Forum Overview

Over 100 participants gathered at Access Living for the Fifth Annual ARCC Town Hall Forum, with about equal representation from community and academic partners. The purpose was to gather input and feedback on ARCC priorities and activities to support and promote community-engaged research. Current ARCC priorities and activities are guided by the ARCC Steering Committee comprised of 13 community and faith-based organizations, 2 public agencies and 10 community-engaged faculty (listed on next page). Participants in the forum represented a broader group of community and university stakeholders. The forum focused on three of ARCC’s priority areas: Capacity Building, Partnership Facilitation, and Fiscal Support (including seed grants), as well as discussions on other areas of interest including engaging communities in clinical trials, patient engagement in research, and the new community health research concentration in Northwestern’s Masters in Public Health program. After brief introductory comments, the winner of this year’s ARCC Community-Engaged Research Partnership award, the Partnership to Advance LGBT Health and Wellness (Center on Halsted and the IMPACT LGBT Health & Development Program at Northwestern) shared background and best practices from their work. After a lively networking session, attendees reconvened for a brief presentation on the State of the Alliance (ARCC). Afterwards, participants split into small group breakout sessions focused on the topics above. Before adjourning, the full group reconvened to share insights from their discussions and provide additional input.

Summary of Input/Feedback

Partnership Facilitation

- Convene meetings that allow for networking, matchmaking, speed dating. Consider thematic meetings (health issue, population).
- Support other local conferences as places to connect with partners (Chicago Consortium for Community Engagement (C3), American Public Health Association conference in Fall 2015).
- Develop an online resource/directory to facilitate matching. Include searchable community and academic profiles. Could include online forum or discussion group that allows for posting needs/questions/resources.
- Publicize ARCC services to provide individual consultation/brokering.
- Assist academics to reach out more (before specific project). Neighborhood tours.
- Continue to engage past ARCC partners, keep them current/engaged.
- Support/guidance for sustaining partnerships.
- Connect with hospitals community health needs assessments

Capacity Building

- Resources related to cultural competency and cultural humility
- Resources to address community mistrust of research & increase understanding of research
- Resources related to translation (IRB, engagement in translation)
- Training for community members on conducting aspects of research conduct (examples of projects that have done this)
- Resources related to dissemination
  - Clear creative ideas for communication, sharing results- event ideas
• Workshop on developing infographics
• Compile concrete dissemination examples from other partnerships
• ARCC-hosted community-based events to disseminate findings
• Bridge to policy change: Resources on policy decision making process, contacts, calendar, advocacy tools

Fiscal Support/Seed Grants
• Partnership development is key.
• Smaller grant amounts cause some partners to not pursue ARCC grants. Too little to allocate between partners. Ensure grant amounts match grant program goals.
• Smaller grant amounts may be a good fit with concrete specific activities (dissemination town halls, training/capacity building opportunities, supplies/food, development of advisory board, etc.).
• Continue/build connections with and among grantees. Hold annual event to bring all grantees together.
• Award grants based on themes (e.g. health literacy, physical activity, etc.). May lead to collaboration.

Community Engagement in Clinical Trials
• Resources to increase community understanding of clinical trials/research process (research literacy)
  o Share trainings like Trial Match, ROAR (Recruiting Older Adults into Research), etc.
• Address transportation barrier (potential participants who cannot get downtown)- off site data collection, provided transportation
• Communicate to public about research/clinical trial successes (counter Tuskegee with positive examples)
• Streamline long consent forms.
• Develop community relationships to build trust with patients and providers
• Develop structures for facilitation of research in community
  o Peer navigation model
  o Engaged clinicians
  o Advertise and be where population of interest is
• Mechanisms to communicate with research participants during study and sharing results afterwards

Patient Engagement in Research
• Resources to increase community understanding of research, transparency of research
• Need continued community presence
• Communicate stories of patient engagement in research/outcomes of research (how is research relevant to community, how will research improve community health)
• Engage/hire study participants to recruit additional participants
• Develop patient advisory board to vet ideas and learn how to respectfully ask questions
• Share research findings/outcomes back with participants/community. Consider how specific community wants to receive this info (event, online, radio, etc).

