

# Center for Clinical Data Analysis (CCDA)

# **ROLE OF OFFICE**

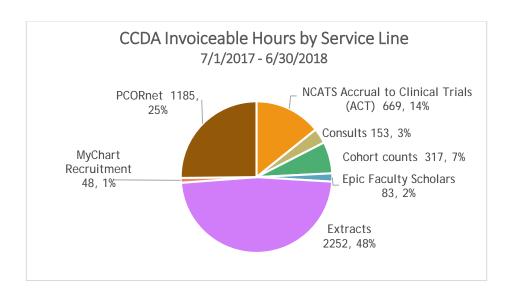
The Center for Clinical Data Analysis (CCDA) assists researchers with access to clinical data. The CCDA works closely with the Data Trust Research Sub-council and the IRB, serving as an institutional honest broker. Our services include providing:

- 1. Preliminary, anonymous data for feasibility, grant applications, and estimating sample sizes
- 2. IRB-approved case-finding for study enrollment, chart review, and cohort/case-control studies
- 3. One-time and ongoing periodic data extracts
- 4. Natural Language Processing to analyze text documents and extract data from the text
- 5. Data de-identification services
- 6. Assistance using self-service tools such as Epic's SlicerDicer
- 7. Specialized study data collection services such as i2b2, and interfaces to REDCap
- 8. SAFE Desktop, a secure data analytic environment

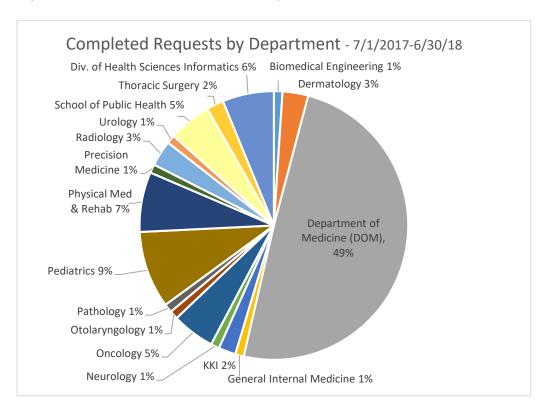
The CCDA is led by Diana Gumas (Director of Operations), Bonnie Woods (Sr. Manager), and Dr. David Thiemann (Medical Director).

### PERFORMANCE IN THE PAST YEAR

In the past year, CCDA had 233 contacts with research teams, up 25% from the prior year. 34% of the requests were fully funded by the two free hours underwritten by the ICTR, 45% required the research teams to provide some payment for the service, and the remaining 21% of the work was provided to CCDA adjunct staff from a department or ICTR staff. For projects that resulted in an invoice, the median hours to complete a project were 30 hours with a range of 1-280 hours. The following graph depicts invoiceable work by service line.



The graph below illustrates the JHM academic departments served by the CCDA core team between July 1, 2017 and June 30, 2018. This graph does not include work done by our CCDA adjunct staff members on behalf of their department.



CCDA received 26 responses to our customer satisfaction survey between July 2017 and June 2018 compared with 15 responses last fiscal year. We continue to focus on improving turnaround time.

- 96% were very satisfied or somewhat satisfied with the promptness of the services.
  - (100 % last fiscal year)
- 97% were very satisfied or somewhat satisfied with the **quality** of the services. (100% last fiscal year)
- 100% were very satisfied or somewhat satisfied with CCDA's ability to meet their needs.
  - (unchanged from last fiscal year)
- 100% were very satisfied or somewhat satisfied with the CCDA's commitment to helping them achieve their goals.
   (unchanged from last fiscal year)
- 100% were very satisfied or somewhat satisfied with the way CCDA communicated with them.
  - (unchanged from last fiscal year)
- 88% were very satisfied or somewhat satisfied with the value for the cost CCDA services.
  - (87% last fiscal year)
- 100% were very satisfied or somewhat satisfied with overall service with the CCDA.
  - (unchanged from last fiscal year)
- 84% thought the turnaround time was shorter or about what they expected.
   (93% last fiscal year)

The CCDA Adjunct program continued to grow, adding 5 additional adjuncts for a total of 15 CCDA adjuncts. Our adjunct analysts are from Cardiac Surgery, the Armstrong Institute Center for Diagnostic Excellence, the Cancer Center, ACCM, Psychiatry, Ophthalmology, Division of Health Sciences Informatics (DHSI), Department of Medicine, the Emergency Department, Computer Science, and the BEAD Core. This popular program helps qualified and trained data analysts extract research data on behalf of their Department or Division.

