

Improving Patient Lives Through Research and Data Analysis

ANNUAL REPORT 2019



Arbor Research Collaborative for Health is committed to improving patient care through research that shapes medical policies and practice. In particular, 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 that are national and global in scope, Arbor Research's scientific collaborations provide valuable and timely information to the worldwide health care community.



From Our

President and CEO and the Chair, Board of Directors

Dear Friends,

The mission of Arbor Research Collaborative for Health is to reduce the burden of chronic disease and improve outcomes for patients. Arbor Research continues to build on our core values of dedication, creativity, credible scientific expertise, and research collaboration to answer complex questions that shape medical polices and improve care. Our passionate and inquisitive staff members are renowned not only for their willingness to dissect these challenging questions, but are also respected for their ability to develop innovative approaches to evidence-based research.

For over 20 years, Arbor Research has provided dependable and timely information to the health care community. Reflecting on the accomplishments and meaningful research our staff has produced over the past year, we couldn't be more proud and honored to be a part of this brilliant and dedicated team. As we seek new opportunities to improve health, we are excited for what the future holds for Arbor Research.

Yours sincerely,





Robert M. Merion, MD, FACS President and CEO

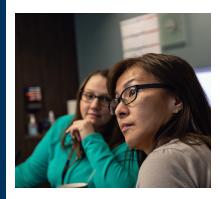


Mark L. Barr, MD Chair, Board of Directors

Research That Effects Change



Support for Living Donors = Federal Savings







Living donor organ transplantation has significant survival benefits for transplant recipients, with minimal risk to donors. For patients facing kidney failure, dialysis treatment is costly and even more expensive with prolonged waiting time on the transplant list. The National Living Donor Assistance Center (NLDAC) is the only federal program of its kind designed to support low-income living organ donors to help defray the expenditure of the transplantation operation. The recipient's insurance covers medical expenses for both the donor and the recipient, but donors are responsible for travel and other personal expenses. NLDAC helps to ease the burden of lost wages, travel expenses, and other subsistence costs related to the transplant surgery, with a maximum of \$6000 per donor. Funds are distributed to donors via controlled value cards (similar to debit cards) to be used for qualifying expenses. NLDAC has provided over \$17 million in support to more than 8000 living organ donors.

In 2018, Dr. Amit Mathur published an article in *Clinical Transplantation* titled "Return on Investment for Financial Assistance for Living Kidney Donors in the U.S." examining whether NLDAC was saving government funds and offering a return on investment. "Kidney donors, particularly those with lower incomes, face significant financial challenges when it comes to getting their evaluation done or going forward with surgery. The National Living Donor Assistance Center is a valuable resource for them," he said.





Estimated Savings & Return on Investment 1-Year \$48.2 M 5x 3-Years \$173.6 M 19x 5-years \$256.2 M 28x

Based on median cost differences between dialysis and kidney transplant, living donor transplant saves **\$51,384** per patient year.

Dr. Mathur et al. found that NLDAC not only helped donors with the burden of transplant-related expenses, but also resulted in significant savings for the federal government, and improved quality of life for patients. Mathur et al. estimated that NLDAC saves five dollars for every dollar spent in a single year; a 5-fold return on investment. Dialysis costs and waiting times for a deceased donor transplant vary by state, so the return on investment also fluctuated based on these state-specific factors. Savings increased up to 19-fold at 3 years and 28.2-fold at 5 years.

"By off-setting dialysis costs in favor of an earlier live donor transplant, the government saves hundreds of millions of dollars in the long-term. There are few health care programs that lead to this type of return on investment when you look at the big picture. Programs that lead to more live donor kidney transplants save payers a lot of money," says Dr. Mathur. "NLDAC program expansion could help achieve this goal and still result in significantly reduced dialysis expenditures, massive savings, and long-term survival benefit for the kidney failure population. It's hard to argue against this."



The Centers for Medicare & Medicaid Services (CMS) spends more than \$80,000 per year for dialysis treatment. This cost drops to only \$30,000 when a patient receives a kidney transplant and no longer needs dialysis.



More than 75% of donors agreed they could not have donated without the support of the National Living Donor Assistance Center.



3%

Out of 2425 applicants, the program granted 1330 donors. That's a total of \$6.76 million, only 3% of the estimated 1-year cost of care.

Home Health Value-Based Purchasing

EVALUATING THE EARLY IMPACT OF MEDICARE'S QUALITY IMPROVEMENT INITIATIVE



2018 marked our first annual impact evaluation of the Centers for Medicare & Medicaid Innovation Home Health Value-Based Purchasing Model.

The model was implemented in nine states in January 2016.

In 2017, there were approximately 2,000 Home Health Agencies.

The purpose of Home Health Value-Based Purchasing (HHVBP) is to support and improve the quality and efficient delivery of home health care services by Medicare-certified Home Health Agencies to Medicare beneficiaries. The Model supports efforts to build a health care system that delivers better care, spends health care dollars more wisely, and results in healthier people and communities.

