

Service users' experiences of hospital-based NHS patient medicines helplines.

Interview Schedule – *Carers*

SECTION 1: Introduction and consent

Thank you for taking the time to speak to me today. Your help with this study is greatly appreciated. I sent you an information sheet about the study. Did you get the chance to read this?

[If yes, continue. If no, read the following: "I will briefly tell you about the study now. Our aim is to learn about the benefits of patient medicines helplines, and ways that they could be improved. We would like to carry out an interview with people who have used the service, about their experiences of this. If you decide to take part, we would like to carry out a brief interview with you over the telephone. The interview will involve me calling you at a convenient time and asking you some questions about your recent experiences of contacting a patient medicines helpline service. It should take approximately 20-30 minutes. The interview will be audio-recorded so that I can keep a record of what you have said. However, all data will be stored anonymously, and in accordance with UK Data Protection laws."]

Do you have any questions about the study, based upon what you read in the information sheet/what I have just told you?

[If yes, answer their questions. If no, continue].

Would you like to take part in the study?

[If yes, continue. If no, thank them for their time and end the call].

Do you have time to carry out the study now?

[If yes, continue. If no, thank them for their time today, arrange a time to call back to carry out the interview, and end the call. When calling back, pick up the conversation from this point].

The interview today will involve me asking you some questions about your recent contact with the medicines helpline service. I would then like to ask you some background questions about yourself. Overall, the interview is likely to take about 20-30 minutes. Although, if you would like to pause at any point, please let me know. Also, your participation is voluntary so if you decide that you no longer want to take part, please also let me know, and we can stop the interview. Stopping the interview will not affect your use of healthcare services nor the

healthcare that you receive.

As mentioned in the information sheet, I would like to audio-record the interview if that's ok with you. The audio recording will be written up word for word so that any identifying information which you may mention in the interview can be edited out before the data is analysed. So, any identifiable information such as people's names or place names that you mention won't be included in the write up of the interview.

Before we begin the interview, I would just like to check that you understand what taking part involves. Please could you briefly describe the aim of the study, and what taking part involves?

[If they are able to do this, continue below. If they have difficulty doing this, advise them that it is important that all participants are able to understand what the study is about and what it involves. If they have difficulty with this, then unfortunately they won't be able to take part in the study today]

Before we begin the interview I also need to check that you consent to take part in the study. I would also like to audio-record the consent process, so that I have a record of it. Is this ok?

[If yes, continue. If no, explain that it is a requirement of the study. If they still definitely do not want to be audio-recorded, thank them for their time and end the call].

[Start recording the consent process]

First of all, please could you tell me your name and today's date?

I will now ask you a series of questions to confirm your understanding of this project. Please answer each one with yes or no.

Please can you confirm that you have received information about the study, that you have had the opportunity to consider the information, ask questions about the study, and have had these answered satisfactorily?

[If 'yes', continue. If 'no', address the concerns and repeat the above consent statement. If still 'no', explain that it is a requirement of the study. Thank them for their time and end the call].

Do you understand that your participation is voluntary and that you are free to withdraw from the study at any time without giving a reason, without your medical care or legal rights being affected?

[If 'yes', continue. If 'no', address the concerns and repeat the above consent statement. If still 'no', explain that it is a requirement of the study. Thank them for their time and end the call].

Do you understand that your anonymised data may be retained for at least 10 years in accordance with the University of Bath Research Data Policy, and that it may be shared and used to support other research in the future?

[If 'yes', continue. If 'no', address the concerns and repeat the above consent statement. If still 'no', explain that it is a requirement of the study. Thank them for their time and end the call].

Do you understand that parts of your interview may be used verbatim in future publications or presentations and that such quotes will be anonymised (i.e., they will not mention you personally)?

[If 'yes', continue. If 'no', address the concerns and repeat the above consent statement. If still 'no', explain that it is a requirement of the study. Thank them for their time and end the call].

Do you consent to take part in this study?

[If 'yes', continue. If 'no', address the concerns and repeat the above consent statement. If still 'no', explain that it is a requirement of the study. Thank them for their time and end the call].

[Stop recording the consent process]

SECTION 2: Collecting background information about the helpline call

Thank you for consenting to take part. The consent process is now complete and I have stopped recording. Before we start the interview, I would like to collect some background information about the helpline call.

To begin with, please could you tell me if you contacted the patient medicines helpline for yourself or for someone else (for example, a partner, or a child)?

