

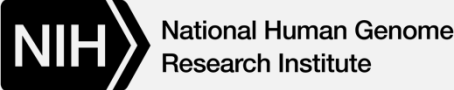
C G T A C G T A
A C G T A C G T

ELSI Research Activities Across the NIH

Lawrence Brody

Division of Genomics and Society

14 September 2020



Overview

A C G
C G T
A C G

- NHGRI ELSI Program
- NHGRI other IC collaborations
- Programs at the NIH
- Data Mining

NIH Funding – Bioethics 2020

Search *Bioethics* - 266

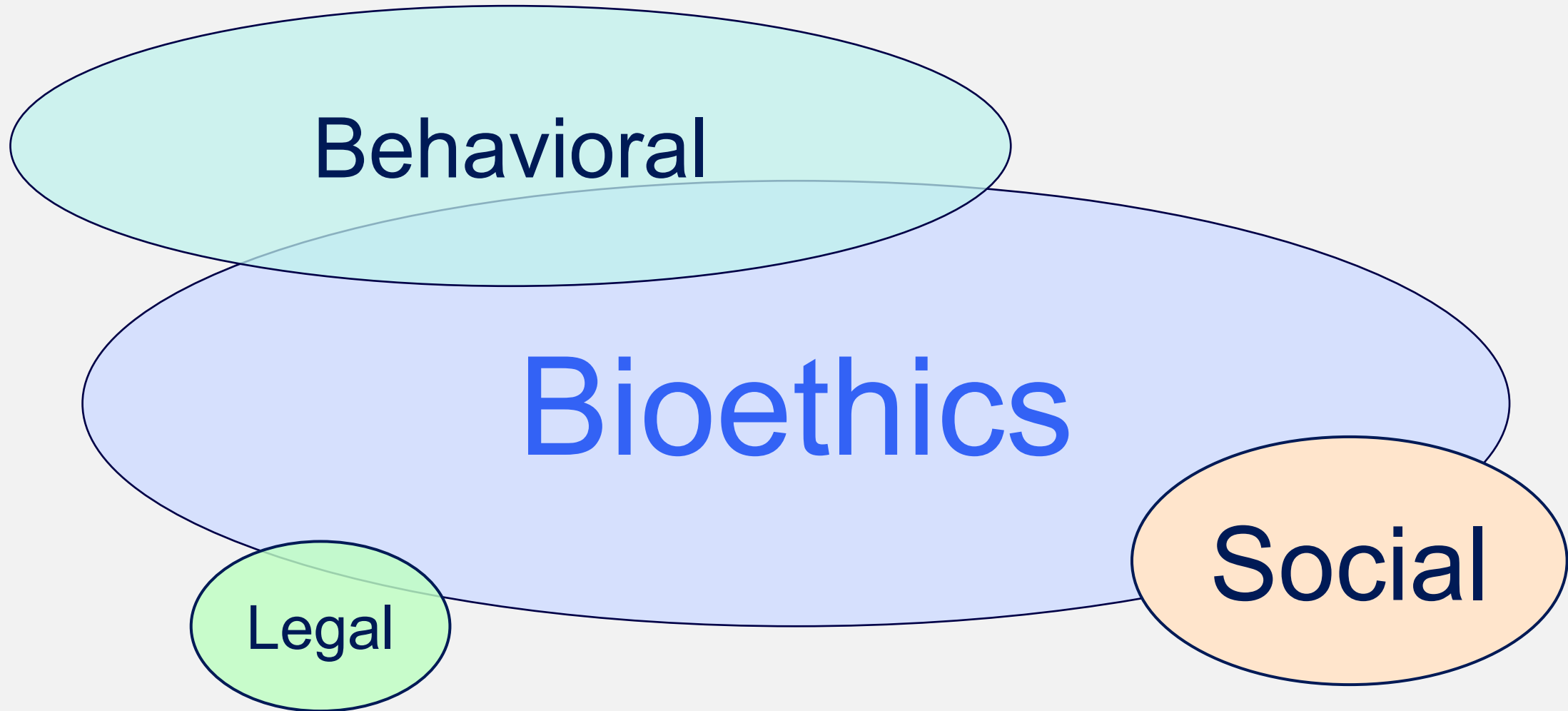
Active “R” Awards

82 Research Grants

21 NHGRI

NIH Research

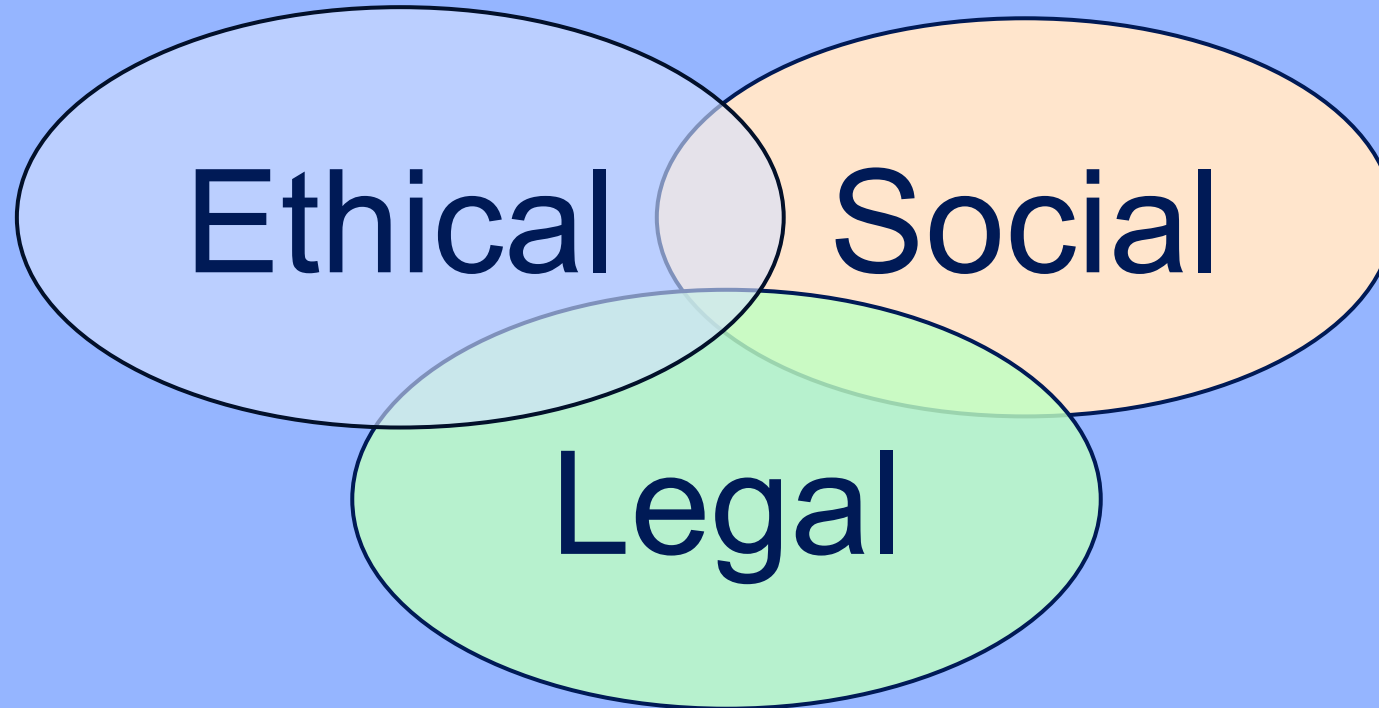
A C G
C G T
A C G



NHGRI Research

A C G
C G T

Genetics and Genomics



NHGRI Research

A C G
C G T
A C G



- Intellectual Property
- Equitable Access
- Data Privacy
- Genetics of Populations

- Implementation
- Clinic/ Research Boundaries
- Data Privacy
- Equitable Access

Ethical, Legal and Social Implications Research Program

The ELSI Research Program fosters basic and applied research on the ethical, legal and social implications of genetic and genomic research for individuals, families and communities.

RESEARCH FUNDING

[ELSI Abstracts and Activities
Database >](#)

RESEARCH FUNDING

[ELSI Publications and Products
Database >](#)

Screenshot

RESEARCH FUNDING

[Sample ELSI Applications and
Summary Statements >](#)

\$20M

A C G
C G T
A C G

~ 65 ELSI Grants

500
NHGRI

50,000
NIH

ELSI Connections

- Historical
- Personal
- Tea Time
- NOSIs
- Pedigree



Funding Opportunity Title

Ethical, Legal and Social Implications (ELSI) Research (R01 Clinical Trial Optional)

Activity Code

R01 Research Project Grant

Announcement Type

Reissue of [PA-17-444](#)

Related Notices

Funding Opportunity

Companion

Components of Participating Organizations

National Human Genome Research Institute (NHGRI)

National Cancer Institute (NCI)

National Eye Institute (NEI)

National Heart Lung and Blood Institute (NHLBI)

National Institute on Aging (NIA)

National Institute of Environmental Health Sciences (NIEHS)

National Institute of Mental Health (NIMH)

National Institute on Minority Health and Health Disparities (NIMHD)

National Institute of Neurological Disorders and Stroke (NINDS)

Other “ELSI-oid” Programs at the NIH

- Vary in intent, scope and stability
- Twenty year trend toward more programs
- Large range of research questions
- Research a mixture of stand alone, embedded and supplemental programs

Office of Behavioral and Social Sciences Research



U.S. Department of Health and Human Services

National Institutes of Health

Division of Program Coordination, Planning, and Strategic Initiatives



Priority One: Improve the synergy of basic and applied behavioral and social sciences research.



