#EquityFlattensTheCurve

AMERICAN
PSYCHOLOGICAL
ASSOCIATION

Building Community Trust to Improve Participation in COVID-19 Testing and Contact Tracing

Building community trust is crucial to improving people's participation in testing and contact tracing efforts during COVID-19. To build a community of trust, public health officials and researchers must develop culturally competent mechanisms and transparent practices to encourage participation among communities made vulnerable by COVID-19.

HOW TO BUILD TRUST ACROSS COMMUNITIES

Several trust-building strategies can promote participation in preventive measures in communities that are highly vulnerable to COVID-19.[1] [2] The following should be considered when implementing preventive measures during a pandemic:

- **Recognize** that many members of the public who are reluctant to participate in testing and contact tracing are active consumers of pandemic-related information but may mistrust such efforts due to current and historical inequitable health care and research practices.
- **Train a culturally competent workforce** to interact with diverse communities. Understand and address the history of mistrust among marginalized communities and populations as a vital step toward building trust.
- **Provide transparency and accountability** in all processes to encourage and promote participation.
- **Build objectivity and fairness into *all* health-related systems** to center the focus on well-being across all segments of society. Engage community members, including those with lived experience, in the development of public health initiatives.

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[1] Renn, O., & Levine, D. (1991). Credibility and trust in risk communication. In Communicating risks to the public (pp. 175-217). Springer, Dordrecht.

[2] Covello, V. T., & Peters, R. G. (1996). The determinants of trust and credibility in environmental risk communication: an empirical study. In *Scientific uncertainty and its influence on the public communication process* (pp. 33-63). Springer, Dordrecht.

- **Collaborate** with community leaders and stakeholders to advise on culturally competent mechanisms for inviting and encouraging participation, as well as to help shape and deliver the message. Partner with community leaders and stakeholders to monitor the efficacy of contact tracing and other initiatives and work closely to identify areas where more culturally competent practices are needed.
- **Create partnerships between health information sources, faith-based institutions and local community organizations** when launching health promotion messages and initiatives. Use community leaders to help identify appropriate networks of churches, mosques, synagogues, and other faith and spiritual organizations, as well as grass roots organizations.[3] [4] [5]
- **Where needed, use an individual lens as opposed to a population lens** when interacting with community members. An individual lens considers the impact of safety measures, resources, and safety net deficits that may impede preventive measures (e.g., quarantine, social distancing).

WHY ARE TRUST-BUILDING EFFORTS NEEDED?

Populations who have difficulty accessing medical information and resources may find their participation in preventive measures pointless or may fear repercussions of doing so.

- A 2017 study found that 32% of African Americans, 25% of Latinas, 14% Latinos, and 16% of LGBTQ persons reported experiencing discrimination when seeking care from a doctor or health clinic. The same survey revealed that a significant percentage of respondents avoided seeking medical care altogether out of concern that they would suffer discrimination, including 22% of African Americans, 15% of indigenous individuals, and 18% of LGBTQ persons.[6]
- Immigrants and refugees may find it difficult to participate in research and public health measures due to their need to manage competing concerns (e.g., immigration enforcement policies, immigration status, and socioeconomic background) and their lack of access to appropriate measures.[7]
- The substandard medical care of incarcerated populations sows seeds of mistrust for those in correctional facilities and their families. This mistrust has a pervasive and long-lasting impact.
- Research protocols may also create barriers for some populations. For example, individuals experiencing homelessness report higher rates of physical and mental illnesses, which lead to high rates of mortality and hospitalization. Although their participation in epidemiological research is essential to address their quality of health, many researchers exclude this population from studies due to concerns related to attendance and maintaining contact.[8] However, these individuals may have competing priorities to secure food, clothing, and shelter that prevent their participation.

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[3] Musa, D., Schulz, R., Harris, R., Silverman, M., & Thomas, S. B. (2009). Trust in the health care system and the use of preventive health services by older black and white adults. *American journal of public health, 99*(7), 1293-1299.

[4] Zlotnick, C., Zerger, S., & Wolfe, P. B. (2013). Health care for the homeless: What we have learned in the past 30 years and what's next. *American journal of public health*, *103*(S2), S199-S205.

