

WEBINAR

Conducting Ethical Research with Unauthorized Immigrant Communities

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Agenda

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|-------------|--|
| 10:00-10:05 | Sana Khoury-Shakour, PhD
CARE-Q Executive Committee Co-chair
Welcome and introductions |
| 10:05-10:50 | Colleen Kohashi, MA, CIP
Lead IRB Administrator
UC Berkeley |
| 10:50-11:00 | Discussion |

Link for continuing education credit will be posted in the chat at the end of the presentation

Conducting Ethical Research with Unauthorized Immigrant Communities

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IRB Administrator, CPHS-2

Unauthorized Immigrants - A Contextual Overview:

In 2023, there were approx. 14 million unauthorized immigrants in the U.S. (Source: [Pew Research Center](#))

An unauthorized immigrant includes any immigrants *not* in the following groups:

1. Lawful permanent residents (green card holders)
2. Refugees formally admitted to the United States
3. People granted asylum
4. Former unauthorized immigrants granted legal residence under the 1986 Immigration Reform and Control Act
5. Naturalized U.S. citizens who entered under categories 1-4 (above)
6. Temporary legal residents under specific visa categories, such as those for foreign students, guest workers and intracompany transfers.

Unauthorized Immigrants - A Contextual Overview:

In 2023, about 6 million (40%) of these unauthorized immigrants had a protected status (like asylum applicants, Deferred Action for Childhood Arrivals [DACA], and Temporary Protected Status [TPS]) that allowed them to legally live and work in the U.S.

Due to recent policy changes, this protected population is estimated to have declined by as much as 1 million in the first half of 2025.

Source: [Pew Research Center](#)

Unauthorized Immigrants - A Contextual Overview:

- The six states with the largest unauthorized immigrant populations in 2022 were: California (1.8 million), Texas (1.6 million), Florida (1.2 million), New York (650,000), New Jersey (475,000), Illinois (400,000)
- Unauthorized immigrants live in 6.3 million households that include more than 22 million people. These households represent 4.8% of U.S. households.
 - In 86% of these households, either the householder or their spouse is an unauthorized immigrant.
 - Almost 70% of these households are considered “mixed status,” meaning that they also contain lawful immigrants or U.S.-born residents.

The Belmont Report, A Framework for Review:

- **Respect for Persons:**

- Treating individuals as autonomous agents.
- Protecting those with diminished autonomy.
- Ensuring truly voluntary and informed consent.

- **Beneficence:**

- Maximizing potential benefits for the community.
- Minimizing potential harm to individuals.

- **Justice:**

- Ensuring the benefits and burdens of research are distributed fairly.
- Avoiding the exploitation of vulnerable populations.

Avoiding Stigmatizing Terminology

- **Human-Centered Language:** Always put the person first.
- **Avoid Dehumanizing Labels:**
 - **Instead of:** "Illegal alien," "illegals"
 - **Use:** "Undocumented immigrant," "person without legal status," "person with precarious status"
- **Avoid Criminalizing Language:**
 - **Instead of:** "Illegal immigration"
 - **Use:** "Unauthorized migration" or "irregular migration"
- **Why it Matters:** Stigmatizing terms perpetuate negative stereotypes, can inflict harm, and erode trust. Respectful language acknowledges the humanity of participants.

The Shifting Landscape of IRB Review

Institutional review levels adapt to the political climate and perceived risk.

- **First Trump Administration:** Research with this population was primarily reviewed at **Exempt** or **Full Board** levels due to heightened risks.
- **Biden Administration:** With a perceived decrease in risk, some research was shifted to **Expedited** review.
- **Second Trump Administration (Current):** Review has returned primarily to **Exempt** and **Full Board** levels, reflecting a renewed assessment of risks.

Exempt Review

An exempt determination requires stringent, verifiable anonymity.

Key Components of an Exempt Determination:

- **Complete Anonymity:** Data must be collected without any direct or indirect identifiers.
- **No Recordings:** Audio or video recordings are **not permitted**, as they can be identifying.
- **Sufficient Sample Size:** The sample must be large enough to effectively mask the identities of individual participants.

Expedited Review

For minimal risk research that does not meet exempt criteria.

Key Considerations for Expedited Review:

- **Prohibited Questions:** No outright questions about documentation status, the status of family members, or questions specific to the experiences of being undocumented are permitted.
- **Data Collection:** Recordings (audio/video) and the maintenance of subject information (e.g., for a longitudinal study) may be allowed, provided robust confidentiality protections are in place.

Full Board Review

For research with potentially greater than minimal risk.

