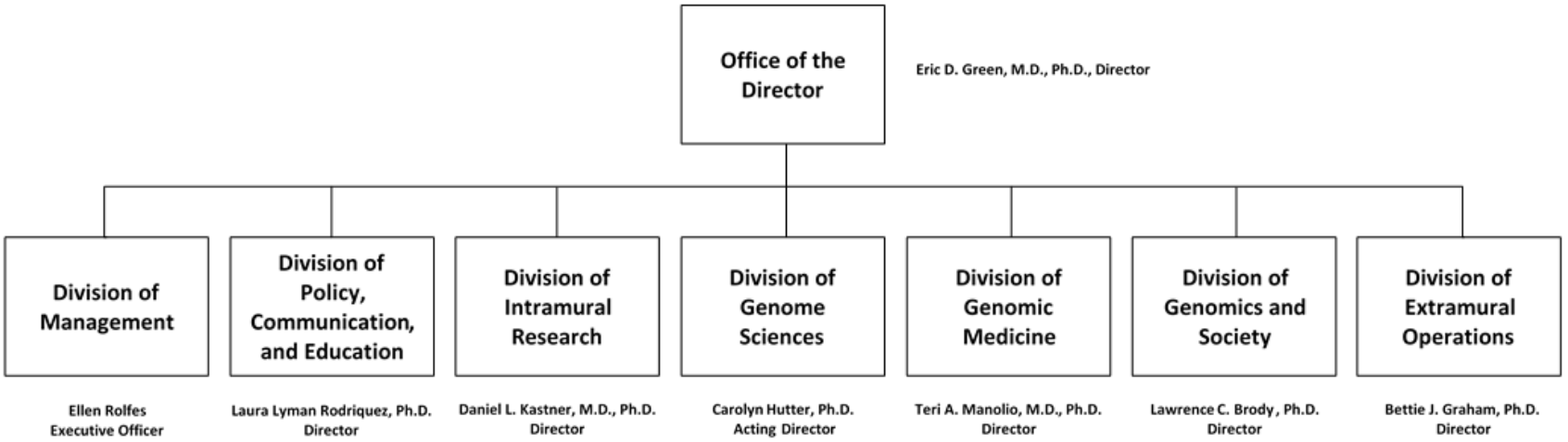
DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

National Human Genome Research Institute (NHGRI)

NATIONAL HUMAN GENOME RESEARCH INSTITUTE
Organizational Structure



NATIONAL INSTITUTES OF HEALTH

National Human Genome Research Institute

For carrying out section 301 and title IV of the PHS Act with respect to human genome research, $399,622,000.

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National Human Genome Research Institute

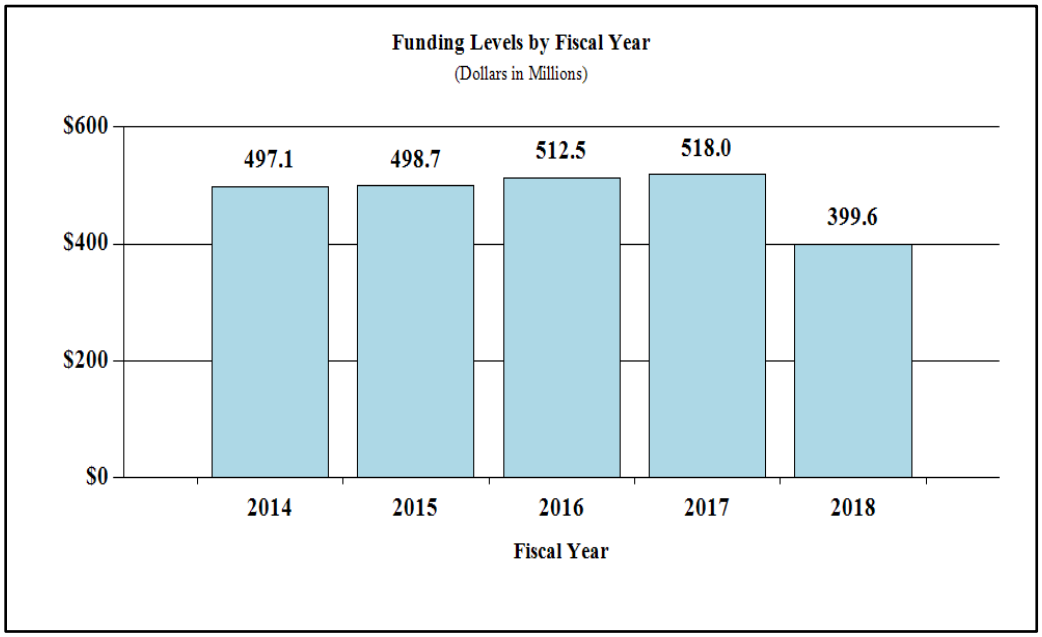
Amounts Available for Obligation[1]
(Dollars in Thousands)

