ICHOM

what matters most

Patient Outcomes and the Transformation of Health Care

this is an
exciting
time to be
in health
care

Introduction

Dear reader,

Value-based health care is no longer merely an aspirational goal or an academic concept to be defined and debated. It is happening now, and evidence shows that it is working: driving improved outcomes for patients and reducing costs. The stories, articles, and case studies in the pages that follow attest this new reality, providing rich examples of individuals and institutions around the world that are leading the way. The cases in these pages show that outcomes measurement is needed (the "why"), feasible (the "how"), and that, once available, outcomes data have huge potential to improve care and curb costs (the "what").

I hope you are convinced and inspired by this book – convinced that now is the time to embrace value-based health care and outcomes measurement, and inspired to champion the transformation within your organization, community, or country. Those who join the effort today will be the leaders of tomorrow. We encourage you to be among them.

We are grateful for the support that has helped us to grow ICHOM into a respected and path-breaking non-profit institution in the past two years. And we thank all of our friends who have generously contributed to this book.

On behalf of the ICHOM team,

Christina Rångemark Åkerman, MD
President, ICHOM

Jens Deerberg-Wittram, MD
Founding President and Executive Board Member, ICHOM

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why

Outcomes are the
results of treatment that
matter most to him.

She is results-oriented –
and her health care
should be, too.

Accessible, reliable outcomes
information allows her
to make informed decisions
about her family's care.

He knows he's getting
the care he needs, at the right
place and the right time.

Knowing his patients' outcomes – right after treatment and over time – means he never stops learning.

Helping patients achieve good outcomes is why she went into medicine.

why out-comes ?

Outcomes are the results that matter most to patients – and, often, to parents seeking the best care for their children. When a child needs medical attention, regardless of the condition he or she faces, parents are concerned about outcomes: the short-term and long-term results of treatment that their kids will experience.

It is 2003. I am in labor. The pain is excruciating. It's six hours after my first contraction and I have arrived at the hospital, one of Chicago's most renowned. My plan is to deliver via VBAC (vaginal birth after Cesarean). My contractions are coming at three-minute intervals, but I am only two centimeters dilated. My care team tells me that this is insufficient, that I should be progressing faster, and advises so-called walking therapy. I realize that a VBAC is off the table, but the pain refuses to let up. It becomes too much to bear. Back in bed, I ask again and again for a C-section. Again and again my pleas are rebuffed.

Another ninety terrible minutes pass. I am told – incredibly – that I am not in labor at all! I am told to head home and come back when I am actually in labor. I will not go home, I tell the care team. I can't go home. They begrudgingly transfer me to a perinatal unit. There, I begin to hemorrhage vaginally. I begin to vomit.

Anxious nurses page the doctors, but only after five separate pages does a doctor arrive. He says I am enduring a massive uterine rupture. The obstetrics team finds my beautiful baby boy, Michael, floating in my abdominal cavity. He has suffered severe brain damage. Days pass, and we remove his life support.

Six years later, Scott and I were expecting, once again. My uterine rupture had left me badly scarred, and doctors had been unsure whether I could become pregnant again, so this was miraculous news. I was overjoyed. I was also determined to take charge this time, to avoid a reprise of the misery and tragedy of six years before, to deliver a healthy, happy baby. Scott was away on business when I went for my routine ultrasound at 20 weeks; I brought along my dad. He was beaming with excitement, and so was I. As Scott had said reassuringly in the days before, the worst we would ever endure was behind us. It had to be. Lightning would not strike our family twice.

In the beginning, the ultrasound was business as usual. But as clinicians shuffled in and out and my routine exam became longer and longer, my unease began to surface. At last, the head echocardiographer handed down the verdict: my baby had TOF (Tetralogy of Fallot), four coexisting malformations of the heart. TOF often brought with it other genetic anomalies, and my baby would likely need multiple open-heart surgeries throughout his childhood. Other outcomes we had to brace for: there was a good chance he would never be physically active and would be especially prone to ADHD. He could also have critical altitude limitations – a particularly difficult challenge for our family of avid skiers.

Lightning struck twice, but I would not be burned again. Ever since Michael's passing, I had been thinking about how I could help improve health care structurally, systemically (my background is in business strategy, so this is how I was trained to think). After my baby's TOF diagnosis, my focus became that medical condition and its outcomes. After mortality, what were the most important TOF outcomes I should worry about? Would my son be able to live a normal life? Could he play sports, take music lessons, or hang out with friends? Would he even be able to go to a traditional school? What complications might he experience after surgery? What would his day-to-day quality of life be? Would he live in pain – or, worse, in fear? My ultimate question: what decisions – about hospitals, surgeons, and treatments – could I make to give my son the best chance at a happy, healthy life? These are questions I think all parents in our situation would ask.

It was jarring to discover that data to help answer such questions were not available. I could find out more about a car – how much it cost, gas mileage, safety ratings – than I could about my son's care. And so Scott and I began our odyssey, from one children's hospital to another, doing the only thing we could think to do: meet with cardiac surgeons and ask them directly those questions to which answers were otherwise unavailable. We visited seven hospitals, where I gathered some of the information I was looking for.

I was only a few weeks away from delivery when the next lightning bolt struck: our baby had a severe TEF (tracheoesophageal fistula), an abnormal structure between the esophagus and trachea that would inhibit his ability to swallow amniotic fluid. The structure needed to be removed. Our baby would now need both a high-risk OB/GYN and a general surgeon. What would be the best hospital for this procedure? Would our baby face acid reflux? Would he have trouble eating and swallowing? Would he need repeated interventions throughout his childhood? TOF and TEF: in those last days of my pregnancy, those six letters consumed me.

Our long quest for good outcomes led Scott and me to a hospital in Boston, and it was there that our son, Mac, was born. He was born with an open sternum. He had a single valve-sparing TOF repair that saved him from future open-heart surgeries, as well as a TEF surgery. He spent three months in the NICU (neonatal intensive care unit), his heart rate constantly in flux, before we all returned home.

Mac is now five. He has had additional surgeries and more than two dozen esophageal dilations. He has faced myriad bouts of pneumonia, between four and six every year. He has a G-tube (gastrosatomy tube) and a J-tube (jejunal feeding tube), which send food directly to his digestive tract. But despite everything, Mac is happy. He has no altitude or exercise restrictions. He skis with us in the winter; he plays the piano and the violin. He goes to school. All things considered, Mac's outcomes were great.

After I lost Michael in 2003, advocating for patients helped me heal. Michael was a victim not of malice, but of mistakes. Medical errors must be documented alongside successes, and this information should be made accessible to both clinicians and patients. Mac's surgeries at birth were performed with amazing dexterity and skill, but they would have been for naught

Mac, five and a half years old, skiing with his family. Mac skis, goes to a traditional school, and plays piano and violin.

had other elements of his care failed. The results of care as a whole are most important, and that means we must measure the outcomes of care as a whole over time.

We have made great strides over the last decade, but we still lack the outcomes data we need. I am proud to serve on the boards of two hospital systems, where I hope to shift our focus toward patient outcomes. Care teams must start measuring outcomes consistently and for all their patients. The data collected will be invaluable. Armed with such information, patients will be able to make informed decisions alongside their providers, and doctors and nurses will be able to integrate best care practices to drive more rapid improvements. Hospital boards will be able to hold their leadership accountable.

Michael would have been eleven-years-old today. That day in 2003 was the start of a nightmare. But it was also the start of a journey to channel pain and tragedy toward good. Margaret Mead once said, "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed it is the only thing that ever has." ICHOM and its partners, by offering providers the tools to focus on outcomes, can be this small group that changes the world for patients.

why ICHOM ?

The Missing Piece

The Movember Foundation's Perspective

Paul Villanti – Executive Director of Programs at the Movember Foundation, Australia

Paul Villanti, Executive Director, Programs.
Paul oversees the Movember Foundation's program investments in prostate cancer, testicular cancer, and mental health initiatives globally.

The Movember Foundation is the leading global organization committed to changing the face of men's health. We achieve this by challenging men to grow moustaches during Movember (the month formerly known as November) to spark conversation and raise funds for prostate cancer, testicular cancer and mental health problems. The Movember community has raised over $559 million to date, funding over 800 programs in 21 countries.

For men diagnosed and living with prostate cancer, the Movember Foundation is committed to making a significant contribution at a population level. Success for us means men diagnosed with prostate cancer receiving the treatment and care needed to remain physically and mentally well.

So, how do we achieve this goal ?

Many of the answers lie in answering critical questions, such as how we distinguish between aggressive and harmless disease and slow or stop the progression of the disease. The Movember Foundation is the largest non-government investor in prostate cancer seeking to answer these questions. While great progress is being made, and Movember is playing an im-

Paul Villanti serves as a Director on the Boards of Prostate Cancer Foundation (USA) and Prostate Cancer Canada and is an Associate Director on Prostate Cancer UK. Over the past 20 years Paul has successfully led and built businesses in Australia across the infrastructure, technology, property and telecommunications sectors.

He has a particular interest in leveraging the Foundation's role as a global funder to accelerate improved health outcomes for men through global collaboration, and is actively involved in leading the Movember Foundation's Global Action Plan.

portant role in accelerating progress, it takes upwards of seven years or more to bring a new test or treatment to market. In the meantime, there are millions of men worldwide that have been treated for prostate cancer and are living long lives with significant side effects – including incontinence, bowel problems, lack of sexual function, pain, fatigue, and anxiety and depression. The number of men treated and living with prostate cancer continues to grow each year. These issues place considerable strain on men, as well as their partners, caregivers, and families.

Addressing this challenge requires taking risks, investing in innovative and positively disruptive methodologies that challenge how we currently treat men diagnosed with prostate cancer. Ultimately, we need to focus on outcomes. We need providers to measure outcomes and we need registries and national health outcomes initiatives to store this outcomes data nationally and to be able to compare outcomes globally.

This is no easy task, but it is something we are determined to achieve. What can we hinge our efforts on? Where do we make our bets?

One missing piece of the puzzle on improving patient care has been defining standard outcome measures for providers to track. We need to know which outcomes to measure. That is where bringing together an international group of experts across multiple disciplines is key. We need doctors, nurses, patients and researchers. We need international perspectives. For continuous improvement in clinical treatment and practice, we need to be able to compare patient results globally, and improve upon these results. This will speed up the identification and adoption of best practices. ICHOM is spearheading this movement on a global scale, and we are proud to be a prominent supporter of their efforts.

That is why we see outcomes measurement as a key focus – better patient outcomes means happier, healthier patients.

The Movember Foundation
The leading global organization committed to changing the face of men's health

A Question I Should Be Able to Answer

A Young Physician's Perspective

Jason Sarfo-Annin, MD – Acute Medicine Doctor at Royal United Hospital Bath NHS Trust, UK

It was my first week as a cardiac surgery senior house officer (resident), and I was excited about the job. Wanting to make a good impression, I reviewed the procedural aspects, risks, and complications of coronary artery bypass surgery in great detail. I expected that I was either going to be tested on this knowledge by the consultant (attending) or be asked by one of my patients.

A nurse approached and informed me that a patient wished to speak to me about his upcoming coronary artery bypass surgery. This patient had just been transferred to the cardiac surgery ward. I reviewed his notes, attended to the patient, and asked how I could help.

"Doctor, I want to know more about this operation," he said.

So, with my newly acquired knowledge, I explained to him the nature of his coronary artery disease and the risks of doing nothing. I then went into the details of the operation and intra-operative, early, and late complications. After a few more questions about the operation itself and his needing to be in a high-dependency unit after the operation, the patient seemed satisfied. However, my feeling of accomplishment vanished after I asked if he had any more questions.

"One last thing. How long will it be before I can go home after surgery, and how quickly will I be able to get back to my regular life? I need to be able to take the dogs for a walk in the mornings and would like to play football with my grandson. My wife also isn't too well, so I would like to get back home as soon as possible."

I stood there, flummoxed. It was a completely reasonable question and one I felt I should be able to answer. I just didn't know if he would be able to perform these activities as well as he was hoping to.

During my time working in cardiac surgery, patients have asked about outcomes ranging from the cosmetic appearance of a surgical scar, to how frequently they would need to use anti-anginal spray. I soon learned that output from services – a patient with blocked coronary arteries having surgical revascularization – and

Jason Sarfo-Annin, a young physician in the UK, recalls an early moment in his career when a patient's simple questions about resuming daily activities post-operation left him utterly stumped, despite years of medical training. As Sarfo-Annin notes, patients want to survive an illness or an operation, but they want more than just to survive: they want to walk their dogs, play sports, and return to their active, normal lives. To provide the best care, this needs to be ingrained into the way physicians practice.

a desired outcome for patients – spending a day at the shopping mall without anti-anginal spray – were not always quite the same thing. Indeed, we are taught to ask patients about their ideas, concerns and expectations, but it doesn't seem that we have made this central to how we practice medicine. I think we need to. And because patients often have their first and most frequent contact with us junior doctors, we are well placed to help make outcomes-based health care a reality.

I have learned that bridging the outcomes gap that I experienced with this patient and others requires me first and foremost to appreciate that such a gap exists. Secondly, to specifically ask for ideal outcomes before planning further management, and third, to facilitate these outcomes in conjunction with the hospital-based multi-disciplinary team. The care from the cardiac surgeons, the anesthesiologists, the physiotherapists, the specialist care nurses, the psychologists and so on combine to provide the outcomes for my patients. Not all of these care providers would have been privy to the outcome-related information provided to me by the patient unless I (or the patient) had explicitly informed them.

This holistic approach is what I as a teenager envisaged medicine to be. Being a good clinician is important but not the only factor that makes a good doctor; something more is needed. As a medical student I thought that being a good communicator was that "special something," but my first few jobs since medical school have highlighted that it is something more. You can be as fantastic an orator as Barack Obama or have the clinical acumen of Gregory House, but if you don't ask and engage with both a patient's story and his hopes and desires for when he no longer needs you, then you will never have an engaged patient. It sounds so simple, but I have come to the conclusion that understanding how a patient feels and therefore understanding what he wants is that "special something."

A doctor with that "special something" is what I still hope to become. This is why ICHOM's outcome-based approach is so exciting: it delivers the satisfaction that you have provided something that a patient wants. Isn't job satisfaction part of the attraction of being a doctor? Whatever a junior doctor's specific motives for studying medicine, we all in some way want to help people. Medical students proceed through medical school assuming that this means treating medical conditions. Outcomes-based medicine would provide a vehicle for uniting our desire to do good with the goals that truly matter to patients.

"I Wanted Us to Use Outcomes to Constantly Question the Status Quo"

An Experienced Physician´s Perspective

Hartwig Huland, MD – Head of Department at Martini-Klinik, UKE Hamburg, Germany

I have devoted much of my medical career to improving treatments for localized prostate cancer. When I was appointed Chair of Urology at Martini Klinik, Hamburg University Hospital in 1992, prostate cancer, though extremely common, was still an inconsistently treated disease. In those days, I found myself completely in the dark about my patients' results, since post-operative care was left to the private urologists outside the hospital who had referred patients to us in the first place. I tried hard to build my own database to store follow-up information, which was mainly used for clinical research at first. There was no real IT system, limited enthusiasm from my residents and from the referring urologists, and no support from clinic management or from our German grant system to finance more staff members.

A few years later, a patient of mine made an extremely generous endowment to the urology department. There were many things I could have done with the donation: build a new hospital wing or laboratory, run a clinical trial or develop more marketing tools. Instead, I decided to invest in an outcomes database. Looking back now, this was one of the best investments I have ever made.

We started by collecting outcomes data in a spreadsheet for every patient we treated. We'd enter all the data ourselves at the end of each day after clinic. As our database grew, we decided to form an "outcomes study group," made up of two documentation assistants, two database technicians, and two research fellows, dedicated to managing the data-capture process alongside clinical staff. Despite the volume of data we collect, ours is an uncomplicated, unfussy system to manage.

We had data, and now we needed to decide how best to use it. I wanted to use the outcomes to challenge the status quo, to adjust old methods or uncover better ones. In 1974, as a resident at Stanford under Dr. Thomas Stamey, I remember being impressed with the open learning culture Dr. Stamey had created within the urology department: he and his colleagues would publish reviews that analyzed and discussed outcomes data. It was a brilliant way to identify weaknesses and build on successes, and I concentrated on developing a similar culture at Hamburg.

Our department didn't just measure patient outcomes; we openly discussed the results with other physicians performing the same operations. The goal was to understand why we found the results we did. Why did one technique, for instance, produce better outcomes than the other? Every six months, we produce individual outcomes reports for each of our surgeons, which include everything from average blood loss to incontinence. We hold regular meetings to review the data and to reflect on our methods. Surgeons with better outcomes help train those with less favorable outcomes.

Our clinic finds the challenge of evaluating outcomes data – such as the benefit and harm of additional radiation after surgery – incredibly stimulating. We love being able to participate productively in international research groups like the International Cancer Genome Consortium and the International Consortium for Health Outcomes Measurement. Our investments in outcomes measurement have already paid off: we have seen higher revenues and an influx of new patients from within Germany as well as from other countries.

Most importantly, our patients are happier: for many years now, we have found that 98 percent of our patients would recommend us to a family member or friend. We are currently also the largest prostate cancer center in the world. We have complication rates far lower than the national German average. And we are still striving towards the best possible outcomes for our patients.

Professor Hartwig Huland, who has been Head of Department at Martini-Klinik since 2004, shares how the Martini-Klinik, a special clinic for prostate cancer treatment, boosted the quality of care offered to its patients by systematically measuring results after surgery and learning from that data.

