



IMAGINATIVE



COLLABORATIVE



ENGAGED

THE PATRICK AND CATHERINE WELDON DONAGHUE MEDICAL RESEARCH FOUNDATION

2016 ANNUAL REPORT

the twenty-fifth

VISION
STATEMENT

We envision continual improvement in people's health as a result of research being converted to practical benefit.

MISSION
STATEMENT

We will be an imaginative, collaborative and engaged participant in the process that begins with rigorous health research and ends in realized health benefits and by doing so give the vision of Ethel Donaghue its best expression.

GOALS

1. Promote knowledge uptake of health research into the realms of healthcare delivery, practice, and policy.
2. Advance the Foundation's mission by collaborating with people and organizations that have the opportunity and responsibility to improve health.
3. Ensure that our grantmaking programs are structured to support rigorous research that more directly leads to a positive impact on health.
4. Identify and support researchers and organizations whose work encompasses the principles of knowledge uptake.
5. Build networks and collaborations to test innovative ideas related to grantmaking and health research.
6. Contribute to efforts, both internal and external to the research enterprise, that optimize the capacity of health research to address the needs of policymakers, practitioners, and consumers.

VALUES

Steadfast in our commitment
Principled and practical
Engaged to the point of effect
Respectful and reflective

"...an imaginative, collaborative and engaged participant..."



Lynne Garner, PhD, President and Trustee and Amy R. Lynch, JD, U.S. Trust, Bank of America, Trustee

FROM THE TRUSTEES

Imaginative. Collaborative. Engaged.

These three key words from Donaghue's mission statement are being featured in this year's annual report. Although we strive to have these attributes as a part of our work in every year, we believe the activities reported in these pages provide a useful example of how our work is informed by being imaginative, collaborative and engaged with those who work to improve health through rigorous research.

Imaginative

- What would it look like if an annual report was more than an annual report? What if we used our obligation to publicly report on past activities to examine issues that will shape our future? As we considered these questions, we developed a plan for the Donaghue Journal to be a part of our next several annual reports. Flip over this year's report and read how three experts in medical research are considering the potential of open science to accelerate the pace of research to solve problems.
- With so many exciting research opportunities, it's relatively easy to imagine different ways that the legacy of Ethel Donaghue could support research to improve health. Our challenge is not what possible things we could imagine doing, but it's to ensure that what we do fits in with our mission and budget. We've learned that solving the challenge of being a small funder with a big imagination involves finding the right partners to collaborate with and the right issues for Donaghue to be engaged in.

Collaborative

- Over the years, Donaghue has had several opportunities to collaborate with other funders, and 2016 was no exception. In January, Donaghue joined the Connecticut Health Foundation, the Foundation for Community Health, the Universal

Health Care Foundation of Connecticut and the State of Connecticut in a public-private funding partnership that enabled a six-state study of health care costs. And during the last half of the year, we worked with the Rx Foundation to increase the number of Greater Value Portfolio awards from three to four.

Engaged

- Our LEAP (Linking Evidence and Practice) awards are one way that Donaghue stays engaged with the wider community of health care providers. These funds are used to connect with organizations whose mission is aligned with Donaghue's ultimate goal of using evidence to improve health.
- Donaghue is engaged in the community of private research funders as an active member of the Health Research Alliance, a network of nonprofit research funders committed to maximizing the impact of our investments.
- Being engaged also means being receptive to new ideas, new possibilities for funding, and new approaches to improve our connection with the research community. Actively seeking feedback from those we fund in our grant programs is a challenging but beneficial activity that Donaghue has recently devoted more of its resources to accomplish.

Lynne Garner

Lynne Garner, PhD
President and Trustee

Amy R. Lynch

Amy R. Lynch, JD
U.S. Trust, Bank of America, Trustee

NEW AWARDS

ANOTHER LOOK

Kenneth Boockvar, MD, MS
The New Jewish Home
Research Institute on Aging
"Adverse Effects of Diuretics
in Nursing Home Resident with
Dementia"

Carrie H. Colla, PhD
Dartmouth College
"Transforming Nursing Home
Care Under the ACO Model"

David Grabowski, PhD
Harvard University
"Impact of Enhanced Primary
Care in Nursing Homes"

Donovan Maust, MD, MS
University of Michigan
"Unintended Effects of
Antipsychotic Reduction in
Nursing Homes"

Helena Temkin-Greener, PhD,
MPH
University of Rochester
"Improving the Quality of
Mental Health in Nursing
Homes"

GREATER VALUE PORTFOLIO

*Funded in partnership with the
Rx Foundation*

Scott Halpern, MD, PhD
University of Pennsylvania
"Behavioral Economics
Approaches to Improve
Palliative Care for Critically Ill
Patients"

Sophia Jan, MD, MSHP
The Feinstein Institute for
Medical Research
"Long Term Care Planning
for Adults with Intellectual/
Developmental Disabilities"

Ateev Mehrotra, MD, MPH
Harvard University
"Just - Google It: What is
the Impact of Health Care
Price Information Being More
Accessible to Consumers?"

