

IVI



INNOVATION AND  
VALUE INITIATIVE



HOSPITAL  
PATIENT

ENDOCRINOLOGY  
ALLERGOLOGY  
STOMATOLOGY

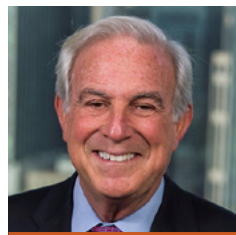
IOLOGY  
THALMOLOGY  
HOPEDICS

TECHNOLOGY  
PHARMACEUTICAL

## 2020 ANNUAL REPORT

The Innovation and Value Initiative is an independent, nonprofit research organization that puts patients at the center of value assessment.

# IVI Is Leading at a Crucial Moment



Reflecting on 2020, it was a year like no other. The COVID-19 pandemic was unprecedented and brought far-reaching change in the global economy, science, health inequalities, and how we value our investments in health care.

What became painfully clear as the pandemic wore on is that our health care system, already under enormous strain and pressures, was ill-equipped to respond to a public health crisis of this magnitude. Tension emerged about how resources are allocated across public and private health systems, and about the tradeoffs that challenge those that deliver, pay for, and receive care.

At the same time, awareness grew about the relevance of patient differences for both treatment choice and vaccine adoption and outcomes, and of the personal loss and cost burdens borne by patients, families, communities, and nations that surpass the price of a drug or intervention.

Emerging from an equally tumultuous political transition, there is consensus that our health care system must focus to a far greater extent on value and innovative health solutions, including digital health, greater access to care, new sites for care delivery, and evidence-based medicine. New approaches are needed to contain health care costs and reimbursement linked to health outcomes and value is an integral component of new payment models. Health care costs are one key variable in the complex equation that results in value to our society.

Which brings me to the important contributions of the Innovation and Value Initiative.

IVI is doing the important work of developing new frameworks for value assessment that test evolving methods and incorporate multiple perspectives. Our principles reflect our belief that value assessment must be a capability that informs careful balancing of resources with broader benefits for society.

IVI believes the patient voice must be incorporated at all stages of value and health technology assessment. And while the cost of treatments and drugs is a key concern, listening to patients gives us insights on other aspects of treatment patients think are important. These include patients' ability to be productive and employed; impacts on their families and caregivers; and patients' ability to be hopeful about their prognoses. Such learning is critical to improving the science behind new treatments, defining optimal treatment pathways, and measuring impact on health and well-being.

To realize this new vision for value assessment, IVI embraces an inclusive approach that brings together a range of stakeholders — patients, researchers, providers, and payers. IVI's Open-Source Value Project demonstrates our commitment to fully transparent and freely available resources for health technology assessment. Both are crucial components of a trust-based dialogue about measuring and paying for value.

IVI's patient-centric, transparent approach to value assessment is right for our times. The challenges confronting our nation's health and health system need creative solutions that can adapt to evolving science, new methods, and a broader definition of value. I hope you'll get involved with our work.

Samuel Nussbaum, MD  
Board President, Innovation and Value Initiative

# Living Out Our Principles



During a challenging year for our country — and the health and well-being of its people — IVI has managed to stay the course in building tools and methods to improve value assessment in health care.

In late 2020, the IVI team developed [Principles for Value Assessment in the U.S.](#) We weren't starting from scratch; patient-centricity, transparency, and fully open-source models have been hallmarks of our approach since the organization's inception.

But more fully articulating our guiding principles was an important exercise. Our vision for high-quality value assessment doesn't quite match the prevailing methods, so we thought it valuable to succinctly make our case. And these principles don't sit on a shelf; they're a roadmap of sorts for our leadership and staff as we work to realize our vision.

IVI believes that patients should be included in the modeling process. We invest heavily in research to identify new methods so that patient input can be authentically represented. Our first Methods Summit in 2020 brought together a range of stakeholders to grapple with these issues. The collective learnings provided important direction to our work, and I'm pleased to report that the Methods Summit will be an annual event.

IVI is nimble. As the grim reality of the COVID-19 pandemic became clear early in 2020, we convened a webinar series in collaboration with The International Society for Pharmacoeconomics and Outcomes Research, exploring healthcare access, the role of research, and the need for global collaboration. As the world was upended by this pandemic, IVI played a small role by exploring its impacts on the healthcare infrastructure.

