

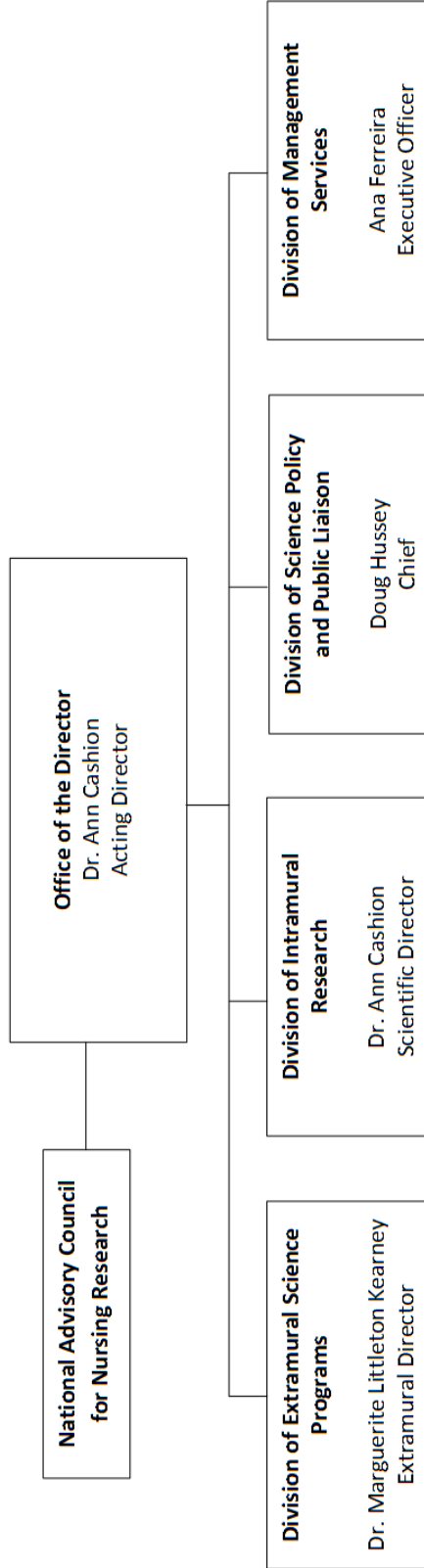
DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research (NINR)

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**National Institutes of Health
National Institute of Nursing Research
Organizational Chart**



NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research

For carrying out section 301 and title IV of the PHS Act with respect to nursing research,

~~[\$162,992,000]~~ *\$140,301,000.*

NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Amounts Available for Obligation¹

(Dollars in Thousands)

Source of Funding	FY 2018 Final	FY 2019 Enacted	FY 2020 President's Budget
Appropriation	\$158,033	\$162,992	\$140,301
Mandatory Appropriation: (non-add)			
<i>Type 1 Diabetes</i>	(0)	(0)	(0)
<i>Other Mandatory financing</i>	(0)	(0)	(0)
Rescission	0	0	0
Sequestration	0	0	0
Secretary's Transfer	-371	0	0
Subtotal, adjusted appropriation	\$157,662	\$162,992	\$140,301
OAR HIV/AIDS Transfers	0	0	0
Subtotal, adjusted budget authority	\$157,662	\$162,992	\$140,301
Unobligated balance, start of year	0	0	0
Unobligated balance, end of year	0	0	0
Subtotal, adjusted budget authority	\$157,662	\$162,992	\$140,301
Unobligated balance lapsing	-29	0	0
Total obligations	\$157,633	\$162,992	\$140,301

¹ Excludes the following amounts (in thousands) for reimbursable activities carried out by this account:
FY 2018 - \$458 FY 2019 - \$851 FY 2020 - \$838

NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Budget Mechanism - Total¹

(Dollars in Thousands)

MECHANISM	FY 2018 Final		FY 2019 Enacted		FY 2020 President's Budget		FY 2020 +/- FY 2019 Enacted	
	No.	Amount	No.	Amount	No.	Amount	No.	Amount
<u>Research Projects:</u>								
Noncompeting	139	\$69,526	167	\$81,481	111	\$57,552	-56	-\$23,929
Administrative Supplements	(1)	36	(1)	20	(1)	20	(0)	0
<u>Competing:</u>								
Renewal	2	830	2	1,000	2	1,000	0	0
New	69	28,803	51	21,121	70	28,216	19	7,095
Supplements	0	0	0	0	0	0	0	0
Subtotal, Competing	71	\$29,634	53	\$22,121	72	\$29,216	19	\$7,095
Subtotal, RPGs	210	\$99,196	220	\$103,621	183	\$86,788	-37	-\$16,833
SBIR/STTR	16	4,557	21	6,046	18	5,205	-3	-842
Research Project Grants	226	\$103,753	241	\$109,668	201	\$91,993	-40	-\$17,675
<u>Research Centers:</u>								
Specialized/Comprehensive	16	\$6,605	11	\$4,909	11	\$4,894	0	-\$15
Clinical Research	0	0	0	0	0	0	0	0
Biotechnology	0	0	0	0	0	0	0	0
Comparative Medicine	0	0	0	0	0	0	0	0
Research Centers in Minority Institutions	0	0	0	0	0	0	0	0
Research Centers	16	\$6,605	11	\$4,909	11	\$4,894	0	-\$15
<u>Other Research:</u>								
Research Careers	29	\$3,662	29	\$3,662	25	\$3,152	-4	-\$510
Cancer Education	0	0	0	0	0	0	0	0
Cooperative Clinical Research	0	0	0	0	0	0	0	0
Biomedical Research Support	0	0	0	0	0	0	0	0
Minority Biomedical Research Support	0	0	0	0	0	0	0	0
Other	2	2,427	2	2,427	1	2,089	-1	-338
Other Research	31	\$6,089	31	\$6,089	26	\$5,242	-5	-\$848
Total Research Grants	273	\$116,447	283	\$120,666	238	\$102,128	-45	-\$18,538
<u>Ruth L. Kirchstein Training Awards:</u>								
	<u>FTIPs</u>		<u>FTIPs</u>		<u>FTIPs</u>		<u>FTIPs</u>	
Individual Awards	36	\$1,398	35	\$1,398	31	\$1,225	-4	-\$173
Institutional Awards	115	6,054	112	6,054	108	5,860	-4	-194
Total Research Training	151	\$7,452	147	\$7,452	139	\$7,085	-8	-\$367
Research & Develop. Contracts <i>(SBIR/STTR) (non-add)</i>	0 (0)	\$4,723 (9)	0 (0)	\$5,093 (66)	0 (0)	\$4,901 (57)	0 (0)	-\$192 (-9)
Intramural Research	28	12,791	28	13,167	28	11,234	0	-1,933
Res. Management & Support <i>Res. Management & Support (SBIR Admin) (non-add)</i>	66 (0)	16,248 (0)	68 (0)	16,614 (0)	68 (0)	14,952 (0)	0 (0)	-1,661 (0)
Construction		0		0		0		0
Buildings and Facilities		0		0		0		0
Total, NINR	94	\$157,662	96	\$162,992	96	\$140,301	0	-\$22,691

¹ All items in italics and brackets are non-add entries.

