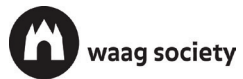


Measuring Less to Feel More

Conversations with users about the Artificial Pancreas

User study
Valorisation call COMMIT/
"Measuring Less to Feel More"



COMMIT/

COMMIT is a public-private research community solving grand challenges in information and communication science shaping tomorrow's society.

Content

Introduction	6
Background	8
Towards a design guideline	12
Lifestyle implications	16
Current relationship	20
Using the Artificial Pancreas ?	24
Meaning of the Artificial Pancreas	28
Recurrent topics	32
Going further	38

Introduction

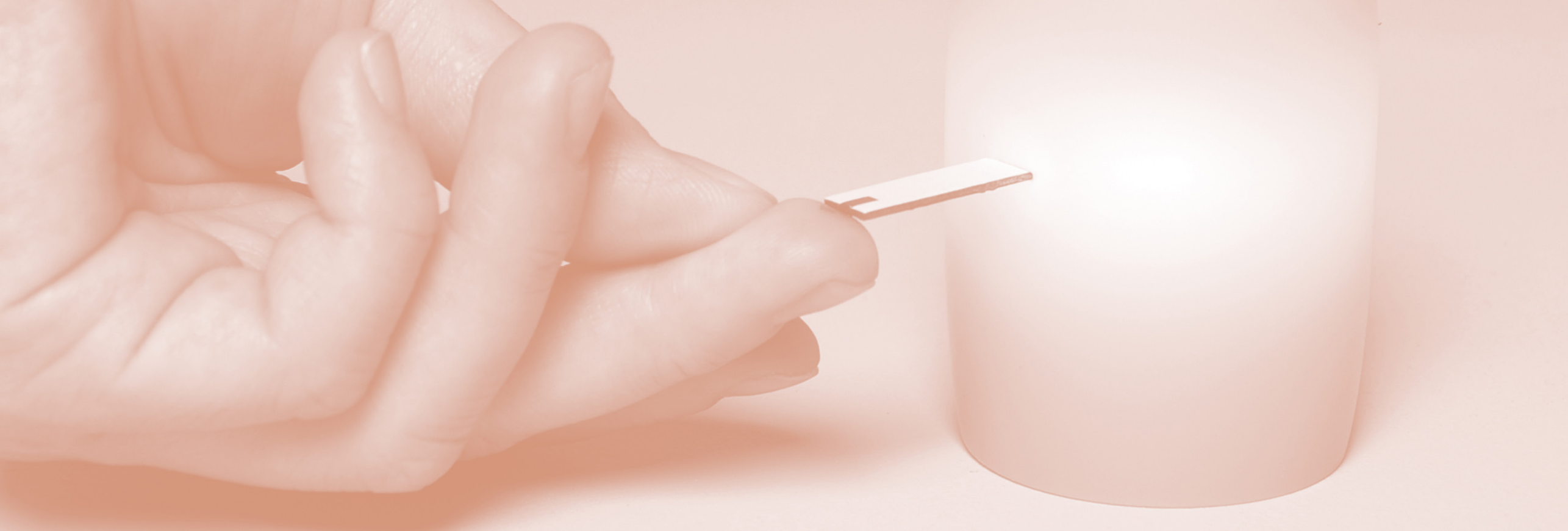
For the collaboration between Inreda Diabetic and Waag Society within COMMIT/, the first steps were to find out how users (persons with type 1 diabetes) would receive, perceive and use a device based on a bi-hormonal closed loop system (commonly called "Artificial Pancreas" or "AP").

We conducted interviews in order to serve as a first inspirational and honest starting point. These interviews were done with five persons living with diabetes and were oriented in a qualitative direction more than a quantitative one. They consisted of a Q&A (on lifestyle implications of living with diabetes, the relationship the interviewed persons have with their current device), followed

by a more projectory phase/story telling (on how they anticipate the use of an AP and what it would mean to them). The flow of the interviews was intentionally kept quite organic, in order to encourage the discussion.

