Co-responsibility in diabetes management: great potential or unnecessary?

A data-enabled design study on friends and family members' co-responsibility in diabetes type 2 management.

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ABSTRACT

Children, adolescents and younger adults are increasingly diagnosed with type 2 diabetes and prediabetes. Overall, the number of people with diabetes worldwide has more than doubled over the past three decades. Lots of research regarding diabetes has been done, resulting in many products that assist diabetes patients to control their disease. However, co-responsibility regarding diabetes has not been explored as thoroughly in literature. By means of a data-enabled design approach, this study explored how friends, family, and other people that might support diabetes patients can be assisted in their co-responsible role. The results indicate that there are two stages in co-responsibility that require different types of products: (I) a foreign stage in which the way of acting and supporting has to be established, and (II) an entrenched stage in which support has been ingrained into the daily routine. Therefore, we propose a central design piece that visualises different types of data, suitable to the stage the users are in, to help co-responsible people support their close ones.

Authors Keywords

Diabetes; co-responsibility; research artefact; data-enabled design.

INTRODUCTION

Diagnoses of type 2 diabetes and prediabetes are increasing among children, adolescents and younger adults. Over the past three decades, the number of people with diabetes Worldwide has more than doubled [8]. In 2017, 415 million people lived with diabetes worldwide, and at that time, an estimated 193 million people had undiagnosed diabetes [6]. In European countries, the management of diabetes is a big challenge to health services, professionals, people with diabetes themselves and other stakeholders [23]. Lots of research regarding diabetes has been done, resulting in many products for diabetes management [3,7,13,13–16,20,27]. However, the potential of addressing co-responsibility to improve the health of people with diabetes type 2 has not been explored as thoroughly in literature.

In this study, we define co-responsibility as the "responsibilities of people being intertwined, not in the sense that people share the same responsibilities, but in the sense that peoples' responsibilities are interdependent" [12]. Like diabetes, co-responsibility regarding health prevention and managing disease has been researched frequently, resulting in many insights and best practices to involve health care professionals and people from the social context [2,9,12,18,21]. This study specifically focuses on co-responsibility regarding a partner, or friends, family, and housemates that might support diabetes type 2 patients.

By means of a data-enabled design approach, this study explored how friends, family, and other people that might support diabetes patients can be assisted in their co-responsible role [5]. First, a generic data-set of someone tracking food intake and activity has been analysed to get a grip of gaining insights regarding these topics. Then, a user study aimed to understand the context of someone needing to monitor their diet was conducted. This user study was by means of a prototype containing multiple sensors that was deployed to one participant for three days. The insights from the contextual step led to the direction of co-responsibility, which has been studied further in the informed step. Again, this was done through a user study involving both quantitative and qualitative data gathered with interviews and a prototype.

The results of this entire study indicate that there are two stages in co-responsibility that require different types of products. First, there is a foreign stage in which the way of acting and supporting has to be established. Secondly, there is an entrenched stage in which support has been ingrained into the daily routine. In this second stage, there is no need to establish support between the patient and the assisting person. However, there is a wish for more transparency in the data that in the current situation, is most often only visible to the diabetes patient themselves. Therefore, we propose a central design piece that visualises different types of data, suitable to the stage the users are in, to help co-responsible people support their close ones.

LITERATURE REVIEW

Diabetes

Diabetes type 2 is a common disease that causes the level of glucose, otherwise known as sugar, in the blood to become too high [26]. An increasing number of people have to deal with diabetes because of population growth, improved longevity, urbanization, physical inactivity, unhealthy diets, and the consequent increase in prevalence of obesity [16]. Over 400 million people are affected by it, of which the greatest part is living with diabetes type 2 [24]. Diabetes is one of Europe's largest health problems in the 21st century and the disease is one of the biggest causes of enormous healthcare costs and death [23].

Much research has been done, which results in a better understanding of (dealing with) diabetes and products that should help patients to get or keep their disease under control. Empowering patients is important to provide quicker results, create more independence for patients, to improve medical outcomes and to lower healthcare costs [7,25]. Some examples of products created to help diabetes patients are 'The "Walnut"' by Seohee Lee, the 'FreeStyle Libre 2' tool, and the 'Diabetes:M' app [4,28,29]. All of these examples fit into the recommendations as made by Kanstrup et al, one of which is the importance of user-generated information [13].

Another example of an app enabling self management of one's condition, is the CONTOUR®DIABETES app [27]. This app to be installed on a mobile device detects and reports blood glucose readings and provides guidance on the patterns as measured. According to Fisher, the app helped users to: (I) understand and manage their disease, (II) feel more engaged with the diabetes management, (III) feel more motivated to stick to the therapy and testing recommendations, and to (IV) test the blood glucose levels more frequently during the day [11].

Co-responsibility

Health is influenced by personal behaviour as well as factors generally outside someone's immediate control. Think of socioeconomic status, access to healthcare, infrastructure, etcetera. Therefore, health is not only a personal, nor social responsibility [9]. Rather, it could be seen as a co-responsibility. In this study, co-responsibility is defined as the "responsibilities of people being intertwined, not in the sense that people share the same responsibilities, but in the sense that peoples' responsibilities are interdependent" [12]. Many studies show the benefit of utilizing co-responsibility [2,9,12,18,21].

Fig. 1. Walnut Probe designed by Seohee Lee (HOARE, 2018)

In healthcare, the physician and the patient's partner are important motivating sources for a patient's (postoperative) lifestyle change [2,12]. This study specifically focuses on co-responsibility regarding a partner, or friends, family, and housemates that might support diabetes type 2 patients [10,22]. As early as 1985, this was researched by Edelstein and Linn [10]. They endorse the notion that patterns of family functioning have an effect on how people manage their disease. Their exploration regarding family environment and the dimensions within this environment are further explored in later studies such as that of La Greca et al, who assessed and compared support by family and friends regarding adolescents' diabetes care in 1995 [17]. Their study reveals that families could support three management tasks (food intake, insulin injections and sugar level monitoring) best, while friends offered more emotional support.

More recent studies regarding co-responsibility in diabetes come to the same conclusion regarding the influence of family. The study by Albanese et al. shows that spousal support makes a noteworthy difference in the patients'

adherence to a healthy diet [1]. Not only patients but also family members are emotionally and behaviorally affected, which is why participation of the family in education regarding the disease should be encouraged [22]. Although many sources agree on the positive influence that family and friends can have on the management of diabetes, there are few products that really address this belief.

DESIGN PROCESS: CONTEXTUAL STEP

Provided data set

A data set provided by the course of this project was analysed as a starting point for this study. The data set consisted of food pictures, step counts & mood surveys from one participant. By annotating the pictures and clustering patterns, it was found that the participant had a good mood in general, regularly high sugar diet and was less active during the weekdays than on the weekends. This could indicate that the participant might not be cautious towards a healthy diet that is focused on low sugar, carb or fat intake. There were no notable patterns found regarding the relation between the food intake, activity and mood. However, there was no sugar level data to add to the analysis because the participant was not actually a diabetes patient. Therefore, it was not possible to trace back how the food intake and activity could have influenced the diabetes-related indicators of the participant. Also, there was no extra, qualitative data to reflect on the data that had been collected.

The provided data set was used to get up to speed regarding the analysis of self-reported data. It was also utilized to gain an idea of what sugar levels are associated with different types of food. Besides, it was learned that an interview to elaborate and ask questions is highly valuable to interpret the gained information correctly. Lastly, it was useful to gain insight into the effort it can cost for participants to collect all the data, and that the effort asked from participants should therefore be handled consciously.

Methodology

Then, a deployment user study was conducted to answer the following question: "How do the behaviour, emotions and context of someone that needs to monitor their diet look during a regular work week?". The information gained from this study was used to find notable phenomena and interesting research directions that could be studied further in the informed step of this project. The sub-questions and full protocol can be read in appendix A.

The user study contained one participant, which was an adult asked to monitor their diet/food consumption. This target group was chosen to represent the actual target group of the study, which are patients with Diabetes type 2. The deployment study consisted of three parts: (I) an introduction and set-up meeting, (II) the deployment stage, (III) and a reflective interview after deployment. The measuring device (Figure 2) was in the home of the participant for three days, in which the participant tracked the diet and activity without any involvement of the researchers. The closing interview was held to check and elaborate on the data that had been tracked.

