

Frequently Asked Questions

What is the COVID IDR?

The COVID Integrated Data Repository (IDR) supports COVID-19 research by importing data from Duke's Electronic Health Record (EHR), REDCap, LabVantage, and other sources. A steering committee guides the product development, and the [COVID-19 Shared Data and Specimen Repository Steering Committee](#) governs the data sharing process.

The COVID IDR dashboard allows researchers with appropriate authorizations to view de-identified patient demographic data from the EHR, research study registration and consent information from REDCap, and collected biospecimens. After using drill-down functionality to select a cohort of interest, users with appropriate authorization can:

- Download de-identified data
- Submit a request for identified information using an honest broker (IRB approval required)
- Contact investigators with samples to inquire about sharing process

What can I do with COVID IDR?

- I can find collected specimens with the attributes I'm looking for and the contact information to determine the availability and sharing process for related samples.
- Use the data to determine feasibility for grant submissions.
- Identify cohorts of interest and download de-identified data to conduct research.
- Identify cohorts of interest and request identified data to conduct research.

How do I access COVID IDR?

Role	Authorizations
Any faculty or staff having a valid Duke Net ID (excludes affiliate accounts)	<ul style="list-style-type: none">• View aggregated data with counts of participants and specimens by protocol• Define a cohort based on specific de-identified clinical parameters such as labs, diagnoses, and demographics; save cohort; view aggregated counts
Research Preparatory to Research (RPR)	All authorizations listed above plus <ul style="list-style-type: none">• View columns of de-identified data (no download capabilities)
Researcher with IRB Protocol Determined Exempt or Approved	All authorization listed above plus <ul style="list-style-type: none">• View and download de-identified data for individual participants
Researcher with Approved IRB Protocol	All authorization listed above plus <ul style="list-style-type: none">• View fully identified data• Receive download of fully identified data with Honest Broker assistance
Application Administrator	Full access to data for support to the user community and the application
Honest Broker	Full access to support the needs of the data management
Governance Committee	Elevated access to allow access to datasets subject to review by the committee

What clinical research protocols are included?

Participating protocols, their descriptions, and contact information are included on the COVID IDR [website](#).

If a specimen is shown in the IDR, can I request it?

The COVID IDR includes specimens collected, but this does not mean a sample is necessarily available. If you would like to obtain samples, note the protocol number and contact the Principal Investigator (PI) to determine if the samples are available and the process for sharing. The protocol numbers with PI name and contact information are available

on the COVID IDR [website](#).

What EHR data is available in COVID IDR?

A current data dictionary for the repository is available for download on the COVID IDR [website](#). We will be adding new data elements in the future, and the list of planned data elements and the timeframe for anticipated availability is also available on the website.

Can I download data?

Yes. Duke researchers with an IRB protocol determined exempt or approved can download de-identified data directly from the COVID IDR.

How do I request identified data from the COVID IDR?

1. Use the COVID IDR dashboard drill-down functionality to select a cohort of interest and save the query.
2. Use the COVID IDR data dictionary to determine the desired data elements you would like to receive as identified.
3. The Duke COVID-19 Shared Data and Specimen Repository (CSDSR) review committee must approve requests for data. Please visit the [CSDSR website](#) for more information and submit the [short-form proposal](#). If the review committee approves the request, a COVID IDR team member will contact you and let you know if there will be any costs involved for you to receive the data.
4. Submit a protocol application to the Duke IRB.
5. Create a PACE account to receive the data.
6. Provide a copy of the approved protocol application to the [COVID IDR team](#). A team member will execute the query, and an honest broker will verify the query matches the IRB approval and deposit the data in PACE.

What if I need additional data from MaestroCare that is not currently included in COVID IDR?

Review the current data dictionary on the COVID IDR [website](#). If the data elements are not listed, contact the [COVID IDR team](#) to let us know what you are looking for. We will determine if the data are included in an upcoming planned release. If they are not, we will connect you with the Duke Health [Analytics Center of Excellence](#).

How can I join the data from COVID IDR with other data sources, such as study-specific REDCap data? Users can download de-identified data and use your preferred analytics tools. Identified data will need to be downloaded into PACE and follow the processes for fully identified datasets.

Will I be charged for using the COVID IDR?

De-identified data: You will not be charged for using the COVID IDR dashboard and downloading de-identified data.

Identified data: The Duke School of Medicine allocated limited funding for the COVID IDR team to extract identified data and save to PACE. Contact the [COVID IDR team](#) with detailed information on your planned research to determine if there will be a charge for identified data extraction services.