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Connecting the Dots to Reduce Disease Burden in the U.S.

Executive Summary

Ever since the landmark Institute of Medicine report "Crossing the Quality Chasm: A New Health System for the 21st Century" exposed the enormous gaps in care that exist in the U.S., countless public health initiatives, research projects, and government reforms have been launched to fix the problem. While incremental progress has been made in pockets, the core challenge persists: disease burden continues to grow, and the efforts in place to address that burden are not always aligned with the areas that need it most.

We believe the primary obstacle keeping U.S. healthcare providers, public health officials, payers, and life sciences companies from making substantive progress in closing those gaps is bad data. For the healthcare industry to best serve its population, patient-level data sets must represent the actual patients, but existing data providers suffer from significant selection and sampling biases. In this whitepaper, we will shine a light on the specific challenges that have prevented a more complete view of the full patient experience, identify the missing links needed to overcome those challenges and propose a path forward that unlocks a new future for healthcare.

U.S. Disease Burden – Making Sense of a Senseless Problem

The United States has the highest disease burden among other comparable nations, and the gap keeps growing. By every measure -- years of life lost, disability, productivity, financial spending, resource constraints and more -- the cost of disease here in the wealthiest nation on earth is greater than any other developed country with comparable GDP figures. People continue to get sicker and die earlier, despite extraordinary progress in medical innovation and unprecedented spending on healthcare.

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But before we can begin to address the problem, we need to understand the complex mix of factors that are contributing to it.

One of the biggest drivers is the growing prevalence of chronic disease, which is responsible for more American deaths than any other cause. Seven out of every 10 deaths in the U.S. is attributable to chronic diseases, such as heart disease and stroke, which cause more than 859,000 deaths each year. Cancer kills almost 600,000 people per year. Diabetes affects more than 30 million Americans and dramatically increases risk for a host of comorbidities, such as heart disease, kidney failure, and blindness.

All told, 1.7 million Americans will die this year due to chronic diseases – and it's only getting worse. By 2030, researchers project an estimated 83.4 million people in the U.S. will have three or more chronic diseases.

On another front, an estimated 25-30 million Americans today are living with a rare disease, illnesses that are typically caused by genetic disorders and impact less than 200,000 individuals. Because they are so uncommon, they can be difficult to detect, often going undiagnosed for decades.

Even after diagnosis, healthcare providers and patients alike miss critical, potentially life-altering opportunities to better prevent and manage chronic, acute, and rare diseases. The World Health Organization estimates that 80% of heart disease and 40% of cancers could be prevented through earlier intervention and better lifestyle behaviors. Poor medication adherence continues to plague the U.S. health system. For example, heart attack victims face a significant risk of recurrence and mortality. Antihypertensives like Aspirin can cut repeat heart attacks by 31 percent and reduce the risk of death by 12 percent. But half of all heart disease patients have poor adherence to their prescribed medications.

There in lies the challenge – and the opportunity. There is a problem in our country that's killing millions and causing runaway spending that accounts for nearly one-fifth of our total economic output – and yet we are missing critical opportunities to stem the tide of disease.

Still, providers, health plans, population health authorities, and life sciences companies have struggled to effectively target at-risk populations because they simply have not had the breadth of data that allows them to see the entire population, the depth to understand individual patient journeys, or the timely data that allows them to intervene with a patient at the ideal moment. No solution has yet been able to factor all relevant variables into the treatment plan. No organization has managed to put all of the disparate pieces together to truly understand the patient journey and start to work together to fix broken links in the chain.

Systemic Challenges – Silos of Episodes

Getting from the present state to a place where healthcare stakeholders can access, track, and draw insights from the complete patient journey in real time requires a fundamental reworking of the status quo.

Today, the healthcare industry is siloed into discrete fiefdoms, each with its own rules, legacy ways of doing things, and incentive structures that sometimes sit at cross-purposes to one another. That ethos starts with the ways diseases are diagnosed and treated and carries forward to the ways individual encounters with the healthcare system are catalogued and tracked.

Consider the current state of type 2 diabetes in the U.S. An estimated 30.3 million people in the U.S. are diagnosed with diabetes at a cost of more than $245 billion per year. About half of these patients will develop nerve damage, 15 percent will develop foot ulcers, and among those with foot ulcers 14-24 percent will require amputation. All of these complications are due to poorly managed disease. In the fee-for-service healthcare system, the primary means of treating diabetes has been to make a clinical diagnosis, write a prescription and follow-up at periodic intervals. Because the healthcare system was designed to address the volume of treatments over the value of outcomes, few healthcare stakeholders were incentivized or empowered to focus on the root causes or address the myriad lifestyle behaviors that cause diabetes and its complications in the first place. Instead, they treated the symptoms, operating within their own siloed realities, making decisions based on their own siloed data.

More recently, as the healthcare industry has started to adopt value-based care -- which bases payment incentives on healthcare outcomes -- providers, health plans, and population health authorities have sharpened their focus on taking a more holistic approach to diseases like diabetes. This includes steps like identifying the clinical, demographic and social factors that may put a patient at greater risk for costly and debilitating complications like neuropathy, ulcers, amputation and vision loss.

Today, as healthcare evolves to a more patient-centered, value-based model that incorporates the full patient experience, risk-scoring variables such as these are becoming an increasingly important component of healthcare. But tracking all of those variables has remained a challenge for the industry.

