

Scientifically informed community-engaged LGBT Health Research

Brian Mustanski, Ph.D.

impact.northwestern.edu

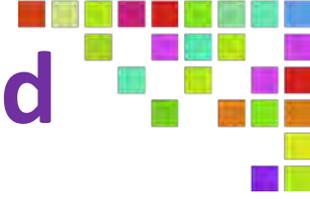
NIH Ethical and Regulatory Aspects of Clinical Research Course:
Ethics of Community Engagement
October 7th, 2015 Bethesda, MD





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IMPACT LGBT Health and Development Program



IMPACT | The LGBT Health & Development Program

Our mission is to conduct translational research that improves the health of sexual minority people and to increase understanding of the development of sexual orientation and gender identity. We seek to develop the capacity of the LGBT community to conduct health research and translate research findings into practical interventions.

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Brian Mustanski, Ph.D.
Director
Associate Professor



Michelle Birkett, Ph.D.
Res Assistant Professor



Kathryn Macapagal, PhD
Res Assistant Professor



George Greene, Ph.D.
Res Assistant Professor

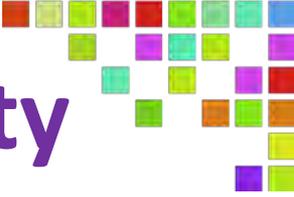


Michael Newcomb, Ph.D.
Assistant Professor



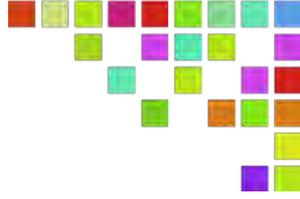
Gregory Phillips, PhD
Res Assistant Professor

IMPACT strategies for community engagement

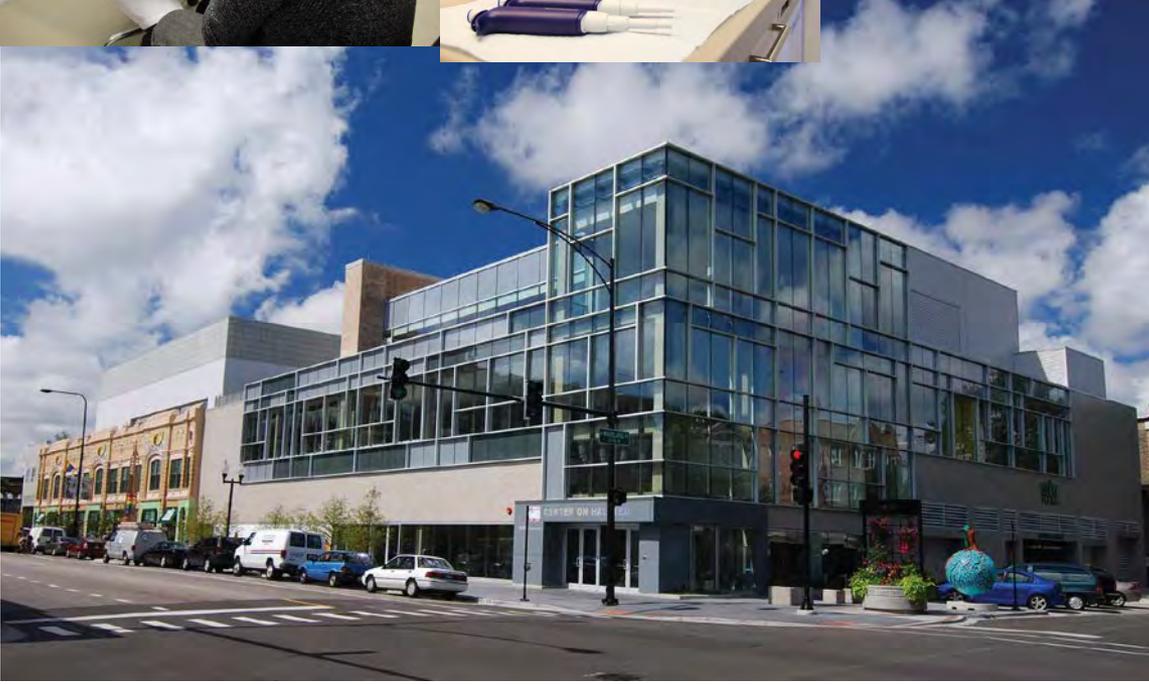


- Embedded in Community
- Sharing our science
- Collaborating by building on unique strengths
- Ethics research to inform research ethics

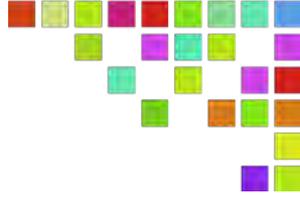
Embedded in Community



*I Love my
Sexuality*



Sharing our science



Home | LGBTQ Youth | Interactive Media | Families | Research | About IMPACT



IMPACT | The LGBT Health & Development Program

Our mission is to conduct translational research that improves the health of the lesbian, gay, bisexual, and transgender (LGBT) community and to increase understanding of the development of sexual orientation and gender identity.

