

## **HCM PATIENT SURVEY - REPORT FOR RESPONDENTS FROM POLAND**



The online survey among HCM patients in the European Union and the EFTA (Switzerland, Norway, Iceland and Liechtenstein) was organized by the HCM Patient Foundation and collected replies between December 5th 2024 and February 16th 2025. In that period 424 people initiated survey replies, of which 337 people from 18 countries satisfied the participation criteria and their replies will be used for the purposes of this summary.

This report reflects the 24 replies received from Polish patients. While not representative, we believe it gives some useful information on what Polish patients experience and on their opinions.

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## Q4 - How do you identify?

24 Responses



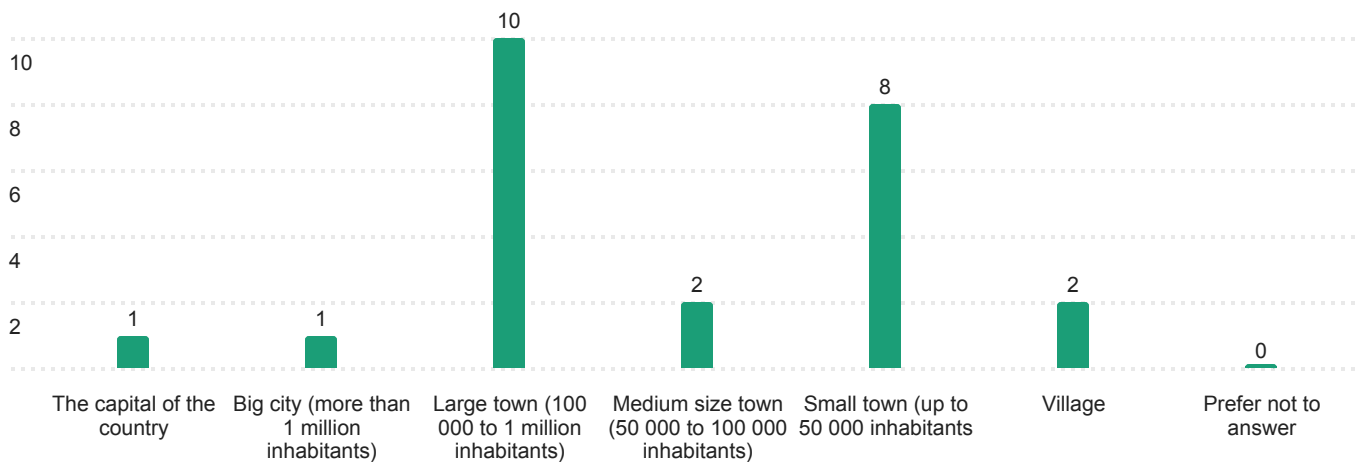
## Q5 - Your current age is

24 Responses

Field	Min	Max	Mean	Standard Deviation	Variance	Responses	Sum
Your current age is	16.00	62.00	42.13	10.83	117.19	24	1011.00

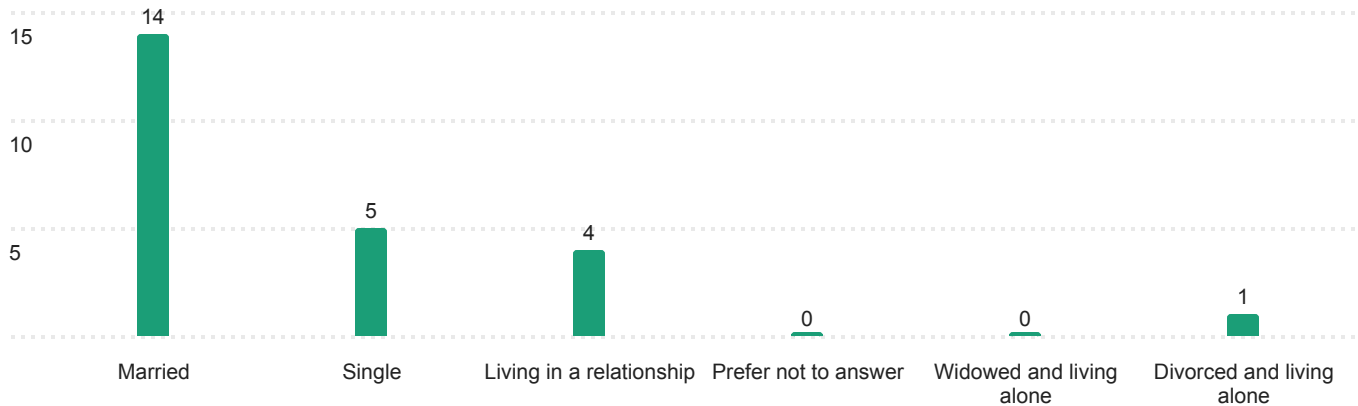
## Q7 - You live in

24 Responses



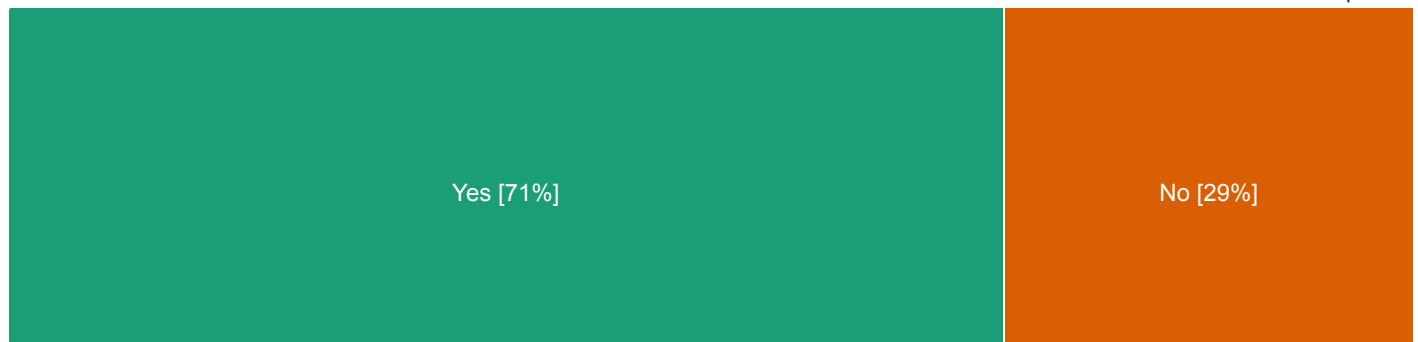
## Q8 - What is your current family status?

24 Responses



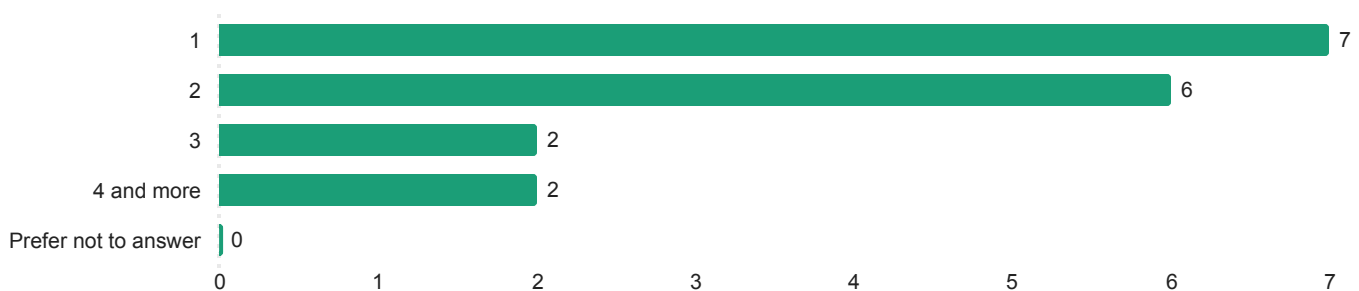
## Q9 - Do you have any children?

24 Responses



## Q10 - How many children do you have?

17 Responses



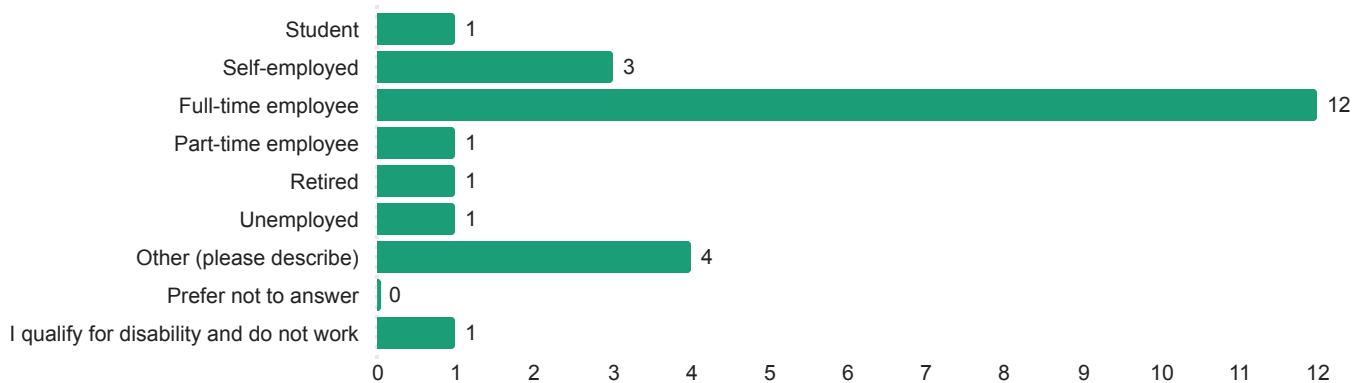
## Q10 - How many children do you have?

17 Responses

Field	Min	Max	Mean	Standard Deviation	Variance	Responses	Sum
How many children do you have?	1.00	4.00	1.94	1.00	1.00	17	33.00

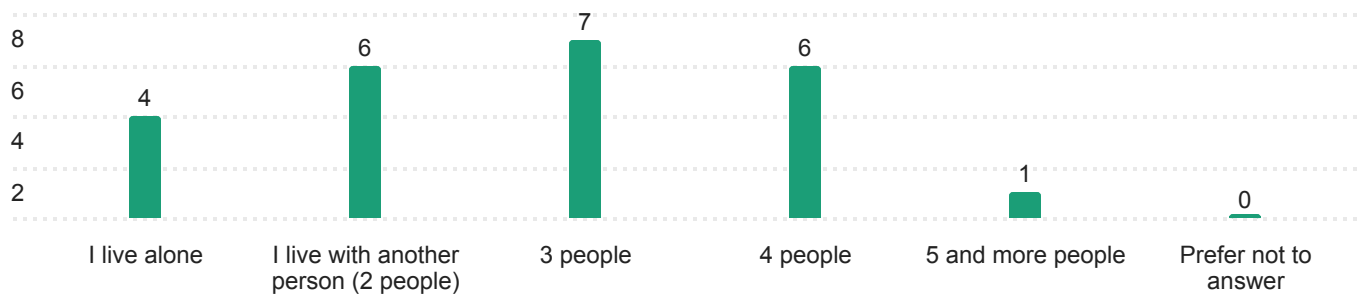
## Q11 - What is your current occupation status?

24 Responses



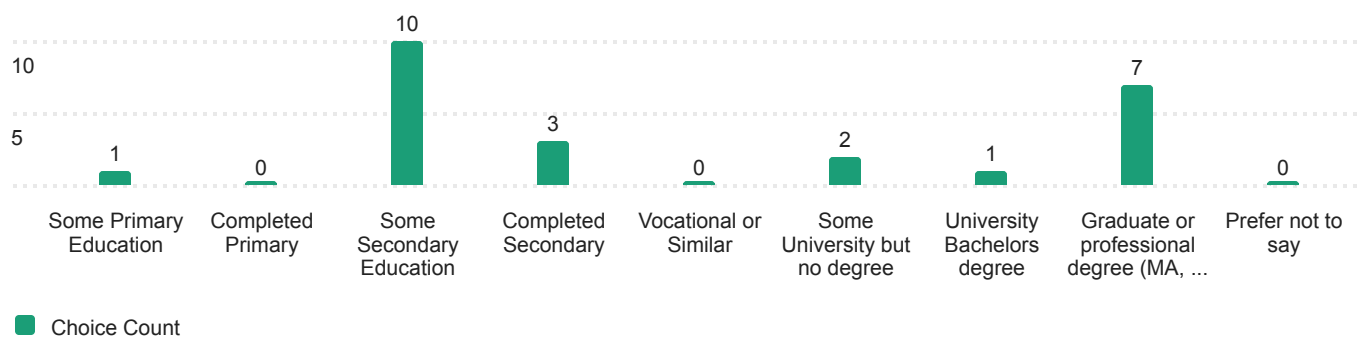
## Q12 - How many people live in your household?

24 Responses



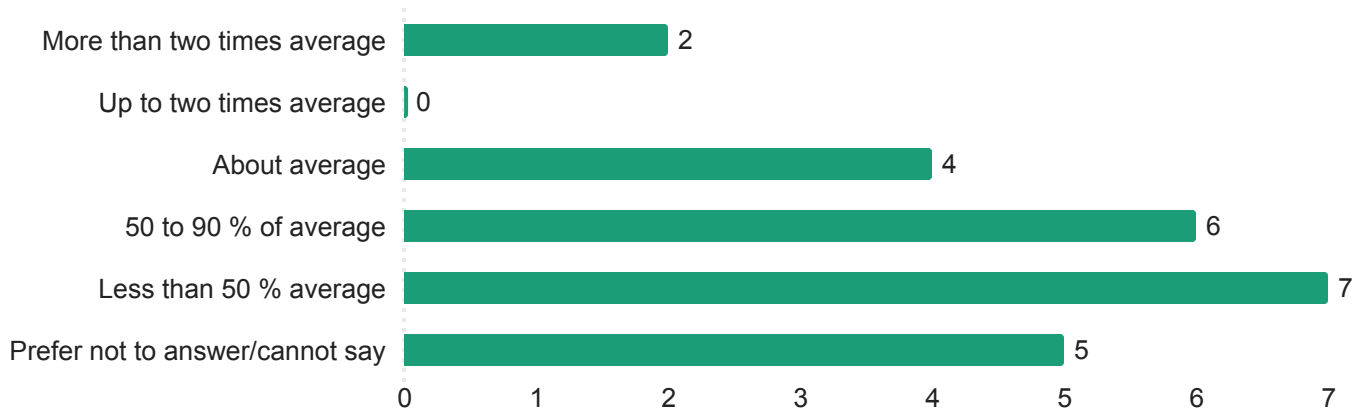
## Q13 - What is the highest level of education you have completed?

24 Responses



## Q14 - What is your annual income compared to the average annual income for the country you live in?

24 Responses



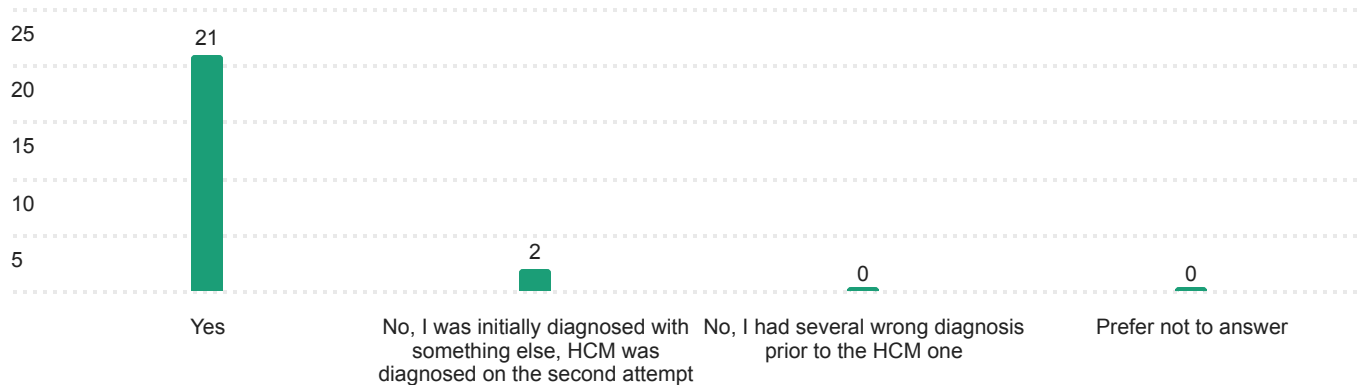
## Q15 - At what age were you definitely diagnosed with HCM?

