

# Towards Internet Communities to Help Improve the Wellbeing and Rehabilitation of Clinically Stable Chronic Patients

Leendert W. M. Wienhofen, Ingrid Svagård

SINTEF ICT

Department of Software Engineering, Safety and Security  
NO-7465 Trondheim, Norway  
Leendert.Wienhofen@sintef.no, Ingrid.Svagard@sintef.no

**Abstract:** The EU project NEXES introduces IT support for integrated healthcare, and attempts to prove through clinical trials how new technology can help improve healthcare. The web-based approach used in the Norwegian clinical trial on wellbeing for chronically ill patients can be seen as a very small health care community for the patients. After introducing the NEXES project, the technical platform used for the wellbeing case, and the collaboration notation in BPMN, a specific case is described in detail and related to how the collaboration between the patient and health care stakeholders can be seen as a small group. Finally reflections are given on how the clinical trial could be extended by adding a ‘competition’ element using online communities in order to motivate the patients to do their rehabilitation exercises, and which technology standard could be used for this approach.

## 1 Introduction

Integrated care has been pinpointed as a major goal for many European projects, including the project NEXES<sup>1</sup> that we will report on in this paper. What characterizes integrated care is the need to put the patients’ needs in focus in the face of multiple care providing organizations. This is however a challenge because collaboration among primary care, specialists, social caregivers, etc. often introduces an overhead into the care process that in the worst case can leave the patient and his/her needs out of the loop.

---

<sup>1</sup> <http://nexeshealth.eu/>

This is in particular the case for chronically ill patients who often move from one institution to another, often frequently. In addition, halting collaboration between caregivers is costly as it results in suboptimal disease follow-up in the primary care services and hence increases the risk of costly hospital readmissions. The overall objective of NEXES is to improve quality of care and reduce costs by improving collaboration and optimizing the work-share between primary and secondary care services.

In the NEXES project we address 4 different programmes, one of which is entitled “Well being and rehabilitation”. This specific programme promotes early diagnosis and healthy life-styles of clinically stable chronic patients, enhancing their self-management and improving compliance with prescribed treatments. The principal components are physical activity and cognitive aspects.

In short, the wellbeing program includes:

- Instruction/tutorials on disease management and physical exercises.
- Physical “work-out” /exercise sessions in groups twice a week
- Physical “work-out”/exercise program to be carried out on his own, twice a week.

In Norway patients have the legal right to a (paper-based) personal plan for long term follow-up by coordinated (public) health services, this is called “*individuell plan*”, an individual plan. The plan contains an overview of the contact information of key stakeholders, the actions to take and the plan-owner’s evaluation of these actions. In NEXES we investigate how this individual plan can be supported by IT tools and how these open the potential to become Collaborative Care Plans (CCP).

In the next section we describe how an online tool helps the patient to better cope with the disease by creating and following an individual plan. The section after that gives a general introduction to how Business Process Modeling Notation<sup>2</sup> (BPMN) is used to describe the care process in order to identify collaboration between different professional stakeholders and the patient. This is followed by a case description and then an impression on how a competitive –health enhancing- element can be obtained when sharing information online with people that are undergoing similar treatment.

---

<sup>2</sup> <http://www.bpmn.org/>

## 2 Technical platform

In NEXES, we use the IT tool SamPro, developed by Visma Unique AS, to contain the CCP mentioned in the introduction. In [Wa05], a case description is provided on how the architectural description framework MAFIIA (Model-based Architecture description Framework for Information Integration Abstraction) is applied to SamPro. Other than this publication, not much scientific information is available on SamPro due to the specialised nature of the tool. Below we describe the main points of the tool, relevant to the case described in section 3.

SamPro is a web-based program, giving the plan-owner (the patient) full control over his own plan. On the other side, municipal health services can follow multiple plans simultaneously, of course, given that the patient has assigned access rights to them as there are very strict regulations as to who is allowed to view the plan.

The CCP is the plan-owner's personal tool for following up his own treatment. In cooperation with his coordinator stakeholders and actions related to the plan can be registered by the user himself. Each action can be evaluated by the user. It is up to the user of the CCP to register and invite stakeholders, which leads to a more active participation in his own situation and plan for follow-up.

The plan-owner can also include a personal social network in the follow-up plan, for example by introducing next of kin which then can express their support both online and by visiting the patient more regularly.