As of July 2018, the SAFE Desktop has been provisioned to 1,838 users, up from about 500 users one year ago.

# CHANGES IN THE PAST YEAR

The SAFE Desktop continues to be a very popular, free service. In late Summer of 2017 we made substantial improvements to the SAFE desktop, including introducing an automated request form to more quickly provision new SAFE desktops, as well as increasing SAFE storage. To learn more, visit https://ictr.johnshopkins.edu/programs\_resources/programs-resources/informatics/secure-research-data-desktop/

In early 2018, the CCDA launched a new service to extract data from text notes using Natural Language Processing (NLP) techniques, hiring a dedicated expert analyst for the service. In conjunction with the Department of Computer Science and the Applied Physics Lab, we formed a new Center for Clinical Natural Language Processing (C2NLP) to share best practices and keep current with the latest tools and techniques.

CCDA began providing services for new national clinical research initiatives, including the NCATS Accrual to Clinical Trials (ACT), the NIH Trial Innovation Network (TIN), and the Johns Hopkins-Tufts Trial Innovation Center (TIC).

CCDA began working closely with the Precision Medicine Platform Virtual Center of Excellence to develop tools and strategies for data provisioning using the future Precision Medicine Analytic Platform (PMAP).

### NEW DEVELOPMENTS FOR THE UPCOMING YEAR

CCDA has been awarded \$25K in Core Coins which are expected to become available by the end of July 2018. Half of the award will be used to provide unfunded Junior Investigators with preliminary, anonymous data for feasibility assessment and grant applications. Junior Investigators will be required to submit a proposal along with a letter of support. The remaining funds will be used to expand the capabilities of our new Natural Language Processing (NLP) service.

CCDA is actively working to streamline access to data. In the Fall of 2018, we anticipate going live with TriNetX, a new data exploration tool fed by data from our Epic system with advanced features for data visualization and trending. TriNetX will also facilitate new opportunities for industry-sponsored clinical trials. Additionally, the CCDA has been working with the IRB and Data Trust Council to develop a new Risk Tier structure to remove unnecessary barriers and streamline approvals, which we expect to be implemented by early 2019.

In September – December of 2018, CCDA leaders will serve as faculty for the Precision Medicine CAMP training program. CCDA will provide new services using the Precision Medicine Analytics Platform when it goes live in early 2019.

CCDA will work with IT@JH and the ICTR Research Data Collection and Storage Service (RDCS) to build an infrastructure that will help researchers comply with the recently released guidance and technical requirements for registries.

http://hpo.johnshopkins.edu/enterprise/policies/268/34187/policy\_34187.pdf? =0.831395567

CCDA is planning to launch a new Clinical Research Informatics Consult Service to better assist investigators with up-front guidance on the data aspects of their protocols. Look for an announcement in August 2018 for research teams that want to pilot the process with CCDA.

CCDA will be improving our outreach to faculty through improvements to our ICTR website, including providing text for researchers to use in grants, posting short descriptive videos of tools and services, and publishing informational sheets with example projects and their associated time and cost.

In order to improve turnaround time and promptness, we would like to hire a project leader to assist our CCDA manager.

# INCORPORATION OF SERVICES INTO GRANT APPLICATION

The CCDA encourages researchers to contact us at least a few weeks ahead of grant submission so that we may provide you with data that you need for your grant, including feasibility counts and cost estimates for service. The ICTR provides 2 complimentary hours of service to each faculty to underwrite this activity.

# **BEST WAY TO WORK WITH PROGRAM**

To learn more about how the CCDA can support your research, visit our website at:

<a href="https://ictr.johnshopkins.edu/programs">https://ictr.johnshopkins.edu/programs</a> resources/programs-resources/informatics/center-for-clinical-data-analysis-ccda/</a>

To request services, submit a request using the iLab portal (https://johnshopkins.corefacilities.org/service\_center/3796)

The CCDA manager will contact you within two business days to schedule a brief intake meeting to discuss your specific requirements.