CBPR Partnership Academy Resource Guide

The following resources are supplemental to the course pack, textbook, and readings provided during the week-long, intensive short course and have been compiled by Partnership Academy staff and instructors. The resources are organized into the same topics as the intensive course and formatted in APA style. In addition to the paper format, these resources are also available in an electronic format on the Partnership Academy Drive.

General CBPR/Research Resources

- Berg, D., Carroll-Scott, A., Greene, A., Harris, K., Lucas, G., Rosenthal, M. & Tinney, B. (n.d**.). Making Research Work for Your Community**. Retrieved from http://yale.edu/hrpp/affiliates/documents/TCF-MakingResearchWorkForYou-june2104.pdf

  This guidebook was created as a result of their work together and the findings of their interviews with 20+ community leaders and university researchers. It is intended to help communities and community organizations in their decisions to: 1. Conduct their own research; 2. Work effectively with university researchers; 3. Maximize the value of community-university research relationships

- Bordeaux, B.C., Wiley, C., Tandon, S.D., Horowitz, C.R., Borwn, P.B. & Bass, E.B. (2007). **Guidelines for writing manuscripts about community-based participatory research for peer-reviewed journals**. Progress in Community Health Partnerships, 1(3), 281-288. Retrieved from http://muse.jhu.edu/journals/progress_in_community_health_partnerships_research_education_and_action/v001/1.3bordeaux.html

  Abstract: Despite the importance of disseminating the results of community-based participatory research (CBPR), community health partnerships face many challenges in getting their work published. The purpose of this article is to present practical guides for writing about CBPR for those who have little experience in writing for publication or those who want to help their partners write strong manuscripts for peer-reviewed journals. The article includes tips on how to organize each part of a manuscript, suggestions on how partners can collaborate on preparing manuscripts, recommendations on how to convey unique aspects of a partnership's work throughout a manuscript, and an annotated bibliography of well-written CBPR articles. By understanding how to prepare a manuscript about CBPR for a peer-reviewed journal, authors should be more effective in disseminating information that will help other communities to benefit from their partnership's work.

- **Community Campus Partnerships for Health: Community Engaged Scholarship 4 Health (CES4Health).** (2015). Available here: http://ces4health.info/

  CES4Health is a free, online mechanism for peer-reviewing, publishing and disseminating products of health-related, community-engaged scholarships that are in forms other than journal articles. Search for tools and resources or submit your own tool for peer-review.

- Community-Campus Partnerships for Health. (n.d.) **CBPR curriculum**. Available here: https://ccph.memberclicks.net/cbprcurriculum

  First published in 2006, this online curriculum is intended to serve as a tool for use by community-institutional partnerships that are using or planning to use a CBPR approach to improving health. The curriculum covers all phases of a CBPR project.

- Indiana Clinical and Translational Sciences Institute. (2012**). CORUS: Working together to advance community engaged research**. Available here: https://ctsacorus.org/home

  CORUS (previously CTSA2Community), is a platform for finding and sharing tools for community engaged research and aims to strengthen the activities of community engaged research programs and their partners by building a robust database of best practices.

Israel, B., Schulz, A., Parker, E., & Becker, A. (1998). Review of community-based research: Assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173-202

Abstract: Community-based research in public health focuses on social, structural, and physical environmental inequities through active involvement of community members, organizational representatives, and researchers in all aspects of the research process. Partners contribute their expertise to enhance understanding of a given phenomenon and to integrate the knowledge gained with action to benefit the community involved. This review provides a synthesis of key principles of community-based research, examines its place within the context of different scientific paradigms, discusses rationales for its use, and explores major challenges and facilitating factors and their implications for conducting effective community-based research aimed at improving the public's health.

- **Research toolkit: A toolkit for health research in partnership with practices and communities**. (2013). Available here: http://researchtoolkit.org/

  This research toolkit provides tools and guidance for all phases of research projects from building collaborations to dissemination of findings and also includes resources on collaboration with Hispanic and indigenous populations.

- Simonds, V. W. and Christopher, S., (2013). **Adapting western research methods to indigenous ways of knowing**. American Journal of Public Health, 103(12), 2185-2192. doi: 10.2105/AJPH.2012.301157

  Abstract: Indigenous communities have long experienced exploitation by researchers and increasingly require participatory and decolonizing research processes. We present a case study of an intervention research project to exemplify a clash between Western research methodologies and Indigenous methodologies and how we attempted reconciliation. We then provide implications for future research based on lessons learned from Native American community partners who voiced concern over methods of Western deductive qualitative analysis. Decolonizing research requires constant reflective attention and action, and there is an absence of published guidance for this process. Continued exploration is needed for implementing Indigenous methods alone or in conjunction with appropriate Western methods when conducting research in Indigenous communities. Currently, examples of Indigenous methods and theories are not widely available in academic texts or published articles, and are often not perceived as valid.

- Wallerstein, N. & Duran, B. 2008. **The Theoretical, Historical, and Practice Roots of Community Based Participatory Research**. In Minkler, M. & Wallerstein, N. (Eds.), Community-Based Participatory Research for Health. San Francisco: Jossey-Bass, 25-46.

- Work Group for Community Development University of Kansas Community. (2014). **Community tool box.** Available here: http://ctb.ku.edu/en

  The Community Tool Box is a public service developed and managed by the KU Work Group for Community Health and Development and partners nationally and internationally. The Community Tool Box is a free, online resource for those working to build healthier communities and bring about social change. This resource contains over 16 different tool kits with a wide range of topics including: enhancing cultural competence, writing a grant application for funding, and implementing a social marketing effort.

CBPR Rationale, Principles and Partnership Development

- Andrews, J., Newman, S., Cox, M. & Meadows, O. (n.d.). **Are We Ready? A Toolkit for Academic-Community Partnerships in preparation for Community-Based Participatory Research**. Available here: http://academicdepartments.musc.edu/sctr/programs/community_engagement/Documents/SCTR%20CCHP%20Are%20We%20Ready%20Toolkit.pdf

  A 75 page toolkit covering a wide range of topics related to development of new CBPR partnerships. Topics covered include: basic tenets of CBPR partnerships, capacity of partnerships, partner operations. The toolkit also includes comprehensive checklists for multiple stages of partnership development.

- Akwesane Task Force on the Environment & Research Advisory Committee. (1996). **Protocol for review of environmental and scientific proposals**. Available here: http://www.ipcb.org/resources/archived/akw_protocol.html

- Chávez, V., Duran, B., Baker, Q.E., Avila, M.M., & Wallerstein, N. (2008). **The dance of race and privilege in CBPR**. In Minkler, M. & Wallerstein, N. (Eds.), Community-Based Participatory Research for Health from Process to Outcome. San Francisco: Jossey-Bass, 91-105.

  Minkler and Wallerstein have pulled together a fantastic set of contributions from the leading researchers in the field. In addition to a fine collection of case studies, this book puts the key issues for researchers and practitioners in a historical, philosophical, and applied, practical context

- Eisinger, A., & Senturia, K. (2001). **Doing community-driven research: A description of Seattle partners for healthy communities**. Journal of Urban Health : Bulletin of the New York Academy of Medicine, 78(3), 519–534. http://depts.washington.edu/ccph/pdf_files/Eisinger.pdf

  Abstract:: Seattle Partners, an Urban Research Center (URC) funded by the Centers for Disease Control and Prevention (CDC), is a partnership of community agency representatives, community activists, public health professionals, academics, and health care providers whose mission is to improve the health of urban Seattle, Washington, communities by conducting community-based participatory research. This article describes the development and characteristics of Seattle Partners. Using primarily qualitative methods, including periodic in-depth interviews, evaluators identified the components necessary for Seattle Partners to maintain a collaborative and establish a research center driven by community interests. Seattle Partners is run by an unrestricted and inclusive board that has spent 5 years developing both an operating structure and various research interventions. Operating under Community Collaboration Principles, the board identified social determinants of health as the priority area in which to work. Collaboration, "small and concrete" accomplishments, skilled individuals, and funder support directly influence the success of the center. Decision making, project selection, and board composition have all been, challenges to work through. Learning how to do and sustain the work are lessons, being learned as Seattle Partners matures.

- Georgetown University Center for Child and Human Development. (n.d.). **National Center for Cultural Competence**. Available here: http://nccc.georgetown.edu/information/organizations.html

  The mission of the NCCC is to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity.

- Giachello, A.L., Ashton, D., Kyler, P., Rodriguez, E.S., Shanker, R., & Umemoto, A., (Eds.) (2007). **Making community partnerships work: A toolkit**. Retrieved from http://www.aapcho.dreamhosters.com/download/PDF/Giachello_MakingCommunityPartnershipsWorkToolkit.pdf

  This toolkit is based on the lessons learned from the national and community partners involved in the Genetics Education Needs Evaluation (GENE) Project. The GENE Project was a 5-year program funded by the Health Resources and Services Administration to investigate the genetics education needs of underserved, minority communities. March of Dimes and its national partners, Genetic Alliance and Family Voices, worked with two communities to determine their cultural and language needs in the area of genetics education and develop action plans to address those needs. This toolkit provides the reader with some insight into how these community partnerships were developed. This toolkit is written for newcomers and seasoned organizers, community-based groups, public and private foundations, as well as local, state and federal government agencies. Although it is written for those interested in public health and human services, this toolkit can still be useful to individuals and groups addressing other community issues.

- Green, L.W., George, M.A., Daniel, M., Frankish, C.J., Herbert, C.J., Bowie & W.R. & O'Neill, M. (1995). **Guidelines for participatory research in health promotion. Study of Participatory Research in Health Promotion: Review and Recommendations for the Development of Participatory Research in Health Promotion in Canada**. The Royal Society of Canada, 41-54.

- Jernigan, V., Jacob, T., the Tribal Community Research Team & Styne, D. (2015) **The Adaptation and Implementation of a Community-Based Participatory Research Curriculum to Build Tribal Research Capacity**. American Journal of Public Health. 105(S3): S424-S432. doi: 10.2105/AJPH.2015.302674

  Abstract: We studied community-based participatory research in American Indian/Alaska Native communities. We have presented a case study describing a community–clinic–academic partnership with the goal of building tribal capacity and infrastructure to conduct health disparities research. The 2-year intensive training was guided by the framework of an evidence- and community-based participatory research curriculum, adapted and implemented with practice-based data collection activities and seminars to address issues specific to community-based participatory research with sovereign tribal nations. The initiative highlighted important challenges and opportunities in transdisciplinary partnerships; identified gaps in conducting health disparities research at the tribal, clinical, and university levels; and led to important policy change initiatives in all the partner settings.

- Montgomery, A. (2013). **Fast facts about responsible research partnerships with Indigenous communities**. Available here: https://depts.washington.edu/ceeh/downloads/FF_Responsible.pdf

- Montgomery, A. (2013). **Fast facts about Indigenous cultural autonomy: Decolonizing autonomy to transform research practices.** Available here: https://depts.washington.edu/ceeh/downloads/FF_Decolonizing.pdf

- Minkler, M., Breckwich, M., Wasquez, V., Tajik, M., & Petersen, D. (2008). **Promoting environmental justice through Community-Based Participatory Research: The role of community and partnership capacity**. Health Education and Behavior, 35 (1), 119-137.

  Abstract: Community-based participatory research (CBPR) increasingly is being used to study and address environmental justice. This article presents the results of a cross-site case study of four CBPR partnerships in the United States that researched environmental health problems and worked to educate legislators and

promote relevant public policy. The authors focus on community and partnership capacity within and across sites, using as a theoretical framework Goodman and his colleagues' dimensions of community capacity, as these were tailored to environmental health by Freudenberg, and as further modified to include partnership capacity within a systems perspective. The four CBPR partnerships examined were situated in New York, California, Oklahoma, and North Carolina and were part of a larger national study. Case study contexts and characteristics, policy-related outcomes, and findings related to community and partnership capacity are presented, with implications drawn for other CBPR partnerships with a policy focus.

