NLM Highlights Essential Role of Clinical Databases in Pandemic

The ClinicalTrials.gov website is more important now than ever as it undergoes various modernization efforts.

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The National Library of Medicine is embarking on an extensive modernization effort of the world’s largest public clinical trial registry and results database, ClinicalTrials.gov, with the COVID-19 response underpinning the importance of the multi-year project.
“This effort to improve the user experience and update the technology platform is critically important for so many things that we do at NIH, our partnerships across the government and our commitment to the American public — the taxpayers and the research participants,” Kelly Wolinetz, associate director for the agency’s Office of Science Policy and NIH’s acting chief of staff, said in a virtual public meeting Thursday.

The agency plans to continue engaging with stakeholders, incorporating feedback given from their recent RFI, as well as develop a strategic roadmap and enhance its internal business processes this year to achieve its goals that began late last year.

Improvements for the website fall under three baseline categories: website functionality, information submission and data standards. The agency also plans to implement user testing for those enhanced features within the next two to five years, with the endpoint being to advance health science and make research study information easily understandable and searchable for potential participants.

The 20-year-old website has experienced an increase in traffic due to a strong interest in clinical studies that could help the pandemic, Wolinetz said. This includes searches for publicly available information regarding clinical trial updates and results for treatments that many federal agencies and news outlets report on, such as the first FDA-authorized treatment for COVID-19, remdesivir. The agency is making sure to update the latest terms and synonyms for COVID-19 search results for participant study enrollment, Wolinetz said.

Additionally, although the novel coronavirus was discovered relatively recently — with the first full sequence of the virus published in NLM’s GenBank in mid-January — there are over 900 clinical trial studies for COVID-19 listed on the website, NLM Director Patricia Brennan noted.

“During this crisis, many libraries have closed and over the last five years many hospital libraries have restricted their services, so never before has the NLM been this important,” she said.
With “rapid-fire efforts” such as the NIH’s Accelerating COVID-19 Therapeutic Interventions and Vaccines (ACTIV) public-private partnership, which aims to accelerate the rate and speed at which potential drug therapies are discovered, more people are also realizing that massive data-sharing efforts and modernizing resources like ClinicalTrials.gov are critical for protecting and ensuring public health.

“The public benefits of a trial registry have really never been so obvious among this time of COVID-19, both in connecting people to research [and] in ensuring the integrity of reporting,” she explained. “It’s really an opportunity to continue to see how essential registries can be in ensuring that results are disseminated in a timely manner.”

Modernizing how the website functions, moreover, will allow the agency to better ensure scientific health studies are reported with stewardship and accountability while also supporting wise investments in clinical research, she said.