

myInsight Survey

Have you or someone you care for been diagnosed with cardiomyopathy?

If so, and you agree to take part, please take 10-15 minutes to complete this survey.

Taking part in this survey is voluntary. Your answers will be treated in confidence.

What is the survey about?

This survey asks about experiences of living with or caring for someone who has cardiomyopathy. We would like to understand experiences of diagnosis, care, support, and the impacts of living with cardiomyopathy. The survey results will help us campaign for improvements in services and support.

Who is the survey for?

The survey is for adults aged 16 or over who have or care for someone with a cardiomyopathy diagnosis in the UK.

We understand that some people will be living with cardiomyopathy and caring for someone with cardiomyopathy. If this applies to you, you will be able to decide who you would like to answer on behalf of (i.e. yourself or someone you care for).

How to take part

For most questions, please cross clearly inside one box using a black or blue pen. Don't worry if you make a mistake; simply fill in the box and put a cross in the correct box.

For some questions you will be instructed that you may cross more than one box. Sometimes you will find that the box you have crossed has an instruction to go to another question. By following the instructions carefully, you will only answer questions that apply to you.

If you have any questions about the survey, please email research@cardiomyopathy.org or call 01494 791224

If you have any questions about cardiomyopathy, please contact the Cardiomyopathy UK nurse team supportnurse@cardiomyopathy.org or 0800 018 1024

This survey was part-funded by Bristol Myers Squibb and Cytokinetics. These companies had no input on the content or methodology and will not have access to data gathered.

Thank you in advance for taking part.

1 I am answering this survey as:

- 1 A person living with cardiomyopathy
→ **Go to Q3**
- 2 A parent or carer of a child with cardiomyopathy
- 3 A carer to an adult with cardiomyopathy
- 4 I do not have cardiomyopathy, nor do I care for someone with cardiomyopathy

→ **Do not complete survey**

2 As you are answering this question on behalf of someone with cardiomyopathy, please tell us how old **they** are.

- 1 They are 0 to 7 years old
- 2 They are 8 to 15 years old
- 3 They are 16 to 24 years old
- 4 They are 25 to 35 years old
- 5 They are 36 to 50 years old
- 6 They are 51 to 60 years old
- 7 They are 61 to 70 years old
- 8 They are 71 to 80 years old
- 9 They are 81 years old or older

3 How old are you? **(the person answering the questionnaire)**

- 1 I am under 16 years old
→ **Do not complete survey**
- 2 I am 16 to 24 years old
- 3 I am 25 to 35 years old
- 4 I am 36 to 50 years old
- 5 I am 51 to 60 years old
- 6 I am 61 to 70 years old
- 7 I am 71 to 80 years old
- 8 I am 81 years old or older

4 Where do you live? **(the person answering the questionnaire)**

- 1 North East (England)
- 2 North West (England)
- 3 Yorkshire and The Humber
- 4 East Midlands (England)
- 5 West Midlands (England)
- 6 East of England
- 7 London
- 8 South East (England)
- 9 South West (England)
- 10 Scotland
- 11 Wales
- 12 Northern Ireland
- 13 I do not live in the UK

→ **Do not complete survey**

5 What condition have you been diagnosed with?

- 1 Amyloidosis cardiomyopathy
- 2 Arrhythmogenic right ventricular cardiomyopathy (ARVC)/ Arrhythmogenic cardiomyopathy (ACM)/ Arrhythmogenic left ventricular cardiomyopathy (ALVC)
- 3 Dilated Cardiomyopathy (DCM) / Non-Dilated Left Ventricular Cardiomyopathy (NDLVC)
- 4 Hypertrophic Cardiomyopathy (HCM)
- 5 Obstructive Hypertrophic Cardiomyopathy (HCM with obstruction/HoCM)
- 6 Left Ventricular noncompaction (LVNC)/ Left Ventricular Hypertrabeculation
- 7 Myocarditis
- 8 Peripartum Cardiomyopathy (PPCM)
- 9 Restrictive Cardiomyopathy (RCM)
- 10 Takotsubo Syndrome
- 11 Cardiomyopathy (don't know sub-type/ no sub-type specified)
- 12 No formal diagnosis received

→ **Do not complete survey**

- 13 Other (please specify)

6 How long has it been since the diagnosis?

- 1 Less than a year → **Go to Q7**
- 2 1 to 2 years → **Go to Q7**
- 3 2 to 5 years → **Go to Q12**
- 4 5 to 10 years → **Go to Q12**
- 5 Over 10 years → **Go to Q12**

Diagnosis

Please answer the following questions about the person with cardiomyopathy.

