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## Graphical user interface, application Description automatically generatedPriorities for the 2026 Holyrood Election Manifestos

## British Heart Foundation Scotland Lived Experience Panel

Report by The Diffley Partnership

July 2025

***From many voices to smart choices***

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# Introduction

With the 2026 Scottish Parliament elections now less than a year away, parties are in the midst of forming their manifestos. The British Heart Foundation (BHF) Scotland is also laying out its own policy priorities that they encourage parties to fold into their platforms. These include preventing heart disease, investing to diagnose heart disease sooner, and supporting people living with heart disease by providing more care in communities.

As part of this process, BHF Scotland commissioned Diffley Partnership to conduct focus groups with members of their Lived Experience panel of people across Scotland who live with cardiovascular conditions. Driven by a motivation to understand how patients viewed specific policy priorities in the context of their own cardiac health, these focus groups discussed BHF Scotland priorities as well as steps the Scottish Government could take to lessen the regularity and impact of cardiovascular disease.

The remainder of this report presents a summary of this research, including the methodology implemented as well as a discussion of key themes and findings from the focus groups.

# Methodology

In 2024, British Heart Foundation Scotland (BHF) commissioned Diffley Partnership, an independent research agency, to create a panel of 100 people with heart conditions across Scotland, with whom to undertake research activities with throughout the year; the panel has 96 members as of July 2025. In June 2025, Diffley Partnership reached out to all panellists with the opportunity to participate in a focus group to discuss the policy priorities of the BHF throughout the manifesto creation process for the 2026 Holyrood elections.

Diffley Partnership created a recruitment form with information about the focus group as well as how participants’ data will be used and worked with the British Heart Foundation Scotland to create a discussion guide relevant to the aims of the research. Diffley Partnership researchers facilitated two focus groups over the Zoom platform, with five and six panellists, respectively, on the 2nd of July. Table 1 below includes the ages, sexes and Scottish Parliamentary Regions of the panellists who took part. Demographics were unknown for one participant due to external recruitment through LEAF (the Lived Experience Advisory Forum).

**Table 1: Participants’ ages, sexes and Parliamentary Regions.**

|  |  |
| --- | --- |
| Age | |
| 35-44 | 1 |
| 45-54 | 1 |
| 55-64 | 3 |
| 65+ | 5 |
| Sex | |
| Male | 6 |
| Female | 4 |
| Parliamentary region | |
| South Scotland | 1 |
| Mid Scotland and Fife | 3 |
| Highlands and Islands | 1 |
| North East Scotland | 4 |
| West Scotland | 1 |

# Findings and discussion

This chapter covers the key findings from the focus group, organised by the following topics of discussion: preventing heart disease, access to diagnosis & timely care, care in communities, digital tools & care connectivity, equity & inclusion and key messages for the Scottish Government.

## Preventing heart disease

The first of the BHF’s three manifesto priorities discussed in the focus groups was preventing cardiovascular (CVD) disease. Panellists were asked about their views towards prevention as a manifesto priority as well their personal experiences of CVD risk factors including understanding and managing risk factors.

Participants unanimously agreed prevention should be a key policy priority when thinking about cardiovascular disease in Scotland. They discussed different elements of prevention such as education and societal or cultural change with regards to lifestyle choices. One panellist spoke about the importance of increasing awareness of risk factors “to be proactive”:

“Part of what I was thinking is perhaps education regarding heart conditions at a very much earlier age to, look at the effects of diet, lack of exercise, I guess drug taking, smoking, you know, and just to educate people very - much earlier than when you're suddenly told by the GP, guess what, you've got a heart condition.” (Participant 7)

Others agreed, one said: “I think [education] is very, very important.” (Participant 10) One panelist said prevention is becoming increasingly important in Scotland due to the ageing population:

“[Prevention] will be really quite important. As a nation, Scotland here we have more people who have trouble statistically, health wise, we're an ageing population and there’s more of us ageing than in England.” (Participant 3)

