

How mHealth can facilitate collaboration in diabetes care: qualitative analysis of co-design workshops

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Abstract

Background: Individuals with diabetes are using mobile health (mHealth) to make and track their decisions regarding self-management. However, individuals can understand even more about their diabetes by sharing these patient-gathered data (PGD) with health professionals. We conducted experience-based co-design (EBCD) workshops, with the aim of gathering end-users' needs and expectations for a PGD-sharing system.

Methods: The first workshop (2017) included patients with Type 2 Diabetes (T2D) (n=4) and general practitioners (GPs) (n=3). The second workshop (2018) included patients with Type 1 Diabetes (T1D) (n=5), diabetes specialists (n=2) and a nurse. The workshops involved two sessions: separate morning sessions for patients and healthcare providers (HCPs), followed by a joint lunch and afternoon session for all participants together. A discussion guide was used to gather input regarding end-users' expectations for the system. Participants then created and explained their own ideas for a data-sharing system, using paper-prototypes. Workshops were audio recorded, transcribed and translated from Norwegian to English. Inductive thematic analysis was performed.

Results: The main emergent themes were mHealth technologies' impacts on end-users, and functionalities of a data-sharing system. Patients and providers agreed that PGD could be used by HCPs to provide more concrete self-management recommendations. Participants made paper-prototypes to explain which data types to gather and display, and how the systems could be used to facilitate shared-decision making. However, all also agreed that a data-sharing system alone was not enough to achieve the full effect of mHealth.

Conclusion: Participants' feedback revealed that both patients and HCPs alike acknowledge that for mHealth integration to be successful, not only must the technology be validated but feasible changes throughout the healthcare education and practice must be addressed. Only then can both sides be adequately prepared for mHealth data-sharing in diabetes consultations. Subsequently, the design of the joint workshop sessions demonstrated that involving both participant groups in the same sessions led to efficient and concrete discussions about realistic solutions and limitations of sharing mHealth data in consultations.

Background

As a medical society, we have increased our knowledge about diabetes beyond managing the cornerstones of self-management: blood glucose, physical activity, medication and diet. In recent years, we have unmasked the effects of less well-known factors as sleep, stress or even temperature, on blood glucose levels[1]. While it is theoretically ideal to understand all factors that affect a disease, in order to effectively treat it, it also inadvertently puts added pressure on healthcare providers (HCPs) and patients to not only track these complex interactions but also understand and react to them. In fact, it was only 50 years ago that patients were even given the ability to check their blood glucose at home, with the

invention of the first commercial glucose meter[2]. Since then, medical devices for diabetes have been developed alongside the necessary systemic changes to the medical system that are required to effectively use such new technology. However, this trend has shifted as commercial technology, such as mobile health (mHealth) apps and devices, now offer patients the ability to easily track all of the indicated disease factors that are expected of them, often without oversight from medical professionals[3].

Lately, the use of mHealth technologies has become common practice for diabetes self-management[4]. Patients are now able to track how decisions affect their health and learn how to react in the best way for them[5]. For example, by connecting one's smartphone app to a blood glucose meter and wearable activity tracker, one can automatically combine blood glucose levels with how far and fast they ran as well as manually entered food and medication intake. Such measures are considered patient-gathered data (PGD) and allow a user to track how their self-management activities affect their health outcomes. With this stored history, the next time an individual chooses to undergo a similar combination of activities, they could easily identify how they chose to eat or what dose of insulin was effective or not for that situation. However, this information is only effective if used correctly; not everyone is able to process and make connections for all of this information on their own. Therefore, while mHealth provides clear potential benefits, there is only so much most individuals can understand without the complementary medical knowledge of the disease itself. This is where the potential of sharing one's own data from their mHealth tools with HCPs can benefit both the patient's understanding of their own health and the provider's understanding of how to best practice personalized and evidence-based medicine.

Unfortunately, when it comes to introducing mHealth and PGD in the clinic, both parties have concerns and unanswered questions. Despite the highly reported potential of PGD to save time during consultations and provide greater insights regarding the patient's health, providers have noted concerns with data overload, liability, interoperability with their own IT systems, and how to use the data for decision-making[6]. Patients are concerned with what to share and how providers can effectively use this information to give personalized health recommendations[7]. Despite a growing effort to research these technologies, most research focuses on exploring the topics of technical security, privacy and policy issues[8], with little focus on how both patients and providers can use PGD together. This is not only due to the concerns and questions mentioned above but also because the gap in disease knowledge between patients and providers has traditionally been too great[9].

However, even more recently, mHealth has added a new dimension of health self-management and fostered an additional form of expertise. In fact, in the field of mHealth, patients' have become vastly more knowledgeable, even considered as "experts" by some[10]. By gaining insight into their own disease self-management, patients are now more capable of bringing this understanding and PDG, as evidence, to consultation discussions with their providers[11, 12]. Therefore, there is a need for systems to provide information that can be understood and used by patients and providers, together. Further, tools for using PGD should facilitate collaboration between patients and clinicians to enhance the patients' ability to manage their own health on a daily basis. Previous studies in the field of health technology have

provided knowledge regarding the needs of data integration and patients' and HCPs' expectations and their needs from data-sharing technologies. However, the majority of these studies have gathered information from patients[13] and providers[14] separately. However, other studies also show that when both end-user groups were engaged together in development discussions, more concrete and realistic solutions can be identified[15].

Experience-based co-design (EBCD) (hereby referred to as co-design) allows patients, and providers to impose their collaborative insights on the design and development of tools and services[18]. Unfortunately, many "patient-centred" research efforts do not always involve patients or end-users in design, and/or development of care interventions or services[16, 17]. By considering patients as "experts" in their own self-management and providers as, of course, experts in the disease mechanics, both parties then have the ability to bring complementary knowledge and skills to diabetes care. Ideally, this is considered the process of shared decision-making, which is characterized by providers and patients collaborating to make decisions about the patient's health, with a balanced focus on both hard clinical evidence as well as the patient's priorities and values[19]. This suggests the necessity of engaging both main end-users in co-design to design and develop the technology that they will use, together[20].

