

# Ethics of Socio-behavioral Research and Community Engagement

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# **Socio-Behavioral Science Research (SBR)**

- Focuses on individual and group behaviors, including decision-making, emotions, motivations, and social interactions.
- Explores the psychological and social factors that underlie these behaviors
- Explores how and why people behave the way they do in certain situations and how this might impact human health and wellbeing
- Lived experiences (phenomenology)

# Social Behavioral Research

- Systematic investigation of human attitudes, beliefs, interactions, and behaviors
- Used qualitative and quantitative methods
  - Positivist and interpretive paradigms
- Explores how and why people behave the way they do in certain situations and how this might impact human health and wellbeing
  - *Examples:*
    - Educational interventions, Public health surveys, sociological/anthropological/political sciences studies etc
    - Social experiments

# Understanding the community



# Socio-behavioral Research Ethics (SBRE)

- SBRE are principles and guidelines that ensure studies involving human subjects are conducted responsibly, protecting participants' rights, safety, and well-being.
- Key principles include obtaining informed consent, protecting confidentiality, avoiding harm, and ensuring justice and fairness in the research process.
- Focus on human participants and the special vulnerability in **social contexts** (e.g., power imbalances, reputational harm)
- Just like in Biomedical Sciences research, ethics is vital for **the integrity, credibility, and validity of the research**

**Aim:** To protect participants and uphold the integrity of the research process.

# Ethical Principles

- **Respect for persons:** SBRs have the obligation to respect individual autonomy and protect those with diminished autonomy; give sufficient information for participants to make voluntary, informed decision to participate
- **Beneficence and non-maleficence:** SBRs maximize potential benefits while minimizing potential harms to participants.
- **Justice:** Participants selection should be fair, and the burdens and benefits of research should be distributed equitably.
- **Informed consent:** Participants fully informed about the purpose, methods, potential uses, and risks of the research before agreeing to take part even with minimal risk studies
- **Confidentiality and privacy:** respect of the privacy of participants and protection of the confidentiality of the information they provide must be protected and maintained.

# Community Engagement IN SBR

- is the process of working **collaboratively** with groups of people affiliated by geographic proximity, special interests, or similar situations to address issues affecting their well-being.
- **CE goes beyond** recruitment of participants and dissemination of findings.
- **CE is a dynamic, continuous process** built on **trust, transparency, and mutual respect**
- Involving the community in **all stages** of the research.

# SBRE and Community Engagement (CE):

*Ethical Principles provide the core guidance for research involving human participants and are fundamental to CE*

| Ethical Principle                                                              | CE Application in CE                                                                                                                                           |
|--------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Respect for Persons:</b> Individuals should be treated as autonomous agents | Ensure <b>voluntary participation</b> and <b>informed consent</b> is truly understood within the <b>cultural context</b>                                       |
| <b>Beneficence:</b> Maximize benefits and minimize potential harms             | Design research for <b>maximum community benefit</b> (e.g., PAR, action-oriented results)                                                                      |
| <b>Justice:</b> Fair distribution of research benefits and burdens             | Avoidance of exploitation of vulnerable populations; ensure the community receives <b>fair compensation and access</b> to the resulting interventions/benefits |

# Beyond participants to Community

- Respect for Community by recognizing and respecting the community as a whole, including its culture, values, and established leadership.

# Key features of Models of CE in SBR

- Community Advisory Boards (CABs): Formal structures for continuous community input and oversight.
- Participatory Action Research (PAR)/CBPR A collaborative approach where communities co-identify research problems, co-design interventions, and co-evaluate results.
- Capacity Building: Empowering stakeholders and communities through targeted training and education.
- Community-Led Initiatives: Leveraging local knowledge and networks for effective outreach, education, and peer support, especially for marginalized and underserved populations.
- Partnership Development: Establishing long-term collaborations with non-governmental organizations (NGOs) and government departments to ensure sustainability and broader impact.

# CE and stages of the research: examples from SBR Protocols

| Stage of Research              | Example of Community Engagement in SBR                                                                                         |
|--------------------------------|--------------------------------------------------------------------------------------------------------------------------------|
| <b>Problem Identification</b>  | Co-develop research questions that address community-defined needs<br>(Sometimes not done)                                     |
| <b>Design/Methods</b>          | Review and provide feedback on protocols, measures, and recruitment strategies <b>(done with LCs, VHTs, gatekeepers)</b>       |
| <b>Data Collection</b>         | Recruit and train community members as research staff (e.g., young researchers (YEP), interviewers/RAs/Guides).                |
| <b>Analysis/Interpretation</b> | Validate findings; help interpret results within the local context-<br>different levels not only national/invite (mostly done) |
| <b>Dissemination</b>           | Co-present findings to community stakeholders in accessible formats.<br>Co-authors                                             |

# Ethical Challenges in SBR and CE

- *Power Dynamics*: Because researchers frequently possess institutional or academic power, CE efforts are essential to reduce and counterbalance this inherent disparity actively
- *Informed Consent*: Obtaining consent at both the individual and community level (often requires engaging community leaders)
- ***Confidentiality vs. Context***: In small or tightly-knit communities, anonymity can be difficult to maintain, increasing the risk of identification.
- *Community Misrepresentation*: Research findings could unintentionally stigmatize or inaccurately portray the community.
- “Data extractors”: Conducting research, taking the data, and leaving without returning results or engaging in a lasting relationship (highly unethical).

# Promising practices for Ethical CE in SBR

- Prepare before, during and after phases
- Know the community- mistrust and exploitation.
- Establish partnerships early and involve them in defining the research questions and design- community-identified needs and priorities.
  - Early and Continuous Engagement: Engage with the community before solutions or research protocols are decided
- Share power and build capacity –distribute power, resources, and responsibility equitably between academic and community partners.
- Seek informed consent and broader approval.
- Reciprocity and Mutual Benefit
- Transparency and Communication
- Provide ongoing feedback throughout the project lifecycle.

# Conclusion and Reflections

- While SBR and biomedical research differ in scope and methods, both are united by a common set of core ethical concerns
- Ethical SBR is inseparable from good CE as the goal is to shift from studying participants to partnering with collaborators; a continuous process
- CE transforms research validity (making it more relevant) and impact (making it more actionable)
- Prioritize building long-term, continuous engagement over one-off data collection for meaningful outcomes
- Effective and ethical conduct of SBR depends on robust and reciprocal community engagement beyond mere consultation, a committed partnership between researchers and the community is essential to ensure studies are culturally appropriate, ethically sound, and directly relevant to local needs.
- Adopting participatory models not only enhances the scientific rigor and validity of the research but is also a moral imperative for respecting the autonomy, dignity, and privacy of participants, ultimately fostering trust and maximizing the positive impact of SBR on Ugandan society.

# Deep in the community during data collection: Privacy is paramount



***THANK YOU***