**WP3 Additional questions for all participants at FU2 **

**Annex 1: Interview guide**

**Aims and background**

We aim to gain insight in the access to and (non)-use of services and possible reasons behind this. The use of combined methodology using both qualitative and quantitative outcomes will yield a far broader insight into the reasons why people with dementia and their carers use, or do not use, available services, and these outcomes will be essential for a better alignment with patients’ needs. A timely arrangement of formal care services i.e. a personalised optimal timing (not too soon, not too late) at which the transition from informal care to formal care takes place may offer significant benefits in the future that relate to the quality of life of people with dementia and their carers. Timely service utilization might have important implications such as delaying institutionalisation. Knowledge about enabling and predisposing factors regarding access to care services can advance the state of the art in health systems research into pathways to dementia care, in order to benefit people with dementia and their informal carers.

In order to gain more insight in these issues a few additional *general questions* regarding the timeliness of access to care will be asked to **all** participants. Based on these questions participants will be classified into groups for the analyses of WP4.

* The additional general questions for all participants will be asked during FU2.
* The additional questions are an extension of the service use checklist in Booklet 1 questionnaire 3 “use of services and checklist”. Make sure that you can document the answers to the questions in a clear way.
* For the analyses, please make a clear summary (per question, per individual) that describes the essence of the answers, in English and send this to WP1.

**GENERAL QUESTIONS**

In the service use checklist for all types of formal care the following questions are asked (standard). We have extended these questions: please pay attention to the additions (in italic). Following these questions, please complete the service check-list as previously.

1.     Explain we are interested in the types of services people receive and the reasons people have for taking up some and not others.   
 *“We would like to ask you a couple of questions with respect to care and service use for people with dementia. You might be using certain types of care, or you might have chosen to not use any services. Anyhow, we are very interested in your experiences, and we are hoping you might be able to give us some advice.”*

2.     What type of formal care services are you receiving at the current time, on account of the dementia / memory difficulties?  
*- To what extent are you satisfied with the formal care you are using? (What do you like about it, what do you miss?)*

3.     What were your reasons for accepting these formal care services?  
*- How did you experience the process of finding access to care? What has helped you? What has hindered you?   
- Would you change anything in the process of finding access to care? What would have helped you or what did you miss?*

4.     Were other types of care service discussed with you by the health care professional?

5.     Why did you decline? *Why did you accept? Explore reasons!*

6.     Do you feel that you received care at the right time, too early or too late?

7.     If no formal care has been introduced, do you feel that it should have been?  *-What is the reason for not using formal care?* (*It is important to find the reasons with probes: e.g. if a participant answers that the person with dementia has refused, try to ask additional questions; is it because of the attitude or personality of the person with dementia? Did the health care professional discuss the options with you? Did financial issues withhold you from applying for formal care? Etc.)*

*- To what extent are you satisfied with not having formal care?*

***If no formal care is initiated but people tried to:*** *- How did you experience the process of initiating access to care? What has helped you? What has hindered you?  
-Would you change anything in the process of finding access to care? What would have helped you? (if applicable).*

Based on the above answers to the questions please fill out the following questions (as a researcher). These are considered important to be able to categorize participants regarding the timeliness of care (for WP4 analyses).

1. How did the person with dementia and informal caregiver experience formal care regarding timing?

a The person with dementia received formal care in time

b The person with dementia received formal care too late

c The person with dementia received formal care too early

d The person with dementia did not receive formal care, and both the patient and informal caregiver are satisfied with this situation

e The person with dementia did not receive formal care, and this was considered too late by the patient and informal caregiver or formal care was denied

2. There might be uncertainty regarding the answer (of the previous question 1) due to different opinion between patient and informal caregiver, due to complexity of the situation, or due to another reason. Please indicate how certain you (as a researcher) are on this answer on a scale from 1 to 10, with 1 being very uncertain and 10 being very certain.

Very uncertain 1 2 3 4 5 6 7 8 9 10 Very certain