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Cash Cow

Healthcare Data: Creating a Learning Healthcare Ecosystem

Summary: The future of global healthcare requires a shift towards a real-time, digital learning healthcare ecosystem, but how can we use patient data to achieve this goal?

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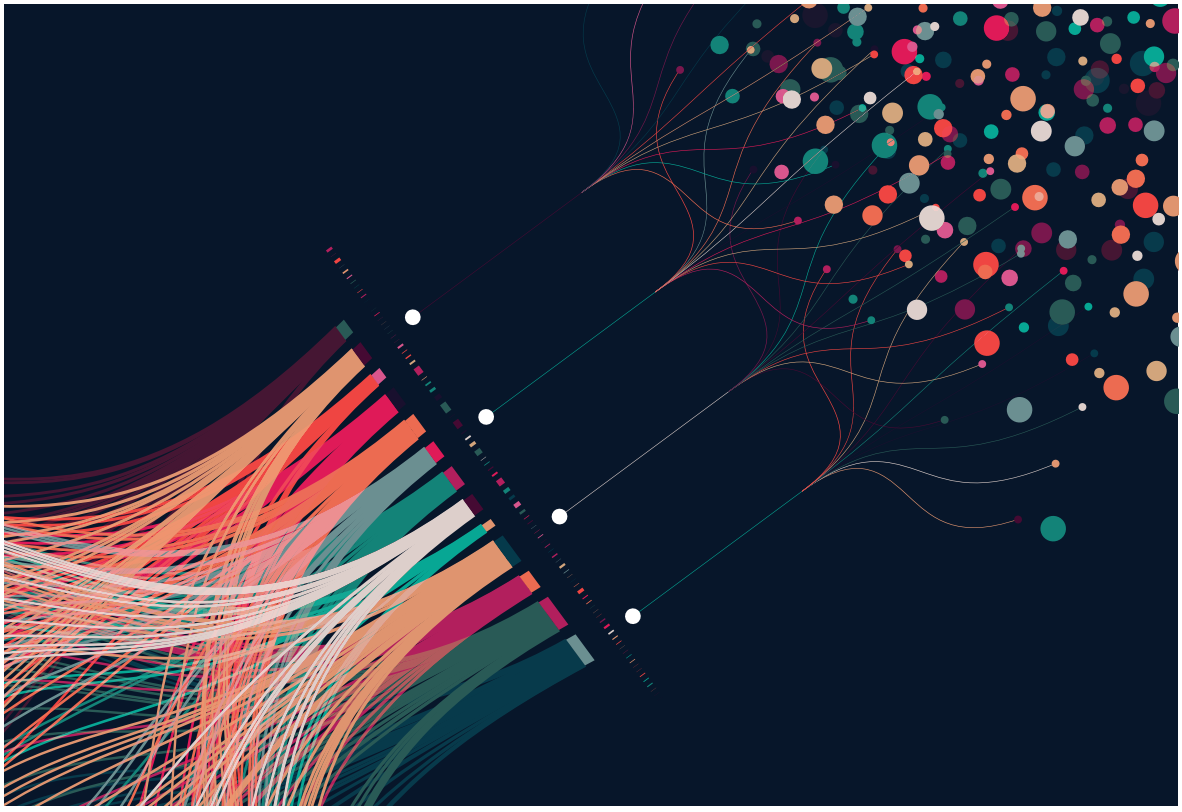

Healthcare data is seen by many as the 'new goldmine,' with many businesses in this field evaluated and sold at a significant value. Flatiron, the start-up acquired by Roche for 1.9 billion dollars, has utilised a specialised Oncology electronic medical record (EMR) system to collect sophisticated data on cancer patients to be used by third parties. Many other companies, including Optum, COTA Healthcare, Concerto Health AI and IQVIA, have built similar business models with different sizes and complexities.

The underlying premise is that once the data is fully de-identified it can be used by third parties for purposes other than the standard of care, empowering discoveries, etc. This has led most pharma companies to invest heavily in 'Real World Data' departments, which purchase, aggregate and analyse data to derive insights and better inform value-based models. Last but not least, de-identification offers a way to collaborate across provider organisations effectively, as Health Catalyst already does for more than 500 hospitals in the U.S. and around the world.

And yet, when we talk about healthcare data we are ultimately talking about patient data, their lives, their disease, their treatments, their deaths.

And often they are kept out of the loop, not benefitting or engaging with how their data is being used. Patients are increasingly demanding a more active involvement in their health, which is difficult to adhere to when the patient data is de-identified. As individuals become increasingly aware of how their data is handled, we will need to evolve more and more towards models that engage the patients and ensure that, wherever possible, they are informed about projects involving their data, and can receive some value back. Many companies are now moving to provide services in this area, such as HUGO Health and Belong.Life, which aims to deliver connected patient communities.

