Section 11

Discussion

Introduction

I think just to say that, you know, it should be a part of the every everyday conversation. You know, heart health, like, you know, they do the bowel cancer screening and all that sort of stuff. It should be. I mean it's harder to do this thing, but it I think it's an explanation as to what if you don't look after that, what it could mean in terms of other diseases and stuff like that. I think a lot of people just think, oh, that's to do with having a heart attack. I'm not going to have a heart attack. I'm fit and healthy. You'd have no clue that you had high blood pressure unless you really could feel it. And you definitely have no clue that you had high cholesterol because you can't feel it. Participant 016_2023AUHBV

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

This PEEK study in heart and blood vessel conditions includes 50 people diagnosed with heart and blood vessel conditions throughout Australia.

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].

Many forms of heart and blood vessel conditions are caused by atherosclerosis, which is a build up of fat, cholesterol and other substances in the arteries[1]. It can reduce or block blood supply to the heart causing angina or heart attack, or reduce or block blood to the brain causing stroke[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]. Treatment of high levels of lipoprotein a includes intensifying preventative treatments such as cholesterol lowering therapy and addressing lifestyle modifications [3].

Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have heart and blood vessel conditions.

In this PEEK study, the proportions of participants that lived in areas with higher socioeconomic status, were higher to that of Australia. There were similar proportions that lived in major cities compared to the Australian population [5,6] There were no participants from the Northern Territory, and there were a lower proportion of participants from New South Wales, while a greater proportion from Queensland compared to the proportion that live in each state[5,6].

Table 12.1: Demographics

Demographic	Australia %	Heart or blood vessel conditions PEEK %
Live in major cities	71	70
Higher socioeconomic status (7 to 10 deciles)	40	50
New South Wales	32	14
Victoria	26	20
Queensland	20	34
South Australia	7	8
Western Australia	10	16
Tasmania	2	6
Northern Territory	1	0
Australian Capital Territory	2	2

Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36

questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with heart or blood vessel conditions participants.

Other health conditions

The majority of PEEK participants had at least one other condition that they had to manage, with an average of 5 other conditions. The most commonly reported health condition was anxiety (66%), followed by depression (62), and insomnia (60%). In other studies, between 26 and 47% of participants with stroke or transient ischemic attack had anxiety or depression[7-9], and 66% of participants with atrial fibrillation had sleep problems [10]. Participants in this PEEK study with more comorbidities had worse pain as measured by the SF36 Pain scale, there were no other significant differences for any other SF36 domain.

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition[11]. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)[11]. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition[11].

In this PEEK study, participants had higher levels of anxiety (66% compared to 13%), depression (62% compared to 10%), arthritis (36% compared to 15%) and asthma (22% compared to 11%)compared to the Australian population.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[12]. 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[12]. In this PEEK study, on average participants had low scores for role functioning physical health indicating that physical health often interfered with work or other activities for

participants in this study. They had high scores for physical functioning, emotional well-being, social functioning and pain, indicating that physical activities were slightly limited, emotional problems sometimes with work or other activities, had good emotional well-being, social activities were slightly limited, and participants had mild pain.

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the heart and blood vessel conditions community in this PEEK study compares with the Australian population[13]. The heart and blood vessel conditions PEEK participants on average had considerably lower scores for all SF36 domains with the exception of emotional well-being and pain.

In other studies of people with heart or blood vessel conditions, subgroup differences in health related quality of life was described. Poor health related quality of life was associated with depression and anxiety[14,15], disease severity[14,16,17], having multiple comorbidities[9,16], having lower socioeconomic status[18], being unemployed[9] and being female[9]. Better health related quality of life was associated with those that had made progress in rehabilitation[19], and people living in rural locations had less pain and higher perceived health. In this PEEK study, subgroup differences were seen for comorbidities, those with fewer comorbidities had less pain measured by SF36, and had better health scores for all the AQOL domains. Females in this PEEK study had better scores for the AQOL senses domain.

Key points
- **Participants in this PEEK study had an average of 5 health conditions other than heart or blood vessel conditions that they had to manage**
- **Participants had low scores for role functioning physical health indicating that physical health often interfered with work or other activities for participants in this study**

Risks and Symptoms

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

The most common symptoms reported by participants in this PEEK study experienced before diagnosis were dizziness, weakness of face, arm, or leg, confusion (n=9, 18.00%), and trouble walking (n=9, 18.00%). Other symptoms included trouble walking, lack of coordination, headache, memory loss, vision problems, fatigue, short of breath, weakness, trouble speaking, nausea and vomiting. The symptoms with the worst quality of life were, weakness of face, arm, or leg and, lack of coordination, vision problems, trouble speaking, nausea and vomiting. The most common symptoms that led to diagnosis were shortness of breath, headache, irregular heartbeat, fatigue, dizziness and chest pain.

Screening and diagnosis

Approximately half of the participants in this PEEK study sought medical attention relatively soon after experiencing symptoms. Other participants were either did not seek medical attention initially or they had no symptoms and were diagnosed during routine health check-ups. Participants in this PEEK study had an average of 2 diagnostic tests and for the majority it was not a significant cost burden.

Understanding and knowledge

Absolutely nothing. I was fit, I was going to the gym, I was eating properly and doing all the right things, and I thought I'd be okay, but I have a family history of heart problems, which sort of lingered in the background all the time.
Participant 031_2023AUHBV

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings[20,21]. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis[22,23] others, especially those who have symptoms for long periods before diagnosis, will gain information in terms of how to live with or adapt to symptoms they experience[24]. For some people, the first time they have heard of their chronic condition is when they are diagnosed[23]. At the time of diagnosis, it may be useful for the healthcare professional to talk about how much a patient knows about a condition so that appropriate information can be given, and correct misconceptions[23].

In this PEEK study, the majority of participants had little or no knowledge of their condition when they were diagnosed. The majority were given some information at diagnosis, however, almost half of the participants did not think they were given enough information, and nearly 20% were given no information.

In other studies, young people with stroke had a lack of awareness of stroke in young people when diagnosed[25]. Those that had a TIA had not heard of the condition at diagnosis[26]. Others described having difficulties in understanding hereditary nature of condition[27]

Support at diagnosis

More than half of the participants in this PEEK study reported having no emotional support at diagnosis, almost 40% felt they had enough support.