National Institutes of Health
Office of Behavioral and Social Sciences Research

What can we help you find?



Home

Research Support

Program Coordination

Training

Events and News

Resources

About

Priority Two: Enhance and promote the research infrastructure, methods, and measures needed to support a more cumulative and integrated approach to behavioral and social sciences research.

Priority Three: Facilitate the adoption of behavioral and social sciences research findings in health research and in practice.



NHGRI



🔍 COVID-19 is an emerging, rapidly evolving situation.

- Latest COVID-19 public health information from the U.S. Centers for Disease Control and Prevention (CDC)
- Latest COVID-19 research information from the U.S. National Institutes of Health (NIH)
- COVID-19 resources for global health researchers from Fogarty

🔍 [View all research topics](#)

Bioethics news, resources and funding for global health researchers

Fogarty aims to strengthen research bioethics expertise in developing countries by providing resources and information to bioethicists, research ethics committee members, researchers, students, and everyone else involved in international health research. In keeping with its wider commitment to building the capacity to conduct research in low- and middle-income countries (LMICs), Fogarty believes it is important to build in-country bioethics capacity. This enables local ethics review of research, improves research into the distinctive ethical problems in LMICs, and increases the representation of different voices in on-going global discussions of the ethics of health research.

Bioethics Resources

- **For Teachers and Students** - teaching tools, career path advice, and online education information
- **For Investigators and Ethics Committees** - regulations, guidelines, practical aids, committee information
- **For Bioethics Researchers** - journals and granting agencies
- **Bioethics Materials in Other Languages** - networks, trainings, journals, and guidelines and regulations in a variety of languages



Program transforms bioethics landscape in Nigeria

Grantee designs program to serve as bioethics resource for all West Africa

[Learn More](#) 🔍

Related Fogarty Opportunities

- [International Bioethics Training](#)

Related NIH Opportunities

The Department of Bioethics

- About Us
- Our People**
- Bioethics Consult Service
- Publications
- Courses, Lectures, & Training
- Fellowship Opportunities
- Alumni
- Contact Us

Our People

Chief



[Christine Grady, RN, PhD](#)

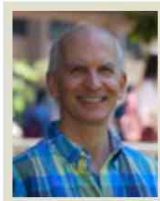
Faculty



[Benjamin Berkman, JD, MPH](#)



[Marion Danis, MD](#)

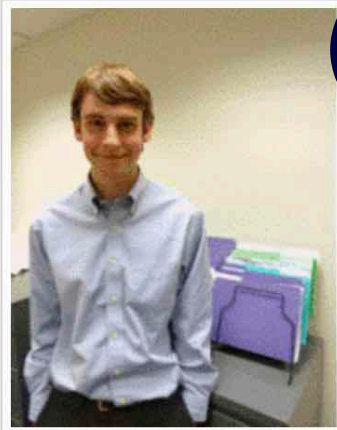
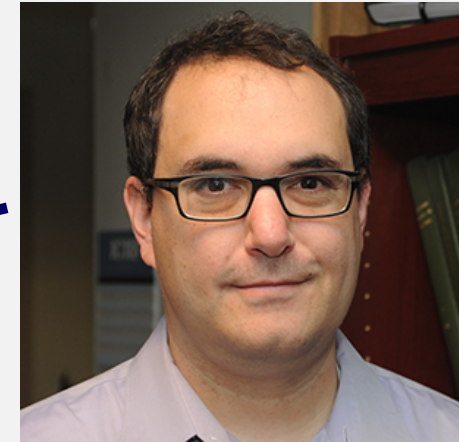


[David DeGrazia, PhD](#)



[Sara Chandros Hull, PhD](#)

Ethics Consultation Service
14 Research Faculty
14 Trainees





Epidemiology and Genomics Research Program

Charlisse Caga-anan, J.D.

Home / About EGRP / Staff List / Charlisse Caga-anan, J.D.