16 Responses

Field	Min	Max	Mean	Standard Deviation	Variance	Responses	Sum
At what age were you definitely diagnosed with HCM?	2.00	38.00	16.63	10.78	116.23	16	266.00

## Q17 - Were you correctly diagnosed with HCM from the start?

23 Responses



## Q18 - Did you display any symptoms prior to your HCM diagnosis?

24 Responses



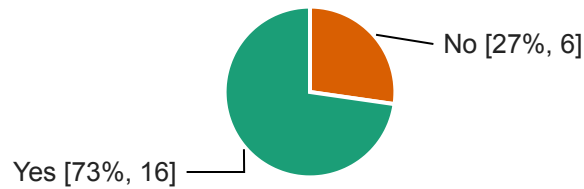
## Q19 - Which symptoms did you display at diagnosis and how impactful were they on your well-being and daily life? (select all that applicable)

8 Responses

Field	Mean	Responses
Shortness of breath / feeling winded	3.71	7
Chest pain	3.71	7
Heart Palpitations	2.43	7
Fatigue/Feeling generally tired	4.14	7
Dizziness or lightheadedness	3.86	7
Fainting spells	3.00	6
Other (please specify)	5.67	3

## Q20 - Do you currently have symptoms?

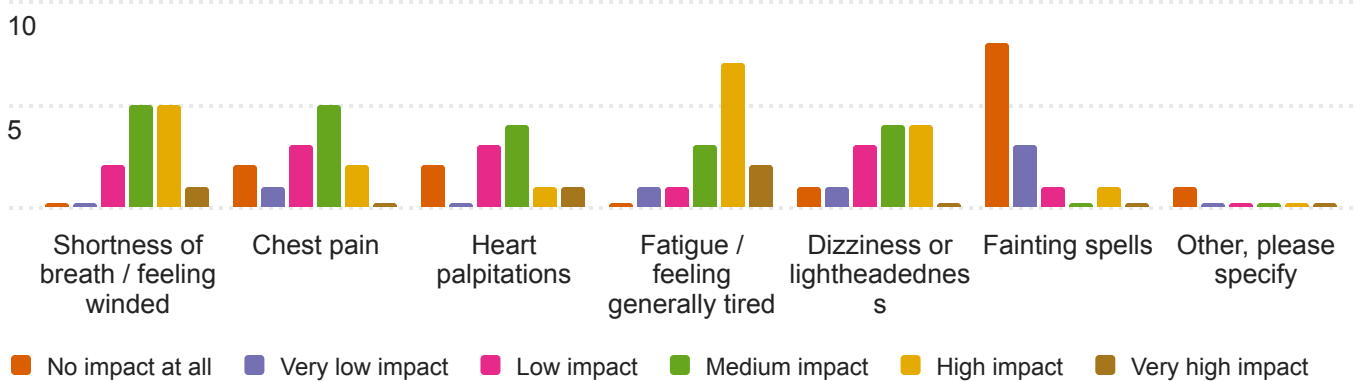
23 Responses



■ No ■ Yes

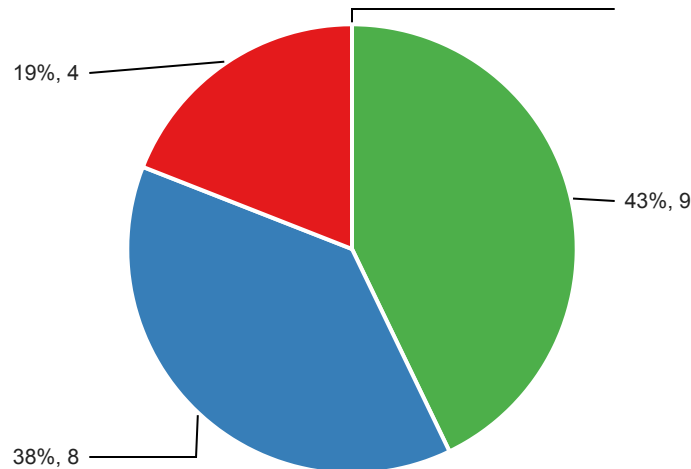
## Q21 - Which symptoms do you currently have and how impactful are they on your wel...

14 Responses



## Q22 - How do you feel currently (over the last 6 months) compared to when you were initially diagnosed with HCM?

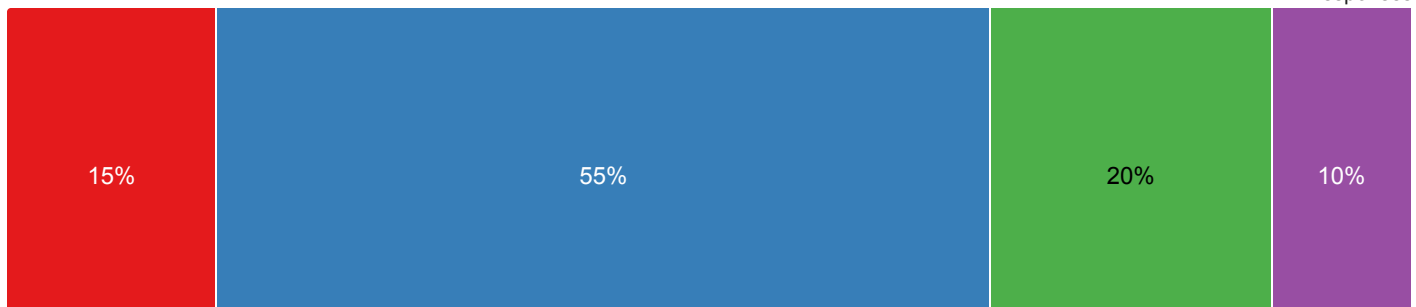
21 Responses



- I cannot/prefer not to answer
- I feel worse than when I was first diagnosed
- I feel about the same as when I was first diagnosed
- I feel better than when I was first diagnosed

## Q23 - How physically active have you been overall before the HCM diagnosis?

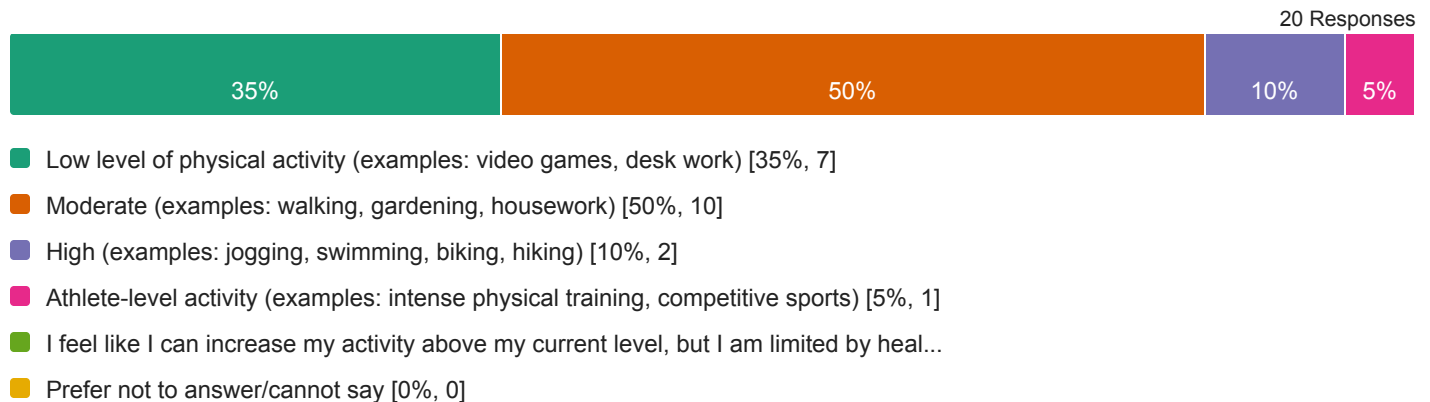
21 Responses



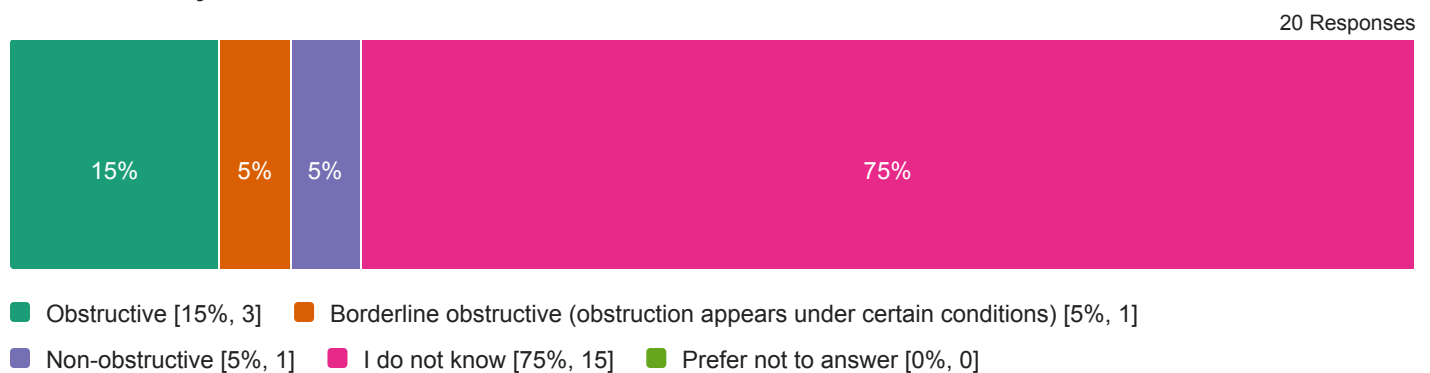
- Low level of physical activity (examples: video games, desk work) [15%, 3]
- Moderate (examples: walking, gardening, housework) [55%, 11]
- High (examples: jogging, swimming, biking, hiking) [20%, 4]
- Athlete-level activity (examples: intense physical training, competitive sports) [10%, 2]
- I felt like I could increase my activity above the level at the time, but I was limited...



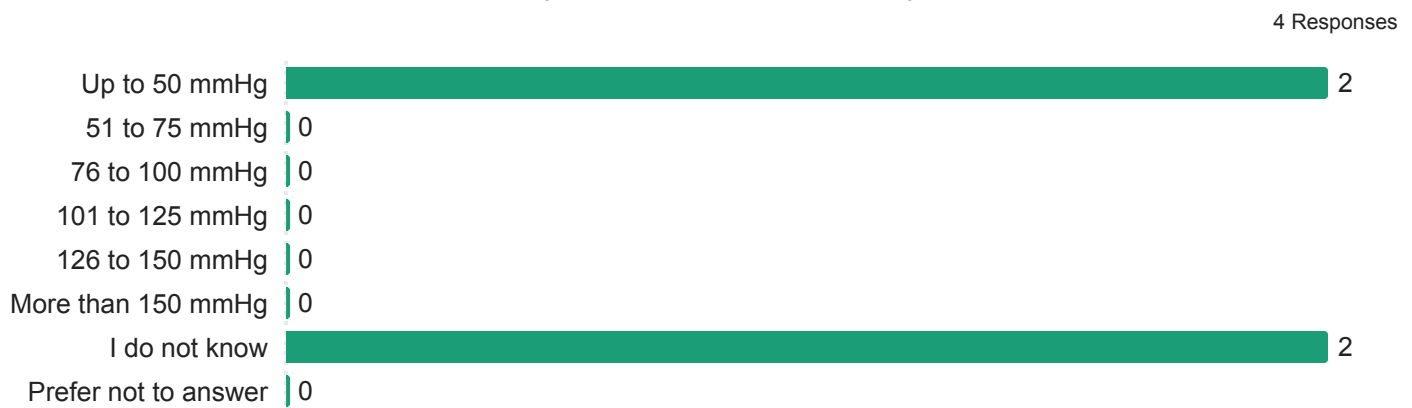
## Q24 - How physically active have you been overall lately (over the last 6 months or since your HCM diagnosis, if it was sooner than 6 months)?



## Q25 - Do you have obstructive or non-obstructive HCM?



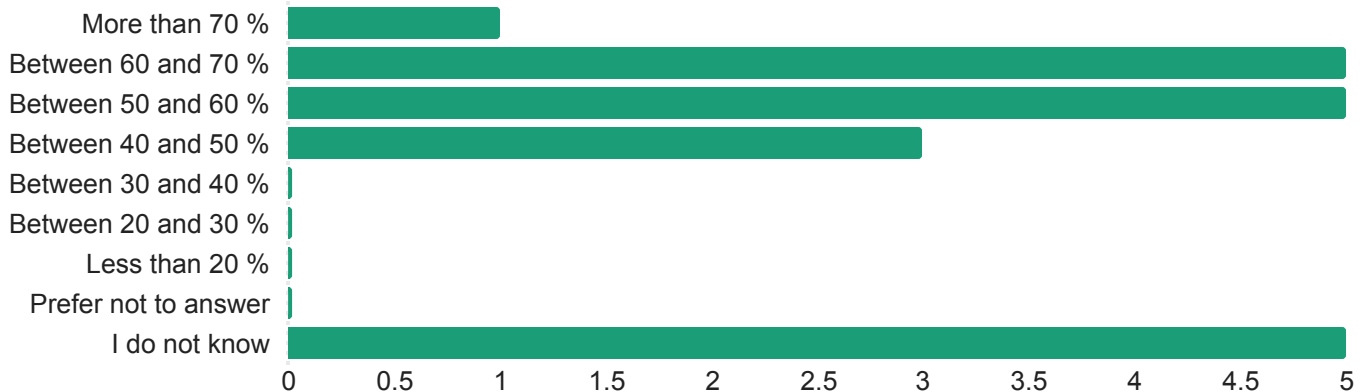
## Q26 - What was the value of your obstruction at your last examination?



## Q27 - What was the value of your Ejection Fraction (EF) at your last examination?

/Ejection fraction is a measurement, expressed as a percentage, of how much blood the left ventricle pumps out with each contraction/

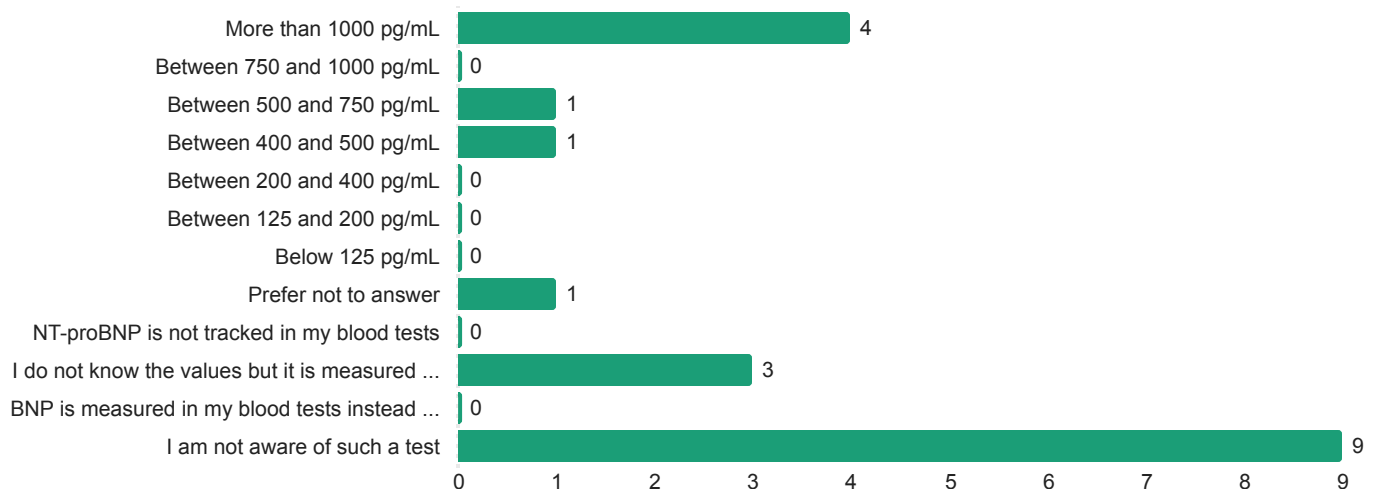
19 Responses



## Q28 - What was the value of your NT-proBNP at your last examination?

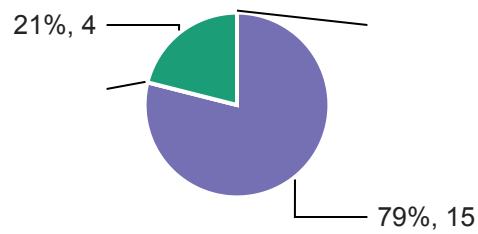
/NT-proBNP measures the levels of N-terminal pro-brain natriuretic peptide (NT-proBNP) as a measure of stress on the heart/

