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The Ethics of Using Big Data in Medicine

Progress vs Protection

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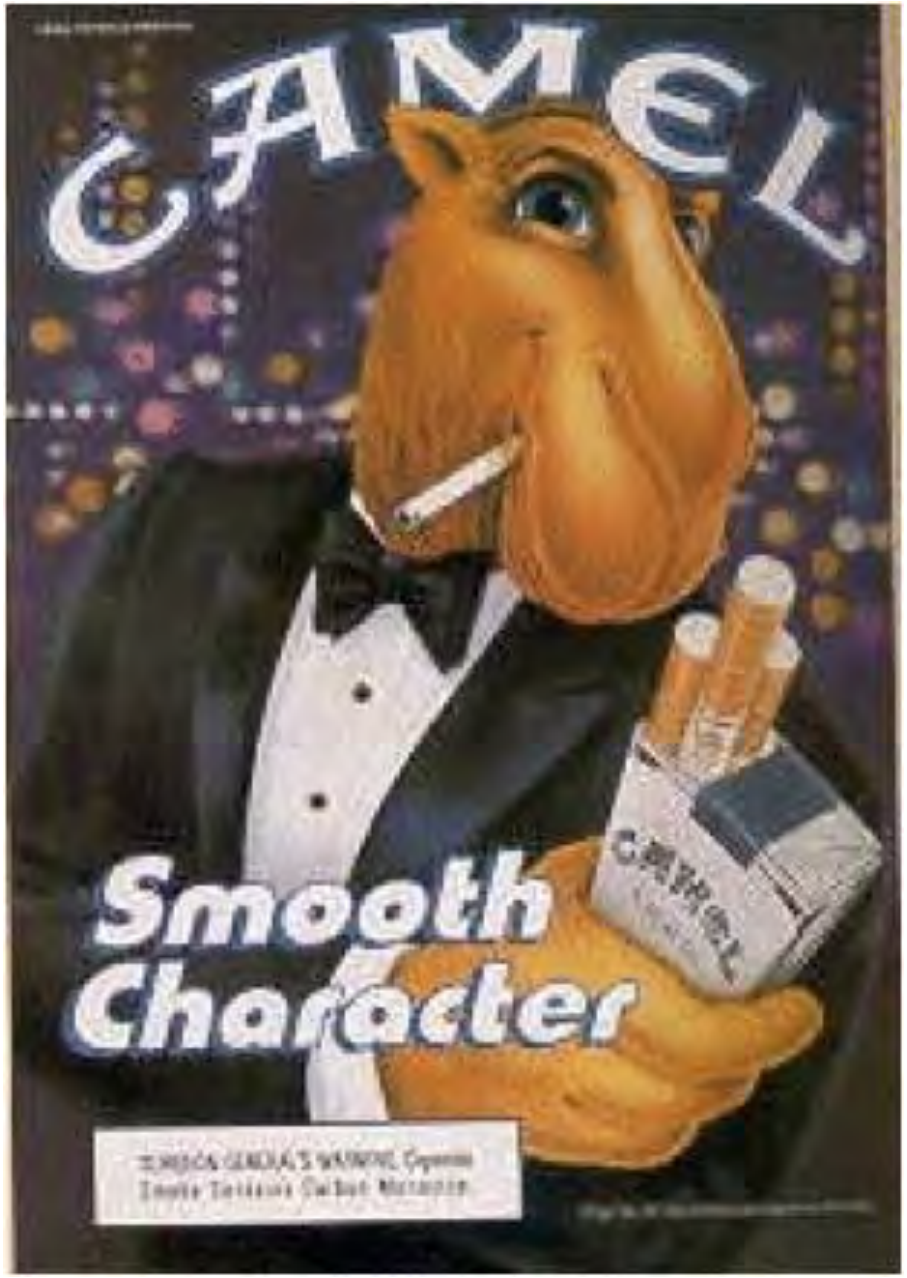
Overview

