How Can We Support Your Research Data Needs?

Eileen Antico and Helen Williams are a specialized team of Data Analysts within Nemours Research Administration, dedicated to supporting the needs of researchers and research projects. We work one on one to understand your data needs, gather requirements and determine the best process to retrieve and deliver information from Epic.

Research Requests Types and Examples

Research Projects that we can help with include but are not limited to the types listed below:

- Cohort population counts for study feasibility
- Statistics / Unique patient counts for grant applications
- Medical record information for retrospective reviews
- Custom data extracts for analysis
- Dashboard Development
- We can incorporate external data, from multiple formats and / or sources with Nemours patient data from Epic within a dashboard.

Big Research versus little research

It can be a challenge determining if Research Administration should complete a research data request. Determining factors include:

- The Office of Sponsored Projects is working with the Researcher on a specific Activity
- Data for potential study or grant which will be or is tied to revenue
- Medical Students or Fellows as an educational research requirement

Process Improvement and Turnaround Times

We handle several types of data requests. Through Continuous Process Improvement, training and leveraging previous work, we have positively affected our data delivery turnaround time.

- Requests for Unique Patient Counts for a grant application – we have shortened the turnaround time for completion from 2 weeks to 1-2 days. Minimal de-identified information compiled to determine if Nemours has sufficient population for proposed project.
- Our most common data requests, of medium complexity, used to take six weeks to complete. We have shortened delivery time to two weeks or less.
- Retrospective longitudinal studies with Case and Control Cohorts are our most complex requests. We have significantly shortened delivery time from six months to six weeks.

Longitudinal Retrospective Case and Control Cohort Studies

Advantages of using data obtained from the medical record include the ability to access large amounts of aggregated, clinical data, the ability to study associations between exposure and disease over long periods, and the ability to match case patients with control patients on up to 12 variables including:

- Age
- Gender
- Race
- Ethnicity

- Location
- # of years of data in the system
- Minimum # of appointments
- Minimum number of times diagnosed
- Insured vs not insured
- BMIPC / BMIZ
- Gestational Age
- Patient Status

An example of this type of request along with the de identified data set can be found on TeamShare Research Home > Conference Resources / Presentations > NOHSP Webinar Using Clinical Data in Research - Documents

Please note: It is common for a request to have several iterations/re-querying after the Researcher reviews the data set. Often times, Researchers like to build upon the first set of data by requesting additional information. We will happily provide this information if it is a derived field from IRB approved fields or the IRB has approved the receipt of the additional fields.

IRB Approval VS No Approval or Not yet Approved Data Collection

We are unable to provide ePHI prior to receiving a copy of the IRB approval letter and which data fields are approved for your project. In the case of preparatory to research you may receive ePHI in order to complete a chart audit to determine if you have a sufficient population to move forward with an IRB approval request. This initial dataset cannot be used for an IRB approved project.

IRB Approved Studies:

Once the requestor receives and provides a copy of the IRB approval letter, research provides the patient identifiable data (ePHI), as requested.

- Determining your patient population
  - Date range (specify dates)
  - Diagnosis (ICD9/10), Procedures (CPT4), Testing (lab, radiology.)
  - Medication (level of granularity)
  - Does the patient need to have a specific number of encounters during a time frame
- Restrictions/Exclusions to apply
  - Age (at what time – current or at time of diagnosis, procedure)
  - Race, ethnicity
  - Deceased patients
  - Site, Location and/or department
  - Previous history of diagnosis, test…
- What data fields are needed (minimum necessary)
  - Demographic, Anthropometrics,
  - Dates of service (all or first and last)
- First time diagnosed with problem
  - We are limited to our medical records and patient could have been seen elsewhere previously and diagnosed
  - Does the patient need to have been diagnosed within the date range or merely seen during the data date range?
- Be specific when requesting diagnosis, procedure, lab test by providing codes (ICD, CPT)

- We are able to scan the progress note for specific phrases, but this does take additional time (minimum of 2 additional weeks)
- Do you need case and control sets of patients?

Process - How to Submit a MyTech Ticket to Research – It Takes Less Than 5 Minutes!

1. All requests for data must have a MyTech ticket submitted. When entering your MyTech ticket be sure to indicate "**Yes**" to question "**Is this process related to research, A3 or CI Envent?**" in order for your request to be transferred into our work queue.
2. If data request is an urgent nature due to grant submission timeline, please provide detailed requirements and deadline date.

The information below will help you submit a MyTech Ticket to Research Team.

Quick Steps:

1) Navigate to the Nemours Home Page.
2) Click on "**My Tech**".
3) Click on "**Product & Services**".
4) Click on "**Enterprise Solutions**".
5) Click on "**I want a data extract/import**" then click on "**Enter Details**"
6) Check the "**HIPPA**" acknowledgement.
7) From the **"I want"** pick list, select what most accurately reflects the service you require. In the "**value statement**" box enter "Attn: Research department" and then your value statement. In the **"Description"** box, enter as much detail as possible to clarify your request.
8) Complete the Query request or Data Preparatory to Research form and attach to your "MyTech" ticket.
    - If your data request is for an IRB approved study, you must attach the approval letter to your "MyTech" ticket.
9) When finished, select the 

icon.
10) If you are submitting this request for another person, specify the individual in the **"Requested for"** box. If there are any additional details, please document in the **"Special Instructions"** box and attach required forms. When finished, select the 

icon.

If you have any questions, please contact us. We look forward to working with you.

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