In this paper, we present the qualitative analysis of transcripts and paper-prototypes from two co-design workshops involving both patients and HCPs regarding the design of a system to share patient-gathered diabetes self-management data during consultations. These workshops were conducted as part of a larger research project to create and test a system for sharing PGD between patients and providers, called the "Full Flow of Data Between Patients and Healthcare Services" project (2016-2020)[21]. Previous workshops within the same research project reported the differences in self-management foci and challenges between those with T1D and T2D, as well as differences in how specialists and GPs meet their patients and their clinical practice needs. These results were published elsewhere [22]. In this paper we focus on our end-users' intentions for the use of, needed functionalities and ideal discussion based upon data presented by such a data-sharing system.

Objective

By arranging two co-design workshops, where patients and HCP together discuss expectations and design ideas for an mHealth data-sharing system for diabetes, we aim to understand how a system can present patient-gathered mHealth data and be used effectively by both parties to facilitate shared-decision making and collaboration in diabetes care.

Methods

Co-design workshops

Two co-design workshops were conducted with the aim of inviting both stakeholder groups to discuss the concept of sharing and using patient-gathered diabetes self-management data. The first involved

patients with type 2 diabetes (T2D) (n=4) and GPs (n=3) (2017) and the second involved patients with type 1 diabetes (T1D) (n=5), diabetes specialists (n=2) and a nurse (2018).

Participants were invited to attend the workshops at the Siva Innovation Centre in Tromsø, Norway. The workshops were held in Norwegian, the participants' native language. Convenience sampling was used to expedite recruitment and draw from a population with experience or interest in the particular field of mHealth for diabetes self-management. Patients were recruited by messages sent through the Diabetes Diary app[23], which is available on Google Play app store. At the time of recruitment, there were approximately 7000 downloads of this app in Norway. Patient participants had to be 18+ years with either T1D or T2D and be willing to travel to Tromsø, Norway for the workshop. All who expressed interest and met inclusion criteria were included. All participants presented a signed consent form prior to the workshop. HCPs, who currently see patients with diabetes, were recruited via e-mail requests. Participants were given the option to withdraw their participation at any time.

During each daylong workshop, patients and clinicians were split into their respective groups in the morning. Following a common lunch, all participants were combined for a joint session in the afternoon. The intention of joining both groups was to allow participants to present their views to each other and to discuss and correct assumptions and expectations regarding mHealth technologies and data-sharing during consultations. A moderator used a semi-structured discussion guide, which was developed by the co-authors (see Additional file 1).

Participants first filled out post-it notes in response to questions, presented them orally to the group and then placed the notes on a poster-board, allowing them to form their own opinions before engaging in group discussions. The poster board was split into three main sections: one for the patient session, one for the provider session, and one for the joint session. Next, each participant was asked to create, and then describe how to use, his or her own paper-prototype of an ideal data-sharing system. Paper cut-outs that represented functionalities and features of the system's interface were provided. These included cartoon representations of data sources, such as mobile phones, wearables and sensors, data types, such as blood glucose and physical activity, how to display data, such as graphs, arrows and scales, and the main computer screen, through which the system is meant to be accessed.

Single-page summaries were made by the research team, within a month following each co-design workshop, and sent to all participants. Participants were encouraged to correct these reports, comment or ask any additional questions before further data analysis was performed.

All of the sessions were audio recorded, transcribed and translated into English, and de-identified by a native Norwegian speaker. Narrative summaries for each of the six co-design sessions were discussed amongst the other co-authors, followed by open-ended discussions to ensure collective understanding of the transcripts. Grounded theory was used to iteratively and inductively identify codes within the transcripts, which were then grouped into progressively higher-level themes. Analysis followed the three stages of grounded theory[24]: 1) open coding, using short descriptive phrases, was applied to each paragraph of text within three of the six transcripts as a means to establish mutual understanding of the

transcripts. 2) iterations of axial coding, whereby similar codes were grouped under common sub-themes and then overall themes, were used to note relationships between emergent concepts. Finally, 3) selective coding focused the analysis on relevant quotations and paper-prototypes that related to shared-decision making between patients and providers across the transcripts. An example of this process is provided in Table 1. Quotations will be formatted with brackets indicating omitted words, e.g. “it”, “they”, that are replaced with the words to which these articles refer[25]. Citations will be formatting to include the session type, i.e. patient, HCP or joint, followed by the participant type, i.e. T1Dpatient, T2Dpatient, GP or Specialist, and speaker number for that session. Therefore the following citation: (Joint_T1DPatient#3) would indicate a quotation from a T1D patient during a joint session.

Table 1. Process (left to right) of categorizing quotable text from the transcript into codes, followed by the grouping of codes into progressively higher-level themes.

Session_Person	Quotation from transcript	Codes	Sub-themes	Theme
HCP_Specialist#2	“Could you possibly assimilate so much data? Shouldn’t you pick out [and show] some very relevant data and have a few data instead of having 20? How much data can you incorporate into a [15-minute] consultation?”	<ul style="list-style-type: none"> · Question: how much data can incorporate into consultation? · Preference to see selected/relevant data 	<ul style="list-style-type: none"> · Which data to share/look at · Time capacity of consultations 	Data-sharing (concerns)

Results

Co-design workshops

Seven individuals attended the first co-design workshop, related to T2D, and eight individuals attended the second workshop, related to T1D. While it was not required for participants to offer these information, as the focus was on development of the data-sharing system, some did offer some personal information when asked introductory and ice-breaker questions. The available details are provided in Table 2. HCPs offered only basic information about themselves before offering their opinions of mHealth and data-sharing (Table 3).

