Living with cardiovascular disease (CVD): Exploring the biggest challenges for people affected by CVD in the UK, and their use (or not) of online resources

Sarah-Ann Burger
Picker Institute Europe, sarahannburger@gmail.com

Alan J. Poots
Picker Institute Europe, alan.poots@pickereurope.ac.uk

Anna Perris
Picker Institute Europe, Anna.Perris@lshtm.ac.uk

Helen Crump
Picker Institute Europe, helen.crump@cogency.live

Helen Thorne
Picker Institute Europe, Helen.Thorne@warwick.ac.uk

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Authors

Sarah-Ann Burger, Alan J. Poots, Anna Perris, Helen Crump, Helen Thorne, Sally Hughes, and Jacob West

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Sarah-Ann Burger, *Picker Institute Europe, sarahann.burger@uq.edu.au*
Alan J. Poots, *Picker Institute Europe, alan.poots@pickereurope.ac.uk*
Anna Perris, *Picker Institute Europe, Anna.Perris@PickerEurope.ac.uk*
Helen Crump, *Picker Institute Europe, helen.crump@cogency.live*
Helen Thorne, *Picker Institute Europe, Helen.Thorne@warwick.ac.uk*
Sally Hughes *British Heart Foundation, hughess@bhf.org.uk*
Jacob West, *British Heart Foundation, jacob.west@bhf.org.uk*

Abstract

As death rates decrease, people affected by cardiovascular disease (CVD) continue to live with these diseases and the associated challenges, long-term. We aimed to identify the biggest challenges for people affected by CVD in the UK and explore the sources of support and information used to help manage conditions, to inform future service provision. An online questionnaire was sent and advertised to people over 16 years old in the UK self-identifying as affected by CVD (living with CVD, had risk factors, or a carer). There were 13,885 responses. The top five challenges were: feeling down, sad, or depressed; making changes to the way or amount of exercise; anxiety, fear, and uncertainty about the future; having one member of staff to speak to about all aspects of care; and being given information on the side effects of medications. Key challenges were not restricted to a particular condition, indicated by minimal variation between types of CVD. One-quarter of respondents indicated they do not use online resources or digital technologies to help manage their health. The volume and inconsistency of online sources were reported as barriers to using these. The results highlight the psychological and physical consequences of living with CVD. Fragmented care and variable access to information and support further compound these issues. Providing holistic care needs attention; the acknowledgement of psychological needs and access to support, alongside physical challenges is necessary. Stakeholders in healthcare and information technology should work together to ensure online information and support is clear, consistent, and reliable.

Keywords

Continuum of care, surveys and questionnaires, cardiovascular diseases, emotions, health resources

Introduction

There are an estimated 7.4 million people living with cardiovascular disease (CVD) in the UK.[1] Of these, approximately 2.3 million people live with coronary heart disease, over 1.3 million are affected by stroke, and 620,000 live with an inherited heart-related condition. In 1961, CVD was attributed to more than half of all deaths in the UK; however, mortality rates have declined by 75% between 1969 and 2017.[1] While lower mortality rates are a positive outcome, progress in reducing premature deaths from CVD means that there are now more people living with these diseases long term and facing challenges associated with these, including an increase in treatment and hospitalisation.[2] There have been calls for policy and practice in the UK to respond to the "shift in relative burden from mortality towards morbidity."[3] This is

important to ensure provision of sustainable services in the future.

People living with CVD, and those providing care and support to them, experience a wide range of challenges related to the physical and psychosocial impacts of CVD, daily living, and clinical management. There is a wealth of literature examining these challenges; however, it is typically focused on particular needs and conditions. For example, exercise is challenging for people affected by peripheral arterial disease,[4–6] congenital heart disease,[7,8] and coronary heart disease.[9] Mental well-being and depression is challenge for people affected by congenital heart disease[10] and heart failure.[11] Self-care is difficult for people with heart failure,[12,13] congenital heart disease,[14,15] and psychological impacts and loneliness affect people who suffered acute events[16] and stroke.[17] The psychological needs of people affected by ischaemic heart

disease[18] and ischaemic stroke,[19] and social support requirements for people affected by coronary heart disease have been investigated.[20] There are examples of literature discussing several conditions, but with a particular focus, for example stress,[21] self-care,[22] or seeking to derive educational intervention.[23] Further, where all CVD types are considered, attention is focused on prevention,[24] call to action for treatment,[25] or a hospitalised group,[23] rather than the experiences of people living with CVD. There is a gap in understanding the most prominent challenges and priorities for people affected by CVD. While the literature suggests overlapping challenges for people living with different conditions, a comprehensive examination of challenges across all groups is lacking.

