Report from Workshop on Sociotechnical Interventions for Health Disparity Reduction

Katie Siek, Ph.D. and Tiffany Veinot, Ph.D.
Background

- Definition of “health disparities”: disease incidence, prevalence, morbidity, mortality, or survival is worse in a population subgroup than in the general population
- Emerge from health system disparities and socioeconomic factors which:
  - Provide differential access to “flexible resources” including money, status, power, freedom, knowledge and social capital
    - Flexible resources can be used to reduce negative health exposures and adopt health-enhancing behaviors
  - Differential resource access linked to:
    - inequity in education, occupational prestige and income
    - residential segregation
    - environmental barriers
    - stigmatization and discrimination.

(Branstrom et al., 2016; Drum et al., 2009; Hatzenbuehler, Phelan & Link, 2013; Iezzoni, 2011; Masters, Link & Phelan JC, 2015; Phelan & Link, 2005, 2015; Phelan, Link & Tehranifar, 2010)
Background

- 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
Intervention-Generated Inequality (IGI): when interventions disproportionately benefit advantaged groups.

Perspective

Good intentions are not enough: how informatics interventions can worsen inequality

Tiffany C. Veinot, Hannah Mitchell, and Jessica S. Ancker

1School of Information and School of Public Health, University of Michigan, Ann Arbor, Michigan, USA and 2Department of Healthcare Policy & Research, Division of Health Informatics, Weill Cornell Medical College, New York, New York, USA

Corresponding Author: Tiffany Veinot, MLS, PhD, School of Information, University of Michigan, 3443 North Quad, 105 S. State Street, Ann Arbor, MI 48109-1285, USA (tveinot@umich.edu)

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ABSTRACT

Health informatics interventions are designed to help people avoid, recover from, or cope with disease and disability, or to improve the quality and safety of healthcare. Unfortunately, they pose a risk of producing intervention-generated inequalities (IGI) by disproportionately benefiting more advantaged people. In this perspective paper, we discuss characteristics of health-related interventions known to produce IGI, explain why health informatics interventions are particularly vulnerable to this phenomenon, and describe safeguards that can be implemented to improve health equity. We provide examples in which health informatics interventions produced inequality because they were more accessible to, heavily used by, adhered to, or effective for those...
Smoking Rates Among Individuals Ages 25 and Older, by Education Level, 1940–2012

Source: CDC
THE WASHINGTON POST
Paper - IGI and Intervention Stages

- Baseline Health Inequality
- Inequality in Access
- Inequality in Uptake
- Inequality in Adherence
- Inequality in Effectiveness
Paper - Model for Intervention-Generated Inequality Prevention
Access-Related Precautions: Non-traditional dissemination, Design for older & mobile technology infrastructures, Universal access policies

Uptake-Related Precautions: Social network- and opinion-leader outreach, Training and technical support, Trust-centered design

Adherence-Related Precautions: User-centered and participatory design, Universal precautions for literacy burden

Effectiveness-Related Precautions: Target social and physical environment, Reduce structural and technological complexity
Evaluation and Reporting-related Precautions

- Identify equity-relevant independent variables
- Choose at least one equity-relevant outcome variable
- Recruit diverse participants, and report their sociodemographics in detail
- Ensure sufficient statistical power for subgroup analysis or analysis of effect modifiers
- Plan for qualitative data collection regarding potential unintended consequences, probing for equity-relevant issues
Working Group on Interactive Systems in Healthcare

Nov 4 - 8, Washington, D.C.
AMIA 2017 Annual Symposium

Precision Informatics for Health: The Right Informatics for the Right Person at the Right Time
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Sociotechnical Interventions for Health Disparity Reduction: A Research Agenda

April 9-10, 2018
New Orleans Riverside Hilton
Hilton New Orleans Riverside, Poydras Street, New Orleans, LA, United States

Overview	Agenda	Organizers

The burden of negative health outcomes is, unfortunately, differential in the United States (US) and other countries, a phenomenon known as health disparities. Health disparities are differences in the incidence and prevalence of disease, as well as disease-related morbidity, mortality, and survival rates in one group when compared to the general population. Health disparities may emerge on the basis of socially stratifying factors such as socioeconomic status, race, gender, disability, sexual orientation, and place of residence. Critically, although there have been significant, coordinated governmental investments of resources to eliminate health disparities over the past 25 years in the US and elsewhere, there remain substantial and troubling inequities.

