

# SOCIOTECHNICAL INTERVENTIONS FOR HEALTH DISPARITY REDUCTION: A RESEARCH AGENDA

*CCC Briefing @ mPower, June 2020*

*Tiffany Veinot, University of Michigan*

*Katie Siek, Indiana University and CCC Council*

*Elizabeth Mynatt, Georgia Tech and former CCC Council*



**CCC**

Computing Community Consortium  
Catalyst

# COMPUTING COMMUNITY CONSORTIUM

The **mission** of the Computing Research Association's Computing Community Consortium (CCC) is to **catalyze** the computing research community and **enable** the pursuit of innovative, high-impact research.



**Bring the computing research community together to envision audacious research challenges.**

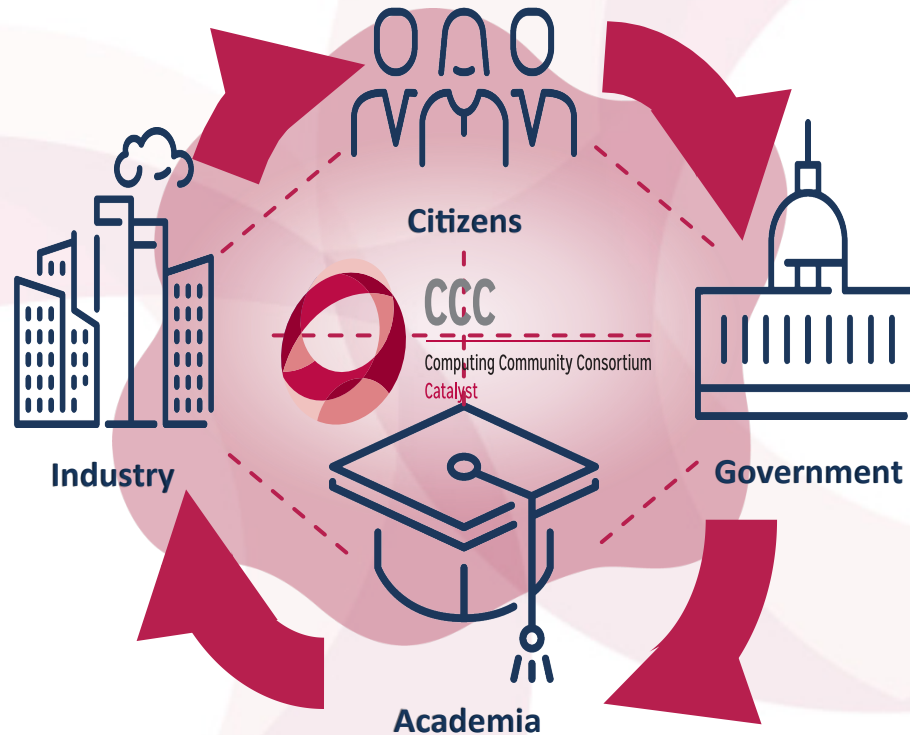
**Communicate** these challenges and opportunities to the broader national community.

**Facilitate investment** in these research challenges **by** key stakeholders.

**Inculcate** values of **leadership** and service by the computing research community.

**Inform and influence early career researchers** to engage in these community-led research challenges.

# COMPUTING COMMUNITY CONSORTIUM (CCC): CATALYZING I.T.'S VIRTUOUS CYCLE



**Pre-competitive white papers &  
workshops catalyzing I.T. research for  
the nation's benefit**

# CCC VISIONING PROCESS

- **Fall 2017:** AMIA Working Group on Interactive Systems in Healthcare Panel - Good Intentions Are Not Enough: Health Informatics Interventions That Worsen Inequality



Tiffany Veinot, MLS, PhD



Jessica S. Ancker, MPH, PhD



Courtney Lyles, PhD



Andrea G. Parker, PhD



Katie A. Siek, PhD





# CCC VISIONING PROCESS

- **Fall 2017:** CCC approves Veinot & Siek proposal; organizing committee begins to plan workshop to take place before Society for Behavioral Medicine's 39th Annual Meeting.
- **Fall 2017 / Spring 2018:** Invited participants with background in health informatics, behavioral medicine, health disparities, and computing.