[If they contacted the helpline for themselves, use 'Background Information Data Collection Form 1 (Patients)' to collect participants' background information, and then continue from Section 3 using the 'Interview Schedule – Patients' document. If they contacted the helpline on behalf of someone else, use the 'Background Information Data Collection Form 1 (Carers)' document instead, and then continue from Section 3, below].

SECTION 3: Interview with participants (carers)

Thank you for answering those questions.

I will restart the recording shortly, for the interview. Before I begin, I would like to remind you that this interview is about what you thought of contacting the helpline service. If at any point you start providing personal details about the person you care for, I will pause you and guide you back to the questions about your experiences of the helpline service.

After I press record, I will begin by saying your unique participant ID number and the date. Are you happy for me to start recording the interview now?

[If 'yes', continue. If they do not want to be audio-recorded for the interview, explain that it is a requirement of the study. If they still definitely do not want to be audio-recorded, thank them for their time and end the call].

[Start recording]

This is the interview with participant *[ID number]* on *[date]*.

[If they contacted the helpline for someone else, continue below. If they contacted the helpline for themselves, use the 'Interview Schedule – Patients' document instead]

[General probes to be used throughout the interview, where relevant -

- Please can you give me an example of XXX?*
- Please can you tell me more about XXX?]*

[Q1-4 = info about pre-helpline service experience; Q5-8 = info about the helpline service experience; Q9-13 = info about post-helpline experience]

Q1	Prior to using the helpline service recently, please can you tell me what you would typically do if you had a question or concern about medicines?
	<i>For example, a GP, or a community pharmacist, or NHS 111 or NHS Direct.</i> <i>Probe – Have you used the patient medicines helpline service in the past? If so, what was your experience of using the helpline previously?</i>
Q2	How did you hear about the medicines helpline service?
Q3	Could you please tell me why you contacted the medicines helpline service on <i>[date]</i>?
	<i>[Additional questions about the medicines issue/query...]</i> <i>Probe – How did you feel about the medicines before you contacted the medicines helpline service?</i> <i>Probe – What impact (if any) did this issue <i>[use their words]</i> have before you contacted</i>

	<p>the medicines helpline service and spoke to a pharmacist?</p> <p><i>Probe</i> – Please can you tell me your thoughts about the seriousness of the issue/situation <i>[use their words]</i>? (and why)</p> <p><i>Probe</i> – Was there anything else you contacted the medicines helpline service about? (If so, what?)</p> <p><i>[Additional questions about other sources of information...]</i></p> <p><i>Probe</i> – Please can you tell me about any other sources of information that you may have considered using? For example, what these were, and why you didn't contact these. Why you contacted the medicines helpline instead. (Or if you did use any other sources of information before contacting the helpline service, what were your experiences of using them?). What are the advantages of the helpline service compared to the other options you considered?</p>
<i>[If a medicines-related error has been disclosed, go to Q4. If not, go to Q5]</i>	
Q4	You said that there was an error with the patient's medicines/omission/lack of information or instructions <i>[use their words]</i>. Please can you tell me about this?
	<p><i>Probe</i> – What was the error/omission/lack of instructions?</p> <p><i>Probe</i> - How did you realise that there was an error/omission/lack of instructions?</p> <p><i>Probe</i> – When did you realise that there was an error/omission/lack of instructions?</p> <p><i>Probe</i> - How did you feel when you realised that there was an error/omission/lack of instructions? (How did you react?)</p> <p><i>Probe</i> – Has this issue been fully resolved? If so, how?</p> <p><i>Probe</i> - How do you feel about this issue now?</p>
Q5	Please can you tell me about the conversation you had with the pharmacist when you contacted the helpline?
	<p><i>Probe</i> - How well did you feel that the pharmacist understood your query/concern/issue?</p> <p><i>Probe</i> - What did they say or do to make you feel this way?</p>
<i>[If not already known from the previous question...]</i>	
Q6	Please could you describe what information or advice the pharmacist gave you when you contacted the helpline service?
	<p><i>Probe</i> – How well did you understand the information that the pharmacist gave you during the call? (What about your understanding of the information by the end of the call?)</p> <p><i>Probe</i> - Was there anything else that the pharmacist said to you? (If so, what?)</p> <p><i>Probe</i> - How did you feel about the information/advice you received from the pharmacist?</p> <p><i>Probe</i> – Was anything left unresolved? If so, what? Why was it left unresolved?</p> <p><i>Probe</i> – How did you feel directly after using the helpline service? (e.g., worried/anxious, reassured?) If so, why?</p>
Q7	Please can you tell me your thoughts about the medicines helpline service?
	<p>For example, could you tell me about ...</p> <ul style="list-style-type: none"> – what it was like accessing the service? (e.g., time taken to get through to the service; whether you had to call back? (if so, how was this?); whether you had to leave a message and someone got back to you? (if so, how was this?)) – the pharmacist? – the time taken to answer your enquiry? – the amount of information you received? (e.g., was it enough? Too much?) – the advertisements for the service?

