

Data Ethics Toolkit

A companion to the
Data Ethics Guidebook



Contents

This Toolkit is a companion resource to the Guidebook for Ethical Thinking. Its contents represent practical tools for putting the Guidebook recommendations into practice, from a one-page map for ethical thinking to customizable consent forms to Stories from the Field.

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Framework for Ethical Thinking

		EVALUATION PHASE			
		PLANNING	IMPLEMENTATION	DATA ANALYSIS	REPORTING
ISSUE AREA	POWER & OWNERSHIP ISSUES	<p>Who is this for?</p> <p>Who will benefit? Who could be harmed?</p> <p>Does the benefit outweigh the potential risks and costs for those involved?</p>	<p>Does everyone have the power to raise a concern if they have one?</p>	<p>Who gets to participate in data analysis? Who gets to decide what the data means?</p> <p>Have we considered how our analysis or interpretation of the data may be biased?</p>	<p>Who presents the findings, and gets to decide how they are framed?</p> <p>Who will have access to the findings and how will they be used? Who owns and will have access to the data going forward?</p>
	REPRESENTATION & INCLUSION ISSUES	<p>Is it possible to work with local community (versus outside) evaluators?</p> <p>What is the intended purpose of seeking demographic data? Can it be served without such data?</p>	<p>Are pacing and timeline sufficient to include all stakeholder communities?</p> <p>Do data collection tools address accessibility (e.g., language, reading levels, delivery mode, special needs)?</p>	<p>Do all involved in sensemaking have sufficient understanding of the context in which data was collected?</p> <p>Are stakeholders invited to participate in meaning-making?</p>	<p>Is the data presented with disaggregation where appropriate?</p> <p>Have we considered accessibility of reporting for stakeholders (e.g., offering translation, closed captioning for findings webinar, etc.)?</p>
	COMPENSATION & CONSENT ISSUES	<p>Will participants be offered appropriate compensation for time, data, and perspectives?</p> <p>What resources exist to support participants if there are sensitive or triggering topics?</p>	<p>Have we obtained free, prior, and informed consent? Are there dynamics that may inhibit consent from being freely given?</p> <p>Has everyone gathering data had training on ethical data collection and obtaining consent?</p>	<p>Can participants withdraw consent at any time, including at the analysis stage?</p>	<p>Did participants give consent to be quoted or to have their images shared?</p>
	COMMUNICATION ISSUES	<p>Have we transparently communicated intent, who will be involved, and how the evaluation will be used?</p> <p>Are the funding entity/ evaluation commissioner's values reflected in the design?</p>	<p>What safeguarding measures exist for participants to ask questions or raise concerns?</p> <p>Has participant outreach considered language, identity, literacy levels, and cultural context?</p>	<p>Are we transparent in acknowledging bias or limitations of analysis?</p>	<p>Can findings be shared back with participants?</p> <p>Can findings be shared publicly?</p> <p>Have we limited jargon in reporting?</p>
	SECURITY ISSUES	<p>What's the minimum data that can be collected to answer the evaluation question?</p> <p>Considering the political, legal, and social context, is it safe to collect and store the types of data collected?</p>	<p>How will data be stored, accessed, and protected?</p> <p>Are we following data protection standards?</p> <p>What confidentiality agreements need to be in place?</p>	<p>Should the data be de-identified before moving to analysis?</p>	<p>What will happen to data post-evaluation? If kept, how, by whom, and for how long will it be stored and protected?</p>