Tiffany Veinot, MLS, PhD



Katie A. Siek, PhD



Elizabeth Mynatt, PhD



Heather Cole-Lewis, PhD



Syed Haider, PhD



Eric Hekler, PhD



Predja Klasjna, PhD

# CCC VISIONING PROCESS

- **Fall 2017:** CCC approves Veinot & Siek proposal; organizing committee begins to plan workshop to take place before Society for Behavioral Medicine's 39th Annual Meeting.
- **Fall 2017 / Spring 2018:** Invited participants with background in health informatics, behavioral medicine, and computing.
- **April 2018:** 1.5-day workshop held: panel on sociotechnical theory and blackboxes, break out groups, cross-cutting breakout/discussions, & draft report inputs.



Society for Behavioral Medicine's 39th Annual Meeting

# HEALTH DISPARITIES: OUR FRAMEWORK

- Health disparities are: inequities in disease prevalence, incidence, morbidity and mortality rates
- Health care disparities: differences between groups in health insurance coverage, access to and use of care, and quality of care.
- Disparities have socio-economic, political, and historical origins
- Populations which experience disparities are socio-economically and politically marginalized



**CCC**

Computing Community Consortium  
Catalyst

# HEALTH DISPARITY POPULATIONS = MARGINALIZED GROUPS

Lower  
Socioeconomic  
(SES) Status  
People

Pacific  
Islanders/Native  
Hawaiians

Rural and Urban  
Residents

African  
Americans

Native  
Americans/Alaska  
Natives

LGBTQ+ People

Hispanics/Latinos

Women or Men  
*(varies by indicator)*

People with  
Disabilities

# Aims

- Theory to Design and Implementation
- Sociotechnical System Blackboxes
- Sociotechnical Systems to Inform Theory
- Multidimensional Evaluation to Reduce Health Disparities at Population Level



**CCC**

Computing Community Consortium  
Catalyst



# DAY 1

- Sociotechnical Theory in Health Disparity Contexts Panel



Computing:  
Lena Mamykina, PhD  
Columbia University



Behavioral Medicine:  
Jasmin Tiro, PhD  
U. Texas Southwestern

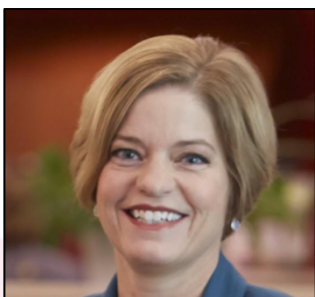


Health Disparities:  
Robert Newton, PhD  
Louisiana State University



Health Informatics:  
Madhu Reddy, PhD, FACMI  
Northwestern University

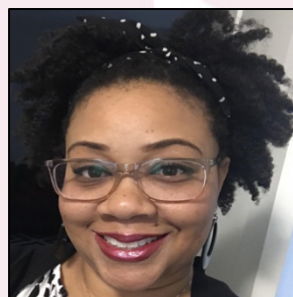
- Sociotechnical Blackboxes and Multidimensional Evaluation to Reduce Health disparities Panel



Computing:  
Tammy Toscos, Ph.D.  
Parkview Mirro Center



Behavioral Medicine:  
Kathy Kim, PhD, MPH, MBA  
U. Of California Davis



Health Disparities:  
Jamilia Sly, PHD  
Mount Sinai



Health Informatics:  
Robert Lucero, PhD, MPH, RN, FAAN  
University of Florida



# DAY 2

- Lightning Intro Talks
- Breakout Groups
- Problem Selection
- Breakout Groups
- Report Out



# CCC VISIONING PROCESS

- **Fall 2017:** CCC approves Veinot & Siek proposal; organizing committee begins to plan workshop to take place before Society for Behavioral Medicine's 39th Annual Meeting.
- **Fall 2017 / Spring 2018:** Invited participants with background in health informatics, behavioral medicine, and computing.
- **April 2018:** 1.5-day workshop held: panel on sociotechnical theory and blackboxes, break out groups, cross-cutting breakout/discussions, & draft report inputs.
- **May 2018:** AMIA webinar summarizing the findings and insights from the workshop.
- **August 2019:** Workshop report released. Vetted by participants, CCC, & external experts.
- **June 2020:** Presentation to mPower.



# CCC Workshop Themes

- **Theory to Design and Implementation**
- Sociotechnical System Blackboxes
- Sociotechnical Systems to Inform Theory
- Multidimensional Evaluation to Reduce Health Disparities at Population Level



**CCC**

Computing Community Consortium  
Catalyst

How do we identify and map theory to design, implementation, & evaluation in a health disparity context?

