

Cardiovascular disease (CVD) prevention:

engaging those at greatest risk



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Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) was asked by Scottish Government and NHS Inform to conduct engagement into the public's awareness of cardiovascular disease (CVD) and its risk factors; their preferences for accessing CVD prevention-focused information; and their experiences of using this information to take action on their cardiovascular health.

Additionally, to address inequalities within CVD risk factor awareness and management, Scottish Government and the ALLIANCE proposed targeted engagement with groups at increased risk due to genetic, socioeconomic, lifestyle and other systemic factors, including South Asian communities, women, and people living with socioeconomic deprivation. This engagement also endeavoured to address specific challenges faced by digitally excluded people.

The ALLIANCE's role was therefore to hold conversations with these target groups against the below engagement goals:

- Understand public needs regarding information and awareness of cardiovascular disease (CVD) risk factors, including high blood pressure, high cholesterol, and their impact on development of heart disease and stroke.
- Gain insights into knowledge and understanding of conditions that increase a person's risk of heart disease or stroke, and insights into how people prefer to access information.
- How to use this information to reshape public facing resources for the greatest impact, looking specifically at the experiences of groups at higher risk of CVD.

The following report summarises the learning from this engagement, which was conducted through four in-person and three online focus groups, speaking directly with 71 participants, from November 2023 to March 2024. The findings from this report have been considered in the development of NHS Inform's [Cardiovascular Hub](#), and further work is planned to establish appropriate terminology to better suit audiences (for example, the term cardiovascular disease was felt to be not well understood, but some user testing is required to agree an alternative). The feedback from this engagement has also been shared as part of a wider review of NHS Inform's public-facing information resources, and will help shape the recommendations from this review.

Finally, this report is also being used by Scottish Government to inform future approaches to better support both communities at greater risk and the wider population under Scotland's CVD prevention agenda.

NHS Inform is Scotland's national health information service, which aims to provide the people in Scotland with accurate and relevant information to help them make informed decisions about their own health and the health of the people they care for. NHS Inform currently hosts information about cardiovascular disease and its risk factors (e.g., high blood pressure and high cholesterol), as well as advice on preventing cardiovascular disease.

The ALLIANCE has a strong history of facilitating dialogue and discussion, and extensive experience of employing different approaches to engage with a wide cross-sector of people, including citizens, community and third sector representatives. This has given the people of Scotland the opportunity to inform policy and service design. One of our three core aims is to ensure the voices, expertise and rights of disabled people, people with long term conditions and unpaid carers drive policy and sit at the heart of design, delivery and improvement of support and services.



Context

Heart Disease Action Plan (HDAP) 2021: cardiovascular disease prevention and health inequalities

Priority 1 of the Heart Disease Action Plan (Prevention - tackling risk factors) seeks to improve the detection, diagnosis, and management of risk factor conditions for cardiovascular disease (CVD), in a way that is mindful of health inequalities, and 'reaches people from communities that are particularly underserved by current models'¹.

A key goal of CVD prevention policy is to reduce cardiovascular deaths and morbidity by improving awareness, knowledge and understanding of CVD and its risk factors within the Scottish population. Furthermore, policies need to ensure that members of the population at greatest risk are empowered and enabled to access preventative interventions and resources to reduce their future CVD risk, and to improve their lifestyle and health outcomes.

Acknowledging the fact that CVD is among the largest contributors to health inequalities, accounting for one-fifth of the life expectancy gap between most and least deprived communities², there needs to be a specific emphasis on key groups: those living with socioeconomic deprivation, South Asian communities, women and digitally excluded people.

Groups at higher risk of cardiovascular disease

Cardiovascular disease (CVD) remains a leading cause of mortality and morbidity worldwide, and in Scotland still cause 29% of deaths³, yet prevalence and impact of CVD risk factors can vary among different populations due to a combination of genetic, lifestyle, socioeconomic, and cultural factors⁴. Groups identified at higher risk in Scotland prior to engagement include (but are not limited to) people experiencing economic deprivation, South Asian communities, women, and digitally excluded people.

People experiencing socioeconomic deprivation

In Scotland, individuals experiencing socioeconomic deprivation encounter a higher risk of cardiovascular disease due to a confluence of adverse factors. Those living in the most deprived areas are significantly more likely to have CVD risk factors such as excess weight or obesity, low levels of physical activity, and a higher propensity to smoke⁵.

These lifestyle factors contribute to conditions like hypertension and diabetes, which further elevate the risk of heart and circulatory diseases. Moreover, the prevalence of these risk factors among the socioeconomically deprived has been linked to higher rates of morbidity and mortality from cardiovascular events – the British Heart Foundation reported that the rate of death amongst 45-74 year-olds due to coronary heart disease in Scotland is more than five times higher in the most deprived decile than it is in the least deprived decile⁶.

South Asian communities

South Asian communities (people of the Indian subcontinent including people from India, Pakistan, Bangladesh, and Sri Lanka) in Scotland face a heightened risk of cardiovascular disease (CVD) due to a combination of genetic, lifestyle, and environmental factors.

Genetically, South Asians are predisposed to central obesity and insulin resistance, which contribute to a higher prevalence of type 2 diabetes—a significant risk factor for CVD⁷. Diabetes in the South Asian community is diagnosed at a younger age and at higher rates compared to the general population.

Furthermore, traditional South Asian diets can be high in saturated fats and carbohydrates, often due to traditional cooking methods like frying, which may contribute to a higher risk of obesity, diabetes, and heart disease. Lifestyle factors also contribute, with studies suggesting South Asians, especially women, do less physical activity and lead more sedentary lifestyles⁸.

