



ARCUS

GROWTH AND IMPACT

FEBRUARY 2021









ARCUS

## SUMMARY

Arcus impacts research across nearly half of CHOP's Divisions. Research projects tripled to 86 from a year ago; half are collaborations across multiple Divisions. Patient Family Partners tell us education and transparency build trust in our stewardship of their data. Awareness is growing at CHOP and beyond with a 40% increase in search-driven traffic. Data sharing drives an increase in secondary research using existing data assets. Total technology costs are down by half for twice as many users year over year.

## ABOUT ARCUS

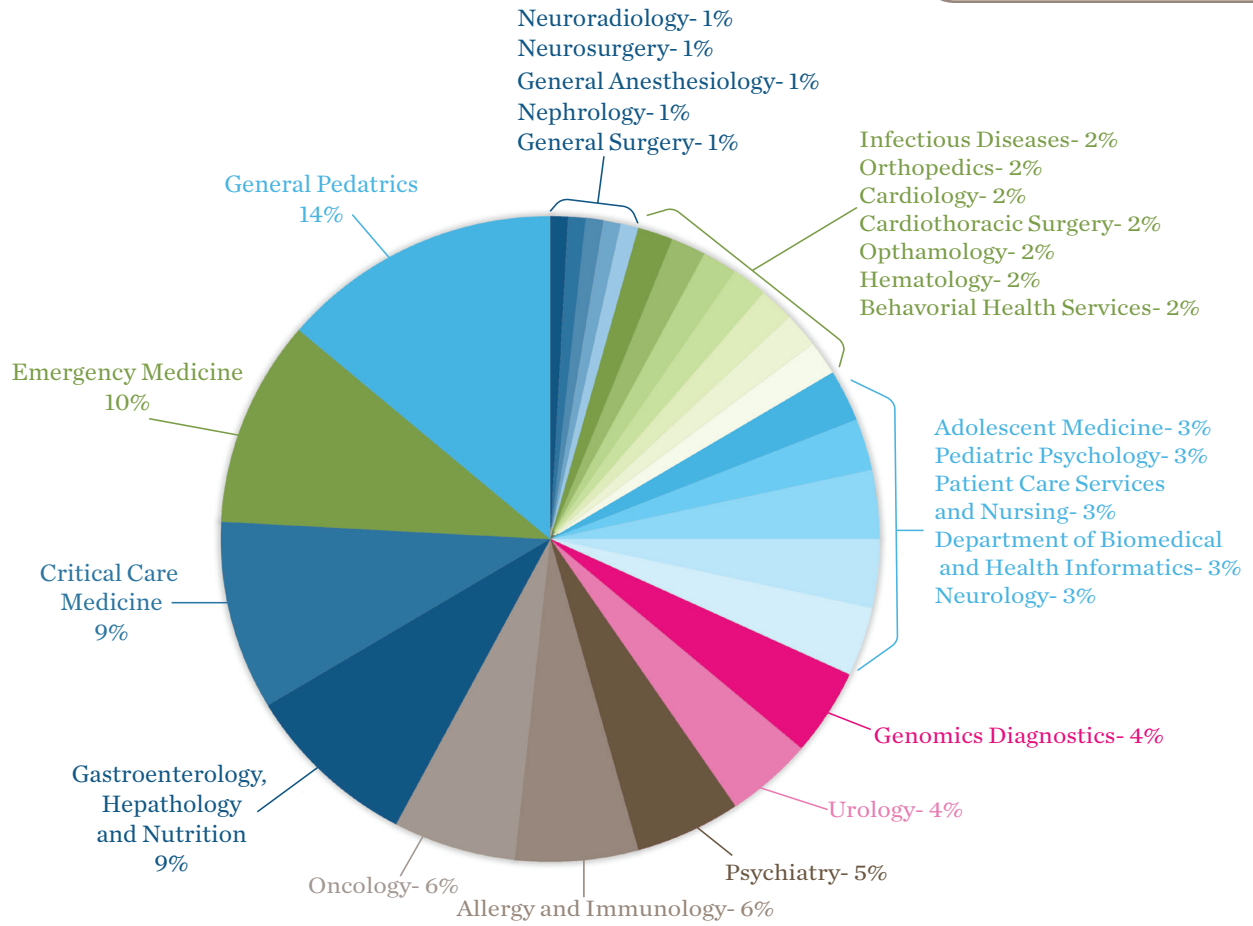
Arcus is an initiative by the Children's Hospital of Philadelphia (CHOP) Research Institute which aims to connect clinical and research data. We enable biomedical researchers to conduct highly innovative, data-driven, computationally complex, and reproducible research. We join researchers in collaborative endeavors that promote science and scientists and we stand at the forefront of new research practices boosting science that is transparent, ambitious, and nimble. Arcus was formed in 2017, launched pilots in 2018, transitioned to operations in 2019, scaled from 20 to over 80 projects in 2020.

