

# Sampling experiences from type 2 diabetes patients for identification of problem areas

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## Abstract

**Purpose:** The aim of the study was to investigate which problems type 2 diabetes patients encounter in their everyday life and whether certain problems are of strong presence at the beginning of their diagnosis.

**Method:** 65 diabetes-related problems were identified through a literature review and then rewritten into 93 experiences with patient and expert involvement. An online data-gathering method was developed and used in a user study where 25 type 2 diabetes patients logged experiences over two months.

**Results:** The sample did mostly encounter positive experiences, and the two most dominant problems were food and exercise. No overall difference was found in probability for positive experiences between the newly diagnosed (N=11) and the experienced (N=14) group ( $p=0.491$ , 95%CI[-0.057, 0.116]). The probability for positive experiences varied between different problem areas. The method was evaluated by interviewing four of the participants.

**Conclusion:** With the proposed improvements to the method it has the potential to enable more rapid identification of problem areas, and make type 2 diabetes patients reflect upon their experiences.

**Keywords:** *Type 2 diabetes, remote user study, experience sampling, self-report*

## 1 Introduction

Diabetes is an illness on the rise and according to [Salari et al. \(2019\)](#) more than 400 million people worldwide were diagnosed with diabetes in 2019, and this number is expected to increase to 600 million by 2040. It is estimated that 90% of people with diabetes have type 2 diabetes.

Self-care is a keystone in managing a chronic illness such as diabetes ([Fearon-Lynch et al., 2019](#); [Salari et al., 2019](#)). Adequate self-care can help a diabetes patient to maintain a stable blood glucose level and reduce the risk of complications in the future ([Fearon-Lynch et al., 2019](#); [St. Jean, 2012](#)). According to [Fearon-Lynch et al. \(2019\)](#), guided reflection has the potential to improve self-care

behaviors and knowledge within diabetes management. Guided reflection is where the patient will be engaged to take part “[...] *in the discovery of knowledge through reflection on prior experience*” ([Fearon-Lynch et al., 2019](#), p.67).

Type 2 diabetes patients have to collect information about their illness and induce behavior changes based on this information to be able to manage their diabetes ([St. Jean, 2012](#)). 34 type 2 diabetes patients were interviewed, in the study by [St. Jean \(2012\)](#). Among other things, it was discovered that the type of and need for information changed during the course of the participants’ diabetes. The three main reasons for this were:

1. At the beginning of their diagnosis, there was more of a need for general information about diabetes but as they progress more detailed and specific information is needed.
2. Many of the participants mentioned that they did not receive the needed information at the beginning of their diagnosis. Later in the course of their diabetes, they have learned things that they would have liked to know earlier.
3. During the course of having diabetes their attitude to having diabetes changed. At the beginning of their diagnosis, they did not want to accept it and therefore simply did not search for information about it. Later on, they learned that this information is needed to manage their illness.

The study by [St. Jean \(2012\)](#) indicates that there is a difference in what information type 2 diabetes patients need to manage their illness depending on how long they have been diagnosed. Further, the finding that type 2 diabetes patients think information is missing at the beginning of diagnosis is supported by [Peel et al. \(2004\)](#); [Pikkemaat et al.](#)

(2019).

The purpose of this study is two-fold; first, it is investigated what kind of diabetes-related problems type 2 diabetes patients encounter in their everyday lives, and second, whether any certain problems are of strong presence at the beginning of their diagnosis.

## 2 Literature review

A literature review was conducted to determine which diabetes-related problems are experienced by people with type 2 diabetes. 56 studies were included and the process of searching for and selecting these studies can be seen on the flowchart on Figure 1. A list with 65 problems that type 2

