

Focus Group 1

Information about the appointment

Date: 15.09.2023

Participants: TN1, TN2, TN3 and TN6

Transcript

GA: A first question just in general, um, you've all looked after diabetes patients in some way, haven't you? At some point, be it in-patient or out-patient, GP locum, have you all had contact with diabetes patients? Have you ever looked after or seen patients with technology, with a sensor?

TN6: Both.

TN3: I look after them myself, but I also have friends and colleagues who have a sensor or a pump or something.

GA: Okay, okay. And what do you think is... so, one can start and then others can add, what are the challenges that diabetes patients might experience in everyday life and where is the problem of managing diabetes well?

TN1: So you know that my husband has type 1 diabetes... (phone rings, TN1 apologizes and leaves the room briefly)

GA: Maybe you can start (TN3)?

TN3: Yes, okay. So I have... (TN3 asks if dialect is okay and then continues speaking in dialect). I have a colleague who has type 1 diabetes and she has a pump and, I mean, I've known her since we were teenagers and that's when it started to be a challenge for me, now, for example, drinking alcohol. Where is the limit... Well, I mean, if you drink too much then maybe you can no longer operate the device and afterwards you have a bad reading or she told me how as a child she always had to watch her mother at night because of the hypoglycemia. And that's perhaps a challenge that people aren't even aware of, because the technology itself is mega fascinating when you read up on it, that you can simply treat such a metabolic disease with a device, with a sensor, and she's virtually cured, but there's also a lot of compliance and knowledge from the patient behind it. And I think she's an intelligent woman, that's what I've always thought, who can "do it" and get out of it, with math and everything, so whatever, it's good. And for someone who is perhaps not as well educated or has a bit of trouble with numbers, who is perhaps a foreigner or also has language barriers, it's not as easy as you might think and you can see that... so at Balgrist (hospital) I saw that with the diabetic feet, what they... They simply can't cope with it, but they also have too little external support, don't want to accept enough support and the consequences are devastating. So it's a very wide range, so there are a lot of possibilities, but a lot depends on you.

GA: Very well summarized. So beautiful. TN1, you were about to say something and we interrupted you.

TN1: So my husband has type 1 diabetes and he has this sensor and this progression is very challenging. And I see my husband, he always has to think, "Okay, what am I eating? What's my stress level? Can I exercise later?" Ehm, there are so many factors with diabetes and for me that was interesting to see my own curve and what an impression or influence can have. Ehm, when I get up, I'm under stress or I've been breastfeeding or what, I've eaten a banana and then I see that it's gone up like this. And that was a reason for me, I always have to (pause for thought), you have a greater perspective on the factors for blood sugar and also what the influences of inflammation from high blood sugar or high stress, the positive influence of exercise after eating or exercise before eating for example. Because we have this blood sugar in us, but we don't think about it, we go on and we do what we want.

(Nods of agreement and approving noises from the other participants)

GA: Fine.

TN6: Yes, I think because I've experienced it with patients, but also with friends, that it's simply a very big challenge when you have diabetes / that it's simply a very big challenge when you have diabetes to manage your blood sugar because it's simply a very complex cycle that depends on many things and you simply have to readjust it now.

(TN2 enters the room slightly late and sits down quietly)

TN6: And ehm, you can see that some patients come here to have their blood sugar adjusted. They've had type 1 diabetes for a very long time, for years, and now all of a sudden for one or two years they've constantly had values over 20 and you don't know why, so you have to find a new approach somehow. So even if you've managed to find something good for yourself in one episode of your life, metabolic things may change over the course of your life. And while I have a friend who manages her blood sugar relatively well, always has relatively good values and compensates for this with sport, I have another friend, for example, who no longer likes going outside in summer because the heat always sends him into hypoglycemia somehow and he constantly has to eat something and then he doesn't even like doing sport outside anymore because he feels so physically unwell. And you can just see the limitations and ehm, yes, I think that's where you're directly confronted with the challenges for the patients. So yes, at my point, for example, I wouldn't have any good suggestions for people on how to do things better.

(GA briefly informs TN2 about the audio recording)

GA: We asked so briefly, you've probably also seen diabetes patients like that...

TN2: Yes, totally.

GA: And also probably patients, with a sensor or...?

TN2: But even with a sensor. I have the feeling that this is especially true for those with type 1 diabetes, because they have had it for much longer... so...

GA: ...section)

TN2: ...in the stage of life. Most type 2 diabetics don't have it until later in life and the type 1s, most of them at least, have lived with it since they were young. And I just think that having this sensor like this is important, because I also had some people at school, for example, who had type 1 diabetes, for whom it was unpleasant in the middle of the day to say: "Sorry, I have to go and get a prick because of my blood sugar". And that they simply no longer have this stigma and don't just say: "I have to step away from life for a moment to do this". Instead, the sensor just keeps running, so to speak. I mean, with the Freestyle 3, it's the direct connectivity, they don't even have to hold the phone to it anymore, I think they can participate in life instead of having to constantly step away because of something. I think it's just so cool for them.

GA: I'll probably start with you, TN6, and then we can go through it like this. You were very interested in wearing it yourself. Can you tell us what your experience was like from the beginning up to a fortnight? What stayed with you? What information and ehm, were there any problems?

TN6 (nods): Well, my interest actually came from having an insight into the body that you don't really have otherwise. So blood sugar levels are something you might measure once at the doctor's, you do HbA1c and for the settings, but otherwise I don't know what's going on in my body. And I've noticed myself when I'm under stress, when I'm having a hard day, I feel shaky and then I eat something and then I feel better and somehow that's where the interest came from: "Okay, what's actually going on with my blood sugar?" Then I also

experienced relatively quickly that when I work in the emergency department and am stressed, even if I have eaten a lot, I have very low blood sugar levels, i.e. too low. And that made me realize that I need to eat even more to somehow compensate for this. At the same time, I also noticed that when I'm at home or on a quiet shift on the ward, for example, everything is actually relatively balanced. And it was very interesting to see the effect that stress or mental strain or physical strain has on this. Whereas physical stress wasn't so much in the foreground, because when I went for walks, it was still well balanced, so to see that the body can control it really well. And also to get a feeling for which foods have which influence, for example a very balanced meal with lots of protein actually caused a relatively stable curve and you felt very good, whereas a very carbohydrate-rich meal with almost exclusively carbohydrates caused big peaks. In the case of instant noodles, some of these peaks exceeded the normal values, which was very interesting to see.

GA: Those were Chinese noodles, weren't they?

TN6: Yes, those instant ramen noodles. It was interesting to see this effect and then also to see what patients are confronted with when I already have a supposedly healthy salivary gland. Ehm, problems that could result from this for me now are that, for example, I have seen very low blood values, I was already stressed on the emergency ward, but that is not a dangerous situation for me. That I'm not at risk of negative consequences from hypoglycemia because my body still has a different metabolic capacity. And that's where I perhaps see the limits of the whole thing, that you might underestimate the problems of people with diabetes if they have these values. So that's what struck me.

GA: You have the feeling that your consciousness has changed a bit in this direction? Can you say that?

TN6: Exactly. Or that's where I see the danger in tracking yourself and then seeing: "Ah, I'm still doing well," for example.

GA: Yes. How was it for you, TN3?

TN3: Yes, um. I actually just did it out of interest to have a go. It's fun and exciting to see what kind of values you have and then I'm, um, also clearly, I've also observed it a bit when you do sport, sometimes hiking, sometimes eating something. I'm then somehow, I'm also quite enthusiastic: "Now I've eaten something, now I'm holding it up (the cell phone to the sensor), now it's certainly mega high." And then I was a bit disillusioned, because somehow it was always just always within the normal range. At most 4.8, 4.7 from time to time / And then I was a bit disillusioned because it was always somehow just always within the normal range. At most 4.8, 4.7 now and then, even when I was hiking, when I had the feeling "Now I'm really hypoglycaemic, really dehydrated, hypoglycaemic", then I measured it and it was actually normal. And then you realize a bit: "Yes, of course it's normal, I have a functioning pancreas." I don't have a problem, so I might feel hypoglycaemic, but probably just like she (TN6) said, I'm not in any danger because my body can regulate my metabolism. And that is, yes, I have sometimes noticed that you stick to values and it's also kind of cool, but I think it can also put you under stress to always have to orientate yourself to a value. Also that colleague I was talking about earlier, she got depressed because she was so fixated on having a perfect HbA1c. So if you only focus on numbers and no longer pay attention to your physical well-being and "How am I doing?" and no longer listen to yourself and only listen to the value, like: "I have a bad value, I have to feel bad now...". So... (pause for thought), what I still experienced as a difficulty, and what I wouldn't have thought, was the night-time measurements. You explained that to us, three times a day, every 8 hours, no problem. I mean, I measured it much more than three times a day anyway, but then suddenly you wake up in the morning and: "Oh, it's more than eight hours!" So maybe you don't sleep for eight hours, but then you measure, so you realize: "Aha, I have to hold it right before I close my eyes and just when I get up I have to hold it." And otherwise you're no longer in the eight-hour range and it's so difficult. And then I had to set an alarm clock at the weekend so that I wouldn't forget, because otherwise... (Surprised noises from the other participants) Yes, but I can imagine that it's a challenge for patients to have the whole time management and the whole thing in their heads. Yes, exactly.

GA: And if you imagine, well, you didn't have any need, so this is out of interest: "Okay, is there an interruption?" If you forget, that's not good, so set an alarm clock, but it can have consequences for patients.

TN3: Exactly, it has consequences for them, so they certainly have a different motivation for doing it. But it's not that relevant for us.

GA: Yes, interesting. With you, TN2?

TN2: Yes, I found the study itself really interesting. Because, I mean, most freestyle studies are geared more towards diabetics, I mean, I think very few have been done on healthy subjects. Ehm, and just out of interest, which is what TN6 meant, if you adjust your food intake in this way. So if you eat the proteins first and then the carbohydrates, then I've already seen that the spike was flattened out afterwards, but then on the other hand there's a bit of a feeling of guilt because you know that you're going to eat the chip packet now, because you know that the spike will come straight away and it did. So that was exactly the expectation. And then I also found it really interesting that, because I had it the other way around with TN6, when I... my blood sugar always spiked when I was stressed. I was never, hardly ever, hypoglycemic. And I've also seen this, for example, with the circadian rhythm, so somehow at five o'clock in the morning, that the sugar went up so quickly and then I just felt so awake, but then I also felt awake. And then with a stressful situation, for example, I once had someone with TN1 on the ward where we thought she might have a bleed in her head. And I was actually still completely sober, but I noticed how stressed I was myself and then I happened to see in the app afterwards how my blood sugar went up and then down again with a bit of a time delay, even though I was still sober. It's also a bit like confirmation, like: "Yes, the job can be stressful from time to time." And that's the real-life correlation to it. Because I know myself, I was sober, so I hadn't eaten anything and the spike was actually supposed to happen when I ate, so it was probably the cortisol spike and that was the real-life correlation. And then it was like: "Yes, it was definitely more balanced at the weekend without duty." (laughs)

GA: So weekends are good for you as far as glucose metabolism is concerned at least. TN1, how were your 14 days with the sensor, what was your experience like?

TN1: When I don't sleep so well, then in the morning the value is always high. I have observed which food makes it higher or lower and ehm, you hear the benefits of different foods and foods, oh you know, you have to eat banana or you have to eat yeast. But you see the individual response with different foods. I've always tried taking apple cider vinegar to control when I've had some high sugar and that has an effect. Or running a bit after carbohydrates with a meal, and that also had an effect.

GA: Did you have any problems with the sensor wear time? Did something go wrong or...?

TN1: No, no.

GA: Okay. With TN6, with you, was there anything where you intuitively didn't believe before the sensor that you would be able to achieve these insights? Was there anything or where you say, more or less, my intuition spoke against my intuition, that was something totally surprising?

TN6: Hmm... I was surprised by the results. Of course I expected that there would be fluctuations, but I didn't think that my stressful everyday life would bring me, i.e. my blood sugar, to my knees like that. And ehm, that even on a balanced day there are still curves that are still within the normal range, but are still relatively pronounced. Ehm... yes, even though I'm supposedly so healthy. And that I've also reflected on how unfortunately the job can sometimes be disruptive for the body. That was one value that we measured and it would be interesting to measure other values again that also respond to stress and so on. Yes, that was something I wasn't expecting.

GA: Yes. For you, TN3? Something surprising, something where you say, yes, I totally didn't expect that from this self-tracking?

TN3: No, so now I realize again, when she (TN6) says what kind of fluctuations she has, that it totally unsettles me, because I haven't had that. So it's like that again, like I said before, it's like a comparison. So you have the feeling, why is it now up with her and not with me, so that you somehow... yes, so that you just... that it's mega individual you notice even more through that, I think. And ehm, what I didn't expect either, it's described in such a super relaxed way: "Yes, no problem, you just do it there (points to your own upper arm) and then it doesn't bother you at all." But in the shower, when you get into the shower in the morning and you're so stressed out, I'm like "Wow!", so I've been a bit too roughly short. Or even when you're sleeping, you can still feel it a bit if you're lying on it the wrong way, so it bothers you a bit and I don't think you're aware of it beforehand.

GA: Yes, yes. With you, TN2?

TN2: I find that with the sensor, in terms of the values, I'm a bit surprised that it went up so often for me. Ehm, but also this other point that TN3 mentioned earlier. I mean, it's not actually invasive, we just have to remember to pick up the phone every eight hours. And even then, you forget a bit, because if you sleep for longer than eight hours, you're automatically over it.

GA: Yes.

TN2: Then I imagine what it was like in the past, when you didn't even have a Freestyle Libre and then you had to prick your finger all the time. So I was a bit bothered by those eight hours, but then with the: "Yes, what was it like in the past when you had to look for the device, prick your finger and hold on to it like that." That's a lot more effort, and you don't even realize beforehand how much effort it takes to simply have diabetes.

GA: Yes, and also the time involved, right. Getting the blood glucose meter out, and then preparing and ehm the whole thing. Nice. With you, TN1?

TN1: I also think that we ehm... (pause for thought). I don't know how to explain that in German. Can I say that in English? [Engl: It's when you wear the sensor it's a visible sign of your disease. And uhm, before, people see the sensor and they say "Oh, they have type 1 diabetes." And in the US people are wearing it more and more for this reason to just know the curve, to know the inflammation. So, it's not a sign of your diabetes, it's actually a sign of "I'm a very health conscious, very health literate person." For me, that was interesting. Because first I would always look at my husband and say, "Everyone knows he has Diabetes.," because everyone sees it's here (TN1 points to her arm) and then he used to put it here (TN1 points to her loin / lumbar region) for more privacy. And then I started wearing it and then people would say "Do you have Diabetes, do you have Diabetes?" and I said: "No, I'm doing a study." So, it's an interesting perspective].

TN1: (translated from English): When you wear the sensor, it's a visible sign of your disease. And before that, people see the sensor and say, "Oh, you have type 1 diabetes." And in the US, people are wearing it more and more for that reason, just to know the curve, to know the inflammation. So, it's not a sign of diabetes, it's actually a sign of "I'm a very health-conscious, very health-educated person." For me, that was interesting. Because before, I always looked at my husband and said, "Everyone knows he has diabetes." Because everybody sees that he's here (TN1 points to her arm) and then he put it here (TN1 points to her loin/loin area) for more privacy. And then I started wearing it and then people were like, "Do you have diabetes, do you have diabetes?" And I said, "No, I'm doing a study." So it's an interesting perspective.

GA: Very good.

TN3: Yes, I think a resident saw that I had this and thought: "You know, TN3, this is the first really sexy medical device that you can wear. Because it shows that you're... Yeah, it's just cool, you're tracking yourself." And I was like, "Huh?" So I couldn't relate to it at all, but obviously, like TN1 said, it's more and more something that people are using that describes you as a person who's interested in their health.

GA: Yes, it's interesting that this change has also taken place, at least in certain countries. Switzerland will probably join in later, but we don't know.

TN1: In America there's a waiting list for this um, app called Levels. And Levels measures the blood sugar curve and says, "Oh, you have inflammation from these high levels." And everybody's waiting for Levels and they buy it and it's like a status symbol that you think about it.

GA: Are there already studies there, about these people who carry themselves...?

TN1: Mhm, yes. They are in studies.

TN3: But that's kind of stupid, isn't it? So reducing your health to your blood sugar level is the epitome of a person who is intelligent enough to inform themselves and gather so much information from everywhere but then feel that: "If I'm wearing this, then I'm doing myself just the right thing". I mean, if everyone was smart enough, become an endocrinologist, I mean it's so complex, there's so much more to it than just a blood sugar reading.

GA: You said it so well, because in the end it's still integrative information about health. The problem is, it's only fractions that are available to us. Like TN1 says, we don't even know what our blood sugar is without measuring it. Especially if someone has diabetes. Of course, with good regulation like yours (TN3), you don't even need to know because it will be good. But very probably not in diabetic patients. If you could tell me now, okay now we're putting ourselves in the shoes of patients, what benefits could this technology bring? From your point of view, for example, TN6?

TN6: The advantage, at least as I perceived it, is of course the wearing comfort. It holds firmly, it's somehow weatherproof, water-resistant, you don't have to restrict yourself too much, you can even go to the sauna. So first of all, as far as the sensor is concerned, you can do everything you need during the day. Of course, you have to take less material with you, you don't have to prick yourself, make sure it's... so it's also kind of hygienically sealed. It lasts for two weeks, which is relatively good to start with, and of course it's super easy to use. So you don't have to attend a big training course, do you? Even you, Gurpreet, showed me how to do it once and then it was easy. Or you just have to hold your cell phone up to it. Ehm, yes, the limitation is of course if the cell phone doesn't work, if the cell phone isn't there, you can't measure your blood sugar level. If there is a malfunction in the device, which can certainly happen from time to time, then you can't measure your blood glucose directly, so you would have to resort to other things. And yes, there is certainly also the problem that it might also be uncomfortable and you feel identified as someone with an illness. But otherwise I have to say, I actually see quite few disadvantages there, so yes.

GA: What do you, TN3, see as the benefits for patients to adopt and continue to use such technology for management?

TN3: Yes, certainly everything she said. Well, I said earlier that it's a bit uncomfortable, but I think it's very convenient overall and a good device. Ehm, and the other advantage for patients is of course that your diabetologist has a much better overview of what your values are. Otherwise you can somehow say: "Yes, everything's fine." And of course, you always have the HbA1c, but still, with a device, just like she (TN2) said, the new one always measures and the pumps always measure. And you also have the nice curves where you can see exactly how an individual responds to how much insulin, so you have the chance to achieve much better long-term sugar with a device.

GA: Great, very nice. For you (TN2)?

TN2: I can imagine, especially when... very, very young type 1 diabetics... When children have this, I mean, it's a lot of effort for parents. And especially I think in the USA, some of them have such a link with the insulin pumps that it is then automatically linked to the app in order to achieve such a level. I think that's also a lot easier for

the parents, instead of telling the children: "This is how finger pricking works and now you have to inject so and so much." Instead, it's a bit more of a... It's just going on all the time, as long as there's no system error. I think that's also more relieving for the parents.

GA: An app like that, which is semi-automatic, so that they don't have to worry so much. Yes, and for you (TN1)?

TN1: I think that's an advantage when you see the information in a curve, not in discrete data points. Because afterwards you always have to do that and ehm, you forget this curve. You just see this number and ehm, health is like a curve and you have to integrate so many factors and you see that with this device that it shows a... not just a point, that's a story.

GA: There is a before and after.

TN1: Yes, yes.

TN6: And one thing I can perhaps add is that there is another thing that we have also described, which is simply to see exactly which diet influences blood sugar and how. So to see that on the basis of a curve and also certain lifestyle decisions and stress and the job, you can see that much more clearly on the basis of several values and not just points. And I think it's very valuable to adjust a little bit and see that you have a more balanced blood sugar level.

(Everyone nods in agreement, or makes noises of agreement)

TN3: And depending on that, it also warns you if you get into hyperglycemia, I mean, in the past you might have just suddenly been lying somewhere and nobody found you and now you are warned by the device. I think that's certainly a great relief.

GA: There is probably also courage to lower high values because you have a bit of security. I don't know if that could be a factor...

