

BIBLIOGRAPHY: Workshop on Improving Health Research for Small Populations

BACKGROUND READING

[Organization of the Workshop](#)

[Small is Essential: Importance of Subpopulation Research in Cancer Control](#). *AJPH* (2015).

[What is a Small Population?](#)

This bibliography is organized by workshop session and speaker. A number of presenters provided extensive bibliographies on their topics.

SESSION 1: What do We Mean by Small Populations? How to Decide when a Small Population Is Important or Meaningfully Different Enough to Study?

Howard Koh, Harvard T.H. Chan School of Public Health, *The Importance of Health Research on Small Populations.*

Baggett, T.P., Chang, Y., Porneala, D.C., Bharel, L., Singer, D.E., and Rigotti, R.A. (2015).

Disparities in cancer incidence, stage, and mortality in Boston health care for the homeless program. *American Journal of Preventive Medicine*, 49(5):694-702.

Boehmer, U., and Elk, R., eds. (2015). *Cancer and the LGBT Community*. Heidelberg, Germany: Springer International Publishing.

Gallup. (2017). See: <http://news.gallup.com/poll/201731/lgbt-identification-rises.aspx> [March 2018].

Journal of the American Medical Association. Forums: See:

<https://newsatjama.jama.com/2017/02/08/jama-forum-health-equity-matters-for-asian-americans-native-hawaiians-and-pacific-islanders> [March 2018]. And See:

<https://newsatjama.jama.com/2016/11/10/jama-forum-improving-health-care-for-homeless-people/> [March 2018].

National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in Action: Pathways to Health Equity*. Washington, DC: The National Academies Press. Available: https://www.ncbi.nlm.nih.gov/books/NBK425848/pdf/Bookshelf_NBK425848.pdf [March 2018].

O'Connell, J.J. (2015). *Stories from the Shadows: Reflections of a Street Doctor*. Boston, MA: Boston Health Care for the Homeless Program.

Pew Research Center. (2015). *The Changing Face of America, 1965-2065*. Available: <http://www.pewresearch.org/fact-tank/2016/03/31/10-demographic-trends-that-are-shaping-the-u-s-and-the-world/> [March 2018].

Torre, L.A., Sauer, A.M., Moon, S.C., Kagawa-Singer, M., Jemal, A., and Siegel, R.L. (2016). Cancer statistics for Asian Americans, Native Hawaiians, and Pacific Islanders 2015: Convergence of incidence between males and females. *CA: A Cancer Journal for Clinicians*, 66(3):182-202.

U.S. Department of Health and Human Services. (2014). *Sexual Orientation and Health Among U.S. Adults: National Health Interview Survey, 2013. National Health Statistics Reports*, 77. Available: <https://www.cdc.gov/nchs/data/nhsr/nhsr077.pdf> [March 2018].

World Health Organization. *Constitution and Principles*: See:
<http://www.who.int/about/mission/en/>.

Zaza, S., Kann, L., and Barrios, L.C. (2016). Lesbian, gay, and bisexual adolescents: Population estimates and prevalence of health behaviors. *Journal of the American Medical Association*, 316(22):2355-2356.

Scarlett Lin Gomez, University of California, San Francisco, *Data Issues in Studying Small Populations: Challenges, Opportunities, and a Case Study*.

Asian American Center for Advancing Justice. (2013). *A Community of Contrasts. Asian Americans, Native Hawaiians, and Pacific Islanders in California*. Available:
https://www.advancingjustice-alc.org/wp-content/uploads/2013/03/Communities_of_Contrast_California_2013-1.pdf [March 2018].

Gomez, S.L., Von Behren, J., McKinley, M., Clarke, C.A., Shariff-Marco, S., Cheng, I., Reynolds, P., and Glaser, S.L. (2017). Breast cancer in Asian Americans in California, 1988-2013: Increasing incidence trends and recent data on breast cancer subtypes. *Breast Cancer Research and Treatment*, 164(1):139-147.

Gomez, S.L., Quach, T., Horn-Ross, P.L., et al. (2010). Hidden breast cancer disparities in Asian Women: Disaggregating incidence rates by ethnicity and migrant status. *American Journal of Public Health*, 100(Suppl 1):S125-S131.

Pew Research Report. (2012). *The Rise of Asian Americans*. Available:
<http://www.pewsocialtrends.org/files/2013/04/Asian-Americans-new-full-report-04-2013.pdf> [March 2018].

Lisa Signorello, Division of Cancer Prevention, National Cancer Institute, *Fielding Studies in Underrepresented Populations: Challenges and Considerations*.

SESSION 2: Challenges in Using Available Data for Small Population Health Research

Kelly Devers, NORC, *The Feasibility of Using Electronic Health Records and Electronic Health Data for Research on Small Populations*.

Bradley, C.J., Penberthy, L., Devers, K.J., and Holden, D.J.. (2010). Health services research and data linkages: Issues, methods, and directions for the future. *HSR: Health Services Research*, 45(5), Part II:1468-1486.

Brown, P.J. (2016, June 16). *Federal mandate aims to improve how gender identity is recorded in HER*. AAP Newsletter.

Cahill, S.R., Baker, K., Deutsch, M.B., Keatley, J., and Makadon, H.J. (2016). Inclusion of sexual orientation and gender identity in stage 3 meaningful use guidelines: A huge step forward for LGBT health. *LGBT Health*, 3(2):100-102.

Cowie, M.R., Blomster, J.I., and Curtis, L.H., et al. (2017). Electronic health records to facilitate clinical research. *Clinical Research in Cardiology*, 106(1):1-9.

