

COVID-19 Registries

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The SARS-CoV-2 (COVID-19) virus continues to spread within the United States and around the world. There is still much to learn about the epidemiology and natural history of infection—including how to prepare for future pandemics and outbreaks, as well as how to plan for long-term health, social, and economic impacts. RTI International believes COVID-19 registries could fill many of these knowledge gaps, including the risk of virus reactivation or reinfection and the long-term sequelae of infection.

Overview and History of Health and Disease Registries

Public health registries, including disease-specific registries, identify and follow people with a specific exposure or disease over time to determine the long-term outcomes of the exposure or disease. Unlike most epidemiological studies, registries usually include only persons with the condition of interest. A public health registry is an attempted census of the persons exposed to a disease, but resources can be prioritized to maximize inclusion of the most affected persons, if necessary. Registries facilitate the study of physical and mental health consequences of an infection or another health condition and can also inform policy regarding the trajectory of the illness and other associated societal and economic impacts resulting from the disease.

Hundreds of disease registries currently enroll individuals in the U.S., including registries focused on cancer, genetic diseases, autoimmune diseases, and other conditions. Some examples of disease registries include the Surveillance, Epidemiology, and End Results (SEER) Program—a population-based cancer registry; state cancer registries; and the Muscular Dystrophy Surveillance, Tracking, and Research Network.

Importance and Benefits of COVID-19 Registries

COVID-19 has infected millions of people, and the long-term impact of post-recovery re-infection is still unknown. Information is needed to address the following key public health and policy areas:

- Preparing for future pandemic waves and outbreaks
- Planning for long-term health, social, and economic impacts from the disease.

Better information results in more focused prevention efforts, fewer negative impacts of mitigation measures, fewer deaths, and less severe economic consequences.

A registry with longitudinal follow-up could answer the following questions:

- What are the medium and long-term comorbidities from severe COVID-19 infection, and do any result from mild, moderate, or asymptomatic infection?
- Do recovered individuals have immunity to a new wave of infection? If yes, how strong is the immune response and how long does the immunity last?
- Merged with contact tracing data, what proportion of exposed people get infected? What are the characteristics of (1) these individuals or (2) their exposure that predict infection?



- What are the long-term consequences of social distancing/isolation measures on individuals and families from health, health planning, and economic perspectives?
- What further health communications and promotions would be beneficial to develop for the COVID+ community or those at risk of infection?

COVID-19 registries for targeted populations have been created; however, the eligibility criteria, information about disparate populations, and collected data elements will limit the ability to combine data across registries. Today's technological capabilities for communicating and gathering information make a large-scale registry of COVID-19 survivors feasible. A national registry would allow less common disease presentations, routes of infection, and sequelae to be identified and tracked.

History shows that successful registries are implemented as soon as possible after an outbreak occurs. Appropriate timing ensures high-quality health data, maximizes community and individual participation in the baseline registry, and yields more positive outcomes for future follow-up studies.

Proposed Registry Opportunity

RTI will leverage existing and new registries and cohort studies to implement a COVID-19 registry in the United States. Many existing studies have incorporated data collection about COVID-19 into their studies. With the appropriate consent, recovered or currently affected individuals identified through these data collection instruments could be enrolled in a COVID-19 registry. Enrollment could be expanded through active recruitment among individuals with positive test results, individuals identified through seroprevalence surveys, or self-enrollment.

The following strategies could be used to generate a registry:

- **Positive test results:** Obtain a list sample and contact information for individuals with COVID-19 positive test results from hospitals, local health departments, or the Centers for Disease Control.
- **Population-based:** Select a national or local address-based sample at random. All respondents could enter in the registry or only those who are currently infected with COVID-19, depending on the goals.

RTI proposes conducting the following COVID-19 registry work:

1. Identify the registry population.
2. Send a survey to all individuals to better understand factors related to demographics, COVID-19 exposure, pre-existing health conditions, recent symptoms, COVID-19 knowledge, attitudes/beliefs, and health behaviors.
3. (If strategy number 2): Collect a self-administered collection kit to test for COVID-19 antibodies.
4. Conduct follow-up surveys by mail, web, or telephone to determine the trajectory of individuals with COVID-19.

RTI's Health Registry Highlights

RTI has worked on several environmental exposure registries, including the following projects:

- National Registry of Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions (GenTAC)-Data Coordinating Center
- North Carolina Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet)
- International Registry of Aicardi Syndrome
- World Trade Center Health Registry (WTCHR)
- Tremolite Asbestos Registry (TAR)
- Katrina and Rita Exposures (KARE) Registry

Disease Registry Activities

Typically, implementing a health registry involves the following six main tasks:

1. **Design:** Scientific stakeholders enumerate the specific exposures included in the registry and identify the eligibility criteria for the registry. A survey questionnaire is developed and tested. Methods for enrollment are identified. Approvals are secured for human subjects research.
2. **Public health outreach:** The registry team develops a media and community outreach campaign to motivate potential registrants to participate. This step is critical to overcoming any distrust that many of the affected communities and individuals may have toward research.
3. **Sample building:** The team uses a multi-pronged recruitment strategy to maximize the number of identified and enrolled registrants. Recruitment methods include public health outreach, collection of lists of eligible persons, and self-identification through a toll-free number and website.
4. **Tracing the registry population:** As possible registrants are identified, the team updates contact information when potential registrants have dispersed or when incomplete information is available for them. Tracing is often conducted by submitting available contact information to vendors who match that information with publicly available databases to generate new addresses or phone numbers.
5. **Data collection:** Registrants' key exposures, physical, and mental health data can be collected using telephone, in-person, web, SMS, or other interviewing techniques. The questionnaires often take about 30 minutes to complete. Biological samples could be collected at various points in time as well, such as saliva for DNA extraction or cortisol, blood spots for immunologic or inflammatory markers, or nasal or buccal swabs.
6. **Data dissemination/health communications:** Local, state, and federal health authorities could disseminate summary statistics and key health information to the affected population as well as to the public at large given the ongoing risk of infection. Materials can be provided to link individuals to services to help address any unmet physical or mental health needs related to the infection.