To comply with Norwegian legislation and regulation, the clients are the owners of the content and manage the access to their own client information. The client are also users and take part in the discussion upon own health situation.

Each plan involves at the minimum one service recipient and one coordinator, due to the law-regulation. Coordinators are most often nurses or physiotherapists, rarely psychologists or doctors. Coordinators belong mainly to primary health care services.

The SamPro platform provides the following services:

- CCP including mapping, action, goals and evaluation functionality is the most central service. Important information in relation to the CCP is the objectives of the plan and evaluation of the client at different stages.
- CSCW – supporting sharing of information, messaging (internal e-mail), instant messaging and discussion board/blog functionality available in next version. Messages may be alerted by mobile phone SMS functionality
- Agenda – planning of client.
- Profile management – management of users is based on a roles and access rights related to the roles. Caregivers can have different roles related to different clients.
- Patient management module – it supports simple management of the client profile. (The patient management module is not connected to the electronic patient records at the hospital or in municipalities.)
- Statistics: Statistical data can be extracted, such as amount of plans operative or not in the municipality/organization, level of use, etc.
- Logging: Available for all participants to see changes in planning activities done by whom and when, visitors to the plan (no changes made, but information received).

## **2.1 Mapping the interactions**

As indicated in the introduction, many interactions between the patient and the different stakeholders take place. In order to understand and externalize existing chronic care processes we have employed BPMN. Please refer to [FS09] for details on why this standard was chosen and the lessons learned while creating care process diagrams in BPMN. An example of the Norwegian wellbeing care process described according to the BPMN notation is found in figure 1. In short, it shows that the patient is checked for participation qualification in the clinical trial, and in case the patient is found to be suitable, the process is described from the patients and care givers view. The following section gives an overview over how the patient and care services collaborate in more detail (the case is based on the interactions described in figure 1) and how this is supported by the SamPro tool introduced in the previous section.