While other participants stressed the importance of prevention amongst groups who may be at higher risk of CVD such as those in areas of greater deprivation, “there is a link between some of the cardiovascular conditions and the social deprivation index” (Participant 8). Generally, panellists spoke about preventative measures related to lifestyle and overall health, including diet, exercise and smoking and some identified the need for a cultural shift in Scotland related to lifestyle choices:

“I feel that towards eating and drinking, there's a kind of quite an aggressive culture in Scotland… we seem to laugh this off that we’re very hard, they were tough, that this is part of our culture and it's what we are. And I think there's socially, I think there's a problem there that that has never really been addressed effectively. And in my opinion, it's part of the whole preventative process really… I mean, by the time you get to diagnosis, you could argue it's almost too late that I mean, it's like 12- and 13-year-olds that need to be educated.” (Participant 1)

One participant further suggested that the communication around lifestyle changes for prevention could be improved by being more specific:

“[Advice about prevention] is just generalised and, you know, ‘have a good diet, make sure you've, got a good diet.’ But the vast majority of people do not know what a good diet is. It's too general. Everything you know, exercise, what kind of exercise should be doing? How often should you be doing it? it's just all these general things. And I think that needs to be much more specific because I think people are much more likely to stick to something if they have a specific routine to stick to, where prevention's concerned.” (Participant 2)

### Communication of risk for CVD

While several participants did not have any significant risk factors prior to a CVD diagnosis, those who did reported mixed views regarding their understanding of risk prior to a diagnosis. Certain respondents reported not being told by their healthcare team what could happen down the line in terms of cardiovascular disease if they did not manage and control their respective risk factors. One participant noted:

“When I was diagnosed with high blood pressure, there was nothing said [about] what it led to or anything. I was just put on the medication, and I’ve never had any explanation of what could happen since then.” (Participant 6)

The same participant reflected on the experience of one of their friends, who was at risk due to general overall poor health, but was never sent for tests and did not understand the risk posed by his lifestyle choices:

“One of my friends just recently had a stroke, and he’s kind of the first of my group to have something like that. We could tell that he was the most unfit person in the group, but he’d never been tested or anything, never been to the doctor before that happened. So if he had been going for tests, then probably could have prevented it and been warned about it. Again, as [Participant 2] says, he’s the one that wasn’t looking after himself. So you have to take responsibility for your lifestyle as well.” (Participant 6).

A different participant noted that with their Type 1 diabetes diagnosis, they understood that there was risk of cardiovascular disease but also that their lifestyle did not control the diabetes well:

“…I am part of the risk factor because I’m Type 1 diabetic on insulin. I get that … For years in my job, I was out. I was out all the time. So I would eat where I could eat and I was never eating the right thing. So I think risk factors are a problem, but I think it’s how we eat as well.” (Participant 10)

### Managing risk factors

Following on from an understanding of their personal risk factors, participants were asked about their confidence to manage their risk factors and their cardiovascular conditions. Participants felt largely able to manage these with time and experience, but largely felt this would be improved or expedited with greater support from medical professionals:

“Now I’m a little bit down the road, ok, yeah, fine. Initially though, my experience was I was discharged from hospital 48 hours later with no support. So that’s taken me three years to get to a point where I feel confident to manage it independently, whether it’s that there’s not a whole lot of support out there or if there is, you have to find it yourself. But yes, day-to-day I’m confident to manage my condition.” (Participant 11)

Another participant shared they don’t feel as if they have any option other than managing their risk factors and conditions themselves, if they want to remain healthy. They said:

“Well, the blunt answer is that we have no choice. That’s the situation. So, you either crack on and get on with it or you don’t.” (Participant 9)

One participant also discussed the added difficulty of intersecting health issues. When someone has multiple conditions that impact one another, “it becomes a bit more convoluted and a little bit more unpleasant.” (Participant 5) They emphasised that it isn’t always as simple as making lifestyle changes to manage their risk factors or conditions, but that patients need direct support and input from medical professionals.

This participant mentioned that they use the BHF website for information which they often find helpful in supplementing medical advice and empowering them to manage their condition but caveated that it can feel dense or overly technical at times.

