DSST INSIGHTS

Musings from the front

The human data source

Introducing “Singular Medicine”

About the author

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Liam Holohan is the CTO and founder of DSST, a UK company that has created the **noink platform**. **noink** allows users to generate and take control of their real world health data for themselves and their loved ones, irrespective of any particular medical condition. Liam has over 25 years of experience in technology spanning financial services, defence and healthcare.

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About the series

This series of insight papers reflect the insights and lessons learned from working with technology in healthcare. They are based on experience of real-world delivery of technology and lessons learned. The series of papers range from broad national level problems to specific technology challenges within healthcare systems.

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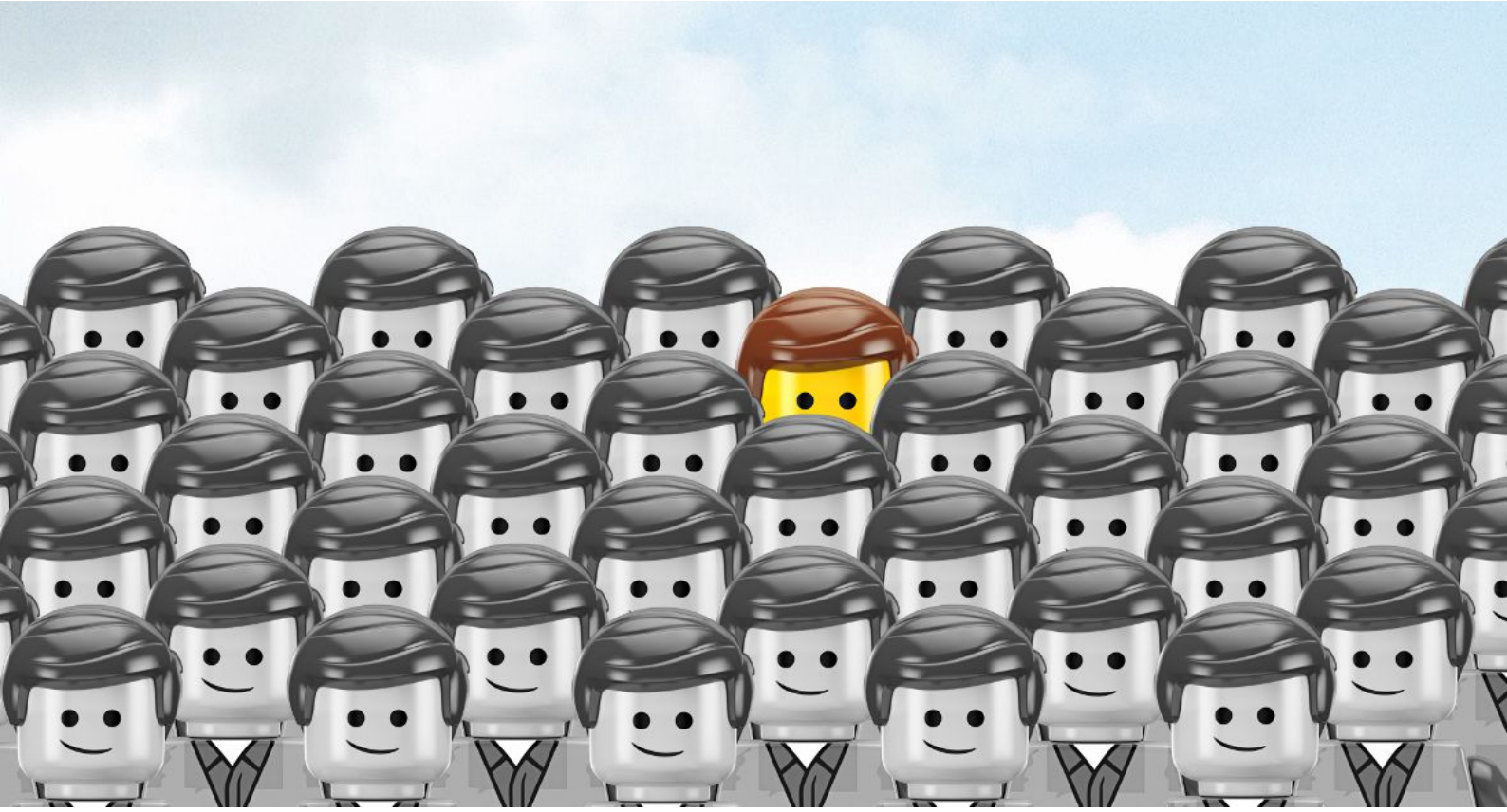
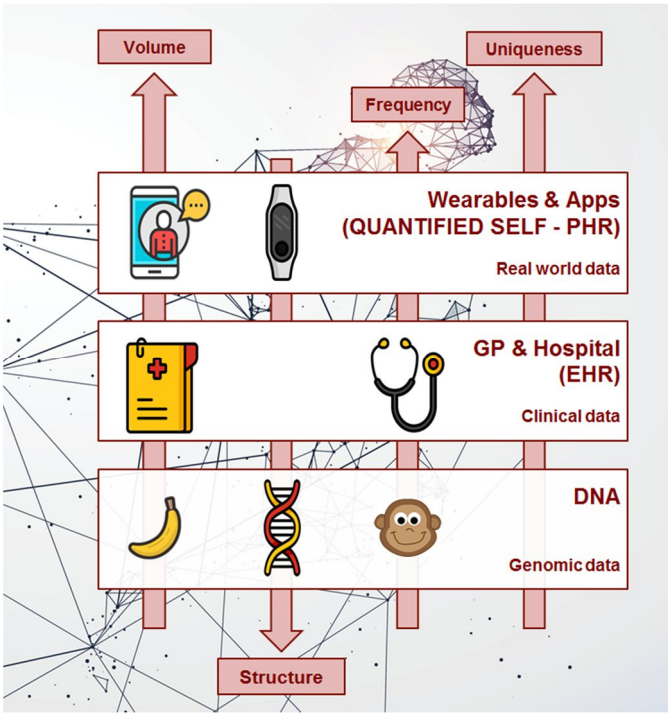


