Childhood. 2008;93(5):428-32.

48.   Coulter A. Editorial: Promoting realistic expectations. Health Expectations. 2000;3(3):159-60.

49.   Zarcadoolas C, Pleasant A, Greer D. Understanding health literacy: an expanded model. Health promotion international. 2005;20(2):195-203.

50.   Muir K, Santiago-Turla C, Stinnett S, Herndon L, Allingham R, Challa P, et al. Health literacy and adherence to glaucoma therapy. American journal of ophthalmology. 2006;142(2):223-6.

51.   Morrow D, Clark D, Tu W, Wu J, Weiner M, Steinley D, et al. Correlates of health literacy in patients with chronic heart failure. The Gerontologist. 2006;46(5):669-76.

52.   Jordan J, Osborne R, Buchbinder R. Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. Journal of clinical epidemiology. 2011;64(4):366-79.

53.   The Department of International Health. Measuring health literacy in Europe. Maastricht University. 2011 [22.12.2011]; Available from: http://inthealth.eu/research/health-literacy-hls-eu/measuring-health-literacy-in-europe/.

54.   Schwartz K, Roe T, Northrup J, Meza J, Seifeldin R, Neale A. Family medicine patients' use of the Internet for health information: a MetroNet study. Journal of the American Board of Family Medicine. 2006;19(1):39-45.

55.   Eysenbach G, Kohler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. The British Medical Journal. 2002;324(7337):573-7.

56.   Woloshin S, Schwartz L, Byram S, Sox H, Fischhoff B, Welch H. Women's understanding of the mammography screening debate. Archives of internal medicine. 2000;160:1434-40.

57.   Schwartz L, Woloshin S, Black W, Welch H. The role of numeracy in understanding the benefit of screening mammography. Annals of Internal Medicine. 1997;127(11):966-72.

58.   Mills E, Jadad AR, Ross C, Wilson K. Systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccination identifies common barriers to vaccination. Journal of clinical epidemiology. 2005;58(11):1081-8.

59.   Lloyd A. The extent of patients' understanding of the risk of treatments. Quality in Health Care. 2001;10 Suppl 1:i14-8.

60.   Robinson E, Kerr C, Stevens A, Lilford R, Braunholtz D, Edwards S, et al. Lay public's understanding of equipoise and randomisation in randomised controlled trials. Research Support, Non-U.S. Gov't. NHS R&D HTA Programme, 2005 Mar. Report No.: Contract No.: 8.

61.   Ganther-Urmie J, Nair K, Valuck R, McCollum M, Lewis S, Turpin R. Consumer attitudes and factors related to prescription switching decisions in multitier copayment drug benefit plans. American Journal of Managed Care. 2004;10(3):201-8.

62.   Iosifescu A, Halm E, McGinn T, Siu A, Federman A. Beliefs about generic drugs among elderly adults in hospital-based primary care practices. Patient education and counseling. 2008;73(2):377-83.

63.   Woloshin S. How can we help people make sense of medical data? Effective clinical practice. 1999;2(4):176-83.

64.   Dickersin K, Braun L, Mead M, Millikan R, Wu AM, Pietenpol J, et al. Development and implementation of a science training course for breast cancer activists: Project LEAD (leadership, education and advocacy development). Health Expectations. 2001;4(4):213-20.

65.   Murray E, Burns J, See T, Lai R, Nazareth I. Interactive Health Communication Applications for people with chronic disease. Cochrane database of systematic reviews. 2005(4):CD004274.

66.   Wantland D, Portillo C, Holzemer W, Slaughter R, McGhee E. The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes. Journal of Medical Internet Research. 2004;6(4):40.

67.   Lewis D. Computer-based approaches to patient education: a review of the literature. Journal of the American Medical Informatics Association. 1999;6(4):272-82.

68.   Grol R, Baker R, Moss F. Quality improvement research: the science of change in health care. In: Grol R, Baker R, Moss F, editors. Quality improvement research: understanding change in health care. London: BMJ Publishing Group; 2004. p. 1-5.

69.   Craig P, Dieppe P, Macintyre S, Mitchie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: new guidance: Medical Research Council; 2008. Available from: www.mrc.ac.uk/complexinterventionsguidance.

70.   Van Bokhoven M, Kok G, Van der Weijden T. Designing a quality improvement intervention: a systematic approach. In: Grol R, Baker R, Moss F, editors. Quality improvement research. London: BMJ Publishing Group; 2004. p. 147-64.

71.   Campbell M, Fitzpatrick R, Haines A, Kinmonth A, Sandercock P, Spiegelhalter D, et al. Framework for design and evaluation of complex interventions to improve health. The British Medical Journal. 2000;321(7262):694-6.

72.   Pope C, Van Royen P, Baker R. Qualitative methods in research on healthcare quality. In: Grol R, Baker R, Moss F, editors. Quality improvement research. London: BMJ Publishing Group; 2004. p. 51-63.

73.   Eccles M, Grimshaw J, Campbell M, Ramsay C. Research designs for studies evaluating the effectiveness of change and improvement strategies. In: Grol R, Baker R, Moss F, editors. Quality improvement research: understanding change in health care. London: BMJ Publishing Group; 2004. p. 97-114.

74.   Statistics Norway. [Use of health services by sex and age]. Statistics Norway,: SSB; 2009 [updated 26.6.2009; cited 2010 01.12.2010]; Available from: http://statbank.ssb.no/statistikkbanken/Default_FR.asp?PXSid=0&nvl=true&PLanguage=0&tilside=select varval/define.asp&Tabellid=04217.

75.   Westin S. [Post-modern anti-vaccination movement]. Tidsskrift for Den norske Legeforening. 2002;20(122(8)):772.

76.   Horton R. A statement by the editors of The Lancet. The Lancet. 2004;363(9411):820-1.

77.   Goldacre B. Medicine and the media: MMR: the scare stories are back. The British Medical Journal. 2007;335(7611):126-7.

78.   Danielsen S. Pasientmedvirkning fra pasientens perspektiv -partnerskap eller paternalisme? En kvalitativ studie [Masteroppgave i Klinisk Sykepleievitenskap]: Høgskolen i Oslo; 2011.

79.   Francis J, Eccles M, Johnston M, Walker A, Grimshaw J, Foy R, et al. Constructing questionnaires based on the theory of planned behaviour: A manual for health services researchers. 2004:[42 p.]. Available from: www.rebeqi.org/ViewFile.aspx?itemID=212.

80.   Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London: Sage; 2006. XIII, 208 p.

81.   Billson JM. The power of focus groups: a training manual for social, policy and market research. 4th ed. Barrington, Rhode Island: Skywood Press; 2004.

82.   Malterud K, editor. [Qualitative methods in medical research]. Oslo: Universitetsforlaget; 2004.

83.   Kitzinger J. Focus groups with users and providers of health care. In: Pope C, Mays N, editors. Qualitative Research in Health Care. London: BMJ Publishing Group; 2001. p. 20-9.

84.   Kummervold P, Chronaki C, Lausen B, Prokosch H, Rasmussen J, Santana S, et al. eHealth Trends in Europe 2005-2007: A Population-Based Survey. Medical Internet Research. 2008;Oct-Dec; 10(4): e42.

85.   Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, editors. Analyzing qualitative data. London: Routledge; 1994. p. 173-94.

86.   Grol R, Wensing M, Hulscher M, Eccles M. Theories on implementation of change in healthcare. In: Grol R, Wensing M, Eccles M, editors. Improving patient care The implementation of change in general practice. London: Elsevier limited; 2005. p. 15- 40.

87.   Eccles M, Grimshaw J, Johnston M, Steen N, Pitts NB, Thomas R, et al. Applying psychological theories to evidence-based clinical practice: identifying factors predictive of managing upper respiratory tract infections without antibiotics. Implement Science. 2007;2:26:1-14.

88.   Ajzen I. The Theory of Planned Behavior. Organizational Behavior and Human Decision Processes. 1991;50(2):179-211.

89.   Conner M, Norman P. Theory of planned behaviour and health behaviour. In: Conner M, Norman P, editors. Predicting health behaviour : research and practice with social cognition models. 2nd ed. Maidenhead: Open University Press; 2005. p. 170-222.

90.   Armitage C, Conner M. Efficacy of the theory of planned behaviour: A meta-analytic review. British Journal of Social Psychology. 2001;40:471-99.

91.   Eccles M, Hrisos S, Francis J, Kaner E, Dickinson H, Beyer F, et al. Do self- reported intentions predict clinicians' behaviour: a systematic review. Implementation Science [Internet]. 2006 1664582]; 1: 28. Available from: www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=17118180.

92.   Stead M, Tagg S, MacKintosh A, Eadie D. Development and evaluation of a mass media Theory of Planned Behaviour intervention to reduce speeding. Health Education Research. 2005;20(1):36-50.

93.   Krones T, Keller H, Becker A, Sonnichsen A, Baum E, Donner-Banzhoff N. The theory of planned behaviour in a randomized trial of a decision aid on cardiovascular risk prevention. Patient education and counseling. 2010;78(2):169-76.

94.   Renz A, Ide M, Newton T, Robinson P, Smith D. Psychological interventions to improve adherence to oral hygiene instructions in adults with periodontal diseases. Cochrane database of systematic reviews. 2007(2):No.: CD005097.

95.   Gatt S, Sammut R. An exploratory study of predictors of self-care behaviour in persons with type 2 diabetes. International Journal of Nursing Studies. 2008;45(10):1525-33.
96.   Luzzi L, Spencer AJ. Factors influencing the use of public dental services: an application of the Theory of Planned Behaviour. BMC health services research. 2008;8:93.
97.   Ramsay C, Thomas R, Croal B, Grimshaw J, Eccles M. Using the theory of planned behaviour as a process evaluation tool in randomised trials of knowledge translation strategies: A case study from UK primary care. Implementation Science. 2010;5(71):9.
98.   Tickner S, Leman PJ, Woodcock A. The Immunisation Beliefs and Intentions Measure (IBIM): Predicting parents' intentions to immunise preschool children. Vaccine. 2010;28(19):3350-62.
99.   Webb T, Joseph J, Yardley L, Michie S. Using the Internet to Promote Health Behavior Change: A Systematic Review and Meta-analysis of the Impact of Theoretical Basis, Use of Behavior Change Techniques, and Mode of Delivery on Efficacy. Journal of Medical Internet Research. 2010;12(1):e4.
100.   Moan IS, Rise J. Quitting smoking: Applying an extended version of the theory of planned behavior to predict intention and behavior. Journal of Applied Biobehavioral Research. 2005;10(1):39-68.
101.   Edwards P, Roberts I, Clarke M, Diguiseppi C, Wentz R, Kwan I, et al. Methods to increase response to postal and electronic questionnaires. Cochrane database of systematic reviews. 2009(3):MR000008.
102.   Austvoll-Dahlgren A, Helseth S. What informs parents' decision-making about childhood vaccinations? Journal of Advanced Nursing. 2010;66(11):2421-30.
103.   Austvoll-Dahlgren A, Sørum R, Helseth S. Cognitive factors predicting intentions to search for health information: an application of the Theory of Planned Behaviour. 2012.
104.   Austvoll-Dahlgren A, Helseth S. Public health nurses' barriers and facilitators to the use of research in consultations about childhood vaccinations. Scandinavian Journal of Caring Sciences [Internet]. 2011.
105.   Sillence E, Briggs P, Harris PR, Fishwick L. How do patients evaluate and make use of online health information? Social science & medicine. 2007;64(9):1853-62.
106.   Peterson G, Aslani P, Williams KA. How do consumers search for and appraise information on medicines on the Internet? A qualitative study using focus groups. Journal of Medical Internet Research. 2003;5(4):e33.
107.   Weinstein N. What does it mean to understand a risk? Evaluating risk comprehension. Journal of the National Cancer Institute. 1999(25):15-20.
108.   Tickner S, Leman P, Woodcock A. Factors underlying suboptimal childhood immunisation. Vaccine. 2006;24(49-50):7030-6.
109.   Stead M, Eadie D, Gordon D, Angus K. "Hello, hello - it's English I speak"! a qualitative exploration of patients' understanding of the science of clinical trials. J Med Ethics. 2005;31(11):664-9.
110.   Andreassen H, Sandaune A, Gammon D, Hjortdahl P. [Norwegian use of Internet health services]. Tidsskrift for Den norske Legeforening 2002;122(17):1640-4.
111.   Quintana Y, Feightner J, Wathen C, Sangster L, Marshall J. Preventive health information on the Internet. Qualitative study of consumers' perspectives. Canada Family Physician. 2001;47:1759-65.
112.   Morville P. User Experience Design; honeycomb model. 2004 [cited 2010 19.05]; Available from: http://semanticstudios.com/publications/semantics/000029.php.
113.   Bjørndal A, Flottorp S, Klovning A. Knowledge management in medicine and health sciences [Kunnskapshåndtering i medisin og helsefag] Oslo: Gyldendal akademisk; 2007. 195 p.
114.   Trevena L, Davey H, Barratt A, Butow P, Caldwell P. A systematic review on communicating with patients about evidence. Journal of evaluation in clinical practice. 2006;12(1):13-23.

