Data Ethics Guidebook

Cultivating an ethical mindset in research & evaluation

2022

Introduction

"If evidence matters, we must care how it gets made."

– CHICAGO BEYOND

In 2022, the David and Lucile Packard Foundation invited Informing Change to reimagine the Guidebook on data ethics we produced for the Foundation in 2010. In doing so, we considered the evolving ecosystem of values, players, and circumstances in which evaluation is now happening in philanthropy.

While appreciating the insights evaluation work can yield, we acknowledge the ways evaluation can do harm. First, this Guidebook establishes baseline practices for reducing the risk of causing harm through unethical approaches. It also offers more equity-oriented, participatory approaches beyond this baseline to add care or increase the value of participation to communities sharing their data.

This Data Ethics Guidebook is a planning tool and go-to resource for evaluators, Foundation staff, and other social sector commissioners of evaluation. It is concerned with 'data ethics'*—the potential ways in which data-related activities can adversely impact people and society. It offers practical guidance to assess and respond to ethical issues that show up in applied research and evaluation activities. Throughout the Guidebook, Stories from the Field capture the real-world experiences of practitioners grappling with how to do evaluation more ethically.

This Guidebook is intended for anyone engaging in research or evaluation activities outside a formal academic setting, such as nonprofits, philanthropies, or agencies. It's designed for foundation staff, evaluators, and nonprofit partners who may collaborate on evaluation activities. In this context, we want to acknowledge the Guidebook's limitations; it doesn't deliver legal advice for compliance with any laws or regulations governing research. And while ethical issues in philanthropy arise in other areas such as grantmaking, investment strategy, and communications, the scope of this Guidebook does not encompass those wider arenas.

In its broadest sense, ethics concerns itself with the principles that define and guide moral behaviors or actions. The breadth of human endeavors that must consider ethics has expanded alongside developments in technology and an increasingly interconnected world. As our Stories from the Field illustrate, binary prescriptions of right or wrong are overly simplistic. Instead, we offer a framework for developing an ethical mindset that boosts skillfulness in adapting to changing contexts and needs.

At the end of the day, this Guidebook is a tool. You can use it to:

- Explore data ethics issues as they affect research and evaluation today

- Think critically about these issues as they emerge during your work

- Gain insight into how others are wrestling with data ethics issues

- Practice applying a critical, ethical lens to common issues in evaluation and research

We aim to help users of this Guidebook meet the moment with increasing skill, sensitivity, and confidence at every stage of the evaluation process. We encourage you to take up ethical approaches that go beyond mitigating institutional liability and move your institution's evaluation and research processes toward the highest and best ethical standards.

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*   We discuss data ethics issues as they emerge during evaluations conducted by foundations, nonprofits, and the social sector at large. However, many of the issues raised in this Guidebook are also applicable to research processes involving people within the contexts of their respective communities. Evaluation is the systematic determination of the merit, worth, or significance of something, while research is the systemic investigation into something to establish facts. In other words, because data ethics fundamentally deals with what we value (evaluation) and what we perceive as true (research), the words "evaluation" and "research" are both used throughout this Guidebook.

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Using this Guidebook to support ethical thinking throughout the evaluation cycle

The use of data has grown exponentially over the last two decades, permeating every aspect of our lives. Likewise, ethical concerns have multiplied surrounding the ownership, use, and commoditization of personal and collective data. Foundations and their grantees interact with reams of data in myriad ways. Data includes information collected about individuals, such as survey and interview results, but also data collected through grant applications, existing repositories, observations, and other interactions.

> "Data is an extension of a person or groups of people, and therefore should be treated as you would treat people—respectfully. For instance, data are the words, thoughts, feelings, expressions, interactions, and contributions from individual people, it is not abstract, objective nor distant/removed from people."
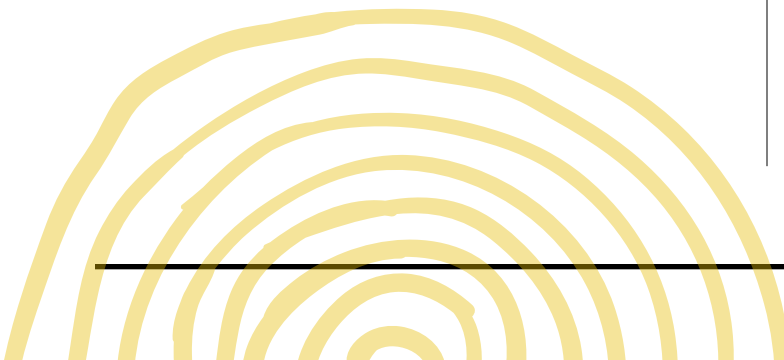
– BILLIE JOE ROGERS, RECIPROCAL CONSULTING

How to use the Guidebook

If you're new to this topic, we invite you to move sequentially through the Guidebook. Anyone more familiar with issues of data ethics may wish to jump to sections of special interest detailed in the Contents. Section I of the Guidebook is organized by the four major phases of evaluation work:

1. **Planning:** Data ethics in the design and commissioning of evaluation

2. **Implementation:** Creating the conditions for participant safety

3. **Analysis:** Guiding interpretation with participant input and context-setting

4. **Reporting & Sharing:** Ethically discerning and communicating findings

Each section summarizes how people working on evaluations may encounter data ethics issues, proposes approaches to identifying those issues, and provides some guiding questions to consider.

While substantive, the Guidebook isn't exhaustive: all possible data ethics issues are not captured. That said, the Guidebook delves into themes that emerged most in conversations with practitioners during our research—from consent and compensation to youth-led research and cross-border evaluations. As the scale and complexity of data processes continue to grow, so will the ethical dimensions in need of consideration. Tools in the associated Data Ethics Toolkit allow you to capture insights and create feedback loops within your team and community.

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Throughout, we share Stories from the Field to illustrate key concepts and the complexity within which today's practitioners are navigating. These and additional stories are also compiled in the accompanying Toolkit where they can be used as fodder for team discussions on data ethics or further reflection.

> "Data ethics is a mindset, rather than a checklist of things."
>
> – TWISHA MEHTA, HUMANITY UNITED

Moving from "doing no harm" toward "adding value and doing with care"

Discussions of ethics in evaluation often return to two overarching questions: **Why is an evaluation being undertaken in the first place?** and **Who gets to make decisions about the evaluation along the way?** Decision-making encompasses what gets evaluated, what will count as credible evidence, and whether, how, and with whom evaluation findings will be shared and acted upon. Asking these questions—which echo those of feminist scholar Donna Haraway's[1] **"What counts?"** and **"Who decides?"**—brings an ethical lens to evaluation.

In an earlier (2010) iteration, the Guidebook assumed a more top-down relationship between "researcher" and "human subject" in which researchers define what constitutes "protection." By contrast, this (2022) Guidebook does not use the term "human subjects" but refers to "participants" in recognition of individual agency and autonomy. A consistent tension within the current and evolving evaluation paradigm is how we seek to balance values—like equity and participation—within the framework of protection.

Our takeaway from the process of updating guidance for data ethics is that we should actively seek to build in care and add value to interactions with participants, not only to avoid unethical approaches. It is essential, however, to meet the basic principles of "doing no harm" first. As discussed in the following pages, local community and stakeholder input are critical when determining what constitutes "doing harm," "building care," or "adding value." It's also possible that these concepts can change over the course of the evaluation cycle. Developing a data ethics mindset is about adopting a stance of continuous learning that allows us to respond with ever greater skillfulness.

BUT WHAT IF...

I have questions or want help translating this into practice?

In the Toolkit, we include a list of Further Reading. Start there to find pointers to additional material of interest. The Toolkit also contains additional ways to integrate ethics into practice: The Framework for Ethical Thinking offers an at-a-glance reference for planning and implementing evaluations. The Learning & Decision Log prompts you to record insights and decisions your team makes about how it wants to do evaluation in future.

SECTION 1

Data Ethics by Evaluation Phase

Planning

Data ethics in the design and commissioning of evaluations

The planning phase involves establishing the evaluation purpose, guiding questions, overall timelines and work plans, and data collection instruments. It encompasses the initial decision-making process that led to asserting the need for an evaluation in the first place. This phase is critical in setting the tone for the rest of the evaluation, including the expected uses of evaluation results. The following section explores how to apply a data ethics lens to five key areas of the planning phase:

- Drivers of Evaluations
- Community Input & Context
- Ethics & Equity in Evaluation
- Evaluation Scope & Methods
- Availability & Interest of Evaluation Participants

Summary of Good Practices During Planning

ADD VALUE/CARE

- Develop evaluation purpose in concert with the priorities of participating communities.
- Select design or methods that add value for participants or will leave them with additional resources or training.
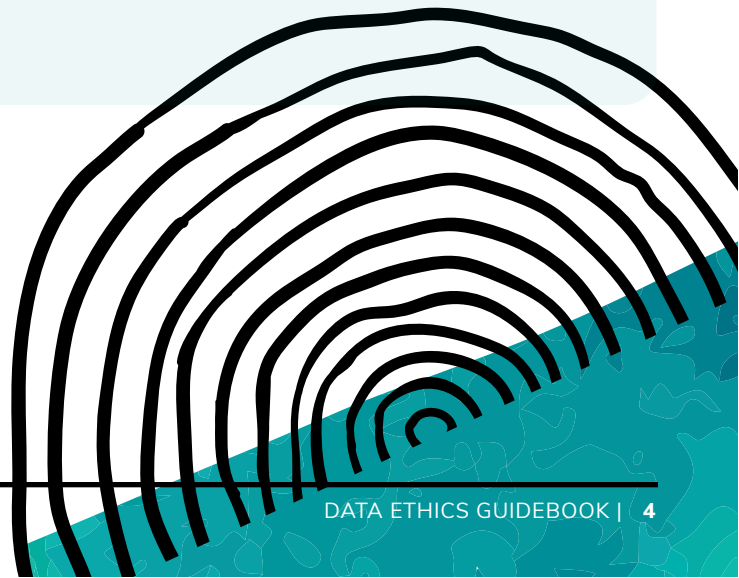
DO NO HARM

- Be transparent about the purpose of the evaluation and the intended use of its findings.
- Consider participants' contexts and expertise in developing evaluation timeline and methods.