Biomarkers or genetic markers

I should definitely have them because every woman in my family has had a stroke. I've got two girls so I think it would be really important for them to have that.
Participant 039_2023AUHBV

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course.

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]. Treatment of high levels of lipoprotein a includes intensifying preventative treatments such as cholesterol lowering therapy and addressing lifestyle modifications [3].

Very few participants (14%) in this PEEK study reported having discussions about biomarkers, genomic and gene testing that might be relevant to treatment, and fewer (4%) recalled having these tests. However, 43% of participants knew their lipoprotein a status. This may highlight a lack of discussion or information about the

importance of some diagnostic tests and the implications the results have on treatments.

Most commonly, participants had a family history of heart or blood vessel condition (n=25, 56.82%), followed by Lipoprotein A (LPa) status (n=19, 43.18%). There were 7 participants that were and not sure (15.91%), and 2 participants that had no markers (4.55%).

In other a study of people with familial hypercholesteremia, participants described that they had been contacted for screening due to risk factors, this increased awareness in some, though others did not understand the importance of their diagnosis. They described providing information to family members which sometimes resulted in family member testing[27]

> **Key points**
> - **Participants had little or no knowledge at diagnosis and were not given enough information**
> - **Participants in this PEEK study lacked discussions or information about biomarkers, genomic and gene testing relevant to treatment**
> - **Three**

Decision making

Yeah I think, well I feel, I think initially, because I was quite shell shocked, I would generally just go with whatever I was told to do. I think since then, I feel like I'm, what's the word? I feel more empowered to make my own medical decisions and be able to find resources and people that I can talk to about my different options. Participant 035_2023AUHBV

The decision-making process in healthcare is an important component in care of chronic or serious illness[28]. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare[29,30], highlighting the importance of healthcare professional communication. In addition, the role of family members in decision making is important, with many making decisions following consultation with family[31]. Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous consultations and results[32,33].

Less than 20% of participants in this PEEK study described taking part in treatment decision making when first diagnosed. Sometimes they were unable to

make decisions because it was a medical emergency, or that they were too young or incapacitated and unable to make decisions. Similarly, another study described people not taking part in decision making due to being toi sick to make decisions[34]. Most participants in this PEEK study described decision making changing over time, this was mostly due to them becoming more assertive and more informed over time.

Goals of treatment and decision-making

My goal is not to die before I'm 60, which is pretty much my mother's side. They've all died before they're 60. So, you know, my, my goal is to and I lead by example because I want to be able to eat healthy, exercise and you know, and do all that sort of stuff. And you know, if at the end of the day that doesn't help me, well, you can't beat genes. But you know, that is my main goal. You know, I was told that if I didn't make all these dietary changes, I was going to be dead by 40. I'm 44 on Sunday, so I am still here. So, yeah, I don't have any long term goals, you know, beyond that sort of, you know, take it a year by year at this stage.
Participant 028_2023AUHBV

Most participants in this PEEK study took multiple considerations into account when making treatment decisions. The most common considerations were side effects, efficacy, the advice of their clinician, quality of life, their own research, their ability to follow treatments, and the impact on their family or dependents.

Likewise, in other studies people with heart and blood vessel conditions considered side effects, efficacy, the advice of clinicans, ability to follow treatment, quality of life and the impact on family [27,35-37]. Other considerations were previous experience of treatment, cultural considerations, co-morbidities and conflicting health priorities, and cost[27,35-37].

When participants in this PEEK study described their goals of treatment, the most common goals were to to make lifestyle changes to be fit and healthy, have physical improvements in their condition, and to have quality of life or to return to normality. In other studies, people with heart and blood vessel conditions described having goald to improved their mobility and to do domestic tasks, some described that a lack of discussing their goals led to unrealistic expectations [34,38].

Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having heart and blood vessel conditions are collected.

Access to health professionals

Half of the participants in this PEEK study were mainly treated by a general practitioner, and 42% described a specialist as their main provider of care. For more than 80% took an hour or less to travel to appointments with their main care provider. More than half pf the participants had access to allied health care (56%), most commonly a dietician, physiotherapist or a psychologist or counsellor.

Affordability of healthcare

Yeah, I mean, obviously there's been costs involved. It costs to go to the breathing specialist, it costs to go to the GP, It costs to go to the cardiologist, It costs to purchase the medication, do the tests. Yes. So yes, there's costs.
Participant 019_2023AUHBV

Almost half of the Australian population have private health insurance with hospital cover [11].. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from about 8% to 14%[11]. In this PEEK study, a higher proportion had private health insurance compared to the Australian population.

In the online questionnaire, the majority of participants in this PEEK study noted that they did not have problems paying for healthcare appointments, prescriptions or basic essentials, however their was a significant cost burden for those that had to quit their job or reduce working hours. In the structured interviews, participants elaborated on costs, describing medications, tests and scans, healthcare appointments and time of work all adding up to a cost burden. For this population, individual costs may not be a particular burden on their own, but due to the ongoing nature, the cumulative cost may be a burden.

Treatment

PEEK participants most commonly had drug treatments (80%), more than half had allied health care (56%), and approximately a third had surgery (34%). The majority of participants had made lifestyle changes (84%), and approximately a third used complementary therapies (36%).

Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of heart and blood vessel conditions.

The most common allied health services used by PEEK participants were seeing a dietician, followed by physiotherapy, and psychology or counselling. On average they found seeing a dietician and physiotherapy as effective, and psychology or counselling somewhat effective.

Lifestyle changes

Many chronic diseases share the modifiable risk factors of poor diet, little exercise, smoking , and excessive alcohol consumption. The majority of participants in this PEEK study had made lifestyle changes, most commonly diet and exercise.

Complementary therapies

Complementary therapies include taking supplements, mindfulness and relaxation techniques, massage therapy and acupuncture and many others. Approximately a third of PEEK participants had used complementary therapy, most commonly mindfulness or relaxation techniques.

