Breakout Session 2: Track A

Framing the Ethical-Framework Guided Metric Tool – Lessons Learned

Dr. Bankole Olatosi (Moderator)
Associate Professor, University of South Carolina

AN ETHICAL FRAMEWORK-GUIDED TOOL FOR ASSESSING BIAS IN EHR BASED BIG DATA STUDIES R01AI164947-02

2024 NIH ODSS AI Supplement Program PI Meeting

Bankole Olatosi PhD, FACHE, Shan Qiao, PhD, George Khushf, PhD, Jiajia Zhang, PhD & Xiaoming Li, PhD

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Big Data Health Science Center
UNIVERSITY OF SOUTH CAROLINA

OUTLINE

- Summary of Project
- Project Goals
- What we did
- What we found
- Research Outputs
- Challenges
- Future work

PROJECT SUMMARY/GOAL

- The primary goal of the parent project (R01R01164947) is to develop an ML predictive model of viral suppression among persons with HIV based on EHR and other relevant data from multiple sources in South Carolina.

- One of the ethical challenges encountered by the parent research project was how to ***assess potential biases in its data curation, acquisition, linkage, and integration***.

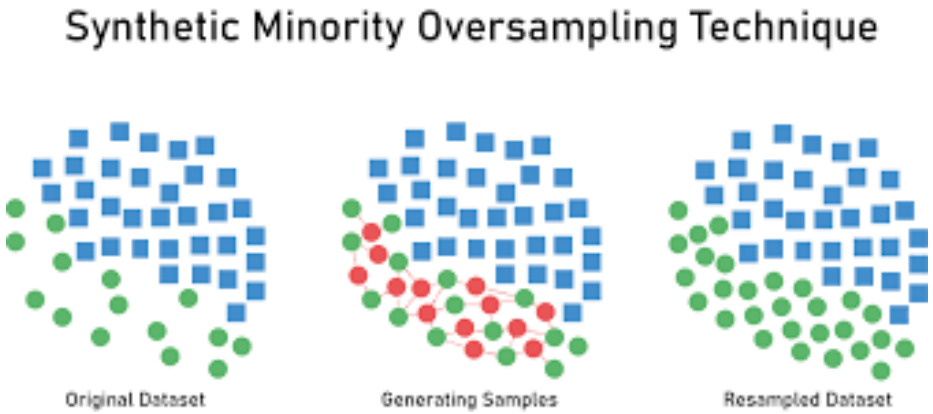
Goal: Develop an ethical framework-guided metric tool for assessing biases in HIV relevant EHR data

