HEALTHIER TOGETHER

Connecting the science of modern medicine with the wisdom and care of a community

Meet Orleans

Orleans, a 6th-grade, cat-loving science enthusiast, was recently diagnosed with Crohn's disease. Overnight, life for this little girl and her family changed forever.

Orleans wants to understand what's wrong with her and how she can feel better.

She doesn't know if her friends will understand or make fun of her.

Orleans' parents need Answers and Support

Orleans' parents, Jody and Floyd, grapple with trying to understand how this could happen.

What does it mean for their daughter's future?

They wonder if they are somehow to blame.

They desperately want to know anything and everything about how they can help Orleans, and how to adjust to managing Orleans' life-altering chronic illness.

Navigating the healthcare system

The way the healthcare system works now, it's hard to find the answers to all these questions.

As a family, they feel lost in the maze of a complex and sometimes mystifying healthcare system, not to mention all the other needs that fall outside the halls of medicine.

Dr. Roan wants the best for her patient

Orleans' gastroenterologist, Dr. Roan, is a world-class specialist.

Dr. Roan must hone in on a treatment or combination of treatments that will alleviate Orleans' symptoms or stop disease progression.

Treatment options are derived from randomized, controlled clinical trials. These trials are the 'gold standard' in medicine.

But the 'best' treatments only reflect the average outcome that a single treatment has on a narrow and very specific group of patients enrolled in that trial.

Navigating patient care

Practicing medicine in the real world means even experts like Dr. Roan don't know how patients like Orleans will respond to treatments.

Medical experts often struggle to help individual patients, each with their own very specific set of needs and reactions to treatments.

And Dr. Roan doesn't know how to help Orleans and her parents deal with all their non-medical needs.

The way the story usually goes...

Despite incredible advancements in science and technology, Orleans' story usually goes like this:

Jody scours the internet and finds lots of scary information. She also finds a variety of support groups for parents of children with Crohn's disease.

Floyd eagerly anticipates the visit with Dr. Roan so he can find the 'magic bullet' that will fix this.

Orleans doesn't want to talk about it. She's nervous about what will happen.

?

… an unsatisfying ending

At the clinic, Jody shares what she's learned, while Floyd and Orleans wait for Dr. Roan to give them the answer.

Dr. Roan focuses on the differential diagnosis and describes treatment options that they can try – nothing is a sure thing, though.

Everyone leaves feeling vaguely disappointed that more couldn't be done.

Just because this is the way it's been, doesn't mean there isn't a better way; a way that breaks through unnecessary barriers to vital information, support and care.

We live in a world of rapidly advancing health care technology, innovation, and science. Yet the nation's healthcare system fails to deliver the best possible outcomes, despite very high costs.

