Webinar: Best Practices in Research with Newcomers

May 14, 2025, 3:00 – 4:30 PM ET

Transcript

Introduction

Caroline Diltz: Hello, everyone. Welcome. Thank you all for taking the time today to attend our training on Best Research Practices with Newcomers.

Today's Speakers

CD: I will introduce our speakers for today. My name is Caroline Diltz. I work as the program manager for refugee-related research at the Research Program on Children and Adversity at the Boston College School of Social Work. I have over seven years of clinical social work experience working in home and community settings for children and families with a specialization in holistic and trauma-informed care. My current work focuses on strengthening resettled Afghan families through the Family Strengthening Intervention for Refugees, or FSIR, an evidence-based mental health program.

I'm delighted to introduce our other speakers today. First, we have Mr. Farhad Sharifi, who is a recent Afghan evacuee. He is a social worker and serves as a cultural expert and research associate at the Research Program on Children and Adversity, or the RPCA, at Boston College. Also focusing much of his work on the Family Strengthening Intervention for Refugees. Previously, he was working with internally displaced populations in Afghanistan with Jesuit Refugee Services.

Finally, we also have Rochelle Frounfelker on today. She is an assistant professor in the College of Health at Lehigh University. She's a social epidemiologist who uses mixed methods to investigate the life course impact of social and environmental adversities on psychiatric disorders among war-affected populations. She implements new or adapted evidence-based interventions to reduce negative mental health outcomes. She assesses the effectiveness of interventions in clinical and community settings. She has her MSW and MPH from Columbia University and her SED from Harvard Chan School of Public Health.

Learning Objectives

CD: With that, we can dive into the learning objectives for today's webinar. First of all, what we'll hope to learn by the end of this session and that you'll be able to do is to explain consent and confidentiality protocols that protect research participant safety while respecting different backgrounds and ethical research standards. Identify signs of suicide risk, intimate partner violence, and other crises when conducting research with refugee and newcomer communities. Apply trauma-informed strategies and techniques for working across cultures to assess and respond to research. Finally, we will describe three strategies for effectively sharing research findings with newcomer communities and enhancing services and policies based on those findings.

1. Introduction to Research with Newcomers

Poll Question

How familiar do you feel with ethical research standards?

CD: I will kick us off today with Section 1, an introduction to research with newcomers. In this section, we'll introduce the subject by describing some basic research ethics and the importance of following ethical procedures when developing or conducting a research project with newcomer participants in order to foster a respectful and trustworthy research environment.

We will kick off with a Slido today. We'd like to hear from all of you. To do this, we'll use Slido throughout today's webinar. You can join today's Slido session in two ways. You can either join by scanning the QR code here on the screen, or you can go to slido.com and put in the code 3748 163. It looks like all of you have already figured this out. Our question today to start out was just: how familiar do you feel like you are with ethical research standards? Somewhat familiar, fairly familiar, not familiar at all, or very familiar.

It looks like most of you are somewhat familiar, which is good to hear. We're excited to teach you a little more about some of these research ethical standards today so that you will definitely feel very familiar by the end of this webinar. I think we can dive right in.

NIH Key Ethical Principles

CD: Firstly, we want to just go over some key ethical principles. The National Institute of Health, or NIH, which we will reference a few times during this presentation, identifies seven key ethical principles to follow when conducting research. Why is this important? Maintaining high ethical standards in research is vital for supporting the integrity of the research project, for protecting research participants, and to foster a positive and educational research environment.

Firstly, we have social and clinical value, which is the justification for asking people to participate in research with its inherent risks and demands. It lies in the expectation that the answers that we find will either deepen our scientific understanding of health or it can translate into tangible improvements in disease prevention, treatment, or care. Does the project have social and clinical value? Does the project have scientific validity?

A well-designed study is essential for obtaining meaningful answers to big questions. This requires a answerable question of valid and feasible methods to find that answer, and adherence to accepted principles and reliable practices. Flawed research is unethical due to its wasteful use of resources and the unwarranted risks it poses to participants. Next, we have fair subject selection.

The scientific aims of a study should be the fundamental criterion for participant recruitment, ensuring equitable selection, rather than relying on vulnerability, privilege, or other unrelated attributes. Those who undertake the risks of research should have a reasonable expectation of sharing in its potential benefits. Excluding particular participant groups, like women or children, from research participation requires a robust scientific justification or evidence of specific elevated risk.

Is there a favorable risk-benefit ratio? Clinical research inherently involves some level of uncertainty regarding the extent of risks and benefits. These risks can range from minor to severe, and may be temporary or lasting. They can manifest physically, psychologically, economically, or socially. We will talk about this in our next section a little more. Therefore, every effort must be made to reduce risks and inconvenience for research participants while enhancing the potential benefits, ultimately ensuring that the benefits justify or outweigh the potential risks.

It's important to have independent review as well. To minimize conflicts of interest and ensure ethical approval before a study begins, an independent review panel should examine the proposal and address key questions. Are the researchers unbiased? Are the participants adequately protected? Is the study ethically sound? Is the

benefit-to-risk ratio acceptable? This panel also provides ongoing monitoring during the study, and this can be called the Institutional Review Board, or IRB, which we might reference during this presentation as well.

Importantly, which we will get into a little further and dive into deeper is informed consent. Prospective participants should independently decide whether to join or remain in a research study. This requires informed consent where individuals are accurately informed about the study's purpose, methods, risks, benefits, and alternatives. They also helps to understand this information and its personal relevance, and they can voluntarily make their decision about participation during this process.

Finally, respect for potential and enrolled subjects. Individuals approach for research, regardless if they are enrolled or not, those participating in or after a study, they deserve to be treated with respect. This involves protecting their privacy and confidential information, respecting their right to withdraw at any time without penalty, if the research no longer aligns with their interests, keeping them updated on any new information that could alter their understanding of the study's risks and benefits, monitoring their wellbeing, ensuring appropriate care and study withdrawal if they experience adverse events or changes in health, and then informing them on research findings, making sure the research just doesn't end there for them.

