Sample Discussion Guide for Focus Group Discussions with Cancer Patients

Introduction and Ice-breaker
- Can you briefly introduce yourself?
- What do you know about cancer?

Pre-diagnosis
- **Before** you were diagnosed, what did you know about cancer?
  - From where did you receive that knowledge?
- How serious did you think cancer was as a disease?
- Did you expect that you might get cancer yourself? Why/why not?
- When you started to feel unwell or discovered first symptoms, who did you talk to about your symptoms?
- How did you know where to go?
- What made you decide to see a health provider/traditional healer? What symptoms did you have?
  - How long did you wait before seeking care after you noticed symptoms?

Diagnosis
- How were you diagnosed?
- How was your diagnosis shared with you?
  - And were there other ways in which you were told about it?
- Who were you with when you were first told about the diagnosis?
- What was your reaction?
- What information about the disease did you receive when you were diagnosed?
- Did you ever feel that a provider was giving you wrong information? Why?
  - Did you seek a second opinion?
- Did you seek information about the disease from other sources after diagnosis? Please explain.
- What were the next steps given to you after diagnosis? Did you understand them?
- Were you given information on support groups?
- Who did you tell about your diagnosis, and why did you tell these people?
  - And who did you choose not to tell?
- How did people react?
- What should family and community members know, when someone close to them is diagnosed with cancer?
Treatment
When we talked in the beginning, you said that your treatment includes ____________.
Let us talk more about this.

- What was explained to you in relation to treatment and care?
- Did you seek information from other sources? Where did you look for it?
  - Where did you/are you getting information from?
- What additional information would you have liked to receive about treatment?
  - From who?
  - How would you like to get the information?
- How far along the treatment plan are you now?
- Do you believe that the cancer treatments that are available to you work well to fight the disease?
  - Do you think some of the treatments work better than others? Please explain briefly.
- What does a cancer patient have to do to make it through the process? And what else?
  - Do you feel that you are able to do this? Why/why not?
- Have you considered other types of care? What / why?
- Who was your primary care giver?
- And who was your main support person, if not the same?
  - How did he/she support you?
- Who else might you have wanted by your side?
- If you think back to the full journey you have gone through so far, what are the main other challenges you went through that we haven’t talked about yet?
- What are your fears, for now and for the future?
  - How are you managing these fears?
- What would you have liked to be done differently?

Current sources of Information and education about cancer
- What more would you like to know about cancer?
- Where do you receive information about cancer?
- Which would be your preferred way to receive information about cancer?
- And who would you talk to for more information? Or where would you go?
- What would be your preferred language for information about cancer?
- Who else do you think needs better information about cancer? Why?

Winding up
- Do you have any additional comments, or questions in relation to what we have talked about?