

# Addressing the Social Causes of Health Disparities in Intervention Design

# What we think we know about this topic?

**Theory:** Fundamental Cause Theory - idea of flexible resources; Cultivation Theory - understanding influence of media on behavior; Social Norms Theory - understanding descriptive norms vs. behavior

**Methods:** Designing with the population; Opinion leader interventions;

**Environment:** Technology is not neutral; Factors are not uniform across all communities; Lack of upstream interventions ; Need design that rely less on effort, behavior and choice; Stereotyping is reinforced in design and potentially hides possibility of design /Inclusive design; Why stigmatized populations don't engage; Community signals, language and interaction practices; Complexity reduction can impact disparities; Some problems need both offline and online strategies; The lack of boundaries between online and offline; Inclusive design makes technology better for everyone

# What do we not know?

- How can stereotyping be countered meaningfully in design
- How to operationalize structural causes of health disparities in design
- How do we make sure that we are not designing for just the middle, but also capture those on the “edges”
- How to operationalize different levels of complexity that scales
- How to design for things beyond the individual or group (i.e. ambient computing, network interventions)
- What are the limits of what technology can solve and what it can't
- How do we create pipelines to get representation into the design space?
- What are the unintentional consequences in “datafying” people’s lived experiences
- How do we communicate what we know across disciplines?
- Upstream interventions – complexity of evaluation is enormous – what are group level impacts that go beyond individuals
- Ethical boundaries – who decides what are the ethical boundaries?
- Know more about the design of environments through technology (i.e. Architecture)

# Who or what do we need to answer these topics?

Interdisciplinary teams

Inclusivity of community members

Health in all policies

Cross training and re-evaluation of training content

Faster dissemination pipelines

More connections with public health

Better support for policy makers

# Selecting Theories for Disparity Populations

# What we think we know about this topic?

We know we need clarification of terminology

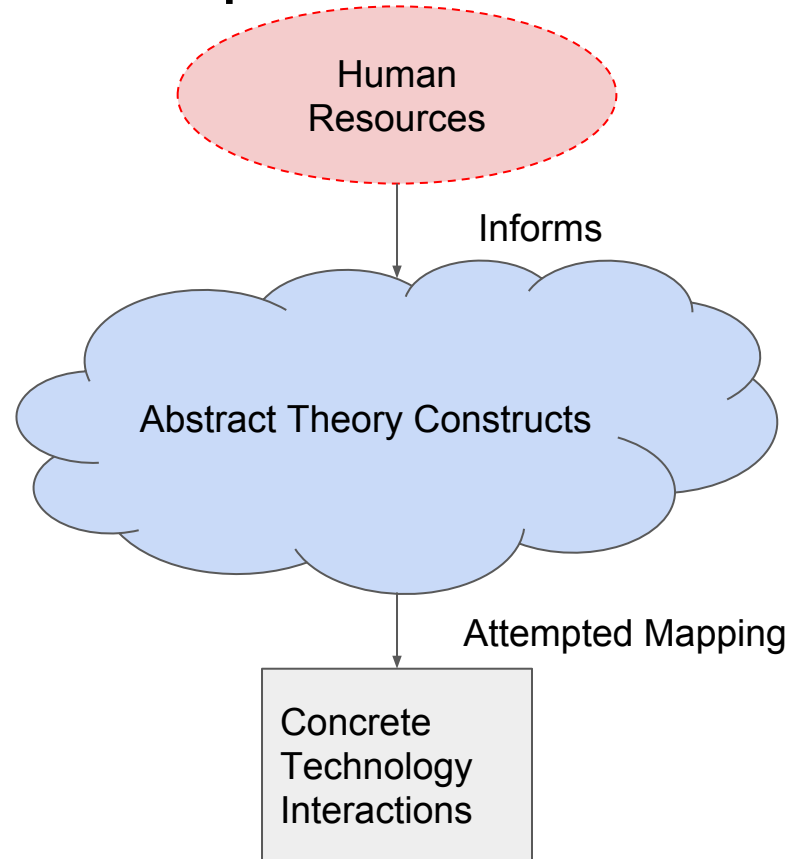
Theory simplifies human behavior and context