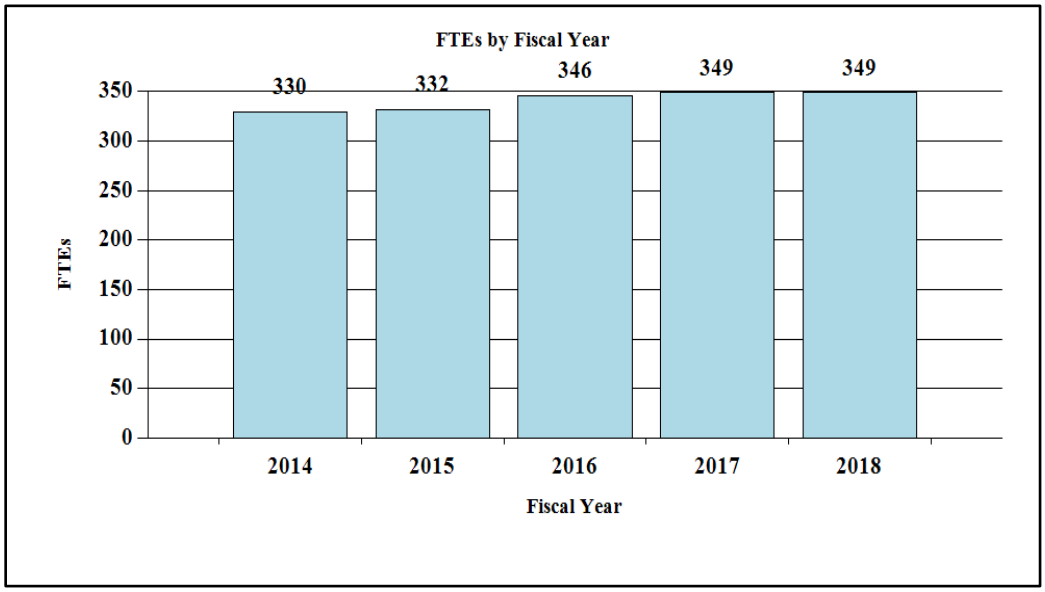
Source of Funding	FY 2016 Actual	FY 2017 Annualized CR	FY 2018 President's Budget
Appropriation	$518,956	$518,956	$399,622
Mandatory Appropriation: (non-add)			
Type 1 Diabetes	*(0)*	*(0)*	*(0)*
Other Mandatory financing	*(0)*	*(0)*	*(0)*
Rescission	0	-987	0
Sequestration	0	0	0
Zika Intra-NIH Transfer	-718	0	0
Subtotal, adjusted appropriation	$518,238	$517,969	$399,622
OAR HIV/AIDS Transfers	-5,729	0	0
Subtotal, adjusted budget authority	$512,509	$517,969	$399,622
Unobligated balance, start of year	0	0	0
Unobligated balance, end of year	0	0	0
Subtotal, adjusted budget authority	$512,509	$517,969	$399,622
Unobligated balance lapsing	-22	0	0
Total obligations	$512,486	$517,969	$399,622

[1] Excludes the following amounts for reimbursable activities carried out by this account:
FY 2016 - $25,037 FY 2017 - $25,287 FY 2018 - $18,965

Fiscal Year 2018 Budget Graphs

History of Budget Authority and FTEs:





NATIONAL INSTITUTES OF HEALTH
National Human Genome Research Institute

Authorizing Legislation

	PHS Act/ Other Citation	U.S. Code Citation	2017 Amount Authorized	FY 2017 Annualized CR	2018 Amount Authorized	FY 2018 President's Budget
Research and Investigation	Section 301	42§241	Indefinite	$517,969,000	Indefinite	$399,622,000
National Human Genome Research Institute	Section 401(a)	42§281	Indefinite		Indefinite	
Total, Budget Authority				$517,969,000		$399,622,000

NATIONAL INSTITUTES OF HEALTH
National Human Genome Research Institute

Appropriations History

Fiscal Year	Budget Estimate to Congress	House Allowance	Senate Allowance	Appropriation
2008	$484,436,000	$493,996,000	$497,031,000	$495,434,000
Rescission				$8,655,000
Supplemental				$2,589,000
2009	$487,878,000	$504,603,000	$501,411,000	$502,367,000
Rescission				$0
2010	$509,594,000	$520,311,000	$511,007,000	$516,028,000
Rescission				$0
2011	$533,959,000		$533,127,000	$516,028,000
Rescission				$4,531,033
2012	$524,807,000	$524,807,000	$505,783,000	$513,844,000
Rescission				$971,165
2013	$511,370,000		$512,920,000	$512,872,835
Rescission				$1,025,746
Sequestration				($25,742,690)
2014	$517,319,000		$513,881,000	$497,813,000
Rescission				$0
2015	$498,451,000			$499,356,000
Rescission				$0
2016	$515,491,000	$505,551,000	$526,166,000	$518,956,000
Rescission				$0
2017[1]	$513,227,000	$531,438,000	$534,516,000	$518,956,000
Rescission				$987,000
2018	$399,622,000			

[1] Budget Estimate to Congress includes mandatory financing.

