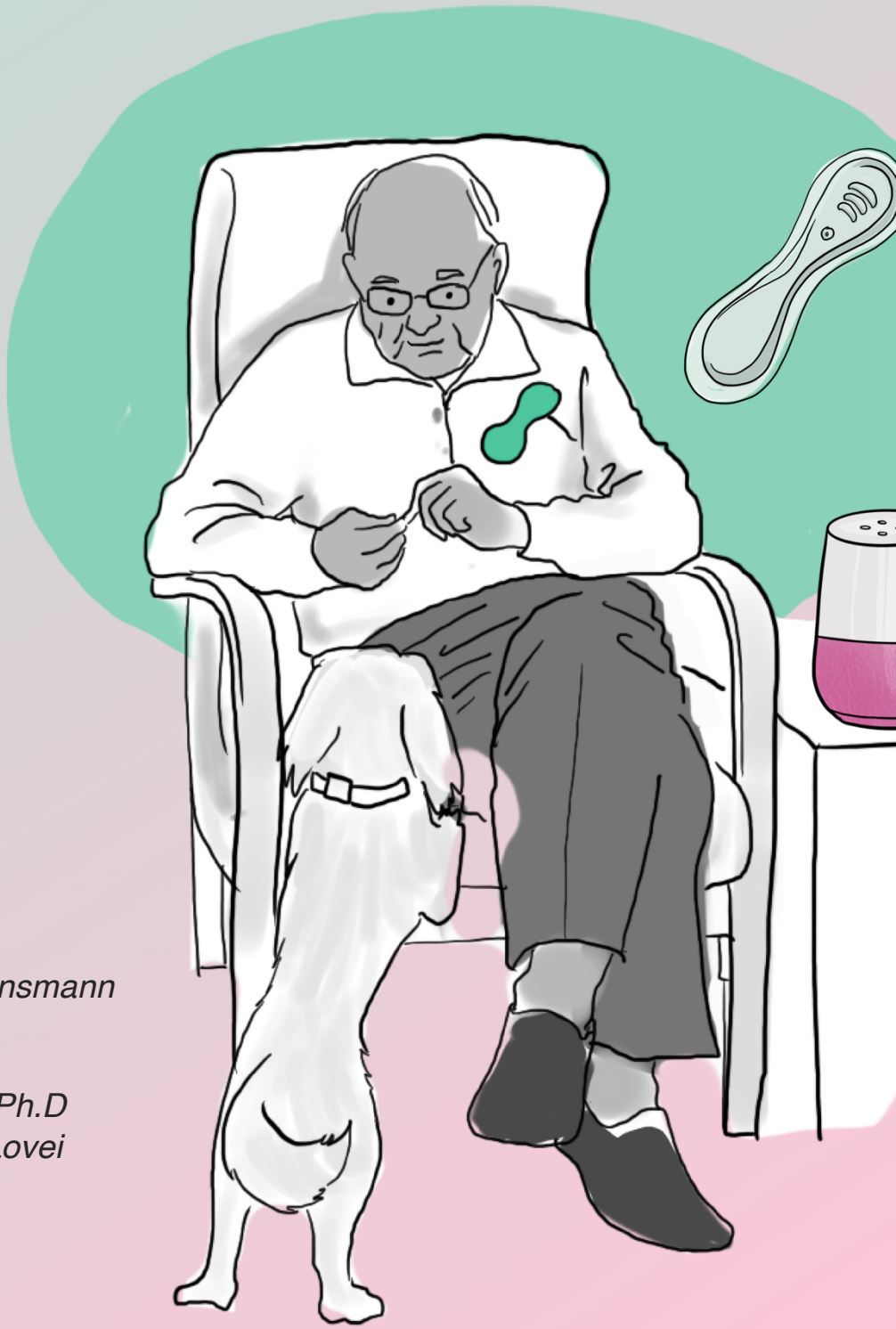
APPENDIX

LIVEsese: A Continuous and Collaborative Goal Setting System using Sensor Data for Transcatheter Aortic Valve Implantation (TAVI) Patients

Master thesis - Anindya Paramaarti



Project chair:
Prof. Dr. Gerd Kortuem

Project Mentor:
Prof. Dr. ir. Maaike Kleinsmann

Collaboration:
AMC - Marije Vis, MD, Ph.D
Philips Design - Peter Lovei

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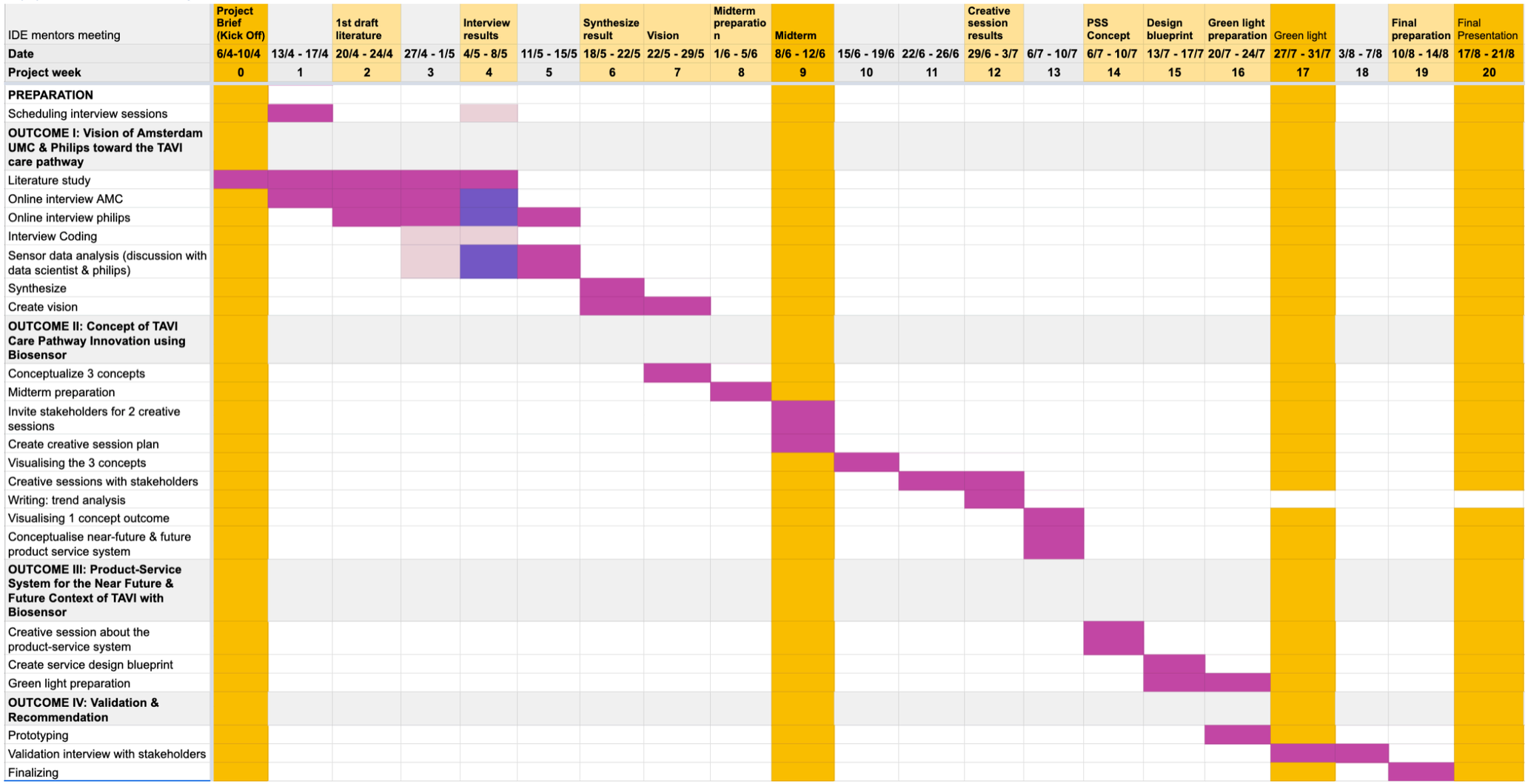
Appendix B: Project Plan



Appendix C: Extracted events from text analysis

Events before TAVI treatment	Experience
• Experiencing burdens from the aortic valve stenosis symptoms. (Lauck et. al 2015) • Reduce in quality of life because of less social activity. (Lauck et. al 2015)	They are experiencing changes in their body related to the symptoms of Aortic Valve Stenosis. In a lot of cases it limits people's daily activity. Common symptoms are shortness of breath, fatigue and chest pain (Lauck et. al 2015). Respiratory problem is the most limiting symptoms (Kirk, 2017). The symptoms might have started far before the first discussion with a cardiologist. Lauck (2015) quoted an 86 year old male patient who participated in the qualitative study who explained, "In the last year or year and a half, it's started to get harder and harder to breathe. And just now when I change my shoes, you know, when I bend over now and I get up, I got to stop and puff for a while, for a bit." Lauck (2015) also mentioned that the limiting symptoms are lowering the patient's quality of life. For example it becomes more difficult for them to engage in a social activity. One participant of the study, an 86 year old male, explained, "We belong to a walking club which I did every once a week, but I've quit that in the last probably 3 or 4 months because I just couldn't keep up with them. They'd go and I said, "Well, I'll go half way" and they still got back before I did, so I said, "I guess I'll quit because it just hinders you guys"'
• Consulting with a family physician or cardiologist at their hospital. (Olsson et. al 2016) • Trust in family physicians. (Olsson et. al 2016) • Receive confusing explanations from the family physician. (Olsson et. al 2016)	Patients rely on the physicians to give them information about their condition and treatment options. Some patients had visited the same doctor for a long time and already built his/ her trust. But Olsson (2016) described that some patients get inconsistent information from their formal supports. In the study, a patient participant mentioned his/ her experience when receiving a confusing information from the physician. "I was a little bit discouraged when I spoke to 1 of the doctors at my home hospital and got the message that this operation is only done on senile people, so I didn't take it seriously. I don't know how seriously it was meant, but it was a stupid answer and if you are undergoing such an operation yourself. It was not psychologically right I think." Combined with a lower trust toward the physician, the confusing information could become a barrier to patient in the later decision making process.
• Being offered to get a TAVI treatment by their cardiologist. Discussing the risk and benefit. (Olsson et. al 2015) • Having a discussion with the family member (informal support). (Olsson et. al 2015) • Thinking about whether to get the TAVI treatment or not. (Olsson et. al 2015) • Start formulating expectation about the outcome of TAVI. (Olsson et. al 2015)	Based on a qualitative study conducted by Olsson et.al in 2015 about the decision making process of TAVI patient, there are 3 types of patients based on the way they make the decision. 1. First is called "ambivalent patient". These patients have a tolerable symptoms of aortic valve stenosis. They are not sure about the risk and benefit of TAVI and might not have enough trust with the physician's skills. Getting the TAVI treatment was also seen as time consuming. In the study it was identified that for this group of patients, the decision making will be easier if they could discuss their considerations with others, for example, a family member. 2. Second is "obedient patient". They are patients who do not trust their own decision and give the decision to experts or family member. They have either or both of the formal support (experts) and informal support (family) (Lauck, 2016).They trust that the doctors are skilled and therefore would make the best decision for them. From the family member, based on the study it is usually the children. In some cases even the patients themselves were skeptical about the treatment but would still do it anyway. In this group of patients the severity of symptoms range from tolerable to very limiting towards their source of enjoyment on life. 3. Third is "reconciled patient". These patients have no other options beside getting the TAVI, but they are sure that getting a TAVI treatment is the right thing to do. They are facing a reality of having a low prognosis and declining condition. Patients form a realistic expectation about the outcome of TAVI. In the study conducted by Olsson et.al in 2015, a patient described what he expected after the treatment: "I can only take 4, 5 steps. It only gets worse, I'm dying. I cannot wait any longer, cannot take it anymore. I don't expect to become a new person like

	the person I was before, but I hope that I will become so well that I can be out and maybe use a walker in the summer and have some nice time. (Man, 87 years)" From these 3 patient categories identified above, the severity of symptoms, the way risk and benefit are discussed and the access to informal support have an effect on the decision making.
• Being dependent on their support network's availability for helping them traveling to the hospital. (Lauck et. al 2016) • Experiencing long journey for a short appointment. (Lauck et. al 2015)	After patients decided to be assessed for TAVI, they need to travel to reach the specialized hospital who does the TAVI treatment. In this phase the barriers and facilitators related to transportation emerge. Referred patients might have to travel far. In that case, they depend on the availability of their informal support. Therefore the proximity of patients with the specialized hospital and with their informal support system will influence this step (Lauck et al., 2016). Sometime the travel itself takes more time than the assessment appointment, and that is seen as a hassle. Lauck (2015) quoted a participant in their qualitative research, an 89 year old female, who said, "Two nights in the hotel. Well, that's not too bad. You know, the drive from here is five, six hours, and then I'm there less than an hour. It doesn't really make sense…" In that study it is also explained that in some cases the patient and his/ her family had to stay overnight because the appointment was early in the morning.
• More factors are involved in building the expectation about the outcome of TAVI treatment, including what the clinicians said and how they said it. (Olsson et. al 2016)	Patient's interaction with health providers could influence the expectation towards the outcome of TAVI. Baumbusch et. al did a qualitative study on 31 TAVI patients in 2018. They identified the source of influence on expectation which are the care providers and the patient's social circle. The research article quoted a participant, who is a son from a TAVI patient, saying "She was a prolific walker and I guess her doctor made the comment to her one day that 'well, once you have this procedure you'd be able to climb mountains'.". A qualitative study by Olsson in 2016 about patient's experience when waiting for TAVI shows that the language used by the care provider could influence the way patient perceive their condition and therefore their expectation. A patient participant in the study said, "And the doctor said, 'You have problems with 2 valves, but 1 of them is disastrously bad.' Then I understood, he looked so worried, so I thought, yes this is probably the end."
• Experiencing increase of symptoms. (Olsson et. al 2016) • Managing anxiety when the symptoms appear. (Olsson et. al 2016) • Planning their daily life with the symptoms as part of the considerations. (Olsson et. al 2016) • Keeping an eye of potential incident. (Olsson et. al 2016) • Dealing with uncertainty of TAVI acceptance. (Olsson et. al 2016)	Patients who are scheduled or waiting to be scheduled for TAVI are experience an increase of symptoms (Olsson et al., 2019) However, at this point they start to try to make sense of the reality of their condition. Based on Olsson's study in 2016 about the experience of patient while waiting for TAVI, most patients understand the risk of having aortic valve stenosis, but they try to adjust the way they live to keep experience life as before. They start to manage their activity based on the limitation's pattern, for example, by scheduling most activities in the morning before the chronic fatigue come in the evening. Patients are trying to normalize the way the live with the condition. Patients try to "balance between trying to live a normal life and suddenly being reminded of their vulnerability" (Olsson et al., 2016). They are aware that incidents might happen so they try to be in control. When the symptoms come, it might trigger anxious thoughts. The same study quoted a patient participant saying, "Of course, when you lie awake and feel that you can't breathe, you get a little worried, it is natural," showing that patients are trying to manage having anxious thoughts as a part of their life. The study addresses that having a support from the formal caregiver about preserving their sense of self will be helpful for patients in managing their life alongside the symptoms.
• Coming to the hospital for appointment after being admitted for TAVI. (Olsson et. al 2016) • Feeling safe that they are admitted to the specialized hospital for TAVI. (Olsson et. al 2016) • Trusting the physicians. (Olsson et. al 2016)	Olsson (2016) explained that After experiencing uncertainties while waiting, once patients are admitted to the specialized hospital, they feel confident and safe. Coming to the hospital and meeting the clinicians in person makes them feel more relaxed, in some cases for the first time since many weeks passed. A patient participant in the research expressed how the physical proximity to physician and the hospital environment affect her/him, ''Oh, I feel very safe. To come here and be surrounded by competent people, doing everything they can to make me feel better.''

Shortly after the treatment:

Events shortly after the TAVI treatment	Experience
• Being cautious about experiencing symptoms after discharge. (Kirk et. al 2019)	Patients have an expectation to still experience the AOS symptoms initially upon discharge and therefore they would be relying on help from other people. However most of this expectation does not happen and patient feels surprised with the result of treatment (Kirk et. al 2019).
• Patients who live alone feel less safe after the discharge because during treatment they were accompanied by their family. (Kirk et. al 2019)	Patient's living situation is influencing how safe the patient feels after being discharge from the hospital who performs TAVI. Kirk et. al in 2019 explained that patients who live alone felt less safe after discharge compared to before the treatment because he/ she was with the family and after discharge he/ she was back to living alone. A patient participant in that study was quoted, "I felt safe knowing that I wasn't alone, that I was with family".
• Regaining self-image after changes in physical condition. (Kirk et. al 2019)	Some patients have an existing physical problems before the treatment. Kirk et al (2019) quoted a patient participant who were dealing with this, saying "I think that I've become a very old man when I see myself in the mirror. I don't like it". The study also described that for the patients, accepting changes in their self-image is not easy and it requires effort.
• Some patients experience noticeable body relief. It gives them confidence to be able to do meaningful activities. (Kirk et. al 2019) • Experiencing the benefit of TAVI. (Kirk et. al 2019) • Informal caregiver of patients who experience relief but less noticeable sees that the patients have more confident in living their daily life. (Kirk et. al 2019) • Improved sleep because of les anxiety that was caused by having symptoms prior to TAVI. (Kirk et. al 2019) • Experiencing transformation of bodily sensation. (Kirk et. al 2019)	Patients are experiencing symptoms relief shortly after the treatment. Kirk et al (2019) quoted a patient who describe the respiratory-related symptoms relief after he/ she received TAVI as, "I don't have a normal amount of oxygen, but at least it's better". Patients who experience this sees the benefit of TAVI. Kirk et al (2019) also described that in some patient whose symptoms relief happens in a more gradual way, it is the informal caregiver who observes the difference in patient's ability prior and after TAVI. Improvement in patient's ability to breath made them feel happy and brings confidence that they could live their daily life. Patients have more energy, because as their symptoms decrease they become less anxious which leads to a better sleep quality. Patients are able to "renew their enjoyment of life." (Kirk et al, 2019)
• When patient's expectation meets unexpected reality. (Baumbusch et al., 2018) • When informal caregiver's expectation about the TAVI impact meets the reality. (Baumbusch et al., 2018) • Trying to adjust expectation with reality. (Baumbusch et al., 2018)	Patients might expect their condition to become like before they were experiencing aortic valve stenosis symptoms. This expectation could make the patient push themselves too hard. The patients need to understand their limitations. (Baumbusch et al., 2018) The family or the informal caregivers also need to manage their expectations about patient's condition after TAVI. A patient's 78 year old husband in a qualitative research done by Baumbusch et al in 2017 was quoted saying, *"like I thought that with this valve being replaced, I thought it would be not a miracle reaction, but I figured she'd be in better shape than she was"*

In the recovery phase:

Events in the recovery phase	Experience
• Continue taking medicine makes patient feels unsure if there will not be any other problem with their body in the future. (Kirk et. al 2019) • Reconciling with reality about living with limitations. (Kirk et. al 2019)	Kirk et al (2019) explained the effect of the continuation of medicine in the recovery phase. For example, a patient who needs to continue taking diuretic after TAVI become worried that he/she might need another treatment and if there will be problem with their condition in the future. Medication reminds patient about their physical vulnerability. Another perspective is if patients are able to reconcile with living alongside physical limitations that exist before TAVI.
• The regained ability to walk represents the patient's progress. (Kirk et. al 2019) • Being able to walk enables patients to participate in social activity again. (Kirk et. al 2019) • Being able to walk brings a sense of control over patient's own live. (Kirk et. al 2019)	Kirk et al (2019) mentioned that the ability to walk shows the patient's progress and it brings enjoyment in the patients. It is the form of exercise commonly recommended by the physician beside rehabilitation training. Walking also enabled patients to engage in social activities, as a patient participant in Kirk et al's 2019 study was quoted, *"The pace is not as fast any more so it takes a little bit more time. But that doesn't matter. That's just a detail. You have to be grateful that you can put your coat, go outside and do the shopping. Not only that, I think that going for a walk is wonderful"*

• Improvement of physical condition needs patient's effort, for example by doing the exercise. (Kirk et. al 2019) • Patients join rehabilitation because they are aware that they need to do something to improve or maintain their condition. (Kirk et. al 2019) • Patients who do not join rehabilitation see doing activities related to daily life (household task for example) would bring the same benefit as doing a rehabilitation program. (Kirk et. al 2019) • 'Independent' rehabilitation program makes patients regain control of managing their own daily task and which one to do. (Kirk et. al 2019) • 'Independent' rehabilitation program is lack of control and support function from a formal caregiver. (Kirk et. al 2019)	Physical condition improvement is not something that would instantly happen without patient's effort. Kirk et al (2019) quoted a patient saying, : *"But I also really think that I have to do something to benefit from it. It doesn't happen just by going to the hospital and getting a spare part. I also have to exercise on my own. Otherwise it is not possible"* TAVI patients are offered rehabilitation after the treatment, but only half participated in the rehabilitation. Those who do not participate see the rehabilitation activity programs as not very relevant for them to regain their physical fitness. They see alternatives such as walking, doing household task and using exercise bike to bring the same benefit as rehabilitation as well as regaining back their sense of control; of doing what they want to do.
• Goal setting related to physical activity is important. (Kirk et al 2019)	Personal goals, for example, able to ride bicycle, walking certain meters and etcetera are important in motivating the patients to put effort in improving their physical condition (Kirk et al 2019)
• Recovery from TAVI treatment while dealing with aging and comorbidities. (Kirk et al 2019) • Being alert of bodily sign of possible illness. (Kirk et al 2019) • The effect of TAVI might be good but the overall physical condition might not fully improved because of comorbidities. (Baumbusch et. al 2017) • Distinguishing the symptoms of comorbidities and symptoms of AOS. (Baumbusch et. al 2017)	Patients with comorbidities have concerns about what would happen is there are additional illnesses that need another treatments. These concerns creates an awareness of bodily sign that patients would think if it was a sign of another illness (Kirk et al 2019) Baumbusch et al in 2017 explained an example of recovering from TAVI with comorbidities. A wife of patient participant in that study said, " *We're more than 100% satisfied and grateful, and it gave him a huge new quality of life. When he talks about being satisfied or disappointed, it's because of his other conditions that disable him from doing the activities he loves to do.*"

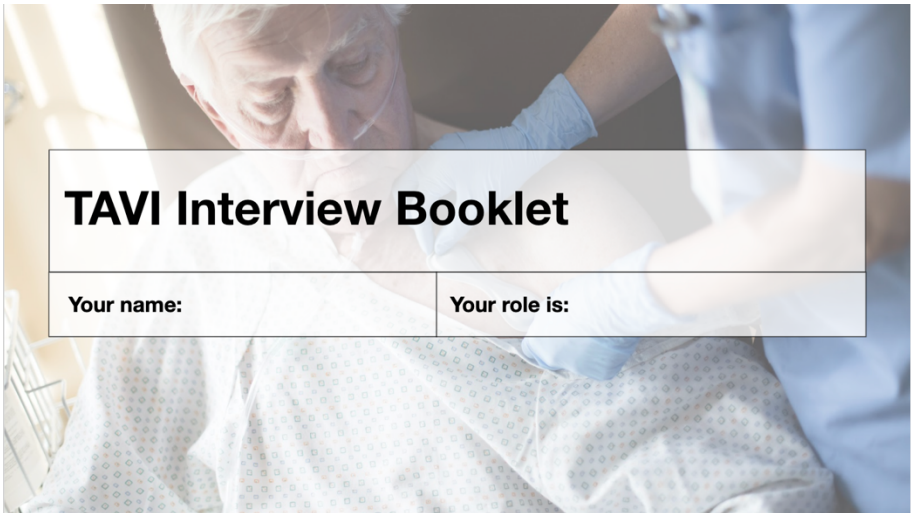
Appendix D: Text analysis Table

EVENTS	NOTE	CATEGORY
Experiencing burdens from the aortic valve stenosis symptoms. (Lauck et. al 2015)	Daily life	Living with symptoms & limitations
Reduce in quality of life because of less social activity. (Lauck et. al 2015)	Affecting social activity	Living with symptoms & limitations
Consulting with a family physician or cardiologist at their hospital. (Olsson et. al 2016)	consultation	Travel Needs
Trust in family physicians. (Olsson et. al 2016)	trust	Trust & uncertainty in the procedure
Receive confusing explanations from the family physician. (Olsson et. al 2016)	uncertainty	Trust & uncertainty in the procedure
Being offered to get a TAVI treatment by their cardiologist. Discussing the risk and benefit. (Olsson et. al 2015)	referred	Decision Making
Having a discussion with the family member (informal support). (Olsson et. al 2015)	role of informal caregiver in decision making	Decision Making
Thinking about whether to get the TAVI treatment or not. (Olsson et. al 2015)	considering	Decision Making
Start formulating expectation about the outcome of TAVI. (Olsson et. al 2015)	expectation	Managing expectation
Being dependent on their support network's availability for helping them traveling to the hospital. (Lauck et. al 2016)	dependent	Travel Needs
Experiencing long journey for a short appointment. (Lauck et. al 2015)	travel	Travel Needs
Experiencing increase of symptoms. (Olsson et. al 2016)	daily life	Living with symptoms & limitations
Managing anxiety when the symptoms appear. (Olsson et. al 2016)	Daily life	Living with symptoms & limitations
Planning their daily life with the symptoms as part of the considerations. (Olsson et. al 2016)	Daily life	Living with symptoms & limitations
Keeping an eye of potential incident. (Olsson et. al 2016)	cautious	Keeping an eye on own condition
Dealing with uncertainty of TAVI acceptance. (Olsson et. al 2016)	uncertainty	Trust & uncertainty in the procedure

Coming to the hospital for appointment after being admitted for TAVI. (Olsson et. al 2016)	travel	Travel Needs
Feeling safe that they are admitted to the specialized hospital for TAVI. (Olsson et. al 2016)	accompanied	Being accompanied
Trusting the physicians. (Olsson et. al 2016)	trust	Trust & uncertainty in the procedure
Being cautious about experiencing symptoms after discharge. (Kirk et. al 2019)	careful	Keeping an eye on own condition
Patients who live alone feel less safe after the discharge because during treatment they were accompanied by their family. (Kirk et. al 2019)	living alone	Being accompanied
Regaining self-image after changes in physical condition. (Kirk et. al 2019)	recovery	Regain control by being able to walk
Some patients experience noticeable body relief. It gives them confidence to be able to do meaningful activities. (Kirk et. al 2019)	measuring improvement	Measuring improvement/ changes
Experiencing the benefit of TAVI. (Kirk et. al 2019)	measuring improvement	Measuring improvement/ changes
Informal caregiver of patients who experience relief but less noticeable sees that the patients have more confident in living their daily life. (Kirk et. al 2019)	informal caregiver	Being accompanied
Improved sleep because of les anxiety that was caused by having symptoms prior to TAVI. (Kirk et. al 2019)	measuring improvement	Regain control by being able to walk
Experiencing transformation of bodily sensation. (Kirk et. al 2019)	measuring improvement	Keeping an eye on own condition
When patient's expectation meets unexpected reality. (Baumbusch et al., 2018)	expectation	Managing expectation
When informal caregiver's expectation about the TAVI impact meets the reality. (Baumbusch et al., 2018)	expectation	Managing expectation
Trying to adjust expectation with reality. (Baumbusch et al., 2018)	expectation	Managing expectation
Continue taking medicine makes patient feels unsure if there will not be any other problem with their body in the future. (Kirk et. al 2019)	Daily life	Living with symptoms & limitations
Reconciling with reality about living with limitations. (Kirk et. al 2019)	expectation	Living with symptoms & limitations

The regained ability to walk represents the patient's progress. (Kirk et. al 2019)	measuring improvement	Measuring improvement/ changes
Being able to walk enables patients to participate in social activity again. (Kirk et. al 2019)	measuring improvement	Regain control by being able to walk
Being able to walk brings a sense of control over patient's own live. (Kirk et. al 2019)	independent	Regain control by being able to walk
Improvement of physical condition needs patient's effort, for example by doing the exercise. (Kirk et. al 2019)	effort	Motivation to put effort in recovery
Patients join rehabilitation because they are aware that they need to do something to improve or maintain their condition. (Kirk et. al 2019)	effort	Knowledge & Motivation to put effort in recovery
Patients who do not join rehabilitation see doing activities related to daily life (household task for example) would bring the same benefit as doing a rehabilitation program. (Kirk et. al 2019)	Daily life	Knowledge
'Independent' rehabilitation program makes patients regain control of managing their own daily task and which one to do. (Kirk et. al 2019)	independent	Knowledge
'Independent' rehabilitation program is lack of control and support function from a formal caregiver. (Kirk et. al 2019)	independent	Being accompanied
Goal setting related to physical activity is important. (Kirk et al 2019)	goal	Motivation to put effort in recovery
Recovery from TAVI treatment while dealing with aging and comorbidities. (Kirk et al 2019)	comorbidities	Living with symptoms & limitations
Being alert of bodily sign of possible illness. (Kirk et al 2019)	Daily life	Keeping an eye on own condition
The effect of TAVI might be good but the overall physical condition might not fully improved because of comorbidities. (Baumbusch et. al 2017)	comorbidities	Measuring improvement/ changes
Distinguishing the symptoms of comorbidities and symptoms of AOS. (Baumbusch et. al 2017)	careful	Measuring improvement/ changes

Appendix E: Interview tools



Dear participant,

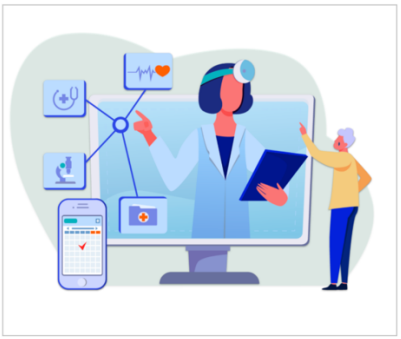
We are Winnie and Nindy, graduate researchers in TU Delft CardioLab. Our research goal is to "Designing TAVI Care Pathway toward Full Recovery using Biosensor" and "Designing shared understanding with data among actors in TAVI care path through sensor tele-monitoring."

This booklet (consists of 8 sections) is to help us empathise better with your role in the care path, and will be used solely for this graduation project. There is no right and wrong answer, please feel comfortable to share your thoughts.

Thank you very much for spending your precious time participating in this research project!

Best,
Nindy & Winnie

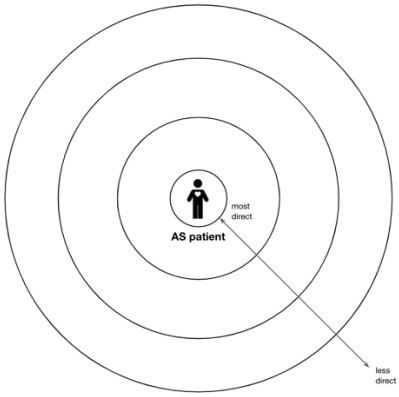
anindyaparamaarti@student.tudelft.nl
w.chen-18@student.tudelft.nl



01 Could you share what are the main tasks you're responsible for?

task 1	task 2	task 3

02 Could you sketch out the medical team members who are involved in TAVI care? (Please draw whoever has more direct contact to the patient closer to the center)



for example:

03 Could you briefly describe your typical workday in AUMC? Please also mark the emotions of your day (for example: tired, energized, focused…)

7:00 → 18:00

your activities

your emotions

04 Could you share what are scenarios you communicate during the treatment? Please identify important elements (for example: ways you work, challenges you face…)

scenarios communicating with your colleagues

scenarios communicating with your patients

06 Can you write down what will be the benefits / concerns if sensor remote monitoring is implemented in TAVI care?

Admission Phase	Pre-procedural Phase
What do you think needs to be improved on this step?	What do you think needs to be improved on this step?
How do you think Biosensor could help in this step...	How do you think Biosensor could help in this step...
These are the sensors in the device. Please mark ones that you think would be important in this phase ❑Position/ posture ❑Step count ❑Fall detection ❑Respiratory rate ❑Single-lead ECG ❑Heart rate	These are the sensors in the device. Please mark ones that you think would be important in this phase ❑Position/ posture ❑Step count ❑Fall detection ❑Respiratory rate ❑Single-lead ECG ❑Heart rate
How would you use the information from the checked sensors?	How would you use the information from the checked sensors?
Why?	Why?
What else you would like to know about the patient that are not currently in the sensor's features?	What else you would like to know about the patient that are not currently in the sensor's features?

Post-procedural Phase (up to 72 hours after treatment)	Recovery (up to 1 year after treatment)
What do you think needs to be improved on this step?	What do you think needs to be improved on this step?
How do you think Biosensor could help in this step...	How do you think Biosensor could help in this step...
These are the sensors in the device. Please mark ones that you think would be important in this phase ❑Position/ posture ❑Step count ❑Fall detection ❑Respiratory rate ❑Single-lead ECG ❑Heart rate	These are the sensors in the device. Please mark ones that you think would be important in this phase ❑Position/ posture ❑Step count ❑Fall detection ❑Respiratory rate ❑Single-lead ECG ❑Heart rate
How would you use the information from the checked sensors?	How would you use the information from the checked sensors?
Why?	Why?
What else you would like to know about the patient that are not currently in the sensor's features?	What else you would like to know about the patient that are not currently in the sensor's features?

08 These are the current diary function of the biosensor. In what way would this information affect the TAVI treatment?

Diary Functions:

Sleeping **Sitting** **Walking** **Falls** **Sports**

How would the current diary function affect the TAVI treatment?

Interview Guide
TU Delft MSc IDE Graduation - TAVI

Interviewers:
Anindya Paramaarti - MSc Strategic Product Design
Winnie Chen - MSc Design for Interaction

Project Follow-up

1. Challenge on our side: Thank you for the packing up the data sets for our preliminitary understanding. We are still continuously contacting ICT and Anita, hoping to get our account to access AMC IT environment.

2. Our research questions: Nindy : How to design an inclusive biosensor system for post-procedural outpatient care? Winnie: (still scoping) How to speculate perioperative patient-doctoral interaction with sensor system?

3. Disclaimer: With no possible patient contact at the moment, we are trying to gain patient perspective from expert point of view. You are one of the research expert we recruited as our expert interviewee, which means your opinion will be fully credited. Please let us know in the process if there's anything you

Interview Questions

Overall: What do the patients experience in the end-to-end care pathway

We have the AMC protocol from Marja in a standardised, hospital point-of-view manner. However, we are curious from your contact with patients, how does the patient go through ...

PATIENT PROFILE
You mentioned you have interviewed 6 patients regarding their psychological and physical health status of TAVI patients. Could you share in general ...

- What are some repetitive challenges/problems they faced?
- What are the factors that benefit the patients?
- How would you categorize the patients, interms of how motivated and informed of informtation?
- What changes have you observed?

PROTOCOL INTERVIEW

1. **Admission process:**

- How do the patients experience the admission process from their referring hospital to AMC?
- Who do they interact with in AMC?
- How is the interaction, in terms of receiving information and communication?
- In your point of view, what would AMC want to improve in this part?
- What are the data points scheme in AUMC (with & without biosensor) ?
- About the frailty assessment?

2. Pre-procedural:

- How do the patients experience the pre-procedural process?
- What are the role of hospital when patients are waiting for TAVI?
- Who are involved in the discussion that require patient's decision making?
- Who do they interact with in AMC?
- How is the interaction, in terms of receiving information and communicating with AMC?
- What would AMC want to improve in this part?
- How is the data being used in the pre-surgery assessment meeting?

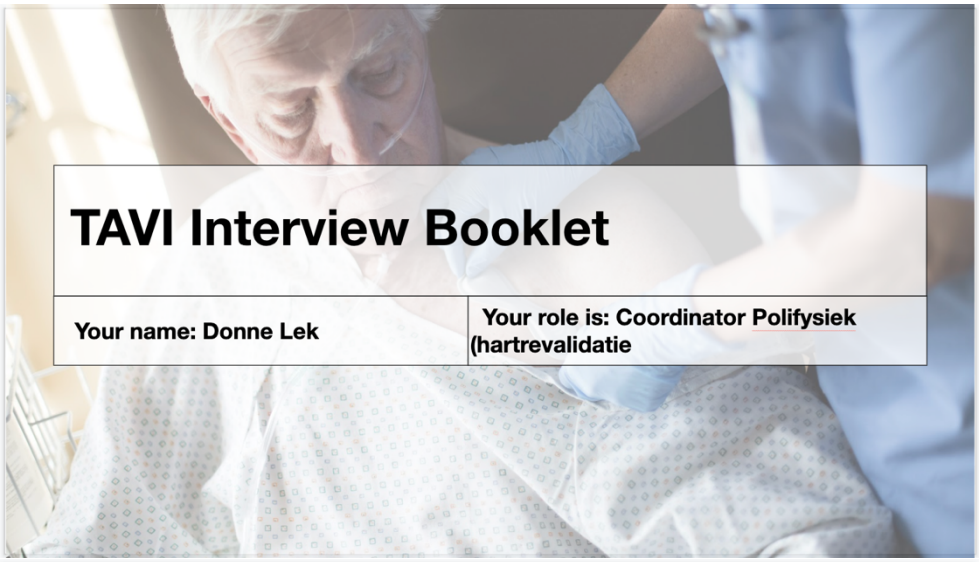
3. Post-procedural

- How do the patients experience the post-procedural process before discharge?
- Who do they interact with in AMC?
- How is the interaction, in terms of receiving information and communicating with AMC?
- How do they experience the follow up sessions?
- How is the data being used in the post-urgery tracking?
- What are the current devices being used that records data as well?
- What would AMC want to improve in this part?

RECOVERY

- How is the corelation between patient's involvement and their recovery process?
- Who are the person who interacted the most with patient throughout the care process?
- How do they mantain their state of health throughout the 1 year follow up?
- Balancing hope with reconciling with reality —> how does this manifests in the recovery process?