Women

In Scotland, women face specific risk factors for cardiovascular disease that may impact them differently than men, due to a combination of physiological and social factors.

At a physiological level, research suggests that high blood pressure, smoking, and diabetes may have a more pronounced effect on women's heart health^{9,10}. Women are also reported to experience higher levels of stress and anxiety, which can negatively affect cardiovascular health; and conditions like Long Covid, metabolic diseases, and anaemia are seen as increasing the risk¹¹. The menopause can also cause changes in the body that increases risk of cardiovascular disease¹².

However, societal gender biases also present a significant barrier. Research suggests that women are more likely to experience longer delays when it comes to presentation, investigation, diagnosis, treatment, and follow-up of coronary artery disease syndromes, and are less likely to receive the same guideline-directed therapy as their male counterparts who present with the same condition¹³. A 2018 study by University of Leeds found that women with a total blockage of their coronary artery were 59% more likely to be misdiagnosed than men, and that UK women had more than double the rate of death in the 30 days following a heart attack¹⁴.

Digitally Excluded People

In Scotland, digitally excluded people - those without access to digital technologies or the internet - may face increased risk factors for cardiovascular disease (CVD). This group often includes older individuals, those living in deprived areas, and people for whom English is not their first language¹⁵.

Evidence suggests that digital health interventions (DHIs), such as smartphone applications, may reduce cardiovascular risk¹⁶, while the lack of digital access can lead to reduced availability of health information, fewer opportunities for telehealth services, and challenges in managing health conditions due to limited access to resources. Consequently, this can result in poorer health literacy, delayed diagnoses, and relatively lower engagement rates in preventive health behaviours. Furthermore, the accelerated use of digital technologies within healthcare due to the pandemic has been associated with negative health outcomes for digitally excluded people¹⁷, and a further expansion of the digital divide and health inequalities.

It's important to note that these risk factors are not mutually exclusive, and individuals often face multiple risk factors simultaneously. Prevention and management strategies should consider the unique challenges faced by these populations and address both traditional and non-traditional risk factors. Our engagement analysis attempts to reflect this.



Methodology

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, and we have close working relationships with many NHS Boards, academic institutions, third sector and community organisations, as well as a diverse membership of individuals and organisations, many of whom have lived experience of heart disease. However, a core goal of this engagement was to speak to people and groups that so far have been seldom involved in discussions around support and prevention of cardiovascular disease (CVD).

Our approach was to reach out to, and partner with, community organisations that have existing links with our target groups highlighted for this engagement programme, speaking directly to individuals within settings that they are comfortable in, in collaboration with partner organisations that they trust. As such, we hosted five focus group discussions with partner organisations. We also hosted two sessions with existing ALLIANCE groups: one with the Heart Disease Lived Experience Network, and one with participants in the ALLIANCE Women’s Health Plan engagement programme. In total, we spoke to 71 individuals.

While this engagement sought to explore awareness of risk factors primarily among individuals without lived/living experience of CVD, we also spoke to individuals who have either had a CVD diagnosis and/or have experienced an acute CVD event (e.g., heart attack or stroke), in order to understand what approaches may have better supported them to reach an earlier diagnosis.

Our engagement also spoke directly to organisational staff involved in supporting our target groups, to gain insights on their perception of key issues and trends for how their group access and use health information; hear the common concerns raised by their group; and to hear their recommendations for how their groups may be better supported in future. To support this, one partner organisation – Minority Ethnic Health Inclusion Service (MEHIS) – submitted a summary of their wider related learning from their community link worker awareness programme on diabetes and cardiovascular disease with minority ethnic communities in Lothian. Key information from this submission will be included throughout the analysis and discussion in this report.



The specific phrasing of our engagement questions varied depending on the group we engaged with, however, questions asked to all target engagement groups covered two key areas of investigation:

- 1 Awareness and perception of risk factors:** exploring knowledge of general risk factors for heart disease and stroke, as well as specific risk factors experienced by different demographics.
- 2 Managing risk and taking action:** exploring how much of a priority it is for participants to know about their individual risk of heart disease and stroke; establish preferences for accessing relevant health information; highlight common barriers to accessing and implementing this information; and improvements to information sources required to encourage behaviour change.

We also investigated participant's understanding of terminology typically used in information around cardiovascular disease, to ascertain levels of understanding and explore more accessible ways of communicating this information.

Participant groups

We engaged with 71 individuals across seven participant groups (listed in chronological order, between November 2023 and March 2024:

ALLIANCE Heart Disease Lived Experience Network, national network

The ALLIANCE established the Heart Disease Lived Experience Network to provide opportunities for people with lived and living experience of heart disease to inform and influence the implementation of the Scottish Government's Heart Disease Action Plan.

We hosted an online focus group with 13 network members, to explore what approaches they believe may have better supported them to reach an earlier diagnosis.

The Feel Good Women's Group, Govanhill, Glasgow

The Feel Good Women's Group has been serving ethnic minority women in Govanhill for over 15 years. The group is a health and well-being non-profit for women that provides fitness classes, swimming classes, a nutritional lunch club, education and awareness services and outdoor day trips. It's a safe space for women of all ages and backgrounds to come together, socialise, exercise selfcare and work on their physical and mental fitness. Classes and activities are held on a weekly basis, mostly in the local community centre.

We held an in-person focus group with 15 participants including the group coordinator, all of whom were South Asian women. Individuals were a mix of first and second language English speakers, and some participants communicated via translators.

