

Towards standardised clinical pathways for the chronically ill - a project report

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Abstract

This paper is a project report on the ongoing European project NEXES, running from 2008-2011. The project overall vision is improved quality of care for the chronically ill and elderly, through more active follow-up of the patient in his/hers own home and improved collaboration processes between primary and secondary care services. A series of randomized clinical trials, to be carried out at three different sites, in Barcelona; Spain, Athens; Greece and Trondheim; Norway are at the heart of the project, and deployment and evaluation of Information and Communication Technology (ICT) in the trials is a core objective. The project will contribute to standardised clinical pathways for chronically ill and produce requirements and guidelines on ICT deployment in such processes. The project has adopted the Business Process Modelling Notation (BPMN) standard as a tool for development of the clinical pathways. This standard seems well suited in that it provides a common view for all care stakeholders, and aids in clarifying core issues regarding collaboration and information flow. Regarding the issue of ICT, the technology evaluation processes to be carried out in the project will constitute an important set requirements for future development of dedicated ICT solutions for chronic care processes.

Keywords: *Integrated health care systems, Continuity of patient care, Clinical trials-Randomized, Information systems*

Introduction

Ageing of the population together with changes in lifestyle are central factors to explain the increasing prevalence of chronic disorders. This is expected to continue over the next decades leading to further dysfunctions of healthcare systems worldwide. It is well accepted that chronic diseases represent close to 80% of the burden on healthcare systems in Europe. The health care provided at general hospitals has increased in all age groups [1]. This has resulted in a continuously ongoing

process towards more outward care, fewer hospital beds and reduction of days with inward care.

Typical properties for the targeted processes are:

- Chronically ill patients are frequently in need of specialist care services, resulting in frequent hospital admissions.
- At the same time many of the patients have homecare services provided by the municipality. In addition there are informal caregivers and other health institutions involved.
- The goal in all these processes is to keep the patients as long as possible at home. This is desired by the patients and by the involved health institutions, resulting in better quality of life which is the ultimate need for the patients.

The urgent need for introducing substantial changes in delivery of care for chronic patients, as well as its articulation with social support services is widely accepted. In 2002, the World Health Organization (WHO) launched the Innovative Care for Chronic Conditions (ICCC) [2] initiative formulating basic principles and strategies to enhance management of chronic patients. There is no doubt that current fragmentation among levels of care and with community services constitute major limiting factors for a practical adoption of the principles formulated in the Chronic Care model. There is a strong need to move toward the development of preventive integrated care strategies addressed to early stages of chronic diseases and improved collaboration between key care stakeholders, across primary and secondary care levels.

A major issue will be the extensive introduction of information and communication technologies (ICT) as enabling tools to facilitate new ways of sharing information across the system among professionals and citizens, as well as formal and informal care givers.

The European project NEXES addresses these issues, by testing a range of new chronic care programs and technical platforms in large field studies in three different sites and coun-

tries: Barcelona;Spain, Athens;Greece and Trondheim; Norway.

The project objectives and the activities of the project that has been initiated to meet those objectives is the scope of this paper. Some preliminary results from the Norwegian site are also presented.

The NEXES project: Towards standardised clinical pathways for chronic care processes

“NEXES-Supporting Healthier and Independent Living for Chronic Patients and Elderly” [5] is a EU project within the CIP programme (Competitiveness and Information framework Programme) within the programme theme “ICT for accessibility, ageing and social integration”. The project runs from 2008-2011 with an overall work effort of 480 person months.

The project consortium is led by Hospital Clinic, Barcelona, and consist of partners from both clinical, commercial and academic organizations. The Norwegian partners are St Olavs Hospital, Trondheim kommune, Helse Midt-Norge RHF and SINTEF (Norway).

The overall vision of the project is to improve quality of life and ensure efficient health and social care for the ageing population and the chronically ill by specifying and demonstrating innovative ICT enabled products and services.

The project objectives can be described as follows

- Define clinical pathways for chronic patients that improve quality of care, enhances the patients own ability for self-management. An important subgoal is to contribute to standardisation of these pathways.
- Demonstrate and evaluate the role of ICT in the clinical pathways for chronic patients.
- Evaluate the pathways and ICT through Randomized Clinical Trials

The chronic diseases focused are patients with Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD) and stroke. “Frail patients”, indicating typically elderly patients with severely weakened functional abilities are also central in the project studies.

The objectives listed above are highly coincidental with the Norwegian project “Samhandlingskjeden for Kronisk Syke” (SKS) currently running in Helse Midt-Norge and led by St Olavs Hospital, a central partner in the NEXES project. This has led to close integration of the two projects’ activities.