- Curtis, L.H., Brown, J., and Platt, R. (2014). Four health data networks illustrate the potential for a shared national multipurpose big-data network. *Health Affairs*, 33(7):1178-1186.
- Davidson, A.J., Xu, S., Oronce, C.I.A., Durfee, M.J., McCormack, E.V., Steiner, J.F., Havranek, E., and Beck, A. (2018). Monitor depression rates: Use of electronic health records. *Journal of Public Health Management Practice*. doi: 10.1097/PHH0000000000000751 [epub ahead of print].
- Devers, K., Gray, B., Ramos, C., Shah, A., Blavin, F., and Waidmann, T. (2013). *The Feasibility of Using Electronic Health Records (EHRs) and other Electronic Health Data for Research on Small Populations*. A report by the Urban Institute, delivered to the Office of the Assistant Secretary for Planning and Evaluation at HHS. See: <https://aspe.hhs.gov/report/feasibility-using-electronic-health-data-research-small-populations> [March 2018].
- Devoe, J.E., Gold, R., Cottrell, E., et al. (2014). The ADVANCE network: Accelerating data value across a national community health center network. *Journal of American Medical Information Association*, 21(4):591-595.
- Fleurence, R.L., Curtis, L.H., Califf, R.M., Platt, R., Selby, J.V., and Brown, J.S. (2014). Launching PCORnet, a national patient-centered clinical research network. *Journal of American Medical Information Association*, 21(4):578-582.
- Hernandez, R.K., Wade, S.W., Reich, A., Pirolli, M., Liede, A., and Lyman, G.H. (2018). Incidence of bone metastases in patients with solid tumors: Analysis of oncology electronic medical records in the United States. *BMC Cancer*, 18(1):44. doi: 10.1186/s12885-017-3922-0.
- Hughes, K.S., et al. (2017). Identifying health information technology needs of oncologists to facilitate the adoption of genomic medicine: Recommendations from the 2016 American society of clinical oncology omics and precision oncology workshop. *Journal of Clinical Oncology*, 35(27):3153-3159.
- Kahn, M.G., et al. (2015). Transparent reporting of data quality in distributed data networks. *eGEMs: Generating Evidence & Methods to Improve Patient outcomes*, 3(1):1052.
- Kaplan, R.M., Chambers, D.A., and Glasgow, R.E. (2014). Big data and large sample size: A cautionary note on the potential for bias. *Clinical and Translational Science*, 7(4):342-346.
- Kho, A.N., et al. (2015). Design and implementation of a privacy preserving electronic health record linkage tool in Chicago. *Journal of American Medical Information Association*, 22(5):1072-1080.
- Kim, K.K., Joseph, J.G., and Ohno-Machado, L. (2015). Comparison of consumers' views on electronic data sharing for healthcare and research. *Journal of American Medical Information Association*, 22(4):821-830.
- McGlynn, E.A., Lieu, T.A., Durham, M.L., et al. (2014). Developing a data infrastructure for a learning health system: The PORTAL network. *Journal of American Medical Information Association*, 21(4):596-601.
- Myers, S.R., Carr, B.G., and Branas, C.C. (2016). Uniting big health data for a national learning health system in the United States. *Journal of the American Medical Association*, 170(12):1133-1134.

- Pan Asian Cohort Study. Preliminary Findings for Diabetes Prevalence. Palo Alto Medical Foundation. Available: <http://www.pamf.org/pacs/men.jpg> [March 2018].
- Patel, V., Hughes, P., Barker, W., and Moon L. (2016). *Trends in Individuals' Perceptions regarding Privacy and Security of Medical Records and Exchange of Health Information: 2012-2014*. ONC Data Brief, No.33. Washington DC: Office of the National Coordinator for Health Information Technology.
- Stoto, M., Parry, G., and Savitz, L. (2017). Analytical methods for a learning health system: 4. Delivery System Science. *eGEMs (Generating Evidence & Methods to improve patient outcomes)*, 5(1):31. doi: <http://doi.org/10.5334/egems.253>.
- Stoto, M., Oakes, M., Stuart, E., Savitz, L., Priest, E.L., and Zurovac, J. (2017). Analytical methods for a learning health system: 1. Framing the research question. *eGEMs (Generating Evidence & Methods to improve patient outcomes)*, 5(1):28.
- Thompson, C.A., Kurian, A.W., and Luft, H.S. (2015). Linking electronic health records to better understand breast cancer patient pathways within and between two health systems. *eGEMs (Generating Evidence & Methods to improve patient outcomes)*, 3(1):1127. doi: <http://dx.doi.org/10.13063/2327-9214.1127>. Available at: <http://repository.academyhealth.org/egems/vol3/iss1/5>.
- Tomayko, E.J., Flood, T.L., Tandias, A., and Hanrahan, L.P. (2015). Linking electronic health records with community-level data to understand childhood obesity risk, *Pediatric Obesity*, 10(6):436-441.
- Tomayko, E.J., Weinert, B.A., Godfrey, L., Adams, A.K., and Hanrahan, L.P. (2016). Using electronic health records to examine disease risk in small populations: Obesity among American Indian children, Wisconsin, 2007-2012. *Preventing Chronic Disease*, 13:150479.
- Washington, V., DeSalvo, K., Mostashari, F., and Blumenthal, D. (2017). The HITECH era and the path forward. *New England Journal of Medicine*, 377:904-906.
- Website: NIH Collaboratory Living Textbook of Pragmatic Clinical Trials Chapters. <http://www.rethinkingclinicaltrials.org/>
 Under DESIGN are discussions of: Experimental designs and randomization schemes; Endpoints and outcomes; Analysis plan; Consent, disclosure, and non-disclosure; Using electronic health record data, Data and safety monitoring; Designing with implementation and dissemination in mind, and Assessing feasibility.
 Under Conduct are discussions of: Study startup and Participant recruitment
 Under Dissemination are discussions of: Data sharing and embedded research; Dissemination and implementation; and Dissemination approaches for different stakeholders.

