

Sussex Heart Failure Survey

For adults living with heart failure and those who care for them

About this survey

We want to improve our heart failure services so that people can access high-quality care across the whole of Sussex. To help us make the right changes, we're keen to understand your experiences and hear what you think a good service would look like.

Sussex Health and Care brings together hospital and community NHS Trusts, general practices, social care, and others to plan and deliver services that meet the needs of the people of Sussex.

Survey deadline

If you live with heart failure or are a carer or family member of someone who does, please complete the following survey **by 8th September 2023** and let us know your thoughts.

Returning the survey

Please return to:

FAO: Matthew Moors – Public Involvement Team, FREEPOST RTUZ-ECYG-ERRK, NHS Sussex ICB, Wicker House, Worthing, BN11 1DJ

If you would prefer to complete an online version of the survey, please scan the QR code opposite or visit:

www.smartsurvey.co.uk/s/HeartFailure

Please note: NHS Elect has designed this survey and will undertake an independent analysis of the results. The information you provide will only be used for the purpose above.

Thank you for taking part.

Yours truly,

Sussex Health and Care

Survey Questions

Please tick the box that applies to you:

I am someone who lives with heart failure

I am a carer or family member of someone who lives with heart failure

Part 1: About your heart failure

1. What type of heart failure do you have? Please tick all that apply.

- | | |
|--|--|
| <input type="checkbox"/> Reduced ejection fraction | <input type="checkbox"/> Cor pulmonale / Right sided heart failure |
| <input type="checkbox"/> Preserved ejection fraction | <input type="checkbox"/> Cardiomyopathy |
| <input type="checkbox"/> Systolic dysfunction | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Diastolic dysfunction | <input type="checkbox"/> Other (please write on the line below) |
-

2. Do you also live with any of the following conditions? Please tick all that apply to you.

- | | |
|--|---|
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> A previous heart bypass or valve replacement |
| <input type="checkbox"/> Hypertension | <input type="checkbox"/> A permanent pacemaker or defibrillator |
| <input type="checkbox"/> A previous heart attack | <input type="checkbox"/> Lung disease e.g. COPD, emphysema, or asthma |
| <input type="checkbox"/> A previous stroke | <input type="checkbox"/> Dementia |

3. How long has it been since you were told you have heart failure?

- | | |
|---|---|
| <input type="checkbox"/> Less than a year | <input type="checkbox"/> 5-10 years |
| <input type="checkbox"/> 1-2 years | <input type="checkbox"/> More than 10 years |
| <input type="checkbox"/> 2-5 years | |

4. How were you first told you have heart failure?

- | | |
|--|---|
| <input type="checkbox"/> By your GP | <input type="checkbox"/> During a visit to A&E |
| <input type="checkbox"/> By your practice nurse | <input type="checkbox"/> During a stay in hospital |
| <input type="checkbox"/> By a heart failure specialist | <input type="checkbox"/> Other (please write on the line below) |
-

5. How long were you breathless and/or had swollen ankles before you were told you had heart failure?

- | | | |
|---|---|-----------------------------------|
| <input type="checkbox"/> Less than a week | <input type="checkbox"/> 3-6 months | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> 1-4 weeks | <input type="checkbox"/> 6-12 months | |
| <input type="checkbox"/> 1-3 months | <input type="checkbox"/> More than a year | |

6. In the past 12 months, how often have you had to stay in hospital due to heart failure?

- | | | |
|-------------------------------|--------------------------------------|-----------------------------------|
| <input type="checkbox"/> None | <input type="checkbox"/> 2-5 | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> 1 | <input type="checkbox"/> More than 5 | |
-

Part 2: About your care

7. When did a healthcare professional last see you about your heart failure?

- | | | |
|---|--|---|
| <input type="checkbox"/> In the last 3 months | <input type="checkbox"/> In the last 12 months | <input type="checkbox"/> I have not been seen yet |
| <input type="checkbox"/> In the last 6 months | <input type="checkbox"/> More than 12 months ago | <input type="checkbox"/> Not sure |

8. Who do you see about your heart failure? (Please tick all that apply)

- A specialist heart failure team at the hospital A nurse in the local community (closer to my home)
 A specialist heart failure team in my local community (closer to my home) Not sure
 A GP or nurse in my practice No one

9. Thinking about how heart failure affects your life, how much do you agree with the following?

	Strongly agree	Agree	Disagree	Strongly disagree	Unsure	Not applicable
Heart failure has a negative effect on my quality of life						