Al Masaar Women's Group, Stirling

Al Masaar: The Path to Progression is a charity run by the locals for the locals in Forth Valley. They were set up in response to the needs of Falkirk's ethnic communities and they provide practical and social support to members of the local BAME community, especially those facing isolation and vulnerability.

We held an in-person focus group with seven participants including the group coordinator, all of whom were South Asian and Black women. Individuals were a mix of first and second language English speakers, and some participants communicated via translators.

Health Defence Hub, Chest Heart & Stroke Scotland, Maryhill, Glasgow

The Health Defence Team is a community health outreach team based in the Maryhill Hub in Glasgow, and they offer free health screening for the local population, which includes blood pressure, cholesterol, diet, weight, and lifestyle advice. They work in a person centred way to offer support with behaviour change, helping individuals identify any health goals that they might want to work towards. In addition to their free health screening programme, they offer a health walk, which operates on a weekly basis in partnership with Paths for All, as well as a monthly health club for people to share support and ideas regarding their health concerns.

We joined their weekly health walk and spoke to 10 individuals about their experience attending the hub and accessing their services, and we also held an interview with Gillian McLeod, the Health Defence Coordinator at the Hub.

ALLIANCE Women's Health Plan participant group, national network

The ALLIANCE is working with the Scottish Government to create opportunities for women to engage with the Women's Health Plan 2021-2024, including facilitation of a Women's Health Plan Lived Experience Group, and hosting open conversations about women's health with its wider membership and beyond.

We hosted an online women's focus group with three ALLIANCE members to discuss their perspectives on gendered disparities in cardiovascular health information and support.

Boots and Beards community group, Glasgow

Boots and Beards is a Glasgow-based organisation which focuses on bringing together people from the city's black and minority ethnic (BAME) population to have fun in the outdoors, and enhance health and wellbeing through physical activity.

We held an in-person focus group with 15 participants, all of whom were South Asian males, including the group coordinator. Two group members identified themselves as unpaid family carers.

Minority Ethnic Health Inclusion Service (MEHIS), Lothian region

MEHIS works with all minority ethnic communities, refugees, and asylum seekers across Lothian. It provides a link worker and advocacy service, tackles health inequalities and promotes equality in health service planning and provision.

We held an online focus group with Smita Grant, the Service Manager, as well as seven multilingual community link workers, serving Pakistani, Indian, Bangladeshi, Chinese, Arabic, African and Filipino communities.

Report outline

This report explores the lived experience of accessing and using prevention-focused information on cardiovascular disease (CVD), across several thematic areas:

- Key trends and preferences for accessing information
- Common barriers to accessing and using information
- Suggestions from participants for alternative or supporting approaches to prevention-focused information awareness

The outliers section details the feedback that we heard during our engagement that we believe to be of relevance for wider CVD prevention strategies, but were deemed to be out of scope for this project focused on Priority 1 of the Heart Disease Action Plan (Prevention - tackling risk factors).

The final section includes concluding observations on the experiences and feedback shared across the engagement, and future opportunities for development.

Our report will highlight specific challenges faced by individual groups, but also any areas of commonality experienced by all groups.

Thematic analysis

Key trends and preferences for accessing information

Audiovisual resources

When discussing preventative personal health research (i.e., an individual accessing information prior to experiencing any cardiovascular event or concern), individuals we spoke to consistently raised that they are unlikely to actively search for traditional text-based information, whether online or not. Instead, a shared trend across all groups is to consume information via short videos on YouTube.



The women here find it easier to access information in video format rather than written. They access YouTube to find videos to help them. (Focus group participant)



Yes, YouTube is easier, any audiovisual resource is definitely easier. Bitesize pieces, making it clear. (Quote from a community link worker)



When I am cooking or having a bath, I have time to listen to information. If there are videos that I can watch or listen to when I am in the kitchen, this would be helpful. Accessing this on YouTube would be really helpful. I don't have a lot of time to sit down and read things. (Focus group participant)

There was also strong demand for short videos available in different languages, and creating easily digestible content in various other formats (posters, videos, leaflets), focusing on practical heart-healthy lifestyle changes. Individuals shared that they would also be more likely to share video-based information, compared to written, within their networks.



Social media clips are easily available at the click of a button, rather than having to navigate a website in English and access machine-translated content, which is difficult if you have low digital literacy. (Quote from a community link worker)

One of the engagement partners, MEHIS, shared that in their experience, they have found Diabetes UK's animations on **cholesterol** and **blood pressure** useful to explain the link between diabetes and cardiovascular disease in a more accessible way.

Culturally tailored information

We heard a consistent call across groups, particularly in minority ethnic communities, for healthcare information to be presented in a more culturally tailored manner that they can relate to.

Conversations with community link workers supporting minority ethnic communities repeatedly stressed the importance - and success - of considering cultural and lifestyle diversity within health messaging:



In our communities it is prevention that is key, but they don't have the right information they need. If it was available in their own language and culturally appropriate, then we would see greater success. (Quote from a community link worker)



Making changes is difficult for people. They are trying to find things they can change within their culture, not just doing it the Scottish way. Having information culturally rooted is the most effective way. (Quote from a community link worker)



Changing lifestyles is hard, and finding areas of congruence with their own belief systems provides 'hooks' on which to hang preventive messages, validates their collective and individual identities, and can enable people take practical steps to change their behaviours. (Quote from a community link worker)



From my experience in Chinese community, high blood pressure and cholesterol rates are high. For soy sauce, one tablespoon has 2.5mg of salt, but they don't have a clue how much salt is in the sauce. I have been working with a dietician to make them aware of this. (Quote from a community link worker)



Health literacy and numeracy can have implications on how preventive messages are framed. Body size and weight perception are culturally influenced, so different barriers are constructed. Messages have to be sensitively framed to modify perceptions for normal weight and avoid negative backfire effects. (Quote from a community link worker)

Organisational partners expressed a desire for healthcare resources to be developed and reviewed in direct consultation with community stakeholders to ensure cultural relevance and language appropriateness.

