



National Institutes of Health
Turning Discovery Into Health



**MULTI-REGIONAL
CLINICAL TRIALS**

THE MRCT CENTER of
BRIGHAM AND WOMEN'S HOSPITAL
and HARVARD

Your Voice Matters!

Help Shape a New NIH Policy for Sharing Summary Level Study Results with Participants

Public Listening Session

April 27, 2026

Welcome!

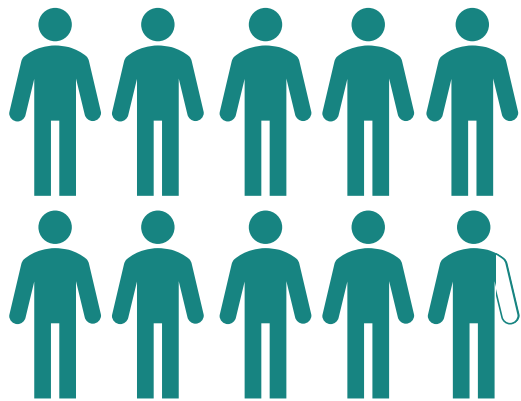
Lyric Jorgenson, PhD
Associate Director for Science Policy &
Director, Office of Science Policy

Goal: Foster Integrity, Transparency, & Trust in Clinical Research



Sharing results with participants is integral to enhancing engagement with the public, incentivizing participation, and increasing transparency and accountability to the public for use of taxpayer dollars.

People want results from clinical research

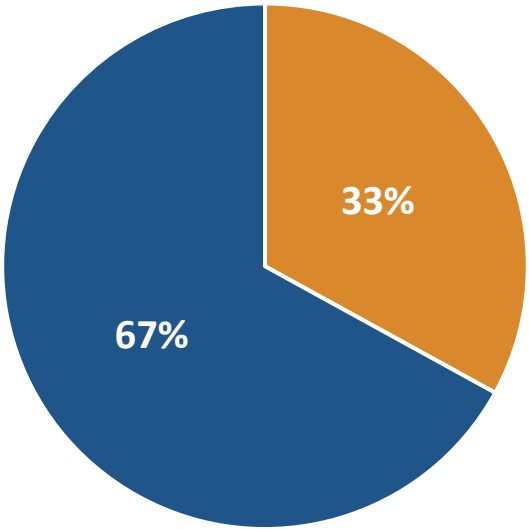


98%

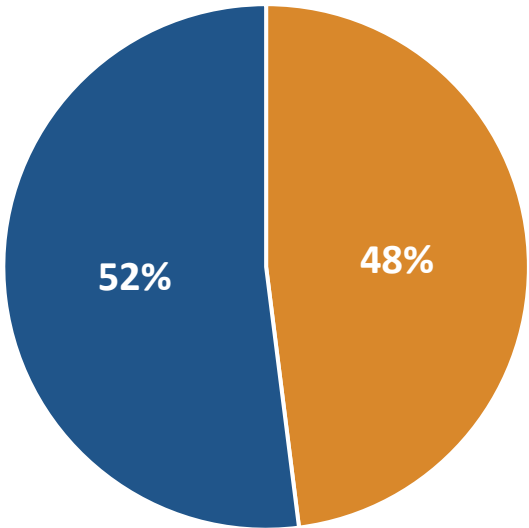
of participants want their data from studies they participate in

Kent DA, et al. Returning individual research results to participants: Values, preferences, and expectations. J Clin Transl Sci. 2024 Sep 18;8(1):e126. doi: 10.1017/cts.2024.568.

Percent of participants who actually receive research results



Percent of participants who are asked if they'd like their results returned



Yes No

Long, CR, Stewart, MK, Cunningham, TV, Warmack, TS, McElfish, PA. Health research participants' preferences for receiving research results. Clin Trials Lond Engl. 2016;13(6):582–591

NIH Director Priority



“NIH will work with the community to make the return of participant research results standard practice. **Initial efforts will focus on returning summary-level research results...**

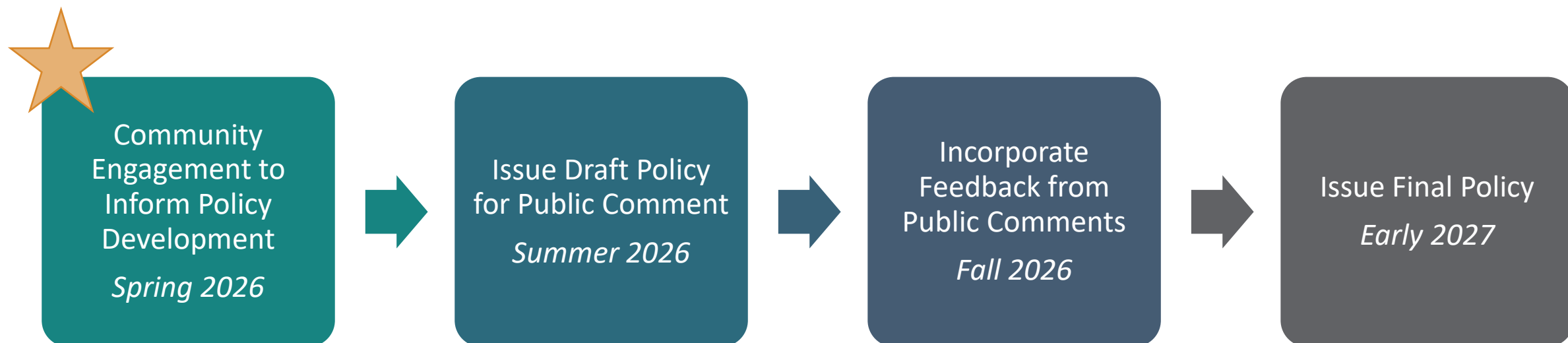
Providing individuals with their research data so they can make their own healthcare decisions is one of my top priorities as NIH Director.”

- NIH Director Dr. Jay Bhattacharya

NIH Policy Development Process: Return of Results



NIH Policy Development Process: Sharing Summary Results Policy



TODAY'S GOAL: WE NEED YOUR FEEDBACK!

1. What should be included in the summary results shared with participants?
2. How should they be shared?
3. When should they be shared?

All comments are welcome and will be considered

We want your feedback even after the webinar!

On-demand commenting is available on OSP's Website.

<https://osp.od.nih.gov/policies/return-of-research-results#tab2/>





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Sharing Summary Level Study Results with Participants: Current Landscape

Barbara E. Bierer, MD

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