

[Organisation name]

Participant Information Sheet and Consent Form for [engagement activity and year]

Organisations need to review and update this document accordingly and complies with their organisation's privacy and data policies, before it is shared with participants.

Why is this study being done?

Thank you for your interest. [Organisation] is working with [partners here] to understand what people's experiences have been with [topic/service here]. To ensure people's needs are properly reviewed before new services are commissioned, [Organisation] is speaking to local people for their feedback.

Who is conducting the study?

[Organisation] has been approached by us, [commissioner] to undertake an independent exercise that will help us understand your experiences about the support we provide you; what has gone well and what could be improved and if there are any services you may like to be offered or given information about. [Optional to add, remove if not relevant:] We would also value the views of your family and carers where possible.

What will I be asked?

You will be asked to answer some questions about your recent experiences using [insert service here and key themes the questions will cover]. You can do this in a few different ways: [list different ways here, e.g. online survey, phone interview, etc.].

[Delete following paragraph if it is not applicable to the engagement activity you are undertaking, e.g. if only doing online and paper surveys.] If you choose to do a phone or video call interview, we would like you to sign the "Informed Consent" form once you are happy to take part.

[Organisation] will then contact you to arrange a time to talk with you and your family and/or carers if appropriate. Due to Covid-19 guidance, this



conversation can take place over the phone or via a video call. It should take no more than [time estimate] and we will ask you a series of questions about the services you receive. There are no right or wrong answers to these questions, we really want to know your thoughts and opinions. With your permission, what you tell [Organisation] will be recorded and written up.

Recordings are helpful as it means the person speaking with you doesn't need to take notes. If you don't want your conversation to be recorded, that's absolutely fine, please let us know and notes will be taken instead. It's possible [Organisation] may need to get back in touch to clarify some things or to ask a few more questions after the first conversation with you. They may do this by coming to see you again or by giving you a call. It will be entirely up to you if you are happy for this to happen.

Participating is voluntary and your responses will be anonymous, so we won't know who has participated and cannot identify you. Taking part in this study will not affect your care or any future care you may need.

The information you give us will be analysed by [Organisation] and [list any others who will review data if applicable] so that we can work out the best way to support people.

Can a relative, friend or carer be with you when <a>[Organisation] comes to talk to you?

Yes, of course. We would value hearing from anyone who has had involvement in your care.

How will my data be used?

Your answers will be anonymous, and we will take all reasonable steps to make sure that they remain confidential. Your email address will be removed from the rest of the answers you give before any analysis takes place and will be deleted as soon as the study finishes. Your email address will not be passed to any third parties.

Because data is anonymised, it will not be possible to withdraw your answers after they have been submitted but you can withdraw from future surveys at any point. Your IP address will not be stored. Data will be stored for a minimum of [input time here, e.g. 3 months] after publication or public release of the findings.



Who will have access to my data?

[Name of data controller] is the Data Controller for this project with respect to your personal data, and so will decide how your personal data is used in the study. [Name of data controller] will process your personal data for the purpose of the engagement activity outlined above.

Responsible members of [Organisation], [list partners for this work] and funders may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines, or as otherwise required by law.

Can you change your mind about being involved in this project after you have said "Yes"?

Yes, it's completely up to you whether or not you take part. If you agree to take part, you are free to change your mind at any time without giving us a reason (you just need to call or email us at the details below).

How do I find out about the results?

Results will be used to inform [review/report/service/etc.], which [will/will not] be publicly available at [location of where the report will be if it will be public].

Who do I contact if I have a concern about the study or I wish to complain?

Please contact [Organisation] at [email] and a member of our team will respond as soon as possible.

You also have the right to lodge a complaint with the Information Commissioner's Office (ICO) should you wish to do so.

Contact details

If you have any questions, need to raise an issue or complaint or wish to withdraw consent at any time, please don't hesitate to contact:

Name: [add here] Email: [add here] Tel: [add here]



Address: [add here] Website: [add here]

[Optional to add, remove if not applicable – e.g. online survey:] Thank you for considering taking part in this study and taking the time to read this information. If you are willing to be involved in this study, please complete the consent form on the next page.



Informed Consent form for the [engagement activity]

Consent to Share Personal Information About								
Title	Mr		Mrs		Miss 🗆	Ms 🗆	Other:	
Surname					Forename	(s)		
Address								
Person Responsible for Acquiring Consent								
Nar	ne							
Position								
Organ	isati	on						
					Declaration	on		
Please read the following statements carefully and place a tick in each box to acknowledge your agreement. If you have any concerns please discuss them with the person who is seeking your consent.								
I confirm that I have read and understood the Participant Information Sheet, or it has been read to me. I have had the opportunity to consider the information and I have been able to ask questions about the project and my questions have been answered to my satisfaction.								
I understand that my participation in this project is voluntary and that I am free to withdraw at any time, without giving a reason.								
I understand that taking part in the project involves [Organisation] contacting me to ask me about aspects of my care. I understand that the information I give will be digitally recorded and then transcribed or written notes will be taken.								
I understand that information I give may be anonymised and used by [Organisation] in future publications, reports or presentations.								
I agree that my information can be quoted in any publication, report or presentation but it will be anonymised.								
I understand that any personal data that could be used to identify me will be removed from the transcripts or notes of my conversations and that I will not be identified in any publications, reports or presentations.								
identify me	understand that personal information collected about me that can dentify me, such as my name, telephone number, email address or where I live, will not be shared beyond [Organisation].							
I consent to taking part in the study								
Name (in CAPITALS)								



Signature (E-signature or typed name also suitable if completely on a computer.)	Date