Practical advice for behaviour change

In addition to more targeted, culturally specific information, individuals also stressed the need to combine this with specific, practical examples of behaviour change that they can understand and implement, contrasting this with the more “abstract”, clinical information that they state is typically shared with them. For example, despite widespread awareness within our engagement groups that typical South Asian diets with high saturated fats and cholesterol are a risk factor, one individual shared that they still find it difficult to research and implement changes to their diet, highlighting that the ‘Eatwell Guide’ doesn’t represent their diet:



I find it difficult to plan, but I would find specific info much more helpful. What kind of cereal should I have? What should I have for breakfast? We cook from scratch, tell us what oils to change and use less of it. Would be good to have minority-specific advice, to allow us to keep our traditions. Without this we don’t know what changes we can make. (Focus group participant)

Staff from support organisations that we spoke to also shared that, in their experience, successful health promotion efforts involved placing the focus primarily on enabling practical behavioural changes that are realistic for the individuals and families involved, rather than solely clinical information sharing. This approach instils “motivation for hope and change”, by providing tangible resources and emphasising the potential benefits of lifestyle modification. By choosing this focus, they find that it “makes information real to people”:



In the initial stage, very few people signed up for our Group Education sessions. On analysing why this was happening, we concluded that our sessions were aimed at providing information and increasing knowledge rather than activating change. If people were to be empowered to take charge of their health, they needed to hear some ‘hard hitting’ facts, and have the hope that the risk can be reduced and gain confidence in their ability to act on that knowledge. (Quote from community link worker)



We need to be thinking wider in terms of general health and behaviours, targeting our overall mindset change. We’re trying to move away from that more clinical point of view, as a lot of people know the basics, ‘I need to do more exercise, I need to eat more healthy, more fruit and veg’, and so on. It’s instead about finding a way of making it realistic for them, through visual resources, like cans of lager, bottles of wine, what the amount of saturated fat you should have in a day looks like, to bring clinical information to life and move away from that medicalised, almost prescription approach. For the likes of cholesterol, when you actually explain with visuals what it is doing to your blood vessels, then it’s bringing it home to people. This lets us adapt to different individual and population needs. (Quote from community health practitioner)

Community outreach approaches

The success of direct, in-person community outreach was consistently raised by focus group participants as having the greatest impact on their personal health awareness and behaviours. They also highlighted the additional benefits that community group settings have for providing peer support opportunities and reaching digitally excluded people:



We have a wellbeing nurse who sees the women at the community centre and the men at the mosque. We discuss any health concerns we have and find it quicker and more effective than going to our GP. The nurse can refer them to any further healthcare services we require. The wellness nurse is great for people who are not tech savvy and can't access information online. (Focus group participant)



I already had an awareness of my risk factors to some extent, with family history, poor diet and so on, but I only started coming here for the health check when I saw the poster in the shop window. I don't consume any online information at all, but I like the community hub as I can come for the health walk, then get in-person information and advice. (Focus group participant)



The knowledge we gain from the group, from friends and passing this on to others has been the best thing for the group. A lot of us have changed our lifestyle and diet and have lost weight. (Focus group participant)



People are unlikely to search for this information and this needs to be taken into consideration. There's this fear factor of getting checked, but community group settings and easily available services can get past this. (Focus group participant)



We would welcome organisations going to our group to talk to us directly. We would find this useful as we can get the information firsthand and can ask questions. (Focus group participant)

Use of social media platforms

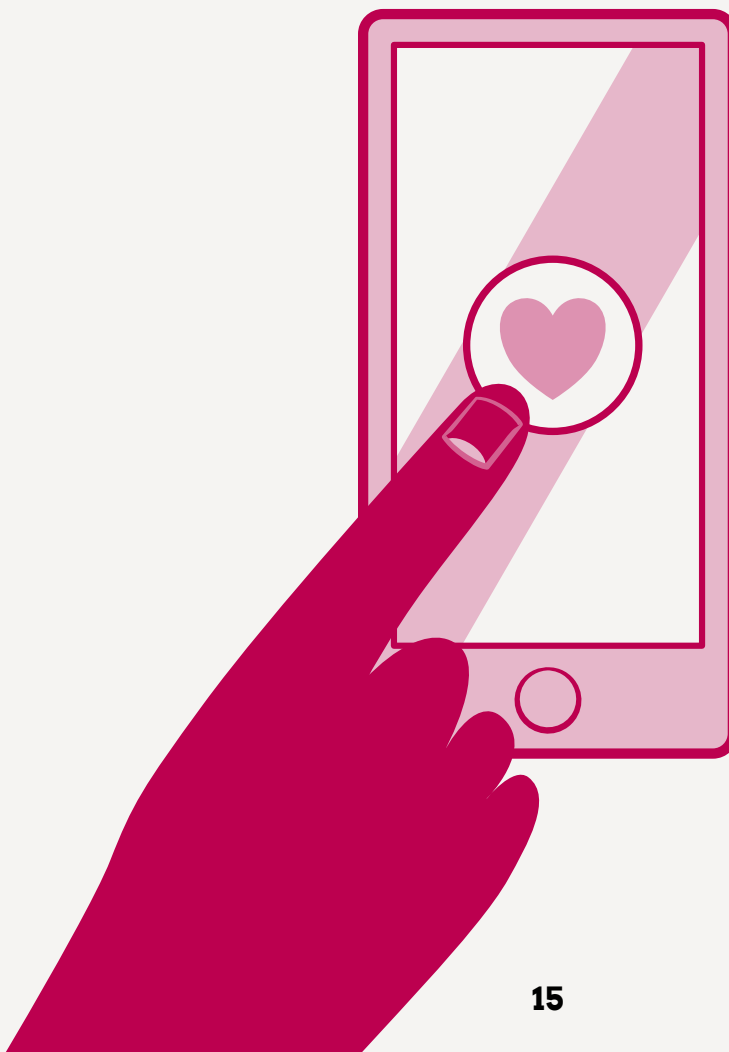
The use of social media platforms for consuming and sharing health information resources was a shared trend across the majority of groups engaged with during this project. Participants raised the importance of expanding information promoted on social media, appealing to health authorities to “meet people where they are”, using creative and targeted approaches, a wider variety of languages, and providing clear pathways for behavioural change and monitoring via these platforms:



Social media must have a place in this in order to reach people. Meet people where they are. Infographics. Less written text that people have to sift through, immediately impactful. Really guide people through what they should ask for at appointments. Clear pathways from identification, behavioural change and monitoring. (Focus group participant)



Websites are not fashionable to access information anymore, social media and WhatsApp chat groups are easier for them to access health information. (Quote from community link worker)



Common barriers to accessing and using information

Experiences of NHS Inform

Feedback and experiences shared across all engagement groups reflected either a lack of awareness of NHS Inform, and/or a preference for other forms and sources of information:



No, we have heard of NHS24, but no one here knows about NHS Inform. We don't use that as a source of information. We talk to our friends, take advice on what works for them, and would then look it up online to confirm. (Focus group participant)



We need to be more aware of how to get that information out there, not everyone wants to read NHS Inform. Take the message to them. Make it more visible, give more pointers, share information on waiting room boards. (Focus group participant)

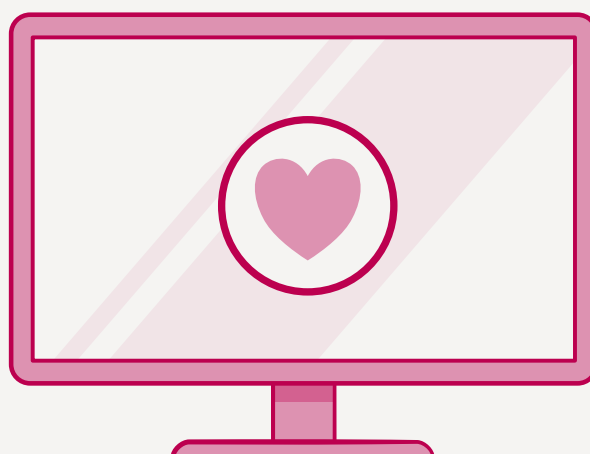
Conversations with individuals and organisations in a support role for minority ethnic communities shared similar feedback:



Everything is in English. They were given a link by GP, but they don't know how to access it. NHS Inform is such a big website and is hard to navigate. Computer illiteracy is a big thing in my community. (Quote from community link worker)



For the African community, NHS Inform is not the best place for them to go. Even if you signpost them to the site, they don't know where to start. It is hard to navigate. They have been told by their GP to go to the NHS website but when they try to use it, they can't find the information they are looking for. It doesn't help them. (Quote from community link worker)



Furthermore, something we have consistently heard in relation to NHS Inform, and other text-based health information websites, is that due to the reality of people's "time poor" lives, people don't feel they have the time to "trawl" through the information, especially in a preventative capacity (i.e., if they are not experiencing symptoms). Participants frequently discussed feeling overwhelmed by the wealth of information on NHS Inform, which leads to either frustration or abandoning research altogether:



You panic when you are given too much information. When you hear a term like cardiovascular disease, and you are told there are big changes you need to make, but there is no support to make them, what do you do? She was just given pages and pages of information, but it was too much for her to take on.

(Focus group participant)



I have tried to look on NHS Inform, but the information is not clear. Normal life goes on and I don't have time to trawl through the information. (Focus group participant)



No one even uses the NHS website or other websites. When they search, they get so much information, so they don't know what to look at, or what is the correct information. The women here find it easier to access information in video format rather than written. They access YouTube to find videos to help them.

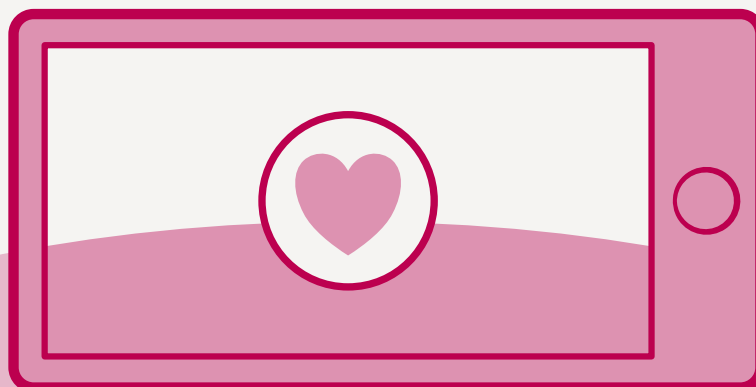
(Focus group participant)

Again, focus group participants often raised that, while they are aware that certain risk factors put them at risk of cardiovascular disease and other health conditions, what they lack from current information sources including NHS Inform is clear and practical advice on how to change their habits:



I'm aware of NHS Inform, but if you are busy and time poor, then it's no use. The information should be clearer to pick up, should have suggestions as to what you can have for breakfast, lunch, dinner. Make it easy for us to access and to put into use.

