Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (25.53%), will include having choice including availability, accessibility, transparency and discussions in relation to treatment options (21.28%), and will be more effective, targeted, or personalised (17.02%). Other themes included have fewer or less intense side effects and more discussion about side effects (12.77%), involve a more holistic approach (10.64%), more access to rehabilitation (10.64%), involve more clinical trials, including to access new technologies and treatments and funding (8.51%), and will manage symptoms and prevention of disability (8.51%). There were 6 participants (12.77%) that were satisfied with experience.

Expectations of future information

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (29.79%) and will allow people more time to meet with their clinician (17.02 %). Other themes included that communication will be more transparent and forthcoming (14.89%), will be more understandable (14.89%), will include a multidisciplinary and coordinated approach (10.64%), will include listening to the patient (8.51%), and will be more holistic, including emotional health (8.51%). There were 15 participants (31.91%) who were satisfied with the communication they had.

Expectations of future care and support

Participants 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. The most common expectation for future care and support was that care and support will include being able to connect with other patients through peer support (17.02%), will include a multidisciplinary and coordinated approach (17.02%), and will include practical support for example home care, transport, and financial support (12.77%). Other themes included future care and support will include more long-term condition management (10.64%), will include specialist clinics or services where they can talk to professionals, in person, by phone or online) (10.64%), will be more holistic, including emotional health (10.64%), and include more access to support services (8.51%). There were 4 participants (8.51%) who were satisfied with the care and support received (8.51%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff, including access to specialists (42.55%), low cost or free medical care through the government (27.66%), and the entire health system (19.15%). Other themes included access to private healthcare or private health insurance (12.77%), and timely access to diagnostics (6.38%).

Values in making decisions

The most important aspects were How safe the medication is and weighing up the risks and benefits, and The severity of the side effects. The least important were Ability to follow and stick to a treatment regime and The ability to include my family in making treatment decisions.

Values for decision makers

The most important values were "Quality of life for patients", and "All patients being able to access all available treatments and services". The least important was "Economic value to government and tax payers".

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n = 32, 64.00%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There was 1 participant (2.00%) that thought that medicine delivered by IV was most effective, 22 participants (44.00%) thought that pill form was most effective, and 11 participants (22%) that thought they were equally effective. There were 16 participants (32.00%) that were not sure.

Messages 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 to the health minister 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%). Other themes included to improve rural services (19.15%), to invest in prevention (19.15%), to increase investment in general (17.02%), to help raise community awareness (14.89%), to invest in health professionals to service the patient population (14.89%), and to have a holistic approach to the condition that includes emotional support (10.64%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (25.53%), will include having choice including availability, accessibility, transparency and discussions in relation to treatment options (21.28%), and will be more effective, targeted, or personalised (17.02 %). Other themes included have fewer or less intense side effects and more discussion about side effects (12.77%), involve a more holistic approach (10.64%), more access to rehabilitation (10.64%), involve more clinical trials, including to access new technologies and treatments and funding (8.51%), and will manage symptoms and prevention of disability (8.51%). There were 6 participants (12.77%) that were satisfied with experience.

Future treatment will be more affordable

Cost, but I don't really know because I've never technically been on any proper treatments. Participant 007_2023AUHBV

The main thing I would say for me is cost. So any of the treatments that I've had haven't caused the any major side effects. Yeah, one once, you know, my system got used to it. Participant 015_2023AUHBV

They definitely need to be covered by the government cost-wise. Because when I think of stroke, I think diabetes is often involved normally. If you think about someone's diabetic and they've had a stroke, they will have insulin costs, they may have sensors. They'll have additional costs that go along with their diabetes alone. If they're on a pension, they've had a stroke, they've got diabetes, chances are they've had high blood pressure. Numerous things are going to add up to lots of pennies, lots of dollars. I know we're very lucky to live where we live. Participant 050_2023AUHBV

Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)

I think providing equal access to treatments for everybody and having good, good value. In the medications too, because that's quite an issue, like some medications are quite restricted. So you've got to meet a certain criteria to be able to even get on get a medication that might work. So that could be a bit frustrating for people. So I think those sort of things are really important to be able to, to achieve equality I guess.

Participant 011_2023AUHBV

So I think the first thing that comes to mind is cost, although it doesn't have the same effect on me as it does someone else. Like it's it is a burden. If I didn't have that burden, that'd be fantastic. And I imagine it'd be even more better. It would be even more amazing. But other people didn't have to deal with it. So I think, I think cost is like probably the biggest and availability actually growing, growing up in a country, semi country, semi rural town is the availability of not having to travel 3 1/2 hours to get, you know, just to see a cardiologist or whatever would be fantastic. If you could just do it from the hospital that was literally 250 metres from my house, that would be fantastic. But that wasn't available. So you would travel, but if that was a different option, that would be great. Didn't have to miss days of school, which sometimes you wanted to as a kid, but you know whatever. And mom and dad didn't have to take days off work to take us to these appointments. That'd be that'd be fantastic. Participant 012_2023AUHBV

I think cost and accessibility to the treatments. Yes, accessibility and cost. The side effects, to me they're secondary. The cost and accessibility would be the major things I would like to see happen across the board, in the country and in the cities, even throughout the world, the states. Participant 049_2023AUHBV

Future treatment will be more effective and/or targeted (personalised)

I think for me. So I I think a little bit of differentiated sort of care like as far as treatments go, your condition whilst maybe heart related is not the same as your condition and care more care and treatment more specific to the heart condition in my sense relative to me not an overall this is how we treat heart patients plan. I think, I think that you know, being more aligned to me and and what happened to my heart would would be a better approach. It's same with the cardiac rehab, you know, being more more specific to my treatment plan.

Participant 009_2023AUHBV

PARTICIPANT: So something that applies to my situation, not just that stereotypical Change your diet. Stop eating McDonald's. INTERVIEWER:You know, something applicable, yes. So something's effective for you.

PARTICIPANT: Yeah, yeah.

INTERVIEWER:Anything else you'd like to see from your treatments? PARTICIPANT: That's, that's first and foremost. Participant 020 2023AUHBV

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Future treatments will have fewer or less intense side effects/more discussion about side effects

I think all, all, all drugs have have side effects but I think the if they can minimize them as much as possible and that that can be a continual ongoing process. You know it's not just the right, this is a drug, it works, but these are the side effects and not look at it anymore just continually looking at how they they can lessen the the side effects of of drugs. So that's the main thing. And then I think making the treatment as easy as possible. So for example, you're not having to go for regular hospital appointments or things like that. Things can be done within your daily routine at home.

Participant 017_2023AUHBV

Fracture-proof leads, for devices. Something to improve lead fractures. What else would I like? Yeah, less lethargy related to the medication. That would just be fantastic. Or side effects, you know, less of the side effect profile for the medications. What else would I like? A treatment that would fix my arrhythmias, so that my condition would not be there anymore. And I know that they're working towards all of that continually, so that might be something that comes along, which would be an amazing blessing. Participant 030_2023AUHBV

Satisfied with experience

Look, no, no, I've. I've had a pretty fair run with it. So I I've got no issues. Yeah, right. So it's pretty, pretty clear, you know, the people, everyone tries their best. Participant 004_2023AUHBV

I don't know, I'm quite happy, yeah with what my situation, I suppose. I've never really thought about it. This is working for me. Participant 016_2023AUHBV

No, I don't. I think I believe like my care was perfectly good and perfectly fine. I probably wouldn't have me

personally. I wouldn't want to change anything to do with my care, as yeah, it was pretty easy to just follow, follow with and cooperate with to get myself better. So I don't, yeah. I personally believed I would change anything.

Participant 029_2023AUHBV

Future treatment will involve a more holistic approach

From my own point of view, there's probably nothing, but I'm quite sure there are people who aren't in my situation that would need that ongoing rehabilitation if they weren't able to be proactive for themselves, that ongoing rehab services, which is you that you know that emotional and and also you know physical things that you need to do. I think that would probably be a benefit to a lot of people. And I mean it was, it was, it was truly the best thing that could happen to me after. Like to manage my condition after that and to have it ongoing, to have it not just finish after a fixed period of time and for that to be ongoing for people, I think that would be an absolute bonus. Participant 013_2023AUHBV

I would like to see medication be cheaper. We travelled over an airline to be able to go to a different chemist to get to a big brand name chemist to get our medications cheaper because our local chemists are extremely expensive. I feel that support groups and more information would be very beneficial to people having strokes.

