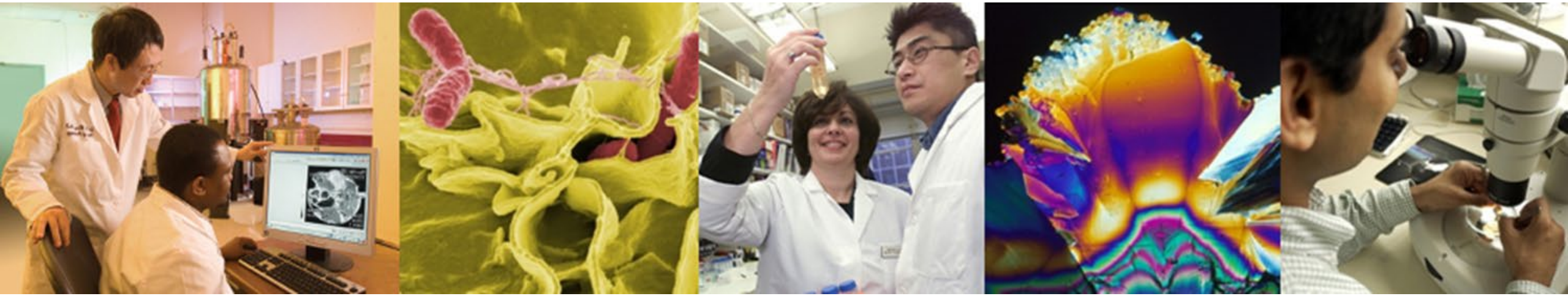
NIH Update

Council of Councils Meeting
January 24, 2020



Lawrence A. Tabak, DDS, PhD
Principal Deputy Director, NIH
Department of Health and Human Services

Topics for Today

- Budget Update
- Artificial Intelligence
- INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome)
- Ending Sexual Harassment in Biomedical Research

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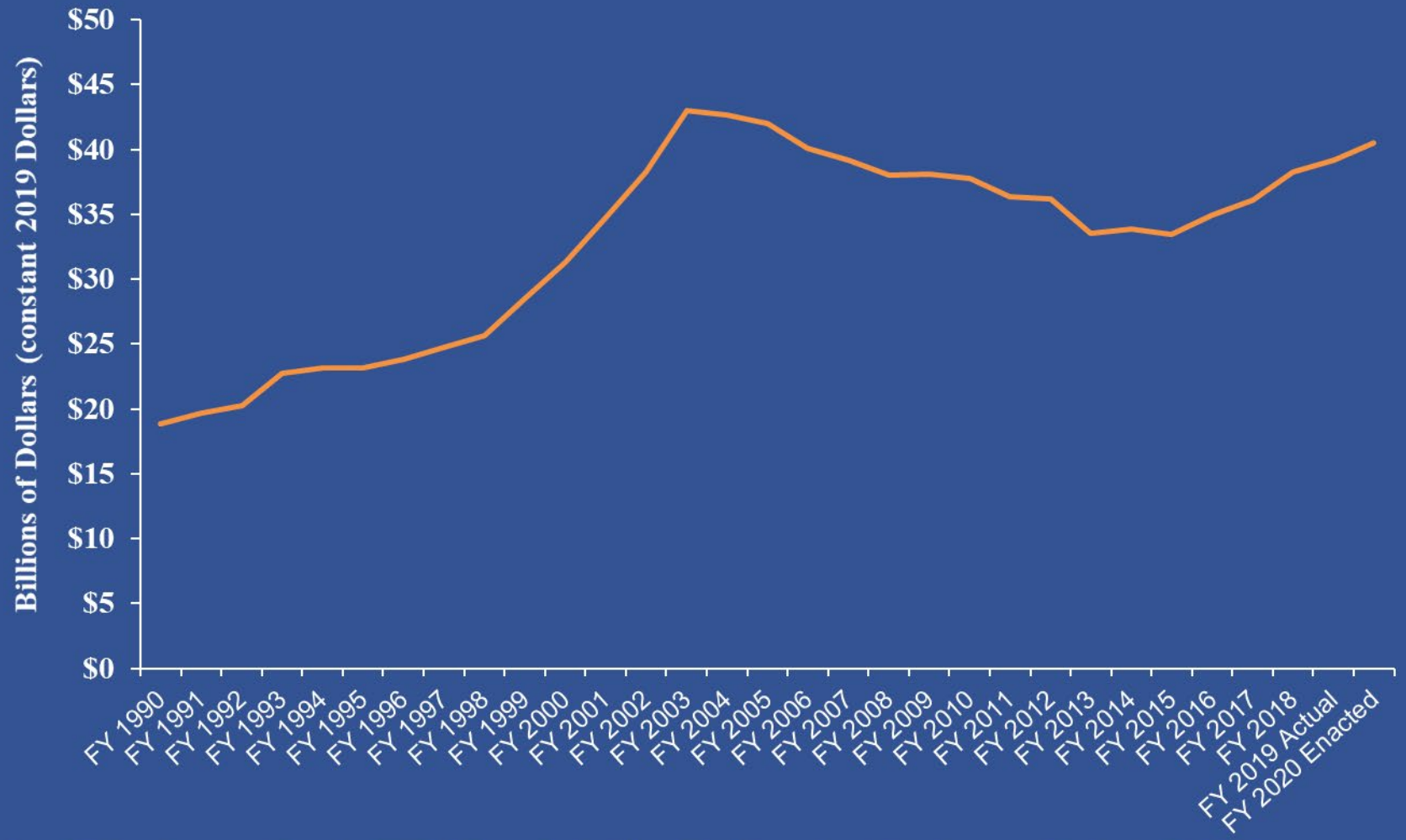
National Institutes of Health Funding
1990-2020



Note: Dollar values are adjusted to 2019 dollars using the Biomedical Research and Development Price Index (BRDPI), http://officeofbudget.od.nih.gov/gbiPriceIndexes.html

Source: NIH Office of Extramural Research and Office of Budget source data (January 2019 - January 2020).

