We partnered with the James Lind Alliance to complete a ‘priority setting process’ to identify the top 10 priorities for future cardiomyopathy research. The process brought together people affected by cardiomyopathy and healthcare professionals to decide on these 10 research priorities.
The 10 research priorities

After several months of consultation and analysis, the list of the 10 research priorities for cardiomyopathy has now been published:

| 1 | What are the emotional and psychological impacts of living with cardiomyopathy? How are these best treated and managed? |
| 2 | How often should family members at risk of developing cardiomyopathy be screened and which are the best tests to use? When is it safe to stop screening? |
| 3 | Should treatment for cardiomyopathy be tailored to the individual, e.g. based on their specific gene variant, age or gender? |
| 4 | What triggers the start of cardiomyopathy (e.g. age, stress, pregnancy, other health conditions)? How do these triggers work and can they be blocked? |
| 5 | Are there treatments which can prevent cardiomyopathy developing in people at risk? Are there treatments to stop it getting worse in people with symptoms? |
| 6 | What are the biological mechanisms that change heart muscle cells in cardiomyopathy? Could this understanding lead to new treatments? |
| 7 | Why are people with the same genetic variant affected differently? Why do some people with a genetic variant never develop cardiomyopathy? Could this understanding lead to new treatments? |
| 8 | Do people with cardiomyopathy experience better outcomes if they are treated at a specialist clinic rather than a general clinic? |
| 9 | What does ongoing monitoring and long-term care for people with cardiomyopathy need to include? |
| 10 | What are the best approaches to cardiac rehabilitation for people with cardiomyopathy? |
Timescales

2023
The Priority Setting Partnership was launched

Spring 2023
The steering group was set up

June 2023
The first survey was open, 1020 people submitted over 2000 questions they would like answered by research

August 2023
The questions submitted in the first survey were analysed and shortlisted

October 2023
The shortlisting survey was open, 660 people responded and 26 questions were shortlisted for the workshop

February 2024
The 10 priority research questions for cardiomyopathy were published

February 2024
A priority setting workshop took place to finalise the 10 priority research questions

February 2024
Dissemination of the final priority research questions

Next steps
Cardiomyopathy UK partners with researchers on cardiology research projects. We’re keen to support further research into these priority topics. If you want to conduct, fund, or otherwise support research relating to any of the top 10, please get in touch for more information:

research@cardiomyopathy.org

To learn more about the priority setting process, scan the QR code or visit:

www.cardiomyopathy.org/future-research