Arbor Research Collaborative for Health

ANNUAL
REPORT
2021

Improving Patient Lives Through Research and Data Analysis

ArborResearch.org

ARBOR RESEARCH
COLLABORATIVE
FOR HEALTH

Arbor Research Collaborative for Health is committed to improving patient care through research that shapes medical policies and practice. Arbor Research conducts health outcomes research on chronic disease and end-stage organ failure, with expertise in biostatistical analysis, clinical practice, health economics, public policy, database management and integration, and project coordination. Through research projects national and global in scope, and a longstanding commitment to identify and address health inequities amenable to changes in policy or health care delivery, Arbor Research's scientific collaborations provide valuable and timely information to the worldwide health care community.

Dear Friends,

This year was unprecedented and challenging to everyone as the world dealt with the COVID-19 pandemic. The daily work of our dedicated staff at Arbor Research Collaborative for Health continued uninterrupted, even as our building was mostly vacated for over a year. Research was able to proceed from the relative safety of home, thanks to the flexibility of our team members and the dedication of our expert IT team. Existing projects were carried out, and new projects were started. We recruited, hired, and onboarded new staff remotely.

We are grateful to celebrate the accomplishments of the past year. We are proud to have added COVID-related contributions to our existing health care research portfolio; our findings were disseminated via workshops, webinars, expert research panels, and peer-reviewed publications. Leading experts were brought together to examine research initiatives specific to COVID-19 and the safety of dialysis during the pandemic.

Arbor Research's mission to conduct research supporting policy change and clinical practices that benefit patients continued. To achieve our mission in this most challenging of years, we maintained a firm commitment to our core values of dedication, credibility, innovation, and collaborative spirit.

The work outlined in this year's report is a testament to achieving success in light of many challenges faced every day, not just during a pandemic. We are truly proud to be part of this culture of excellence!

Robert M. Merion, MD, FACS,
President and CEO

Marianne Udow-Phillips, MHSA
Chair, Board of Directors

Extraordinary year.
Extraordinary employees.

Since 1997, Arbor Research Collaborative for Health has supported national and international research of chronic disease and end-stage organ failure to identify best practices for improving patient outcomes. Over the years, Arbor Research has constructed a solid base of expertise by collaborating with people around the world dedicated to exploring research that shapes policy and improves patients' experiences.

It is because of our dedicated and passionate staff that we enjoy a reputation of research integrity. There is a common set of core values among our staff that serves as our foundation. People have always been the heart of the code of ethics that Arbor Research embodies. These shared values unite us under the common goal of progress and fuel an unstoppable standard of excellence in even the toughest of years.

MISSION
AND VISION

For almost 25 years, Arbor Research Collaborative for Health has committed to improving patient care through research that informs medical policies and practice. Arbor Research was founded on strong core values that have made us leaders in health outcomes research with expertise in biostatistical analysis, clinical practice, health economics, public policy, project coordination, and database management and integration. It is because of this foundation that we provide valuable and timely information through scientific research collaborations, internationally and locally.

Our Core Values

Our core values represent what is expected of and important to our employees. We embody these values and demonstrate them in our work. These shared values unite us and promote our strong culture.

Expertise

The complexity and utility of the work we do helps attract and retain talented individuals who can fully apply their skills as they collaborate with talented colleagues on groundbreaking research.

Collaborative Spirit

Creativity

Credibility

Dedication

ArborLink
Electronic Data Collection

In December 2020, the Information Services department released a new version of the ArborLink Core. ArborLink was developed by Arbor Research as a highly configurable web-based electronic data collection (EDC) system, designed to support studies with enhanced needs for data quality validation, protocol guidance, integrated study management, and longitudinal tracking across patient timepoints and information sources.

"New features in ArborLink 4.1 include functionality to promote efficient collection and management of collected biosamples, as well as patient-reported outcomes and SMS-based feedback…" said Beth Kirschner, the Product Manager for ArborLink. "In addition, we are excited to be able to offer a tool with functionality and processes that are CFR 21 Part 11-compliant," Kirschner added, referring to requirements for data submitted to the US Food and Drug Administration (FDA) in the drug approval process.

