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Recommended Citation

Maier, Edith; Reimer, Ulrich; Guttormsen Schär, Sissel; and Zimmermann, Philippe G., "SEMPER: A Web-Based Support System for Patient Self-Management" (2010). *BLED 2010 Proceedings*. 27.

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SEMPER: A Web-Based Support System for Patient Self-Management*

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Abstract

The paper discusses an eHealth project which is currently developing an interactive web-based platform that assists patients to self-manage work-related disorders and alcoholism. The focus is on motivating long-term behaviour change. This is supported by an online assessment component based on the technique of motivational interviewing and a feedback component which visualizes actual behaviour in relation to intended behaviour. Disease-specific information is provided through an information portal that utilizes lightweight ontologies (associative networks) in combination with text mining. Emotional support is provided via virtual communities. The paper discusses the design rationales underlying the approach taken and outlines some implementational aspects. The paper also briefly outlines how the effectiveness of the self-management tool will be measured based on an outcome model particularly suited for health promotion.

* The work reported in this paper is funded by the Swiss Confederation's innovation promotion agency (CTI) under grant number 9937.2.

Keywords: e-health, patient self-management, patient motivation, semantic search, associative nets, ontologies, health literacy, health promotion, prevention, evaluation

1 Introduction

The health system in Switzerland as in other industrialised countries is facing two major challenges:

1. A growing share of the burden of disease – i.e. the direct and indirect health costs – is accounted for by chronic conditions, which requires a shift in health policy to more prevention and self-management.
2. Given limited resources, a systematic evaluation of the impact and the effectiveness of such interventions is required.

Health authorities across Europe have come to realise the tremendous costs involved in chronic care. According to estimates of the World Health Organisation (WHO) chronic diseases such as rheumatic pains, diabetes, cancer, cardiovascular disease as well as obesity account for 60 per cent of deaths and 46% of the worldwide burden of disease. This figure is expected to increase, especially as the population ages. It is therefore not surprising that countries are shifting in health policy towards more self-management and patient-centred care.

However, self-management of disease is a skill that cannot be taken for granted but has to be learned and most people need assistance for this task. Motivating people to change their behaviour and lifestyle has emerged as the central challenge in this respect. Tailoring the information to the needs and requirements of the individual user has found to be another prerequisite for success.

The SEMPER¹ project takes up these challenges. It is underpinned by the following premises:

- Support and education for self-care is essential for compliance with therapy and long-term behavioural change.
- Self-care tools and online interventions can provide useful assistance.
- Information and communication technologies (ICT) are particularly suited for supporting personalised monitoring and information access.

The online components are not meant to replace consulting or obtaining advice from one's doctor or other health professional. Rather, we want to use the advantages of interactive technologies to lessen the burden of health professionals and complement face-to-face treatment. Interactive self-management systems help patients to

- change their habits and lifestyle by giving them feedback on what they have achieved (e.g. through regular exercises) relative to what they had planned,
- connect with other patients to exchange information and experiences and emotional support,
- provide easy access to relevant information that is tailored to a patient's specific situation and needs.

¹ see <http://www.sempere-net.ch/index.php?lang=en>

User orientation plays an important role in SEMPER because setbacks in self-management initiatives in the past have also been attributed to the lack of personalisation in the provision of information (Kennedy et al. 2007).

Overall, patient education and self-care programs promise reduced costs alongside higher patient satisfaction. This has placed them onto the agenda of many regional, national and international health agencies. There is a growing knowledge base on the effectiveness of prevention and health promotion measures. Evaluations of some of these programs have shown fewer hospitalizations and days spent in the hospital as patients become more confident in caring for themselves. The preliminary evaluation of the Swiss-based ONESELF project on lower back pain suggests a reduction in both medical consultation and the use of painkillers and a gain in declarative and procedural knowledge (Rubinelli, Schulz and Vago 2008). The TEN-HMS Study carried out at the University of Hull showed cost savings of 10% for remote patient management via telemonitoring vs. Nurse Support and 26% fewer days in hospital. (Lorig et al 1999) found a total health savings of ten times the cost of the self-care program.

Based on these evaluations it can be concluded that combined with organisational changes and the development of new skills, online interventions can help to deliver better care for less money within citizen-centred health delivery systems.

