

# "I think I had PTSD": challenges and unmet needs of people affected by Cardiovascular Disease

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## OBJECTIVES

Approximately 7 million people live with cardiovascular disease (CVD) in the UK.<sup>1</sup> In 2014, CVD was the second main cause of death despite recent declines in death rates.<sup>2</sup> To provide insight into the support for people affected by CVD, the study aimed to identify the top challenges and unmet needs for people affected by the disease in the UK.

## METHODS

- An **online survey** was developed from findings of a rapid literature review (167 eligible articles), five focus groups, and eight interviews with people affected by CVD (n=44).
- The survey aimed to understand the challenges faced by people affected by CVD and the support they seek.
- The **survey was sent by email** to people affected by CVD including those diagnosed with CVD, those with high risk factors, and carers.
- Descriptive statistics, bivariate analyses, and correlations were used to identify priority areas. Qualitative data were analysed by thematic analysis.
- Data were triangulated to gain insight into challenges and unmet needs of people affected by CVD.

## RESULTS

The survey yielded 13,885 useable responses.

### Emotional Support

**24%**

Had high need for help with **feeling down, sad, or depressed.**

**23%**

Had high need for help with **anxiety, fear, or uncertainty about the future.**

### Continuity of care

**20%**

Had a high need for help in having a **single point of contact.**

### Exercise

**24%**

Had a high need for help with making changes to the way or amount they **exercise.**

### Information support

**19%**

Had a high need for receiving **information on the side-effects** of the medications

"I think I had PTSD."  
"I was not aware that after a heart attack I would feel so vulnerable, exposed and I suppose depressed."

"I have struggled... what if I do it wrong, what if it happens to me again while on an exercise bike or something."

"Having someone who can and will take time to discuss with me the whole person aspect of all my conditions."

"Being able to discuss side effects with a knowledgeable health professional who will take account of other medical aspects of my life."



**1 in 4**

**Do not use online resources for health**

### Seeking Support:

- Information was viewed as inconsistent, overwhelming, and often untrustworthy.
- For those who required help to use online technology:
  - 67% needed information about alternative resources to help manage their condition, such as Apps, wearables or websites.
  - 72% needed to know about available non-medical/digital resources, e.g. support groups.
- Guidance from reliable sources, such as healthcare professionals or reputable organisations, about accuracy and appropriateness of information was desired.



## CONCLUSION

- Results highlighted the psychological and physical consequences of CVD, in addition to fragmented care provision and variable access to information and support.
- Providing holistic care needs attention: many called for the acknowledgement of psychological needs and access to support, alongside physical challenges.
- By identifying challenges and unmet needs from a large sample, triangulated with qualitative data, we provide strong evidence for improvement initiatives.
- More accurate information from trustworthy sources are required to encourage self-care behaviours
- Empowering people to manage the condition and the consequences by providing the tools, information and support is crucial to improve quality of life and reducing burden on the healthcare system.

[1] BHF Statistics <https://www.bhf.org.uk/what-we-do/our-research/heart-statistics>

[2] Bhatnagar P et al. 2016 *Heart* 102:1945–1952.

