



Heart Valve Disease Insight Study Summary

A South London Cardiac ODN commissioned study in
collaboration with Mabadiliko CIC



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Method

Method Broad Research Questions and Targets

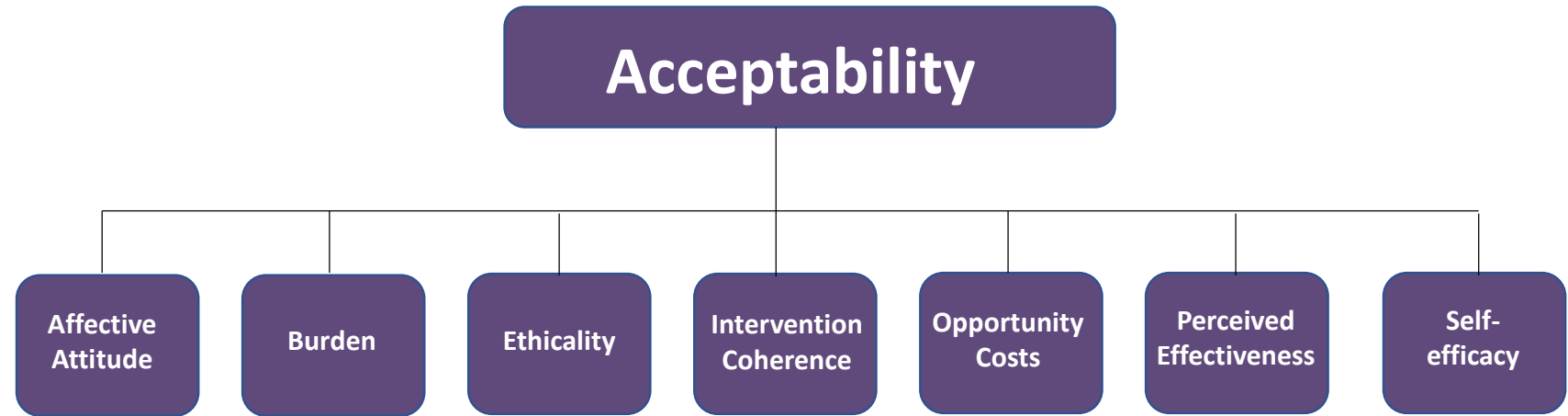
Broad Research Questions:

1. What does the target audience know about valve disease incl. warning signs, investigations/ treatments and actions they need to take?
2. What are the attitudes towards valve disease and treatment options?
3. How can we improve trust and engagement with health services? Including:
 - How can we improve earlier presentation to GP and face to face reviews by GP for patients with valve symptoms or in high risk groups?
 - What are the wider perceptions and experiences of healthcare e.g. trusted (and not!) sources of information, opinions of professionals?
4. How can we improve diagnostic echo scans without delay and referrals into the tertiary valve clinic without delay (ideally directly from the echo clinic)? Including understanding the patient experience of mobile valve clinics?
5. How can we improve (if TAVI is recommended) culturally sensitive clinician communications to take account of different perceptions and acceptability of procedural risk? incl. why patients do or do not act on advice?

Participant targets: Black African and Caribbean (BAAC) communities over the age of 50 that exist within the remit of SEL CCG. Study will focus on the general public (vs. patients with lived experience of HVD).

Method - Theoretical Framework of Acceptability

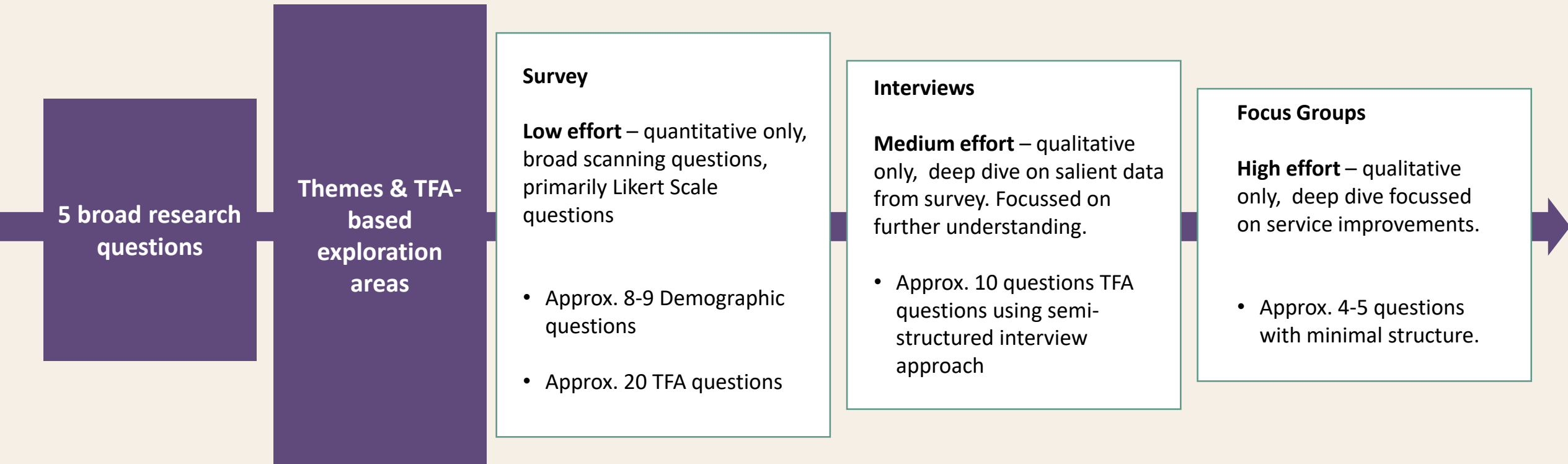
We used the Theoretical Framework of Acceptability as an evidence-based model for understanding health behaviour and acceptability of health interventions (e.g. TAVI).



TFA construct	Definition
Affective Attitude	How an individual feels about the intervention
Burden	The perceived amount of effort that is required to participate in the intervention
Ethicality	The extent to which the intervention has good fit with an individual's value system
Intervention Coherence	The extent to which the participant understands the intervention and how it works
Opportunity Costs	The extent to which benefits, profits or values must be given up to engage in the intervention
Perceived Effectiveness	The extent to which the intervention is perceived as likely to achieve it's purpose
Self-efficacy	The individual's confidence that they can perform the behaviour(s) required to participate in the intervention

Study aimed to have broad coverage across all TFA constructs for completeness

Method - Tiered data collection



Method – Recruitment and Data Analysis



Recruitment – We developed a range of culturally sensitive study promotion materials including an educational video which needed to be viewed before participations. Materials were distributed through our existing networks as well as partner organisations who had access to target patients across South East London. The survey was used to recruit to interviews and at the end of each interview participants were asked if they would be willing to join a focus group. All interviews and focus groups were delivered by a facilitator trained in Mabadiliko culturally-sensitive approaches. All participants signed consent forms before partaking in an interview or focus group. This included information about how their information would be stored, used and ultimately deleted at the end of the project. Participants were made aware that they could withdraw from the study at any point up to two weeks from the interview or focus group without providing an explanation. Mabadiliko complied with GDPR requirements.



Quantitative Data Analysis - Survey data was analysed using Excel to produce summary graphs for each of the survey questions asked. Due to the small sample size, statistical significance was not calculated. However, results will provide a useful guide when triangulated with the qualitative results.