19 Responses



## Q29 - Have you performed a study to identify the gene causing HCM in your case?

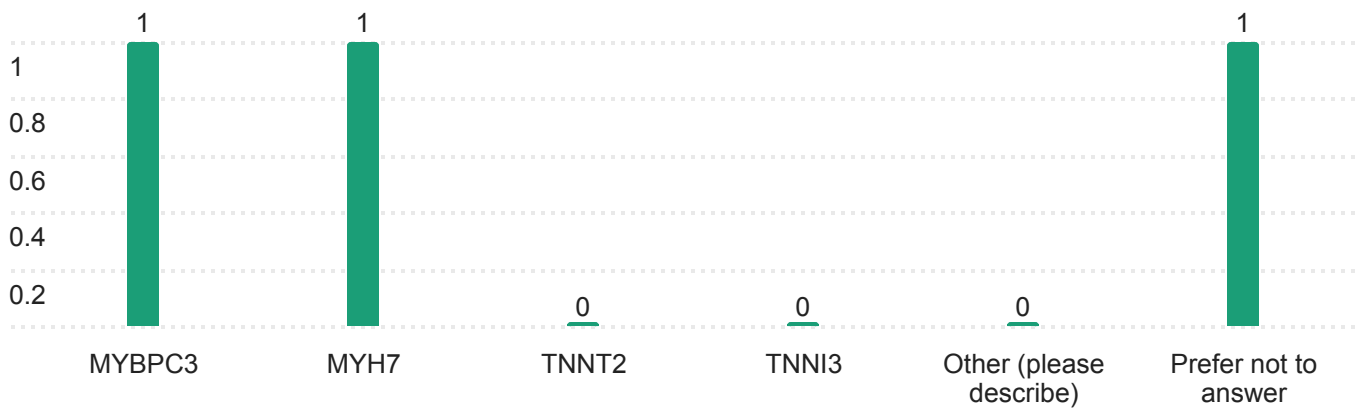
19 Responses



■ Prefer not to answer 
 ■ No 
 ■ Yes, with inconclusive results 
 ■ Yes, with conclusive results

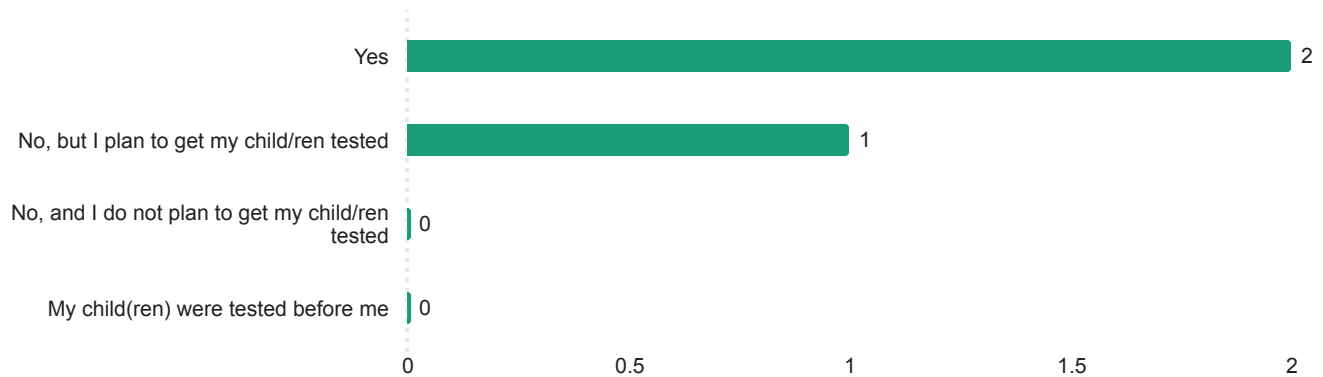
## Q30 - Which gene was identified as responsible for causing HCM in your case?

3 Responses



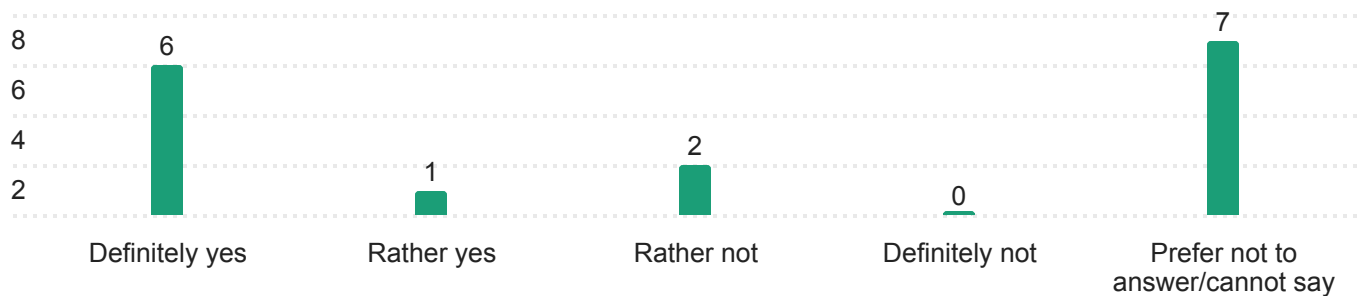
### Q31 - After getting a conclusive result, did you also perform genetic tests on your child or children?

3 Responses



### Q32 - Do you see any added value in genetic testing for HCM?

16 Responses



### Q33 - Which of these statements about genetic testing do you agree with?

17 Responses

Field	Prefer not to answer/cannot say	Definitely disagree	Rather disagree	Neither agree nor disagree	Rather agree	Definitely agree
It is important for me to know the cause of the disease	3	3	1	1	2	7
It is important for my family/children	2	2	2	0	1	8
Patients with the positive result of genetic testing have worse prognoses	6	2	2	1	0	5
It can help me to have gene therapy treatment for potential cure of my condition	6	1	3	2	2	2

## HCM PATIENT FOUNDATION

It can help me choose the better medication or surgical treatment for my condition

4

2

0

2

4

3

### Q33 - Which of these statements about genetic testing do you agree with?

17 Responses

Field	Min	Max	Mean	Responses
It is important for me to know the cause of the disease	0.00	5.00	3.00	17
It is important for my family/children	0.00	5.00	3.33	15
Patients with the positive result of genetic testing have worse prognoses	0.00	5.00	2.13	16
It can help me to have gene therapy treatment for potential cure of my condition	0.00	5.00	1.94	16
It can help me choose the better medication or surgical treatment for my condition	0.00	5.00	2.60	15

## Q35 - What is the first word that comes to your mind when the words "gene therapy" are mentioned? /please write a single word in the text field/

11 Responses

What is the first word that comes to your mind when the words "gene therapy" are mentioned?

/please write a single word in the text field/

Nie wiem, nie myślałam o tym

Eksperymenty

Zdrowienie

Nie wiem, nie słyszałam o tym

Trudne

Lekarze nic o tym nie wiedzą

Ratunek

Nadzieja

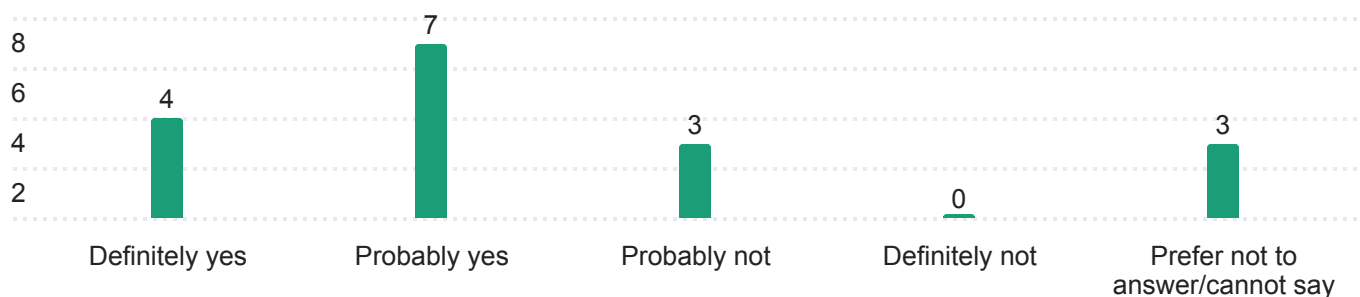
Rodzina

lepsz diagnoza

Zdrowie

## Q36 - Would you consider gene therapy for yourself?

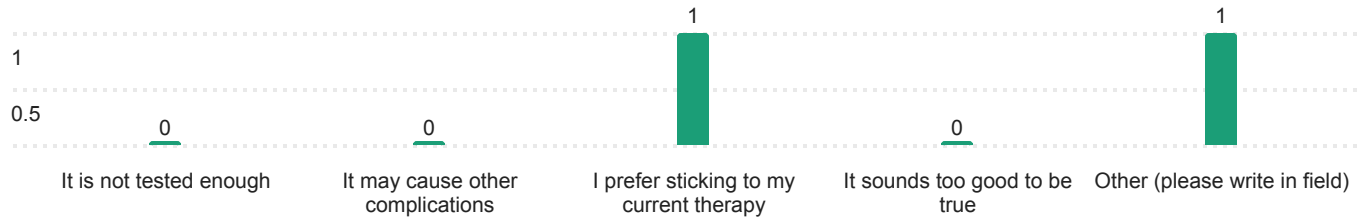
17 Responses



## Q37 - What are the factors that would eventually stop you from trying gene therapy?

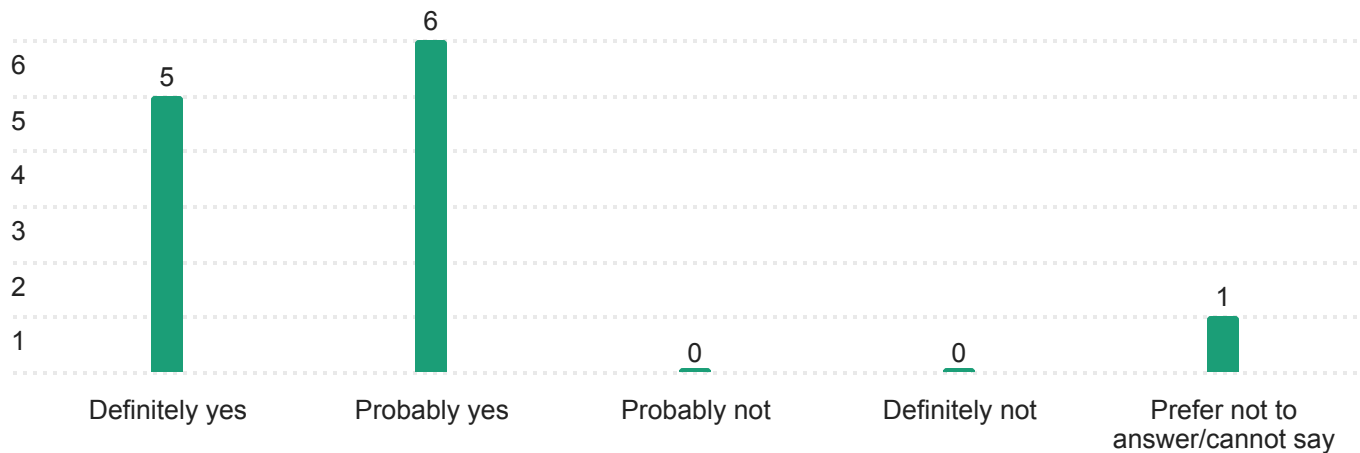
/please mark as many as applicable/

2 Responses



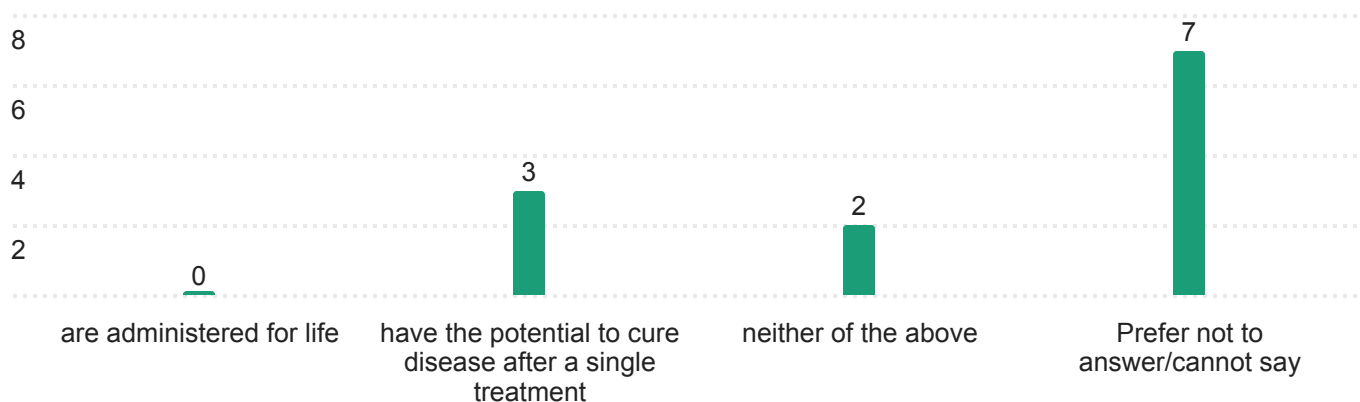
Q38 - If there were a gene therapy clinical research trial for your disease-causing genetic change, would you consider joining?

12 Responses



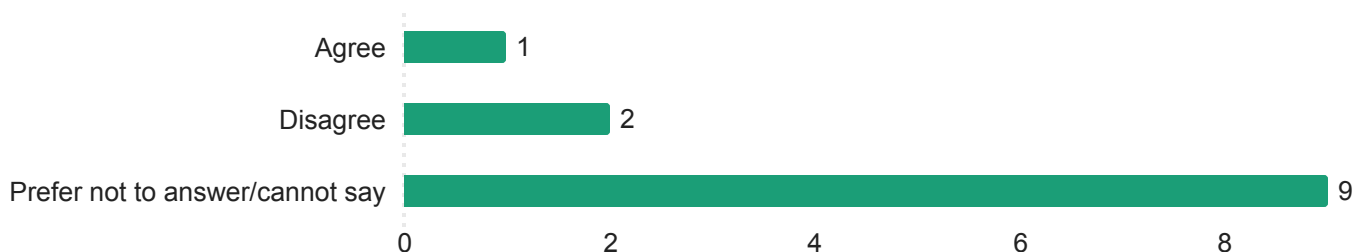
Q39 - In my understanding, gene therapy treatments

12 Responses



Q40 - If someone gets successful gene therapy, their children could potentially avoid being born with the same disease-causing genetic change

12 Responses





## Q41 - Which one of these gene therapy related topics would you be interested in?

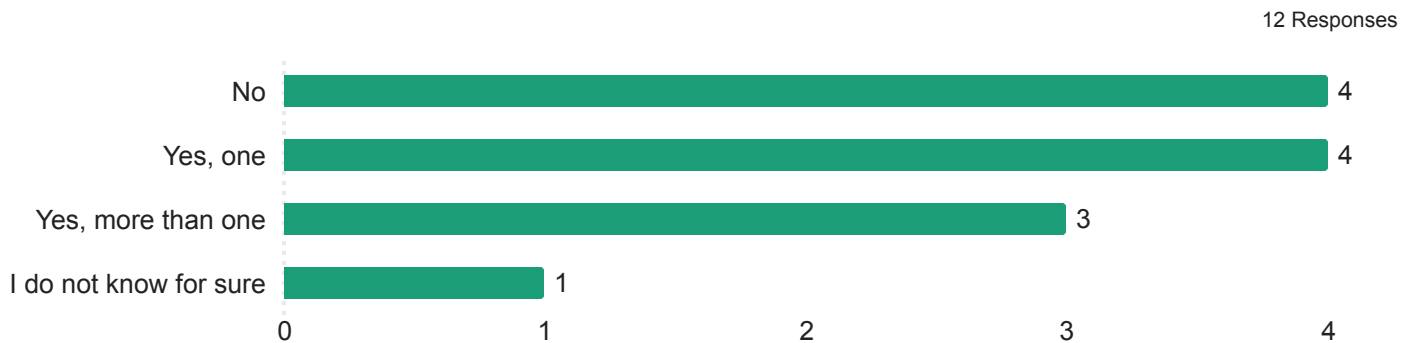
Field	Min	Max	Mean	12 Responses
				Responses
How is the genetic treatment developed?	3.00	5.00	4.17	12
How is the genetic treatment tested?	3.00	5.00	4.18	11
How is the genetic therapy done?	3.00	5.00	4.27	11
Is the genetic therapy safe?	3.00	5.00	4.30	10
Can I receive genetic therapy again in the future?	2.00	5.00	4.00	10
What are the associated costs with genetic therapy?	3.00	5.00	4.40	10
Where can genetic therapy be performed?	3.00	5.00	4.36	11
How does genetic therapy compare to other treatments?	3.00	5.00	4.40	10
What are the possible side effects of genetic therapy?	3.00	5.00	4.40	10
Other (please write in field)	3.00	5.00	3.67	6

Q42 - Please rank in order of preference the channels via which you would prefer to learn more about genetic therapy.