## UPSTREAM INTERVENTIONS

### **Workshop Participants Raised these Questions:**

How can we operationalize structural causes of health disparities in intervention design, and their bi-directionality?

How can we design multi-level interventions with technology (i.e. individual, networks, living/working conditions, policy, institutions)?

When is there a need for a mixture of online and offline interventions? What types of “blended” interventions are effective, and for whom?

# **EQUITY-CENTERED INTERVENTION UPTAKE/ RECRUITMENT AND ADHERENCE/RETENTION**

## **Workshop Participants Raised these Questions:**

Do “standard” recruitment strategies work for marginalized groups? For whom? When? For what health issues?

How can we promote uptake among “disinterested” populations?

What kind of technology training and support is needed for interventions with different marginalized groups?

How and when should we re-engage?



## OPPORTUNITIES

- Developing and evaluate upstream and multi-level interventions to reduce health disparities by impacting community, social, economic, and political factors.
- Develop and evaluate methods of recruitment/uptake and retention/adherence or studies/interventions that involve marginalized communities.

# Aims

- Theory to Design and Implementation
- **Sociotechnical System Blackboxes**
- Sociotechnical Systems to Inform Theory
- Multidimensional Evaluation to Reduce Health Disparities at Population Level



**CCC**

Computing Community Consortium  
Catalyst

How can we understand when  
sociotechnical systems elicit +/-  
health outcomes?

# PARTICIPATORY METHODS FOR STUDY AND TECHNOLOGY DESIGN

## Workshop Participants Raised these Questions:

How do we build capacity for communities to meaningfully participate in research and technology design?

How do we mitigate power issues between researchers/technologists and marginalized communities?

How do we know what participatory methods to choose for a given study/intervention? How do we evaluate the effectiveness of these methods? How can we compare methods across fields?



**CCC**

Computing Community Consortium  
Catalyst

# UNDERSTANDING DATA QUALITY IN EXISTING SYSTEMS

## **Workshop Participants Raised these Questions:**

How do we identify and report on data provenance — especially in marginalized groups?

How can we better communicate algorithmic abstractions so that all stakeholders understand the limitations of the data provided?

What are the impacts of the characteristics of marginalized users and their living/working environments on data quality from sensors, location tracking, medical devices?

# DESIGNING DOSING SCHEMES

## Workshop Participants Raised these Questions:

For a given intervention, how often should doses be given for which groups, and through what mechanisms?

For a given intervention, what mix of dosing of technological and non-technological elements are needed to achieve a given outcome? (e.g., community or social network characteristics may moderate effectiveness.)



CCC

Computing Community Consortium  
Catalyst



## OPPORTUNITIES

- Ensure access to resources to build and maintain community-based research collaborations and participatory methods.
- Conduct pilot studies and iterative design to ensure initial conditions (e.g., data quality) are correct.
- Evaluate the “dose” of sociotechnical systems to better understand the frequency of use, as well as the dosing contexts and infrastructure support available.
- Support broader impacts in research to ensure researcher are addressing issues that are important to communities.

# Aims

- Theory to Design and Implementation
- Sociotechnical System Blackboxes
- **Sociotechnical Systems to Inform Theory**
- Multidimensional Evaluation to Reduce Health Disparities at Population Level



CCC

Computing Community Consortium  
Catalyst

```
graph TD; A([Sociotechnical Systems]) --> B([Theory]); B --> A;
```

Sociotechnical  
Systems

Dosing?

Theory

# BUILDING BETTER THEORIES

## Workshop Participants Raised these Questions:

What data streams can best inform dynamic theories that address the social origins of health and health disparities?

How can we identify better data streams and come closer to a ground truth understanding for marginalized groups?

How do we develop and validate dynamic and personalized theories in marginalized groups?



CCC

Computing Community Consortium  
Catalyst

# TAILORING AND OPTIMIZATION

## Workshop Participants Raised these Questions:

How do we collect all of the data needed for tailoring without unduly burdening participants or violating their privacy — especially in marginalized groups that have previously been exploited for research gain?

How do we make sense of all of the available data streams to ensure they are providing an accurate picture of users' contexts, lives, and cultures?



**CCC**

Computing Community Consortium  
Catalyst

# OPPORTUNITIES

- Document instruments, data streams, and mappings between sociotechnical systems and theories used.
- Develop dynamic new theories that can account for future sociotechnical systems and capture the social contexts of marginalized populations.
- Create and document equity-relevant metrics that can capture appropriate levels of detail to contextualize user groups and interventions.
- Develop, evaluate, share, and validate study designs and theories for interventions.