Participant 047_2023AUHBV

Future treatments will include more access to rehabilitation

Yeah. Up here I would like to have more support with heart failure staff as far as doing rehab. Participant 033_2023AUHBV

I think rehab needs to be more realistic when they try and help people back into the community, because it's more clinical. Participant 044_2023AUHBV

My only concern is the length of rehabilitation. I had three months of rehab. It's not long enough. You do your three months then you're on your own. I've spoken to the Stroke Foundation and I've spoken to seminars of medical practitioners where I've suggested that follow-up rehab. You do your treatments at rehab and that's it. If there could be a six-monthly or 12-monthly follow-up. That doesn't

happen right now, but I truly believe that that would make the stroke recovery journey a lot better. Participant 045_2023AUHBV

Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)

I mean, I guess, medications with less side effects. In LOCATION METROPOLITAN, there was a pacemaker that I could use. The trend is they are getting smaller and smaller. Participant 023_2023AUHBV

New treatment? Smaller implants. I know there is a small implant now, but I'm not sure how good that is, how effective it is, how long it'll last, all of that. I need to have a valve replaced, and I know you can do that without major surgery, so I'm happy with the progress that medicine is taking. Maybe one day they will grow a heart out of your own genes. Participant 034_2023AUHBV

I'd probably wonder what causes it. I mean I could look it up, I guess, what causes it, and what I should be doing that I'm not doing to live longer and if there's

any new drugs, like my mother took out something, so is there anything better than that? It seems to be working. I'm not having palpitations. I'm not having any chest pain. I'm not having any symptoms at all. Participant 037_2023AUHBV

Future treatments will include managing symptoms and prevention of disability

PARTICIPANT: Yeah. Well, obviously you want more treatments, so that would be good, if there were more treatments to manage symptoms, and reduced symptoms could increase my heart function, so that would be good. So that's what I can say for myself, and I can be more proactive about it too, I just don't -- I just sort of haven't.... Participant 032_2023AUHBV

I think there's a lot of work being done on research to provide treatment to disability. That would be the best thing I'd like to see. I'd like to see whether they can get an injection that will stop our disability. As an example, the way I talk to you, my vulnerability. Those are the two things that concern me the most. Participant 040_2023AUHBV

Expectations of future treatments			Had LP	r(a) test	LP(a) test				Blood vessel conditions			Heart conditions		0 to 5 other conditions		L other itions
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Future treatment will be more affordable	12	25.53	5	27.78	7	24.14	2	22.22	7	41.18	3	14.29	5	18.52	7	35.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	10	21.28	1	5.56	9	31.03	2	22.22	2	11.76	6	28.57	3	11.11	7	35.00
Future treatment will be more effective and/or targeted (personalised)	8	17.02	1	5.56	7	24.14	2	22.22	3	17.65	3	14.29	5	18.52	3	15.00
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	12.77	3	16.67	3	10.34	2	22.22	1	5.88	3	14.29	3	11.11	3	15.00
No particular comment - satisfied with experience	6	12.77	3	16.67	3	10.34	1	11.11	1	5.88	4	19.05	3	11.11	3	15.00
Future treatment will involve a more holistic approach	5	10.64	0	0.00	5	17.24	0	0.00	3	17.65	2	9.52	3	11.11	2	10.00
Future treatments will include more access to rehabilitation	5	10.64	1	5.56	4	13.79	0	0.00	3	17.65	2	9.52	3	11.11	2	10.00
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	4	8.51	1	5.56	3	10.34	0	0.00	0	0.00	4	19.05	3	11.11	1	5.00
Future treatments will include managing symptoms and prevention of disability	4	8.51	2	11.11	2	6.90	1	11.11	2	11.76	1	4.76	3	11.11	1	5.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	1	3.70	2	10.00

Expectations of future treatments	All part	icipants	Fen	nale	М	ale	Aged 2	5 to 44	Aged 45 and older		Regional or remote		Metro	Metropolitan		Mid to low socioeconomi c status		her onomic tus
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Future treatment will be more affordable	12	25.53	7	26.92	5	23.81	6	25.00	6	26.09	6	40.00	6	18.75	7	28.00	5	22.73
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	10	21.28	6	23.08	4	19.05	5	20.83	5	21.74	4	26.67	6	18.75	5	20.00	5	22.73
Future treatment will be more effective and/or targeted (personalised)	8	17.02	6	23.08	2	9.52	3	12.50	5	21.74	4	26.67	4	12.50	6	24.00	2	9.09
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	1	6.67	5	15.63	2	8.00	4	18.18
No particular comment - satisfied with experience	6	12.77	4	15.38	2	9.52	2	8.33	4	17.39	0	0.00	6	18.75	3	12.00	3	13.64
Future treatment will involve a more holistic approach	5	10.64	4	15.38	1	4.76	1	4.17	4	17.39	2	13.33	3	9.38	2	8.00	3	13.64
Future treatments will include more access to rehabilitation	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	3	20.00	2	6.25	3	12.00	2	9.09
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	1	6.67	3	9.38	1	4.00	3	13.64
Future treatments will include managing symptoms and prevention of disability	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	1	6.67	3	9.38	2	8.00	2	9.09
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	6.38	3	11.54	0	0.00	3	12.50	0	0.00	0	0.00	3	9.38	1	4.00	2	9.09

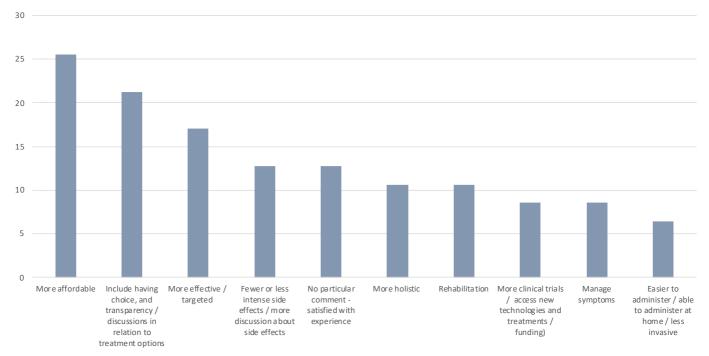


Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment - subgroup variations

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Expectations of future treatments	Reported less frequently	Reported more frequently
Future treatment will be more affordable	Heart conditions	Blood vessel conditions Regional or remote
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	Had LP(a) test 0 to 5 other conditions	6 to 11 other conditions
Future treatment will be more effective and/or targeted (personalised)	Had LP(a) test	-
No particular comment - satisfied with experience	Regional or remote	-
Future treatment will involve a more holistic approach	Had LP(a) test High cholesterol under 50 years of age	-
Future treatments will include more access to rehabilitation	High cholesterol under 50 years of age	-
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	-	Heart conditions

Expectations of future information

Participants 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. The most common response was they were satisfied with the information they received (21.28%). The most common themes in relation to what they would like to see in the future were that information will be in a variety of formats (17.02%), and that information will provide more details about disease trajectory and what to expect (17.02%). Other themes included that information will be easier to understand (14.89%), will be more holistic, including emotional health (12.77%), will be more accessible/easy to find (10.64%), will include the ability to talk to or access to a health professional (8.51%), will provide more details about the causes of their condition (8.51%), and will provide more details about where to find support including peer support (6.38%).

Satisfied with experience

PARTICIPANT: It's another hard one to answer because it's sort of didn't and doesn't really affect me...If I wanted to know something, I just have to ask Participant 005_2023AUHBV

No, no, no. I get. I get as much information as required through a product professor of cardiology. Participant 006_2023AUHBV

No, I think it was pretty good, actually. Like, yeah, they were pretty. They were pretty good with communication information. They were pretty good with keeping my mom in the loop as well, making her aware of they'd give her phone calls when I was there, making her aware of my test results, etcetera. So no, Yeah. Would say that they were pretty good with it all, so.

Participant 029_2023AUHBV

Nothing comes to mind. Yeah, I don't feel like there was ever anything that I couldn't get information on. Yeah.

Participant 035_2023AUHBV

Future information will be in a variety of formats

Yeah, probably what I just mentioned. So maybe a list of the top suggested. OK. Yeah, natural supports and maybe a written form, so like a pamphlet would be great, excellent. Participant 019 2023AUHBV

I think a lot of it was all reading for me. I'm very visual, so for me I would have liked to have had some illustrations that kind of point to like I know the main heart and the main I guess arteries and all that sort of stuff. But I wasn't quite able to work out which branch or which artery is where my issue is and but if I could visualize it, it would make it a lot easier for me. Participant 021_2023AUHBV

Future information will provide more details about disease trajectory and what to expect

Just simple things like, is it fixable or is a lifelong illness we have to control? Stuff like that. It's that simple. Yeah, 'cause it's like...Well, maybe it's just my thought, "Tablets and whatever and then it all fixes up." And then in LOCATION they said, "You've got that for life. That's just part of you now." Participant 038_2023AUHBV If you have a stroke at a young age and years like mine have gone by, my body is now getting-- I'm probably going backwards and not forward, information about being aware of your body will break down probably earlier than it would naturally. To have ongoing treatment every two or three years, that sort of information is not there, you have to go and find that, whether it's normal or not. I found that when I was feeling things happening in my stroke hand, affected hand, that I didn't know whether I could access services or what to do about it, whether it was normal that my hand was doing what it was doing. That thing, that what happens, having a stroke at a young age, what's your long-term effects and conditions. If that makes sense.

