Contextual Integrity via Community Participation

Darakhshan Mir

Bucknell University,
Data & Society Research Institute

(Joint work with Mark Latonero, Yan Schvartzshnaider)

The Lens: Privacy Disparity

❖ 52% of Americans in the lowest-earning group (with an annual household income of less than $20,000) are "very concerned" with not knowing what personal information is being collected about them or how it is being used.

❖ compared with just over a third (37%)of those in the highest-income households (with an annual household income of over $100,000).

(Madden '17)

The Lens: Privacy Disparity

❖ "New kinds of "networked privacy" harms, in which users are simultaneously held liable for their own behavior and the actions of those in their networks, may have particularly negative impacts on the poor. "

(Madden, Gilman, Levy, Marwick '17)

Questions I am interested in...

❖ Framing privacy in terms (and relevant contexts) that resonate with the "data experiences" of vulnerable communities?

❖ Understand, study, and eliminate these privacy disparities.

  ❖ Empower communities to articulate their privacy experiences, expectations, anxieties.

❖ Use (contextualized) computational processes and tools to capture and support the above.

SURGEON GENERAL.GOV

ABOUT PRIORITIES REPORTS & PUBLICATIONS USPHS COMMISSIONED CORPS

ome > Priorities > National Prevention Strategy > Strategy > Elimination of Health Disparities

Text Size: A A A   Shar

Elimination of Health Disparities

America benefits when everyone has the opportunity to live a long, healthy, and productive life, yet health disparities persist. A health disparity is a difference in health outcomes across subgroups of the population. Health disparities are often linked to social, economic, or environmental disadvantages (e.g., less access to good jobs, unsafe neighborhoods, lack of affordable transportation options). Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health on the basis of their racial or ethnic group, religion, socioeconomic status, gender, age, mental health, cognitive, sensory, or physical disability, sexual orientation or gender identity, geographic location, or other characteristics historically linked to discrimination or exclusion. Many health concerns, such as heart disease, asthma, obesity, diabetes, HIV/ AIDS, viral hepatitis B and C, infant mortality, and violence, disproportionately affect certain populations. Reducing disparities in health will give everyone a chance to live a healthy life and improve the quality of life for all Americans.

- **Fact Sheet: Elimination of Health Disparities (PDF - 537 KB)**

Community-Based Participatory Research

NIH National Institute on Minority Health and Health Disparities

Subscribe to our Email Newsletter

| About | Programs | Funding Opportunities | News and Events | Resources |

Extramural Research

Research Interest Areas

Research Centers

Research Endowment Program (REP)

Community-Based Participatory Research Program (CBPR)

Minority Health and Health Disparities International Research Training Program (MHIRT)

Small Business Innovation

Community-Based Participatory Research Program (CBPR)

- Program Description
- Goals
- Additional Information
- Eligibility

Program Description

The NIMHD Community-Based Participatory Research Program (CBPR) supports collaborative research efforts between scientific researchers community members to address diseases and conditions disproportionately affecting health disparity populations. Recognizing the strength of each partner, scientific researchers and community members collaborate on all aspects of the project, including needs assessment, planning, research intervention design, implementation, analyses, and information dissemination. The community is involved in the CBPR program as an equal partner with the scientists. This helps ensure that interventions created are responsive to the community's needs.

Program Contact

Dr. Regina James

Regina.James@nih.gov

Community-Based Participatory Research (CBPR)

❖ "Integrates education and social action to improve health and reduce health disparities."

❖ " More than a set of research methods, CBPR is

  ❖ an orientation to research that focuses on relationships between academic and community partners, with principles of co-learning, mutual benefit, and long-term commitment and

  ❖ incorporates community theories, participation, and practices into the research efforts."

  (Wallerstein and Duran '06)

Community-Based Participatory Research (CBPR)

❖ "Integrates education and social action to improve ~~health~~ privacy and reduce ~~health~~ privacy disparities."

❖ " More than a set of research methods, CBPR is an orientation to research that focuses on relationships between academic and community partners, with principles of co-learning, mutual benefit, and long-term commitment and incorporates community theories, participation, and practices into the research efforts."

Privacy + CBPR = Participatory Privacy

❖ Privacy regulation is conceptualized as a participatory process, that empowers participants to exert "control over data gathering and sharing according to their context and preferences". (Shilton et al. '08)

❖ Not merely individual empowerment, but recognizing the community-based relevance of the problem.

Participatory Privacy meets CI

❖ Privacy regulation is conceptualized as a community-based participatory process, that empowers communities to exert "control over data gathering and sharing according to their context and preferences".

❖ What conceptual and computational frameworks can enable this?

How/Why CI?

- How can a community-based participatory articulation of privacy be captured in a formal framework?