Sociotechnical interventions hold promise for reducing disparities and improving the health of marginalized populations – but this potential is yet to be fully realized. At the same time, researchers must take care when developing any sociotechnical intervention in the health domain, since such interventions can generate unintended consequences that exacerbate disparities, as research concerning patient portal implementation shows.

In this cross-disciplinary workshop, we will bring together leading researchers in computing, health informatics, and behavioral medicine to develop an integrative research agenda regarding sociotechnical interventions to reduce health disparities and improve the health of socio-economically disadvantaged populations. As part of these discussions, approaches for guarding against unintended consequences of general interventions will also be explored. To do so, this workshop will focus on integrating insights and findings from each of these fields, identifying gaps in understanding between fields, and surfacing opportunities for future interdisciplinary research to address relevant challenges.

The workshop will be held before the Society for Behavioral Medicine’s 39th Annual Meeting on Monday, April 9 and Tuesday, April 10, 2018 in New Orleans, Louisiana. Participants will be drawn from academia, industry, and government. During the 1.5 day workshop,
CCC Workshop Organizers

Tiffany Veinot, University of Michigan (Co-Chair)
Katie Siek, Indiana University (Co-Chair)
Elizabeth Mynatt, Georgia Tech (CCC Liaison)
Heather Cole-Lewis, Johnson and Johnson (SBM Digital Health Council Liaison)
Syed Haider, Johnson and Johnson (SBM Scientific and Professional Council Liaison)
Eric Hekler, University of California San Diego (SBM Program Co-Chair)
Pedja Klasnja, Kaiser Permanente Washington Health
Donna Spruijt-Metz, University of Southern California

Computing Community Consortium and Society for Behavioral Medicine (SBM)

Khari Douglas, CCC
Brian Mosley, CCC
Erin Trimmer, SBM
Lindsay Bullock, SBM
CCC Workshop Themes & Guiding Questions

Theory to Design and Implementation

- How do researchers appropriately identify and map theory to design, implementation, and evaluation, specifically in a health disparity context?

Sociotechnical Systems to Inform Theory

- How do the data that sociotechnical systems collect impact theory to help address health disparities? How do we negotiate the dosing of sociotechnical systems from what is clinically needed to what health disparity populations are willing to use?
CCC Workshop Themes & Guiding Questions

Sociotechnical System Blackboxes

- How researchers can understand when sociotechnical systems elicit positive, negative or neutral health outcomes for disparity populations, can we identify why? How do we identify the individual or combined impacts of theory and design?

Multidimensional Evaluation to Reduce Health Disparities at the Population Level

- How can researchers understand, or guard against, unintended consequences such as intervention-generated inequalities?
Theory to Design and Implementation

- Equity-Centered Intervention Uptake and Study Recruitment
- Equity-Centered Engagement/Adherence and Study Retention
- Upstream Interventions
Equity-Centered Intervention Uptake and Study Recruitment

● Problems
  ○ Unequal uptake in sociotechnical interventions (e.g., patient portals)
  ○ Recruitment bias in studies of socio-technical interventions
  ○ Current methods favor engaged populations; difficulty of engaging disinterested populations
  ○ Trust of researchers/interventionists among disparity populations

● Open Questions
  ○ Do “standard” recruitment strategies work for marginalized populations?
    ■ For whom do they work? For what health issues/behaviors? When do they work?
  ○ What new uptake/recruitment strategies are possible to reach marginalized populations and are they effective?
  ○ How can we promote uptake among disinterested populations?
  ○ What are the best methods for building trust between interventionists/researchers and marginalized populations?
  ○ What kind of an “on ramp” is needed for interventions with marginalized populations? How do they differ for different groups?
Equity-Centered Engagement/Adherence and Study Retention

- **Problems**
  - Differential engagement/adherence (e.g., differential dropout by education level in many sociotechnical interventions)
  - Limited understanding of reasons for drop-out and non-use
  - Unclear understanding of temporal trajectories of use, and when interventions should end

- **Open Questions**
  - What drives differences in engagement/adherence and retention in disparity populations?
  - Do “standard” engagement strategies (e.g., gamification) work for disparity populations?
    - For whom do they work? For what health issues/behaviors? When do they work?
  - What new engagement strategies are possible to reach disparity populations and are they effective?
  - What kinds of supports are needed to facilitate engagement/adherence and retention?
  - What can we learn from other sectors (e.g., community organizations, industry) on how to engage marginalized populations?
  - How can interventions accommodate short-term or intermittent usage?
Upstream interventions