Table 2. Demographics of T1D and T2D patient participants in both co-design workshops

Diabetes type _Patient#	Gender	Age range (yrs)	Duration of diabetes (yrs)	Reported technology used	Reported self-management foci
T1D_Patient#1	F	40-50	N/A	N/A	N/A
T1D_Patient#2	M	20-30	2	Apps, insulin pen	Physical activity, BG
T1D_Patient#3	M	50-60	N/A	Insulin pump, CGM, app	BG, physical activity, insulin, carbohydrates
T1D_Patient#4	M	40-50	38	Insulin pen, app	BG, insulin
T1D_Patient#5			N/A	App, insulin pen	BG, physical activity, sick days, insulin, diet
T1D_Patient#6	M	60-70	8	Smartwatch, insulin pen	Physical activity, insulin, BG
T2D_Patient#1	M	60+	N/A	Paper diary, app	BG, physical activity, diet
T2D_Patient#2	M	60+	N/A	BG meter, insulin pen, paper diary, app	Diet, medications (non- diabetes related), insulin, physical activity
T2D_Patient#3	M	60+	N/A	BG meter, app	Diet, physical activity, well- being
T2D_Patient#4	M	60+	N/A*	BG meter, paper diary	BG, input from doctor

*Participant stated that they were “in the introduction phase” of their diabetes

Table 3. Demographics of participating HCPs in both co-design workshops

Provider#	Gender	Age range (yrs)
Specialist#2	M	50-60
Specialist#1	F	60-70
Nurse	F	30-40
GP#1	M	50+
GP#2	F	30-40
GP#3	F	50+

While those with T1D and T2D differed in the specific answers they would like to gain from sharing their data, their motivations for using mHealth and the need for more frequent support from healthcare

services were similar. Likewise, specialists and GPs expected different functionalities and specific information from PGD, yet both expressed frustration with not knowing how to relate to the different mHealth technologies and desired similar levels of engagement and responsibility from their patients.

Main themes identified

Across the workshops, the two main themes were: 1) mHealth technologies' impact on patients and providers, with subthemes concerning both groups' use of patient-gathered data and roles and responsibilities, and 2) data-sharing, with subthemes concerning Expectations of sharing and receiving PGD during consultations, when, what and how to share PGD, electronic health record (EHR) integration and concerns.

Theme 1: mHealth technologies' impacts on patients and providers

As mHealth tools allow patients to monitor more than a single parameter, patients are more able to understand how internal and external factors together affect their health. "Diabetes doesn't happen in a container. There are other things around it." [Patient_T1Dpatient#3].

Subtheme 1A: Use of mHealth and patient-gathered data

Most participants with T1D stated that they used mHealth technologies to review historical self-registered data in order to find patterns in their data. One T1D participant stated, "Data collecting gives you experience...If you track the data and get a curve" [Patient_T1Dpatient#3]. Another added that "we can go back and look at similar situations or essential things. I rarely eat ice cream so I can go back and look at how much insulin I took then, and how [my BG] was afterwards." [Patient_T1Dpatient#5]. Patients concluded that this helped them to "spend less time and energy on self-managing" [Patient_T1Dpatient#2].

Similarly, participants with T2D stated "I use [PGD] for control" [Patient_T2Dpatient#3] and they found benefits when "evaluating the measurements - the results for stress level, drinks, and such. I tried to find the causes for high blood glucose...to compare the days, sometimes a month sometimes three months between the evaluations" [Patient_T2Dpatient#2].

However, some were frustrated with the lack of support from the healthcare system, asking, "where is the course where I can learn as a patient? I take more responsibility for my own health when using mHealth tools...[and get] a better overview...But even though I know a lot...I want to know more and I want to do better" (Joint_T1Dpatient#1).

Providers agreed that mHealth technology should aid the patient first in their own self-management, that the "use of technology needs to create patient action." [HCP_Specialist#1]. Especially given that healthcare personnel struggle to provide detailed recommendations in such a short period of time, all seemed to agree that, "We want these sort of [patient-gathered] data to be self learning technology" (HCP_Specialist#1).

Subtheme 1B: Roles and responsibilities

Specialists asserted that even before they could consider discussing patient responsibilities they are making judgements about patients' ability to use the technology, "we have to start differently and expect differently from our patients. So this is about individualization of treatment" (HCP_Specialist#1). Especially regarding the use of mobile health devices, one specialist stated that, "For some individuals, I put a [continuous glucose monitor] on them and say "you are supposed to use it" while others, I keep it away from them" (HCP_Specialist#2), because not all technology is useful or appropriate for everyone.

After establishing that they would be focusing their discussion on the specific subset of patients who use mHealth technologies, HCPs stated that they expect patients "to make the appointments, and to bring some own generated data" (HCP_Specialist#2) and then to "be prepared for the consultation. Because we have so little time" (HCP_Specialist#1). However, if the patient has not reviewed or attempted to understand their own-generated data before sharing it with the doctor, "then it's useless" (HCP_Specialist#2). The expectation of the HCPs was that patients are to be active in using and understanding the data they generate to foster the discussion because of the limits of their time to interpret the volume of individual data that can be generated.

Both GPs and specialists commonly emphasized, "We can't change anything, we can just give advice. The data by itself needs to help the patients to do the best thing...because our task is to be advisors" (HCP_Specialist#1). Another expressed that, "they are our pupils, and we're their teachers and when they do homework, of course I want to see what they've done. And then...I can begin to give some advice" (HCP_GP#3).

Patients saw that their "role [in sharing data] could be to be more exact in documenting information, such as diet, physical activity and everything that can help the GP confirm where I am in the process" (Patient_T2Dpatient#2). Others acknowledged, "you have to take responsibility for the things not being done by healthcare...you have to follow up yourself" (Patient_T1Dpatient#3). This difference in role from passive data-collectors to active interpreters similarly reflects the concerns of the HCP above in the different understandings and roles that patients may adopt which may limit or support the use of technology in consultations.

Regarding their expectations of HCPs, all patients wished for more detailed, individualized feedback. For example, "more specific answers on situations and questions when I am in meeting with the nurse. I have sometimes questions about different situations... two similar situations can become two completely different ones. [And the nurses] never has any good answers" (Patient_T1Dpatient #5). More importantly, was the immediacy of their concerns, urging that they "wish for answers right then, not three months later" (Patient_T1Dpatient #3).