David Meltzer, MD, PhD
University of Chicago
"Longitudinal Effects of
the Comprehensive Care
Physician Program"

R3 - 2nd OPPORTUNITY AWARD

Arietta Slade, PhD
Yale University
"Minding the Baby™:
From Research to Service
Expansion"

William Zempsky, MD
Connecticut Children's
Medical Center
"Strategies for Education
in the Emergency
Department - 2"

FUNDING PARTNERSHIPS

Office of the Healthcare
Advocate
Study on State Healthcare
Costs Containment Strategies
Funded with Connecticut
Health Foundation, Universal
Health Care Foundation of
Connecticut, and Foundation
for Community Health to
supplement funding provided
by the State of Connecticut

2016 CONTINUATION AWARDS

ANOTHER LOOK

Marie Boltz, PhD and Jane
Flanagan, PhD
Boston College
"Post-Acute Outcomes in
Nursing Home Residents with
Dementia"

Susan H. Busch, PhD, MS
Yale University
"Reducing Inappropriate Use
of Anti-Psychotic Medications
in Nursing Homes"

Andrew B. Cohen, MD, PhD
Yale School of Medicine
"End-of-Life Care for Nursing
Home Residents with
Guardians"

Stephen Crystal, PhD, MS
Rutgers University
"Data Driven Quality
Improvement for Safer
Dementia Care in Texas"

Lara Dhingra, PhD
Metropolitan Jewish Health
System
"Institutional Special Needs
Plans and Hospice in Nursing
Homes: Prevalence and
Patterns"

Sean Jeffrey, PharmD
University of Connecticut
"Preventing Medication-
Associated Delirium"

Mark S. Lachs, MD
Cornell College of Medicine
"Annual Prevalence of
Resident-to-Resident
Mistreatment"

Pamela Nadash, PhD
University of Massachusetts
"Nursing Home Satisfaction
Measures: What is Their
Relationship to Quality"

Jennifer Perloff, PhD
Brandeis University
"Accountable Care: Impact
on Nursing Home Services"

GREATER VALUE PORTFOLIO

Jeffrey T. Kullgren, MD, MPH
and Eve A. Kerr, MD, MPH
University of Michigan
"Patient, Provider, and Health
System Effects of Provider
Commitments to Choosing
Wisely"

Valerie A. Lewis, PhD
Geisel School of Medicine at
Dartmouth College
"Demonstrating Methods to
Integrate Clinical Care, Public
Health, and Social Services
with Value-Based Payment
Models"

Dale Ellen Lupu, PhD MPH
George Washington University
"Implementing Shared-
Decision Making with Chronic
Kidney Disease: Testing its
Impact on Improved Quality
of Life and Reduced Health
Care Costs"

FUNDING PARTNERSHIPS

Amber Barnato, MD, MPH
University of Pittsburgh
"Consumer-Directed Financial
Incentives"
Funded in partnership with
the Robert Wood Johnson
Foundation

Elizabeth Bradley, PhD, MBA
and Leslie Curry, PhD, MPH
Yale University School of Public
Health
"Identifying Effective Strategies
for Coordinating Health Care
and Social Services"
Funded in partnership with the
Commonwealth Fund

Alexander Ommaya, DSc
Association of American
Medical Colleges
"Advancing Effectiveness
Implementation Science
in Community/Academic
Partnered Research"

GRANT PROGRAMS

Another Look

Funding to use existing data
for research to improve
the health of elders in care
facilities.

Funding Partnerships

Donaghue works with other
funders to leverage its
resources.

Greater Value Portfolio

Projects for three, four or five
years to test new ways to
increase the benefits of health
care delivery to more people
at an equivalent or reduced
cost.

R3 - Making Research Relevant & Ready Second Opportunity

R3 funds enable grantees
to access experts in areas
relevant to scaling, spread
and implementation.



Ethel Donaghue

Miss Donaghue said in her will that her trustees should seek out useful health knowledge through research, and she gave them permission to undertake unusual and non-standard activities in furtherance of her purpose.



The Patrick and Catherine Weldon Donaghue Medical Research Foundation is a charitable trust created pursuant to the will of Ethel F. Donaghue, late of West Hartford, Connecticut. The Foundation, which began operations in 1991, is governed by Bank of America, N.A. and Lynne Garner, PhD, Trustees. The Foundation is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code of 1986, is a private foundation within the meaning of Code Section 509(a), and is subject to the jurisdiction of the Probate Court for the District of West Hartford.

The search for knowledge by Donaghue-funded scientists has been made possible by the vision of Ethel F. Donaghue, who died in 1989 without immediate family to inherit her wealth. Her father died in 1910 of heart disease when Ethel was only fourteen, and her mother succumbed to cancer in 1933. Spurred on by living through several family health problems and outliving her entire immediate family by over three decades, Miss Donaghue developed an abiding interest in health care and research. Her commitment to advancing health culminated in a trust devoting the bulk of her estate to The Patrick and Catherine Weldon Donaghue Medical Research Foundation, which honors the memory of her parents.

The testamentary intent of Ethel Donaghue is the immutable mandate for the Donaghue Foundation trustees. Miss Donaghue said in her will that her trustees should seek out useful health knowledge through research, and she gave them permission to undertake unusual and non-standard activities in furtherance of her purpose. Therefore, a frequent question in trustee discussions of policy and program design is "If she had the facts that we do today, what would Miss Donaghue do?"

