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**Conversation guide**

For professionals talking to a patient or carer about involvement in a project for the first time.

***Part 1: Setting the scene***

This initial part of the conversation is about making the patient/carer feel comfortable and giving them an idea of what to expect. At this stage, the aim is to:

* Open the conversation
* Outline the purpose of the conversation to the patient/carer
* Set the expected outcome of the conversation

As part of making them comfortable, consider:

* Where the conversation is taking place (for them)
* Any distractions/considerations that mean the patient/carer isn’t able to focus on the conversation
* Communication barriers that could get in the way
* That the conversation is happening at a time that is right for the patient/carer

Suggested conversation prompts:

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| * *Hi could I speak to (use first name only)*
* *I’m XXX (insert name) from XXX (include role and organisation)*
* *Your details were passed to me by XXX (insert name or team)*
* *Check/verify you are speaking to patient*
* *Is now a good time to have a quick chat about this?*
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If patient/carer agrees/is able to talk to you, move onto next section, if they disagree or are unable then abandon or arrange another time.

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| * *Thanks XXXX (insert their name)*
* *Today I wanted to talk to you for 5- 10 mins about a project we are running which we hope will help us make changes and improvements to the services that you and other patients receive when being treated for (insert symptom)*
* *Is that ok?*
* *And can I just check that if now is convenient, that you are comfortable to have a conversation for the next 10 minutes?*
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***Part 2: The main conversation***

This part of the conversation is about filling in the background detail to help the patient/carer make a decision about being involved.

It needs to cover what exactly would be involved, anticipated timescales, and the methods that would be used. At this stage, the aim is to ensure the patient/carer understands and trusts:

* You and what your role is in the project
* An ‘Elevator pitch’ of what the project is/why it is happening now
* How long the project is expected to last
* Why patient experience is needed in the project
* What the expected outcomes and outputs of the project will be (again in brief)

Suggested conversation prompts:

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| * *That’s great, thank you.*
* *Just so you’re aware I won’t be recording this conversation today.*
* *This chat/conversation is so I can tell you more about my role, who I work for, the project I’m part of and why we would be interested in involving you, as a patient/carer in this work.*
* *At this stage it’s important that you understand that this project has no impact on the treatment you are receiving as a patient.*
* *So, whether you do choose to take part, or you decide not to, this won’t affect the treatment you receive, or any decisions your health care team make about your treatment.*
* *We can’t see any of your medical records – so the only information that we have about you, at any stage of the project, is the information you choose to tell us.*
* *Does that make sense/Is that clear/have I explained that part well enough? Do you need any more clarity?*
* *My role is XXXX (insert brief details) and I am XXX (insert details of role in project/activity)*
* *The project that I am working on is XXXX (insert brief details)*
* *After we’ve spoken, I can send you details of our website where you can read more about me and the team I’m part of.*
* *Do you have any questions so far or are you ok for me to continue?*
* *So, as I’ve mentioned already, the project I’m working on is really keen to understand more about you experiences.*
* *We want to hear from patients and their carers who have had or are having the treatment.*
* *This is why we would be interested in speaking to you.*
* *The project aims to capture the views and experiences of patients and carers.*
* *In those views and experiences we want to hear honest feedback about what was good and what was not so good, and what could have been better, and ideas you have for change so that we can aim to make improvements to the quality of care that patients receive in the future.*
* *By involving you and planning the changes together, we hope that the project will have better outcomes than if we worked alone.*
* *Does that make sense so far/ is there anything about what I’ve just said that you would like me to clarify/do you have any questions so far?*
* *So, the next part is for me to explain exactly how we would aim to gather that feedback.*
* *We expect that we would gather this feedback over a period of XX months and that during that time we would want to hear from you XX times.*
* *How we hear from you, can be something that we agree between us – and to an extent will be guided by you.*

*For example, we could interview you…** *by phone*
* *or we could come and meet with you and interview you face to face*
* *or we could set up a video call using zoom and interview you that way*

*Or if you would prefer…** *we could send you a list of questions that you could respond to*
* *this could be by letter*
* *or by email.*
* *or we could send you a multiple choice questionnaire*

*If you are interested in being involved, we would like to encourage you to tell us what method would work best for you.**Do you have any questions?*  |

The patient may ask some of these questions:

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| * *What will I be asked at each interview?*
* *How long would each session last?*
* *Can I bring someone with me?*
* *What if I want to make a complaint about the service?*
* *How long would I have to answer questions by e-mail or letter or complete a questionnaire?*
* *Will I be reimbursed for my time?*
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| *How does that sound?** *If you don’t have any further questions – I would like to send you some notes covering what we’ve talked about today.*
* *I will also include some information about what would happen next, what consents we would ask you to complete and how we would store and handle your data.*
* *Would you be happy to share an email address with me so I can send you some information – I will only use the address to send this to you?*
* *Would you be happy if I called you in a couple of weeks to see what you think? If in the mean time you want to get in contact with me – you can do so by replying to the email I’ll send you.*
* *Is there anything else I can answer for you today about this project?*
* *Thanks and good bye*
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***Part 3: At the end of the conversation***

* Follow up with an email
* Send information about the project and your team
* Let the therapist/person who referred the patient/carer know you’ve had an initial conversation (if relevant)
* Send the patient/carer a summary of what you’ve discussed
* Include a summary of the next steps including the consents/confidentiality/GDPR and right to withdraw information