Towards an Informed Development Practice of eHealth Services for the Ageing Society

P. Hannele Hyppönen, research manager, STAKES

Abstract—The aim of this study is to generate an outline of an informed eHealth service development practice that takes into account the needs of the ageing society. Action research was used as the main method: The project partners were given two "mirrors" on eService development - an analysis of methods and information used in their own development practice and those suggested in the literature. Project actors detected important differences and took actions to alleviate them. The similarities and important differences were used as a basis to depict an outline of an informed development practice.

Keywords: eHealth, medical informatics, Self Care, health services for the aged, planning methodologies, patient participation, evaluation

I. INTRODUCTION

According to a recent study on European eHealth policies, initiatives, roadmaps, and deployment, majority of EU member states (25/27) had a documented eHealth policy at the end of 2006. Telemedicine and electronic health services for citizens were mentioned among the key tools for meeting the eHealth policy aims. The aims included reforming the health care system, improving health care system performance for more efficiency and quality of care, and promoting quality of life and citizen centeredness in care. [1, 2].

There is a growing consensus that patients can and should be active partners in their health and healthcare. Patient empowering represents changing the relationships of the citizen with the other actors that participate in the complex network involved in healthcare organization and provision. [2]. Part of the reasoning behind promoting citizen centred care and patient empowerment is based on wide literature of benefits of prevention and self-care in management of chronic conditions. [3-7].

Citizen's eHealth services cover a variety of services and applications. A common feature is that they all provide an online or off-line electronic interaction channel between the client and the caregiver. Applications have also been developed to be used independently by patients, especially in psychiatry. Interactive eServices for self-management of diseases have been developed for people with chronic diseases (e.g. diabetes, coronary disease, asthma, COPD, Parkinson's disease, Alzheimers disease and arthritis. The applications combine health information, decision support, peer support and support for behavioral change.[8]. In addition to these, also electronic applications are being developed for parts of the service process. These include general health information eServices, Call Center services, eBooking services for care appointments, eLaboratory services, interactive eAdvice services and eAccess to own medical data (including ePrescriptions) [1, 8]. The deployment of electronic health services and telemedicine applications is still modest [1], but there is a clear trend leading towards development of a "Health Care Broadband" to clients' homes. Services which the clients can use themselves via internet will be transferred there in order to free scarce health care resources and to improve efficiency.

This trend concerns especially ageing people. A majority of primary care doctor visits are made by the older age groups [9]. In Finland people over 65 made 2587 primary care doctor visits per 1000 persons of the same age in 2006, whereas for 15-64 -year olds the figure was 1474 [10]. Many of the telemedicine applications and all of the eHealth service applications are client-to-business or client-to-client-services. There is evidence that older adults often experience more problems than the young in internet use [11]. The trend may lead to increased access to services for some, but decrease it for many others.

Overall there is insufficient evidence to make recommendations regarding ways to improve access to primary care. However, it is regarded important that, as new initiatives are planned, well-designed evaluations are commissioned simultaneously. [12]. Systematic reviews of outcomes of telemedicine and eHealth applications recommend that policy markers are cautious about recommending increased use and investment in unevaluated eHealth technologies [7].

The aim of this study was to exploit a conceptual framework to structure information to be collected from users and contexts of use for the purpose of supporting and evaluating citizen's eHealth services.

II. METHODS

The context of the study was a citizen's eService development project in Oulu, Finland. The project is the lead project in a national citizen's eHealth service development programme, financed by the Technology Agency (TEKES) and the Ministry (STM). City of Oulu also coordinates the work in other projects in the national programme. The project is developing a wide array of citizen's eHealth applications in their own project:

- health information (Health maintenance/terveyden ylläpito)
- information on illnesses (terveysongelmat)
self-management of diabetes, asthma, RR, including home measurements, weight control, health behaviour diaries and messaging between carers (aktiivinen omahoito)
• discussion with peers (keskustelut)
• doctors and nurses’ health advice service (terveysneuvonta)
• information on health services ("yellow pages", terveyspalvelut)
• information on associations (järjestöt)
• personal health record (oma terveyskansio)
• electronic laboratory results (laboratoriotulokset)

The user interface is depicted in fig. 2.