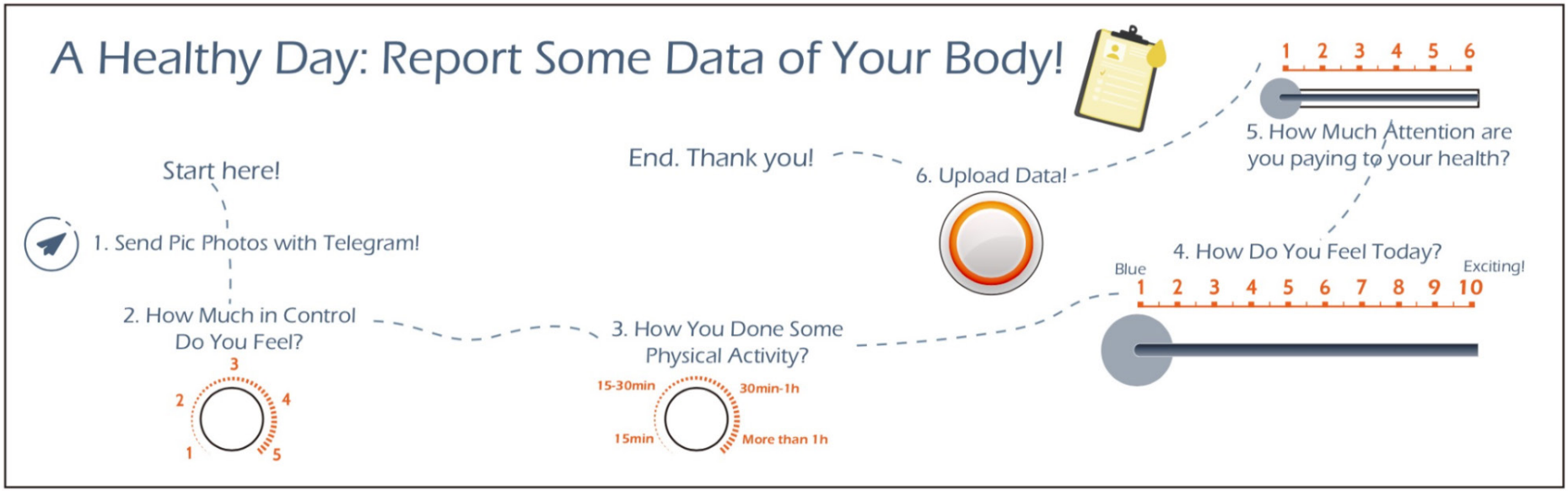


Fig. 2. Layout of the self-reporting prototype

Prototype

The study materials consisted of a measuring device and a Data Foundry chatbot. The measuring device allowed the participant to track answers to the following four questions: (I) How much in control do you feel?, (II) How much attention are you paying to your health?, (III) How do you feel today?, (IV) How physically active were you today?. By means of the chatbot, photos of the food and drink intake were captured. The participant was asked to write a short description alongside the photo for analysis purposes later.

Results and discussion

Data input

During the deployment the participant sent a total of 18 annotated pictures, and three self reports over the course of three days. A timeline of the three days was made and all of the food pictures and their respective time-stamps were mapped and annotated. These annotations were then used to create clusters by means of the affinity diagram method [19]. These themes consisted of for example eating habits, attention to health and exercise as can be seen in Figure 3. The full data set consisting of the quantitative and qualitative data can be found in appendix F.

Target question

Figure 4 shows what data the participant has submitted each evening. However, not all of the data points as received were in line with what the participant wanted to submit, which will be discussed later in this chapter. From the submitted data and interview can be concluded that the participant practiced approximately 15 minutes of (semi-)intensive sports like walking, running or fitness during each monitoring day. The participant paid attention to maintaining a consistent eating schedule that contained healthy, self prepared food and lots of water. In this case, healthy is defined as a varied and consistent diet, without too many snacks, fats and sugars. The mood of the participant got a grade of "7" on average. At the time of deployment, the participant was living in a student home with multiple other people present. The results indicate that the participant was already able to define what activity levels and dietary habits were healthy. Mainly the food intake was already established in a consistent routine focused on healthy food.

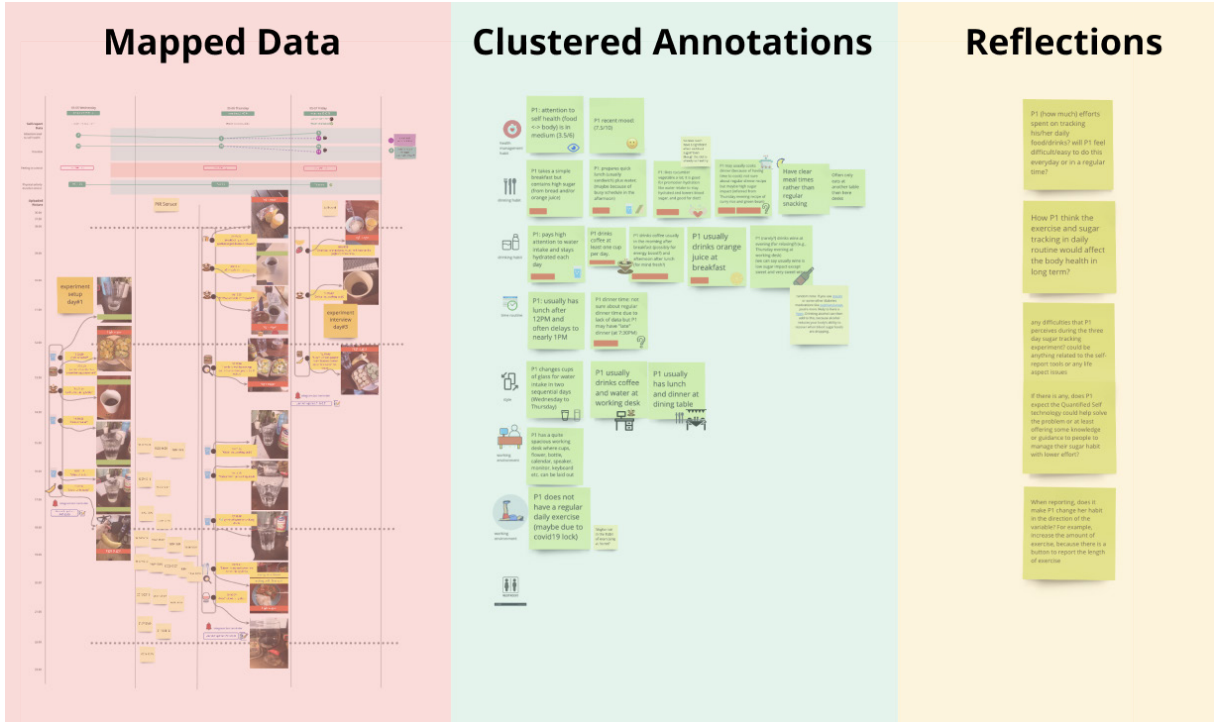


Fig. 3. A visual, showing all of the raw data mapped, annotated and clustered from the contextual step

Method	Data Collected
PIR sensor	Use of restroom
Telegram	Food pictures
Self-report	How much in control do you feel?
Self-report	How much physical activity did you have?
Self-report	How much attention are you paying to your health?
Self-report	How do you feel today?

Table 1. Data-collected in contextual steps

Methodology and prototype

The interview with the participant revealed that monitoring the diet through the device and chatbot was intense and easy to forget. The sliders on the prototype worked best as they had a clear start and end point and the submit button was experienced positively because of the feedback. Some of the questions were too broad, which left for personal interpretation by the participant (Table 1). When checking the data in the interview, it was found that not all data was submitted as intended, which was discussed with the participant to set right before data analysis. The Telegram Data Foundry bot offered a good user experience because of its clarity, privateness, suggestions and feedback. From these statements can be concluded that the questions regarding the prototype need to be very specific and that less submission moments might be a lower burden on the participants' efforts. Extra feedback from prototype to participant is of added value, as the participant can check what data is being entered and submitted.

DESIGN PROCESS: INFORMED STEP

Methodology

After the contextual step, the research direction of co-responsibility was chosen. By means of the user study in the informed step, it was aimed to understand how friends, family or other surrounding people support a diabetes type 2 patient in their environment. Another objective of this study was to gain insights into how co-responsible people

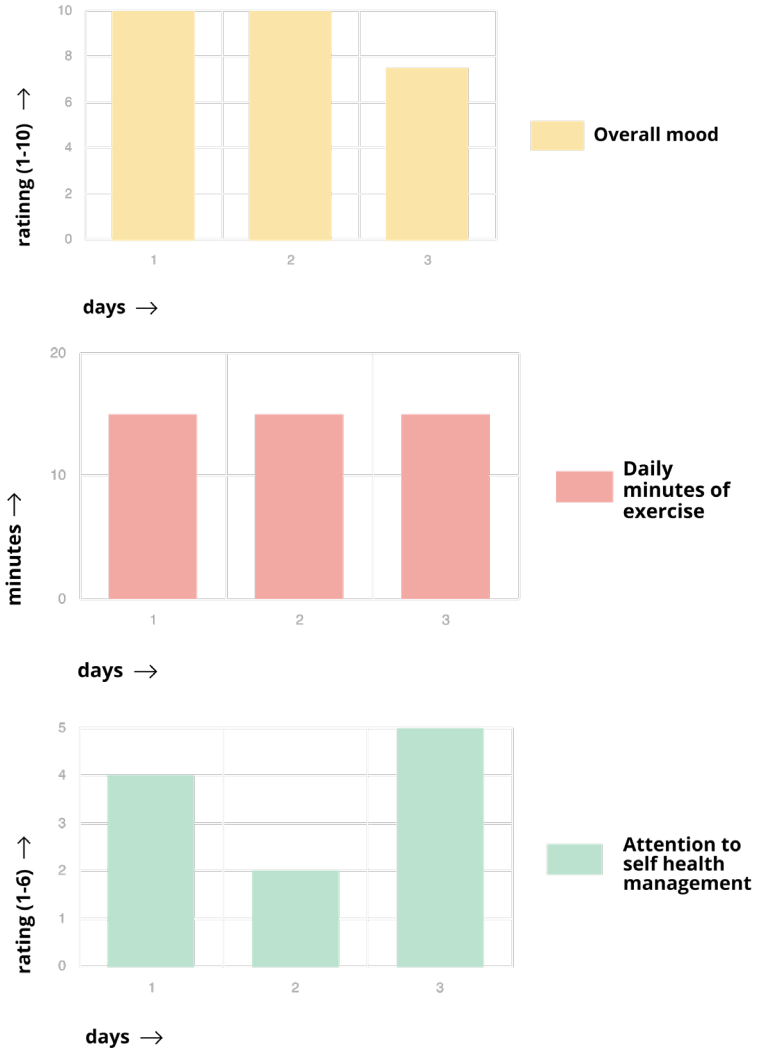


Fig. 4. Three graphs visualizing unchecked data from the contextual step prototype

can be helped when supporting diabetes type 2 patients. The main question of this study was: “How might we use data to help friends and family support type 2 diabetes patients in maintaining healthy eating and physical activity habits?”. The full protocol including sub-questions is documented in appendix B.