Justification of Budget Request

National Human Genome Research Institute

Authorizing Legislation: Section 301 and title IV of the Public Health Service Act, as amended.

Budget Authority (BA):

	FY 2016 Actual	FY 2017 Annualized CR	FY 2018 President's Budget	FY 2018 +/- FY 2017
BA	$512,509,000	$517,969,000	$399,622,000	-$118,347,000
FTE	346	349	349	0

Program funds are allocated as follows: Competitive Grants/Cooperative Agreements; Contracts; Direct Federal/Intramural and Other.

Director's Overview

The sequencing of the human genome by the Human Genome Project (HGP) is one of the most profound and valuable scientific achievements of our time. Led in the United States by the National Human Genome Research Institute (NHGRI), this herculean effort provided a fundamental understanding of humanity's molecular makeup and laid the foundation upon which scientists from across biomedical disciplines are building an in-depth knowledgebase about the genomic contributions to health and disease.

In FY 2018, more than a quarter century after the launch of the HGP, the Institute has expanded its research portfolio from a near-singular focus on studying the structure of the human genome to a widening array of programs that range from basic research to elucidate how the genome functions to high-powered discovery projects to discern the genomic bases of health and disease to innovative programs piloting the implementation of genomic medicine. This expanded scope of research reflects the reality that genomics is a key part of the backbone for all biomedical research.

A cornerstone of NHGRI's fundamental science portfolio is the Encyclopedia of DNA Elements (ENCODE) Project, which will enter its fourth phase in mid-FY 2017. For the past 13 years, ENCODE researchers have been developing an online catalog of functional elements in the human genome, such as genes and genomic segments that control the expression of genes. The suite of tools developed by ENCODE greatly enhance the abilities of researchers around the world to investigate biological phenomena and human disease. The impact of these efforts is notable – at the start of FY 2017, there were more than 1,500 publications citing ENCODE data published by non-ENCODE investigators, and more than 550 published by ENCODE investigators themselves. In FY 2018, ENCODE investigators will apply even newer approaches to identify and annotate functional regions of the human genome, and to conduct outreach to the broader research community to maximize the utility of the ENCODE resource.

Moving toward the study of human disease, NHGRI's flagship Genome Sequencing Program (GSP) is one of the lynchpins that will help genomicists and other scientists elucidate the genomic contributions to rare and common diseases. The Program's overall goal is to establish how to use genome sequencing most effectively to discover genomic variants that play a role in disease. GSP's largest component, the Centers for Common Disease Genomics (CCDG), is studying common diseases to identify the key risk-conferring (and -protecting) variants, with a focus in FY 2018 on cardiovascular diseases, neuropsychiatric diseases (including epilepsy and autism), and inflammatory diseases (including asthma and diabetes).

Complementing NHGRI's efforts in studying common disease, the Institute continues to emphasize the refinement of genomic approaches for studying rare diseases. Among these efforts is the Institute's leadership of the NIH Undiagnosed Disease Network (UDN), part of the NIH Common Fund program. The UDN is conducting research to understand the underlying etiologies of undiagnosed diseases, to improve the capacity to diagnose these often-devastating afflictions, and to create an integrated and collaborative research community for improving patient care and treatment. As of December 2016, the UDN has received 1,019 applications and accepted 401 patients from across the country. Working together, UDN investigators have provided long-sought diagnoses to 52 patients, with six of these cases revealing readily available treatment options. FY 2018 funds will be used to support UDN's infrastructure, which will enhance patients' participation in this unique program.

Among NHGRI's youngest programs are several that focus on genomic medicine implementation. Such efforts seek to translate technologies and genomic knowledge from the bench to the bedside as rapidly and as safely as possible. For instance, the Newborn Sequencing in Genomic Medicine and Public Health (NSIGHT) program investigates the possibility of using genome sequence information in the newborn period to further understand and to better treat pediatric disorders. NSIGHT projects include studies examining the use of genomic approaches for establishing a diagnosis with acutely ill neonates, as well as those studying the relevance of complete genomic information for healthy newborns and their parents. FY 2018 funds will allow the projects to complete their initial proposed studies, providing a better understanding of the use of genome sequencing for the care of newborns.

NHGRI also supports work in several crosscutting areas that are fundamental and synergistic to the above major research areas. One of these – bioinformatics and computational biology – is very much aligned with the growing attention to data science in biomedical research. Genomics, almost by definition, is a 'big data' discipline, and virtually all NHGRI's research programs demand an ever-growing set of bioinformatics and data science tools and approaches for analyzing the resulting data.

NHGRI has long supported data science research and development, providing leadership and funding for over 20 data analysis tools that are now considered vital for the genomics and broader biomedical research communities; these efforts are highlighted further in a Program Portrait below. Another of these crosscutting elements reflects the importance of research programs that examine the societal implications of genomic advances. For this, the Institute supports basic and applied research that serves to ensure the appropriate societal stewardship of

genomics research, to inform policy development, and to cultivate the realization of benefits from genomics for individuals, families, and communities.