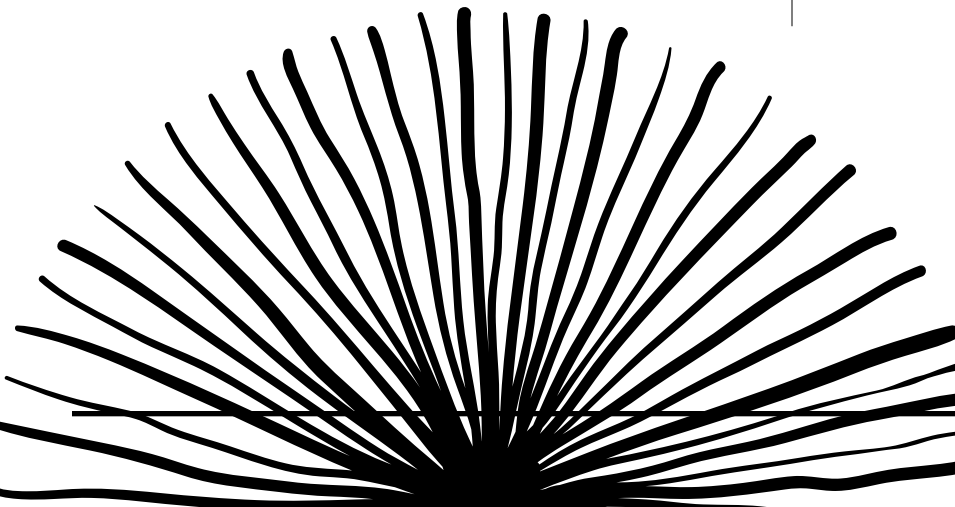
Stories from the Field

Several vignettes (Stories from the Field) are shared in the Data Ethics Guidebook. These, along with additional stories from foundations grappling with data ethics today, are compiled below, together with discussion questions.

These stories are designed to deepen your team's ethical thinking capacities. Storytelling offers a powerful mechanism for creating shared learning experiences and eliciting group insights. As such, we suggest making time to read and discuss stories as a group. They reinforce the message that there is no single "silver bullet" solution to addressing the complex and evolving issues that arise in advancing ethical research practices. This isn't a process for checking boxes, but rather a tool with which to build and strengthen an ethical mindset. Deepening our awareness that both intent and impact matter in research and evaluation builds our capacity to address challenges with sensitivity and act with greater integrity.

As a process, we suggest:

- Start by selecting one story to read and discuss according to a key theme of interest.
- As a group, consider the prompts and explore what additional questions arise. What ethical issues do these stories raise? How might you resolve them?
- Invite participants to reflect on their own experiences in the past and how these may shape the perspectives they hold today.
- Given the complexity and context, there may not be a single "right answer." How do the perspectives of various stakeholders shape the way issues are understood?
- Alternate process for a workshop: Select a story and ask participants to consider the issues from one perspective out of a group of relevant stakeholder groups (e.g., foundation legal counsel or program officer, internal evaluator, external evaluator, participant in a project being evaluated, nonprofit evaluation commissioner).
- Consider ways this Toolkit, and the associated Guidebook, can support your planning and decision-making in the future.



ETHICAL ISSUES IN DESIGN

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

THE STORY

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 method) 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 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 are 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

ADDITIONAL RESOURCES

Sections on “Community Input and Context”, “Who Benefits from the Findings?” in the companion Guidebook.

Section 3 of “For Community Organizations” in Chicago Beyond’s [“Why am I always being researched?”](#)

ETHICAL ISSUES IN REPORTING

What does transparency mean in politically sensitive contexts?

THE STORY

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

KEY THEMES

Reporting, data use

ADDITIONAL RESOURCES

Sections on "Evaluation Scope & Methods", "Data Collection", "Who Benefits from the Findings?" in the companion Guidebook.

Section on "Ethical Risk" of Open Data Institute's "[Assessing risk when sharing data: a guide.](#)"

CONCERNS ABOUT CAPACITY

What happens when evaluations become overly burdensome?

THE STORY

Suppose you are a project manager at a community-based family services organization. Your organization serves low-income families and provides a range of frontline services, addressing immediate needs ranging from housing and food access to job training, education, and career counseling.

You are speaking with one of your funder's program officers about renewing your grant for the upcoming year. They inform you that, as part of the grant renewal process, the foundation has commissioned an evaluation firm to assess the effectiveness of your organization. Your program officer assures you that this project has been designed to improve your organization's evaluation capacity, that the evaluators will not impose undue burden on your staff or your program beneficiaries, and that the foundation is also awarding your organization with additional funding and training with this goal in mind.