Prof. Huland is the president of the German Association of Urology and a member of the German, European and American Association of Urology.

why
now
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A Health Care Revolution: Refocusing Our Health Systems on Value

The Cofounders' Perspective

Michael E. Porter, PhD – The Bishop William Lawrence University Professor at Harvard Business School, U.S.
Stefan Larsson, MD, PhD – Senior Partner and Managing Director at The Boston Consulting Group, Sweden

In 2012, Professor Michael Porter joined forces with Stefan Larsson and Professor Martin Ingvar of Sweden's Karolinska Institutet to found ICHOM. They outlined the organization's main mission: to "unlock the potential of value-based health care by defining global standard sets of outcome measures that really matter to patients for the most relevant medical conditions and by driving adoption and reporting of these measures worldwide."

Here, Michael Porter and Stefan Larsson discuss with each other the benefits of value-based health care.

Dr. Stefan Larsson: Michael, thank you very much for taking time to meet today. What was it that triggered your interest in health care? It has not been your field historically.

Professor Michael E. Porter: It's a very personal story. I think almost everybody has one of those stories. In my case, it was Elizabeth Teisberg, who used to be a strategy professor here at Harvard Business School, with whom I've written much of my work. Elizabeth had not one but two children who had some serious medical issues. As her supervisor, I talked with her for many, many hours about what she was going through and the dysfunctions of the health care delivery system. It was out of those discussions, and her personal journey, that we got fascinated with what was really going on.

Michael Porter is a pioneer in the field of modern strategy and is considered one of the foremost thinkers on management and competitiveness. Porter's core field is competitive strategy. His ideas are taught in business schools around the world and his book "Competitive Strategy: Techniques for Analyzing Industries and Competitors" is in its 63rd printing. He has spent considerable time focusing on social problems involving health care, the environment, and corporate responsibility.

Professor Porter articulated the key ideas of value-based health care with Professor Teisberg in their groundbreaking book, "Redefining Health Care: Creating Value-Based Competition on Results" (Harvard Business School Press, 2006).

As a competition professor at the core, I'm a true believer in competition. I think competition is good. I think it's one of those forces that allows human endeavor to be better. But in health care it seemed not to be working. And this, for me, was a great puzzle.

What fascinates me is that health care is an industry with an extraordinary number of highly qualified individuals – very smart people who have been trained, educated, and have lived their lives in the system, and who are known to be innovative in medicine. Why haven't we gotten further, in spite of all these qualified individuals?

First of all, I agree with everything you said. And I would also add that these people work hard. It's not lack of effort. It's not lack of commitment. So all the normal reasons why something fails, or something isn't what you hope it is, don't apply here. I think it comes from putting our medical professionals in a system that doesn't allow them, ultimately, to be successful.

And the other thing I've come to see is that people in medicine really are scientists. They are trained as scientists. They're trained very narrowly. They're trained to look very specifically at particular procedures, particular interventions, and particular drugs. It's the whole notion of the clinical trial: you do a very tightly controlled study, you have one endpoint, and you carefully design your experiment to make it a great experiment. That mindset has simply reinforced the way the system is today.

One of the observations I made when I looked at this in Sweden is that many physicians are asked to focus a lot more on costs than they feel comfortable with. And my sense is that people have become cynical. Rather than engaging in change, they've moved away from it. They feel it's something that others are forcing on them. I think value-based health care addresses change in a different way.

You are totally right. The starting principle of value-based health care is that the right goal is value, not cost. It doesn't make any sense to save money by reducing outcomes, because we know that the most powerful driver of cost in the long term actually is good outcomes. That is, if we get patients healthy, if we get them healthy faster, if we provide them with better functionality, that's the way to save money. It's not having an office visit in 13 minutes instead of 15 minutes so that we can see more patients per day. That's the wrong way of looking at the problem.

I think most physicians I talk to are perfectly aware that we have to be efficient. We don't have infinite resources. We can't have 50 percent of the national budget to spend on health care. So it's not that they're against efficiency. But what they are against is efficiency for its own sake. So I think the value framework is getting a lot of traction among the provider community because it really puts the focus where it should be.

I think we've had zero-sum competition in health care. People have been trying to get more money from the other guy – get higher reimbursement, push down reimbursement, pass costs to the patients, pass costs to the government. That's not anywhere near the way forward. Now we're trying to create a positive-sum competition where, if we improve value, everybody benefits.

We did a case study in one of the Swedish hospitals that ranked very poorly in myocardial infarction care. We interviewed the physicians and the nurses and asked them, what happened when you were ranked as poorly as you were? And in fact, the response was, this brought us together. We got together and we improved it. Within a year, this hospital reduced mortality by 50 percent. That's a very dramatic change. But it was not a negative change. It was a positive change. They teamed together for something they cared about.

And the central driver of value improvement is outcomes measurement. This is apparent not only in this wonderful work that you've done – which I think is really breaking new ground – but also in all the other work we have available showing the same thing.
For example, in the United States, we have stumbled into outcome measurement in only two areas really comprehensively. One is organ transplants, where we have universal measurement, because in order to receive an organ to transplant, doctors have to guarantee that they will report their outcomes. The second area is more of an odd case. It's in vitro fertilization. Every clinic has to report every case to the Centers for Disease Control and Prevention. And if you look at what's happened, the minute they started reporting outcomes and those outcomes started getting transparent, the improvement process took off. It happens every time. It's a law of nature. It's the force of gravity.

Sweden is a small and quite homogeneous market. How relevant are some of these analyses for the United States and other larger countries?

I think these analyses are universal. I've now had the opportunity to work at some level of depth on health care delivery in the United States, the United Kingdom, Sweden, Denmark, Finland, Japan, Taiwan, and elsewhere. And what I find is that although insurance

Stefan Larsson is a Senior Partner and Managing Director in the Stockholm office of the Boston Consulting Group. Stefan is leading BCG's Global Payer and Provider Practice. He is dedicating a significant share of his time to studying and facilitating the practical application of value-based health care and exploring its strategic implications for the health care industry as a whole.

Stefan co-founded ICHOM in 2012 and and serves on the Board.

is very different in different parts of the world, the problems of delivery are virtually identical. If you were blindfolded and you didn't know where you were, and they took you into a hospital – it could be Germany, it could be Japan – it would look the same. The organization of care and many of these issues are a function of the same fundamental level of training and the same way that medical science has developed. These issues are universal.

What would you say are the three most important barriers to overcome for value-based health care to happen?

The first barrier is to change the mindset and really understand how to look at the problem from this different perspective. For example, I still see a lot of people making the mistake of thinking that the problem is cost reduction, not value improvement.

Secondly, we have a critical lack of both outcomes data and also a critical lack of cost understanding. One of the fascinating things is that in a field that's been preoccupied with costs for 30 years, we actually know very little about costs in a way that's relevant to delivering better care, because of the way we measure costs. Like so much in health care, it all fits together. We organize around interventions, we measure around interventions, we accumulate cost around interventions – but that's not relevant for understanding value for the patients. So I think a lack of some of the fundamental data and knowledge about the value equation is a second barrier.

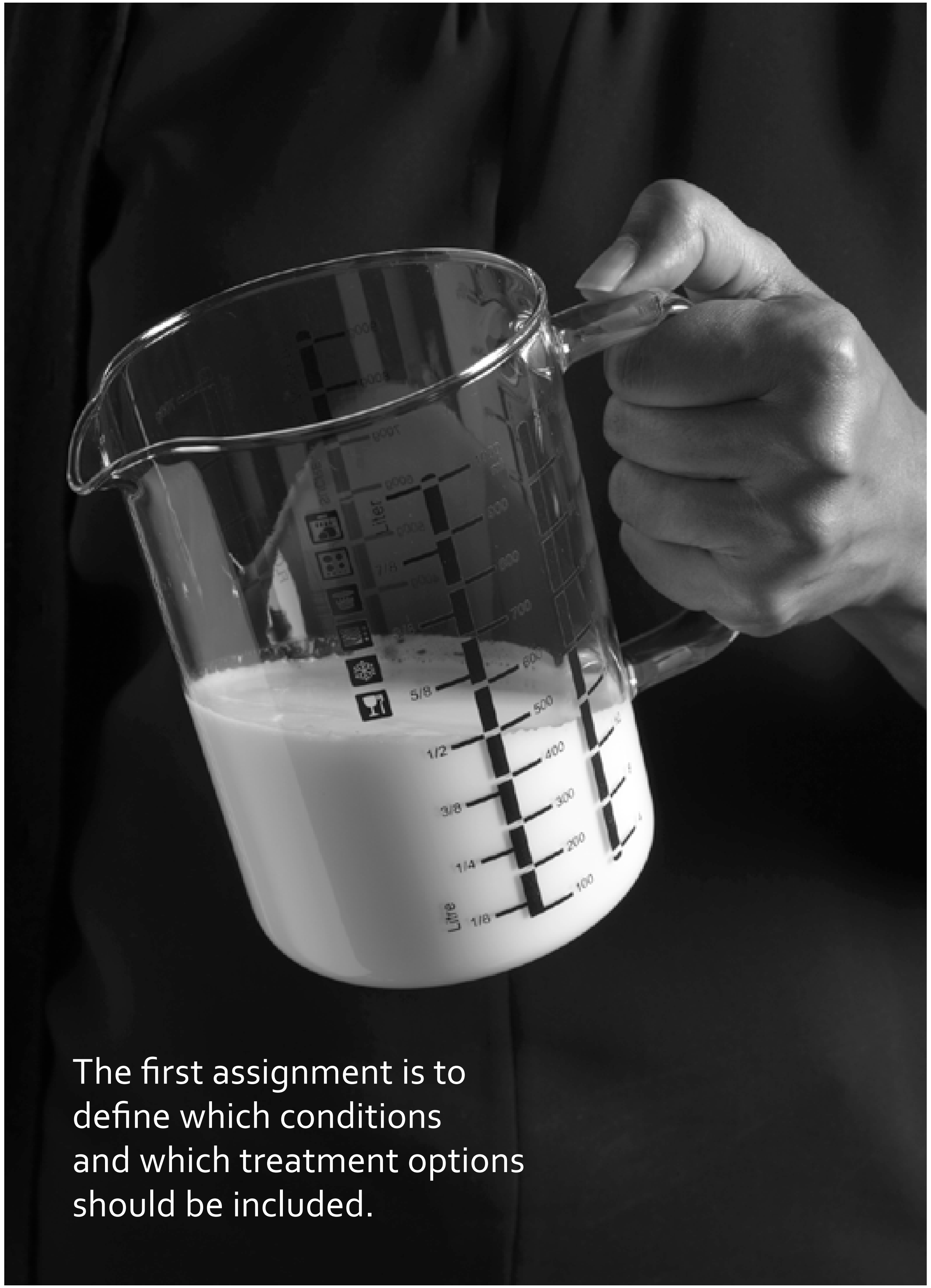
And then, third, I think that we still have a lot of misalignment among the stakeholders because the incentive structure tends to pit one party against another.

I remember when we decided to create ICHOM a few years ago. The outlook for the health care system was bleak: growing costs, aging population. Not a sustainable model. We needed to catalyze the value-based health care revolution and refocus the health care system on what matters for the patient.

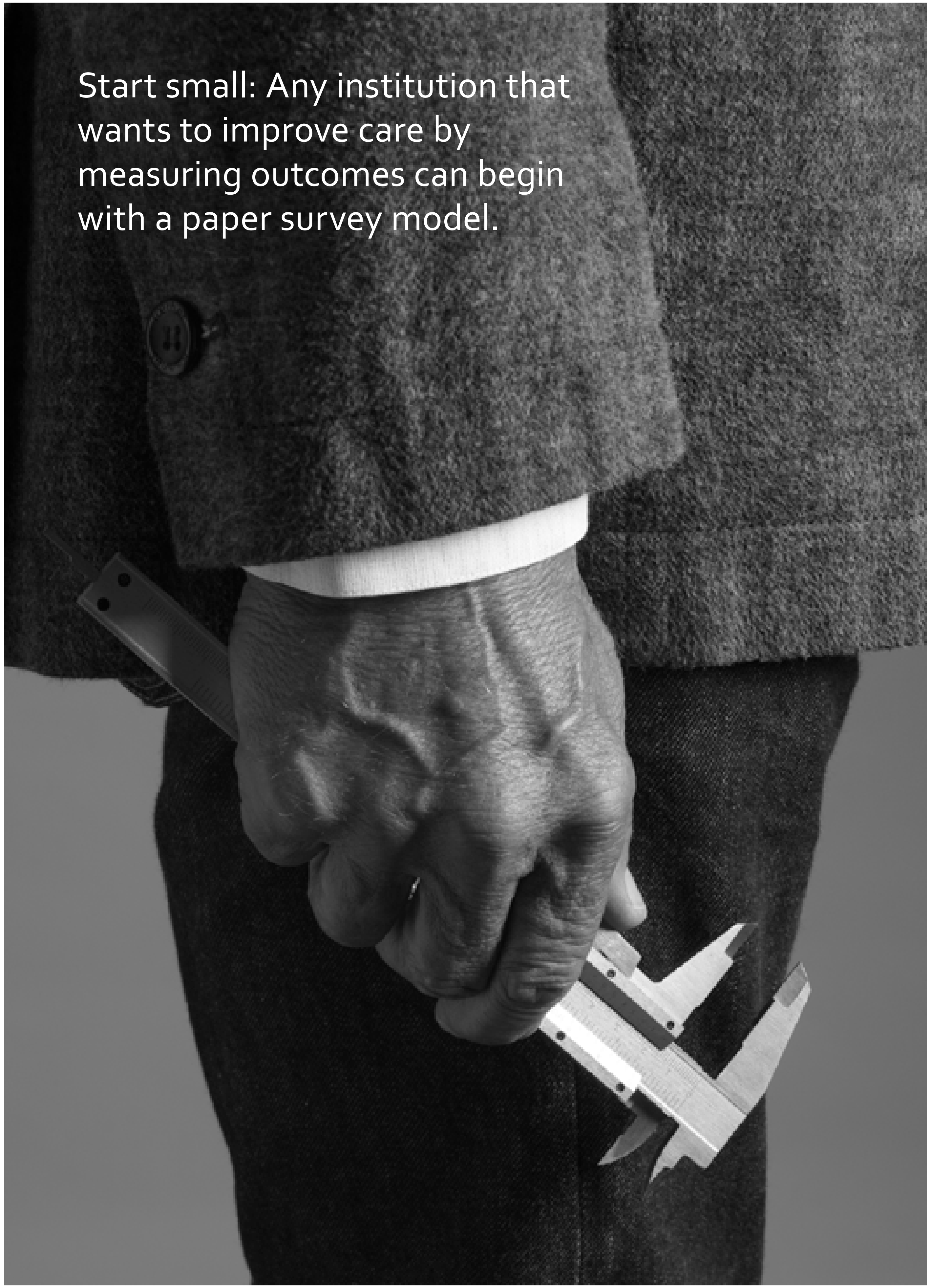
That's right. What we need is more evidence and data on both sides of the equation: outcomes that matter to patients and costs for relevant patient conditions and population segments. We need more evidence about the impact of outcome measurement on progress. And as you and I have talked about for a long time, there's a lot of reinvention of the wheel going on, particularly as we look across the world. The ability to pull together what's known about outcomes in 10 or 12 – or 15 or 20 – of the most important medical conditions will be an enormous accelerator of progress. Once people see that these are the ten measures that the most experienced colleagues around the world have agreed to be critical, then all of a sudden they don't have to go through an agonizing process. They can just get on with it. And that's the crucial role ICHOM needs to play. We need to be an organization that can catalyze the change, provide a common language to measure outcomes all over the world, and that enables transparent reporting. That's the first step of the health care revolution.