Major Changes in the Fiscal Year 2020 President's Budget Request

Major changes by budget mechanism and/or budget activity detail are briefly described below. Note that there may be overlap between budget mechanism and activity detail and these highlights will not sum to the total change for the FY 2020 budget request for NINR, which is \$140.3 million, a decrease of \$22.7 million from the FY 2019 Enacted Budget. The FY 2020 President's Budget reflects the Administration's fiscal policy goals for the Federal Government. Within that framework, NINR will pursue its highest research priorities through strategic investment and careful stewardship of appropriated funds.

Research Project Grants (RPGs) (-\$17.7 million; total \$92 million):

Non-competing RPGs will decrease by 56 grants for a decrease of \$23.9 million in FY 2020 due to a large cohort of grants completing their performance period. This will allow NINR to maintain a success rate of about 10 percent and fund an increase of 19 Competing RPGs that will total \$7.1 million.

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Summary of Changes

(Dollars in Thousands)

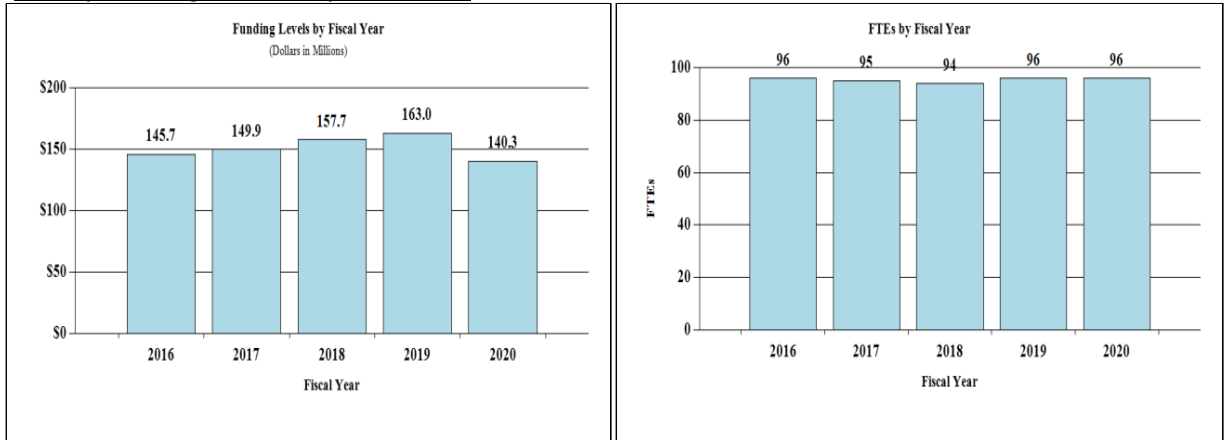
FY 2019 Enacted	\$162,992
FY 2020 President's Budget	\$140,301
Net change	-\$22,691

CHANGES	FY 2020 President's Budget		Change from FY 2019 Enacted	
	FTEs	Budget Authority	FTEs	Budget Authority
<u>A. Built-in:</u>				
<u>1. Intramural Research:</u>				
a. Annualization of January 2019 pay increase & benefits		\$4,896		\$6
b. January FY 2020 pay increase & benefits		4,896		20
c. Paid days adjustment		4,896		18
d. Differences attributable to change in FTE		4,896		0
e. Payment for centrally furnished services		1,885		91
f. Cost of laboratory supplies, materials, other expenses, and non-recurring costs		4,453		165
Subtotal				\$300
<u>2. Research Management and Support:</u>				
a. Annualization of January 2019 pay increase & benefits		\$10,710		\$10
b. January FY 2020 pay increase & benefits		10,710		29
c. Paid days adjustment		10,710		40
d. Differences attributable to change in FTE		10,710		0
e. Payment for centrally furnished services		1,613		88
f. Cost of laboratory supplies, materials, other expenses, and non-recurring costs		2,629		118
Subtotal				\$285
Subtotal, Built-in				\$585

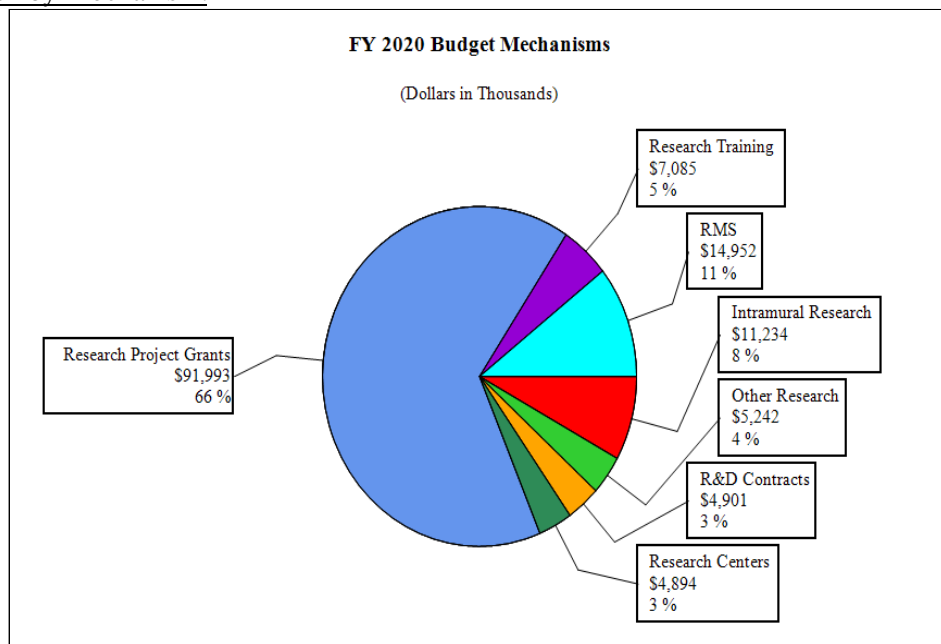
CHANGES	FY 2020 President's Budget		Change from FY 2019 Enacted	
	No.	Amount	No.	Amount
<u>B. Program:</u>				
<u>1. Research Project Grants:</u>				
a. Noncompeting	111	\$57,572	-56	-\$23,929
b. Competing	72	29,216	19	7,095
c. SBIR/STTR	18	5,205	-3	-842
Subtotal, RPGs	201	\$91,993	-40	-\$17,675
2. Research Centers	11	\$4,894	0	-\$15
3. Other Research	26	5,242	-5	-848
4. Research Training	139	7,085	-8	-367
5. Research and development contracts	0	4,901	0	-192
Subtotal, Extramural		\$114,114		-\$19,097
6. Intramural Research	<u>FTEs</u> 28	\$11,234	<u>FTEs</u> 0	-\$2,233
7. Research Management and Support	68	14,952	0	-1,946
8. Construction		0		0
9. Buildings and Facilities		0		0
Subtotal, Program	96	\$140,301	0	-\$23,276
Total changes				-\$22,691