DONAGHUE GRANT PROGRAMS



Donaghue is delighted to be working with the Rx Foundation for the 2016 Greater Value Portfolio program, which has funded four exciting research projects for a total of \$2,167,756. The Rx Foundation funds innovative people and projects to improve healthcare quality and access in the U.S.

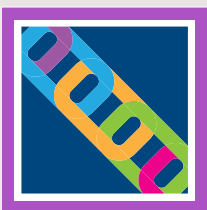
The Greater Value Portfolio program supports research projects that demonstrate and test new approaches to increasing value in health care delivery.



Another Look – Better Health for Elders in Care Facilities was established to provide funding for research projects that can improve the quality of care for the elderly population in nursing homes or other care facilities. Researchers must use data that already exists for their study. In addition, researchers applying for this grant must identify a stakeholder in the care delivery or policy arena with whom they will either consult or collaborate and who is willing to work with the researcher to develop a research product that may be readily used to improve care.



R3 — Making Research Relevant & Ready — was created to help promote the knowledge gained from Donaghue-funded research so that it will improve health. This grant program recognizes that expertise from disciplines outside those traditionally eligible for research funding is needed for scaling, dissemination, and the sustainability of evidence-based programs and practices. Donaghue grantees, past and present, are eligible for the R3 program and are welcome to contact the Donaghue office if they may be interested receiving an R3 grant award. In addition to the R3 grant described to the right, two R3 – Second Opportunity awards were provided.



Through its Linking Evidence and Practice portfolio, the Donaghue Foundation allocates funds to support initiatives by other organizations whose work is aligned with the Donaghue mission of funding research that will be of practical benefit in improving health. Through LEAP, the Foundation offers sponsorship support for events and programs that connect research evidence and evidence creators with leaders in healthcare policy and health systems, practitioners, patients, and the public. In considering requests for funds, Donaghue places special emphasis on programs that promote collaboration among diverse stakeholders or advance the work of past and current Donaghue grantees.



Strategies for Education in the Emergency Department (SEED)

This grant continues the work of William Zempsky, MD and Biree Andemariam, MD in providing training and support to emergency room clinicians to more quickly and effectively treat patients who are experiencing the pain of sickle cell disease. With their first R3 award, the team produced an instructional video to increase emergency department clinicians' knowledge of sickle cell disease and its symptomatic pain and to standardize the approach to sickle cell disease care across emergency departments in Connecticut. This work will continue with the Second Opportunity award and a focus on meeting medical, nursing and emergency department leadership in Connecticut hospitals to reinforce the use of the educational video among hospital staff, develop and disseminate other SEED online training materials, and collect data to assess quality and cost indicators for sickle cell disease treatment in Connecticut.



Minding the Baby™: From Research to Service Expansion

Minding the Baby™, a mentorship program for first time mothers, used its first R3 grant to develop models for sustainable funding through service delivery and the replication of the programs in additional Connecticut cities. The current R3 2nd Opportunity grant expands on the original R3 goals with a more targeted effort to identify potential grant funding sources and possible third-party reimbursement for the clinical services provided by the program.

PARTNERSHIP GRANTS



A Connecticut Public-Private Funding Partnership

Donaghue joined with three other Connecticut-based health philanthropies and the State of Connecticut to fund a study on healthcare cost containment strategies used by other states and to recommend a cost containment strategy or set of strategies for Connecticut. The Connecticut Health Foundation, the Universal Health Care Foundation of Connecticut, The Foundation for Community Health, and Donaghue contributed \$190,000 (Donaghue's share was \$15,000) to the total project cost of \$363,450.

The study was commissioned by Lieutenant Governor Nancy Wyman, chair of the Health Care Cabinet, to assist the Cabinet in making recommendations on cost containment as required by Public Act 15-146. The study focused on successful practices in Oregon, Maryland, Vermont, Rhode Island, Washington and Massachusetts that monitor and control costs, enhance competition and increase the cost effectiveness of the healthcare market, improve the transparency of healthcare costs, and improve quality of care and health outcomes.

Donaghue decided to join with the other three health funders because the study is well-aligned with its major grant program, the Greater Value Portfolio. Over three years, Donaghue expects to commit \$5.4 million in research grants to test new approaches to achieving a higher value healthcare system.



Scott Halpern, MD, PhD

University of Pennsylvania

"Behavioral Economic Approaches to Improve Palliative Care for Critically Ill Patients"

The well-described mismatch between the care seriously ill patients want and the care they receive stems, in part, from clinicians' failures to engage patients in discussions about their goals and preferences in a timely manner. For example, ICU clinicians struggle to adhere to recommendations that they discuss prognosis and palliative options with patients and caregivers. A pragmatic, stepped-wedge, cluster randomized trial will test the effectiveness of two electronic health record interventions designed to increase ICU clinicians' engagement of critically ill patients and caregivers in discussions about alternative treatment options, including care focused on comfort. It is hypothesized that patient-centered outcomes can be improved without raising costs by simply requiring ICU clinicians to document a prognostic estimate (Intervention A) and to provide justification if they choose not to offer patients the option of comfort-oriented care (Intervention B). The primary outcome of this study is a composite measure of in-hospital mortality and length of stay, which has previously been shown to be patient-centered. Secondary outcomes include nurse-assessed quality of death, other clinical outcomes, palliative care process measures, and costs.