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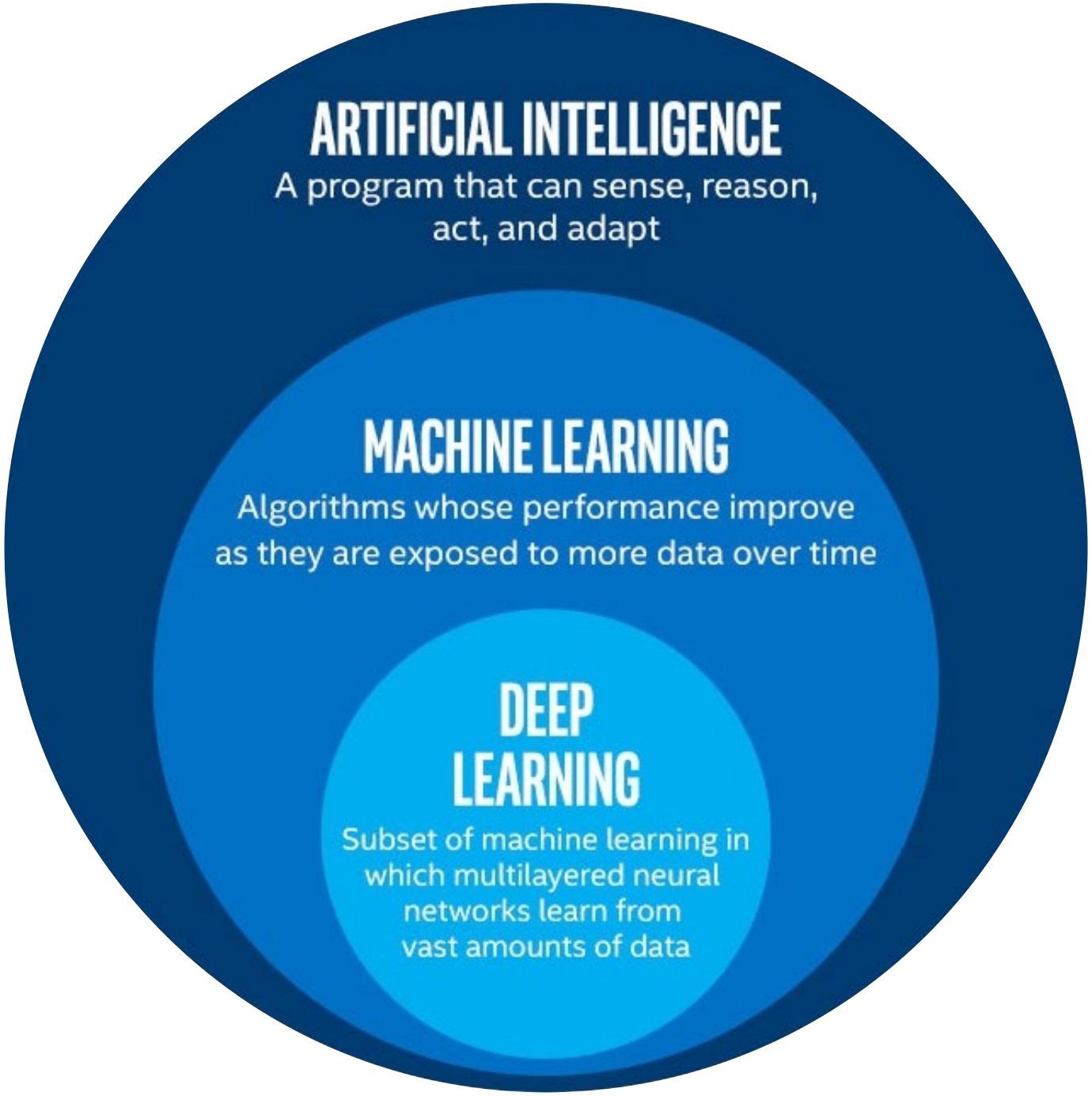