In the following, Section 2 discusses the objectives to be achieved by the SEMPER platform and its components in more detail. Section 3 outlines the approach adopted to measure the effectiveness of patient self-management with SEMPER. Section 4 presents preliminary results and concludes with an outlook on work still to be done.

2 SEMPER: A Support System for Patient Self-Care

2.1 Application Scenarios

In the SEMPER project we are developing an interactive, web-based platform that provides patients with ongoing assistance and encouragement for dealing with problems such as alcohol dependency and work-related disorders, especially those related to office work (e.g. stress, eye strain, repetitive strain injury or RSI). The focus is on long-term behaviour change. This will be realised through online assessment, disease-specific information, personalised monitoring and feedback as well as social and emotional support via virtual communities. The inclusion of new fields of application and/or target groups will be possible by the open architecture of the platform.

We have two major application scenarios: Work-related disorders and alcohol dependency.

1. Work-related health problems

Work-related health problems include a wide range of health complaints and impairments caused or made worse as a result of adverse factors present in a workplace (e.g. physical, chemical or biological expositions) or a specific characteristic of work (e.g. stress, noise, etc.). The most frequent health problems include bone, joint or muscle problems, breathing, hearing and skin problems, stress, depression and anxiety attacks, as well as headaches or sleep disorders. Costs of work-related musculoskeletal disorders alone account for 2 to 4 billion CHF caused by direct and indirect health costs in Switzerland. The total costs of stress within the Swiss workforce amount to even 7.8 billion Swiss francs or 2.3% of the Swiss GDP (Ramaciotti and Perriard 2000). In Switzerland lower back pain generally is the second main cause of medical consultation with a frequency of 5–15% of all consultations and the most frequent (30%) work-related health problem. A relatively small group of patients causes

relatively high health services costs and long absenteeism from work and furthermore shows a high risk to lose employability.

2. Alcohol-related problems

According to the WHO, alcohol consumption causes a considerable disease burden: in 2002, 6.1% of all the deaths, 12.3% of all YLL (years of life lost) and 10.7% of all DALY (disability adjusted life years) in all European regions could be attributed to alcohol exposure. Intentional and unintentional injuries accounted for almost 50% of all alcohol-attributable deaths and almost 44% of alcohol-attributable disease burden. Young people and men were affected the most. Given the epidemiological structure of the burden, injury prevention, esp. for young people should play the most important role in a comprehensive plan to reduce alcohol-attributable burden (Rehm, Taylor and Patra 2006).

It can be concluded that at a societal level the economic impact of a successful solution for learning how to cope with these health problems is enormous.

2.2 Components of Platform

Figure 1 illustrates the main components of the SEMPER platform:

- *Motivation & monitoring support:* The online *self-assessment questionnaire* allows the user to specify the measures for changing behaviour including, for instance, daily exercise, or a certain maximum amount of alcohol intake per day (in the case of controlled drinking instead of absolute abstinence). This results in a personal action plan. Intended and actual behaviour are then compared and the progress visualised.
- *Information portal:* The information portal provides health information and self-care training. This module focuses on increasing users' health literacy and improving their self-management skills. The patients can learn about symptoms, conditions, implications or consequences of their health conditions from a variety of information sources brought together on a single platform. They can learn about how their problems are related to their lifestyles, habits and eventual behavioural changes. The information portal also allows access to relevant online communities by linking to them as well as by including them into the search for information.
- *Maintenance & information cockpit:* This component allows to add or delete contents in the information portal. Moreover, since the ontologies used to enable semantic search (see Section 2.5.2) are automatically extended by the system they need to be manually checked from time to time so that inadequate concepts and relationships can be removed.
- *User administration:* While the information portal of SEMPER can be used without a login, the motivation & monitoring support component requires a user to register and sign in so as to store the action plans and the data entered into the questionnaire. In the case of a registered user the user's personal data like age, date of diagnosis, etc. will be used to personalise the information provided via the information portal.

The following subsections give a more detailed account of the functional components of SEMPER.

