EXPLORING THE RESULTS: INSIGHTS FROM PATIENTS LIVING WITH ELEVATED CHOLESTEROL (IPEC) STUDY

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Executive Summary

Global Heart Hub's Insight from People with Elevated Cholesterol (IPEC) is a patient-led initiative to gather patient experience data about people's experiences, understanding, and unmet needs related to high LDL-C or "bad" cholesterol. The first phase of IPEC included interviews with 50 people diagnosed with high cholesterol in Australia (n=19), Brazil (n=15), and the United States (n=16). Approximately half of the participants also had experienced an ASCVD event (n=22) after their diagnosis of high cholesterol.

Participant Experiences at Diagnosis

Routine health checks were the most common pathway to a diagnosis of high cholesterol (n=25, 50%). However, people are also diagnosed during visits for comorbid conditions (n=12, 24%), most frequently diabetes. One in four participants found out about their high cholesterol only after visiting their healthcare provider for symptoms, such as shortness of breath, nausea, and/or dizziness (n = 13, 26%).

IPEC participants reported feeling overwhelmed (n=13, 26%) and surprised (n=7, 14%) by their diagnosis. This could be due to receiving the diagnosis unexpectedly (e.g., going for a diabetes check-up and learning about high cholesterol status), worries about the increased risk for an adverse cardiac event, or unfamiliarity with the medical terminology used by healthcare professionals when discussing high cholesterol. Several people (n=5, 10%) described being embarrassed by their high cholesterol, admitting that they knew they had not been taking care of their health before diagnosis.

The quality and depth of discussions between healthcare providers and participants at diagnosis varies. These discussions affected the understanding and management of high cholesterol. While some people (n=8, 16%) reported shared decision-making with their healthcare provider to identify and agree on the most suitable treatment plan following their diagnosis of high cholesterol, more than half of the participants (n=32, 64%) were told what to do or what medications to take without involving them in the discussion.

Managing high cholesterol

The study highlights a lack of awareness among some participants about the chronic nature of high cholesterol and that it requires lifelong management. Only around half (n=23, 46%) of the participants were aware that lipid-lowering therapies need to be taken throughout life. One in three (n=18, 36) described a lack of understanding of the seriousness of high cholesterol following their diagnosis.

Following a diagnosis, participants often face challenges in managing their high cholesterol, including making and sustaining lifestyle changes and adhering to medication regimes. Two-thirds (n=33) of participants described trying to make lifestyle changes following their initial high cholesterol diagnosis. Two-thirds (n=34) also described initiating a medication at diagnosis, most frequently a statin. However, for slightly more than a quarter of participants (n=13, 26%), the diagnosis did not stimulate any risk-reducing behavior or initiation of medicine. Some people felt they had already implemented many recommended lifestyle changes, such as diet and exercise. Life factors such as work schedules and travel, as well as lack of adequate insurance or out-of-pocket costs, also created barriers.

Participant experiences with ASCVD events

Most of the 22 people in IPEC who had experienced an ACVD event (n=15, 68%) did not immediately recognize the event as heart-related, which delayed care-seeking. Frequently (n=11, 50% of those who experienced an ASCVD event), participants described feeling unwell with flu-like symptoms, chest pain, fatigue, coughing, nausea, or paleness. Other barriers to seeking care were a reluctance to cause disruptions to work or other activities or not wanting to be a burden on their family. About one in five participants (n=4, 18% of those who experienced an ASCVD event) reported that an outside person, e.g., a family member or colleague, had convinced them that the symptoms were serious or called for emergency care after finding the participant incapacitated.

Participants felt unprepared for the ASCVD event, worried for their families, and scared they were going to die during the event. Following their event, participants described taking more responsibility and initiative regarding their care plan. Many described significant improvements in their adherence to lifestyle changes. Discussions about medicines and lifestyle changes were also more frequent during follow-up appointments than after the initial LDL-C diagnosis. This was not a universal change; however, some individuals (n=7, 32%) described continued gaps in knowledge and support, as well as a lack of concern from their care team following the event.

The emotional toll of living with high cholesterol, especially after experiencing a cardiovascular event, can be profound and impact adherence to care plans. Participants described feeling overwhelmed by multiple concurrent diagnoses, unfamiliar medical terms, and concerns about cardiac risk, with personal and family health histories deeply influencing their perception of the seriousness of high cholesterol.

Interactions with healthcare providers & information sources

Healthcare providers were participants' major source of information (n=27, 46%), followed by internet resources (n=20, 40%), e.g., Google, the Mayo Clinic, TikTok/YouTube videos or WebMD. Facebook groups, the experiences of family and friends, organisations such as the American Heart Association, and the scientific, peer-reviewed literature were also mentioned as sources of information. Many participants expressed a need for clearer communication and more targeted information regarding the risks of high cholesterol and the importance of maintaining treatment and lifestyle changes.

Cardiologists often play a more prominent role in post-event disease management than in preventive treatment after the initial diagnosis of high cholesterol. About one-third of participants described changing physicians (n=8, 36% of those experiencing an event) or adding a cardiologist (n=11, 50% of those experiencing an event) to their care team after an event.

IPEC participants described a desire for enhanced patient education, better integration of care services, and more personalized treatment plans to improve outcomes.

High cholesterol and the IPEC research project

Atherosclerotic cardiovascular disease (ASCVD)

Atherosclerotic cardiovascular disease (ASCVD) is an umbrella term that describes various diseases caused by the build-up of fatty deposits – or plaque – in arteries. Silently building up over time, many people do not experience symptoms until the plaque in the arteries unexpectedly ruptures. If this happens, the damaged artery can bleed, causing blood clots to travel to different body parts. This may lead to a heart attack or stroke.[2]

Cholesterol

Cholesterol is a fatty substance essential to a body's normal functioning. A high cholesterol level does not generally cause any symptoms. Cholesterol levels can be measured by taking a simple blood test. It is recommended that adults have their cholesterol checked regularly if they have a cardiac history or are already on cholesterol-lowering treatment.[3]

Some people are not able to achieve the recommended levels of cholesterol through lifestyle changes alone and will require medication if their levels of LDL-cholesterol are too high. Certain causes of high cholesterol are non-modifiable and may not be able to be controlled through lifestyle adjustments or behavior changes alone. For example, certain genetic conditions, including Familial Hypercholesterolemia (FH) and lipoprotein(a) or Lp(a) can put people at greater risk for high cholesterol and ASCVD.[4,5] Adoption of positive lifestyle changes and the use of appropriate medical therapies slow down the progression of ASCVD, lowering the risk of cardiac events such as strokes and heart attacks.[6]

IPEC Objective

There is a lack of high-quality, patient-led research about people's experiences, decisions, and perspectives on being diagnosed and living with high cholesterol. To fill this gap, we adapted the National Health Council's Patient Experience Mapping Toolbox (PEMT)[1] to document people's experiences with high cholesterol and ASCVD events in three countries with very different health systems: Australia, Brazil, and the United States. This report describes our findings, including:

- Pathways and barriers to a high LDL-C diagnosis
- The burden of managing high LDL-C, including the impact on family members, work or student life, comorbidities, finances, and other life factors/social determinants of health
- Patient awareness of the association between high LDL-C and other risk factors for heart disease and stroke.

Methods

Steering committee

This project was guided by a seven-member Steering Committee (see Acknowledgements), which included patients, patient advocates, researchers, and cardiologists. The committee met at project kickoff to review and provide feedback on the study protocol, interview guide, and screening criteria. The steering committee was convened two additional times throughout the research to review preliminary findings and discuss the next steps for dissemination.

Additionally, many steering committee members provided individual consultation calls regarding the study approach and conclusions.

Participant recruitment

We targeted the recruitment of 45 individuals. All participants were required to meet the eligibility criteria listed in Table 1. Half of the participants had experienced an ASCVD event, while half had not (Table 2). Since we were interested in understanding the impact of high cholesterol and ASCVD on people's lives, we required time to have passed since the original diagnosis or event. These criteria may result in a sample with individuals more likely to be adherent and have survived their ASCVD event.

Table 1. Inclusion and exclusion criteria

Inclusion Criteria		Exclusion Criteria
Adult ("Age of majority") in their state or country		Currently Incarcerated
Diagnosed with high cholesterol (high-LDL-C) by a physician **at least two years ago**		
Able to participate in an interview lasting approximately 60 minutes		
Able to read and communicate in: • AUS English (Australia) • Portuguese (Brazil) • US English (US)		
Resident of: • Australia (n=15) • Brazil (n=15) • The United States (n=15)		
Has an internet connection with a laptop, desktop, or tablet		

Table 2. Sampling of individuals who have experienced an ASCVD event

Approximately half of the participants from each country must have one of the following:	**At least one year ago**, experienced a hospitalization for any of the events below: ☐ Heart attack (myocardial infarction or MI) ☐ Unstable Angina ☐ Ischemic Stroke ☐ Peripheral Artery Disease Diagnosed with high LDL-C **at least one year** before the cardiac event. ☐ Yes ☐ No (not eligible)

Participants were recruited via social media, referrals from healthcare providers, market research databases, and patient advocacy organizations. Participants were required to present evidence of having a physician-confirmed diagnosis rather than a self-reported high cholesterol diagnosis. The diagnosis was confirmed via a physician's note, copies of health records, or

photos of the patient's current medication (i.e. a statin) before allowing respondents to participate in the study.

In alignment with the NHC's Patient Engagement Fair-Market-Value Calculator, participants were compensated monetarily ($175 United States; $75 Brazil; $195 Australia) for participation in the interview and providing documentation of a confirmed high LDL-C diagnosis.[7]

Ethical review

A study protocol was developed and submitted to an independent Institutional Review Board (IRB), Advarra, for advisory review *(Pro00074986)*. Advarra's IRB is registered with the FDA and the Office for Human Research Protections (IORG = 0000635 and IRB Registration = 00000971.) Advarra's Institutional Review Board determined the research met the criteria for exemption from IRB oversight under 45 CFR 46.104(d)(2). A consent information sheet describing the procedures and risks of the study was provided to the participants during the screening process. Participants were asked to consent following the completion of the screening phase and verbally before the interview began but after the recording was initiated.

Interviews

To develop a comprehensive interview guide and assent/consent form, we adapted the Patient Engagement Mapping Toolbox (PEMT).[8] The PEMT was developed to help researchers capture patient experience data holistically and in a standardized manner across chronic diseases. The PEMT includes project planning and data collection tools. All patient-facing tools in the PEMT were developed by patients, patient advocates, and other experts, reviewed externally by health literacy experts, and refined through patient interviews.

The "Map My Experience" conceptual model was shared with participants before the interview and displayed via Zoom using the share screen function to guide the interview.[9] The PEMT interview guide was adapted to include questions relevant to the study population (see Appendix I). All patient-facing materials were standardized before IRB submission. Interviews were conducted virtually and lasted up to 60 minutes. Participants could decide whether to be on or off-camera for the interview. Interviews were conducted between November 2023 and March 2024.