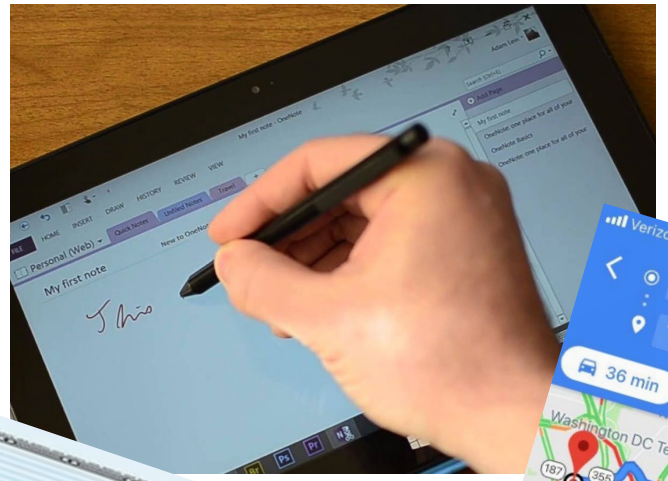
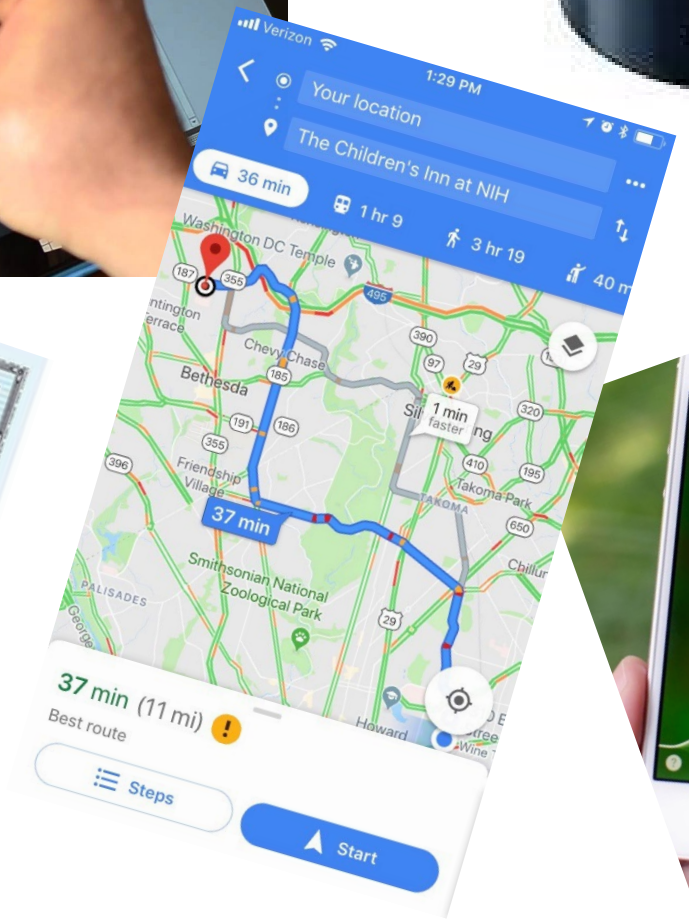
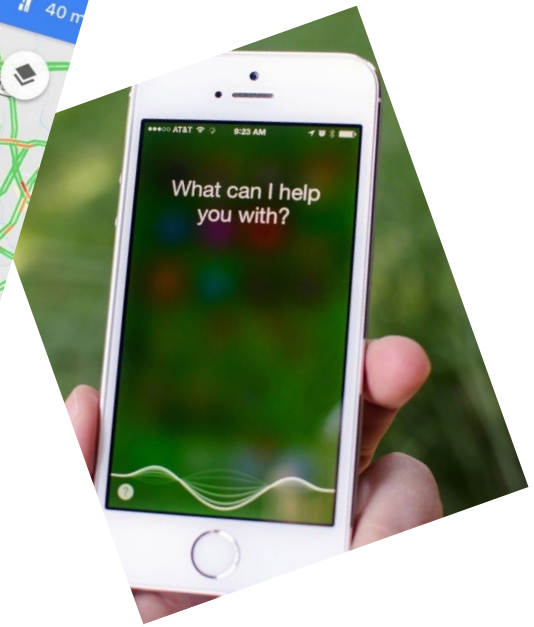