- Mariella, P., Brown, E., Carter, M. & Verri, V. (2009). **Tribally-driven participatory research: State of the practice and potential strategies for the future**. Journal of Health Disparities Research and Practice, 3(2), 41-58.

- National Association of County and City Health Officials. (2010). **First things first: Prioritizing health problems**. Retrieved from http://chfs.ky.gov/NR/rdonlyres/B070C722-31C1-4225-95D5-27622C16CBEE/0/PrioritizationSummariesandExamples.pdf

  This resource includes different methods for decision making and priority setting that are applicable for prioritizing health problems and other topics.

- Office of Quality Improvement University of Wisconsin-Madison. (2007). **Facilitator tool kit: A guide for helping groups get results**. available here http://oqi.wisc.edu/resourcelibrary/uploads/resources/Facilitator%20Tool%20Kit.pdf

  The facilitator tool kit is a comprehensive, easy-to-use guide to tools, methods and techniques for assisting groups with planning and improvement projects and interactive meetings. It's clear, simple explanations and directions lead the reader through the selection and application of practical tools that have been tested with university groups.

- Ross, L.F., Loup, A., Nelson, R.M., Botkin, J.R., Kost, R., Smith, G.R. & Gehlert, S., (2010). **The Challenges of Collaboration for Academic and Community Partners in a Research Partnership: Points to Consider.** Journal of Empirical Research on Human Research Ethics, 5(1), 19-31. doi: 10.1525/jer.2010.5.1.19

  Abstract: The philosophical underpinning of Community-Engaged Research (CEnR) entails a collaborative partnership between academic researchers and the community. The Community-Based Participatory Research (CBPR) model is the partnership model most widely discussed in the CEnR literature and is the primary model we draw upon in this discussion of the collaboration between academic researchers and the community. In CPBR, the goal is for community partners to have equal authority and responsibility with the academic research team, and that the partners engage in respectful negotiation both before the research begins and throughout the research process to ensure that the concerns, interests, and needs of each party are addressed. The negotiation of a fair, successful, and enduring partnership requires transparency and understanding of the different assets, skills and expertise that each party brings to the project. Delineating the expectations of both parties and documenting the terms of agreement in a memorandum of understanding or similar document may be very useful. This document is structured to provide a "points- to-consider" roadmap for academic and community research partners to establish and maintain a research partnership at each stage of the research process.

- Schoultz, J., Oneha, M.F., Magnussen, L., Hla, M.M., Brees-Saunders, Z., Dela Cruz, M., & Douglas, M. (2005**). Finding solutions to challenges faced in community-based participatory research between academic and community organizations.** Journal of Interprofessional Care, 20(2), 133-144. Available

from the Association of Asian Pacific Community Health Organizations:
http://www.aapcho.dreamhosters.com/download/PDF/Schoultz_FindingSolutions.pdf

Abstract: Partnerships between communities and academic institutions have been vital in addressing complex health and psychosocial issues faced by culturally diverse and hard-to-reach populations. Community-based participatory research (CBPR) has been suggested as a strategy to develop trust and build on the strengths of partners from various settings to address significant health issues, particularly those persistent health issues that reveal disparities among minority populations. There have been many challenges to developing these partnerships in the United States. The purpose of this paper is to discuss approaches and solutions used by this research team in response to the challenges they have faced in using CBPR. The team uses CBPR to understand and support the process of disclosure of intimate partner violence (IPV) within the context of the community health centers that provide services for multicultural and multi-lingual populations. While CBPR provides a route to develop trust and build on the strengths of partners from various settings, there are multiple challenges that arise when partnering organizations present with different infrastructures, missions, resources and populations served. Examples of common challenges and solutions from the literature and from the team's experience will be discussed. Implications for partners, partnerships, practice and research will be explored.

- Seifer, S.D. & Sgambelluri, A.R. (Eds.). (2007). **Proceedings from Community-Campus Partnerships for Health's 9th conference, walking the talk: Achieving the promise of authentic partnerships**. Partnership Perspectives, 6(1). Seattle, WA: Community-Campus Partnerships for Health. Available from Community Campus Partnerships for Health

- Tervalon, M. & Murray-Garcia, J. (1998). **Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education**. Journal of Health Care for the Poor and Underserved, 9(2), 117-125. doi: 10.1353/hpu.2010.0233

Abstract::Researchers and program developers in medical education presently face the challenge of implementing and evaluating curricula that teach medical students and house staff how to effectively and respectfully deliver health care to the increasingly diverse populations of the United States. Inherent in this challenge is clearly defining educational and training outcomes consistent with this imperative. The traditional notion of competence in clinical training as a detached mastery of a theoretically finite body of knowledge may not be appropriate for this area of physician education. Cultural humility is proposed as a more suitable goal in multicultural medical education. Cultural humility incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations.

- Trinh-Shevrin, C., Islam, N., Tandon, S.D., Abesamis, N., Hoe-Asjoe, H., & Rey, M. (2007). **Using community-based participatory research as a guiding framework for health disparities research centers**. Progress in Community Health Partnerships, 1(2), 195-205.

Abstract: There has been growing interest in conducting community-based health research using a participatory approach that involves the active collaboration of academic and community partners to address community-level health concerns. Project EXPORT (Excellence in Partnerships, Outreach, Research, and Training) is a National Center for Minority Health and Health Disparities (NCMHD) initiative focused on understanding and eliminating health disparities for racial and ethnic minorities and medically underserved populations in the United States. The New York University (NYU) Center for the Study of Asian American Health (CSAAH) is 1 of 76 Project EXPORT sites. This paper describes how CSAAH developed partnerships with varied Asian American community stakeholders as a first step in establishing itself as a

Project EXPORT center that uses community-based participatory research (CBPR) as its orienting framework. Three guiding principles were followed to develop community–academic partnerships: (1) creating and sustaining multiple partnerships; (2) promoting equity in partnerships; and (3) commitment to action and research. We discuss strategies and action steps taken to put each principle into practice, as well as the successes and challenges we faced in doing so. Developing community–academic partnerships has been essential in our ability to conduct health disparities research in Asian American communities. Approaches and lessons learned from our experience can be applied to other communities conducing health disparities research.

- Yonas, M., Aronson, R., Coad, N., Eng, E., Petteway, R., Schaal, J., & Webb, L. (2013**). Infrastructure for equitable decision making in research.** In Israel, B.A., Eng, E., Schulz, A.J., & Parker, E.A. (Eds.), Methods for Community-Based Participatory Research for Health. 2nd Edition. San Francisco: Jossey-Bass, 97-126 (CH 4)

Survey Methods in CBPR

- Cohen, A., Lopez, A., Malloy, N. & Morello-Frosch, R. (2011**). Our environment, our health: A community-based participatory environmental health survey in Richmond, California**. Health Education and Behavior, 38(6), 1-12. doi: 10.1177/1090198111412591

  Abstract: This study presents a health survey conducted by a community-based participatory research partnership between academic researchers and community organizers to consider environmental health and environmental justice issues in four neighborhoods of Richmond, California, a low-income community of color living along the fence line of a major oil refinery and near other industrial and mobile sources of pollution. The Richmond health survey aimed to assess local concerns and perceptions of neighborhood conditions, health problems, mobile and stationary hazards, access to health care, and other issues affecting residents of Richmond. Although respondents thought their neighborhoods were good places to live, they expressed concerns about neighborhood stressors and particular sources of pollution, and identified elevated asthma rates for children and long-time Richmond residents. The Richmond health survey offers a holistic, community-centered perspective to understanding local environmental health issues, and can inform future environmental health research and organizing efforts for community–university collaboratives.

- Formea, C.M., Mohamed, A.A., Hassan, A., Osman, A., Weis, J.A., Sia, I.G. & Wieland, M.L. (2014). **Lessons learned: Cultural and linguistic enhancement of surveys through community-based participatory research.** Progress in Community Health Partnerships: Research, Education, and Action 8(3), 331-336. DOI: 10.1353/cpr.2014.0037

  Abstract: Background: Surveys are frequently implemented in community-based participatory research (CBPR), but adaptation and translation of surveys can be logistically and methodologically challenging when working with immigrant and refugee populations.
  Objective: We sought to describe a process of participatory survey adaptation and translation.
  Methods: Within an established CBPR partnership, a survey about diabetes was adapted for health literacy and local relevance and then translated through a process of forward translation, group deliberation, and back translation.
  Lessons Learned: The group deliberation process was the most time-intensive and important component of the process. The process enhanced community ownership of the larger project while maximizing local applicability of the product.
  Conclusions: A participatory process of survey adaptation and translation resulted in significant revisions to approximate semantic, cultural, and conceptual equivalence with the original surveys. This approach is likely to enhance community acceptance of the survey instrument during the implementation phase.

- Hull, P.C., Canedo, J.R., Reece, M.C., Lira, I., Reyes, F., Garcia, E. ... Husaini, B.A. (2010). **Using a participatory research process to address disproportionate Hispanic cancer burden.** Journal of Health Care for the Poor and Underserved 21(1A), 95-113. DOI: 10.1353/hpu.0.0271

  Abstract: Community-based participatory research (CBPR) offers great potential for increasing the impact of research on reducing cancer health disparities. This article reports how the Community Outreach Core (COC) of the Meharry–Vanderbilt–Tennessee State University (TSU) Cancer Partnership has collaborated with community partners to develop and implement CBPR. The COC, Progreso Community Center, and Nashville Latino Health Coalition jointly developed and conducted the 2007 Hispanic Health in Nashville Survey as a participatory needs assessment to guide planning for subsequent CBPR projects and community health initiatives. Trained community and student interviewers surveyed 500 Hispanic adults in

the Nashville area, using a convenience sampling method. In light of the survey results, NLHC decided to focus in the area of cancer on the primary prevention of cervical cancer. The survey led to a subsequent formative CBPR research project to develop an intervention, then to funding of a CBPR pilot intervention study to test the intervention.

- Krieger, J., Allen, C.A., & Takaro, T.K. (2013). **What's with the wheezing? Methods used by the Seattle-King County healthy homes project to assess exposure to indoor asthma triggers**. In Israel, B.A., Eng, E., Schulz, A.J., & Parker, E.A. (Eds.), Methods in Community-Based Participatory Research for Health. 2nd Edition. San Francisco: Jossey-Bass, 335-363 (CH 12).

- Lewis, T. C., Robins, T. G., Joseph, C. L. M., Parker, E. A., Israel, B. A., Rowe, Z., … Brown, R. W. (2004). **Identification of gaps in the diagnosis and treatment of childhood asthma using a community-based participatory research approach**. Journal of Urban Health : Bulletin of the New York Academy of Medicine, 81(3), 472–488. doi:10.1093/jurban/jth131

Abstract: The goal of this investigation was to use a community-based participatory research approach to develop, pilot test, and administer an asthma screening questionnaire to identify children with asthma and asthma symptoms in a community setting. This study was conducted as the recruitment effort for Community Action Against Asthma, a randomized trial of a household intervention to reduce exposure to environmental triggers of asthma and was not designed as a classic prevalence study. An asthma screening questionnaire was mailed and/or hand delivered to parents of 9,627 children, aged 5 to 11 years, in two geographic areas of Detroit, Michigan, with predominantly African American and Hispanic populations. Additional questionnaires were distributed via community networking. Measurements included parent report of their child's frequency of respiratory symptoms, presence of physician diagnosis of asthma, and frequency of doctor-prescribed asthma medication usage. Among the 3,067 completed questionnaires, 1,570 (51.2% of returned surveys, 16.3% of eligible population) were consistent with asthma of any severity and 398 (12.9% of returned surveys, 4.1% of eligible population) met criteria, for moderate-to-severe asthma. Among those meeting criteria for moderate-to-severe asthma, over 30% had not been diagnosed by a physician, over one half were not taking daily asthma medication, and one quarter had not taken any physician-prescribed asthma medication in the past year. Screening surveys conducted within the context of a community-based participatory research partnership can identify large numbers of children with undiagnosed and/or undertreated moderate-to-severe asthma. These children are likely to benefit from interventions to reduce morbidity and improve quality of life.

- Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). **Comparison of healthcare experiences in Autistic and Non-Autistic adults: A cross-sectional online survey facilitated by an academic-community partnership**. Journal of General Internal Medicine, 28(6), 761–769. doi:10.1007/s11606-012-2262-7

Abstract: Background: Little is known about the healthcare experiences of adults on the autism spectrum. Moreover, autistic adults have rarely been included as partners in autism research.
Objective: To compare the healthcare experiences of autistic and non-autistic adults via an online survey.
Methods: We used a community-based participatory research (CBPR) approach to adapt survey instruments to be accessible to autistic adults and to conduct an online cross-sectional survey. We assessed preliminary psychometric data on the adapted scales. We used multivariate analyses to compare healthcare experiences of autistic and non-autistic participants.
Results: Four hundred and thirty-seven participants completed the survey (209 autistic, 228 non-autistic). All adapted scales had good to excellent internal consistency reliability (alpha 0.82–0.92) and strong construct validity. In multivariate analyses, after adjustment for demographic characteristics, health insurance, and overall health status, autistic adults reported lower satisfaction with patient-provider

communication (beta coefficient −1.9, CI −2.9 to −0.9), general healthcare self-efficacy (beta coefficient −11.9, CI −14.0 to −8.6), and chronic condition self-efficacy (beta coefficient −4.5, CI −7.5 to −1.6); higher odds of unmet healthcare needs related to physical health (OR 1.9 CI 1.1–3.4), mental health (OR 2.2, CI 1.3–3.7), and prescription medications (OR 2.8, CI 2.2–7.5); lower self-reported rates of tetanus vaccination (OR 0.5, CI 0.3–0.9) and Papanicolaou smears (OR 0.5, CI 0.2–0.9); and greater odds of using the emergency department (OR 2.1, CI 1.8–3.8).

Conclusions: A CBPR approach may facilitate the inclusion of people with disabilities in research by increasing researchers' ability to create accessible data collection instruments. Autistic adults who use the Internet report experiencing significant healthcare disparities. Efforts are needed to improve the healthcare of autistic individuals, including individuals who may be potentially perceived as having fewer disability-related needs.

Research Design in CBPR

- Agency for Healthcare Research and Quality. **What is comparative effectiveness research. Agency for Healthcare Research and Quality.** Available here: http://effectivehealthcare.ahrq.gov/index.cfm/what-is-comparative-effectiveness-research1/

- Cerda et al. (2012). **Reducing violence by transforming neighborhoods: A natural experiment in Medellín, Colombia**. American Journal of Epidemiology, 175(10): 1045-1053.

  Abstract: Neighborhood-level interventions provide an opportunity to better understand the impact that neighborhoods have on health. In 2004, municipal authorities in Medellın, Colombia, built a public transit system to connect isolated low-income neighborhoods to the city's urban center. Transit-oriented development was accompanied by municipal investment in neighborhood infrastructure. In this study, the authors examined the effects of this exogenous change in the built environment on violence. Neighborhood conditions and violence were assessed in intervention neighborhoods (¼25) and comparable control neighborhoods (n¼23) before (2003) and after (2008) completion of the transit project, using a longitudinal sample of 466 residents and homicide records from the Office of the Public Prosecutor. Baseline differences between these groups were of the same magnitude ae random assignment of neighborhoods would have generated, and differences that remained after propensity score matching closely resembled imbalances produced by paired randomization. Permutation tests were used to estimate differential change in the outcomes of interest in intervention neighborhoods versus control neighbor-hoods. The decline in the homicide rate was 66% greater in intervention neighborhoods than in control neighborhoods rate ratio¼0.33, 95% confidence interval: 0.18, 0.61), and resident reports of violence decreased 75% more in intervention neighborhoods (odds ratio¼0.25, 95% confidence interval 0.11, 0.67). These results show that interventions in neighborhood physical infrastructure can reduce violence

- Diez-Roux, A. (2011). **Complex systems thinking and current impasses in health disparities research.** American Journal of Public Health,101: 1627-1634.

  Abstract: Complex systems approaches have received increasing attention in public health because reductionist approaches yield limited insights in the context of dynamic systems. Most discussions have been highly abstract. There is a need to consider the application of complex systems approaches to specific research questions. I review the features of population health problems for which complex systems approaches are most likely to yield new insights, and discuss possible applications of complex systems to health disparities research. I provide illustrative examples of how complex systems approaches may help address unanswered and persistent questions regarding genetic factors, life course processes, place effects, and the impact of upstream policies. The concepts and methods of complex systems may help researchers move beyond current impasse points in health disparities research.

- Glasgow, R.E., Lichtenstein, E. & Marcus, A.C. (2003). **Why don't we see more translation of health promotion research to practice? Rethinking the efficacy-to-effectiveness transition**. American Journal of Public Health, 93: 1261-1267. Retrieved from http://proxy.lib.umich.edu/login?url=http://search.proquest.com.proxy.lib.umich.edu/docview/215100027?accountid=14667

  Abstract: The gap between research and practice is well documented. We address one of the underlying reasons for this gap: the assumption that effectiveness research naturally and logically follows from successful efficacy research. These 2 research traditions have evolved different methods and values; consequently, there are inherent differences between the characteristics of a successful efficacy

intervention versus those of an effectiveness one. Moderating factors that limit robustness across settings, populations, and intervention staff need to be addressed in efficacy studies, as well as in effectiveness trials. Greater attention needs to be paid to documenting intervention reach, adoption, implementation, and maintenance. Recommendations are offered to help close the gap between efficacy and effectiveness research and to guide evaluation and possible adoption of new programs.

- Green, L.W., & Glasgow, R. (2006). **Evaluating the relevance, generalization, and applicability of research: Issues in external validation and translation methodology**. Evaluation & Health Professionals, 29(1): 126-152. doi: 10.1177/0163278705284445

  Abstract: Starting with the proposition that "if we want more evidence-based practice, we need more practice-based evidence," this article (a) offers questions and guides that practitioners, program planners, and policy makers can use to determine the applicability of evidence to situations and populations other than those in which the evidence was produced (generalizability), (b) suggests criteria that reviewers can use to evaluate external validity and potential for generalization, and (c) recommends procedures that practitioners and program planners can use to adapt evidencebased interventions and integrate them with evidence on the population and setting characteristics, theory, and experience into locally appropriate programs. The development and application in tandem of such questions, guides, criteria, and procedures can be a step toward increasing the relevance of research for decision making and should support the creation and reporting of more practice-based research having high external validity.

- Glasgow, R.E., Vinson, C., Chambers, D., Khoury, M.J., Kaplan, R.M. & Hunter, C. (2012). **National institutes of health approaches to dissemination and implementation science: Current and future directions**. American Journal of Public Health, 102: 1274-1281. doi: 10.2105/AJPH.2012.300755

  Abstract: To address the vast gap between current knowledge and practice in the area of dissemination and implementation research, we address terminology, provide examples of successful applications of this research, discuss key sources of support, and highlight directions and opportunities for future advances. There is a need for research testing approaches to scaling up and sustaining effective interventions, and we propose that further advances in the field will be achieved by focusing dissemination and implementation research on 5 core values: rigor and relevance, efficiency, collaboration, improved capacity, and cumulative knowledge.

- Hawe, P. & Schiell, A. (2000). **Social capital and health promotion: A review**. Social Science & Medicine, 51: 871-885. doi:10.1016/S0277-9536(00)00067-8

  Abstract: Interest in social capital and health has emerged at an exciting time. In public health, there is a renewed interest in mechanisms that link social inequalities and health. In epidemiology, there has been a critical interrogation of methods and a call for a more explicit use of theory. In health promotion over the last 20–30 years, social health interventions have been somewhat marginalised in an era dominated by interest in traditional cardiovascular disease risk factors. Now that social hypotheses are being reborn in health, there is a risk that the sophistication that has developed in social health promotion and the literatures that have informed it could be overlooked. In this paper, we present a brief history of social capital and how it has come into recent prominence through the debate linking income inequality and health. We present the background to this, the earlier literatures on social environmental influences on health and the possible processes thought to underlie this relationship. Social capital has relational, material and political aspects. We suggest that, although the relational properties of social capital are important (eg, trust, networks), the political aspects of social capital are perhaps under recognised. The paper also reviews how complex social processes at the community level have come to be operationalised by social theorists and intervention

agents in other fields. We suggest that social capital research so far has inadequately captured the underlying constructs, in particular the qualitative difference between the macro/context level and the micro/individual level. While being cautious about the science, we conclude that social capital's power as rhetoric and as a metaphor may be of value. We conclude by suggesting that the coalescence of interests in context-level influences on health now invites a revitalisation of theories and interventions inspired by diverse fields, such as geography and ecological community psychology.

- Hawe, P., Shiell, A. & Riley, T. (2004). **Complex interventions: How "out of control" can a randomized controlled trial be?** BMJ, 328: 1561-1563. doi: 10.1136/bmj.328.7455.1561

  Abstract: Many people think that standardisation and randomised controlled trials go hand in hand. Having an intervention look the same as possible in different places is thought to be paramount. But this may be why some community interventions have had weak effects. We propose a radical departure from the way large scale interventions are typically conceptualised. This could liberate interventions to be responsive to local context and potentially more effective while still allowing meaningful evaluation in controlled designs. The key lies in looking past the simple elements of a system to embrace complex system functions and processes.

- Hawe, P., Shiell, A. & Riley, T. (2009). **Theorising interventions as events in systems**. American Journal of Community Psychology, 43: 267-276. DOI 10.1007/s10464-009-9229-9

  Abstract: Conventional thinking about preventive interventions focuses over simplistically on the "package" of activities and/or their educational messages. An alternative is to focus on the dynamic properties of the context into which the intervention is introduced. Schools, communities and worksites can be thought of as complex ecological systems. They can be theorised on three dimensions: (1) their constituent activity settings (e.g., clubs, festivals, assemblies, classrooms); (2) the social networks that connect the people and the settings; and (3) time. An intervention may then be seen as a critical event in the history of a system, leading to the evolution of new structures of interaction and new shared meanings. Interventions impact on evolving networks of person-time-place interaction, changing relationships, displacing existing activities and redistributing and transforming resources. This alternative view has significant implications for how interventions should be evaluated and how they could be made more effective. We explore this idea, drawing on social network analysis and complex systems theory.

- Institute of Medicine. (2009) **Initial national priorities for comparative effectiveness research.** Washington, DC: National Academies Press.

  Description: Clinical research presents health care providers with information on the natural history and clinical presentations of disease as well as diagnostic and treatment options. In today's healthcare system, patients, physicians, clinicians and family caregivers often lack the sufficient scientific data and evidence they need to determine the best course of treatment for the patients' medical conditions. Initial National Priorities for Comparative Effectiveness Research(CER) is designed to fill this knowledge gap by assisting patients and healthcare providers across diverse settings in making more informed decisions. In this 2009 report, the Institute of Medicine's Committee on Comparative Effectiveness Research Prioritization establishes a working definition of CER, develops a priority list of research topics, and identifies the necessary requirements to support a robust and sustainable CER enterprise.