Soon after the evaluation begins, however, you find evaluators are asking frontline staff to gather a lot of data that isn't part of your existing processes. Having already limited time with their clients, your staff soon begin to prioritize collecting only what's needed for case management and not what's required for the evaluation. Your leadership's excitement about finally having some additional funding and training to build up their own evaluation capacity quickly turns to frustration as frontline staff raise issues regarding the evaluation. You call a staff meeting, during which staff members discuss the burdens imposed by the additional data collection tasks and question whether some of the data was too personal to be gathered.

The meeting discussion reaches a topic of particular interest to you: the risk of asking questions about

issues for which frontline staff have no support to offer. The organization itself is not a provider of any mental health services—and there are limited resources elsewhere in your area—and yet, one of the data points to be collected is about mental health. When a staffer asks “What if someone disclosed a serious form of depression?” you realize your organization would have no immediate resources to offer. Another staffer makes what you feel is an intriguing analogy: “I feel like we are the NFL, saying we can't ask anyone about symptoms of brain trauma because we're not prepared to take any action on it if you say ‘yes.’”

DISCUSSION QUESTIONS

- What were the ethical concerns the foundation was trying to resolve by situating the evaluation within local organizations instead of having it carried out by third-party evaluators? What new ethical issues were created by that decision?
- How would you proceed in this situation? Consider the different stakeholders involved (e.g., frontline staff, organizational leadership, the foundation) and the stakes (i.e., grant renewal).
- Could this evaluation have been implemented differently? What changes to the process or procedures would you recommend?
- What would you change, if anything, about your answer if a partner organization could be tapped to accept mental health referrals?

KEY THEMES

Evaluation implementation, appropriateness of design to context, capacities

ADDITIONAL RESOURCES

Sections on “Drivers of Evaluation”, “Data Collection”, “Who Benefits from the Findings?” in the companion Guidebook.

“YOU CAN’T SHOW ME THAT!”

How can the confidentiality of information be protected when it is tied to funding?

THE STORY

Suppose you are a program officer at a foundation based in a large city within the US.

Over the past few weeks, you have been conducting site visits to various women’s rights organizations (WROs) as part of an evaluation of a gender-based violence program. You arrive at a local WRO—one within your grant portfolio, in fact—that the foundation is funding to support advocacy and campaigning on legal reform and improved sector coordination. As their program officer, you are also aware this organization receives funding from other funders to provide case management and legal and psychosocial support to women survivors of violence.

During your visit, a WRO staff member shows you some of their case management files, which include a series of photographs of women’s abuse injuries. Women’s personal details—including their names and date of birth—are visible. You feel uncomfortable about what is being shared and tell the WRO staff it is not necessary to share these details. Moreover, you remind them sharing this kind of information is a violation of the code of conduct for data ethics they had been required to sign as grantees. The staff member in question responds with surprise, “Other donors always want the personal stories!”

DISCUSSION QUESTIONS

- What ethical concerns are raised by this story?
- How would you address the situation?
- What about those “other funders”—does the evaluation commissioner have a responsibility to ask them to change their ways?
- What would you change, if anything, about your answer if you consider this situation from the perspective of the WRO staff member?

KEY THEMES

Data privacy, funder-grantee power dynamics

ADDITIONAL RESOURCES

Sections on “Data Collection”, “Who Benefits from the Findings”, and “Data Storage: Ownership and security” in the companion Guidebook.

Section on “Negotiating an Ethical Research Framework with Refugee and IDP Communities” in Pittaway, E., Bartolomei, L., and Hugman, R. (2010). “‘Stop Stealing Our Stories’: The Ethics of Research with Vulnerable Groups.” *Journal of Human Rights Practice* 2:2. for related examples.

ETHICAL ISSUES IN IMPLEMENTATION

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

THE STORY

Suppose you are 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 members design a research plan, which successfully proceeds through the IRB approval process at your university. You also prepare consent forms each interviewee signs.