Self-care and management is a key aspect of living with CVD.[12] Many self-care interventions aim to empower patients by improving their understanding of their condition, to take responsibility and control of their own health, and increase self-efficacy.[22] Access to online resources (e.g., websites), digital technology (e.g., wearable devices), or sources of support (e.g., support groups) could be a positive addition to the tools available to patients and carers to manage their wellbeing.[24] However, there are concerns over the privacy and accuracy of digital technologies for the management of health.[25–27] The 'information revolution' has allowed people to have a greater and more immediate connection to any information they could want as a consumer. Yet, little is known about what resources people access or seek out to address their unmet needs, or assist with self-management or self-care.

The overarching aim of this study was to examine the key challenges and unmet needs of people affected by CVD in the UK and to identify the resources or sources of support that they use to help manage their health. In particular, the study explored respondents' use of online or digital technologies, and other non-medical resources. The research questions were:

1. What are the biggest challenges and unmet needs of people affected by CVD in the UK?
2. What, if any, online resources and digital technologies do people affected by CVD use to help manage their condition?

Methods

Questionnaire Design
A questionnaire was developed to understand the key challenges faced by people affected by CVD, and to capture information on the resources they use for self-management of their disease. Questionnaire content was informed by desk and qualitative research. This included a rapid review of existing literature, a social media analysis for mentions of CVD, and focus groups and semi-structured interviews with 45 people affected by CVD. Five focus groups with 37 participants were conducted, one with each of the following condition groups: congenital heart disease; inherited cardiovascular conditions; acute events, such as heart attack or stroke; people living with the known risk factors of heart disease; and people who have undergone surgery to address CVD. Eight telephone interviews were conducted with people living with heart failure, as this cohort were deemed less able to travel to focus groups. Participants were recruited by advertisements posted online and local print media, social media, and promoted by the British Heart Foundation (BHF) to their existing contacts and communities. A semi-structured topic guide sought to capture in depth information about the experiences and needs of people living with CVD, including support and information needs. Thematic analysis identified people's needs, the resources they draw on or would like more of, and the extent to which participants have needs and requirements in common.

A list of 35 key challenges was derived from the desk research and qualitative data (Appendix A), and grouped into three broad themes: physical challenges, emotional or psychological challenges, and medical, information or support challenges. This was achieved via working meetings between the project team iterating designs that synthesised information into a useable number of items. The questionnaire was designed to capture the extent to which participants experienced a specific challenge, their need for help with that challenge; and whether they received support to address that challenge (need met), if required. It captured participants' use of digital, technological or alternative resources in general and to help manage their condition, and demographic questions. Overall, the questionnaire contained 26 questions including demographics (Table 1).

Questions were scripted into Snap Surveys 10 and implemented via Snap Webhost. The landing page provided information about the study and outlined who was eligible to participate. Contact details at the British Heart Foundation (BHF) were provided for concerns about health and a separate contact for queries about the survey. Respondents were asked if 'partial data' could be used if they did not complete the survey or press submit at the end of the survey.

Sampling
Anyone over the age of 16 years and living in the UK affected by a heart or circulatory condition or their risk factors, including friends or family (referred to as carers), was eligible to participate.

In August 2018, approximately 250,000 people on the BHF's mailing lists were sent an email with information about the survey, inviting them to participate and included

a hyperlink to the survey. The mailing list included all individuals within databases held by the BHF, representing people who had opted-in to communications by email, constituted the insight panel, or comprised a patient network group. Members include the public, event participants, and patients. Social media adverts, posted on Facebook and Health-Unlocked, included information about the survey and a hyperlink.

Responses logged were fully anonymous. The questionnaire was in field for four weeks and closed in September 2018.

Analysis
Data were extracted from Snap Webhost and imported into SPSS v23 for analysis. Data were cleaned, by (i) removing partial responses for those people who did not consent for their partial data to be used; and (ii) removing partial responses with no data for the questions asking about specific challenges or needs, as the survey relied on information from these questions for routing.