Data analysis

Interviews were audio-recorded, transcribed, and qualitatively analyzed. The research team followed the steps outlined in FDA's PFDD Guidance 2 to conduct content analysis using anonymized transcripts. We adapted Giesen and Roeser's recommendations for structuring a team-based approach to coding qualitative data.[10] The analysis team met regularly to discuss new codes or emerging questions. Coding was conducted in Atlas.ti.[11]

Coding and synthesis were guided by the patient experience stages represented on the "Map My Experience" conceptual model, and the results were also organized around the stages on the map. Other topics, including life factors, are listed throughout the results section. Stages include:

- Life before getting a diagnosis
- Getting a diagnosis
- Living with a diagnosis

The methods and interim results were presented and discussed among the project team (GHH and AppliedPX staff) during biweekly meetings and during Steering Committee meetings held in February and March 2024.

Note: For simplicity, throughout the results, we refer to elevated LDL-C as “high cholesterol” and ASCVD event as “cardiac event.”

IPEC Participants

We recruited 50 people diagnosed with high cholesterol more than two years ago. Among these participants, 22 (44%) had an ASCVD event at least a year after their high cholesterol diagnosis (see **Table 3**).

Participants had a mean age of 54.7 (SD: 10.4). The overall study sample was balanced between males and females (50% each), married (54%), had never smoked (66%), self-reported being overweight (48%), and lived in a suburban setting (64%). Among those who experienced an ASCVD event, the most common events in our sample were heart attacks (28%) and peripheral artery disease (14%). Diabetes (40%) and high blood pressure (66%) were the most common comorbidities reported.

Table 3. Participant characteristics

Variable	Total		Australia		Brazil		United States	
n (%)	50		19	38%	15	30%	16	32%
ASCVD (n, %)								
Yes	22	44%	7	37%	7	47%	8	50%
No	28	56%	12	63%	8	53%	8	50%
Age (mean, SD)	54.7	10.7	61.9	11.5	48.3	11.5	51.2	10.1
Age Category (n, %)		0%						
Less than 45	12	24%	2	11%	7	47%	3	19%
45 to 64	27	54%	8	42%	8	53%	11	69%
Over 65	11	22%	9	47%	0	0%	2	13%
Sex (n, %)		0%		0%		0%		
Female	25	50%	4	21%	10	67%	11	69%
Male	25	50%	15	79%	5	33%	5	31%
Marital Status (n, %)								
Married	27	54%	9	47%	11	73%	7	44%
Never Married	14	28%	8	42%	2	13%	4	25%
Divorced	7	14%	1	5%	2	13%	4	25%
Widowed	2	4%	1	5%	0	0%	1	6%
Smoking (n, %)								
Never smoked	33	66%	10	53%	9	60%	14	88%
Current smoker	7	14%	3	16%	3	20%	1	6%
Ever Smoker	10	20%	6	32%	3	20%	1	6%
Weight (n, %)								
Underweight	0	0%	0	0%	0	0%	0	0%
Normal Weight	17	34%	6	32%	7	47%	4	25%
Overweight	24	48%	13	68%	5	33%	6	38%
Obese	9	18%	0	0%	3	20%	6	38%
Rurality (n, %)								
Rural	3	6%	1	5%	0	0%	2	13%
Suburban	32	64%	18	95%	5	33%	9	56%
Urban	15	30%	0	0%	10	67%	5	31%
Education (n, %)								
Some High School	4	8%	4	21%	0	0%	0	0%
High School	5	10%	1	5%	4	27%	0	0%
Some College	10	20%	1	5%	2	13%	7	44%
College Graduate or Above	31	62%	13	68%	9	60%	9	56%
Event (n, %)								
Ischemic Stroke	5	10%	0	0%	2	13%	3	19%
Heart Attack	14	28%	4	21%	5	33%	5	31%

Variable	Total		Australia		Brazil		United States	
Peripheral Artery Disease	7	14%	3	16%	2	13%	2	13%
Unstable Angina	3	6%	0	0%	2	13%	1	6%
Comorbidity (n, %)								
Diabetes	20	40%	4	21%	10	67%	6	38%
High Blood Pressure	33	66%	10	53%	12	80%	11	69%

Familial hypercholesterolemia or other genetic causes of high cholesterol

In the United States, one participant was diagnosed with familial hypercholesterolemia (FH), which went undiagnosed until they suffered a heart attack.

> The doctor just was puzzled. He suspected it was FH right from the start. But he couldn't prove it, obviously, because he had to wait until there was actual legitimate testing… we actually discovered that I had all these genetic issues. Not only do I have FH, but I have elevated lipoprotein A. – Participant from the United States who experienced an ASCVD event

Meanwhile, other participants shared experiences that could potentially indicate FH or another genetic predisposition to high cholesterol, but they had not been diagnosed. Our interview guide did not ask about genetic testing specifically. However, several participants mentioned that they suspected a genetic component and had brought this up to their HCP, but it had been dismissed. Others described genetics when asked about their knowledge of risk factors, but they did not suspect a genetic component to their own high cholesterol.

> Both parents of mine have really high levels of cholesterol. I've brought it up to providers, and they've kind of brushed it off. Just me, my own research, I've seen that when it is like that, when it is due to genetics, they usually recommend a particular type of medication. And I brought that up to two doctors, but they have not addressed that particular aspect of it. – Participant from the United States who experienced an ASCVD event

Chapter 01. Pathways to diagnosis

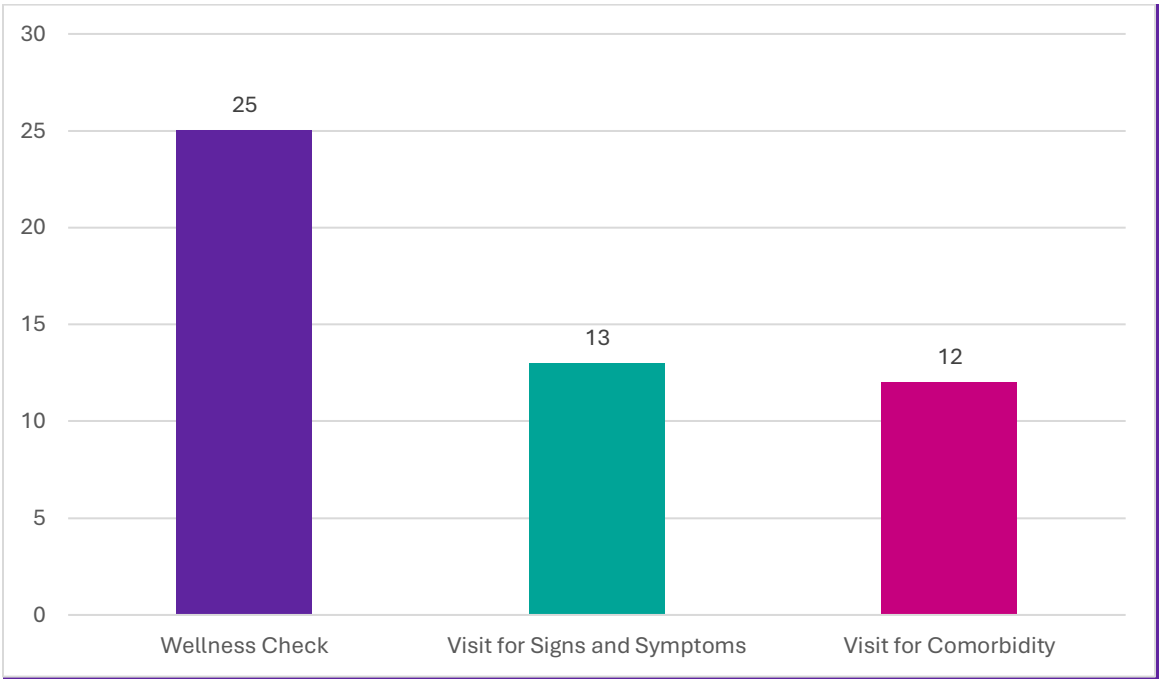

Figure 1. Pathways to diagnosis

The patient experience conceptual model has two general "starting points": "I or someone close to me noticed something was different or I didn't feel right" or "A healthcare provider found a problem." In our study, all participants received their diagnosis during a visit with a healthcare provider.

Among participants in Australia and the United States, the most common pathway to diagnosis was that a primary care physician made their initial diagnosis of high cholesterol during an annual physical examination (n=25). During these appointments, healthcare providers routinely conducted blood tests, often prompted by age or standard protocols, which revealed elevated cholesterol levels. **This pathway was the least common pathway described by people from Brazil.**

> And my doctor, [doctor's name], who I've been seeing for over 25 years said, "I think you're at the age now where we should do a full bloods," and everything came back perfect except the cholesterol. – Participant from Australia who has not experienced an ASCVD event

One quarter of participants described experiencing symptoms such as shortness of breath, nausea, dizziness, or a general sense of feeling unwell before their diagnosis (n=13). They made primary care appointments to discuss these symptoms with an HCP. In these cases, the HCPs decided to run blood tests, which revealed comorbidities in addition to high cholesterol. This pathway also encompasses the experiences of people who were admitted

to emergency departments with signs and symptoms, even if they were unrelated to cardiovascular disease (e.g., gallbladder removal).

The **remaining quarter were already in the health system regularly because they had a diagnosed comorbidity** (n=12), most often diabetes, and were undergoing routine care or follow-up for their comorbidity (e.g., seeing an endocrinologist for diabetes care) or preparing for a related medical procedure when a blood test was administered, revealing elevated cholesterol. This occurred across countries but was most frequently discussed by individuals from the United States.

I went for an X-ray, a chest ultrasound, a kidney ultrasound, because I had kidney stones, and then the doctor, at the time of the test, discovered that I had steatosis, fatty liver, and then she did it, about two years ago, two years and a bit, and then she asked for tests to check triglycerides, cholesterol, everything. That's when I discovered that everything was high, my cholesterol was above high. – Participant from Brazil who experienced an ASCVD event

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Key Takeaways: Pathway to Diagnosis	▪ In Australia and the United States, the most common pathway of diagnosing high cholesterol was through routine physical exams by primary care physicians (n=22). ▪ In Brazil, high cholesterol diagnoses were less frequently the result of routine screenings (n=3) and more often identified through symptomatic presentations and unrelated emergency visits (n=8).