The SKS project is financed by the Norwegian Health Directorate and Helse Midt-Norge in line with the Norwegian National Health plan (2007-2010), which stresses the need for integrated and seamless care services across the traditional levels of care. The clinical research is supported by the Research Council of Norway and led by the Norwegian University of Science and Technology (NTNU). SKS’s core objec-

tive is to focus on the potential that lies in improved collaboration between primary and secondary care services. A SINTEF report from 2008 concludes that there are severe communication problems between primary and secondary care when older patients are discharged from hospital all over Norway [3] In Norway health professionals and politicians have been discussing how collaboration between primary and secondary care can reduce the pressure on general hospital beds [4]. The SKS project seeks to remedy this situation and has raised awareness of this issue also in the NEXES project. The SKS influence has to led to an increased focus on the collaboration dimension in the NEXES work of development of clinical pathways.

Health care process modelling

An objective of the NEXES project is to contribute towards standardised clinical pathways in the domain of chronic care. Chronic care processes are complex and resource intensive in that they require ongoing involvement of expertise across the traditional levels of care. This is as opposed to treatment of acute disease where interaction between primary and secondary care services is confined to only a few points in time, i.e. when a person is admitted to hospital and then discharged from it. New collaboration processes are required that overcome the organizational barriers related to chronic care. Graphical process descriptions like Business Process Modelling (BPM) tools can be a useful tool in that they can serve as a common language for care providers from different organizations and care traditions [6]. The BPM standard adopted by Nexes (and SKS) project is the BPM Notation (BPMN). BPMN was first released by the Business Process Management Initiative in 2004 and has since been adopted by the Object Management Group as a OMG standards specification (2006).

BPMN aims at defining, in a (semi-)formal way, the procedures and processes that exist in an organization. It is also appropriate as a standardisation tool, as the notation provides very accurate and consistent process descriptions, and hence well matched to the job of defining clinical pathways in NEXES. Figure 1 shows an example of such a clinical pathway [8].

The project partners at the three trial sites (Barcelona, Athens and Trondheim) are currently engaged in deploying BPMN to describe the clinical pathways that will be the basis for the clinical trials to be carried out at each site. To ensure ownership of the resulting diagrams, and commitment to the individual care entities role and responsibility in the resulting care process, representatives from all involved care entities must be involved in the development process. Multidisciplinary care teams, with representatives from all levels of care and target patient groups must come together and refine and detail the diagram in workshops dedicated to this end. This process is currently well under way in Helse Midt-Norge.

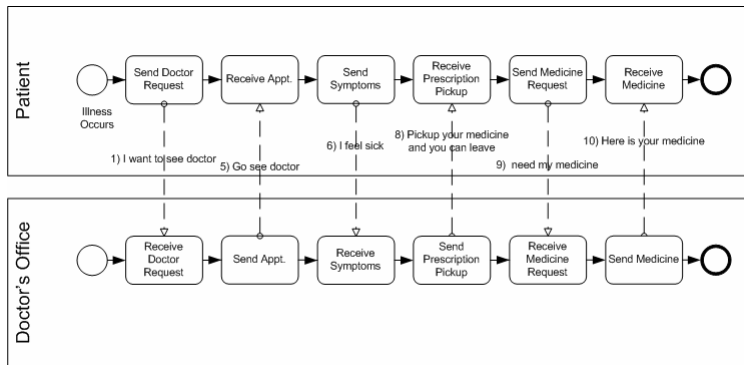


Figure 1: Example of a BPMN diagram

As can be seen from the example diagram, a “horizontal “pool” is dedicated to each care entity taking part in the process. A rectangle in a pool indicates the activities that the pool “owner” is responsible for. The horizontal arrows within each pool indicates the order in which activities are carried out and arrows between pools describe information flow between the different activities. By clarifying responsibilities and identifying the required information to be exchanged (for example related to the process of patient discharge from hospital) quality of care can be improved.

The patient’s own role as stakeholder in the care provision process has traditionally not been clearly defined or highly valued. More often than not, the patient is viewed as an “object”, requiring little activity on his/her behalf other than passively complying with the care ordered. By introducing the “Patient ” as a BPMN pool in the diagrams on equal terms with the official care entities, like “General practitioner” and “Home care services”, the patient’s status as a participant and actor in own care provision is established. The patient and the patient’s next of kin are invaluable resources in any chronic care process. The patient’s activities and responsibilities must be clearly defined and adapted to the collaboration processes with the clinical care givers. We believe process diagrams that clearly define the patient’s role in this way, can be a tool to establish true patient centric care processes. Another detail supporting this notion is to place the patient pool at *top* of the page. This puts health care services in the appropriate place relative to the patient, as *underlying* services that supports the patient, not services that “use” the patient for their own purposes.