12 Responses

Field	Mean	Responses
Personal cardiologist	1.75	12
Genetic advisor	2.58	12
Webinar / podcast	5.58	12
Website	4.08	12
Video	4.08	12
Brochure	4.67	12
Support groups (in person or on social media)	5.25	12
Other (please write in field)	8.00	12

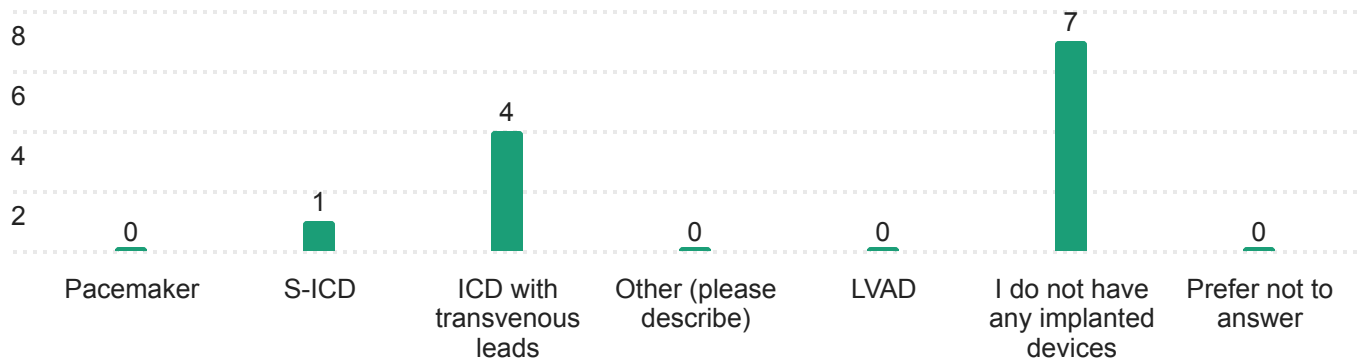
Q43 - Do you know of any HCM-related deaths in your family?



## Q44 - Do you have any devices implanted in your body to support your heart function?

(select as many as applicable)

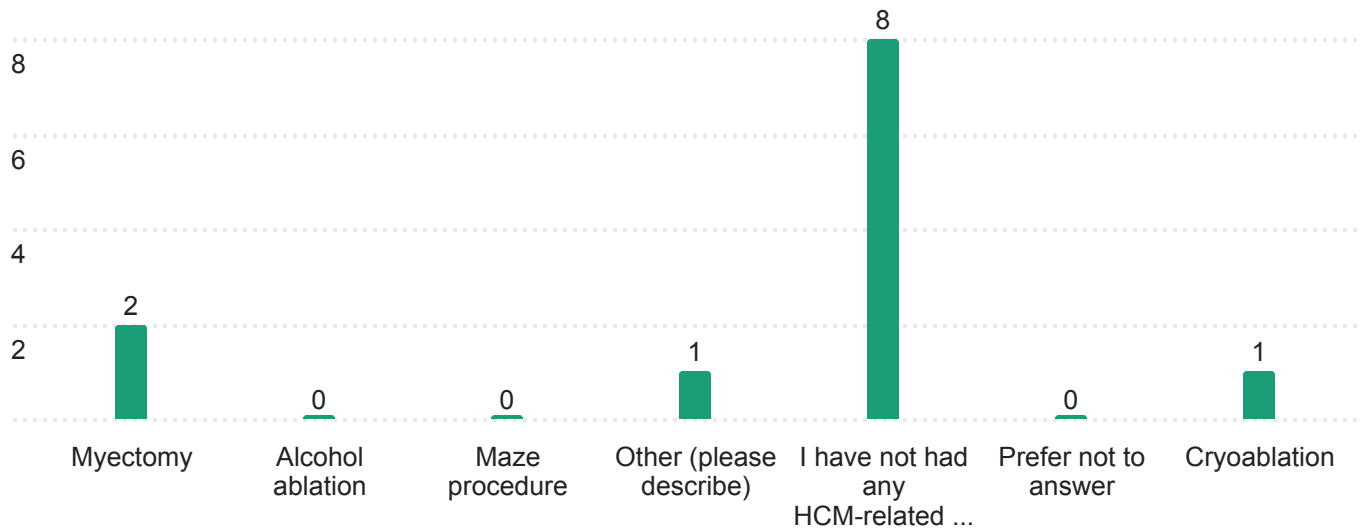
12 Responses



## Q45 - Have you ever had any surgical intervention related to HCM?

(select as many as applicable)

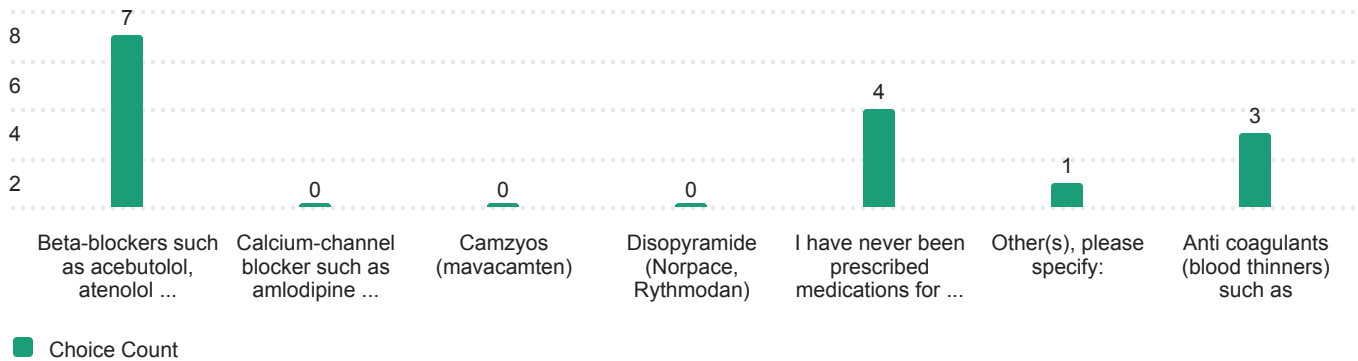
12 Responses



## Q46 - Have you ever been prescribed any of these medications?

/select as many as applicable/

12 Responses



## Q47 - Have you ever had side effects from any of these medications?

/leave empty if you have had no side effects/

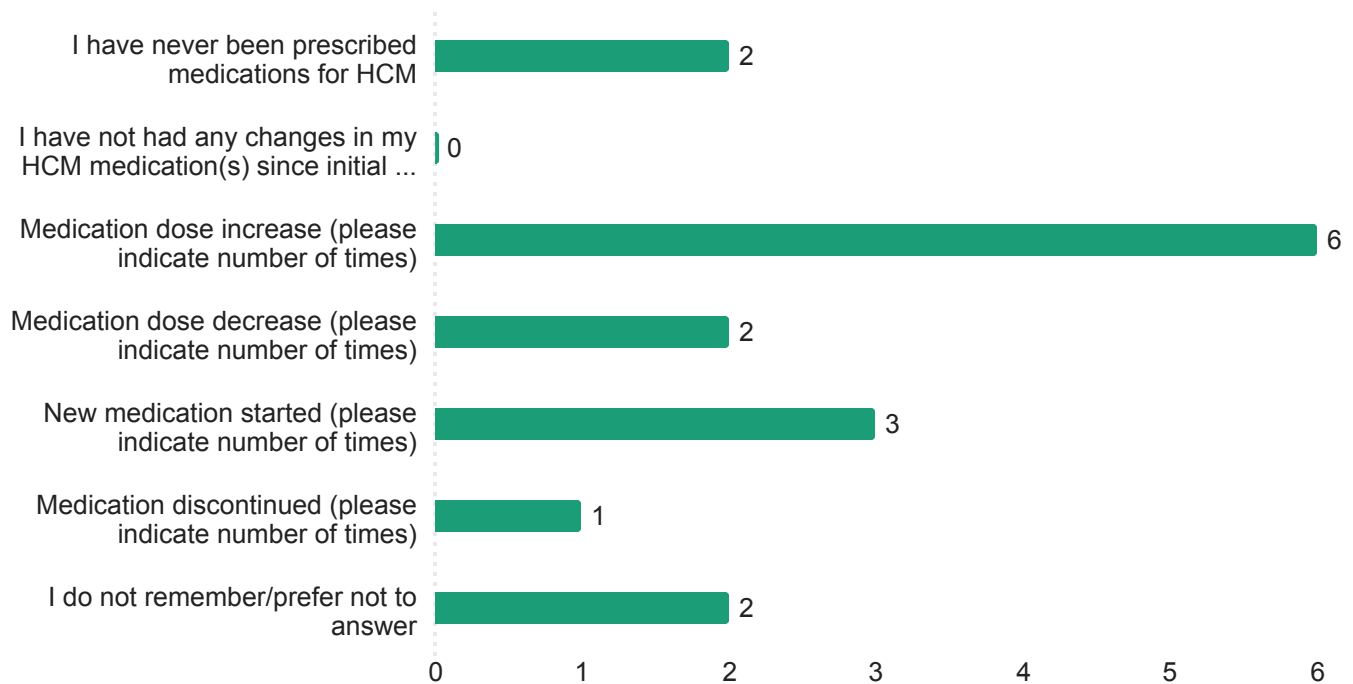
6 Responses

Field	Moderate side effects	Medium side effects	Serious side effects (had to discontinue)
Beta-blockers such as acebutolol, atenolol (Tenormin), bisoprolol (Zebeta), metoprolol (Lopressor, Toprol XL), nadolol (Corgard), nebivolol (Bystolic), propranolol (Inderal, InnoPran XL)	4	1	0
Calcium-channel blocker such as amlodipine (Norvasc), diltiazem (Cardizem, Tiazac), felodipine, isradipine, nicardipine, nifedipine (Procardia), nisoldipine (Sular), verapamil (Calan SR, Verelan)	2	0	0
Camzyos (mavacamten)	1	0	0
Disopyramide (Norpace, Rythmodan)	1	0	0
Anti coagulants (blood thinners) such as warfarin, Eliquis, heparin, etc.	1	0	0
Other, please specify:	1	0	0
Other, please specify	0	0	0

Q48 -Since you started taking medication for HCM, have you ever experienced dose adjustments (increased or decreased dose) of an existing prescription, discontinuation of a medication, or starting of a new medication (besides your initial regimen)?

Please specify the number of times each has occurred in the text box, if you remember it (if not leave the box empty)

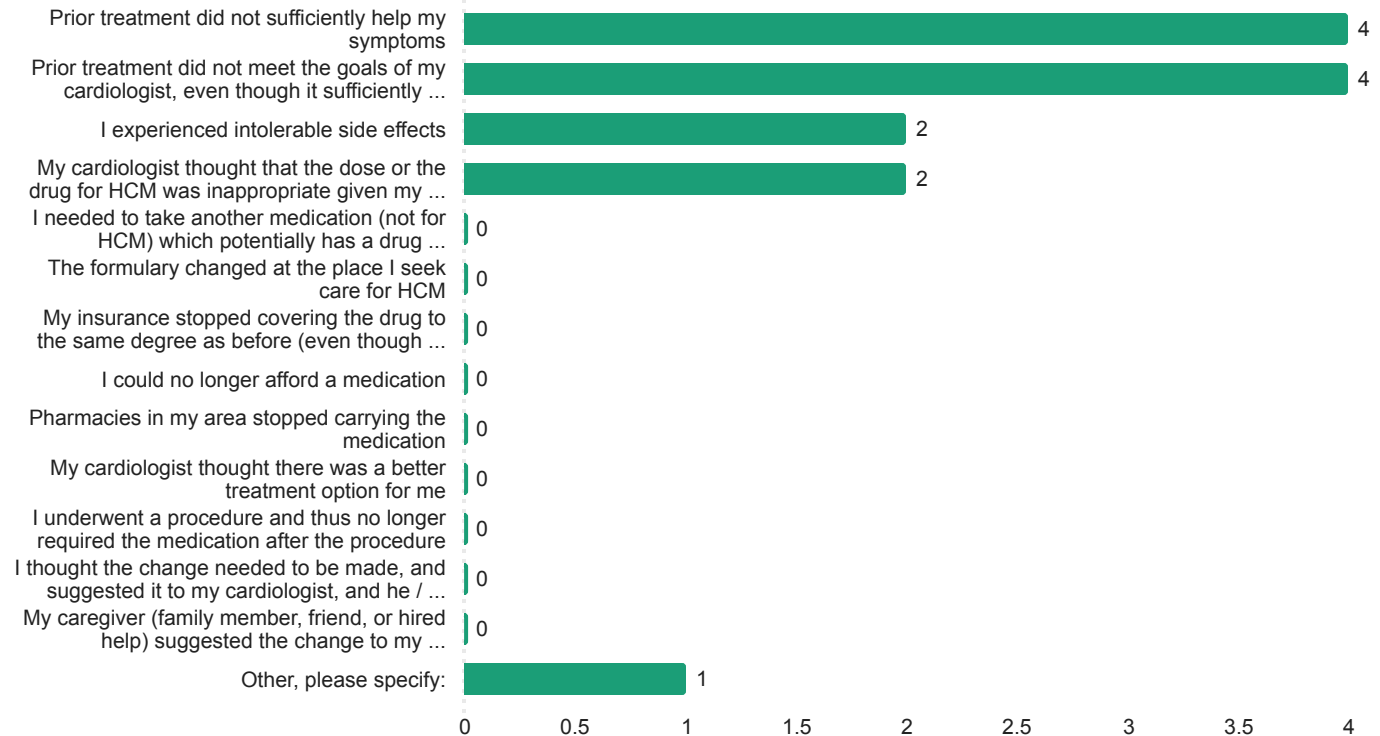
11 Responses



## Q49 - What were reasons for medication dose adjustment(s), discontinuation(s), or addition(s)?

Select all that apply

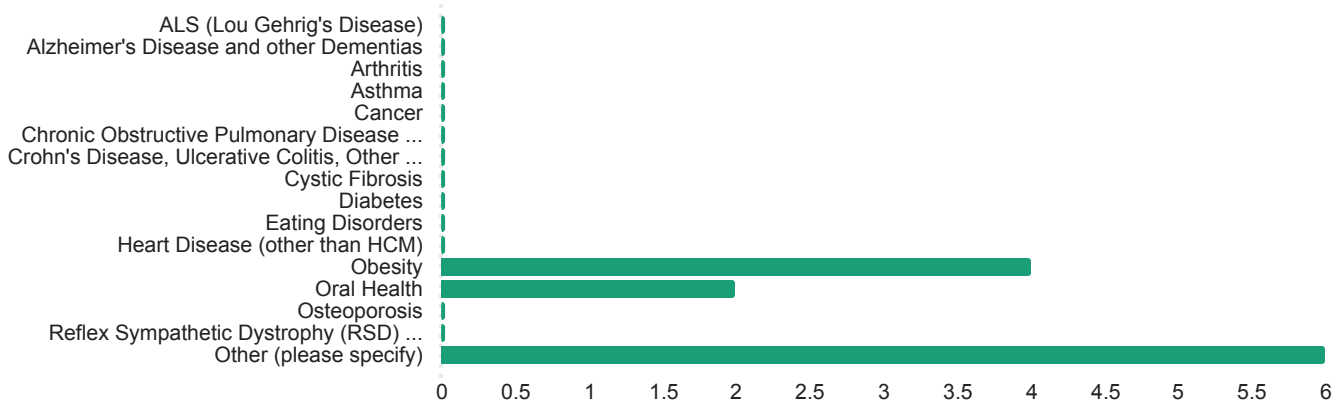
9 Responses



## Q50 - Do you suffer from other chronic illnesses apart from HCM?

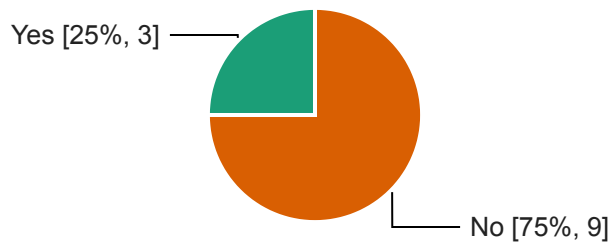
/please mark all that apply/

7 Responses



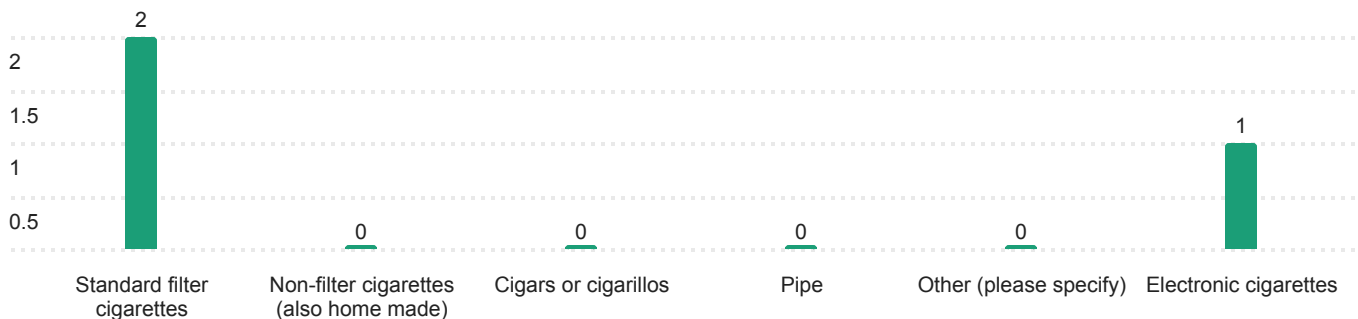
## Q51 - Do you smoke tobacco?

