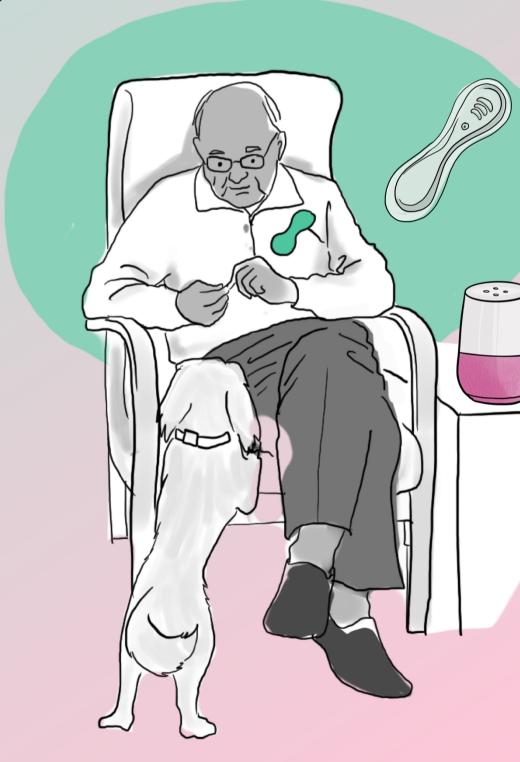
LIVEsense

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

Master thesis - Anindya Paramaarti









Master Thesis Delft, September 2020

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LIVEsense

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

Master thesis

Anindya Paramaarti September 2020

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Abstract

This report is the result of a master thesis project that finalizes 2 years of Strategic Product Design master program at the Industrial Design Engineering faculty. The project is about designing a data-informed clinical care process for Transcatheter Aortic Valve Implantation (TAVI) patient. Transcatheter Aortic Valve Implantation (TAVI) is a treatment that aims to reduce symptoms of Aortic Valve Stenosis (AOS). Most TAVI patients are in the above-75 population. The project brief is to improve TAVI patient's experience using sensor data.

To understand the context of TAVI care pathway, a literature review and stakeholders interviews were done, resulting in a comprehensive understanding of the care pathway. The opportunity to improve the period after TAVI was addressed.

To understand the underlying problem among patients in the post-TAVI period, text analysis from the literature was done, followed by coding, categorizing and framework creation. The framework was iterated in a series of 5 co-reflection sessions with the stakeholders. The result is that TAVI patients are managing confrontations throughout the care pathway, which prevent/ limit them from doing enough physical activity.

The proposed vision is a continuous and collaborative goal setting system using sensor data. A concept ideation was done, followed by concept testing sessions that resulted in the list of concept requirements.

The final proposed product-service system concept is called LIVEsense, a continuous and collaborative goal setting system using sensor data and voice-based conversational agent. LIVEsense consists of three main steps: baseline collection, collaborative goal setting and monitored goal pursuit. Patient wears the sensor and interacting with the voice assistant during the monitored goal pursuit. The sensor collects and compares patient's heart rate and activity data.

The proposed product-service system was validated in a co-reflection session with stakeholders. LIVEsense satisfied all elements of the Quadruple Aim (Bodenheimer & Sinksky, 2014) and it brings most value for the period right after TAVI. Other elements that needs to be further explored are the implementation of LIVEsense in the care pathway that consists of multiple organizations.

Project Brief

The clinical care discussed in this project is Transcatheter Aortic Valve Stenosis (TAVI). TAVI is a valve implantation done via catheterization procedure aiming to reduce symptoms of Aortic Valve Stenosis (AOS). The most common AOS symptoms are excessive tiredness and shortness of breath. About 3% of the population above 75 year old suffer from AOS, a condition where the aortic valve could not open and close properly (Olsson, 2016).

This project is done in a collaboration between CardioLab TU Delft, Academic Medical Center (AMC) and Philips Design. AMC is a university hospital that is part of University of Amsterdam. The cardiology department of Academic Medical Center (AMC) is involved in this project as the stakeholder who performed TAVI and conduct researches on to improve TAVI care pathway through remote monitoring. Philips is a health technology company that was founded in 1891 in Eindhoven, The Netherlands. The vision of Philips as a company is to improve the outcome of the whole health continuum and also improving people's health. Philips Design, a department inside Philips, is involved as the technology provider for the explored remote monitoring system. The external mentors of this projects are Dr Marije Vis from the cardiology Department at AMC and Peter Lovei from Philips Design.

Both AMC and Philips Design hypothesised at the beginning of the project that Philips Biosensor, a wearable sensor patch that detects vital signs, would be useful for improving patient's experience. In this project the patient's experience is investigated to address the problem. The role of remote monitoring technology in improving patient's experience, including but not limited to the Philips Biosensor, is explored. The outcome is a product-service system that aims to improve TAVI patient's experience using remote monitoring technology.

Report Structure

The overall process on this project follows the double diamond model (Design Council, 2005). As illustrated in Figure 1, with this method the design process is divided into 4 phases; discover, define, develop and deliver.

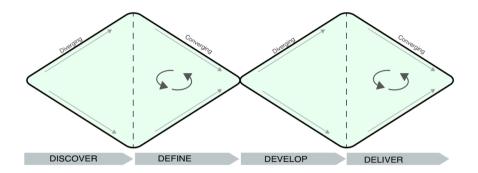


Figure 1: Double Diamond model developed by Design Council (2005)

This report is divided into four section based on the double diamond phases. The overview of each phase are:

Overview of Phase 1: Discover

The discovery phase consists of 2 parts; background research and understanding of the TAVI care pathway.

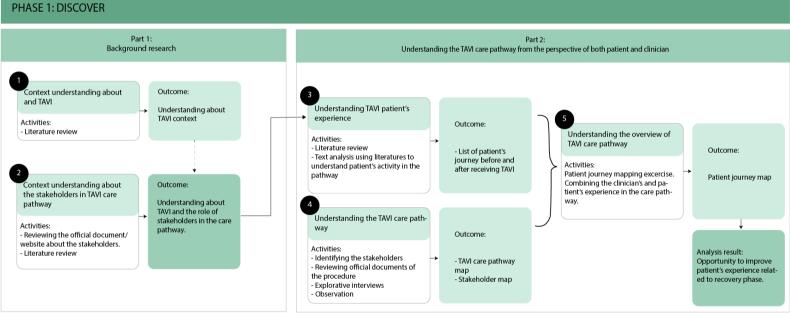


Figure 2: Overview of the Discovery Phase

In Part 1: Background Research, the context about TAVI and the stakeholders are investigated. The outcome would then become a starting point at the beginning of Part 2: Understanding the TAVI Care Pathway from the Perspective of Both Patient and Clinician.

The second part consist of three goals. The first is to understand the clinician's perspective to be able to map the care pathway, followed by understanding the patient's layer in the care pathway, then both understandings are combined as a complete overview of the care pathway. The outcome is a patient journey map that consists of multiple layers of different stakeholders. From the patient journey map, an opportunity to improve patient's experience related to the recovery part is then identified.

Overview of Phase 2: Define

Phase two consist of two part. The first part aims to define the problem in patient's experience related to the recovery phase. The second part is when the problem definition is translated into design vision.

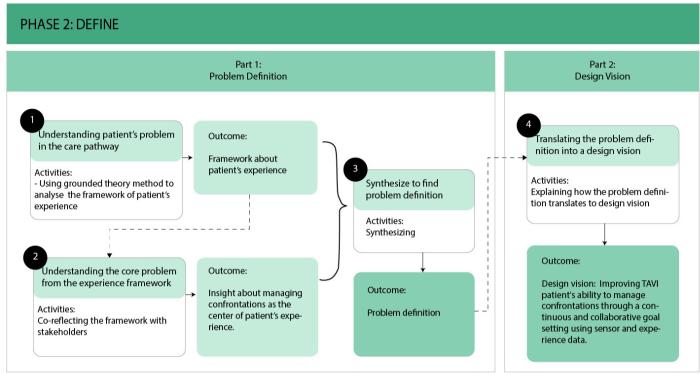


Figure 3: Overview of the Define phase

Overview of Phase 3: Develop

Phase three consist of one part which is about developing the concept based on the design vision. This phase consist of ideation, concept testing and a description of the requirements for the final concept (see figure 4).

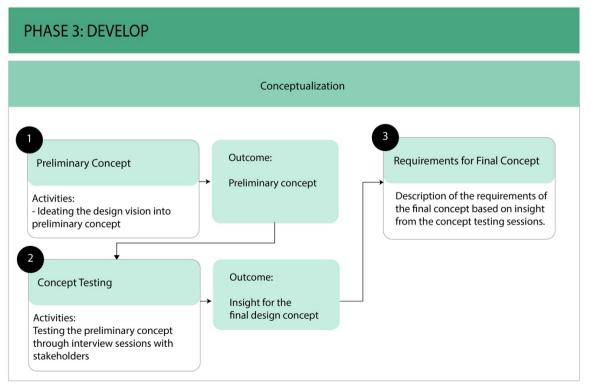


Figure 4: Overview of the Develop phase

Overview of Phase 4: Deliver

Phase four consist of the structure and flow of the product-service system, a scenario where a patient uses the product-service system, validation and general discussion (see figure 5).

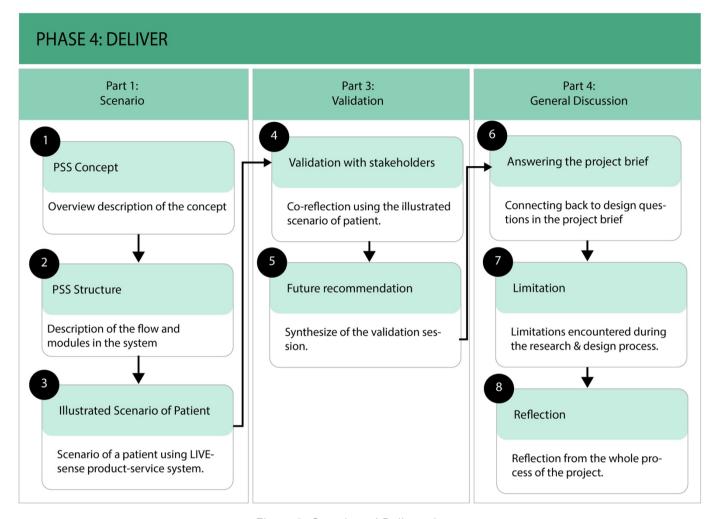


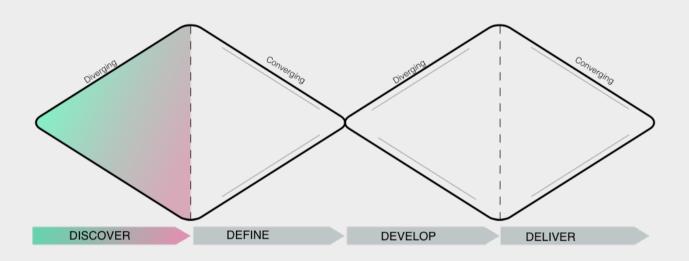
Figure 5: Overview of Deliver phase.

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PHASE ONE: DISCOVER



Chapter 1: Background Research

The questions that are answered in this chapter are:

- 1. What is Transcatheter Aortic Valve Implantation (TAVI)?
- 2. Who are the stakeholders in TAVI care pathway?
- 3. What are the role of each stakeholders in the pathway?

To answer those questions, a background research is done based on literature review from scientific journal, official clinical procedure document from Academic Medical Center (AMC) and official releases from Philips. This chapter consists of two sub-chapter (see Figure 6). In sub-chapter 1.1, the context about Transcatheter Aortic Valve Implantation (TAVI) is discussed. In the 1.2 sub-chapter, context about the project's stakeholders is discussed. The goal of this chapter is to understand how the project's stakeholder envision the improved Transcatheter Aortic Valve Implantation (TAVI) care pathway.

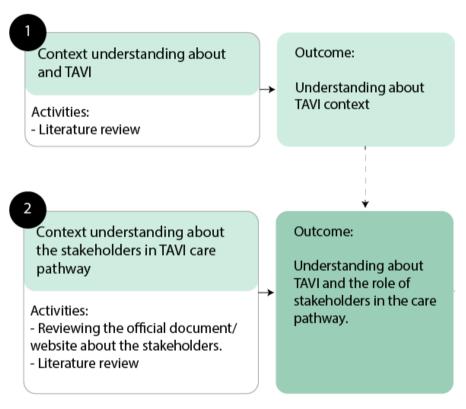


Figure 6: Overview of Chapter 1

1.1 Context about Transcatheter Aortic Valve Implantation

Transcatheter Aortic Valve implantation (TAVI) is a valve implantation via catheterization procedure for patients with Aortic Valve Stenosis (AOS). AOS is a disease where the aortic valve deteriorates, making it unable to open and close properly (see figure 3.1), disturbing the blood flow from the heart to the rest of the body. The most common symptoms of AOS are shortness of breath and fatigue so this disease could limit people's daily activities. This disease affects around 3% of the population above 75 and with the aging population the number is predicted to increase (Olsson, 2016).

Aortic Valve Open Closed AORTIC VALVE STENOSIS Open Closed Closed

Figure 7: Aortic Valve Stenosis (source: https://intermountainhealthcare.org/services/heart-care/conditions/aortic-valve-stenosis/)

The way to reduce AOS symptoms is by putting a valve implant on the aortic valve (Osnabrugge et al. 2013). The valve replacement would be able to open and close properly and reduce the disturbance of blood flow to the body (Osnabrugge et al. 2013). Olsson (2016) described two ways of placing the valve implant; through open surgery and through catheterization (TAVI). Patients who are old and have existing comorbidities are mostly referred to undergo TAVI (Olsson 2016; lung 2008). In TAVI treatment, the intervention cardiologist inserts the valve replacement via a catheter with balloon. The balloon will press the aortic valve and put the replacement there (see figure 8).

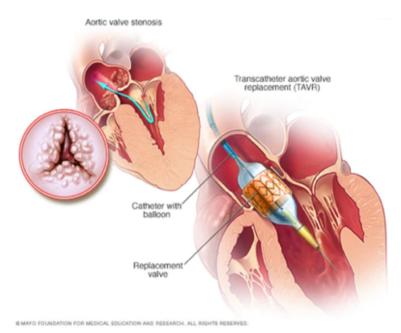


Figure 8: Placing the valve implant (source: https://www.mayoclinic.org/tests-procedures/transcatheter-aortic-valve-replacement/about/pac-20384698#dialogId24009443)

TAVI treatment consists of multiple assessments and cross-disciplinary consultations. Therefore TAVI is usually provided at a specialized hospital (Lauck et al., 2016). Therefore most patients are referred from smaller hospitals. After receiving TAVI, the patient will be readmitted to the referring hospital and there will be rehabilitation period. Therefore based on the TAVI care pathway discussed in this sub-chapter and in the Project Brief, the identified stakeholders in this project are:

Academic Medical Center (AMC)

- Referring hospital
- Heart rehabilitation center
- Philips

1.2 Context of the TAVI Stakeholders

In this sub-chapter the context of each stakeholder is discussed. Based on the official TAVI care pathway guideline at AMC, Patients who undergo TAVI treatment at AMC are mostly referred from a smaller hospital. After the procedure, patient will be readmitted to the referring hospital for post-procedural monitoring, rehabilitation and follow up (see Figure 9). Therefore in this sub chapter the context of AMC, cardiology outpatient at referring hospital and rehabilitation center are explained based on literature study.

A				
Cardiology	Cardiology	Cardiology	Rehabilitation	Cardiology
outpatient clinic in	department in	outpatient clinic in	Center	outpatient clinic in
hospitals	AMC	hospitals		hospitals

Figure 9: Healthcare providers along the care pathway

1.2.1 Academic Medical Center (AMC)

Academic Medical Center (AMC) is a university hospital located in Amsterdam. It is part of the Faculty of Medicine of the University of Amsterdam (UvA). AMC provides healthcare services, education and conducts research.



Figure 10: The AMC Building (source: https://www.ad.nl/binnenland/inspectie-amc-mag-medicijn-maken-maar-onder-voorwaarden~a67dafc5/?referrer=https://www.google.com/)

AMC offers TAVI treatment. Based on official TAVI care pathway guideline at AMC, currently the goals of TAVI treatment in AMC are; 1.) reduction of aortic stenosis that results in fewer symptoms and 2.) Safe, sterile and good aortic valve implantation. Based on the initial interview with stakeholders from the cardiology department at AMC, TAVI patients in AMC are patients who are referred from other hospitals, because only a few hospitals perform TAVI treatment in The Netherlands. Care treatment starts when the patients are referred from their hospital to AMC, and patients are discharged at least 72 hours after receiving the treatment.

Before admitting patients for to receive the TAVI treatment, AMC does a thorough screenings to determine if the patients are in a suitable condition. A multidisciplinary team discussion is conducted to decide if the patient is admitted for TAVI or not, based on the risk and benefit (Olsson 2016; Kappetein et al., 2013). AMC accept patients who have at least one year of mortality after receiving TAVI treatment. In the screening phase in AMC, patient's mortality are analyzed using test results from their referring hospital (CT scan, echocardiograph, coronary assessment and blood test) and frailty score from a frailty assessment conducted at AMC.

Frailty is described as a "geriatric condition characterized by an increased vulnerability to external stressors." (Dent, 2016). It is an age-related condition and it occurs when there is a decline in more than one physiological systems in the body. With the majority of TAVI patient in the elderly group, frailty is one of the important factors to consider in the screening process. Frailty is measured with a combination of scores about the symptoms, for example walking speed.

Before admitting patients for TAVI, AMC conducts a screening process. Currently AMC seeks opportunity in improving the screening process. One of those is by analyzing the patient's condition in the recovery process and evaluating the screening methods based on the outcome of previous treatments. AMC sees opportunity in evaluating and improving the screening of TAVI using remote monitoring technology.

1.2.2 Referring Hospital

The referring hospitals mostly located in the same city where the patient live. Research by Lauck et al in 2016 described that clinicians from both referring hospital and specialized hospital are seen as an important source of guidance and information in the TAVI referral process. A participant in the qualitative study by Lauck et al (2016) said that he goes with what his usual doctor told him. The research shows that some patients only rely on information from clinicians who worked with them in their previous health problem, so clinician in the referring hospitals can be seen as a facilitator that connect patient with the TAVI providers (Lauck et. al. 2016).

1.2.3 Heart Rehabilitation Center

Based on official TAVI care pathway guideline at AMC, TAVI treatment is followed by a rehabilitation program at a heart rehabilitation center. Heart rehabilitation program has a multidisciplinary approach and aiming for the patient's recovery in the physical and psychosocial aspect following a cardiac treatment (Kraal et al, 2017; Steg et al, 2012). Heart rehabilitation that centered around exercise activity has been proven to prevent patient's readmission to hospital and increase patient's quality of life (Kaal et al, 2017; Vries et al, 2015). However, there are barriers toward an effective exercise-based heart rehabilitation.

The first barrier, Kraal et al (2017) describes, is the low participation of heart rehabilitation that takes place at a rehabilitation center. The reason behind that barrier is practicality: the required effort from patient to travel and allocate time for the rehabilitation. Another reason is that patients might feel reluctant to join a group-based session and instead prefer individual program (Kraal et al, 2017; Vos et al, 2013). The second barrier is the low long term impact of the heart rehabilitation (Kraal et al, 2017; Yu et al, 2003). Exercise-based heart rehabilitation programs is useful for patient's short-term physical fitness improvement, but not enough for improvement in patient's lifestyle (Kraal et al, 2017).

In this project, CardioVitaal HvA, a heart rehabilitation facility in the AMC premises, is consulted. CardioVitaal HvA is affiliated with Amsterdam University of Applied Science (Hogeschool van Amsterdam), so the facility focuses on both care providing and education.

1.2.4 Philips

Philips is a health technology company that was founded in 1891 in Eindhoven, The Netherlands. Philips' vision is to improve the outcome of healthcare services and also improving people's health. Philips has a wide product portfolio in the healthcare sector, from at-hospital diagnostic imaging and patient monitoring to consumer health products. Some examples of Philips' products are InnoSpire Go, a portable nebulizer to deliver aerosol medicine (see Figure 11), and Philips EPIQ, a cardiology ultrasound system (see Figure 12).



Figure 11: Philips portable nebulizer (Source: https://www.philips.nl/healthcare/solutions/slaap-en-respiratoirezorg/respiratoire-toediening-van-medicijnen)

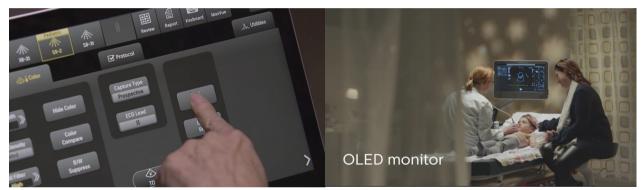


Figure 12: Philips EPIQ (Source: https://www.philips.nl/healthcare/solutions/ultrasound/cardiovascular-ultrasound)

In this project, the collaboration is done with Philips Design department. Philips Design use human-centered approach in creating the innovation. Philips generated a general patient's journey that helped them generate 3 focus areas: (1) critical care, (2) transitional care and (3) personal wellness (see Figure 13). Critical care phase is when patients are in an acute-level condition and needs to be closely monitored. Transitional care phase is when the condition of patients are improved and there is a transition from acute-level ward to general ward, from general ward to rehabilitation facilities or patient's home. The last phase, personal wellness, is when patients are already recovered and going back to their daily life. This project focuses on the TAVI care pathway experience outside the catheterization procedure itself. The care pathway consists of multiple transitions (see Figue 13) therefore this project fits into the second focus area: transitional care.



Figure 13: Philips' Patient Care Journey: Critical care, transitional care and personal wellness. (Source:

https://www.usa.philips.com/healthcare/innovation/research-and-exploration/connected-sensing)

In this project, AMC and Philips hypothesized that Philips Biosensor would be helpful for remotely monitoring **TAVI** patients. Based the product specification page Philips' official website (https://www.usa.philips.com/healthcare/innovation/research-and-exploration/connected-sensing), **Philips** Biosensor was designed to fit into the 'Transitional care' of the patient's care journey. The product aims at atrisk patients who are being transitioned from a high acuity to lower acuity ward. Values of the sensor that are proposed by Philips for this phase of the care journey are:

- Wearable sensor that continuously measures respiratory and heart rate, single-lead ECG, skin temperature, posture and activity data for at-risk patients who are in a low acuity ward.
- Seamless integration between the wearable biosensor and the clinical monitoring software & services
- Enable care providers to detect early signs of deterioration so an early intervention can be delivered.

Based on the specification page in Philips' official website, Philips Biosensor's system consists of a wearable sensor, a relay device, Guardian software, spot check monitor and an a mobile device for paging. Data from the sensor is transmitted to the relay device, which will send the data to the Guardian software. Then the Guardian software transmits the data to the spot check patient monitor and the hospital's event management & paging system.

The maximum coverage area of the relay device is 10 meters. So the patient who wears the biosensor should not be further than 10 meters from the relay, otherwise the relay device needs to be carried in a pouch to keep the sensor functional.



Figure 11: Philips Biosensor wearable patch. The sensor is placed on the patient's chest. (source: https://www.philips.nl/healthcare/product/HC989803196871/wearable-biosensor-wireless-remote-sensing-device)



Figure 12: Spot check patient monitor and relay device kit including its charger and a wall-mount. (source: https://www.philips.nl/healthcare/product/HC989803196871/wearable-biosensor-wireless-remote-sensing-device)

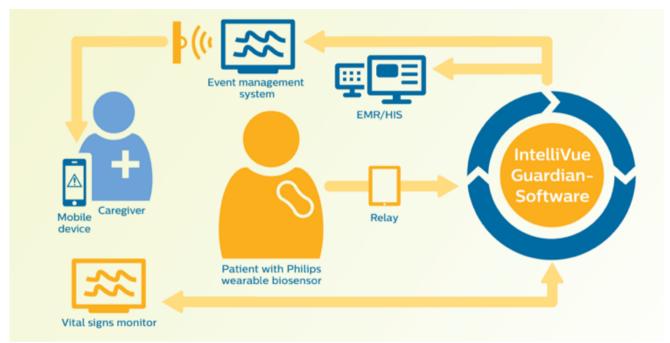


Figure 13: Philips Biosensor System

(source: https://www.philips.nl/healthcare/product/HC989803196871/wearable-biosensor-wireless-remote-sensing-device)

In monitoring at-risk patient, care provider has been relying on the spot check monitor to understand the patient's condition. The spot check monitor shows patient's body temperature, blood oxygen saturation and blood pressure. The biosensor is used alongside the spot check monitor. It generates raw data, then the Guardian software system would continuously measure the parameters. The raw data are:

- Accelerometer
- ECG
- Skin temperature
- Breathing
- Posture angle phi
- Posture angle theta
- SMA2
- RR interval
- QRS amplitude
- QRS area

Each parameter consists of a combination of raw data. The parameters are:

Parameter	Raw data combination
Heart rate	ECG, RR interval, QRS amplitude, QRS area

Respiratory rate	Breathing per minute.
Body posture	Angle phi and angle theta. The combination of raw data shows pattern that could be differentiated as laying down, standing, walking or sitting.
Fall detection	Accelerometer & body posture.
Activity level	Accelerometer & breathing per minute.

