Good Intentions Are Not Enough:

Taking action to ensure that health informatics interventions do not worsen inequality

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Health Disparities:

inequity in disease prevalence, incidence, morbidity and mortality rates.
Health Disparity Populations

- 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.
Example

Smoking Rates Among Individuals Ages 25 and Older, by Education Level, 1940–2012

Smoking percentage by education level in 2015

- GED: 43%
- High school: 21.7%
- Associate degree: 17.1%
- Undergrad degree: 7.9%
- Graduate degree: 5.4%

Source: CDC
THE WASHINGTON POST
Health informatics interventions pose a particular risk of producing intervention-generated inequalities (IGI) by disproportionately benefiting more advantaged people.
IGI and Intervention Stages

- Baseline Health Inequity
- Inequality at Efficacy Stage
- Inequality at Service Access/Provision Stage
- Inequality at Uptake Stage
- Inequality at Usage/Adherence Stage
Taking Action to Prevent IGI
Stage 1: Efficacy

- General Socio-Economic, Cultural, and Environmental Conditions
- Institutions
- Public Policy

Diagram:
- General Socio-Economic, Cultural, and Environmental Conditions
- Institutions
- Public Policy
- Living and Working Conditions
- Social and Community Networks
- Individual Behavior

Upstream Determinants of Health
Downstream Disease & Disability
Stage 1: Efficacy

“The need to urge behavioral change is symptomatic of failure to establish contexts in which healthy choices are default actions.”

– Thomas Frieden, CDC Director (2009—2017)
Stage 1: Efficacy

• Physical activity interventions for older adults
  – Greater increase in PA for men than women (Harris et al., 2015)
  – Decrease in PA for older women, but not older men (Peels et al., 2014)

• Diet & obesity-focused interventions
  – Tailored, web-based nutrition education intervention
    • Higher-SES showed more improvements (fewer high-energy dense snacks) (Springvloet et al., 2015)

• Efficacy may be demonstrated across a sample
  – Despite increased gaps between subgroups
Stage 1: Efficacy
Challenges in Assessment

- Systematic review: mHealth interventions in vulnerable populations
  - Low-SES + racial & ethnic minority groups
  - 73 papers

- Demographics under-reported

- High variation in measures of health behaviors & user experience

<table>
<thead>
<tr>
<th></th>
<th>Formative Studies (n=34)</th>
<th>Evaluation Studies (n=56)</th>
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<tbody>
<tr>
<td><strong>Race</strong></td>
<td></td>
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</tr>
<tr>
<td>African-American</td>
<td>32.25% (11)</td>
<td>73.21% (41)</td>
</tr>
<tr>
<td>White</td>
<td>17.65% (6)</td>
<td>33.93% (19)</td>
</tr>
<tr>
<td>Asian</td>
<td>2.94% (1)</td>
<td>19.64% (11)</td>
</tr>
<tr>
<td>Native American</td>
<td>2.94% (1)</td>
<td>8.93% (5)</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>0% (0)</td>
<td>5.36% (3)</td>
</tr>
<tr>
<td>Multiracial or Other</td>
<td>11.76% (4)</td>
<td>28.57% (16)</td>
</tr>
<tr>
<td>Not Reported</td>
<td>58.82% (20)</td>
<td>23.21% (13)</td>
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<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
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<tr>
<td>Latino/Hispanic</td>
<td>47.06% (16)</td>
<td>62.50% (35)</td>
</tr>
<tr>
<td>Not Latino/Hispanic</td>
<td>2.94% (1)</td>
<td>12.50% (7)</td>
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<tr>
<td>Other</td>
<td>5.88% (2)</td>
<td>3.57% (2)</td>
</tr>
<tr>
<td>Not Reported</td>
<td>41.18% (14)</td>
<td>33.93% (19)</td>
</tr>
<tr>
<td><strong>Socioeconomic Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>47.06% (16)</td>
<td>75% (42)</td>
</tr>
<tr>
<td>Middle</td>
<td>11.76% (4)</td>
<td>19.64% (11)</td>
</tr>
<tr>
<td>High</td>
<td>2.94% (1)</td>
<td>5.36% (3)</td>
</tr>
<tr>
<td>Not Reported</td>
<td>55.88% (19)</td>
<td>26.79% (15)</td>
</tr>
</tbody>
</table>
Stage 1: Efficacy

How do differences arise?

• Some populations are better positioned to take advantage of and be positively supported by health tech

• Socioeconomic status
  – resources including education, money
  – access to networks that support the sharing of novel information
  – access to social capital

• Neighborhood factors
  – Access to resources
  – Norms
Stage 1: Efficacy

How do differences arise?

• Gender
  – Societal norms & gender roles that can impact likelihood & level of use

• Racial inequities
  – Discrimination + cumulative effects of stressors that may put people at a disadvantage
  – Differential treatment in medical contexts (prescribing, diagnosis, etc.)
  – Minority groups: less likely to have a usual source of care

• Ignoring these contextual factors when we create individual-level interventions could result in perpetuating disparities
Stage 1: Efficacy

Opportunities to avoid IGI

• Upstream Approaches

• Design interventions
  – in the context of community-based institutions
  – & in combination with programs that are able to more effectively impact upstream determinants

• Design tools that help people to better advocate for change
  – Lay advocates for healthy behaviors (creating positive social norms in neighborhoods)
  – Activism: better leveraging social networking platforms that try to bring about change
  – Tools that help people to study + critique the inequities in their neighborhoods
    • Citizen science
Stage 1: Efficacy

Opportunities to avoid IGI

• Develop tailored interventions for health disparity populations
  – But pay attention to the diversity within the “vulnerable” group:
    • not monolithic and there are further within-group disparities (e.g., Black women living longer than Black men)
  – There is a need for more intersectional work
Stage 2: Access

MyUofMHealth.org

ACTIVE U 2017
“Short walks are a good way to PUT MYSELF FIRST”

MOVE YOUR WAY TO WELL-BEING
It doesn’t take a ton of time to put your well-being first. You just have to make the choice to do it! And Active U is a great way to start. Sign up as part of a team or do it on your own. Set your physical activity goal, and then get moving! You’ll be on your way to more energy, more strength and simply feeling good.

Join Active U Now! Track activity January 10 – April 3
mhealthy.umich.edu/activeu
Stage 2: Access
Stage 2: Access
Stage 2: Access
Stage 3: Uptake
Example of Online Patient Portals

GAO Analysis of HHS EHR Incentive Program Data (GAO-17-305)

<table>
<thead>
<tr>
<th>Professionals</th>
<th>Hospitals</th>
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<tbody>
<tr>
<td>Offering electronic portal access</td>
<td>87%</td>
</tr>
<tr>
<td>Patients using portal</td>
<td>88%</td>
</tr>
<tr>
<td>Proportion of Patients</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td>15%</td>
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Stage 3: Uptake
Portal Adoption in Early Adopter Site

EXHIBIT 1

Use Of Online Applications At kp.org, 2008-13

- Viewing lab results
- Secure e-mail with providers
- Rx refills
- Booking appointments

73%
Registered
As of September 2013 approximately 73 percent of KPNC patients had registered on the kp.org website.

Pearl R. Health Affairs. 2014 Feb;33(2):251-7

Portal Use at Kaiser Northern California by Race/Ethnicity

Sarkar et al. JAMIA 2011 May 1;18(3):318-21

- White
- African American
- Latino
- Asian
- Filipino
- Multiracial/Other Immigrants

■ Requested Password  ■ Logged On
Stage 3: Uptake
Portal Adoption in Safety Net Setting

Overall high interest in portal functionality: 71% expressed in electronic communication with providers

- % of Patients

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<thead>
<tr>
<th></th>
<th>Study Participants, n=93</th>
<th>Clinic Comparison Group, n=2462</th>
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<tbody>
<tr>
<td>Initiated sign-up</td>
<td>19.5%</td>
<td>7.8%</td>
</tr>
<tr>
<td>Logged in at least once</td>
<td>20.5%</td>
<td>8.9%</td>
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</table>
Stage 3: Uptake  
Importance of Skills and Usability

Uptake influenced by usability and digital literacy barriers:

<table>
<thead>
<tr>
<th></th>
<th>Limited Health Literacy</th>
<th>Adequate Health Literacy</th>
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<tbody>
<tr>
<td>Mean # portal tasks</td>
<td>1.3</td>
<td>4.2</td>
</tr>
<tr>
<td>completed without assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of participants with novice</td>
<td>69%</td>
<td>10%</td>
</tr>
<tr>
<td>computer barrier</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Tieu L, Lyles CR et al. *JAMIA* April 2017, Pages e47–e54
Stage 4: Adherence

https://commons.wikimedia.org/wiki/File:Peanut-Butter-Jelly-Sandwich.jpg
Stage 4: Adherence

My Kitchen at 11pm on Wednesday
Stage 4: Adherence
Lower Education = Lower Adherence

Mental Health
• Internet-Based Relaxation RCT (Alfonsson et al. 2016)
• Web-based Psychotherapy Interventions RCT (Karyotaki et al. 2015)

Smoking
• Quitting via web-based and/or phone (Nash et al. 2015)
• Web-based quitting (Strecher et al. 2008)
• Mobile app for cessation (Ey et al. 2015)

Alcohol Consumption
• Adherence & retention for web-based intervention (Murray et al. 2013)
• Web-based game for adolescents (Jander et al., 2016)

Physical Activity and Nutrition
• Web based weight loss program (Svensson et al. 2014)
Stage 4: Adherence

Adherence vs. Adaptation

Kurzweil: http://etec.ctlt.ubc.ca/510wiki/File:Kurzweil_Highlighting.png
Natural Reader Pro: https://itunes.apple.com/us/app/naturalreader-pro/id835387034?mt=8
But....

Consumer Health researchers are already using commodity systems
Goals
1. Design an intervention to provide the big picture
2. Accommodate preferences

Methods
Participatory Design
CBPR
User Centered Design
Good intentions are not enough: The role of evaluation and reporting

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Division of Health Informatics

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Today, I’ll argue that reporting standards can improve the quality of research.

For my first example, you need to recall a factoid from basic statistics...

• Estimates from small samples tend to be more variable than estimates from big samples!

\[
\text{Standard error} = \frac{SD}{\sqrt{n}}
\]
In the 1990s, systematic reviews were revealing the possibility of publication bias.
Journal editors addressed the problem with the CONSORT Statement

In studies evaluating reports of >16,000 trials, most CONSORT items were more completely reported in endorsing journals than in non-endorsing journals

(Turner et al, Cochrane Database Systematic Reviews, 2012)
Do any sort of research you want...

But only research that meets these criteria will get published in the best journals!

www.clinicaltrials.gov

CONSORT
TRANSPARENT REPORTING of TRIALS

the bmj

JAMIA

JAMA

Annals of Internal Medicine

THE LANCET

The New England Journal of Medicine

University of Michigan School of Information
Weill Cornell Medicine
UCSF CVP
Northeastern University

SCHOOL OF INFORMATICS, COMPUTING, AND ENGINEERING
If we were to require **health equity considerations** to be included in published reports, what should we be thinking about?

- **Demographics**
  - Participants
  - Drop-outs/losses to follow-up
  - Outcomes stratified by sociodemographic groups of concern

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- **Place of residence**
- **Race/ethnicity/language**
- **Occupation**
- **Gender/sex**
- **Religion**
- **Education**
- **Socioeconomic status (SES)**
- **Social capital**
- **Plus:** Age, sexual orientation, disability

**PROGRESS-PLUS**

O’Neill *Journal of Clinical Epidemiology* 2014
What should we be measuring and reporting?

• Outcome measures relevant to health equity

• For example:
  – not only whether hA1c was reduced on average, but whether reduction was consistent across demographic groups of concern
  – not only whether hA1c was reduced on average, but how many individuals did not benefit and why
Recipe for health equity in informatics research and reporting

1. Identify equity-relevant independent variables
2. Choose at least one equity-relevant outcome variable
3. Report sociodemographics of:
   – those who participate
   – those who refuse (if possible)
   – those who are lost to follow up
4. Ensure sufficient statistical power for stratified, subgroup, or interaction analyses to assess differential effectiveness by equity-relevant independent variables
5. Analyze effect of differential adherence rates on outcomes

Place of residence
Race/ethnicity/language
Occupation
Gender/sex
Religion
Education
Socioeconomic status (SES)
Social capital
Plus: Age, sexual orientation, disability

PROGRESS-PLUS

O’Neill Journal of Clinical Epidemiology 2014
Advocate for attention to health equity by journal editors and policy-makers
Thank you!

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http://vivo.med.cornell.edu/display/cwid-jsa7002
Taking Action to Prevent IGI