The Federal investment in genomics over the last quarter century has already returned dramatic economic returns. In FY 2018, as NHGRI continues to lead genomics for the biomedical research community, the innovation, rigor, and sense of urgency that has always undergirded the Institute's culture and research portfolio will continue to propel the field forward and bring the long-term promise of the HGP closer to fruition.

Overall Budget Policy:
The FY 2018 President's Budget request is $399.622 million, a decrease of $118.347 million compared with the FY 2017 Annualized CR level. These reductions are distributed across all programmatic areas and basic, epidemiology, or clinical research.

Program Descriptions and Accomplishments

Understanding the Structure of Genomes: The foundational blueprint guiding the development and operation of all organisms is reflected by the As, Ts, Gs, and Cs that make up the DNA 'alphabet' of the genome. Because the order (i.e., sequence) of those letters is responsible for encoding the functional information that carries out biological processes, NHGRI has made the development of ever-improving technologies for sequencing DNA a high priority. Specifically, the Institute has invested over $155 million in the development of DNA sequencing technologies over 12 years. The fruits of this Genome Technology Program (GTP) have played a central role in revolutionizing biomedical science by reducing the cost of DNA sequencing nearly a million-fold,[1] enabling the generation and analysis of genome-sequence information to become a bedrock of biomedical research in an important and fundamental fashion.

In FY 2017, the GTP embarked upon two important new directions through the Novel Nucleic Acid Sequencing Technology Program and the Novel Genomic Technology Development Program, which together should drive the genomics field forward during FY 2018. The Novel Nucleic Acid Sequencing Technology Development Program brings technology development for direct RNA sequencing into the NHGRI research portfolio for the first time. RNA (the single-stranded 'transcript' product of the genome's double-stranded DNA instructions) has long been known to encode proteins, but details about the mysteries of its other functions—such as influencing gene expression, gene function, and protein stability—remain elusive because of a general lack of ability to directly sequence RNA molecules. From this program innovative abilities to study RNA function should emerge, which will be important for efforts in genomic medicine and precision medicine implementation, among other applications.

In contrast, the Novel Genomic Technology Development Program is designed to catalyze investigator-initiated technology development that will advance genomics research within five to seven years. The program aims to enable a wide swath of genomic technology development,

[1] Wetterstrand KA. DNA Sequencing Costs: Data from the NHGRI Genome Sequencing Program (GSP) Available at: www.genome.gov/sequencingcostsdata.

including single-cell methods, transcriptome analysis, and functional genomics. FY 2018 funds will enable researchers to analyze genomes and genome function in exciting ways that will accelerate scientific discovery. It is notable that this program encourages researchers to assemble teams of scientists from fields outside of genomics, such as bioengineering and computer science, to tackle high-risk/high-reward projects. FY 2018 funds will foster cutting-edge innovation able to advance genomic science. These programs illustrate the Institute's continued commitment to technology development as a core component of its research portfolio.

Understanding the Biology of Genomes: While genome sequence information provides the blueprint text governing how cells, tissues, and organs function, it also provides the rules for how that text is read. Scientists must understand these rules in conjunction with the text itself in order to unravel the biological underpinnings of genome function. NHGRI supports several programs that aim to advance our understanding of the biology of genomes, including the Centers of Excellence in Genomic Science program (CEGS; described in the Program Portrait below) and the ENCODE Project highlighted above in the Director's Overview.

Other initiatives in this area of NHGRI's portfolio aim to determine how the genome modulates the regulation of gene expression and how genomic variation (differences in DNA 'spelling' among people) contributes to health and disease. The Genomics of Gene Regulation (GGR) project works to understand how regulatory 'switches' in the genome turn genes 'on' or 'off' in different cells (and even 'up' or 'down' within the same cell at different times). Such switches often work together in a highly coordinated fashion through complex regulatory networks, so GGR builds upon the ENCODE initiative's effort by establishing how the various functional elements in the genome interact. GGR will also help to shed light on the importance of the near 99.0 percent of the human genome that resides outside of protein-coding sequences (also referred to as 'non-coding regions').

A complementary effort, the Non-Coding Variants (NoVa) Program, funds investigators to develop and test statistical approaches to predict which genomic variants in non-coding regions affect disease susceptibility, beginning with studies of cancer and arthritis. FY 2018 funds will help to develop methods for analyzing gene-regulatory networks and developing general approaches to identify non-coding genomic variants, increasing the knowledge base available to researchers seeking to understand how genomic variation influences biological systems.

Program Portrait: Centers of Excellence in Genomic Science (CEGS) Program

FY 2017 Level: $17.4 million
FY 2018 Level: $14.8 million
Change: -$2.6 million

Recent advances in DNA sequencing technologies have led to the routine generation of an immense amount of genomic data. These data alone, however, cannot unlock the clues that the human genome holds about human health. More basic research must be conducted to further characterize the human genome and identify the important biological information that it contains. To meet this challenge successfully, researchers must innovate and find new ways to decode and interpret genomic information, so as to build an ever-stronger foundation upon which to layer the fundamental knowledge about the human genome that will ultimately enable the implementation of genomic medicine.

