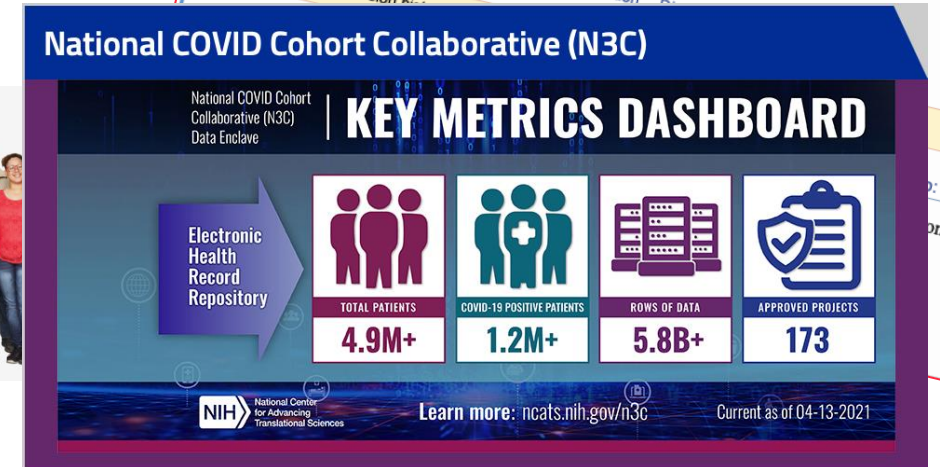


What Has the COVID-19 Pandemic Taught Us About Data Sharing and Open Science?

Patricia Flatley Brennan, RN, PhD
Director, NLM

What Kind of Data is NIH Sharing?

- Molecular
- Clinical trials summary data
- Specialized collections: All of Us, National COVID Cohort Collaborative (N3C)
- Literature and preprints
- De-identified data from research projects



NIH COVID-19 Specific Projects

NIH Research Initiative on
Post-Acute Sequelae of SARS-CoV-2
Infection (PASC)



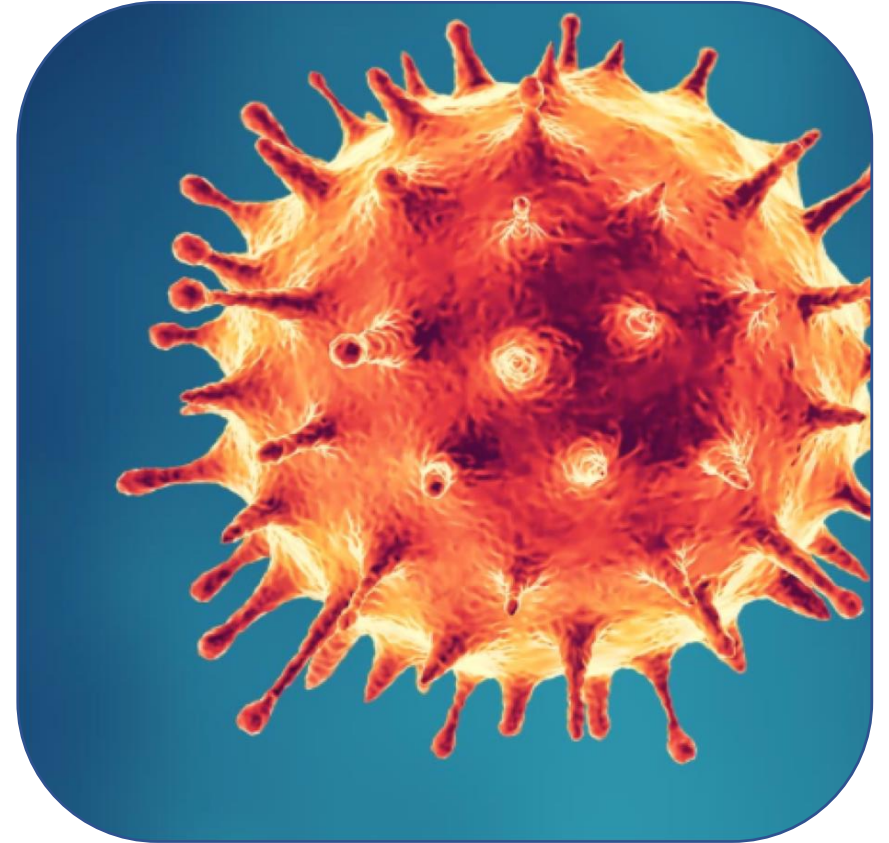
Rapid Acceleration of Diagnostics
(RADx)