Discussions with HCPs upon diagnosis

All study participants stated that their diagnosis was confirmed through a laboratory blood test. The sequencing of lab testing varied among participants:

- Underwent testing before their appointment
- Blood drawn during the appointment itself
- Referred for testing after the appointment

Consequently, participants either discussed the results during their visit, as part of a follow-up appointment, or accessed them through an online portal after their annual visit. While some people (n=8, 16%) reported experiencing a shared decision-making process to identify and agree on the most suitable treatments for their newly diagnosed conditions, more than half of participants (n=32, 64%) were told what to do or what medications to take without involving them in the discussion. **More than half** of the participants reported receiving a **prescription for a statin during their diagnosis**. Others did not receive medicine at diagnosis. Instead, their **HCP recommended initiating lifestyle changes before prescribing a lipid-lowering therapy**. Some of these participants were ultimately prescribed a statin before an ASCVD event occurred because their HCP was not comfortable with their lab values due to lifestyle changes alone.

> He said that the risks are that the plaque will build up in your arteries, and at some point, that plaque can break free, and you could have a heart attack or a stroke, if a small piece were to move into your blood vessels in your brain. So, he thought that we should you know definitely take care of that… he continues to suggest that even though the medication seems to be controlling it quite well, that I should watch my diet and cut down on red meat, and that I should exercise and get my weight down; and that all of those things were contributing factors, as well. – Participant from the United States who has not experienced an ASCVD event

One participant in Australia described that their HCP initially recommended lifestyle changes and fish oil instead of a prescription medicine.

> So, I had high cholesterol for a while but in the early several years, I didn't take the cholesterol lowering medication because GP say, "Oh, it's better to use a natural way to see whether you can lower the cholesterol, for example, doing exercise and going on diet and all, and then swallow lots and lots of fish oil... So, for quite a few years, I swallowed a lot. And then I found that was not very effective, so I decided to just get on to cholesterol-lowering medication rather than swallow lots and lots of fish oil. – Participant from Australia who has not experienced an ASCVD event

Lifestyle changes and medication experiences are described in greater detail in Chapters 2 and 4.

Key Takeaways: Discussions with HCPs upon diagnosis	▪ All participants in the study received a high cholesterol diagnosis confirmed by lab tests, with variations in testing timing—either before, during, or after their appointments. ▪ Discussions about lab results and treatment options occurred during the initial visit, a follow-up, or via an online portal. ▪ While over half were prescribed statins immediately, others were advised to try lifestyle modifications first; some among the latter group eventually received statin prescriptions due to their healthcare providers' concerns over lab results despite lifestyle changes.

Perceptions about high cholesterol at diagnosis

At diagnosis, some participants described **feeling overwhelmed** (n=13, 26%) and surprised (n=7, 14%). This could be due to:

- **concurrent diagnoses** (e.g., going in for a diabetes check-up and learning about high cholesterol status)
- **lack of familiarity with the medical terminology** used by healthcare professionals when discussing high cholesterol
- **concern about their risk for a cardiac event**

They've [the laboratory results] been explained over time. **Initially, it's like alphabet soup. It's like LDL, HDL. Those things are too close to each other.** – Participant from the United States who experienced an ASCVD event

"So **I'm very scared. And then I got depressed**... Oh, but it's just cholesterol, but it's *not* just cholesterol. **Some people don't realize how serious untreated cholesterol is, right**? The consequences. – Participant from Brazil who has not experienced an ASCVD event

Participants who had observed close family members live through the consequences of unmanaged cholesterol often took the diagnosis seriously. For example, one participant in Australia described his mother's experience with a stroke and being paralyzed for ten years before death as their reason for taking high cholesterol seriously.

So, I knew that from my mother's case, right? She had high cholesterol and then she got stroke, so I knew that was the evidence that I had to be very careful and very alertful about the potential implication on my health. And also my mother got stroke, paralysed in bed for 10 years, so I certainly don't want to repeat that experience. **So, I didn't ask my GP what that means because I know from my personal experience, all of that**. – Participant from Australia who has not experienced an ASCVD event

In other cases, they took the diagnosis seriously due to "no-nonsense" discussions with the HCP who diagnosed them. In these cases, the **HCP conveyed the seriousness alongside a realistic care plan**. Approximately **half of participants said their HCP discussed the link between high cholesterol and cardiac events at diagnosis**. Others stated they **already were aware** of the link between high cholesterol and heart disease due to family history, having heard or read about it previously, or they worked in medicine.

Even participants who did discuss the link between high cholesterol and heart disease with their HCP at diagnosis **did not always perceive their *own* short-term risk of heart disease as elevated**. Many felt reassured because they believed they had already adopted many of the recommended lifestyle changes, such as diet and exercise. Others **attributed their high cholesterol diagnosis to a short-term behavior change** that preceded their lab test. For example, one participant stated that she knew she had been eating more butter recently and assumed that had caused her lab test to show elevated cholesterol.

Other participants described *not* understanding the seriousness of high cholesterol upon diagnosis. Participants sometimes **felt reassured because their HCP recommended lifestyle changes instead of initiating medicine upon diagnosis**. This highlights the importance of conversation tone and wording when HCPs communicate with patients about the role of lifestyle changes, as well as risk factors.

I don't know that I felt that the doctor took it seriously. So, I didn't take it seriously. It was sort of like, hey, your cholesterol is elevated. That can be a precursor for this and that. So, you want to watch your diet, watch your salt intake, and thanks for coming, you know, we'll see you next year or whatever. And that was about it. – Participant from the United States who experienced an ASCVD event

Others perceived that their HCP was not particularly worried about their high cholesterol because the HCP **emphasized treatment of their comorbidities instead of medicines**. For example, prioritizing medicines to treat blood pressure or diabetes. Others said they understood the need for treatment but were not worried or surprised by their diagnosis because they expected it, given their **age.**

In one case, a participant in Australia described taking his cholesterol seriously because shortly after their diagnosis, an optometrist described seeing cholesterol in their eye, which was shocking to the participant.

I remember… my GP is amazing and he's very gentle but he's also very straight to the point as well, which I appreciate. He just told me, and he advised that medication would be the best preventative measure I guess, is the right word. And then obviously continuing with exercise. Maybe I wasn't exercising as well as what I should at that point. You know, reducing alcohol and all the things that have driven it up in the first place. So, it was pretty succinct in terms of this is going on and this is how we're going to approach the situation, yeah. – Participant from Australia who has not experienced an ASCVD event

Several participants (n=5, 10%) described being embarrassed by their high cholesterol, admitting that they knew they had not been taking care of their health before diagnosis.

I was actually a little surprised. Shouldn't have been because my diet wasn't what it should have been at the time anyway. And I was a little scared because like I said, with the incidents of heart disease and everything that my family has experienced. I did feel scared, and I felt the need to get the numbers lower. So, I felt a need of urgency to take care of that. – Participant from the United States who has not experienced an ASCVD event

I guess I suppose I'm a little bit embarrassed that I let it get to that point in the first place and it's something that weighs on me a little bit in terms of what it's going to evolve into. You know, like, it does worry me because yeah, I don't want to be unwell like anybody. So, I suppose it does weigh on me mentally. – Participant from Australia who has not experienced an ASCVD event

Key Takeaways: Perceptions about high cholesterol at diagnosis	▪ Participants at diagnosis often felt overwhelmed by multiple concurrent diagnoses, unfamiliar medical terms, and concerns about cardiac risk, with personal and family health histories deeply influencing their perception of the seriousness of high cholesterol. ▪ Healthcare professionals' direct communication about the risks associated with high cholesterol, alongside a realistic care plan, was pivotal in fostering a serious attitude towards the diagnosis, although some participants felt reassured by their healthy lifestyles or considered high cholesterol a result of temporary dietary choices.

Chapter 02. Managing High Cholesterol

Follow-up care after diagnosis

Following diagnosis, **most participants in the US reported that their follow-up care for cholesterol was managed by a primary care doctor**; in **Australia, they typically described seeing a general practitioner (GP); and in Brazil, participants described going to a health center or seeing a GP**, including through private clinics such as Dr. Consulta.

Across countries, people with comorbidities are more likely also to see a cardiologist or another specialist who manages their cholesterol. Many described cholesterol monitoring through laboratory testing at regular intervals, ranging from every three months to annually as part of their wellness check-up.

"I see my cardiologist more often, right, who is the one that I see the most. I say he's not just a cardiologist, he monitors everything, everything. I came to him last Monday with a complaint and he said, oh, let's look into it, even though it wasn't a heart complaint, but let's look into it. So he made some referrals and ordered other tests. He and the endocrinologist are my support doctors, right? I have general practitioners, but follow-ups are very rare." – Participant from Brazil who has not experienced an ASCVD event

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At diagnosis and throughout their experiences living with high cholesterol, most described they are not familiar with their specific LDL-C target values (n= 30, 60%).

They interpret their results based on indicators (e.g. color codes) listed on their lab results or located on the internet. Many also rely upon their HCP to interpret the numbers on their behalf. Some also report using the internet to identify target thresholds.

When I go to my little portal, all the results are there. **And I can look at it and if it's too high, it's in red. If it's at a good level, it's black. If it's too low, it's, I think, yellow**. And then on the side, it says what it should be, but I don't have those in my mind. Just like blood pressure, I have no clue what a normal blood pressure is because I have high blood cholesterol – Participant from the United States who experienced an ASCVD event

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Key Takeaways: Follow-up care after diagnosis	▪ In the management of cholesterol post-diagnosis, care patterns differ by country: in the United States and Australia, primary care doctors and general practitioners (GPs) predominantly handle follow-up care; in Brazil, care occurs at health centers or through GPs, sometimes via private clinics like Dr. Consulta. ▪ Across all countries, individuals with comorbidities commonly consult cardiologists or other specialists for cholesterol management, with regular cholesterol monitoring through lab tests ranging from every three months to annually. ▪ Despite receiving regular care, many participants described lacking detailed knowledge of their specific LDL-C target values, interpreting lab results through basic indicators such as color codes or relying on healthcare providers to explain the numbers. Some people also use the internet to understand acceptable cholesterol levels.

Lifestyle changes

Two-thirds of participants described trying to make lifestyle changes following their initial high cholesterol diagnosis [Australia=14; Brazil=8; United States=11]. These included trying to eat more healthily, reducing or stopping drinking alcohol, reducing or stopping smoking, losing weight, or reducing stress. For example, one participant in Brazil who later went on to have a heart attack described losing weight but continuing to smoke and drink.

Among those who tried to eat more healthily, many focused on eating less meat, more fish, and reducing salt and processed foods. In many cases, **participants described their family's important role in their success in adopting and sustaining healthy eating**. For example, some participants described living with a spouse or parents who did not want to make lifestyle changes to eat healthy foods themselves. A small number described having children who are picky eaters. In general, they described difficulty coordinating separate healthy meals for themselves while cooking foods they knew were unhealthy but were palatable to their family members.

Others described **difficulty sustaining diet and exercise regimens due to their daily routines**. Many participants stated that it is easier to eat healthily when you are at home, but daily routines may make it easier to eat out regularly. Some participants described busy work schedules, while others said that their work was not stressful, but it was inconvenient to find healthy lunch foods near their office.