General
Socio-Economic, Cultural, and Environmental Conditions

Institutions (including health care)

Public Policy

Living and Working Conditions
Social and Community Networks
Individual Behavior

Flexible resources
Upstream interventions

● Problems
  ○ Dearth of multi-level theories, and theories that account for the bi-directional nature of SDOH
  ○ Complexity of interventions - e.g., how to operationalize intersectionality
  ○ Operationalization of culture is flawed/lacking
  ○ Technology may not always be the best solution

● Open 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)?
  ○ What are the limits of what technology can solve and what it can’t?
  ○ When is there a need for a mixture of online and offline interventions? What types of “blended” interventions are effective, and for whom?
  ○ How can we best incorporate cultural issues into the design of interventions?
Sociotechnical Black Boxes

- Participatory methods for study and tech design
- Understanding data quality in existing systems
- Designing Dosing Schemes
Sociotechnical Black Boxes

Sociotechnical Systems
Sociotechnical Black Boxes

- Participatory methods for study and tech design
- Understanding data quality in existing systems
- Designing Dosing Schemes

Sociotechnical Systems

Utilizing participatory methods for study and tech design
Sociotechnical Black Boxes

- Utilizing participatory methods for study and tech design
- Understanding data quality in existing systems
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Sociotechnical Black Boxes

Utilizing participatory methods for study and tech design

Sociotechnical Systems

[Understanding data quality]

Identifying appropriate dosing
Sociotechnical Black Boxes

Utilizing participatory methods for study and tech design

Sociotechnical Systems

[Understanding data quality]

Identifying appropriate dosing

Health Outcomes
Sociotechnical Black Boxes

Sociotechnical Systems

[Understanding data quality]

Utilizing participatory methods for study and tech design

Identifying appropriate dosing

Health Outcomes
Participatory Methods for Study and Tech Design

- What do participatory methods add to the research process?
- What participatory method should we choose?
  - When in the design process do we do it?
- How do we evaluate the effectiveness of participatory methods?
  - How do they work?
  - When can we say they work?
- How can we compare methods to other fields and to each other?
  - What are the metrics of comparison?
  - Survey how people facilitate various aspects
    - Provide a safe space for not knowing, learning, and reporting failure
- How do we facilitate in highly stigmatized, low trust populations?
- How do we build capacity for communities to meaningfully participate?
Understanding Data Quality in Existing Systems

○ How do we identify and report on data provenance?
  ■ Data accuracy
    ● 3D accelerometer vs. step count
    ● Galvanic Skin Response vs. Stress
  ■ Algorithmic Abstraction
  ■ Implications for replication

○ How do we understand the implications of our technical measures?
  ■ Biases in the underlying data
  ■ Selection biases based on study design

○ How can we better understand what we measure?
  ■ What are the roles of unobtrusive measures?
  ■ What is the role of automation vs. self report?
  ■ How and when do we use experience sampling/ecological momentary assessments?
Designing Dosing Schemes

○ Understand how often and what mechanism to use for a “dose”
  ■ Dose is broadly defined
    ● Technology dose (e.g., designing for silence)
    ● Interaction dose (e.g., with a sociotechnical system, health professionals, etc.)
    ● Societal dose (e.g., interventions may work better in areas with less crime)

○ Understanding the Burden - Engagement Trade-off
  ■ Participant burden
    ● Using the system
    ● Engaging in interventions
    ● Responding to study instruments

  ■ Researcher burden
    ● Managing the system
    ● Facilitating the study
    ● Analyzing multiple data streams
Sociotechnical Systems to Inform Theory

Sociotechnical Systems

Theory
Sociotechnical Systems to Inform Theory

- Human Resources
  - Informs
  - Abstract Theory Constructs
    - Attempted Mapping
      - Concrete Technology Interactions
Sociotechnical Systems to Inform Theory

Human Resources

Abstract Theory Constructs

Informs

Concrete Technology Interactions

Attempted Mapping
Sociotechnical Systems to Inform Theory

Human Resources

Informs

Abstract Theory Constructs

At tempted Mapping

Concrete Technology Interactions
Building Better Theories (Bringing Theories to *Life*)