> **"The minute an organization starts reporting on outcomes and those outcomes start getting transparent, the improvement process takes off. It happens every time. It's a law of nature. It's the force of gravity."**
>
> Professor Michael E. Porter

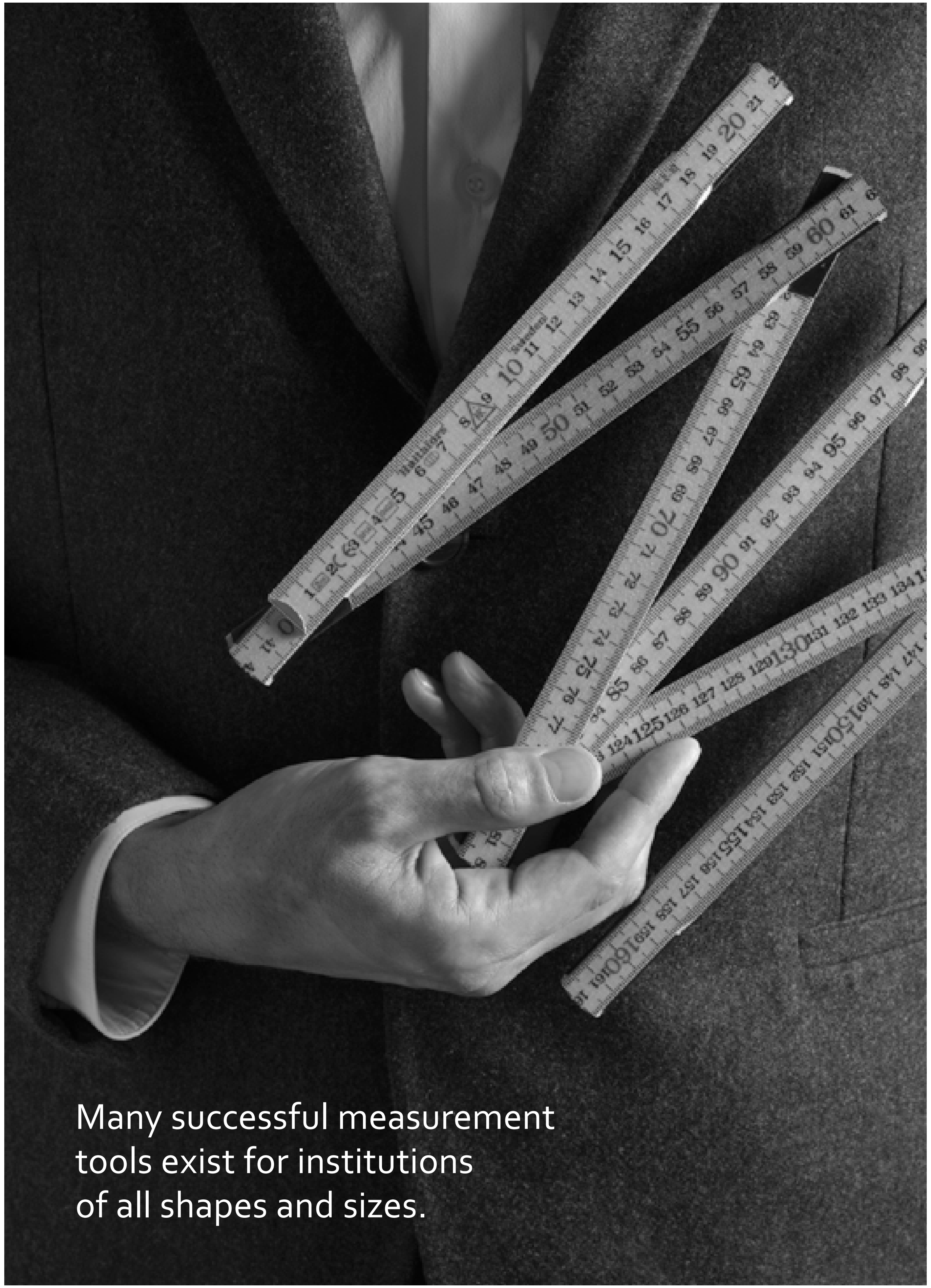
how



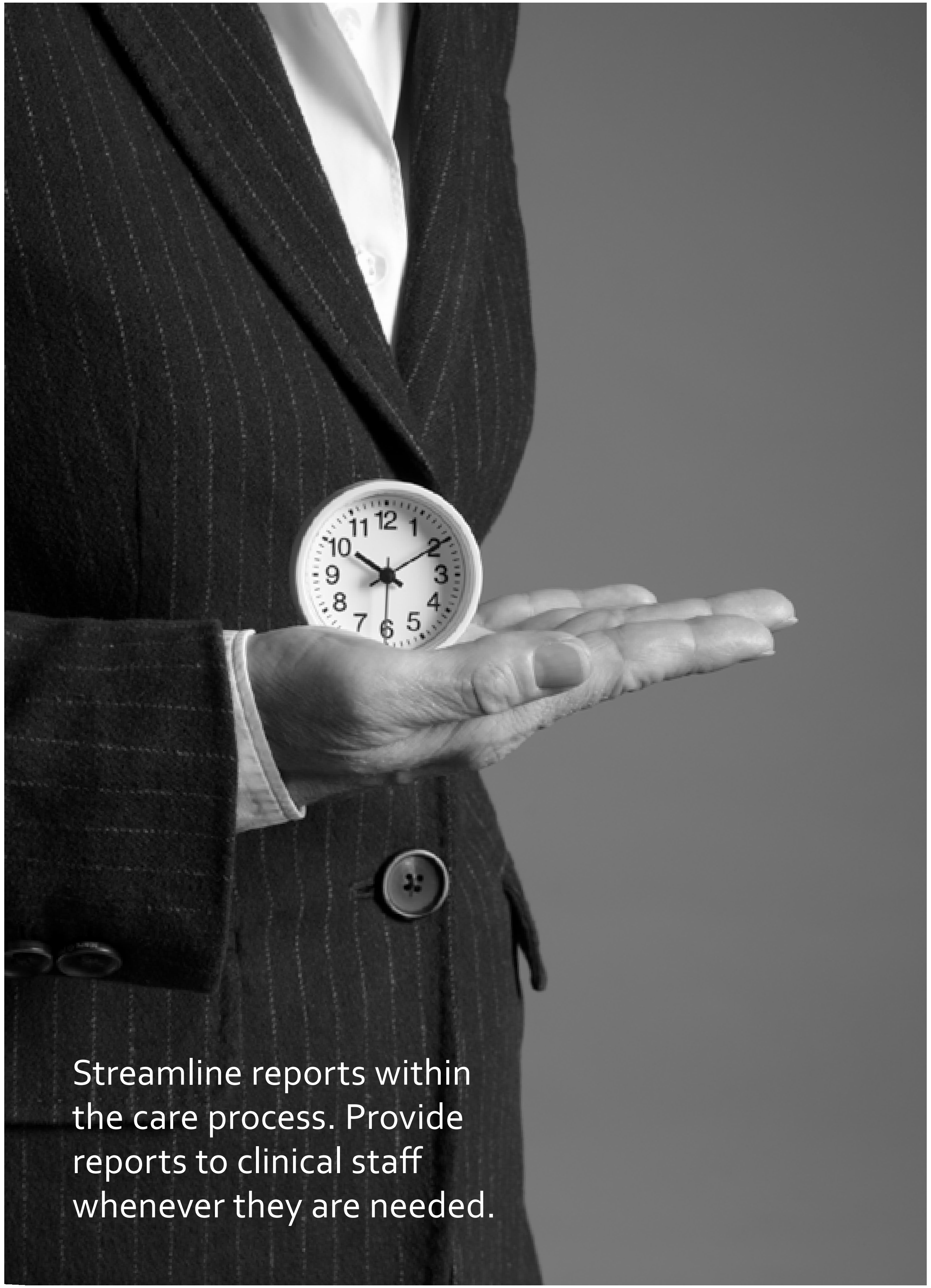
The first assignment is to define which conditions and which treatment options should be included.



Start small: Any institution that wants to improve care by measuring outcomes can begin with a paper survey model.



Many successful measurement tools exist for institutions of all shapes and sizes.

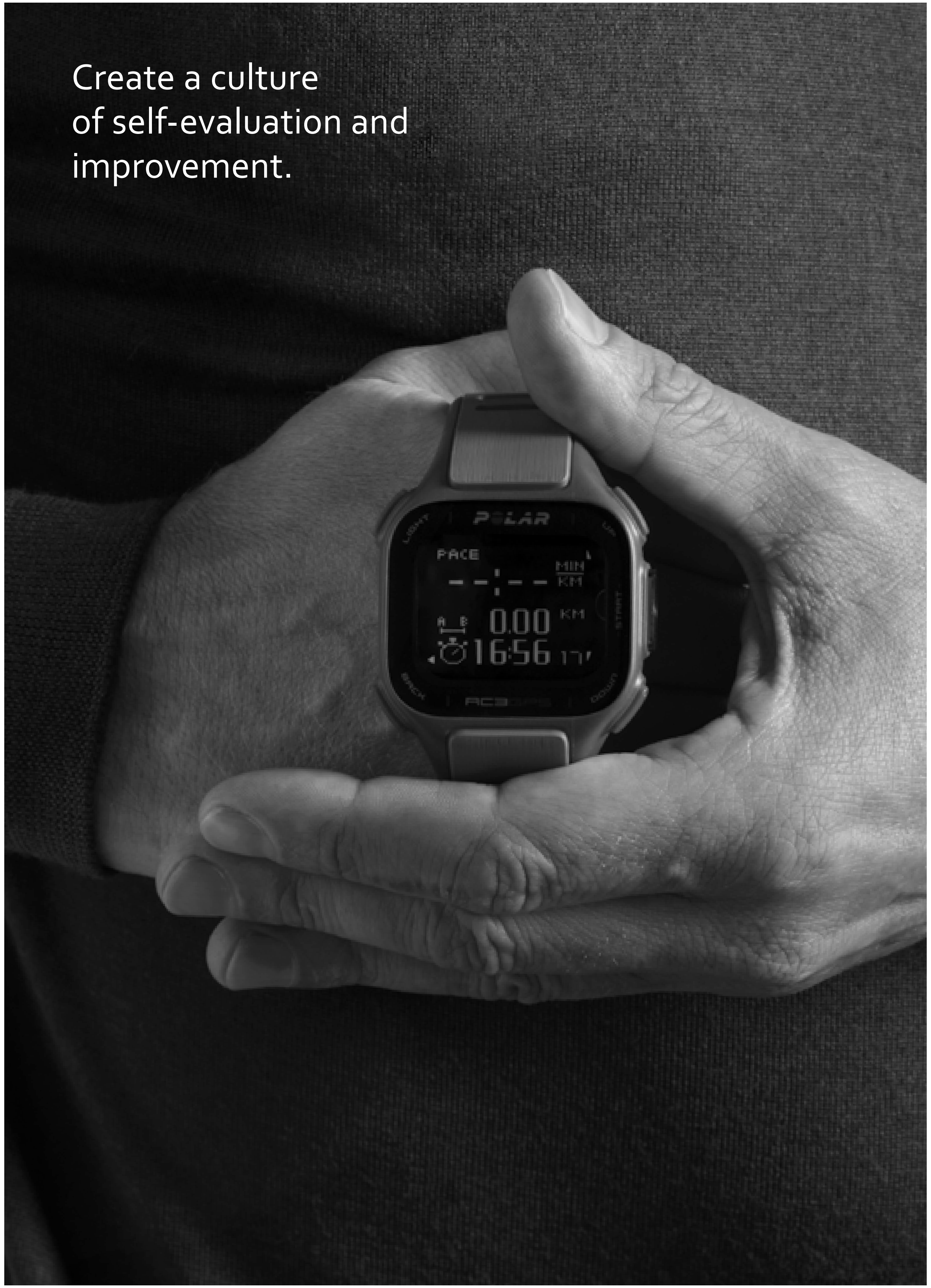


Streamline reports within the care process. Provide reports to clinical staff whenever they are needed.

Balance simplicity and clarity with comprehensiveness.

Make interpretation of reports simple.

Ensure proper analysis
and risk adjustment.


Create a culture
of self-evaluation and
improvement.

how to implement outcomes measurement

The Implementation Journey

Engage the organization

Convince the management
Obtain support from the staff
Identify evangelists
Prove the case

Set up data collection

Set up governance and project team
Assess the starting point
Develop the project budget
Identify the right tools to capture data

Measure & analyze

Ensure quality of data
Risk-adjust data
Prepare reports

Drive change

Report data
Act on data
Disseminate best practices

how to get started

The ICHOM Standard Sets: What to Measure

ICHOM is developing international standards to measure what matter to patients, at both the medical condition level and for the full care cycle

What outcomes should we be measuring? Look to patients for answers. The current health care world already deals with plenty of indicators – blood pressure, cholesterol, white blood cells count – and these indicators are at the core of a physician's work. But these measurements are mostly obscure to patients, whose chief concerns are tangible outcomes. How much pain will I feel after surgery? Will I be able to go back to work again? Will I still be able to do my shopping and live independently? Besides mortality, which is widely measured, very few health care organizations in the world track outcomes that really matter to patients.

The ICHOM Standard Set

At ICHOM, we wanted to solve two problems. First, measurement of outcomes is usually performed at the procedure level (e.g., spine surgery, prostatectomy or heart catheter). We believe outcomes should be measured on the level of a patient's medical condition (e.g., back pain, localized prostate cancer, or coronary artery disease) for the full care cycle, making it possible to compare treatment options and inform patients about treatment choices. Second, very few international standards exist that recommend what measures of success should be systematically tracked.

Let's consider a condition such as low back pain. Surgery is not the only treatment option. Conservative therapy (e.g., physical therapy, chiropractic,...) can be a good choice in many cases. But to make an informed choice on their treatment options, patients need to be able to compare outcomes of each and select the one that seems the most appropriate for their medical condition and personal situation. This can only be achieved if outcomes are tracked for a given medical condition, in a standard way and for the full care cycle.

ICHOM is thus developing Standard Sets of outcomes – a list of outcomes that should be systematically tracked – for several of the most common and burdensome medical conditions.

Basic Approach: Working Groups

What exactly are the outcomes that should be measured for a given medical condition? To answer this question, ICHOM assembles Working Groups of leading physicians, patient representatives, and outcomes experts from registries. Working Groups are typically made up of 15-25 people from around the world who cover the range of specialties and procedures involved in the treatment of a specific medical condition. Most importantly, our Working Group members are volunteers who have equal voice in determining a Standard Set.

Each Working Group is led by a senior physician who also collaborates closely with the ICHOM project team to develop proposals for the full Working Group to debate. The ICHOM project team is made up of a project leader (who works from ICHOM's Cambridge (US) or London offices and liaises with other working group members), the ICHOM management team, and a research fellow (typically a resident physician who provides key research support).

The first assignment for each Working Group is to agree on the exact scope of a Standard Set: defining which conditions and which treatment options should be included in the set. ICHOM's project team guides the Working Group through the stages required to define the outcomes domains, the instruments needed, and the risk factors and baseline information to be collected. ICHOM has refined its methodology such that a Working Group is able to develop a functional Standard Set for a medical condition within six to eight months, with one two-hour meeting each month.

The goal of each Working Group is not only to define a list of outcomes that should be systematically measured, but also to recommend how to measure them, and over what time frame. The result is the Outcome Wheel, accompanied by a reference guide that provides clear instructions for measurement.

At the end of each development process, we aim to publish the Standard Sets in leading peer-reviewed scientific journals. We are proud to have the Standard Set for Localized Prostate Cancer published in European Urology. The first of many to come.

Using Standard Sets

ICHOM Standard Sets are designed specifically as "minimum sets," meaning that they include only the few most essential outcomes of a given medical condition. Those who adopt a Standard Set can continue to track various processes or choose to track additional outcomes. We, however, encourage those using Standard Sets to follow them in their entirety, so that international communities can eventually organize meaningful comparisons of outcomes.

ICHOM's Philosophy

We do not aim to reinvent the wheel.

Our approach is squarely pragmatic. We build on existing instruments, and complement them with additional measures where necessary. The Working Group's research fellow takes the lead on reviewing these instruments, outcomes, and best practices for the medical condition being discussed.

We are consensus-driven.

We strive for a democratic approach to decision-making. After every group meeting, members fill out a web survey; all actions require the backing of at least two thirds of the members to move forward.

We are rooted in a robust theoretical framework.

Our Working Groups follow the guiding principles inspired by the value-based health care theory of Harvard Business School Professor Michael Porter. We leverage his tiered outcomes hierarchy to build comprehensive Standard Sets that encompass all the dimensions that matter to patients.

We also insist that every Working Group has patient representation.

Patients help prioritize outcome domains and, by attending every call, maintain the focus on the patient even during more technical discussions. Every Standard Set includes patient-reported outcome measures (PROMs), which capture the real-life impacts of treatment on patients' symptoms.

ICHOM Guiding Principles

1 **Full Care Cycle**
Define outcomes around the full care cycle for a medical condition, not just the specialty or the procedure.

2 **Condition**
Clinicians from the multiple specialties who treat patients with a given condition and patients who have suffered or continue to suffer from the condition define the Standard Set together.

3 **Focus**
The Standard Set at its core focuses exclusively on the outcomes that matter to patients.

4 **PROMs**
Every Standard Set includes patient-reported outcomes in order for the sets to capture burden, functional status, and quality of life.

5 **Risk Factors**
Every Standard Set includes a "minimum set" of initial conditions /risk factors to facilitate meaningful comparisons.

6 **Comparison**
All time points, definitions, and sources of data are always clearly defined to allow for comparisons.

Doctors in their own words: why they decided to support ICHOM's work

> "Measuring globally the outcomes that matter to patients, with standardized definitions, will allow us to build a rich source of information to make patients' lives better."

Dr. Matthew Smuck is Medical Director of Rehabilitation Services for Stanford Hospitals and Clinics and Associate Professor of Orthopaedics at Stanford University. He was part of our Low Back Pain Working Group.

> "If physicians make treatment decisions based on outcomes, patients are more likely to receive high quality care – at the right time."

Dr. Ramasamy Kim is Chief Medical Officer at the Aravind Eye Hospital in Madurai. Dr. Kim was part of our Macular Degeneration Working Group.

> "As physicians, to preserve our integrity in guiding our patients, we have to be accountable to them for knowing the outcomes of treatment options."

Dr. Nancy Mendenhall is a radiation oncologist in Jacksonville, Florida who was part of our Localized Prostate Cancer Working Group.

> **“I sincerely hope this work is only the beginning of a journey: we now have to implement the ICHOM Standard Sets globally and understand what improves value.”**

Günter Feick is Chairman of the Charitable Prostate Cancer Patient Support Organization of Germany and participated in the Localized Prostate Cancer Working Group.

> **“ICHOM’s work builds a foundation to engage with patients in a constructive dialogue”**

Dr. Pik Pin Goh is a Medical Doctor specialized in Opthalmology who was part of our Cataract Working Group. She served as a Hubert H. Humphrey Fellow in 1999 and a Prime Minister fellow for Malaysia in 2000.

About our Working Groups

Working Groups are typically made up of
15-25
people from around the world

16
Patients representatives are part of the Working Groups

Our experts are spread out over
6
continents

Experts from
29
countries are involved

A Working Group is able to develop a functional Standard Set within
6-8
months,

at a pace of one meeting of
2 h
a month, a process that is particularly efficient and optimized.

So far, more than
260
physicians and outcomes experts have participated in ICHOM Working Groups.

how to measure outcomes

Four Models for Outcomes Data-Capture: An Evolutionary Process

Many health care institutions around the world are already collecting patient outcomes data. Some have been collecting this data for years and have found ways to integrate the data collection process seamlessly into their daily clinical routine. Others are only just beginning to measure outcomes and are still exploring how best to allocate their finite resources. Whether starting small in a single department, scaling up across multiple provider sites, or outsourcing the process altogether, it is always possible to transition from one model to another in order to progress along the "evolutionary chain" of outcomes data-capture.