 <b>2.1 Million</b> CHOP Patients & Research Participants	 <b>13,228,881</b> Files	 <b>792 TB</b> Size
 <b>52</b> Labs	 <b>85</b> Scientific Projects	 <b>27</b> Divisions

# NUMBER OF SCIENTIFIC PROJECTS PER DIVISION

**27** Total Divisions  
**85** Scientific Projects

**45%** of all CHOP divisions are now engaged in Arcus



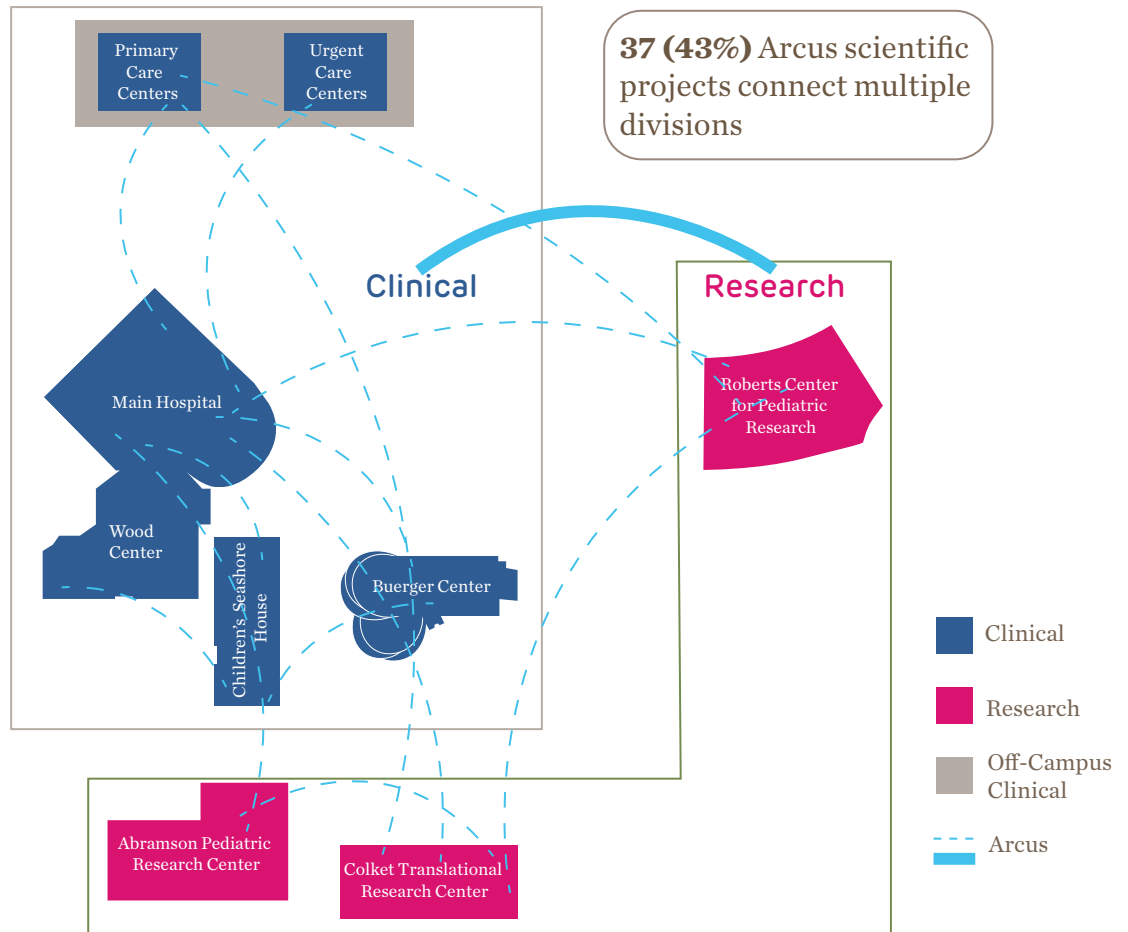
- Increase of **17** divisions and **60** projects since March 2020
- **6** projects completed
- **8** new Federal grants supported in 1st half FY21
- **4** Federal grants awarded of 9 supported in FY20