## Access to diagnosis and timely care

These focus groups also discussed BHF Scotland’s goal to promote early diagnosis and treatment. Conversations touched on panellists’ experiences in receiving a diagnosis, how they felt about their ability to access diagnostic tests and the impact of waiting times on their condition and overall wellbeing.

### Experience receiving a diagnosis

When discussing receiving a CVD diagnosis, multiple participants reflected on the need for greater support post-diagnosis. Several reiterated how upon being told they have a cardiac condition, they felt they were left to process the information and manage it themselves.

One participant suggested providing a medical professional such as an Advanced Nurse Practitioner who could sit down with patients post-diagnosis and discuss it with them. Multiple participants seconded this suggestion. They suggested that something akin to the support provided to cancer patients would be beneficial: “If you have cancer, you get a Macmillan nurse, but if you have heart disease, you don’t get anybody.” (Participant 2)

One participant who agreed with this further commented that while its implementation might initially put more strain on NHS staff resourcing, it could alleviate the burden on the health system in the long run by better empowering cardiac patients to cope with and effectively manage their conditions.

### Accessing diagnostic tests

Participants made generally positive remarks about their ability to access diagnostic tests through NHS Scotland but also suggested making echocardiograms (ECGs) more routine would aid with early diagnosis of heart conditions. Where respondents reported good experiences with diagnostic tests, they tended to emphasise they felt particularly lucky to have a positive story to tell.

For instance, one participant told the group they had annual ECGs every year and feel well looked after. They caveated this by saying that access to diagnostic tests seemed to be a “postcode lottery” in Scotland and that not everyone is as fortunate as they had been (Participant 4). Another said:

“Well, I mean, for me what happened was that I got into the medical practice to see the nurse for something totally different. And she said to me, ‘Oh look, I’ve had a cancellation. You haven’t had an ECG for a while. I’ll do one until the next patient comes.’ So it was purely coincidental that my condition was picked up. I guess I was just very lucky, you know, fortune smiled on me.” (Participant 7)

With regards to the efficiency of the diagnostic pathway, one participant commented that their experience felt highly efficient but to the point of being mechanistic and at the cost of feeling holistically cared for:

“I had [an angiogram] done and it was all very thorough, but it was a bit, you know, ‘this is what it is, this is what you need to do’ and straight into the system. And it was efficient, but it wasn't particularly helpful. There was no suggestion of what would come afterwards until after the operation had taken place… The impression I got was you were going into a system. So you went in, you had, in my case, the bypass, and came out the other side and were left to get on with it. That's just my experience.” (Participant 5)

### Impact of waiting times

The experiences of participants also varied greatly when it came to waiting times for treatment. Several spoke about the urban-rural divide in healthcare, mentioning either firsthand or anecdotally, how patients from the Highlands and Islands region often had to access out-patient appointments in other areas of Scotland as there is not any provision nearby:

“We’re at NHS Highland, we go to Greater Glasgow and Clyde for outpatient appointments, and I am still waiting and that is now seven months since the referral went into vascular. I haven't heard anything, not nothing at all.” (Participant 2)

They continued that to avoid from being too impacted by this wait they “try not to think about it.” (Participant 2). Another participant mentioned the lack of provision in rural Scotland and considered the impact of this on waiting times as well as the impacts on those who live in rural areas:

“They are flying people from Shetland, the Outer Hebrides and the North of Scotland down to Glasgow or Edinburgh for treatment, for specialist heart treatment. And in some cases young children or babies are having to be sent to Glasgow or Edinburgh.” (Participant 8)

One discussed their experience being prioritised by their GP surgery due to their condition:

“So for instance, me, my wife and two children, we’re all with the same practice. My wife rings up and says ‘I’ve got a sore chest and a sore throat’. She’ll get an appointment in two days. I ring up and say ‘I’ve got a sore chest and a sore throat’. The doctor is out within three hours. You know, it’s like, wow. And then when I asked him why he came out so quick, he said, ‘well, you’ve got a marker on your record.’ (Participant 10)

Similar to the participants who reflecting on their access to diagnostics as being lucky, this participant went on to say:

“But it is like a lottery. … I’m in Loch Lomond, Balloch, I don’t want to tell everyone to feel like I’m winding people up, but there just seems to be a lot of services to help people with heart conditions locally. But listen to everyone else tonight.” (Participant 10)

This was a common theme seen throughout the focus groups, where patients with positive experiences assumed that they were in the substantial minority.