Informed Consent

CD: I have a nice little quote from the University of Oxford on informed consent here. Informed consent is one of the founding principles of research ethics. Its intent is that human participants can research freely, voluntarily, with full information about what it means for them to take part, and that they give consent before they enter the research. For the purpose of this seminar, we are going to discuss informed consent and confidentiality much further, as these are some crucial concepts to know when you're starting research for newcomer populations.

In the history of informed consent in medicine and research is closely linked to the broader development of ethical practices and legal standards that prioritize autonomy. Unethical medical experiments, like the Tuskegee study of untreated syphilis in the Negro male, and the Nazi human experiments during World War II, show how important this concept is for anyone engaging as a participant in research, as the informed consent process was not executed appropriately, if at all, in those projects.

We'll talk a little more about what components come into a valid informed consent. Firstly, there needs to be this disclosure of information. As I mentioned earlier, that includes the risks, the benefits, what is the purpose of the study? Are there alternatives? Contact information. We'll go into that a little more, too in a bit. I think at the end of this slideshow, we actually have a resource with a informed consent template that you can also work with.

Additionally, the second major component is voluntary nature of the decision. Emphasizing this participation is voluntary. You do not force anyone to do research, is the principle of ethical research right there. The third one is going to be the competency of the participant or surrogate to make a decision. Making sure that the person is competent to be able to participate. Is the person competent? Figuring that out.

There's a lot of barriers that can come with consent, and I'll talk specifically about how this might come into play when you're working with newcomers. To ensure the ability to provide informed consent across diverse backgrounds, a lot of strategies must address the language barriers, cultural differences, power dynamics, age-related considerations, and other factors that could impact understanding and decision-making. This includes using accessible language, ensuring cultural sensitivity, and considering power dynamics that may influence a person's ability to freely consent.

Language accessibility, let's get into that a little more. Using clear and simple jargon, hiring interpreters, offering visual aids, if helpful, especially for those who maybe are not literate. With working across cultures, we want to develop appropriate ways to disclose the information from the informed consent. We want to respect local norms, consider cultural beliefs related to topics like health, and consult community leaders, especially as

you are developing this consent or developing this research project, is consulting with the community on what would work best.

Power dynamics. Recognizing and addressing power imbalances is important. Be aware of how power dynamics can influence the consent process and ensure that individuals feel comfortable and empowered to make decisions. Make sure that the individuals are fully aware of your role as a researcher to avoid any miscommunications. Make sure they know why you're there, what this is, as sometimes people might misunderstand what the opportunity is that they're signing up for. Of course, being very clear there.

Providing sufficient time for reflection. Make sure that people can have ample time to consider all of this information that you provided them, and that they can ask you any questions before they decide if they want to participate in the research or not. Ensure voluntariness. I know I've said this a few times, but emphasizing that the participation is voluntary and that individuals can withdraw at any time without penalty or coercion.

Considering age-related barriers. Providing age-appropriate information, tailoring the language and the content of the consent material to the individual's age and developmental stage. Involving guardians for minors, as they can give consent for minors. Ensure that they understand what they are giving consent for, for their child or who they're taking care of, and that they can provide informed consent on behalf of them. Also with that, seeking assent when appropriate. It's important to also involve children in these discussions too.

Even if they cannot provide their full informed consent, it's good to still share the consent with them and hear and receive assent from them about their participation. Ensuring that they understand what they're doing as well. Respecting the autonomy of older adults. Acknowledging that older adults might have varying cognitive abilities and preferences for involvement in decision-making. Something to keep in mind as well as a barrier.

Key sections to actually physically include in your consent form. US federal research regulations require a thorough and detailed explanation of the study and its potential risks. When developing a consent form, here are the key sections that you should be including. Once again, there is a sample one at the end of this presentation. You'll be able to get a template for this as well if you're needing assistance. First of all, there needs to be an introduction, which explains the purpose of the study and it explains, again, voluntary participation.

Study procedures. A description of the procedures, what is going to happen? We're going to ask you five questions, and then we will go in here and take a test or that kind of thing. Also talking about the duration because that's important, too, to let people know. "This is going to take about 30 minutes," or, "We have this many questions to get through," that kind of thing. Also, we want to talk about risks and discomfort. If there are any foreseeable risks and how we can help with that risk management, and what benefits are there? What potential benefits? Sometimes these might not be direct benefits for the participants, but it could be a benefit for the community as a whole. Making sure to list that and remind participants of this.

Of course, very important is confidentiality. Making sure that participants know that their information is safe with you, that the data is protected. Compensation and incentives, if applicable. If you are providing like a gift card or $20 or some incentive, make sure that that's clear in the consent as well. Then contacts. Contact information is very important here because if there's something that goes wrong or if the participant wants more information, they need to be able to contact whoever is the running the study.

Essentially, if there is like an IRB or a review board involved, there should be contact information for them as well in case of any ethical violations or anything. Also, of course, a voluntary participation statement. Knowing that they have the right to withdraw, they voluntarily participate and they say, "Yes, you checked that off." Future use of data. It's really important to also talk about where is this data going because people will want to know that. In the newcomer community, there might be some distrust with research and with these kind of questions that they're being asked, given trauma histories and experiences previously with being interrogated or anything like that. It's really important that you're very transparent in all of this and that you are letting them

know how the data is being stored, how is it protected, and then when are you going to use it, what will it be used for.

Confidentiality

CD: We will talk more about confidentiality as this is a very important concept. Confidentiality can be defined as agreements with persons about what may be done with their data. Confidentiality and research would be defined that way. In layman's terms, making sure that no one other than the researcher knows who participated in the study or what information they provided for the study. In terms of NIH recommendations, de-identification, applying appropriate. Unless participants explicitly consent to sharing identifiable data, the data should generally be shared only in a de-identified format.

What does that mean? That means assigning maybe a number or a letter, or a code to each participant so that you don't see their name or any identifying information that way. Establishing scientific data sharing and use agreements. It's really good to have clear agreements when sharing research data, especially through online collections. These agreements they set rules so everyone knows how to share and use information correctly. It's really important that the data can only be accessed with permission as it helps everyone understand that what they're supposed to do and what they're expected when using people's information.

