Appendix

Improving Shared Understanding with Hart

designing a telemonitoring smart care agent
to support transcatheter aortic valve implantation
patient care in perioperative journey

Winnie (Wei Ju) Chen

Supervised by
Prof. dr. Gerd Kortuem / Prof. dr. Maaike Kleinsmann

Glossary

Project brief

A - biosensor documentation

B - List of scanned website

C - Observations

D - Sensitising probe

E - Interview questions and highlights

F - Impression of analysis process

G - TAVI perioperative journey

H - Stakeholder interview with Philips

I - Impression on storyboarding

J - Others

Explore the details of the final design concept:

https://miro.com/app/board/o9J_knEK6aM=/

Project brief

DESIGN FOR our future

TU Delft

IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT
Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME
Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy".
Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name: Chen
initials: W.J. given name: Wei Ju (Winnie)
student number: 4919114
street & no.:
zipcode & city:
country:
phone:
email:

Your master programme (only select the options that apply to you):
IDE master(s): ( ) IPD (★) DfI ( ) SPD
2nd non-IDE master:
individual programme: - - (give date of approval)
honours programme: ( ) Honours Programme Master
specialisation / annotation: ( ) Medisign ( ) Tech. in Sustainable Design ( ) Entrepeneurship

SUPERVISORY TEAM **
Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair: Gerd Kortuem dept. / section: IoT
** mentor: Maaike Kleinsmann dept. / section: MOD
2nd mentor:
organisation:
city: country:

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..

Second mentor only applies in case the assignment is hosted by an external organisation.

comments (optional): This graduation project is in collaboration with TU Delft CardioLab, Philips Research and the cardiology department of the Amsterdam UMC.

Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

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Procedural Checks - IDE Master Graduation

APPROVAL PROJECT BRIEF
To be filled in by the chair of the supervisory team.

chair Gerd Kortuem date 4 - 4 - 2020 signature

CHECK STUDY PROGRESS
To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair.
The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: _____ EC
Of which, taking the conditional requirements into account, can be part of the exam programme _____ EC
List of electives obtained before the third semester without approval of the BoE

( ) YES all 1st year master courses passed
( ) NO missing 1st year master courses are:

name date - - signature

FORMAL APPROVAL GRADUATION PROJECT
To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **.
Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: ( ) APPROVED ( ) NOT APPROVED
Procedure: ( ) APPROVED ( ) NOT APPROVED
comments

name date - - signature

extended to September 7th
due to COVID-19 pandemic

Personal Project Brief - IDE Master Graduation

TU Delft

Design shared understanding for AS care path via sensor telemonitoring — project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 25 - 03 - 2020 — 21 - 08 - 2020 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

In the aging society, aortic valve stenosis (AoS) is a prevalent progressive heart disease, where a narrowing aortic valve restricts the blood flow and can eventually lead to heart failure [1]. In severe cases, AoS patients are being admitted to Transcatheter Aortic Valve Implantation (TAVI) as a less invasive replacement treatment.

This thesis looks into the Philips biosensor, a wearable device that collects vital signs (like heart rate, respiratory rate and posture data) for a non-intrusive and ambulatory care [2]. With the use of wearable biosensor and the collected data, data-driven design interventions will potentially improve the AoS patient-doctor relationship. The end goal of the project is to mitigate healthcare burden and enhancing patient's quality of life.

In a previous TELE-TAVI study [3] from Amsterdam UMC and Twente University, the reliability and physical usability of the wearable device is examined. However, an overview of the care journey, exploration of possible solutions and understanding the meaning of the sensor data for different actors are lacking.

With the above in mind, this project aims to understand the barriers/enablers of shared understanding of different actors in AS care path and generate near-future design concepts to improve shared understanding in telemonitoring solutions

Supervised by Prof. dr. Gerd Kortuem and Prof. dr. Maaike Kleinsmann, the design researcher will be graduating within TU Delft CardioLab. Collaborate with Phillips Research and Amsterdam UMC will be established to generate supportive insights from both academic and practical perspectives.

References:
[1] "Aortic stenosis overview". Retrieved on Jan 09, 2019 from American Heart Association https://www.heart.org/en/health-topics/heart-valve-problems-and-disease/heart-valve-problems-and-causes/problem-aortic-valve-stenosis
[2] "Phillips Wearable Biosensor". Retrieved on Jan 09, 2019 from https://www.usa.philips.com/healthcare/clinical-solutions/early-warning-scoring/wireless-biosensor#!
[3] "The Philips wearable biosensor in transcatheter aortic valve implantation treatment workflow. Usability and feasibility of the wearable biosensor." Braem, C.I.R (2019)

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introduction (continued): space for images

image / figure 1: Phillips Wearable Biosensor for Vital Signs. Source: https://www.usa.philips.com/healthcare/clinical

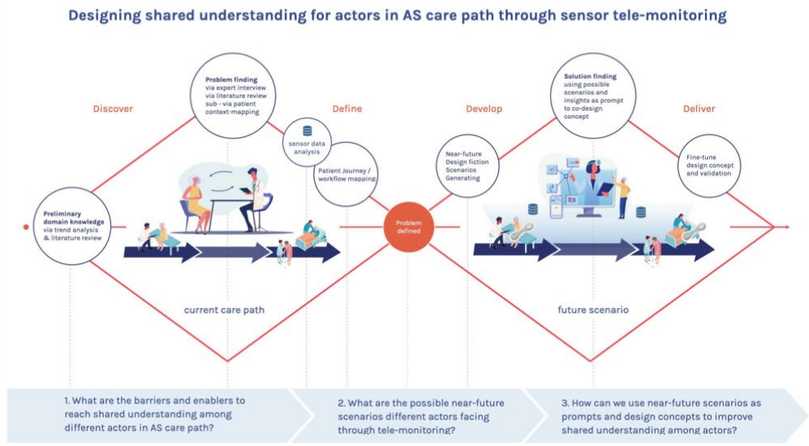

image / figure 2: Overview of Design Approach.

Personal Project Brief - IDE Master Graduation

TU Delft

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

This project focus on the perioperative care path of AS. The actors involved including the AS patients, caregivers (such as peer/partner/family), medical teams (such as AUMC), and sensor technology providers (Philips).

Empathising the current unique situation of COVID-19 and preliminary findings from stakeholder interviews, patients can be out of reach due to extreme pandemic measures, difficulty in traveling or personal reasons. Such lack of inclusiveness is a threat for delivering quality of care. By incorporating sensor technology for telemonitoring could potentially build a more inclusive care path for both patients and medical care teams.

However, the challenge of remote communication is to come to a shared understanding among different actors.

From medical team/sensor technology provider point of view:
A shared understanding of patients through collected data is essential for improving quality of care.
The collected functional/emotional data represents the health status of the patient for pre-surgery frailty assessment and enables medical staffs to remotely track post-operative recovery progress in reality.

From AS patients/caregiver point of view:
A shared understanding between the medical team and AS patients/caregivers is critical for improving quality of life.
Current patient-doctor communication highly relies on single face-to-face touch-points. Telemonitoring enables patient to engage in more inclusive, personalised care plan.

To conclude, how would different actors understand and respond to the telemonitoring remains largely unknown.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, … . In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

This project aims to understand the barriers/enablers of shared understanding of different actors in AS care path and generate near-future design concepts to improve shared understanding in telemonitoring solutions

How would different actors understand and respond to the telemonitoring is largely unknown, hence, this graduation project aims to (1) understand the barriers/enablers of shared understanding of different actors in AS care path and (2) generate near-future design concepts to improve shared understanding in telemonitoring solutions

The following sub research questions will be answered in each design stage:
1. What are the barriers and enablers to reach shared understanding among different actors in AS care path?
2. What are the possible near-future scenarios different actors facing through telemonitoring?
3. How can we use near-future scenarios as prompts and design concepts to improve shared understanding among actors?

Initials & Name W.J. Chen Student number 4919114

Title of Project Design shared understanding for AS care path via sensor telemonitoring

Personal Project Brief - IDE Master Graduation

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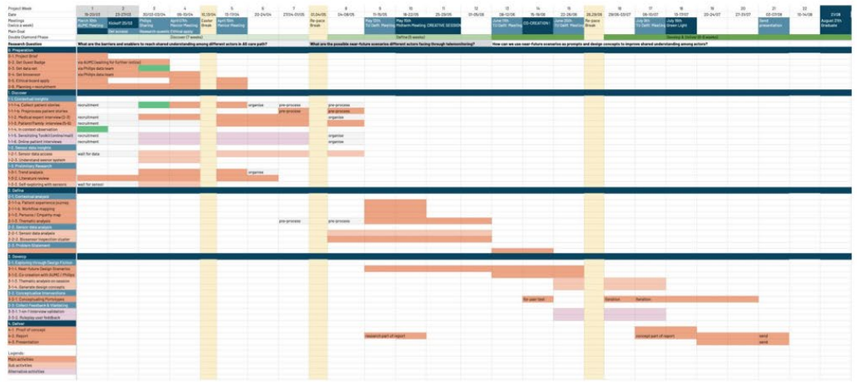
PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 25 - 3 - 2020 21 - 8 - 2020 end date



* View Online Gantt Chart: https://tinyurl.com/r8xalyr

The project will kick off on 25th of March and aim to end on 21st of August.
Following the double diamond design approach, the research questions are answered through the following stages:

For the problem-finding phase, (1) Experts/Stakeholder interviews and (2) literature review on topics of tele-monitoring experience would be understanding the barriers and enablers to reach shared understanding among different actors in AS care path.
The limitation of this phase is the access to hospital and patients, which as alternative, hence patient insights would be distilled from experts and literature review. However, depending on the pandemic situation, (3) Patient interviews with context-mapping would be conducted to generate richer findings.

For the solution-finding phase, I plan to use near-future scenarios as a prompt to co-design possible solutions with stakeholders. (4) Insights analysed from previous finding and (5) findings from sensor data analysis will help to create a scenario worth discussing. (6) Feedbacks from the co-creation session will be extracted to conceptualise an intervention to improve shared understanding.
The limitation of this phase is due to the measurements, the feasibility to experiment on different storytelling techniques may be restricted (i.e. no video filming) and the researcher may need to seek alternative ways to facilitate co-creation session with AUMC and Philips. Exploration of online tools and stakeholder communication will be done to achieve ideal outcome.

Initials & Name W.J. Chen Student number 4919114

Personal Project Brief - IDE Master Graduation

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MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... Stick to no more than five ambitions.

My future career goal is to work with complex systems and make meaningful impacts through design.

Regarding of personal motivation, I understood the topic of "Designing shared understanding for different actors in AS care path via sensor telemonitoring" requires the ability to analyse the complexity of healthcare regiment. The research assignment in near-future allows me to experiment using design ficiton as a research tool to co-create possible solutions. Furthermore, graduating in a trying time of COVID-19 pandemic outbreak also challenges my skills as a designer to think creatively and positively.

I believe from previous courses such as "Context and Conceptualisation", "User Experience and Usability Assessment Design", "Design for Emerging Market" have prepared me for fundamental knowledge as an interaction designer. My project experience including "re-designing Sunrise medical's electrical wheelchair joystick module interaction for future elderly users", "designing a ADL platform for autistic kid patient, parent, and therapist", " contextual analysis for laparoscopic surgeries in LMICs" have equipped me to take on complex research challenges in healthcare context.

Last but not least, I am thrilled to have the opportunity to co-work with my chair Gerd Korteum, my mentor Maaike Kleinsmaan, medical team from AUMC, and the Philips data team. Each one of them are respectful experts in their own fields and I expect myself to humbly learn fom them. Recalling my first touching point of data-enabled design, it started from working with TG3D Studio to explore the use of 3D body scanning technology in fitness and rehabilitation segment. In continuation of the design path, I proactively joined ThingsCon IoT conferences and join courses as "AI and Society" to seek inspirations. This graduation will be a great opportunity to further expand my experience towards data-enabled design.

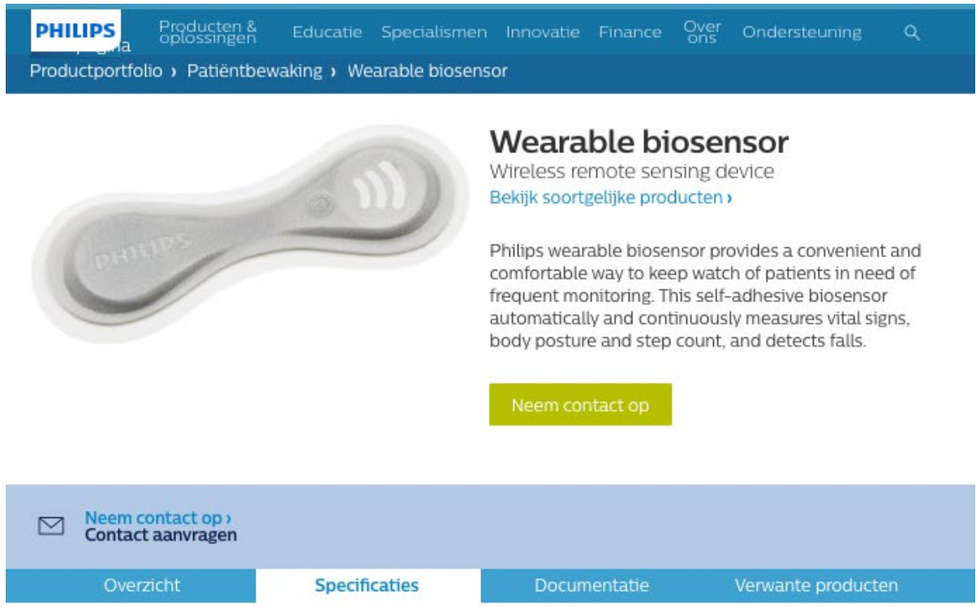
FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Initials & Name W.J. Chen Student number 4919114

Title of Project Design shared understanding for AS care path via sensor telemonitoring

A - Biosensor documentation



Technische specificaties

Sensor technology			
ECG electrodes	Detects heart rate	3-axis MEMS accelerometer	Detects motion
Thermistor	Detects skin temperature		
Form factor			
Size	1mm x 36mm x 8mm	Weight	12g, with integrated sensor module
Adhesive			
Gentle Grade	Silicone adhesive, recommended for low activity, low perspiration and low humidity levels	Active Grade	Hydrocolloid adhesive, recommended for moderate to high activity, moderate perspiration and moderate humidity levels
Battery			
Type	Zinc air battery (disposable with device)	Life	Up to 4 days

[1] The coverage area is the line of sight within 33 feet (10 meters) of the relay device. Beyond the coverage area, the patient needs to carry the relay device in a pouch for continuous or frequent measurement.

Screenshot from https://www.philips.nl/healthcare/product/HC989803196871/wearable-biosensor-wireless-remote-sensing-device/specificaties, accesssed on March 25th, 2020.

Detailed raw data collected are reference from <The Philips wearable biosensor in transcatheter aortic valve implantation treatment workflow Usability and feasibility of the wearable biosensor> (Braem, 2019, Chapter 3)

B - List of scanned website

Hartstiching
https://www.hartstichting.nl/verhalen

HARTPATIËNTEN
https://www.hartpatienten.nl/

Harteraad
https://harteraad.nl/ervaringsverhalen/

BHF HealthUnlocked
https://healthunlocked.com/bhf/posts/136175899/introducing-our-heart-stars

QuantifiedSelf
https://quantifiedself.com/show-and-tell/?topic=39

Mended Heart
https://mendedhearts.org/

Aortic Hope
https://www.aortichope.org/new-blog

Women Heart
https://www.womenheart.org/blog/

American Heart Association
https://supportnetwork.heart.org/

Care for your heart HK
https://www.careheart.org.hk/?page_id=85

Share my health journey
https://www.sharemyhealthjourney.com/post/zach-g-story

Facbook groups:
Aortic Valve Replacement Group
UK Aortic Valve Replacement Group
Aortic Stenosis (support group and meeting place)
Heart Disease Support Group
Heart Valve Surgery Support Group
Heart Disease - information and discussion
Heart Disease Survivors Support Group

Youtube TAVI patient stories:
https://www.youtube.com/results?search_query=Aortic+Valve+Stenosis+patient+story
https://www.youtube.com/results?search_query=TAVIpatient+story

C - Obeservations

Pre-surgery group information session

A visit is paid to Amsterdam UMC and a patient group session is being observed. The observation started from following the specialist nurse leaving the heart team meeting room, preparation and full participation in the patient group session. After the session, unstructured interviews were done with a TAVI specialist nurse and a researcher.

Main impressions and discoveries from the observation are presented as follows: participants, procedures, artifacts, and roles of medical staff.

PROCEDURE

The aim of holding a patient group session is to provide TAVI-related information to the patients. The session is held in between a full day check-ups (such as CT Scan, ECG, and polyclinic). The whole group session lasted an hour with slide presentations. At the end of the session, 1-on-1 consultation was provided.

A discovery from the procedure is **with the long length and large amount of information given, it is hard for the patients to absorb all.** During the follow-up interview with the specialist nurse, they mentioned a TAVI patient folder is given to the patients at the end.
If more information is desired, the patient can consult in the polyclinic or reach the heart team via phone calls.

PARTICIPANTS

Eight groups of patients were present, aged between 70 - 90, mostly accompanied by their family member, partner or caregiver. Learnt from the specialist nurse, the patients are brought to the group session room from 2nd floor heart department by the receptionist in between their check-ups.

Patient's interaction and energy level are being observed, of which following findings are noted:

1. **Energy level drops** in the middle of the presentation, which the Patients seemed to be too exhausted keeping up with a long presentation.

2. **Accompaniment of the family member or partner is important as a support.** For example, at the end of the group session, the family members leaned in to help communication between patients and medical staff by giving supplementary information observed in patient's daily life.

3. Interaction in groups is valuable. Patients showed keen interest to hear what are the similar questions others have in mind.

ARTIFACTS

A tangible heart model and an artificial valve model were displayed as supplementary education material. At the end of the session, the information was given to the patients in the form of paper leaflets. It is important to **keep in mind the level of digital literacy and ensure readability** for the patients.

Figure 12
A snapshot of the observed group information session.

ROLES OF MEDICAL STAFF

Five medical staff, including four specialist nurses and one researcher, were responsible for the group session. From unstructured interviews, the importance of this gathering was emphasised. For instance, one specialist nurse pointed out **this is the first touchpoint both medical staff and patients meet in person,** since most of the TAVI patients are referred from outpatient hospitals. **Information giving is not only practical, but to manage expectation and ease anxious feelings.**

" It is important that after the surgery, the patients return to their healthy life rhythm. Some patients think after the surgery they cannot move at all and take their pajamas planning to stay in the hospital bed all day... this is not good for them. It is important to let them know what they can do. "

- Specialist nurse, 2020

Post-surgery online group rehabilitation coaching session

A remote rehabilitation session was observed (figure 12). Due to the strict measures of COVID-19 pandemic, CardioVitaal has been delivering remote exercise session to provide rehabilitation care. The unique situation provided an opportunity to understand how the trainers and patient interact remotely in their home environment.

The whole exercise session lasted for an hour and divided into three parts. Within each part, the instructor gave a set of physical activities with gradually increased intensity (figure 11). Two physical trainers (one as instructor/another as observer) and three patients participated. Main impressions and findings are discussed.

FINDINGS

1. Trainer's role in teleconsultation

The trainer **constantly switched between the role of a guide and an evaluator** in the remote rehabilitation:

- After every session, the trainer asked participants to evaluate how they rate themselves on the BORG scale. The rating is compared with participant's observed status (amount of sweating, perceived tiredness).
- However, in order to demonstrate the moves with the whole body visible, the trainer was facing side direction and far away from the screen, which makes it difficult to evaluate at the same time. In the observed case, **a second trainer is present as an observer** to assess the patient's status.

In some situation, trainers **also took the role as a facilitator to ensure the remote session runs smoothly**:

- Some challenges came from set-up of the screen. For instance, when performing moves in a lower position, patients cannot view the screen properly; likewise, the instructor is not able to see participants' leg movements.
- To overcome the challenge of visual blind spots, the instructor demonstrated both the correct / wrong way, and continuously asked how the patients are feeling for feedback.
- One of the participants found himself struggling with balancing moves. Together with the trainer, they creatively arranged some chairs as support which can be used for daily training.