TN3: So how...?

GA: You can understand a patient's fear, can't you, of hypoglycemia? And even more so if you can't see the values. And with the sensor you can see the values, then you can probably see better.

TN3: Yes, definitely.

GA: So now you've actually recognized glucose metabolism for a bit longer, 14 days. And now, if a patient comes in with diabetes and he doesn't have a sensor. Would you perceive this patient differently and approach them differently or has nothing really changed much with the sensor?

TN6: So the question was whether patients who now have small sensors should be looked at differently?

GA: Yes.

TN6: Well, I just think that dealing with the subject of blood glucose yourself naturally heightens your awareness of what are normal blood glucose values and what are not, and of course when I see someone's diary I can also think my way back into the curve that I saw on the Freestyle Libre and then draw my conclusions. Is the person doing well or not?

GA: Beautiful!

TN6: I think I'm honestly much more interested in it now. So before, blood sugar was always something like: "Oh, now the person also has diabetes, now I have to cover that somehow." And you were always happy if the person had a good regimen that worked well, then you might have injected a bit more as the disease

progressed, but then it worked. And to be honest, when patients came in who... where it was always exacerbated, you were a bit like: "Oh, now you have to take care of it." But now that I've done it myself, I've actually got to the point where I'm really, really interested in it and really want to look at it with the patients and identify what might be there. So regardless of whether they have a sensor or not, that had the effect on me at least.

GA: Yes, fine. With you (TN3)?

TN3: I don't think I quite understand the question...

GA: So, the question is: We have our own understanding of a disease through the books we have read, or: "This disease means this." You don't have this disease and you've seen your glucose regulation with the sensor, ehm and if you think, okay, what would such a curve look like in a patient with diabetes, you can probably imagine that the fluctuations are greater than they were in your case. Can you now see the patient with diabetes sitting next to you, can you see him or will you see him differently? Your awareness of a potential patient with diabetes has changed so that you don't just see them as someone with diabetes, but also as a person behind them who can make mistakes, who could have problems with scanning, then forget it, if they don't have a sensor they will probably measure once, ignore once, inject insulin once, not inject once. That you would register the patient a little differently as a human being?

TN3: Yes. So I mean, point: "Why don't they have a sensor?" You can say: "Huh, it's so simple, it would make your life so much easier, why wouldn't they want that?" I think I've always been able to understand that, because I think it's just a huge burden for many people, and it's like, you're confronted with this disease all the time and you're confronted with the fact that your values are crap all the time. And, I'm sorry to put it like this, but it must also be a psychological burden, depending on how resilient you are / because I think it's just a huge burden for many people, and it's like, you're confronted with this illness all the time and you're confronted with the fact that your values are shit all the time. And, sorry to put it this way, but it must also be a psychological burden, depending on how resilient you are. And somehow, purely on the basis of this study, I don't think I necessarily need more.... Of course, I've had an insight into what it's like myself, but I don't have the feeling that I can understand it any more. I think, just with my studies, with the medical profession, but also, I was on the rotation at Balgrist, lots of diabetes patients... of course, you get more and more insight into the fact that it's a challenge, or also in the environment, but...

GA: Yes, yes. With you, TN2?

TN2: Yes, well, I mean, we were confronted with the fact that we were constantly looking at our blood sugar levels and I mean, with myself I was constantly thinking "Wow, if I'm under stress all the time, my HbA1c would probably have gone up somehow over this time if I was stressed 80% of the time." (everyone laughs) And that's why I just think to myself: "Yes, I totally understand that diabetics... I mean, that a disease like this somehow takes up so much of their lives." Somehow that understanding is also there now, I mean, you know beforehand that diabetes is not a nice disease if you can't control it well. And for some people, it's really difficult to control their blood sugar levels if they need triple therapy and still have a bad HbA1c... And when I imagine that they're confronted with it all the time, at some point they really get problems with polyneuropathy, and then they don't even notice that they're becoming hypoglycaemic. I mean, in my case with the stress phases where it goes so high, but for them it's like, "I eat this now and then my blood sugar goes so high", it's no longer controllable. So the understanding is then on a different level.

GA: TN1, with you?

TN1: Ehm, I also think for younger people it's so easy, so convenient (= practical), it's not so strenuous to use. But for older people, maybe, they don't like it with a device... well, they are dependent on a device, they always have to be in contact with a device and these older people, they don't like smartphones or it's also a foreign presence in their lives. And that's also different, it's a different philosophy than we have.

GA: That means you have to work individually...

TN1: ...decide.

GA: ... to see with the patient what his needs and wishes are and what he is prepared to participate in? Yes.

TN3: Yes, or simply recognizing that a patient will never have good values. So we tried again and again and again and he ... he just can't get it right. You can support him with Spitex or whatever, but... Well, not everyone will have an HbA1c that's perfect.

GA: And even on their own, the doctors are also confronted with the fact that they have to realize that they can't get all patients well adjusted if the patient himself doesn't work in the team and isn't there. Because he probably does the main work and we are only there as coaches and whatever to support him. Ehm, is there something, TN6, where you say, okay, for that I can also recommend others to wear a sensor themselves, because that has helped me in this respect. Or for that I would say, no, save yourselves this sensor?

TN6: That means especially people who have diabetes? Yes, I have to think about that because I recommended it to my little sister. My little sister has PCOS and has put on a lot of weight, which has improved with hormone therapy. However, we have already talked to her doctor about possibly starting Fomin, because she has glucose sensitivity, but it doesn't fit the definition of diabetes or anything else. She has now managed to change her diet a lot and everything is much better now. I think it would be really interesting for her to see how her blood sugar responds to physical activity, stress and certain foods in the daily curve. Precisely because she has changed her diet so that she no longer gets such high spikes. So I think that if you're familiar with it, it might help from this point of view. And I also think that athletes might be interested to know when they are running their ultramarathon when they need to eat something in order to have the perfect level. That might also make sense. But then, for someone who doesn't have a certain level of fitness, I think I would be reluctant to recommend that, because putting the values in context perhaps also requires a certain understanding of the body and a certain calmness, that just because you sometimes have high values and sometimes have low values, that's not a bad thing. So I think that the risk of developing a kind of hypochondriac with your blood sugar is too high and also because it might not necessarily have a benefit for you. So... yes.

GA: For you, TN3, what would you recommend to others and what would you say "Yes, not really" for?

TN3: Yes... (pause for thought). Well, my sister does very ambitious mountain marathons and ultramarathons and so on. And she, well, she wanted to do that once and I told her "Yes, sure, you can try it out with a sensor like that." But of course she also sees all her fellow athletes doing it. But otherwise I don't think I would recommend it either, because if there is no indication for it, because (pause for thought) it takes more than just knowing which values are normal values to understand the blood sugar. So I don't think even I understand it the way I would like to understand it. From that point of view, no, I wouldn't.

GA: Yes. With you, TN2?

TN2: I don't think I would recommend it to the average person who doesn't have any pre-existing conditions, because they just don't understand it. And I think you can get obsessed very quickly and I can imagine people who have a tendency towards orthorexia and eating disorders that it could have a negative impact. (All agree) The only thing I could perhaps think about is people who are pre-diabetic somehow because of lifestyle changes, who don't quite know that this might be indicative for two weeks, just that they see "Oh, the meals don't work at all, then my blood sugar somehow goes to 12 or whatever". Somehow it might be a trial for them, but even then I would be cautious, because I think, as I said, they don't have the background to know how to interpret the values. Maybe just as a maximum to know "Oh, I totally react to these things with an extreme blood sugar spike", so that you then know that you should perhaps reduce them a little. Because everyone reacts a bit individually to foods that cause a high blood sugar spike, but even then I would be cautious. So for a lifestyle change...

TN1: I realize that too, you can get fixated. (Pause for thought) You can also have a competition with yourself and that's also dangerous, it's for no reason. I also realized that I was eating yeast for a reason, I wanted to stimulate my milk production. And then I saw that it was so high and then I thought, "Oh, I shouldn't eat yeast." And that doesn't make sense. There are just pros and cons and sometimes, you know, you see an elevated blood sugar with different foods. But that doesn't mean you should never eat yeast or you know... It depends. And you have to have that perspective.

GA: Now, we are slowly coming to the end. TN6, how comfortable would you feel in the future with a patient with a sensor in hospital if the patient is currently under your care? How comfortable and confident would you feel caring for him and probably also supporting him if he had any problems with the sensor?

TN6: I would feel comfortable, in the sense that if I had the patient in front of me now and we were talking about diabetes, I would immediately be interested in him showing me the cell phone and that I could take a look at what it looks like.

GA: Yes, nice!

TN6: Then I could say directly: "Ah, I used to have that too." And then you have a direct connection to the patient, that's also what's fun about treating patients, when you can create a connection that goes beyond talking about how ill this person is or what you need to do now. So I'm always happy when you have something that connects you. Yes, and I would be even more motivated to ask what problems there are, simply because I've always looked at that myself. To what extent I'm capable of dealing with his problems is another matter, but yes ...

(While TN6 was answering, TN1 had to leave the room, her cell phone rang. She did not come back during the conversation)

GA: So you'll be better at making contact?

TN6: Yes, definitely.

GA: With you, TN3?

TN3: Yes, probably above all the point, ehm, that you can take the patient's cell phone and have a look at it. I don't think I was aware of that before, so I think I would have known somehow, but just not so actively and now I'm much more aware of it and you look at it much more. And it's actually a lot of information that you get there.

GA: So beautiful! Yes. With you, TN2?

TN2: Also what TN6 and TN3 said, simply that you have a bit of a connection with the patient and can also build it up, so yes, I know what it's like to have worn one of these things. And then you can also simply correlate what the patient says with their values directly on their cell phone: "Yes, okay, good, it fits."

GA: Chiara, do you have any additional questions that I forgot to ask?

CA: Yes, I find the relationship exciting. So you also think that it's well received from the patient's perspective when treating physicians can say: "I've tried this too." Or when you talk about a device, if you can say: "I've had that experience too?" Do you see this more positively from the patient's perspective or does it not play such a role because they have an idea of the content without self-experience (i.e. the doctors)?

TN3: I think if I were a patient who was now confronted with a metabolic disease, i.e. a new diagnosis, and the doctor said to me: "I can understand you or you can understand me, I've already worn the device", then I think I would feel a bit stupid. Because somehow, you may have worn the device, but you don't have the disease, so that's another two fundamental differences. Sure, it's great in itself that someone can tell you first-hand what it

felt like with the device, / Sure, it's great in itself that someone can tell you first-hand what it felt like with the device, but the connection you share is very limited.

GA: Yes, yes.

CA: I can see that point, yes.

GA: Is there anything we have forgotten to ask where you say, yes, this information is probably also relevant to your studies, probably important to tell us?

TN6: Perhaps I've just thought of an addition to the question of which people should perhaps wear this.

GA: Yes!

TN6: I mean, we did the self-experiment with ourselves as doctors and if we say that it has helped us, it would of course be a suggestion that other people try it out when treating such patients. But on the other hand, it occurred to me that it's also interesting, for example, when parents have children, small children, and they are very involved in seeing what the child is like. For them, of course, to see "how does it compare with me?" so that's another group I can think of where it makes sense. Or in partnerships, if you're involved as a partner, you're also always involved if you have a partner with diabetes, that it's still interesting for them. That's the only thing I wanted to add. But no other questions really.

GA: Great. And is there a possibility that other colleagues have also asked you, everyone knows that you are taking part in the study, have they asked you what your experience has been so far with wearing the sensor?

TN6: Well, I think the exchange was primarily with the colleagues who had it. Although of course, I was on the emergency ward, where I picked it up fresh and of course everyone immediately asked: "How is it now?" And because they were of course so low (the values), everyone wanted to know: "Has the value gone up now, really?" And so on. But in that sense, there was an interest and also a kind of fascination that you could measure a healthy person like that.

GA: Great! Any other additions?

(Silence, shaking head)

GA: Then I would say thank you very much. Now we would turn it off.

Focus Group 2

Information about the appointment

Date: 27.10.2023

Participants: TN4, TN5, TN7, TN10

TN8 unfortunately had to cancel the appointment spontaneously and will write a reflection as compensation

Transcript

GA: So, the question is, what do you see as the challenge in diabetes? Otherwise, without ever having worn a sensor. You can probably start?

TN10: No matter what type of diabetes, type 1, type 2...?

GA: Yes. Both.

TN10: And now in relation to myself or in general? Well, I mean, me of course...

GA: Generally about patients, diabetes patients.

TN10: I think the main challenge is that diabetes is a disease that affects many people and is often asymptomatic at the beginning. That you simply have, firstly, or good screening programs to filter out or catch those who have it at an early stage. And, of course, good treatment, where the main aim is to prevent or avoid all complications. And of course, or not just drug therapy, but also trying to implement other measures and ehm, including or optimizing exercise, compliance, that you can often motivate the patients, who are not always very easy. Ehm, that they see or why you have to make a certain effort to prevent late damage.

GA: Hmm, and the type 1, you asked earlier...?

TN10: I think type 1 is probably easier or, because these are often younger people who are diagnosed relatively acutely and who are probably more aware of what it means if you don't take it seriously. Type 2 is probably more likely, I mean, it's very much about lifestyle modification things, where people are comfortable, or. And ehm, if the doctor can do something, it's easier than if you have to do something yourself. I think that's less of a problem with type 1, from my non-diabetologist point of view.

GA: Yes.

TN7: Can I say something about that in principle, or is it a sequence? I think it really is such a discussion, isn't it?

GA: Yes, of course. It's a discussion.

TN7: So I think for type 1 or, so it's, so it's mostly younger, or and a bit more reflective, or. And ehm, it's just as difficult, probably a bit more, because they think about it a lot more. And I mean, we've all experienced what it's like now, because you can't really assess what sugar is like. Or even after eating, we've also had sugar spikes a few times, after eating spaghetti, we didn't feel any of it at all, we were just a bit shocked. and I think that somehow shows that you don't feel any of your sugar at all. And if you have type 1, and you just know how dangerous it is, depending on how much you inject, because they usually inject more than type 2 or. So I think that's...

GA: You inject less. The dose is less but more often.

TN7: Yes, but they do inject more often or. So they always have to be extremely concerned with that or what I eat or... and I think we've become a bit of experts in that respect too or during these two weeks, haven't we?

GA: I'm glad to hear that.

TN7: So you already knew a little bit. So if you eat salad, then the sugar remains relatively between six and seven. Or if you eat spaghetti or pizza, pizza is really bad, isn't it? (everyone laughs) then it goes way up. Or when you do sport, or. Well, I found that really blatant, or, I have hypos from time to time, where I get down to three or, and then I've also or, so then I've sometimes done sport and then ehm at the beginning I realized, "Oh, now it's getting a bit critical" and then you can always measure and so and then you see exactly, now the sugar goes up like this and then you know, "Okay, now the gluconeogenesis in the liver is boosted". And I think somehow that's really cool with the sensor on the one hand, but you're constantly dealing with the sugar. Even with type 1, where you don't have to increase the dose overall, but you do have to increase the interval or...it's a big challenge or. And ehm, in the past we probably didn't have the sensor, always there with the pricking, I imagine that's terrible, isn't it? Ehm and with, you actually have to be an expert on food, on food, just when you go to a restaurant, you don't know what other hidden sugars are in there, when you cook yourself you know, "okay, you can have so and so much". And with the sensor, I think it's..., you can monitor it a bit better or. So from that point of view, I couldn't say that it's totally different for one and two. They're just different groups.

GA: There are probably other challenges.

TN7: Exactly, other challenges exactly.

(TN5 arrives slightly late and sits down)

GA: TN5, we've already started, so acoustic recording. The question was, what is your general perspective on the challenges of diabetes. So without having worn a sensor before, what were your thoughts?

TN5: So what were my thoughts before?

GA: Yes.

TN5: So I'm very, well, I wondered very much how well you find out in these two weeks with the sensor, how well you get a feel for it. Because I have to say, it depends on a lot of different things how your blood sugar is, especially how hungry you are and how quickly you eat. That's what I noticed above all. And then there were a few strange peaks that I couldn't imagine or explain, like three hours later, when it suddenly went up like that again.

GA: Hmm.

TN5: And ehm, I was particularly interested, I don't know who from this group attended this training yesterday from the eating disorder specialist. She said that type ones and type twos, especially teens, ehm, have a high risk of developing an eating disorder if they have been diagnosed with diabetes 1 young. And ehm, I can understand that now in hindsight, because you focus a lot, like "Ah, now it's shitting me, why is the sugar so high now, I haven't eaten anything that bad." And so on, and that's in the teenage years, when you have to find yourself anyway. And we all know the teenage type-ones who don't have a diagnosis of an eating disorder, who just aren't that compliant. Where we ask ourselves, "Yes, why aren't you so compliant now?" It's just really annoying when you have to deal with food all the time. And I was particularly interested in how that came out for me beforehand.

GA: Hmm, nice. TN4, with you?

TN4: So, in general...?

GA: In general, first of all outside of this study.

TN4: I believe what TN10 has already said. I also have a patient with diabetic foot syndrome who will probably need a lower leg amputation. That's now really stuck in my craw, actually as a late complication, but in this patient it's one of the first complications. I also think that many patients are not aware of what this actually means, for example the young patients you mentioned, who can lose weight by not injecting themselves, but are not at all aware of the consequences, as you mentioned earlier. And I don't think I could have imagined before what it would be like to know exactly what kind of sugar you have all the time. I was particularly interested in whether it would have an effect on my eating habits or how much sport I do or whatever. In other words, whether I let myself be influenced by the values I measure and what I eat. And whether that also stresses me out somehow when I always know: "Oh, no, now I'm going to eat pizza, now it's mega high when I measure."

GA: Hmm. Good. And, now may I ask you, what was your motivation for taking part in the study?

TN10: One motivation was to support you...

GA: Oh, thank you! That's nice now.

TN10: ...to make your work easier. And one motivation was that I wanted to try it out, how it feels, what it means. I couldn't imagine what it would feel like or what it would do to you and ehm, yes, I mean, it does something to you. I mean, you look at your phone even more, whether that's good, probably not. And ehm,

(pause for thought) I was still surprised at some of the values that I measured. So what was exciting, of course, was the rise in cortisol in the morning, which was also higher with the sugar. But partly or I also had the feeling that I now have a massive hypo and it was still completely normal. And then on the other hand the counter-regulation after eating and I really almost went into a hypo, but didn't notice anything. So I think it's extremely difficult just to feel it. I didn't manage to do that, so at least what I felt wasn't what I actually felt afterwards.

GA: Did you have any problems while wearing the sensor? Was there anything where you somehow said, that bothers me now, or?

TN10: I only had to give up certain fitness exercises. That didn't bother me too much, but that's what I had to do. (all laugh)

GA: Okay, otherwise it would have come out...?

TN10: So Scots curls, exactly where you're somehow pressing on thirty or forty kilos, that didn't work. Ehm, sometimes it bothered me a bit when I was sleeping and I was always a bit scared when I was putting on and taking off my clothes: "Will I rip it off now?" or. So it was a slight restriction, but there was a certain slight restriction.

GA: And when you see yourself again as a doctor wearing a sensor without having an illness. Has somehow also helped to change perspective about the patient or to think differently about patients, what challenges might patients have to overcome in everyday life.

TN10: So the challenges and restrictions that I have had, they probably have to put up with them too. And then I thought to myself, I have to carry this for two weeks, others have to carry it for a lifetime. Unless there are further developments, which will certainly be the case. But of course that's not something fun. It's not something you do voluntarily for a long time. But I think that on the other hand, I mean the alternative to pricking several times a day, I think it's a massive improvement in the quality of life of patients.

GA: Yes, yes. Thank you.