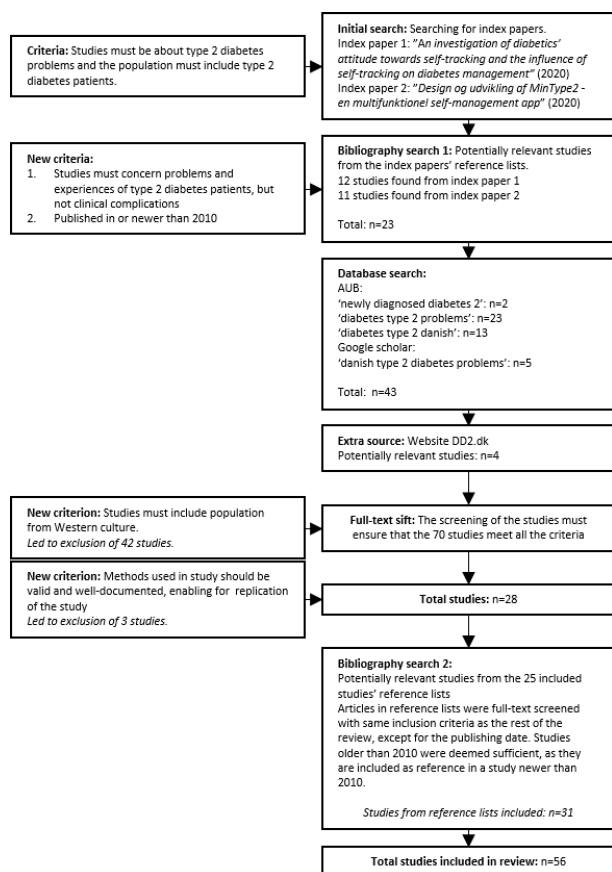


Figure 1: Flowchart that illustrates the steps in the literature search and study selection.

diabetes patients can experience in their everyday life was extracted from the literature review. There are often several aspects of a problem. For example, experiences for the problem 'stigma' could be 'I have been told that I have brought diabetes upon myself' or 'I have experienced that the media showcases type 2 diabetics as fat and lazy'. So, it can be difficult to determine whether a problem is

experienced. Therefore, the problems were rewritten to 93 concrete experiences through an expert workshop, followed by a verification of the experiences by two type 2 diabetes patients.

## 3 Method

The user study was a combination of a survey and a diary study, inspired by the method used in the study by Lund et al. (2019). In this user study, the target group was Danish type 2 diabetes patients and the purpose was to map whether this target group encountered the 93 identified experiences in their everyday life. Each of the experiences was assigned a value in accordance to whether it would be positive or negative for a diabetes patient to encounter them. Further, the experiences were grouped into 13 different categories, and the names of these can be seen in Appendix A.1. If a participant logged a substantial amount of negative experiences within a certain category it was identified as a problem area.

The participants were instructed to log whether they had encountered any of the 93 experiences. This should be done multiple times over the course of several weeks. The participants logged their experiences on a website called DO which stands for *din Diabetes Oplevelse* (Eng: Your diabetes experience), and the website will from now on be referred to as DO.

The link to DO and the participants' login was sent to them by email. The homepage on DO contained information about the study and a login button. After the participants logged in, they were met by an answering page that contained one of the 93 experiences. An example of the answering page can be seen on Figure 2.

Figure 2 shows that the participants had three response options; have experienced, have not experienced, or they could skip the experience. Each time a participant had given a response, a new experience was shown to them. The presentation order was controlled for each participant with a Latin Square Design. The skip button was intended to be used if the participant did not think the experience was relevant for them to respond to. For example, if a participant skipped an experience about medication because they do not treat their diabetes with medicine. The participants could also go back to the previous experience. Lastly, there was a help button that could be clicked to view information on how to interpret the different buttons.

**Jeg har delt mine diabetes  
relaterede problemer med andre  
diabetikere**

Har oplevet      Har ikke oplevet

<< Tilbage      Spring over hvis det ikke er  
relevant for dig

Hjælp

Figure 2: Example of experience on answering page: 'I have shared my diabetes-related problems with other diabetics', and the response options presented in DO: 'Have experienced', 'Have not experienced' or 'Skip if not relevant for you'.

Each time a participant had logged 25 experiences, DO would suggest taking a break from logging experiences. When the participant had logged 93 experiences they would be met by a finish page informing them that they had logged all experiences and they were also encouraged to log experiences again another day.

Upon enrollment, participants had to fill out a demographic survey. This contained five demographic questions: gender, age, diabetes duration, type of medication they are taking for their diabetes, and what their latest HbA1c value<sup>1</sup> was. The survey also contained 13 yes/no questions, see Appendix A.2.