2. Educating on physical performance

After each exercise session, the BORG scale (Borg, 1982) is used to allow participants subjectively evaluate their level of exertion (figure 13). At the end of the session, a traffic light model is also introduced to educate patients how to safely exercise on their own (figure 14).
In the cases of TAVI rehabilitation, the Katz Index of ADL is another matrix more likely to be used, which will be discussed in detail in chapter 4. exploring the meaning of data.

An interesting finding is the emphasis on educating the patients to self-evaluate their own training. The **self-evaluation criteria not only assesses physical activity performance (i.e. duration, intensity, energy expended), but also the perceived safety to engage in exercion (i.e. sweating, feeling of breathe, subjective tiredness).** For instance, the following shows conversation when the instructor is explaining how to use traffic light model to the patients:

" I: Okay first at green light, it is okay to have an increased heart rate, to sweat and to breathe faster, and feel a bit tired.
P1: What does it mean an increased heart rate?
I: Well that's different for everybody. You are not always able to measure it. But we look at you guys and we ask you at which BORG you are and react to that. "

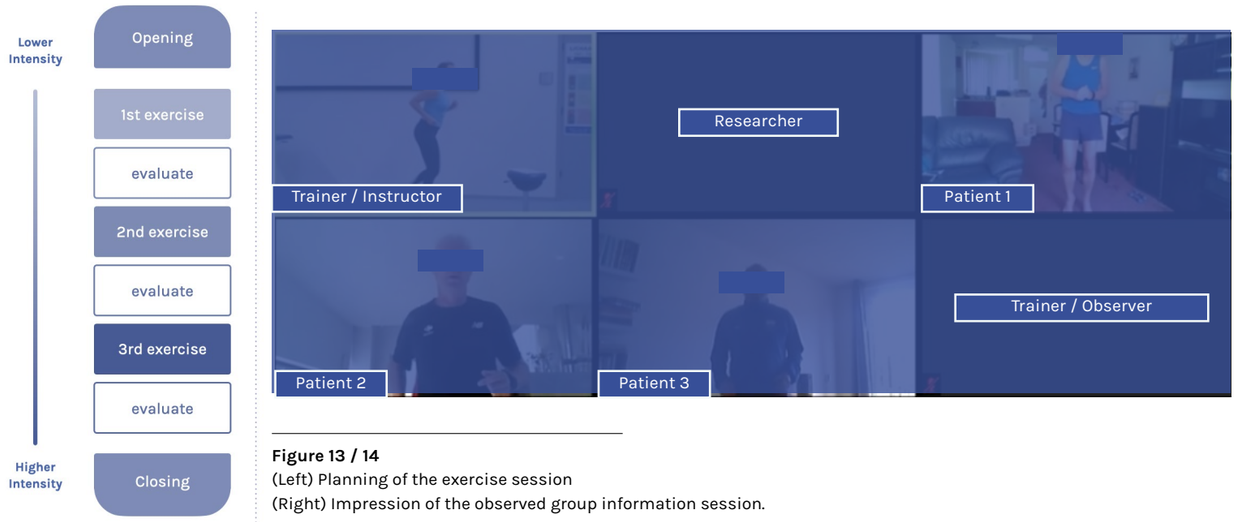


Figure 13 / 14
(Left) Planning of the exercise session
(Right) Impression of the observed group information session.

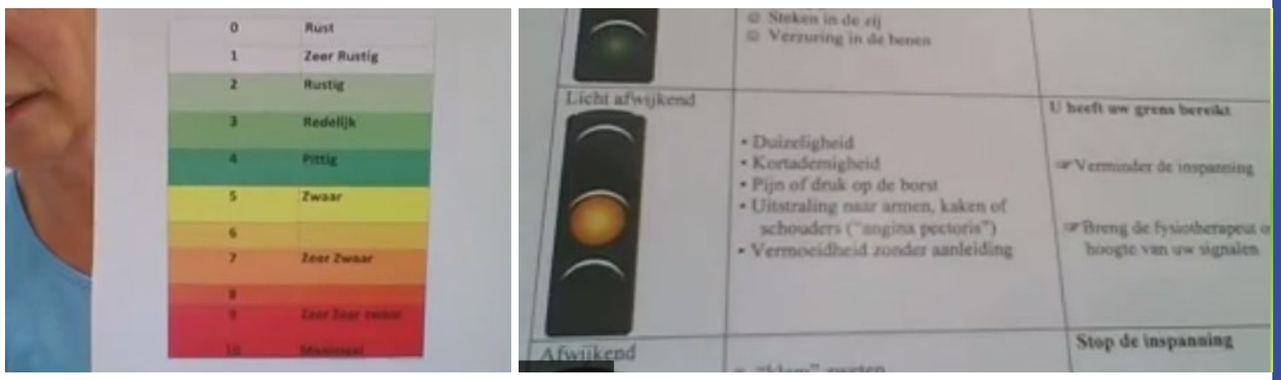


Figure 15 / 16
(Left) The physical trainer asking patient's to self-evaluate perceived exertion level according to the BORG scale
(Right) The physical trainer educating patient's to reflect base on the traffic light model

Self-evaluation tools such as the traffic light model was introduced for patients to self-reflect on what they can take on. Instead of having patients worrying about having a measuring device available at reach and interpreting their vital signs, it is more important to develop a habit of a healthy lifestyle and enjoy the exercise safely.

3. Involvement of family/partner

From the conversation, the patient's family or partners were also involved in daily exercises. The topic is also resonated among the other patient:

" P3: ...I'll make sure I exercise enough.
I: Yes and also cycling outside?
P3: No, not yet.
I: Is there an obstacle?
P3: Well, it was during a run that I passed out and they had me resuscitated, so my wife doesn't allow me to go outside on my own. She or a buddy of mine always needs to accompany me. ...
P2: ... I am also familiar with the story about the wife that doesn't agree with you walking individually. I am also not allowed.
I: Oh okay, you too? well let's start exploring it together, step by step..."

The participation of the patient's family or partners could give sense of secure and social support by accompanying the patient. However, it also posed a second opinion on the daily exercises.

4. Personalised goal-setting

Since the patients interact with different trainers bi-weekly, the session opens up with updates of each patient. Questions including blood pressure, heart rate, how the patient is feeling and exercising in the previous week are asked.

Personalised goal-setting is different from a fixed-structured fitness menu. The goals surround what would the patient want to achieve in the following week? How can they reach their goal that can fit their daily life? Patient's physical capability and routine is taken into consideration. For instance, one of the patients is fasting during the rehabilitation, which he contacted the dietitian and cardiologist to ensure he is participating in good health. The following is another patient's back and forth consultation with the trainer:

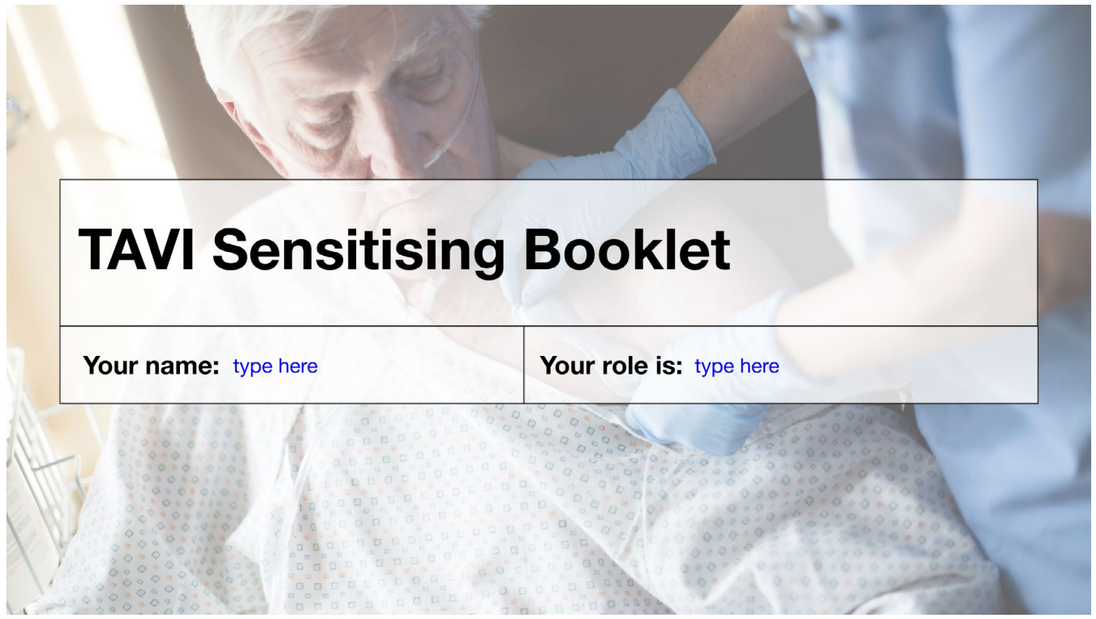
P2: Yeah, but I have a motoric deficit anyway. I have never been good at keeping my balance. If I run on a straight path I will fall down. That has been the case for my whole life now.
I: Okay, that is fine. For the steps to the side, you can always use a chair to hold yourself. So make sure there is one you can use. You can do it your own way since you know the best.

Cardiac rehabilitation centers in the Netherlands mostly follows the KNGF Guideline Cardiac Rehabilitation (2017).

goal	final outcome	evaluation instrument	when
1. exploring one's own physical limits	Patient is aware of their own physical limits, i.e. they know what level of exertion is possible.	• ask for 5 most problematic activities (PSC) • ask patient to carry out problematic activities and score for duration and quality, and possibly on the Anxiety and/or Angina and/or Dyspnea scales • score using Borg RPE scale (6–20) for fatigue and dyspnea • monitor heart rate and blood pressure if indicated by physician	at start and end of rehabilitation and / or exercise program monitoring heart rate, measuring blood pressure and scoring on Borg RPE scale before, during and after each session
2. learning to cope with physical limitations	Patient can cope with physical limitations.		
3. optimizing exercise capacity	Exercise capacity is at optimum or target level for this patient.	**by physician** • maximum or symptom-limited exercise test (or in very exceptional cases SWT) plus Borg RPE scale (6–20); possibly scoring Anxiety, Angina and/or Dyspnea scales **by cardiac rehabilitation coordinator** • subjective physical score on KVL-H questionnaire	maximum or symptom-limited exercise test at start and end of exercise program
	Functional exercise capacity is at optimum or target level.	**by physical therapist** • as for goals 1 and 2 • SWT or 6MWT • possibly MET list and/or SAS	at start, every 4 weeks and at end of exercise program
4. diagnostic	Patient's physical condition and trainability are clear.	• as for goal 3 • scoring on Borg RPE scale (6–20) before, during and after exercise	continuous monitoring during rehabilitation process
5. overcoming fear of physical exertion	Patient is no longer afraid of exertion.	• history-taking and observation • questionnaire: see *Multidisciplinaire Richtlijn Hartrevalidatie 2011* (www.nvvc.nl) (in Dutch)	at start and end of rehabilitation and/or exercise program
6. developing an active lifestyle	Patient has adopted a physically active lifestyle.	• history-taking (motivational interviewing) • *Monitor Bewegen en Gezondheid* (www.tno.nl) (in Dutch) • post-rehabilitation activities started	at start and end of rehabilitation and/or exercise program
Focal points			
acquiring information about secondary prevention	Patient is familiar with secondary prevention	• checklist for risk factors / unhealthy behavior • Phase III activities started	at start and end of rehabilitation and/or exercise program
goals of relaxation program	Patient is familiar with the relaxation program and is able to relax.	• evaluation list • using a flowchart: see *Verantwoording en Toelichting* (review of the evidence), section A.3.3 (in Dutch) (www.kngfrichtlijnen.nl)	at interim and final evaluation of rehabilitation and / or relaxation program

Borg RPE scale = Borg Rating of Perceived Exertion; KVL-H = Kwaliteit van Leven vragenlijst voor Hartpatiënten (Dutch quality of life questionnaire for heart patients); 6MWT = 6-Minute walking test; MET = metabolic equivalent of task; PSC = Patient-specific complaints; SAS = Specific activity scale; SWT = Shuttle walk test.

Figure 17
KNGF guideline cardiac rehabilitation, 2017



TAVI Sensitising Booklet

Your name: type here

Your role is: type here

Dear participant,

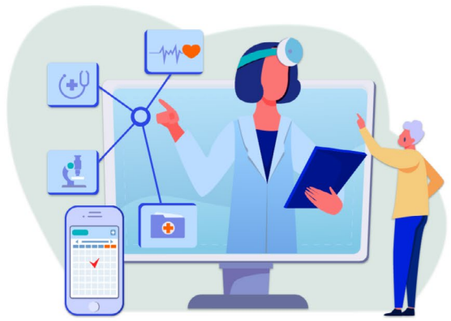
We are Winnie and Nindy, graduate researchers in TU Delft CardioLab. Our research goal is to “Designing TAVI Care Pathway toward Full Recovery using Biosensor” and “Designing shared understanding with data among actors in TAVI care path.”

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

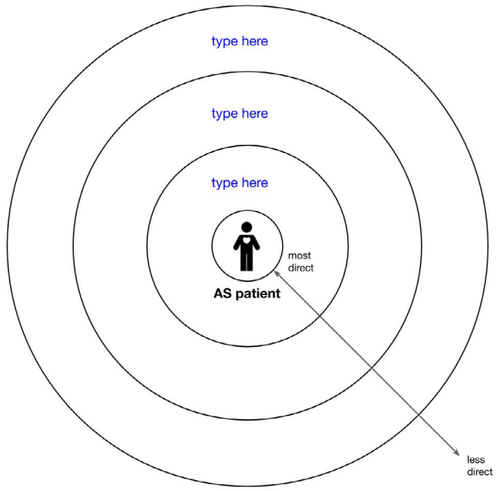
anindyaparamaarti@student.tudelft.nl
w.chen-18@student.tudelft.nl



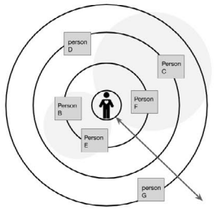
01 Could you share what are the main tasks you’re responsible for?

task 1	task 2	task 3
you can explain in drawings and put the picture here	you can explain in drawings and put the picture here	you can explain in drawings and put the picture here
type here	type here	type here

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

type here

your emotions

type here

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

type here | type here

type here | type here

scenarios communicating with your patients

type here | type here

type here | type here

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? Type here ...	What do you think needs to be improved on this step? Type here ...
How do you think Biosensor could help in this step… Type here ...	How do you think Biosensor could help in this step… Type here ...
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? Type here ...	How would you use the information from the checked sensors? Type here ...
Why? Type here ...	Why? Type here ...
What else you would like to know about the patient that are not currently in the sensor's features? Type here ...	What else you would like to know about the patient that are not currently in the sensor's features? Type here ...

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? Type here ...	What do you think needs to be improved on this step? Type here ...
How do you think Biosensor could help in this step… Type here ...	How do you think Biosensor could help in this step… Type here ...
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? Type here ...	How would you use the information from the checked sensors? Type here ...
Why? Type here ...	Why? Type here ...
What else you would like to know about the patient that are not currently in the sensor's features? Type here ...	What else you would like to know about the patient that are not currently in the sensor's features? Type here ...

07 These are the current output of the biosensor. In what way would this information affect the TAVI treatment?

Table 3.3 *Overview of patient monitor output characteristics.*

Data name	Unit	Fs (Hz)
5-lead ECG	micro Voltage	125
Heart Rate	Beats/minute	0.98
Impedance pneumography	mG	62.5
Respiratory rate	Breaths/minute	0.98

Type here ...

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?

Type here ...

E - Interview questions

Understanding your role

What is your role?

Can you briefly describe a typical workday for you? When is the most stressful/most smooth?

Understanding TAVI care path

From Diagnosis to Referral to AMC:

- What is the process of diagnosing patients with AoS? How do patients usually respond to the diagnosis?

- What is the patient health information being examined before referring to AUMC?

- How do patients usually respond to getting referred to do TAVI?

- Are there any challenges in referring patients to AUMC?

- If TAVI is not the ideal treatment, what will also be suggested to the patients?

- Who is communicating the most with the patients from diagnosis to referral?

- Who is your contact person in AUMC?

After the Treatment at AMC:

- When patients are referred back from AMC, how do you process the information?

- Do patients go to rehabilitation? What are the challenges?

- Who is communicating the most with the patients after receiving TAVI from AMC?

Recovery process (after rehabilitation, within 1 year after TAVI):

- After the rehabilitation, how is the follow up process? What would you like to be improved?

- Who is communicating the most with the patients in the recovery phase?

- How do patients usually respond to the follow-up appointments? What are the topics discussed?

- How do you see the effect of TAVI toward the patient's lifestyle?

- From your experience, what are the challenges for patients in this phase?

- From your experience, how is the involvement of the family/ caregiver of the patients since the beginning until the recovery phase?

Understanding the Meaning of Data for you

The Philips biosensor patch is a light-weighted, wearable device that collects the following data:

- Is ECG data valuable for you? Why and how can it be useful for you?

- Is Respiration data valuable for you? Why and how can it be useful for you?

- Is Posture / Stepcount data valuable for you? Why and how can it be useful for you?

- Is Level of Physical Activity data valuable for you? Why and how can it be useful for you?

- Is Heart Rate data valuable for you? Why and how can it be useful for you?

- In the near-future, what are the potential use cases you find valuable to use the biosensor?

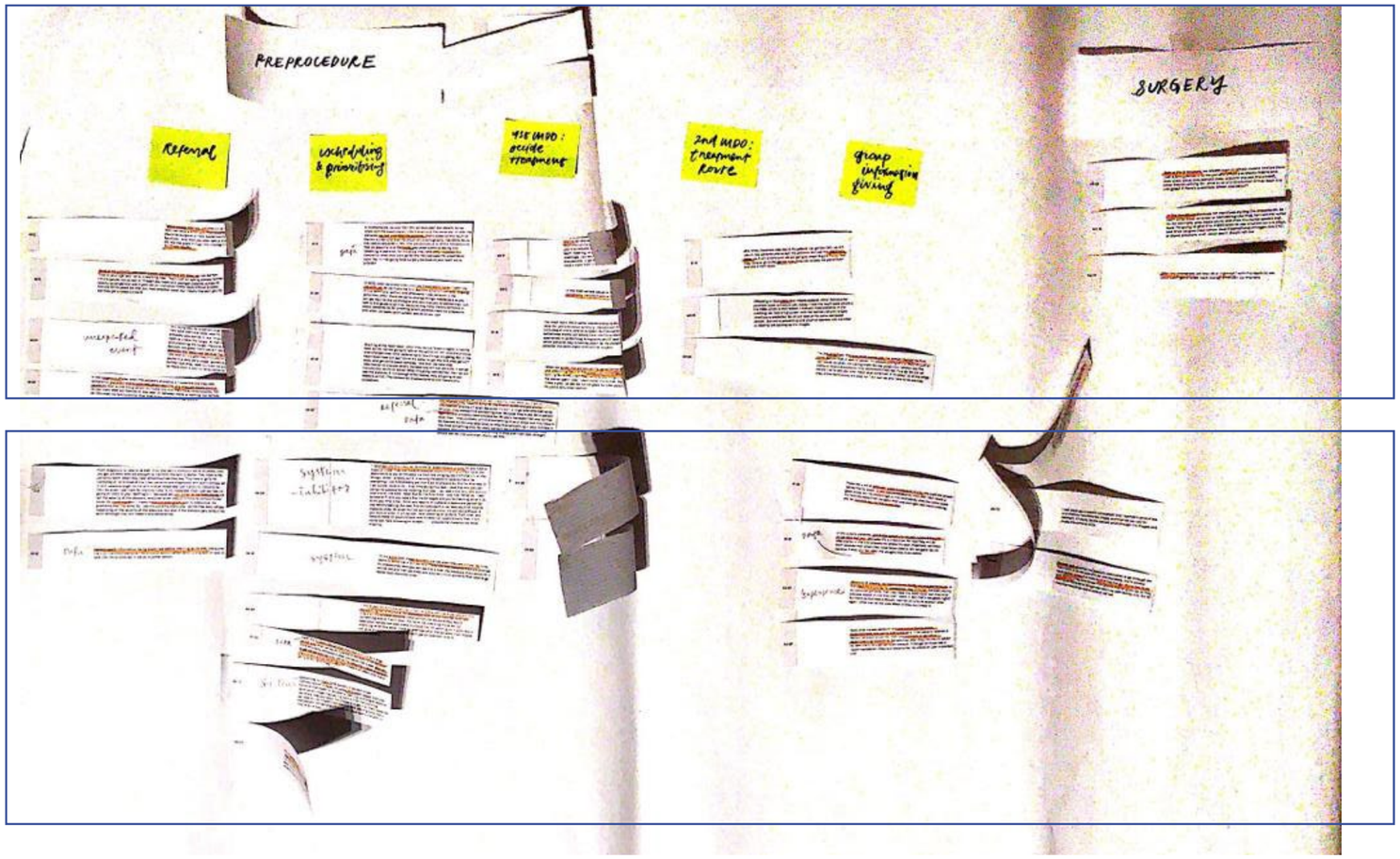
- Is there any data missing that you would like to have?

