Different Ways of Engaging the End-Users in mHealth Services

Lessons learned from Swedish case of "Health in Hand" Project

Yan Hu, Sara Eriksén

Department of Creative Technologies
Blekinge Institute of Technology
SE-371 79 Karlskrona, Sweden
Email: {yan.hu, sara.eriksen}@bth.se

Cecilia Fagerström

Blekinge Center of Competence
Blekinge County Council
SE-371 81 Karlskrona, Sweden
Email: cecilia.fagerstrom@ltblekinge.se

Jenny Lundberg, Hanna Tuvesson, Lina Nilsson

Linnaeus University
Vaxjö/Kalmar, Sweden
Email: {jenny.lundberg, hanna.tuvesson,
lina.nilsson}@lnu.se

Malin Hofflander

Hofflander Consult AB
SE-294 95 Sölvesborg, Sweden
Email: malin@hofflander.se

Abstract— **mHealth services are becoming common all over the world. However, the acceptance and use of mHealth services are not always as expected. In this paper, we discuss the lessons learned from our recently finished research project "Health in Hand". Based on the Swedish case study on using mHealth services to support patients with Type 2 Diabetes (T2D) in living a healthy life, we propose strategies for engaging the end-users in mHealth services. These strategies include moving user-driven participation from the margin to the center, building up a professional education team to support both patients and healthcare providers, strengthening user motivation through gamification and supporting the sharing of knowledge within and between different user groups. We believe that these strategies could improve the design of mHealth services through higher user engagement.**

Keywords-mHealth; user engagement; type 2 diabetes; lessons learned; strategies.

I. INTRODUCTION

We have collaborated in an interdisciplinary Indo-Swedish research and development project, "Health in Hand" [1], concerning design of mobile services for health promotion and disease prevention. The Swedish case within the project focused on how to support people with type 2 diabetes (T2D) in living a healthy life through mobile technologies. In this case, a mobile application for communication of blood sugar values, etc., and comprehensible overview of health history, for self-management and a supportive dialog with healthcare providers, was studied. In this paper, we will present lessons learned from the Swedish case study in the project.

There are about 400 000 Swedes, or 3-4% of the population, who have diagnosed T2D. The risk of T2D increases among elderly people. Among those over 75 years old, an estimated 10% or more have T2D [2]. Diabetes is becoming more and more common, not only in Sweden but around the world.

mHealth is already being used to monitor a variety of conditions of chronic disease [3]. The use of mHealth tools itself engages more people to focus on improving their health. Research shows that mobile based interventions with clinical feedback for patients with diabetes improve glycemic control (HbA1c) in the short-term, compared to standard care or other non-mHealth approaches [4].

This paper presents some points on how we should engage the end-users in mHealth services for sustainable use, based on our experiences from the Swedish case study in the "Health in Hand" project. Section 2 provides a brief background of global T2D and global guidelines for managing older people with T2D. Section 3 gives an overview of our experiences from our Swedish case, while in Section 4, we propose some strategies to engage the end-users in mHealth services. The conclusion and future work are presented in the last section.

II. BACKGROUD

A. T2D: A global epidemic in aging populations

T2D is a chronic progressive disease resulting from an imbalance between insulin sensitivity and insulin secretion. It is the most common form of diabetes, responsible for at least 90% of all cases of diabetes [5]. T2D is a lifestyle disease which typically hits people as they grow older. The number of diagnosed cases of T2D has increased rapidly worldwide during recent decades, to an extent that has lead researchers to speak of a global epidemic [6]. In 2015, according to statistics from the International Diabetes Federation (IDF) [5], 1 in 11 adults worldwide had diabetes, and it was estimated that by 2040 this would have reached a level of 1 in 10 adult worldwide living with diabetes [5]. In 2015, approximately 12% of global health expenditure was spent on diabetes. Yet, at that time, IDF also estimated that 1 in 2 adults with diabetes was undiagnosed.

B. Global Guideline for managing older people with T2D

In 2013, IDF, recognizing the relative lack of clinical trials and guidelines concerning elderly people with T2D, published a global guideline specifically focused on managing older people with diabetes [7]. The guideline was developed to provide clinicians with recommendations that assist in clinical management of a wide range of older adults, not only those who are relatively well, but also those who, due to frailty, or dementia, or both, are functionally dependent. "While there is increasing recognition that diabetes care for all people should be individualized it is apparent that for many older people with diabetes, care is sub-optimal and often fragmented leaving a substantial portion of adults with unmet clinical and social need." [7] The guideline takes as its starting point that informal caregivers are often the primary source of everyday advice, emotional support, and practical help for a large number of older people with diabetes, although this is often overlooked by healthcare professionals involved in diabetes care. One of the key principles underpinning the guideline refers to quality use of medicines, including using non-medicine options first if possible, pharmacovigilance, and de-prescribing. Further, the guideline uses three main categories for older adults with diabetes when it comes to determining how to manage their care: those who are independent, those who are dependent, and those who have a life expectancy of less than 1 year and need end of life care.