Using colours can be an effective way to enhance communication. A project standard for use of colours in combination with the BPMN has hence been adopted from the SKS project, using green for primary care service organizations and blue for secondary care service organizations. In addition, we reserve the colour yellow for the “Patient ”. This colour scheme” is now well adopted by the other European partners of the NEXES project. Standardized colours schemes will simplify comparison between care processes in different European countries, identify the national differences and similarities and help the work towards standardised clinical pathways.

Large scale field studies of state of the art chronic care services

A core objective of the NEXES project, as described earlier, is to evaluate the clinical pathways- and the chronic care services they describe - through Randomized Clinical Trials.

Similar clinical trials will be carried out in parallel in three different health regions in the three participating project countries: in Central Norwegian Health Region ,St Olavs hospital, Norway; Catalonia health region,Hospital clinic Barcelona, Spain; and the region of Attica, Sotiria hospital, Greece. By running comparable studies at three different sites, (with same patient inclusion criteria and evaluation parameters) both regional and cultural differences are captured and common technological aspects can be identified e.g. concerning the important issue of interoperability.

The chronic care services to be implemented and studied are:

- Field study 1: Well being and rehabilitation:**
 This study will address self management and maintenance of health through a program of patient empowerment and physical training and with a structured follow-up. The objective is to improve the quality of health services offered and strengthen the patients’ autonomy, thus reducing the need of professional health care services.
- Field study 2: Enhanced Care support for frail patients.** Patients with advanced chronic diseases and several co-morbid conditions generate a high burden on the health system, both on primary and secondary care services. Two groups of “frail” patients will be studied. The first group are patients that have shown frequent exacerbations generating repeated emergency room consultations and/or hospitalizations over the year (“revolving doors”-patients). The other group are elderly patients with several co-morbid conditions that need home-based care, but do not show frequent hospital admissions.
- Field study 3: Home hospitalisation & early discharge.** The program provides complete substitution of an acute hospital stay in the patient’s home. Patient eligibility is assessed in the emergency room/day hospital settings or in the general ward within the first 72 hours of admission (early discharge). Eligible patients are transferred to home and receive and initial and daily visits by one physician or one specialized nurse. The program provides home equipment and services, diagnostic testing, and other services.
- Field study 4: Support diagnostic and/or therapeutic procedures.** The Support program will set up and evaluate efficacy of interventions in two lines of services ; that is: a) reinforcing primary care potential for

diagnosis and follow-up of complex therapies; and, b) supporting tertiary care interventions at home by specialized teams (and with strong interactions with the primary care team).

Although the health care requirements related to chronic care processes are the same in each country, organizational differences between the health care systems in the partner countries make some studies less relevant for implementation. Consider for example Field Study 3 “Home hospitalization and early discharge”. In many countries in southern Europe, including the partner countries Spain and Greece, secondary care services play a much more central role in overall care services, and hospitals often constitute the first point of contact for a person requiring medical care. To cope with the increased pressure on hospital services (which indeed is a common problem to all countries), the model of “hospital at home” is gaining ground in these countries; where the hospital extends its specialist services right into the patients home, enabling early discharge of acutely admitted patients. This model is however contrary to the model that Norwegian health authorities are working towards: Strengthening primary care services, including the role of the family doctor, to develop a competent and well-functioning “screening/gate-keeper service” towards the expensive and highly pressured specialist care services. (This requires both dedicated training at primary level but also development of effective collaboration processes between the levels, -which is the essence of this project.) This makes Field study 3 not applicable for Norwegian implementation.

The studies and their underlying clinical protocols are currently being planned in detail on each site. Close collaboration between the partners is essential in this process to ensure that the data captured on each site are comparable.

The technology dimension: the quest for suitable ICT solutions

Correctly deployed ICT has large potential in supporting both the process of closer monitoring and follow up of the patient in his own home, and the collaboration processes between the care stakeholders. In the clinical pathway for chronic care, one can envisage a large range of ICT solutions that could improve care process quality and efficacy. Some examples are: a common digital workplace, or “collaboration care plan” (CCP), where all information regarding patient care related activity and medical status could be shared between all care stakeholders, irrespective of level of care; tele-health solutions (e.g. videoconferences) for remote consultations with the patient at home, “do it yourself patient kits” for home-based medical measurements with automatic transmission and storage in the CCP.

An objective of NEXES is specifically to study this topic. However, large scale technology development is not within project scope, only existing technology platforms are candidates as basis for the studies. This precondition proves to be a challenge for the project, as ICT solutions with the functionality described above are not readily available for direct de-

ployment in the projects clinical studies. Another related issue is that of deploying the same ICT solutions on the different sites. Although highly preferred, it was not practically possible to find a common ICT platform on all sites, as ICT solutions (for handling patient sensitive data) are mostly nationally developed solutions not suitable for porting to another country (e.g. due to language barriers, interoperability issues and legal constraints). The solution to these challenges have been to let every site choose their own ICT focus and choose ICT solutions independently.