  As part of the 2009 American Recovery and Reinvestment Act, Congress appropriated $1.1 billion in federal support of CER, reflecting legislators' belief that better decisions about the use of health care could improve the public's health and reduce the cost of care. The Committee on Comparative Effectiveness Research

Prioritization was successful in preparing a list 100 top priority CER topics and 10 recommendations for best practices in the field.

- Izumi, B.T., Schulz, A.J., Mentz, G., Israel, B.A., Sand, S.L., Reyes, A.G.... Diaz, G. (2015). **Leader behaviors, group cohesion, and participation in a walking group program.** American Journal of Preventive Medicine 49(1); 4149. doi:10.1016/j.amepre.2015.01.019

- Kaholokula, J., Mau, M., Efird, J., Leake, A., West, M., Palakiko, D. ... Gomes, H. (2012**). A family and community focused lifestyle program prevents weight regain in Pacific Islanders: A pilot randomized controlled trial.** Health Education Behavior. 39(4), 386-395. doi: 10.1177/1090198110394174

Abstract: Preventing weight regain after the loss of excess weight is challenging for people, especially for ethnic minorities in the United States. A 6-month weight loss maintenance intervention designed for Pacific Islanders, called the PILI Lifestyle Program (PLP), was compared with a 6-month standard behavioral weight loss maintenance program (SBP) in a pilot randomized controlled trial using a community-based participatory research approach. Adult Pacific Islanders (N = 144) were randomly assigned to either PLP (n = 72) or SBP (n = 72) after completing a 3-month weight loss program. Successful weight maintenance was defined as participants' postintervention weight change remaining ≤ 3% of their preintervention mean weight. Both PLP and SBP participants achieved significant weight loss maintenance (p ≤ .05). Among participants who completed at least half of the prescribed sessions, PLP participants were 5.1-fold (95% confidence interval = 1.06, 24; p = .02) more likely to have maintained their initial weight loss than SBP participants. The pilot PLP shows promise as a lifestyle intervention to address the obesity disparities of Pacific Islanders and thus warrants further investigation.

- Kaplan, G.A., et al. (2008). **Lifting gates, lengthening lives: Did civil rights policies improve the health of African American women in the 1960s and 1970s?** Making Americans Healthier: Social and Economic Policy as Health Policy. R. F. Schoeni, J. S. House, G. A. Kaplan and H. Pollack. New York, Russell Sage Foundation.

- Khoury, M.J., Gwinn, M. & Ioannidis, J.P.A. (2010). **The emergence of translational epidemiology: from scientific discovery to population health impact**. American Journal of Epidemiology, 172(5): 517-524. doi: 10.1093/aje/kwq211

Abstract: Recent emphasis on translational research (TR) is highlighting the role of epidemiology in translating scientific discoveries into population health impact. The authors present applications of epidemiology in TR through 4 phases designated T1–T4, illustrated by examples from human genomics. In T1, epidemiology explores the role of a basic scientific discovery (e.g., a disease risk factor or biomarker) in developing a "candidate application" for use in practice (e.g., a test used to guide interventions). In T2, epidemiology can help to evaluate the efficacy of a candidate application by using observational studies and randomized controlled trials. In T3, epidemiology can help to assess facilitators and barriers for uptake and implementation of candidate applications in practice. In T4, epidemiology can help to assess the impact of using candidate applications on population health outcomes. Epidemiology also has a leading role in knowledge synthesis, especially using quantitative methods (e.g., meta-analysis). To explore the emergence of TR in epidemiology, the authors compared articles published in selected issues of the Journal in 1999 and 2009. The proportion of articles identified as translational doubled from 16% (11/69) in 1999 to 33% (22/66) in 2009 (P = 0.02). Epidemiology is increasingly recognized as an important component of TR. By quantifying and integrating knowledge across disciplines, epidemiology provides crucial methods and tools for TR.

- Kneipp, S., Lutz, B., Levonian, C., Cook, C., Hamilton, J., Roberson, D. (2013). **Women's experiences in a community-based participatory research randomized controlled trial** Qualitative Health Research, 23(6), 847–860. DOI:10.1177/1049732313483924

  Abstract: Integrating community-based participatory research (CBPR) into traditional study designs can enhance outcomes in studies with disadvantaged groups. Little is known, however, about study participants' experiences with these approaches, the underlying processes involved in creating more positive outcomes, and whether undesirable effects on study outcomes occur simultaneously. We conducted focus group interviews with 31 disadvantaged women who participated in a CBPR-driven randomized controlled trial (RCT) both to explore their study experiences and to obtain their interpretations of select study findings. Using dimensional analysis, we found the tailored health questionnaire, treatment by study staff members, and RCT participants' understandings of and responses to randomization were salient to what women described as transformative experiences that occurred over the course of the RCT. These findings have implications for understanding how CBPR and non-CBPR aspects of interventions and study designs have the potential to affect both process and endpoint study outcomes.

- LeBron, A.M.W., Schulz, A.J., Bernal, C., Gamboa, C., Wright, C., Sand, S... Caver M. (2014.) **Storytelling in community intervention research: Lessons learned from the walk your heart to health intervention**. Progress in Community Health Partnerships, 8(4): 455-463.

  Abstract: Background: Contextually and culturally congruent interventions are urgently needed to reduce racial, ethnic, and socioeconomic inequities in physical activity and cardiovascular disease.
  Objectives: To examine a community-based participatory research (CBPR) process that incorporated storytelling into a physical activity intervention, and consider implications for reducing health inequities.
  Methods: We used a CBPR process to incorporate storytelling in an existing walking group intervention. Stories conveyed social support and problem-solving intervention themes designed to maintain increases in physical activity over time, and were adapted to the walking group context, group dynamics, challenges, and traditions.
  Lessons Learned: After describing of the CBPR process used to adapt stories to walking group sites, we discuss challenges and lessons learned regarding the adaptation and implementation of stories to convey key intervention themes.
  Conclusions: A CBPR approach to incorporating storytelling to convey intervention themes offers an innovative and flexible strategy to promote health toward the elimination of health inequities.

- Rapkin, B. & Trickett, E. (2005). **Comprehensive dynamic trial designs for behavioral prevention research with communities: Overcoming inadequacies of the randomized controlled trial paradigm**. In E. Trickett & W. Pequegnat (Eds.), Community Interventions and AIDS, pp. 249-277. New York: Oxford University Press.

- US Department of Health and Human Services. **ARRA accelerating adoption of comparative effectiveness research (CER).** US Department of Health and Human Services. Available here: https://www.cfda.gov/?s=program&mode=form&tab=step1&id=bdc35994177bf2499ac8189e5f4b7d40

Focus Groups in CBPR

- Barrow, S.M., Alexander, M.J., McKinney, J., Lawinski, T., & Pratt, C. (2014). **Context and opportunity: Multiple perspectives on parenting by women with a severe mental illness.** Psychiatric Rehabilitation Journal, 37(3), 176-182. doi:10.1037/prj0000078

  Abstract: Objective: The capabilities framework and a community-based participatory research (CBPR) approach frame this study. We consider the real opportunities for parenting available for women with serious mental health diagnoses, despite complications posed by their own capacity, material constraints, social network disruptions, and, by law, custom and policy related to mental health conditions and child custody decisions.
  Method: We convened focus groups with mothers currently living in shelters apart from their children, service providers in supported housing programs, grandmothers caring for children of mothers with mental health and substance use problems, and a policy discussion with mental health administrators. Qualitative analyses explored common and divergent perspectives on parenting experiences and aspirations of particularly marginalized mothers.
  Results: Perspectives of mothers and other stakeholders converged in recognizing the parenting challenges facing mothers experiencing homelessness and mental health and substance use problems, but their views on the implications of this diverged sharply. Mothers' current aspirations were limited by contextual obstacles to maintaining contact with children; other stakeholders saw contact as risky and reunification as improbable. All stakeholders described systemic barriers to supporting contact and ongoing mothering roles.
  Conclusions and Implications for
  Practice: Evidence-based parenting interventions require facilitating policy contexts that do not foreclose parenting possibilities for mothers whose current challenges dictate modest immediate parenting goals. CBPR amplifies voices of lived experience to demonstrate what is possible over time for mothers with complex lives and histories. These become possibilities that a person can imagine for herself and are essential to inform the evidence base for practice and policy.

- D'Alonzo, K.T. (2010). **Getting started in CBPR: Lessons in building community partnerships for new researchers**. Nursing Inquiry, 17, 282–288. doi: 10.1111/j.1440-1800.2010.00510.x

  Abstract: There is a growing interest in community-based participatory research (CBPR) methods to address issues of health disparities. Although the success of CBPR is dependent upon the formation of community-researcher partnerships, new researchers as well as seasoned investigators who are transitioning to CBPR often lack the skills needed to develop and maintain these partnerships. The purpose of the article is to discuss the competencies needed by new researchers to form successful CBPR partnerships. The author presents a series of strategic steps that are useful in establishing academic–community partnerships and in initiating, maintaining and sustaining CBPR projects. These steps include suggestions regarding community engagement, selection of community advisory board members, outreach, the community's role in problem identification, selection of research methodologies, considerations related to the community setting, need for flexibility and patience, 'insider vs. outsider' conflicts, commitment and training issues, timing concerns for tenure-track faculty and the process of community empowerment. Community-based participatory research is both rewarding and time consuming, for both the researcher and members of the community. Given its promise to address health disparities, it is imperative that researchers acquire the skills needed to develop and cultivate durable community-researcher partnerships.

- Kieffer, E., Willis, S., Odoms-Young, A., Guzman, R., Allen, A., Two Feathers, J., Loveluck, J. (2004). **Reducing disparities in diabetes among African American and Latino residents of Detroit: The**

essential role of community planning focus groups [Suppl.]. Ethnicity and Disease, 14(3), S1-27-S1-37. available here http://www.ishib.org/journal/ethn-14-03s-0027.pdf

Abstract: Diabetes is prevalent among African-American and Latino Detroit residents, with profound consequences to individuals, families, and communities. The REACH Detroit Partnership engaged eastside and southwest Detroit families in focus groups organized by community, age, gender, and language, to plan community-based participatory interventions to reduce the prevalence and impact of diabetes and its risk factors. Community residents participated in planning, implementing, and analyzing data from the focus groups and subsequent planning meetings. Major themes included: 1) diabetes is widespread and risk begins in childhood, with severe consequences for African Americans and Latinos; 2) denial and inadequate health care contribute to lack of public awareness about pre-symptomatic diabetes; 3) diabetes risks include heredity, high sugar, fat and alcohol intake, overweight, lack of exercise, and stress; and 4) cultural traditions, lack of motivation, and lack of affordable, accessible stores, restaurants, and recreation facilities and programs, are barriers to adopting preventive lifestyles. Participants identified community assets and made recommendations that resulted in REACH Detroit's multi-level intervention design and programs. They included development of: 1) family-oriented interventions to support lifestyle change at all ages; 2) culturally relevant community and health provider education and materials; 3) social support group activities promoting diabetes self-management, exercise, and healthy eating; and 4) community resource development and advocacy.

- Watson, M., Kaltman, S., Townsend, T.G., Goode, T., Campoli, M. (2013**). A collaborative mental health research agenda in a community of poor and underserved Latinos**. Journal of Health Care for the Poor and Underserved, 24(2), 671-687. DOI: 10.1353/hpu.2013.0079

Abstract: The goal of this project was to engage community members and grassroots organizations in a discussion regarding perceived mental health needs and priorities of the population of underserved Latinos in Montgomery County, Maryland. Community-based participatory research was used to establish structures for participation and to design studies that effectively address local mental health needs. Four focus groups with 30 Latino lay health promoters and 20 key informant interviews were conducted to ascertain communal mental health needs and priorities. The main issues that emerged included mental health stigma, consequences of immigration-related stress, violence and alcoholism, and concerns about psychotropic medications. Ideas to address these issues and foster wellness through research were generated during a community-based workshop that included consumers, primary care and mental health clinicians, researchers, and representatives of local organizations and federal agencies. The product of this process was an implementable mental health research agenda, which is presented and discussed.

