

TOOL 4: GENERIC PROXY INTERVIEW GUIDE

Contacting the PROXY before the interview:

Hello, am I speaking to ... (contact details of the proxy who completed the questionnaire)? My name is ... (your first name and surname). I am contacting you as part of the **NEED** project on "Assessing the needs of patients with **[the disease/health condition being studied]**", 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 interview** is to explore the topics covered in the questionnaire in greater depth so that we can better understand patients' needs. The interview lasts approximately one hour and a half and can be conducted online or in person, whichever you prefer. The information gathered during this interview will be treated confidentially. The interview will take place between you and me, unless you feel that the person you represent could also actively participate in the interview and therefore accompany you. You can either tell me now or confirm this before the interview.

Before we get into the practical details, could you confirm that you are indeed close to the person you are representing, that you spend a lot of time with them, and that you are familiar with their experiences, their situation, and their preferences. Is that correct? *(Disclaimer: if the person asks if another close friend or relative could participate, ask why they are making this suggestion. If this proxy really cannot participate, then make sure that the other person proposed meets the criteria for a proxy).*

Just checking, are you still on board to participate in the interview? Which day and time would suit you best? *(Set the appointment)* Would you prefer to do this in person *(specify the location)* or remotely via Teams/Zoom *(choose)*? The interview can be conducted in *(possible languages)*. Which language are you most comfortable with? You will receive confirmation by ... *(choose SMS/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 very much again for your participation in this research project. Your contribution is greatly appreciated.

Note for the person conducting the interview:

This interview was designed to be conducted with the proxy alone, who will provide information on behalf of the patient. In order to participate, the proxy must have a close relationship with the patient (e.g., a family member, neighbour, volunteer), AND spend significant time with them, AND be familiar with their situation, experiences, and preferences. In the context of this research, professional carers — i.e. people who are paid to provide care services (e.g. healthcare professionals) — cannot act as proxies. Close people with a recognised legal status as a 'carer' are considered proxies, provided they meet the above criteria.

If the proxy is accompanied by the patient for a one-on-one interview, we recommend using the generic patient interview guide.

Structure of the interview guide

The **question column** contains the questions that the interviewer asks the proxy (either verbatim or adapted to the context), the **follow-up column** contains questions (non-exhaustive list) that help to deepen or restart the discussion in order to have enough material to cover the topic, and the **"objective" column** gives the objective of the associated questions. Notes that should not be read to the proxy are written in italics in the document.

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 disease 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 in the questionnaire (exact impacts, context, mechanisms, possible solutions, etc.).

Adapting the wording of questions

The questions have 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 be conducted as much as possible in the form of a guided conversation, in a natural and spontaneous tone, while maintaining a professional and caring attitude, free from judgement.

Patient's point of view versus proxy's point of view

In most questions, we first refer to the patient's point of view, i.e. the proxy reports what they have seen/heard/understood from the patient's point of view. If this is not possible, the proxy will be asked for their own point of view, i.e. the proxy gives their own opinion on the question. It is advisable to clearly guide the proxy towards the desired perspective, which will be indicated in the question.

Terminology used

There are a few challenges to highlight regarding the terms used. We have used the term "**proxy**" to refer to the person participating in the interview. We have used the term "**relative**" for the patient, in the assumption that the patient is a family member of the proxy. This choice was made to avoid an overly familiar tone by using only their first name, and to prevent creating excessive distance by using their first and last names. However, if the proxy is not a relative, use a term that is appropriate (e.g. 'your friend', 'your neighbour'). Furthermore, if the proxy repeatedly uses another term during the interview, such as "my mum", and you feel it is appropriate, you may adopt that term instead.

Specific section on the experience of the proxy as "informal carer"

Towards the end of the interview, we also have specific questions about the proxy's experience if they are acting as an "informal carer". This section should only be asked if the proxy identifies as an "informal carer". To confirm this, a specific question has already been asked in the questionnaire and will be asked again here at the beginning of the interview.

Start of the interview with the interviewee

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 the Federal Centre for Health Care Expertise and Sciensano]. *My name is ... and I am ... (the interviewer introduces themselves).*

The aim of this project is to understand the experiences and 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 this interview be conducted? First, I will ask you a few questions about your role and your relationship with the person you are speaking on behalf of today. Then, I will ask you questions about your *relative's* experiences and state of health. Please adopt their point of view and answer as you think they would do. In other words, today you will be the spokesperson for their experience. It will not be about your own viewpoint, but theirs. However, if for certain questions this perspective is not possible, you may give your personal opinion on the matter, but please clarify when it is your opinion and not theirs. If you do not know how to answer from your *relative's* point of view, please let me know.