Thank you very much for participating in the interview! Are there any other experts you would suggest us to talk to?

Questions specifically for patient communication specialist

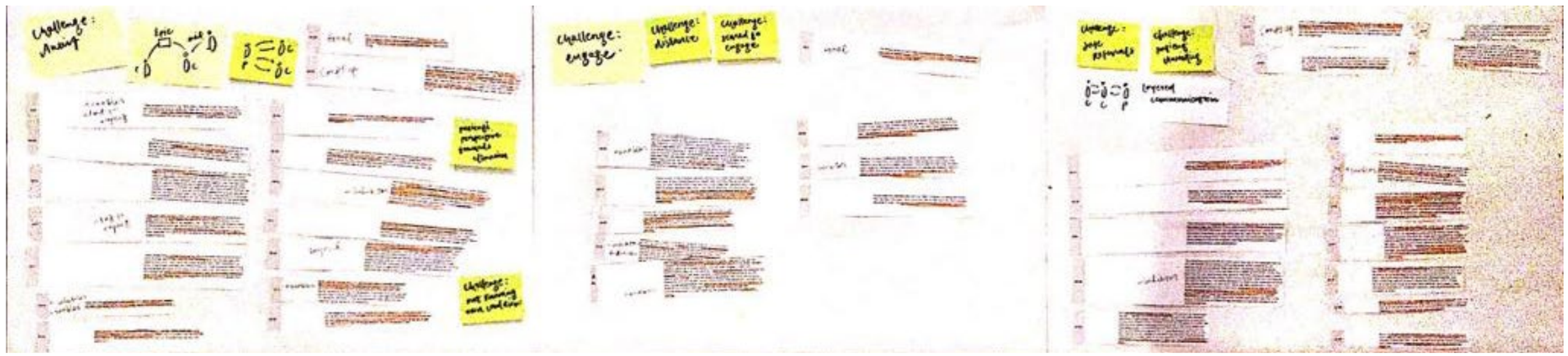
1. Could you share what's your main tasks and responsibilities as a communication specialist?
2. In your opinion, what is the goal of patient communication (i.e. knowledge sharing ...) ?
3. Are there any existing/developing measures of patient experience? (i.e. effectiveness, ...)
4. What kind of **patients** profile do you communicate in hartcentrum?
5. What are the topics you communicate with patients?
6. What are the existing ways you communicate with the patients?
7. Are there other ways you are looking into to improve patient communication?
8. Who are the **team** working with you?
9. What are the existing ways to communicate with them?
10. Are there other ways you are looking into to improve patient communication?
11. Is sensor monitoring being used in the hartcentrum? If yes, can you share how the system set-up looks like? What kind of data collected and how?
12. How do patients in HartCentrum experience the current TAVI journey? Can you share some of your observations? Are there any expectations / complaints from the patients?
13. What are your perceived benefits/concerns for patients in sensor monitoring?

F - Impression on analysis



care activities (partial view)

status quo of data flow (partial view)



clusters of challenges

Codebook

P1		Patient Communication Specialist	A1		AUMC Specialist Nurse	A2		CardioVitaal Coordinator	A3		AUMC Cardiologist
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences
P1-1		"I **work as a communication specialist** at the same heart centre, where the medical doctor also takes care for me. I was born with congenital heart disease and I was always interested in science, especially cardiology. And since 2007, I have become a **patient advocate.** A few years ago, I started a foundation. We are a foundation for the adults with congenital heart disease. Because I think we are not represented in the Netherlands, not represented in research, but also we want to bring the gap between the professional and the patient."	A1-1		There are two main things: (1) It's important that we can do more research, we get more data so we can develop and give better care. (2) The other thing is we can select the good patients who can go home faster than now.	A2-1		I'm a teacher, my studies are physical therapy and medicines. We have a joint venture with the AMC, because I'm working at the Department of Health from HDO, and we started from polyclinic, and we are specialised in heart referdation interdiscipline. My job is to manage that. So half of my personal career is also teacher, and the other half works in the hospital. My workplace is not only for patient care, but also for research and education. For example, there are six PhDs studying what we're doing.	A3-1		First, for patient care that's my main task. That includes doing interventions like PCI or TAVI. And I also have, but that's not very much time, but I do also have polyclinics. So that's the main part for patient care. So the patient came from home and then I can ask them how they're doing or if there is a complaint or if there needs to be some more investigations. Sort of preclinical phase.
P1-2		"Now it's 2020, **I am also also busy with shared decision making, value based healthcare, and always prioritising the patient experience for improving healthcare.** Because removing a technical problem or curing is not always possible for cardiology patients. So you have to take care of those patients. And it's not always just about surgery or a device like a pacemaker. **It's more about how we can help you for as long as you're here in the AMC or in the VUMC? How can we take care of you in our best ways? "**	A1-2	Advisor & Reactor	At the beginning, the patients will be referred to the heart team via the AUMC secretary. She says I've got a new patient and we're going to look at it. **I have given the secretary instructions so that she knows what to do / who to select.** But there are also things that aren't clear or have a high urgency. So then we talk about it, that's where it starts. But sometimes also **a referral cardiologist calling or emailing, when they don't know for sure if they must go into the TAVI surgery, I will advise him.**	A2-2		So that's my job, it's very operational. Are there enough people? What's the quality of the GCI? Which standard? It is a very nice job because all my studies came together and I like to work with people. And also when someone is sick or we do not have enough medical staff, I fill in because I have all the knowledge to do heart rehabilitation. I also specialise in psychology, when someone is very anxious or in a lot of stress, I will talk to him, otherwise they need to go to the social worker or to the psychologist.	A3-2		In my second task, which is like 40-30% of the time, I'm head of education for cardiology residents. And so I have to do all them to make sure that they have a good education and a lot of discussions about education schemes, the projects they have to learn, and also their well being. And also with the teachers, of course, teach them as well.
P1-3		" My advice is more for the professional to **keep the experience of the patient in their mind.** Because professionals are always wearing the same glasses, the science glasses or the research glasses. But what does it mean if a patient underwent TAVI? What does it mean in daily life? … For example, can I cycle again or can I play with my grandchildren again? Or for me it's important to walk one kilometres without having chest pain or anything. So I also give them advice for **patient reported outcomes, the Proms and Prems.** We also have **the PEM, that's also a patient experience measurement,** we have that on a yearly basis."	A1-3		We will look at what examination they need more, like a CT scan or echography or blood samples… that's the first step. Then we look where the patient is located? And what does he/she need? Do we need more examination or do we wait for the examination results from the referral hospital? Because things are coming out of the CT scan. We call it Neva-befitting (dutch word), then we find things that are new and not good. And we go further when we have all the right information in a MDO meeting, the doctor will decide what's the right treatment and I'll say which patients we have to discuss about. I will present all the patients and afterwards when they need to meet to discuss some other things, I will arrange that.	A2-3		I'm also doing coordination. When we find someone doesn't fit in the programme, are very angry, or he doesn't know how to deal with the whole situation, then I talk to him.	A3-3		The third task that's mostly related to the research we did with students from the technical medical department or medical students.
P1-4	Mesure patient experience	last year we did the PPP. That's also a measuring for a TAVI patient's experience, how well they were informed before the surgery of the procedure. Questions like, how safe they felt at the procedure? if you were experiencing fear or something like this, were you able to ask the nurse or the doctor a question? Or questions for the waiting room, how long have you been waiting? And how did you experience that waiting time? Some people said, Yeah, I, I needed to wait, but I didn't care. Some of the people said, Yeah, I needed to wait. And I did care, because I didn't know why, what the reason was there was a delay	A1-4	Frailty	After MDO, they have decided if the patient can get the TAVI, we will inform the patients and screen the patients and **use the VMS frailty score.** It's from Elderly unit, we are going to check they're frailty. Then they have to go to the geriatrician, they can assess the patient's in one and a half hours.	A2-4		There are 10 vital factors, it become a heart problem. The 10 factors are very important for the outcome of the disease. With all that factors you pay extra attention to, and you get a personal pathway to improve it, only if you want it. These are the same factors that also causes cancer, diabetes, COPD… the typical western diseases. We know all the factors: that's fitness, stress, diet, blood pressure, lipid… the vital 10. The 10 factors you can change, and that is the factors why you get bad blood vessels on your heart or your leg or your head. And it is very important that you improve them. If not, you get TAVI and you wait till the next problem.	A3-4		First of all is the direct contact with the patients. That's via the polyclinic and also in the cath lab (examination room) with the patients. And then I'm coworking with a lot of nurses in the polyclinic. But in the cath lab, we have specialised nurses who are trained as a CathLab nurse who helped me at the table or gave all the materials, etcs. And also we have some cardiologists who've trained to become an interventional cardiologist, but also trainees to become cardiologists. And then we of course have an important role, that's the Secretary and the planning office, who do the track and trace of all the patients (i.e. examinations they, or need appointments they make with other specialised departments like the anesthesiology or the geriatric department).
P1-5		I think my kind of advice is "be transparent". Why are you doing what you are doing? Explain.	A1-5		When we screen the patient, at the same moment we are educating and informing them in the group information session. When they're coming for AUMC, then they can discuss things in the polyclinic with the doctor again, like," I don't know this or that." Once or twice or three times a year, we decide it's not good for a few patients to do the TAVI. It's just a very small portion.	A2-5		So the rehabilitation team is working on the 10 factors: we have psychology education, fitness, physical therapy … The whole team is covering the 10 factors.	A3-5		In the heart team, we already have 25 doctors. But also because we're an academic centre, so I have a sub-specialisation like intervention. We also have imaging cardiologists like who's performing Echo, MRI, CT, etc. We have electrophysiology, cardiologists who are doing rhythm problems and interventions. We have general cardiologists who are doing supervision supervising roles in the clinic.
P1-6		If the patient is saying, I don't want to hear anything, just get it done, then it's alright. But if a patient is very scared, most of them don't feel the freedom to ask questions because they think they are bothering the doctors or maybe the doctors do not have much time.Maybe the doctor thinks me thinks me I'm stupid or anything. These are regularly, thoughts of the patients in the hospital. So, I am telling them and them I mean the professionals have the awareness of the fear of the experience of patience.	A1-6	Value-based care	I think it's necessary that we know what's good for the patients and what kind of special care they need. For example the situation at home, we also discuss it with the patients like "Are you living alone? Do you have children? Do you have good contact with your neighbours?" So we can discuss with patients how they can do the care when they return home.	A2-6		I will describe the pathway of the patient. The patient is sent in from the cardiology department. The first step is the nurse, he/she look at what do you want to reach during the rehabilitation. The nurse also make a screening of the 10 factors. After that you get a test on the bike, to see if it's safe to exercise. We also monitor the heart rate and the ECG. If it's alright, you can also go to the fit programme, which is very intense.	A3-6		When the referring hospitals refer patients, they send a letter which contains the complaints of the patients, the investigations they've done (i.e. laboratory, echo, sometimes CT scanning, catheterization). They sent by letter and they sent the images of the echo and the computerization to the planning office or the secretary. They prepare these information for our heart team, then we discuss the patient. Sometimes we make a telephone call between the AUMC and outpatient cardiologist, when we have questions or doubt if this is the best treatment they want, that kind of thing.
P1-7		The Proms and Prems is always measured after the procedure. So for the professionals, it's very important to take those Proms and Prems with them for the care of today, they can improve their health care today and tomorrow. So the Proms and the Prems are always dynamic. And yes, also individual but because you ask a variety of patients, you have an idea	A1-7		And afterwards, we plan the TAVI, we have seen the patient, so we know with the examination information and the conversation with the patients, **we can prioritise the patients. That's based on the result of the frailty test and also the result of the echography, like alpha below 0.6, radius above 90 or 100,** that are indicators to do the procedure as fast as possible. And the frailty you understand by seeing and speaking to patients. For instance, they have other diseases (i.e. cancer) or when they can't go for the TAVI because the anesthetist says "No, I'm not going to do surgery because of your heart valve problem."	A2-7		The fitness programme is **not only about the fitness levels, it's also about "Do you dare to move? Do you know how to listen to your body? Do you know how to climb to a better fitness level?"**	A3-7		For the TAVI, the patients will contact the secretary at the planning office or the specialised nurses if they have questions.
P1-8		I think the other challenge for patients is yeah monitoring, tele-monitoring. Because if TAVI patients underwent the procedure and the next day they're going to their own hospital or maybe going home. Then the thoughts of the patients are always: 'Oh my god, how do I do that?' You How do I know if my heart is doing well? How do I know?	A1-8		Sometimes the patient is a caretaker for his/her partner, or when they have a child who's living in another country, then you have to discuss what's the best moment for the patients to do the surgery. We inform the patients in advance when they have bad parameters or bad echography results. It goes like "We normally plan about six weeks, but now we're going to three weeks because your daughter is coming then."	A2-8		Before we start the programme, we have a MDO meeting. We discuss what the client wants. Where can he improve? And which steps do we have to make? For example, three months training, go to the stress management course, go to the social worker, three PEPs, psychology, patient education… there's a lot of things. I have a diagram where you can see the steps the client makes and what we can do with the client. What we do is not new or unique, there is an international multidisciplinary heart referdation, that's the standard. For example, we know a lot of people come for the first time, they're a little bit depressed or anxious. So there's a specialised questionnaire, so you can measure depression.	A3-8		Typical workday: Because I'm head of education, I always have to be here at eight o'clock in the morning. Because we have a meeting to communicate about the patients who are admitted the night or special things from the night shift. We discuss this in the morning session with all the images from echo and catheterization. Most of the time that takes about 15 or 20 minutes. And after this we have some kind of education, which is a whole programme every morning until nine. Then from nine o'clock, either I go to the cath lab to do PCI procedures or TAVI, or I have meetings because of the education, or I do research. Email is also a very big thing, which I don't like.
P1-9		If I'm feeling this way, is this something I need to talk about with my doctor? Or if I'm feeling that, it's also a very blurry in their heads. They are going home with a lot of information with a lot of folders or telephone numbers or an appointment for the follow up next week and also lots of information about medication.	A1-9		We want to give the best care, and **the best care is also for patients feeling comfortable, having faith, knowing he/she's going to be okay when going home, or their need is taken care of.** Sometimes the patient's partner has dementia and the child is working so only take certain days off to take care of their partner. So I think when they are relaxed and having faith, everything will go better. That's not what they want to just become a case number. I think it's better when you know that's Mr. or Mrs. with a name.	A2-9		We call the healthcare system in the Netherlands a DBC model. So it's based for three months. If you send in for a heart referadation for three months, everything is specified. For example, 12 times fitness, 4 times psychological consulting … If you do three PEPs, you get paid for this amount. And we also have a first line, healthcare contacts to check if the benefits are also going on, but we don't have to follow it. That's the next step we have to do. Patients start a lifestyle change, it's not finished. So a lot of digital follow ups are based on the goal of your lifestyle change.	A3-9		MDO is for the heart team I just mentioned, that's a multidisciplinary meeting. That's what we have daily, sometimes you're scheduled for that. Or we have twice a week like the TAVI team meeting, which is also an MDO. And we have several other meetings: like neuro cardiovascular meetings once a week, valve discussions in general, surgeons once a week, difficult patients once a week from the surgeons in charge…

A4		AUMC Secretary	A5		Outpatient Cardiologist						
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences						
A4-1		"First I will check the mails and check the numbers, for example p-wave. And then I will first check all those things, if they're not really good, like p max of 150 we had last week. It's like, oh, what's happening? Then we have to hurry up the process and quickly submit these patients than normal." → secretary serve as the first checkpoint	A5-1		I'm a cardiologist specialised in the heart. And I'm not working academically. I'm working in a small hospital. And they say it's one of the ten smallest hospitals in the Netherlands. I work a lot with AMC.						
A4-2		"When being referred, patients are not admitted. The first thing is to CT, then we have a MDO, and then we will decide which treatment, sometimes it could be surgical or TAVI. Sometimes they need more research, like lung function, and then you also have all kinds of things they could find on the CT, not the good things, like oncology in the lungs. So now we have to wait for those results."	A5-2		Compared to Dr. Vis who is doing a lot of interventions, I do a lot of outpatient clinic work. So I always make the diagnosis, and I make a plan for my patients. What I always say to my friends in the AMC, "See, I'm catching the big fishes and I bring them to them to the bears (AMC)" I work three and a half days, mostly seeing the patients.						
A4-3		"After the MDO, when they are accepted for TAVI I will call them, and then we plan them for introduction and information and the polyclinic with Marja normally. After Marja or Elena say it's okay with them then I will inform them that they're accepted and they are on the waiting lists. So all the time I'm making contact with them. And they can also call me."	A5-3		During my work time, I'm not so stressed. Because **I think you get most of the stress when you are really thinking, "Oh, I only have** 10 **minutes for my patients** and I really have to do it in 10 minutes" I'm not at all like that. So I'm talking and I just see how it goes. Some consult going very fast while others take much longer. For example, **when you have to explain when TAVI is indicated and the care pathway you have to describe, that takes time.**						
A4-4		"Most of the time I contact patients by phone because most patients are a little bit older. But if they want by mail it's okay with me. Sometimes if we need to hurry and I can't send the mails by post, then I will send them by email. A lot of the time they don't have email, so I have to explain everything by phone and let them make notes (i.e. you have to go over there then you do this thing). But more and more often they will have email or their family will have email so they can help. Like daughters or sons, which will guide them to this hospital."	A5-4		From diagnosis to referral to AMC, first, the aortic stenosis has to be severe. Often you get patients who are brought to me from the family doctor. They listen to the patient's heart, when they hear abnormalities, they say "You have to go to the cardiologist." And most of the time, patients are diagnosed with aortic stenosis, but it isn't severe enough. So it's still mild or moderate, but there's no indication for TAVI. So when I see them for the first time, if it's moderate, then I just say "Now, I'm going to listen to your heart again." Because you can listen to the heart sounds and tell the severity of the stenosis, and then when they still have no complaints and I think it's moderate then, I make the echocardiogram, just to measure all the gradients over the aorta. So I see the patients every year, sometimes every half year, depending on the severity of the stenosis, but also if the stenosis gets worse on the echo, although they still haven't any complaints.						
A4-5		"Sometimes it's just the (outpatient) secretary, just contact me like the patient is getting worse or have some questions. Sometimes it's the family, especially when they're not urgent, they will be on a waiting list. Urgent patients will always come before them, sometimes it can take weeks before they're it's their turn, then they get all like, "Oh, don't you forget me!""	A5-5		Patients need TAVI when stenosis is severe and they have complaints, or the condition is getting worse. then you have to think they have no complaints but it gets more severe. So I think it's better that you get a TAVI before it gets even worse.						
A4-6		"They just want to know when is it going to be my time? The acceptance letter says six to eight weeks. So after five weeks, they're calling "Do you already know the date of my surgery?" No, I don't. But you can double check if the problems didn't get worse, and also comfort them like "I think it's now two or three weeks". I think it's nice for them to have one person to go to. They have seen my name on all the letters, and they talked to me with all the appointments."	A5-6		Most of the patients who need a valve replacement are elder, so I can tell them, "Due to your age, your valve is working less. That's just an ageing process. "And then I think people can accept it. Though you have also younger patients, but then it's mostly by congenital and it gets earlier stenosis. That's more difficult to explain. You are 50-55 years old and you need another valve, but mostly they don't get a TAVI but they get a classical SAVR.						
A4-7		"They're always complaining, "Why does it take so long?" But that is just normal because they're suffering. They can't do all the things they normally did. And they know then when they get treated, it will be better, probably. So there are complaints but that's okay." → waiting experience for patients	A5-7		The patients usually respond to the diagnosis, I think fine. You just have to explain to them what it is. You can't predict how fast it will get more severe or how fast you get symptoms. If you have symptoms, then there is a reason to to operate patients.						
A4-8		"Now because of the COVID-19 crisis,we are also doing a lot of applications from the VUMC. And there's a total difference and we are trying to get in the same as the AMC. Because most of them are coming from (name of outpatient hospitals), and they didn't get any information. They don't know why they are doing the CT. They don't have all the information and you see those people come to the hospital and they don't know what to expect." → previous experience shape expectation	A5-8		Most of the time the patients come with a family member. Because most of the patients are older, they also have comorbidities. So I also talk to the family. You always have to think "Do you still want to do it?" When you don't do it, then you are dying within one or two years.						
A4-9		" I think especially the group information session, you see, they have some connection with the other patients which make them feel like they're not alone. And also Oh, what a good question from him / her!" You see the comfort for all those people there, it's really good. And also when you see them later in the waiting room, you say "Good luck!". That's really nice. " → peer support, comfort	A5-9		I think that's also part of the process. If you have to do a TAVI yes or no. Do the patients only stay in the house, don't go outside anymore, and they are just sitting for the TAVI? That's something different than when you have patients who are still outgoing and really want something.						

