British Heart Foundation
Data Science Centre

Led by Health Data Research UK

Public survey to identify the most important areas for research into cardiovascular disease

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Public survey to identify the most important areas for research into cardiovascular disease

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Abstract

The British Heart Foundation (BHF) Data Science Centre aims to improve the use of data in cardiovascular disease research. To help us prioritise our work we carried out a UK wide survey to gather input from patients and the public. The survey was co-designed with our group of patient and public representatives (Public Advisory Group). Survey questions asked participants to rate the importance to them of areas of research and ways that research is prioritised. We also organised workshop discussions with our Public Advisory Group.

There were 354 survey respondents, including 66% who were women and 83% who had or knew someone with cardiovascular disease. The three most important areas of research were “Treating the disease”, “Improving the quality of life of patients” and “Diagnosing the disease”. The three most important methods of prioritising research were “Makes a positive impact on the lives or experience of patients”, “Has the potential to be used in healthcare in the UK” and “Is an important question to address”. Workshop discussions covered additional ways to gather patient and public input and methods to reach wider audiences for future surveys. The results of this survey will be used to guide future work of the BHF Data Science Centre.

Introduction

Cardiovascular disease is the commonest cause of death and disability worldwide, responsible for over 17 million deaths per year [1]. In the UK, cardiovascular disease affects 7.6 million people and is estimated to cost £9 billion per year in healthcare costs and £19 billion per year in costs to the wider economy [2]. Despite significant reductions in premature death from cardiovascular disease there remain large disparities, with people from deprived populations nearly 4 times more likely to die prematurely from these diseases compared to those from the most affluent populations [3]. Many of these premature deaths could be prevented by lifestyle changes, early diagnosis, or identification of individuals at high-risk due to conditions such as high blood pressure and raised cholesterol. Cardiovascular research has enormous potential to improve the nation’s health, through improved prevention, diagnosis, and treatment, as well as improving patient experience, satisfaction, and quality of life.

The BHF Data Science Centre aims to improve cardiovascular health through research using health data into the causes, prevention, and treatment of cardiovascular disease. We work with a wide range of partners including patients, public, clinicians, researchers, industry, and healthcare organisations to help them carry out research. There are abundant research questions that could be addressed by the BHF Data Science Centre and other research groups. However, as resources are finite, it is important to prioritise these questions so that the most important questions can be addressed first. Involving the views of patients and the public in this prioritisation is essential so that researchers perform relevant, important, and patient centred research, which ultimately leads to benefits for patients.

Incorporating the views of patients and the public into the planning, conduct and dissemination of research is now a routine part of many studies. Previous work to identify the research priorities of patients and the public has focussed on specific conditions. For example, the James Lind Alliance performed a priority setting exercise to establish research priorities in children and adults with congenital heart disease [4]. They identified topics including improving antenatal screening, reducing the impact of interventions, developing new treatments for advanced heart failure, and improving life expectancy. However, broader views from patients and the public on the types of cardiovascular disease research that should be prioritised, and how these should be prioritised, are needed.

To help prioritise which areas of research the British Heart Foundation Data Science Centre should focused on, we carried out a survey to gather input from patients and the public. This United Kingdom wide survey aimed to gather broad views from patients and the public, to inform our future research.

Methods

Survey design

The survey was co-designed with our Public Advisory Group. This included ensuring that all survey information, questions, and response options were written in plain English and that the online form could be easily completed by members of the public. The survey was carried out using an online tool (SurveyMonkey, https://www.surveymonkey.com, Supplementary Information) and ran from 23rd June 2022 to 21st August 2022.

Survey questions

The survey included two main questions, additional questions regarding basic demographic information and free-text comment boxes.

Responses were filtered to exclude those from respondents not resident in the United Kingdom. Basic demographic questions were optional and included information on age group, gender, and ethnicity. No personally identifiable information was collected.

The first main question asked participants to, “Help us identify which areas of research are most important to patients and the public.” Participants were provided with a list of 10 types of cardiovascular disease research and were asked to rate these from 1 (not at all important) to 5 (very important).

The second main question asked, “There are lots of different ways that are currently used to assess which research studies should be funded and carried out. Which of the following are important to you?”. Participants were presented with 13 ways of assessing research studies and asked to score each from 1 (not at all important) to 5 (very important).

Survey communication

The survey was widely communicated across public engagement networks and social media to ensure as broad a range of participants as possible. It was distributed to public involvement groups (directly, via email, newsletters, and by asking contacts to disseminate), via a paid Twitter advertising campaign, and emails to professional societies with potential patient links. It was also advertised on social media, including Twitter, LinkedIn, Facebook and YouTube, along with a link to an article on our website providing additional information to potential survey respondents (https://www.hdruk.ac.uk/news/have-your-say-can-you-help-us-understand-what-matters-most-in-cardiovascular-research/?utm_source=News+story&utm_medium=Twitter&utm_campaign=Cardiovascular+survey&utm_id=Cardiovascular+survey).

Patient and public workshop discussions

Once the results of the survey were available, we discussed these with our Public Advisory Group in a workshop attended by 15 patient and public representatives. The workshop focused on four main areas: general thoughts on the survey, how we might gather broader input, how we might communicate the results of the survey, and their views on the lowest rated questions.

Statistical analysis

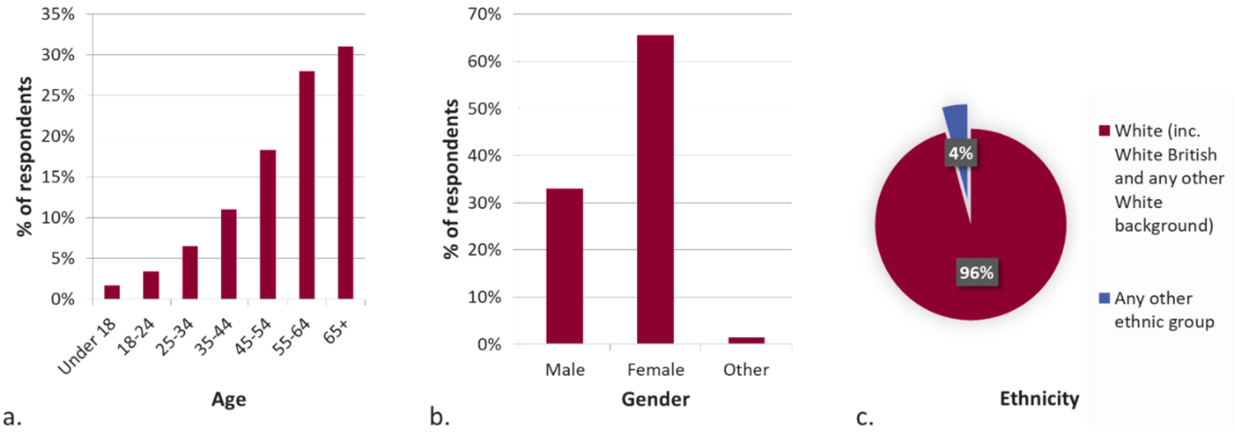
Statistical analysis was carried out using Excel (Microsoft Office, version 16.0) and R (Version 4.0.3, R Foundation for Statistical Computing, Vienna, Austria). For each question response the mean ± standard deviation score was calculated. A higher numerical mean score indicated a higher priority. Statistical significance was assessed using Student’s *t*-test with a two-sided p-value of <0.05 deemed statistically significant. Free-text responses were manually reviewed and categorised. Responses that included multiple suggestions/comments on different subjects were divided, so each response related to a single suggestion or subject.

Results

Survey participant characteristics

There was a total of 487 survey responses, and when limited to respondents from the United Kingdom there were 354 available for further analysis. Of the participants that provided information on demographic characteristics 59% (n=209/354) were aged 55 or above and 66% (n=231/352) were female; 4% (n=15/351) were not of white ethnicity (Figure 1), compared to 18% of the UK population[5]. Most participants (83%, n=293/353) had or knew someone who had cardiovascular disease.