ABOUT THE PROGRAM

[Overview](#)

[Staff List](#)

[Job Opportunities](#)

[Organizational Structure](#)



Program Director
[Genomic Epidemiology Branch](#),
Epidemiology and Genomics Research
Program

Telephone: [\(240\) 276-6738](tel:(240)276-6738)
Fax: (240) 276-7920
E-mail: charlisse.caga-anan@nih.gov

Contact for questions about:

Bio-ethics

Ethical, Legal and Social Implications (ELSI)

Genomic Data Sharing



Bioethics Research

- + [Trans-NIH Bioethics Funding Awards](#)
- + [Active Bioethics and ELSI \(Ethical Legal and Social Implications\) Funding Opportunities \(Updated 04/30/2020\)*](#)
- + [NIH Bioethics Points of Contact](#)
- + [Relevant Documents and Resources](#)

Clinical and Healthcare Research

- > [Clinical Research Policy](#)
- > [Healthcare Research Policy](#)

\$5,000,000 per annum

ICs nominate grants

ICs administer funding

A C G
C G T
A C G

National Institute on Drug Abuse

- Predictive modeling: the role of opioid use in suicide risk

National Institute of Nursing Research

- Engaging patients, family members and caregivers in end-of-life and palliative care research: Addressing the bioethical challenges

National Institute of Allergy and Infectious Diseases

- Bioethical Issues in the use of Mobile Phone Data for Public Health Research in Uganda
- Ethical aspects of clinical xenotransplantation: a national survey of African Americans

National Institute of Dental and Craniofacial Research

A C G
T
A C G

- Bioethics of syndrome diagnosis using 3D image analysis
- Orofacial Clefts, Whole Genome Sequencing and Incidental Findings: Ethical considerations.



—

Landscape for Genomics and Genetics?

