



September 24, 2021

Francis S. Collins, MD, PhD  
Director  
National Institutes of Health  
9000 Rockville Pike  
Bethesda, Maryland 20892

Dear Dr. Collins,

The Council for the Advancement of Nursing Science (CANS) and the American Academy of Nursing (Academy) appreciate the opportunity to offer comments regarding the Advanced Research Projects Agency for Health (ARPA-H) Initiative and applaud the administration for having the foresight to catalyze scientific efforts to solve problems and address equity. The Academy serves the public by advancing health policy through the generation, synthesis, and dissemination of nursing knowledge. Academy Fellows are inducted into the organization for their extraordinary contributions to improving health locally and globally. With more than 2,800 Fellows, the Academy represents nursing's most accomplished leaders in policy, research, administration, practice, and academia. As the scientific voice for the Academy, CANS formulates and advances research, scientific training, and career development within the profession. In the effort to promote better health, CANS enhances communication among nurse scientists and the public to develop, disseminate, and utilize nursing research, including health promotion, prevention, managing acute and chronic conditions, and care at the end of life.

The vision of the Academy is Healthy Lives for All People. To actualize this vision, the Academy's mission is to improve health and achieve health equity by influencing policy through nursing leadership, innovation, and science. The ARPA-H Initiative provides immense opportunity for those of us in health care organizations and particularly for nursing leaders in science and innovation to achieve health and wellness for all. The written comments reflect CANS' oral comments provided on July 30, 2021 and the Academy's reflections from participating in the recent public listening session on August 3, 2021.

### **Research Approaches to Rapidly Address Health Disparities and Save Lives**

Regarding opportunities that could be used to leverage science, tools, and processes that would be game changing, CANS and the Academy believe that to truly improve health, policies must expand access to quality care across the lifespan through novel approaches, grounded in rigorous science and aimed at eliminating discrimination and racism while improving health equity. This requires a distinct focus on removing disparities and enhancing health care experiences. ARPA-H funded research could identify critical gaps and prioritize research funding that includes all communities and capitalizes on nurses' traditional and historic roles in communities. In recent and past decades, however, payment, support, and commitment has been lacking for health care services, and just as critically, health care providers who practice in underserved areas. The nation has seen the unfortunate results of this underinvestment through widespread health inequities as well as the trauma and tragedy of the COVID-19 pandemic. Increased support for the discipline of nurses in science, innovation, and leadership would lead, in our opinion, to better outcomes through community led and supportive innovations. The

Academy's Edge Runner<sup>1</sup> initiative has shown this to be true in nurse led and driven transitional care models such as the Program of All-Inclusive Care for older adults<sup>2</sup>, and maternal and infant models like the Nurse Family Partnership<sup>3</sup> and birthing centers. These are research-based and need to be further implemented in a more widespread manner.

During study design, vulnerable populations are often left behind by the rigid structures of inquiry that are used in biomedical research. The ARPA-H Initiative presents an opportunity to create access and include participants from diverse communities. During the COVID-19 pandemic, we have seen the importance of telehealth. However, access to telehealth in rural and other underserved areas that lack the technology infrastructure will only exacerbate rural health disparities. The Academy and CANS are on record recommending the expanded use of telehealth as well as ensuring the needed infrastructure investments are made to create a system where everyone, regardless of location or background, continues to receive high quality care. There is also a need to conduct rigorous research to further define the barriers and identify who is most likely to benefit from telehealth interventions, while tailoring intervention accordingly. While digital tools, biosensors, remote monitoring/data-capture, etc. are all additive, individuals who reside in rural areas, or areas with poor/no/expensive broadband access, or lack a personal device (computer, internet, smartphone, tablet, etc.) are increasingly being left behind. This is not only a major public health issue but a critical target for research the ARPA-H Initiative should prioritize.

Moreover, there are cultural issues related to the use of technology in health care settings, particularly around trust. Therefore, there is a need for a holistic view that considers individual preferences and capabilities, and a need for better understanding these preferences. This warrants new and different solutions to health care research and to deliver healthcare and record as well as store individual health/well-being information regardless of an individual's location, financial means, digital literacy, etc. Telehealth remains underused and its effectiveness should be studied for the delivery of simple preventative screenings, such as for hypertension, glucose screening, and vision screening. We encourage the ARPA-H Initiative to address this issue. Innovative solutions developed through the ARPA-H Initiative that truly change lives and favorably affect health and are broadly applicable as well as available are greatly needed.

Additionally, multi-omics approaches to understanding health and disease in large, diverse, longitudinal cohorts are needed as are the integration of genomics, social determinants of health, and exposome data into electronic health records that are designed to be research-friendly. While initiatives like these ideas are sometimes funded by existing Institutes at the National Institutes of Health (NIH), the projects funded by NIH are largely small-scale efforts, due to statute constraints of grants in terms of budget and length of project performance periods. Larger efforts and thus more risk-taking behavior in research such as what is being proposed in the ARPA-H Initiative are needed for a leap forward in this area.

