

2025 Current Fiscal Year Report: National Advisory Council for Human Genome Research

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1. Department or Agency

Department of Health and Human
Services

2. Fiscal Year

2025

3. Committee or Subcommittee

National Advisory Council for Human
Genome Research

3b. GSA

Committee No.

943

4. Is this New During Fiscal Year?

No

5. Current Charter

05/08/2024

6. Expected Renewal Date

05/08/2026

7. Expected Term Date

8a. Was Terminated During Fiscal Year?

No

8b. Specific Termination Authority

8c. Actual Term Date

9. Agency Recommendation for Next Fiscal Year

Continue

10a. Legislation Req to Terminate?

Not Applicable

10b. Legislation Pending?

Not Applicable

11. Establishment Authority Statutory (Congress Created)

12. Specific Establishment Authority

42 USC. 284(a)

13. Effective Date

11/20/1985

14. Committee Type

Continuing

14c. Presidential?

No

15. Description of Committee Other Committee

16a. Total Number of Reports

No Reports for
this Fiscal Year

17a. Open

0

17b. Closed

0

17c. Partially Closed

0

Other Activities

0

Meetings and Dates

No Meetings

Current Next
FY FY

18a(1). Personnel Pmts to Non-Federal Members	\$0.00	\$0.00
18a(2). Personnel Pmts to Federal Members	\$0.00	\$0.00
18a(3). Personnel Pmts to Federal Staff	\$0.00	\$0.00
18a(4). Personnel Pmts to Non-Member Consultants	\$0.00	\$0.00
18b(1). Travel and Per Diem to Non-Federal Members	\$0.00	\$0.00
18b(2). Travel and Per Diem to Federal Members	\$0.00	\$0.00
18b(3). Travel and Per Diem to Federal Staff	\$0.00	\$0.00
18b(4). Travel and Per Diem to Non-member Consultants	\$0.00	\$0.00
18c. Administrative Costs (FRNs, contractor support, In-person/hybrid/virtual meetings)	\$0.00	\$0.00
18d. Other (all other funds not captured by any other cost category)	\$0.00	\$0.00
18e. Total Costs	\$0.00	\$0.00
19. Federal Staff Support Years (FTE)	0.00	0.00

20a. How does the Committee accomplish its purpose?

Section 492 of the PHS Act states that The Secretary...shall by regulation require appropriate technical and scientific peer review of -- (A) applications...; and (B)...biomedical and behavioral research and development contracts.... This council is composed of both scientific and public members who provide the second level of peer review; advise on policy development, program implementation and evaluation; and research

needs and opportunities of the National Human Genome Research Institute (NHGRI). The National Advisory Council for Human Genome Research reviewed 2,745 applications requesting \$4,967,931,357.00.

20b. How does the Committee balance its membership?

The Council will consist of no more than 18 members appointed by the Secretary (appointed members) and at least 5 nonvoting ex officio members. Of the appointed members, two-thirds will be selected from among the leading representatives of the health and scientific disciplines (including not less than 2 individuals who are leaders in the fields of public health and the behavioral or social sciences) relevant to the activities of the NHGRI. One-third of the members will be appointed by the Secretary from the general public and will include leaders in the fields of public policy, law, health policy, economics, and management.

20c. How frequent and relevant are the Committee Meetings?

Meetings are held not less than three times each fiscal year. The committee met on February 12-13, 2024, May 20-21, 2024, and September 9-10, 2024. The National Advisory Council for Human Genome Research provides advice on a continuing basis on the type of scientific research programs that should be supported and on how to carry out the designated mission and responsibilities of the Institute. It also provides ongoing review of the relevance and effectiveness of the existing programs.

20d. Why can't the advice or information this committee provides be obtained elsewhere?

The National Advisory Council is composed of both scientific and public members who provide the second level of peer review; advise on policy development, program implementation and evaluation; and research needs and opportunities of the National Human Genome Research Institute. The quality, scope, and balance of advice from this council cannot be obtained from NIH staff or from other established sources because the membership of the council is constituted to meet the specific requirements of the mandated mission of the council and of the Institute.

20e. Why is it necessary to close and/or partially closed committee meetings?

The meetings of the National Advisory Council for Human Genome Research were either closed or partially closed to the public for the review of grant applications and/or contract proposals. Sections 552b(c)(4) and 552b(c)(6) of the Government in the Sunshine Act permit the closing of meetings where discussion could reveal confidential trade secrets or commercial property such as patentable material and personal information, the disclosure of which would constitute a clearly unwarranted invasion of personal privacy.

