Developing Advanced Technology Services for Diabetes Management: User Preferences in Europe

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Abstract. This paper analyzes the methodology and preliminary results of four focus groups conducted for the diabetes project Reaction, a four year European project that aims to develop an intelligent service platform for remote monitoring of glucose levels with diabetes management and therapy to patients in different healthcare regimes across Europe. The focus groups aimed to investigate opinions, concerns, issues and ideas about management of disease, technology services, privacy and confidentiality of people involved with diabetes. The focus groups were conducted in four different European countries to assist in the user centric design of the services to reach beyond the boundaries of the project.

Keywords: Focus groups, diabetes management, user preferences.

1 Introduction

Diabetes mellitus has reached worrying proportions in western countries making, diabetes one of the fastest growing chronic conditions in the world. Diabetes has been estimated to affect 60 million Europeans. Given the increasing trends towards sedentary lifestyles and obesity related problems, this number is expected to increase in the coming years.

Diabetes can cause many complications if the disease is not adequately controlled. Adequate treatment of diabetes, as well as increased emphasis on blood pressure control and lifestyle factors, may reduce the risk of long-term complications. Self-management of diabetes is an area that offers exceptionally good prospects, both in clinical and business terms [1]. Information and communication technologies (ICT) may offer useful capabilities to improve illness prevention and safety of care. ICT may facilitate active participation of patients and enable the personalisation of care, allowing new opportunities in health and disease management [2].

This paper analyzes the methodology and preliminary results of four focus groups conducted for the diabetes project REACTION[1]. REACTION is a four year European project that aims to develop an intelligent service platform for remote monitoring of glucose levels with diabetes management and therapy to patients in different healthcare regimes across Europe. The REACTION platform plans to execute various

[1] http://www.reactionproject.eu/news.php

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clinical applications, such as monitoring of vital signs, feedback provision to the point of care, integrative risk assessment, event and alarm handling as well as integration with clinical and organizational workflows and external Health Information Systems focusing on improvement of continuous blood glucose monitoring and tight/safe glycaemic control. Diabetic outpatients will be able to better control their disease, with prompt feedback from formal carers and medical systems and appropriate risk assessment services that can be deployed in any healthcare system in Europe. On the other hand, REACTION is expected to have an impact on formal carers in hospital wards by improving glycaemic control of admitted patients with diabetes using continuous blood glucose monitoring and therapy feedback.

The organization of the focus groups aims to be an exploratory study of user preferences beyond the boundaries of the project in four different European countries. It is a novel work in that it explores user preferences of technology features involved in diabetes management while the technologies are being implemented outside of the boundaries of the project. Rather than testing an already developed service, the study explores preferences about the REACTION services using end users who are not involved in the project. Also, the study offers an expanded view of technology management of diabetes that involves individualized care and cultural differences.

The focus groups examines what diabetic patients, nurses, doctors as well as healthcare professionals and informal carers expect from technology, in addition to identifying values, beliefs, hopes, concerns and needs related to the use of tele-monitoring services. Focus groups also highlight how the use of information technology could potentially change the experience of living with diabetes. Understanding societal factors is a core prerequisite for addressing ethical and social issues at the design stage of technology development.

2 Methodology

A series of four focus groups have been organized in different European countries between November 2010 and May 2011. The results of the focus groups are collected, analysed, and formulated in terms of requirements that give direction to the iterative design process. The main objective of the focus groups is to understand the relevant personal, social and cultural factors related to diabetes management and the REACTION services. In order to explore the potential impact of Reaction services beyond the boundaries of the project, focus groups were organized in European countries that do not participate in the clinical trials foreseen in the project. They took place in Greece, Italy, Cyprus and France with a range of participants including doctors, nurses, social scientists, technical personnel, patients, carers, nutritionists and lawyers. Each focus group included 6-8 participants. The questions that guided the discussions focused on several topics including information and risk management of diabetes, security privacy and confidentiality issues, quality of living, monitoring and alert systems, device and sensors design, technical skills, daily activities, concerns and suggestions. Discussions were informal, encouraging all participants to express their opinion and relate their experiences with diabetes care. Table 1 presents the focus group list.