This study consisted of the same parts as user study in the contextual step. However, to gain insights into the perspective of the participant, there first was an interview to elaborate on the support given by the participant, towards the diabetes type 2 patient. In this interview, the parameters to track were defined in co-creation with the participant. This co-creation style was chosen to supplement the understanding of the researchers with insights from participants more experienced regarding the topic diabetes. The prototype was adjusted based on the insights from the interview (Figure 5).

The user study consisted of one participant, which was recruited based on convenience sampling. They were specifically selected because they are a long-term partner of someone that has to deal with diabetes type 2 disease. This target group was chosen in order to collect valuable insights regarding co-responsibility, and how this can help in the case of diabetes. There were no specific age, gender or other demographic requirements that participants from both the contextual as the informed step had to meet.

Prototype informed step

The prototype from the informed step was based on the self-report prototype from the contextual step. It included four sliding potentiometers & four push-buttons as input for several self-reporting questions, since these sensors also worked well on our previous prototype. A small LCD display is also integrated into the prototype to better echo participant input. For the housing of the electronics a 3D-printed boxed was designed in order to provide more durability to the prototypes as seen in Figure 4. This 3D-printed box was unfortunately not finished before the deployment so a cardboard housing (Figure 6 & 9) was used in order to let the process continue. The procedure of sending data was as follows: (I) turn on the device, (II) enter input with the buttons and sliders, (III) check the data on the screen and (IV) send the data with the ‘send’ button on the prototype.

Results & discussion

Slider input - support given and received

The data from the self-report prototype was sent over for 6 days and then analyzed by means of two charts distinguished by the input form as in this case, the sliding potmeter and the buttons (Figure 7 and Figure 8). While there are some small variations in the data, there are no outliers or striking results that could point into a specific design direction. Figure 7 shows that ‘support received’ is lower than the ‘support given’ in some cases. When contacting the participant about this difference, it became clear that this was not the intention, and that the participant and patient always agreed on the level of support. The participant stated they did not realise they were able to check the data input on the screen.

Fig. 5. 3D render of the informed step data-collection prototype

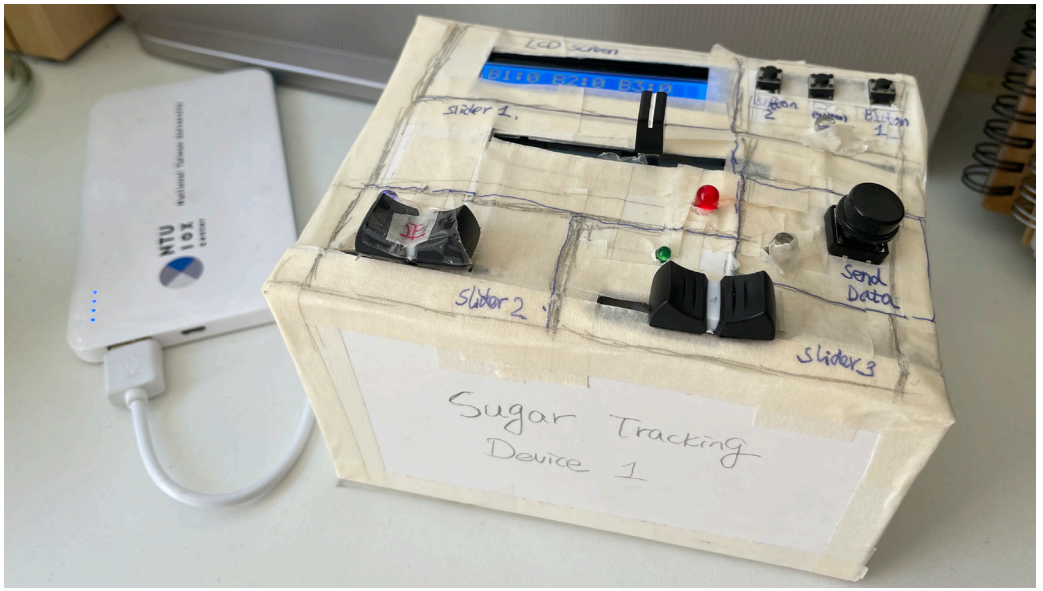


Fig. 6. Final informed step prototype during deployment

In Figure 7 it can be seen that on the second day, a significantly lower level of all measures of support was reported. This could mean that on this day both the participant and the patient were not able to provide and receive this support for a particular reason. This was confirmed by the participant. That particular day was a workday where the participant wasn't around the patient and they followed the established routine which made the participant feel like not much support was provided.

Button input - information regarding sugar levels

From the data tracked with the buttons, also no major patterns can be observed. The fact that the impact of physical activity was never clicked by the participant is striking. However, the participant did want to access the sugar levels and information on the impact of food on several occasions. This was confirmed in the interview. Previously, the participant has done a lot of research to learn about diabetes and the management of this disease. At the moment of user testing, this has been established into a routine that is mostly consistent during the work week. Weekends and holidays might result in more outliers due to a more flexible routine, which is something future research could address.

Interview results and conclusions

The results from tracked data and interview in the informed step reveal that monitoring sugar levels is most important for the co-responsible person. This would help to keep track of the data, allowing for more seamless communication and support. Support is given in the form of advice and buying healthy food which helps prevent temptations to eat unhealthy, sugary foods that influence the sugar levels strongly. The interview revealed that the support in this particular case has evolved over time. At first, the diabetes patient was more resistant towards suggestions whereas now, the patient is in an established habit for managing the diabetes. The participant stated that suggestions are too much at times, while at other times, they might be necessary. Sensing the right way and timing to offer help has grown over time.