Fiscal Year 2020 Budget Graphs

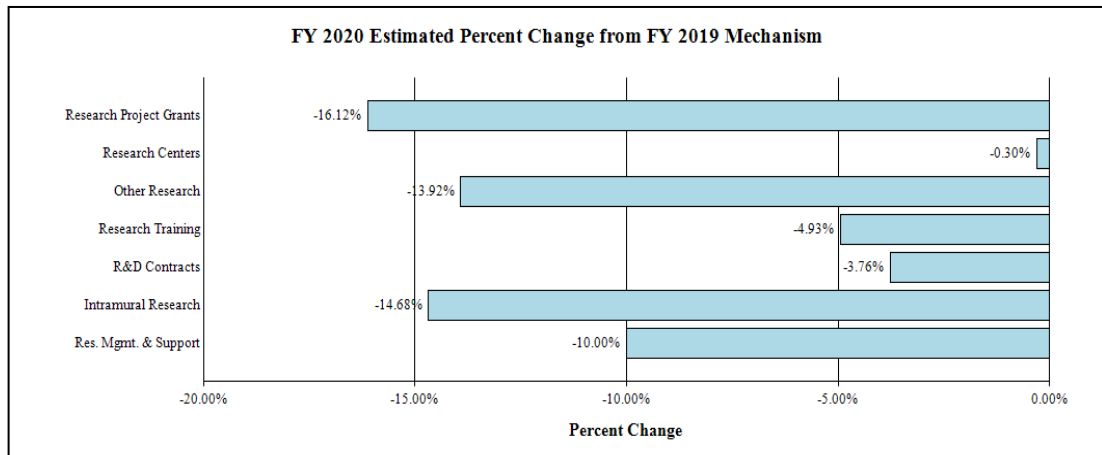
History of Budget Authority and FTEs:



Distribution by Mechanism:



Change by Selected Mechanism:



NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Budget Authority by Activity¹
(Dollars in Thousands)

	FY 2018 Final		FY 2019 Enacted		FY 2020 President's Budget		FY 2020 +/- FY 2019 Enacted	
	<u>FTE</u>	<u>Amount</u>	<u>FTE</u>	<u>Amount</u>	<u>FTE</u>	<u>Amount</u>	<u>FTE</u>	<u>Amount</u>
Extramural Research								
<u>Detail</u>								
Symptom Science		\$26,676		\$27,627		\$23,667		-\$3,961
Self-Management		22,043		22,829		19,556		-3,273
Wellness		36,076		37,363		32,007		-5,356
21st Century Nurse Scientists		14,717		15,242		13,057		-2,185
Promoting Innovation		11,687		12,104		10,369		-1,735
End-of-Life and Palliative Care		17,424		18,045		15,458		-2,587
Subtotal, Extramural		\$128,623		\$133,211		\$114,114		-\$19,097
Intramural Research	28	\$12,791	28	\$13,167	28	\$11,234	0	-\$1,933
Research Management & Support	66	\$16,248	68	\$16,614	68	\$14,952	0	-\$1,661
TOTAL	94	\$157,662	96	\$162,992	96	\$140,301	0	-\$22,691

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

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Authorizing Legislation

	PHS Act/ Other Citation	U.S. Code Citation	2019 Amount Authorized	FY 2019 Enacted	2020 Amount Authorized	FY 2020 President's Budget
Research and Investigation	Section 301	42§241	Indefinite	\$162,992,000	Indefinite	\$140,301,000
National Institute of Nursing Research	Section 401(a)	42§281	Indefinite		Indefinite	
Total, Budget Authority				\$162,992,000		\$140,301,000

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Appropriations History

Fiscal Year	Budget Estimate to Congress	House Allowance	Senate Allowance	Appropriation
2011	\$150,198,000		\$149,963,000	\$145,660,000
Rescission				\$1,278,982
2012	\$148,114,000	\$148,114,000	\$142,755,000	\$145,043,000
Rescission				\$274,131
2013	\$144,153,000		\$144,590,000	\$144,768,869
Rescission				\$289,538
Sequestration				(\$7,266,402)
2014	\$146,244,000		\$145,272,000	\$140,517,000
Rescission				\$0
2015	\$140,452,000			\$140,953,000
Rescission				\$0
2016	\$144,515,000	\$142,701,000	\$147,508,000	\$146,485,000
Rescission				\$0
2017 ¹	\$145,912,000	\$150,008,000	\$151,965,000	\$150,273,000
Rescission				\$0
2018	\$113,688,000	\$152,599,000	\$155,210,000	\$158,033,000
Rescission				\$0
2019	\$145,842,000	\$159,920,000	\$163,076,000	\$162,992,000
Rescission				\$0
2020	\$140,301,000			

¹ Budget Estimate to Congress includes mandatory financing.

Justification of Budget Request

National Institute of Nursing Research

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

Budget Authority:

	FY 2018 Actual	FY 2019 Enacted	FY 2020 President's Budget	FY 2020 +/- FY 2019
BA	\$157,662,000	\$162,992,000	\$140,301,000	\$-22,691,000
FTE	94	96	96	0

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

Director's Overview

The National Institute of Nursing Research (NINR) is dedicated to improving the health of individuals, families, and communities across America. NINR accomplishes this mission by supporting nursing research that will ultimately improve clinical practice, and help people and families live well in their daily lives, regardless of illness. Nurses provide care in nearly every health care setting, as well as in schools, in the community, and in our homes. They have a unique view of the health and health care challenges faced by individuals and families, as well as the possibilities for making things better. Nurse scientists understand what patients need and use their knowledge to improve health for all people in the clinic, at the bedside, and in the community, whatever their age or condition. Drawing on the unique experiences and expertise of the nursing science community, NINR will continue to support research and training to address the most pressing health challenges faced by the Nation.

As outlined in our strategic plan, NINR's current priorities for research and training include:

- Advancing symptom science by uncovering underlying mechanisms of symptoms, and promoting personalized health strategies to address symptoms such as fatigue and pain;
- Discovering new ways to enhance wellness through promoting health and preventing illness in diverse populations;
- Identifying effective strategies to self-manage illness on a daily basis to improve quality of life for individuals with chronic conditions and their families;
- Understanding the needs, experiences, and challenges of caregivers across the life span and assisting them with improving and maintaining their own health;
- Building end-of-life and palliative care science to improve management of symptoms in advanced illness, family decision-making, and communication with health care providers;
- Developing and applying new technologies to improve health from rural to urban communities and from hospital rooms to homes; and,
- Preparing the next generation of nurse scientists, from early to mid to late career, to advance nursing science and to address 21st Century health and health care challenges.