(Focus group participant)



Low digital literacy across communities was also raised as a challenge for accessing online resources, particularly in relation to NHS Inform, where complexity and lack of user-friendliness/navigability posed significant obstacles for many participants:



A couple of years ago, one of our members got diagnosed with diabetes and the doctor said he would give her information, but she couldn't access the online resources he provided. When they come up against barriers like these, they immediately and fully disengage. They will not work hard to find information.

(Quote from community group coordinator)



It is important to us that the information comes from a reliable source, and we are aware of NHS Inform, but find the information hard to locate on the site. (Focus group participant)



NHS Inform is too big and hard to navigate. A demo showing how to use NHS Inform would be helpful. (Focus group participant)

Language barriers

Feedback from individuals and organisations highlighted that language barriers remain a significant challenge in accessing healthcare information, and encountering this barrier is likely to stop individuals from continuing their research. This remains an issue for many participants using NHS Inform, as the site currently does not have any cardiovascular health information available in Urdu or Punjabi, for example.

Another trend highlighted by participants is that among South Asian and African communities, the reliance on family members (particularly children) for translation poses challenges, especially when dealing with complex medical information. There was a recognition that children may not always have the proficiency or ability to accurately translate health information and medical records, emphasising the need for more accessible forms of information, such as audiovisual resources:



Children brought up in this country don't have the best proficiency in their parents' language and it can be different for them to translate. If it was an audiovisual clip this would be a lot easier for them to understand. (Quote from community link worker)

Complexity of clinical information

Organisational support staff consistently raised concern about the disparity between the clinical language used by many health information sources and the level of health literacy within their communities, highlighting the need for simplified, accessible, and culturally appropriate explanations:

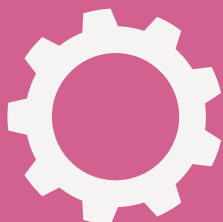


For online resources, I think we need less wording more pictures. We're moving away from language like 'physical activity' to things like 'movement matters', trying to make it sound less clinical and more accessible. (Quote from community health practitioner)



As awareness raising sessions at faith and community settings can include a range of people from those who are highly educated to those who have missed out on education, we went back to basics. 'Cardiovascular disease' was changed to 'Heart and Blood Vessel diseases', and pictorial and moving images were used where possible and we tried to keep it simple so everyone can understand. (Quote from a community link worker)

It is worth noting that many individual participants were unsure what is meant by the term 'cardiovascular disease', and instead preferred more instantly understandable terms including 'heart and circulatory health' or 'heart and blood vessel health'.



Gender disparities in health awareness and clinical information

Many women participants hold the perception that health information is not tailored to them, referencing that, for example, symptoms of heart disease are presented primarily from the male experience within awareness raising campaigns. The concern for many of the women we engaged with is the impact that this has on women's underestimation of their own risk factors, and a lack of awareness that their symptoms may present differently to the examples they typically see:



Information is not tailored - or not perceived to be tailored - towards women. While symptoms of heart disease present differently between men and women, we typically see the male symptoms of heart disease. (Focus group participant)



Without my other health conditions, I would be less aware of the lifestyle preventative measures for my heart health. We tend to put our head in the sand about it, as it's hard work. As a female, without those additional risk factors, I would be less conscious of my heart health. This is down to a misperception around perceived heightened risk for males. (Focus group participant)



It's particularly poor for women. There's a huge lack of awareness that cardiovascular disease is a bigger killer than cancer in women, there's a lack of awareness of our traditional risk factors, and there's a problem with perception and awareness of additional risk factors including mental health and stress. (Focus group participant)



From an NHS Inform perspective, I would like to see the messaging more up front and centre in relation to women's heart health. Currently the messaging is much too generalised. (Focus group participant)

Many women participants, particularly those from the South Asian community, shared that they were not aware of the specific heart disease risk factors faced by women.

Another common concern raised by women participants is that due to the perceived male focus particularly on heart disease awareness, they feel that women are too often not empowered with the information they need to advocate for themselves and ask questions about their health when interacting with clinicians:



Women don't know what to bring to appointments, because it's not on their radar, and they're not empowered to bring questions to their clinicians. (Focus group participant)

Rising misinformation

Across groups, we identified widespread awareness of online health misinformation. Participants appreciated the value of reputable health information sources, however the barriers experienced trying to access this, as discussed within this report, present a significant obstacle to engaging with more reputable sources:



It is important to us that the information comes from a reliable source, and we are aware of NHS Inform, but find the information hard to locate on the site. I don't have time to scroll through lots of information, so quick, clear and easily understandable information is crucial. (Focus group participant)

A shared concern raised by both individual participants and supporting organisational staff is the risk of being “outflanked” by health misinformation shared on different platforms. Support organisations and community link workers were clear in their growing concern about this, particularly in relation to misinformation shared on YouTube, which especially for minority ethnic communities we spoke to during this engagement is a preferred platform for health information:



When asked how they verified what information was correct, people had not really thought about it. In any case, how can one verify online information? The backbone of prevention is aimed at spreading the right message. It is now equally important to denounce false information as more people start using social media as their information source without realising the potential of misinformation and disinformation. Easily accessible, culturally appropriate, NHS-endorsed information would help counteract the misinformation and disinformation.