7 What first prompted you to seek medical attention before your cardiomyopathy was diagnosed?

Please cross X in all boxes that apply.

- 1 When symptoms first appeared
2 When symptoms got worse
3 A friend or family member was worried about symptoms
4 Family history of heart problems
5 I was advised to have cardiac screening / genetic testing
6 I didn't, my diagnosis followed a check up or medical attention for another condition
7 I didn't, medical attention was sought on my behalf (e.g. medical emergency)

→ Go to Q9

- 8 Other
9 Don't know / can't remember

8 What was the first thing you did to seek medical attention for symptoms of cardiomyopathy or a cardiac event?

- 1 Contacted my GP practice
2 Called 999
3 Called NHS 111
4 Went to A&E or an urgent care centre (via my own form of transport)
5 Contacted a pharmacy for advice
6 There were no symptoms (e.g. diagnosis was after family screening or a regular check-up or health check-up)

→ Go to Q10

- 7 Don't know / can't remember
8 Other - Please specify:

9 How long did it take from the time you first spoke to a healthcare professional about your symptoms, to having a confirmed diagnosis?

- 1 Less than one month
2 1-3 months
3 3-6 months
4 6-12 months
5 1-2 years
6 More than 2 years
7 Don't know / can't remember

10 When you were first diagnosed with cardiomyopathy, were you given information about your condition in a way you could understand?

- 1 Yes, definitely
2 Yes, to some extent
3 No
4 I did not receive any information
5 Don't know / can't remember

11 When you were diagnosed with cardiomyopathy, did you receive enough support to come to terms with diagnosis?

- 1 Yes, definitely
2 Yes, to some extent
3 No
4 Don't know / can't remember

Ongoing Care and Treatment

Please answer the following questions about the person with cardiomyopathy.

12 Do you have a care or treatment plan that details your care and support? This can either be paper or electronic.

Please note, a care or treatment plan should include details about treatment and highlight mental health and support needs for everyday living.

- 1 Yes
2 No
3 I don't know

Still thinking about the person with cardiomyopathy...

13 In the last **two years**, have you received any of the following forms of health or social care support?

	Yes, and this was useful	Yes, but this was not useful	No, but I wanted or needed this	No, but I did not want or need this	Don't know / can't remember
Mood or emotional support	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Support around physical activity	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Sexual or reproductive health support	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Nutritional support	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Cardiac rehabilitation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Social care support	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

14 In the last **two years**, have you been able to access the following **NHS** healthcare professionals when you needed to?

	Yes, always	Yes, sometimes	No, but I wanted or needed this	No, but I did not want or need this	Don't know / can't remember	I accessed this privately
Cardiac Nurse specialist	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
Cardiologist	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
Dietitian or Nutritionist	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
Mental health professional (e.g. a psychologist or counsellor)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
Occupational therapist (e.g. to talk about changes to the home)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
Physiotherapist or exercise physiologist	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
Genetic Counsellor	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
Devices specialist (e.g. ICD nurse specialist or similar)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>

15 Since your diagnosis, what additional support or information have you accessed?
Please cross X in all boxes that apply.

- 1 Cardiomyopathy UK helpline
- 2 Cardiomyopathy UK support group
- 3 Cardiomyopathy UK information sheets
- 4 Cardiomyopathy UK online forums
- 5 Cardiomyopathy UK MyLife magazine
- 6 Cardiomyopathy UK emails
- 7 Cardiomyopathy UK conference or events
- 8 Information or support from another charity
- 9 NHS website
- 10 Other websites
- 11 I have not sought any further information or support
- 12 Don't know / can't remember

Still thinking about the person with cardiomyopathy...