### 3.1 Recruitment

Participants were recruited through type 2 diabetes Facebook groups and by contacting Danish diabetes associations. It was a requirement that all participants could read Danish as DO and the demographic survey were in Danish. There was distinguished between newly diagnosed diabetics and experienced diabetics to be able to investigate possible differences between what the two groups experience in their everyday lives. Participants who had been diagnosed less than one year ago were defined as newly diagnosed, the rest as experienced. The design was within-subject, as all participants had to log the same 93 experiences.

<sup>1</sup>A blood sample that measures the amount of glycated hemoglobin. This can indicate what the average blood sugar levels have been for the last 2-3 months (Diabetesforeningen, 2021)

### 3.2 Data-gathering

The duration of the study varied for some of the participants, as the first participant was recruited on March the 9th and the last participant was recruited on March the 25th. Data was gathered until April the 30th. During the data-gathering period, participants were continuously sent reminders to encourage them to keep logging experiences on DO. After data-gathering, exit-interviews were conducted with some of the participants. "[...] if you can collect data via multiple methods, you can obtain a more holistic view and fill in gaps any single method can miss" (Baxter et al., 2015, p.195).

### 3.3 Data analysis

Data was analyzed based on the values that were assigned to each of the experiences. An experience with a positive value was interpreted as positive when participants experienced it, whereas it was interpreted as negative if participants had not experienced it. Likewise, an experience with a negative value was interpreted as negative if it was experienced while positive when not experienced. This was done to obtain an equal likelihood for positive and negative experiences, as the amount of positive and negative experiences in each category was unequal.

## 4 Results

In the data analysis, the probability for positive experiences was used, rather than the frequencies, to analyze differences between the two diabetes duration groups. This was due to the unequal amount of experiences in each category and variance in response frequency by participants.

### 4.1 The sample

27 participants agreed to participate in the study, however, two of them did never log any experiences on DO. Both participants had diabetes for less than one year. It is unknown why they did not log experiences as they did not respond to the reminders that were sent to them. So, 25 participants logged experiences on DO. The participants in the newly diagnosed group (N=11) had an average diabetes duration of 3.8 months (SD=3.01) whereas this was 117.4 months (SD=116.02) for the experienced group (N=14). The sample consisted of 16 males and 11 females with a mean age of 61.5 years (SD=14.5). This resembles the Danish type 2 diabetes population (Sundheds-

datastyrelsen, 2018). Three participants did not treat their diabetes with medication, while the majority treated their diabetes with pills. Only one participant used insulin to treat his diabetes. According to Diabetesforeningen (2021), a desirable HbA1c value is around 48 mmol/mol, and this applies to most participants ( $M=56.4$ , median=48,  $SD=25$ ). The large standard deviation in HbA1c value is caused by two participants with values above 100 mmol/mol. Those two are both newly diagnosed, which could point towards newly diagnosed diabetics having larger HbA1c values, but no significant correlation between HbA1c and diabetes duration was found ( $p=0.073$ ). Six of the participants made contact through email during the data-gathering. Three of them commented that it did not make sense to log experiences every day as they did not encounter new experiences.

#### 4.2 Sources of errors

After initiating the user study the finish page had not been added to DO. This error only affected the first recruited participant, since it was corrected quickly. During the data-gathering, it was discovered that participants seemed to log more than the 93 experiences they were supposed to log daily. The cause for this could be that the finish page contained a link that would restart the experience logging when clicked. 20 participants were enrolled in the study, at the point where the link was removed.

#### 4.3 What was experienced?

The 25 participants logged 9292 experiences in total, making the mean number of experiences per participant 372 ( $SD=373.8$ ). On Figure 3 the frequency of logged experiences and the distribution of responses per participant can be seen.

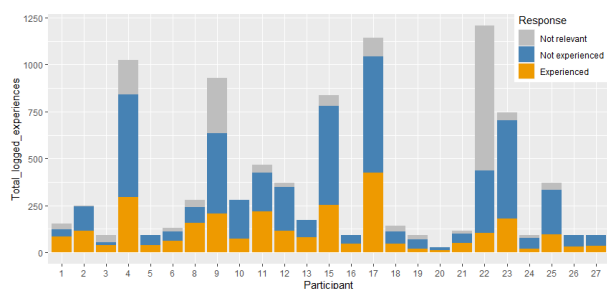


Figure 3: Frequency of logged experiences by each participant, and the distribution of the three responses: 'experienced', 'not experienced' and 'not relevant'.