Participant 049_2023AUHBV

Future information will be easier to understand

Obviously, you know a lot of people learn better from reading and so forth. You know, that's not to say that I don't learn from reading or research, but I do learn better from, you know, that one-on-one environment or that environment where you're able to freely ask a question and you actually get a presented answer in an understandable format. But then that's, you know, I suppose that that comes into the ability of communication and, you know, people's comprehension of things. Participant 018_2023AUHBV

Table 9.3: Expectations of future information

Expectations of future information			Had LP(a) test Did not H LP(a) te			High cholesterol under 50 years of age		Blood vessel conditions			art itions	0 to 5 other conditions			1 other itions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
No particular comment - satisfied with experience	10	21.28	5	27.78	5	17.24	0	0.00	5	29.41	5	23.81	8	29.63	2	10.00
Future information will be in a variety of formats	8	17.02	4	22.22	4	13.79	3	33.33	2	11.76	3	14.29	5	18.52	3	15.00
Future information will provide more details about disease trajectory and what to expect	8	17.02	1	5.56	7	24.14	1	11.11	3	17.65	4	19.05	3	11.11	5	25.00
Future information will be easier to understand	7	14.89	3	16.67	4	13.79	2	22.22	1	5.88	4	19.05	4	14.81	3	15.00
Future information will be more holistic (including emotional health)	6	12.77	2	11.11	4	13.79	1	11.11	4	23.53	1	4.76	3	11.11	3	15.00
Future information will be more accessible/easy to find	5	10.64	3	16.67	2	6.90	2	22.22	2	11.76	1	4.76	3	11.11	2	10.00
Future information will include the ability to talk to/access to a health professional	4	8.51	1	5.56	3	10.34	0	0.00	0	0.00	4	19.05	3	11.11	1	5.00
Future information will provide more details about the causes of their condition	4	8.51	0	0.00	4	13.79	1	11.11	1	5.88	2	9.52	2	7.41	2	10.00
Future information will provide more details about where to find support (including peer support/support groups)	3	6.38	1	5.56	2	6.90	1	11.11	2	11.76	0	0.00	1	3.70	2	10.00
Future information will provide more details on subgroups and specific classifications of their condition	3	6.38	0	0.00	3	10.34	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00
Future information will provide more details to support carers	3	6.38	0	0.00	3	10.34	0	0.00	2	11.76	1	4.76	3	11.11	0	0.00

Expectations of future information	All part	icipants	Fer	nale	М	ale	Aged 2	5 to 44	44 Aged 45 and older		older		older		Regional or remote				Mid to low socioeconomi c status		socioec	gher conomic atus
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%				
No particular comment - satisfied with experience	10	21.28	6	23.08	4	19.05	6	25.00	4	17.39	5	33.33	5	15.63	6	24.00	4	18.18				
Future information will be in a variety of formats	8	17.02	4	15.38	4	19.05	7	29.17	1	4.35	4	26.67	4	12.50	7	28.00	1	4.55				
Future information will provide more details about disease trajectory and what to expect	8	17.02	5	19.23	3	14.29	4	16.67	4	17.39	1	6.67	7	21.88	4	16.00	4	18.18				
Future information will be easier to understand	7	14.89	4	15.38	3	14.29	7	29.17	0	0.00	3	20.00	4	12.50	5	20.00	2	9.09				
Future information will be more holistic (including emotional health)	6	12.77	4	15.38	2	9.52	0	0.00	6	26.09	2	13.33	4	12.50	4	16.00	2	9.09				
Future information will be more accessible/easy to find	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	0	0.00	5	15.63	0	0.00	5	22.73				
Future information will include the ability to talk to/access to a health professional	4	8.51	1	3.85	3	14.29	1	4.17	3	13.04	1	6.67	3	9.38	2	8.00	2	9.09				
Future information will provide more details about the causes of their condition	4	8.51	3	11.54	1	4.76	2	8.33	2	8.70	2	13.33	2	6.25	2	8.00	2	9.09				
Future information will provide more details about where to find support (including peer support/support groups)	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55				
Future information will provide more details on subgroups and specific classifications of their condition	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	1	6.67	2	6.25	0	0.00	3	13.64				
Future information will provide more details to support carers	3	6.38	1	3.85	2	9.52	0	0.00	3	13.04	1	6.67	2	6.25	1	4.00	2	9.09				

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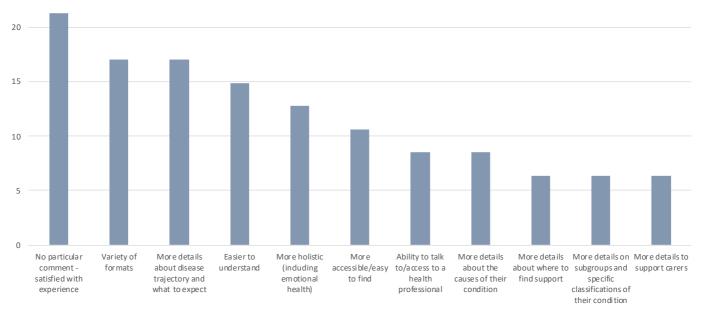


Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information - subgroup variations

Expectations of future information	Reported less frequently	Reported more frequently
No particular comment - satisfied with experience	High cholesterol under 50 years of age 6 to 11 other conditions	Regional or remote
Future information will be in a variety of formats	Aged 45 and older Higher socioeconomic status	High cholesterol under 50 years of age Aged 25 to 44 Mid to low socioeconomic status
Future information will provide more details about disease trajectory and what to expect	Had LP(a) test Regional or remote	•
Future information will be easier to understand	Aged 45 and older	Aged 25 to 44
Future information will be more holistic (including emotional health)	Aged 25 to 44	Blood vessel conditions Aged 45 and older
Future information will be more accessible/easy to find	Regional or remote Mid to low socioeconomic status	High cholesterol under 50 years of age Higher socioeconomic status
Future information will include the ability to talk to/access to a health professional	-	Heart conditions

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (29.79%) and will allow people more time to meet with their clinician (17.02 %). Other themes included that communication will be more transparent and forthcoming (14.89%), will be more understandable (14.89%), will include a multidisciplinary and coordinated approach (10.64%), will include listening to the patient (8.51%), and will be more holistic, including emotional health (8.51%). There were 15 participants (31.91%) who were satisfied with the communication they had.

Satisfied with experience

No, because they're most that I've spoken to, all of them I spoke to have been pretty open and straightforward about it. You know, if you deal with people squarely, they deal with it squarely. Participant 004_2023AUHBV

No. I think once I was diagnosed, it's all been very straightforward. Participant 014_2023AUHBV

Not my doctors, no, no. I think they're doing a great job. Yeah. Participant 025_2023AUHBV

No, not really. I've had a good relationship with all the health professionals who I know with. Participant 040_2023AUHBV

No. Look, I don't think so. As I said before, I've been fairly lucky I guess. Both my neurologists have been pretty good. No, I don't think so. Participant 043_2023AUHBV

Future communication will be more empathetic

Oh gosh, maybe some more empathy and empathy. Participant 003_2023AUHBV

Just talk to patients. Treat them like they are a human being, not just a sample in a room. Participant 038_2023AUHBV

Yes. In my communication with health professionals, my communication with rehabilitation people was perfect. My communication with doctors was less than perfect. The distinct lack of empathy, that when you're a stroke survivor, you need that empathy and I found my interaction with doctors lacked that empathy.

Participant 045_2023AUHBV

Future communication will allow people more time to meet with their clinician

I think in in general I would like to see put put in in into their routine opportunity for them to spend the time to do that, to spend time talking to somebody about a condition, talk to somebody about where to go for information or if not have somebody that they can refer you to that can do that. I think that's that is the thing that overall in in in health service and and other services is that there is isn't enough time and resources given to doing the sort of preventative. And I think that it's someone like me who isn't a dangerous level could get more information and do more preventative work. Know that they're on the right lines with their diet. Know that they're on the right lines with their exercise and their lifestyle changes and then less likely to have a heart attack and the cost and the the effort that that will cause in the long term. Participant 017_2023AUHBV

I suppose that's more from the GPs, but a lot of it as an age and a personality-type issue. There's two different styles. But, I mean, I think it is important that there is a focus on that sort of communication and some time available that it is a proper consultation and just in and out. Yeah. Participant 023 2023AUHBV

I think the main thing I see when I go to the doctor's is the massive amount of people for the short period of time. Especially at the specialist. The GP takes his time with you. You never feel rushed. At the specialist, I went to the eye specialist recently. It cost me hundreds of dollars and you wait hours for a 7 AM appointment. Then you work out that there's five 7 AM appointments and whoever arrives first gets seen first. I think health professionals need to take a step back and say we need to give quality time to each person and not book so many people because it's impossible to give quality time to people when you say, push the time yourself. Participant 037_2023AUHBV

Future communication will be more transparent and forthcoming

We have touched on that one before with the cardiologist, but yeah, anything, anything else, just that they that they do communicate really well because I think sometimes they know in their own minds what the plan forward is or what the reasons are for doing certain things. But they don't necessarily feel the need to communicate that to the patient. You just sort of expected to go there and do what you're told, which I find difficult because I do need to. I need to understand why I'm doing what I'm doing. Participant 019_2023AUHBV

Yes. I'd like to feel like I was a person not a condition. I feel they're more interested in the condition than me. It's not all of them but most of them. I'd like them to be able to tell me-- Give me the information rather than we have to ask for it. Participant 041_2023AUHBV

Future communication will be more understandable

PARTICIPANT: I would like to see for other people, the medical professionals to be honest. INTERVIEWER: Yes, honesty is very important, I agree. PARTICIPANT: Yes, explain the medications or the treatments in a clear manner, no jargon talk. Straight points, don't do jargon. [laughs] Participant 049 2023AUHBV

Future communication will include a multidisciplinary and coordinated approach

I think talking layman's terms, you know, and explain the next step perhaps. But yeah, that's a hard one. I don't know.

Participant 009_2023AUHBV

I'd just like them 'to' communicate. I'd just like them to just give someone some information when they leave the hospital, or somewhere to go, or someone they can call, or something. Just nothing. Again, I have to say, I'm extremely lucky. I'm smart, well-educated, successful career, family support, all of that, and it was bloody hard, and not everyone has that. Participant 046_2023AUHBV

Future communication will include listening to the patient

Just the compassion side of things, I think like to know that someone's struggling so bad and they were in the beginning a little bit I. It wasn't until I had that second by the 1st ablation when he went in and said this is the worst case I've seen in a very long time. He was that that was the first time anyone that had, I felt like I'd been listened to properly. Do you know what I mean? Before that, it was like, I'll take this medicine, you'll be fine. It's like, no, you're not understanding. Yeah.

