

BEST PRACTICES GUIDANCE ON CONSENT

Consent is the expressed voluntary agreement to participate in any data collection or service, and it is an essential part of any study, assessment or interview or focus group. This document is designed to serve as a reference point for front-liners while drafting consent statements for data collections carried out at their organizations. It also provides guidance on delivering consent throughout the data collection and includes examples of consent forms.

PRINCIPLES

ENSURE WILLINGNESS TO PARTICIPATE

Consent must express a trustful willingness to participate. By no means it should reflect a vulnerable person's abandonment of their decision-making power.

BE TRANSPARENT

It is important to provide the participant with all the relevant information and options available to her/him so that they can make informed choices and do not develop false expectations.

'DO NO HARM'

Sensitive questions should only be asked by well-trained data collectors. If the participant becomes uncomfortable at any point, or if the data collection triggers disclosure of sensitive details by the participant (e.g. being a SGBV survivor), do not probe into sensitive topics. Instead, offer a referral.

BE CLEAR AND ENSURE UNDERSTANDING

Consent should be presented in a language adapted to the age and capacity to understand of the participant" (as some participants might be educated and/or understand well without extra simplification, which could be stigmatizing).

CONSENT IS AN ONGOING PROCESS!

Consent is not just a "checkbox", but should be continuously reaffirmed and reinstated throughout the data collection. You can achieve this by checking in with the participant to see if they feel comfortable and reassure them of their right to withdraw at any point.

'BEST INTEREST'

Best interest of the participant should always be at the heart of the consultation.

GRANULARITY: ONE SIZE MAY NOT FIT ALL

Remember that you have the option to seek consent separately for different types of data! For example, when collecting location information, when sharing data with other agencies, and when delivering services.

ENSURE CONSENT IS VALID

Consent must explicitly expressed either verbally, through a signature or a gesture from a person having the maturity as well as the mental and legal capacity to legitimately do so. It should never be seen as being granted by default.

WHAT ABOUT CHILDREN?

In the case of children, consent should generally be obtained from the child's parent or guardian. At the same time, consent or assent should also be sought from the child according to the child's age and maturity. "Assent" is the expressed willingness or agreement of the child. The way in which consent/assent is expressed must be appropriate to the age and capacity of the child and to the particular circumstances in which it is given, in line with the child's best interest.

HOW TO DRAFT & PRESENT CONSENT?

1 EXPLAIN THE PURPOSE AND OUTCOMES OF THE DATA COLLECTION

Why did you decide to conduct this study and what do you hope to achieve from it? Ensure the respondent has a clear idea of the purposes of the data collection, as well as the possible benefits, risks and outcomes, especially regarding future access to assistance.

2 EXPLAIN HOW THE PARTICIPANT WAS SELECTED

Was the selection random? Or non-random? Inform the participant based on which factors they were selected and how you obtained their contact details.

3 ENSURE PARTICIPANT IS COMFORTABLE

Carefully monitor for behavioural and verbal signs of discomfort or dissent and make sure you attend to them. Encourage the participant to pause and ask questions if they need.

4 CONTACT DETAILS

Provide contact details for any future questions, requests or complaints. Be prepared for data collection to trigger further questions, particularly relating to services and assistance.

5 RESPONDENTS' RIGHTS TO THEIR DATA

Remind respondents that they are the rightful owners of data relating to them and that they can demand for their data to be handed over to them, modified or removed from your systems within 72 hours. They may also demand to be deleted from your systems ("right to be forgotten").

6 CONSENT IS VOLUNTARY!

Highlight that consent is always voluntary and that the respondent has the right to withdraw or not to answer any question at any point. Mention that there is no penalty or justification sought for withdrawing.

7 TIME COMMITMENT

Indicate the estimated time needed to complete the survey or interview.

8 DATA PROTECTION

Explain the steps you are taking to protect the respondents' data and privacy. Explain the key findings of the privacy impact assessment and the data-related risk assessment (if available).

9 ACTORS AND ROLES

Are there multiple partners in the study? Will any of the data be shared with the host country government? Introduce all partners and stakeholders involved in the process as well as their roles. Explain limits to confidentiality and ask about possible concerns related to privacy.

10 RETENTION POLICY

Communicate how long and where the data will be stored, and how and when it will be destroyed.

EXAMPLES OF CONSENT FORMS

The following few examples are real life examples of consent forms used in past surveys, assessments and other data collections.