### **Addressing Systemic Gaps in the R&D Enterprise to Speed Progress**

We would like to see a truly transformative review process. The ARPA-H Initiative provides a unique opportunity for NIH to spark innovative research that may not be possible under the agency's current authorities and practices. This research may be higher risk than existing NIH projects and must be facilitated to assure rapid uptake into practice. The ARPA-H Initiative will also require independent oversight to ensure that ARPA-H projects are successful, but also to maximize opportunities and

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<sup>1</sup> *Edge Runners - American Academy of Nursing Main Site*. (n.d.). American Academy of Nursing. Retrieved from <https://www.aanet.org/initiatives/edge-runners>

<sup>2</sup> *Living Independently for Elders Center - American Academy of Nursing Edge Runners*. (n.d.). American Academy of Nursing. Retrieved from <https://www.aanet.org/initiatives/edge-runners/profiles/edge-runners--living-independently-for-elders-center>

<sup>3</sup> *Nurse-Family Partnerships - American Academy of Nursing Edge Runners*. (n.d.). American Academy of Nursing. Retrieved from <https://www.aanet.org/initiatives/edge-runners/profiles/edge-runners--nurse-family-partnerships>

evaluate progress on ARPA-H projects. This independent oversight body will not only ensure the ARPA-H Initiative is fulfilling its potential to supplement current federally funded research but also reassure government officials and the public that resources are being expended wisely. Additionally, this change will also require a visionary director for ARPA-H who has an expansive view. Moreover, the makeup of review panels will require serious consideration and oversight to achieve the vision of ARPA-H.

### **Challenges to Commercialization, Implementation and Dissemination of Research**

If commercialization, implementation, and dissemination are to be included as part of ARPA-H funded research, it will require the development of a nimble yet rigorous review process that takes these areas into consideration. These components and objectives will need to be clearly communicated in order for applications to be successfully completed and reviewed. The Academy and CANS recognizes and laud nurse leaders in science and others who take evidence and innovation to the real world in practice and business. It is nurses who are often the implementers of the innovations in health science, we teach students how to innovate, and increasingly are using design thinking in the classroom to prepare leaders of the future who will help move innovation from discovery to practice. It will be vital that strong controls are in place similar to the Defense Advanced Research Projects Agency (DARPA), so that transformative change is widely advanced, accessible to all, and its benefits clearly communicated. One major challenge to this goal are the traditional academic metrics for tenure/promotion that are built on success rather than failure (a distinct culture within DARPA that is philosophically at odds with academia). There is little regard to commercialization in most tenure/promotion criteria. Changing this will require much discussion and possibly incentives to institutions to support more rapid translation of innovations into practice.

One idea that may help advance research in this way is to require investigators to submit a clear plan for commercialization, implementation, and dissemination. The current NIH requirements do not require great specificity of these processes. In ARPA-H grant applications, perhaps the plan for commercialization, implementation, and dissemination could be part of the review process rather than more narrowly focused on the standard NIH significance, investigators, innovation, approach, and environment scores. A review process similar to the one used by the Patient-Centered Outcomes Research Institute (PCORI) would be an example to consider. Most certainly, the review process will need to be radically different and nimble.

### **Partnership and Collaboration Strategies**

We need our biomedical workforce to better represent the diverse population of our country. The current lack of diversity severely limits research opportunities to achieve health equity through equity in health careers. We appreciate NIH's focus on the diversity of the biomedical research workforce through the UNITE Initiative and other programs. CANS and the Academy recommend that the ARPA-H teams include multiple disciplines, backgrounds, and diverse skill sets that work well together to deliver research products in a timely manner. These teams will need to embrace the idea of "fail forward." Moreover, composition of these teams will require individuals who might not have the usual NIH biosketch track record (i.e. product engineers working in industry). Members of the nursing profession have collaborated with leaders in engineering, business, and law as well as industry partners in robotics to transform care in multiple settings. Inclusion of individuals with industry backgrounds will also require rethinking the review criteria. The needs and perspective of health care consumers should also be addressed. Similar to NIH's All of Us Initiative and PCORI methods, there is a need to create the most diverse health databases, but also participation of health care consumers in developing, conducting, disseminating and applying research findings.

The ARPA-H Initiative has great potential to address gaps in biomedical research, but will be unable to do so if it operates in a vacuum. As it is being developed, the Academy and CANS encourage

collaboration with other federal health agencies, including but not limited to the Centers for Disease Control and Prevention, Centers for Medicare and Medicaid Services, and the Food and Drug Administration.

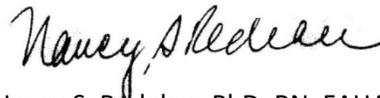
It may also be useful for ARPA-H to establish “problem sections” or think tanks. A director could choose a group of applicants to develop a radical idea to address a pressing health issue. This group of experts could then meet over a set period of time to develop a solution to the problem. These groups would ideally be comprised of people from various sectors and diverse backgrounds. We also recommend that consumers should be included in some of these in order to be sure solutions are practical for the general public.

The Academy appreciates the NIH’s efforts to hear from diverse groups on the ARPA-H Initiative, which has great potential to supplement and support federally funded biomedical research. We stand ready to answer any questions you may have or provide more information. In the meantime, please call on the Academy and CANS as vested partners in this work. If we can be of any assistance to you or your staff, please do not hesitate to contact the Academy’s Senior Director of Policy, Christine Murphy, at [cmurphy@aannet.org](mailto:cmurphy@aannet.org) or 202-777-1174.

Sincerely,



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