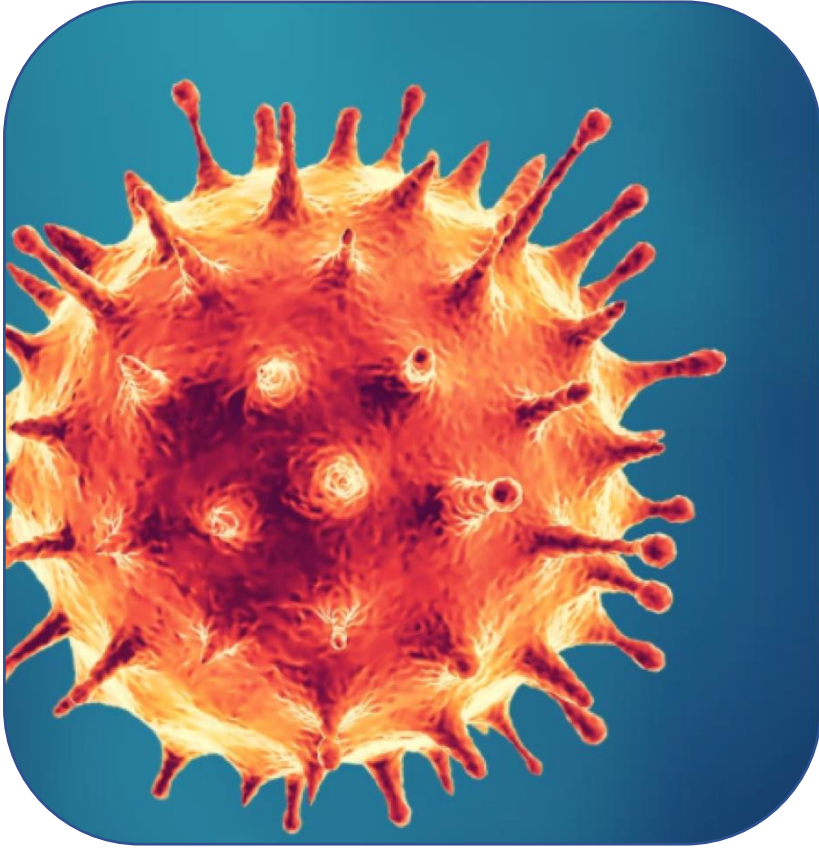
Almost \$2B in New Research

What Happens When Data are Shared and Science is Open?

- Vaccines enter phase 3 clinical trials within 180 days
- Timely characterization of variants
- Rapid evaluation of therapeutics
- Interventions designed in real time
- Isolated experience of symptoms organized into syndromes
- Public reassured

