

TOOL 3: GENERIC PATIENT INTERVIEW GUIDE

Making contact with the patient before the interview:

Hello, am I speaking to ... (patient contact = person who completed the questionnaire)? My name is ... (your first and last name). I am contacting you as part of the **NEED** project on "Assessing the needs of patients with [the disease/health condition under study]", in which you recently participated by completing a questionnaire. We sincerely thank you for your contribution and your interest in participating in the interview, which is why I am calling you today.

The purpose of **the individual interviews** is to explore the topics in the questionnaire in greater depth so that we can better understand your needs. The interview will last approximately one hour and a half and will take place either online or in person, whichever you prefer. Please be reassured that the information collected during this interview will be treated confidentially. The interview will take place between you and me. (Disclaimer: if the patient asks you to bring a loved one, this is possible, but you will need to use the same interview guide. This means you will need to direct your questions to the patient first, as it is the patient's opinion that we are primarily interested in. There is no "caregivers" section, as it would not be appropriate to ask these questions in front of the patient).

Just checking, are you still on board to participate in the interview? What day and time would suit you best? (Set the appointment) Would you prefer to do it in person (give the location) or remotely via Teams/Zoom (choose)? The interview can be conducted in (possible languages). Which language are you most comfortable with?

Please note that a confirmation will be sent to you by (choose *text message/email*), with my contact details, so that you can reach me in case of any unforeseen circumstances. I will send you a text message (*or email*) the day before to confirm the appointment.

Thank you once again for participating in this research project. Your contribution is very valuable.

Note for the interviewer:

Structure of the interview guide

The **questions column** contains the questions that the interviewer asks the person (either as they are, or adapted to the context), the **follow-up questions column** contains questions that help to deepen or restart the discussion in order to have enough material to cover the subject, and the **"objective" column** provides the objective of the associated questions. Notes that should not be read to the interviewee are written in *italics* in the document.

Adapting the wording of questions

The wording of the questions has been designed to be as simple and clear as possible. However, the interviewer will adapt the interview to the person being interviewed, and the questions may be asked in a different order, depending on the topics raised by the person. The interview will follow a semi-guided conversation as much as possible, in a natural and spontaneous tone, while maintaining a professional and friendly attitude, free from any judgement.

Preparing for the interview

The content of the interview should be prepared by first reading the person's answers to the **NEED** questionnaire. This will be relevant at several points in the interview. For example, the questionnaire provides information on the person's living situation, their professional activity, any comorbidities,

whether they have been hospitalised because of their health condition, and any impact of the health condition on their reproductive life. You can also note down their answers to open-ended questions, which can be used as follow-up questions. The aim of this interview is to gain a deeper understanding of the unmet needs identified through the questionnaire (what impacts exactly, context, mechanisms, possible solutions, etc.).

Start of the interview with the interviewee (= patient or patient + proxy)

Thank you for agreeing to participate in this interview as part of the project "Assessment of the needs of patients with **[the health condition]**". This study is conducted by a group of researchers from the Federal Health Care Expertise Centre and Sciensano*. My name is ... and I am ... (the interviewer introduces themselves).

The aim of this project is to understand the experiences and the needs of people with **[the health condition]**. This will help us highlight important issues and to suggest ways of improving care for people with **[the health condition]**. How will the interview work? I will ask you questions about your experiences with your health condition and what it means in your daily life, and then I will ask you if you have any suggestions for improvement. I am interested in your point of view and your concrete experiences to enrich the various topics covered in the questionnaire.

The interview will last approximately one hour and a half. Please let me know if you have less time available or if you have any time constraints. I would like to record the interview so that I don't have to take a lot of notes and can focus more on our conversation. This will also allow me to remain faithful to your words when I transcribe the interview for analysis. The recording will be deleted once the transcript has been completed and will not be shared outside of the project. The content of the interview will be anonymised, meaning that no information that could identify you will be published.

Please note that there are no right or wrong answers and that you are entirely free to answer the questions or not. What matters most is your experiences and your opinions.

I will now read the informed consent form to you and explain its content. Then I will ask you to sign it, and I will sign it as well.