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Drivers of Evaluations

Clarity of purpose and transparency can help mitigate power dynamics

ASK YOURSELF

- Who is this evaluation for? Who stands to benefit? Who may have something to lose? Who could be harmed?
- Does the benefit of conducting this evaluation outweigh the risks and costs for those involved? How?
- Who will participate in the design process?
- How are our organizational values reflected in the evaluation design? Are the values of the communities we serve reflected in its design?
- What is the plan to communicate the choices made in the design process with stakeholders in the evaluation?
- Will this project require Institutional Review Board (IRB) approval? If not (or in addition to) an IRB process, should other ethics review processes be used?

Unequal power dynamics are inevitably present between funders, commissioners of evaluations, and those providing data for the evaluation, or whom the evaluation is intended to benefit. Clearly articulating the evaluation's purpose and background—and ensuring a shared understanding among evaluation stakeholders (internal and external to the commissioning organization)—helps level this dynamic by creating transparency around goals and expectations. It also opens avenues to consider whether an extensive evaluation—one that may inadvertently cause harm or discomfort—is the best method for accomplishing stated objectives.

The goal should be to undertake an evaluation only if its benefits merit the time and effort of all stakeholders involved. By plainly acknowledging the drivers of an evaluation, commissioners avoid creating false expectations of the evaluation results; surface and address any real or perceived conflicts of interest between evaluators, their

organizations, and/or other stakeholders; and open avenues for feedback and design considerations from relevant stakeholders.

The "why" is central to the integrity of the evaluation: Could the evaluation objectives be achieved via secondary research, existing data, or other mechanisms? Is the goal to demonstrate to board members and/or other funders that expended dollars have generated sufficient impact (i.e., is the "return on investment" satisfactory)? If so, do the intended users of the evaluation understand both the limits and possibilities of social research to establish causal connections between funding and outcomes?[*] Or is the impetus to consider a change in a foundation's strategic priorities? Is the project a grantee-led effort intended to demonstrate impact in pursuit of diversification of their funding streams? Is the evaluation intended to document and understand a particular model of a program that could be replicated in other communities?

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[*] Lynn, J., Stachowiak, S., and Coffman, J., observe that, as philanthropy has waded into increasingly complex waters, it is increasingly common for its practitioners to recognize "that attribution—definitively isolating whether an outcome would not have happened without a particular effort—is difficult to impossible to attain in complex and dynamic settings." Thus, many foundations have instead embraced the alternative of demonstrating contribution—"determining whether a credible and plausible case can be made, based on evidence, that causal connections exist." Others, however, have reacted to the limits of social research to demonstrate attribution by abandoning causal analysis altogether, thereby failing to explore questions of how and why particular changes have come about [Lynn, J., Stachowiak, S., and Coffman, J. (2021). Lost Causal: Debunking Myths about Causal Analysis in Philanthropy. The Foundation Review, 13(3). https://doi.org/10.9707/1944-5660.1576]

Community Input & Context

Inclusion and representation honor the wisdom and experience of participants while helping the evaluation to avoid blind spots

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ASK YOURSELF

- Who decides which questions are more important to ask or which methods will be used?
- Whose voices/identities need to be represented and included during the evaluation?
- Considering the specific political, legal, and social contexts of the evaluation, is it safe to gather and store the types of data that will be collected?

Evaluation participants themselves are best poised to understand the context in which the evaluation unfolds, as well as what types of driving questions and approaches are most suited for the effort. Omitting participant input risks missing key information and insights, or worse, causing harm through misguided approaches and insensitive questions.

Local communities and stakeholders are also experts in their own experiences and can guide evaluators in understanding nuances that ripple across all aspects of the evaluation life cycle. For instance, they can shed light on whether similar data has been collected recently by another entity, the level of burden this type of evaluation might have on participants, or whether the evaluation tools and design are best suited for answering the evaluation questions. Going further, communities can weigh in on whether the evaluation questions truly match what's most needed or help shape those strategies and goals.

ETHICS & EQUITY IN EVALUATION

As philanthropy and other fields within the US contend with their own processes that perpetuate systems of inequity, centering equity in evaluation is vital. Taking steps to practice data ethics has some overlap with taking steps to center equity. For example, both encourage transparency around the purpose and use of evaluation.

That said, data ethics practices are not a substitute for practices that center equity and vice versa. Consider designing evaluation with equity principles in mind alongside ethics practices. For more resources on this, check out work on Equitable Evaluation,[2] Culturally Responsive and Equitable Evaluation,[3] feminist evaluation,[4] and gender transformative approaches.[5] These frameworks and methods are among those that attend to power differentials that are among the structural drivers of inequities.

Ethics issues in evaluation

Equity issues in evaluation
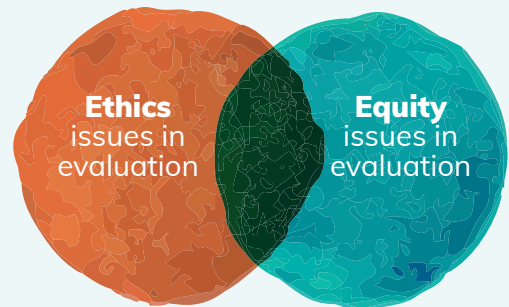
Evaluation Scope & Methods

Minimize security issues and unintended harms
with clear communications and feedback loops

ASK YOURSELF

- Is it necessary to collect new data or can the evaluation design draw on secondary data (data collected previously during another process)?
- What's the minimum amount of data that can be collected to answer the evaluation questions?
- Has the data needed already been collected elsewhere?
- Is it possible to work with local evaluators who know the nuances and context rather than evaluators from outside the community?
- If demographic information is sought, what (and whose) purposes is it intended to serve?

Like the underlying drivers and impetus for an evaluation, the design of an evaluation's scope can have serious implications for participants. Without careful consideration of the study's timeline, methods, and participant representativeness— as well as the level of involvement and input of community members and local stakeholders—the evaluation may create ethical issues.

For instance, are timelines driven by internal foundation deadlines that don't align with the time needed to fully collect and process information shared by participants? While time and other constraints will always exist, it's important to be clear about the limitations of the evaluation to avoid raising false expectations about its potential benefits and to ensure participants are fully in control of the boundaries of their participation.

Examine evaluation methods for their potential to raise ethical issues in the level of risk posed to participants, including the appropriateness of methods to address the evaluation questions. Some are much less likely to cause harm (such as a data review), while others may have the potential to cause triggering situations (such as a focus group of people with different views

discussing a hot-button topic) or worse. Selected methods and location should also be considered for accessibility: are language translation or special accommodations for disabilities needed? Have these been appropriately anticipated in the evaluation's budget?

BUT WHAT IF...

everyone is really busy?

Building relationships and ethically sound processes take time. And everyone's time, whatever their role in the evaluation, is valuable and limited. We all find ourselves in situations where we realize the ideal process is unobtainable and we look for "the next best step." When tension between what feels possible and what feels ethical emerges, return to the foundational question: Does the benefit of doing this evaluation outweigh the risk of doing harm through this evaluation? And remember that "risk of harm" is not something evaluators can credibly assess on their own; consult participants to understand risks.

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Availability & Interest of Evaluation Participants

Balance meaningful community engagement with the time burden for participants

ASK YOURSELF

- Will everyone who participates in the evaluation be offered appropriate compensation for their time, data, and perspectives?
- What resources will be available to support participants if the evaluation concerns topics that may be sensitive or triggering?

Typically, evaluations necessitate periods of engagement with local communities through data collection efforts. If the evaluation is participatory in nature, local communities may play a role in other phases of the evaluation as well. These periods of high engagement could lead to ethical concerns regarding too many requests and expectations placed on communities, or questions about whether the burdens outweigh the benefits.

Consider ways of balancing what is expected and required of local communities, even as community input is being sought to shift the power dynamic between funders and beneficiaries.* Furthermore, do due diligence by questioning what data, time commitments, and feedback are expected from participants, and whether you have other means of accessing comparable information that asks less of participants.

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* For further discussion of these power dynamics, see the special issue of The Foundation Review on "Shifting Power in Philanthropy."
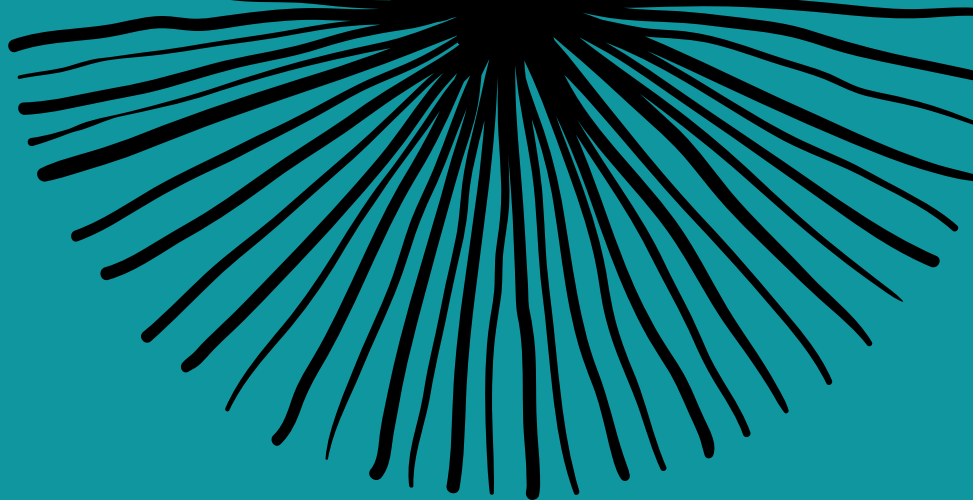
STORIES FROM THE FIELD

Ethical Issues in Design

Who gets to decide which methods are used
in an evaluation?