Chris Fowler, Pennsylvania State University, *Using Geospatial Methods with Demographic Data to Identify Populations*.

Family Life Project: A longitudinal study on children and families in rural Pennsylvania and North Carolina. See: <http://flp.fpg.unc.edu/about-flp> [March 2018].

- Fowler, C.S. (2016). Segregation as a multiscale phenomenon and its implications for neighborhood-scale research: The case of South Seattle 1990-2010. *Urban Geography*, 37(1):1-25.
- Fowler, C.S., Spielman, S., Folch, D.C., and Nagle, N. (2017). Who are the people in my neighborhood? The contextual fallacy of measuring individual context with census geographies. <http://doi.org/10.17605/OSF.IO/VHMZQ>.
- Root, E.D. (2012). Moving neighborhoods and health research forward: Using geographic methods to examine the role of spatial scale in neighborhood effects on health. *Annals of the Association of American Geographers*, 102(5):986-995.

Ellen Cromley, Consultant, *Using Geospatial Methods with Other Health and Environmental Data to Identify Populations*.

- Cromley, E.K., (2007). Risk factors contributing to motor vehicle collisions in an environment of uncertainty. *Stochastic Environmental Research and Risk Assessment (SERRA)*, 21(5):473-486. doi: 10.1007/s00477-007-0130-5.
- Cromley, E.K., Wilson-Genderson, M., Christman, Z., and Pruchno, R.A. (2015). Colocation of older adults with successful aging based on objective and subjective measures. *Journal of Applied Geography*, 56(1):13-20. doi: 10.1016/j.apgeog.2014.10.003.
- Cromley, E.K., Wilson-Genderson, M., Heid, A.R., and Pruchno, R.A. (2016), Spatial associations of multiple chronic conditions among older adults. *Journal of Applied Gerontology*, 1-25. doi: 10.1177/0733464716672044.
- Cromley, E.K., Schensul, J.J., Singh, S.K., Berg, M.J., and Coman, E. (2010). Spatial dimensions of research on alcohol and sexual risk: A case example from a Mumbai study. *AIDS & Behavior*, 14(S1):S104-S112.
- Fotheringham, S., Brunsdon, C., and Charlton, M. (2002). *Geographically Weighted Regression: The Analysis of Spatially Varying Relationships*. Chichester, England: John Wiley & Sons Ltd. Software for performing GWR analyses is available at: gwr.maynoothuniversity.ie/gwr4-software/.
- Hägerstrand, T. (1970). What about people in regional science? *Papers in Regional Science*, 24(1):6-21.
- Jutte, D.P., Roos, L.L., and Brownell, M.D. (2011). Administrative records linkage as a tool for public health research. *Annual Review of Public Health*, 32:91-108. doi: 10.1146/annurev-publhealth-031210-100700.
- Magnani, R., Sabin, K., Saidel, T., and Heckathorn, D. (2005). Review of sampling hard-to-reach and hidden populations for HIV surveillance. *AIDS*, 19(Suppl. 2):S67-S72.
- Olsen, S.J., et al. (2003). Transmission of the severe acute respiratory syndrome on aircraft. *New England Journal of Medicine*, 349(25):2416-2422.
- Pierce, J.R., and Denison, A.V. (2006). Place-of-residence errors on death certificates for two contiguous U.S. counties. *Population Health Metrics*, 4(6). doi: 10.1186/1478-7954-4-6.
- Radil, S.M., Flint, C., and Tita, G.E. (2010). Spatializing social networks: Using social network analysis to investigate geographies of gang rivalry, territoriality, and violence in Los Angeles. *Annals of the Association of American Geographers*, 100(2):307-326. doi: 0.1080/00045600903550428.

- Stevens, G.A., et al. (2016). Guidelines for accurate and transparent health estimates reporting: The GATHER statement. *PLOS Medicine*, 13(8):e1002116. doi: 10.1371/journal.pmed.1002056.
- Troped, P.J., et al. (2014). Relationships between the built environment and walking and weight status among older women in three U.S. states. *Journal of Aging and Physical Activity*, 22(1):114-125. doi: 10.1123/japa.2012-0137.
- Wang, J.-F., Stein, A., Gao, B.-B., and Ge, Y. (2012). A review of spatial sampling, *Spatial Statistics*, 2:1-14. doi: 10.1016/j.spasta.2012.08.001.

Websites

- In December, 2017, *The Guardian* published a very interesting piece titled “Bussed Out” on programs to bus homeless people from one city to another, complete with animated maps (www.theguardian.com/us-news/ng-interactive/2017/dec/20/bussed-out-america-moves-homeless-people-country-study).
- Spatial health web site at the University of North Carolina
<http://spatialhealth.web.unc.edu/projects/presentprojects/incorporating-geographic-context-into-randomized-controlled-trials-case-studies-on-the-rtss-malaria-and-the-oral-cholera-vaccines/>
- Malaria Atlas Commons: See: <https://map.ox.ac.uk/> [March 2018].

SESSION 3: Techniques Used in Survey Research to Identify and Find Small Populations for Health Research

Marc Elliott, Rand, *Probability Sampling Methods for Small Populations*.

- Marshall, G.N., Schell, T.L., Elliot, M.N., and Chun, C.A. (2005). Mental health of Cambodian refugees 2 decades after resettlement in the United States. *The Journal of the American Medical Association*, 294(5):571-579.

Sunghye Lee, University of Michigan, *Two Applications of Respondent Driven Sampling: Ethnic Minorities and Illicit Substance Users*.