Research, Condition, and Disease Categorization Program

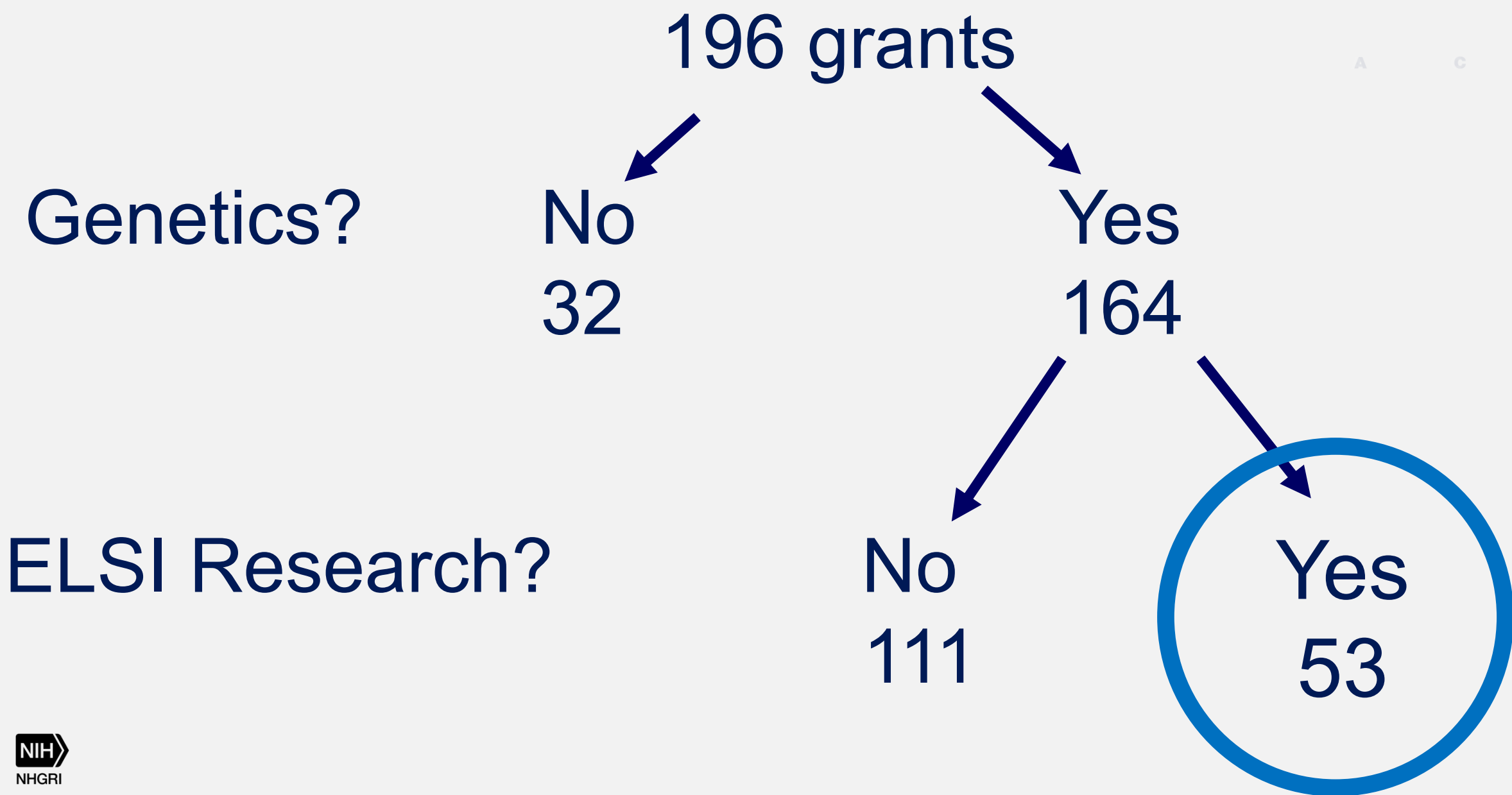