10. How does heart failure affect your quality of life?

11. Does your heart failure ever stop you from leaving the house?

- Yes, often Yes, but hardly ever Not sure
 Yes, sometimes No, never

12. Are you ever seen by a healthcare professional in your home about your heart failure?

- Yes, often Yes, but hardly ever Not sure
 Yes, sometimes No, never

13. Thinking about how the cost of living has affected your heart failure, how much do you agree with the following?

	Strongly agree	Agree	Disagree	Strongly disagree	Unsure	Not applicable
It has sometimes been hard to afford my prescriptions						
It has sometimes been hard to get to appointments (for example due to travel or parking costs)						
I have had to go without my prescription and/or missed an appointment due to my financial situation						

14. Have you had feelings of sadness, depression, or anxiety since being told you have heart failure?

- Yes, often Yes, but hardly ever Not sure
 Yes, sometimes No, never

15. Have you been told about or offered any of the following support?

	Yes	No	Not sure	Not applicable
A heart failure support group in the local area (either online or in person)				
An exercise programme especially for people who live with heart failure, sometimes known as cardiac rehab				
Support to help with feelings of sadness, depression, or anxiety				

16. Thinking about your heart failure care overall, how much do you agree with the following?

	Strongly agree	Agree	Disagree	Strongly disagree	Unsure	Not applicable
I was happy with how a healthcare professional told me I have heart failure						
I was diagnosed with heart failure in good time						
I am involved in decisions about my care						
I feel my care is tailored to my needs						
I know what to do and who to call if my heart failure gets worse						
I am able to speak to my GP if I need to						
I am able to speak to a specialist heart failure service directly if I need to						
I am seen by a heart failure specialist when I need to be						
If I've been sent home after a stay in hospital, I've been reviewed in the community within two weeks						
The people I see about my heart failure are knowledgeable about the condition						
I am happy with the overall quality of my heart failure care						

17. What do you like best about the heart failure care you have been given?

Part 3: How heart failure services are provided

18. Thinking about how care is provided, how much do you agree with the following?

	Strongly agree	Agree	Disagree	Strongly disagree	Unsure	Not applicable
I am happy to have telephone appointments where appropriate						
I am happy to have video appointments where appropriate (e.g via Zoom)						
I prefer to have appointments in person						
I am happy to be cared for by a virtual ward (also known as a hospital at home) rather than being admitted to hospital if it is appropriate for my needs						
I am happy to use technology to monitor my heart failure from my home						
I am happy to have appointments with a heart failure specialist at my local health centre or a community clinic closer to my home						
I prefer to travel to hospital for appointments with a heart failure specialist						
The time spent with me at my last heart failure appointment at the GP surgery was right for my needs						
The time spent with me at my last heart failure appointment with a specialist was right for my needs (e.g. with a heart failure specialist nurse or consultant)						
I have discussed or agreed a personalised care plan with a healthcare professional that will guide my future care						

19. Thinking about how you live with heart failure, how much do you agree with the following?

	Strongly agree	Agree	Disagree	Strongly disagree	Unsure	Not applicable
I would like to learn more about how to live with heart failure						
I would like to be part of a support group with other people who live with heart failure (either online or in person)						
I would like more information about exercise and heart failure						
I would like more information about diet and nutrition and heart failure						
I would like access to emotional support to help manage my heart failure						

20. Where do you go to find more information about heart failure? (Please tick all that apply)

- | | | |
|---|--|---|
| <input type="checkbox"/> British Heart Foundation website | <input type="checkbox"/> GP practice website | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Pumping Marvellous website | <input type="checkbox"/> Council website | <input type="checkbox"/> Leaflets |
| <input type="checkbox"/> Local hospital website | <input type="checkbox"/> NHS.uk website | <input type="checkbox"/> Other (please write on the line below) |
-

21. What could be done to improve your heart failure care? Please write as much detail as possible.

Part 4: About you (optional)

We want to make sure that we seek the views of a wide range of people. We will only use the information on this form to help us understand who we are reaching, and where we need to do more to hear from other communities.

The answers you provide are anonymous and confidential and cannot be linked back to an individual. If you are filling this survey in on behalf of someone else, please provide information about them and not yourself.

Your data and privacy

All responses are handled anonymously and confidentially. We are committed to protecting your privacy, in accordance with the Data Protection Act 2018 and will not use any information we may hold about you for any purpose other than that for which it was collected.