Appendix F: Interview Results



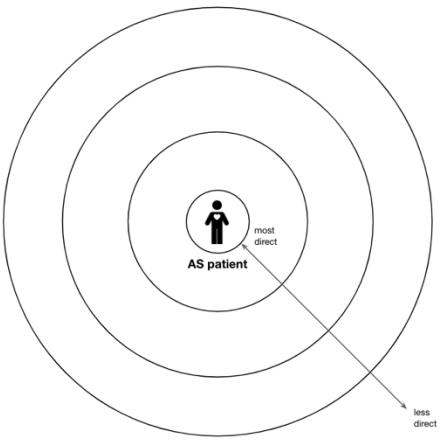
TAVI Interview Booklet

Your name: Donne Lek	Your role is: Coordinator Polifysiek (hartrevalidatie

01 **Could you share what are the main tasks you're responsible for?**

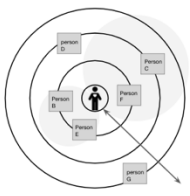
task 1	task 2	task 3
coordination of the heart revalidation interdisciplenair	trias academica: Reserach, client treatment and education Hva/Amc	quality of the health-care

02 **Could you sketch out the medical team members who are involved in TAVI care? (Please draw whoever has more direct contact to the patient closer to the center)**



direct:
-fysiotherapeut,
-nurse,
-ergotherapeut
less
-psycholoog
-maatschappelijk werk
-dietiste
distance
-cardioloog
-arts

for example:



03 **Could you briefly describe your typical workday in AUMC?**
Please also mark the emotions of your day (for example: tired, energized, focused…)

7:00 → 18:00

your activities

8:30 arrive at Polifysiek, briefing with front-office
9:00 administration, (personeel, ziekte, bijzonderheden)
10:00 meetings
11:00 meeting
12:00 Multi-disciplinair meeting
13:00 help with the 4 rev. fit groups and individual approach clients:

your emotions???? mostly very energiek and joyfull

06 **Can you write down what will be the benefits / concerns if sensor remote monitoring is implemented in the care?**

Phase 1:	**Phase 2:**
What do you think needs to be improved on this step? During (get familiar) / After (integrate in daily living)	What do you think needs to be improved on this step?
How do you think Biosensor could help in this step… Does it motivate them or noe, find out during CR	How do you think Biosensor could help in this step...
These are the sensors in the device. Please mark ones that you think would be important in this phase ❑Position/ posture → important if connected to ECG ❑Step count → does it also work when biking/rolling ❑Fall detection → more for hospital ❑Respiratory rate → nice, but what's normal for this person? ❑Single-lead ECG v ❑Heart rate v	These are the sensors in the device. Please mark ones that you think would be important in this phase ❑Position/ posture ❑Step count ❑Fall detection ❑Respiratory rate ❑Single-lead ECG ❑Heart rate
How would you use the information from the checked sensors?	How would you use the information from the checked sensors?

1. Specialist Nurse

MARJA HOLIEROOK, SPECIALIST NURSE @AMC	
Quote	**Note**

I think 2 things. At the end it is important that we can do more research, we get more data so we can develop and give better care. The other thing is we can select the goodpatient who can go home faster than now.	R&D
also at the for the patient its all about studying and getting information also. How they do at one year. We don't have that much information now and we can educate them better or train them better so I think since it's the beginnign so mostly for getting more data for us to get further.	R&D
What I do is.. Process is like, patient going from the heartteam, and roosje said ah I have a new patient then we are going to look and I will send her instruction so she know what to do, what to select. But there are also things that are unclear and has a high urgency.	Escalation from plan manager for immediate action
Its important that we can get more research, that we can get more data, so we can give better care and the othe rhtings is we can select the good patients who can go home faster than now.	R&D
The patient is relieved when you can explain how it works	about patient
In their head they are thinking oh how is it going to be when I am laying on the table? The conversation is not medical.. But it is important.	about patient
When patient has simple question, roosje answer. If the question is complicated roosje will call us.	escalation from plan manager
Patient calls afterwards than before. I think they like it when they have a face. They ask is it a problem if I call?	about patient
The age of the patient also… oh the doctor know, I will wait. I think younger people call more often. Oh they are busy, its another age group	younger patient calls more
I see low risk patient more and a bit younger, so they use more internet	low risk patients are young and they use internet
The older group don't search on the internet. What we said is the truth, not very critical.	older group/ higher risk don't search. What we say is the truth
Question about confusion in filling in forms with different point scale. Seems like we asked the same question.	pain points in filling in multiple scales
Sometimes you have a patient whos 90 but a lot better than 75 who have a lot of comorbidity. So theres a lot of difference between the group.	about patient
I think when we know the basic of the patient, we know how we can train the patient.	being confident
Especially the patient who used to be active. They experience a lot of problem. They should like it a lot when they watch what they did.	patient expectation
some patient scared. When my heart race below 100 it's okay. For the confidence of patients.	need information from sensor
when they have fallen before, it is not good. I am curious if they fell afterwards, less than before.	need information from sensor
Whe don't know who the patient is until the doctor sent us a letter	start of the touchpoint with patient
I am curious if they, how much they exercise coming out of bed, I am curious if they become active immediately or if they wait a little time. Because we said in our info that they have to go active asap and doesn't have to wait. I am curious if they really do that	need information from sensor

We think people would act as we said but most of the time they don't understand the way we mean it so Im curious how they do in real.	aware that patient might not understand
Now: when I started I saw the patient after procedure, now no longer. When I saw the patient I get a lot of info. Sometimes patient said immediately: oh I can breathe easily, but also patient: I need a new hip, after I get a new hip I will start exercising so no change.	patient experience after TAVI
We have a registry that is necessary. NHR. Natioanal heart registry. Not my job. But important. You can see how the other hospitals are doing. For example with admission time, pacemakers, some endpoints. They want to know how all other hospital doing the tavi. on hospital level, not patient level.	Ecosystem (NHR)
In NHR: like comparing apple with pears. You think you look at truth but it is not. Its not that informative. I'll ask if I can get more specific info, intersting to see how the frailty and the outcome. That's what I want to know but I don't have the information.	Data in NHR is not complete
Low frailty, a lil bit frail, I research to see that it said something about the outcome. We don't know for sure.	Data in NHR is not complete
everybody in NL use the same scale so its nice.	same scale in NL so it's nice
We don't know what is the best way to measure.	Don't know whats the best way to measure
We used to look at endpoint as mortality and admission rate but now we see change, patient-important outcome. When I talk to patient then I discuss risk with TAVI they mostly say something about oh I don't want to live in vegetative, that's important for them but it is different from the important outcome in the study. maybe you can measure things about mortality but patients want to know what they can do afterwards.	PCC
I am glad that I can do shopping alone	patient expectation
I want to run 5 k again and still be alive. But maybe hes not happy if he cant run.	patient expectation
person who can do grocery again will be happy.	patient expectation
They are more afraid of losing control of their life than death. Dependency. That's very important for patient. You can measure that to understand what might be the effect in the endpoint.	patient afraid of dependency
Patient don't always talk about what they expect. They are thinking about how will the procedure be and oh I will be at home in a few days later. Then they start thinking oh everything went well.	patient did not realy understand what to expect about the treatment
We are now in a discussion, which provider of the information to give them	AMC trying to improve communication
They get a lot of information. But you cant give all the information at the same time. They think will I be alive	AMC trying to improve communication
The information does not get in their head.	AMC trying to improve communication
that's why we tried to do it in part. Via internet but it doesn't do well. We are exploring the provider of information. Which via flyer,	AMC trying to improve communication

From the referral to us, there is a gap.	Gap between being referred and 'arrived' at the cardiology dept
Look and see if you get confident enough to start moving again and when you feel you are scared or not confident please contact your own cardiologist or GP and start to talk about whats the best way for you. Because sometime the physical therapist can come to patient's home, when they have a patient who are too frail to go to the hospital. Maybe that is the better option.	Confidence of patient in start moving again
We put information education on the internet. Medify. Then change to Medimark. But there are different problem. We are trying but sometimes it is difficult. Sometimes it is money. Because medimark was a good tool. Patient can login and see in which step they are in the process.	Digital platform for patient-facing account & info: Medimark
Most patient experience lack of information from the time the cardiologist says "im going to write a letter". There are weeks until the referral cardiologist. Some referring cardiologist can send all the document the same day to AMC, but some takes 2-3 weeks, then it is still not complete. The patient then feels "oh I am waiting and the AMC is not doing a thing. where am I? Am I in my own hospital? Am in already in AMC?"	Gap between being referred and 'arrived' at the cardiology dept
When they are referred from the heartteam to us, they said "Oh thank God, I am not a number anymore, I am who I am and patients are relieved then."	Patient feels they are a number during the gap
We try a lot of different things. It doesn't work that well, but we are trying.	AMC trying to improve communication
We are thinking about it (moving the first touchpoint more upfront) but we haven't started because we started to talk to all referral hospital and they have to do the same thing and that's very very difficult. Wo we are thinking to start with a referring hospital who refer the most. Thats also about the shared decision making. We dont know which patient dont get the TAVI because they decided not to do.	Collaboration with referring hospital
We think about it. Patient should know early in the process and maybe referring cardiologist have to refer them more early in the illness phase. But I don’t know if the referring hospital or referring cardiologist wants that because maybe they get the feeling oh they are taking my patient.	Collaboration with referring hospital
Sometimes you see patients who were referred very late, and it should have been better if they were referred to us earlier. Maybe to ask for the opinion, not the procedure, so for example "what do you think about this patient. "	Moving the care upfront
also when you talk about frailty sometimes you can do the procedure maybe earlier.	Moving the care upfront
and sometime you have a patient with severe AS who has no complaint yet but he has a partner who has dementia and living at home.	Moving the care upfront
maybe you should give the patient more early about the option to do TAVI because of the complete situation at home. But that's very complex because you have to deal with the insurance company and it is difficult.	Insurance
its very difficult for the whole process. We have our perspective; my perspective when they knock the door at AMC. But for the patients it's starting earlier and ends later.	Patient journey start earlier than AMC

the gap afterward is easier to capture I think, because we know who the patient are, compared to before, we don't know who the patients are until they knock on our door from the referral cardiologist. That's the gap that's difficult. We think about it but we still dont know how to make it the best way.	gap between TAVI & recovery
There are patient who get it femoral, not all TAVI. I think then the TAVI 60-80 a year.	TF TAVI patients are 60-80 year old
you have a grey area of what is sport. If they cycle, is that sport?	need to understand context
fall. When they did not fall but missteps.	need to understand context
Posture, now I am sitting. But when I walk upstair, I am doing the laundry, what is that?	need to understand context
maybe oh its walking, but then I sit for 5 minutes, go to garden, do something, so I don't know how easy it is for the patient if they have to fill it in for a longer time.	need to understand context
I think to ask to do it one or to days I think they do it more specific than do it for a week. Maybe it affect how they are going to do the activity.	Data point
I can imagine it is inrofmative when you put it with the other data like heart rate or respiratory rate to see if it is effective because you know when you sleep it goes down and when you walk it goes up.	Data point
Functional rate is important. But also depends on how the patients experience it. For example someone who cycle a lot and do eveyrhting by bike. They fall and they cant cycle anymore its more different than patient who didn't cycle at all. But its very important for all patient that they are not dependent. They want to do their own things. SO when you look at functionality we also ask it to look at frailty	need to understand context
theres also people who married for 50-60 years. The woman does everything, household, shopping. And the man, his functional is low, when you look at what they do, but that is normal. So that's difficult.	need to understand context
We look at it when they are very dependent, the functionality is low we say they are more often frail. But you see you have to know the context again.	
it is a tool indeed we know when the functional is low. But it doesn't have to say something about what he should be able to do but what it is now, the whole patient.	need to understand context
TAVI every week 5-7 get a TAVI.	
We cant see them, se spoke half an hour to ask question, then we plan the procedure.	
nice to see the patient, then you can get a better impression.	seeing patient in person can give better impression because can see them walk & talk
I see them by phone bcs they are old and they don't Zoom. Less than 10% able to Zoom. There are other oportunities to do it at AMC when you see it at patient clinic but they havent been then before, they have a link, it's the best we can do	most TAVI patient cant use video call, only phone call
its best to see the patient, to see them walk, to see how they react with the other patient so its nice to start again.	seeing patient in person can give better impression

	because can see them walk & talk
No interaction with patient: does it mean they don't see the patient?	
No interaction between cardiac surgeon and the patient.	
Sometimes anestesiologist do see the patient	
when we decide patient needs to do procedure with anesteshia then they have to see them, otherwise not. But not every patient.	
Interaction between patient & cardiologist:	
Intervention cardiologist don't speak with patient before TAVI. Nurse talk with patient and ask what they want and how they feel. But when the procedure day the cardiologist talk with the patient	
the anesthesiologist often see the patient, more than the intervention cardiologist	
intervention cardiologist only see patient on the day	
but they decide what's the best treatment for the patient	
and we see the patient	
There is no imaging cardiologist involve..	drag N drop
I think the anestesiologist should go to a more inner circle than the cardiologist, they see the patient more often than the intervention cardiologist. Sometime they do but very small group	
More info needed during MDO: how?	
we will arrange with the plan coordinator. She can send email.	
sometime in CT scan they find new things then need to look first if its cancer or smt like that then we need to talk to the referring	unexpected findings in CT scan
sometime need to ask the surgeon of an operation half a year ago, plan coordinator will do that	contacting previous surgeon
Sometimes people don't have family but have a good friends who's not family.	
not always caregivers.. In NL we call it naasten, helping with hospital visit. Sometimes it's a good friend or a neighbor.	
Or mantelzorg. That's different from naasten.	
before procedure, patient is admitted at the ward. U have the procedure then they will go to 2-4 hours to the CCU. And if they sometimes they need pacemakers but its less than 10 percent. Pacemakers needed if there is complication, placed in the kateterisasi room not in the cardiac care unit.	

interention cardiologist informs the family when procedure is done. They call the first contact person to talk about how the procedure went. They are the one that inform the family. The one who did the procedure is the one who call	first contact of patient
I would like to see them but there is no time. For most patient is very busy day.	
happens a lot with patients and family.	
we decided its better for the patient because of all the impression	
Patient spend the longest time at the ward, it's a dept where they are admitted the day before.	patient mostly spend time at the ward
interaction at personal level will be with nurses in the ward. They are the one who will help patients get out of beds, other thing. Alse help before TAVI when they admited	patient mostly spend time at the ward
from ward after procedure they are going to their own hospital	patient mostly spend time at the ward
they call the patient from the kafkamer when they are ready for the procedure for the day they will come sometimes in the cardiac care unit sometimes at the ward	patient mostly spend time at the ward
last person seen at AMC: nurse & doctor of the ward.	patient mostly spend time at the ward
who are in the ward?	
CCU is a specialised unit where they can monitor the patients better. It s a kind of ICU for cardiac patient, you only come there if you have bad condition.	
the informal caregiver allowed to enter CCU. The first contact is allowed.	
when a wife of a person cant drive and she lives far away sometimes they say I will call and talk and will see him in the referral hospital.	sometime caregiver do not come but contacted via phone
patients who are alone?	
when they have nobody, most of the time very complitaed patient, they have some psychiatry problem. They have caretakers	there is always someone involve but not always visit and not always family
there is always someone involve but they ar enot always come and visit them.	there is always someone involve but not always visit and not always family
I think it is possible to involve these caretakers in the new solution. Even when there is no family there should be caregivers.	
There are people who can come to their home twice a week because they arent able	
I can imagine something like this	

patient only can go home when we are sure that this is okay	Hospital make sure patient can manage themselves before they are discharged
sometime they have family but far from the neighborhood	
I only can come in the evening because I have a job	
we call it thuiszorg. They have to arrange it. Its a condition sith the hospital that the patient can only go home when there is somone, some organization who will take care of the patient. Somebody who come 2-3 times a week to wash, sometime nurses come by watch if patients take their medicine, its very different	
when its necessary to get the patient home the hospital will arrange it	hospital can arrange thuiszorg
now we say when patient go home they can wash themselves, they can get themselves food, the instruction we give them is to be a little quiet, don't carry things, don't stand long for making dinner but they can go home	
less than 5% need carateker when they get home, it's a very small group now.	
imagine ppl need biosensor and they can go home the day afterward and then patient only can go home when there is something arrange with the biosensor,	discharged early if there is biosensor
I think it should be the caretaker, not AMC	
there a lot of different org. small, big..	
they don't realy collaborate with AMC, but they are a lot.	caretaker org not collaborating with AMC
example: epinurse, cordaan is the famous one	
when you search thuiszorg amsterdam then a lot of different caregivers at home	
nurse arranging that	
when the patient is at the AMC they go with an ambulance the day afterward to the referral hospital. Then they are the one reposnible to get the patient home	
90% of patient are not AMC patient	most TAVI patients are not AMC patient
they have their own connection in the area	
some hospital have rehabikitasion program, some don't	
so whenpatien ask I can give them clear answer	
some hospital do a great job in recovery, but its different some patients want to get trained, some said "I will see, if I'm okay I'm okay I don't need that."	patient do not engage in rehabilitation
"I want to see how far I can go so its very different."	
knowldegde transfer from AMC to hospital	
letter from nurse level and cardiologist level	

how the procedure went, what the problem was, why they came, something bou tbefore and all the measurement during their stay at the hospital, the conclusion, not a lot of difficult info but a LOT of info. U want to write about the examination before and after	data transfer between institution is not organized and standardised
different because there are doctors who write more than other doctor	data transfer between institution is not organized and standardised
recommendation about how long they need to be admitted for rhytim control. U have to look at kidney how they will do	knowledge transfer to referring hospital about the next actionables
that's very less not much	
the cardiologist in the region talk with each other and there's a little bit of "I will do it my way" and it goes well.	cardiologist in referring hospital has ownership of the case
mostly patients are talking with cardiologist of referring hospotal	
when there is a heart failure theres reason why nurse involved. But more cotact with cardiologist	
I see 3, 6, 12 montsh that's not right anymore.	
we say between 4-8 weeks, and 4-12 months, so they go twice to the caridologist	recovery follow up schedule
we say there have to be echocardiography and some blood samples. We write it 2 years ago that we don't see patien tin AMC anymore because patient group getting bigger and expertise of cardiologist become better so we felt it was safe to let the referral cardioloist see the patient then we advise what to do	
so we communicate it 2 yrs ago very frequently and now we don't, so its not in the letter	
we wanted to be contacted by hospital about the follow up	
about the information, to evaluate the care, its nice to read what happens when the patient leave the hospial	goal of getting data for AMC is to evaluateh the care
so we asked them to send letter after they left the referring hospital after treatment, if they stay 2-3 days, or maybe longer, and why is it	Info for AMC to evaluateh the care
but they don't send it and also not about the follow up	
if we want that info we have to call and mail and be very annoying then we get the information	have to be annoying to get the evaluation data from referring hospital
the referral cardiologist are very good doctor also. When they see something they can explain and want a second opinion or more specilised doctor they will make contact with AMC just like before. So the only reason is to evaluate the care.	trusting the referring hospital

there is no good infrastructure in sending that information	No infrastructure in sharing information across institution
no one is responsible to send us the info.	No infrastructure in sharing information across institution
they don't see the benefit from themselves I think	No infrastructure in sharing information across institution
	No infrastructure in sharing information across institution
I think there is a collaboration but sometime a bit of not a competition but sometimes maybe they are afraid that AMC is stealing their patient, but that's a very small group who's afraid	collaboration between hospitals
the referral hospital also want their expertise that they know the patient	referral hospital wants to developt their expertise
there is a competition between hospitals who do the same procedure, but its more subtle	
because the more patient you get of your own the more you can dot he next year and you can grow for a better expertise.	different payment scheme AMC & hospital
in NL the academic care like AMC we have 8 centers. Other org and other ways money goes than the referral smaller hospitals.	different payment scheme AMC & hospital
cardiologist in AMC is somebody who get paid no matter what. And the referral hospitals then have to see the patient to get paid by patients its not completely like that but it's a little bit different	different payment scheme AMC & hospital
probe about one single system that always go with patient: respons:	
I think intersting you said it before also, who is responsible for the biosensor	owner & actor of sensor system
who is responsible if something goes wrong	owner & actor of sensor system
who is responsible in getting the data	owner & actor of sensor system
who will act when theres something	owner & actor of sensor system
is it only sensor to see thing, is it also a warning system	
very important to patient that that is clear.	expecttaion of patient about the sensor system
with heart failure nurse you also have something like this and patient sometimes seems to think that I can do everything then when somethng isnt right it would go off but that's not the case. Its very impirtant that for patient they know what the meaning of biosensir is, what it can do and cant do.	Existing case example where patient have different expectation about a sensor system
the existing system?	