As the model has taken ground, healthcare data has evolved to become its own asset class. When evaluating a start-up, venture funds price healthcare data assets based on two variables: total number of patients covered and the depth/granularity of the data (number of years of follow-up, the richness of data from clinical, to genomics, to imaging, and level of completeness). When surveyed, most patients are willing to donate their data to research, but they are more enthusiastic to do so when they can learn how their data has benefitted others affected by the same disease or the future of research. Through the de-identification process, it is hard to communicate back to the patient any of the findings and to conduct longitudinal studies. Also, there are several uses of de-identified data that are driving highly commercial use cases (eg analysing market share across geographies or demographics for a specific product) which patients would be less likely to support especially if it is associated with a brand or company that has been in the news for the wrong reasons.

This situation often leaves many healthcare providers with highly debated questions:

- Do we rent/sell the data of our patients and is it ethical to do so?
- Do we sell it via one of the intermediary companies that exist already or pursue our own commercialisation route?
- Do we want to limit the permitted uses for our data and how do we enforce it?
- How do we make sure our organisations and patients benefit beyond the revenue stream that this might generate?

So far, different provider organisations have chosen to answer these questions in radically different ways, from some that forbid any commercial activity pertaining their data, to those that exercised it as a pure revenue diversification option, which re-sell it to multiple commercial providers and has no active engagement in the process. But there are some fundamental principles to consider when pondering these questions and how Health Catalyst will build out our life sciences business using our relationships with our providers and their patients' data.

Why Sell Data? Why Not Just Monetise its Analysis?

At Health Catalyst, we have chosen not to sell the de-identified data that we obtain from our clients, though we do provide it to academic entities for non-commercial uses. Our focus is to work with industry on specific projects that will have an impact on patient outcomes and/or advance R&D of new therapies where its use can be tracked.

We are not the only company squarely focused on outcome improvement. Many digital therapeutics companies use data and digital means to improve patients' lives, one example is Omada Health. As Lucia Savage, their Chief Privacy and Regulatory Officer pointed out in her testimony to the U.S. Senate HELP committee recently, there is a growing consensus that a clinical fact (eg your blood glucose reading from this morning) cannot be purchased and sold, as it is a biological reality that belongs to the patient that provided the blood sample. That is not to say companies cannot create revenues by organising or analysing those facts to improve outcomes. But it raises the emerging idea that the underlying data ought not to be purchased and sold.

> "HEALTHCARE DATA IS SEEN BY MANY AS THE NEW GOLDMINE"

Clearly ethical and legal positions differ from one country and state to the other, but I believe we are moving towards a next-generation revenue model in this space that will revolve less around the licensing of the data, and more on how the data can be used to derive value, as healthcare is pushed further and further towards value-based models.

Outcome-Driven Neutral Third Parties Are Key

Healthcare worldwide is driven primarily by three

types of entities: payers, providers and manufacturers. If we accept that data has become a very precious asset that can be utilised in a wide variety of ways, we must also accept that it can be used in more ethical ways (eg improving clinical outcomes for patients) and less ethical (increasing profits for one of the primary healthcare players without improving outcomes or, worse, decreasing clinical outcomes).

Therefore, it would be best if large data assets were not handled by entities that are owned by one of the three elements of the ecosystem, but by third parties focused on improving clinical outcomes. Some of the current players are directly owned by one industry entity, eg Flatiron acquired by Roche, a pharma company, and Optum belongs to a payer United Healthcare. While these companies are certainly aware of the potential conflicts of interest and attempt to mitigate them, a neutral ecosystem would be more conducive to drive the interest of the patient.

Diverse Data Sets

Larger healthcare systems are tempted to think that their data is so extensive that it should warrant its own dedicated internal commercial strategy. Similarly, some hospitals create their own collaborations and partnerships with a few other hospitals to build collaborative datasets. Health systems should resist this temptation. What we routinely hear from pharma and other industries is that they still see a very fragmented picture of a patient journey.

When a pharma company is using the data to understand the patients' pathway and outcomes, they need to see the full richness and diversity. Especially the differences that exist across states, countries, rural and urban environments and race, ethnicity, age, gender and also socioeconomic status. As we move towards a data-centric world and we utilise more analytics and artificial intelligence, the richness of the data used becomes crucial. At Health Catalyst, we already bring together data from more than 150 million patients, with a broad diversity, across several countries and most U.S. states. This also benefits providers as they can leverage much broader populations for benchmarking or for research studies.

