Informed Consent

Before we collect data about a person, we must obtain their *informed* consent.

informed

Informed means the person is aware of why you need the data, how it will be used, with whom it will be shared, and what rights they have.

And yes, there is the fundamental, age-old power differential between the humanitarian agency and the refugee or vulnerable person. And so, when the humanitarian agency asks for the data (PII and beyond) of their vulnerable stakeholders, they will often share it without question because they feel they have no choice and fear if they say no, they will not receive assistance.

The thing is, they have choice and they have rights. It is our obligation to ensure they understand them. Often, our policies are more focused ensuring our organisations are legally covered and complying with the relevant laws; too little is said in our policies about the rights of the refugee and how their rights should be a critical consideration in our operations.

Here are three practical considerations:

Informed Consent

Creatively Communicate early, often, clearly and in multiple ways about the rights of those affected especially when it comes to sharing their data, how it is used, the choices they have, the opportunities digital presents and how to live wisely in a digital world. Use SMS, IVR, banners, pamphlets, videos, radio, sound trucks, conduct group chats for specific vulnerable groups (i.e. women and girls) or even a voice recording done by a local leader or respected person.

Listen. We can continually improve if we keep showing up, engaging, and learning. It is critical for us to invest time and resources in listening to those affected, especially in face-to-face communication, asking them how we can help them understand their rights better, the value of their data, and how they can protect it.



Ensure there is Choice and Alternatives for the people we work with. This should be standard practice for us, we must ensure there is an alternative available for people to refuse to provide data but still receive aid and that our frontline staff do not feel they will be accused of fraud because they provided aid without collecting data first.

Expect pockets of the people we work with to be linguistically or digitally illiterate or both.