“It Takes a Village”: A Community Based Participatory Framework for Privacy Design

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Joint work with Mark Latonero (D&S),
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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: Networked 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)

Privacy Disparity

Design Gap

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Communities who experience the (disparate) impacts.

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Researchers/Technologists who design privacy solutions

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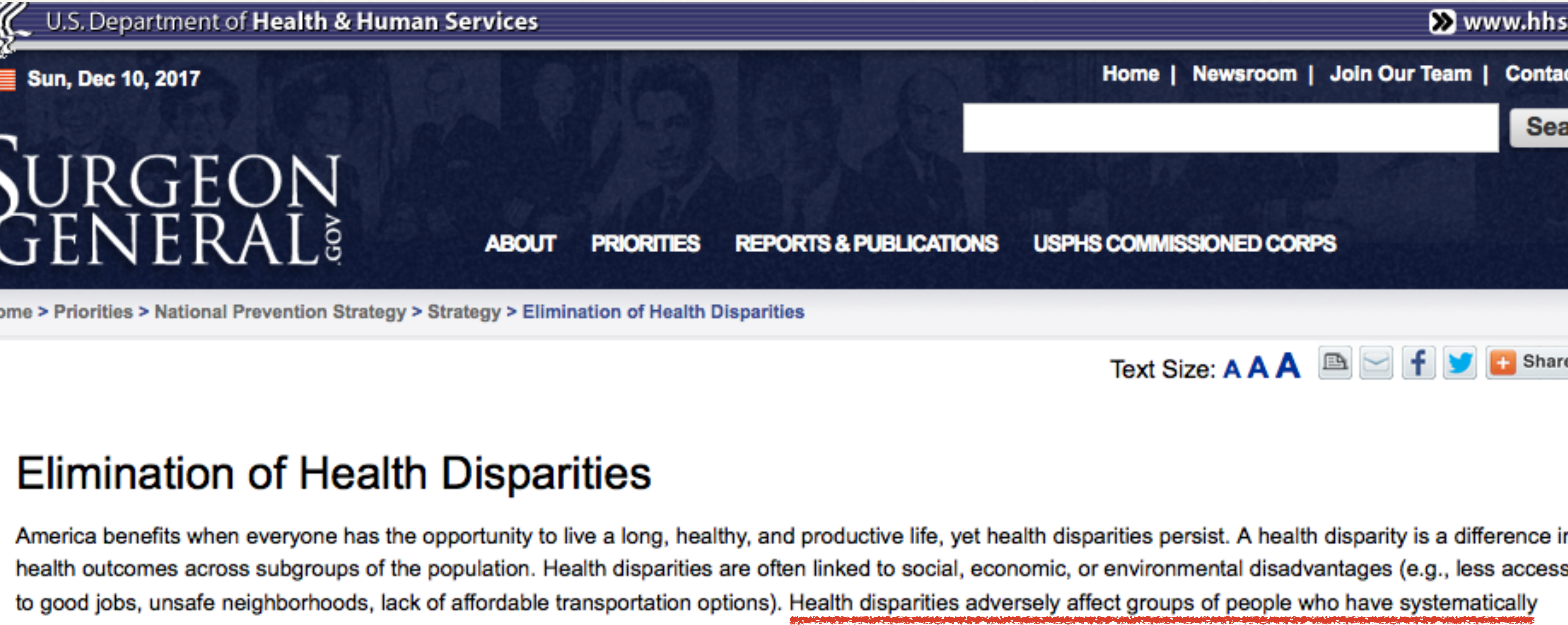
- What kinds of conceptual (and computational) frameworks can capture these articulations into a formalized, enforceable "rules"?
    - Privacy governance systems

What kinds of frameworks can bridge these gaps?