12 Responses



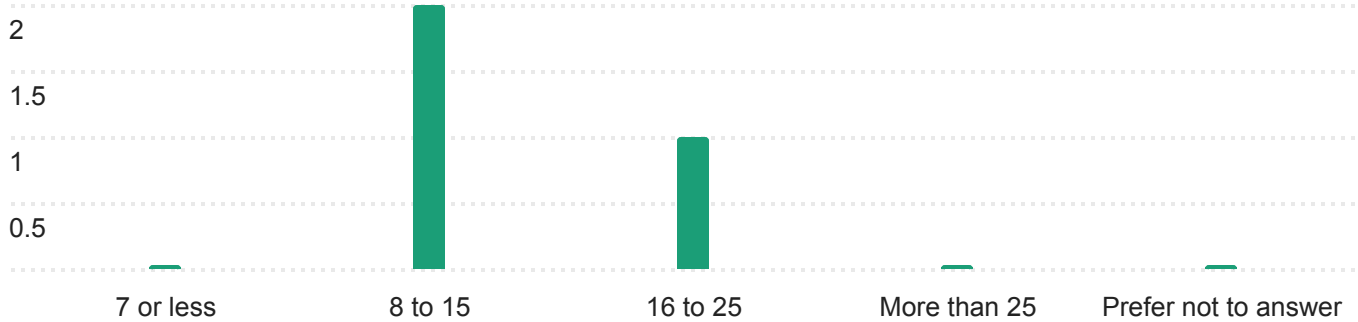
## Q52 - What kind of smoking do you practice?

3 Responses



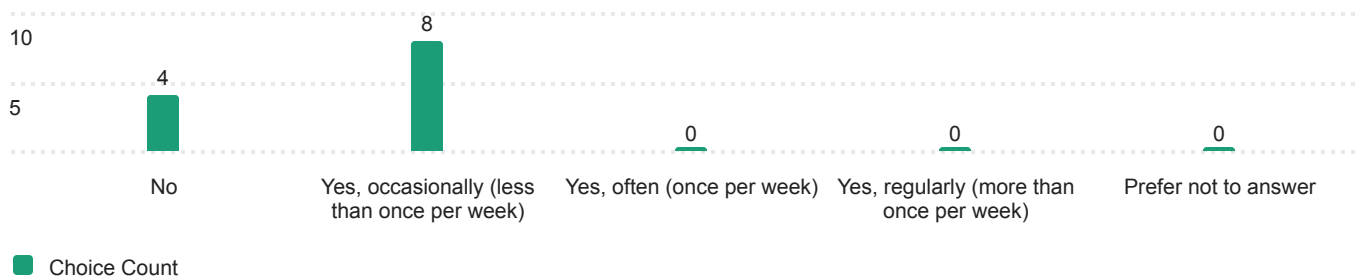
### Q53 - How many cigarettes per day do you smoke?

3 Responses



### Q54 - Do you drink alcohol?

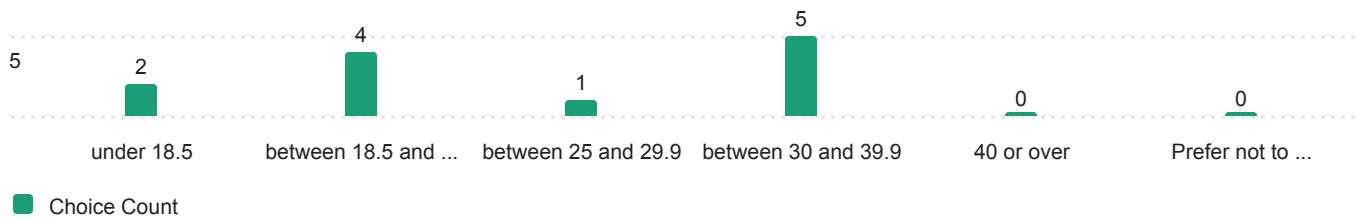
12 Responses



### Q55 - What is your body body mass index (BMI)?

Body mass index (BMI) is a measure of body fat based on height and weight that applies to adult men and women.

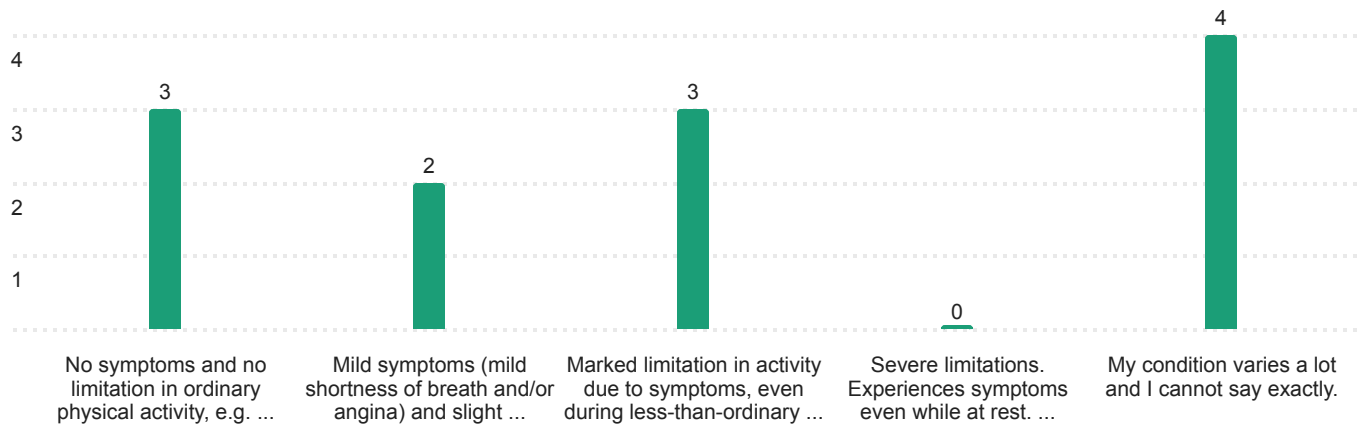
12 Responses





## Q56 - How would you describe your current physical condition?

12 Responses



## Q57 - What has been the impact of your heart condition on the following aspects o...

12 Responses

Field	Min	Max	Mean	Standard Deviation	Variance	Responses	Sum
Financial situation	1.00	5.00	2.75	1.79	3.19	12	33.00
Relationship with partner	1.00	6.00	1.73	1.48	2.20	11	19.00
Relationship with other family members and friends	1.00	5.00	2.25	1.48	2.19	12	27.00
Work	1.00	5.00	2.33	1.70	2.89	12	28.00
Mental state and well-being	1.00	5.00	3.27	1.29	1.65	11	36.00
Sex life	1.00	6.00	2.50	1.66	2.75	12	30.00

## Q58 - Would you agree with the following statements?

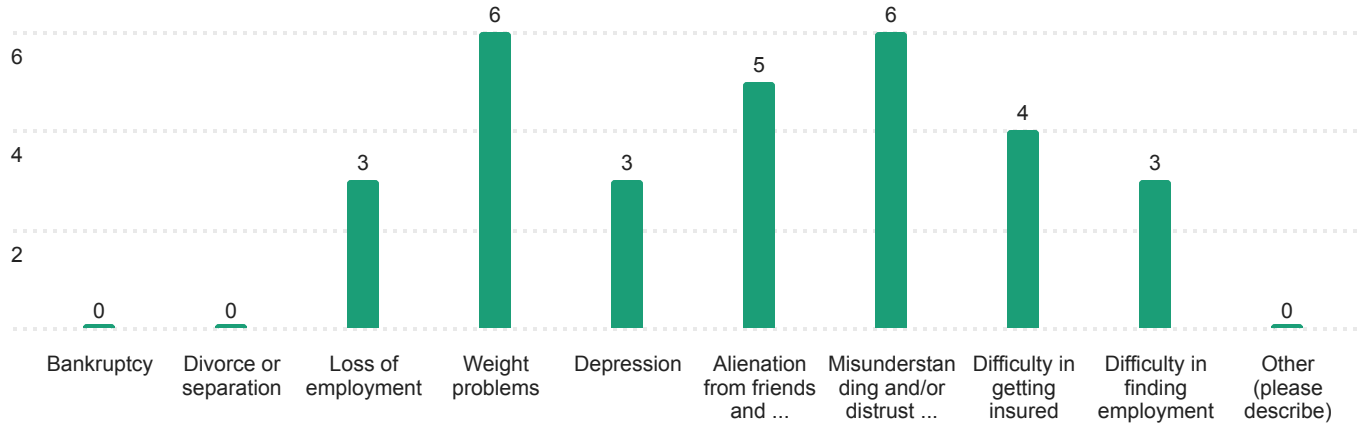
12 Responses

Field	Min	Max	Mean	Standard Deviation	Variance	Responses	Sum
I understand well my heart condition	3.00	5.00	4.00	0.71	0.50	12	48.00
I trust my doctors to take all decisions related to my heart condition	2.00	5.00	3.64	0.77	0.60	11	40.00
One can live a fairly normal life with HCM	1.00	5.00	3.42	1.11	1.24	12	41.00
I am afraid of passing the HCM gene to my child/ren	1.00	5.00	3.91	1.00	0.99	11	43.00
I am willing to take measured risks in life	3.00	5.00	3.67	0.62	0.39	12	44.00
I am willing to endure constant physical discomfort to minimize risk from death	1.00	6.00	3.75	1.59	2.52	12	45.00
I am afraid of my heart condition more than anything else in my life	1.00	6.00	3.33	1.60	2.56	12	40.00

## Q59 - Which of these events have you experienced because of your heart condition?

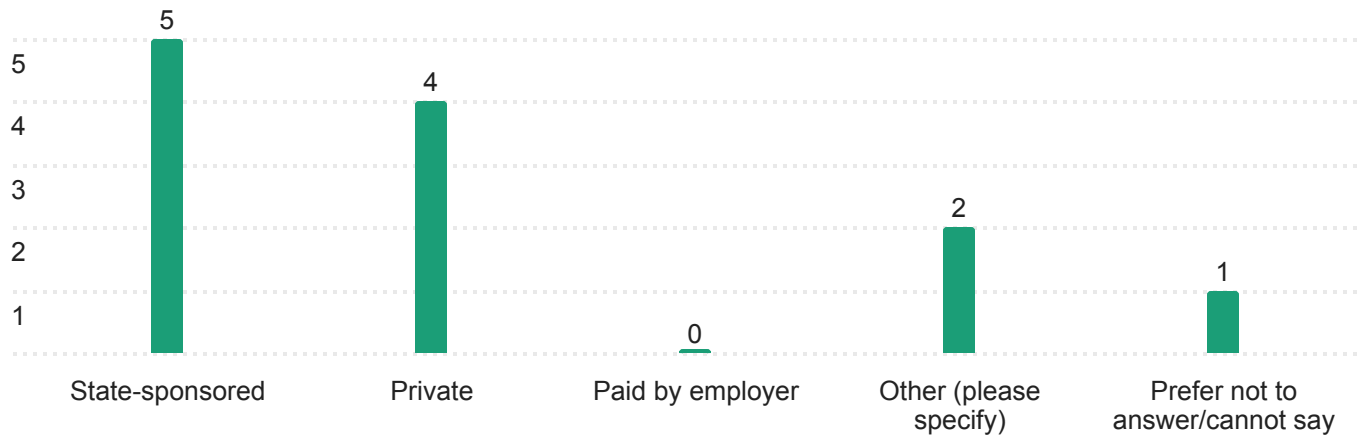
(select as many as applicable)

9 Responses



## Q60 - What type of medical insurance do you have?

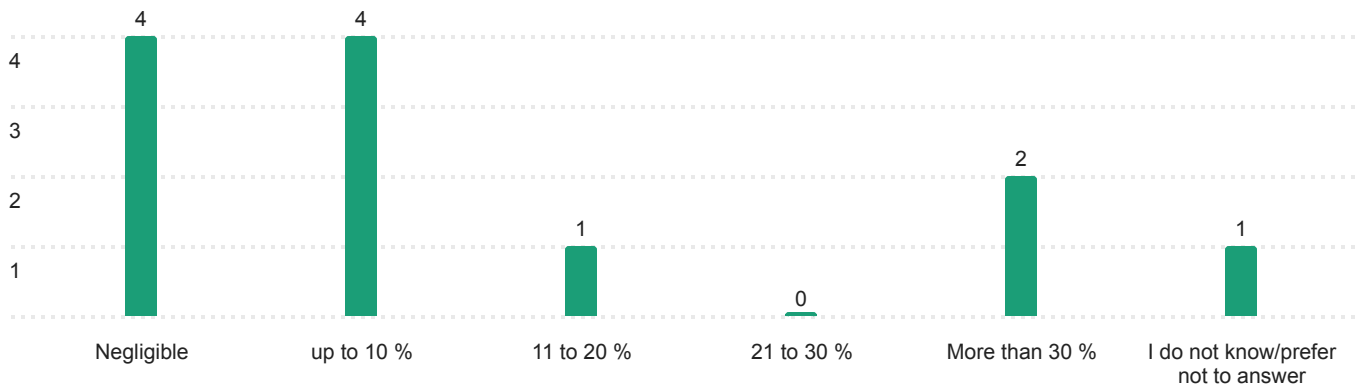
12 Responses



Choice Count

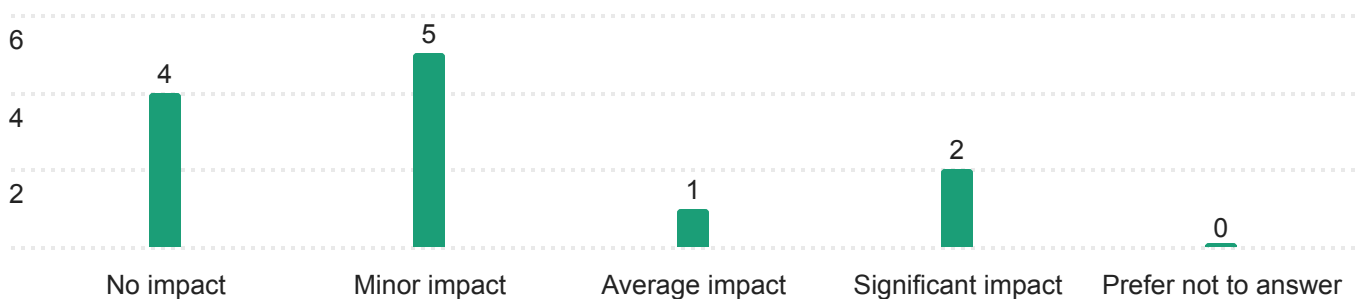
## Q61 - What percentage of your income is spent on HCM medications and treatments?