ARTIFICIAL INTELLIGENCE
A program that can sense, reason, act, and adapt
MACHINE LEARNING
Algorithms whose performance improve as they are exposed to more data over time
DEEP LEARNING
Subset of machine learning in which multilayered neural networks learn from vast amounts of data

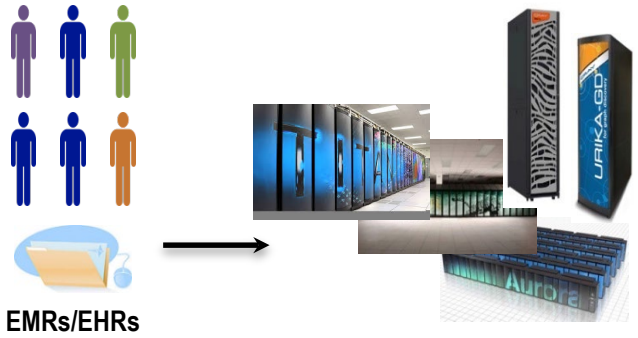
Every Day Artificial Intelligence Applications



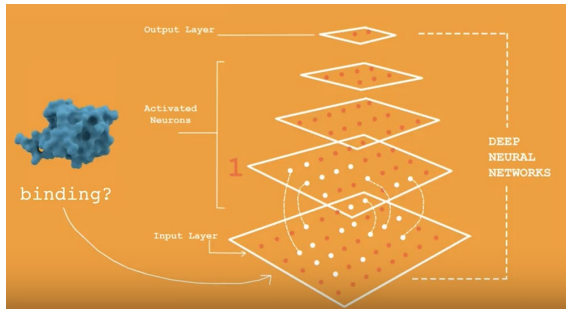




AI in Biomedicine: Opportunities

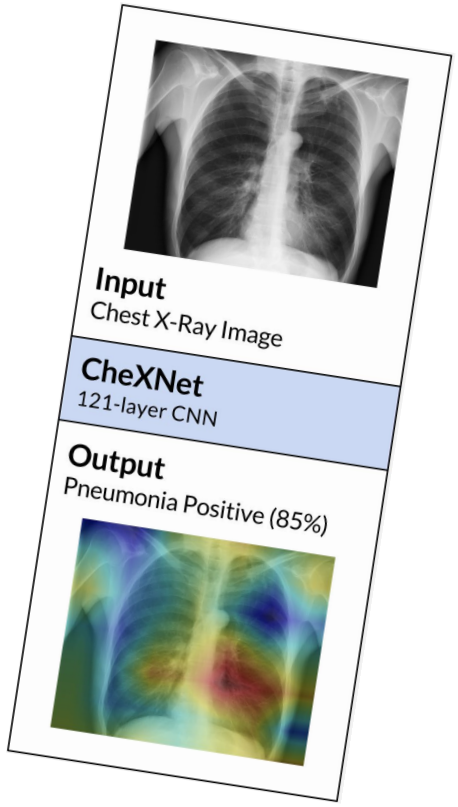


Extract medical information from text in EMRs/EHRs

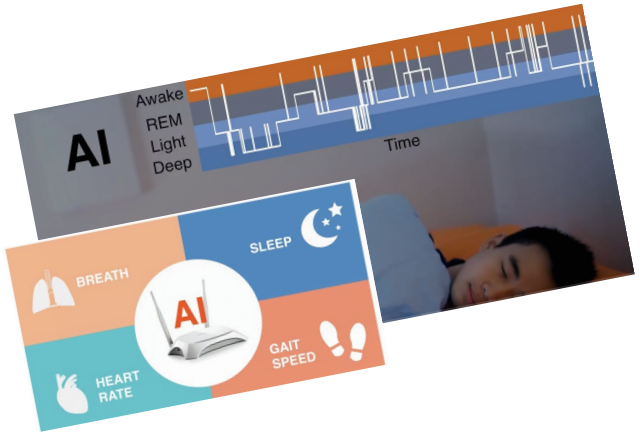


Interpret genomic sequence data to understand impact of mutations on protein function

Read medical images and help diagnose diseases like pneumonia and cancer



Monitor sleep and vitals to send information about health at home to doctors



Determine which calls to child welfare systems warrant deployment of family support and prevention resources to protect at-risk children

Examples from Katabi, Ng, Putnam-Hornstein, Troyanskaya, and others

AI in Biomedicine: Legal and Ethical Challenges

RESEARCH ARTICLE

Obermeyer et al., Science 366, 447–453 (2019)

ECONOMICS

Dissecting racial bias in an algorithm used to manage the health of populations

Ziad Obermeyer[1,2]*, Brian Powers[3], Christine Vogeli[4], Sendhil Mullainathan[5]*†

Health systems rely on commercial prediction algorithms to identify and help patients with complex health needs. We show that a widely used algorithm, typical of this industry-wide approach and affecting millions of patients, exhibits significant racial bias: At a given risk score, Black patients are considerably sicker than White patients, as evidenced by signs of uncontrolled illnesses. Remedying this disparity would increase the percentage of Black patients receiving additional help from 17.7 to 46.5%. The bias arises because the algorithm predicts health care costs rather than illness, but unequal access to care means that we spend less money caring for Black patients than for White patients. Thus, despite health care cost appearing to be an effective proxy for health by some measures of predictive accuracy, large racial biases arise. We suggest that the choice of convenient, seemingly effective proxies for ground truth can be an important source of algorithmic bias in many contexts.

Pathology Archive and Database

ACD Artificial Intelligence Working Group Members

Rediet Abeme
Harvard

Greg Corrado
Google

Kate Crawford
AI Now Institute

Barbara Engelhardt
Princeton

David Glazer
Verily (Co-Chair)

David Haussler
USCS

Dina Katabi
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Science & AI Lab

Daphne Koller
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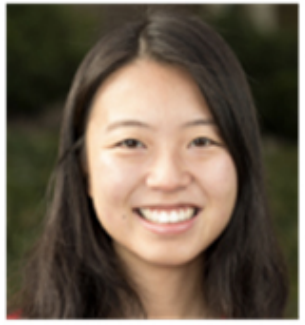
Stanford Univ

Eric Lander
Broad Institute

Jennifer Listgarten
Berkeley

Michael McManus
Intel

Lawrence Tabak
NIH (CoChair)