III. LESSONS LEARNED FROM THE PROJECT

Admittedly, when the "Health in Hand" project started in 2014, we were focused, in the Swedish case study, on developing mobile services for supporting people with T2D in managing their diabetes and developing and maintaining a healthy lifestyle. We aimed to include not only people with T2D but also family members and informal caregivers, as well as healthcare providers, as important actors and participants in the design process. Our aim was to contribute to transforming healthcare delivery through co-construction of mobile health services which focus on factors that support human health and well-being [8] [9], and not only, or primarily, on factors that cause disease (pathogenesis). We were using Participatory Design (PD) as a research method, of which one of the goals was to promote participatory design for mHealth development with the local design of design methods, techniques, and tools.

A. Challenges facing Swedish diabetes healthcare

From our case study, we found that there are several challenges faced in Swedish diabetes healthcare. Most of the patients diagnosed with T2D do not measure their blood glucose regularly. Instead, they are called in to the primary care centers or clinics to have it measured once or twice a month. For security reasons, which currently preclude the use of e-mail and mobile messaging, the healthcare providers spend a great deal of time calling patients on the telephone or sending them regular mail. This results in unnecessary visits if the values are normal, while, on the other hand, for patients whose values are abnormal, visits should have

occurred earlier. Some patients measure their blood glucose themselves at home, but in many cases there is little or no support for recording and sharing their values with their healthcare providers.

B. mHealth for people with T2D

Our study, with its focus on people aged 65 and older who have been diagnosed with T2D, and healthcare teams working with this group of patients, eventually opened our eyes to issues of functional impairments due to aging (such as poor eyesight, stiff fingers, difficulties in remembering passwords or how to do things from one time to the next on a mobile phone), as well as to multiple comorbidity among an aging population. Managing a healthy lifestyle, for many of these people, involved not only managing T2D but also managing other health- and aging-related issues, making the situation in which they were expected to use mHealth services more complex than we had anticipated. Even healthy elderly patients who are diagnosed with T2D but are not simultaneously having to cope with other chronic diseases may have varying needs concerning mHealth services – and these individual needs could vary over time. Basically, the art of engaging end-users in the design, development and sustainable use of mHealth services hinges on identifying these users' perceived needs and addressing them in ways that can make a difference in everyday life for the individual end-user. End-users bring valuable insights about user needs and use context which can inform not only design and development of mHealth services, but also choices concerning how these services might be introduced and implemented more successfully in a healthcare context.

One of the people with T2D whom we interviewed mentioned that we should perhaps focus on "windows of opportunity" for providing mHealth for people with T2D, rather than clustering them all in one category and trying to reach them all, at all times. "When you are diagnosed with T2D," he said, "it comes as a shock. For about 6 months, you are shaken and trying to adjust to living with this disease, which can potentially be fatal. During those 6 months, you are especially susceptible to trying to change your lifestyle." Those 6 months, he suggested, would be the best time to introduce the mHealth services, because that is when the person diagnosed with T2D is looking for a lifeline. This brings us back to trying to develop ways to communicate with and understand the needs of people with different conditions, and to listen to their point of view.

Even with great interest and motivation to use mobile services in home-based T2D healthcare, older people with T2D felt that they were encumbered by a lack of awareness, knowledge and support for self-management. One T2D patient we interviewed said: "For most patients who have T2D, it is not necessary to go for a check-up at the hospital very often, we can check blood glucose at home ourselves if we are taught to do so. In addition, we can measure our blood glucose at home whenever we don't feel well. If I find any values abnormal, I could communicate with the nurses as soon as possible." She suggested that there should be a technical support team with professionals who have knowledge, both of healthcare and diabetes care, and

Information Technology (IT), to educate users before delivery of mHealth services.

C. mHealth for healthcare support team

In Sweden, the healthcare support team for patients with T2D includes healthcare providers, both in hospitals and primary healthcare centers, and informal caregivers, as well as family members. This support team was supposed to cooperate for providing patient-centered healthcare for T2D patients through mHealth services. However, from our study, we found that at least until now, the promotion of mHealth services is still coming from hospital healthcare workers. In our case, doctors or hospital nurses have been given the access right to the data recorded through the mobile application by the patient. In most situations, patients are suggested by the doctors to use the mobile application. The patients therefore get the impression that the healthcare provider should teach and support them when using mHealth services. One doctor in a diabetes center mentioned, "IT has developed so fast that if we ask our patients to try a new technology, like a mobile application, it seems that we also have the responsibility to teach them to use it, but, actually, we are not good at technology either." The lack of knowledge and competence about IT risks reducing the enthusiasm about mHealth services over time.