However, after the first few interviews, your team members report feeling uncomfortable. What they observe is interviewees signing the consent forms without any real option to decline to participate. The farmers are part of organizations that receive grants from the funder commissioning the study and they seem to feel some pressure to participate. Your team members agree the Western way of doing research, and the IRB process that you all went through, all now seem out of place in the context of the rural communities. You're concerned 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 concerns are raised by this story? What should you do?
- What are the power dynamics in this situation and how do they influence the process of obtaining consent?
- What are some other steps that could have been taken to address those dynamics or ensure informed consent?

KEY THEMES

Consent, power dynamics, cross-border evaluation

ADDITIONAL RESOURCES

Sections on “Consent & Compensation” and “IRA & Their Limitations, and “IRB Alternatives” in the companion Guidebook.

Section on “Informed Consent” in Ackerly, Brooke. (2010). *The Framework for Research Ethics and Evaluation: Justification and Guidelines*.

ETHICAL ISSUES IN DATA ANALYSIS

Can the anonymity of grantee feedback always be guaranteed?

THE STORY

Suppose you are a staff member at a nonprofit organization 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 food access and 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?
- Would you raise these suggestions to the evaluator or foundation? If so, how?
- 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

Data privacy, data use

ADDITIONAL RESOURCES

Section on "Gathering Demographic Data with Care" in the companion Guidebook.

[Reducing Stereotype Threat: An Online Compilation of Resources from Barnard College and the Alfred P. Sloan Foundation.](#)

CHERRY-PICKING PROGRAM FEEDBACK

How should evaluations be designed when a foundation’s reputation is at stake?

THE STORY

Suppose you are a project director at an evaluation firm specializing in leadership and management consulting.

You are retained by a funder to assess their leadership development program. The funder is a high-profile institution, and this leadership development initiative is their flagship program. Because your firm is based in another city, you and your colleagues recruit and train a local evaluator as a subcontractor to conduct interviews with program participants.

Midway through the evaluation, the subcontracted evaluator informs your team that it is becoming abundantly clear from the interviews that the program has significant issues and that participants have been unhappy with how it is being run. You decide to broach a discussion of these issues with the funder, only to be told the subcontractor must have incorrectly selected interviewees. After insinuating the current feedback should be discarded, the funder cherry-picks a new set of program participants for your subcontractor to interview.

Your subcontractor reluctantly agrees to interview this new group of program participants, who end up giving more positive feedback. You report this to the funder, who again suggests the earlier interviewees’ perspectives should be discounted.

DISCUSSION QUESTIONS

- What ethical concerns does this story raise?
- How should you handle this situation going forward? What could you have done differently?

KEY THEMES

Data analysis, funder-grantee power dynamics

ADDITIONAL RESOURCES

Sections on “Bias & Context in Analysis”, “Representation”, and “Who Benefits from the Findings?” in the companion Guidebook.

A tool to broach this discussion at the beginning of a project, from [Data Ethics Maturity Model – A Tool for Benchmarking Your Approach to Data Ethics](#). [Accessible](#).

ETHICAL ISSUES IN YOUTH-LED PROJECTS

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

THE STORY

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 a list of recommendations resulted. 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 the 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

ADDITIONAL RESOURCES

Section on "Youth & Youth-led Research" in the companion Guidebook.

Kelly, Caitlin, et. al. (2017). "Youth-Led Research: Supporting the Design and Implementation of Youth-Led Research Projects. Retrieved from: <https://www.sfcg.org/wp-content/uploads/2017/05/Guidance-Youth-led-Research-dr-3.pdf>

Kim, Jangmin. (2016). "[Youth Involvement in Participatory Action Research \(PAR\): Challenges and Barriers.](#)"

ETHICAL ISSUES IN COMPENSATION

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

THE STORY

Suppose you are a researcher who has been hired by an international aid agency to determine whether Roma children working on the street in a post-conflict nation were “trafficked” according to an international definition and to evaluate local responses to the situation, if so.

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 only recently been formed and 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 in children’s ability to earn a livelihood, and 2) being observed and potentially punished for talking to someone who wasn’t offering money and might be recording or taking notes.

As part of its general research policies, 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 to be consumed while briefly inside 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

ADDITIONAL RESOURCES

Sections on “Consent & Compensation” and “Capacity of Evaluation Participants” in the companion Guidebook.