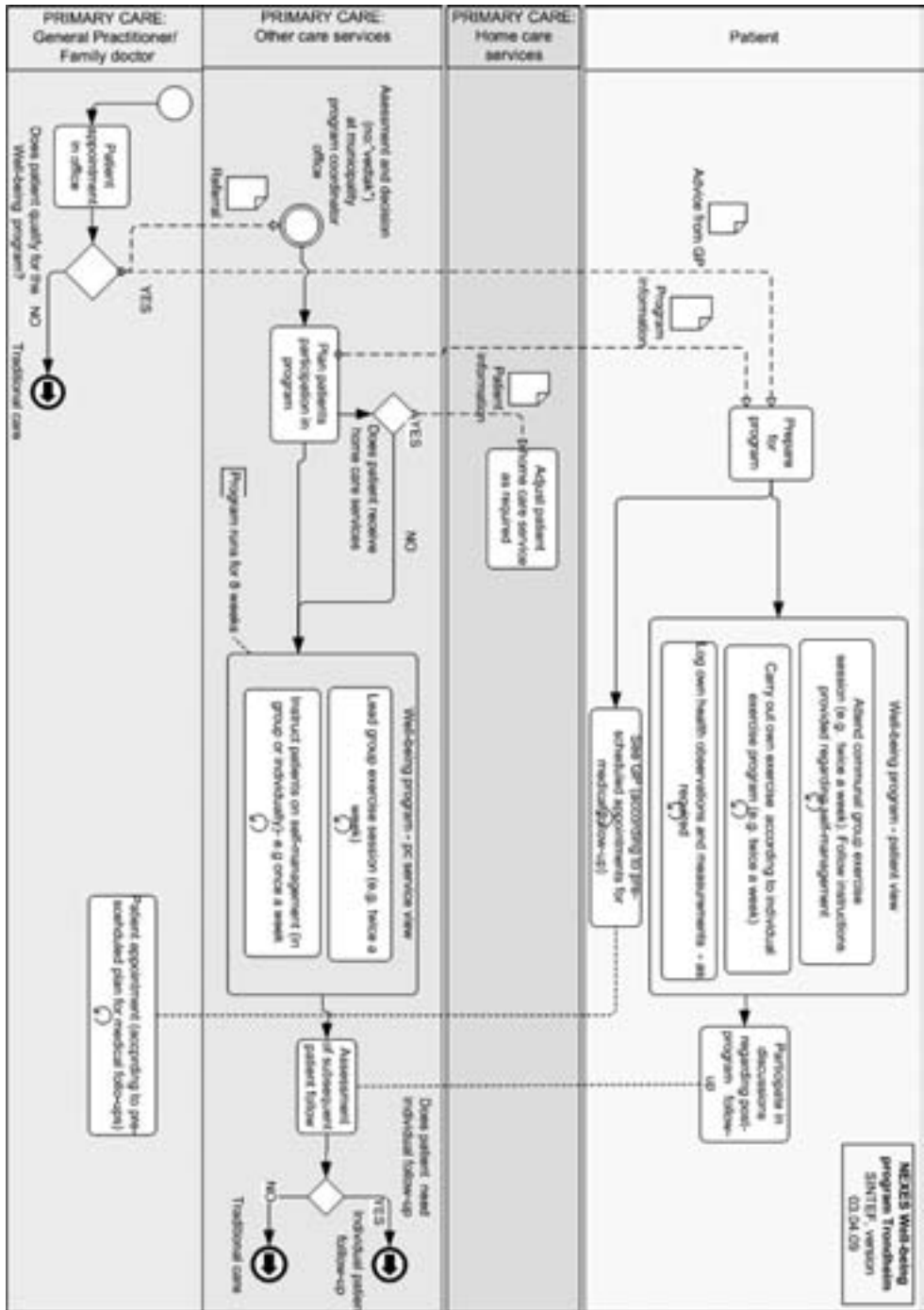


Figure 1: Example of the wellbeing process represented in BPMN.

### **3 Well being and rehabilitation programme – a case**

In this section, a case from the well being and rehabilitation programme is presented as a storyboard. The intention of storyboards in NEXES is to present as much as possible of the interaction between the different stakeholders and how technology can support these interactions. The storyboard below describes the enrolment of a patient called Rolf to the wellbeing programme; it starts at the General Practitioners (GP) office:

The patient, Rolf, is given a blood pressure monitor for home measurements and a pulse oximeter and instructed on how to use it. He is also asked to weigh himself regularly. Dr. Olsen then asks Rolf whether he has a PC with a broadband connection and is familiar with using it. As Rolf confirms this, Rolf is told that Dr. Olsen wants to follow up on Rolf on-line via the web-based collaboration tool SamPro, and that he will contact him approximately every 2 or 3 weeks to check on his progress. He will receive detailed training on how to use the tool from the NEXES program manager in the next few days.

A few days after the visit to the GP, Rolf is contacted by the NEXES program manager for detailed instructions on the exercise program and the follow-up he will receive. She teaches him how to use the Collaborative Care Plan (CCP) she has created for him with SamPro. The CCP will be Rolfs own tool for writing a daily journal, bi-weekly registration of the physiological data measurements, and bi-weekly answers to a checklist regarding his health and well-being. The registrations will help Rolf himself assess his own health and help his progress, but it will also help the GP to provide specialist advice regarding his disease, and the exercise team leader to adjust his training program. In essence, the CCP will function as a communication tool for all the persons that are involved in the care program for Rolf; the GP, the NEXES program manager and the exercise team leader. A very tiny private internet community indeed, though Rolf is instructed however, that he has full control on who is allowed to access the different parts of the plan, and see his personal data. This also means that Rolf can invite relatives into the programme.

In addition to communication via the CCP, Rolf will receive weekly SMS'es with hints, tips and reminders regarding his exercise plan and overall disease management. The reminders are generated automatically, while more detailed information such as the hints and tips are created by one of the health care stakeholders following Rolf's progress.

Three weeks into the program Rolf's attitude to the program is positive, but a bit ambiguous. He likes the group exercises, and he finds the weekly educational session very motivating and useful. He is taught about how to cope with the disease, the purpose and role of physical exercise and instructions on exercises he can carry out on his own. However he has no motivation whatsoever to exercise on his own. The SMS'es he receives every week sometimes helps him "remember" to do the exercises, but not always. Still, he duly follows up and answers the questionnaires, and carries out the measurements. After three weeks, the GP sends him a message via the CCP, telling him that he thinks he is doing fine, and encouraging him to keep up the good work.