Big Data and Inequity

- Examples
- Medical Hubris

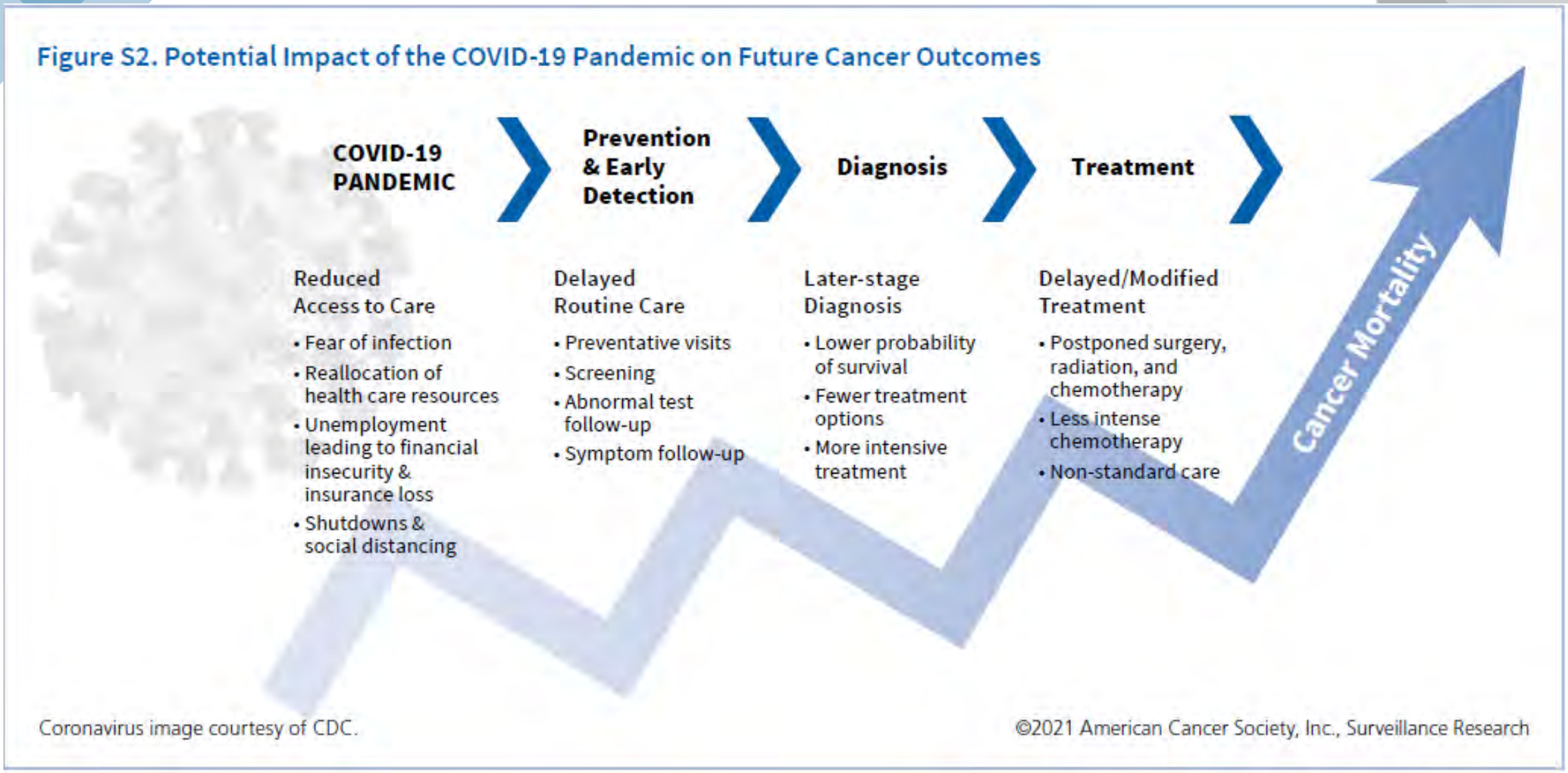
How do we protect communities?