TN7: Well, that's what it is or, you see it too. Or so, where I've just been with you, I've been approached a lot or. Some people have no idea, even doctors or. At the infectiology congress I walked in with it and so, most infectiologists didn't know what it was or. Ehm, the ones who are a bit better internally, they came in and said: "Eh, do you have diabetes now?" And so, or, I thought that was funny, but I also spent a lot of time on the streetcar or somewhere I was, because it was summer there, or very hot, and then I always wore T-shirts where you could see it. And I was approached a lot, found it really interesting and somehow explained it and, and most of them were like ah, yes, they'd already seen it, right. And most of them have heard about it or something. So actually it was still an interesting thing, but if you're a patient and then you have to explain to everyone why you have it now and that you have diabetes and so on, or. Ehm, then it's probably not so funny, is it? And of course, then you probably start wearing stuff like that. So once I was at a gala dinner and I thought to myself: "Should I wear something that covers this?" Because otherwise yes, it looks a bit stupid and you can just see it, ehm, and I think that's probably also a point for patients in the long term, that you're approached about it or that you're somehow labeled, or.

GA: Hmm, Hmm.

TN7: Whereby...

TN5: But all of them, so if you're at the gala dinner and the alternative is that you have to prick your finger, then that's even more so, isn't it?

TN7: Yes, but if you think like that, I mean, I have to say, I've never, I've never paid that much attention when people have worn it. I have to say. So either I've never seen it or there really isn't that much or are they hiding?

Because there are, well, I just didn't notice that in any other environment that people were walking around with one. And then I did a lot of reading about the sensor. There's a movement now for normal people without diabetes to wear them to lose weight, which I can totally understand. Because you can, so at the beginning it was almost like an addiction for me or, then you do it all the time, or and then: "Ah, great" and so or, or somehow: "Ah, now if I just eat the little salad, it stays mega in that range." And somehow I also think it's being pushed in the media now, or if you go and look somehow, or, maybe there's a change, that maybe everyone will be walking around with it at some point or. Like everyone is somehow taking the pill to lose weight and so on, or, but so far it hasn't actually been something that I've seen in public. And even in hospital, I have to say, it has changed a bit for me now, when someone has diabetes, or I ask: "Do you have a sensor?" Or maybe I look beforehand on the ward round and see something on their arm or that they have a sensor. But I didn't visualize that beforehand.

GA: So that means it's something that has at least changed in your consciousness? This has simply led to you actively asking about it, the patient probably has a sensor... That's easy.

TN7: Exactly, or simply say: "Look, that would be a good thing." Because sometimes I've actually had a discussion on the streetcar or something, and then they started discussing it with me, saying that they thought it would be good. And then I said, I can only recommend it, it's totally cool. Well, it was still funny, wasn't it? It's not like everyone has it yet.

GA: Fine! No, not all of them.

TN7: I kind of had the feeling that that's just what you have. But that's just not the case.

TN5: And he doesn't always get paid, does he?

GA: It is only paid under insulin therapy, but in US as you say, there is now....

TN7: Yes, it's become a huge movement there.

GA: ...there's a movement, it always comes from Silicon Valley by the way, they want to track themselves for all health parameters and become even healthier, even healthier. And that's what Levels means, let's see. There's a long waiting period, by the way, because this Levels is also similar to a sensor, but it also provides information based on previous values of blood sugar with food, so that it comes like a message: "Last time with this food the blood sugar rose so much, is it still such a good idea to eat biscuits now, or could it be something else."

(Everyone laughs and expresses their astonishment with "oh", "wow")

TN7: That's a real limitation.

TN4: I think it should be discussed whether this...

TN10: Then the location is matched and when you walk past the Mac (McDonald's), it's like: "Hey, don't go in there now!" Hahaha, so cool.

(everyone laughs even more)

TN4: But I think it goes a bit into the same discussion with the Journal Club with Ozempic or whatever, so you have to critically question whether it's clever. So I also found it really exciting for two weeks, but I can also imagine, as you (TN7) say, it triggers something in you. Like: "Hmm, yes, now I might want to keep it low. Now I'd rather eat a salad." And especially for people who are even more susceptible to this, who probably want to track themselves like this, it can somehow result in an eating disorder or whatever. So I think it's a fundamental question of how much unnecessary testing you want to do. There's no indication now for a... for me at 27 that I need a glucose sensor if I'm otherwise healthy.

GA: Yes, yes. Now a question based on the discussion. When I hear this, it was also the case in the last group that people really reflected critically, not only mentioning the advantages, but also the disadvantages. Do you see an advantage of education, that is, the patient gets the information: "Look, this is a tool that can do this and this and this, but it also has a downside." The patient receives the information and of course tries to use it sensibly and not overuse it. We call it alarm fatigue. This means that alarms can be used with the sensor. That means low alarms and high alarms, and if the patient is constantly disturbed by alarms, he doesn't do anything, but gets tired of alarms. You have to set alarms that really make sense, that you're not unnecessarily disturbed every day, that you set certain times. Because it's like a hammer, if we need a hammer but we don't need it, then it hurts us. But if we need it unnecessarily, it's also useless.

TN7: Yes, but now, these boundaries are also extremely important. I have hypos from time to time. Not as often as in previous years, because I simply know very well when they're going to happen. And during these two weeks, I've dropped to three twice. And then the alarm actually went off. And that's when I realized that it might be getting to that point again. But the problem with hypos is that you don't notice it for so long and then suddenly you're in it. And I also find that, well, it happens so quickly and it can then go in the wrong direction if you don't eat something and from that point of view, well, the alarm has already brought me something there, that I knew: "Okay, now I'm just low again, now I should eat something again or not just, I don't know, run somewhere or something." Because that's exactly what can cause it to go even lower. I think it's important to draw the line when it comes to diabetes, because it's even worse there, isn't it? And just the example of my friend, three weeks ago he was still rowing with one, and he was on the boat with two ladies. And one of them got on with the sensor and then somehow I think it was four. And then she said: "Ah, stupid," and so, "Yes, I might have to eat something small." But then she just ate quickly and certainly far too little, didn't she? And then, after three or four hours, they actually ended up in an emergency situation. And luckily she was still able to get ashore, so there was a restaurant there and the restaurant staff then, well, she wasn't able to dock there, but the restaurant staff then put something on the boat so that she could have a drink, because she simply didn't have anything with her. She didn't have anything with her. And then I thought, yes, well, that's important with the diabetes. Somehow I wasn't aware of it or, it happens so quickly and she was still physically active and then it's just not the case that gluconeogenesis is stimulated like it is with us, where you can compensate for it. What you're saying is probably good, that people should be told that they shouldn't measure every hour, but that they should be given a schedule of when it's good to measure, but that they should have alarms, or if the sugar, I don't know, goes above a certain limit, that they should then, I don't know...

GA: ... can react.

TN7: ... that you can react, right. Otherwise it's not much use, is it?

GA: Yes, you're right.

TN7: Well, that just sank in for me, the example, because they really had to, so they were in distress, so she was solvent on the boat. And the other two had to row ashore and just because they simply didn't, she was probably already in the hypo and didn't really realize the situation or...

GA: Hmm. An experience with sport that surprised you? So you expected something and it came out differently from the sensor. Was there anything else in the course of the two weeks, a sensor value, where you can't explain, where you say: "I didn't expect that now"?

TN5: In the context of sport or in general?

GA: Generally speaking, too.

TN5: So in the context of sport, it was actually as I would have expected. The fact that you can't really absorb the extreme peak, a really extreme peak like pizza, but you can absorb a full meal relatively well. But otherwise there were really two or three episodes where there was a second peak after two or three hours, which I

couldn't explain exactly, even though I hadn't actually eaten anything. And ehm, it was probably somehow a change in gastric emptying or something.

GA: Hmm. So after two hours after the meal...?

TN5: Yes, so then there's a postprandial peak and then back down to six or five and a half or five and then there's a second peak two or three hours later after the meal, when I haven't actually eaten anything, which I didn't understand exactly.

GA: Yes. We see this peak in diabetes consultations with complex meals. This means that if there is a lot of protein and a lot of fat, then the body needs to process fat and protein first and glucose digestion comes later. And that is why there is a later rise in blood sugar.

TN5: Yes, I don't remember what it was, it wasn't particularly complex, but yes...

TN4: I've never really thought about it like that, but then you have like a rise in blood sugar during exercise. And I was like, so... well, it makes sense, but I was amazed that it went up at first and then afterwards you fell much lower. And then I always have this feeling, you often have this feeling during exercise: "Wow, now I'm starting to feel a bit dizzy." But your blood sugar was actually higher afterwards than before you started exercising. What I also found exciting is that I still had nights during the sensor.

TN5: What did you have?

TN4: One week of nights. (meaning night shifts)

TN5: Ah, yes, that must have been a mega mess.

TN4: And that's just, just, I... it was so much more jagged there than during the week where I had a regular routine.

TN5: Yes, that's been interesting for me too, especially now when I've been awake at night because of the children, it's been different to when I've slept through the night. So if I've been awake for longer, it just spikes a bit. And it's like no more... I can't really explain it, you're just awake, I haven't eaten anything, but it still fluctuates more than when you're just asleep, then it just shushes (gestures a stable horizontal line with his hand) and then at the end he comes up a bit again.

TN7: And in the evening I also noticed, maybe it has something to do with the tiredness, that it goes up really quickly, even if you don't... even if I somehow ate something small at six o'clock, so somehow before I went to train. And then it somehow caused mega spikes, where otherwise he was actually able to control it. I found that strange.

(TN4 and TN5 start talking at the same time)

TN4: I also have...

TN5: Wasn't that also a hunger phase? Well, I really noticed it when I was hungry. So I also ate there, or at the Knabenschiessen or Sechseläuten. Knabenschiessen, I didn't eat anything until three o'clock and then a bread roll and then I was nine and a half. Although I didn't eat much, I've never managed that before with just a small meal.

(other participants grin a little and agree)

TN5: And I think that's simply because I was hungry and the stomach just pushed it on directly. And then it just rises faster. So I had the feeling that hunger was the trigger, that it increased extremely quickly.

TN7: Well, I'm not extremely hungry in the morning, but I somehow had the feeling that it's just very unstable. So very quickly somehow a bit spiky in the morning, stable and good and... maybe that's the tiredness too.

GA: Yes, that could be the case. Have you had any experience with similar meals but different blood sugar levels that surprised you? So it was the same meal, why more now...?

TN5: So I would have to go on for another three or four weeks to really be able to predict it myself.

TN10: So pizza, for example, on repeat, or it's been different. Once, when I really had a massive increase, I ate two sour sausages beforehand...

(all laugh)

TN10: ... and apparently it was just so much sugar, or that it was just...

TN5: But I also have worms once, I did some extra testing and nothing happened at all with two worms...

(the others express their surprise with "Ah, Hmm, oh")

TN4: I think ...

TN7: I don't think so with me either... I just think pizza, just...

TN5: Yes, I think that's when you're hungry.

TN10: I was probably just so hungry, or. Most likely...

TN5: I think when you're hungry, the stomach pushes it straight on, because the stomach wants to empty, doesn't it?

TN4: Really fast.

TN10: Hmm, yes. What was exciting was that I never saw a big change in sport. It's just remained really constant. But once, after a meal that wasn't excessive, it really went up a bit and then came down massively about half an hour later.

GA: Hmm. So now, based on your experience, it's very interesting, the information we get. What do you think about the fact that we, as diabetes doctors, give patients a fixed scheme: "Look, this is a scheme for insulin and just adjust your blood glucose levels like this." How good is this solution?

(pause for thought)

TN10: Not good. So because it's quite unpredictable...

GA: So you have good glucose regulation...

TN7: But I think if someone is intellectual, so there are a lot of people who are very concerned with the body and everything, then it works great. But it doesn't work for someone who somehow thinks "diabetes..." and who somehow doesn't have the same understanding. And I think you have to differentiate between the two, don't you?

GA: Yes.

TN7: And that can also be a doctor or not a doctor, or, that somehow has nothing to do with it. There are just people who check, right? And you can commission them to do it, but not everyone can.

TN5: I think what you're getting at is that you should actually instruct a patient what they're eating and how many carbohydrates and how many other substances they have. And prescribe accordingly and not based on blood sugar levels or.

GA: So blood sugar level is probably only one piece of the whole puzzle where blood sugar causes glucose regulation. Sport, stress, how hungry he is, how much insulin was injected beforehand, how much insulin is still in the body? There are so many factors and this also makes the patient tired. In other words, as you say, the patient has to decide every time. There are so many decisions in everyday life concerning diabetes that affect the patient, where patients say: "Okay..."

TN10: That's what we see in the department, when you simply give a fixed scheme, you are, you always have

TN5: It's actually always off, isn't it.

TN10: ... always too low or too high. So you're never where you actually want to be.

(others agree)

TN10: So I think you really have to look at it more individually or take a lot more factors into account. I think that is certainly extremely important.

TN7: That's why the insulin pump would be best, right?

TN10: Some kind of algorithm, yes.

GA: If the patients say yes.

TN7: That would be something that is simply implanted in there (points to the upper arm), where it simply gives off automatically or. That would be the best.

GA: Yes. It still needs patient interaction, you still have to give the amount of carbohydrates, the amount of insulin, yes, and so it always needs a certain amount of interaction. Whether it's a sensor and pump, or measuring blood sugar and insulin. So that's the disease that as much as you say TN7, patient needs to be on it, patient needs to look...

TN7: Yes. But now also from your experience or. Now there's also a type 2 diabetic who has to adjust or, then it just sucks, or. I mean, he doesn't always want to calculate what he eats and deal with it and we have lots of discussions with our relatives about it. And you always explain somehow: "You know, spaghetti is carbohydrates." And so, that's just extremely difficult or. And that's probably also part of the disease or, because if someone is very sensitized to it, then maybe you can adjust the sugar better or you used to do more lifestyle things so that it didn't come to that. It's like a part that all type 2 diabetics have, I would say, and we have to live with it. And now I don't have a solution for it either, apart from a pump so that they don't have to think about it anymore. And sure, you can talk about it and all that, but it's like saying they should lose weight. Now even people without diabetes, that won't work.

TN5: But in the case of non-insulin-dependent diabetics who simply need to be adjusted nutritively, for example, or a little with Fomin, is there a sensor that you can give them to see what it does?

GA: We do that, so there's no data like that, but we do put a diagnostic sensor and motivate them to make lifestyle modifications. Because our experience is when we just blindly give them a sensor and say: "Eat the way you always eat and just observe how your blood sugar levels are and report back to us after two weeks when we evaluate them." So don't evaluate, don't judge, but say: "Interesting, what experiences have you had?" And patients come up with ideas: "Yes, I've seen that grapes aren't good. I've seen that I need to eat differently in future." These are like aha moments that the patients themselves report.

TN5: And then they pay for it themselves, don't they?

GA: Ehm, certain patients say it's worth it to me, I'll pay for it myself. Because the health insurance company says only under insulin. So it's ...

TN7: How much does it cost?

GA: Ehm, it costs around CHF 4.83 per day. So like a coffee in Station.

TN7: But now it's just a matter of showing it to someone for two weeks to try it out.

GA: You can try it out from time to time, that's right. So how often have you forgotten to scan, as we said, for 8 hours?

TN4: Yes, where I've had nights, sometimes it's just... I've gone home and gone to sleep and then woken up in the evening and not done it.

TN5: Well, I only have it when I do it at night... I sleep late. So if I have it at ten o'clock and I can scan at eight o'clock...

TN7: You do have children... (laughs)

TN5: Yes, but at night you have to put the phone as far away as possible, it has to stay dark, otherwise the children will wake up.

(all laugh)

TN5: Ehm, they go to sleep at eight o'clock, and then ehm, no then I didn't scan it at ten o'clock a few times, and then it just stopped at four o'clock in the morning and then started again at six o'clock when I got up and then you just lost two hours.

TN5: Especially towards the end, right?

(all agree)

TN5: At the beginning you are all the time and then...

TN10: For me it's mainly at the weekend, just or, if I've got up at five o'clock, then the eight hours have become longer from time to time or.

GA: But that's so nice or that we also forget. Even if we get good instructions, it can be forgotten because other things come up in life. Now my question is potentially about the department where a diabetes patient is currently being cared for, he has a sensor, do you have the feeling of well-being, your own feeling of well-being as a doctor to care for this patient, to have a conversation with him, to check his interests, has anything changed through your own information or has it not changed much from this point of view?

TN4: I think people are perhaps a bit more understanding of this, but I think it tends to be patients who are a bit unsatisfactory for me. Because you're like, ah, you've already said so much, you have to look well and then they still don't look and then you see a lot of reports from you about the consultation and then somehow they still don't do it. I don't think that has really changed anything or. More so maybe not even with our patients, but for me, especially younger ones, who I would see now, where you understand a bit more what that means, yes. But more just in relation to the application of the freestyle and not necessarily in general.

TN7: I do have the feeling that it has changed something a bit. Well, but I generally have the feeling that everything I've experienced myself, including my operations with my knee problems and so on, has changed me a lot. That I can understand patients better and that has now been a virtual situation again, where I felt like a

diabetes patient. And I already have the feeling that it has changed something. Not that I understand everything or anything, but that it's such an important part and that you always have to measure and think about what you're injecting and so on. That these are actually poor patients, so that sounds a bit stupid with the "poor" or, but it's not just that you can swallow a pill for a heart attack or an aspirin and then it's good, or. So, you know, or...

TN10: It's not that easy there either...

TN7: Yes, but you really have to keep at it every day, don't you?

TN10: Yes, yes.

TN7: ...it's not like you can just put it aside for a day. so I think that, I realized that.

TN10: I think there are just, for me it's a bit different. So for type 1, I have to say that I think the awareness is certainly greater. So when I see someone wearing a sensor like that, I think it could probably be something like that. And there, I have to say, I see the advantages above all that they no longer have to inject themselves all the time, or have to measure their blood sugar all the time by taking blood samples. With type 2, I have to be honest and say that it's perhaps a bit of deformation professionnel, I find it really tedious at times. Because quite honestly or, it would probably be possible to avoid a lot of these problems with a lot of lifestyle modification. And people are just comfortable and... I don't think I'm sure whether wearing a sensor like that, that's my personal opinion, without injecting insulin, would help that much. Or, because they tell themselves all the time that they know what they're eating isn't good, or if they see sugar now, I'm not sure if that will change their behavior that much.

TN4: You didn't, or that they always have to inject themselves, we didn't deal with that during the.... So yes, you can...

TN7: So I've always thought, now I should somehow, now I should actually do a bit more or, you know. I've already thought about it, or I should think about it, or now I want to eat the pizza, or, now I know, it's getting like this, I've already thought about it. I mean, it's quite intellectual work that you always have to do. So that comes on top of it.

TN4: I think that anyway, it's always been so difficult to assess. That's what we were discussing a bit earlier, but now I've eaten something and thought, yes, that's not so... just a small, just a small waffle down there... (everyone laughs)... but that then made a much higher peak than a portion of risotto or whatever you've cooked for dinner. And I've already thought about that, so how could I have calculated that correctly? Yes, because it just never... didn't always do what I expected. So how can you really anticipate that you're going to make the right splash?

GA: Yes, interesting. Now a question, let's imagine we have an ideal world where we don't have a lack of resources and we can also supplement the training for junior doctors in that sense. So not only theory, that they learn what glucose regulation is, but they also wear a sensor. And then they start looking after patients. From your point of view, you could also go back, how would I potentially approach my patient differently now, treat them differently? And in the ideal world, how can I use the sensor to develop an understanding of the disease and, above all, to develop an understanding of the patient? Do I see a benefit from the sensor or do I see no benefit, i.e. it is not a permanent sensor, but a one-off experience?

TN7: I think another important point is what I wanted to say earlier. If you wear a sensor like this yourself and then talk in such a way that the patient naturally understands... Well, they realize that you've had this before, so you just talk differently. That also has an incredible effect on the patient. So I see it on the ward round, sometimes when I talk about my spondylodiosis, I suddenly grab patients because they know that I've been through it too and so on. And I can imagine exactly the same thing happening when the diabetic realizes: "Hey,

we've had this experience too, we know it." And it's not just something theoretical, then you can somehow get together as a team and perhaps make a plan. And that could have a positive effect.

TN10: Couldn't it perhaps even be counterproductive? So that the patient then thinks: "Well, wearing the sensor is one thing, but I still have to inject and you didn't have to do that!"

TN7: Then perhaps the insulin syringes should be...