The current system also prevents patients and families, clinicians, and researchers from working together to achieve transformative outcomes.
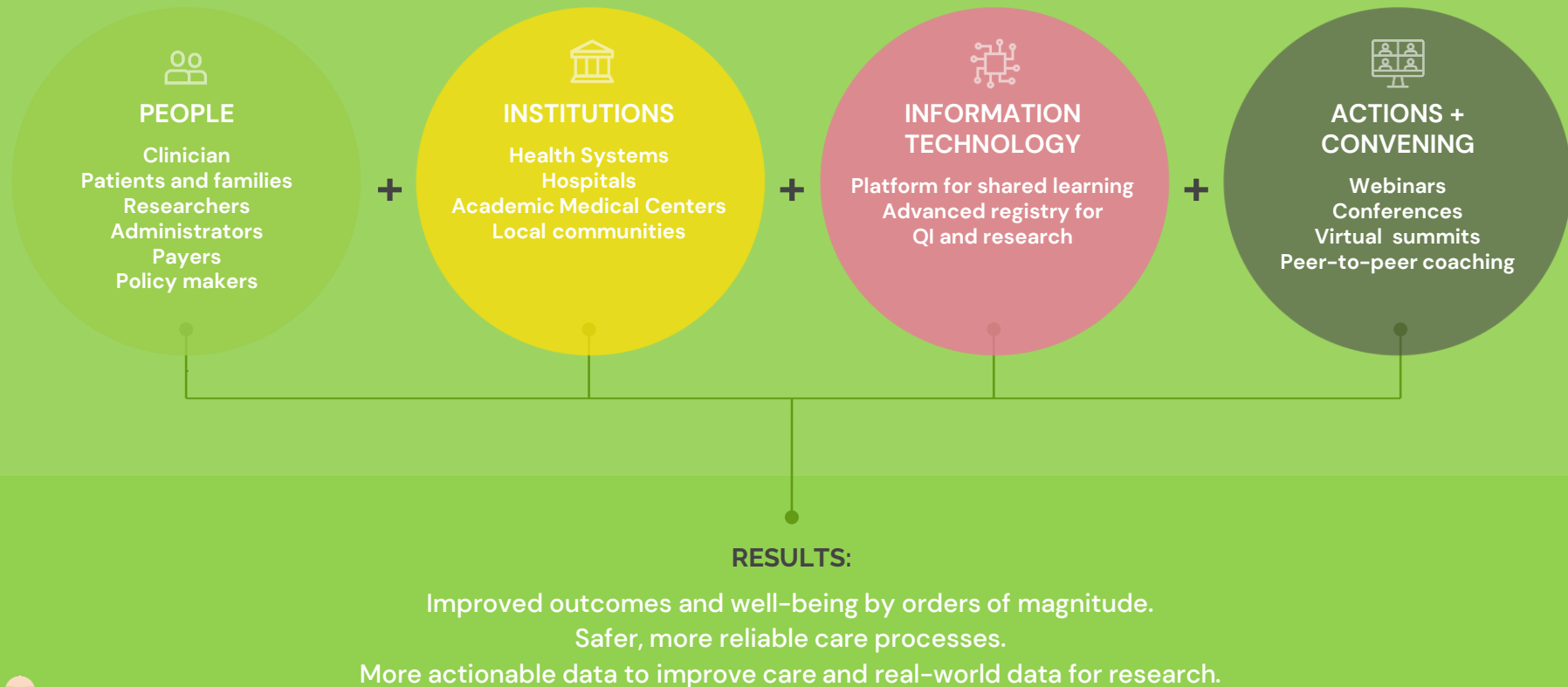
It doesn't have to be this way.

Learning Health Networks are demonstrably saving thousands of lives, helping hundreds of thousands of patients and families, cutting hundreds of millions in costs and accelerating research by more than a decade.

Learning Health Networks (LHNs) bring together large, engaged communities of patients, clinicians, and researchers combining their insights and expertise with the best science, tools, and technology.

Learning Health Networks Bring Together

PEOPLE

Clinician
Patients and families
Researchers
Administrators
Payers
Policy makers

+

INSTITUTIONS

Health Systems
Hospitals
Academic Medical Centers
Local communities

+

INFORMATION TECHNOLOGY

Platform for shared learning
Advanced registry for
QI and research

+

ACTIONS + CONVENING

Webinars
Conferences
Virtual summits
Peer-to-peer coaching

RESULTS:

Improved outcomes and well–being by orders of magnitude.
Safer, more reliable care processes.
More actionable data to improve care and real–world data for research.

Bianca: the expert patient who wants to help

A recent college grad, Bianca was diagnosed with Crohn's disease at age 11. She learned to manage the condition and sees herself as an expert patient.

Bianca successfully navigated the social difficulties of telling friends she has a chronic intestinal disease and has lived experiences with treatments like an ostomy.

As someone living with Crohn's, Bianca knows the wisdom she's gained can make a difference for others with the disease, particularly for a young girl like Orleans.

Dr. Kapour: the researcher with a good idea

Dr. Mitch Kapour developed a system for patients to track the effects of treatments, like the treatments that Dr. Roan, Orleans and her parents are considering.

The information Dr. Kapour tracks helps physicians, current patients, and future patients make the best, most informed decision about their care.

Protocol of a Pilot Study of Technology-Enabled Coproduction in Pediatric Chronic Illness Care

Nurse Mars:
the patient care expert

Nurse Mars uses Dr. Kapour's system to help patients and clinicians share information and learn together about which treatments might work best for an individual patient.

