HERALDING THE ERA OF HUMAN DATA SCIENCE

The healthcare industry is entering an exciting and especially rewarding era. The dual goals of curing the sick and preventing the healthy from becoming sick are increasingly attainable. In support of these aims, we at IQVIA are exploring a new discipline – Human Data Science – that brings the complexity of human science with data science to improve health outcomes. Human Data Science is the confluence of data about people (as individuals, as patients segments and as broad populations), of the tools and expertise to protect that data while making it usable, and of the scientific background to generate insights. Human Data Science, by combining fields that have been treated as distinct in the past, will allow us to understand what works in healthcare ... and to reimagine what is next.

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Why Human Data Science

Elizabeth[1] was meeting with her doctor to go over the results of her 20-week pregnancy scan. In her late 30s and expecting twins, she was already considered high risk. This was her second 20-week scan, ordered to confirm earlier detection of a birth defect. The OB-GYN and two specialists conferred and agreed that Twin B had a congenital diaphragmatic hernia (CDH) while Twin A appeared perfectly healthy. Elizabeth received multiple options, including experimental treatments. All options intended to adjust the risk of the affected twin, but some put both twins and even Elizabeth at risk. No one could compare the risks of the different options – no known analysis existed to translate the severity of Twin B's type of CDH on outcomes. Elizabeth went to another set of specialists and received different options, but again, no more data on the potential outcomes. This lack of information put the pressure on a non-expert, the patient, to make the most critical of decisions.

Data science has been a key enabler in visions of transforming healthcare. In "Data Science and the Healthcare Revolution," Forbes describes data science as poised to help answer a fundamental question: How do we know what is working?[2] In observing that healthcare decisions are typically based on averages – average patients, average dosages, average compliance – we are not truly optimizing the individual patient's care. By leveraging sources together such as medical records, claims data, and genetics, we can better understand diseases to develop more valuable treatments and find the individuals who will benefit from them.

With total spending on medicines in 2016 topping $1 trillion globally,[3] payers are keen to only pay for what is working. The FDA is also pushing to expand the use of data beyond clinical trials to inform the drug approval process.[4] Other stakeholders have similar interest in using data to improve their internal operations as well. For example, life sciences companies are eager to optimize commercialization costs as precision medicine will drive them to reach more targeted sets of physicians and patients. Then there is speed. The desire to move to more real-time or near real-time decision-making requires knowledge-based tools to make these decisions on scale.

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This excitement about the possibility of applying advanced analytics, large data sets and new technologies to solve healthcare's problems is growing. And yet, the application of analytics developed by, and applied in other industries, is incomplete. Our IQVIA team understands that improving health outcomes has unique issues that need to be addressed while also providing value to healthcare providers, payers and life science partners. That the focus on human health has a limitless array of applications. Our clients, our teams and many other stakeholders are making advances in human science – aspiring not just to cure sick patients but also to prevent disease occurrence. And the potential is even greater. These insights about health can help stakeholders engage with each other to reimagine healthcare, including new care delivery systems and reimbursement models.

Ironically, using Big Data in healthcare also allows us to tailor designs to focus more on the unique individuality and sanctity of people by tailoring decisions.

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HUMAN DATA SCIENCE

What is human data? We often talk about patient records, genomics data and digital data in connection with healthcare and data science. Since human data includes information generated when people are healthy as well as if they become patients, the type and quantity of data is expansive, especially outside of traditional healthcare sources. In fact, many factors such as people's behaviors, which affect health outcomes, are often not even collected in healthcare settings. With the ever expanding internet of things, reframing data to include health information generated outside the traditional healthcare system is critical for developing a complete picture of value and outcomes.

The complexity and lack of uniformity of human data poses unique challenges in data capture, linking and visualization. It also necessitates concerted efforts to ensure privacy protection. In addition, healthcare will increasingly rely on disciplines beyond machine learning such as semantic modeling and inference. In contrast to machine learning, which results in a network of weighted links, a semantic model approach relies on explicit, human understanding of the relationships between words and concepts based on the knowledge domain expertise of human science.

It then crystallized. Human Data Science. Bringing together data science, deep healthcare expertise and innovative thinking to measure and improve human health decisions and outcomes. This integrated approach is going to help us understand what works and reimagine what is possible. Better patient outcomes. More efficient workflow. For IQVIA, it means that we are in the business of mobilizing unparalleled data, technology, expertise and analytics through services and offerings that bring stakeholders together to improve human health.

THE HUMAN FACTOR

Human Data Science is focused on humans as both the beneficiaries of healthcare as well as decision makers. It means understanding the person and those characteristics that define our human condition, which is an integration of our physiology, environment, status, behavior and genetics. And it means being able to understand the whole person, through the various ways they share their information. For example, social media helped teach us why multiple sclerosis patients switch between oral, self-injectable and IV therapies. "Four reasons accounted for more than 90% of all switches: severe side effects, lack of efficacy, physicians' advice, and greater ease of use."[5] This can help physicians consider human preferences as well in order to make the right treatment decisions.