from the heart failure nurses they have telemonitoring. A lil bit like this. At home and they put information in it. Sometimes they have it to themselves sometiemes they get things to do and its connected to the computer	Existing case example where patient have different expectation about a sensor system
I read articles about it and sometimes heard from nurses that patient have different expectation about what is the meaning of the device	Existing case example where patient have different expectation about a sensor system
you call it 'telemonitoring' and there all kind of devices and person in the market who want to get data xxxx	
difference between patient expectation and the expectation of the caregivers	
you have some kind of device a the pacemakers then at home they can see what the heart rhitym is when they have complaint and the hart failure nurses in AMC don't use them anymore,	
very small group, I can give you the name of a person who work with it,	
other similar system in AMC?	
no	
probably there are but I don't know	
we want to do it but most of the time there are a lot ofproblem with implementation of system	reason why new digital platform did not work at AMC
I see more tings but it didn't stay very long because it takes a lot of time also and it doesn't benefit that .. When you put a lot of time, you want to get the time back. That was one of the problem	reason why new digital platform did not work at AMC

2. Intervention cardiologist

MARIJE VIS, INTERVENTION CARDIOLOGIST @ AMC **Quote**	**Note**
My main task is patient care. For doing intervention like PCI or TAVI. Then I do also have outer clinic, but not very much time.	

My second taskL 30% of the time I am the head of education for cardiology residents. I make sure they have a good education. Discussion about projects they have to learn, their wellbeing, a lot of conversation with them and the teacher.	practice, education & research
Third task, developing the TAVI treatment, especially via research, like with Matthijs.	practice, education & research
And I am cohersion with a lot of nurses. Wnith outdoor clinic with marja and elena. In catlab we have specialised nurse who help me at the table. Also fellow cardiologist who became interventional cardiologist and also trainee to become a cardiologist	
also the secretary also the planning office who do the investigation of patient, connecting with geriatric & anestesiology department	
Communication with referring hospital:	
Pretty good. Normally when they do refer patient they sent a letter which contain the complaints of the patients with the test they had done like laboratory, echo, sometimes CT scan & cateterisation. They send by letter and they send the images of the echo and kateterisaton to the planning office or the secretary then they put it together in our heartteam. then we discuss the patient and sometimes we make telephone call (BETWEEN THE CARDIOLOGIST) if we have question or if we doubt this is the best treatment they want.	
Pasien kalo lagi nunggu TAVI kontaknya ke mana:	
most of the time for the TAVI they will contact the planning office or the specialist nurses like Marja or Elena.	
email is also a very big thing which I don't like	don't like email
there is a weekly meeting with different specialist to discusss the patient.	
MDO: ecg, laboratory, etc	
we always ask for risk factors in the shared decision making. Older patient sometimes say, well doctor you say whats best. Other patient saiys they look on the internet and say I don't want to take any medication, they give me side effect..	decision making discussion with patient
I hope patients and myself included, like when it's a sunny day, and maybe my complaints are not that bad.	hope for tele tavi
the most important thing is to get that period of time. You want to avoid futility	hope for tele tavi
that's the most important thing I hope this telemedicine can help us.	hope for tele tavi
I think more like a month, because AOS is not really a fast progressive. So more like a month.	AOS not fast progressing
but I can imagine that only if you have a watch or something that patient wants to wear it everyday.. Otherwise I think it would be best to do one day every 3 weeks or something like that, then you can compare 3-6 months.	data points

and probably different times of day.. Or weekend days or during the week, weekday… or when they do sport.. Or just a relax day.	data points
trends. Its really important.	data points
the complaints or AOS are especially during exercise and also because of calcification of the valve and its conduction system that can be a measure as well.	AOS complaints appear especially during exercise
if you have a broaden purxxxxes, duration, or a conduction disturbances during night or whatever, that can be helpful for the decision making.	condition disturbances during the night for decision making
I think when a patient is asymptomatic then it wont help that much. Normally we catch AOS on the echo and if patient say they don't have symptoms, we perform a treadmill exercise in which you can see the condiiton, what the ekg does, what the blood pressure does, kind of thing.	
so that mimics this telemedisch thing like the heart rate, ekg, respiratory rate, step counts, and from that kind of things you can see when they get the complaints how good their condition is.	SENSOR DATA
the decision is made, the schedule, they are on the waiting list, I think that is the best for comparing afterwards, how they improve.	
so the step count is not that much helpful. They wont exercise very much because if the health complaints, but maybe you can help here in differentiating which patient has to be treated first and which patient have to wait a little bit longer	before & after
how do you capture anxiety	
I think its also a little bit in the edmonton frailty. I think it's in the frailty score. Or the	CHECK
the "did you often feel sad or stress.."	
using self-reporting score	
in pre clinical phase sometimes it is difficult. You try to convince the patient that they need the treatment but they were so anxious about it that they don't want it. So that's sometimes diffcult	patient is anxious so they refuse tavi
you only try to explain once again what the side effect can be if they don't to the treatment and then during the intervention we always tell patient that its normal to be anxious and that we only hope that afterwards they can tell	telling patient it is normal to be anxious
also for the rehabilitation I think it can be very helpful that they know when they are in their home situation.. This is normal, this is not normal.., do I have to contact the doctor, or that kind of thing.	guiding duirng rehabilitation
after the procedure is mostly about conduction disorder.	

patient go to the other hospital or their home, depending on how everything goes, their social environment	
normally between 3-5 days at home, the rehabilittaion program should start, which can be done at home and I think biosensor can help a lot in the heart rehabilitation program	enabling rehabilitation to start earlier with biosensor
Cardiovitaal	
I don't know if before the surgery the patien knows about rehabilitation program	
It is mentioned in the group session	
fisioterapist they past by during the admission so they can give exercises already. They can refer to the rehabilitation department.	example of how to move rehabilitation upfront
in my own poli we have a button for Cardiovitaal. We just have to press then it is going to assign to cardiovitaal.	
admission for rehabilitation	
cardiovitaal is not involved before TAVI treatment	
treat the treatment with all the side effects as well.	
what do they seek after treatment? It is not written anywhere but I think mostly related to family, they want to see their children grow up, or they want more social things, catchup with family, for that they need to be able to walk.	what patient want after treatment is related to family or social things
We don't discuss that in MDO. In MDO we discuss all the measurements like shortness of breath, angina, etc	
I think it would be very helpful in the MDO, especially with the frail geriatric patients, dementia etc, I think you can better die from AOS than from dementia.	discussing what the patient want in MDO
Marja performs the edmonton frailty & exercises. If they have a special alarm points then she contact the geriatricisant by phone then they decide if they should consult.	Go with you
When patient go to geriatric department Marja doesn't go with them.	
sometimes you see new diagnosis from the CT scan, which are not known before. Sometimes things have to be sorted out before they can get TAVI.	Comorbidities that have to be sorted out before TAVI

what would be helpful from this (self-reporting diary) is if they are less frail after the TAVI than before TAVI. Because they have less symptoms and they can walk better, support themselves better, so that they will become less frail.	before & after
You hope they will exercise more.	before & after
Rehabilitation is 6 week but it started 6 week after hospital release.	
3 months after they finish the program. We have an MDO. About their complaints, if they have symptoms, if they frail, we look at their ekg if there is disturbances, or change in ekg, and we look at the echo to see the performance of the new valve.	hyphotetical MDO after TAVI if there is biosensor
follow up meeting: cardiologist, echocardiographist,	
the best would be if most images from echo are labeled, because they make more images than necessary sometimes. Example: image number 43, that's how you can see the valve	
Interventional cardiologist, heartteam, multidisciplinary meeting MDO daily	
twice a week TAVI MDO	
go to EPIC. open EPIC right	
MDO: big screen	
EKG, lab, letters	
ADMISSION	
it's really a state of moment, what you tell about your complaint. most important to get the period of time. avoid futility	
period of time?	
more like a month	
AS is not relly fast progressive, so more lika a month.	

only if patient wants to wear everyday. or one day every 3 week then compare in 3-6 months. probably different times of day, weekend, weekday, during sport, relax day.	
important to measure trends.	
complaints especillly during exercise	
between 3-5 days at home rehab san start	
to improve heart rehabilitation	
the fisioterapis pass by during admission, give exercise, refer to the rehabilitation or any other clinic	
METS: exercise they can deliver. measure the condiiton of the patient. 6 METS is like walking stairs.	
what do they seek —> never written down.	
want to see grandchidlren grow up, dll, more social things.	
Marja perform the questionnaire, if the points special then she contact geriatics by phone then they decide.	
echo	
complaints symptoms	
look at ekg	
follow up meetings	
cardiologist	
echocardiografis	
nurses who perform the test	
best: images are labeled, like image number 43: thats the valve	
what is this an that	
they make more images	
what is the tima after TAVI? Is it when they are discharged from AMC, is it directly after the procedure?	the way cardiologist see step

then when they are going to regular ward then they are not attached to monitor but they have a mobility telemetry so they can walk around but on a scope on a different place nurses can look at the rhyitm and alarms are going when the rhytm is not okay or there is a disconnection	alarm system existing
and you have different type of alarm. High alert is when we have a ventricular fibrilation and immediate action is necessary	alarm level high
we have a low alarm because there was one extra beat that doesn't mean anything	alarm level low
telemonitoring: 3 leeds, these leeds are attached to a mobile device	alarm system existing
its hanging on their neck, with that they can walk around within the distance of the wifi	alarm system existing
biosensor is an addition to telemetry. But if you can replace telemonitoring with device then people can go home earlier.	biosensor can be an addition or replacement to the telemetry
Duration of telemetry need 72 hours to make it reliable.	data point duration goal
the next day, so that's earlier than 72 hrs they go to the referring hospital until the 72hrs so they get the rhytim check there	telemetry period is in referral hospital
they cannot look up the rhytim disturbance in AMC, but it's a good recommendation, but not possible	data accessed across institution
only patient who are in the outer clinic of AMC they will be sent to cardiovitaal, so it more in the neighborhood	only AMC patient get access to early rehabilitation from cardiovitaal HvA
normally we have a fisioterapist they have a connection with cardiovitaal but its only for AMC patient in amsterdam	only AMC patient get access to early rehabilitation from cardiovitaal HvA
starting some rehabilittaion in the hospital. They walk the stairs with fisioterapis for exmple they have strairs at home and we are not sure if they can go ghome already.	rehabilitation activity match with patient's living situation
it's a collaboration. It s on its own	vision of cardiologist about the rehabilitation being a collaboration

outdoor clinic is like polikiniki. We call hospital when patient need a bed. When its just a visit it is outdoor clinic	differentiate hospitalisation with just hospital visit
its good what you said. Maybe even better to put the pink line with the biosensor system in between the environment and the referring hospital bar, because then you point out the importance of the biosensor system.	drag and drop
that's what we thought about now but you can also make the biosensor system a different party	position of biosensor system
we also have a system in NL where AMC is working with that HARTWATCH and they don't have this biosensor continuous registration but they do blood pression and if youhave palpitation you will wear this device on your finger and it will be sent to a central system so that would be possible as well	existing connected system hartwatch
difficult because for example when u are in ahome situation as soon the responsible cardiologist in the beginning phase it is the responsisbilty of cardiologist in the referring hospital. When in AMC it is the responsibiity of the AMC cardiologist.	changing PIC throughout the system
I thik bcs you want to see trend at that point it would be very helpful if you do like what they are going to do in the rehabilitation so that yu can compare what they are able to do before and after	before & after
that would be very helpful in the waiting period	before & after
as long as it is before treatment, does nt matter if it is before or after MDO	before & after
if it works during the 72 hours, then patient can go home earlier	biosensor can reduce the telemetry stay duration
sensor before TAVI, who will be managing the sensor?	who will be managing the sensor
I think it would be best to be managed by cardiovitaal for example	who will be managing the sensor
now cardiovitaal not involved at the front but it can be a suggestion	problem is, only AMC patient can have access to cardiovitaaal by system
when the symptoms are shorness ofbreath then they also have lung disease, then you don't know if they are performing better after TAVI because of the new valve or that they ar enot very good in exercising due to the lung disease	cardiologist not sure of effect in relation to comorbidities
evaluating the impact of tavi for future treament	goal of collecting data

3. Patient Communication Specialist

DAYENNE ZWAAGMAN, PATIENT COMMUNICATION SPECIALIST **Quote**	**note**
Last year I did PPP (measuring via angket for the TAVI patient) how well they are informed before the surgery of the procedure and also more hospital question. how safe they felt at the procedure.	
questions like if you were experiencing fear were you be able to ask the nurse or the doctor a questions. some people said I needed to wait and I did/ did not care. sometimes they do not know what the reason was if there was a delay.	
If I advice the heart kateterisation room, (HTK) we advised them to put on a clock and tell them if you think 10 minutes is a good time for us as a team to inform a patient about delay or why, my advice is to be transparet and explain, is the patient is saying I dont wanna hear anything then its alright. if patients are scared, most of them dont feel the freedom to ask question because they think they are bothering the doctors. doctors have not much time, if I am worrying my fear to doctor maybe the doctor thinks im stupid. thats regularly the thoughts of the patients in the hospitals. I talk to the profs	
OMG how do I know if my heart is doing well?	Patient's uncertainty and concern
If I am feeling this, is this something to talk with my doctor? they are going home with a lot of information, and info about follow up nest week, about medication, I think we can give them more information about rehabilitation, fisioterapi, doing sports, how high is good or do I need to call my doctor if it is higher than whats good for me. I think they can be more 'accompanied' or guided.	Patient's uncertainty and concern
App for family of patient. MEDIMAP. Give information to family about the patient. ongoing development. coronary disease (PCI) & aorta klep stenosis.	Digital platform for patient & family
MEDIMAP	
You have to physically goto RS to have an account. you have a patient portal for appointment. then you have access to medimap.	
currently the tavi patient does not have that account. esp the referred.	
nor very common to have amc account esp the elderly.	
most of the cronicle who are always amc patient have an account.	
Admission	
AMC does not know the patients	
to imporve: professionals to have a good coherence, partnership. it sa challenge because AMC only the place to do TAVI.	Coherence in care pathway

importand that referred hospital share the information about protocol, expectation manageemtn, why TAVI cannot be done in the referrred hospital. most of TAVI patient are 70yrs or older, some says idontcare. but the younger patient or the family member will ask question. if the answer is diffeernt then not good, different expectation. I think its important to look for partnership between the referring & referred hospital about the shared expectations.	Family member ask question
some patient who come to AMC doesnt really know how the procedure is going. is it open heart, transcateter. I or we really dont know why it is not mentioned in the referred hospital.	inconsistent information
the confusion affect the trust in healthcare.	confusion affect trust
relates to the anxiety level. enxiety levelin vcardiology patient is always high. costor doing the proceudr eevryday, 5 times a dy. he doesnt aware of the anxiety of the patient. patients always think thers something wrong with his heartthat his goin gto die. even if from rprfos perstective its not a big problem.	doctor is not aware of anxiety of the patient
as a petient perspective way thers always a group who want to know the heart rate and. agrup who find it confrinting and scared of this knowldege. I think it is very individual.	
if you put the sensor on the patient, it is importan hwere do you want me to put it. is it itchy, faling off. its more on the daily life what does it mean to me. wht if ppl ask question about this, if this visible	
important for future patient if youhave sensor ready you publish in medical magazine but you cn also publish in patient organization magazine. put the knowledge in the heartstichting. spread the new about this sensor.	patient community
the patient has a community. hungry for info until 6 month after treatment then get back to work. some patient wants to be engaged at this medical field.	patient community
POST	
lying on the..	
trust their own heart again, with their new biological TAVI kelp. later on it si more a mental challenge. some people are not so gloomy, a little bit depressed. i think it is important to also help them with that or give them the possiblity to get help on the mentsl situation. but it is good to mention that its possible to have some unhappy feeling.	trusting their own heart again
you set to urself i wanna walk to 1km. you dont come to that goal. its good to say its okay to the patient. and maybe its and acceptance that you can never reach thtah goal.	help patient accept
maybe insight about healthy lifestyle, sleep,	
fromt the patient persepctive maybe fine to give advice for lifestyle change and prevention. or the mental acceptance.	
peer to peer contact, buddy project, oo to discuss and talk about the	
heartstichting raise money for research and give advice of lifestyle changes. patient already affiliated with heartstichting the moment the become a patient.	patient community
maybe good to create a page bout TAVI in heartstcihsitng.	patient community
awareness of patient about rehabilitation plan. you both work with its own system but patient should know you are one organization.	coherence in care pathway
how you can inform and how you know what time is the right time to inform the patient of this? about paliative care	

when the treatment stops, whats next, what are tehe options. there are also patients who do not want to discuss this subjrc. that is a very vulnerable sbject. but I think if you cannot cure then you need to take care to patient who are living with this disease 24/7 if there s no treatment at all the profs needs to dicsuss paliative.	include dicsussion about palliative care
common in the onkology dept, not so much in cardiology. very very important to know what is next.	
motivation:	
how can I enlarge my quality of live? live longer with good quality of life? the patient is in charge. important. i think if patient is saying yes to the biosenro it is based on equality and how can I help the doctor to improve this procedure to the next one.	patient should have the ownership of participating in the biosensor system
different. one time vs chronical which patient needs to live with. the chronical is more equal because they already build a longer relationship. but the one time procedure, there's nothing. there needs tobe a safe haven just for the time that patient is admitted. TAVI patients are consideren one time patient. but with this sensor you can build on that relationship with that specific patient.	
if you are giving that sensor you can contact the patien tonce in 3 month or a half year. is everything fine, do you have question.	
What is the impact of peer to peer discussion?	
IMPACT OF PEER TO PEER DISCUSSION: you all have the same exact procedure you have had. one word is enough if you are talking about pain, trouble, panic, doctor will never understand that way if you are bringing up that subject. i think its beneficial to talk to equal. safe space. sometimes if you havea bad experience ou do not always dare to tell your specilist, but with p2p you tell everything, the good n the bad. the profs shouldalso know the bad to improve.	peer to peer interaction space as a safe haven
conerns: expectation management	
be very transparrent.	
if you want to know what patient want, just ask, do not fill in. just ask what their opinion. are you goin gto wear it. dont talk about them but speak with them.	just ask the patient, do not just fill in
1.Confrontation, manage expectation, do another way. Device can be reminder of confrontation. Like a scar in a mirror that remind of limitation. Now there is a scar. Another device, extra scar. Shame, feel the need to tell story about where scar coming from. Some ppl are very proud. Double sided. Surviving a war. Relates to social interaction. Relatives always worried about you. If they ask how are you we say good. If its not they're worried that there is something with heart again.	
2.Confrontation and going back to life: this is where they try to understand their limitation. "its okay to take it slow" can feel my body healthy. If im sitting at the couch I don't know what I can do	
3.Focus on what you can do. Lose some win some.	
4.Get back trust in your own body. If you train you see that you are growing. Of what you thought you never gonna reach. "Is it safe for me to do this? Yes/no?" 24/7 daily basis. Some are taking more risks than other. Some chills.	

