BMJ Outcomes is a new global initiative that aims to improve the value of healthcare interventions by accelerating the development and use of robust outcome measures that matter to patients. This inaugural collection of articles, specially commissioned from experts in the science and practice of outcome measurement, highlights challenges and progress towards more meaningful measurement of the value of healthcare intervention.

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Many current medical interventions and their resulting outcomes for patients not only exhibit extreme variation internationally, but can also show extreme local variation. Healthcare quality measures that try to examine patient outcomes are often not constructed in standardised formats to allow for comparisons over time of providers or regions and countries, or to allow for benchmarking.

BMJ Outcomes will work to create a global community around outcomes of greatest importance to providers, patients, payers and other major healthcare stakeholders. That community will have access to a repository of measures, documented use of those measures, and related tools and evidence that support advancement of outcome measurement.
The Dutch National Health Care Institute (NHCI) has an important role in maintaining the quality, accessibility and affordability of healthcare in the Netherlands. We encourage all efforts to improve healthcare quality. To that end, the NHCI aims for quality indicators that measure outcomes and experiences that matter to patients and that are based on (disease-specific) quality standards. BMJ Outcomes will provide us with an overview of outcome measures used around the world, and provide a platform for collaboration and learning that can be applied to improvements in healthcare in the Netherlands. The NHCI is supporting this initiative as it will increase our knowledge of outcome measures and their impact on quality of healthcare.

CZ is a Dutch health insurance company and wants the best possible care for its insured. Creating more patient value through value based healthcare procurement is our core business. By basing our procurement decisions upon the goals of the patient, the patient is truly the focus of our work at CZ. Outcome measurement is essential to find out whether patients’ goals are truly met. We are proud to support the BMJ Outcomes initiative to improve patient outcomes locally through global learning and exchange.

We are seeking additional associates and partners to collaborate with BMJ Outcomes across the globe. Please contact us to discuss opportunities for your organisation to play a leading role in BMJ Outcomes.
Good research employs rigorous methods to prove or disprove a causal connection between action and reaction, medical or surgical intervention, and health outcome. From this we derive guidelines to help providers make clinical decisions according to the best available evidence. However, by failing to examine just as methodically whether the outcomes we aim to achieve with evidence do indeed capture the full spectrum of outcomes that matter most to the patient, we are missing important, essential pieces of the picture of the value we are delivering to patients and to society.

Incredible shining lights have begun to appear in diverse organisations around the world, which offer brilliant examples of how this challenge can be met. One organisation committed to involving patients in defining the goals of care from the outset, when the rest of healthcare was still wondering whether involving patients was possible. They have much to teach us now on how to overcome the hurdles to collaborating successfully with our patients on measure development. Another is beginning to tackle the complexity of matching insight into cost with their success in improving their quality according to patient-centred metrics. Several illustrate the dramatic value to be gained in extending our measurement of quality beyond the acute healthcare episode and into the patient’s life beyond our walls. You will read calls to action from voices across many aspects of healthcare, all joining together to insist that we commit to finding our way, though the challenges will be great, to measure what matters, to ensure that our efforts to improve health are guided by that emerging data, and by so doing to achieve a more powerful impact on the health of the world’s people.

“First do no harm” – yet most physicians aim much higher than this. We owe them and other healthcare providers the insight into their patients’ outcomes that would empower them to continue to improve on the care they are delivering. Our hope is that by convening leaders among healthcare providers and organisations around the world, we can, together, lead the way. We hope you will join us.

At BMJ we have always been committed to doing our part in creating “a healthier world”, and we are continually looking at how we can help to move healthcare in the right direction. Are there ingrained practices that need to be challenged, powerful interests whose commitment to transparency requires examination, or our own core beliefs that might need questioning in the light of new evidence? As we look around the world today, in every region there is a growing call for reorienting healthcare systems towards value, which begs the question: how do we measure that value?
Measuring the value of healthcare delivery: a call to action

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Introduction

Governments, individuals, providers, professionals, and insurers are struggling to cope with rising costs of care. A core issue is the search for value: are we getting the best outcomes for the dollars spent? Yet to determine the value of care, we have to be able to measure it, report on it, and compare it. Although we have thousands of indicators available in indicator clearinghouses, and the term ‘value’ has become commonplace in discussing challenges in healthcare, we know very little about the comparative value delivered by providers.

This state of affairs is historically understandable, but needs to be — and can be — overcome. First of all, current measures are provider- rather than patient-centred, and they focus on processes or outcomes of individual steps rather than the overall key outcomes of care that matter most to the patient. Current measures attempt to capture the quality of diabetes care of a specialist or the stroke care of a hospital, while the patient’s outcome is determined by the total process of care delivered by a whole range of professionals and providers with interplay from the community surrounding the patient. Second, we still rarely integrate quality measurement with proper cost measurement — although only by doing so can value be captured. Third, partially due to these previous points, we strive to capture more and more information about the care process, increasing the documentation burden for professionals and providers while we underuse data already available. Most importantly, we underuse a source of data that should be central to our efforts: the patient.

In addressing these issues, measuring value — and thereby contracting and properly paying for value — will appear to be more within our reach than is often thought.
From valuing what we measure to measuring value. Not mistaking the trees for the forest

Process measures provide only a narrow, yet important, perspective on quality of care; there are many more decisions and processes that occur in the course of caring for patients. Because the majority of quality measures have been developed for the purpose of tracking individual professional responsibility/certification, benchmarking between providers, or internal governance, they primarily focus on the structure and processes of care. Are professionals adequately trained to deliver the care, and do they use the necessary guidelines properly? Providers can be held accountable for the scores on such measures, and points of improvements are directly apparent. Outcomes are more difficult to measure, require risk adjustment, and are less directly useful from the individual provider’s or professional’s point of view. How can one hold a professionals’ group responsible for the outcomes of acute stroke care when the rehabilitation of these patients is delivered by another provider? How can a diabetes specialist be held responsible for the longer-term outcomes of a diabetic patient who is also seen by a primary care doctor and other professionals? Although structure and process measures are essential to providers and professionals in managing their work, it is these ultimate outcomes that matter most to the patient, the payer, and society. Excellence lies in more than perfected individual steps: to generate optimal outcomes, the whole care process has to run smoothly, adapted to individual patients’ needs, and integrated with the ongoing care that extends out of the healthcare delivery system into the patient’s community.

Private or public payers who place too much emphasis on reporting or rewarding process and structure scores risk mistaking the forest for the trees: scores may go up, but overall outcomes may remain the same. In Michael Porter’s words, payers should not tell providers how to do their work and thus destroy value in micromanaging professionals. Rather, they should tell them what kinds of outcomes they would like to see realised. Providers and professionals are best placed to put the processes and structures in place to generate these outcomes at the lowest cost, thus generating value through professional innovation.

Guidelines and indicators

It is often assumed that the indicators that measure clinical quality have to be derived from evidence-based guidelines. Because guidelines usually focus on the steps to take in the light of a given clinical problem, it follows that derived indicators will be primarily structure and process measures. In fact, the relation between outcome indicator and guideline is inverse: the guideline describes best available evidence on how healthcare professionals should respond to a given clinical situation. Defining what the optimal outcomes should be, and therefore how they should be measured, are rarely addressed in the evidence-based guideline approach to quality in healthcare.
Measuring outcomes that reflect patients’ goals of care

Another consequence of the history of quality indicator development is that most existing measures try to capture the quality of the work of individual professions or organisations (see figure 1). Yet even if one wanted to do so, measuring outcomes of parts of an overall care process is very difficult. What happens between the hospital walls in the case of acute stroke care is difficult to separate from the quality and speed of the pre-hospital admission process; likewise, it is hard to untangle the quality of the medical oncologist from the surgeon in measuring patient outcomes of most cancer care. Interestingly, outcome measurement becomes more feasible when focused on what counts for patients: what was the condition the patient had when s/he entered care, and is the core goal of this care met?

While each individual patient may prioritise outcomes differently, a common set of important outcomes for those patients facing a common diagnosis and treatment pathway can be defined by consulting with the experts in what matters to patients – the patients and families. For example, the core outcomes for maternity care are a healthy baby and a healthy mother, and a care process that is experienced as highly patient-centred and self-empowering. For conditions like cataract, hip, or knee arthrosis – conditions for which elective interventions exist and can ‘solve’ the problem – the most relevant outcomes are the alleviation of symptoms, improved functional status, and the avoidance of unnecessary risk through either under- or over-treatment.
Different types of conditions not only have in common what constitutes relevant outcomes: they also share the timeframes appropriate for looking at outcomes. Maternity care, elective care, and also most types of acute care are episodic in nature, and outcomes can be measured at the end of the episode – say 30, 90, or 180 days after treatment or the onset of the acute event.[15, 16]

For chronic conditions, such as diabetes, COPD, rheumatoid arthritis, Parkinson’s and others, both the timeframe and the types of outcomes that matter differ. Chronic care is typically continuous, and outcomes are measured as changes in health status over time.[17] The outcomes that matter most for such conditions are a high quality of life, and the freedom (as far as possible) from short- and long-term exacerbations and complications. Here as well, the experienced patient-centeredness of the care is a crucial outcome measure (see figure 2).

When patients become frail or multimorbid, care remains continuous but the relevant outcomes of treatment change. For such patients, attempting to achieve optimal outcomes-per-condition is actually harmful.[18] Although there is much less evidence to help guide professionals’ actions, freedom from avoidable pain, exacerbations and complications, wellbeing and satisfaction with the care received would be deemed to be key outcomes of care.

Measuring outcomes for people that are not (yet) sick, as in basic primary care, would focus on remaining healthy, being treated in a patient-centred and empowering way, and seeking to avoid either under- and over treatment.

Who decides what outcomes matter most?

Invariably, the care for a condition will have more than one relevant outcome measure. Individual patients may value one outcome (eg the infection rate after the hip operation, or the level of pain) over another (eg ability to walk longer distances). In theory, some providers could be better in realising one outcome, while others could excel in the other outcome. In comorbid patients, multidimensional and sometimes conflicting goals are very common – and the question of ‘what matters’ acquires additional significance. Yet for the purposes of measuring and comparing value, the 80/20 approach we pursue here will bring us from the state of almost complete value-opacity into a much more transparent environment. The quest for perfection will be much more realistic once this first step is realised.

Measuring value: integrating two separate worlds

Measuring value (the quality gained per dollar spent) implies looking at quality outcomes and costs jointly; for example, the quality outcomes achieved three months after onset and treatment of an acute myocardial infarction should be juxtaposed to the costs of that care. Although this may appear obvious, managing, measuring, and reporting ‘quality’ and ‘cost’ separately is still routine in most healthcare organisations and healthcare systems.[19]

In addition, the ability to calculate the true cost of care for a patient with diabetes or stroke, for example, is generally underdeveloped; few healthcare organisations have had to attribute costs to outcomes delivered that way. Costs of operation theatre time, bed days, or staff in hospitals are generally only roughly attributed to specific patient groups, so that a hospital cannot tell what it would mean financially to focus on one type of care rather than another.[20] There are few countries globally where payers and especially patients have insight in the total costs from their perspective. In the USA particularly, what the cost is for an individual patient’s diabetes care, hip replacement care, or acute stroke care from the many providers involved is all but unknown to patients and providers alike.

However, stakeholders increasingly discuss the added value of the care delivered, attempting to measure costs and quality while publishing outcomes and overall price.[21] Activity-based costing is emerging as a powerful way for providers to understand patient trajectory-based cost better, including time spent by professionals and utilisation of spaces and materials. Demonstrating that one’s care for a specific patient population is low cost and high quality benefits the patient, payer, and provider. Since poorer quality is generally reflected in higher overall costs, high performing providers will be well positioned (see figure 3).
A fresh look at data sources

Traditionally, provider organisations were the source for data on effectiveness and safety, and patient surveys measured in a general sense the patient centeredness of that organisation. To look across organisational boundaries, however, data sources are required that can follow the patient along his or her journey through the healthcare system. Many clinical registries, sometimes built on electronic health records (EHRs), are starting to fill this gap, but most clinical registries’ insight is limited to the healthcare provider’s field of vision.