Participant 008_2023AUHBV

I wish they would listen to their patients. I really do. I'd love to help other people when they first have their stroke, what to expect, and be their support person, follow their journey with them. Participant 042_2023AUHBV

Future communication will be more holistic (including emotional health)

It would be really good for some kind of pre preparation program to have someone check in like the cardiac nurse check in and say how you're traveling, what are you worried about this week? So I'd like there to be more awareness of the emotional journey.

Participant 010_2023AUHBV

What I was going to say is just to make a few more be a bit more sort of for lack of a better word like make the disclaimer be like hey, I know what I know, but like a chronic condition, you know there there's no quick fix. And yes we can offer like we we or we may be able to offer a pharmacological treatment but it's not going to be the end all be all like really you you need the the crux of it like they really need to just sort of add in the holistic side on like especially for these chronic diseases and just be like hey yes you know the there we we the the drug or the pill could be like the ambulance at the bottom of cliff or whatever. But there is a whole lot more efficacy and value if you actually focus Mr. Mrs. Patient if you focus your energy and efforts on behavior change you'll just get a lot more mileage and investment in retu'n for your investment. If you Mr. Mrs. Patient focus on some of the self-care strategies and and holistic therapies. You know some of it's just behaviour change. Participant 001_2023AUHBV

Expectations of future communication	All part	All participants		P(a) test		ot had) test	High cholesterol under 50 years of age									
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
No particular comment - satisfied with experience	15	31.91	8	44.44	7	24.14	2	22.22	5	29.41	8	38.10	9	33.33	6	30.00
Future communication will be more empathetic	14	29.79	5	27.78	9	31.03	4	44.44	5	29.41	5	23.81	7	25.93	7	35.00
Future communication will allow people more time to meet with their clinician	8	17.02	3	16.67	5	17.24	1	11.11	2	11.76	5	23.81	4	14.81	4	20.00
Future communication will be more transparent and forthcoming	7	14.89	2	11.11	5	17.24	2	22.22	3	17.65	2	9.52	3	11.11	4	20.00
Future communication will be more understandable	7	14.89	2	11.11	5	17.24	0	0.00	3	17.65	4	19.05	4	14.81	3	15.00
Future communication will include a multidisciplinary and coordinated approach	5	10.64	2	11.11	3	10.34	2	22.22	0	0.00	3	14.29	1	3.70	4	20.00
Future communication will include listening to the patient	4	8.51	1	5.56	3	10.34	1	11.11	1	5.88	2	9.52	2	7.41	2	10.00
Future communication will be more holistic (including emotional health)	4	8.51	1	5.56	3	10.34	2	22.22	1	5.88	1	4.76	3	11.11	1	5.00
Future communication will include developing a care plan with follow-up	3	6.38	0	0.00	3	10.34	0	0.00	3	17.65	0	0.00	1	3.70	2	10.00

Table 9.5: Expectations of future healthcare professional communication

Expectations of future communication	All part	icipants	Fen	nale	M	ale	Aged 2	25 to 44	•	45 and der		nal or note	Metro	politan	socioe	o low conomi atus	Hig socioec sta	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
No particular comment - satisfied with experience	15	31.91	6	23.08	9	42.86	9	37.50	6	26.09	5	33.33	10	31.25	9	36.00	6	27.27
Future communication will be more empathetic	14	29.79	8	30.77	6	28.57	9	37.50	5	21.74	6	40.00	8	25.00	8	32.00	6	27.27
Future communication will allow people more time to meet with their clinician	8	17.02	5	19.23	3	14.29	3	12.50	5	21.74	2	13.33	6	18.75	4	16.00	4	18.18
Future communication will be more transparent and forthcoming	7	14.89	5	19.23	2	9.52	3	12.50	4	17.39	3	20.00	4	12.50	3	12.00	4	18.18
Future communication will be more understandable	7	14.89	5	19.23	2	9.52	4	16.67	3	13.04	4	26.67	3	9.38	6	24.00	1	4.55
Future communication will include a multidisciplinary and coordinated approach	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	0	0.00	5	15.63	1	4.00	4	18.18
Future communication will include listening to the patient	4	8.51	3	11.54	1	4.76	0	0.00	4	17.39	0	0.00	4	12.50	2	8.00	2	9.09
Future communication will be more holistic (including emotional health)	4	8.51	3	11.54	1	4.76	2	8.33	2	8.70	2	13.33	2	6.25	2	8.00	2	9.09
Future communication will include developing a care plan with follow-up	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	2	13.33	1	3.13	3	12.00	0	0.00

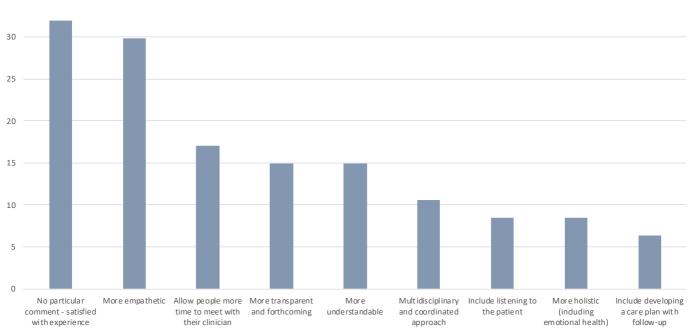


Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Expectations of future communication	Reported less frequently	Reported more frequently
No particular comment - satisfied with experience	-	Had LP(a) test Male
Future communication will be more empathetic	-	High cholesterol under 50 years of age Regional or remote
Future communication will be more understandable	High cholesterol under 50 years of age Higher socioeconomic status	Regional or remote
Future communication will include a multidisciplinary and coordinated approach	Blood vessel conditions Regional or remote	High cholesterol under 50 years of age
Future communication will be more holistic (including emotional health)	-	High cholesterol under 50 years of age
Future communication will include developing a care plan with follow-up	-	Blood vessel conditions

Expectations of future care and support

35

Participants 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. The most common expectation for future care and support was that care and support will include being able to connect with other patients through peer support (17.02%), will include a multidisciplinary and coordinated approach (17.02%), and will include practical support for example home care, transport, and financial support (12.77 %). Other themes included future care and support will include more long-term condition management (10.64%), will include specialist clinics or services where they can talk to professionals, in person, by phone or online) (10.64%), will be more holistic, including emotional health (10.64%), and include more access to support services (8.51%). There were 4 participants (8.51%) who were satisfied with the care and support received (8.51%). Future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I think again coming back to, if it's possible, a way for women with this kind of diagnosis to be able to connect. And I did find a Facebook group, but I found it quite late in my journey. By then I was pretty much well on my way to recovery. But it would've been nice to connect with people. So I'll just mention, the Facebook group, there's a lot of women on there that are suffering from PTSD and anxiety, so ' don't actually think that kind of environment is helpful to someone that's newly diagnosed. I feel like they feed on each other's anxiety a bit too much, so something that, you know, whether it was a charity or whoever put up the support, but maybe more people that have been through'similar les that are on the other side that can offer hope and support. Not make things worse. Yeah.

Participant 035_2023AUHBV

I'd like to see more information out there and more groups. There's no groups in LOCATION METROPOLITAN, LOCATION STATE. There's nothing whatsoever. There's absolutely nothing. Where I live now, there's nothing in my area. There's groups on the other side of the city, miles and miles, but since I had my stroke I can't drive anymore, and my wife doesn't drive as my carer. Yes, that's one thing that we've found. There's nothing whatsoever. Participant 042_2023AUHBV

I really would like to see more information and support groups for people of young stroke and community understanding of fatigue and hidden disability.

Participant 047_2023AUHBV

Future care and support will include a multidisciplinary and coordinated approach

I think they're out there. I just think that they're in cities and I find and I know I choose to live remote, but that's my big struggle. No physio here or exercise physiologist even knew what the acronym stood for, let alone were able to give me a treatment plan. So I don't know. I don't even know how you fix that. You can't have some specialist people in every small town. I know that. But. Yeah, yeah, it could be something that they look at, could look at telehealth wise, you know, making it more available, you know. Participant 014_2023AUHBV Yes, I think like the community health course that I went on. And it's easier cheaper access to people like dietitians, exercise physiologists because the one I go go to having said there's no out of pocket expenses, I I do pay to see her. So it's it's it's more more access to things like that. It can help you manage I prevention. Participant 017_2023AUHBV

Look, I think for me, I think the allied health sector is probably the key area that that I've learned to do with with heart conditions. You know, and it again it's it's accessibility to those programs, you know, where you're limited to how many sessions you get which which is understandable but you know, gaining ex access to, you know, like hydrotherapy and things like that. Like it seems like I was told that hydrotherapy would be a really good option for me. But where I am it was quite difficult and to the point where I wasn't even able to to secure that type of thing. So I was left with you know treadmills and cycling machines and things like that. So, you know, I would have preferred the water, but yeah. Participant 028_2023AUHBV

Future care and support will include practical support (home care, transport, financial)

Yes, for the people that had a stroke in the country and can't drive, there needs to be more support for that because we don't have public transport and we have very long distances to get to doctors. I can get taxi vouchers to go around my town but I can walk everywhere in my town. What I need is a taxi to get to LOCATION METROPOLITAN to the doctor. Participant 041 2023AUHBV

I'd like to see a service developed where people help you go back to living in your house and living independently in that first bit when you leave the hospital. Even just someone who's going to come over two days later to make sure that you've eaten some food or been able to do that sort of thing. That, I think would make a huge difference. Even just like providing food for someone for the next three or four days, while they work out what they're actually capable of in their own home.