115.   Keselman A, Logan R, Smith CA, Leroy G, Zeng-Treitler Q. Developing Informatics tools and strategies for consumer-centered health communication. Journal of the American Medical Informatics Association. 2008;15(4):473-83.

116.   Epstein R, Alper B, Quill T. Communicating Evidence for Participatory Decision Making. Journal of American Medical Association. 2004;291(19):2359-66.

117.   Woloshin S, Schwartz L, Welch H. Know Your Chances: Understanding Health Statistics. London: University of California Press; 2008. 158 p.

118.   Irwig L, Irwig J, Trevena L, Sweet M. Smart health choices: making sense of health advice. London: Hammersmith; 2008. xi, 242 p.

119.   Benestad H, Laake P. [Research Methodology in the Medical and Biological Sciences]. In: Benestad H, Laake P, editors.: Gyldendal akademisk; 2004.

120.   Johannessen A, Tufte P, Kristoffersen L. [Introduction to social science methodology]. Johannessen A, Tufte P, Kristoffersen L, editors. Oslo: Abstrakt forlag as; 2007.

121.   Regionale forskningskomiteer. [Research ethics]. 2012 [24.01.2012]; Available from: http://www.etikkom.no/no/Forskningsetikk/.

122.   Kim P, Eng T, Deering M, Maxfield A. Published criteria for evaluating health related web sites: review. The British Medical Journal. 1999;318(7184):647-9.

123.   Gagliardi A, Jadad A. Examination of instruments used to rate quality of health information on the internet: chronicle of a voyage with an unclear destination. The British Medical Journal. 2002;324(7337):569-73.

124.   Milne R, Oliver S. Evidence-based Consumer Health Information: Developing Teaching in Critical Appraisal Skills. International Journal for Quality in Health Care. 1996;8(5):439-45.

125.   Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. Journal of epidemiology and community health. 1999;53(2):105-11.

126.   Raffe A, Gray J. Screening: Evidence and practice. Oxford: Oxford University Press; 2007.

127.   Stacey D, Bennett C, Barry M, Col N, Eden K, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. Cochrane database of systematic reviews. 2011(10):CD001431.

128.   IPDASI. Criteria for judging the quality of patient decision aids. 2005 [cited 2010 18. 05]; Available from: http://www.ipdas.ohri.ca/what.html.

129.   Steinsbekk A. [Patient Activation Measure]. Tidsskrift for den Norske Legeforening. 2008;128(20):2316-8.

130.   Charnock D. Håndboken DISCERN. Kvalitetskriterier for helseinformasjon til forbrukere om hvilke behandlingsalternativer som finnes1998:[65 p.]. Available from: http://www.nifab.no/pasientveiledning/hvordan_vurdere_informasjon/discern_verktoey_for_evaluering_av_helseinformasjon.

131.   O'Connor A, Stacey D, Jacobsen M. Ottawa personal decision guide. 2007 [24.01.12]; Available from: http://decisionaid.ohri.ca/docs/das/OPDG.pdf.

132.   DiCenso A, Bayley L, Haynes R. Accessing preappraised evidence: fine-tuning the 5S model into a 6S model. Annals of Internal Medicine. 2009;151(6):99-101.

133.   Baker R, Camosso-Stefinovic J, Gillies C, Shaw E, Cheater F, Flottorp S, et al. Tailored interventions to overcome identified barriers to change: effects on professional practice and health care outcomes. Cochrane database of systematic reviews. 2010(3):CD005470.

134.   Treweek S, Zwarenstein M. Making trials matter: pragmatic and explanatory trials and the problem of applicability. Trials. 2009;10(37):9.

135.   Roland M, Torgerson D. What are pragmatic trials? The British Medical Journal. 1998;316(7127):285.

136.   Godwin M, Ruhland L, Casson I, MacDonald S, Delva D, Birtwhistle R, et al. Pragmatic controlled clinical trials in primary care: the struggle between external and internal validity. BMC medical research methodology. 2003;3(28):7.

137.   Haug C. [Panic pandemic?]. Tidsskrift for Den norske Legeforening. 2009;129(10):979. Epub 2009/05/19. Panikkpandemi?

138.   The Norwegian Institute of Public Health. The vaccination handbook e-book [Vaksinasjonshåndboka e-bok]: The Norwegian Institute of Public Health; 2007. Available from: (www.fhi.no/eway/).

139.   Cassell J, Leach M, Poltorak M, Mercer C, Iversen A, Fairhead J. Is the cultural context of MMR rejection a key to an effective public health discourse? Public Health. 2006;120(9):783-94.

140.   Tickner S, Leman PJ, Woodcock A. 'It's just the normal thing to do': exploring parental decision-making about the 'five-in-one' vaccine. Vaccine. 2007;25(42):7399-409.

141.   Benin A, Wisler-Scher D, Colson E, Shapiro E, Holmboe E. Qualitative analysis of mothers' decision-making about vaccines for infants: the importance of trust. Pediatrics. 2006;117(5):1532-41.

142.   Gellin BG, Maibach E, Marcuse E. Do parents understand immunizations? A national telephone survey. Pediatrics. 2000;106(5):1097-102.

143.   Haug C. [Prioritization on the paper--and in practice]. Tidsskrift for Den norske Legeforening. 2008;128(8):917. Prioritering pa papiret--og i praksis.

144.   Teasdale E, Yardley L. Understanding responses to government health recommendations: public perceptions of government advice for managing the H1N1 (swine flu) influenza pandemic. Patient education and counseling. 2011;85(3):413-8.

145.   Rygg M. [Skepticism against vaccination--paradox of preventive work]. Tidsskrift for Den Norske Laegeforening. 2006;126(22).

146.   de Boer M, Versteegen G, van Wijhe M. Patients' use of the Internet for pain-related medical information. Patient education and counseling. 2007;68(1):86-97.

147.   Diaz J, Griffith R, Ng J, Reinert S, Friedmann P, Moulton A. Patients' use of the Internet for medical information. Journal of general internal medicine. 2002;17(3):180-5.

148.   Sabel M, Strecher V, Schwartz J, Wang T, Karimipour D, Orringer J, et al. Patterns of Internet use and impact on patients with melanoma. Journal of the American Academy of Dermatology. 2005;52(5):779-85.

149.   Wainstein B, Sterling-Levis K, Baker S, Taitz J, Brydon M. Use of the Internet by parents of paediatric patients. Journal of paediatrics and child health. 2006;42(9):528-32.

150.   Bylund C, Gueguen J, Sabee C, Imes R, Li Y, Sanford A. Provider-patient dialogue about internet health information: An exploration of strategies to improve the provider-patient relationship. Patient education and counseling. 2007;66(3):346-52.

151.   Tuffrey C, Finlay F. Use of the internet by parents of paediatric outpatients. Archives of Disease in Childhood. 2002;87(6):534-6.

152.   Gordon MM, Capell HA, Madhok R. The use of the Internet as a resource for health information among patients attending a rheumatology clinic. Rheumatology. 2002;41(12):1402-5.

153.   Bozionelos G, Bennett P. The theory of planned behaviour as predictor of exercise: the moderating influence of beliefs and personality variables. Journal of health psychology. 1999;4(4):517-29.

154.   Opheim E. Brukermedvirkning på systemnivå: en kvalitativ studie av nytteverdi av kurs i kunnskapsbasert praksis for brukerrepresentanter. [Mastergradsoppgave]: Høgskolen i Bergen; 2011.

155.   Poland G, Jacobson R. Understanding those who do not understand: a brief review of the anti-vaccine movement. Vaccine. 2001;19(17-19):2440-5.

156.   Allen A. Vaccine: the controversial story of medicine's greatest lifesaver. New York: Norton; 2007. 523 p.

157.   Steinman M. Using patients to promote evidence-based prescribing: comment on "Communicating uncertainties about prescription drugs to the public". Archives of internal medicine. 2011;171(16):1468-9.

158.   Pilling S, Williams M, Brackett R, Gourley R, Weg M, Christensen A, et al. Part I, patient perspective: activating patients to engage their providers in the use of evidence-based medicine: a qualitative evaluation of the VA Project to Implement Diuretics (VAPID). Implementation Science. 2010;5:23.

159.   Kinnersley P, Edwards A, Hood K, Cadbury N, Ryan R, Prout H, et al. Interventions before consultations for helping patients address their information needs. Cochrane database of systematic reviews. 2007(3):CD004565.

Appendixes

Appendix 1: Copy of Interview guides focus groups

Intervjuguide foreldre

Introduksjon

Dere har nå alle i løpet av de siste tre månedene vært til konsultasjon med helsesøster om vaksinasjon. Fokuset for gruppediskusjonen vil være deres opplevelse av konsultasjonen med helsesøster og om beslutningsprosessen rundt vaksinasjon. Avslutningsvis vil jeg gjerne høre deres meninger om det å oppsøke og ta i bruk forskning om helse som støtte i beslutninger.

- Introduksjon av moderator og sekretær
- Avklare uavhengighet
- Hva er en fokusgruppe
- Oppfordre til diskusjon- målet er ikke å oppnå enighet men meningsutveksling
- Regler underveis (la en og en snakke ut, la alle slippe til, evt pause etc)
- Introduksjon av deltakere (hvorfor/ hvem)

Beslutningsprosessen

1. Hvordan opplevde dere generelt konsultasjonen med helsesøster om vaksinasjon?
Probe:

> - Hva var positivt? Hva var negativt?

2. Hvordan opplevde dere informasjonen som ble gitt i konsultasjonen med helsesøster om vaksinasjon?
Probe:

- Hvordan ble informasjonen gitt?
- Var noe av denne informasjonen forskningsresultater som beskrev fordeler og ulemper ved å la barnet vaksineres eller ikke vaksineres?

3. Hva var det dere baserte beslutningen om vaksinasjon på?
Probe:

- Helsesøsters råd, egen kunnskap forut for konsultasjon, annet?
- Oppsøkte dere noen informasjon om vaksinasjon på egen hånd?
    a. Hvis, ja i så fall hvor?

b.   Var noe av denne informasjonen forskningsresultater?

4. Hvordan opplevde dere beslutningsprosessen om vaksinasjon?
Probe:

- Hva var til hjelp? Hva var til hinder?