Administrative data (claims data, encounter data, or other types of data registered as part of an administrative process) can be a powerful source to follow patients’ paths through the delivery system over time. This allows not only a focus on costs but also on outcomes such as death, (re) admissions, the occurrence (or absence) of complications, care dependency, and utilisation. When linkages can be made with data on socio-economic status, education level and so forth, these data become even more powerful.

An as yet underutilised data source that is truly patient centred is the patient reported outcome measure (PROM). The PROM builds on the simple idea that the patient’s experience is the ‘gold standard’ by which many medical interventions can be judged. In medical science, PROMs are widely used to determine whether a new drug treatment is more effective than another in combating migraine, for example, or whether a new technique for knee operations has better results than traditional methods. PROMs have been around for decades, yet it is only some 10 years ago that the Bupa hospital group in the UK decided to use these PROMs for evaluating the clinical outcome of their procedures. The idea is simple yet revolutionary: rather than asking the doctor whether the total hip replacement went well, the patients who have undergone the operation are asked if the operation relieved their pain and has restored their previous physical ability.
Excellent stroke care (including stroke units that adequately integrate rehabilitation) improves survival rates as well as reducing disability and care dependency, reducing overall care costs for the acute stroke episode including the one-year follow up period (green quadrant).

When high quality providers become more aggressive users of expensive diagnostics and therapeutic interventions than the guidelines call for, their outcomes may remain good, but their costs will rise (orange quadrant).

Providers with poorly organised stroke care may see a lower unit-cost for the acute care episode itself, but these ‘savings’ are undone by the higher costs of post-discharge disability care – not to speak of the lost lives and quality of life (the red quadrant).

Finally, poorly organised and accessible care may of course result in lower costs and poor outcomes – the kind of ‘savings’ no healthcare system should aim for.

When embedded in the care process as both patient decision aids and outcome measure instruments, their potential to increase value is even more impressive. When the quality of care is high, patient outcomes are better, and when costs are low, value increases even further. This principle is illustrated in Figure 3, showing the four quadrants of value:

- **Upper left quadrant (green)**: Lower costs and better outcomes (high quality care).
- **Upper right quadrant (orange)**: Higher costs and better outcomes (aggressive care).
- **Lower left quadrant (red)**: Lower costs and lesser outcomes (poor care).
- **Lower right quadrant (yellow)**: Higher costs and lesser outcomes (very poor care).

It is rare that one data source will be able to cover the core outcomes that need to be measured. For hip replacement, patient reported outcomes scores are crucial, but so is the surgical revision rate. The major step forward in measuring value lies in the combination of the different data sources discussed. The sum of the insight we gain by triangulating and juxtaposing these sources is greater than any of the individual sources could generate in isolation, and leads to a much reduced registration burden (often only a few core clinical data items are needed when seen as complementary to administrative and PROMs data).

Figure 4 illustrates this principle, showing how a base of longitudinal administrative data is the powerful foundation on which to build. Of course, this often requires sharing information between payers (claims data) and providers (clinical information). Fortunately, the awareness that professionals, providers, and payers can gain much by such data sharing is growing.

Although it will always remain imperfect, it is possible to create a categorisation of conditions (including multimorbidity; see figure 2) within which the types of outcomes that matter most to patients are very similar. Likewise, experience has shown that the types of data required to measure outcomes within these categories of conditions (administrative, PROMs, clinical) are similar as well. This greatly facilitates the search for the best measures and the instruments and data required to populate these.

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29] [30, 31]
Conclusion

Paying for value rather than for volume is central to most healthcare reform efforts around the world. Yet we currently threaten to have an overload of information on matters crucial to the management of the care process, coupled with a dearth of real insight in what outcomes these processes bring to the patient.

With some key steps, however, this gap in insight can be overcome – and we can make enormous strides forward using data sources that are already available.

Figure 4.
Combining data sources for outcomes transparency.

- **Administrative claims data**: A core set of patient-centred outcomes of care is most practically built upon a foundation of administrative data - the most longitudinal and complete data set available.
- **PROMs/patient satisfaction**: Just using administrative data would bring much transparency where it is now often absent - yet there are clear limits. PROMs and patient satisfaction measures are key outcomes in many forms of care. When linked with administrative data, these measures truly help us come out of the current state of value-opacity.
- **Clinical registry data**: Fewer clinical measures - and lower provider documentation burden - will be needed if outcomes are built on core of administrative data supplemented by PROMs.

100% outcomes transparency
References


Consumer Quality Index – measuring patient experience in the Netherlands

The Miletus Foundation ("Miletus"), an alliance of Dutch health insurance companies focused on measuring patient experience, plays a major role in the development, validation, and adoption of patient-driven measures in the Netherlands.[1] Miletus collaborates with patient organisations and healthcare providers to conduct national standardised questionnaires and benchmark measurements. By generating patient experiences in a uniform and reliable way, Miletus aims to increase transparency of quality information from the patient’s perspective.[Vriens B and Braam C, “Transparency in the quality of hospital care” presentation, 2015] This effort provides valuable information to health insurers for purchasing care and stimulating better performance, and also provides patient organisations and the broader healthcare provider community with valuable insights into patient experience. Miletus develops and validates the measurements, gathers data from the reporting entities, and coordinates with other organisations to produce a report of the measure results.[Vriens, personal communication, 2015]

One initiative that Miletus spearheads is the Consumer Quality Index (CQI), which sets validated patient experience measures for a range of care processes.[1] Eighteen CQI questionnaires have been developed and validated with a focus on: care and health insurance, hospital care, diabetes, cataracts, hip/knee replacement, low back pain, physiotherapy, breast cancer care, outpatient mental healthcare, varicose veins, asthma/chronic obstructive pulmonary disease, pharmacy, rheumatism, heart failure, Parkinson’s disease, hearing aid, maternity care, and cancer care.[1] Some of these (for example varicose veins and hip and knee replacement) are accompanied by patient reported outcome measures.

In 2005, insurer and founder of Miletus, Agis, developed the CQI methodology, in coordination with Netherlands Institute for Health Services Research and the Department of Social Medicine at Academic Medical Center Amsterdam.[1, 2] Two experience of care measurements informed the CQI methodology: the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program[3] and the Quality of Care Through the Patient’s Eyes (QUOTE).[4] Each questionnaire is developed by workgroups of health insurance companies, surveyed healthcare providers, and relevant patient organisations. Patients are often involved in priority setting early in the development process. For the CQI that measures patient experience during breast cancer treatment, referred to as “mammapractice”, a focus group of patients are responsible for defining what “ideal” breast cancer care entails and the Dutch Breastcancer Association is responsible for updating criteria on an annual basis for how this should be captured.[B Vriens, personal communication, 2015]

Each measurement is vetted by a peer review group of methodological researchers and subsequently pilot tested. Miletus coordinates with healthcare providers to distribute the questionnaires. Patients are informed that their participation is voluntary and the data is processed anonymously. Miletus compiles the measure results, along with an analysis of the population assessed, into a single report that is made available to participating insurers and their healthcare providers.[1] Healthcare providers can also access a secure online portal to view the results. When the data is sufficiently validated by the insurers and providers, it is published in an accessible format that is available to consumers as well. Generally, after data collection it takes two months to create the benchmark, one month for providers and insurers to validate the results, and another three months are taken into account to give providers a chance to study the results before they are published.[B Vriens, personal communication, 2015]
The CQI measurements have been widely adopted across the Netherlands. The CQI for pharmacy, an assessment of a patient’s encounter with a pharmacist, has been adopted by approximately 1,279 pharmacies, and insurance companies plan to use it in their value-based healthcare initiatives.\[B Vriens, personal communication, 2015\] Furthermore, the mammacare measure is used by all 105 Dutch hospitals, with 89 of them with data registered in the Nabon Breast Cancer Audit. Some hospitals have paired up and created one “mammateam”, and all mammateams are accounted for in the collected data. The Dutch Breastcancer Association’s website (www.borstkanker.nl) uses data from the mammacare measure to rate the care delivered by breast cancer care providers and designates three ratings: below average, average, and above average. Two insurance companies, CZ and VGZ, also publish the mammacare results for customers to use when choosing a health plan or provider. On the CZ website (www.cz.nl), an individual can compare breast cancer care based on five ratings:

1. Best care: Score best on criteria
2. Very good care: Score best on criteria and improvement signals, but less on volume
3. Good care: Score good on criteria
4. Can do better: Care is according to CZ criteria but not optimal
5. Does not meet our criteria: There is no contract for this type of care. Since CQI measures are used to stimulate provider performance and inform purchasing decisions, Dr. Barbara Vriens, Program Coordinator for Miletus, speculates that “one reason for the considerable uptake is that healthcare providers may be more receptive to measurements when they are initiated by insurers.”[B Vriens, personal communication, 2015]

Yet the widespread implementation of CQI measures has not come without challenges. Since the CQI initiative began, Miletus has addressed issues related to data accuracy, time lags between treatment and questionnaire distribution, questionnaire optimisation, and ability to benchmark at different levels.[Vriens B and Braam C, “Transparency in the quality of hospital care” presentation, 2015] Because the criteria for each measure changes annually to set achievable goals, benchmarking can be challenging.[B Vriens, personal communication, 2015] Further, the patient organisations involved in the measure development have struggled to build a business case for their involvement.

Looking to the future, two additional questionnaires are in development targeting birth care and heart failure.[1] Efforts are also underway to develop patient-reported outcome measures that will align with the cancer, mammacare, cataract, low back pain, coronary disease, artery disease, and pharmacy CQI measures. This is a development that is only possible in partnership with providers and combined with the information in quality registries that allow for comparisons of providers after necessary case mix corrections are applied.[B Vriens, personal communication, 2015]

References
Outcomes as a foundation for designing and building population healthcare systems in England

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The current state of healthcare is such that care is distributed among different jurisdictions, institutions, professions, regulators, and inspectors, which has led to “the healthcare archipelago” of distributed services. This seriously hinders the ability of the health profession to focus on the needs of the patients and populations it is accountable to.

This distributed nature of healthcare services has led to many problems, including:

- Patient harm
- Unwarranted variation in outcomes
- Inequity
- Failure to prevent the preventable
- Waste of finite resources (financial and human).

These problems are all being faced in the context of rising need, demand, and expectations from patients.
Defining outcome targets for population-based healthcare systems

At Better Value Healthcare (www.bettervaluehealthcare.net) we work with payers and providers, mostly in the UK and Europe, to redesign healthcare systems to focus more on patient outcomes. To this end, we work through a framework in which we see healthcare divided into systems, networks, and pathways, and we define these terms as follows:

**System** - Defines the outcomes delivered to patients

**Network** - Determines who delivers the outcomes (i.e., GPs, surgeons, social care)

**Pathway** - Determines how the outcomes are delivered

To design population-based healthcare systems it is essential that we work with multi-stakeholder groups (i.e., patients, GPs, specialists, nurses, para-health professionals, IT, etc.) to capture every perspective on what an ideal patient outcome should be, and compose a shared vision on the outcomes all are aiming to achieve for that population. For example, for a system for people who need hip replacements, stakeholder perspectives on ideal patient outcomes could be as follows:

- Patient: ensure they are able to garden or play with their grandchildren or walk to the supermarket
- Surgeon: ensure there are no complications post-surgery
- Nurse: ensure the patient is stable and comfortable post-surgery
- Physiotherapist: ensure the patient’s rehabilitation is progressing according to plan.
Lessons learned in defining outcome measures for a population health approach

Over the past several years the most important lesson we have learned in implementing population-based healthcare systems is the importance of engaging with stakeholders on the ground to take ownership of the approach. In our engagement with stakeholders there were three key concerns that kept coming up:

1. Availability and/or access to data
2. Fear of potential criticisms stemming from making their data publicly available
3. Concern about being compared to others.