NHGRI's Centers of Excellence in Genomic Science (CEGS) program plays a central role in supporting researchers who are willing to take risks in the pursuit of novel technologies, analysis methods, and biomedical concepts that will substantially advance the state-of-the-art in genomics. The CEGS program began in FY 2001, and has supported interdisciplinary research teams that include basic and clinical researchers, computational biologists, engineers, statisticians, and ethicists. By the conclusion of these grants, the associated projects often yield new toolsets and resources that are made available to other researchers for application to their scientific programs, sometimes through commercialization. Often, the projects discover or develop ground-breaking technical concepts that in turn advance the field. For example, a past CEGS grant supported the development of some fundamental concepts behind the DNA sequencing methods that underpin the recent explosion of genome sequence data. Another CEGS grant supported an investigation about the genomic basis for differences in body forms in fish, producing new understanding about how evolution occurs through changes in gene expression; these gene-expression mechanisms are the same in fish and humans, with some directly related to human disease. Furthermore, the CEGS program has provided outstanding career-development opportunities for trainees, including a special focus on underrepresented populations. To date, 13 CEGS have completed their funding after five to ten years of support, while seven CEGS have ongoing research projects.

For FY 2018, several of the active CEGS grants share a common theme: developing concepts and methods to measure the concentration of molecules in cells with unprecedented sensitivity. Until recently, detecting the chemical signatures on DNA called epigenetic marks, which reflect the impact of environmental factors on genome function, required large samples (e.g., hundreds of thousands of cells or large pieces of tissue). Now, some of the CEGS are developing innovative approaches that will allow the use of very small amounts of starting material (down to single cells), which has great potential to be translated into clinical use for analyzing very small biopsy samples. With such a capability, researchers should be able to understand in greater detail the chemical and mechanical circuits that operate within cells, including how cells respond to environmental changes.

Using Genomics to Understand the Biology of Disease: As genomics increasingly becomes a foundational element for biomedicine, there is a growing emphasis on increasing the scale of studies that aim to understand how genomic variation plays in role in health and disease. As discussed in the Director's Overview above, NHGRI's flagship Genome Sequencing Program is structured to conduct very large-scale studies for discovering the genomic contributions to both rare and common diseases and to elucidate the genomic commonalities underlying them. In addition to the previously described UDN initiative, the Centers for Mendelian Genomics (CMGs; part of NHGRI's Genome Sequencing Program) rounds out the Institute's portfolio of rare-disease studies through its emphasis on high-throughput strategies to uncover the causal genes responsible for Mendelian (or rare) disorders. Mendelian disorders are most typically caused by DNA-based defects in a single gene. Collectively, more than 25 million Americans suffer from rare diseases, making these disorders a substantial public health concern. In FY 2018, the CMGs aim to improve the efficiency and approaches for discovering the molecular

bases for the ~3,000 Mendelian diseases for which the responsible gene has not yet been discovered.

Additional genomic insights about the biology of disease are being obtained through the Electronic Medical Records and Genomics (eMERGE) Network. eMERGE, now in its third phase, brings together sites from across the country (including a growing number of affiliate members) to develop and validate approaches for analyzing electronic medical and health information associated with genomic data. These efforts are helping to identify genomic variants that play a role in complex traits (e.g., disease manifestation or differences in drug response); integrate this knowledge to improve genomic risk assessment, prevention, diagnosis, and treatment; and improve the accessibility of tools that are critical for genomic medicine implementation. FY 2018 funds will also continue to support research that examines the ethical, legal, and social implications (ELSI) of using electronic medical records for genomic discovery and genomic medicine research, such as informed consent, the protection of research participant data, and the return of medically actionable genomic information to patients and their healthcare providers. The findings of this component of eMERGE will inform NHGRI's promotion of responsible genomic medicine research, which is highly relevant to many broader NIH programs (including the Precision Medicine Initiative).

Using Genomics to Advance Medical Science: With an ever-growing appreciation of the genomic contributions to human disease, researchers and clinicians will increasingly develop innovative genomic medicine and precision medicine strategies for the prevention, diagnosis, and treatment of disease. This area of NHGRI's portfolio seeks to advance medical science through genomics, and includes programs that address particular opportunities (e.g., the NSIGHT program highlighted above that investigates the use of genomic information in the newborn period), develop genomic medicine resources for broad use in clinical practice, and contribute to the evidence base needed for genomic medicine implementation in a variety of healthcare delivery settings.

