



## Hypertrophic Cardiomyopathy patient research - final

Sweden

## Information and disclaimer

### Introduction

This report is developed by SKIM, on behalf of Bristol Myers Squibb (BMS) and the patient organization Hypertrofisk Kardiomyopatis Svenska Sällskap. The primary objective of this research is to gain a comprehensive understanding of the current landscape of hypertrophic cardiomyopathy (HCM) in Sweden, including patient experiences, treatment pathways, and unmet needs. By leveraging the unique insights and expertise of all involved parties, this report aims to provide valuable data that can inform future strategies to improve patient outcomes and access to care.

### Disclaimer

This report has been prepared for informational purposes only. The findings and conclusions contained herein are based on data collected and analyzed by SKIM and are subject to the limitations inherent in market research methodologies. While every effort has been made to ensure the accuracy and reliability of the information presented, neither BMS, Hypertrofisk Kardiomyopatis Sällskap Sverige, nor SKIM can guarantee its completeness or applicability to all situations. Unless stated differently, all statements correspond to interviewed patients, and not a full representative patient population. The information in this report should not be construed as medical advice or used as a substitute for professional healthcare consultation. Any actions taken based on the insights provided in this report are at the sole discretion and responsibility of the reader.

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## Objectives

Gain a solid, deep understanding of the HCM patients' journey and touchpoints, their experiences and needs.

- **In-depth understanding** of who the **HCM patient** is, what the clinical and non-clinical characteristics are.
- Understand the **typical patient journey** of the HCM patient (from symptoms to diagnosis, treatment and ongoing management) to identify the most relevant and effective **touchpoints** that could potentially lead to **earlier diagnosis and improved care**.
- Explore the **emotional journey, patient hopes and struggles** throughout the journey as well as their **coping mechanisms**, their emotional needs and ways these could be addressed.
- Identify the challenges and opportunities for BMS to **improve the patient experience**: pinpoint tangible and impactful ways to **provide support, develop services** or products aiming at optimizing the patient experience throughout the entire patient journey.

## Methodology

The 3-step approach is used for the mapping of the patients' journey & identify key milestones in the journey that pose the biggest challenges for patients.

### Methodology: 3-step approach

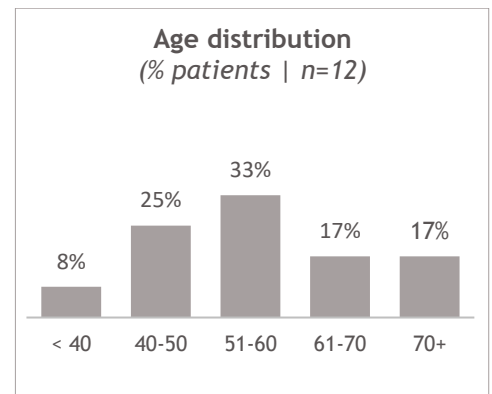
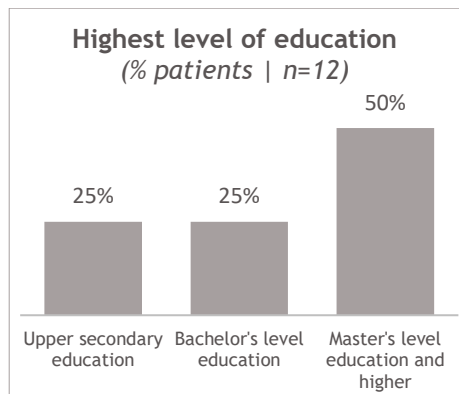
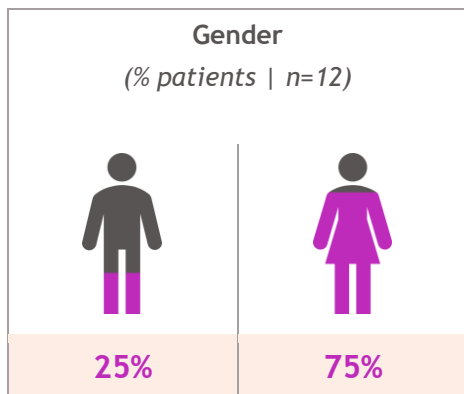
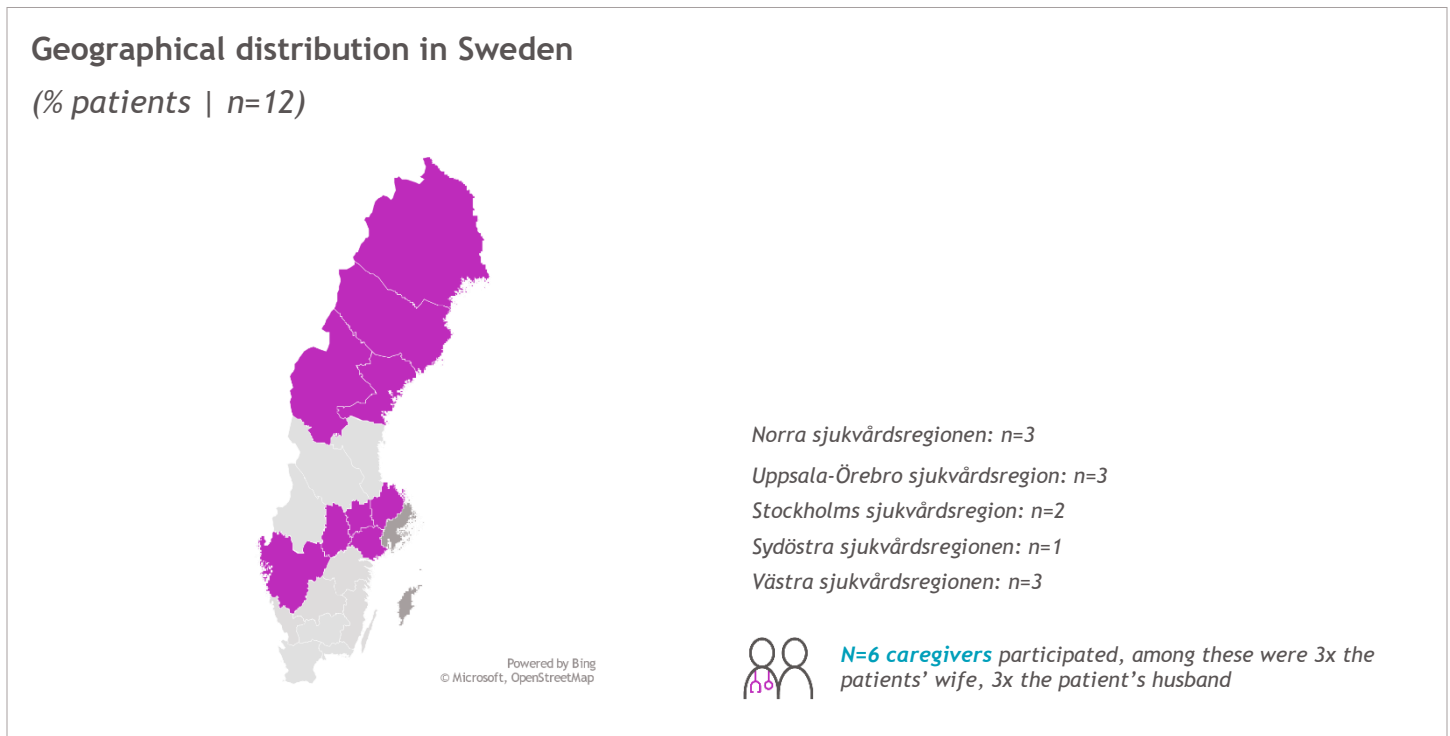
01	02	03
Patient journey & key milestones	Needs & wants	Solutions

### Discussion guide outline

01	Background and warming up
02	Patient Journey Mapping: symptoms, diagnosis, referral and treatment
03	Emotional impact of the diagnosis & treatment
04	Understand the patient's needs: information and support
05	Wrap up and closure

## Sample specifications: Demographics

75min in-depth interviews with n=12 Hypertrophic Cardiomyopathy patients in Sweden, all currently treated with specific medication.



## Type of HCM

(% patients | n=12)