	<p><i>Probe</i> - Why were these particular aspects <i>[use their words]</i> <u>helpful</u> to you?</p> <p><i>Probe</i> - Why were these particular aspects <i>[use their words]</i> <u>unhelpful</u> to you?</p> <p>Could you tell me about any other aspects of the service that you may have found to be either helpful or unhelpful?</p>
Q8	Please can you tell me your thoughts about <i>improving</i> the helpline service?
	<p><i>Probe</i> – If you could change the service in any way, to make it more useful for you and other people, how would you change it? (and why?)</p> <p><i>[The probes for the previous question may be relevant here]</i></p> <p>Can you think about any other useful ways in which you would have liked to communicate with the medicines information service? (Why would these be useful?)</p>
Q9	How have things been in the XX weeks since you used the helpline service?
	<p><i>Probe</i> – Can you tell me about any other sources that you may have used to get information or advice about the medicines, since contacting the medicines helpline service? (For example, a GP, another pharmacist, online?)</p>
<i>[If not already known from the previous questions...]</i>	
Q10	Please can you tell me about any changes to the medicines since you contacted the helpline service?
	<p><i>Probe</i> – What were the reasons for making this change?</p> <p><i>Probe</i> – What effects (if any) has this change to the medicines had? (e.g., any positive effects; any downsides as a result of the change)</p> <p>Please can you tell me what you think about the safety of the medicines? (Probe how this was before the helpline use compared to afterwards)</p>
<i>[If not already known from the previous questions...]</i>	
Q11	Please tell me about any other changes you may have experienced since you contacted the medicines helpline service?
	For example, regarding your understanding of the medicines.
Q12	How do you currently feel about the medicines being taken by <i>[the person you care for]</i>?
Q13	How do you currently feel about the hospital or NHS Trust?
<i>(If not already known...)</i>	
Q14	What would you have done about this issue <i>[use their words]</i>, had the helpline service not been available?
	<p><i>Probe</i> – Please can you tell me what you think would have happened had you not contacted the helpline service? (Try to probe for their thoughts about avoided harm).</p> <p><i>Probe</i> – Please could you tell me the reason why you would've instead <i>[use their words, e.g., 'gone to your gp']</i> about this particular issue rather than any other source of support?</p> <p><i>Probe</i> – What would you have done if the helpline service was operated from another NHS Trust in the region to the one where you recently received care? (Probe why)</p> <p><i>Probe</i> – What would you have done if the helpline service was a national helpline, instead of local to you? (Probe why)</p>

Q15	Those are all of the questions that I have about your recent use of the patient medicines helpline service. Although, is there anything else which you would like to say about your use of the medicines helpline service, which you feel would be important to share at this point?
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[Stop the recording]

SECTION 4: Collecting demographic information

To finish the interview session, I would like to ask a few demographic information questions about you.

[Use 'Background Information Data Collection Form2' to collect participants' demographic information].

SECTION 5: Finishing the interview

Thank you once again for your time today, this has been a really helpful interview.

Would you like to receive the results of the study, once they become available? They can be sent to you by email or post – whichever you prefer. Participants' contact details are destroyed at the end of the study. However, if you would like to receive the results of the study, this would mean that I would retain your contact details for a little longer, until the results have been sent to you. Your contact details would be stored securely at the University of Bath and would only be accessible to the research team, which comprises of me and my three supervisors.

[If "yes", collect their desired means of receiving the results – email or postal address. If "no", continue below].

[Arrange sending them the £10 voucher for taking part. This can be either an Amazon voucher, which can be sent by email, or a Love2Shop voucher, which will be sent by post – whichever they prefer]

[Thank them again, and end the call]