> "The real problem is that, because of our lifestyle at the time, I was traveling for business 150,000 miles a year, a lot. Yeah, sometimes six days a week, I was gone, and my wife was very, very, very busy at work. So, we were eating out almost every day, and when you eat out, you can't control what they're putting in the food. So, even if you get a salad, it's covered in some dressing that's 50% oil and it's this and it's that, you know? So, or the amount of salt or whatever they're doing. So, that was an issue." – Participant from the United States who experienced an ASCVD event

Participants described several strategies to implement lifestyle changes after diagnosis. These included: building time for self-care into their daily routine and seeking support from HCPs, including physical therapists and nutritionists. For example, one participant described shortness of breath and fatigue when they started trying to exercise after diagnosis. But, they worked with a physical therapist and, over time, have increased their exercise to one hour, five days a week.

Key Takeaways: Lifestyle changes after diagnosis with high cholesterol	▪ Two-thirds of participants attempted lifestyle modifications post high cholesterol diagnosis, with efforts including healthier eating habits, reducing alcohol and tobacco use, weight loss, and stress management; however, some participants described making lifestyle changes (e.g., losing weight) but continuing other behaviors (e.g. smoking or drinking). I ▪ Adhering to healthier diets proved challenging due to family dynamics, such as resistant spouses or picky children, making it hard to maintain separate diets and causing participants to struggle with preparing healthy meals for themselves while serving different food to family. ▪ Participants found maintaining diet and exercise routines difficult due to the demands of daily life, with healthy eating being easier at home compared to navigating food choices while working full time.

Medicines

Most participants initiated on a statin at diagnosis (n=29) and were satisfied with their medicine. Among the individuals who did not initiate a medicine at diagnosis (n=17), half eventually initiated a statin (n=8). Switching occurred among people who experienced a side effect, experienced a financial barrier, or their lab values were not reaching targeted thresholds. Participants described switching to a different statin (n=4), switching from another medicine to a statin (n=4), or increased their dose (n=2). Side effects reported by participants include tiredness, stomach upset, abdominal pain, muscle and joint aches, headaches, allergic reactions (e.g., lip swelling) and sexual dysfunction.

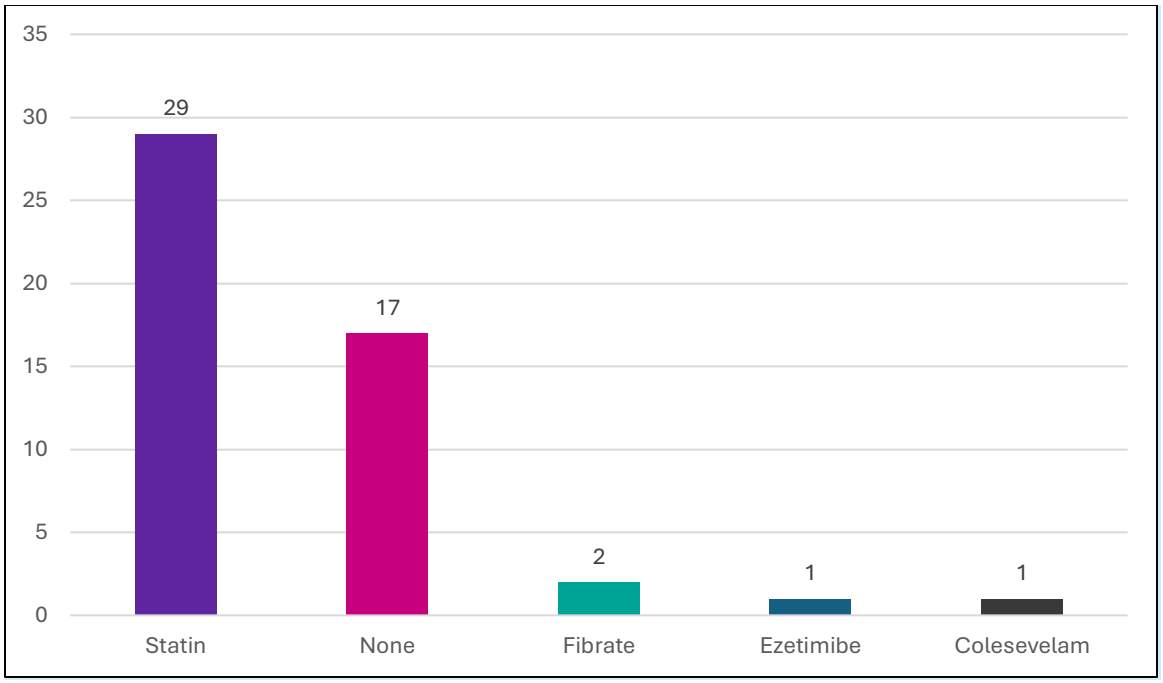

Figure 2. Medicines prescribed at diagnosis

Understanding medicines for high cholesterol need to be taken throughout life

Slightly less than half of the participants (n= 23, 46%) were *not* aware that lipid-lowering therapies need to be taken throughout their life. Among those who are aware, people fell into one of four categories. Most individuals indicated that either their care provider made this clear during diagnosis or they were already aware of the life-long nature of high cholesterol through their own personal experience (e.g., with a family member or through a medical occupation). Others report both not being aware of the link and that it was not discussed with their care provider. This occurred most often in interviews with people in the United States. Finally, some participants could not recall when they learned that high cholesterol medicines need to be taken throughout life. One participant described frustration because she thought that she would be able to stop taking a medicine if she successfully lost weight.

> "We had the conversation as though like I'll be off of it real soon. That's what I was under the impression of five years ago, that we're going to do some more blood work in a year or so and that you can be off of it…But that never happened. That never, ever happened. Like I said, each time another year would roll around, I'm like I'm still on these pills… I decided to lose weight. And so, at that point I was thinking I can get off some of these pills now because I'm 140. So, I'm like I know I can get off some of these pills because everything should be looking better with my blood work and everything. And he said no. So, I was kind of confused, actually... I don't know, maybe in my mind I just thought – I associated losing weight with high cholesterol." – Participant from the United States who experienced an ASCVD event

By far, the most frequently mentioned strategy for medication adherence was establishing a consistent routine for taking their medicines. Strategies include weekly pill organizers, establishing a daily schedule to take their medicines, and storing them in a specific spot. This strategy was effective if the participant's daily routine did not change. Changes in routine due to travel or work are often cited as the reason for missing medicine doses.

I put together my pills. I have a certain number that I take first thing in the morning, and then another dose of some of the same, some different in the evening. But I take them all at once. I package them together in these little pill packs, and I do it once a month. In the morning, I just grab that day's little box and take my morning meds… And then, later on in the day, I take my evening meds... sometimes I get caught up and get busy, and I notice the box is still sitting there come lunchtime. And some days I'll just remember and take it late, and other days it might be that it's gotten to be so late that I'll just decide and wait and take my evening doses. – Participant from the United States who has not experienced an ASCVD event

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Discouragement & frustration

Some participants described feeling discouraged and frustrated when they were adherent to their medicine and lifestyle changes, but their lab values did not change. Several participants in Brazil stated that they were adherent to their medicines, but it was not bringing their cholesterol numbers down. Rather than prescribing a different medicine or increasing their dose, their HCP emphasized that the participants needed to stay on their current medicine and take their lifestyle changes more seriously.

But I told him, I said, Doctor, I'm trying to improve my diet, it's not always that I can eat what's convenient, but as far as possible I'm trying. But I have never stopped taking my medication. I've never stopped taking my medication. I've never gone a day without taking my medication. Do you understand? I'm scared. – Participant from Brazil who experienced an ASCVD event

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Other people described not being able to find the motivation to commit to lifestyle changes, especially during the start-up phase of implementing these changes. For example, they felt out of shape as they initiated a plan to improve their fitness and make progress towards a healthy weight.

Part of it's laziness. The other part is because I haven't been active in so long, that when I do start to walk or do those types of things, I get out of breath quickly, and that discourages me from continuing to push through and do it more regularly, so as to eliminate that. Probably laziness would be the biggest. I'm my own enemy. – Participant in the United States who has not experienced an ASCVD event

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Key Takeaways: Medicines after diagnosis	▪ Most of the study participants were initiated on statins upon diagnosis (n=27), while half of those who did not start medication initially (n=16) later began taking statins. ▪ Participants were not always aware that lipid-lowering therapies are lifelong medications. ▪ Medication changes are often due to side effects, financial constraints, or not achieving lab targets. ▪ Participants described establishing a routine, in terms of both time and location of medicines, and utilizing weekly pill organizers as methods to improve adherence. ▪ Participants described feeling frustrated and discouraged when they felt they were diligently following their treatment and lifestyle plans but failed to achieve their lab values.

Impact of gender

Several female participants mentioned gaps in knowledge and care for women with high cholesterol and heart disease.

> And I've listened to a lot of information, a lot of podcasts and a lot of GPs will admit that they're not even… there's hardly any material that they're made to study and I'm like, for something that affects women for a decade plus of their life and it affects half the population, I think it's crazy that not more funding and study goes into it. Because it's a big deal and it can really dramatically affect a woman's life which in turn affects those around her. – Participant from Australia who has not experienced an ASCVD event

> My daughter died in her prime years from a heart attack that we didn't even know why, right? She died at home in my arms. And I don't think anyone should have to go through pain like that. And we didn't know why. So the lack of information... she wasn't a lay person, she was a person who studied, went to university, was an architect, but a person who didn't have information in real time. – Participant from Brazil who experienced an ASCVD event

One participant in the United States also described how her experience with high cholesterol and ASCVD was shaped by the interaction between race and gender.

> Definitely, definitely. Racism and sexism because white men, oftentimes, disregard my voice. That has been a running issue when I presented myself into the ER. Before I went down into a coma, I was disregarded and told I was a hypochondriac and told to go home and that it was just me coughing, that it was just me overweight. Just being a woman I think is sometimes even greater of a disregard than being a person of color. Having both, yeah, you're completely disregarded. You're completely silenced to even simplest complaint, just even to complain. You don't have a voice.

You shouldn't have a voice a lot of times in healthcare. – Participant from the United States who experienced an ASCVD event

Patient-focused medical product development

Attributes of an ideal treatment

When asked about a perfect treatment that wasn't a cure, sixteen participants described being satisfied with their current treatment. The most frequent suggestion for improving current therapy was reduced administration frequency (n=21), with responses ranging from weekly to annually. Non-tablet forms were the second-most requested attribute of an ideal treatment (n=16). Injections were the most frequently described specific form (n=6), but other non-tablet or pill forms (e.g., liquid, patch, implantable) were mentioned by ten people. People also described their ideal treatment as having reduced side effects relative to their current therapy (n=11); additional features of an ideal treatment included improved efficacy over current therapies (n=10), combination therapies for managing comorbid conditions (n=6), and affordability.