**50%**

Obstructive HCM

**25 %**

Non-obstructive HCM

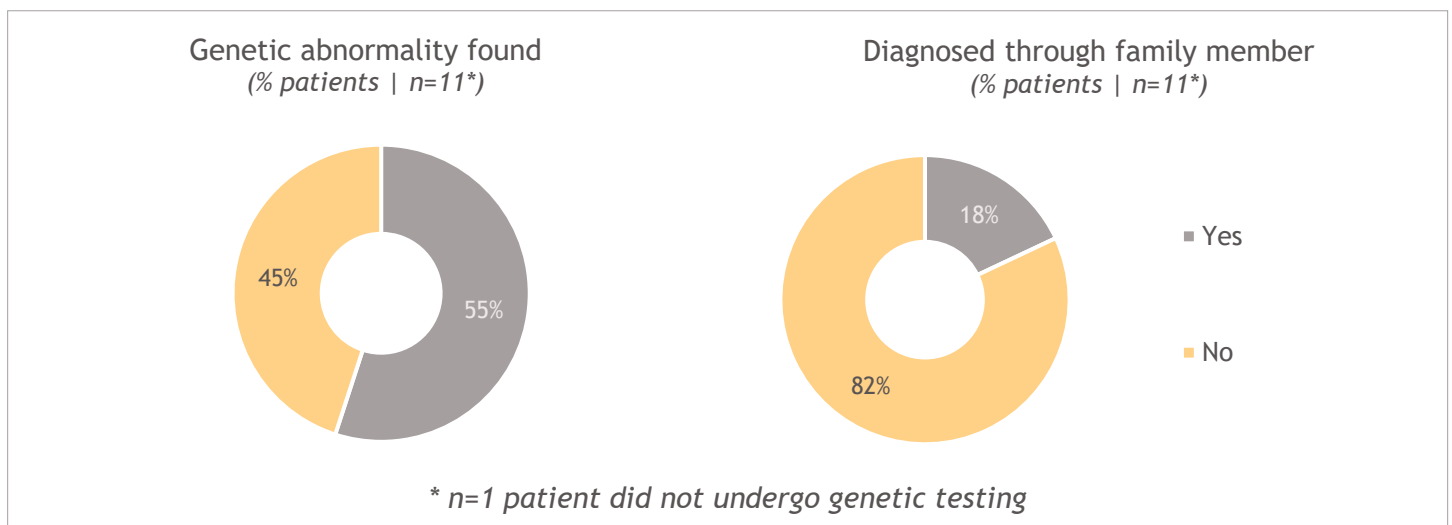
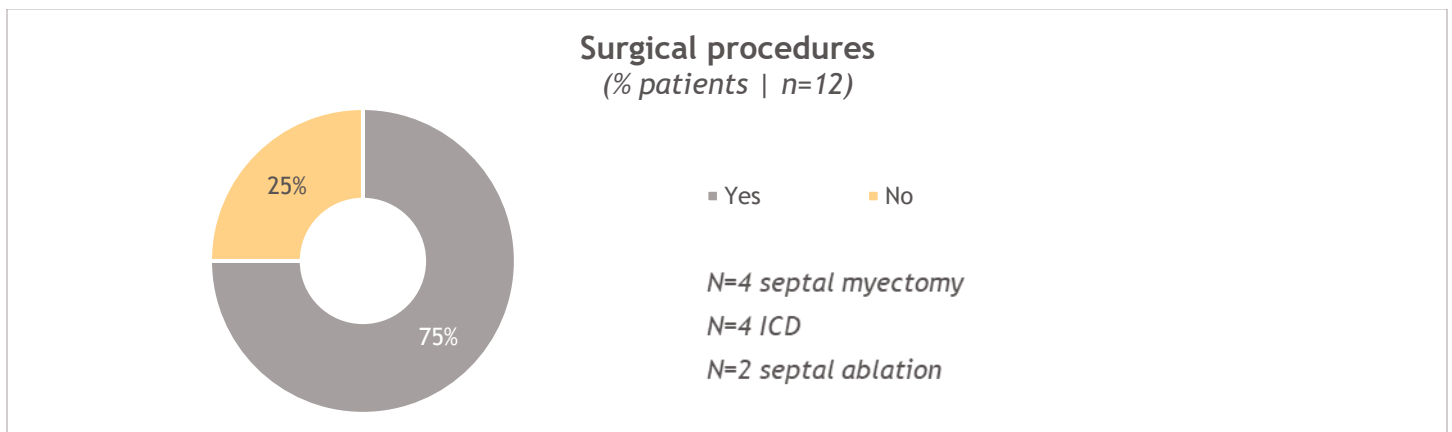
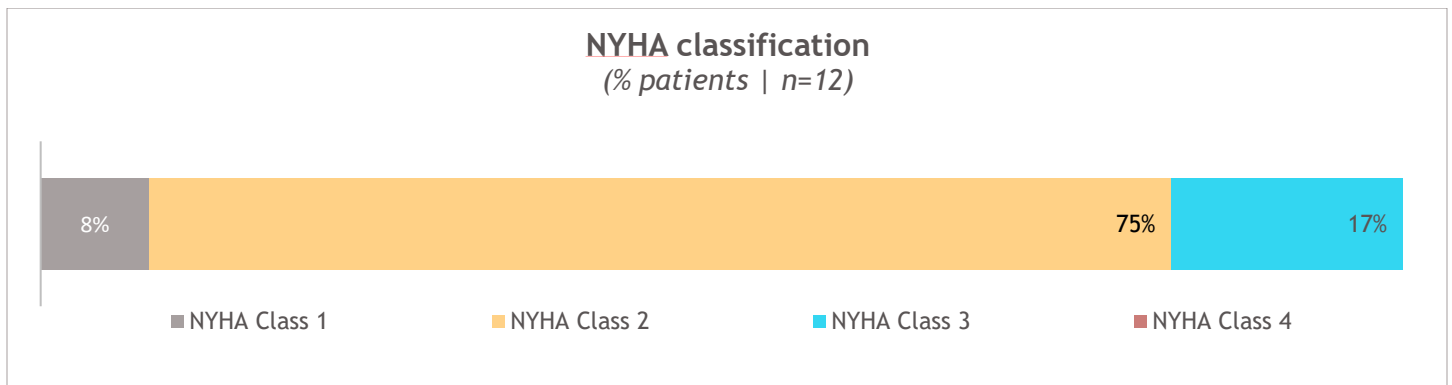
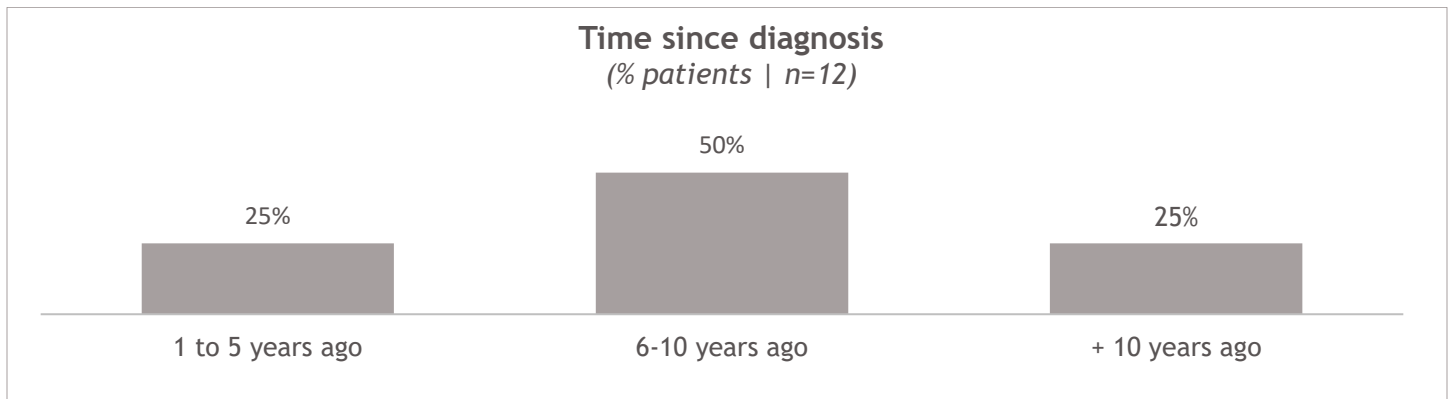
**17 %**

Unsure which HCM

**8%**

Apical HCM

## Sample specifications: HCM diagnosis and procedures types



## Executive summary: Overarching needs

### Patient journey

The route to diagnosis can be a very **long and complex process**. Challenges are faced mostly before patients see a cardiologist, when they don't recognise and validate their own symptoms or when they received an incorrect diagnosis. Also **systematically Sweden faces many hurdles with the referral of patients from the regional to the academic centers**, and the sharing of patient information.

### Emotional journey

Initially, **most patients are quite overwhelmed and stressed when they hear the confirmed diagnosis**. After the initial insecurity, some patients described to be frustrated and irritated about how the process went down, as some have been running around with an incorrect diagnosis for many years. While patients do manage to adapt their lifestyle to their diagnosis, and have come to peace with their diagnosis, the **bitterness towards the provided healthcare remains high**.

### Informational journey

According to patients interviewed, cardiologists often **lack in providing sufficient information to the patients**. This results in a sense of loneliness and frustration among the patients, as they have to rely on themselves to gather necessary knowledge about their condition and possible treatments, including potential surgeries. Patients who have a dedicated cardiologist and a reliable follow-up system reported to be more satisfied with the information they received.

## HCM patient journey overview: key milestones & challenges

### 1.The patient journey starting points:

Starting points differ between patients ranging from acute symptoms, to discovery through a family link, to chance discovery.

### 2.Getting help:

Through HCPs missing symptoms as well as patients not clearly communicating regarding their symptoms leads to challenges in identifying HCM.

### 3.Referral pathway to the cardiologist

While all patients end up with the cardiologist, the journey there isn't always smooth or clear.

### 4.Confirmation of the diagnosis

Access to the right diagnostic tests is difficult due to a number of potential issues the patient can run into.

### 5.Discussion of treatment options

Patients feel that they have to advocate for themselves to be able to receive the treatment option they want.

### 6.Monitoring

While some patients attend follow-up visits with their cardiologists, others do not have a cardiologist to turn to.

### Each patient has a unique journey that led them to seek care and ultimately lead to the HCM diagnosis

#### Vague symptoms

**Patient 1** experienced symptoms such as **dizziness for over 3 years** but the **HCPs did not take her seriously** and she only got a heart and lung x-ray. She started to see another GP, who referred her to the hospital again where they diagnosed her with systolic anterior motion (SAM), and even gave her a paper that stated it is NOT HCM. **She then researched her dad's autopsy report** to find the “thickened cardiac wall” as cause of death, which she then took with her to the cardiologist.

#### Coincidental screening

**Patient 2** knew he had HCM in the family, having a cousin who had passed away from the condition. However, as it didn't affect his life, he chose to not do anything with the information. However, **at an appointment to renew his license a cardiac murmur was found**, this led the patient to the hospital where he discussed his family link to HCM and he received his diagnosis.