Research Design and Statistics

- Norman G.R. & Streiner, D.L. (2007). **Biostatistics: the bare essentials**, **3rd ed**. Hamilton, ON, Canada: B. C.Decker

  This book translates biostatistics in the health sciences literature with clarity and irreverence. Students and practitioners alike applaud Biostatistics: as the practical guide that exposes them to every statistical test they may encounter, with careful conceptual explanations and a minimum of algebra. The new Bare Essentials reflects recent advances in statistics, as well as time-honored methods. For example hierarchical linear modeling, which first appeared in psychology journals and only now is seen in medical literature, is described. Also new is a chapter on testing for equivalence and non-inferiority, and another on getting started with the computer statistics program, SPSS. Free of calculations and jargon, Bare Essentials speak so plainly that you won't need a technical dictionary. No math, all concepts. The objective is to enable you to determine if the research results are applicable to your own patients. Throughout the guide, you ll find highlights of areas in which researchers misuse or misinterpret statistical tests. We have labeled these C.R.A.P. Detectors (Convoluted Reasoning and Anti-intellectual Pomposity), which help you to identify faulty methodology and misuse of statistics.

- Robert , A., Hanneman, A., Kposowa, J. & Riddle, M.D. (2012). **Basic Statistics for Social Research**, **13th ed.** Jossey-Bass

  Basic Statistics for Social Research offers an introduction to core general statistical concepts and methods. It covers procedural aspects of the application of statistical methods for data-description; and hypothesis-testing; distributions, tabulations, central tendency, variability, independence, correlation and regression. The use of math and theory are deliberately limited, and the authors focus on how the concepts and tools of statistics are used in the analysis of social science data, rather than on the mathematical and computational aspects. The book also emphasizes the use of computer software to calculate statistics. The book is designed for students in the social sciences.

- Krieg, E. (2011). **Statistics and data analysis for social science 1st ed.** Pearson Publishing

  This first edition text seeks to answer the question, universally asked by the social science student, "Why statistics?" The author introduces only those statistical concepts that are necessary to understand, interpret, and present social science research. All concepts are introduced in the context of a social science application, and strong emphasis is placed on demonstrating what data "looks like," as opposed to giving theoretical explanations. Complexity of calculations is reduced to those elements necessary for understanding the statistical concept. Optional technology use is paired with the core elements of the course, making this text a pragmatic and engaging introduction to the practice of social statistics.

- Collins, K.M.T., Onwuegbuzie, A.J. & Jiao, Q.G. (2006). **Prevalence of mixed-methods sampling designs in social science research.** Evaluation and Research in Education, 19:2, 83-101.

  Abstract: The purpose of this mixed-methods study was to document the prevalence of sampling designs utilised in mixed-methods research and to examine the interpretive consistency between interpretations made in mixed-methods studies and the sampling design used. Classification of studies was based on a two-dimensional mixed-methods sampling model. This model provides a typology in which sampling designs can be classified according to the time orientation of the components (i.e. concurrent versus sequential) and the relationship of the qualitative and quantitative samples (i.e. identical versus parallel versus nested versus multilevel). A quantitative analysis of the 42 mixed-methods studies that were published in the four leading school psychology journals revealed that a sequential design using multilevel samples was the most

frequent sampling design, being used in 40.5% (n=17) of the studies. More studies utilised a sampling design that was sequential (66.6%; n=28) than concurrent (33.4%; n=14). Also, multilevel sampling designs were the most prevalent (54.8%; n=23), followed by identical sampling (23.8%; n=10), nested sampling (14.3%; n=6) and parallel sampling (7.1%; n=3). A qualitative analysis suggested a degree of interpretive inconsistency in many studies.

- Stolberg, H.O, Norman, G. & Trop, I. (2004). **Fundamentals of clinical research for radiologists.** American Journal of Roentgenology, 183, 1539-1544.

  Abstract: Preceding articles in this series have provided a great deal of information concerning research design and methodology, including research protocols, statistical analyses, and assessment of the clinical importance of radiologic research studies. Many methods of research design have already been presented, including descriptive studies (e.g., case reports, case series, and cross-sectional surveys), and some analytical designs (e.g., cohort and case-control studies).
  Case-control and cohort studies are also called observational studies, which distinguishes them from interventional (experimental) studies because the decision to seek one treatment or another, or to be exposed to one risk or another, was made by someone other than the experimenter. Consequently, the researcher's role is one of observing the outcome of these exposures. By contrast, in experimental studies, the researcher (experimenter) controls the exposure. The most powerful type of experimental study is the randomized controlled trial. The basic principles of randomized controlled trials will be discussed in this article.

- Onwuegbuzie, A.J., Leech, N.L. (2007). Sampling designs in qualitative research: Making the sampling process more public. The Qualitative Report, 12(2), 238-254. Retrieved from: http://go.galegroup.com.proxy.lib.umich.edu/ps/i.do?id=GALE%7CA172525649&v=2.1&u=lom_umichanna&it=r&p=AONE&sw=w&asid=551c8c99f975eceea3c413acaf5efdf1

  Abstract: The purpose of this paper is to provide a typology of sampling designs for qualitative researchers. We introduce the following sampling strategies: (a) parallel sampling designs, which represent a body of sampling strategies that facilitate credible comparisons of two or more different subgroups that are extracted from the same levels of study; (b) nested sampling designs, which are sampling strategies that facilitate credible comparisons of two or more members of the same subgroup, wherein one or more members of the subgroup represent a sub-sample of the full sample; and (c) multilevel sampling designs, which represent sampling strategies that facilitate credible comparisons of two or more subgroups that are extracted from different levels of study.

- Campbell, D. (1986**). Relabeling internal and external validity for applied social scientists.** New Directions for Program Evaluation, 31: 67-77.

  Abstract: An attempt is made to reduce confusion about the meaning of validity in quasi-experimental research through relabeling different types of validity. Internal validity is retermed "local molar (pragmatic, atheoretical) causal validity," & external validity is reconceptualized as the "principle of proximal similarity." Each is explained in depth along with the rationale for choosing the new terms. Their utility for applied social science is discussed.

Responsible Conduct of Research

- Brown, P., Morello-Frosch, R., Brody, J., Altman, R.G., Rudel, R.A., Senier, L., & Simpson, R. (2010). **Institutional review board challenges related to community-based participatory research on human exposure to environmental toxins: A case study**. Environmental Health, 9(39):1-12. Available here: http://www.ehjournal.net/content/9/1/39

  Abstract: Background: We report on the challenges of obtaining Institutional Review Board (IRB) coverage for a community-based participatory research (CBPR) environmental justice project, which involved reporting biomonitoring and household exposure results to participants, and included lay participation in research.
  Methods: We draw on our experiences guiding a multi-partner CBPR project through university and state Institutional Review Board reviews, and other CBPR colleagues' written accounts and conference presentations and discussions. We also interviewed academics involved in CBPR to learn of their challenges with Institutional Review Boards.
  Results: We found that Institutional Review Boards are generally unfamiliar with CBPR, reluctant to oversee community partners, and resistant to ongoing researcher-participant interaction. Institutional Review Boards sometimes unintentionally violate the very principles of beneficence and justice which they are supposed to uphold. For example, some Institutional Review Boards refuse to allow report-back of individual data to participants, which contradicts the CBPR principles that guide a growing number of projects. This causes significant delays and may divert research and dissemination efforts. Our extensive education of our university Institutional Review Board convinced them to provide human subjects protection coverage for two community-based organizations in our partnership.
  Conclusions: IRBs and funders should develop clear, routine review guidelines that respect the unique qualities of CBPR, while researchers and community partners can educate IRB staff and board members about the objectives, ethical frameworks, and research methods of CBPR. These strategies can better protect research participants from the harm of unnecessary delays and exclusion from the research process, while facilitating the ethical communication of study results to participants and communities.

- Buchanan, D., Miller, F., Wallerstein, N. (2007). **Ethical issues in community-based participatory research: Balancing rigorous research with community participation in community intervention studies**. Progress in Community Health Partnerships: Research, Education, and Action, 1(2), 153-160. DOI: 10.1353/cpr.2007.0006

  Abstract: Problem: Concerns have been raised that community participation might compromise scientific rigor in community-based participatory research (CBPR).
  Purpose: The purpose of this paper is to identify potential sources of tension between the values of scientific rigor and community participation in CBPR.
  Key Points: CBPR lies at the nexus of two major underlying ethical concerns—respect for community autonomy and the fair allocation of limited public resources—which have generated considerable controversy about appropriate criteria for evaluating CBPR grant proposals. The complexity of evaluating CBPR proposals is compounded by the multiple purposes that it serves: (1) an ethical function of demonstrating respect for community autonomy; (2) a research method for eliciting ideas for interventions to improve population.
  Conclusions: Growing use of CBPR raises two new ethical issues that deserve greater public attention: first, the problem of securing informed consent and demonstrating respect for community autonomy when the locus of research shifts from the individual to community level; and second, fair distribution of scarce public resources when practical constraints make the most

rigorous research designs for assessing the effects of community interventions virtually impossible. In light of recent federal initiatives, it is critical to achieve a common understanding of appropriate ethical and scientific standards for assessing the merits of CBPR.

- Canadian Institutes of Health Research. 2007. **CIHR guidelines for health research involving Aboriginal People: Executive summary**. Available here: http://www.cihr-irsc.gc.ca/e/29134.html

- **CITI Program: Collaborative Institutional Training Initiative at the University of Miami.** (n.d.) Available here: https://www.citiprogram.org/index.cfm?pageID=22

  The Collaborative Institutional Training Initiative (CITI Program) at the University of Miami is a leading provider of research education content. Their web-based training materials serve millions of learners at academic institutions, government agencies, and commercial organizations in the U.S. and around the world. The CITI Program makes available many courses related to responsible conduct of research including topics such as: "Conflicts of Interest", "Good Clinical Practice", and "Information Privacy and Security".

- Cottrell, B., & Downie, J. (2001). **Community-based research ethics review: Reflections on experience and recommendations for action.** Health Law Review, 10(1), 8+. available here http://go.galegroup.com.proxy.lib.umich.edu/ps/i.do?id=GALE%7CA80320347&v=2.1&u=lom_umichanna&it=r&p=AONE&sw=w&asid=82d0b65864f455241f84fbad85d5444c

- Hyatt, R., Gute, D., Pirie, A., Page, P., Vasquez, I. & Dalember, F. (2009). **Transferring knowledge about human subjects protections and the role of institutional review boards in a community-based participatory research project.** American Journal of Public Health. 99(3), S526-S531. doi: 10.2105/AJPH.2008.155390

  Abstract: Among the first tasks in a collaboration between Tufts University and community organizations in Somerville, MA, was designing an interview instrument to assess occupational health needs among immigrant workers. Human subjects protections was a critical issue, but community partners were not well informed about the need for such protections or the role of the institutional review board (IRB).
  During research meetings, members of the team from Tufts trained community collaborators to work with research participants and organized a presentation by a key university IRB administrator.
  We present findings from the process evaluation of this project and suggest ways to (1) assess community partners' understanding about working with research volunteers, (2) train collaborators, and (3) involve IRBs.