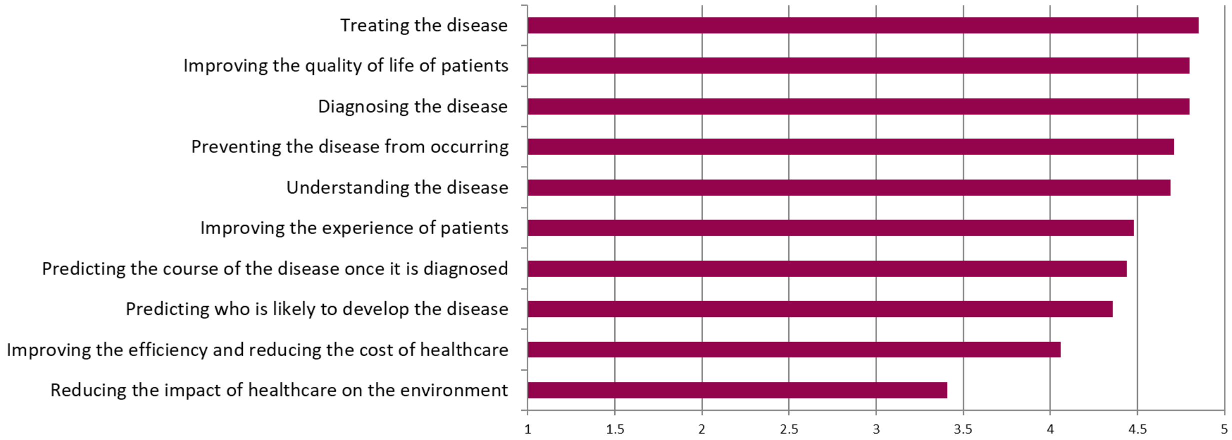
Figure 1. Demographic characteristics of public or patient survey respondents including (a) age, (b) gender and (c) ethnicity.



Which areas of research are most important to patients and the public?

Participants were asked to rate ten areas of cardiovascular disease research based on their importance (Figure 2). The three most important areas of research were “Treating the disease” (mean rating 4.85 ± 0.41), “Improving the quality of life of patients” (mean rating 4.80 ± 0.51), and “Diagnosing the disease” (mean rating 4.89 ± 0.65). Over 80% of respondents rated these questions as “very important” with the highest score of 5 (Supplementary Table 1). The questions “Preventing the disease from occurring" and "Understanding the disease" were rated close behind, with over 70% of respondents rating each of these with the second highest score of 4 or more. The area of research that patients and the public rated the lowest importance was "Reducing the impact of healthcare on the environment" (mean rating 3.41 ± 1.23), with only 24% respondents rating it as very important with a score of 5, and over 50% of respondents rating it with a score of 3 or below.

Figure 2. Mean rating of answers to the question "To help us identify which areas of research are most important to patients and the public. Please score from 1 to 5, with 1 being not at all important and 5 being very important."



Compared to men, women gave higher ratings to the questions "Improving the quality of life of patients" (mean rating 4.86 ± 0.45 versus 4.69 ± 0.60, p=0.003), "Understanding the disease" (4.75 ± 0.54 versus 4.59 ± 0.67, p=0.019), "Improving the experience of patients" (4.57 ± 0.71 versus 4.27 ± 0.81, p<0.001) and "Reducing the impact of healthcare on the environment" (3.56 ± 1.12 versus 3.11 ± 1.37, p0.001, Supplementary Table 2). People over the age of 55 years gave higher ratings to the questions "Preventing the disease from occurring" (mean rating 4.83 ± 0.49 versus 4.55 ± 0.80, p<0.001), "Predicting the course of the disease once it is diagnosed" (4.54 ± 0.76 versus 4.30 ± 0.89), p=0.007), "Predicting who is likely to develop the disease" (4.52 ± 0.79 versus 4.12 ± 0.97, p<0.001), “Improving the efficiency and reducing the cost of healthcare” (4.18 ± 0.97 versus 3.89 ± 1.01, p=0.006) and “Reducing the impact of healthcare on the environment” (3.53 ± 1.26 versus 3.23 ± 1.16, p=0.027) (Supplementary Table 3). People who had, or knew someone who had, heart or circulatory disease gave higher ratings to the questions “Understanding the disease” (mean rating 4.72 ± 0.58 versus 4.55 ± 0.62, p=0.041) compared to those who did not (Supplementary Table 4).

Respondents were asked to submit suggestions of any other areas of heart and circulatory disease research that they thought were important for future research. A total of 220 additional suggestions were submitted, including 148 that suggested other research questions or aims and 72 that primarily highlighted specific cardiovascular conditions. These were summarised into themes (Table 1). The most common theme related to the relationship between heart and circulatory disease and lifestyle e.g., diet, exercise, sleep, and stress. Many of these suggestions were focussed on a better understanding of the role of diet and nutrition, including sugar, salt, and artificial sweeteners, and a vegan or vegetarian diet, on disease causation or risk.

Table 1. Summary of the additional suggestions submitted as free text suggestions.

General Theme	**Additional detail/examples**	**Number**
Lifestyle	Impact of lifestyle e.g., diet and exercise	20
Genetic risk	Genetic risk and family history	15
Prevention	Improving understanding of prevention strategies, enabling actionable advice	15
Inequalities	Differences between cardiovascular disease in men and women, equity for women in research, understanding and addressing inequalities in healthcare and disease	14
Risk factors	Other risk factors e.g., ethnicity, socioeconomic status, pregnancy, pollution	13
Comorbidity	Interactions between cardiovascular and other diseases	13
Treatment	Developing improved and new treatments, and understanding treatment effectiveness	12
Diagnosis	Improving screening and diagnosis	11
Patient support	Improving support for patients	9
Awareness/education	Educating patients and the public	4
Patient and public involvement and engagement	How to communicate and collaborate with the public	3
Quality of life	The effect of disease and treatment on quality of life	3
Rehabilitation	Improving heart function and repair, and reducing recurrence	2
Young/teenage patients	Cardiovascular disease in the young/teenagers and their experiences	2
Other research topics suggested a single time	Effect of disease on the economy, gene therapy, transplant rejection, dissemination of research, training of healthcare professionals	12
Specific condition	Postural Orthostatic Tachycardia syndrome (POTS)	15
	Coronary artery disease	8
	Atrial fibrillation	6
	COVID-19 or COVID-19 vaccine	6
	Valvular heart disease	6
	Aortic disease	5

	Congenital heart diseases	4
	Heart failure	4
	Cardiomyopathy	3
	Sudden cardiac death	3
	Arrhythmia	2
	Takotsubo Cardiomyopathy	2
	Other conditions suggested a single time, including pulmonary embolism, pulmonary hypertension, spontaneous coronary artery dissection	8

How should research be prioritised?

With the help of the steering group and Public Advisory Group, thirteen commonly used domains for prioritising research were translated into plain English descriptions for use in the survey (Table 2).

Table 2: Domains for prioritising research and the plain English descriptions used in this survey.

Domain for prioritisation	**Plain English description**
Impact	Makes a positive impact on the lives or experience of patients
Translation	Has the potential to be used in healthcare in the UK
Importance	Is an important question to address
Address inequalities	Reduces inequalities in health care
Relevance	Is relevant to the patients who are taking part in the research
Patient involvement	Involves patients and carers in shaping and managing the research project
Cost, Cost effectiveness	Is a good use of money
Feasible	Experts think that the research is likely to be possible
Answerable	Is likely to have a clear result
Affordability	Is something that we can afford to do
Frequency, Prevalence	Is focused on a common disease
Novel	Is new and has not been done before
Environmental impact, sustainability	Doesn't negatively affect the environment or society

Participants were asked to rate the importance of these thirteen ways that research can be prioritised (Figure 3). The highest rated methods were “Makes a positive impact on the lives or experience of patients” (mean rating 4.77 ± 0.56), “Has the potential to be used in healthcare in the UK” (mean rating 4.59 ± 0.72), and “Is an important question to address” (mean rating 4.33 ± 0.80). Over 80% of respondents rated “Makes a positive impact on the lives or experience of patients” with the highest score of 5 (Supplementary Table 5). The lowest rated domains were “Is new and has not been done before” (mean rating 3.67 ± 0.99) and “Doesn’t negatively affect the environment or society” (mean rating 3.46 ± 1.16).