From the case study, we also found that each healthcare worker works with approximately 3–5 different IT systems in their daily work, and some amount of repeated work is involved. For example, identical information about a patient is updated manually in these different systems. Not only does this cause extra work and frustration, it is also a security risk in that the information may deviate across different systems. The main tool for digital communication between healthcare workers is an internal journal system that serves to share patients' data among different healthcare providers. Due to security and privacy legislation and concerns, not all the data are shared by all the healthcare providers. Although most T2D patients were taken care of by other healthcare providers than hospital staff, such as primary healthcare center staff, or informal care givers, until now, at least in Blekinge, these groups of healthcare providers have no access to the T2D data recorded from mobile applications. These kinds of interoperability problems are another big challenge for mHealth services in Swedish healthcare.

IV. STRATEGIES TO ENGAGE THE END-USERS IN MHEALTH SERVICES

On the one hand, Sweden's population is ageing; in 2040, nearly one in four Swedes will be 65 years or older [10]. On the other hand, Sweden aims to "be best in the world at using the opportunities offered by digitization and eHealth to make it easier for people to achieve good and equal health and welfare, and to develop and strengthen their own resources for increased independence and participation in the life of society [3]". Therefore it is essential to provide social and health care to elderly people through digitization and eHealth. mHealth services, as one of the potentially effective ways, will play a significant role in future elderly healthcare. How to engage the end-users in mHealth services, especially

mHealth for older people, for sustainable use, needs to be addressed and further explored.

A. User-driven design method of mHealth services

As we mentioned before, PD was our overarching research method in the Health in Hand project. One of the project goals has been to promote participatory design for mHealth services development. From our study, we found that PD fits quite well with the current patient-centric paradigm which is commonly referred to in nursing and caring for patients with chronic disease, e.g., T2D. PD in a healthcare context concerns not only the technical platform and solutions, but also the work practices in different healthcare organizations. To sustain long-term engagement in a patient-centric mHealth project, user-driven participation should, we argue, be moved from the margin to the center [11]. When the patients, such as older people with T2D, are engaged in co-design mHealth services, it enables them to learn more about their condition and about developing and sustaining a healthy lifestyle despite their chronic illness. It also allows them to have a say in deciding what kind of mHealth support they need and want, in a constructive dialogue with healthcare providers and other involved stakeholders. When designing a new mHealth service, it is often useful to consider whether the design goal can be achieved by fostering creative uses of services they already are familiar with and using. In the project, we could not just simply bring different new mHealth services to be tested and used in a clinical setting at the hospital or a primary healthcare center, as this would be adding to the frustration and heavy work load of the healthcare providers rather than supporting their work [12]. Instead, we chose a mHealth service which was already partly implemented at the hospital as a starting point for further prototyping to explore user needs and how they could be managed with a further enhanced mHealth service. Although we mainly focused on healthcare workers on the T2D team and relatively healthy T2D patients, end-users with special needs should also be taken into account for early design phase participation.

B. Professional education team to support

Lack of IT knowledge of end-users seems to be a great challenge when it comes to user engagement in mHealth currently. Not only elderly people mentioned this, but also healthcare providers were reluctant to engage with mHealth services due to what they perceived as their lack of IT knowledge. Patients expected the healthcare providers to teach them to use the mHealth service, but in most situations, the healthcare providers had neither knowledge nor time to do so. Most of them required more time to learn to use the new technology themselves. From this, we drew the conclusion that there is a need for some kind of a professional education team to educate and support the end-users of mHealth services, especially concerning technical issues, but also concerning content and how to interpret various health indicators etc. Different educational programs should be designed to address different groups of end-users. A support center for mHealth services should also be set up when these services are delivered to large populations.

C. Strengthen end-users' motivation of mHealth services

In the future, concerning design of patient-centric mHealth services, strengthening the patients' motivation is one of the key factors for achieving long-term use of the services. In many cases of chronic disease, patients are suggested to do physical exercise as a main method of controlling their condition. And one of the future needs of elderly care is effective preventive healthcare [10]. Gamification in mHealth services is one approach which is being tested. Mobile games have shown promise of being a successful way of influencing health behaviors recently [13]. A successful mobile game for health, especially for older people, will not only influence the health behaviors, but also support elderly people in having fun by playing games. Normally, the factors affecting users' motivation and engagement in games for entertainment depend on experienced game developers. For those games for health, we still need excellent game developers to design highly attractive games or game elements. Additionally, the input of healthcare providers and behavioral scientists will be essential to delivering an effective mHealth service [13].