However, participants with T2D believed that GP's "really lack the knowledge in which we diabetics struggle with [because they] do not have enough education to cope with those specific health issues" (Patient_T2Dpatient#2). One patient considered alternatively that, "there are also diabetes nurses...they

can maybe give more input about what you should do and not do...Let the doctor take the more serious, while nurses help along the way” (Patient_T2Dpatient #5). Here, by demonstrating their different expectations toward various HCPs, patient participants also highlighted that they value the HCPs as supporters and educators in diabetes care. However, they also note that this value is based upon HCPs’ understanding of the patients’ everyday reality of living with diabetes.

Theme 2: Data-sharing system

Subtheme 2A: Expectations of sharing and receiving PGD during consultations

During the discussion of participants’ ideal data-sharing systems, one patient noted that, “maybe [HCPs] can help me more if they see that there’s a reoccurring problem...if I’m high during the evening...we can try to talk more specifically” (Patient_T1Dpatient #4). Based on their own experience, another patient noted that, “the [HCPs] could interpret data with the knowledge they have and then give specific tips and feedback on the data...I do feel I get specific tips with things [the HCPs] extract through the data which I don’t feel like I see myself. I’ve gotten advice that works” (Patient_T1Dpatient #2).

Two GPs echoed one another with regards to the fact that data would be easier to understand and interpret if the data were presented in a summative form that provided specific and relevant information first. “If the patient comes with [PGD] and it is easy to understand” (HCP_GP#2), because “specific information will save us time. Instead of trying and trying to make people tell us” (HCP_GP#1).

Subtheme 2B: When to share data

Patients and providers disagreed about when was an appropriate time to share PGD. Patients believed, for example, that “if I could say that now I’m struggling with something, and question if you [the HCP] could connect up and see the data...easier than booking an appointment” (Patient_T1Dpatient#2). The alternative was to have “data already be shown for the doctor before a consultation, so we have a baseline....To not waste time” (Joint_T2Dpatient#1).

GPs, on the other hand, were the most vocal about patients being prepared and presenting their data in-person during the consultation, otherwise, “without the patients, it is not useful. The patients should be there to use it for discussion and planning...knowing what’s going on” (HCP_GP#2). One GP asserted that they did “NOT want [PGD] in advance [of the consultation]” (Joint_GP#3). For the GP participants in general, data on its own was of limited meaning without the patient being there to provide context to aid interpretation.

However, during the T2D joint session, all agreed that data was important to share, for example, “if [the situation is] suddenly changing, the values go up or down, their health situation is getting worse or something, it could be okay to have more values, to see what is actually happening” (HCP_GP#1).

Subtheme 2C: What and how to display data

Patients were aware that not all data was equally as relevant: “I can collect irrelevant data - I can gather data about my own situation that may not be relevant for doctors” (Joint_T2Dpatient#4). In terms of specific data types, specialists wanted PGD that reflected “an intensive period [worth of data], maybe some days or weeks before they come to me because I want to see variation. And document pretty carefully...Then we can see the context...So these very like, these short, tiny, detailed periods is very valuable for me even if it’s not representative for the long life” (Joint_Specialists#1).

Suggestions from both patients and providers were similar in that they would like a system that summarized the PGD, with the option of choose which data to explore further when trends or outlier points were identified. One specialist “would first like to see the fluctuation over 24hours - it’s the most important for me. Then have a look at some data because there was something special going on” (HCP_Specialist#1).

The other specialist presented a system that showed trends for “the last week or 14 days...where you can see meals, calibrations - to see that you calibrate correctly - physical activity and illness...to explain why you are high the whole night, and of course insulin doses. Additionally, if the algorithm can pull statistics and say “ok, you are always low after correcting extra” or such things” (Joint_Specialist#2).

GP’s were more varied in their paper-prototypes. Some illustrated a “type of compressed summary...Instead of having to look at a thousand measurements” (Joint_GP#3). Others “tried to get in everything at once [to] see a correlation if you have [different PGD] together...You won’t bother to plot it every day, but rather if it was something special, [you’d have] a marker of some sort” (Joint_GP#1).

The paper-prototypes designed by both groups of patients, with T1D and T2D, illustrated their wish for feedback about their progress, for example, suggesting “we could get a sign on the graphs...maybe statistics on how the blood glucose is...in the evenings or afternoons” (Joint_T1Dpatient#5). Patients also wished to be able to explore and understand their own data first by “just having summaries of the data, and then click on blood to get [more details]...what you’ve done that day and time and all. Everything in a submenu of the main” (Joint, T2Dpatient#2).

Subtheme 2D: Electronic health record integration

Different types of HCPs preferred different ways of accessing and integrating the data into their everyday practice. Specialists were open to “automatically getting the continuous glucose values for the last week, into my electronic diabetes journal system... and the use of insulin or automated data easily, visually presented” (HCP_Specialist#1). However, GPs argued that, “we don’t need to load into the EHRs, because there are many problems and overload of information. And, why should we keep it? (HCP_GP#3). Instead, GPs preferred “to type [notes about PGD] myself...write it short. Reminder [to focus on this] for next time” (HCP_GP#3).

Subtheme 2E: Concerns

Despite participants' optimism and the potential that they saw with sharing PGD, HCPs consistently noted their concerns that "it's always a chance of overload...a whole lot of data. We can't relate to it" (HCP_GP#1). One specialist's thoughts of automatic data-transfer into the EHRs was "please stop it! Because if you are the patient and I get your data continuously for your whole life on my screen, then if you have a traffic accident with hypoglycaemia it's my responsibility because I should have seen that last week you had several hypoglycaemias" (HCP_Specialist#1).

Of particular concern for specialists was resource management. Continuous data transfer potentially meant the need "to have a diabetes nurse continuously, 24 hours-a-day, checking on continuous glucose monitors (CGMs) like we do with hospital patients. We don't have resources for this" (HCP_Specialist#1). And for patients with CGMs "10% use the CGM. Then those patients get much more consultations with the nurses because they need to be taught the CGM, they need follow-ups. So this small group...maybe they use 80% of the nurses' time" (HCP_Specialist#2).