Grant database with text mining and visualization tools

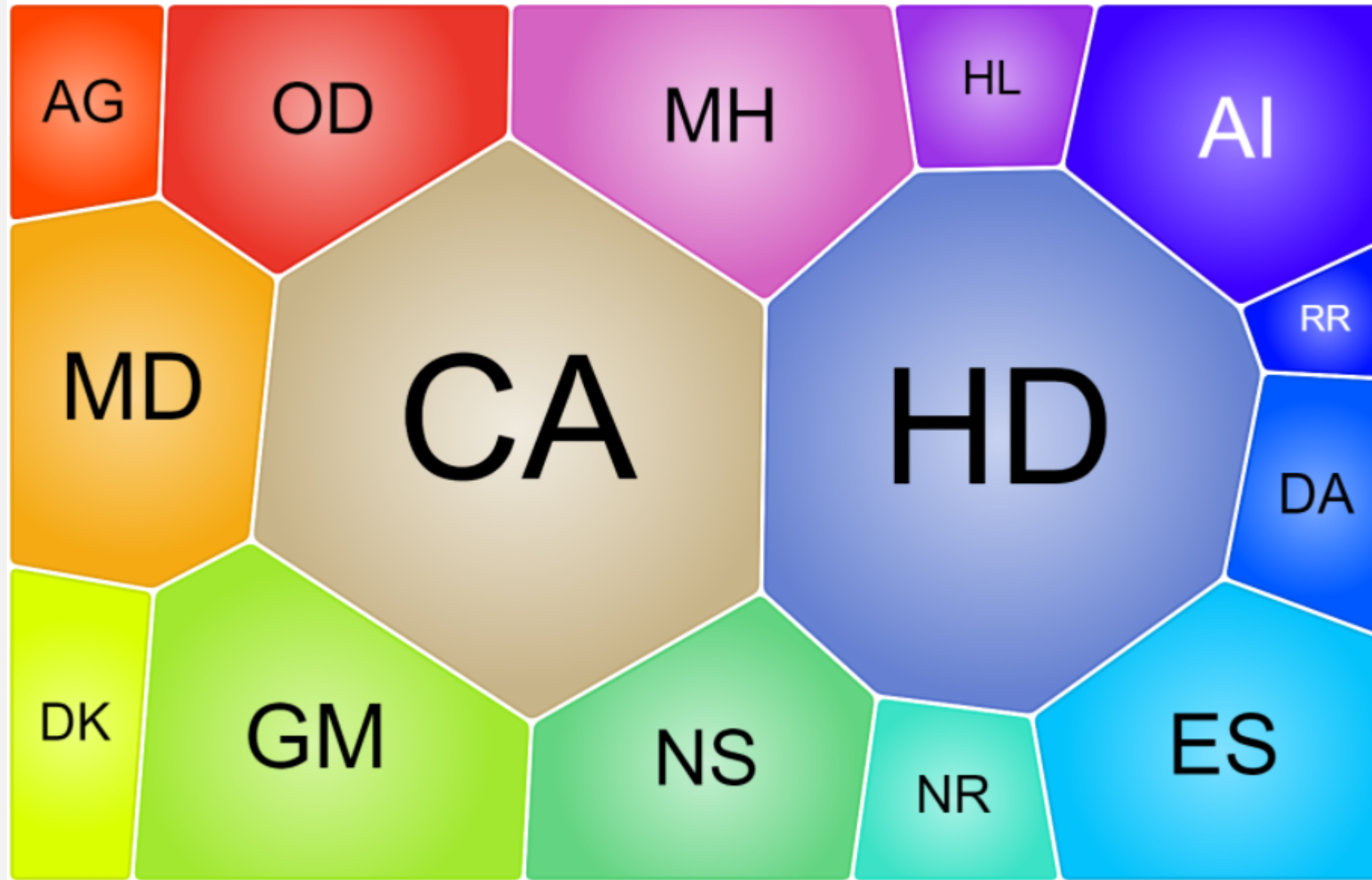
(and very helpful staff)