Table 1. Focus group details

Focus Group	City & Country	Participants
1	Thessaloniki, Greece	2 doctors, 2 patients, 2 nurses, 1 carer
2	Florence, Italy	3 doctors, 2 patients, 1 dietician
3	Nicosia, Cyprus	3 doctors, 2 patients, 1 nurse, 2 carers
4	Paris, France	2 doctors, 2 patients, 1 nurse, 1 social scientist

The moderators of the focus groups guided the discussions and kept extensive notes as participants were expressing their opinions. Recording devices were not used and answers have not been attributed to specific participants in order to maintain confidentiality and privacy [3]. Data analysis of the focus groups includes translation of interviews conducted in Greek, to English, and identification of themes across European countries. Based on the analysis, suggestions and requirements will feed the iterative design process of REACTION services.

3 Results

Preliminary analysis of the focus group discussions identified several topics involved in diabetes and new technologies. Focus group participants discussed issues about autonomy and self-management, privacy and confidentiality, person – care provider relationship, and health management. The following paragraphs present some of the views and opinions of participants about these topics. Table 2 provides a summary of the results.

Table 2. Themes and participant opinions

Theme	Participant opinions
Autonomy & self-management	Technology as personal assistant & facilitator of autonomy Expanded medical view to include social & psychological management of diabetes Technology at affordable cost
Privacy & confidentiality	Complete disclosure of data to personal physician Need for encrypted data exchange Anonymized use of data for research purposes
Diabetic person – care provider relationship	Balanced exchange of information to avoid overload Technology as facilitator and not replacement of personal contact New models of care to include technology advancements
Health management	Perceived benefit will facilitate data entry Need for continuous motivational and psychological support to ensure compliance

Autonomy and self-management: A person who is afflicted with diabetes runs short and long term risks such as hypoglycaemia, ketoacidosis, retinopathy, nephropathy, cardiovascular disease. Technology can assist users to regain a measure of autonomy in managing their condition and preventing long term risks. Focus group participants also viewed technology as a potential personal assistant. An application on a mobile phone could be designed to provide personalized estimation of insulin needs, messages for motivation and support as well as alerts. Based on the opinion of a doctor involved in remote management of diabetes with a mobile application, continuous monitoring may not be essential for improved management of outpatient diabetes and could be seen as information overload without clear benefits. Participants expressed their view that diabetes is not just a physical condition, but also a social and psychological one. Participants felt that advances in technology design and functionality may improve not only the physical management of the disease but also the social and psychological one. However, they also believe that widespread availability of technology at an affordable cost and integration into the national health systems remain open issues.

Privacy and confidentiality: One of the objectives of data protection is to avoid the use of data concerning health for purposes different than disease management and, in particular, by someone who may abuse such information. At the same time, redirecting health data can be a successful part of the treatment of disease using remote monitoring systems. Focus group participants expressed their willingness to disclose all information relevant to their condition to their physician, without particular attention to how this information is transmitted. However, if they had the option they would like all information transmitted to be encrypted. Participants would like to be informed about who is seeing their data and are interested to be able to discern whether their information is shared with trustworthy persons and with someone who may abuse their data. However, participants were willing to allow their data to be used anonymously for research purposes. Participants with diabetes appeared less concerned about trust in the use of an internet platform in conveying personal medical information. However, they were concerned about downtime of devices, inaccuracy of advice and loss of personal information.

Diabetic person-care provider relationship: All participants expressed that diabetes management benefits from a close relationship between the person with diabetes and the health care provider team including the physician, nurses, nutritionist, psychology and others. Participants felt that technology may allow for a more accurate, faster response to crisis, as well as better overall management and prevention of complications. However, some participants felt that a careful balance between information and communication is important to avoid information overload and excess. Technology for diabetes management may bring about profound changes in self-care and empowerment of people with diabetes, as well as, in depth communication with the health providers. During the focus groups, it has been acknowledged that a model of care with the inclusion of technologies will be significantly different to the usual model of patient physician relationship of face to face interactions. Convenience, frequent monitoring, and better management are some perceived advantages offering increased autonomy, attention and guidance. While, less frequent face to face visits, potential downtime of services and impersonal care were perceived as possible disadvantages.