2002

2020

ArborLink was launched as a data capture tool for use in Japanese dialysis facilities for the Dialysis Outcomes and Practice Patterns Study (DOPPS)
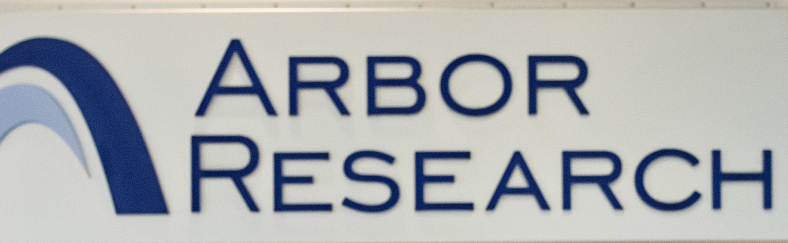
In the intervening years, Arbor Research Information Services has developed software offering invaluable context and insight and providing a product with value for every study it supports.
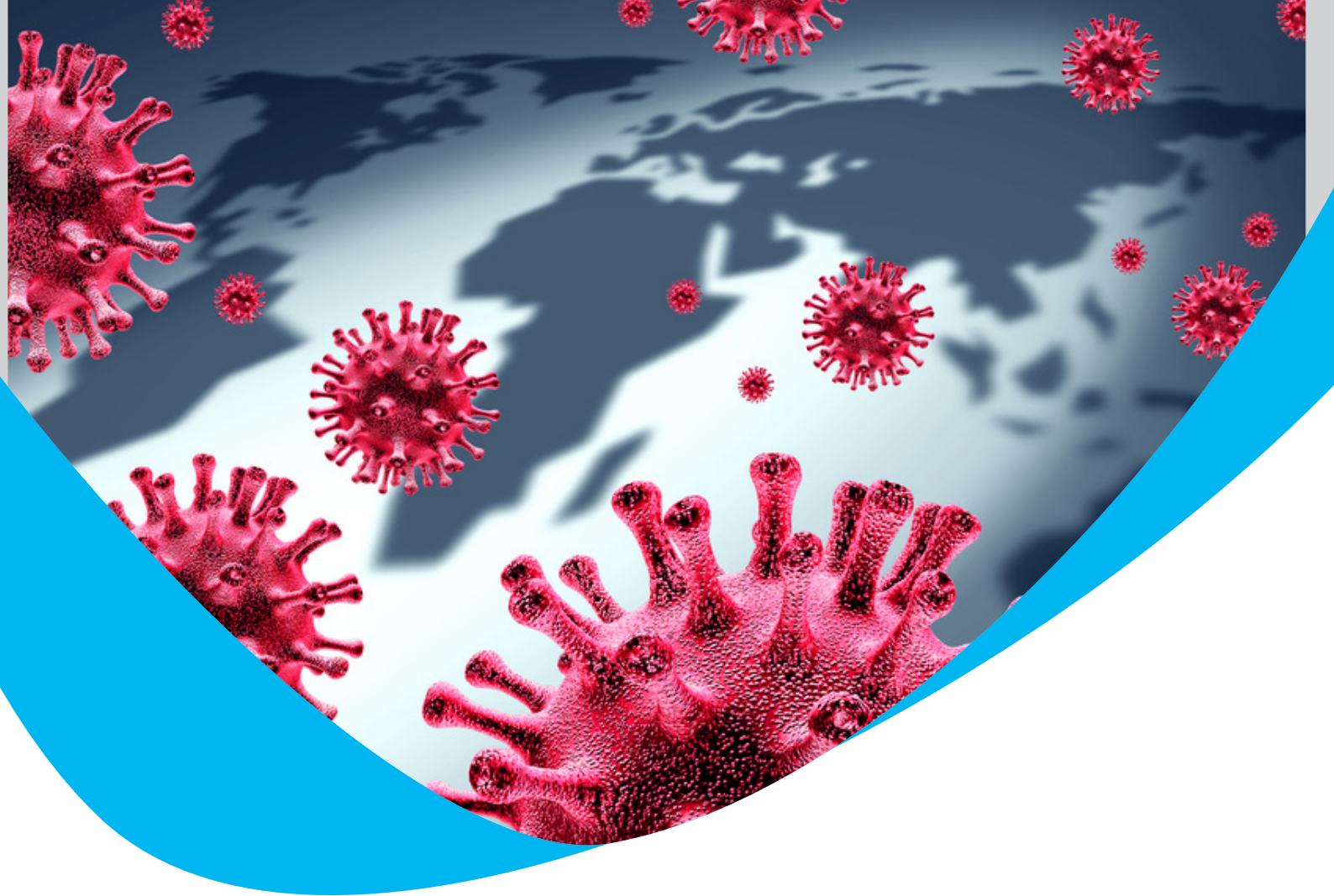
ArborLink is now used in over 20 countries to collect patient data. It is used for streamlining data collection in privately-funded research consortia and for the National Institutes of Health (NIH).