Ateev Mehrotra, MD, MPH

Harvard School of Medicine

"Just Google It: What Is the Impact of Health Care Price Information Being More Accessible to Consumers?"

The growing interest nationally in price transparency is motivated by the wide variation in prices seen across providers and the increasing out-of-pocket cost burden on patients. The hope is that patients will use price transparency initiatives to identify lower-cost providers and save money. Unfortunately existing price transparency initiatives have largely been unsuccessful. The websites are rarely used because patients find them difficult to find and navigate. The goal of this study is to evaluate the impact of making provider price data easily accessible on the internet through a unique partnership between Google, Harvard, and the State of New Hampshire. New Hampshire has a relatively sophisticated price transparency website, but it is rarely used. In early 2017, Google will begin displaying the price information on New Hampshire's website when a relevant search is made by a user in New Hampshire. This study has three aims: measure utilization and engagement of the price data by Google users; survey New Hampshire residents to evaluate whether the initiative increases their ability to find relevant price data; and use health plan claims to evaluate whether making price data more easily available led more New Hampshire residents to shift to lower-cost providers. The overall goal is to add to our understanding of how best to encourage price transparency and price shopping, while also having a practical positive benefit to New Hampshire residents for whom price information will become easier to find.



Sophia Jan, MD, MSHP

The Feinstein Institute for Medical Research

"Long Term Care and Future Planning for Adults with Intellectual/Developmental Disabilities"

Most adults with intellectual/developmental disabilities outlive their parents. Unfortunately, the publicly-funded long-term care delivery system — which includes home health care, adult daycares, and nursing homes — cannot keep up with demand. Most families recognize the need to develop long-term care plans. Yet few do, leading to crises, emotional trauma, and at its worst, inappropriate or unwanted and costly placement in nursing home settings. Identifying individuals at highest risk for emergent placement and intervention targets for long-term care planning can significantly improve the quality of life, independence, and personal choice of adults with intellectual/developmental disabilities while also improving the impact of public funding and effectiveness of existing long-term care support services.

By partnering with a social services agency and focusing on intellectual/developmental disabilities adults 18-64 years, an age at which many long-term care decisions are initiated, the specific aims of this study are to develop a predictive model identifying adults with intellectual/developmental disabilities at greatest risk for institutional placement; identify long-term care planning activities among aging caregivers living with adults with intellectual/developmental disabilities; identify strategies to promote long-term care planning through focus groups of aging family caregivers; and develop and test a long-term care planning tool to help adults with intellectual/developmental disabilities and family caregivers understand projected health needs and plan ways to remain in their own homes when crises occur.



David Meltzer, MD, PhD

University of Chicago

"Longitudinal Effects of the Comprehensive Care Physician Program"

Health care costs and adverse health outcomes are concentrated in a small fraction of the population at increased risk of hospitalization. Hospitalized patients often experience discontinuities between inpatient and outpatient care that increase costs and impair outcomes. This has been especially true as hospitalists have increasingly provided hospital care instead of traditional primary care physicians, who no longer typically have enough patients in the hospital to make it economically viable for them to see hospitalized patients.

With funding from the Center for Medicare and Medicaid Innovation since 2012, 2,000 patients for a randomized to test whether Medicare patients at increased risk of hospitalization experience better outcomes if they can receive inpatient and outpatient care from the same physician. The preliminary results suggest substantially improved care experience, outcomes, and costs with comprehensive care physicians' over 18 months, but longer follow-up is needed. The goal of this study is to conduct this long-term follow up to assess whether outcomes improve and total resource use declines over four years if patients receive inpatient and outpatient care from a comprehensive care physician compared to different inpatient and outpatient physicians.



ANOTHER LOOK



Donovan Maust, MD

University of Michigan

"Unintended Effects of Antipsychotic Reduction in Nursing Homes"

Stakeholder Organizations: Centers for Medicare and Medicaid; Michigan Great Lakes Chapter of the Alzheimer's Association

While evidence suggests that the rate of antipsychotic use for the behavioral and psychological symptoms of dementia in long-term care has decreased, anecdotal evidence suggests that prescribers may have simply shifted to alternative but unmeasured agents such as valproic acid or benzodiazepines to help control the behaviors. Unfortunately, these antipsychotic alternatives have their own associated harms and even less evidence of benefit for the problematic behaviors. So, while antipsychotic use has dropped, the replacements may be even worse. This study will use Medicare data from 2008-2013 to examine whether the recent reduction in antipsychotic use among long-term care residents has been accompanied by increased use of alternative psychotropic medications. This information is critically important for policymakers so they can learn whether the strong emphasis on reducing antipsychotic use, when implemented in the absence of an equally strong strategy to improve non-pharmacological behavioral management, simply caused a shift in prescribing to even worse agents.