1

paper

Getting Started:

How Wexner Medical Center at the Ohio State University Collects Outcomes Data on Paper

When Dr. Safdar Khan joined The Ohio State University in 2011 as Assistant Professor of Orthopedics, he wanted to see Ohio State become a global leader in surgery. From his clinical and research expertise, Khan knew that patient and physician-reported outcomes were essential to improving quality of care. Having seen it work nationally at other centers, Khan was determined to realize his vision.

So, Khan began collecting additional patient outcomes data independently.

"I created questionnaires based on what was already out there and put questions together in a paper packet," Khan says. "I then implemented them into my clinic as a standard collection of outcomes for patients."

In Khan's paper-and-pen system, patients check in for their clinic visit, then complete his paper questionnaire when possible – often as a medical assistant takes vitals and prepares the patient for the consultation. The forms are then scanned into the patient's electronic medical record (EMR) as an image and stored for tracking outcomes.

"Patient-reported outcomes (PROMs) aren't perfectly integrated with the EMR, but we can still refer to the reports and manually trend data to see how patients are doing," says Kari Stammen, Khan's Clinical Research Coordinator. "This has proven especially useful for complicated patients with chronic pain."

Khan is already planning how to evolve the data-capture process in his department.

"We have been figuring out how to integrate PROMs data-capture into our clinic flow," he says. "This will involve harnessing a scanning system so that data on completed forms is automatically captured as searchable items rather than as a single image. We are very excited to advance our data-capture process to the next level."

Wexner Medical Center at the Ohio State University

Department: Orthopedics

Medical or surgical conditions tracked: low back pain

Metrics: 80-100 patients/week

Experience measuring outcomes: 3 years

2

electronic and integrated

Clinic Flow Integration: How UMass Memorial Health Care Uses Data Collection Kiosks

Data collection can be a burden if it runs as a parallel process at a busy clinic. In fact, collection often isn't completed if it adds to the many duties a busy clinic staff is already tackling.

UMass is one of few U.S. institutions to have found a way to traverse this problem. In 2007, it decided to implement PROM data collection kiosks at the ambulatory clinic of its Arthritis and Joint Replacement Center in order to facilitate clinic flow integration. The system has been in place ever since, even expanding to the Spine and Hand and Upper Extremity Clinics.

The integration process is simple: after checking in, patients report information at collection kiosks, where they complete a computerized symptom survey while waiting for their appointment.

The survey results are then immediately available to both patient and physician during the consultation and, after the visit, stored along with other patient records in a searchable database.

Implementing such a system is not without challenges – for instance, obtaining software, training clerks – but this approach ensures that data is collected without adding to the clinical staff's workload. Furthermore, with access to this new data, physicians and patients can devote more time together during the visit to discussing best possible care options.

UMass Memorial Health Care

Departments: Orthopedics and Physical Rehabilitation, Arthritis & Joint Replacement, Spine, Hand & Upper Extremity

Medical or surgical conditions tracked: Osteoarthritis

Metrics: >1 million item measures, 45,000 patients, 100,000 PROMs

Experience measuring outcomes: 7 years

3

outsourced

Outsourcing:
How FORCE-TJR Centralizes the Data Collected From Many Separate Providers

Rather than building new infrastructure, some providers have opted to outsource the process of outcomes data collection altogether. FORCE-TJR, a Massachusetts-based research registry for total joint replacement cases that collects PROMs data nationwide.

"Centralized registry staff collect comparable data at complementary time points from multiple sites, risk-adjust the data, and report the information back to each of these various sites," explains FORCE-TJR's Director of Research, Dr. Patricia Franklin.

The remote collection of data can also fit neatly into any clinic's workflow. After patients have scheduled surgery with the clinic, they receive a call from one of FORCE-TJR's staff requesting their consent to have PROM questionnaires sent to their home. Patients sign the consent forms and complete their questionnaire either through a web-based survey or on paper that can be scanned at a later time.

Patients can also complete the survey online from a home computer, a tablet, or on paper right at the doctor's office (if that office has hired a dedicated staff member to manage in-person data collection). At specified intervals after additional doctor's visits, FORCE-TJR sends questionnaires to patients directly, following up with telephone reminders to encourage a response. The adjusted data are stored in the national registry, and are accessible by the treating surgeon any time through a secure website.

Outsourcing guarantees patient information is still delivered and collected at consistent time points after total joint replacement, while requiring no additional technological or human resources within the clinic itself.

Functional & Outcomes Research for Comparative Effectiveness in Total Joint Replacement (FORCE-TJR) Registry

Medical or surgical conditions tracked: Osteoarthritis

Metrics: 30,000+ patients of 121 surgeons across 22 US states over 85% follow-up

Experience measuring outcomes: 3 years

4

integrated into EMR

Clinic Flow and Data Interface Integration: How Stanford Health Care Fully Integrates Data Collection Into Existing EMR System

Stanford has not only managed to integrate electronic outcomes data collection into clinic flow, but has also managed to incorporate the data collection interface into its EMR system, Epic. A physician can therefore visualize clinic notes, test results, and PROMs data as part of the same dashboard, allowing seamless input to diagnostic and clinical management pathways. The overall result is an electronic data-capture process that doesn't add to the workload of clinic staff: outcomes data-capture is nearly as fundamental a part of the care process as the clinical intervention itself.

Alison Kerr, Executive Director of Neuroscience Service Line, Psychiatry & Behavioral Sciences, says their outcomes reporting project has changed the way the Neurosurgery Spine Clinic approaches patient care. "Moving from pen and paper to using the EMR is a change in culture, but it is easy." Staff can now say, "If I use the tools in this way, look at what I can do with the data." Keeping their systems streamlined was a key part of the process. "We didn't want to duplicate our data collection infrastructure," Kerr adds. "We wanted to keep things lean and use Epic as a single source for our data-driven quality improvement projects and clinical processes." So with some small-scale iterative modifications and without significant additional resources, the Epic interface was set up for data collection.

Stanford's model allows clinical care and data collection to act in synergy, the ultimate aim of any quality improvement or research initiative seeking to better patient care.

"Integration with clinic flow is one thing, but integrating data interfaces on top of this has made everything so much more efficient," Associate Professor of Neurosurgery Dr. John Ratliff says.

"We don't just want to be as good as everyone else. We want to be the preeminent center for medical and surgical care in the country," Ratcliff says. "The 'nirvana' is to have clinical and quality improvement processes working in sync. This is what we are aiming for."

That "nirvana," it seems, is no longer out of reach.

Stanford Health Care

Departments: Neurosurgery Spine Clinic

Medical or surgical conditions tracked: low back pain

Experience measuring outcomes: 3 years

Conclusion

What Can We Learn from these Four Models of Outcomes Data-Capture?

First, start small: any institution that wants to improve care by measuring outcomes can begin with a paper survey model, which is still an effective source of outcomes data. Second, many successful measurement models exist for institutions of all shapes and sizes to follow, whether data is collected on paper within a single department or collected using Epic across multiple sites. Finally, institutions can move between models, transitioning into more and more efficient data-capture processes.

It is important to consider your starting point and your goals when designing your data capture model. Engaging multiple disciplines (e.g. clinical, business, IT, analytics) in the design of this data-capture model is key to ensuring that the process is optimized for all involved. This will ensure that your data capture model will succeed.

how to report outcomes data

Reporting the Data Doctors Really Want and Patients Really Need

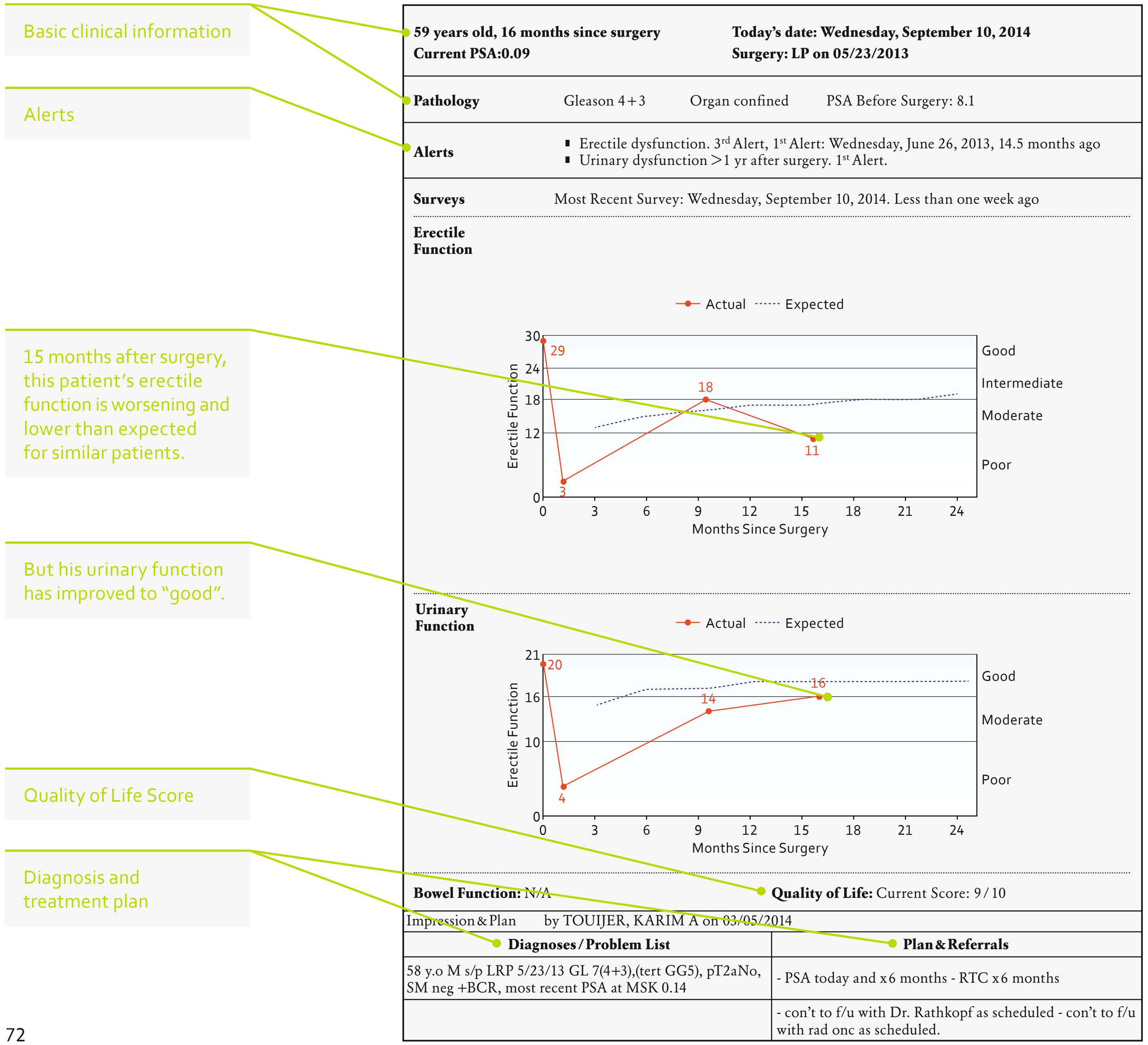
High variation in outcomes prompted doctors and researchers at Memorial Sloan Kettering Cancer Center to develop a sophisticated system for collecting and reporting patient-reported data in order to enhance patient care.

Over the last two decades a number of studies have revealed unsettling variation in patient outcomes following treatment for prostate cancer. Urologists at New York's Memorial Sloan Kettering, the world's oldest and largest private cancer center, have long been dissatisfied with the lack of information available to them and their patients regarding the outcomes of their care. While the center's medical records include basic data on mortality and complication rates, they offer little insight into how patients recover over time at home. Are patients regaining sexual function? Are they suffering from incontinence? To answer these questions, surgeons have to ask their patients directly.

Dr. Andrew Vickers, a biostatistician at the center who has been researching better approaches to prostate cancer treatment for decades, had an idea for how this could be done. In 2009, he started to use the Web Survey Core, an online platform developed at MSKCC that allows patients to report their outcomes directly to their physicians. The system automatically emails patients a link to a survey on their symptoms, which they can complete at home prior to their doctor's visits.

Figure

The report shows changes in a patient's sexual and urinary functioning scores at baseline and following radical prostatectomy. The patient's scores (red) are compared to their expected scores based on outcomes data from patients with similar baseline characteristics (blue).



Basic clinical information

Alerts

15 months after surgery, this patient's erectile function is worsening and lower than expected for similar patients.

But his urinary function has improved to "good".

Quality of Life Score

Diagnosis and treatment plan

59 years old, 16 months since surgery **Today's date: Wednesday, September 10, 2014**
Current PSA:0.09 **Surgery: LP on 05/23/2013**

Pathology Gleason 4+3 Organ confined PSA Before Surgery: 8.1

Alerts
- Erectile dysfunction. 3rd Alert, 1st Alert: Wednesday, June 26, 2013, 14.5 months ago
- Urinary dysfunction >1 yr after surgery. 1st Alert.

Surveys Most Recent Survey: Wednesday, September 10, 2014. Less than one week ago

Erectile Function

Urinary Function

Bowel Function: N/A **Quality of Life:** Current Score: 9 / 10

Impression & Plan by TOUIJER, KARIM A on 03/05/2014

Diagnoses / Problem List	**Plan & Referrals**
58 y.o M s/p LRP 5/23/13 GL 7(4+3),(tert GG5), pT2aNo, SM neg +BCR, most recent PSA at MSK 0.14	- PSA today and x6 months - RTC x6 months
	- con't to f/u with Dr. Rathkopf as scheduled - con't to f/u with rad onc as scheduled.

Alternatively, patients can complete the survey on an iPad in the clinic while waiting to be seen. As soon as a patient completes a survey, the doctor can view a comprehensive report of the responses.

In the day-to-day bustle of a medical clinic, it can be difficult for doctors to be sure they asked their patients all the right questions, and important information about patients' symptoms can fall through the cracks. Prostate cancer patients also often struggle with sensitive symptoms like erectile dysfunction and incontinence, symptoms they may feel uncomfortable talking about, even with their doctor. But, as Vickers points out, studies show that patients feel very safe recording outcomes, even about sensitive issues, on a computer. And, because Web Survey Core uses secure encryption in its data collection process, sensitive data is not saved on the device used to complete the survey, so patients can complete surveys anytime and anywhere, without concern for their privacy.

Web Core system provides doctors with accurate information on a patient's functional status before they enter the consulting room, allowing them to make better use of their time in the clinic. Doctors are able to focus their attention on solving their patients' problems, rather than identifying them. In addition, since Web Core saves all the data collected from patients in a single database, it also serves as a rich resource for research.

The Web Core system hit a snag soon after it rolled out. Most patients were not completing the surveys. When they did complete the surveys, patients said, their doctors still asked all the same questions during their appointments. What was the point of filling out a survey beforehand?

Doctors said that they weren't using the program in their clinics because viewing the survey data in the context of other clinical data required sorting through multiple windows within the electronic medical record, which took too much time in their already overbooked days. The reports generated on survey data were also hard to interpret, offering doctors little information they could use in their discussions with patients.

So, Vickers and his team began working directly with Sloan Kettering's urologists to redesign Web Core's reports. They discussed which patient outcomes the reports should highlight and the most helpful ways of presenting this data. Vickers' team narrowed in on several key changes that would make the reports more useful to patients and easier to access for doctors.

First and foremost, they made sure doctors could access the reports easily before they entered the exam room. The reports were also redesigned to display key clinical information such as the patient's date of surgery, Gleason score (a grading system used to evaluate the prognosis of patients with prostate cancer based on the tumor's pathology), diagnosis, and treatment plan, further cutting time doctors had to spend navigating data.

Many of the urologists Vickers' team spoke to also pointed out that their patients didn't need to know whether or not they were improving – that they could easily know from their symptoms. Patients wanted to know if they were improving as expected. Was their experience normal? Should they be concerned? Vickers' team employed prediction algorithms to calculate patients' expected progress and predicted recovery given their current point in the recovery process.

The doctors also needed the report data to be presented in context for clinical decision making. The raw scores presented in initial versions of the reports were uninformative: did a score of 10 indicate good recovery or poor recovery? Could the score be much higher (or lower)? To eliminate confusion, Vickers' team added guides or rulers to the reports that allowed doctors to quickly interpret raw data.

A doctor viewing the redesigned reports (see figure) could see, for instance, that at 15 months after surgery, his patient has good urinary function (although slightly worse than expected), but poor and worsening erectile function. So, after a quick glance at the report, that doctor could greet his patient and say, "It looks like you are doing well with your urinary function, but your erectile function seems to be getting worse. Let's talk about that."

Since these overhauls in patient outcomes reporting, participation in the Web Core program by both patients and clinicians has increased dramatically. Now, six of the seven urologists at Sloan Kettering regularly use Web Core reports during visits with their post-radical prostatectomy patients. That translates to more efficient, more tailored, and more responsive care for over 2,000 patients.

The Web Survey Core program has been such a success that Vickers' team is now expanding beyond urology to offer similar programs for other surgical services as well as in the Departments of Medicine, and Radiation Oncology. Other institutions, too, are following Sloan Kettering's model, using Web Core to collect and store their own patient-reported outcomes data. Moving forward, Vickers and his team plan to develop an online system in which doctors can share their outcomes data with institutions across the globe, an important first step for creating a worldwide community of shared learning and improvement.

As Vickers' team discovered through the process of developing the outcomes reporting program at Sloan Kettering, simply making data available to physicians is not enough to improve the quality of care these physicians offer. Outcomes must be reported in a way that is integrated with the clinical care process. To figure out how to best do this, you must consider the needs of clinicians and focus on making sure things work well within the existing workflow.

