

*Please note the interview topic guide is a living document. The design is iterative to tailor the interview to the needs of the participant, and the issues that they feel are most important. As analysis occurs concurrently the topic guide is likely to be adapted over time - questions might be added, amended or omitted – and used flexibly.*

## **Plan of interview**

1. Introduction
2. Referral for an ICD
3. Information sources
4. Making the decision
5. Living with an ICD
6. The Future
7. Improving information giving
8. Feedback

### **1. Introduction**

- Thank you agreeing to take part in this interview. As you know, we are interviewing people about their decisions around whether to have an ICD implanted or not. We are interested in understanding the types of information and support people need when making a decision about having an ICD.
- With your permission I would like to record the interview; all details will be confidential. I am not a clinician so if there are any questions about your device it would be helpful to hear them to understand what you would like more information about but they would be best answered by your doctor or physiologist.
- Taking part in the study won't affect your care. There are no right or wrong answers and if you feel uncomfortable about any question we can move on to another topic or stop the interview.
- Do you have any questions or concerns?
- *Obtain written consent.*

## 2. Referral for an ICD

- Please would you tell me about the events leading up to your referral for an ICD? Were you offered your device after an acute event or as a preventive measure?
- What did the doctors tell you about why you needed an ICD?
- How did you feel when you were told you were eligible for an ICD?
- What is your understanding about your ICD (what does the device do, what doesn't the device do?)

## 3. Information Sources

- Can you tell me about any materials you received from your doctor? Written materials or websites?
- Did you or someone you know get information about ICDs from the internet or another source?
- Have you talked with someone who already has an ICD?
- Is there anything that wasn't discussed with your cardiologist that you would have liked information about?

## 4. Making the decision

- Who did you discuss your options with besides your cardiologist (friends, family, others)?
- Can you tell me what your cardiologist told you about the benefits of getting an ICD?
- Can you tell me what your cardiologist told you about the risks and consequences of getting an ICD (probes: possible surgical complications, battery changes, impact on quality of life)?
- Have you talked about what happens with the device as you get older?
- To what degree were your family/friends involved in the decision-making process?
- What was the most important factor that influenced your decision? Probes: "Some people have told us that they wish to [follow doctor's advice/are acting on advice or wishes of family members/wish to prolong life, etc.]

## **5. Life with an ICD**

- What is it like to live with an ICD, what is working well? What's not working as well?
- Was anything different to how you expected? Has anything surprised you?
- What do you like/value about the device?
- What do you dislike about the ICD?
- How has the ICD affected your day to day life?
- Are there any activities that you avoid? Which ones and why?
- How do you feel about your device?
- How does living with an ICD affect your relationships (with partners, family)?
- Have you ever received a shock from your device? If so how would you describe that experience?
- Have you had any other complications related to the device (probe: infections, lead fracture)?
- Do you worry about or have concerns about your ICD?

## **6. The Future**

- Have you talked with your cardiologist or physiologist about what might happen in the future with your device as you get older?
- Is there anything that concerns you?
- Would you ever consider having your device turned off? In what circumstances would you consider this?

## **7. Improving information giving**

- Do you have any worries or unanswered questions about your ICD? How do you handle these worries and unanswered questions?
- If you could tell patients who are considering getting an ICD anything about what it's like, what would you tell them? What's most important for them to know in making the decision?
- Is there anything you know now that would have been helpful to know before you made your decision to get the ICD?

## **8. Feedback**

- *Thank you for your time.*
- *What made you take part in this interview?*
- *Are we asking the right questions?*
- *Do these questions allow you to talk about the most important issues for you?*
- *Is there anything else you think it would be useful for us to know?*