Suppose you are an evaluator whose team has been commissioned by a large private foundation in a major US city. The foundation is seeking an evaluation of an initiative through which it has funded small neighborhood-based projects throughout the city for several years. Shortly after your team is commissioned, your program officer tells you the foundation wants to take a participatory approach to data collection activities and selected your team because they believed you all to be adept at such methods. Together, you and your team decide to use a participatory research methodology using photos and videos for the project.

Concerns begin to crop up soon after you inform community groups they will be receiving video training (as part of the evaluation) and then making videos about their neighborhood. These groups are worried about how these videos will be used; they believe they will ultimately have little to no control over the narrative the videos might be used to illustrate. Some see the appeal of a method rooted in storytelling, while others have concerns about the potential for the videos to perpetuate existing stereotypes about predominantly Black neighborhoods in the city. The latter group is particularly skeptical of the fact that your team is based in another city (one with a predominantly white population) and that neither you nor your team members have any ties to the neighborhoods that are the focus of the project.

DISCUSSION QUESTIONS

- What kinds of ethical concerns does this story raise?

- How would you proceed as it relates to your team? Your program officer? The community groups with whom you're working?

- What kinds of design choices, if any, could you have made differently? What could the foundation have done differently?

- What would you change, if anything, about your answer if most participants were excited about the evaluation method and only a subset of folks raised concerns?

KEY THEMES
Evaluation design and implementation, power dynamics

Implementation

Creating the conditions for participant safety

The implementation phase is when participants in the evaluation process actively use the instruments and methods (e.g., observations, surveys, interviews, focus groups, etc.) to answer the evaluation questions.

The following section explores how to apply a data ethics lens to three key areas of the implementation phase:

- Consent
- Data Collection
- Data Storage

Summary of Good Practices During Implementation

ADD CARE/VALUE

- Collect data that will be an asset to participants/communities and return data to the participants/communities as and after it's collected.
- Partner with local communities and support their capacity to collect data themselves.

DO NO HARM

- Make consent processes simple, accessible, and participant-centered.
- Collect the minimum data needed for the evaluation.
- Collect demographic data to understand disparities and consider not collecting this data if there's no compelling need to disaggregate results.

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Consent

Putting the concepts of free, prior, and informed consent into practice

ASK YOURSELF

- Has free, prior, and informed consent been obtained? Are there any reasons or power dynamics that would influence why it might not be possible for consent to be freely given?

- Can participants withdraw consent at any time during the evaluation? Is this clear to them?

- Have accessibility issues (e.g., language, reading levels, mode of delivery, special needs of participants) been considered and addressed in how the research is explained, especially for the purpose of obtaining consent?

As discussed in the design phase recommendations, all prospective participants must be fully informed about and understand the purpose of the evaluation—ideally well in advance of data collection. This includes the impetus for the evaluation, specific goals, procedures, and methods, as well as how these were developed, potential risks, privacy, and confidentiality measures, and intended use for the data and project. Participants should also understand their participation is voluntary. Ways for them to decline participation or withdraw their consent should be simple and clearly explained.

Ethics issues may arise if the conditions under which consent is obtained are heavily subject to the power dynamics at play. For example, prospective participants may consent to the evaluation out of the hope it will improve their conditions, but without the ability to shape what those improvements might look like. If participants are already involved (e.g., if they are asked to consent at the beginning of an interview or focus group for which they are already present), they may not feel fully free to decline.

Evaluators should also endeavor to make the consent language clear and transparent for participants—while legal language may be required, it should not impede participants from various backgrounds from fully understanding what they are consenting.

> "You get somebody coming in with an official T-shirt with a logo on it, and they're introduced by somebody senior in the community, and they say, 'Please, will you assist in the gathering of this data?' The citizen, the local community member, doesn't feel the agency to say 'no' because there is that asymmetry of power. They may feel obliged even though you read them the consent forms."
>
> – CANDICE MORKEL, CLEAR-AA

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Data Collection
What, how, and by/from whom?

ASK YOURSELF

- Has everyone who might be collecting data received training on ethical data collection including obtaining consent ethically?

- What safeguarding measures exist for participants? How will they ask questions or raise concerns during the evaluation?

- Is the timeline for the evaluation sufficient to allow for the inclusion of communities? Are there options in place to extend the evaluation if additional perspectives or broader representation need to be obtained?

The data collection process is one of the most high-touch phases between evaluation implementers and beneficiary communities. Data ethics issues may arise regarding:

- **Type of information collected:** What constitutes sensitive information (personally identifiable information or information that might surface trauma) varies by context. Consider whether the information is necessary to achieve the evaluation objectives or if it can be omitted. Similarly, consider consulting with local experts or beneficiary communities to determine whether the local context plays a role in what might constitute sensitive information. For instance, gender or sexual orientation information can pose various levels of risk and/or potential trauma depending on the socio-political environment in which it is collected.

- **Who is collecting the information:** Technical expertise is not a substitute for a deep understanding of the context of communities participating in the evaluation. A lack of this understanding may lead to situations where data collection becomes ineffective or evaluation participants experience harm or discomfort. Consider partnering with local evaluators or community members who can create a caring environment in which data collection can take place. Prepare resources to respond to triggering situations that arise for participants, especially if the evaluation topic has been identified as potentially sensitive.

WHAT IS SENSITIVE INFORMATION?

Information is considered sensitive if it might cause perceivable damage to someone or something if it is revealed to people who are not entitled to the information. Examples include HIV status, religious beliefs, sexual history, where someone lives, information about drug use, and information about prescribed medications.

Sensitive information can also be considered part of a continuum and should be addressed accordingly. Consider information that has the potential to cause embarrassment or discomfort on the one hand, and information that could pose a real and serious risk to a person's life on the other.

- **From whom data is collected:** Defining the group of participants for a project involves a variety of factors—requirements of the study design, susceptibility to risk, the likelihood of benefit, practicality, and fairness. It's important to pay particular attention to the needs and issues of vulnerable populations (e.g., children, prisoners, pregnant women, participants with mental disabilities, or economically-/educationally-disadvantaged persons) while at the same time not overprotecting vulnerable populations by unnecessarily excluding them.

- **How the information is collected:** Consider whether a participant may experience harm or discomfort from the way data is collected. For instance, participants may be inclined to share personal or sensitive information because of the power dynamic at play—they may hope for something to improve because of the evaluation, and hence, be more willing to share information that others might prefer to keep private. Ensure methods and timelines reduce barriers to participation. Some methods may assume access to technology or a certain degree of comfort with written language, or they might require participation at inopportune times that disrupt participants' daily lives. Finally, consider ways of building feedback loops. Are there mechanisms for ongoing feedback that allow for adjustments in scope, timeline, or other aspects of the evaluation?

Gathering Demographic Data with Care

Demographic data (e.g., gender, race, ethnicity, sexual orientation, or age) can be a vital part of an evaluation. There are ethical reasons to collect this data and ethical concerns that come up when this kind of data is collected.

A reason to collect this kind of data is to ensure an evaluation is not masking identity or group-based disparities. For example, Funders for LGBTQ Issues has lifted up that when foundations report their "total giving for LGBTQ causes" without further disaggregation they may mask disparities in access to grant dollars for some kinds of LGBTQ organizations—for instance, for transgender rights or to Black LGBT people. Ethically, it's especially important to collect demographic data when it will be used to better understand who is and isn't benefiting from funding or services and to take action to correct inequities.

One concern about demographic data collection is related to privacy. It would be unethical to require someone to share something about their identity they don't wish to disclose. This is a reason to offer anonymous data collection options, de-identify data, and include a "prefer not to state" option for all demographic questions.

The collection of demographic data can also be uncomfortable for people because the categories used to describe identities may be socially constructed and may not adequately capture the multiplicities of our identities. Acknowledge that all of us are more than our demographic identities and that the categories themselves are limiting when collecting this kind of data. Allow respondents to select multiple options when they respond to demographic questions that include lists (for instance, allow people to select multiple racial or ethnic identities).

Another area of ethical concern is related to issues of "stereotype threat" (Steele and Aronson, 1995) and "belonging uncertainty" (Walton, 2007). These concepts from psychology describe what happens when people feel at risk because of an aspect(s) of their identities, such as gender or race, that is/are marginalized in society. When we collect demographic data, we may inadvertently suggest someone's identity is invalid or unacceptable (e.g., by providing only "male" or "female" as gender options, or even "female," "male," or "other"). Just by drawing attention to identity, even in the interest of researching the effect of negative stereotypes about identity, we can increase, even subtly, the degree of risk a person feels in the moment. For this reason, consider placing demographic questions at the end of a survey rather than upfront.

ADDITIONAL RESOURCES

Reducing Stereotype Threat: An Online Compilation of Resources from Barnard College and the Alfred P. Sloan Foundation.

Funders for LGBTQ Issues. Data Collection Best Practices.

Data Storage
Ownership and security

ASK YOURSELF

- How will the data be stored, accessed, and protected during the evaluation? Are recognized data protection standards (including legal requirements such as those in healthcare settings) being followed?
- What confidentiality agreements might need to be in place during the evaluation? Under what conditions, if any, would these agreements need to change?