This booklet presents the outcome of a user study, based on interviews that give a voice to the people living with diabetes.

This study was conducted between January and July 2014 by Waag Society (Mickael Boulay, Sabine Wildevuur) in collaboration with Inreda Diabetic for the COMMIT/ valorisation call "Measuring Less to Feel More".



Background

The goal of “Measuring Less to Feel More” is to rethink the care of diabetes patients in a user-driven way. Stress has a high impact on the successful management of diabetes. Field research suggested that the devices diabetic people use to check their blood sugar level stresses them out. Stress releases more sugar into the bloodstream, thus creating a vicious circle.

There is apparently too much focus on numbers, instead of meaning. As an alternative to displaying numerical values, the position of LED and colour shown by the interface of the device will simply reveal whether the blood sugar level is high, low or balanced. This type

of intuitive interface will be combined with an Artificial Pancreas, developed by the company Inreda Diabetic BV, which enables diabetes patients in an unobtrusive way to better regulate their blood sugar level at home. Also, the growing number of older adults with diabetes can stay at home independently for longer when supported by this device.

“Measuring Less to Feel More” will improve diabetes treatment and quality of life, eventually resulting in lower costs for society.

lifestyle

a healthy life [] is good for anyone

now guessing, knowing, calculating you are busy all the time

not doing work all the time "why why why"

out of routine = surprise (often bad one)

not flexible anymore

you have to have discipline it is not always easy to have discipline JK.

safe environment of a company

try to imagine the unexpected

down = more complicated less fun you are worried about it & other people

if something happens - think of first

out on time, when others all day busy with time & normal life

if you want to stop making think of that that should i go?

most stressful aspect

makes you step out of normal daily life

when it's right because no person said so no other just will then it's right

also overlaps or it will hit more

questions for Inreda

sport make? (see exercise & regularity)

it has to react fast (h1?)

to prepare for pump

waiting

if contains something out of comparing with with AP?

responsibility? (if pump only suggest and approval)

idea, reaction from pump

to go for a walk and get a bit of exercise

very often

need to work very early it's too early, not good a normal person you do not work

the AP also include you with (see and to not 20 to see 25 in blood)

AP don't work, you just it say fast, think

relationship with GM

never forget look back to previous numbers

wherever i go, have to have it like a part of my body

measuring = norms habit -> CONTROL

you can't feel if AP doing good?

using AP?

it need to have an indication of what he is doing

don't need to know exact number once it's proven

need to know why it's being done

just not still working well

the device isn't great

interface JK on body + not to simple

have to add the amount not an automatic device so responsible for that the pump does

when you expect things that the device tell you what's happening

can't happen at that, need to use it

that's weird you don't think about what your pancreas does?

can't think about it

not on stomach

not visible & compact

just "lip" when you have a plan

light enough info after a while

press a button and see what's happening if you want to see

not every 5 minutes

light was for reward for me enough

not only a body also psychological, mental.

TRUST

being use to it = trusting it

it explains what it does

once it's proved

give me trust, if I check if it does correct

can't be a pro to see the number

curiosity?

he says i am working on it than it's do for me

you can estimate it, rubber arms, do pattern

in the beginning need to know that works good and stay using good

you are used to check pump with so with AP you do not because you are used to do that

blame not out to it

more spontaneous!

very nice to have a big help

compare with cars that drive by themselves would you trust it?

compare what you do what it does

I'd need to pass on judgement to machine... impossible?

difficult to trust

or otherwise you must not have it.

meaning of AP

much more easier! life will be so much easier

to have a normal life finally.

don't worry anyone

if I trust that device, i don't think of hypo anymore, will be so nice

not different from other people

stop lifting finger every day...

TRUST time

3 months without problem =

for me, very hard to let go it will take months, years

First to be certain (it can be wrong if it's broken)

think in the long run you should check with

say far w/ AP but i don't like it because it is technical

drinking, eating, laughing, not worrying about the night (just about the hangover)

that should give me quietness, less stress

if it works, that I can be like this is a nice feeling you can let it go for a few hours, with less

it is like this

BG+ pump in 1 device not possible yet

when it is possible i ask my doctor to sign me in for the program

"BECAUSE I'M TIRED OF MY DEVICE AND NOT ROBOCOP"

MORE

JK

Towards a design guideline

From these interviews, it appears that Diabetes implies before all a daily life which needs to be structured around a (vital) discipline.