P1		Patient Communication Specialist	A1		AUMC Specialist Nurse	A2		CardioVitaal Coordinator	A3		AUMC Cardiologist
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences
P1-10		I think we can give them more information about rehabilitation. Physical therapy, sports doing sports. Am I able to do sports? What kind of sports? How high can my heart rate go? How high is it? Is this good or do I need to call my doctor if it's higher? What's good for them? So I think they can be more "begeleiding"	A1-10		**The information we get depends on referral** a cardiologist. Sometimes they are very precise in the description and that you know it, but there are also a lot of cardiologists who don't put a lot of information in the letter. They only need to write the data from the examination, and that's it. But the patient is much more than that. So I think in less than 50 % we know more, and more than 50 % we really have to see the patient and talk to the patient. **We have more questions then it's in a referral letter.**	A2-10		For example, if you have high blood pressure, the doctor will give you a beta blocker; if you have a high anxiety level and you want to improve, you go to the stress management probably six times, and then you learn how to workout the legs. The programme is not the same for every patient, but it's a personal fit on the goals you have to get a better outcome.	A3-10		(Showing on Epic) Poly, that means outdoor clinic. And here for example (open schedule tab), today I have the heart team which is the MDO, which is this button. I discuss these patients. In the meeting, we have a big screen with the beamer, where the Epic interface is projected. So we can look at the same computer screen. But one is presenting and what we decided and the other is reading and pulling up the images.
P1-11		"MediMap is in development for two groups of patients, coronary disease and aortic stenosis TAVI patients. MediMap is an app for the patient or family of the patient who is giving information at the station or at the periods the patient is in the health care path of the hospital, the process. Okay, but also who is my doctor? Or who is the one going to operate on me? You have a picture of the doctor. "	A1-11		**When you tell the patients "I'm gonna look what's the best moment. and I hear what you say." You can see the patients are relaxing,** because it's something a lot of patients don't discuss with their doctor. When you discuss it, the patient is relieved, and then you can explain how it works. Because they think " Oh, how's gonna be when I'm laying on the table ..." They are busy within their head. It's not medical, but for patients it's important.	A2-11		There is not much difference between TAVI and other heart diseases in the approach to treatment. For example, if you have surgery on your chest, then there will be a delay of six weeks, because it has to heal. It's too long. You don't want negative interference with the outcome. So now we are researching on a way to start the treatment earlier, because they get a surgery and then six weeks they are at home. They don't dare to move.	A3-11		In the MDO we talk about all the measurements by echo and the symptoms like shortness of breath, angina...
P1-12		"For now it's very, because of the GDPR. You have to physically go to the hospital to open an account. Then your patient portal for appointments, letters or lab results. So you need to have that first. "	A1-12		The heart team, there some interventional cardiologists, the one who does PCI (percutaneous coronary intervention). There's also a cardiologist and a cardiac surgeon. So there are two professionals, sometimes there's somebody from the ICU or cardiologist who specializes in performing echography and CT scans. So it depends on which patients they're talking about. So the standard ones are two persons: the cardiologist and cardiac surgeon.	A2-12		There are two kinds of patient groups: Patients with open heart surgery, and they have to start rehabilitation six weeks later. And the other group, stent, they can start rehabilitation the next day. If you have TAVI, patients are in the waiting group. Because they think "I can not do anything... It's very painful..." If you have six weeks of waiting and doing nothing, your fitness level goes down, your endorphins come down, and that's only because the hospital said "Well, you have to take it easy for the next six weeks, and then you can start with the programme."	A3-12		Everything is in Epic (EHR system). If we want to see catheterization images, it's called ISCV. Intelli space, that's the name of that platform. So when a referring cardiologist wants to send us an image, they do it by EVOCS. Then the planning secretary, they pull down the images and put it in intelli space. So we have all the images from the AMC and referring hospitals in one system. Echoes and CT scans are done here in the AMC, so they're all in Epic.
P1-13		"Currently the patient does not have the patient portal, because the aortic stenosis patients are I think 80 or 90% comes to the Amsterdam UMC via another (outpatient) hospital. So we have to discuss it in the MDO. So that the doctors are having a meeting about this patient who is not in the Amsterdam UMC already. Yeah it's by far certain that the patient is coming for pre-operative screening, and this starts with a CT-scan. And then the patient is physically in Amsterdam UMC."	A1-13		Starting at the heart team, when they decide "Open surgery is not the best option, we are going to look at the option of TAVI" and the process also changes over time, depending on how things are going. But in the heart team they will say"I think it's better to get the TAVI, they get a CT scan, and get some blood samples." And then we have that information to discuss what's the best way to treat patients. It can go transfermol, aortic or apicol. When it's going transfermol, then we will see the patients. If it's through other routes, they are going to see doctors at CDC (The Centers for Disease Control and Prevention) outpatient.	A2-13		Now we're planning to go to the bed of the patient in the hospital, and to explain what they can do in the six weeks before they start. Normally they start after six weeks of surgery with the online programme and with the rehabilitation, but now we want to give them information. This is still in the development stage. We want to give them digital information, so they can join remote revalidation, then they have the same benefit.	A3-13		I can show you a patient. For example, and I opened a patient tab, and then we have here the images. And then we can see for example, CT scans. So then we can scroll through the images and that's the same for echo.
P1-14		"So it's our challenge to keep the other hospitals informed about the (MediMap) project, so that they can already talk to the patient that there is a way to be informed. Because Amsterdam UMC is only doing the procedure and then the patient is going back to their (outpatient) hospital again. So that's, that's our challenge."	A1-14		It started from the secretary, she will call the patients to tell them she planned a CT scan and what they need to do. She also sent the flyer with information and questionnaires. That's the first contact most patients have with the AUMC. The communication depends on the questions patients have. When they have simple questions, the secretary will answer them; when it's more complicated questions, she will refer to us by phone call. I think they like it when they have a professional to consult, but they don't call often.	A2-14		We have a PhD project to personalise the patient's behaviour or communication style. So the patients do a lot of questionnaires (i.e. quality of life, 10 factors...), and also different workshops. Then you can divide people into different segments. With the questionnaire, we really can personalise the motivation tools. Because if I want to motivate you, there are unique communication styles. MBTI, for example, patients get personalised that will motivate them. We defined the people in six segments. That's not good, but it's better than only one. We call it personalised motivation. For example, a message saying "well done with your own goal!" and you get in a group with other similar patients so you can talk about your problems.	A3-14		Hopefully everything can be linked to Epic.
P1-15		"The other challenge is you have to register via Digi-ID. "	A1-15		I think the age of the patients also plays a role. Elder patients think the doctor knows and I will wait, they will think "The doctors are busy and I will wait... " Younger patients call more often, they're more like "I have a question and they said I can call!"	A2-15		**It's not about training more of what they're doing in our rehabilitation center, it's about that they have to move more in their own home surroundings.** So you can use the biosensor as a feedback instrument for themselves. We can also see the patient's failures from the sensor, then we can **give them feedback with online coaching.** It would be very useful, if you can use a lot of step counts, runkeeper.	A3-15		Before the procedure, we always sign in, which means that we have just a few questions to the patient where everybody listens and then says, Okay, this patient, date of birth? We ask the patient, what they're coming for, what kind of procedures? If they have any allergies? If there's questions about procedure?
P1-16		"Yeah, some of them. Yeah, not all because it's not very common for a patient to have one portal patient portal. Especially not for the elderly. Or for the patients who are just going to the AMC for just one procedure and then doing all the rest via their referred hospital. But most of the chronical patients were always the AMC patients. Most of them have an account. But that's not always TAVI, because the TAVI is just a procedure AMC is doing and then the patient is going back to their referred hospital. "	A1-16		We started TAVI from very ill patients with a lot of comorbidities. Now we are also developing from my very high risk to moderate or low risk. From my observation of four years working experience, I see lower risk patients are mostly the younger patients who use more internet, but this older group mostly didn't search on the internet and what you tell is the truth, and they are not very critical towards what you're telling. Elder patients care more for things like how will the condition go with my partner or when I'm home I need home care for that kind of thing.	A2-16		From the medical side, we're interested in the ECG and heart rate. Because there is a difference between training and moving. In the first step, we want them to move but also to train. In the test we do also with a scale, we know which level they have to reach to train directly related to the heart rate. You can get feedback if you're training. For example, at the beginning test we also measure ECG, and if for example a patient said, "Well, I can't go on because something goes wrong." Then you can make it objective. Because all the people are scared to move and do higher exercise levels.	A3-16		In the procedure because I'm sterilised during the procedures, so I can't write down an order or something like that. So I tell the nurse to, for example, give medication. And then the nurse speaks out loud. I'm going to give this medication to see whether we are align. And then we give medication. And if something changes like EKG or blood pressure, and I don't see it, they'll tell me.
P1-17		"I think the challenge or my concern is that the Amsterdam UCA doesn't really know the patients. You only have the imaging or the MDO or a report from the cardiology referred hospital. So, what do you think needs to be improved on this step? I think it's good from professional to professional to have a good yeah, coherence or how do you say it's they're having a partnership? And it's pretty challenging because the AUMC is only the situation or the location where the procedure is taking place. And from a patient perspective, yeah, maybe only need the minimum thing, but that's just in the very early stage of development."	A1-17		Sometimes TAVI patients said "I filled in that form and that form, and it seems like the same questions?" That's sometimes annoying for the patients. For example the anestesia has a seven point scale, and we have a five point scale, so it seems like we asked the same questions. And there's also a very small group who have questions when they come to the polyclinic, sometimes they bring a note. I will say "Very good! You read the flyers!" There are also patients like "You tell me." In the elder patients, it's more like the doctor says it's okay, it's okay. That's the difference compared to patients with a mean age of 40, they have their own work.	A2-17		It would be wonderful, because it's not only the two times a week for 12 time coaching in the rehabilitation center, you can give coaching on distance.	A3-17		After the procedure, we also do a "sign-out" with the team to see what went good, what went wrong, what can we improve.
P1-18		"So I think it's important for the referred hospital that they are sharing their information about the protocols of AUMC. Expectation management. What can the patient expect when they arrive at AUMC? And I think it's also very important to tell the patient why the TAVI procedure cannot be done in an outpatient hospital. "	A1-18		**There's a lot of difference between the patients.** You see, sometimes you have a patient who's age 90 is a lot better than a patient of age 75 who has a lot of comorbidity. **Age is not just the only way to tell the patient's frailty.**	A2-18		We see a follow-up statistic from a study, a lot of people are dropping down to the previous level. When you have a psychological problem, with specialised people can help you do the right thing; but when you're on your own, it's a lot of failure to fall back. So we're also searching for feedback or sensors to track follow-up, and then you can discuss how the patient is doing.	A3-18		For the patient we have of course the informed consent, which is by law, and that you have to get permission from the patient, that you explained: what is the therapy, what are alternatives, what are the side effects... so the patient can make good decision for themselves. We call that shared decision making.

A4		AUMC Secretary	A5		Outpatient Cardiologist						
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences						
A4-10		"We are sharing information more on the internet. I think like 40% of them have email. They're not very interested, it's more than family is interested. Then you can give them more information with a group information session and say, "Well, you can go to that website or that website and find the information." Those people who want can find it on the internet. I don't think they need more from us." → information sharing	A5-10		When patients have family with them, you can get a lot of information. Sometimes people come already in the hospital with big complaints like they are compensated, fluid retention and they have very short feathers. Then we say okay, "You have a severe aortic valve stenosis and need TAVI, but how much are your oxy radius six months ago?" It's very difficult because sometimes they're cognition is bad or they have delirium. Sometimes I also go to a family doctor, and I asked, "Do you think it's still useful to get it a TAVI?" So first you have to be patient. But then you have your own clinical vision of the patient and you look to somebody's biological age, family, family doctor and geriatrician.						
A4-11		"I think the family just wants to control the situation. I think they want to grab any information to manage it. Just because when it's your mom, you also want to take care of her and know everything will be okay. Some calls it's just to push me "Please plan the surgery for my mama." And sometimes it's just because they want the information about death rates or other risks that can happen." → family's want	A5-11		**It's difficult to say if the patients will improve if they get a TAVI, so then we ask the geriatrician. The geriatrician always investigates the social conditions and physical issues of the patients, and then we can together make a decision.**						
A4-12		"All week is different ... Normally on Thursdays I don't work, that's my day-off. Now because of the COVID-19 crisis, I'm working most of the time from home. I take the long mornings like early starting and like 13 or 14 o'clock I'm finishing to get the afternoon free for the kids. I work five days a week, so I split my hours during the week and yesterday, my last one to have some oil companies. So he came home early, and then I rushed to the AMC to get some work done in the AMC like the letters but we don't have that much applications at this moment. I think two or three, most of them are clinical. So it's our urgent patients. On Mondays and Wednesdays I have to prepare the MDOs, which is on Thursday." → Secretary's typical workday	A5-12		That is difficult because sometimes we say "I don't think it's a good idea.." But the family of the patient still wants to have it. Then we called the AMC cardiologist by phone and we said, "We don't think it's very wise, but the patient still wanted TAVI. Can you see the patient? What do you think about it?" So we can help each other with our expertise.						
A4-13		"Every day I will check the new applications and prepare to set them in my Excel. This is my working file (excel) because Epic (EHR system) can't give me summaries like this. These are all the patients are that are managed by me. You can see when the heart team schedule is. These are the orders and the info I've sent when the CT scan is and because of when I know when the CT scan is I can plan which date for the MDO. Now after MDO, sometimes we need more information, you can see my notes in case for more examination for any reason. Then I can check when things are planned. Sometimes I have to arrange the examinations myself, sometimes I have to contact the doctor for extra information. Then I can plan when we can admit. This is the planned date of the group's meeting and polyclinic meeting with Elena of Marja, and this is if there is any need for anesthesia. If that's all done, then we go to the waiting list. Yellow shows all arrangements for a date, the greens are done this year. You can see over here, I've got a black and a green, the green are already done. Some black are still standing on the waiting list. Because I really want when people call asking how long they still need to wait, I can check over here. I've got a formula in it. How many weeks he/her is already waiting for this treatment." → Way to manage appointments	A5-13		Patient health information being examined before referring to the AMC: Oof course the ECG, the blood pressure, the physical examination, echo, a lung test, CT scan to look into the coronaries, or we do a catherization.						
A4-14		" If it's between one and four or three weeks (for waiting), then we did a good job. Between four and seven weeks, it's okay. Eight and more, well, he's waiting very long. So that is the green, the orange and the reds. And then you can see over here now for most of the time we're doing okay. " → Waiting time	A5-14		How do patients usually respond to getting referred to to do TAVI: We have to explain everything. We also tell them that the risk by saying "We try to do good, but there can always be complications." If they say yes, then there is no problem.						
A4-15		"I don't communicate with patients how long they will wait. I can't tell at the beginning if it will be a long time or not. But after the group information session specialist nurses have half an hour with each patient individually. They can tell at that moment "you have to go urgent, it will not take that long" or "we will prepare for six to eight weeks." And sometimes we have cases in which it prioritises and goes faster, but most of the time it will be around six weeks. So if you say six to eight weeks then you will be safe and they will be okay. If they have more complaints, they will call or otherwise the (outpatient) cardiologist will call. Most of the time it's the same people who were already calling before, some people just want to call every day."	A5-15		If there are other treatments, it will also be suggested to the patient. I think you have to look if the patient is still suitable to do open surgery, or technique like minimal open surgery. So that is also possible in other centres.For example, I had a patient she went especially to Belgium because she was too young for TAVI, but she did it in the endoscopic way						
A4-16		"Besides the treatment schedule, they also share a lot of personal stories. "I'm alone", "I can't go to my daughter because I can't walk long distances" or "I can't go to the grocery store to get my own groceries." I'm just listening and working. Sometimes they just want to tell their story. "	A5-16		Who is communicating the most to patients from diagnosis: Me, the referral cardiologist was coordinating everything, but when the patient is referred, then there is a heart team in the AMC, there's also a nurse, all the patients are invited by them and get also very much information from her.						
A4-17		"Sometimes they're living alone. And then it will be hard because they can't walk or they can't bike. They can't do the normal stuff that is before. You get a lot of personal stories, which is nice, sometimes really hard."	A5-17		I don't have a particular contact person in AMC. It's just I know how to call the secretary, and then I asked who is the interventional cardiologist on the shift. If the patient is already referred, then I know that they are accepted and in the pathway of AMC. Then I email sometimes the nurse to ask "do you know how it is with the patients? At what stage are the patients at? And that's how it goes.						
A4-18		"Now due to COVID-19, we (VUMC and AMC) are planning in a totally different way. I can't see the patient in person. Normally I have like one week ahead to plan, most of the time we call patients like five to seven days before their appointment. It's not often I have to call people to say "Sorry, it's cancelled." That's why we are planning just a week and a half before, because if you're planning more ahead and getting colliding clinicals, cancelling appointments for patients is really hard."	A5-18		After the treatments, how do you process information: We also have our EPD, so we call the clinical doctor, and they put everything in the EPD. Just copy paste the letter, we have to type everything. And we will see the patient and do additional examinations (like ECG, physical examinations, laboratory test if it is necessary)						