ETHICAL ISSUES IN DATA MANAGEMENT

Who owns the data when research involves multiple stakeholders?

THE STORY

Suppose you are a doctoral student who leads a research team.

You have been commissioned to conduct a randomized control trial examining the impacts of a national education nonprofit on students. Because you are 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 the 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 as well as to own and control their own data in the context of this story?

KEY THEMES

IRBs, data ownership, data privacy

ADDITIONAL RESOURCES

Sections on “IRBs & Their Limitations” and “Data Ownership” in the companion Guidebook.

Ethics Learning & Decision Log

Evaluation practice is comprised of myriad decisions that inform choices and outcomes. The Learning & Decision Log is designed to capture insights and record decisions that can serve as a valuable tool for tracking growth toward our highest objectives. As your team discusses ethical considerations in evaluation, reserve time to take stock of lessons learned and record any decisions that have influenced your own practices as a result.

To prompt discussion, consider:

- To what extent are our evaluation practices in alignment with the principles and ideas discussed in the Guidebook?
- In what ways might we make changes to our current practices?
- How can we support one another in bringing a stronger ethical lens to evaluation practice?
- What decisions are we making—at the team or foundation/organization level—based on what we have learned?

DATE	PROJECT/EVALUATION	ETHICAL ISSUE/TOPIC	WHAT WE LEARNED	DECISIONS MADE AND BY WHOM	NEXT STEPS

Sample Evaluation Consent Form

Suggested Language for Researcher Obligations to Participants

STANDARD CONSENT FORM (DO NO HARM)

Introduction

You are invited to participate in a research study investigating [state what is being studied]. This study is being conducted by [researcher name and organization]. You were selected as a possible participant in this research because [state how and why the subject was selected]. Please read this form and ask questions before you decide whether to participate in the study.

Background Information

The purpose of this study is to [state what the study is designed to discover or establish]. Approximately [XX] people are expected to participate in this research.

Procedures

If you decide to participate, you will be asked to [in a step-by-step fashion, describe all steps and procedures you will follow, including their purposes, how long each step will take, any repetitions, and where the research will take place]. This study will take approximately [indicate the length of time the subjects will be participating in the study during each interval minutes/hours over XX sessions].

Risks & Benefits

The study has several [or use words like “very few,” “no real,” or “minimal,” if that is the case for your study] risks. First, _____; second, _____ [risks must be explained, including the likelihood of the risk. Describe discomforts and inconveniences the participants may reasonably expect. If the participants will be told of significant physical or psychological risks to participation, they also must be told under what conditions the researcher will terminate the study. If there is a risk of causing emotional distress on the part of participants, list resources such as crisis lines or counseling centers here].

The benefits to participation are [state benefits. If there are no direct benefits to the participants, which is often the case, state, “There are no direct benefits to you for participating in this research.”]. [If applicable, describe appropriate alternatives to participation that might be to the individual’s advantage. Any standard benefit or treatment that is being withheld must be disclosed.]

Compensation

If you participate, you will receive [include payment or reimbursement information here. Explain when disbursement will occur and the conditions of payment].

Confidentiality

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified, or identifiable, and only group data will be presented. [If it applies to your study, include ways in which you will maintain confidentiality, e.g., “No one in the daycare center will know your child’s results.” If you release information to anyone for any reason, you must state the persons or agencies to whom the information will be furnished, the nature of the information to be furnished, and the purpose of the disclosure.]

We/I will keep the research results in a password-protected computer and/or a locked file cabinet in [state where] and only I [or the researcher(s) named in this form] and our/my advisor will have access to the records while we/I work on this project. We/I will finish analyzing the data by [specify the ending date of your research]. We/I will then destroy all original reports and identifying information that can be linked back to you. [If recordings are made, explain who can access them, if they will be shared with others, and when they will be erased or destroyed.]

Voluntary Nature of the Study

Participation in this research study is voluntary. Your decision whether to participate will not affect your future relations with [the name of any other cooperating institution] in any way. [If the study includes survey items or an interview, you may state that participants can refuse to answer any question if they choose.] If you decide to participate, you are free to stop at any time without affecting these relationships, and no further data will be collected.

