

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





Partnership

VALUE OF PARTNERSHIP

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
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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

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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





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

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Ethics Guidance Document - *Essential Voices & Research Choices*

At Risk & Homeless Youth Research Guidelines



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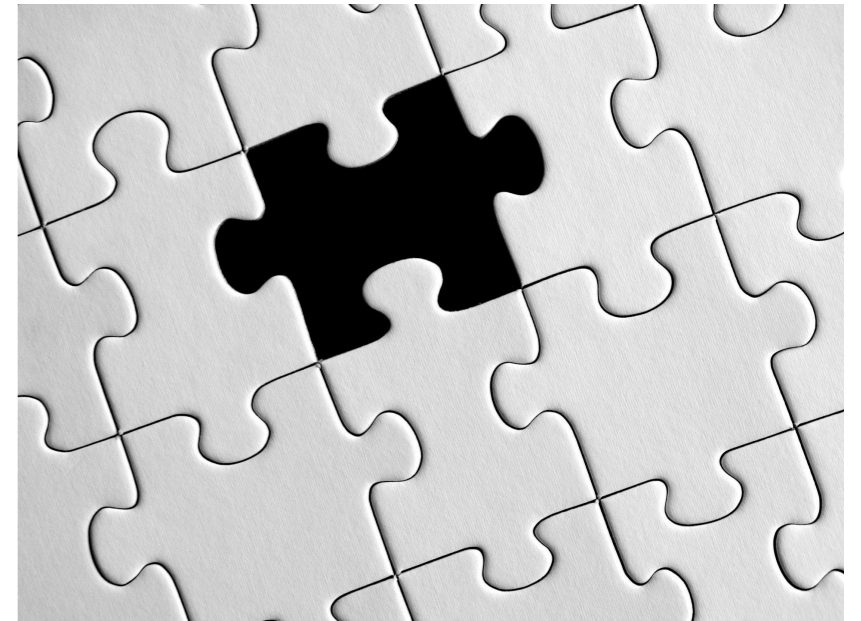
MAIN TOPICS

- **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

BEYOND THE REB



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.*

Questions?

THANK YOU



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