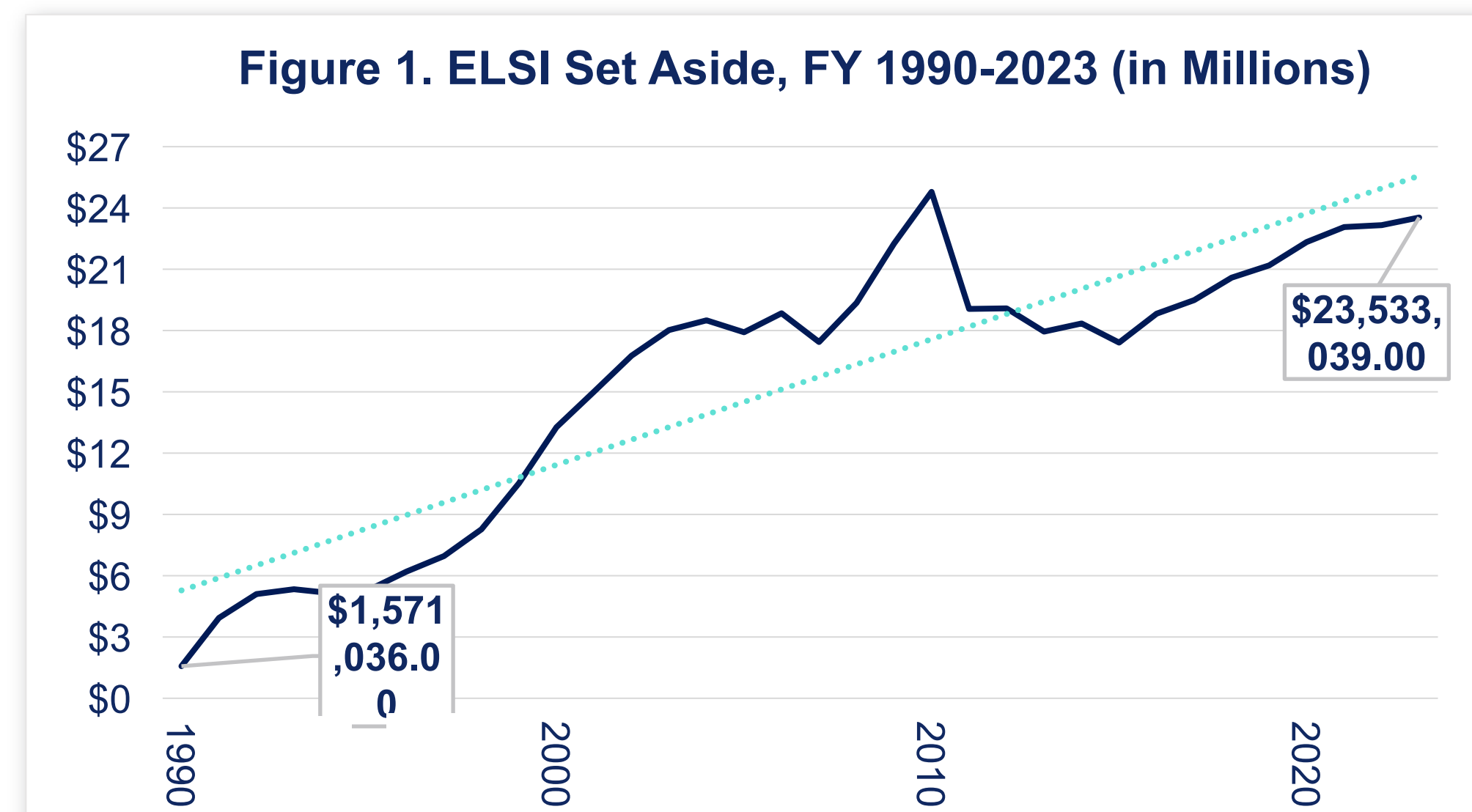


## Program Overview

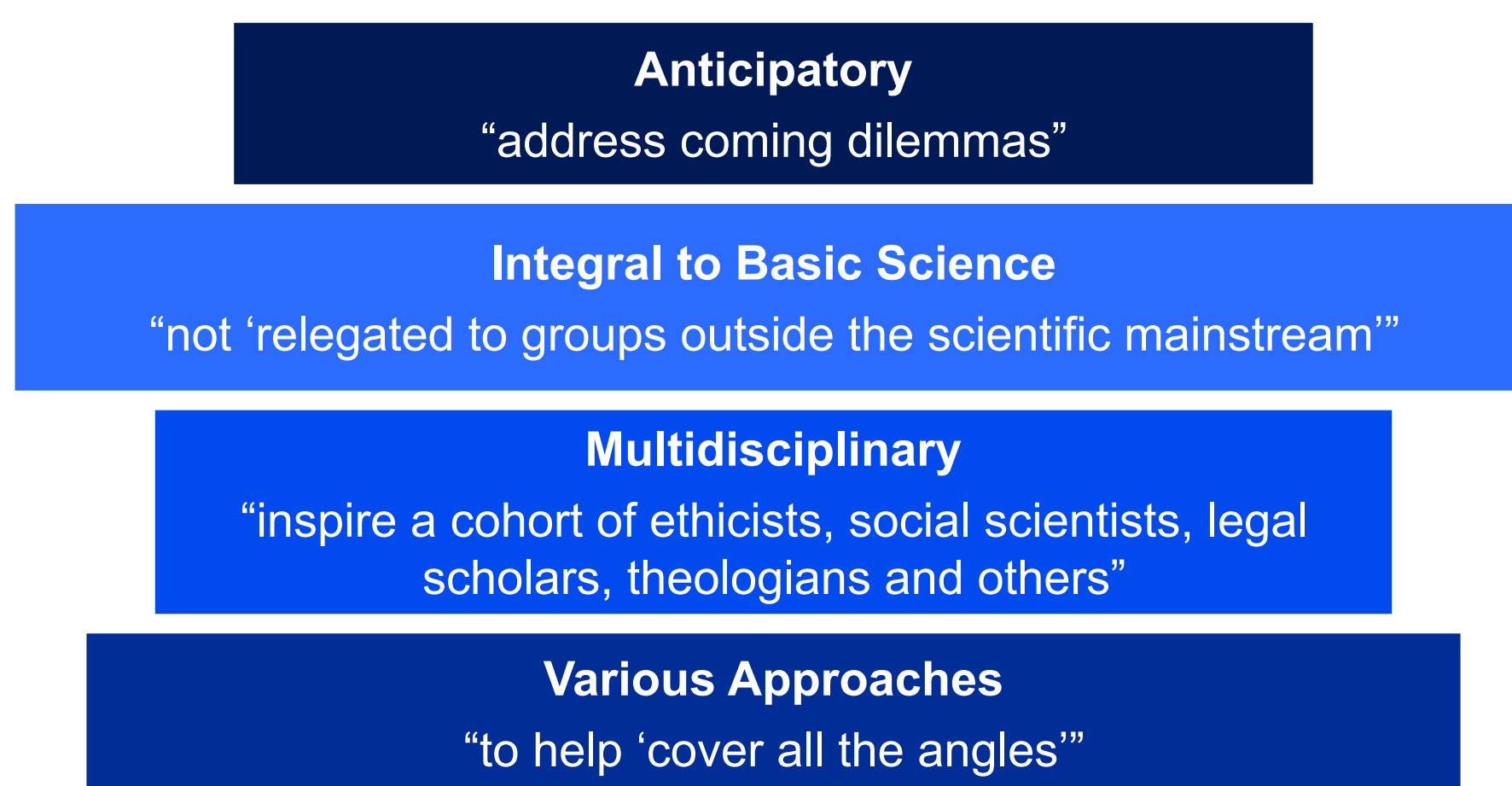
The National Human Genome Research Institute's (NHGRI) ELSI Research Program was established as part of the Human Genome Project in 1990 to explore ELSI issues. The program is funded by a **Congressionally mandated set-aside of at least five-percent (5%) of the NHGRI extramural program budget**. In FY 2023, the 5% set-aside totaled \$23.53M (see Figure 1), providing funding for research, research training, resource development, and other extramural funding opportunities.