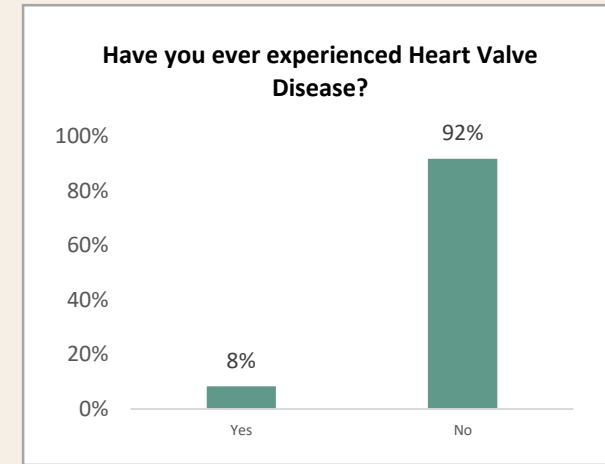
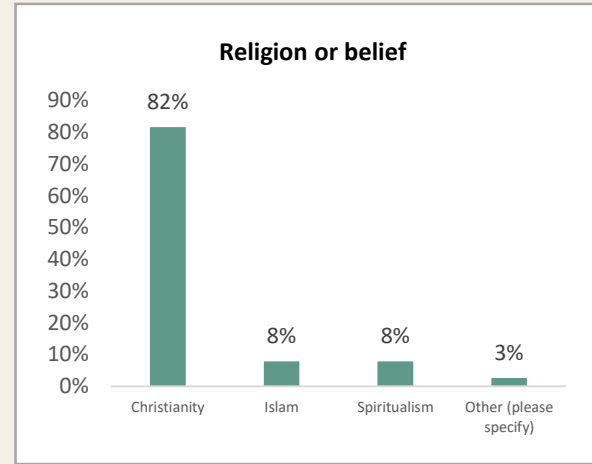
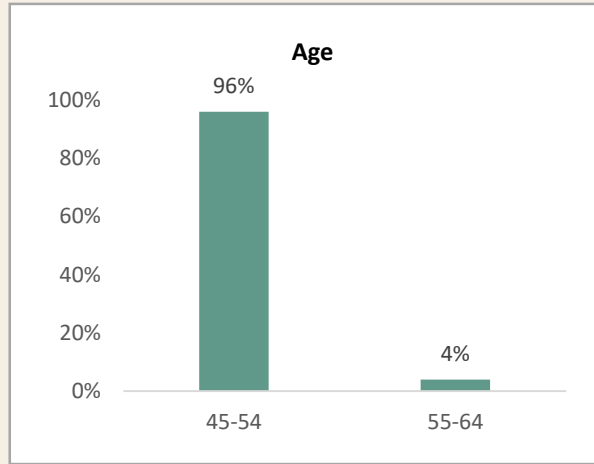
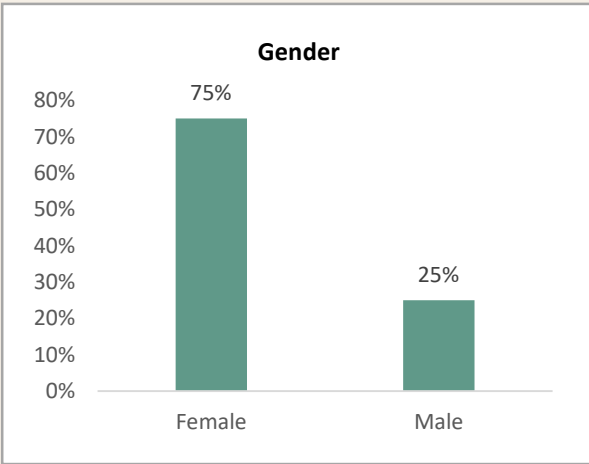
Qualitative Data Analysis – Data collected from the interviews and focus groups were recorded and transcribed using Zoom or other similar technology. All transcripts and notes were anonymised before submission to coders for analysis. A thematic analysis approach was taken to code key words and paragraphs to themes. To minimise bias and enhance the validity of the analysis, an assistant coder independently coded and analysed the data before the lead coder performed a secondary review.

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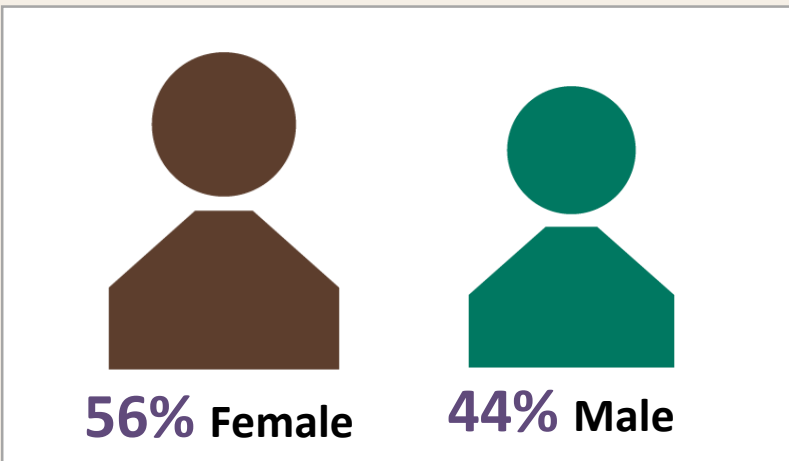
Summary of results and key themes

Results - Study Participants

86 Survey Participants (that met eligibility criteria)



45 Participants contributed to qualitative data collection

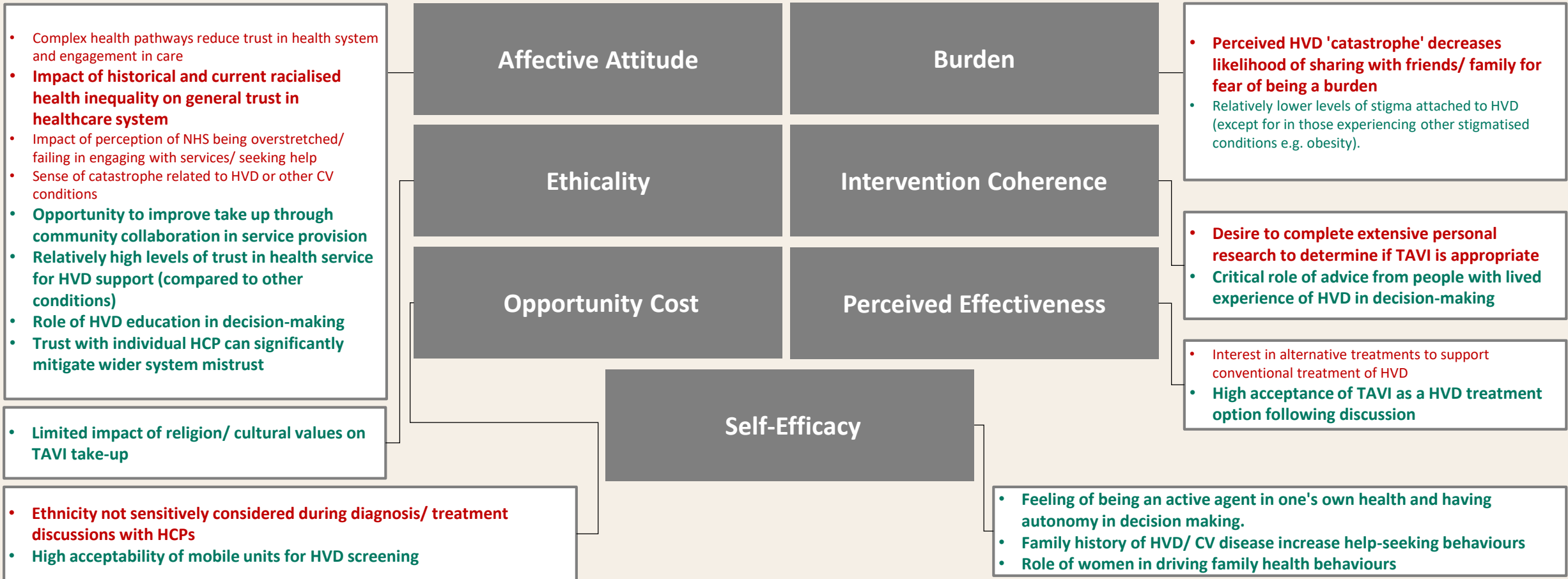


All participants were invited to view a short educational video about HVD



Results - Summary of key themes

Across each of the TFA constructs, a number of themes were generated in data collected through the survey, interviews and focus groups. In terms of the question that were central to our study, acceptability of TAVI, Affective Attitude themes presented the most significant barriers and Perceived Effectiveness themes presented the most significant enablers. Themes within these constructs were largely related to the second key question in our study, how to increase trust. Finally, with respect to acceptability of mobile units for HVD screening, key themes exist within the Opportunity construct, with broadly high acceptability. Items highlighted bold were the most significant themes (**key barriers/ key enablers**). Please see the appendix for further detail about selected themes.



