

CONSENT

Information Management Working Group

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Aim:

- What to include
- Principles
- How to conduct process



Consent is just a textbox



Once the participant has given us their consent, this means that they have to complete the assessment



The consent-making process doesn't imply any obligations of the participant towards us.



Once the participant has given us their consent, this implies that we will share their data

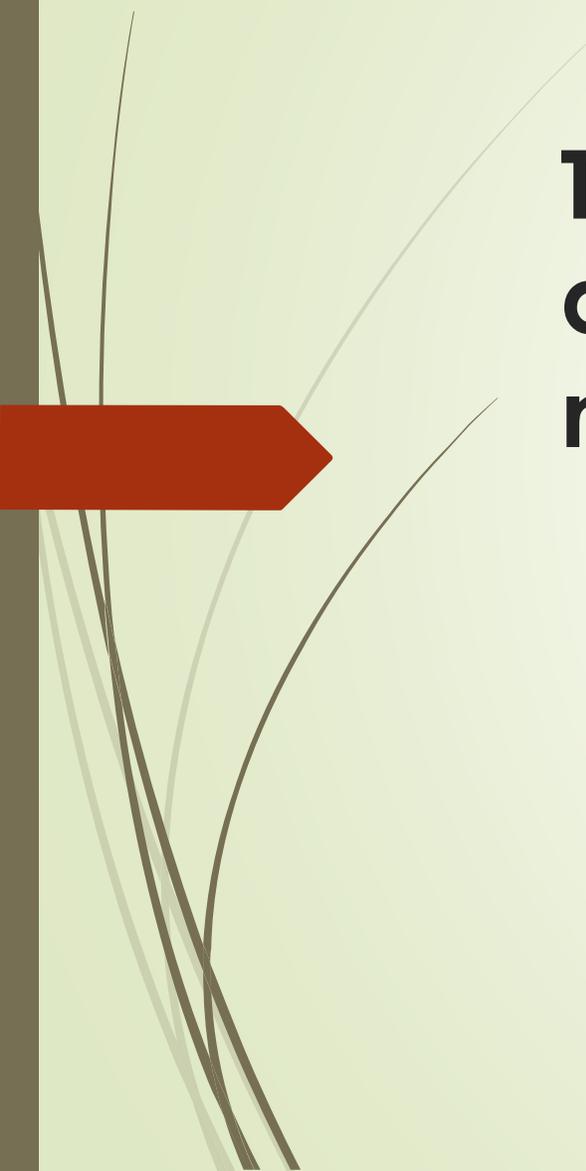


If data may be shared, be very explicit about it:

- ▶ E.g *“I hereby authorize UNHCR to share information with its implementing and operational partners on the understanding that this is strictly limited to what is necessary to meet fundamental needs”*
- ▶ (from UNHCR Registration Declaration Form)



We should follow the “do no harm principle”



The participant could make assumptions based on the consent-making process



There is one-size-fits-all format for consent



**It is sufficient if the participant just skims
through the consent form**



GOING BEYOND



RECAP:

- Checklist
- Principles
- How to conduct process

What is consent?

➤ An agreement that is:

Voluntary

Mutual

Clearly
communicated

Informed

- An **active agreement** (a participant can withdraw it at any time)
- A **prerequisite** - allows us to proceed with the next step (i.e. data collection)
- A **mandatory** part of any data collection
- Consent cannot be implied or assumed