# ARCUS BUILDS BRIDGES

Arcus connects CHOP's clinical and research data and currently includes data from:  
**2.1 Million** CHOP individuals (patients and research participants)

Data contributions from research efforts include:  
**315,000+** participants having both clinical and research data  
**5600+** participants with both clinical and genomic data

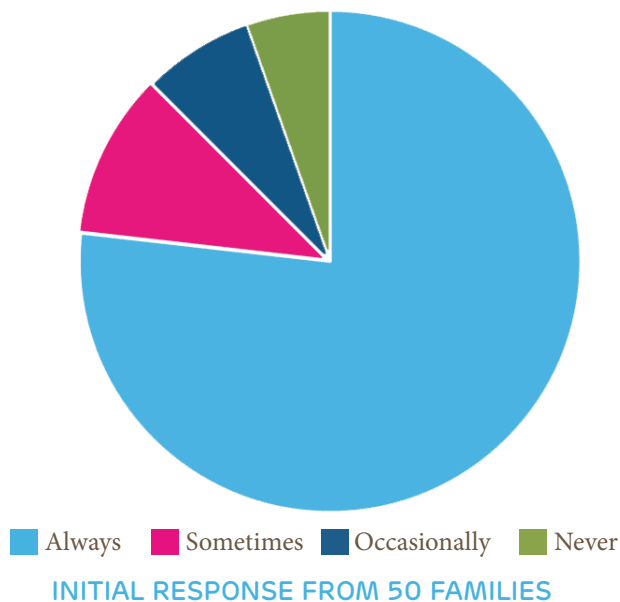


One novel collaboration generated by Arcus: “Dissecting the exposome’s role in suicidal behavior in youths presenting to CHOP ED” (LiBI and Emergency Medicine)

# PATIENT FAMILY: TRUST = EDUCATION + TRANSPARENCY

The patient and family voice is a guiding light for Arcus. Arcus Family Partners are a diverse group of 10 families with children cared for by CHOP. Arcus and the Family Partner teams are jointly surveying a larger group of CHOP patient families to understand parents knowledge and feelings about how their child's data are being used for research.

**If it were technically possible, how often would you like to know when you and/or your child's information has appeared in a dataset that includes their identifying information?**



“I hadn't given any of this any thought...I didn't realize my child's data was being used. I'm okay with it being used, however, I do feel that it belongs to me and a parent should be made aware and made to give consent for its use.”