Even patients were concerned with data-overload because when they have "a lot of data...I get little use out of meeting diabetes nurse. Last time she said it wasn't much she could help me with" (Patient_T1Dpatient #3).

Discussion

The co-design workshops focused on one option for integrating mHealth as a supportive tool for diabetes care – a system for sharing patient-gathered mHealth data during consultations. We aimed to address what it would take to make the collaboration between patients and healthcare providers over PGD possible and useful for all users. All participants provided an overall optimistic view of sharing and receiving patient-gathered data during consultations for better diabetes care. Although patients and providers did disagree about some topics, such as whether to share data before or during the consultation, both agreed that the ideal way to review the data was to begin with an overview. For example, when discussing paper-prototypes, most described the presentation of PGD in a summary on the first screen of the system, with the option to select more detailed views and combinations of information on subsequent screens. In doing so, this could facilitate shared decision making whereby both parties could choose which data to look at, and then agree upon feasible solutions together. This differs from many commercial options or other tested interventions available at the time, whereby the responsibility and ability to interpret the data and make decisions is one-sided - either skewed toward patient self-management, such as Google's Google Fit, or clinical monitoring or oversight of a patient such as most CGMs [26]. In either of these cases, the type of information presented is tailored to one intended user, not both parties in diabetes care. For example, an individual with T1D would like to see, in detail, how each type of food affected their BG levels to meet their goals, whereas an HCP may prefer to see summaries of data such as medication use and response, which can then be compared to lab results. The presented results support the notion that this is not as effective as identifying common needs of both parties and designing systems to support those.

However, both patients and providers also noted the obvious limitation of healthcare services today. While much emphasis was placed on how both parties could use the data, all also demonstrated an understanding of one another's limitations and needs regarding data-sharing. We learned that while patients may hope that providers can relate to and interpret PGD, providers were quick to explain that it is an unrealistic expectation because the healthcare system does not provide resources to teach providers about how to discuss the various mHealth technologies in care practice.

These sentiments are not limited to these workshops; our participants echoed other international examples whereby similar limitations and needs, for such data-sharing systems to take into account the context, relationships and additional workload expected from patients and HCPs, were noted. For example, our participants with T2D argued that GPs need more support from their employers and work environment to effectively integrate mHealth data into health practices. Similarly, a qualitative study by Sanders et al. revealed that major barriers to mHealth uptake in clinical care were largely due to concerns that such uptake would interfere with existing health care services[27].

These arguments bring up another important point - much attention in mHealth intervention research is placed on the barriers of acceptance and hypothetical facilitators[28-30], and less on practical solutions to not only use PGD but moreover to consider services that could support the use of PGD and mHealth.

“Increased knowledge clearly implies increased responsibility.”

- Nicolaas Bloembergen[31]

As researchers and healthcare providers working with diabetes, we must remember that if we suggest systems that provide new information and knowledge, we also have the responsibility to investigate how to support the use of the information appropriately. Patients are being given more information about what influences their diabetes, followed by the expectation to then incorporate that knowledge into their everyday lives. It is inevitable that they turn to options - such as mHealth technologies - that are capable of giving them the ability to meet this new expectation.

However, while trends in social media and the news imply that mHealth apps and technologies are replacing traditional healthcare, with the Do-It-Yourself movement and online patient support groups as powerful examples[32, 33], the presented co-design workshops demonstrated something slightly different. While these results, and other studies in recent years, emphasize the trend of “The Quantified Self Movement”, whereby patients are using personal mHealth technologies to better understand how their actions and lifestyles affected their diabetes management, on their own[34], they still wished to consult with, and valued, medical professionals[7]. Moreover, while our participants noted that a data-sharing system alone was not enough to make mHealth integration a reality, they were equally eager to share their ideas for supplemental healthcare resources that could provide the time and explanation of PGD and mHealth that patients desired from the healthcare field. In fact, while research has been focusing on developing and testing individual mHealth and data-sharing interventions, few organizations have been developing frameworks and guidelines for mHealth integration, such as the WHO's MAPS

Toolkit[35] and the U.S. Department of Defence's Mobile Health Practice Guide[36]. Like our participants, these frameworks emphasize the need for healthcare systems to invest resources in development and training toward integration of PGD, mHealth and clinical practice by offering comprehensive strategies for mHealth integration.

With respect to the research method itself, it is important to note that these presented results highlighted a significant difference, and challenge, of mHealth research compared to traditional research. Traditional research on medical devices and interventions follows a thorough, focused and lengthy process. Spending much time on these interventions options is expected and healthcare providers, thanks to the validated and trusted methods of inquiry, accept the results. However, mHealth research requires a more user-involved, comprehensive and rapid approach. It calls for not only validation of the technology – which still lacks a standard process, but at the same time, the production of feasible options for integration into medical system workflows. Therefore, we as researchers must re-evaluate how best to perform research that answers traditional questions, e.g. hard health outcomes, as well as those that are unique to mHealth and personal health alternatives, e.g. displaying data that both healthcare providers and patient, as experts in their own health, can understand. This includes taking advantage of new resources, e.g. expert patients in mHealth and social media, and more actively collaborating with healthcare authorities and organizations to determine feasible health service options to support mHealth integration for both patients and practitioners. Many co-design workshops do involve patients and HCPs. However, they do so most commonly in separate sessions [37]. In research practice, the interpretation of the resulting participant feedback, especially about similar topics, would have to be inferred rather than explicitly stated. In other words, there is limited or no possibility for participants in different groups to correct one another's assumptions. We hope that by demonstrating the type of realistic and collaborative suggestions that can be gained by allowing both patients and HCPs to discuss solutions together, this method for EBCD could become more common in mHealth intervention research.