The data were analysed using descriptive statistics, bivariate analysis, and correlations. Frequency tables were produced to display responses to all survey questions. The top five challenges were identified based on the combined proportion of people reporting a '*high*' or '*moderate need for help*' with a specific challenge, ranked by percentage of responses (see Table 1). This was repeated by type of CVD (demographic variable) to examine the top challenges for each condition.

'Unmet needs' were identified based on the proportion of participants who responded they received '*no help at all*' with the specific challenge (see Table 1). Only those respondents who indicated a '*high…*' or '*moderate need for help*' with a specific challenge were asked to report whether they received any support or help to manage that challenge, thus base sizes vary.

To determine if there was a relationship between the identified top five challenges and the other 35 challenges asked in the survey, Kendall's tau-b correlations were calculated and assessed against a threshold of 0.6.

Bivariate analyses were used to examine the relationship between categorical demographic variables (including age, gender and type of CVD), and each of the 35 listed challenges, and use of technology. Chi-square statistics were used to judge the level of association between these variables. Z-tests were conducted to explore differences

Table 1. Survey question areas and response categories

Question	Response Categories
Need for help with a specific challenge *For **each item**, please select the box that best describes if and how much you have needed help (if at all) as a result of being affected by a heart & circulatory condition or their risk factors*	35 items/challenges, asked to all • This was not a problem for me / I have not needed help • This was a problem for me and I have had a low need for help • This was a problem for me and I have had a **moderate need for help** • This was a problem for me and I have had a **high need for help**
Received help for their self-identified needs *If you have needed help or support, did you receive the help you needed?*	Asked of those people indicating they needed help with specific challenge (variable number of items, depending on answer to previous question) • Not applicable • **Not at all (I have not received any help)** • Yes, to some extent • Yes, definitely (I have received all the help I needed)
What they would have liked to have been done differently if their needs were unmet	Asked of those who received no or little help with specific challenge (variable number of items, depending on answer to previous question) • Open - freetext
Anything exceptional that helped address their needs	Asked of those who received help with specific challenge (variable number of items, depending on answer to previous question) • Open - freetext
Use of digital resources and technology in general, and to help manage health	Multi-choice

Table 2. The top five challenges as identified and ordered by the proportion of people reporting a 'high or moderate need for help' and an indication of help received

A. Top five challenges	B. Need for help Proportion indicating a 'high or moderate need for help'	C. Unmet need Proportion who received 'no help or support at all' (of those indicating a 'high' or 'moderate need for help')
1. Feeling down, sad, or depressed	24% (2965/12,312)	36% (829/2276)
2. Making changes to the way or amount of exercise	24% (3118/13,261)	29% (639/2229)
3. Anxiety, fear, and uncertainty about the future	23% (2781/12,338)	37% (785/2143)
4. Having one member of staff to speak to about all aspects of care	20% (2060/10,579)	47% (841/1786)
5. Being given information on the side effects of medications	19% (2031/10,646)	46% (808/1777)

between individual pairs, or response options within the bivariate analyses.

Freetext data from open-ended questions were examined using thematic analysis: grouping responses into broad categories, that were iteratively derived.

Patient and Public Involvement and Engagement
The BHF commissioned the project to inform their strategy development, which was advised by a Patient and Public Advisory Group. This group commented on the study design and the survey content circulated to the BHF before launch, with changes to phraseology and question format made as a result. They advised on dissemination of the results, including to study respondents and the wider patient community, which has taken place via press releases and social media activity as part of the BHF's strategy.

Results

As the questionnaire did not force response, the number of respondents to each question varied as not everyone answered every question. After cleaning the data set there were 13,885 useable responses, of which more than 9000 provided details on demography and use of digital resources. The following section outlines the key challenges reported, and the sources of support sought. Respondent characteristics are available as Appendix B.

Challenges
The top five challenges were identified by the proportion of people stating they had a '*high or moderate need for help*' with a specific challenge (Table 2). The largest proportion of respondents reported a challenge relating to '*feeling down, sad, or depressed.*' Other key challenges related to exercise, uncertainty about the future, continuity of care, and access

to information about potential side-effects of medications. Of those respondents indicating that they had a 'high or moderate need for help' with a challenge, significant percentages were not receiving the help they needed. For example, 47% (841/1786) of respondents who reported a challenge relating to '*Having one member of staff to speak to about all aspects of care*' indicated that they had received '*no help or support at all*' for this.

