

The Risks of Bias and Inequities in Precision Oncology Care

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Disclosures

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Relevant Financial Relationships:

- Salaried employee at Data & Society Research Institute
- Receives honoraria as member of the All of Us Research Program Institutional Review Board
- Has received funding from the Robert Wood Johnson Foundation

Non-Financial Relationships:

- Member of the American Anthropological Association

What is Precision Medicine?



"an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person." -Barack Obama, 2015

Precision Medicine Approaches

Risk Prediction

Diagnosis/Detection

Treatment

Example 1: Risk Prediction

SPECIAL ARTICLE

“Simulations showed that the inclusion of even small numbers of black Americans in control cohorts probably would have prevented these misclassifications” –Manrai et. al 2016

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“Since the passage of Revitalization Act in 1993, less than 2% of more than 10,000 cancer clinical trials funded by the National Cancer Institute included enough minority participants to meet the NIH’s own criteria and goals.”

Example 3: Treatment

State sues maker of Plavix for misleading marketing in Hawaii

Fairness

in

Precision

Medicine

February 2018

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Historical Bias in Clinical Research Data

“[Here are the] guidelines for lung cancer screening, so you must be 55 to 80, and you must have 30 packs per year of smoking. This all came from a study...the National Lung Screening Trial. **Of those 53,000 people, only four percent were African-American.** So...we now have lung cancer screening guidelines based on that four percent...”

“because you had such low minority enrollment in the study, you didn't look at the smoking habits of some urban communities. They don't smoke 30 packs a year. They smoke differently; they smoke menthol cigarettes. You don't have to smoke a pack a day if you smoke menthols...So now, when I do lung cancer screening in the community, **most of the community members that we screen don't qualify** because they don't have the smoking history.”

Key Questions

- How do we balance a need to improve medical research and care with concerns for equity? Can we advance *both* health innovation and fairness?

*Shift the frame from precision medicine as a project just about individuals, to also the potential impacts on **groups**.*

- How do we move beyond percentages to provide greater context, especially when using big data in precision interventions?

Think about data and the possibility for bias along multiple dimensions. Ask how and why groups may be missing from biomedical research data, and think about how disease presentations in clinical records can be a result of historical, embedded biases.



Thank you!

- @KadijaFerryman
- @datasociety
- www.datasociety.net

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