Study limitations

Limitations of these workshops resulted mainly from the convenience sampling from such a small geographical location. One resulting weakness was a lack of gender balance amongst our participants. While we aimed to recruit equal numbers of male and female participants, few female participants were able to come, especially during the T2D patient session, in which there were only men. The convenience sampling also relied on recruiting patients through the in-house developed Diabetes Diary app and therefore already engaged in mHealth for diabetes. The benefit of focusing on such participants was that such a group would be likely to consider sharing their app data with their HCPs and would ideally know what they would want from a system designed to do so. However, we do acknowledge that a resulting limitation of this is that these participants were not representative of all patients with diabetes. Patient participants also reported that they were unfamiliar with the co-design process. Further, discussion guide questions focused on data, technology and healthcare consultations, not on the demographics of the participants. This led to a lack of information about duration of diabetes, exact age, HbA1c, education

and other potentially relevant factors, nor the differences between T1D and T2D therein. Participants also expressed that they would have rather had concrete examples of data-sharing systems to comment on instead of conceptually building them from scratch. We aim to address this weakness by focusing on more concrete and straight forward workshop and question design in future workshops.

Conclusion

These co-design workshops have demonstrated the importance and value of including both patients and healthcare professionals in designing a system for integration of PGD during consultations. Future design efforts should focus on designing a system that provides mutually understandable and relevant information to facilitate the best collaboration in diabetes care. In addition, the healthcare system should consider support services and resources surrounding mHealth and PGD integration, such as topic-specific education for providers and additional vetted information and services for patients about how to use mHealth optimally outside of the consultation.

Declarations

Ethics approval and consent to participate

The co-design workshops were found to be expect from the purview of the Norwegian Regional Committee for Medical and Health Research Ethics (REC) committee (ref. no 2017/1759). They were instead acknowledged by the Data Protection Officer (Personvernombud) at the University Hospital of North Norway, September 2017 (ref. no 2017/5235). Consent to participate was gathered by each participants prior to the start of each workshop.

Consent for publication

Not applicable.

Availability of data and material

Due to the small population from which the participants were recruited, we believe that sharing the transcripts would be exposing too much identifiable information. Therefore, we will not be making the data openly available.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

MB, RM and EÅ created the discussion guides. EÅ and MB conducted the recruitment, workshops and follow-up as well as created all material used therein. EÅ served as the moderator of the sessions. MB and AG served as facilitators of activities during the workshop sessions. MB, EÅ and RM discussed the transcripts and main themes for analysis. MB performed thematic analysis of the transcripts and paper-prototypes. AG provided input on the questions asked in the discussion guides and co-moderated one of the workshop sessions. All authors read and approved the final manuscript.

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Abbreviations

mHealth Mobile health

PGD Patient-gathered data

T1D Type 1 Diabetes

T2D	Type 2 Diabetes
EBCD	Experience-based Co-design
HCP	Health Care Provider
GP	General practitioner
EHR	Electronic Health Record
CGM	Continuous glucose monitor

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Figures



Figure 1

Post-it notes and paper-prototypes resulting from the first co-design workshop illustrating the T2D patients' and GPs' situations and their expectations of a system for sharing patient-gathered data.