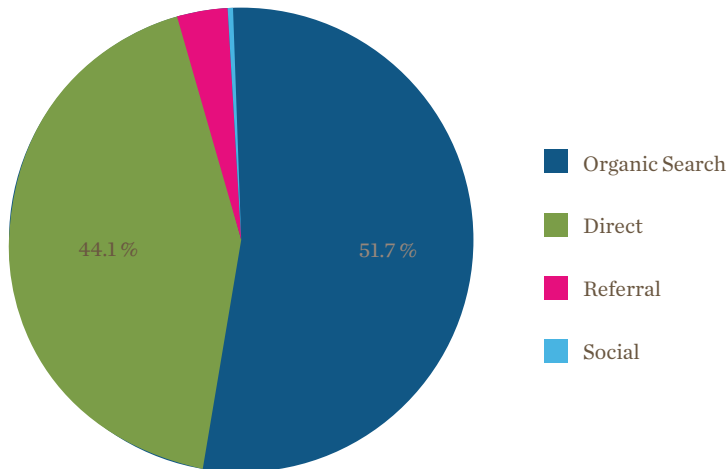
“With the advances in medicine, I'm always wary that information can be used for the betterment of our society as well as not for the betterment. Our medical community needs to aware of the mistrust that people of color have with sharing their medical information.”

“We've participated in many studies throughout our son's care and I learned a lot about how his information is used just via the questions in this survey. That concerns me, as I'm not sure patients and families understand how 'teaching hospitals' use data from points of care throughout the patient experience. It may be exciting for families to know how the data has made a positive impact on patient care, as well.”

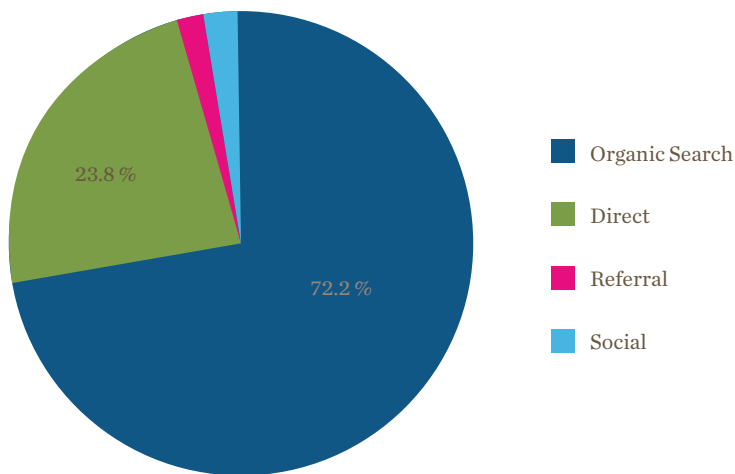
# ARCUS AWARENESS

## HOW USERS FIND THE ARCUS EDUCATION WEBSITE

### First Half of 2020



### Second Half of 2020



## ARCUS BIMONTHLY NEWSLETTER

- Distribution – 2,750 investigators and research Staff
- Vol. 1 – 8/2020 - 30 % open rate
- Vol. 2 – 10/20 – 35% open rate
- Vol. 3 – 12/20- 28% open rate
- Vol. 4 – Feb, 2021, to be released

## PUBLICATIONS

Rametta S, Fridinger S, Gonzalez A, Xian J, Galer P, Kaufman M, Prelack M, Sharif U, Fitzgerald M, Melamed S, Malcolm M, Kessler S, Stephenson D, Banwell B, Abend N, Helbig I. Analyzing 2,589 child neurology telehealth encounters necessitated by the COVID-19 pandemic. *Neurology*. 2020 Sep 01; 95(9):e1257-e1266

Weiss S, Balamuth F, Chilutti M, Ramos M, McBride P, Kelly N, Payton J, Fitzgerald J, Pennington J. Identification of pediatric sepsis for epidemiologic surveillance using electronic clinical data. *Pediatr Crit Care Med*. 2020 Feb 01; 21(2):113-121

Pennington J, Ruth B, Miller J, Peterson J, Xu B, Masion A, Krantz I, Maganella J, Gomes T, Stiles D, Kenna M, Hood L, Germiller J, Crenshaw EB. Perspective on the development of a large-scale clinical data repository for pediatric hearing research. *Ear Hear*. 2020 Apr 01; 41(2):231-238