5.The question us in the stadium of confrontation, stepping forward, it's a dynamic process, always comes back. Oh maybe I can set up a goal to work again? Then the question start, is it safe for me. The question always come back whatever phase.	
6.Like the covid now. Dr tells patient stay home, do not go out, but u see everyone is going outside, patient is always the one who decide, "if I'm going at 7 then no one is inside, I can take the risk getting grocery but not getting. " the choose to step/ do/ do nothing is always in the patient. As a patient u always bedice yourself. U know your own body.	
7.Probably elderly is more accepting with scar but not everyone.	
8.answer: a way of trial and error. Fail bcs of getting symptoms and limitation.	
9.Difference between man & woman. Maybe man is more ok with scar. Woman: what is the woman wearing? Is more skin exposed than seein g the scar. Going to beach wearing bikini, scar is visible.	
10.They become more intuitive.	
11.Not used to feel/ listen to their own body.	
12.If you ask few times a day: what does my body tell me? Oh that was a good run, but is my body experiencing the same as what I feel?	
13.How does your heartbeat feel? How does your body feel?	
14.If you experience everytime the same heartbeat or the same muscle pain, u don't have to worry about that and can do it.	
15.Limited cognitive process: caregiver watching, asking, how do you feel, how does your heartbeat	
16.They could be the eye.	
17.May he just goes without questioning. Like a child. Just cry, but if you ask why you cry, he says Im experiencing pain but	
18.the expression of symptom	
19.Patient who do the activity because they want to manage by themselves.	
20.Recovering,	
21.Grief about losing function	
22.Comorbidity patient more difficult for good quality of life	
23.Not about technical problem in body but about the daily life	
24.Side effect. Then steps to treat side effects.	
25.Patient centered care.	
26.Family get more intuitive too. Trial and error also happens with them.	
27.Having faith it would work	
28.Why sorry just see	
29.Worrying is holding people more back	
30.Then you know it's safe	

4. Plan Coordinator

Roosje, Plan Coordinator @ AMC **Quote**	**Note**
Check all those small things	
Pmax high, make progress quicker	
not sure of doctor have told them about theo outcome	
call the CT	
check the information	
by phone	
if need to hurry, send mail	
the patient dont have email	
in the phone explain step bys step	
their family will have email so they will help.	family help in communication
in waiting list when. weeks before its their turn.	questioning registration status
They are asking is it already my time?	questioning registration status
in the letter 6-8 week.	questioning registration status
they call after 5 week, asking when	questioning registration status
she double check if the problem doesnt get worse	checking condition while waiting for registration status
reassure	checking condition while waiting for registration status
they all see my name in all the letter	Personal touch because of name
I get cookies, flowers from them	Personal touch because of name
they complain why does it take so long	questioning registration status
they cant odo all the things theyn ormally did	waiting while experiencing symptoms
they get information (in the presentation)	
then we have the group meeting	
all the time I make note.	
most come from alkmaar xxx ziekhuis. they dont know what to expect, dont get enough info from the referring hospital.	patient do not get enough information from referring hospital
feel connection	benefit of peers among TAVI patient

ah what a good question	benefit of peers among TAVI patient
in waiting room : oh good luck!	benefit of peers among TAVI patient
we were checking on application on the internet	
around 40% have email. more the family is interested.	
family wants to take control, wants to kknow everything.	family wants to take control
push me, please maintain my mama.	family wants to take control
DAYS	
preparing MDO	
checking new application	
set my excel file	
EPIC cant give me summary like these	
I have separated excel	
there are dates of admission, CT scan schedule, MDO schedule,	
one patient per row until the very right side	
separated tab for waiting list	
if people call whens. my time	
I check the waiting list tab. I can see how many weeks she has been waiting	
they talk about personal story on the phone	sharing personal struggle
sometime they live alone	sharing personal struggle
talk about how they cant do that normal stuff	sharing personal struggle
plan just a week ahead	scheduling TAVI treatment a week ahead
if more ahed then more cancels	scheduling TAVI treatment a week ahead
cancelling appointment is really hard	scheduling TAVI treatment a week ahead
now, elena & marja are calling the patient. I plan the CT. where they do poli, now they do by phone.	

sometimes there are personal connections	
once in a time I will check all my on-hold patient.	
excel is more like my checks for my working list.	
overview of all the patient. I cant find it workable in EPIC.	
first time was 5 minutes per person	
technical most important:	
diameters of right & left	
distance of coronyfr om aorta valve	
the AVA	
kidney function	
if not sure I can always ask. I can just call them and help!	
the schedule are color coded	
make tavi difficult because patient have different journey	
if they from amc they have so much info	amount & depth of information patient received it unstandardized
if they from other hospital they dont get much info	amount & depth of information patient received it unstandardized
in the CT they always find something else	new findings in the middle of test
because they old. will find something in the lung, checkin with lung speacilist, kidney dll. easy patients are not that common.	new findings in the middle of test
first time meet marja elena	
I go to the group meeting but I dont have to	
dijklande hospital in hoorn & purmerend	
dxxx ziekenhuis	
if pmax above 90 then discuss with marja that u got a high risk patient. is surface is smaller than 0.6 then high rish	knowledge about problem excalation to other experts
pressure above 90 is high risk	knowledge about problem excalation to other experts
checking critical number.	knowledge about problem excalation to other experts

get this percon asap is urgetn.	knowledge about problem excalation to other experts
I'm aware of those critical number and aware to contact the nursing specialist to rush them. death rate will be lower bcs of that.	knowledge about problem excalation to other experts
now im working with VU. they were freezing all the program. we decided to get some files open. I find out that they had some patient with the 150 max pressure. she wasnt aware bcs she didnt know. Im aware and she isnt I feel I want to scream for help to marja	knowledge about problem excalation to other experts
have a medical background. I guess it helps. And in VU they are changing shift so the file is not managed by only 1 person.	knowledge about problem excalation to other experts
just some rule that it is critical and it is not	knowledge about problem excalation to other experts
everyday I save a new file	
their biggest fear is to be forgotten	patients fear to be forgotten in the system while waiting
waiting is always too long	patients fear to be forgotten in the system while waiting
if you can give them anything of connection that will comfort them and make them not forget they still working with me	patients fear to be forgotten in the system while waiting
"this is an urget patient	
"but this already waiting for 6 week	
"but their rates are not that bad	
"but this is 6 weeks ago!	
thats my discussion with elena	
with sticker you can get the real time condition of the patient	
you can call them, comfort them or change the medication	
planprocedure faster	

sometime it could be months before accepted bcs sometimes they need to check lungs, oncholgy, etc	
the lungs	
the prognosis have to be more than a year	

5. Physiotherapist

Donne Lek, Physiotherapist @ CardioVitaal HvA **Quote**	**Note**
There are 10 factors of heart problem. We look at these factors per patient then create a pathway that are suitable to their condition	
fitness, stress, diet, blood pressure, lipid… etc.. The vital 10. There are 10 factors to get bad blood vessels on your heart, legs, etc. it is very important that you improve it.	
the team is working on the 10 factors.	
Fit program. It is not only about the fitness level but also "do you dare to move, do you know how to listen to your body."	
before start we have MDO. We discuss what the client wants and what can be improve. Which PEP we have to make. For example 3 months training stress management, social work, patient education.	
we know a lot of people the first time they are a bit stress of anxious so there are also specialise questionnaire we ask to see.	
Duration:	
DBC, we get paid by them for 3 months. So if you get 3 months rehabilitation everything is specified. For example 12 fit, 5 psychological.	
you start a lifestyle change, then the digital follow up should go on with your lifestyle change.	go with you
if you have high anxiety level you go to stress manament. Its 6 times course and you know how to relaks	
so what we are doing is not the same for eveyone. But it ispersonal fit on the goal you have to get a better outcome.	
not everyone can follow the pgoram. They have to have a surgeyr or anginaperxxxx and referred to us. So all heart disease can be referred to rehabilitation if they are being sent by a specialist.	
TAVI for us is a small group.	
so it is also for example heart transplantation, etc, from very low to high. First group is from heart failure and heart transplantation.	

its different between TAVI and other heart disease. If youhave surgery on your chest, there is a delay in 6 weeks because it has to heal first. Now there is a PhD project that says the 6 weeks can be too long, because the happens a lot of things that have a negative impact with the outcome.	for open heart surgery its normal to wait for 6 weeks to wait for the wound to heal but not for catheterization
heart surgery: start 6 weeks later	
there is other that start the next day.	
if you have TAVI and they are in the wait stance. Because they think I may not do anything it's very painful. So its very devastating if you have 6 week of waiting and do nothing, your fitness level goes down, your endorphin goes down and its only because the hospital said you have to do very a easy for the next 6 week and then you can start with the program.	Problem: 6 weeks waiting n do nothing
same case with aorta klep	
we have a plan to come to the patient to the hospital and tell them what they can do, even 6 weeks before they start	ongoing effort in bringing the rehabilitation more upfront in the process
the rehabilittaion start online, with coaching in the online world. Now we give them information. We want to give them information and they join the digital world and they have the same benefit.	online rehabilitation ongoing
patients are grouped based on which communication style motivates them better.	motivation strategy
for example, "I get very joyful if I am with other people." so people get very motivated if they have the personalised motivation tools. If I want to motivate you I have to follow your communication style.	motivation strategy
that is very new.	
for example you get motivation from special language. From the questionnaire we know what kind of language will motivate you.	motivation strategy
we divide people in 6 groups of personalised goal & motivation.	motivation strategy
personalised motivation for lifestyle behavior. Its a PhD trayek	
I am also in contact with the owner of the program. He will be interested because he was also looking for a sensor.	
its not about training that we are doing on our location, it's about that they gonna move more in their own surrounding	Live in their own surrounding
so you can use the biosensor as a feedback for themselves and if he can also see the value of the sensor he can give them feedback with online coaching so it will be very useful because you have a lot of step count, … we are also from the medical side interested in the ECG and the heart rate because there is a different between training and moving.	online coaching
in the first step we want them to move and also to train. And in the test we do, also for the TAVI, we know which level they have to reach to train, related to the heartrate.	training and moving
you have a feedback if you are training.	

for example if there is a simple ECG at the beginning if there are some special things for example if patient says "I can't go on because something goes wrong," then you can make it objective because older people are scared to move and to do high exercise level	people are scared to move
it will be wonderful because its not only 2 times they are on the place. You can give medical coaching on distant	
2 times a week for 12 times and then the funding (?) stops	rehabilitation regulation
we see a lot of people are falling down to the earlier level. For example when you have obesitas almost psychological problem, so in the surrounding with added people, with specialised people, with the right thing (at AMC). But in your own environment there are a lot of risk of failure of falling back.	a lot of risk of failure when patients are in their own environment. Because a lot of the triggers are psychological
we want to use a sensor to make a follow up and to make you can discuss what someone is doing.	
if I ask did you do the right thing, did you do a lot of movement everyday, you can say yes. But if you have sensor you can discuss what happen.	can discuss what happen based on sensor
you can also do it during a treatment itself. Now we have a big machine with 12 things to do ECG. Also a little part on finger for heart rate and oxygen. If we get more information and they can go on.	
if they feel something, we need to look if it is a green or red, from the stoplight. Sometimes you don't know so if you have biosensor you can look at it.	
I also have a biosensor and it give stress level. Its based on … if you have a high anxiety you get a bleeding on your skin.	
you also have a little device that give your anxiety level or heart rate variability	HRV
stress and anxiety levels are underestimated problem.	stress
obesitas, stress and activity level are very important. And it corelates with each other. Because if I very fat I don't move and my stress is high and my lipid are also high. My blood pressure also high.	stress
we see them as 10 separate things but there are a few main things.	
now doing rehabilittaion online due to corona	
its very nice to do it	
the things you do gain possibility makes the outcome	
you do it by zoom, theres only 5 patient With normal condition. now there're 12 patients with 3 fisikal terapist. There's also a nurse and a doctor.	telefit enable wider participants
and we first talk to all the people and we ask how dod it go last week, what have you done outside, what physical activity have you done, how did you take your medication	questions in the beginning of telefit
there should be another person in the room also. If they get problem you can act	but in the observation no other person in the room
if there is problem I will put them in separate zoom room with the nurse and doctor	problem/ emergency situation during telefit

20 minutes to ask if they have some problem, if they know what to do, if ready with this, what is your goal. So I know if he wants to hike or he wants to bike again. So I know them very well.	telefit session
then I do the exercise, it's hit training, 7 exercise, and then we discuss the Borg scale. From exausted to lying in bed, scale 1-10	telefit session
they have to be at 6	telefit session
3 rounds, they will be sweating	telefit session
sometime nurse looks at eac patient. Will ask if patients are stopping. So not only the exercise but also the story around it.	telefit session
because what we are doing is.. Cardiovitaal is 10 places in the netherlands where we do the rehabilitation in the same way. I think you have to also talk with the chief of cardiovitaal.	about cardiovitaal
We have AMC patients but we are not AMC healthcare anymore.	
we dont only work withc patiwnt from AMC	
it's not AMC healthcare, it's cardiovitaal healthcare now	
they want to go more digital. Cardiovitaal.	cardiovitaal wants to go more digital
you have different social level. Sometimes heart disease patients are from the lower social classes, don't earn much money, eat a lot of fat, don't move, from ….. Genetic.... More heart disease.	
and a lot of the people are not digital. Because I think if we have sensor then you have to use smartphone.	a lot of patients are not digital
everyone who do rehabilitation has a login username but a lot of people do not use computer or they don't know how to use it because they don't speak dutch	
not discriminated, but a lot of diseases are common from lower social level because they live more unhealthly.	
how can we reach this vulnerable people in the surrounding of the lower social class	maybe this is the extreme point
they get the polar device, it's a watch, and they send the steps and the heart rate. Like fitbit	using POLAR sensor in telefit
that's the fatty liver research..and the… intervention is very high extreme and a biosensor or polar they get challenge to do 10.000 steps a day	probably this is the wearable device seen in the observation. So they get 10.000 steps a day challenge
its not specialsed for heart patient.'	
for each modulation you have separate device. It would be very helpful if we can combine it into one unit for all heart patient.	
I think the main thing I want to know is the heart rate and the ecg.	
the respiratoratory is nice, but you have to do a zero measurement first to see what is normal for this person	need to understand inidividual baseline first
during my work the fall detection is not so important. Position is also not so imprtant. Well maybe its important because if they have a strained ECG, then what position do they have	Data needed
step counts. I think heart rates, ECG step count and respiratory rate	Data needed

the step counts that work when you are biking. I don't like step count if.	Data needed
you want people at home to move the way they would move. And that's not for everyone walking,	move @ home
I want to see how much they move, but STEP COUNT is only small part of possibilities they are doing.	data needed
someone like to bike, but step count says zero, that's not good. Or row	data needed
there are different types of sport	data needed
a lot of ecg work only with movement of the arm. It doesn't work with biking	
I think if you want that they use it right when they finish the rehabilitation you have to use it during the rehabilitation then they get rehabilitation. If you give it after the rehabilitation finish it doesn't work	sensor in the pathway
you have to integrate it with your daily living	sensor in the pathway
there are a lot of people who like it, people who like it. Some people get joyful, others don't.	find paper
you can find out during the rehabilitation.	
PhD trayek about what kind of motivation do you need.	
we have a digital surrounding called EPIC, you can only see if you have license. Cardiologist give order in EPIC or he will send by safemail. Mostly a letter of 4-5 pages. Also with the operation procedure, the comorbidities, what kind of medication did he has. and we stay in contact because when we think he has too much medicine and his heart rate won't increase then we contact the cardiolog can you change the medicine because he has too much BETTERBLOK for example.	
so there is always contact with the person who sent them in. also the end letter is going to the general doctor at his home and the specilaist of the hospital	user journey
the treatment of rehabilitation is in the real other world. We would be interested in their data because we can see, …. You getTAVI, you use the biosensor, normally you only start 6-7 week wirht rehabiltation but if you wear biosensor and I explain it while you were in the hospital to the patient, then I can give them feedback about what he's doing. then I can say well I see that you are doing almost nothing, well also login to the biosensior. I give you goal if you can double your steps.	
so we can start, especially for TAVI, we can start on distance with the biosensor	can start rehabilitation earlier with biosensor
If you look into the organisation of the healthcare there are 1st, 2nd, etc line.	
1: doctor on the street & fisikal terapis	
2: hospita	
3: specialised institute	
we are 1.5 line. Its a different paymnt, different organisation so if we got the patient from AMC, he leave AMC and other payment and administration.	

and other responsibility.	
that's very important to know. So the specialist of the hospital, his work is done, he will see you after 3-4 months after you have done your rehabilitation and everything go well. And then he get the letter from us and the story of the patient.	
follow up meeting until 1 year is with the first (referring) cardiologist	
the only change medication when we discuss it with the first cardiologist	
before corona he is looking for way to do it more digital. There is an interest already	
most people are sent to rehabilitation.	
percentage of people who go to rehabilitation: if we compare the output of AMC and the inclusiveness of our rehabilitation then it is 30-40 percent doesn't go to rehabilitation. We have the same goal to reach all the patient	inclusivity of rehabilitation
language.. Very old..	
we have a specialised program for older people who cant come. At hospital they well see the nurse and the fisikal terapis that they will see at the home situation.	
the carebridge. The bridge between hospital. Only for the people with problem.	
in the hospital the patient see the same terapist as at home and that's very good because he will get less disorientated, and its warm briefing and the first day the terapis know him already.	changing clinicians in the pathway
it's a small group but we try to reach program to each group.	
there is a phd program of ambulance c-path. We want to do the test in the home environment to know what does the ecg.. What does…his fitness level, which problem occurs when he is doing exercise, cuz there are a lot of thngs going on with the heart rehabilitation.	