Participant 046_2023AUHBV

Well, I live at LOCATION REGIONAL, up where the aerials are. It's a 40-minute drive to LOCATION METROPOLITAN for the treatment at the universities. I'm not allowed to drive. They want four-days notice to get me transported. Anglicare is handling that very well. They're the only ones who'll do it. There's been

no effort in trying to get me driving again. If I could drive, even if I could only go down and do my shopping or get to another thing or buy something at the shop, that's all I want to drive at. Participant 048_2023AUHBV

Future care and support will include more long-term condition management (care planning)

Future care and support. Again I direct this at my specific heart disease. I would like there to be a follow up with the specialist that has an interest in it. I feel like they need to be following up more with what my post-operative symptoms are now. I would like more studies done in this particular disease. I think that would be great. I think there's so much that's unknown about it. But, the average GP doesn't know about it. I'd like for them to know more about what we go through and what our symptoms are. And what's normal. And how our symptoms can change. It's a very, varying disease and that can change from one day to another, and then back again. That just seems to confuse everybody. That I suppose and for us to be able to be acknowledged that it is an illness that we deal with every day. I know that's a hard thing to change. There's a lot of other illnesses I get that. Participant 036_2023AUHBV

As I've already said, the ongoing catch-ups with stroke survivors. If somebody has a stroke, there's three months of rehab, then they're on their own. A 12monthly meeting between a stroke survivor and a stroke professional to help that person map out the next 12 months. That doesn't happen. There's that initial interaction with health professionals then it stops. There is nothing. There needs to be an ongoing interaction. It doesn't have to be long. Just long enough to establish the new goals, to evaluate how that person's traveling. One of the overwhelming aspects for a stroke survivor is loneliness because you survived, you didn't die and you've now got a condition. It could be a very lonely, lonely place to be. Participant 045 2023AUHBV

No. I think I would've liked to have more constant visits to the neurologist and more accessibility to physios, rejigging and reconnecting, and getting to know new treatments and things like that that weren't available when I was younger. I think that's what I would like to see happen. That's what I wanted to happen, I thought was going to happen to me, that I would have those connections ongoing throughout my life, but I haven't. Participant 049_2023AUHBV

Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

Well, at the risk of repeating myself, just being linked in with that heart failure nurse, so I have someone I could ask questions of without having to make an appointment to see the cardiologist. Participant 032 2023AUHBV

More verbal information out of them. So they can explain everything to you, more time with you, I suppose. Rather than being just a number, you're here for 10 minutes, or for 15 so be it, or 20 so be it. If you can explain it properly, then -- yeah. Participant 038 2023AUHBV

Future care and support will be more holistic (including emotional health)

That's a tricky one for me to answer because I had such a good family support, so I don't feel like I was lacking in that way. Yeah, but yeah, definitely. There's always the options of some charity support and keeping. Yeah, helping people with their mental health when they're going through things like that. Yeah, great, okay.

Participant 008_2023AUHBV

I think maybe like other than cardiology. For someone at my stage anyway, I think maybe support services is in specifically mental support services for that particular so for coronary artery disease or heart disease or any form of heart disease specifically and where you can link in with with other people in the community and be able to have a talk and I don't know anything around. My area at the moment or anyone that that does that and I haven't been told about anything like that but it certainly would be it would be beneficial.

Participant 011_2023AUHBV

Future care and support will include more access to support services

People with your condition too. Well yeah, I like my my other idea just to have a bit more of a. There might be some possibly some NGOs or disease sort of organizations out there, maybe the Australian Heart Association or whatever. But you know where they're. You have some offerings, you know in the community where either virtually or in person you can meet up with others. And then have a bit of an some educational sessions and explore some of the, you

know, some of the nuance and some of the yeah and some of the patient experiences. And just to hear from others and just to kind of chew some of that over and have some of those discussions, some robust discussions with other similar patients, yeah. Participant 001_2023AUHBV

He ended up in the hospital in March. He had an abscess on his appendix totally out of the blue. He ended up in the hospital for five days. It was like, "How am I going to manage?" I don't drive. How am I going to manage? What am I going to do? He was worried about it. He rang Carers LOCATION STATE, because he's registered with them. They didn't bother to ring him back. Participant 033 2023AUHBV

Satisfied with experience

Well, my observation is that I've been offered a lot of stuff. A lot of support. And I actually -- I'm a member of Heart Support Australia. We have monthly meetings, and we do exercise programmes. We do go and walk at a basketball stadium, because it's under cover and out of the sun. There's all that sort of support, and there's probably, I don't know, 10 of us, and we'll sit and chat and discuss our conditions sometimes, and fix all the problems of the world, but that's sort of as far as I go. I see my cardiologist, but it's really more about treatment and where are we going with things. But I don't do anything else. I don't access anything else.

Participant 031_2023AUHBV

Table 9.7: Expectations of future care and support

Expectations of future care and support		All part	icipants	5	Had L	P(a) test		ot had) test	under	olesterol 50 years age		vessel		eart litions		5 other ditions	6 to 1 cond	1 othe itions														
	n	=47		%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%														
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)		8		17.02						17.02				17.02						11.11	6	20.69	2	22.22	4	23.53	2	9.52	5	18.52	3	15.0
Future care and support will include a multidisciplinary and coordinated approach		8	17	7.02	4	22.22	4	13.79	3	33.33	1	5.88	4	19.05	3	11.11	5	25.0														
Future care and support will include practical support (home care, transport, financial)		6	12	2.77	1	5.56	5	17.24	0	0.00	4	23.53	2	9.52	3	11.11	3	15.0														
Future care and support will include more long-term condition management (care planning)		5	10	0.64	2	11.11	3	10.34	1	11.11	2	11.76	2	9.52	2	7.41	3	15.0														
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)		5	10	0.64	0	0.00	5	17.24	0	0.00	1	5.88	4	19.05	2	7.41	3	15.0														
Future care and support will be more holistic (including emotional health)		5	10	0.64	0	0.00	5	17.24	0	0.00	3	17.65	2	9.52	2	7.41	3	15.0														
Future care and support will include more access to support services		4	8	.51	3	16.67	1	3.45	1	11.11	0	0.00	3	14.29	3	11.11	1	5.00														
No particular comment - satisfied with experience		4	8	.51	2	11.11	2	6.90	0	0.00	2	11.76	2	9.52	3	11.11	1	5.00														
Future care and support will include health professionals with a better knowledge of the condition		3	6	.38	0	0.00	3	10.34	0	0.00	1	5.88	2	9.52	1	3.70	2	10.0														
Expectations of future care and support	All part	ticipants	Female		Female		N	ale	Aged 2	25 to 44		45 and der	•	onal or note	Metro	politan	socioe	to low conomi	•													
															c st	atus	sta	lus														
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	c st n=25	atus %	sta n=22	s %														
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	n=47 8	% 17.02	n=26 4	% 15.38	n=21 4	% 19.05	n=24 3	% 12.50	n=23 5	% 21.74	n=15 3	% 20.00	n=32 5	% 15.63																		
other patients through peer support (support groups, online															n=25	%	n=22	%														
other patients through peer support (support groups, online forums) Future care and support will include a multidisciplinary and	8	17.02	4	15.38	4	19.05	3	12.50	5	21.74	3	20.00	5	15.63	n=25 6	% 24.00	n=22 2	% 9.09														
other patients through peer support (support groups, online forums) Future care and support will include a multidisciplinary and coordinated approach Future care and support will include practical support (home	8	17.02 17.02	4	15.38 19.23	4	19.05 14.29	3	12.50 25.00	5	21.74 8.70	3	20.00 33.33	3	15.63 9.38	n=25 6 5	% 24.00 20.00	n=22 2 3	% 9.09														
other patients through peer support (support groups, online forums) Future care and support will include a multidisciplinary and coordinated approach Future care and support will include practical support (home care, transport, financial) Future care and support will include more long-term condition	8 6	17.02 17.02 12.77	4 5 5 5	15.38 19.23 19.23	4 3 1	19.05 14.29 4.76	3 6 3	12.50 25.00 12.50	5 2 3	21.74 8.70 13.04	3 5 2	20.00 33.33 13.33	5 3 4	15.63 9.38 12.50	n=25 6 5 4	% 24.00 20.00 16.00	n=22 2 3 2	% 9.09 13.6 9.09														
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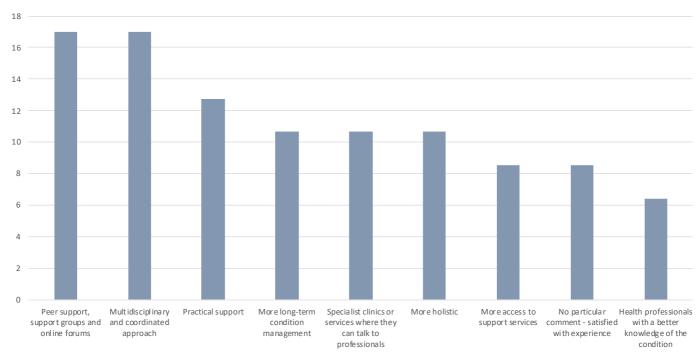


Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Expectations of future care and support	Reported less frequently	Reported more frequently
Future care and support will include a multidisciplinary and coordinated approach	Blood vessel conditions	High cholesterol under 50 years of age Regional or remote
Future care and support will include practical support (home care, transport, financial)	High cholesterol under 50 years of age	Blood vessel conditions
Future care and support will include more long-term condition management (care planning)	Mid to low socioeconomic status	Higher socioeconomic status
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	Had LP(a) test High cholesterol under 50 years of age Regional or remote	•
Future care and support will be more holistic (including emotional health)	Had LP(a) test High cholesterol under 50 years of age Higher socioeconomic status	•

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff, including access to specialists (42.55%), low cost or free medical care through the government (27.66%), and the entire health system (19.15%). Other themes included access to private healthcare or private health insurance (12.77%), and timely access to diagnostics (6.38%).

