Community-Engaged Research (CEnR)

• Approach for conducting research in a collaborative way
• Bidirectional exchange of expertise between academics (scientific experts) and communities/stakeholders (local, cultural, practice experts) that results in informed decision-making about design/conduct/use of research.
• **Broad spectrum:** minimal collaboration to equal partners in all aspects of the research
Why is dissemination to community important?

―Dissemination of research results beyond scientific publication, specifically, to study participants and the general public, is an ethical responsibility of researchers‖ - Chen et al. American Journal of Preventive Medicine. 2010

• It’s the community’s knowledge! Deserve access to what they made possible through their participation or engagement

• Can lead to dialogue!
  – Opportunity to talk about implications of the research
  – Community input on next steps/intervention
  – Reduce the gap between research and practice

• Allows change to happen! Want knowledge to not just be shared, but used
Traditional vs Engaged dissemination

- **Traditional**: targeted distribution of knowledge and intervention materials to a specific public health or clinical practice audience

- **Engaged**: Process of collaboratively working with community members to develop and implement action strategies for change, based on the research findings
Dissemination as Dialogue

• Not one way, iterative process
• Two-way exchange, feedback
• Step that continues data interpretation/analysis
• Designed to be open to input, criticism, suggestions
• Respectful and Responsive to engagement principles
• More likely to influence practice
• How will changes based on input be implemented? Be communicated back?
Engaged Project vs Non-Engaged Project

- Partners already engaged?
- May be different partners in dissemination
- Begin engagement in dissemination phase?
- Partners will not be engaged?

- Follow engagement principles
  
  Collaboration    Respect    Equity
  Transparency    Impact
How to engage partners in dissemination?

• Dedicated meeting
• Retreat
• Present to community advisory group
• Input on drafts (messages, materials)
• Capacity building in necessary skills (writing, speaking, infographics)
Prep to Disseminate from Beginning

- Before you have anything to disseminate
- During prep of research study proposal
- Incorporate into project aims- makes it priority, fosters accountability, allows for resource allocation
- Who will be involved/needed capacity
- Necessary resources- budget, time, staff, skills
- Agreements about possible issues
Engagement in Dissemination

• Who to engage?
  – Partners already engaged?
  – Engage new or additional partners?

• How are partners engaged?
  – Roles
  – Decision making

• Document agreements about decisions/potential issues in partnership/projects agreements or MOU
Potential issues to Discuss

– Who decides dissemination goals/strategies/key messages?
– Who can present/respond to media? Both community & academic partners represented when possible?
– Who’s acknowledged?
– What if there are findings partners don’t want to publicize? Any restrictions on dissemination or plan for framing of data that are negative or unanticipated or potentially harmful to community?
– Will there be spin?

Discuss potential problems **before** they are problems!
Dissemination Plan: Goal

- Impact you hope to have - will impact ‘what’ is disseminated
- Translating ‘research findings’ into dissemination messages
- Translating ‘findings’ into actionable policies/changes/interventions
- Practical implications of findings
- Contextualize findings - why research was done, why findings are important, what change should be made
- Need process, time, partners to do this

- Disseminate process too
Dissemination plan: Audience

- Who is affected by the research?
- Who has power to make changes/take action based on findings?
- Likely multiple audiences

- Research participants - disseminate in same places you recruited
- Partners
- Funders
- End users - individuals, service providers, policymakers, clinicians
- Affected communities
- General public
Dissemination plan: Timing

- During study
- Afterwards
- Associated with related event? Window of opportunity
Dissemination plan: Who

• Who will develop dissemination messages?
• Who will approve these?
• Who will carry out dissemination activities? Who is best messenger?
  – Humanize academics/PI, personal interest
• Who gets acknowledged? Who gets credit?

• Involve community partners in academic dissemination and academic partners in community dissemination
  – Speak together, present together
Dissemination plan: Resources

- Budget: translation, printing, event costs, design (materials/online)
- Staff
- Time
- Skills: do you already have these on the team or do you need to hire/find? - design
Dissemination plan: Medium

• What is most effective way to reach each audience?
• Different audiences > different products. Multiple audiences > multiple formats.
• Consider your audience= language/literacy needs
Materials

- Research brief
  - Conclusions/bottom line, tips/recommendations, photo/graphic/quote, definitions, citation, contact info, acknowledgements

- Infographic

- Community/Organizational Newsletter articles

- Online: Social Media/Listservs/Website/YouTube/Blogs

- Policy Brief/White paper, lobbying, testimony- ID key policymakers

- Community Fact Sheets, posters, flyers, brochures

- Handbooks/toolkits/Maps

- Report to funders
Events

- Community meeting presentation, Town hall, Workshop
- Hosting or taking part in existing events
- Interaction - time for discussion/questions/feedback
- Follow up - one on one meetings, more in-depth, new partnerships, future collaboration