Helen Temkin-Greener, PhD

University of Rochester

"Improving the Quality of Mental Health in Nursing Homes"

Stakeholder Organization: Finger Lakes Health System Agency

Although nursing home residents are characterized by high and increasing prevalence of mental health disorders, the delivery of mental health services in nursing homes has been described as inadequate due to insufficiently trained staff, insufficient specialty psychiatric care resources, problematic practices such as inappropriate and often excessive use of antipsychotic and anti-depressive medications, and a high rate of hospitalizations among residents with dementia or mental health disorders. The overall goal of this study is to identify and develop process and outcome-based measures of care quality for nursing home residents with mental health and behavioral disorders and to explain variations in these measures across facilities and regions or states. Nationally, these findings will help fill knowledge gaps and provide research direction to help inform the near-term development of clinical and policy interventions for this population. Regionally, these findings will inform nursing home care by developing and disseminating benchmark performance measures for all Finger Lakes Performing Provider System nursing homes.



Kenneth Boockvar, MD

The New Jewish Home Research Institute on Aging

"Adverse Effects of Diuretics in Nursing Home Residents with Dementia"

Stakeholder Organization: Continuing Care Leadership Coalition/Greater New York Hospital Association

Nearly half of all nursing home residents with hypertension are prescribed diuretics, but diuretics' adverse effects (e.g., water loss, urinary incontinence, and falls) may be especially problematic



for these residents. The objective of this study is to examine the use and effects of diuretics in this population. Specifically, it will describe the prevalence of diuretic use in nursing home residents with hypertension and dementia; examine predictors of diuretic use including resident characteristics, prescriber characteristics, and organization characteristics; and determine the association between diuretic use and adverse outcomes including urinary incontinence, dehydration, falls, and hospital and emergency department use, as compared with use of other hypertension medications. This project will create knowledge that could improve health for nursing home residents with dementia and hypertension by helping providers make prescribing decisions according to symptoms and function, a key principal of geriatrics and palliative care.



David C. Grabowski, PhD

Harvard Medical School

"The Impact of Enhanced Primary Care in Nursing Homes"

Stakeholder Organization: OptumCare

Many long-stay nursing home residents have very poor access to primary care, which often leads to unnecessary health care utilization and poor health outcomes. The Evercare Model, offered by UnitedHealthCare as a Medicare Advantage plan to nursing home residents, provides a treat-in-place model of care for enrollees through the use of nurse practitioners. The objective of this study is to understand the impact of the Evercare Model on outcomes for long-stay nursing home residents, including emergency department and acute care inpatient utilization, rates of readmission, as well as the amount Medicare spends on care. This study will provide the first large-scale evaluation of whether an Medicare Advantage plan with an increased clinical presence can improve outcomes, which may have a profound impact on the delivery of services to the nearly one-million long-stay nursing home residents in this country.



Carrie H. Colla, PhD

Geisel Medical School at Dartmouth College

"Transforming Nursing Home Care Under the ACO Model"

Stakeholder Organization: Federal Coordinated Health Care Office

Nursing home residents require complex care coordination across a range of settings, providers, benefit plans, and payment models. As a result, nursing home residents are particularly susceptible to fragmented care that can be high in cost and low in quality. Accountable care organizations (ACO) present a payment and delivery model with the potential to improve quality and reduce costs for nursing home residents through an enhanced focus on care coordination and provider integration. With an aging population increasing the national demand for high quality nursing home services, there is an urgent need for research to determine the impact of the ACO model on this unique population. Medicare claims data will be linked to Minimum Data Set assessments to evaluate the performance of ACOs in managing nursing home residents across measures of spending, utilization, outcomes, and quality, as well as examine how treatment patterns for nursing home residents, including the types of physicians and settings from which they seek care, affect attribution to ACOs. This research will provide nursing facilities, ACOs, and policymakers with timely, actionable information on innovative care coordination strategies and characteristics of successful ACO-nursing home relationships to directly improve the health of nursing home residents.



LINKING EVIDENCE AND PRACTICE PORTFOLIO



Connecticut Practice Transformation Congress Community Health Center Association of Connecticut

The Transformation Congress was held in September to mark the completion of the Community Health Center Association of Connecticut's first year working with community health centers and key stakeholders from across the Connecticut as part of the Transforming Clinical Practices Initiative (TCPI). The TCPI initiative, funded by the Centers for Medicare and Medicaid Services, is designed to prepare health centers for the migration from a fee-for-service payment model to one based on quality and value. The work of the grant is focused on helping health centers identify best practices and care models and to provide training and support to achieve the TCPI goals.



Improving End-of-Life Care in Connecticut with Dr. Angelo Volandes Qualidigm

This program brought healthcare thought-leaders together for a meaningful discussion on strategies to improve end-of-life care in Connecticut with guest speaker, Angelo Volandes, MD. Dr. Volandes is a physician, researcher, and an internationally recognized expert on the use of video decision support tools, decision science, and ethics who leads ACP Decisions. ACP Decisions has created a library of video decision aids to support shared decision-making by helping patients with serious illness and their families envision what different treatments will entail and how they will affect their quality of life. The goal of the program was to engage health systems to promote end-of-life decision-making support for Connecticut residents.