I'm proud to say the IVI team has been living out these principles effectively. There is meticulous work ahead to develop patient-focused, adaptable models for value assessment — and IVI is doing that hard work, collaboratively and deliberately. The new economic model under development for major depressive disorder, under the guidance of a multi-stakeholder Advisory Group, is but one example.

I hope this report will give you a better sense of our work. And if you see alignment with our vision, I encourage your organization to become a member. As an independent nonprofit, member involvement is key to IVI's continued success.

A handwritten signature in black ink that reads "Jennifer Bright".

Jennifer Bright, MPA  
Executive Director, Innovation and Value Initiative





## Authentic Patient-Centricity

★ **IVI is expanding patient partnerships in governance, priority setting, and the creation of models. Our founding principle is that value assessment should reflect the diversity of patient experiences.**

IVI created the [Patient Advisory Council](#) in 2020 to ensure that patient-centricity and transparency remain central to its research and programs. Comprised of patient advocates and leaders, the council's deliberations help inform research strategy and priorities for IVI — and foster authentic patient engagement.

As part of developing its next Open-Source Value Project model in major depressive disorder, IVI is partnering with the Patient-Driven Values in Healthcare Evaluation Center at the University of Maryland to pilot the use of patient-derived value elements. The model will prioritize elements that matter most to people living with this condition. Life impact and social impact, for example, are important elements typically not incorporated in value assessment.



*If 2020 has meant anything it has meant redefining what we value in health and healthcare. The role that IVI can play has only become more essential.*



—Donna R. Cryer, JD, Founder & CEO, Global Liver Institute

# Advancing the Science

★ **Anchored by the Open-Source Value Project, improving the science of transparent value assessment was perhaps IVI's most notable contribution in 2020.**

In early 2020, IVI released an updated version of its economic model for rheumatoid arthritis (RA) therapies. Iterating and improving on models is a hallmark of the development process. The improved model incorporates additional treatment options, updated treatment effect estimates based on additional randomized controlled trial evidence, and updated cost estimates. The model helps decisionmakers identify high-value therapies by simulating the lifetime costs and benefits of different strategies for treating patients with moderate to severe RA.

IVI believes that active engagement from a variety of stakeholders is key to developing patient-centric value models. Since its inception, the major depressive disorder model has been informed by a 20-member Advisory Group. Comprised of patients, employers, clinicians, innovators, payers, and researchers, the Advisory Group has yielded valuable insights for model design.

An ongoing challenge in value assessment is quantifying and measuring patient preferences. Through a partnership with the RAND Corporation, IVI is exploring the potential of direct patient input to inform value and health technology assessment. Via online patient communities, RAND researchers tested a system for collecting patient-important outcomes using goal attainment scaling, with the ultimate goal of incorporating the value of care to patients themselves.



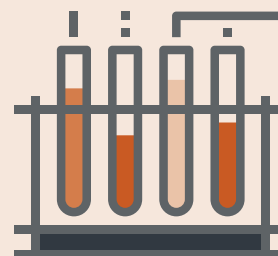
*Employers need value assessment models that incorporate real-world patient experience and employer-relevant costs and sources of value, including absence and productivity consequences. With a more comprehensive understanding, employers can feel confident in offering higher-value benefits to employees and their families.*



—Bruce Sherman, MD, Medical Advisor  
National Alliance of Healthcare Purchaser Coalitions

**\$1.65**

**million invested in research projects in 2019 and 2020**





Andrew Hu, MPP, Director of Public Policy & Government Relations for the Patient-Centered Outcomes Research Institute, addressing participants at the IVI Methods Summit in February 2020.



## Convener for Value Assessment

**★ As IVI does the painstaking work of improving the methods for patient-centered value assessment, convening forums for broad input and collaboration is crucial.**

IVI hosted a first-of-its-kind Methods Summit in February 2020, supported by a Patient-Centered Outcomes Research Institute award.\* A cross-section of healthcare leaders identified gaps in value assessment and prioritized scientifically valid avenues for doing better — from improving data inputs, to understanding better total cost of care factors, to evaluating novel methods. Plans are in place for a Methods Summit in fall 2021.