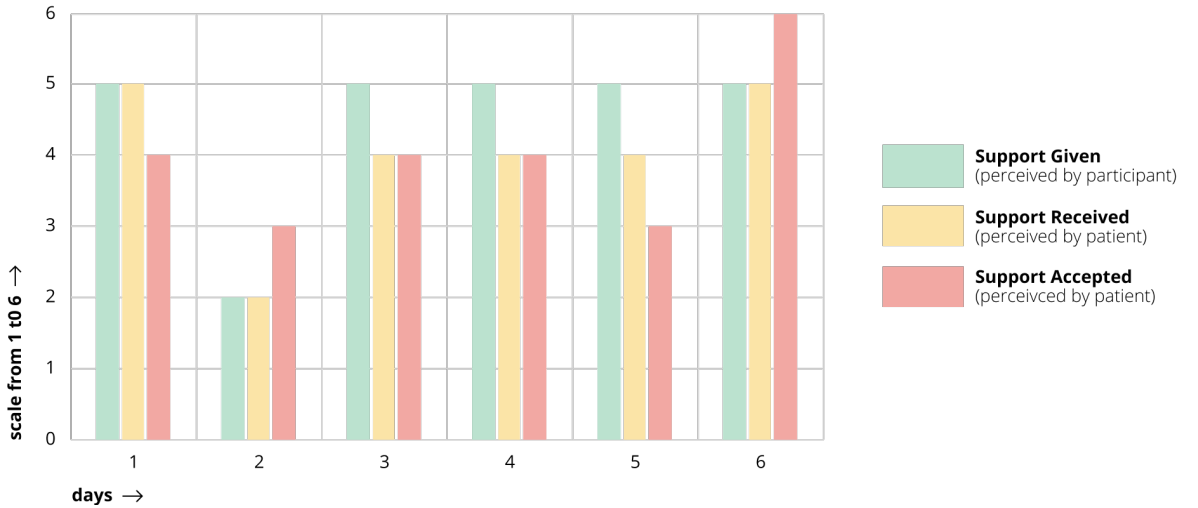


Fig. 7. Grouped bar-chart of the slider input

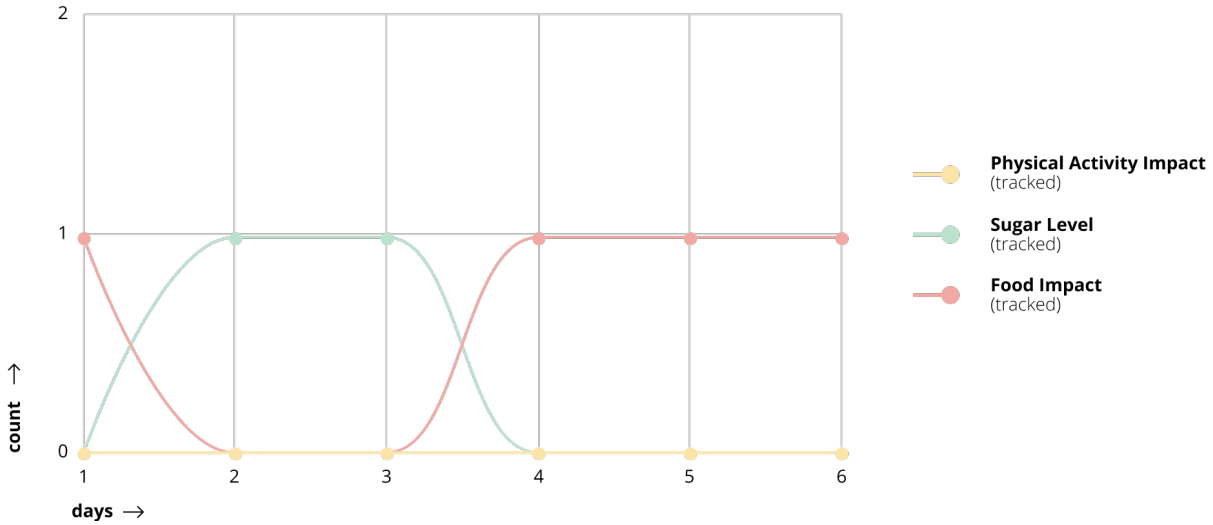


Fig. 8. Line chart of the button input

These results indicate that this particular diabetes patient wants to be in control of their own choices, rather than being told what to do. The findings suggest that there is a fine balance between what support is useful or irritating to the diabetes patient. It also shows that knowledge of diabetes is critical when offering good support. Further research should be conducted to study the experience of support, and how a product or service could assist the supportive role.

Limitations

In this explorative study, the sample size has been really small. The first user study was conducted with someone that is not a diabetes patient which will have influenced the results. For instance: the objectives and motivations of someone with diabetes might be stricter towards managing the disease in comparison with someone that is not a diabetes patient. Also, user studies with people from other age groups, varying severities of the diabetes disease and other home situations need to be conducted to evaluate the suggestions and comments made in this user study.

Testing with diabetes patients themselves is also important to include in future research as they might have different insights on a product that could support them and the people co-responsible for their situation. Lastly, the relationship between the co-responsible person and patient needs to be mentioned. In this research, the informed step included a study where the participant has a long-term partner with diabetes. These people have been together for over thirty years, which will have an influence on the support that has been established over the years. A young, new couple might have a very different knowledge level regarding diabetes and the support that is desired from both sides. Future research could address these different types of relationships to assess whether this has an influence on what product or service is desired when establishing and maintaining support regarding diabetes management.

DESIGN INTERVENTION

The design intervention resulting from this project is 'The Knot', as can be seen in Figure 10. The results show that after many years of marriage and experiences with diabetes treatment, a very stable support system between the patient and co-responsible person has been set. Measuring support to track the feelings of given and received support is not needed anymore as the support is already tailored to the existing situation and relationship. However, communicating blood sugar levels is still relevant at this stage. In the beginning stages of a (platonic) relationship or when someone has just been diagnosed, co-responsibility coaching might still be of added value.

Based on this idea, a subtle installation that will provide co-responsibility guidance for patients and their supporters has been created. In the early stages of the illness or relationship, the product will assist by collecting and visualizing the level of support that the partner feels has been given and the level of support the patient has perceived. The height of the glowing dot shows these two levels of support in the art installation. The expected outcome is a raise in awareness for both parties involved due to the reflection moment and the visualisation that can be checked at any time.

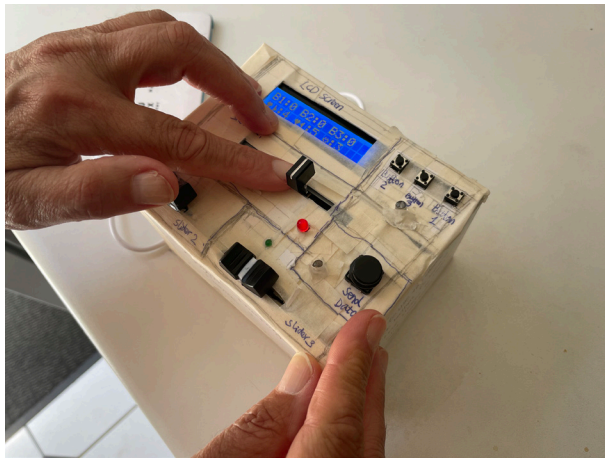


Fig. 9. Picture from the deployment in the informed step

Fig. 10. Design intervention 'The Knot'

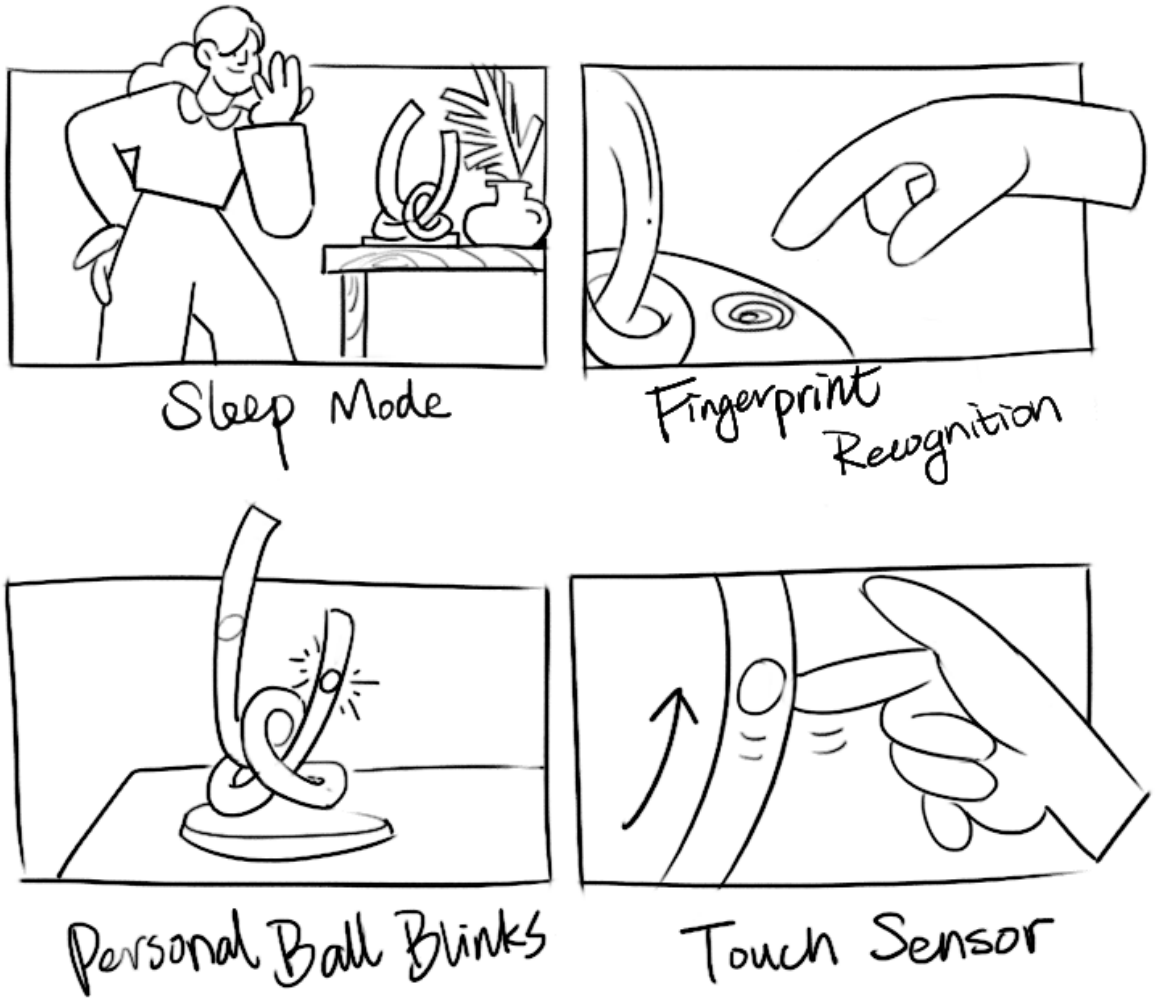


Fig. 11. Storyboard of Design intervention 'The Knot'

If the two levels of support are consistently out of balance, the device can provide guidance information via the mobile app or voice assistant that could be built in. This could for instance happen when the person giving support thinks the level of assistance is much higher than the support the patient feels they received on most days of the week.

The definition of support is left open on purpose, as this can be different based on varying situations and personal preference. However, the tips to improve support could be in the form of facilitating communication, recommending healthy recipes, and recommending healthy activities such as walking or fitness.

When the users have established a consistent support routine and no longer feel the need for co-responsibility guidance, they can manually switch to "objective data display mode." The device will then display the patient's blood-sugar level and insulin intake which can be interpreted personally by the users. This way, the tracked data is not only visible to the patient, but also to the co-responsible person(s). The data in the form of the glowing dot is only visible to people with access through, for example, a fingerprint, because it concerns privacy-sensitive data. In the non-activated state, the small bulb does not glow, so there is no need to worry about personal information being leaked when guests arrive. If users prefer that the data is always shown, this can always be adjusted through the settings of the device.

In the learning phase, data input is designed to be done through finger-touch sensing as can be seen in Figure 11. This means that to enter the level of support provided/received, users unlock the system and slide the glowing dot towards the level of support they think is accurate. The glowing dot relevant for that person will glow a different color, indicating that it can be changed. The system can also be unlocked to check what the current levels are, so that a reflection moment to improve the support routine can be set. In the later, established diabetes management phase, the data to be visualised is obtained from a third-party blood sugar monitoring device or app used by the user. This time, the current sugar level and insulin intake can be visualised. Again, in a discrete, subtle way that protects the privacy of its users.

The design is an organic, knotted shape that resembles the intertwined state of the factors having an influence on each other. Whether it is given and perceived support or the sugar and insulin level, both are highly connected to each other. The two ends are a kind of bar chart type visualisation that show their value by the adjustable lights in the tube. The design has been created in such a way that it could almost be a decorative piece within the home. This allows it to fit into the existing situation without visually communicating its purpose regarding diabetes too clearly.

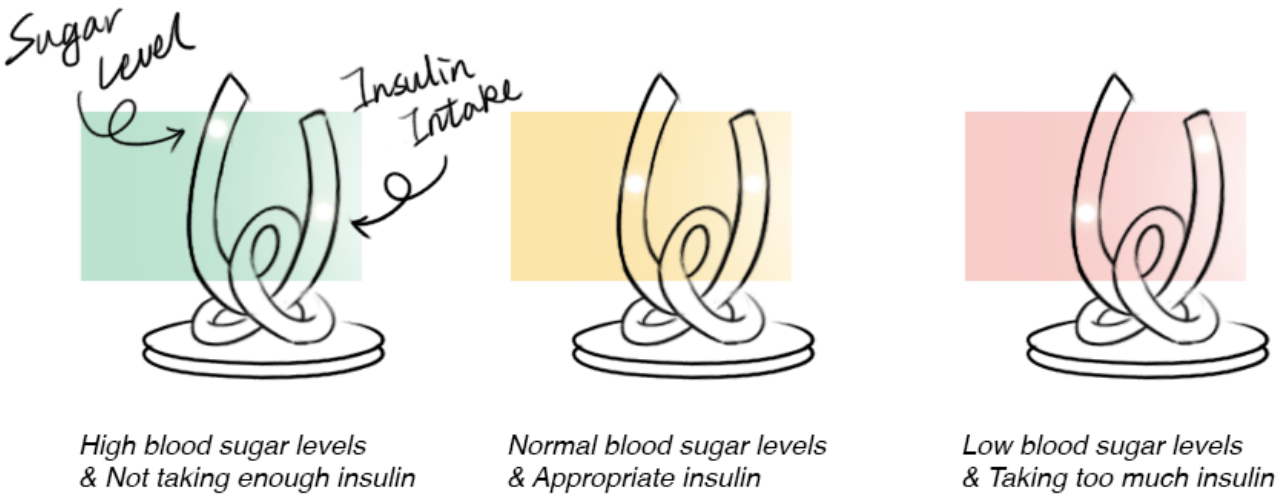


Fig. 12. Design intervention 'The Knot'

Feedback on the design

Unfortunately, the design could not be tested with the target group yet. However, the participant from the informed step was contacted to give feedback on the first explanations and visuals of the concept. It was stated that the design was great and a nice addition to the home as a decorative piece, without it being too clear that it is a disease management product. This is particularly nice when guests come over. Diabetes management can be tedious and annoying, but this design is a good improvement as it can offer information fast, without having to work with an app or something similar (Figure 12).

"You can have a quick look and continue with your day right away"

The fact that not only the diabetes patient but also the co-responsible person has access to the data makes the collaboration easier, less explicit and more informal. This is because the patient does not have to provide information or ask for something, rather the initiative can be taken more easily by the co-responsible person. Lastly, it was suggested that the product could start off "more in the foreground of the attention" whereas later, it could become less intrusive. This way, the product starts by actively informing less educated people about the situation, after which the help by the product can decrease and become something that is more in the periphery of people with a good routine. Future research should be conducted to validate these statements in real-life context and to improve the design.

Conclusion

Previous research has shown that diabetes is an important and growing problem worldwide. By means of the data-enabled design approach, this study aimed to better understand the context of people living with diabetes. The results indicate that there are many solutions regarding diabetes management present in the form of monitoring tools and mobile apps. The importance of co-responsibility has also been proven in literature, although there seem to be few products on the market that address this opportunity to improve the situation of diabetes patients. Therefore, this study has focused on co-responsibility and how this can be supported by a service or product.

The results show that there are two stages in co-responsibility that require different types of products. The first stage is a foreign stage in which the way of acting and supporting has to be established between the people. This way of support seems to be highly dependent on the situation and relationship between the two people. The second stage is an entrenched stage in which support has been ingrained into the daily routine between the patient and co-responsible person. In this phase, support establishment is less relevant. On the other hand, monitoring sugar levels and insulin intake is still very important.

Therefore, we propose a central design piece that visualises different types of data, suitable to the stage the users are in, to help co-responsible people support their close ones. The hypothesis is that 'The Knot', as this design has been named, can help people in both phases of support by showing different types of data in a private yet easily accessible way. The reactions to the design are promising as participants state that the design is aesthetically pleasing and useful for a quick check-up by not only the patient but also co-responsible people. Further research is needed to evaluate whether this design could be useful and valuable to support diabetes patients and their surrounding people in the future.

REFERENCES

1. Ariana M. Albanese, Jeff C. Huffman, Christopher M. Celano, Laura M. Malloy, Deborah J. Wexler, Melanie E. Freedman, and Rachel A. Millstein. 2019. The role of spousal support for dietary adherence among type 2 diabetes patients: a narrative review. Social Work in Health Care 58, 3: 304–323. https://doi.org/10.1080/00981389.2018.1563846
2. Christine Aramburu Alegría and Barbara Larsen. 2017. Contextual care of the patient following weight-loss surgery: Relational views and maintenance activities of couples. Journal of the American Association of Nurse Practitioners 29, 1: 17–25. https://doi.org/10.1002/2327-6924.12372
3. Eirik Arsand, Ragnhild Varmedal, and Gunnar Hartvigsen. 2007. Usability of a Mobile Self-Help Tool for People with Diabetes: the Easy Health Diary. In 2007 IEEE International Conference on Automation Science and Engineering, 863–868. https://doi.org/10.1109/COASE.2007.4341807
4. Behance. Seohee Lee on Behance. Behance. Retrieved June 21, 2021 from https://www.behance.net/seohee_lee
5. Sander Bogers, Janne van Kollenburg, Eva Deckers, Joep Frens, and Caroline Hummels. 2018. A Situated Exploration of Designing for Personal Health Ecosystems through Data-enabled Design. In Proceedings of the 2018 Designing Interactive Systems Conference (DIS '18), 109–120. https://doi.org/10.1145/3196709.3196769
6. Sudesna Chatterjee, Kamlesh Khunti, and Melanie J Davies. 2017. Type 2 diabetes. The Lancet 389, 10085: 2239–2251. https://doi.org/10.1016/S0140-6736(17)30058-2
7. Jorgo Chatzimarkakis. 2010. Why Patients Should Be More Empowered: A European Perspective on Lessons Learned in the Management of Diabetes. Journal of Diabetes Science and Technology 4, 6: 1570–1573. https://doi.org/10.1177/193229681000400634
8. Lei Chen, Dianna J. Magliano, and Paul Z. Zimmet. 2012. The worldwide epidemiology of type 2 diabetes mellitus—present and future perspectives. Nature Reviews Endocrinology 8, 4: 228–236. https://doi.org/10.1038/nrendo.2011.183
9. Ignaas Devisch. 2012. Co-Responsibility: a New Horizon for Today's Health Care? Health Care Analysis 20, 2: 139–151. https://doi.org/10.1007/s10728-011-0175-y
10. Jacqueline Edelstein and Margarette W. Linn. 1985. The influence of the family on control of diabetes. Social Science & Medicine 21, 5: 541–544. https://doi.org/10.1016/0277-9536(85)90038-3
11. William Fisher, Andreas Stuhr, Jane Wallace, Sergey Zhuplatov, Timothy S. Bailey, and Scott Pardo. 2018. User Experience with a New Smartphone Application for Blood Glucose Monitoring (BGM) in an Information-Motivation-Behavioral Skills (IMB) Model Study. Diabetes 67, Supplement 1. https://doi.org/10.2337/db18-692-P
12. Jos-Marien Jansen, Karin Niemantsverdriet, Anne Wil Burghoorn, Peter Lovei, Ineke Neutelings, Eva Deckers, and Simon Nienhuijs. 2020. Design for Co-responsibility: Connecting Patients, Partners, and Professionals in Bariatric Lifestyle Changes. In Proceedings of the 2020 ACM Designing Interactive Systems Conference (DIS '20), 1537–1549. https://doi.org/10.1145/3357236.3395469
13. Anne Marie Kanstrup, Pernille Bertelsen, Marie Glasemann, and Niels Boye. 2008. Design for more: an ambient perspective on diabetes. In Proceedings of the Tenth Anniversary Conference on Participatory Design 2008 (PDC '08), 118–127.
14. Sachin Khunti, Kamlesh Khunti, and Samuel Seidu. 2019. Therapeutic inertia in type 2 diabetes: prevalence, causes, consequences and methods to overcome inertia. Therapeutic Advances in Endocrinology and Metabolism 10: 2042018819844694. https://doi.org/10.1177/2042018819844694
15. Taylor King. 2021. Emphasis on Lifestyle Adjustment Initial Type 2 Diabetes Diagnosis: Solutions for Improved Life-Long Disease Management at the Veterans Administration. Lynchburg Journal of Medical Science 3, 1. Retrieved from https://digitalshowcase.lynchburg.edu/dmscjournal/vol3/iss1/36
16. David. Klonoff, David. Kerr, and Shelagh A. Mulvaney. 2020. Diabetes digital health. Elsevier, Amsterdam. Retrieved April 22, 2021 from https://search.ebscohost.com/login.aspx?direct=true&scope=site&db=nlebk&db=nlabk&AN=2351312
17. Annette M. La Greca, Wendy F. Auslander, Peggy Greco, Dante Spetter, Edwin B. Fisher Jr., and Julio V. Santiago. 1995. I Get by with a Little Help from my Family and Friends: Adolescents' Support for Diabetes Care1. Journal of Pediatric Psychology 20, 4: 449–476. https://doi.org/10.1093/jpepsy/20.4.449
18. Peter Lovei, Ruben van Dijk, Jos-marien Jansen, Eva Deckers, Karin Niemantsverdriet, Anne Wil Burghoorn, Ineke Neutelings, and Simon Nienhuijs. 2020. Together in Shape: A Co-responsibility System to Support Bariatric Lifestyle Changes. In Companion Publication of the 2020 ACM Designing Interactive Systems Conference (DIS' 20 Companion), 361–364. https://doi.org/10.1145/3393914.3397094
19. Andrés Lucero. 2015. Using Affinity Diagrams