#### Sudden cardiac discomfort

**Patient 3** felt like she was having a **heart attack**. She went to the primary care center, who took her to the **emergency department in the hospital**. Here she got a coronary angiography and they identified the thickened heart muscle and started genetic testing.

#### Family with HCM

**The mother of Patient 4 had seen a cardiologist and had advised Patient 4 to do the same**. This led to the patient visiting her GP who ran an echocardiogram. The results of the echo concerned the GP who thought she was having a heart attack and sent her to the Emergency Department. However inconclusive tests led her to a private clinic where her HCM was diagnosed.

## While some patients ignored their symptoms, others do not know where to find care or received a wrong diagnosis

### Challenges

#### Symptom-blind

- Some patients indicate to deliberately or accidentally **ignore their own symptoms**. Often for HCM patients, the **symptoms develop gradually**, leading to the patients to think that their dizziness and other issues are normal.
- As a consequence, **patients downplay their symptoms** to their HCP or do not seek care at all. Two patients indicated to not have any strength or energy / fainted for 3 years before deciding to reach out for help.

#### Care-seeking confusion

- While some patients ignore their symptoms, there are also patients who **do not know where to go for help** when it comes to their symptoms.
- Several patients have **multiple HCPs overseeing their health**. Therefore, they sometimes do not know what to raise with the cardiologist or when they need to go to their GP.

#### Incorrect diagnosis

- One patient was **diagnosed with asthma**, only after he started pushing the HCPs, they further investigated his symptoms.
- One patient was **diagnosed with anxiety** and has been told to be a *'complicated psychological case'*, even though she explained that she was physically unwell. After she ended up in the ER they started to perform necessary tests.
- One patient did **not receive a diagnosis** for several years. She received **unnecessary tests** such as a lung and chest X-ray that didn't lead to anything. Only after changing HCPs, they started to check cardiac issues as her **father had passed away from it**.

## While some patients ignored their symptoms, others do not know where to find care or received a wrong diagnosis

### Challenges

#### Symptom-blind

*"It came so slowly and gradually. I don't know if I can really say when I had the first symptoms. But it started with that I got shorter of breath than usual, while active."*

- Female patient

#### Care-seeking confusion

*"No. It had continued like that, and I didn't seek help, because I didn't really know what I should seek help for. But it was through the surgery that I was examined and got diagnosed."*

- Female patient

#### Incorrect diagnosis

*"It started with that I got really short of breath, but I became really dizzy and pale, and sweaty, and the heart rate was constantly 120 in periods, and strange arrhythmias; my heart jumped." "All the signs of anxiety", so if you want, you can make it into the diagnosis of anxiety. And I said that it is not anxiety, I don't feel that way. I don't usually have that. But they didn't believe me."*

- Female patient

“

“I sought help for **exercise-induced asthma**. And it just continued. And then, I read an article on a person who had angina pectoris and was **not taken seriously, because he was way too fit**, so it never showed at rest. And when I read about his journey, **I saw myself in it**; that’s it. I don’t have exercise-induced asthma, but I have angina pectoris.”

- Male patient



## For quality care, interviewed patients had to travel to academic hospitals

### Regional hospitals

- Are perceived to lack the substantial knowledge about HCM to identify the correct diagnostic tests and procedures needed for these patients
- Cardiologists are perceived unable to provide essential information the patients need to understand their diagnosis and cope with its consequences
  - When patients are unsatisfied with the care they receive, patients end up going to **private clinics or academic hospitals to seek better care**

“I have asked them what they do with patients with HCM, and if there is someone who is knowledgeable about it. “No we can do little about it, all of us” they said. And I am not satisfied with that answer. I will go to university hospital next time”

- Female patient



While patients can get diagnosed in **private clinics**, the challenge is that they cannot get treated, and therefore have to move to yet another hospital.



### Larger academic

- Able to help patients in a manner with which the patients are satisfied and have sufficient knowledge regarding HCM to test and diagnose
  - **Geographic distribution of academic hospitals in Sweden** is challenging for patients, as it sometimes causes them to have very long travel times to their cardiologist.

### hospitals

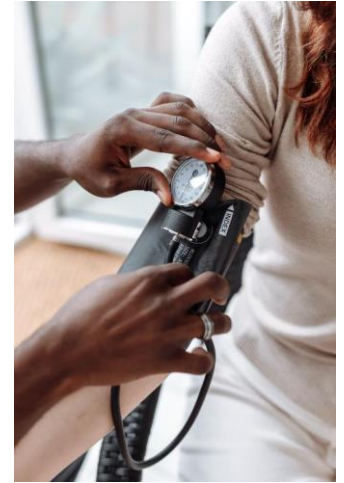
“My doctor in [city] felt insecure with the disease, so they asked advice from a university hospital”

- Female patient

“

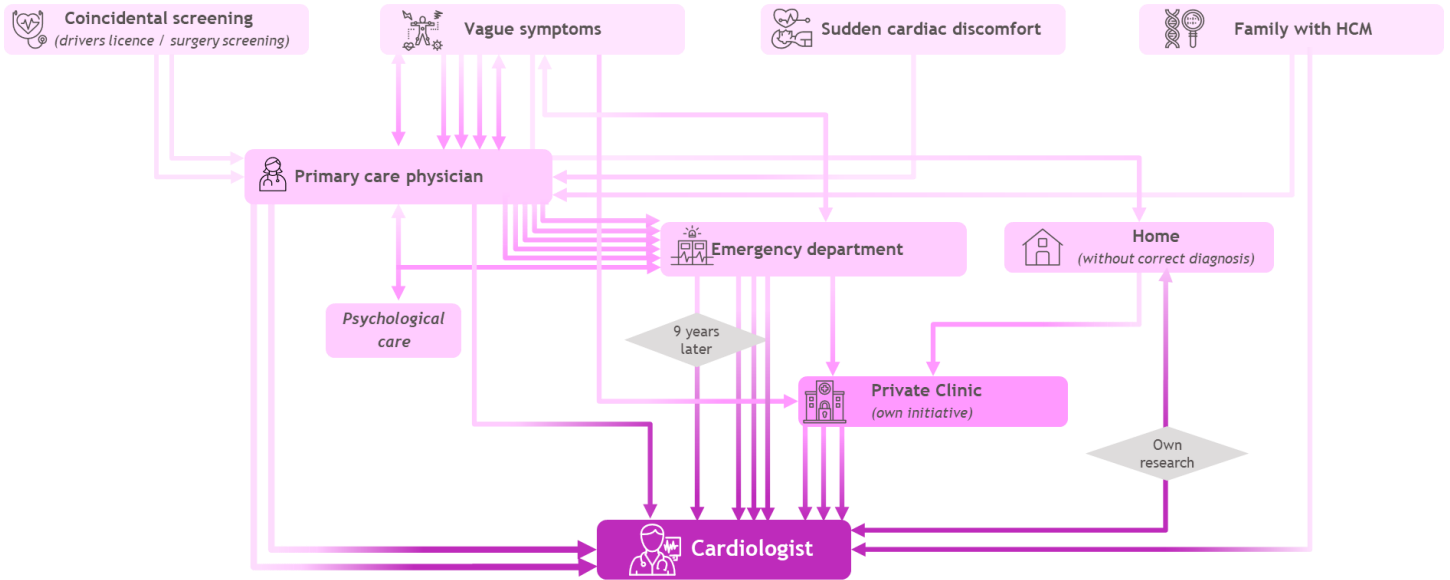
“I had **travelled 3.5 hours by train for the MRI**, and when I came there, they said that I was **not scheduled** for that day. “I have received a letter.” “No, you are not there.” And I was able to show them the letter, as I had saved it digitally. And they saw that I had received it. “You came from so far away. We will see if we manage to squeeze you in.” And eventually, I was examined. I had to go in and out many times, and they adjusted things. And it took over an hour. Eventually, they said they cannot do the MRI, as **they cannot set the machine to calibrate with my ECG**, as my ECG was so strange. ”

- Female patient



### 3. Pathway to cardio.

Patients jump from HCP to HCP, and hospital to hospital prior to arriving at the cardiologist who set their diagnosis



1 arrow = 1 patient

## The infrastructural hurdles causes patients to not get certain tests or travel long distances

Most patients are rather **indifferent** about the conducted tests, but are generally aware of the tests they underwent. The types of tests weren't questioned as patients focused more on the ultimate diagnosis.

The **specific details** and timings around the tests and diagnosis were **not clear anymore** for some patients who were not recently diagnosed.



Often, together with **their caregiver**, they are able to recall more details from this time in their lives. While sometimes the caregiver had a **better overview of the timeline**, other times patients corrected their partner with more detail.



Blood sample / B-Type Natriuretic Peptide (BPN) Test



Electrocardiogram



Echocardiogram



Cycling exercise tests on the bike



Genetic test: not offered to all patients, one patient read about it and suggested herself



MRI: two people were offered an MRI, a couple others requested it, but the cardiologist challenged them as they didn't think it was necessary.



Holter: two patient mentioned using the holter monitor, one 24-hours before or after follow-up, one was wearing it prior to diagnosis

*"I said that I would like to have an MRI, but they thought it is not necessary, as they didn't see anything with ultrasound. They did some examinations, and I said that I don't feel secure with that. I myself contacted a cardiologist in a private clinic, and I said that I would like to have an MRI, and they did it."*

*- Female patient*

## Several hurdles with testing are faced, such as genetic testing not always being offered, to forgetting which tests took place

01

Several hurdles with testing are faced: one patients received **unnecessary tests** such as lung & chest X-rays, to only years later get a confirmed HCM diagnosis.