There exists models and frameworks for designing studies (e.g., CBPR)

- At the cost of some research priorities

Examples of Health Disparity Theories

- Theory of Positive Deviance (could be)
- Reserve Capacity Model



# What do we not know?

(i.e., Research Questions)

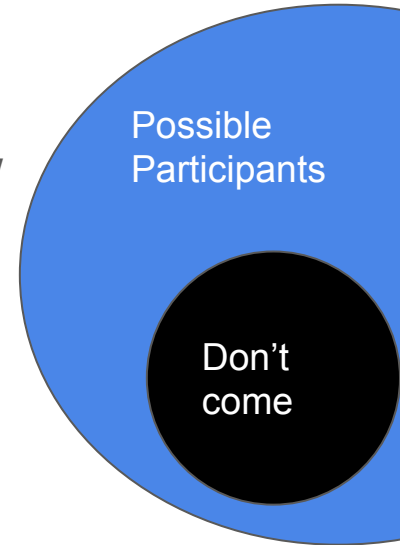
/\* We are missing something in healthcare since disparity persists \*/

We don't understand the people who do not show up

How are constructs defined?

How to measure constructs?

What was the context of the theory creation (meta-data)?



# Who or what do we need to answer this topics?

## TARGET POPULATION @ Table to Create RQs

Functionally, how do we do JTAI/data driven theories

More meta data on past theories to figure out what theories to use

Interdisciplinary, community-based (general population) collaborations

Beyond clinical category

Creativity



# The Theory – Design Relationship

What we think we know about this topic?

- Falsification and predictability discriminate theory from models
- Theory should have a measurement model that needs to be defined.
- Theory need to be congruent with the level of the measure.
- Theory and Question need to match.

# What do we not know?

How do we define concepts that are theoretically testable?

What are the “right” measures?

What are the contextual features that may impact the design of innovations and outcomes?

How do we optimize theory in the design of innovations? In other words, beyond static information used for BUT NOT NECESSARILY in the design of innovations.

We don't know the language that will be acceptable to allow designer to test the theory rigorously....test the ingredients on outcomes. Need to be able to describe the theoretical process.

# Who or what do we need to answer these topics?

Who

We need translation teams.

What

Transdisciplinary--a culture of shared understanding, or a dissolving of disciplinary boundaries, breaking methodological and theoretical boundaries.

# Creating and Extending Theories to Address Disparities

# What we think we know about this topic?

## Who knows this?

- A lot of existing theories (coming from diverse fields and disciplines)
- Theories provide focus and starting point for interventions
- Theories help to generalize between interventions

## How do they know it?

- Theories developed but did not take into account broader populations
- Don't address cultural differences or subpopulations

## New opportunity:

- New ways of capturing data

# What do we want to know?

## What we want from a theory

- Computational models of theory that we can measure
- Agile theory, flexible, incorporate new knowledge, toolbox, adapt as needed
- Consistency in measurements across studies
- Need for measures beyond efficacy that can be used to feed back into theories and models
- Need proxies: passively captured data that does not lead to measurement burden

# Who or what do we need to answer these topics?

(Beyond funding)

- We need to go beyond behavioral medicine (e.g., behavior economists)
- We need individuals to conduct computational modeling to build and expand theories continuously, adaptively
  - With foundation, heart, community centered, etc.
  - Some measures surface - account for more
- How do we optimize the theories



#### Positives:

- Help to generalize beyond study - general class of solution
- Investigate a concept

#### Negatives:

- Antiquated theories

#### What we want from a theory

- Computational models of theory that we can measure
- Agile theory, flexible, incorporate new knowledge, toolbox, adapt as needed
- Same measurements
- Theories that are modelable
- Start and build on measures
- Purpose of theory to begin with: what are the mediators/ moderators that lead and contribute to health
- Common data elements