Andrew Vickers, PhD, Attending Research Methodologist in the Department of Epidemiology and Biostatistics at Memorial Sloan Kettering Cancer Center. His research interests range from clinical trials to surgical outcomes research and molecular marker studies with a particular focus on the detection and initial treatment of prostate cancer.

The Physicians Perspective: Three Questions for Karim A. Touijer

We had the opportunity to speak with Dr. Karim Touijer, a urologic surgeon who specializes in treating prostate, bladder, and kidney cancer at Memorial Sloan Kettering Cancer Center and who was intimately involved in the development of the outcomes measurement and reporting program.

Karim A. Touijer is a urologist specializing in the treatment of genitourinary cancers such as prostate cancer. His primary interest is the development of innovative minimally invasive surgical techniques to treat genitourinary cancers.

How did you get involved with the development of the Web Survey Core?

Well, about 12 years ago, I was working under the leadership of Dr. Peter Scardino on developing objective outcome metrics for urologic oncology. At the time it was clear there was variation in the surgical performance and subjectivity in assessing its outcomes. In addition, cancer care at Memorial Sloan Kettering is organized in disease management teams – surgeons, medical oncologists, and surgical oncologists working closely together to treat patients with genito-urinary cancers. So, we sought to develop standardized outcome metrics across these disciplines to assess our performance and conduct comparative effectiveness research.It turned out that many of the metrics I was working in the clinical setting were the same ones that Andrew Vickers was considering for the Web Survey Core. So, we started working together. I provided the clinical expertise for the development of the surveys that are now used to collect data with the Web Survey Core.

What would you say was the biggest challenge that had to be overcome in the development of the Web Survey Core?

When this all started, interest in detailed patient-reported outcomes was more integrated in academic research than routine clinical care. In our academic focus, we were running large clinical trials with complex designs. At one point we were handing booklets containing very detailed questionnaires with up to 300 questions to patients to complete! So, obviously, the project was costly and participation rates were low. We had to shift our academic ambition to a more pragmatic one.
Focusing on patient-centered outcomes, things like quality of life and functional recovery, and using shorter questionnaires emerged as the best ways to get high quality data that we could use both for research and clinical practice. In fact, we broke the boundaries separating research and clinical practice, integrating both in a single effort thus improving quality on both aspects and reducing cost.
The next big challenge was the logistics of how to collect this data. Like I said, we started out collecting data with pen and paper-giant booklets of questions that we sent in the mail. Moving to a web-based program was key. It greatly increased participation and improved the quality and utility of the data. With the paper method, there was a six-week time lag between when the patient completed the survey and when the data was available in the database for our use. With the web-based method, we have the data in real time.
Also, by removing the middle man – the researcher who had to enter patients' answers into the database – we basically eliminated transcription errors, greatly improving the fidelity of the data.

Has the Web Survey Core changed the way you practice medicine?

Definitely. It enables me to use my time in clinic better – it focuses my conversations with my patients. I look at the report of my patient's outcomes before entering the consultation room, which tells me my patient's basic clinical information and how he is doing functionally. So, when I enter the consulting room, I already know what to focus on to best address my patient's needs.

And my patients like it too. The predicted recovery milestones allow them to know where they are compared to where they should be in the recovery process. It provides patients with a realistic understanding of what to expect throughout the care process. Aligning patients and surgeons in a true partnership.

A Culture of Improvement, a World of Transparency

Collecting high quality data on patient-centered outcomes is just the first step – the data must also be reported in a way that drives tangible improvements in health care.

Patients, physicians, and institutions can benefit from reporting outcomes data in a myriad of ways. Physicians can use patient-reported outcomes for shared decision making with their patients. Outcomes reporting can also be used to evaluate physician performance, to target and evaluate quality improvement efforts, to drive a culture of learning and improvement, and to increase transparency in health care. We highlight here some excellent examples of outcomes reporting programs from around the world.

The Five Key Components of a Successful Reporting Program

In our experience, all successful reporting programs follow a few key rules:

1 Get stakeholders at all levels of your organization involved from the beginning.

Ensure that administrators are visibly involved and committed.

Engage your clinical staff in the program's development and implementation.

2 Allocate sufficient resources and talents.

Ensure appropriate funding from the start.

Mobilize necessary personnel such as project managers, data analysts, and IT specialists.

3 Streamline reports within the care process and make interpretation simple and intuitive.

Provide reports to clinical staff when and where they are needed.

Balance simplicity and clarity with comprehensiveness so that reports facilitate the clinical care process.

4 Provide high quality data.

Develop a system for validating the data against other records.

Involve physicians and biostatisticians to ensure proper analysis and risk adjustment.

5 Go beyond reporting data – create a culture of self-evaluation and improvement.

Educate staff on the goals of the program.

Provide structured and protected time for clinicians to discuss outcomes and learn from each other.

Informing Doctors of Their Outcomes
Memorial Sloan Kettering Cancer Center, U.S.

Doctors spend their lives taking tests – from exams required to get into medical school, to the deluge of exams during medical school, to the exams required to become (and stay) licensed to practice. These exams provide a score and an indication of how that score ranks compared to the examinee's peers. So, doctors are used to getting regular feedback about how they are doing compared to their peers.

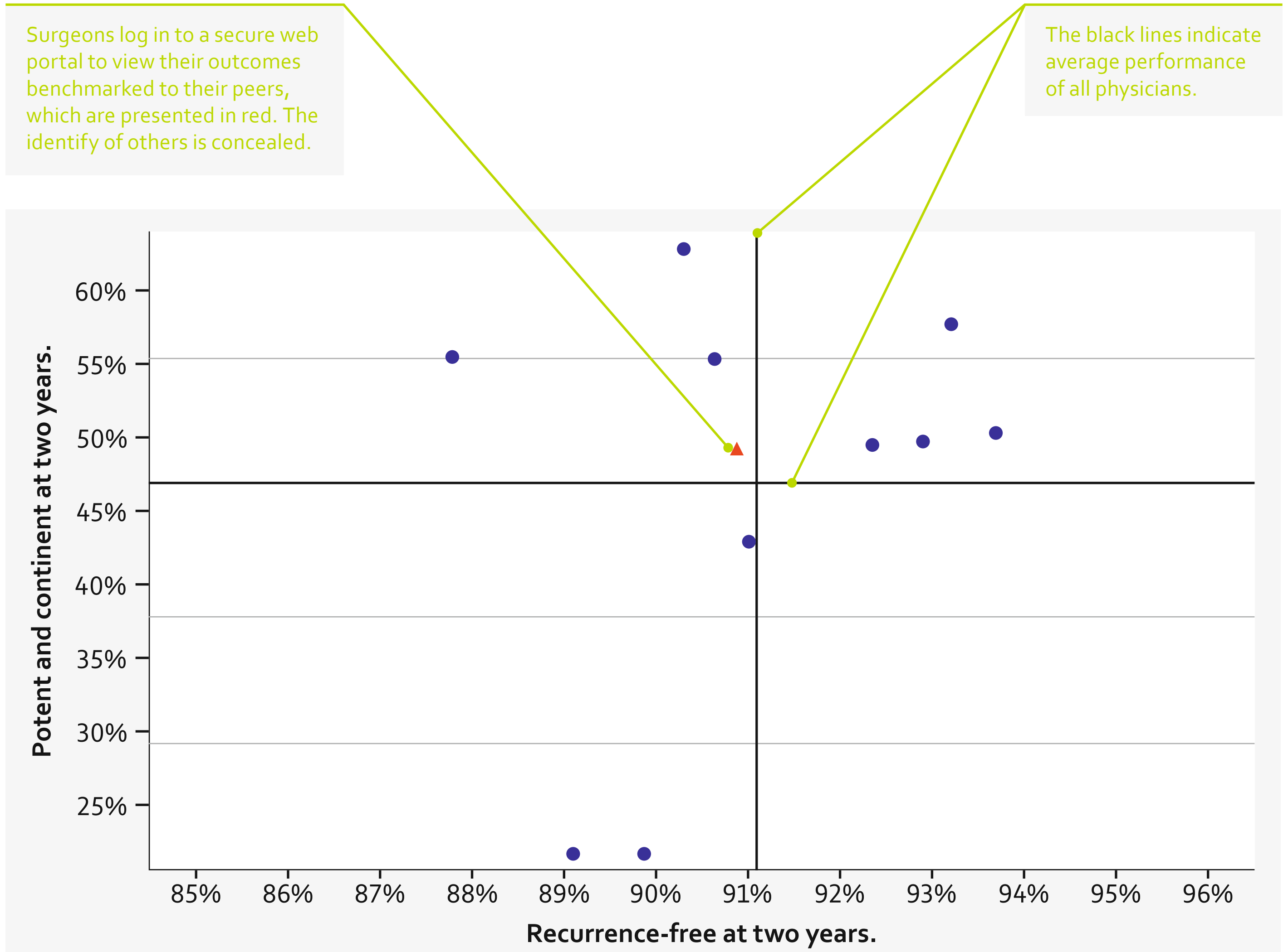
But these exams only test medical knowledge – clinical care is different. Once doctors graduate medical school, they spend their days taking care of patients with little insight into the outcomes of their care. It can be a jarring experience. Many seasoned physicians can relate stories of how shaken and unconfident they once felt by this sudden absence of feedback. Am I doing a good job? Do I need to improve? How will I know?

Some institutions have started to address this problem by providing their physicians with regular report cards. Urologists at New York City's Memorial Sloan Kettering Cancer Center, for instance, can log in to a secure web portal to view a report of their average risk-adjusted outcomes, aggregated over all of their patients who have undergone radical prostatectomy (Figure 1 shows one view of this report).

The urologist's own outcomes are represented in red while results of his or her colleagues are plotted in blue. In this example, the urologist will see that some colleagues obtained higher rates of potency and continence with lower rates of recurrence. So, although this physician's outcomes are close to average, the report shows clear room for improvement.

For such report cards to successfully influence how physicians practice, physicians must trust and respect the method of evaluation. Many physicians are wary of using outcomes to measure their performance. Their main concern is that adjustments for differences in case mix or patient characteristics between physicians are insufficient. To address these concerns, Sloan Kettering involved its urologists directly in the selection of risk factors for adjustment. The urologists were essentially designing their own report cards.

Figure 1
A report displaying urologists' mean potency and continence scores averaged across all patients treated with radical prostatectomy in the past two years plotted against their average rate of recurrence for the same group of patients. Unique reports are generated for each physician and accessed via secure log in.



Surgeons log in to a secure web portal to view their outcomes benchmarked to their peers, which are presented in red. The identify of others is concealed.

The black lines indicate average performance of all physicians.

Your recurrence-free rate:
Your rate of 90.0% with 375 surgeries is 6th highest out of 11 surgeons.

Your functional recovery rate:
Your rate of 49.3% with 207 surgeries is 8th highest out of 11 surgeons.

Helping Physicians Know How to Improve

Martini Klinik at Hamburg University Hospital, Germany

The Martini Klinik at Hamburg University Hospital, a center dedicated solely to the treatment of prostate cancer, has taken a direct approach to solving the problem of showing physicians how they can improve. The Klinik boasts some of the world's best patient outcomes in the treatment of prostate cancer. Dr. Hartwig Huland, Founder and Faculty Member, attributes this excellence to the clinic's strong culture of self-evaluation and improvement.

Every six months, the clinic's 11 surgeons meet to learn about and discuss their outcomes. The clinic's biostatistician prepares a set of slides detailing the outcomes of each surgeon for the discussion. An example of one of these slides (names redacted for this publication) is presented here (Figure 2). If, following proper risk adjustment, significant differences between surgeons' outcomes are found, surgeons with poorer outcomes undergo additional training with their more successful colleagues.

Huland jokingly admits that everyone's blood pressure gets a bit elevated in the days preceding these meetings. However, the atmosphere during these meetings is always positive and supportive. This is due in part to the clinic's policy that everyone, no matter their level of seniority, is subject to the same standards: even Huland has gone through additional training with colleagues to improve his outcomes. Martini-Klinik also benefits from its small size and its hand-picked clinical team, enabling it to function like a large family.

Figure 2
The table shows patients' erectile function before and after surgery, broken down by individual surgeons and the difference in erectile function between these points of time. The percentage of patients using drugs for erectile dysfunction treatment is also indicated. Erectile dysfunction after surgery is an important patient-reported outcome indicating the quality of unilateral or bilateral nerve-sparing surgery.

Martini-Klinik
Prostatakrebszentrum
am Universitätsklinikum Hamburg-Eppendorf

Surgeon	Preoperative erectile function score			3 month post surgery erectile function score			Erectile Function Difference (pre–post operative)		Percent of patients potent at 3 months post surgery
	N	Median	IQR	N	Median	IQR	Median	IQR	
A	77	22	17-25	77	6	3-18	-9	-17;-2	38 (52.8)
B	66	23	17.5-25	66	5	3-15	-11	-18.8;-6	33 (50.8)
C	71	22	9-25	71	5	2-7	-13	-19;-4.8	36 (52.9)
D	79	23	13-24	79	6	3-15	-8	-18;-3	29 (42.6)
E	91	21	10-24	91	5	2-7	-14	-18;-5	34 (38.6)
F	56	21.5	10.5-24.75	56	4	2-16.25	-7.5	-16;-3	20 (36.4)
G	33	23	8.5-24.5	33	6	2.5-12.5	-8.5	-18;-1	11 (34.4)
H	61	21	14.5-24	61	3	2-10.5	-12.5	-18.3;-4	18 (30.5)
I	53	18	7-22	53	3	2-4.5	-14	-19;-5	12 (23.1)
J	34	21.5	11-25	34	4	2-6.25	-15.5	-18;-9	10 (31.3)
K	28	21.5	17-24.25	28	5	2.25-12	-15	-16;-5	9 (36)

For patients undergoing unilateral or bilateral nerve sparing radical prostatectomy

If after proper risk adjustment, differences between surgeons are statistically significant, surgeons with poorer outcomes undergo additional training with their peers.

Figure 3
A chart displaying an opthalmologist's average surgical outcomes for all cateract surgeries performed in the past month. The opthalmologist can compare his or her outcomes to the average of surgeons with similar levels of training and experience as well as to average of all surgeons in their organization.

Physicians can select who they are compared to. The doctor in this example is an officer, but residents might choose to benchmark against other residents.

They can benchmark their outcomes to those of their peers.

Physicians log in to a secure web portal to review thier outcomes.

Bench Marking Report - Surgeon Vs Surgeon Category

Starting Month: Jan 2014
Ending Month: Jan 2014
Surgeon Name : HARIPRIYA G.DR
Source: ALL
Surgeons: Medical Officers
Surgery Types: ALL
IOL Model: ALL
Volume Category: ALL
Hospital Category: Large Hospital
Risk Category: ALL

Parameters	Yours	Over All Medical Officers	Best Medical Officers
Total Surgeons		110	
Total Surgery	211	5,126	
% with < 6/60 Pre - op Vision	26.07	51.91	
% with Advance Cataract	4.74	13.43	
Surgery Types			
% Phaco Surgeries	97.63	40.00	
% SICS Surgeries	2.37	59.22	
% ECCE Surgeries	0.00	0.34	
% Lens removal Surgeries	0.00	0.37	
Anaesthesia			
% of surgeries under topical anaesthesia	55.45	20.58	100.00
% of Patients With Intra OP Complication	0.95	1.50	0.00
Intra OP Complication Score	7.58	13.70	0.00
% of Patients with Post-OP complication	3.32	3.77	0.00
Post-OP complication Score	14.22	18.61	0.00
% Resurgeries	0.00	0.80	0.00
Immediate Post OP Pinhole VA . (Discharge)			
6/6	64.45	42.63	100.00
6/9 and Better	82.46	70.96	100.00

Opting for a Hybrid Approach

Aravind Eye Hospital, India

Aravind Eye Hospital in India first opened in 1976 as an 11-bed clinic with a mission to eliminate needless blindness due to cataracts. It has since grown to a network of six-hospitals and multiple clinics. Today it is one of the largest providers of cataract surgery worldwide, performing over 370,000 cataract surgeries a year, with each ophthalmologist performing about six operations an hour.

Aravind succeeds in maintaining a high quality of care while performing high-volume surgery because of its robust system for informing surgeons of their outcomes and strong culture of evaluation and improvement.

As in Memorial Sloan Kettering, doctors log in to a secure portal to view their outcomes data and benchmark their performance to that of their peers. (Figure 3 shows one view of this report)

But at Aravind, physicians also meet privately with hospital leadership every quarter to discuss their outcomes, identify areas of weakness, and devise a plan for improvement. According to Dr. Haripriya Aravind, Chief of Intraocular Lens and Cataract Services at Aravind's Hospital in Madurai, physicians in her department appreciate knowing their outcomes and feel these check-in meetings represent an investment by the hospital in their personal success.

In addition, the Aravind Eye Hospital has a strong culture of quality assurance. Data on surgical outcomes and complications is compiled weekly and all clinical staff, from physicians to paramedical staff, meet every Friday to discuss this data. If a complication has occurred, the group discusses ways to prevent similar situations in the future. Staff members at all levels are encouraged to voice concerns or provide suggestions for how to improve.

Targeting and Evaluating Quality Improvement Efforts

Sahlgrenska University Hospital, Sweden

In today's competitive health care market, it's of utmost importance for a hospital to be constantly improving. Outcome measures play a major role in highlighting areas in need of improvement and in ensuring high quality of care even as changes to processes are introduced.