In FY 2020, NINR will continue to build and expand activities reflecting both the Institute's mission and the research vision established by the NIH Director. Consistent with the NIH Director's emphasis on building on basic science, NINR supports research to improve our understanding of how underlying genetic and biological mechanisms can provide clues on potential causes and treatments of chronic conditions and their associated symptoms. For example, NINR scientists embarked on a series of studies to determine the role of gene activity in injury, recovery, and symptoms following blast-induced traumatic brain injury (TBI) in active duty military personnel.^{1,2} Comparing those individuals with a record of blast-induced TBI (or moderate blast exposure) to control participants without TBI, the researchers identified genes that were regulated or expressed differently in personnel with TBI. Their findings provide a roadmap for characterizing and measuring the symptoms and effects of blast-induced TBI both acutely, and in the months and years following a blast injury. These findings also establish a critical pathway toward the accurate diagnosis of blast-induced TBI and for predicting the trajectory of recovery in military personnel.

Nurse scientists are also doing important research to uncover connections between social factors, such as perceived discrimination, and our genes, that might help explain how negative social experiences contribute to poor health. NINR-supported researchers examined whether perceived racial discrimination in African American women is associated with alterations to DNA that affect whether certain genes are expressed (i.e., turned on or off). Their results provided evidence of associations between changes in how some disease genes (e.g., genes associated with asthma) are expressed and perceived racial discrimination in African American women.³ Studies such as this one can shed light on the complex ways that social factors, such as discrimination, may alter our genetic functioning, which then contributes to poor health.

Other NINR-supported researchers are examining complex connections between our genes and the experience of symptoms, such as fatigue. A team of scientists analyzed the genomes of men with prostate cancer who were experiencing significant fatigue a year after radiation treatment.⁴ They found that certain genes helped predict which patients were more likely to experience fatigue. Studies like this one could help find potential ways to treat cancer-related fatigue based on people's genetic makeup.

NINR also supports research that reflects the NIH Director's focus on transformational tools and technologies. Receiving care in the Intensive Care Unit (ICU) can exacerbate patient symptoms

¹ Heinzelmann M, Reddy SY, French LM, Wang D, Lee H, Barr T, Baxter T, Mysliwiec V, Gill J. Military personnel with chronic symptoms following blast traumatic brain injury have differential expression of neuronal recovery and epidermal growth factor receptor genes. *Front Neurol*. 2014 Oct 9;5:198. PubMed PMID: 25346719

² Gill J, Cashion A, Osier N, Arcurio L, Motamedi V, Dell KC, Carr W, Kim HS, Yun S, Walker P, Ahlers S, LoPresti M, Yarnell A. Moderate blast exposure alters gene expression and levels of amyloid precursor protein. *Neurol Genet*. 2017 Sep 27;3(5):2017. PubMed PMID: 28975156;

³ de Mendoza VB, Huang Y, Crusto CA, Sun YV, Taylor JY. Perceived Racial Discrimination and DNA Methylation Among African American Women in the InterGEN Study. *Biol Res Nurs*. 2018 Mar;20(2):145-152. <https://www.ncbi.nlm.nih.gov/pubmed/29258399>

⁴Feng LR, Fernández-Martínez JL, Zaal KJM, deAndrés-Galiana EJ, Wolff BS, Saligan LN. mGluR5 mediates post-radiotherapy fatigue development in cancer patients. *Transl Psychiatry*. 2018 May 30;8(1):110. www.ncbi.nlm.nih.gov/pubmed/29849049.

such as anxiety, and can be costly, especially for patients who need a machine to support their breathing (i.e., mechanically ventilated patients, or MVPs). Current pharmacological treatments for anxiety often have adverse side effects. To address this issue, NINR-supported researchers examined music listening as a nonpharmacological intervention or tool to treat anxiety for MVPs. The researchers demonstrated that a patient-directed music intervention reduced anxiety in patients undergoing ventilatory support, and it also reduced health care costs.⁵ This finding is significant in that it demonstrates a cost-effective alternative to pharmacological interventions for reducing anxiety in MVPs.

In addition to supporting research, NINR will continue to support the development of the next generation of nurse scientists and equip them with the innovative tools and research methodologies they need to address the health and health care challenges of the 21st Century. NINR provides numerous training and career development opportunities, as well as research intensives, for scientists and trainees at all career levels, particularly new investigators who bring new ideas and help to further expand research programs. As we look to the future, NINR will continue to support nursing research and training to improve the daily lives of individuals and families, across the life span, and regardless of illness or condition.

Overall IC Budget Policy:

The FY 2020 President's Budget Request is \$140.3 million, a decrease of \$22.7 million or 13.9 percent compared with the FY 2019 Enacted level. Investigator-initiated research projects, support for new investigators, research training, and career development continue to be the Institute's highest priorities. Overall in FY 2020, NINR will maintain a strategic balance between solicitations issued to the extramural community in high-priority areas of research, and funding made available to support investigator-initiated projects. Scientific reviews, with recommendations from the National Advisory Council for Nursing Research, inform the level of recommended support for all research applications. NINR will continue to support new and early stage investigators.

Program Descriptions and Accomplishments

Symptom Science: Promoting Personalized Health Strategies

Adverse symptoms, such as fatigue, sleep disturbance, and pain, can be life-changing and difficult to treat. NINR supports research to devise new and improved ways to manage debilitating symptoms of acute and chronic illness, and to help people live well in their daily lives. NINR-supported researchers seek to identify underlying biological and genetic mechanisms of symptoms, and to develop innovative methods to study and manage symptoms. For example, a recent NINR-supported study of obstructive sleep apnea (OSA) revealed connections between OSA symptoms and the thinning of the brain's cerebral cortex, as well as differences in these brain changes among women and men.⁶ Their findings suggest that the greater damage to the cognitive centers in women's brains due to OSA may help explain greater

⁵ Chlan LL, Heiderscheid A, Skaar DJ, Neidecker MV. Economic Evaluation of a Patient-Directed Music Intervention for ICU Patients Receiving Mechanical Ventilatory Support. *Crit Care Med*. 2018 May 4. [Epub ahead of print] <https://www.ncbi.nlm.nih.gov/pubmed/?term=29727366>

⁶ Macey PM, Haris N, Kumar R, Thomas MA, Woo MA, Harper RM (2018) Obstructive sleep apnea and cortical thickness in females and males. *PLoS ONE* 13(3): e0193854. <https://doi.org/10.1371/journal.pone.0193854>

cognitive deficits for women with OSA, while overall thinning of the brain may be related to disordered breathing in both women and men with OSA. In another study, NINR-supported researchers are examining whether biomarkers predict which of two treatments is most effective for managing pain in children with functional abdominal pain gastrointestinal disorders. NINR is also leading an initiative to encourage interdisciplinary research to decrease symptom burden and enhance health-related quality of life in persons with chronic illness. To equip the next generation of nurse scientists with the latest methods and technologies in symptom science, NINR hosted a “Precision Health: Smart Technologies, Smart Health” Symposium in 2018 aimed at engaging graduate nursing students, nursing faculty, and clinicians interested in the clinical applications and clinical focus of smart health, smart technologies, digital health data, wearables and sensors, virtual/augmented reality, and molecular omics data.