- Heckathorn, D.D. (1997). Respondent-driven sampling: A new approach to the study of hidden populations. *Social Problems*, 44(2):174-199.
- Heckathorn, D.D., Semaan, S., Broadhead, R.S., and Hughes, J.J. (2002). Extensions of respondent-driven sampling: A new approach to the study of injection drug users aged 18-25. *AIDS and Behavior*, 6(1):55-67.
- Lee, S., Suzer-Gurtekin, Z.T., Wagner, J., and Valliant, R. (2017). Total survey error and respondent driven sampling: Focus on nonresponse and measurement errors in the recruitment process and the network size reports and implications for inferences. *Journal of Official Statistics*, 33(2):335-366. doi: <https://doi.org/10.1515/jos-2017-0017>
- Korean Life Study. See: <http://sites.lsa.umich.edu/korean-healthlife-study/> [March 2018].

Patrick Sullivan, Emory University, *Venue-Based and On-line Sampling*.

- Beyer, C., et al. (2012). Global epidemiology of HIV infection in men who have sex with men. *Lancet*, 380(9839):367-377.
- Delaney, K.P., Kramer, M.R., Waller, L.A., Flanders, W.D., and Sullivan, P.S. (2014). Using a geolocation social networking application to calculate the population density of sex-seeking gay men for research and prevention services, *Journal of Medical Internet Research*, 16(11):e249.
- Hernandez-Romieu, A.C., Sullivan, P.S., Sanchez, T.H., Kelley, C.F., Peterson, J.L., Del Rio, C., Salazar, L.F., Frew, P.M., and Rosenberg, E.S. (2014). The comparability of men who have sex with men recruited from venue-time-sampling and Facebook: A cohort study. *Journal of Medical Internet Research*, 3(3):e37. doi: 10.2196/resprot.3342.
- MacKellar, D.A., Gallagher, K.M., Finlayson, T., Sanchez, T., Lansky, A., and Sullivan, P. (2007). Surveillance of HIV risk and prevention behaviors of men who have sex with men—A national application of venue-based, time-space sampling. *Public Health Reports*, 122(Suppl1):39-47.
- Sullivan, P.S., Khosropour, C.M., Luisi, N., Amsden, M., Coggia, T., Wingood, G.M., and DiClemente, R.J. (2011). Bias in online recruitment and retention of racial and ethnic minority men who have sex with men. *Journal of Medical Internet Research*, 13(2):e38. doi: 10.2196/jmir.1797.
- Wejnert, C., Hess, K.L., Rose, C.E., Balaji, A., Smith, J.C., and Paz-Bailey, G. (2015). Age-specific race and ethnicity disparities in HIV infection and awareness among men who have sex with men—20 U.S. cities, 2008-2014. *The Journal of Infectious Diseases*, 213(5):776-783 doi: 10.1093/infdis/jiv500.
- Zlotorzynska, M., Sullivan, P., and Sanchez, T. (2017). The annual American men's Internet survey of behaviors of men who have sex with men in the United States: 2015 key indicators report. *JMIR Public Health and Surveillance*, 3(1):e13.

Krista Gile, University of Massachusetts, Amherst, Invited Discussant

SESSION 4: New and Emerging Designs for Intervention Studies

Amy M. Kilbourne, University of Michigan, *Designs for Dissemination and Implementation Research for Small Populations.*

- Bauer, M.S., Miller, C., Kim, B., Lew, R., Weaver, K., Coldwell, C., Henderson, K., Holmes, S., Seibert, M.N., Stolzmann, K., Elwy, A.R., and Kirchner, J. (2016). Partnering with health system operations leadership to develop a controlled implementation trial. *Implement Science*, 11, 22. doi: 10.1186/s13012-016-0385-7.
- Brown, C.H., Curran, G., Palinkas, L.A., Aarons, G.A., Wells, K.B., Jones, L., Collins, L.M., Duan, N., Mittman, B.S., Wallace, A., Tabak, R.G., Ducharme, L., Chambers, D.A., Neta, G., Wiley, T., Landsverk, J., Cheung, K., and Cruden, G. (2017). An overview of research and evaluation designs for dissemination and implementation. *Annual Review of Public Health*, 20(38):1-22. doi: 10.1146/annurev-publhealth-031816-044215.
- Curran, G.M., Bauer, M., Mittman, B., Pyne, J.M., Stetler, C. (2012). Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and