- Jetter, K., Yarborough, M., Cassady, D., Styne, D. (2015**). Building research capacity with members of underserved American Indian/Alaskan Native communities: Training in research ethics and the protection of human subjects.** Health Promotion and Practice, 16 (3), 419-425. doi: 10.1177/1524839914548450

  Abstract: Objective. To develop a research ethics training course for American Indian/Alaskan Native health clinic staff and community researchers who would be conducting human subjects research.
  Method. Community-based participatory research methods were used in facilitated discussions of research ethics centered around topics included in the Collaborative Institutional Training Initiative research ethics course.
  Results. The community-based participatory research approach allowed all partners to jointly develop a research ethics training program that was relevant for American Indian/Alaskan Native communities. All community and clinic partners were able to pass the Collaborative Institutional Training Initiative course they

were required to pass so that they could be certified to conduct research with human subjects on federally funded projects. In addition, the training sessions provided a foundation for increased community oversight of research.

Conclusions. By using a collaborative process to engage community partners in research ethics discussions, rather than either an asynchronous online or a lecture/presentation format, resulted in significant mutual learning about research ethics and community concerns about research. This approach requires university researchers to invest time in learning about the communities in which they will be working prior to the training.

- Kahnawake Schools Diabetes Prevention Project. (2007). **Code of Research Ethics**. Available here: http://www.ksdpp.org/media/ksdpp_code_of_research_ethics2007.pdf

  The Kahnawá:ke Schools Diabetes Prevention Project (KSDPP) Center for Research and Training in Diabetes Prevention is a community-based participatory research project. The purpose of the KSDPP Code of Research Ethics is to establish a set of principles and procedures that will guide the partners to achieve the goals and objectives of the KSDPP. The KSDPP Code of Research Ethics outlines the obligations of the partners throughout all phases of the research process.

- Khanlou, N., Peter, E. (2005**). Participatory action research: Considerations for ethical review**. Social Science & Medicine, 60(10), 2333-2340. doi:10.1016/j.socscimed.2004.10.004

  Abstract: This paper addresses the distinctive nature of participatory action research (PAR) in relation to ethical review requirements. As a framework for conducting research and reducing health disparities, PAR is gaining increased attention in community and public health research. As a result, PAR researchers and members of Research Ethics Boards could benefit from an increased understanding of the array of ethical concerns that can arise. We discuss these concerns in light of commonly held ethical requirements for clinical research (social or scientific value, scientific validity, fair subject/participant selection, favourable risk–benefit ratio, independent review, informed consent, and respect for potential and enrolled participants) and refer to guidelines specifically developed for participatory research in health promotion. We draw from our community-based experiences in mental health promotion research with immigrant and culturally diverse youth to illustrate the ethical advantages and challenges of applying a PAR approach. We conclude with process suggestions for Research Ethics Boards.

- Minkler, M. (2004). **Ethical challenges for the 'outside' researcher in community-based participatory research.** Health Education & Behavior. 31(6), 684-697. doi: 10.1177/1090198104269566

  Abstract: Although community-based participatory research (CBPR) shares many of the core values of health education and related fields, the outside researcher embracing this approach to inquiry frequently is confronted with thorny ethical challenges. Following a brief review of the conceptual and historical roots of CBPR, Kelly's ecological principles for community-based research and Jones's three-tiered framework for understanding racism are introduced as useful frameworks for helping explore several key challenges. These are (a) achieving a true "community-driven" agenda; (b) insider-outsider tensions; (c) real and perceived racism; (d) the limitations of "participation"; and (e) issues involving the sharing, ownership, and use of findings for action. Case studies are used in an initial exploration of these topics. Green et al.'s guidelines for appraising CBPR projects then are highlighted as an important tool for helping CBPR partners better address the challenging ethical issues often inherent in this approach.

- Morton, D.J., Proudfit, J., Calac, D., Portillo, M., Lofton-Fitzsimmons, G., Molina, T... Majel-McCauley, R. (2013). **Creating research capacity through a tribally based institutional review board**. American

Journal of Public Health. 103(12):2160-2164. Retrieved from:
http://proxy.lib.umich.edu/login?url=http://search.proquest.com.proxy.lib.umich.edu/docview/1467837355?accountid=14667

Abstract: Tribal groups work tirelessly to maintain sovereignty rights, preserving and upholding tribal authority and protection over their land, people, businesses, and health. Moreover, the conduct of health science research by outsiders has had its share of an unethical, misguided, and abusive past. Tribally based institutional review boards (IRBs) are addressing these issues in an effort to control new health science research, set their own research agenda, and protect their people in the same spirit as has been accomplished through the perpetuation of sovereignty rights. We describe the success of a tribally based IRB at creating new capacity for health research and enhanced levels of trust, including bidirectional cultural education between academic researchers and tribal IRB committee members.

- National Aboriginal Health Organization. 2006. **OCAP (Ownership, Control, Access and Possession) Principles**. Available here: http://www.naho.ca/jah/english/jah01_01/journal_p80-95.pdf

Abstract: The principles of ownership, control, access and possession (OCAP) crystallize themes long advocated by First Nations in Canada. Coined by the Steering Committee of the First Nations Regional Longitudinal Health Survey, the principles are discussed as an expression of self-determination in research. The key notions outlined in this paper relate to the collective ownership of group information; First Nations control over research and information; First Nations' management of access to their data and physical possession of the data. Following a critical review of colonial research practices and recent institutional efforts to improve ethics in Aboriginal research, this paper highlights policies and strategies adopted by First Nations organizations – approaches which offer a way out of the muddle of contemporary Aboriginal research and the ethical dilemmas that characterize it. The benefits of OCAP are described including the rebuilding of trust, improved research quality and relevance, decreased bias, meaningful capacity development, and community empowerment to make change.

- Pacific Aids Network. (2014). **CBR Tips: Compensating Peer Researchers.** Available here: http://pacificaidsnetwork.org/wp-content/uploads/2014/06/CBR-Tips-Compensating-Peer-Researchers-Pacific-AIDS-Network-Final.pdf

This document was developed in consultation with PRAs, research coordinators, administrative staff/financial managers at community-based organizations, and academics within British Columbia. It outlines some important considerations to take into account when developing compensation plans and policies for community-based research.

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- Santos, L. (2008). **Genetic research in native communities**. Progress in Community Health Partnerships. 2(4): 321-327. DOI: 10.1353/cpr.0.0046

Abstract: People are living longer because of advances made through biomedical research. The challenge in genetic research on indigenous peoples is that it raises a complex range of legal, ethical, social, spiritual, and political issues. The current research paradigm is one of paternalism and biocolonialism. Such was the case of the Havasupai, who believed their blood samples were to be solely used for their collective benefit and well-being, and Native Hawaiians, who are opposed to genetically modified taro. Pertinent questions that should be considered before conducting research with and amongst Native communities include:
Is there informed consent or the need for re-consent?
Is cultural knowledge respected?
Are indigenous beliefs, values, and practices taken into account?
Is there potential for group harm?

Is there accountability to community?
Establishing a community Institutional Review Board may be the most effective means toward achieving equal and ethical treatment in population/group-based research. Research should be about ethically rigorous processes and effectively tailored interventions that address community needs, interests, and values.

- Shore, N., Ford, A., Wat, E., Brayboy, M., Isaacs, M., Park, A., … Seifer, S. (2015). **Community-based review of research across diverse community contexts: Key characteristics, critical issues, and future directions**. American Journal of Public Health, 105(70, 1294-1301. doi: 10.2105/AJPH.2015.302588

  A growing number of community-based organizations and community-academic partnerships are implementing processes to determine whether and how health research is conducted in their communities. These community-based research review processes (CRPs) can provide individual and community-level ethics protections, enhance the cultural relevance of study designs and competence of researchers, build community and academic research capacity, and shape research agendas that benefit diverse communities. To better understand how they are organized and function, representatives of 9 CRPs from across the United States convened in 2012 for a working meeting. In this article, we articulated and analyzed the models presented, offered guidance to communities that seek to establish a CRP, and made recommendations for future research, practice, and policy.

- Solomon, S., Bullock, S., Calhoun, K., Crosby, L., Eakin, B., Franco, Z., ... Spellecy, R. (2014). **Piloting a nationally disseminated, interactive human subjects protection program for community partners: Unexpected lessons learned from the field.** Clinical and Translational Science, n/a-n/a. doi: 10.1111/cts.12155

  Abstract: Funders, institutions, and research organizations are increasingly recognizing the need for human subjects protections training programs for those engaged in academic research. Current programs tend to be online and directed toward an audience of academic researchers. Research teams now include many nonacademic members, such as community partners, who are less likely to respond to either the method or the content of current online trainings. A team at the CTSA-supported Michigan Institute for Clinical and Health Research at the University of Michigan developed a pilot human subjects protection training program for community partners that is both locally implemented and adaptable to local contexts, yet nationally consistent and deliverable from a central administrative source. Here, the developers and the analysts of this program discuss its development, its content, and the results of its evaluation.

- Solomon, S., Eakin, B., Kirk, R., Piechowski, P., & Thomas, B. (2014). **Piloting a nationally disseminated, interactive human subjects protection program for community partners: Design, content, and evaluation.** Clinical and Translational Science, 7(2), 177-183. DOI: 10.1111/cts.12154

  Abstract: Funders, institutions, and research organizations are increasingly recognizing the need for human subjects protections training programs for those engaged in academic research. Current programs tend to be online and directed toward an audience of academic researchers. Research teams now include many nonacademic members, such as community partners, who are less likely to respond to either the method or the content of current online trainings. A team at the CTSA-supported Michigan Institute for Clinical and Health Research at the University of Michigan developed a pilot human subjects protection training program for community partners that is both locally implemented and adaptable to local contexts, yet nationally consistent and deliverable from a central administrative source. Here, the developers and the analysts of this program discuss its development, its content, and the results of its evaluation.

- Styres, S., Zinga, D., 2013. **The community-first land-centred theoretical framework: Bringing a "good mind" to indigenous education research?** Canadian Journal of Education, 36(2), 284-313. Retrieved from:
http://proxy.lib.umich.edu/login?url=http://search.proquest.com.proxy.lib.umich.edu/docview/1491105497?accountid=14667

Abstract: This article introduces an emergent research theoretical framework, the community-first Land-centred research framework. Carefully examining the literature within Indigenous educational research, we noted the limited approaches for engaging in culturally aligned and relevant research within Indigenous communities. The community-first Land-centred research framework was created by reflecting on how we engaged in research collaborations with Indigenous communities. This process of reflection led us to realize that within our research we had been developing a research framework that was culturally-aligned, relevant, and based on respectful relations that differed in important ways from other community oriented research framework. We articulate how we differentiate this framework from community-based approaches to research and discuss the community-first Land-centred research framework's foundational principles. We draw upon lessons learned through our various collaborations over the past seven years.

Interpreting and Applying Data to Inform Community Change

- The Asset-Based Community Development Institute for Policy Research. (1999). **Newspapers and Neighborhoods: Strategies for Achieving Responsible Coverage of Local Communities.** Available here http://www.abcdinstitute.org/docs/abcd/MediaText.pdf

- Baker, E.A., Motton, F., Barnridge, E., & Rose, F. (2013). **Collaborative data collection, interpretation, and action planning in a rural African American community: Men on the move. In Israel**, B.A., Eng, E., Schulz, A.J., & Parker, E.A. (Eds.), Methods in Community-Based Participatory Research for Health. 2nd Edition. San Francisco: Jossey-Bass, 435-462 (CH 15).

- Everyday Democracy. (n.d.). **Resources for Changemakers.** Available here: http://everyday-democracy.org/resources#. VVOPHPnBwXA

  Everyday Democracy provides discussion guides, how-to handbooks, trainings, and other adaptable resources organized by issue, by type of resource, and by phase of project. Everyday Democracy focuses on creating community dialogues and movements for social change.