The current level of blood sugar, the amount of carbohydrates consumed, and time seem to almost always be on people's minds, whatever they are doing (even in the most enjoyable or relaxed moments).

On top of that, measuring and injecting insulin are (stressful) tasks to be performed several times a day.

The Artificial Pancreas (such as Inreda Diabetic is developing it) has the potential to take away many of those moments by providing a device which measures and adjusts (lowering or highering) the blood sugar level in a fully closed automated loop, ensuring a better and more stable blood sugar level.

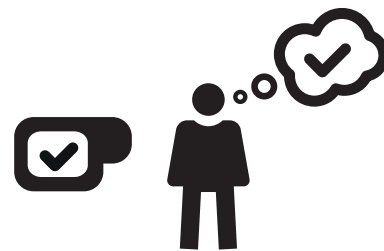
Once the device has gained the user's trust, it has the potential to bring more peace of mind and reduce the amount of times he/she would have to face "wake-up calls" (hypoglycemia for example) due to diabetes.

The Artificial Pancreas will give its users more time to enjoy life.

On every level, the Artificial Pancreas should be developed with this idea in mind. Here are 3 concrete examples how.

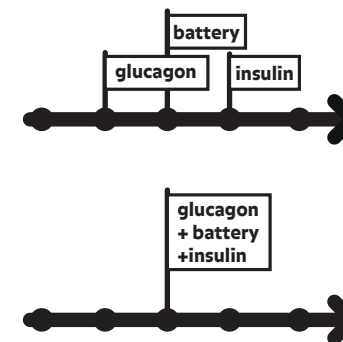
1- Interaction

So intuitive that users don't need to spend time understanding it. The product and its interface are based on a very intuitive model. So when something needs to be done, users always know how to perform it.



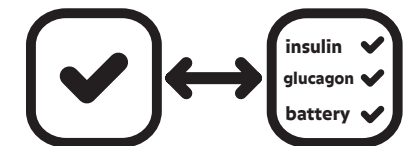
2 - Maintenance

Consumables (glucagon, insulin, sensors, battery) are ideally to be changed in one single moment. When possible, the "maintenance moments" will be combined into one single maintenance moment.



3 - Feedback

The amount of information given is reduced to what is relevant at the given time only. However, users can choose to get more information about the past and current situations anytime.





Lifestyle implications

How diabetes influences their daily life

You know, a healthy life for everyone - which brings the responsibility of eating well, eating regularly, exercising, stuff like that - doing that with or without diabetes is good for you.

It's knowing, guessing, calculating... So you are busy all the time; take eating a very nice meal for instance. You are thinking "Ok, ok. Stammpot...How much?...Oh soup, what's in there?" And it just goes on and on.

It makes a dinner more complicated. And less fun.

My boyfriend just jumps on his bike, maybe checks if he has his wallet and he is off. And

I have to think: when do I have to change my insulin pod?

Do I have enough battery? Enough measuring strips for today? And maybe we meet up with friends. Will we come back here to have dinner? Or maybe we'll eat out?

I am not flexible anymore. I have to have a certain pattern in my lifestyle.

It is not nothing [...]. You have to eat on time, you have to give insulin on time etc... The whole day you are busy with the time.

I am not going to give up my job and start my own company. I will always stay in the safe environment of a company that hires me.



- What is the most stressful aspect of living with diabetes ?

- Planning. I am not so good at planning, and you need it for diabetes...you need it.

You have to have a good discipline. And that's not always easy, to have discipline. Because other things in life, sadness or things that happen around you are the same as someone without diabetes. So you are sad...or angry or... other emotions. And this is sometimes difficult for your diabetes.