5. Hvem var det som til syvende og sist tok beslutningen om å vaksinere eller ikke vaksinere?

Nå skal jeg spørre dere noen spørsmål om medisinsk og helserelatert forskning

(Holdninger)

6. Hva mener dere om det å oppsøke og ta i bruk forskning som støtte i beslutninger om vaksinasjon?
Probe:

- Hva er fordeler? Hva er ulemper?
- Er det noe som særlig gjelder i forhold til vaksinasjon sammenliknet med andre helsebeslutninger?

(Subjektive normer)

7. Kjenner dere til noen som ville synes at det var positivt eller negativt om dere oppsøkte forskning som støtte i beslutninger om vaksinasjon?
Probe:

- Helsestasjon? Familie? Andre individer eller grupper?

(Opplevd kontroll med atferden)

8. Hvilke faktorer eller omstendigheter påvirker om dere oppsøker og tar i bruk forskning som støtte i beslutninger om vaksinasjon?
Probe:

- Hva må ligge til rette? Hva gjør det vanskelig?

Avrunding (signalisere at gruppen nærmer seg slutten)

9. Er det andre emner som dere kommer på når dere tenker på det å ta i bruk forskning i beslutninger om vaksinasjon?

Oppsummering

- Dobbeltsjekke konklusjoner med mulighet for mer debatt
- Identifisere forskjeller, kontrasterende meninger
- Gjøre en siste runde for lufting av meninger mulig
- Takke!

Intervjuguide helsesøstre

Introduksjon
Fokuset for denne gruppediskusjonen vil være deres opplevelse av møtet med foreldre i konsultasjoner og beslutningsprosessen om vaksinasjon. Avslutningsvis vil jeg gjerne høre deres meninger om det å oppsøke og ta i bruk forskning som støtte i konsultasjoner.

- Introduksjon av moderator og sekretær
- Hva er en fokusgruppe
- Oppfordre til diskusjon- målet er ikke å oppnå enighet men meningsutveksling
- Regler underveis (la en og en snakke ut, la alle slippe til, evt pause etc)
- Introduksjon av deltakere (hvorfor/ hvem)

Beslutningsprosessen

10. Hvordan opplever dere generelt konsultasjonen med foreldrene om vaksinasjon?
Probe:

- Hva er positivt? Hva er negativt?
- Kan dere gi eksempler på hvordan dere informerer?
- Hva legger dere vekt på i møtet?

11. Hvordan opplever dere informasjonen/ressursene dere har tilgjengelig i rådgivningsarbeidet når det gjelder vaksinasjon?
Probe:

- Er noe av denne informasjonen forskningsresultater som beskriver fordeler og ulemper ved å la barnet vaksineres eller ikke vaksineres?
- Oppsøker dere informasjon om vaksinasjon andre steder enn retningslinjene som støtte i rådgivningsarbeidet?
  - a. Hvis, ja i så fall hvor?

b.   Er noe av denne informasjonen forskningsresultater?

12. Hvordan opplever dere beslutningsprosessen om vaksinasjon?
Probe:

- Hva er til hjelp? Hva er til hinder?

13. Hva opplever dere at foreldrene baserer beslutningen sin om vaksinasjon på?
Probe:

- Helsesøsters råd, brukernes egen kunnskap forut for konsultasjon, annet?

14. Hvem er det som til syvende og sist tar beslutningen om å vaksinere eller ikke vaksinere?

Nå skal jeg spørre dere noen spørsmål om medisinsk og helserelatert forskning

(Holdninger)

15. Hva mener dere om det å oppsøke og ta i bruk forskning som støtte i konsultasjonen med foreldre om vaksinasjon?
Probe:

- Hva er fordelene? Hva er ulempene?
- Er det noe som særlig gjelder i forhold til vaksinasjon sammenliknet med andre helsebeslutninger?

(Subjektive normer)

16. Kjenner dere til noen som ville synes at det var positivt eller negativt om dere oppsøkte og tok i bruk forskning som støtte i konsultasjonen med foreldre om vaksinasjon?
Probe:

- Kollegaer? Brukerne? Andre individer eller grupper?

(Opplevd kontroll med atferden)

17. Hvilke faktorer eller omstendigheter påvirker om dere oppsøker og tar i bruk forskning som støtte i konsultasjonen med foreldre om vaksinasjon?
Probe:

- Hva må ligge til rette? Hva gjør det vanskelig?

Avrunding (signalisere at gruppen nærmer seg slutten)

18. Er det andre emner som dere kommer på når dere tenker på det å ta i bruk forskning i konsultasjonen med foreldre om vaksinasjon?

Oppsummering

- Dobbeltsjekke konklusjoner med mulighet for mer debatt   - Identifisere forskjeller, kontrasterende meninger   - Gjøre en siste runde for lufting av meninger mulig   - Takke!

Appendix 2. Copy of questionnaire including TPB, PAM and Honeycomb

høgskolen i oslo

1) Svaralternativene til hvert spørsmål består av en skala. Husk å lese hvert spørsmål grundig før du krysser av svaret ditt da skalaene varierer noe fra spørsmål til spørsmål*

2) Jeg ønsker å oppsøke informasjon på egen hånd til bruk i fremtidige helsespørsmål:

○ 1 Svært uenig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Svært enig

3) Jeg forventer at jeg kommer til å oppsøke informasjon på egen hånd til bruk i fremtidige helsespørsmål:

○ 1 Svært uenig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Svært enig

4) Jeg har intensjoner om å oppsøke informasjon på egen hånd til bruk i fremtidige helsespørsmål:

○ 1 Svært uenig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Svært enig

5) Angi hvor usannsynlig eller sannsynlig de følgende påstander er for deg. Hvis jeg oppsøker informasjon på egen hånd til bruk i helsespørsmål:

	Usannsynlig 1	2	3	4	5	6	Sannsynlig 7
Vil det gi meg mer innsikt	○	○	○	○	○	○	○
Vil det gi meg nyttig bakgrunnskunnskap i konsultasjon med helsepersonell	○	○	○	○	○	○	○
Vil det være til hjelp hvis jeg er usikker på hva jeg skal gjøre i en helsebeslutning	○	○	○	○	○	○	○
Vil det gi meg mer kunnskap hvis jeg opplever at informasjonen jeg får fra helsepersonell er ufullstendig	○	○	○	○	○	○	○

6) Angi hvor uønskelig eller ønskelig de følgende utfall er for deg:

	Svært uønskelig	Uønskelig	Noe uønskelig	Verken uønskelig eller ønskelig	Noe ønskelig	Ønskelig	Svært ønskelig
Å få mer innsikt er	○	○	○	○	○	○	○
Nyttig bakgrunnskunnskap i konsultasjon med helsepersonell er	○	○	○	○	○	○	○
Å ha informasjon til hjelp hvis jeg er usikker på hva jeg skal gjøre i et helsespørsmål er	○	○	○	○	○	○	○
Å få mer kunnskap hvis jeg opplever at jeg får ufullstendig informasjon fra helsepersonell er	○	○	○	○	○	○	○

---

7) Det å oppsøke informasjon på egen hånd til bruk i helsespørsmål er:

○ 1 Verdiløst ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Nyttig

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8) Det å oppsøke informasjon på egen hånd til bruk i helsespørsmål er:

○ 1 Positivt ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Negativt

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9) Det å oppsøke informasjon på egen hånd til bruk i helsespørsmål er:

○ 1 Skadelig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Fordelaktig

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10) Angi hvor negative eller positive de følgende grupper vil være til at du oppsøker informasjon på egen hånd til bruk i helsespørsmål:

	Svært negative	Negative	Noe negative	Verken negative eller positive	Noe positive	Positive	Svært positive
Familie og venner	○	○	○	○	○	○	○
Helsepersonell	○	○	○	○	○	○	○
Andre sosiale grupper eller foreninger du deltar i (f.eks kollegaer, pasientforeninger etc)	○	○	○	○	○	○	○

11) Hva familie og venner mener jeg skal gjøre er viktig for meg:

○ 1 I svært liten grad ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 I svært stor grad

12) Hva helsepersonell mener jeg skal gjøre er viktig for meg:

○ 1 I svært liten grad ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 I svært stor grad

13) Hva andre sosiale grupper eller foreninger som jeg deltar i mener jeg skal gjøre er viktig for meg:

○ 1 I svært liten grad ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 I svært stor grad

14) Angi hvor usannsynlig eller sannsynlig de følgende påstander er for deg. Hvis jeg oppsøker informasjon på egen hånd til bruk i helsespørsmål:

	Usannsynlig 1	2	3	4	5	6	Sannsynlig 1
Føler jeg at det er vanskelig å få oversikt over all informasjonen	○	○	○	○	○	○	○
Føler jeg at jeg ikke har kunnskap nok til å vurdere kvaliteten på informasjonen jeg finner	○	○	○	○	○	○	○
Opplever jeg at det er tidkrevende å finne informasjonen jeg leter etter	○	○	○	○	○	○	○

15) Angi til i hvilken grad de følgende faktorene påvirker deg når det gjelder sannsynligheten for at du oppsøker informasjon på egen hånd til bruk i helsespørsmål:

	Mindre sannsynlig at jeg oppsøker informasjon 1	2	3	4	5	6	Mer sannsynlig at jeg oppsøker informasjon 7
Opplevelsen av at det er vanskelig å få oversikt over all informasjonen gjør det:	○	○	○	○	○	○	○
Det å ikke ha kunnskap nok til å vurdere kvaliteten på informasjonen gjør det:	○	○	○	○	○	○	○
At det å søke etter informasjon kan være tidkrevende gjør det:	○	○	○	○	○	○	○

16) Generelt sett opplever jeg at personer som er viktige for meg synes at jeg skal oppsøke informasjon på egen hånd til bruk i helsespørsmål:

○ 1 Svært uenig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Svært enig

17) Generelt sett føler jeg sosialt press til å søke etter informasjon på egen hånd til bruk i helsespørsmål:

○ 1 Svært uenig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Svært enig

18) Generelt sett opplever jeg at det er forventet av meg at jeg oppsøker informasjon på egen hånd til bruk i helsespørsmål:

○ 1 Svært uenig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Svært enig

19) Jeg føler at jeg mestrer det å oppsøke informasjon på egen hånd til bruk i helsespørsmål:

○ 1 Svært uenig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Svært enig

20) Jeg har tillit til at jeg kan klare å oppsøke informasjon på egen hånd til bruk i helsespørsmål:

◉ 1 Svært uenig ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Svært enig

21) Under står noen utsagn som folk av og til bruker når de snakker om helsen sin. Angi i hvor stor grad du er enig eller uenig med hvert utsagn. I utsagnene brukes ordet 'behandling', tenk på at forebyggende tiltak og livsstil også er behandlinger.

	Helt uenig	Nokså uenig	Nokså enig	Helt enig	Ikke aktuelt
Når alt kommer til alt er jeg selv ansvarlig for å ta hånd om min egen helse	○	○	○	○	○
Det aller viktigste for min egen helse og funksjonsevne er at jeg tar aktiv del i behandlingen	○	○	○	○	○
Jeg er sikker på at jeg kan gjøre det som er nødvendig for å forebygge eller redusere symptomer eller problemer som skyldes min helsetilstand	○	○	○	○	○
Jeg vet hvordan de forskjellige medisinene jeg har fått foreskrevet skal virke	○	○	○	○	○
Jeg vet når jeg trenger medisinsk hjelp for et helseproblem og når jeg kan ta hånd om det selv	○	○	○	○	○

22) Fortsatt fra forrige side. Angi i hvor stor grad du er enig eller uenig med hvert utsagn.