ArborLink Features

- Subject Management & Task Management
    - Eligibility screening
    - Randomization
    - Protocol compliance
- Biospecimen and Material Management
    - Repository data reconciliation
    - Chain of custody tracking
- External Data Integration
    - Legacy data

- Case Report Forms
    - Cross field/form validation
    - Data quality queries
- Reliable Security
    - 21 CFR Part 11 compliance
- ePro Participant Surveys
    - Texts/email/mobile
- Reports & Notifications
    - Progress, enrollment, and compliance
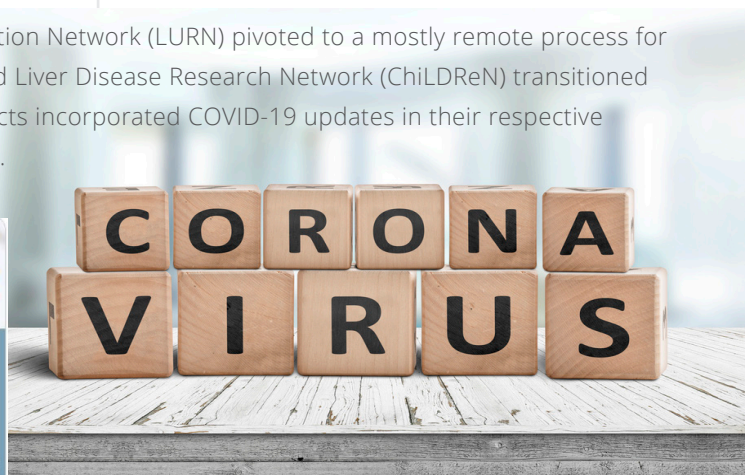
COVID-19 & Research During the Pandemic

Tackling a virulent virus like COVID-19 requires crucial early interventions to keep ahead of the disease. Supportive and easily accessible research is essential to ensuring public safety, especially for people facing compromised immunity and chronic diseases. Over the past year, the multiple projects housed under Arbor Research Collaborative for Health have actively contributed to a variety of international COVID-19 research platforms, with study operations and data collection continuing remotely. As the world transitioned to online conferencing, so did the research projects housed under Arbor Research.

The Lower Urinary Tract Research Dysfunction Network (LURN) pivoted to a mostly remote process for the launch of study phase 2. The Childhood Liver Disease Research Network (ChiLDReN) transitioned to completely remote monitoring. All projects incorporated COVID-19 updates in their respective questionnaires to facilitate future research.