Figure 1. The home page of citizens’ eServices in City of Oulu

At present, the system is in clinical testing phase on one health centre. Diffusion of the system is anticipated to all 7 health centres in the city of Oulu during 2008-2009.

An action research method was used to answer the following questions:
1. What kind of information is collected in different project phases about the users and contexts of use ("mirror I")?
2. What information does the literature recommend to be collected ("mirror II")?
3. What are the commonalities and differences between literature and practice, and how can they be used to benefit the project and in formulating an informed development practice?

III. RESULTS

This chapter provides an overview of the information and methods for client data collection at each phase. It has to be noted that citizen’s eHealth services covered a variety of applications in the project, and it was not possible to present application-specific information required for all different applications in different phases of development.

A) Client data in literature and project in planning phase
The literature review revealed one key difference in eServices compared to traditional services, which changes profoundly the nature of the service development process and consequently the baseline data needed. That is the role of the patients or clients. Traditionally in health services research, e.g. health economics (e.g. [19, 20]), the clients have been regarded as objects of services, not as subjects. Consequently data on clients' health and service use are collected, but not on other aspects of client inputs, resources, and processes. This information is also missing in calculations on service efficiency, cost-benefits and impacts. With eServices, clients become active participants in care, and thus also active elements in the sociotechnical system to be developed. Without specific baseline data on clients' inputs and processes, problems and needs, there is a gap in the baseline information that can be crucial for uptake of the services. With clients as gatekeepers for eService use, this can have a crucial impact in determining the success or failure of the development: It is difficult to make clients use systems that are not available, accessible, affordable or appropriate for their needs [2, 21]. If the clients do not use the electronic services, for most part neither can the professionals. After all, most eServices are C2B-services, requiring client and professional interaction.

For health service planning and development, there is plenty of statistical information. This includes information on population structure, needs and health behaviour, citizens' health and well-being, incidence and prevalence of illnesses, and use of different health services in municipalities. There are also ready indicators that can be used to follow the change [10]. There is also increasingly information on health care quality indicators [22]. ICT development literature [17, 23-25] recommends that information on potential clients be used in design early on, already in the planning phase. Literature on Inclusive Design [21, 26] shows categories of information that are important to be included in the baseline data collection from citizens in order to ensure acceptability of the eServices also for older people. This includes information on citizens' functional abilities and availability, accessibility, affordability and appropriateness of ICT services to client groups with different abilities. Examples of client input, process and output data to be collected at baseline stage are depicted in Tab. 2.

This information was regarded important by the case project participants to be incorporated in an eService development. However, the case project had already passed the planning and also the development stage when the study began. In addition, the service concept was novel, and the actors found it difficult to set objectives beforehand. Of tab.2 information categories, only one category of client information was formally covered in the project planning phase: A questionnaire-based study had been made on clients' interests in using internet [27]. All other baseline client data remained as undocumented "silent" knowledge of the project participants. This type of information is important, but it cannot be used when evaluating the change due to implementation of a new system.

Plans had been made to collect rest of the baseline information as a first task of the project, but this work task did not receive funding. The study had, however, convinced the project participants of the importance of the baseline data. New funding was applied for an ex ante-ex post design evaluation of client impacts and service provider resources that are allocated to clients before the uptake of eServices and after the implementation.

B) Client data during concept development in literature and project

The baseline data should for most part be available already in the planning phase of an eService project. The baseline data can be compared to a good practice and benchmarked, detecting problem areas in services. These can be formulated into development objectives, for which the project constructs solutions. This way the objectives become measurable: when the eService is implemented, the changes in the baseline data indicate the extent to which the objectives have been met.

With innovative new solutions, it is not always easy to set measurable objectives in advance. With an iterative, human-centred design methodology [17], novel solutions can be constructed with feedback from key user groups. Participation of "critical" user groups [26] is essential in order to make the solution work for all service users. Age has a strong correlation with many of the variables in Tab. 2. [28]. Age is therefore one of the most relevant criterion when planning client participation and information collection from the clients.

