

Chapter 14

Health Information Crossroad: An Opportunity to Deliver Real Measurable Outcomes for Better Health and Well Being

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Abstract There is so much data and information in health care, but has and will it be used to truly change outcomes, cost and quality? As the focus changes to population and individual health, even more data will be needed to ensure that personalization supplants a one-size-fits-all model. Those entities that crack the code of using data for true insights and game-changing actions will reap benefits while others may fail. It is an amazing time for personal technology that can and will be used more in the future for improving individual health. The industry must undo so much in the way of process and care models now that fee-for-service is disappearing as a payment standard. This is requiring new leadership, thinking and direction unprecedented in this slow-to-change environment. As new entrants join the effort and push those who are entrenched in the past, progress is accelerating. Data and information need to play an actionable, economic and real role in changing for the better. There are more exciting examples of the new way to do it right. The future is bright and the journey is difficult. Embracing it means investing energy and courage in considerable quantities.

Keywords Outcomes • Information • Insights • Data • Transformation • Consumerism • Health reform • Engagement of individuals • Convergence

14.1 The Current Dilemma

Health care and the models that deliver, finance and document it are undergoing dramatic change in all areas of the world. It is an industry that is made up of amazing professionals who focus on changing people's lives. The data captured by the

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industry has over time grown exponentially and specifically based on the entity capturing and using the data. The cost of health care has captured continuous headlines in most countries and is showing little chance of abating in the near future [1]. So many efforts are underway to change these trends and data will a dominant part of the success or failure. However, it cannot be the kinds and types of data that have always driven this industry. Instead it will need to be actionable, pragmatic, comparative, transparent, longitudinal, consumer friendly and always available.

A key filter that will be mentioned throughout this chapter is whether data and information create a landfill [2] or truly, measurably change the industry in ways not seen to date. The opportunities for data are exploding within an industry facing dramatic change and a burdensome task of creating real value before it hurts economies and individuals even further.

Every country, state, employer, payer, provider and individual are affected by current data and have a monumental hope for improvement in the future. Data is the only universal output from this industry and must become truly impactful not just be available to do processes and reporting. Everyone involved is facing dramatic and difficult decisions about healthcare and data must help not just ride along with the change.

There are pockets of the industry that are much more integrated in their organizational structures and data handling than the general industry. They are to be commended but it is difficult to extrapolate their model in most cases. However, they can share their experiences in a context that the other entities can relate to their individual pieces. Even the best fall significantly below what is needed. Neither the outcomes, costs, transparency nor engagement of individuals meet the needed levels for a successful future (Fig. 14.1).

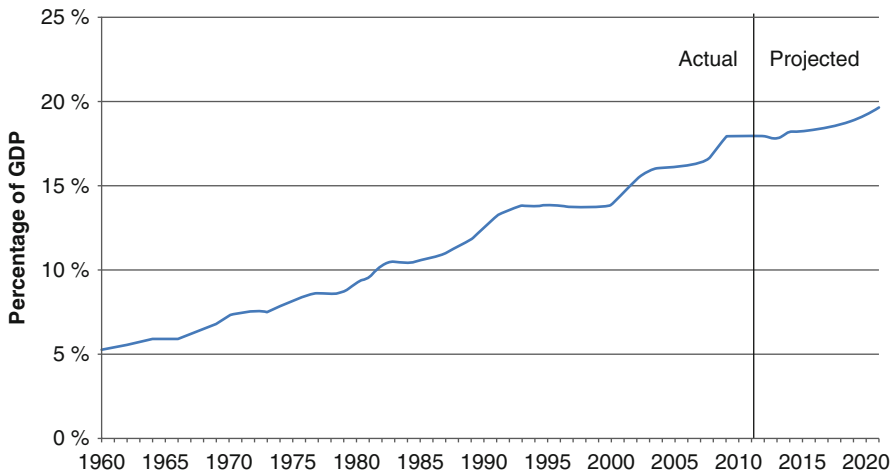


Fig. 14.1 U.S. National Health Expenditures as a Share of GDP, 1960–2021 (Source: Centers for Medicare and Medicaid Services)