- implementation research to enhance public health impact. *Medical Care*, 50(3):217-226. doi: 10.1097/MLR.0b013e3182408812.
- Grayling, M.J., Wason, J.M., and Mander, A.P. (2017). Group sequential designs for stepped-wedge cluster randomised trials. *Clinical Trials*, 14(5):507-517. doi: 10.1177/1740774517716937. PMID: 28653550.
- Grayling, M.J., Wason, J.M., and Mander, A.P. (2017). Stepped wedge cluster randomized controlled trial designs: A review of reporting quality and design features. *Trials*, 18(1), 33. doi: 10.1186/s13063-017-1783-0.
- Kegeles, S.M., Rebchook, G.M., Hays, R.B., Terry, M.A., O'Donnell, L., Leonard, N.R., Kelly, J.A., Neumann, M. (2000). From science to application: The development of an intervention package. *AIDS Education and Prevention*, 12(Suppl 5):62-74
- Kelly, J.A., Somlai, A.M., DiFranceisco, W.J., Otto-Salaj, L.L., McAuliffe, T.L., Hackl, K.L., Heckman, T.G., Holtgrave, D.R., and Rompa, D. (2000). Bridging the gap between the science and service of HIV prevention: Transferring effective research-based HIV prevention interventions to community AIDS service providers. *American Journal of Public Health*, 90:1082-1088.
- Kilbourne, A.M., Neumann, M.S., Pincus, H.A., Bauer, M.S., and Stall, R. (2007). Implementing evidence-based interventions in health care: Application of the replicating effective programs framework. *Implementation Science*, 2(42). doi: 10.1186/1748-5908-2-42.
- Kilbourne, A.M., Nord, K.M, Kyle, J., Van Poppelen, C., Goodrich, D.E., Kim, H.M., Eisenberg, D., Un, H., and Bauer, M.S. (2014a). Randomized controlled trial of a health plan-level mood disorders psychosocial intervention for solo or small practices. *BMC Psychology*, 2(1):48. doi: 10.1186/s40359-014-0048-x.
- Kilbourne, A.M., Almirall, D., Goodrich, D.E., Lai, Z., Abraham, K.M., Nord, K.M., and Bowersox, N.W. (2014b). Enhancing outreach for persons with serious mental illness: 12-month results from a cluster randomized trial of an adaptive implementation strategy. *Implement Science*, 9:163. doi: 10.1186/s13012-014-0163-3.
- Kilbourne, A.M., Almirall, D., Eisenberg, D., Waxmonsky, J., Goodrich, D.E., Fortney, J.C., Kirchner, J.E., Solberg, L.I., Main, D., Bauer, M.S., Kyle, J., Murphy, S.A., Nord, K.M., and Thomas, M.R. (2014c). Protocol: Adaptive implementation of effective programs trial (ADEPT): Cluster randomized SMART trial comparing a standard versus enhanced implementation strategy to improve outcomes of a mood disorders program. *Implement Science*, 9:132. doi: 10.1186/s13012-014-0132-x.
- Kolko, D.J., Campo, J., Kilbourne, A.M., Hart, J., Sakolsky, D., and Wisniewski, S. (2014). Collaborative care outcomes for pediatric behavioral health problems: A cluster randomized trial. *Pediatrics*, 133(4):981-992. doi: 10.1542/peds.2013-2516. PMID: 24664093.
- NeCamp, T., Kilbourne, A., and Almirall, D. (2017). Comparing cluster-level dynamic treatment regimens using sequential, multiple assignment, randomized trials: Regression estimation and sample size considerations. *Statistical Methods in Medical Research*, 26(4):1572-1589. doi: 10.1177/0962280217708654.
- Wyman, P.A., Henry, D., Knoblauch, S., and Brown, C.H. (2015). Designs for testing group-based interventions with limited numbers of social units: The dynamic wait-listed and

regression point displacement designs. *Prevention Science*, 16(7):956-966. doi: 10.1007/s11121-014-0535-6.

Websites

NIH PAR 16-238: Dissemination and Implementation Research in Health (R01). See for example: <https://grants.nih.gov/grants/guide/pa-files/par-16-238.html>.
Penn State Methodology Center SMART design examples: <https://methodology.psu.edu/ra/adap-inter/projects>.

Christine Lu, Harvard Medical School, *Quasi-experimental Designs with Application to Small Populations*.

- Lu, C.Y., Soumerai, S.B., Ross-Degnan, D., Zhang, F., and Adams, A.S. (2010). Unintended impacts of a Medicaid prior authorization policy on access to medications for bipolar illness. *Medical Care*, 48(1):4-9.
- Lu, C.Y., Adams, A.S., Ross-Degnan, D., Zhang, F., Zhang, Y., Salzman, C., and Soumerai, S.B. (2011). Association between prior authorization for medications and health service use by Medicaid patients with bipolar disorder. *Psychiatric Services*, 62(2):186-193.
- Lu, C.Y., Zhang, F., Lakoma, M.D., Madden, J.M., Rusinak, D., Penfold, R.B., Simon, G., Ahmedani, B.K., Clarke, G., Hunkeler, E.M., Waitzfelder, B., Owen-Smith, A., Raebel, M.A., Rossom, R., Coleman, K.J., Copeland, L.A., and Soumerai, S.B. (2014). Changes in antidepressant use by young people and suicidal behavior after FDA warnings and media coverage: Quasi-experimental study. *British Medical Journal*, 18(348):g3596. doi: 10.1136/bmj.g3596.
- Zhang, Y., Adams, A.S., Ross-Degnan, D., Zhang, F., and Soumerai, S.B. (2009). Effects of prior authorization on medication discontinuation among Medicaid beneficiaries with bipolar disorder. *Psychiatric Services*, 60(4):520-527.

Diane Korngiebel, University of Washington, *Addressing the Challenges of Research with Small Populations*.

- Fisher, P.A., and Ball, T.J. (2003). Tribal participatory research: Mechanisms of a collaborative model. *American Journal of Community Psychology*, 32(3-4):207-216.
- Israel, B.A., Schulz, A.J., Parker, E.A., and Becker, A.B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19:173-202.
- Israilov, S., and Cho, H.J. (2017). How co-creation helped address hierarchy, overwhelmed patients, and conflicts of interest in health care quality and safety. *American Journal of Ethics*, 19(11):1139-1145.
- Korngiebel, D.M., Taulii, M., Forquera, R., Harris, R., and Buchwald, D. (2015). Addressing the challenges of research with small populations. *American Journal of Public Health*, 105(9):1744-1747.

- Srinivasan, S., Moser, R.P., Willis, G., et al. (2015). Small is essential: Importance of subpopulation research in cancer control. *American Journal of Public Health*, 105(Suppl 3):S371-373.
- Tauaii, M., Quenga, J., and Samoa, R. (2014). Understanding diversity among indigenous people: Conducting research with Native Hawaiians and Pacific Islanders. In T. Solomon (Ed.), *Conducting Health Research in Native American Communities*. Washington, DC: American Public Health Press.
- Turakhia, P., and Combs, B. (2017). Using principles of co-production to improve patient care and enhance value. *American Journal of Ethics*, 19(11):1125-1131.
- Van Dyke, E.R., Blacksher, E., Echo-Hawk, A.L., Bassett, D., Harris, R.M., and Buchwald, D.S. (2016). Health disparities research among small tribal populations: Describing appropriate criteria for aggregating tribal health data. *American Journal of Epidemiology*, 184(1):1-6.
- Walker, R.D., and Bigelow, D.A. (2011). A constructive Indian country response to the evidence-based program mandate. *Journal of Psychoactive Drugs*, 43(4):276-281.
- Woolf, S.H., Johnson, R.E., Phillips, R.L., Jr., and Philipsen, M. (2007). Giving everyone the health of the educated: An examination of whether social change would save more lives than medical advances. *American Journal of Public Health*, 97(4):679-683.

