

# Section 1

## Introduction and methods

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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)<sup>1</sup>. 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 strokes<sup>1</sup>.

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<sup>1</sup>. 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<sup>1</sup>.

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<sup>1</sup>.

Lipoprotein a levels increase likelihood of a stroke or heart attack, particularly with familial hypercholesterolemia or symptoms of coronary heart disease<sup>2</sup>. **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<sup>3</sup>. The European Atherosclerosis 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<sup>4</sup>. Treatment of high levels of lipoprotein a includes intensifying preventative treatments such as cholesterol lowering therapy and addressing lifestyle modifications<sup>3</sup>.

### ***Personal Experience, Expectations and Knowledge (PEEK)***

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.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

### **Position of this study**

A search was conducted in Pubmed (October 6, 2023) to identify studies of cardiovascular diseases (cardiac arrhythmia, heart attack, myocardial infarction, coronary artery disease, stroke, hypercholesterolemia, high cholesterol, or aortic stenosis) with patient reported outcomes, or patient experience conducted in the past five years in Australia. Meta-analysis studies, interventional studies, studies with children, and studies of less than five participants were excluded.

There were 56 studies identified, the majority had participants with stroke (n=45), other conditions included Atrial Fibrillation (n=3), Familial hypercholesterolaemia (n=1), and one study each on Cardiac rehabilitation, Cardiovascular disease, Coronary heart disease, Inherited heart conditions, Myocardial infarction, and Spontaneous coronary artery dissection

This PEEK study has 50 participants with heart or blood conditions, it is a very comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

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### **Participants**

To be eligible for the study, participants needed to have been diagnosed with a heart or blood vessel condition, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study.

### **Ethics**

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS\_Q4\_03).

### **Data collection**

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, [www.zoho.com/survey](http://www.zoho.com/survey)).

There were five researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance.

### **Online questionnaire (quantitative)**

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)<sup>5</sup>, a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)<sup>6</sup>, the Short Fear of Progression Questionnaire (FOP12)<sup>7</sup>, and the Partners in Health version 2 (PIH)<sup>8</sup>. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

### **Structured Interview (qualitative)**

Interviews were conducted via telephone by registered nurses who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

### **Questionnaire analysis**

Statistical analysis was conducted using R included in the packages “car”, “dplyr” and “ggplot2” (R 3.3.3 GUI 1.69 Mavericks build (7328)). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by condition type, number of other conditions gender, age, location of residence, and socio-economic status. Scales and subscales were calculated according to reported instructions<sup>5-8</sup>.

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics<sup>9</sup>.

The level of socio-economic status of participants was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics<sup>10</sup>.

For comparisons by condition type a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kruskal-Wallis rank sum test on care was conducted with post-hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons between groups, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

### **Structured interviews analysis**

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into CCDR’s custom data analysis program. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in CCDR’s custom data analysis program. The minimum coded unit was a sentence with paragraphs and phrases coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than 5 times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Data analysis and final reporting was completed in June 2021.

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Myocardial infarction, and Spontaneous coronary artery dissection

There were 27 studies that collected data by interview with between 5 and 51 participants. Of these studies, 9 were focused on Quality of life<sup>11-19</sup>, 4 studies were focused on Information<sup>20-23</sup>, 3 studies were focused on Rehabilitation<sup>24-26</sup>, studies each were focused on Care coordination<sup>27,28</sup>, Decision making<sup>29,30</sup> and Unmet needs<sup>31,32</sup> and a single study each focused on Communication<sup>33</sup>, Diagnosis<sup>34</sup>, Health literacy<sup>35</sup>, Physical activity<sup>36</sup>, and Unmet needs<sup>31</sup>.

There were 3 studies that collected data by focus groups with between 7 and 30 participants, the studies were focused on Communication<sup>37</sup>, Information<sup>38</sup>, and Quality of life<sup>39</sup>.

There were 27 studies that collected data by survey with between 19 and 28 115 participants, the largest of

these studies were analysis of the Australian Stroke Clinical Registry.

There were 6 studies focused on Health related quality of life<sup>40-45</sup>, 6 studies that were an analysis of the Australian Stroke Clinical Registry<sup>46-51</sup>, 3 studies focused on Symptoms<sup>52-54</sup>, 3 studies focused on treatment adherence<sup>55-57</sup>, 3 studies focused on Unmet needs<sup>58-60</sup>, 2 studies focused on Comorbidities<sup>61,62</sup>, and a single study each focused on Clinical trial participation<sup>63</sup>, Decision making<sup>64</sup>, and Physical activity<sup>65</sup>.

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**Table 1.1: PEEK position**