Additional funding in 2010 from the American Recovery and Reinvestment Act (ARRA) Source: NHGRI, 2024

Key tenets from the start of the program remain relevant today (see Figure 2). A robust ELSI scholarship has informed the field of genetics and genomics, with contributions from a broad array of disciplines, including history, religion, philosophy, art, literature, bioethics, behavioral and social sciences, law, medicine, public health, health services research, and data science.

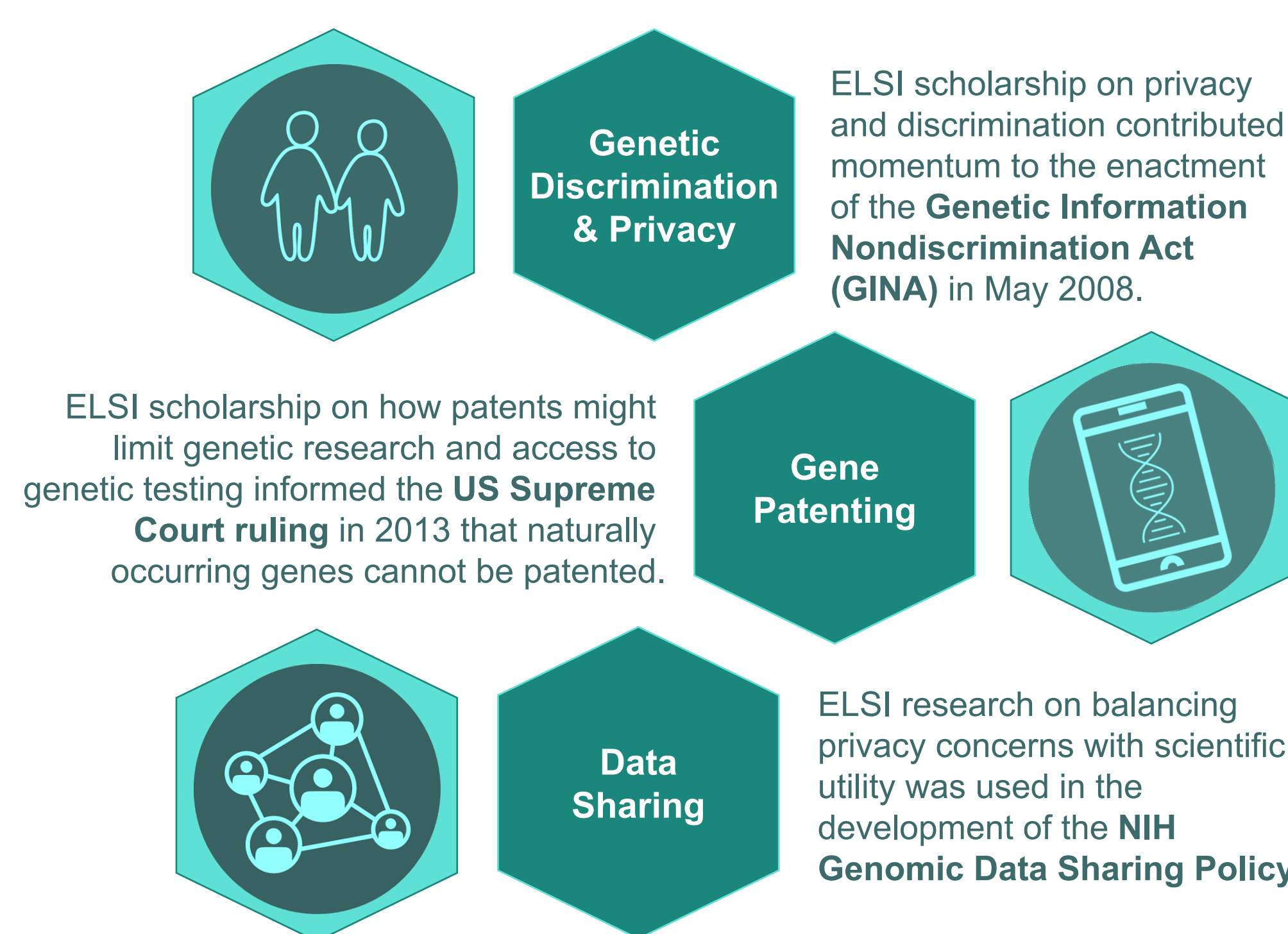
Figure 2. Key Tenets of the ELSI Research Program



Source: Juengst ET, 2021. doi:10.1002/ajmg.a.62405

Over the decades, ELSI investigators have had a discernable impact on the conduct of research, the practice of medicine, and the development of guidelines, policy and regulation. Figure 3 highlights areas where the influence of ELSI is clear.

Figure 3. Impact of the ELSI Research Program (examples)



Source: Boyer JT, et al, 2017. https://doi.org/10.1002/9780470015902.a0005181.pub3

As the availability and use of new genomic knowledge, data, and technologies increase in number and complexity, the ELSI Research Program will remain at the Forefront of Genomics.

## ELSI Research Areas

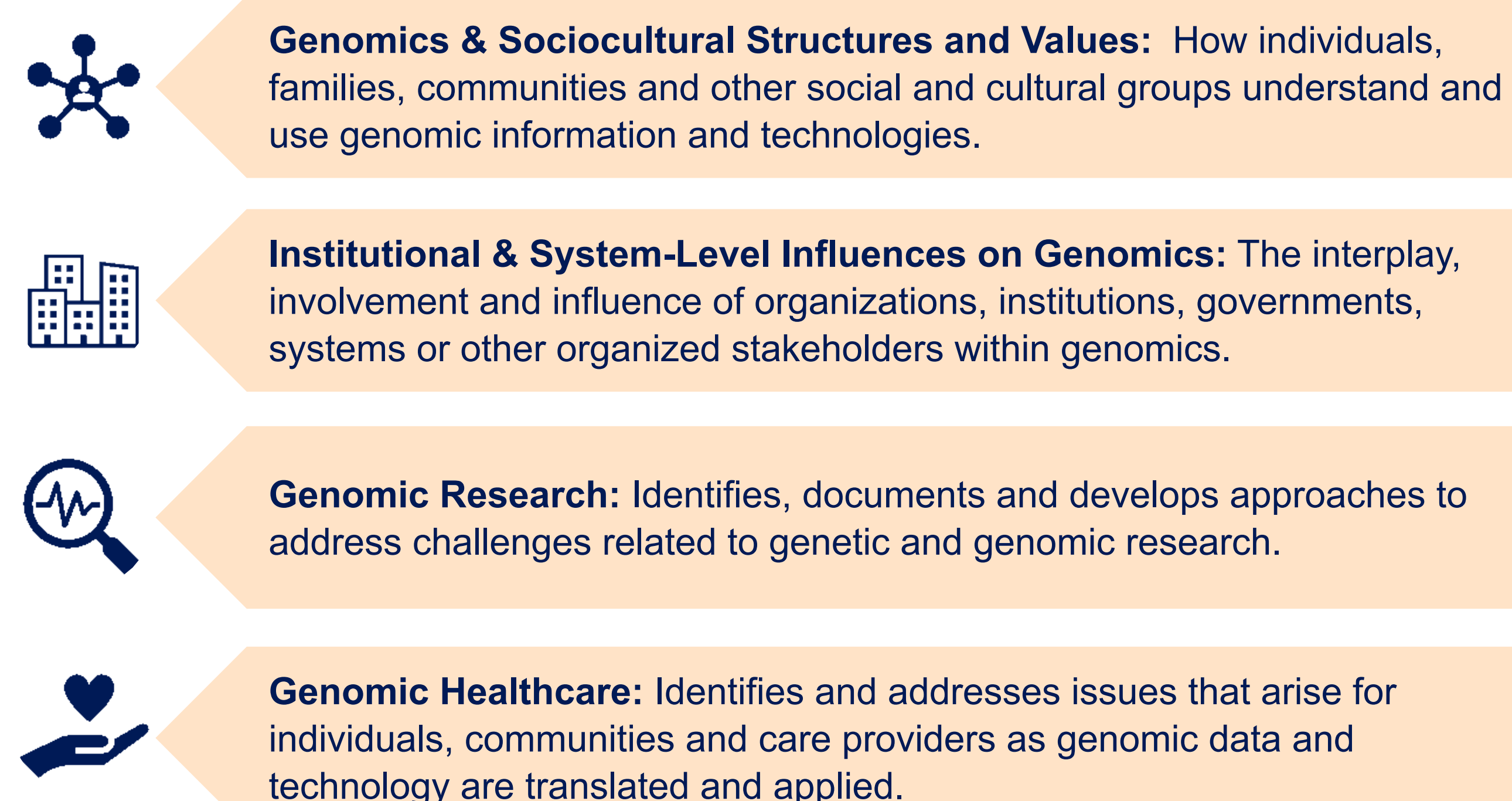
ELSI Research addresses the new and sometimes unexpected ways genomics interacts with many aspects of daily life – what it means to be human, how to deliver healthcare, whether participating in research will return any benefit, or where will information about your genomic data end up.