Figure 3 and the standard deviation greater than

the mean number of logged experiences, show a large variation in the amount of logged experiences across participants. Some participants logged more than 1000 experiences, while others logged less than 50 experiences. The participants also varied in how often they skipped experiences. For example, participant 22 skipped more than 50% of the experiences, while participant 10 never skipped an experience. The following list shows an English translation of the experiences that were skipped by at least 10 participants.

- The people I live with are reminding me of checking my blood glucose levels.
- I have checked my blood glucose levels the number of times I have been recommended by my doctor.
- I have worried that I could not get help if I experience hypoglycemia.
- My mood and emotions have had a positive impact on my blood glucose levels.
- I forgot to measure my blood glucose levels.
- I felt that my blood glucose levels were more stable when I have taken my diabetes medication.
- I have told people around me how they can help me if I get diabetes-related problems.
- I have eaten by my doctor's recommendations.
- The people I live with have told me that I manage my diabetes well.

Especially, experiences about blood glucose, following recommendations, and social interactions were skipped. The following list shows an English translation of the 10 experiences that were encountered most frequently by the participants.

1. I have felt happy and been in a good mood.
2. My diabetes management is going well.
3. I have followed the prescription for my diabetes medicine.
4. I have taken my diabetes medicine exactly as my doctor has told me.
5. I woke up and felt fit and re-energized.
6. I have had a surplus energy to exercise.
7. I have felt I should do more physical activity.
8. I have had surplus to cook healthy food.

9. I have had to avoid certain food.

10. I have had the feeling that my diabetes medicine does what it is supposed to do.

Only two of these ten experiences, number 7 and 9 in the list, might be considered as being negative by the participants. This indicates that the sample contained diabetes patients who encountered positive experiences to a high degree. When negative experiences were encountered they tended to concern diet and exercise.

On Figure 4 it is visualized how the participants answered within the 13 categories.

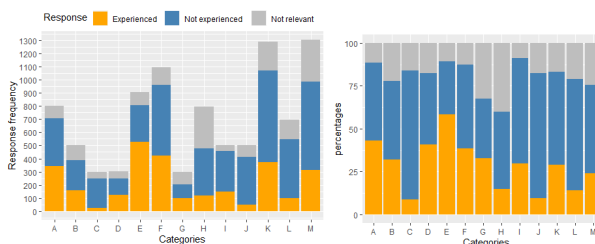


Figure 4: Bar charts of the distribution of responses in the 13 categories. The bar chart at the left shows the frequency of responses while the bar chart to the right shows responses in percentages.

The bar chart to the left on Figure 4 shows a lower frequency of responses in some categories, for example, C (diabetes disturbs life), D (changed eating habits), and G (exclusion from social life) than others. This is primarily a result of having different amounts of experiences within the 13 categories and partly because participant 20 did not log all 93 experiences, see Figure 3. The bar chart to the right on Figure 4 illustrates that some categories have a large proportion of skipped experiences, such as category H (support from others) and G (exclusion from social life).

#### 4.4 Differences between newly diagnosed and experienced group

For each of the 25 participants, the mean probability for positive experiences within all of the 13 categories was calculated. The box plots on Figure 5 show the distribution of the mean probabilities for positive experiences in relation to diabetes duration.

Considering the mean probability for positive experiences in the two groups, Welch's two samples t-test showed no statistically significant difference between the groups ( $p=0.491$ , 95%CI[-0.057, 0.116]). This is supported by the box plots

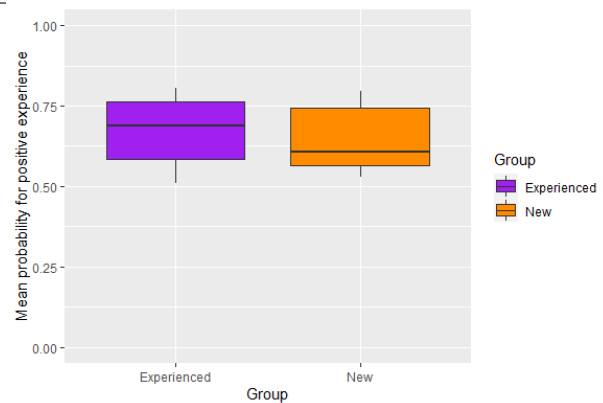


Figure 5: Box plots that illustrate the distribution of mean probability for positive experiences within the experienced group, purple box plot, and the newly diagnosed group, orange box plot. The thick black line in the boxes shows the median for the two groups.