Clinical Trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to

participants include new treatment may not be as effective, and side effects.
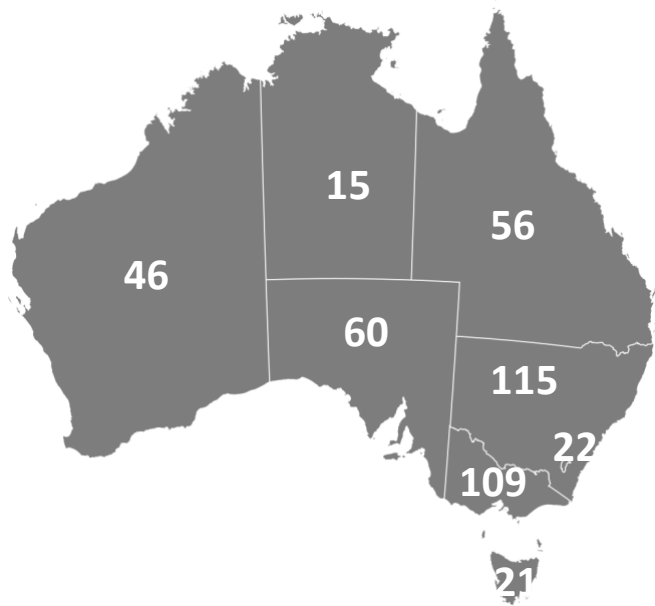
Figure 12.1: Distribution of clinical trials for heart and blood vessel conditions in Australia

To have an estimation of clinical trials available in this patient population, a search of the Australian New Zealand Clinical Trials Registry was conducted on October 11 2023. The search included interventional clinical trials registered on the ANZCTR, that were open to recruitment, were conducted in Australia, and were in the condition category "cardiovascular". A total of 370 clinical trials were currently open for recruitment. There were 115 clinical trials in NSW, 109 in Victoria, 60 in South Australia, 56 in Queensland, 46 in Western Australia, 22 in the Australian Capital Territory, 21 in Tasmania, and 15 in the Northern Territory.

Very few participants in this PEEK study had spoken about clinical trials for their condition, and only one participant had taken part in a clinical trial. In another study, people with heart of blood vessel conditions described being motibated to take part in clicnial trials to help other people, and the barriers to taking part included relevance of research question, travel and transportation to treatment, or the amount of time needed to take part[39].

Patient treatment preferences

Maybe a slight inconvenience to your life would be a mild side effect, maybe a little bit sick, maybe a little bit of a light headache, maybe a little bit of a lack of energy, that kind of thing.

Participant 020_2023AUHBV

Fatigue is definitely a severe side effect for me. It changes everything. I can feel fine one minute and 15 minutes later I'll be on the couch and not being able to move. It greatly affects. I have two teenage children who still need lots of help and assistance. It definitely greatly affects their lives as well.
Participant 047_2023AUHBV

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance.[40-42] Patient preferences and priorities vary across different health issues, preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle[40,43].

To help inform patient preferences in the heart and blood vessel conditions community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Mild side effects were described by providing examples, or as side effects that have a short duration or do not interfere with life. Examples of specific mild side effects included pain, fatigue, headaches or nausea. In a similar way, participants describe severe side effects, broadly as those that impact every day life, or using the examples of pain, or cognitive difficulties, emotional impact, and fatigue,. It is interesting to note that participants described, nausea and pain as both mild and severe side effects. Discussing both a list of side effects and the potential impact on daily life may be important for treatment decision making.

Participants in this PEEK study most commonly described adhering to a treatment for a specific amount of time, usually two to three months. They also described adhering according to the advice of their doctor or as long a side effects were tolerable. In other studies, participants with heart and blood vessel conditions described that adherence to treatment was facilitated when they were motivated to get better, when they were well informed about treatment, having support from family, and having a routine[44-49]. Barriers to treatment adherence included not being able to cope with the treatment, intolerable side effects and forgetfulness[44,46,48,49].

Participants were asked in the structured interview what their expectations of future treatments are. Some described expectations in terms of accessibility,

they wanted accessibility, transparency and discussions in relation to treatment options, and more clinical trials including to access new technologies and treatments. Other described treatment expectations in terms of treatment targets or outcomes , such as treatments that are more effective, targeted, or personalised, have fewer or less intense side effects, or will manage symptoms and prevention of disability. Some participants described wanting more holistic treatments and more access to rehabilitation.

> **Key points**
> - **For this population, individual costs may not be a particular burden on their own, but due to the ongoing nature, the cumulative cost may be a burden.**
> - **Very few PEEK participants had discussed or participated in clinical trials.**
> - **Participants want to be informed about all available treatments and have access to them.**

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving[50]. Components of self-management include information, activation and collaboration[50].

Information

I think they all play a part differently. I know early on, the reading would have been really hard for me to be able to read and then cognitively understand. So different forms, seek different people at different times, I now can see the computer and read information online. Early on, that was too exhausting. Participant 047_2023AUHBV

Information is a key component of health self-management[51,52]. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management[51,52].

Participants in this PEEK study accessed information from a range of sources, most commonly from the internet, their healthcare team, charities and from other people with heart and blood vessel conditions. In terms of format of information, the main preferences were online, talking to someone, written or a combination of formats. Similarly, in other studies people with heart and blood vessel conditions described getting information from a variety of sources including the internet, charities, healthcare professionals, clinical settings, family and friend, apps, videos, and workshops, and that a variety of formats is important[26,53-55].

Participants in this PEEK study described reasons why they preferred different formats for information. Participants preferred talking to someone because it allowed them to ask questions, the information given was relevant to them, body language can help with their understanding, and at times it was the only way to get information due to cognitive symptoms of their condition. Information from the internet was preferred because it was accessible, and that information could be digested at their own pace. Information from the internet and from written documents were preferred because they were easy to refer back to. Likewise, in another study, people with heart and blood vessel conditions preferred verbal information because it was reassuring, written information was easy to retain the information and could be refered back to, and online information was accessible[53].

In terms of timing of information, participants in this PEEK study wanted information at different time points. For many it was from the beginning or when the shock of diagnosis subsided, others wanted information continuously or when there were changes to their condition. Some were unreceptive to treatment for a year of more after diagnosis, or until treatment was finished. In other studies, people with heart and blood vessel conditions described wanting information during the first couple of weeks after dianosi or when being discharged from hospital[26,53,54,56], they did not want to be overwhelmed with information as it was difficult to remember everything[26,53], while others wanted information continuously was beneficial as information needs changes at different times[53].