2.3 Motivation Support

SEMPER supports behavioural change by using the technique of motivational interviewing, which is an approach first reported in the addiction literature and now widely applied in other settings where change of behaviour is to be achieved (Miller and Rollnick 2002). For alcohol-related problems, the technique has been developed further into so-called Motivation Enhancement Technique. Both techniques are used to determine a patient's readiness to engage in healthy behaviour and help to address and resolve ambivalence and resistance to change. The skills and strategies applied respect the patient's autonomy and facilitate the patient's decision-making. In contrast, traditional patient counselling usually attempts to persuade or convince a patient to adopt healthy eating habits, for instance, by providing extrinsic motivation in the form of arguments, advice or judgments.

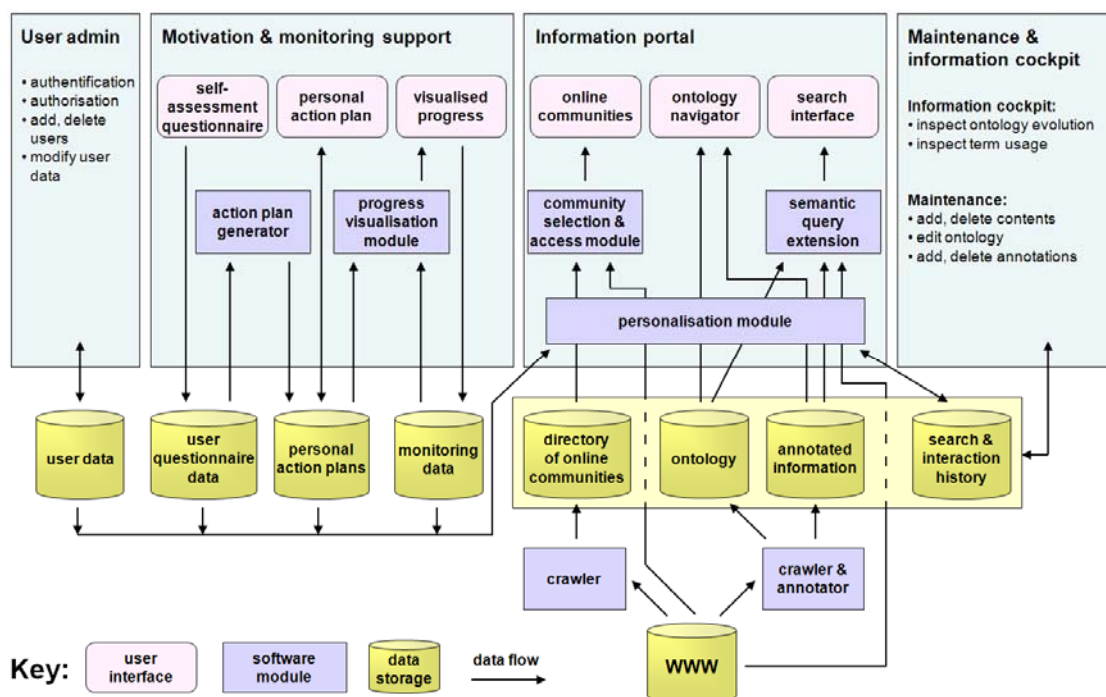


Figure 1: System architecture of SEMPER

The personal action plan forms the central core of the motivation and monitoring component. The plan will be developed automatically on the basis of the answers given by the patient in the self-assessment questionnaire which also includes questions about specific goals (e.g. reduce alcohol consumption), actions planned to achieve them and how to overcome possible barriers. The personal action plan may also be agreed between health professional and patient and then translated into Web-based format. Figure 2 illustrates the different steps of personal action planning.

