

## **CORE FOR CLINICAL RESEARCH DATA ACQUISITION (CCDA)**

### **ROLE OF OFFICE**

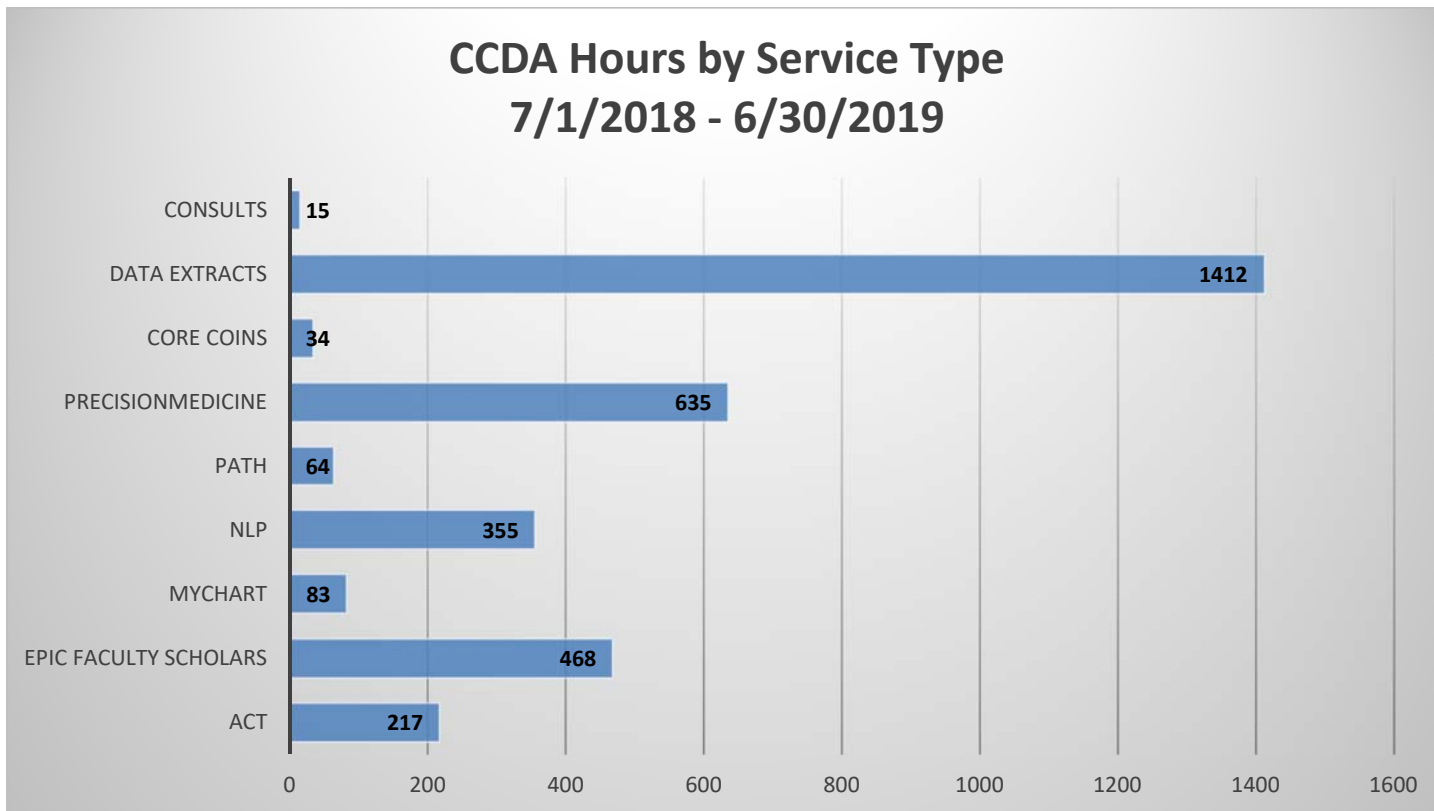
The Core for Clinical Research Data Acquisition (CCDA) assists researchers with access to clinical data. The CCDA works closely with the Data Trust Research Sub-council and the IRB, serving as an institutional honest broker. Our services include providing:

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, including review of de-identification methods to comply with HIPAA guidelines.
6. Assistance using self-service tools such as Epic's SlicerDicer and TriNetX
7. Specialized study data collection services such as i2b2, and interfaces to REDCap
8. SAFE Desktop, a secure data analytic environment
9. Honest broker services