21. Remarks

Committee Function: Other- National Scientific and Advisory. Reports: This committee did not produce any public reports during the fiscal year. The DFO and Decision Maker are the same person, the Deputy Director, Division of Extramural Operations. This is a small Institute and the Director decided not to separate these roles. Members Joseph Berry, Laura Bierut, Kyle Brothers, Gail Jarvik, Lynn Jorde, and Iftikhar Kullo whose terms were set to expire on

9/30/2024 were administratively extended to 03/29/2025 while nominees and new members were delayed in completing the appointment process. Dr. Lawrence Tabak's title was updated from Performing the Duties of the NIH Director to Principal Director, NIH this fiscal year. Dr. Monica Bertagnolli was appointed as Director, NIH this fiscal year. Dr. Tabak stopped serving as an Ex Officio member when Dr. Bertagnolli was appointed as Director, NIH The Charter allows the Committee to have 23 authorized members including but not limited to SGEs and Ex-Officios. There are three Ex-Officios (Secretary Becerra, Dr. Bertagnolli, and Dr. Green). This data is preliminary and will be finalized at a later date).

Designated Federal Officer

Rudy Pozzatti Deputy Director, Division of Extramural Operations

Committee Members	Start	End	Occupation	Member Designation
Becerra, Xavier	03/19/2021	01/20/2025	Secretary of Health and Human Services	Ex Officio Member Special Government Employee (SGE) Member
Beery, Joseph	02/12/2023	03/29/2025	Data Science Consultant	Ex Officio Member Special Government Employee (SGE) Member
Bertagnolli, Monica	11/09/2023	01/20/2025	Director, NIH	Ex Officio Member Special Government Employee (SGE) Member
Bierut, Laura	01/30/2022	03/29/2025	Professor, Washington University in St. Louis	Ex Officio Member Special Government Employee (SGE) Member
Brothers, Kyle	01/16/2022	03/29/2025	Endowed Chair and Chief, University of Louisville	Ex Officio Member Special Government Employee (SGE) Member
Cho, Judy	02/12/2023	09/30/2025	Ward-Coleman Professor in Translational Genetics	Ex Officio Member Special Government Employee (SGE) Member

Cox, Nancy	05/07/2023	09/30/2025	Mary Phillips Edmonds Gray Professor of Genetics	Special Government Employee (SGE) Member
Frazer, Kelly	08/25/2024	09/30/2026	Professor, University of California, San Diego	Special Government Employee (SGE) Member
Jarvik, Gail	01/30/2022	03/29/2025	Professor, University of Washington Medical Center	Special Government Employee (SGE) Member
Jorde, Lynn	01/18/2022	03/29/2025	Professor and Chair, University of Utah	Special Government Employee (SGE) Member
Korf, Bruce	08/25/2024	09/30/2026	WAYNE H. AND SARA CREWS FINLEY ENDOWED CHAIR IN MEDICAL GENETICS AND ASSOCIATE DEAN FOR GENOMIC MEDICINE, University of Alabama at Birmingham	Special Government Employee (SGE) Member
Kullo, Iftikhar	01/18/2022	03/29/2025	Professor, Mayo Clinic College of Medicine	Special Government Employee (SGE) Member
Reddy, Timothy	01/29/2022	09/30/2025	Professor, The Jackson Laboratory for Genomic Medicine	Special Government Employee (SGE) Member
Robinson, Peter	08/28/2022	03/29/2025	Professor, The Jackson Laboratory for Genomic Medicine	Special Government Employee (SGE) Member
Tabak, Lawrence	12/20/2021	01/20/2025	Acting Director, NIH	Ex Officio Member

Number of Committee Members Listed: 15

Narrative Description

NIH's mission is to see fundamental knowledge about the nature and behavior of living systems and the application of that

knowledge to enhance health, lengthen life, and reduce illness and disability. NIH works toward that mission by: conducting research in its own laboratories; supporting the research of non-Federal scientists in universities, medical schools, hospitals, and research institutions throughout the country and abroad; helping in the training of research investigators; and fostering communication of medical and health sciences information. Section 492 of the Public Health Service Act states that The Secretary...shall by regulation require appropriate technical and scientific peer review of (A) applications...; and (B) ...biomedical and behavioral research and development contracts... The National Advisory Council for Human Genome Research provides second level peer review, makes recommendations for support of grants, contracts proposals, and cooperative agreements; advises on policy development, program implementation and evaluation; and research needs of the National Human Genome Research Institute.

What are the most significant program outcomes associated with this committee?