	Helt uenig	Nokså uenig	Nokså enig	Helt enig	Ikke aktuelt
Jeg er trygg nok til å kunne ta opp det jeg ønsker, selv om helsepersonell ikke spør	○	○	○	○	○
Jeg er sikker på at jeg kan gjennomføre den foreskrevne medisinske behandlingen hjemme	○	○	○	○	○
Jeg forstår både hva helseproblemene mine dreier seg om og årsaken til dem	○	○	○	○	○
Jeg vet om de ulike behandlingsmuligheter for min helsetilstand	○	○	○	○	○
Jeg har opprettholdt de endringer i livsstil som jeg har gjort for helsens skyld	○	○	○	○	○
Jeg vet hvordan jeg skal forebygge forverring av min helsetilstand	○	○	○	○	○
Jeg kan finne løsninger når det oppstår nye situasjoner eller problemer med min helsetilstand	○	○	○	○	○
Jeg kan opprettholde endringer i livsstil, for eksempel kosthold og trening, også i perioder med stress	○	○	○	○	○

Til slutt vil vi spørre deg noen spørsmål om hvordan du opplevde nettportalen Sunn skepsis.

23) Angi hvor nyttig du opplevde Sunn skepsis:

○ Svært unyttig

○ Unyttig

○ Noe unyttig

○ Verken eller

○ Noe nyttig

○ Nyttig

○ Svært nyttig

24) Angi hvor brukervennlig du opplevde Sunn skepsis:

○ Svært lite brukervennlig

○ Noe lite brukervennlig

○ Verken eller

○ Noe brukervennlig

○ Brukervennlig

○ Svært brukervennlig

25) Angi hvor troverdig du opplevde Sunn skepsis:

○ Svært lite troverdig

○ Noe lite troverdig

○ Verken eller

○ Noe troverdig

○ Troverdig

○ Svært troverdig

* 2 to 20= TPB, 21 to 22=PAM and 23 to 25= Honeycomb

Appendix 3. Summary of the ratings in usability test

Usability	Focus group 1	Focus group 2	Focus group 3	Focus group 4	Focus group 5
1. Usable	+	+ -	+ -	+ -	+ -
2. Useful	+	+ -	+	+	+
3. Valuable	+	+ -	+	+	+
4. Accessible	+ -	+ -	+ -	+ -	+
5. Desirable	+	+	+	+	+
6. Credible	+	+	+	+	+

* Summary of the ratings per usability category across interviews based on the Honeycomb model by Moreville (38), courtesy of Danielsen (78). + = Positive feedback - = Negative feedback

Appendix 4. Summary of changes after usability test

Problemområde	Forslag løsning	Utført
Forsiden		
Titler endres i knapper foran	Utføres	Ja
Logo må på forsiden	Logo legges til	Ja
Usikkerhet rundt hva som 'samler' siden, hva er helheten som samler delene?	Utvikle et samlende konsept for forsiden.	Ja
Tag-cloud oppleves forvirrende	Gjøre om til lenkesamling til utvalgte artikler i stedet for å lenke til indexside	Ja
Kritisk vurdering		
Discern for lang	Vurdere å bruke kortversjonen	Ja
Skåringsverktøy for Discern	Legges til som tilleggsfunksjon	Ja
Søk etter forskning		
Vanskelig å navigere søkesidene	Omorganisere søk etter forskning	Ja
For mange steder å søke i presise søk	Vurdere om vi skal kutte noen	Ja
Lenkene til 'hurtigsøk' og 'presise søk' gjøres penere	W3spor fikser	Ja
Finner ikke forskning (det er ikke alt det er forskning på)	Legge til en tekst: finner du ikke det du leter etter? ….	Ja
Finner ikke ut av hvor man kan lese om sykdom	Legge til at man får info om dette under omtaler	Ja
Sjekkliste til konsultasjonen		
Språk i lista er litt vanskelig	Skrive om samt kutte ned på noen spørsmål	Ja
Generelt		

Kommentar om at 'les mer' lenker ikke gir nok informasjon til blinde	Disse lenkene har en annen tittel allerede som de blinde leser	Ja
Hvorfor kan man ikke bare søke i google- hva bidrar sunn skepsis med?	Legge inn tekst på dette	Ja
Kommentar om at man burde kunne søke i alle databaser samtidig gjennom SS	Det er ikke gjennomførbart teknisk ei heller ønskelig pga av hensikten med å øke brukernes egne kunnskaper og ferdigheter innen søk og forskning	Nei
Tale i film må legges til som tekst	Utføres	Påventes
Grønne epler i småbokser blir oppfattet som lenker	Epler fjernes	Ja
Småbokser vanskelig å få øye på	Skifte farge på småboksene	Ja
Menypunkter annen farge enn resten av designet	Skifte farge slik at det passer med resten av fargeskjemaet	Ja
Søke i sunn skepsis forvirrende	Designbyrået legger til en beskrivende tekst. I tillegg vil søkeboksene i 'presise' søk bli lagt til	Ja
Det må være mulig å printe sjekklistene	Printikon	Ja
Uthevet fet tekst for å øke synlighet av stikkord	Utføres	Ja
Andre revisjoner etter brukertest		
HON-code verifisering	Utføres	Ja
Lenker til databaser gjøres om til knapper	Utføres	Ja
Om risiko	Utføres	Ja
Om validitet, kritisk vurdering + lenke til kbp.no	Utføres	Ja
Legge inn caser under alle tre hovedkapitler	Utføres	Ja
Bi-effekt versus feilbehandling	Droppe i denne omgang- vil være relevant ved seinere utvidelse av portal	Nei
Skille på nivåer i diagnostikkteksten	Utføres	Ja
Legge til at discernkalkulatoren også kan brukes for de som utvikler	Utføres	Ja

pasientinformasjon		
Ingen forskning er ikke det samme som ingen effekt (eller bi-effekt)	Utføres	Ja
Legge inn lenke på skolemedisin/ alternativmedisin til søkesiden	Utføres	Ja
Legge inn tekst med omtaler, oversikter og enkeltstudier	Utføres	Ja
Se over språk ny side om beskrivelser av kilder	Utføres	Ja
Endre tittel på filmer	Utføres	Ja
Bilde på side om forskning	Utføres	Ja
Legg inn snutt om forskningsetikk + deltakelse i forskning under om forskning	Utføres	Ja

Appendix 5. Results of TPB utility testing across the samples and studies

	Questionnaire sample 1: Mixed population (n=30)				Questionnaire sample 2: Parents (n=45)				Randomised controlled trial sample: Parents (n=66)			
	Correlation coefficients (Pearson R)				Correlation coefficients (Pearson R)				Correlation coefficients (Pearson R)			
	Direct measures				Direct measures				Direct measures			
Direct measures	Intentions	ATT	SN	PBC	Intentions	ATT	SN	PBC	Intentions	ATT	SN	PBC
Attitudes (ATT)	0,58**	-			0,58**	-			0.56**	-		
Subjective Norms (SN)	0,24	0,49**	-		-0,16	0,22	-		-0.01	0.18	-	
Perceived Behavioural Control (PBC)	0,70**	0,55**	0,28	-	0,44**	0,47**	0,07	-	0.41**	0.59**	0.69	-

* Correlation is significant at the 0.05 level (2-tailed) ** Correlation is significant at the 0.01 level (2-tailed)

Papers I-V

II

III

IV

Evaluation of a web portal for improving public access to evidence-based health information and health literacy skills: a pragmatic trial

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Running head: Improving access to evidence-based health information and health literacy skills

Abstract

Background: Using the conceptual framework of shared decision making and evidence-based practice, a web portal was developed to serve as a generic (non disease-specific) tailored intervention to improve the lay public's health literacy skills.

Objective: To evaluate the effects of the web portal compared to no intervention in a real life setting.

Methods: A pragmatic randomised controlled parallel trial using simple randomisation of 96 parents who had children aged <4-years. Parents were allocated to receive either access to the portal or no intervention, and assigned three tasks to perform over a three-week period. These included a searching task, a critical appraisal task, and reporting on perceptions about participation. Data were collected from March to throughout June 2011.

Results: Use of the web portal was found to improve attitudes towards searching for health information. This variable was identified as the most important predictor of intention to search in both samples. Participants considered the web portal to have good usability, usefulness and credibility. The intervention group showed slight increases in the use of evidence-based information, critical appraisal skills, and participation compared to the group receiving no intervention, but these differences were not statistically significant.

Conclusion: Despite the fact that the study was underpowered, we found that the web portal may have a positive effect on attitudes towards searching for health information. Furthermore, participants considered the web portal to be a relevant tool. It is important to continue experimenting with web-based resources in order to increase user participation in health care decision-making.

Introduction

The active involvement of healthcare users (hereafter referred to as 'users') is argued in respect for individual autonomy, as a critical component of sustainable health and healthcare [1,2], and as central to evidence-based practice [3]. However, effective participation is dependent on access to research-based information, and skills that would enable users to obtain, understand, evaluate, and act upon the information available [2]. Such health literacy skills include basic reading and numeracy (functional literacy), as well as critical and social skills [2,4]. Health literacy is described by the World Health Organization as the main desired outcome of health education [5], as an asset in itself, and as a public health issue [2,5]. Through health literacy, it is argued that people are able to take better control of their own lives and health, including the personal, social and environmental determinants of health [2,6,7]. In a systematic review of the evidence, low health literacy levels were associated with poorer health, increased health care utilisation, inappropriate drug use, and the low uptake of disease prevention services (such as vaccinations) [8].

Although access to health information has been improved greatly by new information technologies, evidence-based information is not readily available to the lay public [9,10,11]. Studies have found that users may be overwhelmed and frustrated by the vast amount of information available and unsure about who or what they should trust [12,13]. Moreover, people struggle to understand and critically appraise health information, do not effectively check the accuracy of health information they find and overrate the trustworthiness of such information [13,14,15,16,17,18]. Specifically, people are unfamiliar with the principles of medical and health related research and concepts such as randomisation, risk, uncertainty, and causality [17,19,20,21,22,23]. Research has also shown that many people are sub-optimally involved in

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decision making, unaware of their rights or of treatment alternatives, and uncertain about what they need to ask their health care provider [24,25,26,27,28].

Theoretical and empirical studies suggest that the development of initiatives targeting critical and interactive skills among users is needed, and that these efforts should be evaluated in order to inform practice [4,29,30]. Essential skills includes basic reading, writing and numeracy skills (*functional* or *fundamental literacy*), but also critical and social literacy skills, including scientific literacy, civic literacy and cultural literacy [4].

Coulter and Ellins' comprehensive review of the evidence indicates that interactive online interventions may be effective strategies for health education [30,31,32]. This method of learning is associated with high levels of user satisfaction [30] and may also be more cost-effective and flexible compared to traditional methods of health education [32]. The content can be also be easily updated and made available to all.