TN10: You might have to do that too, yes. Or maybe inject a placebo, yes. I do believe that the understanding for someone who has to wear a sensor like this, i.e. that you perhaps have to behave a little aesthetically or a little differently as a patient. I think that's better. Would you really be able to make better therapies for patients? I don't know, I think you can empathize with patients a little better, at least in part. And you can't simulate sugar measurement or something like that in the same way as with sensor wearables. And I'm not sure whether that's the bigger burden for patients.

GA: And what is your perception of the post-injection regimen now? When patients with diabetes we always prescribe this post-injection regimen, which means that you only inject bonus insulin when the blood sugar levels are high. And if someone already has diabetes, has this somehow changed their memory as to whether the post-injection regimen has any benefit at all for diabetes patients or should they not rather cover their food properly before eating? Or is it difficult?

TN5: That's a good question, I think in the end it just comes down to... The patient is at home and you have to adjust them optimally, or now with us, the patient is there and has an acute somatic problem and then the blood sugar changes anyway. And then we simply don't want the blood sugar to be above twelve and not below five.

GA: Yes.

TN5: And from that point of view, the post-injection scheme is simply, I think, like the emergency solution for the week he's there. Of course it's not ideal and of course it's not ideal if you don't know what he's eaten and so on, we then have like a different requirement there in the department. We just want, if it's over ten and under three, it's certainly bad for infection control and everything else doesn't play such a huge role, does it? But of course it's relevant for the instructions if a patient has a blood sugar of eleven and we don't think it's that bad, he might ask himself: "Yes, should it be like that at home?" That's certainly the case.

GA: Yes, very good point. Ehm, Chiara do you have any additions or questions that interest you?

CA: No, just now, because of the transfer of self-awareness into the treatment of patients, I wanted to ask whether there can also be negative sides to the self-awareness of treating physicians, but then the discussion was already brought up. And that's all I have left at the moment.

GA: Have we forgotten something we should ask? Or is there any burning issue that has not yet been discussed? Where we can add something now.

(Silence)

TN7: So now we can delete the app? Because I've left it for now.

GA: Yes. (All laugh) App can be deleted.

(laughter)

TN7: No, I left it alone because I thought we had to hand in the minutes. I mean, that might also be interesting. Somehow, unconsciously, you might have had the feeling that you might have to hand it in.

(Everyone laughs, participants agree)

GA: No, I said only screenshots of interesting history where we can discuss. Because the data is then no longer available in the app.

TN7: So if you don't delete it, the data is still in the app, isn't it?

GA: So we can look at that.

TN7: No.

TN4: No, I don't want that.

(All participants laughingly refuse and wave off)

GA: Of course, it depends on you whether you want to show data.

TN4: But to be honest, what I would also find an interesting study is really, even if you were to do something like this, where you look at the values of healthy people and then perhaps work more with the protocol of what you have eaten. And then you could really see how healthy test subjects react differently in some cases and perhaps apply this to them...

GA: That would be such a controlled study then, or that you really give them controlled food and create controlled conditions, okay, there's sport, food, sleep, so that you can assess the data more precisely. That's a good idea, material for the next study.

CA: But wouldn't that be exactly the feeling you've all had now: "No, I don't want to show it!" Does that help you to understand how a patient might feel when they have to go to the doctor with their values, which really aren't like that?

(Participants agree).

GA: That's a problem, but they can't hide the values from us, because we have our system where all the values are there. but we have also developed a process over time, we first look at the green values, and then we say: "Exciting, what have you done there, the values are so good?" And then they slowly realize: "Okay, the values are good, so it's not all bad." And then we go step by step: "So could we do something different?" Because the ideas have to come from the patients, because if we give them the ideas that they need to impress, the patients don't do it at all. Our experience is that patients don't want to tell us about hypos. They think it's a mistake, they couldn't manage it, so they deliberately don't tell us about hypos. We have to actively ask: "Has there been a hypo where someone had to actively help you?" If we don't ask, there will be no answer. And of course this is also extremely important for us when adjusting therapy: do we need to reduce the dose of insulin a little and tolerate the higher values? Yes or no? Because it's always a balancing act, either they're too high or they're too low, they're not always in the green zone all the time. And we don't expect that either, we only expect 70% in the green range, 30% in the... so of 30%, 5% in the lower range and 25% in the higher range. But this is also a repetitive process.

TN4: That's actually funny, because I would now be much more interested in my high values... so I would like to show my higher values much less than my lower ones. So from a doctor's point of view, it's kind of like, well, I have the feeling that high is for me so yes...

TN7: Yes, but you don't have diabetes.

TN10: Yes, exactly.

GA: Exactly, and you have glucagon and glucagon prevented...

TN4: Yes, but if I had to choose what to show now, I would rather show: "Ah yes, I've only had five to seven for a whole day like this or now, for example. It's also interesting that it's the other way around with patients. Even with patients, if I imagine I had diabetes now, I would try to keep my sugar as low as possible, i.e. in the lower range, because ultimately it's better for my outcome. That's why I find it interesting that patients see things differently.

GA: So it's psycho-diabetology. Diabetes is not a disease of glucose, it is a disease of the interaction of glucose with the person. And that's why the psychological aspects are so enormously important. And patients do what they do, the influence of the doctor is really so minimal. But the influence of the doctor, who has built up a relationship of trust with the patient, is greater. And that's why the doctor's first investment is really trust, trust, trust. And then probably just give a little hint as to whether they might consider changing. I remember a type 1 patient, a very young one in USZ, who didn't trust the sensor values and measured his blood sugar 50 times a day because he wasn't convinced that his blood sugar could be between five and seven. So he couldn't tolerate that. He was always chasing his blood sugar. So blood sugar high, he injects, blood sugar goes low, he eats. So that's a patient that has stayed with me. So certain patients put themselves under a lot of pressure and then they're not capable of giving good advice.

TN7: So that's also an important point that we often forget, that it takes an incredibly long time until the patient has confidence or. And I'll come back to my own example, but I think... Moritz, my son, also has psychological counseling and I often think somehow, what are they discussing and it's not about.... They don't even look at the problems? And she just told me again last time: "The most important thing in the next two or three years is that he has confidence." And that she has a good relationship. Because the problems with the ADHD come in puberty anyway and then the relationship has to be good and that takes an incredible amount of energy and we sometimes just forget that. I mean, our older patients aren't always the easiest and their brains aren't like that anymore, or... that they don't just see a doctor once and then it's just there. Or, it takes several visits or experiences together to be able to trust them and then do what they say. So I'm still kind of stuck in my ways and that it can also be a goal that the patient simply always comes to you and that you talk a bit about how things are going and make small changes.

GA: That's the case.

TN7: And that you don't do big things or as long as he comes to you and has confidence.

GA: That's exactly it.

TN5: But that's when you get on your own nerves, so often when somehow patients don't go well, then I get on my own nerves or something.

GA: Hmm, yes.

TN5: And the patient is annoyed because it's not working either. But if you take it personally because the patient isn't doing well, then you're not helping him either.

GA: So it's, the patients feel when we talk like this...

TN5: If you are not satisfied.

GA: ... and we are so totally dissatisfied with our patients inside, they feel that the doctor actually already, what he says and what he feels, they find a difference or. And that's why I try to say: "I'm a bit frustrated." And I explain to them why I'm frustrated, but of course I can't change anything. What can I do, what can I easily change? And patients also appreciate that certain patients say: "Look, I need a certain amount of pressure from the doctor." Patients are also different. Certain patients either do the opposite when you put pressure on them, but certain patients need pressure. They say: "I can't discipline myself otherwise, if you don't give me pressure, then I won't change anything." In other words, you have to get a sense of what kind of patient has this illness as

well as the illness itself. Because the treatment of the illness is about the patient. Without the patient, we can't treat the disease, especially diabetes. He has to deal with it himself. Thank you very much!

TN7: Please.

TN10: Thank you too.

GA: We made it three minutes earlier.

Focus Group 3

Information about the appointment

Date: 03.11.2023

Participants: TN9, TN11, TN12, TN14, TN21

Transcript

GA: The sensor is used for diabetes care. I think there are also inpatients here who wear a sensor. Did you already have some experience with the sensor before this study or was it completely new to you? Someone can start and then just keep going...

TN9: Well, I've never seen anyone. Well, I've seen it on the street but not now...

GA: Not otherwise?

(TN9 shakes his head)

GA: Okay. With you?

TN11: Well, I've seen them on the ward from time to time and I've always found it great to be able to read them out quickly. And with me as a non-diabetic, you're somehow still a bit inhibited about going to someone to be pricked and to take measurements and everything somehow anyway. It's normal for those who don't know any different. And I actually thought it was great when it happened so quickly. I never knew exactly how reliable it really was. How ehm, what you can probably do now with the several values that you have, somehow, how relevant to therapy it really is now. That also surprised me a bit, because there are simply a lot more values and a lot more data and a progression that you probably didn't have before. So you didn't see a daily profile like this.

(Telephone TN11 rings and TN11 briefly announces quietly that a meeting is taking place and will call back)

TN14: I haven't had any experience like that before.

GA: But have you ever heard of this technology?

TN14: Yes, they do introduce it in the diabetes lectures.

GA: Ah, so they're already presenting?

TN14: Yes, exactly.

GA: Okay, great. Now I come to your own experience. How did you feel during this sensor wearing period? Were there any inconveniences, anything that bothered you or where you say, yes, that was an insanely huge effort for you? So where you say you couldn't even imagine something like that?

(TN12 joins quietly and sits down)

GA: TN12, ehm, she is Chiara Amstutz, a psychology student from Bern, she is taking part and we will record everything in audio.

TN12: Ah okay. Sorry for the delay.

TN11: TN12 was too late.

(all laugh)

GA: In the qualitative evaluation, we found that one participant arrived too late.

TN9: By two minutes.

(all laugh)

GA: So yes, then. Personal experience?

TN21: Yes, I found it pretty exciting and easy. I also had the problem that I had the sensor on for one day and then it stopped working. That's why I came back and I didn't understand why it suddenly stopped working. And I have to be honest and say that I forgot about the sensor for two weeks. Because it's just so inconspicuous. Then when I was showering I was sometimes so afraid that it would come off, but in principle it didn't bother me at all over the two weeks. I was actually only ever afraid that it would come off again.

GA: Yes. And how difficult was it to hold up and scan at least three times, once every eight hours?

TN21: That was very difficult. (laughs)

GA: Already very difficult?

TN21: Yes, yes. I've always forgotten about it. I was also on night duty at the time, I was a bit out of rhythm. But yes, I did forget from time to time before going to bed. I don't know, does it report when the sugar is too high?

GA: If the values are conspicuously high, then you can set alarms and it will report this.

TN21: Yes, because otherwise I probably wouldn't have noticed. So I think it's important to pay attention to it regularly.

GA: Yes, that's strict?

TN21: Hmm.

GA: Okay. Were there any realizations for you that you say, "Yes, without wearing the sensor I wouldn't have had these?"

TN21: Yes, I just noticed, for example, when I was jogging and hadn't eaten for a really long time and then got so shaky, I could track that in the curve. I found that really exciting.

GA: Okay. What do others think?

TN9: It bothered me a bit, especially at the beginning. It bothered me a little at the beginning, then a little less in between and then at the end it really bothered me again. I really wanted to take it off, it was so itchy and I really couldn't forget it.

GA: Disturbed that you wore it, ah okay! But you still just wanted to go through with it for two weeks?

TN21: Yes, yes. Yes, it didn't bother me so much that I...(shrugs) But if I had to wear it for the rest of my life, it would probably annoy me.

GA: Okay, that's an interesting insight.

TN9: Hmm. I forgot a bit about measuring towards the end. At the beginning I was very curious and just measured every three seconds (everyone laughs). I also found it super exciting to see how it behaves. I haven't always been able to do that either, so I would still be interested to see how my sugar levels really are, I'm not entirely sure whether the measurements are really so... (pause for thought)... good or not.

GA: Yes. And what surprised you when you said you weren't sure if the measurement was really good?

TN9: Yes, so I'm sure it happened once just after dinner when I fell into the hypo. I only did that once, so it only happened to me once, but it could be a pre-diabetic sign.

GA: But did you also have symptoms?

TN9: No, I felt fantastic! And once I was a bit hypoglycemic, but I felt great... Yes, big daily fluctuations. And when I was showering, I also had the feeling that it would have been a shame if I'd had the ten... That would really bother me a lot if I'd had it for longer. And I also don't like always having the feeling: "Now I always have to be on my phone so that the sugar somehow..."

GA: So this dependence on the device?

TN9: Yes, well, I would probably be on my phone all the time anyway, but if I know I have to, then it bothers me.

GA: Okay, with you, TN14?

TN14: I also measured quite often at the beginning and forgot a bit at some point. But the values didn't really surprise me.

GA: And now if you put yourselves in the shoes of patients: Forgetting (to measure) happens to many? Happens to many, doesn't it? What do you think of patients, how often does this happen to them innocently and how often extra because they don't want to see the probably not so good values?

TN9: It depends on what kind of personality you have. Whether you want to control it a bit or whether you want to control everything so obsessively, it varies a bit.

GA: In other words, it's common to have different personalities in diabetes, just like in life.

TN9: Hmm, but I can imagine, I'm certainly a bad patient, poor compliance.

TN11: I still find it difficult to conclude from the blood glucose measurement, which doesn't have a direct consequence for us, whether I would be very non-compliant if I had diabetes. I think I would measure it differently if I knew: "Okay, I have to inject now and I need to know what the sugar is." Then I have the feeling that I would be more conscientious. I think it's certainly possible to forget and everything, but I have the feeling that there's a big difference. Because now it's a bit, certainly a bit interesting to observe and everything, but ehm, if I forget, it's not so bad and everything, exactly.

GA: Yes. How have you been, TN12?

TN12: So the sensor didn't bother me. Only once or twice did I think: "Oh no, I would go swimming now", but then I didn't go because I just didn't want it to fall off or something.

TN11: I did all that.

(all laugh)

TN9: and I think it was also a day early, it suddenly stopped after thirteen days. Ehm, but I didn't find it difficult at all to measure three times a day. I was measuring about thirty times a day. (everyone laughs) The sensor almost drove me a bit crazy because I just had the feeling that I had diabetes. Because somehow I never got mega low, almost never got mega low with the values. And what also worried me a lot was that in stressful situations, you could really see how my blood sugar rose. Somehow I couldn't really stop that, because seeing it was even worse. And then I always had to try to forget about it and just have the sensor. And then it usually just normalized again, but... yes, well, not so... I didn't find the study so relaxing because it just stressed me out a bit that the values were so borderline...

GA: Mainly because of your own values, which behaved differently than you expected?

TN9: Exactly, so they never hit the bottom or the top, but they tended to be a bit borderline too high for my liking, or what I would expect for myself. And I then somehow drew the conclusion that I might have to adjust my lifestyle a little. From that point of view, it might be good, but it also stressed me out a bit. So I did a lot of looking, but after jogging, especially in the morning, after eating, then somehow in the afternoon at work, so I measured a lot.

GA: You have been able to observe your own glucose regulation for at least a fortnight. And then you've probably also seen factors that have a stronger influence on blood sugar, certain factors have less of an influence. Is there anything where the sensor surprised you and you said: "Yes, I wouldn't have expected that from my studies and my knowledge of diabetes"? Or was it something where you said: "Okay, that's something that's also known."?

TN9: Gummy bears, whooop! (Gestures with his index finger straight up towards the ceiling) Through the ceiling.

(All laugh)

TN12: That's really bad.

TN9: I didn't expect it to be so extreme, so much more than chocolate or something. So there were also differences in the chocolate, not every chocolate rose to the same extent. (laughs)

TN11: I was surprised, especially early in the morning before I got up, I had quite a few hypoglycaemic episodes. Somehow I fell to three each time and I hadn't expected to fall so low. I've always, I don't know, some people say they can feel it a bit when they're hypoglycaemic, but somehow I've never had it in the morning. And yet the sensor showed me several times that my blood sugar was a bit low. I wouldn't have expected that, especially in the morning when you still have the cortisol release and everything. That I would get so low.

GA: But as soon as you get up, the value goes up again?

TN11: Yes, I usually eat something for breakfast anyway and then it's clear that it's been up again later. But even during the day, he sometimes got that low, but that didn't surprise me like early in the morning, I wouldn't have expected that.

TN9: I once had a little, almost almost hypoglycemia after work and I didn't even notice it. I think I had eaten a snack an hour or maybe an hour and a half before, probably. And then I climbed the stairs, that's about six floors, and really before and after that I was no longer hypoglycemic. And as I said, that was a very short time, and I didn't expect that, but I've never given it a second thought. But yes, I still found that exciting. You can explain that, the stress, where sugar is released, which is then used by the muscles, but...

TN12: I was still amazed that I never, well, I really never came close to real hypoglycemia, so maybe once under four and really only briefly. And even when I didn't actually eat anything and when I did sport.

GA: And you kind of wished that you could slide down a little deeper?

(all laugh)

TN12: Right at the bottom. That somehow never happened. That amazed me.

TN21: For me it was the other way around, I somehow ate sweets and then I measured and thought: "Wow, now it's going to go really high." But somehow it never really went that high. I found that strange.

TN11: Yes, I felt the same way.

TN21: So I thought to myself: "Oh gosh, more!" And nothing happened.

GA: Oh, nothing happened later either?

TN21: Yes, not really. So not as much as I would have expected. I would have expected a higher peak somehow, but yes.

GA: How, um, do you feel good when you see diabetes patients? So is it a comfort level good when you also have to look after diabetes patients in the department, alongside all the other illnesses?

TN9: No, not good.

TN11: No.

TN9: No.

TN11: So what...

TN9: ... so in terms of medication, I find it difficult somehow.

GA: So insulin would be challenging?

TN9: Yes, I mean, I can turn it up and down, two or four units if it's too much. I can do that, but I think I still have an inhibition threshold when it comes to initiating therapy.

TN11: Yes, I still find it difficult when someone has extreme secondary complications and everything. And there are a lot of cases where it's just a bit difficult, where it's neglected or ignored, suppressed. And that's difficult there, you actually want to start treating as much as possible and say: "Yes, you have to do it now." And on the other side is the patient, who then tends to say that they didn't want all this and then it's difficult to bombard them with x amount of medication. I think that's the most difficult thing.

TN12: I also find it difficult, you always have to put it in the context of the patient, don't you? I've had several patients who were poorly adjusted, who were otherwise very old, very elderly, barely at home or in a nursing home. Where you also have to ask yourself how well you can still control their blood sugar: "What is the most appropriate control option that you can still implement at home with the available resources within a reasonable framework?" Sometimes I still find that difficult, because then you have to think about which long-term or twice mixed (regimen) or should you inject at all or not at all? What is the goal? Sometimes I still find that a bit difficult, the degree of pragmatism that you should still have somehow.

GA: And what do you think are the possible patient factors that make treatment easier and make treatment very complicated. You mentioned some of them, suppressing illness, not even thinking about it...

TN12: Cognition and age.

GA: ...cognition and age.

TN9: Psychiatric disorders, probably still.

TN11: Yes, and simply understanding the disease, or simply that they know what exactly the problem is. And what the individual medications change or how they work, I think that's very important, yes...

TN21: Well, actually...

TN11: And I think there is, maybe here in the inpatient it is perhaps explained almost too little or. Ehm, what exactly the effect is, yes.

TN21: Yes, I also believe that yes... So education is an important point. But for many, it's perhaps simply the level of education, how they take it in and whether they can take it in and understand it at all. And then of course people who work in shifts and have a very irregular rhythm are probably also very difficult to integrate.

GA: Okay. Now I come to another question, let's imagine an ideal world where we have no problem with resources and every patient with diabetes, regardless of whether they need medication or lifestyle intervention or insulin, gets a sensor implanted at least once so that they can deal with their own blood glucose levels and learn from them. Having seen your readings, which were mostly good, could you still imagine that this would bring any additional benefit to the patient or even be harmful? What are your thoughts on this?

TN11: Well, I do believe that it can be useful. I think, yes, it simply requires that you look at the figures and think about them. And I think that's something important or. If you're not aware of it or you're not conscious of it, then you're not going to pay that much attention to it. Ehm, so I don't think it can have a harmful effect, I think it's more useful if you actively think about it. Of course, with us, we have a bit of background knowledge and everything, so it's a bit easier to perhaps find the numbers more exciting and everything and... prefer to observe and everything, but I think that just has to come with it, doesn't it? I think just sticking one on someone or somehow applying a sensor and then saying, "Yes, watch your numbers." I don't think that's enough. Exactly.

