CENTRE FOR COMMUNITY-DRIVEN RESEARCH

personal experience, expectations & knowledge

DECISION-MAKER BRIEF 2023

Heart & Blood Vessel Conditions

Brief for decision-makers considering treatments and services for people diagnosed with heart & blood vessel conditions

Purpose: When making decisions about the type of diagnostics, treatments and services people diagnosed with heart & blood vessel conditions can access, decision-makers need to understand the context in which their decisions are being made, what characterises the patient population, and ensure assumptions are not being made on behalf of this patient population.

This brief provides this context and information about the experience and expectations of people diagnosed with heart & blood vessel conditions - considered high-risk for future incidents - based on the knowledge of 50 people diagnosed with these conditions as experts with lived experience.

Introduction: Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). PEEK studies give us a clear picture of what it is like to be a patient at a given point in time. PEEK studies give us a way forward to support patients and their families with treatments, information and care. The data presented from the PEEK study in heart & blood vessel conditions is available at www.cc-dr.org/2023auhbv

Background: Heart and blood vessel conditions are a major cause of disease burden in Australia. Coronary heart disease and stroke are common types of heart and blood vessel conditions. In 2020 to 2021, over half a million adult Australians were living with coronary heart disease (2.9% of Australians aged 18 and over)[1]. In 2018 approximately 387,000 people aged 15 and older had a stroke in some time in their life, and in 2020 there were 39,500 stokes[1]. Risk factors for heart and blood vessel conditions include smoking, poor diet, not enough exercise, and alcohol consumption. Other risk factors include high blood pressure, abnormal blood lipids, raised cholesterol, diabetes and being overweight[1] Lipoprotein a levels increase likelihood of a stroke or heart attack, particularly with familial hypercholesterolemia or symptoms of coronary heart disease[2]. The Australian Atherosclerosis Society recommends Lipoprotein a testing in high-risk patients including those with premature atherosclerotic cardiovascular disease and those at intermediate to high risk of atherosclerotic cardiovascular disease[3]. The European Artherosclerotic Society recommends testing at least once in adults, and cascade testing for those with familial hypercholesterolaemia, family history of high lipoprotein a, or premature atherosclerotic cardiovascular disease[4].

Baseline health: The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[22]. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function. SF36 General health scale measures perception of health. The overall scores for the cohort were in the middle quintile for SF36 Role functioning/emotional (median=50.00, IQR=100.00), SF36 Energy/Fatigue (mean=40.10, SD=22.07), SF36 General health (median=55.00, IQR=35.00), SF36 Health change (median=50.00, IQR=37.50), indicating moderate emotional role functioning, moderate energy, moderate general health, about the same as a year ago. The overall scores for the cohort were in the second lowest quintile for SF36 Role functioning/physical (median=25.00, IQR=100.00), indicating poor physical role functioning.

Understanding of prognosis: Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (31.91%), that they were monitoring their condition until there is an exacerbation or progression (23.40%), and that their prognosis was positive, that their condition is manageable (21.28 %).

I had a pretty ordinary day today, so yes. It's frustration is what my outlook is. Just continued frustration. I think now that I've accepted that this is how I have to be for the rest of my life. Participant 043_2023AUHBV

[1] Australian Institute of Health and Welfare (2023) Heart, stroke and vascular disease: Australian facts, AIHW, Australian Government, accessed 12 October 2023.
[2] Reyes-Soffer G, Ginsberg HN, Berglund L, et al. Lipoprotein(a): A Genetically Determined, Causal, and Prevalent Risk Factor for Atherosclerotic Cardiovascular Disease: A Scientific Statement From the American Heart Association. *Arterioscler Thromb Vasc Biol* 2022; **42**(1): e48-e60.
[3] Ward NC, Watts GF, Bishop W, et al. Australian Atherosclerosis Society Position Statement on Lipoprotein(a): Clinical and Implementation Recommendations. *Heart Lung Circ* 2023; **32**(3): 287-96.
[4] Kronenberg F, Mora S, Stroes ESG, et al. Lipoprotein(a) in atherosclerotic cardiovascular disease and aortic stenosis: a European Atherosclerosis Society consensus statement. *Eur Heart J* 2022; **43**(39): 3925-46.