6. Referring Cardiologist

Liem Su-San, Cardiologist @ Amstelland Hospital **Quote**	**Note**
Im catching the big fishes and bring them to the grizzly beats. Im making the diagnosis. work 3.5 days only see patients. during my wokr not so stress	referring hospital as the GATEKEEPER
stress: oh only 10 minutes	only have short time to extract information patient
AOS has to be severe. mostly u get ppl who is brought to u from the GP. he listen to the heart and heard shuffle and say u hv to go cardiologist. mostly not severe enough so no indication for tavi.	cardiologist at horpital receive patients referred from GP
moderate: listen for half a year	if the symptoms are moderate then they will be monitored for half a year

depends on the secerity of the stenosis.	if the symptoms are moderate then they will be monitored for half a year
if it gets worst in echo although without complaints. they need tavi when they had complaints or if the severity get 0.3 meter per second without any complaints.	no complaints but bad echo: need TAVI
most person who need another valve are older. I say due to your age. its an aging process. ppl can accept this. for younger patient, thats more difficult to explain, u re 50 and you ned another valve. most of the time they do classical way to get a new valve.	older people can accept better because cardiologist explain it's due to age. But for the younger (50ish) it s more difficult to explain but usually they go TAVR
cant predict how fast it get severe	cannot predict how fast AOS progresses
most patient are older and the family is there. I also talk with the family. that is also part of the process, if u have to do tavi, how is your living situation, sitting/cooking/,? its different when you have someone who is outgoing. from family can get this information.	family as a source of information about patient's living condition
sometime ppl come with already severe condition. axio radius 6 month ago.	
difficult bcs bad cognition and delirium. sometime I call the family doctor to ask how it was and if its still useful to do the TAVI	referring hospital as GATEKEEPER
look at the biological age. family. family doctor. medical specialist in elderly people. social condition and physical condition of the patient.	
sometime family think its not a good idea, then I will can dr.vis and discuss.	discussing with GP or intervention cardiologist before making recommendation
patient. family, gp. geria, what do the academics think about it, and myself.	
lung test, ecg, echo, ct scan to look to the coronaries or cateterisation.	
how do patient respon?	
we explain everything, the risk & complication.	
if tavi not suitable: open surgery, small open surgery, endoscokip way but its even more than a tavi, patient too young for tavi referred to belgium	
communicate the most:	
me. but when the patient is referred there is heartteam, valve team, nurse	
I know how to call the secretary, then I ask for who is the cardiologist	
AFTER THE TREATMENT	

we have and EPD. we put everything in our EPD. we call it the art assistant, the clinical doctor put everything in the EPD. we will see the patient and exam. What exam? they have echo in AMC, then we do that	
lab when necessary, fisikal, blood pressure, then 3 days of telemetry. to look is there is disturbance of the .. no AV block.	
when you give tavi you press old valve on the side and that can disturb the electrical mechanism of the heart.	TAVI complication
Rehabilitation?	
when the go out of hospital, our rehabilitation nurse will call the patient. usually 18 session in 9 week.	rehabilitation start after TAVI
who's inteacted the most? clinical doctor & fisioterapis	clinical doctor & physiotherapist interacted most with the patient
AFTER REHAB	
We see them when they are going home, when itis complicated you see them in the outpatient clinic. we havent standardized the 4-5, 6-12,	
the cardiologist is the key in the whole process.	cardiologist IS THE GATEKEEPER
all patient go to rehabilitation. most patient like it in the program because they get to do it with othet people. I hv patient who still come every week in our hospital, not a rehabt, but … they drink together	rehabilitation as a social activity
some ppl too far, so they get terapi at their village	
FOLLOW UP	
respond well, how it goes with symptoms. you hope they are no shortness of breath, no fluid retention, no syncope. you inform yourself how they respond to tavi	after TAVI: finding out how patients responded to TAVI
if successful they can do more and have less complaints	
for the prognosis, you do it for the symptoms. the morbidity is still high so you really have to do it for the symptoms.	determining TAVI prognosis for reducing symptoms
tbh you make already a shift before they get tavi. some ppl dont want tavi, or some high comorbidity cant do tavi. then its a symptomatic treatment, or paliation. patient who get tavi is better than those who dont.	determining TAVI prognosis for reducing symptoms
so hopefully they can do more	
involvement of family:	
if the fam is involved, they will say something about the fragility. if no fam is fragile paitent. with more social support its less fragile.	patient with more social support is less fragile

most of the time you decide..it can play a role to decide not give a tavi. if the family is very involved that is also make the patient less fragile. the rehabilitation will be better without social support. i think social supoort is very important. for example with all the test in RS nicer, not everything alone. driving.	patient with more social support is less fragile
ECG: to see electrical disturbance after TAVI after opname. 10 percent need pacemaker. mostly within few days after. I dont need it in outpatient clinic	ECG is to see electrical disturbance
ECG at home, I dont know. in a clinical POV idk if it is handy.	
Respiraton rate is a very sensible to look how it goes with patient, sometime too sensible	
I am afraid u get a lot of data and a lot of noise. aaa I have something to do with the patient but heyre doing fine. fear that all dr have u have so much data and noise and u give urself a lot of work to treat number but not the patient. my concern.	don't want to work with too much data. Fear of treating number but not patients.
until now telemonitoring can be helpful. you have a goal for treatment but	
Posture & fisikal aktiviti: both I think almost the same. u want to know if ppl can have more activity after tavi	posture & physical activity data is to see if eople have more activity after TAVI
i think useful but more useful now for research question and clinical success. the 2 last one is most useful for clinical success. the rest is research data. if they have complaint they shuld just come.	
not the number but how do u feel. then we can make action on it,	
the data will be used in academic but not in little hospital. if step count low before tavi, can be due to aos, i think it is difficult that it place a role to yes or no	the learning will be useful for academic but not in little hospital
we dont know in which path the patient is sitting now.	
when it is moderate & symptoms, u have to look at other reason why they have shortness of breath. moderate no complaints then we see them after 6mo/ 1 year. we inform the family doctor that we know the diagnosis. cant predict how fast it goes from moderate to severe.	
they ask dr.liem.	
I am the chief. im their cardiologist. I said just call me if u dont hear anything from the AMC then I can see how it goes.	

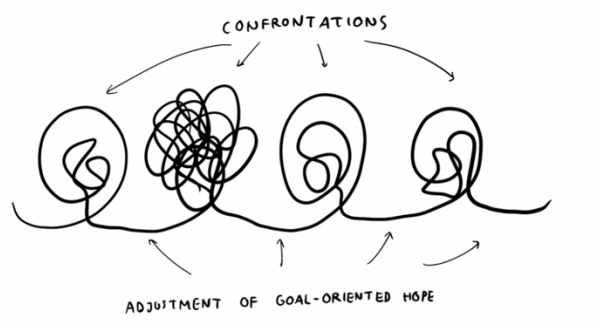
get data & interperet a lot of time. its an academic question. I just want to know the result but dont give me everyday result ofd data.	benefit for little hospital will be to receive some summary but not everyday result
prognosis: you get years with less symoptoms, not more years. interesting how to see patient improving and perhaps be combine with the list of quality of life. can u do more fisikal, boes he feel better. fisikal, sikologi, more happy. for the patient i think its less interesting if they dont go better, usee them at the emergency room. data & interpretation is interesting for the NEXT generation TAVI patient.	prognosis: not more years, but years with less symptoms
if ECG u see AF that is new u can interact more quickly. but thats a sign that patient not going well.	
if sensor can see earlier	
for indivudial basedL early detector	
big pictureL more for the next patient	
after follow up:	
sometime AMC ask patient to back at AMC outpatient. it is my patient, sometime they like to see them 4 mo to see have it goes.	ownership of patient case
the data kept in hospital.	
evey year echo just follow up. that is also nice for academic.	
european sociaty of valve guildeline. part: AOS,	

Appendix G: Concept Testing

Concept Testing Session

08 July 2020

Anindya Paramaarti
a.paramaarti@gmail.com
anindyaparamaarti@student.tudelft.nl



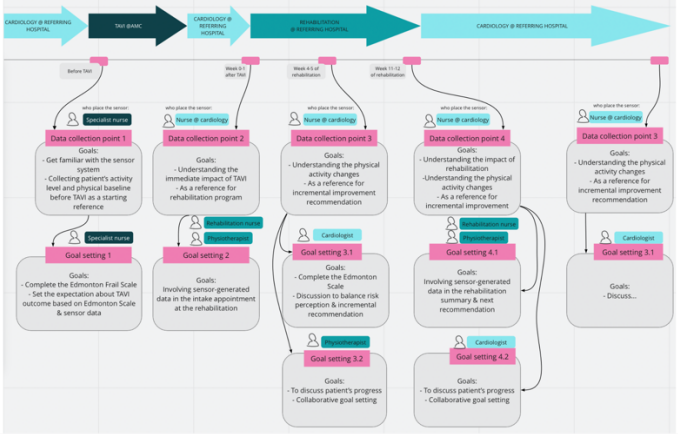
a patient expects to clean his house in 3-4 hours straight [initial goal],.....
but he gets tired after a short time [facing confrontation]....
then he thinks he cannot clean the house in the same way as before [goal adjustment] ....
so he spread the cleaning task into 4 days instead of 4 hours [goal pathway adjustment] ....
and he know he can manage it [trust on oneself].

Design Vision

Improving TAVI patient's ability to manage confrontations through a continuous and collaborative goal setting using sensor and experience data.

As patients are continuously finding balance between life struggles and hope (Olsson et. al, 2016), an increased ability in managing confrontations would mean an increase in the hopeful aspect. This would lead to an improve in patient's psychological wellbeing.

Data collection period | Goal setting | Goal pursuit in real context



When referring patient to AMC, clinician registers patient to LIVEsense and explain about the sensor.

Later the patient is contacted by LIVEsense. LIVEsense would arrange the device & account. Patient is given options to have the device delivered or to come to the hospital.

In this scenario patient decides to have the sensor delivered.

His daughter come to help

Patient activate the account and choose the data collecting duration.

Patient continues his regular activity

And logging in short description of their experience.

After the data collection period is ended, patient remove the patch.

LIVEsense process the data & create summary for the clinicians.

The summary from the data collection is discussed with clinician at the hospital (first goal setting)

Data that are collected:

- Activity level during data collection period
- Physical baseline during data collection period
- Experience perception about activities in the data collection period.

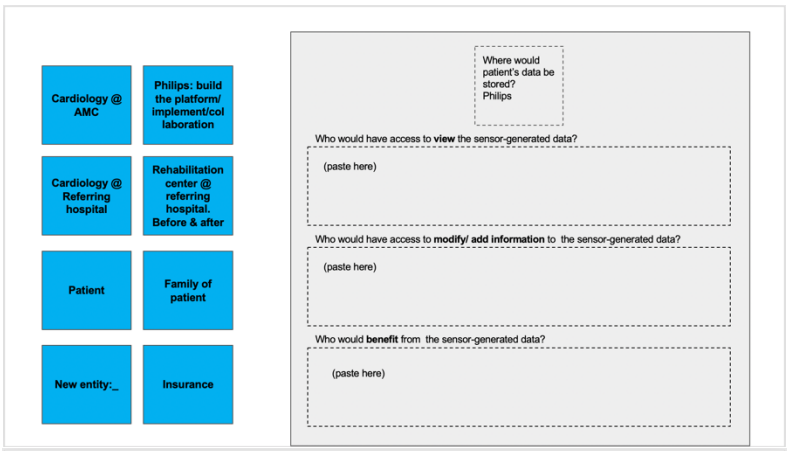
What can be summarised from those data?
(write everything that comes to your mind)

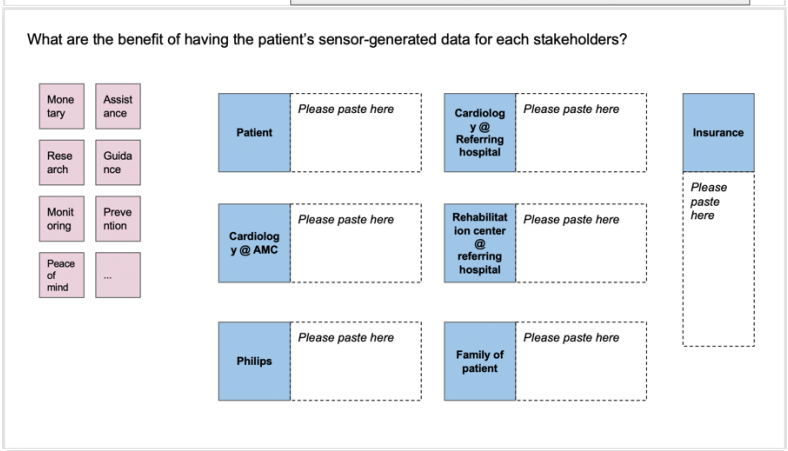
Goal Setting

Data that are collected:

- Activity level during data collection period
- Physical baseline during data collection period
- Experience perception about activities in the data collection period.

What can be discussed in the goal setting?
(write everything that comes to your mind)


Cardiology @ AMC
Philips: build the platform/ implement/col laboration
Cardiology @ Referring hospital
Rehabilitation center @ referring hospital. Before & after
Patient
Family of patient
New entity:_
Insurance
Where would patient's data be stored? Philips
Who would have access to view the sensor-generated data?
(paste here)
Who would have access to modify/ add information to the sensor-generated data?
(paste here)
Who would benefit from the sensor-generated data?
(paste here)


What are the benefit of having the patient's sensor-generated data for each stakeholders?
Mone tary
Assist ance
Rese arch
Guida nce
Monit oring
Preve ntion
Peace of mind
...
Patient
Please paste here
Cardiology @ Referring hospital
Please paste here
Insurance
Please paste here
Cardiology @ AMC
Please paste here
Rehabilitation center @ referring hospital
Please paste here
Philips
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Family of patient
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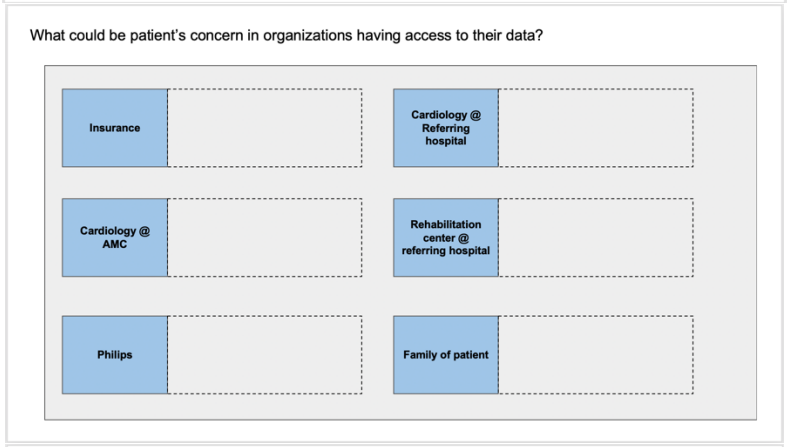
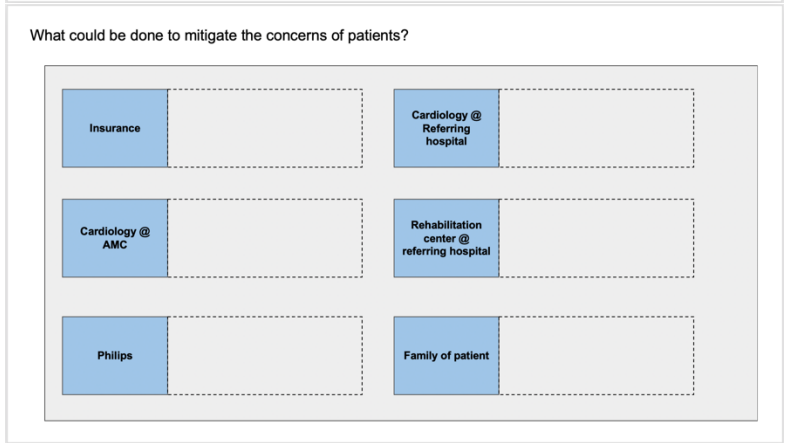
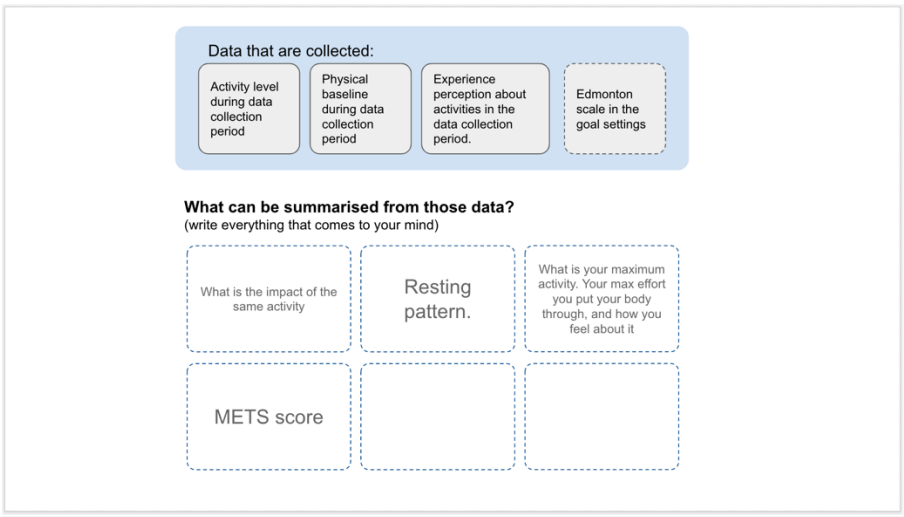
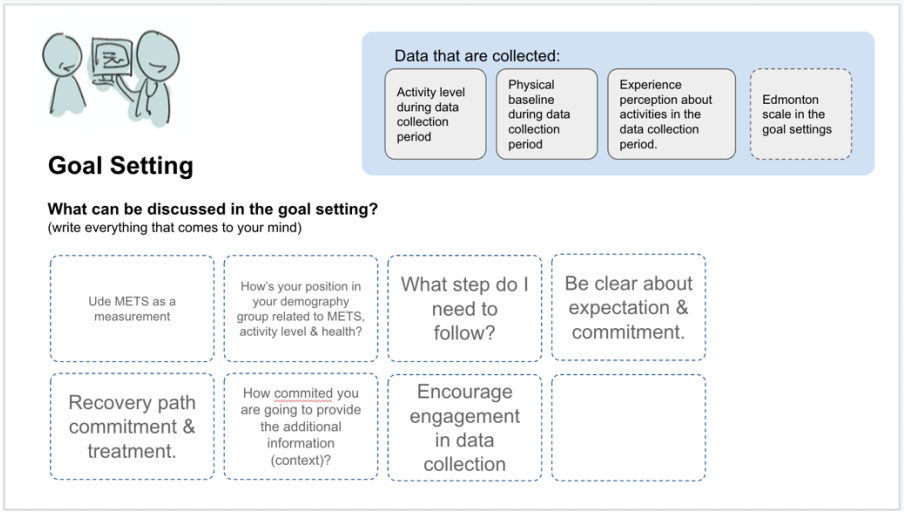