Table 1: Data Parameters of Philips Biosensor

In this project, the value proposition of Philips Biosensor in improving patient's experience is explored. The solution however is not limited to the existing functionalities of the current Biosensor.

1.3 Summary

In this chapter, the three questions are answered.

1. Understanding of Transcatheter Aortic Valve Implantation (TAVI)

TAVI is an aortic valve implantation placed through a catheterization treatment. TAVI aims to reduce symptoms of Aortic Valve Stenosis (AOS). AOS mostly appears in the elderly population, thus TAVI patients are mostly the elderly.

2. Stakeholders in TAVI care pathway

There are multiple organizations involved in the TAVI care pathway, and each has its own responsibility in different phase of the pathway. These are AMC, referring hospital and heart rehabilitation center.

3. The role of each stakeholders in the pathway

Referring hospital is the 'gate' for patient to get access to receive TAVI at AMC. After receiving TAVI, patient is readmitted at the referring hospital to arrange the heart rehabilitation at the rehabilitation center.

Chapter 2: Understanding the Care Pathway of Transcatheter Aortic Valve Implantation

In this chapter, the perspective of clinicians and patient are combined to have an overview of TAVI care pathway. Then the care pathway is visualized into a patient journey map. From the patient journey map, a design opportunity is addressed.

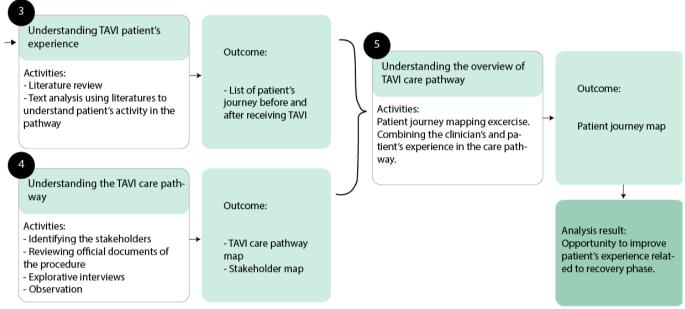


Figure 14: Overview of Chapter Two

2.1 Understanding the Patient's Activities

Based on the official TAVI care pathway guideline at AMC, the TAVI care pathway at AMC starts when patient's referral information is received by AMC and ends mostly with patients being transferred back to their referring hospital with an ambulance. However, from the patient's perspective, the patient's journey lasts until the recovery phase (Olsson 2016). Olsson categorized TAVI patient's journey as "a journey of balancing between life-struggle and hope.". To understand the events that made this balancing journey, an analysis of existing studies related to TAVI patient's experience is done using literature review.

When browsing for the literature online, the criteria are:

- Research published in the last 5 years
- Qualitative method
- Covers the subject of patient's experience related to TAVI treatment

From those criteria, the keyword used for searching the articles are "TAVI patient experience qualitative", "TAVI experience", "TAVI patient qualitative". Search results that seem suitable were stored in a 'TAVI Patient Journey' folder in a reference management platform Mendeley (see figure 15). Then each article was skimmed to filter out articles that did not meet the criteria.

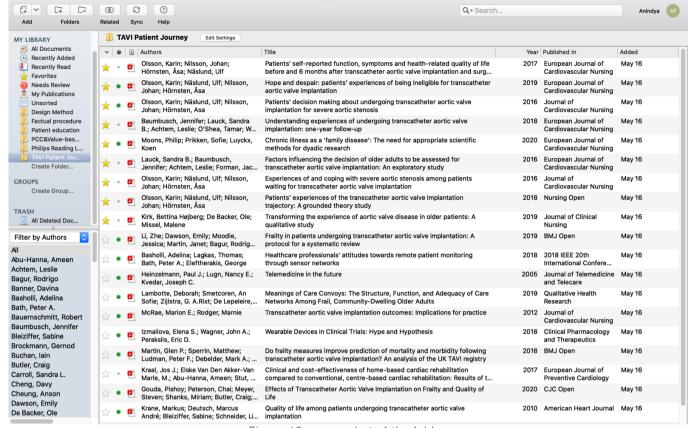


Figure 15: screenshot of the folder

Articles that meet the criteria were bookmarked. The bookmarked articles are:

	Reference
1	Moons, P., Prikken, S., & Luyckx, K. (2020). Chronic illness as a 'family disease': The need for appropriate scientific methods for dyadic research. European Journal of Cardiovascular Nursing, 19(2), 98–99. https://doi.org/10.1177/1474515120902376
2	Olsson, K., Näslund, U., Nilsson, J., & Hörnsten, Å. (2018). Patients' experiences of the transcatheter aortic valve implantation trajectory: A grounded theory study. Nursing Open, 5(2), 149–157. https://doi.org/10.1002/nop2.124
3	Olsson, K., Nilsson, J., Hörnsten, Å., & Näslund, U. (2016). Patients' self-reported function, symptoms and health-related quality of life before and 6 months after transcatheter aortic valve implantation and surgical aortic valve replacement. European Journal of Cardiovascular Nursing, 16(3), 213–221. https://doi.org/10.1177/1474515116650342
4	Olsson, K., Näslund, U., Nilsson, J., & Hörnsten, Å. (2016). Experiences of and Coping With Severe Aortic Stenosis Among Patients Waiting for Transcatheter Aortic Valve Implantation. The Journal of Cardiovascular Nursing, 31(3), 255–261. https://doi.org/10.1097/jcn.000000000000000000000000000000000000
5	Olsson, K., Näslund, U., Nilsson, J., & Hörnsten, Å. (2019). Hope and despair: patients' experiences of being ineligible for transcatheter aortic valve implantation. European Journal of Cardiovascular Nursing, 18(7), 593–600. https://doi.org/10.1177/1474515119852209
6	Kirk, B. H., De Backer, O., & Missel, M. (2018). Transforming the experience of aortic valve disease in older patients: a qualitative study. Journal of Clinical Nursing. https://doi.org/10.1111/jocn.14732
7	Olsson, K., Näslund, U., Nilsson, J., & Hörnsten, Å. (2016). Patients' Decision Making About Undergoing Transcatheter Aortic Valve Implantation for Severe Aortic Stenosis. The Journal of Cardiovascular Nursing, 31(6), 523–528. https://doi.org/10.1097/jcn.0000000000000282
8	Lauck, S. B., Baumbusch, J., Achtem, L., Forman, J. M., Carroll, S. L., Cheung, A., Ye, J., Wood, D. A., & Webb, J. G. (2016). Factors influencing the decision of older adults to be assessed for transcatheter aortic valve implantation: An exploratory study. European Journal of Cardiovascular Nursing, 15(7), 486–494. https://doi.org/10.1177/1474515115612927
9	Baumbusch, J., Lauck, S. B., Achtem, L., O'Shea, T., Wu, S., & Banner, D. (2017). Understanding experiences of undergoing transcatheter aortic valve implantation: one-year follow-up. European Journal of Cardiovascular Nursing, 17(3), 280–288. https://doi.org/10.1177/1474515117738991

Table 2: The bookmarked articles

Text analysis was done using the bookmarked articles. Parts that described an event or action were highlighted then put into a table. These parts were then paraphrased and 'extracted' into bullet point of events. For some examples of the text analysis, see table 4 below:

Paraphrased text	Extracted Events
Olsson et al (2016) explained that once patients are admitted to the specialized hospital, they feel confident and safe. Coming to the hospital and meeting the clinicians in person makes them feel more relaxed, in some cases for the first time since many weeks passed. A patient participant in the research expressed how the physical proximity to physician and the hospital environment affect her/him, "Oh, I feel very safe. To come here and be surrounded by competent people, doing everything they can to make me feel better."	 Coming to the hospital for appointment after being admitted for TAVI. (Olsson et al, 2016) Feeling safe that they are admitted to the specialized hospital for TAVI. Trusting the physicians. (Olsson et al, 2016)
Patient's living situation is influencing how safe the patient feels after being discharge from the hospital who performs TAVI. Kirk et. al in 2019 explained that patients who live alone felt less safe after discharge compared to before the treatment because he/she was with the family and after discharge he/she was back to living alone. A patient participant in that study was quoted, "I felt safe knowing that I wasn't alone, that I was with family".	 Discharged from the specialized hospital. (Kirk et. al 2019) Going back to living on his own (Kirk et. al 2019) Patients who live alone feel less safe after the discharge because during treatment they were accompanied by their family. (Kirk et. al 2019)

Table 3: Example of how events are extracted from text in the articles.

Events extracted from articles are first divided into 'before TAVI' and 'after TAVI' in a chronological way.

Events before TAVI	Εv	rents after TAVI	
1. Experiencing burdens from the aortic valve stenosis	1.	Being cautious about experiencing symptoms after discharge. (Kirk et. al	
symptoms. (Lauck et. al 2015)		2019)	
2. Reduce in quality of life because of less socia	2.	Discharged from the specialized hospital. (Kirk et. al 2019)	
activity. (Lauck et. al 2015)	3.	Going back to living on his own (Kirk et. al 2019)	
Consulting with a family physician or cardiologist a	4.	Patients who live alone feel less safe after the discharge because during	
their hospital. (Olsson et. al 2016)		treatment they were accompanied by their family. (Kirk et. al 2019)	
4. Trust in family physicians. (Olsson et. al 2016)	5.	Regaining self-image after changes in physical condition. (Kirk et. al 2019)	
Receive confusing explanations from the family	6.	Some patients experience noticeable body relief. It gives them confidence to	
physician. (Olsson et. al 2016)		be able to do meaningful activities. (Kirk et. al 2019)	
6. Being offered to get a TAVI treatment by their		Experiencing the benefit of TAVI. (Kirk et. al 2019)	
cardiologist. Discussing the risk and benefit. (Olssor	8.	Informal caregiver of patients who experience relief but less noticeable sees	
et. al 2015)		that the patients have more confident in living their daily life. (Kirk et. al 2019)	
Having a discussion with the family member (informa	9.	Improved sleep because of les anxiety that was caused by having symptoms	
support). (Olsson et. al 2015)		prior to TAVI. (Kirk et. al 2019)	
8. Thinking about whether to get the TAVI treatment of		Experiencing transformation of bodily sensation. (Kirk et. al 2019)	
not. (Olsson et. al 2015)		When patient's expectation meets unexpected reality. (Baumbusch et al.,	
Start formulating expectation about the outcome or		2018)	
TAVI. (Olsson et. al 2015)		When informal caregiver's expectation about the TAVI impact meets the	
Being dependent on their support network's		reality. (Baumbusch et al., 2018)	
availability for helping them traveling to the hospital		Trying to adjust expectation with reality. (Baumbusch et al., 2018)	
(Lauck et. al 2016)	14.	Continue taking medicine makes patient feels unsure if there will not be any	
11. Experiencing long journey for a short appointment		other problem with their body in the future. (Kirk et. al 2019)	
(Lauck et. al 2015)		Reconciling with reality about living with limitations. (Kirk et. al 2019)	
12. Experiencing increase of symptoms. (Olsson et. a	16.	The regained ability to walk represents the patient's progress. (Kirk et. al	
2016)		2019)	
13. Managing anxiety when the symptoms appear	17.	Being able to walk enables patients to participate in social activity again. (Kirk	
(Olsson et. al 2016)		et. al 2019)	
14. Planning their daily life with the symptoms as part o	18.	Being able to walk brings a sense of control over patient's own live. (Kirk et.	
the considerations. (Olsson et. al 2016)		al 2019)	
15. Keeping an eye of potential incident. (Olsson et. a	19.	Improvement of physical condition needs patient's effort, for example by doing	
2016)		the exercise. (Kirk et. al 2019)	
16. Dealing with uncertainty of TAVI acceptance. (Olssor	20.	Patients join rehabilitation because they are aware that they need to do	
et. al 2016)	١	something to improve or maintain their condition. (Kirk et. al 2019)	
17. Coming to the hospital for appointment after being	21.	Patients who do not join rehabilitation see doing activities related to daily life	
admitted for TAVI. (Olsson et. al 2016)		(household task for example) would bring the same benefit as doing a	
18. Feeling safe that they are admitted to the specialized		rehabilitation program. (Kirk et. al 2019)	
hospital for TAVI. (Olsson et. al 2016)	22.	'Independent' rehabilitation program makes patients regain control of	
19. Trusting the physicians. (Olsson et. al 2016)		managing their own daily task and which one to do. (Kirk et. al 2019)	

23.	'Independent' rehabilitation program is lack of control and support function
	from a formal caregiver. (Kirk et. al 2019)
24.	Goal setting related to physical activity is important. (Kirk et al 2019)
25.	Recovery from TAVI treatment while dealing with aging and comorbidities.
	(Kirk et al 2019)
26.	Being alert of bodily sign of possible illness. (Kirk et al 2019)
27.	The effect of TAVI might be good but the overall physical condition might not
	fully improved because of comorbidities. (Baumbusch et. al 2017)
28.	Distinguishing the symptoms of comorbidities and symptoms of AOS.
	(Baumbusch et. al 2017)

Table 4: Event before and after TAVI.

From this analysis, the chronological activities of the patient are identified. In the next sub-chapter, the perspectives of the clinicians in the care pathway are investigated. In the end of this chapter, the understanding of patients' activities and clinician's perspectives are combined into a comprehensive patient journey.

2.2 Understanding the Clinician's Perspective

2.2.1 Arranging the Interview & Observation

Understanding the care pathway is done through interview with the stakeholders. The stakeholders are from AMC, Amstelland Hospital, Cardiovitaal HvA and Philips. Amstelland Hospital is one of hospitals in the Netherlands who refers patients who need TAVI treatment to AMC. Cardiovitaal HvA is a rehabilitation center located in the AMC environment. It is a part of Cardiovitaal, a heart rehabilitation network of rehabilitation center in the Netherlands, that collaborate with the physiotherapy department of Amsterdam University of Applied Sciences/ Hogeschool van Amsterdam (HvA).

All interviews were conducted online using Zoom video call platform. The interview participants are:

	Referring Hospital (Amstelland Hospital)	AMC	Rehabilitation Center (Cardiovitaal HvA)	Philips
Partici	Cardiologist who has	- Intervention	- Physiotherapist/	- Data designer (1)
pant	referred AOS patients	cardiologist (1)	rehabilitation manager	- Business unit manager
	for TAVI to AMC (1)	- Specialist nurse (1)	(1)	of Connected
	, ,	- Plan coordinator (1)	- Physiotherapy	Healthcare (1)
		- Patient communication specialist (1)	researcher (2)	- Data researcher (1)

Table 5: Stakeholder Interview Participant

There were two rounds of interviews. The first round was to gain an understanding about the pathway. Initial understanding based on the existing TAVI procedure document at AMC was mapped as the base of the first round of explorative interview. The information gained in the interview were then visualized into stakeholder maps and were discussed and validated with the stakeholder in the second round of interview.

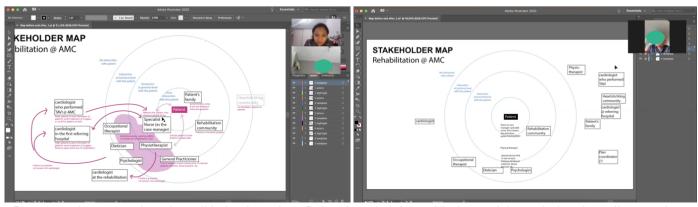


Figure 15: documentation of a validation interview. Doing drag and drop with the participant during the online session.

Beside interviews, two observations were done. The first observation was during the information session at AMC where the nurses would explain the procedure of TAVI to patients & family caregiver. The first observation happened right after the kick off meeting with AMC stakeholders on early March 2020, and was part of introduction from the AMC stakeholders.



Figure 16: The meeting room for the information session at AMC where patients & their family came.

The second observation was on April 2020, when the Covid19 pandemic hit the Netherlands and some part of healthcare service became online. In the first round of interview with the rehabilitation manager of CardioVitaal HvA, it became clear that the ongoing rehabilitation has been transformed into online rehabilitation. An observation was arranged to get familiar with how online rehabilitation was done. The observation was done in an online rehabilitation facilitated by the Cardiovitaal HvA Rehabilitation Center via video conference platform (Zoom.us).

The interviews and observations happened in parallel. The results are described as a flow and stakeholder maps in the following sub-chapters.

2.2.2 Cardiology Outpatient at Referring Hospital

The role of the cardiology outpatient at the referring hospital is discussed into two part; referring and readmitting the patient. In this section the referring and readmitting procedure as well as the involved stakeholder in each part are discussed.

A. Referring the Patient for TAVI

Patient and his family have a discussion with the cardiologist at the referring hospital about the AOS symptoms, its implication to patient's daily life, patient's living condition and the possible treatment. The cardiologist would refer patient to do a set of health check (lung test, echocardiography check, CT scan and coronaries catheterization). Based on the result, the cardiologist would start giving options for the treatment.

The treatment recommendation depends on the severity of patient's symptoms. If patients are having a low to moderate symptoms, they will be monitored for half a year and a treatment is not yet recommended, and reasons other than AOS will be investigated. Most AOS patients who need a new valve are older because one of the risk factors is aging. Younger patients would undergo the open heart surgery (SAVR) and the older ones usually would get TAVI. The cardiologist participant said, "Older people can accept this (the AOS diagnosis), but for the younger patients it is more difficult to explain.. you are 50 and you need another valve."

Sometime the cardiologist would talk with the patient's general practitioner if patient is in a bad condition or having delirium, to discuss if it would still be useful to do TAVI. The discussion could also be with the intervention cardiologist at AMC to consult about the possibility of TAVI with patient's health condition. Beside health check results, patient's living situation is also being taken into consideration. Cardiologist gets a lot of information about this from the patient's family. A stakeholder map is visualized to represent this step.

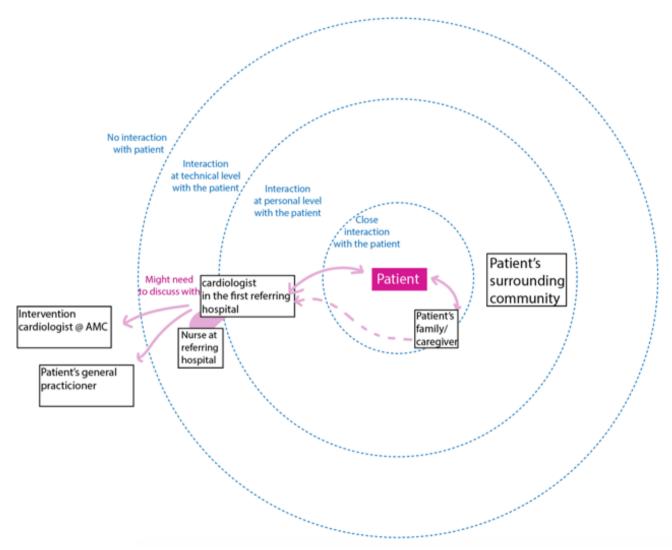


Figure 17: Stakeholders in the period before patient is referred for TAVI

Before referring patients to AMC for TAVI, cardiologist at the referring hospital needs to understand information about patient's physical condition and living situation, all while having a limited time for the direct interaction with patient. With roughly 10 minutes per discussion. The cardiologist participant mentioned, "The source of stress can be because we only have 10 minutes to know all of this, "is 10 minutes enough?". But for me it is fine!"

When the patients finished the TAVI treatment at AMC, they are being sent back with an ambulance to the referring hospitals. A rhythm monitoring using telemetry will be done in the referring hospitals. The goal of the rhythm monitoring is to see if there is any heart rhythm disturbance, since the implanted valve is pressing patient's valve and there is a risk of electrical disturbance in the heart. The recommended duration for the rhythm monitoring is 72 hours, before the patients can be discharged from the hospital. Intervention cardiologist at AMC sees the rhythm monitoring phase as something that could be improved with the use of biosensor, "If patient can wear the biosensor and continue being monitored at home they can leave earlier."

Before patients are discharged from the hospital, 3 things are arranged:

- Make sure that the daily needs of patients at home can be arranged, whether by the patients themselves or with the help of family, loved ones or caregiver.
- Patients will be referred to do a heart rehabilitation program. The rehabilitation can be in the referring hospital or in another organization (if there is no rehabilitation center at the hospital).
- Two follow up sessions will be scheduled. One in within 4 8 weeks after TAVI and one within 4 12 month after TAVI.

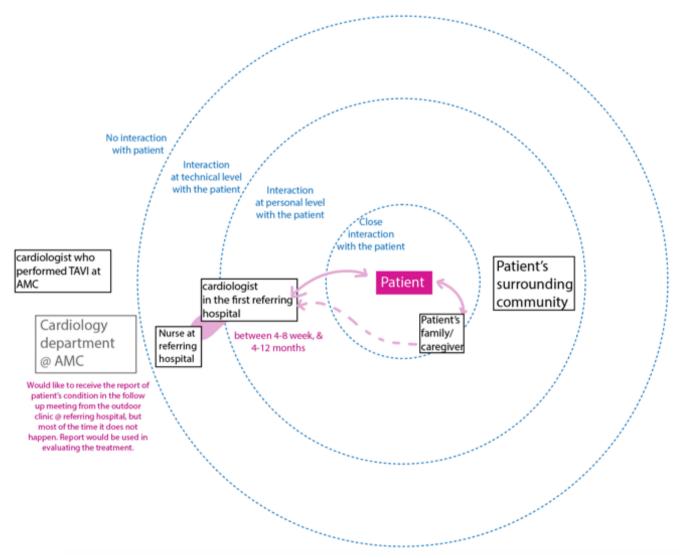


Figure 18: Stakeholders in the period of readmission at the referring hospital after TAVI

The two follow up sessions happen during patient's recovery period. In the follow up session, cardiologist will ask the patient if they have shortness of breath and syncope, and would check if there is any fluid retention in the body. If patients can do more activities and have less complaints then the treatment is considered successful. Amstelland Hospital cardiologist explained that if a patient wears sensor that produces data, the

information from the sensor would be useful. The physical fitness data that would be useful in monitoring the recovery process is respiratory rate,

- Respiratory rate so see the effect of TAVI toward the AOS symptom.
- Physical activity level to see if patients can do more activity after TAVI.
- ECG to keep an eye on the occurrence of rhythm disturbance so the clinicians can act quickly.

However, there is a concern about futility of patient's physical fitness data that might impact the way cardiologist work with the patient. "I am afraid you would get a lot of data and a lot of noise.. that makes me think I have to do something with the patient although they are doing fine." Sensor data is only one perspective of patient's condition, and when the portion of it is larger than the other perspective (e.g how patient feels), then the doctor might put too much focus on the numbers. "I fear that doctors would have so much data and noise and you give yourself a lot of work to treat number, not the patients."

C. Summary

Amstelland Hospital cardiologist described that the success indicator of TAVI treatment is when patients have less symptoms and therefore a higher quality of life, but not necessarily more years. Physical fitness data is more meaningful when combined with changes in patient's quality of life, therefore doctor would have a richer perspective of patient's condition. "It is interesting to see patients improving... can he do more? are they happier? feel better?."

Cardiology outpatient at the referring hospital is the first and last healthcare touchpoint in the journey of AOS patient undergoing a TAVI treatment. The role of cardiologist at referring hospital can be seen as the captain of the patient's case. "I am the chief, I am their cardiologist. I said to them if you don't hear anything from AMC then (let me know) I can see how it goes." However, there is a different perception about the usefulness of sensor-generated data. "I just want to know the result, but don't give me daily data.. that might be interesting for the next generation of TAVI patient, research for clinical success. But we are in the smaller hospital and our goal is to treat the current patient." In the Background Research chapter it is explained that AMC wants to be able to evaluate the TAVI outcome to improve the screening and treatment of TAVI for future patients. The referring hospitals however do not share this motivation because their focus is on treating the existing patient.