SPECIFIC AIMS

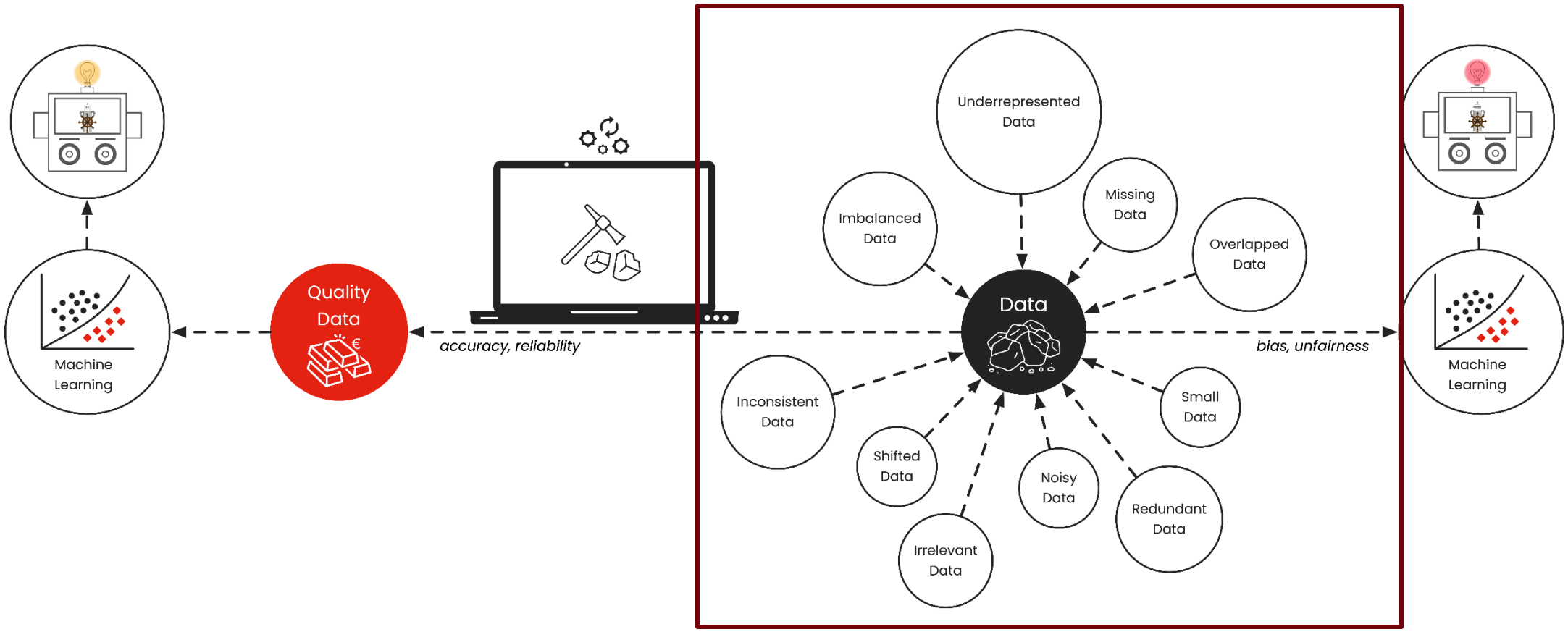
- **Aim#1.** Develop an ethical framework for unbiased and inclusive Big Data research through a literature/policy review and conceptual analysis.
- **Aim#2.** Create and modify a metric tool to assess potential biases in EHR data based on in-depth interviews of key stakeholders of the parent project.
- **Aim#3.** Refine and disseminate the metric tool through a community charette workshop among interdisciplinary scholars (ethics experts and disciplinary experts) and key stakeholders (data curators, data management experts, data repository administrators, healthcare workers, and patients) and pilot test it in the parent project.

CONTEXT: EHR DATA SPECIFIC

- Representative guidance on managing bias
- NIST and Aequitas measures might be insufficient
- User Alert – SMOTE does not cover class imbalance anymore, and bias more complicated



CONTEXT: DATA QUALITY EVALUATION



SEEKING, MEASURING & MANAGING BIAS

- Generally Unavoidable
- Implicit and non-exhaustive
- Normative negative bias perpetuates **structural injustices**
- Ethical, social & legal contexts relationships
- Human-in-loop + statistical + algorithmic approaches needed

NIST REPRESENTATIVE GUIDANCE

Bias cannot just be regarded as a ***statistical phenomenon***, e.g., "an effect that deprives a statistical result of representativeness by systematically distorting it" or as "systematically inaccurate behavior" of an AI system where a "reference value deviates from the truth" (IOS definition). ***Nor can fairness just be evaluated in relation to algorithm (mis)classification*** or ***utility of results in relation to a specified reference group***.

NIST Special Publication 1270: Towards a Standard for Identifying and Managing Bias in Artificial Intelligence (March 2022)

SEEKING, MEASURING & MANAGING BIAS

Today's Bias Approach

- Identification
- Measurement
- Management

Research constructs and application driven

Refining the Approach (add-on)

