

Cardiomyopathy^{UK}

Future Research Priorities

This is a survey for people affected by cardiomyopathy, their loved ones, carers and health professionals. It is a survey to discover what the most important research questions are for cardiomyopathy going forwards.

The survey is part of the Priority Setting Partnership work Cardiomyopathy UK is doing with the James Lind Alliance to discover the top ten research priorities for cardiomyopathy.

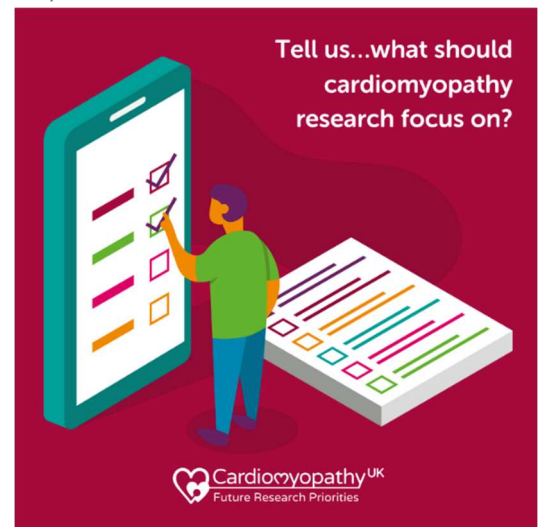
If you are supporting someone with cardiomyopathy to complete the survey, you can also complete the survey again on your own behalf.

The survey is available digitally. If you would prefer to complete the survey online you can access it using the QR code or link below



<https://bit.ly/cardiomysurvey>

For any support to access or complete the survey please email research@cardiomyopathy.org or call 01494 791224 Mon-Fri 09:00 – 17:00.



Who can take part in this survey?

If you are UK-based, aged 16+ and affected by cardiomyopathy

- Living with cardiomyopathy
- A parent, loved one or friend
- A carer
- At genetic risk of cardiomyopathy
- Bereaved due to cardiomyopathy

Or a UK-based healthcare professional working with people affected by cardiomyopathy,

All types of cardiomyopathy are included, including:

- Dilated cardiomyopathy (DCM)
- Hypertrophic cardiomyopathy (HCM)
- Arrhythmogenic cardiomyopathy (ACM)
- Other types of cardiomyopathy

Please complete all questions marked with a *

Eligibility screening

1. Are you UK-based? *

- Yes
 No

2. Do you have a connection to cardiomyopathy? *

For example

- You are someone with cardiomyopathy (or a genetic risk of it) yourself
- You are a parent/loved one/friend of someone with cardiomyopathy
- You are a professional working with people with cardiomyopathy
- You have been bereaved due to cardiomyopathy

- Yes
 No
 Not sure

Your connection to cardiomyopathy

3. Which of the following best describes you? (tick all that apply)*

- A person with cardiomyopathy
- A parent of a child with cardiomyopathy
- A carer (including professional carer)
- A loved one/friend
- Someone with a genetic risk of developing cardiomyopathy
- Someone who has been bereaved due to cardiomyopathy
- A healthcare professional working with people affected by cardiomyopathy
- Other (please specify)

4. Which of the following types of cardiomyopathy do you, or the person in your life with cardiomyopathy, have? *

- Dilated cardiomyopathy (DCM)
- Hypertrophic cardiomyopathy (HCM)
- Arrhythmogenic cardiomyopathy (ACM)
- Restrictive cardiomyopathy (RCM)
- Left ventricular noncompaction cardiomyopathy (LVNC)
- Peripartum cardiomyopathy (PPCM)
- Takotsubo cardiomyopathy
- I am a healthcare professional working with people with various types of cardiomyopathy
- Not sure/don't know
- N/A
- Other (please specify)

Questions you want answered by research

We want to help researchers understand what questions you most want answers to. These could relate to any topic to do with cardiomyopathy, such as:

- Causes
- Diagnosis
- Treatment
- Ongoing care
- Impacts e.g. on your relationships, lifestyle, physical activity, other health conditions
- Emotional wellbeing
- Genetic testing
- Differences between different people (e.g. males and females)
- Other

Please draw on your experience as someone affected by cardiomyopathy / as a healthcare professional. You can ask as many or as few questions as you want.

5. What question(s) do you have about cardiomyopathy treatment/care for people with, or at genetic risk of, cardiomyopathy that you would like answered by research?*

6. What question(s) do you have about the impacts of cardiomyopathy on day-to-day living that you would like answered by research?*

7. What other question(s) do you have about anything else to do with cardiomyopathy that you would like answered by research?

Please tell us about yourself

We want to make sure that we hear from people from a wide range of backgrounds, across the UK. This information will not be used to identify you.

8. What is your gender?

- Female
- Male
- Prefer not to say
- I prefer another term (please specify).

9. Where in the UK do you live?

- | | | |
|---|---|---|
| <input type="checkbox"/> North East England | <input type="checkbox"/> South West | <input type="checkbox"/> Fermanagh |
| <input type="checkbox"/> North West England | <input type="checkbox"/> North Wales | <input type="checkbox"/> Londonderry |
| <input type="checkbox"/> Yorkshire & the Humber | <input type="checkbox"/> Mid Wales | <input type="checkbox"/> Tyrone |
| <input type="checkbox"/> East Midlands | <input type="checkbox"/> South East Wales | <input type="checkbox"/> Aberdeen & North East Scotland |
| <input type="checkbox"/> West Midlands | <input type="checkbox"/> South West Wales | <input type="checkbox"/> Highlands & Islands |
| <input type="checkbox"/> London | <input type="checkbox"/> Antrim | <input type="checkbox"/> Tayside Central & Fife |
| <input type="checkbox"/> South East | <input type="checkbox"/> Armagh | <input type="checkbox"/> Edinburgh & Lothians |
| <input type="checkbox"/> Other (please specify) | <input type="checkbox"/> Down | <input type="checkbox"/> Scotland South |

10. What is your age?

- 16-19
- 20-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+
- Prefer not to say
- Other (Please specify).

11. How would you describe your ethnicity?

- Asian or Asian British
- Black, Black British, Caribbean or African
- Mixed or multiple ethnic groups
- White British
- Prefer not to say
- Other ethnic group (please specify)

Next steps

Please return the completed survey to our representative at your clinic or support group today.

Otherwise please return by post, to:

Future Research, Cardiomyopathy UK, 75A Woodside Road, Amersham, HP6 6AA.

Please provide your contact details below if you would like to hear about the survey results and how to get involved in the next phase of this project.

Your contact information will be separate from your survey responses, which will remain anonymous in line with our safeguarding policy.

Your personal information will be kept confidential. We are committed to protecting your privacy when you use our services. You can find more information at www.cardiomyopathy.org/privacy-policy

12. Contact details

Name

Email Address

If this survey has brought up any issues you'd like support with, please call our helpline: 0800 018 1024, Mon-Fri, 08:30 – 4:30.

Thank you for completing this survey.

You can find out more about Cardiomyopathy UK, the James Lind Alliance and the project to identify the top 10 priorities for future cardiomyopathy research using this QR code.