Exploration of the top five challenges by CVD condition found only some differences in ordering and a few instances of a different challenge presenting in their respective top five. Table 3 presents the top five challenges for each CVD condition. Where a challenge is different from the overall top five, that challenge is described in the table.

The overall top five challenges are statistically significantly correlated with a number of the other 35 challenges asked in the questionnaire. For ease, Table 4 only presents those challenges that correlate with the top five challenges at a threshold of 0.6 using Kendall's tau-b correlation. For example, '*feeling down, sad or depressed*' was associated with other challenges linked to mental health and a feeling of needing to hide being unwell. The challenge of '*being given information on the side effects of medications*' was associated with other unmet informational needs.

Resources & Support Used
While 93% (9175/9846) of respondents reported that they use online resources or digital technologies in their day-to-day life, only 22% (2224/9961) of respondents regularly used online resources specifically for their health, and 54% occasionally used them (5423/9961). These respondents were asked a multi-response follow-up question on reasons for usage (Appendix C1). The most common

Table 3. The top five challenges by cardiovascular disease condition are identified and ordered by the proportion of people reporting a 'high or moderate need for help' with a challenge. (Numbered items indicate the challenge and rank in the overall top five. A full description of a challenge is provided when different to overall top five, in *italic*s.)

Order of challenges for condition type	Congenital Heart Disease	Arrhythmias	Inherited Heart Disease	Disease of the heart valves	Coronary Heart Disease	Heart Failure	Stroke	Peripheral Arterial Disease
First	3. Anxiety	2. Exercise	1. Depressed	3. Anxiety	2. Exercise	2. Exercise	3. Anxiety	2. Exercise
Second	1. Depressed	1. Depressed	3. Anxiety	2. Exercise	3. Anxiety	*Feeling weak/ lack of energy*	2. Exercise	3. Anxiety
Third	2. Exercise	3. Anxiety	2. Exercise	*Feeling weak/ lack of energy*	1. Depressed	3. Anxiety	1. Depressed	4. Single contact
Fourth	*Feeling weak/ lack of energy*	4. Single contact	*Receiving consistent information from healthcare professionals*	1. Depressed	4. Single contact	1. Depressed	4. Single contact	5. Side-effects
Fifth	4. Single contact	5. Side-effects	*Maintaining a good quality of life*	4. Single contact	5. Side-effects	*Work around the home (e.g. cleaning, cooking, eating, washing)*	*Maintaining a good quality of life*	*Maintaining a good quality of life*
Top ranked challenges for overall dataset **1. Depressed: Feeling down, sad, or depressed** **2. Exercise: Making changes to the way or amount of exercise** **3. Anxiety: Anxiety, fear, and uncertainty about the future** **4. Single contact: Having one member of staff to speak to about all aspects of care** **5. Side-effects: Being given information on the side effects of medications**								

response was *'Websites to get information about the condition or diagnosis'* (87%, 6073/7469), followed by *'Resources to help with general health e.g., healthy eating, recipe websites or tips to stay in shape'* (65%, 4882/7469), *'Websites to get information on how to manage the condition at home'* (55%, 4124/7469), and *'Websites to get information about different treatment options'* (55%; 4031/7469).

Nearly a quarter of respondents never used online resources specifically for their health (23%; 2314/9961). Male respondents (X^2 83.94 $_{(2)}$ p<0.001; Appendix C2) and respondents over 65 years (X^2 307.02 $_{(12)}$ p<0.001; Appendix C2) were significantly less likely to use online resources to help manage their health. For those respondents who indicated that they do not use online or digital resources to get information or help manage their health or condition, the main reasons can be summarised as concerns about information quality (inconsistency across websites (41%; 1872/4553), lack of trust (20%;

921/4553), quantity being overwhelming (18%; 839/4553), and privacy concerns (15%; 666/4553)); and motivations of the individual (not needing more information (28%; 1273/4553), not wanting any (6%; 268/4553), and being scared by the information (14%; 652/4553)). Ability to use and access to digital technologies were infrequently selected (Appendix C3). Free-text comments from those who selected *'Other'* (10%; 453/4553) suggested that they prefer to seek information or advice from medical professionals in person, rather than online.

