



Calling all people who live and work with advanced heart failure



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What questions do you want answered by heart failure research?

Please return your survey in the FREEPOST envelope provided, or give it to your healthcare provider,

OR

Fill in the survey online at <https://oxford.onlinesurveys.ac.uk/ahfmsp>.



What is heart failure?

Heart failure doesn't mean your heart has stopped working – it just needs some support to help it work better. It can happen at any age, but is most common in older people. Heart failure means the heart is unable to pump blood around the body well enough, which can lead to symptoms of breathlessness, palpitations, ankle swelling and fatigue.

We want to find out what research is needed for people with '**advanced**' heart failure. For this project our definition is a person with a known diagnosis of heart failure who has symptoms, such as breathlessness, which impact on what they are able to do, require them to take lots of medications or go into hospital.

This is an opportunity for you to help

If you are a person with heart failure, or look after someone with heart failure, we would like to hear from you.

What are we doing?

We are asking people who are affected by advanced heart failure, their families, friends and health and social care professionals who look after heart failure patients to help us identify the top ten questions that they want answered by heart failure research. This will help guide heart failure research and make sure that researchers focus on the needs of people living with the condition.

What do I have to do?

Tell us about what questions you have about advanced heart failure you would like to see answered by research. You don't need to answer all the sections.

Your questions in your own words are what we are looking for. The most important thing is to draw on your own experience and what is important to you.

Website: www.jla.nihr.ac.uk/priority-setting-partnerships/Advanced-heart-failure

Facebook: www.facebook.com/oxprimarycare

Twitter: @OxPrimaryCare

Email: heartpsp@phc.ox.ac.uk



Who are we?

We are a group of patients, carers, care professionals and researchers who want to find out what research is needed to help people with heart failure living in the community. This work is supported by an organisation called the James Lind Alliance
<http://www.jla.nihr.ac.uk/priority-setting-partnerships/>

Which describes you best? [Please tick a box]

- I am a person with heart failure
- I am a relative, neighbour or friend of a person with heart failure
- I am a health care/social care/patient representative professional
- Other – please state

Please contact us via the details below if you would like a copy of this survey in a different format or language.

There are two sections to this survey:

Section one: Your opportunity to ask questions about advanced heart failure that you think are important for research to look at. We are looking for your questions about **symptoms, treatments and day-to-day life**, which if answered by research, could make a real difference to people living with heart failure.

Section two: Some information about you to help us understand who is responding to the survey. **You may also leave contact details if you would like to continue to help with this project.** Any contact details will only be used for this purpose. Remember all personal information will be treated confidentially.

Section one:

You can ask as many or as few questions as you want. It does not matter if you are not sure that something is directly linked to heart failure. You can write questions about how you feel now or how you have felt at any time since diagnosis.

1. What questions do you have about the physical impact of advanced heart failure?

For example: What can help me with my tiredness?
What can help me sleep better?
Will exercise help my heart failure?



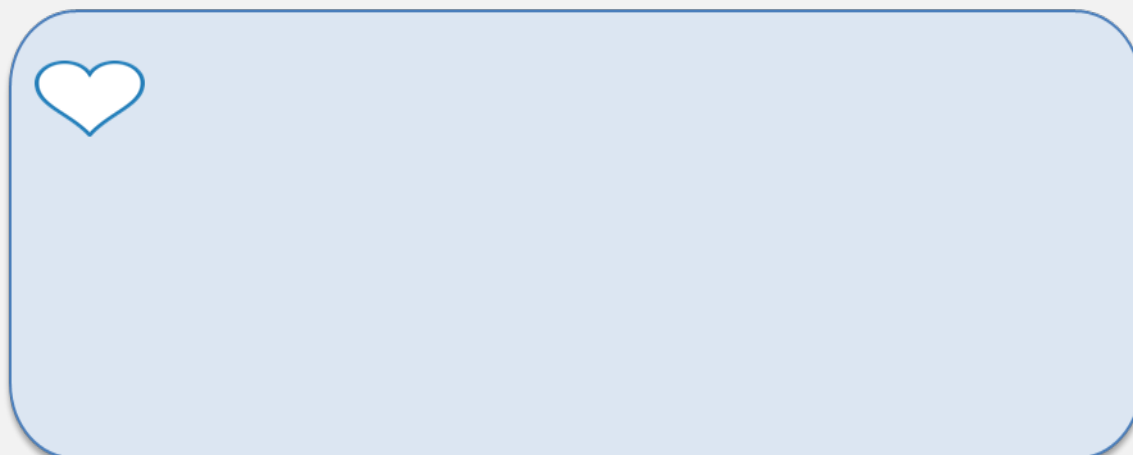
2. What questions do you have about the emotional impact of advanced heart failure?

For example: Who is it best to see if I am feeling low?
Will yoga help me with my anxiety about heart failure?
Is it safe for me to take antidepressants?



3. What questions do you have about the treatment, support or help provided for people with advanced heart failure?

For example: Who should I talk to about my medication- nurse or doctor?
How can I get a GP appointment if I start to feel worse?



Section two:

Some questions about you: It would be really helpful for us to know more about you, so we would be grateful if you could fill in the questions in this section. Please tick the boxes as appropriate. **However if you prefer not to, just leave it blank.**

Question 1: Only answer if you are a person with heart failure.

a) What is your age?

- Under 40yrs
- 40-50yrs
- 51-60yrs
- 61-70yrs
- 71-80yrs
- 80+yrs

b) How long have you been living with heart failure?

For example: 6 months or 5 years.

c) To which gender do you most identify?

- As a man
- As a woman
- In some other way
-
- Rather not say

d) How would you describe your ethnicity?

- White
- Mixed or multiple ethnic groups
- Asian or Asian British
- Black, African, Caribbean or black British
- Other ethnic group
- Prefer not to say

Question 2: Only answer if you are a (care) professional.

a) Which describes you best?

- I am a health professional e.g.GP, nurse, consultant, pharmacist
- I am an allied health professional e.g. psychologist, occupational therapist
- I am a social care professional
- I am part of an organisation/charity representing persons with heart failure
- Other – please state

b) Do you work primarily in?

- Primary/community health care
 - Secondary health care
 - Both primary and secondary care
 - Primary /secondary care interface
 - Community social care
 - Other
-

What will we do with the results?

We will share the outputs of this project as widely as possible with groups that fund and carry out research. We will also inform the charities that work with people affected by advanced heart failure.

What will happen with my information?

There will be no linkage to individual people or organisations. Any personal information will be confidential.

What happens next?

We would like to get back to you to help us to put the research questions into order of importance and urgency. If you would like to take part in this stage, please add your contact details below.

Name:

Address:

Telephone number:

Email:

Thank you!



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