2.1.2 Cardiology Department at AMC

TAVI treatment is managed and performed in the cardiology department at AMC. Patient interact the most with the specialist nurse and plan coordinator. The treatment is performed by an intervention cardiologist. As a university hospital, specialists in AMC also have education responsibilities. Beside doing the TAVI treatment, the intervention cardiologist also manage the research and development of TAVI and guiding doctors in cardiology/ intervention cardiology education program.

A. Registration Process

To refer a patient for TAVI at AMC, the cardiologist at the referring hospital sends an email to the plan coordinator at AMC. The patient's health test results (blood test, ECG and CT scan) are attached. Plan coordinator will make sure the data is complete then look at the critical number of patient's health test result. If plan coordinator sees an alarming number, for example, blood pressure above 90, then she will contact the specialist nurse to consult if the patient could be prioritized. The next step for the plan coordinator is to arrange a multidisciplinary meeting (MDO).

The MDO consists of the intervention cardiologist, cardiac surgeon and anesthesiologist. The goal of the MDO is to decide if the patient is suitable to take the TAVI screening test. If the patient is decided to be suitable, then the plan coordinator would inform the patient about the procedure and arrange the screening test. The test must take place at AMC. The screening test consist of:

- CT scan of the heart, coronaries and peripheral vessels
- Blood test
- ECG

Then a second MDO will be arranged to decide if the patient is suitable for TAVI. The intervention cardiologist, cardiac surgeon, anesthesiologist and a specialist nurse are involved in the second MDO. In some cases, condition that is unknown to the patient is discovered in the CT scan and therefore the patient needs to be referred to other specialist.

B. TAVI Screening

If the decision is to proceed the patient for TAVI, then an appointment between patient and the specialist nurse at AMC will be arranged in the outpatient clinic. Also, the patient will be given an account in AMC's patient communication platform, Medify. In this phase patient will receive some education material about TAVI and a questionnaire in the platform.



Figure 19: Medify platform for TAVI patients at AMC https://vimeo.com/medifymedia

The goal of the appointment are:

- To inform patient and his family about the procedure of TAVI, including the risk and possible complication.
- To gain information about what the patient wants to get from the TAVI treatment.
- Screening for risk.
- Does physical examination/ frailty test with Edmonton scale.
- Decide if the patient needs to be referred to a geriatrician or other specialist prior to receiving TAVI treatment.
- Walk through the patient's existing medication and advise if adjustments are needed.

After the appointment, the plan coordinator will put patient's data in the waiting list to be scheduled. Patient is asked to wait for up to 6 weeks to be scheduled. The plan coordinator will do prioritization of patients based on the physical condition in a discussion with specialist nurse. The longer it take before patient gets

scheduled, there is a concern that the physical condition data might be outdated. The plan coordinator explained, "'This patient is already waiting for 6 week'.. 'but their rates are not that bad'.. 'But this information is from 6 weeks ago!' that is my discussion with the specialist nurse."

The procedure is scheduled a week before the day. When the patient is already scheduled, the plan coordinator will inform the patient via phone call and letter. Therefore, patient and his family are being kept in the dark about the schedule for up to 6 week. The plan coordinator gets a lot of call from patients or family of patients who are not yet scheduled. "Their biggest fear is to be forgotten.. if you can give them anything of connection.. that will comfort them and make them not forget 'AMC is still working with me'." (Plan coordinator)

The stakeholders who are involved in the registration and screening of TAVI are mapped in the figure below. The patient is at the center of the circle, in the middle of 4 layers of interaction. The closer the stakeholders to the middle means the closer & more often the interactions are. In the figure it is shown that there are multiple roles involved in this phase, and the people patients interacted the most are their family, the plan coordinator and the specialist nurse.

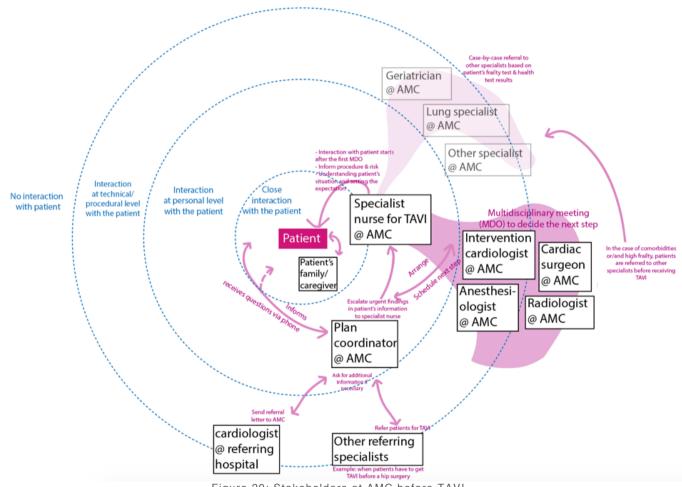


Figure 20: Stakeholders at AMC before TAVI

The intervention cardiologist envision Philips Biosensor to be useful in the phase between being accepted for TAVI until the procedure day. A comprehensive data about patient's physical condition and activity before TAVI can be compared to the data after TAVI to later see the difference. "Patients might not be able to do a lot at this time.. because they are limited by the symptoms, but the data will be useful to see if they can do more after TAVI." (Intervention cardiologist)

Another hypothesis is that the biosensor could be useful for a pre-habilitation program prior to the treatment. Pre-habilitation is a physical activity training prior to the treatment, aiming at improving patient's condition and therefore improving the TAVI outcome.

C. TAVI Procedure Day

The patient is admitted to the cardiology ward a day before the procedure. Patient will be seen by the ward doctor and nurse. On the procedure day, patient will be mobilized to the catheterization room. This is when the patient meet first time with the intervention cardiologist. The intervention cardiologist review the patient's data before the procedure and discuss the procedure, risk and indication with the patient. The patient's hope to get from the treatment is also discussed.

During the procedure, the people involved are:

- · Intervention cardiologist as the one executing the treatment
- 2 intervention nurse (1 sterile and 1 non-sterile)
- Anesthesiologist (optional)



Figure 21: TAVI Procedure at AMC

Source: AMC Youtube account https://www.youtube.com/watch?v=BZ9CRRpI5aA

After the procedure, the patient is being brought back to the cardiology ward. The patient's first contact (usually the family) will be contacted. In small number of cases where there is complication, patient will be moved to the Cardiac Care Unit (CCU). In the cardiology ward, the patient will be connected to a monitor for a short term telemetry monitoring for about 2 hours. The goal is to check if there is any rhythm disturbance in the heart. Then the intervention cardiologist will come and discuss with patient & his family about the steps after this and what they can do at home.

If there is no complication, the patient is being mobilized and readmitted to the referring hospital with an ambulance. A referral document from the intervention cardiologist and specialist nurse is sent to the referring hospital. Information in the document is:

- Patient's condition when admitted.
- How the TAVI procedure went.
- The condition after TAVI.
- Recommendation for telemetry monitoring at the hospital.

After patient is being readmitted to the referring hospital, AMC does not record the patient's condition. AMC has been requesting the referring hospital to send the patient's follow up data but most of the time it does not happen. The reason could be because of a lack of infrastructure and system for such information sharing, and because the referring hospital would not benefit from the data sharing so it get less prioritized. "If we want the data... we have to be very annoying, calling multiple times." (Specialist nurse)

In improving the screening process, collecting data about the outcome of TAVI would be useful. The intervention cardiologist sees opportunity in implementing Philips Biosensor for this phase, to be able to see the changes in patient's condition after TAVI. The information will be used for improving the screening procedure. "That way we can see.., patient with certain comorbidities might or might not benefit from TAVI, then we can improve the screening." (Intervention cardiologist)

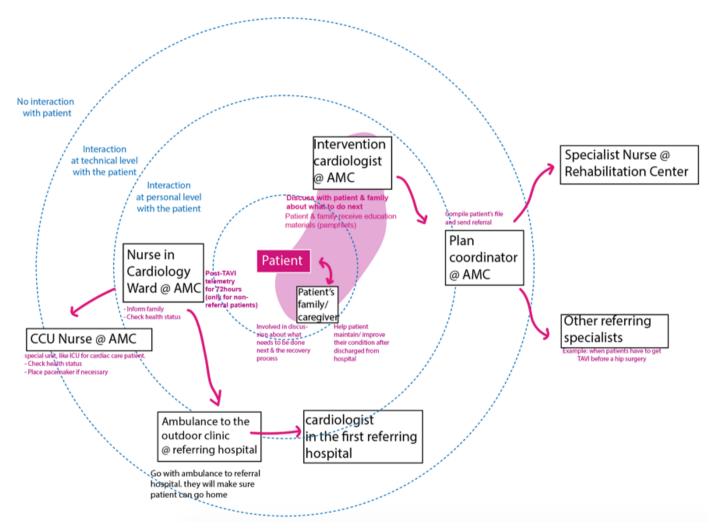


Figure 22:: Stakeholders at AMC after TAVI

D. Summary

In improving the screening process, collecting data about the outcome of TAVI would be useful. The intervention cardiologist sees opportunity in implementing Philips Biosensor for this phase, to be able to see the changes in patient's condition after TAVI. The information will be used for improving the screening procedure. "That way we can see.., patient with certain comorbidities might or might not benefit from TAVI, then we can improve the screening." (Intervention cardiologist)

2.2.3 Heart Rehabilitation Center

A. Intake Process

Heart rehabilitation center in the TAVI care pathway can be in the referring hospital or in another institution, depending on the services provided by the hospital. Either way, patient is being referred by his first cardiologist to the rehabilitation center. In the heart rehabilitation center patient will be offered a personalized treatment plan based on the intake health check by the physiotherapist. Rehabilitation for TAVI patient usually start a week after being referred.

During the intake, patient's physical health check (ECG, respiratory rate while exercising) and psychological condition will be considered. The psychological condition of patient's closest support network (e.g spouse or family) will also be investigated, and it is possible that the close support network is participated in the rehabilitation sessions.

The Multidisciplinary Guideline for Cardiac Rehabilitation in The Netherlands (2011) explained that the heart rehabilitation plan should be tailored based on the patient's needs. There are 4 types of goals based on the needs. The goals are for long term, even when the rehabilitation sessions are completed. These goals are:

Goal	Description
Physical Goals	 Patient understands his physical limitation boundaries objectively so he can deal with the limitation in daily life. Patient is able to do different kinds of movement/ load while confronted with the physical limitation. To reach this, patient needs to accept the limitation. Patient is able to function at the desired capacity related to his work, hobby or sport. Patient is able to overcome unnecessary self-restriction. After a heart problem, patient has a tendency to underestimate his own capacity and therefore restrict himself.
Psychological Goals	 Patient overcomes the fear that cause self-restriction. This is related to point number 4 in the physical goal. Patient is able to find his emotional balance. In some cases there are complaints related to symptoms of depression and anxiety. These need to be treated to improve the quality of life. Patient is able to deal with heart disease while continue being functional.
Social Goals	 Patient is able to gain the emotional balance related to his social environment (family, relationship, work, etc). Patient is able to resume his roles in the social environment. Patient is able to resume his leisure-related activities The patient's caregiver of support network are able to regain their emotional balance.
Influencing Risky Behavior	 Patient is familiar with his risk factors. Patient stops smoking. Patient maintains a physically active habits. Healthy diet. Adherence to the prescribed medication.

Table 6: Goals of heart rehabilitation

B. Rehabilitation Process

With the existing regulation, heart rehabilitation normally last for 12 weeks, with 2 sessions per week. The treatment plan will be personalized according to the discussed goals. For example, a patient could get 4 sessions of psychological therapy and 20 sessions of physiotherapy.

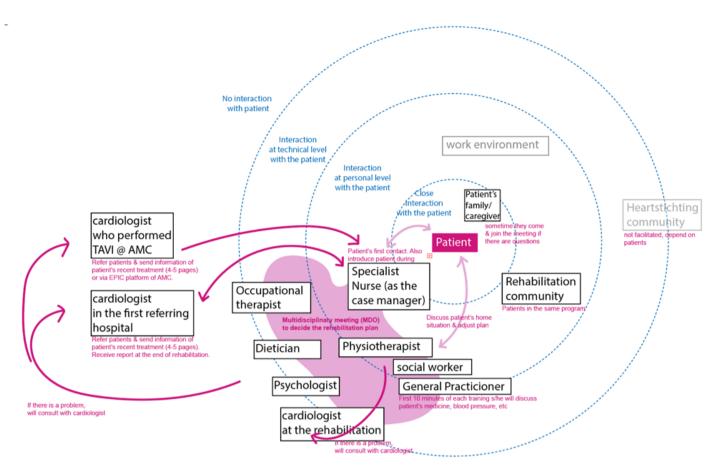


Figure 23: Stakeholders in the heart rehabilitation process

In response to Covid-19 pandemic measures on March-May 2020, where activities in the hospitals are postponed, the Cardiovitaal HvA is starting to shift their rehabilitation online. For this research an observation in one of the physiotherapy sessions was done. They are using a video call platform (Zoom.us). The session is led by a physiotherapist (woman in the blue shirt in figure 2). Before starting the session, physiotherapist ask them about their blood pressure, heart rate and how they have been feeling. Some patients are wearing a wearable sensor on their wrist and look at it when answering. The exercise is divided into 3 sessions with 15 minutes each. In the end of each session the physiotherapist ask all patients to measure their level of perceived exertion using Borg scale.

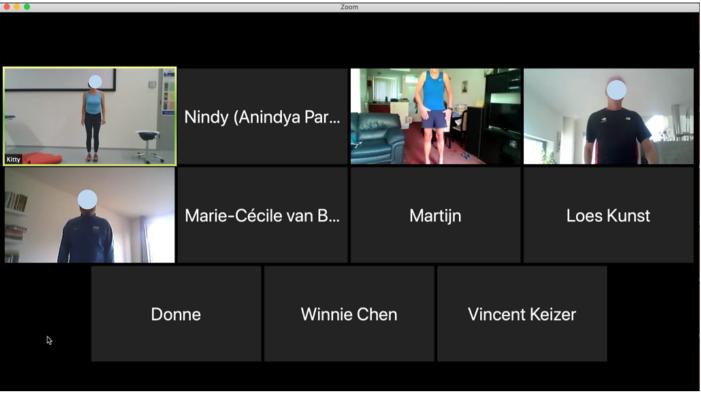


Figure 24: Online Rehabilitation Session from Cardiovitaal HvA.

The heart rehabilitation sessions can also be a social activity. Cardiologist at Amstelland Hospital mentioned, "There are patients who do not really need to do rehabilitation but they still come so they can meet the community and hang out afterwards." However, 30-40% of referred patients do not do the rehabilitation.

C. Summary

By shifting to online rehabilitation, the barriers that are related to transportation is far reduced. Online rehabilitation is also more efficient. Physiotherapist in Cardiovitaal HvA explained that sometime one session dan be arranged for 2 rehabilitation combined. However, online rehabilitation might not offer the same level of social activity as the offline one. Also, for the older patients who are not familiar with technology, there can be a challenge in setting up the devices to be ready for the online rehabilitation at their home.

Physiotherapist at Cardiovitaal HvA explained that it is important that patients are able to sustain the new lifestyle after they completed the rehabilitation. "We see a lot of people are falling down to the earlier condition... for example when you have obesity, it is a psychological problem.. when surrounded by the specialists at the right environment you may perform well.. but in your own environment there are a lot of risks.. of failure of falling back." In an uncontrolled environment, with no access to the formal caregiver, there are risks of relapse.

To help TAVI patients to recover, knowing their activity level is useful, but it needs to be combined with the patient's anxiety level, as they are corelated. Cardiovitaal HvA physiotherapist explained that the elderly patients are usually scared to do high level of exercise. This fear could contribute to the stress level and form a loop. The physiotherapist gave an example, "If I don't move then my stress is high and my lipid is also high.. my bool pressure high..". With a biosensor in the picture, the physiotherapist hypothesizes that if patient could see objectively that he is still moving within his physical capacity, it will reduce the fear. For example with an ECG sensor, patient can learn which level is their limit and adjust their expectation accordingly.

2.2.4 Discussion about the Role of Healthcare Provider in TAVI Care Pathway

Based on the interview results and observation, the overall pathway for an AOS patient when receiving TAVI treatment consist of 3 organizations: the referring hospital, AMC and rehabilitation center (this can be in the referring hospital in some cases). The order of these organization's involvements are illustrated in the figure below.

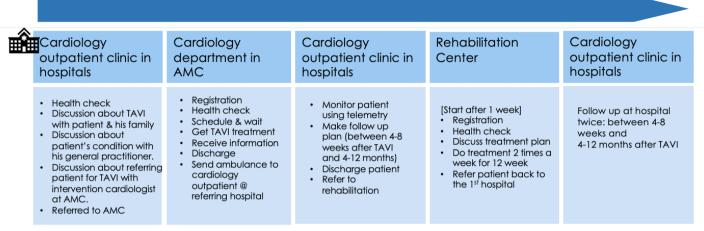


Figure 25: Procedure in the healthcare touchpoint

Since experiencing aortic valve stenosis symptoms until recovering from the TAVI treatment, patients go through at least 3 different organization or department. In the figure above, there are 2 layers of context: patient's own environment is in the first layer and it is a continuous line. The second layer is the healthcare layer which illustrate the involvement order of these 3 organizations.

In the next sub-chapter, the understanding of patient activities (see sub-chapter 2.1) is combined with insights from stakeholder interviews and observation, resulting in a comprehensive patient journey map in the TAVI care pathway.

2.3 Overview of Transcatheter Aortic Valve Implantation Care Pathway: Patient Journey Map

In this sub-chapter the steps of clinicians and patient are synthesized into a patient journey map (see figure 26 and 27). In the journey before TAVI (figure 26) the layers are patient, family, cardiology outpatient at the referring hospital, AMC, data flow and patient's emotion. In the journey after TAVI (figure 27) a layer for heart rehabilitation center is added.

Patient Journey & Care Pathway: Before TAVI

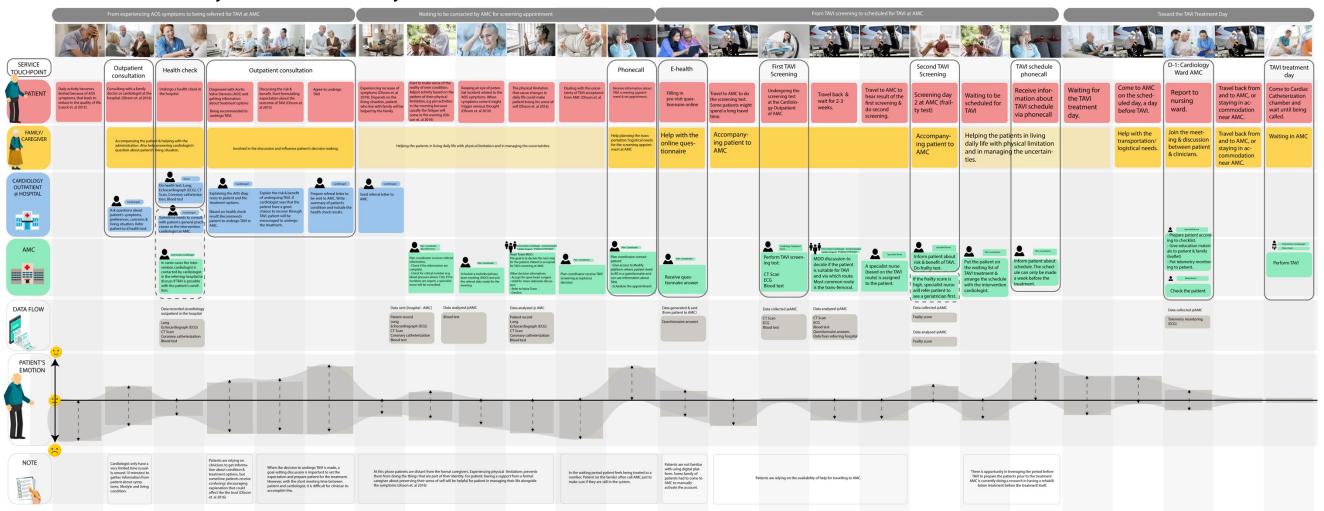


Figure 26: Patient Journey & Care Pathway Map : Before TAVI

Patient Journey & Care Pathway: After TAVI

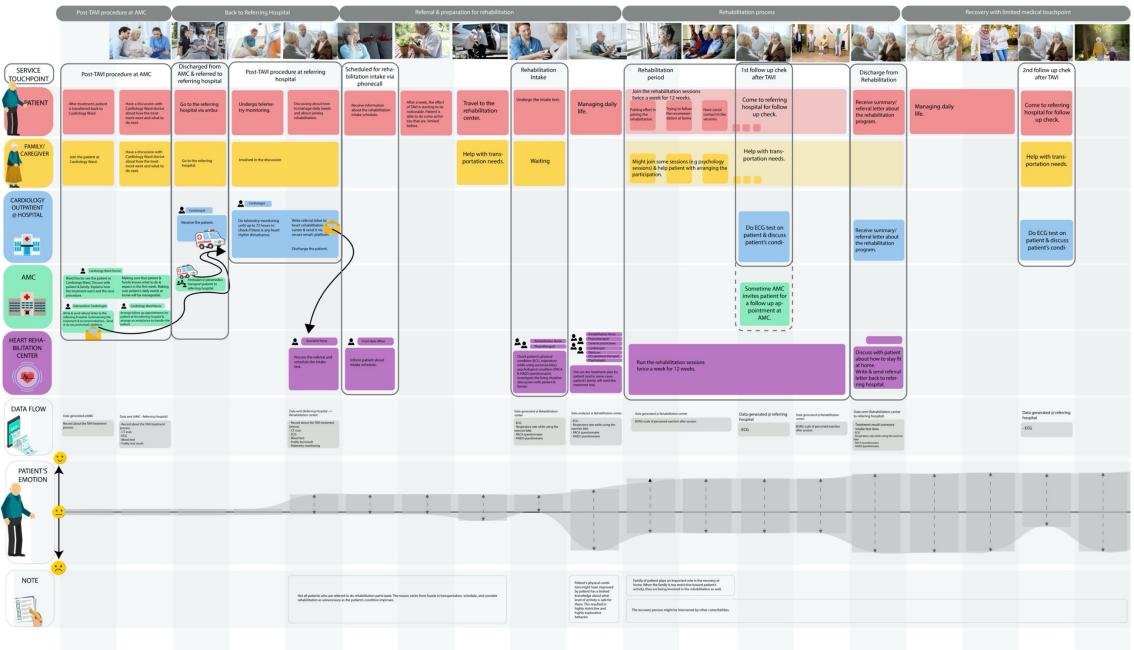


Figure 27: Patient Journey & Care Pathway Map: After TAVI

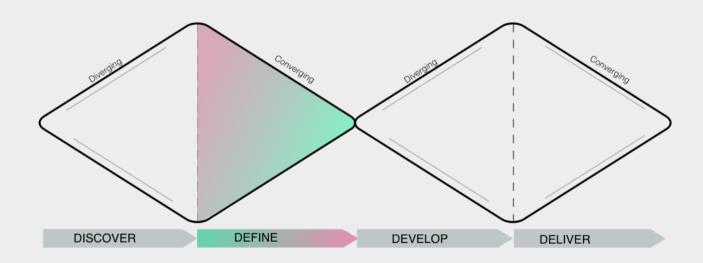
Patient's emotion is shown as a range from positive and negative emotion. Some patients might feel a positive emotion while others feel the negative emotion even though they are at the same phase. In figure 2.18, the range of positive and negative emotion after the rehabilitation period is wide. The experience depends on patient's own expectation about physical capability, the way patient manages physical limitations, the presence of comorbidities, et cetera.

Patient is monitored until up to 1 year after TAVI. However the medical touchpoints are very limited in this phase. Also, not all patients are joining the heart rehabilitation. Therefore there is an opportunity to design for improving patient's experience in the recovery phase.

2.4 Chapter Summary

The end of this chapter is the end of the discovery phase. An overview of patient's and stakeholder's activities in the care pathway is visualized as a patient journey map. Gap in the recovery phase is identified, which leads to the decision to narrow down the project toward the recovery phase. The next chapter is the defining phase, where a problem statement related to recovery phase will be drawn and translated into design vision.