Even if the data doesn't have names attached, we should still think about these agreements to make sure it's used responsibly and that people's privacy is protected. Also, to understand and communicate legal protections against disclosure and misuse. What does that mean? There are various laws at the federal, tribal, state, and local levels that control how scientific research data can be shared and used. Researchers and their institutions need to figure out which of these laws apply to their work.

It's particularly important for researchers and institutions to understand the institution's certificates of confidentiality like NIH because these offer legal protection for the privacy of research participants.

CBPR

CD: We will talk a little more about community-based participatory research. Community-based participatory research, the reason we want to discuss this today is because it is a great approach for newcomers. What we call CBPR.

It's a fair and inclusive research approach that brings together the researchers, the organizations or institutions, and the community members to collaborate on every aspect of a project. It enables all stakeholders to share their expertise and engage in decision-making processes. This can be done in a number of ways. One thing that we've done at our lab multiple times is developed a community advisory board. I'll get into that in a moment. The aim is to also enhance understanding and awareness of specific issues and use this knowledge to develop interventions that positively impact the community.

There's extensive evidence that shows that community-based participatory research is a promising approach in conducting research with newcomer populations. What does that look like in practice? Involving newcomer communities in actually developing the concept and design of the study. As I mentioned before, you might develop what's called a community advisory board, or a CAB. This is a group of individuals from a specific community who come together to provide guidance, to provide feedback, support to organizations, projects, or any initiatives that are impacting their community.

These are really useful to use in health care, education, research, and community development projects to ensure that the voices of community members are heard and that they're considered in decision-making processes from the very beginning. A second one that's really important when working with newcomers is employing newcomer staff for recruitment, engagement, and data collection with research participants. This

can help in a number of ways that it can overcome linguistic barriers and cultural barriers that might occur, and it offers just a great trust building environment for the researchers.

Also including the community in data analysis and dissemination translation efforts. Including them in data analysis and translation of results. This is important to just, again, keep in mind that CBPR is using the community in every part of the process. That includes, at the end when you are disseminating or translating any findings for the community to review as well. With that, I will now hand it over to my colleague, Farhad, who will discuss preventing and minimizing risk in research.

2. Preventing and Minimizing Risk in Research

Poll Question

What are some risks that might occur during research with newcomers?

Farhad Sharifi: Thank you, Caroline. In this section, I will mainly talk about the risk in research, some categories of research, and some examples. Before I start, would you all please scan the QR code again to respond to this question? You can go to that browser at slido.com and add that code. The question is, what are some risks that might occur during the research process when working with newcomer communities? We will spend a few minutes, not minutes, a little time.

Yes, language barriers, lack of understanding, re-traumatization, a lot of language and communication barriers, misunderstandings, cultural issues, fears. Great responses. Misinformation. Thank you for all the great responses and similarly, let's talk a little bit of what do you mean by risk and how to prevent some of that.

Identifying and Preventing Risk

FS: Whether we are working as a researcher or a research assistant, many of us can be in that role, we have an ethical obligation to identify, minimize, and disclose any potential risk or discomfort that participants might experience during the study.

This disclosure and some of these risks might explicitly be part of the consent process and what we call consent forms, as Caroline was talking about. For example, and if relevant to your research, we better communicate to the potential participants that they might become distressed when recounting traumatic experiences and as a principle, we need to have a plan in place to connect participants with mental health support services if this risk occurs during the interview.

In other words, there should be a system of referral in place and already budgeted to do that referral in case such thing happens. The next important point is the fact that we need to communicate any risk that could potentially occur during the research to the participants and of course, those risks must be disclosed in the informed consent because if we don't talk about the risks, it is not an informed consent, it's just a paper form.

As an example, you need to tell explicitly to the participant that some of these questions that I ask might bring up difficult memories or feelings. This is a risk of participating in this study. However, if this happens, you need to explain it to the participant that if something happens that you are sad, we can help you get to a professional that you can talk about all these memories, if you want to.

Another very important piece of information that needs to be disclosed during the consent process is the fact that we are mandated reporters in cases of risk of harm. What it means is that you need to tell to the participants that if you or your child, for example, tells me that someone is hurting them or the child is hurting herself or himself, or they are planning to hurt someone else, in such cases, I am a mandated reporter to talk to my supervisor. Obviously, the supervisors, they have a risk of harm protocols to follow up and so that

everyone are safe. This piece of information is very important to disclose in your consent process and it is a participant's right also to understand all this.

The next point is the fact that in any scientific research, the potential benefits should outweigh the risk. I think Caroline a little bit touched upon this. Any research that potentially has psychological distress, social repercussions, or breach of confidentiality should also have benefits which should outweigh the risk. For example, as I think Caroline said, the research finding could potentially lead to improvements in the healthcare services that benefit the general public or a certain community or a group of people in the future.

Types of Risks

FS: Okay, next slide, I'm going to talk about types of risks. As we can see here, a category of potential risks associated with any research. There could be physical risks, including physical discomfort, pain, injury, illness, et cetera. There could be psychological risk with negative affective states, such as anxiety, depression, and trauma-related reactions. Next, there are social risks that might affect relationships. For example, if a research is asking a question from a child about how they are doing at the school and potentially his parents didn't know what the child issues are at the school, this could lead, maybe, to a strain in their relationship if things are not managed properly.

Other social risk examples are embarrassment, loss of respect, labeling participants in a way that will have negative consequences. Similarly, there could be economic risk if the research leads to damage to employability based on participation and if their sensitive data are breached. Another risk is the loss of confidentiality, meaning there could be breaches in data storage and data security. If the research data containing personal or sensitive information is not stored that securely, it could be accessed by unauthorized individuals, or even you might have a breach of confidentiality during data collection.

For example, there's a conversation for the interview process of the research, and then someone overhears. It is also important to consider the legal risks. For example, if the research procedures in a way that it is so that participants will be liable for violation of law, especially if a participant reveals that they have or they will engage in an illegal act. This could be both ways, meaning that we also need to disclose and talk about all these risks and harm with participants. That if we don't do that, there might be severe legal and ethical consequences, including lawsuits, fines, potential criminal charges, especially if participants are harmed or laws are violated.

Researchers and their institutions may face financial burdens, damage to reputations, and even have their research halted or their funding revoked. Next slide.