Sahlgrenska University Hospital in Sweden, one of the largest public hospitals in northern Europe, has been struggling with the growing pressure to reduce costs and increase competitiveness faced by most public hospitals. The hospital turned to value-based health care for solutions. In 2013, it piloted value-based transformation in its orthopedics department, focusing on care processes in hip replacement surgery. A multidisciplinary working group formed to lead the pilot.

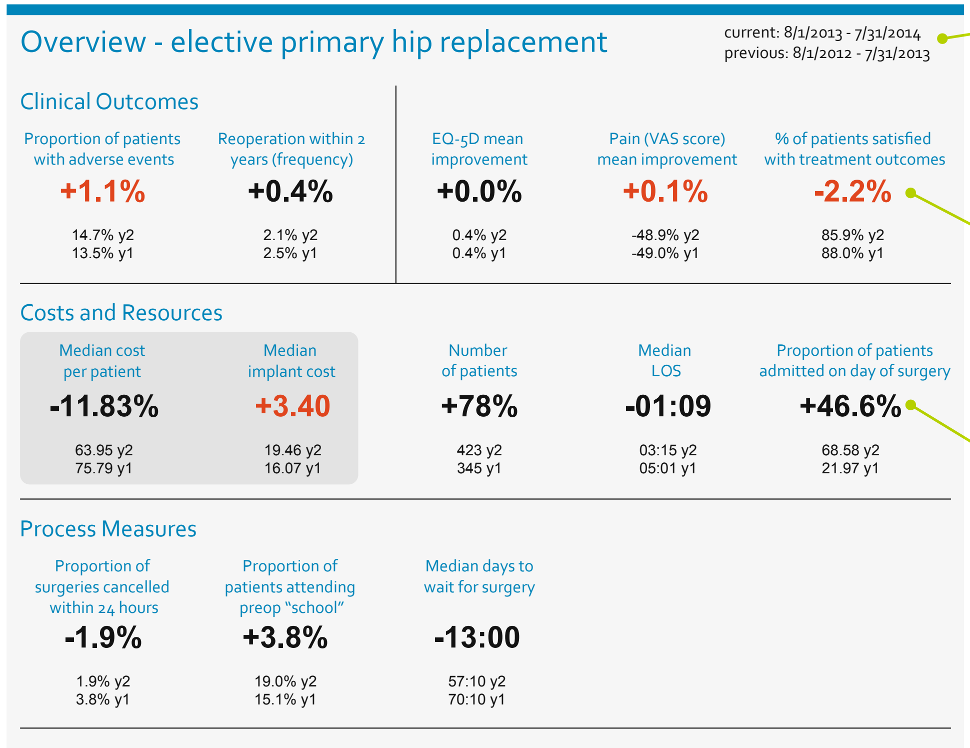
The working group selected 13 outcome measures to track that represented important outcomes for patients and were helpful in evaluating the effects of the new care process being implemented. They presented these outcomes in a dashboard that updated in real time, allowing them to monitor changes in outcomes, cost, and efficiency at a glance (Figure 4a).

The working group also developed detailed reports consisting of supporting measures that could be viewed using different filters (Figure 4b). Measures, for instance, could be viewed for different time periods or groups of patients or at the level of an individual physician or patient. Changes noted in the dashboard, particularly negative ones, required an explanation and a proposed solution. These detailed reports enabled working group members to easily investigate trends and develop solutions to problems that arose.

Go to page 106 to read the complete story.

Figure 4a
A dashboard displaying changes in 13 main clinical, cost and financial, or process measures over the past 12 months.

Figure 4b
A more detailed report of additional measures that can be used to identify the root cause of improvements or deteriorations in outcomes presented in the main dashboard.



Overview - elective primary hip replacement

current: 8/1/2013 - 7/31/2014
previous: 8/1/2012 - 7/31/2013

Clinical Outcomes

Proportion of patients with adverse events	Reoperation within 2 years (frequency)	EQ-5D mean improvement	Pain (VAS score) mean improvement	% of patients satisfied with treatment outcomes
+1.1%	+0.4%	+0.0%	+0.1%	-2.2%
14.7% y2 13.5% y1	2.1% y2 2.5% y1	0.4% y2 0.4% y1	-48.9% y2 -49.0% y1	85.9% y2 88.0% y1

Costs and Resources

Median cost per patient	Median implant cost	Number of patients	Median LOS	Proportion of patients admitted on day of surgery
-11.83%	+3.40	+78%	-01:09	+46.6%
63.95 y2 75.79 y1	19.46 y2 16.07 y1	423 y2 345 y1	03:15 y2 05:01 y1	68.58 y2 21.97 y1

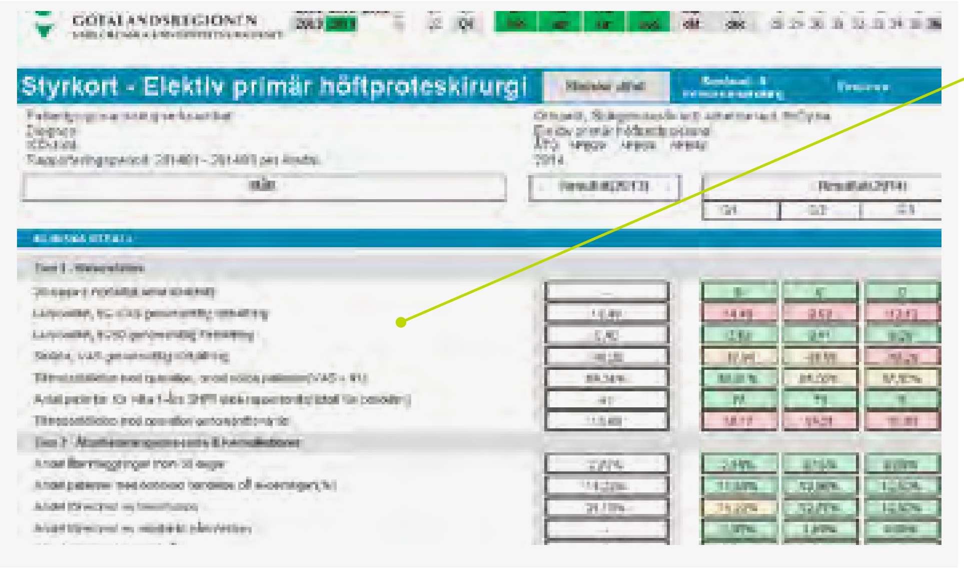
Process Measures

Proportion of surgeries cancelled within 24 hours	Proportion of patients attending preop "school"	Median days to wait for surgery
-1.9%	+3.8%	-13:00
1.9% y2 3.8% y1	19.0% y2 15.1% y1	57:10 y2 70:10 y1

The running average calculated over a 12-month window is compared to the average of the previous 12-months.

Negative trends in outcomes are highlighted in red.

Dashboard highlighting changes in key outcomes.



VÄSTRA GÖTALANDSREGIONEN

Styrkort - Elektiv primär höftproteskirurgi

Users can also access detailed reports of additional outcome measures to easily investigate changes highlighted in the dashboard.

Reporting Outcomes to the Public

The Society of Thoracic Surgeons, U.S.

An institution that publicly reports outcomes makes a powerful statement. Reporting helps to create transparency in health care, inspires trust, and empowers patients to make informed decisions when choosing where to obtain care.

Public reporting of outcomes can also provide institutions with tangible benefits. It may highlight areas of care in which an institution excels, leading expansion of these service lines down the road. In addition, better than average outcomes can help justify higher than average spending. Most importantly, public reporting of outcomes is an excellent way to engage in a culture of shared learning and improvement. A great way to reap these benefits is to participate in a national registry or outcomes reporting consortium.

Sometime, it is challenging to present outcome information in a meaningful way that can easily be understood by patients. This is particularly true for the most vulnerable parts of our society, the less educated, elderly and frail patients. Thus, a simple presentation of data that is actionable for patients and the same time scientifically correct is needed.

One good example of such a program from the Unites States is the Society for Thoracic Surgeons (STS). It hosts a voluntary reporting program for cardiac surgery outcomes (Figure 5). Participating provider organizations receive composite scores for key areas of care. To make the comparison even easier, these scores are translated into star ratings. Providers with a score equal to the national average (with a probability of 99 percent) receive two stars for that domain. Those with scores lower than the average receive a 1-star rating and those with higher scores receive three stars. An example report of institutions in Alabama performing coronary artery bypass graft (CABG) surgery is presented on pg. 89. By collapsing across multiple outcome measures and producing risk-adjusted composite scores, the STS allows patients to directly compare providers' performance in a small number of simple categories.

If John Doe, a resident of Mobile, Alabama, is told by his cardiologist that he needs CABG surgery, he can consult the STS website. At a glance he can see that his local institution provides average overall care quality. But if he travels about five hours by car, he could get his surgery at Huntsville Hospital, which boasts higher than average care quality. Although this reporting system is not based on patient-centered outcomes, it provides patients with the power to choose their own care options. Our John Doe will then have to decide if the trip to Huntsville is easible, but at least now he has the information he needs to decide.

Figure 5

A screen shot of the STS report of the quality of care for patients undergoing CABG surgery in the 3 hospitals in Alabama performing this surgery. Hospitals are evaluated on 5 main outcome or process measures. Hospitals receiving 2 stars score the same as the national average on these measures while those receiving 3 score better than the national average.

Compare all of the hospitals in your state that share data on 4 main measures and a composite score.

Numeric Value: 88.2% of patients (risk-adjusted) who did not experience any major morbidity

Search CABG Data by Hospital

Hospital name:
Year: Jan 2013 – Dec 2013
State: AL

Name ^	Overall Composite Score (?)	Absence of Operative Mortality (?)	Absence of Major Morbidity (?)	Use of Internal Mammary Artery (?)	Receipt of Required Perioperative Medications (?)
Huntsville Hospital Huntsville, AL	★★★	★★	★★★	★★	★★★
Northeast Alabama Regional Medical Center Anniston, AL	★★	★★	★★	★★	★★★
Providence Hospital Mobile, AL	★★	★★	★★	★★	★★★

what

The Movement Disorder Society's Unified Parkinson Disease Rating Scale (MDS-UPDRS) measures if anxiety keeps patients away from activities of daily living

The Catquest 9-SF measures the patients' visual functioning after cataract surgery

The Rose Dyspnea Scale
measures patients' level
of dyspnea with common activities

The Patient Health Questionnaire (PHQ 9) measures whether patients show little interest or pleasure in doing things

The Oswestry Disability Index (ODI) measures the patients' ability to travel after back pain treatment

The Parkinson's Disease Questionnaire (PDQ-8) measures patients' sleep disturbances

what do we learn from outcomes measurement?

Outcomes data can be used to directly impact treatment of patients. In Sweden, some hospitals leverage patient-reported outcomes to adapt the course of treatment and give more attention to patients in need.

Six years ago, Elin, a retired teacher living in the cozy Swedish town of Ljusdal, began to experience pain in her left hand. She was 68, newly retired, and spent most of her days outdoors in the crisp fall, raking leaves and taking care of her garden. She always had a passion for gardening and her recent retirement gave her ample time to spend time outdoor doing what she loved.

The pain, she reasoned, must be from this burst of physical activity. But when the pain spread quickly to her other hand, Elin decided to see a doctor. Ljusdal is beautiful – lost somewhere in the Swedish woods, surrounded by lakes – but remote – four hours north of Stockholm. Since a general practitioner only visited town once a week, Elin had to wait until the following Wednesday for her appointment. Elin's GP tentatively diagnosed her with rheumatoid arthritis, but recommended that she see a specialist in Gävle, the capital of their county. Back home, Elin researched RA on her own, and learned, to her dismay, that it was a painful autoimmune disease with no cure. Descriptions of RA that she found on her own also came with a long list of other manifestations; this compounded her anxiety. The disease, she also learned, could evolve over time and cripple her hands, a severe blow to an active gardener like Elin.

Two weeks after Elin's first appointment with her GP, Dr. Tegmark at the Gävle hospital confirmed the worst: Elin indeed had rheumatoid arthritis. He outlined the treatment that would keep her pain under control. He also explained to Elin that she could participate in a national registry in Sweden that tracks the progress of patients like her. She would need to regularly connect to a website before each consultation to answer simple questions relating to her condition. Tracking her pain and progress over time would make it possible to adapt treatments to what was working best for Elin, Dr. Tegmark explained, and information in the national registry facilitated research and contributed to a better understanding of the disease as a whole. Elin was happy to oblige, and a nurse helped her navigate the website for the first time before she left the office. The questions the platform offered were easy to answer. One asked her to point out on a picture of a body where she felt pain. Others asked about her quality of life – including whether or not she was able to perform her daily activities – and her level of fatigue. Some anti-inflammatory drugs used to treat RA have unpleasant side effects, and the online platform could track the effects of those drugs as well.

Before her second visit half a year later, Elin connected to the platform and reported on her health. She answered the usual set of questions about her pain level and ability to perform daily tasks. Happily, at her second consultation, Dr. Tegmark told Elin the arthritis had slowed; medication was working. He would see her again in six months. For a calm few years, Elin’s RA was under control. She learned to access her results online from home, and could remind herself, on days when she felt particularly bad, that she had logged far worse days in the past. Seeing her progress made the relentless pain of her disease easier to bear. Elin also liked seeing how different medications were helping (or not helping), and she liked being so involved in her own care. She had reclaimed agency; her disease could not control her.

More on Swedish Rheumatoid Quality

The Swedish Rheumatoid Quality Registry was launched in 1995 by Dr. Staffan Lindblad, an academic rheumatologist at the Karolinska University Hospital and prominent member of the Swedish Rheumatology Association (SRA). The registry evolved over time and now comprises three modules:

1 **The patient module** allows patients to report on their health from home or from a waiting room and retrieve their data in easy-to-read reports and charts.

2 **The physician module** allows doctors to call up patient-reported data as well as medical records (e.g., lab tests) and compare them with other data from patients of the physician or clinic.

3 **The national module** aggregates data to make it available for research and for national open comparisons.

The SRQ contains information about more than
60.000
rheumatic patients in Sweden

more than
½
are using the patient module to report on their health

all
60
rheumatology clinics in Sweden report in the registry

70%
of all cases use the real-time decision support function of the registry

6.000.000 $
annual budget

She did not like, however, traveling two hours to Gälve so regularly to see a specialist, especially when the result of the consultation was to keep the medication unchanged. She was getting older, and driving such distances just to renew medication or hear that her disease was under control proved exhausting. Elin was delighted, then, when Dr. Tegmark told her in 2012 that she would be enrolled in a new system: the open/tight clinic. She would simply continue reporting her health results from home and see the specialist only when necessary. She would monitor her own pain regularly from home and a nurse would review the results. In case of need, the nurse would call her and they would decide together if a consultation was required.

In the spring of 2013, Elin suffered a severe arthritis flare. She reported it online, and her nurse called back within a few hours with recommendations to temporarily alleviate the pain. The nurse also scheduled Elin for an in-person appointment just two days after the flare. The open/tight clinic model had freed Dr. Tegmark's schedule to see patients when they needed him most. The wait time at the clinic, the nurse explained, was virtually zero.

Yet another year has passed since Elin was diagnosed with this incurable disease, one that was supposed to mean chronic pain and significant loss of function. And while Elin still endures episodes of pain from time to time and reduced mobility, her disease has evolved slower than it does for Dr. Tegmarks's average patient, and she has not been saddled with frequent but mostly useless consultations. Tracking her own health care results combined with the open/tight clinic gave Elin her freedom back.

The EuroQol-5D (EQ-5D) measures patients' ability to do usual things

NHS Breaks Barriers: Public Reporting of Individual Physician Outcomes

In recent decades, England's National Health Service (NHS) has been plagued by string of scandals involving negligent care, including highly publicized cases of malpractice at the Mid-Staffordshire Trust and the Bristol Royal Infirmary. Overall confidence in the health care system was beginning to fall. Public inquiries inevitably followed, and a new approach to quality and safety was demanded.

Five years later, the NHS is publicly reporting outcomes at the individual physician level, an initiative unprecedented in a field that has globally resisted such transparency. The Healthcare Quality Improvement Partnership (HQIP), working with the Royal College of Surgeons of England, managed the release of the first national reports detailing care results from individual consultants across ninesurgical specialties and one medical specialty last summer – the first publication of its kind in the world. A second Consultant Outcomes Publication followed in September 2014, with three more surgical specialties. These sweeping reports are a welcome milestone in the United Kingdom's move towards accountability in health care.

"The failings related to the Bristol and Mid-Staffordshire inquiries had eroded public trust in the NHS, which needed to be re-built through transparent and granular reporting," explained Rebecca Cosgriff, Project Manager for HQIP's Consultant Outcomes Publication. This was part of a wider international initiative involving the declaration of all government-owned data freely available to the public.

Clinical audit was pioneered by the British as early as the days of Florence Nightingale, and fortunately, a series of rigorous national audits were already in place by the time U.K. scandals took place. However, they clearly weren't having the desired impact on quality of care. Thus, in 2012, the NHS selected ten audits for open-access publication that would include complete data on the number of procedures carried out by consultants in England, as well as the survival rates of their patients. Valuable data, then, had been steadily collected, but questions remained over what specific information should be published and how it should be presented. What would practicing physicians be comfortable divulging and how many would be willing to participate? Would pursuing outcomes data alienate physicians? Would the data paint an accurate picture about quality of care?

One of the greatest barriers to universal outcomes reporting in health care is physician culture: many doctors are uneasy about publicly reporting the results of their care, citing poor data quality and weak risk-adjustment algorithms.

A large-scale project such as the Consultant Outcomes Publication requires large-scale collaboration. To dispel doubts, HQIP has a project team and an independent advisory group to work closely with specialist societies across the nation, one society for each of the ten specialty audits publishing results.