PHASE TWO: DEFINE



Chapter 3: Defining the Problem in Patient's Experience Related to the Recovery Phase

In this chapter, a framework about patient's experience is generated from a grounded theory analysis method (sub-chapter 3.1) using the list of patient's activities explained in the previous chapter. In sub-chapter 3.2, the framework is iterated and analyzed using co-reflection method. The outcome is a problem statement that is translated into a design vision.

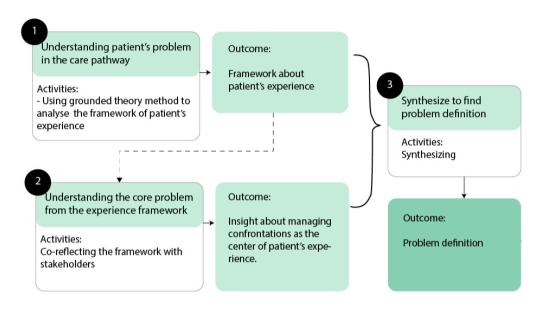


Figure 28: Overview of Chapter 3

3.1 Understanding the Framework of TAVI Patient's Experience

Grounded theory method is used for analyzing patient's events data into a theory. As explained in the previous chapter, literature about TAVI patient experience published within 2015-2020 that used qualitative research method are analyzed. Using grounded theory method, raw data can be analyzed to draw a conclusive theory (Strauss, 1994). In this project, the raw data are the text in literature.

Patient's events are extracted from the text. See table 3 in the previous chapter for an example of how events are extracted from the article text. The approach in this step resembles an initial coding in the grounded theory method process, which aims to identify data that are essential (Birks & Mills, 2011). The next step is focused coding, which aims at clustering the essential data with relevant characteristics into categories (Birks & Mills, 2011). The events are categorized into 11 categories. The third step is called theoretical coding. This is when the data is analyzed into an abstract knowledge. (Birks & Mills, 2011). In this step the relations among these 11 categories are defined in the theoretical coding step.

3.1.1 Creating the Categories

The list of events from table 4 in previous chapter was put in an excel file. Each event was labeled, the same approach as memo-writing step in grounded theory method (Birks & Mills, 2011). Then the name of clusters or categories were written in the right column (see figure 29)

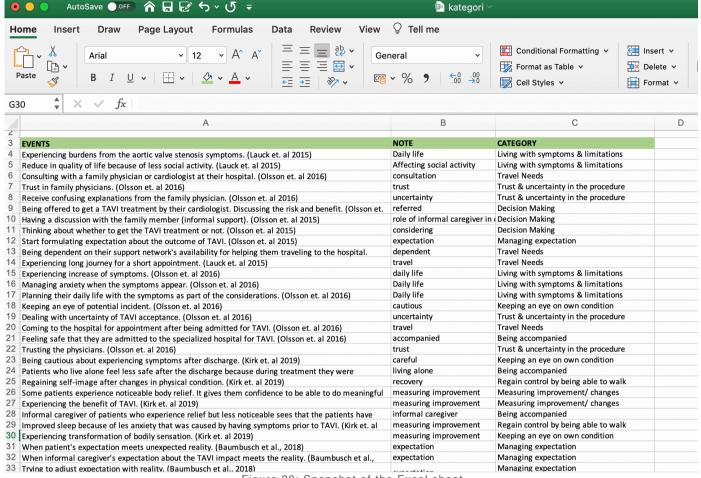


Figure 29: Snapshot of the Excel sheet

In this step, eleven categories were created, namely: living with symptoms and limitations, keeping an eye on own condition, managing expectation, trust & uncertainty in the procedure, decision making, travel needs, being accompanied, knowledge, regain control by being able to walk, measuring improvement/ changes and motivation to put effort in recovery. In the next section, these categories are clustered into themes.

3.1.2 Creating the Themes

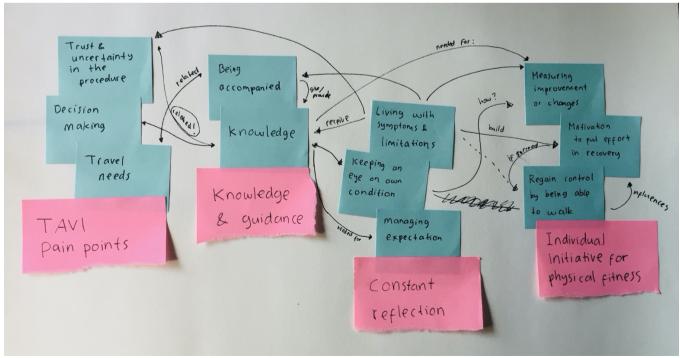


Figure 30: The process of creating the themes

To create the themes, the categories were first clustered. Then connections between categories were drawn. In this process, the list of events inside each categories were constantly checked for reference. After the connections among categories were drawn, the clusters were labeled into themes. The list of themes are:

Themes	Category	Events
Constant reflection process	Living with symptoms	· Experiencing burdens from the aortic valve stenosis symptoms. (Lauck et. al
	& limitations	2015) Reduce in quality of life because of less social activity. (Lauck et. al 2015)
		Experiencing increase of symptoms.(Olsson et. al 2016)
		· Planning their daily life with the symptoms as part of the considerations.
		(Olsson et. al 2016)
		Continue taking medicine makes patient feels unsure if there will not be any other problem with their body in the future. (Kirk et. al 2019)
		· Reconciling with reality about living with limitations. (Kirk et. al 2019)
		• Recovery from TAVI treatment while dealing with aging and comorbidities.
		(Kirk et. al 2019) · Managing anxiety when the symptoms appear. (Olsson et. al 2016)
	Keeping an eye on	Keeping an eye of potential incident. (Olsson et. al 2016)
	own condition	· Being cautious about experiencing symptoms after discharge.(Kirk et. al 2019)
		Experiencing transformation of bodily sensation. (Kirk et. al 2019) Being alert of bodily sign of possible illness. (Kirk et. al 2019)
	Managing expectation	Start formulating expectation about the outcome of TAVI. (Olsson et. al 2015)
		· More factors are involved in building the expectation about the outcome of
		TAVI treatment, including what the clinicians said and how they said it.
		When patient's expectation meets unexpected reality. (Baumbusch et al., 2018)
		· When informal caregiver's expectation about the TAVI impact meets the
		reality. (Baumbusch et al., 2018)
		 Trying to adjust expectation with reality. (Baumbusch et al., 2018) Waiting to receive TAVI. The wait is even longer in the period of Covid-19
		pandemic wave as hospitals postpone the treatment for about 2 months.
		Reconciling with reality about living with limitations. (Kirk et. al 2019)
2. TAVI Procedure Pain Points	Trust & uncertainty in	 Goal setting related to physical activity is important for motivation. Trust in family physicians. (Olsson et. al 2016)
2. TAVITTOCEGUIE Faiii Foiiits	the procedure	Waiting to receive TAVI. The wait is even longer in the period of Covid-19
		pandemic wave as hospitals postpone the treatment for about 2 months.
		Dealing with uncertainty of TAVI acceptance.(Olsson et. al 2016) Trusting the physicians because of actual contact. (Olsson et. al 2016)
		Receive confusing explanations from the family physician.
	Decision making	· Being offered to get a TAVI treatment by their cardiologist. Discussing the risk
		and benefit. (Olsson et. al 2015)
		· Having a discussion with the family member (informal support). (Olsson et. al 2015)
		• Thinking about whether to get the TAVI treatment or not. (Olsson et. al 2015)
	Travel needs	· Consulting with a family physician or cardiologist at their hospital. (Olsson et.
		al 2016) · Being dependent on their support network's availability for helping them
		traveling to the hospital. (Lauck et. al 2016)
		· Experiencing long journey for a short appointment. (Lauck et. al 2016)
		Coming to the hospital for appointment after being admitted for TAVI. (Olsson et. al 2016)
Knowledge and Guidance	Being accompanied	• Feeling safe that they are admitted to the specialized hospital for TAVI. (Olsson
		et. al 2016)
		Patients who live alone feel less safe after the discharge because during
		treatment they were accompanied by their family. (Kirk et. al 2019) · 'Independent' rehabilitation program is lack of control and support function
		from a formal caregiver. (Kirk et. al 2019)
	Knowledge	· 'Independent' rehabilitation program makes patients regain control of
		managing their own daily task and which one to do. (Kirk et. al 2019) Improvement of physical condition needs patient's effort, for example by
		doing the exercise. (Kirk et. al 2019)
		· Patients join rehabilitation because they are aware that they need to do
		something to improve or maintain their condition. Patients who do not join rehabilitation see doing activities related to daily life
		(household task for example) would bring the same benefit as doing a
		rehabilitation program.

4. Individual initiative to put effort to improve or maintain physical fitness	Regain control by being able to walk	Regaining self-image after changes in physical condition.(Kirk et. al 2019) Improved sleep because of less anxiety that was caused by having symptoms prior to TAVI. (Kirk et. al 2019) Being able to walk enables patients to participate in social activity again. (Kirk et. al 2019) Being able to walk brings a sense of control over patient's own live. (Kirk et. al 2019)
	Measuring improvement/ changes	Some patients experience noticeable body relief. It gives them confidence to be able to do meaningful activities. (Kirk et. al 2019) Experiencing the benefit of TAVI.(Kirk et. al 2019) Informal caregiver of patients who experience relief but less noticeable sees that the patients have more confident in living their daily life. (Kirk et. al 2019) The regained ability to walk represents the patient's progress. (Kirk et. al 2019) The effect of TAVI might be good but the overall physical condition might not fully improved because of comorbidities. (Baumbusch et. al 2017) Distinguishing the symptoms of comorbidities and symptoms of AOS after TAVI (Baumbusch et. al 2017)
	Motivation to put effort in recovery	 Improvement of physical condition needs patient's effort, for example by doing the exercise. Patients join rehabilitation because they are aware that they need to do something to improve or maintain their condition. (Kirk et. al 2019) Patients who do not join rehabilitation see doing activities related to daily life (household task for example) would bring the same benefit as doing a rehabilitation program. (Kirk et. al 2019) Goal setting related to physical activity is important for motivation. (Kirk et. al 2019) Experiencing the benefit of TAVI .(Kirk et. al 2019)

Table 7: Themes, categories and events

In the next section connection between themes and categories are analyzed and summarized into a framework of patient's experience.

3.1.3 Creating the Framework

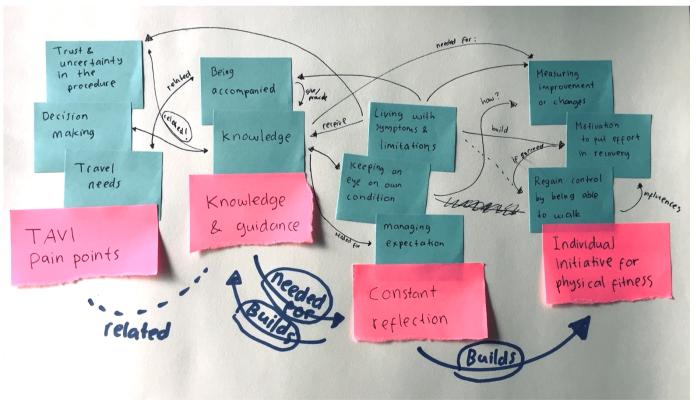


Figure 31: connection between themes

Categories and themes are analyzed into framework. The connection between categories created 4 themes as illustrated below:

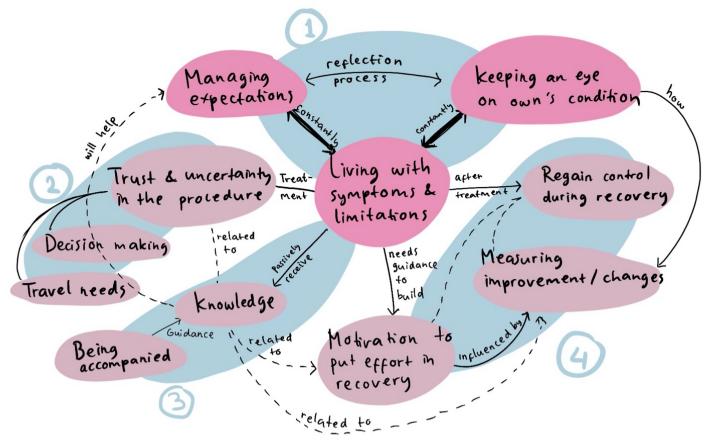


Figure 29: Experience framework

Theme 1: Constant Reflection Process

In living with symptoms & limitations, patients are keeping an eye on their condition while constantly reflecting their expectation with reality. These are happening before TAVI, when patients are still experiencing AOS symptoms, and after TAVI when the symptoms might be reduced but patients still have to deal with limitations from comorbidities. Expectations start to be formulated as early as when the option to undergo TAVI was presented on the discussion, then the constant reflection starts from there. Aligned with what Olsson (2016) concluded about TAVI patient's experience, the constant reflection process is revolving around dealing with their limitations and living their life as normal as possible.

There are elements of learning to accept the reality while having an optimistic but realistic view about their capabilities. In accepting their condition the patients need to understand what are still possible for them to do (the baseline), then the optimistic view upon it would be how to make the most of it. This understanding could build their motivation to put effort in improving or maintaining their physical fitness. Due to the possibilities of a decline in the patient's physical condition, the baseline could constantly change and patients need to understand this aspect to be realistic. Part of being realistic is being aware of a possible incident and have a system that support the patients in the case of incident.

Theme 2: TAVI Procedure Pain Points

Paint points about the TAVI procedure are related to uncertainty of the process, such as waiting time, complicated practicality such as having to travel far and inconsistent information that affect the decision making process. In improving patient's experience, it is important to design a system that make information transfer, decision making discussion and travel burden easier for patients.

Theme 3: Knowledge & guidance

The knowledge about what the patient could expect, the procedure, and about how to maintain their condition are provided to them mostly by the formal caregiver during the medical touchpoint. Meanwhile, existing medical touchpoints do not cover the patient's entire journey. Especially in the recovery phase, patients are mostly in their own environment. When they are not in the hospital, the patients still need the knowledge that are relevant to theme number 1. For patients, having a system that provide feedback toward their constant reflection process will be helpful.

From the events before TAVI, shortly after TAVI and in the recovery period we learn that the role of informal caregiver, which in most cases the family of patient, is interacting closely with the patient since the beginning. Cardiovascular disease, including aortic valve stenosis, does not only affect the patient but also the patient's family (Moons et al., 2020). Family, especially the spouses, often take up the role of informal caregivers. They go through stressful periods of experiencing the patient's consequences of illness. Their high involvement means they could play an important role in improving the care process. Involving families in the patient care improves outcome, adherence and reduce the number of mortality (Moons et al 2020; Luttik et al 2017). Therefore it is important to also consider informal caregivers in the process.

Theme 4: Individual initiative to put effort to improve or maintain physical fitness.

Patient's own initiative and motivation has a big influence in regaining control over their daily life (related to Theme 1). Being able to notice an improvement in physical fitness is a source of motivation, but not all improvements are immediately noticeable. For example in cases where symptoms relief after TAVI happens in a very gradual way (Kirk et al., 2019). Therefore it is important to be able to make physical fitness state tangible and understandable by the patient, for example through sensor-tracking and feedback. By having a physical fitness data available, formal caregivers (e.g physiotherapist or specialist nurse) could provide feedback and coaching based on it. By including physical fitness data to give objective feedback to patients in a home-based rehabilitation program, patients are able to maintain their fitness level (Kraal et al., 2017).

3.2 Validating the Framework of Patient's Experience in the Care Pathway

Co-reflection exercises was done together with stakeholders. The goal is to address the core of the problem so the solution would start from there. The theoretical framework is used as a starting point. The co-reflection session was conducted individually, and the order of the sessions was based on participant's availability. The result of each session is reflected in the next session, as illustrated in figure 30 below. The participants were the patient communication specialist at AMC, data designer at Philips, specialist nurse at AMC, intervention cardiologist at AMC and physiotherapist at Cardiovitaal HvA.

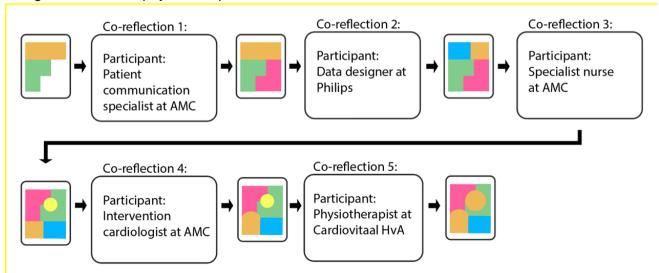


Figure 30: Co-reflection process. The changing shape and color represents how the outcome of one session was brought in the next session.

3.2.1 Co-Reflection 1

The first co-reflection session was done with the Patient Communication Specialist at AMC. At AMC, the Patient Communication Specialist is the person who advocates the patient's perspectives to be considered when designing a procedure. The Patient Communication Specialist in the co-reflection session was also a heart patient who is active in the Heartstichting.

The co-reflection session was done online using a video conference platform (Zoom.us). In the session, the framework was shown in a shared screen and discussed. The result and synthesize from the session are explained below.

A. Result: Narrowing down to Theme #1

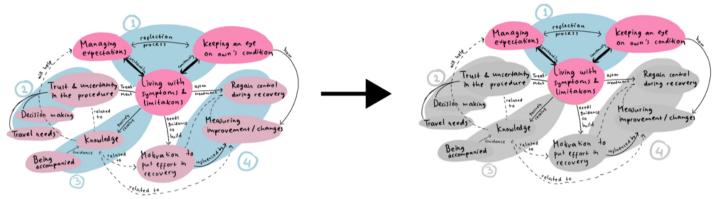


Figure 31: Narrowing down to Theme #1

The framework is centered around the first theme; constant reflection process. The theme is about constantly adjusting own expectation when encountering challenging reality. The focus is shifted toward the moments of encountering the confronting reality. For example, being reminded of having the disease, experiencing physical limitation while doing an activity and doubting own physical ability before doing certain activity.

B. Synthesize: Managing Confrontation

'Constant reflection process' is iterated into 'managing confrontation' because the reflection happens when patient encounter confrontations. AMC patient communication specialist mentioned, "Patients are constantly reminded of being ill.... whether from people around them who are always worried or themselves.. questioning 'Is this safe for me?' before deciding to do something."

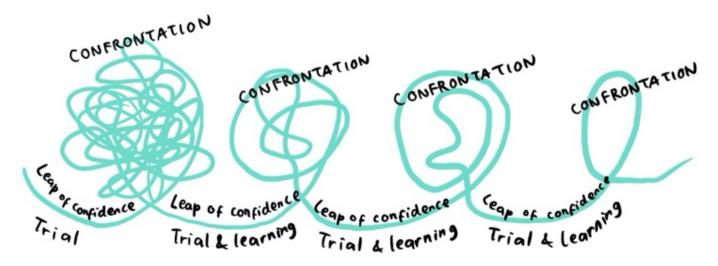


Figure 32: Confrontation loop

'Managing constant confrontation' is visualized as a loop. In managing confrontation, patients are taking action and take some learnings before dealing with another confrontation. For example, a patient has the question "is this safe for me?" in mind prior to do something. Then this patient does the activity while being observant of how his body responds to the activity. In the example, the confrontation is the uncertainty of "is this safe for me?". The patient is managing the confrontation by taking a leap of confidence enabling the process of trial and learning. The confrontation could become easier as the patient does more rounds of trial and learning (see figure 32).

3.2.2 Co-Reflection 2

Participant in the second co-reflection is the data designer at Philips. The data designer has been part of this project and is familiar with the biosensor and some previous e-Health projects inside Philips. In this session, the synthesize from previous co-reflection is being co-reflected. The session was done via video conference platform Zoom.us. Visuals of the previous synthesize (see figure 31) was shown and discussed.

A. Result: The need to identify possible confrontation factors

From the discussion, some of the possible confronting factors are:

- Physical ability
- Expectation about own physical ability
- Reminder of being in/ having been through a bad condition
- Etcetera

The more often a patient deals with a confronting factor and experience the trial and learning process, the less complicated it becomes. The source of these confronting factors could vary. It may come from the patient himself or from the patient's living environment. Cardiac disease does not only affect the patient but also the family (Moons et al., 2020). Therefore the family or informal caregiver of patients often experience the confrontation too, which sometime manifested in restricting the patient's activity.

With the wide variation of possible confrontations, the scope of this project needs to be defined clearly: which confrontation?

B. Synthesize: Focus on confrontations that are related to physical activity

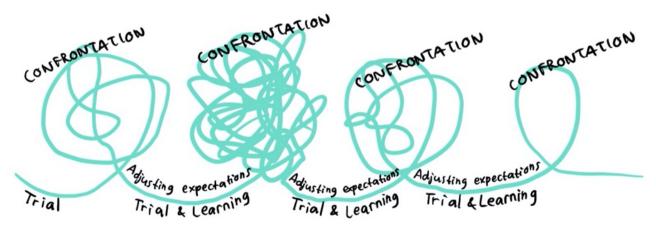


Figure 33: iteration of the confrontation loop.

In this project, the focus is on confrontations that are related with patient's physical activity. The reason is because exercise-based heart rehabilitation has been proven to increase the quality of life of patient (Kaal et al, 2017; Vries et al, 2015). When the confrontations are narrowed down into exercise-related, the confrontation loop is also iterated. In figure 32, patient manages confrontation by taking a 'leap of confidence'. In the new iteration (see figure 33), patient manages confrontation by adjusting their expectation. The expectation could be related to their level of physical ability, their level of activity performance, etcetera.

3.2.3 Co-Reflection 3

Participant in the third round of co-reflection was the specialist nurse who handles TAVI patients at AMC. The co-reflection session was done online using video call platform Zoom.us. In the session, the confrontation loop (see figure 32) and the earlier version of it (see figure 31) were shown. Two illustrations about both version of the confrontation loop were also discussed (see figure 34 and 35).

Confrontation Trial & learning Leap of confidence Taking 'baby steps' "I want to take Afraid to move something from the and feel safer because afraid because turns out kitchen. Maybe it of exertion if is okay to walk is okay to walk to the kitchen a bit.

Figure 34: Illustration about the first version of confrontation loop

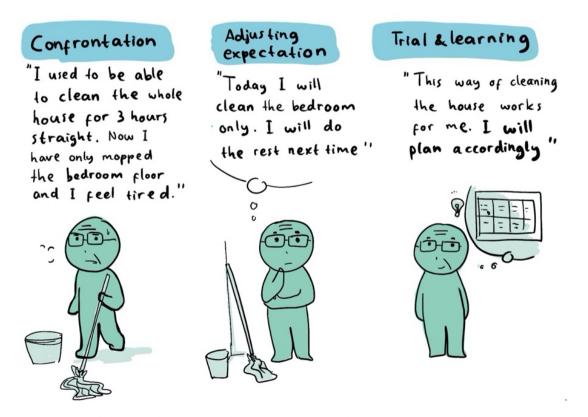


Figure 35: Illustration about the second version of confrontation loop

A. Result: Patterns in patient's behavior

The confrontations in the two illustrations represent two kinds of behaviour patterns commonly seen by the specialist nurse. The first one (figure 34) is patient who is afraid of doing physical activity and tends to restrict himself from doing physical activity. The second one (figure 35) is patient who has a high expectation of his physical ability and may encounter difficulties when facing the reality.

B. Synthesize: Two spectrum of patient's behavior; restrictive and explorative

A spectrum of patient behavior pattern is identified. There are 2 extreme behaviors on each polar; on the left is patient who is afraid to do any physical activity and on the right is patient who is eager to go back to his physically active life.



Figure 36: Patient behaviour spectrum

Among patients in the restrictive spectrum, often upon doing a physical activity the patient questions to himself, "Is this safe for me?". While patient in the explorative spectrum has an unrealistic expectation about what he could do. The specialist nurse explained, "I often see patient who expect to do a lot after TAVI.. if someone said he wants to cycle 20 kilometers, I recommend them to try 3 kilometers first.. and if they feel something is wrong with their body then they should contact their doctor."

Both behaviors need to manage confrontation by adjusting their expectation. The restrictive patient needs to adjust his low expectation about his own ability, while the explorative patient needs to adjust the high expectation to be more realistic. When the expectation is adjusted and patient successfully do the activity, some learnings will be gained. The learnings will feed into the next confrontation and build patient's intuition in managing the same confrontation factor over time.