Examples of Risk Situations

FS: We have some examples of risky situation or the risk situation for what we call human subject research. As you can see from the bullet points here, I will elaborate on each of them, traumatic events, unwanted stimuli, labeling, minor emotional risk, participant relationships, and personal information and how there is a risk in any of them.

Next slide is the one specific example of risk situation in which, let's say, a graphic memory or a distressing event is triggered. As interviewers they might even see changes in the face, so you need to just pick up the cues to just pick up if the participants are triggered or not. Maybe I watch the eyes or shifting. All these cues, we need to be careful. We need to read the room, of course, to pick up these cues ideally and so that it helps us to mitigate the risk.

There are a number of activities and plans that we could have in place to mitigate such risk. For example, if we have a buy-in from the community about topics that we are going to ask, that's helpful. This simply means that the community with whom we do the research should know enough about the topic and they should be

convinced that this is for the good of the community, if that works for them. Another way to mitigate this kind of risk is by disclosing the topics, the study activities, what we are going to do, or just give them a general idea of what type of questions we are going to ask so that they know what they are signing up for.

Another way, as I mentioned earlier, read the room, monitor the participants for signs of distress. Providing participants with community resources will be helpful also, especially in case of referrals. These are some of the ways that we can mitigate this risk. Similar to that, hiring a trained clinician could be another way to mitigate some of this risk. Being purposeful and thoughtful about timing when asking sensitive questions, that's also helpful. It means that sensitive questions should generally not be asked at the very beginning of an interview or interaction.

It's crucial to first build the trust and the rapport with the participant, making them feel comfortable and safe. Starting with less sensitive demographic questions could be a better idea, or talking about general experiences allows the participant to just have a comfortable situation and they have a better conversation with you. Finally, if you have training for the research assistants so that they understand how to discuss sensitive topics in an appropriate and thoughtful manner is another way of mitigating the risk.

Next slide elaborates on another risk situation that is unwanted stimuli. What do we mean by that? Exposure to unwanted or upsetting stimuli could lead to harm or discomfort. For example, if your research topics are around pornography, substance use, suicide, et cetera, in which case researcher should definitely elicit clear and informed consent to mitigate risk. What do we mean by clear informed consent? This is a simply you need to explain the purpose of these questions or the survey so that to ensure that participants fully understand that the research might involve exposure to upsetting or difficult content, and that they willingly agree to participate despite this possibility.

Eliciting clear consent goes beyond just the mere form to sign. It's not only a form or a signature. It means that we need to make ourselves ensure that they fully understand all the potential stimuli and all the potential triggers there. We need to have an explanation of all the specifics that what's going to happen, and they should have enough information so that they freely participate.

Having clear consent also means ensuring voluntary agreement. Making yourself absolutely sure that the participant feels no pressure or coercion to consent and they willingly want to be part of this research. Participants need to know they can say no also. This is at any moment of the research. During the consent process you need to explain to them that once they start their research, though initially they agree, at any moment during the research they can withdraw from their participation.

Another important aspect that makes consent informed and clear is that we don't want to use very research-heavy terminologies and jargon. Instead we want to use verbal explanations with opportunity for questions. For individuals with low literacy, a verbal consent process that is documented, that's also necessary. Clear consent also means opportunity to ask questions. We should have a safe space where participants ask their question and we patiently answer these questions until the participant is satisfied and they fully understand.

Last but not least, clear consent means participants have the right to withdraw at any moment, as I just said previously. We need to make it clear that even if they initially consent, at any moment they can just stop because they might feel discomfort or distress. Another strategy just to mitigate is to avoid exposing higher risk groups to unwanted stimuli. For example, if you're working with forced migrants, showing videos of war could be an unwanted stimuli. As we mentioned earlier, always have safeguards in place to mitigate risk. This could also involve hiring a clinician to support participants.

Next slide talks a little bit about the risk of labeling. Participants who don't have knowledge of clinical terminology may feel they are being labeled when they are answering questions from assessment like a depression measure. They may associate themselves with depression even if they are not clinically diagnosed. In simple terms, labeling risk refers to the potential for participants to feel categorized, judged, or stigmatized

based on their answers to questions. Particularly when these questions come from assessment that use clinical or specialized terminologies of which the participant might be unfamiliar.

Participants also, especially those from diverse linguistic and cultural backgrounds, who may not have prior experience with formal assessment or clinical language might answer questions without fully understanding the underlying concepts or what the assessment is intended to measure. Their responses could mean lead to just being assigned a label, for example, psychotic, which in fact does not represent them. This can be disempowering and potentially stigmatizing.

Even with translation, clinical or psychological terms can be difficult to convey its accurate meaning and its accurate use. It is common sense that concepts of mental health, well-being, and social issues can have different meaning across cultures. To mitigate this, we need to ensure participants understand by appropriately and clearly naming the scales being used, or remove the measure names altogether. What it means, that we need to be transparent with participants and explain the surveys or the measure's purpose and what this measure it means in simple terms.

We need to explain that in accessible language. For example, instead of saying, "We are going to administer a CST scale," so we better say, "I would like to ask you some questions about how you have been feeling lately, about your mood and energy levels. This set of questions help us understand common experiences with sadness or worry." If you explain like this, the focus is on explanation and the content and the purpose of why we are having this session.

Next slide talks about the minor emotional risks, which simply means mental fatigue, and sometimes embarrassment, discomfort, or frustration. One strategy to mitigate such risks could be shortening the duration of the survey. If your survey, for example, takes three hours, which I heard about, maybe it's a good idea to look into possibility to make it one hour or so. If your research design allows, or even if you could ask the questions within breaks. There were examples of surveys that research assistants did one hour of the survey, because it was too long, and then they had to come back another day, based on the availability of the family or the participant timing.

Similar to other risks, we need to also disclose this information also to the participants in the consent form, I guess, a little bit we discuss about this. The next slide we talk a little bit about the risk of straining participant relationship. In research, there is the risk of causing a strain on relationships, for example, causing a fight between a couple when they are each asked about their household spending habits together. This reminds us about the setting of the interview session also, which is important. Maybe it is good idea to keep privacy and confidentiality measure even between closer relationship, like parents, child, or like between the couples.