It is always on my mind, whatever I do.

About getting hypoglycemia :

It's not so pretty. Because then you have a confrontation with it, with the diabetes. And you know then "oh yes I should know what is the time, I ought to know what I should take, there are many things..." Then I think: "Oh...the diabetes..."

note : The situation looks like a "wake-up call", where diabetes suddenly puts you on the sidelines of the routine you were having.

"When I get stressed, my values are much higher".



Current relationship

What the relationship with their own devices is like

Wherever I go [...] I always have to have it. It's like a part of my body. It's something which is there.

It's not emotional but like I said : I can't do without. It is a necessity, which is not like I consider the glucose meter my friend. It is a handy thing and it tells me something that I can't figure out for myself. So, as such, it's valuable

I look at the current number, I compare it to the last one. Which I remember, I don't have to look on my meter. And then I know if I am doing better, good, bad or worse.

I am not using it to put in my carbohydrates

or whatever. I don't do that. I just want to see now. Because I know what I ate, and I know how many carbohydrates should be in there so it's no use for me putting those in there. And I never look back.

- Never ? Not even after a tough week when you would ask what happened that day...

- No. Never, never, never. No, because I know!

Otherwise it would mean that I have to put everything I do, and everything I eat, and everything that happened that day in a diary. Because there are so many things that you can explain but as many things that you can't explain. So I would have to write down everything, because then it would



make sense ! People don't write down that they are stressed, unless it is "really really stress".

note : big stress is noticeable. But not a little stress. So stress is often not taken into account by the person when trying to calculate current blood sugar level.

My doctor is also happy that I do that because he thinks people with diabetes are testing too much. That they over-react about testing.

When you expect that the device will always tell you what's happening, it's not good. Because then it's your brain that does not work. In my opinion.

If I'm attached to it?... I am not happy with it, the fact that I need to use it.

*- Then it calculates how much insulin I need.
- And the pump releases this amount automatically ?
- No, I must validate it, because I am responsible for what the pump does. It's not an automatic device.*

Without, I would be stressed. It reassures me. [...] It is part of my life... It belongs to me. Without, I don't feel safe.

When I have something important to do, I want to know how my blood glucose is. So I want to check because I don't want to meet somebody and suddenly not feel well. So I want to know with which numbers I am starting the conversation.



Using the Artificial Pancreas?

What it would be like for them to use an AP

I don't think I need to know the exact number once it's proven it works. I need to have an indication of what it's doing. So I would need to see "it's in the low range, and I (the device) am going to make sure it is going up". Then I can say "Ok, let's go!".

I don't need to be that precise, but I need to know that I am doing the right things. Just like I would have to know that the device does the same thing (the right thing). If I have a high blood sugar and I need to inject insulin, I do that. The exact amount is always a guess because you don't know if it's enough or not. Something needs to be done and I would have to have the insurance that the device does that.

Then I don't have to worry about my blood sugar level anymore. Maybe I just worry about...I think you have to fill it up with insulin or glucose, glucagon or something. So I think I will be thinking "hum... Is it still working well?"

-I think I want to know what it does... That's strange actually, isn't it?

-Why?

-Well, you, you don't think about your pancreas if it works alright?

-In the beginning I think you want to know if it works, in the beginning.

I like these colors much. So that it show this when it is ok. Maybe it should display something more... But that it says "I am



working on it" and then it's ok for me.

In the "ok zone". Between 4 and 10. I want to know if I am between 4 and 10.

You are used to all the things you have to do, before the Pancreas. You do that the all day, it's in your head, to check and to prick. So I think if you have the Pancreas device, you do something because it is a habit to do something. So that when you have it the first time, you look if it is all good.

When it only shows the light (no number)? That is good for me. If I see "oh it is white" then I am good. Or it is lower, then I see that : I know it, I can do something. So if I

know this, it is also good. Enough for me, I think. And no numbers and only this (light feedback), then I know it too.

When I have this device, an automatic device, then I would like to have a device where, on the machine, I can see what it is doing. That is possible with light.