Figure 3. Mean rating of answers to the question “There are lots of different ways that are currently used to assess which research studies should be funded and carried out. Which of the following are important to you? Please score from 1 to 5, with 1 being not at all important and 5 being very important.”

Compared to men, women gave higher ratings to the themes “Reduces inequalities in health care” (mean rating 4.44 ± 0.81 versus 3.92 ± 1.21, p<0.001) and “Doesn't negatively affect the environment or society” (mean rating 3.59 ± 1.09 versus 3.19 ± 1.24, p<0.003, Supplementary Table 6). People over the age of 55 years gave higher ratings to the themes “Involves patients and carers in shaping and managing the research project" (mean rating 4.36 ± 0.84 versus 4.00 ± 0.99, $p<0.001$), "Is a good use of money" (mean rating 4.22 ± 0.96 versus 3.92 ± 1.03, $p=0.005$), "Is focused on a common disease" (mean rating 3.95 ± 1.00 versus 3.42 ± 1.25, $p<0.001$) and "Is new and has not been done before" (mean rating 3.80 ± 0.95 versus 3.49 ± 1.02, $p=0.005$), compared to those younger than 55 years (Supplementary Table 7). People who had or knew someone who had heart or circulatory disease gave higher ratings to the themes "Makes a positive impact on the lives or experience of patients" (mean rating 4.80 ± 0.53 versus 4.62 ± 0.66, $p=0.026$) and "Involves patients and carers in shaping and managing the research project" (mean rating 4.26 ± 0.92 versus 4.00 ± 0.88, $p=0.044$) compared to those who did not (Supplementary Table 8).

Respondents were also asked to submit any additional factors that should be considered when prioritising research questions as free text. A total of 49 suggestions were submitted with the most common being related to considering the opinions of patients (Table 3).

Table 3. Additional points raised about how to prioritise research.

General theme	Additional detail/examples	Count
Importance to patients	Addresses questions patients think are important, prioritised by patients, and/or patients should be involved in co-designing the research	10
Addresses gap in knowledge	Addresses gap in knowledge that may benefit treatment or improve lives	4
Wide applicability	Has wide applicability across the world, supports equality, diversity, inclusion and access	4
Impact	Has potential to lead to large benefits	3
Prioritise new/novel ideas	New or innovative ideas, or in new areas	3
Translation into clinic	Could be adopted into clinical practice	3
Checking current understanding	Checking that current practices and historical understanding is still relevant	2
Health inequalities	Addresses differences in health across the population to increase equity	2
Positive impact on quality of life	How much it could improve patient quality of life	2
Value for money	Potential cost benefit	2
Factors suggested a single time	Including enabling people to look after themselves, identifying conditions early, potential for alternative funding	14

Additional survey comments

Respondents were able to submit any additional comments as free text, with a total of 85 comments submitted. Most reinforced points already raised in response to the two main questions. The most frequent novel comments focussed on praising the healthcare received from the National Health Service, whilst also raising the issues of the the need for additional resources and the support for National Health Service staff, and positive comments regarding the work of the BHF and this survey.

Patient and public involvement group workshop

Members of the BHF Data Science Centre Public Advisory Group shared their general thoughts on the survey which they felt reflected their views overall. However, they suggested the need for more specific questions that could capture the nuances of their individual experiences. They also suggested the use of different methods such as focus groups and interviews to supplement the survey data. The group emphasised the importance of survey accessibility and suggested that a potential avenue for future implementation could be the placement of surveys within general practitioner surgeries.

The group brainstormed ways to gather broader input. Members suggested the use of social media, community forums, and local events to reach a wider audience. They emphasised the need to tailor the methods used to the specific target audience, considering language barriers, literacy levels, and cultural differences. They also proposed exploring databases of contacts from other healthcare providers, approaching charities and community groups, and acknowledging the potential for bias towards input from older individuals when discussing cardiovascular disease.

The low rating of 'impact on the environment' on healthcare was attributed to various factors. The group suggested that the connection between healthcare resource utilisation and the environment is not always recognised by patients and there is a general lack of awareness on this topic. They also felt that patients prioritise treatments or research that can help them or their peer group, and environmental impact is often ignored unless it is particularly significant. It was suggested that environmental concerns are a lower priority when people are focused on life threatening illnesses.

Finally, we explored methodologies for effectively disseminating results of this and other surveys to patients and the public. The group suggested the use of flyers, posters, and BHF media resources to promote the survey results. They also suggested involving community leaders and stakeholders to help spread the word.

Discussion

This survey explored the views of patients and the public on the types of cardiovascular disease research that were important to them, and how these should be prioritised. The survey was co-designed with our Public Advisory Group and the results presented here summarise the views of over 350 patients and members of the public from the United Kingdom. The three most important areas of research were “Treating the disease”, “Improving the quality of life of patients” and “Diagnosing the disease”. The three most important methods of prioritising research were “Makes a positive impact on the lives or experience of patients”, “Has the potential to be used in healthcare in the UK” and “Is an important question to address”. The results of this survey will be used to guide future work of the BHF Data Science Centre.

The results of this survey will have impact for other groups involved in planning, performing, and funding research studies. All the research questions were rated as important to some degree, but patients and the public rated improving treatment, quality of life, and diagnosis as the most important. We noted differences in ratings based on gender, age and whether the participant had or knew someone who had heart or circulatory disease. Women rated questions regarding quality of life, understanding the disease and environmental concerns higher than men. People over the age of 55 years rated questions regarding prevention, prediction, cost, and environmental concerns higher than those younger than 55 years. People who had or knew someone who had, heart or circulatory disease gave higher ratings to understanding the disease than those who did not. Many of the additional research suggestions focussed on increasing understanding of risk factors for cardiovascular disease, including lifestyle choices, genetic and other risk factors. Another common research suggestion was the use of this information to improve prevention strategies. When taken together these suggestions highlight the importance survey respondents placed on enabling the public and patients to improve their own cardiovascular health and reduce risk of developing disease. We also received over 70 suggestions for specific cardiovascular and related conditions that were perceived as topics for of future research. However, this survey was not designed to choose between cardiovascular conditions and instead focussed on the importance of general themes of research questions.

In terms of how research should be prioritised the highest rated domains were impact, translation, importance and reducing inequalities. Research that focussed on the impact on the environment or society was again rated the lowest. Again, we noted differences in ratings based on gender, age and whether the participant had or knew someone who had heart or circulatory disease. Women gave higher ratings to domains regarding inequalities and environmental concerns compared to men. People over the age of 55 years gave higher ratings to patient or carer involvement, cost effectiveness, focusing on common diseases and novelty. People who had or knew someone who had heart or circulatory disease gave higher ratings to impact for patients, and patient or carer involvement. These results highlight the importance of working alongside the public and patients in setting research priorities and co-designing research studies.

Interestingly, reducing the impact of healthcare on the environment was rated lowest in both questions of the survey. This is possibly because the impact of healthcare on the environment is not widely known, or because the other survey options which could have an immediate personal impact were rated higher. Environmental concerns were rated higher by women and people over the age of 55 years, highlighting the importance of considering different groups when setting research priorities. During the workshop with our Public Advisory Group interesting points were made about the lack of knowledge of the impact of healthcare on the environment.