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SEXUAL ORIENTATION & GENDER INSTITUTE

LGBTQ HEALTH CONFERENCE
 Bridging Research & Practice

IMPACT
 The LGBT Health and Development Program

LATEST IMPACT NEWS



YOUTH BLOG—TRANSITIONING IN COLLEGE

Transitioning in college carries its own set of challenges on top of academic responsibilities. Unsure where to go for help? Start here.



RESEARCH BLOG—GATING VIOLENCE IN YOUNG QUEER COUPLES: IS IT DIFFERENT FROM STRAIGHT COUPLES?

Straight or queer, violence in romantic relationships is alarmingly common, but LGBTQ youth may face additional challenges.



HOW I BECAME AN LGBT HEALTH RESEARCHER: Q&A WITH KYLE MADRINI

What makes a career in LGBT health worthwhile? Kyle, Project Director of KILI, discusses experiences that led to her path to success.



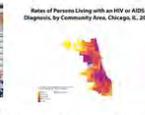
RESEARCH BLOG—COMING OUT AS AN ALIEN IN SEXUAL ORIENTATION AND ATTRACTION FOR TRANS MEN?

What does research show about shifts in sexual orientation and sexual attraction for trans men?



INTERN THIS SUMMER WITH THE IMPACT PROGRAM

We're looking for five exceptional interns this summer! Applications are due May 10th.



Rates of Persons Living with an HIV or AIDS Diagnosis, by Community Area, Chicago, IL, 2011




Transgender Works: Creating a Transgender-Inclusive Work Place



A Healthy Chicago for LGBT Youth



An IMPACT Program White Paper on Health Disparities in Chicago's LGBT youth

GENDER IDENTITY & EXPRESSION

BEYOND THE BINARY



NEITHER

MASCUINITY

FEMININITY

BOTH

New to the concepts of gender identity and expression?

Explore our interactive gender identity map!



Collaborating by building on unique strengths



“You try to partner with an organization that’s better at some things than you are. You figure out what you’re good at, what they’re good at and then you don’t have to waste your resources trying to replicate what someone else can do better. There are so many things Center on Halsted does that Northwestern can’t even touch. And there are things we do that they can’t. So that’s what a good partnership is all about.”

President Schapiro, 2014

LGBTQ
ADOLESCENT
SCIENTIFIC
ACCESS PROJECT



asap ●

R01 MD009561, PIs: Mustanski & Fisher

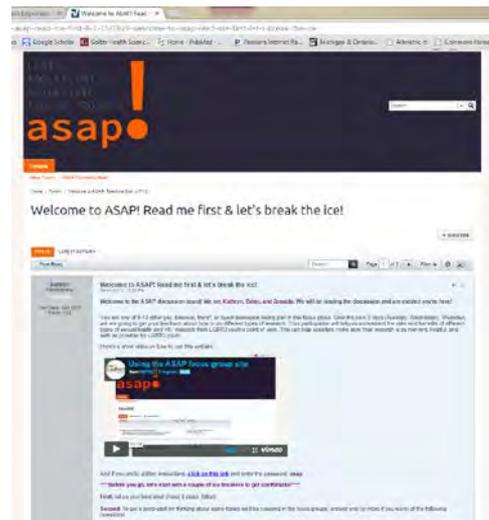
Ethics research to inform research ethics:

Study phases:

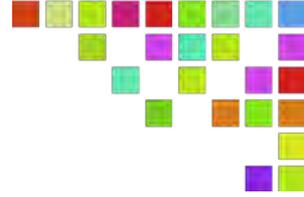
- Years 1-2: Online focus groups and surveys will generate data on LGBT youth's thoughts on
 - The risks/benefits of HIV prevention studies ranging from recruitment to access to post-trial care and publishing
 - Focused on studies involving surveys, HIV testing, and PrEP
 - Whether guardian permission is a reasonable requirement for participating in a range of HIV prevention studies (surveys, HIV testing, PrEP)
- Years 3-4: An interactive online tool will be designed to assess consent preparedness of LGBT minors vs LGBT youth who are legal adults

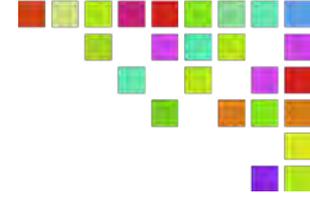
Phase 1: Mixed methods elicitation

- 74 participants ages 14-17 (M = 15.87) recruited online through social media
- Phone screened to confirm consent capacity
- Baseline survey, online 3 day focus group, post-focus group survey



Attitudes Toward Research Involving HIV Testing: Video-based study descriptions





Would LGBTQ Youth Participate in HIV Testing Study if Guardian Permission is Required?