We addressed these concerns as follows:

1. When determining the patient outcomes, we tried to ensure a balance between the relevance of the metrics and the practicality of collecting them. Furthermore, wherever possible, we indicated where data could be accessed via national databases.
2. For the second concern, our strategy was to stress that our approach was not a top-down approach where they would be criticised based on their results; our approach was designed to help healthcare providers take strategic steps to be proactive and improve the services they are delivering to their populations.
3. The concern about being compared to others was addressed by stressing that data should be used to drive constructive comparisons and could help to create networks where different healthcare services could interact with each other and share information about success or failure of different types of initiatives being taken.

Our approach is time-intensive but we have continued using it because we have been able to get active engagement and commitment from healthcare services to collect data about their healthcare services. We continually try to increase the efficiency of our approach and we suspect that as we get greater buy-in and acceptance of our approach, stakeholders will sign on more readily.
Outcomes-driven population healthcare systems: going global

A key focus for us is to create a robust data and analytics platform that can be used to help payers and providers use the collected information to make strategic decisions about how to improve the value of healthcare services being delivered to their populations. We are also keen to engage with international partners, which we have started through an EU project involving several European countries, to start a benchmarking initiative globally so we can answer questions like:

- Is the asthma service in Birmingham of higher value than the service in Liverpool?
- Who is responsible for liver services in Toronto?
- How many osteoarthritis services are there in Shanghai and how many should there be?
- Which atrial fibrillation service in London provides the best value?
- Is the variation in outcome for people with psychosis increasing or decreasing across Boston and across categories of race, gender, and socioeconomic class?
- Who will be responsible for publishing the annual report of diabetes services in Buenos Aires?

We hope this approach and the answers to questions like those above will allow us to derive evidence and experience-based strategies on how healthcare services should be redesigned to deliver maximum value to the populations we serve.
Why outcomes research matters to patients - and consumers

John Santa, Doris Peter, Joel Keehn and Tara Montgomery, Consumer Reports

Almost 80 years ago a group of American consumer activists (some might even call them "radicals") recognised the growing power of the modern advertising industry and decided to fight back. They knew that all those ads would be good for big business, but how would that affect consumers? In some ways, consumers might benefit, as branding, mass marketing, and some performance information might - in theory anyway - reward the best products and services. But the trend toward sophisticated mass-market advertising also allowed perception to matter more than reality, for appearance to trump outcomes, for "spin" to matter more than data. That group of activists found that trend troubling, and so Consumer Reports was born: a way to provide consumers with meaningful, objective information, so they could make informed choices about the products they buy.

Consumer health issues have always been a focus of Consumer Reports. The first edition of the magazine in January 1936 reviewed Alka Seltzer, whose claims, the magazine's editors wrote, "vanished like the gas bubbles in the air." In other focus areas, Consumer Reports became known for its savvy engineers who tested products in ingenious ways, leading to outcome results that provided meaningful information about how well products really performed. Consumer-oriented journalists provided readers with information that served as antidotes to sales slogans and strategies that gave shoppers a chance in showrooms. The magazine's designers developed graphics - think of that little red circle - that made it possible for consumers to quickly compare products. Most of all, consumers could be certain that Consumer Reports was an independent voice, not beholden to industry.

Independence - with robust outcomes presented as comparisons, in easy to understand presentations - drove subscriptions. It worked and continues to work, especially in markets where advertising dominates, like cars, appliances, and electronics.

Advertising in the US healthcare industry is particularly disruptive when claims are made about performance and outcomes, often with little basis in fact or science. It can even mislead healthcare providers themselves. Consumer Reports has tried to counter the effect of such advertising by providing independent, evidence-based comparisons to consumers.

For example, in 2004 Consumer Reports launched its Best Buy Drugs initiative, which relies on high-quality, comparative effectiveness systematic reviews to provide independent assessments of drugs to consumers. Consumers have responded positively to this content. They want an alternative to drugs ads.

Consumer Reports has also worked to help consumers make informed choices about hospitals. Consumer activists have helped pass legislation in at least 27 states, requiring public reporting of healthcare-acquired infections. This effort, in turn, led to a 2010 effort by Consumer Reports to rate more than 1,200 hospitals on central line infections, using data from state databases and the Leapfrog Group. As more infection data became available - thanks in part to infrastructure funded by the Affordable Care Act as well as the utilisation of a national database, the Center for Disease Control, and Prevention's National Healthcare Safety Network (NHSN) - Consumer Reports expanded its ratings to include other public data on hospital-acquired infections (eg surgical site infections, catheter-associated urinary tract infections), and thousands more hospitals. Hospitals and doctors had not been transparent about healthcare acquired infections. Consumers now know they are preventable, not inevitable.
Consumer Reports has partnered with other organisations to make outcomes data available to consumers. In 2010, about 200 heart surgery groups voluntarily made coronary bypass surgery performance outcomes public on Consumer Reports’ and The Society of Thoracic Surgeons’ website. Now about 400 groups that perform bypass and aortic valve surgery do so. But there is more work to be done. More than 600 heart surgery groups still do not make their data publically available, and while the federal government has made more healthcare data publically available, many large databases crucial to consumers remain hidden, even when they have data about cancer, heart disease, and maternity outcomes.

Consumer Reports has also worked with physicians and other healthcare providers to identify what works and what doesn’t. In 2012, Consumer Reports partnered with the American Board of Internal Medicine (ABIM) Foundation on the Choosing Wisely campaign, which asks healthcare providers themselves to identify overused tests and treatments based on the best outcomes evidence available. Virtually all physician associations are now part of Choosing Wisely, as are associations for nurses, physical therapists, and dentists; hundreds of millions of consumers have seen this content. However, Choosing Wisely has not stopped drug companies, hospitals, and doctors from advertising the same overused services.

The demand by consumers for trustworthy health information has led many organisations to wade into the world of clinical outcomes, performance measurement, and consumer presentation. Some of them focus on more “pragmatic” approaches, generating outcome information that may not be as precise as randomised controlled trials but is more real world. Others focus on outcomes more meaningful to some people: pain control, performance of daily life and work activities, quality of life. A scientific approach to personal preferences and cultural context seems possible in an environment less biased than an advertisement, and the use of social media and personal tracking devices open up intriguing new opportunities to gather new types of patient-reported outcomes data to add to the body of knowledge.

Consumers expect quality information to include outcomes information. They need outcomes research and information that reflects their personal health priorities, and they need a seat at the table in defining what outcomes really matter to them.

Consumer Reports welcomes collaborative international efforts that aim to catalyse the collection and dissemination of high quality outcomes research and effectively put that information into practice, to benefit patients and consumers and make them better-informed partners in their care. Such efforts may cause some near term confusion, but should lead to better products and services, better communication of the results, and healthier consumers. Consumer Reports believes that many patients would rather have conflicting or inconsistent information than no information at all.

Hopefully this transition will lead to clinicians taking the lead in keeping track of their outcomes and demanding relevant outcomes from hospitals, doctors, and pharmaceutical companies. Only then we will be able to be confident that the science of medicine is catching up with the art.
All aboard, getting nationwide indicators on the rails

Collaborative governance as a strategy for developing effective national quality indicators for hospital care

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Introduction

Many countries have, or are in the process of developing, national quality indicators (QIs) for healthcare.  Although there is ample literature on the QIs themselves, we found no published research on strategies to develop QIs that impact the quality of care nationwide. Since the Dutch Healthcare Inspectorate started using QIs for hospital care 11 years ago, meaningful nationwide improvements have been achieved in a broad range of patient safety and quality related domains. This article explores the strategy behind the Dutch national hospital QIs and suggests that the “collaborative governance” strategy plays a vital role in its effect. Collaborative governance is a process focused on making and implementing a public policy that benefits the population as a whole and that cannot be reached without collaboration. It is defined by seven characteristics (table 1). Other nations could learn from the Dutch experience.

Definition of QI

QIs are commonly meant to measure the quality of care. However, often this goal turns out to be unobtainable. The Dutch government spent 31 million Euros between 2008 and 2013 to establish QIs for this goal, but the practical value of these QIs was deemed disappointing by the national Court of Audit. Interestingly, their conclusion failed to recognise that QIs can be very effective when the goal is not to measure, but to seek out possible quality issues. In this article, we define QIs as a proxy measure of quality issues that are difficult or impossible to measure directly. For example, the percentage patients with residual tumour after breast cancer surgery which in extremes is a direct measure, but has a bandwidth of outcome that needs further exploration before a judgment can be made on the quality of the delivered care. Provided these QIs are established with a clear goal, and through a thorough process, they can have a major effect on quality improvement, as this article will argue.

The Dutch system for national QIs

In 2003, the Dutch Healthcare Inspectorate introduced what was then called “performance indicators” as a tool to gain insight into the performance of hospitals. All hospitals were mandated to publish their data on these indicators to enhance transparency of hospital performance and to allow for improved regulation. However, hospitals and healthcare professionals were not convinced of the validity nor the relevance of these indicators; opposed the administrative burden; and feared unfair comparisons and unjust sanctions. In reaction, the inspectorate engaged stakeholders in the process of indicator development, thus creating a notable collaboration (table 2). The initial goal of the collaboration was to define a fixed set of indicators to monitor healthcare quality for multiple consecutive years. However, the collaborators discovered that indicators needed to be adapted to the dynamics of the healthcare sector to remain useful. The collaborators also experienced that some QIs set changes in motion whilst others did not, thereby shifting the focus from defining QIs to defining the desired change and developing QIs in support of that change. Within several years the common goal shifted from monitoring to improving healthcare quality and the name changed to “quality indicators.” The collaboration itself also matured from downright hostile in the beginning, towards increasingly cooperative, as
collaborators gained trust, came to understand their mutual interdependency, and experienced the positive impact indicators had on patient care. In 2009, the collaboration was formalised in a document with explicit ground rules, two of which are that the total amount of variables (data points for QIs) will not exceed a fixed maximum (so for each new QI, an existing one is dropped) and that the annual adjustments will not exceed 25%. This limits the bureaucratic burden for healthcare providers and the analytic burden for the inspectorate. In the collaboration process (see table 3), the medical specialist and nursing societies contribute scientific and medical-technical knowledge. They use the QIs to promote their quality agenda amongst their peers (eg adherence to a new guideline). The hospital federations contribute a reality check on the administrative burden of each proposed QI and use the process to promote those QIs that support their own quality agenda. The inspectorate uses the process to influence the quality agenda and create QIs that differentiate between those hospitals that are on track and those that merit supervisory action. The inspectorate presides over the meetings and has the ultimate authority to include, substitute or exclude a QI in the indicator set. The process of QI development takes about two years from the initial suggestion to nationwide registration. Thus a dynamic set of 20 to 30 QIs consisting of 307 data points is annually adapted to best achieve the desired effect. The five collaborating actors each have their own role and responsibility, but are interdependent in their common goal to improve the quality of hospital care nationwide.

The process in which the Dutch national QIs are developed fits the description of collaborative governance. Collaborative governance is mostly known outside of healthcare but its approach has been described as strategy in a wide variety of healthcare related problems (ie improving compliance with hand hygiene, optimising patient flow in an academic hospital, graduate medical education governance and increasing population health).[8-11]

**Effect of the Dutch national QIs**

A direct effect of the QIs on healthcare quality improvement is hard to prove. However, it seems safe to say that a positive effect of the QIs is plausible, as these nationwide examples suggest:

- Surgeons have published a 50% decrease in mortality after pancreaticoduodenectomy in four years’ time, which they ascribe to a shift of patients from low volume to high volume centers as a direct result of a QI focused on patient volume[12]
- Further concentration of cancer surgery in high volume centres, made possible after the first volume-QI, has led to a 25% decrease in 30 day mortality for cancer surgery in the three year period between 2007-2009 and 2010-2012[13]
- At the onset of the Dutch Surgical Colorectal Audit, a QI was made on participation of surgeons. In two years 94% of hospitals participated[14]
- Prevalence of pressure ulcers in Dutch hospitals decreased 80% in the eight years of the QI[15] It was stable in the years preceding the public indicator and remained stable again after the indicator was discarded
- The use of medical nutrition has increased by 13% per year since the introduction of a malnutrition QI[16]
- Residual tumour after breast cancer surgery has dropped from 21% to 11% in the first four years after becoming a QI[17]
- The percentage of patients receiving thrombolysis within one hour after stroke increased from 65% to 84% in three years time after becoming a QI[17]
## Conclusion

Dutch hospital care has shown meaningful improvements in quality following the introduction of QIs. These QIs were created in collaboration between multiple stakeholders with the common goal of improving, not simply monitoring, healthcare quality. Other countries stand to learn about and benefit from the “collaborative governance” approach.