In our experience, in our research lab, we try to interview participants separately in private spaces where they feel comfortable rather than together. Again, to mitigate this, we need to disclose this potential risk in the informed consent that there is this potential risk of straining relationship. If I can elaborate a little bit about these two terms, I guess it is a little researchy heavy. We need to differentiate between whether the relationship distress is study-induced or unintentionally researcher-induced, which simply means that it is the researcher's responsibility to monitor for signs of relationship strain among participants and carefully consider the cause.

What does a study-induced means? It means if there's tension between the couple or between the parent and child is a direct result of the research activity or no. Unintentional researcher-induced means if something the researcher did that inadvertently caused the problem. This could be a miscommunication, a failure to maintain confidentiality, a lack of cultural sensitivity that led to misunderstanding or offense between the participant outside the formal research session.

The last slide that I'll be talking about risks is regarding the risk of personal information being breached. In some research, we might collect personal information, maybe more than some, I guess. There's a marginal risk of this data being breached and to mitigate that, of course, we will clarify and talk about how we are going to

safeguard personal data and what is our policy, what is our mandates, all that. We can explain to them that we do our best to keep your data secure, but there is a margin and risk that their data might be breached and they have the right to know that.

Case Scenario: Zahra

FS: Next, I'm going to read a case scenario followed by some question. As you can see, this case, a researcher is conducting a survey with resettled Afghans to learn more about mental health challenges in their community. The researcher meets with a 40-year-old mother named Zahra who arrived in the US shortly after the evacuation in 2021. Zahra came with two of her children and her husband remains in Afghanistan.

The researcher begins the survey by asking question about war-related experiences, such as if the participant has experienced the death of a family member, being beaten, or the destruction of their house. Zahra becomes visibly uncomfortable, looking down, and shifting in her seat as she responds. Finally Zahra speaks up, "I was told the questions were going to be about life in the US. I'm not comfortable with these questions and want to end the interview early." Zahra leaves the interview distressed and dissatisfied.

Discussion Question

What could the researcher have done to mitigate Zahra's distress?

Consider this scenario. I think you are familiar how to scan the QR code or join this browser with the code to answer this question based on the scenario. What could the researcher have done before the interview to mitigate Zahra's distress? I hope you remember some of the points we discussed.

Ensure to stay on topic. Be clear about the procedure. Exactly. Disclose risks. Yes. Build rapport, definitely. Not immediately ask about distressing memories. Be transparent about the kind of questions they will be asked. Remember that some of the research, they do not allow the exact question to be discussed before the interview session starts, but you can just give them a general idea of what you are going to talk about, but that's good. That was a good response. Yes, clearly explain what the process was and why you are asking. Yes, if they can be willing to answer these questions. Learn about Zahra's background. Thank you.

Okay, we can go to the next question. What could the researcher have done during the interview to mitigate Zahra's distress?

Pause and ask if she's okay. Definitely. Acknowledge and validate her anxiety. Stop questions. Yes. Watch for physical cues. Read the room. Exactly. Notice body language. Apologize. Ask different questions. Take cues from Zahra. That's all great. Thank you. We can go next, Rochelle.

3. Case Study in Managing the Risk of Harm

Case Background

Rochelle Frounfelker: Hi, everyone. Thank you, Farhad and Caroline, for the great discussion, and you're covering really important topics and issues, presenting a lot of the facts and exploring some of the risks. Now I want to talk a little bit about a case study in managing risk of harm. As you just heard from Farhad, there might be an array of different risks that could happen because of participation in research, but I'm going to zoom in and more specifically talk about risk of harm issues that may arise during research participation.

By that three, specifically three things. One is self-harm. If someone expresses wanting to harm themselves, suicidal ideation, or if there has been you're worried about suicide attempts. The second is harm to others. Is a

participant talking about wanting to harm someone else, whether it be in their family or their community? This could be homicidal ideation or other kinds of abuse and things like that. Then the third issue of risk of harm will be around to you suspecting or observing or hearing about abuse that is currently going on, specifically, let's say, to that research participant. It might be child abuse. It might be elder abuse, things that might be going on in the person's life.

What I'm going to do is talk a little bit about this within the context of work that I've done with the ethnic Nepali Bhutanese community. I've been working with this community and conducting research with this community in partnership with the community for over a dozen years now. One of the things that's really significant in this community are the high rates of suicide.

There was a CDC article published back in 2012, 2013, after Bhutanese started arising in the U.S. that indicated the suicide rates were roughly double that of the general population in the United States. At that point in time, I started working as a project manager on a research study that was community-based participatory research, looking at mental health and family functioning of Bhutanese communities in Massachusetts, more specifically in the Boston area and in western Massachusetts.

What's relevant about that is a couple things. One, as Caroline mentioned earlier, one of the strategies that I think can help facilitate and help address risk of harm is doing work collaboratively with the community. This was certainly the case with the research we were doing. By CBPR, then more specifically, we had research assistants and program leaders that were from the community itself. We also had a community advisory board. We had a team of researchers I was supervising. We were doing mixed methods research and included children as young as age 10 and then caregivers and adults. Since then, I've gone on to work with older adults in the community.

This is significant in a couple ways. One, we are doing both qualitative interviews and quantitative surveys, so the way risks may be identified might be a little different, whether you're doing interviews with someone or in a focus group versus completing a survey. The other thing that's significant here is that we were working both with children and youth and adults, and so thinking about how risk of harm might come up specifically around children and how do you respond to that. Within that context, the next slide I want to talk about some really practical ways that I would recommend developing and designing a risk of harm protocol in response to this.

Training and Preparation

RF: A couple of things I want to highlight here. First, all the things that Caroline was saying and Farhad were saying about understanding informed consent and privacy and confidentiality and potential risk of harm are critical things to be reviewing and training any research team members on. That is absolutely critical in understanding what that means and what is the role of the research assistant and research team member in addressing these concerns. A couple things to facilitate that in terms of training materials is developing a really clear flow chart for risk of harm protocols.