D. Knowledge sharing among healthcare providers

Current Swedish eHealth services have, to some extent, achieved sharing of patients' information among healthcare providers. To deliver an effective patient-centric and empathetic healthcare for older people, who often have more than one chronic disease, or complex health conditions, information sharing is not enough. Knowledge sharing, which is about transferring of ideas, experiences, skills, practices etc. among healthcare providers is needed. Knowledge sharing about what kinds of interaction works best in specific situations with a specific person among healthcare providers will help to cope with different special situations. It will not only improve the work practices of healthcare providers [14], but also increase the sustainable use of mHealth services by patients with different special conditions and in specific situations.

V. CONCLUSION

In this paper, we have introduced a Swedish case study from our recently finished research project "Health in Hand", which is focused on transforming healthcare though mHealth services. We have listed several points based on lessons that we have learned from the case study. We conclude that, to promote mHealth services, sustaining end-users' engagement is crucial. Form our experiences, we propose that applying user-driven design methods, having professional education about and support for use of mHealth services, improving users' motivation through games and support for sharing knowledge among healthcare providers could make some contribution to high end-user engagement in mHealth services in the future.

Digitalization of healthcare needs to be supported on all levels of health care organizations. There is also a need to reserve time and space for testing new ways of working. We have several projects in the planning stage on end-user engagement in mHealth services. In the future, the suggested strategies presented in this paper will be drawn up and further explored within these projects.

REFERENCES

[1] S. Eriksén, M. Georgsson, M. Hofflander, L. Nilsson, and J. Lundberg, "Health in hand: Putting mHealth design in context," in *2014 IEEE 2nd International Workshop on Usability and Accessibility Focused Requirements Engineering (UsARE)*, 2014, pp. 36–39.

[2] "Type 2-diabetes," *Diabetes.se*. [Online]. Available: /diabetes/lar-om-diabetes/typer/typ-2/. [Accessed: 22-Feb-2018].

[3] "Vision for eHealth 2025," Ministry of Health and Social Affairs, Sweden, Mar. 2016.

[4] S. Kitsiou, G. Paré, M. Jaana, and B. Gerber, "Effectiveness of mHealth interventions for patients with diabetes: An overview of systematic reviews," *PLOS ONE*, vol. 12, no. 3, p. e0173160, Mar. 2017.

[5] "International Diabetes Federation - What is diabetes." [Online]. Available: https://www.idf.org/about-diabetes/what-is-diabetes.html. [Accessed: 22-Feb-2018].

[6] W. H. Herman and P. Zimmet, "Type 2 diabetes: an epidemic requiring global attention and urgent action," *Diabetes Care*, vol. 35, no. 5, pp. 943–944, 2012.

[7] "International Diabetes Federation. IDF Global Guideline for Managing Older People with Type 2 Diabetes." [Online]. Available: https://www.idf.org/e-library/guidelines/78-global-guideline-for-managing-older-people-with-type-2-diabetes.html. [Accessed: 22-Feb-2018].

[8] B. Lindström, "Salutogenesis – an introduction." [Online]. Available: http://www.centrelearoback.org/assets/PDF/04_activites/clr-GCPB121122-Lindstom_pub_introsalutogenesis.pdf. [Accessed: 22-Feb-2018].

[9] A. J. Mahmud, E. Olander, S. Eriksén, and B. J. Haglund, "Health communication in primary health care-A case study of ICT development for health promotion," *BMC Med. Inform. Decis. Mak.*, vol. 13, no. 1, p. 17, 2013.

[10] "Elderly care in Sweden," *sweden.se*, 14-Jun-2013. [Online]. Available: https://sweden.se/society/elderly-care-in-sweden/. [Accessed: 14-Feb-2018].

[11] V. Righi, S. Sayago, A. Rosales, S. M. Ferreira, and J. Blat, "Co-designing with a community of older learners for over 10 years by moving user-driven participation from the margin to the centre," *CoDesign*, vol. 14, no. 1, pp. 32–44, Jan. 2018.

[12] S. Eriksén, M. Hofflander, L. Nilsson, C. Borg, M. Georgsson, and J. Lundberg, "Transforming Healthcare Delivery: ICT Design for Self-Care of Type 2 Diabetes," *Des. Self-Care Everyday Life*, p. 17, 2014.

[13] D. King, F. Greaves, C. Exeter, and A. Darzi, "'Gamification': Influencing health behaviours with games," *J. R. Soc. Med.*, vol. 106, no. 3, pp. 76–78, Mar. 2013.

[14] S. S. R. Abidi, "Healthcare knowledge sharing: purpose, practices, and prospects," in *Healthcare Knowledge Management*, Springer, 2007, pp. 67–86.