Community Engagement and Population Health Research at NYU

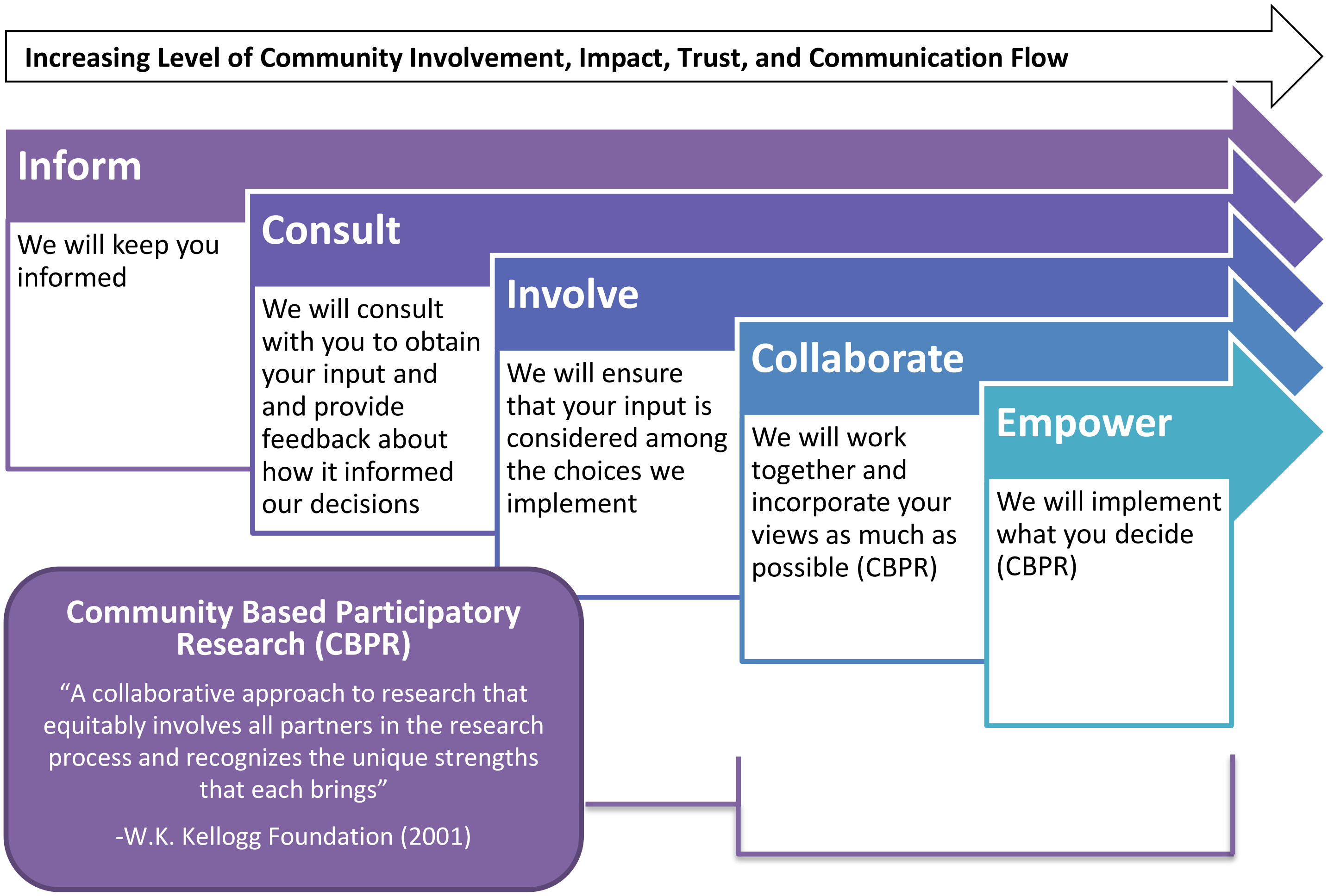
Did you know? As part of NYU Langone Health's Clinical and Translational Science Institute, the Community Engagement and Population Health Research (CEPHR) program, is available to provide training and education necessary for faculty members, post-docs ,health professionals, community providers, community members, and students to engage in translational research and to strengthen the relationships among these stakeholder groups.

For more information: https://med.nyu.edu/departments-institutes/clinical-translational-science/community-engagement-population-health-research-program

What is Community-Engaged Research (CEnR)?

"The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people"
- Centers for Disease Control and Prevention, 2005, Principles of Community Engagement

Spectrum of Community Engagement



Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

Inform

We will keep you informed

Consult

We will consult with you to obtain your input and provide feedback about how it informed our decisions

Involve

We will ensure that your input is considered among the choices we implement

Collaborate

We will work together and incorporate your views as much as possible (CBPR)

Empower

We will implement what you decide (CBPR)

Community Based Participatory Research (CBPR)

"A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings"

-W.K. Kellogg Foundation (2001)

Why is Community Engagement Important for Researchers?