Participant describes being grateful for healthcare staff (including access to specialists)

To me it's the, I guess it's the expertise in everyone that I've dealt with. Like everyone right up from your specialists down to your physiotherapists. They know their stuff. They've they've all been very friendly, all been understanding. You know, no one, no one has shrugged me off which has been, which has been really good. Maybe I've been lucky as well in in coming across those type of people because I I do know that you can just be a tick and flick and just get them out of the room. But the professionalism I think has been, has been quite good. Like, you know, when when you're dealing with the nurses or whatever, I have no idea how many patients they've dealt with that day, that week, how they've been abused. But when it came for me walking through that door, I'll go treated, treated like it was the first person of the day. And that's good to hear that, you know, alleviates, I guess that stress a bit. You know that it's just to, you know, reassure you that everything's good. Yeah, so I I haven't had personally a bad experience. Participant 028_2023AUHBV

I'm definitely grateful for the support that they gave me. Definitely grateful for, yeah. Just the communications that they gave me, the check up it's always making, making me aware that I was cared for and thought about a lot to make sure it's okay. Participant 029_2023AUHBV

Well, obviously there's an abundance of quality physicians available. It's probably particularly in LOCATION METROPOLITAN, not so much here in LOCATION METROPOLITAN there are a lack of specialists here. I think there are only about three or four neurologists. Certainly in LOCATION STATE, they could do with some more specialists, absolutely. I don't think they have like most cities have a dedicated stroke unit, I'm not sure if they have one here. Yes, that's something that they could certainly work on. Participant 043_2023AUHBV

Participant describes being grateful for low cost/free medical care through the government (Public health system in general)

That you have been able to access in the Australian health system telehealth as is by far the best Medicare having a cap on Medicare because we had some high medical consults lots of frequent consults on when I first got ill So yeah the Medicare system and and and having things close I mean not we're we're in Melbourne, Frankston that's everything is free access easy access in person if otherwise totally health is incredible.

Participant 003_2023AUHBV

Yeah, look, the public health system, public hospitals that I was in, I I wouldn't go to a private hospital again. Ever public system the public nurse, the doctors, the nurses, the teams, couldn't speak more highly of them. I've forgotten what the question actually was about.

INTERVIEWER: Is there anything you've been particularly grateful for?

PARTICIPANT: Oh yeah, no, definitely. Yeah, yeah, the public health care system for sure.

Participant 009_2023AUHBV

Just well, I was extremely thankful for the healthcare card. Other than that, not really just the therapy, haven't really gone to. Much up since all those appointments haven't any other big medical problems.

Participant 007_2023AUHBV

I am extremely grateful of the fact that I didn't have to go bankrupt to pay for my treatment, that most of that was covered. I am extremely grateful for my GP NAME DOCTOR, that I've spoken about, I'm very grateful that I've had his support. Participant 046_2023AUHBV

Participant describes being grateful for the entire health system

PARTICIPANT: I think it's been fantastic. I can't believe we've got, we have got the best health system in the world, I believe. INTERVIEWER: And is there anything particular that you benefited from? PARTICIPANT: Yes, I'm alive. Participant 025_2023AUHBV

Just to say thank you. Thank you so much. Participant 027_2023AUHBV

No. I was happy with everything. Participant 044_2023AUHBV

Participant describes being grateful for access to private healthcare/private insurance

Well, I think the Australian health system is outstanding. It's not cheap. I have private health cover which is expensive but my understanding is, even if I didn't have the private cover, I would have had the same treatment and the same attention if I'd have been on a lesser cover. I think we're well served by the health system.

Participant 045_2023AUHBV

Oh yeah. I mean, I've only lived in Australia so I don't really know what the rest of the world lives through, but I've had friends from the US and those sorts of things and or even the UK for example, where there's just a much bigger population to service and like. We don't really like like it can be expensive but it's not as expensive as you know remortgage the house sort of thing thankfully. So in that in that sense like the the cost in itself is not as burdensome which is like fantastic and you know it's lucky that you we don't even really have to cost isn't really a consideration for a lot of people. Sometimes the wait time is a consideration and that that's unfortunate, but that's what happens when you have limited resources. I'd like to see the resources obviously increase, but there's people in positions and hopefully people smarter than me that are dealing with those issues now. But I think more so than anything, I've probably not the best person to ask because I've gone through the private system basically my whole, my whole life. So I think you know we haven't had to wait too long, well at all For me it was book a date and rock up sort of thing and then the cost has been minimal covered by private health but also obviously aovernment subsidy at the same time that that's been fantastic. Participant 012_2023AUHBV

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All partici		icipants		Had LP(a) test		t Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=	=47		%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes being grateful for healthcare staff (including access to specialists)	2	20	42	2.55	11	61.11	9	31.03	6	66.67	10	58.82	4	19.05	11	40.74	9	45.00
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	1	13	27	7.66	4	22.22	9	31.03	4	44.44	6	35.29	3	14.29	6	22.22	7	35.00
Participant describes being grateful for the entire health system	1	9	19	9.15	1	5.56	7	24.14	1	11.11	3	17.65	4	19.05	3	11.11	5	25.00
Participant describes being grateful for access to private healthcare/private insurance		6	12	2.77	2	11.11	4	13.79	1	11.11	2	11.76	3	14.29	2	7.41	4	20.00
Participant describes being grateful for timely access to diagnostics		3	6	.38	2	11.11	1	3.45	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
What participants are grateful for in the health system	All part	icinants	Fer	nale	M	ale	Aged 2	5 to 44	Aged	45 and	Regio	nal or	Metro	nolitan	Mid t	wol or	Hig	her
What participants are grateful for in the health system	All part	icipants	Fer	nale	M	ale	Aged 2	25 to 44		45 and Ider		nal or note	Metro	politan	socioe	to low conomi atus	Hig socioec sta	onomic
What participants are grateful for in the health system	All part n=47	icipants %	Fer n=26	nale %	M n=21	ale %	Aged 2	25 to 44 %					Metro		socioe	conomi	socioec	onomic
What participants are grateful for in the health system Participant describes being grateful for healthcare staff (including access to specialists)		·							ol	lder	ren	note			socioe c st	conomi atus	socioec sta	onomic tus
Participant describes being grateful for healthcare staff (including	n=47	%	n=26	%	n=21	%	n=24	%	ol n=23	lder %	ren n=15	note %	n=32	%	socioe c st n=25	conomi atus %	socioec sta n=22	onomic tus %
Participant describes being grateful for healthcare staff (including access to specialists) Participant describes being grateful for low cost/free medical	n=47 20	% 42.55	n=26 11	% 42.31	n=21 9	% 42.86	n=24 9	% 37.50	ol n=23	lder % 47.83	ren n=15 6	note % 40.00	n=32	% 43.75	socioe c st n=25 11	conomi atus % 44.00	socioec sta n=22 9	onomic tus % 40.91
Participant describes being grateful for healthcare staff (including access to specialists) Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	n=47 20 13	% 42.55 27.66	n=26 11 8	% 42.31 30.77	n=21 9	% 42.86 23.81	n=24 9 7	% 37.50 29.17	ol n=23 11 6	% 47.83 26.09	ren n=15 6	% 40.00 40.00	n=32 14 7	% 43.75 21.88	socioe c st n=25 11 8	conomi atus % 44.00 32.00	socioec sta n=22 9 5	onomic tus 40.91 22.73

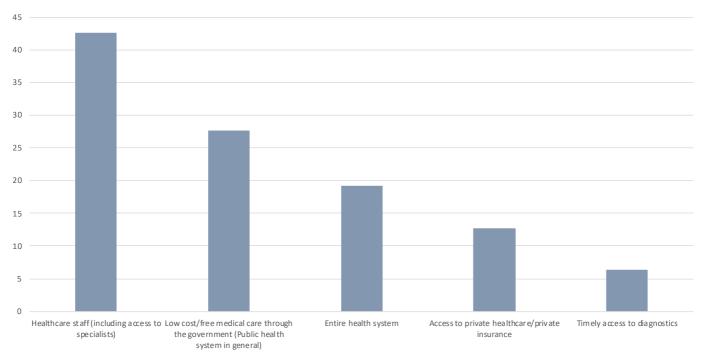




Table 9.10: What participants are grateful for in the health system – subgroup variations

What participants are grateful for in the health system	Reported less frequently	Reported more frequently
Participant describes being grateful for healthcare staff (including access to specialists)	Did not had LP(a) test Heart conditions	Had LP(a) test High cholesterol under 50 years of age Blood vessel conditions
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	Heart conditions	High cholesterol under 50 years of age Regional or remote
Participant describes being grateful for the entire health system	Had LP(a) test	-
Participant describes being grateful for access to private healthcare/private insurance	Regional or remote	•

Values in making decisions

The most important aspects were How safe the medication is and weighing up the risks and benefits, and The severity of the side effects. The least important were Ability to follow and stick to a

treatment regime and The ability to include my family in making treatment decisions.