12 Responses



## Q62 - Would you say that HCM has had an impact on your career?

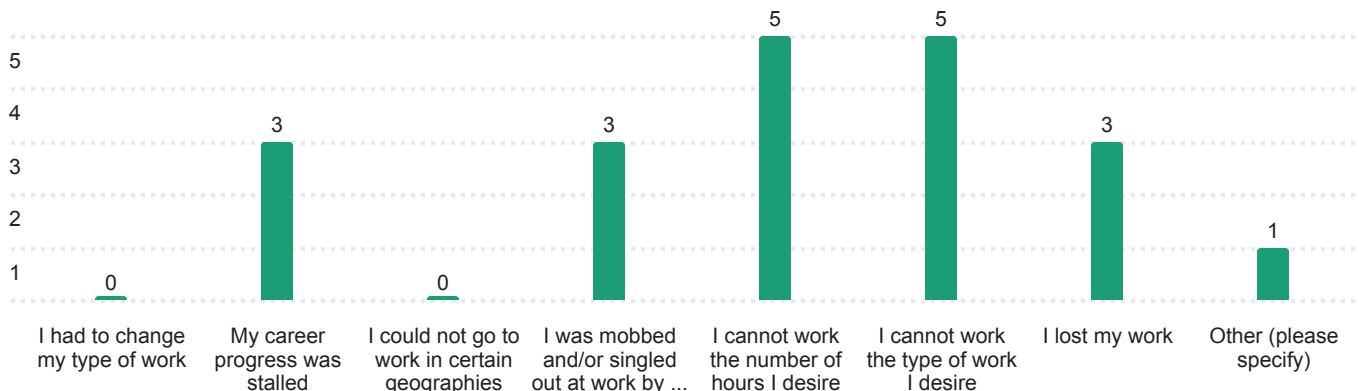
12 Responses



## Q63 - Please specify in what ways HCM has impacted your career?

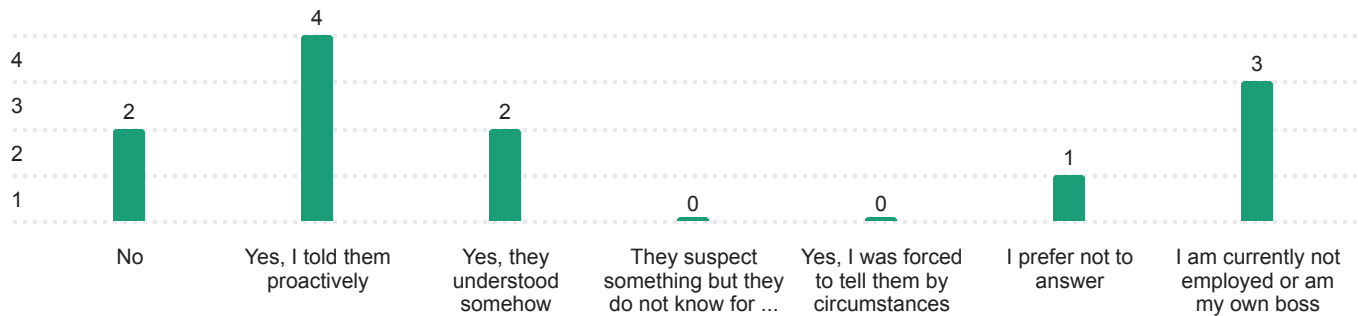
/select as many as applicable/

8 Responses



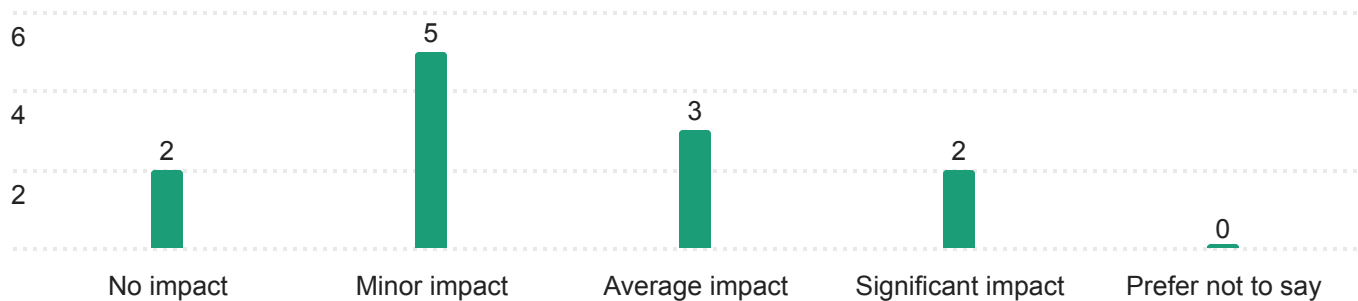
## Q64 - Are your current employers aware that you have HCM?

12 Responses



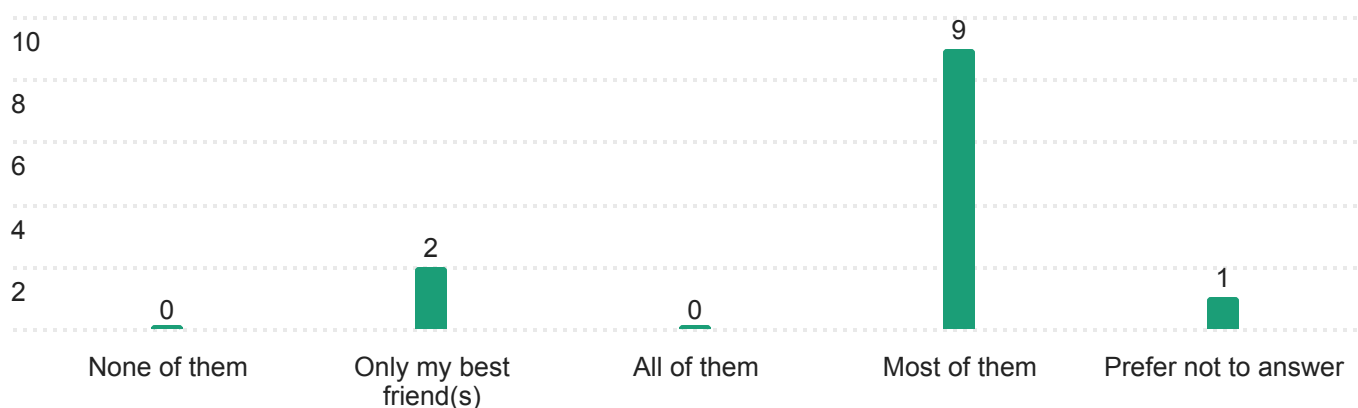
## Q65 - Would you say that HCM has had an impact on your relationship with family and friends?

12 Responses



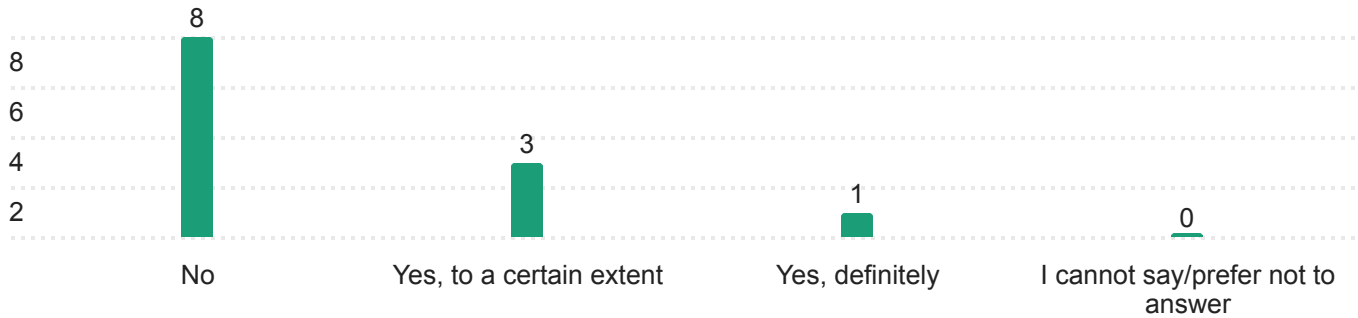
## Q66 - Are your friends aware that you have HCM?

12 Responses



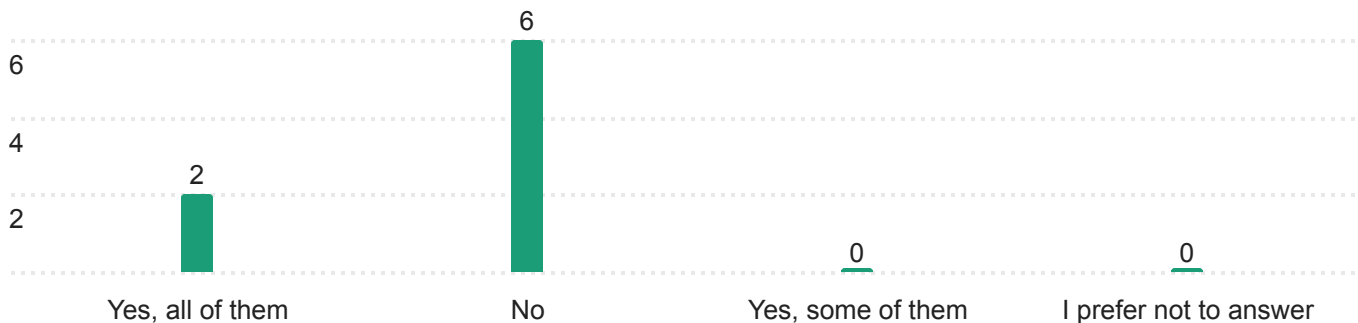
## Q67 - Has HCM impacted your decision to have children?

12 Responses



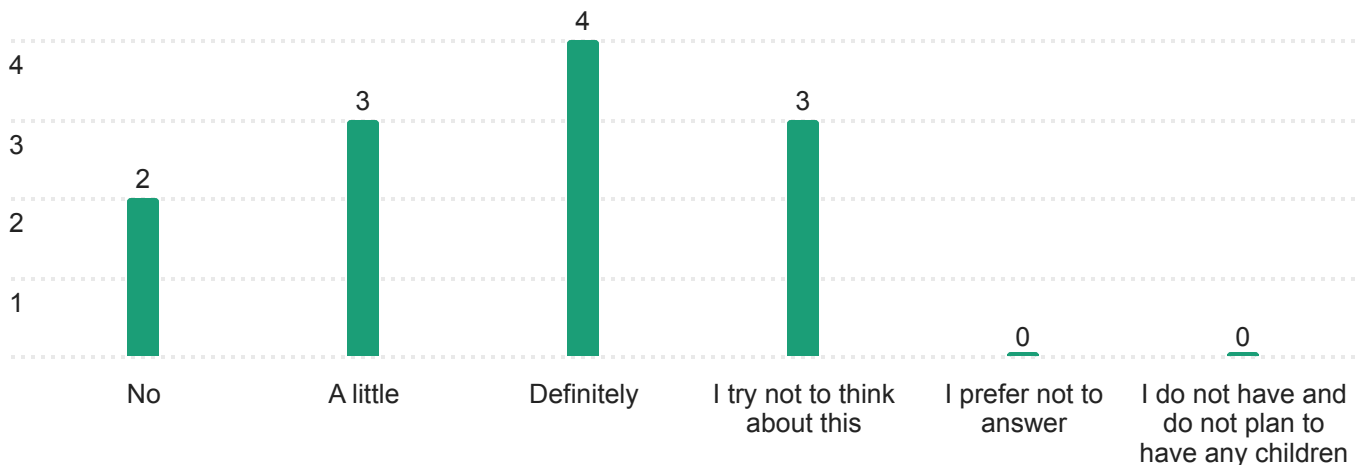
## Q68 - Do you know if your child/ren has/have inherited HCM from you?

8 Responses



## Q69 - Do you feel guilt that you have transmitted or might transmit HCM to your children?

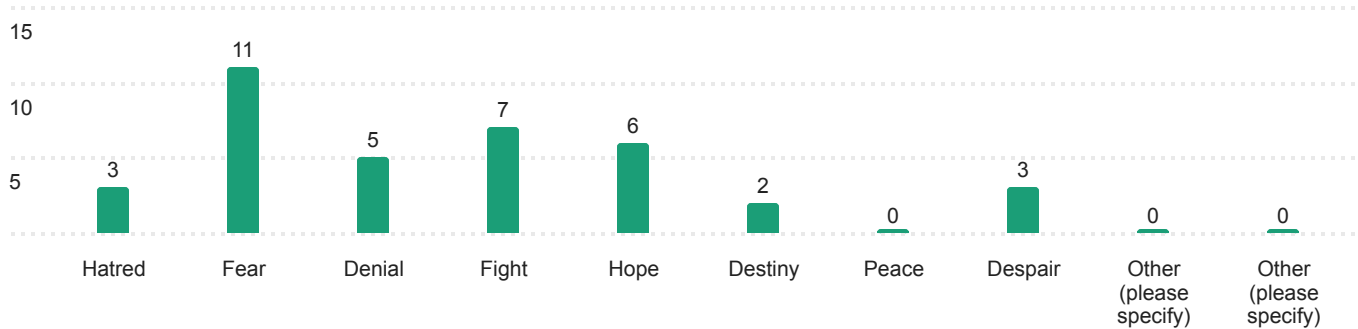
12 Responses



## Q70 - Which of these words describe how you feel towards HCM?

/mark the top three words that best describe your feelings/

11 Responses



No data found - your filters may be too exclusive!

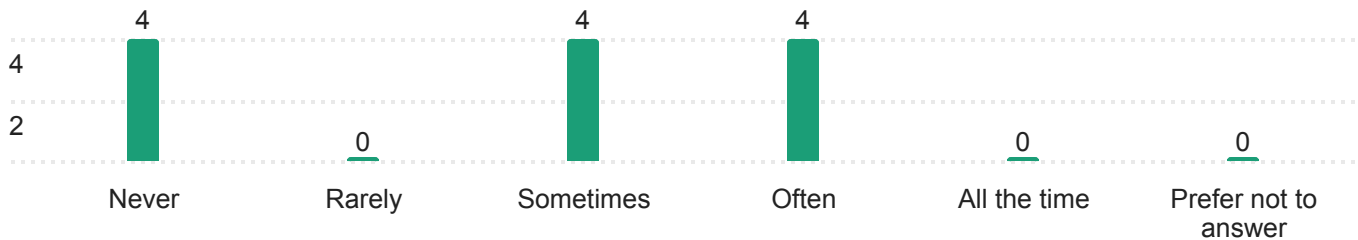
## Q71 - Would you say that you forget or try to forget about having HCM?