This 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 this interview so that I don't have to take a lot of notes and can concentrate better on our conversation. This will also enable me to remain faithful to your words when I transcribe the interview for analysis. The recording will be deleted once the transcription is complete 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 or the person you represent 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. Because you are not the person affected by the disease, it is perfectly normal that you may sometimes find it difficult to answer. Please do not hesitate to let me know if this is the case.

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

	Questions	Follow-up	Objective
	ICE BREAKER		
	Careful, this first part is actually about you and not the person you represent. So report your personal point of view.		
1	How are you today?		Encourage conversation Put the interview into context
2	What motivated you to participate in the online survey and agree to today's interview?		
3	What is your relationship with the person you are representing today?	Please specify: • A family member: for example, parent, child, spouse, partner, grandparent, etc. • A close relationship: e.g. friend, neighbour • Other:	
4	Why can't your relative participate in the interview today?		
5	To help me better understand your interactions with your relative, could you give me some examples of the help or support you provide?	Type of help: E.g. • personal care (such as getting dressed/undressed, going to the toilet, etc.) • mobility assistance (help getting around) • household tasks (such as preparing meals, cleaning, etc.) • Practical support (such as monitoring health, accompanying the person outside to medical appointments or other appointments, etc.) • Moral or psychological support (spending time with the person to provide moral support) • Support with administrative tasks (budget management, contacting health insurance providers, social services, etc.)	
5bis	Based on what we have just discussed, do you consider yourself to be an "informal caregiver"?	For example, a parent helping their child with mobility problems to get around on a daily basis, or a family member or friend helping a loved one regularly with dressing and washing.	

	An informal caregiver is someone who helps a close person because of their illness, on a regular basis, and without being paid to do so. (If the person does not define themselves as an informal caregiver but regularly helps the person due to their illness on a non-professional basis, then you should consider them an informal caregiver and ask them the questions in the specific section at the end of the interview. In this study we are interested in informal caregiving, regardless of the person's "legal status" – in some countries there is legal recognition but this irrelevant here).		
6	Are there other people who help your relative on a daily basis? If so, what kind of help do they provide?		
7	How would you explain your relative's [health condition] to someone who is not familiar with it?	Were you familiar with the [health condition] before?	
We will now focus on your relative's experience, starting with their "diagnostic journey". Please keep in mind that what is important to us is understanding your relative's perspective.			
8	How did your relative find out they had [the health condition] ?	• What were the first signs or symptoms that made you think something was wrong? • How much time passed between when they first felt something was wrong and when a doctor was contacted to discuss it? • Who made the decision to contact a doctor? • Who made the diagnosis? • When was the diagnosis made? • Did he/she see several healthcare professionals before the diagnosis was made? • How long was the time between the first consultation and the diagnosis? • Was the diagnosis communicated in an appropriate manner, i.e. respectful, clear and sufficiently detailed? • How long did it take before he/she started treatment or follow-up (if applicable)?	Needs related to the diagnosis
9	How does your relative's condition manifest on a daily basis?		Context, health needs

	We will now explore the role of [the health condition] in everyday life and review any difficulties your loved one may have encountered as a result of their health condition. We will first try to understand these difficulties before exploring any suggestions your relative may have to improve the situation. Please bear in mind that what is important to us is understanding your relative's perspective.		
10	What difficulties does your relative encounter because of their [health condition]? (If you have noted any comorbidities in the questionnaire, ask the follow-up question related to those comorbidities)	In terms of: • Physical symptoms? • Psychological symptoms (mood, emotion management)? • Family consequences? • Social consequences? (e.g. going out, seeing friends, etc.) • Consequences for their schooling or studies? • Professional consequences? (quality of work, functioning, responsibilities, working hours, need to change jobs, relationship with employer) • Financial consequences? • How will it affect daily life? • Interactions with other health issues (including dental problems, etc.) • (In their emotional [and sexual] life (Disclaimer: "and sexual" only if the person mentions it themselves) • In their desire/ability to have children? • Other types of difficulties? ...	Identify the impact on the patient, their health needs, and their broader social needs
11	How is your relative's condition treated? (if the patient is taking treatment, otherwise phrase the question in the past tense)	• Prescribed medication • Over-the-counter medication • Surgery • Dietary adaptations • Physiotherapy, occupational therapy, speech therapy, etc. • Supportive or adaptive equipment • Complementary and alternative therapies (acupuncture, osteopathy, homeopathy, etc.) • Individual or group psychological support • Other...	Identification of therapeutic needs