## Care in communities

The next part of the focus groups was devoted to discussing BHF Scotland’s third policy priority – supporting people living with heart disease by providing more care in communities. Participants were asked about the availability of community services in their local area, as well as the extent to which they thought support for controlling risk factors (i.e. smoking cessation programmes) would be useful in their community.

Participants widely agreed that care in communities was vital. One specifically spoke about the lack of rehab facilities in their area and saw this as a major oversight in terms of support and prevention: “I do think that rehab can make such a difference to people who have had a heart attack or have had an episode or have had surgery… I think [Scottish Government] are storing up problems in the long run.” (Participant 2) They expressed being frustrated when the Scottish Government say this is important “but their actions are not speaking it.” (Participant 2)

Another emphasised that improving and increasing care in communities supports prevention or at least prevents deterioration by keeping people healthy so that they don’t need further formal medical intervention in hospital: “If you can't get that care when you need it in your home, then it's a problem.” (Participant 3)

A few participants mentioned the importance of peer support, even if it is not directly going to improve their health the way a medical intervention might. One mentioned that part of what they appreciated about their rehab exercise classes was the peer support:

“There are other people who've got similar problems to you or don't need that. And it's just to say, we'll just have a chat. Not necessarily always talking about health, but you know, ‘How do you cope with this? How do you do that?’ And that's good.” (Participant 4)

Another participant spoke about discussions with other patients, such as those which occur as part of the BHF Lived Experience Panel as something they find helpful in feeling less alone with their condition:

“I do think that we are kind of left just to maintain ourselves and crack on with it. And so having these sort of conversations and the experiences that I've had in joining these forums, I felt has been really beneficial, really good where you just are connecting with other people who are in a similar sort of position, experiencing the same. Any isolation that I may have felt is reduced by that.” (Participant 9)

### Availability of community services

Most respondents were unaware of community care services in their local area. Some respondents posited that these services might be available, but that they weren’t immediately visible to them. When asked if services like rehab facilities or peer support groups were available in their local area, two participants said:

“I’m not sure they are. I guess they are, but I’m not sure. And I certainly haven’t done my own digging into it. But it isn’t easily seen. It isn’t visible. It isn’t clear, nobody is phoning me up to invite me to something. You know, I would have to probably really search for that.” (Participant 9)

“To be really honest with you, I’m unaware of anything other than what’s on offer at the local GP clinic. So I can’t really comment on that.” (Participant 1)

Other participants considered the differing levels of community support and rehab that are available to patients with differing conditions or characteristics. One panellist, who had a heart attack and now has access to rehabilitation services, noted the inequity of this, saying:

“You only seem to get cardiac rehab if you have a heart attack, which is ridiculous because there’s more to do with the heart than actually just a heart attack. But when I spoke to rehab I said ‘Why have I not seen you before?’ She said, ‘I’ve only seen you now because you’ve had a heart attack and a stent fitted.’ And I think that’s ridiculous… You should be able to get the same rehabilitation for your heart condition just the same as someone who has had a heart attack, because isn’t it better to have prevention than crisis management?” (Participant 10)

Another participant agreed with this, and added that as a young woman, the support they were offered left them feeling alone due to a lack of other attendees with similar characteristics to them:

“I mirror what [Participant 10] said. I was offered cardiac rehab because I had a heart attack, and I went there, and I was the youngest person in the room and I was also the only woman in the room. And I asked them if they had any peer support groups. I’m up in Aberdeen. And I asked, ‘Is there anything up here?’ You know, Aberdeen’s not a little city, but is there any peer support groups? No there’s not. If you want to create one you can. Great. Yeah, I’ve got the time and energy for that.” (Participant 11)

They went on to share why they value peer support:

“It is helpful to listen to people who have got lived experience. You've not just read it in a textbook and you you're living it, you understand it and it looks different for every single one of us. But that's helpful to understand too. I think it gives us, one, it kind of an appreciation for the quality of life we do have, but also an understanding of what could potentially come down the hill next or what treatments have worked.” (Participant 11)

