Discover Data@Duke Clinical Data Assets and Tools

The ACT Network is a nationwide federation of leading academic research institutions that share aggregate patient counts from electronic health record data. i2b2, the tool that allows you to query ACT, is a simple drag-and-drop interface that allows Duke researchers to create queries for EHR clinical information maintained at Duke (i2b2) and across the consortium of Clinical and Translational Science Awardee institutions. The ACT Network is a real-time platform that allows researchers to explore and validate feasibility for studies across the CTSA consortium, all from the comfort of your desktop. ACT currently contains over 125 million patient records, and by the end of 2019 will include ~90% of the CTSA consortium.

At Duke, you have two options for using ACT to obtain aggregate counts:
- Use ACT Local via i2b2 to query only Duke EHR data
- Use ACT National via SHRINE to query EHR data from all participating ACT sites

If you
- Are a clinical investigator[5]
- Have some "big-picture" EHR data needs
- Are doing translational or mechanistic studies
- Are thinking about a single site or multi-site study
- Are interested in exploring patient cohorts/research questions
- Designing a study and need to analyze feasibility
- Seeking funding and IRB approval
- Looking for/forming collaborations

And you don't need to:
- Search directly through the text of medical records[6]
- Access identifiable data

ACT Network Use Cases (for multi-site research):

Dr. Hu is considering applying for a grant that studies the effect of a newly released medication meant to help patients with cognitive disorders. Since the medication is new, Dr. Hu thinks it best to include a few other institutions in the study to increase the patient population. He needs a way to determine a list of institutions to contact who could provide at least 50 patients who have taken the new medication in the past 6 months.

Dr. Washington is planning a multi-site clinical trial of a behavioral intervention for opioid use disorder in the Carolinas. He would like to identify sites that have a large prevalence of diverse individuals with this condition who have been treated with a morphine equivalent dose of 40 or higher the past 6 months.

Dr. Jay is working on a complex research proposal in which the grant application asks for a count of the local patient population with a specific diagnoses. Because the grant involves all the patients in North Carolina, Dr. Jay needs a way to count the number of potential research subjects not just at Duke, but throughout the state. Dr. Jay knows it will be tough to get patient counts for all patients in NC but wishes to capture as many as possible within the tight deadline.

Dr. Dolor is writing a proposal to conduct a multi-center study of chronic low back pain. She is interested in collaborating with 3 other institutions in different regions to have representation across the US. She would like to assess how many patients are potentially eligible for the study (along with demographic characteristics) at other institutions in other regions prior to contacting potential collaborators to determine the feasibility of recruitment.

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[5] For public health /outcomes researchers, ACT may not be the best tool as the data are not risk-adjusted and, currently, public, comparative reporting of query results is not supported by the ACT data use agreement

[6] ACT uses a limited data set and does not currently index text from medical records