

Appendix A: Interview Guide

1. To begin, please tell me about yourself.

Probes:

- Tell me a bit about your health.
- Please walk me through how you first became involved with Arthritis Research Canada's Arthritis Patient Advisory Board (APAB).
- What role(s) have you played in research?

2. How easy or difficult have you found being involved in research? Please elaborate.

Probes:

- What do you like or dislike about being involved in research?
- Thinking about your experiences, could you tell me what helps you take part in research?
- Have you found there are any downsides to being involved in research? Could you give an example?
- Can you describe what leads you to continue to be involved in research?
- Can you talk me through what led you to leave APAB? [Emeritus APAB members only]

3. Could you describe your interactions with researchers at Arthritis Research Canada?

Probes:

- To what extent do researchers partner with you in research?
- To what extent do you feel that your contributions are valued by researchers?
- Have there been any changes in your interactions with researchers over time? Please elaborate.

4. Could you describe what you think is/has been important for APAB's development?

Probes:

- Thinking back, what was important for APAB's development in the early years? Has this changed over the years? [More Experienced Members only]
- What can/does/should APAB do that no other organization does or can do as well?
- Can you describe where APAB has most impact?
- Could you describe what you like or dislike about the culture within APAB?
- Can you describe what you like or dislike about how APAB operates?
- Can you talk me through how APAB has secured funding?
- How do you hope to see APAB develop in the short-term/long-term?
- To what extent does ARC support you to engage in research?

5. Are there any benefits to being involved in research at Arthritis Research Canada? If so, please elaborate.

Probes:

- To what extent do you feel that your involvement is recognized?
- Has being involved in research affected the way that you manage other priorities/manage your health? If so, to what extent?

Thank you very much for your time. We really appreciate you sharing your experiences.