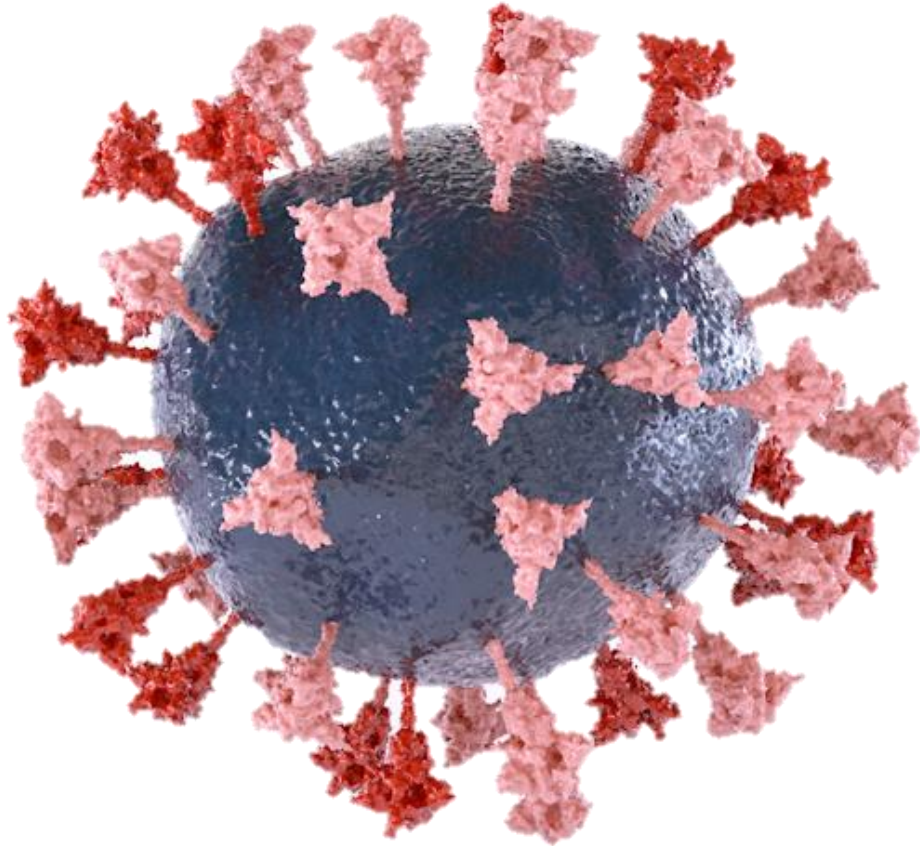


What Else Can Happen?



- The sociology of science shifts
 - "Pay it forward" data management
 - Balancing investigator incentives with scientific social good
- The self-correction cycle speeds up
- The public's expectation of certainty conflicts with the rapid release of information

NIH Laid the Groundwork...



- **Policies and Practices**

- Data management & sharing
- Desirable Characteristics of Generalist Data Repositories

- **Public Access Policy**

- **Partnerships**

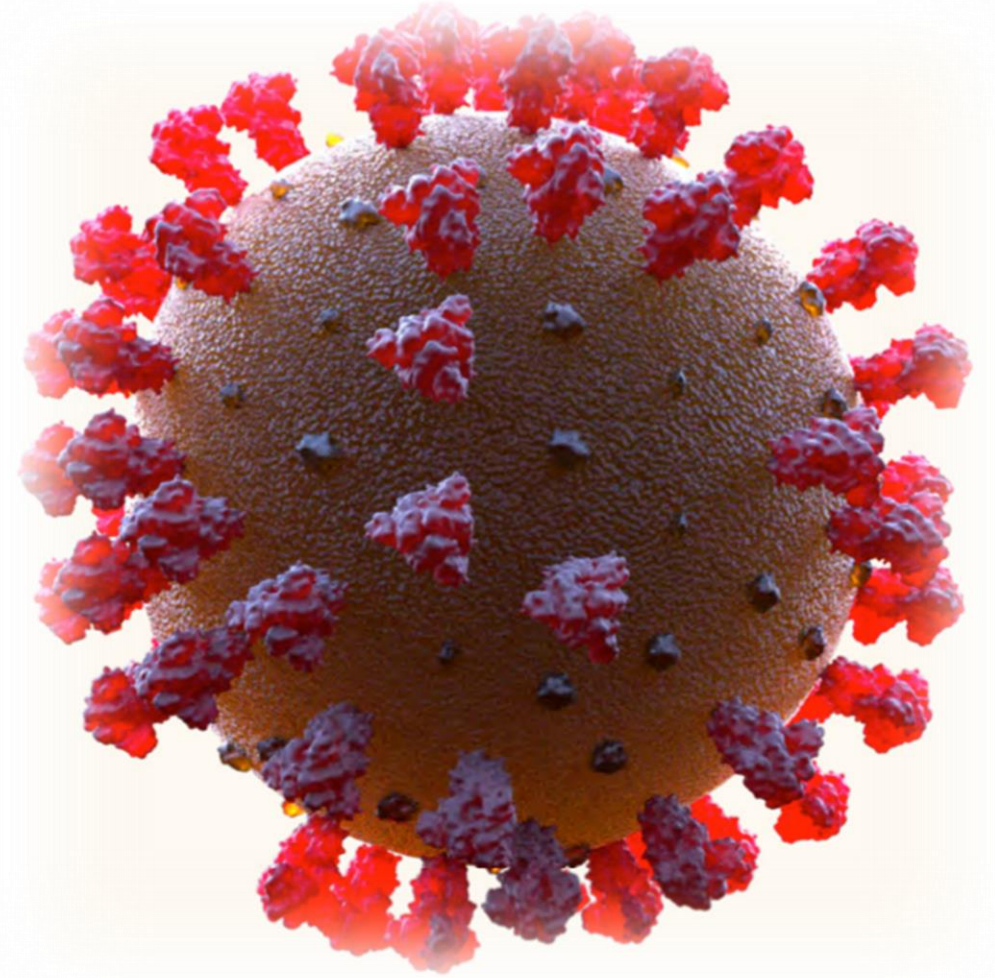
- CDC
- International Nucleotide Sequence Database Collaboration (INSDC)