Is it good? Can I take an ice-cream [...] Can I decide to take extra sugar or must I stop because the machine says to me "you are little bit high. I must first work to get it right again".

It must be possible to press a button for example and to see what's happening. If you want to see it. Because I am the manager of

my device, and the device is not my manager. I am not a robot.

I don't have a pump. I don't like it. It's too much on my body. [...]

But a pump is not the Artificial Pancreas...

note : That suggests that the benefits of using the AP are so great that they would overcome the trouble of wearing a device on the body.

- Do you have idea what you want to know?
- If it works and if it keeps working.

Somebody who manages diabetes well will be very motivated. But when someone is not motivated with this type of device, then

it is very difficult to make somebody feel sure [...] It will depend on the person. It is not only about the body, it is also psychology, mental.



Meaning of the Artificial Pancreas

What using an AP would mean for them

That would be much easier than the way I do it now.

If I would have a device that would do that for me, that would be a big help.

note : a help. not a solution

For me, that should give me peace. Less stress. Yes, I think it would make me less stressed.

If it works, I don't look at it every 5 minutes. I think if it works, I can almost be diabetes-free. Because that is a nice feeling of course:if all works, you can let it go ! For a few hours, I imagine.

*- Can I say I would let it go for half a day ?
- Well, would you do that ?
- Yes, I think. I think I could let it go, I could let it do its work.*

I think that the device makes it possible to live as a very normal person. It is easier to live with your diabetes. You don't need to test again, again, again.

note: testing = not normal

A lot of people see this device as a cure for diabetes. And that's not how I see it. It's a device to manage your diabetes better.



Some people think "Once I've got that device, I can do everything". For me, it is "I can do more". But not everything.

I think when this device is an option, I ask my doctor to sign me in for the program. Because you don't have to... I don't know, but I think you don't need to prick your fingers a couple of times a day anymore.



Recurrent topics

1 - Natural vs artificial organ

Is the natural organ the model for the artificial one? Should the artificial organ be simply the man-made copy of the natural one? Can it even be so?

If the Artificial Pancreas remains outside of the body (unlike its natural equivalent, beneath our skin) can we turn those differences into opportunities (for example : an opportunity for a direct dialogue between the user and the pancreas)?

Does «A.P.» (common abbreviation for «Artificial Pancreas») stand for «Artificial Pancreas» or should it be standing for «Assistant of your Pancreas»?

In other terms, does the device replace or complement a part of the human body? These are two slightly different ways to perceive the role of the device and its future relationship with its user.



2 - From measuring by yourself to ... ?

A glucose meter, an insulin pen and an insulin pump are seen as tools which give control to their users. An Artificial Pancreas, being an automated closed loop system, may be perceived as taking away this control, asking the user to "let it go".

The Artificial Pancreas is no longer considered a tool that you use to take care of yourself, but a machine which is taking care of you. This opens up the discussion of what the future of diabetes care will be and what the role(s) of the diabetic patient will be.

3 - Trust ?

Almost all interviews ended on this critical point: trust. Everybody agreed that Trust is not something you get: Trust is something you build.

