QUESTION GUIDE

Preamble

1. Thank the participant(s) for agreeing to be part of the research

2. Introduction of researcher and the purpose of the interview/focus group:

a. to understand the experiences of clinicians (doctors, clinical nurse specialists), patients, and relatives around decision-making in advanced pancreatic cancer (APC) treatment, and

b. The possibility of using an online tool to help in this process.

3. Provide information on duration of the interview/focus groups (maximum of 1 hour)

4. Let the participants know that they can stop the interview/focus group at any time.

5. Remind participant(s) that the conversation will be recorded

6. Let the participants know that they are free to not answer any question. There are no right or wrong answers

PATIENTS

Asking about their experience

1. Could you tell me about when you first became unwell?

2. Could you describe the treatment thereafter? (assuming they have started treatment)

3. How is it impacting on your life (work, socially, physically)?

4. What are the major symptoms that you contend with?

5. Describe any appointments with the nurses/doctors that you remember.

6. Describe how your treatments were explained to you.

7. Could you tell me what kinds of decisions you are contending with regarding your treatment? About the information tool

8. How do you feel about using a web-based information tool in providing you with the information that you may require?

9. What functions do you want the tool to do for you?

10. How do you want your caregivers/family/relatives to get involved with the decision-making process of your treatment?

11. What sort of information do you need to decide on the choice of treatment for you?

Conclusion

12. Is there anything else you would like to add? 1

3. What question would you like to ask me?

RELATIVES

About their experience and role

1. Can you tell me how you know [the patient] and if you are involved in any way in their care?

2. What role do you play in the kind of treatment that they are currently receiving?

3. In what ways do you support them?

4. Are you involved in helping them to make decisions about their care?

5. If so, how do you find information to help you? About the information tool

6. How would you feel about an online tool to help support decision-making in APC treatment?

7. Describe what you want most out of an online tool to help you assist [the patient].

Conclusion

8. Is there anything else you would like to add?

9. What question would you like to ask me?

DOCTORS AND NURSE SPECIALISTS

The consultation

1. Can you describe a typical conversation/consultation that you have with a patient with APC during the consultation?

2. How many consultations do you typically have with a patient? How do you come to this number?

3. In your experience, what are the most important pieces of information during consultations about the treatment options for a patient of APC?

4. What are your considerations when offering treatment options to patients?

5. How often do you have conflicting opinions in choice of treatment for your patient?

6. How do you resolve and agree on a path when there is contrary opinion with other specialists involved in the treatment of your patient?

7. How do you involve family members in the consultation?

8. What are the problems you encounter when discussing treatment options with patients with APC? Focussing on APC

9. What are the most important prognostic factors in general to look out for a patient with APC?

10. Based on your experience, what do patients need to know about APC and its treatment? About the proposed information tool

11. What are your thoughts/perceptions about using a web-based, interactive information tool in assisting with this doctor-patient consultation?

12. What would you expect from a web-based information tool to do in terms of providing information for you and your patient during an appointment?

13. Can you describe any information tool/decision aid tool that you have used in the past and why you find it helpful or not?

14. What do you foresee as challenge of using this means of facilitating the process in the consultation (based on your experience)?

Conclusion

15. Is there anything else you would like to add?

16. What questions would you like to ask me?

FOCUS GROUPS: CLINICAL NURSE SPECIALISTS

Preamble

1. Thank the participant(s) for agreeing to be part of the research

2. Introduction of researcher and the purpose of the interview/focus group:

a. to understand the experiences of clinicians (doctors, clinical nurse specialists), patients, and relatives around decision-making in advanced pancreatic cancer (APC) treatment, and

b. The possibility of using an online tool to help in this process.

3. Provide information on duration of the interview/focus groups (maximum of 1 hour)

4. Let the participants know that they can stop the interview/focus group at any time.

5. Remind participant(s) that the conversation will be recorded

6. Let the participants know that they are free to not answer any question. There are no right or wrong answers

The consultation

1. Can you describe a typical conversation/consultation that you have with a patient with APC during the consultation?

2. In your experience, what do you think is most important during a discussion about the treatment options for a patient of APC?

3. How often do you use patient decision aids during consultation?

4. What are your considerations when offering treatment options to patients?

5. How often do you have conflicting opinions in choice of treatment?

6. How do you resolve and agree on a path when there is contrary opinion with other specialists involved in the treatment of your patient?

7. How do you involve the family members in the consultation?

8. What are the problems you encounter when discussing treatment options with patients with APC? Focussing on APC

9. Based on your experience, what do patients need to know about APC and its treatment? About the proposed information tool

10. What are your thoughts/perceptions about using a web-based, interactive information tool in assisting with the medical consultation?

11. What would you expect from a web-based information tool to do in terms of providing information for you and your patient during an appointment?

12. When is the right time to introduce this information tool?

13. Can you describe any information tool/decision aid tool that you have used in the past and why you find it helpful or not?

14. What do you foresee as challenge of using this means of facilitating the process in the consultation (based on your experience)?

Conclusion

15. Is there anything else you would like to add?

16. What questions would you like to ask me? Think-aloud sessions and anonymous survey responses were used for the quantitative data collection.