P1		Patient Communication Specialist	A1		AUMC Specialist Nurse	A2		CardioVitaal Coordinator	A3		AUMC Cardiologist
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences
P1-19		"I don't know if it's a constant confusion. But most of the TAVI patients are 70 years old or older. So some of them say, I don't care. I don't want to hear anything. I just underwent the procedure. So let's get it done. But the family of the patient or the younger patients will ask how does that work? Or why is that? How do you do that and what can I expect when I am at the AUMC? Mm hmm. And if there is a difference, then it can be a bad experience. Because of the expectation management. Yep. It's not there's something happening, what's not being told at the referral hospital. I think it's important to look for a partnership from the AUMC you'd say and the referred hospital, there's less of those mis-expectations."	A1-19		I think **when we know the basics of a patient, then we know how we can train or advise the patient** what's good. When I see at a polyclinic, I see a lot of different patient profiles. Some people you asked how they are, they say "I'm fine, but a half year ago, I was running five kilometres twice a week. But now just walking will the end of the street, now I have a lot of complaints." Or the patient who says "No, I have more complaints of my hip." So there are a lot of different patients. I can imagine the patients who used to run a lot have lower heart rates. So you can train or inform the patients in different ways. Especially the patients who used to be active have experienced a lot of problems, because now they can't and they want, I think they would like it a lot to see improvement with a new valve. I don't know enough about heart rates and exercise programmes, but that's what I think about improvements.	A2-19		**If I asked the patient "Did you do the right thing? Did you have a lot of movement every day?" They can say yes. If we have a biosensor, discuss what happened.** › **Evidence based care**	A3-19		The patient engagement in shared decision making, well, it really differs a lot between patients. Like older patients, they sometimes say, "Well, doctor you say what's best!" Other patients look at the Internet and say, "Yeah, I've read about this and that, what do you think about it?" or "I don't like to take medication, they give me side effects."
P1-20		"Some of the TAVI patients who came to the AUMC don't really exactly know about the procedure. If it's an open heart surgery, or maybe aortic surgery or via the lag, transfermol. That's experienced last year but I or we as a team really don't know why it's not mentioned in the referred hospital. Is it because the patient is not getting the right information, or is it because the patient is older and maybe a little blurry in their heads or scared and didn't hear the details of the procedure."	A1-20		There are also patients who are scared. And when they know "When my heart rate stays below 100, it's safe." It's for comforting patients.	A2-20		You can also use the biosensor during the treatment itself. Because now when there's a problem, we have a very big machine with 12 lead ECG, but then you have to stop the exercise and measure. We also have a little box that you can put your fingers in and you also get the heart rate. So if we get more information and they can go on. A big thing of the treatment is that if they feel something, we have to check if it's green or red from the traffic light model.	A3-20		Lifestyles are so very different between patients. Well, you can look at them and know about their lifestyle. Also by medication, if they have diabetes or something else. We always ask for "risk factors" because of our detection. So like smoking, diabetes, hypertension, hypercholesterolemia, cholesterol Lamia, family, that kind of same thing.
P1-21		"You put your hands in the professional and if you experience some blurriness on these simple things your trust in health care can be decreased."	A1-21		In the elderly patients, one of the questions **we ask is also if they fall in the last half year. Because it's a prediction for how they will do afterwards.** In the pre-procedural phase it's also important, we know from studies that when they have fallen before, it's not good. So I'm curious if they will fall after the surgery less than before.	A2-21		I would like to see heart rate, ECG, steps... I also have a biosensor and it measures your stress level. It's based on if you have high anxiety, you get electrical beating on your skin, and HRV. It's very much underestimated. Problem is that anxiety or stress level is a biochemical that has a direct correlation to heart disease.	A3-21		My impression about how biosensor can help is. Sometimes patients may think, "Oh, today it's a sunny day. I have a good emotion, so my complaints are not that bad." It's really a moment patients talk about their complaints, but about a period of time. The most important thing is to get the period of time, because then you know if a treatment will help or not. So you want to avoid futility. So that's the most important thing. I hope these telemedicines can help us.
P1-22		"Because the anxiety of the cardiology patient is always high. Mm hmm. And for a doctor, the procedure is his work or her work. He or she is doing it every day, five times a day. So he is unaware of the anxiety of the patients. Patients always think because it's, yes, there's something wrong with his heart that he's gonna die."	A1-22		For the patients it starts at the moment the referral doctor says "I'm going to write a letter to AMC, to ask how do they think about giving you a new heart valve." But for us it starts after the patient comes to AUMC to meet the heart team. We don't know who the patient is until the outpatient doctor sends the letter.	A2-22		Stress level and activity level are important, they're correlate with each other because if I'm obese, I don't move and stress is high, then my lipids and blood pressure are also high. We see them as 10 separate factors, there are a few main factors. So if you can focus on that.	A3-22		What I meant was a period of time, I'm thinking more like a month. Because aortic valve stenosis is not really fast progressive. So it will be more like a month, in general.
P1-23		"Did the patient already get the TAVI treatment? If not yet, that's difficult to buy a sensor. I think it's more a medical question. But for me as a patient or from a patient perspective, there's always a group who wants to know what their heart rate is. But there's always a group who finds it confronting and gets scared at this information. I think it's very individual."	A1-23		I'm curious how much they exercise afterwards, like coming out of bed or walking through the wards. I'm curious if they're becoming active immediately or take a little time thinking "No, I will do it carefully." Because we also say in our information, they have to become active as soon as possible. But I'm curious if they really do that. **Because we try to educate and inform patients,** we think patients understand and will act as we say. But most of the time patients didn't understand the way we meant. So I'm curious how they do in real life.	A2-23		During COVID-19 we're doing rehabilitation online, which is very nice. Because like I said, the surgery is one thing, but the things you do afterwards optimises the outcome. So we do it with zoom, and with only 5 patients. Normally in the group there are 12 patients with 3 physical therapists. There's also a nurse and a doctor.	A3-23		But I can imagine that only if you have a watch or something, that the patient wants to wear every day. But otherwise, I think it would be best to do one day, every three weeks, etc. And then you can compare it in like three to six months. And then probably different times of day, comparing between weekends and weekdays, or when they do sports versus just having a relaxed day. It's really important to measure trends.
P1-24		"If you put the sensor on the patient, then I think it's important for the patient to know where. Where do you want me to put it? Can anybody else see the sensor? Or is it underneath my clothes? If I'm moving, is it itchy, or is it falling off? I think from a patient perspective it's more on the daily life, what does it mean for me? So I put it here and everybody is looking at it and they're going to ask me questions about it. Not every patient wants to tell everybody about this sensor. "	A1-24		When we started TAVI, I saw the patients after the procedure, but now I don't see the patients after the procedure anymore. They go back to their own cardiologist. So sometimes you get some information from their own cardiologist, but it's different from when I see the patient in person.	A2-24		We first talked to all the patients, and then we asked "How did it go last week? What have you done outside? Have you moved? Did you have your medication with you?" There should be another person in the room also, because if they get a problem, then someone and take action. And if there is a problem or a question, I can put them in a separate room with the nurse or the doctor. That takes around 20 minutes. Just asking "How is your day? Did you experience some problems? Do you know what to do if you're experiencing this? What is your goal?" At least I know if the patient wants to hike or bike again, and the patients think I know them very well.	A3-24		Because the complaints of aortic valve stenosis are especially during exercise. And also because of calcification of the valve and its conduction system, that can be measured as well. If you have a broadened (sth) duration, or conduction disturbances during night, or whatever, that can be helpful for the decision making as well. Now in the referral letter, you can see the heart rate in the EKG, but the other things are not included.
P1-25		"When receiving the patient, I think at first it needs to be informed by the medical doctor. But if you are further in this project, then maybe you can ask an experienced patient how did you do it and how was his experience? What are the do's and don'ts or do you have tips, questions or anything? "	A1-25		Sometimes the patients say immediately after the TAVI, "Oh! I can breathe more easily!" But they're also patients, like I said before, they need a new hip, and they say, "After I get a new hip, and then I can start exercising." And they don't experience any change right away. So that's different between all the patients. But these are patients with clearer opinions, like "I feel a lot better" or "I don't feel better, I can't exercise more because of my hip." There's also a grey area of patients, you don't know what they're doing in normal life and what they expect.	A2-25		And then we do exercise. Training consists of 7 exercises, 30 seconds exercising and 20 seconds rest, and then we discuss it on the BORG scale. It's a scale from 10 "I'm exhausted" to 0 "I'm lying in bed". So How heavy the exercise is, it has to reach at level 5-6. Then you also do the cardiac little to max training. And we do three rounds.	A3-25		I think when patients are asymptomatic, then the biosensor won't help that much. Normally, when we have found a severe aortic stenosis on the echo, and patients say they don't have symptoms, we perform a treadmill exercise. During the exercise you can see the condition, what the EKG performs or what the blood Pressure does. So that mimics these telemedicine measurements (like the heart rate, EKG, respiratory rate, step count.) And these measures, you can see when they get the complaints, how good the condition is.
P1-26		"I think it's also very important for the future patients that if you have the biosensor ready, you publish in medical magazines, but maybe you can also publish in your patient organisation magazines, for example, hearts stichling and the bigger organisations. Or maybe make an animation from a patient perspective. Nowadays patients are very handy with the dr.Google, you can find everything you want on the internet. So if you have information also important for patients, then you have to put that knowledge. Yeah. For example on the HartStichting. "	A1-26		There's a lot of difference between the patients and the information you get from different referral cardiologists. It's difficult to study the improvement afterwards.	A2-26		Sometimes you see the patients are sweating, shows that's very good. Sometimes a second nurse is also looking at each patient, because when the trainer is doing the exercise like this (demonstrating exercise), the trainer can't see the patient anymore. So the nurse signals the trainer when someone is stopping, and then we ask "Why are you stopping?"	A3-26		When the TAVI decision is made, and they're scheduled or on the waiting list for the procedure, I think the biosensor is the best for comparing afterwards, how the patients improve. So the step count is not that helpful at the pre-procedural stage, they won't exercise very much because of the complaints. But maybe you can help this phase in differentiating which patient has to be treated first or which patient can wait a little bit longer on the waiting list.

A4		AUMC Secretary	A5		Outpatient Cardiologist
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences
A4-19		"Now in COVID-19 we don't have a group information session. Only specialist nurses are calling the patients by phone, they're checking all things like medications and what they normally do in the polyclinic appointments. So I'm only sending the information, planning the CT, and checking everything for the administration (i.e. plan for the bed orders and for treatments appointments)."	A5-19		Do patients go to rehabilitation, what are the challenges: They go to you for rehabilitation. Physical therapists are already in the clinic, so when the patients had the TAVI, the doctors come mostly a day later or two days later at our clinic to visit or inform the patient.
A4-20		"Normally patients get acceptance letters after their appointment with specialist nurses after the polyclinic. Now we don't send acceptance letters. When we can do a group meeting again, I will check all those people who still have to go and invite them for a group information session. If that's possible for small groups like three people at this moment, because it's a fairly big area, maybe we can set up three people, and still inform them to do a polyclinic like we did. Yeah, it's different.."	A5-20		When they are discharged, after two-three weeks, our rehabilitation nurse will call the patient, and then they go into a rehabilitation programme at our hospital, and they get physical exercises with the physicians. It takes about 18 sessions in nine weeks, two times a week. And then we have also consultation with psychologists, dieticians, a cardiologist like me who is informing "what the patient had, what was the procedure..." So these consultations 4 times.
A4-21		"After the surgery, they go back to their own hospital or to their own (outpatient) doctor. For me, my responsibility ends when I plan for the treatment. Some people I see again after surgery, a few patients I had more contact with because I have met them in the hospital myself, it was like "Oh, it's nice to meet you again! How are you doing? Are you still laying in the bed?" But that's just my own personal interest for them. But for my job, I plan the surgery, I arrange everything for the treatments, transfer to the nursing, and then their own hospital will take over. They do post-surgery check-ups by their own hospital, not in the AMC."	A5-21		After the treatment, most of the patients already had echo in the AMC, so we will do that again in our hospital, ECG, laboratory test where necessary, physical exam, blood pressure pills, etc. And telemetry also, within three days long, to look if there is no LBTTP or that there is no AV block that kind of thing. Because when you give TAVI, you pressure the old calce fall on the side and that can compress the electrical mechanism of the heart. You just want to check that for 72 hours, we call it telemetry and ECG.
A4-22		"I think you can find everything in Epic, only you can check per patient. And my working list is my Excel. So yesterday I was at the hospital, and I will check all my on-hold patients, most of the time because they found something else at the CT scan. It's more like checking my to-do list. Specialist nurses can also check my Excel file. I'm working on it and they're checking. With this excel I have an overview of all the patients, Epic maybe can give an aggregated view, but I can't get an overview (due to authorisation). "	A5-22		Who is communicating with the patient after TAVI: I think that's the clinical doctor in shift, and also the physical therapist.
A4-23		"I counted like 70 clicks just to make an appointment in Epic. So you have to make an order, then you have to make an appointment, and then have the documents to put all the data (i.e. from the imaging lab, from the CT) all the things I know I already put it in so only the doctors have to check. So everything I can find already put it on Epic to prepare for the file. And now all I do is click, click, click, .. first time doing this task I took five minutes per person to prepare for the meeting. And now I can read a file very, very quickly and find all the data I need. But for the first time, I was like, "What do I need to look for?" And you have a file like 20 pages and you're checking all of it. So if it's your first time, I think you need 10 minutes to prepare one person for the (MDO) meeting. But now, five minutes each or so. Now you first have to make an order. An order it's like just a lot of clicks, it's not very difficult. If you have to order, it will be over here (showing on screen).. From that, you have to make an appointment, and if there's an appointment, then it will come over here (showing on screen)." → prepare the materials for MDO meeting	A5-23		After rehabilitation, how is the process? what would you like to improve?: We see them when they are going home, then after two-three weeks, within two weeks they are called by the rehabilitation nurse and then they are going into the programme. It depends how it went. When it's uncomplicated, then I see them about six to eight weeks; when it's really complicated, and yolu see them earlier at the outpatient clinic. If there is no echo after the TAVI then you make an echo, otherwise you make an echo after about one year.
A4-24		"What the doctors check is the alpha, the diameters of the blood vessels from the aortic valve to the legs, they need five or six millimetres to operate through with a catheter, also which medication. Anything I can already prepared, the doctors are already happy with. After checking the information they make a note. And it will be like this (showing on screen), this is from MDO. Most of the thing I have to accept it. If it's accepted, I can go further to inform the outpatient hospital. Which person planned with the polyclinic or the group information session. But there can also be situations that need more research until they can be accepted. The diameters of left and right legs. The distance from coronaries to the aortic valves. The alpha, showing how big the valve is. That's the technical, the most important thing to prepare. Yeah, and the lung and kidney function. If I'm not sure I can always ask the doctor. I'm not an expert in this (diagnosis), and the doctors in AUMC are really nice, I can just call them to help me out." → parameters for risks	A5-24		So the first outpatient visit is between four to eight weeks, the second is mostly between four to six months. We haven't standardised and it's just some cardiologists like me prefer to see them within four months, but when it's really going well you can also see them for about six months.
A4-25		"When the patients are referred to a geriatrician during admission, I will not know, but the specialist nurses know and I can check that with them. Most of the time, I'm checking with the GR when there's an appointment. When I know what date the appointment is, I can just set it in my Excel file. On Fridays and Mondays will be the MDO meetings, I will probably have CT results at that time, so I can send the data over here (shown on screen). When it's colored, indicates it's planned. That makes it easier for me when I have to make an agenda for the MDO, I can check all those coloured columns and prepare them for the MDO."	A5-25		Who's communicating the TAVI patient in the recovery phase: I think that is really within the rehabilitation programme. And I think the cardiologist is the key to everything in the whole process.
A4-26		"Sometimes I arrange the referral to the geriatrician for them, sometimes their own hospital arranges it for them and the (outpatient) secretary will send me an email well, date is planned and I will keep you informed. So every time is different. That makes TAVI a little bit difficult because every patient has a different journey. If they are from the AMC then they already have so much information from their own doctor because these doctors are experienced."	A5-26		In rehabilitation there are all kinds of patients after operation. For example after infarction, after PCI, and also heart failure patients. Most of the patients really like it to join the programme, because then they are with more people doing exercises and it's give a good balance.

P1		Patient Communication Specialist	A1		AUMC Specialist Nurse	A2		CardioVitaal Coordinator	A3		AUMC Cardiologist
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences
P1-27		"Maybe if my neighbour needs the TAVI within one month, and I read that article about the sensor. Then I can tell him 'Hey neighbour, you got the TAVI your I got some information about the sensor that you get.' The patients often belong to a tight community, and there's always people like me who know a lot of Cardiology and then they can advise peer to peer."	A1-27		In MDO, when we make a decision, we (heart team) haven't seen the patients yet. So we make the first decision of which catheter is going in (i.e. femoral or aortic). And afterwards I see patients in the polyclinic. When there are some strange things needed to discuss, I will get back to the cardiologist and we'll discuss. Or sometimes I will talk to the geriatrician first, because they have more experience in eldery patients. As for planning which patients need the procedure and when, we (specialist nurses) decide on our own.	A2-27		Sometimes the patients stop and say "Well I'm afraid I'm doing too much", then we reply "It's okay, I don't think you can do too much for this moment. Just give it a try." It's not only the exercise, but also the context around it.	A3-27		Measure of anxiety, we have it in the frailty score questionnaire. In the preclinical phase, t's sometimes very difficult. Because you try to convince patients that they need the treatment, but they're so anxious about it, and they don't want it. But that's not good, right? So that's sometimes difficult. You can only try to explain once again, what can be the side effect if they don't treat it.
P1-28		"Relying on their physical rehabilitation. Trust their own body again with their new biological valve. And later on, it's more a mental challenge. "	A1-28		For follow-up with the TAVI surgery, we have a registry that is necessary to enter the NHR (National Heart Registry), and that's not my job. But there are a lot of people who are putting data and to see how we (AUMC) are doing and how other heart centers are doing. So you can see how the other hospitals doing (i.e. pacemakers or admission time or some endpoints) NHR want to know from all the hospitals doing TAVI how they are performing. So it's not particularly on patient level, but on hospital level. With the individual patients we don't know.	A2-28		CardioVitaal has 10 places in the Netherlands, where they do heart rehabilitation in the same way. Three years ago it was AMG, but they have outsourced it because they are a specialised hospital and the government doesn't want to pay for the common things. So we have AMC patients, but it's not AMC healthcare anymore. We also get patients from CRM, also specialised polyclinics for heart problems and they also do cardiology there. So we don't only do patients in AMC, but other hospitals who send in, we accept.	A3-28		During the intervention, we always tell patients that it's normal to be anxious because it's unknown to them, and that we only hope that afterwards they can tell that it was quite okay.
P1-29		"Some people are not so active or that little bit depressed. So I think it's important to also help them with that. Give them the possibility to get help on the mental situation. I think it's also good that you only just mentioned it. For instance, 'it's possible to have some unhappy feelings' or here you are at rehabilitation and you said to yourself, 'I want to walk for one kilometres', and you don't come to that goal. I think it's good to say it's okay. Maybe tomorrow, you will finish that goal. And maybe it's a way of acceptance that you probably can never reach that goal. That's very personal. "	A1-29		After the treatment, I don't see the patients at the outpatient clinic. So when the patient has post-procedure problems or the referral cardiologist makes an echography and finds abnormalities they want to discuss, we will answer those questions. Very few patients later on have questions, the referral cardiologists will solve the problems themselves. That is not the main responsibility of my role.	A2-29		My concern about implementing biosensors is that patients have different social levels. For example, BME groups are often vulnerable people from lower social groups, they tend to have higher risk. And a lot of the people don't have high digital literacy or don't know how to use a smartphone or laptop, that will be a problem. How can we reach these vulnerable people in lower social groups? → the access to digital resources and the ability to understand these information would be kind of creating a barrier for these people to join the telemonitoring programme	A3-29		For rehabilitation, I think it can be very helpful that they know when they're in their home situation, what is normal, what is not normal. When do I have to contact the doctor? Yeah, that kind of thing.
P1-30		"I think if a patient says yes to this biosensor wants to get to know about this disease, what does it mean? To be as healthy as I can be? How can I enlarge my quality of life? How can I live longer, with the good quality of life. The patient is in charge. That can be important for patients because they are a part of the treatments. I think it's based on equality. How can I help the doctor to improve this procedure for the next one. So if I'm sharing my experience with the doctor because he wants to know all of my data, then I know I can be a part of that circle, if you can help others. I think that's the motivation of the patients who are saying yes to the biosensor."	A1-30		I think, for example, it's interesting to see how frailty of the patients is and how the outcomes are. Because you can imagine more frail results in longer admission time. That's not the only reason, but it's what I want to know, but I don't have that information. So I'm now doing research on my own, from frailty to not patient level but group level, like low frailty a little bit frail. To see if it's true the tool we now use says something about the outcome. Do patients have higher morbidity? We actually don't know for sure.	A2-30		A problem is that for each sensor module you have separate devices. It would be very helpful if we can combine all in one, so you can track the heart patient.	A3-30		The post-procedure is mostly about conduction disorders. "Braddy" means very slow heart rate, under 35 and "tacky cardiac" is above 100. Best would be that you get an alarm, like "This is too slow." Or when patients get dizziness or something like that, they can push a button, and then you immediately can check what the rhythm is at that moment. This kind of device is not used in TAVI treatment. Only sometimes we have alters we give them, but that's when they complain about palpitations. Of course 72 hours after the treatment, they are monitored in the hospital. It's real time, there are always nurses looking at the screens and early warning alarms.
P1-31		"Is the relationship between patient and doctor equal now? That's a difficult question because I think that's also depending on if it's just a one lifetime experience that needs to be done or if it's more a chronic disease where a patient is living with. For the chronical patients, I think it's more on an equal basis, because they have built on a long term relationship with their specialists. There's trust and a good relationship. However, with the patient who was only coming to the Amsterdam room for just one procedure, there is nothing. Yeah, there needs to be a safe trusting just for the time that the patient is admitted. But when the patient is going home or to the hospital, you don't need to build on that relationship. That's too short in time"	A1-31		There are a lot of different ways to measure frailty. We used the (check name) frailty scale. In the Netherlands they said with TAVI, that's a good scale, as the advantage is that everybody uses the same scale. it's nice because from surgery they use strength like hand shaking... etc. So it's nice we use the same tool.	A2-31		For rehabilitation, I think the main thing I want to know is the heart rate, single lead ECG, and step count. The respiratory rate is nice, but I have to do a zero measurement: what's normal for this patient. During my work, fall detection is not so important.But in a hospital that is the main thing. Position is also not so important. Well, it's important because by specialised problem, it's very important if they have a strange ECG, what position were they in?	A3-31		(Showing the guardian ward monitoring system after procedure) So this patient for now is admitted to the ward, and we now have a real time look of what the monitoring of this patience looks like. So it's rhythm, heart frequency, blood pressure, respiratory rate.
P1-32		"But if you are implementing this biosensor, then I think you can build on that relationship with that specific patient. Maybe it's just maybe it's still the patient of the other hospital. But if you're giving that sensor or monitoring then I think you can contact the patient once in three months or voice dying off are you doing? Are everything fine? Do you find that the biosensor yes questions. Can I help you with something? Then the patient is feeling Oh yeah, yeah this sensor I'm wearing is from researchers where I underwent my TAVI procedure. Then they can put the pieces in the puzzle of this whole mixed process."	A1-32		But besides from the frailty scale, there are a lot of other measurements that can say something about frailty. So like, BME (Black, Minority and Ethnic group), height and weight that say something, (element) in the blood can say something, Kidney functioning... So there are a lot of things, and we don't know yet what's the correlation of all the things. What's the most important factor, we don't know yet.	A2-32		Does step count work also when you're biking? I want to see how much the patients move, but the step count is only a small measure of the possibilities they are doing. For example, a patient likes to bike, but then the step count says it's zero while he's doing the right thing for rehabilitation. Another example, a lot of ICD works only work the movement of the arms. So if someone walks, he moves his arms, then he gets a higher heart rate. But it does not track when he's biking.	A3-32		After 72 hours, they go to other hospitals, until they go home or to a rehabilitation ward. Depending on how everything goes and how their social environment is. But normally between three and five days, they're going home, and then a rehabilitation programme should start. The rehabilitation can be done at home already, and I think the biosensor can help a lot.
P1-33		"I think the benefit for the patient from peer to peer is that you all have experienced sort of the same exact procedure. One word is enough. The doctor will never understand it in that way if you're bringing up this subject as your peer partner will help. And of course, it's always personal, but there are always experiences we can resonate with. Either mental mental challenges or physical challenges.."	A1-33		I heard from my colleague, there was a study about the heart rate before TAVI says more than all the other things. So we don't know what's the best way to measure. So that's also what I meant, it's also to study to get more data and more information, because there's a lot we still don't know. So we can put measures in and see if the result says something.	A2-33		I suppose if the patients want to use the biosensor after the rehabilitation, they have to use it during the rehabilitation, so they get familiar with it. You have to integrate it in their daily lives.	A3-33		The physical therapist, they pass by during the admission of rehabilitation, so they can give some exercises already. And then they can refer the patient to the rehabilitation department. Or in the polyclinic, we have a button from CardioVitaal, which you only have to press and then they're assigned to CardioVitaal.
P1-34		"It's also a safe space. If you have a bad experience you do not always dare to tell your specialist about that experience. What but within peer to peer contact, you always tell everything. The good and the bad. And I think for the professional, it's also good to know the bad experience because then you can help improve your health care for the other patients."	A1-34		The end points are now in discussion. Because we are used to looking at the endpoint like mortality and admission rate, but we now have a change in mind to look at what's important for the patient. That's also when you have the patient who says, "I'm glad when I can do my shopping alone," or you have a patient who says "I want to run the five kilometres again." They are both still alive, but the patient who wants to run five kilometres again may be not happy when he can't start running, and the other patients can do his groceries and he's happy. So it's also different. It can be that that heart rate will say something at the end about mortality, but does it also say something about how the patient is doing.	A2-34		Same people get very joyful from tracking and other people don't, so it's not a fit for everyone. People like it because it's nice to see data about your own function, and they get motivated.	A3-34		Biosensor improvement: METs. It's the exercise physical therapists can deliver, which measures the condition of the patient. For example, 6 METs is like walking stairs. This is a way to access their exercise capability.