02

Several patients **fought to get an MRI** to confirm or further investigate their condition, although the cardiologists did not deem this necessary. The MRI has been the defining test to receiving the HCM diagnosis.

03

While the patients expect the **interhospital communication** to be well arranged, it appeared to be the opposite. Some patients registration and appointments in a different hospital were **not in the system** while other patients had to **retake the tests** as the results weren't shared

04

Several patients indicate **long travel hours** to be able to receive specific tests or surgery. Especially patients in more remote areas tend to have travel times around 4 hours prior to receiving the care or test they requested.

“

*“I mentioned it [her father died by 35 from a cardiac condition] myself, actually. They called and **said that they will not take any more tests**. I can't remember how it was exactly, but I asked if it mattered that **my biological father had died of something related to heart when he was 35**? And then, there was a **long silence**. Then, they said that **I should have an MRI**. If I hadn't mentioned it, the importance of what I might not have understood myself, there wouldn't have been any MRI, and the diagnosis would have been delayed with a year or two.”*

*- Female patient*



## Patients do not perceive huge improvements when on treatment, with some even experiencing side effects

### Medication

- Most patients receive **treatment immediately after diagnosis**. Patients stay on a certain treatment regime for a very long time and are not aware of the changes they have gone through over time. Treatments patients are on include:
  - Beta Blockers (which all patients take)
  - Calcium Channel Blockers
  - Long-acting nitrates
  - Diuretics
  - Others
- Patients do not always feel that their symptoms are under control with the treatments they are currently taking and feel like they are **still searching for a better alternative**.
- When starting treatment, patients hope that the treatment would make them feel better and allow them to do more. However, for two patients the **treatment** has done the opposite, making them **feel more tired, sluggish, and it slowing them down**.

## Most patients received surgery but access to myectomy and ablation success is limited

### Surgery

- The **ICD is the most prevalent** (n=7) intervention patients were offered, of which one had to advocate for it herself.
- The **myectomy** is raised often by the patients in the interview as all patients who received it (n=4) had **to request it themselves**. Patients feel they did not receive support from their hospital, having to advocate for themselves and 'fight' for a formal referral from their main hospital.
- Two patients received **alcohol septum ablations**, however, both patients had to have a second ablation as the **first one wasn't successful** or didn't relieve enough symptoms.

*"If I hadn't read about myectomy, I would probably have had alcohol ablation conducted. In my case, it wouldn't have worked because I had the mitral valve that needed to be repaired as well."*

*- Female patient*

Main challenge is the **communication issues among hospitals**. Most patients need a referral to get to a hospital that can conduct the surgery, but the poor communication hinders the patients getting the care they need.

“

“I did a *self-referral* to [city], they stated that it is important to operate it, as otherwise, I will die. But they needed to get a referral from my main cardiologist, who didn't want to send any referral from here to [city]. I had to fight several months. And *I planned to move just for the surgery*. My cardiologist was not interested, and they didn't say why. Eventually, through discussions back and forth, *I managed to make them understand that I needed a surgery*. My main hospital cannot operate as they don't have the knowledge. But I had *to fight several months*.”

- Female patient



## The frequency of follow-ups depends on whether or not the patient has a dedicated cardiologist

There seems to be **no protocol in place** when it comes to follow-ups: while some do not have a dedicated cardiologist and regular scheduled check-ups, some do have regular scheduled check-ups (typically once a year). Since most patients do not know what to expect, they sound complacent. *“This is just the way it is in Sweden”*. For some patients, their disease is really not under control and they end up in the hospital regularly before their scheduled follow-up.

*Patients do not have a cardiologists and do not have regular check-ups*

**Patients receive regular follow-up consultations from one cardiologist**



*“So, I don’t really have my own cardiologist. I understand that this is the case for many people. The disease HCM is taken care of by different sub-specialists (...) I think that is one of the shortfalls of the Swedish system”*

- Male patient

*“I still haven’t been able to see him. I send a message through 1177, and he replies. I have never been able to see the doctor.*

***Everything happens only by phone, and never anything more than what I demand. Never any initiative to do something.”***

- Female patient

*“I assume I am going to see him again in the autumn. The one who did the surgery was another cardiologist. I assume I am going to see him instead from now on. It doesn’t matter. But I don’t know if I still have the same or if I have another one.”*

- Female patient

*“It is once or twice per year. I had annual check-ups after the surgery, but when my son passed away, we have seen each other more often. He was really sorry about that he was not able to prevent it. So, I see him maybe twice a year now.”*

- Female patient

## Interviewed patients face several challenges in their journey, leading to frustrations and emotional fatigue

### Emotional journey

Patients’ **emotional experience** varies depending on how they received their diagnosis. While some quite easily accepted their condition, others are bitter and unsatisfied about how they got diagnosed.

Most patients are quite **overwhelmed and stressed** when they hear the confirmed diagnosis. After this initial shock, some patients got **frustrated and irritated about how their diagnostic process went down**, as some have been running around with an incorrect diagnosis for many years. While patients do manage to **adapt their lifestyle** to their diagnosis, the bitterness towards the provided healthcare remains high.

## Interviewed patients go through a roller-coaster of emotions before reaching acceptance

### Initial stage: stressed

Most patients are quite stressed when they first hear the diagnosis. Doctors seem to be in a hurry, which puts additional stress on the patients. The patients do not know what the disease is, but they do get informed about the genetic aspect and the potential impact of this.

What does this mean?

What will be the impact on my life?

What are the consequences?

What will the future look like?

Why me?

What about my family?

What if my children test positive?

Can I accept the outcome?

### Second stage: realisation & anger

Once the patients come to the realisation of the impact condition and are able to link the symptoms they had in the past to their condition, most patients experience anger. Especially those receiving an incorrect diagnosis or patients who felt they were not taken seriously.

I know what to watch out for.

I know how to control my symptoms

I do not live in fear

I can live with this disease

### Third stage: clarity and answers

After the initial months, patients often are able to get answers to their questions and clarity about the condition's impact on their family. Once they have the genetic results, patients start to come to peace with their situation.

### Final Stage: working to acceptance & lifestyle changes

Ultimately, all patients have been able to adapt their life and get used to living with the condition. Nevertheless, in Sweden some patients remain bitter over the way that their diagnosis went and the care they received.

## Initial Stage: Feelings of sadness and stress overflow a patients mind once they receive the confirmed diagnosis

### Feeling sad and stressed at diagnosis

#### Sad

Initially, the confirmation of the HCM patients made the patients feel very sad, especially when thinking about the conditions impact on their family. Hearing about the HCM diagnosis is both physically and psychologically very impactful. Some patients described an instant feeling of weakness and dizziness falling over them.

## Stressed

Patients get stressed about what the future will hold. A feeling of despair and insecurity falls over them, and stress about their children and family.



Some patients also indicated that their **family and caregiver** found it more stressful than themselves.

## Worthless

Some patients highlighted to have lost all their confidence, in themselves and in the healthcare system as they have been trying to get a correct diagnosis for a long time.

## Loneliness

*“It is much about the life. You are lonely. You are born alone, and you will die alone.”*

- Female patient

## Planning

*“You need to get many tools to make it. You need to plan a lot. You need to research everything that can optimize the general health condition.”*

- Female patient

## Bumpy road

*“It is difficult. Maybe a road going ahead. This is something that just happens.”*

- Male patient

## Shock

*“When learning that I have the disease, when so many other things in life had to be paused. So, it was the greatest shock.”*

- Female patient

“

*“Your self-esteem as a person gets... when you know that you are ill but you don't get any help, you feel **so worthless**. When you see that other people with other diagnoses get help, even if they are not as ill. And even if you fight for many years, it doesn't matter how strong you are. Eventually, you get broken.”*

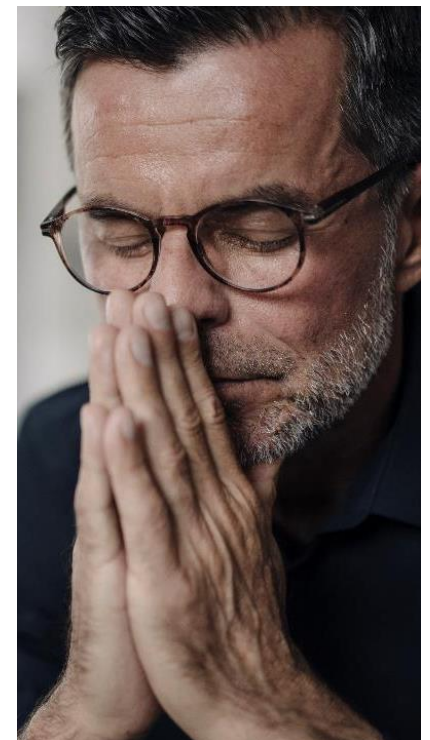
- Female patient

*“It was **stressful**. A lot going on, everyone's in a hurry. Different doctors. The usual dilemma in Swedish healthcare; there are different doctors all the time. It is really stressful all the time. They were not good at taking care of me; it is about me, not about them.”*

- Female patient

*“I would say that **it followed me for long time**. For a quite long period of time, I had many thoughts circulating. It became a bad spiral; I started focusing on things I was not able to do, and at the same time, I was worried and had death anxiety. **I was afraid of going to any secluded places** in case I would get sudden death.”*

- Female patient



## Initial Stage: Although interviewed patients could openly talk about how they are feeling, most did downplay their symptoms at the start

### Full transparency

Most patients feel safe to openly and transparently communicate with their cardiologists. However some patients find it challenging to find the right words to describe their experience. One female patient highlighted that she finds it a lot harder to talk to male cardiologists, this led to her to switch to a female HCP where she feels more comfortable.

