GENETIC EXCEPTIONALISM: STATE OF THE CONCEPT

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ORIGINS OF THE CONCEPT

• Genetic Exceptionalism: The concept that genetic information is qualitatively different than other types of medical information and therefore needs “special” attention (ex. in policies)

• Fears of discrimination or stigmatization

• Concept gained momentum in the 90’s as the genetic testing options grew and the human genome project advanced
LEGACY OF GENETIC EXCEPTIONALISM

• Genetic Exceptionalism in Policies
  • Genetic Privacy Legislation

• Genetic Exceptionalism in Practice
  • Genetic testing oversight (ex EGAPP)
  • Historically genetic information rarely had a large impact on health outcomes

• Genetic Exceptionalism in Ethics

FACE Facts: Why Human Genetics Will Always Provoke Bioethics

Eric T. Juengst
• Predictive nature of genetic information

• Impact of genetic information for families

• Use of genetic information to discriminate or stigmatize

• Genetic information can cause significant psychological harms
GENETIC EXCEPTIONALISM IN THE GENOMIC ERA

- Concerns about “Reverse Genetic Exceptionalism”

- Genetic and genomic information in the electronic medical record
  - McGuire et al/Evans and Burke
  - eMERGE

- Genomic information as a unique identifier

- Patient control of information vs. Clinical utility of information for health care providers
• Genomics as the “key” to personalized medicine (James)

• Access to sequence information
  • Issues of privacy and confidentiality remain
  • Open source data

• Added claims
  • Incidental findings
  • Variants of unknown significance

• Research vs. Practice
THANK YOU

- Kyle Brothers
- Nanibaa’ Garrison

- Center for Genetic Research Ethics & Law (2P50-HG-003390).