14.2 Data in Health and the Surrounding Industry

Each of you reading this can probably tell a compelling story about your health data, the volumes, redundancy and complexity. Most would profess that the information is important during an episode or procedure but has little use for you ongoing. Even chronically ill who live daily with issues struggle to have their data be useful, available and actionable. Care models throughout the world are made up of many processes, caregivers, systems and locations. This has helped fragment data for decades and is changing slowly [3]. Most data is kept as part of process, compliance, care documentation, and research, but does it make a real difference to changing value, quality or outcomes before, during and especially after care. Picture a beautiful quilt made from many disparate pieces of cloth into a magical and pleasing pattern. Compare that to healthcare where most entities consider their data the final product rather than making it an important part of the data about an individual who has data pieces in many caregiver and payer environments. Owning the data is a mantra of importance that many entities hold dear to their success. An admirable individual approach but will delay and actually block game-changing data sharing and usage. It is so difficult to transform data in an industry where success of individual entities is based on them being good at their piece and protecting their data. The countries and others mentioned above will be doing everything possible to redefine success factors based on value, true cost structure reduction and better population health. Only those who accept that the current world healthcare directions are not sustainable will survive the change necessary to ensure healthcare spending doesn't ruin economies, businesses and individuals seeking care.

Data standards is a subject that gets much attention and has seen progress in some countries but is not advanced at all in others. Without standards, sharing of information and real transformation will be fragmented at the very best. Countries who have not even automated basic information and its sharing.

So much is being written about the growing issue of chronic diseases such as diabetes.¹ Data and information about this disease have been available to care givers and individuals for decades but the incidence continues to rise. Devices such as glucometers, free supplies, nutrition guidelines, an internet full of information and caregivers who know how to treat the disease cannot slow its increase. The opportunities of data and information used in new ways may offer a brighter future. Such possibilities will be expanded in each of the paragraphs below to show approaches using information and process. Discussions of statistics, data, and information however can become numbing and overwhelming to the general public. As a person, who is a patient, one wants to know about themselves, in their lives and their context. So data, information and processes must matter one person at a time to show real outcomes and improve the well-being of individuals

¹ *Epidemiology/Health Services/Psychosocial Research*: Venkat Narayan et al. [8]

14.3 The New Wave of Data Sources

Smart phones, apps, social media, and wearables like fitbits etc. have changed each of your lives in an amazingly short time [4]. Monitoring patients, wherever they are, e-visits and telehealth are examples of the new data sources being embraced by the healthcare industry. More data sources whose data must be captured, stored and used. Much like you have junk mail in your inbox, what is the junk mail from these new sources? Even more importantly, what is worthwhile, to whom, for what, against real value that makes a dent in the cost, quality and outcomes so sorely needed? This data will dwarf in volume the data that has been and continues to be used in today's processes. When discussing these new sources they are considered additional to what happens now not replacements or enhancements to the old. An industry that truly needs transformation cannot just keep adding on while not replacing or making markedly significant ROI on these new sources. These new sources beg for an architecture of data for every entity that hopes to survive and thrive in this new world ahead. Just because data can be accessed doesn't help this "hoarder" industry break its habits and enhance the future.

Continuing the diabetes thread, there is an application available by smart phone for diabetics developed in Austria. You have probably heard that often, but let's dig deeper. It is an application built by individuals who have and live daily with diabetes; therefore, understanding the minute to minute life impacts. As you listen to the developers explain it's capabilities that improve their daily lives it excites you about all people's lives. Further the cost is surprisingly low and affordable, the information gathered is used to the benefit of all individuals and the application can be offered by a country to all its citizens who have diabetes. Personal to each, built by like diabetics and used differently by each person; an exciting approach for all ages, geographies and environments.

14.4 Data as a Conduit to Value

Just look around as you go about your normal day. What data/information are worthwhile in your life, influences your behavior and you would not want taken away. A car insurance company offers a plug-in device to evaluate your driving. It captures your driving tendencies and judges your capability. If you are good per their evaluation you get good rates! We all know that a credit score is kept on us that impacts offerings for large purchases like homes and cars. Social media has exploded with opinions about most any subject including your health, diseases and treatments. Further many people consider these opinions as valuable as those from care givers. Throw in travel sites with prices and reviews for destinations around the world, plus the new ability to schedule a taxi, track its arrival and have a set price ahead of time, people want convenience focused on them. Service, convenience and immediate access are imbedded in our daily lives. Welcome to dealing with people under their terms and conditions. How and when can the health care industry really engage in this reality of people being people and help influence their health and well-being.