*“I feel secure, actually. I do. They know how I function. They know that I go home and google, and that I come with a long list of questions. It feels good.”*

- Female patient

*“I don’t have problems to tell, but the challenge is, as a patient, to find a good word to describe my experience. I have noticed that when I go to see a doctor, I need to prepare myself by writing down how I feel and what I experience. The healthcare could be better in reminding us patients not to rely on the doctor alone, but to be prepared, so that you can ask the right questions.”*

- Female patient

### Minimizing symptoms

Half of the patients indicate that they minimised their symptoms from their cardiologists. Often they did so because in the beginning they did not recognise what could be symptoms or because they want to ignore their disease as thinking about it makes them feel like a patient.

*“In the beginning, at the primary care centre, definitely. And to certain extent, towards my current cardiologist. I am sometimes thinking that there are thousands of people who get palpitations. That is normalized.”*

- Female patient

*“Afterwards, I would say that I did when I thought I had the exercise-induced asthma. But not after having seeing the cardiologist. But before that... I think that it has been more serious than what I thought and felt.”*

- Male patient

“

“I started having symptoms; I got **numb**, especially after meals. I got up, and I got numb. It felt like blood didn’t circulate. And I felt dizzy. I was thinking I would seek help due to it, but **I was not sure how I could explain it**. And it was a short moment...and it came irregularly. Over years, it started coming more and more often. And I fainted for a couple of times. And I didn’t seek help, as I was thinking that I have low blood glucose.”

- Female patient



## Second Stage: After the diagnosis sinks in, frustrations resurface regarding lack of clear and consistent approach to HCM care

### Lacking healthcare services

Generally, patients are often overwhelmed when entering the hospital, afraid of not knowing what is going to happen. Nevertheless, in Sweden the patients' experience is worse due to:

#### 1. Always seeing a new cardiologist

Several patients indicate not to know who their dedicated doctor is. They see different cardiologists all the time, making it uncomfortable and difficult to reach out to a physician as there is no one point of contact to ask questions. This leads to the patient having to tell their full story every time which is frustrating for them.

#### 2. Not being taken seriously and receiving a wrong diagnosis

Some patients received a wrong diagnosis for several years prior to receiving their HCM diagnosis. They indicate that they had to advocate for a re-examination and look into their own family history as the HCPs did not provide guidance or support in this.

Thinking back of this makes the patients bitter. They wish to have received better and more compassionate care.

*"Of course, you wish to be able to see just one cardiologists whom you know. It is also the same with the communication; when they moved me to a different hospital for the follow-up, nothing followed. I asked if they could look at the previous images, they said that they don't have it, and we would start from the beginning. I asked [cardiologist] if they didn't send the images, and he said that he has sent everything, but they are not able to pick it up. This is what it is."*

- Male patient

*"It is disturbing to have a new doctor every time. To have a stable contact. I think it would make me more comfortable to call between the annual appointments."*

- Female patient

## Third stage: Genetic testing doesn't always bring reassurance or clarity for the patients

The genetic tests could give some peace of mind to the patients, but patients still feel responsible for potentially giving the condition to their children. If anything happens to their children related to HCM the patients carry that burden with them for the rest of their lives.

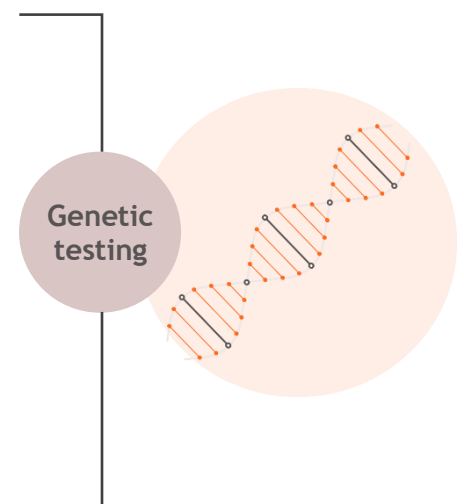
*"He [her son] didn't have the gene. I was really happy. But I was really concerned during that time, while waiting for the results."*

- Female patient

*"When they said that it is genetic, it is hereditary, it was quite hard, because I have three active sons. And one of the sons was competing with road cycling."*

- Male patient

Genetic tests do not always provide clarity. Sometimes the result is inconclusive, leaving the patients with more questions and uncertainty.



Patients hope that with new investigations, it could maybe lead to more conclusive results.

*“The result of genetic testing was inconclusive. It took over a year, and they were not able to neither confirm nor exclude it. If I decide to redo the testing, as now, they have found more genes than what they had back then. So, it could be possible to have it confirmed. I am still considering that. I didn’t even get any genetic counselling before the test was done. It is also an important thing to have. And I think they have improved it.”*

- Female patient

## Third stage: Most patients have seen a family member pass away from HCM, making it even more emotionally difficult

### Emotional impact on the patient

Most patients highlighted that **losing a close family member** was the **most devastating** moment in their lives. Often the patients aren’t worried about their own lives, but they are deeply concerned about the health of their children.

*“I was actually never worried about myself. I have never been. But it is just that I felt worried about, or guilty, because of the children.”*

- Male, 49 years

*“The worst event is that my son died. I feel that he got the disease from me, and I wanted to go to see the doctor with him, but he didn’t want to; he was 31. He didn’t want to go with his Mom”*

- Female, 57 years

### Impact on the patients’ family

Not only the patients themselves are impacted by receiving the diagnosis, also the patients partner, parents, friends, and other family members are impacted.

Some patients **wait with telling their loved ones**, to lower the burden on them. Others also mention that their family was more worried about the diagnosis than the patient herself.

*“I was lying in the hospital for a couple of days. I think that my family was much more worried than I was. I felt that I have had this for a while, and now, I understand what it is. I have got medication for this. It will be followed up. I continued to work as usual. I am like it is what it is. But I cannot say that it is what the family feels.”*

- Female, 65 years

“

*“First, I **spoke about it with my husband only**. During our trip, I spoke to him alone. After that, I talked to my Mom. I was thinking that she is really worried herself, so she doesn’t need to know while I am travelling. It would **burden her a lot**. I talked to her. And it took some time until I spoke to others, such as my friends, etc. But I did it.”*

- Female, 41-50 years



## Final Stage: Although patients' hobbies & ambitions were negatively affected; some experienced a positive impact on their social life

### Quality of life

While some patients state to be satisfied with their overall quality of life, others indicate many area's in which they became limited due to their diagnosis. Mostly patients complain about their poor physical condition.

### Professional ambitions

While some experienced **no effect on their professional ambitions**, others saw their work impacted by the diagnosis. One patient **switched to a less stressful job**, two struggled physically, with one avoiding certain tasks and another facing **unemployment** as a result.

### Hobbies

The most impact on hobbies is found on **active hobbies**, such as jogging or hiking. While some have had to stop these activities, others are able to cope with their condition by taking more breaks.

### Social interactions

One patient discussed how the diagnosis **opened up their relationship** with their partner as well as friends, being more open with friends. However, others struggle as they **can't take part in the activities** they imagined doing with their friends which has led to adjustments.

### Family Life

Most feel that the disease hasn't impacted their family day-to-day life. The only impact is the hereditary aspect and having passed it on to children/grandchildren and having to cope with this.

## Verbatim on Quality of Life

### Quality of life

*"I have a really poor condition. I am not able to walk and speak at the same time. I get really tired when going up stairs. I prefer to stay still. I sweat like a pig. So, it does have an impact on me. I have an office job; I would never manage to have a job where I need to move around."*

- Female, 57 years

### Professional ambitions

*"I had warned nine months in advance that I want to stop working as a manager, but I could never believe that I wouldn't have any work at all. I was a bit angry and bitter about it. Of course, it was due to the disease that I was not able to continue working."*

- Female, 65 years

### Hobbies

*"We would go up to a hill, and I have been there before, and I managed to get there again. Of course, you need to stop and take a break sometimes. You don't run up, so to say"*

- Male, 51-60 years

## Social interactions

*“In a positive way; I have become **more open to discuss my feelings**. I have always done that with my husband, but I have become **more open with my friends**. And I feel they perceive me as more open as well, because we have talked more about such issues. It has rather been positive.”*

- Female, 41-50 years

## Family Life

*“Over the last six years when I have got grandchildren and be active with them. I don’t have energy for that the way I would if I was healthy. But I don’t think it matters that much. Our children don’t live close to us, they live far away. When we see, it is more intense, and then you go home and rest.”*