What could be patient's concern in organizations having access to their data?
Insurance
Cardiology @ Referring hospital
Cardiology @ AMC
Rehabilitation center @ referring hospital
Philips
Family of patient

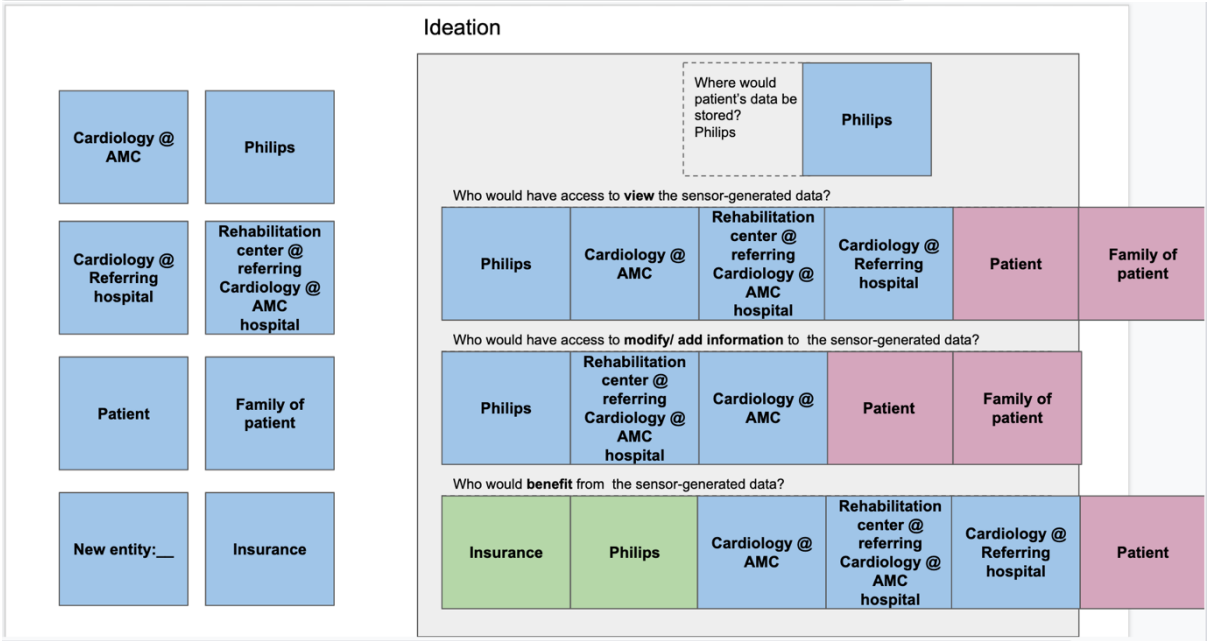

What could be done to mitigate the concerns of patients?
Insurance
Cardiology @ Referring hospital
Cardiology @ AMC
Rehabilitation center @ referring hospital
Philips
Family of patient

Appendix H: Concept Testing Result

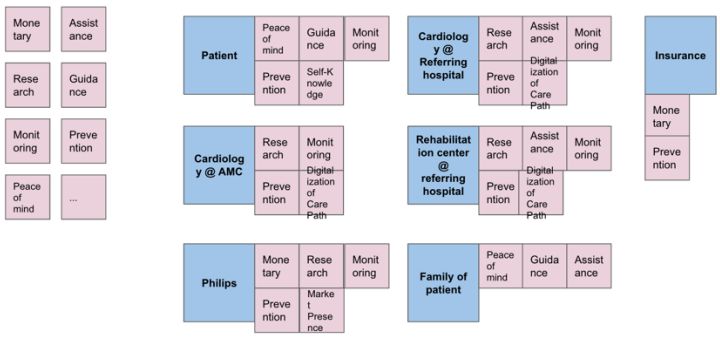
1. Data science researcher @ TU Delft



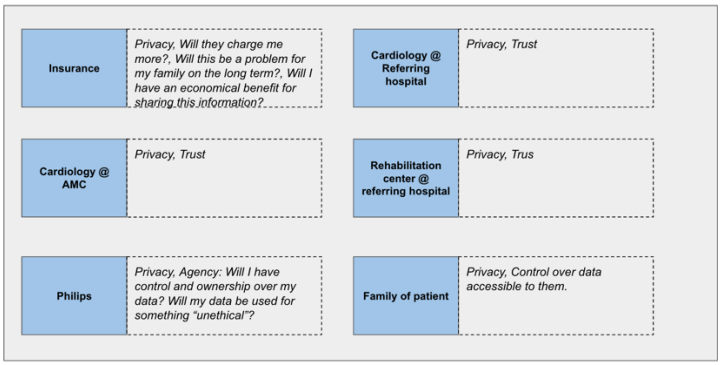




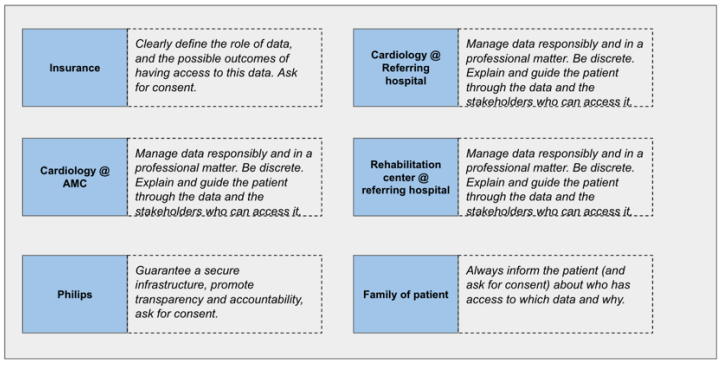
What are the benefit of having the patient's sensor-generated data for each stakeholders?



What could be patient's concern in organizations having access to their data?



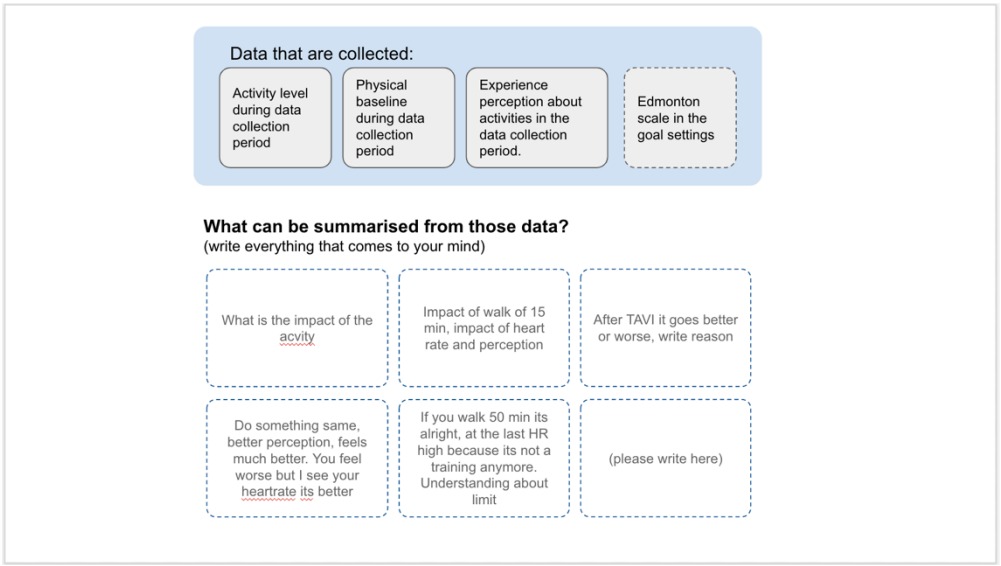
What could be done to mitigate the concerns of patients?

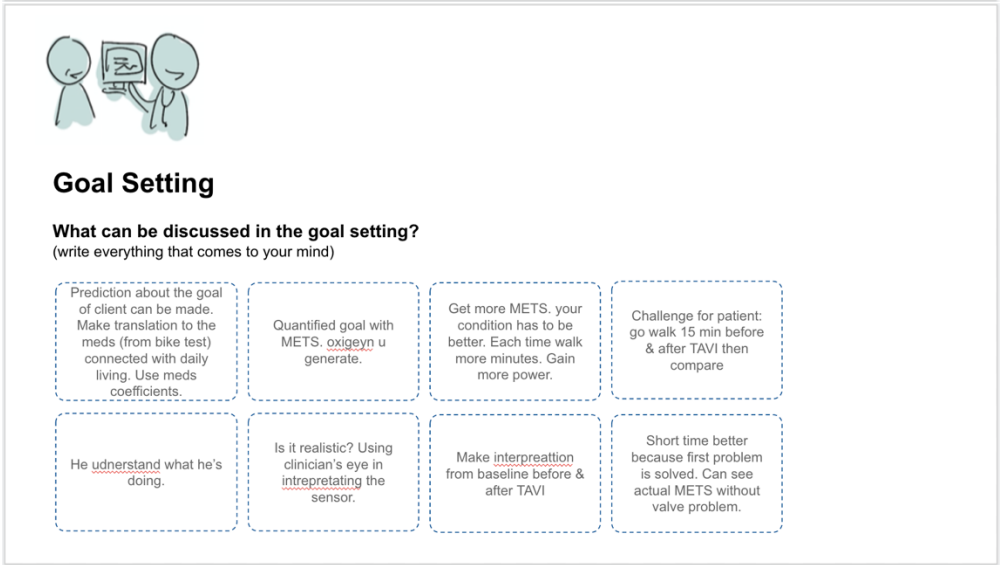


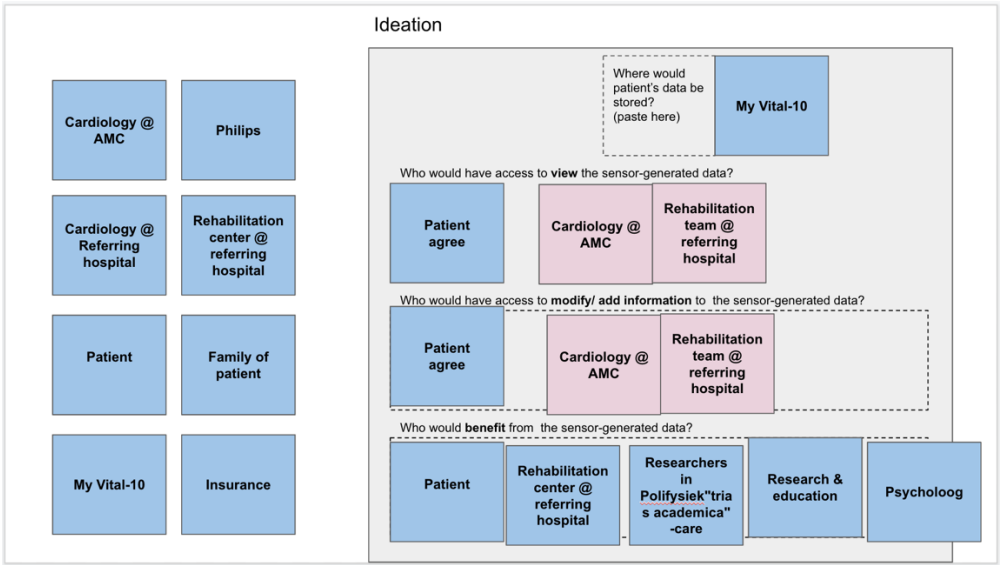
The role of data

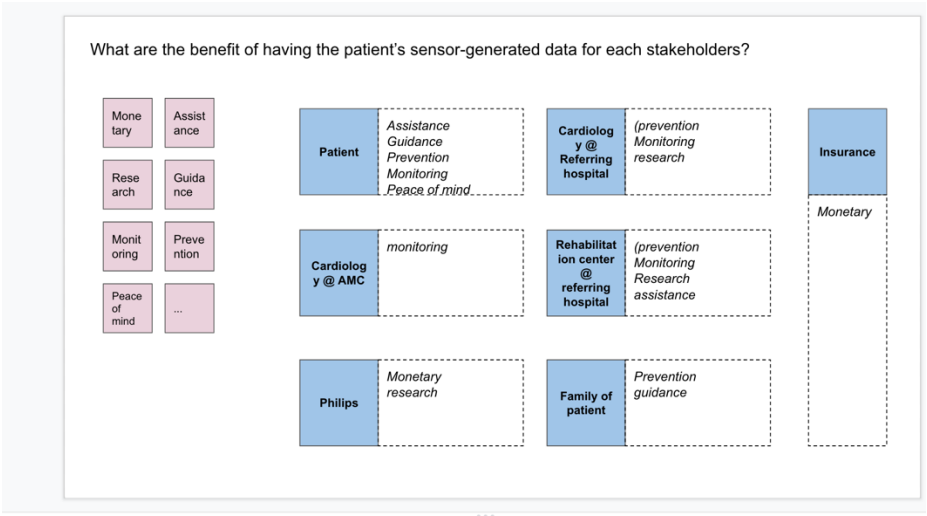
(METS scale) Knowledge about physical baseline. For both patient & clinician	~~Motivation~~ Activity tracking. For both patient & clinician.	~~Emergency~~ Give recommendation to patient. For clinician	~~Activity kinds~~
Physical activity level)accelerometer)	Differentiating 'active' activity level with 'exercising' activity level. to guide patient about the level of activity	Correlation between story and physical baseline.	ECG: how intense to your heart
ECG: how intense to your heart	Identify different kinds of exercise (walk, cycle, etc) to guide patient about the kinds of activity		Accelerometer
Patient story/ context	Correlated ECG with position. For example low heartrate but you know he's sleeping		

2. Physiotherapist

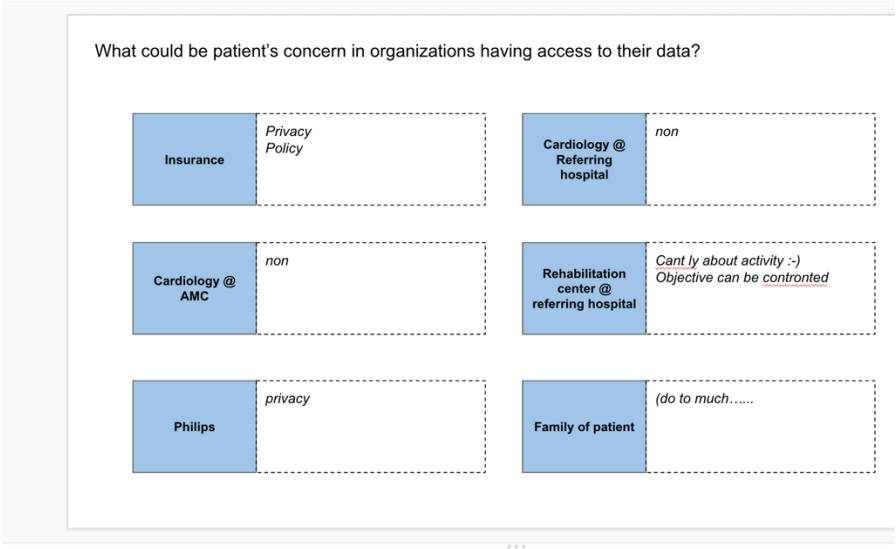








Talk with insurance, "please can you pay the tele-rehab because there is no other way. Then we get the price of the tele. Happen quick because of corona. Now they see the use of it and it works very well. It will be part of rehab. Now we want to do first 2 week 2 times, longer using teleguidance. The biosensor can be very useful for it."

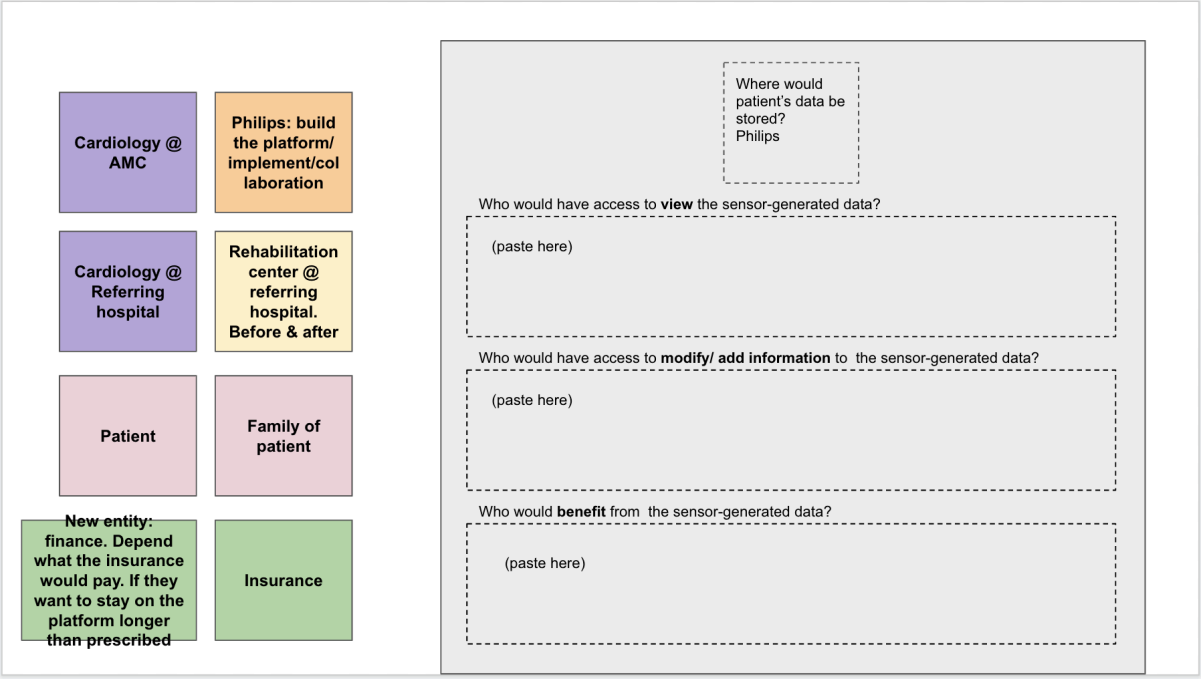


Insurance: not part of healthcare, why do they have to know my walk? Policy, more expensive bcs I walk less
Rehab: cant overgrade their activity. What they're hope to do often replace what they done.

