Design and Research Ethics

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I am not your data, nor am I your vote bank,
I am not your project, or any exotic museum object,
I am not the soul waiting to be harvested,
Nor am I the lab where your theories are tested…
- Abhay Xaxa, 2016

As implementers and practitioners, we know that all information we collect about the people and households we work with is deeply personal. We want to do all we can to ensure they are informed and willing participants whose private information we protect.

While the idea that people's lives and experiences are centered in HCD and participatory design work, as opposed to starting with the service or technology itself, such approaches alone cannot guarantee the project is ethical. Special attention needs to be paid to avoiding ethics concerns that can occur during the design of the HCD process, data collection activities, and co-creation activities.

Proper research ethics can also mitigate four main concerns:

1. **Confidentiality**: Revealing information about someone could cost participants their job, land them in jail, deport them, cause them to lose members of their social networks, etc.
2. **Harm**: Questions on sensitive topics for the participant could bring up past trauma for them, data in the wrong hands could bring physical or financial harm to them, etc.
3. **Exploitation**: Data collection processes are often extractive, and can replicate the same colonial tendencies often pointed out in the sector.
4. **Data Integrity**: People may give inaccurate answers if they are worried about what would be done with this information, or because they feel coerced into participation because they believe they will lose something valuable if they refuse.

Learn More	• Roglà, J. (2022). Navigating the Ethics of Human Subjects Research. In R. J. Huddleston, P. James, & T. Jamieson (Eds.), *The Handbook of Research Methods in International Relations*. Northampton: Edward Elgar Publishing. • (Hesketh 2016). A tool for considering ethics in Human Centred Design • (D-lab 2015). The Lean Research Framework

Adapted from the d-lab's Lean Framework, iDE and ISF identified six principles for qualitative forms of research -- including HCD research.

Principle	Definition
Transformative	Inspires positive change for participants and researchers through the process of the research.
	Inspires positive change for programs and organizations from the outcomes of the research
Respectful	Protects human and legal rights and maintains the dignity of participants and stakeholders.
	Proactively involves a diversity of participants and prioritizes their satisfaction with the research process.
Relevant	Generates and disseminates rich and useable insights.
	Suitable for the cultural, geographic, and situational context.
Right-sized	Adopts relevant, simple, and convenient tools and techniques.
	Effectively and efficiently leverages time, money, and skillsets.
Rigorous	Employs a systematic approach to sampling, collection, analysis, and interpretation.
	Ensures well-founded, plausible, and justified insights, supported, and refined by existing evidence.
Reflexive	Engages openly about assumptions and other complementary and conflicting perspectives.
	Remains aware and honest about dynamics of power between the participants, researchers, and the broader stakeholders.

The following sections outline some of the basic steps you should take to ensure your data collection is ethical, and when you need to seek formal ethical board approval.

Formal Ethics Approval

- **Government Ethics Boards and IRBs**
  - Your research becomes subject to federal regulations (and requires formal approval) if it meets the legal definition of human subjects research in your country, whether you realize it or not.
  - This definition is generally divided into two parts in each country's context: what types of human subjects data counts, and what counts as

research. **Although data collected for program evaluation or program management purposes is generally excluded from the definition of research for human subjects purposes, monitoring and evaluation research still fall under the standard definition of research used around the globe if the data analyzed is meant to contribute to generalizable knowledge and collected from a living human.**

- Essentially if you are trying to take lessons learned from data collected from living people and make recommendations to others beyond your population of study, or publish your evaluation findings, you still fit the legal definition of human subjects research. This is true regardless of whether you share or publish the data - the fact you are collecting it at all means these protections apply.
- **Additionally, most peer-reviewed publications require proof of human subjects research approval before publishing, even if the country where you are collecting data does not have its own ethics board.**
- So, if you perform experiments, surveys, interviews, focus groups, field observations, or even use pre-existing data sets with identifiable information, your research fits the legal definition of human subjects research in your country, or the country or territory where you will be collecting data, you are subject to the rules of those bodies. Many require formal pre-approval processes.
- If you are required by law in the country where you are collecting data to obtain formal ethical approval, by law you may **not** begin any data collection until the project receives formal approval. Contact the appropriate Ethics Board right away to access the most current form of the application, application fees, timeline, and understand all that will be involved.