The COVID-19 pandemic has disrupted myriad aspects of daily life worldwide. IVI and The International Society for Pharmacoeconomics and

Outcomes Research responded with a **series of five webinars**. Experts explored healthcare access, the role of scientific research, the need for global collaboration in achieving effective (and cost-effective) care — and the role that value and health technology assessment can play amidst this grave pandemic.



**708**

participants in IVI-ISPOR COVID-19 webinar series

**73**

participants in National Alliance of Healthcare Purchaser Coalitions/ National Health Council roundtables with patient group and employer representatives, funded by IVI

**35**

organizations represented at 2020 Methods Summit



\* PCORI Eugene Washington Engagement Award (EAIN #00101-IVIF)

# Making the Case

★ Armed with a new vision for value assessment, IVI is making its case in the “public square.”

## The Importance of Collaboration in Pursuit of Patient-Centered Value Assessment

Mark T. Linthicum, Susan dosReis, Julia F. Slejko, T. Joseph Mattingly II & Jennifer L. Bright

*The Patient - Patient-Centered Outcomes Research* (2020) | [Cite this article](#)

723 Accesses | 1 Citations | 3 Altmetric | [Metrics](#)

### Introduction

Economic theory suggests that patients as the ultimate consumers of care are an essential component of any assessment of value in healthcare [1, 2]. Economic analysis aims to support efficient resource allocation by shedding light on the value of available alternatives, but capturing patient-centered value remains the focus of much theoretical debate and methodological uncertainty. Major advances not only

in research environment and through coordinated

FIRST OPINION

## Covid-19 and remdesivir: rethinking how we measure a drug's 'value'

By Patricia Deverka, Louis Garrison, and Samuel Nussbaum June 15, 2020

Reprints



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As pharmaceutical and biotech companies scramble to identify treatments for Covid-19, a new disease that initially had none, we must begin to figure out what is an appropriate pricing approach — and price — for emerging therapies. Remdesivir, Gilead Sciences' repurposed antiviral drug, offers the first opportunity to do this.

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r pricing of future st recovery for the by comparing the is standard of care for tion.



### Defining Value Starts with Patients

Authors: Alan Balch and Donna Cryer

The vast majority of experts agree that we could, and should, be doing a lot more to include input from patients in value assessment, from conceptualization to data inputs to implementation. The crux of the problem is that in today's world, we end up with models that assign a value to treatment, devoid of useful information to patients. Patients care about data related to aspects of a treatment like its side effects and the burden the treated patient may place on their families or caregiver. They also differ in their preferences — the priorities for care delivery and outcome that are important to them. For example, some patients may prefer a treatment that offers improved mobility and independence over one that has the potential for greater survival. In short, today's models are based on math, but the math doesn't necessarily have meaning.

## Jennifer Bright of The Innovation and Value Initiative: Five Things We Must Do To Improve The US Healthcare System

Dr. William Seeds Follow Jul 30, 2020 · 11 min read

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Collaboration has to happen. An open learning environment and sharing of data has to be the norm. And we have to stop saying it's difficult and instead leverage data for action by taking down the walls and making value assessment an open environment for learning and collaboration — so that we can determine a benefit to everyone.

As a part of my interview series with leaders in healthcare, I had the pleasure to interview Jennifer Bright.

Jennifer is an Executive Director for the Innovation and Value Initiative (IVI). Mrs. Bright brings over two decades of health...

## Scrip Asks...What Does 2020 Hold For Biopharma? Part 3: Policy And Regulation

Pricing And Value Questions Dominate

09 Jan 2020 | ANALYSIS

Written by Eleanor Malone @ScripEleanor | eleanor.malone@informa.com Joseph Haas | Joseph.Haas@informa.com

### Executive Summary

The US election will intensify the spotlight on drug costs, regulators will have their hands full with advanced therapy filings, and the need to address rising infectious disease threats will mount. Biosimilars, cannabis and Brexit are among other hot topics for 2020.



### Patients at the Center of It All

April 29th, 2020 | Blog

Making our way through a global pandemic will require all the assets and brain power our health system and leaders have to offer. And yet while the pandemic has been a novel disruptor, it has also served to highlight the problems our system has experienced for years, even decades. Whether we are discussing COVID-19 or any other disease, we always struggle to answer the same fundamental questions: what is the most valuable treatment for patients? How do we assess which treatments work the best and for whom? What trade-offs are patients and society willing to make to achieve health?