Table 4. Participant-described attributes of an ideal treatment for high cholesterol

Attribute	Illustrative quotes from interviewees	Frequency
Satisfaction with current treatment	**Participant from Australia who had experienced an ASCVD hospitalization:** Well, basically my magic pill already is called [statin brand name]. I mean, it would be wonderful to be off medicine altogether, but I'm not, so I'm very happy with the way it's been managed.	16
Non-daily dosing	**Participant from Brazil who experienced an ASCVD hospitalization: I** would like the treatment for cholesterol to be like one of those different contraceptives out there that you take, you take a quarterly dose and that's it. It's not just birth control, there's also vitamin D, there's vitamin, there's various vitamins that you take once every 3 months and you're, you know, you're immunized for those 3 months, I think that would be a way to take some of the worry off your mind, right? **Participant from the United States who had not experienced an ASCVD event:** To be honest, it wouldn't be something that I would have to take every day. [. . .] I would – I, more than likely, would not miss a dose. [. . .] But that's the most important I can think of. Not missing a dose.	21
Non-capsule or non-tablet dosage form	**Participant from Brazil who had experienced an ASVCD hospitalization:** It would be injectable so I wouldn't have to take it every day, for example in the morning, when I take medicine in the morning it's horrible because I get nauseous a lot, when I take the medicine, I take it fasting so it's horrible, I would inject it, you inject it there, that's it, it's done. **Participant from the United States who experienced an ASCVD hospitalization:** But also, throughout a couple of these questions, I've also thought if I could go in once a year for an infusion where I would only have to worry about it at that point in time as opposed to something that I'm taking on a day-in/day-out basis. I don't really want injections because those don't really work.	16
Minimal or reduced side effects	**Participant from the United States who experienced an ASCVD hospitalization:** It'd be fast. Side effects would be minimal. Something that you could do or take or have done that you would feel the difference immediately, almost like a recreational drug where you did it, and you felt good. You thought this is something you should continue to do because you feel good, and it's making you healthier and that sort of thing where you look better. **Participant from Australia who had experienced an ASCVD hospitalization:** I would like a cholesterol tablet that didn't cause you cramps.	11
Improved efficacy	**Participant in Australia who experienced an ASCVD event hospitalization:** Your cholesterol decreases, rather than what I see it as keeping it more... it's not rising or anything like that, but it would be good if you took a pill and it just automatically decreased your cholesterol. **Participant in the United States who experienced an ASCVD event hospitalization:** A perfect treatment would just bring all of my numbers in line with what is "considered normal." I don't think I can ask for anymore than that.	10
Combination therapy for multiple conditions	**Participant in the United States who experienced an ASCVD event hospitalization:** About the medication I'm currently taking, okay. I would see if some of the pills could be rolled into one. [. . .]. Like I said, for blood pressure I'm taking three, then I take some for IBS, then my therapist has me on about three different meds. No, let's just roll them all into one and let it do its job.	6
Affordable	**Participant in the United States who had not experienced an ASCVD event hospitalization:** Probably making it free. It's not that expensive, but still, over time, it's going to add up. Making medication free or very cheap, and any medication that I need to go on further, moving forward, because I'm sure as I age, more medication might get changed or added. So, like yeah, make it more affordable, because seriously, I don't want to have to worry about when – my husband's our provider in this house, so when he can't be with me no more, who's going to pay for my medicine? I don't think Medicare's going to do it.	2

Survival and quality time with loved ones were top priorities for participants. They also found motivation in seeing improvements in their lab results because it provided confirmation that their treatment and lifestyle changes were effective.

- **Improvements in lab values:** Participants frequently highlighted the importance of seeing an improvement in lab values as an outcome they valued, typically in the context of showing that their adherence to lifestyle change, pharmaceutical therapy, or both was successful and that they were on track to reduce the risk of undesirable outcomes.

- **Avoid ASCVD Event:** People frequently discussed their desire to avoid an ASCVD event. This was consistent whether the individual wanted to prevent an initial event or a subsequent event.

- **Long life:** Participants expressed a desire to live as long as possible. This response was often linked to a desire to spend more time with loved ones, including family and friends.

A desire for improved quality of life, particularly around being able to engage in daily activities outside the home and the ability to travel, as well as travel, and increased physical activity and energy, were also mentioned by some participants.

Key Takeaways: Ideal Treatment Attributes, Patient-Relevant Outcomes, and Meaningful Treatment Benefit	▪ Many participants are satisfied with their current treatments, appreciating the ease of use and integration into their daily medication routines. ▪ Participants desire treatments with fewer side effects, improved efficacy, compatibility with other therapies for comorbid conditions, and affordability. Injections are the most preferred specific dosage form, though other forms like liquids, patches, and implants were also described as ideal by participants. Many desired treatment features, like less frequent dosing and injections, are already available in approved products across three countries. ▪ Seeing improvements in lab results is crucial, affirming the effectiveness of treatment and lifestyle changes. Participants who had experienced ASCVD events and those who had not both described the desire to avoid an initial or future event. Participants described the importance of overall survival, most often in the context of maximizing time with family or others they cared about.

Life factors and emotional health before event

Family and support system

Support or lack of support of friends and families in the care plan emerged across countries as an important factor impacting participants' ability to adhere to their care plan, especially lifestyle changes. Participants who had support from family or friends in adopting lifestyle changes or who made these changes alongside them found that this support improved their own adherence to the new habits.

> The only impact really is like my children, they will remind Mommy of things that she should not consume. They try to get me to become more active. They try to make sure that I do take my medication when I'm supposed to. So, they're thinking about my health a little more than I think they should. Or should have to, I should say. – Participant from the United States who has not experienced an ASCVD event

The two most common forms of support discussed were related to diet and physical activity. Some participants mentioned loved ones adjusting their own diets to align with the individual's high cholesterol diagnosis or being understanding and supportive of the need for a customized diet to maintain a healthier lifestyle after the diagnosis. Additionally, participants spoke about family and friends who encouraged them to increase their physical activity levels, leading to both more frequent and higher-quality exercise, resulting in noticeable improvements in overall weight towards a healthier range. Having a partner in this transition to a healthier lifestyle was seen as crucial by participants.

Participants described a lack of family support that was more indirect than overt. None mentioned a family member who outright dismissed their high cholesterol diagnosis or the importance of heart health. Instead, the lack of support was seen in a broader sense, particularly in relation to the lifestyle changes needed to achieve their target cholesterol level. This lack of support often manifested among close family members living in the same household, who were unwilling to make dietary changes conducive to good heart health. For instance, several individuals mentioned partners who, while verbally supportive and aware of the need for change due to the high cholesterol diagnosis, did not actively prepare heart-healthy meals or refused to eat the food the individual prepared with heart health in mind.

> We've got these two little girls, and they don't want to eat anything. So, I become sort of the dad chef, and because, you know, there's just not enough time in the day to fix food for them and food for me and food for my wife. So, I end up, we end up eating what they eat, because it's just easier and the stuff that you fix for kids is not necessarily – because I'm trying to get them to eat something, you know? [A]nd I want them to eat vegetables, so, I've got to make those vegetables taste really good to kids. You start adding butter and you start adding this and you start, you know. So, at first, it's like, okay. I'm just going to eat a little bit of this and then I'm going to eat healthy, but you know, before long that goes out the window. – Participant in the United States who experienced an ASCVD event

Work

Participants from various countries identified the primary barrier to adhering to their care plans as the conflict between their healthcare regimen and the demands of their career. Specifically, individuals expressed the daily challenges of balancing a full-time work schedule with incorporating time for physical activity and healthy eating. A recurring issue was the time-consuming nature of commuting to work.

Participants highlighted the significant stress associated with their work, often leading to unhealthy habits such as poor dietary choices, smoking, and excessive alcohol consumption.

Additionally, work-related travel was a barrier to maintaining the routines set in place to promote medication adherence and lifestyle changes.

> The real problem is that, because of our lifestyle at the time, I was traveling for business 150,000 miles a year, a lot. Yeah, sometimes six days a week, I was gone, and my wife was very, very, very busy at work. So, we were eating out almost every day, and when you eat out, you can't control what they're putting in the food. So, even if you get a salad, it's covered in some dressing that's 50% oil and it's this and it's that, you know? So, or the amount of salt or whatever they're doing. So, that was an issue. – Participant in the United States who experienced an ASCVD event

In some cases, **participants described receiving a diagnosis and a follow-up monitoring plan, but they decided not to follow through with it because of work obligations**. One individual in Brazil described receiving a prescription for a statin at diagnosis and then not going on to fill the prescription or continue with care following diagnosis. He stated that the reason was due to work schedules and obligations. The individual did not return to the health system for three years after diagnosis.

A participant in Australia shared how their **job environment played a positive role in their lifestyle shift. They had a colleague at work who was also trying to eat healthy, which made it easier to choose healthy options at lunch**. However, upon retirement, it became more difficult because they did not have the same support on a daily basis. To account for this, the participant described being very careful with grocery shopping to avoid buying unhealthy foods they ate when bored.

> Yeah, but I think it was easier for me because when you're retired, you tend to... you get a bit bored and you open up the fridge. The good thing with me is, I open up the fridge and there's nothing really there except for raw ingredients I might have for dinner. But if I had it stuffed with brie and camembert and blue and stilton and cheddars and Jarlsberg cheese, I would have a few slices on crackers. I don't have that in the fridge. – Participant from Australia who experienced an ASCVD event

Geographic location and transportation

Healthy foods may not be easily accessible for people living in rural settings. For example, one participant in the United States who had not experienced an ASCVD event, described the impact of living in a food desert on their access to high-quality, healthy foods. They stated that their closest grocery store was 40 minutes away, but a fast-food chain was only 10 minutes away. This contributed to unhealthy eating.

Insurance and access to care

Across all three countries, the **overall quality of the care routine was impacted by insurance type**. The widest variation was observed in the United States and Brazil. For example, in the United States, where health insurance markets are fragmented, individuals expressed satisfaction with private insurance plans provided through their employer and with Medicare. However, participants with Medicaid described a lack of availability of providers and less appointment availability among those providers.

Participants in Brazil, including those who have had an event and those who have not had an event, described experiencing **significant differences in the quality of care between public and private insurance**, to an extent not characterized in other countries. They described that private health insurance opens the door to a wider network of care providers, as well as more time and consistency with providers. They described access and quality of care issues with Unified Health System (Sistema Único de Saúde; SUS) and spoke positively about private-sector insurance, particularly around access to specialists and detailed follow-up care.

Well, because when you have health insurance, you have unlimited access to health care, right? So you have professionals. **If you don't like one of them, you find another one, it's different from SUS, when you have to rely on SUS, right?** So you have to go to this doctor, you have to make an appointment for a test that you don't even know when you're going to have it. So there's all that. Today, thank God, I have medical insurance, I don't know about tomorrow, but today I have medical insurance. – Participant from Brazil who has not experienced an ASCVD event

Look, I really like Doctor Consulta now, you know, their doctors. Of course it's expensive, right? But when you pay, go there and have a consultation, you seem to have more freedom, you know, to question, to ask questions, you know? **Because you're paying, so you're there as long as you can get your questions answered, whatever you want to ask, right? Health plans also cover many people, right? SUS, by the way, isn't enough, right? So you can't extend it too much, you can't go too deep, right?** I prefer that system, yes, but of course it's expensive, right? **You go back, you pay, you know, then you have the right to go back to the same doctor**. – Participant from Brazil who has experienced an ASCVD event

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Key Takeaways: Life factors and emotional health before event

- **Family:** Support from family and friends plays an important role in successful adherence to lifestyle changes after diagnosis with high cholesterol. Examples include adopting healthy diets and exercise plans together. On the other hand, family resistance to lifestyle changes, such as reluctance to adopt heart-healthy diets at home, presents a significant obstacle to managing high cholesterol effectively.
- **Work**: Work demands, including travel and long hours, were cited as major obstacles to adhering to cholesterol management plans.
- **Geographic location:** Healthy foods may not be easily accessible for people living in rural settings.
- **Insurance and access to care:** Insurance type significantly influenced care quality in the U.S. and Brazil, with U.S. participants preferring employer-provided or Medicare plans over Medicaid due to better provider availability and appointment access. Brazilian participants described differences between public and private insurance, with private plans offering broader and more consistent access to HCPs and follow-up services.

Chapter 03. Sources of information & messages

Most participants stated that their primary source of information upon diagnosis and throughout their experiences with high cholesterol is their HCP (n=27, 46%). Other sources include internet sources (n=20, 40%), such as Google searches, YouTube videos, MayoClinic, TikTok, and WebMD. Most describe trying to differentiate between reliable and unreliable online sources. Facebook groups and voluntary health agencies, including the American Heart Association, were occasionally mentioned. A small number described looking into the peer-reviewed literature, via Google Scholar. As described throughout this report, other family member's experiences were also a source of information throughout.

> "My doctor. And the person who helped me a lot was my niece, who is a nutritionist. And every time I have any doubts or want to change something, she's the one who helps me, you know?" – Participant in Brazil who experienced an ASCVD event

Participants offered suggestions for messages they thought other people with high cholesterol should hear at diagnosis and regularly after diagnosis (see Table 5).

Table 5. Example messages suggested by participants

Message	Illustrative quote
Share examples from real people living with high cholesterol	**Participant in the United States who experienced an ASCVD event hospitalization:** I would start off with the education part of lowering your cholesterol could significantly lower your chances for heart disease, heart attack. I would try to give examples of things that I have done myself, and show little snippets of – or videos of me actually doing these things. And I guess trying to appeal to the sense that I'm living. Had I not been taking these medications, or if I'm not taking it correctly…what the effect of that would be.
Preventing a cardiac event is easier than recovering from one	**Participant in the United States who experienced an ASCVD event hospitalization:** Don't wait until you've fallen off the cliff to try to get back up. So be careful. Be careful, because then it's much harder to go back and try to fix it than it is to prevent it.
Take it seriously because the effects of not taking it seriously are physically painful	**Participant in Brazil who experienced an ASCVD event hospitalization:** Look, I know I felt terrible. It felt like death. So whoever can, whoever has a health plan, whatever, get yourself treated, go and get your tests done to make sure you don't have anything, to take care of yourself because it's very bad. It's terrible.

Message	Illustrative quote
Be blunt about risk of cardiac events	**Participant in Australia who had not experienced an ASCVD event hospitalization:** I think, personally, the world in general has become too afraid to be direct, do you know what I mean? I think the message doctors need to give is direct, to the point, and even throw a little bit of scare factor in. And come to think of it, [doctor's name] did say it could lead on to heart disease, and he did also mention about my weight. He always mentions my weight, and he's given me charts of what I should eat and what I shouldn't. I think people just need to realize, look, if you've got it, take your tablets. It's a very simple regime to do and it becomes automatic and hopefully doesn't lead to... I don't know. You basically really gotta be more blunt and say, "Okay, if you don't take your tablets, you're gonna have the heart attack and you're gonna end up with problems with your heart." So, I don't know. It's hard. It's very hard to say.
You need to take your medicines	**Participant in the United States who experienced an ASCVD event hospitalization:** You just have to try and live every day the best that you possibly can. And I know that, for a lot of people, they don't like taking meds. But they are a life-saving tool. There's no question about it."
Repetition	**Participant in the United States who experienced an ASCVD event hospitalization:** Probably in my case, it's effective just to hear it all the time. I can be stubborn and tend to do things at my own pace. So, I'm the kind of individual that constantly needs to hear it, probably, for it to be most effective.

Key Takeaways: Sources of information & messages

- Healthcare providers are the main source of information for many people with high cholesterol. Other important sources include online resources, family experiences and expert advice from within personal networks
- Participants emphasized the need for direct, clear communication about the risks of high cholesterol and the importance of medication adherence, with personal stories and persistent messaging

Chapter 04. Experiencing an ASCVD Event

Approximately half of the participants in our study (n=22) were required to have experienced an ASCVD event at least one year after their diagnosis of high cholesterol. Across countries, **participants described a range of events leading to hospitalization for their first cardiac event**. Some participants described **feeling unwell with flu-like symptoms, chest pain, fatigue, coughing, and paleness**. Others described nausea and vomiting. **Many participants did not immediately recognize their symptoms as heart-related (n=15, 68%) and assumed they had come down with a serious cold**. Participants sometimes waited hours or days before seeking care. One participant in Brazil described experiencing symptoms for ten days before he ultimately drove himself to the emergency room when friends remarked on his appearance.

> I had high cholesterol for years and years and years. It hasn't changed, regardless of taking medication, watching my diet or anything, just never changed, never went down. And it slowly crept up a little bit, and before I knew it, I was having a quadruple bypass. – Participant from Australia who experienced an ASCVD event

Table 6. Types of ASCVD events experienced by participants

	Total		Australia		Brazil		United States	
Ischemic Stroke	5	10%	0	0%	2	13%	3	19%
Heart Attack	14	28%	4	21%	5	33%	5	31%
Peripheral Artery Disease	7	14%	3	16%	2	13%	2	13%
Unstable Angina	3	6%	0	0%	2	13%	1	6%

In other cases, participants **experienced symptoms and immediately called for emergency care or somebody else sought emergency care on their behalf.** Some participants sought primary care or urgent care and were referred to an emergency department, while others went straight to an emergency department.

> I noticed a feeling of something not being right…but I didn't put two and two together. I found myself a couple of times having to stop in the street and rest. And then I had some… what was obviously an event, but I didn't even… I wasn't even informed enough to call an ambulance, so I just stayed there and tried to be quiet so as not to interrupt my partner. the next day I called a taxi and went to a local medical center, and when I got there, they recognized what was going on and called an ambulance for me….it's all a bit of a blur, I suppose. – Participant from Australia who experienced an ASCVD event

Participants often described that **a family member, colleague, or somebody else was instrumental in helping them enter the health system (n=4; 18% of those who experiences and ASCVD event).** These people convinced the participant that the symptoms were more serious than a cold and encouraged them to seek care or they called for emergency care after finding the participant to be impaired.

That Monday, I woke up and I was taking my children to school; and I said, "Man, I have zero energy." The flu symptoms were just so bad." So, I called my mom and I said, "Can you come over and help take care of" – I had a niece that I minded – I said, "Could you just take care of her, or can you get me to a doctor? Because I'm very sick." And she came over and she said, "I'm taking you to the hospital emergency room. You don't look well." – Participant from the United Stated who experienced an ASVCD event

In many cases, participants described **delaying care because they did not want to be a burden or a disruption** to work, family, events, or other activities. Many participants had difficulty remembering the very specific details about their hospitalization because of medications, unconsciousness, or due to time since their event.

To a certain degree [the laboratory results after the heart attack made sense], but I was a bit out of it with the drugs and stuff. It took me a while to absorb it all. I had shock because I still can't believe I had a heart attack. I still can't today. – Participant from Australia who experienced an ASCVD event

Most described **feeling very surprised and scared they were going to die during the event**. They described feeling they were not prepared emotionally and worried about their family members' well-being, emotional health, and futures.

Follow-up care after event

Across countries, people were referred for follow-up care after their event, most often to their primary care doctor or a cardiologist, sometimes the same cardiologist they had seen during hospitalization. **In many cases, cardiologists played a larger role in their care after an event than they had before their event**. About one-third of participants described changing physicians (n=8, 36%) or adding a cardiologist (n=11, 50%) to their care team after an event. The speed with which these follow-ups were arranged varied across the sample and ranged from a few days to more than a week.

During follow-up appointments, participants described discussions about medicines and lifestyle changes.

Medications after event

Following an event, participants reported initiating a statin for the first time (n=8), remaining on their pre-event medicine with no change in dosage (n=5), switching medicine class (n=4), switching statins (n=4), increasing the dose of their existing medicine (n=2) and adding a medicine while remaining on their pre-event medicine (n=2).

Immediately following an event, statins, either alone or in combination, remained a cornerstone of therapy for most individuals throughout the study (statin alone, n=15: statin in combination, n=2). Only two individuals who experienced an ASCVD event, one in Australia and one in the United States, reported receiving proprotein convertase subtilisin/kexin type 9 serine protease (PCSK9) inhibitors. The participants in the United States reported discontinuing

due to side effects and returning to a statin. Participants reported starting additional medicines for comorbid conditions, such as ACE inhibitors for high blood pressure or anticoagulants to prevent future strokes.