to Evaluate Interactive Prototypes. In Human-Computer Interaction – INTERACT 2015 (Lecture Notes in Computer Science), 231–248. https://doi.org/10.1007/978-3-319-22668-2_19

20. Shelagh A. Mulvaney, Lee M. Ritterband, and Lindsay Bosslet. 2011. Mobile Intervention Design in Diabetes: Review and Recommendations. Current Diabetes Reports 11, 6: 486–493. https://doi.org/10.1007/s11892-011-0230-y

21. Ineke Neutelings, Pierre Levy, Tom Djajadiningrat, and Caroline Hummels. 2017. Enhancing co-responsibility for patient engagement. The Design Journal 20, sup1: S2273–S2283. https://doi.org/10.1080/14606925.2017.1352743

22. Tuula-Maria Rintala, Pia Jaatinen, Eija Paavilainen, and Päivi Åstedt-Kurki. 2013. Interrelation Between Adult Persons With Diabetes and Their Family: A Systematic Review of the Literature. Journal of Family Nursing 19, 1: 3–28. https://doi.org/10.1177/1074840712471899

23. T. Tamayo, J. Rosenbauer, S. H. Wild, A. M. W. Spijkerman, C. Baan, N. G. Forouhi, C. Herder, and W. Rathmann. 2014. Diabetes in Europe: An update. Diabetes Research and Clinical Practice 103, 2: 206–217. https://doi.org/10.1016/j.diabres.2013.11.007

24. Maxim Verboven, Lisa Van Ryckeghem, Jamal Belkhouribchia, Paul Dendale, Bert O. Eijnde, Dominique Hansen, and Virginie Bito. 2019. Effect of Exercise Intervention on Cardiac Function in Type 2 Diabetes Mellitus: A Systematic Review. Sports Medicine 49, 2: 255–268. https://doi.org/10.1007/s40279-018-1003-4

25. Laurie Visser, Suleman Shahid, and Abdullah Al Mahmud. 2014. Point-of-care testing for diabetes patients: investigating diabetes management by older adults. In CHI '14 Extended Abstracts on Human Factors in Computing Systems, 1645–1650. https://doi.org/10.1145/2559206.2581193

26. Type 2 diabetes. nhs.uk. Retrieved June 21, 2021 from https://www.nhs.uk/conditions/type-2-diabetes/

27. De CONTOUR DIABETES app. Retrieved June 19, 2021 from https://www.diabetes.ascensia.nl/Producten/contour-diabetes-app/?gclid=Cj0KCQjw7pKFBhDUARIsAFUoMDbWYcIiASX2RJ3MdtPXi14AuKfiQVJAaVkAWEV8xqHykUZj2TqKnGUaAj-9gEALw_wcB#Sub-Menu-2

28. Home - FreeStyle Libre | Abbott. Retrieved June 21, 2021 from https://www.freestyle.abbott/nl-nl/home.html

29. Diabetes:M. Diabetes:M - Your Diabetes Management App. Retrieved June 21, 2021 from https://www.diabetes-m.com/

APPENDIX A: FULL PROTOCOL USER STUDY - CONTEXTUAL STEP

MAIN QUESTION

How do the behaviour, emotions and context of someone that needs to monitor their diet look during a regular work week?

SUB QUESTIONS

What is someone that needs to monitor their diet eating during a regular work week?

What does the context of someone that needs to monitor their diet look like?

What is the behaviour of someone that needs to monitor their diet, specifically regarding food consumption?

What are the emotions of someone that has to monitor their diet?

OBJECTIVE

By means of this user study, we aim to understand the context of someone that needs to monitor a diet (in this case sugar)

METHOD

This deployment study will consist of three parts: (I) an introduction and set-up meeting, (II) the deployment stage that doesn't contain involvement of the researchers, (III) and a reflective meeting in which the measuring device is removed from the context. All of the participants will first be introduced to user study, after which they are asked to sign the consent form. The measuring device containing multiple sensors will be set up and an explanation will be provided so that the participant understands what to do at which times of the day. The measuring device will be in the home of the participant for at least three days in which the device and participant himself will track the diet and activity without any involvement of the researchers. After the deployment phase, the researcher will meet with the participant to have a reflective interview and to remove the measuring device.

The user study aims for one to two participants, which are adults monitoring their diet/food consumption. This target group was chosen to represent the actual target group of the study, which are patients with Diabetes type 2. There are no specific age, gender or other demographic requirements that participants have to meet. Participants will be recruited through the Data-enabled design course that this study is part of. After the initial contact for invitation, participants will receive a document with a short introduction and consent form to sign before the user study starts.

SCRIPT

Introduction meeting

Thank you for participating in this user study. We would like to ask a few things of you. First, we would like you to submit a few things using the measuring device each day. You don't have to do this continuously, just once at the evening time, possibly around 20:00. The things we would like to know are:

- How much in control do you feel regarding your diet?
- Have you done some physical activity?
- How much attention are you paying to your health (good food + activity)?
- How do you feel today?

Besides, we would like you to submit what you are eating and drinking at the time of the event via the Telegram Bot on your phone. You can use this chatbot to send us a picture accompanied by a short description of what the food and/or drink is.

Reflective interview

- How was your overall experience using the measuring device over the last couple of days?
- How did submitting all of the data entries go?
- In case the participant doesn't understand the question: Were you able to complete all submissions as we asked you to? Did you take and submit pictures of everything you ate and drank for instance? Did you manage to submit your input with the buttons and sliders each evening?
- How did you experience having to monitor your diet?
- How did you experience having to monitor your emotions during the week? Were you able to accurately submit them?
- Can you check your step count for the last few days and tell what they are? We are interested in the days of deployment only.
- Is there anything else you would like to tell me that can be relevant to the study?

APPENDIX B: FULL PROTOCOL USER STUDY - INFORMED STEP

MAIN QUESTION

How might we use data to help friends and family support type 2 diabetes patients in maintaining healthy eating and physical activity habits?

SUB QUESTIONS

How does the target group currently support the diabetes patient?

How does the target group want to support the diabetes patient in the ideal situation?

What does the target group need to provide the support they want to provide?

What type of data can be communicated in order to understand the diabetes patient and their situation better?

OBJECTIVE

With this study, we will focus on co-responsibility. By means of this user study, we aim to understand how friends, family and other surrounding people can be helped when supporting diabetes type 2 patients.