### Table 1
**Characteristics of collaborative governance:**
- A state-initiated arrangement
- Includes non-state actors
- Should include three perspectives to be effective: the political, the scientific/technical, and the local or experience-based perspective
- Participants engage directly in the process
- Process is formally organised
- Process is consensus-oriented
- Outcome is focused on public policy to agree on changes in the indicator set and to discuss the progress and collaboration.

### Table 2
**The collaborating partners for the Dutch national hospital QIs:**
- The Dutch Healthcare Inspectorate
- The Dutch Hospital Association
- The Federation of University Medical Centers
- Federation of Medical Specialists
- Association of Nursing and Nurturing (joined in 2012)

### Table 3
**The collaborating partners participate in three parallel series of meetings:**
- Monthly meeting to discuss the progress
- Biannual meeting with all specialist societies (e.g., Society for Surgery) and several nursing specialty groups to discuss the current developments within their specialty, the associated patient risks, and related (potential) QIs
- Biannual board level meeting to agree on changes in the indicator set and to discuss the progress and collaboration.
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Consumer-driven reporting in the Netherlands

As part of their efforts to ensure access to quality healthcare for all, NPCF has several initiatives to promote transparency of healthcare quality and performance information. One such initiative provides an online platform for reporting of healthcare quality information to empower informed decision-making among patients and consumers. Consumers have access to a public website called Zorgkaart Nederland (“Care Map Netherlands”) in which they can post a review of a healthcare provider or read other’s reviews when in need of care. Consumers can search for providers by occupation (or specialty), organisation (eg hospital, practice, nursing home), and location. Beyond submitting general comments about an interaction with a provider, consumers can provide ratings on the following elements: accommodation, appointments, treatment, information, listening, and contributors. These six ratings are averaged to produce an overall rating for each provider, all of which is publicly available.

The website launched in 2009 and has been widely successful. The website was originally a collaboration between NPCF and a publisher. However, since 2013, NPCF has been the owner of ZorgkaartNederland.nl. The website attracts approximately one million visits per month, and the number of visitors grows each year. Once the website launched, news of the initiative quickly spread by word of mouth among the public, and consumers began posting reviews immediately, reflecting their desire to share and learn from each other’s healthcare experiences. Some healthcare professionals

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Founded in 1992, the Federation of Patients and Consumer Organisations in the Netherlands (NPCF) (http://www.npcf.nl/) is a national membership organisation that brings together patient and consumer organisations to speak as one voice on areas of common interest in health and healthcare. Thirty-two national patient advocacy networks, representing roughly three million Dutch citizens and a range of disease and target population interests (eg elderly, chronically ill, or those with physical or intellectual disabilities) comprise NPCF’s membership.

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were initially critical of the effort, since the reviews were specific to an individual provider and unedited. Over time, however, providers have grown to view the initiative as necessary for informed healthcare decision-making. While patient need drove adoption of the website, NPCF also attributes success to strong support from the Dutch government and a willingness to try new ideas in engaging patients and consumers to become active participants in healthcare transformation.

In addition to the consumer reporting site, NPCF is working to publish more objective data based on standardised indicators such as patient reported outcomes and experience of care measures. [H Post, personal communication, 2015]

In partnership with the major insurers and medical organisations, NPCF is in the process of defining the specific outcomes that should be publicly reported and determining the best methods for presenting this information to consumers. Some measures have proved to be more controversial or challenging than others, such as those that reflect variation in clinical practice performance or those that require a sophisticated approach to data aggregation.

NPCF has also learned that the goals of quality and cost measures do not always align and have struggled to strike a balance between the two. In efforts to address these challenges, NPCF leads discussions with stakeholders from across the healthcare sector to make progress on their shared goal of improving patient outcomes.

Together with their membership, NPCF is working to improve care and reduce healthcare costs by fostering a culture of patient engagement and informed decision-making.

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The hard work of improving healthcare outcomes

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Whether healthcare is viewed as a right or a privilege, one thing is clear: as science and technology continue to advance, healthcare is on the verge of becoming untenably expensive, and yet the science of improving the value of healthcare has lagged behind. The good news is that leading health systems and innovative organisations have begun to prove that the difficult is not impossible. Achieving a learning health system that delivers continuous improvement in the outcomes and value that matter to patients and payers alike is a serious and important challenge. We’d like to share our experience in tackling head on two of the biggest barriers that must be overcome: credible, actionable, measurement data; and engaging physicians in redesigning care.

It begins with good data

As consumers, we judge the value of a product according to a very simple equation, regardless of industry:

\[
\text{Value of product} = \frac{\text{quality of the product}}{\text{cost of the product}}
\]

In healthcare, that equation becomes:

\[
\text{Value of healthcare} = \frac{\text{quality of healthcare}}{\text{cost of healthcare}}
\]

Measuring the quality of healthcare has, so far, been the measurement of secondhand proxies for quality, not quality itself. We measure processes of care and infer quality from those processes, but few would argue otherwise that those inferences are quite often wrong. Instead, most patients and physicians would argue that the quality of care should be measured more directly. Quality is defined by the combination of the patient’s perception of quality combined with the functional health outcome of that patient following their purchase and receipt of care. However, we do not collect functional outcomes of care. Two years ago, my orthopaedic surgeon repaired my torn ACL, MCL, and fractured tibial plateau. The surgery took about three hours to complete. I visited him once, post-operatively, per his protocol, and have not seen him again since. He has no clue as to whether my outcome has been better, worse, or average for a 55-year old man.

It was up to me to find, screen, and choose a physical therapist, and describe to her my injury and surgery, which I did. She was a PhD, US Army captain, who previously served the physical therapy and rehabilitation needs of 400 Army troops in Afghanistan for two years. When she accepted me as a patient, the first thing she asked was, “What is your definition of rehabilitation success? What activities do you want to be able to do and how soon?” I had no data to turn to for assistance in establishing realistic goals, so I took a naïve guess and told her that I wanted to ride a bicycle on a strenuous mountain road in six weeks, mountain bike in four months, ski in six months, and run sprints in nine months. With that input from me—aggressive as it was—she developed an equally aggressive and personalised protocol by working backwards from my patient-driven outcomes goals. Throughout my rehab, she constantly measured my muscle growth, flexibility, balance, strength, and agility. She entered those measurements into an algorithm that provided a composite indicator of my overall progress. With her coaching, we met or surpassed every goal.

That, my friends (thanks to my physical therapist) is protocol-driven, data-driven, outcomes-driven healthcare.

It is worth noting that my physical therapist entered my data into her version of an electronic health record (EHR), which had no interoperability with my surgeon’s EHR system. Her EHR was designed much differently
Data empowers physicians

While we commonly hear the phrase “first do no harm,” physicians aspire to do far better than that. As Daniel Pink describes,[4] physicians are motivated by the same needs as the rest of us: a desire for mastery, autonomy, and purpose. They want a chance to develop and master a skill in which they can be proud—practicing medicine and improving the health of their patients. They want to be surrounded in a supportive environment if they need help, but for the most part they want to be left alone to practice the skills that they’ve mastered, and not be micromanaged. And they want to feel as if they are serving a purpose in life which is larger and more important than themselves. Nearly all physicians are naturally driven to provide the very best care to every patient, and to excel in their chosen field. Yet we put physicians in a position to pursue these aims largely in the blind, like a pilot without cockpit instruments flying in a thunderstorm. They are left to using their best judgment and consulting the best available evidence in the scientific literature to guide their decisions, but without any insight into the outcomes that their own patients are achieving or an evidence- and data-driven plan for optimising those outcomes.

When you give physicians the data they need in the cockpit at the point of care, and you place them in a position to practice their mastered skill without burdensome oversight, and, because they are better informed about the best options available for treating their patients, these physicians feel a greater sense of purpose, too. At Intermountain Healthcare, we provided physicians and nurses with this data-rich environment, including statistical predictions of outcomes based on treatment options.[5]  Intermountain’s leadership culture was also very light-handed and communal, leaving it up to physicians to determine how best to reduce variability and improve outcomes. As a result, Intermountain achieves better healthcare outcomes at an average of 34% lower cost than the general US healthcare delivery system.[6] We need to learn from and propagate the Intermountain model for outcomes improvement.

Stepping up to the challenge of outcome measurement

This is an exciting time in healthcare. Empowering physicians and the health systems in which they work with the tools to pursue their patient’s desired outcomes is a challenge that can and must be overcome. Outcomes data on patient care is one of the single most valuable pieces of data missing in our healthcare ecosystem.[7]  At the heart of this movement will be defining the outcomes that matter to patients, tailoring our outcomes project plan to the goals and abilities of the patient. Without outcomes data, healthcare is guessing at best practices, not actually practicing best practices.

References

Building a self-measuring healthcare system with computable metrics, data fusion, and substitutable apps

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To create an information economy that underpins healthcare reform, the US federal government has invested $48 billion promoting instrumentation of hospitals and practices with electronic health records (EHRs) certified to meet federally-defined criteria for Meaningful Use. The return on investment is predicated on a theoretical capability to repurpose useful and comprehensive data collected during the routine care of patients. These data would be pressed into service to measure outcomes, guide care, and link payment to quality and value.\[^{1}\]

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<td>Category 2</td>
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<td>Category 3</td>
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<td>Category 4</td>
<td>Population-based payment</td>
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Table 1.
Healthcare payment according to how providers receive payment to provide care\[^{2}\]
Desiderata for a self-measuring healthcare system

Computable metrics. Ultimately, the success of value-based payment models requires nimble, ongoing population health monitoring. Process and outcome metrics should be calculable using electronic data collected during the routine process of care. Unfortunately, existing health metrics are often not computable. Take, for example, the Choosing Wisely campaign to reduce utilisation of low value services. A recent analysis of a sample of 45 of the 300 Choosing Wisely guidelines found that for only six was compliance measurable with data routinely found in EHRs or claims sources. For example, the admonition “Do not perform routine cancer screening for dialysis patients with limited life expectancies without signs or symptoms” was flagged by reviewers for relying on data not captured in EHRs and also for insufficient specificity in terminology.

In contrast, efforts to define electronic Clinical Quality Measures (eCQPs) for the Meaningful Use reporting program have taken an EHR-centric approach, providing structured, computable measure definitions intended to enable automated reporting. While eCQPs leverage available EHR data, it omits a wide range of structured data available from emerging sources, and by definition, focuses on measuring what is currently measurable rather than attempting to fully address what matters.

Standardised data collection. There should be a uniform, systematic process for collection of the data elements required by computable metrics. EHRs vary widely in approach to information collection, storage, and display. Harmonising across products is extremely challenging because while a handful of EHR vendors dominate the market, there are literally hundreds of certified products. Hence, implementing an innovation or a measurement framework requires the attention and diligence of the EHR market leaders but also herding many other cats. The software version will vary across installations even within one vendor’s product line, and so will the data collected and displayed due to local customisations.

Data fusion. The totality of the patient experience is not captured by an EHR. Computable metrics should be comprised of multimodal data collected across sites of care and from patients at home. EHR data generally reflects the care delivered at a single institution, practice, or network; measurement of process and outcomes are fragmented when patients receive care across institutional boundaries. As such, the preponderance of data sources that could characterise an individual patient’s processes and outcomes are missing from any one EHR data set.