Results - Description of key themes

Affective Attitude		
Barriers	Complex health pathways reduce trust in health system and engagement in care	Smooth health information sharing / flow within NHS are a necessary ingredient of engagement. Negative experiences impact trust and engagement.
	Impact of historical and current racialised health inequality on general trust in healthcare system	Survey data indicates that people have inconsistent levels of trust with the health system, although this does not appear to be mitigated by having HCPs of the same ethnicity or socioeconomic status as patients. There is some benefit of HCPs of the same gender but interview and focus group data suggests that this is not specifically relevant for HVD. Interview and focus group data indicates that there is mistrust developed over generations with awareness of historical race-related health ‘scandals’, recently exacerbated by negative perceptions about the COVID vaccine roll-out. It is worth noting that despite participants typically emphasising this mistrust during interviews and focus groups, ultimately, the perceived risks of HVD, coupled with a trusted individual HCP ultimately mitigate these trust concerns significantly and the majority of participants indicated that in principle, TAVI appears acceptable.
	Impact of perception of NHS being overstretched/ failing on engaging with services/ seeking help	Concerns about the capacity within and pressure on the NHS to deliver health services and the consequential impact on care provided. Participants expressed empathy for NHS workers, and frustrations about the impact on services.
Enablers	Sense of catastrophe related to HVD or other CV conditions	Broadly participants felt that receiving a HVD diagnosis would indicate significant risk to life. Compared to other health conditions, it appears that this fear is a driving force in positive health-seeking behaviours and willingness to comply with treatment options.
	Opportunity to improve take up through community collaboration in service provision	Participants described the benefits of community based support and community-NHS partnerships in helping drive positive health behaviours. This was supported by survey data where (alongside written resources and advice from doctors) participants expressed interest in education through community organisations and those suffering from similar health issues. This focus on collaboration was emphasised by participants expressing gratitude that their opinions were being sought as part of this study.
	Relatively high levels of trust in health service for HVD support (compared to other conditions)	Despite a high degree of mistrust in the wider health service, when participants were asked about which information sources they would rely on for HVD advice, overwhelmingly (if not sometimes hesitantly) participants reported that doctors would be their most reliable source of information based on technical expertise. Informed by perception that HVD is ‘physical’ compared to (for instance) mental health and may require ‘physical’ and ‘medical’ intervention. Ultimately they <i>want</i> to be able rely on doctors for HVD support although this depends on how much they feel they <i>can</i> .
	Role of HVD education in decision-making	Overwhelmingly in the survey, interviews and focus groups, participants noted very little previous HVD knowledge before the study and watching the educational video shared as part of registration. They noted being aware of other CV illnesses but also that while they may not have specifically heard about HVD, it is possible that friends and family had experience or died as a result of it without every fully disclosing or being specific about underlying conditions. Participants expressed gratitude for the educational opportunity provided through participation.
	Trust with individual HCP can significantly mitigate wider system mistrust	As noted earlier, despite wider system mistrust, participants noted that an individual HCP providing empathetic, respectful and human-centred communication can temporarily mitigate trust issues and make a patient more inclined to accept medical advice. There was however high degree of variability in terms of how often participants engaged with HCPs they felt they could trust.

Results - Description of key themes

Burden		
Barriers	Perceived HVD 'catastrophe' decreases likelihood of sharing with friends/ family for fear of being a burden	Despite the catastrophic perception of HVD, participants noted that they may not be inclined to share a diagnosis with friends and family, feeling this would put a burden on them. This could impact social support received and increase the burden on the patient, presenting a barrier to seeking help at the right time.
	Relatively lower levels of stigma attached to HVD (except for in those experiencing other stigmatised conditions e.g. obesity).	Whilst participants expressed not wishing to share a HVD diagnosis with friends and family due to fear it will put burden on them, they did not report significant stigma associated with HVD, except for where there is a perception (driven by low levels of HVD awareness) about a connection to poor lifestyle choices. Specifically, there was a perceived link between obesity and HVD. Survey data indicates that there was inconsistency in the degree to which people believed that BMI was a relevant measure of healthy weight.

Ethicality		
Enablers	Limited impact of religion/ cultural values on TAVI take-up	Participants did not report a significant role of religion or cultural values with respect to TAVI take up. It is noted that the majority of participants noted Christianity as their religion or belief system. Where religious or cultural views may exist in the wider community, most participants felt that HVD was serious enough that they would need to take decisions based on medical advice.

Intervention Coherence		
Barriers	Desire to complete extensive personal research to determine if TAVI is appropriate	Although HCPs were deemed as good source of information for HVD, participants expressed a need to complete extensive personal research to validate HCP advice with respect to TAVI and potentially identify alternative treatment options for HVD. This includes seeking second opinions from medical professionals in their networks or seeking advice community-based health organisations. The internet was also noted as a source of information, despite some concern about the accuracy of internet information.
Enablers	Critical role of advice from people with lived experience of HVD in decision-making	In addition to general internet-based research and seeking advice from medical professionals within personal networks, participants expressed a particular desire to understand HVD and TAVI from people they relate to (e.g. based on ethnicity) who have lived experience of both. This may include feedback on specific HCPs (particularly surgeons) from previous patients.

Results - Description of key themes

Opportunity Costs		
Barriers	Ethnicity not sensitively considered during diagnosis/ treatment discussions with HCPs	Linked to system mistrust, participants had concerns that medical treatments are primarily designed for White Europeans and not reflective of physiological differences with Black African/ Caribbean bodies. They expressed concern that these differences are not considered when HCPs offer treatment advice. There is also belief that Black African/ Caribbean patients maybe specifically disadvantaged due to racial discrimination within the system (e.g. not being offered the best options) and that the impact of racialised trauma on Black health outcomes is not appropriately considered. Patients would like ethnicity to be considered in determining diagnosis and treatment options, but in a way that avoids stereotyping and discrimination.
Enablers	High acceptability of mobile units for HVD screening	Whilst in initial survey data, participants expressed a preference for HVD screening in GP practices and hospitals, during interviews and focus groups (and therefore after further discussion) the majority of participants were open to HVD screening in mobile units including in community spaces. There was also high acceptability of pharmacy-based screening as participants expressed good relationships with local pharmacies. Mobile units were felt to offer access flexibility and for some reduced concerns with respect to hospital attendance. Mobile units are acceptable as long they are run by appropriately qualified professionals, offer privacy and availability of required equipment.