Masters of Public Health Community Health Research concentration
• Field experiences
  o Expand to suburbs
  o Incorporate provider and consumer viewpoints
  o Assign a university designee to field site contacts
• Include these topics as possible courses:
  Grant writing          Policy making and research
  Non-profit management/fiscal management  What data means- epi & community
  Secondary data analysis, software for data analysis
  Focus group design     Entering/ exiting communities
  Topics (e.g. Stigma and isolation for people with disabilities)

Next Steps

▪ ARCC Steering Committee & staff will consider participant input/feedback during their
  summer strategic planning retreat & goal development for upcoming programs & activities.
▪ Summary & other participant feedback will be shared with Northwestern institutional leaders.
▪ Additional town hall forums and other opportunities for gathering feedback from broad
  stakeholder groups will be scheduled regularly.

Evaluation

• Vast majority of attendees felt town hall met its objectives and were very satisfied.
• Most useful aspects of event were networking, small group input sessions, and learning
  about each other’s work. Suggested improvements include more networking time and more
  focus on partner matching.
• Suggestions for future sessions and resources included cultural/community competency,
  partner directory/connections, and funding
• More than 3 quarters of respondents use one or more ARCC/CCH resources (workshops,
  websites, and seed grants were highest).

Learn more at: www.ARCConline.net and www.ARCCresources.net

The **Alliance for Research in Chicagoland Communities** mission is growing equitable and
collaborative partnerships between Chicago area communities and Northwestern University for
research that leads to measureable improvement in community health. **Steering Committee:**
Access Living, Apostolic Faith Church, Cambodian Association of Illinois, Casa Central,
Chicago Youth Programs, Chinese Mutual Aid Association, Coalition of Limited English
Speaking Elderly, Healthcare Consortium of Illinois, Korean American Community Services,
Logan Square Neighborhood Association, Vida/SIDA, Westside Health Authority. **Public
Agencies:** Chicago Department of Public Health, Chicago Public Schools. Northwestern
University Faculty: Amy Eisenstein, PhD Rebecca Ford-Paz PhD, George Greene, PhD, Ruchi
Gupta MD MPH, William Healey PhD, Gail Huber, PhD, Darby Morhardt PhD LCSW, Melissa
Simon MD MPH, Karen Sheehan MD MPH, David Victorson PhD.
April 22nd 2015 ARCC Town Hall Forum Agenda

9:30 AM Welcome/Opening Remarks/Introductions
Rowland Chang, Director, Institute for Public Health & Medicine (IPHAM) at Northwestern
Tom Wilson, Healthcare Community Organizer, Access Living
Sherida Morrison, Community Co-Chair, ARCC Steering Committee, CEO, Demoiselle 2 Femme

Introductory video about ARCC and community-engaged research: https://www.youtube.com/watch?v=bPmnVHPJAwM

10:05 Presentation - 2015 ARCC Community-Engaged Research Partnership Award Winner
Introduction: Jorge Cestou, ARCC Steering Committee Member, Director of Programs & Services, Vida/SIDA, Puerto Rican Cultural Center
Partnership to Advance LGBT Health and Wellness, partnership between Center on Halsted and IMPACT LGBT Health & Development Program at Northwestern University
Represented by Julie Walther, Chief Program Officer, Center on Halsted and Brian Mustanski, Director of Northwestern’s IMPACT Program

10:30 Networking Bingo - Facilitated by Megan Erskine, ARCC Steering Committee Member, Healthy CPS Project Manager, Chicago Public Schools