Budget Policy:

The FY 2020 President’s Budget request for this program is \$23.7 million, a decrease of \$4 million or 14.3 percent compared to the FY 2019 Enacted level. Symptom science will remain a high priority area of focus for NINR, as identified in the Institute’s strategic plan. NINR will continue high priority research efforts across all of NINR’s focus areas. As part of a strategically balanced research portfolio, policies for research grants will be implemented in this program that are consistent with those applied to the other programs described in this justification.

Program Portrait: The Science of Caregiving

FY 2019 Level: \$25.6 million

FY 2020 Level: \$21.9 million

Change: -\$ 3.7 million

As people live longer and acute illnesses become chronic conditions, the need for formal and informal caregiving has grown tremendously. In 2015, it is estimated that approximately 43.5 million caregivers provided unpaid care to an adult or child. And the need for caregiving is only expected to increase as our Nation ages. Moreover, it is not only older adults who may need caregiving services—one in 15 children in the U.S. have multiple chronic conditions that could require caregiving services.

As in all areas of health and healthcare, improving our understanding of the science of caregiving will lead to better health outcomes and quality of life for patients and their caregivers. In August, 2017, NINR and partners presented, the “Science of Caregiving: Bringing Voices Together” Summit. The Summit provided perspectives across the spectrum of caregiving, including the importance of caregiving across the lifespan, as well as current and future directions for research to improve the health of patients and caregivers. This event brought together an audience of researchers, advocates, healthcare providers, educators, and others interested in the science of caregiving.

In addition to the Summit, NINR supports research to understand the challenges of caregiving and to develop interventions to improve health and quality of life for caregivers. For example, NINR-supported investigators are testing a web-based training for grandmother caregivers who are either raising grandchildren or providing care for grandchildren living in a multigenerational household. Since grandmothers in this situation often experience stress and are at risk for depression and poor health, the goal of the intervention is to improve personal and social resourcefulness of grandmothers and to ultimately improve personal and family well-being.

Having to suddenly provide care for a loved one with serious illness or disability, with no support or training, can lead to burden and poor health outcomes for both the caregiver and loved one. NINR-supported researchers are designing and testing interventions to prepare caregivers and give them the skills they need. For example, NINR-supported researchers are testing the efficacy of a transitional care intervention for seriously ill patients returning home from skilled nursing facilities, who depend on family caregivers for help with activities of daily living. The intervention includes the creation of a transition plan of care and a supportive nurse home visit after discharge from

the facility, with the goal of improved transitional care from hospital to home and improved outcomes for both the patient and caregiver. In another example, NINR-supported researchers are testing a telephone-delivered intervention for caregivers of stroke survivors. The intervention focuses on improving skill-building and self-management strategies, as well as the use of technology (e.g., eBook, interactive website, FaceTime), to improve caregiver health.

In addition, NINR currently leads two initiatives to stimulate research on caregivers: one is focused on using self-management to promote the health of caregivers involved in assisting others with activities of daily living and medical tasks, and the other seeks to encourage research that addresses caregiver symptoms and quality of life through the use of technology, including assistive medical devices, remote communication and monitoring tools, sensors (wearables, in-home devices), mobile technologies, and alert systems.

Wellness: Promoting Health and Preventing Illness

NINR supports wellness research to promote health and prevent illness across health conditions, settings, the lifespan, and for diverse populations. NINR-supported researchers in this area focus on the physical, social, behavioral, and environmental causes of illness, and they also develop and test interventions to prevent chronic conditions and to help people continue to live well with illness. For instance NINR-supported researchers are examining: complex relationships among maternal weight, social disadvantage, and racial/ethnic disparities on serious threats to maternal health and survival at delivery and postpartum; effectiveness of a personalized, interactive smartphone application for reducing asthma morbidity in adolescents at high risk for asthma complications; and the efficacy of a wellness promotion program to increase the ability to participate in valued community activities among middle-aged adults living with long-term physical disability. In a study of over 3,000 low-risk full-term births at an academic medical center between 2005 and 2012, researchers supported by NINR and other organizations found that first-time mothers experienced differences in labor management based on the type of health provider.⁷ First-time mothers were found to have more unplanned caesarean sections and labor interventions, including oxytocin use, regional anesthesia use, and delivery with the use of forceps or vacuum, when treated by an obstetrician versus a nurse-midwife. In addition, NINR leads an initiative to support research on biobehavioral and technological interventions to reduce cognitive decline in individuals with dementia, mild cognitive impairment, or cognitive decline related to disease or age. In FY 2018, NINR offered a one-day workshop, entitled “State of Rural Health Disparities: Research, Gaps, and Recommendations.” The workshop brought together researchers from across the country and included topics such as: health promotion/disease prevention, health disparities, and management of chronic conditions in rural areas.

Budget Policy:

The FY 2020 President’s Budget request for this program is \$32 million, a decrease of \$5.4 million or 14.3 percent compared to the FY 2019 Enacted level. Wellness will remain a high priority area of focus for NINR, as identified in the Institute’s strategic plan. NINR will continue high priority research efforts across all of NINR’s focus areas. As part of a strategically balanced research portfolio, policies for research grants will be implemented in this program that are consistent with those applied to the other programs described in this justification.

⁷ Carlson NS, Corwin EJ, Hernandez TL, Holt E, Lowe NK, Hurt KJ. Association between provider type and cesarean birth in healthy nulliparous laboring women: A retrospective cohort study. *Birth*. 2018 Jan 31. <https://www.ncbi.nlm.nih.gov/pubmed/?term=29388247>

Self-Management: Improving Quality of Life for Individuals with Chronic Conditions

Managing a chronic illness, such as asthma, arthritis, or diabetes, can involve a lifelong struggle to find effective strategies to maintain daily functioning and quality of life. This is true of individuals across the lifespan, and their family members and caregivers who help care for them while trying to maintain their own health. One key component of managing an illness is medication adherence, or taking medications as prescribed. Patients often struggle with this task, which can then have negative effects on their health. NINR-supported researchers examined issues related to medication adherence and symptoms, such as trouble breathing, which can signal higher risk for hospitalization in individuals with heart failure. They found that medication adherence was related to fewer heart failure symptoms and cardiac events in patients with heart failure.⁸ In other examples of NINR-supported self-management research, investigators are: incorporating the views of older adults and family members to further develop a self-management intervention for chronic illness that uses in-home and wearable sensors to measure health outcomes and provide health alerts; and developing and testing a technology-based sleep self-management intervention for children with juvenile idiopathic arthritis and their parents. In addition, NINR leads two initiatives to promote self-management research: one to encourage research that examines the relationship between asthma, obesity, and self-management; and the other to stimulate research in promoting caregiver health using self-management.