Nurse Mars puts together educational materials for her patients to walk them though setting up the app and what to track. She shows them how to take the tracking tool and connect it with a dietary modification.

Nurse Mars also recommends a cookbook written by patients and parents in her network. The cookbook serves a companion to the app that allows patients to figure out how to match dietary restrictions with delicious, nutritious recipes that help alleviate symptoms and improve day-to-day life.

Caring & Connecting

They may have shared motivations and goals, but Bianca, Dr. Kapour, and Nurse Mars live and practice in different cities. They don't even know each other.

And they've never heard of Dr. Roan, Orleans, and Orleans' family.

These are nine people with penetrative insights from different vantage points into a single chronic illness.

These are nine out of potentially thousands, hundreds of thousands, and even millions of people willing and eager to contribute first-hand experiences, insights, expertise, resources and knowledge.

These contributions can be synthesized to produce inexhaustible answers to meet and exceed the needs of everyone joined together in a sharing and learning network; a community dedicated to improving the lives of people living with chronic illness.

Results

BEFORE LEARNING HEALTH NETWORKS

It takes 17 years from evidence
to application in practice

Widespread disparities in practice

Inefficiencies slow study completion which prevent
approval for treatments, therapies, tests, and devices.

Physicians lack the data to tell their patients what to
expect based on the last 1,000 patients like them.

Patients and families not involved in
deciding research priorities

**The old model cannot keep up with the
explosion of new evidence and technology**

AFTER LEARNING HEALTH NETWORKS

Less than 3 years to design and diffuse new evidence (e.g.
new models of care for opioid exposed babies, treatment of
infants with hypoplastic left heart syndrome, etc.)

Reliable implementation of evidence and best practices across
hundreds of hospitals that ordinarily compete

Organized clinical research communities used real world data
needed to achieve FDA approval of a life-saving device

Large patient registries with real-time data shared transparently
across hundreds of healthcare organizations.

Patient designed educational tools and videos. Patient-
driven research priorities

**The new model is adaptive, dynamic and fast.
Everyone can contribute.**

HEALTHIER TOGETHER NETWORK RESULTS:

Increased remission from 60% to 82% among children and youth with Crohn's Disease and Ulcerative colitis across **110 centers and 30,000 patients.**

– ImproveCareNow Network

Across 140+ children's hospitals in the "Solutions for Patient Safety Network" (examples):

- Decreased serious safety events by 32%
- Adverse drug events by 74%
- Unplanned extubations by 42%

In 2020, these results and more **saved 18,631 children** from serious harm and **saved $380 million.**

40% reduction in mortality from hypoplastic left heart syndrome (HLHS) and **reduced growth failure from 30% to <10% for 95% of all children** with this condition in the U.S.

– National Pediatric Cardiology QI Collaborative

Decreased stroke rates **by 50%** in children with heart failure who require a cardiac assist device **across 50 hospitals.**

– ACTION Network

Used real-world data **to achieve FDA approval** for life-saving cardiac devices in children previously available only to adults.

– ACTION Network

HEALTHIER TOGETHER NETWORK RESULTS: (CON'T)

Decreased elective preterm birth 75% across birth hospitals in Ohio (**sustained reduction of >65,000 elective preterm births over 10 years)**

– *Ohio Perinatal Quality Collaborative*

Reduced births before 32 weeks' gestation **by 6.6%** *across Ohio*, including reductions in repeat early preterm births in women insured by Medicaid **(17% decrease)** and African American women **(20% decrease)**

– *Ohio Perinatal Quality Collaborative*

Reduced late-onset infections in infants born at 22 to 29 weeks gestation **by 20%** among 24 NICUs in Ohio

—*Ohio Perinatal Quality Collaborative*

Reduced hospital length of stay for infants with Neonatal Opioid Withdrawal Syndrome by **2 days** across all of Ohio

– *Ohio Perinatal Quality Collaborative*

HEALTHIER TOGETHER NETWORK RESULTS: (CON'T)

43% improvement (from 46% to 66%) in the percentage of 11,000 Cincinnati Public School children proficient in 3rd grade reading reflecting hundreds of additional urban children reaching the target

– All Children Thrive Network

18% reduction in bed days (about **190 fewer days in the hospital/year) for children in the 3 poorest neighborhoods** of Cincinnati with **8,800 children**

– All Children Thrive Network

Reduced acute rejections in children with kidney transplants 44% across 12 pediatric nephrology centers.