One panellist shared that the cardiac rehab they were offered was fleeting, and said the rehab facility told them, “’Our aim is to get you out of rehab, to get you away.’ And, you know, the day that they said, ‘Right, you don't need to come anymore. Now you can take responsibility for yourself.’” (Participant 4) This participant had wanted to continue their rehabilitation classes and were able to access regular private cardiac rehabilitation, but acknowledged that because everyone may not be able to pay for this, this is not accessible to everyone: “I am lucky enough that I could afford it, but I know there’s some people who aren’t.” (Participant 4)

### Community risk factor support

Participants were also asked to consider their views on the importance of community-based support for risk factor management, such as smoking cessation programmes or services that empower patients to make other healthy lifestyle changes. While most participants agreed that risk factor support was important, many questioned its practicality or value in the context of cost to the public purse.

One participant noted that this support was useful, but questioned its ability to prevent heart disease if you need to already have a CVD diagnosis to access the services:

“One of the things that jumps out to me is how are you going to manage to access that? Do you have to wait for a referral? Can you just walk in? You know, how is that feeding it? We have to have the diagnosis before you can walk through the door. How much of this is preventative when in actual fact you have to wait to get the diagnosis first? And is it that you have to wait for your doctor to refer you? So you’ve got the access, you know, how many barrier steps do you have to go through to get the actual support?” (Participant 11)

Another participant agreed – they receive these types of risk factor support services, but wondered if they only had access due to the intersection of multiple health concerns rather than just their cardiac condition.

“…I don’t know if it’s because I’m Type 1 diabetic, because four times a year I go see a specialist to make sure my bloods are ok…but [as a] part of all of that, I get offered smoking cessation, that weight loss management. So I don’t know if I would have got the same help if I just had a heart attack.” (Participant 10)

Other participants reported not having considered this type of risk management support service or believed that the money might be better spent elsewhere. For example, two participants mentioned the use of GP surgeries for support – with one flagging the importance of triage and another reporting that they would tend to use their local practice for support rather than other community groups or services.

“You could spend a lot of money providing that sort of facility in various communities across Scotland and you would get issues that [Participant 11] has raised about how do you access … but if you spent the same money … on providing the consultants for us to have access to when required, or for people to be able to get through to a GP and then on to a consultant quick quickly. I mean, that’s where the service would be helped, I think. (Participant 9)

“It’s not something I’ve ever actually considered. But I think at the moment, it’s probably not something that I would tend to use. But you know, if my condition deteriorated or if I didn’t have my partner to support me, perhaps I would look at something. But I’m not really a group person, you know, I like to do my own thing. And you know, as I said, contact the doctor’s surgery if I need something.” (Participant 7)

## Digital tools and care connectivity

Considering the emergence of digital tools that assist in the management of long-term medical conditions including diabetes, hypertension and respiratory illnesses, participants were asked the extent to which they use digital tools to manage their cardiac conditions. They also discussed their views on their perceptions of connectivity and communication within their healthcare team.

### Use of digital tools for care

Most participants reported not using any digital medical tools for their cardiovascular conditions other than blood pressure monitors on smart watches. One participant shared that tracking apps have been integral in their health management: “So go into the GP and being able to dump a month's worth of data and say, look, that's what my blood pressure did, that's what my oxygen levels were is really helpful for me.” (Participant 11)

Where respondents did report other positive uses of technology in their care was related to online appointment booking. One participant said:

“I find Patient Access is ideal in so much as you can avoid the 8:00am telephone call and you can order medications, you can arrange online e-consults, which would usually end up with you having to ring the surgery in the end anyway. But that seems to work quite well.” (Participant 5)

Some spoke about being sceptical when using the internet to search for information, particularly results produced by AI, because they “want a trusted source of information, not on AI or Doctor Google” and “think misinformation can be worse than no information sometimes.” (Participant 4)

### Data sharing and communication

Patients overwhelmingly reported negative experiences with communication between different parts of their healthcare team. One highlighted poor data sharing between their cardiologist and their pharmacy:

“I’ve gone to the doctor’s and he said, ‘Right, the cardiologist wants you to start these meds.’ And then the pharmacy will ring me up and say, ‘I’ve noticed you’re on these meds, why are you on it? … You’re on three new medications from your consultant since you’re last stent.’ Yes, and the consultant said to stay on them for good. ‘Yes but we’ve spoke to your doctor. We don’t know anything about that, so we’re going to put you on them for three months like we normally do.’ And I’m like, ‘Why is my consultant or the doctor at the heart hospital not putting it on the system what he’s saying?’…I had to argue with my doctor, then argue with my local hospital.” (Participant 10)

They offered another example of poor data sharing with regards to being treated for multiple conditions by different practitioners:

“I went to my local hospital for an appointment with my eyes to do with my diabetes and my heart, but the lady couldn’t see that I had a bad heart because it’s on a different computer. She didn’t know anything about my cardiac issues, she said, and ‘we should know that before we freeze your eyes to do your test.’” (Participant 10)

Another participant commented on the lack of continuity between different IT elements within NHS Scotland leading to disrupted care:

“So when a professional says, ‘Oh yeah I’ll just put it on the system’, you think one system… There’s lots of systems. Everybody has their own system and there isn’t a way to marry things together. So if you come from one side of Scotland to the other side of Scotland, there’s a good chance that your information is not available. If you even move from one country into, you know, things can change.” (Participant 9)

This same participant went on to describe the IT systems as ‘horrendous’ and pointed out that fixing this issue would allow the health service to work more efficiently.

Some participants also shared experiences of poor communication between their medical team and themselves leading to confusion and misunderstandings. One panellist was left wondering if they had alternatives to the medication they were put on, but felt this was not adequately discussed or explained:

“The doctor said to just go on [statins] now. I kind of thought, ‘Me on statins for the rest of my life…’ but maybe at the time, maybe my diet had not been so good recently or something, or something if I'd been given just a few months before, get another test and maybe I wouldn't need statins because I've never had high cholesterol before. But nothing was really explained about that.” (Participant 6)

Another participant felt the details of their operation had not been properly shared with them, which led to some anxiety when they were left to use the internet to find more information:

“It may have been explained to me, but I can't remember sometimes with all the technical words, you know, you can't remember these things. But I didn't know I was going to have open heart surgery and what a big thing that was, having your chest opened up and everything. And I didn't actually know that until after I'd had the operation. And I think for me, I just, I didn't know about how serious it was and I did the wrong thing of looking up at Doctor Google, which I've learnt is a really, really bad thing to do.” (Participant 4)

## Equity and inclusion

Participants were next asked to reflect on their perceptions of equity and inclusion within NHS services and whether there were any barriers that they have experienced firsthand or believed could be present for different communities in Scotland.

Participants again mentioned the urban-rural divide in accessing out-patient care. One said that when you live in a rural area, things are always a little but more difficult and further away.” (Participant 3) Another described the additional barriers this creates with regards to transport:

“We’re NHS Highlands & Islands, but we actually go to Glasgow and Clyde for appointments because, well, the alternative for me would be probably Inverness, which is about six hours away … I don’t think I could get public transport from here… a big problem is transport.” (Participant 2)

Others mentioned additional personal circumstances which have created barriers to their care. One participant who has unpaid caring commitments shared this makes scheduling difficult: “It's not always easy for me to attend appointments, check-ups, things like that.” (Participant 11)

They also spoke about the difficulty of feeling able or empowered to advocate for themselves due to their identity as a younger woman, which is not the typical stereotype of someone with a heart condition:

“The fact that when you go to the GP and you're not a male over 60, that suddenly they maybe wouldn't look at you with that light and wouldn't maybe think ‘Oh perhaps there's something underlying there.’ … Do you have the ability to advocate for yourself in those situations? You know, there's a lot of stigma as well. You know, if you don't walk in there and you're not overweight, a drinker and a smoker, would they even ask?” (Participant 11)

Another participant discussed concerns they had about being potentially discriminated against as a foster carer due to their condition and called for better understanding of the diverse needs and capabilities of those living with heart conditions:

“I want better recognition, better understanding, better provision for what we need, all of that. But somehow I don't want to be treated as an invalid. And I don't want that sort of barrier to exist. So I have to have a medical exam every year for the purpose of foster care. And it's doubly difficult for me to persuade them that I am a safe pair of hands because immediately they're drawn to the fact that I've got a heart condition. And so I don't want to be living in that world. I want it to be, you know, careful, but I don't want that to be the type of barrier that I have to live with.” (Participant 9)

## Key messages for Scottish Government

The focus groups were concluded by asking participants if they had any key messages for the Scottish Government. Some spoke specifically about political timelines and stressed that they would like to see politicians thinking longer term about what is best for their constituents, rather than their positions’ in the next election:

“I’d like to see politicians looking a lot further ahead than just the next election.” (Participant 2)

“They’re scared to increase tax because they’ll lose their job at the next election. But if you speak to most people, they’d be quite happy to pay more tax if it went on the NHS and things like that.” (Participant 6)

Others spoke about the need for increased support, echoing points brought up earlier in the focus groups: “I think there needs to be early support and it needs to be ongoing.” (Participant 2)

And many emphasised the importance of listening to people with lived experience when making decisions:

“I think my message would be that nobody chooses to be ill and illnesses are something that can sometimes be treated, sometimes they can't. But whatever type of illness you have, you deserve to be treated with the dignity of being listened to. (Participant 7)

“Whatever policies you're going to put forward, make sure that you have had some direct communication with people who have a lived experience.” (Participant 9)

“One size does not fit all. And please, please do not lose the human element of caring for people.” (Participant 11)

# Conclusion

In the run up to the 2026 Holyrood elections, political parties are developing their manifestos with their key policies and actions. BHF Scotland is also forming a manifesto with the cardiology priorities which they would like to see the parties adopt. BHF’s top three priorities are preventing heart disease, investing to diagnose heart disease sooner, and supporting people living with heart disease by providing more care in communities.

BHF Scotland commissioned Diffley Partnership to hold focus groups with members of the BHF Scotland Lived Experience panel in early July to discuss these priorities and get panellists’ input. Diffley Partnership facilitated two focus groups with 11 panellists to get their feedback on these priorities as well as what patients would more broadly like to see with regards to cardiology care in Scotland.

Panellists unanimously agreed on the importance of preventing heart disease and suggested greater public education, communication from medical professionals and increased support for those with risk factors could be beneficial in preventing CVD. Participants spoke about varying experiences with accessing care and waiting times; some felt prioritised by their doctors and felt services and diagnostic tests were easy to access in their areas, while others were stuck on waiting lists for months and felt they needed more support. Many described this as being due to luck or ‘postcode lottery.’ Most panellists were not familiar with many community care services in their area but thought these would be beneficial. Local rehab centres and peer support groups were each mentioned as services with high demand but low or no supply; views on community-based support for risk factor management were mixed, some thought these would be useful while others felt resources could be better spent elsewhere.

Multiple panellists shared experiences of poor data sharing or communication between medical professionals on their care teams leading to frustration and confusion and barriers relating to one’s identity or geography were mentioned as creating inequalities in care.

Finally, panellists shared that their primary message to the Scottish Government would be to listen to those with lived experience when making policy decisions and consider the diverse needs and circumstances of people living with heart disease in Scotland.