For the first publication in 2013, HQIP asked consultants for explicit consent to publish the outcomes of their care, thus giving consultants the chance to voice their concerns about the project and HQIP teams the chance to respond to these concerns. Throughout the data collection process, HQIP organized open forums for clinicians to share views and ideas and corresponded openly about progress on the project with medical directors, communications staff and audit teams.

Over 90 percent of the consultants contacted responded, and 99 percent of those consented to reporting of their outcomes data. Moreover, the vast majority of consultants surveyed wholeheartedly supported the idea of a nationwide Consultant Outcomes Publication. Those who hesitated did so due to anxiety over the quality and proposed presentation of the data and timescale of the project, not the initiative itself. Professor Danny Keenan, Medical Director of HQIP and Consultant Cardiac Surgeon, suggested that UK clinicians chose to be involved largely because they were keen to have a hand in producing outcomes reports that were accurate representations of their practice, and that were constructive rather than destructive. "Without our involvement in this inevitable process, the data may be presented in ways that are not helpful," Keenan said. "With our involvement, this can be developed scientifically and presented usefully."

Most clinicians recognized, too, how patients could benefit from transparency of information. Releasing results for each individual physician also provides more precise feedback for how each can improve the care they give. Indeed, Keenan has found that through the process of reporting individual outcomes, clinicians review their own practices with a view to improving them."Several colleagues decided to review their surgical methods when they saw that their outcomes were poor," he said. "Should it have taken a public release of results to stop them from doing surgery?"

Auditing and open publication of outcomes data unequivocally give rise to higher quality care for patients. In the UK, it took dangerous failings in the health care system to turn the wheels on a nationwide initiative for transparent outcomes measurement. Following the first unofficial cardiac surgery publication of consultant outcomes in 2005, vast improvement in mortality rates has been seen. The HQIP initiative is expected to drive improvement across the other involved specialties.

But other health care institutions around the world should take note: why delay until serious, systemic problems emerge to push for large-scale results reporting? Transparency in health care needs to happen now.

Sahlgrenska University Hospital: A Transformation that Matters to Patients

The Sahlgrenska University Hospital in Sweden is one of Northern Europe's largest hospitals with over 16,000 employees and 2,000 beds. It provides emergency, basic, and specialized care for much of western Sweden, with renowned programs in pediatric cardiology, organ transplant, and immunology. Like many public hospitals, however, Sahlgrenska is facing growing pressure from the local government to reduce costs. In addition, it must anticipate the introduction of value-based reimbursement and an increasing emphasis on patient choice. These pressures have heightened competition and increased the importance of efficient care delivery. Sahlgrenska's CEO, Dr. Barbro E. Fridén, turned to value-based health care (VBHC) as a solution.

In the fall of 2013, Sahlgrenska engaged in an ambitious transformation program. Fridén's idea was to employ value-based health care to reorganize how care is delivered in the organization. It would not be a traditional "lean" approach in which a project team tries to standardize care delivery and eliminate processes that do not add value. Instead, Sahlgrenska would use systematic review of outcomes to review its care processes. The goal? Optimization of care delivery based on what matters to patients.

Initially, Sahlgrenska identified the areas of care most ripe for a value-based health care transformation. The aim was to analyze existing care processes and identify relatively weak areas that provided the potential for "quick wins" to drive further interest in the transformation process. They also assessed the availability of outcomes data to measure the impact of these transformations on patients and helped identify service lines in which a transformation might differentiate the hospital from its competitors.

Four areas were chosen to pilot the transition to value-based health care: bipolar disorders, prostate cancer, hip arthroplasty, and pediatric cardiac surgery. In these four areas, care processes would be streamlined, while outcomes were monitored to ensure that any changes not only increased efficiency but also delivered better outcomes for patients.

ICHOM spoke with Dr. Ola Rolfson, an orthopedic surgeon with a PhD in health outcomes research, and the clinical lead for Sahlgrenska's hip arthroplasty pilot. He shared his experience with us.

Orthopedic surgeons at Sahlgrenska were aware that care processes could be improved. The average length of stay seemed longer than necessary, a source of frustration for some patients and staff. But, the staff didn't know how to improve.

This changed at the onset of the value-based transformation pilot. An initial review of the hospital's outcomes data for hip replacement surgery revealed that Sahlgrenska had an average length of stay twice as long as a Danish public hospital of similar size, with equal long-term outcomes. That Danish hospital had recently instituted a new care process for hip replacement surgeries greatly increasing its efficiency. Sahlgrenska wanted to follow suit, but it needed a way to ensure that quality of care remained high as the new care process was implemented.

A multidisciplinary working group of physicians, nurses, health economists and data analysts was formed to guide the transition process, as well as a smaller project team, led by Dr. Rolfson, that carried out the day-to-day work of the transformation process. The working group's first task was to choose which outcomes should be tracked to evaluate care quality as well as the efficacy of the new care process. As Sweden has a strong tradition of outcomes measurement via national health registries, a wealth of outcomes data was already available. The key was to choose the ones that best represented increased efficiency and enhanced value for patients and then to present the data in a user-friendly and actionable way.

The working group chose 13 outcome measures and decided to display them in a dashboard that updated in real time (see page 87 for an example), which allowed them to track changes in patient outcomes, cost, and efficiency at a glance. However, due to its technical complexity, this approach required the working group to commission a private data management and IT solution provider to handle the task.

But identifying trends in these main outcomes was only part of the transformation. Any changes to measures observed in the dashboard, particularly negative changes, required an explanation and a solution. Therefore, the working group also developed supporting reports to present additional outcome measures that could be viewed using a variety of different filters. Measures, for instance, could be viewed over different time periods or groups of patients, or at the level of an individual physician or patient. This additional tool enabled working group members to investigate with ease trends in the 13 main outcomes and identify solutions to problems that emerged.

In its first few months of use, the dashboard indicated an increase in the rate of adverse events of about eight percent, which concerned the team. Using the more detailed reports, working group members were able to determine that this was due in part to an increase in number of falls during inpatient recovery. But, more interestingly, they then found that the patients who had fallen during their hospital stay had not received the proper risk assessment upon

The Short Form 36 Questionnaire (SF-36) measures patients' vitality

admission. In response, the working group developed a program to emphasize the importance of this screening process and the need for additional precautions with patients at high risk for falling.

In another example, using the dashboard and detailed reports, the working group identified nausea as the most common patient complaint following surgery. By changing patients' pre-surgical medication and the anesthetics used during surgery, post-surgery nausea has been greatly reduced. This, in turn, helps to decrease patients' length of stay and increase their satisfaction with their care.

The dashboard was developed in parallel with the implementation of a new care process for hip replacement surgery in Sahlgrenska's orthopedics department known as Fast Track. Fast Track is based on a number of clinical studies showing that getting hip replacement patients up and out of bed within the first 24 hours following surgery leads to better long-term outcomes. It employs small but effective tactics to encourage patient mobility, such as removing all TVs from individual patient rooms and replacing them with a communal TV room down the hall. Patients thus had incentive to get out of bed, speeding their recovery.

The dashboard showed that with Fast Track, the average length of stay for hip replacement surgery decreased by 50 percent. Consequently, the hospital managed to increase the number of hip replacement surgeries it performed each year. In addition, the cost per-patient of the surgery decreased, despite the use of more expensive prostheses that have been shown to yield better long-term outcomes.

The pilot was a success: transitioning to value-based health care resulted in more efficient care, with better patient outcomes. Providing the necessary data to address long-standing problems was a key element in this success.

Rolfson feels that the transitions required significantly more time and resources than expected, he is excited that Sahlgrenska now has the infrastructure and experience needed to expand value-based transformation to the rest of the hospital, opening the doors for enormous benefits down the road. However, the pilot project in hip arthroplasty made clear that adopting value-based health care is an ongoing process: data must be continuously collected and care processes must be constantly re-evaluated. The outcomes dashboard made it easier for working group members to identify weaknesses in how patients were cared for. It also makes possible the next step: for all levels of a hospital, from clinicians to nurses to administration, to join efforts in targeting these problem areas leading to constantly improving care.

Measurable, Tangible, Better: Improving Eating Disorder Care at Roseneck Hospital

The motto of the Schön Klinik, the fifth-largest private hospital group in Germany, is "Measurable. Tangible. Better". Nowhere is that motto more apt than at Schön's flagship Roseneck Hospital, the first hospital in Germany to have a dedicated eating disorders ward and also the country's leading inpatient provider for patients with anorexia nervosa and bulimia nervosa. The Schön group prides itself on constantly improving care and has long had a comprehensive outcome measurement system throughout its hospitals, beginning with Roseneck, which has been measuring results since 1985.

At the time Roseneck Hospital was founded, there existed no well-established therapies for eating disorders, so the hospital's first medical director was adamant that all of his clinic's treatment approaches be systematically validated. Even during the earliest years of operation, all Roseneck Hospital clinicians were required to measure and report their own results. Outcomes reporting created a hospital culture that places enormous value on the patient experience. Those working at Schön today still recognize that measurable quality is the most important strategic aspect of their activity.

In 1997, Schön Klink began widely implementing patient-reported experience measures. A year later, a separate Department of Quality Management was formed to help extend outcomes measurement throughout the organization. The department spearheaded development of medical "scorecards" to carefully track results of patient care, at first just using existing data. Leading physicians in each department also worked to generate lists of key outcomes by condition, and over time, physicians refined the scorecard metrics and even developed new measures to capture additional outcomes that previously had gone uninvestigated. In line with its mission of unrelenting self-evaluation and improvement, Schön also began publishing an annual Quality Report, accessible publicly on its website. By 2012, Schön was tracking over 3,000 measures across 150 physical and mental health conditions.

Some physicians were understandably wary about outcomes reporting, fearing for their job security. But because the goal of outcomes reporting has always been to root out areas of care that need improvement and is not just simply firefighting, physicians at Schön received help, not penalties, for poorer outcomes. At Roseneck, outcomes, patient satisfaction, and quality initiatives were reviewed at monthly quality meetings, where hospital leadership and senior clinicians discussed how to work with the eating disorder wards that were achieving poorer results.

These regular meetings to scrutinize patient results have led to several innovations in how Roseneck treats its eating disorder patients. Just one example: All Schön hospitals had been marking anorexia patients' weight gain progress on a visual chart, with a hard threshold at 700 grams. But when patients reached the threshold, they would cut back on eating again. To alleviate the renewed anxiety patients felt when they reached this threshold, Bad Staffelstein, another Schön hospital, began providing its anorexia patients with a "weight corridor" between 700 to 1,000 grams, encouraging them to enter and stay in this "corridor" instead. Roseneck implemented this innovation, and a year later, its outcomes had surpassed those at Bad Staffelstein.

In 2011, anorexia patients experienced on average an encouraging 2.29 increase in BMI during their stay at Roseneck. Since the implementation of systematic outcomes measurement, as well as regular meetings to discuss them, outcomes for Roseneck's anorexia patients have improved on every single measure. In 2012, Roseneck even won a Golden Helix Award from the Association of Hospital Managers in Germany, which specifically called out the hospital's "scientifically proven diagnostic questionnaires and follow-up surveys."

Roseneck, however, isn't resting on the laurels of these measurable, tangible positive results, continuing to chase the third element of its motto: better.

Compete and Compare: Santeon's Recipe for Success

Dr. Wim van den Bosch will always remember one pivotal meeting in Nijmegen, the Netherlands, in October of 2011. That morning, the Chief Executive Officers and Chief Medical Officers of six leading hospitals in the Netherlands met to discuss the upcoming projects for Santeon, the umbrella organization under which their hospitals collaborate to improve care, reduce costs and innovate. The health care landscape in the Netherlands was changing, with patients and insurers alike demanding more transparency in how care is given. Because of the volume effect, the government had begun to consider centralizing some complex care processes in a few leading centers in the country. For the Santeon hospitals, it was of strategic importance to find the right way to respond to this changing environment.

St. Antonius Hospital and Catharina hospitals brought to the table a groundbreaking idea: what if Santeon hospitals openly reported the outcomes they achieved, for their patients and the public to see? To support this idea, they showed the group the Outcomes Book of the Cleveland Clinic in Ohio as well as the early results of a local initiative, "Meetbaar Better" in cardiology and cardiothoracic surgery. The reaction was immediate and enthusiastic. After all, Santeon hospitals were already among the best in the country. Why not further demonstrate their excellence by reporting hard facts? The Santeon board asked Dr. van den Bosch, Senior Advisor at the St. Antonius Hospital, to develop a proof of concept.

"It was important to have all Santeon hospitals on board," van den Bosch explained. "That's why we picked two medical conditions for which each of the hospitals had significant volumes: lung and prostate cancers. We started to call the senior physicians who would need to be involved in the outcomes reporting process. Their reactions were also positive."

"The project came at the right time," said Dr. Franz Schramel, a pulmonologist at the St. Antonius Hospital in Utrecht. "As physicians, we knew that discussions to centralize oncology care in a few centers were ongoing. This initiative was a great opportunity to show that the quality of care in the Santeon hospitals was more than just good." Furthermore, specialty societies were developing new quality indicators. A Santeon-wide outcomes reporting initiative was also a way to get a seat at the table alongside the payers and the authorities in shaping the evolution of the Dutch healthcare system and the discussion about indicators that really matter to patients.

"I want to show our outcomes book to my patients during their consultations! I want to show them the outcomes they can expect," said Dr. Harm van Melick, Urologist.

Van den Bosch assembled a multidisciplinary team to implement outcomes reporting. Their first task was to reach a consensus on what measures should be tracked and reported, before launching any comparisons. According to van den Bosch, the team whittled down a list of 80 candidate outcomes indicators.

"At that time, ICHOM did not yet exist – we used Michael Porter's health outcomes hierarchy to select the ones that were most relevant and widely measured," he said. "We also used retrospective data from the Santeon hospitals to test the feasibility, validity, and predictive power of each candidate indicator as well as the predictive value of each case mix factor and only select the most appropriate ones."

Within a few months, the team began to analyze the results which would later be published in the "Care for Outcomes" book. Several patterns from the dashboard immediately piqued physicians' interest.

"We realized that, for our stage III lung cancer patients, the outcomes were significantly better in Eindhoven compared to Utrecht, two of our Santeon hospitals," Schramel said. After looking more closely at the treatments each hospital was delivering to its cancer patients, the team realized Eindhoven was using a more powerful form of treatment, concurrent chemotherapy. "We also noticed that survival of patients with stage IV non small cell lung cancer had worse survival in Utrecht," explains Schramel. At first sight, the data revealed that fewer patients with stage IV disease were treated in Utrecht. But after analysis, and correction for case mix, this difference disappeared. "What it means? Details matter!", notes Dr. Schramel.

"After adjusting our care methods, we are now able to provide the best care out of all the hospitals, building on the strengths of each of the Santeon members", Schramel said. "That's great proof we can learn from each other and that nobody is the best in everything!"

Van den Bosch also pointed out that by analyzing outcomes data, hospitals noticed that patients who were referred for prostatectomy by an urologist to a surgeon in another hospital had better survival expectancy than patients whose surgeons were also the ones setting out the diagnostic and treatment plan.

"This was a eye opening!," van den Bosch said. We realized that referring physicians and surgeons were using different thresholds for when to recommend surgery. We went back to our surgeons and made sure that they adjusted their thresholds for deciding to undertake an operation."

In early 2014, the Santeon board met again. Van den Bosch proudly presented the hospital system's own outcomes book, which Santeon was able to publish for the first two conditions they had chosen to measure. The physicians also highlighted several examples of changes to care at the Santeon hospitals that were introduced in response to the systematic review of outcomes.

"I think we found the recipe to improve outcomes together", van den Bosch recalled one of the board members saying. The proof of concept was established.

Four questions for Leonique Niessen

We had the opportunity to speak with Leonique Niessen, Director of Santeon, an umbrella organization under which six leading hospitals in the Netherlands collaborate.

Leonique Niessen, Program Director at Santeon

ICHOM: Why did six private hospitals work together to improve care? What was the business rationale?

Leonique Niessen: We simply believe that one hospital cannot improve quality alone. A single hospital can set up improvement programs but will need to compare its performance with others to understand where it can improve and which procedures deliver the best outcomes. Together, with the six Santeon hospitals, we cover around 10 percent of the national volume. It is more than enough to generate insightful data, to compare, and to improve. We are widespread in the country and not competing against each other for most of our volumes. Together we are stronger and do a better job. The fact that we can prove we are six leading learning hospitals is an unique selling point for patients and health insurance companies. We are building a strong brand, based on quality and trust. By reporting on our outcomes transparently, we build trust with patients, payors, and authorities. Finally, we want to be prepared. We believe in a world where care providers are paid based on the outcomes they achieve. Investing now in outcomes is a way to be prepared and be ahead of the pack. We also anticipate a trend to centralize complex care in a few leading organizations in each country. By proving that we have strong outcomes, we position ourselves.

How was the initiative welcomed by the public and by the payors?

Very well received. We use our data to enrich patient-physician discussions. We also use them in our discussions with payors. Measuring outcomes systematically and comparing with each other gives us a competitive advantage.

What is the recipe for success?

I would point out a few key success factors. Ours is a physician-led and patient-focused initiative. Physicians are in the lead to decide and validate results at every step, while the metrics are highly relevant to the patients.

1 We combine retrospective and prospective data to get results quickly.

2 We leverage as much as possible existing data. We use medical students to crawl through the medical records if required!

3 We have an interdisciplinary support team that accompanies the physicians, making sure they can analyze and act on the data.

What are the next steps?

We want to make the results easily accessible to our patients and the public. We also want to expand to more medical conditions. And finally, we want to compare internationally. Our goal? Being fully transparent in the next years.