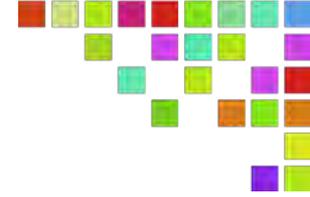
	Out to at least 1 Parent	Not Out to Parents	Total
No	5 (18%)	21 (68%)	26 (44%)
Maybe	13 (46%)	7 (23%)	20 (34%)
Yes	10 (36%)	3 (10%)	13 (22%)
Total	28	31	59

Reasons for “no” or “maybe”

Out me to parents

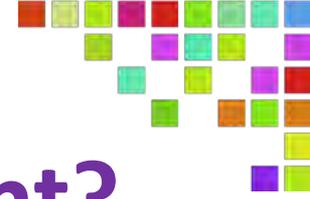
Fear of punishment/kick me out of house

Parents would ask questions



Can LGBTQ Youth Provide Informed, Rational and Voluntary Consent if GP is Waived?





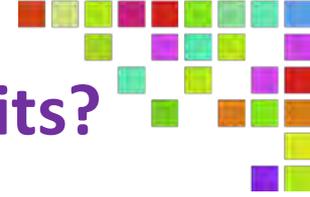
Can Youth Give Voluntary Consent?

86% would feel comfortable asking questions

78% were comfortable refusing to participate

- “I’m fine with saying no”
- “Its my body and I make the final decision”
- “[The researchers] expect some people to say no”
- Others: “It might be difficult, but I’d eventually do it”

Do Youth Understand Research Risks & Benefits?



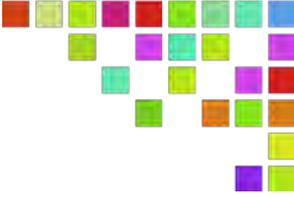
Perceived Benefits of Participation

HIV Protection in a PrEP study

- *“Having protection against HIV on a daily basis”*
- *“Help me put my partner at ease”*
- *“Help me focus more on the possibility of getting HIV and in turn make me practice better sex”*

Community Benefits

“Because it would not only benefit myself, but possibly thousands of LGBTQ teens across the country in getting the help they need to prevent HIV”



Privacy Risks & Protections

Privacy Risks

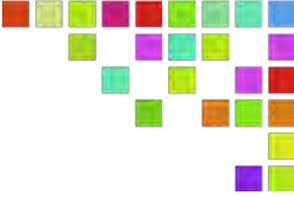
- “Fear of being potentially outed or getting into trouble with my family”
- “Someone seeing the texts or pills” “someone glancing over or pick up my phone”

Privacy Protections

- “No one goes through my phone aside from my friends, and those that do know that I am not straight”
- “I usually delete my texts”
- “If I was that worried about privacy, I wouldn’t be a part of that kind of study

Medical Risks

- *“Weak bones...that’s terrifying to me because I already have a very weak immune system”*
- *“Don’t know long term effects”*
- Doesn’t prevent STI’s *“Pills can’t be too strong if missing it is a problem”*



Can LGBTQY Make a “Reasoned” Participation Decision

Health implications:

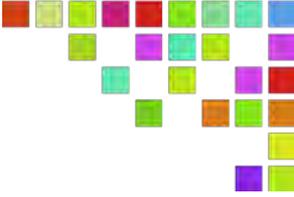
- Whether I could “tolerate side effects”
- “My only concern would be the pill affecting my bones, but in the video they said there would be check-ups every couple of months so I would always make sure to ask how my bones were doing”
- It’s important to take into account risks when starting any medication”
- Risks are “nothing compared to living with HIV”

Perceived HIV risk

- “I would think about where it would fit in my lifestyle and if I needed it”
- “How sexually active I’ve been recently and the likelihood of me becoming active”
- I’d weigh risks and benefit “both personal and for others”

Logistics

- To many requirements: “Taking pill everyday”
- Coming for appointments; “I wouldn’t know how to get there without telling my parents”

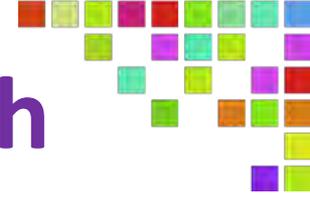


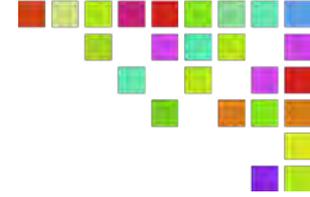
The Importance of Empirical Data on LGBTQY Consent

When information is fitted to youth's maturity and experience....