When asked about the what information was useful, participants in this PEEK study most commonly described the sources of information they found helpful, for example information from other people's experience, talking to their doctor or specialist, health charities, medical journals, or from videos or webinars. The only topics that were described were hearing what to expect and lifestyle advice. In other studies people with heart and blood vessel conditions, people also

described information from charities as helpful because it was credible[55], information from other people with their condition as helpful because it was relatable and supportive [53]. In terms of topics, practical information, information about emotional support, information that was specific to their condition or subtype of condition, and information about what to expect was described as helpful[53-55,57]

When asked about information that was not helpful, participants in this PEEK study most commonly responded that there wasn't any information that was not helpful, and some were confident in deciding what information was and was not helpful. Information that was not helpful included information from healthcare professionals, information that was not credible, that was not specific enough, or that had used too many medical terms that were not easily understood by lay people. In other studies people with heart and blood vessel conditions, people also described information that was too technical, and information that was not specific to their condition as not very helpful [53,55]. They also described a lack of information, or information that was withheld as not helpful, [26,55].

Participants in this PEEK study were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. They described that they wanted information in a variety of formats, information that is easy to understand, the ability to talk to or access to a health professional, and information that is easy to access. In terms of topics, participants wanted more information about disease trajectory and what to expect, information that is more holistic and includes emotional health, more information about the causes of their condition, and where to find support including peer support. In other studies, people with heart and blood vessel conditions described wanting more information that is specific to their condition or age group, that includes information about health risks, what to expect including emotional impact, and expected clinical pathways[25,26,55,56,58,59].

Participants in this PEEK study described a range of preferred information formats, sources, topics and different times when they were more receptive to information. This indicates that a range of different formats and sources of information are needed and that information is an ongoing need for people with heart and blood vessel conditions.

I think it gets easier the longer you have it because you understand it and accumulated information over time. At the beginning it's all very new. So it's like any kind of new learning. It's always hard at the beginning, but the longer you've been with it, the easier it gets.
Participant 019_2023AUHBV

Activation (skills and knowledge)

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire[60]. On average, participants in this study had very good knowledge about their condition and treatments, had a good ability to manage the effects of their health condition, had a very good ability to adhere to treatments and communicate with healthcare professionals, and had very good recognition and management of symptoms.

Key points
- **Information needs to be presented in different formats, available from a number of sources, and offered throughout treatment and management of condition.**

Communication and collaboration

Well probably they didn't give me very much information. They just probably gave me a script and said, "Come back and see me in so many months. We'll send a letter to NAME DOCTOR." I mean to be perfectly honest, I never discussed anything really
Participant 037_2023AUHBV

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support [51,52] Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[61-64].

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making[65].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[65]. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding[65]. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands[65]. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources[65]. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire[66]. On average participants had moderate communication with healthcare professionals, good navigation of the healthcare system, they rated their care coordination as good and rated their quality of care as good.

In other studies, people with heart and blood vessel conditions described a lack of care coordination after hospital or rehabilitation discharge, with long waiting times and a lack of follow up[26,34,38]

Patient understanding of their condition and ability to seek care when needed was improved when information was delivered in a two-way exchange. [67,68]

In this PEEK study, participants most commonly described that that overall communication with healthcare professionals was good. Good communication was described as supportive and with two way conversations, and poor communication as dismissive, one way conversations, lacking care coordination, and having a lack of time. In other studies, people with heart and blood vessel conditions described communication as good when there was empathy, friendliness, cooperation, and two-way conversations[38,69,70]. Poor communication was described when healthcare professionals did not understand the condition, did not understand the extent of physical limitations of the participant, when appointments were rushed, when information was incomplete, and when participants where dismissed [34,54,55,58,70]

Participants in this PEEK study described what they expected for future communication. Some of the expectations were about how healthcare professionals interact with patients, with participants expecting empathy, for healthcare professionals to listen to them, and to communicate with them in a way that a lay person can understand. Some expectations were about having more communication including more time, information that is transparent and forthcoming. Others wanted communication between healthcare professionals, and for their care to have multidisciplinary and coordinated approach that is holistic and includes emotional health. In other studies, people with heart and blood vessel conditions also wanted more time to talk with healthcare professionals, empathy and for healthcare professionals to listen to patients[59,71,72]

Care and support

Healthcare workers have been wonderful, as I've said. I had to change GPs because I wasn't happy with one of my GP. The current GP, I had a good chat to him, and we started from the base, and that's when we discovered that I had severe hypertension and thus I had severe left ventricular hypertrophy. I'm very happy with what he's done. Support from my family, my immediate family is always very good. They make sure I don't -- sometimes they're just a bit too much and make sure I'm not carrying stuff or -- they're gushing a bit much. I think before the AF, my immediate family kind of thought she's okay, she'll be fine, and that's how it's always been done. I think that's why my brother was so devastated when I got sick, I would say, because he didn't actually realise how serious -- although, yeah. Yeah, so no. I don't know. Everyone's great.
Participant 034_2023AUHBV

Participants in this PEEK study described support in terms of where they got support and the types of support they received. The sources of support were their hospital or clinical setting, from family and friends, peer support or other patients. The type of support most commonly described was domestic services or home care. Almost a third described that they did not receive any formal support, others described that they did not need or seek help or

support, and some described the challenges of finding or accessing support. Likewise, In other studies, people with heart and blood vessel conditions described getting support from family and friends, in a clinical setting, from healthcare professionals[54,73], and also they described difficulties in accessing support and not knowing where to find support or information[55,73].

Participants in this PEEK study were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. Some participants expected care and support to be delivered through their healthcare team, where they described wanting a multidisciplinary and coordinated approach to their care, more long-term condition management, a holistic approach that included emotional health, and specialist clinics or services where they can talk to professionals, in person, by phone or online. Others wanted more practical support for example home care, transport, and financial support, and more access to support services in general. Similarly, in other studies, people with heart and blood vessel conditions wanted care coordination and follow up, and emotional health support[25,26,38,39,55,56,59,72]. In addition, they described wanting financial support, age appropriate care, access to peer support, remote support, and support for social participation[25,55,59,71,72,74]

Key points
- **Participants would like communication to have adequate time, be delivered with empathy and for transparency and forthcoming information**
- **Participants would like care and support to include a multi-disciplinary and coordinated approach**

Anxiety associated with condition

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease[75].