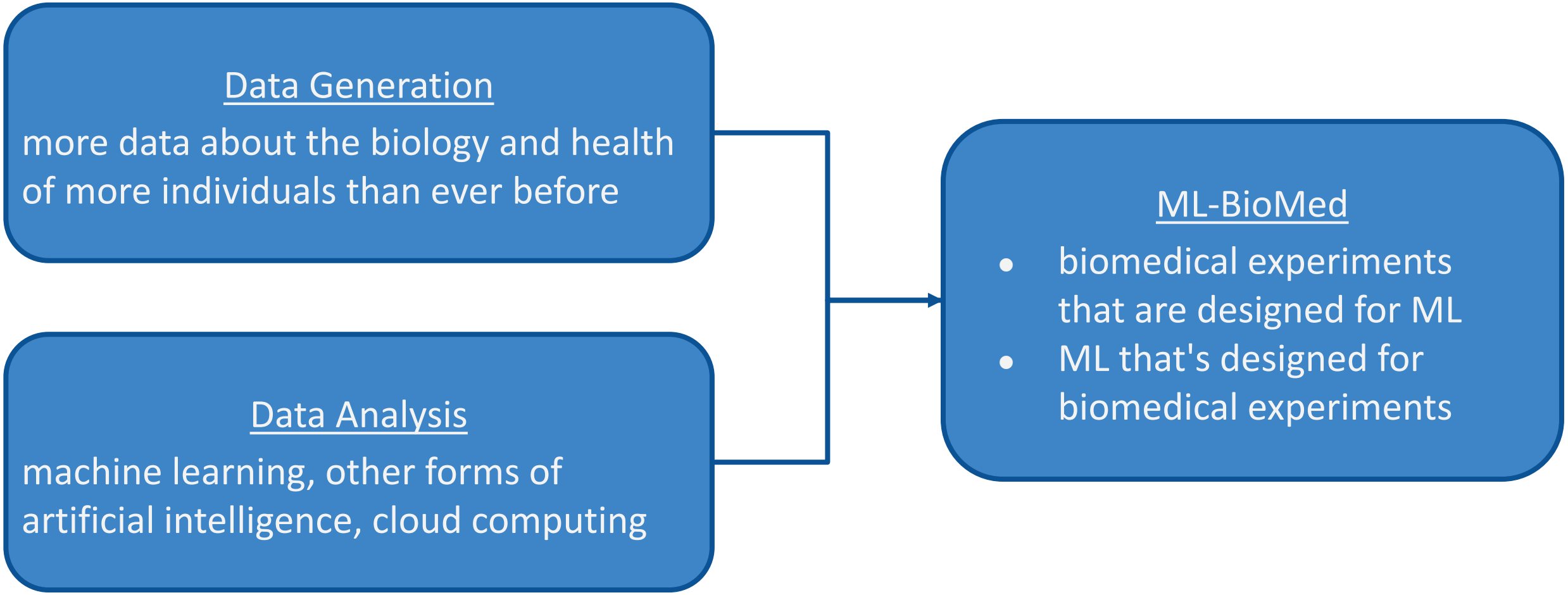
Serena Yeung
Sanford

https://acd.od.nih.gov/documents/presentations/12132019AI_Report.pdf

Charge to the AI WG (December 14, 2018)

- What opportunities exist for cross-NIH efforts in AI that reach broadly across biomedical topics and have positive effects across many diverse fields?
- How can NIH build a bridge between the computer science community and the biomedical community?
- What can NIH do to facilitate training that marries biomedical research with computer science?
- What are the major ethical considerations as they relate to biomedical research and using AI for health-related research and care? How should NIH build these considerations into AI-related activities?

Parallel Revolutions:
Fusing Biomedicine and Machine Learning



(1) Support flagship data generation efforts to propel progress by the scientific community

Support flagship efforts that generate large-scale experimental data, with billions of data points designed to:

i. be well-suited for ML analysis and inference
ii. address key biomedical challenges
iii. stimulate new approaches in machine learning

And that implement processes designed to:

i. develop improved criteria and technical mechanisms for data access
ii. strengthen ethical criteria for dataset use (consent, privacy, accountability, ...)

Projects should:

- address key biomedical challenges using ML methods
- advance ML methods for future use in biomedicine
- produce transformative data sets, designed with ML in mind
- propel new ways to gather massive data in biomedicine
- **involve strong engagement from leading ML researchers**

Project review should:

- **incorporate expertise in ML as well as traditional biomedical domains**

(2) Develop and publish criteria for ML-friendly datasets

Publish criteria for evaluating datasets based on their value for ML-based analysis.

- what makes a dataset most useful for ML-based analysis?
- what attributes are and aren't addressed by existing datasets?
- start as guidelines; within two years recommend a subset as requirements

Examples of potential criteria:

- **clear provenance:** as much metadata as possible, to detect & correct for batch effects
- **well-described data:** what does each variable mean? what's the distribution of values?
- **accessible data:** flexible data access policy, reasonable data access process
- **large sample size:** to allow training (and evaluation) without overfitting
- **multimodal data:** to study complex systems from multiple perspectives
- **perturbation data:** includes outcomes ("outputs") as well as measurements ("inputs")
- **longitudinal data:** to allow modeling and prediction of progression
- **active learning:** data grows over time, incorporates new data-gathering techniques, and uses ML-based analysis of existing data to inform future data generation

(3) Design and apply “datasheets” and “model cards” for biomedical ML

- Develop and publish best practices for:
  - “datasheets” that describe & evaluate training datasets
  - “model cards” that do the same for generated models
- Test the best practices in the real world:
  - build after-the-fact examples for existing datasets
  - apply to new datasets, and update the best practices
- Once best practices have been updated:
  - require datasheets and model cards for all NIH extramural grant applications and NIH intramural projects that involve ML research
  - encourage journals to do the same for paper submission and publication

Potential datasheet best practices:

- demographics and UBR characteristics
- privacy, consent, and copyright issues
- known blind spots, which could otherwise create hidden biases

Potential model card best practices:

- what training data was used
- how training and validation were done
- known limitations on applicability
- intended use, and potential harms of inappropriate use

(4) Develop and publish consent and data access standards for biomedical ML

Charge a working group to address the substantial gap between consent standards typically required in biomedical research and consent standards typically applied in ML.

- Standards should ensure appropriate consent for biomedical ML, by reconciling:
  - common ML practices;
  - existing biomedical best practices; and
  - ongoing efforts in the global biomedical community to harmonize consent and data use standards to facilitate the widest responsible use of data, while ensuring protections against potential harms
- Once standards are developed and refined, implement appropriate mechanisms to ensure adherence.

Background: it is common practice for ML developers to create training sets for ML models by scraping the internet for public text, images, and videos without explicit additional consent for such reuse.

(5) Publish ethical principles for the use of ML in biomedicine.

Charge a working group to develop ethical principles for ML in biomedicine.