In Norway, the SAMPRO platform was chosen. SAMPRO is a web-based tool developed by Visma Unique AS (www.visma.no) as an implementation of the “Individual Plan” (In Norway patients have the legal right to such a personal plan- called “Individuell Plan”- for long term follow-up by coordinated (public) health services.) SAMPRO, viewing it as a collaborative ICT tool, contains functionality for shared planning, for defining objectives and activities for the different care providers, and for personal notes for the patient; all in accordance with the requirements for a “Collaboration Care Plan”. The functionality for access control to the different parts of the plan is well developed and lets the patient have full control over who should be able to see what data. On the plus side in relation to its use in clinical trials is also the maturity of the platform; more than 50 Norwegian municipalities have adopted SAMPRO as tool for “Individuell Plan”. However, further refinement of the platform is needed, and the Norwegian is currently in dialogue with Visma regarding this issue. A dialogue has also been initiated with the Norwegian data privacy directorate (no: Datatilsynet) regarding the legal aspects of sharing (sensitive) patient data via such a web-based platform.

Technology evaluation

As described in previous section, the NEXES project trials will be based on a range of different technology platforms and devices, dependant on chosen ICT focus, and ICT availability- and maturity of available solutions on each site. On this background it is important to find a methodology for technology evaluation that can provide generic feedback on the shortcomings and potential of ICT in the domain of chronic care. The technology evaluation processes to be carried out in NEXES, should be viewed rather as a process of technology requirements gathering, than evaluation of final versions of proposed technology solutions. It will also be important, in the training processes leading up to the clinical trials, to leverage the users’ expectancies to the ICT solutions, since – at this stage- the solutions have not been fully adapted to the care process and the user scenarios in question. We are using the Unified Theory of Acceptance and Use of Technology (UTAUT)[7] as an overarching framework for the technology evaluation in NEXES. The model is illustrated in the figure below.

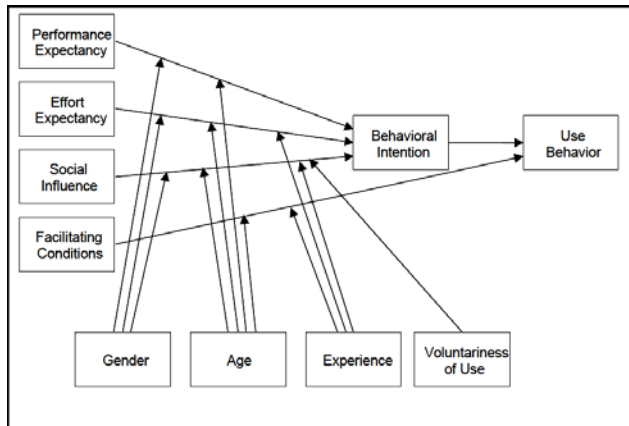


Figure 2: The model of the Unified Theory of Acceptance and Use of Technology (UTAUT).

The model states that there are four core group of factors that will influence a persons behaviour and actual usage of a system:

- Performance expectancy: the perception of how useful the system is
- Effort expectancy: the perception of how easy the system is to use
- Social influence: the perception of the expectations of other people on own system usage
- Facilitation factors: the perception of the degree of compatibility with own work processes and the degree of IT-support received

A *generic* questionnaire will be developed within the project that covers all of these factor, to be used equally by all sites. In addition, *specific* questionnaires shall be developed for each site, within each UTAUT “influencing factor” category (e.g. the first influencing factor is “Performance expectancy”) with questions that are specific to the technology objectives on that site.

Conclusion

This paper has reported on the status and activities of the ongoing European project NEXES. The project is currently planning a series of similar randomized clinical trials in the participating countries, Spain, Norway and Greece to test clinical pathways for the chronically ill. An objective of the project is to contribute to standardisation of these pathways.

The project has adopted the Business Process Modelling Notation (BPMN) standard for development of these pathways. This seems to be an appropriate choice. BPMN provides a structured means of describing all entities that are involved in a care process, their activities and responsibilities and the information flow between them. The project has suggested how the standard can be annotated with a standardised colour scheme that can be used to additionally enhance understanding and aid comparison between the sites.

The work carried out has also led to an increased understanding of the organizational differences of health care systems in the participating countries. Particularly it is clear that primary care services have different roles and emphasis in Norway in comparison with Spain and Greece. “Hospital at home” care models are suitable for areas without well developed primary and social care services. In Norway, however, main focus is on strengthening the primary care services and maintaining these as a strong gateways function towards the hospital services.

A core objective is deployment and evaluation of ICT in the clinical trials. A preliminary conclusion regarding this issue is that suitable and readily deployable ICT solutions to support chronic care processes are missing. The technology evaluation processes to be carried out in the project will constitute an important set requirements for future development of dedicated ICT solutions for chronic care processes.

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