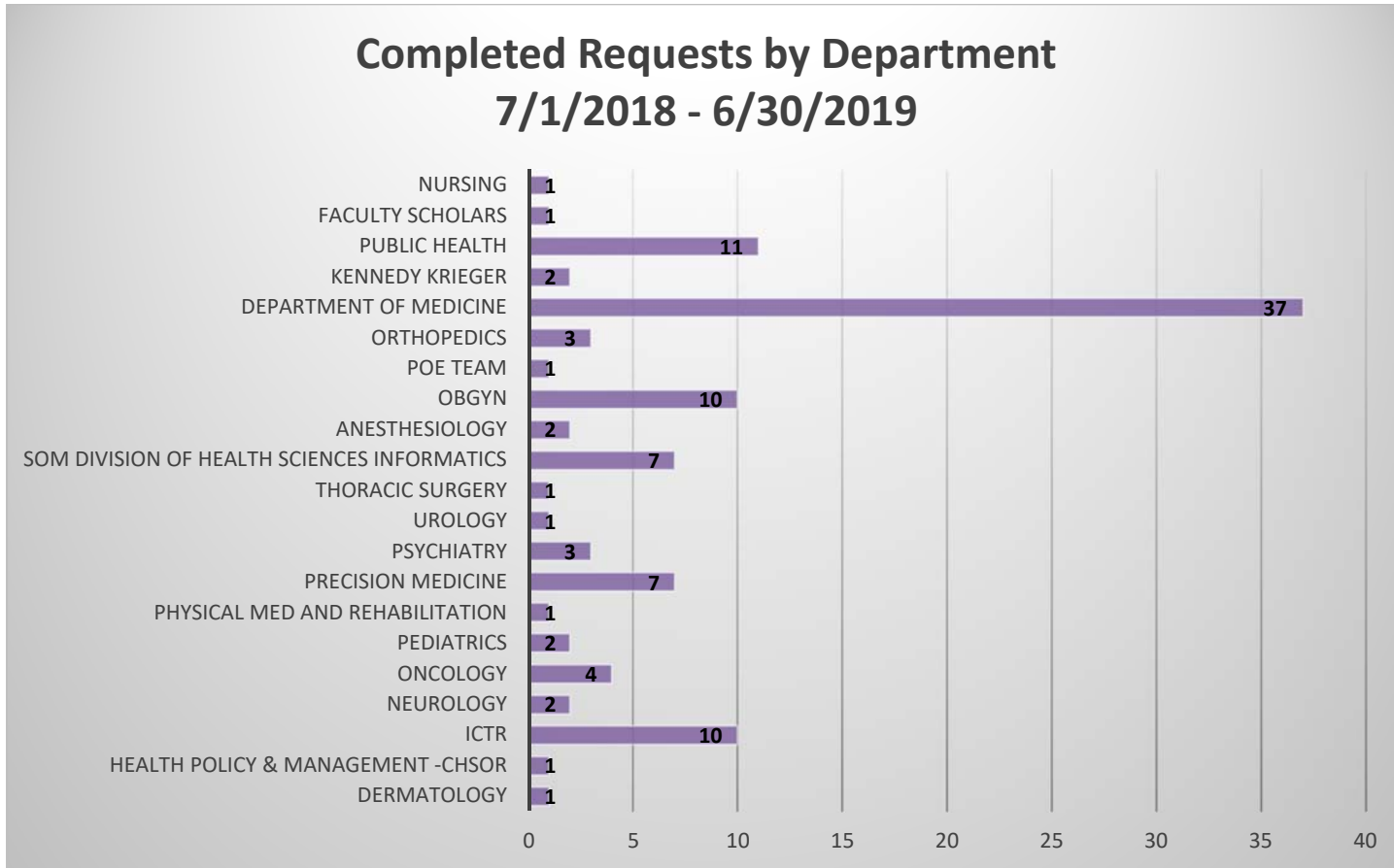
The CCDA is led by Diana Gumas (Director of Operations), Bonnie Woods (Sr. Manager), Dr. David Thiemann (Medical Director), and Maithilee Mitra (Project Manager).

## PERFORMANCE IN THE PAST YEAR

In the past year, CCDA had 237 contacts with research teams, up 2% from the prior year. 17% 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 13% of the work was provided to CCDA adjunct staff from a department or ICTR staff. For projects that resulted in an invoice, the average hours to complete a project were 43 hours with a range of 1.9-334 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, 2018 and 6/30/2019. This graph does not include work done by our CCDA adjunct staff members on behalf of their department.



## CUSTOMER SATISFACTION

CCDA received 22 responses to our customer satisfaction survey between 7/2018 and 6/30/2019 compared with 26 responses last fiscal year. We continue to focus on improving turnaround time.

- 95% were very satisfied or somewhat satisfied with the **promptness** of the services. (96 % last fiscal year)
- 100% were very satisfied or somewhat satisfied with the **quality** of the services. (97% 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)
- 95% were very satisfied or somewhat satisfied with the **value** for the cost CCDA services. (88% last fiscal year)
- 95% were very satisfied or somewhat satisfied with **overall** service with the CCDA. (100% last fiscal year)
- 68% thought the **turnaround time** was shorter or about what they expected. (84% last fiscal year)

## ADJUNCT TEAM MEMBERSHIP

The CCDA Adjunct program continued to grow, adding 1 additional adjunct for a total of 16 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, the BEAD Core, and Department of Hospital Epidemiology and Infection Control (HEIC). This popular program helps qualified and trained data analysts extract research data on behalf of their Department or Division.