The Clinical Genome Resource (ClinGen) program seeks to fill the acute need for a comprehensive knowledge base to guide the use of genomic information in clinical diagnosis and patient care across medical disciplines. ClinGen investigators, and the hundreds of its collaborating researchers and clinicians, are developing methodologies and standards to address the technical and policy challenges related to assessing analytical and clinical validity of genomic tests, the data-sharing requirements across clinical and research boundaries needed to develop such a resource, and the human and machine-based strategies for interpreting genomic variants with the associated clinical implications. By aggregating methods and evidence for assessing the clinical relevance of genomic variants, ClinGen is leading the way in removing some key barriers to the use of genomic information in clinical care. In FY 2018, ClinGen investigators will continue to curate phenotypic and clinical information associated with genomic variants, develop consensus approaches to identify clinically relevant genomic variants, and disseminate information about genomic variants to researchers and clinicians using genomic-medicine and precision-medicine approaches as a component of patient care.

Building on the success of the Clinical Sequencing Exploratory Research (CSER) program to develop methods for the integration of genome-sequence information into clinical care, the

Clinical Sequencing Evidence-Generating Research (CSER2) program will identify real-world barriers to integrating genomic, clinical, and healthcare-utilization data within a health system to build a shared evidence base for genomics-oriented clinical decision-making. FY 2018 funds will enable improvements to recruitment processes and enable enhancements in the data generated to ensure genomic medicine research studies benefit all.

Using Genomics to Improve the Effectiveness of Healthcare: The final research domain along the continuum from basic to applied research within the NHGRI research portfolio focuses on implementing genomic medicine to improve the effectiveness of healthcare. Several NHGRI programs provide strategic contributions and leadership in this area, including the Implementing Genomics in Practice (IGNITE) Network. IGNITE is designed to demonstrate the feasibility of, and develop methods for, utilizing patients' genomic findings for their clinical care. Investigators in this network also develop and pilot methods for effective implementation, diffusion, and sustainability of genomic medicine in diverse clinical settings to promote broad accessibility to genomic advances.

Other NHGRI-led programs relevant to this important area include the UDN, with its initiatives to build a collaborative network of clinicians caring for patients with extremely rare diseases and the establishment of best practices for connecting patients with healthcare teams across the country. Additionally, NSIGHT investigators are developing rapid pipelines for analyzing genome sequences generated from infants in the neonatal intensive care unit, where quick and successful diagnoses can lead to treatment options that can dramatically improve the health outcomes of acutely ill neonates.[2]

FY 2018 funds will support existing projects that are examining the implementation of genomic medicine to improve healthcare effectiveness and make genomic advances accessible to all Americans.

Bioinformatics, Computational Biology, and Data Science: The data-intensive nature of genomics has catapulted the field to the leading edge of data science in biomedicine. NHGRI has a long and productive track record of supporting the establishment and operation of key data resources and of funding the computational-based research essential for extracting knowledge from genomic data. All of this will continue in FY 2018. The Institute's ongoing commitment to stimulate innovation in data science associated with genomics research and the development of 'big data' solutions to data integration and management are illustrated by the efforts described in the Program Portrait below. NHGRI will continue to collaborate with NIH leadership and other data-intense efforts at NIH, such as Big Data to Knowledge and *All of Us*^{SM} (Precision Medicine Initiative) programs to foster creative and cost-effective solutions to advance data science infrastructure and data resource development.

[2] Petrikin JE, Willig LK, Smith LD, Kingsmore SF. Rapid whole genome sequencing and precision neonatology. *Semin Perinatol.* 2015 Dec;39(8):623-31.

Program Portrait: Resources for Analyzing Genomic Data

FY 2017 Level: $51.9 million
FY 2018 Level: $44.7 million
Change: -$7.2 million

By its very nature, genomics is at the leading edge of the 'big data' revolution in biomedical research. Developing solutions to meet the challenges of processing, managing, interpreting, and utilizing the reams of data that NHGRI-funded scientists generate through genome sequencing has always been a high priority for the Institute. NHGRI has worked aggressively and consistently to stimulate and support the tool development and capacity building needed to analyze genomic data efficiently, so that researchers across many disciplines can benefit from genomic advances. To date, NHGRI has supported more than 20 resources used nationally and globally that are critical for the management and analysis of large volumes of genome sequence data. Several of these resources, Galaxy and the Model Organisms Databases (MODs), are highlighted here to illustrate the variety and complexity of these resources and how they contribute to the dissemination of genomic approaches across the biomedical research landscape.

Galaxy is a publically available, web-based genome sequence analysis platform maintained by researchers at Penn State University and Johns Hopkins University, with funding from those universities as well as NHGRI and the National Science Foundation. Galaxy allows researchers to study their genome sequence data on a platform capable of supporting computationally demanding analyses that involve a wide range of tools and reference data; importantly, it also allows the results of these analyses to be shared readily with other researchers to foster collaboration and reproducibility. Galaxy is used widely by the genomics research community; individual investigators at smaller institutions and those whose primary expertise is not genomics; and educators teaching genomics and data science. In these ways, Galaxy empowers a diverse sector of the research community to use genomics for advancing their studies. Additionally, the Galaxy team members are committed to providing online training, which will continue to be a crucial aspect of promoting its accessibility to those new to the use of genomic approaches. In FY 2018, Galaxy plans to further leverage its educational capabilities for training young bioinformaticians and data scientists. Institutions hosting the Galaxy resource will work towards more innovative ways of scaling its reach as a routine data-analysis platform.