Author, Year	Location	Number of participants	Data collection	Focus	PEEK SECTION								
					2: Health status, co-morbidities	3: Diagnosis experience	4: Decision making	5: Treatment, healthcare system use	6: Information, communication	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9: Expectations, preferences and messages	
Skoss, 2022 <sup>34</sup>	Familial hypercholesterolaemia	51	Interviews	Diagnosis		X	X						
Janssen, 2022 <sup>26</sup>	Stroke	33	Interviews	Rehabilitation				X					
Tse, 2022 <sup>19</sup>	Stroke	30	Interviews	Quality of life								X	
Chen, 2022 <sup>28</sup>	Stroke	26 (26)	Interviews	Care coordination			X		X	X	X		
Quigley, 2019 <sup>27</sup>	Stroke	24 (10)	Interviews	Care coordination					X				
Pelly, 2023 <sup>23</sup>	Myocardial infarction	22	Interviews	Information Treatment adherence					X				
Levy, 2022 <sup>66</sup>	Stroke	20	Interviews	Treatment adherence				X					
Espernerberger, 2023 <sup>36</sup>	Stroke	19	Interviews	Physical activity								X	
Shipley, 2018 <sup>18</sup>	Stroke	19	Interviews	Quality of life					X		X	X	
Shipley, 2020 <sup>31</sup>	Stroke	19	Interviews	Unmet needs									X
Yeates, 2022 <sup>30</sup>	Inherited heart conditions	18 (2)	Interviews	Decision making			X						
Jin, 2020 <sup>35</sup>	Coronary heart disease	18	Interviews	Health literacy					X				
Finch, 2021 <sup>17</sup>	Stroke	17	Interviews	Quality of life					X		X	X	
Jackson, 2022 <sup>16</sup>	Stroke	15	Interviews	Quality of life							X		
Ajwani, 2021 <sup>15</sup>	Stroke	11	Interviews	Quality of life							X		
Amoah, 2023 <sup>32</sup>	Stroke	10 (3)	Interviews	Unmet needs			X				X	X	
Geldens, 2021 <sup>22</sup>	Stroke	10	Interviews	Information				X	X	X			

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Hutton, 2019 <sup>14</sup>	Stroke	10	Interviews	Quality of life								X	
Pryor, 2020 <sup>13</sup>	Stroke	9	Interviews	Quality of life								X	
Ferguson, 2022 <sup>20</sup>	Atrial Fibrillation	8	Interviews	Information					X				
Cheng, 2023 <sup>21</sup>	Stroke	8	Interviews	Information					X				
Hoyle, 2023 <sup>12</sup>	Stroke	8	Interviews	Quality of life									
Chin, 2022 <sup>24</sup>	Stroke	8	Interviews	Rehabilitation				X					
Purcell, 2020 <sup>25</sup>	Stroke	8	Interviews	Rehabilitation				X					
Walder, 2020 <sup>33</sup>	Stroke	6	Interviews	Communication			X		X	X		X	
Kelly, 2022 <sup>29</sup>	Stroke	6	Interviews	Decision making			X		X	X			
Hodson, 2019 <sup>11</sup>	Stroke	5	Interviews	Quality of life								X	
Murphy, 2022 <sup>39</sup>	Spontaneous coronary artery dissection	30	Focus groups	Quality of life					X	X		X	
Finch, 2022 <sup>38</sup>	Stroke	15 (4)	Focus groups	Information					X				
D'Souza, 2021 <sup>37</sup>	Stroke	7	Focus groups	Communication					X	X			
Dwyer, 2021 <sup>50</sup>	Stroke	28,115	Survey	Registry	X								
Dalli, 2023 <sup>49</sup>	Stroke	13,594	Survey	Registry	X								
Lynch, 2022 <sup>51</sup>	Stroke	8,555	Survey	Registry	X				X				
Mosalski, 2021 <sup>45</sup>	Stroke	8,397	Survey	Health related quality of life	X								
Phan, 2021 <sup>48</sup>	Stroke	6,852	Survey	Registry	X								
Thayabarathan, 2018 <sup>47</sup>	Stroke	2,853	Survey	Registry	X								
Dalli, 2022 <sup>57</sup>	Stroke	1,500	Survey	Treatment adherence				X					
Sun, 2023 <sup>44</sup>	Stroke	1,163	Survey	Health related quality of life	X								
Tjokrowijoto, 2023 <sup>46</sup>	Stroke	623	Survey	Registry	X			X					



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Smith, 2019 <sup>65</sup>	Cardiovascular disease	535	Survey	Physical activity								X	
Weerasekara, 2021 <sup>63</sup>	Stroke	445	Survey	Clinical trials				X					
Kadhim, 2019 <sup>62</sup>	Atrial Fibrillation	442	Survey	Comorbidities	X								
Waller, 2023 <sup>43</sup>	Stroke	401	Survey	Health related quality of life	X								
Thayabarathan, 2023 <sup>42</sup>	Stroke	244	Survey	Health related quality of life	X								
Unsworth, 2020 <sup>64</sup>	Stroke	183	Survey	Decision making			X						
Keating, 2021 <sup>60</sup>	Stroke	171	Survey	Unmet needs									X
Haslam, 2020 <sup>54</sup>	Stroke	106	Survey	Symptoms		X							
Tse, 2019 <sup>61</sup>	Stroke	100	Survey	Comorbidities	X								
Stolwyk, 2022 <sup>53</sup>	Stroke	87	Survey	Symptoms		X							
Walters, 2019 <sup>41</sup>	Atrial Fibrillation	78	Survey	Health related quality of life	X								
Sapuppo, 2023 <sup>59</sup>	Stroke	76	Survey	Unmet needs									X
Minshall, 2021 <sup>40</sup>	Stroke	72	Survey	Health related quality of life	X								
Beauchamp, 2020 <sup>56</sup>	Cardiac rehabilitation	60	Survey	Treatment adherence				X					
O'Connell, 2020 <sup>52</sup>	Stroke	58	Survey	Symptoms		X							
Pacleb, 2020 <sup>55</sup>	Familial hypercholesterolaemia	54	Survey	Treatment adherence				X					
Finch, 2020 <sup>58</sup>	Stroke	20	Survey	Unmet needs						X			X

## Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
HER2	Human epidermal growth factor receptor 2
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
p	Probability value. A small <i>p</i> -value (typically $\leq 0.05$ ) indicates strong. A large <i>p</i> -value ( $> 0.05$ ) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group differ from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 7significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.
$\chi^2$	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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