Point of care delivery of population health insight. Population health programs often depend on insights gleaned from large dataset analysis outside the EHR, and out of necessity, interventions often circumvent the point of care. Case managers, for example, may attend directly to patients algorithmically identified as high risk, or attempt to make the providers and care teams aware through traditional phone, fax, and email channels. In contrast, the linkage of population health analytics directly to point of care management through EHR and related health IT workflows would improve efficacy of the programs and the efficiency of case managers. However, the point of care is no more amenable to uniform clinician decision support methods than it is to universal data collection.

Requirements for a self-measuring healthcare system

Achieving care improvement based on value and quality necessitates a harmonisation of metric and guideline design with systematic approaches to both data collection and influencing the point of care. We propose a two-pronged solution.

Informatics-aware metrics development. Designers of quality metrics should become well-versed in properties and types of EHR data. Metrics design must acknowledge which data are or can be routinely collected, and select those data points that are of high information value either alone or when fused with other data. The burgeoning focus on precision medicine is producing a rigorous set of methods for deep-phenotyping based on available data in EHRs and claims data. These methods can be leveraged for quality metrics development as well.

EHR data critically complements traditional data measuring outcomes, enabling superior collection of phenotype, outcomes, and therapeutic efficacy data. Not only do EHRs store diagnosis, pharmaceutical, laboratory, and procedure data, they also have clinical notes that enhance the resolution
of phenotype and outcomes when subject to natural language processing.[10, 11]

A data fusion approach supports the inclusion of patients’ perspectives on symptoms,[12] quality of life,[13] functional status, and response to therapy, a modality of recognised importance to epidemiologic, safety, and effectiveness research. Mounting evidence supports the timeliness and reliability of adverse symptom reporting by patients,[14-16] and a willingness to share data for research and population health.[17, 18] The announcement of mobile advances, such as Apple’s HealthKit, are a cause for optimism that patient-reported data and data from a patient’s devices at home will be valid and available components of measurement. Importantly, these data fusion methods will yield population-level insight even when they don’t provide results accurate enough for clinical grade decision-making at the individual patient level. For population-level assessments, “noisier” data can advance care.

Current-stage EHRs neither collect nor link these data sources together. Current guidelines don’t anticipate the availability these data sources, their performance in metrics, or the computational approaches for their fusion.

An apps model for EHRs. There is a systematic method for reshaping the point of care – an “application programming interface” or “API.” Across industries, APIs present data uniformly and consistently to the apps that use them. iPhones and Android devices have leveraged APIs to great effect, spawning hundreds of thousands of apps developed by third parties. When an EHR presents core data across an API, it becomes transformed into a smartphone-like platform that can run substitutable apps - apps that can be selected from an “app store” and readily added deleted locally.[19] The SMART Health IT project has demonstrated clearly that when an EMR adopts the SMART API, it can run substitutable apps in patient context, inside the normal EMR workflow. To date, these apps have focused on presenting data from the EHR in new visualisations or data transformations. However, apps could also collect new data and store it in the app itself, or in the EHR data core. These demonstrations have been sufficiently convincing that major commercial EHR vendors are implementing the SMART API. This EHR apps model would permit the exchange of data between the EHR data core and clinician and patient facing apps. If handled correctly, a uniform public API could emerge and be adopted by EHR and other health IT vendors, enabling an app written once to run anywhere.

Key functions for apps in a self-measuring healthcare system include patient-level linkage[20] of multiple data sources for presentation to doctors and patients at the point of care, and delivery of insight back to the point of care to drive improvement. To the extent that certain valuable metrics require uniformly structured EHR data, beyond the natural “ambient” data collected currently across the diversity of data entry templates and dictation methods, apps could also facilitate enforcement of uniform data collection for computable metrics from clinicians and from patients at home.

Conclusion

The health system only becomes self-measuring if metrics are readily computable. Accurate metrics require multimodal data collection, including during the patient visit. There has been enough momentum toward a public API for healthcare,[21, 22] beginning with the SMART Health IT project[23] that the third version of the meaningful use certification requirements is expected to recognise the importance of APIs and EHR-backed apps. Wide scale adoption of a uniform public API will enable a reshaping of the EHR façade with apps to collect data for measures and also to influence and inform providers and patients. This new era in EHR technology will set the stage for a concerted effort to ensure that metrics and guidelines are computable, recognising the availability of traditional data sources, such as Centers for Medicare and Medicaid Services (CMS) claims, but also the opportunity to engage clinicians and patients and their devices at that point of care and patients at home in a self-measuring healthcare system.


Meetbaar Beter: A ‘doctor-driven, patient-centered’ initiative

BMJ Outcomes

A unique initiative underway in the Netherlands – Meetbaar Beter (Measurably Better) (http://www.meetbaarbeter.com/) – uses patient-relevant outcome measures to improve quality and transparency of care for Dutch patients with heart diseases. Headquartered in Eindhoven, a city in the south of the Netherlands, the Meetbaar Beter initiative engages heart centres across the country in outcome measurement to capture the value delivered to patients along the entire episode of care. By sharing lessons learned from outcome-based improvement programs and sharing best practice, they work to inspire a “learning” environment for physicians while providing patients and insurers with valuable insights into care delivery.[DV Veghel, personal communication, 2015]

This national initiative began in 2012 with the two largest Dutch heart centres, Catharina-hospital and St. Antonius hospital, both recognising that process and structural measures were not painting an adequate picture of the quality of care being delivered (Stichting Meetbaar Beter, 2014). They further observed that existing Dutch reports on quality did not have sufficient impact on the patient, provider, and insurance communities.[DV Veghel, personal communication, 2015] The centres decided it was time to change the “quality” conversation, and began exploring the leading edge in value-based healthcare. With the goal of creating a “doctor-driven, patient-centred” initiative, cardiologists and thoracic surgeons of participating hospitals, with methodological support from The Decision Group, developed patient-relevant outcome measures for major heart conditions. The outcome measures cover the full spectrum of care from acute outcomes of the intervention to longer-term health benefits and quality of life.

With the support of an independent academic advisory council and a national stakeholder sounding board, which includes representatives from the government, the Dutch patient group (“hart en vaatgroep”), and health insurance companies, the two heart centres published the results of their first outcome measures on coronary artery disease in 2012 (Stichting Meetbaar Beter, 2014). After the publication of the first ‘Meetbaar Beter’ book, several other heart centres expressed interest in the initiative and the Meetbaar Beter Foundation was formed. Today, 14 of the 16 heart centres in the Netherlands are reporting on Meetbaar Beter outcome measures. [DV Veghel, personal communication, 2015] Now the effort is expanding to centres that perform percutaneous coronary interventions (PCI) without thoracic surgery capabilities, which increases the number of reporting centres to more than 20.
As the first initiative in the Netherlands with a focus on outcome reporting, key features of the project are that participation is voluntary and that signing on means committing by contract to publish results, whatever the outcome (Stichting Meetbaar Beter, 2014). The selected outcome measures cover all tiers of Michael Porter’s outcome hierarchy, including survival, quality of life, complications, and reinterventions. While outcomes after a cardiac intervention are traditionally gathered based on “in hospital” or “30-days” post intervention, several Meetbaar Beter measures extend well beyond 30 days, with some looking at patient outcomes at 120 and 360 or more days post intervention.[DV Veghel, personal communication, 2015] The provider community has widely accepted these longer-term measures and interestingly believe that they will lead to greater coordination among providers involved in patient care and recovery.

The work of Meetbaar Beter contributed to a range of improvements in participating heart centres. Participating hospitals have reported significant improvements in mortality rates after CABG and PCI. Hospitals have also reported a decrease in the number of deep sternal wound infections after coronary artery bypass graft (CABG) procedures, reexplorations after CABG, and tamponades during pulmonary vein isolation (Stichting Meetbaar Beter, 2014). Beyond improvements in clinical outcomes, Meetbaar Beter has developed several methodological innovations, for example the maintenance cycle for outcome measures.[DV Veghel, personal communication, 2015] Meetbaar Beter also inspired a range of initiatives outside of heart care to measure and improve patient outcomes, such as a project focused on oncology outcomes.

Deliberate integration of the patient perspective at various levels in the outcome measure development and selection process continues to be a priority for Meetbaar Beter.[DV Veghel, personal communication, 2015] Participating centres use measure selection criteria developed based on patient relevance, and solicit guidance from patients whenever necessary. Efforts are underway to identify innovative methods for presenting measure results to patients, which may include creating a tool that would generate patient-specific measure results. While progress has been made, Meetbaar Beter staff recognise that ensuring patient centeredness is a continuous process that will evolve and improve over time.

One exciting opportunity is how Meetbaar Beter’s patient-relevant outcome measures could influence healthcare costs. An early decision among the Meetbaar Beter founders was to table discussions related to payment or cost, since creating national outcome standards would undoubtedly be challenging.[DV Veghel, personal communication, 2015] Yet with widespread implementation of the outcome measures among Dutch heart centres, some members of the Dutch community are now considering how outcome measurement could address issues of cost and further incentivise value in the Dutch healthcare system.

The Meetbaar Beter initiative has demonstrated tremendous ambition and success in its first several years and illustrates a prime example of how outcome measurement can improve the quality, and potentially cost, of heart care.
The arts and health messaging: Exploring the evidence and lessons from the 2014 Ebola outbreak

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Introduction

The arts have been shown to be an effective and efficient means for communicating health information to large audiences. The arts enhance emotional engagement with messages, and thus optimise social learning patterns and motivation to change behaviours. This article explores the roles and impacts of the arts in public health, including recent use of the arts for health messaging in the Ebola response in West Africa. Arts in public health is defined as a discipline, and outcomes related to use of the arts for health communication are presented along with examples of arts-based initiatives that were engaged to communicate critical health messages within the Ebola crisis of 2014-15. Recommendations for building the evidence base for arts in public health programs and for advancing evidence-based practice are offered.
Use of the arts as a means to educate the public, foster community engagement and social change, and influence behaviours has a long history. Arts-based health promotion has its roots in traditional cultures where storytelling, drama, and music are primary means for enforcing the belief systems that guide behavior. The University of Florida Center for Arts in Medicine defines arts in public health as an emerging discipline that “engages the arts in public health programs for health promotion and disease prevention” (http://artsinmedicine.arts.ufl.edu/2015). Arts in public health is emerging in alignment with the global priority to enhance population health through wellness and prevention. Within this discipline, artists and public health professionals partner in using the arts to engage and mobilise community members, better understand local cultures, convey health messages, and enhance health and wellbeing through community arts and cultural activities. Such activities themselves have been shown to enhance health and wellbeing, and even to extend the lifespan.

This discipline aligns with the discipline of arts in medicine, in which professional artists and arts programs provide patients, family members, caregivers, and other health-related populations with opportunities for creative engagement. The discipline serves as an adjunct to medical care, utilising evidence-based arts practices to support health, healthcare, and wellbeing. Studies of arts interventions clearly document positive outcomes, including reductions in stress and anxiety, reductions in surgical and procedural recovery times, improvements in mood, positive distraction, reduction in the need for pain medication, reduced length of inpatient stay, improved patient-caregiver communication, and cost savings to healthcare systems.

Arts in public health outcomes

While systematic reviews of outcomes literature pertaining specifically to arts in public health programs have yet to be published, several literature reviews have been undertaken to identify outcomes related to use of the arts in health promotion. These reviews acknowledge a lack of consistent measurement tools and scientific rigor in the literature. They also reveal that the arts can be used to effectively facilitate communication to individuals and communities, to raise awareness of health issues, to promote community engagement, to reach large audiences, and to impact some of the major determinants of health (eg community cohesion, social capital, social exclusion, and access to healthcare services). Key studies find that the arts have been shown to be a uniquely effective means for accomplishing all of these components, and to be a highly effective and efficient tool for broad dissemination of critical health information, particularly when they are used as a part of multi-modal structured messaging approaches.