(Quote from community link worker)



Joe Bloggs don't tend to know about evidence-based information and how to access it. And that's the trouble we're in. People are now accessing that information from TikTok, Instagram and all the rest of it. How the NHS are going to address this, I don't know. Are they missing a trick by not hosting information on YouTube to tap into that? (Quote from community health practitioner)

Individuals shared that they would watch and share video resources on cardiovascular health if published by NHS Inform or NHS24. There are currently no video resources on NHS24's YouTube channel explaining cardiovascular health, looking at heart disease, stroke, blood pressure or cholesterol. NHS Inform's YouTube channel features some information on cardiovascular health as BSL translations but does not feature audio translations or visual representations.

Suggestions from participants for alternative or supporting approaches

During focus group discussions, participants shared a variety of suggestions for alternative approaches to prevention-focused information awareness that could better reach their communities. These include suggestions both from individuals' own perspective and experience, or from organisational/community representatives speaking on behalf of the community they support, and the needs and preferences that they have identified through this role.

Storytelling and diverse representation

Lived experience stories and case studies were raised as powerful tools to engage and connect with people. The importance of making the issue relatable and human was highlighted as a key strategy to reach individuals who may not usually consider themselves at risk of cardiovascular disease, and encourage further research and action:



How do we reach people who aren't engaged, and don't consider themselves to be at risk? The power of stories can connect people, if you have the right case study. Create something that connects with people. It is about finding that individual to highlight the human side of it, that will reach people, even shock people. Celebrity stories do a lot for this as well. (Focus group participant)

The importance of more diverse representation within storytelling initiatives was also raised as critical for this information to "resonate":



Seeing someone in a case study or video that looks like us and has the same lifestyle as us would make it resonate and would make us pay attention. We need to see ourselves in these things. (Focus group participant)



Holistic approaches

Support staff raised the importance of implementing holistic strategies that consider the broader lifestyles of individuals and their communities as a whole.



For example, for South Asians, a family and community approach rather than a purely individualistic focus is more effective. Most health messages are framed in a purely bio-medical model and may be useful in a secular context, but for minority ethnic communities where faith and spirituality are central, a more holistic approach can be more helpful. (Quote from community link worker)

Additional points were raised specifically about the foundation of good physical health being good mental health, and the need to support good mental wellbeing strategies as enablers to living more healthy lives:



The thing that I think goes undiscussed is the mental health aspect. Again, we've made mental health sound too clinical as well. But at our monthly support group, we talk about our 'happiness chemicals' and our 'Five Steps to Mental Wellbeing', and if you're hitting your five steps, you're in a far better place to then take on these new behaviours. This is moving away from your 'make sure you eat your five fruit and veg, do 150 minutes of exercise' advice, and instead towards these natural things, like connecting with other people, getting fresh air, that sort of thing. You're naturally already taking those steps towards healthier living. (Quote from community health practitioner)



Outliers

This section details the outlying feedback that we heard during our engagement that we believe to be of relevance for wider CVD prevention strategies, but were deemed to be out of scope for this project. Whilst beyond our focus of prevention focused information, it was felt that these points were worthy of noting as related issues that matter to people.

Demand for health check services

There was consensus across all groups that a free health check service (measuring key health indicators including blood pressure and cholesterol levels) is what participants expect to be available to support them in taking preventative action.

For individuals, there is an awareness that ideas around high blood pressure and cholesterol remain too “abstract” if they have no way of measuring their levels, and the absence of health check services as a “reality check” makes behaviour change less likely:



Because the ideas around heart health are so general, it doesn't focus the mind in the same way. Having more targeted outreach, offering health checks so people are presented with numbers to actually take action on, is really beneficial. (Focus group participant)



We also need resources beyond awareness. We need practical pointers to organisations that can help, where we can get mental health, genetic, clinical support. Where can people get health checks? What are the practical, behavioural changes that people can implement right now? (Focus group participant)



Before Covid, there were health checks at the mosque after prayer but that hasn't returned since Covid. It would be useful if they could come back. People would use the service. (Focus group participant)

Organisational staff providing support to our target communities also raised the important role that such services play in the prevention agenda, and the appetite they are seeing for these services:



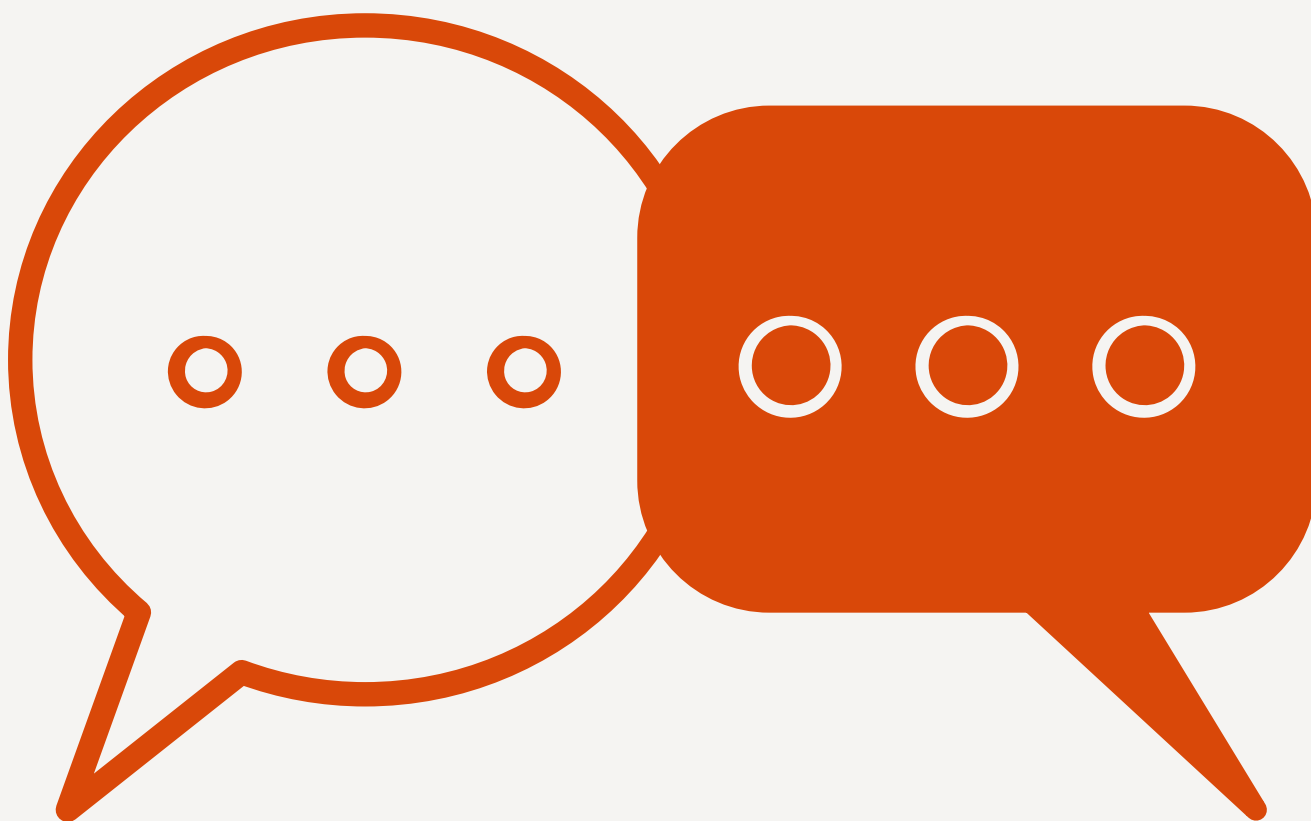
MEHIS staff also noted that raising people's awareness to prevent diabetes and CVD, which are invisible diseases, is not adequate, as 'crisis presentation' is well known in BME communities. People only seek help when there is no other choice. Participants for group education faced barriers when they requested blood tests from GPs. Despite advocacy from MEHIS staff, most participants did not have their blood profile during group education sessions. Health services need to 'be geared up' for the prevention agenda.

(Quote from community link worker)



We're in one tiny bit of Glasgow, but the amount of calls we get asking us to visit other areas to provide this service is incredible. We could literally be doing this in every bit of Glasgow, never mind Scotland.

(Quote from community health practitioner, discussing their free community health check service)



Concluding observations

The cardiovascular disease (CVD) prevention agenda in Scotland has multiple complex challenges to address, and tackling health inequalities must remain at the core of this work. For the Heart Disease Action Plan to achieve its goal of more equitable provision of care, we need to improve our understanding of how we can better support our communities at greatest risk of CVD, and to do so requires a consistent effort to listen to and amplify a broader range of lived experience. The insights shared from participants throughout this engagement programme have raised both profound questions and new solutions for how public health strategies can reach further and deliver greater impact on CVD prevention.

This engagement has highlighted that the way people access health information is changing: preferences for short-form, audiovisual, and culturally relevant information, available on a wider variety of platforms, demonstrate the limitations of our current approaches to preventative care. Feedback from individuals and organisations suggests that successful behaviour change is not achieved solely through text-based clinical advice, but instead through a holistic prevention strategy that understands these changing trends and preferences for accessing and sharing information; that communicates with people in a language and style that they understand; harnesses the power of storytelling and representation; and that supports community outreach and relationship-building. It is also suggested that these actions could contribute to addressing additional challenges including gender disparities and rising online misinformation.

The success of personalised and community-based interventions that resonate culturally, are accessible to diverse populations, and better reflect the reality of people's lives has been demonstrated by both individuals receiving services and the organisations delivering them. The impact of these community models of care, paired with feedback indicating appetite for health check services in the community, highlight the potential success of an expanded community care model that might better engage minority ethnic, socioeconomically deprived, and digitally excluded communities in primary prevention. This evidence supports the goals of action 4.1 of the Heart Disease Action Plan¹⁸, on the value of community models of detection, diagnosis, and management of CVD risk factors, that may better "reach those who may be less likely to engage with healthcare".

Furthermore, feedback suggests that collaboration with community organisations and leaders can enhance the impact and uptake of health promotion efforts. Wider research has demonstrated the efficacy of culturally tailored South Asian health education interventions in improving cardiovascular risk factors and reducing major adverse cardiac events¹⁹, which mirrors the success and value that our engagement partner organisations have found in providing culturally tailored health education within their primary CVD prevention programme.

There is no one-size-fits all approach that can deliver population-wide improvements on the primary CVD prevention agenda. However, by considering the experiences shared by these communities and implementing new strategies, health information providers may foster greater engagement and empower these communities to take proactive, preventative steps towards their cardiovascular health.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,600 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.



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people at the centre

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