Table 9.11: Values in making decisions

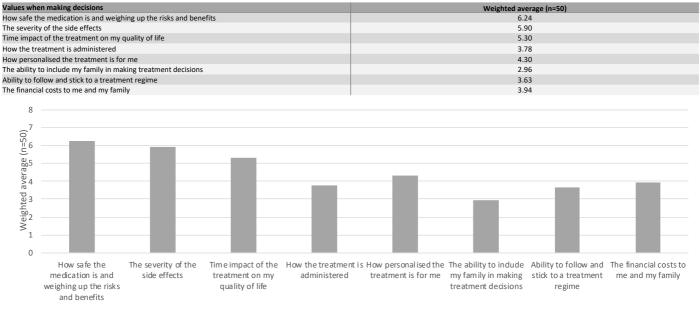


Figure 9.6: Values in making decisions

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were "Quality of life for patients", and "All patients being able to access all available treatments and services". The least important was "Economic value to government and tax payers".

Table 9.12: Values for decision makers

Values for decision makers	Weighted average (n=50)
Economic value to government and tax payers	1.56
Economic value to patients and their families	2.62
Quality of life for patients	4.1
Compassion	3.06
All patients being able to access all available treatments and services	3.66

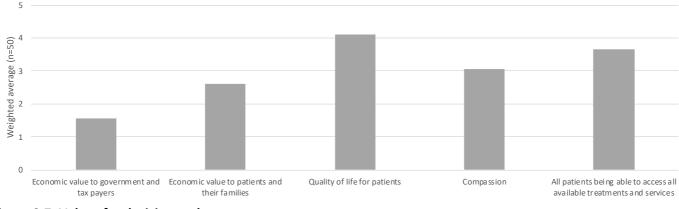


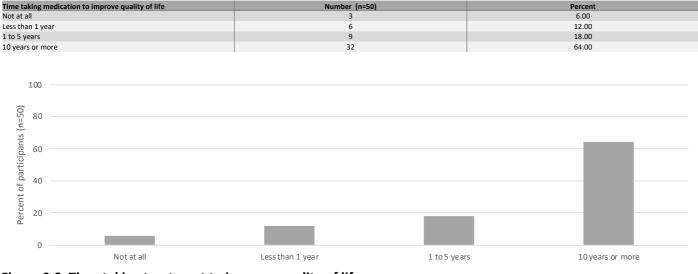
Figure 9.7: Values for decision makers

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure.

The majority of participants (n = 32, 64.00%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

Table 9.13: Time taking treatment to improve quality of life





Most effective form of medicine

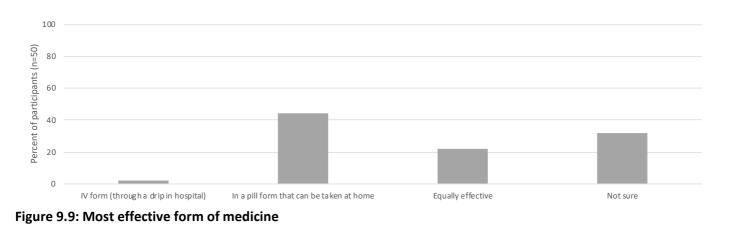
Participants were asked in the online questionnaire, in what form did they think medicine was most effective in.

There was 1 participant (2.00%) that thought that medicine delivered by IV was most effective, 22

participants (44.00%) thought that pill form was most effective, and 11 participants (22%) that thought they were equally effective. There were 16 participants (32.00%) that were not sure.

Table 9.14: Most effective form of medicine

Treatment most effective in what form	Number (n=50)	Percent
IV form (through a drip in hospital)	1	2.00
In a pill form that can be taken at home	22	44.00
Equally effective	11	22.00
Not sure	16	32.00



Messages 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 to the health minister 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 %). Other themes included to improve rural services (19.15%), to invest in prevention (19.15%), to increase investment in general (17.02%), to help raise community awareness (14.89%), to invest in health professionals to service the patient population (14.89%), and to have a holistic approach to the condition that includes emotional support (10.64%).

Timely and equitable access to support, care and treatment

PARTICIPANT: Yeah. I think that absolutely ties into that question then. Because, the cardiac rehab facility. Controlled exercise because you become afraid of your body. And afraid of how far to push it. To be able to go into a controlled environment like that we're you're being told, "This is okay and your fine to push yourself that little bit further." And to be around people that are two months ahead of you with recovery, and two months behind you in recovery. You then become the mentor for people. Then other people become the mentor for you. That kind of support I found with that, within cardiac rehab was so good at that time. I was looking at the 85-year-old guy that was doing laps around me. He was power walking around the little walking course we had after his open-heart surgery. I was like, "Wow. If he can do it I can do it. I've got to try and catch up with him." INTERVIEWER: Yeah. No it's an excellent point.

PARTICIPANT: That was really good. Then you pass that onto people that are just coming in new. They're fresh out of surgery. They're six weeks post op and they're terrified of their heart, and then they listen to your story and go, "Okay. I can do it."

INTERVIEWER: Yeah. That kind of sharing of experience is so important.

PARTICIPANT: Absolutely. It was imperative. I think that needs to be available. I was just, because I work at a private hospital close to me, and I actually had to do a blood test on a lady the other day who was oneweek post op from open heart. She was in her bed crying, and scared, and her husband had her on deaths door. I actually cracked open my shirt and I showed her my scar. I'm like, "I'm three years post open heart surgery. I've had similar thing to what you've done." I said, "You can do this." I sat there and chatted with her for about 20 minutes and she was so grateful, and happy by the time I left. That kind of support just needs to be available to people when they need it. Participant 036_2023AUHBV

I just really feel that knowledge, support and just continual access because I don't think probably that I was offered enough of that early on and I didn't realise that I probably was entitled to it. Participant 047_2023AUHBV

Treatments need to be affordable

I think I'm not. Overall, I'm happy with how it went for me because we have private health. Yeah. One thing we have reflected on is if we didn't have private health, like it was a very tough 12 months for us. Yeah, if I didn't have private health, that would have been much, much longer if I was going through the public system. So I would say to take it a little further for the

public system to sort of help people if they don't have private health. Participant 008_2023AUHBV

I would honestly say we need to throw more money in the public sector to be honest. Like it's. Yeah, it's easy to say that you need more money, but the waiting times and things like that are quite high and you know, and if you can't afford to go private. You could, you could be dead by the time you get around to seeing a specialist. You know, they talk about you know 12 months or more waiting lists just to get in to see someone and that's just to get a test and then you've got to wait again. You know that it it is, it is quite difficult to get in and and even even then you know there's not that many specialists available. So you know you sometimes you have to consider consider traveling quite large distances depending on which part of the country you're in. Participant 028_2023AUHBV

For government, I guess make treatments accessible and affordable to everybody. I guess that would be not just for heart research or not just for heart treatment, but for anything else. While you're well, I think that it's easy enough to say this medication is expensive, let's not -- but I think that you need to have more compassion within government. With medical staff, I think they just need to be respectful. I'm very happy that I've had that, but I am mindful that, particularly with older people who might not know as much about their condition, they need to be treated with respect.

Participant 034_2023AUHBV

Grateful for the healthcare system and the treatment that they received

It's actually pretty excellent. Participant 019_2023AUHBV

No, no, no as so much special. I want to tell you earlier that my experience was a fabulous like I don't need, like I want to say that we are giving the very good healthcare services in in our state like they are the fabulous. Everything was a perfect form, a very early step to the last step. Participant 027_2023AUHBV

I think my experience has been one of, like I've been so grateful for everything that I've had exposure to. And I haven't paid for a thing apart from my medications. And to have the free healthcare that we have in this country, I'm born in LOCATION OVERSEAS, and so I know what other countries have and I think we are so fortunate to have as many resources available for free. And I feel the quality of those resources are actually quite, quite good. Yeah and so I would probably want to say that I'm grateful for those. I would hope that they would always be a priority and that they would continue to offer those resources to people.

Participant 035_2023AUHBV

Improve rural services

I'd say that they haven't had access to much at all. And I I I'd say that you know, in general hearts in general, you know there needs to be more access in a regional and rural sense as well. You know, to get, you know get the care everywhere, you know having and whether it's hearts or whether it's anything to have to, you know. Unfortunately I only had to go 2 hours in my family, but I think you know having services. Are more readily available in regions and rural areas. Would be my big, would be my big plug. Participant 009 2023AUHBV

Hold on the lines of access, telehealth, access to probably out more allied health for people living in remote.

Participant 014_2023AUHBV

PARTICIPANT: I think I have excellent care even for someone who is living in the country like me. I had excellent care. I'm very lucky because I'm alive. The statistics on brain haemorrhages aren't good. Yes, I had very good care.