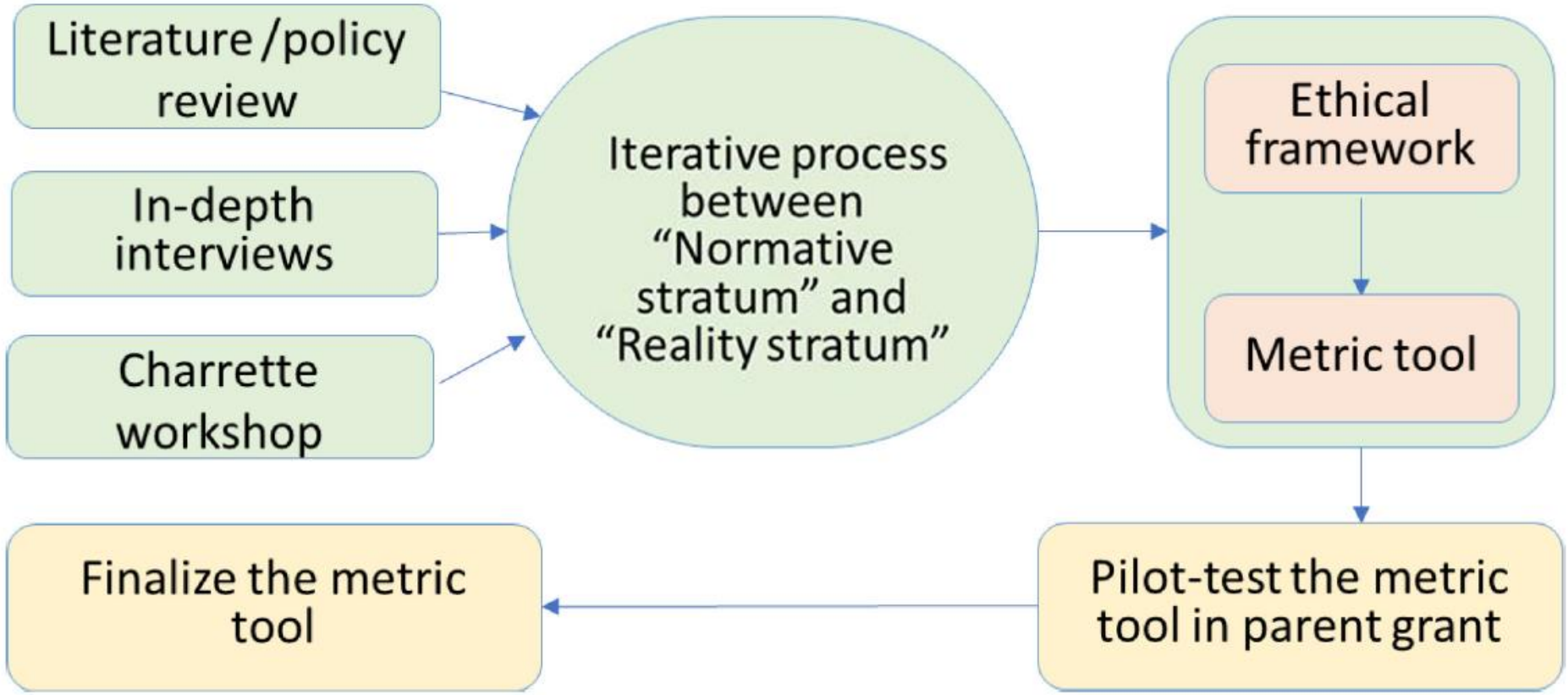
- Taxonomy and measures for general purpose
- Statistical approach vs human+contextual
- Backward refinements
- Support an undefined range of unspecified studies and applications

Rely on **both Technical Statistical Tools "and" human factor/contextual analysis**

THINKING ABOUT BIAS OF GENERAL PURPOSE DATABASES

- Linking and integrating different data sources
- Bias exhibited in ways EHR data is entered or recorded
- Attributes used for defining reference groups

WHAT WE DID


Literature /policy review
In-depth interviews
Charrette workshop
Iterative process between "Normative stratum" and "Reality stratum"
Ethical framework
Metric tool
Pilot-test the metric tool in parent grant
Finalize the metric tool