Creative media, including images, theatre, song, and dance, give meaning to health information and can improve understanding, retention, and utilisation of information.

Recent studies indicate that incorporation of the arts into health-promotion programs can enhance both health behaviours and outcomes, and that when direct participants share information with others, even greater behavioural effects are found in those reached indirectly. Involvement of community members is a vital factor for the success of messaging interventions, as is the level of clarity of the message being relayed. The arts enhance this clarity, as well as understanding of health messages. Additionally, persistent and repetitive messaging, which is easily accomplished through art forms such as music, increases knowledge and positively influences behavioural change.

Arts and health messaging in the Ebola response

For many months at the onset of the Ebola epidemic in West Africa, efforts to control the spread of the virus were compromised by the inability for culturally appropriate health messages to be disseminated, understood, and acted upon in an efficient manner. Public health efforts were slow to engage and mobilise communities, and to utilise local knowledge and culture for communication. Health information was eventually assimilated into the affected areas, but not until long after the spread of the virus was out of control. Grassroots arts initiatives, including popular music, murals, and radio drama, were critical components in the ultimate dissemination of health information. A repository of these arts initiatives has been compiled (see http://arts.ufl.edu/repos/)

Arts responses to the Ebola crisis

Early in the crisis, grassroots efforts by local artists emerged. One of the earliest responses was the song Ebola in Town, written and produced by Liberian rap artists, Shadow and D12, in May of 2014. Within three days of its internet release, the song was playing on Liberian radio stations and in dance clubs, and soon topped the local charts. While the lyrics were improvised by the artists and not informed by health professionals, the song demonstrated the power of popular music to convey Ebola messages and paved the way for the release of dozens of other songs and music videos.
created through collaborations between artists and health professionals to deliver more targeted messages.

UNICEF took a strong role in supporting local musicians to create songs, including the popular Ebola is Real, and also catalogued and helped disseminate the music (see Soundcloud: https://soundcloud.com/unicef-liberia). In addition to music, storytelling and drama were engaged by many local and international organisations to communicate messages and fight stigma.[39] PCI Media, in partnership with UNICEF Liberia, launched Stop Ebola Now: Through Creative Storytelling, a campaign including serial radio dramas, call-in radio and TV shows, and arts-based community mobilisation campaigns, including songs, billboards, and use of mobile technologies to help inform and engage the public with critical information (figure 2; see http://mediaimpact.org/ebola/). The International Organisation for Migration (IOM) Liberia, the Liberia Ministry of Health and Social Welfare, WHO, and UNICEF together engaged a local artist to create a graphic story in comic book format, called Spread the Message, not the Virus (figure 3; see http://liberia.iom.int/2014/12/10/comic-book-spread-the-message-not-the-virus/).

Radio is a primary means of communication in Ebola affected regions, and served as a natural host for dozens of radio dramas that used the power of mass media and drama to communicate messages in an appealing, engaging, and personally relevant manner. In Sierra Leone, Search for Common Ground, through its Talking Drum Studio project, responded by shifting the focus of its weekly radio drama – the most popular in the country – to Ebola (see http://www.newyorker.com/news/daily-comment/ebola-culture-makers). Film and video have also played significant roles in raising awareness and reducing stigma both within and outside the affected regions. The Liberia Film Institute implemented a major capacity-building and nationwide Ebola prevention outreach project, Ebola Must Go, including ten new films focused on Ebola and a national film festival.

PCI Media, in partnership with UNICEF and Vulcan Productions, also produced #ISurvivedEbola, a series of videos and radio programs that feature Ebola survivors from Liberia, Sierra Leone and Guinea sharing their stories and perspectives (see http://isurvivedebola.org/campaign). The multimedia campaign was the first to directly engage Ebola survivors in delivering key messages to affected communities, and to highlight stories of hope and resilience in the midst of the ongoing epidemic.

These efforts and many others have attracted widespread attention and enthusiasm, both locally and abroad, reaching massive audiences more quickly and efficiently than standard health messaging approaches. While the general public often views health professionals with distrust, such as has been demonstrated in Ebola-affected areas, artists are generally viewed as peers and non-threatening to community members. They are also available resources in affected areas, and have a unique understanding of local cultures and expertise in human engagement.

Social learning is an important component of these programs. Recent studies in the affected regions have shown that even under extreme conditions, communities can rapidly internalise positive health messages, abandon negative health messages, and refine known health messages through social learning constructs.[38] When people engage emotionally with correct information through the arts, they share that information with others, creating an organic and meaningful dissemination of knowledge. In all of these ways, the arts have been demonstrated to be an ideal tool for the delivery of complex health messages in efforts to rapidly educate people affected by a widespread health issue. While the arts programs engaged in the Ebola response have not yet been formally evaluated, their impacts on awareness and the dissemination of targeted messages are unquestionable.

Structuring utilisation of the arts in future epidemic responses

Spurred by the lack of systematic review consolidating the literature and by the urgency created by the recent Ebola outbreak in West Africa, the University of Florida conducted a systematic review of the arts and health messaging literature, as well as a study of use of the arts in public health in Uganda, where the arts have been highly utilised in public health since the 1950s. The findings of these studies define six key concepts that can guide effective evidence-based use of the arts for small and large scale health messaging.
1. Effective health messaging programs are multi-modal, highly structured, and interdisciplinary. Arts-public health partnerships are highly synergistic, and arts-based messaging campaigns are most effective when designed within broadly interdisciplinary partnerships and within a comprehensive set of messaging modalities. Planning, leadership, and oversight by a range of interdisciplinary partners are crucial elements for success.

2. Effective arts-based health messaging programs are built on clear theoretical foundations, and on local knowledge and culture. Social learning theory is at the heart of arts-based health messaging. Effective programs also utilise local knowledge, leadership, history, and culture.

3. Various forms of drama, music, and the visual arts can be used to focus and clarify health messages. Serial dramas presented via radio, television and live forum, popular and traditional music, and visual arts modalities including murals and illustrations simplify, clarify, and focus health messages, providing a means for communication that is engaging, relevant, memorable, and compelling.

4. Through culturally and personally relevant narratives, the arts engage people emotionally and can facilitate behaviour change. Effective behaviour change interventions must be embedded in local realities. The arts facilitate dialogue, allow communication around culturally sensitive subjects, and reveal underlying social issues that influence behaviours, including social and cultural beliefs, stigma, and tradition. Familiar scenarios and characters that elicit empathy spur audience members to consider their own realities and make new choices.

5. Arts-based messaging campaigns utilising celebrity artists and mass media formats can reach large target audiences. Mass media formats such as serial radio drama, popular music, and murals are effective means for rapid and large-scale messaging. Effective programs target population segments, design themes around behaviour change using behavioural theories, include strong evaluation frameworks, and integrate a wide range of interpersonal reinforcement activities. Involvement of celebrities utilises expansive social networks and brings credible message endorsement.

Peer-to-peer social learning expands the reach of arts-based messaging and can catalyse even greater behaviour change than direct learning. Messages relayed through social learning and parasocial interaction, such as interaction with performers and arts media, are effective in changing behaviours.

The studies also found that the most effective arts-based health messaging programs were developed through broad interdisciplinary partnerships that invested considerable periods of lead time, sometimes more than one year, into in-depth community-based program planning and mobilisation processes. Figure 1 consolidates these processes into a best practice model for planning arts-based health messaging initiatives.
Collaborating with the global outcomes community to measure impact

There is a clear need for better quality studies on the use of the arts in public health, particularly in low income and low resource regions, where research capacities are limited but programs are often prevalent. Much of the research performed on arts-based public health campaigns is of moderate to poor quality. Additionally, inadequate attempts to measure changes in knowledge, behaviour, and other outcomes without adequate timeframes, sample sizes, and consistent epidemiologic and other measures are consistently reported.[20, 26-28, 29, 39-41]

In addition to large-scale epidemiologic studies that can measure impact at the population level, a higher value—in the context of traditional research hierarchies—needs to be placed on qualitative and mixed methodologies that can illuminate how arts interventions make a difference and can lead to the development of a theoretical basis and best practices for the discipline. Clift et al suggest seven approaches that are also important for assessing arts and health programs: 1) retrospective qualitative evaluations; 2) prospective evaluations; 3) experimental evaluations; 4) economic effectiveness studies; 5) systematic reviews; 6) development of theoretical frameworks; and 7) emergence of an academic community of arts and health researchers.[42]

The case of health messaging in the Ebola response highlights the importance of establishing outcome measures for arts-based public health interventions and presents an opportunity for retrospective studies that can significantly inform the development of best practices pertaining to health messaging in both urban and rural areas. It must not be overlooked that in the Ebola response, the arts were employed at both the grassroots and formal levels to reach large populations of people with critical health information, which is presumed to have played a significant role in slowing the spread of the virus. In order to now measure this impact, qualitative and quantitative study designs representing multiple disciplinary approaches that are also important for assessing arts and health programs: 1) retrospective qualitative evaluations; 2) prospective evaluations; 3) experimental evaluations; 4) economic effectiveness studies; 5) systematic reviews; 6) development of theoretical frameworks; and 7) emergence of an academic community of arts and health researchers.[42]

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A new initiative to measure head and neck cancer outcomes

BMJ Outcomes

In collaboration with the Dutch Head and Neck Society (NWHHT), the Netherlands Federation of University Medical Centres (NFU), Health Insurer CZ, and the patient association ‘Klankbord’ (“sounding board”), the Scientific Institute for Quality of Healthcare (IQ Healthcare), part of the Radboud University Medical Centre located in the eastern-central part of the Netherlands, has a quality measurement initiative underway to improve care and health outcomes for patients suffering from head and neck cancers. [R. Hermens, personal communication, 2015] The project entails working with head and neck oncology centers and their preferred partners across the Netherlands to implement process, structure, and outcome measures. The measure results will be published in a new national quality registration system for head and neck cancers that is supported by the Dutch Head and Neck Society (NWHHT), Dutch Head and Neck Allied Health Care Workers Society (PWHHT), and both societies’ patient organisations.

The initiative began with several stakeholder groups – medical specialists, allied healthcare workers, patients and patient associations – sharing a common goal of gaining insight into the results of intensive head and neck cancer treatments. [R. Hermens, personal communication, 2015] With funding from a healthcare insurer to support an online web portal and database, IQ healthcare was tasked to create a set of standardised measurements that head and neck oncology centres and their preferred partners could implement as part of their quality improvement efforts. Measures were developed and selected using the Rand-modified Delphi Method. Three expert panels were convened of medical specialists (including otorhonolaryngologists, oral and maxillo-facial surgeons, and radiation and medical oncologists); allied healthcare workers (including physiotherapists, speech therapists, dieticians, oral hygienists, oncology nurses, and radiotherapy technicians); and cancer patients (from hospitals belonging to NWHHT and patient associations). The process consisted of four steps:

1. Selection of relevant outcomes of head and neck cancer care and key recommendations (for process and structural measurement) of integrated care for patients with head and neck cancer from international and national literature and guidelines by a junior researcher

2. Individual rating of the relevant outcomes and key recommendations by the medical specialists and allied health expert panels using a questionnaire. Key recommendations were rated based on four criteria: prolonging the (disease free) survival; improving quality of life; the quality of the healthcare process, and improving efficiency

3. Separate panel consensus meetings of medical specialists and allied health experts in which panel members were provided personalised summary reports to compare their individual ratings with the overall panel’s distribution and means. Discussions focused on keeping, reformulating, or removing the selecting relevant outcomes or recommendations as well as suggesting new outcome or recommendations to consider

4. Approval of the final set by all three expert panels and the health insurers.
Cancer patients played a key role in the measure development by sharing their needs and preferences early on in the process. [R. Hermens, personal communication, 2015] They also reviewed the measures selected by medical specialists and allied health professionals to ensure that the measures were relevant. This often required translating medical jargon to lay language so that the patient panel could make informed decisions about the measures. Despite the additional time and effort that was occasionally needed, project organisers were committed to patient engagement and viewed patient involvement as a practical necessity since the project’s overall goal is to improve care for cancer patients.