- Female, 61 years

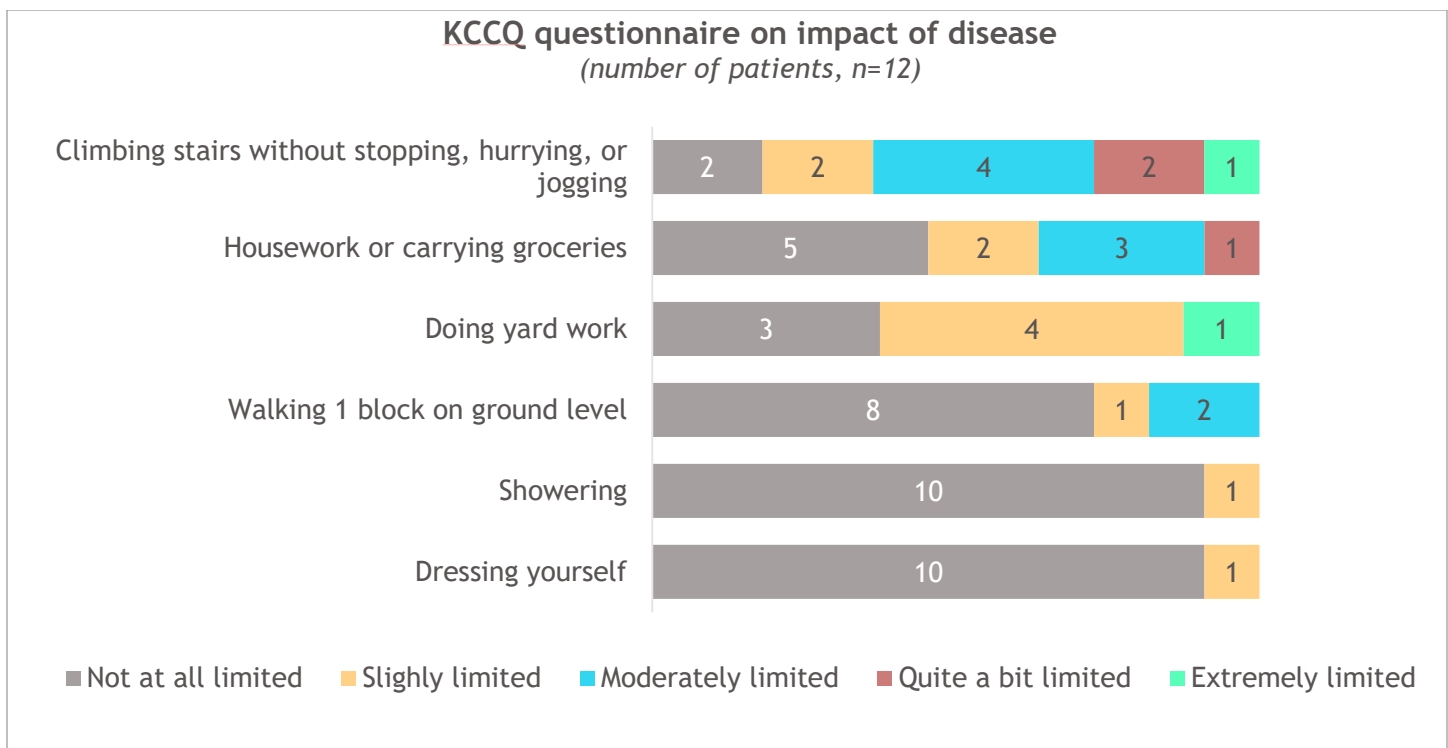
## Final Stage: Patients that received surgery state that it significantly improved their physical fitness and overall quality of life

Based on the patients self-assessment, it appears that **their condition only slightly impacts their physical fitness levels**.

However, several patients mentioned that **only after their successful surgery**, these scores apply. Prior to surgery, some patients were highly affected by their condition.

*“Before the surgery, I took many breaks, and walked a really slow pace. Everyone in the family had to learn that I will set the pace. Once, after the surgery, my sister said that it was easy to follow my pace, and now, I am speeding up. Now I have no limitations, unless it is a really warm day, as that affects me much.”*

- Female, 61 years



*\*Not all participants answered the statement regarding yard work due to not having a yard. One participant did not answer the KCCQ questions*

## Final Stage: While patients have learned to live with their condition, most are still bitter about the (poor) care they received

### Finding acceptance with their condition

#### Uncertainty remains

Patients are **bitter & annoyed** reflecting back about the care and support they received. Not having a fixed contact point, having no cardiologists at all, or having to see different doctors all the time, frustrates the patients.

#### Questions and coping

While a few patients are quite satisfied with the care they received, **some patients still question the healthcare system**, complaining about everything that went wrong in their diagnostic phase.

#### Settled into life with their condition

All patients did get **accustomed to living with their condition**, made the necessary adaptations and continue to live their lives to the fullest (as far as possible). The confirmation of genetic tests was mentioned as a starting point for accepting their condition.

#### Inevitable

*“Life goes on anyway.”*

- Female, 32 years

#### Hope

*“I think that there is still some hope, there is some peace that has settled. The endlessness, the eternity, that you have to live with it the rest of your life.”*

- Female, 41-50 years

#### Active

*“I’m always up to something. I am not a person who does nothing.”*

- Female, 70 years

#### Nature

*“Yes. I stand outdoors in the nature and do what I want.”*

- Male, 49 years

## Patients find it challenging to identify a highlight; the worst point was clearly linked to the hereditary aspect & poor quality of care

### Highest point in their journey

Patients find it difficult to identify the highest point of their journey, with some patients also **not being able to answer this question**.

Patients who were able to name a point mostly focus on:

- **Their diagnosis:** gaining an understanding of what is happening to them
- **Their surgery:** A big change to the patients’ lived with a close to immediate effect on the way they feel.
- **Their children’s genetic test result:** hearing that their son did not have the gene.

*“When I got my first ICD, it was a high point, as it gave me a huge relief. And also, when I had the second one operated, as you are always a bit worried before a surgery, but it didn’t take even ten minutes. He just started, and it was over. It incredibly exceeded the expectations. The both events are high points.”*

- Female, 41-50 years

## Lowest point in their journey

Patients low points mostly relate to the **family/hereditary aspect of the disease** and the poor quality of care they have received

- In terms of the hereditary aspect, patients find it difficult that they (may) have passed on the condition to their family members, but also having to **see the consequences of the disease for their family**.
- In terms of the poor care, this focusses on not having a specific cardiologist, feeling like they have **not been taken seriously and belittled**, a lack of knowledge amongst the HCPs, and a lack of communications with the HCPs.
- Regarding the impact the condition had on her **professional ambitions**.

*“When I found out that it is hereditary. And when they wanted to insert the Reveal. My heart was racing, and it didn’t stay calm, so it might have been time for the ICD. But it is actually these two times when I have felt really bad myself, mentally.”*

- Male, 49 years

## While caregivers play a crucial role in the wellbeing of the patient, cardiologists completely disregard them



**Caregivers** play a crucial role in helping the patients **remember** and understand the various steps of their medical journey.

Caregivers often have a **better recollection of the tests conducted** and HCPs visited compared to the patients themselves.

Unfortunately, some caregivers feel **excluded from conversations** with the HCPs, as they have encountered situations where they were not allowed to actively participate or ask questions.

*“I was there once, but it didn’t go well at all. I didn’t feel myself welcome. I was absolutely not allowed to say anything”*

- Husband of patient ID25

While patients may have reached a level of acceptance and an understanding of their condition, caregivers often experience a **constant fear and anxiety for their loved ones**.

The uncertainty of whether their partner may not wake up or **suddenly pass away can be terrifying** for caregivers, adding an additional emotional burden to their role.

*“I feel like this knot is in my brain all the time. I have to be cautious; I have to be really careful with his life”*

- Wife of patient

- Importance of **acknowledging and involving caregivers in the healthcare journey of HCM patients**.
- By recognizing their invaluable perspective and addressing their concerns, healthcare providers can better support both the patient and their caregiver, ultimately improving the overall quality of care.

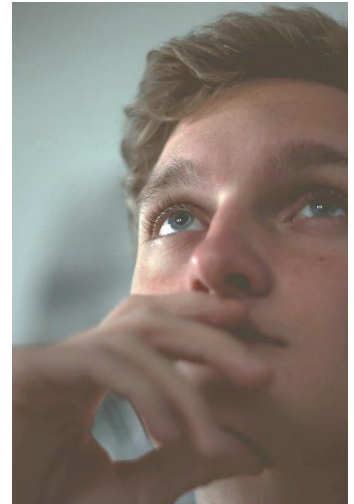
*“They [cardiologists] spoke over my head”*

- Husband of patient ID17

“

*“[Partner] Both of us felt that he had more knowledge than the others you have seen. And it felt really good, because I haven’t had so much confidence **as I myself have been neglected regarding some procedures**. But this doctor was different, as he had a **wide knowledge on HCM**. Which made you feel really confident with him. [Patient] Yes. I feel myself and really well taken care of. [Partner] And well informed. [Is there always a different cardiologist?] They have tried to keep the same, but it usually varies between two or three of them. It seems that this is how it is.’*

- Female, 44 years



## Patients need a better support system when being diagnosed with HCM, a counsellor or dedicated staff to contact in case of questions

### Informational journey

Patients are very dependent on themselves in receiving additional information about their condition.

While most patients search online, some patients trust their cardiologists and do not feel the need to do additional research.

- The patient association was described as a **great source of information** where they can easily find fellow patients and hear about their experience with HCM.

HCPs provide **too little information to the patients**.

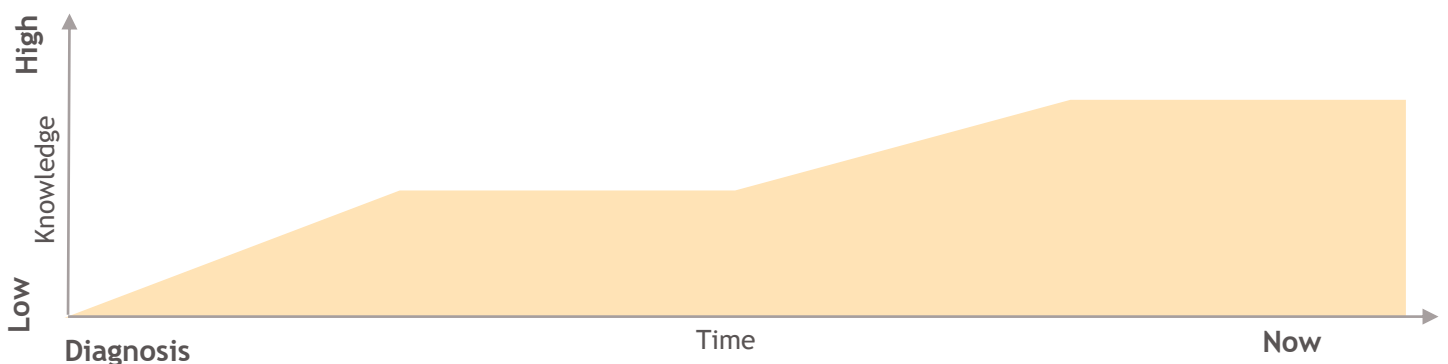
- Most patients felt very **lonely** in their process to finding information.
- Not only about what the condition entails and what the future would look like, but many patients also had to **inform themselves about potential surgeries that would be indicated for them**.