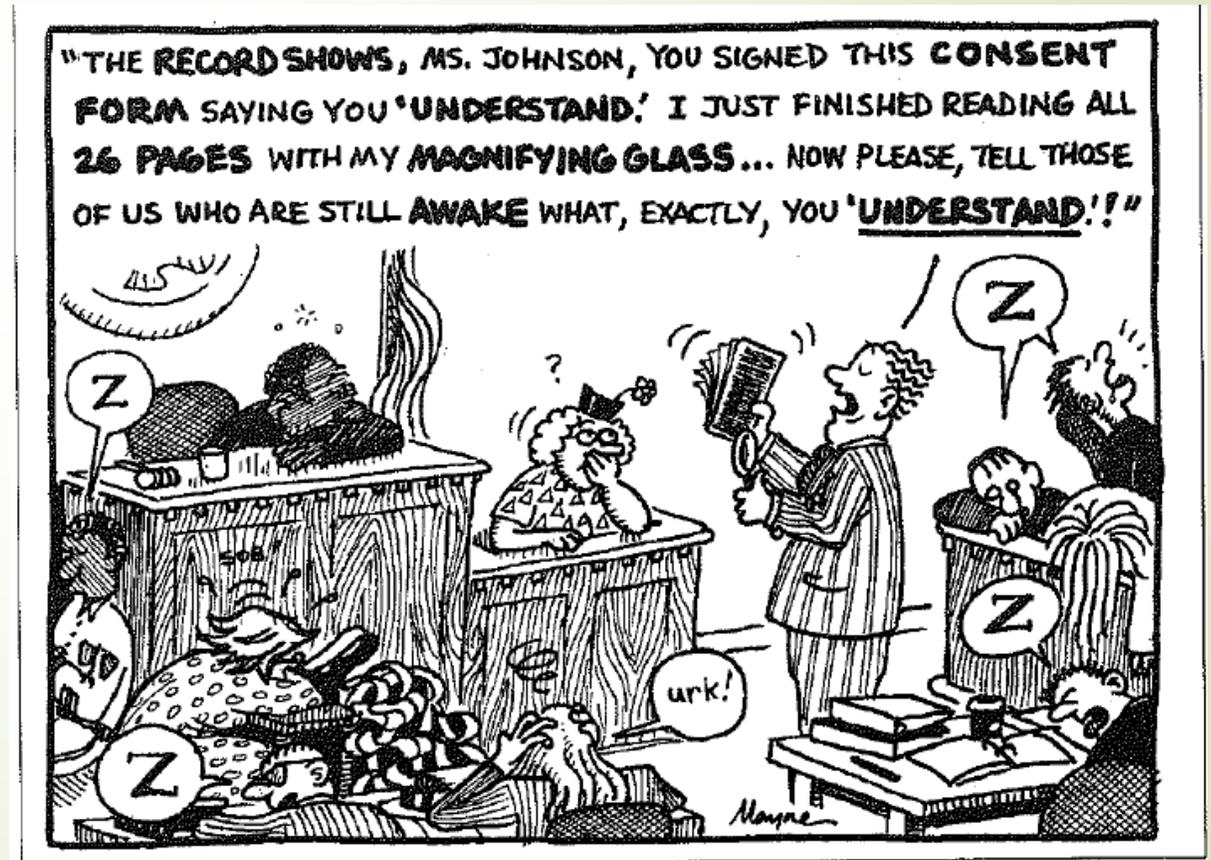


“The single biggest problem in communication is the illusion that it has taken place.”

- George Bernard Shaw

What is the purpose of consent?

- ▶ To provide sufficient information so that participant can make **an informed decision** whether or not they wish to participate





Why is consent important?

- ▶ To respect the participant's **autonomy**
- ▶ To help the participant understand that the **responsibility to make the decision to take part is theirs**
- ▶ To ensure that the participant understands the **purpose of the data collection** and is comfortable with it
- ▶ To provide space to ask questions before data collection starts and discuss their options
- ▶ To mitigate **discomfort** and misunderstanding
- ▶ To follow “do no harm” principle



What should a participant understand?

- ▶ **Why** is their data being collected
- ▶ **How** their data will be used
- ▶ **What** they will or will not receive as a result of the data collection
- ▶ What are the **risks and triggers** associated
- ▶ That their participation is voluntary
- ▶ That they have the right to withdraw at any time

What could happen if we do not obtain informed consent?