Budget Policy:

The FY 2020 President's Budget request for this program is \$19.6 million, a decrease of \$3.3 million or 14.3 percent compared to the FY 2019 Enacted level. Self-Management will remain a high priority area of focus for NINR, as identified in the Institute's strategic plan. NINR will continue high priority research efforts across all of NINR's focus areas. As part of a strategically balanced research portfolio, policies for research grants will be implemented in this program that are consistent with those applied to the other programs described in this justification.

End-of-Life and Palliative Care: The Science of Compassion

As the lead NIH Institute for end-of-life research, NINR supports research to assist individuals, families, and health care professionals in managing the symptoms of life limiting conditions, understanding the potential benefits of palliative care, and planning for end-of-life decisions. NINR recognizes that high-quality, evidence-based palliative care is a critical component of maintaining quality of life at any stage of illness, not just at the end of life, and for all individuals across the life span from infants to older adults. For example, NINR-supported researchers are examining: the effectiveness of a model of concurrent care (i.e., receipt of both curative treatments and hospice/palliative care) to improve health-related outcomes for children and their families; improving palliative care delivery in intensive care units; and understanding the medical decision-making processes and preferences for end-of-life care of adolescents and young adults with advanced heart disease. NINR continues to support the expansion of the Palliative Care Research Cooperative (PCRC) as an interdisciplinary research community committed to advancing rigorous palliative care science and improving care for people with serious illness. The PCRC has grown to a network of over 400 multidisciplinary scientists in 145 clinical trial

⁸ Wu JR, Moser DK. Medication Adherence Mediates the Relationship Between Heart Failure Symptoms and Cardiac Event-Free Survival in Patients With Heart Failure. *J Cardiovasc Nurs.* 2018 Jan/Feb;33(1):40-46. <https://www.ncbi.nlm.nih.gov/pubmed/?term=28591004>

research sites. NINR also supports research to address gaps in knowledge about barriers to effective end-of-life and palliative care, such as low health literacy, where individuals do not have the capacity to obtain, process, and understand information to make essential and personal decisions regarding their own health care. To help address this issue, NINR is leading an initiative to support research to identify key barriers to effective health literacy about end-of-life and palliative care in diverse settings and populations, and to create new strategies, interventions, and models of care to improve health literacy about end-of-life and palliative care. In addition, NINR-supported investigators found that a nurse-led palliative care intervention for patients with non-small-cell lung cancer and their family caregivers, designed for use in community-based health settings, improved physical, emotional, and functional well-being of patients, and better prepared family members to care for their seriously ill loved one in their home.⁹

Budget Policy:

The FY 2020 President's Budget request for this program is \$15.5 million, a decrease of \$2.6 million or 14.3 percent compared to the FY 2019 Enacted level. End-of-Life and Palliative Care will remain a high priority area of focus for NINR, as identified in the Institute's strategic plan. NINR will continue high priority research efforts across all of NINR's focus areas. As part of a strategically balanced research portfolio, policies for research grants will be implemented in this program that are consistent with those applied to the other programs described in this justification.

Program Portrait: Building Palliative Care Science and Helping Patients and Families with Serious Illness

FY 2019 Level: \$15.9 million

FY 2020 Level: \$13.6 million

Change: -\$ 2.3 million

Receiving a diagnosis of serious illness is never easy for individuals and families. Palliative care, which is comprehensive treatment of the discomfort, symptoms, and stress of serious illness, can help ease suffering and enhance quality of life. Individuals with serious illness are often unaware that they can receive palliative care and that it can be beneficial at any age or stage of illness, not just at the end of life. NINR continues to lead the way in transforming and expanding palliative care research and in providing important information about palliative care to individuals and families who are dealing with serious illness.

NINR supports research on palliative care to increase our knowledge of the needs of individuals and families dealing with serious illness, and to identify effective interventions to enhance their quality of life. For example, one project is testing a palliative care mobile health intervention that is using smartphone technology to support self-management of pain for advanced cancer patients and assist oncology providers in opioid management. NINR-supported researchers are also examining the efficacy of a community-developed, culturally-based palliative care intervention for hospitalized African American and White older adults with life-limiting illnesses that uses teleconsult to bring palliative care expertise to individuals in the rural south. Other NINR-supported researchers are testing an intervention to increase quality of life in children with advanced cancer and their parents using a web-based system that collects patient-reported outcomes and generates feedback reports for families and providers, combined with a palliative care consulting team.

NINR recently supported a new research center focused on improving palliative care for adults who have multiple chronic conditions (MCC), a particularly vulnerable group with complicated health care needs and poor health

⁹ Nguyen HQ, Ruel N, Macias M, Borneman T, Alian M, Becher M, Lee K, Ferrell B. Translation and Evaluation of a Lung Cancer, Palliative Care Intervention for Community Practice. *J Pain Symptom Manage.* 2018 Nov;56(5):709-718. <https://www.ncbi.nlm.nih.gov/pubmed/?term=30076966>

outcomes. There is a lack of research on the unique palliative care needs and experiences of adults with MCC. The center aims to address knowledge gaps in palliative care for this group, such as identifying strategies for symptom management (e.g., management of fatigue and pain), best approaches for palliative care across different care settings (e.g., hospital, home), and methods to ensure that patients get care that matches their preferences. Unique to this approach is the incorporation of the scientific expertise of the NINR-supported Palliative Care Research Cooperative (PCRC) and partnership with the Visiting Nurse Service of New York to determine how to best provide vulnerable populations with palliative care.

NINR also continues to build the Palliative Care: Conversations Matter® campaign to increase the use of palliative care for children living with serious illness. The campaign provides evidence-based information and resources to give children, families, and providers the tools they need to start and manage conversations about palliative care. NINR recently updated the Palliative Care: Conversations Matter® tear-off pad, one of its tools for providers, to ensure that the content reflects the most current research and terminology. The format was also redesigned to make it more user-friendly, and was tested with a focus group of health care providers.

In addition, NINR recently updated its brochure, “Palliative Care: The Relief You Need When You Have a Serious Illness.” The brochure, available in English and Spanish, is designed to provide patients with serious illnesses and their families with clear, evidence-based information about what palliative care is, who it benefits, and how it works. The brochure also addresses certain misconceptions about palliative care, such as that palliative care is only for those nearing the end of life.