We have literally a flow chart with three arms, one risk of harm to self, another harm to others, and another potential abuse or neglect that is going on, and being really clear about the pathways and the follow-up steps to go through all of that. That cheat sheet is information we walk through and we train on as a team. Then the research assistants would go out into the community interviewing people, and they had a copy of that protocol with them at all times if something needed to be enacted. That was one thing, to be really clear and walk through what that process was.

The second thing I would say is also in terms of making sure you have referrals and resource lists that may come into play. I'll be talking about that a little bit more as we get into the examples. The second thing here is being also really clear on what is the role of the community of a research assistant. They are certainly, which it may or may not be the case, but in my case, they were certainly, they were not clinicians.

They did not have any advanced training, so we're absolutely clear with them and that their responsibilities were not related to needing to do in-depth assessment and response. What their role was as community research assistants is to protect the well-being of participants and then figure out the appropriate next steps in involving the people above them on the research team if need be. That is the other thing.

For step number three is be really clear on the responsibilities of the research team supervisor and the PI in a study. I always wanted to make it absolutely clear with my research assistants that they should never feel that they are alone out in the field having to make important decisions around risk of harm. They should always have access to my phone number or somebody on backup if they would need to reach out and problem solve and talk about what is going on, because they should never be the one in the position of having to make a decision on what they should be doing. It's really a team effort between the research assistant who's there on the scene with a participant and the research leaders.

I think the fourth big thing here, as I mentioned earlier, suicide is a big issue in the Bhutanese community, and as a team and certainly as a research team supervisor for myself to really educate myself on dynamics of suicide within the Bhutanese community and have those discussions and understanding what do people understand might be risk factors, how do people talk about suicide in the community, what things might you be concerned about and things like that.

One thing I'd say, for example, in the Bhutanese community, where in some ways, because suicide is such a big problem in the community, people will discuss it quite frequently, and so in some way, sort of a radar to identify when this is something to follow up on can be a bit challenging. That was also talking to the research team who are from the community about the difference between as part of a research project, these are responsibilities to ensure our participants are being taken care of.

Certainly then, and number five is maintaining that good communication in the field. Like I said, I would always make sure our research team members going out and doing interviews in people's homes or in the community in any location had contact with me, or if I was not going to be available and I knew they were going out and doing interviews, having somebody else that could be backup for them to talk to and call if something goes on. Finally, I'd say it's really important to have a debriefing and research team meetings if something does happen.

I think this is important as any kind of response and processing among the team. It's certainly not a therapy session, but discussing what happened, how did we respond? What is any follow-up? If we know of any follow-up from what happened after this risk was identified in the field and making sure that everybody feels like they've discussed what happened and figuring out also are there things that we could change to be better prepared in the future. This is always a work in process and we can always be learning and developing better strategies and moving forward and improving identifying risk of harm.

Responses

RF: In the next slide, what I want to do is sort of with framing this and what we had in terms of the team that I was working with, the teams I currently work with in terms of their training and in terms of our preparation, walking through some examples of disclosures around suicidal ideation that we had when I was working with the Bhutanese community. The first instance is that of a child disclosure, and the context of this was a qualitative interview that a research assistant was doing with a 10-year-old.

During this interview, the 10-year-old disclosed that they had written a suicide note in school and had turned this suicide note in along with an assignment to a teacher, their teacher in the class. This is something that came out in the interview. I did not get contacted at that point in time by the research assistant. They did contact me after the interview and told me about it and were asking me what we need to do to follow up.

What I would say is I do believe that the parent, of course, because there should be parental consent to this, was told about this as well. The RA was wondering what would be the best, "Is this follow-up enough, or what else we should do?" I said, "Well, I think I would like to meet with the parent," whether or not they want to have

the child be there, but it's more about making sure was this risk-- did the school respond? did the teacher respond? Was there any concerted effort on the part of the school? Where was this currently at, and is there someone else that we should refer these individuals to?

I met with the research assistant who had done this interview and the parent and myself. We met at a community organization and I just asked questions about what had happened, was she aware, was there follow-up from the school? She had told me that yes, there was follow-up in the school and that it was being addressed. I think that's a straightforward, pretty clear example, just making sure, so if you've closed any communication loops between parents and schools and other people that are interacting with youth.

The second example I can provide is from adolescent disclosure during an interview. In this case, it was pretty complicated given the overall home environment was really under great distress. The adolescent had reported during an interview to the research assistant about feeling like killing themselves. The research assistant reported this to me on the spot, calling me and working through what was the actual risk at this point in time? What were some of the other dynamics going on? Was there a parent around the child that you could speak to about it?

It sounded like there was overall, there was the adolescent was suicidal because of some domestic violence that was going on between her parents and the household. The mother was-- like she heard and listened to the research assistant and talking about what their child had said. At that point, in terms of what we had evaluated, it was a very low risk at that moment. For follow-up for that, I went out to the home, which they agreed to, and I met with both the adolescent and the parent and the research assistant to figure out what was going on, what were the dynamics going on, and also be talking to them about any current services they were receiving for mental health care or other social services given their needs.

What kind of danger was there actually in the household in terms of harm to the adolescent with the context of there had been some domestic violence in the home? The follow-up from that was for me to reach out to agencies and individuals that I had already established communication with who were service providers in the community. With that is going back to being prepared and ready with a resource and referral list when I start engaging in any research, because I want to be able to provide people with linkages really directly to help facilitate any services they might need in response to things that they have talked about.

In this case, I also would really recommend doing outreach like one-on-one with service providers, talking to people saying, "We're doing this research study right now. If something comes up, would you be open to us referring people to your staff? Do you have the capacity to work with and take on new clients?" and things like that. In this instance, with this adolescent, this ended up being actually a family that was very well-known to the social services in the area. They were already connected to a lot of services, so we felt like there was appropriate follow-up and care that was currently going on.

The final example I'll give is specific to working with older adults. This was some research I was doing more recently with older adults in the Bhutanese community. It included a quantitative survey that contained specific questions around suicidal ideations and past suicide attempts. It also included information evaluating symptoms of PTSD and depression and anxiety. This is actually an instance where the research assistant didn't call me during the interview as this was going on, which we again had a discussion afterwards about that's probably something that they should have done and moving forward to make sure that did come into play.