In this PEEK study, anxiety associated with heart and blood vessel conditions was measured by the fear of progression questionnaire[76]. The participants in this

PEEK study had moderate levels of anxiety in relation to their condition.

Quality of life

Look it definitely affects it. There's a lot of stuff that I don't do. I don't go roller-skating with my daughter. I don't go jogging with my son. If, they were to go snow skiing in the winter I don't feel that I could do that. I think I'd get halfway through you know as I'm with them, and I'd be exhausted. There is a lot that I don't do. I have adapted to that fact, and there's a lot of stuff that we do, do together instead of. It doesn't affect me mentally like it used to. I've adjusted emotionally to the fact that what I can't do anymore. It definitely has affected my quality of life. For sure.
Participant 036_2023AUHBV

The majority of participants in this PEEK study described a negative impact on quality of life from having a heart or blood vessel condition. The main reasons for a negative impact were the emotional strain, the reduced capacity for physical activities, having to manage side effects and symptoms, reduced social interaction and reduced ability to work. Likewise, In other studies, people with heart and blood vessel conditions described poor quality of life due to physical limitations, cognitive problems, personality changes, changes in family dynamic, personal identity changes, loss of confidence, reduced social interaction, future goals lost, and an inability to work or work at full capacity[38,55,77,78].

Mental health

Yes. It's very emotional. Some days I'm really good and others are not. I did see a psychologist for a while to help with that. Probably a grieving of how my life had changed. It is something I probably should do all the time.
Participant 047_2023AUHBV

Participants in this PEEK study described that having a heart of blood vessel condition had at least some impact on their mental health. Participants described activities to maintain their mental health, most commonly consulting a mental health professional, meditation or mindfulness, exercise, remaining social and participating in hobbies, taking medication and pacing themselves.

Participants also described everyday activities to maintain their general health. The most common activities for general health were doing physical

exercise or being physically active, self care for example more rest, accepting help, pacing themselves, and maintaining a healthy diet. Other activities included complying with treatment or management of their condition, mindfulness and/or meditation, making healthy lifestyle changes, maintaining a healthy weight, and managing stress.

Similarly, other studies described the activities for mental and general health performed by people with heart and blood vessel conditions. They described seeking help from a mental health professionals, peer support, mindfulness, seeking medical attention when experiencing symptoms[7,34,38,55,58].

Yeah, it's it's just keeping up with sort of my newer habits. Yeah. Because if I can do some exercises throughout the week, I mean, I I've got my, I'm keeping my physical conditioning and and then, of course, my mental health stays intact because I already get the pleasure of knowing that I've looked after my body, you know?
Participant 001_2023AUHBV

Impact on relationships

Participants in this PEEK study described a mix of changes to relationships die to their condition. Positive impacts were from people being supportive and well-meaning, and from family relationships being strengthened. Negative impacts were from the dynamics of relationships changing, people withdrawing from relationships and not knowing what to say, intimacy challenges, and others not believing the impact of the condition.

In other studies, people with heart and blood conditions described similar impacts on relationships. Relationships were strengthened, and also changed due to the emotional impact, changes in role and family dynamics, physical symptoms interfering with social and sporting activities, people not understanding the impact of the condition, relationship breakdowns and intimacy problems[34,55,56,58,78]

That's a tricky one. I think it changes things for the positive, actually, in that there's a greater sense of appreciation for someone who has been in a life-threatening situation. It's a hard one to answer because there's people who can't deal with it, and they can't respond, and they don't know how to respond for their own reasons, but it can create more distance, but on the other hand, for me, there's a group of people who I'm probably closer to now. So

it's also just where you choose to focus, I guess. Yeah. So for me it's mostly been positive, I would say.
Participant 023_2023AUHBV

Characterisation

There were 50 participants with heart or blood vessel conditions in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. More than half were female and the majority were aged under 54.

Physical health often interfered with work or other activities for participants in this study.

Before diagnosis with a heart or blood vessel condition, participants commonly had no symptoms. For those that had symptoms, they had dizziness or weakness.

This is a group that had an average of 5 health conditions other than heart or blood vessel conditions to deal with, most often anxiety, depression, and sleep problems.

Most participants sought medical attention after noticing symptoms and were diagnosed in the hospital emergency department. This is a patient population that often had no symptoms and were diagnosed due to a routine check-up.

This is a cohort that were mostly diagnosed with heart and blood vessel conditions without experiencing symptoms, or they had shortness of breath. On average, this group had two diagnostic tests for heart and blood vessel conditions, they were diagnosed by an emergency doctor in a hospital. The cost of diagnosis was not a burden to them and their families. They were mostly diagnosed with heart conditions. This is a group that did not have any emotional support, though they had some information at the time of diagnosis. This is a cohort that did not have conversations about biomarkers, genomic, or gene testing, though they are interested in having these tests.

This is a study cohort that had limited knowledge of heart and blood vessel conditions before they were diagnosed. This patient population described prognosis in terms of medications needed to manage their condition, or monitoring their condition until there is a progression.

This is a patient population that had discussions about multiple treatment options, very few described participating in the decision-making process.

This is a study cohort that took into account the side effects and efficacy as part of many considerations when making decisions about treatment.

Within this patient population, most participants had changed decision making over time, this was because they had become more informed and assertive.

When asked about their personal goals of treatment or care participants most commonly described wanting to make healthy lifestyle changes to become fit and healthy.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a general practitioner, and it usually took less than an 30 minutes to travel to medical appointments.

Two-thirds of this cohort had private health insurance, most commonly treated as public patients treated in the public hospital system. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to heart and blood vessel conditions were somewhat of a burden.

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family did not have to change their employment status. The loss of family income was an extremely significant burden.

Most participants had drug treatments for heart and blood vessel conditions. The majority used allied health services, and made lifestyle changes.