METHOD

This deployment study will consist of four parts: (I) an introduction interview, (II) a set-up meeting, (III) the deployment stage that doesn't contain involvement of the researchers, (IV) and a reflective meeting in which the measuring device is removed from the context. In this last phase, there will also be an interview to reflect on the deployment phase. The participant will first be introduced to user study, after which they are asked to sign the consent form. There will first be an interview in a co-creation style to define which parameters to track during the deployment phase. The measuring device containing multiple sensors will be set up accordingly and an explanation will be provided so that the participant understands what to do at which times of the day. The measuring device will be in the living space of the participant for at least three days in which the device and participant himself will track parameters as defined based on the interview, without any involvement of the researchers. After the deployment phase, the researcher will meet with the participant to have a reflective interview and to remove the measuring device.

The user study aims for one participant, which are adults that have a friend, family member or other close person like a colleague that has to deal with diabetes type 2 disease. This target group was chosen in order to be able to provide valuable insights regarding co-responsibility, and how this can help in the case of diabetes. There are no specific age, gender or other demographic requirements that participants have to meet. Participants will be recruited based on convenience sampling. After the initial contact for invitation, participants will receive a document with a short introduction and consent form to sign before the user study starts.

SCRIPT

Introduction meeting / interview

Thank you for participating in this user study. I am part of a team that is doing a project regarding diabetes, and how we can help people in managing this unfortunate disease. In this interview, I would like to gain an understanding of your situation. I would also like to determine what data to track together with you, since you are one of the experts in this field. You can ask me to stop the interview and recording at any time without an explanation. We will stop the user study in that case.

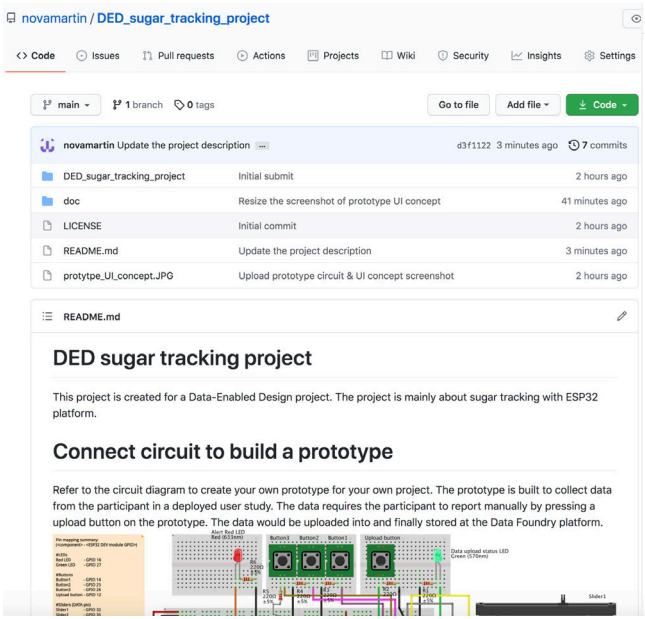
- Could you first explain your relation to the person in your life that has diabetes?
- How are you supporting that person in their situation regarding diabetes?
- Did you have to adjust your own lifestyle to support the person with diabetes?
- How did you establish your current way of supporting?
- How are you communicating with the person with diabetes regarding the disease and your supportive role?
- Did your way of supporting the diabetes patient change over time? The last couple of years, months…
- To what extent do you feel that your support is helping the person in question?
- How could external help by a person or product improve the support you are able to give currently?
- In our study, we are aiming to understand your situation better. That is why we would like to deploy a measuring device in your living space for three days. With this device, you can track data to give us as researchers, but maybe you yourself too insight into the support you are providing.
- What type of data do you think would help us to gain insight into your situation?
- What type of data do you think would help you to gain insight into your situation?

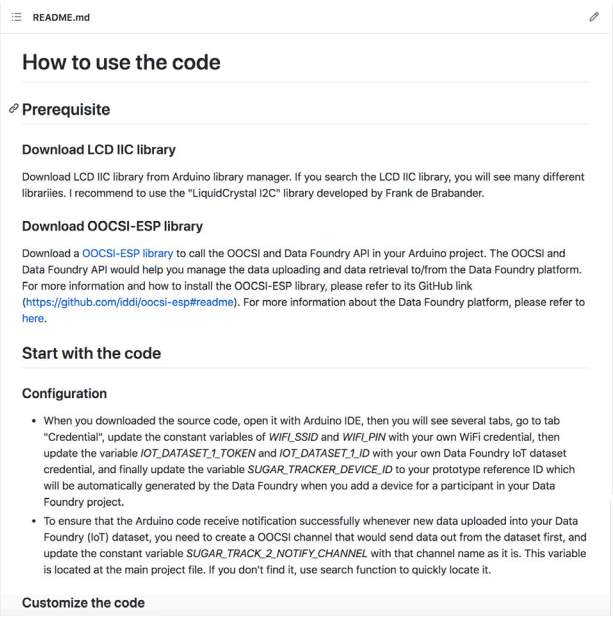
Reflective interview

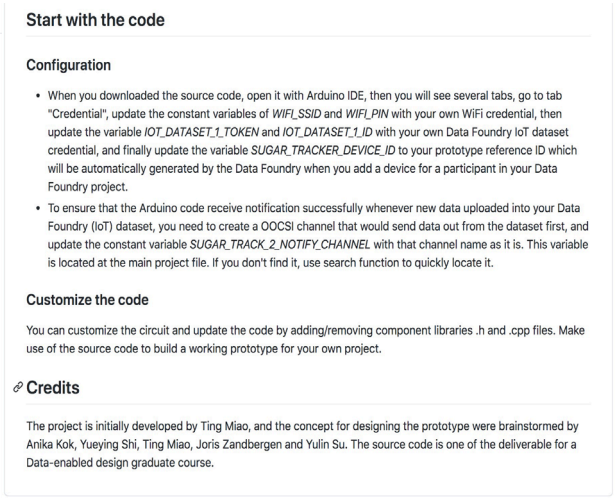
- How was your overall experience using the measuring device over the last couple of days?
- How did submitting all of the data entries go?
- In case the participant doesn't understand the question: Were you able to complete all submissions as we asked you to? Did you take and submit pictures of everything you ate and drank for instance? Did you manage to submit your input with the buttons and sliders each evening?
- How did you experience having to monitor the parameters as we defined them?
- Were you able to accurately submit them?
- How do you look back on the parameters?
- Are they still relevant or do they need iterating?
- Is there anything else you would like to tell me that can be relevant to the study?

APPENDIX C: GITHUB

The project source code has been shared with GitHub and the project is accessible from the link below. (https://github.com/novamartin/DED_sugar_tracking_project)
Some screenshots of the GitHub project are shown below.