# ARCUS DATA CONTRIBUTIONS

Data Contribution	Total Files	Total Linked CHOP Patients and Research Participants
Division of Genomic Diagnostics (DGD)	14,874	4,729
Dynamic Microbiome	18,207	276
EGRP Epilepsy Genetics Research Project	2,302	600
PECARN Medical Record Registry	209	306,773

Internal Data Sharing

## RESEARCH DATA MANAGEMENT CONSULTATIONS

Number of consults: **26**

Number of individual researchers/staff engaged via consults: **65**

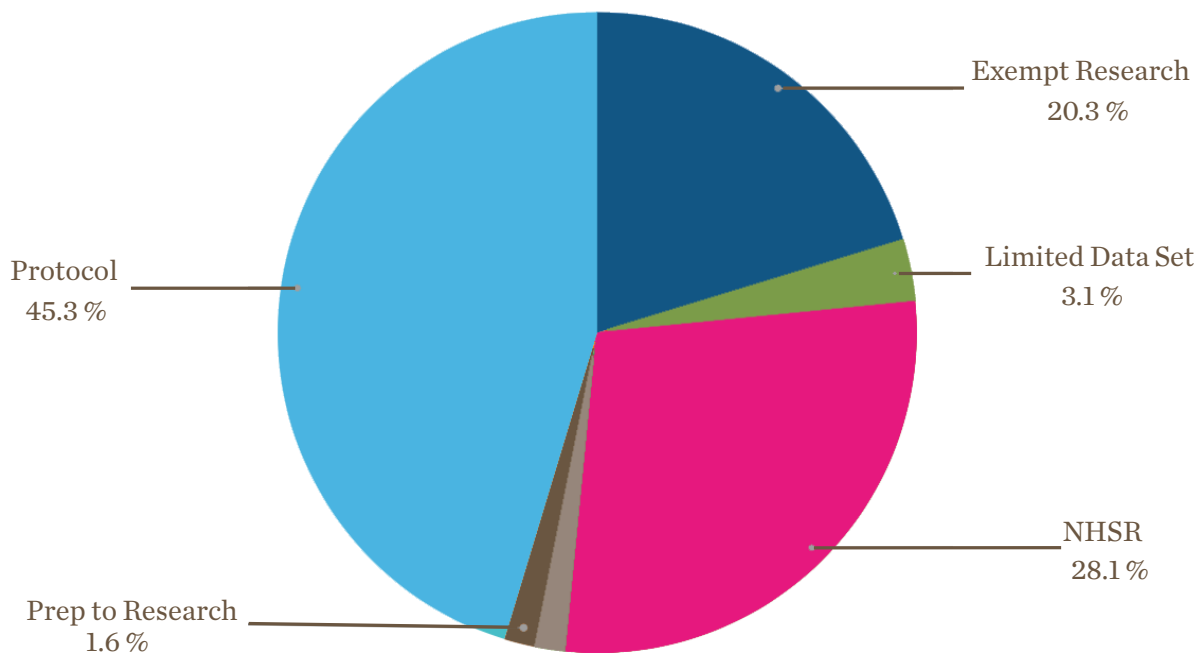
Number of resources providing expert data consultations: **8**

Expert Advice

Reference Cohort	Total Queryable CHOP Patients and Research Participants in Arcus Data Repository (ADR)
Healthy Participants	127,761
Primary Care Birth	608
Allergic Rhinitis	31,576
Asthma	35,556
Atopic Dermatitis	23,071
Food Allergy (Allergic March)	7,846
Sepsis	4,724
Suspected Bacterial Infection	16,483
Covid-19 Positive PCR Test	5,244
Covid-19 Positive Serology Test	63
Frontier PPIES Food Allergy	1,735
Frontier EOE Food Allergy	4,129
Frontier IgE Food Allergy	109,434