SAMPLE THEMES QUALITATIVE INTERVIEWS

Workflow process among healthcare providers around SDoH

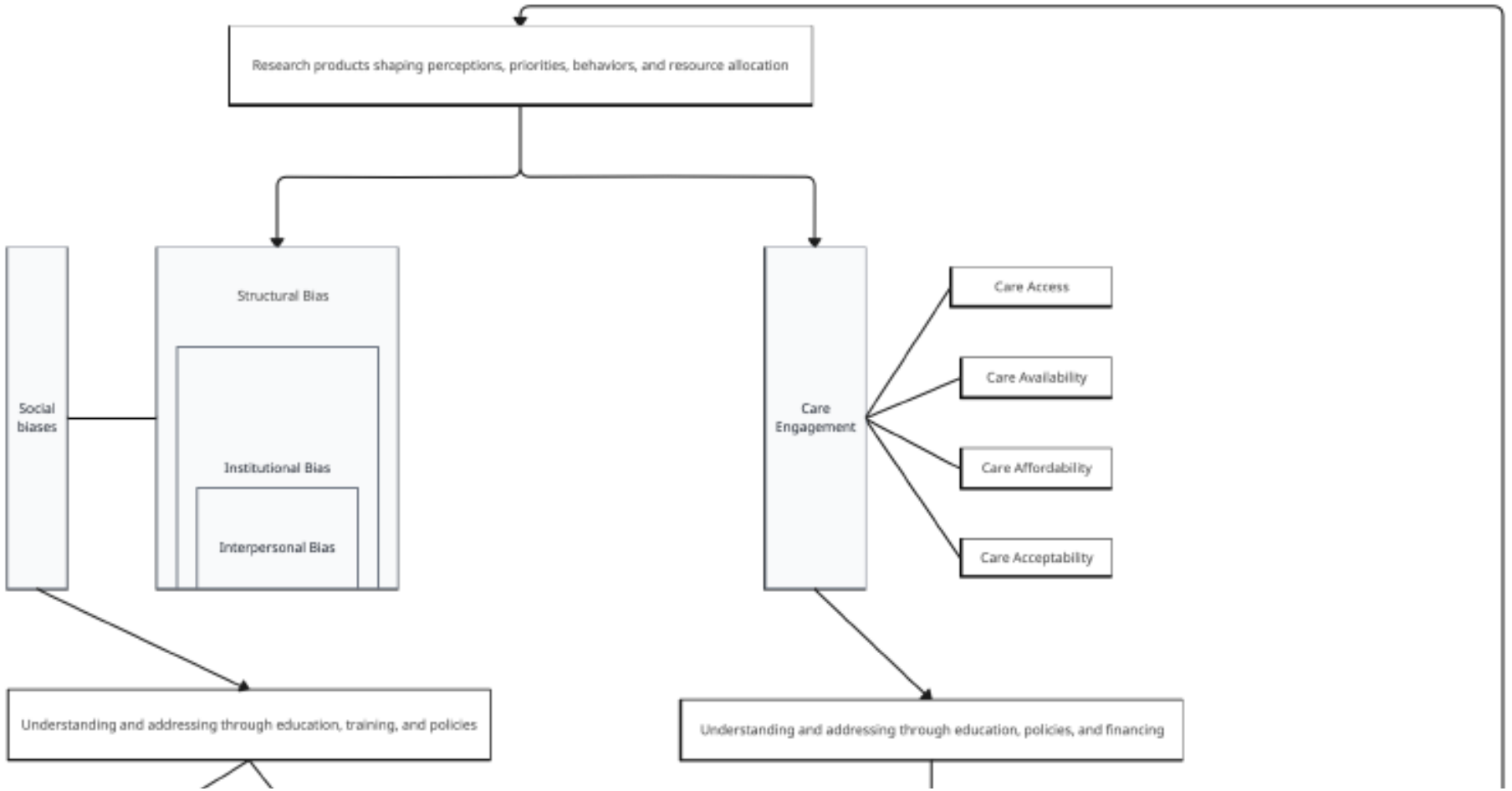
(Before, During & After Medical Appointments)

- Facilitator/Barrier: Influence of (dis)comfort, (dis)trust, stigma, and discrimination
- Facilitator: Equal treatment of patients
- Facilitator: Affirmation of identity (e.g., pronouns)
- Facilitator/Barrier: Healthcare Inquiry about SDoH Dependent on physician motivation to ask
- Barrier: Healthcare Provider (HCP) discomfort in asking about SDoH
- Barrier: Healthcare Provider (HCP) unwilling to be offensive in asking about SDoH
- Facilitator: Influenced by patient comfortability and trust
- Barrier: Lack of standardization of SDOH related questions
- Facilitator Barrier: Dependent on technical options available in the EHR systems
- Facilitator: Charts reviewed by users (e.g., physicians, nurses, caseworkers)