on Figure 5. Although this difference was not significant, there could be differences within the 13 categories as they represent different problem areas. The plot of means on Figure 6 illustrates the probability for positive experiences within the different categories in relation to the diabetes duration grouping. The probability of positive experiences

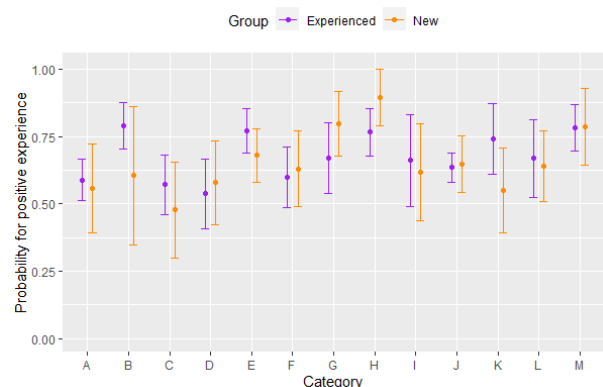


Figure 6: Plot of means that shows the probability for positive experiences in each category with 95% confidence interval. Purple is the experienced group and orange is the newly diagnosed group.

seems to be affected by diabetes duration in some categories, see Figure 6. This can be investigated by calculating the effect sizes of diabetes duration within each category. The effect size measures the standardized magnitude of the observed effect and the measure of Cohen's  $d$  will be used (Cumming, 2011, Ch.2). A large negative effect of diabetes duration was found within category H ( $d=-0.849$ , 95%CI[-1.719, 0.021]) while a large positive effect of diabetes duration was found within category K ( $d=0.836$ , 95%CI[-0.033,

1.705]). This is supported by the plot of means on Figure 6 which shows that in category H (support from others) the newly diagnosed group had a higher probability for positive experiences, while in category K (fear or concern) the experienced group had a higher probability for positive experiences.

#### 4.5 Variance in data

As the overall difference in mean probability for positive experiences could not be explained by diabetes duration, linear mixed-effects models were constructed to identify meaningful predictors. The models were compared with ANOVA to find the model of best fit. The model that explained the most variance in the overall mean probability for positive experiences contained category and two of the yes/no questions as predictors; question 3 and 7. That the probability of positive experiences varies as a result of the categories is supported by Figure 4 which shows that the distribution of response options varied across the categories. On Figure 7 it is illustrated how the responses on the two yes/no questions affected the probability for positive experiences. From Fig-

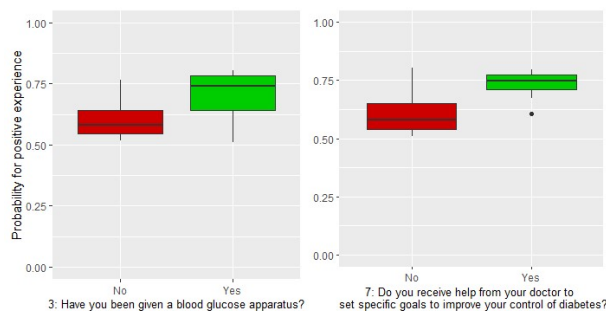


Figure 7: Box plots illustrating mean probability for positive experiences in relation to response on question 3, box plot to the left, and response on question 7, box plot to the right.

ure 7 it can be seen, on the box plots to the left, that participants who responded 'No' to question 3 (N=9), red box plot, had a lower probability for positive experiences than the participants that responded 'Yes' (N=16), the green box plot. The box plots to the right on Figure 7 show that participants who responded 'No' to question 7 (N=15), red box plot, had a lower probability for positive experiences than the participants who responded 'Yes' (N=10), the green box plot.