Websites

- Common rule, the Belmont Report, and 45 CFR Part 46. See:
<https://www.hhs.gov/ohrp/regulations-and-policy/regulations/common-rule/index.html> [March 2018].
- Co-production and Co-creation. See the *AMA Journal of Ethics*, November 2017, Vol. 19, No. 11.
 See: <http://journalofethics.ama-assn.org/2017/11/toc-1711.html>.
- IDEO Methods. <http://www.designkit.org/methods>.
- Nielsen Norman Group. User experience. <https://www.nngroup.com/>.

Patrick H. Tolan, University of Virginia, Invited Discussant.

James Allen, University of Minnesota.

- Trickett, E.J., Trimble, J.E., and Allen, J. (2014). Most of the Story is missing: Advocating for a more complete intervention story. *American Journal of Community Psychology*, 54(1-2):180-186.

SESSION 5: Recruitment, Retention, and Collection of Data with a Focus on Small or Hard to Reach Populations

Vetta Sanders Thompson, Washington University in St. Louis, *Issues and Challenges Associated with Recruitment and Retention for Health Research*.

F. Douglas Scutchfield, University of Kentucky, *Improving Health Research in Rural Areas*.

Appalachian Regional Commission, Distressed Counties, 2018.

https://www.arc.gov/program_areas/mapofarcdesignateddistressedcountiesfiscalyear2018.asp.

Models of Collaboration Involving Hospitals, Public Health Departments, and Others: Improving community Health through Successful partnerships. See:

<http://www.uky.edu/publichealth/studyOverview.php> [March 2018].

Kathi Mooney, University of Utah, *Using Technology for Recruitment, Retention. Data Collection, and Intervention Delivery.*

Alkhaldi, G., Hamilton, F.L., Lau, R., Webster, R., Michie, S., and Murray, E. (2016). The effectiveness of prompts to promote engagement with digital interventions: A systematic review. *Journal of Medical Internet Research*, 18(1):e6.

Cantrell, M.A., and Lupinacci, P. (2007). Methodological issues in online data collection. *Journal of Advanced Nursing*, 60(5):544-549.

Gibbons, C.J. (2016). Turning the page on pen-and paper questionnaires: Combining ecological momentary assessment and computer adaptive testing to transform psychological assessment in the 21st century. *Frontiers in Psychology*, 7:1933.

Gupta, A., Calfas, K.J., Marshall, S.J., Robinson, T.N., Rock, C.L., and Huang, J.S. (2015). Clinical trial management of participant recruitment, enrollment, engagement, and retention in the SMART study using a Marketing and information Technology (MARKIT) model. *Contemporary Clinical Trials*, 43:185-195.

Hall, E.W., Sanchez, T.H., Stein, A.D., Stephenson, R., Ziotorzynska, M., Sineath, R.C., and Sullivan, P.S. (2017). Use of videos improves informed consent comprehension in web-based surveys among internet-using men who have sex with men: A randomized controlled trial. *Journal of Medical Internet Research*, 19(3).

Kaye, J., Curren, L., Anderson, N., Edwards, K., Fullerton, K., and Kanellopoulou, N. (2013). From patients to partners: Participant-centric initiatives in biomedical research. *Nature Reviews Genetics*, 13(5):371-376.

Kaye, J., Whitley, E.A., Lund, D., Morrison, M., Teare, H., and Melham, K. (2015). Dynamic consent: A patient interface for twenty-first century research networks. *European Journal of Human Genetics*, 23:141-146.

Lane, T.S., Armin, J., and Gordon, J.S. (2015). Online recruitment methods for web-based and mobile health studies: A review of the literature. *Journal of Medical Internet Research*, 17(7).

Marcano Belisario, J.S., Jamsek, J., Huckvale, K., O'Donoghue, J., Morrison, C.P., and Car, J. (2015). Comparison of self-administered survey questionnaire responses collected using mobile apps versus other methods. *Cochrane Database of Systematic Reviews*, 7, Art. No.:MR000042.

Mehl, M.R. (2017). The electronically activated recorder (EAR): A method for the naturalistic observation of daily social behavior. *Current Directions in Psychological Science*, 26(2):184-190.

- Rupert, D.J., Poehlman, J.A., Hayes, J.J., Ray, S.E., and Moultrie, R.R. (2017). Virtual versus in-person focus groups: Comparison of costs, recruitment, and participant logistics. *Journal of Medical Internet Research*, 19(3).
- Sonne, S.C., Andrews, J.O., Gentilin, S.M., Oppenheimer, S., Obeid, J., and Brady, K. (2013). Development and pilot testing of a video-assisted informed consent process. *Contemporary Clinical Trials*, 36(1):25-31.
- Voruganti, T., Grunfeld, E., Makuwaza, T., and Bender, J. (2017). Web-based tools for text-based patient-provider communication in chronic conditions: Scoping review. *Journal of Medical Internet Research*, 19(10).
- Whitaker, C., Stevelink, S., and Fear, N. (2017). The use of Facebook in recruiting participants for health research purposes: A systematic review. *Journal of Medical Internet Research*, 19(8).
- Yardley, L., Spring, B.J., Riper, H., Morrison, L.G., Crane, D.H., Curtis, K., et al. (2016). Understanding and promoting effective engagement with digital behavior change interventions. *American Journal of Preventative Medicine*, 51(5):833-842.