[5] McLaughlin, R. H., & Alfaro-Velcamp, T. (2015). The vulnerability of immigrants in research: Enhancing protocol development and ethics review. *Journal of Academic Ethics*, *13*(1), 27-43.

[6] NPR, Robert Wood Johnson Foundation and Harvard T.H. Chan School of Public Health (January 2018). Discrimination in America: Final Summary. https://www.hsph.harvard.edu/horp/discrimination-in-america/

[7] De La Rosa, M., Babino, R., Rosario, A., Martinez, N. V., & Aijaz, L. (2012). Challenges and strategies in recruiting, interviewing, and retaining recent Latino immigrants in substance abuse and HIV epidemiologic studies. The American Journal on Addictions, 21(1), 11-22.

[8] Ojo-Fati, O., Joseph, A. M., Ig-Izevbekhai, J., Thomas, J. L., Everson-Rose, S. A., Pratt, R., ... & Okuyemi, K. S. (2017). Practical issues regarding implementing a randomized clinical trial in a homeless population: strategies and lessons learned. Trials, 18(1), 1-10.

ADDITIONAL MESSAGING TO SHARE WHEN DISCUSSING COMMUNITY MISTRUST WITH PUBLIC HEALTH OFFICIALS AND RESEARCHERS

The information in this section can be used to guide discussions about barriers to preventive measures with public health officials, researchers, and community members. Public health officials have too often characterized persistent wariness of public health initiatives, particularly among marginalized communities, as driven solely by limited or unsophisticated scientific understanding.[9] Current reports citing hesitation in some communities to participate in contact tracing during the COVID-19 pandemic voice similar sentiments. This line of thinking ignores the fact that many members of the public are indeed active consumers of pandemic-related information.[10] [11]

Framing the Problem of Community Mistrust

- Although contact tracing has been a successful strategy in past outbreaks of disease such as SARS, measles, and tuberculosis, it is important to recognize that many communities are likely to opt out of participating in COVID-19-related contact tracing initiatives due to mistrust of public health systems and other government-related organizations. [12] [13] [14] [15]
- It is critical to understand the historical antecedents of community mistrust of contact tracing and other public health initiatives particularly in populations subjected to long- entrenched bias, discrimination, and/or systemic racism. Public health systems must not simply look backwards, but should reflect upon and address current inequitable health care and research practices that foster mistrust and may impede participation by individuals and communities at large. For instance, in recent months information about Native American and Alaska Native exposures and related deaths have not been included as part of the federal COVID-19 census reports, and allocated federal monies to fund health care and other much needed support for these communities were delayed. At the same time, indigenous populations have been ravaged by the impact of COVID-19 due to inaccessible health care treatment, impoverished living conditions, and pre-existing health comorbidities. Similarly, individuals with a range of physical, intellectual, and mental health disabilities are often excluded from epidemiological or public health research for reasons that are both implicit (e.g., exclusion criteria) and explicit (e.g., inaccessible interventions), despite being at significantly elevated risk and having higher rates of poor health outcomes and mortality.[16]

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[9] Bangerter, A. (2014). Investigating and rebuilding public trust in preparation for the next pandemic.

[10] Bangerter, A., Krings, F., Mouton, A., Gilles, I., Green, E. G., & Clémence, A. (2012). Longitudinal investigation of public trust in institutions relative to the 2009 H1N1 pandemic in Switzerland. *PLoS One*, *7*(11), e49806.

[11] Larson, H. J., & Heymann, D. L. (2010). Public health response to influenza A (H1N1) as an opportunity to build public trust. *Jama*, *303*(3), 271-272.

[12] Cairns, G., de Andrade, M., & MacDonald, L. (2013). Reputation, relationships, risk communication, and the role of trust in the prevention and control of communicable disease: a review. Journal of health communication, 18(12), 1550-1565.

[13] Abraham, T. (2009). Risk and outbreak communication: Lessons from alternative paradigms. *Bulletin of the World Health Organization*, 87, 604 –607.

[14] Gilson, L. (2003). Trust and the development of health care as a social institution. *Social Science & Medicine*, 56, 1453 – 1468.