Data collected may include sensitive or personal information, or it may have been obtained under a promise of confidentiality or anonymity. Similarly, modern data collection methods often include additional data, such as location data or IP addresses, which are identifiable and unnecessary for the evaluation. Data ethics issues may also arise if the data isn't stored securely. Multi-institution collaborations are not uncommon and pose additional concerns regarding secure storage, such as determining how to share data and which members of each institution have access to it. Finally, if efforts are made to share data ownership with participants, how will it be done securely?

STORIES FROM THE FIELD

Ethical Issues in Implementation

Is it possible to give consent to participate in a study within unequal power dynamics?

Suppose you're a researcher who works at a large university in Australia. A US-based funder hires you to assess its investments in agricultural and economic development projects in rural Indonesia. The study involves collecting qualitative feedback from rural farmers mostly working on small and family farms. After assembling a research team, you and your team design a research plan, which successfully proceeds through the IRB approval process at your university. You also prepare consent forms.

However, after the first few interviews, your team members are uncomfortable. They observe interviewees signing the consent forms without any real option to decline participation. The farmers are part of organizations that receive grants from the funder commissioning the study. Your team members agree that the Western way of doing research and the IRB process you conducted now seem out of place in the context of the rural communities. You're concerned that the interviewees are not fully aware of what they're participating in, why, or what they are signing. Yet, without this evaluation, the funder might not continue supporting these communities.

DISCUSSION QUESTIONS

- What ethical issues are raised by this story?
- What are the power dynamics in this situation and how do they influence consent?
- What are some other steps that the funder or the evaluator could have taken to address those dynamics or ensure meaningfully informed consent?

KEY THEMES

Data collection methods, consent for data collection

Data Analysis

Guiding interpretation with participant input and context-setting

Analysis, or sensemaking, involves the process of analyzing and interpreting results from the data collected. During this phase, researchers and evaluators formulate answers to the evaluation questions informed by their data and background research. This phase typically determines the main findings to come out of the evaluation effort.

The following section explores how to apply a data ethics lens to three key areas of the analysis phase:

- De-identification
- Bias & Context Analysis
- Representation

Summary of Good Practices During Data Analysis

ADD CARE/VALUE

Create mechanisms for participatory meaning-making and interpretation of data together with participants.

DO NO HARM

Carefully consider ways of disaggregating data in analysis to understand differences between groups.

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De-identification

ASK YOURSELF

- Should the data be de-identified?
- What are the implications, for participants and for the evaluation, of choosing either to de-identify or not to de-identify data?

Depending on the kind of data collected, an early but crucial step in the analysis process may be the de-identification of data. This involves recognizing that data protection is imperfect and taking steps to strip data of markers that could allow it to be traced back to an individual. However, de-identifying data isn't a "free pass" to leave it unsecured.

> "Data-intensive projects carry less risk when individuals cannot be readily identified. Nevertheless, advances in data analysis tools and computing power mean that basic privacy protections are not sufficient to truly protect data that can paint fine-grained and revealing individual profiles of research subjects or program beneficiaries."
>
> — DAVID ROBINSON & MIRANDA BOGEN, UPTURN

Bias & Context in Analysis

ASK YOURSELF

- Have we considered the ways in which our analysis or interpretation of the data might be biased? (Are we open to changing our minds based on data that challenges what we believe to be true?) Have we made room for others to point out biases we may not recognize?
- Does everyone involved in sensemaking have sufficient understanding of the context of the work and in which the data were collected?
- Have we been transparent in acknowledging bias in or limitations of analysis?

In evaluation, data analysis is the basis from which conclusions and future decisions are made. Frequently, the analysis process involves only a few individuals making interpretations for large groups of people and runs the risk of being biased (if unconsciously) without review and input from diverse stakeholders. Ethics issues may arise without the proper feedback loops that add nuance and situate the data within the context necessary to understand it. While analyses may be geared toward testing a particular hypothesis and following a rigorous plan, additional input can guide analysts and evaluators in adequately telling participants' stories through the data they've provided. Without broader input and context setting, results run the risk of not only being incorrect but actively harming communities.

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PHASE THREE: DATA ANALYSIS

Representation

ASK YOURSELF

- Who gets to participate in data analysis? Who gets to decide what the data mean, or which data is most important to foreground?

As part of the analysis process, make efforts to disaggregate and consider differences among groups to ensure their distinct experiences are represented. Decisions about what that disaggregation entails—and what differences are significant or make sense to consider—should be made alongside those with knowledge about the participating community or after a vetting process that is as representative as possible of the participating community.

STORIES FROM THE FIELD

Ethical Issues in Data Analysis
Can the anonymity of grantee feedback always be guaranteed?

Suppose you are a staff member at a nonprofit that serves a small rural community in the US. One day, you receive an email from an evaluation firm. They introduce themselves as a third-party evaluator reaching out on behalf of one of your biggest funders, and they request you fill out an anonymous grantee survey. The email emphasizes the importance of your organization's response: "Your input will support the foundation's efforts to effectively tackle issues of health equity in your local communities and at the state and federal levels."

However, upon reviewing the survey questions, you see one of the pieces of data collected is demographic information about the grantees' leadership. Your organization's director identifies as Native American. After discussing the grantee survey with him, you both realize it is easy to identify responses to the survey based on this demographic data. You believe foundation staff could easily find out, for example, which grantee is led by an Asian American man or by a white person who identifies as transgender. Your director is torn on whether to fill out the survey since the data and feedback, as it is collected, is not truly anonymous, particularly for organizations led by people who identify as part of minority groups.

DISCUSSION QUESTIONS

- What ethical concerns does this story raise?

- How could this survey process be handled differently?

- What would you change about your answers, if anything, if you knew the survey results would help channel more grants to organizations led by leaders from communities that have historically had a harder time accessing funding?

KEY THEMES
Offering anonymity, demographic data

Reporting & Sharing

Ethically discerning and communicating findings

The data use and dissemination phase includes the process of creating the report with the main findings from the evaluation and the subsequent decisions made based on the data and/or report.

The following section explores how to apply a data ethics lens to two key areas of the dissemination and reporting phase:

- Data Ownership
- Who Benefits from the Findings?

Summary of Good Practices During Reporting & Sharing

ADD CARE/VALUE

- Encourage participants or local communities to use evaluation results in additional ways they deem beneficial.
- Share back results with participants and build accountability by explaining the expected use of the results.
- Create mechanisms for shared ownership of data going forward.

DO NO HARM

- Move beyond seeking attribution of benefits to learning about what works and what doesn't.
- Act on the findings, don't allow the report to "sit on a shelf."
- Use asset-based framing.

Ethics in communicating findings applies to both what is communicated and how it is communicated. Likewise, how findings are used and what happens to data after the evaluation ends are two foci for ethical issues. The field of communications has also advanced ethical thinking that applies to sharing evaluation findings. For example, using asset-based framing in the evaluation narrative can mitigate the risk of perpetuating negative stereotypes.[*] Getting language about identities right especially matters. Guides to using language to describe identities and people are numerous and available online, such as the resource list for communicating about social change maintained by Jennifer Lentfer, or the RadComms Resource Directory maintained by Radical Communicators Network.[**]

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[*] For a one-minute video, see Trabian Shorters define asset-based framing here: https://youtu.be/O04CuqStRvM. For a reflection on how The Annie E. Casey Foundation introduced this concept into their workforce development programs, see: https://workforce-matters.org/a-reflection-on-asset-framing-for-workforce-development/

[**] Find Jennifer's excellent list at https://docs.google.com/document/d/1egKCiD3lH_yHiKDbnTBqDCOoFKXRPOdYCXlGeJPB-3A/edit and visit her website at https://www.how-matters.org/. Find the Radical Communicators Resource list at https://www.radcommsnetwork.org/resources/

Data Ownership

ASK YOURSELF

- Who will have access to the findings?
- Who owns the data going forward? If it will be kept, how will it be stored and protected?
- Can evaluation findings be shared back with all participants? Can they be shared publicly?

In the age of ubiquitous digital data collection, concerns about who owns the data and how it can be used are still catching up to current legal regulations. Analogous concerns exist within evaluation processes and with the data generated by evaluation participants. This data, in its raw form and after it has been neatly packaged in a report or deliverable, holds value in ways that influence decisions and tell a story about a particular community.

Data ethics issues arise when considering who owns this data. Is it community members or institutions from which the data originate? Or is it those who collected and store it? Have mechanisms truly been put in place to allow participants to access or modify their data or retract it as necessary? Even when attempting to solve these issues, additional considerations of infrastructure and privacy can come up. If a shared data ownership model is developed, what does the infrastructure for storing and accessing the data look like, and where does the data actually "live"?

STORIES FROM THE FIELD

Ethical Issues in Data Management
Who owns the data when research involves multiple stakeholders?

Suppose you are a doctoral student who leads a research team. You've been commissioned to conduct a randomized control trial examining the impacts of a national education nonprofit on students. Because you're collecting data from students, you complete the university's IRB process as part of the study design phase and share your university's standard IRB process explanation via email with the nonprofit. Your team proceeds with extensive data collection activities during which the students are identified, and the evaluation eventually reaches its final stages.

As you prepare to report back your findings, the education nonprofit's evaluation team requests you provide them with the data your team collected from its students to inform its own ongoing internally led evaluation efforts. You respond by explaining that sharing this data is prohibited by the IRB through a measure designed to ensure its privacy. The nonprofit argues the data belongs to them—not you, your team, or the university. Having reached an impasse, both you and the nonprofit plan to appeal to the foundation supporting the study to resolve the conflict.

DISCUSSION QUESTIONS

- What ethical concerns does this story raise?
- Should the funder try to resolve the dispute?
- What could the funder do in future to mitigate the likelihood of a conflict like this occurring when they support evaluations?
- What about the students whose data is at the heart of the dispute? How should the funder consider their rights to privacy in the context of this story?