By bringing together data from different countries and health systems, patients will also benefit. As an example, many biotech companies are developing new curative gene therapies for rare diseases and they often struggle to find enough patients for participation. If we had global access to digital health information these companies could have a worldwide reach, in real-time, giving hope to many that would otherwise die. Similarly, by comparing and learning from some of the most advanced academic centres, smaller less sophisticated health systems can benefit from improved diagnosis methods and treatment pathways for their patients. Unfortunately, the disparity in how patients are diagnosed and treated is very wide. Digital technologies could significantly bridge this divide.

Data Use for Measurable Improvements

At Health Catalyst, we commit to empowering our clients to obtain measurable improvements which are data-driven, verified and are sustained over time to impact outcomes, efficiency and streamlining of operations. We also publish those improvements to explain how they were achieved methodologically and have so far published more than 200 success stories. As we aggregate data from millions of patients and build a life sciences business we remain focused on ensuring that a pharma-sponsored project delivers improved outcomes for the patient.

> “PATIENTS ARE INCREASINGLY DEMANDING A MORE ACTIVE INVOLVEMENT IN THEIR HEALTH”

For example, these can be the creation of an algorithm to identify patients that can benefit or should avoid a drug intervention, the deployment of training and management tools to adhere to new published clinical guidelines, or the creation of a risk-based pharma-provider contract through us, where payment is issued on the basis of measurable outcome improvement. As providers embark on third party use of the data, and want to adhere to their mission and their ethical frameworks, this guiding principle helps to navigate the ground between ‘doing nothing out of fear’ (never use the data with third parties) and ‘selling data’ (with no control over how it is used). Ultimately, the more patient-centric these models become, the more patients can engage and be informed about their

data, allowing providers to navigate this middle ground more positively.

The Shifting Healthcare Landscape

If we truly care about improving healthcare globally, we must recognise the complex ecosystem we have created around it and how rapidly it is shifting. Employers in some countries like the U.S. are starting to create their own strategies to improve employee health. Start-ups are disrupting many areas, from the natural language processing of clinical notes to the enrolment of patients in trials and the creation of virtual clinical trials. Governments and private payers are shifting their models to value-based care. Manufacturers are investing in digital health as well as building contracts directly with providers for expensive drugs. Global large not-for-profit organisations, as well as corporations, are shifting financial and innovation boundaries, rapidly giving access to digital health to economies in the developing world. Given the pace of change, the ability to coordinate and interact with other organisations under the premise of a very well-defined purpose is fundamental and requires open access to data, purpose-driven revenue models, and utilisation of digital technologies to solve future challenges.

Moving Towards a Global Learning Healthcare Ecosystem

One day a mother in a small town in Indonesia will wake up to find her son severely sick with very unusual symptoms. She will pick up her phone and activate a video chatbot, describe the symptoms and shoot a video of the child. The chatbot will access an open and intelligent digital ecosystem of knowledge, data, expertise and capabilities worldwide and determine the top three most likely diagnoses in real-time. Three of the top specialists will be notified and will create a virtual board to determine a single diagnosis. If further tests are needed they will be ordered automatically and delivered efficiently by drone or at a locally affiliated nail salon.

Once the diagnosis is clear, all treatment options will be evaluated, taking into account personal and logistic factors, which will then be communicated to a local community worker to explain the pros and cons. When the mother exercises her choice, all the necessary supplies, logistics and appointments will be scheduled and sent to her and her community worker for acceptance or modification.

If the mother chooses a clinical trial, as soon as her son's outcome is measured in real-time and achieves statistical significance, it informs all other organisations, doctors and patients involved in similar trials to modify their design and the risk profile communicated to the patient. All payments have been handled under a Netflix-like, subscription-based model and adjusted based on the clinical outcome, income and insurance coverage of the patient in question.

Conclusion

We have all the elements required to create a learning healthcare ecosystem. We have learnt to digitise biological and medical data, we have wearable devices, chatbots, global virtual presence. So far, they all live in very small silos, as each organisation focuses on their turf. If we can all shift towards the massively transformational purpose of a real-time, connected, digital learning healthcare ecosystem, our children and grandchildren will hopefully see a world where most diseases will be prevented, diagnosed and treated for all citizens and hospital stays will be a thing of the past for most patients. ■

KEY POINTS

- Patients want to be more involved in their health, this can be difficult to implement when data is de-identified.
- Next-generation revenue models will start to focus on how data can be used to derive value instead of the data licensing.
- Large data assets should be handled by third parties focused on improving clinical outcomes.
- The richness of the data used in analytics and artificial intelligence is crucial.
- Health Catalyst wants to empower clients to obtain measurable improvements in their healthcare systems.