Inspired by these findings we developed a web portal, with the aim of improving the public's access to evidence-based health information and health literacy skills. What health literacy skills really entail has been conceptualised in many different ways. We used the multi-dimensional model formulated by Zarcadoolas and colleagues which contains four central domains: fundamental literacy (reading, writing, speaking and working with numbers), science literacy (understanding and using science and technology), civic literacy (skills and abilities that enables awareness, participation and involvement), and cultural literacy (skills and abilities to recognise, understand and use beliefs, customs, world-views and social identities) [4]. The web portal was designed from a public health perspective to target both healthy people as well as patients, and to be used either independently or in consultation with health providers. The web

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portal was intended to be used by those who are interested in searching for health information, who would like to know more about medical and health-related information, or need support in decisions related to health. Its content and key intervention targets were informed by extensive literature searches as well as explorative pre-studies with input from people within our target audiences, including focus groups and a questionnaire study based on the Theory of Planned Behaviour (TPB) [24,33,34,35]. Three key barriers to obtaining information were identified; not knowing where to find reliable and relevant information, the inability to understand and critically appraise health information and the inability to exchange information in consultations [35]. The content of the web portal was tailored to address these barriers by facilitating specific domains of health literacy through a choice of evidence based strategies [35]. The web portal was developed within the conceptual framework of the shared-decision making model and evidence based practice, encouraging participation and emphasising the importance of that decisions should be based on the best available evidence [1,3]. Using illustrations of typical healthcare topics, the web portal focused on *how* research is conducted and *why* this is important rather than just reporting conclusions and expert interpretations. Generic and non-disease specific in focus, the web portal was designed to be applicable to a range of healthcare decisions and settings, and included three facilitators or tool-sets to address each of the main barriers to obtaining information:

1. Access to medical and health-related research databases, an introduction to research methods, the principles of science (based on the steps of the evidence based practice model) and levels of evidence synthesis [36,37]

2. A checklist for critically assessing health information (DISCERN) [38] and information

about why critical assessment is important

3. A checklist for consultations with health care providers [39] and information about what decision making related to treatment and screening entails.

The development and content of the web portal is described in more detail in another paper [35], or can be viewed online at www.sunnskepsis.no. An overview of the targeted barriers, the content of the intervention, the hypothesised corresponding health literacy domains targeted are presented in table 1.

The objective of this study was to evaluate the effects of this web portal intervention compared to no intervention in a real life setting on:

- Beliefs about searching for health information and overall activation (participation)

- Searching for research-based information and the development of critical appraisal skills

In addition, we also wanted to get feedback from the participants on their satisfaction with the web portal.

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Barriers identified in pre-studies and literature search	Facilitators/content of intervention	Health literacy domains*	Evaluated in pragmatic trial
All	Shared decision making (promoting an active role) and evidence based practice as conceptual framework (promoting evidence based decisions)	Civic literacy (system and relationships) Science literacy	TPB **(attitude and subjective norms associated with search)/ PAM***
Inability to understand and critically appraise health information	Improving critical appraisal skills *Introduction to scientific concepts and (checklist for) evaluating trustworthiness of health information*	Science literacy *Examples: Validity, uncertainty, causality* Functional literacy (numeracy) *Example: Understanding risk* Civic literacy (media literacy) *Examples: How research and scientific discourse are presented in the media*	Searching task/ critical appraisal task/ TPB (perceived behavioural control and attitudes towards search)
Not knowing where to find reliable and relevant information	Improved access to reliable research based sources of health information *Introduction to searching for evidence based information (adapted EBP-model)*	Science literacy *Examples: Basic study designs and assessment of relevance* Civic literacy (media literacy) *Examples: Search strategies, publication types and sources*	Searching task/ TPB (perceived behavioural control and attitudes towards search)
Inability to exchange information in consultations	Enabling exchange of health information *Introduction to clinical decision making and checklist for the consultation*	Science literacy Civic literacy (system and relationships) Cultural literacy (understanding of concepts used in decision making about health care)	PAM

* Health literacy domains based on the model by Zarcadoolas and colleagues [4], **Theory of planned behaviour, ***Patient activation measure

Table 1. Overview of the intervention components, corresponding hypothesised health literacy domains targeted based and measurements to evaluate these

Methods

Design

      The study was a pragmatic parallel-trial in which one group received access to the portal and its tools (the intervention group) while the other group received no intervention (the control group).

Participants and recruitment

      Our intention was to include typical users for the web portal in the participant sample. In addition, we wished to increase the probability that the portal would be used by participants in association with visits to health professionals during the trial. Parents with children under the age of 4-years of age were therefore targeted. At this life stage, parents are typically having many questions about treating and preventing health problems. They are also healthcare users with the highest number of health visits per year both for themselves (a mean number of visits per year of 4. 6), and for their children (mean number of visits of 3) [40]. Such parents are also statistically more likely to search for health information online [41].

Sample size justification

      Sample size calculations should be based on assumptions about expected underlying population event rate and minimum detectable difference in means (and standard deviation of the response) in previous studied populations [42]. Few studies, however, have targeted the publics' health literacy skills including domains other than functional literacy. Thus, for the outcomes included in this trial we had very little previous experience to rely on. Considering that the intervention was passive in nature, we anticipated the effects to be modest. We assumed a

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conservative minimum detectable difference of means (amounting to a one point difference on seven point scale with a standard deviation of 2,1) on the outcome 'beliefs about searching'. These assumptions were supported by the means and standard deviations observed in the piloting phase and in the validation study of the TPB questionnaire [34]. Furthermore, we based our sample size calculations on a power of 0.80, a level of significance of 0.95 and the use of a two-sided t-test for statistical analysis. Hence, the required sample size was estimated as 140 persons. (see Figure 1 for the CONSORT flow diagram).

Sources and methods of recruitment

Information about the study was distributed at maternity and child health centres, in online advertisements on social media networks, on Internet sites such as Google, and discussion forums for parents. Those who were interested and wished to participate were directed to a recruitment web page.

Informed consent and inclusion of participants

People who expressed an interest in participating received information about the study, were asked to give written consent to participation, and directed to an online questionnaire for inclusion criteria screening. Participants were excluded if anyone else in their household was already participating in the study (to ensure that participants were blinded and to protect against potential sample contamination) and if they did not have children aged <4-years. If a participant did not meet these inclusion criteria, he or she was sent automated feedback describing the reasons why they were ineligible to participate.

CONSORT 2010 Flow Diagram
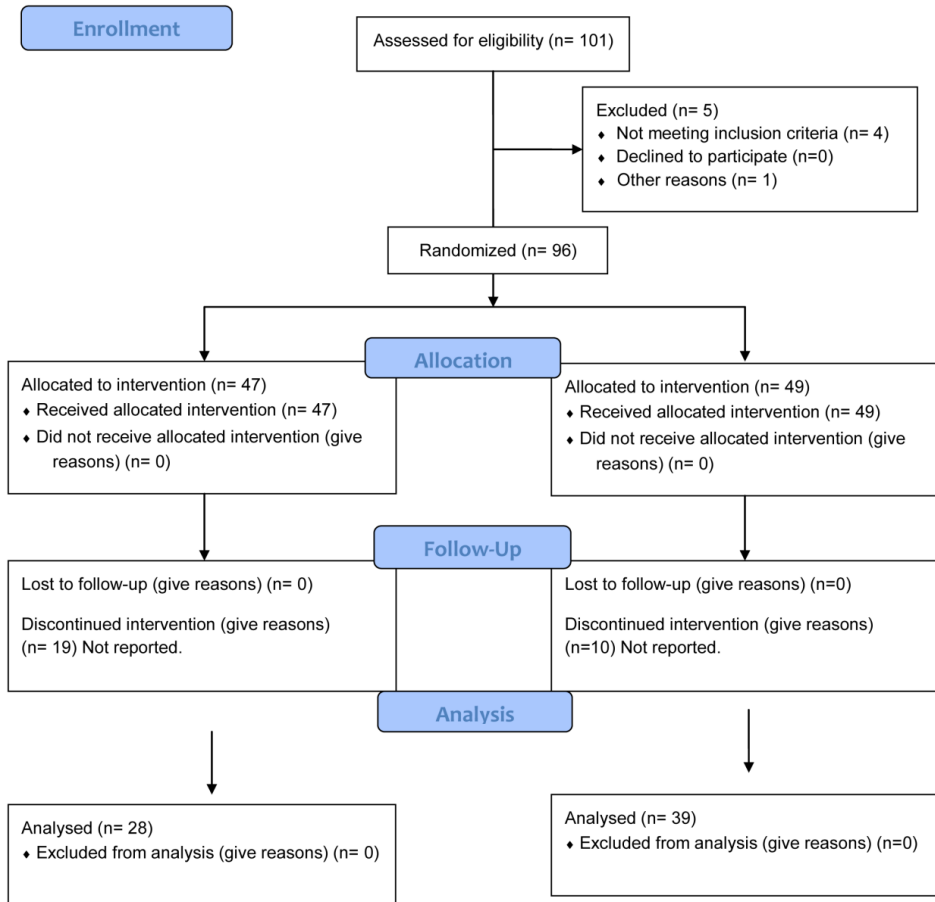
Figure 1. Consort 2010 flow diagram

Randomisation methods and allocation concealment

    Those who met the inclusion criteria were randomised using a simple randomisation

procedure developed by SPSS. The study was single blinded in that participants were not

informed about the study group to which they were allocated. All participants were told that they would be participating in testing a new web portal resource but that they would receive initial access to the portal at different times. All participants were given the same information and treated equally through the use of automated online systems and standardised emails.

Intervention delivery

All information was delivered online, and data were collected using an online questionnaire system. Participants were sent tasks by email (Figure 2) at three different times. The intervention group was allowed access to the web portal immediately after randomisation, and given three days to explore its content and tools before receiving the first task. Each of the tasks corresponded to the web portal's three main content sections, namely: the improved use of research based information, improved critical appraisal of health information, and improved beliefs about participation (search and activation). The tasks were as follows:

1. Searching task: Using research-based information

The purpose of the first task was to evaluate the degree to which participants used research based sources to obtain healthcare information. Participants were asked to formulate a question and to answer it by searching for online information. The intervention group was not asked specifically to use the web portal for this task and were thus free to search for information using any resource they felt would be useful, including the web portal.
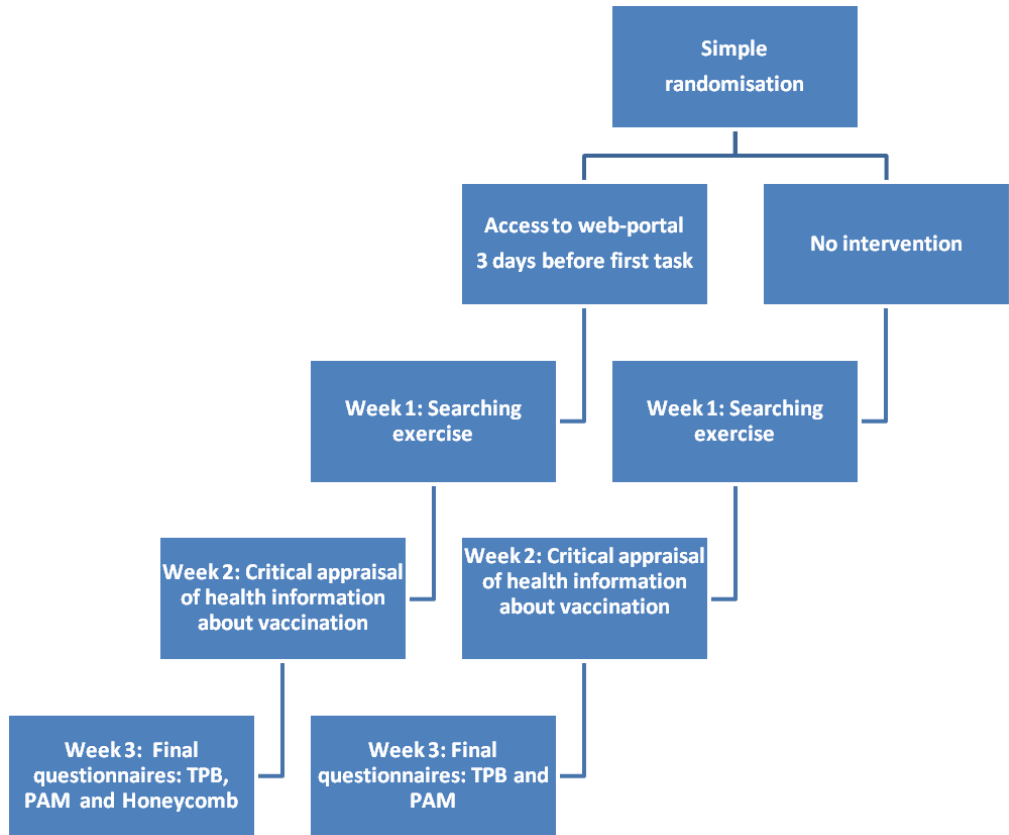
Figure 2. Overview of the study design

2. Critical appraisal task

     The purpose of the second task was to evaluate participant critical appraisal skills related to

health information. All participants were asked to rate the trustworthiness of an online article

describing how to prevent swine flu, and that included information about vaccinations and

alternative therapies. The intervention group was asked explicitly to use the DISCERN critical

appraisal tool which was provided on the web portal [38]. DISCERN is an instrument for patients

and other lay-users of health information and is designed to allow them to evaluate the reliability of written information about treatment choices [43]. Swine flu was chosen as the subject for this task for a number of reasons. All vaccinations are voluntary in Norway, and related healthcare decisions were therefore seen as a topic that would be of concern to all parents. Moreover, there has been considerable discussion about vaccinations in the media over the last few years, characterised by strong and often conflicting viewpoints [23,44,45,46], including debate about swine flu vaccinations [47,48]. We therefore viewed this topic as having considerable potential interest to participants. The specific material we chose for evaluation was taken from a health information site identified using a Google search and was typical of the kind of information available on sites used by lay-people searching for health information.