The exercise team leader also checks Rolf's data. She logs on to the CCP from her office and gets an overview over all the patients care plans that she is in charge of. Her weekly routine is to scan through the registered data for each one, and if she finds deviations from expected values, she will call the person by phone, or she will leave a message in the CCP, for example with a follow-up question. Seeing that Rolf is having trouble in doing his own exercises, she decides to call him the next morning.

The case described above is an actual care programme description of the NEXES project. This specific case will run on a target group and a control group, starting September 2009. In the next section, we discuss additional technology that can enhance this programme, though note that it is not part of the actual NEXES programme.

#### **4 Towards internet communities to help improve the wellbeing and rehabilitation of clinically stable chronic patients**

In the case above, an awareness aspect is very apparent. Knowing what information to provide to whom and which information to receive enables the patient to be motivated to do the exercises and therewith improve the rehabilitation. In a sense, this type of awareness is similar to what is being described in [SR07], where software development teams were followed in order to identify the awareness networks. In our case, to a large extent, the awareness network is defined by the patient following the CCP, specialised care giving group. Though, the patient can include others than just the stakeholders defined in the CCP, in principle it is completely up to the patient whom to include, though, as the SamPro tool is not very open (due to legislation), some patients might find it useful to alternatives. By expanding the awareness network with others than the given stakeholders, the patient is able to create his own care community.

In [Ey08] we see that new web technology enables and facilitates 1) social networking, 2) participation, 3) apomediation, 4) openness, and 5) collaboration, within and between these user groups. Personal health records (PHR) such as Google Health<sup>3</sup> or Microsoft's HealthVault<sup>4</sup> are two alternatives [to SamPro] where the patient can register and publish his PHR. The paper [Go08] introduces both systems and how Google and Microsoft implement security and privacy systems in order to gain the trust of the user.

---

<sup>3</sup> <https://www.google.com/health>; "With Google Health, you can store and manage all your health information in one place. In Google Health, you can also chose to share your medical records with family members, friends, doctors or anyone else in your care network in order to coordinate your care. By creating and opening up an account, you have the possibility to let other patients find you and create a private care network."

<sup>4</sup> <http://www.healthvault.com/>; "HealthVault offers you a way to store health information from many sources in one location, so that it's always organized and available to you online. HealthVault is working with doctors, hospitals, employers, pharmacies, insurance providers and manufacturers of health devices – blood pressure monitors, heart rate monitors and more – to make it easy for you to add information electronically to your HealthVault record. With a more complete picture of your family's health, you can work with your healthcare professionals, and with all the Web sites that connect with HealthVault, to make more informed decisions."

Both systems can be used to enter information relevant for the wellbeing programme. When other patients with a similar programme are registered, they can share their experiences, exchange ideas, motivate each other and even ‘compete’ in their rehabilitation process. We suggest that the dropping motivation to exercise on their own –as described in case in the previous section- can be triggered by introducing some sort of ‘competition’ element. The type of competition element enabled by online communities is well shown by Nike’s Men vs. Woman running challenge<sup>5</sup>. Even though this running competition is not a scientifically proven method for verifying anything, it does show that it can trigger people to a healthier lifestyle by introducing an element of competition.

The Continua Health Alliance (CHA) has proposed a reference architecture [Ca07] (see figure 2) for a full end-to-end approach to technology support for healthcare. The reference architecture itself is rather generic, though the focus of the CHA is to provide interoperable wireless interfaces [Sc07] between health-related devices. The data emerging from these can cater for the healthcare ecosystem as described in the paper.

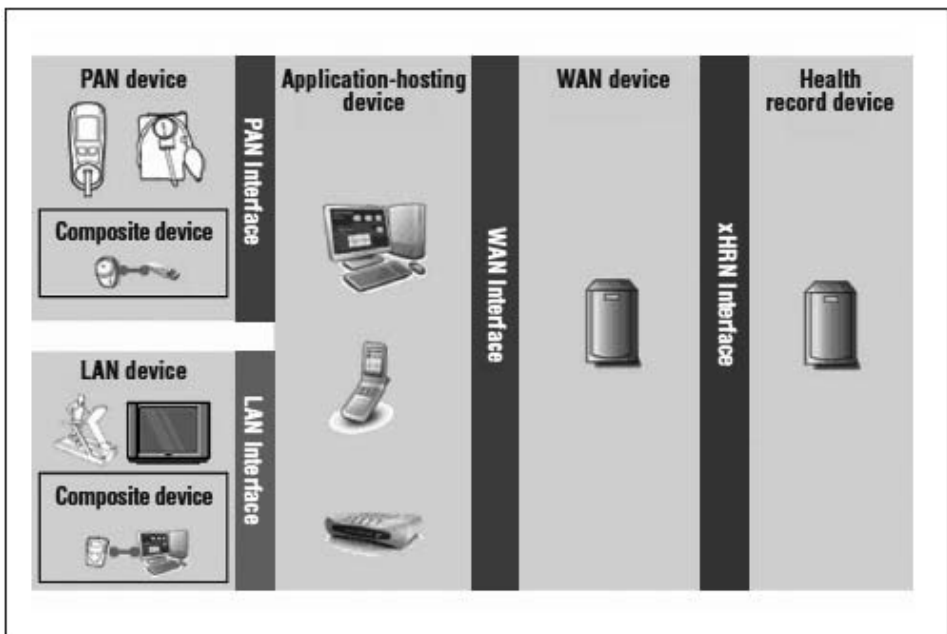


Figure 2: The Continua End-to-End reference architecture (copied from [Ca07])

<sup>5</sup> www.nikeplus.com



In our wellbeing case, most information is to be plotted into SamPro by hand, which in itself could be demotivating. In order to ease the proposed competition element (at least in a technical sense), we agree with CHA that standardized wireless transfer of data helps to enable this as the user does not need to worry about cables or interoperability. Workout data is uploaded automatically and the results can (ultimately) be automatically compared, giving back the motivation to actually do the exercises also when being on their own.

## 5 Conclusion and further work

In this paper we have shown the NEXES approach to a wellbeing and rehabilitation case and we have proposed ideas which can help enable a better programme once technology is mature enough.

The actual wellbeing and rehabilitation case will be one of the randomized clinical trials within the project, and will be started in September. The trial will run for 9 months and after this the use of the tool will be evaluated. The competition concept in order to prevent demotivation while patients are working out on themselves in their homes can not be part of this study as technology is not yet mature enough.

## 6 Acknowledgement

The work reported in this paper is a result of our involvement in NEXES. Parts of the work are funded by the European Commission (Grant Agreement No 225025).

## 7 References

- [Ca07] Carroll, R. Cnossen, R. Schnell, M. Simons, D. , Continua: An Interoperable Personal Healthcare Ecosystem. IEEE Pervasive Computing, Publication Date: Oct.-Dec. 2007. Volume: 6, Issue: 4, pages: 90-94
- [Ey08] Eysenbach, Gunther, Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness, J Med Internet Res. 2008 Jul-Sep; 10(3): e22. Published online 2008 August 25. doi: 10.2196/jmir.1030.
- [FS09] Babak A. Farshchian, Ingrid Svagård, Using business process modelling to model integrated care processes: Experiences from a European project. To be presented at: IWAAL'09 1st International Workshop of Ambient Assisted Living 2009 (IWAAL'09) 10th - 12th June, 2009 - Salamanca, Spain
- [Go08] Greg Goth, "Power to the Patients," IEEE Distributed Systems Online, vol. 9, no. 5, 2008, art. no. 0805-o5001.
- [Sc07] L. Schmitt, T. Falck, F. Wartena, and D. Simons, Towards Plug-and-Play Interoperability for Wireless Personal Telehealth Systems, 4th International Workshop on Wearable and Implantable Body Sensor Networks (BSN 2007), Springer Berlin Heidelberg, ISSN 1680-0737 Volume 13, 2007, Pages 257-263

- [SR07] Souza, C.R.B.d., and Redmiles, D. "The Awareness Network: To Whom Should I Display My Actions? And, Whose Actions Should I Monitor?," ECSCW'07: Proceedings of the Tenth European Conference on Computer Supported Cooperative Work, Springer, Limerick, Ireland, 2007, pp. 99-117.
- [Wa05] Ståle Walderhaug, Erlend Stav, Stein L Tomassen, Lillian Røstad and Nils Brede Moe, "MAFIIA – an Architectural Description Framework: Experience from the Health Care Domain," book chapter in Interoperability of Enterprise Software and Applications, D. Konstantas, J.-P. Bourrières, M. Léonard and N Boudjlida (Eds.). Geneva, Switzerland: Springer Verlag, 2005, pp. 43-54.