Preparing the bioethics research workforce: Challenges and opportunities

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Overview

- Describe current bioethics research training opportunities
- Share a conceptual model that illustrates the diversity of bioethics research methods
- Offer an example of bioethics training opportunities in a multidisciplinary study

Key Training Opportunities for the Bioethics Research Workforce

Career stage	Programs	Number
Post Doctoral Training	Fellowships • NIH T32 and F32	17 Fellowships (bioethicsdirector.net)
Early Career Faculty	NIH Career Development: K mechanism	Unknown
Mid Career Faculty	Greenwall Foundation Faculty Scholars Program	56 Scholars since 2003 (greenwall.org)

Challenges

- Topical emphasis in Genomics and Neuro-ethics(NIH) and Palliative Care (Foundation)
- Limited options for JDs at NIH (only NHGRI)
- No NIH "RCD category" for **bioethics** to track awards

Association of Bioethics Program Directors "snapshot" of postdoctoral trainees: 41 trainees at 25 programs

Degree	28 PhD
	2 PhD/JD
	3 JD
	7 MD
Focus	18 Research
	9 Research and Clinical
	13 Clinical
Funding	10 NIH
	25 Institutional
	6 Other

Association of Bioethics Program Directors "snapshot" of postdoctoral trainees: 41 trainees at 25 programs

Gender	29 Female 10 Male
Race/ethnicity	31 White 3 Hispanic/Latinx 3 Asian 2 Black or African American 1 American Indian or Alaska Native 1 Native Hawaiian or other Pacific Islander

Developing Bioethics Research Objectives

Question Type →	*Descriptive*		*Prescriptive*	
Method				
Conceptual				
Empirical				
Qualitative				
Quantitative				
Consensus/Engagement				
Question Stage →	Hypothesis generating	Hypothesis Testing	Hypothesis generating	Hypothesis Testing

Mathews DJH, Hester DM, Kahn J, McGuire A, McKinney R, Meador K, Philpott-Jones S, Youngner S, Wilfond BS. A conceptual model for the translation of bioethics research and scholarship. *Hastings Center Report*. 2016; 46: 34-39.

Developing Bioethics Research Objectives

Question Type →	*Descriptive*		*Prescriptive*	
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Conceptual				X
Empirical				
Qualitative		X		
Quantitative	X			
Consensus/Engagement			X	
Question Stage →	Hypothesis generating	Hypothesis Testing	Hypothesis generating	Hypothesis Testing

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CHARM
Cancer Health Assessments Reaching Many

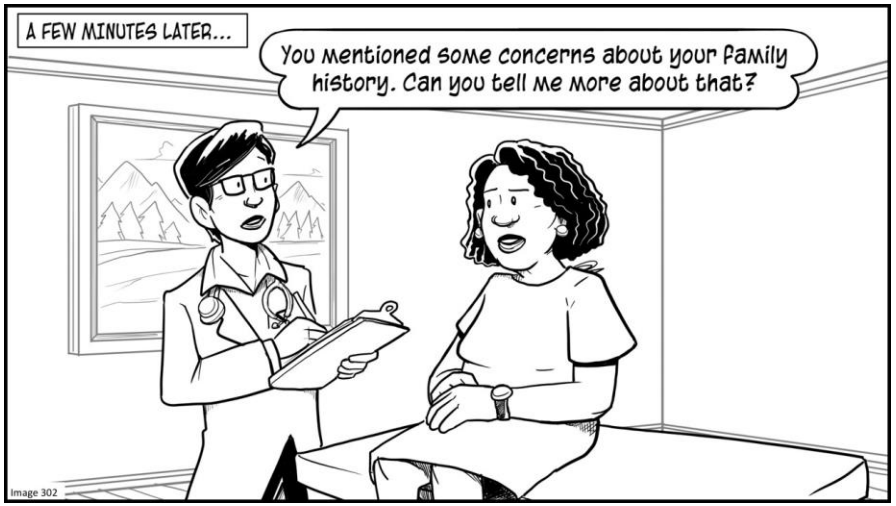
cser
Clinical Sequencing Evidence-Generating Research

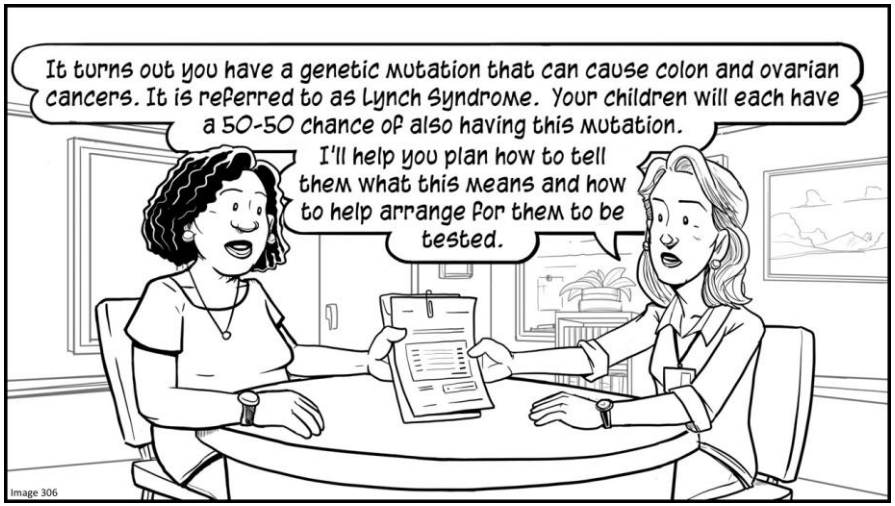
Research Team

70 people across 10 institutions, including disciplines of genetic epidemiology, medical genetics, genetic counseling, health communications, health informatics, economics, anthropology, biostatistics, and bioethics

Objective

Evaluate interventions to increase genetic testing access for hereditary cancer syndromes in low income, low literacy, and minority populations





Interventions to improve access

Process	Intervention	Evaluation Method(s)
Identify individual	1. Outreach via email/text	
Collect family history	2. Online standardized patient-facing tool	
	3. Ask about limited family information	
Assess risk	4. Online automated risk assessment	
Education, consent & select test	5. Online pretest education and consent	
	6. Decision aid for secondary findings	
	7. Preselect clinical exome test	
Sample collection	8. Self collection of saliva at home	
Results disclosure	9. Letter for some negative results	
	10. Phone counseling	
	11. Modified genetic counseling	
	12. Training for interpreters	
Downstream care		

= Randomize = Accuracy/adherence = Process measures = Interview

= Survey

CHARM training awards and supplements

Stephanie Kraft JD (Seattle Children's) K01

- Respect for Persons in Genomic Research Enrollment with Diverse Populations

Sarah Knerr PhD (UW Public Health) K08

- Population Management for Hereditary Cancer Prevention within a Learning Health System

Jessica Hunter PhD (Kaiser) Sexual Minority supplement

- Family Communication among Sexual Minorities in the Context of Hereditary Cancer Syndromes

Kate Mittendorf PhD (Kaiser) Diversity supplement

- Evaluating the Impact of a Literacy Focused Risk Assessment Tool for Hereditary Cancer Syndromes in Diverse Populations

Amanda Freed MD (UW Genetics) Administrative supplement

- A Randomized Trial of a Decision Aid for Selection of Secondary Findings