



## RESEARCH DATA COLLECTION AND STORAGE (RDCS) SERVICE

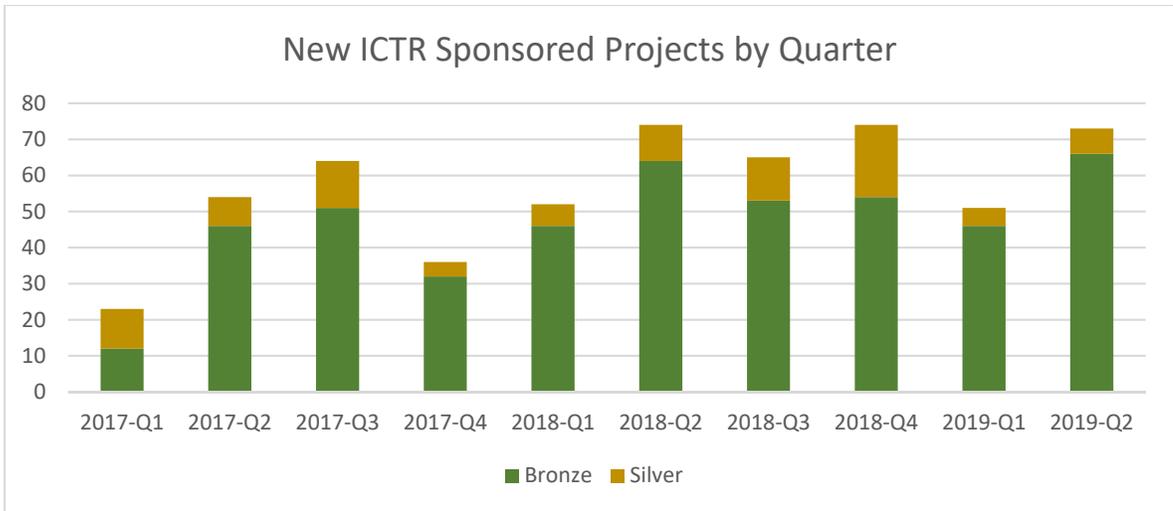
### ROLE OF OFFICE

The Research Data Collection and Storage (RDCS) service (<https://ictr.johnshopkins.edu/rdcs>) assists researchers with secure solutions for data collection beyond the use of Epic. The most commonly provided service is REDCap ([https://ictr.johnshopkins.edu/programs\\_resources/programs-resources/informatics/redcap/](https://ictr.johnshopkins.edu/programs_resources/programs-resources/informatics/redcap/)). RDCS can also assist investigators with other services including:

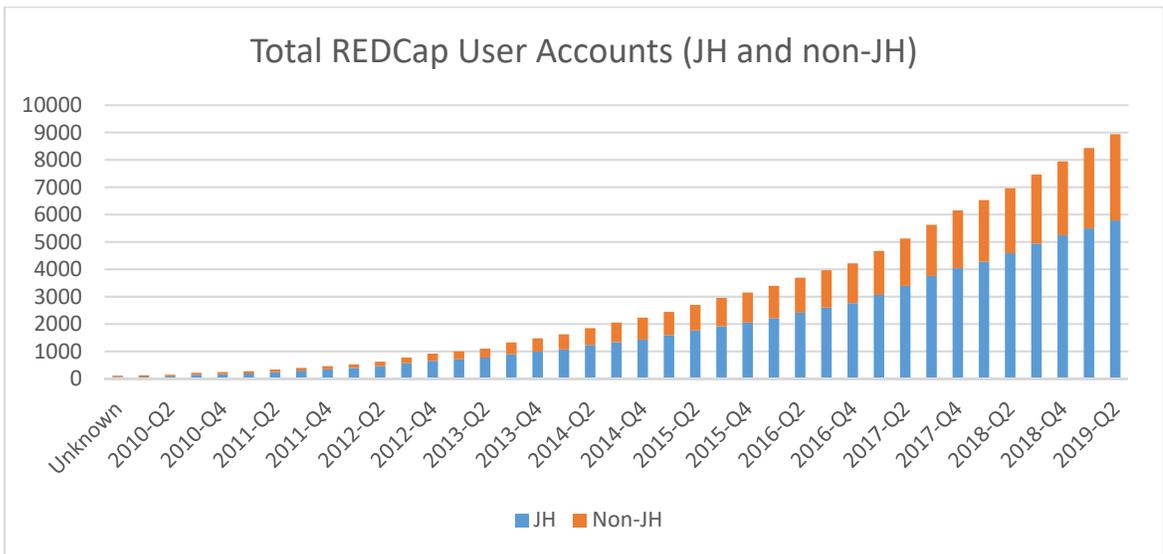
1. Setting up and maintaining secure SQL Server databases which comply with Data Trust guidelines for clinical research registries.
2. Migration of existing MS Access databases or Excel spreadsheets to more secure solutions.
3. Secure non-REDCap questionnaire solutions, such as our Johns Hopkins School of Medicine Qualtrics application
4. Advice on database construction, design, and remote access.
5. Specialized interfaces to collect data from research instruments.