I was actually looking at this person's responses, the quantitative survey, and was concerned about some of the responses around current suicidal ideation and some of the extremely, very symptomatic in terms of depression. I reached out to the research assistant and I just asked about how the interview went, what was going on, what was happening, what was that research assistant's take on the dynamics and what was going on? He said this person did get distressed during the interview.

The other thing he did know is this person also was very well connected with services, with clinical services, and there was connected with medication management for mental health issues. I asked him to go back and

follow up with this individual another time and just make sure if there's anything else that was needed and making sure this person was still connected and had the things that they needed to provide assistance with their distress that they were experiencing at that time. Those are three basic examples.

Next, I'm curious and really interested to hear from you. Oh, I guess we're—okay, I'm moving on.

4. Sharing Research with the Community

Research Dissemination

RF: All right. Now, my final thing I want to talk about is actually something I love to do is thinking about how do we share our research with the communities that we're working about? I'm really passionate about this and doing CBPR work to make sure our research has a life beyond a publication and to be able to share that.

When I talk about research dissemination, on the next slide, I'm really talking about how we're-- oh, wait, oh, sharing findings with the community. This can be what are the specific details of the research we did? What were the outcomes? Sharing these findings as a way to empower individuals and the communities with knowledge, inform them about issues that might be affecting their lives, and it helps to promote trust and collaboration in initiatives moving forward.

With the next slide, about focusing on how do we share our findings with the community? First off, a lot of times when I'm writing grant proposals, I'll already be talking to community members about potential ways we could disseminate our findings, which I might actually include in my grant proposal. Many times I'm, of course, talking about publications, but I want to talk about what would be meaningful in terms of these findings with both short, medium, and long-term. Then thinking about are there existing forums within this community that we can integrate these findings into current work they're doing, into other community events, and things like that? What are sort of would be a natural fit of our findings?

Then finally, I think, and whether or not you're doing CBPR work or not, I think it's imperative to make sure that all the different stakeholders that have been involved in the research and individuals from a community are involved and have a chance to participate in these dissemination efforts. That's about acknowledging people's contributions, and that's also about our researchers being experts in their own lives, our community members. What are different ways that you can disseminate and different kinds of dissemination projects?

In the next slide, we have a couple of different examples. The first stuff I'd say, we talk about publications, and in academia, this is like a really clear-cut priority. We want to have journal articles published. It might be related to policy briefs or fact sheets or things like that. I think these can be, they're instructive, and they can be important, depending upon the people who are looking at your results. I think in my experience overall, this should never be the endpoint for community work, nor is it very impressive to community members, understandably so, if they really want to be action-oriented.

Another way, though, that you can disseminate is with looking at funding applications. I look at all of the work that I do with communities, and I'm thinking about, even if it's not me, with my next research proposal with them, what is data that they can get from this research that they could use to inform and apply for additional funding. If we identified this need in this research, how can that be integrated as you're securing more funding for services, for example, or you want to get money to add additional staff. It's perfect to frame and provide support for your argument about things that might be needed that are different from what you've done in the past and have been funded in the past.

Another strategy, another type of dissemination is around presentations, and I think these could be actually really creative and fun. While I think about presentations in terms of academic or like public health conferences or professional conferences, I also look at, are there conferences and presentations for the community? For example, I was asked to present in August at a youth conference among Bhutanese youth to

share at this youth conference some of our findings around substance abuse among youth and young adults in the community. That is most definitely something I would do in collaboration with community members that were involved in the research, if at all possible.

The last thing I'd say is always be thinking about multimedia products. What are things like podcasts, social media, infographics, brochures, and things like that that can be developed and be creative with, again, in terms of sharing with findings and key findings in the community. I'd also say, actually, these things are incredibly relevant for also other external stakeholders to the community.

For example, this work I'm doing right now on substance abuse among youth and young adults in the Bhutanese community, we're also developing dissemination products for law enforcement, which were included in the data collection, and as researchers, we're developing material for probation officers, for educators to understand dynamics of substance abuse in the community, and if they're identifying this among youth in schools.

I think it's really important to think about materials that can be of use for the community itself, but also as they're trying to make improvements and change the services that people are getting and providing more competency and care that people might be getting to make sure you're also addressing other audiences. That is, I think, to keep in mind, there might be some potential negative consequences to dissemination. I think the first is making sure there isn't a misuse of research findings.

I always want to be really clear about the parameters of what the research is about. What is the scope? Who is it about, and who is it appropriate for? Which you have some level of control over in terms of the forms that you might be sharing of the findings, and also being really clear about what you think the implications should be, and inviting others to discuss, however, about what their thoughts are.

The next one is being really careful about breaches of privacy when you are sharing findings. This is something I may worry about this a bit more when it comes to qualitative research where we have a lot smaller samples, and maybe I'm using a direct quote from somebody. I always want to make sure that I'm using quotes that would not lead to really easily identifying the participant that may have been part of the research study. Third, thinking about harm to participants and the community. I really want to be mindful about, again, clear about, again, what I think the implications are.

Overall, making sure that there is privacy among people in the community. I do also think there needs to be some sensitivity around some of the topics, at least that I work on around mental health, that there is stigma around in the community, or I think, let's say, around the topic of substance abuse in the community. There's an acknowledgement it's a really important issue, but it's also really painful to talk about and really challenging. To make sure that you're sharing findings in a sensitive way that people can absorb and identify maybe potential action steps for.

Finally, we always want to make sure that we are not violating the ethical obligations, which we've outlined from the very beginning of the study in terms of informed consent and privacy and confidentiality. We are not sharing information with people about who exactly participated in the study. I've had study participants who are happy to say, want to let everybody know that they have participated in the research. I said, "That is fine if you want to do that, but just know I will never be sharing your name with anybody, okay?"

If somebody is open to sharing that they participated in their experience, that's absolutely fine, but we need to honor and be respectful and what we agreed upon for them participating.

Discussion Question

What strategy are you most excited to use for sharing research findings with newcomer communities or enhancing your services and policies?

RF: A last slide out here, if you're still with me, just for the brainstorm of what strategies might you use, thinking about within communities you might work with to effectively share research findings and any and all thoughts here or questions you might have about that.