Important points raised by members of the BHF Data Science Centre Public Advisory Group emphasised several important points during their discussions. They highlighted the significance of addressing research questions that could be implemented today, as well as those that could facilitate new areas of treatment in the future. They stressed the need for a diverse range of research questions that would capture the nuances of their individual experiences. It was noted that patients would generally prioritise research that directly impacted them on an individual level. To facilitate increased public involvement in future surveys, the group suggested several methods to broaden engagement. This included increasing the range of places that survey information was available, such as making it available in general practice surgeries, working with other organisations and public involvement groups to broaden engagement, incorporating focus groups and individual interviews to explore topics more deeply and gather more detailed feedback, and to specifically target underrepresented audiences. They recognised that certain groups, such as those from low-income backgrounds or those with disabilities, may be less likely to participate in surveys. Respondents to the survey were overwhelmingly of white ethnicity, and therefore it is not possible to segment the data based on ethnicity. For future surveys it is vital to specifically targeted these underrepresented audiences to gain insights from more diverse populations. The survey also did not ask questions regarding socioeconomic status, which would also be valuable for future assessment. To overcome this, they suggested tailoring the survey to specific groups and ensuring that the survey was accessible and easy to complete.

This survey has some limitations which should be acknowledged. Firstly, although this survey was widely advertised and is the largest published survey of its type, it does represent a small subset of the UK's population who are likely to be engaged in this topic. Future surveys should aim to recruit a wider range of the population, and more individuals of a range of ethnicities. The survey methods used were chosen in collaboration with our Public Advisory Group to be possible to complete by the widest range of people possible. However, digital literacy and internet access were still required, so future surveys should take this into consideration. It should also be noted that the methodology used in this survey (rating of responses to questions, rather than forced ranking) was designed to allow respondents to provide input that fairly reflected their opinion on the importance of each option, rather than identify which option was considered to be the most important.

The results of this survey will be used to inform the work of the BHF Data Science Centre across its thematic areas. We have already used this information to guide a prioritisation exercise to identify the most important research questions for cardiovascular imaging research. These results will also be of value for anyone planning, designing, performing, or funding research studies. We hope that this study will prompt further discussion of the views of patients and public regarding cardiovascular research.

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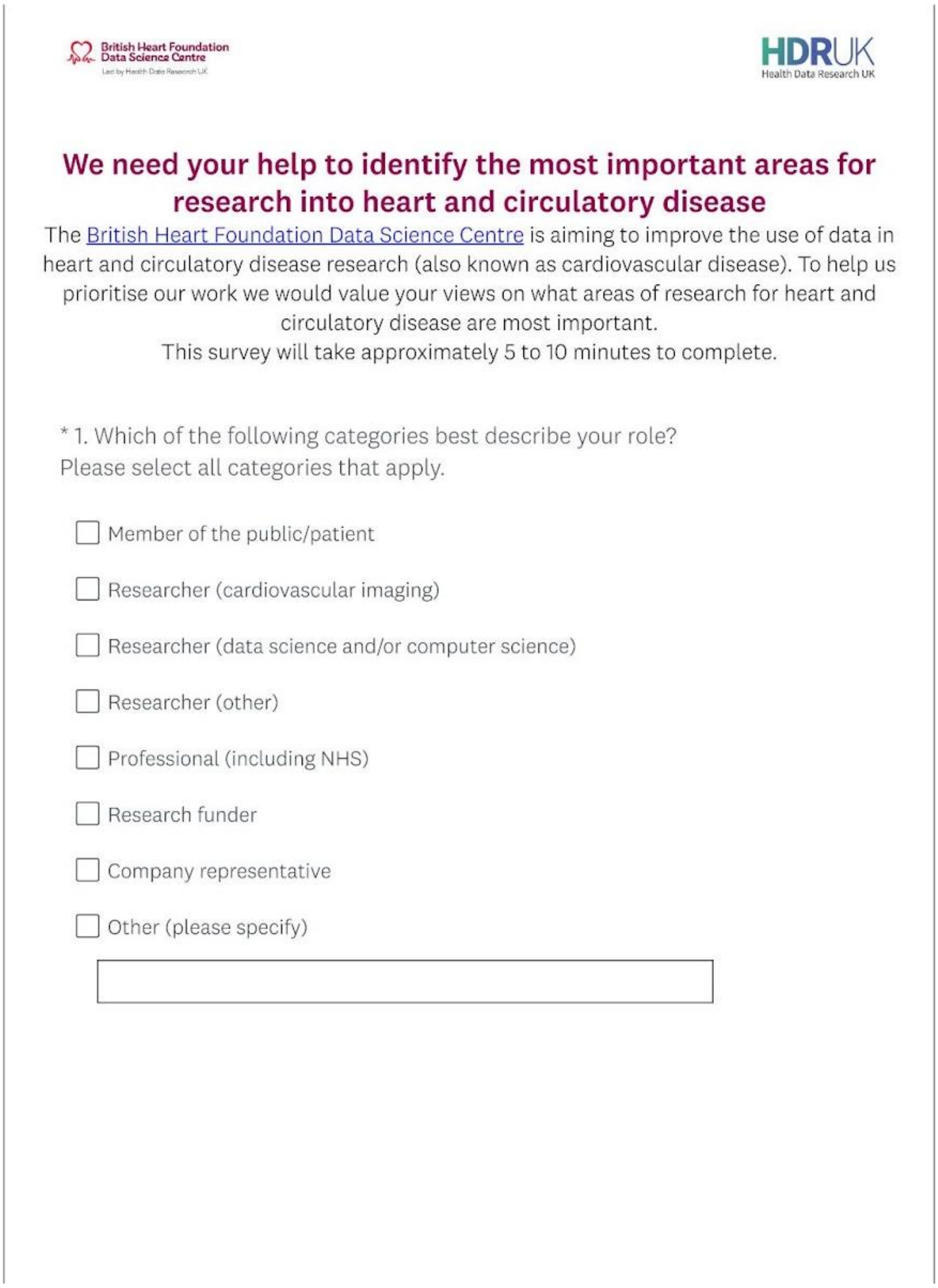
Disclosures

MCW has given talks for Canon Medical Systems, Siemens Healthineers, and Novartis.

Supplementary information

Supplementary Figure 1. Survey to identify the most important areas for research into heart and circulatory disease.



We need your help to identify the most important areas for research into heart and circulatory disease

The British Heart Foundation Data Science Centre is aiming to improve the use of data in heart and circulatory disease research (also known as cardiovascular disease). To help us prioritise our work we would value your views on what areas of research for heart and circulatory disease are most important.

This survey will take approximately 5 to 10 minutes to complete.

* 1. Which of the following categories best describe your role?
Please select all categories that apply.

☐ Member of the public/patient
☐ Researcher (cardiovascular imaging)
☐ Researcher (data science and/or computer science)
☐ Researcher (other)
☐ Professional (including NHS)
☐ Research funder
☐ Company representative
☐ Other (please specify)

We need your help to identify the most important areas for research into heart and circulatory disease

* 2. To help us identify which areas of research are most important to patients and the public. Please score from 1 to 5, with 1 being not at all important and 5 being very important.

