

# Enabling 21<sup>st</sup> Century Applications for Cancer Surveillance through Enhanced Registries and Beyond

## Policy Opportunities for Advancing Progress: Ethics, Privacy, and Cancer Registries

Aaron Goldenberg, PhD

Case Western Reserve University

School of Medicine

Department of Bioethics



# Ethics, Privacy, and Cancer Registries:

## *Key Distinctions for Policy and Governance\**

*“the most important thing in this is understanding, first, your responsibility for those tissues in the patients who they came from. So holding their identities confidential, and in that sense, serving as the honest broker, is the fundamental principle.”*

*“But it’s really important to be thoughtful of participants as real people who are on equal footing to scientific researchers when you’re setting up a biobank, that scientists’ needs and desires can’t trump the needs and desires of the people that these biobanks are meant clinically to serve, or the communities that they eventually will serve.”*

*Ethics of Networked Biorepositories  
Goldenberg, A and Brothers, K  
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Lynette Gerido, PhD MPH MBA



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