- address unique ethical challenges in this space, that add to existing challenges for the use of ML in other public and private sector settings
- include expertise in ML, biomedicine, law and public policy, Science and Technology Studies
- include representation of communities that could be negatively impacted by ML in biomedicine
- refine the draft principles by testing them against new publications, and reviewing the gaps
- once refined, recommend appropriate mechanisms to ensure adherence

Principles are likely to cover:

- **fairness and equity:** avoid reinforcing existing biases; don't contribute to future health disparities
- **privacy and consent:** coordinate with Recommendation 4
- **reliability, safety, and security:** extend existing mechanisms as needed to work with ML-powered tools
- **accountability and governance:** extend existing mechanisms as needed to account for the unique attributes of ML-powered tools
- **education:** coordinate with Recommendation 6 to include ethics content in curricula; inform broader audiences

(6) Develop curricula to attract and train ML-BioMed experts

Curricula goals are to:

- **help experts from all fields successfully collaborate across disciplines**
- entice upcoming and established data experts into biomedicine
- inform upcoming and established biomedical experts about modern ML techniques, strengths, and limitations
- invite social scientists and humanists to collaborate and inform on best practices
- raise the awareness of biomedical policymakers and decision makers about ML opportunities and risks

Potential curriculum elements include:

- emphasis on fundamental concepts, not technical details or fact memorization
- risks of mis-applying ML in biomedicine, such as hidden bias from training sets.
- (in ML courses) motivating examples from biology and clinical medicine
- (in ML courses) hands-on exercises to build models from real-world biomedical datasets
- (in bio courses) hands-on exercises to use real-world ML tools to train and evaluate biomedical models

(7) Expand the pilot for ML-focused trainees and fellows

- Piloted in summer 2019 with three ML projects in the Civic Digital Fellowship and two in the Graduate Data Science Summer Program.
- Make ML a major ongoing focus of these and similar programs going forward.

(8) Convene cross-disciplinary collaborators

- Support biomedical tracks and workshops at leading computational conferences.
  - piloted with workshop at NeurIPS in December 2019
- Expand to other types of conferences.
  - including general biomedicine and scientific conferences
- Explore other opportunities for convening experts from different fields.

Topics for Today

- Budget Update
- Artificial Intelligence
- HEAL (Helping to End Addiction Long-term)
- **INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome)**
- Ending Sexual Harassment in Biomedical Research

INCLUDE: The Three Major Components

FY18 The NIH INCLUDE Project Research Plan

- Basic science studies
  - Targeting high-risk, high-reward
- Cohort Study
  - Connect existing resources and expand to inclusion of individuals with Down Syndrome
- Clinical trials network
  - Create a “medical home” for individuals with Down Syndrome and encourage their inclusion into ongoing clinical research

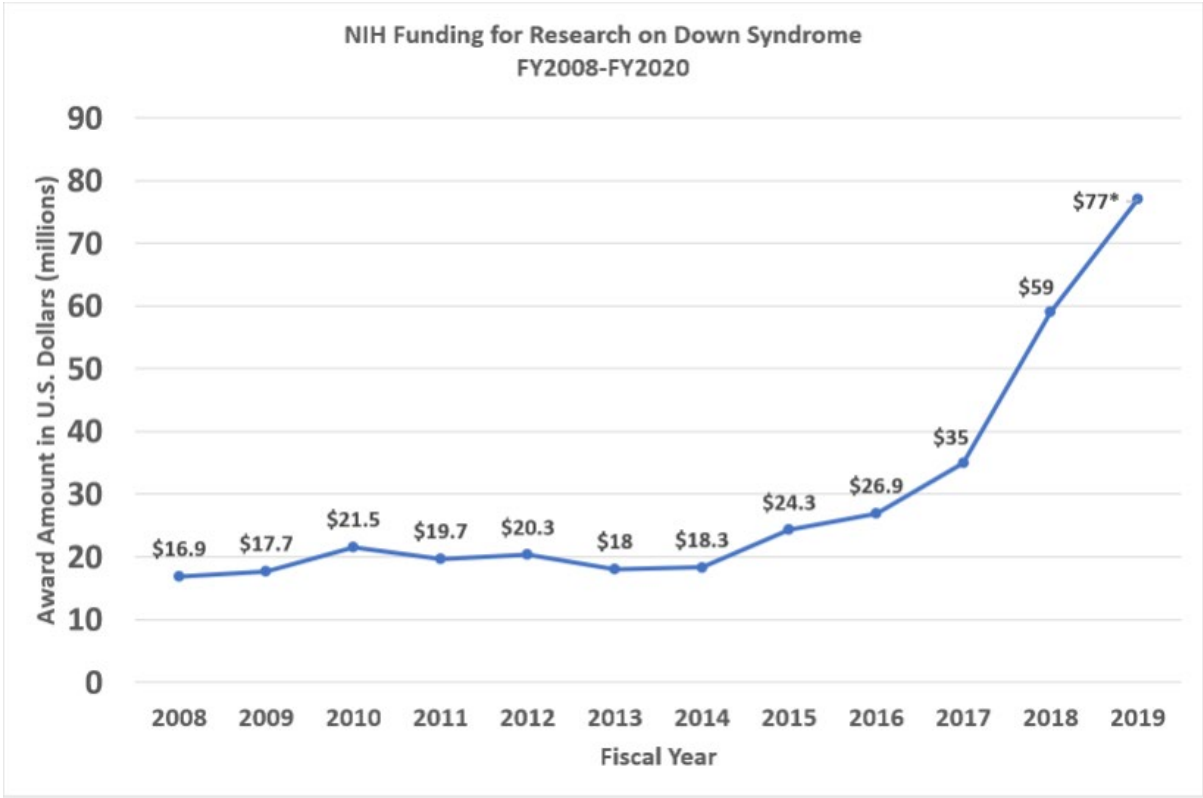
Building Investments at NIH

FY19 (year 2): Building a Research Program

- Supported new awards and RFAs
- Strategically used competitive revisions and supplements
- Community Engagement