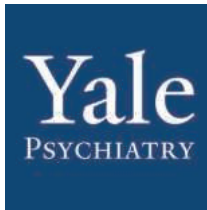
Connecticut State Health Improvement Coalition: 2017 Action Summit Connecticut Department of Public Health

The Summit convened over 175 partners from across Connecticut to review progress made in 2016 implementing and meeting the State Health Improvement Plan goals and to set 2017 priorities. The full day event provided an overview of current Connecticut health reform initiatives, alignment opportunities with CDC's 6 | 18 initiative, and small group discussions by focus area for each aspect of the plan. Participant input provided the groundwork for defining the 2017 SHIP policy agenda. During a lunchtime presentation, DPH Commissioner Raul Pino recognized the contribution, effort and dedication of SHIP Advisory Council members, Action Team Lead Conveners, and active members of the seven SHIP Action Teams.



2016 New England Minority Nurse Leadership Conference
National Black Nurses Association

This conference brought the New England Chapters of the National Black Nurses Association and the National Association of Hispanic Nurses together for the first time to discuss nursing diversity and the unique leadership challenges and opportunities for minority nurses. When healthcare leaders, educators and the healthcare workforce overall reflect the communities they serve, an understanding of the needs of the community, trust, and the ability to ensure health equity are cultivated. The conference explored the many ways that leadership diversity provides for various perspectives, enhances quality decision-making, and promotes cultural competence resulting in improved health outcomes and fewer care disparities.



Yale Neuroscience 2016: From Aggression to Recovery
Yale Department of Psychiatry

The primary goal of this annual conference is to make cutting-edge research knowledge available to mental health professionals, consumers, and their families. Yale researchers provide non-technical summaries of their research geared toward informing the general public. These presentations highlight recent advances in basic and clinical neuroscience and explain their promise for advances in the diagnosis, treatment, and prevention of mental illness. After the presentations, audience members speak in small groups with the researchers. Participating partners include the Connecticut Mental Health Center, the Department of Mental Health and Addiction Services, the Connecticut Chapter of the National Alliance on Mental Illness, and the Yale Department of Psychiatry.



Yale InnovateHealth Mentor Program
Yale School of Public Health

InnovateHealth Yale is a home for those at Yale University interested in creating innovative solutions to challenges in health and education. This program brings to Yale accomplished mentors who are using the principles of social entrepreneurship to improve the health of underserved communities and low resource countries. The mentors, through their advice, connections, and support, shape the work of students who are exploring the path of social entrepreneurship to make healthcare better for all. Mentors hold office hours to meet with students, give talks and lectures to the greater student body, and connect with faculty and staff engaged in social entrepreneurship teaching and training.

FINANCIALS

RESEARCH GRANTS

Institution	New	Continuation	Total
Association of American Medical Colleges		1	1
Boston College		1	1
Brandeis University		1	1
Connecticut Children's Medical Center	1		1
Connecticut Office of the Healthcare Advocate	1		1
Dartmouth University	1	1	2
George Washington University		1	1
Harvard University	2		2
Metropolitan Jewish Health System		1	1
New Jewish Home Research Institute on Aging	1		1
Rutgers State University of New Jersey		1	1
University of Chicago	1		1
University of Connecticut		1	1
University of Massachusetts	1	1	2
University of Michigan	1		1
University of Pennsylvania	1		1
University of Pittsburgh	1		1
University of Rochester	1		1
Weill Cornell Medicine		1	1
Yale University School of Medicine	1	3	4
	13	13	26

FINANCIALS

Investment in marketable securities	\$66,390,640
Cash and cash equivalent	\$ 1,339,756
Other assets	\$ 10,247
Total assets and fund balance	\$70,224,871
Income	\$ 1,161,007
Expenditures	
Program	
Grants	
Another Look	\$ 1,038,317
Funding Partnerships	\$ 309,192
Greater Value Portfolio	\$ 1,028,625
R3 - Making Research Relevant & Ready	\$ 66,000
Linking Evidence and Practice	\$ 28,919
Subtotal	\$ 2,471,053
Program support and Foundation-administered projects	\$ 232,704
Management and General	\$ 585,159
Investment Management	\$ 134,418
Total Expenditures	\$ 3,423,333

Note: In addition to these expenditures, an estimated amount of up to \$2,528,495 has been earmarked for future spending in support of ongoing grants.

The figures listed above are unaudited. Fair market values are approximate.

FUNDS AWARDED BY GRANT PROGRAM FOR GRANT CYCLE

Another Look	
New (5)	\$398,279
Continuing (10)	\$640,038
Funding Partnerships	
New (1)	\$ 15,000
Continuing (3)	\$294,192
Greater Value Portfolio	
New (4)	\$415,019
Continuing (3)	\$613,606
R3 - Making Research Relevant & Ready	
New (2)	\$ 66,000
Continuing (0)	

2016 LEAP AWARDS

Connecticut Center for Primary Care "9th Annual Primary Care Summit"	\$500
Connecticut Department of Public Health "Connecticut State Health Improvement Coalition: 2017 Action Summit"	\$5000
Community Health Center Association of Connecticut "Connecticut Practice Transformation Congress"	\$500
National Black Nurses Association "2016 New England Region Minority Nursing Leadership Conference"	\$2000
Prevention Partners "National Healthy Places Summit: Entrepreneurial Leadership to Advance Healthy Workplaces & Healthy Communities."	\$5000
Qualidigm "Improving End-of-Life Care in CT with Dr. Angelo Volandes"	\$5419
Qualidigm Better Health Conference "It's Your Health, Take Charge"	\$500
Yale University 2016 Health Care Conference "Creating Value and Sustaining Gains: The Next Decade in Healthcare"	\$500
Yale University School of Medicine, Department of Psychiatry Neuroscience conference "Neuroscience 2016: From Aggression to Recovery"	\$5000
Yale University School of Public Health "InnovateHealth Yale Mentorship Program"	\$5000

