

APPENDIX B: INTERVIEW GUIDE

Patient Interview Guide

For caregiver interviews: rephrase all questions mentioning “you” to “your loved one’s”

At the cancer clinic, patients are routinely asked to complete a screening tool for issues that are commonly important to patients called PPF (Putting Patients First – ESAS-r with Canadian Problem Checklist).

How useful has the PPF (Putting Patients First – ESAS-r with Canadian Problem Checklist) been for you? How did your clinicians review your answers with you at your visit/s? How did your care or treatment plan change because of the answers? Are there any changes you would make to the tool itself? Are there changes you would make to the way it is collected?

Palliative Care and what it means

1. What does palliative care mean to you?
2. Palliative care is an added layer of support for patients and their families or loved ones, who are living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment. Some elements of palliative care are provided by your family doctor and cancer doctors and nurses, while other elements are provided by specially trained doctors and nurses who work with your existing team to provide that extra layer of support, for example in your own home as “palliative home care services”.

How much does this description fit with what you thought about palliative care?
What are your thoughts on the term ‘palliative care’? is there a term that you would prefer to use?

Are you currently receiving palliative care services?

If not...

- a. When should palliative care services be added to your cancer care? When should information about palliative care first be provided to you? How should this information be presented to you (written, website, in person)? Who should be present for these discussions?

If yes

- a. When would you say palliative care was added to your cancer care?
How was it presented to you?

3. What has your experience of palliative care been like so far? Would you change something?

Communication regarding your diagnosis and care

4. How/when/by whom was your diagnosis/diagnoses communicated to you? What went well? What could have gone better?
 - a. Specifically, how was your diagnosis of advanced cancer communicated to you? What went well? What could have gone better?

5. How would you have liked information about your diagnosis to be communicated to you? (website, brochure, youtube video, one-on-one, e-mail, face-to-face discussion?)
In order to have better prepared yourself for your initial visits to the cancer centre, is there any information that should've been provided to you that would've helped you during those visits?
6. Which sources do you currently use for information?
7. Which resources have you received from the TBCC?
8. What is your opinion on the resources you receive during your TBCC (Tom Baker Cancer Centre) visit(s)?' examples are:

<https://myhealth.alberta.ca/Alberta/AlbertaDocuments/Living-Your-Best-During-Systemic-Treatment.pdf>
<http://www.cancercare.ns.ca/site-cc/media/cancercare/support%20knowledge%20hope.pdf>
9. Reflecting on your experiences, what information is lacking?
10. Do you know who to call when you have a question? How about on weekends and weeknights?
11. Have you reached out to anyone before when you had a question or concern? If so, who and approximately how many times?
12. Would you like your care team to contact and check-in on you regularly to see how you're doing or would you prefer to contact the care team when you need to?
13. Who are the current members of your care team? Who would you like to be a part of your care team to discuss your treatments and care?(e.g. Your medical oncologist, Family doctor, family member)
14. From your perspective, ideally how should the palliative nurses and doctors work with your oncologist (cancer doctor)?
 - a. How should your family doctor be involved?
15. Is there anything specific you think could be or should be provided within your community's family doctor's clinic to help you more?
16. When should discussions about homecare supports take place?
17. What supports are most needed for caregivers and what is the best way to provide that support?

Advance Care Planning

Advance Care Planning (ACP) is a process of reflection on and communication of a person's future healthcare preferences. ACP encourages ongoing dialogue between a patient, his or her family, and the health care team that can guide medical decision-making including when a person becomes incapable of consenting to or refusing healthcare.

ACP is Advance Care Planning is a process that helps you to: 1) Think and talk about your goals for healthcare. 2) Create plans that reflect your goals and 3) Document your future healthcare plans.

Should you be ill or injured and unable to speak for yourself, Advance Care Planning ensures that you have someone else to speak for you so your healthcare wishes are heard and respected.

18. When would you like discussions about advance care planning to take place? e.g. Initial consultation (first time the diagnosis of metastatic cancer is discussed) The first follow up visit after the initial consultation, whenever the patient brings it up etc
19. When discussing advance care planning, who should be in the room to support you and/or take part in the discussion?

Cost of Care

20. What additional costs have you incurred due to cancer? (that you had to pay yourself and not covered by insurance)

Before we wrap up, is there anything else that you would like to add or do you have any questions for me?