#### 4.6 Exit-interviews

Four participants were interviewed, after they finished logging experiences on DO, to explore the

participants' opinions on the method and the interpretation of their logged data. In summary, the exit-interviews showed that participants had used the skip button as intended, meaning they skipped experiences that had no relevance to them. This was important because participants should not log irrelevant experiences as 'not experienced', as this could lead to faulty interpretations of the experiences logged as 'not experienced'. Despite this, the exit-interviews revealed that some experiences were still incorrectly interpreted as either positive or negative. Especially, when interpreting a positive experience as negative, if it was not experienced. Based on this, 12 experiences should either be removed or rephrased.

In terms of using the results to quickly identify problem areas, this succeeded to some degree. The participants in the exit-interview mostly agreed with the interpretations of the categories, however, some categories were not a correct representation of the problem area they were supposed to cover. The names of the categories and the experiences they contain could therefore be reconsidered. Participant 23 found it confusing that he had to log the same experiences over and over again because he did not encounter new experiences. But after a few days, he understood that he should log the experiences even though they had not changed since the last time he logged them. Apart from this, participants had a positive attitude towards logging experiences through this method, as it helped them reflect upon their diabetes. Although most participants did not consider it appropriate to use DO for completely newly diagnosed patients, as it would be overwhelming for them.

## 5 Discussion of results

In the user study, two participants never logged any experiences and some participants only logged the 93 experiences once. Perhaps the instruction of logging experiences over the course of multiple days was not clear or the participants might find it tedious to log the same experiences for several weeks. The emails received from three of the participants and the results from the exit-interviews point towards it being unnecessary to log experiences every day as daily changes in experiences are uncommon. It could be considered to encourage participants to log

experiences on DO once a week instead. Participants should be sent reminders, to reduce the risk of participants forgetting to log experiences. The number of responses in this study could have been increased by sending more reminders. The reminders that were sent either made participants log more experiences or contact the researchers with comments. In the exit-interview, participant 23 suggested that weekly reminders would have been helpful to prompt him to keep logging experiences.

The experiences that were skipped the most concerned blood glucose, following recommendations, and social interactions. This points towards that this sample did not have to check their blood glucose and did not receive special recommendations in terms of diet by their doctor. The experiences about social interaction might have been skipped because the participants have already informed people in their social circle about their diabetes or they live alone.

It might be difficult to assign values to diabetes-related experiences the way it was done in this study. The exit-interview participants commented that interpretations of experiences were not always correct and that it can be difficult to assign values to some experiences. This is because it depends on the individual diabetes patient whether they find a certain experience positive or negative, and some experiences might be neither. Investigating whether the experiences are assigned correctly as either positive or negative should be part of a second iteration of this user study. It would be recommended to involve professionals who work with diabetes patients, like a doctor or diabetes nurse. They could contribute with knowledge about what is thought to be a positive or negative experience for a diabetes patient, and what experiences cannot be assigned either a positive or negative value. This might reduce the risk of wrongfully interpreting the experiences. Another option could be to not assign values to the experiences and instead only consider whether the diabetes patients have or have not encountered the experiences. Then the patient could for example discuss the most and least encountered experiences with their doctor to determine whether the patient is satisfied with what they have experienced. However, this would

make the process of identifying problem areas more time-consuming.

No overall difference in probability for positive experiences was found between the newly diagnosed and the experienced group. This is opposed to the findings by [St. Jean \(2012\)](#), who did find differences in what type of information newly diagnosed diabetes patients needed compared to experienced diabetics. The experiences about information, used in DO, were not all in the same category, which could be why the results by [St. Jean \(2012\)](#) are not supported in this study. This implies that some experiences might not have been categorized properly which the exit-interview findings also implies.

A different reason that no overall differences was found, could be that the distinction between new and experienced is not accurate. Perhaps type 2 diabetes patients do no longer feel as being newly diagnosed after having had the diagnosis for almost one year, which was the used distinction in this study. It could also be because the differences in diabetes duration in the experienced group varied from one year to 31 years. Therefore, there might be variation in probability for positive experience within the group. These two points could be reasons for the similar probability for positive experiences within the two groups, as seen on [Figure 5](#). To account for the duration variance in the experienced group it could be considered to distinguish between three diabetes duration groups instead.

Finding no overall difference between the two diabetes duration groups could also be because the recruited sample of diabetes patients are not experiencing problems with their illness. Considering that eight of the 10 most frequently encountered experiences were positive there might primarily have been recruited diabetes patients with surplus energy. This can have influenced the results to look more positive than how it might be for the population of type 2 diabetes patients. However, it could also be that type 2 diabetes patients in Denmark generally have a positive attitude towards their illness and therefore do encounter more positive experiences than negative.