The project started with the selection of outcome measures as a basis for the quality registration system. Other measures selected for the first year were mostly process measures, with a handful of structure measures. [R. Hermens, personal communication, 2015] Patient-reported outcome measures were selected to assess quality of life and experience of care. In addition, a set of three risk-adjusted outcome measures at the provider level were developed to focus on:

1. Status (yearly survival) of a patient treated for head and neck cancer. This measure will be registered yearly during the following five years after completion of treatment for head and neck cancer.
2. Occurrence of a relapse after a treatment for head and neck cancer. The physician will check this during the yearly follow-up for the following five years after completion of the treatment for head and neck cancer.
3. Occurrence of complications after a treatment with surgery, radiotherapy, chemotherapy, or chemoradiation for head and neck cancer from 30 days up to three years after completion of the treatment.

While the “status of the patient” and “occurrence of relapse” measures are relatively easy to define and extract from the medical record, the “occurrence of complication” measure has proved to be more challenging. [R. Hermens, personal communication, 2015] While the provider community understands that complications are an important aspect in capturing quality of care, some are fearful that defining quality is difficult and that reporting on complications could be misinterpreted as poor quality care. The NWHHT has convened a small panel of medical specialists to define and select the important complications.

The initiative has rapidly spread among Dutch head and neck oncology centres. Four centres have implemented the measures, and by July 2015, IQ healthcare hopes to involve 10 more centres. [R. Hermens, personal communication, 2015] Preliminary results will be gathered by the end of this year with the hope of gathering data and trends over a five-year span. With time, IQ healthcare plans to assess the relationship between the process/structure measures and the outcomes measures, with the ultimate goal of refining the process and structure measures to those that best support the most relevant outcomes. In the long-term, the project’s goal is foster measurements that support informed patient decision-making, quality improvement, and value-based payment efforts, with the ultimate goal of improving patient outcomes.
Palliative care quality measures: challenging and urgent

Diane E. Meier
Director of the Center to Advance Palliative Care

The science of quality measurement remains in its infancy. Despite decades of research, we are still only good at measuring the low-hanging-fruit among quality outcomes, such as life expectancy, the HbA1C, the occurrence of vaccinations or colonoscopies, or the number emergency visits and hospitalisations. Among the population with multiple chronic conditions, threats to their independence, disabling levels of symptom distress, and burdened and exhausted family caregivers, other outcomes are more important. Remaining independent and at home is important. Relief from physical and emotional suffering is important. Support for their exhausted families is important. Avoiding personal bankruptcy is important. Yet we do not measure these outcomes. If we don’t measure them, we can’t improve them. What is to be done?

Aging populations
The global population is aging rapidly. The dominant threats to health among older persons are chronic conditions that lead to debility, functional dependency, cognitive impairment, and symptom distress. Traditional medical (fix the problem) and public health (prevent the problem) approaches fail to address the needs of this population for home and family supports, expert pain and symptom management, and clear communication about the reality of the illness and what to expect in the future.

Concentration of risk and spending
It is important to focus on the needs of the seriously ill for moral and quality of care reasons, but the motivation of governments and health systems to do so is additionally driven by the disproportionate healthcare costs of this group. Healthcare exists to provide care to those most in need of help. Hence healthcare spending is, as it should be, highly concentrated upon care of the sickest and most complex patients. The 5% of all patients who are seriously ill and need the most medical care account for a disproportionate 50-60% of total healthcare spending. The problem is not that caring for the sick and the complex costs more than caring for the well and healthy; of course it does. The problem is that how we spend that money typically fails to address the top priorities of such patients and their families and caregivers.

Goals of care among high risk groups
While the desire to live a long life is near universal, it is not an unqualified goal. When asked what is most important to them in survey research, the majority of older persons prioritise remaining independent (first), and free of disabling symptom distress (second). They rank “living longer” last among these three priorities. They are concerned about the burdens of their care on their loved ones. They are worried about money and how the cost of their care is compromising the best interests of the family. They seek dignity, the company of the circle of intimates, familiar places, and familiar faces. Healthcare systems focus
predominantly on prevention when prevention is possible, on cure when cure is possible, and where cure is not possible, on life prolongation. When prolongation of life involves provision of social and emotional support and attention to suffering and to family needs, healthcare systems are — to a great degree — helpless. There is more to the ends of medicine than a blinkered focus on the disease alone. There is also the person living with the illness to be considered. What matters most to them? What matters most to their family caregivers?

**Impact of Palliative Care**

Palliative care is a relatively new interdisciplinary specialty focused on improving quality of life for people with serious and complex illnesses, and their families. By working alongside the patient’s regular medical team and focusing on relief of pain, symptoms, and stresses of serious illness, the palliative care clinician provides the patient and family the support needed to focus care received on outcomes they care about.

The use of acute care to manage predictable and preventable symptom crises, caregiver exhaustion, and patient and family uncertainty about what to expect and how to manage it is not only low quality and burdensome, but is also the main driver of high spending. Studies of palliative care delivery in a range of patient populations, care settings, and countries, show improvement in patient and family quality of life and a subsequent reduction in reliance on emergency services and hospitalisation. As a result of palliative care’s impact on quality, a review of 40 studies found a significant reduction in health spending among patients receiving palliative care (with or without concurrent disease treatment) as compared to control groups receiving only usual care. A recent study of cancer patients also show improved survival among patients receiving both palliative and best cancer care, as compared to patients receiving only usual cancer care.

**Goals of Payers and Policy Makers**

The organising principle behind health policy is strengthening the value equation, or the ratio of quality to cost. Public health interventions such as clean water and vaccination save millions of lives and cost very little per capita, the exemplars of high value care. Low value interventions, such as ICU care for persons with advanced dementia, not only cause suffering and fail to improve quality or length of life, but are also expensive. Studies show that such patients have actually been subject to increasingly burdensome ICU and hospital care in recent years. Given the vulnerability to suffering and low value care in the sickest and costliest 5%, most of whom are not at the end of life (figure 1), interventions known to improve quality of life and care should be incented, measured, and integrated into health systems. The desired result is better quality leading to fewer crises and lower need for emergency and rescue medicine, leading to lower total spending.

**Figure 1.** Costliest five percent of patients
Reformatted with permission from Meier, D.
Implications of rise in risk bearing models

In the U.S., the Affordable Care Act and the process of privatisation of both Medicare and Medicaid have shifted the financing of healthcare delivery away from fee-for-service with its incentives for higher volume and towards acceptance of risk-bearing payments emphasising prevention of unnecessary utilisation. Palliative care is vital to the success of such risk-bearing entities because of the concentration of healthcare spending among seriously ill patients and palliative care’s ability to improve value (ie raise quality and thereby reduce costs) for this group.

Need for meaningful quality outcomes for high cost high risk populations

Given the pressure to control health spending and the concentration of such spending among a small group with the most complex and advanced disease, the movement towards risk-bearing carries hazards for stinting and undertreatment. The only protection against undertreatment is a rigorous and transparent set of quality measures that hold providers and payers to standards that protect this vulnerable group. Yet, the science of quality measurement is not advanced enough to measure what matters most to the sickest and most complex patients, in part because it is difficult to determine preferences which often change over time, and in part because we do not yet have the capacity to allocate the resources needed to achieve a patient’s goals for care.

For example, a recent front page article in the New York Times tells the story of 89-year-old Joseph Andrey whose only goal was to remain in his own home with the personal care support he needed until he died. Since neither Medicare nor Medicaid (he had both) would cover the necessary 24-hour personal care support, and his only daughter had a full time job (and most importantly, define a common palliative care denominator population. A major multi-sector financial investment in measure development, testing, and implementation is needed to honour the commitment to assuring quality for the most vulnerable.

In stark contrast to Mr. Andrey’s experience in the U.S., Dame Cicely Saunders, British founder of the modern hospice and palliative care movement, spent the last months of her life living at home alone in a three-story row house. She had metastatic cancer to bone and pain requiring around-the-clock opioid therapy. Nonetheless she was able to live comfortably by herself in her own home until the last few weeks of her life because of what the British call a “tuck-in” service. An aide would arrive each morning to get her up, bathed, dressed, and help her down two flights of stairs to the kitchen. There she would fix breakfast for Dame Cicely, lay out her medicines for the day, put lunch in the refrigerator, settle her in a chair in the sitting room with phone and remote close to hand, and leave. A hot meal was delivered each evening. At 8pm each night, another young woman would come and reverse the steps, helping Dame Cicely back upstairs and tucking her safely into bed. With this minimal support, she remained independent in her own home, as was her wish, until the last few weeks of her life. We cannot pay for such services in many countries, but if we could reallocate our resources on achieving outcomes people want (in Mr. Andrey’s and Dame Cicely’s cases, remaining at home with support) then we could deliver the care that we would all want for our own parents – and ourselves – to receive.

Which measures would help us know that Mr. Andrey’s care, though exorbitantly costly and predominantly institutional, was of poor quality? And in contrast, which measures would tell us that Dame Cicely’s care at home with the social and human supports she needed resulted in much higher quality outcomes? This is the challenge we face.

Measuring what matters

Discussion of the need to redress the gap in measurement of outcomes valued by the sickest and most complex patients has been ongoing for years. Everyone agrees we need investment in meaningful, actionable, and valid measures for this population. Yet the goal is honoured primarily in the breach. Measurement development and field-testing across clinical categories and care settings (most of this population has multiple chronic conditions and moves frequently between and among care settings) is costly, complex, and time consuming. The palliative care and hospice communities do not have access to sufficient resources. The U.S. government has shied away from investing in measure development for this population because of its complexity, cost, and because of a failure of effective political advocacy by the major organisations in the field. Yet the urgency is clear. What will it take to address this quality chasm?

In a harbinger of progress, the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association have initiated Measuring What Matters, a field-driven consensus process of measure identification and prioritisation. To date, the process has yielded a list of top 10 validated measures. In the future, the project will develop e-spezifications; patient-reported outcome measures; field-test altered, expanded or untested measures; and most importantly, define a common palliative care denominator population. A major multi-sector financial investment in measure development, testing, and implementation is needed to honour the commitment to assuring quality for the most vulnerable.

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In a harbinger of progress, the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association have initiated Measuring What Matters, a field-driven consensus process of measure identification and prioritisation. To date, the process has yielded a list of top 10 validated measures. In the future, the project will develop e-spezifications; patient-reported outcome measures; field-test altered, expanded or untested measures; and most importantly, define a common palliative care denominator population. A major multi-sector financial investment in measure development, testing, and implementation is needed to honour the commitment to assuring quality for the most vulnerable.
Conclusion

If quality measurement is to achieve its purpose, the industry must tackle the measurement of outcomes that matter to persons at highest risk of neglect, undertreatment, overtreatment, and suffering. This will require collective action from government, the private sector, patient advocacy groups, and clinicians. Collective action requires leadership and coalition building. The momentum of the Measuring What Matters initiative holds promise for achievement of this goal. If we are successful, the care Dame Cicely received (remaining independent at home, social and nutritional needs met, pain and symptoms controlled) would exemplify quality. The care my fellow New Yorker, Mr. Andrey, received would qualify as a never-event, an exemplar of poor care with real accountability consequences. Cost containment is urgent and necessary. But so is protection of those patients most likely to need healthcare and least able to advocate for themselves.

References

Changing the way healthcare is delivered: Patient-centered Parkinson’s disease care

ParkinsonNet is an initiative headquartered at the Radboud university medical centre (Nijmegen, the Netherlands) whose mission is to guarantee the best possible care for people suffering from Parkinson’s disease in the Netherlands and worldwide. There are approximately 50,000 patients in the Netherlands with Parkinson’s disease and the number is expected to double in the coming decades.\(^1\) Led by the ParkinsonNet founders, Prof. Bastiaan Bloem and Dr. Marten Munneke, the initiative brings around 3,000 medical and allied health professionals together to facilitate specialisation, collaboration, and the exchange of knowledge.