Technological Challenges – Data Fragmentation and Interoperability

The key constituencies in healthcare -- providers, payers, life sciences companies, the government, and patients -- are all producing petabytes of patient data every day, but storing it differently, omitting important contextual information and limiting accessibility to other constituencies.

The result has been an incomplete picture of the patient journey through the healthcare system that has stymied efforts to better understand and holistically treat disease - from the individual to the population level.

Failed attempts to harness the power of patient-level data have relied on legacy resources, such as electronic medical record (EMR)-based sources, single-payer data sets and aggregated claims data sets, all of which contain incomplete, inconsistent and dated information.

For example, claims databases are the most common sources used by the healthcare research community, life sciences companies, providers, and health plans to try to piece together the critical components of the patient journey. These data sets, which can be accessed from the Centers for Medicare and Medicaid Services (CMS), private sector health plans, and large employers – or data vendors who aggregate claims from multiple sources – contain de-identified, patient-level data captured at the moment when a claim for payment of healthcare services is filed.

The limitations of these claims datasets are widely published in research studies, which have found that even the most complete claims databases often contain inaccurate billing codes, missing encounters, erratic sampling, and significant time lag – often six months or more.

Other sources, such as EMRs, often miss important links in the healthcare journey when patients visit specialists or outpatient providers who use record-keeping systems that are not interoperable or linked to their primary data source. In fact, most EMRs in operation today were never designed to serve as a hub for longitudinal population-level data. As such, they are often missing key components of the full patient experience, such as pre-existing conditions, comprehensive clinical data, and social determinants such as family, economics, and lifestyle factors.

Toward a Solution – Building a Comprehensive Healthcare Map

Today, by leveraging the power of AI, along with strategic partnerships with health plans, providers, life sciences companies and the government, it is possible to address both systemic and technological hurdles to create a comprehensive map of individual patient journeys at scale.

That is the key to establishing the **ground truth of healthcare**, the empirical baseline for evaluating gaps in care and targeting interventions that will have the largest impact. Establishing the ground truth requires representation for all patients, including the diverse range of interactions they have with the system: physicians visits, diagnostic tests, treatments, complications, and outcomes as well as social and lifestyle factors.

But doing that requires more than just collecting and aggregating data. Simply bringing together more data will never help if it doesn't provide a holistic view of the patient journey, and at a population level. To obtain value from the trillions of new explicit and implicit data points that the healthcare system generates daily requires a framework that provides context, ensures fidelity, and produces clarity of action:

Data collection and analysis must be **patient-centric**, meaning that the fundamental goal must be to understand every aspect of the patient journey — from socioeconomic status to specific disease diagnosis to treatment to outcome — so that all of the potential variables that create gaps in care can be addressed.

Data should be **deep, broad, connected, and timely**. For an accurate understanding of disease, data sets need to be complete, capturing all data for every encounter a patient has with the healthcare system, up to the present moment. That means being able to look at data from multiple different "silos" of the healthcare landscape, including patient charts, labs, prescribing data, genomic data, vital stats from wearables, and social factors.

Data security must be at the center of this effort, with all analysis based entirely on linked but de-identified patient information to ensure the privacy of the patient is protected at all times, while still allowing for critical signals in the data to be tracked at the patient level.

Systems that store and manipulate data must be able to accommodate its **dynamic** nature and ingest fresh information as inputs continually change. This is becoming particularly important as a new generation of wearables starts to populate healthcare databases with real-time vital stats.

Most importantly, healthcare providers, public health officials, payers and life sciences companies need to be able to **act on the data**, drawing out insights that chart the course to real-world interventions that can be targeted to specific patient populations.

With the technology available today, it is possible to combine data from multiple discrete sources – such as claims, eligibility files, prescription drug data, lab results, and EMR data to achieve these goals.

By collaborating with stakeholders from different parts of the healthcare industry, leveraging data from multiple different sources and focusing on building linkages between these seemingly disparate data sets, it is possible to create a comprehensive healthcare map that makes large scale change possible.

From Potential to Reality

From a **provider** perspective, the ability to track each episode of care at the individual patient level and the population level makes it possible to not only deliver better, more tailored treatment, but

also to manage value-based payment models more accurately.

From a **payer** perspective, this holistic view of the patient journey opens breakthrough opportunities to create population health initiatives that intervene sooner, preventing and better managing diseases before they become a runaway cost center.

From a **life sciences** perspective, this longitudinal view sets the stage for targeting precision therapies and developing treatments that are aligned with the most significant needs of specific populations.

Most importantly, from a **patient** perspective, this approach to data creates confidence that the healthcare system – the various actors tasked with taking care of you or your loved one – are taking the best possible action on your behalf to optimize your health. Instead of trying to remember the advice of your diabetologist when sitting with your cardiologist, all while wondering what your insurance will cover, patients will be able to trust the healthcare system to guide them to the best outcomes based on their own unique backgrounds.

It may sound like an idealized vision of a healthcare future that many have tried – and failed – to deliver. But it is achievable today. The fundamental cornerstone that has been missing was the complete picture of healthcare today -- the "ground truth" of healthcare. This complete view could make it possible to build truly comprehensive solutions that address the continuum of patient experience. With that foundation in place, it is possible to optimize healthcare as a whole, fundamentally changing the way we treat disease.

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