One-third (33%, 3277/9875) of respondents stated they use digital technologies or devices, such as wearable technologies (e.g., pedometers), to help them manage their health or condition. The 67% (6598/9875) of people who selected that they do not use any digital technologies or devices were asked why in a follow-up question (Appendix

Table 4. Kendall's tau-b correlations of the top five challenges with other challenges in questionnaire, where threshold of 0.6 or greater.

	1. Feeling down, sad, or depressed	2. Making changes to the way or amount of exercise	3. Anxiety, fear, and uncertainty about the future	4. Having one member of staff to speak to about all aspects of care	5. Being given information on the side effects of medications
Anxiety, fear, or uncertainty about the future	τb 0.693*				
Feeling down, sad, or depressed			τb 0.693*		
Feeling isolated or lonely	τb 0.714*				
Feeling the need to hide being unwell	τb 0.601*				
Making changes to diet		τb 0.672*			
Information about managing the condition at home				τb 0.617*	τb 0.705*
Information about medications and their purpose					τb 0.798*
Information on what to expect after an operation or procedure					τb 0.620*
Knowing about self-help resources for dealing with anxiety or fears	τb 0.645*		τb 0.618*		
Primary care staff able to answer questions				τb 0.629*	
Consistent information from healthcare professionals				τb 0.641*	τb 0.647*
Understanding the advice given by healthcare professionals					τb 0.608*

C4). The most common option selected was that they are *'too expensive'* (32%, 1903/5966); and 21% selected they *'do not trust that these technologies will work or help'* (1276/5966). The 25% (1490/5966) who selected *'Other,'* noted most frequently that they do not need these devices or are uninterested in using them. While there was no evidence of difference in the use of digital technologies by gender, people under 65 years were significantly more likely to say they use digital technologies (X^2 233.94 $_{(6)}$ p<0.001; Appendix C5).

Discussion

The results from this study describe the experiences of a large, self-selected sample of people affected by CVD in the UK. The purpose of the research was to provide insight into the biggest challenges and unmet needs of people affected by CVD, as well as the resources they accessed to help address their support needs.

The top five challenges for people affected by CVD, based on the proportion of people indicating they had a need for

help, span psychological, physical and care needs (Table 2). The survey results confirm that the key challenges are not restricted to a particular condition, indicated by the minimal variation of the top five difficulties between types of CVD (Table 3).

The most prominent challenges related to emotional wellbeing, with one-quarter of people stating they a had moderate or high need for help with feeling down, sad, or depressed, as well as feelings of anxiety, fear, and uncertainty about the future. Feelings of isolation, loneliness, and the need to hide being unwell from family and friends strongly correlated with these challenges. Further, more than two-thirds received no support to address these needs. It is well documented that people affected by CVD may experience mental ill health; for example, depression is relatively common in patients with heart disease and associated with an increased risk of mortality and morbidity.[28] Equally, psychological factors, such as stress, can contribute to the development and progression of CVD.[29] Hopelessness, for example, is "one symptom of depression that appears to have particularly adverse effects on health."[18] Therefore it is vital that attention be given to assessing and addressing the mental wellbeing of people affected by CVD.

The role of exercise in reducing risk of cardiac events[30,31] and supporting rehabilitation in CVD[32–34] is well established in the literature. However, one-quarter of respondents noted that they struggle with making changes to the way and amount they exercise. This correlated with challenges associated with making changes to diet, indicating a struggle with adjusting lifestyle, and the need for support to make these changes. There is evidence that exercise improves psychological symptoms associated with poor health-related quality of life.[19] Nevertheless, some patients avoid exercise following a cardiac-related diagnosis or event[7] due to uncertainty about safety and appropriateness and lack of support.[4,35] This was echoed in our study; a number of respondents noted that although they were eager to do physical activity, with limited personalised guidance they were afraid they may push themselves too far, restricting the amount of exercise they were mentally comfortable doing. For people who had received help, the most common source of support that people found beneficial was cardiac rehabilitation.

