End-user and stakeholder participation in the European eHealth project RE-SAMPLE

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In this position paper, we reflect on the end-user and stakeholder participation in the European eHealth project RE-SAMPLE. We outline the different roles of stakeholders that were involved in different activities during requirements elicitation and iterative development of the eHealth technology. Various methods and outreach activities were performed to reach a large number of end-users and stakeholders and lower barriers for participation. We reflect on these activities and the lessons learned in terms of the level of participation that took place, which level we could not reach yet (i.e., joint decision making) and how this could be improved.

CCS Concepts: • **Applied computing** → **Health care information systems**; • **Human-centered computing** → **Participatory design**; **Empirical studies in HCI**.

Additional Key Words and Phrases: multi-stakeholder, COPD, eHealth, involvement

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1 INTRODUCTION

In this position paper, we reflect on the process of continuous end-user involvement and stakeholder participation in a large European eHealth project. The European project RE-SAMPLE aims to develop a virtual companionship program for patients living with chronic obstructive pulmonary disease (COPD) and other complex chronic conditions. COPD is a chronic inflammatory lung disease that causes obstructed airflow from the lungs, is progressive and often accompanied by phases of acute worsening of respiratory symptoms. Patients who are diagnosed with additional chronic conditions may experience overlapping symptoms (e.g., breathlessness could be caused by COPD, heart failure or anxiety).

The RE-SAMPLE virtual companion will enable patients to self-manage their condition by collecting real-world data, monitoring their health, receiving coaching and personalized care through predictive modeling of exacerbations and disease progression. By providing healthcare professionals (HCPs) access to the data and predictions via a dashboard, shared decision making is supported based on data, patient and professional. In addition, a cohort study will be established, which consists of hundreds of patients from all three clinical sites (Italy, Estonia, The Netherlands). These patients will collect real world data (e.g., daily symptom diary, quality of life, physical activity) that together with clinical and environmental data will be used to learn about key determinants of exacerbation risk prediction.

2 END-USER AND STAKEHOLDER PARTICIPATION

In the beginning of the project, several activities and studies were carried out where we wanted to involve end-users and stakeholders. Figure 1 provides an overview different end-users and stakeholders involved as well as their role as perceived by the researchers carrying out the studies.

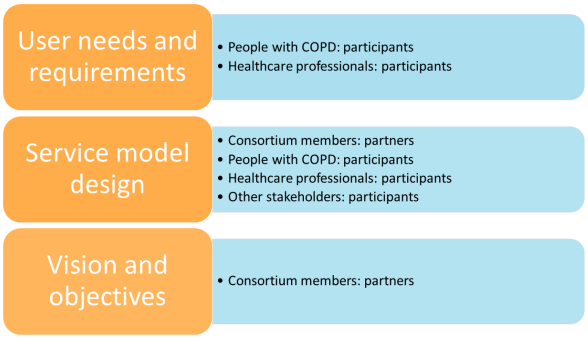

Fig. 1. Overview of end-users and stakeholders involved in the different tasks

The first tasks in the project were related to the user needs elicitation and user requirements specification. Here we invited patients and HCPs from different disciplines (e.g., pulmonology, psychiatry or psychology, physical therapy, nurse practice, cardiology, internal medicine, general practice) to participate in a variety of activities utilizing a mixed-method approach. Inclusion criteria for patients were that they have a clinical diagnosis of COPD and preferably at least one comorbidity (diabetes, chronic heart failure, ischemic heart disease, anxiety, depression), are ≥40 years, able to understand, read and write the language spoken in the country of the clinical pilot site (The Netherlands, Estonia, Italy), and that they gave informed consent prior to participation. Inclusion criteria for HCPs were that they gave informed consent and that they have experience in treatment of patients with COPD, even if their main focus was on one of the comorbidities.