- Consider the origin of theories - the target population; data collection; analysis
  - Understand how, if at all, theories are validated in marginalized populations
  - How do we identify blind spots that theories can introduce?
- Acknowledge researchers’ implicit ideas of how things work by *explicitly* identifying the theory utilized
- Explore the Design-Theory Gap
  - Understand the scope of technology mapping in theoretical constructs
- Leverage ?better? data to inform theory
- Build dynamic theories for dense data collection by sociotechnical systems
- Identify how to iteratively validate dynamic and new theories
  - How do we decide when a construct does not work anymore?
  - How do we define valid?
- How do we *future proof* new theories without overstepping data collection burden and privacy expectations/ethics?
Tailoring and Optimization

- Identify how to personalize and optimize theories based on Social Determinants of Health (SDOH)
- Understand the merits of targeting vs. tailoring
  - Targeting an application for a specific population
  - Tailoring an application for individuals
- Investigate how to tailor applications for diverse populations
  - Create application adaptations based on context (physical or journey)
  - Develop adaptive interventions
  - Design adaptive visualizations
  - Investigate scalability progress and new measurement methods when everything is so personalized
- Share what we wish we did and did not collect (easier said than done)
- Understand what non-use means - even long after the study is done
Multidimensional Evaluation to Reduce Health Disparities at the Population Level

Assessing health equity impacts and unintended Consequences

Ethics of Capturing Data regarding context
Assessing Health Equity Impacts

● Problems
  ○ Many studies lack statistical power for subgroup analyses; comparisons lacking
  ○ Selection of equity-relevant independent and dependent variables
  ○ Appropriate level of analysis may be unclear (individual, family, network, community…)
  ○ Differentiating between the effectiveness of an approach vs. a particular instantiation of it

● Open questions
  ○ What have been the health equity impacts of some of our prior interventions? (need for equity-focused systematic reviews - see PRISMA (http://prisma-statement.org/Extensions/Equity.aspx)
  ○ What are the appropriate outcomes for evaluation of upstream interventions?
  ○ How to evaluate the impact of interventions in situations of intersectionality?
  ○ What impacts for contextual factors have on intervention effectiveness (e.g., moderation)?
  ○ Need for comparative research to understand what aspects of an intervention are generalizable, and what works for whom
Assessing Unintended Consequences

● Problems
  ○ Problem of intervention-generated inequality is well-documented (e.g., obesity interventions)
  ○ Who defines what is a positive/negative/neutral effect?
  ○ Short-term follow up in many intervention studies
  ○ Difficult to predict unintended consequences
  ○ Studies rarely address whether interventions reinforce or disrupt existing power dynamics

● Open Questions
  ○ What impacts do interventions have on power dynamics?
  ○ For marginalized groups, what types of unintended consequences may be the result of sociotechnical interventions?
    ■ How and why do they emerge?
    ■ Over what time period do they emerge?
  ○ What study designs and communication mechanisms are needed to assess/understand unintended consequences? Who should assess unintended consequences?
Ethics of Capturing Data regarding context

● Problems
  ○ Increase in capture of context (e.g., geospatial data, social networks, SDOH) may help to better inform interventions, but it comes with increased privacy risks
  ○ Risk to users may be dynamic - e.g., it is difficult to predict risks in terms of disclosures
  ○ Terms of service with existing platform providers (e.g., ancestry.com, Fitbit), and implications for use in research/interventions

● Open Questions
  ○ What are the risks to those whose contextual data are captured? How do they change over time?
  ○ What constitutes validity for capturing context?
  ○ What are the tradeoffs between valid measures vs. patient-centered and ethical measures?
  ○ How should we handle informed consent for secondary use of data?
  ○ How do we know when we are doing better? Are there benchmarks?
  ○ How do we include diverse perspectives on these ethics in an effective manner?
Interdisciplinary Bridges

- Identify knowledge gaps
- Share experiences
- Learn from an expert
- Build bridges
- Develop summer schools
- Seek funding for Consumer Health Informatics Consortium
  - Collaborative network of researchers
  - Create reusable components
  - Share algorithms and data approaches for transferability
Next Steps

● Final Report - Research Agenda forthcoming
  ○ Will be posted here: https://cra.org/ccc/resources/workshop-reports/

● Download the paper: