DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
Bethesda, Maryland 20892

www.nih.gov

CHARTER

NATIONAL ADVISORY COUNCIL FOR HUMAN GENOME RESEARCH

AUTHORITY

Required by 42 U.S.C. 284a, section 406 of the Public Health Service (PHS) Act, as amended. The National Advisory Council for Human Genome Research (Council) is governed by the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C. app.), which sets forth standards for the formation and use of advisory committees.

OBJECTIVES AND SCOPE OF ACTIVITIES

The Council will advise, assist, consult with, and make recommendations to the Secretary of Health and Human Services (Secretary) and the Director, National Human Genome Research Institute (NHGRI, also referred to as Institute) on matters related to the activities carried out by and through the Institute and the policies respecting these activities.

DESCRIPTION OF DUTIES

The Council may recommend to the Secretary, in accordance with section 231 of the PHS Act, as amended, acceptance of conditional gifts for study, investigation, or research on the development of knowledge basic to understanding genomic research, for the acquisition of grounds, or for the construction, equipping, or maintenance of facilities for the Institute.

The Council may review applications for grants and cooperative agreements for research and training and recommend approval of applications for projects which show promise of making valuable contributions to human knowledge; may review any grant, contract, or cooperative agreement proposed to be made or entered into by the Institute; may collect, by correspondence or by personal investigation, information as to studies which are being carried on in the United States or any other country as to genome research and, with the approval of the Director of NHGRI, make available such information through appropriate publications for the benefit of public and private health entities, health professions personnel and scientists, and for the information of the general public.

The Council may prepare, for inclusion in the Biennial Report prepared by the Director, National Institutes of Health (NIH), under section 403 of the PHS Act, as amended (1) comments reflecting the activities of the Council in the fiscal years in which the report is prepared; (2) comments on the progress of the Institute in meeting its objectives; and (3) recommendations respecting the future directions and program and policy emphasis of the Institute.

AGENCY OR OFFICIAL TO WHOM THE COMMITTEE REPORTS

The Council will advise the Secretary; the Assistant Secretary for Health; the Director, NIH; and the Director, NHGRI.

SUPPORT

Management and support services will be provided by the Division of Extramural Research, NHGRI.

ESTIMATED ANNUAL OPERATING COSTS AND STAFF YEARS

The estimated annual cost for operating the Council, including compensation and travel expenses for members, but excluding staff support, is $85,878. The estimated annual person-years of staff support required is 0.4, at an estimated annual cost of $42,683.

DESIGNATED FEDERAL OFFICER

The Director, NHGRI, will assign a full-time or permanent part-time NHGRI employee to serve as the Designated Federal Officer (DFO) of the Council. In the event that the DFO cannot fulfill the assigned duties of the Council, one or more full-time or permanent part-time NHGRI employees will be assigned these duties on a temporary basis.

The DFO will approve or call all of the Council's and subcommittees' meetings, prepare and approve all meeting agendas, attend all Council and subcommittee meetings, adjourn any meeting when it is determined to be in the public interest, and chair meetings when directed to do so by the Director, NIH, or Director, NHGRI.

ESTIMATED NUMBER AND FREQUENCY OF MEETINGS

Meetings of the full Council will be held not less than three times within a fiscal year. Meetings will be open to the public except as determined otherwise by the Secretary in accordance with subsection (c) of section 552b of Title 5 U.S.C. Notice of all meetings will be given to the public. In the event a portion of a meeting is closed to the public, as determined by the Secretary, in accordance with the Government in the Sunshine Act (5 U.S.C. 552b(c)) and the Federal Advisory Committee Act, a report will be prepared which will contain, as a minimum, a list of members and their business addresses, the Council's functions, dates and places of meetings, and a summary of the Council's activities and recommendations made during the fiscal year. A copy of the report will be provided to the Department Committee Management Officer.

DURATION

Continuing.

TERMINATION

Unless renewed by appropriate action prior to its expiration, the Charter for the National Advisory Council on Human Genome Research will expire two-years from the date it's filed.

MEMBERSHIP AND DESIGNATION

The Council will consist of 18 members appointed by the Secretary and 5 nonvoting ex officio members: the Secretary; the Director, NIH; the Director, NHGRI; the Chief Medical Director of the Department of Veterans Affairs; the Assistant Secretary of Defense for Health Affairs (or their designees); and any additional officers or employees of the United States as the Secretary determines necessary for the Council to effectively carry out its functions. Of the 18 appointed members, 12 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 NHGRI, particularly representatives of the health and scientific disciplines in the areas of genomics and other large-scale approaches to biology, molecular genetics and molecular biology, human and medical genetics, medicine, information science, chemistry, mathematics, engineering, bioethics, social science, and behavioral science. Six of the members will be appointed by the Secretary from the general public and will include leaders in the fields of public health, public policy, law, health policy, economics, and management. All non-Federal members will serve as Special Government Employees. A member who has been appointed for a term of four years may not be reappointed to this Council before two years from the date of expiration of that member's term of office. A quorum for the conduct of business by the full Council will consist of a majority of currently appointed members.

Members will be invited to serve for overlapping four-year terms, except that any member appointed to fill a vacancy for an unexpired term will be appointed for the remainder of that term. A member may serve 180 days after the expiration of that member's term if a successor has not taken office.

The Chair of the Council will be selected by the Secretary from among the appointed members, except that the Secretary may select the Director, NHGRI, to be the Chair. The term of office of the Chair will be two years.

SUBCOMMITTEES

As necessary, subcommittees and ad hoc working groups may be established by the DFO within the Council's jurisdiction. The advice/recommendations of a subcommittee/working group must be deliberated by the parent advisory committee. A subcommittee may not report directly to a Federal official unless there is statutory authority to do so.

Subcommittee membership may be drawn in whole or in part from the parent advisory committee. All subcommittee members may vote on subcommittee actions and all subcommittee members count towards the quorum for a subcommittee meeting. A quorum for a subcommittee will be three members. Ad hoc consultants do not count towards the quorum and may not vote. The Department Committee Management Officer will be notified upon establishment of each standing subcommittee and will be provided information on its name, membership, function, and estimated frequency of meetings.

RECORDKEEPING

Meetings of the Council and its subcommittees will be conducted according to the Federal Advisory Committee Act, other applicable laws and Departmental policies. Council and subcommittee records will be handled in accordance with General Records Schedule 26, Item 2 or other approved agency records disposition schedule. These records will be available for public inspection and copying, subject to the Freedom of Information Act, 5 U.S.C. 552.

FILING DATE

May 8, 2014

APPROVED **2014 - 2016**

3/31/14
Date

Francis S. Collins, M.D., Ph.D.
Director, NIH