2008 to 2020

G
T
A
C
G

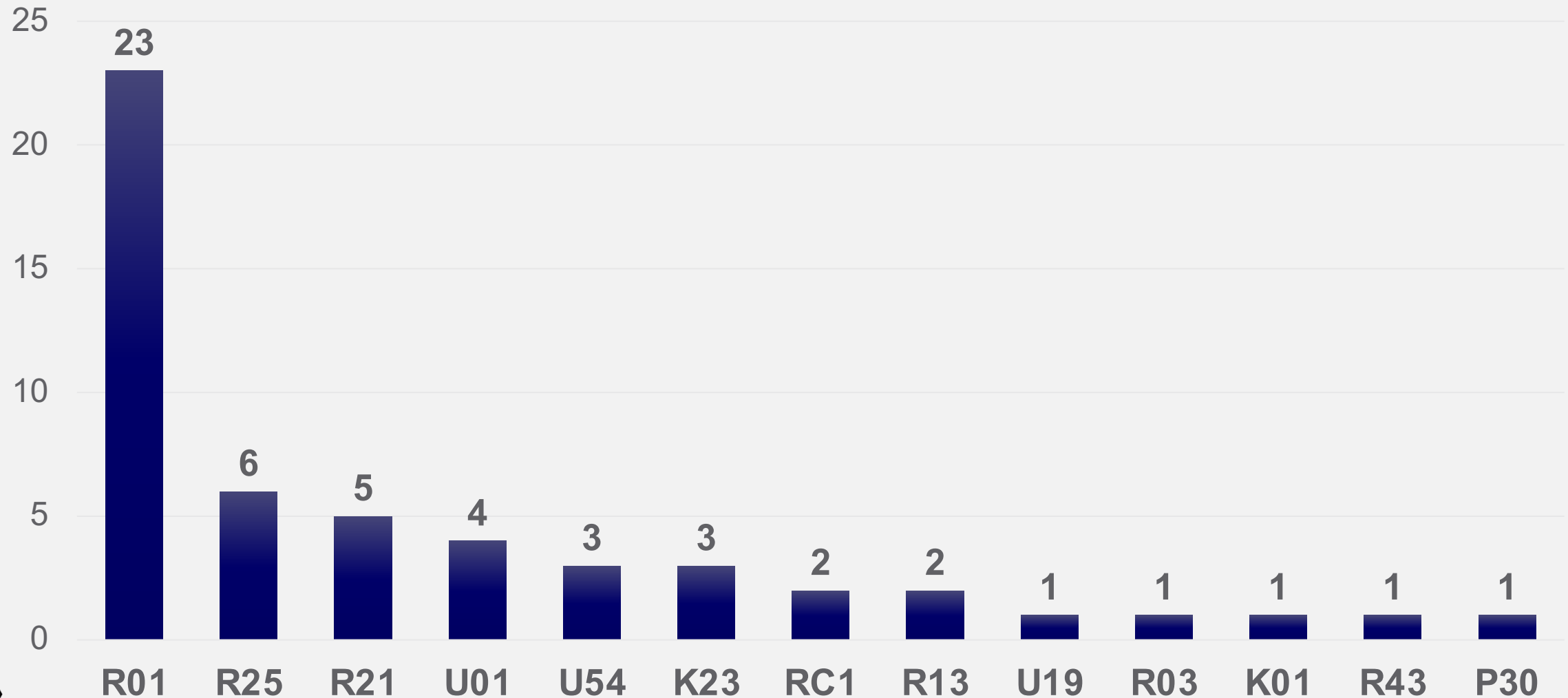


Awarded ELSI Projects by IC, 2010-2020



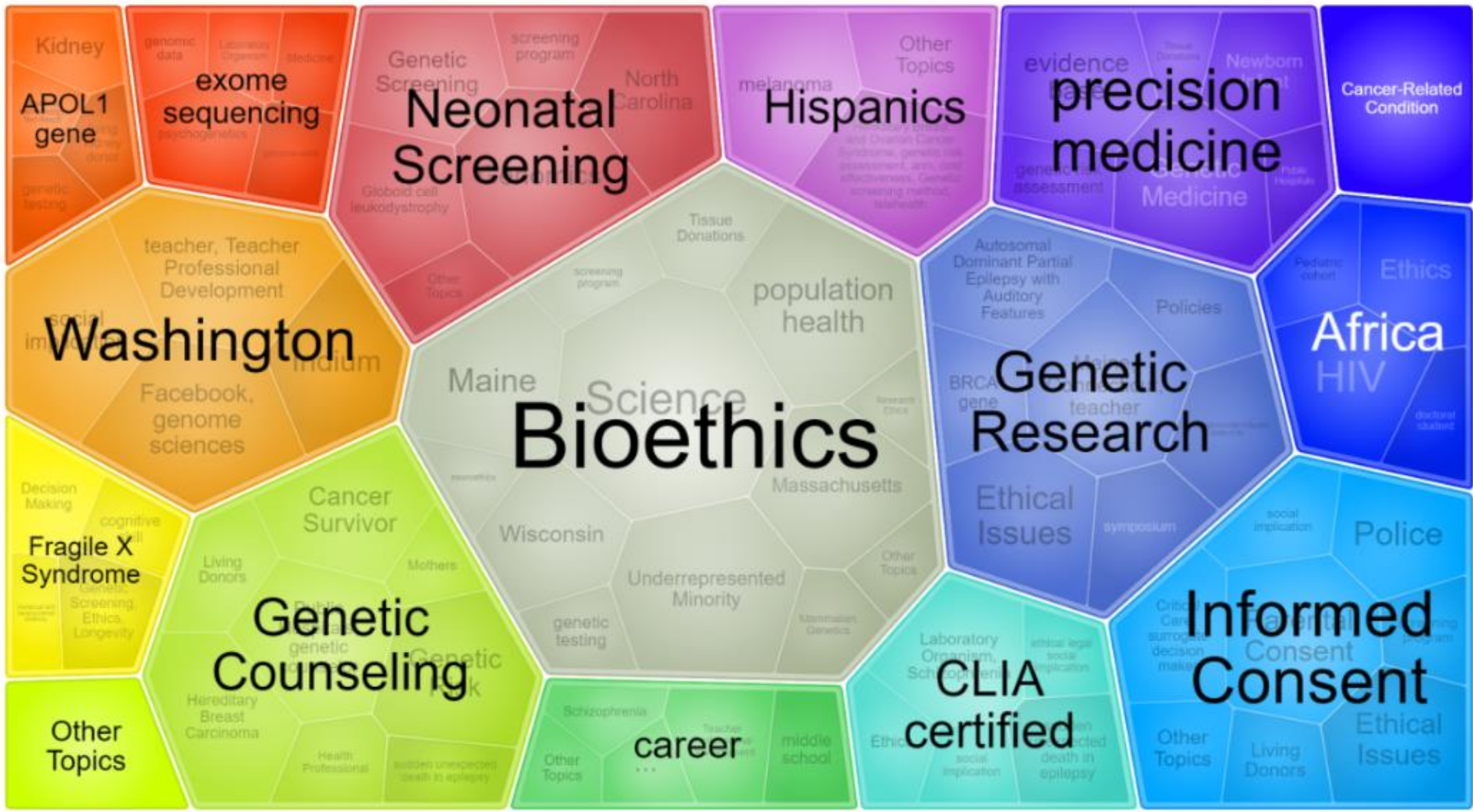
N=53

Awarded ELSI Projects by Activity Code, 2010-2020 (n=53 projects)