	Questions	Follow-ups	Objective
	ICE BREAKER		
1	How are you today?		Encouraging participants to talk Contextualise the interview
2	What have been your motivations to participate in the survey and to accept today’s interview?		
3	How would you explain [the health condition] to someone who is unfamiliar with it?	Did you know about [the health condition] before it affected you ?	
	We will now focus on your experience, starting with your 'diagnostic journey'.		
4	How did you find out that you had [the health condition]?	- What were the first signs or symptoms that made you think something was wrong? - How long was it from the time you first thought something might be wrong with you until you first contacted a doctor to talk about it? Who made the decision to contact a doctor? Who made the diagnosis? - How long ago were you given this diagnosis ? - How long did it take between your first consultation and obtaining the diagnosis? - Did you see several health professionals before the diagnosis was made? - Was the way in which the diagnosis was communicated to you adequate in your opinion (were you told in a sensitive way, in a clear way, with sufficient information)? - How long did it take before you started treatment or follow-up (if applicable)?	Needs related to the diagnosis
5	How does your [health condition] manifest in your daily life?		Context, health needs
	We will now explore the place of [the health condition] in your daily life and review any difficulties you may have encountered as a result of your health condition. We will first try to understand these difficulties before exploring any suggestions you may have to improve the situation.		

6	What kinds of difficulties do you experience in your daily life because of your [health condition]? <i>(If you have noted any comorbidities in the questionnaire, ask the follow-up question associated with comorbidities).</i>	In terms of: – Physical symptoms? – Psychological symptoms (mood, managing emotions)? – Family consequences? – Social consequences? (e.g. going out, seeing friends, etc.) – Impact on your schooling or studies? – Professional consequences? (quality of work, functioning, responsibilities, working hours, need to change jobs, relationship with employer) – Financial consequences? – Daily functioning? – Interactions with other health issues (including dental problems, etc.) – (In your emotional [and sexual] life? <i>(Disclaimer: "sexual life" only if the person brings it up themselves)</i>) – In your desire/ possibility to have children? – Other types of difficulties? ...	Identify the impact on the patient, health needs, and broader social needs
7	How is your [health condition] treated ? <i>(if the patient is taking treatment, otherwise phrase the question in the past tense)</i>	– Prescribed medication – Over-the-counter medication – Surgery – Dietary adaptations – Physiotherapy, occupational therapy, speech therapy, etc. – Supportive or adaptive equipment – Complementary and alternative medicines (acupuncture, osteopathy, homeopathy...) – Group or individual psychological support – Other...	Identification of therapeutic needs
7-	[IF NO TREATMENT] Why are you not receiving any treatment (medication, physiotherapy, surgery, or other)?	– Treatment stopped due to improvement in health – Nothing was suggested – Cost of treatment – Do you distrust the proposed treatments? – Treatment stopped due to side effects or problems taking treatment as directed? - No consultation ? Obstacles to consultation: – Lack of information about who to consult? – Fear of not being taken seriously	Identify treatment pathway needs (access to care, access to treatment)

7+ a) [IF TREATMENT] How did you come to take this/these treatment(s) and/or undergoing surgery (to be adapted according to response in Q7)?		– Fear that healthcare professionals do not have sufficient knowledge of the problem – Financial cost – Other obstacles... – Other reason(s)...	Identify network
b) Who advised/prescribed you these treatments?		– Doctor (general practitioner? Specialist?) – Other healthcare professional – Close one – Other patients via groups – Internet – Other	
c) Do you take the treatment(s) yourself or does it/do they need to be administered by someone else?			Identify information needs
d) When you started the treatment, to what extent was it clear for you what you needed to do?		– Did you receive sufficient information to be able to make an informed choice about treatment? – Did you receive sufficient information to know when and how exactly to take the treatment? – Was the information sufficiently understandable?	
8	[IF TREATMENT] What difficulties do you encounter with regard to different treatments (medication, physiotherapy, surgery, etc.)?	In terms of: – Effectiveness? (i.e., the treatment's ability to combat the disease, reduce symptoms and help you get better) – Side effects? – Complications/consequences of surgery? – Information about side effects/complications	Identify therapeutic needs, information and financial needs related to treatment