KEY THEMES
IRBs, data ownership, data privacy

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Who Benefits from the Findings?

At the end of the evaluation, results may be presented to a foundation's board or staff, at a conference, used for fundraising, or published more broadly. Benefits from these types of dissemination are clear for evaluators and commissioners of evaluations but can be less clear and obvious to evaluation participants. Ethics issues may arise if the evaluation process was more burdensome than the benefits, or if the full set of results is not shared back with participants promptly that allows for changes.

This also raises the question of evaluators' obligations to participants, particularly their obligation to fulfill participant expectations about the evaluation and its benefits to them. Consider examining the level of accountability the foundation and/or evaluators should feel toward participants and how to communicate this.

STORIES FROM THE FIELD

Ethical Issues in Reporting
What does transparency mean in politically sensitive contexts?

Suppose you are a senior program officer who manages a grant portfolio that funds organizations working on issues of climate change regulation. You work at a large environmental funder, which has recently completed an evaluation of its climate change regulation advocacy grantmaking within the US; your entire grant portfolio was included, as well as those of your colleagues involved in climate issues abroad. You believe the evaluation went well and review the final report, which tells a story of how incremental but important successes were achieved within a context of polarizing policy advocacy and research dissemination on climate change.

In recent years, your foundation's board has made a high-profile commitment to share what it learns from its evaluations publicly on its website; this transparency has been viewed as an important component of its value of being accountable to the communities it seeks to serve. However, foundation staff are split on whether to publish the climate change evaluation. Your colleagues, especially those whose grants were involved in the evaluation, worry those working in opposition to climate change regulation will use the insights about strategy shared in the report as "opposition research," perhaps unintentionally leading to the undermining of their grantees. On the other hand, the foundation's board feels not releasing the report would be untrue to the commitment it had made to share its learnings. Moreover, board members feel withholding it would be close to being a form of self-censorship, possibly contributing to a culture of indifference around climate change.

DISCUSSION QUESTIONS

- What kinds of ethical concerns does this story raise?

- What are the implications of publishing the report as it affects your grantees? Your and other program officers' grantmaking? The foundation at large?

- What should the foundation do?

- What kinds of data are always "sensitive," and what kinds of data might be potentially sensitive based on context?

- Have you experienced a situation in which you had to weigh obligations to transparency against obligations to privacy, safety, or simply a desire to support grantees' own strategic goals? How was it resolved?

- What would you change about your answer, if anything, if the report was very high stakes for the foundation or personally important to the foundation's board or leadership?

KEY THEMES
IRBs, data ownership, data privacy

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SECTION 2

Special Topics for Data Ethics in Evaluation

Consent & Compensation
Valuing participants and their time

Obtaining voluntary informed consent is a critical component of the evaluation and an area where data ethics issues may arise if not adequately planned for. In a sense, the process of obtaining consent demonstrates a minimum level of appreciation and respect for evaluation participants by acknowledging their autonomy and right to understand the projects in which they are involved.

Consent

Obtaining informed consent is a requirement of any evaluation that includes a person's active involvement. Participants must be fully informed about the purpose, impetus, and constituents (e.g., funding institutions, implementers) of the evaluation and should understand the terms of their participation in the evaluation, including the timeline, methods, privacy, confidentiality terms, intended uses of the data and results, and potential risks and benefits. If participants have not reached the age of majority in their country, or otherwise cannot provide full and informed

consent, a parent or guardian must also provide written consent.

Depending on the circumstances of the evaluation, staff should consider whether written or verbal consent is best suited for the evaluation. There are six basic elements that potential participants should understand to grant informed consent.

BUT WHAT ABOUT...
photos?

Participants need to give specific consent for the use of any photos or images in which they appear. Parents or guardians need to provide consent for use of any images of minors. Consent forms should clearly explain how the images will be used and in what contexts they will be shared. See the Toolkit for a sample photo release form.

Six Basic Elements of Informed Consent

These should be presented clearly and concisely in ways that give participants all the reasonable information required to make an informed decision about whether to participate in the evaluation.

WHAT: A statement of the type of project (evaluation or research), its purpose, the anticipated duration and expected involvement of participants, and the study process.

HOW: A statement describing the extent to which privacy and confidentiality will be maintained (who will have access and how it will be used), as well as the procedures for storing and maintaining any data.

WHO: The contact person for questions about the project, its procedures, and participants' rights.

RIGHTS: A statement that participation is voluntary, can be discontinued at any time, and that refusal to participate will involve no penalty or loss of benefits to which the participant is otherwise entitled.

BENEFITS: A description of any benefits to the participant or others from the project.

RISKS: A description of any foreseeable risks or discomforts to the participant.

View the accompanying Toolkit for a customizable sample consent form. According to the design of the study, modify the consent form if there is not an opportunity to obtain written consent—such as if the evaluation consists mainly of phone interviews and verbal consent will be used—or if cultural and/or accessibility considerations mean that another method for obtaining and documenting consent should be used (e.g., fingerprints or recorded statements).

Once consent is obtained, consider how the evaluation adds value to participants and the communities they represent.

Incentives & Compensation in Evaluation

As discussed throughout this guide, evaluation commissioners and practitioners should seek ways of truly living up to the principles of "doing no harm" and, if possible, adding care or value to participants through evaluation processes. In that spirit, consider building incentives or compensation for evaluation participants into proposed budgets and evaluation plans. This acknowledges participants' time and contribution to the evaluation. It can also create a welcoming environment and facilitate the participation of a broader range of individuals. For instance, offering food (if culturally and contextually appropriate), covering transportation costs, and/or providing childcare can contribute to the wellbeing of participants and enable greater participation in the evaluation process.

- **Compensation versus incentives:** Note a distinction between incentives and compensation in evaluation. Incentives are typically offered to encourage response rates to surveys. For example, Stanford University's School of Medicine pledged to donate $1 for every completed survey when it conducted research on communities' COVID-19 experiences in 2020. Typically, incentives are used when an evaluation requires general participation from individuals in a group (e.g., researchers want a 25% response rate to

their survey from anyone who is on the staff of a nonprofit in California). Compensation is used when the time or insights of a specific person are required (e.g., the evaluation will need to interview the 10 nonprofit staff who participated in a specific training program).

If compensation is monetary, consider the following factors:

- **Amount:** Determine what constitutes an appropriate amount given the time commitment and effort required of participants. Also, consider the livable wage standards of the region. (See page 24 for some examples of compensation structures and benchmarks drawn from our own experience in the evaluation field.)

- **Format:** It's also important to determine the best avenue for distributing compensation in ways accessible to participants (e.g., gift cards, electronic transfers, checks) and per foundations' policies. Similarly, if compensation will be in the form of retail gift cards, consider location as well as value alignment. Finally, compensation should be appropriate to the expected level of participation and should not be so high as to cause participants to agree to take on risks they might not otherwise accept.

- **Timing:** Provide compensation as soon as possible after the required involvement of the evaluation participant as a way of honoring and respecting their time. In certain situations, such as multi-phase or long-term evaluations, compensation may be given at appropriate intervals throughout the process rather than at a single time in the end.

- **Legality:** Determine whether special considerations should be made to account for compensation for minors participating in the evaluation; whether there are requirements for additional IRS reporting depending on the amount compensated; or whether gaming or other state laws come into play for inviting participants to enter a raffle.

Sample Compensation Structures in the US

The following considerations and examples are informed by 13 evaluations conducted by Informing Change in recent years. They were determined jointly with the respective evaluation commissioners.

CONSIDERATIONS

- **One-on-one versus group-level data collection methods:** Compensation is typically greater for 1:1 data collection (e.g., interviews). In our experience, amounts range between $1–$2 per minute required to participate. When collecting data from participants in a group setting (e.g., focus groups), typical compensation ranges between $0.50–$1 per minute.

- **Data collection versus advisory role:** Compensation structures for individuals who are asked to provide feedback and input into the design of the evaluation, data collection instruments, and meaning-making typically receive higher compensation amounts than individuals providing data via data collection instruments. The hours that advisors spend on the evaluation can be considered active meeting hours or "offline" hours reading materials and providing written feedback. In our experience, compensation for these individuals falls in the range of $2–$4 per minute. It is also more likely to be structured as an "honorarium" and may or may not include public recognition in addition to monetary compensation.

- **Is participating in the evaluation already a part of an individual's job?** The staff of well-resourced institutions, for example, may be expected to participate in interviews or surveys about their work as a part of their job description. In these cases, further compensation is not necessary.

Conversely, if someone must take time off from work to participate in an evaluation (e.g., a parent takes time off from work for which they receive an hourly wage to participate in a focus group of families at their child's school), compensation will need to be greater to account for their insights as well as their lost income from taking time off work.

REAL WORLD EXAMPLES

- A corporation offered $10 to interns who completed a 10-minute survey. The number of interns at this company ranges from 300–600 at any given time.

- A nonprofit offered $15 Starbucks gift cards for teens to participate in a 30-minute interview.

- A large private foundation offered $100 to alumni of a specific leadership program to participate in a 90-minute focus group.

- A large private foundation offered $150 for one-hour interviews to interviewees who were leaders of a cohort of grantees.

- A mid-size public foundation offered a $1,000 honorarium for representatives of small nonprofit organizations to participate in a four-hour participatory evaluation session.

- A research institution offered members of an evaluation advisory board $100 per hour (up to $1,200) for their advisory expertise over the course of 15 months.

- A large private foundation awarded supplemental grants of $2,500 to grantees who were asked to participate in gathering additional data, requiring about 15–20 hours of staff time.