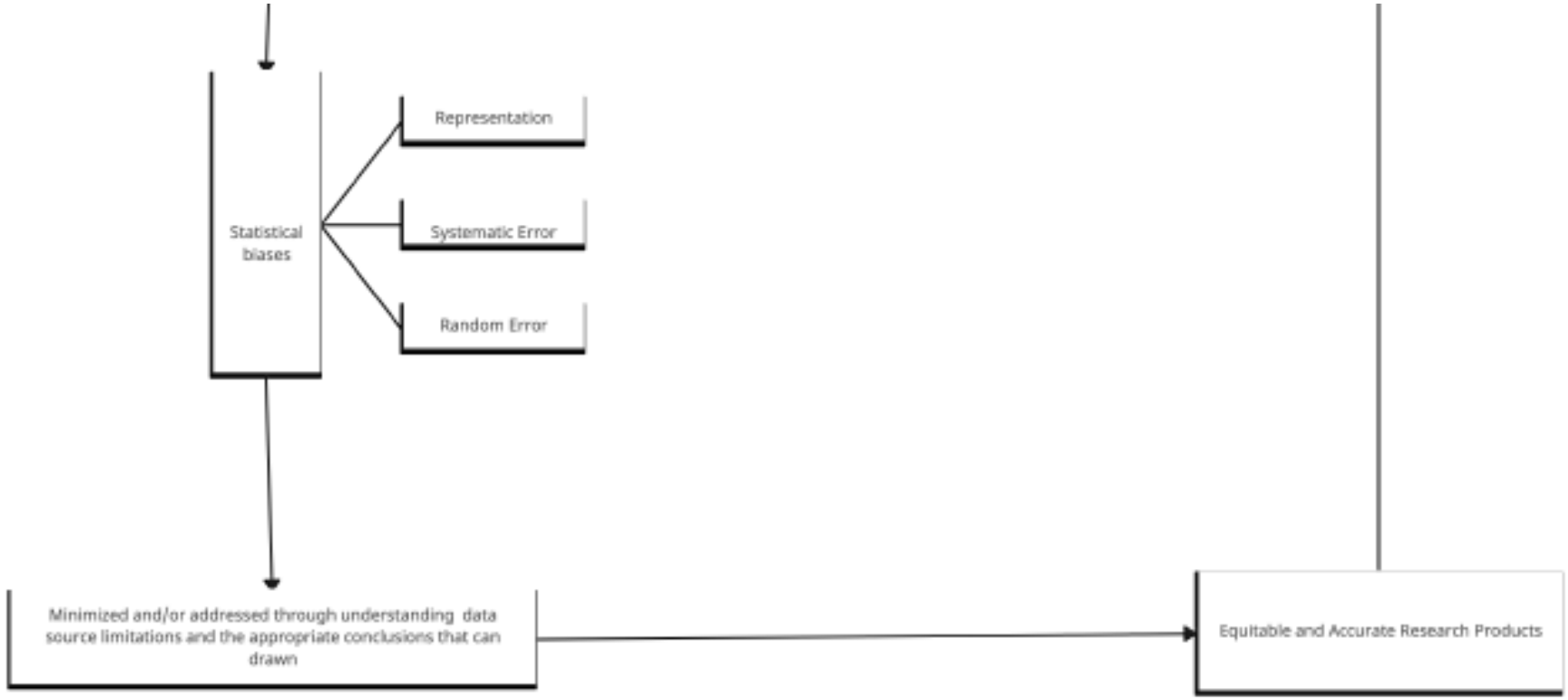
IMPACT

- Biased data
- Biased algorithms
- Distrust of algorithms and AI by HCPs
- Distrust of algorithms AI by Patients
- Risk of Perpetuation of structural problems by data scientists