Continuity of care is a fundamental component of person-centred care,[36] yet one-fifth of respondents lacked a single point of contact with whom they could discuss their condition or care. The need for a single point of contact was positively correlated with the need for continuity between primary and secondary providers. This included the need for General Practitioners (GPs) or community-based healthcare staff to be able to answer questions and receiving consistent information from healthcare professionals. Poor coordination can further impact the

quality and consistency of information. Respondents reported that having sufficient information about medications and their side-effects was problematic. This is noteworthy, as almost one-half of respondents who needed information about medications and their side-effects had not received any help. The implications deserve further research, as information can impact adherence. For example, a study examining how negative media coverage may affect people's attitudes and behaviours towards statins found that, concerns about side-effects were associated with poor adherence; conversely, people who had confidence in their GPs had increased willingness to adhere to statins.[37]

Correlations between the top challenges and other needs presented in the survey, suggest that lack of information or knowing how to access alternative resources could exacerbate challenges. For example, the need for help with *feeling depressed, or fears about the future* was correlated with knowing about self-help resources for dealing with anxiety or fears. Similarly, the need for a single point of contact correlated with needing to be given information about managing the condition at home.

Our study explored the sources of support and information that people with CVD used to help manage their condition. While the majority of respondents stated that they use online resources or digital technologies in day-to-day life, far fewer regularly used these resources to access information about their condition and to help manage their health. Of those who reported using online resources for health, the main reason was to access clinical information about their condition, followed by resources about general health, such as healthy eating and tips on staying in shape.

Key barriers to accessing information and support online included inconsistency of information, trust in the accuracy of information, and accessibility. Respondents stated that it was hard to determine the accuracy and trustworthiness of online information, particularly given the sheer volume of websites available. Some respondents reported concerns about the functionality and accessibility of digital technologies and preferred to seek information and advice in person from medical professionals. There were concerns about the privacy of data captured by digital technologies, such as apps and wearable devices.

Implications
Overall, our study shows that there is a clear need for a holistic approach to care to support patients' psychological, physical and other support needs. Consistent and timely use of a holistic needs assessment (HNA) tool could ensure people's physical, emotional and social needs are identified and appropriate support provided. HNAs have been introduced as standard practice for all cancer patients in the UK as part of the

NHS Long Term Plan.[38] Similar policy for people affected by CVD should be considered.

Our findings indicate the prevalence of mental and emotional ill-health among people affected by CVD, highlighting the need for policy and practice to prioritise strategies in this area. Depressive disorders are among the most common causes of disability (measured as years lived with disability) and are "identified as increasingly important contributors to overall burden across the UK."[3]

Our findings further emphasise the need for policy and practice to mitigate the consequent demand for services and the potential negative economic impact. HNAs could support people having their psychological needs identified and to access psychological and emotional wellbeing support. These should take place whenever patient's needs change and support should be adapted. There are a number of studies highlighting the benefits of psychosocial interventions for CVD patients[28,39] including alternative or complementary approaches such as mindfulness.[40,41] Referral to psychological services and signposting to charity counselling and advice services could be helpful for patients and carers, and make use of community-based support.

Provision of support to do physical exercise needs improvement. This could mitigate some of the mental health challenges people face, as studies have shown the interplay between physical activity and mental wellbeing.[19,42] There have been encouraging developments in this area since we conducted our study, with the NHS Long Term Plan prioritising cardiac rehabilitation,[38] particularly for patients with heart failure and heart valve disease.[43] However, our results indicate that for this to be impactful, people need personalised guidance about the type and amount of exercise that is appropriate for them. Furthermore, access to cardiac rehabilitation and other forms of exercise support should be available for all condition types, as exercise was present in the top five challenges for all conditions in our study.

Individuals living with CVD are routinely encouraged to engage in self-care as part of their daily disease management. Yet, there is a clear need for clarity and guidance from reliable sources, such as healthcare professionals or reputable organisations, to support people with navigating the overwhelming volume of online information and resources, and to understand which are appropriate and accurate. Our results mirrored other studies that reported barriers to utilising online health information, particularly studies examining choice in healthcare.[44,45] As Hibbard and Peters noted, "having an abundance of information does not always translate into it being used."[46] The accessibility of information is crucial to ensure intentions are not undermined. A challenge is to avoid simply overloading patients with information and to

ensure it is presented and targeted in a meaningful and digestible format. The design should take into consideration the range of user skills and literacy. Information producers and providers should understand and utilise existing research to ensure an evidence-based approach is used to design information and platforms (such as websites) to enhance the successful use of information. Drawing on the principles of person-centred care, patients and carers should be decision makers in the design of support packages to ensure they are fit for purpose.

The role of third sector organisations in addressing some of these unmet needs through, for example sign-posting, advocacy, and provision of up-to-date information and resources, should be explored. Improved coordination between healthcare providers could help standardise messaging and support packages. Interactions with healthcare professionals are valued, and results highlight the need for personalisation of advice and information. Thus, online resources and digital technologies should be used to complement and not replace tailored advice and support provided to patients.