Ethical Issues in Compensation

How should evaluators or researchers proceed when there are few or no regulations to guide them?

Suppose you are a researcher hired by an international aid agency that serves children. You are tasked to determine whether Roma children working on the street in a post-conflict nation were "trafficked" according to an international definition and, if so, to evaluate local responses to the situation. As you develop your research plan, you realize the aid agency has no institutionally specific standard practices governing the conduct of research specifically involving children and no requirement that researchers obtain the informed consent of participants. The nation in question has no local laws you can find from which to seek guidance. The extensive and detailed IRB requirements you've used in prior university-affiliated research seem contextually inappropriate.

Your research plan entails direct communication with children who were observed being dropped off by a van in a central public square. You are aware talking with these children could cause harm by, 1) interfering with their ability to earn money, and 2) placing them at risk of retaliation.

The aid agency requires research participants not be paid to avoid any perceived conflicts of interest. In the context of your research, you believe this requirement poses significant risks to the children because of potential lost income and its repercussions. You elect to personally pay the children the amount they earn in a typical hour, and for a meal in a restaurant, where visibility from the street is impossible. You choose not to use any kind of consent form because there are no legal guardians available, and the children don't know how to read.

Instead, while in an open public setting, you ask each child's permission to "talk for a bit to help me learn about your work" in exchange for a meal plus [an amount equal to one hour's income] and make it clear they can stop talking whenever they like without forfeiting the meal. If you see the van or the child seems afraid, you pay them without conducting an interview.

DISCUSSION QUESTIONS

- What ethical issues are raised by this story?

- What are the power dynamics in this situation, and how do they influence consent and compensation?

- Should this research have been commissioned at all? If not, what alternatives might the aid agency have used to answer its evaluation questions?

KEY THEMES

Cross-border evaluation, participant safety, compensation, youth participants in evaluation

Youth & Youth-Led Research

There has been a growing call to involve youth in research and evaluation over the past two decades. In heeding this call, organizations—from local nonprofits to international government bodies—have begun to publish literature, create jobs, and establish coalitions to empower youth to meaningfully contribute to the future of their communities. This section covers two complementary impulses in this vein: 1) how to engage ethically with youth when designing and conducting research and evaluations, and more specifically, 2) ethical considerations for youth-led research.

What is meant by "youth"?

The definition of "youth" differs across—and even within—different countries and cultures. In the US alone, various governmental bodies have defined youth to encompass those as young as 10[6] and as old as 34.[7] The most widely accepted definition comes from the United Nations, which defines "youth" as "those persons between the ages of 15 and 24 years without prejudice to any other definitions made by Member States."

This section covers general issues for youth engagement and specific issues related to working with those below the age of consent. In the spirit of recognizing this nuanced relationship between age and "youth," consider how the very concept of "youth" raises ethical concerns regarding the field of evaluation itself: Who is allowed to conduct evaluations, for whom, and to what ends?

Engaging Youth in Research & Evaluation

That youth are not involved in research and evaluation by default reveals another issue in data ethics: many evaluations are designed by adult researchers, who are answering requests for proposals by adult program officers, who go on to design programs involving youth, all with little or no engagement by young people. Instead, researchers and evaluators should intentionally engage with youth at every step of the process, especially when their interests are at stake:

In the design of the evaluation...

- Consider to what extent the issue being studied affects youth. Would a more participatory approach (i.e., youth-led research) be appropriate for the questions being raised? If not, then how will youth be engaged throughout the evaluation? Why or why not?

When implementing the evaluation...

- Consult youth, or at minimum, adults who frequently engage with youth, when creating survey and interview protocols for youth.

- Contextualize language used to communicate with youth and check with youth themselves to ensure the language used is relevant and appropriate.

- Consider whether you can promise confidentiality to youth, especially if they speak about experiences of abuse or other illegal activity. Mandated reporting laws may preclude confidentiality.

- When evaluations involve sensitive topics, consider how processes (e.g., pre-briefing, offering resources, involving parents) can be designed to mitigate potential harmful effects on children.

- Consider how survey and interview protocols can be designed to avoid the elicitation of negative emotions. For instance, avoid asking many questions about non-participation in activities, or about negative emotions and experiences, and design questions to reduce the possibility of unintentionally contributing to stigma (e.g., by emphasizing how a broad range of responses are all "normal").

- Evaluations of situations involving, or programs addressing, trauma require unique and age-appropriate considerations for all individuals.

When making meaning of data...

- Remain aware of how much change occurs, often rapidly, for youth as they grow. For example, in an evaluation of a program for young adolescents, participants were asked whether the program was helping them consider a career in STEM and whether they wanted to go to college. While all youth can certainly consider these things, the answers they give to questions like these may change over short periods and carry different meanings when the respondent is 14 and when the respondent is 17.

- As with any evaluation, consider how identities, especially race, class, gender, sexual orientation, disability status, etc., impact young people's experiences.

- If possible, involve youth in considering, contextualizing, and making sense of the data together with researchers.

When Considering Youth-Led Research

Youth-led research can provide evaluators with valuable insight into the communities studied and the relationships built over the course of evaluations. In turn, it can provide youth with opportunities to develop technical skills and stronger relationships within their communities. That said, youth-led research may or may not be the best approach to certain evaluations. Consider the following questions to determine whether youth-led research is appropriate:

- **Do youth need to be involved in the first place?** Do youth stand to benefit from the proposed research activities? Is there a compelling reason to have youth lead research activities, or can they be engaged in other ways (e.g., as interviewees, survey respondents, or advisors)?

- **Are the adults involved able to support youth-led research?** Does the organization involved in the evaluation have the capacity and resources to ensure any potential harm—

both to the youth themselves and those with whom they engage—is minimized? Is the organization willing to take responsibility for harm or other implications that may result from youth-conducted research?

- **How does the social/cultural context of the location affect the prospects of engaging in youth-led research?** Consider how youth may or may not be perceived at each stage of the evaluation. What perspectives do they bring to the evaluation and what might be missing? How might others' perceptions alter the data collected by youth?

- **Questions for youth leaders of evaluation to ask themselves:** Youth themselves may want to consider their readiness to participate ethically in data collection processes. For instance, do they feel ready to listen well and respect the privacy and confidentiality of others? Do they have sufficient emotional or social support in their own lives if they were to come across information that was upsetting or difficult in the process of the evaluation?

When designing evaluations, intentionally prioritize the autonomy and wellbeing of youth, whether they have direct input into the process or not. Put another way, the data ethics issues raised by the involvement of youth demand we recognize their views and knowledge of the world are partial, and that youth and adults working together on evaluations may well serve their communities better.

Key Considerations for Research with Minors

Recruiting children or youth below the age of consent for research or evaluation purposes poses specific risks because children often have limited ability to provide informed consent. For example, children may not understand the concept of voluntary participation and may not know they can withdraw at any point. Therefore, any research or evaluation involved with child/youth participation should be designed to have appropriate parental permission and child assent processes.

It's also important to consider the sensitivity of the data being collected (e.g., asking a child about their opinion about a class is not as risky as asking their about sexual activity). Any project that entails collecting sensitive information from children should seek IRB approval.

While parental/guardian consent processes should be in place, respect requires allowing all participants to choose—to the extent they are able—whether to participate in the research or evaluation. This means obtaining consent to participate from both the parent/guardian and the child.

Ethical considerations and privacy laws may also differ for children. For example, parents or guardians, in addition to children themselves, will need to permit the use of images of the child, or images taken or produced by the child.

Research in Public K–12 Schools

Because public schools are federally funded, they're also governed by federal laws and regulations. Consequently, any research or evaluation conducted in public schools must follow the federal regulations in place, including written consent by parents/legal guardians of student participants. When collecting data in public schools, consider seeking IRB approval unless the sole method used is observation. Consider also whether similar procedures are appropriate for data collection in private schools.

In the US, federal regulations and laws also apply specifically to research or evaluation within public schools. The Family Education Rights and Privacy Act (FERPA) gives parents certain rights over the content of their children's educational records. Because of FERPA, schools must have written permission from the parent or eligible student before releasing any identifiable information from a student's record (e.g., religious affiliation, citizenship, disciplinary status, attendance, gender, ethnicity, grades/exam scores, and progress reports).

The Protection of Pupil Rights Amendment (PPRA) is designed to provide parental control over the content of surveys, particularly in cases where surveys inquire about sensitive information. Sensitive information in this case includes the following eight categories.

Eight Categories of Sensitive Information

1. **Political affiliations or beliefs** of the student or the student's parent
2. **Mental and psychological problems** of the student or the student's family
3. **Sexual behavior or attitudes**
4. **Illegal, anti-social, self-incriminating, or demeaning behavior**
5. **Critical appraisals of others** with whom students have close family relationships
6. **Legally recognized privileged or analogous relationships**, such as those with lawyers, physicians, and ministers
7. **Religious practices, affiliations, or beliefs** of the student or student's parents
8. **Income,** other than that required by law, to determine eligibility for participation in a program or for receiving financial assistance under such a program

Selected Additional Resources

- BetterEvaluation's Article on Evaluating With, Rather Than By and For, Children
- A Guide to Child-Led Data Collection
- Ethical Research Involving Children's Website
- Nick Petten's Blog Post on Developing an Assent Framework for Children's Participation in Evaluation
- UNICEF's Guide to Ethical Research on Violence Against Children

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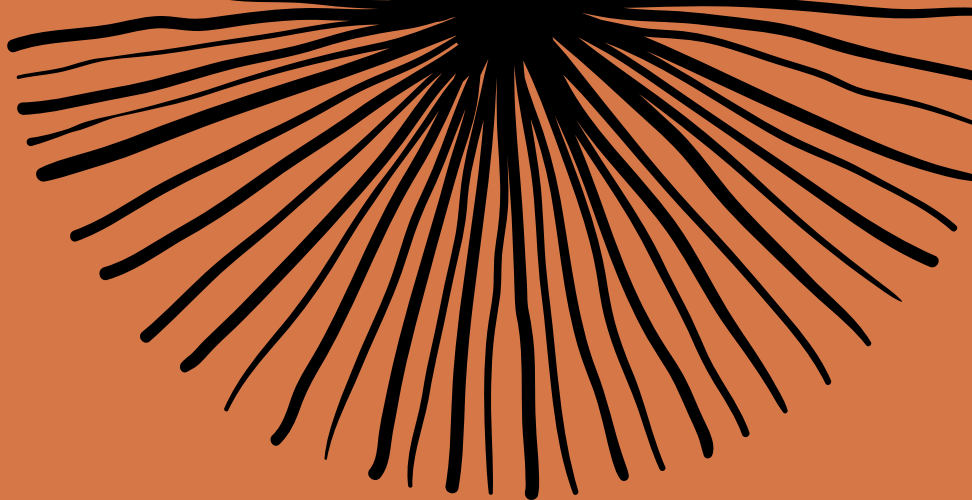
Ethical Issues in Youth-led Research

What does it mean to fully include youth in research and evaluation?

