

Interview Schedule (Semi-structured)

Introduction / Demographic

- Could you tell me about your family? (i.e. siblings, parents, spouse, children)

Open-ended Questions:

About the condition and receiving the diagnosis

- Can you tell me more about how you were diagnosed with your cardiac condition?
Prompts:
 - When were you first diagnosed? (How long ago? How old were you?)
 - Did you have any prior symptoms?
 - What prompted you to see a doctor?
- Do you remember when you received the diagnosis? Can you tell me more?
Prompts:
 - Who was with you when you received the diagnosis?
 - Who gave you the diagnosis? *i.e. Doctor, nurse, etc*
 - How did you feel at that point in time?
- Were there any specific issues that were raised when you were given the diagnosis?
i.e. lifestyle changes, the need to inform family, the need for other interventions/management methods
- What was your immediate concern / worry?
- Is there anything you would have liked to be done differently when you were given the diagnosis?
- Do you have any positive memories around the time of receiving your diagnosis? Were there any aspects about the way the healthcare team treated you that were helpful?

Communication with family regarding diagnosis

- Have you spoken to your family members about the diagnosis of your condition?
(i.e. extended family: aunts, uncles, cousins)
Prompts:
 - Individually / together?
 - Who did you tell in your family? How did you tell them?
 - Why did you tell these family members and not others?
- Do you think this is important information to know?
 - Important & told
 - Important but don't know how to tell
 - Not important
- How was your experience of sharing this information with them?
- What information did you tell them about your condition?
- What is their understanding about their risk?
- What made you want to tell / not tell them about it?
Prompts:
 - Did other members of the family have similar symptoms?
- *(if they have not shared information)* Do you think there would be a situation where you would tell your siblings (i.e. if the experienced cardiac problems / if they had another illness)
Prompts:
 - If it was your sibling who was diagnosed, would he/she tell? Would you want to know?
- *(if they have shared the information)* Now that you have told them, what do you think they will do with this information?
Prompts:
 - Have they scheduled appointments to get their heart checked?

Any other issues

- Do you see genes as having a role in developing health problems?
- Are there any other aspects of your experience that you feel are important but have not been discussed?