Very few had conversations about clinical trials, however they would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects using a specific example, and those that do not interfere with daily life.

This is a study cohort that described severe side effects as symptoms such as pain, they also described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population which described an amount of time they were willing to adhere to a treatment before giving up, or adhering according to their doctors' advice. This is a study cohort that needed to see a reduction in a specific symptom, or in physical signs to feel that treatment is working as well.

Participants in this study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing

symptoms, and were very good at adhering to treatment.

Participants were given information about treatment options, disease cause, disease management, diet and physical activity from health care professionals, and searched for disease cause, treatment options, disease management and, how to interpret test results most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, their treating clinician or a health charity.

This is a study cohort that found information form other people's experience, talking to a doctor or from health charities as being most helpful.

Participants commonly found no information unhelpful, or information from their GP or specialist, and from sources that are not credible was not helpful.

This is a group that preferred talking to someone as a the main way to get information. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication was dismissive, or that it was a one way conversation.

The participants in this study experienced good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced moderate communication from healthcare professionals.

This is a patient population that most found support from the hospital or clinical setting.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on family, and changes to relationships.

Life was a little distressing for this group, due to having heart and blood vessel conditions.

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they used coping strategies such as consulting a mental health professional, and meditation and mindfulness in maintaining their mental health.

Within this patient population, participants described being physically active, and the importance of self-care, in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments, because of interaction with their medical team, and when experiencing side effects from treatment or symptoms from their condition. To manage vulnerability, they relied on self-help, for example resilience, acceptance and staying positive.

This cohort most commonly felt there was an overall negative impact on their relationships, because the dynamics of relationships changing due to anxiety of difficult decisions.

Participants felt they were not a burden on their family. Those that felt they were a burden due to the extra household responsibilities that their family must take on.

Most participants felt there was some cost burden which was from the costs of treatments, tests and scans, and also from having to take time off work.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to be more affordable, and for there to be more open and informed discussions about treatments.

This is a study cohort that would like more information about in a variety of formats and to have more details about disease trajectory and what to expect. Many participants were satisfied with the information they had received.

Participants in this study would like future communication to be more empathetic, and to have more time to meet with their clinician. Many participants were happy with their communication with healthcare professionals.

Participants would like future care and support to include peer support, and a multi-disciplinary and coordinated approach.

This patient population was grateful for the healthcare staff, and the public health system in general.

Participants' message to decision-makers was the need for timely and equitable access to support, care and treatment.

This is a patient population that wished they had known what to be assertive, an advocate, informed, and ask questions. They also wished they had known the early signs and symptoms of their condition.

The aspect of care or treatment that participants in this study they would most like to change is to have had a better understanding of their condition, however, many wouldn't change any aspect of their treatment or care.

References

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.

5. Australian Bureau of Statistics, 2016, Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2016, 'Postal Area, Indexes, SEIFA 2016 ', data cube: Excel spreadsheet, cat. no. 2033.0.55.001, viewed 24 October 2019, https://www.abs.gov.au/AUSSTATS.

6. Australian Bureau of Statistics. (2020). National, state and territory population, June, 2020. Retrieved March 4, 2021, from https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/jun-2020.

7. Tjokrowijoto P, Stolwyk RJ, Ung D, et al. Factors associated with mental health service access among Australian community-dwelling survivors of stroke. *Disabil Rehabil* 2023; **45**(3): 504-11.

8. Thayabaranathan T, Andrew NE, Kilkenny MF, et al. Factors influencing self-reported anxiety or depression following stroke or TIA using linked registry and hospital data. *Qual Life Res* 2018; **27**(12): 3145-55.

9. Waller A, Fakes K, Carey M, et al. Quality of life and mood disorders of mild to moderate stroke survivors in the early post-hospital discharge phase: a cross-sectional survey study. *BMC Psychol* 2023; **11**(1): 32.

10. Kadhim K, Middeldorp ME, Elliott AD, et al. Self-Reported Daytime Sleepiness and Sleep-Disordered Breathing in Patients With Atrial Fibrillation: SNOozE-AF. *Can J Cardiol* 2019; **35**(11): 1457-64.

11. Australian Bureau of Statistics 2017-18 National Health Survey (NHS). Accessed from https://www.abs.gov.au/statistics/health/health-conditions-and-risks/national-health-survey-first-results/latest-release.

12. 36-Item Short Form Survey (SF-36) Scoring Instructions. n.d. https://www.rand.org/health/surveys_tools/mos/36-item-short-form/scoring.html (accessed 10 February 2017.

13. Australian Bureau of Statistics 1995, National Health Survey: SF36 Population Norms, Australia, 1995. cat. no. 4399.0, ABS, Canberra.

14. Walters TE, Wick K, Tan G, et al. Symptom severity and quality of life in patients with atrial fibrillation: Psychological function outweighs clinical predictors. *Int J Cardiol* 2019; **279**: 84-9.

15. Minshall C, Ski CF, Apputhurai P, et al. Exploring the Impact of Illness Perceptions, Self-efficacy, Coping Strategies, and Psychological Distress on Quality of Life in a Post-stroke Cohort. *J Clin Psychol Med Settings* 2021; **28**(1): 174-80.

16. Phan HT, Gall SL, Blizzard CL, et al. Sex differences in quality of life after stroke were explained by patient factors, not clinical care: evidence from the Australian Stroke Clinical Registry. *Eur J Neurol* 2021; **28**(2): 469-78.

17. Thayabaranathan T, Baker C, Andrew NE, et al. Exploring dimensions of quality-of-life in survivors of stroke with communication disabilities - a brief report. *Top Stroke Rehabil* 2023; **30**(6): 603-9.

18. Sun YA, Phan H, Buscot MJ, Thrift AG, Gall S. Area-level and individual-level socio-economic differences in health-related quality of life trajectories: Results from a 10-year longitudinal stroke study. *J Stroke Cerebrovasc Dis* 2023; **32**(8): 107188.

19. Mosalski S, Shiner CT, Lannin NA, et al. Increased Relative Functional Gain and Improved Stroke Outcomes: A Linked Registry Study of the Impact of Rehabilitation. *J Stroke Cerebrovasc Dis* 2021; **30**(10): 106015.