GA: Yes. That means it should be accompanied by instruction and then also...

TN11: Sure, yes. And that you then also discuss and evaluate it and everything, yes, I think that's part of it.

TN14: I know, just visualizing it for two weeks so that you can really just see how it is could also be helpful. And that you can see the direct impact. And you can really see it, it's not just a number, you can see the curve.

GA: So that's the advantage, that instead of just a number you see a curve, you can see how the curve develops.

TN14: Yes, and also, for example, where the peak was, whether it was still...

TN11: Yes, and above all you can see the effects, which are probably very easy to understand. And then you can say: "I'm going to do more sport or something else this week and then see what the curve looks like." So I think that's a huge advantage that you can... I think it's necessary or that you write down the blood sugar in your tables and everything in your diabetes books, but somehow an overview for the patient, I don't know how he has that. It's just a huge collection of numbers and of course if there's a nice curve or something, it's much easier to see what the effect of these measures has been.

GA: Are there any additions from you? Now I would say that you are still a medical student. At the moment we don't have the sensor as a tool that we can use before you go to the diabetes lecture. That you can see your own blood glucose level and then you go to the lecture, can you imagine if there was the possibility, would you attend diabetes lectures more attentively? Or would you understand more about it?

TN14: I generally have the feeling that if you have some kind of connection to yourself in the lectures, then you are somehow always a bit more attentive. From that point of view, if you had somehow dealt with it beforehand, you probably would have.

GA: What do you think, you are still a long way from your medical studies. Could you imagine that in an ideal world, sensors are available everywhere?

TN11: So only for students or only for medical students?

GA: For medical students?

TN9: So self-experimentation...

TN11: Yes, I think diabetes is such an important topic, so if it simply passes a medical student or any other student by, then that's not good. So I think that almost everyone is aware of that, or that you have to deal with it and I don't know how much additional benefit it brings. I think maybe you can do it better, so maybe you're already more attentive and everything, but it's a question of time until you're faced with a problem where you have a patient who has diabetes and then you have to take a closer look at it again and make your own considerations. Yes, my opinion.

TN21: Well, I think it would have... When I think about how I went to the lecture, when I went, it would have helped a lot. Because you... diabetes is a really important topic, but I think especially as a medical student, when you're so overwhelmed with all the options and can't really prioritize what to do.... I don't know whether the training in Germany is perhaps a little different to that in Switzerland, that may also play a part, but diabetes is a big issue. But I also didn't realize that it was such a huge topic. That it actually affects every second internal medicine patient. And also these figures with blood sugar levels, what's normal, what's not normal. You somehow learn so many numbers during your studies and try to memorize them somehow. So I think it would have been pretty cool for me to see that beforehand and really understand it in practice.

GA: Would this tool also help to understand the patient's perspective? That you feel like you're doing an intervention that diabetes patients potentially have to do with themselves and I've gotten to know this intervention a bit and I can put myself in the shoes of the patients, how would they feel? Because in addition to the sensor, they also have to regulate their blood sugar levels, they have to inject insulin or take medication. Do you now think differently about everyday life than you did before?

TN9: I would like to say something about the first question. I think I've benefited a lot from a sensor like this, simply because it arouses my interest more. So learning by seeing, doing, hands on. Rather than just the theory, but more as a gimmick and an interest. Then I might have thought about why someone or why I'm becoming hypoglycemic, what the... what DDs are from that or something. Yes, and I don't find the second question. Because nowadays someone has a watch and checks their pulse all the time and so on, so I mean, everyone is always shook (shocked), so they're checking it all the time. I think that's just one more curve they're looking at. So I don't think that makes you feel like a patient. That's my impression.

GA: Yes, yes.

TN11: Well, I was most likely to feel that way when I was at the swimming pool or somewhere else. So when you were approached: "Hey, do you have diabetes?" Or colleagues... That's what got me into it the most, I have to say, where I realize that it's also somehow a signal that somehow has an effect on those around you and they also notice when you're wearing something like that. And some of the reactions were a bit cautious and everyone didn't know how to ask. That's what helped me the most, but I think the blood glucose measurement itself... Ehm, I've now... I think it's more like... maybe it's given me a bit of an understanding of how a diabetes patient has to deal with it.

(Others agree)

GA: TN12, do you have any additions?

TN12: I might have another aspect. I think that the possibility that you have because of the sensor, that you can always read it out quite easily, can probably also put you under a bit of pressure. That you should actually have it so well under control, because after all, you can track it. And depending on the personality of the diabetes patient, it can also be difficult or lead to situations where someone says: "Why is your diabetes still so poorly controlled, you have such a sensor, you could do that?" I just think about it, that's something I've already caught myself thinking a bit. For me as a healthy person, it's also been a bit of a burden, because then I have the feeling: "What's going on, what can I optimize so that I don't get sick... so that I don't become diabetic or something?" But I don't think that's the case with these patients, you should also bear in mind that it can also put someone under a bit of pressure.

GA: After wearing the sensor yourself, do you feel like managing diabetes for the patient is much more challenging than you thought it would be, or just as challenging, or even easier when they have a sensor like this?

TN12: I think that's what you would think, that it should be or is easier now.

GA: So easier than before?

TN12: Yes. But as a study participant, I didn't have to react to the values in any way or, not necessarily. And I think it's difficult to assess this question in this way, I think you would have to ask patients.

TN9: But I think what else...

TN11: I think it's certainly getting easier. So I have the feeling with the technology, you can see that at any time with the numbers. But I clearly see this simply as an intermediate step until you simply have a fully automatic insulin pump afterwards and that is the next step, that you don't actually have to do this anymore or that it automatically measures and applies insulin or. That's simply the intermediate step that we have now or and I think that simplifies it.

TN9: Well, I think I remember a scene from a school friend of my older sister who had diabetes. And when she was with us, she disappeared into the toilet to do her thing and I think that's an image that has stayed with me. It's a bit... obvious, but it's also somehow discreet when you're wearing something like that and it's not exactly visible or it's somehow no longer like that, yes, you don't have to go and get pierced. And I think that's a huge advantage, that you don't always have to get pricked. And I was also surprised how little it hurt... well, it didn't actually hurt at all, like getting it in. It's...

GA: In other words, blood glucose monitoring has become less painful than before.

TN11: Yes.

GA: And potentially, if you now have a future patient who also has the Freestyle Libre sensor, do you have a different approach to talking to the patient or do you have the feeling that wearing the sensor yourself didn't help very much in this respect and yet it did help?

TN11: Yes, I don't think I've looked at it enough with the patients and talked about it and evaluated what they think about the sensor. I don't think I have enough experience to be able to say that. Because then we just have our blood glucose values, which we look at and the HbA1c, which we determine and talk about that, but we don't talk about how he does it and what he thinks about it. That's where we lack a bit of time in each case. And I think that's very time-consuming care, where you simply need to keep the appointments, the check-ups, and you usually have them very regularly. So I wouldn't presume to do that on an inpatient basis.

GA: And in the ward, when patients have insulin, you take four blood glucose measurements. Will you see these four absolute figures differently now that the sensor has been worn or will you still see them as absolute figures? Can you present a curve there, or has there not been much change?

TN11: Well, it's always been clear to me that blood sugar is something that fluctuates extremely, especially now with diabetics. And that it's simply a slight reference value and ehm, we noticed that immediately, as soon as you've eaten something, the value... You can... You know something's wrong, you have to look at it very critically, the values you have there. But of course we're still a bit interested in where he is, whether he's over thirty or not. So I have to say, I'm very cautious, I'm not somehow, I don't take every figure at face value, of course.

GA: And when you yourselves looked at your very, very tight blood sugar regulation, the blood sugar hardly fluctuated much. But what factors have you realized that still have an influence, a regular influence on blood sugar? Peaks or troughs?

TN11: Yes, sport, sleep, I have the feeling.

TN12: Stress.

TN11: Yes, stress...

TN9: Well, I just didn't do enough sport and certainly always slept too little, so... (shrugs)

TN12: Same. Too much stress.

(All laugh)

TN9: Well, I haven't really had much hypoglycemia either...

GA: With you, TN14?

TN14: Yes, especially sleeping, which has had an effect, and sport. Yes.

GA: And now, if I may ask you, there is another study underway where you not only have a sensor but you can test the meals and you can really objectify more precisely how the blood sugar behaves. And you would have to recruit candidates, from what information would you say: "Yes, yes, do it"? And what criteria would make you say: "Ehh, it's no good." What would you say?

TN11: So what is it about?

GA: To take a closer look at how food, which food affects blood sugar and how.

TN9: So: "What happens when you have eaten a Vermicelles?"

TN11: So...

TN9: Yes, I still find it exciting that you have a bit of an idea. But it's more a question of interest, I mean, in the end it doesn't really matter if it's always measured anyway.

GA: So your main motivation was interest? How is my blood sugar behaving in my body? Do I understand correctly?

(Participants nod)

TN9: Yes, well, I also paid a bit of attention to myself, at the beginning I also wrote down what I ate. So I was interested, that's why I saw that gummy bears are so bad.

GA: And, TN11, you briefly mentioned earlier that, firstly, we don't have enough time in the inpatient setting for patients to receive in-depth diabetes care and they also have separate appointments for this. But sometimes they come to hospital with hyperglycaemic derailment, which means that this is the main reason why they

come to hospital, because they can't manage at home. If you potentially have such a patient, would you be able to interact differently with the patient thanks to your information or will it be similar to before? My specific question is, in training to create more awareness for patients, has this sensor had any effect on you, made an impact or not?

TN21: I could show the patient a lot more understanding that he doesn't measure that often and that it just slipped his mind. I think that's my main point, which I think I draw from the fact that you can really just forget about it.

GA: And that's the only reason he's not a non-compliant patient.

TN21: Yes, exactly! That you're not immediately stigmatized or anything.

GA: It can happen...

TN9: It makes sense...

GA: Do you have any other additions?

TN11: Yes, I think the exceptional situations, when there is somehow a youthful hyperglycemia derailment, we haven't noticed that ourselves. That's why I find it now... I don't know what it would trigger in me if I suddenly measured a sugar of thirty. Then I would probably react differently, but we can't do that in this simulation if you just measure it in a healthy person. So I have less of that now, it has helped me. I also think I can somehow understand that better because of the compliance.

GA: Yes.

TN9: What I also found exciting was to see that there is not necessarily a correlation between how you feel and what you measure.

GA: Hmm, interesting.

TN9: That means that a patient doesn't even notice, so to speak... I always have the feeling that you probably know that, but it's true. I thought that was cool. I still think it's good that you simply can't rely at all on what you... so there are certainly people who feel it well, but...

GA: That means you don't have to be able to feel blood sugar well. You can, but you don't have to.

TN9: Exactly.

GA: Chiara, do you have any questions?

CA: Yes, perhaps when we come back to the use in training or the self-awareness of doctors, you all mentioned some of the disadvantages of the sensor... Would you say it's worth experiencing the disadvantages for yourself, for the self-awareness that you can gain afterwards for the transfer to your profession? In other words, if you try it on healthy people, to experience the disadvantages too?

TN9: So absolutely ethically justifiable.

TN12: Yes, sure.

TN21: If it just itches or someone has an allergic reaction or something... Then of course not.

TN9: Unless someone has... Yes, or someone really has a strong hypochondriacal disorder or something, then it's somehow no longer. So really that they can't sleep afterwards and so on, then it's no good, but otherwise really...

CA: So with restrictions, actually yes...

TN14: Well, if it's voluntary anyway, you can't force anyone to do something like that.

CA: Yes, of course.

TN14: So for people who are confident and who just want to know. Those who aren't interested won't do it.

TN9: I think you need to offer a bit of a point of contact for someone when questions arise. I think that would be important, that you're not on your own. Or that you can say: "Oh, what is it now? What do I have to do with this?" Because questions are sure to come up and uncertainties are sure to arise, so that you can also accompany people if there is any indication of a diagnosis... So I think that would be important.

GA: Hmm. How important do you find this relationship of trust between doctor and patient in diabetes? Is it very important or ...

TN9: It's always big, no matter what specialty.

TN12: Hmm, I think so too.

TN11: Yes, I think it's particularly important with a chronic illness like diabetes, where a lot of checks and so on are necessary. Much more so than with other problems and long-term care is somehow the most sensible. Above all, I think that it can simply be someone and not somehow... I always find it a bit problematic when a diabetes situation derails and you're always in different hospitals, I don't think that's ideal. Because then there are too many people talking and changing and everything, I think that, yes... Someone simply has to bring it all together and they always have to be able to discuss it. I think there's so much that you have to talk through with the patient and report and explain again and so on, it can't possibly be spread over several people.

GA: Yes. Is there anything that anyone can say about being able to better understand glucose regulation from your own perspective and from the perspective of patients? Was there anything in this study that would probably not have been possible for you without studying? So it's about additional advantages for you, was there any advantage where you say: "Yes, without having had self-experience it would be difficult to read about it in a book, for example."?

TN11: So I think... I think... you can still read about a lot of things, but it's always, I still find it extremely fascinating how my body simply reacts and how you can admire how well it somehow works for you. And so I think that's what we tend to forget a little bit, how many people are simply ill and how many people have it and that it just doesn't work. But I still find it extremely impressive how it works in a healthy person. And when I saw the curve, which is simply flat, sometimes even though I've eaten something or other, that really amazed me and everything. I thought it was nice to see that somehow or other. Otherwise we see, we're already influenced and mostly just see the extreme cases and that's not really normal. I mean, the majority of us still don't have diabetes and yes, we shouldn't forget that.

GA: Yes. What is it for you, TN12, without participating in the study... So new knowledge, I say, thanks to the study?

TN12: Yes, the direct effects of certain meals or feelings or sensitivities on blood sugar, I wasn't so aware of that, but otherwise...

GA: TN21?

TN21: I think for me it's the point that I've already said, to have this understanding for patients who somehow don't measure so consistently all the time. Because I don't know now how I would have measured if it had had a consequence, then I would probably have done it differently. But just that in general, yes, you can understand much better that people forget this in everyday life.

GA: Hmm, thank you. TN9?

TN9: I always think it's good, self-awareness, I always think it's good. It simply promotes empathy, always.

GA: Well, you could all say that it was at least an empathy-promoting experience, even if you didn't always think about patients every day.

(All agree)

GA: With you TN14?

TN14: Yes, just how quickly the body reacts, especially to food, how quickly the sugar goes up but then comes down again. It's logical, actually, but I think it's different when you look at it like that.

GA: I would also like to mention very briefly that in the first Focus Group interview, one of the participants said that it is now slowly becoming a trend that is being pushed in the direction of a healthy lifestyle. There is also a company in America called Levels, which simply offers these sensors to the healthy population with a certain identity, so that those without diabetes who wear the sensor have a healthy lifestyle, because they will consistently pay attention to everything and change something accordingly. What are your opinions on this, what do you think critically or uncritically, what do you think? Is it a good solution or not necessarily?

(TN9 shakes his head)

TN12: I think it depends on the personality of the wearer. It can lead to absolute compulsiveness or an eating disorder or depending on the breeding ground of the personality. I think if someone can handle it well and has a healthy relationship with their body or an illness, it can be interesting. Perhaps also protective, preventative, but I think it can also... Well, in relation to me, not just positive, depending on your personality, it can probably drive you crazy and therefore also your environment, depending on whether you somehow align your entire eating or sports or other behavior with this sugar.

TN11: I have the feeling that it's really more the people who are inclined to do this who have this disposition anyway.

(All laugh)

TN11: Well, I think I'm a bit critical of that too. It was just in the newspaper the other day, somehow it really is a glucose diet and all sorts of things that are available now.

GA: That was also in the NZZ, wasn't it?

TN11: Yes, I think I saw it in the Tagesanzeiger, exactly...

GA: Tagesanzeiger, yes.

TN11: ... where it was about that. And I think that, so that, yes, I mean ultimately you can measure everything that you somehow have in your body, and the question is simply whether you are allowed to do that and whether it somehow leads somewhere where it makes sense. Personally, I have to say that I do certain things... I'm happy to take part in a study like that, but to be honest I don't want to know everything that's going on inside me, I don't want that either. And that's just the fear that I have a bit, that people will always want to know everything, and then finally explain it all somehow and it's questionable what the consequences are, so yes...

TN9: I think if you want to get hold of it for a while out of curiosity, out of interest in physiology or something like that, I think that's justifiable, everything else I find narcissistically disturbed. So really, it's just a kind of self-... Well, narcissistic might be the wrong word, but it's just eternal self-optimization instead of just using a bit of

common sense and finding out a bit about healthy eating. And not always eating ready-made products and ehm... Yes, I think our...

GA: Or gummy bears...

(All laugh)

TN9: Yes, sure... But I didn't let that influence me.

GA: Yes, and there should be three or four jelly babies in there too, right?

TN9: So just concentrating a bit on life and not just concentrating on controlling and everything and everywhere and in every area we have to be super woman/man and... I think that's just pathological, it's just not healthy. And I think our society, I mean our food, the food that's on offer in our grocery stores is debatable anyway. So I think it's interesting to take a broader approach there. And then you say, if someone has prediabetes, you say: "Yes, maybe it makes sense for them to see what's happening, to get a feel for their lifestyle." Again, I think that makes sense, but then it might have an effect. But otherwise, I think it's just a question of... If you say in America that the average American moves twenty minutes a day, including going to the toilet, then the problem is somewhere else. So, but I'm a bit very critical. I also find it strange when people monitor their sleep all the time. I also find it interesting to see how I sleep... Once! And then it's just like...

GA: Yes. With you, TN21?

TN21: I also find it very critical, because in principle it's also a question of what is the consequence? Someone who is young, healthy and probably does an hour of sport a day will probably get a tracker like this, a blood glucose tracker. But that's not the target group that will develop diabetes. And as medical staff, we'll probably be forced to refer patients who are so... so anxious that they come to us with a curve and say: "Yes, now what should I do with it?" And we say: "Nothing." But they just want something to be done somehow and ehm, yes, that's why I don't really think it makes sense. So as TN9 says, I think it's great to try it out, but I just don't think it makes sense to track yourself permanently.

GA: Yes. So when I summarize, I see from your experience that benefit simplification for blood glucose control where it's needed because if someone has diabetes or also has to inject insulin, of course they need some number and also number to number relationships so that they can adjust that. But outside of that, curiosity so you know the physiology, no added benefit anywhere else. Prediabetes, to prevent that, that they know what's the connection with food, but otherwise, actually, you should also mention the critical points that you don't use something a little bit too much that it even becomes detrimental in everyday life. That you are really forced to see the numbers, because otherwise you don't feel the numbers. Is there anything we have forgotten to ask you where you think this information would be important for this study in terms of blood glucose regulation, in terms of understanding from the patient's perspective?

(Silence, shaking head)

TN21: I can't think of anything.

GA: Have we actually discussed all the main points?

(Participants nod)

GA: Very good, in that case many, many thanks for taking part!

Focus Group 4

Information about the appointment

Date: 08.11.2023

Participants: TN13, TN15, TN16, TN20, TN24, TN25

Transcript

GA: So, it's about the map of diabetes before you even heard about the sensor from here, that there was a study. How far have you been aware, what has changed in the last twenty years? Someone can start.

TN13: So I think for me it's, I knew that there is now much more continuous glucose monitoring and that there are now also new pumps that can recognize both upward and downward trends and work against them. And ehm, that actually many more patients with type 1 almost all tend to have pumps and no longer inject themselves.

GA: Are there any additions?

TN15: I have experience with the sensor from my personal environment, at least a few years ago. And yes, it was actually very well received by my friend. There was still the question of the costs, the health insurance, which was a burden for her, especially at the beginning. That it was like spare buttons, so to speak, that were not reimbursed. So...

(GA's phone rings, as does that of another participant, both go out briefly and return shortly afterwards)

CA: So if one falls off, the replacement is not remunerated.

TN15: Only a certain number, yes exactly.