## Initially, patients receive very little information, causing them to search for answers themselves online

### Knowledge of HCM over time

*“I didn’t understand then. I have had to read afterwards. I understand that there is a type that is not genetic, but you can get in anyway. **Everything doesn’t go through genes**, but I know too little about it today. I have read that you can have the gene anyway, even if you have been tested. Sometimes, they test again. But they haven’t done that in my case”*

- Female, 70 year



## Throughout their journey, patients have different levels of knowledge

Initially, patients receive basic information from their cardiologists. Three patients indicated that this was the first time they had heard from HCM.

While some patients were quite satisfied with this info, other felt a severe lack of information from their cardiologist and indicated that there is too little time to truly digest the diagnosis and ask questions.

Most patients started to actively search for more in depth information online after they had come home from the hospital. It was described as a lonely journey as the patients were personally responsible for finding all the information themselves.



Sometimes, it is not only the information or advise itself that patients are searching, but it someone to discuss their thoughts with.

*“My husband who is sitting here has been a great support. [husband] But I didn’t have so many advice to give. [Patient] No. But we are always able to discuss things. But I think that I had to find all the information myself. And in that sense, it has been a really lonely journey. I understand. As I mentioned, I didn’t receive any information sheet.”*

- Female, 61 years

## Common information sources are online articles, Facebook, 1177\*, YouTube, only limited information comes from the cardiologist

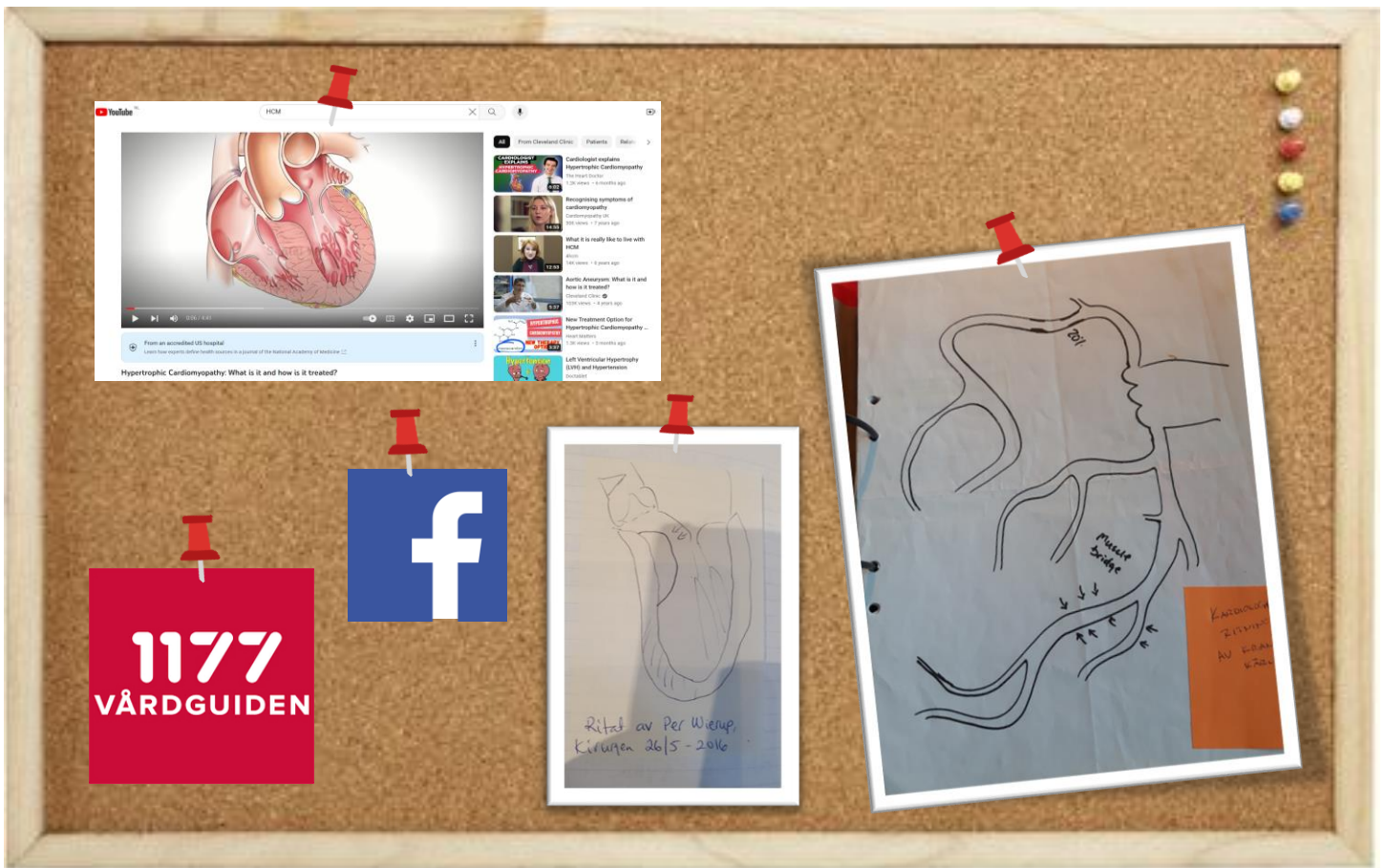
### Type of information sources mentioned

- Cardiologists in the hospital: drawings, referral to “Heart Education Classes”
- Conversations with family members: personal experiences
- Internet:
  - (American) Scientific articles
  - 1177.se website → information too general
  - YouTube video’s → very specific and clear explained
- HCMA Sweden (Patient Association Group) & Facebook Page: For asking questions, reading along with other patients personal experiences, and learning about the course of HCM.

Majority of the patient mentioned that their most important support is at home, their partner, parents etc., all who helped search for information and are able to openly discuss with the patient.

*“I would say that it was when I found American articles and read how they do in other countries. [How did you find the articles?] I started from 1177, and there is some information, and you go further and start searching for the terms, so that you get to the sites that are for specialists. You search for the terms. And you need to try. It is not so easy every time. It is difficult to know if they are relevant or not.”*

- Female 57 years



*“The best support I have had has been my father. He has been asking how I feel, and followed with me to the appointments.”*

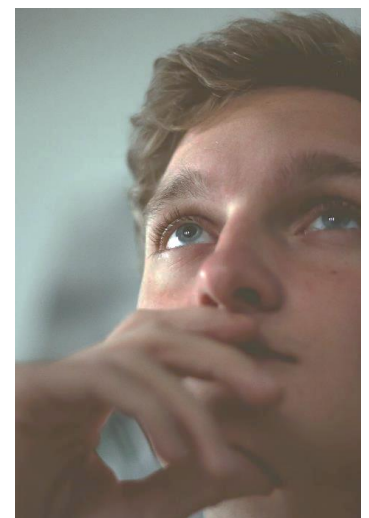
*- Female, 32 years*

\*1177 is the Swedish healthcare website providing information and advice on how to treat yourself from home

“

*“More information. Yesterday, I was thinking of a question in the homework. It was “Do you have any information material left that you got at diagnosis?” And the answer options were just Yes or No. **I didn't receive any materials.** There were no information materials. (...) I want to know everything. I would like to have all scientific articles that are available. But something... **It was a really lonely journey, as I didn't know anyone who had the same condition.** I didn't have Facebook back then, as I didn't have time for it.”*

*- Female, 61 years*



## Patients need a strong relationship with the cardiologist to gain better understanding of the physical and emotional aspect of HCM

### Information needs

While all patients have different information needs, most of them felt at one point that the information shared with them was not sufficient. Even after living with their condition, patients indicate to lack information about both the physical and emotional / psychological impact of their condition. Several patients highlighted that any form of counselling or emotional support would have been appreciated.

### Quiet time to research the diagnosis

As patients feel like they do not have sufficient time to absorb information during their doctors appointment, some mentioned to find it very important to have **the peace and quiet time at home to digest the information.**

Patients understand the lack of time of the cardiologists, but would therefore like the option to talk to a **nurse or counsellor who is specialized in the diagnosis**

*“I am really satisfied, but I would have appreciated if I received more support, mentally. I got **nothing, and was never offered counselling.**”*

*- Female, 41-50 years*

### Answers to their questions

Questions remain among patients regarding the **physical impact and the uncertainties the future holds.** Most common questions were:

- How will the disease progress for me?
- How will my physical condition change in the future?
- What is the risk I have of getting a sudden cardiac arrest?

*“It is the risk assessment. It can take several hours for the cardiologist to go through different values. And they don't have the time, neither the knowledge. This is what I would like to know more about.”*

*- Female, 63 years*

## A systematic problem with the HC system is identified, the quality of care and communication highly depend on the cardiologist

### Satisfied patient

*“I feel that there is quite **good support from healthcare.** The ones I see there feel professional. I feel secure with the help I get. But I know that it can progress and get worse. There are different stages. It is nothing that will disappear, but I will always have it.”*

*- Male, 51-60 years*

- Patients who experienced a **smooth referral and easy diagnostic process** are often quite satisfied with the Swedish HC system as they don't feel the lack of support.
- Patients talk positively about their cardiologists if he has a **clear communication style**, if he is **considerate about the emotional impact** of the condition on the patients' life, and if he takes **time to explaining** the tests, the results and impact the condition will have on their lives.
- Three patients indicated that their cardiologists was the one **providing most important information** and the most crucial support.