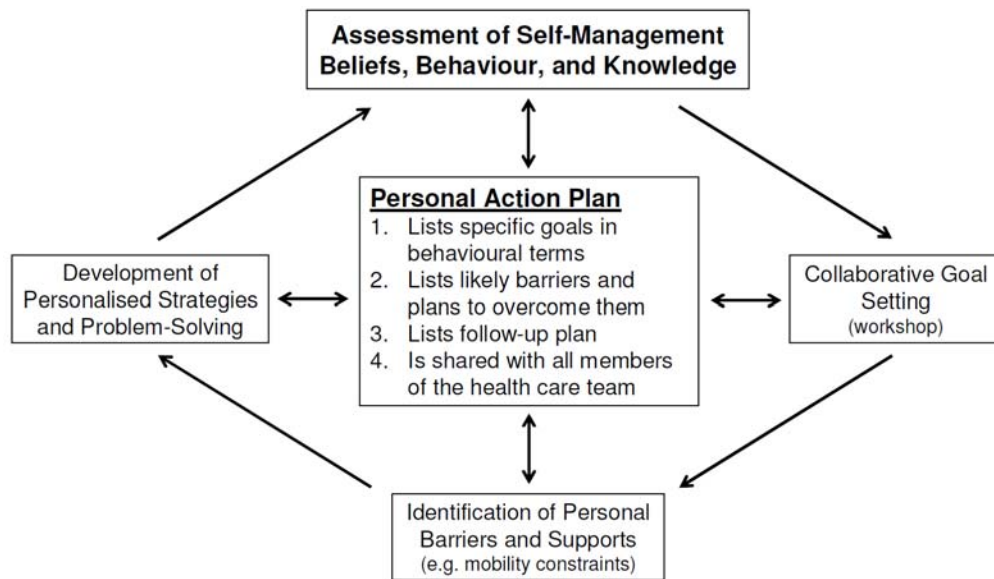


Figure 2: Personal Action Plan (based on (Glasgow and Bull 2001))

For behavioural change to persist feedback and monitoring are essential. Patients are encouraged to monitor their own progress and compliance. Using an online diary a patient gives a regular account of his/her actual behaviour. The personal progress is visualised on the screen which is expected to reinforce behavioural change. Depending on the kind of illness feedback can also be given via bio sensors, e.g. for measuring blood pressure, or the amount of alcohol in the blood.

2.4 Community Support

Apart from the general benefits provided by (face-to-face) support groups, virtual support groups have additional benefits: Because participation is independent of time and space, virtual communities let people relate to each other without being in close proximity. They therefore present a valuable social lifeline for those homebound due to illness, age or handicap, or those isolated in rural settings. Besides, in the case of alcohol-related problems, some may prefer the anonymous exchange online because of the social stigma attached to alcohol dependency.

From the information portal of SEMPER the online communities relevant for the application scenarios will be directly accessible. Additionally, the informal knowledge that is documented in the discussions and blogs is made accessible via the search function in the information portal (see Section 2.5).

The knowledge in online communities represents an untapped resource which could contribute significantly to the quality of patient care and to measurable outcomes such as improved compliance rates. The pooling of isolated fragments of experiential knowledge present in online postings will gradually form a rich web of collective intelligence into which also health care professionals and researchers are interested to tap in so as to supplement their more structured research and to gain insights that might otherwise be lost. The information on the platform is tagged as coming from an official or from a community site so that it is always clear if it is quality-checked or not.

2.5 Information Portal

The information portal provides health information and self-care training. The information has to be easy to understand by patients without higher education or with a

migration background, as research has shown that these could benefit most from self-management support. This component offers three types of information sources:

- *Internal:* This is information of high quality made available by the organisations and experts involved in the SEMPER project. It includes information about specific clinical pictures of the illnesses, activities/actions to reduce or eliminate symptoms, aids for coping with the illness, case histories, example cases and demonstrations, e-learning courses or quizzes/games.
- *External from community sites:* This refers to information gathered from the discussion forums and blogs of community sites. Although informal and not quality-checked, it can be still very helpful for individual patients.
- *External from the Web:* This includes a variety of relevant information sources on the Web.

All the information can be accessed via navigation as well as search.

In the following subsections we describe how SEMPER goes beyond standard information retrieval by employing associative nets and text mining.

Semantic Search with Associative Networks

There is a huge gap between the information needs of a patient and their transformation into an appropriate query for obtaining the relevant information. Even for experienced users it can be quite cumbersome to find the information they are looking for because there may be many ways to refer to a particular concept (e.g. “MSD”, “Musculoskeletal disorder”, “lower back pain”). More importantly, some users may use a term from the subject-specific terminology while others use (and only know) a corresponding popular term. Even worse, patients often do not even know exactly what they are looking for and therefore have no clue about which terms to use in their search. This is the reason why finding relevant information by means of standard search engines like Google can be very time-consuming and frustrating.