### PERFORMANCE IN THE PAST YEAR

Between July 2018 and June 2019, RDCS created 317 new REDCap projects, with 78% of those databases at the free Bronze level. During the past year we improved our free Bronze REDCap service along with advanced services at the Silver and Gold levels: [http://redcap.jhu.edu/NewREDCapModel\\_20170104a.htm](http://redcap.jhu.edu/NewREDCapModel_20170104a.htm).



As of June 2018, there were 8,937 REDCap users, up from 6,961 users the prior year. REDCap has become the “go-to” tool for projects working with multiple institutions. Multi-site research continues to grow the number of non-Johns Hopkins users.



## CHANGES IN THE PAST YEAR

### IMPROVED SUPPORT SERVICES

We offered 23 free REDCap Walk-In Clinic sessions throughout the year, with 128 user sign-ups. Registration is required, and sessions are limited to 8 users to allow time to answer everyone’s questions. Emails are sent to active REDCap Bronze users monthly announcing upcoming

sessions. This upcoming year, we will send a survey to each attendee following the session to gauge satisfaction with the session's format and content.

Based on common questions received via customer support emails, the team developed sample REDCap projects to demonstrate various REDCap functionality and created a "Getting Started with REDCap" user guide, available on the REDCap web site:

<http://redcap.jhu.edu/GettingStartedWithJHREDCap.pdf>.

## **CUSTOMER SATISFACTION SURVEY**

We developed and distributed a new customer satisfaction survey to assess our current performance and help us identify areas in which we could improve our services.

Thank you to the 757 research team members who completed the questionnaire. We were pleased with the overall level of satisfaction. Overall 86% were very likely or likely to recommend use of REDCap to their colleagues. Respondents reported that ease of use was what they liked most about REDCap particularly the prompts, drop-down menus, double-data entry system and calendar mode.

When asked how REDCap service could be improved better support, guidance and training on the use of REDCap was mentioned by 15%, making REDCap more intuitive was mentioned by 7%, and having a better interface by 6%. We also appreciated learning more about some specific improvements that were suggested.

Based on suggestions, we have developed several short, topic-focused videos ("REDCap Minutes") that are tailored specifically to study teams' questions. This year, we will create a suite of short videos to serve a general audience and will post these videos to the REDCap web site.

## **EPIC INTEGRATION**

REDCap users often must review patient charts in Epic, particularly unstructured clinic notes, in order to enter their findings in REDCap. We developed a proof-of-concept to demonstrate a new feature to display Epic notes from within REDCap. This feature includes dynamic keyword searching of EPIC clinic notes containing those keywords. This feature is set to go live in September 2019 and will greatly help projects that are heavily dependent on research data abstraction from Epic notes.

Additionally, we worked closely with the Core for Clinical Research Data Acquisition (CCDA) on three custom projects to automate the extraction of discrete data points from Epic into REDCap research projects. These efforts aim to increase accuracy and decrease data abstraction times.

Data migrations are in progress for the Scleroderma and Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) Precision Medicine Centers of Excellence. The projects involve the migration of disparate datasets into integrated REDCap projects that will serve as the source of each PMCOE's research registry and will then be ingested into the PMAP environment for the purposes of longitudinal data analysis and clinical decision support.

## **NEW DEVELOPMENTS FOR THE UPCOMING YEAR**

### **DATA SECURITY**

To improve data security and access to Johns Hopkins protected health information, RDCS will separate internal Johns Hopkins REDCap projects from projects that require external users to have access. In September, we will implement a second REDCap instance that will be used for internal projects. This new instance will use JH enterprise authentication and will be the required platform for large registries and QI projects. The original REDCap instance will be used for collaborative projects requiring access by other users from outside of JH.

### **FACULTY OUTREACH**

RDCS will improve our outreach to faculty through enhancements to our ICTR website, including providing text for researchers to incorporate into grant proposals, posting short descriptive videos of tools and services, and publishing informational sheets with example projects and their associated time and cost. We will develop a project-specific customer satisfaction survey that we distribute at the time we invoice for services to help us identify areas in which we can continuously improve our services.

Additionally, we will provide informational content about REDCap in a “Did you know?” section of the ICTR web site and will present at upcoming ICTR events where appropriate.

### **ENHANCED EPIC INTEGRATION**

RDCS is currently working with Precision Medicine Centers of Excellence to ingest unstructured narratives (laboratory and procedure test results) and parse the results into discrete data fields in REDCap. We have also consulted with Vanderbilt and the Epic Corporation to develop a plan to allow Epic users to enter and save REDCap data from within Epic Hyperspace. We expect to complete this project within the first three months of 2020, following the separation of REDCap into internal and external instances.

### **NON-REDCAP SERVICES**

This year, RDCS will develop custom tools using Microsoft SQL Server to better accommodate projects where REDCap is not a good fit. We will complete the retirement of Teleform scan forms and migrate this service to an external platform.

## **INCORPORATION OF SERVICES INTO GRANT APPLICATION**

RDCS encourages researchers to contact us at least a few weeks ahead of grant submission so that we may provide you with detailed information and budget estimates for any services. The ICTR provides two complimentary hours of service per faculty to underwrite this activity.

## **BEST WAY TO WORK WITH PROGRAM**

To learn more about RDCS and how to request a consultation, please visit our webpage on the ICTR website:

<https://ictr.johnshopkins.edu/RedCap>