- One-one communication, word of mouth
- Photovoice/Art/Theater
Media

- Print, radio, TV- community/ethnic media
- Press release
- Coverage, purchased
- University or partners may have communications office/staff
- University or partners may have rules about engaging media/policymakers
- Public Narrative
Acting on dissemination

- Process of adoption, adaptation, implementation
- Training
- Mentoring - community to community mentoring
Dissemination during study

• Updates during study (quarterly, annually)?
• Another form of engagement, help retain participants, sustain partner relationships
• Participants and key stakeholders
• Project website, Social media, Newsletter

• How will you get info to participants? Add question to data collection? project website?
• Afterwards- thank you letter for participating
Dissemination plan: Evaluation

• How will success be measured?
• Did you reach your intended audiences?
• Did they understand your findings/messages?
• Were changes made based on those messages?
Academic Dissemination - community dissemination may not be valued or valued less

- Seminar
- Works in Progress
- Peer-reviewed journal articles
  - Progress in Community Health Partnerships & other journals that publish CEnR
  - CCH October 2016 workshop materials on academic writing
- Conference oral presentation
- Poster presentation
- University newsletters/listservs
- Disciplinary newsletters/listservs
- www.CES4Health.info
Creatively disseminating Youth Research Findings

- Partners: IL Caucus on Adolescent Health/Northwestern
- Art: Zines/cups/lemonade stand
- Video: https://www.youtube.com/watch?v=EZ4VpLxswWY
Physical Activity in South Asian Women

- Partners: Metropolitan Asian Family Services/Northwestern
- Community event with family exercise
- MAFS newsletter
- Co-presentations
- Study poster hanging at MAFS
- Partner with ethnic media
Refugee Communities: Disability, Health, & Inclusion Project

- Partners: Access Living/Northwestern
- Resource directory
- Policy brief- Chicago/National versions
- Town hall meeting- testimonials, interpreters
- Media
- Outreach/advocacy to policy makers
Healthy Snack Vending: The Chicago Park District Experience

- Partners: Logan Square Neighborhood Assoc/CLOCC Chicago Park District/Northwestern


- Public Release Event- Speakers from Public agencies, researchers, park district
Student Media-based Asthma Research Team (SMART): Chicago Public Schools & Ruchi Gupta (NU/Lurie)

**Healthy:** Lifestyle  
**Unhealthy:** Lifestyle

- Photovoice
- Videovoice
- Public Service Announcements

Students gathering and dancing in school corridors after school

School meals – “I don’t know if this is healthy.”


The Illinois Violent Death Reporting System (IVDRS) is a part of the National Violent Death Reporting System, which pulls information about the "who, when, where and how" of violent deaths to provide a more complete picture and deeper insight into "why" they occur. This IVDRS Data Brief is a first in a series about violent death in the City of Chicago over three time points: 2005, 2010 and 2015. The first data brief examines homicide rates in the City of Chicago overall, and by demographic group and weapon type: We present rates by age, gender, race/ethnicity and by the type of weapons used to commit homicides. Information about how the data are collected is presented in Appendix.

Table 2 shows homicide rates per 100,000 in the City of Chicago by race in males and females, from 2005 to 2015.

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<table>
<thead>
<tr>
<th>Year</th>
<th>Rate per 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>3.26</td>
</tr>
<tr>
<td>2010</td>
<td>3.10</td>
</tr>
<tr>
<td>2015</td>
<td>3.06</td>
</tr>
</tbody>
</table>

This information can be used to prevent IPV. Law enforcement, for example, can use this information to identify and work with those who are affected by IPV to develop future acts of IPV and IPV. Assistant Chief Lisa Snow of the Chicago Police Department states, "I believe this is another level of engagement in the community and in our police department. We need to be able to do things as a society to prevent violence and IPV, and we're trying to take a more active role in doing so.""}

**RESOURCES**

**If you or someone you know is experiencing domestic violence and needs help:**

**State of Illinois Domestic Violence Hotline**

- **Domestic violence programs located throughout Chicago provide stability assistance to victims of domestic violence.**
- **Safelinc:** 24-hour phone hotline, counseling, safety planning, legal advocacy, children's services, temporary foster care housing, and outreach.

http://www.safelinc.org/ or phone: 1-800-720-0278

If you want to learn more about what you can do to end domestic violence.

**Illinois Coalition Against Domestic Violence**

The Illinois Coalition Against Domestic Violence (ICADV) is a non-profit, member organization that operates an extensive network of women's shelters, hotlines and legal services, helping hundreds of thousands of women and their children each year. ICADV is committed to advocating for the rights of battered and abused women, their children and their families. For more information, including resources for survivors and their families, please visit our website: icadv.org.