10:50 ARCC State of the Alliance - Jen Brown, ARCC Director

11:10 Small Group Breakout Sessions
1. Partnership Facilitation: Feedback on resources to help community and academic partners find each other and build and sustain strong research partnerships.
2. Capacity Building: Feedback on resources to help community & academic partners build capacity to form partnerships, plan & implement engaged research projects, & disseminate & implement research findings.
3. Fiscal Support/Seed Grants: Feedback on what type of fiscal resources or seed grants may help community and academic partners build capacity to form partnerships, plan and implement engaged research projects, and disseminate and implement research findings.
4. Community Engagement and Clinical trials: Feedback on resources to help Northwestern clinical researchers understand how to respectfully engage communities in clinical trial design and participation, as well as resources that may help community partners/communities members understand and assist in the design, conduct, and dissemination of clinical trials research.
5. Patient Engagement: Feedback on resources to help Northwestern researchers understand how to respectfully engage patients and patient advocacy organizations in research design and implementation, as well as resources that may help patients and patient advocacy organizations to understand and assist in the design, conduct, and dissemination of research.
6. Proposed Community Health Research (CHR) concentration: This group will focus on the new CHR concentration in Northwestern’s Masters in Public Health program. Feedback on core components of the CHR concentration to help maximize the concentration’s impact for MPH students and community stakeholders working with these students.

11:55 Large Group Report Back/Discussion - Facilitated by Rebecca Ford-Paz, ARCC Steering Committee Member, Assistant Professor of Psychiatry, Lurie Children’s Hospital/Northwestern

12:15 pm Next steps/Evaluations - Facilitated by Cathy Samatas, ARCC Steering Committee Member, Program Manager, Coalition for Limited English Speaking Elderly

12:30 Adjourn
Alliance for Research in Chicagoland Communities: **5th Annual Town Hall Hall Forum**

April 22, 2015
Welcome

Rowland (Bing) Chang, MD MPH, Northwestern University
Director, Institute for Public Health and Medicine (IPHAM)

Tom Wilson, Access Living
Health Care Community Organizer
Housekeeping

• Silence cell phones
• Restrooms
• Sign in/materials
• Thanks to Access Living
• If you tweet... please tag us:
  – @CCH_NU @NUCATSInstitute
  – #ARCC @nu_ipham
ARCC STEERING COMMITTEE

Logan Square Neighborhood Association
Casa Central
Cambodian Association of Illinois
Chinese Mutual Aid Association
Access Living
Apostolic Faith Church
Healthcare Consortium of Illinois
Korean American Community Services
Westside Health Authority
Vida/SIDA
Demoiselle 2 Femme
Coalition of Limited English Speaking Elderly

Government Agencies: Chicago Department Of Public Health, Chicago Public Schools

Northwestern Faculty: Amy Eisenstein PhD, Rebecca Ford-Paz PhD, George Greene PhD, Ruchi Gupta MD MPH, Bill Healey PT EdD GCS, Gail Huber PT PhD, Darby Morhardt PhD, Karen Sheehan MD MPH, Melissa Simon MD MPH, David Victorson PhD

ARCC Staff: Jen Brown MPH, Gina Curry, Maryann Mason PhD, Gini Bishop MD MPH
Plan for Morning

- Presentation from 2015 ARCC Award Winner
- Networking
- ARCC State of the Alliance
- Small & Large Group Discussions
- Next Steps
ARCC 2015 Award Winner

Partnership to Advance LGBT Health and Wellness
2015 State of the Alliance

**Mission**: Promoting and supporting collaborative research partnerships between Chicago area community-based and faith-based organizations & Northwestern University that lead to measurable improvements in community health

[www.ARCConline.net](http://www.ARCConline.net)
Strategic Focus Areas

- Participatory Governance
- Partnership Facilitation
- Capacity Building
- Fiscal Support
- Institutional Support
ARCC Resource Directory

The ARCC Resource Directory is an online website providing access to materials and resources to help interested community and faith-based organizations and academic partners to learn about how they can build capacity to conduct community-engaged research and support building, strengthening, and sustaining their partnership.