The solution lies in applying Semantic Web technology and going from word-based information retrieval to concept-based retrieval. To this end, an ontology is needed which relates semantically similar concepts with each other so that a search can extend a person’s query to include related concepts which are not referenced in the query (Reimer et al. 2002). For example, entering the search term “work-related disease” would also retrieve documents that contain the words “occupational disease” or “work-related disorders” if the underlying ontology contains the proper relations between these terms. Of course, creating a sufficiently detailed ontology for the whole area of medicine is not feasible, but since SEMPER is aimed at patients with work-related diseases and alcohol dependency the ontologies are limited to these application domains. Although SEMPER adopts a disease-specific approach it is still generic in that it can be extended to further kinds of illnesses, which would involve adding the corresponding domain-specific ontologies.

The quality of the semantic search is further enhanced by taking the context and the individual user profiles into account (see personalisation module in Fig.1). Each user is characterised by a profile which is automatically built up in the background based on user-specific data (like date of diagnosis, education level, etc.) and the queries and interactions of the user himself and patients with similar problems. The user profiles allow interpreting a search term within the user’s context. For example, a search for back pain will show (among others) documents about MSD if that is what the user is suffering from. User-specific tailoring also exploits the relationships given by the ontology.

Automatic Learning of Associative Networks and Ontology Population

As mentioned before, the semantic search is enabled by an underlying ontology. Only so-called lightweight ontologies are needed to solve the most common retrieval problem where a search term does not occur in relevant documents. Lightweight ontologies are associative nets which have only untyped associative relations between concepts, possibly with a numerical weight between 0 and 1 that indicates the strength of the association. For example, a patient with work-related back pain might enter the query

lifestyle "back pain"

However, most relevant documents may not contain the term "lifestyle" but terms like "stress", "nutrition", "physical exercise". Thus the underlying associative net should relate these terms with the term "lifestyle" so that the original query can be automatically expanded as shown in Figure 3.

Given that many associative nets like the one shown in Figure 3 are needed and since it is not clear beforehand which terms they should contain, it would be quite unrealistic to try and create them manually. We therefore adopt an unsupervised learning approach as illustrated in Figure 4 to acquire the associative nets automatically. At the core is the neural net learner ai one™ provided by the project partner semantic system ag. It is, unlike any of the traditional neural nets (Gurney 1997), biologically inspired in that it mimicks the behaviour of neurons in the human brain in terms of firing rates and patterns as well as building and removing connections.