3. Beliefs about search for health information and activation

The third task was designed to explore potential differences between the intervention and control groups in terms of beliefs about health information searches (attitudes, social expectations, perceived behavioural control and intention to search). It also served to explore differences in overall levels of activation. In this final task, the intervention group was also given four additional questions in order to evaluate their satisfaction with the web portal.

Each of the tasks was sent to participants at weekly intervals. This timing and the overall length were decided on for two reasons: firstly, participants were provided with sufficient time to complete the tasks at their own pace. Secondly, longer periods or shorter intervals between tasks could possibly have had potentially negative consequences on the response rate and result in participation fatigue. At the end of the study, after all data had been collected, the control group

was also given access to the web portal. The time-frame for data collection was pre-specified, beginning March and lasting throughout June 2011.

Participant retention

Basic non-sensitive background information and email addresses were kept on file to allow for a descriptive analysis of losses to follow-up. One automatic reminder per task was sent to participants if they failed to respond within six days.

Missing data

No attempt was made to impute missing data. All analyses were performed using available cases, but based on the principle of intention to treat (ITT) (i.e. all participants were analysed in the group to which they were randomly assigned).

Outcome assessment and analysis

Few tools are available for evaluating improvements in health literacy skills, and most map only general reading and numeracy skills (in other words, only functional literacy) [49]. Our intervention was intended mostly to target and evaluate critical and social skills and we identified no single available instrument suitable to achieving these goals. The outcomes of this study were therefore evaluated using a selection of instruments which, when combined, were considered adequate to evaluating most of the important health literacy skills targeted by our intervention. The main outcomes and corresponding instruments are described in further detail below (see also table 1) and include both actual behaviour as well as behavioural beliefs. All data were

automatically exported into SPSS via the online data collection program.

The searching task: using research-based information

The outcome was evaluated by categorising the accessed Internet material (identified by hyperlinks) as information that either had or had not been based on research. The information was considered to be 'research-based' if it took the form of a report about original research (e.g. a primary study) or summarised research that had been based on explicit and systematic criteria (e.g. a systematic review or decision support). The information was excluded if no references were provided or identified, and if there were no explicit systematic criteria related to how and why any included references had been chosen. The material (identified by hyperlinks) was categorised by two independent and blinded researchers with training in the field of evidence-based practice and evidence synthesis. Their conclusions were then discussed further with the lead researcher. It was expected that research based information would be found by more participants in the intervention group than the control group. This hypothesis was tested by calculating the relative risk and corresponding confidence intervals.

Critical appraisal of health information

We used DISCERN appraisal tool (item number 16) to compare overall respondent ratings of the swine flu information [43]. This tool measures the respondent's overall rating on a scale of 1-5, where a score of 1-2 indicates 'low quality' (serious or extensive shortcomings), 3 indicates 'moderate' quality (potentially important but not serious shortcomings) and a rating of 4-5 indicates that respondents felt the material to be of 'high quality' with only minimal shortcomings [43]. The study group's mean value information rating was measured against

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ratings of the same material made by two blinded external experts with professional research and healthcare backgrounds. Based on results from previous studies using DISCERN, the mean overall score of the intervention group was expected to be closer in value to the experts' rating than the control group [38]. We also expected that the overall quality rating made by the intervention group would be lower, given that evaluations based on explicit criteria tend to be more critical compared to personal opinion [50]. The effects of the intervention were measured by calculating the mean differences between the groups and applying one-sided t-tests.

Beliefs about intention to search for health information and activation

This outcome was measured using two instruments. A questionnaire was designed specifically for the purpose of evaluating beliefs about searching for health information, based on the TPB [34]. The Patient Activation Measure (PAM) was used, with permission from Insignia Health, to evaluate overall activation and participants' self-management abilities [51].

Measuring beliefs about search for health information

The TPB is a social cognition model rigorously tested and widely used to predict behavioural intentions [52,53,54]. According to this model, there are three cognitive variables that can predict behavioural intentions (Figure 3)[52,55]. These are:

1. Attitudes towards the behaviour (beliefs about the consequences of the behaviour, and positive or negative judgements about these consequences)

2. Subjective norms about the behaviour (a person's own perception of social pressure or

expectations and motivation to comply)

3. Perceived behavioural control (how much a person has control over the behavior and how confident a person feels about being able to perform or not perform the behavior)
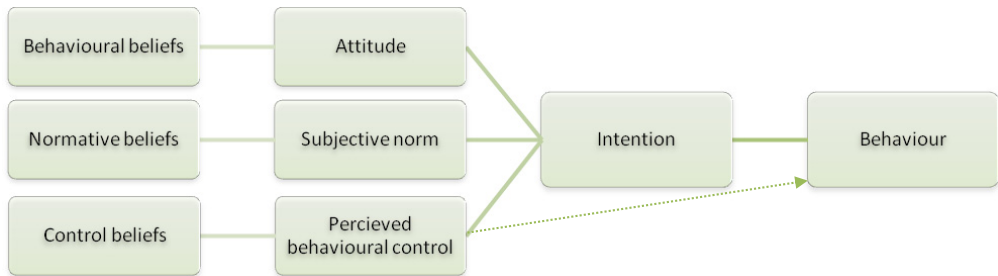
Figure 3. Model of the Theory of planned behaviour by Ajzen 1991 [55]

These three variables are measured using direct and indirect measures [52]. While the direct measures describe the overall beliefs associated with behavioural intentions, in this study of intention to search for health information, the indirect measures represented the specific beliefs that underlay the overall assessments and were seen as explanatory factors. To evaluate the influence of the intervention on the direct and indirect TPB components, we calculated the differences in mean overall scores and specific beliefs using a two-sided t-test. The minimum and maximum mean composite score for direct measures were 1 to 7, -21 to +21 for specific indirect measures and -63 to 63 for overall composite indirect score for subjective norm and perceived

behavioural control, and -84 to +84 for attitude (where higher values indicate more favourable attitudes, greater social pressure and higher perceived behavioural control). The intervention group was expected to have stronger beliefs than the control group.

To explore the effects of the intervention on predicting intention to search, the dependency between 'intention' and the composite direct measures from the TPB questionnaire was investigated using a multiple regression model in which 'intention' was the dependent variable. Group assignment (web portal vs. no intervention), and the three composite scores from the TPB model (namely 'Attitudes towards the behaviour', 'Subjective norms' and 'Perceived behavioural control') were entered as independent variables. In addition, we estimated the effect of the intervention on the dependency between the three composite scores and the intention by entering the interaction terms between group assignment and each of the three composite scores as independent variables in the model. Furthermore, the TPB model, and consequently the questionnaire, consists of several operationalisations of theoretical constructs with certain assumptions about interrelationships between these (Figure 3). These relationships were explored by computing simple bivariate correlations using Pearson's r. The direct TPB measures are hypothesised to be positively correlated with intention, but the direct measures may also be interrelated as these are not seen as categories independent of each other [55].

Measuring overall activation

Overall activation was measured using the Patient Activation Measure (PAM), a validated instrument applicable to both patients and healthy people [51,56]. This instrument includes four key domains (believing the patient role is important, having confidence and knowledge necessary to taking action, actually taking action to improve one's health, and staying the course under

stress) which are measured by a total of 13 items [56,57]. Overall activation is scored on a rating from 0-100, where 100 indicates high activation and 0 indicates no activation [56,57]. We anticipated that activation levels in the intervention group would be higher than activation levels for the control group. To evaluate this outcome, a two-sided t-test was used to measure and test the difference in mean overall score.

Satisfaction with the web portal

We obtained user satisfaction feedback from the intervention group about the web portal. Our evaluation of this was based on the Honeycomb model [58], a useful instrument applied to measurements of Internet site user experiences [59]. The model encompasses seven domains to assess whether a website is accessible, usable, credible, valuable, findable, desirable and useful [58]. In our study, questions were used to assess three of these measures of user satisfaction (credibility, usefulness and usability), each measured on a satisfaction scale from 1-7 (higher values indicating greater satisfaction). The following data were then summarised for each domain: mean values, standard deviation, median, and interquartile range.

Safety monitoring and adverse events

A tool to encourage participation could create potentially unnecessary pressure on users. This domain was captured using the TPB questionnaire (subjective norm). Other adverse effects were deemed unlikely.

Data were treated anonymously, and ethical approval was granted by the Norwegian Social Science Data Services (NSD), and Regional Committees for Medical and Health Research Ethics (REK). The trial was registered under the ClinicalTrials.gov identification number NCT01266798.

Results

Description of study participants

Four participants were excluded from the study because they did not meet the inclusion criterion of having children aged <4-years. One respondent provided incomplete contact details. In total, 96 participants were included, of which 47 were randomised to the intervention group and 49 to the control group. The overall response rates for the intervention group and control group were 60% (n=28) and 80% (n=39) respectively (Table 2). Those who chose to complete the first task generally continued throughout the whole study.

	Intervention	Control
Response rates total	60 % (n=28)	80 % (n=39)
% Men	20 %	22 %
% Females	80 %	78 %
% Primary school	9 %	0 %
% High school	16 %	12 %
% 1-3 years of college/ University education	22 %	22 %
% 3+ years of college/ University education	53 %	66 %

Table 2. Description of participant characteristics

Improved use of research

Two research-based sources were identified in the intervention group, and one in the control group. The relative risk was 2.8 (CI 0.3- 29.2) (p=0.39).

Critical appraisal

The mean rating of the information was 2.41 (SD 0.80) by the intervention group and 2.44 (SD 1.02) by the control. The mean difference was - 0.03 (p=0.904).