To capture this diversity of issues, the ELSI Research Program has identified four broad areas of research (see Figure 4). These four areas are overlapping, and many research projects proposed by investigators and trainees address issues cut across two or more areas.



Scan for a more detailed discussion of each research area.

Figure 4. NHGRI's ELSI Research Areas



Source: NHGRI, 2024

## New to ELSI Research?

**ELSIhub** is a key resource funded by NHGRI to support those interested in ELSI research. Monthly, ELSIhub holds one-hour webinars on the second Friday of the month called the **ELSI Friday Forum**. ELSIhub also hosts **ELSI Conversations**, a series of networking events focused on topics proposed by attendees and others. Events are recorded and archived online.

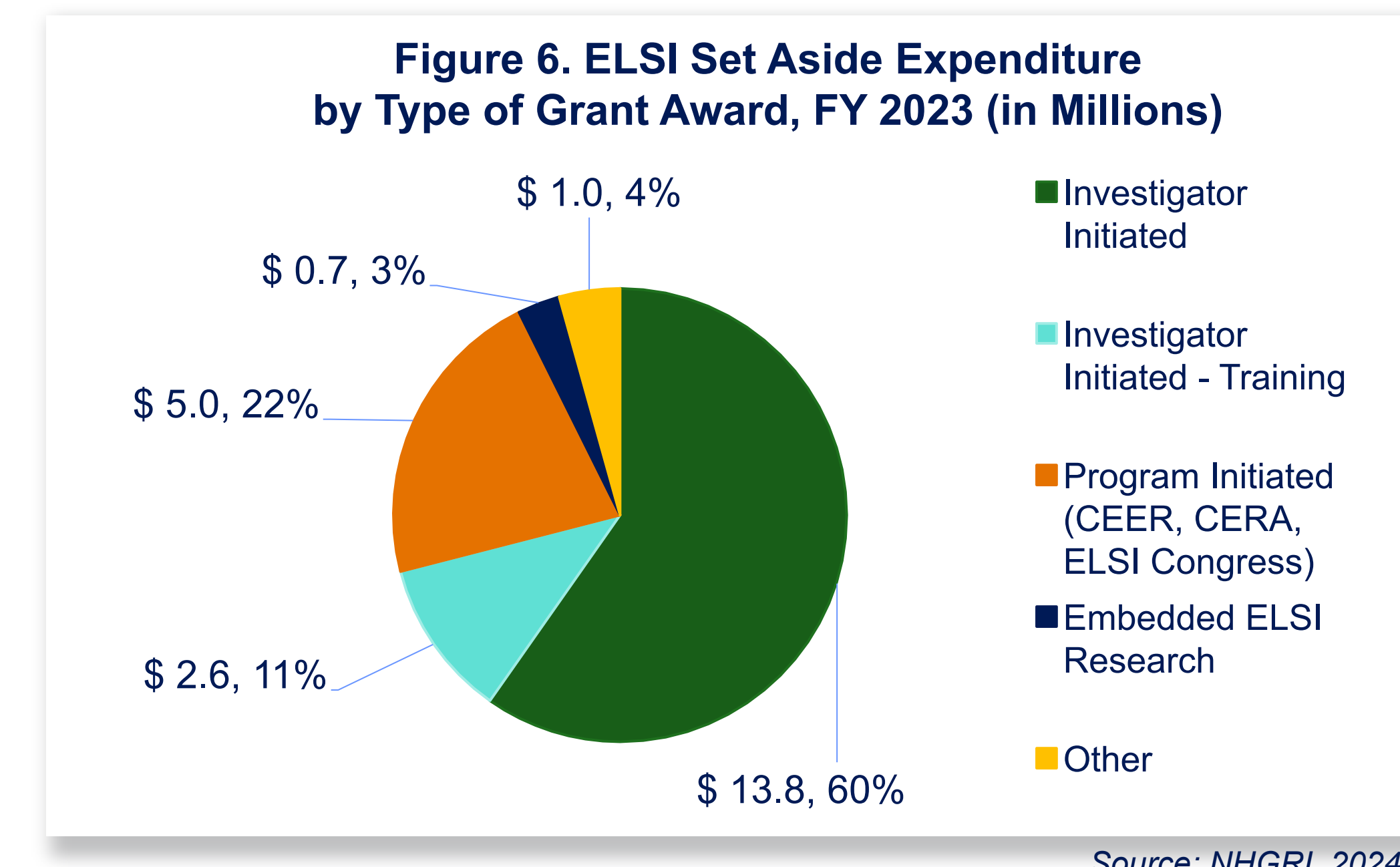
These are two great ways to learn more about new, evolving, and persistent ELSI issues, and to connect with others interested in ELSI research.