[15] Abraham, T. (2010). Personal view: The price of poor pandemic communication. BMJ, 340, 1307.

[16] Rios, D., Magasi, S., Novak, C., & Harniss, M. (2016). Conducting accessible research: including people with disabilities in public health, epidemiological, and outcomes studies. *American journal of public health, 106*(12), 2137-2144.

Examples of Bias and Discrimination Experienced by Communities Made Vulnerable That Can Prohibit Their Participation in Preventive Measures:

Historical Discriminatory Practices

- A highly publicized example of overt racial discrimination in health related practices was the Tuskegee Syphilis Study (1932-1972) in which African Americans were subjected to unethical medical treatment over a 40 year span. The lack of transparency and disregard for well-being contributed to a legacy of mistrust that continues to manifest as health inequities among the African American population.[17]
- The Havasupai Tribe of the Havasupai Reservation v. Arizona Board of Regents and Therese Ann Markow case in 2009 described researchers' misuse of DNA from members of the Havasupai Tribe in research studies for which the member did not provide informed consent.
- The health and human rights of women with disabilities have been and continue to be jeopardized across many health systems. Historically, state sanctioned practices involving forced sterilization have robbed women with intellectual disabilities of their reproductive choices.[18] While state mandated sterilizations no longer exist, court systems pressure many women with intellectual disabilities and poor to utilize contraception or undergo other procedures as a means of reducing sentences or otherwise seek lenient treatment.
- The U.S. Public Health Service's sexually transmitted disease experiments in Guatemala from 1946-1948 were another egregious example of unethical behavior in the name of research/science. Guatemalan prisoners, children, and women were injected with STDs without their consent and received only an apology from the United States 62 years later. [19]

Bias and Present-Day Discrimination

Populations who have difficulty accessing medical information and resources may find their participation in preventive measures pointless.

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Reinforcing Discrimination in Health Care Practices

Negative, marginalizing, and demeaning experiences with health systems can fracture trust. Research suggests that some BIPOC populations, disabled individuals, older adults, individuals with a low socioeconomic status, and LGBTQ communities anticipate negative experiences when interacting with health officials due to negative interactions in their past.

- In 2011, the Institute of Medicine (now the National Academy of Medicine) reported that some "... LGBT individuals face discrimination in the health care system that can lead to an outright denial of care or to the delivery of inadequate care. There are many examples of manifestations of enacted stigma against LGBT individuals by health care providers. LGBT individuals have reported experiencing refusal of treatment by health care staff, verbal abuse, and disrespectful behavior, as well as many other forms of failure to provide adequate care."[21]

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[17] Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: understanding mistrust about research participation. *Journal of health care for the poor and underserved*, *21*(3), 879.

[18] Tilley, E., Walmsley, J., Earle, S., & Atkinson, D. (2012). 'The silence is roaring': sterilization, reproductive rights and women with intellectual disabilities. *Disability & Society*, *27*(3), 413-426.

[19] Spector-Bagdady, K., & Lombardo, P. A. (2019). US Public Health Service STD Experiments in Guatemala (1946–1948) and Their Aftermath. *Ethics & human research*, *41*(2), 29-34.

[20] NPR, Robert Wood Johnson Foundation and Harvard T.H. Chan School of Public Health (January 2018). Discrimination in America: Final Summary. https://www.hsph.harvard.edu/horp/discrimination-in-america/

[21] Institute of Medicine (2011). *The health of lesbian, gay, bisexual, and transgender people: building a foundation for better understanding.* Washington, DC: The National Academies Press.

COVID-19-SPECIFIC RESOURCES TO DEMYSTIFY CONTACT TRACING IN LOCAL COMMUNITIES

The resources provided in this section can assist community leaders in the development of tools that prepare contact tracers to work with communities made vulnerable due to COVID-19.

- Interim COVID-19 Contact Tracing Communications Toolkit for Health Departments
- Social Stigma associated with COVID-19
- Demystifying COVID-19 digital contact tracing: A survey on frameworks and mobile apps
- How Contact Tracing Breaks the Chain of COVID-19 Transmissions
- What Contact Tracing Isn't
- Doing it Right: Contact Tracing and Health Equity (Webinar)