INTERVIEWER: That's great. You wouldn't tell anything to the health minister, any change? PARTICIPANT: If people can't drive in the country they need more funding for transport to make it equal to people in the city. Participant 041_2023AUHBV

Invest in prevention

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. And if people knew that they had this elevated Lycoprotein A, you know, that would give them the chance to become more proactive with their health. So maybe exercise more if they smoke to, to try and quit good nutrition to try and eliminate all sorts of stress. Maybe, you know, get onto some medication to try and lower your LDL. I

think that's really important at the moment. I don't think there's enough enough knowledge about it as well in Australia or about lipoprotein A and its effects. So I think that's a big that would be a big message. Participant 011_2023AUHBV

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

Increase investment (general)

I would honestly say we need to throw more money in the public sector to be honest. Like it's. Yeah, it's easy to say that you need more money, but the waiting times and things like that are quite high and you know, and if you can't afford to go private. You could, you could be dead by the time you get around to seeing a specialist. You know, they talk about you know 12 months or more waiting lists just to get in to see someone and that's just to get a test and then you've got to wait again. You know that it it is, it is quite difficult to get in and and even even then you know there's not that many specialists available. So you know you sometimes you have to consider consider traveling quite large distances depending on which part of the country you're in. Participant 028_2023AUHBV

I went to Canberra as a delegation for the Stroke Foundation asking for money for telehealth. I think telehealth is a big thing that should be in the regional areas, and there should be more funding put into foundations like the National Stroke Foundation. There should be more funding for campaigns to help with stroke, more facilities for stroke survivors to live independently or assisted living. I believe the medication should be on the PBS and available and accessible to everyone. Participant 049_2023AUHBV

Help raise community awareness

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

I wish he would realise-- They push on breast cancer and prostate, but stroke-wise, no, nothing. Nothing is there, no information. That's why it's frustrating. It's another illness. It's another killer and the government doesn't care. It's a hidden one. They don't talk about it, they don't mention it there, they don't acknowledge it. That's why it's frustrating. Participant 042_2023AUHBV

Invest in health professionals to service the patient population

I think that more access to, you know, nurses, not just the doctors, to give valid, helpful information. So opening up more opportunities for learning from really intelligent people without the need of going to the doctor. So maybe people be more inclined to seek help if it's not an actual GP, but there's taking a step in preventative care and getting information from trained professionals. Participant 003_2023AUHBV

I'd tell him to get a job, go out in the real world. Go and work with some nurses for a week and come back and tell tell me what you had to tell me. Go and stand on the front line with them and combat the idiots falling out of ambulances out the front or using the ambulance for a a taxi right to get to there they are feeling all right. Now walk down the street where they're going to go to like the gifts and then go into try out, walk in a stand at the front end and listen to what they're putting up. But that's what I'd be telling the Health Minister if I was standing in front of him. I'd say make the public aware through media, electronic media. Educate them better about these disease, what you can do to prevent it. Don't think you are too. You are on bulletproof. Participant 006_2023AUHBV

Holistic approach to the condition (including emotional support)

There's access to those therapies, so there'd be no barriers in terms of cost or capacities of access. Yeah, I guess that it's as easy as possible for the patient. I think to also consider -- I mean, this is a hard one. The side effects and the mental state of health of patients,

and the impact certain things will have. There's a high correlation between heart disease and mental health issues or depression. Yeah, just being mindful of that. I mean, I do understand that if it's a life-threatening condition then that has to take precedence, but it's just awareness of the impacts that that has. Mental health, and patient access, and fairness and so on. That's probably all that's coming to mind. Participant 023_2023AUHBV I would say to the minister, "Will you please ensure that medical practitioners receive stroke education? That medical practitioners are made aware of the emotional aspects of stroke as much as they're made aware of the physical aspects." Participant 045_2023AUHBV

Table 9.15 Messages to decision-makers

Message to decision-makers		All parti	icipants	;	Had Li	P(a) test		ot had) test	under	olesterol 50 years age		vessel itions		art itions		other		1 other litions
	n=	=47	1	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Timely and equitable access to support, care and treatment		12		5.53	3	16.67	9	31.03	1	11.11	3	17.65	8	38.10	6	22.22	6	30.00
Treatments need to be affordable		9	19	9.15	4	22.22	5	17.24	2	22.22	1	5.88	6	28.57	3	11.11	6	30.00
Grateful for the healthcare system and the treatment that they received		9	19	9.15	4	22.22	5	17.24	1	11.11	2	11.76	6	28.57	5	18.52	4	20.00
Improve rural services		9	19	9.15	3	16.67	6	20.69	1	11.11	5	29.41	3	14.29	5	18.52	4	20.00
Invest in prevention		9	19	9.15	3	16.67	6	20.69	2	22.22	4	23.53	3	14.29	5	18.52	4	20.00
Increase investment (general)		8	17	7.02	4	22.22	4	13.79	1	11.11	3	17.65	4	19.05	4	14.81	4	20.00
Help raise community awareness		7	14	1.89	2	11.11	5	17.24	2	22.22	3	17.65	2	9.52	2	7.41	5	25.00
Invest in health professionals to service the patient population		7	14	1.89	4	22.22	3	10.34	1	11.11	2	11.76	4	19.05	7	25.93	0	0.00
Holistic approach to the condition (including emotional support)		5	10	0.64	0	0.00	5	17.24	0	0.00	2	11.76	3	14.29	2	7.41	3	15.00
Compassionate and empathetic		3	6	.38	1	5.56	2	6.90	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00
Improve care coordination		3	6	.38	1	5.56	2	6.90	0	0.00	0	0.00	3	14.29	2	7.41	1	5.00
Unsure what to say		3	6	.38	2	11.11	1	3.45	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
Message to decision-makers	All part	ticipants	Fer	nale	м	ale	Aged 2	5 to 44	0	45 and der		nal or Iote	Metro	politan	Mid t socioed c sta	onomi	Hig socioec sta	onomic
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Timely and equitable access to support, care and treatment	12	25.53	4	15.38	8	38.10	6	25.00	6	26.09	4	26.67	8	25.00	5	20.00	7	31.82
Treatments need to be affordable	9	19.15	4	15.38	5	23.81	3	12.50	6	26.09	4	26.67	5	15.63	5	20.00	4	18.18
Grateful for the healthcare system and the treatment that they received	9	19.15	6	23.08	3	14.29	6	25.00	3	13.04	3	20.00	6	18.75	5	20.00	4	18.18
																	4	18.18
Improve rural services	9	19.15	5	19.23	4	19.05	5	20.83	4	17.39	6	40.00	3	9.38	5	20.00	4	
Improve rural services Invest in prevention	9	19.15 19.15	5 4	19.23 15.38	4 5	19.05 23.81	5 4	20.83 16.67	4 5	17.39 21.74	<mark>6</mark> 2	40.00 13.33	3 7	9.38 21.88	5 7	20.00 28.00	2	9.09
	-						-			-	-		-					9.09 22.73
Invest in prevention	9	19.15	4	15.38	5	23.81	4	16.67	5	21.74	2	13.33	7	21.88	7	28.00	2	
Invest in prevention Increase investment (general)	9 8	19.15 17.02	4 4	15.38 15.38	5 4	23.81 19.05	4	16.67 20.83	5 3	21.74 13.04	2 4	13.33 26.67	7 4	21.88 12.50	7 3	28.00 12.00	2 5	22.73
Invest in prevention Increase investment (general) Help raise community awareness	9 8 7	19.15 17.02 14.89	4 4 4	15.38 15.38 15.38	5 4 3	23.81 19.05 14.29	4 5 3	16.67 20.83 12.50	5 3 4	21.74 13.04 17.39	2 4 2	13.33 26.67 13.33	7 4 5	21.88 12.50 15.63	7 3 5	28.00 12.00 20.00	2 5 2	22.73 9.09
Invest in prevention Increase investment (general) Help raise community awareness Invest in health professionals to service the patient population	9 8 7 7	19.15 17.02 14.89 14.89	4 4 4 3	15.38 15.38 15.38 11.54	5 4 3 4	23.81 19.05 14.29 19.05	4 5 3 3	16.67 20.83 12.50 12.50	5 3 4 4	21.74 13.04 17.39 17.39	2 4 2 0	13.33 26.67 13.33 0.00	7 4 5 7	21.88 12.50 15.63 21.88	7 3 5 3	28.00 12.00 20.00 12.00	2 5 2 4	22.73 9.09 18.18
Invest in prevention Increase investment (general) Help raise community awareness Invest in health professionals to service the patient population Holistic approach to the condition (including emotional support)	9 8 7 7 5	19.15 17.02 14.89 14.89 10.64	4 4 3 3	15.38 15.38 15.38 11.54 11.54	5 4 3 4 2	23.81 19.05 14.29 19.05 9.52	4 5 3 3 0	16.67 20.83 12.50 12.50 0.00	5 3 4 4 5	21.74 13.04 17.39 17.39 21.74	2 4 2 0 2	13.33 26.67 13.33 0.00 13.33	7 4 5 7 3	21.88 12.50 15.63 21.88 9.38	7 3 5 3 2	28.00 12.00 20.00 12.00 8.00	2 5 2 4 3	22.73 9.09 18.18 13.64

30

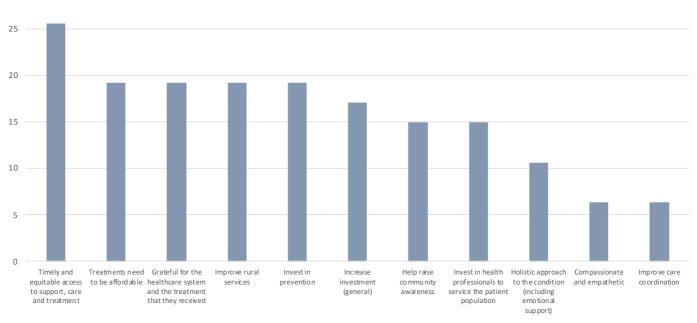


Figure 9.10: Messages to decision-makers

Table 9.16: Messages to decision-makers – subgroup variations

Message to decision-makers	Reported less frequently	Reported more frequently
Timely and equitable access to support, care and	High cholesterol under 50 years of age	Heart conditions
treatment	Female	Male
Treatments need to be affordable	Blood vessel conditions	6 to 11 other conditions
Improve rural services		Blood vessel conditions
		Regional or remote
Invest in prevention	Higher socioeconomic status	
Help raise community awareness		6 to 11 other conditions
Invest in health professionals to service the patient	6 to 11 other conditions	0 to 5 other conditions
population	Regional or remote	
Holistic approach to the condition (including emotional	Had LP(a) test	Aged 45 and older
support)	High cholesterol under 50 years of age	-
	Aged 25 to 44	