# Appendix A: Discussion guide

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| --- |
| BHF Panel – June/July Focus GroupsDiscussion Guide, July 2025 |
| **Set up – 5 mins** |
| Thank you for joining us to discuss manifesto priorities for cardiac health ahead of the 2026 Holyrood elections.  Introduce Diffley Partnership Team and BHF team.  Welcome to the focus group–   * This focus group discussion will last up to 90 mins * There will be plenty of time to get your views across and discuss issues between yourselves, something we encourage; my role is to keep the conversation flowing, ensuring we cover the broad areas we need to and ask any follow-up questions, * Fully anonymous and confidential; The Diffley Partnership abide by the Market Research Society Code of Practice and the SRA Ethical Guidelines and are members of both organisations * Everything from this focus group will be reported anonymously. * Request permission to record discussion – with your permission I will record the discussion; this is just so we can go back and listen again after the discussion   **Do you have any questions before we start?** |
| **Introductions and priorities – 10 mins** |
| **To get us started, could everyone introduce themselves and if you feel comfortable, share what support – medical or nonmedical – you have found most helpful to manage your heart condition?**  **Now we are going to talk about the upcoming Holyrood election. We are less than a year away from the next election and parties are beginning to form their manifestos.**    **Is there anything that springs to mind when you think about what topics relating to heart health you would like to see in these manifestos?**    **As a part of their campaigning efforts leading into the 2026 Holyrood election in less than a year’s time, the BHF are focussing on three key priorities that they are engaging political parties on. These are:**   * **Preventing heart disease** * **Investing to diagnose heart disease sooner** * **And supporting people living with heart disease by providing more care in communities**     **We will go into more detail on each of these priorities a bit later, but what are your initial reactions to these?**  *PROMPTS: Do they make sense based on your experience as a patient?*  *Are there any other areas you think should be included in these priorities?* |
| **Prevention and Risk Factors – 15 mins** |
| **In this focus group, we want to do a bit of a deeper dive into each of these priorities – we would like to get your experience as a patient with each of these areas. The first is preventing heart disease and understanding of risk factors. We recognise that not all of you will have had some of these risk factors, but we still want to hear your perspective.**    **For those of you who had risk factors identified prior to a CVD diagnosis, what were your experiences with early identification?**  *PROMPTS: Did you feel that your healthcare team helped explain your risk of CVD?*    **How confident do you feel about your understanding of your condition and managing risk factors?**  *PROMPTS: Have there been any resources and services that have been helpful in managing risk factors?*  *e.g. high cholesterol, high blood pressure*  *Do you feel you have up to date information about your risk factor readings and their potential impacts?* |
| **Access to Diagnosis and Timely Care - 20 mins** |
| **Turning next to the second priority, access to diagnosis and timely care…**  **Could you describe your experience receiving a diagnosis of heart disease?**  *Prompt: How was this communicated with you?*  *PROMPTS: Did you have any experiences in the diagnostic pathway that you felt ran efficiently or effectively?*    **What have your experiences been with regards to accessing diagnostic tests (e.g. an echocardiogram)?**  [Probe on barriers to receiving tests if not mentioned organically, particularly waiting times]    **[IF MENTION WAITING TIMES] How have waiting times affected your health or wellbeing?**  *Prompts: Physical, mental health, quality of life*  *Is there any support or information you think could have been helpful for you whilst you were waiting?* |
| **Community Care – 15 mins** |
| **The third priority is supporting people living with heart disease by providing more care in communities.**    **How would you describe the availability of services in your community (such as rehab facilities or peer support groups)?**  *PROMPTS:*  *If available: Have you accessed these? What was your experience like? Do you find them helpful?*  *If not available: Would you value these in your community? Is there anything in particular you’d like to see locally?*    **To what extent would you think a community cardiology service with links into services that offer support such psychological, weight management and smoking cessation could help you manage your condition?** |
| **Digital Tools and Care Connectivity - 10 mins** |
| **We’re now going to talk about digital tools and connectivity.**  **Firstly, have you used digital tools (apps, remote monitoring, online consultations) in your heart care? What has been most helpful?**  *Prompts: Did you receive enough guidance to use these tools confidently?*    **How would you describe your experience with data sharing or communication between different aspects of your care?** |
| **Equity and Inclusion – 10 mins** |
| **The BHF are also focussing on eliminating barriers to accessing care based on geographic location, socio-economic status, or personal characteristics.**    **Are there any barriers – either that you have experienced yourself or you imagine exist in Scotland - for people who belong to these groups?**    **Do you have any suggestions for making cardiovascular services more inclusive or accessible?** |
| **Wrap Up and Thank you – 5 mins** |
| **Great, that brings us to my final question which is, what key message would you want the Scottish Government to hear about living with heart disease?**    **Great, thank you everyone. Is there anything we didn’t touch on that you want to mention?** |

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***From many voices to smart choices***

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