Applying Big Data to Address the Social Determinants of Health in Oncology: A Workshop

October 28 - 29, 2019

#NatlCancerForum
REVISITING WORKSHOP GOALS

• Examine how the social determinants of health affect cancer risk and outcomes
• Explore novel big data sources & methodologies to assess the social determinants of health
• Consider ethical dimensions of big data research & opportunities to promote health equity
• Examine opportunities for collaboration & data sharing
• Discuss policy & research priorities to advance progress on improving health equity and reducing disparities in cancer
KEY WORKSHOP THEMES
EXAMINE HOW THE SOCIAL DETERMINANTS OF HEALTH AFFECT CANCER RISK AND OUTCOMES

• Precision with terminology: SDOH distinct from social needs
• Which social risk factors are most impactful on cancer-related outcomes?
• Systems-based approach to defining the social determinants of health
• What are the opportunities for ongoing research to identify the contributing factors to cancer health disparities and how these factors change over time?
• How can complexity & intersectionality be applied to better understand social risk and prioritize opportunities for interventions to promote health equity?
KEY WORKSHOP THEMES
EXPLORE NOVEL BIG DATA SOURCES & METHODOLOGIES TO ASSESS THE SOCIAL DETERMINANTS OF HEALTH

• Critical roles of trust and context
• Research should be aligned with patient and community priorities and concerns
• Conduct research with a purpose
• Data & methods are needed to capture, evaluate the complexity of exposures, context, & diseases across time
• Novel data sources & methods can be leveraged to complement and extend traditional paradigm of clinical trials research
• Specifying common data models—tradeoffs
• Data standardization, validation, and appropriate use of novel methods, analytics
KEY WORKSHOP THEMES
CONSIDER ETHICAL DIMENSIONS OF BIG DATA RESEARCH & OPPORTUNITIES TO PROMOTE HEALTH EQUITY

• What technical, policy, and governance mechanisms can better protect patient privacy and data security?
• Are new regulatory paradigms and laws needed for ensuring data security & patient privacy without hampering research, especially in the big data era?
  • How can patients be protected without degrading the data?
  • Tradeoffs with fairness and privacy
  • Penalties for re-identification of patients
• How can trust ensure more equitable participation in research, and what are the opportunities to build trust?
KEY WORKSHOP THEMES

EXAMINE OPPORTUNITIES FOR COLLABORATION & DATA SHARING

• Collaborations, data sharing, and data fusion will be critical to advancing progress
• Investments in data infrastructure will facilitate progress
• Involving appropriate participants to ensure buy-in, identify champions, and promote transparency
• Prioritization of interventional-focused research that can scale
• Foster collaborations with community partners and federally-qualified community health centers
KEY WORKSHOP THEMES
DISCUSS POLICY AND RESEARCH PRIORITIES TO ADVANCE PROGRESS ON IMPROVING HEALTH EQUITY AND REDUCING DISPARITIES IN CANCER

• Workforce and infrastructure development to analyze and use big data to address social determinants of health
• Broad, equitable patient access to clinical research and advances derived from research
• Mechanisms and incentives to hold health care organizations & insurers accountable for population health
• Experimentation with payment and care delivery models to expand precision oncology care to those who need it
CONCLUDING COMMENTS

- Standardizing the language of the social determinants of health
- Need to ensure EHRs incorporate the social determinants of health
- Ensuring that actionable interventions—based on big data research on social determinants—are implemented and appropriately scaled
- Collaboration requires compromise
- "In reach" may also be important to refining social determinants of health issues
Thank You!