- Prospective community engagement
- Transdisciplinary Research
- Call to Action



- Lung Cancer Screening underutilization continues
- Differential impact based on region, and race
- Impact of the Pandemic, worsening screening access and follow up
- Can we use technology to level the playing field?
- Targeting of historically marginalized communities continue (Black and Indigenous, blue-collar workers and LGBTQ communities)

Potential impact of Covid-19 on Future Cancer Outcomes



Practical Applications of AI and Big Data

- Big Data has many applications in medical care
- Physicians tend to be overly optimistic about the use of technology
- Evidence based data and data mining can be complimentary or antagonistic. *What about patient reported data?*
- Historically excluded communities are vulnerable to exploitation
- There are some protections federally to protect communities (14th Amendment) but they are not strong

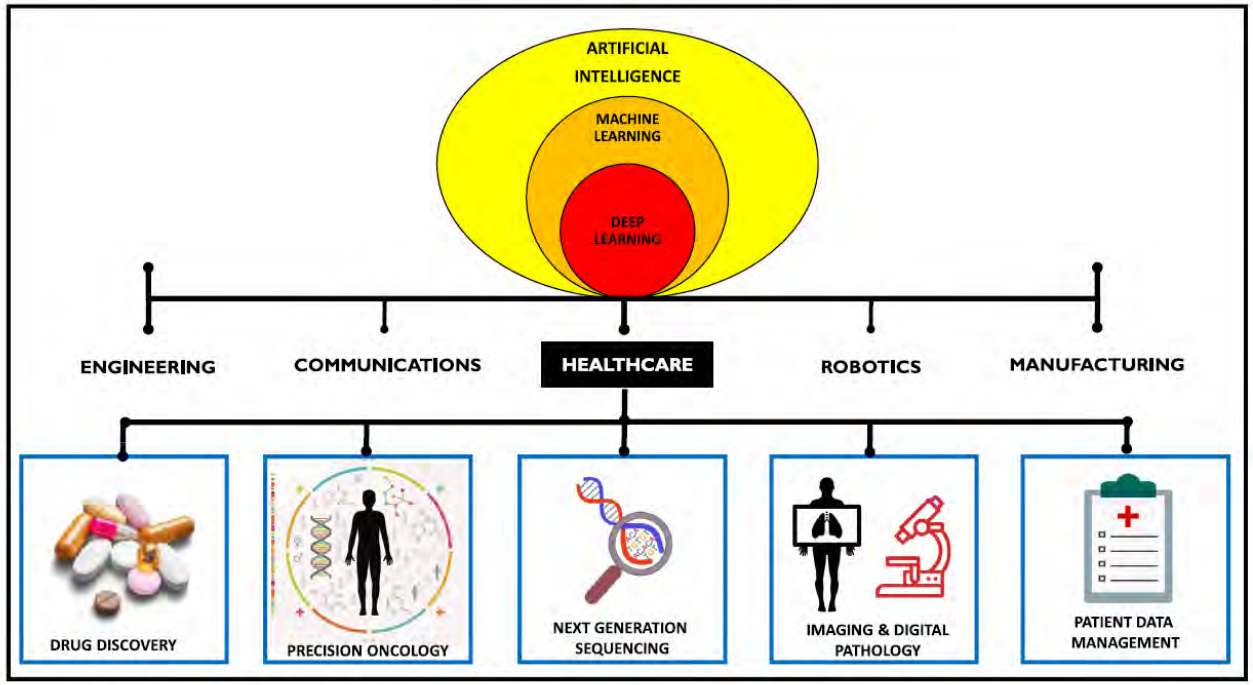


Fig. 1. An overview of the applications of artificial intelligence in some major sectors. Artificial intelligence (AI) and machine learning (ML) have important applications in healthcare and precision oncology. ML is a subset of AI that uses neural networks to solve healthcare problems and predict treatment outcomes by pattern recognition in patient datasets. The accuracy of the data is warranted by implementing deep learning of machines [4–10].