- Youth demonstrate the ability to understand risks and benefits and to make a rationale participation choice
- They feel empowered to make voluntary participation decisions
- They understand the scientific rationale for random assignment and judge it as fair
- IC can be enhanced through fact sheets, respectful and caring delivery, welcoming questions, giving time to decide, and involving a youth advocate

How do parents feel about such waivers?





Parental Attitudes about Youth Participation in Research



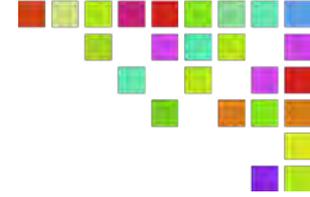
CDC/CDPH NHBS-YMSM

Chicago PIs: Mustanski & Newcomb

- 31 in-depth interviews with parents with LGBT children
- Aim: understand parents' perspective on the ethics and safety of youth participation in research studies, both with and without parental permission
- Parents were recruited via support groups for parents of LGBT individuals and snowball sampling

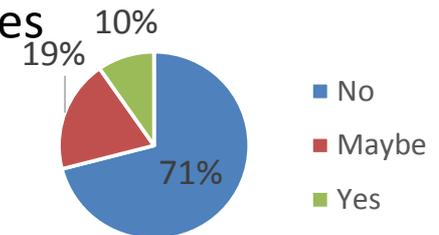
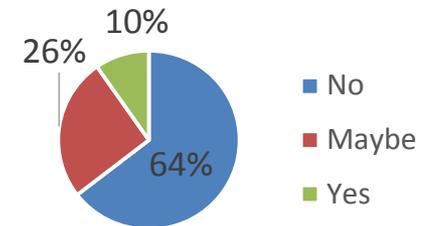
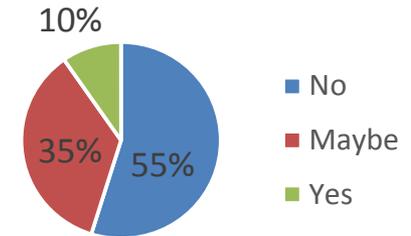
Newcomb et al. (in preparation)

Stepped Vignette Protocol

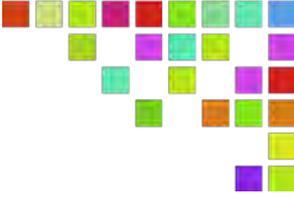


- Brief vignette described study in which young men ages 13-17 completed a brief survey and received HIV testing
- Next, we informed parents that teens can receive HIV testing in Illinois without parental permission at age 12 and asked if that changed their opinion.
- Finally, we informed parents that government agencies make decisions about funding for HIV prevention services based on data collected through research and asked if that changed their opinion.

Should parental permission be required?



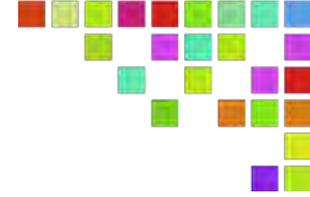
Newcomb et al. (in preparation)



Qualitative Results

- Parents who believed permission should be waived most frequently noted issues related to youth safety and compromised validity of research as reasons
 - Safety: *“Every child needs, especially a lesbian or gay child, to know that they are safe. And for them to have a place to feel safe, that trumps the parental consent issue.”*
 - Research validity: *“I mean, we know what happens with CDC research and how it gets trickled down into all kinds of other stuff. And so, a good sample, without parental consent, will represent a larger number of people and that will result in better data that can fund prevention and education and also fund additional research, which will, yeah. I mean, it’s kind of a no-brainer for me...”*

Newcomb et al. (in preparation)



- Build collaborations that take advantage of unique strengths and capacities.
- Being embedded in the community creates opportunities for formal and informal collaboration and mutual learning.
- Commit to sharing findings.
- Value of ethics research to formally illicit community perspectives on research process so as to conduct research ethically.

Thank you funders

