

Appendix 1

Interview schedule: Colorectal cancer

Introduction

- Call participant and confirm that it is still a good time to talk (comfortable, minimal distractions).
- Remind of aim of interview/study and format of interview. Also remind that interview will be recorded, information will be kept confidential, and will take 30–60 min.
- Reassure that they can stop the interview at any time or choose not to answer specific questions.
- Reconfirm consent to take part and ask if there are any questions before beginning the interview.

TOPIC 1: Diagnostic route

Tell me about how you came to be diagnosed.

- (If symptomatic), what prompted you to seek help?
- (If investigated for another problem), what happened to raise suspicion of cancer?
- How did you feel about the length of time before first seeing a doctor?

TOPIC 2: Diagnostic interval

Tell me about the first time you saw a GP/doctor.

- What was your prior relationship with this GP/doctor/clinic?
- How did the GP/doctor initially react (sense of concern/urgency)?
- How did you feel about the length of time in primary care/with first doctor?

Tell me about tests you had before you were diagnosed.

- What tests did you have?
- What was the test that found cancer?
- Before you had the test, was cancer mentioned/raised? Can you recall when cancer was first mentioned/ raised?

Tell me about the referral for the test that found cancer.

- What did you understand about having this test/did the doctor explain why you were referred?
- Was there a sense of urgency in this referral?
- When this referral was made, did the doctor discuss or provide information about public vs private healthcare options for the test? (Do you have private health insurance?)
 - Did your doctor talk about any differences in the two systems in their cost, wait time, distance, other needs (eg language, mobility, transport)?
 - Did you feel this was explained clearly?
- Did having/not having private insurance influence the referral for this test? How?

- Did the doctor discuss or provide information about anything else in relation to the test, such as:
 - Cost, waiting times, where/distance, other needs (eg language, mobility, transport)?
 - Did you feel this was explained clearly?
 - Did these factors influence the referral for this test? How?
- Did you have a say in who and where you were referred?
 - If yes, what did you consider in making a decision (eg family/friends, cost, quality of care, distance)?
 - If no, why do you think you were referred to that particular provider?
- Did you ever consider switching/changing to receive the test through (public or private) health services? What prompted this thinking?
 - Did you change? Why/why not?
 - If yes, were there difficulties making the change (eg cost, wait time, other implications)?
- Who organised the test booking/appointment? How was this for you?
- How was the communication/coordination between health professionals/between health professionals and you?
- How did you feel about waiting times for the test and to receive results?

TOPIC 3: Pretreatment interval

Tell me about when you found out you definitely had cancer and how you were referred to a cancer specialist/ for treatment.

- What was the role of the referring doctor?
- Was there a sense of urgency in this referral?
 - How long did it take to see a specialist? How did you feel about this waiting time?
- When the referral to the specialist was made, did the doctor discuss or provide information about public versus private healthcare?
 - Did the doctor talk about any differences in the two systems in their cost, wait time, distance, other needs (eg language, mobility, transport)?
 - Did you feel this was explained clearly?
- Did having/not having private insurance influence the referral to the specialist? How?
- Did the referring doctor discuss or provide information about anything else in relation to this specialist referral, such as:
 - Cost, waiting times, where/distance, other needs (eg language, mobility, transport)?
 - Did you feel this was explained clearly?
 - Did these factors influence the referral to the specialist? How?

- Did you have a say in who and where you were referred?
 - If yes, what did you consider in making a decision (eg family/friends, cost, quality of care, distance)?
 - If no, why do you think you were referred to that particular provider?
- Who organised the appointment? How was this for you?
- How was the communication/coordination between health professionals/ between health professionals and you?
- Was any information missing? Is there anything you would have liked more information about?

Conclusion

Is there anything else you would like to discuss that you think is relevant to our talk today?

Thank you for your help. We will be combining people's responses to better understand how people come to be diagnosed and treated for cancer.

Tell me about the time between diagnosis and starting treatment.

- When you saw a specialist, did they discuss or provide information about public versus private healthcare?
 - Did the doctor talk about any differences in the two systems in their cost, wait time, distance, other needs (eg language, mobility, transport)?
 - Did you feel this was explained clearly?
- Regarding costs of care:
 - Did you feel that your specialist doctor was transparent about the costs of your care and you were adequately informed?
 - Did your specialist provide you with independent information about the costs (eg additional resources or pamphlets)?
 - Did your specialist advise/lead you to asking about costs and actively invite you to participate in the discussion?
 - Did your specialist mention anything about higher cost = better outcome?
 - Did your specialist talk about the potential for unexpected out-of-pocket costs?
- Did you consider getting a second opinion or having treatment somewhere else? Or ever consider switching/changing to a specialist/hospital in the (public or private) health system?
 - What prompted this thinking?
 - Did you change? Why/why not?
 - If yes, were there difficulties making the change (e.g. cost, wait time, other implications)?
- What was the role of your GP in the time between diagnosis and treatment? What was their role afterwards?
- How was the communication/coordination between health professionals and you?
- How did you feel about waiting time to start treatment?

TOPIC 4: Support, information and resources

Tell me about any support you received from family or friends in the time to diagnosis and treatment.

- How much were they involved? Was this important to you? Why/why not?

Tell me about information or resources you received in the time to diagnosis and treatment.

- Did you find, or were you given, any information/resources about your cancer, treatment or support services?
 - What was this about? Where/who was this from? What format?
 - Was there any information you particularly liked? Why?