Dlamini et. al. *Artificial intelligence and Big data in Cancer and Precision Oncology* , Comp Struct Biotech J 2020. Beckman et. al. *Reconciling evidence-based Medicine in the era of Big Data. Challenges and Opportunities,* Genome Medicine 2016 Richardson, *Data-Driven Discrimination: A Case for Equal Protection in the Racial Disparate Impact of Big Data*. Georgetown Journal of Law and Modern Critical Race Perspective 2020

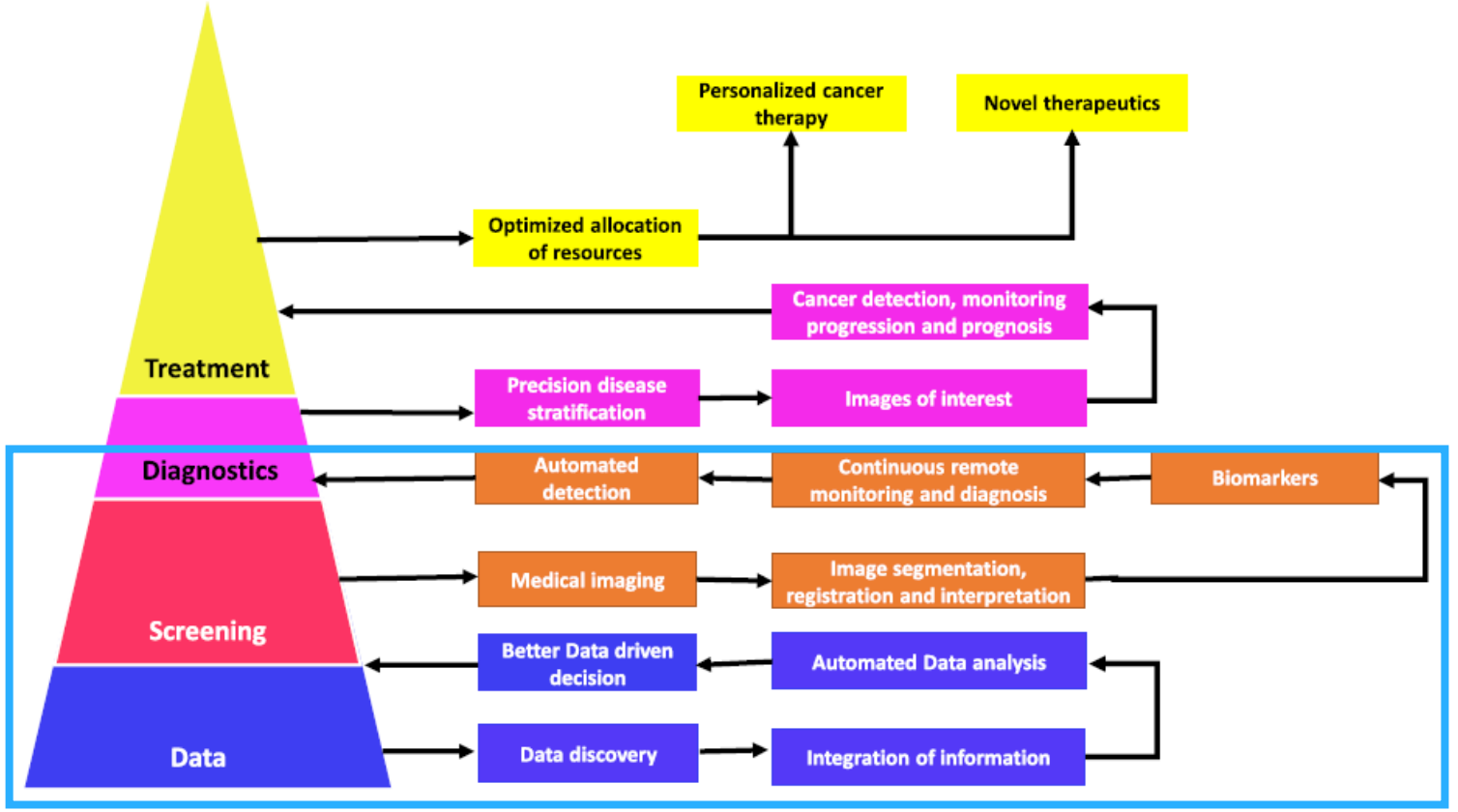


Fig. 3. Artificial intelligence (AI) in cancer medical imaging. Deep learning algorithms in healthcare begins with the gathering of large amounts of data. The curation of this data is then used in the screening of patients to make better data driven diagnosis. Patients can be screened with medical imaging and the presence of biomarkers for disease. Image analysis involves the identification of image of interest and the areas of the image that are important. The application of information from datasets as well as the results of patient screening results in automated detection of malignant tumours. Through classification of different tumours, the application of AI algorithm's will then allow for the use of specific treatments optimised for each individual patient [48].