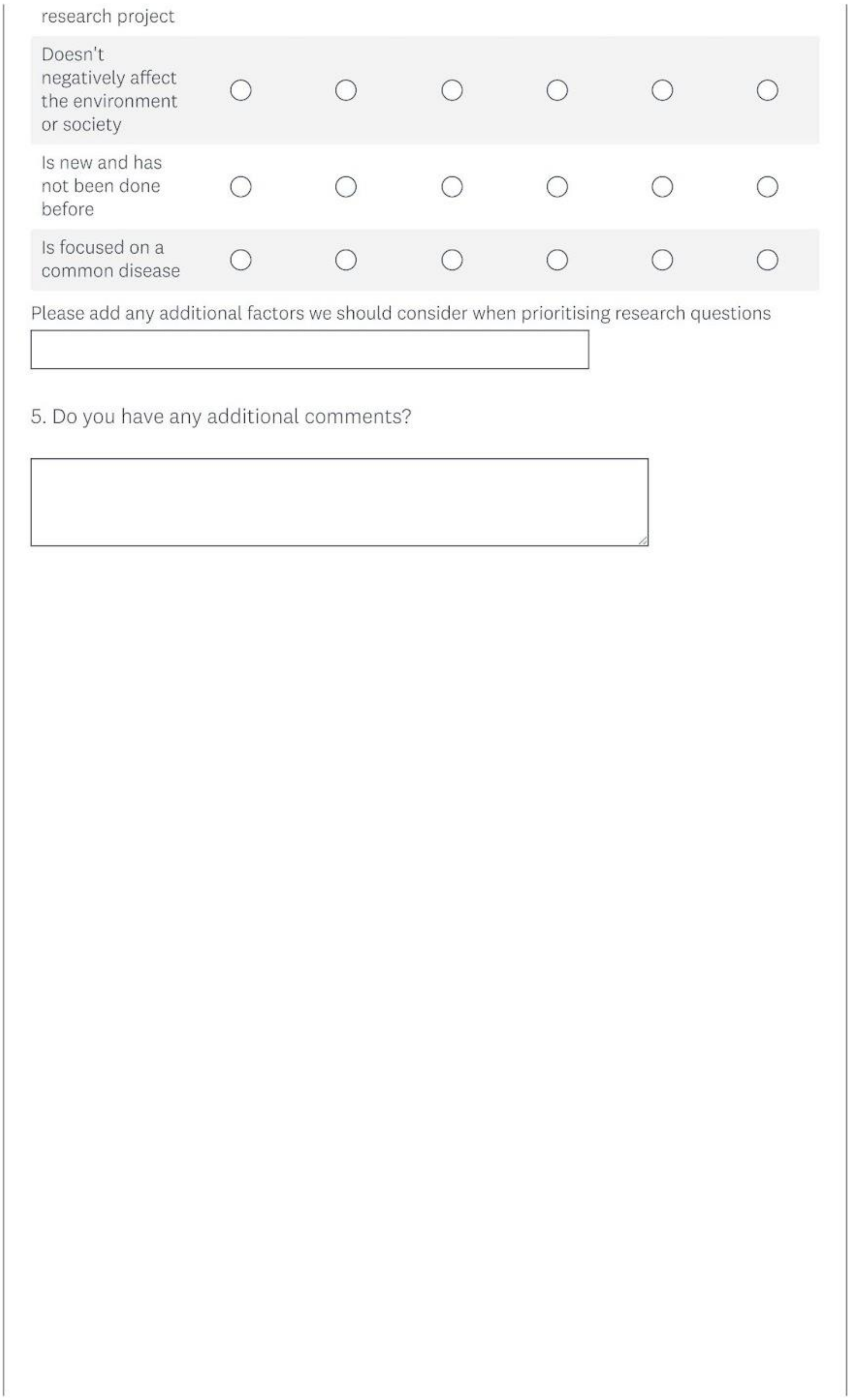
	1 (Not at all important)	2	3	4	5 (Very important)	N/A
Predicting who is likely to develop the disease	○	○	○	○	○	○
Diagnosing the disease	○	○	○	○	○	○
Treating the disease	○	○	○	○	○	○
Preventing the disease from occurring	○	○	○	○	○	○
Predicting the course of the disease once it is diagnosed	○	○	○	○	○	○
Understanding the disease	○	○	○	○	○	○
Reducing the impact of healthcare on the environment	○	○	○	○	○	○
Improving the experience of patients	○	○	○	○	○	○
Improving the efficiency and reducing the cost of healthcare	○	○	○	○	○	○
Improving the quality of life of patients	○	○	○	○	○	○

3. Are there any other areas of heart and circulatory disease research that you think are important for future research?

* 4. There are lots of different ways that are currently used to assess which research studies should be funded and carried out. Which of the following are important to you? Please score from 1 to 5, with 1 being not at all important and 5 being very important.

If the research:

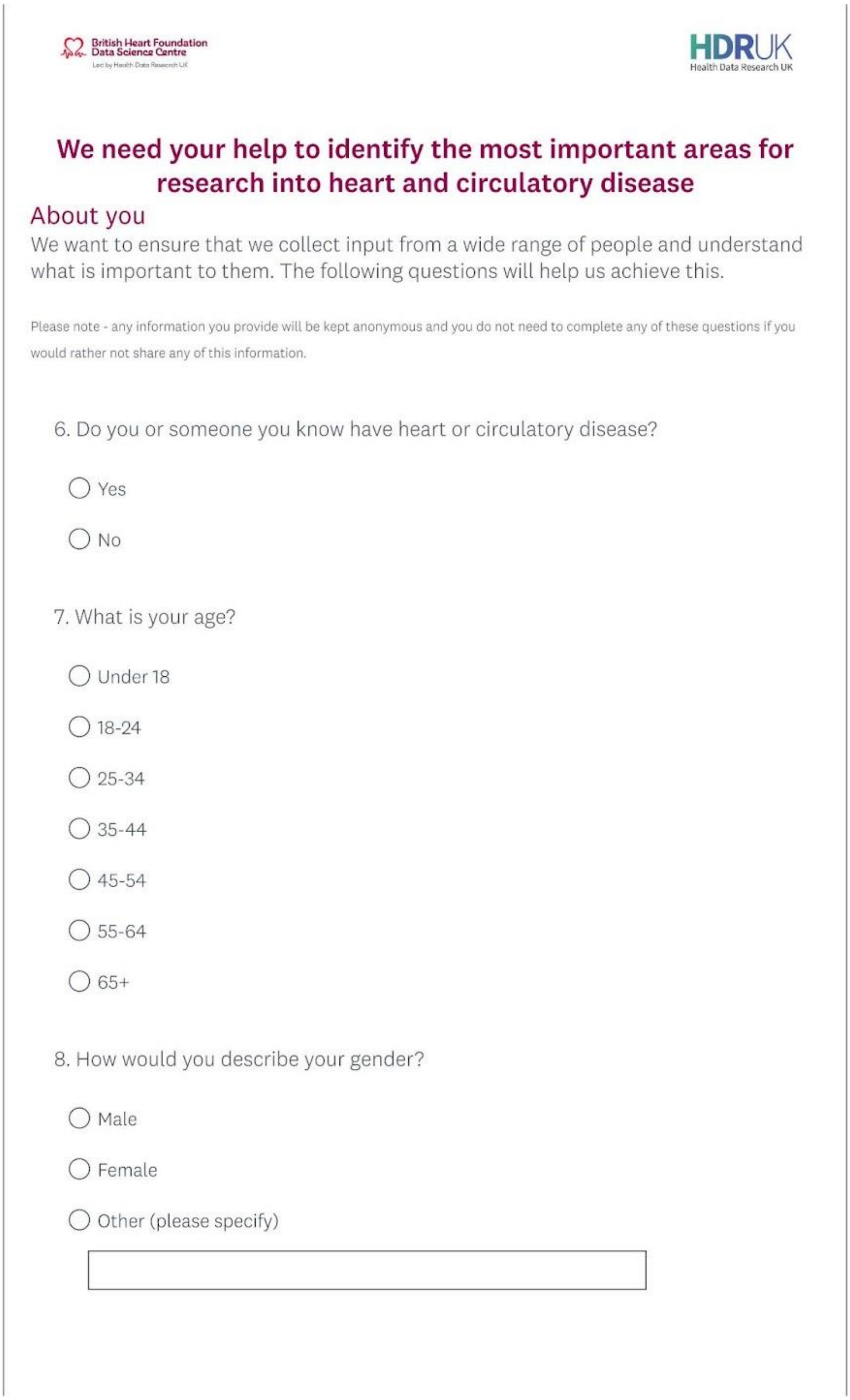
	1 (Not at all important)	2	3	4	5 (Very important)	N/A
Makes a positive impact on the lives or experience of patients	○	○	○	○	○	○
Has the potential to be used in healthcare in the UK	○	○	○	○	○	○
Is an important question to address	○	○	○	○	○	○
Experts think that the research is likely to be possible	○	○	○	○	○	○
Is a good use of money	○	○	○	○	○	○
Is something that we can afford to do	○	○	○	○	○	○
Is likely to have a clear result	○	○	○	○	○	○
Reduces inequalities in health care	○	○	○	○	○	○
Is relevant to the patients who are taking part in the research	○	○	○	○	○	○
Involves patients and carers in shaping and managing the	○	○	○	○	○	○



research project						
Doesn't negatively affect the environment or society	○	○	○	○	○	○
Is new and has not been done before	○	○	○	○	○	○
Is focused on a common disease	○	○	○	○	○	○