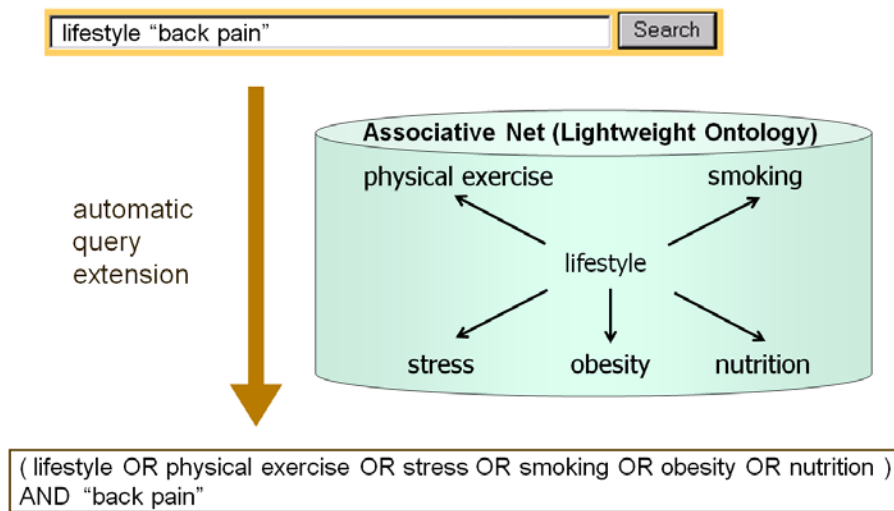


Figure 3: Query expansion using an associative net

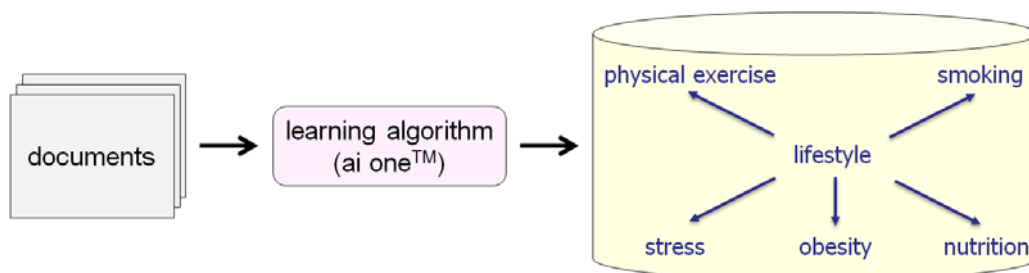


Figure 4: Scenario for unsupervised learning of associative nets

The ai oneTM component is basically concerned with creating associations from co-occurring stimuli. The more frequent the co-occurrence of two stimuli, the stronger their association weight. In the SEMPER application scenario the stimuli are words in a text or search terms. The creation of associations takes context (i.e. (sub-)sentences, paragraphs) as well as higher-order co-occurrences into account (Kontostathis and Pottenger 2002).

For the purposes of this paper, we focus on the overall learning scenario and regard the learning algorithm underlying ai oneTM as a black box which creates appropriate associations and can be substituted by any other algorithm suitable for this task, although we expect ai oneTM – possibly combined with more traditional approaches like (Landauer, Foltz and Laham 1998) – to perform better. Building on associative nets instead of using full-fledged ontologies has the advantage that learning, except for regular manual pruning, happens mostly automatically (see Drumond & Girardi 2008 for an overview).

The associative nets learned by ai oneTM comprise undirected associations as is the case with other algorithms that are based on co-occurrences. However, a closer look at Figure 3 reveals that the associations needed in SEMPER for expanding terms in a query are directed. This is important because while it makes sense to include “smoking” when the query contains the term “lifestyle” it does not make sense to expand the search term “smoking” with the term “lifestyle” (see also (Lemaire & Denhière 2004)).

We impose a direction on the learned associative links by adopting a particular learning set-up. The learning of an associative net starts with the concept that is to be expanded with other concepts. We call these concepts “seed concepts”. In terms of input the learning algorithm only receives documents which contain the seed concept (determined via an ordinary search engine) and then learns which other concepts occur significantly frequently when the seed concept is present. In statistical terms we talk about “conditional probability”, i.e. the probability that e.g. “smoking” occurs in a document when the seed concept “lifestyle” is present. A directed association has more semantics than an undirected association and resembles a semantic implication like hyponymy or partonomy.

It is impossible to manually provide all possibly relevant seed concepts in an application domain because no one knows a priori which terms users will use in a search. Therefore we need a procedure that automatically identifies seed concepts. We have two different ways to do this:

- *A priori*: Sample documents from the application area are analyzed and the most prevalent terms are extracted and taken as seed concepts. We apply a lexicon-based lemmatization to get rid of word inflections.
- *Incremental*: Terms used in a user query are taken as seed concepts if they have not been considered before. Since learning of an associative net takes some time, the actual query will not benefit from the learned net but subsequent queries using the same term will.

A seed concept results in a directed associative net only if at least one association is learned whose weight is above a given threshold.

Besides the learning of associative nets SEMPER also employs a full-fledged domain ontology which is used to acquire facts from texts (a so-called “ontology population” (Cimiano 2006)). This is achieved by learning patterns that indicate a certain kind of statement. These patterns make use of linguistic criteria, word occurrences and background knowledge and are acquired by a supervised learning approach using ai oneTM. For example, a domain specialist highlights the names of drugs or diseases in a sufficiently large number of documents whenever a statement is made about applying a

drug for a disease. By applying the learned patterns to new documents, facts about drugs and their use for treating certain diseases can be automatically acquired (within a certain error margin). We are currently exploring this learning scenario in various experiments.

3 Measuring the Effectiveness of Online Health Promotion

Measuring the success and effectiveness of health promotion interventions is regarded as a major challenge because health promotion and disease self-management actions tend to be more complex than traditional types of health interventions or clinical trials which have so far been typically addressed in the literature, e.g. in the Cochrane Collaboration Index. Nevertheless, a vast array of research has been published over the last decade concerning the evaluation of health promotion initiatives in general (e.g. Glasgow, Vogt & Bowles 1999; Raphael, 2000; Rootman 2001), and more recently, concerning the evaluation of online health promotion systems, in particular (e.g. Wandtland et al. 2004; Danaher et al. 2006).