CCC

Computing Community Consortium  
Catalyst



# Aims

- Theory to Design and Implementation
- Sociotechnical System Blackboxes
- Sociotechnical Systems to Inform Theory
- **Multidimensional Evaluation to Reduce Health Disparities at Population Level**



CCC

Computing Community Consortium  
Catalyst

How can we design safeguards to assist researchers become more aware of intervention generated inequalities?

# ASSESSING HEALTH EQUITY IMPACTS AND UNINTENDED CONSEQUENCES

## **Workshop Participants Raised these Questions:**

What are the equity-related consequences of existing (and future) socio-technical interventions in health?

How can health-equity-relevant phenomena such as resilience, culture, context, and patient-centered goals be more effectively measured?

How can we better measure intervention effects across micro, meso, and macro levels? How can we effectively account for interactions between different levels of outcomes?

# ETHICS OF CAPTURING DATA REGARDING CONTEXT

## **Workshop Participants Raised these Questions:**

What are the risks to those whose contextual data are captured? How do they change over time? How can they be mitigated?

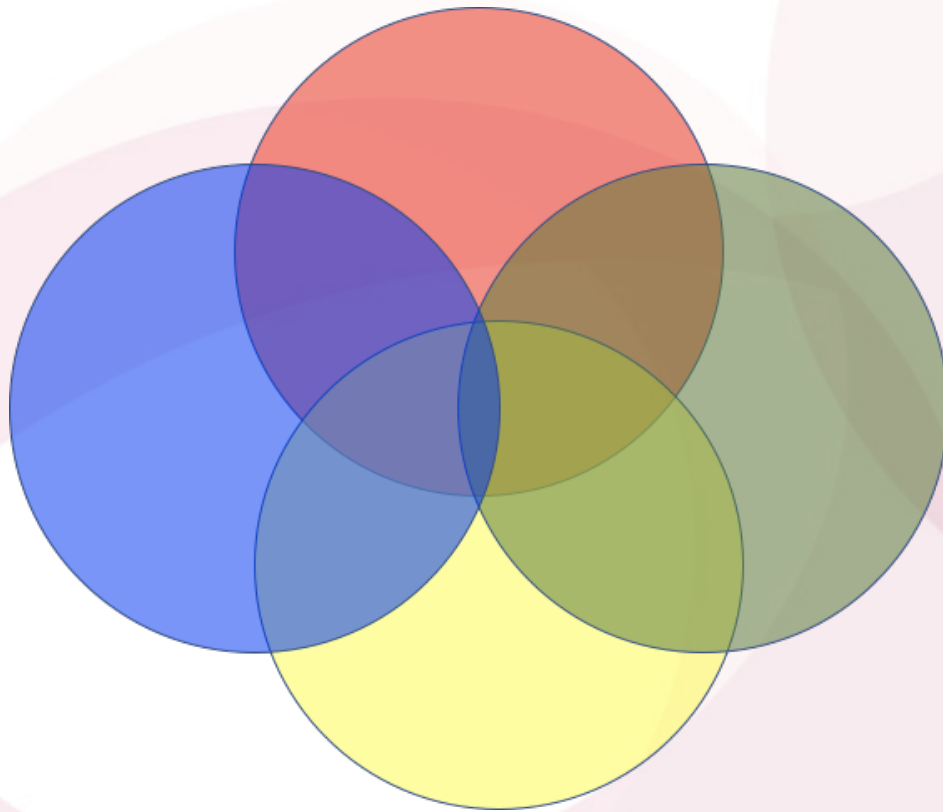
What are the ethical implications of use of contextual data to tailor interventions, diagnose health conditions, and identify health risks?

How can we include more diverse perspectives in discussions of research ethics?

# OPPORTUNITIES

- Assist researchers in identifying ethical issues and proactively assessing risks with benefits.
- Develop dynamic new theories that can account for future sociotechnical systems and capture the social contexts of marginalized populations.
- Establish research processes that check on what groups, data, or resources are unaccounted for and monitor unintended consequences.
- Engender a research culture in which learning, sharing, and disclosing failures are encouraged.

## A WAY FORWARD



Sustained research collaborations and community partnerships

Connect and coordinate efforts to address larger problems – e.g., theory development

Create training opportunities

Share reusable components, processes, measures, algorithms and data