20. Lewis SA, Noyes J, Mackereth S. Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review. *BMC Pediatr* 2010; **10**: 103.

21. Zahradnik A. Asthma education information source preferences and their relationship to asthma knowledge. *J Health Hum Serv Adm* 2011; **34**(3): 325-51.

22. Attfield SJ, Adams A, Blandford A. Patient information needs: pre- and post-consultation. *Health Informatics J* 2006; **12**(2): 165-77.

23. Schulz GB, Grimm T, Buchner A, et al. Benefits and Complications during the Stay at an Early Rehabilitation Facility after Radical Cystectomy and Orthotopic Ileum Neobladder Reconstruction. *Urol Int* 2019; **103**(3): 350-6.

24. Roddis JK, Holloway I, Bond C, Galvin KT. Living with a long-term condition: Understanding well-being for individuals with thrombophilia or asthma. *Int J Qual Stud Health Well-being* 2016; **11**: 31530.

25. Amoah D, Prior S, Mather C, Schmidt M, Bird ML. Exploring the Unmet Needs of Young Adults with Stroke in Australia: Can Technology Help Meet Their Needs? A Qualitative Study. *Int J Environ Res Public Health* 2023; **20**(15).

26. Geldens N, Crowfoot G, Sweetapple A, et al. Patient readiness for risk-reduction education and lifestyle change following transient ischemic attack. *Disabil Rehabil* 2021; **43**(3): 400-5.

27. Skoss R, Brett T, Bulsara C, et al. Participant experiences of intervention to detect and manage familial hypercholesterolaemia in Australian general practice: A qualitative descriptive study. *Aust J Gen Pract* 2022; **51**(9): 687-94.

28. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; **284**(19): 2476-82.

29. Barnes S, Gardiner C, Gott M, et al. Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *J Pain Symptom Manage* 2012; **44**(6): 866-79.

30. Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004; (2): CD003751.

31. Lamore K, Montalescot L, Untas A. Treatment decision-making in chronic diseases: What are the family members' roles, needs and attitudes? A systematic review. *Patient Educ Couns* 2017; **100**(12): 2172-81.

32. Griffin SJ, Kinmonth AL, Veltman MW, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. *Ann Fam Med* 2004; **2**(6): 595-608.

33. Wetzels R, Harmsen M, Van Weel C, Grol R, Wensing M. Interventions for improving older patients' involvement in primary care episodes. *Cochrane Database Syst Rev* 2007; (1): CD004273.

34. Walder K, Molineux M. Listening to the client voice - A constructivist grounded theory study of the experiences of client-centred practice after stroke. *Aust Occup Ther J* 2020; **67**(2): 100-9.

35. Yeates L, McDonald K, Burns C, Semsarian C, Carter S, Ingles J. Decision-making and experiences of preimplantation genetic diagnosis in inherited heart diseases: a qualitative study. *Eur J Hum Genet* 2022; **30**(2): 187-93.

36. Unsworth DJ, Mathias JL, Dorstyn DS, Koblar SA. Stroke survivor attitudes toward, and motivations for, considering experimental stem cell treatments. *Disabil Rehabil* 2020; **42**(8): 1122-30.

37. Kelly J, Dowling A, Hillier S, et al. Perspectives on rehabilitation for Aboriginal people with stroke: a qualitative study. *Top Stroke Rehabil* 2022; **29**(4): 295-309.

38. Chen L, Xiao LD, Chamberlain D. Exploring the shared experiences of people with stroke and caregivers in preparedness to manage post-discharge care: A hermeneutic study. *J Adv Nurs* 2022; **78**(9): 2983-99.

39. Weerasekara I, Baye J, Burke M, et al. What do stroke survivors' value about participating in research and what are the most important research problems related to stroke or transient ischemic attack (TIA)? A survey. *BMC Med Res Methodol* 2021; **21**(1): 209.

40. Kim C, Armstrong MJ, Berta WB, Gagliardi AR. How to identify, incorporate and report patient preferences in clinical guidelines: A scoping review. *Health Expect* 2020; **23**(5): 1028-36.

41. Cronin RM, Mayo-Gamble TL, Stimpson SJ, et al. Adapting medical guidelines to be patient-centered using a patient-driven process for individuals with sickle cell disease and their caregivers. *BMC Hematol* 2018; **18**: 12.

42. Sleath B, Carpenter DM, Slota C, et al. Communication during pediatric asthma visits and self-reported asthma medication adherence. *Pediatrics* 2012; **130**(4): 627-33.

43. Ross CK, Steward CA, Sinacore JM. The importance of patient preferences in the measurement of health care satisfaction. *Med Care* 1993; **31**(12): 1138-49.

44. Purcell S, Scott P, Gustafsson L, Molineux M. Stroke survivors' experiences of occupation in hospital-based stroke rehabilitation: a qualitative exploration. *Disabil Rehabil* 2020; **42**(13): 1880-5.

45. Chin LF, Rosbergen ICM, Hayward KS, Brauer SG. A self-directed upper limb program during early post-stroke rehabilitation: A qualitative study of the perspective of nurses, therapists and stroke survivors. *PLoS One* 2022; **17**(2): e0263413.

46. Janssen H, Bird ML, Luker J, et al. Stroke survivors' perceptions of the factors that influence engagement in activity outside dedicated therapy sessions in a rehabilitation unit: A qualitative study. *Clin Rehabil* 2022; **36**(6): 822-30.

47. Dalli LL, Andrew NE, Kim J, et al. Understanding of medications and associations with adherence, unmet needs, and perceived control of

risk factors at two years post-stroke. *Res Social Adm Pharm* 2022; **18**(9): 3542-9.

48.	Pacleb A, Lowres N, Randall S, Neubeck L, Gallagher R. Adherence to Cardiac Medications in Patients With Atrial Fibrillation: A Pilot Study. *Heart Lung Circ* 2020; **29**(7): e131-e9.

49.	Levy T, L JC, Killington M, Laver K, Crotty M, Lannin NA. "Just that four letter word, hope": stroke survivors' perspectives of participation in an intensive upper limb exercise program; a qualitative exploration. *Physiother Theory Pract* 2022; **38**(11): 1624-38.