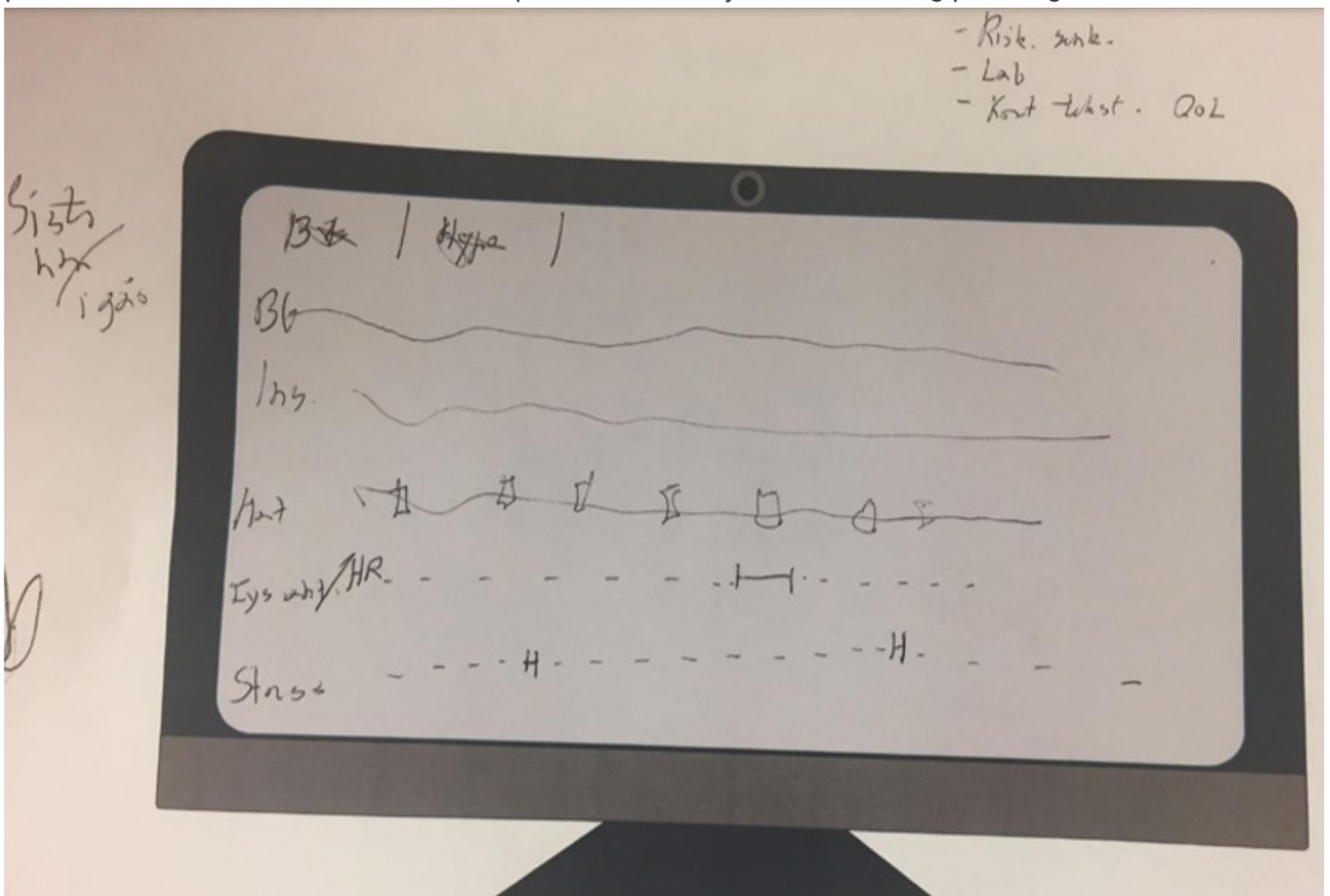


Figure 2

Specialist#1's paper-prototype for an ideal data-sharing system display

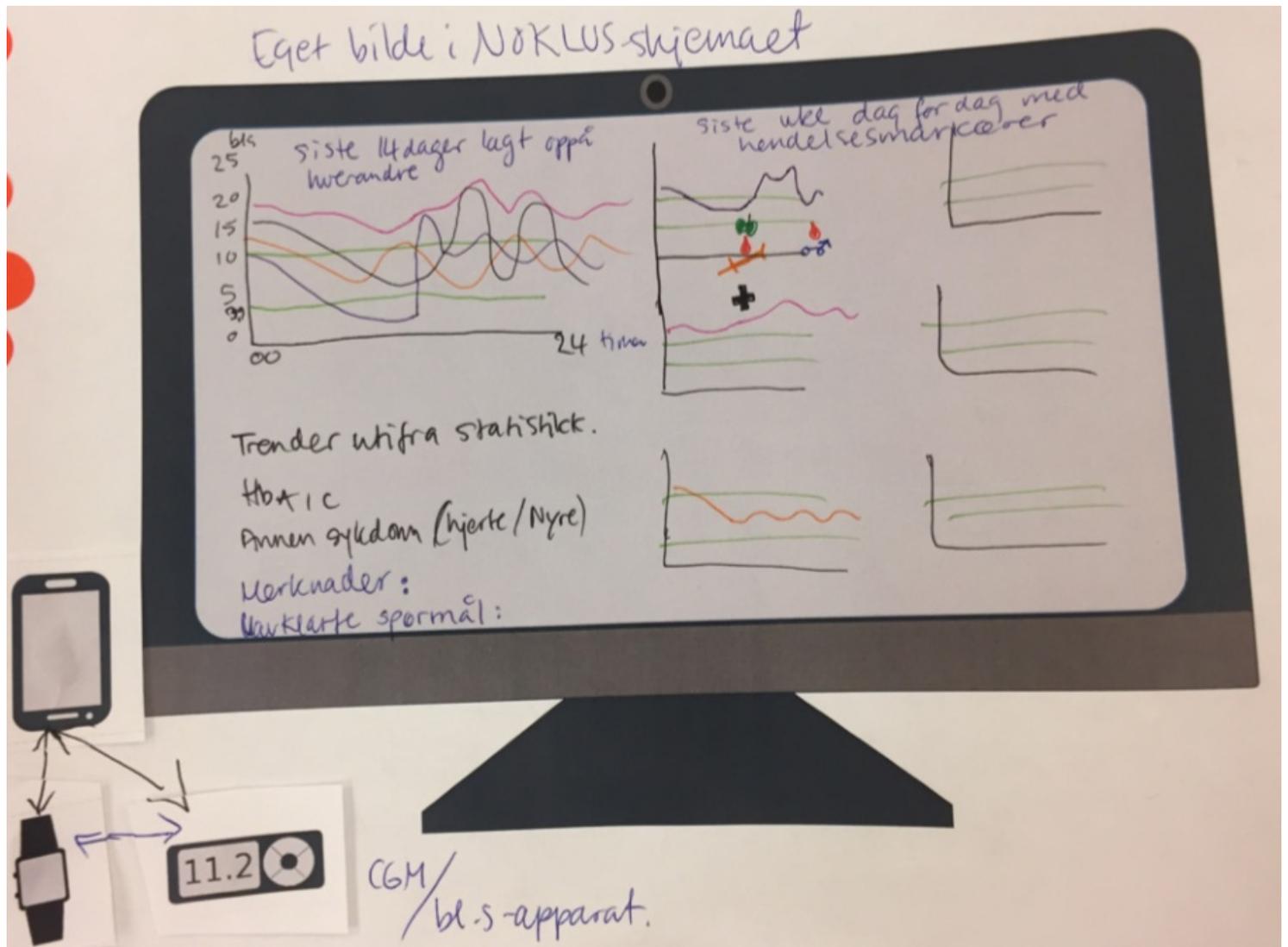


Figure 3

Specialist#2's paper-prototype for an ideal data-sharing system display

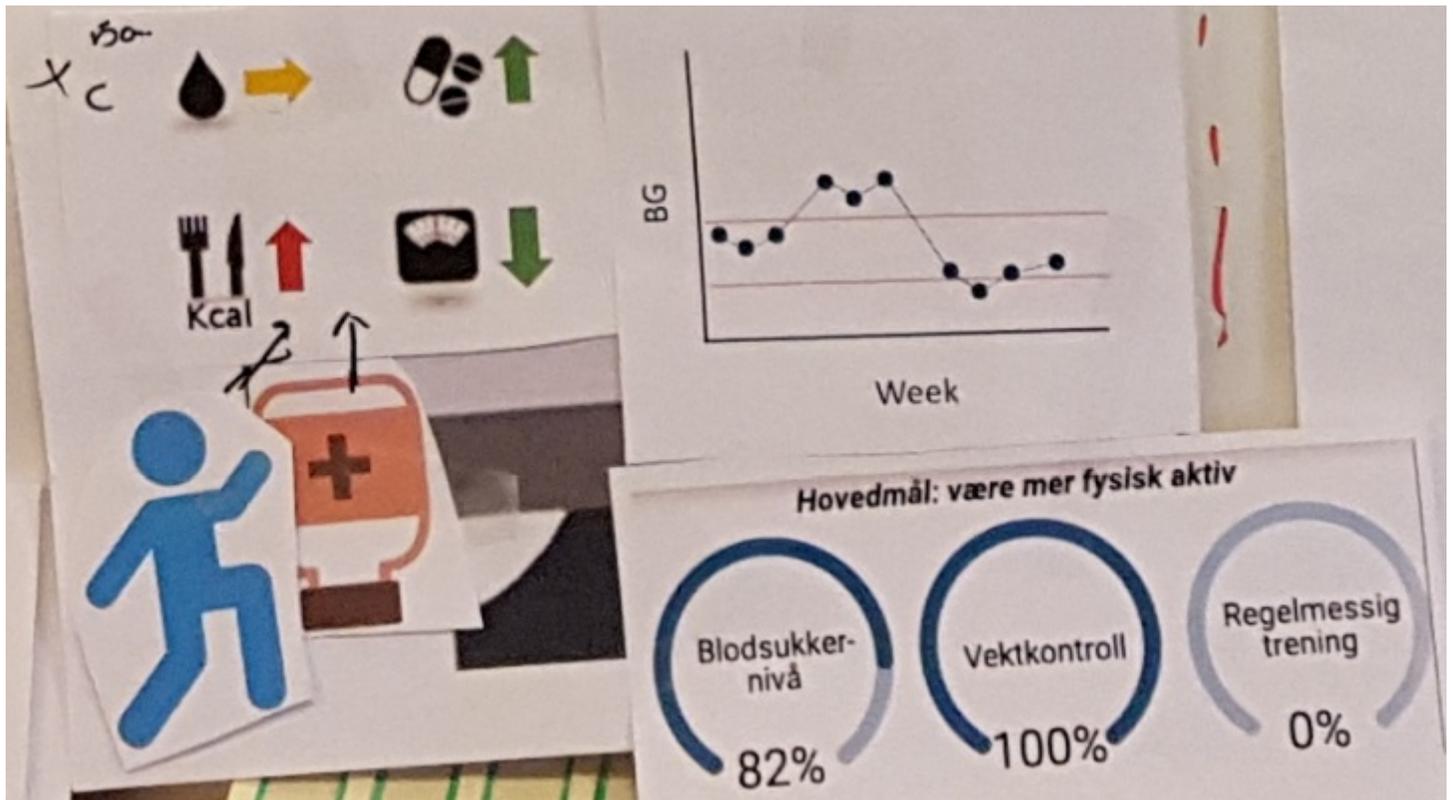