Please add any additional factors we should consider when prioritising research questions

5. Do you have any additional comments?



British Heart Foundation
Data Science Centre
Led by Health Data Research UK

HDRUK
Health Data Research UK

We need your help to identify the most important areas for research into heart and circulatory disease

About you

We want to ensure that we collect input from a wide range of people and understand what is important to them. The following questions will help us achieve this.

Please note - any information you provide will be kept anonymous and you do not need to complete any of these questions if you would rather not share any of this information.

6. Do you or someone you know have heart or circulatory disease?

○ Yes

○ No

7. What is your age?

○ Under 18

○ 18-24

○ 25-34

○ 35-44

○ 45-54

○ 55-64

○ 65+

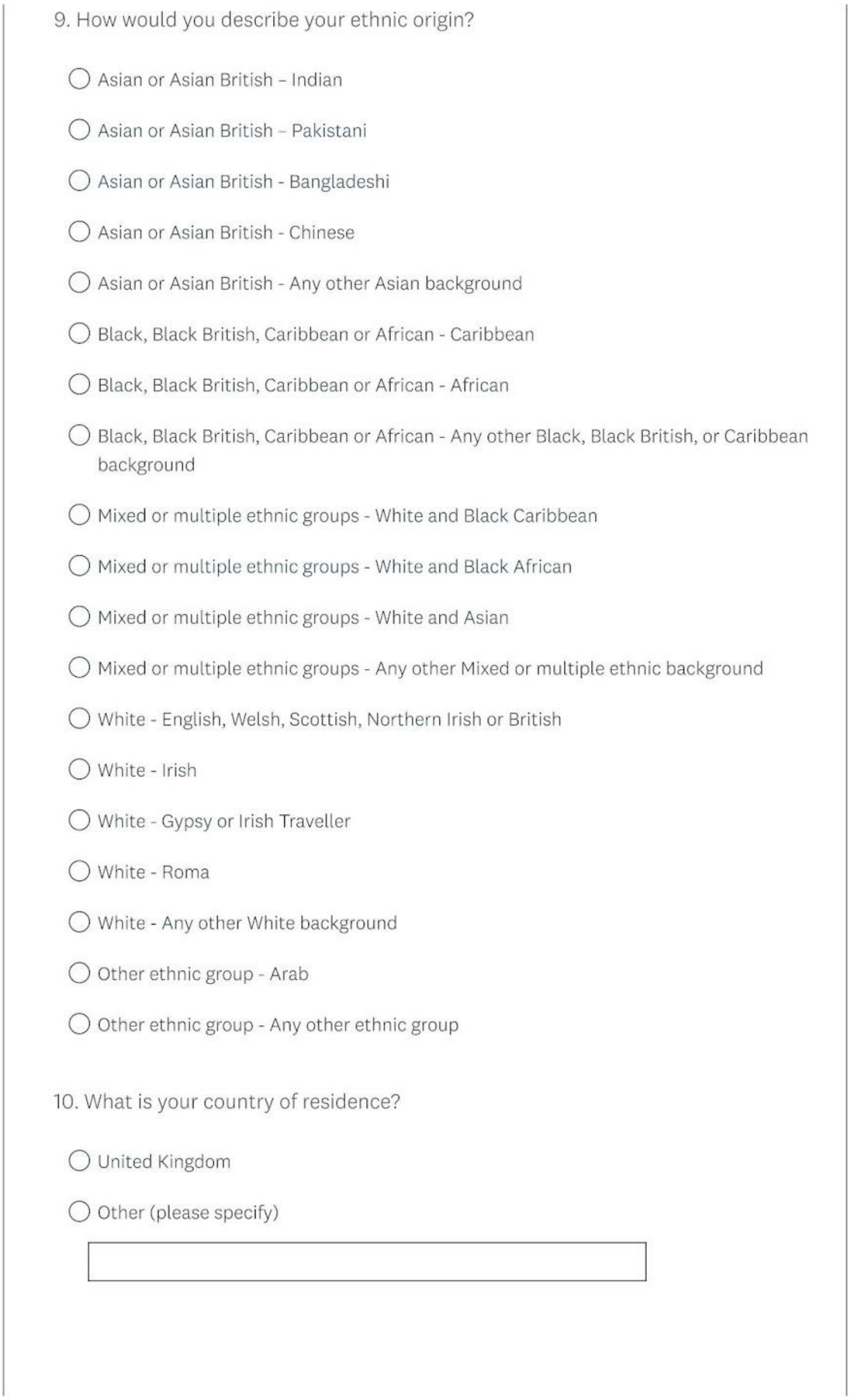
8. How would you describe your gender?

○ Male

○ Female

○ Other (please specify)

☐

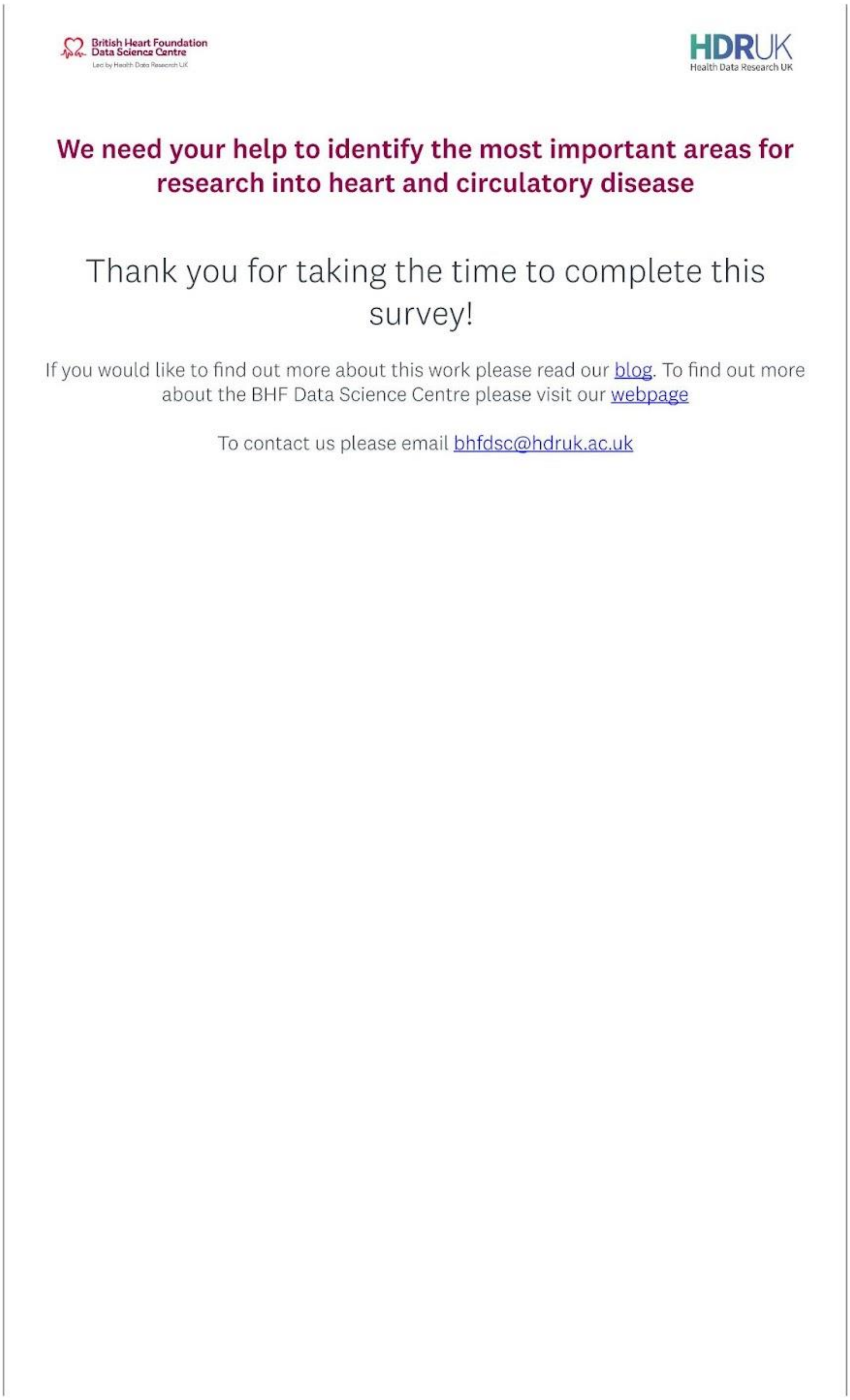


9. How would you describe your ethnic origin?

○ Asian or Asian British – Indian
○ Asian or Asian British – Pakistani
○ Asian or Asian British - Bangladeshi
○ Asian or Asian British - Chinese
○ Asian or Asian British - Any other Asian background
○ Black, Black British, Caribbean or African - Caribbean
○ Black, Black British, Caribbean or African - African
○ Black, Black British, Caribbean or African - Any other Black, Black British, or Caribbean background
○ Mixed or multiple ethnic groups - White and Black Caribbean
○ Mixed or multiple ethnic groups - White and Black African
○ Mixed or multiple ethnic groups - White and Asian
○ Mixed or multiple ethnic groups - Any other Mixed or multiple ethnic background
○ White - English, Welsh, Scottish, Northern Irish or British
○ White - Irish
○ White - Gypsy or Irish Traveller
○ White - Roma
○ White - Any other White background
○ Other ethnic group - Arab
○ Other ethnic group - Any other ethnic group

10. What is your country of residence?

○ United Kingdom
○ Other (please specify)



We need your help to identify the most important areas for research into heart and circulatory disease

Thank you for taking the time to complete this survey!

If you would like to find out more about this work please read our blog. To find out more about the BHF Data Science Centre please visit our webpage

To contact us please email bhfdsc@hdruk.ac.uk

Supplementary Table 1: Survey answers to the question "To help us identify which areas of research are most important to patients and the public. Please score from 1 to 5, with 1 being not at all important and 5 being very important."

	N	**1**	**2**	**3**	**4**	**5**	**NA**	**Mean Rating**
Treating the disease	352	0	1 0.3%	4 1.1%	40 11%	306 87%	1 0.3%	4.85 ± 0.41
Diagnosing the disease	350	4 1.1%	1 0.3%	6 1.7%	39 11%	299 85%	1 0.3%	4.80 ± 0.51
Improving the quality of life of patients	353	1 0.3%	1 0.3%	9 2.6%	46 13%	295 84%	1 0.3%	4.80 ± 0.59
Preventing the disease from occurring	353	1 0.3%	4 1.1%	20 5.7%	45 13%	281 80%	2 0.6%	4.71 ± 0.65
Understanding the disease	352	0	2 0.6%	18 5.1%	66 19%	265 75%	1 0.3%	4.69 ± 0.59
Improving the experience of patients	351	1 0.3%	5 1.4%	36 10%	92 26%	215 61%	2 0.6%	4.48 ± 0.76
Predicting the course of the disease once it is diagnosed	353	3 0.9%	8 2.3%	34 9.6%	91 26%	215 61%	2 0.6%	4.44 ± 0.83
Predicting who is likely to develop the disease	353	3 0.9%	12 3.4%	44 13%	91 26%	202 57%	1 0.3%	4.36 ± 0.89
Improving the efficiency and reducing the cost of healthcare	354	6 1.7%	20 5.7%	68 19%	111 31%	148 42%	1 0.3%	4.06 ± 1.00
Reducing the impact of healthcare on the environment	353	27 7.7%	54 15%	101 29%	79 22%	85 24%	7 2.0%	3.41 ± 1.23

N, Number; NA, not answered.

Supplementary Table 2: Mean rating of answers from male and female survey participants to the question "To help us identify which areas of research are most important to patients and the public. Please score from 1 to 5, with 1 being not at all important and 5 being very important."

	Male	**Female**	**p**
Treating the disease	4.81 ± 0.51	4.88 ± 0.34	0.150
Improving the quality of life of patients	4.69 ± 0.60	4.86 ± 0.45	0.003
Diagnosing the disease	4.73 ± 0.72	4.84 ± 0.52	0.099
Preventing the disease from occurring	4.72 ± 0.6	4.73 ± 0.61	0.862
Understanding the disease	4.59 ± 0.67	4.75 ± 0.54	0.019
Improving the experience of patients	4.27 ± 0.81	4.57 ± 0.71	<0.001
Predicting the course of the disease once it is diagnosed	4.42 ± 0.87	4.46 ± 0.81	0.646
Predicting who is likely to develop the disease	4.44 ± 0.88	4.32 ± 0.88	0.211
Improving the efficiency and reducing the cost of healthcare	4.06 ± 0.99	4.06 ± 1.00	0.973
Reducing the impact of healthcare on the environment	3.11 ± 1.37	3.56 ± 1.12	0.001

Mean ± standard deviation.

Supplementary Table 3: Mean rating of answers from survey participants above and below 65 years of age to the question “To help us identify which areas of research are most important to patients and the public. Please score from 1 to 5, with 1 being not at all important and 5 being very important.”

	Age less than 55 years	**Age greater than 55 years**	**p**
Treating the disease	4.86 ± 0.39	4.85 ± 0.42	0.985
Improving the quality of life of patients	4.79 ± 0.50	4.80 ± 0.53	0.874
Diagnosing the disease	4.77 ± 0.58	4.82 ± 0.60	0.450
Preventing the disease from occurring	4.55 ± 0.80	4.83 ± 0.49	<0.001
Understanding the disease	4.67 ± 0.64	4.71 ± 0.56	0.536
Improving the experience of patients	4.47 ± 0.76	4.48 ± 0.76	0.890
Predicting the course of the disease once it is diagnosed	4.30 ± 0.89	4.54 ± 0.76	0.007
Predicting who is likely to develop the disease	4.12 ± 0.97	4.52 ± 0.79	<0.001
Improving the efficiency and reducing the cost of healthcare	3.89 ± 1.01	4.18 ± 0.97	0.006
Reducing the impact of healthcare on the environment	3.23 ± 1.16	3.53 ± 1.26	0.027

Mean ± standard deviation.

Supplementary Table 4: Mean rating of answers from survey participants who did or did not have or know someone who had heart or circulatory disease to the question “To help us identify which areas of research are most important to patients and the public. Please score from 1 to 5, with 1 being not at all important and 5 being very important.”

