May 14, 2025

# **Best Practices in Research with Newcomers**

Safety, Sensitivity, and Ethical Standards

## Switchboard connecting resettlement experts



# **Today's Speakers**





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Research Associate, BostonAssistant Professor, LehighCollege Research Program onUniversity College of HealthChildren and AdversityChildren and Adversity





## **Rochelle Frounfelker, PhD**

# **Learning Objectives**

By the end of this session, you will be able to:

## **EXPLAIN**

consent and confidentiality protocols that protect research participant safety while respecting different backgrounds and ethical research standards

### IDENTIFY

2

signs of suicide risk, intimate partner violence (IPV), and other crises when conducting research with refugee and newcomer communities

## APPLY

3

trauma-informed strategies and techniques for working across cultures to assess and respond to research participant distress and high-risk situations



## 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**

Key Ethical Principles and Community-Based Participatory Research





## How familiar do you feel with ethical research standards?

(i) The <u>Slido app</u> must be installed on every computer you're presenting from





# NIH Key Ethical Principles

- Social and Clinical Value
- Scientific Validity
- Fair Subject Selection
- Favorable Risk-Benefit Ratio
- Independent Review
- Informed Consent
- Respect for Potential and Enrolled Subjects



"Informed consent is one of the founding principles of research ethics. Its intent is that human participants can enter 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."

## — University of Oxford

**Research Services** 





# History of Informed Consent

- Closely linked to the broader development of ethical practices and legal standards
- Past unethical experiments show how important this concept is for anyone engaging as a participant in research



# Valid informed consent for research must include three major components

Disclosure of information



Competency of the participant (or surrogate) to make a decision



## The voluntary nature of the decision

# Addressing Barriers to Consent



## Language barriers

- Use clear and simple language
- Hire interpreters
- Offer visual aids

## Working across cultures

- Develop a consent process that respects clients' local customs and considers clients' cultural beliefs related to the research
- Consult community leaders



## Power dynamics

- Provide sufficient time for reflection
- Ensure voluntariness
- Consider age-related barriers



- Introduction
- Study Procedures
- **Risks and Discomforts**

### Benefits

- Confidentiality
- Compensation (if applicable)
- Contacts
- Voluntary Participation Statement
- Future Use of Data

# **Key sections** to include in a **consent** form



# Confidentiality

**Best Practices** 





use agreements



Understand and communicate legal protections against disclosure and misuse



## Apply appropriate de-identification

# Establish scientific data sharing and

# Community-Based Participatory Research (CBPR)

- Fair and comprehensive research approach
- Enables all stakeholders to share their expertise and engage in decision-making processes
- Aims to enhance understanding and awareness of specific issues to develop interventions that positively impact the community



## **CBPR in Practice**



Developing the concept and design of the study with the community 2

Employing newcomer staff for recruitment, engagement, and data collection





Including community in data analysis and dissemination/ translation efforts

# 2

# **Preventing and Minimizing Risk in Research**





In your experience, what are some risks that might occur during the research process when working with newcomer communities?







# Identifying and Preventing Risk

- Ethical obligation to identify, minimize, and disclose any potential risks or discomforts
- Potential risks must be disclosed in the informed consent
- Potential benefits should outweigh the risks



## **Types of Risks in Research with Newcomers**



**Social Risks** 



## **Economic Risks**

## Loss of Confidentiality

## Legal Risks

## 

**Unwanted Stimuli** 

# **Examples of Risk Situations in Human Subject Research**

- Labelling
- Minor Emotional Risk
- Participant Relationships
- **Personal Information**



**Traumatic Events** 

# **Traumatic Events**

**Recalling distressing events** can be triggering for participants.

We can mitigate this risk through...

- Disclosing topics, study activities, or questions in informed consent
- Monitoring participants for signs of distress
- Providing participants with community resources
- Considering hiring a trained clinician
- Being purposeful and thoughtful about timing when asking sensitive questions
- Training research assistants to discuss sensitive topics in an appropriate and thoughtful manner



Getting buy-in from the community about topics that will be asked about

# **Unwanted Stimuli**

**Exposure to unwanted or upsetting** stimuli can bring harm or discomfort (e.g., pornography, substance use, suicide).

## Eliciting clear consent

- war)

We can mitigate this risk through...



Protecting higher risk groups from exposure (e.g., exempting forced migrants from watching videos of

Putting safeguards in place

# Labelling

Participants who do not have knowledge of clinical terminology may feel they are being labelled when they are answering questions from an assessment.

We can mitigate this risk through...

Ensuring participants' understanding by A. clearly and appropriately naming the scales being used or B. removing the measure names altogether



# **Minor Emotional** Risk

Minor emotional risk can include mental fatigue, embarrassment, discomfort, or frustration.

We can mitigate this risk through...



## Assessing study activities before administering them (e.g., reviewing a survey to shorten its duration)

Always disclosing potential minor emotional risk in informed consent

# **Participant Relationships**

Some study activities risk straining pre-existing participant relationships.

We can mitigate this risk through...