Scan for schedule and recordings →



## Notices of Funding Opportunity (NOFO) for ELSI Research and Training

The majority of ELSI set-aside supports research and training grants initiated by investigators (71% in FY 2023), followed by NHGRI-initiated grants for research and resources (see Figure 6).



Source: NHGRI, 2024

Since 1991, the "ELSI PARs" (Program Announcements with Special Review Criteria or Receipt Dates) have been the primary NOFO for investigator-initiated ELSI research at NIH (see Figure 7).

Figure 7. ELSI Research Program Funding Opportunities for Research

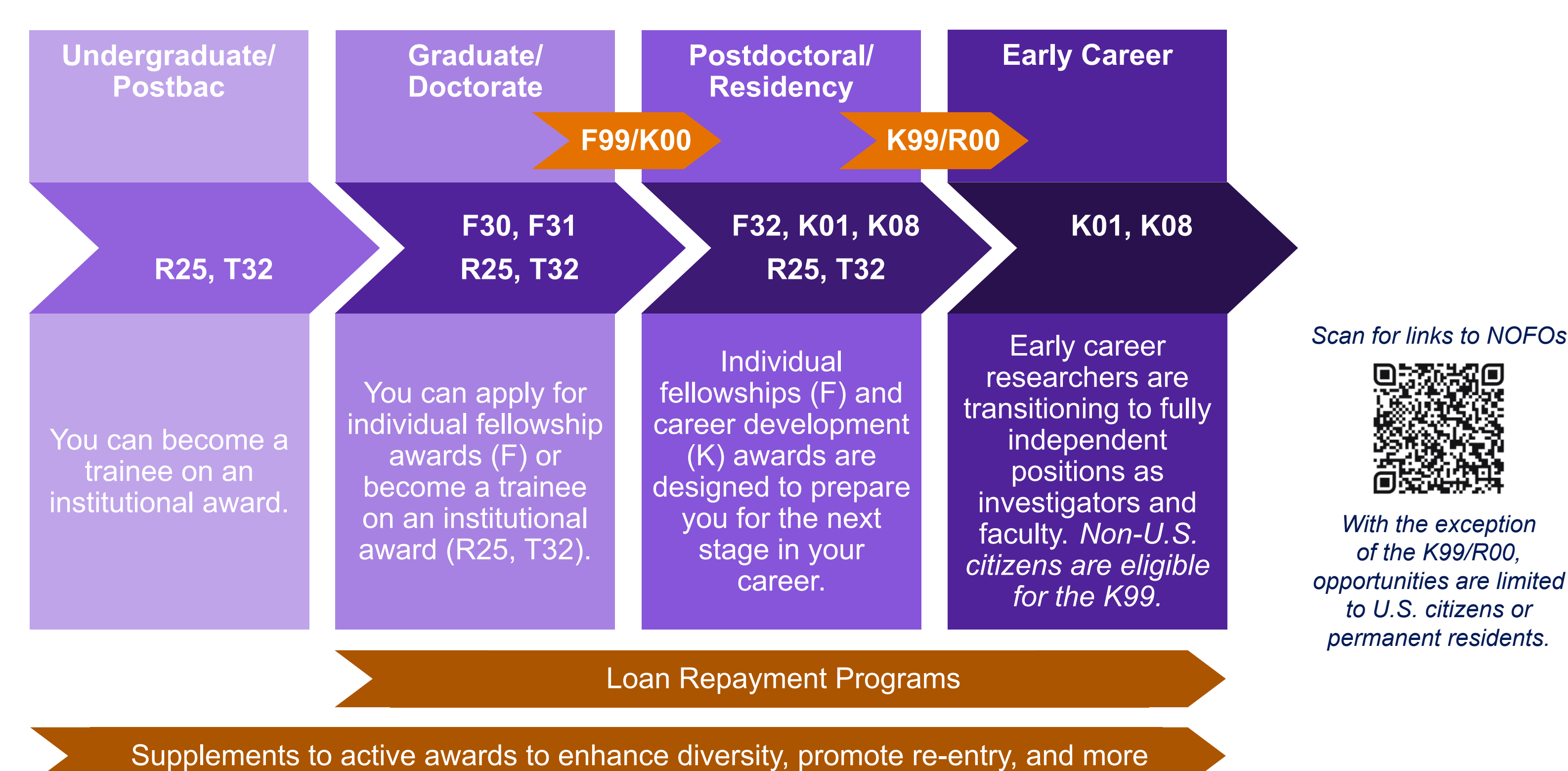


Source: NHGRI, 2024

Current program-initiated awards support the **Centers for Excellence in ELSI Research (CEER)**, the **Center for ELSI Resources and Analysis (CERA)** also known as **ELSIhub**, and the **Biennial ELSI Congress**.

The ELSI Research Program intends to publish a new NOFO in July 2024 titled, **Building Partnerships and Broadening Perspectives for Advancing ELSI Research (BBAER) (UM1)**. Eligible organizations include domestic organizations located in the U.S. and its territories that received less than \$30 million per year in

Figure 8. NHGRI Supported Opportunities for ELSI Research Training and Career Development