Another task next to the elicitation of requirements was the iterative development of the service model with the key stakeholders per pilot site that were considered crucial for the successful implementation of the virtual companionship program. These stakeholders included patients with COPD, researchers (clinical, junior, senior), pulmonologists, healthcare specialists, specialized nurses, research nurse, rehabilitation physician, physiotherapist, employees from

the hospital (laboratory, technical data consultant, and IT cloud and infrastructure-architect), EU Affairs officer, assistant professor, social worker, representative of local city government, local ministry of social affairs, health insurance fund.

Other stakeholders involved in participatory activities were technical partners and clinical partners from the project consortium. The consortium met several times to discuss overall goals, big picture of the project and the features, service model and value proposition of the virtual companionship program. Finally, the European Commission can also be considered a stakeholder, representing the objectives written in the proposal and in the description of work, which influence decision making and goals and objectives of other actors.

3 RECRUITMENT AND INVOLVEMENT THROUGHOUT THE ITERATIVE DEVELOPMENT

The initial recruitment was carried out or supported by the clinical pilot sites, that recruited from their patient base. This was preceded by an internal ethical approval that outlined the nature of the activities (e.g., workshop, interviews, diary study). The clinical partners either provided contacts of patients and healthcare professionals to be contacted, or in the case of Estonia and Italy contacted them to carry out the activities themselves. In the Netherlands, we were able to call the patients ourselves. During those calls we emphasised that they are the experts living with the condition, and that thus their knowledge and insights are very important for us.

Patients that participated in the initial activities were asked whether we were allowed to contact them again for future studies. After each activity, a summary was provided in written form and as video (with audio), which was shared with all participants. It was also shared with people who participated in earlier activities and wanted to be contacted for future studies but could not or did not want to participate in the current activity. Furthermore, these summaries were also used as outreach to inform the public about our results (e.g., via social media, e-mail, newsletters, blog posts, patient associations). At the end of each video, we included a message that the involvement of patients continues and how people can contact us if they want to participate as well. An end-user panel was set up via the University website, where interested patients and professionals could sign up to be involved in our studies. These were advertised online and via paper-based leaflets in waiting rooms. Finally we also made an inventory of local and European networks, where we could send our information and/or invitations for participation (e.g., patient associations, condition specific organizations).

We utilized a variety of methods and modalities, depending on the activity at hand, but also practicalities and preferences of participants (workshops, interviews, diary, survey, usability testing). The different methods complemented each other, for example, with the diary method, people do not have to recall what they did in terms of self-management but can report it on the same day. Furthermore, given the COVID-19 pandemic, we also offered to organize workshops online, so that participants could participate from the comfort of their home. Even before the COVID-19 pandemic, we carried out interviews with patients in their home, to lower the barrier for participation considering that some were not able to travel but also did not want to do the interview on the phone or online.

Given the heavy workload and overlapping rosters of healthcare professionals, scheduling focus groups or workshops was challenging. Here we carried out 1-on-1 interviews and surveys, as this enabled professionals to participate when it suited them best. Another alternative was to join a department meeting and adapted the workshop to fit in the time available.

For the service model development, we used a step-wise approach, where the stakeholder identification (workshop with clinical partners in the consortium) and the assessment of their importance (survey, distributed in the network of the consortium) was conducted first to decide who should be invited to the workshops.

4 DECISION-MAKING BASED ON END-USER AND STAKEHOLDER INVOLVEMENT ACTIVITIES

The decision-making was fully based on activities where end-users and stakeholders were involved and shared their perspective. In this section we only provide a few examples to illustrate this.

The decision on which parameters are considered important to collect for the prediction of exacerbations and disease progression was based on activities with patients and healthcare professionals. Following feedback from patients who started collecting data with the virtual companion, it became clear that the number of questions and questionnaire were too high. Attempts were made to reduce the parameters as much as possible, balancing the workload of patients with the need for standardized questionnaires for accurate prediction modeling [1, 2]. Furthermore, the technical developers also made changes to the user interface so that it is easier for patients to respond to questions.