12	[IF NO TREATMENT] Why is your relative not receiving any treatment (medication, physiotherapy, surgery or other)?	• Treatment stopped because of improvement in health • Nothing was suggested • Cost of treatment • Does not trust 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 ▪ Fear that healthcare professionals do not have enough knowledge about the problem ▪ Financial cost ▪ Other obstacles... ▪ Other reason(s)...	Identify treatment pathway needs (access to care, access to treatment)
12bis a	[IF TREATMENT] How did your relative come to undergo this treatment and/or resort to surgery (adapt according to the response in Q11)?		
b)	Who recommended/prescribed these treatments?	• Doctor (general practitioner? specialist?) • Other healthcare professional • Family • Other patients via groups, patient associations • Internet • Other	Identify networks
c)	Who is responsible for administering the treatment(s)?	• The person with the condition themselves • The proxy • A relative • A healthcare professional • Other:	

d)	Adapt the wording according to the answer to question c) To what extent did your relative clearly understand what he/she had to do? OR To what extent did the person administering the treatment clearly understand what he/she had to do?	• Did they receive enough information to make an informed decision about treatment? • Did they receive enough information to know exactly when and how to take the treatment? • Was the information easy enough to understand?	Identify information needs
13	[IF TREATMENT] What difficulties does your relative encounter with regard to the various treatments (medication, physiotherapy, surgery, etc.)?	In terms of: • Effectiveness? (i.e., the treatment's ability to fight the disease, reduce symptoms and help the person get better) • Side effects? • Complications/consequences of surgery? • Information about side effects/complications? • Burden? (e.g. a treatment that must be taken very often, or requires hospital visits, or must be injected, etc.) • Will you be able to follow the treatment as advised? • Type of approach (e.g. compartmentalised or too general, etc.) • Availability of treatment? • Out-of-pocket expenses (the price paid before receiving any refund)? • Reimbursement? Timeframe/procedures • Treatment available? Availability of healthcare professionals to prescribe or administer treatment? Other difficulties related to treatment...	Identify therapeutic, informational and financial needs related to treatment
14	What difficulties does your loved one face in getting treatment? (if the patient is taking treatment, otherwise phrase the question in the past tense)	E.g. • Distance/accessibility of healthcare facilities • Logistical assistance required (mobility, etc.) • Language • Fear • Lack of time • Lack of information • Interaction with other health problems	Identify treatment pathway requirements (e.g. access to care, acceptability of care, information)

		• Other difficulties	
15	How do you think your relative assesses the medical care related to [the health condition]? (if the patient's opinion cannot be given, ask the proxy for their opinion)	What aspects of your relative's care have worked well for them? What aspects of the 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 who see the patient, exchange of information and collaboration between different professionals) • Navigating the healthcare system, knowing which professional to consult and when • Being able to get an appointment when necessary • Perceived clinical quality of the care • Impression that healthcare professionals have the necessary expertise • Out-of-pocket costs of care and treatment • Reimbursement	Identifying needs in terms of treatment, care organisation, support and finances
16	What solutions do you think your relative would consider helpful to improve the management of their [health condition]? (if it is not possible to obtain the patient's opinion, ask the proxy for their opinion)	In terms of: • prevention (if relevant) • treatment • follow-up and care provision • information • administrative • financial (prices, reimbursements, etc.) • support, social support • interactions with other health problems) • Other possible solutions	Identify solutions to any therapeutic, informational, care, support or financial needs
17	How do you think your relative would describe their relationship with the healthcare providers they see? (if the patient's opinion cannot be given, ask the proxy for their opinion)	In terms of: • Professional's available time • Listening • Feeling comfortable asking questions • Receipt of clear and understandable information	Identify relationship needs with professionals, information needs

		• Receiving useful information • Respect • Being taken seriously • Inclusion in decisions • Language • Cultural sensitivity • Punctuality • Communication of information • Trust in professionals • Other: ...	
17bis	[IF DIFFICULTIES EXPERIENCED] What solutions do you think your relative would consider helpful to overcome the difficulties you have just described? (if it is not possible to give the patient's opinion, ask the proxy for their opinion)	What could be done to improve the situation?	Identify solutions to any care needs, relationships with professionals, therapeutic needs, information needs
18	What difficulties does your relative encounter from an administrative point of view (e.g. with the authorities, health insurance, insurance, etc.)?	For example: • Formal recognition of illness • Recognition as occupational disease (if relevant) • Obtaining reimbursement from health insurance • Other procedures with health insurance • Knowing where to go for which procedure • Other:	Identify administrative requirements related to the healthcare system in general
18bis	[IF DIFFICULTIES ENCOUNTERED] What solutions do you think your relative would consider helpful to overcome these administrative difficulties be overcome? (if the patient's opinion cannot be obtained, ask the proxy)	What could be done to improve the situation?	Identify solutions to administrative support needs