The more a patient deals with a certain confrontation, the more intuitive he will become in managing it. However, factors that shape the confrontations are dynamic. In category 1 of Patient journey analysis in chapter 2, 'Living with symptoms & limitations', it is possible that patient's physical ability is increased after getting the TAVI treatment, but after some time there are symptoms of other comorbidity. Therefore behaviors in different range of the spectrum could appear in the same person depending on the situation.

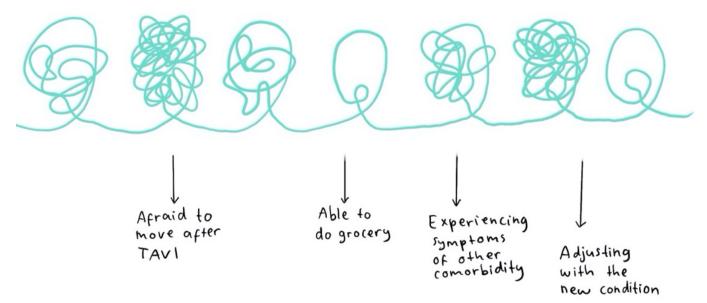


Figure 37: Integrated flow of confrontation moments

3.2.4 Co-Reflection 4

Participant in the fourth round of the co-reflection is the intervention cardiologist who performed TAVI at AMC. In this round, the behaviour spectrum (see figure 36) and how the two extreme behaviours could be exhibited by the same person in different phase during the recovery were shown and discussed.

A. Result

The participant could relate with the synthesize result of the previous co-reflection round. Both kinds of patient, who are afraid of doing physical activity and who want to be quickly back to a physically active life are common. The characteristic in both behaviour patterns were discussed. The intervention cardiologist mentioned, "Patient who wants to become active right away after TAVI has a higher motivation compared to patient who is afraid.. even when the expectations are not realistic." Therefore both restrictive and explorative patients might have the same low level of knowledge about their own physical ability, but they have a different level of motivation.

B. Synthesize: Identifying the dimensions when managing confrontations

From the discussion about the characteristics of each behaviours, possible dimensions in the behaviour spectrum were generated. There are three dimensions in the behaviour spectrum: knowledge, acceptance and motivation.

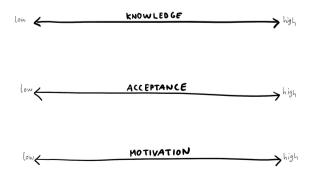


Figure 37: Ideation result of the dimensions in the behaviour spectrum.

In each moment, the level of the 3 spectrums change, whether goes more to the left or the right.

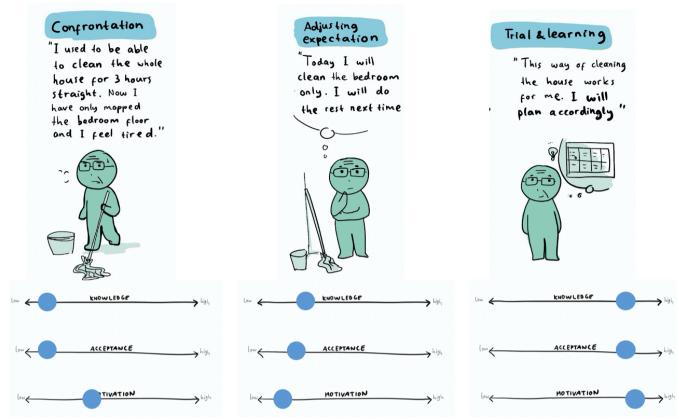


Figure 38: Example of dynamic between knowledge, acceptance and motivation

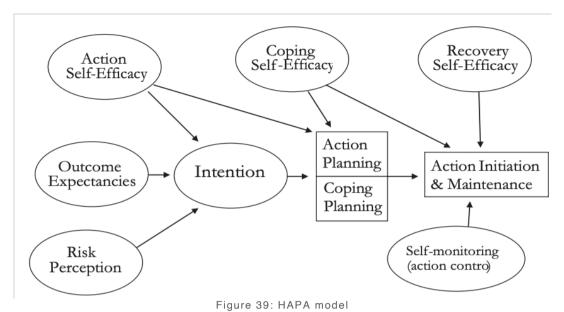
3.2.5 Co-Reflection 5

Participant in the fifth co-reflection round is the physiotherapist at CardioVitaal HvA. In the session, the synthesize from all previous co-reflection rounds were shown and discussed.

A. Result

During the discussion, the three dimensions in patient's behavior spectrum (see figure 37) sparked idea in the participant that there might be an opportunity to implement an existing health behavior change model that aims to create a sustainable health behavior change in patients. One of the discussed models was the Health Action Process Approach (HAPA). In Health Action Process Approach (HAPA) model, health-related behavior change needs two processes, namely motivation and volition (Schwarzer, 2008). Schwarzer (2008) describes that the motivational phase is the goal setting related to the intended behavior, while volition phase is the goal pursuit. The volitional phase can be seen as a sequence of "planning, initiation, maintenance and relapse management".

Each phase has its elements. In the motivational phase the elements are 'action self-efficacy, outcome expectancies, risk perception and intention'. The first 3 of those elements would affect the level of intention. While in the volition phase the elements are coping self-efficacy, recovery self-efficacy, action control, action & coping planning and maintenance.



B. Synthesize: Identifying the dimensions when managing confrontations

With the HAPA model comes into the picture, the dimensions in the behavior spectrum are iterated into the elements that shape intention, planning and initiative toward health behavior change (see figure 40)



Figure 40: Iteration of dimensions in the behavior spectrum and how they contribute to intention, planning and initiative.

3.3 Synthesize

In this step, information from the literature study, stakeholder interview and co-reflection sessions are synthesized into a comprehensive understanding of TAVI patient's experience. The synthesize is discussed in 5 part. The first part is about the way patient manages confrontations. The second and third are about collaborative and continuous goal setting. The fourth is about technology-enabled goal setting. And the fifth is where the personas are discussed.

3.3.1 Managing Confrontations by Making Adjustment of Goal-Oriented Hope

In the result of a qualitative study by Olsson et. al (2016) it is described that the overall experience of TAVI patient along the care pathway is "balancing between life struggles and hope". Patient's experience is varied, sometimes good and sometimes not. The life struggles explained by Olsson et. al (2016) are:

- Being in a frightening situations where patient is reminded that he is old and having a bad condition, going through the test and examinations and agreeing to undergo a treatment that could be life or death.
- Perceiving rehabilitation process as a demanding experience. Some patients experience slow recovery than expected or another problem related to the treatment such as urinary problem after removal of the catheter. Shortly after undergoing TAVI, some patients become weaker than before, which could make them become dependent and feel helpless. The occurrence of bad unexpected outcome causes disappointment because before TAVI the patients mostly have a good expectation about the outcome.
- Experiencing struggle related to their physical limitations. In Olsson et. al (2016)'s study, these
 limitations exist mostly because of comorbidities or aging. The limitation could hinder patient from
 having enough social life, making them feel lonely and isolated. In that research patient also reported
 being highly dependent.

These life struggles are the moments of confrontation that patient has to constantly manage. Big part of the confrontation moments are concerning physical limitations. Olsson et. al (2016) concluded that having hope is important for the wellbeing of TAVI patients. In the rehabilitation phase, hope that is goal-oriented is useful (Olsson et. al, 2016; Tutton et. al, 2009). Therefore in managing the confrontations, having a goal-oriented hope would be essential.

Hope theory developed by Snyder in 2002 describes hope as "the perceived capability to derive pathway to desired goals and motivation to use those pathways.". When a patient with high level of hope is facing a barrier, he would be able to iterate the goal and a realistic pathway to achieve it (Olsson et. al, 2016; Snyder, 2000). When the recovery turns out to be slower than expected, some patients in the study of Olsson et. al (2016) participated in adjusting the exercise program, the recovery goals and build trust on themselves.

In managing confrontations, there is an adjustment in the goal and the pathway to reach that goal. This aligned with the story from AMC specialist nurse explained int he third iteration of the co-reflection sessions; a patient expects to clean his house in 3-4 hours straight [initial goal], but he gets tired after a short time [facing confrontation] then he thinks he cannot clean the house in the same way as before [goal adjustment] so he spread the cleaning task into 4 days instead of 4 hours [goal pathway adjustment] and he know he can manage it [trust on oneself].

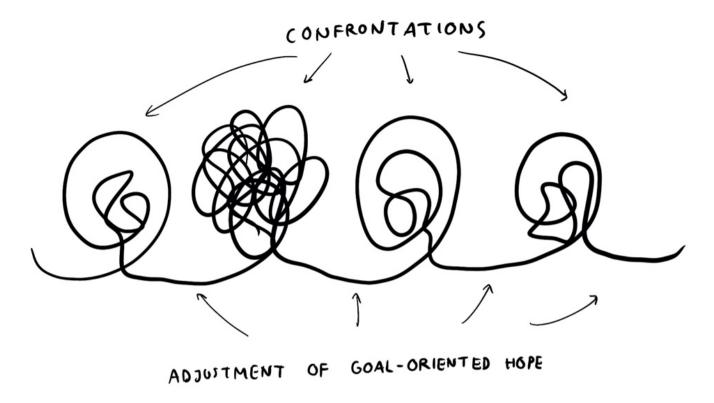


Figure 41: Managing confrontations by making adjustment in the goal-oriented hope

Therefore to have a goal-setting that aims to guide patient in making adjustment of goal-oriented hope in their journey of managing confrontations in important.

3.3.2 Collaborative Goal Setting

In healthcare services, hope is created in an environment or interaction where patient could trust the clinicians, felt respected and participated in the decision making of the treatment (Olsson et. al 2016). It is in line with shared decision making approach, where patients and clinicians both share the best evidence to inform a decision making process and make the decision also based on the patient's preference toward the available options (Elwyn & Coulter, 2010). A study conducted by Schulman-Green, et. al in 2006 mentioned that compared to other groups, elderly patient is less likely to be involved in a shared decision-making. In contrary, patient perceives being present while not included in the discussion as humiliating (Olsson et. al, 2016). Therefore having the shared decision-making approach is important, but to reach that, a strategy to improve TAVI patient's participation is needed.

One of the barrier of TAVI patient's participation in a shared decision making is addressed in a study in 2015 by Olsson et. al that TAVI patients are less likely to trust their own decision and give the decision to the expert or family member. Schulman-Green (2006) identified the barriers of having a collaborative goal setting among clinician and elderly patients:

- Discussion about patient's goal is not seen as a priority from both clinician and patient, especially with clinician's limited time during the appointment. The discussion mainly focuses on symptoms.
- Both patient and clinician do not perceive that goal setting is necessary. Goal setting discussion is not seen as part of a care pathway.
- Clinician thinks goal setting discussion should start at the first session. While the patient needs to build trust toward the clinician before he is able to talk about goal. Patient sees goal as something that is personal, and to share it before a rapport has been built is difficult.

• Some clinicians are not trained to facilitate the elicitation of patient's goal.

Those barriers come from both patient and clinician side. Meanwhile, to have a decision making that involves patient and clinician, both should be willing and able to participate (Rose, 2019).

Schulman-Green (2006) explained that to make goal setting discussion happens with shared decision making process, the goal setting itself should have these elements:

- 1. Building rapport.
- 2. Give structure to the conversation to facilitate the elicitation of patient's goal.
- 3. The goal setting process itself should be formalized in the clinician's paperwork.
- 4. Information during the session could be accessed by other providers to reduce a fragmentation in the care pathway.

3.3.3 Continuous Goal Setting

The next step is to find the right moment in the care pathway for the collaborative goal setting to happen. In section 3.3.1 we learned that understanding patient's goal at the beginning of the treatment is useful for the clinician but for patient it requires rapport to be built first. Also, patient's physical condition is changing throughout the care pathway. Schulman-Green et. al in 2006 explained that among nurses, goal setting is perceived as a continuous conversation. The article shows an example of how at the beginning the patient is walking using a walker, then when he could walk well with a walker, the next goal is to be able to walk with a cane and so on. Therefore the goal setting should happen continuously throughout the care pathway, instead of a one-time session. The goal itself is evolving, based on patient's condition and the rapport built.

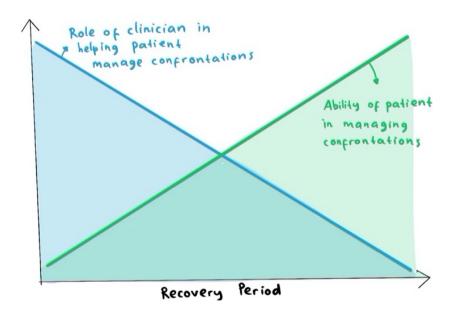


Figure 42: The level of involvement of the healthcare providers should go down as the level of patient's ability in managing confrontation goes up.

The confrontations happen in patient's own context. Therefore the goal setting system should aim to increase patient's ability in managing the confrontations in patient's own context. At the beginning of the system, as rapport is being built, the influence of clinician in the goal setting process is relatively higher compared to when rapport has been built and patient has more ability in managing confrontations.

In the co-reflective session, intervention cardiologist at AMC explained that it is important to have the goal setting conversation before TAVI. One of the reason is to understand patient's initial expectation toward the

outcome of TAVI. Although rapport might not have been strong at the beginning, by having the first goal setting conversation before TAVI, clinician could better understand patient's expectation about the outcome of TAVI while start building rapport.

3.3.4 User Target

Based on the identified behavior spectrum among patients explained in the co-reflection iteration phase, 3 personas of patients in the recovery phase are created.

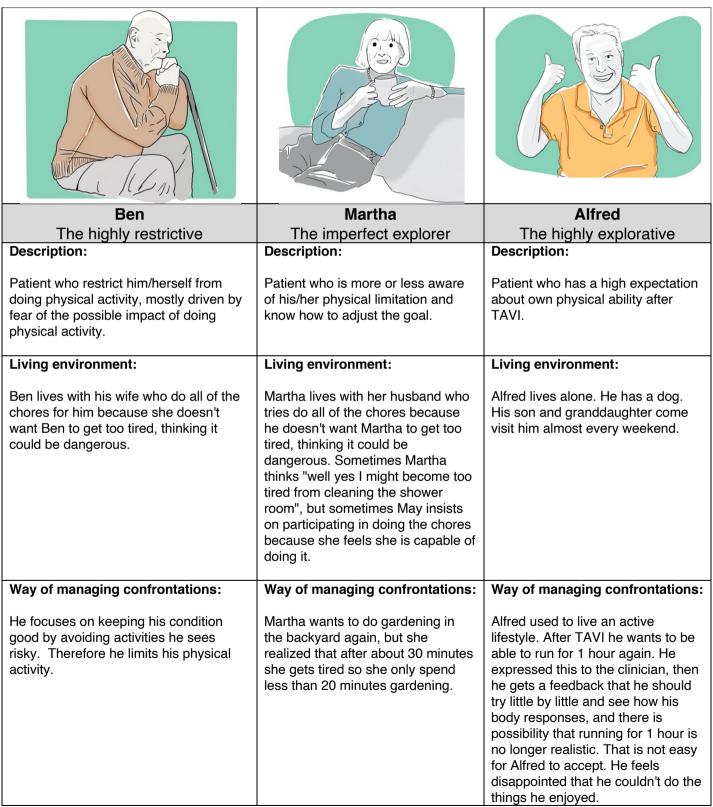


Table 8: The three personas

Among the three persona explained in table 8, the imperfect explorer has the highest ability to manage confrontations. These patients understand their limitation although not precisely, and are exploring how might they do the activities they desire despite the limitation. The imperfect explorer know how to constantly adjust their goal. The highly explorative persona, on the other hand, might have less ability to manage confrontations compared to the imperfect explorer due to their tendency to overestimate their physical ability. The highly restrictive persona has an opposite characteristic compared to the highly explorative persona. They tend to highly underestimate their own physical ability, stopping themselves from doing the activities.

In the HAPA theory explained in sub-chapter 3.2.5, the first step toward a health behavior change is to build the intention. Dimensions that shape the intention are action self-efficacy, outcome expectancy and risk perception. Action self-efficacy is the belief of own capability to successfully perform an activity (Bandura, 1997). Schwarzer (2008) explains that risk perceptions are the ability to consider the balance of pros and cons of an action's consequences. Outcome expectancies are the ability to build assumptions about the possible result from the action. The levels of these three dimensions among the three personas are illustrated below (figure 43, 44, 45)

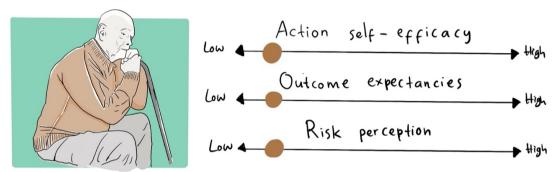


Figure 43: Levels of dimensions that shape intention in the highly restrictive persona

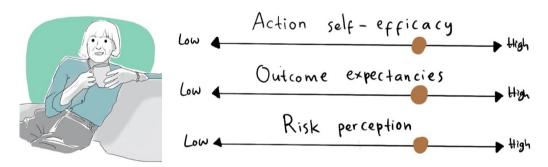


Figure 44: Levels of dimensions that shape intention in the imperfect explorer persona

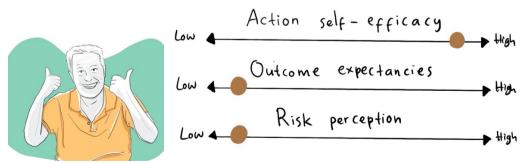


Figure 45: Levels of dimensions that shape intention in the highly explorative persona

Among the three personas, the highly restrictive patients have the least ability to build intention toward health behavior change. Therefore in the next phase the focus will be toward the highly restrictive patient.

3.3.5 Technology-Enabled Goal Setting

Schwarzer (2008) describes that in the HAPA model, the process is divided into motivational (goal setting) and volitional (goal pursuit). Therefore there is an opportunity in developing a solution and map the value of biosensor based on this division. The role of technology is divided into goal setting and goal pursuit.

For the goal setting part, aligned with sub-chapter 3.3.2, the role of technology is to support the collaboration between patient and clinician. There is an opportunity in enriching the shared decision making discussion with data about patient's activity and physical condition. Remote monitoring system would enable clinicians to better understand patient's condition in the real life situation and discuss that information in the goal setting session with the patient. Remote monitoring is also valuable for guiding patient in executing the goal pathway and making adjustment when necessary. To be able to do so, two streams of data are needed:

- Physical activity
- Subjective perception of the activities
- Measurement of the impact of activities toward patient's physical condition

In the goal pursuit period, the role of technology is to collect data to be discussed with clinician and to build patient's ability in managing confrontations. There is an opportunity to leverage a conversational agent to help patient in managing confrontations during goal pursuit period. Therefore the value of biosensor is in collecting data during goal pursuit period to be: 1.) discussed in a goal setting and 2.) integrated with a conversational agent to build patient's ability to manage confrontations.

3.4 Problem Statement

TAVI patient's overall experience is about managing confrontations. This happens both before and after TAVI. However, after TAVI, patients have less contact with clinician. Therefore to improve the patient's recovery experience the ability to manage confrontation needs to be improved. This could be done through goal setting conversations between patient and clinician. As patient's condition is changing throughout the pathway, continuous goal setting is important for TAVI patient. However, in the current care pathway, goal setting only exist as a part of the rehabilitation period. Besides that, the goal setting is currently based on patient's physical condition only at the exact moment of data collection.

For TAVI patients who are highly restrictive, there is an opportunity in building their ability to manage confrontation during the recovery process by designing a system for a continuous and collaborative goal setting. Biosensor data can be collected during goal pursuit period and discussed in a collaborative goal setting. Also, patient's ability to manage confrontation could be built through guidance during the goal pursuit period. Using data, the goal settings could be highly tailored to patient's physical condition, activity and experience.

3.5 Chapter Summary

In this chapter the framework of patient's experience is developed from literature analysis. The understanding of patient's experience is iterated through a series of co-reflection sessions. The result is that managing confrontations through a constant goal-related hope adjustment is an essential elements in the TAVI care pathway. The problem scope focuses on patients who have an over-restrictive behavior related to their physical activity. All the findings were synthesized into a problem statement: improving patient's experience during the recovery process by designing a system for a continuous and collaborative goal setting for TAVI patient.

Chapter 4: Design Vision

4.1 Design Vision

The design vision is:

Improving the ability to manage confrontations among the highly restrictive TAVI patients through a continuous and collaborative goal setting using sensor and experience data.

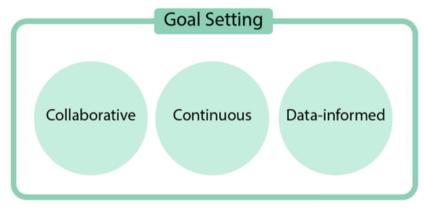


Figure 46: Design vision

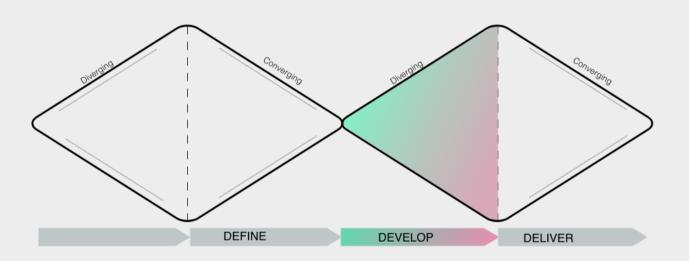
As patients are continuously finding balance between life struggles and hope (Olsson et. al, 2016), an increased ability in managing confrontations would mean an increase in hope. Olsson (2016) describes that this would lead to an improve in patient's psychological wellbeing. Therefore the design vision would have a positive impact toward the patient's psychological wellbeing.

4.2 Summary of the Define Phase

Based on the analysis, in this phase a design vision of a collaborative, continuous and data-informed goal setting is created. Connecting back to how this project started, which is to find the value of Philips Biosensor in the TAVI care pathway, this is where the answer comes: as an enabler in continuously collecting the patient's physical condition and activity in their own context to be discussed in collaborative goal setting sessions. However, the biosensor cannot stand on its own. The biosensor should be part of a remote monitoring system that collects and processes both physical and experience data to be discussed in the goal setting session.

In the next chapter, the design concept is explored and iterated.

PHASE 3: DEVELOP



Chapter 5: Conceptualization

In this chapter, an ideation is done, resulting in an initial concept. This concept is tested with the stakeholder in a series of individual co-reflection session. Based on the concept testing result, the concept is iterated, tested again then refined.

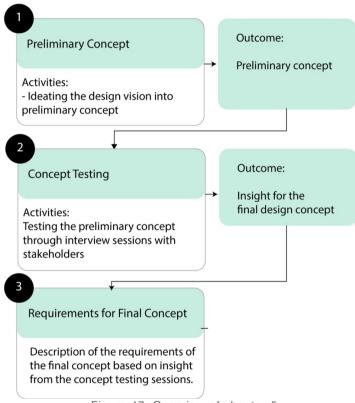


Figure 47: Overview of chapter 5

5.1 Preliminary Concept

Based on the HAPA model (see sub-chapter 3.2.5) where goal setting and goal pursuit are categorized into two phases, in the initial concept, these two phases are also separated. Based on the synthesize in chapter 3.3.2 about collaborative goal setting, the role of data is to inform the goal setting discussion. Therefore data collection period is placed before the goal setting discussion. In summary, the idea about continuous, collaborative and data-informed goal setting is divided into 3 periods:

- Data collection period: This is the period when patient is wearing the biosensor and data is collected in the biosensor system.
- Goal setting session: The interaction between patient and clinicians where the result from data collection period is discussed and decision is made through a shared decision making process.
- Goal pursuit period: The period where patient is supposedly doing the recommendations from the goal setting session in the real context.



Figure 48: First ideation: Three periods in the concept

The data collection and goal setting period are illustrated into story. Figure 49 and 50 show the preparation prior to the data collection period. Patient and clinician have a discussion about the data collection period, then the sensor will be delivered to the patient home (figure 49).



Figure 49: Preparation of data collection (1)

With the help of a family member, patient will activate the sensor and the mobile application.



Figure 50: Preparation of data collection (2)

Figure 51 shows that the patient is doing his usual activity while wearing the sensor and 'reporting' how he feels during the activity to the mobile application. After the data collection period ended, patient will go back to the hospital to do a goal setting discussion.



