Big Data, Big Science, and our Invisible Communities

All of Us℠ Research Program

Option vs. Obligation

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NEW YORK TIMES BESTSELLING AUTHOR
OF THE GREAT STAGNATION

AVERAGE IS OVER
POWERING AMERICA
BEYOND THE AGE
OF THE GREAT STAGNATION
The Butterfly IQ gets FDA Approval
The New York Times

Why America’s Black Mothers and Babies Are in a Life-or-Death Crisis

The answer to the disparity in death rates has everything to do with the lived experience of being a black woman in America.

By LINDA VILLAROSA APRIL 11, 2018

1850
• Black : White ratio = 1.6

2015
• Black : White ratio = 2.2
Higher Education and Increased Income do not protect black moms and babies from dying.
“My hope is that this becomes the foundation, the architecture, whereby in 10 years from now we can look back and say that we have revolutionized medicine.”

- President Barack Obama
A Tale of Two Outcomes

“As someone who has personally benefited from precision medicine, I am excited for this study to intersect with other fundamental changes in medicine and research to empower people to live healthier lives.”

Eric Dishman
All of Us Research Program Director

Your struggle is my struggle, and I’m here to fight with you. To the ones with too much pride, and who don’t like going to the doctor because they are too proud and can handle it all, I have high hopes that my journey and story brings you back down to earth.

Timothy Francis Jones, AKA DJ Tim Buck2
All of Us Mission and Objectives

Nurture relationships with one million or more participant partners, from all walks of life, for decades

Catalyze a robust ecosystem of researchers and funders hungry to use and support it

Our mission
To accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us

Deliver the largest, richest biomedical dataset ever that is easy, safe, and free to access
The *All of Us* Research Program

- The cornerstone of the larger PMI – led by the NIH

- One million or more volunteers, reflecting the broad diversity of the U.S.

- Opportunities for volunteers to provide data on an ongoing basis

- Data shared freely and rapidly to inform a variety of research studies
Initial Core Values

- Participation is open to all
- Participants reflect America’s rich diversity
- Participants are partners
- Participants have full access to their information
- Data is broadly accessible for research purposes
- The program will be private and secure
- The program is a catalyst for positive change
A Transformational Approach to Diversity

Reflecting the country’s rich diversity to produce meaningful health outcomes for communities historically underrepresented in biomedical research.
A Transformational Approach to Data Access

- Data sharing will be a priority to both researchers and participants
- Participants will have access to study information and data about themselves
- Data collection will start small and will grow over time
- Privacy and security will adhere to the highest standards
- Will invest to level the playing field so diverse researchers can play
Traditional Way: Bring data to researchers

Problems
- Security (data handoffs)
- Data sharing = data copying
- Huge infrastructure needed
- Fixed amount of compute

PMI Way: Bring researchers to the data

Advantages
- Threat detection and auditing
- Cost
- Increased Accessibility
- Elastic compute
We Must Meet These Challenges Head On

Indian Tribe Wins Fight to Limit Research of Its DNA

SUPAI, Ariz. — Seven years ago, the Havasupai Indians, who live amid the turquoise waterfalls and red cliffs miles deep in the Grand Canyon, issued a “banishment order” to keep Arizona State University employees from setting foot on their reservation — an ancient punishment for what they regarded as a genetic-era betrayal.
Structural Violence:
A form of violence wherein some social structure (e.g. racism, sexism, classism etc.) or social institution may harm people by preventing them from meeting their basic needs; it is strongly associated with increased premature death (Johan Galtung et al 2007)
RED-LINING

Home Owner’s Loan Corporation (1933-1935)

• 4 - Tiered assessment
• Measured sale and rental demand, % ownership, social status of population, utilities, schools, churches, business, transportation

• GRADES
  • A – Green “hot spots”
  • B – Blue “developed”
  • C – Yellow “aged”
  • D – Red “undesirable population”
What Contributes to these Disparities
An Uneven Distribution of Services

Racial Segregation & access to quality healthcare

SOCIAL DETERMINANTS OF HEALTH

- HEALTH CARE
- HOUSING
- EDUCATION
- FOOD
- BUILT ENVIRONMENT
- POLLUTION
- COMMUNITY AND DOMESTIC VIOLENCE
- CRIMINAL JUSTICE
- EMPLOYMENT
- GOVERNANCE
People have different disease risk and variable drug response

Challenge: Can we use “big data” to discover and predict health variability?
Geography Matters (Zip code vs. Genetic code)

- Two sisters
- Raised together in the same town
- The same home
- Under the same circumstances
- Subsequently grow up and move apart
Geography Matters (Zip code vs. Genetic code)

The Gold Coast in the city of Chicago
- Is very affluent (high income)
- It has access to the lake front, gyms, parks
- Many farmers markets and markets
- Top universities, hospitals, etc.