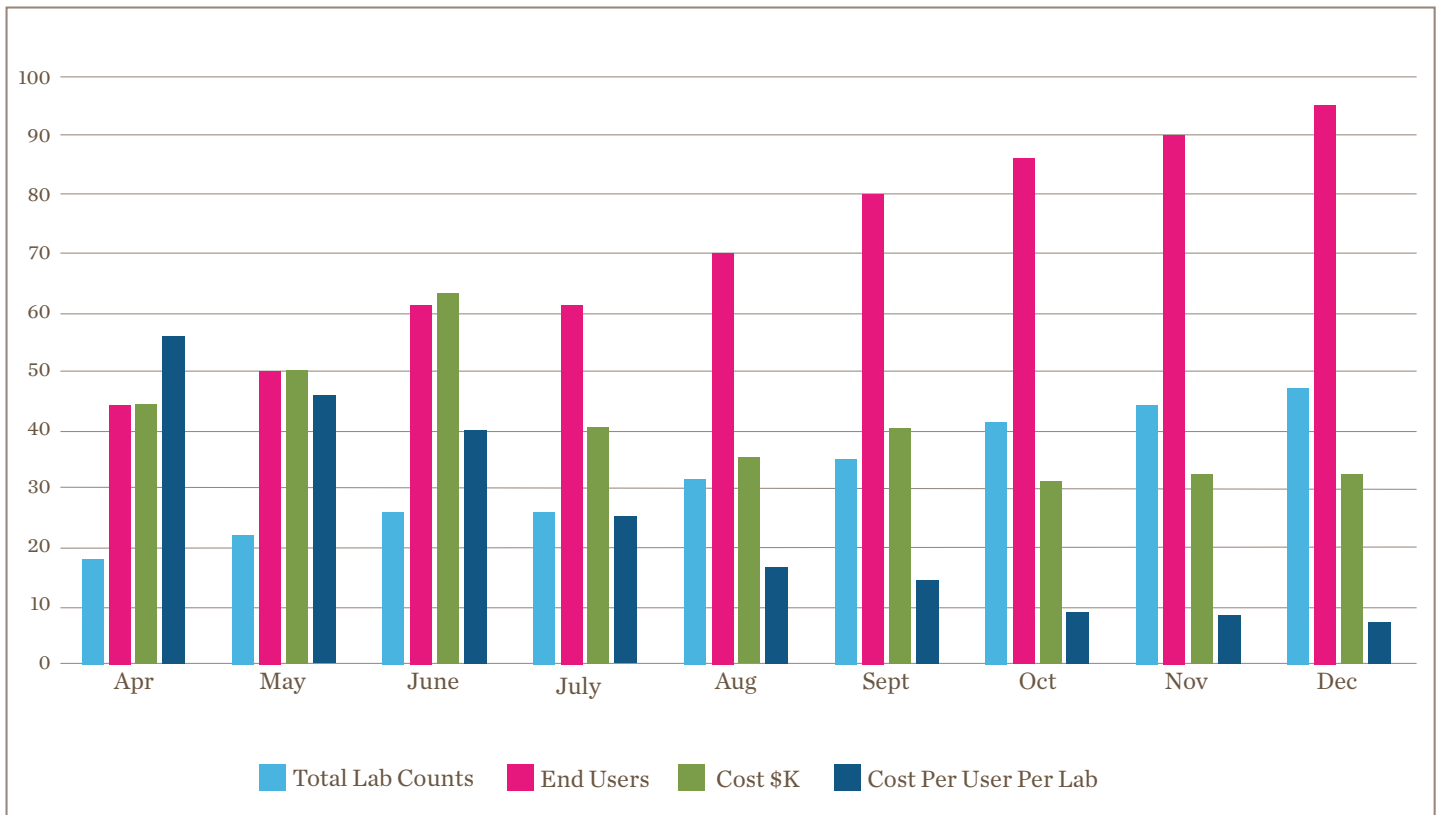
Sharing Computed Phenotypes

# SCIENTIFIC PROJECTS BY REGULATORY TYPE



**61** Primary Scientific Projects  
**24** Secondary Scientific Projects

# ARCUS MONTHLY SPENDING/LAB/USER



Per-user direct, variable cost **decreased over 500%**

Cut cloud cost in half while doubling number of users