The MODs support the use of genomics for research involving model organisms, enhancing the longer-term potential of using model organisms to better understand biology and human disease. NHGRI manages five independent MODs covering such important model organisms like yeast, mouse, zebrafish, and fruit fly. Individual MODs are relied upon extensively by their respective research communities, but to keep pace with the integrated, data-intensive methodologies associated with current genomics research, these data resources need to develop new modalities for presenting information and connecting it to data available for other model organisms. To facilitate the establishment of such capabilities, a single platform is being developed under a combined-effort consortium, called the Alliance for Genome Resources (AGR). The AGR aims to provide a resource that will allow easier comparison and integration of data across different model organisms, allowing for better annotation of model organism genome sequences and enhancing the acquisition of biological insights. In FY 2018, the MODs will continue the transition from independent and unconnected databases to the combined AGR. This transition will occur over the next three years as a pilot to assess the feasibility of more fully integrating these data resources.

The volume of genomic data will continue to grow at a breathtaking pace, accentuating the need for ongoing innovation in data science tools and resources. NHGRI will continue its leadership and catalytic stimulation of cutting-edge approaches to meet these large data science needs and to extend the research community's ability to utilize genomics for their important studies of human health and disease.

Genomics Education and Training: As genomics becomes pervasive across biomedical research and, increasingly, healthcare, it is critical that the next generation of scientists and clinicians is prepared to work at the leading edge of genomics and genomic medicine. Many of the Institute's signature programs (e.g., the GSP) include training initiatives, and several of those include targeted plans for increasing the diversity of individuals engaged in genomics research.

Additionally, NHGRI continues its efforts to educate healthcare professionals in various healthcare settings about genomics and the integration of genomic information into clinical care.

Genomics and Society: Since the earliest days of the Human Genome Project, NHGRI has recognized that genomic advances have important implications for society, and these merit thoughtful, in-depth analysis and consideration. To this end, approximately 5.0 percent of the Institute's research budget each year is dedicated to studying the ELSI of genomics. Through this long-standing commitment to 'beyond the bench' research, NHGRI has become a leader and a model for other emerging research fields—from nanoscience to neuroscience. Today, the Institute is the largest funder of bioethics research in the world. NHGRI's Division of Genomics and Society oversees the Institute's ELSI Research Program; in FY 2018, this Division will continue to shape a diverse portfolio of normative and empiric research projects, which include both independent studies and 'embedded' projects (with the latter having ELSI research aims directly integrated with bench or clinical research objectives). The Program Portrait below describes the NHGRI's Centers of Excellence in ELSI Research (CEERs) and how they catalyze the formation of interdisciplinary teams for pursuing important research projects.

Program Portrait: Centers of Excellence in ELSI Research (CEER) Program

FY 2017 Level: $6.1 million
FY 2018 Level: $5.3 million
Change: -$0.8 million

The rapid pace of technological innovation and research advances that characterize genomics demands thoughtful deliberation and intentional stewardship. Since the Institute's inception, studying the ethical, legal, and social implications (ELSI) of genomics has been a core component of the NHGRI research portfolio. The ELSI Research Program and the investigators that it has funded have provided important leadership within the genomics community since the Human Genome Project (HGP), providing insights and expertise on topics ranging from the forensic use of DNA to carrier screening for genomic variants linked to cystic fibrosis to the development of methods for engaging communities in the International HapMap Project. The latter paved the way for the onslaught of studies investigating the genomic underpinnings of common diseases, such as cardiovascular disease and diabetes. The complex and multi-faceted nature of the issues that ELSI research addresses, and of genomic knowledge itself, necessitates that difficult questions be addressed through the lens of many different disciplines (e.g., ethics, social science, and law) to inform the scientific community (as well as policymakers) about the opportunities, challenges, and potential vulnerabilities related to the dissemination of genomic applications in society.

In FY 2004, NHGRI created the Centers of Excellence in ELSI Research (CEER) program to establish unique, flexible, and multidisciplinary research centers to perform a wide range of ELSI studies that were particularly relevant as genomics moved beyond the HGP. These centers stimulate the formation of rich networks of investigators from diverse fields, such as bioethics, philosophy, literature, social science, genomics, and clinical research, in addition to more applied research domains, such public health, public policy, and law. The assembled teams work across disciplinary boundaries to address prescient genomics issues. For example, gene patenting and intellectual property were the focus of one of the first CEERs, which was then poised to inform policymakers and others leading up to the 2013 Supreme Court consideration of that issue. In FY 2016, a CEER was funded to examine issues related to genomic privacy, including the legal framework for protecting genomic information through the development of enhanced privacy protection strategies, which was the focus of proposed legislation in the last Congress. In addition to conducting research, the CEERs are charged with providing training and mentoring opportunities for the next generation of ELSI researchers. After 13 years, the CEERs have contributed to the establishment and growth of an impressive cadre of young ELSI investigators, with several now having launched successful independent research careers, bringing new institutions into the ELSI research community, and building new and diverse loci of ELSI research and genomics policy-relevant expertise.