#### Build interventions that are theory driven

- How and when to measure outcomes
- Need proxies
-

## Theories are useful

- Try to find patterns in chaos
- No theory explains everything
- Always evidence that pushes in another direction
- Theory is a good starting place - well known
- What do theories not incorporate? Blank spaces

# Science of Recruitment and Retention

Elisabeth, Julie, Robert, Kathy, Jasmin

# What we think we know about this topic?

There are “standard” strategies people use for recruitment and retention: offering incentives, phone, email, mailings, participant pools, through clinics, etc. - these are often not reaching health disparate populations.

There are often trust issues with researchers that we need to overcome.

## **Who “knows” this?**

Survey researchers, clinical trialists, social marketers, CTSA investigators, public health researchers, community health organizations

## **How do they know it?**

Testing incentive strategies (mode), incentives (conditional, unconditional)

# What do we not know?

- How is “retention” defined and how does it relate to engagement?
  - We tentatively defined it as people staying in your study and completing data collection, whereas engagement was engaging with the actual intervention or care.
- Do “standard” recruitment and retention strategies work for health disparate populations?
  - Studied in a systematic way and disseminated along channels that will reach our disparate research populations
- What new recruitment and retention strategies are possible to reach underserved populations and are they effective?

# Who or what do we need to answer these topics?

- Can we learn from industry / business strategies on how to reach and engage people ethically for research studies?
- Informing grant review committees that it's okay to have a higher budget and timeline for recruitment and retention to account for the difficulties
- What can we learn from community health organizations who are on the ground working with health disparate populations about reach?
- We need a good resource for sharing effective recruitment and retention strategies with different populations - e.g., what are good advertising methods, keywords, etc. - how do we educate IRBs to understand these methods require iteration and refinement over time?

# Strategies for Engagement

- Study Design, Research Process, with the Community
- Designing systems for use until goals are met

# What we think we know about this topic?

- Phase 1: Design Phase: Strategies for reaching those who need it
  - Needs assessment and community partnership (we know CBPR works; past experience)
    - Engagement, prepare for broad reach and recruitment strategies
    - Partner with the community for shared goals (equal footing)
  - Participatory design for technology
  - Experimental design that includes a protocol for engagement and retention
    - Use Step-Wedge design so everyone is part of intervention; Or careful active control
- Phase 2: Trial Launches, Recruitment begins, Engagement over time
  - Recognize and mitigate gatekeeper bias in participant selection
  - Avoid self selection for enrolling/refusing
  - Address reasons for refusing (eg., transportation, child care)
  - Frame the intervention toward something they and the community cares about
  - Monitor system use; intervene quickly to get people back on board
  - Extra resources in the beginning to develop new behaviors
  - Predict when disengagement might happen; Strategy for re-engagement



# What do we not know?

- **The reason for low enrollment:** What are the reasons for some of the health disparity populations not enrolling? How can we address these issues?
- **Answers to ethical questions:** What to do when behaviors aren't appropriate (e.g., drug use)? What are the limits that researchers should follow to create engagement? How to make participants feel comfortable for allowing research assistants into the home (and vice versa)?
- **How to allocate resources:** For retention and engagement (in person, phone, web conference, text)
- **Re-engagement:** When do we re-engage? (shockingly little research on engagement strategies for retention)
- **Group dynamics:** How to measure group-dynamics for social engagement/interventions?