16 Have you been provided with enough information about your ongoing care and treatment?

- 1 Yes, enough information
- 2 Some, but not enough information
- 3 Little or no information
- 4 Don't know / can't remember

17 Do you feel involved in decisions about your care and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

18 In your opinion, do the different healthcare professionals involved in your care work well together?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

19 Do health care professionals speak with you in a way you can understand?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

20 In the last **two years**, has your cardiology team discussed your mental health and wellbeing with you?

- 1 Yes → **Go to Q21**
- 2 No, but I wanted or needed this → **Go to Q22**
- 3 No, but I did not want or need this → **Go to Q22**
- 4 Don't know / can't remember → **Go to Q22**

21 As a result of your cardiology team discussing your mental health and wellbeing, were you referred on or signposted to relevant support services?

- 1 Yes, and this was useful
- 2 Yes, but this was not useful
- 3 No, but I wanted or needed this
- 4 No, but I did not want or need this

Genetic testing and family screening

Please answer the following questions about the person with cardiomyopathy.

22 Have you been offered genetic testing for cardiomyopathy?

- 1 Yes, and I took up or am taking up the offer
- 2 Yes, but I did not take up the offer
- 3 No, but I would like this
- 4 No, but I do not want this
- 5 Don't know / can't remember
- 6 Not applicable (e.g. my cardiomyopathy is unlikely to be genetic) → **Go to Q27**

23 Have your family members been offered genetic testing for cardiomyopathy?

- 1 Yes → **Go to Q24**
- 2 No → **Go to Q27**
- 3 Not applicable → **Go to Q27**
- 4 Don't know / can't remember → **Go to Q27**

24 Were you provided with a letter or information to pass on to your family relatives, about genetic testing?

- 1 Yes
- 2 No
- 3 Not yet (I have been told it will be provided)
- 4 Don't know / can't remember

25 Did your family members who were offered genetic testing take it up?

- 1 Yes, all of them → Go to Q27
- 2 Yes, some of them → Go to Q26
- 3 No → Go to Q26
- 4 Not yet → Go to Q26
- 5 Don't know / can't remember → Go to Q27

26 Please explain why all or some of your family members have not taken up genetic testing in the box below:

Impact of cardiomyopathy

Please answer this section about your health and wellbeing.

27 In the **last two years**, have any of the following been negatively impacted because of having or caring for someone with cardiomyopathy?

Please cross X in all boxes that apply.

- 1 Self-confidence
- 2 Mental health
- 3 Friendships
- 4 Family relationships
- 5 Relationships with partner/s
- 6 Sexual activity
- 7 Pregnancy
- 8 Family planning
- 9 Caring responsibilities
- 10 Independent living
- 11 None of the above

28 In the **last two years**, have any of the following been negatively impacted because of having or caring for someone with cardiomyopathy?

Please cross X in all boxes that apply.

- 1 Employment
- 2 Education or training
- 3 Socialising
- 4 Volunteering
- 5 Exercising
- 6 Mobility
- 7 Travel or holidays
- 8 Accessing life or travel insurance
- 9 Driving
- 10 Other (please specify)
- 11 None of the above

Employment and Income

Please answer this section about your employment and income.

29 Which of the following best describes your current work status?

Please cross X in all boxes that apply.

- 1 In full-time / part-time employment
- 2 In full-time / part-time education or training
- 3 Self-employed or freelance
- 4 On long-term sick leave or not able to work because of my cardiomyopathy
- 5 On long-term sick leave or not able to work due to a reason other than my cardiomyopathy
- 6 On maternity or paternity leave
- 7 I am looking for work
- 8 I am retired
- 9 I am a full-time carer to a child or adult (unpaid)
- 10 Other

30 Has your ability to work ever been impacted by having or caring for someone with cardiomyopathy?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Not applicable
- 5 Prefer not to say

31 Have you received any of the following benefits and/or financial support in the last **two years** as a result of having or caring for someone with cardiomyopathy?

Please cross X in all boxes that apply.