12 Responses



## Q72 - Do you sometimes feel alone in your HCM fight?

12 Responses



Choice Count

## Q73 - Do you have somebody to help you dealing with HCM and its consequences on regular basis?

12 Responses

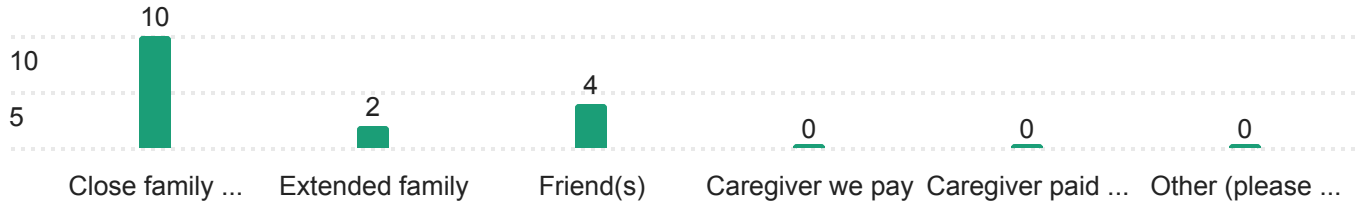




## Q74 - Who is helping you to deal with HCM and its consequences?

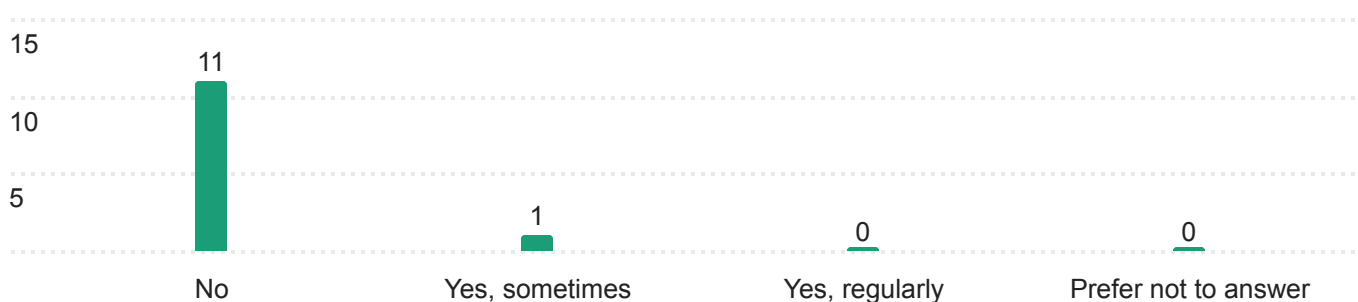
/select all that apply/

10 Responses



## Q75 - Do you visit a psychologist to help you with HCM-related issues?

12 Responses



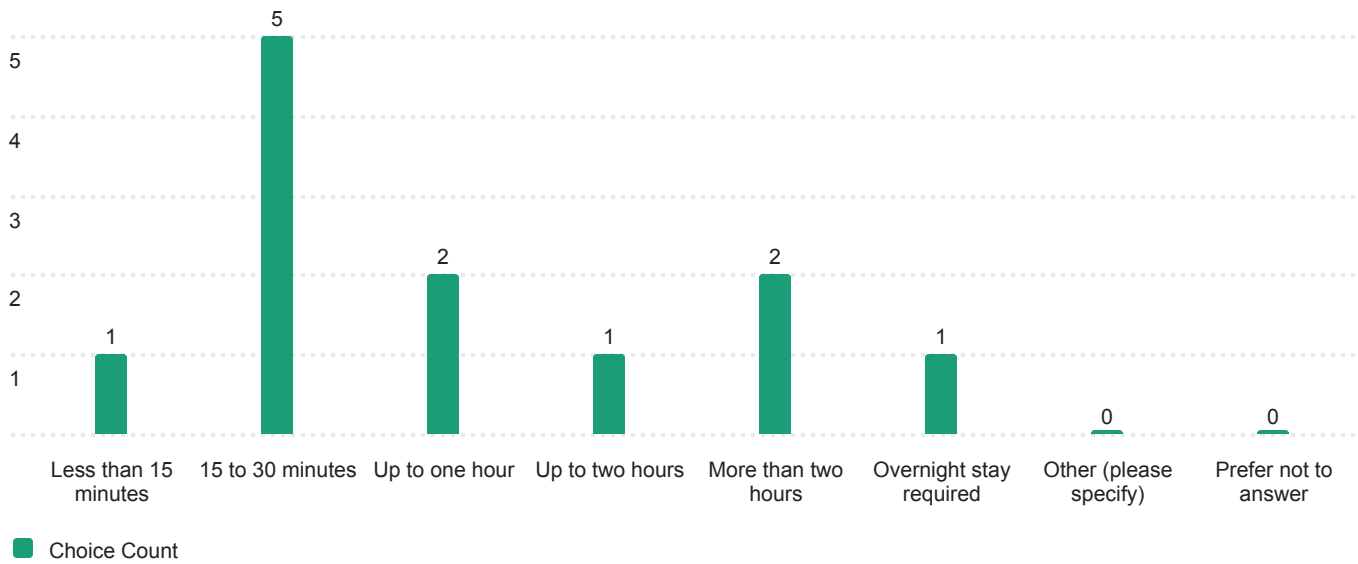
## Q76 - Do you take any medication(s) to help you fight psychological consequences from HCM like stress, depression, fear, etc.?

12 Responses



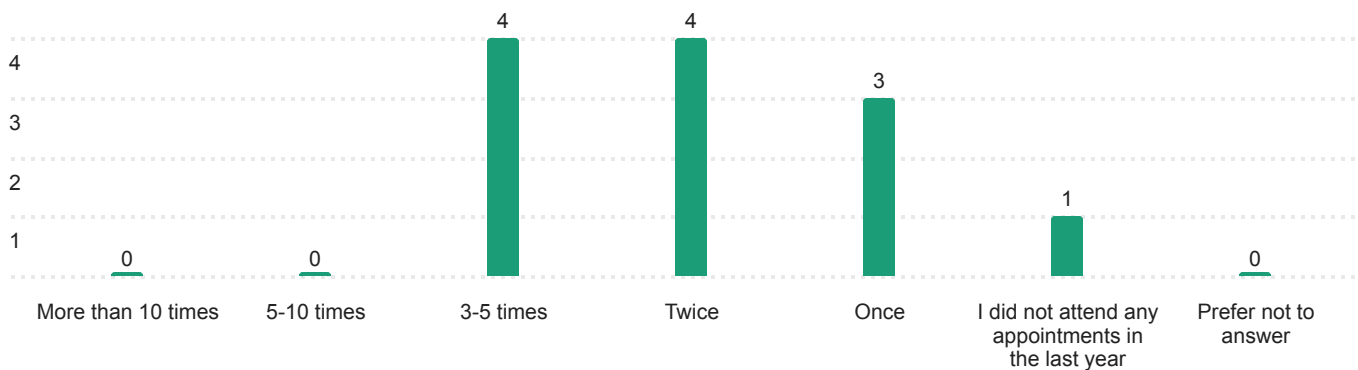
## Q77 - How long do you need to travel to go to your main place of care/cardiologist?

12 Responses



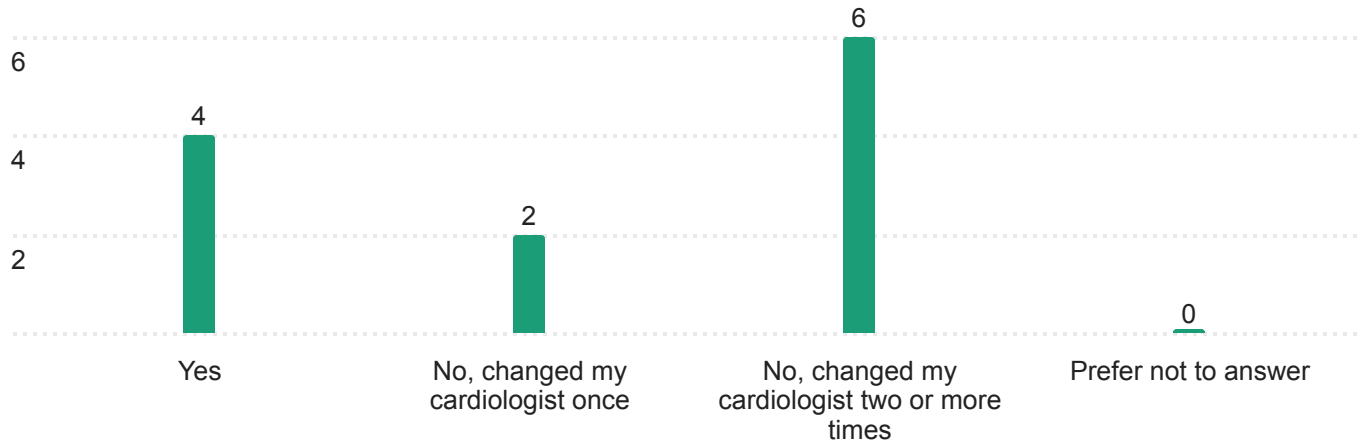
## Q78 - In the last 12 months, how many times did you meet your cardiologist?

12 Responses



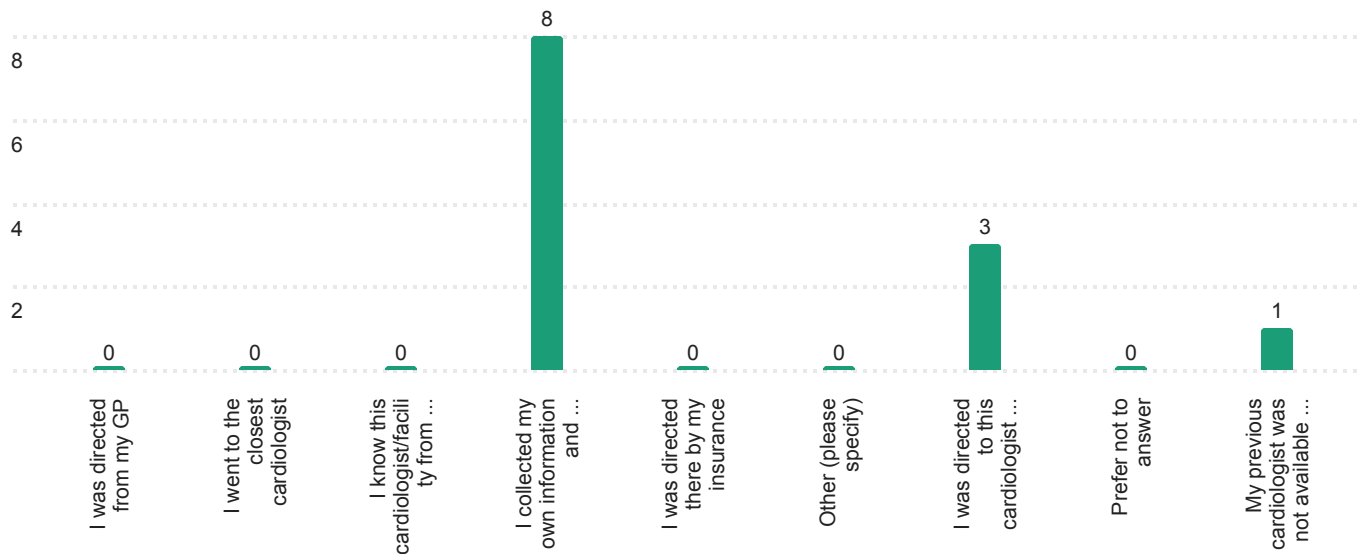
## Q79 - Have you had the same cardiologist since diagnosis?

12 Responses



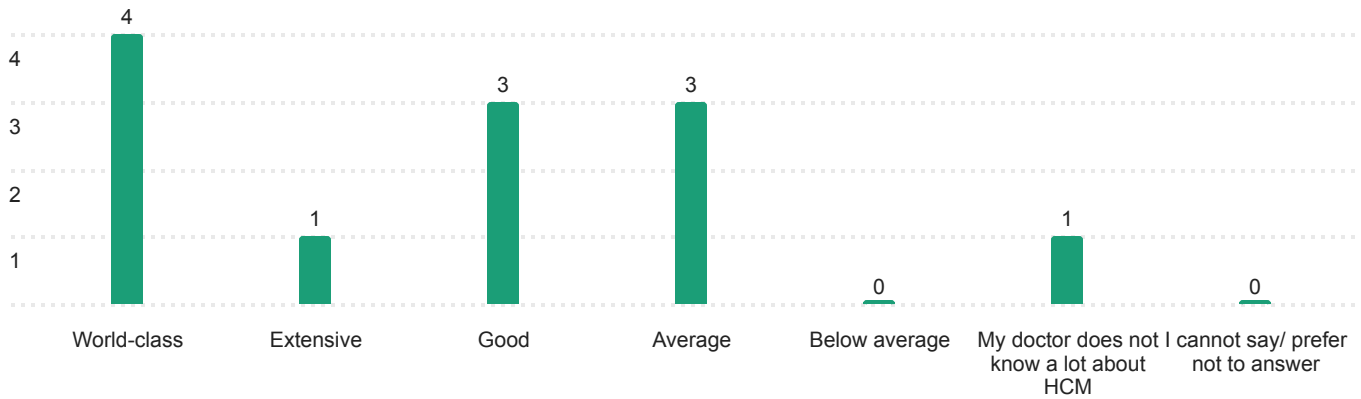
## Q80 - How did you end up with your current cardiologist and medical treatment facility?

12 Responses



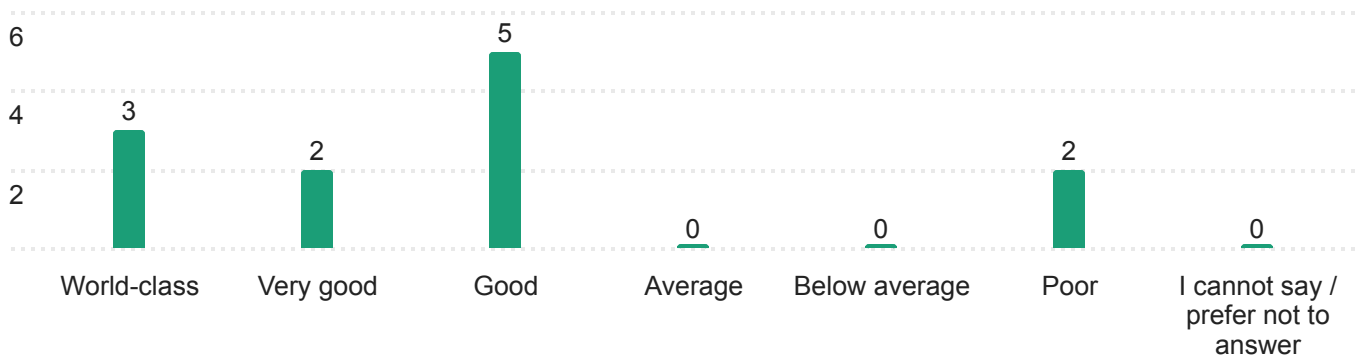
Q81 - How would you rate the HCM expertise of the cardiologist who is currently treating you?

12 Responses



Q82 - How would you rate the quality of the medical facility (hospital, clinic, etc.) which is currently taking care of your HCM condition?

12 Responses



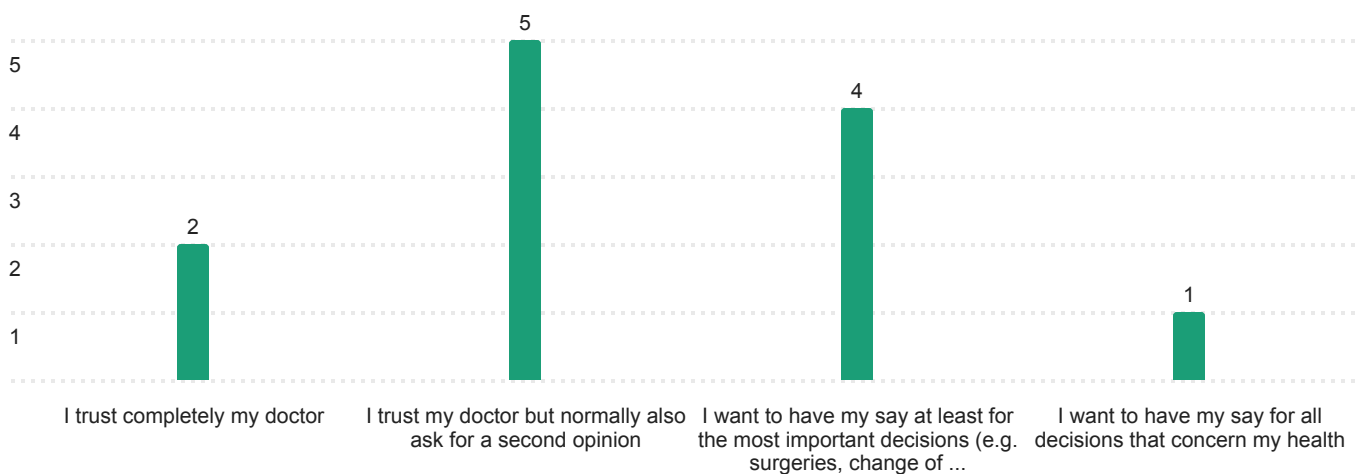
## Q83 - How important are for you these qualities in your treating cardiologist?

12 Responses

Field	Not important at all	Somewhat important	Average importance	High importance	Very high importance
Ability to listen	0	0	0	5	6
Dedicates enough time for me	0	0	0	5	6
Writes up all conclusions in a clear and concise way	0	2	0	4	6
Approachable	1	0	1	5	4
Easy to make an appointment with	0	1	1	5	5
Compassionate	5	1	1	3	1
Knows well my medical history	0	0	2	5	5
Works in a world-class medical facility	1	1	1	5	2

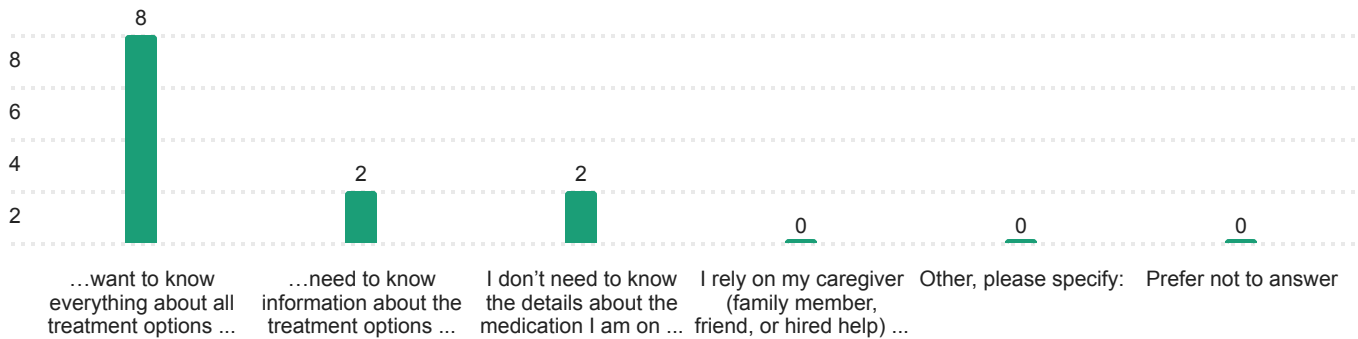
## Q84 - What is your approach to and involvement in the treatment decision process for HCM?