Scan for links to NOFOs

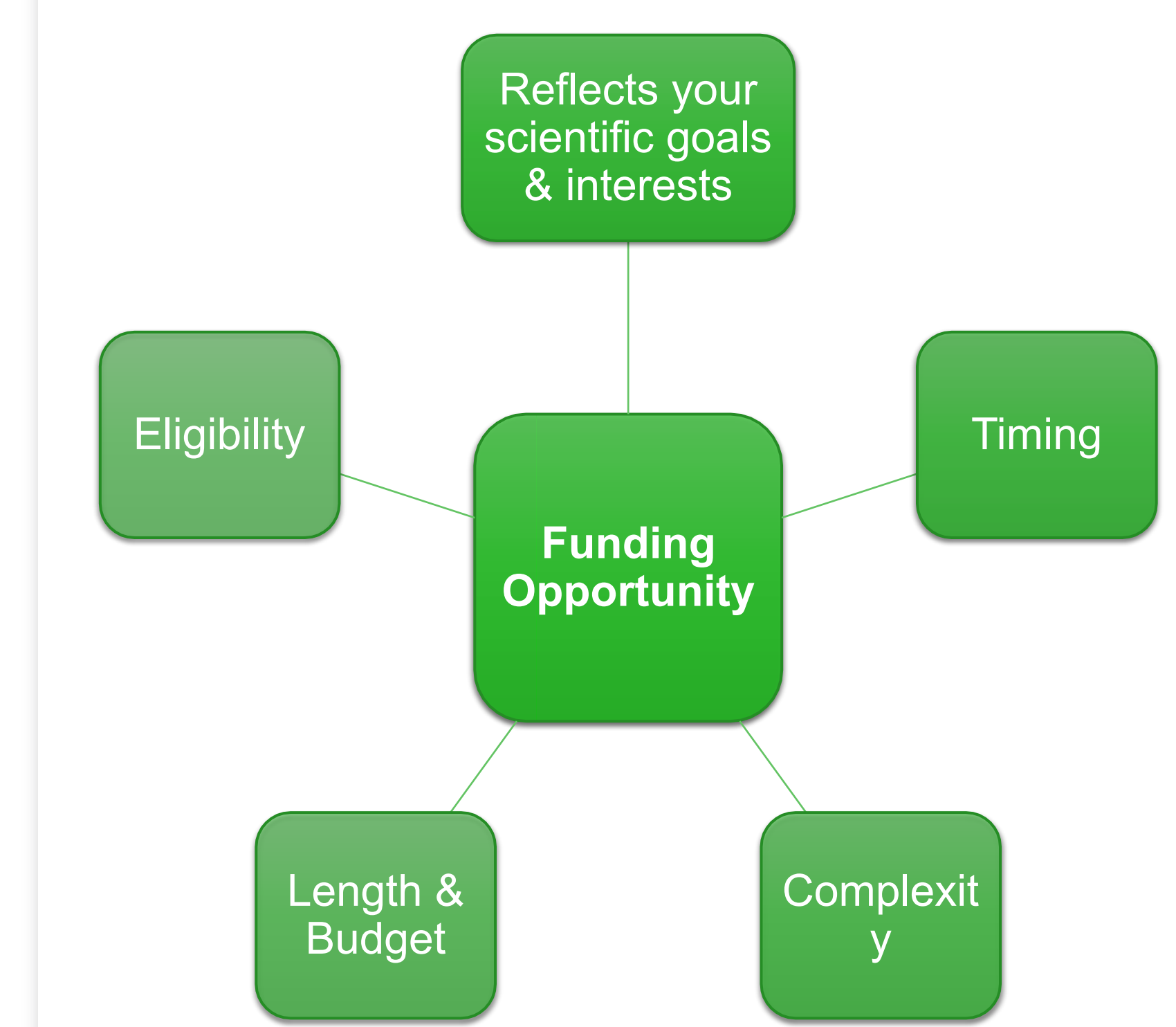
With the exception of the K99/R00, opportunities are limited to U.S. citizens or permanent residents.

Source: NHGRI, 2024

For those who are not yet independent investigators, NHGRI supports several opportunities for research training and career development (see Figure 9). These opportunities include grants awarded to institutions who provide placements for undergraduates on through postdocs (R25, T32); and grants awarded to individuals through U.S.-based institutions. ELSI research can be proposed across current NOFOs.

In general, when deciding whether to apply to a particular NOFO, potential applicants should be sure to **read the entire NOFO**. Keep in mind that similar programs may vary in specific requirements across NIH Institutes, Centers, or Offices. Never hesitate to contact the program officer listed in the NOFO about your research ideas and any questions you may have.

Figure 9. Key Considerations for NOFO Selection



Source: NHGRI, 2024

total NIH funding for the past three years. Four required elements include: 1) Transdisciplinary ELSI research projects, 2) Research teams with community representatives, 3) ELSI research capacity building, and 4) Workforce development.



## Additional Resources

**Historical reflections on ELSI** – Hear from former ELSI program director – Joy Boyer



**NIH Reporter and Matchmaker** – Learn which NIH Institutes/Centers/ Offices fund your research area



**NIH Webinars on Applying for Grants** – Updated regularly with new events & recordings



**NIH Office of Extramural Research** – Join a listserv(s) for updates on funding, policy & other grants related news



**Funding Opportunities & Resources for International Scholars** – Listing from the NIH Fogarty Center



**NIH Supports a Diverse Genomics Workforce**



**NIH Supports New & Early-Stage Investigators**



**Sample ELSI Grant Applications, Summary Statements and Biosketches**



**ELSIhub Webinars on Grantsmanship** – Info & tips on the writing & review of ELSI grants



**ELSI TraineeHub** – Private space on ELSIhub for trainees with networking sessions & resources



## NHGRI Division of Genomics & Society ELSI Research Program Staff

Feel free to email us anytime regarding funding opportunities of interest, grant application requirements, NIH policy, research project ideas, draft specific aims, or other questions you may have. We are happy to provide feedback on your research ideas **before** applications are submitted. We also can provide feedback **after** applications are reviewed.

We'd love to hear from you!



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