Yes, posters, yes. Yes, community advisory boards, absolutely. I actually didn't mention that. Always going back and sharing the findings as you're going along with your community advisory boards member. Social media is fantastic. My work with the Bhutanese community, they have a really strong presence on community organizations and social media, like Instagram and Facebook, things like that. Yes, that's really great. It can have like snippets of findings to engage people with and share what is going on, yes.

Yes, I love going to community events. I love going to community celebrations, [laughs] and we'll always say, can we set up something there to talk about their research and what our findings are and to hear from people in the community and make them aware of the work that we're doing and get their feedbacks and thoughts. All right. Now I'm going to hand it back over to Caroline if she wanted to facilitate any questions that you might have about anything about our presentation.

Q&A Panel

CD: Yes, thank you, Rochelle. Love listening to your stories of being in the field. Thank you all, though, for listening to our presentation so far. We'll take this time to answer any questions from the audience about what we discussed today. Please continue to put questions in the Q&A on your Zoom screen, it looks like we don't have any right now, and we'll try to answer as many as we can.

However, we did ask this before putting on the webinar if anyone had any questions and we did receive a couple of good ones from you all that I can go through today briefly. One that I liked was someone asked about—

What are the best practices in working with translators when conducting research?

CD: Like if you're doing qualitative interviews, that kind of thing. Rochelle or Farhad, do you have any thoughts on best practices with translators?

RF: Yes, a couple of thoughts to that and then Farhad I'm sure has a lot of good ideas. I would say if you are working with a translator, I think in research, they should be trained in research ethics and required ethics trainings just like everybody else because they are a member of the research team, and the same rules and be training for them around confidentiality and privacy and things like that. I think when it comes to-- certainly, you don't want somebody who's a translator that knows the person as a family member, friend and things like that because you want to have somebody, again, that can help ensure the privacy and confidentiality of the things they're going to be sharing.

I'd also say it's really important when training translators on doing research to talk about the importance of being really as precise and accurate in terms of the questions that we're asking of participants because it's absolutely critical to be getting the same data across participants in response to the same question as much as possible, so there's not room for a lot of improvisation. I would say also that in terms of live translation of a participant's responses, I think certainly on quantitative surveys, that might be a bit easier if you're telling them out loud what their options are.

I'd say in terms of qualitative interviews or focus groups, it's again, asking and talking with the translator about being as conceptually accurate as possible in their response in order for us to fully get and capture exactly what that person was telling us. There might be a feeling on the part of a translator of maybe wanting to protect a participant or they said this, but I shouldn't say that out loud. We really, again, want to honor the time

of our participants and what they want to disclose and to keep it as accurate as possible. I don't know Farhad if you have other thoughts.

FS: No, I think you pretty much covered it all. However, in case some of the measures are being translated, I think there's this WHO best practice of translation of measures and within research translation that is back and forth translation from the original language to the target and then back translate to just see if in the meantime, the concepts are not changed dramatically. Sometimes during our work, we had to explain a little bit details or more explanation to provide context why after a text or a question is translated just to make it more culturally relevant and understandable for the RAs to explain. Sometimes the RAs or the research translators would explain a little bit, but as you said, not change it in a dramatic way. That's what I could say.

CD: Thank you. Thank you, Luis, for that correction that for oral communication, they are called interpreters and translation is writing. Thank you for that quick correction for us. I have one more question maybe that we can probably try to fit in here. I liked this one a lot because I feel like there might be a few of you out there who do direct service.

How can I set boundaries with clients between direct service provision and research participation?

RF: Yes, I would say this, and a couple of things, I think it goes back to the very beginning and ensuring that participants understand what research is, and that it is different from the services that a person would be getting. I don't think this is always an easy thing to explain or to understand, but that's really critical because that can set the tone for understanding what these boundaries are. Maybe I have a clinical background, but in this instance, in our interaction, this is about a qualitative interview, and so that is outside of any services you're going to be getting. That is one thing, and I think to continually making sure you're emphasizing that in your interactions with individuals.

Another thing I'd say is I think if there are instances, let's say a risk of harm, I think it can be quite common, and honestly, not just with that, of participants wanting to follow up with a research team member because they liked meeting with them and had good conversation. Maybe they're from the community and they're asking them for help with other things. I think there then I'd say it's important to have training on the part of the research team for them to have more clarity about what their role is and their role isn't.

One other thing I'd say about that is though being really mindful and acknowledging that if I'm working with individuals on a research team who are a member of the community in addition to being a research assistant, and sometimes they are also wearing another hat of being some kind of a community leader, that delineating these things can be very complex. I think in those cases, my advice is to sit down and be working with a team to talk through what is happening, to talk through what they feel would be an appropriate response, what they would be comfortable with, what we'd be comfortable with as a research team member, and to figure out and chart a path forward. Those are a couple of thoughts there.

Conclusion

Reviewing Learning Objectives

CD: Great, thank you so much. As we wrap up today, we just want to review the learning objectives. You should be able to explain consent and confidentiality protocols that protect research participant safety while respecting different backgrounds and ethical research standards, identifying signs of suicide risk, IPV, and other crises when conducting research with refugee and newcomer communities, apply trauma-informed strategies and techniques for working across cultures to assess and respond to research participant distress and high-risk situations, and then describe three strategies for effectively sharing research findings with newcomer communities and enhancing services based on those findings.

Recommended Resources

CD: Thank you all for listening to us today. We have a survey that before we share our recommended resources, we just would like you to help us help you. It's really important to help improve future trainings. Our survey is only three questions long, it takes 30 seconds to complete, so if you could just take 30 seconds out of your day right now to complete the survey, and then we can learn what we need to do better, what works well, and how we can improve our trainings in the future.

All right, and here are a few recommended resources. These will be in the slides that you'll be able to access on the website if you wanted to take a look at any of these related to what we discussed today. We also have our references in this slide deck as well, where we got our information from.

Stay Connected

CD: All right. For more training and technical assistance, please stay connected with Switchboard. On behalf of Switchboard and all of us here presenting, we want to thank you so much for learning with us, and we hope to see you again soon.

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