**Click here to access a brief guided video tour of the website.**

It was developed and is maintained by the Alliance for Research in Chicagoland Communities (ARCC). ARCC is guided by a steering committee of community- and faith-based organizations from across the Chicagoland area, public agencies, and faculty at Northwestern University. ARCC supports and promotes collaborative research partnerships between community- and faith-based organizations and Northwestern University that leads to measurable improvements in health. Learn more at ARCConline.net

Community-engaged research (CEnR) is an approach characterized by collaborative partnership development, cooperation & negotiation, & commitment to addressing local health issues. Engagement is on a broad spectrum from minimal collaboration to collaboration as equal partners (e.g. community-based participatory research (CBPR)).
Institute of Medicine Recommendation: Ensure Community Engagement in All Phases of Research....

- ensure patients, family members, health care providers, clinical researchers, & other community stakeholders are involved across the continuum of research

- ensure active & substantive community stakeholder participation in priority setting & decision making across all phases of clinical and translational research and in the leadership & governance of research programs
“…meaningful involvement of patients and other stakeholders in all steps of the process. Bringing together all stakeholders in the healthcare enterprise to set research priorities, with patients at the center….\text{”}.
What we do and don’t know

• Most current engaged research focuses on community/public/population health and health services research

• What does engagement look like across the research spectrum?

• Few examples/knowledge in other types of research

• Need help of researchers who conduct other types of research to understand possibilities there

• Need help of communities to understand how they want to engage in other types of research (not just as subjects/participants)
Addressing the new opportunities

- New partnership building- external & internal
- Balance between current and new focus areas
- Funding
Small Group Discussions

- Partnership Facilitation
- Capacity Building
- Fiscal Support/Seed Grants
- Community Engagement & Clinical Trials
- Patient Engagement
- Community Health Research-MPH Program
Next Steps

• Thank you

• Compile & use feedback from today

• Stay in touch
  – arcc@northwestern.edu
  – www.ARCConline.net
  – www.ARCCresources.net

• Evaluation
Upcoming...

• Conducting Research with Chicago Public Schools: May 6

• Community-Engaged Academic Research Staff Meeting: May 19

• Faith-based Community-Engaged Research Network: May 21
The Alliance for Research in Chicagoland Communities (ARCC) promotes and supports a community-engaged approach to research that leads to improvement in community health.

**ARCC currently focuses on 5 priority areas:** participatory governance, partnership facilitation, capacity building, fiscal support, and institutional support advocacy.

**Participatory Governance:**
- **Steering Committee:** Add/orient new/additional members as needed. More to be added summer 2015.
- **2014 Partner Survey:** Focus groups planned for spring-fall 2015 to dig deeper in several areas.
- **Annual Town Hall Forum**

**Partnership Facilitation** for community and academic partners:
- **Space to network** at all ARCC events.
- **Individual consultation** to any community or Northwestern partner seeking partners. 12 ARCC seed grants resulted from ARCC connections.
- **Faith-Based Community-Engaged Research Network:** Co-facilitate this new collaboration for interested faith and academic partners with the Center for Faith & Community Health Transformation.

**Capacity Building** for community and academic partners:
- **Interactive workshops.** Topics in past year included strategies for conducting research with Chicago Dept. of Public Health and Chicago Public Schools. Total: 50 workshops held. Invited presentations/seminars for community organizations and academic departments
- **One-on-one technical assistance** with partnership/project development /implementation and proposal preparation. E.g. conducted over 100 consultations regarding possible partnerships/partnership issues and review/assistance with submissions for NIH, PCORI, and private foundation funding.
- **Online Resource Directory:** [www.ARCCresources.net](http://www.ARCCresources.net) online website of materials and resources related to conducting community-engaged research and building, strengthening, and sustaining partnerships. **Monthly listings of Resources and Opportunities:** posted on ARCC website.
- **Academic research staff meetings:** quarterly informal sessions to create connections and share best practices across research teams and departments.
- **Manuscript Writing Retreats** held quarterly with CCH. Includes consultation with experienced journal editor/reviewer. Resulted in more than 12 publications so far.