In FY 2018, the CEERs program will continue to explore and address areas relevant to the development and deployment of genomic medicine and the use of genomic approaches in research and clinical care, including efforts such as the Precision Medicine Initiative and the use of genomics to combat infectious disease threats like HIV and Zika virus. These centers will retain an emphasis on training ELSI researchers, but will now also focus on the full academic pipeline from undergraduate to post-graduate trainees. This will broaden the training reach to include students en route to non-research careers, which is vital given the ever-growing range of uses for genomic information in society.

Research Management and Support (RMS): RMS funds are used throughout each year for programmatic support that facilitates the research mission of the Institute. In FY 2018, the Extramural Research Program anticipates convening several strategic planning meetings to acquire feedback from the genomics research community and other stakeholders about current scientific opportunities, challenges to achieving the Institute's research goals, and the relative priorities among the various identified needs. In addition, the Division of Policy, Communications, and Education will use RMS funds to engage the general public as well as specific stakeholder groups (e.g., healthcare practitioners) about genomics research and genomic medicine. FY 2018 funds will also enable substantive interactions and outreach to promote genomic literacy. The highly successful NHGRI-Smithsonian exhibition, *Unlocking Life's Code*, will continue its tour to large and small museums and science centers across North America, including visits to multiple venues in Canada.

NATIONAL INSTITUTES OF HEALTH
National Human Genome Research Institute

Detail of Full-Time Equivalent Employment (FTE)

OFFICE/DIVISION	FY 2016 Actual			FY 2017 Annualized CR			FY 2018 President's Budget		
	Civilian	Military	Total	Civilian	Military	Total	Civilian	Military	Total
Division of Extramural Operations									
Direct:	13	-	13	14	-	14	14	-	14
Reimbursable:	2	-	2	1	-	1	1	-	1
Total:	15	-	15	15	-	15	15	-	15
Division of Genome Sciences									
Direct:	14	-	14	14	-	14	14	-	14
Reimbursable:	1	-	1	-	-	-	-	-	-
Total:	15	-	15	14	-	14	14	-	14
Division of Genomic Medicine									
Direct:	11	-	11	11	-	11	11	-	11
Reimbursable:	1	-	1	1	-	1	1	-	1
Total:	12	-	12	12	-	12	12	-	12
Division of Genomics and Society									
Direct:	4	-	4	4	-	4	4	-	4
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	4	-	4	4	-	4	4	-	4
Division of Intramural Research									
Direct:	200	8	208	202	7	209	202	7	209
Reimbursable:	27	3	30	29	3	32	29	3	32
Total:	227	11	238	231	10	241	231	10	241
Division of Management									
Direct:	42	-	42	44	-	44	44	-	44
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	42	-	42	44	-	44	44	-	44
Division of Policy, Communications and Education									
Direct:	15	-	15	14	-	14	14	-	14
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	15	-	15	14	-	14	14	-	14
Office of the Director									
Direct:	5	-	5	5	-	5	5	-	5
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	5	-	5	5	-	5	5	-	5
Total	335	11	346	339	10	349	339	10	349
Includes FTEs whose payroll obligations are supported by the NIH Common Fund.									
FTEs supported by funds from Cooperative Research and Development Agreements.	0	0	0	0	0	0	0	0	0

FISCAL YEAR	Average GS Grade
2014	12.3
2015	12.5
2016	12.6
2017	12.6
2018	12.6

NATIONAL INSTITUTES OF HEALTH
National Human Genome Research Institute

Detail of Positions[1]

GRADE	FY 2016 Actual	FY 2017 Annualized CR	FY 2018 President's Budget
Total, ES Positions	2	2	2
Total, ES Salary	355,046	362,502	369,390
GM/GS-15	38	38	38
GM/GS-14	28	28	28
GM/GS-13	66	67	67
GS-12	43	45	45
GS-11	13	14	14
GS-10	1	1	1
GS-9	4	4	4
GS-8	17	17	17
GS-7	0	0	0
GS-6	0	0	0
GS-5	0	0	0
GS-4	0	0	0
GS-3	1	1	1
GS-2	1	1	1
GS-1	0	0	0
Subtotal	212	216	216
Grades established by Act of July 1, 1944 (42 U.S.C. 207)	0	0	0
Assistant Surgeon General	0	0	0
Director Grade	6	6	6
Senior Grade	4	3	3
Full Grade	0	0	0
Senior Assistant Grade	1	1	1
Assistant Grade	0	0	0
Subtotal	11	10	10
Ungraded	125	125	125
Total permanent positions	225	228	228
Total positions, end of year	350	353	353
Total full-time equivalent (FTE) employment, end of year	346	349	349
Average ES salary	177,523	181,251	184,695
Average GM/GS grade	12.6	12.6	12.6
Average GM/GS salary	107,401	109,656	111,739

[1] Includes FTEs whose payroll obligations are supported by the NIH Common Fund.