The specific goals are to:

- Provide financial incentives for delivering better quality care with greater efficiency;
- Study new potential quality and efficiency measures for appropriateness in the home health setting; and
- Enhance the current public reporting process.

Our role is to understand how the shift in financial incentives under the HHVBP Model may influence agency behavior and impact quality of care, Medicare expenditures, beneficiary experience, and the utilization of Medicare services.

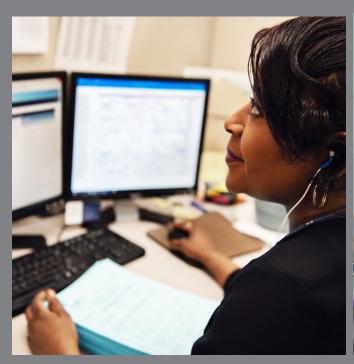
Through 2016-2017, we observed:

- An early reduction in the growth in Medicare spending and modest improvements in certain aspects of quality of care.
- No evidence of HHVBP impact on patient experience measures.
- No reports of broad or overall impact on Home Health Agencies' operations or quality improvement activities. Early changes were relatively focused and similar to ongoing activities.

The ESRD Quality Incentive Program

2010-2018: Ensuring Value & Quality in Dialysis Delivery

Congress developed the Quality Incentive Program (QIP) to link the quality of dialysis facility performance with payment. We provide the Centers for Medicare & Medicaid Services (CMS) with objective data analyses to arrive at responsive policy decisions. Together, we achieve goals of continuing to improve the quality and efficiency of dialysis care for all end-stage renal disease (ESRD) patients.





ADVANCES DURING OUR CONTRACTS WITH THE CENTERS FOR MEDICARE & MEDICAID SERVICES

ESRD QIP was designed to promote quality of care through financial incentives that reward improvement. Initially, QIP used measures of anemia and hemodialysis adequacy; it now includes a broad set of clinical, safety, and reporting measures. With the recent Meaningful Measures Initiative, CMS is interested in a measure set that reflects the highest priorities for quality measurement and improvement.

Generally, performance has improved over time under the QIP for many indicators of quality of care, and has remained relatively stable.

During 2017-2019, the majority of ESRD QIP-eligible facilities had no payment reductions. Dialysis facilities that did receive recurring payment reductions under the program had lower performance across a range of quality measures. Mortality, utilization, and Medicare payments were substantially higher for patients treated in facilities whose performance on ESRD QIP measures resulted in a payment reduction.

Many indicators varied by facility characteristics, including ownership, hospital-based versus freestanding, and size. For example, facilities not affiliated with large chains often had consistently lower performance (e.g., peritoneal dialysis adequacy, hospitalizations) or took longer to achieve similar performance levels (e.g., hemodialysis adequacy, fistula use).

Variation in performance on some indicators based on patient and facility characteristics suggests continued opportunities for improvement. The findings are consistent with the hypothesis that the ESRD QIP measures and scoring system capture meaningful determinants of health care quality and value.

CMS recently awarded Arbor Research a contract renewal to continue supporting the Medicare ESRD QIP for an additional 5 years.

Dr. Roberto Pecoits-Filho

MD, PhD, FACP, FASN

WELCOMING OUR NEW SENIOR RESEARCH SCIENTIST WHO ADDS A WEALTH OF GLOBAL PERSPECTIVE AND EXPERIENCE TO THE DOPPS TEAM



Roberto's careerspanning
engagement in all
facets of global
kidney health is the
core of what makes
him and Arbor
Research a great
partnership. His
leadership is exhibited
through participation
in projects that impact
patients worldwide.

Roberto Pecoits-Filho joined Arbor Research in September 2018. This was a natural collaborative segue, as he had served as a Chronic Kidney Disease Outcomes and Practice Patterns Study Steering Committee member and Country Investigator for Brazil since study initiation in 2014. Roberto excels in clinical care, research, and education, has over 240 publications in international indexed journals, and has lectured in 50 countries.

An Opportunity to Lead Global Strategy

Roberto has been a global participant in nephrology throughout his career. He has contributed to numerous organizations, and currently volunteers on the Executive Committee of the International Society of Nephrology (ISN). Roberto summarized his enthusiasm about this experience as rooted in the opportunity to "sit in a room where strategic decisions for a global society are made, and contribute my opinion to the pathway forward."

Contribution to the KDIGO Clinical Position on Potassium

In October 2018, Roberto co-chaired the Kidney Disease Improving Global Outcomes (KDIGO) Controversies Conference on Potassium Management. The event convened a global panel of multidisciplinary clinical and scientific experts to identify and discuss key issues in potassium management. The panel and participants articulated related controversies and critically identified evidence underlying common disagreements. A conference report to be published in the fall of 2019 by *Kidney International* will help guide KDIGO and other organizations on potassium management and future research.

The Standardizing Outcomes in Nephrology Group (SONG) Initiative

During his recent sabbatical in Australia, Roberto became involved with the SONG initiative. This group conducts qualitative research on patient opinions and priorities for kidney disease clinical trials. This patient-centered work has produced interesting findings. For example, although mortality was reported as the highest priority by clinicians, patients expressed greatest interest in reducing and managing fatigue. This outcome has been translated and reflected in the Dialysis Outcomes and Practice Patterns Study (DOPPS) patient questionnaire.