## SAFE VIRTUAL DESKTOP

As of July 2019, the SAFE Desktop has been provisioned to 3,250 users, up from about 1,800 users one year ago.

The SAFE Desktop continues to be a very popular, free service. The Precision Medicine Analytic Platform (PMAP), the IRB Office, and the Data Trust Research Subcouncil have required that researchers utilize the SAFE desktop and its storage capabilities to share and analyze patient protected health information. The Technology Innovation Center (TIC) hired an assistant product manager to serve as the liaison between the SAFE desktop user community and the IT@JH technical teams to provide continued user support, facilitate outreach, and implement improvements to the SAFE desktop environment, including new applications and performance-tuning.

## NATURAL LANGUAGE PROCESSING (NLP)

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 Whiting School of Engineering's 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. Since January of 2018, the CCDA has received 27 requests for NLP services. The average hours to complete a project were 60 hours with a range of 2-280 hours.

#### PARTICIPATION IN MULTI-SITE RESEARCH NETWORKS

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). The CCDA completed eight TIC/TIN network query requests, ranging in time from 2 to 27 hours. A total of 200 hours was spent supporting ACT, and 80% of an FTE was spent supporting clinical research for the Patient-Centered Clinical Research Network (PCORNet).

#### TRINETX FOR PATIENT COHORT DISCOVERY

Using the ACT database as the data source, the CCDA worked with the TriNetX Corporation to provide a self-service, advanced analytics platform for researchers to obtain feasibility counts for their desired patient populations. TriNetX was brought online in January of 2019, and currently, 183 users have been granted access after completing training. Training sessions are offered monthly. Users access TriNetX using their Johns Hopkins ID.

#### PRECISION MEDICINE

CCDA began working closely with the Precision Medicine Platform Virtual Center of Excellence to develop tools and strategies for data provisioning using the Precision Medicine Analytic Platform (PMAP). Activities include: development of training materials for adjunct staff and research study team members; project management oversight, updating of metadata, and usability and design feedback for the PMAP data catalog; testing and building database projections; participating in PMAP teams to with APL, IT@JH, and the PMAP infrastructure team; co-leading the CAMP program for researchers interested in PMAP; and collaboration with the IRB Office and Data Trust Research Subcouncil to create PMAP-specific study protocols that minimize data security risk and comply with data management best practices and HIPAA regulations.

#### SCHOOL OF MEDICINE SUPPORTED RESEARCH

This year, the CCDA provided data extraction services and feasibility counts for 24 Epic Faculty Scholars, awardees of the first- and second-year School of Medicine award that funds data acquisition, storage, and analysis services as well as statistical and manuscript support to the grantees from the funds allocated.

The CCDA also supported 14 study teams who were awarded Core Coins, a funding mechanism designed to encourage investigators to access core services and facilities. Eight study teams received feasibility support, and six teams received Natural Language Processing (NLP) support.

The CCDA was able to hire a project manager to support EFSP, Core Coins, and PMAP projects. The position has been partially funded by these programs, as well as from study teams requesting CCDA services. This project manager is improving our ability to more quickly respond to requests.

The CCDA collaborated with the REDCap team to complete three Epic-to-REDCap integration projects. Two additional Epic-to-REDCap projects are currently underway for PMAP, with others expected over the upcoming year.

## **NEW DEVELOPMENTS IN THE UPCOMING YEAR**

As the Precision Medicine Analytics Platform evolves, the CCDA will play an important role helping researchers to navigate the data available in PMAP, projecting data sets to researchers, and assisting with data de-identification and other data management services. Using our existing CCDA adjunct program as a model, we will continue to minimize what is required to be done by the central CCDA team, introducing additional training to expand access in a way that complies with Data Trust and IRB policies. This will include working with the PMAP Data Science Committee and the Technology Innovation Center to create training and certification programs to develop the skills of existing Johns Hopkins Data Managers so that they can work with projected data in the PMAP environment. With funding from PMAP we will hire a programmer analyst to increase capacity for PMAP data support. We will continue developing NLP tools on the PMAP platform on both an enterprise-wide level and a study-specific level.

As part of our new CTSA grant, CCDA will work with the University of Maryland and the Johns Hopkins Clinical Research Data Network to increase use of TriNetX and to provide technical support and guidance for cross-institutional research data initiatives.

As Johns Hopkins All Children's Hospital prepares to implement Epic in the Fall of 2020, the CCDA will work with All Children's Research IT leadership on a plan for the support of their Epic research data needs.

Finally, the CCDA continues to focus on improvements to streamline operations in order to reduce the time and cost required to deliver operational data to the research community.

## **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 THE PROGRAM**

To learn more about how the CCDA can support your research, visit our website at:  
<https://ictr.johnshopkins.edu/CCDA>

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