**Physical Activity**

Kids and adults should participate in at least 60 minutes of physical activity daily. This includes activities such as walking, dancing, playing sports, or any other form of exercise that raises your heart rate and makes you breathe harder.

**Opportunities to Support Schools in Implementing Enhanced P.E.**

For more information on the Illinois Violent Death Reporting System, please contact:

**Stanley Manne**

Children's Research Institute

[phone number]

[website]

**Ann & Robert H. Lurie**

Children's Hospital of Chicago

[phone number]

[website]
**BMI Use in Program Evaluation**

**PROS & CONS**

**The Pros**

- **Simple to Measure**: BMI is simple to measure because it only calls for height and weight. All you need is a scale and a measuring device.
- **Inexpensive**: BMI is easy to calculate and does not require a highly trained professional to administer. There are many free BMI calculator programs available online.
- **Standardized**: BMI offers a straightforward standardization that is applicable to the general population.

BMI as an outcome measure can be appropriate for a program where participants are enrolled and followed for years, but measuring BMI before and after a 6-week course is not appropriate because it is unlikely that 6 weeks is long enough to affect a change in body composition. (See Fairing measure: KAB???)

**The Cons**

- **Time Span**: Programs that wish to include BMI as an outcome measure must be sure to allow for a long enough follow-up period. For example, behavior change and weight loss take a long time to achieve.
- **Intervention Intensity**: Behavior change and weight loss are difficult to achieve. The intensity levels must be appropriate in order to expect changes to BMI.
- **Only Outcome**: BMI only measures body composition. Only addressing BMI can ignore other program achievements, undermining its ability to talk about its success.

**Considerations/Examples/**

- **Time Span**: Measuring BMI for a 6-month clinical weight-loss intervention with a comprehensive curriculum of 48 nutrition education classes, 48 hours of group physical activity and 24 private counseling sessions is appropriate; however, an 8-week healthy cooking class that meets twice a week for 2 hours is likely not intense enough to expect to see changes in participants’ body composition.

- **Intensity**: A nutrition education and cooking class that only measures BMI might not see any change among participants and might look to be “failing” its participants. Focusing only on BMI does not allow the program evaluation to look for other measures of success such as individual’s increase in knowledge about cooking healthy, confidence with cooking and increases in reports of cooking healthier meals at home – all of which are successes worth knowing and sharing.

**How to calculate/ etc.**

\[ \text{BMI} = \frac{\text{weight (kg)}}{[\text{height (m)}]^2} \quad \text{or} \quad \frac{\text{weight (lb)}}{[\text{height (in)}]^2 \times 703} \]

**BMI is age- and sex-specific for children and teens. Be sure to look over the BMI-for-age percentiles to interpret results.**

<table>
<thead>
<tr>
<th>BMI Percentile</th>
<th>Weight Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 5th</td>
<td>Underweight</td>
</tr>
<tr>
<td>5th - 84th</td>
<td>Healthy weight</td>
</tr>
<tr>
<td>85th - 94th</td>
<td>Overweight</td>
</tr>
<tr>
<td>95th - 100th</td>
<td>Obese</td>
</tr>
</tbody>
</table>

Find the BMI-for-age charts here: [http://www.cdc.gov/growthcharts/clinical_charts.htm](http://www.cdc.gov/growthcharts/clinical_charts.htm)
Resources

- Sample partnership policies- dissemination procedures, authorship guidelines: [http://www.cbprcurriculum.info/](http://www.cbprcurriculum.info/) Unit 6

- Speaking Truth, Creating Power: Guide to Policy Work for CBPR Practitioners [https://ccph.memberclicks.net/assets/Documents/CBPRCurriculum/AppendixD/ritas.pdf](https://ccph.memberclicks.net/assets/Documents/CBPRCurriculum/AppendixD/ritas.pdf)

Center for Community Health Resources

- Partnership brokering & development - patient & stakeholder engagement
- Workshops/seminars, team training, online resources - Writing retreats, spring workshop on dissemination to policy audiences
- Funding assistance - ARCC/PBR seed grants, NUCATS dissemination & implementation pilot grants
- Consultation, proposal review & support - Stakeholder Academic Resource Panels
Alliance for Research in Chicagoland Communities Resources

- Monthly Resources & Opportunities Listings

[www.ARCCresources.net](http://www.ARCCresources.net)

Visit arcconline.net »

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)).
National Resources

- Resources
- Skill-Building Online Curriculum
- Listservs
- IRB and Ethics

- Patient and Family Engagement Rubric
- Sample Patient Engagement Plans

http://www.pcori.org/get-involved/what-is-engagement-in-research