Introduction

The purpose of health care is to improve people's health in a caring manner. A challenge to delivering on this purpose is that health care professionals often don't know if the care that they deliver or pay for improves people's health. And it's not for lack of trying to measure – health care is *awash* with measures. In fact, many health care providers feel like they are drowning in measures and reporting requirements, and that is because they are! Your organization probably tracks a number of indicators that are required by regulators or payers, or because they are linked to internal quality-improvement initiatives. But take a step back and ask yourself how many of those measures actually measure the impact on *patient health* during or after care? Odds are, the answer is "not many." Instead, most existing measures focus on assessing how individual health care providers, clinics, and hospitals are performing. The measures don't focus on answering the question of how people's health has or has not improved, although this is starting to change as the use of patient-reported outcome measures grows.[1] And simply complying with reporting requirements is not enough.

The idea of measuring the results of health care and focusing on patient outcomes is not a new one. Florence Nightingale and Ernest Codman demonstrated the importance of this in the mid-to-late 1800s[2,3] – yes, the 1800s! Unfortunately, the idea did not gain traction, and here we find ourselves in the twenty-first century still struggling to make patient outcome measurement commonplace.

To get us back on the path to measuring the results of health care – the patient's outcomes – it is important to understand how we have lost our way. This starts with a brief visit to the history and evolution of measurement in health care. Once we have done that, we can reorient ourselves to the measurement of outcomes and pursue it fervently!

The Current Health Care Measurement Landscape

The current measurement landscape is characterized by countless measures that are designed in order to evaluate the "quality" of health care. What does "quality" in health care really mean?

In 1966, Avedis Donabedian conceptualized a framework for assessing the quality of medical care that came to be known as the Donabedian framework.[4] It is organized into three categories: structure, process, and outcome. Donabedian described **structural measures** as measures to evaluate the setting in which care is delivered that may include such measures as the number of board-certified physicians in a clinic or hospital, adequacy of the facilities, and so on. **Process measures** measure the processes of care, such as the time it takes to get from the emergency room to the cardiac catheterization lab for patients presenting with an acute myocardial infarction (heart attack). **Outcomes** include the measurement of survival, the degree of recovery from illness, and/or the regaining of function in an area where it was lost.[5]

While Donabedian described outcomes in a way that aligns with how we think about patient-centered outcomes today, current measurement efforts reflect a focus on structure and process measures, and usually define outcomes as measures of clinicians' outcomes – that is, how well they have performed in delivering care. This may be the result of a narrow interpretation of Donabedian's framing around *medical* quality assessment as the need to evaluate providers of medical care instead of the receivers of medical care.

Defining quality in health care as achieving success in all three categories – structure, process, and outcome – makes measuring it and differentiating it from outcomes challenging. What needs to be made clear in our thinking about quality is that the ultimate measure of quality in health care is improved outcomes. The structure and process measures in Donabedian's framework are the *inputs* of the health care system. Conversely, measures in the outcomes category are the outputs of health care. Measuring and improving the inputs of care delivery should only be done to the extent that it improves the output: outcomes for individuals receiving care.

Typically, inputs are easier to collect as they are more clearly time-bound and straightforward and don't necessarily require information from patients. Measuring processes, in particular, provides a way to account for the application of the best medical knowledge to-date, knowing that the ideal outcomes may not be attainable because of the limitations of medical science at any given point in time. To measure the true and longitudinal outcomes of health care delivery at the time that Donabedian published his framework seemed daunting. With the vast array of technology available today to support longitudinal outcome measurement, and with the increasing acceptance of patient-centered outcome measurement, feasibility should no longer be considered a major barrier to measuring outcomes. Nevertheless, longitudinal outcome measurement remains rare in practice.

Today we find ourselves swimming in a sea of certifications and process measures, without at least a commensurate – and ideally unyielding – focus on

measuring outcomes.[6] Part of this proliferation is not without reasonable cause and positive intent. Certifications and processes are important inputs of the health care system that should be optimized. But they do not guarantee and may not even correlate with good health outcomes.

In an effort to increase safety and promote quality in health care, the US federal government started requiring quality measurement in the late 1990s, when the field of quality improvement was still very nascent. In 1998, President Bill Clinton established the Advisory Commission on Consumer Protection and Quality in the Health Care Industry. This commission's charge was to lead a national effort to improve health care quality in the USA. It led to the creation in 1999 of the National Quality Forum (NQF), a national clearinghouse for consensus-based, standardized quality measures. In addition to setting national quality standards, the NQF convened a Strategic Framework Board in order to develop a strategy for a national quality reporting system and identify priority areas and potential barriers.[7] The NQF currently oversees a plethora of measures, although not enough of them are patient-centered outcomes.

Reorienting to the Measurement of Patient Health

In an effort to reorient ourselves and create a foundation for measuring the outcomes of health care, let's start by defining some key terms: health, health care, and outcomes.