- **Organizational Ethics Boards**
  - Even if your research does not need formal ethical approval by a government ethics board in the countries where you are collecting data, **your organization may still want to create internal minimum ethical standards or a mechanism for study review** to identify any potential issues in their research design. An internal review process can provide an extra layer of assurance that your research does no harm to the individuals and households you work with.
- **For more information - country-by-country ethics standards:** click here
- **For more information - formal research ethics training:** click here (paid option) or click here (free).

Informed Consent

- Informed consent is a process designed to give people all the information they need to make an informed decision about participating in design and/or data collection activities through weighing the risks and benefits of giving their personal information to a researcher or organization. Participants must know ahead of time information such as:
  - Any potential benefits through participation
  - Any potential harm that could come to them - including emotional harm from the content of the questions - by participating
  - What will be done with their ideas, prototypes and data and who will have access to any identifiable information
  - They have the right to stop their participation without giving a reason at any point or refuse any question
  - The right to know what participation entails and any future obligations arising from participating
  - What questions the study seeks to answer or challenges it seeks to design solutions for
  - Contact information for the researchers in order to get more information
  - They have the right to lodge a complaint if something was not right during the study/research process
- Part of the informed consent process is ensuring that the participant understands each of these points. If the participant cannot read, you will need to read out each element. Whether you read it out loud or the participant reads a written version, check for understanding of each point along the way.
- Allow them to keep a copy of a document that outlines all the points you are making, regardless of whether or not they consent.
- The informed consent process ends with the researcher asking the potential participant if they are willing to participate in the process. You can have them sign the document, fingerprint if they cannot read, or do a verbal consent process where no signature is needed (this eliminates one more way to match the participant with the data collected). If the participant agrees, you can continue with the data collection.
- Be sure you comply with everything you committed to in the informed consent process.
- **For more information - informed consent templates:** click here.

Put the "Co" in Co-Creation

- **Ensure that participants in the design process are set up to make successful contributions** by fully using all the methods that participatory design approaches employ (Steen 2015).

        - **Promote cooperation** through kindness, patience, and attention to participants.
        - **Foster curiosity and openness** in participants and facilitators to allow spaces for new ideas.
        - **Promote the generation of new ideas together** or combining ideas.
        - **Avoid extracting information from participants in order for the "experts" to design**, and instead put the ideation and design power into their hands. Share power to disrupt traditional power dynamics. Do not assume people need help. Allow participants to be the main contributors rather than receive facilitator ideas.
        - **Avoid going into design processes with predetermined ideas**, as they can overly restrict the data you decide to collect during the discovery phase and stifle participation and creativity from the participants.
        - **Do not ignore the moral or philosophical questions that may arise** during the design process. They may be inherent in a process that asks people to imagine what they believe to be a desirable solution to a challenge. Acknowledge that people may have different moral standards. Work to create spaces that allow for empathy between individuals, and that allow people to design solutions based on one another's experiences, rather than choosing whose experience should count in the design process.
    - **For more information:** click here and read more about the HCD mindsets

Inclusive Data Collection

- **Design and collect data in participants' native language and accommodate those who cannot read.** Facilitators, workshops, surveys, translators and enumerators should use a language that participants are comfortable in. If anyone in any party cannot read or the language is not written, make accommodations so that they can still participate. This enables participant ease, higher data quality, and representative samples.
- **Involve stakeholders - including clients - in the design or research design process** to help you identify elements where ethics can be improved.
- **Share information with participants, their peers, and to all stakeholders** to help mitigate the extractive nature of data collection and provide a more tangible benefit to those participating in the research. *But adherer to Data Protection and Storage and Confidentiality mentioned below.
- **Ensure your sample is inclusive.** While a representative sample may not be needed for every type of design process or research (for example, pilots), consider who you may be leaving out and the effect it could have on your project goals. How will these absences affect the applicability/generalizability of your results? How will people within the communities you are working with perceive

your choice about who you talked to, and will that affect the answers they give during workshops or data collection?
    - **Ensure your collaborators' contributions are properly and fully publicly acknowledged**. Partners in the process should be included as co-authors on any type of report or publications, or other types of contributions should be clearly acknowledged in any text.
    - **For more information - literacy accommodations:** click here or click here.
    - **For more information - translation:** click here.
    - **For more information - participatory methods:** click here or click here.