Perceived Effectiveness		
Barriers	Interest in alternative treatments to support conventional treatment of HVD	Generally high levels of interest in alternative e.g. 'natural' or homeopathic treatment options have been observed, driven by general awareness about opportunities for alternative treatment in managing health conditions. However, there was also some doubt about the appropriateness for natural treatments for HVD specifically, with some participants expressing that they would not expect to find appropriate non-medical treatment options for HVD.
Enablers	High acceptance of TAVI as a HVD treatment option following discussion	Despite issues with trust and the likelihood of seeking second opinions and further information about TAVI, after an explanation of the TAVI intervention by facilitators, the majority of participants expressed high acceptability of the treatment. Note the importance of education here, as in initial survey data, participants reported low acceptability of TAVI. Indeed, participants were surprised and pleased to hear that such a minimal access option was available for what is perceived as a catastrophic illness. Acceptability was impacted by perceived need to be pragmatic and do what is best to preserve life and quality of life. Acceptability reduced if there was any perception that TAVI was experimental or offered because it was a 'low-cost' option (compared to other options e.g. 'full' heart surgery that may be deemed more expensive but more effective).

Results - Description of key themes

Self-efficacy		
Enablers	Feeling of being an active agent in one's own health and having autonomy in decision making.	Participants valued the opportunity to be an active agent in understanding a HVD diagnosis and being involved in treatment decision-making. This was associated with a sense of responsibility in one's own health and working alongside HCPs. Also include was a perceived perception of making one's own decisions without being overly influenced by religious and cultural expectations that may exist within communities.
	Family history of HVD/ CV disease increase help-seeking behaviours	Health seeking behaviours are improved when there is a history of HVD or any cardiovascular disease within the circle of family or friends, thus bringing the conditions 'close to home'. Therefore positive behaviours are also impacted by the degree to which communities discuss heart health and are educated about HVD.
	Role of women in driving family health behaviours	Perception that men within the communities have poorer health behaviours than women, including being less likely to acknowledge symptoms and seek support from HCPs, family or friends. As a consequence, participants noted a key role for women in driving health behaviours of the family and community.

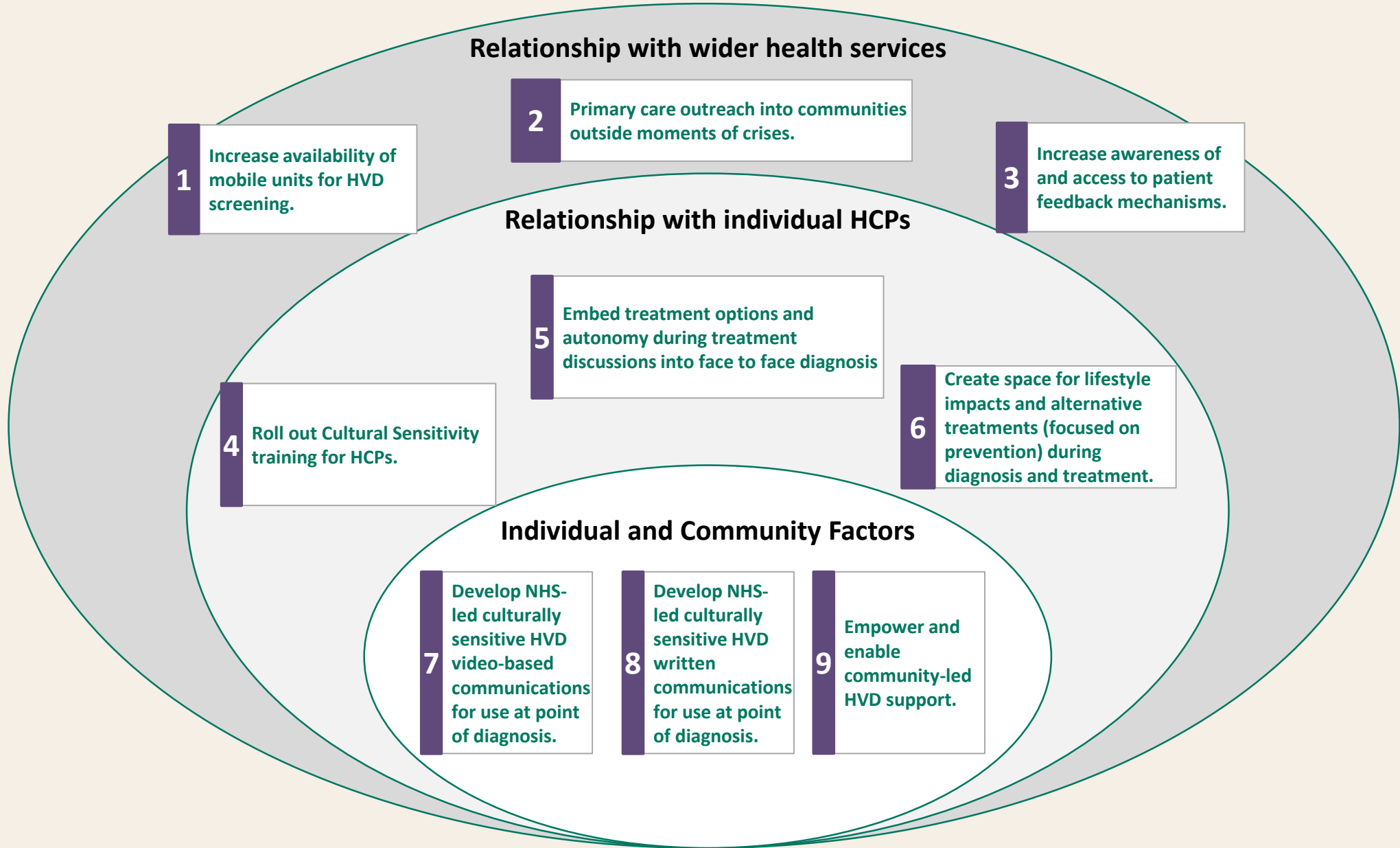
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Summary of recommendations

Summary of recommendations

Recommendations are categorised into 3 broad categories:

- Relationship with wider health services
- Relationship with individual HCPs
- Individual and Community Factors



Recommendations - Relationship with wider health services

1

Increase availability of mobile units for HVD screening.

- Due to the high acceptability of mobile units for HVD screening, take steps to improve opportunities with a particular focus on Community Pharmacy, community organisations such as religious spaces and community halls and 'mobile' units such as health buses which relatively high acceptability for those seeking vaccinations during Covid.
- Consider also upskilling community-based health organisations with appropriate diagnostic capabilities/ tools with resources to sign-post patients to the appropriate NHS services. Clarity in pathway, including pathway through primary and secondary care routes.

Primarily improving
Opportunity Cost.

Addresses research
question 4.

2

Primary care outreach into communities outside moments of crises

- Within both this study, but also parallel studies delivered by Mabadiliko CIC with respect to hypertension and diabetes, participants requested that GP practices in particular are more visible *outside* of their practices and *inside* the communities.
- This includes increases HCP visibility in community-based locations e.g. religious organisations and other community organisations. Critical to this is that HCP presence is based on general outreach and interest in the community, rather than purely focused on a particular NHS health priority. With this approach HCPs are demonstrating interest in the community outside of crisis moments (e.g. a HVD diagnosis) and serves to increase wider trust.

Primarily improving
Affective Attitude.

Addresses research
question 3.

3

Increase awareness of and access to patient feedback mechanisms.

- AT point of diagnosis, ensure that patients are provided information about how, when and how they can provide feedback about their care. Ensure routes include those external that GP practice or hospital including patient advocacy organisations and community-based health organisations.
- Critical that patient feedback, including action taking, is clearly communicated e.g. through posters in GP practices or within hospital settings.

Primarily improving
**Affective Attitude and
Self-Efficacy.**

Addresses research
question 3.

Recommendations - Relationship with individual HCPs

4

Roll out Cultural Sensitivity training for HCPs.