There Is More in the Netherlands:
Improved Value for Heart Care Patients

The Netherlands is one of the most advanced countries in the world when it comes to value-based health care. Another great initiative to point out is the "Meetbaar Beter" ("Measurably Better") initiative, which focuses on cardiology. What started as an ambitious project of medical doctors in the heart centers of Catharina and St. Atonius hospitals (both Santeon hospitals) has developed into an independent national foundation managed by medical doctors in which 12 out of 16 Dutch heart centers participate.

The Meetbaar Beter process starts with the development of a metrics set. Physicians and outcomes experts agree on what should be measured, leveraging the value-based health care theory. Meetbaar Beter has started to build alignment with ICHOM Standard Sets to ensure international comparability. Physicians of participating centers publish results transparently and can then analyze results and compare practices with each other to learn and improve. As Dr. Brandon Bravo Bruinsma from Isala Clinic says "I never had such open and constructive discussions with colleagues from other heart centers. This is true added value of the initiative. We even visit each others centers to share best practices."

Meetbaar Beter now covers nearly all main heart conditions and outcomes are published for more than 70 percent of all invasive or operative treated heart patients in the Netherlands.

This initiative delivers results. Recent successes include a reduction in infection rates through improved surgical nursing protocols and a decrease in mortality and major surgical complications following aortic valve replacement due to optimization of pre-operative care and increased involvement of interventional cardiologists in patient care teams. In the latest outcomes book, one hospital (Isala) outperforms other hospitals on 120-day survival after surgery. In cooperation with Isala, Meetbaar Beter is now sharing the best practice "Isala Safety Check", with participating heart centers, with the goal of improving patient value.

AVR Mortality decrement in Catharina Hospital

1.75% → 1.1%

Tamponade after PVI decrement in Catharina Hospital

2% → ~0%

Deep Sternal Wound Infection decrement in St. Antonius Hospital

1.5% → 0.8%

The Seattle Angina Questionnaire (SAQ-7) measures physical imitations of patients with coronary artery disease

Following Breadcrumbs: Outcomes Data in the Victorian Cancer Registry as Clues to Improvement

Conducting audits and collecting reliable data that identifies poor outcomes is only one part of any quality improvement process. Critically, how can health services pinpoint the factors that lead to poor outcomes?

The Monash University Victorian Prostate Cancer Registry, together with the Prostate Cancer Foundation of Australia, have been able to look at outcomes data from Gippsland, a largely rural region in the Australian State of Victoria, on the South-Eastern coast of Australia. They looked for clues to the specific care areas that are in greater need of process improvement, whether the improvements relate to primary care disease management pathways, access to health care services, screening methodology, or something else further downstream.

The first clue came from outcomes data published periodically by the Victorian Cancer Registry showing that men in the Gippsland region had poorer survival from prostate cancer compared to other areas in the State, after adjusting for age. Dr. Susan Evans, Executive Officer and Senior Research Fellow at the National Health and Medical Research Council Center of Research Excellence in Patient Safety at Monash University, and Associate Professor Jeremy Millar, the Clinical Lead of the Victorian Prostate Cancer Registry and Director of Alfred Health Radiation Oncology, were determined to find out why.

Having identified the variation in survival rates, they “decided to drill down using the data we held in the Prostate Cancer Registry in order to identify factors associated with these poorer outcomes,” Millar says. The Monash Victorian Prostate Cancer Registry was established as a pilot in 2009, but has now expanded to cover 80 percent of the population of the State, with an “opt-off” rate from this population of about two percent The registry collects demographic details, management details, and outcomes details, the most important of which are PROMs. The coverage of the Registry is representative of the State, so this, with the low opt-off rate and the high rates of followup, means that the observations from the registry can be reliably generalised.

The team worked backwards from the knowledge of unfavorable outcomes to identify potential deficiencies in care processes. They discovered that the poorer survival rates for Gippsland men could be traced back to a range of differences in Gippsland, and each point along the prostate cancer care assessment and treatment pathway.

Process improvement is a complicated game with a large number of entry points; the only way to keep the focus on improved care delivery is to start with the end result that needs to be changed – the outcomes.

“The pathways leading to these poorer outcomes were multiple and not necessarily related,” Millar says. “The only way we would’ve traced these is by starting with outcomes and working backwards.”

Using their method of working backwards from known outcomes data, Millar’s team discovered that prostate cancer patients in Gippsland had no evidence of higher rates of co-morbidities than men in other regions of Victoria, but they were more likely to:

1 be diagnosed at an older age,

2 present with more advanced disease,

3 be more likely to have biologically aggressive cancers, shown by larger proportion of high grade histopathology,

4 be diagnosed through an operation to relieve urinary symptoms, rather than through purposeful screening for prostate cancer,

5 wait longer between diagnosis and active treatment, and

6 be much less likely to have surgery when appropriate than men in other parts of Victoria.

Pinpointing all six complex reasons behind poor prostate cancer outcomes in Gippsland men was just the beginning of a much longer investigation. According to both Evans and Millar, the team’s initial discoveries have spurred additional examinations of other possible source areas that needed work.

"Our report from the registry, which includes PROMs, was able to identify a number of causes for this variation across the Victorian state," Evans says. "The relevant stakeholders in the region have treated this as a 'call to arms' and have commenced planning for system-wide responses to try to improve things."

This investigation identified various avenues for further investigation and analysis. The trail of breadcrumbs left by carefully-recorded outcomes data has led to a great deal of positive rethinking of how to provide the best possible care in the best possible ways for patients.

"We have identified primary care pathways for prostate cancer management including age ranges for screening and referral patterns as potential problem areas," Evans says. "It also seems as though patients are not getting enough advice about acting on prostate cancer symptoms."

Surgical training has also been flagged for investigation: outcomes from radical prostatectomies are better for patients who were operated on by registrars (residents) with more supervision from senior surgeons.

Even factors related to public health planning have surfaced as potential target areas for improvement.

"Distance to public transport, or to drive, can affect a patient's decision as to whether they choose surgery, radiotherapy, or a wait-and-see approach," Millar says. Indeed, the theory is well-cited in the public health literature, but how big a problem it is can only be quantified by using data – in this case, outcomes data.

Outcomes measurement offers a way to justify care delivery improvement strategies using hard data, regardless of whether those improvement areas are in public health, primary care, surgical procedure, or medical training. Good data can point a health service towards better ways to care for their patients.

The Expanded Prostate Cancer Index Composite (EPIC-26) measures prostate cancer patients' level of incontinence

what does outcomes measurement mean for payers?

From Volume to Value

All over the world, initiatives are appearing to shift the paradigm in health care from volume to value. If care providers are already using outcomes data to improve the care they deliver, payers are also beginning to understand how outcomes can be used to better reimburse. Payers, as governments or private companies, can benefit significantly from a value-based health care world. By focusing on the notion of value, they can reimburse the right care at the right price. And they can gain back control on their spendings.

Many payors and health systems are thus introducing innovative payment models that incentivize quality and focus on the value delivered for the patients. This can be done in many ways: from basic models that add to the traditional fee-for-service a premium for the outcomes achieved to bundle-payment models where providers are responsible end-to-end for the delivery and the outcomes of a select procedure. We have selected a few examples from around the world.

Value-Based Purchasing All Over the World

USA – Geisinger

Fixed price payment for **Coronary Artery Bypass Grafting** leading to improvement in outcomes and decrease in costs for payor and providers

USA – CMS

Introducing **bundle prospective payment** for up to **48 medical conditions**

USA – Arkansas State Payers *

Perinatal **bundle payment** covering full range of services: **all prenatal care**, care related to labor and delivery, and postpartum care

* Arkansas Medicaid, Arkansas Blue Cross and Blue Shield, and Arkansas QualChoice

USA – CalPERS & BCBS California

Flat fee payment of $30,000 for **single knee and hip joint replacement**, covering the surgery and the hospital stay. Furthermore, CalPERS publishes a list of preferred hospitals that commit not to charge more than that amount, ensuring that the patient will not have any additional costs.

1 How NHS leverages ICHOM Standard Sets for value-based purchasing.

NHS is the main purchaser of health care in the UK. In one county, Bedfordshire, the NHS contracted exclusively with one care provider – Circle Partnership – to deliver all the musculoskeletal care in the area. Instead of just developing a capitation model to better control spendings, the Bedfordshire Clinical Commissioning Group (BCCG) decided to include a premium based on the quality of care delivered. To assess the quality, BCCG developed a simple formula that takes into account several dimensions, including the outcomes achieved for the patient. The ambition of BCCG is to make up to 20 percent of the payment variable. To assess the outcomes achieved, BCCG is relying on the ICHOM Standard Set for Low Back Pain. Circle Partnership reports regularly on the outcomes achieved and the "quality premium" is calculated on a quarterly basis.

Learn more about this example in our ICHOM Case Study **"How the NHS is leveraging an ICHOM standard set for value-based purchasing,"** available on our website.

UK – NHS BCCG [1]

Bundle payment for **musculoskeletal care** with additional financial incentives based on outcome (using ICHOM set)

UK – NHS Staffordshire

Bidding for a **1.2 GBP contract** to manage all **cancer and end-of-life care** in Staffordshire County launched

UK – Department of Health

Eight pilots launched on **outcome-based payment** for **drug/alcohol treatment** (e.g., free from drugs, no offending general health, etc.)

Sweden – Swedish County Council [2]

Introducing **bundle payment** for total **hip and knee replacement**, decreasing two-year complications by 15-20%

Bundle payment for **spine surgery** with performance premium based on patient-reported pain improvement after surgery, varying by -24%/+37%

Germany – Techniker Krankenkasse

Pain center for **Low back pain** receives a **bonus of 10%** if patient gets back to work after six weeks. Malus of 5% if failure after eight weeks

Germany – AOK Hessen

Outcome based bundle payment for **coronary artery disease and stroke program** based on 30-day mortality, stationary recovery within one year, and readmission rate

2 How Stockholm County Council incentivizes quality of care for Spine Surgery

Since 2009, Stockholm County Council (SCC) has reimbursed hip and knee replacements with a bundle payment, where the provider is responsible for any related complications for two years after the operation. The positive results of the project spurred SCC health care administration to pilot a new bundle payment project for spine surgery. But this time, they decide to also include a variable part directly related to the health outcomes achieved. This way, the health care administration increases its control of not only the costs of the procedure and its potential complications, but also the value delivered to the client. Nine modules covering ten diagnosis leading to spine surgery (disc herniation, spinal stenosis, degenerative disc disease, spondylolisthesis, myelopathy, rhizopathy,degenerative deformity, S1-pain, coccygodyny and RA neck) are in scope. For each of them, participating hospitals receive a prospective base payment at the time of surgery. This base payment is adjusted every six months to take into account the case mix. The patient reported outcome measure that is linked to performance payment is called Global Assessment and is reported into the Swedish quality register for spine surgery (SWESPINE). The Global Assessment consists of a simple question: "What is your level of pain (leg/back/arm) today compared to time before surgery?" Depending on the answer, the provider will receive, for this patient, a bonus or malus that can vary from -24% to +37%. The payment related to outcomes is also case-mix adjusted.

facts & figures

About ICHOM

Research Fellows involved in the work
12

40+
sponsors

from
12
countrys

25
Countries present at our conference

12
Employees on two countries

50
organizations actively measuring our first Standard Sets

50 Conditions by end 2017,
75 %
of the disease burden of industrialized countries

37 % disease burdens covered by
12
Standard Sets by the end of 2014

prestigious co-founders
3
Prof. Michael Porter,
Boston Consulting Group,
Karolinksa Institutet

budget in 2014
1.8M $

Founded in
November 2012

the faces behind

Dr. Charlotte Roberts acquired her medical degree from Oxford University before completing a fellowship at Public Health England.

"I am looking forward to helping create outcome standards. I believe that the translation and application of standard outcomes across different systems will ultimately benefit our patients."

"We must measure and report outcomes that matter to patients. This makes sure that the system goals are in line with what patients want. Everyone can then work towards achieving the greatest outcomes and we can learn from those with the best results. ICHOM is helping make this aim a reality."

Dr. Tom Kelley holds a medical degree from Manchester University and an MBA from Oxford University.

"I believe that ICHOM is the organization to lead a paradigm-shift from process and structural indicators towards value-based health care and outcomes that matter to patients. I am proud to be part of this initiative, which will truly change health care."

Dr. Annelotte van Bommel is a medical doctor and PhD student on quality of care at Leiden University.

"I am excited about value-based health care because of its power to ignite competition across the health care spectrum. When patients and others can make informed decisions based on reliable outcomes data, quality will improve."

Isaiah Sterrett holds a Bachelor's degree in political science and a Master's degree in comparative politics, both from Boston College.

"Health care systems are full of parallel processes that fail to collectively focus on the one common goal that matters – patient-centered outcomes. We need to change this – health care needs a revolution."

Dr. Jason Arora holds a medical degree from Oxford University and a Masters in Public Health from Harvard University.

"I believe that for any complex system to change, its current situation needs to be fully understood. In health care, measuring outcomes of most importance to patients is therefore essential. It is truly amazing to be a part of the ICHOM team in pursuing this goal!"

Dr. Sara Sprinkhuizen is a physicist and holds a PhD in Medical Imaging from Utrecht University.

"My clinical training impressed upon me the tremendous need for a greater focus on patient outcomes in medicine. I am thrilled to now be spending my days working toward the creation and world-wide adoption of these outcome measures."

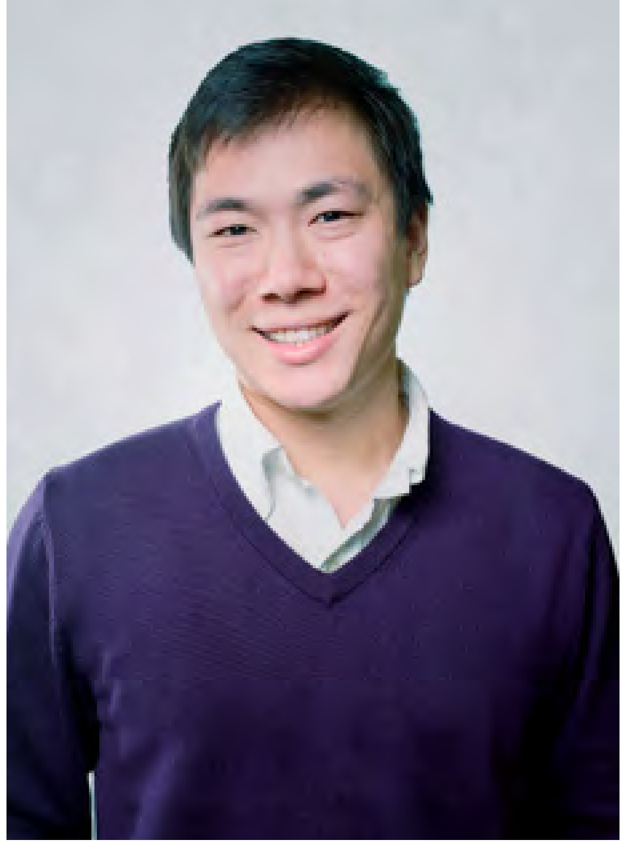
Dr. Stephanie Wissig recently completed her medical training at Albert Einstein College of Medicine in New York and also holds a PhD in Neuroscience.

"My passion to help design and utilize outcomes across the UK, along with my previous experience in delivering innovative healthcare models, led to my joining the ICHOM team UK."

Dr. Claude Pinnock holds a medical degree and is a Public Health Trainee in the NHS.

"My experience at the ALS Clinic at Massachusetts General Hospital impressed upon me that complete physicians do not care for patients solely through the application of foundational science. Rather, they do so by appreciating the implications of limited resources on the health care system, and by understanding the effective interactions amongst patients, physicians, and health care related organizations. ICHOM is changing the way we evaluate health care performance, costs, and quality by creating a common language all three parties can understand."

Teddy Peng studied in human developmental and regenerative biology at Harvard University.



"ICHOM's work not only makes sense for physicians – who are empowered to learn from each other – and for patients – who benefit from more transparency. It also makes sense from a management perspective. As a management consultant, I realized how difficult it was to be in the driver's seat if you are blindfolded on the quality-impact of your decisions."

Jean Stoefs holds a Master's degree in Commerce & Engineering from the University of Louvain (UCL) in Belgium.

“I’ve always been attracted to people and organizations that look at seemingly intractable problems – such as those that many health care systems face today – as opportunities… and challenges to overcome. ICHOM truly embodies that mindset, that type of thinking.”

Jacob Lippa holds a master’s degree in health care policy and management from Columbia University.

“The need for ICHOM was so clear to me from my work with Michael Porter. We were talking for years about value in health care but no one knew how to define it. We took up the gauntlet and, with like-minded believers, decided to push the field forward ourselves.”

Dr. Caleb Stowell is a medical doctor and past researcher with Michael Porter’s value-based health care team at Harvard Business School.

“I have had the opportunity to work as a physician, in the research-based pharmaceutical industry, and most recently in a regulatory body. At the core of all of these positions was the same goal: to help make sure patients received the best possible care. Today, transparency of results is recognized as an essential tool for doing so. But international standardization of measurement by medical condition – the global outcomes “language” – is still missing. By providing stakeholders across the health care spectrum the tools they need to measure the health outcomes that matter most to patients, ICHOM is starting to develop that language!”

Dr. Christina Rångemark Åkerman received her medical degree from the University of Linköping. She has an Executive MBA in General Management from the Stockholm School of Economics.

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Shan Wang
Adina Welander
Maria Wieser
Ji Su Yoo

“I’ve learned that measuring outcomes, analyzing variances, and initiating change is the most effective and ethical way of improving medicine. Having done outcomes measurement on a company level showed me the need for a global approach – this is why I joined ICHOM.”

Lisa van Maasakkers has a background in economics and has worked in the field of outcomes measurement in health care for over ten years.

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