Grants
made since
Foundation's
inception:
\$93,243,897

Current value:
\$70,224,871

Original
value of Ethel
Donaghue's
gift:
\$53,438,074

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MAY 2017

THE PATRICK AND CATHERINE WELDON DONAGHUE MEDICAL RESEARCH FOUNDATION



Our Pressing Need for Innovation
in the Research Enterprise

Harlan Krumholz, MD

Using Open Data to Fight an Often-
Overlooked Global Killer: Air Pollution

Christa Hasenkopf, PhD

Nonprofits Starting to Use Open Science
to Extend Their Missions

Maryrose Franko, PhD

18 NORTH MAIN STREET, WEST HARTFORD, CT 06107-1919

860.521.9011

DONAGHUE.ORG

Open Science

The first *Donaghue Journal* is devoted to open science — the concept of allowing the tools and results of research to be as freely available as soon as practically possible. Storing data collected through research in a format that is free and accessible to those with the qualifications to responsibly use it is a main tenet of “open data.” Reporting research results in journals that do not have a pay wall is “open access.” Together these principals are quietly changing the medical research landscape.

Although there are still unanswered questions about the best ways to design and use open science tools, researchers and their sponsors are increasingly working to make their efforts from research more equitably available to accelerate the pace of solving our health challenges.

Three experts on open science have agreed to share their ideas with the *Donaghue Journal*.

- Harlan Krumholz, MD, MS, is the Harold H. Hines Professor of Medicine at Yale School of Medicine and director of Yale's Center for Outcomes Research and Evaluation. He is also the principal investigator of the Yale Open Data Access project.
- Christa Hasenkopf, PhD, climate scientist, Climate Fellow at Echoing Green, and co-founder of OpenAQ, discusses the role that air pollution plays in mortality world-wide and how an open science approach to quality data can be a part of the solution to this significant source of health inequity.
- Maryrose Franko, PhD, Health Research Alliance Executive Director, discusses how non-profit researcher funders are using open science resources to maximize their research investments.



The Patrick and Catherine Weldon Donaghue Medical Research Foundation
18 North Main Street, West Hartford, CT 06107-1919
860.521.9011
donaghue.org

Our Pressing Need for Innovation in the Research Enterprise

Harlan Krumholz, MD
*Harold H. Hines, Jr.
Professor of Medicine,
Yale University*



People will probably look back on this time as the dark ages of clinical research, in which the progress that was made was often accompanied by a secrecy, inadvertent or not, that impeded more and faster progress. Important articles are published, but only those with subscriptions or access to institutional libraries are able to read them. Academics conduct experiments on people, but about half the time do not report their results. Trialists perform clinical trials, but often resist sharing the individual patient-level data so that others can view, evaluate, and build upon them. Scholars publish observational studies but do not disclose the details about whether the methods and aims changed as the results emerged.

Meanwhile, people with progressive disease cannot wait for scientists and journals and publishers to sort out the inefficiencies and the competition in order to face the problems together in ways that accelerate knowledge generation, even if it results in diminished profits and individual fame. As Sara Riggare, a brave woman with Parkinson's Disease explained to me, time has a different meaning to people with progressive disease. "We cannot wait," she said.

Fortunately, practices are changing. Many organizations, like Johnson and Johnson, are sharing their clinical trial data

*People, who are expert
in their conditions,
need to be welcomed
as partners and given
authentic power in the
governance of research.*

through mechanisms like the Yale Open Data Access Project. Many journals are finding increasing ways to share science with the public immediately upon its publication. Academics are under increasing pressure to report the results of their experiments — and some funders are demanding it. And some are calling for authors publishing observational studies to accompany their work with a narrative of how it evolved from the start.

But these changes are not enough. And they are not happening quickly enough. It is time to innovate the knowledge generation enterprise. People, who are expert in their conditions, need to be welcomed as partners and given authentic power in the governance of research.

Sharing needs to be considered intrinsic to the professionalism of a scientist. Teamwork needs to be encouraged and rewarded. More rapid and efficient ways of leveraging digital health data need to be pioneered, in partnership with people. Trust needs to be engendered through a respect for privacy, a sense of urgency, and a commitment to transparency.

The way that research is conducted, under a cloud of competition and a culture focused on individual stars, will ultimately yield, with proper incentives, to the light of cooperation and a culture of teamwork, which includes scientists and participants working together at the speed commensurate with the needs of those who are suffering or at risk. And along with this change will grow a results-based orientation, in which we will measure our progress by lives saved and bettered — and disease prevented. Recognition based on number of articles published, promotions obtained, and awards received will recede into the past as the community focuses only on what matters most — progress against disease and for health.