Figure 51: Data collection period

The idea of the goal setting is it happens continuously in the TAVI care pathway. In the existing TAVI care pathway, multiple organizations are involved. Therefore in this concept these organizations are potentially involved as well. These are:

- Cardiology outpatient at the referring hospital
- AMC
- Heart rehabilitation center
- Philips (as the technology/ platform provider)

To ideate how might these organizations interact in the proposed idea, a possible flow of data collection period and goal setting throughout the TAVI care pathway is visualized in figure 52.

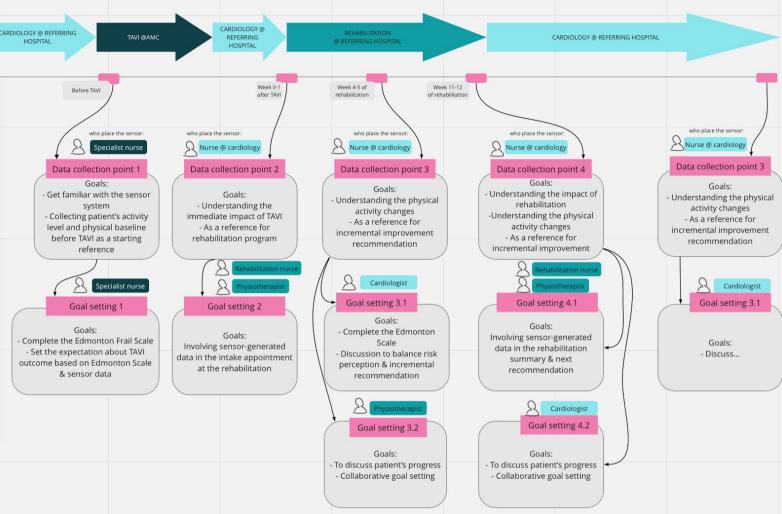


Figure 52: visualisation of how the idea is implemented in the TAVI care pathway.

From visualising the map, it became clear that the value of goal settings may vary, depends on which part in the care pathway it belongs to. For example, before TAVI, the value of goal setting is in setting the first expectation toward the overall outcome of TAVI, why in the goal setting before rehabilitation, the value is in enriching the rehabilitation program with data.

In the next sub-chapter, this preliminary concept is tested with the stakeholders through interview sessions.

5.2 Concept Testing

In this sub-chapter the initial concept is tested with stakeholders. This sub-chapter consists of the methods of the concept testing, the result and the discussion based on the result.

5.2.1 Method

Based on the visualizations, questions for concept testing session are generated (see table 9 below).

Design Questions

1. How to integrate the goal settings with the TAVI patient's journey?

- 2. How to design a data flow that enable multi-organization collaboration?
- 3. How to map the potential actors in the system?

Table 9: Design questions

To generate ideas that answer those question, a series of interviews are conducted with stakeholders. The session is individual. The participants are:

- Philips' data designer
- Physiotherapist from Cardiovitaal HvA,
- Data science researcher from TU Delft
- Specialist nurse from AMC
- Intervention cardiologist from AMC
- Cardiologist from Amstelland Hospital (referring hospital)

The order of the sessions is based on participant's availability. The session is done individually and remotely via online video call. A visual toolkit in an online collaborative presentation file is shared with the participant and discussed during the session, including the map of the preliminary idea (figure 52).

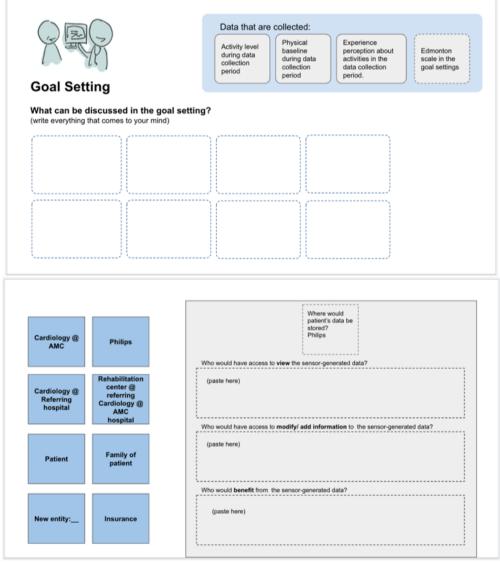


Figure 53: Impressions of the visual toolkit

In the sessions, participant is conditioned to think from multiple perspective of different organizations. The results are described in the following sub-chapter.

Design question 1: How to integrate goal settings with TAVI patient's journey?

Starting a goal setting discussion before TAVI will help setting patient's expectation about the outcome of the treatment. The specialist nurse explained that by having the first goal setting before the treatment, the clinician would be able to better understand patient's expectation about the outcome of TAVI, and therefore a collaborative goal setting discussion could be done. "Sometimes patient before receiving TAVI, they expect to be able to go back to their active life after TAVI." The specialist nurse emphasized that it is important for patients to have their expectation understood first. Then if the expectation needs to be adjusted, the clinician could facilitate that. "For example with patient who have a low expectation, we say, we think you can do more.." The specialist nurse added that the expectation could be more than physical ability, it could also be about patient's expectation in life. "Like in geriatrician's practice, the patient will be asked about what do they want in life?"

Goal setting can happen multiple times in the care pathway. The physiotherapist thinks that by having the same set of goal for patient across different session of goal settings in the care pathway could help in understanding the changes in patient's condition. "For example before TAVI patient is asked to walk for 15 minutes.. then asked to do the same after TAVI so we could see how the body respond to the same activity."

Physiotherapist from the rehabilitation center might be suitable for handling the goal setting, since it suits their capabilities and ongoing initiatives. The physiotherapist mentioned that there has been an ongoing research in Cardiovitaal HvA about conducting the rehabilitation activity before the treatment. "With this sensor system in place it could help that initiative." This is also align with the specialist nurse's remark, "For this discussion to take place before TAVI, the clinician who do rehabilitation is suitable. I think they have the right expertise for this."

Design question 2: How to design a data flow that enable multi-organization collaboration?

For the system to be able to be used by multiple organization, it needs a standardized scale of the patient's physical activity level. The data designer mentioned that it is important to have the same scale for the goal setting discussions since it might be done with different clinicians. The physiotherapist explained that in the existing rehabilitation program, the METs scale is used as a standardized scale when discussing a physical activity. "You could say to the patient, if he wants to do a small run it might be 3 METs.. then we look at his maximum METs and if it is less than 3 then the goal is to increase the METs.."

It is also important to set boundaries on what can be seen during which phase by who. Both the specialist nurse and physiotherapist agreed that only the care provider who is working with the patient at the moment have access to the real time data. Only the summary of the data (e.g summary of activity level before TAVI at AMC) could be accessed by other care providers in the pathway with patient's consent.

The clinicians also do not want to see too many information. The cardiologist from Amstelland Hospital mentioned, "I want to only see the interpretation.. they should interpret the data first." The cardiologist expect that the system's provider has the capability to interpret the data first, so the clinicians only have to look at the summary or data that are already processed.

Design question 4: How to map the potential actors in the system?

All participants agreed that the system should be managed by an external party who also act as the technology provider. In the visual exercise, all participant except the physiotherapist put Philips as the one who would store patient's data (see figure 54). The physiotherapist put My Vital-10 as the one who should manage the system. The reason was because My Vital-10 is the existing patient management platform being used in the rehabilitation program. "It would be difficult if we have to use different platform for different things.." The specialist nurse expressed the same concerns, "It should be easy to use next to our existing system."

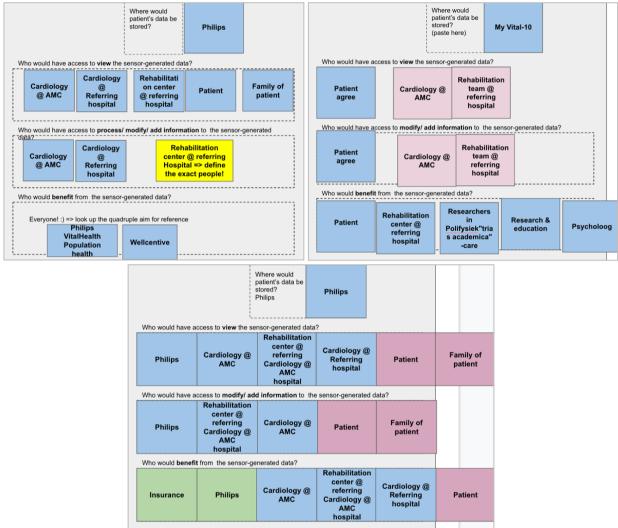


Figure 54: Impression of a part the filled visual toolkit about the stakeholder's access toward the system.

5.2.3 Synthesize

The results explained in previous sub-chapter are then translated into design requirements:

It is a platform that is managed by an external party (not one of the hospital in the care pathway)

The system needs to be managed by an organization who has both technical and medical knowledge. Beside managing the system, this organization should also be responsible for data interpretation, which will be done by a medical team consists of clinician trained to interpret data. This interpretation will then be sent to the clinician who is working with the patient.

Standardized physical activity scale.

Inside the need of standardized goal setting discussion guide, there is also a need for a standardized scale to discuss physical activity level. Metabolic Equivalent of Task (METs) is the ratio of energy spent relative to the person's mass. Based on the interview with CardioVitaal HvA physiotherapist, this scale has been used in the rehabilitation, to discuss the intensity of training that the patient needs to do. Another alternative is using heart rate as an indicator of the activity's intensity.

Voice assistant to collect experience data & help patient manage confrontations during data collection period

Outside of the goal setting, the patients are on their own. In patient's daily life, the platform should help guide the process of managing confrontation by guiding and motivating patient in pursuing the goals and in making adjustment about the goals. The system needs to be constantly 'present' in patient's daily life. There is an opportunity in using conversational agent, specifically voice assistant, because the interaction might feel more natural for elderly patients, compared to typing on a screen.

There are some conversational agent-based products available on the market for the elderly. For example, Tessa, is a robot that helps elderlies with Alzheimer's to remember the structure of their day (figure 55). Tessa would remind the user about eating time, the caregiver visit schedule and other daily task in a friendly conversation.



Figure 55: Tessa by Tinybots (source: tinybots.nl)

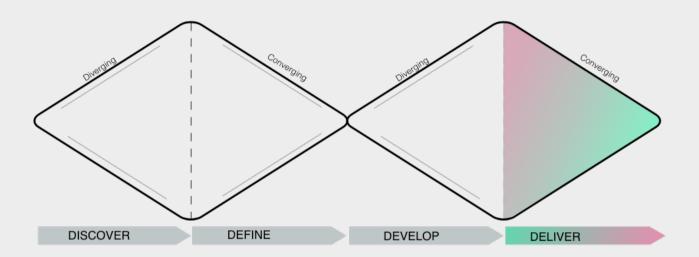


Figure 56: Memory Lane by Stockholm Exergi (source: https://www.stockholmexergi.se/memory-lane2/)

Another example is the Memory Lane project initiated by Stockholm Exergi (figure 56). The project aims to increase the mental wellbeing of elderlies who live alone in Stockholm using a voice assistant that act as conversation partner for user to talk about their life story.

Voice assistant technology has a high potential in improving the wellbeing of elderly. Therefore in the design process, voice assistant as a part of the system is explored.

PHASE FOUR: DELIVER



Chapter 6: Final Concept Proposal

Based on the iterations and feedback during concept testing sessions, a final concept is made. In sub-chapter 6.1, the LIVEsense concept is explained, then the structure of LIVEsense is described in the sub-chapter 6.2 and a scenario is illustrated in sub-chapter 6.3.

6.1 LIVEsense Concept Overview

LIVEsense is a goal setting system that consists of 3 main flows: baseline collection, collaborative goal setting and monitored goal pursuit. LIVEsense use a combination of patient's resting heart rate, training zone heart rate and physical activity data, which are collected using sensor.

The first data is collected in the baseline collection flow. The data is then discussed in a collaborative goal setting. The main output of the goal setting is an activity plan for the step afterward: monitored goal pursuit. In the monitored goal pursuit flow, the patient is wearing a sensor and is guided by a smart voice assistant to complete the activity plan. The result from monitored goal pursuit is then discussed again in another round of collaborative goal setting. The process of collaborative goal setting and monitored goal pursuit happen continuously in multiple rounds in the TAVI care pathway based on discussion between patient and clinician. The concept overview is visualized in figure 52.

LIVEsense is developed and managed by a team, possibly within Philips, with multiple expertise, from business, data analysis to medical-related (see figure 51).

LIVEsense Team's Main Expertise

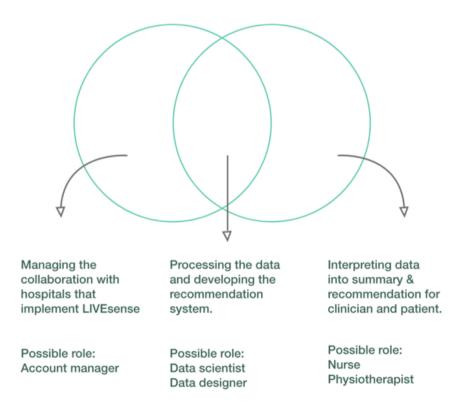


Figure 51: Expertise of LIVEsense Team

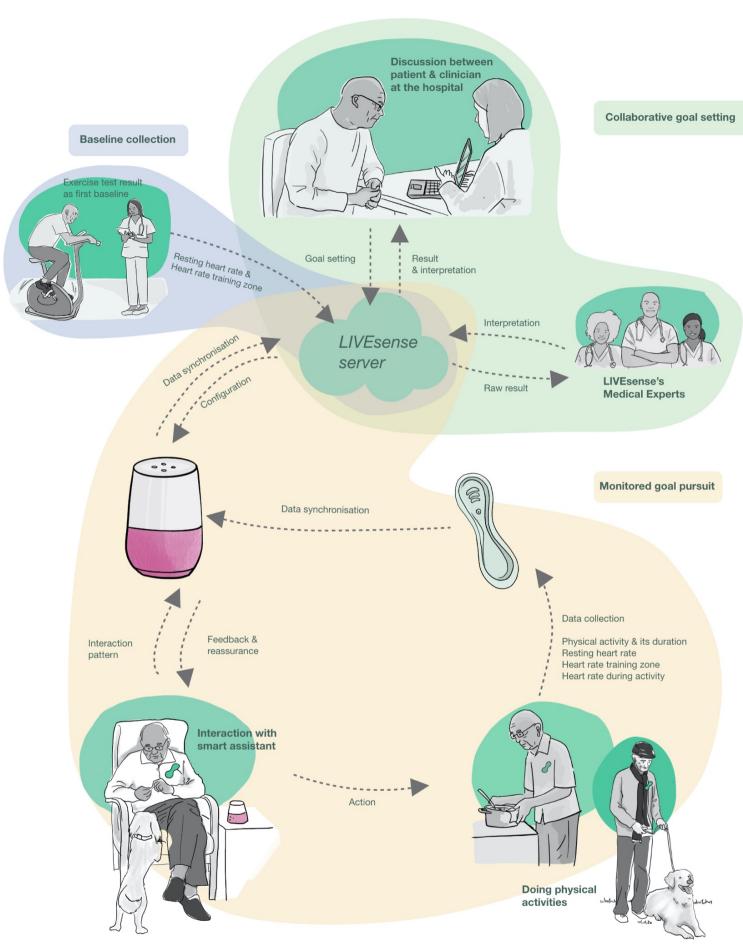


Figure 52: LIVEsense Concept, with the 3 main flow: baseline collection, collaborative goal setting & monitored goal pursuit

6.1.2 Devices in LIVEsense

There are 3 devices in LIVEsense: a sensor with electrocardiogram (ECG) & accelerometer, a smart speaker with a voice-based conversational agent and a screen to access patient's dashboard.



Figure 53: Devices in LIVEsense system

LIVEsense sensor has an electrocardiogram (ECG) and accelerometer components, enabling the device to record patient's heart rate and activity data. The ECG records patient's resting heart rate, heart rate training zone and heart rate during a physical activity. The accelerometer records the period of activity, while a combination of ECG and accelerometer records the type of the activity (see figure 53)

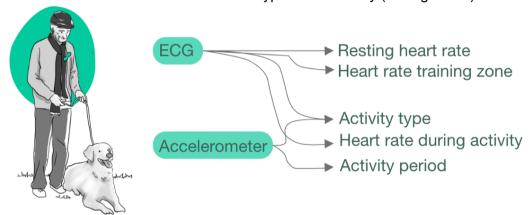


Figure 53: Data that are collected by the sensor

American Heart Association in 2015 describes that resting heart rate is the heart beat frequency per minute when the patient is resting, while heart rate training zone are the lower and upper threshold of heart rate during an exercise. By having the resting heart rate and heart rate training zone data, the system could differentiate activities that can be considered as exercise and normal activity (see figure 54).

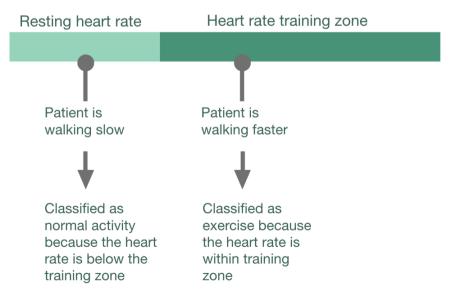


Figure 54: How the heart rate training zone data helps classify patient's physical activity

To be able to collect heart rate and activity data, the sensor device should have an electrocardiogram (ECG) and accelerometer sensor in it. It should also be able to store data in the device before being synchronized with the server, since some of the patient's activities might take place outside of the house. The device's battery should last for at least 7 days so the monitored goal pursuit period is less interrupted by battery change. The minimum period of 7 days is chosen to mimics the existing rehabilitation flow, where for 3 months the patients are having a weekly session with the physiotherapist. Some wearable sensor products are compared in the table below to see which one is suitable for the system.

Device name	Accelerometer	ECG	Battery life	Able to store data temporarily in the device?	Note
Philips Biosensor	Present	Present	4 days	No	Non- disposable
Philips Biosensor BX100	Present	Present	5 days	Yes, for 4 hours	Disposable
Vital Connect VitalPatch	Present	Present	7 days	Yes, for 10 hours	Disposable

Based on the comparison, the Vital Patch has the potential compared to the other devices to be used in the LIVEsense system. It is able to store data locally in the device and the battery last for 7 days.

6.2 LIVEsense Product-Service System Structure

LIVEsense product-service system consists of three main flow: baseline collection, collaborative goal setting and monitored goal pursuit. Each flow consists of one or several modules. The list of modules in each flow can be found on figure 55. In figure 56, the actors and system are explained as a service design blueprint.

In this sub-chapter, each flow is described. In sub-chapter 6.2.1, module and functionalities in the baseline collection flow is explain. In sub-chapter 6.2.2, modules in the collaborative goal setting flow, including a clinician guide for the shared decision making discussion and the platform used in the session are described. In sub-chapter 6.2.3, the monitored goal pursuit flow, including how the voice assistant integrates with the sensor and helps patient manage confrontations are explained.

Product-service system structure



Figure 55: Product-service system structure of LIVEsense

Product-service system design blueprint

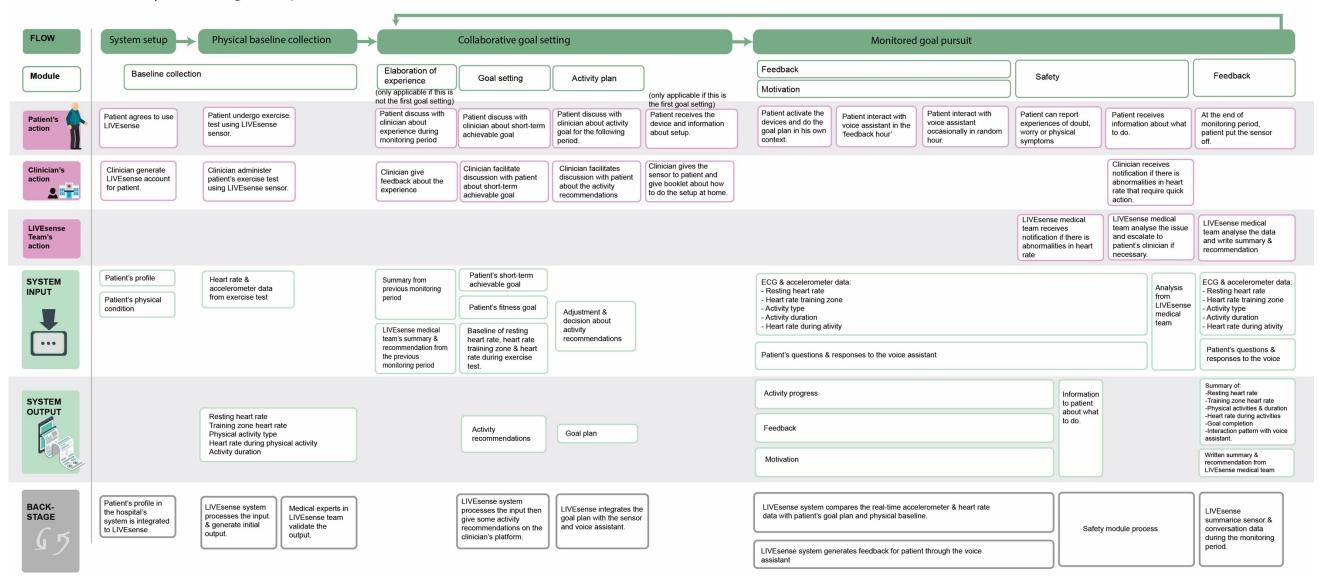


Figure 56: Product-service system design blueprint

6.2.1 Baseline Collection

LIVEsense stars with a baseline collection. This is a step where the patient's physical condition is recorded in the system for the first time, as the first basis for the recommendation system later during the first collaborative goal setting. The baseline is collected in an exercise test, which mimics how the existing heart rehabilitation starts (see chapter 2.2.3).

In the exercise test, patient is asked to perform an exercise, for example, cycling with an exercise bike, while being monitored with the biosensor. The biosensor will collect patient's resting heart rate, heart rate training zone, heart rate during activity, activity type and the activity period (see figure 57). Data are transmitted to a relay device in the exercise test room then sent to the LIVEsense.



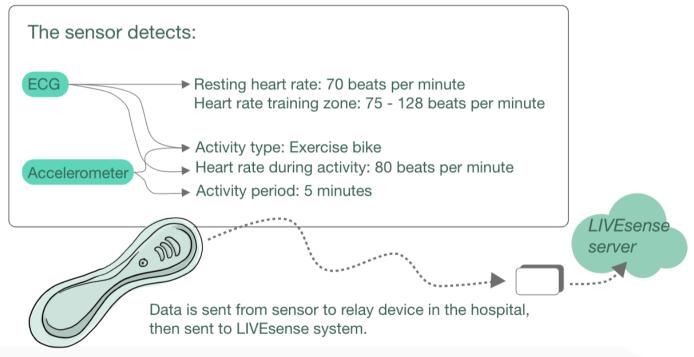


Figure 57: The flow of data in the baseline collection

Baseline collection is followed by the initial collaborative goal setting, which will be explained in the next sub-chapter.

6.2.2 Collaborative Goal Setting

There are two kinds of collaborative goal setting: one that happens right after the baseline collection and another one that happens following a monitored goal pursuit period. In this sub-chapter, the first type is referred as 'initial collaborative goal setting' and the other 'follow-up collaborative goal setting'. What makes

them different is that initial collaborative goal setting only happens once, while the follow up one might happen in multiple rounds based on the discussion between patient and clinician.

A. Initial Collaborative Goal Setting

Initial collaborative goal setting consists of two modules: 1.) Goal Setting and 2.) Activity Plan. In the session, clinician facilitate discussion with the patient while referring to the LIVEsense digital platform. In figure 58 below, how these two modules manifest in the session are explained. The darker boxes are the clinician's discussion topic and the lighter boxes are clinician's action in the LIVEsense platform.

