Rights, Literacy, Control & Choice
By Amos Doornbos

As organisations become more digital and use more digital tools to interact with the world's most vulnerable, we need to ensure we are keeping the rights, and the linguistic and digital literacy, of those with whom we work at the forefront of our thinking. As we build our digital capabilities, we need to consider how we can enable control and choice for the vulnerable in ways they understand, in ways that are appropriate and empowering. This short paper outlines three challenges to be aware of and three critical considerations to discuss.

Rights & Power dynamics

Sitting down in a café, with coffee in hand, I access the Wi-Fi, which requires me to accept the terms and conditions. The T&Cs are 20 pages of legalise protecting the café in line with GDPR laws; my choice is to accept the T&Cs or not access the Wi-Fi. It's the same experience with many websites; accept the cookies they want to put in your browser or don't access the website. Not much of a choice; and all done in the name of data protection and data rights.

When dealing with vulnerable groups (refugees or others), our approach is similar to the café. The majority of organisational data policies are created by legal and audit teams to protect the organisation from lawsuits.

Little is said in our policies about the rights of the refugee and how this is a critical aspect of our operations. We need to ensure we are communicating early, often, clearly and in multiple ways, the rights the refugees are entitled to regarding their data. Specifically, their right to:
- refuse to provide details, but still receive aid
- request for organisations to delete data on them
- understand and be shown how their data is being used by the organisation – where it is stored, who has access to it, etc.

For example, in Colombia, there are local laws stipulating biometrics can be captured, but there must always be an alternative option available. How widely do we communicate this to the Venezuelan refugees?

A fundamental, age-old challenge is the power differential between the NGO and the refugee or vulnerable person. And so, when NGOs ask 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.

In addition to the above, we need to communicate and explain in multiple ways consent – what it is and what people are consenting to and the alternatives/ choices they have. We should be clear what data protection is, data privacy, data security, consent & why it matters. When we don't do this, it is hard to believe we have come anywhere close to achieving consent (even though true, informed consent is unlikely to be possible).

For many vulnerable people, there is a significant need for aid and they will trade their data for it without thinking and without an understanding that they have any options. Frontline staff will try to provide aid when people refuse to share their data, but the audit team doesn't like anonymous distributions because it makes it harder to prove recipients are not receiving double the allowance. To close this loop hole it is becoming harder and harder not to require people to be registered first. The trade-off has become personal data for aid; aid now comes with the mandatory price tag of your data.

Linguistic & Digital Literacy

When you rent a B&B, no one asks you if you know how to cook or turn on a hob, but perhaps they should. I have been cooking and baking for over 25 years, so when I struggled to make the fancy induction hob work at the AirBnB I recently stayed in, I was baffled. Not even a google search for manuals helped. In the end, we called the host to sort it out – something to do with the right pan on the right hob with the right amount of weight.

Digital literacy and responsible data requires us to improve the questions we are asking at the start and to reduce our assumptions. In our rapid assessments we'll ask if people have a phone and a mobile money account. Useful information, but we need to go deeper. Too often, we assume because someone has a phone or an account, they know how to use it. It's important to understand linguistic literacy – can the person read? What languages? What language does the phone work in? Can they read the screen? Who helps them when they are stuck?

Even if a person has a phone, we need to understand if they know how to use it. Perhaps they know how to pick up the phone if it rings or when it beeps it likely means there is money on it. But perhaps they have no idea how to make a call, access the money, or even how to read. Perhaps that's what grandchildren are for. Can they send a SMS? Receive money? Transfer money? Check their balance? Who helps them when they are stuck? Do they have access to electricity for charging? Do they have network connection where they are?

This can feel very basic, but when we overlook these details, our operations fail at the last mile. If our AirBnB host would have asked if I knew how to turn on a hob, I would have said yes, but clearly I didn't know how to work the one in the flat. Additionally, in our questioning of vulnerable people, we need to be careful to uphold their dignity and not embarrass them with our questions. If our approach adds shame to their lives, we may not receive truthful answers and we may do unnecessary harm.

Data Control

In most humanitarian organisations, the registration process digitally captures significant amounts of personally identifiable information (PII) and vulnerability data about the affected person (e.g. Sally), which the organisation needs to store in their systems. Sally has little control over, and knowledge about, how her data will be used and by whom. The organisation needs to manage significant risk due to

management of Sally's information. However, often the registration process is not a one-off, but because there is rarely a master beneficiary list, registration happens multiple times requiring Sally to spend a lot of time providing the same information to different people from different organisations and sometimes people from the same organisation. This frustrates Sally as she sees it as a waste of time, but she feels she has no option if she wants assistance.

Humanitarian organisations have acted as guardians of information about vulnerable people for decades. With the move to digital, the data is now being stored in global central systems for various organisational purposes, but little has been done to enable the individuals, who's data it is, to have any control over it or even any access to it. They cannot use their data themselves. They cannot even decide what data is classed as sensitive or PII. They have little choice or control.

Critical Considerations
Any group of any size is not homogenous. In our operations we need to learn from our marketing colleagues about segmentation. Every group we work with will have differing levels of linguistic and digital literacy (and we should not assume all elderly are digitally illiterate and all youth digitally literate) and our processes must reflect this difference. If we only cater for the majority, we only increase the inequality amongst the vulnerable population. Averages give us an indication, but shouldn't be used for detailed operations; no one has 2.2 kids.

Here are four practical considerations:

1. **Consciously Show Up.** 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.

2. **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 banners, pamphlets, videos, theatre groups, focus groups. Expect pockets of the people we work with to be linguistically or digitally illiterate or both.

3. **Ensure there is Choice** for the people we work with – 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.

4. **Enable Greater Control** for those affected over their data. Where possible, we must give the data we collect about beneficiaries to them. Allow them to access and control it; ideally allow them to use their data however they wish without our involvement (Explore self-sovereign identity options).