50.	In: Adams K, Greiner AC, Corrigan JM, eds. The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities. Washington (DC); 2004.

51.	Grande SW, Faber MJ, Durand MA, Thompson R, Elwyn G. A classification model of patient engagement methods and assessment of their feasibility in real-world settings. *Patient Educ Couns* 2014; **95**(2): 281-7.

52.	Taylor SJC, Pinnock H, Epiphaniou E, et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS - Practical systematic Review of Self-Management Support for long-term conditions. Southampton (UK); 2014.

53.	Finch E, Minchell E, Cameron A, et al. What do stroke survivors want in stroke education and information provision in Australia? *Health Soc Care Community* 2022; **30**(6): e4864-e72.

54.	Ferguson C, Hickman LD, Lombardo L, et al. Educational Needs of People Living with Atrial Fibrillation: A Qualitative Study. *J Am Heart Assoc* 2022; **11**(15): e025293.

55.	Murphy BM, Rogerson MC, Hesselson S, Iismaa SE, Graham RM, Jackson AC. Psychosocial impacts of spontaneous coronary artery dissection: A qualitative study. *PLoS One* 2022; **17**(9): e0273978.

56.	Finch E, Foster M, Fleming J. Disrupted biographies: making sense of minor stroke after hospital discharge. *Disabil Rehabil* 2021; **43**(18): 2632-9.

57.	Pelly M, Fatehi F, Liew D, Verdejo-Garcia A. Artificial intelligence for secondary prevention of myocardial infarction: A qualitative study of patient and health professional perspectives. *Int J Med Inform* 2023; **173**: 105041.

58.	Shipley J, Luker J, Thijs V, Bernhardt J. The personal and social experiences of community-dwelling younger adults after stroke in Australia: a qualitative interview study. *BMJ Open* 2018; **8**(12): e023525.

59.	Shipley J, Luker J, Thijs V, Bernhardt J. How can stroke care be improved for younger service users? A qualitative study on the unmet needs of younger adults in inpatient and outpatient stroke care in Australia. *Disabil Rehabil* 2020; **42**(12): 1697-704.

60.	Petkov J, Harvey P, Battersby M. The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Qual Life Res* 2010; **19**(7): 1079-85.

61.	Williams S, Weinman J, Dale J. Doctor-patient communication and patient satisfaction: a review. *Fam Pract* 1998; **15**(5): 480-92.

62.	Stewart M, Brown JB, Boon H, Galajda J, Meredith L, Sangster M. Evidence on patient-doctor communication. *Cancer Prev Control* 1999; **3**(1): 25-30.

63.	Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract* 2000; **49**(9): 796-804.

64.	Glasgow RE, Davis CL, Funnell MM, Beck A. Implementing practical interventions to support chronic illness self-management. *Jt Comm J Qual Saf* 2003; **29**(11): 563-74.

65.	Makoul G. Essential elements of communication in medical encounters: the Kalamazoo consensus statement. *Acad Med* 2001; **76**(4): 390-3.

66.	Young JM, Walsh J, Butow PN, Solomon MJ, Shaw J. Measuring cancer care coordination: development and validation of a questionnaire for patients. *BMC Cancer* 2011; **11**: 298.

67.	Farias AJ, Ornelas IJ, Hohl SD, et al. Exploring the role of physician communication about adjuvant endocrine therapy among breast cancer patients on active treatment: a qualitative analysis. *Support Care Cancer* 2017; **25**(1): 75-83.

68.	Salgado TM, Quinn CS, Krumbach EK, et al. Reporting of paclitaxel-induced peripheral neuropathy symptoms to clinicians among women with breast cancer: a qualitative study. *Support Care Cancer* 2020; **28**(9): 4163-72.

69.	Cheng BBY, Ryan BJ, Copland DA, Wallace SJ. Prognostication in post-stroke aphasia: Perspectives of people with aphasia on receiving information about recovery. *Neuropsychol Rehabil* 2023; **33**(5): 871-902.

70.	D'Souza S, Godecke E, Ciccone N, Hersh D, Janssen H, Armstrong E. Hospital staff, volunteers' and patients' perceptions of barriers and facilitators to communication following stroke in an acute and a rehabilitation private hospital ward: a qualitative description study. *BMJ Open* 2021; **11**(5): e043897.

71.	Keating J, Borschmann K, Johns H, Churilov L, Bernhardt J. Young Stroke Survivors' Preferred Methods of Meeting Their Unique Needs: Shaping Better Care. *Neurology* 2021; **96**(13): e1701-e10.

72.	Jackson SM, Solomon SD, Barker RN. Recovering is about living my life, as it evolves:

perspectives of stroke survivors in remote northwest Queensland. *Disabil Rehabil* 2022; **44**(15): 3843-52.

73. Finch E, Foster M, Fleming J, et al. Exploring changing needs following minor stroke. *Health Soc Care Community* 2020; **28**(2): 347-56.

74. Sapuppo D, Bernhardt J, Carvalho LB, Churilov L, Thijs V. Self-evaluation of personal needs by community-living young stroke survivors using an online English language questionnaire. *Disabil Rehabil* 2023; **45**(11): 1830-5.

75. DeJean D, Giacomini M, Vanstone M, Brundisini F. Patient experiences of depression and anxiety with chronic disease: a systematic review and qualitative meta-synthesis. *Ont Health Technol Assess Ser* 2013; **13**(16): 1-33.

76. Hinz A, Mehnert A, Ernst J, Herschbach P, Schulte T. Fear of progression in patients 6 months after cancer rehabilitation-a- validation study of the fear of progression questionnaire FoP-Q-12. *Support Care Cancer* 2015; **23**(6): 1579-87.

77. Espernberger K, Fini NA, Peiris CL. Identity, social engagement and community participation impact physical activity levels of stroke survivors: A mixed-methods study. *Clin Rehabil* 2023; **37**(6): 836-50.

78. Hodson T, Gustafsson L, Cornwell P. Unveiling the complexities of mild stroke: An interpretative phenomenological analysis of the mild stroke experience. *Aust Occup Ther J* 2019; **66**(5): 656-64.