- Train HCPs in culturally-sensitive practices including ability to intuit impacts of racial trauma on health outcomes and decision-making around treatment options.
- Training should also include how to have sensitive conversations about identity and oppression.
- Note this recommendation is different from cultural competence which focuses on understanding the 'other' (e.g. the patient). Cultural sensitivity training should include focussing on the 'self', including personal blind spots and our individuals roles and abilities to address health inequities.
- Training should be available to all staff layers including administrative staff (e.g. reception staff), doctors, nurses, HCAs and members of the wider health system. This enables a system-wide approach to embedding cultural sensitivity, including where it plays a role in the development policies, processes and health guidelines.
- Encouragement for training take-up should include messaging about the wider mistrust from the communities in health services, but also the fact that an individual HCP can significantly change the perceptions for one individual patient, and the beneficial role of positive interpersonal interactions on individual (and therefore community) health outcomes.

Primarily improving
**Affective Attitude,
Opportunity Cost and
Perceived
Effectiveness**

*Addresses research
questions 3 and 5.*

5

Embed treatment options and autonomy during treatment discussions into face to face diagnosis

- Ensure that HVD diagnoses are always delivered face to face, and ideally diagnosis conversations should be allocated a greater amount of time.
- Ensure that in the 'script' for diagnosis conversations, patients are presented with the written communications described in recommendation two and that HCPs make it clear the ultimate decision making will sit with the patient and that their goal is to provide the advice based on individual patient factors (particularly with respect to ethnicity, age, co-morbidities and gender).

Primarily improving
**Affective Attitude,
Burden and Self-
Efficacy.**

*Addresses research
questions 3 and 5.*

6

Create space for lifestyle impacts and alternative treatments (focused on prevention) during diagnosis and treatment.

- Ensure that in the 'script' for diagnosis conversations, patients are invited to discuss how they are feeling overall and what factors in their life may be affecting their overall health. Ensure that social proscribing is offered during every diagnosis conversation where appropriate, with a specific focus on emotional and mental health support.
- Provide patients with advice on how to manage the immediate emotional impact of HVD – this should be discussion based followed-up with sign-posting to appropriate resources.
- Where a patient does raise questions about alternative treatments, it is critical that HCPs do not dismiss these questions but treat them respectfully. Rather than focussing on where there is perceived lack of evidence to support treatments, advise patients on which options they can pursue without affecting medical/surgical options provide.

Primarily improving
**Affective Attitude,
Opportunity Cost
Perceived
Effectiveness and Self-
Efficacy.**

*Addresses research
questions 3 and 5.*

Recommendations- Individual and Community Factors

7

Develop NHS-led culturally sensitive HVD video-based communications for use at point of diagnosis.

- Communications should include clear and simple illustration of TAVI treatment, highlighting its minimally-invasive nature and short recovery time. Explain the innovation/ improvement since the dominance of more invasive approaches. Include statistics about recovery rates (compared to recovery rates with more invasive approaches if appropriate) and include rates for target community.
- The ‘messenger’ should primarily be patients from Black African and Caribbean communities who have successfully received TAVI. Testimonials should include the decision-making journey for patients, including transparency about initial concerns (relating to mistrust), how take-up decision was ultimately decided and where they received support (from HCPs, friends/ family and other sources).
- Messaging should include emphasis on the fact that HVD can be treated if addressed early (counteracting ‘catastrophe narrative’), with a focus on impact on quality of life (with less focus on length of life).
- Messaging should also address perception that the NHS is too busy/ stretched to help e.g. ‘we’re here for your right now’.
- Emphasise role of personal responsibility in getting help early and that it’s ‘ok to talk’.
- Communications to be used at point of diagnosis but should also be shared more widely on NHS websites which have relatively high levels of trust.

Primarily improving
**Affective Attitude,
Intervention Coherence,
Perceived Effectiveness
and Burden**

*Addresses research
questions 1, 2, 3 and 5.*

8

Develop NHS-led culturally sensitive HVD written communications for use at point of diagnosis.

- To support video-based communications, create culturally sensitive written communications which provide more practical detail including:
 - The end-to-end HVD care pathway, including hand-offs between e.g. primary and secondary care and how data will flow between to reduce burden on patient (see later).
 - The range of treatment options that may be suggested including pros and cons. Ensure that there is reference to ethnicity e.g. ‘appropriate for Black African and Caribbean patients’ or otherwise.
 - Where patient decision points will be to drive sense of autonomy.
 - Sign-posting to community-based health organisations or within-community peer support organisations where they can go for additional support.
 - Sign-posting to trusted online sources. Include NHS sources which have relative high levels of trust but also sign-post other sources for more options.
- Communications to be used at point of diagnosis but should also be shared more widely on NHS websites which have relatively high levels of trust.

Primarily improving
**Affective Attitude,
Intervention Coherence,
Perceived Effectiveness
and Self-Efficacy**

*Addresses research
question 1, 4 and 5.*

9

Empower and enable community-led HVD support

- Train community-led health orgs in HVD advice provision and where appropriate screening activity
- Enable them to set up regular peer-to-peer support groups for Black African and Caribbean people across South East London
- Equip to deal with low-level HVD advice but with a primary focus on social support and reducing fear/ anxiety.
- Equip them with video and written communications to support patients.
- Provide resource for periodic attendance from HCP for additional support
- Identify through low-effort, equitable procurement process based on equitable long-term financial sustainability

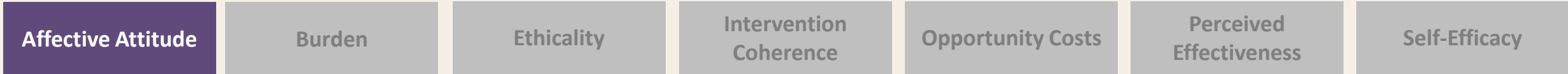
Primarily improving
**Affective Attitude and
Self-Efficacy and Burden.**

*Addresses research
questions 1, 2, 3 and 4.*

4

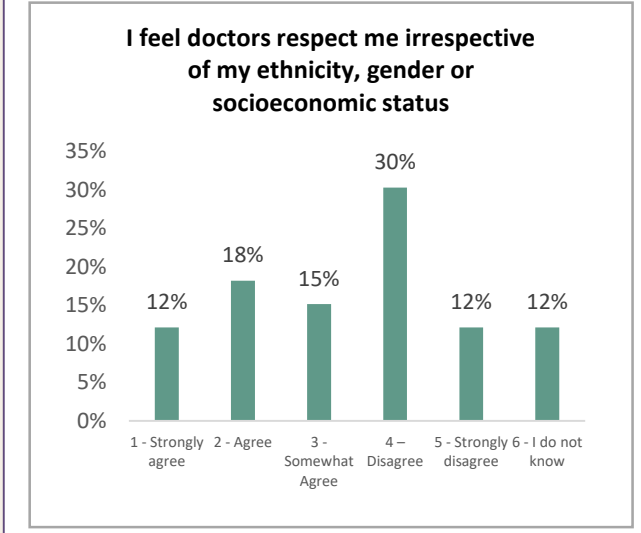
Selected Insights

Selected Insights



Impact of historical and current racialised health inequality on general trust in healthcare system

Survey data indicates that people have inconsistent levels of trust with the health system, although this does not appear to be mitigated by having HCPs of the same ethnicity or socioeconomic status at patients. There is some benefit of HCPs of the same gender but interview and focus group data suggests that this is not specifically relevant for HVD. Interview and focus group data indicates that there is mistrust developed over generations with awareness of historical race related health ‘scandals’, recently exacerbated by negative perceptions about the COVID vaccine roll-out. It is worth noting that despite participants typically emphasising this mistrust during interviews and focus groups, ultimately, the perceived risks of HVD, coupled with a trusted individual HCP ultimately mitigate these trust concerns significantly and the majority of participants indicated that in principle, TAVI appears acceptable.



I think that's why our community don't engage, it's the same reason why we don't engage with giving blood. And the testicular cancer checks, it's a cultural thing, I think. We just need to be educated and we need trust. We're going to hand over our lives, probably to a white person or a South Asian person but there's no trust between us and those communities .

It's not that people don't want to get fixed, it's probably because most of our hearts are broken already and need fixing .

That trust is not there. Look what happened with COVID. Members of my family didn't take the vaccine because they believe it's a conspiracy to inject black people, because they've done it before .

You know, we've been experimented on simply because of the colour of our skin.

Role of HVD education in decision-making

Overwhelmingly in the survey, interviews and focus groups, participants noted very little previous HVD knowledge before the study and the educational video shared as part of registration. They noted being aware of other CV illnesses but also that while they may not have specifically heard about HVD, it is possible that friends and family had experience or died as a result of it without every fully disclosing or being specific about underlying conditions. Participants expressed gratitude for the educational opportunity provided through participation.

I did not know anything about heart valve disease at all. But I presume it's very prevalent in the black community. So it's interesting to me good to know about it.

You can't tell somebody something once, you have to embed, embed, embed, repeat, repeat, repeat. And that's, that's the secret. So you need that film. And then you need to have people like yourself out there, telling them because they don't know, the communities don't know.

Trust with individual HCP can significantly mitigate wider system mistrust

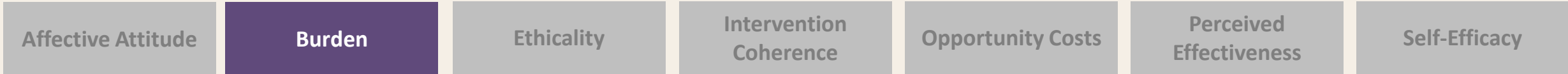
As noted earlier, despite wider system mistrust, participants noted that an individual HCP providing empathetic, respectful and human-centred care can temporarily mitigate trust issues and make a patient more inclined to accept medical advice. There was however high degrees of variability in terms of how often participants engaged with HCPs they felt they could trust.

So it's that stuff that makes me concerned not the surgery about whether or not they are caring, Listening, paying attention writing notes accurately reading notes accurately. It's the is the people that I'm concerned about. And not the surgery itself

A doctor who listens, a doctor who will sit down with you and look at you as a human, yes, you are patient, but let's not let's not treat you as a patient number right now. Let's treat you as a human being that's going through something and we need to work out together how we're going to do this. So someone that will explain things to you listen to your concerns, and not try to railroad you into anything but to give you that chance to think things over. So it's his body language. It's the language they use language I can understand. I don't walk with a medical dictionary. So useless language that I can understand if you say a word, tell me what that means. So that I've got as much information as I can and allow me to talk to you about how I feel no matter how stupid it feels.

She [my GP] is female. She's black. Yeah. So straightaway, that makes me feel comfortable. That if I speak to her about something, she'll, she'll understand a bit more of the, yeah, that she'll understand a bit more.

Selected Insights



Perceived HVD 'catastrophe' decreases likelihood of sharing with friends/ family for fear of being a burden

Despite the catastrophic perception of HVD, participants noted that they may not be inclined to share a diagnosis with friends and family, feeling this would put a burden on them. This could impact social support received and increase the burden on the patient, presenting a barrier to seeking help at the right time.

I think I'd tell very few people.

I don't know how to break that to them without causing some stress and anguish.

I would share it with someone who's like...not necessarily someone who is close to me, but preferably maybe someone who is from a professional point of view, who more understands what is actually happening with you because sometimes when you share it with other people ...I'm not having a go at us as black people. But sometimes the things that we say to each other, makes you feel worse, rather than speaking to a professional person. They're able to balance the scale and you feel a lot more better.

Because they can't help you. They feel helpless. And because they feel helpless, they don't want to hear about it. They feel like when you're talking about stuff, you're asking them, can you help me?

There's some people that cant even call the C word. Yeah. And they believe that if you talk about it, you're gonna empower it, it's a frickin disease, you have got it... If you haven't got it, you've got to do something to make sure you don't get it. Right. But talking about it, wont makes it worse or bring it on. That's not how it works. But some people still feel that, you know, if they talk about it, your empowering it.

Relatively lower levels of stigma attached to HVD (except for in those experiencing other stigmatised conditions e.g. obesity).

Whilst participants expressed not wishing to share a HVD diagnosis with friends and family due to fear it will put burden on them, they did not report significant stigma associated with HVD, except for where there is a perception (driven by low levels of HVD awareness) about a connection to poor lifestyle choices. Specifically, there was a perceived link between obesity and HVD. Survey data indicates that there was inconsistency in the degree to which people believed that BMI was a relevant measure of healthy weight.

Do you believe that BMI (Body Mass Index) is a relevant measure of healthy weight for you?

Response	Percentage
Yes	42%
No	29%
I do not know	29%

But I think I might feel a little bit embarrassed because I might think that, because it might either be because of weight, and I feel embarrassed that I would have let my weight get to a place where it creates an issue like this. And I think that other people might look at me as well, thinking that it's to do with weight.

It's that kind of thing. I think that there's no shame in it [talking about heart valve disease].

I'd want the lifestyle changes to be a little bit more than a 'you just need to lose weight'. Right? I need to know, like, yeah, like, do I need to be, you know, fall within the BMI standards, which I don't necessarily agree with? Or, like, what are you looking for?

Selected Insights

Affective Attitude

Burden

Ethicality

Intervention
Coherence

Opportunity Costs

Perceived
Effectiveness

Self-Efficacy

Limited impact of religion/ cultural values on TAVI take- up

Participants did not report a significant role of religion or cultural values with respect to TAVI take up. It is noted that the majority of participants noted Christianity as their religion or belief system. Where religious or cultural views may exist in the wider community, most participants felt that HVD was serious enough that they would need to take decisions based on medical advice.

I am a person of faith. But there's nothing in my religion that I think would have an opinion about whether I should take the treatment or not.

But me personally, my health is my number one priority really. And my wellbeing so I wouldn't let anybody or anything influence me.

And I guess I'm always balancing the implements of my faith of my values that come from my faith versus my values that come from my scientific background, and I'm quite comfortable balancing those things out. But there's nothing specific I can think about with heart valve disease or TAVI that would make me question it from a religious perspective.

Yes, I would have to consult God first,...what will be right for me to do it. And looking at the pros and cons I will look at would it benefit me? Look at how other people it benefited. How long a life will I live after? And living without it?

And, you know, death is not, you know, I've been taught as a child that death is not the worst thing on earth.

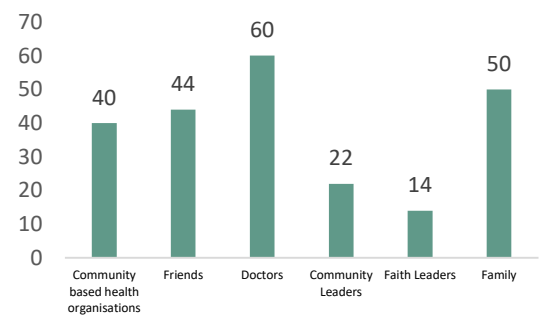
Selected Insights

- Affective Attitude
- Burden
- Ethicality
- Intervention Coherence**
- Opportunity Costs
- Perceived Effectiveness
- Self-Efficacy

Desire to complete extensive personal research to determine if TAVI is appropriate

Although HCPs were deemed as good source of information for HVD, participants expressed a need to complete extensive personal research to validate HCP advice with respect to TAVI and potentially identify alternative treatment options for HVD. This includes seeking second opinions from medical professionals in their networks or seeking advice community-based health organisations. The internet was also noted as a source of information, despite some concern about the accuracy of internet information.

Please share if the people listed below are a good source of health information for you.



I'm aware that GPs have quite general knowledge, I would probably have an initial conversation with the GP but I would be conscious that I would need to go to other medical sources.

I find it [the internet] gives me information. I appreciate that. Sometimes you can go down a rabbit hole and end up looking at things that are nothing to do with your diagnosis. And you can miss diagnose yourself on there, but it's the fact that I can get an answer or even a modicum of an answer. Quickly, quicker than getting a doctor's appointment.

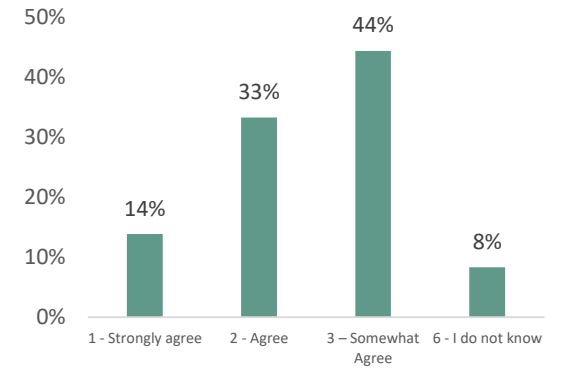
I have a whole organisation called 360 lifestyle support network CIC and its full of professionals and practitioners who deal holistically, some medically too. So I've got that wealth of information to draw on. So I can make 10 phone calls and talk to 10 different practitioners and ask their opinions. So that's what I will do.

I find pharmacy staff to often have a bit more time and be a bit more caring than I find in a GP. So probably quite like to go to a pharmacy more than a community hub.

Critical role of advice from people with lived experience of HVD in decision-making

In addition to general internet-based research and seeking advice from medical professionals within personal networks, participants expressed a particular desire to understand HVD and TAVI from people they relate to (e.g. based on ethnicity) who have lived experience of both. This may include feedback on specific HCPs (particularly surgeons) from previous patients.

I believe there is a difference between the advice provided by doctors and other people I receive advice from

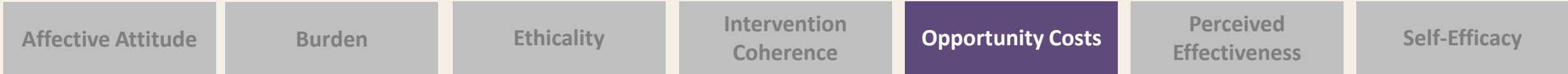


He [the brother who had a stent put in] phones me the next morning and said, Oh, yeah, they're gonna put some dye, you know, in my thing, just to see what's going on. At 11 o'clock, he sent me a text, I've had an operation... That's how quick it was. And that's how good it was, I suppose. Because now you know, he's doing well, back at work. So I was impressed. And I think I understand how things within your body can deteriorate, but I find it amazing that there's such things that you can do, like that procedure that made him, you know, get back to pretty much, you know, a healthy lifestyle, you know, with a few tablets, obviously, to help because of the heart.

Other real people's experience, not just numbers. So if I had a friend who I went to school with who's had that thing, that procedure, talking to them would help.

You know, you want to see the stars the rating? Right? Yeah. So I want like stats, I want to see the rating. So I'd go on the forum and see how many people are saying or I had this operation and it worked or I had this operation and it didn't work or, you know, I want to see how many of those real people are coming in. And then I go to the doctors, and then I'd question the doctor, we often find it and say well, what is the success rate if you want me to operate because my missus has had operations that they think she should have had and should not have had it.

Selected Insights



Ethnicity not sensitively considered during diagnosis/ treatment discussions with HCPs

Linked to system mistrust, participants had concerns that medical treatments are primarily designed for White Europeans and not reflective of physiological differences with Black African/ Caribbean bodies. They expressed concern that these differences are not considered when HCPs offer treatment advice. There is also belief that Black African/ Caribbean patients maybe specifically disadvantaged due to racial discrimination within the system (e.g. not being offered the best options) and that the impact of racialised trauma on Black health outcomes is not appropriately considered. Patients would like ethnicity to be considered in determining diagnosis and treatment options, but in a way that avoids stereotyping and discrimination.

I think medical history is important. And I do think also, this goes in both directions. But there are differences physiologically between black people and white people. I expect them to know that I'm black. But I don't want them to put me into a box or stereotype me or make assumptions about me and I have had that before.

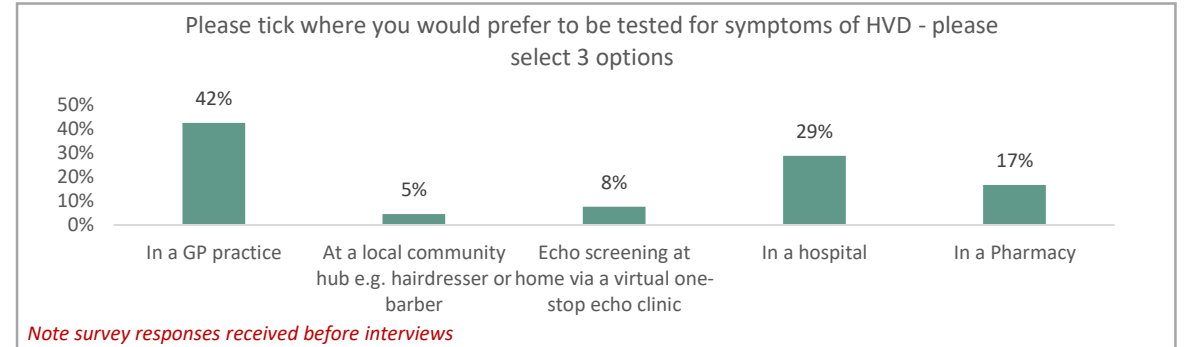
I would regard heart valve disease to a certain degree like sickle cell and all the others. I think it depends on, we as a race of people, our DNA is not the same as others. And I think we have to accept that. And our experience is different to others as well. And the pressures that we encounter, especially here and the conditions and so forth, accumulate to a lot of things happening to us.

More than anything. And there's also the systemic issue. structural racism. I'm very, very aware of it. I know that doctors are under pressure. I believe that the wider system does, either actively, sometimes disadvantages us or through negligence as black people. And those are all things that kind of I take into consideration when I'm deciding whether or not I'm going to take up an option.

Can we just say it out loud ...racism? Can we just say it, no one's gonna fall down and drop dead if we just say it. But they don't want to deal with that bit. So they focus on all their tactical bits. There's a lot that we're living with. You know, and they don't know that and you don't have that opportunity to say and what they don't realise is the stuff that is not hurting me that I'm living with is probably the reason why I got that pain while I'm here.

High acceptability of mobile units for HVD screening

Whilst in initial survey data, participants expressed a preference for HVD screening in GP practices and hospitals, during interviews and focus groups (and therefore after further discussion) the majority of participants were open to HVD screening in mobile units including in community spaces. There was also high acceptability of pharmacy-based screening as participants expressed good relationships with local pharmacies. Mobile units were felt to offer access flexibility and for some reduced concerns with respect to hospital attendance. Mobile units are acceptable as long they are run by appropriately qualified professionals, offer privacy and availability of required equipment.



I mean, me personally, I wouldn't care where I'd go, as long as it's private, I mean, private in the sense that you're not in a hall, and you're having to lift up your shirt, you know, I mean, I'd be fine to have it at the doctor surgery, if they want to come to the house. I have to go to hospital and I think they're scary places to a lot of people, but you know, I think it depends on the person and their relationship that they have with the hospital.

got your GP. My chemist is down the bottom of my road, turn left here and we have good relationship, amazing. A lot of things that I will go for GP for, I will call my chemist. I got his number on speed dial.

As long as the people who were operating those diagnostic tools in the Community know what they're doing, I'd be fine. I'd rather just go one place. Even if a one stop clinic, that's fine, as long as it's plugged into the NHS, and my records.

I think everyone would prefer a hospital it's more equipped. mobile units are something that's has to be stocked frequently, because it's mobile, but at hospital, you've got everything there. The scans are very expensive. But that sort of equipment you're not going to get anywhere else beside a hospital.

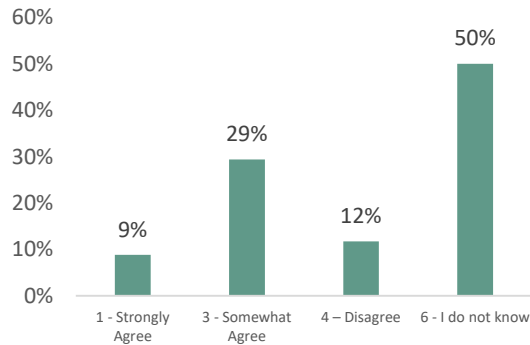
Selected Insights

- Affective Attitude
- Burden
- Ethicality
- Intervention Coherence
- Opportunity Costs
- Perceived Effectiveness**
- Self-Efficacy

High acceptance of TAVI as a HVD treatment option following discussion

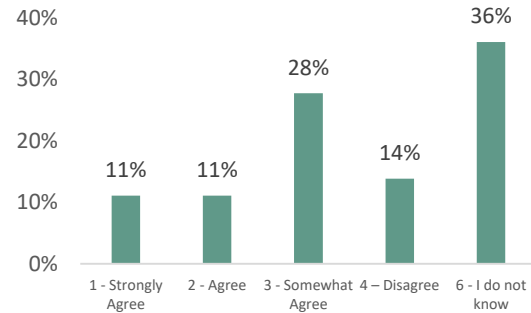
Despite issues with trust and the likelihood of seeking second opinions and further information about TAVI, after an explanation of the TAVI intervention by facilitators, the majority of participants expressed high acceptability of the treatment. Note the importance of education here, as in initial survey data, participants reported low acceptability of TAVI. Indeed, participants were surprised and pleased to hear that such a minimal access option was available for what is perceived as a catastrophic illness. Acceptability was impacted by perceived need to be pragmatic and do what is best to preserve life and quality of life. Acceptability reduced if there was any perception that TAVI was experimental or offered because it was a 'low-cost' option (compared to other options e.g. 'full' heart surgery that may be deemed more expensive but more effective).

TAVI appears to be a minimally invasive procedure



Note survey responses received before interviews

If I was diagnosed with HVD, I would feel confident in accepting TAVI if it was recommended by my doctor



Note survey responses received before interviews

I'm always surprised that the level that they're at with heart technology, and the things that they can do, just so quickly, in such a short space of time, and get people fixed as it were, because, you know, he [the brother that had a stent put in] was fine, as far as we knew, only had a few odd pains.

[TAVI] sounds like it's fairly easy, fairly quick.

So I'm kind of, if it's physical, medical, I'm for it. But if it's kind of not experimental as such, but I'm not taking anything that I don't need to, I'm allowing my body to kind of do its fight in for me, as it were, because that's slightly different.

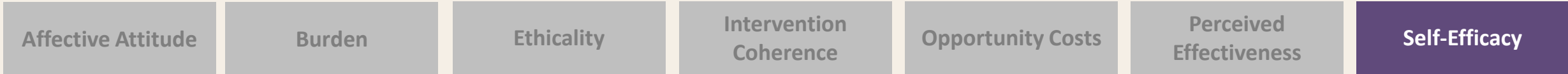
I would never risk doing something where I'm not sure of the end result. I mean, okay, you have an operation, it could go either way. But I think when you're putting something inside you that you don't know what it's gonna do to you. That worries me more.

For something like a damaged valve, it kind of makes intuitive sense to me that you take the damage valve out and put a healthy one in.

Well, let's face it. TAVI is not something that you fly down to put your name down for. But I gotta think of it like this. If I'm in a situation where I need to have it done, yeah, it's necessary. Things that are necessary have to be done.

I'm concerned that this keyhole approach might be less effective than a full surgery. I think the surgery would be more thorough than the keyhole.

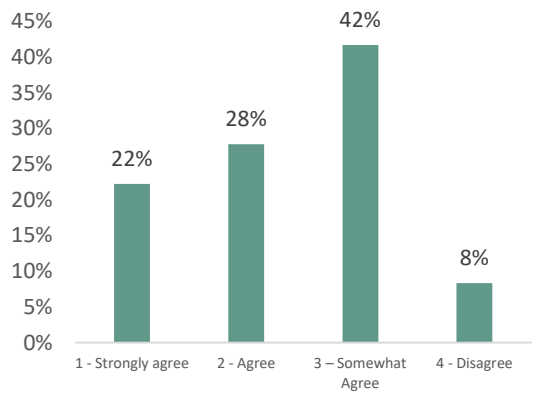
Selected Insights



Feeling of being its active agent in one's own health and having autonomy in decision making

Participants valued the opportunity to be an active agent in understanding a HVD diagnosis and being involved in treatment decision-making. This was associated with a sense of responsibility in one's own health and working alongside HCPs. Also included a perceived perception of making one's own decisions without being overly influenced by religious and cultural expectations that may exist within communities.

I feel I can voice my concerns about proposed treatments with doctors



I think that is something that comes from my personality, but maybe informed a bit about by faith, which is about being a good steward of my body.

I just like to have options [about treatment and tests].

And sometimes I think we need to sort of pull up on ourselves and sort of look and search more within ourselves. There are so much fact finders and stuff, we can find out about our rights within the NHS. But sometimes we just don't think it's important.

There's this arrogance that the doctors have that they think they know everything, and they don't want you to think that oh, we don't really know about that, like, just another virus, because it's easy to say it's a virus, you know? So yeah, I'm, I'm a bit sceptical. So I'd do a lot more research.

Britain is a very hierarchical class based society. So a doctor talks to you, you listens and that's the way it's going to be.

No, I would [challenge my doctor] I think. I'd be able to say, ask, you know, could you give me more information? I'm not sure that I'm, I understand it now. I wouldn't be that person.... And then I don't understand it. If I don't understand it, yeah, I will ask, because clarity is important to, just to know where you are with things.

Family history of HVD/ CV disease increase help-seeking behaviours

Health seeking behaviours are improved when there is a history of HVD or any cardiovascular disease within the circle of family or friends, thus bringing the conditions 'close to home'. Therefore positive behaviours are also impacted by the degree to which communities discuss heart health and are educated about HVD.

And I've always been kind of aware of heart health, for want of a better word. My dad died of a heart attack when he was 48, so it's kind of, you know, I have an awareness of how the heart works and everything else.

I think the first thing that would come into my head [if I was diagnosed with a heart valve disease] is my father who died from a massive heart attack. And I know that he had angina, and maybe other issues that he didn't really talk about. So obviously, I know that it could potentially be within my family.

We don't really want to face it on. Unless it's something you know, maybe sort of in the family that it happens. We just brush it aside.

Role of women in driving family health behaviours

Perception that men within the communities have poorer health behaviours than women, including being less likely to acknowledge symptoms and seek support from HCPs, family or friends. As a consequence, participants noted a key role for women in driving health behaviours of the family and community.

I have a theory about men and health. Cause it's slightly different to women and health. If we feel pain, we're on it straightaway, because we kind of feel a bit more in tune with our bodies. I know there are men that are. But I found with most guys that have things going on with them, they will never do things straightaway. They tend to wait for a day or two. And I just sense it's because nobody wants to think they're going to be ill or they've got something serious wrong with them.

My dad could have had an operation even back then. But he refused to have it. Because he didn't want them, you know, meddling with him operationally, he was not that person, hence why he's not here today.

Women take the responsibility. I'm going to book you a doctor's appointment. You need to see the doctor about this is, you know, because women are much more likely to go to the doctors when something's wrong.



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