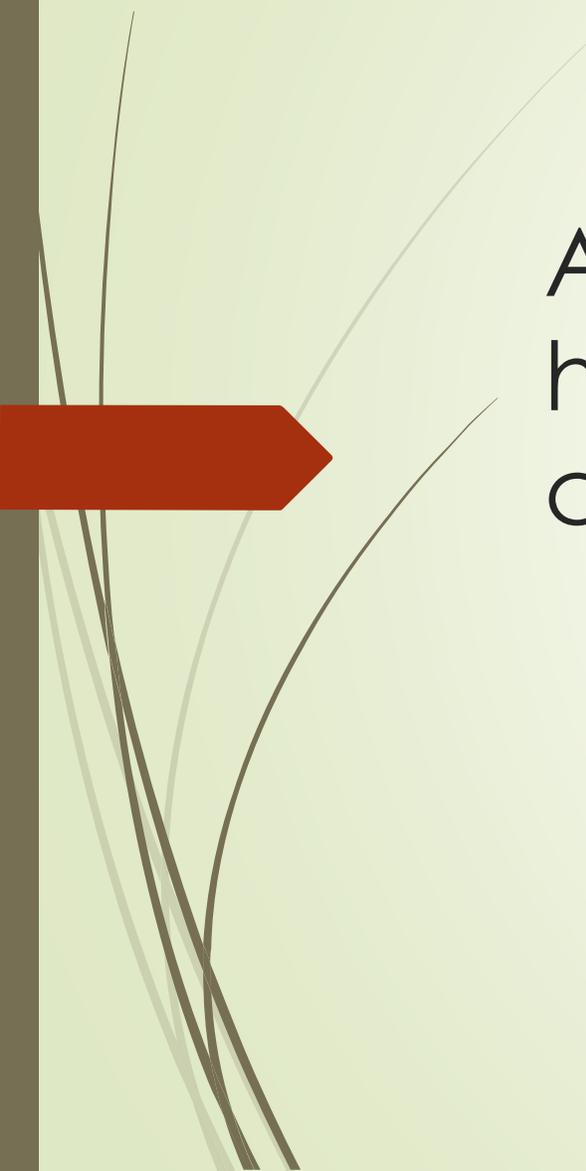
- ▶ **Cannot proceed** with data collection
- ▶ Cannot use data
- ▶ Participants might misunderstand purpose of research
- ▶ This might lead to “**rumours**” being spread
- ▶ Participants might **alter their answers** or behaviour during data collection (e.g. in order to increase their chances of receiving assistance/ asylum)





Things to consider

- ▶ For which **purposes** are we collecting data?
 - ▶ Profiling survey (e.g. VASyR)
 - ▶ Assistance (e.g. cash programmes)
 - ▶ Registration
- ▶ Who is going to use the data?
 - ▶ Some data might be **shared** with partners and/ or the **Government**
- ▶ How does this influence the way we will draft consent?



Any **insights** from consent forms you have drafted for your own data collection?



Best practices for drafting consent:

1. Language

- ▶ Draft consent in the **language of the subject**
- ▶ Use language that can be easily understood
 - ▶ Consider age & literacy level
- ▶ Avoid using language that places pressure on participant or appears to waive the participant's legal rights or release



Best practices for drafting consent:

2. What to include

- ▶ **Who** is conducting the survey
- ▶ **Purpose** of the survey
- ▶ Duration of the survey
- ▶ How was the participant **selected** (Random? Not random?)
- ▶ How will data be **processed** (Anonymized? Not anonymized?)
- ▶ Participation is voluntary
- ▶ Right to withdraw



Best practices for drafting consent:

3. What to include

- ▶ What can the participant **expect as an outcome** of the data collection?
 - ▶ (Will they receive assistance? Or no assistance?)
 - ▶ Outcomes that the data collection WILL NOT lead to
- ▶ Any inconveniences/ **discomfort/ risks** the participant may experience
 - ▶ How are we mitigating for these?
 - ▶ Information on referrals
- ▶ How is the participant required to **protect the data of others**



Best practices for drafting consent:

4. Referrals

- how to best integrate consent and referrals?
- Your **best practices** from the field?



Best practices for drafting consent:

5. Working with minors

- ▶ Assent = consent given by a minor
 - ▶ Parent's/ guardian's consent
- 



CONSENT EXAMPLES

1. Phone call questionnaire

Introduction: Hello, My name is [your name] from [your 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 this information **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



CONSENT EXAMPLES

2. Out of school profiling

Hello, my name is [your name]. We are from [Partner].

We are conducting a **profiling activity** on behalf of a humanitarian organization and we would like to ask you **some questions about your children's education**.

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.