Value requires changing both the existing approach to data as well as the future uses and direction. So much data exists that can be used to build baselines of performance, outcomes and cost that allow new uses of that data against new expected outcomes. Value in healthcare going forward is very difficult to define and measure as every entity tries to change or realign. It takes real leadership to accept so much change to what is successful currently. It is exciting to see governments, employers, payers, providers and individuals demanding a clearer definition of value. Watching entities adopt data models, new methods of scoring performance, and higher standards of interoperability lends so hope but too many are doing it incrementally rather than revolutionizing true value. Value in healthcare has always been based on people as patients or insurance members. Value going forward will need to think of the person as a consumer, parent, child, senior citizen, chronic, employee then patient or member. The data and its value cannot be focused on the entities in healthcare predominantly as it has in the past. Influencing individuals as they live their lives and seek wellbeing on their terms will be paramount. Value will require new sources of data that are available outside normal healthcare process [5]. Many people are asked their preferences by airlines and retail entities. That information is used to tailor value for that person. That type of engagement is almost nonexistent in healthcare so new data can be used in this manner to help value. That data however will not usually integrate well with existing systems or processes. That data used to augment value in the future will make a measurable difference. Value is look at through so many lenses in healthcare that success is dispersed. Will doctors and hospitals embrace scoring and comparisons, can the cost of healthcare be flattened, will employers demand action, and will governments dictate results.

In a European country the Minister of Health authorized the distribution of free glucometers to all diabetics in the country. The individuals are asked to bring the glucometer to each doctor visit so the doctor can actually see the readings covering the time since last visit. This data delivered by the patient to their doctor which chronicles actual readings or gaps in readings is invaluable in care. No generalities, no remembering by the patient and no uncertainty by the doctor exists. The discussion can range from controlling the disease, to daily fluctuations, to environmental effects and so on. The value is real to all involved due to the right data, personalized, accurate and shared with the doctor. An elegant approach that with good process aligned makes the data priceless. Picture further combining the application mentioned above with this capability and you have a precise data flow and information capability for each citizen that has diabetes, about them and for them.

14.5 Information to Change Behaviors and Affect Outcomes

Every healthcare environment is flush with data as discussed above. Turning that data into useable, actionable and continuously refreshed information is a must going forward [6]. Engaging individuals in their health and wellbeing has eluded most all healthcare arenas. Thinking of patients as people and using

information accordingly is a white space yet to be captured by the industry in meaningful ways.

Unless people can really know how to engage with the information available to them everything will continue to be sporadic and episodic at best. That will ensure that 5 years from now current issues will be dramatically worse. The same issue of information is faced by all care givers and support teams in healthcare. How can each caregiver tailor the information they get, need and use to change their work flow to really impact cost, quality and outcomes? No one in the industry can escape the magnitude of data but they want to harness what they really need to fulfill their desire to make a difference every day.

Data has been for so long considered an asset itself and information hard to get that people are skeptical to transformation and weary about the journey [7].²

Data must be evaluated across many dimensions, uses and needs to be more than just a costly corporate asset. Data filtered by worth, usefulness, quality, is one consideration. Data across processes, procedures, patients, care givers and diseases is another consideration.

14.6 The End Game Expectations

True transformation discussed at length in this section requires incredibly strong leadership and foresight at so many levels, if real change is to occur. Are there enough leaders in the industry with the courage to lead toward an unscripted future. That does not just mean at the C level but throughout all levels of an organization. The experience of individuals as patients is usually clouded fractured care, unexpected costs and many insurance claims. The industry must rework itself to make that experience much easier to score from an individual's point of view. Data, information and insights must be a significant conduit to that end, but it must happen sooner not later. Embracing the journey from data to information, knowledge, insights and finally improved outcomes will take all in the industry to achieve. It will require helmets and seat belts for this difficult journey. Accepting this and leading is a true crossroad that some will take and others won't. Let's hope that the takers significantly outweigh those who do engage.

Consider a healthcare industry worldwide that delivers data and information that;

- Explains options available to caregivers and individuals needing care
- Makes everything aligned to age, health status and preferences for each user of the data

²The diabetic examples above teamed with the advancement of genomics, cognitive computing, smart phone applications and coordinated team care models paint a positive outlook for true personalized changes for individuals. Data will abound but must be turned into actionable, personal, useable and simple information that can be used by each person the masses. As health care becomes a consumer business meaning affordable capabilities, changing health status is attainable world wide.

- Educates on the transition of diseases whether one or many together
- Helps the individual get the right care in the right setting on their schedule
- Defines incentives, restrictions, cost variances and provider network alignment
- Seeks an understanding of personal compliance by patient to their care responsibilities
- Allows people to declare whether they understand their medications or diseases.
- Explains care site offerings and home monitoring that really make a difference.

This list is not exhaustive but illustrative of the future vision. Every person in the world is part of this discussion and its issues. It will take many villages to drive this transition. Shame on all of us if we don't attack these opportunities with enthusiasm, strength and vigor.

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