Within category H (support from others) and K (fear or concern) there was found a large effect of diabetes duration on probability for positive experiences. The finding, that the newly diagnosed group to a higher degree than the experienced group receive support from others could be because they are more in need of it. St. Jean (2012) found that experienced diabetics have learned more about their illness and changed attitude towards it, which are possible explanations to why the experienced group in this study encountered less negative experiences in terms of fear and concern than the newly diagnosed group. Medium or small effect of diabetes duration was found for the other categories. Further, it was found that the three predictors; category, question 3 (Have you been given a blood glucose apparatus?), and question 7 (Do you receive help from your doctor to set specific goals to improve your control of diabetes?) explain the variance in probability for positive experiences in the overall data. Receiving a blood glucose measuring apparatus and receiving help from the doctor to set goals, seemed to affect the probability for positive experiences positively, see Figure 7. Category being a predictor means that the 13 categories in fact cover different areas in the life of a diabetes patient. Therefore, it is important to also consider probability for positive experiences within each category and not only the mean probability across all 13 categories. It should be noted that these results might not be representative of the population as the results are based on a sample of type 2 diabetes patients.

DO could become a useful tool within health care. For example, health care professionals could use the the experiences logged by a diabetes patient to focus on specific problem areas for the individual patient within their treatment. In addition, logging experiences with the proposed method has the potential to help type 2 diabetes reflect upon their experiences and thereby improve their self-care.

## 6 Further research

The method used in this study enables researchers to gather experiences from type 2 diabetes patients continuously thus not demanding patients to recall their daily experiences, as in an interview. As the experiences are divided into different cat-

egories, the method can be used to identify certain problem areas in the life of a type 2 diabetes patient. Through the user study, improvement ideas led to reducing the number of experiences to log from 93 to 67 experiences. Less experiences could make the logging less overwhelming for newly diagnosed diabetics. The initial categories were revised and narrowed down from 13 to seven, which can be seen in Appendix A.3. This way, each category holds more experiences and should be covering each area in the life of a diabetes patient more thoroughly. In addition, 20 experiences could be introduced only for people where they are of relevance, for example, experiences concerning insulin.

If the proposed ideas for optimizing this method are implemented, problem areas within type 2 diabetes might be identified more rapidly than through a typical check-up at the doctor.

## 7 Acknowledgement

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## A Appendix

### A.1 Categories for the experiences

The categories are translated from Danish.

- A) Restricting the way you live your life
- B) Lifestyle does not fit to the recommendations
- C) Diabetes disturbs life
- D) Changed eating habits
- E) Feelings related to restricting the way you live your life
- F) Daily diabetes management
- G) Exclusion from social life (loneliness, stigma, etc.)
- H) Support from others
- I) Guilt
- J) Non-disclosure
- K) Fear or concern related to any of the above
- L) Ignorance
- M) Treatment

### A.2 The 13 yes/no questions

The participants could respond 'yes', 'no' or 'do not know' to each of the questions. Question 9a and 10a would only be shown if the participant responded 'yes' to question 9 and 10 respectively. So, some participants might be shown less than 13 questions in the demographic survey. The questions are translated from Danish.

1. Do you have any family members that have diabetes?
2. Are you part of a Facebook group for type 2 diabetics?
3. Have you been given a blood glucose apparatus?
4. Are you encouraged to ask questions at doctor visits?
5. Have you experienced that your doctor did not trust you when you told them you had pain?
6. Is your doctor good at telling you about your numbers?
7. Do you receive help from your doctor to set specific goals to improve your control of diabetes?
8. Does your doctor listen to how you want to do things in relation to your diabetes treatment?
9. Have you attended a course about diabetes?
  - (a) Was the course useful for you?
10. Have you attended a course by a dietitian or other health professional?
  - (a) Was the course educational for you?
11. Do you think that there is missing information about diabetes for your family or/else the people you are living with?

### A.3 Revised categories for the experiences

- A) Daily diabetes management
- B) Restricting the way you live your life
- C) Missing information
- D) Feelings and worries
- E) Social interaction
- F) Guilt
- G) Treatment