# Who or what do we need to answer these topics?

- Ethnographers to investigate reasons for not enrolling or disengaging when enrolled
- HCI people for optimized interfaces and content
- Community participants to engage participants during the research (e.g, leaders/facilitators of online support groups)
- Engineers to help build the sociotechnical systems
- Research evidence base to learn what engagement strategies work when for initial engagement and retention

# Building Better Feedback Loops

- Data to theory
- Data to participant
- Data/participant to researchers

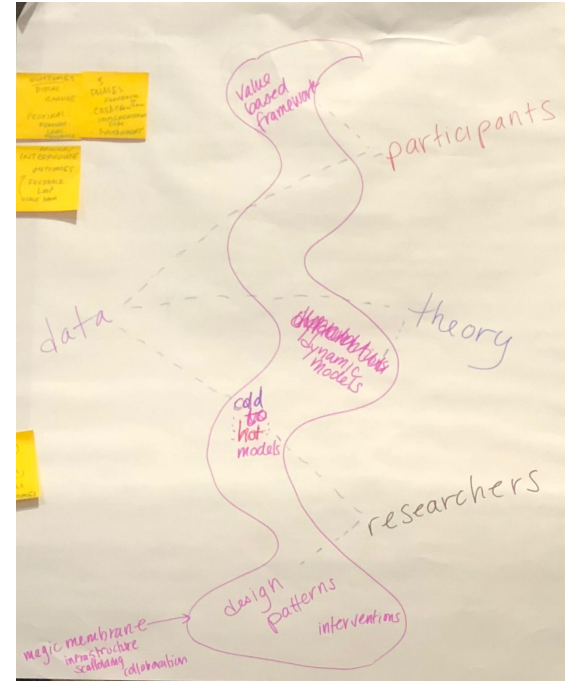
Beth Mynatt, Madhu Reddy, Lauren Wilcox, Marissa Burgermaster, Shawna Sisler

# What we think we know about feedback loops?

- Current feedback models are generally inefficient, non-continuous.
  - There is value to feedback.
  - Feedback is not automatically helpful to theory, participants, researchers.
- Early stages of being able to collect data
- Data → theory, theory → data
  - Hot v. cold (see model)

*Who knows this?* HCI community, value-based frameworks, AI, behaviorist

*How do they know it?* Collaboration, relationships, research, modeling



# What do we not know about feedback loops? Who or what do we need to answer these topics?

- Integration
- Infrastructure
- Interdisciplinary collaboration, across all levels
- Scaffolding
- Participant-driven factors -- ex. value, bx change, motivation
- Intermediary subgroups
- More and more questions -- ex. If feedback became continuous, is that helpful or a good thing?

# Optimization of Interventions

(Identifying the Sweet Spots)

Heather, Stephanie, Maia, Andrea, Sean

# What we think we know about this topic?

- Lots of groups have things they think they should optimize for: resources (cost, time), engagement, outcomes, relationships, intervention components, engagement, behaviors (especially those that are easily sensed), burden, user experience / patient experience
- Research methods that support optimization of different components and timing (SMART, MOST, JITAI)
- Sensors and diagnostic tests have context-dependent / question-dependent acceptable accuracies
- People also have competing priorities and life context

## What do we not know?

- **Value-driven (not \$) optimization and decision support**
- Framework for defining & characterizing what it means to optimize for someone or for a particular problem
- Framework for deciding what to optimize for in a given situation / person
- How does optimizing one measure affect others? (how many others / what others should researchers or others track? How do we avoid trying to solve for all possible measures?)
- How much / when to optimize for individual interventions versus upstream or population interventions?
- How sweet spots evolve over time? (for individuals, for populations, for orgs)
- Are measures we have historically optimized for -- partly because we could measure them -- still the “right” measures as we get new measurement capabilities?



# Who or what do we need to answer these topics?

- Partnerships
  - time and space to build and nurture partnerships across fields and between industry and academia (less pressure for rapid publication?)
  - “healthy” joint appointments among departments / between industry and academia
  - Identification of private orgs that value science (and who in those orgs)
- Career pathways and incentives that support longer-term thinking
- System-level interventions that support whole person; scalable and adaptive
- Feedback loops that cut across fields
- Appropriately optimizing on proximal outcomes (ecological momentary assessment, intervention measuring dosing, analyzing subgroups, sufficient resources for recruiting diverse groups)
- More mature translational science at the intersection of health and tech, with incentives for serving disparate populations
- Training and retention that give professional students exposure to recruiting participants and thinking beyond people like them
- Real-world context --> mechanisms, incentives to integrate qual and quant methods
- Meeting of the minds / candid spaces for debate about methods and outcomes across disciplines || avoid fragmentation among fields
- Computational robustness → ontologies and back ends; ability to reuse libraries

Internal and External

# Ethics of Capturing Context

Haley MacLeod, John Torous, Enid Montague, Laura Bartlett, Young-Ji Lee, Eric Hekler, Wanda Pratt

# What we think we know about this topic?

What does ethics include: responsibility, respect, do no harm, equity, transparency to collection and usage, communicating in their terms with clarity on implications, assessing understanding of consent, beneficence, autonomy, justice, due process, atonement, sharing lessons learned, feedback, literacy (in tech, health, privacy, numeracy, research, etc.), for social good not evil

Harm includes physical, financial, social, psychological/emotional

What does context mean: both internal and external: geolocation, call & text logs, patterns of usage, keystrokes, race, gender, ethnicity, education, etc.

Who knows this? - critical theorists, epidemiologist, philosophers, medical ethicists

How do they know it? -

# What do we not know?

What constitutes validity for capturing context?

What are the tradeoffs between valid measures vs. patient-centered and ethical measures?

What about informed consent for secondary use?

How can we inform Facebook and other companies about good ethical principles in capturing context?

How do we know when we are doing better? Are there benchmarks?

Who are making the choices of risk/benefit choices?

How do we include diverse perspectives on these ethics without causing more problems (ala Brook's Law)?

What if we funded the impacted groups instead of the researchers?

# Who or what do we need to answer these topics?

Need toolkits to help researchers, companies, participants do the right thing

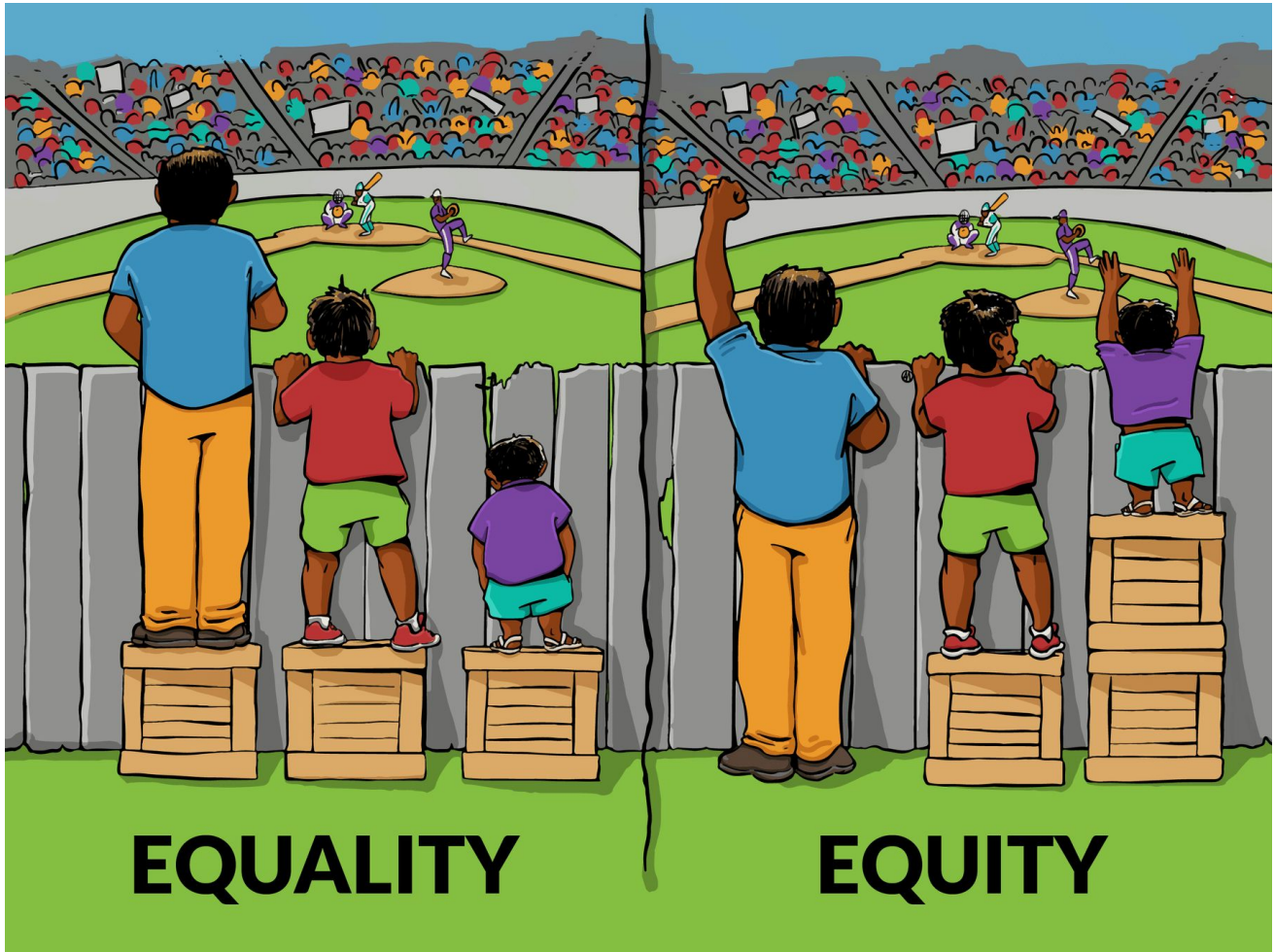
Better privacy literacy for participants, researchers, companies, etc.

Ways to support proactive risk assessment and reconciliation/remediation and education for prevention of similar problems in the future

Tools for describing success and balancing inherent trade-offs in choices

Recognition for hard work in this area--not just recognition for number of publications but getting credit for engaging diverse communities on ethical issues

# Evaluating Health Equity Impacts



**EQUALITY**

**EQUITY**

# What we think we know about this topic?

- Different types of equity to consider (access, financial, education, self-care)
- Different levels of outcomes (individual, group, structural)
- More about barriers than facilitators
- Frameworks
  - Widely accepted metrics to assess impact at different levels
- Who knows this?
  - Expert groups know pieces of this
  - NIMHD



**NIMHD Minority Health and Health Disparities Research Framework**  
**Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual/Gender Minority**  
**Other Fundamental Characteristics: Sex/Gender, Disability, Geographic Region**

Domains of Influence	Levels of Influence			
	Individual	Interpersonal	Community	Societal
Biological	Biological Vulnerability and Mechanisms	Caregiver-Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Societal Norms Societal Structural Discrimination
Healthcare System	Insurance Coverage Health Literacy Treatment Preferences	Patient-Clinician Relationship Medical Decision-Making	Availability of Health Services Safety Net Services	Quality of Care HealthCare Policies
Health Outcomes	Individual Health	Family/Organizational Health	Community Health	Population Health



# What do we not know?

(i.e., Research Questions)

- Optimal approaches for having an upstream impact
- We often make assumptions about what a particular group needs
- How to evaluate intersectionality/overlapping areas of disparities
- The right kind of interventions that work at the broader level
  - How do we turn these things into policy?
  - How we change the political structure?

# Who or what do we need to answer these topics?

(Beyond funding)

- Improved results reporting that accounts for PRISMA health equity extensions
- Examine strengths alongside weaknesses
  - Bias to looking at deficits/do not consider resiliency, positive pieces already in place (full package)
- People from different sectors to contextualize interventions and findings
  - Measure things we may not otherwise consider