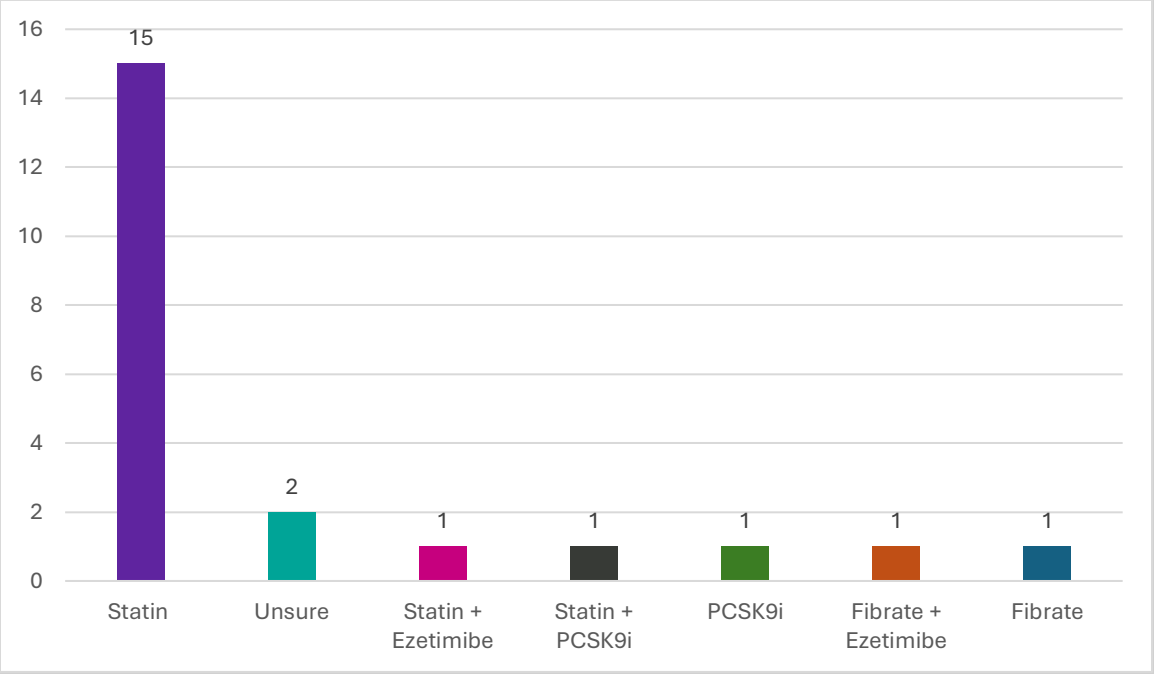

Figure 3. Medicines initiated following ASCVD event

Key Takeaways: Experiencing an ASCVD Event	▪ Approximately half the study participants (n=22) experienced an ASCVD event. Misinterpretation of symptoms as non-cardiac issues, such as a severe cold, resulted in significant delays in seeking emergency care. ▪ Family, colleagues, or friends played a key role in helping participants recognize the severity of symptoms and the need for emergency care. ▪ Participants felt emotionally unprepared for the ASCVD event, worried for their family, and scared they were going to die during the event.

Adherence after event

Following their cardiac event, participants described taking more responsibility and initiative regarding their care plan. Many described significant improvements in their adherence to lifestyle changes. **Reflecting back on their time between diagnosis and experiencing an event, many described realizing that they had not taken lifestyle changes or monitoring their laboratory values as seriously as they should have following their diagnosis** of high cholesterol. They recognized the importance of prioritizing their health and were prepared to make significant changes to avoid additional events. They reported that they internalized the need to change and built new behaviors into their daily activities, such as prioritizing healthy eating, exercise, and reducing or stopping smoking and drinking alcohol.

From that moment on [the heart attack] I became a saint. **I took the right medication, I did everything right, you know? I was prescribed clopidogrel, ASA, losartan, atenolol and atorvastatin 80mg after the heart attack. [. . .] I left the company, moved to another state.** And I changed completely. At that time it was physical exercise, walking, eating lighter. – Participant from Brazil describing post-event changes

After their event, many participants diligently adhered to their lifestyle changes and medicines. However, over time, some described that it was challenging to maintain this level of commitment. This was especially true if they did not have improved lab values. For example, one individual from Brazil shared that despite making significant lifestyle changes and adhering to his medicine following the first event, they subsequently experienced two more events. He was frustrated and eventually started smoking again.

But I was told at one point to lose at least 40 pounds. I did that two years ago… I was applauded for it … And yet my numbers were still elevated. So, I don't personally see it like that was a success, because it didn't really knock my numbers down at all. **–** Person in the United States who experienced an ASCVD event

This was not a universal change; however, some individuals (n=7, 32%) described continued gaps in knowledge and support, as well as a lack of concern from their care team following the event.

Key Takeaways: Adherence after event	▪ Following their cardiac event, participants described taking more responsibility and initiative regarding their care plan. Many described significant improvements in their adherence to lifestyle changes. ▪ Reflecting back on their time between diagnosis and experiencing an event, many described realizing that they had not taken lifestyle changes or monitoring their laboratory values as seriously as they should have following their diagnosis of high cholesterol.

Life factors and emotional health during and after event

Family & support system (During or after event)

In many cases, **participants described support and engagement from family and friends in the period immediately following the ASCVD event**. As mentioned above, it was not uncommon for family, friends, and colleagues to be critical in the individual seeking care for their ASCVD event. One participant described how this level of engagement in their care and care plan eventually returned to pre-event levels of engagement.

Well, yeah. I think they all saw my mortality and I don't think they were really prepared for it. I had 19-year-old twin girls. They had never thought about Dad being sick or any, you know, because they'd never seen me in the hospital or anything, and by the way, they didn't that time, because this was during the pandemic and they couldn't even come. So, they never saw me there, but obviously they know what was happening and whatever, and it sort of hit them, like they saw me as being fine even though I had previous conditions, it's not something that they even thought about. **In the month, in the six months after it was sort of top of mind, they were always calling, hey, how you doing, how you doing, how you doing, how you doing? But, you know, they're 22-year-old girls, now they're like, he's fine, whatever.** – Person from the United States after experiencing an event

Health insurance and access to care (During or after event)

Participants who experienced an event tended to be more critical of the care they received before their event and the quality of that care. Following the event, several people described either **changing physicians or the addition of a cardiologist** to their care team. Interestingly, some individuals who experienced an event described overall satisfaction with care and did not identify any issues with the quality of the care they received before their event, describing it favorably, indicating there be a misalignment between true, high-quality care as defined by clinical guidelines and people's perceptions of what constitutes high-quality care.

Emotional impacts (During or after event)

Participants who had experienced an ASCVD event described the **profound impact the event had on their emotional well-being and overall mental health**, especially among those participants who had experienced more than one event. The most common emotion described was fear or worry associated with the reality that their event could have resulted in death. Additionally, some individuals described guilt over not making lifestyle changes that they were aware could have helped prevent an event.

Some individuals redirect these emotions into making changes to their care plan both in terms of their adherence to medicines and their overall commitment to lifestyle change.

This second heart attack, I certainly feel more mortal, and because I couldn't breathe for a long time after that second one [. . .] I became much more aware of the fragility of life and [doctor's name] got me to have a few echocardiograms and the last one, the technician, as I was walking out the door, and I stress walking out the door, she said to me, "You're very lucky to have survived." I spent a very sobering week and a half until I saw [doctor's name] again, and she was furious with her. She said, "She should never have told you that." – Australian who experienced an event

Key Takeaways: Life factors and emotional health during or after event	▪ **Family & support system:** Following an ASCVD event, participants often experienced an initial surge in support from their family and other members of their support system. ▪ **Health insurance and access to care:** Participants who experienced an event tended to be more critical of the care they received before their event and the quality of that care. Following their event, several people described either changing physicians or the addition of a cardiologist to their care team. ▪ **Bias:** One participant in the United States described the interaction between race and gender when engaging in discussions about her high cholesterol and heart disease treatment, where her voice was disregarded. ▪ **Emotional impacts:** Participants who experienced an ASCVD event described the profound impact the event had on their emotional well-being and overall mental health. They described feeling fear and worry about the event, as well as guilt if they had not adhered to their cholesterol management plan.

Chapter 05. IPEC Participant Calls to Action

Participants were asked if they had recommendations or things they wished specific industries, the health system, individuals, or others should know and act upon.

Participants suggested that education from various sources (e.g., healthcare organizations, providers, and public campaigns) is needed to improve adherence, specifically among newly diagnosed individuals. They emphasized the need for early and comprehensive education on the dangers of high cholesterol, available medical and lifestyle interventions, and the importance of care plan adherence and regular testing.

A major challenge identified was overcoming both personal and healthcare provider apathy towards high cholesterol. This is a barrier to greater adherence to cholesterol management plans, even among individuals who have experienced a cardiac event.

Calls to action for people who are newly diagnosed

- Prioritize your care and advocate for yourself
- View your diagnosis as a motivator to improve your health
- Track your diet and exercise habits
- Invest the time to engage with your care team

Calls to action for healthcare providers

- Be available for people to engage when they are reaching out for help
- Balance messaging to highlight the dangers of high cholesterol without creating panic

Calls to action for policymakers

- Continue to increase awareness and education on the relationship between high cholesterol and heart disease
- Broaden the traditional communication channels used to share information
- Share the experiences of people who haven't made changes and the impact that has had on their health as a result
- Support educational programs and opportunities to increase awareness earlier in people's lives

Concluding Comments

This study provides insights into the experiences of individuals living with high cholesterol and ASCVD, including symptoms (or lack of), patient journeys through the healthcare system from diagnosis to post-diagnosis, treatment approaches, most important attributes of therapy, and strategies to improve care plan adherence.

Many participants reported not experiencing initial symptoms, and often their diagnosis of high cholesterol was discovered during a routine healthcare visit or a visit for another condition. People described the level of engagement in clinical encounters, especially at diagnosis, as a significant facilitator of care plan adherence. Many individuals described balancing work and lifestyle changes as the most significant barrier to care plan adherence. Despite many individuals describing making changes to lifestyle or initiating pharmaceutical therapy following diagnosis, people who experienced an ASCVD event frequently described additional changes beyond the pre-event changes.

All participants had at least two years of experience living with high cholesterol. For individuals with an event, they were at least one-year post-event, AND the event occurred at least one year after they learned about their high cholesterol diagnosis. These participants' experiences may not be generalizable to those who are diagnosed during hospitalization for an ASCVD event or to individuals who have high cholesterol but are currently undiagnosed.

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Supplemental Material

Appendix 1. Interview guide

Pre-event experience with high LDL-C

Before I ask you about your experience with [cardiac event/condition], I would like to know more about your experience with high cholesterol before you had [cardiac event/condition],	
LDL-C: diagnosis	Could you please tell me about when you first found out you have high cholesterol? How long ago was that? Did you find out that you had high cholesterol during a regular check-up or were you at the doctor's office for another reason?
LDL-C: before event/ shared decision-making	Could you describe conversation(s) between you and your doctor after finding out you had high cholesterol, but before you had [cardiac event/condition]. For example, did you discuss risks of high cholesterol? Did you discuss how to manage high cholesterol? What did you discuss? Did you take the link seriously? Why or why not?
LDL-C: medicine before event	Did you start taking medicine? Why or why not? Do you recall what medicines you started taking at that time? Were you aware that medicines for high cholesterol need to be taken throughout your life? Note to reviewers: there is a more detailed section on treatments in the "living with" section.
LDL-C: medicine before event (adherence)	Thinking back, did you take your cholesterol medicine according to your doctor's instructions? Did you doctor discuss potential health consequences of not staying on treatment? Did you ever miss doses of your medicine? Could you tell me more why the medicine(s) was not easy to take?
Lab testing before event	How often did you get lab tests for cholesterol? Did you know what your cholesterol levels should be? Who reviewed the results with you? Did the results make sense to you? Why or why not?
Lifestyle changes	Did you make any lifestyle changes to help you manage high cholesterol? What changes did you make? Examples include: A healthy diet that is low in salt A healthy diet that is low in fat/saturated fat A healthy diet that includes more fish A healthy diet that includes less sugar A healthy diet that includes more fruits and vegetables Exercise Maintaining a healthy weight Stopping smoking Reducing or trying to manage stress What made you decide to make those changes? Who helped you decide on those lifestyle changes?