- 1 Employment and Support Allowance
- 2 Universal Credit
- 3 Carer's Allowance
- 4 Personal Independence Payments (PIP)
- 5 Disability Living Allowance
- 6 Statutory Sick Pay (SSP)
- 7 Local authority or council funding for care needs
- 8 Other
- 9 None of the above
- 10 Don't know / can't remember

32 Have you received any professional advice about claiming benefits in the last **two years** as a result of having or caring for someone with cardiomyopathy?

- 1 Yes
- 2 No, but I wanted or needed this
- 3 No, but I did not want or need this
- 4 Prefer not to say

33 Has having or caring for someone with cardiomyopathy had a negative impact on your financial situation?

- 1 Yes, definitely → **Go to Q34**
- 2 Yes, to some extent → **Go to Q34**
- 3 No → **Go to Q35**
- 4 Prefer not to say → **Go to Q35**

34 How has cardiomyopathy affected your financial situation?

Please cross X in all boxes that apply.

- 1 I go without essentials like food or heating
- 2 I borrow money
- 3 I have fallen behind with utility bills
- 4 I have fallen behind with rent or mortgage
- 5 I go without care and support
- 6 I go without medicines or health services
- 7 I feel lonely/ cannot afford to socialise
- 8 I feel stressed or anxious about my finances
- 9 My cardiomyopathy has become worse due to worries about my finances
- 10 I have had to use a foodbank

Research

Please answer the following questions about the person with cardiomyopathy.

35 Have you been offered the opportunity to take part in cardiomyopathy related clinical research or trials (i.e. new drugs or treatments) in the **last two years**?

- 1 Yes → **Go to Q36**
- 2 No → **Go to Q37**
- 3 Don't know / can't remember

→ **Go to Q37**

36 Have you ever taken part, or are you currently taking part, in cardiomyopathy-related clinical research or trials (i.e. new drugs or treatments)?

- 1 Yes
- 2 No
- 3 Don't know / can't remember

Overall experience of care

If you've decided to answer on behalf of someone with cardiomyopathy, please answer the following questions about them.

37 Overall, how would you rate the care you receive from the **NHS** for your cardiomyopathy?

- 1 Very good
- 2 Good
- 3 Fair
- 4 Poor
- 5 Very poor
- 6 Not sure
- 7 I do not receive NHS care for my cardiomyopathy

38 Overall, is there anything in particular you would like to tell us about, good or bad, relating to your experience of cardiomyopathy treatment and care? **(If you are a parent or a carer, please answer in relation to both yourself and the person you care for)**

About you or the person you care for
Please answer the following questions about the person with cardiomyopathy.

39 Which of these best describes you?

- 1 Male
- 2 Female
- 3 Non-binary
- 4 I describe myself another way (please specify)
- 5 Prefer not to say

40 Other than your cardiomyopathy, do you have any other physical or mental health conditions that have lasted or are expected to last 12 months or more?

- 1 Yes
- 2 No

41 Which of these best describes your ethnic background?

- 1 White
- 2 Mixed/ Multiple ethnic groups (e.g. White and Black African, White and Asian)
- 3 Asian/ Asian British (e.g. Indian, Pakistani, Chinese)
- 4 Black/ African/ Caribbean/ Black British
- 5 Other ethnic group
- 6 Prefer not to say

42 Can Cardiomyopathy UK contact you to further discuss any of the answers you have provided in this survey?

Your contact details will only be linked to your survey responses if you answer yes to this question. Cardiomyopathy UK will keep your contact details for the purpose of discussing the answers provided in this survey, unless you inform them otherwise.

- 1 Yes

Please provide your email address or phone number at Q44 below

- 2 No

43 Would you like to receive email updates from Cardiomyopathy UK?

Cardiomyopathy UK will use your contact details in line with their privacy policy cardiomyopathy.org/privacy-policy

Please cross X in all boxes that apply.

Yes, I'd like to receive updates on the latest support and information for people affected by cardiomyopathy and Cardiomyopathy UK's campaigns, research and ways to get involved.

- 1

Please write your email address at Q44 below

Yes, I'd like to receive updates on the latest research news and opportunities to get involved.

- 2

Please write your email address at Q44 below

- 3 No

44 If you answered yes to **Questions 42 or 43**, please provide your email address (or phone number if you do not have an email):