A4		AUMC Secretary	A5		Outpatient Cardiologist						
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences						
A4-27		"If they're from another (outpatient) hospital they most don't get as much information, they have to come for the first in AUMC and get all the information and the CT scan. Because it's such a large area checked up by CT scan, they always find something else. Because they're old, for a patient aged 82 and probably have smoked for 30 years, because that was normal back then, they probably will find something in your lungs and they have to be checked by the lung specialist, or they find something in your kidneys or they find something else. So, every patient has a different journey. Easy patients (the ones that in CT everything is okay and I can plan straight ahead) are not that common, that's just 10%."	A5-27		I have patients who had an infection 10 years ago, and they still train every week in our hospital. It's not anymore rehabilitation, but a programme calls it "fit for the heart". They come every Wednesday in the afternoon, after that, they are going to bring us together in our restaurant. So it's really also a social happening.						
A4-28		"In the polyclinic, the specialist nurses see the person then for the first time. Before that, it was all paper. I'm always saying in the MDO, it's just all technical. So when I'm calling them for the polyclinic, I always say "the doctors have a discussion and technically they say it's a go. So now we would like to see you and check your condition if it's okay." So at this stage they know technically it's okay for TAVI, but we still have to do one step."	A5-28		Sometimes some patients say it's too far to come twice a week to the hospital, so they get a physical therapist at their village, that's possible. But that's 5-10%. Some patients really don't like to be around with other people, and they say I don't feel like going through the rehabilitation, and they're doing it already very fine at home. Then it's also good. Sometimes our physical therapist is also coming to the patient's house, but it's also a variance. Most of the time they only do it by phone and they say "Okay, you are doing it very well. You don't need the programme." Yeah, we can make a tailored programme for patients, but the standard is coming to our hospital twice a week and do the consultation workshop.						
A4-29		"Most of the time I will try to be present in the group information session just to see them, because I love to see them in person. I think the most of them will come from our biggest referral hospitals, and this will be their first time in the AMC and the first time to go through the CT and on the same day we'll go for a lab. After then they have to wait for the results, and I'm calling them for the polyclinic, or I have to call their doctor please arrange extra examinations."	A5-29		Do you see the effect after TAVI on a patient's life: I think better, so if it is successful, they can do more, and they have less complaints. That is what you want. We really do it for symptoms, because the TAVI patients are elderly patients and the morbidity after the TAVI is still high, so you really have to do it for the symptoms.						
A4-30		"The p max is the highest pressure on the AVA, if above 90, then I have to discuss with the specialist nurses or leave her a note. "Be aware we've got a high risk patient." If the alpha, the surface or the valve is smaller than 0.6 square centimetres, then it's a high risk. So I'm just checking if these numbers are critical or not. So I'm double checking if these numbers are critical, I will call the specialist nurses to hurry up the process of discussion if there's a need for decision making, to get the person as fast as possible. Our specialist nurses always told me our way of working is different compared to other hospitals, because I (as a secretary) am aware of these critical numbers, I can warn the doctors with high risk patients, and the death rates will be lower because of that. I think it's good for the patient, because patients with high risk will be treated faster." → Perhaps a screening when receiving the numbers?	A5-30		I'm very positive, so hopefully patients do feel better. But to be honest, you already make a change when you give somebody a TAVI. We also have a lot of severe aortic stenosis, they don't want an TAIV or they have so much comorbidity that we say that's the alternative. Then we just do symptomatic treatments by medication, theoretics, and also morphine and palliation. So Think the patients who got the TAVI already better than the patients. They didn't get a TAVI although they have severe conditions.						
A4-31		"In my excel files, these numbers are red when they are critical. So if the alpha is below 0.6, it will be reds. These are blue because they are planned for procedures. Here you can see the p max, the pressure, if it's above 90 it will be red and then we know who are the critical patients that need to go faster than the other ones."	A5-31		When you are looking it's an indication for TAVI, you also look at the involvement of family when you're making a decision, yes or no. Because when a patient is totally alone, they can't take care of himself/herself, then the patient is very fragile. It can play a role to decide not to give a TAVI. If the family is very involved and committed, it makes the patient less fragile and most of the time the rehabilitation will be better than without social support.						
A4-32		"For instance, due to COVID-19, VUMC were freezing all the programmes (i.e. CT) last month. Since we were still doing some of the treatments, we decided to get some patient files. And then I found out they have some patience with the 150 p max, but they're still working with them. So for me it was like, "Oh, we need to help this person!" The other secretary wasn't aware because she didn't know. What I heard from the other hospitals, secretaries also don't check that. I think it's because my responsible cases are all about the valvular diseases (i.e. TAVI) and I have like 250 procedures a year, and VUMC has like 60 procedures a year. And there were three people on the VUMC secretary team, so then you have to inform all of them in different shifts. VUMC didn't send the information folder, they didn't do a group information session _ AUMC specialist nurses are trying to get that in the future. In the future, all those things will come to the AMC because we're working together."	A5-32		I think social support is very important for the patients. For example, when they have to undergo all the tests at the hospital, it's nice not to do everything alone. Because some don't have a driving licence, and they can't come to the hospital. For example today I'm now working at home, but I had a patient that I want to see. Because of COVID-19, we reduced the outpatient clinic and I just informed the patient. But he said to me now, I don't want to come to the hospital because normally my son is coming with me, but now he is not allowed to come to the hospital, so I can't come to the hospital. The example says something about the social support and frailty.						
A4-33		"It will be the best if my working list can be arranged in Epic, but I don't think with all the information I'm checking in the file it's possible. Because I'm also getting numbers for management information (i.e. measurements of the valves? Which hospitals referred? How many applications did we have? What are the decisions out of these numbers?) All those things I can get out of my excel. I think you can get it out of epic, but epic won't allow you, probably due to privacy reasons or not authorised. Epic is a good system. It's made for a patient's journey and their file. So it's not made for research or for professionals, it's made for the patient."	A5-33		ECG is useful, because of the possibility of electrical disturbance after TAVI. I think 5-10% of the patients need a pacemaker after TAVI, because there's an electrical disturbance due to the surgery. But that's mostly perioperative, within the few days at the hospital. But do we need an ECG device in the outpatient clinic and to make an ECG at home by biosensor? I don't know. It's interesting for research purposes, but from a clinical point of view, I don't know if this is handy for me.						
A4-34		" I think all the contacts you have with the patient during the process will be good for them. The biggest fear of patients is to be forgotten. Waiting is always long, no matter if it's one day or two weeks, it's always too long. So if you can give them anything to connect, that will comfort them. Let them know the hospital is still working with me because I have these (biosensors) attached."	A5-34		The respiratory rate is a very sensible tool to look at the patient's condition. It's very sensible, perhaps even too sensible. Because when somebody is stressed, they are going to respirate faster.						

P1		Patient Communication Specialist	A1		AUMC Specialist Nurse	A2		CardioVitaal Coordinator	A3		AUMC Cardiologist
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences
P1-35		"If you really want to know what the patient wants, just ask, do not fill in for them. Don't talk about them, but speak with them."	A1-35		So that's what I meant: you can measure things and that have a prediction on mortality, but the patients want to know what he/she can do afterwards. And of course that is important, but they are also at this age, a lot of patients think "Yeah, I'm more afraid of not being dead, but losing more control of my life" And maybe have a complication in which they can't walk / talk anymore or become more dependent.	A2-35		The transfer is via the cardiologist in AUMC given an order in Epic, or the outpatient cardiologist will send by a secured mail, which is a letter of 4-5 pages. The information contains the operation procedure, how it works with the patient, what is the comorbidity, what kind of medication does he have... And we stay in contact with the cardiologist. Because when we think he has too much medicine and his heart rate won't increase, they we contact the cardiologist and ask "Can you change the medicines?" There is always contact with a referral cardiologist. Also the last letter is going to the general doctor at his home and the outpatient specialist of the patient's own hospital.	A3-35		Personal goal would be the patient's motivation to go through the treatments or all the side effects. Unfortunately, that's almost never written down. And then most of the things I think has to do with "family". They want to see their grandchildren grow up, or they want to do more social things like catch up with family like. But for that, they need to be able to walk or not fall.
			A1-36		When we start measuring things, we have to think what affect do we think of? What kind of endpoint? I can imagine that that heart rate doesn't say anything about how their life is afterwards.	A2-36		You have a cardiologist of the hospital, and a cardiologist of the rehabilitation center. The cardiology specialists of the hospital get a report of how it went after three months but do nothing with it, you don't read it only when there's a question. I think he will do nothing because he's very busy with with operation and polyclinic. So the treatment of the rehabilitation is another world. In rehabilitation centers, we will be interested in the data. For example, normally the patient will only start about 6-7 weeks after to do the rehabilitation, but if you're wearing the biosensor and I explain it in the hospital to the patient, then I can give him feedback about what he's doing. And then I can say to him, Well, I see that you're doing almost nothing, so we'll look into the biosensor and give you a goal. If you agree, try to double the steps counts for example.	A3-36		Information such as personal goals are not discussed in the MDO now. I think it would be very helpful in the MDO, especially these are geriatric patients with sometimes already dementia.
			A1-37		When I talk to the patients, they're very different. They don't always tell what they expect. A lot of patients are focused on "Oh, I'm worried about the procedure and I hope I'm gonna be back at home a few days later." And then there's another part and they start thinking, "Oh, everything went well!" There are patients who think very much about the procedure, are confident and do their exercises. But there are also patients who wait "About in about eight weeks, I can go to my cardiologist, and afterwards 'then I try we'll try moving." So that's why there's a lot of difference. And we don't know how different expectations impact the surgical outcome.	A2-37		Especially for TAVI, because they have to wait for six weeks, we can start earlier in distance with biosensor. That's what I hope.	A3-37		Specialist nurses perform the Edmonton frailty score, questionnaire, and some exercises. And if the patient reaches a certain amount of points, then she contacts to geriatric department by telephone. Sometimes after they decide it's better to refer them to a geriatrician consult. If the geriatrician has a recommendation, they will share either by phone or just in the Epic EHR.
			A1-38		It's difficult with the information. The patients get a lot of information, and we are always thinking about how we can do it in the best way. You can't give them all the information at the same time. Because before the procedure, they actually think of the procedure "Will stay alive? Will I be okay?" And actually afterwards, and that's the job of the referral cardiologist. They have to do the next step, because we can't tell it beforehand. It doesn't get in their heads sometimes.	A2-38		If you look at the organisation of healthcare, you have the first line, second line, and third line. The first line is the GPs and the physical therapist. The second line is the hospital. And the third line is the specialised institutes. Now what we are doing is one and a half line. It's a different payment, different organisation. So if we get a patient for the AMC, the patient leaves the AMC, and goes to different payment , administration, and different responsibility.	A3-38		Part of the MDO, also some side findings from the CT scan. Sometimes you see other diagnoses which were not found, but because you make a CT scan. Sometimes things just has to be sorted out before you can get the TAVI.
			A1-39		That's why we're also trying to give the information in parts. Also on the internet, but that didn't work well. We're now in a discussion, which medium of the information, which has lasted for almost a year now. So the information they get is the flyer and the conversation.	A2-39		Now we don't know exactly about the participation rate, but if we see the inclusion of rehabilitation, and we know that the output of the AUMC, 30-40% patients would go to rehabilitation. And we have the goal in AMC and CardioVitaalto reach all the patients. There are a lot of barriers, for example the language, very old. We have now also a specialised programme for all the people who can't go to hospital-based programmes, the nurse and physical therapists will visit at their home. That's only for the people with problems so they can do rehabilitation. The patient will see the same physical therapist in hospital and home. That's good because then the patients get less disorientated and it's a warm feeling. The physical therapist knows him already.	A3-39		The diary function would be helpful that you can see whether the patients are less frail after the taffy than before the TAVI. Because you hope that the patients will exercise more. They have less symptoms, they can walk better, and they can support themselves better, so that they will become less frail.
			A1-40		We had information/education on the internet, it was from Medify, but then they switched to MediMap, but each tool has its own difficulty..., so we're trying, but it's difficult. Sometimes it's about money. For example MediMap is a good tool, as they told us, like, when you are a patient, you can log in and you can see which step you are in the complete process. That's very important for patients.				A3-40		Actually I think it's six weeks for rehabilitation, but it started only six weeks after clinical admission, so indeed the follow-up is three months after they finished the programme. But we don't show outpatient, we only perform echo.
			A1-41		Afterwards there is a gap, I think we can do better afterwards for the patients. But from our point of view it's very difficult, because we get patients referred from 15 different hospitals. And you also see the difference. There are some hospitals who have very good programmes afterwards, but they're also hospitals who have nothing. Because of the age and the travel distance, it's not ideal to say you can come here to the AMC and do the rehabilitation, because patients have to be driven by their family, etc. I'll discuss with patients which hospitals nearby have a good programme.				A3-41		In the follow-up after three months and after one year, we discuss the patient's complaints, if they have symptoms, how they feel. We look at the EKG, whether they have conduction disturbances or change in EKG. And we look at the echo to see the performance of the valve. Hospital readmissions are rare cases, it's more to check how the valve functions.
			A1-42		Sometimes I will also tell the patient "See if you get confident enough to start moving again. When you feel you are scared or not confident, please contact your own cardiologist or your general practitioner, and discuss what's the best way for you?" Because sometimes, a physical therapist can visit a patient's home, when you have a very frail patient who can't come to the hospital. It's very difficult to discuss the recovery plan very specifically before the TAVI.				A3-42		The referring cardiologists, echocardiographers, and specialised nurses who perform the EKG and blood pressure. These are the medical team that is involved in the follow-up.
			A1-43		Most patients experience lack of information. Starting from the cardiologist saying, "I'm going to write the referral letter" and until the AUMC secretary calls them. It takes weeks. There are referral cardiologists who at the end of the day have already written the letter and sent all the papers to the AMC. But there are also referral cardiologists who would do it after three weeks and then when we get it it's not complete. But the patient still thinks," Oh, I'm waiting, but there's no progress, hos is it possible? Where am I? Am I in my own hospital, orr am I already at the AMC?" You see when the patients are referred from the heart team to us, the secretary is calling, they're like, "Ah, thank god! I'm no number anymore, I'm who I am." The patients are relieved then.				A3-43		What can be improved in Epic, would be best if the most important images from echo or catheterization are labelled. Because they make more images, sometimes it's really necessary to have a general information. For example, image number 43, there you can see best the value or you can see the gradient over the valve.
			A1-44		We're thinking about filling in the gap, but we're still not there. Because if we are going to start that, we have to talk to all the referral hospitals, and they have to all set up the same thing. And that's very difficult. We'll think about starting with the three hospitals with the most referrals.						