Suppose you are a program officer supporting the Access to Youth Opportunities priority area of a foundation in Austin, Texas. At a recent conference, you hear panelists speak about youth participatory research projects and decide to commission a similar project. After identifying a group of seven youth leaders from across the city to serve as an advisory body to the project, you task them with designing a research project to understand young people's desires around work and job opportunities in the city.

The research project goes well—young people across the city were engaged in focus groups and generated a list of recommendations. One of these—for a new curriculum to be developed by youth and delivered through youth-led programming—gathers strong interest from the young people working on the project and from other program officers at the foundation. That's when your project hits a wall: The foundation's procurement policies prohibit situations in which teens are commissioned and compensated for designing a curriculum the foundation purchases directly. However you feel it would be unfair to put the teens in competition with more professional adult curriculum developers in an open procurement process. Meanwhile, the youth advisory group feels let down; they had momentum going and now it seems like the foundation doesn't really trust them after all.

DISCUSSION QUESTIONS

- What ethical issues are raised by this story?

- What internal challenges did the foundation face in trying to move more decision-making power to youth in this case? What else might they have done to resolve those?

KEY THEMES
Youth-led evaluation, power dynamics

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SPECIAL TOPIC

Cross-Border & Indigenous Contexts

ASK YOURSELF

- What additional power dynamics exist between the evaluation commissioner, evaluation implementors, and people participating in the evaluation that need to be acknowledged? What additional safeguarding measures may need to be taken as a result?

- What are the unique regulations or standards for research and data ethics, or data privacy and security in the country context that need to be followed?

- What is the social, political, economic, and cultural context for the evaluation, and has that context been considered in the research/evaluation design?

Research and evaluation conducted across national borders raises additional ethical questions due to factors such as heightened power dynamics, different ethics review practices, diverse cultural and political contexts, and different laws or regulations. A local country expert should be consulted to determine if and which national research ethics review boards need to be applied to and to advise on other local norms and practices around data ethics. Data privacy and protection laws also differ from country to country and need to be reviewed.

While the fundamental principles of data ethics should be used in research and evaluation conducted in any locality, commissioning or conducting this work across borders creates another level of complexity. Following US ethical guidelines and regulations may not be sufficient, as other countries may have systems more or less rigorous and may require taking additional measures. For example, many countries have national research ethics review boards and processes, as well as unique regulations regarding the collection and storage of data from individuals. Because ethics guidelines, regulations, or codes differ by country context, it is vital to work with in-country teams or consult in-country experts.

That said, national review boards in any country, including the US, reflect the politics and histories of their place. Because of this, they may reflect the norms of the groups that hold power and may not always serve the interests of those they purport to protect. Following national research guidelines must always be held alongside considerations of context. Community-developed or Indigenous knowledge systems may offer rich ethical guidance not captured in national standards.

Pay special attention to projects that will engage Indigenous communities. For one, national review boards may fail these populations. The UN Declaration of the Rights of Indigenous Peoples (2007) codifies the principle of "free, prior, and informed consent." Applied to research, this creates a minimum standard for ethically engaging in relationships with evaluation participants and requesting their time, perspectives, or personal data. In some contexts, Indigenous communities have organized around deeper ethical principles or offered additional guidance on applying these minimum standards.

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SPECIAL TOPICS: CROSS-BORDER & INDIGENOUS COMMUNITIES

In some countries, indigenous communities have developed their own guidance for data ethics. For instance, First Nations in Canada apply the principles of Ownership, Control, Access, and Possession (OCAP®)* to research and evaluation projects that include their communities. The Global Indigenous Data Alliance has developed the CARE Principles for Indigenous Data Governance (**C**ollective Benefit, **A**uthority to Control, **R**espect, **E**thics). Note the emphasis these principles place on returning control of data gathered to those who provided it—an ethical principle not covered in minimum international standards around consent to collect data.

First Nations evaluators working within the Australian Evaluation Society (AES) have likewise developed a First Nations Cultural Safety Framework[8] to guide evaluation practice. This framework, developed as part of the AES' Reconciliation Action Plan, offers practical guidance to both evaluators and evaluation participants for creating culturally safe evaluation plans.

The Native American Center for Excellence also offers a set of principles for evaluators as part of its effort to reclaim evaluation and research from a history of abuse and misuse.

Consider social and cultural norms in conducting international research. This includes a population's values and ethics, codes of conduct, traditions, and language differences. These influence the work in practical ways. For example, protocols and consent forms may need to be translated into other languages—and they should also be translated so that specific terminologies make sense to the evaluation participants. Also, consider whether conducting analysis within certain frameworks that make sense within the US—such as commonly used racial categories in the US context—are equally applicable in other countries.

> "Whose framework are you using to make sense of the data being shared with you? It's important that researchers/evaluators consider this question, because when worldviews or even understandings of context or landscape are inconsistent with the data, this can create incredibly problematic interpretations of data, and in turn, have harmful consequences. For instance, the concept of 'wealth.' Western mainstream society understands the concept of wealth as monetary, assets, or acquisition of material items. On the other hand, some non-Western understandings of the word wealth include being surrounded by family, having an abundance of love with all relations, and living life in a good way."
>
> – BILLIE JOE ROGERS, LEAD FOR RESEARCH & ETHICS, RECIPROCAL CONSULTING

Reciprocal Consulting is an Indigenous-owned evaluation consulting group in Canada; approximately 75% of its projects are within Indigenous communities. For Reciprocal Consulting, centering OCAP in evaluation means "giving the data back to the individual that we're working with," for example, by returning recordings or transcripts of interviews to participants. Applying "do no harm" principles also means using appropriate frameworks and definitions in the evaluation.

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* Note: OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC).

Beyond the social and cultural context, other countries have different laws and regulations to govern research—especially data collection and data use. One of these is the established legal age for consent. Another that varies across countries is data privacy laws, such as the set of regulations adopted by the European Union (EU) known as the General Data Protection Regulation (GDPR). Because no such set of regulations exists in the US, this could have implications for the managing and storage of data according to project scope and needs. There may also be existing organizations that oversee the protection of research participants, where cooperation and collaboration are needed.

Finally, consider the procedure for an ethics violation. Ensure there are clear guidelines for how to handle a breach of ethics and that the people participating in the evaluation have options for raising concerns and asking questions about the purpose of the evaluation or its methods. For example, the staff at Oxfam frequently find

themselves engaged in evaluation work in multiple international contexts and have learned, sometimes painfully, about the pitfalls of evaluations that fail to build in such safeguards. Their recent effort to adopt safeguarding practices across the organization's different work contexts include the following: conducting risk assessments and setting up the safeguarding or whistleblower measures prior to the start of an evaluation project; obtaining free, prior, and informed consent from all participants; following the EU GDPR guidelines; planning longer lead times for evaluations; and hiring trusted, reference-checked, locally-based learning and evaluation partners throughout the project.

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IRBs & Their Limitations
Decision tree and alternatives

What is an IRB?

An Institutional Review Board (IRB) is a group of qualified individuals* who are charged with monitoring and reviewing research involving "human subjects" to protect the rights and wellbeing of "human subjects" in accordance with ethical standards. An IRB is required by law when an entity conducts research to contribute to generalizable knowledge** involving human participants and is funded by any federal department or agency.[9] In international contexts, IRBs are also called Ethics Review Committees. Academic institutions may have their own regulations and exemptions for when research requires IRB approval. If your work is affiliated with or supported by a government agency or academic institution, refer to its specific guidelines and regulations.

Generally, an IRB reviews research proposals to ensure:

- Minimized and reasonable risks to individuals in relation to anticipated benefits
- Equitable selection of individuals
- Appropriately received informed consent

IRBs should be composed of at least five members of varying backgrounds, and efforts should be made for gender parity. None must have conflicts of interest. Additionally, the characteristics of IRB members must include:

- At least one expert in scientific subject matter and one in non-scientific subject matter
- At least one member not affiliated with the research institution

Apart from the funding source, research requiring an IRB (for generalizable knowledge) is distinct from many research and evaluation activities typically carried out by funders in that these activities are often intended to inform a specific program or strategy or for the purpose of documentation. Research requiring IRB approval is intended to have replicable results that contribute to a specific scholarly discipline and whose results can be applied to a larger population.