19	To what extent do think your relative feels supported in their current state of health? (if the patient's opinion cannot be obtained, ask the proxy)	What positive measures does she/he perceive? What support might she/he feel is lacking? Who are the individuals, professionals, or organisations that could help her/him get the support she/he is lacking? • Healthcare professionals • Mental health professionals • Social workers • Patient groups • Family and friends (or neighbours) • At work (superiors, colleagues) • For education (teachers, management, students, etc.) • Other : ...	Identify support needs
20	Are there any other problems or unmet needs that your relative has told you about, or that you think are important if you put yourself in his/her shoes?	What other things are important and should we know about?	Other unmet needs
Please only ask these questions if the interviewee identifies themselves (or you identify them) as an informal carer. We will now move on to the section about you. Here, we are interested in your personal experience as an informal carer.			
21	You told me at the beginning of the interview that you ...(help/support described in question 5). How much time does this take you on a daily basis?		Describe the frequency of the help and make the link between question 5 and 21 bis.
22	What impact does your relative's [health condition] have on your daily life?	In terms of: • Psychological impact (e.g. stress, mental load, or other)? • Physical impact (disturbed sleep, pain, fatigue, etc.)? • Family consequences (e.g. in terms of family dynamics: tension, conflict, overload, etc.)? • Social consequences (impact on your social life, relationships with those around you)? • Consequences for your schooling or studies?	Identify the impact on the proxy, health and social needs in the broadest sense

		• Professional consequences? (quality of work, functioning, responsibilities, working hours, need to change jobs) • Financial consequences? • How does it affect your daily life? • (In your emotional and sexual life?) (Disclaimer: only if the person mentions it themselves) • In your desire/ability to have children? • Other types of difficulties? ...	
23	What aspects of your role as a carer do you find difficult to manage?	In terms of: • Relationship with healthcare professionals: for example, receiving understandable and comprehensive information from healthcare professionals or for example, taking into account the non-medical skills of the informal carer in the care provided • Ability to delegate certain tasks to professionals • Ability to find a good balance between the role of carer and other roles	Identifying information needs and recognising the role of the informal carer
24	What support do you receive?	• Emotional support (support with healthcare decisions, peer support groups, etc.) • Professional intervention (e.g. home nurse) • Division of tasks with other family members • Help to get time for yourself (respite services, day care facilities) • Financial and administrative assistance	Identify the support needs you have encountered
25	What kind of support do you feel you may be lacking ?	Who are the individuals, professionals, or organisations that could help you get the support you are lacking? • Healthcare professionals • Mental health professionals • Associations for carers • Social workers • Patient groups • Peer support groups	Identify unmet support needs

		• People around you (family, friends, neighbours) • Colleagues or bosses at work/school • Other	
	CLOSING (questions to ask all interviewees, regardless of whether they define themselves as an “informal caregiver”)		
26	To conclude, among all the needs and difficulties your relative has experienced, which ones do you think they feel should be addressed as a priority by scientists and politicians? (if the patient's opinion cannot be obtained, ask the proxy)	First elicit the patient's point of view. Proxy's point of view: If you were a policy maker or scientist, what actions would you take as a priority to improve the daily lives of patients with [the health condition]?	Prioritisation of unmet needs
27	Among all the needs and difficulties you encounter as a relative, 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 take as a priority to improve the daily lives of relatives of individuals with [the health condition]?	Prioritising unmet needs of relatives

Thank you for your participation. As explained in the beginning, this interview will be transcribed, anonymised and analysed alongside the interviews conducted with other participants .

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 published in a report on the website [of the KCE www.kce.fgov.be and the website www.health-needs.eu] and included in the NEED database [timeline].

If completing this questionnaire or thinking about your loved one's illness has caused you discomfort or emotional distress, we encourage you to seek support. You can contact your general practitioner, a psychiatrist or psychologist, or the non-profit organisation Aidants Proches. In an 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 4 : Generic proxy 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.
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