Health management: Management of diabetes requires specific information in predefined time intervals that coupled with personalized algorithms can assist in insulin dosage decisions. A technology platform for diabetes management would require frequent measurements and regular entries of data. Participant willingness for data entry depended on the perceived benefit of the technology services and the time that data entry would require. However, people with diabetes felt that parameters that affect management of their condition, such as emotional and psychological stress, menses, physical exercise, and variability of daily life, are more difficult to define, harder to monitor, predict and account for. A technology service that could take into consideration some of these parameters would be at a relative advantage compared to a service that uses only glucose measurements. In addition, participants felt that the amount of information required to be recorded and the ease of use of the technology services will play an important role in the acceptance and use of the services.

Further analysis is being conducted to investigate these themes for similarities and differences across countries.

4 Discussion

Information and communication technologies have the potential to change health care as well as life style for people with chronic conditions [4]. These changes are occurring concurrently and need to be considered for appropriate design of sensor-enhanced health information systems. Basic functionalities of technology services include emergency detection and alarm, disease management, health status feedback and advice [4] as well as social and psychological support. These functionalities are combined differently based on individual conditions as well as individual needs of chronic patients and their informal carers. Focus groups were conducted in four different countries to identify, needs, opinions and concerns of people directly involved with diabetes about technology services of diabetes care.

Common themes as well as differences are being investigated. Preliminary analysis reveals that management of diabetes is similar across countries. However, significant differences exist in the national health system support of diabetic patients. Differences also occur based on the cultural background of people with diabetes. Cultural background is involved in whether people are open about communicating their disease, asking for help and support, while others prefer secrecy, autonomy and self management with minimum social contact. Cultural differences also occurred in the organization of health care, care teams and patient doctor relationships. Further analysis is being conducted to explore different and common themes across countries in topics including perception of autonomy and the balancing of personal goals, protection of personal data, patient-care provider relationship, and health management.

Participants in general welcomed technology services for supporting diabetes self management and thought it would improve their quality of life, resulting in fewer complications. These findings are in accordance with those of other studies about technology management of chronic conditions [5, 6]. The introduction of new technologies into diabetes care would need to involve appropriate education and adjustment periods to ensure the motivational and psychological support of users. These practices are fundamental in enhancing use of technology services.

5 Conclusions

This paper has presented the methodology and preliminary results of four focus groups conducted in different European countries. The focus groups investigate management of diabetes across countries. Participants expressed their opinions, ideas, issues and concerns about monitoring and personalized feedback functions of technology services including device design, information management, privacy and confidentiality. Preliminary analysis shows that people with diabetes and their formal and informal carers are open to use new technologies for improving self-management of the condition, avoiding complications and enhancing the quality of their lives. The focus groups provide a way to reach beyond the boundaries of the REACTION project. Ideas and opinions expressed during the focus groups will be presented to the consortium to explore ways to incorporate them in the design of the REACTION services. Reaching out to the community during the development of a service provides is necessary in order to inform design and explore user preferences.

Further work is needed to explore formulate the themes addressed in the focus groups into requirements that could be implemented in the REACTION platform. Future work could explore opinions and ideas of a larger number of participants in other parts of Europe not covered in the current research. In addition, analysis of national health system diabetes management across Europe would provide an important foundation for exploitation of REACTION services.

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References

1. Farmer, A., Gibson, O., Tarassenko, L., Neil, A.: A systematic review of telemedicine interventions to support blood glucose self-monitoring in diabetes. Diabet. Med. (10), 1372–1378 (2005)
2. Fursse, J., Clarke, M., Jones, R., Khemka, S., Findlay, G.: Early experience in using telemonitoring for the management of chronic disease in primary care. J. Telemed. Telecare 14(3), 122–124 (2008)
3. Miles, M., Huberman, A.: Qualitative data analysis. Sage, London (1994)
4. Haux, R., Howe, J., Marschollek, M., Plischke, M., Wolf, K.-H.: Health-enabling technologies for pervasive health care: on services and ICT architecture paradigms. Informatics for Health and Social Care 33(2), 77–89 (2008)
5. Bostocka, Y., Hanleya, J., McGowna, D., Pinnocka, H., Padfielda, P., McKinstrya, B.: The acceptability to patients and professionals of remote blood pressure monitoring using mobile phones. Primary Health Care Research & Development 10(4), 299–308 (2009)
6. Verhoeven, F., van Gemert-Pijnen, L., Dijkstra, K., Nijland, N., Seydel, E., Steehouder, M.: The Contribution of Teleconsultation and Videoconferencing to Diabetes Care: A Systematic Literature Review. Journal of Medical Internet Research 9(5), 37 (2007)