*Follow Harlan Krumholz on Twitter
@hmkyale*



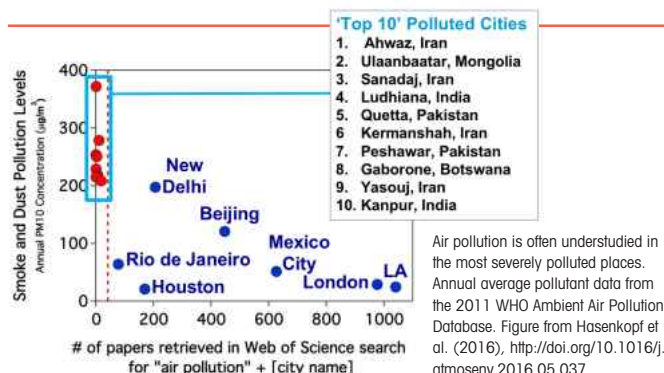
Christa Hasenkopf, PhD
CEO and Co-Founder
of OpenAQ

Using Open Data to Fight an Often Overlooked Global Killer: Air Pollution

Air pollution is one of the most pressing global health issues of our time, responsible for one out of every eight deaths on the planet and more deaths each year than HIV/AIDS and malaria — combined. Yet air pollution research is lacking in the places where it is often needed most. The figure shows that the ten most polluted cities from a 2011 WHO database had a combined total of approximately 41 papers published involving air quality and health. Meanwhile, Houston had nearly 200 papers, alone, and an order of magnitude cleaner air.

The lack of air pollution studies in the most polluted places affects our understanding of air pollution's impact on health. While the causal relationships between different types of air pollution and mortality are well-established through large-cohort epidemiological, toxicological, and exposure studies, how mortality is affected in the most polluted places — where billions live — is not understood with policy-relevant precision.

Open data can help change this picture. In fact, seven out of ten of the most cited large-cohort epidemiological air quality studies relied on open governmental data. These studies had outsized-impacts on countries' national air quality standards



and international guidelines. Additionally, when governments' air quality data are made open, an ecosystem of scientists, journalists, software developers and others can 'humanize' these data, galvanizing local communities.

Our grassroots, global community, OpenAQ (openaq.org), noticed that many countries publicly share air quality data, including in highly polluted places. The problem is that these data are often temporarily available and are always in disparate forms, making it difficult to easily access. Through an open-source effort, we have built a system that aggregates data from 47 countries and makes them truly open. We now receive roughly one million data requests per month to our platform, with uses from health-focused research to apps.

OpenAQ is one of several emerging global, grassroots open-source, open data groups that are opening up new sets of data in several fields and building communities doing impactful work around them. The emergence of collaborative software tools, the availability of cloud computing, and a growing open-source, open data culture are making it possible to build datasets, technologies and resources for scientists and others that otherwise cannot be built through traditional institutions. In the case of OpenAQ, our community is enabling previously impossible science, policy and activism through open data.

Follow OpenAQ on Twitter @Open_AQ

Nonprofits Starting to Use Open Science to Extend Their Missions

Maryrose Franko, PhD
Health Research Alliance
Executive Director



"An old tradition and a new technology have converged to make possible an unprecedented good."

Thus begins the February 2002 document from the [Budapest Open Access Initiative](#), arguably the start of the Open Access movement, now known as Open Science. Scientists have always enthusiastically shared research results to accelerate science. Digital technology now enables sharing results in many forms with anyone, anywhere in real time. When science is "open," research pushes innovation, improves health, and can help solve global problems.

What does it mean for science to be "open"? Initially, access to publications (meaning "free, immediate, online availability of research articles coupled with the rights to use these articles fully in the digital environment", according to SPARC) was the focus. However, the ability to access and reuse research data, materials, and other research outputs has become even more vital to advancing science.

Research funders in the UK seem to be out front of US funders in requiring open data and publications, as tracked by the [SHERPA/JULIET](#) service. JULIET is a database funded by the [Research Libraries UK](#)

that evaluates governmental and nonprofit policies on open access to data and open access publishing. JULIET currently includes [110 funders worldwide](#), 14 of which are in the US, and only a handful of those are nonprofit funders.

When science is "open" research pushes innovation, improves health, and can help solve global problems.

Though not a complete picture of the US landscape, only a minority of US nonprofits have open science policies, partially because it is not yet clear to what platform we should direct our grantees to comply with these policies. Some large funders who have strict open science policies created their own infrastructure (e.g. NIH and Gates). The [Health Research Alliance](#), a collaborative member organization of 75 nonprofit biomedical research funders, has chosen to partner with the NIH's NLM and [Figshare](#) to enable members' open science policies. Figshare and the Center for Open Science's [Open Science Framework](#) are two of several options evaluated in [Nature's](#)

[Scientific Data](#). Recognizing that completely open science is a laudable goal, but not all members can get there at the same time, HRA's Open Science Task Force identifies strategies all along the "open" spectrum and helps members implement those that best align with their missions.

It should be inherent in nonprofit missions that funded research needs to be open so patients and families can make informed decisions and boards and donors are able to evaluate the impact of funding. Even more critical is the requirement that resulting data be published in an easily accessible and machine-readable format to enable reuse and analysis by other researchers. Only then can the impact of the funding be multiplied — increasing the potential for significant and far-reaching advances and scientific innovation.

Read more about Health Research Alliance at www.healthra.org