– Improving Renal Outcomes Collaborative

More than **$75 million in grant funding** from **NIH, AHRQ, CMS, PCORI** and other sponsors.

More than 1**40 publications across leading journals** including *JAMA, British Medical Journal, Pediatrics, Neurology, American Journal of Transplantation, Mayo Clinic Proceedings, JAMA Pediatrics* and many more.

AWARDS

2016 Drucker Prize for
Social Innovation

Children's Hospital Association
25 Biggest Pediatric Health Care
Innovations in 25 Years

2017 National Quality Forum
John M. Eisenberg Patient
Safety and Quality Award

CDC recognition for
leadership in perinatal
quality improvement

2018 RWJF Culture of Health
Award Finalist (All Children
Thrive Network)

RESEARCHER

Learning Health Networks dramatically accelerate research and translation of new evidence to the bedside. The new model leverages real-world data to achieve FDA approval for life-saving devices for children. These new ways of collaborating are eliminating the artificial boundaries between care, improvement and research."

– Angela Lorts, MD, MBA, Associate Chief Quality Officer, Cincinnati Children's Hospital Medicine

PATIENT

By participating in a Learning Health Network of doctors, nurses, patients and families, I found a culture of people who really want to collaborate. I've been able to be vulnerable, to share my experiences and be heard. Everyone in a Learning Health Network can contribute their expertise in ways that make a difference."

– Christian Lawson, Patient Leader, ImproveCareNow Network

CLINICIAN

Learning Health Networks bring an inclusive, all-in approach. Sometimes you are subject to healthy peer pressure, but you know you have the support to do daunting work. The Network provides a mechanism to bring technical information to life. It weaves it into the fabric of the social interactions that are the engine of improvement."

– Trey Coffey, MD, Medical Safety Officer, Toronto Sick Kids Hospital, Associate Clinical Director of Solutions for Patient Safety

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The work that you and your teams have done in QI, patient safety, and social determinants of health has been inspiring to watch. It has provided the conceptual framework and the implementation infrastructure to maintain the social contract between our profession and our patients in the 21st century. Co-design, data, research, QI science, systems-thinking, stakeholder engagement, have improved patient safety in general and disease-specific outcomes in particular. And I think the systematic application of these principles to social determinants in the All Children Thrive program is unique in the country."

—DAVID NICHOLS, MD, MBA,
CEO OF THE AMERICAN BOARD OF PEDIATRICS

"

You have one of the most impressive stories in the nation, by far. Not only data sharing, but robust outcomes and authentic patient/family centricity and co-collaboration. I wish I could clone your initiatives. I also wish I could clone your commitment to keeping the patient the North Star. Sadly, not everyone in healthcare maintains that laser focus."

—LAURA ADAMS, RN, MS, SPECIAL ADVISOR, NATIONAL ACADEMY OF MEDICINE; FOUNDING PRESIDENT AND CEO RHODE ISLAND QUALITY INSTITUTE

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Over 10 years ago, the National Academy of Medicine created a vision for a learning health care system. This vision applies both within organizations and in some even more important ways, among organizations. We always know more, and can learn faster, together than apart. Learning Health Networks are turning this vision into a reality. We need more of them—engaged patients, clinicians, researchers, and health care organizations, networking together, simultaneously improving care and accelerating research. Networks are a transformational approach to improving health and well–being at unprecedented scale and speed. We urgently need to broaden the reach and use of network learning models, for the benefit of patients, families, communities, and health care as a whole."

—DONALD BERWICK, MD
PRESIDENT EMERITUS AND SENIOR FELLOW INSTITUTE
FOR HEALTHCARE IMPROVEMENT

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OUR COMMUNITY OF NETWORKS

We are Healthier Together

THANK YOU