Optimizing Prevention of PD-Associated Peritonitis in the United States

AS A LIFE-SUSTAINING TREATMENT FOR END-STAGE KIDNEY DISEASE, PERITONEAL DIALYSIS (PD) OFFERS MANY POTENTIAL BENEFITS. IN THIS ANCILLARY STUDY, THE PERITONEAL DIALYSIS OUTCOMES AND PRACTICE PATTERNS STUDY (PDOPPS) AIMS TO DEVELOP QUALITY IMPROVEMENT PRACTICES THAT MAKE PD SAFER AND MORE ACCESSIBLE FOR PATIENTS WORLDWIDE.

Arbor Research and Unity Health
Toronto Hospital are co-leading this
5-year contract from the Agency for
Healthcare Research and Quality
to study peritonitis infection in PD
patients. Co-Principal Investigators
Drs. Ronald Pisoni and Jeffrey Perl
are joined in this effort by a team of
international and interdisciplinary coinvestigators and
stakeholders.

PD is linked to superior survival in the first few years, and patients indicate that PD provides benefits that are meaningful to their quality of life. This is achieved with lower treatment costs while attaining clinical outcomes compared with hemodialysis. However, PD uptake is limited by technique failure and infections, such as peritonitis.

There is a need to identify reversible factors that influence peritonitis and technique failure. The Optimizing Prevention of PD-Associated Peritonitis in the US (OPPUS) project aims to identify high-risk patients and clinical practices associated with peritonitis risk to help further inform evidence-based practice guidelines.

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"Many patients prefer homebased peritoneal dialysis, so it is important that we identify and address any issues associated with it, and reduce any subsequent risks," says Co-Principal Investigator Jeffrey Perl of Unity Health Toronto. Working with a broad group of US stakeholders, other key goals of this project are to create a meaningful approach for standardized reporting of peritonitis

episodes, and to promote knowledge dissemination strategies that foster continuous quality improvement and the development of clinical treatment pathways to prevent peritonitis in PD care settings.

"We are very excited and honored to have the opportunity to carry out this work aimed at decreasing peritonitis rates in the US and more broadly across the world."

Co-Principal Investigator Ronald Pisoni of Arbor Research Collaborative for Health.

PD patients across the globe have a widely varying risk of developing peritonitis infections - from, on average, once in 7 months to once in 17 years.

FINANCIAL Statements

| Statement of Activities | 2018 | 2017 |
|--|-------------|-------------|
| Revenues | | |
| Contributions | \$2,034,051 | \$2,729,055 |
| Grants and contracts | 17,542,416 | 16,869,651 |
| Net investment earnings (loss) | (222,546) | 1,434,776 |
| Other income | 8,527 | (1,542) |
| Total revenues | 19,362,448 | 21,031,940 |
| Expenses | | |
| Total program services- research and analysis | 18,142,375 | 18,044,087 |
| Total facilities and administration | 5,874,247 | 5,192,341 |
| Total expenses | 24,016,622 | 23,236,428 |
| Change in net assets | (4,654,174) | (2,204,488) |
| Net assets, begining of year | 13,356,589 | 15,561,077 |
| Net assets, end of year | 8,702,415 | 13,356,589 |
| Statements of Financial Positio | n | |
| Assets | | |
| Cash and investments | 3,838,119 | 10,798,266 |
| Grants and contract receivables | 3,847,707 | 4,927,222 |
| Prepaid expenses and other assets | 872,039 | 403,466 |
| Property & equipment, net | 7,072,825 | 1,166,113 |
| Total assets | 15,630,690 | 17,295,067 |
| Liabilities and Net Assets | | |
| Liabilities | | |
| Accounts payable & accrued expenses | 3,137,990 | 3,272,807 |
| Construction payable | 3,296,828 | |
| Deferred revenue | 493,457 | 665,671 |
| Total liabilities | 6,928,275 | 3,938,478 |

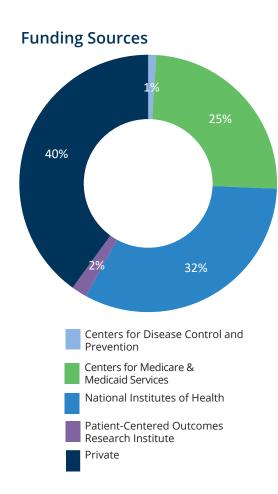


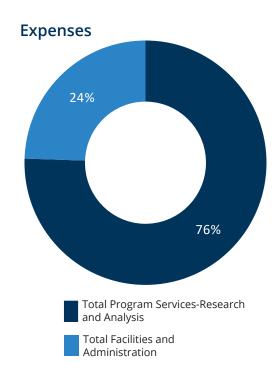
8,702,415

15,630,690

13,356,589

17,295,067





Net assets

Total net assets

Total liabilities and net assets



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