- Gregg, J., Centurion, L., Maldonado, J., Aguillon, R., Celaya-Alston, R. & Farquhar, S. (2010). **Interpretations of interpretations: Combining community-based participatory research and interpretive inquiry to improve health**. Progress in Community Health Partnerships: Research, Education, and Action, (4)2,149-154. Retrieved from http://muse.jhu.edu/journals/progress_in_community_health_partnerships_research_education_and_action/v004/4.2.gregg.html

  Abstract: Background: Latina immigrants from Mexico suffer significantly increased morbidity and mortality from cervical cancer when compared with non-Hispanic White women, largely owing to lack of screening and appropriate treatment.
  Objectives: To demonstrate that by combining the tools of community-based participatory research (CBPR) with the tools of interpretive inquiry, it is possible to address explicit community concerns surrounding a particular problem such as cervical cancer while also examining what other, perhaps less immediately visible, matters consume the time and attention of community members.
  Methods: We first briefly discuss and compare CBPR as an approach to research and interpretive inquiry as a qualitative research method. We then provide a case study from our own research using a CBPR approach to examine beliefs and attitudes about cervical cancer prevention among Oregon Latinos. Methods in that study included extensive discussions with our community advisory board (CAB) and promotores (community health workers) regarding barriers to cervical cancer screening for Latinas and community health concerns in general, and in-depth interviews with more than 50 Latino immigrants.
  Conclusion: Combining the tools of CBPR with the tools of interpretive qualitative inquiry may allow researchers to address explicit community concerns while also examining what other, less immediately visible, issues consume the time and attention of community members. In our specific case, combining the insights of our community partners with the results of our interpretive analysis helped us shift the focus from cervical cancer alone to a focus on gender relations and family health as we design future interventions.

- Healthy Environments Partnership. (2009). **Healthy Environments Partnership Dissemination Guidelines**. Available here: http://www.hepdetroit.org/en/our-research/dissemination-of-findings

  The Healthy Environment Partnership Dissemination Guidelines were adopted in 2001. These guidelines are modeled after those developed by Community Action Against Asthma (Parker et al, CBPR Methods in

Public Health) and are used to guide community and academic partnering in publications, presentations and other dissemination activities.

- Izumi, B.T., Schulz, A.J., Israel, B.A., Reyes, A.G., Martin, J., Lichtenstein, R.L., ... Sand, S.L. (2010). **The one-pager: A practical policy advocacy tool for translating community-based participatory research into action.** Progress in Community Health Partnerships: Research, Education, and Action, 4(2), 141-147. DOI: 10.1353/cpr.0.0114

Abstract: The multiple and diverse perspectives, skills, and experiences inherent in community–academic partnerships make them uniquely positioned to educate policy makers and advocate for health equity. Effective communication tools are critical to successfully engage in the policy-making process. Yet few resources emphasize the development and use of practical tools for translating community-based participatory research (CBPR) findings into action. The purpose of this article is to describe a CBPR process for developing and using a one-page summary, or "one-pager," of research findings and their policy implications. This article draws on the experience of the Healthy Environments Partnership (HEP), a community–academic partnership in Detroit, Michigan. In addition to describing these processes, this article includes a template for a one-pager and an example of a one-pager that was written for and presented to federal policy makers.

- Macaulay, A.C., Ing, A., Salsberg, J., McGregor, A., Saad-Haddad, C., Rice, J… & Gray-Donald, K. (2007). **Community-based participatory research: Lessons from sharing results with the community: Kahnawake schools diabetes prevention project**. Progress in Community Health Partnerships, 1(2), 143-152. Retrieved from http://muse.jhu.edu/journals/progress_in_community_health_partnerships_research_education_and_action/v001/1.2macaulay.html

Abstract: Background: Kahnawake Schools Diabetes Prevention Project (KSDPP) is an ongoing, community-based participatory research project with an Aboriginal community in Canada, promoting healthy lifestyles to prevent type 2 diabetes.
Objectives: To document lessons learned from sharing results with the community, and analyzing feedback from attendees.
Methods: In 2004, a researcher–community team delivered 16 sessions of a contextualized presentation of data collected from 1994 to 2002. The team documented the resulting questions and discussions, attendees completed anonymous questionnaires including open-ended questions, and presenters summarized their impressions.
Results: One hundred eighty-one people attended the presentations and question/discussion periods were summarized. One hundred sixty-two (82%) of attendees (87% female), completed the questionnaires; 99% understood the presentations and 142 (88%) stated they intended to improve their lifestyles. Qualitative analysis of discussions and open-ended comments categorized attendees' comments about KSDPP, the 1994 through 2002 results, the community, and lifestyle habits. Lessons learned included the time needed to develop and make the presentations, the importance of using community knowledge to guide the experience, ways of attracting an audience, difficulty of reaching men, use of feedback from those attending the presentations, and the need to plan prospectively for analyzing attendee feedback.
Conclusions: Community feedback was used to improve interventions and finalize interpretation of the results.

- **The Praxis Project**. (n.d.). Tools. Available here: http://www.thepraxisproject.org/tools/Campaign-Development-Organizing

The Praxis Project has resources and tools for developing and implementing policy advocacy campaigns. Examples of resources include power pyramid worksheets, a guide to developing a policy initiative and a policy advocacy curriculum.

Mixed Methods in CBPR

- Allen, M., Culhane-Pera, K., Pergament, S., Theide, K. (2011). **A capacity building program to promote CBPR partnerships between academic researchers and community members**. Clinical and Translational Science, 4(6), 428-433.DOI: 10.1111/j.1752-8062.2011.00362.

  Abstract: Introduction: Community-based participatory research (CBPR) adds community perspectives to research and aids translational research aims. There is a need for increased capacity in CBPR but few models exist for how to support the development of community/university partnerships.
  Objective: Evaluate an approach to promote nascent CBPR partnerships.
  Methods: Design was a mixed–methods evaluation using interviews, process notes, and open- and close-ended survey questions. We trained 10 community scholars, matched them with prepared researchers to form seven partnerships, and supported their developing partnerships. Sequential mixed–methods analysis assessed research and partnership processes and identified integrated themes.
  Results: Four of seven partnerships were funded within 15 months; all self-reported their partnerships as successful. Themes were: (1) motivators contributed to partnership development and resiliency; (2) partners took on responsibilities that used individuals' strengths; (3) partners grappled with communication, decision making, and power dynamics; and (4) community–university infrastructure was essential to partnership development.
  Conclusions: This program for developing nascent partnerships between academicians and community members may guide others in increasing capacity for CBPR.

- Betancourt, T., Frounfelker, R., Mishra, T., Hussein, A. & Falzarano, R. (2015**). Addressing health disparities in the mental health of refugee children and adolescents through community-based participatory research: A study in 2 communities**. American Journal of Public Health. 105 (S3): S475-S482. doi: 10.2105/AJPH.2014.302504

  Abstract: Objectives: We sought to understand the problems, strengths, and help-seeking behaviors of Somali Bantu and Bhutanese refugees and determine local expressions of mental health problems among youths in both communities.
  Methods: We used qualitative research methods to develop community needs assessments and identify local terms for child mental health problems among Somali Bantu and Bhutanese refugees in Greater Boston and Springfield, Massachusetts, between 2011 and 2014. A total of 56 Somali Bantu and 93 Bhutanese refugees participated in free list and key informant interviews.
  Results: Financial and language barriers impeded the abilities of families to assist youths who were struggling academically and socially. Participants identified resources both within and outside the refugee community to help with these problems. Both communities identified areas of distress corresponding to Western concepts of conduct disorders, depression, and anxiety.
  Conclusions: There are numerous challenges faced by Somali Bantu and Bhutanese youths, as well as strengths and resources that promote resilience. Future steps include using culturally informed methods for identifying those in need of services and developing community-based prevention programs.

- Cashman, S., Adeky, S., Allen, A., Corburn, J., Israel, B., Montaño, J. … Eng, E. (2008). **The Power and the promise: Working with communities to analyze data, interpret findings, and get to outcomes**. American Journal of Public Health, 98(8), 1407-1417. doi: 10.2105/AJPH.2007.113571

Abstract: Although the intent of community-based participatory research (CBPR) is to include community voices in all phases of a research initiative, community partners appear less frequently engaged in data analysis and interpretation than in other research phases. Using 4 brief case studies, each with a different data collection methodology, we provide examples of how community members participated in data analysis, interpretation, or both, thereby strengthening community capacity and providing unique insight. The roles and skills of the community and academic partners were different from but complementary to each other. We suggest that including community partners in data analysis and interpretation, while lengthening project time, enriches insights and findings and consequently should be a focus of the next generation of CBPR initiatives.

- Driscoll, D., Appiah-Yeboah, A., Salib, P. & Rupert, J. (2007). **Merging qualitative and quantitative data in mixed methods research: How to and why not. Ecological and Environmental Anthropology** (University of Georgia). Paper 18. Available here: http://digitalcommons.unl.edu/icwdmeea/18

Abstract: This study assesses the utility of mixed methods designs that integrate qualitative and quantitative data through a transformative process. Two strategies for collecting qualitative and quantitative datasets are described, and processes by which they can be merged are presented in detail. Some of the benefits of mixed methods designs are summarized and the shortcomings and challenges inherent in quantitizing qualitative data in mixed methods research are delineated.

- Greene, J. (2008). **Is mixed methods social inquiry a distinctive methodology?** Journal of Mixed Methods Research, 2(1), 7-22. doi: 10.1177/1558689807309969

Abstract: This article addresses the merits of and warrants for considering mixed methods social inquiry as a distinctive methodology. In each of four methodological domains—philosophy, methodology, practical guidelines, and sociopolitical commitments—the status of the mixed methods field is reviewed. Signal accomplishments are noted in each domain, as are important priorities for further development.

- Hugentobler, M., Israel, B., & Schurman, S. (1992). **An action research approach to workplace health: Integrating methods**. Health Education Quarterly, 19(1), 55-76. DOI: 10.1177/109019819201900105

Abstract: Action research, which combines the generation and testing of theory with social system change, demands multiple sources of knowledge about the research setting and encourages the integration of data collection techniques. This article describes the implementation of a longitudinal multi-methodological research and intervention project aimed both at examining the relationship between occupational stress and psychosocial moderating factors (e.g., social support, participation, and influence over decision-making) and health outcomes; and reducing work stress and improving employee health. Combining qualitative and quantitative research techniques such as semi- structured individual and focus group interviews, field notes and survey data increases confidence in research findings and strengthens the process and outcomes of needs assessment, program planning, implementation, and evaluation. Specific examples are provided that illustrate the usefulness of this approach in identifying and understanding problem areas and in developing and evaluating appropriate health education interventions.

- National Institute of Health Office of Behavioral and Social Science Research. (n.d.). **Best Practices for Mixed Methods Research in the Health Sciences.** Available here: http://obssr.od.nih.gov/mixed_methods_research/section2.aspx#When should mixed methods be used

- Wiggins, N., Hughes, A., Rodrigues, A., Potter, C. & Rios-Campos, T. (2013). **La palabra es salud (the word is health) combining mixed methods and CBPR to understand the comparative effectiveness**

of popular and conventional education. Journal of Mixed Methods Research, 8(3), 278-298. doi:10.1177/1558689813510785.

Abstract: Increasing recognition of the role of social conditions in health has led to calls for methods that can be used to change social conditions. Popular education has demonstrated great promise as a methodology that can be used to address the underlying social and structural determinants of health. To date, most studies of popular education have used qualitative methods and case study designs, making them less compelling for decision makers. La Palabra es Salud (The Word Is Health) compared the relative effectiveness of popular and conventional education using a participatory, quasi-experimental, mixed methods design. Use of this model can enhance our understanding of popular education and raise its profile among researchers and practitioners in multiple disciplines, thus potentially extending its benefits.