Dlamini et. al. Artificial intelligence and Big data in Cancer and Precision Oncology , Comp Struct Biotech J 2020.

Bias is Ubiquitous

Structural racism and classism is not an individual act

It is hard to understand how our data is impacted by our structure. While AI algorithms are helpful, they have been shown to "inadvertently" discriminatory. *Facial Recognition Vocal recognition*

The use of AI algorithms and big data is often touted as objective, leading to governmental use. Often the bias is built in

Insurance, loans, IQ/personality test for jobs, criminal sentencing software

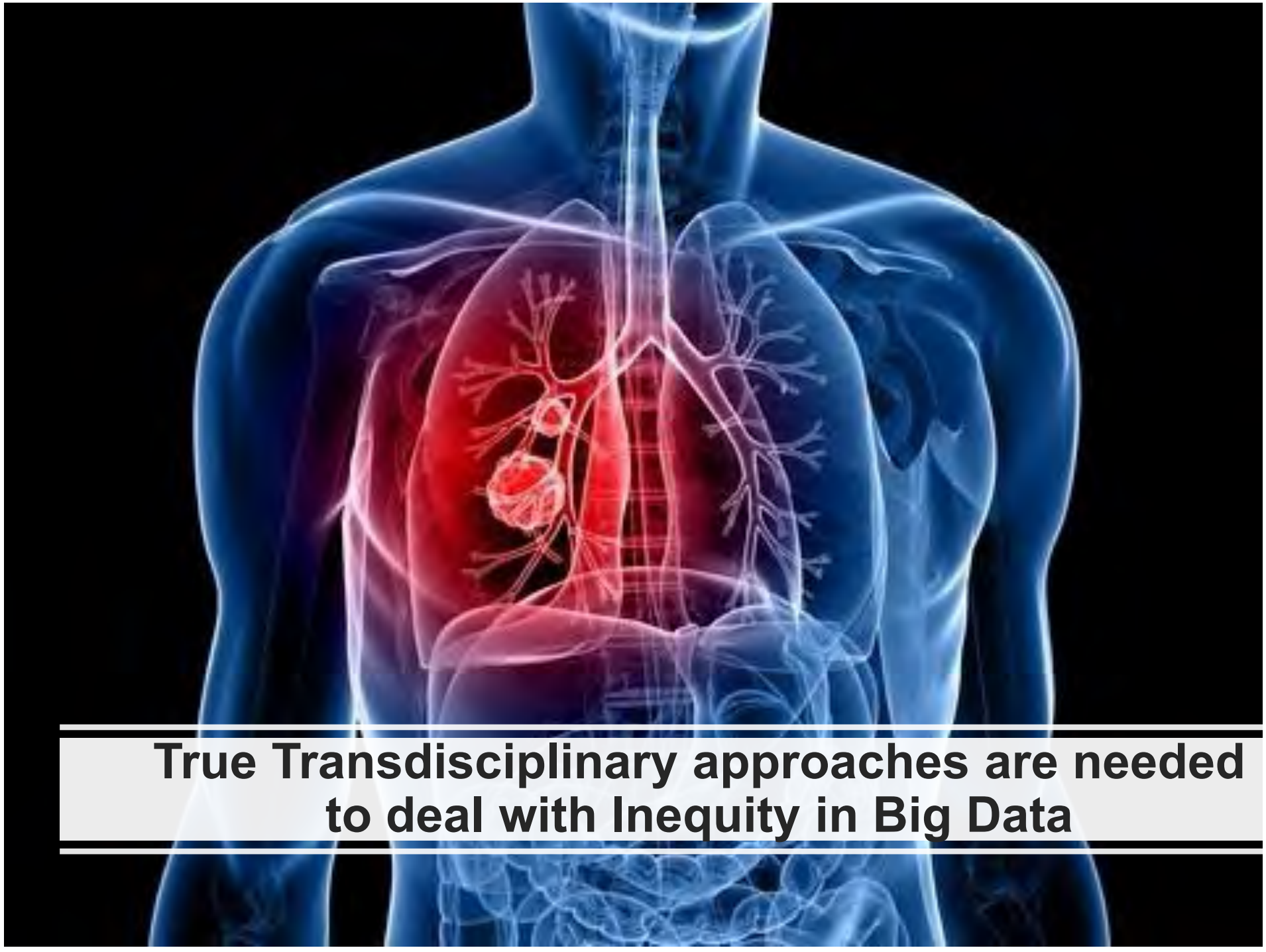
Historically Marginalized communities have a good reason to question the intention of the medical community regarding their data