New Information

If, during this research study, we/I learn about new findings that might influence your willingness to continue participating in the study, we/I will inform you of these findings.

Contacts & Questions

If you have any questions, please feel free to contact me, [name] at [phone number] or [e-mail]. You may ask questions now, or if you have any additional questions later, the Principal Investigator/Director, [contact information], will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact [name and/or IRB institution], the ethics review board that reviewed this study at [phone number] or [e-mail]. You may keep a copy of this form for your records.

Sample Photo Use Consent and Release Form

PURPOSE FOR USE: The photo(s) and/or video provided will be used for [describe use and duration of use, e.g. one-time publication in a report, a PDF that will be downloadable from a website, shared with a blog on a website expected to remain live on the web at, list URL, for one year, available for use in social media posts in perpetuity, etc.].

ATTRIBUTION: [State how credit will be given. (e.g. credits will list the photographer and/ or the organization supplying the photograph, as requested.)]

COMPENSATION: [State any information about compensation offered. If none, state that no compensation is offered.]

CONSENT

Please review the following options and ask questions if you have them. Please only check the box for the option that you agree to.

- [Name of Organization] may use the photo(s) that the organization or individual named below has provided for use in [name of evaluation project or report] commissioned by [name of commissioning foundation or organization].
- [Name of Organization] may NOT use the photo(s) that the organization or individual named below has provided.

Other comments or specific requests for attribution:

I have read the preceding text and I fully understand the nature of this agreement. I freely and voluntarily consent to the use of any photos provided to [name of organization] for this purpose.

Name: _____

Signature: _____ Date: _____

Organization: _____

Phone number: _____ Email: _____

Further Reading

GUIDES AND FRAMEWORKS

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Open Data Institute has several useful tools available on their website:

- [The Data Ethics Canvas – A Tool for Identifying and Managing Ethical Issues](#)
- [Data Ethics Maturity Model – A Tool for Benchmarking Your Approach to Data Ethics](#)
- [Assessing Risk when Sharing Data – A Guide](#)

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Glossary of Key Terms

Data Ethics: A branch of ethics that evaluates data practices with the potential to adversely impact on people and society—in data collection, sharing, and use. (Open Data Institute)

Evaluation: Evaluation is the systematic determination of merit, worth, or significance of something for the purpose of developing or contributing to a body of knowledge.

Individually Identifiable Information: Information is individually identifiable when the data elements have personal information that can be linked to a participant's identity or other characteristics that (alone or in combination) could allow them to be identified. Potential identifiers include name, birth date, dates of admission and discharge, dates of diagnosis, zip code, Social Security number, and demographic details.

Psychological Harm: Psychological harms include discomfort, stress, anxiety, pain, guilt, or instability.

Research: Research is a systematic investigation or experimentation to establish facts or advance knowledge.

Risk: Any potential harm that could be put upon individuals participating in an evaluation or research study. This includes psychological, social, and physical harms.

Safeguarding Confidential Information: Measures to safeguard confidential data include substituting codes for identifiers, maintaining code lists, and storing data files and code lists in separate locations.

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.

Social Harm: Social harms include disruption of family and social relationships; stigmatization; damage to reputation, employability, insurability, or financial standing; or civil or criminal sanctions.

Standard Ethical Guidelines: The following standard guidelines should be ensured for all people who participate in evaluation or research:

- An informed consent process is in place.
- Participants are disclosed information.
- Participants understand what has been disclosed.
- Participants' participation is completely free and voluntary.
- Adequate provisions are in place to protect the privacy of participants and maintain data confidentiality.
- All methods of data collection (e.g., surveys, interviews) have been designed to minimize psychological, physical, and/or social harms.
- Participant selection is equitable.

Vulnerable Populations: Traditionally, people in these populations can include children/adolescents, people who are incarcerated, people with economic and/or educational disadvantages, and people with physical and/or intellectual disabilities. Use of the term "vulnerable" can increase stigma experienced by a person. Another way to think about this concept is to ask: "Are there groups of people participating in this evaluation or research who have less power, voice, or say in decision-making than others?"