EXAMPLE OF A CONSENT FORM USED FOR AN ASSESSMENT:

VULNERABILITY ASSESSMENT OF SYRIAN REFUGEES IN LEBANON (VASYR) 2018

Introduce your survey and your organisation



We are conducting a survey on behalf of the United Nations High Commissioner for Refugees, UNICEF and the World Food Program and we would like to ask you some questions about you and/or your family. Some of these questions relate to your personal data such as your name, the names of your dependents, your address and telephone number in Lebanon.



Explain to the participant what she or he can expect

Why did we select this participant



The aim of the survey is to have a better understanding of the living conditions and vulnerability of Syrian and others refugees in Lebanon. You have been randomly selected. The results of this research will be used by the humanitarian community to improve planning and humanitarian programmes.



Highlight why you're conducting the survey. What's the outcome?

Reassure that participation is voluntary



The interview usually takes about one hour to complete. This is voluntary and you can choose not to answer any or all of the questions. However, we hope that you will participate since the information you will provide is essential to understand vulnerability and challenges faced by Syrian and other refugees.



Reinstate the purpose of the survey

Explain about your data sharing agreements



To ensure the coordination of the needed protection and assistance, we may need to share the collected information, including your personal data, with other humanitarian agencies.

In all cases, measures will be taken to prevent unauthorized dissemination of your personal data in line with international data protection standards.



Reassure the participant of our strict data protection policy

Consent clause to be signed or approved verbally



Declaration: To be signed by the Principal Applicant and all adult members (Electronic signature / Box to be ticked)

I hereby authorize [UNHCR, UNICEF and WFP] to share any such personal data with humanitarian partners on the understanding that this is strictly limited to improving planning and humanitarian programmes and to meet fundamental needs (shelter, food and non-food distribution) and the provision of essential services (medical care, education, social and protection counselling) in Lebanon.



Mention why data sharing is necessary and that you will only share the minimum data necessary for the purpose.

Allow time and space for questions



If you don't have any questions, may I begin now?

EXAMPLE OF A CONSENT FORM USED FOR AN INTERVIEW RELATED TO ASSISTANCE: MULTI-PURPOSE CASH ASSISTANCE (MCAP) INTERVIEW

My name is [interviewer's name] and this is [recorder's name]. We work for [organization] that assists Syrian refugees through multi-purpose cash assistance.

We would like you to take part in an interview. We will be asking you questions revolving around the distribution sessions you attended, the information you received, and the process of withdrawing cash from an ATM.



Explain to the participant what she or he can expect

Manage expectations: indicate whether or not assistance will be impacted



The answers that you give me now will not be shared with anyone outside the organization and UNHCR. Nothing you say will affect whether you continue to get any benefits now or in the future. There is no right or wrong answer.

Participation is completely voluntary, you can choose not to answer any or all of the questions, and you have the freedom to withdraw at any time. In case you refuse, it will not involve any loss of benefits or penalty and your participation does not involve giving up any legal rights.



Highlight that participation is always voluntary and rights are not affected

Mention time commitment required



The interview will take about 30 minutes. Participating in this interview will have no impact on the assistance you receive, but this will help us learn how the gaps that are not filled by the cash assistance in order to ensure that the needs of all beneficiaries are better met.



What will we learn from the interview?

Take time to make the respondent feel comfortable



There is a small risk that talking about these things could make you uncomfortable, but you don't have to answer any questions you don't want to.

Do you agree to participate?
Yes / No

EXAMPLE OF A CONSENT FORM USED FOR A FOLLOW-UP PHONE CALL

Place the survey in a context



Hello, My name is [name] from [organization]. I believe you have been visited by our partners few days ago and you were asked to fill a survey with them.

Did you fill this survey? (Yes, continue, No, thank the respondent and end).

This interview is making sure that we are collecting the correction information so we can better use it to improve how we can assist all Syrian refugees in Lebanon.

All of this is confidential and there is no right or wrong answer, I just want to make sure the enumerators did not miss anything and entered everything as you told them. Nothing you will say will affect if you are receiving assistance now or will receive it in the future.

I will just ask you few random questions, the same as our colleagues asked you few days ago and I will only take 5 minutes of your time.

Do you agree?
Yes / No



Ensure you've reached the correct participant



Mention that there are no right or wrong answers

Provide reassurance that assistance will not be affected (if this is the case)