12 Responses



## Q85 - When it comes to new treatments, I would...

12 Responses



## Q86 - Do you think that your current treatment is the best for your condition?

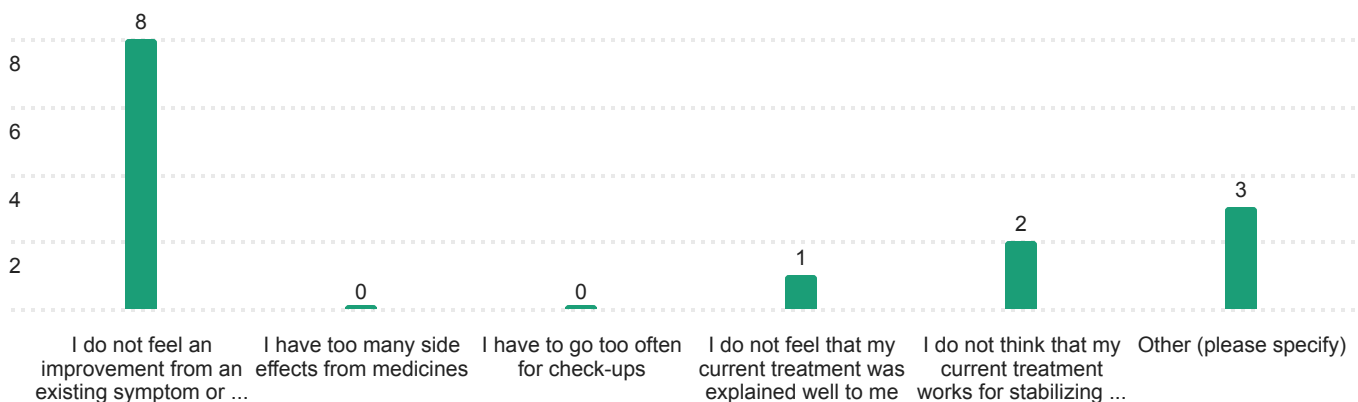
12 Responses



## Q87 - What do you think are the problems with your current treatment?

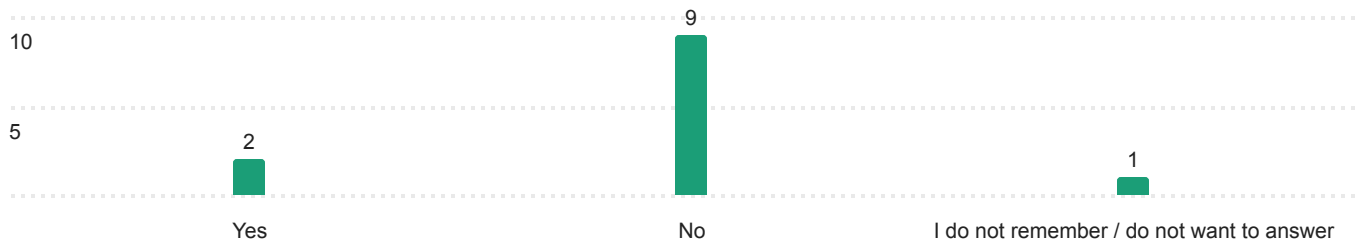
/select all that apply/

11 Responses



Q88 - Did the doctor who currently treats you mention that s/he is following the European HCM guidelines?

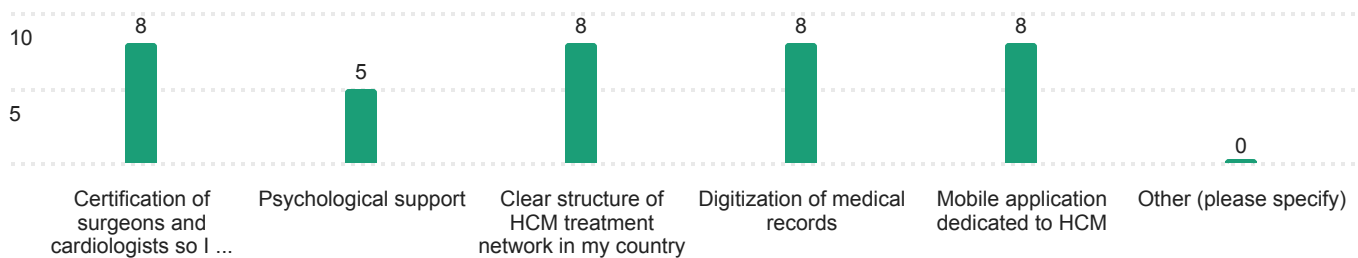
12 Responses



Q89 - Which of these improvements would have a positive impact on your HCM treatment?

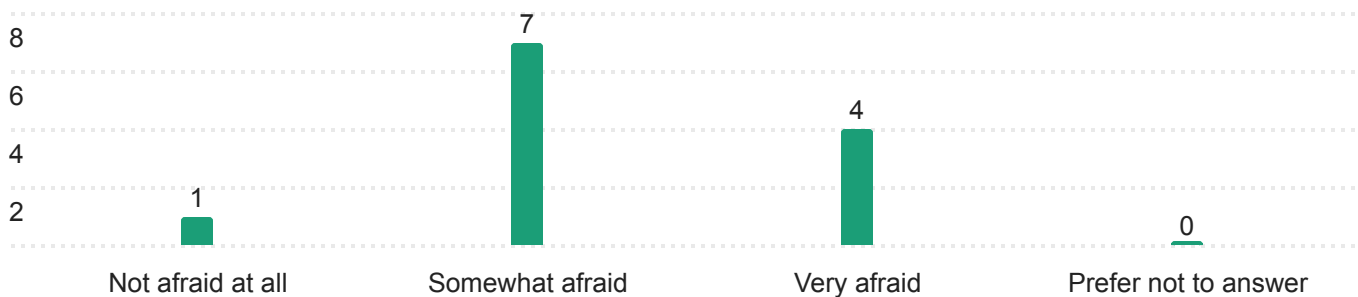
/select all that apply/

12 Responses



Q90 - How afraid are you of surgical procedures?

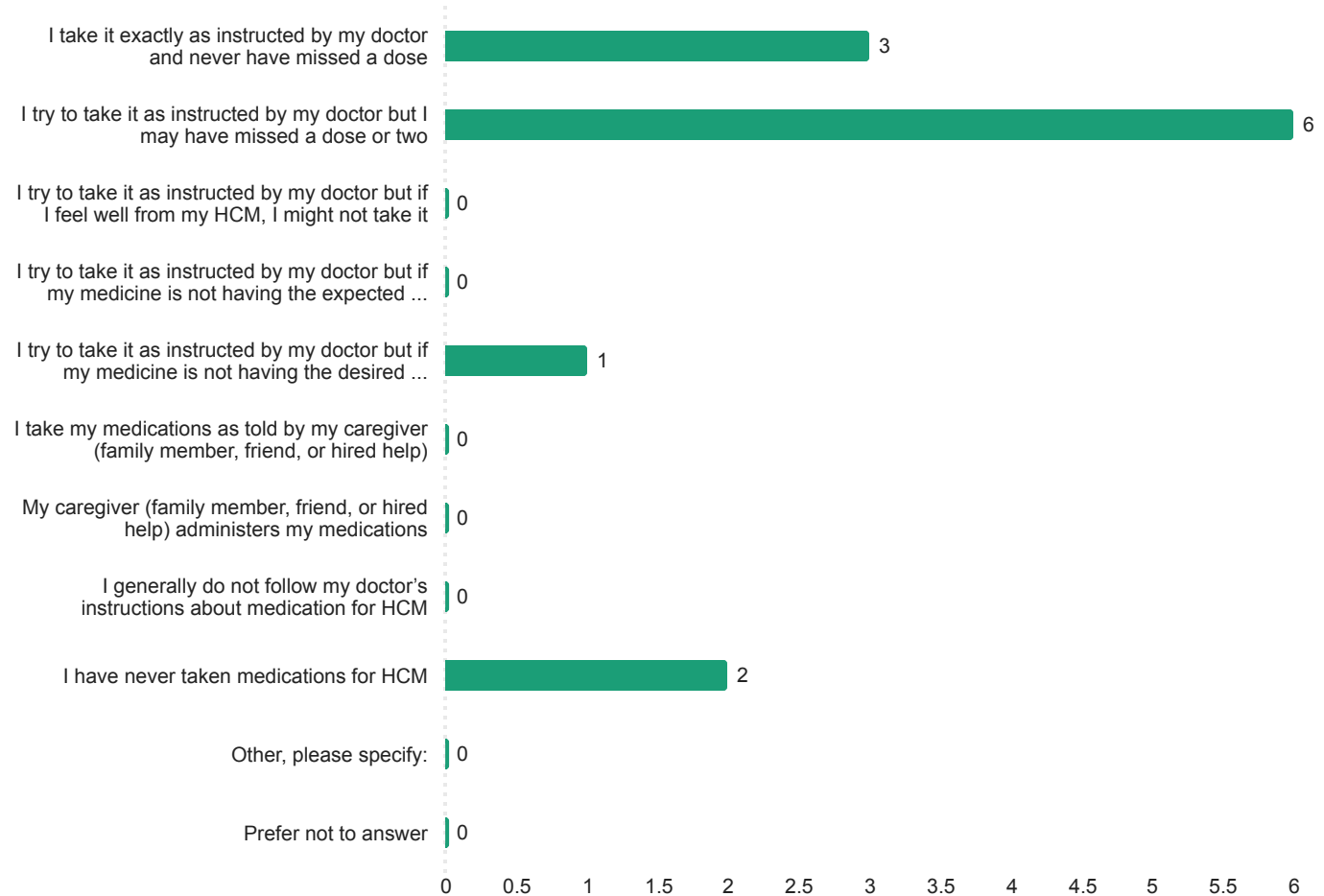
12 Responses



## Q91 - When it comes to taking my HCM medication...

Choose the answer that best describes how you take your medication(s) for HCM.

12 Responses





## Q92 -

Field	9 Responses
Choice Count	
My cardiologist's instructions are not clear	0
I don't agree with my cardiologist that I should be on a given therapy	0
I forget to take my medication	5
I feel fine without taking my medication	2
I cannot get to a pharmacy to pick up a prescribed medication	0
The doctor's office does not complete the paperwork necessary for me to obtain my medications in a timely manner	1
The instructions of the cardiologist are too difficult to carry out (even though it is clear)	0
I have side effects that are intolerable	1
I am concerned about potential side effects (though may not be experiencing any)	0
I am concerned about potential drug interactions between a drug for HCM and another drug which I am / was taking	0
My caregiver (family member, friend, or hired help) disagrees with my cardiologist's instructions, and I listen to his / her recommendations	0
My caregiver (family member, friend, or hired help) is in charge of my medications, so it depends on him / her	0
I don't trust my cardiologist	0
I don't especially care about my outcome with HCM	0
Cost of the HCM medication is burdensome	2
Other, please specify:	1

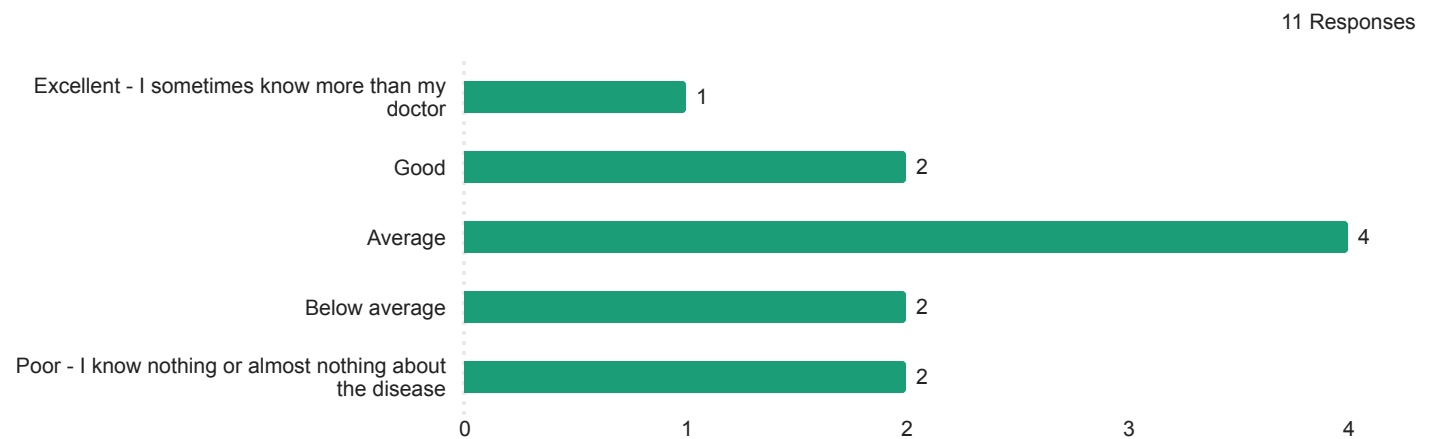
## Q94 -Rank these potential barriers that will make you doubt whether a drug is right for you in order of importance to you?

/Upper position - most important barrier, lowest position - least important barrier

10 Responses

Field	Min	Max	Mean	Responses
Too many side effects	1.00	5.00	2.40	10
Too expensive	2.00	6.00	3.30	10
Difficult to be prescribed	3.00	6.00	4.20	10
Too little research for possible negative side effects in the future	1.00	5.00	3.00	10
Too little information provided by health care provider	1.00	6.00	4.10	10
Effectiveness of the medicine is not guaranteed	1.00	6.00	4.00	10

## Q95 - How would you rate your current knowledge of HCM and its related complications?



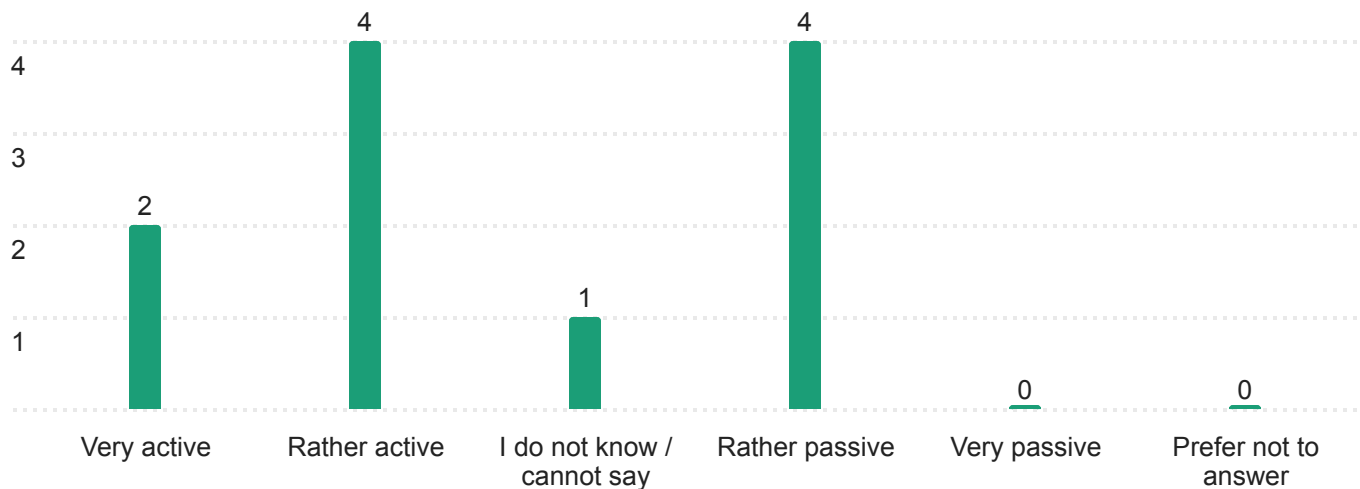
## Q96 - Which channels do you use to get information for HCM?

11 Responses



## Q97 - How active are you in searching for new information and in interacting with other HCM patients (e.g. in support groups, online discussions, etc.)?

11 Responses



We thank all patients and caretakers who participated in the survey, as well as all patient organizations and people who helped in its distribution!

We also thank our partners from Bristol Myers Squibb, Edgewise Therapeutics, Tenaya Therapeutics and D-Heart for supporting this important project!

If you want to support our work you can do so by [becoming a member](#) or by [donating directly](#).