- Met Yan.

We have a VACCINE for that!

Example: HIV prevention among homeless youth

- Envision a data-based intervention in a community.
- Community-based discussion and questions (Initial rounds):
  - What data from us would be useful for the project?
  - How would our data be stored?
  - Would our identities be revealed?
  - Who would have access to our data?
  - In what ways could these data be used?
  - Could it be shared? If so, with whom, and under what conditions?

Insights/Discussions to CI Norms

- A researcher with a CI frame can help construct CI norms by identifying various parameters associated with a CI norm. For example:

  - Is is acceptable for the system to reveal a community member's HIV status to an affiliated researcher if there is a guarantee of confidentiality?

  - Is it acceptable for a community member's HIV status and identity to be stored in the system database, as long as only affiliated researchers have access to it?

  - Is it acceptable for a researcher to reveal in a public document, what percentage of community members are HIV positive, as long as the community is only identified as "a community of low-income youth in a rural area"?

Framework for Participatory Privacy
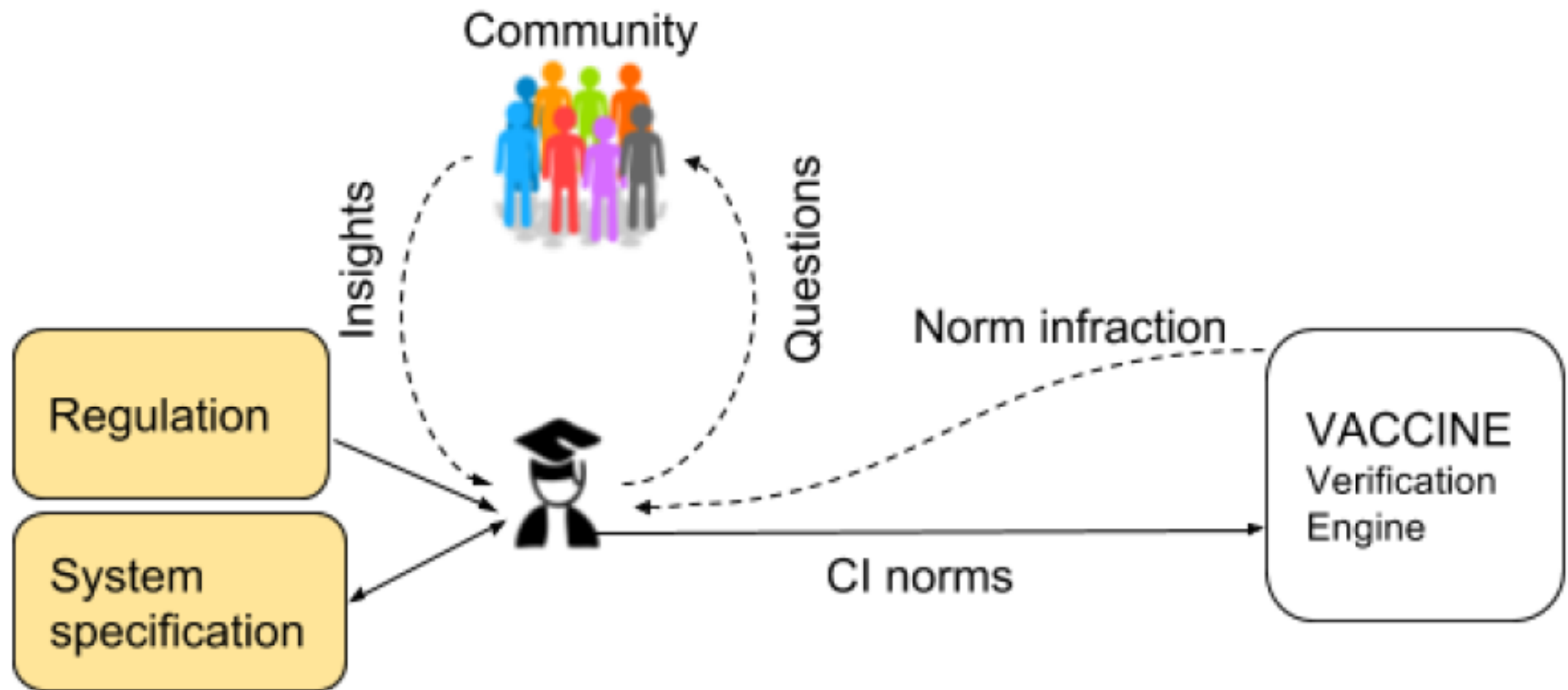
Next Steps

❖ Looking for community-based collaborators to implement our framework in practice.

❖ Goal: articulate a set of community-generated privacy norms in a specific context.

Thank You!