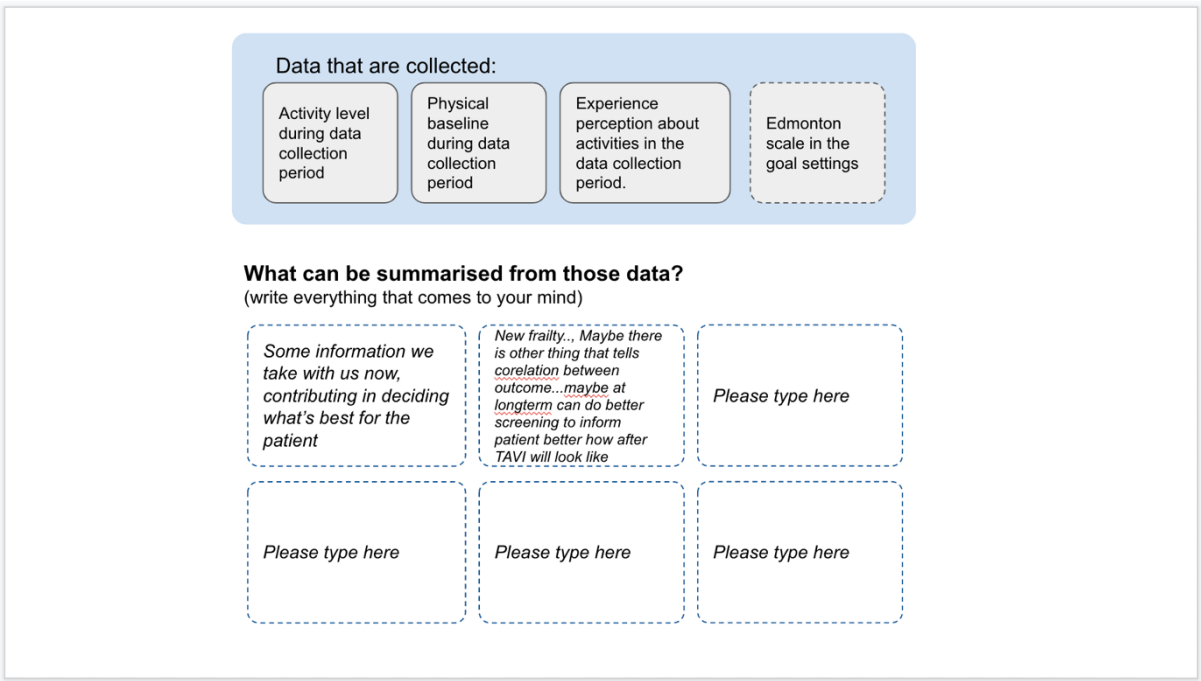
The role of data

Knowledge about physical baseline. For both patient & clinician	~~Motivation~~ Activity tracking. For both patient & clinician.	~~Emergency~~ Give recommendation to patient. For clinician
Physical activity level	Differentiating 'active' activity level with 'exercising' activity level. to guide patient about the level of activity	Correlation between story and physical baseline.
Respiratory Rate	Identify different kinds of exercise (walk, cycle, etc) to guide patient about the kinds of activity	
ECG	Correlated ECG with position. For example low heartrate but you know he's sleeping	
Patient story/ context		

3. Intervention Cardiologist



4. Specialist Nurse

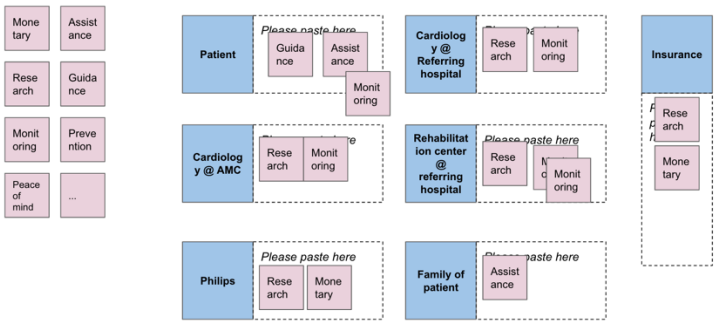


Goal Setting

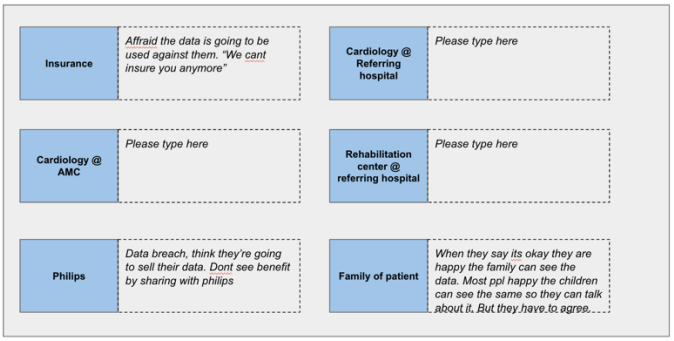
What can be discussed in the goal setting?
(write everything that comes to your mind)

Have somebody who know about physical activity	*Expectation is very important*	*"What do you want in life?" like in geriatrician's practice*	*"We think you can do more…"*
Talk about expectation	-	-	-

What are the benefit of having the patient's sensor-generated data for each stakeholders?



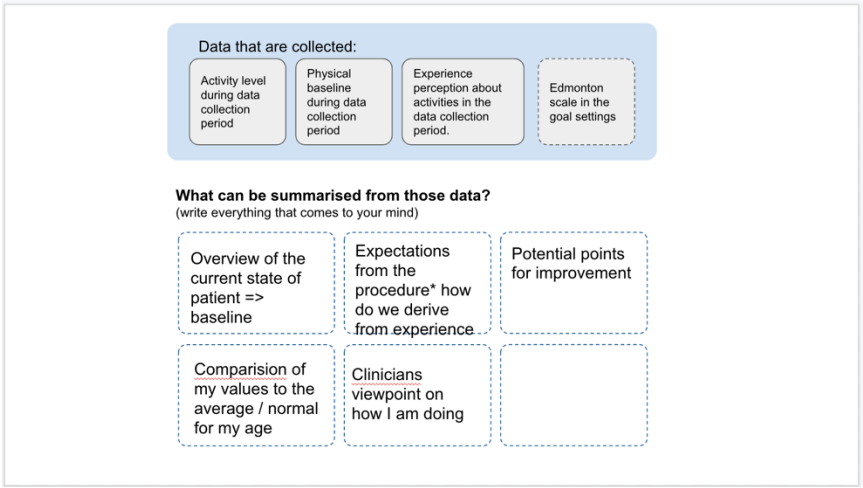
What could be patient's concern in organizations having access to their data?

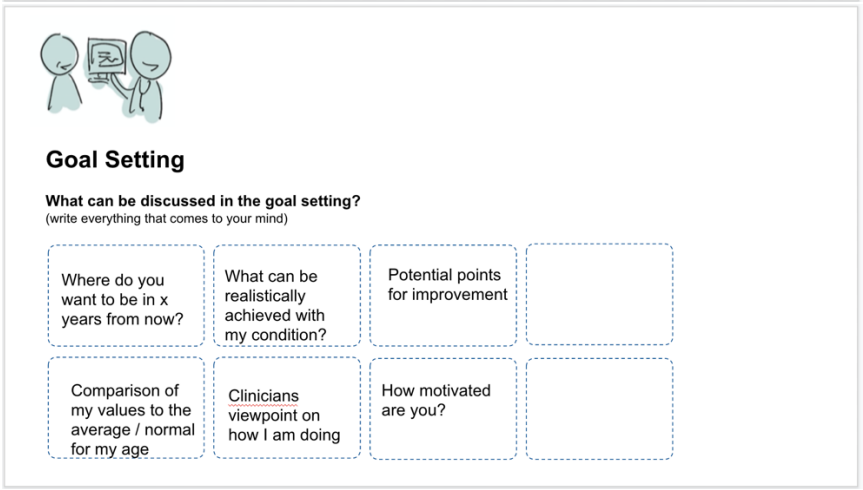


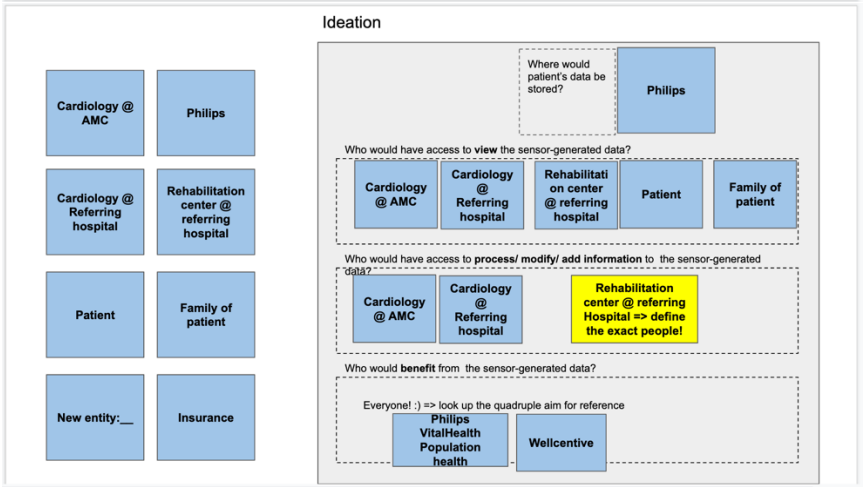
What information needed to understand these points?

Knowledge about physical baseline. For both patient & clinician	Activity tracking. For both patient & clinician.	Give recommendation to patient. For clinician
How much they exercise How long Relationship between complaint & what we measure (can press button when experiencing complaints)		

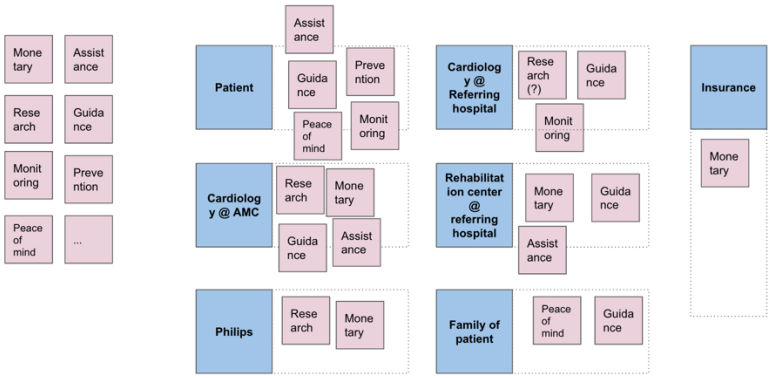
5. Data Designer







What are the benefit of having the patient's sensor-generated data for each stakeholders?



What could be patient's concern in organizations having access to their data?

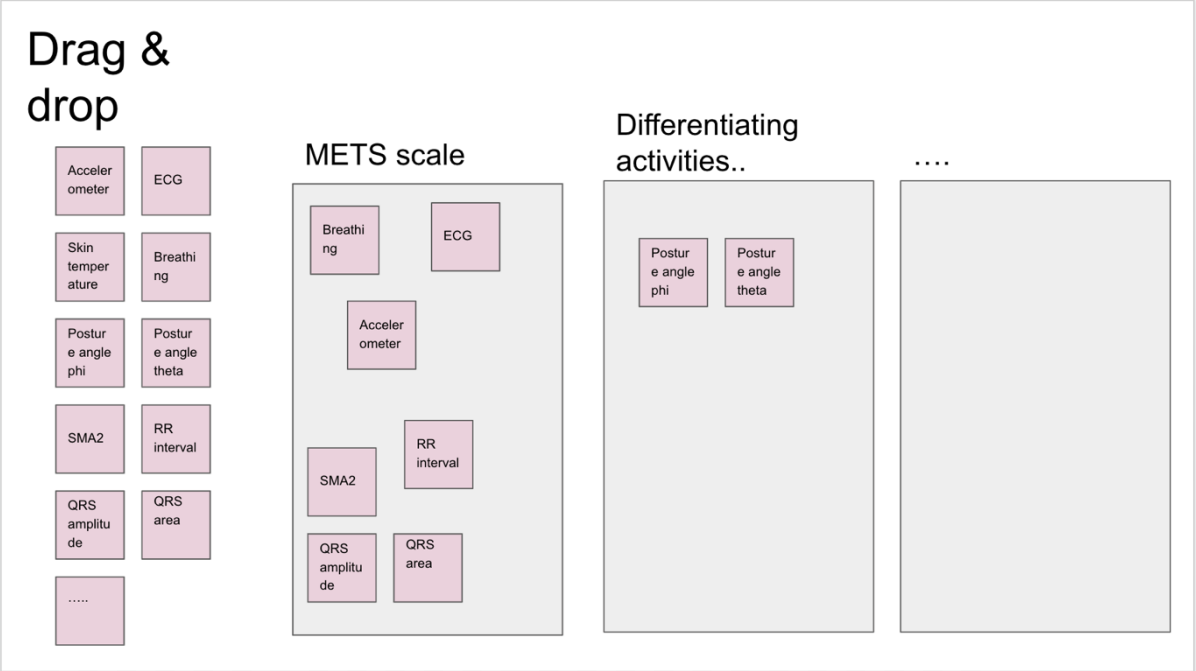
Insurance	Fees increasing / For my condition procedure is not free
Cardiology @ Referring hospital	If the benefits are well explained, no concern
Cardiology @ AMC	If the benefits are well explained, no concern
Rehabilitation center @ referring hospital	If the benefits are well explained, no concern
Philips	Why do they need access? What will they do with my data?
Family of patient	Now I will be controlled more / "Spied" on

What could be done to mitigate the concerns of patients?

Insurance	Explain what are the clear do's and don'ts with the data; make sure the company can be held responsible!
Cardiology @ Referring hospital	
Cardiology @ AMC	
Rehabilitation center @ referring hospital	
Philips	Challenge: explain that otherwise the service is not possible to provide; explain that we are getting access to population level / experience data and not on an individual level
Family of patient	Facilitate a discussion about what they want to see from each other and what absolutely not! Patient needs to be in the center to decide!

The role of data

(METS scale) Knowledge about physical baseline. For both patient & clinician	**~~Motivation~~ Activity tracking. For both patient & clinician.**	**~~Emergency~~ Give recommendation to patient. For clinician**	**~~Activity kinds~~**
Physical activity level (accelerometer)	Differentiating 'active' activity level with 'exercising' activity level. to guide patient about the level of activity	Correlation between story and physical baseline.	ECG: how intense to your heart
ECG: how intense to your heart	Identify different kinds of exercise (walk, cycle, etc) to guide patient about the kinds of activity		Accelerometer
Patient story/ context	Correlated ECG with position. For example low heartrate but you know he's sleeping		



Appendix I: Validation

IDE TU Delft Master Thesis Project
Concept Validation Session. 18 August 2020
Anindya Paramaarti (a.paramaarti@gmail.com)

LIVESENSE

Continuous & collaborative goal setting system for TAVI patient using sensor & experience data.

GOALS

1. Understanding in which part of existing pathway LIVEsense would bring value
2. Understanding how to adjust with the existing pathway
3. Reflection of Quadruple Aim
4. Understanding stakeholder's view about their role

METHOD:

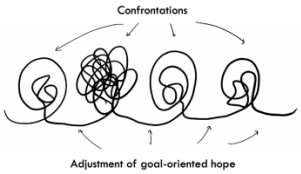
Part 1: Introduction (15 min)
1.1 Problem statement
1.2 Product concept of LIVEsense

Part 2 : Discussion
2.1 Integrating LIVEsense to existing care pathway (10 min)
2.2 The role of stakeholders in LIVEsense pathway (10 min)
2.3 Reflecting with quadruple aim (15 min)

Part 3: Summary (5 min)

PROBLEM STATEMENT

The overall experience of TAVI patients is managing confrontations in daily life by making constant adjustment of goal-oriented hope.



PERSONA

The highly restrictive

Patient who restrict himself from doing physical activity, mostly driven by fear of the possible impact of doing physical activity.

The imperfect explorer

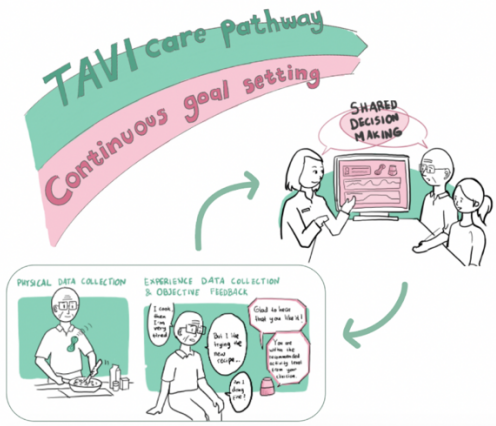
Patient who is more or less aware of his/her physical limitation and know how to adjust the goal.

The highly explorative

Patient who has a high expectation about own physical ability after TAVI.

LIVESENSE CONCEPT

Continuous & collaborative goal setting system for TAVI patient using sensor & experience data.



(PDF FILE)

(show the scenario file)

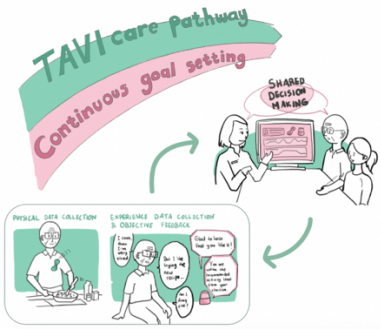
WHAT ARE THE BENEFIT OF LIVESENSE FOR:

1. Before TAVI period?
2. Right after TAVI?
3. Rehabilitation period?
4. Follow up after rehabilitation period?

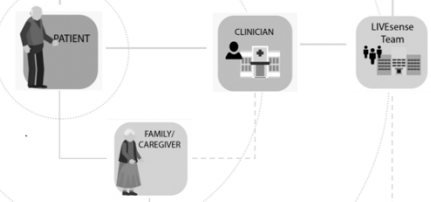
QUADRUPLE AIM REFLECTI(

What are the impact of LIVEsense toward…

1. Patient experience
2. Health outcome
3. Staff experience
4. Cost of care



THE ROLE OF STAKEHOLDERS



[5-10 minutes] Discussion:

1. What are the required expertise of the clinician?
2. Who will be in charge?
3. Which team/ dept?

Scratchpad note from the session:

Before & right after is unclear for patient what they can do, don't wait until rehabilitation days. Before tavi is good if we have uniformed thing to inform patient. Now too much info at once. After tavi not depending on gp, referral dll, patient can make own choice. Now its ending after tavi back to referral hospiral, not all of them offer program.
Between after tavi & before rehabilitation. Biggest gap.

1. Rehab start immediately instead of waiting. Get days earlier to back to his goal. High impact when you do few week very less. You never go back, muscle loose, condition loose. One week not exercising can lose muscle in a week. Loss of muscle,
2. should be clear who is responsible for the data. Is it clinician in amc, gp, referral h? in the beginning burden, but a lot want to invest. More work. So must be clear who is responsible,

start with small group of person who are enthusiastic about it. Because of corona people accept more of this innovation

3. Rehabilitation center has the best experience. Should be helpful for patient not from direct area can benefit from this. So can start in the hospital. Can bring the device to home. You will have a bigger group.
4. If start soon then it's from the hospital, then later taken over by the rehabilitation. About payment. Collaboration, very good start in hospital then go to rehabilitation. From 2nd line to 1.5 line.
5. Referral hospital? Period of staying in amc will be shorter. Patient is not open in their mind yet first few hours after tavi. There are 2-3 referral hospital who sent big patient group.
6. 2 week after discharge come to rehab.
7. Or at the beginning when they come for screening.
8. Has to be easy, not too much to people.