Community engagement provides academic researchers with a unique opportunity to foster trusting relationships between researchers and communities, promote increased relevance of research questions, enhance the quantity and quality of collected data, promotes dissemination of findings and knowledge gained to all partners, and facilitates infrastructure building and sustainability.

What are the Guiding Principles of Community Engagement?

- Promotes active collaboration and participation at every stage of research
- Facilitates co-learning between the academic researcher and the community members
- Ensures research and interventions are community-driven
- Disseminates results in useful ways for community stakeholders
- Ensures research and intervention strategies are culturally appropriate
- Defines community as a unity of identity

How does Community-Engaged Research Differ from a Traditional Research Approach?

Traditional Research	**Community-Engaged Research**	
	Community-placed Research	Community-based Participatory Research
Researchers define the problem	Researchers define the problem with some community input	Community identifies problem or community & researchers collaborate to define the problem
Research **IN** or **ON** the community	Research WITH some community partnership	Research **WITH** community as full partner
People as subjects	People as participants	People as participants & collaborators
Community organizations may assist	Community organizations may help recruit participants & serve on an Advisory Board	Community organizations are partners with researchers
Researchers gain skills & knowledge	Researchers gain skills, knowledge, some community skills-building	Researchers & community work together to build community capacity
Researchers control process, resources & data interpretation	Researchers control research, community may help make minor decisions	Researchers & community share control equally
Researchers own, control use & disseminate data	Researchers own, decide use & disseminate data	Data is shared, researchers and community decide its use and dissemination

Elements of Community-Engaged Research Protocol

Background, Purpose, Objectives	•Have you clearly defined the community or population and the diversity within it that you are seeking to engage? •What is the purpose and goal for seeking to work with this community or population? •How was the community involved or consulted in defining the need? •What are the research objectives? Who came up with the research objectives and how? •Is this research-justified and what is significance of this research project? •What are concrete action outcomes? •Who benefits? How?
Research Methodology	•How will the community be involved in the research? At what levels (e.g. stakeholder interviews, partnership with organizations, developing community advisory boards, etc.)? •What training or capacity-building opportunities will you build in?
Procedures	•Will the methods used be sensitive and appropriate to various communities (consider literacy issues, language and translation needs, cultural sensitivities, etc.)? •How will you balance scientific rigor and accessibility? • Where will research procedures be performed and who is performing research related procedures? If community stakeholders perform research procedures, what type of training and supervision is provided? •If the community members are considered key research personnel, what IRB overssing research at the center.

Participants	•Are you really talking to the “right” people to get your questions answered appropriately (e.g., service providers, community members, leaders etc.)? •How will the research team protect vulnerable groups? •Will the research process include or engage marginalized or disenfranchised community members? How? •Is there a reason to exclude some people? Why?
Recruitment	•What provisions have you put in place to ensure culturally-relevant and linguistically appropriate recruitment strategies and materials? •Have you considered “power” relationships in your recruitment strategies (no coercion!)? •Who approaches people about the study and how? •Are there stigmas associated with the condition that you are studying (e.g. consider whether mental health, HIV and cancer issues is stigmatized among family and friends and in the general community)? People with these conditions may not be as willing to participate for fear of others finding out.
Risks and Benefits	•What are the risks and benefits of the research for communities? For individuals? •Are all risks and measures to minimize them outlined?
Privacy & Confidentiality	•Where will you store data? Who will have access to the data? How? •What processes will you put in place to be inclusive about data analysis and yet maintain confidentiality of participants? •What rules will you have for working with transcripts or surveys with identifying information? •How do you maintain boundaries between multiple roles (e.g., researcher, counselor, peer)? •Will study data shared with community partners ? if yes, will identifyers completely striped?
Compensation	•How will you reimburse people for their time and honor their efforts without it becoming “coercive”? •How will you approach compensation? •What provisions have you made for minimizing barriers to participation (e.g., providing for food, travel, childcare)?

Study Budget

- What provisions have you made for minimizing barriers to participation (e.g., providing for food, travel, childcare, translation services)?
- Will you need extra incentives for participants such as health services, health education, food/refreshments or transportation?
- Will you need incentives to community sites or community partners for their participation in the research process (e.g. serving as a recruitment site, etc.)?
- Who is managing the budget? How are these decisions negotiated?

Conflicts of Interest

- What happens when your job depends on the results?
- What happens when you are the researcher /and/ the friend, peer, service provider, doctor, nurse, social worker, educator, funder, etc?
- How will you appropriately acknowledge and negotiate power differentials?