Limitations
While this was a large study, the respondents to the questionnaire self-selected, and in some cases came from an unknown population through online advertisement. As it was an open link (i.e., no login details were required), the email and survey link could be forwarded to people not on the mailing list. Therefore, the sample may not be representative of the population of people affected by CVD. Furthermore, the effects of CVD on a respondent were self-reported and cannot be verified.

Conclusions
There have been major advancements in the prevention and treatment of CVD, reflected in substantial reductions of premature deaths. However, CVD remains a significant burden, with reports indicating an increase in treatment and hospital admissions in the UK.[2] As death rates decrease, people affected by CVD continue to live with these diseases and the associated challenges, long-term. Our study provides evidence for healthcare providers, voluntary sector organisations (such as the British Heart Foundation), regulators, and national bodies about where improvement initiatives are required, and resources should be prioritised to mitigate the increased burden due to morbidity. Receiving a diagnosis for CVD or living with risk factors can have psychological, social, and physical consequences that require considerable adjustments in an individual's life. Yet many people do not receive adequate assistance. Fragmented care and variable access to information and support, compounds these issues. Providing holistic care requires the acknowledgement of psychological needs and access to services, alongside support for physical challenges. Accurate information

from reliable sources is needed: organisations should work together to decrease the noise and inconsistency. The key challenges are not restricted to a particular condition, indicating that interventions could benefit numerous patient groups, rather than focusing on a single condition. Empowering people to manage their condition and the consequential impacts by providing the evidence-informed tools, information, and support is crucial to improve quality of life and will have knock-on effects for the healthcare system as a whole.

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Appendix A: List of challenges in questionnaire

Physical challenges
- Feeling weak/ lack of energy
- Work around the home (e.g. cleaning, cooking, eating, washing)
- Not being able to do the things you used to, such as driving
- Support with work such as reducing hours or stopping work
- Accessibility in public spaces for people with limited mobility (for e.g. lifts or ramps)
- Activities related to providing care for someone else
- Making changes to your diet/ following a healthy diet
- Making changes to the way or amount you exercise

Emotional or psychological challenges
- Anxiety, fear, or uncertainty about the future
- Feeling down, sad, or depressed
- Feeling the need to hide being unwell from family, friends, and colleagues
- Feeling isolated or lonely
- Knowing about self-help resources for dealing with anxiety or fears
- Having access to professional counselling (e.g. psychologist, social worked, counsellor, specialist nurse) if you, family, or friends need it
- Colleagues and managers being understanding of the impact of the condition
- Maintaining a good quality of life
- Providing care or support to someone close to you

Medical, information or support challenges
- Your needs met by the care you received in the community following discharge from hospital or in between hospital visits
- GPs or other primary or community-based healthcare staff being able to answer your questions, and in a way you could understand
- Having access to NHS rehabilitation services
- Having one member of staff with whom you can talk to about all aspects of the condition, treatment and care (such as the same GP, consultant, or specialist nurse)
- Being given information on what to expect after an operation or procedure
- Being given information about medications and their purpose
- Being given information on the side effects of medications
- Being given information about managing the condition at home
- Receiving consistent information from healthcare professionals
- Understanding the advice given by healthcare professionals
- Being given information about other resources you can use to get more information about the condition, such as websites or charities
- Support when moving from children's services to adult services
- Being given guidance on how much exercise or work can be done
- Being given information about other resources you can use to help manage your condition, such as Apps, wearable technologies (e.g. Fitbit), or websites
- Being given information about other non-medical resources you can access
- Having access to support groups
- Support groups that accept or provide support for carers, friends, or family
- Having access to online support groups

Appendix B: Respondent characteristics

The respondents were roughly equal in number for gender, typically aged 55 and over, and most people affected by CVD had a heart or circulatory condition themselves.

Table B1. Respondent characteristics for the online questionnaire, frequency of response selected and percentages of that response (single selection responses unless marked).