In the case study, participation of the clients took place in the functional prototype testing phase. The clients were not segmented in order to get feedback also from the most critical users. However, it has been regarded important in the project, that the old service concept be maintained in parallel to the new eService concept in order to make the services accessible for all clients.

C) Client data in literature and project in implementation phase

If there is a good set of data from baseline situation, including measurable objectives and indicators to follow the change, evaluation of the service system after implementation is relatively straightforward: repeating baseline data collection after implementation gives ample information on differences between the data sets indicating...
The picture is more complicated in a situation, where measurable objectives have not been set from the start, and they are formulated gradually during a participatory design process. Also in this case the objectives need to be described in a measurable format. It is also possible to collect a set of baseline data later in the project, before implementation of the system, and repeat the information collection after the implementation, when the system has been diffused. This is what is taking place in the case project.

D) Using the Communalities and differences to formulate an informed eHealth project practice

The project group used the two "mirrors" and their comparison to assess their own project practices. The group concluded that in future projects, it is important to have more systematic data collection on service and client inputs, processes and outputs already in the planning phase, and a mechanism to follow up changes in the key indicators that are selected from the data. The challenges of unstructured register data and funding mechanisms not supporting client data collection in technology projects were experienced as the two key difficulties in doing this. The project solved these questions by applying additional funding to collect the missing baseline data. The projects are searching registers, statistics and classifications for structured data contents that can be used to in order to unify the data contents to be collected.

The results of the study were used to generate a first hypothesis of an informed development practice for eHealth services. According to the hypothesis, informed project planning phase requires that there is baseline information on inputs, processes, outputs and impacts of the service entities to be changed on service-specific level (e.g. Self Care support services). Information is required from the service providers' and different client groups' viewpoints. This information is used for generating measurable objectives, service and technology concepts to meet these objectives and in evaluating impacts of their implementation.

IV. DISCUSSION AND CONCLUSIONS

A short empirical phase for data collection from the project is a limitation in the study. The empirical data collection lasted only 9 months out of the 3 year project period. The project was during the study constructing the new eService concepts. Historical data was collected from planning phase of the project, and follow-up has been made on implementation phase as part of a consequent study. A multitude of services, where eService concept was developed, prevented focussing on any single application (e.g. Self care application for diabetics) and detailed client and service data required for developing a useful application. Empirical data collection focussed on one project only, but the wide literature base condensed results of many earlier projects.

It is evident, that strong evidence of impacts of an intervention can be provided with controlled trials. This type of design is only possible after the systems have already been implemented. Lots of resources may have been misplaced if expected impacts will not be achieved or if there are unanticipated adverse impacts. Ex ante - ex post design suggested in this study is a feasible option for gathering evaluation data during the development in order to steer it. Adequate baseline data helps developers to set measurable goals and to steer the development. Much of the baseline and performance data is generated in normal care processes and recorded in registers [29]. This and other assessment data is, however, not commonly used during eHealth system development [29, 30]. One of the reasons for this is that register-based data is not produced for research purposes. There is also a lack of commonly agreed framework for evaluation and indicators to be used for eHealth service development and impact analysis from the point of view of different client and other stakeholder groups. [31, 32]

The study verified the need for a conceptual framework to structure the evaluative information collected on construction and implementation of electronic Health Services for citizens. The framework used in this study (a conceptual model of a sociotechnical system and its development) featured an essential element required of the framework: viewing the clients as active agents in management of their own health and illnesses and as co-producers of the services. This framework facilitates client-centred development of citizen's eServices. The framework is a necessary tool for financiers, constructors and evaluators of eHealth services; all those who are involved in building eHealth services for the ageing society.

The results offer a basis for future research to elaborate the service-specific data required and to select indicators to be used in construction and evaluation of impacts of electronic services from different stakeholders viewpoints [cf. 1, 4], with due emphasis on the viewpoint of ageing citizens - the biggest user group.

ACKNOWLEDGMENT

The authors thank the project participants for their time and efforts that action research inevitably has required of its participants. We thank City of Oulu and STAKES for financing the project.

REFERENCES


10. STAKES, Sokkanet indicator bank, Stakes: Helsinki.


22. OECD, OECD Health Care Quality Indicators Project. 2008, OECD.