Virtual
Outreach

The Dialysis Outcomes and Practice Patterns Study (DOPPS) Practice Monitor began including COVID updates for the quarterly report, starting as early as June 2020. Additionally, the DOPPS hosted a web conference roundtable discussion moderated by Dr. Jeffrey Perl from the University of Toronto, Canada. Dr. Perl is a member of the American Society of Nephrology's (ASN) COVID-19 Response Team and Chair of Home Dialysis subcommittee. The roundtable, titled "COVID-19 and chronic dialysis in the US; What's happened so far and what's next? An open conversation" featured preliminary results from an international DOPPS survey on chronic dialysis practice during COVID. It included nephrologists, clinical staff, and patients. Discussions centered around dialysis practices that have worked well or have failed, as well as unexpected challenges, preparations for the next pandemic experience, and long-term changes in dialysis practice.
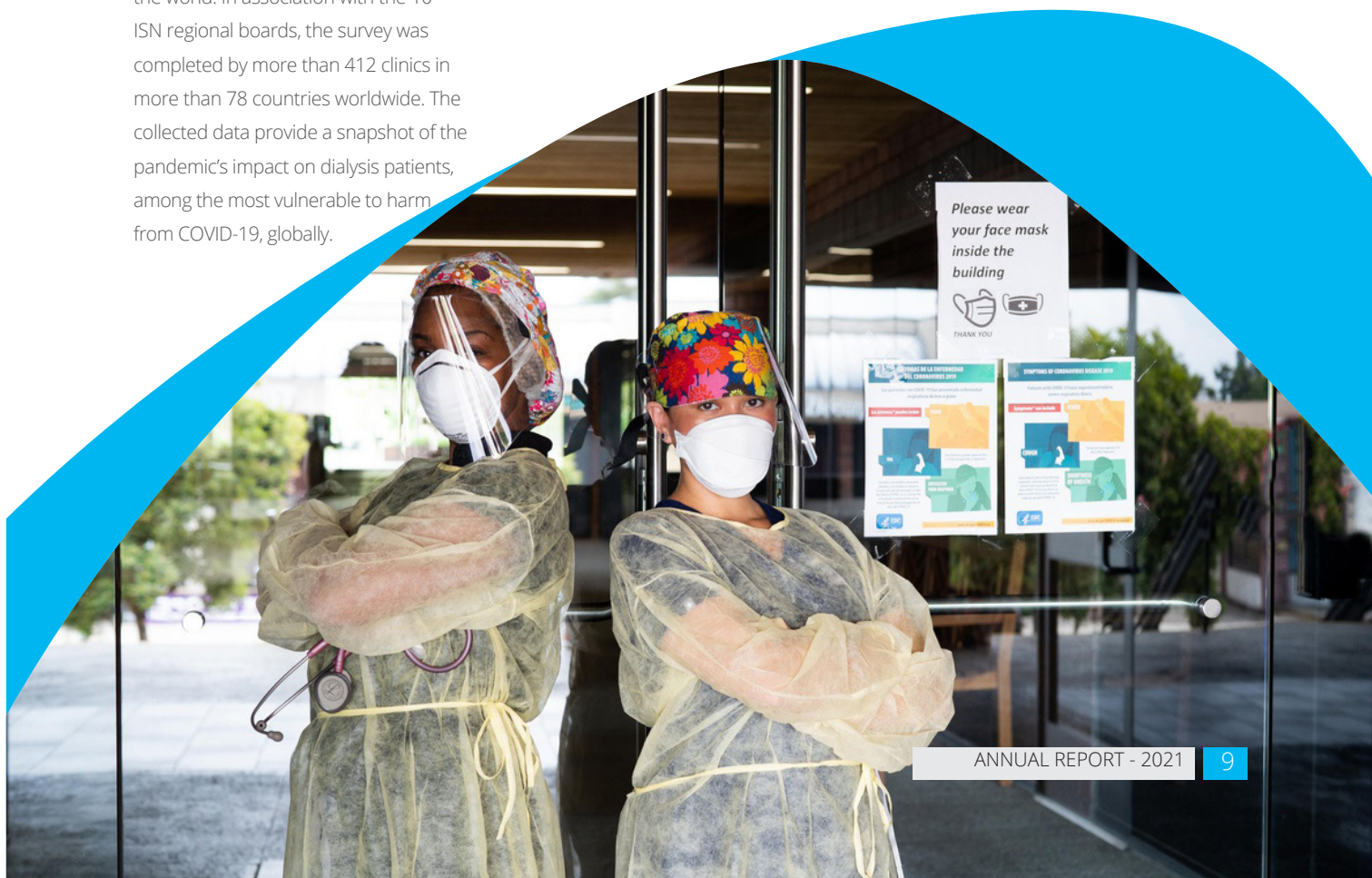
COLLABORATION

The DOPPS teamed with the International Society of Nephrology (ISN) in July 2020 to collaborate on an international collection of COVID-19 data. A practice patterns survey was designed to assess the impact of COVID-19 on chronic hemodialysis and peritoneal dialysis programs around the world. In association with the 10 ISN regional boards, the survey was completed by more than 412 clinics in more than 78 countries worldwide. The collected data provide a snapshot of the pandemic's impact on dialysis patients, among the most vulnerable to harm from COVID-19, globally.

RESEARCH

During ASN Kidney Week, the DOPPS featured COVID-19-related abstracts demonstrating early survey results from dialysis clinics in Europe, the US, and China. These data helped inform guidance for dialysis care during the pandemic.

Modern
Analytics

The long-term End-Stage Renal Disease Quality Incentive Program (ESRD QIP) support project has transitioned to operate under the Center for Clinical Standards and Quality's (CCSQ) new Health Care Quality Information Systems Amazon Web Services (HCQIS AWS) platform that hosts the Centers for Medicare & Medicaid Services (CMS) Centralized Data Repository (CDR) and CCSQ Analytics Platform (CAP). This system offers modern analytical tools for data wrangling and visualization with advanced modeling capabilities, including SAS Visual Analytics, Zeppelin, and other data collaboration tools.

The programming and analytical team at Arbor Research underwent an extensive project conversion to move the production process from SAS to the new web-based SAS Viya environment. This required learning entirely new programming languages and a variety of complicated data storage systems, such as Hadoop and Amazon Redshift, to leverage system efficiency. Arbor Research's technical competency has been praised in several CCSQ communication calls, as the Arbor Research team has helped identify a number of system issues and pursued effective solutions to drastically improve system performance.