The aim of the exercise is to better understand the **education status** of your child and the **barriers** that are preventing him/her for accessing formal education.

This interview will take about [number] minutes. All the information we obtain will remain strictly **confidential and anonymous**.

If you wish **not to answer a question** or wish to stop the interview, please let me know. May I start now?



CONSENT EXAMPLES

3. Winter Post-Distribution Monitoring

My name is [facilitator's name] and this is [recorder's name]. We [NGO name] working with the UNHCR's programme which supports Syrian refugees across Lebanon through **cash assistance**.

This study will help us understand the impact of providing **winter cash assistance** on refugees' lives and on their ability to meet their basic needs.

We would like you to take part in this interview. The answers that you give me now will **not be shared** with anyone **outside the agency** and **UNHCR**. When we share information from this assessment, it will not include your name or any details that could identify you.

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**.

The interview will take about **45 minutes**. You will not receive any direct benefit from taking part in the interview.

CONSENT EXAMPLES

4. Registration of non-Syrian refugees

I **declare** the information I have supplied on and with this form is complete, correct and current in every detail.

I undertake to **inform UNHCR** of any significant changes to my circumstances while my application is being considered, including any changes to my address and contact numbers, the arrival or departure of members of my household or other changes in the composition of my household.

I understand that in the following limited cases, UNHCR may need to **share my basic bio-data** (my name, the names of my dependents, my address and my telephone number in Lebanon and photograph) to ensure needed **protection and assistance**.

In all cases, measures will be taken to **prevent unauthorized dissemination** of the information.

The **Government of Lebanon** has a legitimate interest in obtaining basic bio data, and therefore I understand UNHCR may **share this with the Government of Lebanon**, upon request.

I hereby authorize UNHCR to **share information with its implementing and operational partners** on the understanding that this is **strictly limited** to what is necessary 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. I understand that **not authorizing UNHCR** to do so will have **a direct impact on my access to assistance**, including cash, food and health assistance offered by UNHCR and/or its partners.

I fully acknowledge and understand that persons involved in **armed activities** do not fall under the protection and mandate of UNHCR. **I commit not to take part** in any armed activities.

I understand that any **misrepresentation** may have negative consequences on my case with UNHCR.



CONSENT EXAMPLES

5. Counselling interview for Syrian refugees with the intention to register

I confirm that I have been **fully counseled** by UNHCR on the Government of Lebanon's instructions to suspend registration as **of 6 May 2015** and as such I understand **that I am not registered** with UNHCR at this point.

I hereby confirm that the information that I have provided during today's counseling interview is **complete and correct**. Should there be significant changes to my circumstances, including changes to my contact details and departure of members of my family I will inform UNHCR.

I understand that the information provided **may be shared beyond UNHCR** with the **Government of Lebanon** and other humanitarian organizations solely for the purpose of assessing my or my family's vulnerability and I agree to this sharing. I understand that **not authorizing UNHCR** to do so will have a **direct impact on my access to assistance**, including cash, food and health assistance offered by UNHCR and/or its partners.

Specifically, I understand that the signing of this form **does not entitle me** or my family to receive **material assistance**.



CONSENT EXAMPLES

6. Renewal interviews for refugees who have already registered

I declare the information I have supplied on and with this form is **complete, correct and current** in every detail.

I undertake to inform UNHCR of any **significant changes** to my circumstances while my application is being considered, including any changes to my address and contact numbers, the arrival or departure of members of my household or other changes in the composition of my household.

I understand that in the following limited cases, UNHCR may need to **share my basic bio-data** (my name, the names of my dependents, my address and my telephone number in Lebanon and photograph) to ensure needed protection and assistance.

In all cases, measures will be taken to **prevent unauthorized dissemination** of the information.

The **Government of Lebanon** has a legitimate interest in obtaining basic bio data, and therefore I understand UNHCR may **share this with the Government** of Lebanon, upon request.

I hereby authorize UNHCR to **share information with its implementing and operational partners** on the understanding that this is strictly limited to what is necessary 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. I understand that **not authorizing UNHCR** to do so will have **a direct impact on my access to assistance**, including cash, food and health assistance offered by UNHCR and/or its partners.

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