## Financials

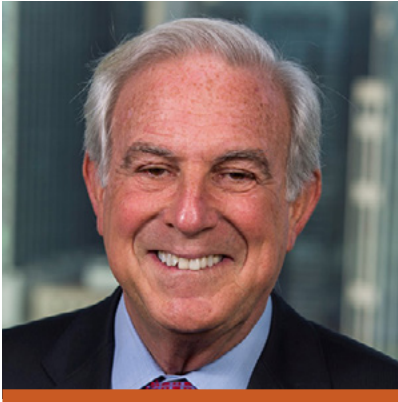
Statement of Activities for the year ended December 31, 2020

	Without donor restrictions	With donor restrictions	Total
<b>Support and revenue</b>			
Membership dues	\$2,152,750	\$853,400	\$3,006,150
Program grants	20,000	-	20,000
Contributions	250,000	-	250,000
Other income	10,275	-	10,275
Interest income	3,612	-	3,612
Net assets released from restrictions	153,000	(153,000)	-
	2,589,637	700,400	3,290,037
<b>Expenses</b>			
Program			
Research projects	799,463	-	799,463
Stakeholder and patient engagement	163,420	-	163,420
Media communications	213,021	-	213,021
	1,175,904	-	1,175,904
Supporting services			
General and administrative	365,503	-	365,503
Fund raising	139,306	-	139,306
	1,680,713	-	1,680,713
Change in net assets	908,924	700,400	1,609,324
Net assets, beginning of year	791,150	153,000	944,150
Net assets, end of year	\$1,700,074	853,400	2,553,474



# Board of Directors

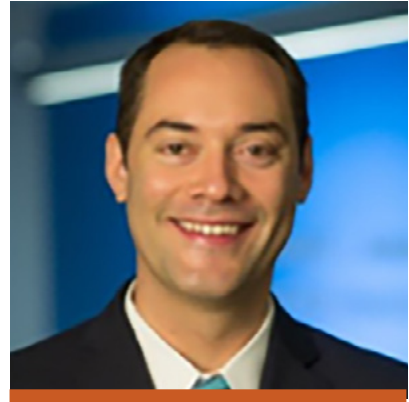
The IVI Board of Directors represents various stakeholders, including research and academia, providers, patients, payers, and pharmaceutical and medical device companies. The Board is responsible for overseeing the financial and strategic direction of the organization and provides advice and leadership support to IVI's Executive Director and staff team.



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*UCB, Inc.*



**Andrea Maresca, PhD**  
*ThornRun Partners*



**Michael Thompson**  
*National Alliance of Healthcare  
Purchaser Coalitions*



**Neil Weissman, MD**  
*MedStar Health*





## Members, 2020

IVI thanks our members for their contributions. Without their resources and expertise, this work would not be possible.

### Innovators Circle Members

AbbVie  
Amgen  
Biotechnology Innovation Organization  
Bristol Myers Squibb  
Genentech  
Merck  
National Pharmaceutical Council  
Pfizer  
PhRMA  
UCB, Inc.

### Organizational Members

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Janssen Scientific Affairs  
MedStar Health Research Institute  
National Patient Advocacy Foundation  
Neurocrine  
Partnership to Improve Patient Care

### Individual Members

Wayne Burton  
Joff Masukawa  
Sam Nussbaum  
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**Join  
today!**

## Leadership Team



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Executive Director



**Todd Bentsen**  
Director of Communications



**Rick Chapman, PhD**  
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**Mark Linthicum, MPP**  
Director of Scientific Communications



**Lisa Malecha, MBA**  
Director of Finance and Operations



**Erica de Fur Malik**  
Director of Membership and  
Patient Engagement



**Melanie Ridley**  
Director of Fundraising



**Judy Thomas**  
Operations Manager



**Richard Xie, PhD**  
HEOR Research Manager



IVI is a 501(c)(3) nonprofit research organization committed to advancing the science, practice, and use of value assessment in healthcare to make it more meaningful to those who receive, provide, and pay for care.

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