Tracy L. Onega, Dartmouth University, Invited Discussant.

SESSION 6: Analysis Techniques for Small Population Research

Rick H. Hoyle, Duke University, *Design and Analysis Considerations in Research with Small Samples*.

- Barnard-Brak, L., Richman, D.M., Little, T.D., and Yang, Z. (2018). Development of an in-vivo metric to aid visual inspection of single-case design data: Do we need to run more sessions? *Behaviour Research and Therapy*, 102:8-15. doi: [10.1016/j.brat.2017.12.003](https://doi.org/10.1016/j.brat.2017.12.003).
- Cochran, W.G. (1977). *Sampling Techniques* (3rd ed.). New York: Wiley.
- Enders, C.K. (2006). A primer on the use of modern missing-data methods in psychosomatic medicine research. *Psychosomatic Medicine*, 68:427-436. doi: 10.1097/01.psy.0000221275.75056.d8.
- Ferrer, E., and Nesselrode, J.R. (2003). Modeling affective processes in dyadic relations via dynamic factor analysis. *Emotion*, 3:344-360. doi: 10.1037/1528-3542.3.4.344.
- Graham, J.W., and Hofer, S.M. (2000). *Multiple Imputation in Multivariate Research*. In T.D. Little, K.U. Schnabel, and J. Baumert (Eds.), *Modeling longitudinal and multilevel data: Practical issues, applied approaches, and specific examples* (pp. 201-218). Mahwah, NJ: Erlbaum.
- Herzog, W., and Boomsma, A. (2009). Small-sample robust estimators of noncentrality-based and incremental model fit. *Structural Equation Modeling*, 14: 361-390. doi: 10.1080/10705510802561279.
- Hopkin, C.R., Hoyle, R.H., and Gottfredson, N.C. (2015). Maximizing the yield of small samples in prevention research: A review of general strategies and best practices. *Prevention Science*, 16:950-955. doi: 10.1007/s11121-014-0542-7.
- Hoyle, R.H. (Ed.). (1999). *Statistical Strategies for Small Sample Research*. Thousand Oaks, CA: Sage Publications.

- Hoyle, R.H., and Gottfredson, N.C. (2015). Sample size considerations in prevention research: Applications of multilevel modeling and structural equation modeling. *Prevention Science*, 16:987-996. doi: 10.1007/s11121-014-0489-8.
- Krishnamoorthy, K., and Thomson, J. (2002). Hypothesis testing about proportions in two finite populations. *American Statistician*, 56:215-222. doi: 10.1198/000313002164.
- Lai, M.H., Kwok, O.M., Hsiao, Y.Y., and Cao, Q. (2017). Finite population correction for two-level hierarchical linear models. *Psychological Methods*, 23:94-112. doi: 10.1037/met0000137.
- Lee, I.A., and Little, T.D. (2012). *P-technique Factor Analysis*. In B. Laursen, T.D. Little, and N. A. Card (Eds.), *Handbook of Developmental Research Methods* (pp. 350-363). New York: Guilford Press.
- Maas, C.J.M., and Hox, J.J. (2005). Sufficient sample sizes for multilevel modeling. *Methodology*, 1:86-92. doi: 10.1027/1614-1881.1.3.86.
- Mashreghi, C., Haziza, D., and Láger, C. (2016). A survey of bootstrap methods in finite population sampling. *Statistics Surveys*, 10:1-52. doi: 10.1214/16-SS113.
- McNeish, D. (2017). Challenging conventional wisdom for multivariate statistical models with small samples. *Review of Educational Research*, 87:1117-1151. doi: 10.3102/0034654317727727.
- McNeish, D. (2017). Small sample methods for multilevel modeling: A colloquial elucidation of REML and the Kenward-Roger correction. *Multivariate Behavioral Research*, 52:661-670. doi: 10.1080/00273171.2017.1344538.
- Moeyaert, M., Rindskopf, D., Onghena, P., and den Noortgate, W.V. (2017). Multilevel modeling of single-case data: A comparison of maximum likelihood and Bayesian estimation. *Psychological Methods*, 22:760-778. doi: 10.1037/met0000136.
- Nelson, T.D., Aylward, B.S., and Rausch, J.R. (2011). Dynamic *p*-technique for modeling patterns of data: Applications to pediatric psychology research. *Journal of Pediatric Psychology*, 36:959-968. doi: 10.1093/jpepsy/jsr023.

Thomas A. Louis, Johns Hopkins Bloomberg School of Public Health, *Bayesian Methods for Small Population Analysis*.

- Bell, W., Basel, W., and Maples, J. (2016). *Analysis of Poverty Data by Small Area Estimation*. In *An Overview of the U. S. Census Bureau's Small Area Income and Poverty Estimates Program*. John Wiley & Sons.
- Bell, W., and Franco, C. (2016). Combining estimates from related surveys via bivariate models. Presentation at 2016 Ross-Royal Symposium, Feb 26, 2016. Presentation slides at https://www.jhsph.edu/departments/biostatistics/_docs/2016-ross-royall-docs/william-bell-slides.pdf [March 2018].
- Carlin, B.P., and Louis, T.A. (2009). *Bayesian Methods for Data Analysis, 3rd edition*. Boca Raton, FL: Chapman and Hall/CRC Press, 3rd edition.
- Chatterjee, N., Chen, Y.H., Maas, P., and Carroll, R.J. (2016). Constrained maximum likelihood estimation for model calibration using summary-level information from external big data sources (with discussion). *Journal of the American Statistical Association*, 111(513):107-131.