- consent
- Differentiating between whether relationship distress is studyinduced or unintentionally researcher-induced



## Disclosing potential risk in informed

# Personal Information

**Asking personal questions** about private information (income, substance use, etc.) may cause distress.

We can mitigate this risk through...

- disclosed



## Clarifying confidentiality policies before asking personal questions

Informing participants about any identifiers that might be revealed or

# **Case Scenario: Zahra**

A researcher is conducting a survey with resettled Afghans to learn more about mental health challenges in their community. The researcher meets with a 40year-old mother, Zahra, who arrived in the U.S. 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 questions 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 U.S. I am not comfortable with these questions and want to end the interview early." Zahra leaves the interview distressed and dissatisfied.



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

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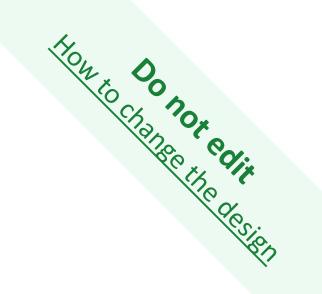






# What could the researcher have done during the interview to mitigate Zahra's distress?

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# 3

# Case Study in Managing the Risk of Harm



# **Case Background**

- Massachusetts



Suicide rates are a troubling issue in the ethnic Nepali Bhutanese refugee community

A program of CBPR research set out to study mental health in the Bhutanese community in

# **Research Team Training and Preparation**



Develop and train research team on clear risk of harm protocol



Identify responsibilities of community research assistants



Identify responsibilities of research team supervisor and leader









Discuss and understand suicide dynamics within the community

Maintain good communication while in the field

Debrief in team meetings

# Responses

Child disclosure 



## Adolescent disclosure

## Older adult disclosure



How can we collaborate with newcomer communities to facilitate sensitive responses to risk of harm issues?

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# 4

# **Sharing Research with the Community**





In your experience, what are some strategies you have used to effectively share research findings with newcomer communities?







# Research Dissemination

Sharing research findings with the community is crucial because it:

- Empowers them with knowledge that can improve their well-being
- Informs them about issues affecting their lives
- Fosters trust and collaboration



# **Sharing Findings with the Community Using a CBPR Approach**



**Identify dissemination** goals with partners early on in the project

**Identify** ways to integrate findings into existing outreach efforts





**Ensure all partners have a** chance to participate in dissemination efforts and acknowledge contributions

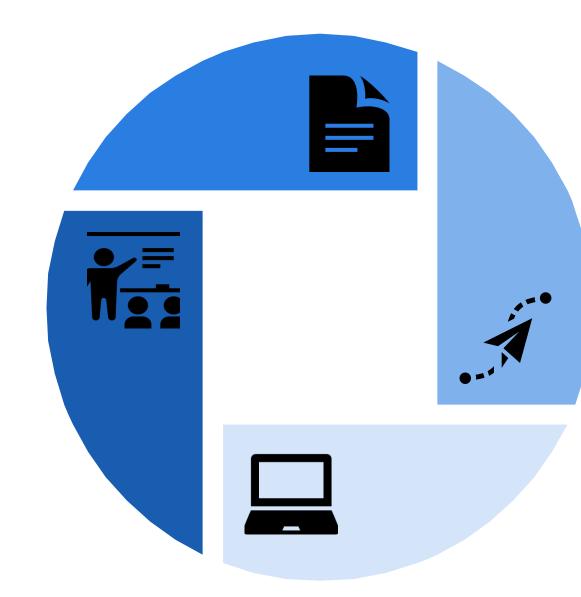
# **Types of Dissemination Products**

## **Publications**

Reports, journal articles, policy briefs, fact sheets

## Presentations

For conferences or stakeholder meetings





## Funding Applications

Presenting results through grant applications

## Multimedia Products

Infographics, videos, websites, podcasts, social media, and webinars

# **Potential Negative Consequences** to **Dissemination**





**Misuse of** research findings

**Privacy** breaches 3

Harm to participants and community





## **Ethical** violations



Which strategy are you most excited to use to effectively share research findings with newcomer communities or enhance your services and policies?









# **Questions?**

Type your question in the **Q&A** 



# **Q&A Panel**





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## Rochelle Frounfelker, PhD

Assistant Professor, Lehigh University College of Health

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# Help us help you!

Scan the QR code or click the link in the chat to access our feedback survey!

- Three questions
- 30 seconds
- Help us improve future training and technical assistance





# Recommended Resources

- Sample Informed Consent—Monitoring and Evaluation Technical Assistance (META)
- <u>Collecting Client Feedback Data Guide</u>— Switchboard
- How can participatory research methods be used to improve research with refugees?—Switchboard
- <u>Guiding Principles in Ethical Research</u>— National Institutes of Health





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# **Stay Connected**



The IRC received competitive funding through the U.S. Department of Health and Human Services, Administration for Children and Families, Grant #90RB0053. The project is 100% financed by federal funds. The contents of this document are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. Department of Health and Human Services, Administration for Children and Families.





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