What is **health?** According to the World Health Organization, health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[8] **Health care**, then, constitutes the efforts to maintain or restore health, usually by trained and licensed professionals. And an **outcome** is the result or consequence of an action – or the absence of action.

So, if the purpose of health care is to maintain or restore health, we need to measure in a way that tells us if the care that we provide achieves that goal. Simply put, does care help improve health? Scott Wallace and Elizabeth Teisberg developed the Capability, Comfort, and Calm outcome measurement framework that enables those who work in health care to measure results on these three important dimensions for people receiving health care.[9] We will use this framework throughout the how-to guide and look at it in depth in Chapter 1.

Why Are Patient Outcomes Not Measured More?

Frankly, it is hard to get started. The questions of which measures to use and how to collect the information are stymying for many. In this guide, we will tackle these and the many other questions that arise. Building an outcome measurement program may seem overwhelming, but it need not be. This guide will walk you through where to begin and how to overcome the most common challenges that you will face.

For a variety of reasons, health care providers as a whole have not placed a high priority on outcome measurement. Although clinicians usually ask informally how a person is feeling, that conversation is rarely part of the patient's medical record or measurement approach. Instead, providers often have to track measurements required by regulators or payers, such as readmissions and health screenings, but rarely push the conversation further. Or they measure the results of process improvement initiatives (e.g., reducing door-to-balloon time for heart attack patients), but not the extent to which those initiatives actually led to better health (e.g., decreased mortality, days at work, improved quality of life).

In some cases, clinicians may not measure outcomes because they think that they already know how patients are doing and do not realize how much *more* they might learn from an in-depth assessment of care results. This in-depth assessment can increase the aspirations of a clinician or care team by giving them insight into how their care impacts outcomes and how they can improve. This cycle of measurement and improvement creates a culture of learning and reinforces the focus of the team on improving outcomes.

Your Personal Reflections Before We Get Started

People work in a variety of capacities within the health care system. As you embark on measuring outcomes, it is important to reflect on why you want to start measuring outcomes and what impact you hope to make by doing so. This how-to guide will provide guidance in different ways depending on the role that you play in health care.

- If you are an individual clinical team member, it will provide you with steps to measure the health of your patients in order to determine if they are getting better and/or staying well physically, mentally, and emotionally, and to assess how the process of accessing and receiving care affects their daily lives.
- If you are a leader of a health care delivery organization, you will learn measurement steps and techniques to determine what kind of results your organization is achieving in terms of improving the health of the people seeking care from you.
- If you work in a health plan, you can also apply these measurement techniques to answer two fundamental questions: Are the people we cover improving their health? How are the provider organizations we contract with helping people improve health?
- If you are a researcher, this guide will offer ways for you to think about what outcome you are trying to influence through your work. Throughout my career, I have reviewed many clinical research proposals designed to answer research questions that are very interesting but will have little

impact on people's health – or that don't even consider the potential impact on outcomes.

If you don't identify with any of these roles in health care, take a few minutes to think of a health care experience that you or a loved one has had. What was the reason for interacting with the health care system? What did you or your loved one need? What questions did you or they have, and were they answered? And how did your experience and the outcomes line up with what you needed or hoped for?

Regardless of which role you identify with, take a few moments to reflect on *why* you want to measure outcomes. Jot down your reasons in the space below.

Before we dive into getting started with outcomes measurement, you need to ask yourself another important question. *Where do I want to go with outcome measurement? What is my goal?* As Stephen Covey says, "Begin with the end in mind."[10] The path to measuring outcomes can be wrought with distraction, especially in the age of big data and sexy data collection and analytic tools that don't necessarily deliver on making outcome measurement easier. If you don't start with a clear objective or purpose, it will be hard to stay on the path. Covey suggests creating a mental model of what you want to achieve, then setting out to bring that mental model to life. This will be critical to your success and help you stay focused on reaching your objectives.

When I led an outcomes team for children's heart surgery, our end goal was to have valid, reliable, and reproducible outcome data that the surgeons could use during surgical consultation. We also wanted to share those data publicly to help people know what they could expect when they came to us for surgery. Once we had set these shared goals, the team and I looked to a leader in health outcome transparency – The Cleveland Clinic – for examples of how to operationalize the work ahead. We kept copies of and referred often to their outcomes books, which provided a strong visual representation of our end goal. We also used them as an example any time that we needed to make the case to others for the imperative, feasibility, and promise of investing in outcome measurement. In this way, The Cleveland Clinic's work helped bring us one step closer to a shared mental model of what is possible.

Spend a few minutes thinking about what your end goal is for outcome measurement. What do you see yourself doing with the data you collect? Close your eyes and try to picture it.

Now write down the end goals that came to mind. You can also draw a picture if that is more helpful to you. Stick figures are welcome!

Ready to start? Here we go!

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