ESSENTIAL VOICES & RESEARCH CHOICES

At-Risk & Homeless Youth Research Guidelines
INTRODUCTION

- Introduction of speakers
- Value of ‘Partnership’
  - Evolution of the Homeless & At-Risk Youth Research Guidelines
  - Community Organization Perspective
- The Journey
- The Guidelines - What was produced?
- Next Steps / Conclusion
What does ‘Partnership’ mean?

- Authentic Partnerships: mutual goals, clear understanding of roles, shared resources, shared power, negotiated outputs
- Capacity Building
- Mutual Benefits - organization and researchers/academics
  - Student engagement with the community
- Output - strength and value to the output of the research

*Bridging the gap between community and academia*
HOW DID THE GUIDELINES EVOLVE?

- Community organization had a need and connected the dots
- The MHE program provides opportunities for hands-on practicum experiences
- Students volunteer to take on policy work
- Continued dialogue & research over many months
COMMUNITY ORGANIZATION PERSPECTIVE

- Outside and independent viewpoints/research was beneficial
- Need to tailor guidelines for specific organizational use (consortium/collaboration opportunities being explored)
- Potential to spin off additional activity, such as:
  - Establishing research advisory committees
  - Training staff on standards and best practices
The Journey
IDENTIFYING THE GAP

- Community organization had a need and connected the dots
- At risk and homeless youth are a highly sought population for research
- Many organizations receive increased requests from researchers for access to service users
- Hidden harms were identified and MUN bioethicist were contacted
- Meet and greet to discuss the gap and next steps
ETHICAL CHALLENGES

- On the surface, requirements of research ethics are met - Consent, REB approval, organizational permission, etc.

- REBS, Researchers and Practitioners:
  - Lack of oversight of cumulative effects of the amount of research being conducted
  - Potential risks to individual clients
  - Researchers with expertise in ethics don’t have the contextual knowledge
  - Collective effects of research fatigue to the organization in general
  - Practitioners may find it difficult to assess hidden harms
  - Imbalanced knowledge of research ethics
With lack of multilateral oversight, breaches in ethics may occur and youth are at elevated risk of harm...

- Research Guidelines
SO...WHAT DID WE DO?

MUN bioethicists and Community Organization partnered to develop a policy framework to enhance safeguards for at-risk and homeless youth.
WHO WAS INVOLVED?

Stakeholders

- Youth at risk for or experiencing homelessness
- Ethicists
- Community health and mental health service providers
- Academic and community-based researchers
- Research Ethics Boards
- Ethical Research Involving At Risk Youth
OUR AIM FOR THE GUIDELINES

- Reduce risks of exploitation
- Minimize research fatigue
- Incorporate principles of justice
- Safeguards to support autonomy, privacy, and overall wellness of potential participants
- Enable research while upholding ethical principles and best practices
The Guidelines
MAIN TOPICS

- Ethics and Research Involving Marginalized Youth:
  - Considering harm in the context of research with marginalized youth
  - Vulnerability and strength
  - Considering harms to youth as a collective
  - Considering harms to institutions that advocate for youth
  - Considering harms resulting from the research questions posed
  - Informed consent
  - Payment and compensation
  - Privacy
A MODEL FOR ETHICAL RESEARCH

- Comprehensive view & understanding of ethical risks
- Co-Design & early engagement
- Researchers assessing the meaning of “partnership” - more than consultation (i.e. bi-directional partnership)
- Youth-engaged
- Knowledge translation
- Community Oversight

Giving youth an essential voice in research...
ROLE OF 3 STAKEHOLDERS

→ Promote the role of all stakeholders in upholding ethical best practices in research with at risk & homeless youth

- Community Organization
- REB
- Researchers
RECOMMENDATIONS FOR COMMUNITY ORGANIZATIONS

● Establish an Organizational Research Advisory Committee
● Ensure that youth are effectively engaged in the research
● Exercise your right to say “no”
● Ensure there is effective knowledge translation and sharing of results
● Create a community organization - researcher agreement
RECOMMENDATIONS FOR REB

- Provide training for REB members
- Ensure sufficient expertise on the REB
- Assess “hidden harms”
- Ask: Is research really collaborative?
RECOMMENDATIONS FOR RESEARCHERS

- Design and negotiate research with youth representatives and youth practitioners
- Pay careful attention to hidden risks and benefits of participation at the outset and throughout research engagement
- Develop a knowledge translation plan that gives back to community collaborators
- Enhance community members capacity for participation in research
Next Steps / Conclusion
Research with at-risk & homeless youth must be pursued & conducted with meaningful engagement & collaboration with organizations and their client populations. We all have a role to play!

-MUN Bioethics Team
WHERE FROM HERE?

- **Capacity Building** - By youth, for youth.

- **Continued Application** - with Community Organization & other youth organizations (local, national, international)

- **Education & Awareness** - Publish & Present findings

Continue the Dialogue
VALUE OF PARTNERSHIP

Partnering is not more work… It is ‘the work’.
It is not harder work… It is smarter work.

Collaboration with youth and youth advocates in research from design to dissemination will produce more meaningful and ethical research in this context.
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