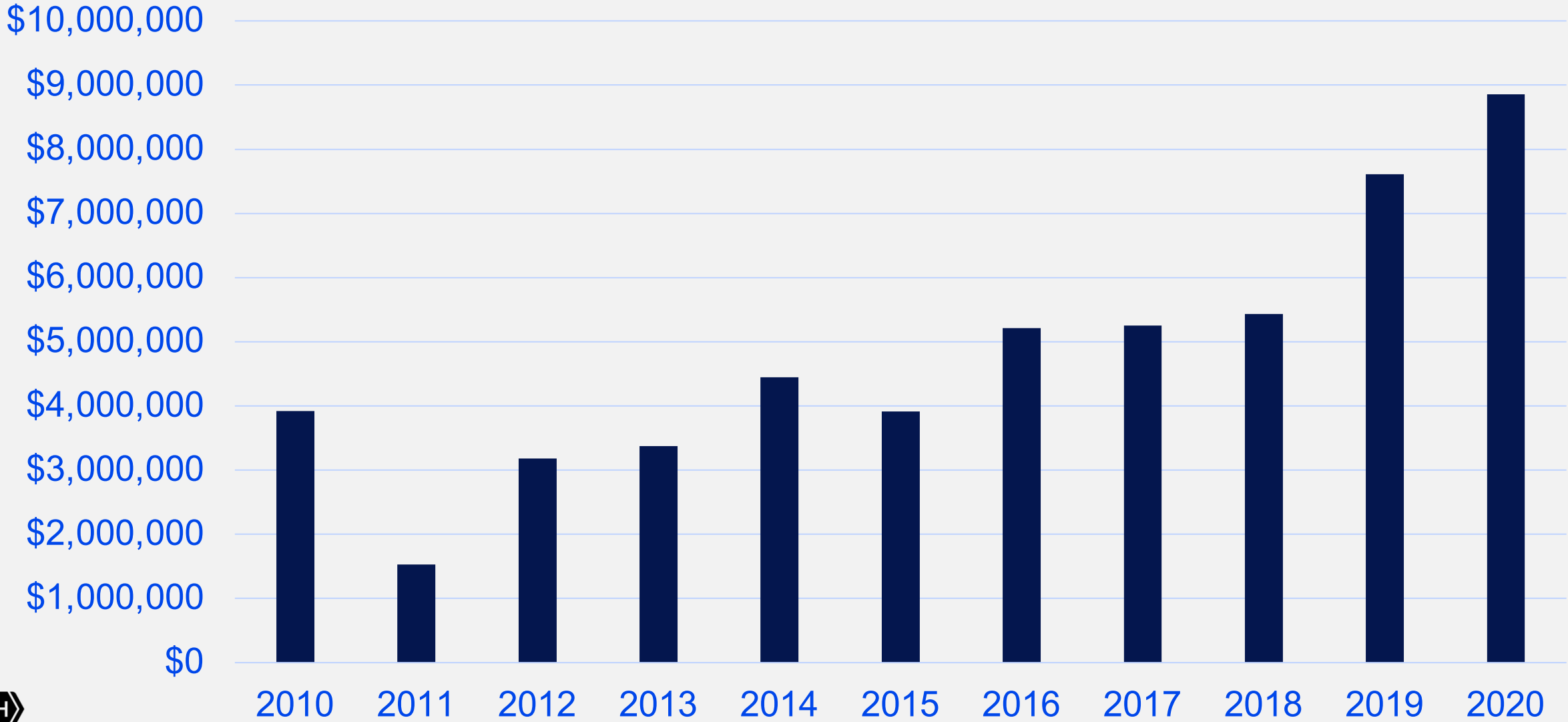


Awarded ELSI Projects by RCDC Thesaurus Concepts, 2010-2020 (n=53 unique projects)

C G T G



Total Cost Across ELSI Projects By Fiscal Year, 2010-2020 (n=153 project-years)



Total Cost Across ELSI Projects By Fiscal Year, 2010- 2020 (n=153 project- years)

Fiscal Year	Total Cost	Project-Years
2010	\$3,921,418	11
2011	\$1,526,737	7
2012	\$3,178,744	9
2013	\$3,376,670	7
2014	\$4,446,880	9
2015	\$3,914,876	10
2016	\$5,215,565	16
2017	\$5,253,099	18
2018	\$5,433,411	20
2019	\$7,611,329	23
2020	\$8,855,712	23
Grand Total	\$52,734,441	153

Bottom Line?

- NHGRI funds the majority of genomics related ELSI research at the NIH
- Some ICs have stable programs
- ELSI research at other ICs “follow projects”
- NHGRI: exemplar, cooperative, collaborative

NHGRI's ELSI Team

A C G
C G T



Joy Boyer, B.A.
Program Director
Division of Genomics and Society



Natalie Pino
Scientific Program Analyst
Division of Genome Sciences



Dave Kaufman, Ph.D.
Program Director
Division of Genomics and Society



Alex Raphael
Program Analyst
Division of Genome Sciences



Nicole C. Lockhart, Ph.D.
Health Sciences Administrator
Division of Genomics and Society



Tasha A. Stewart
Program Assistant
Division of Genomics and Society



Rene Sterling, Ph.D., M.H.A.
Program Director
Division of Genomics and Society



Kathleen Renna
Program Analyst
Division of Genomics and Society



The **Forefront**
of **Genomics**[®]

Total Cost Across ELSI Projects By Activity Code, 2010- 2020 (n=153 project-years)

Activity Code	Total Cost	Project-Years
R01	\$29,065,443	58
U19	\$5,679,274	5
R25	\$5,332,366	22
U54	\$3,408,180	15
U01	\$2,988,398	11
R21	\$2,076,422	10
K23	\$1,385,638	9
RC1	\$962,702	2
P30	\$787,322	12
K01	\$567,324	4
R43	\$225,000	1
R03	\$156,377	2
R13	\$99,995	2
Grand Total	\$52,734,441	153