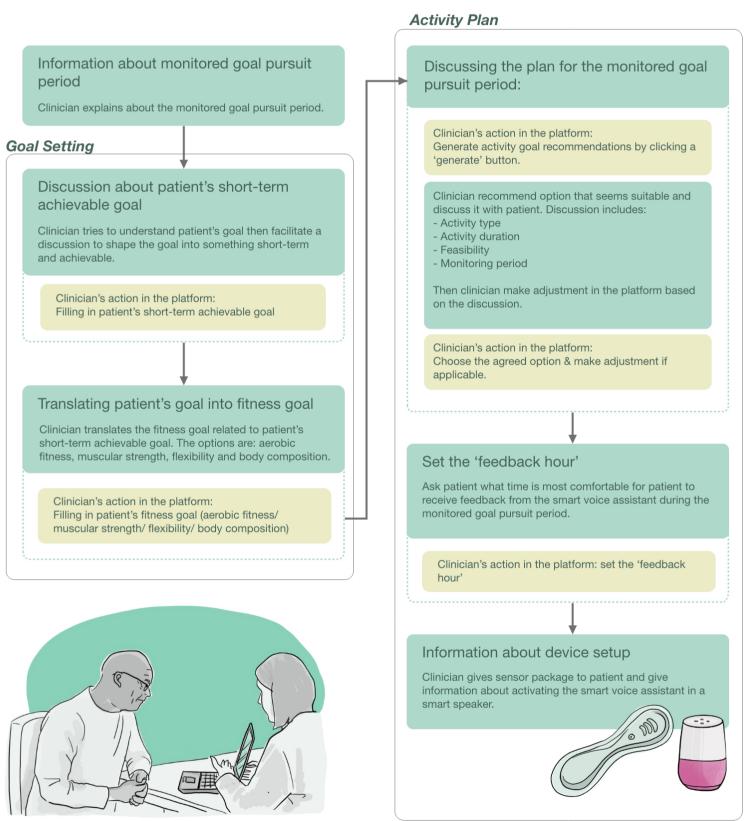


Figure 58: The flow of initial collaborative goal setting

In figure 58, the session starts with an information about the monitored goal pursuit period that comes after the session. Then clinician will start facilitate discussion so patient can set a realistic goal that is achievable within the monitored goal pursuit period. After that, clinician will write the goal in the LIVEsense platform on the computer/ tablet, then translate that goal into fitness goal. There are 4 fitness goal options: aerobic fitness, muscular strength, flexibility and body composition. In the platform, clinician will mark the suitable fitness goal that is relevant with the patient's goal. For example, if the goal of the patient is to be able to do walk to the supermarket by himself, then the fitness goal would be aerobic fitness.

In the 'activity plan' module, clinician click the 'generate recommendations' button in the platform. The platform will create some recommendations of activity plan for the patient. These recommendations are based on patient's, goal, fitness goal and the baseline data (resting heart rate, heart rate training zone, activity during exercise test, heart rate during the activity and the duration of activity). Figure 59 explains the flow of data in the recommendation system.

data source:

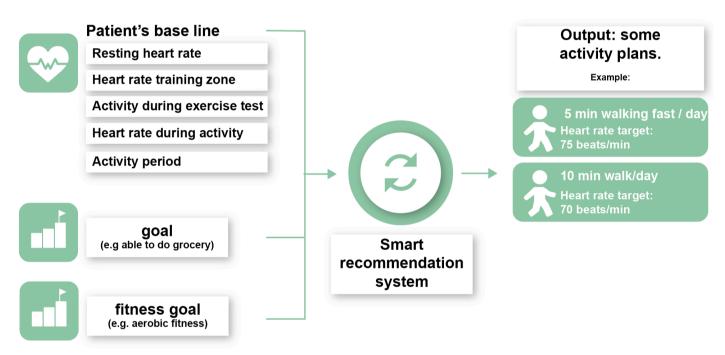


Figure 59: Data source of the recommendation system

Then clinician then facilitate a discussion with the patient about which activity plan to choose for the upcoming monitored goal pursuit period and make adjustment if needed. Duration of the monitored goal pursuit will also be discussed. After that, clinician and patient will agree on a 'feedback hour'. 'Feedback hour' is the time of the day the voice assistant will give daily feedback. The 'feedback hour' is recommended to be at the end of the day.

After that the clinician will give the sensor device to the patient and instruction on how to activate it. The activation instruction for the voice assistant in a smart speaker device will also be provided.

B. Follow-up Collaborative Goal Setting

Follow-up collaborative goal setting happens after a monitored goal pursuit period. Following the initial collaborative goal setting explained above, the patient will do the activity plan in a monitored goal pursuit while wearing the sensor and interacting with the voice assistant. After that, the patient will do the follow-up

collaborative goal setting. The session consists of three modules: 1.) elaboration of experience, 2.) goal setting and 3.) activity plan. The discussion flow is described in figure 60 below.

Elaboration of Experience

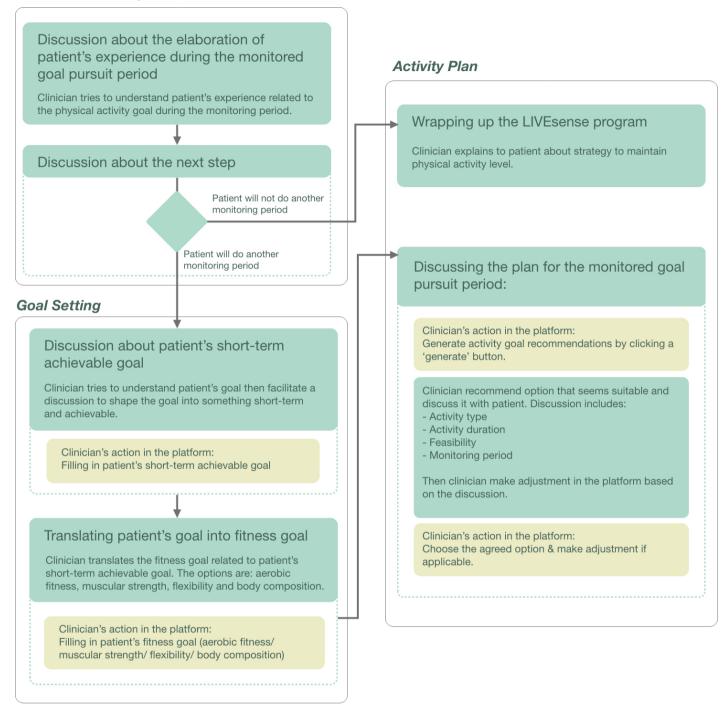


Figure 60: The flow discussion during the follow-up collaborative goal setting

Follow-up collaborative goal setting starts with an elaboration of experience during the monitored goal pursuit. Clinician tries to understand the patient's experience related to the activity plan during the monitored goal pursuit period. Then clinician and patient will discuss about the next step. If another period of monitored goal setting is required, then they will discuss about goal setting, followed by an activity plan discussion. These two steps are similar to the initial collaborative goal setting session. The differences are in the data sources. At the follow-up session, data from the monitored goal pursuit period are processed, on top of the baseline data. The details are explained in figure 61 below.



Figure 61: Data source of the recommendation system in the follow-up goal setting

C. LIVEsense Platform

During the collaborative goal setting sessions, clinician refers to the LIVEsense platform. In this section, visualisation about some parts of the platform are explained.

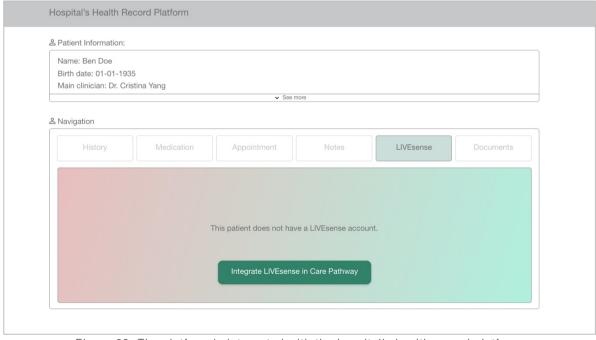


Figure 62: The platform is integrated with the hospital's health record platform

Hospitals are using an electronic medical record (EMR) platform to keep all information related to patients in an organized place. LIVEsense platform is designed to integrate with hospital's existing EMR platform. It can be embedded into the patient's profile data in the EMR (see figure 62).

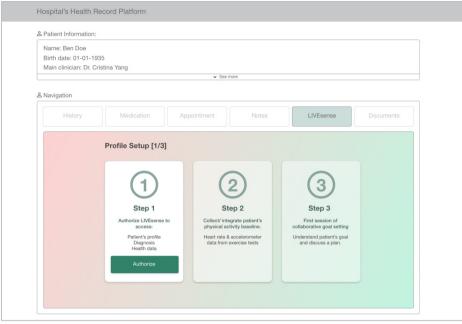


Figure 63: Activating LIVEsense through the EMR platform.

In the initial collaborative goal setting, clinician can see the result from the exercise test (baseline collection) and generate the activity plan recommendation based on the data.

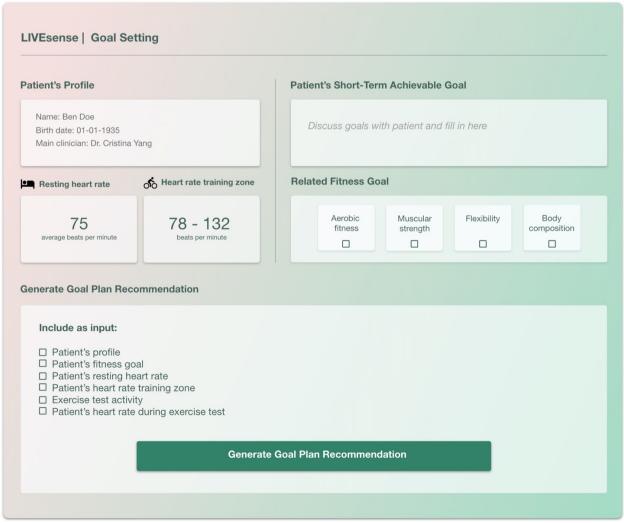


Figure 64: Generating the activity plan during initial collaborative goal setting

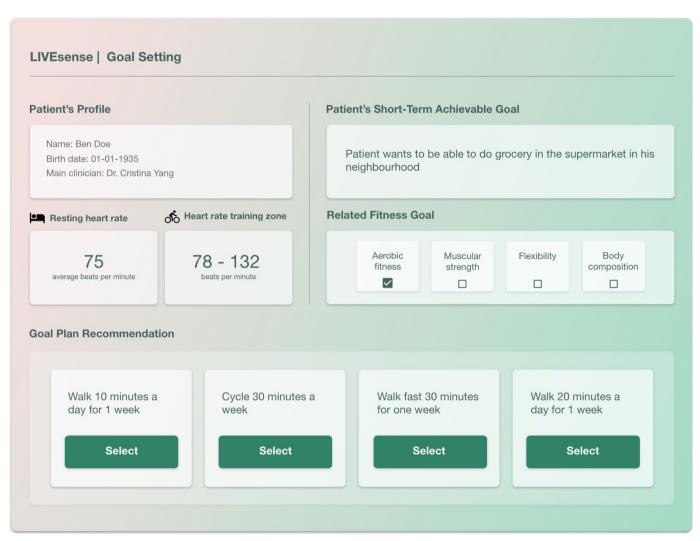


Figure 65: Activity plan recommendations

When activity plan recommendations are generated, clinician and patient are presented with options of activity plans which they could choose and modify based on the discussion.

In the end of a monitored goal pursuit period, patient's data are processed and summarised by the LIVEsense team. The medical expert part of LIVEsense team writes the summary of the monitoring period int he platform, accessible by the patient's clinician (see figure 66). This page is accessed by clinician during the follow-up collaborative goal setting.

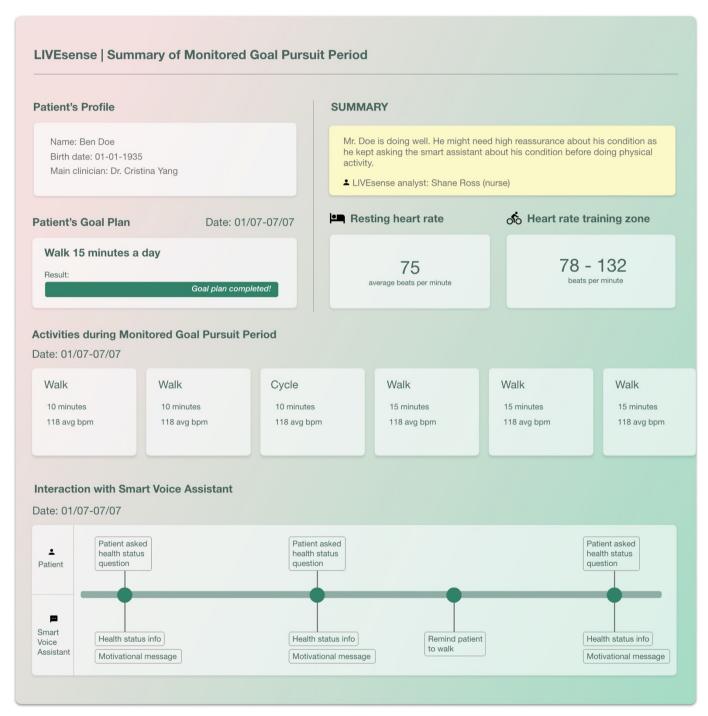


Figure 66: The dashboard page after a monitored goal pursuit period has ended.

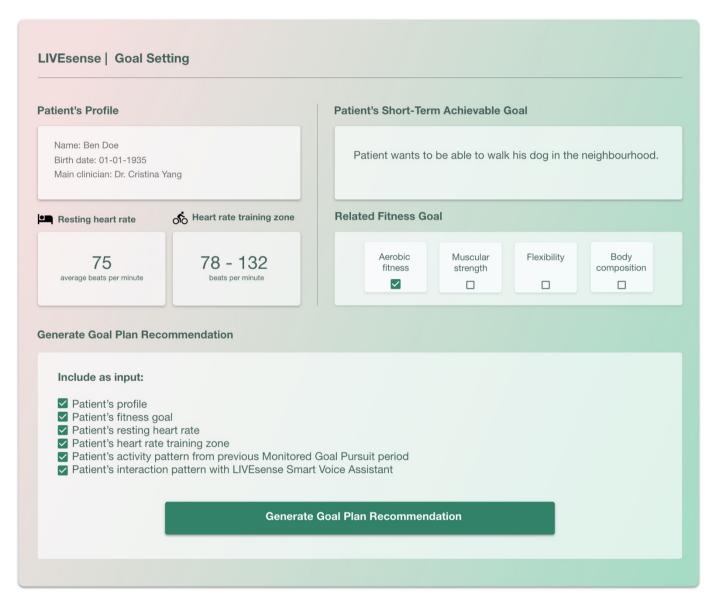


Figure 67: Generating activity plan recommendations during the follow-up collaborative goal setting

In the follow up collaborative goal setting, if the decision was to have another monitoring goal pursuit period then another set of activity plan recommendations is generated. The visualised page can be seen in figure 67.

6.2.3 Monitored Goal Pursuit

In the monitored goal pursuit, the patient is wearing the sensor and interacting with the voice assistant. Heart rate and activity data from the sensor are synchronised with the voice assistant which has been configured with the activity plan made during the collaborative goal setting. That way the system can track the patient's activity plan completion. The complete overview of monitored goal pursuit can be seen in figure 68 below.

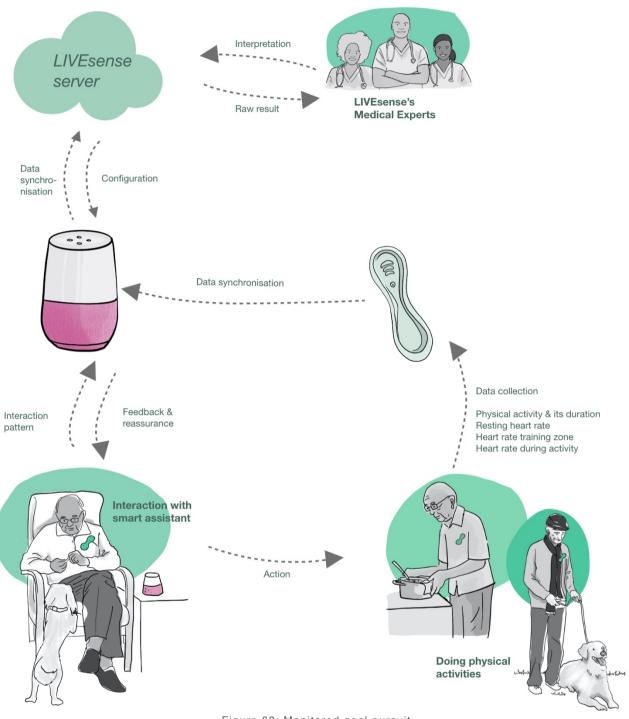


Figure 68: Monitored goal pursuit

Beside synchronizing with the sensor data, the voice assistant also has a role in guiding patient manages his physical activity-related confrontations through its three modules: feedback module, motivation module and safety module. How the voice assistant works are explained in figure 69 below. The structure is divided into two: 'feedback hour' interaction and occasional interaction.

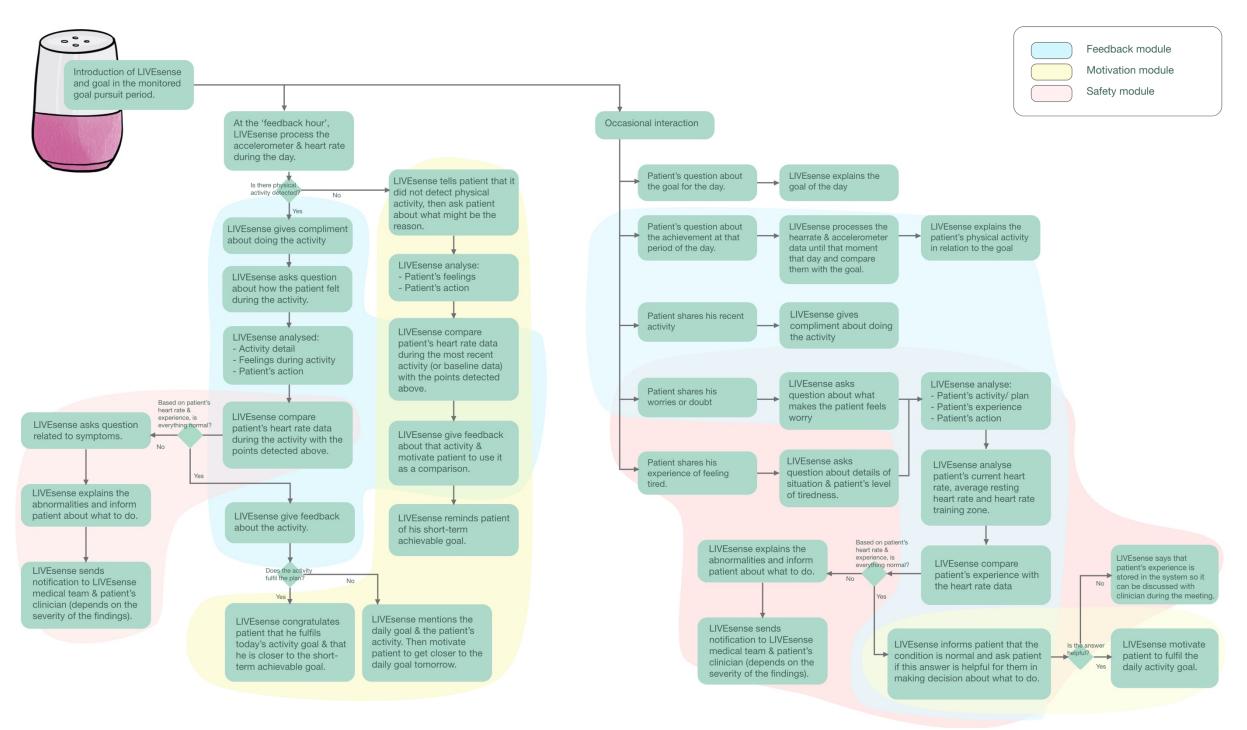


Figure 69: Conversation flow of the voice assistant

The feedback module appears in both 'feedback hour' interaction and occasional interaction. The goal of this module is to give an objective feedback related to patient's physical activity and possible worries/ concerns regarding doing physical activity.

For example, if the patient did a physical activity during the day, later that day at the 'feedback' hour, the voice assistant will give compliment and collect information about how the patient was feeling during the activity (the parts in blue shadow in figure 69, left side). Another example is when the patient has a question about his concerns or worries related to doing physical activity. The voice assistant will give an objective feedback based on how the patient performed in the last available physical activity data (see the parts in blue shadow in the right side in figure 69). For the feedback module, the voice assistant should have the ability to detect emotions, for example worry, concerns or fear from what the patient says to be able to responds accordingly.

The motivation module appears in both 'feedback hour' interaction and the occasional one as well. The goal of motivation module is to motivate patient by reminding patient of the goal when the patient has not fully done the activity plan (see the yellow shadow in figure 69)

Safety module aims to give patient a peace of mind that the patient can do the activity plan without feeling worry of possible consequences. For example, if the patient mentions possible symptoms, the voice assistant will ask patient to elaborate more about it, so the system can inform the patient about what to do and escalate the case to LIVEsense medical team. The other scenario of the safety module can be found in the pink shadow in figure 69.

The combination of the three modules help patient in managing confrontations that prevent them from doing physical activity. By getting an objective feedback, motivation based on the goal and a safety function, the confrontation would become easier to overcome (see figure 70).

In the end of the monitoring goal pursuit period, all the data are processed and translated by the LIVEsense medical team. They analyse the pattern of patient's physical activity, heart rate and how the patient interact with the voice assistant. The result from this analysis is written in the platform, so the patient's clinician can refer to it during the goal setting discussion.

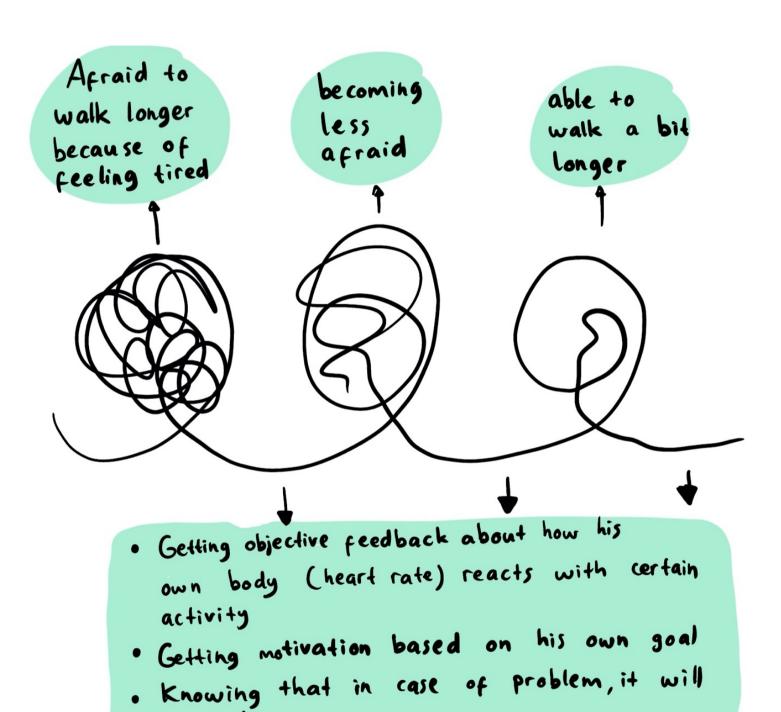
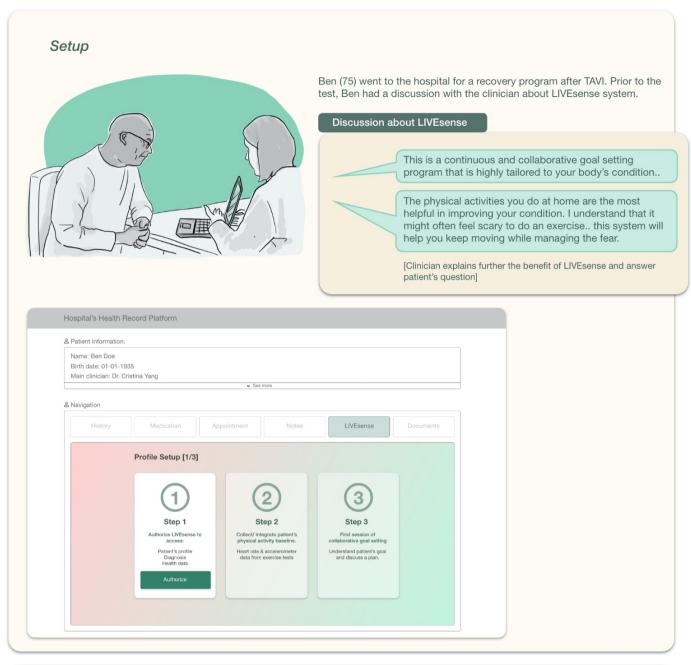


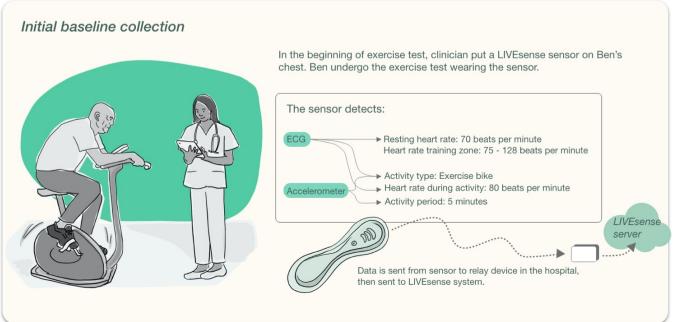
Figure 70: Managing confrontations during the monitored goal pursuit period.

be taken care of.