## Unsatisfied patient

*“There was nothing in Sweden, but 1177 description of symptoms. And you would think that all the doctors have it under control. **Information in general, there was nothing.** And the patient association, I found one in the USA. And no information on what would happen next. And **nobody to talk to.** It would be nice to talk to someone, a nurse or a councillor, immediately.”*

*- Female, 70 years*

- **Support in the form of information and counselling** is needed in Sweden to improve the patients satisfaction with the provided care. Majority of patients talk very negative about their cardiologists. Patients who indicated to **search for all information themselves**, who don't have their own cardiologists and those who had to **switch hospitals several times** were dissatisfied with the support provided.
- Also the **caregivers** highlighted that the cardiologists communication style was inconsiderate.

## Verbatims on satisfaction with communication and care

### Satisfied patient

*“I had a really good doctor. Really straightforward. I appreciated it. It was really hard, the diagnosis. We were talking for quite long time. I think I had a three-hour appointment with her, and we went through... there was an examination conducted, and she explained what she was doing, what she saw, and afterwards, she told me about the disease, and how it can be.”*

*- Female, 32 years*

*“He is really skilled and communicates really well. But in general, to get to the bottom with the psychological and mental part, it should be considered, and not let go just like that. So, that you will see a counsellor? Yes. And I would have appreciated... If you have a diagnosis, you can through the clinic get a counsellor that is specialized to such discussions. It would have been good.”*

*- Female, 41-50 years*

*“I didn't have any complaints. I was really thankful. I think that it went really well. They were nice. I was a bit afraid, but it went well. I feel good about it. I got the help I needed. It is not always like that, but it was so for me.”*

*- Female, 60 years*

### Unsatisfied patient

*“That **they should talk to each other**; to coordinate better. So, it is not that they need to talk to you, but to communicate with each other? Yes. It would be nice. It has an impact on what you say; I don't understand **what is consider heart related**, with anyone else besides the cardiologist. And if I think it is related to menopause, I discuss it with my gynecologist. I select based on what I think is what.”*

*- Female, 57 years*

*“It feels like you need to **fight a lot all the time**. Right now, I am healthy enough to manage it, but I might not be able to do that later on. I am thinking of all those who are not so healthy and who cannot get their voice heard.”*

*- Female, 44 years*

*“It is just that **they should not speak over my head**, but to the person. I am 70 years old, but I am not stupid. I feel pity over them who have dementia and everything. They cannot get themselves heard.”*

*- Female, 70 years*

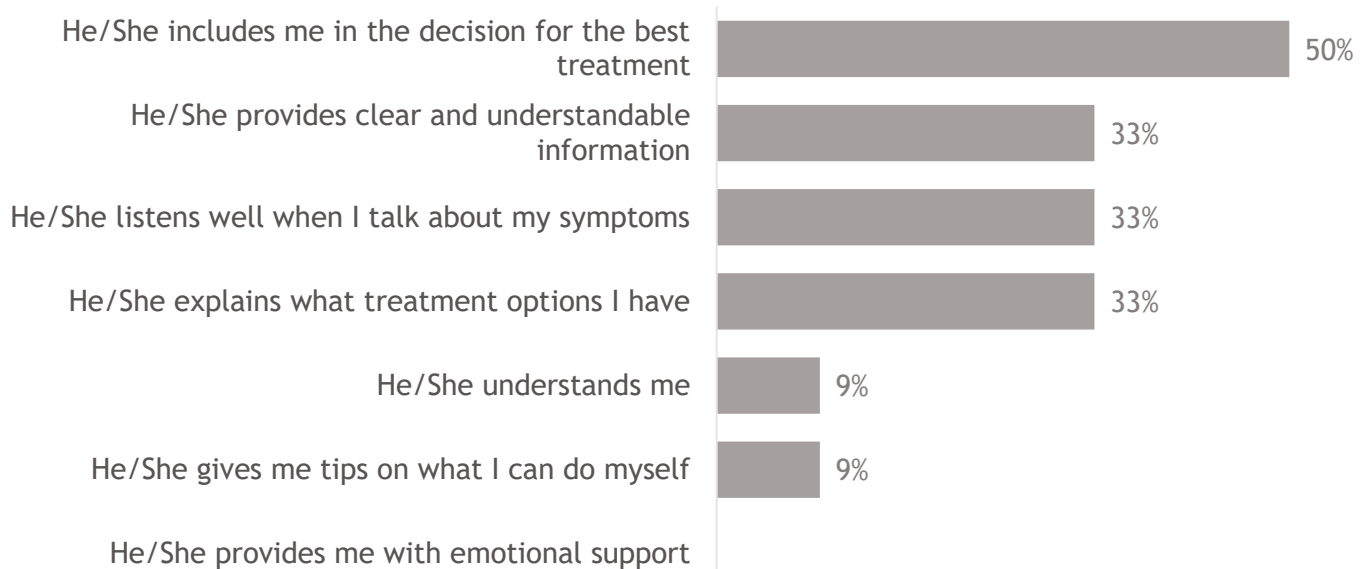
## Providing clear and understandable information and being included in the treatment decisions is what patients need from their cardio

Most patients do not only want to be included in the decision for the treatment, but they would also expect the cardiologists to share information about upcoming developments. Patients expect to be informed by them if a new drug would become available, even if it wouldn't be relevant for them. Some state that every treatment sounds better than the surgical procedure.

*"I knew now, as I had read about it, but it would have been nice to get that information. What is missing today is that not everyone gets all the information on which treatment options are available. The doctor might just say that if you want to try alcohol ablation, it will be fine. And if you are not well informed, you don't know about it. Clear and understandable information. And listens to well. It is also important."*

- Female, 61 years

### Importance of statements regarding communication with the cardiologist (% patients, Top-3 box, n=12)



“

*"I didn't dare to go there alone, but I asked a friend to follow with me. It happened so many times that when they were offensive towards me, I lost my patience often, and got angry or sad, and just left. And I didn't want it to happen. She had to come with me in order to support me. And I had prepared some questions, and he kindly answered my questions. But he spoke to her as much as he spoke to me. As if I was psychologically disabled. It was not any delightful discussion at all, but just that all my symptoms are caused by this."*

- Female, 63 years



## The patient organization leads to a two way street of information and experience sharing

*“This [the patient organisation website] is what I would have liked to have at the beginning. I didn't, but I am happy for everyone who comes after me and is able to get the confidence from their at least.”*

- Female, 44 years

Patients find the patient organization useful as it **allows them to learn from others experiences** on two levels, both in **gaining knowledge** but also **understanding** more about what they can expect from the condition. Additionally, it gives some patients a ‘**benchmark**’, a realization that there are other patients who are in a worse situation.

The patient organization also **allows patients to share their own experiences**, with the hope that others may be helped with the information that is being shared. Information shared includes both the **personal experiences** of the patient but also experiences of **family members**.

Through the patient organization patients are able to **stay updated on developments and interesting news passively**. Most have passed the phase where they are still actively looking for a lot of information. However, through **seeing updates on Facebook and on the website**, patients are aware of any new things happening within the indication.

## Finding a knowledgeable cardiologists and listening to other patients stories is their main advise for other patients

### Find a knowledgeable cardiologist

Many cardiologists in Sweden are not knowledgeable enough about HCM. If patients want good care and answers on their questions, finding the best cardiologist will be essential. One patient mentioned that going to the “*Hearth Education Classes*” helped her a lot.

*“To go to heart education classes. It is not only the educating, it is also the advice. There are different professionals, and I have learnt different things from different professionals. And I find it really good indeed.”*

- Female, 60 years

### Listen to other patients

Getting help from other patients who have gone though it is equally important as getting a good cardiologists. Patients have more information on how it makes them feel and what helped them to cope.

*“Make sure that the cardiologist you have has knowledge on HCM. There are many cardiologists who don't have it. That is definitely the most important. You wonder if you can live a good life with HCM, and you need to have a cardiologist who has knowledge on HCM.”*

- Female, 61 years

### Positivity

Focus on all the things you can still do, life with HCM does not necessarily need to be limiting. Try new hobbies and experience life to the fullest

*“To receive all the help you can get. Don't hesitate. You have to do what is possible to do. And to keep yourself informed and up-to-date.”*

- Male, 51-60 years

## How to support cardiologists in providing better care for the patients?

### Key challenges

Effective touchpoints	<ul style="list-style-type: none"><li>• Cardiologists face challenges in <b>recognizing patient symptoms and providing correct diagnosis</b>, especially in regional hospitals</li><li>• Referral and internal communication systems between academic and regional hospitals <b>lacks efficiency</b>.</li></ul>
Emotional needs	<ul style="list-style-type: none"><li>• Patients (and caregivers) feel <b>left out and misunderstood</b> by the Swedish cardiologists and need more emotional support.</li><li>• Due to lack of quick and accurate diagnosis, patients have <b>lost faith in the healthcare system</b>. While they have found peace the bitterness remains.</li></ul>
Informational needs	<ul style="list-style-type: none"><li>• Patients struggle to absorb the information provided by the cardiologists, <b>feeling overwhelmed</b>.</li><li>• Patients and caregivers lack support from their cardiologists and highlighted their <b>inconsiderate communication style, leading to dissatisfaction</b> with care.</li></ul>