		– Convenience ? (e.g. a treatment that must be taken very often, or for which you must go to the hospital, or that must be injected, etc.) – Follow the treatment as advised? – Type of approach (e.g. compartmentalised or too general...) – Availability of treatment? – Out-of-pocket expenses (the price you pay before receiving any reimbursement)? – Reimbursement? Timeframe/procedures – Treatment available? Availability of healthcare professionals to prescribe or administer treatment? – Other difficulties related to treatment...	
9	What difficulties do you face in obtaining treatment? <i>(if the patient is taking treatment, otherwise phrase the question in the past tense)</i>	E.g.: - Distance/accessibility of the place of treatment; - Logistical assistance required - Language or communication - Fear - Lack of time - Lack of information - Interaction with other health problems - Other difficulties	Identify treatment pathway needs (e.g., access to care, acceptability of care, information)
10	How do you rate the medical care you have received for your [health condition]?	What aspects of your care worked well for you? What aspects of care could be improved? Organisation of health services: - Coordination of services (is there a professional responsible for coordination?) - Continuity of care (consistency in the professionals you see, exchange of information and collaboration between different professionals) - Navigating care, knowing which professional to consult and when - Being able to get an appointment when needed - Perceived clinical quality of the care - Impression that healthcare professionals have the necessary expertise - Out-of-pocket cost of care and treatment - Reimbursement	Identifying therapeutic, care organisation, support and financial needs

11	What possible solutions do you see for improving the management of your [health condition]?	In terms of: – prevention (if relevant) – treatment – monitoring and provision of care – information – administrative – financial (prices, reimbursements, etc.) – support, social support – Interaction with other health problems – Other possible solutions	Identify solutions to potential therapeutic, care, support and financial needs
12	How would you describe your relationships with your healthcare providers?	In terms of: – Professional's available time – Listening – Feeling comfortable asking questions – Receiving clear and understandable information – Receiving useful information – Respect – Being taken seriously – Inclusion in decisions – Language – Cultural sensitivity – Punctuality – Communication of information – Trust in professionals	Identify relationship needs with professionals, information needs
12'	[IF DIFFICULTIES EXPERIENCED] How could the difficulties which you have mentioned be overcome, <u>in your opinion</u> ?	What could be done to improve the situation?	Identify solutions to care needs, relationship with professionals, therapeutic needs, and information needs
13	What difficulties, if any, do you encounter from an administrative point of view or with administrative services (e.g. with a government agency, mutual insurance company, insurance company, etc.)?	For example: – Formal recognition of illness – Recognition as occupational disease (if relevant) – Obtaining reimbursement from the health insurance – Other procedures with your health insurance	Identify administrative needs related to the healthcare system in the broadest sense

		– Knowing where to go for each step of the process – Other: ...	
13'	[IF DIFFICULTIES ENCOUNTERED] How could these administrative difficulties be overcome?	What could be put in place to improve the situation?	Identify solutions to administrative support needs
14	To what extent do you feel supported with regards to your current health ?	What positive measures do you perceive? What, if anything, do you feel is lacking in terms of support? Who are the individuals, professionals, or organisations that could help you get the support you are lacking? – Healthcare professionals – Healthcare professionals working in mental health – Social workers – Patient groups – Family and friends (or neighbours) – At work (superiors, colleagues) – At school (teachers, management, students, etc.) – Other: ...	Identify support needs
15	What other problems or unaddressed needs would you like to tell us about?	What other aspects are important for you and you think we should be aware of?	Other unmet needs
	CLOSING		
16	To conclude, among all the needs and difficulties you encounter, which ones do you think should be addressed as a priority by scientists and policymakers?	If you were a policy maker or scientist, what actions would you prioritise to improve the daily lives of patients with [the health condition]?	Prioritisation of unmet needs

Thank you very much for your participation. As explained in the beginning, this interview will be transcribed, anonymised and analysed alongside the interviews conducted with other participants. The data relating to participants will be combined in such a way as to make it impossible to identify any individual from the published data. Your confidentiality and privacy are therefore protected.

The results will be included in the NEED database and published on the KCE website [www.kce.fgov.be and www.health-needs.eu] [timeline].

If completing this questionnaire or thinking about your health condition has caused you discomfort or emotional distress, we encourage you to seek support. You can contact your general practitioner, a psychiatrist or a psychologist. In case of emergency, you can call 112. If you need to talk to someone anonymously and confidentially, you can call 107.

Do you have any final questions or remarks?

Thank you again for your very valuable participation in this interview.

COLOPHON

Title: TOOL 3 : Generic patient interview guide – Supplement

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Disclaimer:

- This report describes a toolbox for NEED studies, based on the NEED team's experiences. As the tools and instruments will be adapted regularly, based on new insights, experiences and knowledge, the user should make sure to use the latest versions.
- The external reviewers commented on a (preliminary) version of the report. They did not co-author the report and do not necessarily agree with its content.
- This report does not contain policy recommendations that require approval by the Board of KCE. It has been reviewed by Belgian experts, but has not followed the formal validation procedure by independent academic experts. The report will likely be updated regularly based on progressive insights.
- Only the KCE is responsible for errors or omissions that could persist.

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