Biomarker tests and decisions about treatment: Participants were asked in the structured interview if they had any discussion about biomarkers that may be important to the management of their condition. The most common responses were that they did not have any tests and did not describe reasons (48.94%), that they did not have a test but would like to have this type of test (21.28%). This was followed by no test but family history was discussed (12.77 %), and had a test and management of condition was not changed (6.38%). Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were side effects (51.06%), efficacy (38.30%), and advice of their clinician (23.40 %).

Side effects of medication is something to take into consideration. I luckily haven't had any side effects, but that was something that I really did look into. That's about it really. And just I just didn't want to be fatigued and it for it to, you know, impact my life too much. So I wanted to be able to take the medication and still be still have a good quality of life. So that's they were the main things I kind of looked at with treatment. Participant 011_2023AUHBV

Current understanding of condition: The Partners in health total score measures the overall knowledge, coping and confidence for managing their own health. The overall scores for the cohort were in the highest quintile for Partners in health: Knowledge (median=27.00, IQR=8.75), Partners in health: Recognition and management of symptoms (median=21.00, IQR=5.75), Partners in health: Adherence to treatment (median=15.00, IQR=3.00), indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment. The overall scores for the cohort were in the second highest quintile for Partners in health: Coping (median=16.50, IQR=7.00), Partners in health: Total score (mean=74.46, SD=13.75) indicating good coping, good overall ability to manage their health

Care and support: The Care coordination: Quality of care global measure scale measures the participants overall rating of the quality of their care. Overall, the participants in this PEEK study had an average score in the second highest quintile for the **Care coordination: Communication** (mean = 44.72, SD = 9.18), **Care coordination: Navigation** (mean = 26.74, SD = 4.80) **Care coordination: Total score** (mean = 71.46, SD = 12.46), indicating good communication and navigation of the healthcare system. In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common sources of support and were from their hospital or clinical setting (31.91%), from family and friends (19.15 %), domestic services and/or home care (14.89%), and peer support or other patients (8.51%). Almost a third described that they did not receive any formal support (27.66%),

Things are a bit tough for us. The cardiologist just let me down because he hasn't rung or because the neurologist was unable to give me any new advice or thoughts and just told me, "Yes, all good. See you in another six months."…Apart from that, no, I've just really had to advocate for myself and really speak clearly to the professionals about what I want, how I plan on achieving it, and what I need from them.Participant 050_2023AUHBV

Quality of life and vulnerability: In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (65.96%). Others described overall a minimal impact on quality of life (10.64%), overall positive impact on quality of life (8.51 %). In the structured interview, participants were asked if there had been times that they felt vulnerable. Participants reported that they felt vulnerable because of interactions with the medical team (17.02%), and when experiencing side effects from treatment or symptoms from condition (17.02%).

Many times. I felt vulnerable when no-one was listening to me. I felt vulnerable when I needed help in hospital and there was no-one to help me. Participant 032_2023AUHBV

Message to decision-makers: Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common messages were the need for timely and equitable access to support, care and treatment (25.53%), that treatments need to be affordable (19.15%), and that they were grateful for the healthcare system and the treatment that they received (19.15 %), to improve rural services (19.15%), and to invest in prevention (19.15%),

Obviously I think just the the access to more preventative medicine would be what I would put put to them and if if money and resources can be put in to do that and more preventative services and resources. Participant 017_2023AUHBV

I think more testing for lipoprotein A is a big one. Research shows that statistically, that one in five people could be walking around with lipoprotein with elevated levels of lipoprotein A. And I don't think there's enough testing for it. Participant 016_2023AUHBV