# Supplement 3. Interview guide

Interview guide for evaluation of the question prompt list "Talking about the later stages in life in dementia" Translated from Dutch by a professional translator.

#### INTRODUCTION

First of all, thank you for your willingness to participate in this interview, after you have already assessed the question prompt list in a questionnaire. The purpose of this interview is to elaborate on what you think of the question prompt list and how it might be applied. It would be helpful to refer to the question prompt list you received from us during the interview. Of course we can provide a copy if you don't have it with you. We will also ask you about your views on openly discussing end-of-life care and palliative care in dementia in general.

The interviews will be recorded. Your information will be treated confidentially and analyzed in the secure environment of LUMC. The data used for any publication will not be traceable to your personal data. If you agree, please sign the informed consent form.

Do you have any questions before we begin?

## THE QUESTION PROMPT LIST

- 1. What do you think of the question prompt list in its current form?
  - Possible follow-up question: Which themes are missing?
- 2. What do you like about the question prompt list?
- 3. What don't you like about the question prompt list?
  - Possible follow-up questions: Do you have tips on how to improve these points? If so, what are they?
- 4. Are there parts or factors in this question prompt list that could impede the conversation between you and the patient and (loved one) (family)?
  - a. If yes: Which?
  - b. **If no**: Do you feel that the question prompt list as a whole facilitates conversations?

Possible follow-up question: How can these impeding factors be reduced or resolved?

For interviewer, to the participant:

Explain that the subject of the questions will now shift from the question prompt list to discussing sensitive subjects with persons living with dementia and family/loved ones. Also indicate that there will be more questions about the question prompt list later.

### DISCUSSING SENSITIVE SUBJECTS

- 1. How difficult (or easy) do you find talking about the course of dementia and end of life (care) with patients and family/loved ones?
  - a. (if little experience): Which subjects seem most difficult to discuss? What do you think is the easiest way to make them discussible? Do you think this will become easier over the years (experience)?
  - b. (*if very experienced*): Is it easier for you now than at the beginning of your career? What factors played a role? *If yes*: How do you deal with difficult subjects now and how is that different from the beginning of your career?
- 2. Do you think the subjects highlighted in the question prompt list are easy to discuss in general?
- 3. Are there any subjects you find difficult to discuss with patient and family?
  - a. If yes: Which subjects?
  - b. If no: Are all subjects easy to discuss for you?

    Possible follow-up questions: Does this have to do with your experience regarding these conversations? (if not yet discussed under 1., and then elaborate in same manner) Does the question prompt list (also) contain certain example questions that you find difficult to answer?
    - Possible follow-up question: What would you need to be able to answer these questions?
    - Possible follow-up question: How to act when resistance is sensed from patient/family?
- 4. Have you (personally) found ways to make certain subjects easier to discuss in these types of conversations?
  - a. If yes: How do you go about it?
  - b. If no: What do you need to change/improve your approach?
- 5. Will the question prompt list contribute to initiating/starting the conversation with the patient and family/loved ones? And will it influence the moment of initiation?

## IMPLEMENTATION IN PRACTICE

- 1. When a final version is available, would you want to apply this question prompt list? Why/Why not? *If yes*: How would you want to apply the question prompt list?
- 2. Are there any particular preconditions that must be met in order to be able to use this question prompt list?
- 3. Could this question prompt list also be applied by other healthcare professionals? *If yes:* By whom, and would you recommend it?
- 4. Do you think that question prompt lists should be used more frequently in the future in other fields or for other diseases, when available? *If yes: What fields/diseases?*

## QUESTIONS BASED ON QUESTIONNAIRE RESPONSES

## Explanation of goal:

In the final part of the interview, we would like to hear the physician's opinion, based on certain answers he/she provided in the questionnaire. As the answers to the questionnaires will vary from person to person, our goal is to record a few specific questions based on the answers to make sure all of the physician's perspectives and opinions are heard. This allows us to highlight as many different perspectives as possible.

Questions will partly have the same structure (but may deviate):

- In the questionnaire your answer to question [?] was [?]. We would really like to know what reasoning led to this answer. Can you please elaborate on your answer?
- When physician is positive: How do you think [?] can influence the conversations between physicians and persons with dementia and family/loved ones?
- When physician is negative: What should be changed in your opinion? What do you feel is necessary to do this?