TN25: Well, I can perhaps say that I used to work at Zurich University Hospital and we had a different regime there. There it was always clear that patients had to be compliant with insulin application before a sensor was even considered. Now that I've looked into the subject again, it's surprising to me that it's already so widespread. And the other aspect that I still have is that I have fellow athletes who do triathlons, for example, or marathons, or who race bikes, who now voluntarily wear such a sensor to better control their nutrition during training. I've actually heard more about this than about the medical field.

GA: Yes, interesting.

TN16: Yes, I have the same thing. It's also often used regularly for athletes, especially those who do endurance sports.

(TN24 adds)

GA: TN24, we have already started. Chiara Amstutz is a psychology student and as you know, it's being recorded, the interview and we've started, how far did you know the map of diabetes before you even decided to take part in this study? What has changed about diabetes in recent years, what are you so aware of, how do you feel about it?

TN24: Yes, I already knew about social media through Freestyle Libre. So there are bloggers who have type 1 or type 2 diabetes who also write about how they organize life with diabetes, how they get the disease under control. And I think it's really useful for people like that. Then I've also heard about diet and healthy lifestyle applications, that different diets are practiced depending on glucose levels. I think I've also seen a few books that have come out, but I haven't read them.

GA: Now, you've been wearing this sensor for two weeks. For some, it wasn't the whole two weeks, TN16, for you it was only seven days...

TN16: Only seven days yes...

GA: What were some special moments while wearing the sensor, what stood out or what surprised you? You mentioned the problems once, only seven days and then it went away.

TN13: So you mean with the values or with the application?

GA: With your own values and applications, how comfortable is this technology for you to gain experience or has there already been certain disruption where you have said: "Yes, I took part in the study, but it's not that pleasant either."

TN25: Well, I didn't really notice it anymore. It was always pointed out to me because my children tried to tear one off. But I actually found it pleasant. And I found it exciting, ehm, I had in particular... I wasn't aware that my blood sugar always tends towards hypoglycemia an hour after eating. And that also correlated well with the feeling of hunger that I sometimes have an hour after I've eaten something. That surprised me and I have now been able to document that this is indeed the case. And then I also found it interesting to see what effect my eating behavior has in the sense that, for example, if I don't eat anything at work and then eat a sandwich for the first time at 2 p.m., that's really bad for my constant blood sugar level. That messes everything up, as if I really eat a lot and regularly during the day, it doesn't make much difference to my blood sugar at all. And the other thing is that I very rarely drink alcohol, but I once drank alcohol one evening and then there was an immediate spike, so that was impressive.

TN16: It did hurt a bit for me, but I think it's just that a needle bent and that's why it no longer worked. But because the needle was somehow at an angle, I could feel it.

GA: All the time?

TN16: No, just somehow the last two days and then it just stopped working. It probably moved a little during the night or something and then the needle became crooked. But that's why it only hurt a little at the end.

GA: It has happened to four or five participants in total, either they dropped out or it hurt, so it's probably not entirely unproblematic. What else was your experience?

TN16: To be honest, I was always afraid that I had diabetes because I eat so many sweets and a cousin of mine also has diabetes and that was always an issue for me. And I measured my fasting blood sugar once and then it was so close and then I thought: "Okay, I'll do it now, maybe I'll see what the blood sugar levels are like." And then it was exciting to see how they fluctuate and how they are over the course of the day. For example, I once ate grapes as a snack and then I saw that my blood sugar levels had become very, very high, more so than with chocolate or other sweets, for example. But fortunately all the values remained in the good range.

(All laugh)

TN13: I've also found it very interesting, for me too, as soon as I've exercised or done sport, my blood sugar levels have risen and then fallen. But it's really... So I've gone from sitting on the sofa to just emptying the letterbox, my blood sugar levels have risen immediately. And I also found it quite exciting to see when I was doing sport. And ehm, I also noticed that I often woke up at night, for example, because I hadn't slept well, so my sugar levels were higher. So I don't know whether that's ultimately due to the stress hormones. I still found it really exciting. I noticed that the sensor didn't stick so well, so I stuck it on with a plaster at the end. Because it was like... the plaster stuck but the white part at the top of the plaster slowly fell away a bit. Then I thought, yes, it's better stuck on, also because I do a lot of sport where you use your arms. What I found very interesting is that diabetes is actually an invisible disease and this sensor makes it visible. And I've also been approached by lots of people: "What's that? Why do you have this now?" I also... I was still impressed, people are like that, it's been like that, some people are like hmmm, don't know exactly and don't ask and others actively approach it and suddenly it becomes a topic of discussion. And then another thing, I have a good friend of mine who has type 1 diabetes and we compared our curves. But she has a pump. And then it was also exciting to see that it

risers much faster and is much higher and more constant. But it was just exciting to be next to each other and compare.

GA: On your comment that people approached you, why did you... how did you feel about that?

TN13: Well, I just found it, I found that it was actually... Well, of course, they were all people who knew me, and they thought: "She's never had this before, what is it now all of a sudden?" And then I explained what it was and many of them didn't even know what it was. And they did, so I have the feeling that more people know now. But yes, I really thought that, I thought that although it's a mega good tool, it's just like making an invisible illness visible. And that can be good and not good. So I also went for a massage once and he didn't... didn't touch my arm. He didn't touch it. And he did touch the other side and everything else and then I thought, that's a bit weird. So you can ask, as if it was something really bad. So that just struck me very strongly. And then my friend who has diabetes thought it was really great that we were doing it and thought it was really cool that we were doing it and that it was really appreciated by her when we saw and did it.

GA: And what did you yourself feel, was it cool to have tried it out yourself?

TN13: Yes, I found it exciting. But the first... Well, you notice that after two weeks it's like: "Ah yes, you can look at the sugar again." But at the beginning I observed it more.

TN20: Ehm, I also found it incredibly exciting. I've actually, I've also known or seen people check it on their cell phone and that there's an alarm if it's too high and so on. But it was really exciting to do it myself. I was a bit scared of the app now that I've seen it and I have to say I didn't feel it at all, so I'm really positively surprised by it. Afterwards I was a bit afraid that it would fall off or that I would rip it out when I took it off. And even though the adhesive came off a bit on the outside, there's another adhesive on the inside, so it held quite well for me. Exactly, I've also noticed that my glucose levels rise during short periods of sport or exertion and then drop again when I do a bit more endurance. And what I also noticed was that once when I was ill, my blood sugar was much higher.

GA: Do you have any knowledge from your medical studies, because you're one of us with very, very fresh insights into medical studies, can you explain or physiologically explain the fact that your blood sugar rises when you're ill?

TN20: Yes, so with fever the body simply needs more, that it works more. And then I've also read that insulin resistance... that it needs more insulin. Exactly.

GA: And you have now been able to experience this hands-on on your own body.

TN20: ...I saw it, exactly.

GA: How is it with you, TN24?

TN24: I find it really interesting in conversation that everyone is so different. The sensor was a bit stressful for me, I have to say. It's not the first time I've worn the sensor, I don't have diabetes, but I had it in my settings that I had to be alerted to threshold values on both sides. And the same evening that I got the sensor and I drove home, I got an alarm, hypoglycemia, and then I kind of yes, then I eat something, then I ate something. And that was so high in carbohydrates and then after twenty minutes I also immediately got the hypoglycemia alarm. And ehm, so I know this tendency from before, I thought: "Okay, that was a different metabolism." I had the alarm hypoglycemia at four o'clock at night or five o'clock at night and that was a kind of resistant hypoglycemia, so I didn't feel anything but the alarm goes off. So it's really not dependent on body position and no matter what I eat, it will ring again after twenty minutes or so. And then the first day I was stressed, I googled, but then I thought to myself, "Well, I survived until I was twenty-nine." (everyone laughs) I don't feel any of that and I'd rather just turn the whole thing off because I... So the body should somehow regulate itself. So maybe not for everyone from 3.5 to 4.5, I don't know, maybe it's physiological. I don't feel any of that. So I

can sometimes be angry or so conspicuous when I haven't eaten anything. (All laugh) A bit more impatient, but I don't have the feeling that I'm going to faint. And then I turned the whole thing off and I have the feeling that if you don't have that, the alarm on, then the curve will automatically even out. And if you also switch off Bluetooth at night, that's even better. (everyone laughs again)

GA: But then you have no values.

TN24: Yes exactly, then I had to force myself to remember every day to measure a few times and switch on a few times, because I thought, I promised the Gurpreet, otherwise it will be embarrassing and a waste of material if there are no values.

GA: And now when you, it's interesting that you say that you kept getting this hypo alarm but you didn't feel it yourself. And if you put yourself in the patient's shoes, a patient will probably not only get hypo alarms but also hyper alarms. What could be working in this patient, this technology?

TN24: Yes, I think it can cause a lot of uncertainty. But I'm also thinking about it now, on the contrary, as a doctor I can perhaps also perceive it so carelessly, because I can say: "I don't feel it." If the other person says, "I can feel it." Then that's not a bad thing. And we actually had a patient, not recently, but a few weeks ago, who came in for a hypoglycemia alert from Freestyle Libre 2 came in here or something and she didn't feel anything.

TN25: Yes, I could imagine that there can be a certain amount of measurement stress for certain patients, that not everyone is mentally suited to it. We also see that in pneumology, with oxygen measurements or blood pressure measurements, which are not good for certain people.

GA: Yes, that's right.

TN16: But on the other hand, it can also provide security, because then you know: "Okay, the sensor will tell me if my values are too high or too low.

TN24: Or, on the contrary, you wait for the alarm with the fear: "Yes, I have to have something with me and yes, I have to react somehow and I can't completely relax now or somehow go to sleep with the intention of sleeping in and not being woken up at four o'clock."

GA: How limiting can fear of hypoglycemia be for diabetes patients who inject insulin? What is your estimate?

TN13: I think so.

TN15: I think so too.

TN13: Well, I think there are a lot of people who have hypoglycaemia all the time and maybe don't feel it so well anymore and are very afraid of it. So yes, and then they just somehow have the feeling that they always have to have something with them so that they can always eat something. I have the feeling that if you don't have a constant measurement, you have to get used to it and say to yourself: "I'm not always measuring." But you have to try to listen to yourself a little bit and everything that you can measure. Because if you measure again and again, what I've noticed is that it jumps back and forth so much. It's constant on average, but the individual measurements are so different that you can't rely on a single measurement. That's what I decided to do, these blood sugar measurements, you can somehow say it's much too high or it's much too low, but you can't say anything else because it's so dependent on what's going on, is someone ill, does someone have a fever, has someone just been running, has someone been lying around for two hours. So you can't, you can't go into it unless it's far too high or it's far too low. So from my perspective, my sugar has always been in the range but always a bit up and down.

GA: Fluctuating in the range...?

TN13: Yes, exactly.

GA: Were you already aware of this information or did you become more aware of it when you saw your own data?

TN13: More for me. So I knew it wasn't constant. But I've become more aware of how much it varies. So it's not from three to five. But whether it's 4.9 or 5.6, you can't rely on it in any way.

GA: And does it matter if it's 4.6 or 5.6?

TN13: No, not at all.

GA: It probably matters if it's 15 or more...

TN13: Exactly.

GA: Helps... Do you have a feeling for patients when they have to choose between capillary measurement and sensor. What do you think the patients would choose or would you think from the patient's point of view now, which technology would be good if they need blood glucose monitoring.

TN16: I think it depends on the type of patient we have. I would use a sensor on a young patient who is cognitively fit. But perhaps also elderly patients who are no longer cognitively fit, then rather capillary.

TN25: I don't know whether it wouldn't be good for everyone to take conventional measurements at the beginning in order to process and understand the disease. And also to see how compliance is. If they don't do that, then I also get important information as a doctor, which is lost if I give them a sensor and only get these values.

GA: Did the sensor have any effect on you? That you had the feeling that now I have to change my lifestyle? Or was it supportive, a confirmation: "Wow, this lifestyle is really good for me?"

TN15: I'd just been to the emergency and had a very unhealthy diet. And afterwards I ate gummy bears and then I thought: "Oh, now it's going to go up." And then it didn't rise at all and then I thought: "Ah, well then..."

(all laugh)

GA: So there are gummy bears inside?

TN15: Exactly. Not organ juice, I noticed that it had just gone up. No, I actually had a pretty constant progression. I was never too high or too low. And that's why I made a bit of the same observations as you two (TN13 and TN25) with the feeling of hunger, that it was pretty consistent. Then, I have the feeling that it also gives you a sense of trust in your body, that you can rely on your body to look a bit like: "Hey, maybe you should eat something now." And then you do that and then it's already well adjusted.

GA: Olga said earlier that she simply switched off Bluetooth when it interfered. How often did you forget to scan or not think about it or...?

TN13: I have already managed to always scan. In my case it simply interrupted the connection, i.e. signal loss, and then I had to scan again to reconnect. But in the end, I don't think I ever had a gap. What I found a bit stressful was that you have to keep to the eight hours, so now on a good day when you're off work, you really have to do it last thing before you go to sleep and first thing when you wake up... and then you have to think like, just when you get up, "Oh, I have to scan the sugar right now, right now." That's always... Well, I think that's a bit of a shame because the first thing I have to think about is sugar. And ehm, it's just so direct, I find it more pleasant when you can just get up. But it's only if it interrupts, if it's connected, you wouldn't have to scan it every eight hours.

GA: Yes, so the connection is of course already... active scanning helps the sensor to measure the correct value. Because otherwise it will determine some value itself that is not correct with the tissue sugar value. Eight-hourly must be with the sensor, but now there is a new sensor that works continuously via the connection. You don't have to hold it up and scan, it runs continuously.

TN25: I have adapted well. So when the sensor was no longer there, I thought I would have to look again...

(all laugh)

TN13: Yes, it was so strange when he was away.

TN15: I just realized that you're really dependent on your cell phone with it, of course. Otherwise you're already super dependent. I actually wanted to go two days without a cell phone, and then I realized: "Oh no, I have to scan." So it's also mega, it's like something...

GA: Exactly. Was there any experience for you where you want to share, where you say: "I didn't think so, that surprises me now"? Where something was different from your previous perception about glucose regulation or how the sensor works?

TN16: In my case, there were a lot of different values at night, but then you explained that it could also be a measurement error. But I was surprised, I actually thought that the blood glucose value would be more stable in the seam and mine was mega fluctuating, even at night. But apparently it really can be a measurement error.

GA: Or also because you were not in the right place and therefore more came to light. In your opinion, how important are patient-related factors for diabetes management? So is the patient very, very important to be involved in diabetes management or can you simply help the patient with today's education and technology?

TN13: I think that the patient is very important. Especially if you want to prevent the long-term effect. If you have a young patient with type 1, then I think it's more important than if you're giving insulin to old patients, where you can do it via a pump, where they simply don't have to worry about it. Then it's also an option. But that's not the aim, actually with young people you'd rather want them to have this awareness and adapt to the fact that they can also track long-term damage, because it's a disease that doesn't... that lasts for years. That's why I think it's important to train them well and motivate patients to really be involved.

TN25: With type 2, we also want everyone to adapt their lifestyle so that they have as few high sugar levels as possible. And that's a bit like taking away responsibility if you automate everything too much and the patient is no longer responsible. He thinks to himself: "Yes, now automatic measurement, maybe automatic insulin application at some point, why should I care much now?"

TN24: I think it also offers great potential for people with prediabetes. You can virtually save yourself all the medication, all the illness, if you perhaps observe your own body a little and somehow try different diets, interventions and exercise. And ehm maybe you can avoid so much suffering from diabetes. Because I think quite a lot of people have prediabetes and you can achieve a lot by changing your lifestyle.

GA: And this experience, where you yourself have now worn a sensor, which you probably knew about before but didn't wear on your own body. If a patient is now in the department and he already has a sensor, how comfortable do you feel talking to this patient? Has this experience changed how you can talk to the patient, what do you think about such a patient from the patient's perspective? Has there been a change in perspective as a result of your own experience?

TN15: Yes, mega. So also in terms of if he were to get a new sensor like this. Because the questions are often, "Does it hurt?", for example, and it's something regular that you always have to use. And especially in this respect, you can say: "No, it's not painful." And so on. And I think many people still have a bit of the old image that you always have to get pricked, which many people also find unpleasant. Especially in this respect. And I

think it's mainly in this respect that you give the patient this tool and that they can come to terms with it better themselves and it's then more of an empowerment of the patient. So certainly with regard to dementia and so on, of course excluded, but...

GA: But so for a patient who can apply, can probably achieve benefits.

TN15: Completely, yes.

GA: There is probably no guarantee, yes.

TN15: And just that we now know which app and so on, you can help directly and otherwise it was like: "Ah, yes, you have to somehow hold this out..." Otherwise just the practical things.

GA: So that means it has helped you personally?

TN15: Yes.

GA: Okay, what do the others think?

TN13: Yes, I think we have far too many things in medicine where patients always ask us: "Yes, what's that like?" And then we have to say: "Hmm, from experience... ehm." And although now, especially with us who are new, we don't even have the experience, which means: "From stories from experience, it's like this and that..." And now we at least have something where we can say: "Yes, no, as TN15 says, it doesn't hurt, it's super easy, the app is self-explanatory..." Exactly. So of course we don't have the curve afterwards and we don't have the alarms and so we don't know exactly how it will be afterwards. But you can at least say, like... from a practical point of view: "No, no, the sensor doesn't fall off when you take a shower and you can go swimming." And so that we now know all this and don't have to say every time: "I don't actually know that exactly." I find that very helpful.

GA: So that means your knowledge of technology has been able to influence this experience to some extent. Okay, now. Our medical student. If we move into the ideal world, instead of just lecturing frontally about glucose regulation and diabetes, if we give all medical students the experience of wearing the sensor and coming to the diabetes lecture afterwards so that they know what glucose is and what glucose does to you. Would it influence the understanding and interest of medical students to learn more about the disease from your point of view, or...?

TN20: I think so. So I also think it gives you a certain security to be able to say afterwards how to apply it and everything. How it changes, because you have seen it yourself, maybe you can also understand the fears when there is an alarm now is hypo or now is hyper. I think that's good for understanding and for the safety of the patient.

GA: So it can reflect?

TN20: I think medically you learn what influences where and how, but also in patient management, I would have said.

GA: Yes, what do the others think?

TN13: I think it's certainly super cool, but I also think there's a certain amount of hype, health hype, about regulating everything precisely. And that many more athletes are now always measuring their glucose. I think it can make sense for races or something like that, so I have a lot of athletes in my environment, including professional athletes, who have also done this, but somewhere along the line it stops with data collection about your own body, so I think that's when you don't have to. Because in the end, yes, it is, but how often do we really adapt to it afterwards? I've been observing this for two weeks now, I haven't changed my behavior. Because I somehow thought: "Yes, it's okay, so I don't have to change anything." And of course there may be

one or two things that are caught that you have to change, but I think in the end it's also simply collecting data about something where, if you're actually healthy, you don't necessarily need to collect data because it's scary: "Oh, it's back to hypo at night." And then maybe it's because the sensor is set to 4.9, but in healthy people it's not a hypo at 4.9, not even at 3.9 anyway, maybe it would only be one below 3. So it takes a lot of understanding to read it correctly and if you just give it to all lay people, there might be a lot of misunderstanding behind it. So in my opinion, although it also generates a hype where you think: "Yes, you can do it, but it's not much more effective."

TN16: Yes, I think so too. Because there are actually so many different things in medicine that we can actually try on our own bodies, even in medicine, and then it's just difficult to somehow use a blood glucose meter, yes, and I don't know, wear a splint, no. Or... Maybe you could try to go out and about in a wheelchair for two days, that would also be interesting to know, but somehow, maybe it's not possible.

GA: TN25?

TN25: I... So to be specific about the medical students, I don't know if that... so for those who are interested, it can be of some use, but I don't think that imposing something on someone is of any use.

GA: Yes.

TN25: If someone perhaps has no interest in it at all and you are then sometimes relatively far away from reality and everyday life in medical school. Perhaps it helps more to have this opportunity when you are actually working in the field.

GA: That you work directly with patients or directly in diabetology?

TN25: Yes, well, I don't think that an orthopaedically interested assistant doctor or medical student who has no interest at all in internal medicine and finds it all terrible and only does it so that he can somehow get through university would benefit much if you already come with that attitude.