- **No Perfect "Recipe":** Every study is unique.
- **Safe & Coercion-Free Recruitment:** A clear plan to build trust and ensure participation is completely voluntary.
- **Mitigating Confidentiality Risks:** The primary concern.
- **The Focus Group Dilemma:**
 - **Risks:** There's no guarantee of confidentiality among participants.
 - **Potential Benefits:** Can foster a sense of shared experience and community.
 - **Alternative:** Consider individual interviews or **surveys** to eliminate the risk of peer-to-peer disclosure.

Safe Recruitment Practices

Protecting participants from the first point of contact is critical.

- **NO** public flyers or post general advertisements recruiting "undocumented" or "unauthorized" participants.
- **YES** to trusted, private channels for outreach:
 - **Community Partners:** Established organizations can share information within their trusted networks. This is the gold standard.
 - **Closed Listservs:** Private email lists, such as those for campus resource centers or partner organizations.
- **Hire from the community** to help build rapport and navigate cultural nuances

Nuances of Informed Consent

Consent is a continuous conversation, not a one-time signature.

- **A waiver of documented consent:** Verbal consent is the default expectation in this context
- **Ensure True Comprehension:**
 - Plain language, free of academic jargon.
 - Provide materials in the participant's primary language.
 - Investigators must verbally confirm participants' understanding of risks, benefits, and their right to withdraw at any time.
- **Emphasize Voluntariness:** Consent should clearly state that participation is 100% voluntary and will not affect their relationship with any service provider or organization.

Consent Disclosures: Being explicit about risk

Sample language for ensuring true understanding of risk.

- **On Disclosing Legal Status:**

“If you told us that you are undocumented, and your status is disclosed or becomes public, there may be legal consequences.”

- **For Focus Groups (Limits of Confidentiality):**

“The researchers will ask you and the other people in the group to not talk about anything that is said in the group after it ends. However, the researchers cannot guarantee that everyone will keep the discussions private. Therefore, please do not share any information in the group that you do not want to be made public.”

Navigating Compensation Challenges

The Conflict Between University Policy & Ethical Duty

- **The Challenge:** University compensation systems often require Personally Identifiable Information (PII) for payment disbursement.
- **The Ethical Conflict:** This directly conflicts with the investigator's duty to protect the anonymity and safety of unauthorized participants.
- **Consent is Key:** If collecting PII is the *only* way to compensate participants, this must be made explicitly clear during the consent process.

Reciprocity: Providing Tangible Support

How investigators show that they value participants' contributions via compensation and support community well-being matters.

- **Amazon gift cards** can present barriers, as they may require a stable shipping address and have a minimum order for free shipping. **Investigators should consider cash and/or grocery store gift cards instead.**
- **Provide a Resource Guide:** UC Berkeley CPHS usually requests that all participants receive an up-to-date list of local referrals for immigration legal aid services, low-cost or free health and dental clinics, mental health and social support services, food banks, and housing assistance.

Study Procedures: Best Practices for Safety

Minimizing risk during data collection.

- **Confirm Status Off-Record:** If confirming eligibility related to legal status is absolutely necessary, it should be done verbally *before* any audio recording begins. It should not be part of the permanent record.
- **Protect Non-Participants:** Investigators should not ask about the legal status of family members, friends, or others who have not consented to participate.
- **Avoid Questions About Entry:** Investigators should not ask how participants entered the U.S. or about their migration routes. These questions can elicit self-incriminating information and are often traumatic.

Data Security Best Practices

- **Delete identifying information** as soon as it's no longer needed (this includes study data, transcripts, and communication from participants such as emails, texts, WhatsApp messages, etc.).
- **Securely store identifiable study data** in encrypted files on password protected devices and physical documents in a locked, secure cabinet, separate from data.
- **Transcribe audio files as soon as possible** and have a plan to promptly destroy the audio recording.
- **Use campus licensed applications** for AI-generated transcriptions (the data will not be used for improving models).

Resources

- **Pew Research Center**: The Pew Research Center is a nonpartisan American "fact tank" based in Washington, D.C. that provides objective information on the social issues and demographic trends.
- **Migration Policy Institute (MPI)**: MPI is a non-partisan think tank that provides data, analysis, and policy ideas on immigration in the U.S. and worldwide.
- **National Immigration Law Center (NILC)**: NILC defends and advocates for the rights of low-income immigrants. Their website is a great resource for understanding the legal and policy landscape.

Q&A and Thank You

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Continuing Education

**To receive certificate(s), please complete the evaluation.
See link below (also posted in the Zoom chat)**

https://ucsd.co1.qualtrics.com/jfe/form/SV_0HxB1Y9OprQe7fo

Questions? Email us at info@care-q.org

Thank you!



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