Checked if
Applies

- | | |
|---|-------------------------------------|
| Improvements to health or safety | <input type="checkbox"/> |
| Trust in government | <input type="checkbox"/> |
| Major policy changes | <input type="checkbox"/> |
| Advance in scientific research | <input checked="" type="checkbox"/> |
| Effective grant making | <input checked="" type="checkbox"/> |
| Improved service delivery | <input type="checkbox"/> |
| Increased customer satisfaction | <input type="checkbox"/> |
| Implementation of laws or regulatory requirements | <input type="checkbox"/> |
| Other | <input type="checkbox"/> |

Outcome Comments

NA

What are the cost savings associated with this committee?

Checked if Applies

- | | |
|------|--------------------------|
| None | <input type="checkbox"/> |
|------|--------------------------|

Unable to Determine	<input checked="" type="checkbox"/>
Under \$100,000	<input type="checkbox"/>
\$100,000 - \$500,000	<input type="checkbox"/>
\$500,001 - \$1,000,000	<input type="checkbox"/>
\$1,000,001 - \$5,000,000	<input type="checkbox"/>
\$5,000,001 - \$10,000,000	<input type="checkbox"/>
Over \$10,000,000	<input type="checkbox"/>
Cost Savings Other	<input type="checkbox"/>

Cost Savings Comments

NIH supported basic and clinical research accomplishments often take many years to unfold into new diagnostic tests and new way to treat and prevent diseases.

What is the approximate Number of recommendations produced by this committee for the life of the committee?

39,602

Number of Recommendations Comments

The committee reviewed 2,745 grant applications this reporting period.

What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?

0%

% of Recommendations Fully Implemented Comments

Information on the research funded by NIH is available through the RePORT (Research Portfolio Online Reporting Tool) website. RePORT provides access to reports, data, and analyses of NIH research activities that advance the mission of the NIH, including information on NIH expenditures, strategic plans, reports on NIH funding, and reports on the organization and people involved in NIH research and research training. The RePORT website is located at <http://report.nih.gov>.

What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?

0%

% of Recommendations Partially Implemented Comments

Information on the research funded by NIH is available through the RePORT (Research Portfolio Online Reporting Tool) website. RePORT provides access to reports, data, and

analyses of NIH research activities that advance the mission of the NIH, including information on NIH expenditures, strategic plans, reports on NIH funding, and reports on the organization and people involved in NIH research and research training. The RePORT website is located at <http://report.nih.gov>.

Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?

Yes ☒ No ☐ Not Applicable ☐

Agency Feedback Comments

Information is provided to the public at the open session of each Council meeting through reports and the Director's update. The public can view information related to the Council through the council's official website.

What other actions has the agency taken as a result of the committee's advice or recommendation?

Checked if Applies

Reorganized Priorities	<input checked="" type="checkbox"/>
Reallocated resources	<input type="checkbox"/>
Issued new regulation	<input type="checkbox"/>
Proposed legislation	<input type="checkbox"/>
Approved grants or other payments	<input checked="" type="checkbox"/>
Other	<input type="checkbox"/>

Action Comments

An action of "approved" or "recommended" for grants receiving review by this Council does not infer that the grant will be or has been funded. Research grant applications submitted to NIH must go through a two-step review process that includes the initial peer review for scientific and technical merit and a second step of review and approval by a National Advisory Council that includes program relevance. In addition, prior to an award or funding being made, NIH staff must conduct an administrative review for a number of other considerations. These include alignment with NIH's funding principles, review of the project budget, assessment of the applicant's management systems, determination of applicant eligibility, and compliance with public policy requirements. After all these steps have been completed, NIH officials make funding decisions on individual grant applications.

Is the Committee engaged in the review of applications for grants?

Yes

What is the estimated **Number** of grants reviewed for approval

What is the estimated **Number** of grants recommended for approval 2,745
2,745

What is the estimated **Dollar Value** of grants recommended for approval
\$4,967,931,357

Grant Review Comments

The National Advisory Council for Human Genome Research reviewed 2,745 applications in FY24.

How is access provided to the information for the Committee's documentation?

Checked if Applies

Contact DFO	<input checked="" type="checkbox"/>
Online Agency Web Site	<input checked="" type="checkbox"/>
Online Committee Web Site	<input checked="" type="checkbox"/>
Online GSA FACA Web Site	<input checked="" type="checkbox"/>
Publications	<input type="checkbox"/>
Other	<input checked="" type="checkbox"/>

Access Comments

IC Committee Management Officer 240-669-5201