The difference between the expert rating (rated as 1) and the rating of the intervention group was 1.40, and for the control group was 1.43 (difference = -0.03; p=0.904)

The distribution of the ratings across the two groups was not significantly different (Graph 1; Pearson Chi-Square=1.605, p=0.448)
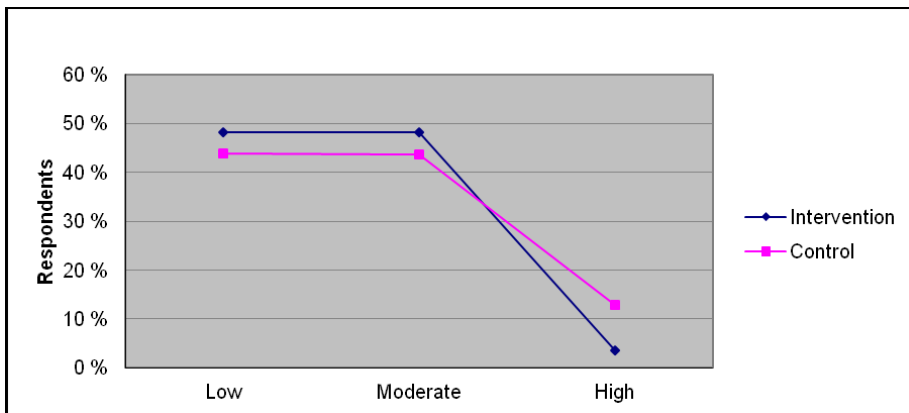
Graph 1: Rating of quality across study groups

Beliefs about searches for health information and activation

A statistically significant difference of 0.63 was found for overall attitude towards search: 0.6 (p=0.03) in favour of the intervention group (see Table 3 for mean scores). The mean differences for the overall subjective norm (-0.2; p=0.49) and perceived behavioural control (0.41; p=0.15) as well as specific beliefs (all three p-values >0.25) related to search, were not statistically significant.

The dependency between the direct composite measures from the TPB and intention to search was found not to differ significantly across the groups (p>0.1 for all three composite scores). The TPB constructs' overall prediction of intention to search across the complete sample was approximately 37% of the observed variation in the intention to search. Attitude was the most important positive predictor of intention (b=0.51; p<0.002), whereas the predictive strength of subjective norm and perceived behaviour control was -0.15 (p=0.25) and -0.06 (p=0.72) respectively.

Direct attitude and perceived behavioral control had a statistical significant and positive correlation with intention (Pearson's r=0.56 and 0.41 respectively), and were also found to be inter-correlated (Pearson's r=0.59) (all p<0.001). Subjective norm had a non-statistically significant negative correlation with intention (Pearson's r=-0.1; p=0.92), and non-statistically significant positive correlation with attitude (Pearson's r=0.18; p=0.15) and perceived behavioral control (Pearson's r=0.69; p=0.58).

The overall activation (PAM) score was 66.5 in the intervention group and 61.9 in the control group, and the mean difference was 4.61 (p=0.20).

Variable	Mean Intervention (SD)	Mean Control (SD)	Mean difference (95 % CI)	P-value
Intention*	6.1 (1.1)	5.8 (1.1)	0.3 (-0.2 to 0.9)	0.20
Direct attitude*	5.8 (1.1)	5.2 (1.2)	0.6 (0.1 to1.2)	0.03
Direct subjective norm*	3.4 (1.3)	3.6 (1.2)	-0.2 (-0.8 to 0.4)	0.49
Direct perceived behavioural control*	5.6 (1.1)	5.3 (1.1)	0.4 (-0.2 to 1.0)	0.15
Overall indirect attitude**	53.7 (24.2)	50.8 (24.8)	2.9 (-9.3 to 15)	0.64
*#1 Provides insight***	14.3 (6.7)	14.0 (6.5)	0.3 (-2.9 to 3.6)	0.83
*#2 Useful as background in consultations***	12.8 (7.8)	11.4 (7.7)	1.4 (-2.5 to 5.3)	0.48
*#3 Helpful if unsure in health decision***	12.4 (6.8)	12.4 (7.0)	0 (-3.4 to 3.4)	0.99
*#4 Provides additional information If incomplete information from health***	14.1 (6.8)	13.0 (7.4)	1.1 (-2.4 to 4.7)	0.52
Overall indirect subjective norm**	13.9 (14.5)	10.3 (12.5)	3.6 (-3.0 to 10.3)	0.28
*#1 Family and friends***	8.1 (6.5)	6.1 (4.9)	2.0 (-0.8 to 4.8)	0.15
*# 2 Health professionals***	0.7 (6.9)	1.0 (7.4)	-0.3 (-3.9 to 3.3)	0.89
*#3 Other social groups (colleagues, patient organisations)***	5.1 (5.1)	3.2 (3.5)	1.8 (-0.3 to 4.0)	0.09
Overall indirect perceived behavioural control**	-4.4 (13.4)	-3.1 (17.3)	-1.3 (-9.1 to 6.6)	0.74
*#1 Difficult to attain an overview***	-0.3 (6.5)	-0.3 (7.2)	0 (-3.4 to 3.5)	0.99
*#2 Not possessing knowledge***	-0.8 (5.4)	-1.2 (6.6)	0.4 (-2.6 to 3.4)	0.79
*#3 Time consuming***	-3.3 (5.9)	-1.6 (7.0)	-1.7 (-5.0 to 1.5)	0.30

*Mean minimum and maximum score possible is 1 to 7 (stronger beliefs indicated by higher) **Mean minimum and maximum score possible is -63 to 63 for subjective norm and perceived behavioural control, and -84 to +84 for attitude. ***Mean minimum and maximum score possible is -21 to 21.

Table 3. Distribution of means and differences between groups

Satisfaction with the web portal

The mean usefulness rating of the web portal was 4.71 (SD 1.11), mean usability 4.14 (SD 0.97) and mean credibility 4.75 (SD 0.93) (see Table 4).

		Usefullness	Usability	Credibility
Mean		4.71	4.14	4.75
Median		5.00	4.00	5.00
Standard deviation		1.117	.970	.928
Percentiles	25	4.00	3.00	4.00
	50	5.00	4.00	5.00
	75	6.00	5.00	5.00

*Mean minimum and maximum score possible is 1 to7 (stronger satisfaction indicated by 7)

Table 4. Satisfaction with the web-portal

Discussion

Study limitations

This study had limitations but also appreciable strengths. Participant recruitment can be a significant obstacle in the research process, and this proved to be a challenge in our study. Given the resources available, we were unable to recruit the number of participants suggested by the power-analysis. The response rates were also lower than expected. Considering that the content of the web portal and tasks included in the trial may be considered as challenging or difficult by many parents, particularly by those with lower health literacy, a higher drop-out could have been

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expected among those with lower education. Although the correlation between health literacy and education is not perfect, it is a relevant predictor [8]. Background data information about those who dropped out of the study revealed no statistically significant differences in sex or education levels, compared to those who did not drop out which is a positive finding. There was, however, a small but borderline statistically significant ($p<0.06$) difference between the intervention and control group in terms of loss to follow-up: more were seen to drop out of the intervention group (Table 2). The difference in drop-out between groups may indicate that people joined the study primarily in order to receive access to the portal. Once they had access, they may have dropped out before the first task was given. Of those who did participate in one or more of tasks, the background characteristics across the intervention group and the control groups showed that participant distributions by sex and education were very similar. The mean level of education, however, was slightly higher in the control group. The fact that the loss to follow-up mainly happened between the time of the first screening questionnaire and the time of the first task may indicate that the tasks included in the trial were considered too extensive.

Using an online questionnaire system was a time-saving and cost-efficient data collection method. It allowed for the confidential treatment of data and provided an opportunity to use automatic systems for keeping track of response rates, sending out reminders, sending notifications directly to participants if data were missing, and to export the data directly into Excel and SPSS. In this way we reduced the risk of potential errors inherent in manual data entry, ensured that all communications were standardised, and that both groups were treated equally.

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Intervention effects on critical skills

The effects of the intervention on the critical skills of participants were evaluated by means of a searching task and a critical appraisal task. Only minor improvements in the intervention group were identified by both tasks and these differences were not statistically significant.

The number of research-based sources reported by participants in the searching task was very low in both study groups. Interestingly, the majority of participants in the intervention group chose to use sources not included in the portal. This may imply that the respondents preferred to rely on sources with which they were already familiar, or that that the three-day interval between being given access and having to perform the first task, may have been too short to allow them to become familiarised with the portal itself.

In the analysis, the sources were categorised based on pragmatic yet strict judgments regarding whether the information was research-based or not. This proved to be difficult, particularly because few of the sites provided references or indicated what their information was based on. This applied even to information provided by government and public health organisations. Consequently, information that was research-based may have been excluded if it lacked appropriate references. One source, for example, which was originally excluded because it lacked references, was then re-included in our study based on the knowledge of our lead researcher (this material was the Norwegian translation of BMJ's Best Practice Patient information). That online health information is often unclear, incomplete or even misleading is supported by reviews of online literature [9,10,45] and underlines the importance of providing users with easily accessible research-based information and the need to improve critical appraisal

skills. But it also indicates that those who present such information on the Internet should critically review their own publishing practices and place greater emphasis on transparency and sources of their information.

Beliefs about participation and intervention effects

Beliefs about participation were evaluated using a TPB questionnaire that addressed intention to search and underlying factors, and the PAM questionnaire describing overall activation. The overall score for beliefs about participation (based on both the TPB and PAM) was high in both groups, indicating that participants viewed taking a more active role favourably. When comparing the two groups, we found small statistically non-significant improvements in favour of the intervention group with both the instruments indicating higher intention to search and higher activation.

In the TPB questionnaire, both groups were also found to have strong favourable attitudes towards searching for health information. Whereas both groups reported high overall perceived behavioural control, their responses to specific beliefs highlighted the fact that certain aspects of searching were perceived as being slightly difficult. The overall social pressure to search was moderate. Of particular interest was the fact that parents experienced very little pressure or expectation from health professionals who might have been anticipated to have a central role in this. Our findings are similar to those from other studies showing that independent searches for health information are rarely discussed, facilitated or addressed during healthcare consultations [60,61,62,63].

The mean differences of direct measures across the groups showed a statistically

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significant difference in favour of the intervention group in terms of overall attitude 0.6 (p=0.03). This suggests that the web portal may be a useful tool for improving attitudes towards searching for health information, and is an interesting finding in view of the fact that attitude was also found to be the most important predictor of intention to search in both groups. That we found favourable attitude to be an important factor associated with searching for health information is supported by other studies [13,60,64], including another study in which the same questionnaire was used [34]. Perceived behavioural control was only a weak and not statistically significant predictor of intention to search but was found to have a strong correlation with both intention and attitude. Thus, although the user feeling of being in control of searching does not directly predict intention, it may still be an important underlying variable. Subjective norm was also found to have a weak relationship with intention and this finding supports earlier research showing that social expectations or pressure do not appear to be an important or positive predictor of intention to search [34].

We identified no statistically significant difference between the groups in terms of the effect of the intervention on the prediction of intention to search. The TPB components' overall prediction of intention to search was satisfactory and generally consistent with other studies in which the TPB had been used to predict behavioural intentions across a range of health topics [53].

Satisfaction with the portal

The satisfaction with the web portal was good. This is encouraging given that the purpose of the web portal, and the concepts introduced, were potentially novel to most respondents. A

challenge in this project was that although we wanted to improve user access to evidence-based information we also wanted to improve knowledge and skills. When developing the web portal, a compromise was therefore reached between usability (how easy it is to access reliable health information) and educational intention (reflected for example by how people are routed through the web pages). Consequently, the web portal may potentially demand more of its users relative to traditional sources of health information. Despite this, the results of this study indicated that we may have come a long way towards achieving this balance correctly.

In the next phase of our research, the web portal will be made publicly available and will be search optimised. This will mean that when people search for health information using a general search engine, the web portal will range high on the list of hits and, in this way, will contribute to making evidence-based health information more available to the general public. The web portal is also in continuous development, and more features will be considered for inclusion. Ideas for expansion include a discussion forum about science and research, and a blog addressing current issues related to medical and health related information in the public debate.