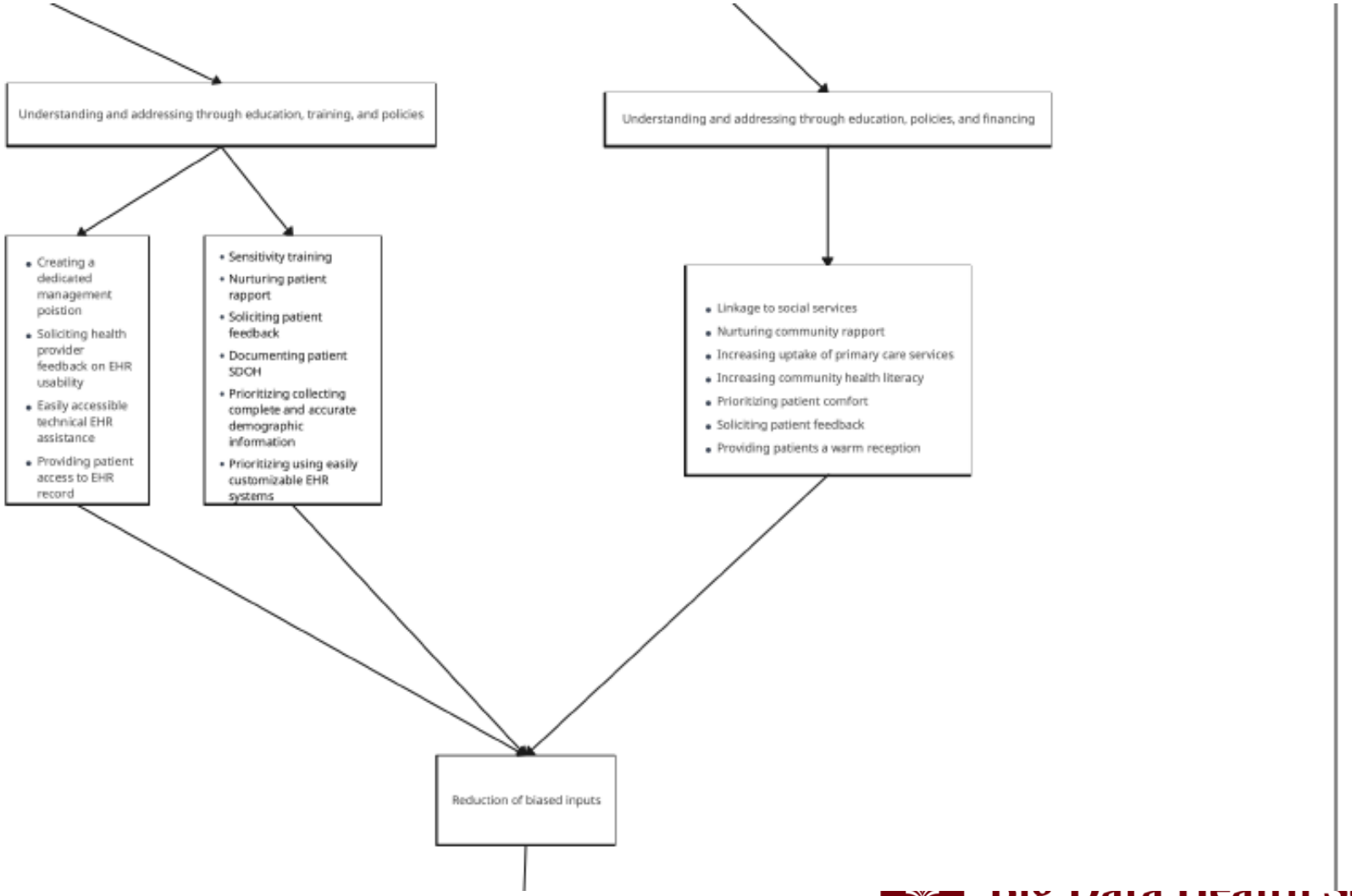
DRAFT FRAMEWORK PT1



DRAFT FRAMEWORK PT2



DRAFT FRAMEWORK PT2



RESEARCH OUTPUTS

- Developing a Taxonomic Framework for Ethically Evaluating the Types of Biases Integral to Big Data EHR Studies: Oral Presentation at the 11th International Conference on Ethics in Biology, Engineering and Medicine, Seattle, WA, April 29th & 30th, 2023

- Protocol Paper: Qiao, S., Khushf, G., Li, X., Zhang, J., & Olatosi, B. (2023). Developing an ethical framework-guided instrument for assessing bias in EHR-based Big Data studies: a research protocol. *BMJ open*, *13*(8), e070870.

CHALLENGES AND FUTURE WORK

- Great Resignation
- Competing priorities for interviewees
- Leadership does not mean knowledge
- Charrette Workshop method
- Larger Scope than envisaged

- Complete qualitative paper
- Refine and develop tool further
- Present as checklist and framework
- Expand scope to other EHR
- Deploy for community to use and improve
- Recommend data domain expert engagement/inclusion on future grants

QUESTIONS?

Email: Olatosi@mailbox.sc.edu

www.bigdata.sc.edu