**Fiscal Support** (Seed Grant program)
- **Referrals to NUCATS voucher and pilot programs:** Help partners consider resources for proposal development and dissemination to community audiences.
- **Annual seed grants** open to community-academic teams. Funded 7 rounds: 85 applications, 34 grants funded, approx. $590K- 15 partnership building, 17 CBPR implementation.
  - Smaller grants in Round 7: Focus on Partnership Development, Project/Proposal Development, and Research Dissemination/Implementation. 2015/Round 8 seed grants currently under review.
### Population

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<td>African American</td>
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<td>Latino</td>
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<td>Seniors</td>
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<td>Asians</td>
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<td>LGBT</td>
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<tr>
<td>Immigrant/Refugee</td>
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<td>People Living with Disabilities</td>
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### Topic

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<tr>
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<tr>
<td>Alzheimer’s</td>
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<tr>
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<td>HIV/AIDS</td>
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<td>Health Care Access</td>
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<td>Diabetes</td>
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<tr>
<td>Disability</td>
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<tr>
<td>Other</td>
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### Department

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<td>Cognitive Neurology Alzheimer's Disease Ctr</td>
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<td>Institute for Healthcare Studies</td>
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### Geographic

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<td>Chicago - West</td>
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<td>Suburban</td>
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<tr>
<td>State Wide</td>
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### Institutional Support:
Advocate within NU, communities within Chicagoland, and broader field for policies & structures that create a more supportive environment for engaged research and partnerships.

- ARCC Annual Community-Engaged Research Partnership Award: 4 awards to date.
- Facilitate community friendly IRB certification training with Northwestern Institutional Review Board.
- Continuing work with public agency partners (Chicago Dept. of Public Health & Chicago Public Schools) to support collaborative research that contributes to practical evidence-based policy. Serve on CDPH’s Partnership for Healthy Chicago.
- Community participation in governance structures- Working with CCH, assisting university institutes & centers to incorporate community representatives/perspectives into their own decision-making bodies.
- Collaborate across NUCATS cores to prepare 2015 CTSA proposal to incorporate community engagement more broadly e.g. proposed community mentors for academic trainees in two programs.

### Community Engagement and Clinical Trials:

- Collaboration with Northwestern’s Center for Clinical Research.
- Convening meetings of diverse community & Northwestern partners to discuss possible collaborations.
- Added questions on clinical research to partner survey.
- Planned focus groups with community-based and patient advocacy organizations, community members.

### Patient Engagement:
Beginning to build relationships with patient advocacy organizations. Informal discussion with representatives from 12 organizations about their interests, concerns, and ideas.

### Progress on Input from 2014 Town Hall Forum

- Resources on research dissemination: Continued ARCC seed grants for research dissemination. Worked with NUCATS to propose dedicated funding/training for dissemination in next CTSA grant.
- Provide resources on best practices and example tools: Continue to add materials to ARCC online resource directory (www.ARCCresources.net).
- Begin clinical trials/research collaboration with trust building: Engaging both community and academic partners in initial clinical research discussions.
Alliance for Research in Chicagoland Communities (ARCC)

ARCC 2014 Partner Survey
Results at a glance...

Survey Participants

Community Partners
- 63

Academic Partners
- 105

Community-Engaged Research experience

Community Partners
- 34% with experience

Academic Partners
- 38% with experience

Community-Engaged Research Capacity

Community partners
- Partnership building
- Organizational emphasis on CEnR
- Fiscal management of CEnR grants

Academic partners
- Understand community factors that contribute to health issues
- Work effectively with/in diverse communities
- Conduct of research

Strengths

Challenges

Top Community-Engaged Research Barriers

Community Partners
- Conflicts with academic partner [18%]
- Lack of organizational support for research [18%]
- Connecting to academic partners [24%]
- Time [35%]
- Money [65%]

Academic Partners
- Lack of CEnR mentorship [23%]
- Lack of departmental support [27%]
- Community partner instability [33%]
- Time [39%]
- Money [44%]
ARCC Seed Grants

6 rounds of funding
30 seed grants awarded
$569,270 grant dollars distributed

19 peer review papers published

$9.4 million in external grant funding

38 proposals developed

16:1 ROI
For every $1 awarded: $16 in external funding

31% Greatly improved community capacity for research & evaluation
32% Greatly improved academics capacity to work with communities

Greatest Gains...

