

Interview Procedure

Part 1: Getting informed consent

- Use the “Informatieblad” to explain to the patient the aim of the study, how the interview will go, voice recording, anonymity and confidentiality of responses, ethical information. You can find all of the necessary information in the “informatieblad”.
- Use the “Informed Consent” form to get the signature of the patient. One copy should stay with the patient and one copy with you. If the participant is unsure about signing the informed consent form, try to explain once again that this is a common procedure that we are required to do. The reason we ask them to do this is that we need to be able to show that they participate willingly, and they are informed about the study. If still they do not want to sign it, you can tell them that they can say it in the recording that they are willing to participate and understand the terms.

Part 2: Introduction and demographics

First, we would like to get to know you a little bit. We have a few general questions about you:		
Q1	Age	How old are you?
Q2	Education	Did you receive any education? <i>Skip if does not apply:</i> Can you read? Can you write? What is the highest level of education that you have finished?
Q3	Household Employment	How many children do you have? Are they still living with you? Do you have a wife/husband? Raising children must be hard to combine with a job. Did you manage to work outside of the house at a job? Are you still working? What job are you doing/did you do? <i>[if applicable]</i> How about your wife/husband?
Q4	Living in NL	Which year did you come to the NL? Which city do you live in?
Q5	Language	What language do you use mostly in your daily life? Is this the language that you mostly use to read/write/speak? What is your level of Dutch? Can you speak Dutch? Can you read in Dutch? Can you write in Dutch?
Q6	Media use	What type of media do you use? For instance: Do you read newspapers? In which language? Do you watch TV? In which language? Do you use the Internet? In what way do you use it? (Facebook, online news, etc.) How do you use the Internet? Do you have access to a: - Smartphone

		<ul style="list-style-type: none"> - Tablet - Laptop - PC? <p>Which language do you use in these tools?</p>
Q7	Religion	<p><i>[Be careful in this question, we just would like to know if they are religious/practicing religion, not everyone is Muslim, so also be careful of different ethnic groups such as Alevites etc.]</i></p> <p>Do you have time to practice religion (<i>if applies</i>: such as going to mosques)?</p>
Q8	Illness	<p>What is your illness? <i>[Use terminology used by the patient to refer to their illness when asking the following questions]</i></p> <p>Where do you have this illness?</p> <p>When did you learn about (diagnosed) this illness?</p> <p>What is the current stage of your treatment?</p> <p>Where are you getting your treatment? (general practice/hospital/other (e.g. physiotherapist)</p> <p>Do you get treatment in Morocco/Turkey?</p> <p>How often do you go there for your treatment?</p> <p>For what type of treatment do you go there?</p> <p>Can you compare those experiences (in MA/TR) with experiences in NL?</p>
Q9	Caregiver	<p><i>[Questions about the person who is with the patient. If there is no one with the patient at the time, you can rephrase the same questions to learn if anyone is there who helps]</i></p> <p>Who is the caregiver?</p> <p>Is this the person who is most commonly with the patient? Why?</p> <p>What are the things he/she does for the patient?</p> <p>Are there more people who help with the treatment of the patient?</p> <p>Who are they and in what ways are they involved?</p>

Part 3: Informational and emotional needs of patients

<p><i>You can use the below paragraph as a transition to this part:</i></p> <p>Once a person gets diagnoses with a disease like yours [cancer / note: use the word the patient used for describing his/her illness], he/she has a lot of questions and concerns. Many patients want to know about, for example, about their disease, what possibilities there are to get treated and to recover, and what the effects of the disease might be on one's daily life. You could, however, also have questions about where to go and how to talk about your disease with family and friends.</p>		
Q10	Information situation patient	<p>What topics do you discuss with your doctor or nurse during your illness? Are there different topics for the different stages of the illness?</p> <p><i>[Stages can be: diagnosis, treatment, after treatment (post-treatment-survivorship, relapse, end-of-life). Ask depending on the stage of the patient]</i></p>
Q11	Additional information needs of patient	<p>What topics would you like to get more information about during the different stages of your illness? This can be on</p>

		topics that are beyond what you discuss with your doctor or nurse.
Q12	Information situation caregiver	[<i>Can directly ask to the caregiver</i>] Do you think the person who cares for you would like to discuss different topics?
Q13	Information search	Do you yourself need to search for information? If yes, what kind of information do you find? Where do you find that information from?
Q14	Missing information	Were there issues that you were not informed about that you wished you were?
Q15	Unwanted information	Were there issues that you were informed about but wished that you were not informed about?
<p><i>Emotional needs [Continue if Emotional needs have not been discussed so far]</i> <i>Introduction paragraph that you can use:</i></p> <p>Patients might not only need information and explanations, but might also face emotions, such as concerns about the future, treatment, or what is going to happen. It might also be difficult for you to discuss with others what emotional struggles you experience.</p>		
Q16	Missing emotional info:	Are there any worries that you would like to discuss or get more information about from your doctor or nurse?
Q17	Unwanted emotional info:	Are there any worries that your doctor or your nurse brought up that you rather did not want to discuss?
Q18	What is most difficult for you? What was most difficult for you?	
Q19	Overall satisfaction	How satisfied are you with the care that you received so far? <i>[If patient says satisfied and stops]:</i> Are there any points that you are not satisfied with? <i>Note: answers to this question can become lengthy. If this is the case, cautiously try to direct the patient to the next question and say that you will come to this topic back later.</i>