Health promotion can be evaluated at three distinct points during the course of planning, implementation and operation of an intervention (see Figure 5):

- *Process evaluation* is used to assess the elements of program development and delivery, that is, the quality, appropriateness and reach of the program. It can also help to develop new programs in a formative evaluation and be used routinely to see if programs remain on track.
- *Impact evaluation* is used to measure immediate program effects and, therefore, can be used at the completion of stages of implementation. This type of evaluation assesses the degree to which program objectives were met, e.g. changes in health literacy, behaviours or behavioural intentions, social action, service delivery, etc.
- *Outcome evaluation* is used to measure the longer-term effects of programs and is related to judgements about whether, or to what extent, a program goal has been achieved. The long-term effects may include reductions in incidence or prevalence of health conditions, changes in mortality, sustained behaviour change, or improvements in quality of life.

Within the context of the SEMPER project we will conduct process and impact evaluations only. Longer-term effects, as measured in outcome evaluations, typically take several months to years to take effect, which is beyond the project timeframe.

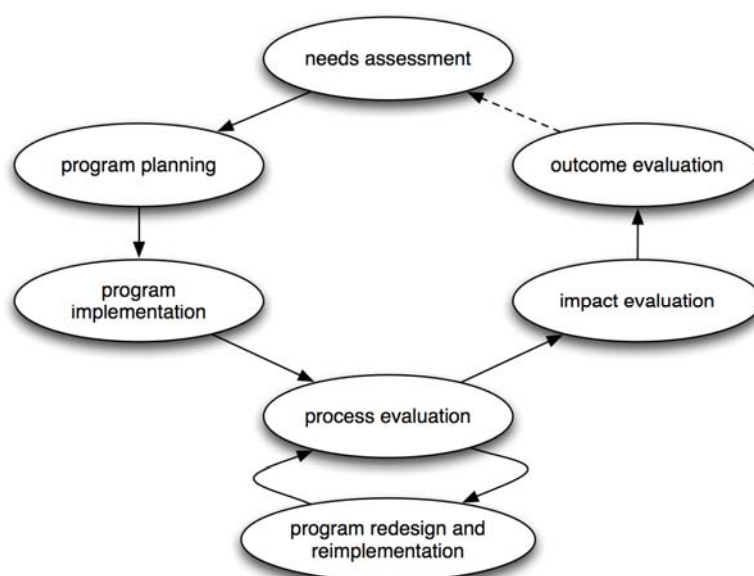


Figure 5: Health promotion program planning and evaluation cycle (adapted from Hawe et al. 1990)

Many of the studies concerned with the evaluation of health promotion and self-management of illnesses are based on one of several existing theories or frameworks, which can be grouped into three levels of influence: (1) Intrapersonal level: Individual characteristics that influence behaviour, such as knowledge, attitudes, beliefs, and personality traits; (2) Interpersonal level: Interpersonal processes and primary groups, including family, friends, and peers that provide social identity, support, and role definition; and (3) Community level, which incorporates institutional factors, community factors and public policy. For the SEMPER project, mainly theories on the intrapersonal level (information portal, motivation & monitoring support) and the interpersonal level (community support module) are of interest. On the individual or intrapersonal level, the most frequently cited theories are the Health Belief Model, the Transtheoretical Model, the Theory of Planned Behavior and the Precaution Adoption Process Model. On the interpersonal level, theories, although labelled diversely, are mostly derived from Social Cognitive Theory. These theories are rather particular and not well suited to serve as a comprehensive framework for SEMPER.

A more recent and comprehensive theory or outcome framework that will be used in the evaluation of the SEMPER project is Nutbeam's (2000) categorisation of health outcomes, which represents the personal (healthy lifestyle), social (effective health services) and structural factors (healthy environments) that can be modified to change the determinants of health.

Based on the project goals and Nutbeam's framework, the SEMPER project can be evaluated in two stages: in a qualitative process evaluation, experts from various fields evaluate different aspects of the platform (e.g. medical accuracy and appropriateness, usability, semantic technology, etc.). And at a later stage, impact evaluation based on Nutbeam's outcome model can be assessed in a randomised controlled trial design (e.g. with web-based and paper-based conditions) with pretest-posttest comparisons.