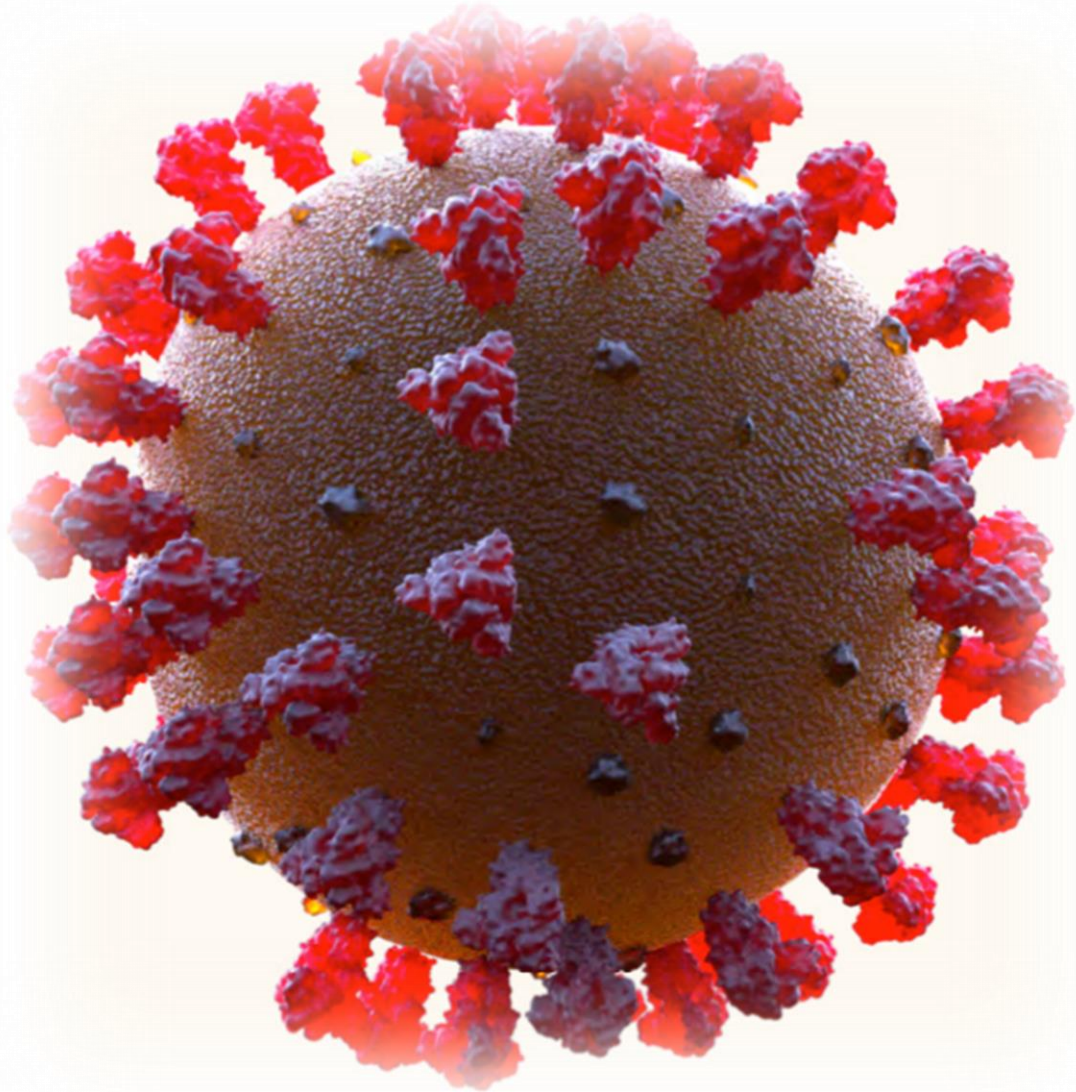
- **Modernizing the data ecosystem**

- SRA in the cloud
- Research Data Hub

Critical Steps Taken by the NIH

- Innovative organization for research
 - Hub-and-spoke project organization
 - Data coordinating centers partnered with individual research projects
- Data life cycle planning
 - Consent with an eye to reuse
- Common data elements (CDEs) and common data models
- Investing in data repositories





What Have We Learned?

- Many stakeholders
- Chain of trust
- Consent is important
- Records linkage and recontact
- Research data re-use
- Where are we going to put it?
- For how long?
- And once it is there, can we find it?



Looking Back in the Rear-view Mirror...

- Effective ways to integrate data from clinical records
- Acquiring near-real time data safely and ethically
- Generalized consent?
- Managing data from special populations

Reaching NLM



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