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 i 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)**



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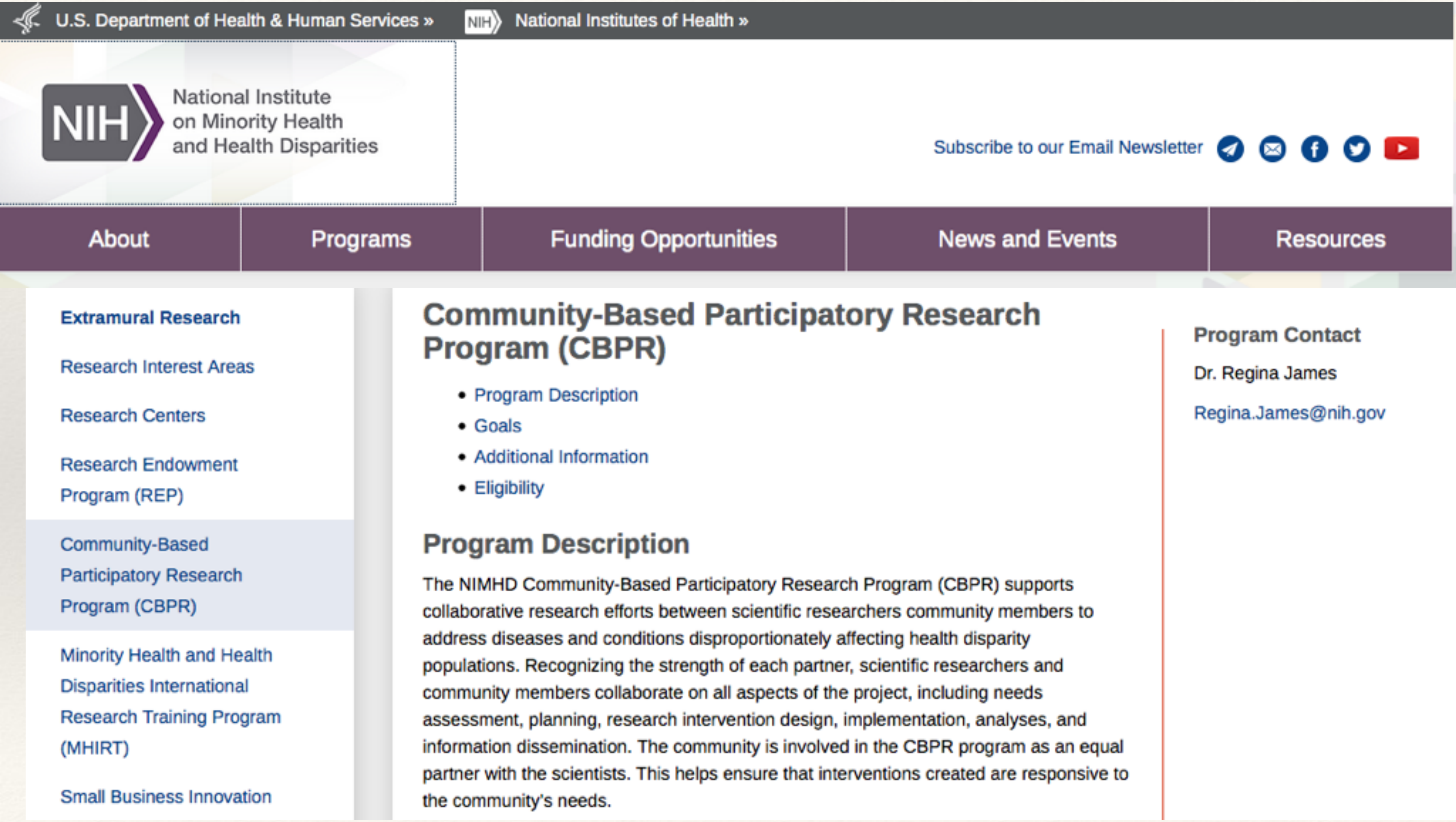
Community-Based Participatory Research



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)

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- But, not only individual empowerment, but recognizing the community-based relevance of the problem.

Participatory Privacy Meets The Public

- 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".
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- "It is acceptable for a community member's HIV status and identity to be stored in a secured system database, as *long as only researchers affiliated with this project have access to it."*
- "It is unacceptable for a community member's HIV status to be revealed to someone unaffiliated with the research team."

Participatory Process meets Contextual Integrity

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  - to regulate information flow as per these rules.

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Capture privacy rules
into systems that enforce them

Next Steps

- Community-based collaboration with communities we have institutional connections with
    - sociologist of inequality on the team who has worked with those communities (in other contexts)
- Multi-year project…
    - empirical work
    - system-building work
- Goal: a set of community-generated privacy norms in a specific socio-technological context.

Thank You!

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