FY20 (year 3): Expanding on Investments

- $60M line item in OD Appropriations
- Reissue FY19 RFAs while adding FY20 Opportunities
- Community Engagement: Workshops
  - “The State of the Science for Meaningful Clinical Trials in Down syndrome” (May 2020)
  - ”Opportunities in Basic Science for Down syndrome” (Fall 2020)



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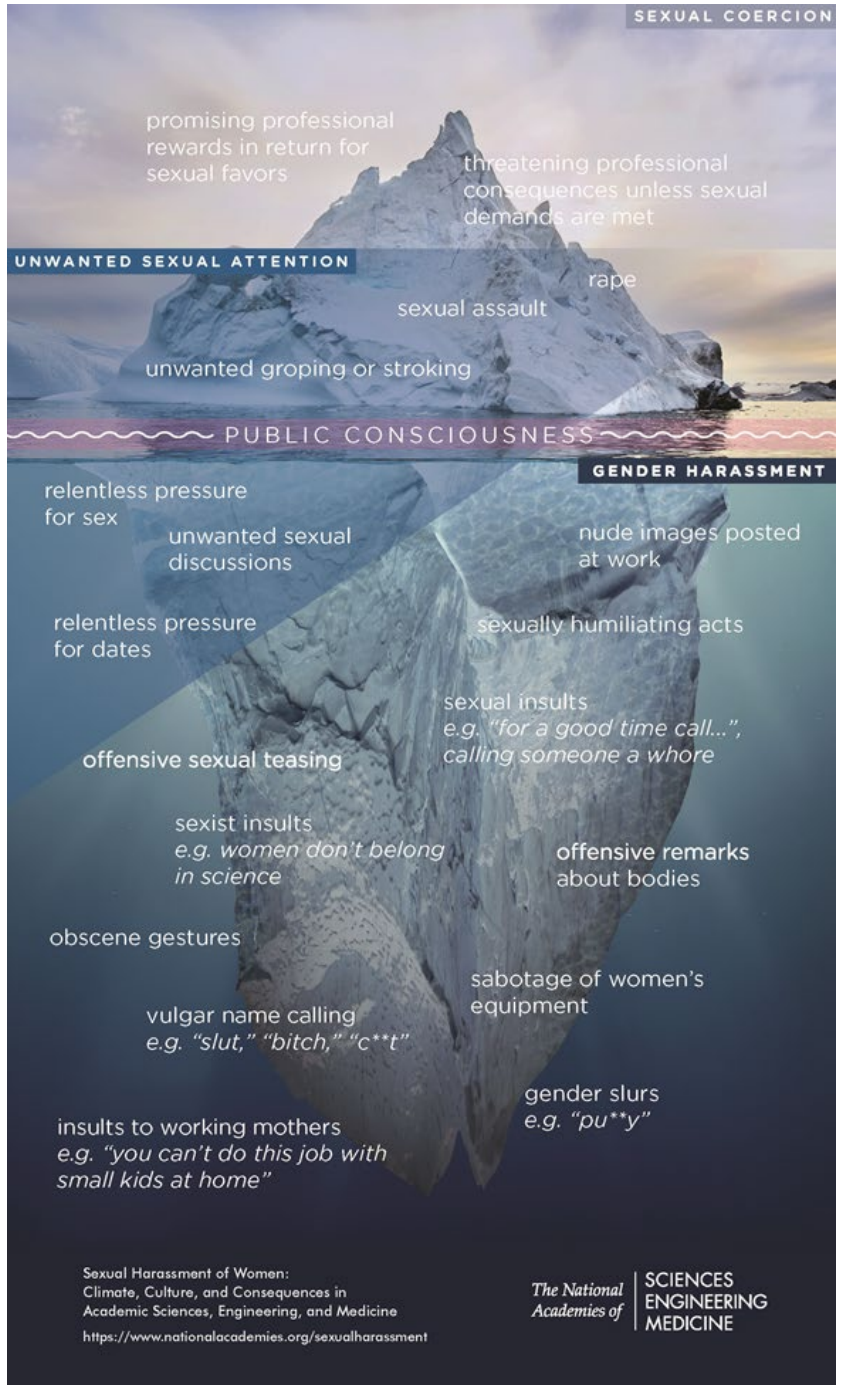


Sexual harassment is morally indefensible, unacceptable, and presents a major obstacle that is keeping women from achieving their rightful place in science

