

Palliative Care

Conference Language

The agreement reiterates the need for NIH to develop and implement a trans-Institute strategy to expand and intensify national research programs in palliative care. The agreement urges NIH to ensure that palliative care is integrated into all areas of research across NIH and requests an update on plans to realize this coordination in the fiscal year 2024 Congressional Justification.

Action taken or to be taken

Summary of Ongoing Activities

Palliative care is specialized medical care for people living with a serious illness and is focused on treating the discomfort, symptoms, and stress of such illness.³⁷⁵ Palliative care has the potential to improve patient care, patient-clinician communication, and patient-centered outcomes while decreasing unwanted burdensome treatments and enhancing quality of life for people with serious illness, their loved ones, and their care partners. NIH recognizes the importance of palliative care, with several NIH Institutes, Centers, and Offices (ICOs) supporting a diverse set of research projects and initiatives focused on this essential area.

For example, the National Cancer Institute (NCI) supports palliative care research as an important component of its portfolio, including an active funding opportunity announcement focused on the survivorship needs of individuals living with advanced cancer, an announcement focused on the conduct of palliative care clinical trials, and a third announcement on the management of treatment toxicities.³⁷⁶ The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) is committed to supporting palliative care research relative to research involving children, pregnant and lactating people, and people with disabilities, with a particular focus on palliative care in critically ill or injured pediatric patients. The National Institute of Nursing Research (NINR) supports palliative care research that addresses issues of health equity, examines social determinants of health and their effects on individuals and families, and examines systems and models of care to improve access to quality palliative care. Recent NINR awards are funding research on improving integration of palliative care in primary care for American Indians, as well as enhancing discussion of palliative care in American Indian communities.³⁷⁷ The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) supports research to adjust treatment approaches and improve patient quality of life in end-of-life care for people with diseases such as end stage renal disease (also called kidney failure) and severe cirrhosis that results in liver failure. In addition to these examples, several other ICOs support a broad range of palliative care research activities.

NIH complements basic and translational research in palliative care with support for several ongoing clinical trials in this area. As one example, the NCI Community Oncology Research Program (NCORP) is a national network that brings cancer clinical trials and care delivery

³⁷⁵ www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care; www.ninr.nih.gov/newsandinformation/what-is-palliative-care

³⁷⁶ grants.nih.gov/grants/guide/rfa-files/RFA-CA-22-027.html; grants.nih.gov/grants/guide/pa-files/par-21-035.html; grants.nih.gov/grants/guide/pa-files/PAR-21-329.html

³⁷⁷ reporter.nih.gov/search/Ohqmi4CpkUmZzqHLtjI5gg/project-details/10431092; reporter.nih.gov/search/VdgUN3-c2k25yyHieMw81Q/project-details/10504687

studies to people in their own communities.³⁷⁸ NCORP supports research in supportive care, symptom management, palliative care, and health-related quality of life. Further, the National Institute on Aging (NIA) currently funds more than a dozen clinical trials on palliative care, including those on dementia-specific palliative care and trials using telehealth to deliver palliative care.³⁷⁹

NIH also supports large research cooperatives that work to benefit the entire field of palliative care. The Palliative Care Research Cooperative (PCRC), funded by NINR from FY 2010 through FY 2022, supports researchers who are developing an evidence base to ensure high-quality care and optimal well-being for persons with serious illness and their care partners.³⁸⁰ Recent activities of the PCRC have focused on reducing inequities through screening social need in pediatric palliative care, palliative care in chronic kidney disease, and the use of virtual reality for management of cancer pain. In addition, other ICOs have collaborated with NINR on PCRC activities. For instance, NIA recently supported an award focused on diversifying and strengthening dementia palliative care clinical trials, an effort that builds on work done by the PCRC under an NIA-supported supplement to develop a curriculum for palliative care clinical trials training.³⁸¹

NIH ICOs also coordinate and collaborate on funding opportunities in palliative care. For example, the National Heart, Lung, and Blood Institute (NHLBI) and NINR both currently participate in a Notice of Special Interest (NOSI) focused on improving quality of life for people with heart, lung, blood, and sleep diseases.³⁸² This notice was issued in September 2020 and will remain active through July 2023.

New Opportunities in Palliative Care Research

Multiple NIH ICOs – including NCI, NHLBI, NIA, NICHD, NIDDK, NINR, the National Institute of Mental Health (NIMH), the National Institute of Minority Health and Health Disparities (NIMHD), and the National Institute of Neurological Disorders and Stroke (NINDS) – have invested in research related to palliative care in the past and continue to support this area of research. In December 2022, several ICOs reissued a joint Notice of Special Interest to facilitate research on palliative care for older adults, including those with multiple chronic health conditions.³⁸³ Participating ICOs include NIA, NHLBI, NINR, NCI, NIMHD, and the NIH Office of Research on Women's Health. The next round of applications is expected in February 2023.

Moreover, NIH ICOs are carrying out efforts to identify new opportunities for research in palliative care. For example, NHLBI convened a workshop in December 2022 on care for people with advanced heart failure.³⁸⁴ The workshop brought together healthcare providers,

³⁷⁸ ncorp.cancer.gov/

³⁷⁹ www.nia.nih.gov/research/ongoing-AD-trials

³⁸⁰ palliativecareresearch.org/

³⁸¹ reporter.nih.gov/search/esFZZNTeDUi5mGiY4CktDw/project-details/10409239;

reporter.nih.gov/search/NaZBHvzsb0CnZ5O16o_rtQ/project-details/9880259

³⁸² grants.nih.gov/grants/guide/notice-files/NOT-HL-20-737.html

³⁸³ grants.nih.gov/grants/guide/notice-files/NOT-AG-22-048.html

³⁸⁴ www.eventbrite.com/e/advanced-heart-failure-trajectories-triage-for-ambulatory-pre-d-d-tickets-470574690567?keep_tld=1

researchers, policy makers with expertise in adult and pediatric cardiology, heart failure, clinical trials, outcomes research, transplantation, mechanical circulatory support, geriatrics, and palliative care. This workshop focused on identifying gaps and opportunities that will help spur research to improve access to palliative care for ambulatory patients with advanced heart failure, such as enhancing integration of palliative care across the continuum of illness. Additionally, NICHD is planning a 2023 State of the Science conference on pediatric palliative care in critically ill children. This conference will convene experts in pediatric palliative care and help identify key gaps and opportunities in this area.

Moving forward, NIA is leading efforts to convene subject matter experts from the ICOs listed above to expand and intensify the strategic coordination of palliative care research efforts as well as identify future research topics and questions that pertain to palliative care.