Partnership strength
Understanding of community organizations
Understanding of community

Smaller gains...

* Community understanding of university
* Negotiating across community-academic institutions
* Collecting data in a way that doesn't interfere with organizational activities

Use of ARCC Resources

www.arcconline.net

35%

16%

11%

27%

16%

30%

Technical assistance
Monthly resources & opportunities listing
Partnership brokering
Did not use any ARCC resources

For more information: www.ARCConline.net
www.ARCCresources.net

ARCC is a program of the Center for Community Health, Northwestern University Institute for Public Health & Medicine and Northwestern University Clinical & Translational Sciences Institute.
The Partnership to Advance LGBT Health and Wellness

Brian Mustanski, Ph.D., Modesto “Tico” Valle, Julie Walther
ARCC Town Hall Forum
April 22, 2015
Center on Halsted

• Established in 1973
• The largest and most comprehensive LGBT center in the Midwest
• Serving the ever-evolving needs of the LGBT community, including a newly opened senior housing complex, comprehensive HIV testing program and state-wide HIV/STD hotline, legal services, mental health services, job training, domestic violence prevention services, and programming for women, seniors, youth, and transgender individuals
The IMPACT LGBT Health and Development Program

- Based in the Department of Medical Social Sciences in the Feinberg School of Medicine at Northwestern University

- **Mission:** To conduct **translational research** that improves the health of the LGBT community and to increase understanding of the development of sexual orientation and gender identity.
Collaborative History

• **Informal Collaboration:** Recruitment for KIU! study
• **May 2011:** IMPACT began conducting research studies at Center Halsted as a resident partner
  - Initial needs assessment
  - Re-engaged Research Review Board
• **October 2012:** First LGBTQ Health Conference held
• **July 2013:** Nation’s first clinical internship track in LGBT health launches at IMPACT and COH
• **December 2014:** Construction of new bio-behavioral research center at Center on Halsted
Annual LGBTQ Health Conference

• Fostering application of emerging research into practice
• Attended by up to 180 clinicians, researchers, students, and community members
• Nationally renowned speakers from CDC and NIH
• Continuing education units, student research awards, networking opportunities
Psychology Internship in LGBT Health

• 1st clinical psychology internship track focused on LGBT health in the United States
• Training sites at COH and the IMPACT Program
• The internship offers (1) integrated training in mental healthcare for LGBT clients in a community setting, (2) consultation and liaison services focused on gay and bisexual men living with HIV/AIDS in an infectious disease clinic, and (3) LGBT public health research and services.
• Funded by HRSA, through the McGaw Medical Center at Northwestern University
LGBT Health Research Center

- Co-branded, **bio-behavioral research lab** embedded in COH
- Currently housing 3 research studies, including **RADAR**, examining HIV among 1300 young men who have sex with men (YMSM) (age 16-29)
  - 1st time that one study will look at drivers of HIV at all levels – the genetics of the virus, effects of medications, individual behavior, relationship characteristics, networks, and community-level factors.
- Ensures immediate linkage to HIV care and wrap-around services for youth and creates a more seamless experience for LGBT youth, many of whom access programs from both organizations.
Keep It Up! 1.5 Service Project

- Online HIV prevention program tailored to YMSM who test HIV negative.
- Uses videos, games, and animation to engage participants.
- Emphasizes the role of community, family, and positive relationships to promote health.
- HIV testing and counseling with 1,976 YMSM (age 13-24) who tested negative and met preliminary eligibility requirements for the KIU! project.
- 551 YMSM completed the online intervention. Preliminary analyses of primary and secondary outcomes appear promising.
- Funded by Chicago Department of Public Health.
Challenges

• Everyone is busy!
• Different communication styles
• Staff changes
• Multiple priorities and commitments within each organization
Keys to Success

- IMPACT conducted interviews with key COH staff before moving in to learn about programs and opportunities
- Tico and Brian have close working relationship
- Co-location and resident partnership
- MOUs for big undertakings
- Committed staff from both organizations
Thank you!