Minimize Data Collected

- **Keep in mind that every data point you collect, you should be analyzing.** Do not collect data or any questions that will not be used because it:
    - needlessly increases the time the participant and enumerator are spending
    - extra time increases the costs to the participant and project
    - one more piece of data that could risk exposure of the participant
    - one more piece of private data we are extracting
    - one more data point you need to pay to digitally store, etc.
- **Take the survey or other instrument to yourself.** Be empathic, would you want to answer that survey? Maybe you have asked many very private questions all together that make you nervous about revealing so much information, or you wouldn't know how to answer a question ("who is the household head?" is one many people struggle with), or a particular question makes you uncomfortable when thinking through your answer. If there is no clear link to the purpose of the study, then redesign or re-phrase the survey or questions.
- **For more information - lean data collection:** click here

Train Enumerators, Facilitators, and Designers*

**Note: "*Enumerator*" will be used here to describe all three of these roles.*

- **Be aware of the "enumerator effect"** (Di Maio & Fialla 2020). There is a lot of evidence that respondents' answers may be influenced by the facilitator or enumerator - both their behavior during data collection as well as characteristics about them like gender, ethnicity, their social status relative to the respondent, their looks, their accent or language used, and even personality traits. The effect is increased when people ask questions on sensitive topics. **Generally, the enumerator/facilitator should be the same gender as the respondent**, and other characteristics should be balanced across the different ways you have divided participants into groups. Clear documentation of how enumerators/facilitators

were recruited/chosen and trained, and their basic demographic profile, should also be included as annexes to any reporting.
    - Train enumerators to be sensitive to ethics concerns. **If a participant starts to get upset at questions or looks uncomfortable**, the enumerator needs to check in with them and reiterate that they can stop the research at any time without penalty.
    - **Ensure the enumerator understands possible power dynamics between them and** participants. If the participant perceives a power differential between them and the enumerator, it can change their answers and/or make them uncomfortable or even fearful information may be used against them.
    - **Provide the enumerator with resources to give the participant** in case they request help.
    - **Create a protocol for if someone refuses to participate**, chooses to skip a question, or chooses to end their participation in the middle of the activity.
    - **Avoid reacting to participant answers,** and keep neutral body language throughout their interaction with participants.
    - **Ensure the amount of time stated in the informed consent is how long the research takes.** Asking participants to spend more time with us often comes at a tangible cost by preventing them from working.
    - **Do not take photos of potential research participants** or other directly identifying objects like participant houses or posted addresses.
    - **Remember that enumerators can also experience harm and trauma from asking questions, so set them up for success.** They may hear upsetting answers, they may feel unprepared to help someone who requests help due to a question they ask, they may feel overwhelmed by many interviews or hard environmental conditions, or feel uncomfortable asking questions. Predict possible harmful scenarios to prevent them.
    - **For more information - enumerator effect:** click here.
    - **For more information - power dynamics:** click here or click here (page 14).
    - **For more information - photo ethics:** click here**.**
    - **For more information - creating distress protocols:** click here or click here.

Data Protection and Storage

- **Remove direct identifiers** (for example: name, address, government issued identification number, telephone number, e-mail address) in the data set as soon as the data is collected.
- **Store data in a secure place** where it can only be accessed by the research team.
- **Ensure only those specified in the informed consent can access identifiable data.**
- **Ensure the data is deleted** at the end of the period you stated in the informed consent.

- **For more information - data protection:** click here.

Confidentiality

- **Ensure data is only used for the purpose stated.**
- **Do not quote anyone** without their explicit permission or include enough information about someone to be able to identify them (if there is only one female over 80 in that village, then the combination of gender/age/village becomes identifying information).
- **Do not post any organizational or personal social media content that includes photos or other identifying information** of research participants without their explicit permission.
- **Remember that "anonymous" and "confidential" are not the same thing.** "Anonymous" means there is no way to identify an individual, which is very hard to practice and not possible to practice if you have collected any direct identifiers. "Confidential" means the shared information will be private or secret. "De-identified" data is a more accurate way to describe removing personally identifiable information (PIIs). Use your words carefully and purposefully.
- **For more information: click here.**

Third Party Data Collection

- It is common to hire an outside consultant or enumerators to collect data. While we may have less control over the process, you can and should include language in contracts outlining and ensuring they comply with your organization's ethical standards. Part of this compliance should include that enumerators have profiles that correspond to the research, that the "enumerator effect" has been properly accounted for as referenced under Inclusive Data Collection, and that they are properly trained on the research topics.