

Health Equity by Design

Presentation to Health Information Technology
Advisory Committee (HITAC)
The Office of the National Coordinator for Health
Information Technology (ONC)

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Health Equity by Design

Use of Data Artificial Intelligence and Machine Learning (AI/ML), Systems Integration & Interoperability

Outline

1. Concept of health equity by design
2. Our commitment and efforts to building health equity by design
3. Recommendations for HITAC

Proposed Definition of the Concept of Health Equity by Design

Concept means: Centering equity, fairness and justice principles in **data and evidence generation** for health, implementing equitable standards and EHR **interoperability** and promoting human-centered **AI and machine learning technology** design and development practices:

- **Timely** and **secure** access of **complete, accurate** and **unbiased** electronic health data, including all relevant sources of health determinants data;
- **Inclusive** and **human-centered** design, development and implementation of AI and machine learning technologies, integrating health equity and racial justice principles along ethical AI dimensions;
- **Fairness** and **transparency** in data and evidence generation including source, quality, diversity and completeness, accuracy;
- Systems interoperability that includes high quality, relevant SDoH **data standards** that captures a complete picture of a patients' health journey, life circumstances, their communities and workplaces;
- **Identifying** and **mitigating** all potential **sources of bias** in AI and machine learning algorithms to prevent harmful effects when used in clinical or healthcare decision-making;
- Establishment of **broadband connectivity** as a SDoH, with formal recognition and adoption of standards and policies including evaluation of broadband-enabled technologies to bridge the digital divide.

IBM commitment to health equity through action



Building **inclusive technology** and promoting inclusive language



Hospital Measures: equity and social needs index: Incorporating community health measures and identifying social needs indicators



Health Insights: Building **health equity dashboards** and metrics



Code for Justice & Call for Code Emb(race) challenge



TechQuity initiative: Integrating health equity, racial justice and ethical AI



Design justice for racial equity to promote inclusive design



Mitigating bias in **artificial intelligence and machine learning algorithms**



IBM Tech for Justice to devise novel and practical ways to promote fairness, racial equity and social justice



Social determinants of health mapping and precision geography with demographics

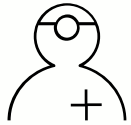
Five Aspects of Bias Across the Data Generation and Technology Development Continuum: Research, Data Science and AI-ML Algorithms and Digital Technologies



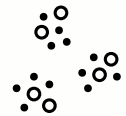
Opportunities to address and mitigate Bias



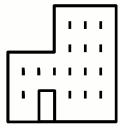
Evidence



Experience / Expertise



Exclusion








Environment



Empathy



Five Aspects of Bias Across the Data Generation and Technology Development Continuum: Research, Data Science and AI-ML Algorithms and Digital Technologies

<h2>Evidence</h2> 	<h2>Experience/ Expertise</h2> 	<h2>Exclusion</h2> 	<h2>Environment</h2> 	<h2>Empathy</h2> 
<p>Research bias: Lack of equitable standards around how our science is funded, conducted, reviewed, published and disseminated; lack of inclusion/diversity in clinical trials, researcher diversity, and limited studies incorporating real-world data for health insights</p>	<p>Provider bias: Provider expertise and experience; cognitive biases; and in-group biases Lack of health data insights and evidence; unconscious biases, pre-existing stereotypes or discriminatory practices from providers or health professionals that can influence data that feeds into EHR and claims data</p>	<p>Embedded data bias: data invisibility, incomplete health data, e.g., missing data or incomplete data in EHR's favoring groups who have access and robust health data profiles; Data bias in sample selection, modeling structure and selection of metrics for predictions Lack of cohort diversity; training data not representative</p>	<p>Environmental, occupational and lifecourse exposures: Lack of data on the complete etiological context and exposures of a patient's health, including lack of opportunities and resources, such as broadband connectivity and social factors that can trigger adverse health outcomes</p>	<p>Data empathy: Lack of knowledge, understanding and/or experience about the people, places, factors that make up the data – unable to recognize the bias and optimize analysis; lack of knowledge of data source and real-world evidence or social implications</p>

References: Dankwa-Mullan, I. Perez-Stable E et. al eds [The Science of Health Disparities Research](#); 2021 Wiley
Dankwa-Mullan, I - [Eliminating bias in health science data](#). Dankwa-Mullan I, [Examining health disparities in precision medicine](#)

Integrate Equity and Racial Justice Principles into Ethical AI Framework for tool development in healthcare

Align equity and racial justice principles across ethical AI dimensions

Ethical AI Dimensions

- Accountability
- Impact of Algorithms
- Data Responsibility
- Design equity
- Discrimination and Bias
- Empathy
- Explainability
- Fairness
- Human Oversight

- Human Autonomy
- Inclusion
- Social Cohesion
- Inclusive Technology
- Moral Agency
- Privacy Protection
- Robustness, Safety
- Transparency and Trust
- Value Alignment

Dankwa-Mullan, I. Scheufele E., et al. ["A Proposed Framework on Integrating Health Equity and Racial Justice into the Artificial Intelligence Development Lifecycle."](#) *Journal of Health Care for the Poor and Underserved*, vol. 32 no. 2, 2021, p. 300-317..

Immediate Steps

- ❑ Start with an honest assessment of the **objectives for your goals for health equity by design**, the **value drivers** you're pursuing, your ethics and business imperatives.
- ❑ Consider the state of **current data sources, architecture** and where and how it needs to evolve for achieving equity in health IT.

Preparing your data requires several key steps:

- Prioritizing data integration across the enterprise by implementing the policies required to break data out of organizational silos
- Establishing protocols and standards to collect diverse, comprehensive, accurate, correct and accessible data
- Establishing a common structure and standard that enables diverse data types and sources to be made consistent and usable by health IT systems
- Implementing checks and balance systems to manage unintentional bias and potential ethical, social and legal concerns

Recommendations

1. Implement digital health IT platforms and an infrastructure that can leverage millions of data points to deliver an **integrated ecosystem** of **health, social and mental health care services** tailored to **diverse patient populations**.
2. Data is the foundation of Health IT. Build integrated care systems that **streamlines clinician workflows** and effectively track the **patient journey** with aggregated sources of relevant clinical, social, and environmental data to ensure a more seamless continuum of care.
3. Harness the power of real time data and build **health equity dashboards** to collect, track and monitor progress to promote health equity, and improve patient safety.
4. Enable connected, seamless, and simplified healthcare experiences to facilitate meaningful, **equity-focused value-creation workflows**, and interactions for when, where, and how patients, clinicians, and administrators need to access it through visual interactive health equity dashboards.

Continued:

5. Promote **data responsibility** that includes ensuring data diversity and inclusion of determinants of health data in training and processing. Ensure data governance, data sovereignty and ownership protocols, the inclusion of race, ethnicity data, language and cultural heritage.
6. Develop and build interoperability and **SDoH data standards** that captures a complete picture of patients' health, life circumstances, their communities, and workplaces to better anticipate their needs and coordinate their care more effectively.
7. Optimize **administrative and clinical efficiency** through well-coordinated care, timely information sharing and prompt referrals, informed through rich clinical and social needs data.
8. Promote **equitable access** to ensure the success of **hybrid care systems** for everyone. Address disparities in broadband access and lack of connectivity for all patients, poor EHR integration. Leverage data-driven platforms and evaluation feedback forms that help assess whether the hybrid care system is delivered in a way promotes equity.