The origin of IRBs can be traced back to the Belmont Report (1979), which first laid out the ethical principles and guidelines for research involving human subjects in the US. In 1991, the Federal Policy for the Protection of Human Subjects, or the "Common Rule" was published in order to codify these principles and formally establish federal requirements for IRBs' membership, authority, review procedures, records, and criteria for approval. The Common Rule was most recently updated in 2018. While individual IRBs offer their own flow charts to guide researchers through the revised Common Rule (see an example), we offer a "light" version of these more comprehensive flow charts following this section. If you review this chart and conclude you might need an IRB review, it's important that you also go through any flow chart offered by the IRB with whom you might work.

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* In the US, IRB members are typically required to register with the Office of Human Research Protections within the Department of Health and Human Services.
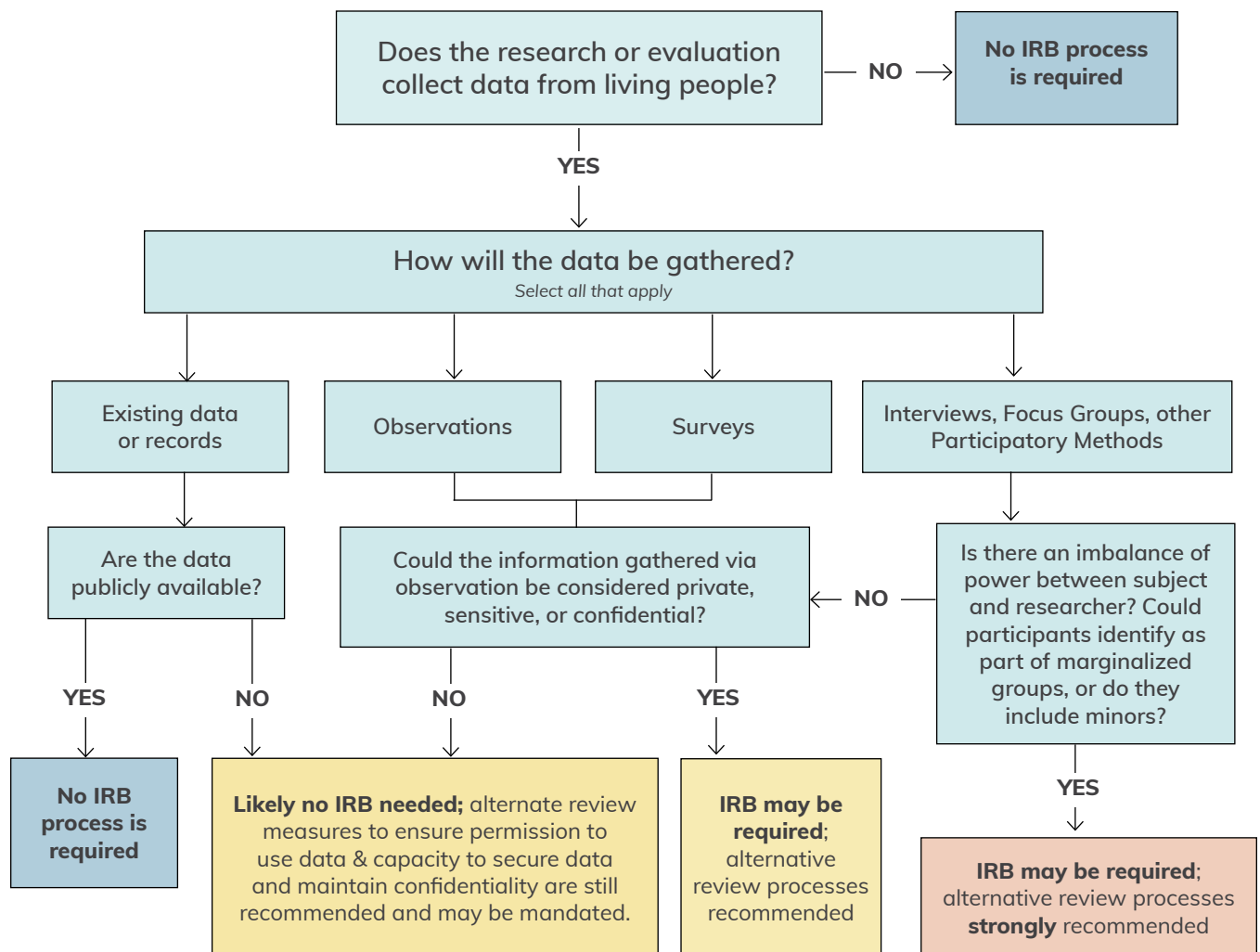
** Generalizable knowledge refers to knowledge that advances the knowledge base of a scientific discipline whose results are applicable to a larger population beyond those from whom the data was collected.

IRB Limitations

While IRBs have certainly improved the protection and wellbeing of human participants in research studies, there are still limitations to their applicability, especially to many research and evaluation efforts that fall outside of traditional medical research. Ostensibly, IRBs are designed to protect human research participants. In practice, IRBs are better at protecting research institutions by providing formal documentation of risk mitigation than determining whether risks are actually mitigated for human participants. The review process may happen infrequently, may have a strong technical tilt, and may be static in ways that do not account for different or changing circumstances and contexts.

Additionally, the set of ethics considerations needed to conduct medical research differs from the set of ethical considerations needed when engaging in social sector research, in particular when considering approaches that aim to level the power dynamic between researcher/evaluator and participant. These approaches may seek to empower and involve participants in research and evaluation processes by sharing varying degrees of ownership of the evaluation cycle between research/evaluators and participants. Ethics considerations that arise in these instances may pertain more to issues of power and ownership, community representation and input, or meaning-making and dissemination of results.

IRB Decision Tree

```
┌─────────────────────────────────┐         ┌──────────────────┐
│ Does the research or evaluation  │   NO →  │ No IRB process    │
│ collect data from living people? │         │ is required       │
└─────────────────────────────────┘         └──────────────────┘
                │ YES
                ▼
┌─────────────────────────────────────────────────────────────┐
│              How will the data be gathered?                   │
│                   Select all that apply                       │
└─────────────────────────────────────────────────────────────┘
     │                │              │                    │
     ▼                ▼              ▼                    ▼
┌──────────┐   ┌────────────┐  ┌─────────┐   ┌──────────────────────┐
│ Existing │   │ Observations│  │ Surveys │   │ Interviews, Focus    │
│ data or  │   │            │  │         │   │ Groups, other         │
│ records  │   │            │  │         │   │ Participatory Methods │
└──────────┘   └────────────┘  └─────────┘   └──────────────────────┘
     │              └──────┬───────┘                  │
     ▼                     ▼                           ▼
┌──────────┐   ┌────────────────────┐   ┌──────────────────────────┐
│ Are the  │   │ Could the          │   │ Is there an imbalance of  │
│ data     │   │ information        │ ← │ power between subject     │
│ publicly │   │ gathered via       │NO │ and researcher? Could     │
│available?│   │ observation be     │   │ participants identify as  │
└──────────┘   │ considered private,│   │ part of marginalized      │
               │ sensitive, or      │   │ groups, or do they        │
  YES   NO     │ confidential?      │   │ include minors?           │
               └────────────────────┘   └──────────────────────────┘
                    NO        YES                   │ YES
                                                     ▼
```

Existing data or records → Are the data publicly available?
- **YES:** No IRB process is required
- **NO:** Likely no IRB needed; alternate review measures to ensure permission to use data & capacity to secure data and maintain confidentiality are still recommended and may be mandated.

Observations / Surveys → Could the information gathered via observation be considered private, sensitive, or confidential?
- **NO:** Likely no IRB needed; alternate review measures to ensure permission to use data & capacity to secure data and maintain confidentiality are still recommended and may be mandated.
- **YES:** IRB may be required; alternative review processes recommended

Interviews, Focus Groups, other Participatory Methods → Is there an imbalance of power between subject and researcher? Could participants identify as part of marginalized groups, or do they include minors?
- **NO:** (routes to "Could the information gathered...")
- **YES:** IRB may be required; alternative review processes **strongly** recommended

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IRB Alternatives

When a formal IRB is not required, an alternative ethical review process can still be important. These IRB alternatives and practices aim to balance the value of community participation and care with that of protection and do no harm.

- **Evaluation Advisory Group:** May comprise members internal to the foundation, grantee staff, and relevant community stakeholders that act in an advisory capacity for the research or evaluation project. Is fluent in the context surrounding the project, responsive to changing circumstances, and able to engage throughout the project.

- **Community Review Boards:** May include broader entities, supported by multiple foundations, which provide guidance and considerations for data ethics issues that arise in research or evaluation processes. It can also serve to build capacity among grantees or foundation staff to identify and address ethical issues that arise in their work.

- **Internal Data Ethics Panels:** This panel of individuals (or single individuals depending on size) can serve as the go-to entity to support program officers or grantees with data ethics considerations. Engagement with the panel can be voluntary or not. Its focus is to support grantees and foundation staff to identify and address ethical issues.

Regardless of the specific configuration a guiding body takes, there are important ways it should interact with research and evaluation processes, including to:

- **Actively focus on continuous questioning, rather than rubber-stamping claims that no harm will be done.** Instead of being transactional, the process should focus on the relational aspect of research and evaluation processes—interactions with communities, delivery of results, meaning-making, and use of results (known and unanticipated).

- **Incorporate community voices and not just those of technical experts.** This could be through the inclusion of community members with vested interests in the evaluation or through consultation processes that include them.

- Build the skills and capacities of grantees and foundation staff to spot and understand data ethics issues, and to build care across their research or evaluation processes in ways that go beyond "doing no harm."

An invitation, in closing

Ethical practices and interpretations of what is appropriate, fair, or valuable in evaluation research continue to evolve. Inevitably then, some of what you find in this Guidebook may fall short of what you expect. Informing Change encourages you to email us at DataEthics@informingchange.com so your feedback may be considered for incorporation in a future edition of this Guidebook.

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