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Ethics, Data Governance, Knowledge Production and Public Engagement in Population Data Science Field from the Perspective of a Brazilian Experience

Bethânia de Araújo Almeida¹, Mauricio L. Barreto², Adalton dos Anjos Fonseca³, and Robespierre Dantas da Rocha Pita⁴

¹CIDACS/Fiocruz Bahia, Brazil

²Center for Data and Knowledge Integration for Health, Salvador, Brazil

³Fundação Oswaldo Cruz, Brazil

⁴Instituto de Computação/UFBA, Brazil

Objectives

To present and discuss the experience and associated ethical, legal and sociotechnical challenges of creating the Center for Data and Knowledge Integration for Health (CIDACS/Fiocruz Bahia-Brazil), initially constructed to link socioeconomic and health data to make it possible to build the 100 Million Brazilians Cohort aimed to investigate the social inequalities in health and the impact of social protection policies on health in low-income and vulnerable populations throughout Brazil.

Infrastructure, data linkage methods, ethical, legal and social implications, are intertwined and context-dependent. Furthermore, it promoted a comprehensive debate surrounding data practices and public engagement as a dynamic and cumulative process, a perspective which may contribute to similar initiatives in high-income countries.

Approach

Presentation of CIDACS' interdisciplinary work focusing on the complexity of building an infrastructure and capacity to conduct record linkage with quality and accuracy and to provide access to deidentified linked datasets to support knowledge production. Based on an interactive discussion was possible exchanging experiences and insights about design and implementing strategies that enable ethical and inclusive data practices aligned with specific characteristics, challenges, and opportunities of Population Data Science in a broader and contextualized perspective.

Results

The production of scientific knowledge supported by linked data, in addition to ethical and legal adherence to regulations, must consider social dimensions which pose new questions and contextualized solutions considering the rights of data subjects in groups and communities to implement strategies to promote dialogue and involvement with society, particularly with groups covered by linked data, as well as other data stakeholders, e.g. data regulators, data managers, policymakers and data users.

Conclusions

From CIDACS' perspective, the workshop discussed how the main topics regarding populational data science, notably in-

