Comments for NIH and OSTP listening session on the proposed ARPA-H on August 4, 2021:

Thank you for this opportunity. I’m Ellie Dehoney, Research!America’s Vice President for Policy and Advocacy.

Research!America is a national nonprofit, nonpartisan alliance spanning patient advocates and the health-focused R&D ecosystem of which patients are part.

We know that medical and public health progress is urgently needed, but hard-won.

We are tremendously grateful to the President for refusing to settle for the status quo.

Patients – and in the arc of our lives, we are all patients – cannot afford stasis.

We fully support the Administration and members of Congress from both sides of the aisle in their efforts to stand-up ARPA-H.

We envision ARPA-H as a resolutely independent incubator, capitalizing on best practices from DARPA and ARPA-E and forging new ground at the intersection of public, private, academic and philanthropic efforts to advance health.

Regarding where ARPA-H is situated within the federal government, at this point our alliance members hold divergent views, so Research!America has not taken a position.

However, based on two alliance member listening sessions and continuing input, there is considerable consensus around the following recommendations:

First, it is crucial for safeguards to be put into place that prevent ARPA-H funding from supplanting NIH investment.

In the same vein and by design, ARPA-H investment should not supplant private sector investment. ARPA-H should build out – not crowd out – progress.

In that context, we strongly oppose funding Taps that divert dollars from NIH into ARPA-H. We also believe NIH should be waived from any co-funding with ARPA-H.

While ARPA-H should have the flexibility to fully fund NIH-associated projects, co-funding would counter-productively draw down from NIH grant and intramural investment.
Further, regardless of whether ARPA-H reports to the NIH Director, it is worth considering establishing ARPA-H as a stand-alone entity physically, structurally, and statutorily distinct from any existing federal agency or program.

The independent entity approach could entail creating a dual role for the NIH director, with separate and distinct responsibilities for overseeing NIH and advising the Director of ARPA-H.

We are concerned that if ARPA-H is constituted as a new division, center or institute within NIH, the die will be cast for NIH-directed dollars to be stretched even thinner than they are today.

In FY22, a separate funding stream is likely for ARPA-H and we are grateful for it, but going forward, appropriators would be allocating to a single federal agency. The larger that federal agency, the more difficult it will be to assure needed funding increases year-over-year.

One of the many reasons to avoid supplanting NIH funding is the negative impact on ARPA-H itself. The ability to advance use-driven projects relies on the foundational knowledge uncovered by NIH-supported research.

Other recommendations: Our alliance supports Dr. Lander and Dr. Collins in asserting that ARPA-H should embrace key features of DARPA and ARPA-E, including:

- the hiring flexibility to engage innovators inpatient for results regardless of their educational and career trajectory before ARPA-H; and
- the use of contracts, which provide the flexibility to
  - enforce milestones;
  - adapt projects midstream; and
  - expeditiously end projects not seeing results.

Finally, we believe ARPA-H’s mission should encompass both health and healthcare innovation. The latter advances health equity and saves lives as surely as biomedical innovation does.

Need, opportunity, and the success of existing ARPAs form a rock solid foundation for ARPA-H.

We stand ready to assist the Administration and Congress as you work to ensure this novel and important innovation incubator joins our nation’s R&D ecosystem in 2021.