	Do you or someone you know have heart or circulatory disease?		**p**
	No	**Yes**	
Treating the disease	4.85 ± 0.44	4.86 ± 0.40	0.962
Improving the quality of life of patients	4.77 ± 0.50	4.80 ± 0.52	0.643
Diagnosing the disease	4.75 ± 0.60	4.81 ± 0.59	0.478
Preventing the disease from occurring	4.77 ± 0.50	4.70 ± 0.68	0.442
Understanding the disease	4.55 ± 0.62	4.72 ± 0.58	0.041
Improving the experience of patients	4.31 ± 0.79	4.51 ± 0.75	0.059
Predicting the course of the disease once it is diagnosed	4.41 ± 0.72	4.45 ± 0.85	0.719
Predicting who is likely to develop the disease	4.39 ± 0.88	4.35 ± 0.89	0.711
Improving the efficiency and reducing the cost of healthcare	4.08 ± 1.04	4.06 ± 0.99	0.866
Reducing the impact of healthcare on the environment	3.42 ± 1.23	3.41 ± 1.24	0.950

Mean ± standard deviation.

Supplementary Table 5: Survey answers to the question “There are lots of different ways that are currently used to assess which research studies should be funded and carried out. Which of the following are important to you? Please score from 1 to 5, with 1 being not at all important and 5 being very important”

	N	1	2	3	4	5	NA	Mean Rating
Makes a positive impact on the lives or experience of patients	354	1 0.3%	3 0.9%	9 2.5%	51 14%	290 82%	0	4.77 ± 0.56
Has the potential to be used in healthcare in the UK	354	5 1.4%	0	18 5.1%	89 25%	241 68%	1 0.3%	4.59 ± 0.72
Is an important question to address	354	2 0.6%	4 1.1%	49 14%	115 33%	180 51%	4 1.1%	4.33 ± 0.80
Reduces inequalities in health care	354	7 2.0%	17 4.8%	43 12%	90 25%	195 55%	2 0.6%	4.28 ± 0.99
Is relevant to the patients who are taking part in the research	354	6 1.7%	17 4.8%	47 13%	88 25%	190 54%	6 1.7%	4.26 ± 0.98
Involves patients and carers in shaping and managing the research project	354	3 0.9%	10 2.8%	71 20%	93 26%	176 50%	1 0.3%	4.22 ± 0.92
Is a good use of money	354	9 2.5%	12 3.4%	70 20%	107 30%	154 44%	2 0.6%	4.09 ± 1.00
Experts think that the research is likely to be possible	354	6 1.7%	14 4.0%	66 19%	131 37%	134 38%	3 0.9%	4.06 ± 0.94
Is likely to have a clear result	354	8 2.3%	19 5.4%	79 22%	120 34%	124 35%	4 1.1%	3.95 ± 1.00
Is something that we can afford to do	354	17 4.8%	22 6.2%	86 24%	121 34%	103 29%	5 1.4%	3.78 ± 1.09
Is focused on a common disease	354	22 6.2%	23 6.5%	84 24%	117 33%	103 29%	5 1.4%	3.73 ± 1.14

Is new and has not been done before	354	7 2.0%	29 8.2%	119 34%	111 31%	83 23%	5 1.4%	3.67 ± 0.99
Doesn't negatively affect the environment or society	354	24 6.8%	44 12%	104	100 28%	75 21%	7 2.0%	3.46 ± 1.16

Mean ± standard deviation.

Supplementary Table 6: Mean rating of answers from male and female survey participants to the question “There are lots of different ways that are currently used to assess which research studies should be funded and carried out. Which of the following are important to you? Please score from 1 to 5, with 1 being not at all important and 5 being very important.”

	Male	**Female**	**p**
Makes a positive impact on the lives or experience of patients	4.70 ± 0.64	4.81 ± 0.52	0.095
Has the potential to be used in healthcare in the UK	4.51 ± 0.77	4.62 ± 0.69	0.169
Is an important question to address	4.24 ± 0.84	4.38 ± 0.77	0.108
Reduces inequalities in health care	3.92 ± 1.21	4.44 ± 0.81	<0.001
Is relevant to the patients who are taking part in the research	4.12 ± 1.08	4.33 ± 0.93	0.064
Involves patients and carers in shaping and managing the research project	4.11 ± 0.99	4.28 ± 0.85	0.107
Is a good use of money	4.17 ± 1.01	4.06 ± 0.99	0.359
Experts think that the research is likely to be possible	3.96 ± 1.02	4.11 ± 0.90	0.167
Is likely to have a clear result	3.94 ± 0.99	3.97 ± 1.00	0.817
Is something that we can afford to do	3.74 ± 1.02	3.80 ± 1.12	0.622
Is focused on a common disease	3.90 ± 1.06	3.66 ± 1.17	0.068
Is new and has not been done before	3.57 ± 1.06	3.72 ± 0.96	0.191
Doesn't negatively affect the environment or society	3.19 ± 1.24	3.59 ± 1.09	0.003

Mean ± standard deviation.

Supplementary Table 7: Mean rating of answers from survey participants above and below 55 years of age to the question "There are lots of different ways that are currently used to assess which research studies should be funded and carried out. Which of the following are important to you? Please score from 1 to 5, with 1 being not at all important and 5 being very important."

	Age less than 55 years	**Age greater than 55 years**	**p**
Makes a positive impact on the lives or experience of patients	4.80 ± 0.47	4.75 ± 0.62	0.377
Has the potential to be used in healthcare in the UK	4.59 ± 0.71	4.59 ± 0.72	0.947
Is an important question to address	4.28 ± 0.81	4.37 ± 0.80	0.270
Reduces inequalities in health care	4.35 ± 0.95	4.22 ± 1.01	0.215
Is relevant to the patients who are taking part in the research	4.17 ± 1.02	4.32 ± 0.96	0.170
Involves patients and carers in shaping and managing the research project	4.00 ± 0.99	4.36 ± 0.84	<0.001
Is a good use of money	3.92 ± 1.03	4.22 ± 0.96	0.005
Experts think that the research is likely to be possible	4.06 ± 0.89	4.06 ± 0.98	0.998
Is likely to have a clear result	3.92 ± 1.04	3.98 ± 0.98	0.588
Is something that we can afford to do	3.71 ± 1.11	3.82 ± 1.07	0.367
Is focused on a common disease	3.42 ± 1.25	3.95 ± 1.00	<0.001
Is new and has not been done before	3.49 ± 1.02	3.80 ± 0.95	0.005
Doesn't negatively affect the environment or society	3.39 ± 1.11	3.50 ± 1.20	0.365

Mean ± standard deviation.

Supplementary Table 8: Mean rating of answers from survey participants who did or did not have or know someone who had heart or circulatory disease to the question “There are lots of different ways that are currently used to assess which research studies should be funded and carried out. Which of the following are important to you? Please score from 1 to 5, with 1 being not at all important and 5 being very important.”

	Do you or someone you know have heart or circulatory disease?		**p**
	No	**Yes**	
Makes a positive impact on the lives or experience of patients	4.62 ± 0.66	4.80 ± 0.53	0.026
Has the potential to be used in healthcare in the UK	4.57 ± 0.59	4.59 ± 0.74	0.854
Is an important question to address	4.34 ± 0.73	4.33 ± 0.82	0.915
Reduces inequalities in health care	4.20 ± 0.98	4.29 ± 0.99	0.494
Is relevant to the patients who are taking part in the research	4.22 ± 0.85	4.27 ± 1.01	0.725
Involves patients and carers in shaping and managing the research project	4.00 ± 0.88	4.26 ± 0.92	0.044
Is a good use of money	4.11 ± 0.88	4.09 ± 1.02	0.857
Experts think that the research is likely to be possible	4.10 ± 0.75	4.06 ± 0.98	0.745
Is likely to have a clear result	3.95 ± 1.02	3.95 ± 1.00	0.996
Is something that we can afford to do	3.85 ± 0.96	3.76 ± 1.11	0.549
Is focused on a common disease	3.72 ± 1.13	3.74 ± 1.14	0.927
Is new and has not been done before	3.51 ± 1.04	3.70 ± 0.98	0.160
Doesn't negatively affect the environment or society	3.44 ± 1.19	3.46 ± 1.16	0.925

Mean ± standard deviation.