- Chen, S., Jiang, J., and Nguyen, T. (2015). Observed best prediction for small area counts. *Journal of Survey Statistics and Methodology*, 3:136-161.
- Gelman, A. (2007). Struggles with survey weighting and regression modeling. *Statistical Science*, 22(2):153-164.
- Gelman, A., Carlin, J., Stern, H.S., Dunson, D.B., Vehtari, A., and Rubin, D. (2013). *Bayesian Data Analysis*, 3rd edition. Boca Raton, FL: Chapman and Hall/CRC Press.
- Henderson, N., Louis, T., Wang, C., and Varadhan, R. (2016). Bayesian analysis of heterogeneous treatment effects for patient-centered outcomes research. *Health Services and Outcomes Research Methodology*, 16:213-233.
- Hui, S.L., and Berger, J.O. (1983). Empirical Bayes estimation of rates in longitudinal studies. *Journal of the American Statistical Association*, 78:753-759.
- Ibrahim, J., Chen, M., Lakshminarayanan, M., Liu, G., and Heyse, J. (2015). Bayesian probability of success for clinical trials using historical data. *Statistics in Medicine*, 34:249-264.
- Jiang, J., Nguyen, T., and Rao, J.S. (2011). Best predictive small area estimation. *Journal of the American Statistical Association*, 106:732-745.
- Kadane, J. (2015). Bayesian methods for prevention research. *Prevention Science*, 16:1017-1025.
- Keiding, N., and Louis, T.A. (2016). Perils and potentials of self-selected entry to epidemiological studies and surveys (with discussion and response). *Journal of the Royal Statistical Society, Series A*, 179:319-376.
- Keiding, N., and Louis, T. (2018). Web-based enrollment and other types of self-selection in surveys and studies: Consequences for generalizability. *Annual Review of Statistics and Its Application*, 5.
- Lin, R., Louis, T., Paddock, S., and Ridgeway, G. (2009). Ranking of USRDS, provider-specific SMRs from 1998-2001. *Health Services and Outcomes Research Methodology*, 9:22-38.
- Lohr, S., and Raghunathan, T. (2017). Combining survey data with other data sources. *Statistical Science*, 32:293-312.
- Louis, T. (1989). *Meta-modeling*. In *Challenges for the 90s*, ASA Sesquicentennial visioning. National Academies of Sciences, Engineering, and medicine. (2017). *Federal Statistics, Multiple Data Sources and Privacy Protection: Next Steps*. National Academies Press, Washington, DC.
- National Research Council. (2000). *Small-Area Estimates of School-Age Children in Poverty: Evaluation of Current Methodology*. Panel on Estimates of Poverty for Small Geographic Areas, Constance F. Citro and Graham Kalton, editors. Committee on National Statistics. Washington DC: National Academy Press.
- Normand, S.L., Ash, A.S., Fienberg, S.E., Stukel, T., Utts, J., and Louis, T.A. (2016). League tables for hospital comparisons. *Annual Review of Statistics and Its Application*, 3:21-50.
- Pearl, J., and Bareinboim, E. (2014). External validity: From do-calculus to transportability across populations. *Statistical Science*, 29:579-595.
- Slud, E., and Ashmead, R. (2017). *VRA Section 203 Determinatinos: Statistical Methodology Summary*. Technical report, U.S. Census Bureau.
- Tarone, R. (1982). The use of historical control information in testing for a trend in proportions. *Biometrics*, 38:215-220.

Katherine R. McLaughlin, Oregon State University, *Estimating the Size of Hidden Populations*.

- Fearon, E., Chabata, S.T., Thompson, J.A., Cowan, F.M., and Hargreaves, J.R. (2017). Sample size calculations for population size estimation studies using multiplier methods with respondent-driven sampling surveys. *JMIR Public Health and Surveillance*, 3(3):e59.
- Feehan, D.M., and Salganik, M.J. (2016). Generalizing the network scale-up method: A new estimator for the size of hidden populations. *Sociological Methodology*, 46:153-186.
- Handcock, M.S., Gile, K.J., and Mar, C.M. (2014). Estimating hidden population size using respondent-driven sampling data. *Electronic Journal of Statistics*, 8(1):1491-1521.
- Handcock, M.S., Gile, K.J., and Mar, C.M. (2015). Estimating the size of populations at high risk for HIV using respondent-driven sampling data. *Biometrics*, 71(1):258-266.
- Johnston, L.G. (2013). *Introduction to Respondent-Driven Sampling*. World Health Organization, Geneva, Switzerland. Available at:
http://applications.emro.who.int/dsaf/EMRPUB_2013_EN_1539.pdf.
- Johnston, L.G., Prybylski, D., Raymond, H.F., Mirzazadeh, A., and McFarland, W. (2013). Incorporating the service multiplier method in respondent-driven sampling surveys to estimate the size of hidden and hard-to-reach populations: case studies from around the world. *Sexually Transmitted Diseases*, 40(4):304-310.
- Johnston, L.G., McLaughlin, K.R., El Rhilani, H., Lati, A., Tou, K.A., Bennani, A., Alami, K., Elomari, B., and Handcock, M.S. (2015). Estimating the size of hidden populations using respondent-driven sampling data: Case examples from Morocco. *Epidemiology*, 26:846-852.
- Maltiel, R.A., Raftery, A.E., McCormick, T.H., and Bara, A.J. (2015). Estimating population size using the network scale up methods. *The Annals of Applied Statistics*, 9(3):1247-1277.
- UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance. (2010). *Guidelines on Estimating the Size of Populations Most At Risk to HIV*. World Health Organization, Geneva, Switzerland. Available at:
http://apps.who.int/iris/bitstream/10665/44347/1/9789241599580_eng.pdf.