4 Preliminary Results

This paper discusses work in progress which is why at this stage we can only present preliminary results. We have reached the first important milestone, i.e. the completion of the requirements analysis for both application scenarios. Given the strong user-orientation of our approach which is a prerequisite for later user-acceptance of our

tools, we have conducted an in-depth analysis of users’ needs and expectations. For each application scenario, experts were interviewed to identify the key issues and develop a series of use-cases. Subsequently, a semi-structured questionnaire was drawn up which formed the basis for the focus group discussions with end-users.

As shown in Table 1, the results have been summarised and subsumed under the categories “functional requirements” and “non-functional requirements” as well as the “objectives” to be achieved.

		Functional requirements	Non-Functional requirements		Objectives
Topics	Self-Assessment	Analysis of current ergonomic conditions and targets to be reached Diagnosis (→ behaviour)	From general to more specific information (filtering) Virtual model of human body Selection of images for illustration purposes	Interactive Image-oriented Flexible Attractive and entertaining Easy to understand Short and precise	Motivation, fun
	Self-Management	Recommendations for reaching targets	Use of dynamic media Mobile media such as podcasts Offer a variety of solutions or measures Group activities	Interactive Efficient Effective Playful/game character Easy to integrate	Motivation, fun Fostering of commitment
		Exercises (→ behaviour)			
		Basic information about <ul style="list-style-type: none"> • Ergonomic products • Preventive/mitigating types of exercise • Dealing with symptoms 	Search with key words	Simple Intuitive Free text	Eliminate barriers to expert/advanced search
	History of results (performance (Measures/Analyses/Search)	-	-	Overview Monitoring Time saving	
	Monitoring	Check validity of original analysis Check appropriateness of suggested measures	System prompts System interventions depending on response	Tailored to individual user on a continuous basis	Optimisation of process Creation of trust
		Alert function	Via e-mail	Unobtrusive Stimulating Can be defined by user	
		Platform for the exchange with others who have similar problems	Chats Discussion fora Social software applications	-	Social support Awareness raising Therapeutic effect
	Expert Advice	Consultation of experts	Dialogue (e.g. via chat)	Short and precise	Creation of trust Professional support

Table 1: Requirements for the self-management platform

5 Further Work and Outlook

Based on the requirements, specifications are being drawn up for the technical implementation of the different components. At the moment, a series of mock-ups for the graphical user interfaces for the semantic search facility are being tested by both experts and end-users. At the same time we are experimenting with the learning of the associative nets and are tuning the learning settings and algorithms.

As can be seen from Table 1 above, the creation of trust has emerged as an important objective. The use of interactive technologies must be accompanied by strong protection of confidentiality. Especially for monitoring and expert consultation, personal data such as age, gender, description of symptom history etc. may be required. Rules for participation must be clearly stated and a clear statement of how the information gathered during registration will be kept secure must be provided.

When implementing our online health education intervention, steps will comprise securing entry to Websites including social software applications, informing participants of how data will be used and keeping data in secure files with limited access. Security is also an issue when subcontracting or outsourcing particular implementation tasks or IT services. For this, a clearly delineated privacy policy is essential. The guiding principle should be to respect participants’ sensitivities and to rigidly adhere to their expressed wish and consent.

There is often concern that patients may spread incorrect or biased information through online communities. One way of coping with this concern is for health professionals to act as a corrective and/or cross-check information with medical sources, which is very time-consuming. A second approach to cope with this is to use the tagging of contents with quality indicators by the users. We expect the resulting community effect to help in identifying inaccurate or even false information.

For the purpose of measuring the effectiveness of our platform, we have adapted Nutbeam's outcome model to the requirements of the SEMPER project (Nutbeam 2000). The indicators that can be derived from the model will have to take into account the health and insurance policies and regulations prevalent in Switzerland. At the moment, a series of changes are pending at the policy level which together should create a climate that favours self-management and self-care initiatives.

For planning and implementing self-management measures we are exploring the procedures presented by Bourbeau and his COPD team of the Respiratory Health Network in Québec (Bourbeau et al. 2006).

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