Data Repository

Data are stored in protected CMS repository

CCSQ Analytics Platform

Integrates Amazon Redshift, Hadoop, SAS, Viya, R, Zeppelin, allowing ease of collaboration and analysis

Arbor Research Analysis

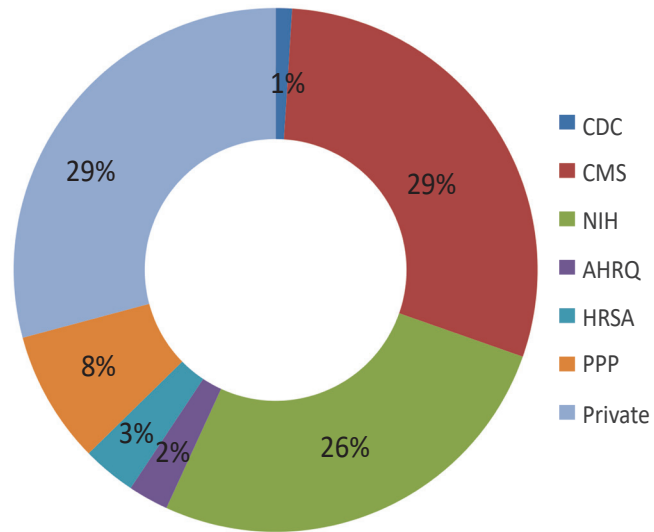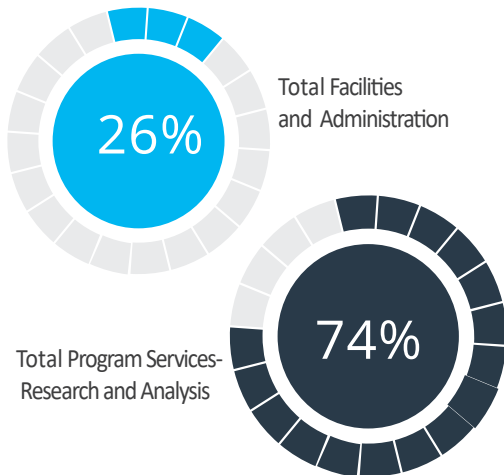Data are processed within the CDR and prepared for analysis

Shannon Li, Director of Data Services at Arbor Research, has worked closely with CMS to ensure a smooth transition to the new format. "It's a highly efficient system that will enhance the analytics and modeling of very large data sets" says Li. "I'm especially impressed by our team at Arbor Research for pulling together to learn this new system while also adapting to working remotely. It was a challenging year with the pandemic alone, even without adopting a new programming structure, and our team did it seamlessly."

The CCSQ CAP is a cloud-based system that provides various analytic tools for modeling large and complicated data sets and includes standardized and cloud-scalable technologies. The modernization of these analytic tools will provide faster and clearer communication to the health care community, as well as easier and more efficient collaboration among data users nationally.

ANNUAL
STATISTICS

Expenses 2020

26%

Total Facilities
and Administration

74%

Total Program Services-
Research and Analysis

Funding Sources

- CDC
- CMS
- NIH
- AHRQ
- HRSA
- PPP
- Private

1%
29%
29%
26%
8%
3%
2%

CDC = Centers for Disease Control and Prevention; CMS = Centers for Medicare & Medicaid Services; NIH = National Institutes of Health; AHRQ = Agency for Healthcare Research and Quality; HRSA = Health Resources and Services Administration; PPP = Paycheck Protection Program

Statement of Activities

REVENUES	2020	2019
Contributions	259,795	189,805
Grants and contracts	18,914,804	17,874,872
Net investment earnings (loss)	400,625	565,765
Other income	1,724,930	(526,350)
Total revenues	**21,300,154**	**18,104,092**
EXPENSES		
Total program services-research and analysis	14,982,175	13,920,140
Total facilities and administration	5,356,686	4,736,566
Total expenses	**20,338,861**	**18,656,706**
Change in net assets	**961,293**	**(552,614)**
Net assets, beginning of year	**8,149,801**	**8,702,415**
Net assets, end of year	**9,111,094**	**8,149,801**

Statement of Financial Position
ASSETS

Cash and investments	7,429,819	3,705,110
Grants and contract receivables	2,833,874	4,293,121
Prepaid expenses and other assets	925,973	1,078,142
Property & equipment, net	14,535,419	15,075,413
Total assets	**25,725,085**	**24,151,786**

LIABILITIES and NET ASSETS
LIABILITIES

Accounts payable & accrued expenses	2,923,514	2,678,131
Construction note payable	10,985,138	11,139,984
Deferred revenue	2,705,339	2,183,870
Total liabilities	**16,613,991**	**16,001,985**

NET ASSETS

Total net assets	**9,111,094**	**8,149,801**
Total liabilities and net assets	**25,725,085**	**24,151,786**

ARBOR RESEARCH COLLABORATIVE FOR HEALTH

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