Conclusion

This study was a pragmatic trial conducted in a real life setting. The recruitment of participants was challenging, the response rates were somewhat low and the intervention effects smaller than expected. Although this resulted in the study being underpowered, we found improvements on attitudes towards searching for health information, a variable identified as the most important predictor of intention to search. The relevance of the web portal to users was confirmed by the fact that the participants considered the web portal to have good usability,

usefulness and credibility.

Implications for practice

It is vital that health practice and decision making should be based on the best available, current, valid and relevant evidence. Recognising that users should play a central role in evidence-based practice, people should be encouraged to take on an active role. Moreover, resources such as web portals should be made available in order to facilitate greater access to, and critical use of, research-based information.

Future efforts should aim at experimenting more with web-based resources in order to encourage user involvement in health care. Large samples are needed to identify more robust results. Furthermore, online resources alone may not be sufficient to improve health literacy skills effectively. More intensive interventions could include the use of the web portal during consultations with health providers, or as part of evidence-based practice courses for users such as patient representatives who have a particular interest in healthcare issues.

(formerly Oslo University College). The authors declare that they have no conflicts of interest.

References

1. Coulter A (2002) The Autonomous patient: ending paternalism in medical care. London: TSO. 121 p.
2. Nutbeam D (2000) Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. Health Promotion International 15: 259-267.
3. Dawes M, Summerskill W, Glasziou P, Cartabellotta A, Martin J, et al. (2005) Sicily statement on evidence-based practice. BMC Medical Education. pp. 1.
4. Zarcadoolas C, Pleasant A, Greer D (2006) Advancing health literacy: a framework for understanding and action. San Francisco, CA: Jossey-Bass. 368 p.
5. Nutbeam D (1998) Health promotion glossary. World Health Organization. pp. 36.
6. Freedman DA, Bess KD, Tucker HA, Boyd DL, Tuchman AM, et al. (2009) Public Health Literacy Defined. American Journal of Preventive Medicine 36: 446-451.
7. Peerson A, Saunders M (2009) Health literacy revisited: what do we mean and why does it matter? Health Promotion International 24: 285-296.
8. Berkman N, Sheridan S, Donahue K, Halpern D, Crotty K (2011) Low Health Literacy and Health Outcomes: An Updated Systematic Review. Annals of Internal Medicine 155: 97-101.
9. Glenton C, Paulsen E, Oxman A (2005) Portals to Wonderland? Health portals lead confusing information about the effects of health care. BMC Medical Informatics and Decision Making. 15 March ed. pp. 8.
10. Hoye S, Hjortdahl P (2002) ["New wonder pill!"--what do Norwegian newspapers write]. Tidsskrift for Den norske Legeforening Jun 30;122(17): 1671-1676.
11. Johansen L, Bjørndal A, Flottorp S, Grøtting T, Oxman A (1996) [Evaluation of health information in newspapers and brochures. What can we believe?]. Tidsskrift for Den norske Legeforening 116: 260-264.
12. Andreassen H, Sandaune A, Gammon D, Hjortdahl P (2002) [Norwegian use of Internet health services]. Tidsskrift for Den norske Legeforening 122: 1640-1644.
13. Fox S (2006) Online health search. PEW Internet and American Life Project: PEW Internet and American Life Project. pp. 22.
14. Schwartz K, Roe T, Northrup J, Meza J, Seifeldin R, et al. (2006) Family medicine patients' use of the Internet for health information: a MetroNet study. Journal of the American Board of Family Medicine 19: 39-45.
15. Fox S, Jones S (2009) The Social Life of Health Information. . PEW Internet and American Life Project. Washington. pp. 88.
16. Sillence E, Briggs P, Harris PR, Fishwick L (2007) How do patients evaluate and make use of online health information? Social Science & Medicine 64: 1853-1862.
17. Robinson E, Kerr C, Stevens A, Lilford R, Braunholtz D, et al. (2005) Lay public's understanding of equipoise and randomisation in randomised controlled trials. NHS R&D HTA Programme. 192 p.
18. Glenton C, Oxman A (1998) The use of evidence by health care user organizations. Health Expectations 1: 14-22.
19. Woloshin S, Schwartz L, Byram S, Sox H, Fischhoff B, et al. (2000) Women's understanding of the mammography screening debate. Archives of Internal Medicine 160: 1434-1440.
20. Weinstein N (1999) What does it mean to understand a risk? Evaluating risk comprehension. Journal of the National Cancer Institute: 15-20.
21. Lloyd A (2001) The extent of patients' understanding of the risk of treatments. Quality in Health Care

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10 Suppl 1: i14-18.

22. Schwartz L, Woloshin S, Black W, Welch H (1997) The role of numeracy in understanding the benefit of screening mammography. Annals of Internal Medicine 127: 966-972.

23. Tickner S, Leman P, Woodcock A (2006) Factors underlying suboptimal childhood immunisation. Vaccine 24: 7030-7036.

24. Austvoll-Dahlgren A, Helseth S (2010) What informs parents' decision-making about childhood vaccinations? Journal of Advanced Nursing 66: 2421-2430.

25. Legare F, Ratte S, Gravel K, Graham I (2008) Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. Patient Education and Counseling 73: 526-535.

26. Bugge C, Entwistle V, Watt I (2006) The significance for decision-making of information that is not exchanged by patients and health professionals during consultations. Social Science & Medicine 63: 2065-2078.

27. Detmer D, Singleton P, MacLeod S, Wait S, Taylor M, et al. (2003) The informed patient: Study Report. Cambridge: University of Cambridge. 53 p.

28. Coulter A, Jenkinson C (2005) European patients' views on the responsiveness of health systems and healthcare providers. European Journal of Public Health 15: 355-360.

29. Nutbeam D (2008) The evolving concept of health literacy. Social Science and Medicine 67: 2072-2078.

30. Coulter A, Ellins J (2006) Patient-focused interventions: a review of the evidence. London: Picker Institute Europe. pp. 277.

31. Wantland D, Portillo C, Holzemer W, Slaughter R, McGhee E (2004) The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes. Journal of Medical Internet Research 6: 40.

32. Murray E, Burns J, See T, Lai R, Nazareth I (2005) Interactive Health Communication Applications for people with chronic disease. Cochrane Database of Systematic Reviews: CD004274.

33. Austvoll-Dahlgren A, Helseth S (2011) Public health nurses' barriers and facilitators to the use of research in consultations about childhood vaccinations. Scandinavian Journal of Caring Sciences.

34. Austvoll-Dahlgren A, Sørum R, Helseth S (2012) Cognitive factors predicting intentions to search for health information: an application of the Theory of Planned Behaviour.

35. Austvoll-Dahlgren A, Danielsen S, Opheim E, Bjørndal A, Reinar L, et al. (2012) A complex intervention: tailoring a web portal to improve user health literacy skills.

36. Bjørndal A, Flottorp S, Klovning A (2007) Knowledge management in medicine and health sciences [Kunnskapshåndtering i medisin og helsefag] Oslo: Gyldendal akademisk. 195 p.

37. DiCenso A, Bayley L, Haynes R (2009) Accessing preappraised evidence: fine-tuning the 5S model into a 6S model. Annals of Internal Medicine 151: 99-101.

38. Charnock D, Shepperd S, Needham G, Gann R (1999) DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. Journal of Epidemiology and Community Health 53: 105-111.

39. Irwig L, Irwig J, Trevena L, Sweet M (2008) Smart health choices: making sense of health advice. London: Hammersmith. xi, 242 p.

40. Statistics Norway (2009) [Use of health services by sex and age]. Statistics Norway,: SSB.

41. Wangberg S, Andreassen H, Kummervold P, Wynn R, Sorensen T (2009) Use of the internet for health purposes: trends in Norway 2000-2010. Scandinavian Journal of Caring Sciences 23: 691-696.

42. Radosevich D (2006) Designing an outcomes research study. In: Kane R, editor. Understanding health care outcomes research. 2nd ed. Sudbury, Mass.: Jones and Bartlett. pp. 23-58.

43. Charnock D (1998) The DISCERN handbook: Quality criteria for consumer health information on

treatment choices. Oxon: Radcliffe Medical Press Ltd.

44. Mills E, Jadad AR, Ross C, Wilson K (2005) Systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccination identifies common barriers to vaccination. Journal of Clinical Epidemiology 58: 1081-1088.

45. Wolfe R, Sharp L, Lipsky M (2002) Content and design attributes of antivaccination web sites. Journal of American Medical Association 287: 3245-3248.

46. Goldacre B (2007) Medicine and the media: MMR: the scare stories are back. The British Medical Journal 335: 126-127.

47. Haug C (2009) [Fear and expectations]. Tidsskrift for Den norske Legeforening 129: 1619.

48. Teasdale E, Yardley L (2011) Understanding responses to government health recommendations: public perceptions of government advice for managing the H1N1 (swine flu) influenza pandemic. Patient Education and Counseling 85: 413-418.

49. Ishikawa H, Yano E (2008) Patient health literacy and participation in the health-care process. Health Expectations 11: 113-122.

50. Eysenbach G, Powell J, Kuss O, Eun-Ryoung S (2002) Empirical studies assessing the quality of health information for consumers on the world wide web. Journal of American Medical Association 287: 2691-2700.

51. Steinsbekk A (2008) [Patient Activation Measure]. Tidsskrift for den Norske Legeforening 128: 2316-2318.

52. Francis J, Eccles M, Johnston M, Walker A, Grimshaw J, et al. (2004) Constructing questionnaires based on the theory of planned behaviour: A manual for health services researchers. . UK: Centre for Health Services Research, University of Newcastle. pp. 42.

53. Armitage C, Conner M (2001) Efficacy of the theory of planned behaviour: A meta-analytic review. British Journal of Social Psychology 40: 471-499.

54. Eccles M, Hrisos S, Francis J, Kaner E, Dickinson H, et al. (2006) Do self- reported intentions predict clinicians' behaviour: a systematic review. Implementation Science.

55. Ajzen I (1991) The Theory of Planned Behavior. Organizational Behavior and Human Decision Processes 50: 179-211.

56. Hibbard JH, Mahoney ER, Stockard J, Tusler M (2005) Development and testing of a short form of the patient activation measure. Health Services Research 40: 1918-1930.

57. Hibbard JH, Stockard J, Mahoney ER, Tusler M (2004) Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. Health Services Research 39: 1005-1026.

58. Morville P (2004) User Experience Design; honeycomb model.

59. Rosenbaum S, Glenton C, Cracknell J (2008) User experiences of evidence-based online resources for health professionals: User testing of The Cochrane Library. BMC Medical Informatics and Decision Making.

60. Wainstein B, Sterling-Levis K, Baker S, Taitz J, Brydon M (2006) Use of the Internet by parents of paediatric patients. Journal of Paediatrics and Child Health 42: 528-532.

61. Bylund C, Gueguen J, Sabee C, Imes R, Li Y, et al. (2007) Provider-patient dialogue about internet health information: An exploration of strategies to improve the provider-patient relationship. Patient Education and Counseling 66: 346-352.

62. Tuffrey C, Finlay F (2002) Use of the internet by parents of paediatric outpatients. Archives of Disease in Childhood 87: 534-536.

63. Gordon MM, Capell HA, Madhok R (2002) The use of the Internet as a resource for health information among patients attending a rheumatology clinic. Rheumatology 41: 1402-1405.

64. Sabel M, Strecher V, Schwartz J, Wang T, Karimipour D, et al. (2005) Patterns of Internet use and

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impact on patients with melanoma. Journal of the American Academy of Dermatology 52: 779-785.

Errata

Feil i referanseliste ble rettet i artikkel V. Samme referanse var oppført to ganger i referanselisten, og er nå erstattet med referanse 34.