Part 4: Health Communicator

You can use the below paragraph as a transition to this part:

Now, you have indicated which issues you think are the most important to discuss and which information you would like to have. We would like to know if the tool we are going to use offers possibilities to provide this information and to discuss your concerns. In order to make communication with the doctor and information better match the needs of the patient, a tool has been developed: the Health Communicator. This tool was created by a general practitioner and his family to be able to ask the patient questions in their own language in order to be well aware of the patient's complaint before the medical encounter. Because the patient answers questions before the consultation, the patient and the doctor are better prepared for the conversation and the conversation can run better. The tool is already being used in several general practices and seems to work well. Within the Health Communicator we want to create a special module for patients with cancer/your disease, to provide targeted information, with videos and references to websites and questionnaires to allow you and your doctor to enter the conversation better prepared. We want to use this tool to

improve communication with the doctor and nurse for cancer patients and to better inform patients about all kinds of topics. We have just talked about the most important topics regarding your illness. We would like to know if this module can help in getting or discussing that information. We want to know what the module for cancer patients should be aimed at and which videos should be made. But first we are curious what you think of the tool.

Show the Health Communicator to the patient

Show the Health communicator video and explain during the video very simply that patients can answer some questions about their illness or topics that they are interested in in the GP's offices. Their answers will be translated to the GP's. Later on, they can

https://www.youtube.com/watch?v=_EdmDCAaofU

Load the Questionnaire: "Hypoglycaemie diabetes suikerziekte"

Load the Video: : Astma 0 to 3 jaar. 01. Hoe herken je benauwdheid?"

Load the Websites: "Grenzeloos dementia herkennen in Turks Marokkaans Nederlands Berber"

Question List: As you can see, you can answer questions regarding health problems that your doctors want to ask you in your own language. When you are finished, your doctor or nurse receives the answers in Dutch. This way, there will be no misunderstanding of information. As you can see if you cannot read, you can just listen to it.

Video: Your doctor can send you informative videos and you can watch them at home.

Websites/Web videos: You can also find websites with information as well as web videos.

E-mails: When you login with your information, you can also send emails to your doctor/nurse.

Now that you have learned about the most important aspects of the Health Communicator, we would like to ask you a few questions about it. Of course, just to check, are you familiar with this system? *[If not, continue]*.

Perceived ease of use	<p>What is your opinion about this tool? <i>THEY LIKE IT:</i> What do you like about it? <i>THEY DON'T LIKE IT:</i> What don't you like about it? What would make it better?</p> <p>Where would you like to use this tool? (at hospital, GP's or at home?)</p> <p>Would you use the question list auditory or by reading?</p> <p>Can you use it at home? (Do they have Internet?)</p> <p>How would you use it at home? (Tablet, phone, laptop/pc)</p> <p>Would you like to use it alone or with a family member?</p> <p>Do you think it is easy to use? Is everything clear? Or is it difficult? Why? [Be aware of the possible functional problems with the elderly such as eye-sight, difficulty in reading, motor functions can make navigation difficult)</p> <p>So, based on what you said, how can we make it easiest for you to use?</p>
Perceived usefulness	Can this tool help you with the problems that you mentioned earlier?

	<p>Do you think the HC is useful to use? For what do you find it useful?</p> <p>What kind of your needs do you think it can fulfill? Can be informational and emotional.</p> <p>If not mentioned ask whether HC can fulfill needs on:</p> <p>Specific information regarding illness</p> <p>The treatment (side effects, alternative medicine)</p> <p>The prognosis</p> <p>The rehabilitation</p> <p>Surveillance</p> <p>Coping with the illness</p> <p>Interpersonal/social information</p> <p>Health care system (e.g. when to go where, patients' rights such as their chance to ask for a professional interpreter when undergoing important decision, financial and legal information).</p> <p><i>If the patient finds it not useful: How can we make it useful?</i></p> <p><i>Check if the caregiver would like to add something.</i></p>
	<p>At the moment the Health Communicator tool can present medical questions to the patient before the consultation.</p> <p>Doctors can give you information with videos and websites.</p> <p>You can email with doctor and your nurse</p> <p>What do you find are the most important functions of the HC?</p> <p>What kind of information would you like to receive from the videos or the websites? (example: explanation of the body, cancer, treatments, procedure in the hospitals? + <i>suggest if patient mentioned something earlier</i>)</p>
Additional features	<p>We can also think about some additional functions such as a personalized page for yourself. This personal page can include functions like:</p> <p>Seeing your appointments</p> <p>Explaining the diagnosis in your own language</p> <p>Explaining the treatment plan in your own language</p> <p>An online social community that you can interact with other patients</p> <p>Would you find such a personalized page useful?</p> <p>What would you like to be in it?</p>

End of the interview

Round up the discussion and ask if there are any further comments / suggestions. Discuss the extent to which individual is willing to join at a later stage and / or would like to know the results.

Questions to be filled out by the interviewer

Participant ID	
Sex patient	Woman or Man
Dutch language proficiency patient	Low/Intermediate/High
Date of the interview	
Where did this interview take place? (house/hospital etc.)	
Duration interview	
How was the interviewing environment? (quiet, easy to focus or very noisy, distractive)	
Notes by the interviewer:	