22. Where did you find out about this survey? (Please tick all that apply)

- | | | |
|--|--|---|
| <input type="checkbox"/> In hospital | <input type="checkbox"/> Via text message | <input type="checkbox"/> Via Healthwatch |
| <input type="checkbox"/> At your GP practice | <input type="checkbox"/> On social media | <input type="checkbox"/> Via Pumping Marvellous charity |
| <input type="checkbox"/> Via email | <input type="checkbox"/> On an NHS website | <input type="checkbox"/> Other (please write below) |
-

23. How would you describe your gender (or the gender of the person you care for)?

- | | | |
|---------------------------------|--|--|
| <input type="checkbox"/> Male | <input type="checkbox"/> Prefer not to say | <input type="checkbox"/> Other (please state): |
| <input type="checkbox"/> Female | | |
-

24. Do you identify as the sex you were assigned at birth?

- | | | |
|------------------------------|-----------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to say |
|------------------------------|-----------------------------|--|

25. What age group are you a part of?

- | | | | |
|--------------------------------|--------------------------------|--------------------------------|--------------------------------|
| <input type="checkbox"/> 17-22 | <input type="checkbox"/> 31-40 | <input type="checkbox"/> 51-60 | <input type="checkbox"/> 71-80 |
| <input type="checkbox"/> 23-30 | <input type="checkbox"/> 41-50 | <input type="checkbox"/> 61-70 | <input type="checkbox"/> 80+ |

26. What is the first part of your postcode? E.g. RH13 or PO18

27. What is your ethnic background?

- | | |
|--|---|
| <input type="checkbox"/> White British | <input type="checkbox"/> Asian / Asian British Bangladeshi |
| <input type="checkbox"/> White Irish | <input type="checkbox"/> Black / Black British Caribbean |
| <input type="checkbox"/> Gypsy and Irish Traveller | <input type="checkbox"/> Black / Black British African |
| <input type="checkbox"/> Mixed White & Black Caribbean | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Mixed White & Black African | <input type="checkbox"/> Arab |
| <input type="checkbox"/> Mixed White & Asian | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Asian / Asian British Indian | <input type="checkbox"/> Other (please write on the line below) |
| <input type="checkbox"/> Asian / Asian British Pakistani | |
-

28. Which of the following best describes your sexual orientation?

- | | |
|--|---|
| <input type="checkbox"/> Heterosexual / Straight | <input type="checkbox"/> Bisexual |
| <input type="checkbox"/> Lesbian / Gay woman | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Gay man | <input type="checkbox"/> Other (please write below) |
-

29. What is your religion or belief?

- | | |
|---|--|
| <input type="checkbox"/> No particular religion | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> Buddhist | <input type="checkbox"/> Agnostic |
| <input type="checkbox"/> Christian | <input type="checkbox"/> Atheist |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> Other religion (please write below) |
| <input type="checkbox"/> Jain | <input type="checkbox"/> Other philosophical belief (please write below) |
| <input type="checkbox"/> Jewish | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Muslim | |
| <input type="checkbox"/> Pagan | |
-

30. Are you disabled? (*The Equality Act 2010 defines disability as 'a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities'*).

- | | | |
|------------------------------|-----------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to say |
|------------------------------|-----------------------------|--|

31. If yes, what type of disability? Please tick all that apply

- | | |
|--|---|
| <input type="checkbox"/> Long-standing illness | <input type="checkbox"/> Hearing impairment |
| <input type="checkbox"/> Physical impairment | <input type="checkbox"/> Visual impairment |
| <input type="checkbox"/> Learning disability | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Mental health condition | <input type="checkbox"/> Other (please write below) |
-

32. Are you a carer? (A carer provides unpaid support to family or friends who are ill, frail, disabled or have mental health or substance misuse problems.)

- Yes No Prefer not to say

33. If yes, do you care for a...?

- | | |
|---|---|
| <input type="checkbox"/> Parent | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Partner/spouse | <input type="checkbox"/> Other family member |
| <input type="checkbox"/> Child with special needs | <input type="checkbox"/> Other (please write below) |
-

34. Would you be happy to take part in a focus group or telephone interview to discuss heart failure services in the local area? If so, please add your contact details below.

Your name: _____

Email address: _____

Telephone number: _____

- Preferred type of focus group: Online e.g. via Zoom
 In-person

35. Do you consent to share your contact details with Sussex Health and Care so that they can contact you in relation to improving heart failure services?

- Yes No

Thank you for taking part in our survey.

Contact Sussex Health and Care

For more information or a different version of this survey (e.g. easy read or a different language), please email: sxicb.involvement@nhs.net specifying the required format.