

Supplemental file 2

Topic guide for the focus groups with oncologists

Introduction:

- Introducing yourself
- I'm ..., the ... investigator for this study. Some of you might know me from previous contact regarding this project.
- Research, background, main research question
 - This research aims to design, test and implement a value clarification tool for patients before they attend the first informational interview regarding their participation in clinical trials. The focus of this study component (the focus group) is on the design of the VCT. To accomplish this goal, we interviewed patients who were referred for an informational interview, and these interviews revealed the life values and themes that they considered to be important in their lives and that also influenced the final choices they make. Based on these interviews, the content of the VCT was designed. We want to learn from oncologists about their current conversation routines, the role of values in their consultations and how they view the use of this tool by the patient.
 - Specifics: purpose of this focus group, place of the focus group in the larger research, main research question
 - The purpose of this focus group is to member check the information we gathered during the interviews and to discuss certain topics that emerged in the interviews in further detail. In addition, a pilot test of the VCT will be presented so that you can see the tools that are available to the patient before they visit you for an interview for the first time.
 - Before we start, we also need to clarify the role/presence of IJsfontein (design company)
 - IJsfontein, the developer of the VCT, is also present here. In the final part of the focus group, they will ask you about the VCT and present a concept. This pilot test was designed based on the themes and values that we extracted from the interviews with patients. We have shared the themes and life values with IJsfontein. Junior researcher 1 also contributed to the content of the tool.
 - Preconditions: safety, confidentiality
 - Recordings and how they will be treated.
1. Introduction: During the interviews, you were asked to characterize the type of patient who attends an informational consultation regarding participation in an early phase clinical cancer trial. With regard to these characterizations, a number of groups could be found: patients with a strong desire for treatment who are motivated and/or who have hope for improvement, patients who are unwilling or unable to give up, and patients who cling to the hospital (and participate, e.g., due to fear or despair), patients who want to participate for the sake of others (family or members of other generations), and patients who ultimately do not think that participation is worthwhile after they have heard the content of the trial.
 - a. Do you recognize these types of patients, and did we miss certain types?
 - b. Which type(s) of patients will benefit most from using the tool?
 - c. Are there any types of patients that you do not think will benefit or are not inclined to use the tool?
 2. A situation in which 'patients and relatives have different wishes/do not agree' is often mentioned as a barrier.

- a. What does the tool possibly mean for the dynamics of the relationships between patients and their relatives?
3. The interviews with oncologists show that patients receive information regarding the upcoming appointment; however, in practice, it appears that an oncologist cannot have any expectations regarding a patient's knowledge of the upcoming conversation because such knowledge varies greatly. However, it appears from the patient interviews that patients also do not know what to expect from the conversation because they have not received or believe they have not received information regarding this topic.
 - a. How do you view this information gap emerging from the interviews? What can be done to address this gap?
 - i. Do you feel that this information gap should be closed in the first conversation with the patient?
 - b. An ideal world was outlined in an interview, indicating the following: the more information you have about the person behind the patient (the factors that drives him, her, or them), the better the conversation will be. Paradoxically, the vast majority of the content of the conversation, if not all of it, consists of informing the patient about Phase I.
 - i. Is this description a correct representation of practice? Is this situation a conscious choice?
 - ii. Can the tragedy of choice occur if the oncologist informs the patient and the patient has to make a choice based on this information? What if these patients are 'utterly lost', i.e., there is no good option to choose? How do you address these tragic circumstances?
4. It emerged from the interviews that life values are sometimes not discussed during the consultation because there is no time to do so, because the patient does not mention this subject or because questions regarding this topic are not actively asked.
 - a. Since it emerged from the interviews that the purpose of the conversation is mainly to inform, (1) what place is given to values in the conversation and (2) what place does this subject deserve in the conversation?

Bridge to 2nd topic: regret and **failure**

5. In one interview, it emerged that it is better not to include people in a study program from the start than to have them drop out after inclusion. How do you view this area of tension?
6. How often do patients regret their decision to participate in a study trajectory or to give feedback about the decisions made during the trajectory?
 - a. Can use of the tool contribute to providing insight in this regard?
7. Introduction: the notions of realism, realistic expectations or sketching a realistic picture with regard to Phase I clinical trials are frequently mentioned in the interviews.
 - a. Why is the emphasis in conversations usually on realism/realistic expectations?
 - b. Who decides what is realistic or unrealistic?
 - c. Why is it important for patients to have a realistic outlook on (the rest of) their lives?

Bridge to 3rd ^{topic}: **palliative care**

8. This project was initiated based on the knowledge that patients for whom standard treatment is no longer available might be eligible for participation in an experimental study. If they 'do not want to participate in such a study, patients can take advantage of palliative care. The interviews with Phase I oncologists produced different results regarding the possibility of

discussing palliative care as an alternative option. Sometimes these interviews indicated that this topic receives too little attention during the first consultation, i.e., that it is secondary to 'treatment' by means of experimental therapy. The patient interviews confirm this finding.

- a. What role do you think the option of palliative care deserves in your consultations?
 - i. Some interviewees noted that the conversation regarding values and the palliative care option should not be held with trial oncologists but rather with the primary or secondary specialists earlier in the care trajectory. What do you think about this claim?
 - ii. Statement: oncologists assume at the **same time** that people do not yet know anything because they are likely poorly or incompletely informed about Phase 1 with regard to the first/second line of care. Should this situation not entail that the patient is also not properly informed of palliative care? Does this situation not entail the responsibility to discuss this topic?
9. Introduction: in the interviews, the word 'treatment'/'treat' was often used to indicate Phase I, while on the other hand you, it was also indicated that misunderstandings frequently occur, such that patients think they will receive a (new) treatment.
 - a. What is the reason for the choice to call Phase I research a 'treatment' (and not, for example, 'participation in an experiment')?
 - b. Does this choice of words help perpetuate the misconception that Phase I is a treatment?