A4		AUMC Secretary	A5		Outpatient Cardiologist						
Code	Theme	Quotes/Evidences	Code	Theme	Quotes/Evidences						
A4-35		"My biggest discussion with specialist nurses is they say "Oh, this is an urgent patient, we have to plan this fast". And then I say, "Well, but this person is already waiting for six weeks, maybe we have to do him now." And they say "but their rates are not so severe." Those measures were taken six weeks ago, how do you know the condition now? So that is always my discussion with the specialist nurses. For them it's nice that I'm always checking with. "Are you sure?" Sometimes they say, "Yeah, you're right, I'm calling." "	A5-35		To be honest, I'm an outpatient cardiologist. Numbers are important, but first you have to focus on the clinic. As an outpatient cardiologist, I'm afraid that I get a lot of data, there will also be a lot of noise. And I look at a lot of data and then I think "oh, have to do something with the patient!" And then you call the patient, but the patient replies "Oh, no, I'm doing fine." That's the difficulty with a biosensor. I think that is a fear that all the doctors have, that you have a telemonitoring solution, that you get so much data that there's so much noise, and then you give yourself a lot of work or treating numbers but not the patient. That is my concern.						
A4-36		"If the patients have a biosensor patch, you can track their health data at home, just by connecting, they don't have to go to the hospital? Is that how it works? Then if the rates are getting more critical, then you can call them, comfort them or change the medication. Or plan the procedures faster than it was. Especially sometimes it's a very long time from the first time we get the file at the heart team and sometimes it has been months before they get accepted because they have the lung function. Sometimes oncology needs to be checked … and then it will be months before another CT scan, and then it will sometimes take four months before they finally accept it. So I think the biosensor patch will be good. If their kidneys / lungs are failing or in a bad condition, they will not be accepted in TAVI. Yeah, they find all kinds of terrible things on the CT. Then they need to go to lung specialists and other professionals. For me, these patients are still stand-by, not on the TAVI waiting list." → value of biosensor: stay connected	A5-36		With the posture, step count and level of physical level, you want to know if patients can do more activity and exercise after the TAVI, so I think that can be useful to know your clinical success.						
A4-37		"It's really bad for a patient to go for a CT just to check if he/her can get a TAVI, and then one week later his her doctor call "We did a CT for the TAVI, probably you can do it, but I'm sorry we found something in your lungs, we need to check the lungs." At that moment the patient is with the oncologist and checking the lungs. They're happy if the prognosis for these lung failures are good. Every patient takes that differently. Sometimes the patients are really sad because they find something else, they say " I want a TAVI, but oh my god they find a tumour in my lungs." It's for the best because you're in a very early stage, sometimes it's nothing and then you can go further, but they need to check the prognosis for all the patients who have to be more than a year to be accepted for the TAVI."	A5-37		If the patients have complaints, they just have to call me. I think that's the most important message you can give to a patient. That's not a numbers., but how do you feel? Better or dangerous? You really have to know us, because then we can take action on it.						
			A5-38		For example, if the step count is low and the level of physical activity is low before TAVI, it can be due to the aortic stenosis. I think it's difficult to play a role in the TAVI decision. Because due to the stenosis, patients are very immobile or have shortness of breath and their respiratory rate is going up. I think it can say something about the condition of the patient, but to make a decision to do TAVI or not, you really need all the other aspects like the clinical examination, frailty, echo... all that kind of things.						
			A5-39		When a patient is accepted, for us it is difficult to see in what part of the pathway they're sitting now. I know in AMC they are working on it to make that more transparent.						
			A5-40		In the diagnosis phase, when the patient's stenosis is moderate and they have symptoms, you also have to look into other reasons why they are mostly short of breath. So that is one thing. When it's moderate and they have no complaints, then we see them after six months or one year. In between there is nothing, but normally we informed the family doctor that they know what the diagnosis is.						
			A5-41		In the diagnosis phase I can't predict how fast it goes from moderate to severe, it can be very fast, but it can also be very slow. So we educate the patients, "what can be the complaints, what symptoms and then you have to call us so we get to see you again early on." So I think you have to inform the patients well.						
			A5-42		When patients are waiting for the admission, they contact me. I'm the chief, I'm their cardiologist. So if there are complaints, then I just say just call me if you don't hear anything from the AMC, and then I can see how it goes.						
			A5-43		I think it has to be faster, because the patient has more complaints. It's important that it won't take too long to wait, and I can reach AMC to ask if there is a possibility to get earlier on the programme because the condition of the patient is getting worse. Sometimes we keep the patients in our hospital and I say, "Don't go out of the hospital before you have the TAVI."						
			A5-44		I think interpreting and getting the data costs a lot of time. So really, at this moment, it's an academic question. To be honest, I'm curious. But I just want to know the results, don't give me every day a list of excel data.						

P1		Patient Communication Specialist		A1		AUMC Specialist Nurse		A2		CardioVitaal Coordinator		A3		AUMC Cardiologist
Code	Theme	Quotes/Evidences		Code	Theme	Quotes/Evidences		Code	Theme	Quotes/Evidences		Code	Theme	Quotes/Evidences
				A1-45		It's also about shared decision making. We don't know which patients don't get a TAVI because they talk with the referral cardiologist and they decided not to do so. There's also a gap, lack of acknowledgement about how often that happens, and do they do the shared decision making with the right information.								
Code	Research	Role		A1-46		We think patients should have more information earlier in the process, we think about maybe referral cardiologists have to refer patients earlier with valvular disease. But I don't know if the referral hospital referral cardiologist wants that, because maybe they get the feeling "Oh, they're taking my patients."								
A	AUMC Expert Interviews			A1-47		The difficulty is sometimes you see patients with late referrals, and then you think, "Oh! It should have been better if they have referred earlier." Maybe to ask from their opinion, not for the procedure, but what do you think about this patient? And also we talk about frailty, sometimes you can do the procedure maybe earlier.								
1	Marja Vis	Specialist Nurse		A1-48		For example, when you have a patient with severe aortic valve disorder who has no complaints yet, but he has a partner with dementia and who's living at home and it's going okay. Maybe you should give the patient earlier the valve replacement because of the complex situation at home. But that's very complex, because you also have to deal with insurance companies and all.								
2	Donne Lek	Cardiac Rehabilitation Coordinator		A1-49		The gap it's difficult for the whole process. We have our perspective when the patients are referred to AUMC, but or the patients it starts earlier and it ends later. The gap afterwards is more easy to cover I think, because at that phase we know who the patients are. But the gap before, we don't know who the patients are until they're being referred by the referral cardiologist. We still don't know how we can fix it in the best way.								
3	Marjie	AUMC Cardiologist		A1-50		We have TAVI patients about one 150–180 a year, and we also see the other patients with the mitral valve and tricovalve health problems. Also not all the patients, only patients undergoing transfermol procedure. The non-femoral procedure patients are around 60–80 a year.								
4	Roosje	Receptionist		A1-51		When I look at the digital sensitising booklet, when I see five leads ECG and micro voltage and heart rate beats per minute, I think it's okay. But the numbers afterwards, Fs hertz, I don't know how to interpret that. So that's not very useful for me. And the ECG, you have to know the heart, so that's good and the unit is okay. But then the impedance pneumography, for me it isn't very helpful. And the respiratory rate? Yeah, it's okay. But The numbers at the end. I don't understand.								
5	Dr. Liem	Outpatient Cardiologist		A1-52		For the self-report diary, if it's for patient's to fill in, you have a grey area. Like what sport? When they cycle, is that a sport? Or when they didn't fall but misstepped, does that count as fall? It also depends on how long patients have to fill this in. When they want to do it right, it takes a lot of time.								
6	Paul Kessen	Physical Therapist Researcher		A1-53		When I think about my day. I'm sleeping and sitting that's clear. But when I walk upstairs to get something or I do the laundry, what's that? Maybe I interpret, "Oh, I'm walking, I'll fill in walking." But then I sit for five minutes and then go to the garden to do something … so I don't know how easy it is for patients.								
7	Dennis	Physical Activity Researcher		A1-54		Especially it's more difficult when they have to fill it in for a longer period time. When we say do it one day or two days, I think they do it more detailedly, compared to when you say do it for a week. Best not to get the patients too busy with all the measures, instead of being in the moment and do the things. Then maybe it will affect what they're going to do, I don't know.								
B	Jos Kraal	Physician		A1-55		I can imagine it's more informative when you put it next to the other data, like heart rate and respiratory rate, to see the correlation. For example, when you sleep, it goes down and when you exercise, it goes up, that will be two groups of data.								
9	Tischa	Geriatrician		A1-56		Functionality rate it's important, but it's also about how the patients experience daily life. For example, a patient in his 80s, who has no driver's licence and is doing everything by bike. And they fall and can't cycle anymore. It's different from patients who didn't cycle at all. But it's very important for all patients that they are not dependent. They want to do their own things. So we also ask about functionality rate when we look at the frailty, but you also have people who are married for 50-60 years, and the woman does everything, and the man is functionally low, but it's their normal life. We look at patients who are very dependent and the functionality is low, we say they're more often frail. But you see, you have to know the context again.								
B	Philips Expert Interviews													
1	Martijn	Cardiology Data Team												
2	Bente de Lat	Connected Care												
3	Peter	Data Designer												
4	Jeroen	Associate Professor												
P	Patient Specialist Interviews													

G - TAVI perioperative journey

Figure B1
Pre-surgery Journey

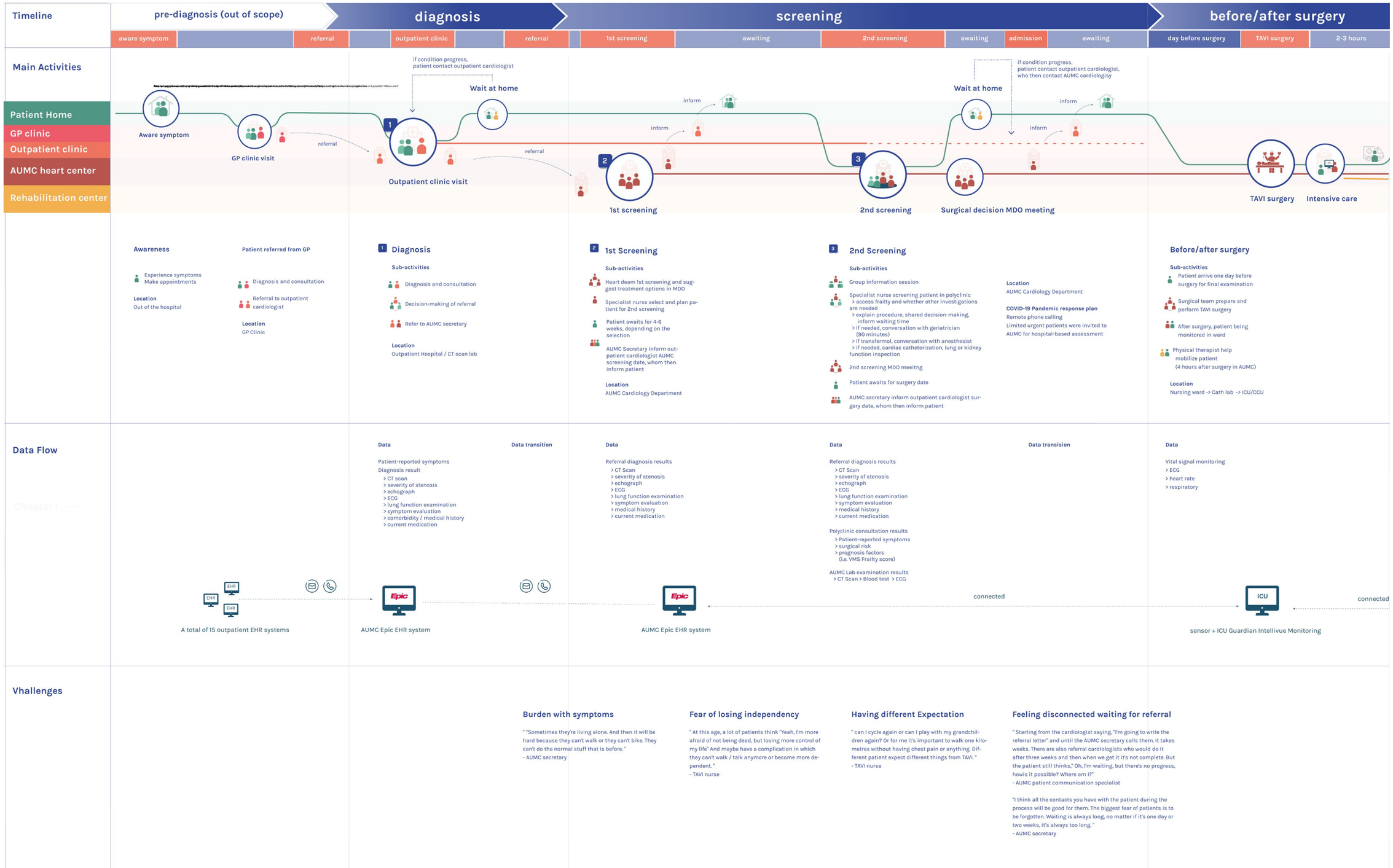
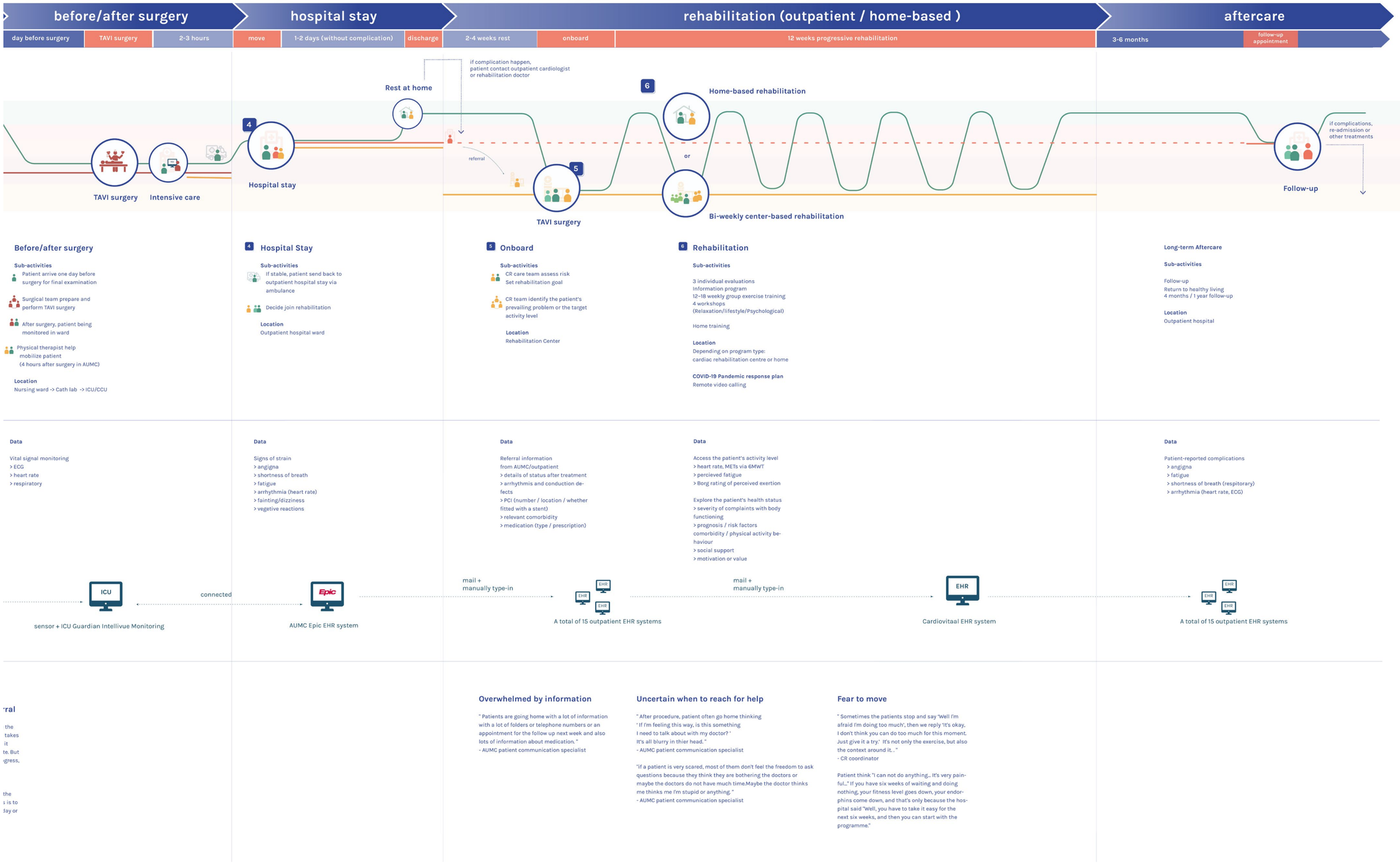


Figure 11
Post-surgery Journey



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Overwhelmed by information

" Patients are going home with a lot of information with a lot of folders or telephone numbers or an appointment for the follow up next week and also lots of information about medication. "
- AUMC patient communication specialist

Uncertain when to reach for help

" After procedure, patient often go home thinking
' If I'm feeling this way, is this something
I need to talk about with my doctor? '
It's all blurry in thier head. "
- AUMC patient communication specialist

"if a patient is very scared, most of them don't feel the freedom to ask questions because they think they are bothering the doctors or maybe the doctors do not have much time.Maybe the doctor thinks me thinks me I'm stupid or anything. "
- AUMC patient communication specialist

Fear to move

" Sometimes the patients stop and say 'Well I'm afraid I'm doing too much', then we reply 'It's okay, I don't think you can do too much for this moment. Just give it a try.' It's not only the exercise, but also the context around it. . "
- CR coordinator

Patient think "I can not do anything.. It's very pain-ful..." If you have six weeks of waiting and doing nothing, your fitness level goes down, your endor-phins come down, and that's only because the hos-pital said "Well, you have to take it easy for the next six weeks, and then you can start with the programme."

H - Philips stakeholder interview

The researcher explores together with Philips stakeholder on thier role in this project and vision of the wearable biosensor.

Set-up

The researcher explores together with Philips stakeholder on thier role in this project and vision of the wearable biosensor. The researcher uses storyboards as prompts to discuss what are potential use cases of the biosensor in TAVI journey.

Discussions

UNDERSTANDING PATIENT HEALTH BASELINE

At the starting few days of wearing the biosensor, the device collects the patterns of the patient's activity level, heart rate, and ECG, which represents what is the current normal range of the patient's health condition. This is valuable for care teams to understand the patient's lifestyle before treatment or training and get an idea how the patient's health condition is compared to the entire patient population.

PREDICTING RISK/PROGNOSIS FACTORS

ECG data can indicate abnormalities of the heart functioning, which is related to several post-surgery complications. When sensing repetitive abnormal patterns, prediction of risks will be valuable for early inspection and change of medication for prevention.

DETECTING HEALTH FAILURE SYMPTOMS

Since aortic stenosis is a progreeive heart condition, severe deterioration can lead to heart failure. After referral and before surgery, there is a period of time that patient is awaiting at home, which will be valuable to track the progress of stenosis condition with signs of heart failure.

TRACKING RECOVERY PROGRESS

To track recovery progress, it is valuable to combine activity data and max heart rate during exercise. If the participants can achieve more (i.e. increasing duration or distance) with the same heart rate, or the heart rate range has lowered with the same amount, both indicate progress.

ALERTING CRITICAL ADVERSE EVENTS

Critical adverse events can be patients suddenly falling due to stroke or cardiac arrest, which needs immediate alert of care. This would be valuable as a safety net for the patients at home.

These knowledge are then used to generate design concepts.