- Lack of representation in cancer genome datasets
- Careless stewarding of data/tissue for marginalized communities
- Eurocentric focus in germline datasets (Dementia)
- "Race medicine"

Lung cancer screening is important & use of AI might be helpful but w/o real efforts to combat bias, and acknowledgement of the past, we will do the same damage

Intent is often separate from impact

*_Weapons of Math Destruction_ Kathy O'Neil 2017, _Automating Inequity_ Virginia Eubanks 2018, _An American Health Care Dilemma_ Byrd and Clayton 2001



True Transdisciplinary approaches are needed to deal with Inequity in Big Data

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Prospective Opportunities

Ask these questions: *

Does the tool increase the agency and self-determination of historically marginalized groups?
Is the data representative and relevant to our actual society?
Do the participants have agency?
Was the community engaged from the start?

Consciously diverse transdisciplinary teams involved with the research

Cross cutting all areas: technical, clinical, translational, basic science, social science, and policy

The only way to keep us from making the same mistake and getting lost again is to take a different path

Transdisciplinary Research

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Three Types of Cross-disciplinary Research

- Multi

  Scientists across disciplines working together, addressing separate research questions

- Inter
  - Attempt to **transfer knowledge** from one discipline to another
  - Health equity innovation has high levels of complexity that challenge this approach

- Trans

  *Mode of collaboration investigators **operate entirely outside their disciplines**. "beyond and outside all disciplines" and forming its own intellectual space*

Cannon, International Journal of Environmental Research and Public Health 2020, Gehlert et al, Social Work in Public Health 2010

How do we protect communities as we move forward with tool development for LDCT ?

Prospective community engagement

- Have you engaged communities and advocates at the start of your data project?
- Engaged faith-based groups, large employers, community leaders and policy experts?
- Do you have the desire to correct algorithms and acknowledge the bias & unintended consequences?

Build transdisciplinary Teams

- Is your technical team inclusive (technical skills, perspective) and representative of marginalized communities?
- Do you want authentic transdisciplinary input into your Data sets and AI algorithms?

Transdisciplinary Challenges

Key Elements	Description of Key Elements	Important Strategies	Significant Challenges
Openness	respect towards multiple perspectives	institutional support for transdisciplinary approaches	labor and time-intensive
Boundary-spanner	PI to bridge different discipline boundaries	diverse team members	difficult to evaluate/find
Flexibility	multiple pathways of integration & collaboration across discipline norms	cross-disciplinary training & opportunities	fear research will not be perceived as rigorous enough
Trust		build it	more reasons not to
Communication	across various discipline-specific languages	shared language and goals in operationalizing the research	academic publishing organized around disciplines
Stability	stability across expertise and subjectivity	make and invest time to build collaborations	difficulty in assigning roles to team members/*time
Complexity		understanding what advances and hinders collaborative research	the need to not define the problem of analysis too narrowly or broadly

Cannon, International Journal of Environmental Research and Public Health 2020, AACR Science of health disparities Plenary Session 2020

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- Medical research has often been used knowingly and unknowingly to categorize and subjugate, immigrants, poor and descendants of slaves in the US.
- Research has not been “agnostic” and has until very recently has overtly frowned upon social justice approaches in medicine.
- The legacy of this remains today Big data and AI are the new frontier. Have we remembered any lessons from the past?
- If you haven’t already, I recommend folks listen the 1619 podcast from NYT episode 4

  “*When the Bad Blood Started*”