Key Definitions

Overarching Themes

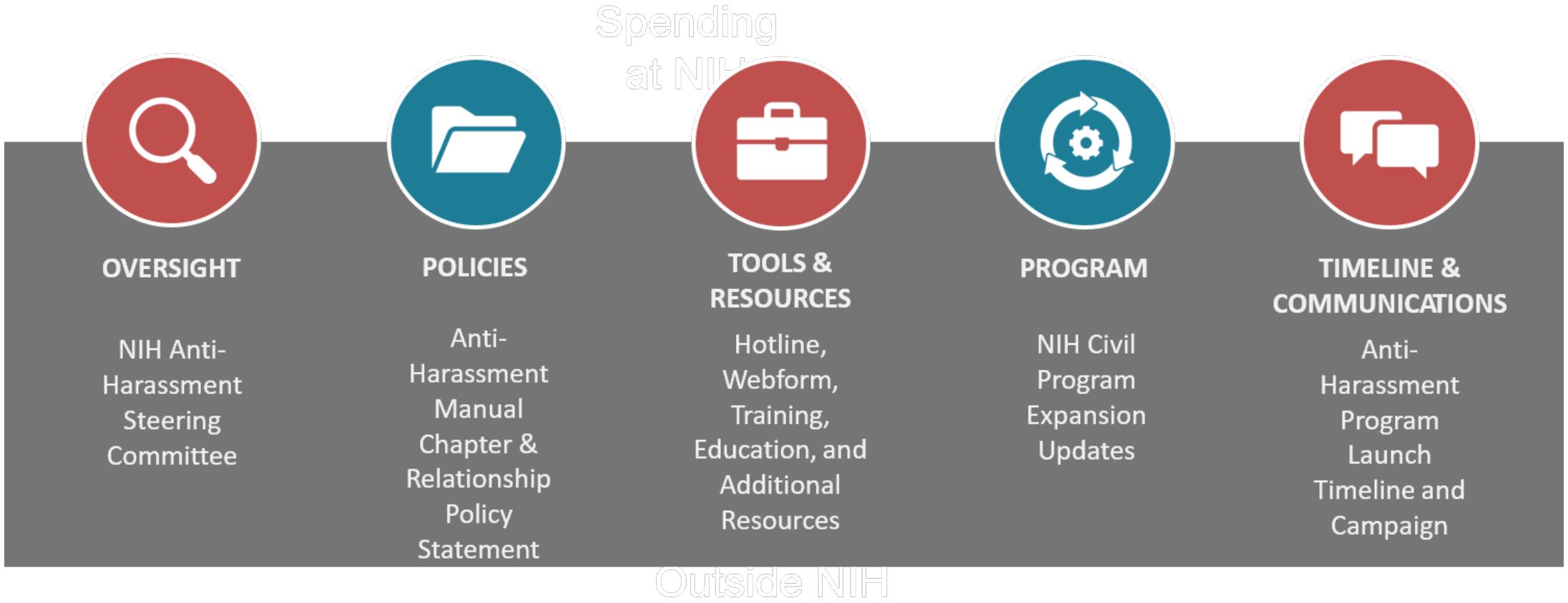
1. Increase Transparency and Accountability in Reporting of Professional Misconduct, especially Sexual Harassment
2. Establish Mechanisms for Restorative Justice
3. Ensure Safe, Diverse, and Inclusive Research and Training Environments
4. Create System-wide Change to Ensure Safe, Diverse, and Inclusive Research Environments

View the Final Report: https://acd.od.nih.gov/documents/presentations/12122019ChangingCulture_Report.pdf

Sparking Introspection

- Are some of the values we hold dear in the research enterprise contributing to risk factors for harassment?
  - “Meritocracy”
  - Lab as “family”
  - Apprenticeship system of training
- Are we too willing to forgive bad behavior in exchange for good science/scientific prestige?
  - Academic freedom vs. freedom of behavior
- How does the way we fund research contribute to the culture that is driving women out of science?

NIH Internal Anti-Harassment Actions



NIH Survey: Goals

1. Prevalence of harassment at the NIH
2. Workplace climate associated with harassment
3. Impact of harassment on mental and physical health
4. Perspectives on reporting harassment

NIH Survey: Participants and Response Rates

- Survey administered from January to March 2019
- Invited all who work at the NIH
  - Federal Employees
  - Trainees
  - Contractors (with company permission)
  - Volunteers
- 44% response rate (all NIH); 56.2% (federal employees)
- Compared to all NIH federal employees, respondents were more likely to be women (62% vs. 58%) and age 18–34 (18% vs. 10%)

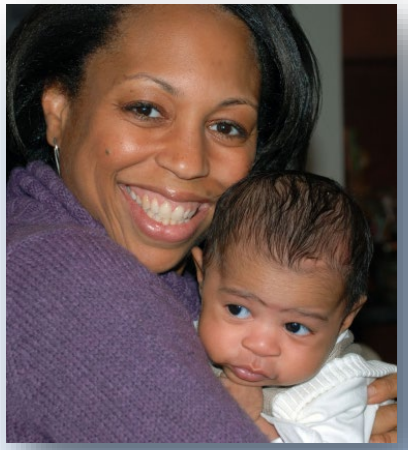
Key Finding from the NIH Survey

- One in five respondents had at least 1 incident of sexual harassment in past 12 months.
- Most vulnerable populations with highest incidence are Women who are trainees (fellows and students), younger individuals, sexual and gender minorities, and individuals with disabilities.
- Over half did not talk to anyone about their experience.
- Those who did not consider their supervisor supportive are more likely to experience sexual harassment.
- Those experiencing bullying are more likely to experience gender and sexual harassment.

Bottom Line: It Is Time for Change

"…sexual harassment is about power. The goal of the perpetrator, most commonly but not exclusively a man, is to objectify, exclude, demoralize, diminish, and coerce the victim, most commonly a woman, to exert power over her. It's morally indefensible, it's unacceptable, and it presents a major obstacle that is keeping women from achieving their rightful place in science." – NIH Leadership (Feb 28, 2019)

We can do better. We must do better!




NIH...

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Turning Discovery Into Health