- Windsor, L. C. (2013). **Using concept mapping in community-based participatory research: A mixed methods approach**. Journal of Mixed Methods Research, 7(3):274-293. doi:10.1177/1558689813479175

Abstract: Community-based participatory research (CBPR) has been identified as a useful approach to increasing community involvement in research. Developing rigorous methods in conducting CBPR is an important step in gaining more support for this approach. The current article argues that concept mapping, a structured mixed methods approach, is useful in the initial development of a rigorous CBPR program of research aiming to develop culturally tailored and community-based health interventions for vulnerable populations. A research project examining social dynamics and consequences of alcohol and substance use in Newark, New Jersey, is described to illustrate the use of concept mapping methodology in CBPR. A total of 75 individuals participated in the study.

- Wing S, Horton RA, Muhammad N, Grant GR, Tajik M, Thu K. (2008). **Integrating epidemiology, education, and organizing for environmental justice: Community health effects of industrial hog operations**. American Journal of Public Health, 98(8):1390-1397. Retrieved from: http://proxy.lib.umich.edu/login?url=http://search.proquest.com.proxy.lib.umich.edu/docview/215095300?accountid=14667

Abstract: The environmental justice movement has stimulated community-driven research about the living and working conditions of people of color and low-income communities. We describe an epidemiological study designed to link research with community education and organizing for social justice. In eastern North Carolina, high-density industrial swine production occurs in communities of low-income people and people of color. We investigated relationships between the resulting pollution and the health and quality of life of the hog operations' neighbors. A repeat-measures longitudinal design, community involvement in data collection, and integration of qualitative and quantitative research methods helped promote data quality while providing opportunities for community education and organizing. Research could affect policy through its findings and its mobilization of communities.

- Zoellner, J., Zanko, A., Price, B., Bonner, J. & Hill, J. L. (2012**). Exploring community gardens in a health disparate population: Findings from a mixed methods pilot study.** Progress in Community Health Partnerships: Research, Education, and Action, 6(2), 153-165. The Johns Hopkins University Press. available here: http://search.proquest.com/docview/1032533892?pq-origsite=summon&accountid=14667

Abstract: Background: Despite recommendations, there have been few efforts to apply the community-based participatory research (CBPR) approach in the development, implementation, and evaluation of community gardens.
Objectives: As guided by the CBPR approach and grounded in a social-ecological model and behavioral theory, the purpose of this mixed methods study was to understand opinions and interests

in developing and implementing a community garden and to understand factors impacting fruit, vegetable, and gardening behaviors.

Methods: Community and academic members collaborated to develop and execute this study. The qualitative phase— targeting regional key informants—was designed to elicit perceived benefits and challenges of community gardens at the environmental, community, and individual levels. The quantitative phase targeted low resourced youth and parents and included a variety of validated theory-based questionnaires to understand factors impacting fruit, vegetable, and gardening behaviors.

Results: Major benefits of community gardens that emerged from the 10 qualitative interviews included increasing community cohesion and improving nutrition and physical activity factors. The quantitative phase included 87 youth and 67 parents. Across 16 items for fruits and vegetables, the average willingness to try was 1.32 (standard deviation [SD] = 0.40) on a 2-point scale. The majority of youth indicated they would work in a garden (n = 59; 68%) and eat food grown in their garden (n= 71; 82%). Among parents, gardening attitude, belief, and self-efficacy scores were all above average; however, gardening intentions were neutral.

Conclusion: This research illustrates the successful partnering a community-academic team and has provided the partnership with a clearer lens to conceptualize and launch future regional community garden efforts.

In-Depth Interviews & Evaluation in CBPR

- **Better Evaluation**. (n.d.). Available here: http://betterevaluation.org/

  Better Evaluation is an international collaboration to improve evaluation practice and theory by sharing and generating information about options (methods or processes) and approaches. The Better Evaluation website has resources organized by evaluation method, approach and themes.

- Canadian Coalition for Global Health Research. (2009). **Partnership assessment toolkit**. Retrieved from http://www.ccghr.ca/wp-content/uploads/2013/05/PAT_Interactive_e-1.pdf

  The CCGHR partnership assessment toolkit was created as a response to the persistent challenge of inequities in health research partnerships, and seeks to empower all stakeholders in health research partnerships with the necessary tools for negotiation and governance across the lifespan of their partnerships.

- Corbin, H., Fernandez, M. & Mullen, P. (2015). **Evaluation of a community-academic partnership: Lessons from Latinos in a network for cancer control**. Health Promotion Practice, 16(3), 345-353. doi:10.1177/1524839914558514

  Abstract: Established in 2002, Latinos in a Network for Cancer Control is a community-academic network supported by the Centers for Disease Control and Prevention and the National Cancer Institute. The network includes >130 individuals from 65 community and academic organizations committed to reducing cancer-related health disparities. Using an empirically derived systems model-the Bergen Model of Collaborative Functioning-as the analytic frame, we interviewed 19 partners to identify challenges and successful processes. Findings indicated that sustained partner interaction created "meaningful relationships" that were routinely called on for collaboration. The leadership was regarded positively on vision, charisma, and capacity. Limitations included overreliance on a single leader. Suggestions supported more delegation of decision making, consistent communication, and more equitable resource distribution. The study highlighted new insights into dynamics of collaboration: Greater inclusiveness of inputs (partners, finances, mission) and loosely defined roles and structure produced strong connections but less network-wide productivity (output). Still, this profile enabled the creation of more tightly defined and highly productive subgroups, with clear goals and roles but less inclusive of inputs than the larger network. Important network outputs included practice-based research publications, cancer control intervention materials, and training to enhance the use of evidence-based interventions, as well as continued and diversified funding.

- Department of Health and Human Services Centers for Disease Control and Prevention National Center for Chronic Disease Prevention and Health Promotion. (2008). **Evaluation Guide: Developing and using a logic model**. Available here http://www.cdc.gov/DHDSP/programs/nhdsp_program/evaluation_guides/logic_model.htm

  The evaluation guide Logic Models offers a general overview of the development and use of logic models as planning and evaluation tools.

- Sandoval, J., Lucero, J., Oetzel, J., Avila, M., Belone, L., Mau, M. … & Wallerstein, N. (2012). **Process and outcome constructs for evaluating community-based participatory research projects: a matrix of existing measures.** Health Education Research, 27(4):680-690 doi: 10.1093/her/cyr087

Abstract: Community-based participatory research (CBPR) has been widely used in public health research in the last decade as an approach to develop culturally centered interventions and collaborative research processes in which communities are directly involved in the construction and implementation of these interventions and in other application of findings. Little is known, however, about CBPR pathways of change and how these academic–community collaborations may contribute to successful outcomes. A new health CBPR conceptual model (Wallerstein N, Oetzel JG, Duran B et al. CBPR: What predicts outcomes? In: Minkler M, Wallerstein N (eds). Communication Based Participatory Research, 2nd edn. San Francisco, CA: John Wiley & Co., 2008) suggests that relationships between four components: context, group dynamics, the extent of community-centeredness in intervention and/or research design and the impact of these participatory processes on CBPR system change and health outcomes. This article seeks to identify instruments and measures in a comprehensive literature review that relates to these distinct components of the CBPR model and to present them in an organized and indexed format for researcher use. Specifically, 258 articles were identified in a review of CBPR (and related) literature from 2002 to 2008. Based on this review and from recommendations of a national advisory board, 46 CBPR instruments were identified and each was reviewed and coded using the CBPR logic model. The 46 instruments yielded 224 individual measures of characteristics in the CBPR model. While this study does not investigate the quality of the instruments, it does provide information about reliability and validity for specific measures. Group dynamics proved to have the largest number of identified measures, while context and CBPR system and health outcomes had the least. Consistent with other summaries of instruments, such as Granner and Sharpe's inventory (Granner ML, Sharpe PA. Evaluating community coalition characteristics and functioning: a summary of measurement tools. Health Educ Res 2004; 19: 514–32), validity and reliability information were often lacking, and one or both were only available for 65 of the 224 measures. This summary of measures provides a place to start for new and continuing partnerships seeking to evaluate their progress.

- University of New Mexico School of Medicine Center for Participatory Research. (2012). **Focus Group Guide for Evaluating & Reflecting on CBPR Partnerships using a CBPR Logic Model**. available here http://cpr.unm.edu/research-projects/cpbr-project/cbpr-model.html

  This focus group guide is a tool CBPR partnerships can use to reflect on their processes, contexts, conditions, barriers and outcomes. Additionally, the guide provides strategies for improving desired outcomes based on evaluation results.

- VanDevanter, N., Kwon, S., Sim, S., Chun, K., B Free CEED Coalition & Trinh-Shevrin, C. (2011). **Evaluation of community-academic partnership functioning: Center for the elimination of hepatitis B health disparities**. Progress in Community Health Partnerships: Research, Education, and Action, 5(3), 223-233. DOI: 10.1353/cpr.2011.0032

Abstract: Background: Process evaluation of community–academic partnership function and fidelity to principles of community-based participatory research (CBPR) is essential to achievement of intermediate and long term partnership goals.
Objectives: This article describes the evaluation of B Free CEED, a community–academic partnership created to address hepatitis health disparities in Asian American and Pacific Islander (API) communities.
Methods: A mixed methods approach with an online survey and qualitative key informant interviews was conducted with all partnership members at baseline and follow-up, 18 months later.
Results: Survey findings showed stability over time, with some consistent differences in community and academic perspectives. Academic members were somewhat more satisfied with the partnership functioning. Key informant interviews provided contextual data key to further defining partnership functioning.
Conclusions: Conducting ongoing partnership evaluations is necessary to reassess and align processes and protocols to enhance partnership functioning and strengthen group cohesion.

- Van Olphen, J., Ottoson, J., Green, L., Barlow, J., Koblick, K. & Hiatt, R. (2009). **Evaluation of a partnership approach to translating research on breast cancer and the environment.** Progress in Community Health Partnerships 3(3), 213-226. doi: DOI: 10.1353/cpr.0.0081

  Abstract: Background: The growing literature on community-based participatory research (CBPR) suggests that a participatory approach benefits science in important ways. However there have been few formal evaluations of a CBPR approach itself, and few standards developed to assist in such efforts.
  Objectives: This evaluation used CBPR guidelines developed by Green and colleagues to evaluate the participatory approach of the Community Outreach and Translation Core (COTC) of the Bay Area Breast Cancer and the Environment Research Center (BABCERC) in translating scientific findings from two key projects to the public.
  Method: To assess key stakeholders' perceptions of alignment between the projects and the guidelines, four COTC members, four researchers, and four community members rated the projects on each of the 26 guidelines. These data were triangulated with transcripts from interviews with the same participants and a focus group with a subset of the participants.
  Results: The participatory approach by the COTC resulted in many important benefits including improved relationships among diverse stakeholders, knowledge generation, increased sensitivity and propriety of the research, and increased community support of research. However, several atypical features of this collaboration—for example, the basic and etiological nature of the science being undertaken, and the multiple communities (lay and activist/advocate) involved—resulted in different levels and qualities of participation among stakeholders.
  Conclusions: Further research should focus on the adaptation of participatory research principles for different kinds of community partners and on the development and refinement of standards and tools to assist in evaluating the process and outcome of participatory research.

- W.K. Kellogg Foundation. (2010). **Evaluation Handbook**. Available here https://www.wkkf.org/resource-directory/resource/2010/w-k-kellogg-foundation-evaluation-handbook

  A thorough guide to planning and implementing a project level evaluation. Also information on how to interpret and utilize data collected from an evaluation. This handbook provides a framework for thinking about evaluation as a relevant and useful program tool.