Comorbidities

Other diagnoses	Still thinking about your experience before having a [cardiac event/condition], did you have any other health conditions besides high cholesterol? Which health conditions? How long have you had [other dx]?

Life Factors

Point to “life factors” on the map.	
Life factors impact on seeking care	Did the life factors impact your experiences with managing high cholesterol before [cardiac event/condition]?

Closing Pre-Event High Cholesterol

	Do you have anything else you’d like to tell me about your experiences with high cholesterol before your [cardiac event/condition]?

Seeking care for cardiac event/condition

Decision to seek care	Thank you very much for answering my questions. I would now like to ask you more about your experience with [cardiac event/condition]. To start off, I was wondering, what was the thing or thing(s) that made you go to the doctor? Did something feel different or not quite right, or did you see a healthcare provider for another reason? What did you notice? What did it feel like? How long did the [symptoms] last? How often did they occur?
Provider type – decision to seek care for cardiac event	Once you decided to seek care, could you tell me about where you went first (e.g., clinic, hospital, etc.)?

Ask about their experiences getting diagnosed with cardiac event/condition

Seeking care	What happened during the appointment/emergency/hospital admission?
Lab tests and high cholesterol-cardiac event	Did you have any lab tests? If so, when did you receive the results? Did the results make sense to you? Do you recall if you had cholesterol tests done at the hospital?
Follow-up care after cardiac event	What instructions did you have for follow-up care? For example, did the [provider type] recommend that you go to see somebody else next, such as a specialist? Did you decide to go? Why or why not? How long did it take after your first visit with the [provider type] to see this [new provider type]? Did any of the life factors impact your decision to follow-up?
Questions after cardiac event	Did you feel like you left the office/emergency department/hospital with an understanding of [Cardiac event/condition]? What questions did you have? Where did you look to find information following your appointment?

Emotional Health & Awareness of Link Between High Cholesterol and Heart Disease

Emotional health after cardiac event	How were you feeling emotionally after having the [cardiac event/condition]? Some people have mentioned feeling calm, worried, overwhelmed, relieved, or angry. Did you feel motivated to treat and monitor your cholesterol levels? Why or why not?
Awareness of heart disease before event	What did you know about your heart disease risk before your [cardiac event/condition]? Did your doctor explain your overall heart disease risk to you before your [cardiac event/condition]? How? Do you have a family history of premature cardiac events/conditions? [men under 55 and women less than 65] What do you know now that you wish you had known then?

Closing before living with a diagnosis

	Before we move on, do you have anything else you would like to tell me about what it was like getting diagnosed with [cardiac event/condition/ event]? High cholesterol?

Ask about their experiences living with cardiovascular disease / high cholesterol

Point to the green icon “living with a diagnosis” on the map.	
General experiences since cardiac event	Could you please tell me more about your experiences since you first got a diagnosis with [cardiac event/condition]?
Health care routine	Which health care providers do you typically see since you received a diagnosis? Tell me about your usual routine. What kind of specialists do you see? How often do you see them? What do you discuss during appointments with your specialists? Do you see healthcare providers for reasons besides high cholesterol and [cardiac event/condition]? Please describe which other providers you see.

Treatment they are currently getting.

Point to “Tried a treatment” on the map.	
Post event Treatment initiation: Shared decision-making	Could you please describe what treatment(s) – if any - are you currently taking/getting for your high cholesterol? What medicines have you taken in the past? When you were prescribed the medication, what was the conversation like between you and your doctor? Did he/she talk about other medications? Or give you options? Are the discussions you have with your doctor about managing high cholesterol different now than they were before you had the [cardiac event/condition]? How so?
Cholesterol Goals & Lab testing	Do you know your cholesterol goal or target numbers? Who told you about them? How often do you get lab tests for cholesterol? Can you tell me more about that process?

	Who reviews the results with you? Do the results make sense to you? Why or why not? How confident are you that you can control your LDL cholesterol level to target by taking medications?
Treatment benefits	What are the biggest benefits of the treatment?
Treatment downsides	What are the biggest downsides or not-so-good things about the treatment? Do you have any side effects from treatment(s)?
Treatment alternatives	What other treatments for high cholesterol do you know about? How did you learn about the different treatments available to you? Have you discussed alternatives with your health care provider?
Interactions with other medicines	Has the medicine you are currently taking, or one you took in the past, interacted with other treatments you're taking for something else? For example, have there been any unusual side effects that could be related to taking 2 different medicines together?

Adherence to medicine

Adherence to medicine	Do you ever miss doses of your current medicine? If you do, on average how many doses of your medicine would you say you miss in a week? Can you tell me more why the medicine(s) is/are not easy to take? How about past medicines?
Strategies for improving adherence to medicine	What do you think would make it easier for you to take your current or past medicines as prescribed? Have you tried any strategies to help you take your medicines according to your doctor's instructions? What have you tried? Examples: day-of-the-week pillboxes, apps on your cell phone or an alarm, taking medicine at the same time every day How did [strategy] help you? How long did you stick with that strategy?
Making permanent changes	Are there habits you think you could adopt to take your medicine as prescribed every day? What are they?
Perspective towards medicine following cardiac event	Have your feelings towards managing high cholesterol changed since the [cardiac event/condition]? How so? What do you do differently now than before? Are there things you wish you had known before the cardiac event that might have made you more likely to take your medicines or stick to lifestyle changes? What are they?

Risk factors for heart disease

Second probe on connection between heart disease and high cholesterol[1]	Do you know if you have any risk factors for heart disease? What are they? Have you ever had any discussions with your doctor about heart disease risk or risk factors? If yes - tell me about what your doctor said? If no - have you ever had any discussions about blood pressure, cholesterol, smoking, diet or exercise?

[1] Several questions on risk of heart disease are adapted from the "Healthy Heart Study: Improving doctor and patient decision making about cardiovascular disease (CVD) risk assessment and monitoring."

Lifestyle changes

Lifestyle changes	Have you made any lifestyle changes to help you manage high cholesterol? What changes have you made? Examples include: A healthy diet that is low in salt A healthy diet that is low in fat/saturated fat A healthy diet that includes more fish A healthy diet that includes less sugar A healthy diet that includes more fruits and vegetables Exercise Maintaining a healthy weight Stopping smoking Reducing or trying to manage stress What made you decide to make those changes? Who helped you decide on those lifestyle changes?
Adherence to lifestyle changes	Have you been able to stick with [lifestyle change]? Why or why not? Have you tried any strategies to make it easier to stick with [lifestyle changes]? What have you tried? What would make it easier for you to stay on track? What do you feel would encourage you or others to take a proactive approach to cardiovascular health?
Motivators to stick with lifestyle changes	What would make it easier for you to permanently adopt [lifestyle changes]? Have you noticed any changes from sticking with lifestyle changes? For example, changes in your lab results?

Trustworthy messengers	Are there particular people or institutions that you are most likely to listen to when it comes to adopting lifestyle changes or taking your medicines every day? Who are they?
When will messages resonate	At what points across your health journey, for example when you first got diagnosed with [cardiac event/condition] or high cholesterol, or at another point, do you think it would be most effective to hear from them?
What messages?	If you were developing a public service or educational campaign to encourage people with high cholesterol to make lifestyle changes or take their medicines as directed, what messages would you use?

Ideal treatment

Ideal treatment	If you had a perfect treatment that wasn't a cure, what would it do for you? How would your life improve if you had a more effective (or better) treatment? If you could wave a magic wand and change something about the medicine you are currently taking, what would it be? For example, how easy it is to take the medicine or how the medicine makes you feel.

Wellbeing and burden of disease

Well-being & high cholesterol	Please think about the daily activities that are important to you or that you like to do. How has [cardiac event/condition] or high cholesterol impacted your ability to those things? Has your diagnosis with high cholesterol affected your family or other loved ones? Has your diagnosis with high cholesterol affected your quality of life? How has your [cardiac event/condition] affected your family or loved ones?
Worry	What worries you most about your high cholesterol? How about previous [cardiac event/condition]?

Care Coordination & Multiple Chronic Conditions

Coordination of care	Do you have other chronic conditions besides [cardiac event/condition]? How do you coordinate your care for these conditions? How has having multiple chronic conditions affected your life? Do your providers communicate with each other and coordinate your care when exploring treatment options? Has having multiple chronic conditions impacted your treatment decisions? Have you had any negative effects occur because your care was not coordinated? Please describe for me how having more than one condition has impacted your: finances profession or career family lifestyle mental or emotional well-being

Satisfaction with care & quality

Satisfaction with care	How satisfied are you with the health care you receive? What makes you say that? Your comments are kept private. Do you believe your providers understand what is important to you – like things you want to see happen in your life? Feel free to talk about past and current providers.
Quality	Have you had any positive or negative experiences you would like health care providers and researchers to know about? This could be anything to do with your high cholesterol such as an experience with symptoms, medication, health care providers, stigma or bias, etc. When you think about the health care system, what do you think are signs of “good” quality care? And what do you think are signs of “bad” quality care?

Desired Outcomes and Life Aspirations

Outcomes	Which outcomes are most important to you when it comes to your high cholesterol or heart health? Outcomes might relate to how you feel, for example, fewer symptoms; how you function, such as being able to exercise or walk to work; or living longer.
Aspirations	How have your aspirations changed because of [cardiac event/condition] or high cholesterol? How have they changed across the map over time?

Questions & Information sources

Outstanding questions	What questions do you still have about [cardiac event/condition] or high cholesterol?
Information sources & resources	Where do you look for information about [cardiac event/condition] or high cholesterol? What information did you find? Did the information that you found answer your questions? What sources of information did you trust or rely on most? Are there resources you wish existed, but you haven't been able to find?

Life Factors

Point to "life factors" on the map.	
Life factors (living with)	How do the "life factors" affect your experience with [cardiac event/condition] or high cholesterol? For example: lack of insurance, cost concerns, not being able to take off work

Closing

Final thoughts	Is there anything else you would like to add about your experience with heart health or high cholesterol that we didn't touch on, but you think is important?
Recommendations to other stakeholders	Is there anything else you would like to tell **researchers** about having [cardiac event/condition] or high cholesterol? Is there anything else you would like to tell **policy-makers** about having [cardiac event/condition] or high cholesterol? Is there anything else you would like to tell **health care providers** about having [cardiac event/condition] or high cholesterol?
Recommendations to other people with high cholesterol	Is there anything you would like to tell individuals who just got diagnosed with high cholesterol? What would you like them to know? How about people who recently were diagnosed with [cardiac event/condition]?

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