GA: Yes, yes. So interest is also crucial, your own interest.

TN25: I think so too.

TN15: Yes, I would have said that too. So you only see things that were offered in a similar direction during your studies. I can't remember exactly... but ultrasound, sonography, for example. It's actually voluntary per se during the course and some people are really keen on it and want to try it out and others aren't interested per se. That's why I think it's more for those who are more interested and then of course it's always a cost-benefit consideration as to whether it wouldn't make sense later. And otherwise generally giving the population something additional that they can actually worry about, I have the feeling that that would be a bit problematic for the healthcare system at some point. If we only see now with the Apple Watch how many people go to the doctor just because of a notification and I don't know whether that wouldn't go beyond the scope somehow instead of doing something good.

TN24: I think almost every medical specialty has contact with patients with diabetes and it's basically beneficial for everyone to see how different people can be. Of course, there may be students or junior doctors who aren't interested. But I think it also gives a good insight into how the patient feels. We've now been in patients' shoes practically every two weeks. We have observed ourselves and developed different tendencies. I think there is quite a lot of understanding of how fluctuating the value can be, what it does psychologically with different people. And so for me personally, it's been quite useful.

TN13: But I also... one part was that we were all there and could say: "How's your curve, show me, do you also have these values?" So we also compared them with each other a bit or I compared them with the friend with diabetes and I think that if you don't have it at all and you're on your own, you can see it, but you don't have

anything to compare it with. So maybe that too, you don't have... There's like a lot of diabetes and hypoglycemia, but there's not so much information when healthy people simply have sugar levels, which is normal. That's why I think it was also important to be able to say to someone else: "Hey, do you also have hypoglycaemia at night?" And so that you can also talk to each other a bit, I think that was also part of it.

GA: In other words, it was nice when a few people got the sensor at the same time to talk: "Okay, what's it like for you?" Personally, I thought it was cool that a few volunteers came forward at first and then one by one more came forward: "I want to do it too, I want to do it too." And it was nice to find that we influenced each other when at the beginning there probably wasn't any interest, but then suddenly you had the interest to see it too. I should actually ask the question first, but what was your personal motivation for taking part in the study? So what was it immediately: "Yes, I want to!"?

TN20: Somehow I've also seen people walking around with it and I thought, I kind of want to do that too. Simply because I was so amazed at what it's like and afterwards I was like: "Oh, I must have diabetes or..." I also think it's important to know where you stand yourself. Yes.

TN13: Yes, for me it's also simply out of interest, because I wanted to know how it feels and what it does. And also simply now, when you're somehow working on the emergency figures, it's so irregular how you eat. You have to somehow make sure that you eat enough and not eat nothing for twelve hours and just see how your body copes with it. And then also to see that even when it drops, it always rises again without me having eaten anything. So it's enormous self-regulation that takes place. And I thought that before, well, I thought that, but I was really interested in what it's really like and that's why I thought I wanted to do it simply out of an interest in self-observation in the end, yes.

TN16: I just wanted to rule out that I have it...

(All laugh)

GA: Although I told you, you can't exclude with the sensor?

TN16: Exactly, it's not a means of exclusion, but I just wanted to feel a bit safe.

GA: Okay, thank you.

TN25: I can only agree with that. I wanted to make the experience and apart from that, if my colleagues here in the company were to conduct a study, I would always take part if it didn't harm me in any way. Because I think you should always support it.

TN15: My curiosity was actually also full and I just had a patient who had received a sensor for the first time a short time before and then I was really surprised.

TN24: Yes, I was interested too, I'm not saying anything new. After all, we are all medical people who would like to learn something about physiology and we ultimately know... well, probably relatively little from the textbooks. These curves are shown, or well, my studies were eight years ago so... basically examples of curves were shown back then but not the example of Freestyle Libre and so on. And I think that's an exciting insight.

TN25: A lot has happened recently, including in terms of medication. And I was simply out of it for a while because I was still doing pneumology and I had to catch up again and read up on what had happened here.

GA: Yes, the technology is changing faster than we are changing as people. Each of you probably has a spectrum of patients, or that's a diabetes patient who understands therapy well and is very motivated, engaged and other spectrum is, the patient doesn't even want to know about the disease and doesn't want to have any influence. And you now only have the experience of your own glucose regulation with effort, where it is associated with the sensor you have dealt with.

(TN16's phone rings, she goes out briefly)

GA: Is the awareness about patient spectrum how might a patient feel who has to live with diabetes every day, where everything is much more fluctuating like yours... Has this awareness changed through the sensor or is it similar?

TN16 (whispering): Gurpreet, how much longer will it take?

GA: About ten minutes.

TN16: Because I have to...

GA: You have to?

TN16: Yes, may I go?

GA: Yes, if you have anything to add, you can add and then leave. Did I forget to ask you something?

TN16: I think I've already answered everything, so that's okay.

GA: Okay, thank you very much!

TN16: Thank you!

TN13: I think the spectrum is a bit difficult to say. Because I was really motivated to measure, but what I noticed is that after two weeks, just within two weeks, I didn't show as much interest at the end as I did at the beginning. Simply that I no longer measure it as often and am no longer as surprised when it goes down or up. I think if someone has it for much longer afterwards...

GA: Interest can...

TN13: Yes, the interest decreases, but you also get less excited about, like: "Ah, yes okay, that's always the case after I've eaten grapes, it always gets so solid. I don't have to worry, it'll come down again." So you can then assess it better. And then I think certain people, even if they've been managing it for years, don't micromanage like that anymore but really do it for days on end. Instead of us, who at the beginning probably do it every hour and later every eight hours. But whether there's a lot more of the spectrum now, that there are people who really aren't interested at all, I haven't had enough contact with them yet.

GA: Okay, hmmm.

TN20: Well, in the beginning I was so enthusiastic and measured almost every three minutes and somehow while eating or after eating I was really eagerly waiting for it to go up. And over time, my interest waned a lot and then also with eating and then, as always, it became a bit more tedious. And I can imagine that if someone has type 1 diabetes and has had it for a lifetime, it can be tedious over time. And I think the glucose sensor is actually really practical for that, because then you don't always have to prick yourself. So I think that takes away a lot of suffering or simply makes everything a bit easier.

(TN25's phone rings, she leaves the room)

TN13: It simply takes a lot of self-discipline.

TN20: Mega yes.

TN13: So that you always measure it and always check it, even if it's an automatic pump, but also if there weren't automatic pumps and you had to enter how much correction was needed. It takes so much self-discipline and I think it's impressive, it really impresses me.

GA: It takes away a part of the patient's life that is management of diabetes. Were you aware of that before?

TN13: I was already aware of it, but it's like, I see it a bit differently now. Precisely because I also measured it and you really have to, as I predicted, the first thing I do when I get up is measure sugar. So you have to do it, like really, it's something you have to do and it's not something you can use when you feel like it. So now, of course, we just do it for the two weeks.

GA: Interesting that you were able to gain so many insights in two weeks in such a short time, even though your glucose levels didn't fluctuate that much.

TN24: I found it interesting, so I find it interesting how different people can be in how they deal with it. As I said, I knew about the sensor about the sensor from a few blogs. I have a few colleagues who have suddenly developed diabetes at a young age. And then they posted on social networks like this: "Yes, I'm now wearing Freestyle Libre, now I've done some kind of sport, now my blood sugar is like this and that." And I... this is not just once, but so regularly and I thought, "Ah, some people just make a deal like this out of their own illness. But at the same time they could obviously manage it well and that probably gives a certain feeling of control over your own life, control over the illness, that you have the feeling that you are healthy again, that you have your life under control again. But at the same time, I could understand people who really don't want to know that. Because you also have to live the here and now and if you're somehow afraid, I can understand that certain people are overwhelmed by the fact that they always have to have something with them, that they always have to have their phone close to them so that they don't miss anything, especially at the beginning.

GA: That means that the challenges of diabetes were perceived differently by you, I can say that.

(Participants nod and agree with "Mhm")

TN15: Yes, I agree, especially that it doesn't have direct consequences. We don't have high blood sugar and then you realize: "Oh, now I'm in pain." But it's like, the understanding of the disease is also... has to be there, but it's just difficult to convince people to stick to it regularly, so to speak, and to have so much discipline, so I've noticed it with myself, I haven't measured regularly. Just because when I was at work, eight hours go by so quickly and then you're... Then I thought: "Oh, my God, luckily you don't have diabetes." Ehm, because yes. And above all, it's not somehow limited in time, but then it's decades. And to be honest, I thought it would be easier. I always thought: "Ah, now there's this great technology with the sensor, it's really easy." But it still takes a lot of discipline, even if it's just stalling and then reacting, but still.

GA: Chiara, you must have saved questions that I didn't ask for you so that you could ask questions?

CA: Not that big, then. Maybe just the self-awareness, you said that it would help you in your practical work with the technology to inform the patients and also a bit of understanding. But do you also see negative aspects of using it on healthy people in training and how would you assess this, how should it be accompanied, or in what form could it be done in the course of study so that it is of benefit to people?

TN13: I think if you do it like this as part of a study or in such a way that you sit together afterwards and discuss and perhaps compare, so that you don't just see your own, but see that it's different for everyone. I found it really interesting that it's different for everyone. Although, on the whole, it's similar again in that it simply fluctuates within a range. That you can then say: "Aha, okay, that's a bit of a rough understanding of normal, which can vary enormously." And then exactly. So I still have this here... because if you're just on your own and only do it for yourself, then afterwards you only know about yourself and nobody else. That's why I think if you really want to use it as training, you have to do it somehow so that you can really exchange ideas afterwards.

GA: Just like any other training.

TN13: As in other training courses, yes.

GA: What do the others think?

TN20: Well, I also find it helpful to gather experience afterwards. I would have found it funny if we had all somehow looked at and compared our blood sugar levels or a daily profile of everyone. Yes, and I think that discussing and gathering information afterwards is a bit more useful than just observing without thinking about it. And what I wanted to say about before, I think that when you see patients with polyneuropathy or consequential damage like that, I don't have the feeling that I was mega, mega understanding sometimes. And I had the feeling: "Yes, it's not that difficult to keep the blood sugar under control." And I have to say that after this experience, I now have more understanding that it's difficult and requires a lot of self-discipline and that it's not so easy to do.

GA: Can you see yourself as more of a partner if you have worn a sensor like this and as a doctor you go to the patient and develop the feeling: "Okay, in the end the patient manages the diabetes themselves." So I can't make a direct recommendation to the patient and the patient simply follows because I as a doctor make recommendations to the patient. That's another way of communicating here, because this is a chronic illness after all. It's not something where an accident has happened and the doctor has to mend the leg and then the problem is solved. What do you think about this?

TN15: I would have said yes, as a team. Not so much: "You have to do this and that now." Because now understanding the illness is much more relevant than, as you say, the leg is broken and you have to patch it up, that's also easier to understand. So I think that has helped in the sense that you know a bit about what it's like. But I would never presume to say that I could really compare myself one-to-one with someone who has that.

GA: Yes, the experience of hypoglycemia is missing.

TN15: Yes.

TN13: And also from being permanently affected. I think that's true, all the friends I have with diabetes say that this is extremely important. So that their doctors, their diabetologists have a good understanding and the partnership and as a team and also that it's them who manage it, where they actually have to do it themselves. I've always heard: "Ah yes, no, she wasn't good. And yes, I feel comfortable there." And that's really important with chronic illnesses. And just like TN15 says, even though I have this experience now, I somehow have a better understanding of it, but I would never say that I now know what it's like. Because diabetes I don't think you can say that and I don't know, I know what it's like to have a sensor on for two weeks.

TN20: I think it also shows how important it is to have constant treatment, to lead people by the hand, but also to discuss it again and again and somehow try something new when there is something new and so on. that it just needs mega regularity and not just one treatment and then it's done, but...

GA: ...stay tuned.

TN20: Exactly.

GA: Good. Did we forget something, what do you always want to share, something came to mind during the study but was forgotten? Is there something?

(Silence)

GA: How did you find this number of participants, is it too big or is it just okay?

TN13: No, it's good.

TN25: Very pleasant.

(other participants also agree)

GA: Good.

TN13: It was a very exciting study.

GA: Thank you, thank you very much. Thank you very much.

(Participants also say thank you and say goodbye)

Focus Group 5

Information about the appointment

Date: 15.11.2023

Participants: TN17, TN19, TN22

Transcript

GA: We are recording this for support, afterwards Chiara can also write. So before you expressed an interest in taking part in the study. What were your points of contact regarding diabetes, what changed there, the world of diabetes, what were you already aware of before?

(Someone comes into the room and then realizes that she is in the wrong room, apologizes and leaves)

GA: Someone can start.

TN17: Yes, simply by studying medicine and working.

GA: And how has the world of diabetes changed?

TN17: Through this study now?

GA: No, what is current, how do you treat diabetes nowadays, what are the technological advances.

TN17: Ah yes, monitoring has simply become a bit different, hasn't it? You can now measure blood glucose almost continuously, you have pumps, you can actually replace basal insulin with a base that is injected continuously.

GA: Yes, and have you already looked after patients?

TN17: Yes, just now on the ward yes.

GA: On ward now.

TN17: yes.

GA: By chance, a patient with a sensor is now also being cared for?

TN17: Yes.

GA: Already?

TN17: Yes.

GA: After the study or before the study?

Tn17: Even before the study, yes.

GA: What has stayed with you since before the study, what was a bit tense for you or different?

TN17: Yes, it's just still good, so... I only had one patient after the study who was so somnolent and then you could just check whether she...

GA: Ah, did she also have a sensor?

TN17: Yes, and she was in a hypo beforehand. So and then you just, you just know it without first... so we measured capillary again anyway, but...

GA: Yes, ha, to have confirmation.

TN17: ...yes, exactly. It's just a good indication of that. Yes.

GA: Okay, interesting. With you, TN22, you've got the ... You're fresh out of university and here comes TN19.

(TN19 comes in the door)

TN19: Sorry!

GA: He's a senior doctor in the emergency department. TN19 We have started and we will record audio. But it will be anonymous, so no names will be mentioned.

(TN19 takes another drink and then sits down)

GA: Does it even have apple juice or what is it?

TN19: No idea.

GA: Okay. Chiara Amstutz is a psychology student from Bern, she's also doing the hard work, transcribing all the transcripts so that we can interpret them afterwards. Ehm, TN19 we asked the question, even before the study, you have a lot of experience with diabetes patients, even before the study... What do you know about how diabetes is treated nowadays, in terms of technology and otherwise?

TN19: Well...that's a very open question...

GA: So your awareness of diabetes, yes exactly. You don't have to go into depth, but roughly speaking, if you have diabetes, what treatment options are available?

TN19: Ah, treatment options. Yes, so lifestyle, medication, oral or injections, insulin or GLP1.

GA: Yes, and the advances in technology.

TN19: I don't quite understand the question, technological advances.

GA: How much can technology help diabetes patients, what do you think is...?

TN19: Oh, so you mean the Freestyle Libre type?

GA: For example.

TN19: Yes, of course, that's great. So we also need that in an emergency, if you have a Freestyle Libre, we actually measure glucose quickly. Ehm, although sometimes you also have to correlate, I've now also learned. Yes, well...

GA: So that wasn't, you know the diabetes world anyway or. The sensor study has probably made you more aware of your own glucose regulation. Now we come to the question, what were the special experiences for you, if you could tell us during sensor wear? What was special, what was different?

TN17: Yes, I had a bit of an expectation, or that you can correlate it quite well, for example, ehm, now I don't eat anything for a long time, then my blood sugar stays low. Ehm, now I have a hunger pang, then I can also see that with the blood sugar or. But on a normal day, for example, I get up, I don't actually eat anything and then I cycle there, which is quite intense for forty minutes. And then my blood sugar always rises, which actually makes sense afterwards. Stress hormones go up or you do sport, blood sugar is delivered into the blood, so to speak. But somehow, I had it a little differently in my head at first, but then I learned from it. But I noticed it when I was on a mountain hike, for example, and I really noticed how I got into a real hunger hole. But somehow you couldn't see it in my blood sugar. I just had it in my head that these sensors are now also being sold to athletes, with the idea of perfectly matching your food intake to your sport. But somehow I don't see that you can only do that with blood sugar. And that's perhaps why I went in with the wrong expectations and learned a bit from that, or that blood sugar itself isn't the only parameter you can use to find out when you're hungry and really need food. Or ehm, yes, that you just don't realize that you burn a lot through exercise.

GA: Do you think, if it's a patient and he has a sensor, what kind of experience do you think he will have if he gets such a sensor?

TN17: So now a diabetes patient?

GA: Mhm.

TN17: Yes, well, it's a completely different expectation where you're going. Because the only goal there is to keep your blood sugar within a certain limit. And there it makes perfect sense, I'm just talking from my perspective as a healthy person. That I initially had expectations that I would look like this and that, but that didn't actually turn out to be the case.

GA: In other words, you expected your blood sugar to fluctuate more, but you were disappointed that it was actually more stable.

TN17: No, I just, I just assumed the wrong thing, so to speak.

GA: How did it go for you, TN19?

TN19: Well, I didn't want to take part at first because I was so afraid that I would have elevated values. And then I was actually surprised that it wasn't even... actually always within the range. And I actually had the same experience. That there was very rarely a correlation with, for example, eating and then it rises. So I also had the feeling, yes, that's exactly what I had, that hunger pangs are not hypoglycemia at all. I could imagine that for a patient with diabetes this is also crucial to know, is this hypo or not hypo? Because that's the only way I've noticed that you can't assess it at all, because you can't feel it at all. You have zero feeling for what the sugar is doing, that was my surprise, that you have zero feeling for it.

GA: And you, TN22?

TN22: Yes, in the beginning I looked quite closely when I ate something to see how high it went. And also when I was exercising and I noticed that it went down relatively quickly after exercise and then peaked again afterwards, which I also found exciting. And I had a look at a Nutella roll or something and then saw how long it lasted and how quickly it went up and then back down again. And I made the same observation as the two others, that you just can't tell when you're that low or something. but I found it very exciting, but I also let it influence me, so that I ate less in between when I wasn't hungry.

GA: Aha, okay. Interesting. Were you able to fulfill the task of always scanning every eight hours or did you sometimes forget?

TN19: Yes, it was only difficult sometimes at night because I didn't want to have the phone next to the bed. And then sometimes in the morning you realized: "Ah, now I haven't had it for too long." But otherwise...

TN17: I think I managed it most of the time, or maybe once or twice during the night. If you don't hold it again in the morning, yes.

TN22: For me, that means at the weekend, when you sleep a bit longer. But during the week, actually.

GA: Okay. And if you go to the patient perspective, how is the effort of glucose monitoring with a sensor when a patient with diabetes has to inject insulin over and over again. Is it a relief compared to old technology or does it come with its own challenges, what do you think?

TN22: Well, I have to say I found the challenges very small and I think you get used to them quickly. You don't have to think about it so much because it actually works automatically.

TN19: Well, I also thought to myself at first: "This thing will get on my nerves." And maybe on the first day I felt it a little bit, just a little bit. And then I forgot about it, so I actually always scanned it, but then I don't know, I didn't think about it anymore. When you take your clothes off, you suddenly realize it's stuck. But otherwise I imagine it's much more pleasant than... And yes, you can work much more accurately. I used to do it more than just three times a day. Well, at the beginning you do it a bit more often, but just out of curiosity from time to time. And if you have to inject insulin now, you have to do it relatively often, measuring blood glucose is more time-consuming. You then have to take material and...

GA: And pain?

TN19: Yes...

GA: So you would prefer that if a patient has to inject insulin, he would probably be better served with a sensor than with daily lancing. Unless a patient says that he really wants to have very accurate values and would therefore prefer to measure capillary.

TN19: Well, I can't understand why you would want that if you've tried the other one.

GA: Yes, there is a small proportion of patients who want this, but the majority of them want to go to the sensor.

TN19: Yes, probably yes.