Informed Consent Process/Authorization

- What does informed consent mean for “vulnerable" populations (e.g., children, who can not consent for themselves)?
- What processes do you have in place fo -obtaining individual consent? If the format and length of the consent document considered based on the population?
- If verbal-informed consent is-being obtained, explain why. Waiver of written consent will need submited to the IRB.
- Will you gather Private health information? Written HIPAA authorization or a waiver of written authorization needs to be submited to the IRB.
- What processes do you have in place for gathering community consent?
- Where minors are to be included as participants, provide a copy of the assent script to be used.
- Are your consent processes culturally sensitive and appropriate for the populations that you are working with?

Outcomes and Results	•How will the research be disseminated to academic audiences? •How will the research be disseminated to community audiences? •How will you partner with community partners to create dissemination materials? •What are the new ways that this research will be acted upon to ensure community/policy/social change? •What type of data be shared with community partners? Who owns data? How will you responsibly make the data available to the different community and other stakeholders?
Ongoing Reflection & Partnership Development	•Do you have a partnership agreement or memorandum of understanding to be signed by all partners that describes how you will work together? •What internal process evaluation mechanisms do you have in place? •When your plans change to accommodate community concerns (as they invariably do in community-based research), how will you communicate this to the IRB?

Topics of Special Interest

Engagement in Research	•Will non-NYU personnel obtain consent, analize private identifyable information, perform essential study procedures? Is it essentail that non-NYU personnel to perform these research activities? If yes, state the name of the IRB of record for this community site/center •Are non-NYU personnel simply informing potencial subjects about the study or performing routine servises that will not merit professional recognition or publication privelages? If yes, no IRB approval is required •Are study procedures performed by non-NYU personnel commercial or fee-for-service procedures? If yes, no IRB approval is needed. A business agreement is required.
Use of Non-NYU Personnel as Research Team	•What specific research procedures non-NYU personnel is conducting? Are they considered to be key research personel (see NYU SOM IRB Policy for definition of "key personnel") ? •Is this personnel part of the community center/ site or they are not affiliated with any community organization? If not affiliated, is this personnel undergoing non-Traditional Volunteer approval process at NYU Langone Health? •If non-NYU personnel is considered key personnel - have they taken Human Subject Protection(HSP) training and what kind? Who is providing it and ensuring it's done? •Do they need to have any additional training prior to conducting study procedures? If yes, what specific training, who conducts it, who confirmes the training goals are met •Who is supervising non-NYU personnel? •How training is documented

References & Relevant Resources

Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards
Flicker S., Travers R., Guta A., McDonald S., and Meagher A., (2007). J Urban Health, 478–493.

Review of community-based research: assessing partnership approaches to improve public health
Israel, Barbara A., et al. (1998). Annual review of public health, 173-202.

Principles of Community Engagement, Second Edition
CTSA Community Engagement Key Function Committee Task Force. (2011). National Institutes of Health.
https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

Toolkit for Developing Community Partnerships
Southern California Clinical and Translational Science Institute, Community Engagement. (2017).
https://sc-ctsi.org/resources/developing-community-partnerships-toolkit
Developing the Community Empowered Research Training Program: Building Research Capacity for Community-Initiated and Community-Driven Research
Kwon, S. & Rideout, C. & Tseng, W. & Islam, N. & Cook, W. K. & Ro, M. & Trinh-Shevrin, C. (2012). Progress in Community Health Partnerships: Research, Education, and Action 6(1), 43-52. Johns Hopkins University Press.

Applying a community-based participatory research framework to patient and family engagement in the development of patient-centered outcomes research and practice
Kwon, S. C., Tandon, S. D., Islam, N., Riley, L., & Trinh-Shevrin, C. (2017). Translational Behavioral Medicine, 8(5), 683-691. doi:10.1093/tbm/ibx026

For case studies demonstrating how NYU-projects have used CBPR principles in practice, please seeing the following:
Community-Based Settings and Sampling Strategies: Implications for Reducing Racial Health Disparities Among Black Men, New York City, 2010-2013.
Cole, H., Schoenthaler, A., Braithwaite, R. S., Ladapo, J., Mentor, S., & Uyei, J. 2014. Preventing Chronic Disease, 11, E105. doi:10.5888/pcd11.140083

Reducing Cardiovascular Disparities Through Community-Engaged Implementation Research: A National Heart, Lung, and Blood Institute Workshop Report
Mensah, G. A., Cooper, R. S., Siega-Riz, A. M., Cooper, L. A., Smith, J. D., Brown, C. H., . . . Perez-Stable, E. J. (2018). Circ Res, 122(2), 213-230. doi:10.1161/circresaha.117.312243