Promoting Innovation: Technology to Improve Health

From smartphone technology to robotics to wearable devices, today’s technologies offer new solutions to improve health. NINR supports research to: develop and test various technological approaches to enhance health in diverse populations; provide needed health care and medical expertise to patients in rural communities; and assist individuals with limited mobility in performing their daily activities. For instance, NINR-supported researchers are refining and testing a novel assistive robotic device (exoskeleton) to prevent and rehabilitate diabetic foot ulcers by reducing pressure on the foot. In another study, investigators are developing a new technology that uses auditory and verbal cues based on real-time measurements of walking for stroke survivors to use at home to improve their mobility. Other NINR-supported researchers are assessing an interactive app-based monitoring system that includes a wrist-worn wearable device to provide individuals with Parkinson’s disease with visual feedback to monitor symptoms and actionable suggestions to discuss with their doctor. In a multi-site study, NINR-supported researchers found that a web-based decision support tool for men with localized prostate cancer, which involved education and communication coaching through text, graphs, and video clips, reduced decisional conflict that patients experienced regarding their treatment options in the weeks after receiving their diagnosis.¹⁰ These researchers demonstrated that a web-based decision support tool can help men with newly diagnosed localized prostate cancer make potentially difficult decisions about their treatment. NINR also leads an initiative to stimulate research utilizing Mobile Health (mHealth) tools aimed at the improvement of effective patient-provider communication, adherence to treatment, and self-management of chronic diseases. Another NINR-led initiative seeks clinical research on self-management interventions and technologies that improve health and quality of life in persons needing assistance to optimize

¹⁰ Berry DL, Hong F, Blonquist TM, Halpenny B, Filson CP, Master VA, Sanda MG, Chang P, Chien GW, Jones RA, Krupski TL, Wolpin S, Wilson L, Hayes JH, Trinh QD, Sokoloff M, Somayaji P. Decision Support with the Personal Patient Profile-Prostate: A Multicenter Randomized Trial. *J Urol*. 2018 Jan;199(1):89-97. <https://www.ncbi.nlm.nih.gov/pubmed/?term=28754540>

and maintain existing functional capabilities, prevent/delay disabilities, and navigate their environment.

Budget Policy:

The FY 2020 President's Budget request for this program is \$10.3 million, a decrease of \$1.7 million or 14.3 percent compared to the FY 2019 Enacted level. Promoting Innovation will remain a high priority area of focus for NINR, as identified in the Institute's strategic plan. NINR will continue high priority research efforts across all of NINR's focus areas. As part of a strategically balanced research portfolio, policies for research grants will be implemented in this program that are consistent with those applied to the other programs described in this justification.

21st Century Nurse Scientists: Innovative Strategies for Research Careers

Since its establishment, the training of nurse scientists has been a fundamental goal of NINR. The Institute invests in the development of nurse scientists at all career levels, and recognizes the importance of supporting new scientists to be prepared to address the health care challenges of the 21st Century. NINR supports numerous training opportunities, career development grants, and research intensives. For example, the Ruth L. Kirschstein National Research Service Awards (NRSAs) and the career development (K) awards enable scientists to be trained to conduct independent nursing research and help develop a highly trained, diverse pool of nurse scientists. In FY 2018, NINR offered its annual Boot Camp, a one-week, intensive research training course at NIH, designed to increase the research capability of graduate students, faculty, and clinicians. This year's Boot Camp focused on "Precision Health: Smart Technologies, Smart Health," and addressed digital health data and technologies that enable "smart health" and improved patient outcomes. NINR's Graduate Partnerships Program is a doctoral fellowship training program that coordinates training and funding for PhD-level nursing students interested in pursuing careers in basic or clinical research. The program combines the academic environment of a university and the breadth and depth of research at NIH. NINR's Summer Genetics Institute provides participants with a foundation in molecular genetics appropriate for use in research and clinical practice. With over 400 SGI graduates making a difference in communities across the country, the program seeks to increase the research capability among graduate students and faculty and to develop and expand clinical practice in genetics among clinicians. In addition, the Institute provides on-line training resources on the NINR website for nurse scientists at all career levels, including a variety of video series providing information on career development and tips for writing a successful grant application.

Budget Policy:

The FY 2020 President's Budget request for this program is \$13.1 million, a decrease of \$2.1 million or 14.3 percent compared to the FY 2019 Enacted level. Innovative strategies for developing 21st Century Nurse Scientists will remain a high priority area of focus for NINR, as identified in the Institute's strategic plan. NINR will continue high priority research efforts across all of NINR's focus areas. As part of a strategically balanced research portfolio, policies for research grants will be implemented in this program that are consistent with those applied to the other programs described in this justification.

Intramural Research Program

The overarching goal of NINR's Division of Intramural Research (NINR-DIR) is to improve our understanding of how individuals with various conditions experience symptoms, and to identify effective ways to treat and manage these symptoms. From men with prostate cancer experiencing fatigue from cancer treatment, to Veterans who are coping with blast-related brain injuries, NINR-DIR investigators seek to discover underlying causes of debilitating symptoms associated with various conditions, which will potentially lead to life-changing treatments and better health outcomes. Other studies in NINR-DIR examine pain and distress associated with digestive disorders and symptoms that occur with rare neuromuscular disorders. In addition, NINR-DIR supports innovative training opportunities to develop the next generation of investigators in symptom science, such as the NINR Summer Genetics Institute, Methodologies Bootcamp, and Graduate Partnerships Program. NINR is now initiating the Symptom Science Center (SSC), a new branch of the NINR-DIR, to support and conduct research to improve our understanding of how people experience symptoms. Research conducted in the SSC will inform personalized health management strategies to ultimately improve health outcomes across the life span. Beginning with a focus on the symptom of fatigue, the SSC will seek to promote biomarker discoveries that can be translated into clinical practice to eliminate or reduce symptom burden and engage patients and families in care. This goal will be achieved through: promoting discovery; developing a data repository; developing new models to predict and treat symptoms; and creating collaborative, interdisciplinary teams and mentoring partnerships at NIH.

Budget Policy:

The FY 2020 President's Budget request for this program is \$11.2 million, a decrease of \$1.9 million or 14.9 percent compared to the FY 2019 Enacted level. In FY 2020, this program will continue to build on recent accomplishments of the IRP, to support innovative research to address the scientific challenges of understanding and managing adverse symptoms or clusters of symptoms, as well as environmental influences on individual health outcomes. This program will also continue to support important training and career development opportunities for innovative investigators.

Research Management and Support

Research Management and Support (RMS) activities provide administrative, budgetary, logistical, and scientific support in reviewing, awarding, and monitoring research grants, training awards, and research and development contracts. The functions of RMS also encompass strategic planning, coordination, and evaluation of the Institute's programs, as well as communication and coordination with other federal agencies, Congress, and the public.

Budget Policy:

The FY 2020 President's Budget request for this program is \$15 million, a decrease of \$1.7 million or 10 percent compared to the FY 2019 Enacted level. In FY 2020, NINR plans to continue addressing the challenges and opportunities that exist in strategically managing a research portfolio of 238 grants and contracts that address areas of science critical to public health.

NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Budget Authority by Object Class¹

(Dollars in Thousands)

	FY 2019 Enacted	FY 2020 President's Budget	FY 2020 +/- FY 2019
Total compensable workyears:			
Full-time equivalent	96	96	0
Full-time equivalent of overtime and holiday hours	0	0	0
Average ES salary	\$0	\$0	\$0
Average GM/GS grade	12.9	12.9	0.0
Average GM/GS salary	\$116	\$116	\$0
Average salary, grade established by act of July 1, 1944 (42 U.S.C. 207)	\$104	\$104	\$0
Average salary of ungraded positions	\$58	\$58	\$0
OBJECT CLASSES	FY 2019 Enacted	FY 2020 President's Budget	FY 2020 +/- FY 2019
Personnel Compensation			
11.1 Full-Time Permanent	8,539	8,571	32
11.3 Other Than Full-Time Permanent	1,907	1,915	7
11.5 Other Personnel Compensation	218	219	1
11.7 Military Personnel	248	256	8
11.8 Special Personnel Services Payments	910	914	3
11.9 Subtotal Personnel Compensation	\$11,823	\$11,875	\$52
12.1 Civilian Personnel Benefits	3,511	3,577	66
12.2 Military Personnel Benefits	149	154	5
13.0 Benefits to Former Personnel	0	0	0
Subtotal Pay Costs	\$15,483	\$15,606	\$124
21.0 Travel & Transportation of Persons	174	121	-53
22.0 Transportation of Things	20	14	-6
23.1 Rental Payments to GSA	0	0	0
23.2 Rental Payments to Others	10	7	-3
23.3 Communications, Utilities & Misc. Charges	92	63	-29
24.0 Printing & Reproduction	1	1	0
25.1 Consulting Services	45	31	-14
25.2 Other Services	3,836	1,756	-2,080
25.3 Purchase of goods and services from government accounts	14,846	13,472	-1,374
25.4 Operation & Maintenance of Facilities	7	5	-2
25.5 R&D Contracts	389	388	-2
25.6 Medical Care	2	1	-1
25.7 Operation & Maintenance of Equipment	147	104	-43
25.8 Subsistence & Support of Persons	4	3	-1
25.0 Subtotal Other Contractual Services	\$19,276	\$15,759	-\$3,517
26.0 Supplies & Materials	410	289	-120
31.0 Equipment	610	429	-181
32.0 Land and Structures	0	0	0
33.0 Investments & Loans	0	0	0
41.0 Grants, Subsidies & Contributions	126,918	108,013	-18,905
42.0 Insurance Claims & Indemnities	0	0	0
43.0 Interest & Dividends	0	0	0
44.0 Refunds	0	0	0
Subtotal Non-Pay Costs	\$147,509	\$124,695	-\$22,815
Total Budget Authority by Object Class	\$162,992	\$140,301	-\$22,691

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

NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Salaries and Expenses
(Dollars in Thousands)

OBJECT CLASSES	FY 2019 Enacted	FY 2020 President's Budget	FY 2020 +/- FY 2019
Personnel Compensation			
Full-Time Permanent (11.1)	\$8,539	\$8,571	\$32
Other Than Full-Time Permanent (11.3)	1,907	1,915	7
Other Personnel Compensation (11.5)	218	219	1
Military Personnel (11.7)	248	256	8
Special Personnel Services Payments (11.8)	910	914	3
Subtotal Personnel Compensation (11.9)	\$11,823	\$11,875	\$52
Civilian Personnel Benefits (12.1)	\$3,511	\$3,577	\$66
Military Personnel Benefits (12.2)	149	154	5
Benefits to Former Personnel (13.0)	0	0	0
Subtotal Pay Costs	\$15,483	\$15,606	\$124
Travel & Transportation of Persons (21.0)	\$174	\$121	-\$53
Transportation of Things (22.0)	20	14	-6
Rental Payments to Others (23.2)	10	7	-3
Communications, Utilities & Misc. Charges (23.3)	92	63	-29
Printing & Reproduction (24.0)	1	1	0
Other Contractual Services:			
Consultant Services (25.1)	45	31	-14
Other Services (25.2)	3,836	1,756	-2,080
Purchases from government accounts (25.3)	10,625	9,304	-1,321
Operation & Maintenance of Facilities (25.4)	7	5	-2
Operation & Maintenance of Equipment (25.7)	147	104	-43
Subsistence & Support of Persons (25.8)	4	3	-1
Subtotal Other Contractual Services	\$14,664	\$11,202	-\$3,462
Supplies & Materials (26.0)	\$410	\$289	-\$120
Subtotal Non-Pay Costs	\$15,370	\$11,696	-\$3,674
Total Administrative Costs	\$30,853	\$27,303	-\$3,550

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Detail of Full-Time Equivalent Employment (FTE)

OFFICE/DIVISION	FY 2018 Final			FY 2019 Enacted			FY 2020 President's Budget		
	Civilian	Military	Total	Civilian	Military	Total	Civilian	Military	Total
Division of Extramural Science Programs									
Direct:	29	-	29	30	-	30	30	-	30
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	29	-	29	30	-	30	30	-	30
Division of Intramural Research									
Direct:	24	3	27	25	3	28	25	3	28
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	24	3	27	25	3	28	25	3	28
Division of Management Services									
Direct:	19	-	19	19	-	19	19	-	19
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	19	-	19	19	-	19	19	-	19
Division of Science Policy and Public Liaison									
Direct:	15	-	15	15	-	15	15	-	15
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	15	-	15	15	-	15	15	-	15
Office of the Director									
Direct:	4	-	4	4	-	4	4	-	4
Reimbursable:	-	-	-	-	-	-	-	-	-
Total:	4	-	4	4	-	4	4	-	4
Total	91	3	94	93	3	96	93	3	96
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								
2016	12.6								
2017	12.8								
2018	12.8								
2019	12.9								
2020	12.9								

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Detail of Positions¹

GRADE	FY 2018 Final	FY 2019 Enacted	FY 2020 President's Budget
Total, ES Positions	0	0	0
Total, ES Salary	0	0	0
GM/GS-15	14	14	14
GM/GS-14	21	22	22
GM/GS-13	17	17	17
GS-12	14	14	14
GS-11	5	5	5
GS-10	0	0	0
GS-9	1	1	1
GS-8	0	0	0
GS-7	4	4	4
GS-6	1	1	1
GS-5	0	0	0
GS-4	0	0	0
GS-3	0	0	0
GS-2	0	0	0
GS-1	0	0	0
Subtotal	77	78	78
Grades established by Act of July 1, 1944 (42 U.S.C. 207)	0	0	0
Assistant Surgeon General	0	0	0
Director Grade	1	1	1
Senior Grade	0	0	0
Full Grade	2	2	2
Senior Assistant Grade	0	0	0
Assistant Grade	0	0	0
Subtotal	3	3	3
Ungraded	28	28	28
Total permanent positions	80	81	81
Total positions, end of year	105	106	106
Total full-time equivalent (FTE) employment, end of year	94	96	96
Average ES salary	0	0	0
Average GM/GS grade	12.8	12.9	12.9
Average GM/GS salary	115,751	116,418	116,418

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