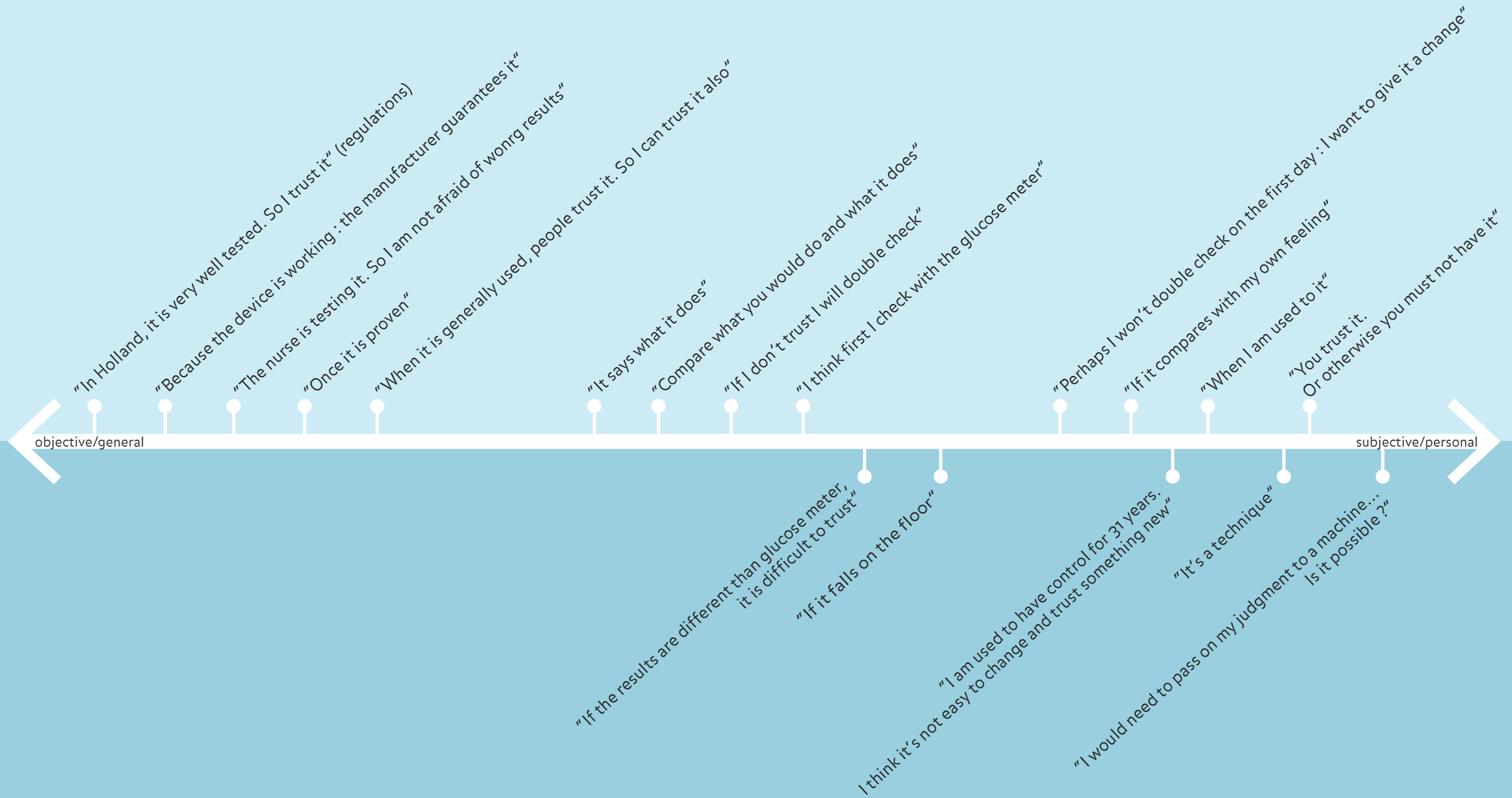
How to build trust? How to preserve it?

When asked which factors will contribute to building trust in the AP, the answers cover a wide range: from the most objective/societal aspect (such as regulations), to the most personal convictions ("if it compares with my own feelings").

Halfway we can find a category which might deserve some attention in designing the AP ("it says what it does").

An overview of these 'trust factors' mentioned in the interviews can be found on the next pages.

Reasons to build trust (or not)
in the Artificial Pancreas



Going further

We plan to put these insights into practice by developing a first prototype of the interface of Inreda's Artificial Pancreas. We will do so by continuing to engage user groups at various steps of our process.

We would like to sincerely thank the first people who shared their authentic experiences and points of view: Inge, Jeroen, Joke, Marieke, and Thijs.

The project shows how we can design better health tools using the right data and translating these into something meaningful for their user. Ideally, this can inspire a whole new range of personal home healthcare devices, inspired by the users and closer to the human body.

This unique device is planned to reach the market within two years; clinical tests and a CE marking are currently in process.

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