Figure 4

GP#1's paper-prototype for an ideal data-sharing system display

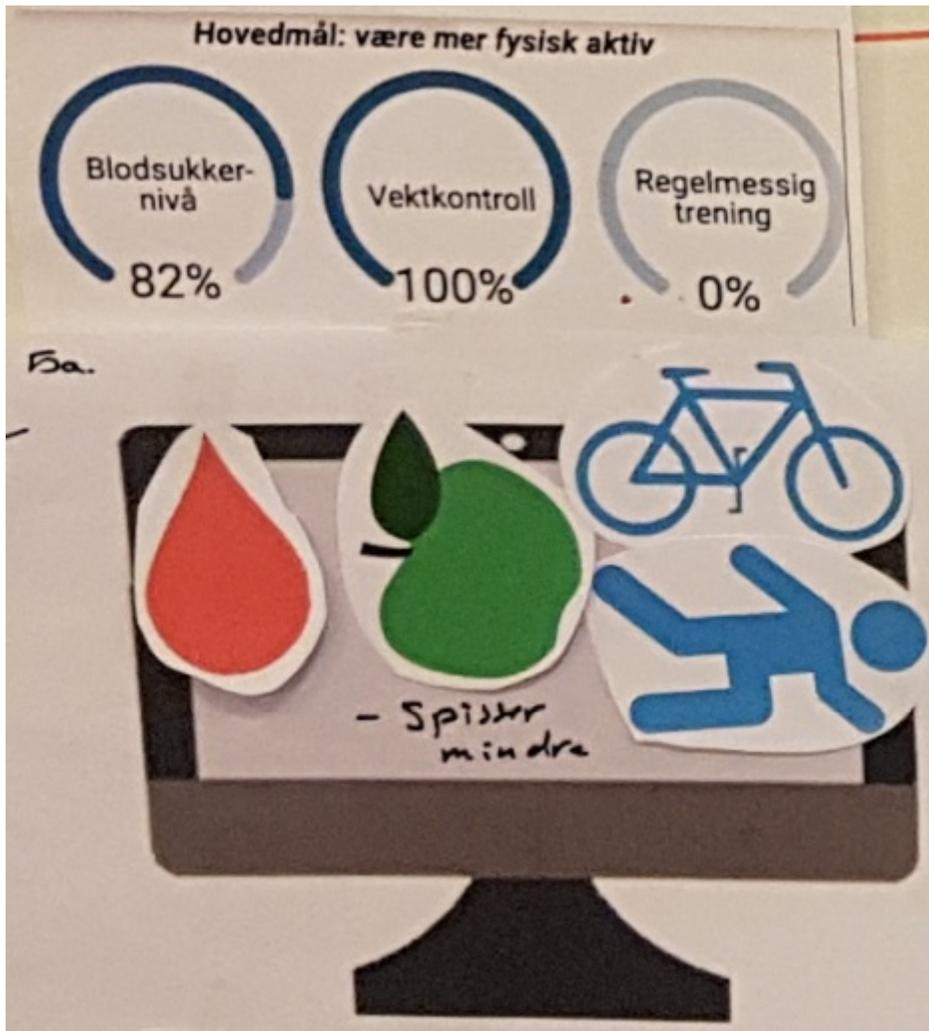


Figure 5

T2D Patient#2's paper-prototype for an ideal data-sharing system display

Supplementary Files

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