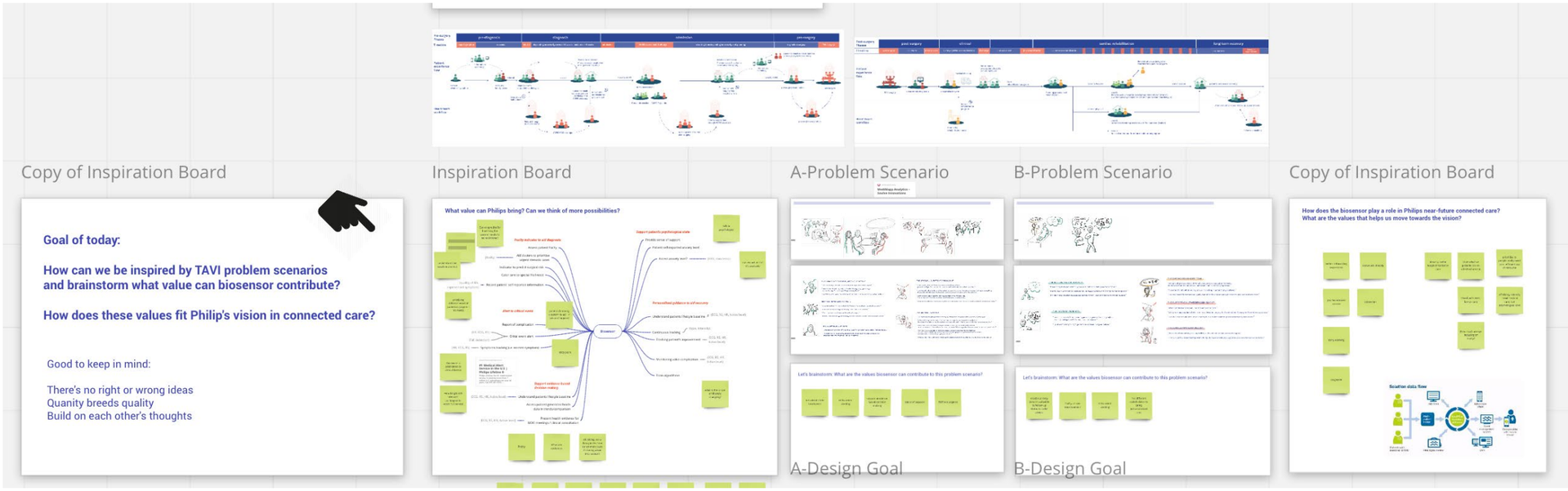
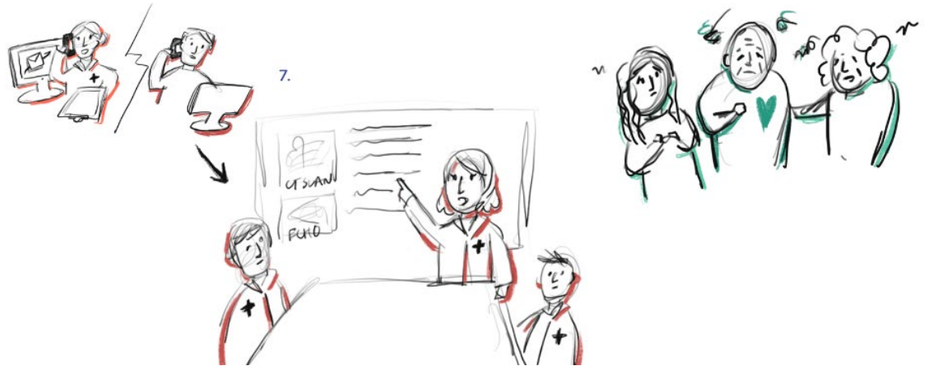
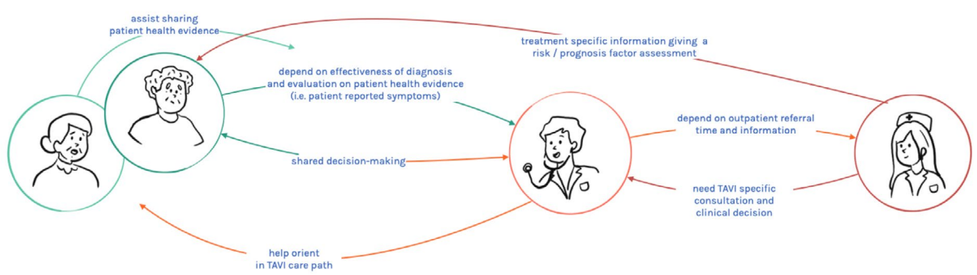


Figure 26
Impression of the creative sessions

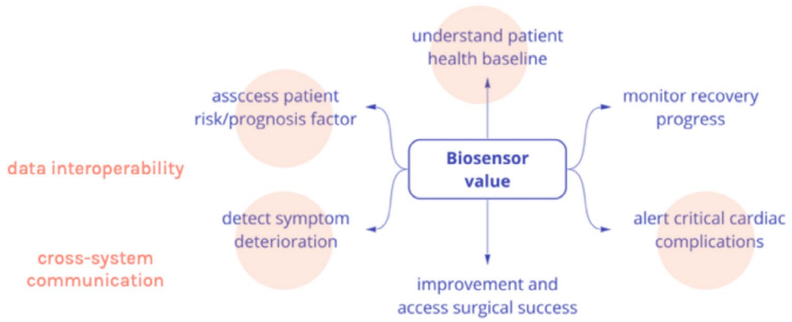
USE CASE 1: REMOTE-SCREENING

current status quo:
Since aortic stenosis is a progressive health condition, it is unsure when it will deteriorate. In the current journey, the diagnosis and selection of patients relies on referral information, which the gap of communication across care teams may delay providing patients appropriate care. During this awaiting time at home, patients feel disoriented and burdened with symptoms, which makes them anxious about the treatment.





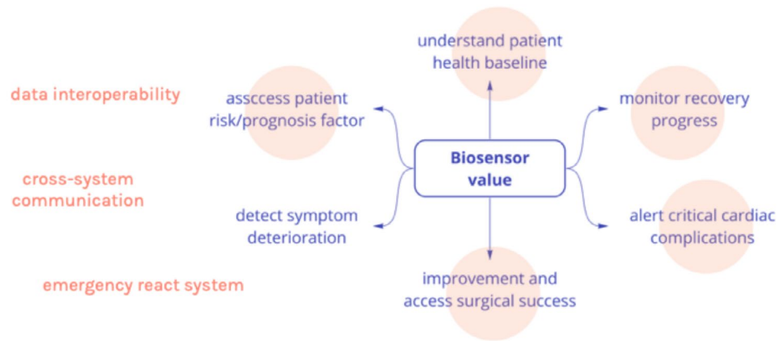
What if the current screening can be supported with remote telemonitoring?



USE CASE 2: HOME-BASED REHABILITATION

current status quo:
While TAVI procedures bring benefits such as shorter hospital stay, patients are uncertain how to safely return to healthy living. Patients and informal caregivers feel uncertain of how active can the patient be, thus results in under-/over-achieving of health goal. Without knowing the patient's health status in the home environment, trainers struggle to provide personalised feedback or support. The problem prevails during a rest gap between hospital discharge to rehabilitation, and again after the rehabilitation.

What if the home-based rehabilitation can be supported with remote telemonitoring?



The outpatient care team

The outpatient care team serves as the secondary line of care. The main duties include diagnosis of the heart valve, making the decision of referral to AUMC / CR care team, and follow-up for post-surgical assessment. A total of 15 outpatient hospitals refers to AUMC in the collaborative scheme.

Outpatient Team

About

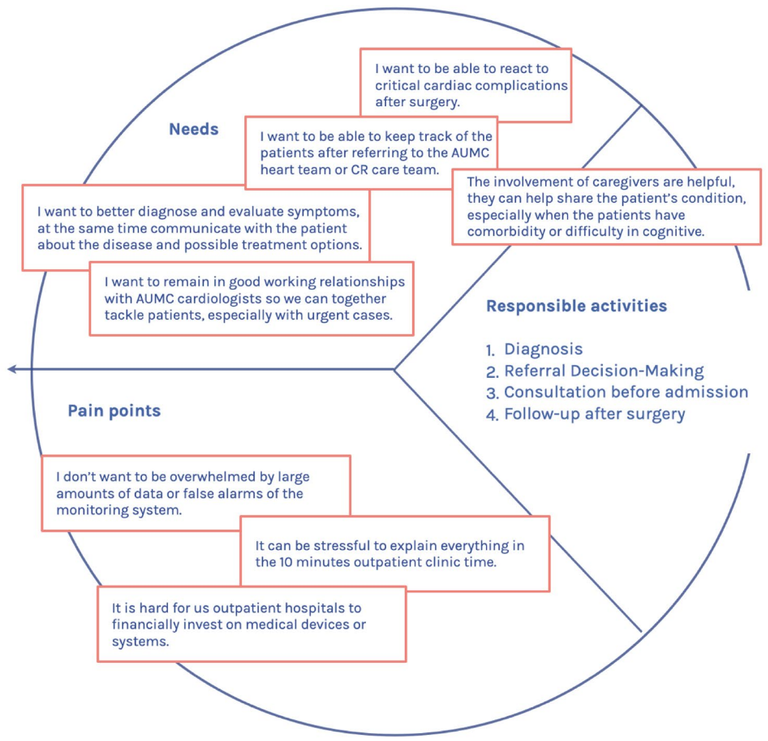
The outpatient care team serves as the secondary line of care. The main duties include diagnosis of the stenosis, making the decision of referral to AUMC / CR care team, and follow-up for post-surgical assessment.

Roles in the care team

Outpatient Cardiologist
CT Scan specialist
Clinical Doctor / Nurses

Involvement in the care path

Pre-surgery diagnosis
Before admission consultation
Post-surgery follow-up



Responsible Activities

1. Diagnosis: When the patient is referred from a family doctor, the patients are examined in the cardiology department of the outpatient hospital. The outpatient cardiologist is responsible for diagnosing the disease based on the echocardiography results and evaluation of symptoms (such as experiencing shortness of breath during exertion, angina, dizziness, or syncope).

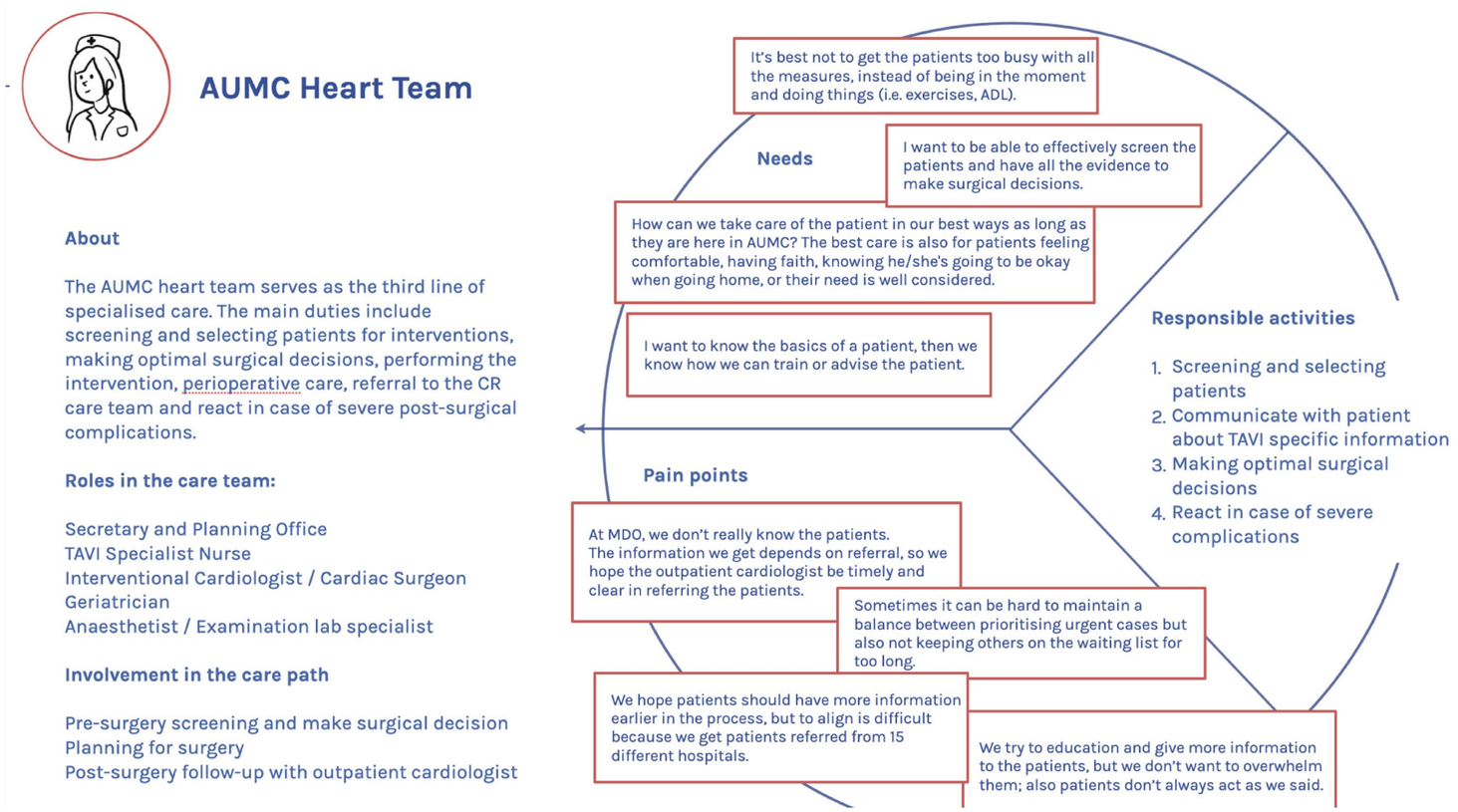
2. Shared Decision-Making: Based on the diagnosis, the outpatient will determine the severity of the condition and together decide with the patients on the suitable treatment. If the patient fits the need of valve replacement surgery and agrees on the treatment option, the outpatient cardiologist will then refer the patient to the AUMC secretary via email or phone. The referred information including the patient's current medication, comorbidity or medical history, result of echocardiography (such as the presence of AS, degree of valve calcification, LV function and wall thickness, presence of other associated valve disease).

3. Main contact before admission: Before the surgery, when the patient experiences any critical progress of the health condition or doubts, the outpatient cardiologist is the main person to reach out to through an appointment or phone call.

4. Follow-up after surgery: 3~6 months after the surgery, the outpatient cardiologist will be responsible for consulting post-surgical symptoms, for instance arrhythmic, stroke, etc. In the follow-up appointments, the above valvular symptoms are inspected to prevent readmission or cure severe complication.

The AUMC care team

The AUMC heart care serves as the third line of specialised care. The main duties include two rounds of screening and selecting patients for interventions, making optimal surgical decisions, performing the intervention, perioperative care, and long term research to improve care.



Responsible Activities

1. 1st Screening - Possible treatments: There are two screenings taking place before the surgery. The first screening takes place in the heart team MDO meeting. Based on the referral information from outpatient heart team (i.e. CT scan, comorbidity, and biological age of the patient), the decision of possible treatment options or no treatment are suggested.

2. 2nd Screening - Making optimal surgical decisions:
Once the patient has accepted the TAVI treatment, a second screening takes place to decide on the viability and make optimal surgical decisions. The patients are invited to AUMC for CT scan, blood sampling and check-up to investigate any risk or prognosis factors that may influence the surgery. If the surgical route of transferol is suggested, an outpatient clinic will be made to consult with the patient.

3. Communicate TAVI specific information: When the patient decides to go for the 2nd screening of TAVI treatment, information folders are sent to the patients by post or email to understand the procedure.

Once admitted to TAVI surgery, the patient and informal caregivers are invited to a group information session for TAVI specific information. Most patients are advised to reach out to their own cardiologists for complaints before surgery, hence outpatient cardiologists may reach out to AUMC care teams to gain TAVI-specific advice.

4. Research:

Positioned as a research medical center, AUMC has a keen drive to improve care through research, which patients are often recruited as participants.

The cardiac reahabilitation (CR) care team

The CR care team serves as the secondary line of recovery care. The main tasks include assessing, setting goals, coaching in physical fitness or lifestyle changes, and providing psychological support in rehabilitation.

CR Care Team

About

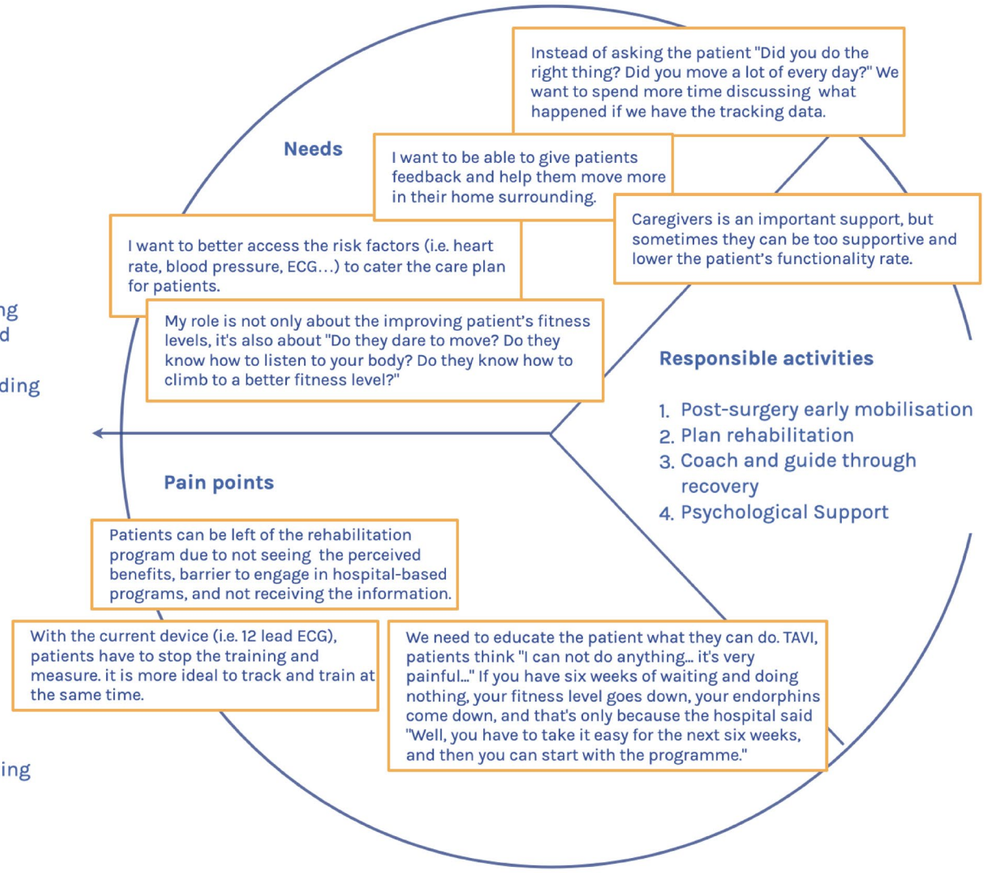
The CR care team serves as the second line of recovery care. The main duties include assessing risk in engaging physical exertion, planning and setting goals of rehabilitation, providing professional coaching and guidance, and providing psychological support.

Roles in the care team

Coordinator
Rehabilitation nurse
Rehabilitation Cardiologist
Physical Therapist
Dietitian / Psychologist / Geriatrician

Involvement in the care path

Clinical rehabilitation
Outpatient rehabilitation
In some cases early preoperative physical training



Responsible Activities

1. Post-surgery early mobilisation: When the
2. Plan and goal-setting in rehabilitation:
3. Physical activity training:
4. Psychological support:

The ptotocol follows the Dutch cariac rehabilitation KNGF guideline (2017).

Quotes from preliminary concept co-reflection

Concept #1. Hart as a supportive examinator

AUMC:
It is ideal to have the baseline already established in screening, so the patient can see what they can benefit after the surgery.
For AUMC, home-based rehabilitation health information is more of a research interest, which can be a long-term value to improve TAVI care.
It's ideal to already communicate the patient's personal goal first, so the care can be catered towards his/her need.

CR:
Rehabilitation normally starts with the PEP group information giving, which aims to educate the patients what they can expect.
During goal-setting, the patient are asked by rehabilitation nurse three activities they enjoy most, and rate out of 10 how difficult is to achieve the
The baseline test is mostly done with an endurance test, to see in a given time/distance, how the max heart rate and functionality rate are.
PSK (patient specific functional scale) or BORG scale can be used to evaluate.
http://www.tac.vic.gov.au/__data/assets/pdf_file/0020/27317/Patient-specific.pdf-http://www.tac.vic.gov.au/__data/assets/pdf_file/0020/27317/Patient-specific.pdf
Inactive/risk/danger are the negative wordings to avoid, may trigger anxiety for patients.
It shall be easy/training/difficult.
It would be valuable to know what was the active level before the training starts that would be the actual health baseline.
Frailty currently is a separate discussion in CardioVitaal, yet important to consider.

Patient-specialist:
EHR integration is essential for accessing the information.
The benefit of delivering the biosensor before the procedure

Concept #2. Hart as a home recovery companion

AUMC:
In AUMC, early mobilisation training starts 4 hours after the procedure.

CR:
Heart rate means nothing if there is no reference. Instead of a range of a safe/risk exercise zone, it is the balance to reach the minimal activity level and intensity that matters in home-training. It's more important to help patients reflect on how they feel to decide on whether they engage in a workout or not (traffic light model).
The trainer focuses on: total workout time, the intensity, distance, heart rate. Then advice therefore can be given as: Why do you move so less? I see you are active, but why mostly at a low heart rate level or too short? It's good that you move a lot, but the exercise seems to exhaust you. Then the conversation can focus on the 'Why' of how they can overcome the barrier.
It is also important to give compliments on progress.
The goal of CR is to have progressive weekly and being able to achieve what the patient desires to do. To achieve an activity, there are the METs they require: for instance, vacuum cleaning requires a MET of 7, yet when the patient can only achieve a MET of 4 at the moment, they know what is the goal to work towards.
The current training scheme is via group coaching, which more general advises are given. Three individual sessions are planned, which are beginning, halfway, and end of the rehabilitation. To give out individual feedback, perhaps a tele-coach is demanded to add to the care team portfolio.

Concept #3. Hart as a safe guard

Outpatient cardiologist or rehabilitation doctors are the ones ideally to react to preventive care. They make the decision of change in medication and appointments for diagnosing complications.
Patients are mostly given the number of hospitals to dial, according to the conversation, they make a decision tree of is it a safe/non-safe situation, and what actions are suggested to take. Patients can also take the extreme as dialing 112 for emergencies. Despite the patient's actions vary, giving the option of action is essential.
The care program then keeps track of the patient's situation on the EHR medical history.
When patients report, it's important to manage their expectations. Real-time feedback is not