The ParkinsonNet team has several patient-driven quality improvement projects underway.\(^[B\) Bloem, personal communication, 2015\] In January 2015, a national quality registry system was launched to measure quality of care. The registry is a joint initiative of the Dutch Association of Parkinson Patients, the Dutch Association of Neurologists and ParkinsonNet. The registry provides feedback to health professionals and transparent information to patients and health insurance companies. ParkinsonNet also operates a web-based tool to publicly share outcomes and other quality measures by region\(^2\) as well as an application that enables patient and provider online communities.

The use of patient-centric measures and the creation of web-based tools has all been done for the underlying goal of changing the way healthcare is approached – from doctor- and supply-driven to patient-driven.\(^[B\) Bloem, personal communication, 2015\] ParkinsonNet leaders have gleaned a number of insights in their efforts to deliver patient-driven care, a few of which are discussed below.

Involve the patient

ParkinsonNet believes that engaging patients in the quality improvement process is absolutely essential since only the patient can speak to quality of care. To foster this engagement, a patient-driven website called “Parkinson Connect” was created. A Facebook-like platform for healthcare, this site brings patients, caregivers, and healthcare professionals together in web-based communities to facilitate coordination of care.\(^[B\) Bloem, personal communication, 2015\] Patients and caregivers can share knowledge and experiences as well as connect in regional online groups. Due to its initial success among patients and caregivers, the site expanded to involve medical and allied professionals. The latest development is a “private community” where patients can now invite their various providers (doctor, nurse, physiotherapist, etc) to become their “friends” and can create a private forum for them all to communicate and to store all relevant medical knowledge, regardless of where the patient is being treated. In many ways, this is a modern version of a true patient’s electronic health record. The hope is that one day this platform will be connected to the doctor’s electronic health record (EHR).
A major source of data for ParkinsonNet’s new national quality registry will come directly from patients via an annual survey. When surveying patients to determine the outcomes of greatest importance to them, ParkinsonNet staff learned that the highest priority needs of patients (eg sexual and sleep complications) were not always the top concerns of physicians (eg tremors). Using these high-priority outcomes identified by patients, various process and outcome measurements were developed, including several patient-reported outcome measures focused on:

- Independence (use of home care, nursing home, residence in a nursing home, voluntary care, day-care and rehabilitation)
- Patients’ quality of life, in light of their experience with Parkinson’s disease (includes items such as mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort)
- Perceived quality of care as seen through the eyes of the patient (includes items such as emotional support, cooperation, accessibility, providing information, participation, and treatment)
- Employment and social participation for patients with Parkinson’s disease
- Burden on voluntary carers of patients with Parkinson’s disease.

These outcome measures go well beyond medical care and treatment. Coupled with process and outcome measures, such as hospitalisations and hip fractures, these measurements will provide insights into both clinical and non-clinical outcomes that are important to patients.

Minimise provider burden

In addition to patient-reported data, the national quality registry relies on data from a nationwide medical claims database and from data submitted by healthcare professionals. The claims database contains a range of patient data, such as medication use and hospitalisation information. Data submissions from healthcare professionals are minimised to the extent possible. When developing the registry, careful consideration was given to what would be requested of healthcare professionals so as to create as little extra work as possible, since this would take away from time with patients. The developers had lengthy discussions on how to streamline data entry so that providers would only have to submit information that was absolutely necessary. Even so, the initial experience shows that providers are still deterred by the time required to enter data, which is in many ways understandable, knowing that – with time – quality registries will also follow for many other chronic neurological conditions. The experience in this first year will therefore be used to make the registry even leaner where this is possible, and in particular to further maximise the extent to which data entry is automated (eg by coupling the registry to the EHR). In time, ParkinsonNet hopes that the patient-reported and claims data will be sufficient to reflect quality of care, so that data from healthcare professionals may no longer be required.

Another obstacle related to provider participation is that the quality registry is separate from the EHR. The Netherlands does not have a national EHR, making interoperability between the registry and various EHR systems a challenge. Providers therefore have to open separate applications during a patient visit, which may be another barrier for uptake or provide buy-in.
Some healthcare providers have been able to sync their EHR with the registry so that upon exiting the patient record, the provider is prompted to respond to five questions from the quality registry. ParkinsonNet hopes to facilitate similar linkages moving forward so that the registry can be seamlessly integrated into the provider’s workflow.

**Promote transparency**

Another initiative sponsored by ParkinsonNet is called ParkinsonAtlas. The website features an interactive map that allows anyone to identify and compare various quality metrics among the 66 regions in the Netherlands. Because the initiative’s goal is to promote collaboration and facilitate sharing of best practices among providers, the quality information is deliberately displayed by region so as not to penalise individual providers or facilities. [B Bloem, personal communication, 2015] The site allows a user to see improvement over time in a specific region, or to compare differences among regions. The ParkinsonNet team has found that simply making quality information publicly available has been a driver for quality improvement and collaboration in and of itself; transparency has encouraged providers to connect with others and share best practices, without publicly shaming those with poor performance.

**Encourage collaboration**

Patients with Parkinson’s disease receive care and treatment from a range of medical and allied health professionals, making coordination of care even more important. In addition to supporting collaboration via ParkinsonAtlas, the ParkinsonNet team purposefully developed metrics for the national quality registry so that multidisciplinary collaboration would be promoted. [B Bloem, personal communication, 2015] It would be much more difficult to decrease hip fracture rates for Parkinson’s patients, for example, if the neurologist, physiotherapist, occupational therapist were not all working together closely.

ParkinsonNet also supports international collaboration to facilitate learning and sharing of best practices. ParkinsonNet leaders have partnered with stakeholders in Germany and the United States to establish networks for Parkinson’s disease patients and providers. [B Bloem, personal communication, 2015] For example, Kaiser Permanente (KP) has taken an interest in the network concept and plans to partner with ParkinsonNet to build a platform, initially in Southern California but with the aim of extending this rapidly across other KP areas. These opportunities have allowed the ParkinsonNet team to share their successes and lessons learned while also learning themselves about innovative patient-centric models in use around the world.

ParkinsonNet is primed to continue to revolutionise care for those with Parkinson’s disease in the Netherlands and potentially worldwide. While ParkinsonNet has championed patient-centred care and treatment through the use of web-based tools, it recognises the need to occasionally pause and take stock of existing efforts. [B Bloem, personal communication, 2015] While innovators (and funders) might focus on the “next best thing”, leaders at ParkinsonNet deliberately assess the healthcare landscape to ensure their efforts are maximised and highly coordinated to the extent possible.

**References**

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ImproveCareNow: centring healthcare on patient-defined outcomes

BMJ Outcomes

Imagine a room in a hotel conference centre, filled with people who have come together to present their work on improving care for a group of patients with a particular chronic disease. The program is full of breakout sessions, Plan-Do-Study-Act (PDSA) quality improvement cycles, and practical, hands-on stories of how different teams have managed to improve the care of these patients. The attendees are keen to share experiences and build upon one another’s achievements.

Now imagine there are nearly as many patients and parents in the room as there are doctors, nurses, and other healthcare professionals – and that the patients and parents are just as actively presenting, sharing, collaborating, and challenging assertions.

From the moment one enters an ImproveCareNow (ICN) Community Conference, the most recent of which took place this March in Chicago, Illinois, USA, it feels like a visit to the future of healthcare. It’s a future in which healthcare professionals have not only discovered how to work collaboratively with one another, but have learned to build a true care team surrounding and including each patient. At ICN centres, the patient and family are equal contributors to the identification of outcomes of care, strategies to test to achieve those outcomes, and targets for PDSA quality improvement cycles. Listening to the co-chairs of the patient leadership committee throw around “PDSA cycles” the way other young people might say “OMG” was a revelatory experience of the tremendous energy we could inject into healthcare improvement if we universally invited patients to the table.

ICN is only the first to benefit from the Collaborative Chronic Care Network (C3N) Project, a unique program launched by a pair of healthcare futurists; one disguised as a paediatrician/epidemiologist named Peter Margolis, the other a psychologist applying social and behavioural science to improving the healthcare system, Michael Seid. The C3N project has facilitated ICN’s robust, multi-centre, multi-national learning healthcare ecosystem around paediatric chronic inflammatory bowel disease, and their upcoming efforts include similar ecosystems for type 1 diabetes and cystic fibrosis.
The achievements by the 73 ICN care centres across the US (plus two centres in the UK at Cambridge University Hospital and Great Ormond Street Hospital) offer a potent vision for what we might achieve in every healthcare endeavour if the focal point was consensus on the goals of care among the patient, the patient’s family, and the entire spectrum of providers surrounding them. The network is composed of tens of thousands (at last count 20,500) of individual study units each composed of a patient, her parent, a researcher, and her clinician all focused on the goal of remission – quiescent disease with minimal or no symptoms. While every team can track the effect of treatment on outcomes, new tools are in the works that will allow even deeper learning. With the Orchestra collaborative tracking tool, each team begins with an agreement between patient and physician on the set of measures the patient will track, including both traditional validated patient-reported outcome measures and measures customised by patients to their goals.[1] Together the members in each “N of 1” study team engage around the mutually agreed upon target outcomes and conduct a series of rapid PDSA improvement cycles, experimenting with real life multivariable tests of the impact of various decisions on the patient’s wellbeing.

This close-knit physician-patient collaboration is powered by a personalised learning system created by C3N which “allows patients with chronic diseases to work collaboratively with their clinicians to identify issues of importance to them, track outcomes, and learn both from the routine changes patients make in everyday life (eg, diet changes, travel, sleep patterns) and formal planned experiments aimed at improving the outcomes most important to them. A web-based interface[2] permits patients and providers to set shared goals and co-design experiments, and lets patients customise data collection via cellular short messaging system (SMS), e-mail, web-survey, and commercially available biosensor devices (eg, Fitbit). The web interface also provides graphical reports of data collected by patients in real time for immediate review by patients and providers, and provides tools for patients and providers to chronicle their observations.”[1]

The brilliance of the network is that the data collected by every clinical team and every one of these “N of 1” study teams is built upon a uniform underlying data structure and a core set of common outcome measures. This registry of shared data points is now building automated data capture from the major EHR systems in the US. The common outcomes data points...
will allow the collective data across numerous N of 1 study teams to be combined into larger scale analysis and evidence building on what works in this challenging disease. This is especially important because paediatric chronic inflammatory bowel diseases meet the National Institutes of Health definition for “rare disease” and even large centres would struggle to assemble sufficiently large study cohorts to achieve statistical significance using a traditional research study approach.

By innovating around the delivery of existing therapies, ImproveCareNow has raised the remission rate for paediatric inflammatory bowel disease from 55% to 78% remission since 2007.[4][personal communication, Peter Margolis, March 2015] For a population of children whose lives revolve around infusion of powerful systemic anti-inflammatory agents, surgeries, stoma, pain, and nutritional malabsorption, this outcome is nothing short of miraculous.

And yet, as impressive as it is, 78% doesn’t begin to capture the totality of the impact of ImproveCareNow’s achievement. To do so would require a set of outcome measures that could track not only disease remission, but also patient and family engagement and empowerment; the strength of the close collaborative relationships developed between patient, physician, clinical team, and researchers; support and sharing of knowledge and intimate personal experiences between patients and families across vast distances; the exponential effect of capturing individual patient trials into a fully powered database to fuel more rapid growth in research evidence in a rare disease; the radical shift in physician and clinical team culture that brings the patient in as an active member of the care team; and the effects on our world of improving the lives and wellbeing of so many young people and their families. C3N is drawing from disciplines inside and outside healthcare to measure all of these elements in the new health ecosystems it is helping to create, while pushing towards further improvements in clinical outcomes. When Peter Margolis announces to the ICN community that the next target is 100% remission in paediatric inflammatory bowel disease, it doesn’t sound like hyperbole or bravado; it sounds like a certainty. This is what happens when you focus on the outcomes that matter and work towards them in partnership with every member of the care team, with the patient at the centre.

References


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