TN17: I managed to get it to fall off once, even when I took off the shirt (points to his T-shirt), it got stuck once. That happened on the very first day. And then I just had to be careful, I don't know, because it was just so tight and then it was always just so tight. But otherwise I think it was a great advantage. I also have a colleague, I know him from the military, and he's a real mountain farmer. He's actually so against technology and has now had to get a cell phone because he's become a mountain guide. And now he needed a cell phone right away. And three or four years ago, he was diagnosed with type 1 diabetes, but even he now has a device like this. Just not via a cell phone, but via a device that you get with it.

GA: Yes, a reader like that.

TN17: Exactly, and he does that too... I just went hiking with him again the other day, and he does that too. But what he does, he doesn't have a pump, because he says it's somehow much easier as a mountain guide, because then you have certain days when he doesn't have to inject anything and certain days when he doesn't do much and then he just has to inject. But I think the device is also a big advantage for him.

GA: Okay, yes. Have you had any other problems with the sensor where you say, "Yes, because of that, there needs to be more improvements in this technology."?

TN17: Yes, what TN19 just mentioned. Well, I don't know, if I had to have it all the time, then I think it would always stress me out a bit that I have to scan within eight hours... especially if you want to sleep a bit longer at

the weekend, that you always remember to scan. But it's probably not that important to always have a constant measurement.

GA: Well, that has already changed, there is now this third version, which measures continuously via Bluetooth itself. So that means the patient doesn't always have to hold out and that's another relief that has already happened. But it's good to try out an old technology and come up with the idea that it should have been better. And so it also happens with technology that you go from the problems to the solutions like this: "Okay, this problem should also be fixed." Do you have any other experience, because now it's easy to imagine that you all have very good glucose regulation, that the body itself strives to keep the values stable. But was there anything where you could say: "I wouldn't have learned this without this sensor." So I have something, you mentioned earlier that you expected your blood sugar to go down after exercise, but then it didn't go down, it went up in some cases and in retrospect you were able to draw that conclusion. Did you have any other experiences?

TN17: Yes, you do notice... Well, in my case I simply noticed when you drink alcohol, so a beer or something and then maybe risotto. There are certain things where I've noticed that it's gone up, especially when you drink alcohol with food.

GA: Were you able to tell whether it was beer or wine?

TN17: Yes, um, I think I only noticed it once when I was drinking beer.

GA: Mhm, because beer also has carbohydrates, so there is a difference between wine and beer. Interesting.

TN19: I didn't even notice that now.

GA: You didn't notice anything?

TN19: No, not with the alcohol.

GA: Yes, with you TN22? You're still fresh out of medical school. Do you think it would increase interest in learning about diabetes besides just frontal lectures, that everyone gets a sensor and learns how their own glucose behaves, would it bring something, would it increase interest?

TN22: Yes, I think so. Especially with the endocrinologists, we've also had a bit of a conversation with them, so I've also sat in a conversation where they've shown a patient the device and explained a bit about how it works and so on. and then try it out for yourself, then you can really say: "It's like this and this. And for me it was like this and this." You also know what you're really giving the patient, because it's easy to test and I think it's very instructive.

GA: What do the others think? For example, we would have a lot of resources, a lot of money to optimize medical studies and also to give hands-on experience. What do you think?

TN19: Well, I think it was a really good experience for me to wear it. I mean, before I would never have thought of recommending it to a patient and now I would do it, I have to be honest. Yes.

GA: And could it also be that the patient feels better if the patient thinks: "Okay, the doctor has his own experience, even though he doesn't have diabetes, has dealt with it a bit and knows how it works"? Could that also help?

TN22: I think so, because I don't know how many thoughts other people have, but even in lectures when a doctor says: "Yes, it doesn't cause any pain", or: "It's not a problem, you don't notice it", then I always think to myself, "Yes, has he tried it?". And if someone were to tell me now: "Yes, I've tried it, it's been like this and like that." Then I would think to myself: "Okay, then it's probably not such a big deal."

GA: You briefly mentioned earlier that it's now being pushed for athletes and non-diabetes people to be able to track their own health a little like this. Like a tracking device. What are your thoughts on this, for or against? So we've had quite a few discussions over the last four rounds about the advantages and disadvantages of sensors after you've worn them on your own body, do you have a different opinion?

TN19: Well, as a general rule, I find it rather problematic. So you can try it out, I think that's actually okay for everyone, but it's actually a joke if I just keep doing it. It just wouldn't help me with anything, it's just resource-intensive and this constant measuring is just not..., so not particularly useful for anything.

TN17: I'm of the same opinion. I also have the feeling that an athlete is not helped by blood sugar alone. Even if that's what's being sold. Because in my case, I've now seen that there's actually zero correlation with a hunger hole or... For me, it's actually been more like this, when I've done intensive sport it's actually always risen and that's why I don't know. That's why, and I'm also of the same opinion, that you can drive people a bit crazy with things like that, when they always try to monitor their food, they always think: "Oh, now it's gone up so much..." But it doesn't really have any relevance. And that's why I actually see it in a negative light.

TN22: I can't imagine how that can help either.

GA: Could you imagine someone who is overweight and has diabetes or pre-diabetes and they don't know what food is good for them and what food is less good for them. Could it be more helpful for lifestyle modification to have seen at least once how the body behaves?

TN17: Yes, perhaps even more so. So I still had the feeling that you were able to correlate a bit more with the food.

GA: So then I also look at the specific population, i.e. I don't just give every healthy person a sensor and let them have a look. There has to be some kind of benefit defined beforehand, why are you doing this? For example, you have now done this as part of a study, so you have pre-defined why you are doing this. Some kind of benefit should be defined beforehand. Do I understand correctly?

TN17: And maybe if someone has prediabetes and then constantly has slightly higher values and then maybe they notice, I don't know if it's like that, but if they then go for a run for maybe half an hour or go cycling, that the values go down a bit and that if they eat more, they go up again. Maybe that could have a positive influence, but maybe more that he's seen it, or.

GA: Exactly, so no permanent treatment?

TN19: Well, exactly, I can't imagine it, I mean you have to eat, the question is what you eat. Whether you can then see that in the sugar, whether that was the wrong thing... I mean, you actually know what you can and can't eat.

GA: Yes.

TN19: I'm not one hundred percent sure whether that will work. But I don't think it's a bad experience, anyone can go through it, even an athlete, to see that it might not help.

GA: Yes, yes, that's also a statement that it doesn't help.

TN19: Well, I think students are a good idea, it's actually not that bad. Everything you've experienced yourself isn't so bad. As a rule.

GA: And if you now have a sensor, what problems can arise and what are the blood sugar levels, has it somehow had an influence on changing the patient's awareness? That you say: "Okay, I don't have diabetes, I just had to check my blood sugar levels. What are the everyday challenges for diabetes patients who actually

have to inject insulin?" Could you put yourselves in that position and think about it, did Sensor bring you a little closer to the patient or was this experience less helpful in this respect?

TN22: So I think specifically for wearing the sensor yes, but all the rest no. It's just a very small part of it where you get an insight.

GA: That means that diabetes patients have a lot more to do to manage diabetes than just monitor blood sugar, yes that's a valid point.

TN22: Yes.

TN17: Yes, I think I'm of the same opinion. I mean, especially if they have to start over somehow, then they have to deal with the food intake and how much I have to inject if I eat so and so much of it. And that's probably the main part. And the sensor only helps to check whether what I have injected has actually been correct or whether I need to make some corrections.

GA: In other words, when the patients receive certain training, the sensor not only shows certain blood sugar values, but the sensor also shows what they have done with them. that is two different pieces of information, what the blood sugar is and what it was and what they have decided and done with it and then they can see the result. Can you put it like that?

TN17: Yes, so I actually mean therapy monitor then. Because it can then ultimately also determine the HbA1C via the values?

GA: Exactly. Did you see that, did you see your HbA1C after the two weeks?

(Participants nod)

GA: Good, yes. Is there any other message from you, I got the information from other participants in the last Focus Group, for example, it can go in the direction of health obsession or disease obsession, that you just constantly look at the values and then don't do anything other than just monitor and treat the values. Or it can help you to choose the right path. So it's both, it can be stressful, but it can also be helpful. It depends on what kind of patient we have wearing it. Do you have any thoughts on this?

TN19: Yes, at the beginning it was a bit like that, that you did it more, then after two weeks the effect is a bit over. Ehm, I think over time, I can't imagine that someone does it obsessively, because it's not that exciting, because it doesn't do what you might expect. The body works somehow, ehm, so I can't imagine that you'd keep doing it like that without the illness, where there's a deeper meaning to it. If I didn't feel the need now, I almost can't imagine that a healthy person would feel the need to measure it all the time. But it certainly exists.

GA: What is your opinion?

TN17: Yes, I'm actually of the same opinion. I probably also looked a bit more at the beginning. But yes, I can imagine that if you're a bit compulsive, you might be a bit surprised how you react to it and go: "What's the sugar like now that I've eaten this?" But for me, yes, I just read it off relatively quickly and didn't spend the whole time looking at what the sugar level was.

TN22: Same opinion.

GA: Okay. Did you experience any disturbance in your sleep?

TN22: More in the morning, I had a bit of muscle pain, but I didn't wake up or anything like that when I was sleeping.

GA: You have nothing... okay.

(Other participants shake their heads)

GA: Is there anything you would like to ask, Chiara?

CA: Yes, I now have the impression that you have received a bit of confirmation that the regulation is working well for you. That it calms you down a bit, almost in that sense. If you were to use it in training with students, for example, you see that as a bit of a danger, that it might be a bit in the students' heads that it works, but you can't do the transfer afterwards with diabetes patients. It doesn't work for them straight away. Could that be a danger, or do you think that with the training otherwise, with the knowledge that you otherwise have as a student, that it won't be a problem?

TN22: I don't think that will be a problem.

(Other participants agreed with TN22)

CA: Don't, okay.

TN19: I think it's more likely that you could imagine what would happen if it went up, i.e. above or below the bar. I could already imagine what it would be like if it were higher. I just think it's always like that, when you do it with students, you discover a few more diabetes. So it's always like that, if you do an ECG on everyone, you always discover something. That would annoy me a bit, wouldn't it? That also annoyed me a bit, because if I actually felt about right, I would have been annoyed if I'd had an elevated HbA1C afterwards. Because then I'd have to draw some kind of conclusion from it, and that would have really pissed me off.

GA: Okay. Have we forgotten something, is there something, a supplement to this, that would be relevant to the study? Because the study question was, what could you learn about your own glucose regulation? You told us all that. And how can wearing a sensor influence the patient's perspective?

(Silence)

GA: Did you feel addressed, did anyone ask you why you have a sensor on now? Other participants were constantly being asked by people: "Have you got diabetes now, or?"

TN19: Yes, of course. It would have been even more in the summer. I'm also, you just forget it then. I also went swimming or something. And also my family or. Yes, yes, that was actually still fun.

GA: And what did you say?

TN19: Yes, the truth.

(All laugh)

GA: That you simply take part in a study and so on. Okay. And what was the question, how did they approach you?

TN19: Ehm... Yes, so one of my sons said: "What have you got there and what is it for?" And then I explained it to him. Although the question has actually come up a lot, because in summer you see lots of people with it at the swimming pool and then the question comes up: "What do people actually have a funny thing there?" But I can't remember anything else right now. But nobody asked me about it and said: "Do you have diabetes?" Nobody has that with me now.

GA: Okay. It was the case with other participants.

TN22: Me too. I've now changed jobs to the USZ (University Hospital Zurich) with new medical students. And everyone actually asked: "Do you have type 1?" Or even during longer operations, I was asked by TOAs and anesthetists whether I had to go out and whether I had to be scanned.

GA: And how now when you take on the role of patients. You've been asked a few times, and these patients who have to wear a sensor all the time and keep coming into contact with people and everyone keeps asking, what are your thoughts on this? How could a patient like that feel?

TN17: Yes, it could be a bit annoying. Because at the end of the day, it's like putting glue on your chest that you have diabetes, so to speak.

GA: In other words, something that the patient himself does not want to perceive is constantly reminded of, not only by the illness itself, but also by other people who come into contact with it. Could that be a disadvantage of this sensor?

TN17: I think it's actually still hidden now, so to speak. So probably less so in summer and also when you go swimming. But now, when I've worn a T-shirt or something, you've only really seen it when you've done something like that. (shows how he stretches his arms up over his head as if he's trying to take something from a high shelf or something similar)

TN19: Yes, yes.

TN22: I also don't think that so many strangers simply approach you like that. I think it's just in the medical field where people are a bit inhibited about asking questions.

GA: That's right.

TN22: I just think, maybe at the beginning, that it might be a bit of a problem because it's new and you're so identifiable with it.

GA: Okay.

TN19: Well, I've also had a patient like that, a young one, who came in twice with a severe hypo. And he was so ashamed of his diabetes. I mean, there are people who are ashamed. And that's a bigger problem when you see it like that. Because you just identify them, well, it's really widespread, I would have said, and you just identify people as: "Ah, you have diabetes." I mean, if that bothers you, that's a problem.

GA: Yes. So the case, I think I've asked all the questions. Is there anything we've forgotten where you say, "Yes, that should be mentioned as well?" From your side?

(Silence, participants shake their heads)

TN22: Maybe that I had a bit of a problem with the sensor because of the atopic dermatitis, that it didn't really go into the skin. That is perhaps still the case and that the adhesive irritated the skin a little.

TN19: Irritated?

GA: Did it irritate you after all?

(TN22 nods)

TN19: I almost didn't take him away.

GA: Already? Did you have to use force...

TN19: No, no, that was fine, but then you had a ring like that.

GA: For a while.

TN19: It could no longer be washed away.

GA: But that's interesting, because normally it goes away.

TN19: Yes, it did go away, but it was really several weeks.

GA: Okay. Good, thank you very much!

Reflections

Reflection TN1

(in addition to the interview, as TN1 had to leave earlier, as noted in the transcript)

What I appreciated about the sensor study was the ability to analyze the body's reaction to subtle influencing factors to blood sugar regulation: sleep, stress, exercising before or after eating, emotional regulation. One had satisfaction in being able to see the curve go downwards... One had satisfaction in a good morning fasting value.

However, I did feel that I did not like how public it was... I did not like that people saw the sensor and were "judging" if I were diabetic. It is not a silent disease anymore and sometimes we need privacy and discretion with our medical diseases.

I also think one can go overboard with it... one can sometimes think Lower is always better even if that is absolutely not true! Lower is not better when it comes to hypoglycemia. It is more about appreciating the return to normal or the steady curve rather than lower is better.

Even though it was easy for me and practical for us, I do wonder if some people will like the traditional fingerstick method (more private, not technologically driven).

Reflection of TN8

Wearing a glucose sensor for two weeks was an exciting experience that revealed problems previously unknown to me in diabetes patients. Until now, I was of the opinion that the Freestyle Libre was a simple, almost obligatory glucose monitor for every diabetes patient. Even though the traceability of one's own blood glucose values is indeed simple and quite comprehensive, I was surprised by the sensor's susceptibility to errors ("hypoglycemia" at night with muscle compression), as well as the "vulnerability" of the sensor in everyday situations such as drying off after showering or sitting on a bench. I lost the sensor three times during the two-week wearing period (once shortly after putting it on).

Keeping to the maximum eight-hour scanning interval also proved to be more challenging than expected. The announced introduction of automatic scanning via Bluetooth is certainly a useful update.

I am generally a big fan of self-experience, as I believe it promotes understanding for patients. Accordingly, I would also support the introduction of such an opportunity for trainee doctors.

Reflection from TN23

I found the experiment very exciting as I have often wondered how high my blood sugar is and how my diet affects it. I was very intrigued at first and scanned very often to see what was influencing everything and how quickly my blood sugar was changing. Over time I got used to it and only scanned before and after a meal. It was reassuring to see how narrow the range of my level was, even after very high sugar meals. It made me think about how limiting it must be not to be able to rely on this physiological regulation. Nevertheless, I like how easy it has become to measure my BG. I didn't actually find the sensor itself restrictive, but I had to remember to take my clothes off more carefully and I bumped into it more often. Unfortunately, my sensor failed after just

one week after I reacted to the adhesive. It was very itchy, so I was almost glad when it fell out. I then asked myself whether there are alternatives for people with atopic dermatitis, for example, so that they can access the sensors despite having easily reactive skin. I think you get used to wearing them over time, but I'm glad I don't have to. The picture of a diabetic patient and the necessary measures for successful therapy become much clearer when you wear the sensor, but I saw it from a more scientific point of view and therefore I didn't fully empathize with the perspective. I don't know how useful this experiment would be for any doctor, as you can certainly just wear it without worrying about it, as you don't really have to take nutrition into consideration if the regulation is working. Perhaps it would make more of an impression if you had to note and consider the exact intake of carbohydrates. All in all, it was an exciting experience that I would do again at any time, with the hope that I will never have to rely on such a sensor myself.

Reflection Prof. Ludwig T. Heuss

Nowadays, we monitor ourselves around the clock and, above all, with our watches: wearables everywhere. The self-measurement of people has become an attribute of modernity or perhaps also a symbol of maintaining the illusion in an increasingly insecure world that we can do something, that we can control ourselves.

I admit it, I too have become a controller of myself. I measure my step count, blood pressure, sleep every day and, above all, my weight. My weight is my enemy, which I have been wrestling with for decades and which is a constant source of pain. But in the last few months I have changed direction! It's a pleasure to reveal that I've been using Mounjaro once a week since August and the weight is melting away - at least so far.

So let me say these two things up front: 1. I myself have succumbed to the fetish of self-measurement and 2. I use a GLP-1, nota bene a diabetes medication for food reduction and weight loss.

I used a glucose sensor twice: once from September 19 to 26 and once from October 23 to November 6. The reason for the double period was that on September 26 I got my arm caught on the door frame on my way to the bathroom in the morning and accidentally tore off the sensor. That was quite a realization: the sensor is practically imperceptible. I had actually expected a little pain, but didn't feel anything. Sometimes it felt like a slight muscle ache, but you only really remembered the sensor when you touched your own arm and felt something hard - or when you touched the door frame lost in thought and accidentally tore it off. You could also simply forget about it in the shower. That was a good feeling. Previously, when I saw young diabetics with a glucose sensor, I always felt a bit sorry for them and thought that it must hurt to live with such a needle in your skin.

I'm sure people around me thought the same. A sensor on the arm is a stigma. Some saw the sensor or watched me download the results and looked pityingly. "Oh, poor Ludwig, he's got it now too... He has diabetes..." When I then explained that no, this was a self-observation study, I received a mixture of admiration for the heroic self-experiment (it really didn't hurt) and skepticism as to what I could find out.

You can learn a lot with such a sensor in your arm. First of all: how constant blood sugar is in healthy people. My values were practically always within the normal range. During the September measurement, they even tended to be slightly higher than in October. I noticed how little the feeling of low blood sugar correlates with hunger. The idea that "I am hypoglycemic" is only true to a very limited extent. In any case, I found it extremely difficult to get a feeling for my own blood sugar. If I hadn't eaten for a long time, I could assume that my blood sugar was rather low. But I didn't really feel it. I found it impressive to observe my blood sugar for the first time after eating a pizza over lunch. It shot up from under 6 to almost 9 mmol/l. But I didn't really feel anything from this either. An unexpected learning point: on October 23, at the beginning of the second measurement, I had also eaten very little during the day and in the evening I went to Heilbronn in Germany to give a lecture. After the lecture, it got late: we went to a winery at around 10 pm and ate (a little) and tasted (a lot) all the different wines that were in the repertoire. It was around 01.30 the next morning before I got up and went to bed. When I read my blood sugar, I noticed that I had probably dropped below 3.4 mmol in the early hours of the morning.

Apparently the liver was unable to adequately utilize the many calories, or the combination with the GLP-1 led to a rather low blood sugar, below the threshold.

Apart from this event, 99% of my BG value was within the target range, the average of the last 30 days was 5.0 mmol/l, there was never an upward outlier. This also gave me an estimated HbA1c value of 5.0%, which was rather reassuring in terms of my self-measurement.

Wearing the glucose sensor was a special experience. I learned how little I subjectively feel the level of my blood sugar and how quickly and with what delay changes in blood sugar can be measured. I was amazed at the consistency of the regulation and how easy, painless and unproblematic it is to use a sensor. Compared to diabetes patients, this has significantly increased my understanding of the mechanisms of continuous self-monitoring.