6.3 Scenario

In this sub-chapter, a scenario of a patient using the LIVEsense system is presented.





Initial goal setting After the exercise test, Ben met with the clinician again to have a goal setting discussion.

Setting the short-term achievable goal

Let's talk about your first goal. What is the thing that you know you will be able to do in short term?

I want to be able to walk my dog in the park again...

How far is the park from your house?

About 15 minutes walk from my house... I usually spend 10 minutes there so it is an hour in total.

Clinician facilitate patient to set a realistic goal that the patient is sure he would be able to achieve.

How about a more simple version of it, as the starting goal? Maybe walking your dog just nearby your house? Later we can set the goal higher.

I haven't even been walking outside so I think that is more realistic.. walking my dog in my neighbourhood.. Yes I agree

Generating & adjusting the Goal Plan

Clinician translates patient's main goal into fitness goal.

Your goal is related to aerobic fitness, so I am going to mark 'Aerobic fitness' in the Fitness Goal..

Clinician generates Goal Plan recommendations in the system.

These are the Goal Plan recommendations. I would recommend 'Walk 10 minutes a day', what do you think?

I think I can do 15 minutes. I did that before..

[Clinician facilitates shared decision making discussion to decide & adjust the Goal Plan]

Deciding 'feedback hour'

A smart voice assistant will tell you how you did that day. What time is the most comfortable for you for that?

What about around 8PM? after dinner, I usually just sit around..

[Clinician set 8PM as the 'feedback hour']

In the end of the session, Ben receives:

Sensor package & information about how to setup

Information about setting up the voice assistant in a smart speaker



Device setup

Ben wears the sensor at home

LIVEsense smart assistant guides Ben in setting up the sensor.

Now the sensor is in a good position. You are good to go!





One day during the Monitored Goal Pursuit period..

At the 'feedback hour', LIVEsense summarised patient's heart rate & accelerometer data and compare them to the Goal Plan

LIVEsense greets patients & give feedback about activity achievement.

Good evening, Ben. Your daily goal is to walk for 15 minutes a day. I see that you walked 5 minutes today. This is an improvement from yesterday. Good job!

LIVEsense collects information about patient's perception during the activity.

What did you feel when you walked?



Today I walked outside for the first time after TAVI.. When I started to feel tired I became afraid then I stopped..

LIVEsense detects:

- Activity detail: walk outside
- Feeling: tired, afraid
- Action: Stopped the activity

LIVEsense processes:

Activity detail, heart rate during activity, & feelings during activity

Good that you walked outside!

It is normal to feel tired when you are doing physical activity. Based on the sensor data, your condition when you walked was normal. When you feel tired, you can slow down or take a break.

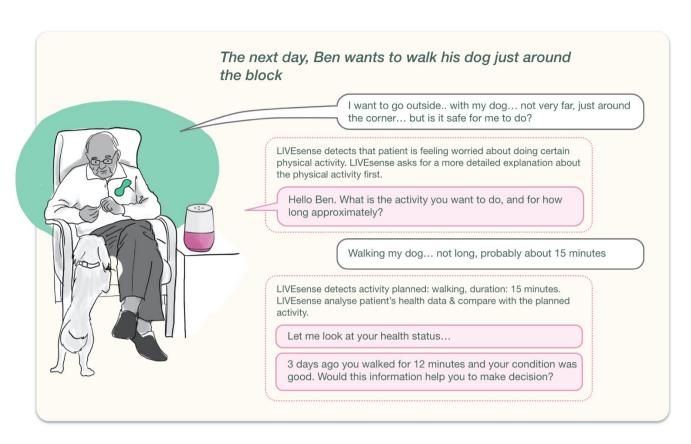
Would you continue doing your daily goal tomorrow?

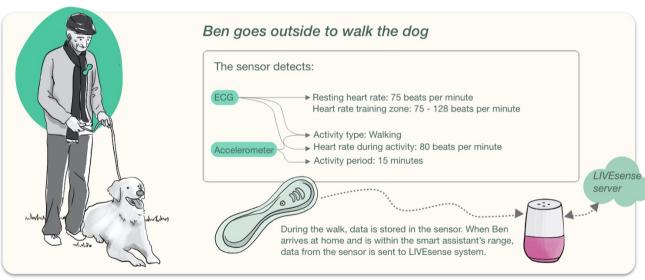


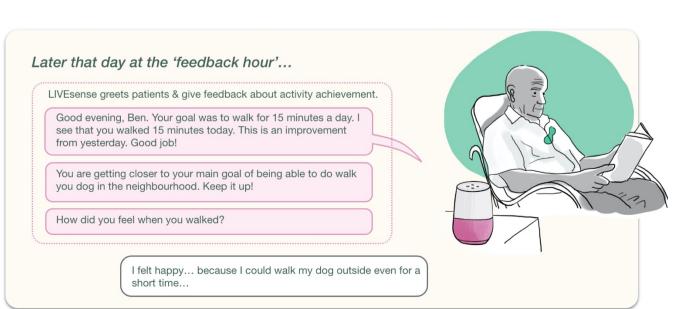
Yes... I will..

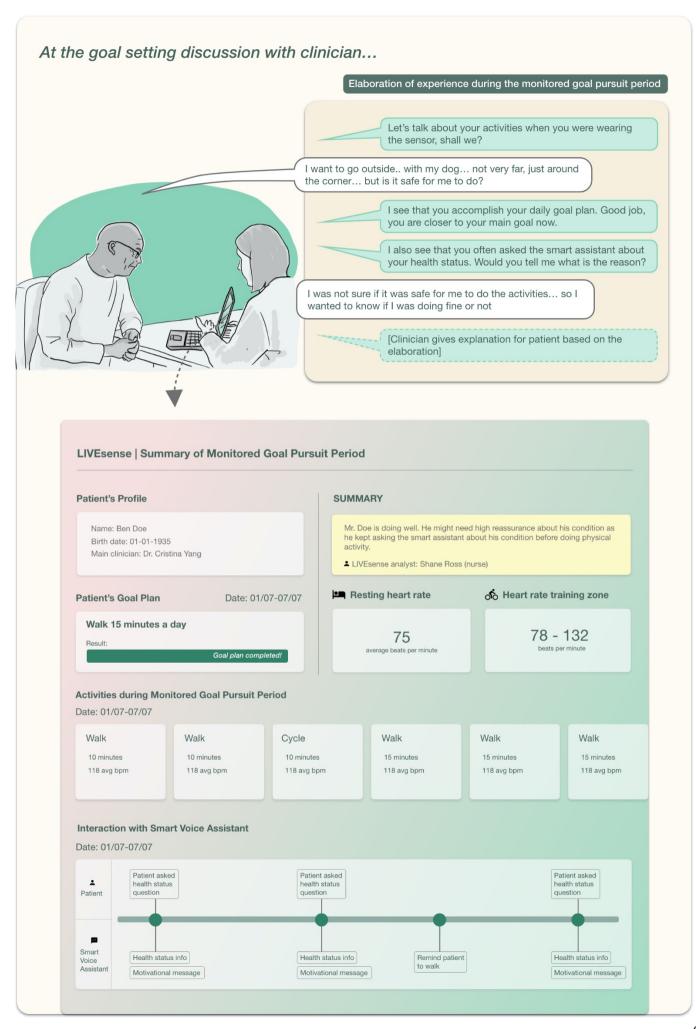
LIVEsense motivates patient to do the Goal Plan tomorrow.

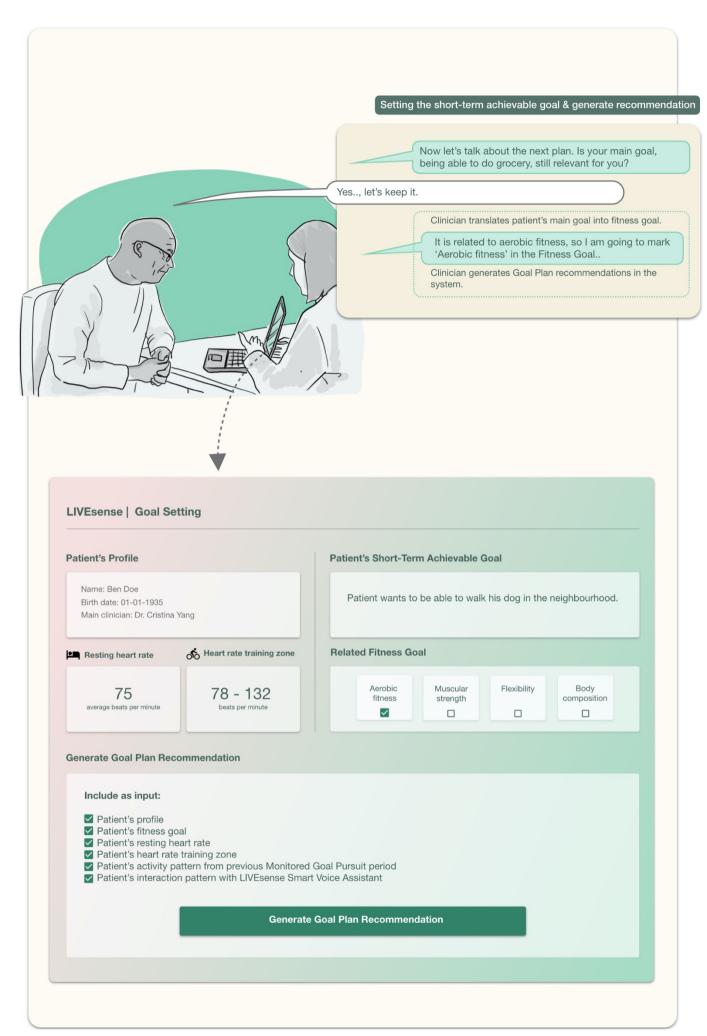
Nice! You did good today and you can do better tomorrow.

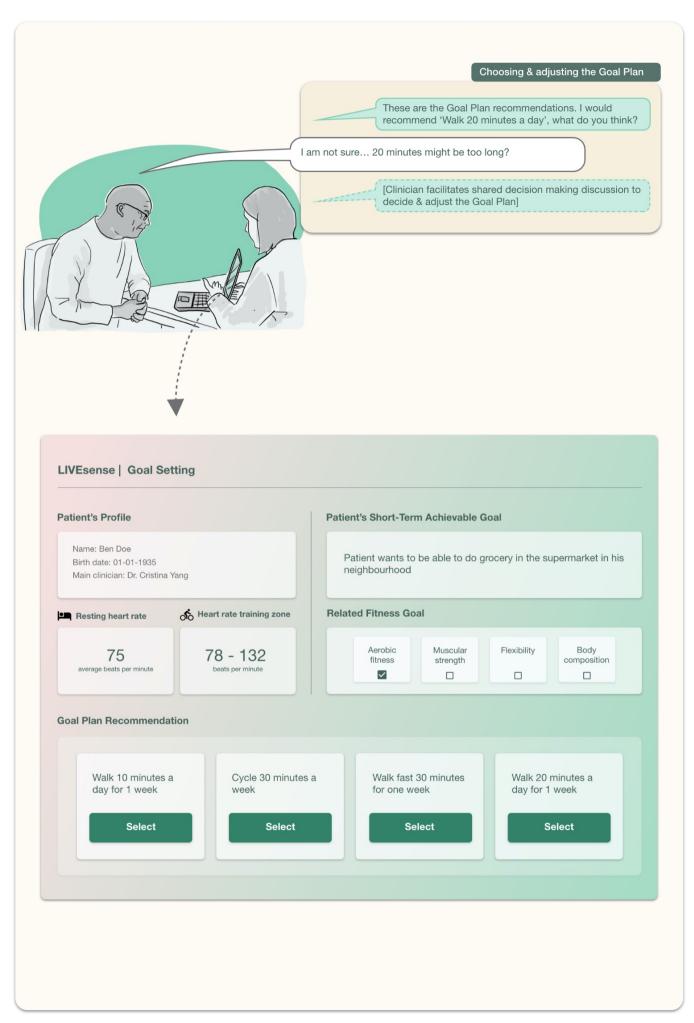












Chapter 7: Validation

The concept was validated with stakeholders in an online session. The goal of the validation session are:

- To get feedbacks about the final concept
- To understand in which part of the TAVI care pathway LIVEsense would bring the most value
- To co-reflect LIVEsense concept using the Quadruple Aim model

In this chapter the method, result and summary of the validation are explained.

7.1 Method

The participants are the physiotherapist from CardioVitaal HvA, researcher from the Cardiology Department of AMC and the specialist nurse who works with TAVI patients at AMC.

The scenario shown in sub-chapter 6.3 is sent to all participants prior to the meeting for practicality purpose and so that participants could take a look at it. The agenda in the session are:

- 1. Sharing the concept and scenario of LIVEsense & feedback session.
- 2. Group discussion about the value of LIVEsense in phases before TAVI, right after TAVI, during rehabilitation and in the follow-up period.
- 3. Group co-reflection of LIVEsense concept using Quadruple Aim model.

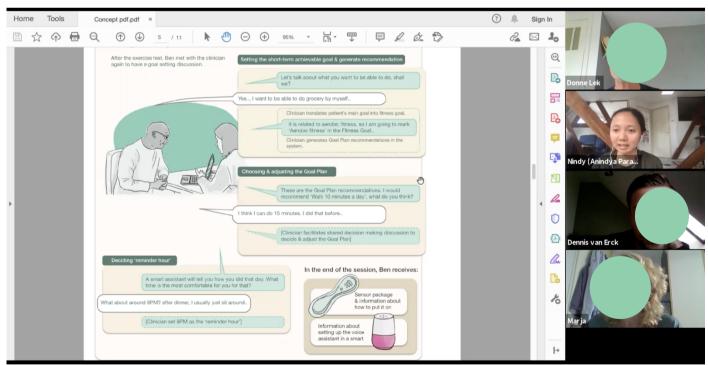


Figure 71: Documentation of the validation session when the concept scenario was discussed

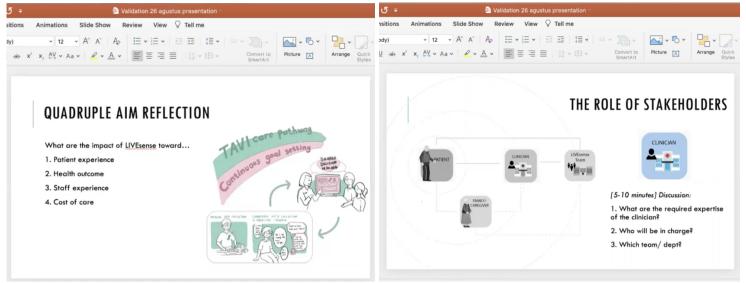


Figure 72: Some impressions of the shared screens during the validation session

7.2 Result

A. General Feedback

The physiotherapist responded positively toward the goal setting discussion scenario. "It is good that the clinician asks the patient about what he wants to do, an then looking at it as a fitness goal." The physiotherapist then explained that there is a goal setting method currently being used in the beginning of heart rehabilitation program. The patient is asked to formulate a goal which the patient himself is sure that he would be able to achieve it. "It is called 'graded activity'..., you choose something you know you will accomplish, so the patient will learn by himself about the factors that make is successful."

The researcher was not sure about the accessibility of voice assistant in smart speakers among the elderly. The specialist nurse added, "Some elderly might deals with hearing trouble, so it might be good if there is option to have it on screen.."

B. Reflection with Quadruple Aim

The Quadruple Aim (Bodenheimer & Sinsky, 2014) are the four points of compass of healthcare innovation. It consists of improved patient experience, health outcome, staff experience and reducing the cost. A coreflection on each of these points toward the LIVEsense concept was done.

LIVEsense improves patient's health outcome by enabling the benefit or rehabilitation earlier in the TAVI care pathway. "Rehabilitation can start immediately instead of having to wait. When the patient does not exercise in a week, they lose muscle and the condition can decrease, it will be hard to go back," the physiotherapist explained. Patient's experience is also improved because they can do the activity at home with guidance.

Regarding the 'staff experience' point in the quadruple aim, the specialist nurse said, "At the beginning of implementation, a new system is going to be a burden to the staff... because of having to get used to new things. But when the benefits are clear then in the longer term it would not be a problem." To tackle that possible problem, the researcher explained, "Usually there are some people who can see the benefit earlier than the other.., the implementation should start from those people, who are already enthusiastic about this kind of innovation, then it would not be a burden for them." Then the researcher added that because of the ongoing pandemic, more people in healthcare are able to see the benefit of digital innovation.

The positive direction in patient's experience, health outcome and staff experience would eventually lead to making the cost of care more efficient. Also, with LIVEsense, the specialist nurse explained that the rehabilitation program would reach a bigger group.

C. Value of LIVEsense in the TAVI Care Pathway

All participants agreed that LIVEsense bring the most value for patient in the period right after TAVI, so patient can have the benefit of the rehabilitation earlier. "The biggest gap is the moment after TAVI until before rehabilitation," the researcher at Cardiology Department of AMC explained.

In the existing pathway, before TAVI and right after TAVI there are lack of knowledge among patients about what they should do. The TAVI specialist nurse explained, "How it is now is, patients are waiting until the rehabilitation start. They do not do a lot of activity in between. Especially in the period after TAVI and before the rehabilitation, it is not good to have some period of time not doing much activity..". The researcher in Cardiology Department of AMC added, "There is a risk of sarcopenia, a condition where the patient's muscle volume is decreasing due to lack of movement. Even with only a week of not doing much, the implication can be bad." The physiotherapist mentioned, "In the period after TAVI, it is unclear for the patients about what they can do. It is good if they don't wait until rehabilitation days."

When discussing about the possible benefit of LIVEsense before TAVI, the specialist nurse expressed that before TAVI, the patients are being taken care of by different hospitals who might have different knowledge. The specialist nurse was also afraid that patients might get overwhelmed with lots of information. "Besides that, before TAVI the patient already receive a lot of information... this (LIVEsense) is good to start earlier but the patient might receive too much information at once..., so it is better to start LIVEsense after TAVI."

D. How will the concept be implemented in the care pathway?

In the existing TAVI care pathway, the heart rehabilitation is done by a rehabilitation center. The specialist nurse mentioned that the physiotherapy team in the rehabilitation has the right capability to administer the LIVEsense program for patients, especially in the collaborative goal setting discussion. "Rehabilitation center has the best experience," the specialist nurse added. "There should be a collaboration with the rehabilitation center, so they can start the program before the patient is discharged.. when the patient is still at AMC."

However, the physiotherapist from the rehabilitation center thinks that due to the existing healthcare system, the early part of LIVEsense should be administered by AMC first, before a hand over to the rehabilitation center. Currently, only patients who receive primary care at AMC and not coming from any referring hospital are able to get the rehabilitation in the AMC premises, done by the CardioVitaal HvA. Therefore giving the responsibility to the rehabilitation would require changes at a higher system level.

7.3 Synthesize

From the validation session, the LIVEsense concept is seen to compliment all aspects of the Quadruple Aim. LIVEsense is most valuable for the post-TAVI period and should at least start right after the procedure. In the existing gap between post-TAVI and rehabilitation, the 'lack of knowledge' described by the specialist nurse (see previous sub-chapter, in the C part) is the confrontations patients are facing. This lack of knowledge causes patients to be over restrictive in doing physical activity. With the LIVEsense system, patients would have a better understanding about their body condition and what they need to do.

However for the system to be successfully implemented, concept testing with the patient is needed to gather more insights about how patients interact with the clinician during goal setting discussion and how the voice assistant help them execute the activity plan at home. Also, with multiple organizations involved in the TAVI care pathway, in integrating LIVEsense some part of the existing pathway, with the respective stakeholders in it, might need to change, therefore an exploration to address the role of stakeholders is necessary.

Chapter 8: Conclusion

8.1 Answering the Project Brief

The project brief was to explore ways to improve the experience of TAVI patient using sensor data, including but not limited to the Philips Biosensor device.

Throughout the project, the TAVI patient's journey is investigated, leading to an opportunity in improving the period after TAVI. Then the problem in patient's experience is investigated, leading to the understanding about how TAVI patients are managing confrontations related to doing physical activity. The concept of LIVEsense, a continuous and collaborative goal setting system using data, aims to help patient in managing the confrontations. LIVEsense consists of baseline collection, collaborative goal settings and monitored goal pursuit steps. The system uses a combination of sensor data, conversational agent and goal setting results. A validation session with stakeholders is done to validate and reflect upon the LIVEsense concept. LIVEsense satisfies all elements of the Quadruple Aim, indicating that LIVEsense is an innovative concept that goes toward the right direction.

The patient wears the sensor during the monitored goal pursuit period while interacting with the conversational agent. The required sensor data are resting heart rate, heart rate training zone, activity type, heart rate during the activity and activity duration. To be able to record the data, the sensor requires an electrocardiogram (ECG) and accelerometer. While to be able to be fully functional in the monitored goal pursuit period, the sensor device needs to be able to store data in the device before being transmitted to the system. This is because the patient's activities are not always indoor at home. Also, it is important that the sensor has a battery life of at least one week, mimicking the period between each visit in the rehabilitation program.

In the beginning of the project, both AMC and Philips envisioned an opportunity to leverage Philips Biosensor in improving the TAVI patient's experience. However, after detailing the device's requirement to support the system, the specification of Philips Biosensor is less suitable for LIVEsense. A comparison with several other wearable sensors affiliated with Philips is done, and the VitalPatch sensor by Vital Connect is found to be suitable as a part of the LIVEsense system. Vital Connect is a company that produces wearable sensors and is affiliated with Philips, thus using VitalPatch can still be part of the collaboration between AMC and Philips.

Connecting back to the project brief, the way to improve TAVI patient's experience is addressed: helping them manage confrontations related to doing physical activities in the period after TAVI. The design solution, LIVEsense, is validated to answer the problem and is on the right direction. The value of sensor data as part of a system that monitors and guides patient in managing their confrontations is addressed.

8.2 Limitation

There are some limitations in doing this project. The first one is in access to gather data from patients. This project happened to start at the beginning of the Covid-19 pandemic, therefore gathering first hand qualitative data from patients is not possible since TAVI patients are part of vulnerable group during the pandemic. Doing observations at the hospital premises is also not possible.

The proposed concept needs to be followed by a testing with the actual users, which is not possible in the limited time frame and also due to limited access to patients. The testing could use data-enabled design

method (Bogers et al. 2016), where the data from sensor device and conversational agent platform are collected real time in parallel with the iteration process of data interpretation.

Furthermore, with the multiple stakeholders involved in TAVI care pathway, all stakeholders need to be involved in plotting LIVEsense throughout the TAVI care pathway.

Personal Reflection

I was involved since the very early part of this project. Together with Winnie Chen, another IDE student who is also working on this topic for graduation, we liaise with the project stakeholders to set the stage ready. It was smooth at the beginning, then there was a pandemic coming and a lot of things become very uncertain. Suddenly it was not possible to work at the university. Also, access to hospitals were restricted and the methods that I initially planned were no longer possible to do. Therefore the project planning had to be iterated.

In the first few months of the project, interview sessions were planned as soon as possible to avoid the possibilities of not having the opportunities to book the stakeholders' time anymore, especially the healthcare providers. Thus this qualitative data collection actually happened in parallel with reiterating the project scope & method planning. Literature research also started in parallel. For me the gathered information became tangled and mixed up. What I learned from this process is that doing synthesize really helps in untangling the information.

In this report I talked about managing confrontations by adjusting own expectation; of discovering own capabilities and limitations and try to work with them. I too, had a lot of expectations about how I wanted the process to be. A lot of those need to be constantly adjusted along the way. I did the project while learning to manage confrontations myself, although in a different context. This helps me grow, both as a designer and as a person.

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