The city of Moline
- High poverty rate (low income)
- High incidence rate and mortality of Breast Cancer
- Lack of access to fresh foods
- Lack of access to top universities, hospitals, etc.
Geography Matters (Zip code vs. Genetic code)

• They both develop breast cancer

• Will the treatment be the same for both sisters

• How does what they eat affect their treatment (e.g. microbiome)

• How will the everyday stresses they have to live with affect their treatments (e.g. epigenetics)
Cancer disparities in Cook County compared to all US counties (N=3141)

Blacks in Cook County have higher incidence and mortality for ALL cancers relative to US Whites

<table>
<thead>
<tr>
<th></th>
<th>WHITES</th>
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<tr>
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<td>19</td>
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*2010-2014 age-adjusted rates per 100K population. Source: https://statecancerprofiles.cancer.gov
Mile Square serves patients across the UI Health PSA and from 59 of the 77 Chicago community areas and other areas outside the city.

• ~35% Latino

• ~35% African American

• 5 of the 10 poorest Chicago communities

• Elevated mortality rates for patients with diabetes, CHF, asthma, cancer & stroke
The new cancer care model is focused on bringing specialized cancer care and the resources of the Cancer Center back to the community.
Ward 20
Alderman
Willie B. Cochran

Mile Square Site: Englewood
Community Areas Represented
- Englewood
- West Englewood
- Greater Grand Crossing

Demographic data
Population: 49,263
Male: 22,226
Female: 26,037

Ethnic Breakdown
Black: 71.63%
Hispanic: 21.56%
White: 4.19%
Asian: 1.25%

Uninsured Rate

<table>
<thead>
<tr>
<th></th>
<th>Englewood</th>
<th>West Englewood</th>
<th>Greater Grand Crossing</th>
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<tbody>
<tr>
<td></td>
<td>20.6%</td>
<td>25.2%</td>
<td>20.1%</td>
<td>19.6%</td>
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Ward Map
## Cancer Incidence Rates

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<tbody>
<tr>
<td>Lung</td>
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<td>87.0</td>
<td>91.9</td>
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<tr>
<td>Breast</td>
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<td>149.9</td>
<td>135.4</td>
<td>119.8</td>
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<tr>
<td>Prostate</td>
<td>203.4</td>
<td>199.5</td>
<td>226.1</td>
<td>143.8</td>
<td>153.9</td>
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<tr>
<td>Colorectal</td>
<td>54.9</td>
<td>63.4</td>
<td>61.4</td>
<td>43.9</td>
<td>50.2</td>
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<td>Head and Neck</td>
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<td>17.5</td>
<td>17.8</td>
<td>11.2</td>
<td>11.6</td>
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<td>Cervical</td>
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<td>20.3</td>
<td>18.8</td>
<td>7.8</td>
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*Incidence and mortality rates are age-adjusted per 100,000 people
**Denotes were n<16 and thus considered statistically insignificant

## Cancer Mortality Rates

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<th>State</th>
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</thead>
<tbody>
<tr>
<td>Lung</td>
<td>76.8</td>
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<td>50.6</td>
<td>51.8</td>
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<tr>
<td>Breast</td>
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<td>29.1</td>
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<td>22.9</td>
<td>23.6</td>
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<tr>
<td>Prostate</td>
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<td>70.3</td>
<td>75.0</td>
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<td>24.3</td>
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<tr>
<td>Colorectal</td>
<td>30.2</td>
<td>31.5</td>
<td>24.4</td>
<td>17.0</td>
<td>18.1</td>
</tr>
</tbody>
</table>

*Incidence and mortality rates are age-adjusted per 100,000 people
**Denotes were n<16 and thus considered statistically insignificant
thank you!
REACH THE WORLD BUT TOUCH THE HOOD First
Big Data, Big Science, and Invisibility

The Benefits of Driving Change from Inside Our Communities

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