Based on the service model workshops, we learned that in some areas patients are not yet used to taking a more active role and hence training needed to be added so that the virtual companion can effectively support them to engage in self-management. The question of who should receive which kind of notifications was challenging to answer, as the empowerment of patients and them becoming more responsible and also taking an active role, needed to be weight against the responsibility felt by clinicians to ensure the well-being of patients who might ignore notifications and not act. A fall-back solution was decided upon in case patients do not act on several notifications, so that the professionals are kept in the loop and can follow-up with their patients if necessary.

5 REFLECTIONS AND LESSONS LEARNED

Finding the right people and inviting them to participate was quite a challenge. In parallel to the recruitment activities for user involvement, clinical partners also had to recruit a high number or patients for the cohort study. The project started in March 2021 and was affected by the COVID-19 pandemic. The target group of our project were people with COPD who are especially at risk. Also the healthcare professionals were difficult to reach, as they were already overworked due to the pandemic.

Similar to other projects, we were also faced with the reality of a potential sampling bias [5], meaning that we risk to only reach 'the usual suspects' (highly educated people, who are already engaged

and empowered) and miss out on those who are difficult to reach, but who might benefit the most. This is a continuous challenge, which we try to overcome by providing accessible information in different modalities (paper and digital; textual and audio-video). As it is not uncommon that participants make positive comments but in the end say that it is not applicable for them [5], we wanted to explicitly explore this. For example, during the end-user walkthroughs of early prototypes we made use of personas and asked patients to give their opinion from the perspective of the persona (i.e., inviting them to empathize with the persona) and also from their own perspective. We further explored with them if there was a discrepancy between the two perspectives. One common reason provided was that such a virtual companion was seen useful rather for patients who were recently diagnosed and were still learning to live and deal with their condition.

Due to the restricted access to stakeholders, the limited time and resources available to the ones we could reach, and the timeline of and the dependencies within the project, decisions could not be made together with stakeholders but based on the input provided by them during all the different studies. This necessitated the alignment of different stakeholder interests common in large projects [4], such as utilizing standardized questionnaires versus number, choice, lengths of and wording within questionnaires. Furthermore, the different work packages, tasks, and processes were difficult to align. For example, internal ethical procedures at the various pilot sites that are necessary before contacting any patient take some time and preparation, outlining exactly the activities to be performed with the patients (for example, focus groups or usability testing of prototypes). Recruiting patients and healthcare professionals and scheduling meetings with them also takes a lot of time. Therefore, testing of new prototypes on short notice when technical partners have something ready is not always feasible and require good planning in advance.

A final reflection relates to the different roles that end-users or stakeholders can have in a project. As seen in Figure 1, we considered people with COPD, healthcare professionals and other stakeholders as participants in our studies. Following ethical code of conduct, we always share an information letter and the informed consent form in advance that needs to be signed before the respective study. However, when it came to the service model workshops, people from Estonia who were asked to participate were confused by this practice. They considered themselves as 'volunteer consultants' of the project and did not think this was necessary.

6 CONCLUSION

Our aim was and still is to continuously involve patients and professionals in all steps of the project, including decision making processes. While the participatory activities highly influenced the project, we would have preferred that stakeholders have an even larger role (e.g., actively participating also in decision-making processes). Unfortunately, high workload, disease burden, recruitment challenges and health risks related to COVID-19, prevented this.

We were facing the dilemma described by [3], namely the "tension between demandingness and inclusivity [that] creates a dilemma for researchers, who are left to choose between participatory research that is either too demanding, and therefore unfeasible, or too uninclusive, and therefore unfair." At the same time, we risk to only reach the usual subjects and miss out on the difficult to reach population, who might benefit the most.

Our goal is to continuously find ways to reach all people that are affected by the technology under development and that are representative of the population - in all of our projects. Building good relationships with the stakeholders and involving them already when writing a grant proposal can help to shape the project in a way that addresses their needs and kick-start outreach activities early on. Furthermore, we believe that delivering first and asking later (e.g., by continuously sharing activities and results from ongoing studies in an accessible way) is a good way to show our commitment to stakeholder involvement. It can also illustrate what we mean by participation, to lower the barriers for people who do not have any experience yet.

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