Characteristic	Number of responses	Percentage
Gender		
Male	4800	51%
Female	4635	49%
Other	4	<1%
Prefer not to say	22	<1%
Responses	*9461*	
unanswered	*4424*	
Age		
16 – 18	2	<1%
19 – 24	10	<1%
25 – 34	85	1%
35 – 44	221	2%
45 – 54	943	10%
55 – 64	2614	28%
65 – 74	3868	41%
75 – 84	1512	16%
85+	217	2%
Responses	*9472*	
unanswered	*4413*	
Impact of CVD		
Had heart or circulatory condition (CVD)	4696	49%
Had a risk factor	3088	32%
Cared for someone with a heart or circulatory condition	515	5%
Cared for someone with a risk factor	218	2%
Other	1012	11%
Responses	*9529*	
unanswered	*4356*	
Previous knowledge of, or engagement with, the BHF (multiple select)		
Used their materials such as booklets, pamphlets or the website	6798	73%
Give financial donations, or charity shop donations	5961	64%
Heard of BHF but have never used any of their services or materials	1228	13%
Participate in BHF events	458	5%
Volunteer or involved in committees, etc.	206	2%
Had not heard of the BHF before today	182	2%
Responses	*9352*	
unanswered	*4533*	

Appendix C: Supplementary results

C1. Resources used for information or to help manage health, 7469 respondents, multiple select

Usage	Number of responses	Percentage
Websites to get information about the condition or diagnosis (e.g. clinical information)	6073	81%
Other online resources to help manage general health such as healthy eating, recipe websites or tips to stay in shape	4882	65%
Websites to get information on how to manage the condition at home	4124	55%
Websites to get information about different treatment options	4031	54%
Health Apps, such as a calorie counter, a steps counter, App or salt calculator	2452	33%
Online resources to get information about mental health and well-being	1940	26%
Online exercise programmes (such as exercise videos)	1427	19%
Internet forums or messaging boards to share or receive information about your health or condition	1173	16%
Online support groups	762	10%
Other online help lines or 'Live Chat' options to get help or information	400	5%
None of the above/ I do not use online resources for health	389	5%
Other	132	2%
Total Respondents	*7469*	

C2. Use of online resources by age and gender

		Yes, I use online resources for health a lot		I occasionally use online resources for health, but not that often		I don't use online resources at all for health	
		Number	Row Percent	Number	Row Percent	Number	Row Percent
A. Gender	Male	915	19%	2589	55%	1220	26%
	Female	1169	26%	2478	55%	882	19%
B. Age group	16 – 34	44	46%	39	41%	13	14%
	35 - 44	87	40%	104	48%	27	12%
	45 - 54	286	31%	489	53%	155	17%
	55 - 64	681	26%	1424	55%	475	18%
	65 - 74	753	20%	2154	57%	877	23%
	75 - 84	218	15%	764	52%	487	33%
	85 +	22	10%	107	50%	83	39%

C3. Reasons for not using online or digital technologies, 4553 respondents, multiple select

Reason	Number of responses	Percentage
Different websites give different information or advice	1872	41%
I don't need any more information or help	1273	28%
I don't trust the information online	921	20%
There is too much health information online / I don't know where to start looking	839	18%
I have privacy and security concerns	666	15%
Looking at or reading the information online makes me worried or scared	652	14%
Other	453	10%
I never get around to looking at it	372	8%
I don't want to know anything more about the condition or how to manage it	268	6%
I don't know how to use digital resource	194	4%
I want to but I don't understand how to use the resources	165	4%
I don't have access to digital resources	55	1%
I am physically unable to use the equipment needed to use online resources	37	1%
Total Respondents	*4553*	

C4. Reasons for not using digital technologies or devices, 5966 respondents, multiple select

Reason	Number of responses	Percentage
They are too expensive	1903	32%
Other	1490	25%
I don't trust that they work or will help	1276	21%
There is too much choice and I don't know which is the best	1089	18%
I do not know what is available	1072	18%
I have privacy or security concerns (e.g. amount of personal data they capture)	903	15%
I don't know how to use them	817	14%
Total Respondents	*5966*	

C5. Respondents using digital technologies or devices, such as wearable technologies, by age group

Age group	Using any digital technologies or devices			
	Yes		No	
	Number of responses	Row Percentage	Number of responses	Row Percentage
16 – 34	37	39%	58	61%
35 - 44	98	45%	121	55%
45 - 54	408	44%	523	56%
55 - 64	1024	40%	1565	60%
65 - 74	1239	32%	2581	68%
75 - 84	306	20%	1191	80%
85 +	42	20%	167	80%