...a new discipline that combines data science, deep healthcare expertise and human data to measure and improve health decisions and outcomes

Human Data Science is flexible enough to use these advances for broad populations and patient segments, down to an n of one. That is because no two people are the same. Even identical twins can be different, as one twin's DNA could differ from the other's at various points on their genomes.[6] Human Data Science allows us to treat an individual patient based on his or her specific situation while leveraging information about related populations to give us confidence in those decisions.

This is a key to thinking about patient centricity. People use the term in a variety of ways, from describing efforts to make experiences better for patients… to giving patients themselves a bigger voice in healthcare discussions… to working with patients as part of the product development process. Human data science does not simplify or focus the definition discussion. But it does contextualize it. It encourages us to think about patients as humans with characteristics, experiences, behaviors and priorities that expand well beyond their interaction in the healthcare setting. Thus, we can better understand what matters to them.

Thus, advances in areas such as patient-reported outcomes, social media and analyzing non-healthcare related factors help us develop better solutions for those patients. It does not provide the "correct" or precise information for a specific person. Instead, it empowers physicians with better insights, serving as an informed consultant. And to move to a more proactive provision of advice instead of reactive analysis once a question arises.

And that type of insight can help inform life science and provider decisions across the continuum. It helps reveal unmet needs and creates a baseline of what current treatments provide. Whereas side effects are always an important consideration, this type of analysis can specify which ones are important enough to change patient behavior. In addition, clinicians and commercial teams can better understand what patients need to know in making their decisions, and clinicians can have that information in treatment discussions with a specific patient. It may also be part of the solution in increasing the compliance of 60 percent of patients on chronic therapy who are not refilling their prescription after six months.[7]

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At IQVIA, we also see providers, payers and regulators as more than companies but as collections of people who need to interact with data in order to make better decisions. A past Harvard Business Review study stated, "companies in the top third of their industry in the use of data-driven decision making were, on average, five percent more productive and six percent more profitable than their competitors." This was true after accounting for labor, capital, purchased services and traditional IT investment. Equally importantly, it was in measurable increases in stock market valuations.[8]

DATA SCIENCE AND HUMAN DATA

Human data cannot – and should not – be decoupled from data science in healthcare. Clearly, skills in R, Python, novel statistical programming in machine learning and Big Data processing software– and machine learning – are vital. But most of a data scientist's time is spent making the data usable. A 2016 Glassdoor study of careers highlights the popularity of data scientists, listing it as the number one job of 2016. Nevertheless, a *New York Times* study notes, "data scientists, according to interviews and expert estimates, spend from 50 percent to 80 percent of their time mired in this more mundane labor of collecting and preparing unruly digital data, before it can be explored for useful nuggets."[9]

Human data lacks universally accepted terms and common data models. A myriad of systems using different identifiers for the same patient makes it challenging to connect the data. At IQVIA alone, we work with more than 800,000 data feeds and 20+ petabytes of unique data with almost two million medical terms to consider. Not just any data scientist can work with this data.

You need a Human Data Scientist.

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The concept of Human Data Science must also respect the critical importance of privacy protection. The growing availability and linking of information and the increased use of analytics will help us realize the benefits of better health, care and cost. However, we need to understand how privacy risk manifests itself in this dynamic environment. Certain health information increases privacy risk and therefore requires greater attention: for example, risks revealed through genetic information; small populations associated with rare diseases; and stigmas associated with certain conditions or treatments. In addition, domain expertise helps us understand how certain combinations of data, certain analytics or the general availability of other data can lead to increased privacy risks associated with health information. Risk-based approaches informed by deep expertise in healthcare, data, privacy and other disciplines will help us realize the benefits and manage the risks. This is another reason why Human Data Science is different than data science generally.

CONCLUSION

For patients like Elizabeth, human data science represents an entirely new future. Her twins were born at 38 weeks. Through keyhole surgery repairing the diaphragm performed on Day 2, Twin B was fortunate enough to have the size of only one lung slightly affected. Years later, no adverse effects of the condition have been seen. The entire family participated in a long-term study, including genetic samples and follow-up physicals to add to the knowledge of CDH and help other families make more informed decisions.

All of this information contributed to generalized research without revealing sensitive health information. By choosing to contribute directly to enriching evidence about CDH, Elizabeth is an advocate for CDH patient registries to help other families with similar experiences. She demonstrates that we all have the power to advance Human Data Science.

This is the time to start discussing Human Data Science. While the underlying concepts have been evolving, they have been kept distinct to the point of missing the real opportunity. It is time to talk about the confluence of data (about humans in general not just healthcare records), technology to mine the data, and deep human health domain expertise to build, configure, and drive technology that comes together to realize the meaning of Human Data Science. It is our objective to offer this opportunity to expand as part of our ongoing passion for using the potential of human data to unleash the power of data science to improve health for humankind.

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