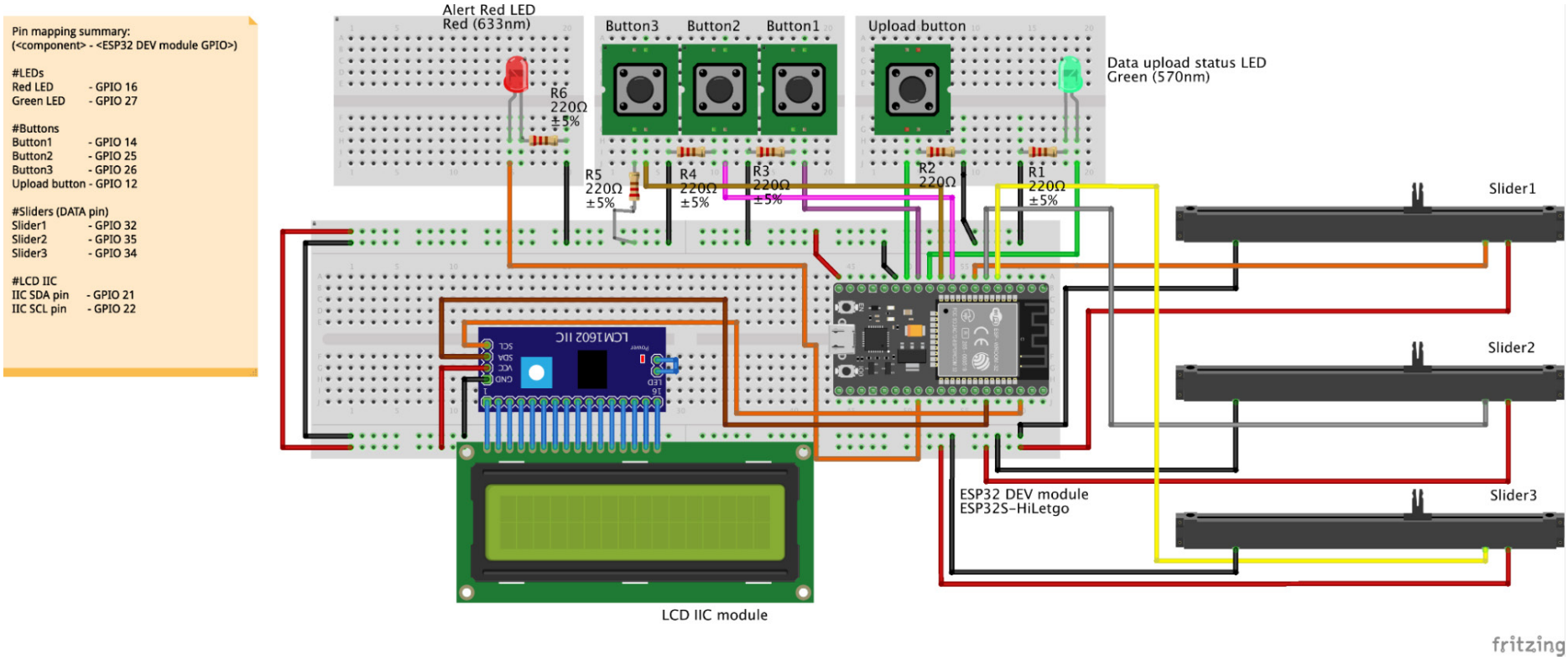






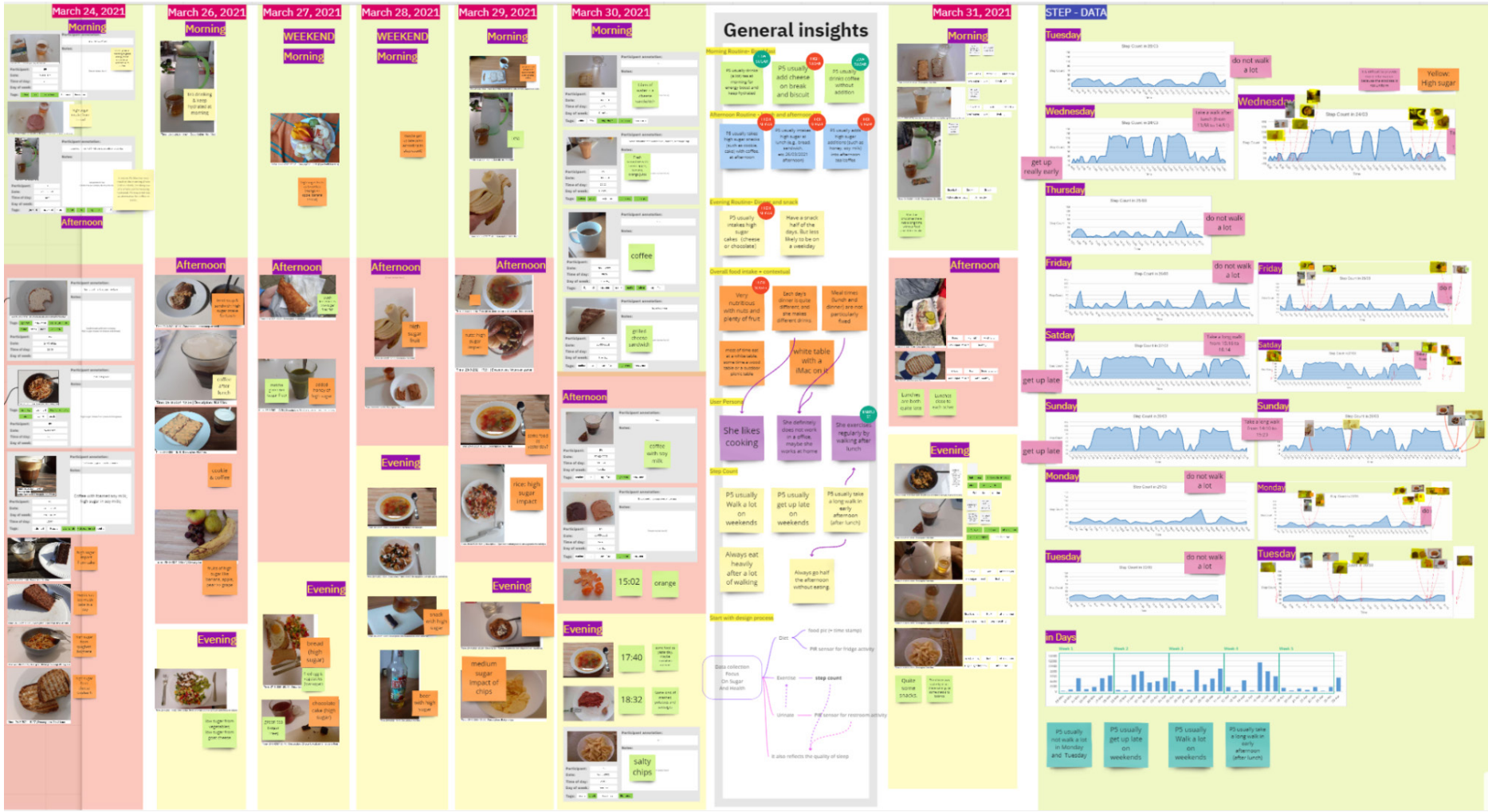
APPENDIX D: CIRCUIT

The prototype circuit is demonstrated as below. The circuit diagram is drawn with software fritzing (https://fritzing.org/). As the diagram shows, two LEDs, three press buttons, three sliders and one LCD IIC module are connected to a ESP32 DEV module.



APPENDIX E: PROVIDED DATA SET

Overview of food data annotations and graph view of the data



APPENDIX F: DATA OF THE CONTEXTUAL STEP

Screenshot of raw csv data from the contextual step

id	device_id	ts	activity	pp1	attention_level_to_health_management(low 1~6 high)	emotion	emotion(bad 1 to exciting 10)	feeling_in_control(low 1 to high 5)	physical_activity(1~4)	user_id	user_item1(btn1)	user_item2(btn2)	user_item3(btn3)
7	-1	2021-05-05T17:23:18	self-logging	sugar2_prototype1	4		10	-1	15mins	mood_team_11			
8	-1	2021-05-05T17:23:18	self-logging	sugar2_prototype1	4		10	-1	15mins	mood_team_11			
9	-1	2021-05-05T17:23:18	self-logging	sugar2_prototype1	4		10	-1	15mins	mood_team_11			
10	-1	2021-05-05T17:23:18	self-logging	sugar2_prototype1	4		10	-1	15mins	mood_team_11			
11	-1	2021-05-05T17:23:18	self-logging	sugar2_prototype1	4		10	-1	15mins	mood_team_11			
12	-1	2021-05-06T21:45:34	self-logging	sugar2_prototype1	2		10	-1	15mins	mood_team_11			
13	-1	2021-05-06T21:45:41	self-logging	sugar2_prototype1	2		10	-1	15mins	mood_team_11			
14	-1	2021-05-07T13:42:31	self-logging	sugar2_prototype1	5		10	-1	15mins	mood_team_11			
15	-1	2021-05-07T13:42:31	self-logging	sugar2_prototype1	5		10	-1	15mins	mood_team_11			
16	-1	2021-05-07T13:42:31	self-logging	sugar2_prototype1	5		10	-1	15mins	mood_team_11			
17	-1	2021-05-07T13:42:32	self-logging	sugar2_prototype1	5		10	-1	15mins	mood_team_11			
18	-1	2021-05-07T13:42:32	self-logging	sugar2_prototype1	5		10	-1	15mins	mood_team_11			
19	-1	2021-05-26T14:11:54	self-logging	sugar2_prototype1	1	good				mood_team_11			
20	-1	2021-05-26T14:11:58	self-logging	sugar2_prototype1	1	good				mood_team_11			
21	-1	2021-05-26T14:14:22	self-logging	sugar2_prototype1	4	happy				mood_team_11			
22	-1	2021-05-26T14:19:03	self-logging	sugar2_prototype_v2	2	good				mood_team_11			
23	-1	2021-05-26T14:23:05	self-logging	sugar2_prototype_v2	4	happy				mood_team_11			
24	-1	2021-05-26T14:25:13	self-logging	sugar2_prototype_v2	3	good				mood_team_11			
25	-1	2021-05-26T14:26:07	self-logging	sugar2_prototype_v2	3	good				mood_team_11	3	1	1
26	-1	2021-05-26T14:27:59	self-logging	sugar2_prototype_v2	4	good				mood_team_11	3	1	1

id	device_id	ts	activity	pp1	pp2	pp3	support_level_been_rated_in_perceive	support_level_like_to_offer	TBD_tracked_item	user_id	user_item1(btn1)	user_item2(btn2)	user_item3(btn3)
197	839	2021-06-07T22:39:13	self-logging	sugar2 prototype	v2.5.0	sugar team 2	5	5	4	p1_sugar2_user_	1	0	0
198	839	2021-06-08T22:59:17	self-logging	sugar2 prototype	v2.5.0	sugar team 2	2	2	3	p1_sugar2_user_	0	0	1
199	839	2021-06-12T12:37:25	self-logging	sugar2 prototype	v2.5.0	sugar team 2	5	4	4	p1_sugar2_user_	1	0	0
200	839	2021-06-13T22:07:31	self-logging	sugar2 prototype	v2.5.0	sugar team 2	5	4	4	p1_sugar2_user_	6	0	0
201	839	2021-06-14T22:13:57	self-logging	sugar2 prototype	v2.5.0	sugar team 2	5	4	3	p1_sugar2_user_	3	0	3
202	839	2021-06-15T21:12:23	self-logging	sugar2 prototype	v2.5.0	sugar team 2	5	5	6	p1_sugar2_user_	1	1	1