The human data source - Introducing Singular Medicine

In a previous article on mHealth[1] We hinted at a method of care delivery and called it **Singular Medicine**. This article will flesh out the thinking behind this and explain the future possibilities for care delivery. To get there we will look at what health data is provided to clinicians and researchers in delivering and improving care.

The human data source

From a data perspective we can consider patients as a data source for all healthcare delivery and research. Like other areas of data science, there are ways to classify this data in terms of structure, volume, change frequency and uniqueness. This is summarised in the following diagram:



We are considering this data as originating from 3 distinct data layers. A genomic, clinical and real-world data layer. Each layer has particular properties and characteristics that we can examine.

1 - Genomic data layer

This is our DNA, Gene therapy[2] aside; this is what data scientists would call **static data**. It does not change for an individual and slowly changes in humans at the speed of evolution; hence we consider it as having low change frequency. It is highly structured (23 chromosomes, 4 Nucleobases giving lots of combinations, ~3bn in humans but is not particularly unique[3]). Being highly structured and static means the volume of this data is less of a defining feature for data processing[4].

2 - Clinical data

The next layer up is clinical data, housed (hopefully) in an EHR[5]. This is hospital and GP medical records, There is more of it, it is less structured than genomic data and produced more often per person. This is the **core data used in healthcare delivery today**.

The use of data from the genomic and clinical layers in concert for healthcare delivery or clinical research is what is called **Precision medicine**[6,7]. It is hoped to create efficiencies in care and better therapeutics from these 2 data layers. However it should be noted that using these 2 data layers does not currently address the unique needs of an individual. Precision medicine is still not about an individual but a **cohort** within the general population.

3 - Real world data

Finally we have the real-world data source. This is created at a much higher volume & frequency. The capture of this data is currently very ad-hoc via a combination of mHeath and wearable devices (i.e. unstructured). Think of this as healthcare telemetry per person, an attempt at a quantified self[8]. This data is truly unique as it quantifies your lived experience within your environment. Not the prison of your genes or the occasional doctor visit.

The ad-hoc nature of this data capture at present is simply a result of the newness of this industry and the sheer number of wearable (IoT[9]) device manufacturers. This will eventually give way to more standards compliant data outputs across all device manufacturers and better integration with current clinical systems.

This means it will become more structured over time as standards are adopted. In an ideal world we will get to a position where real- world data is high volume & frequency, highly structured data sets that are unique to an individual. Upon clinical acceptance[10] of this technology, integration with clinical systems and robust AI; we will achieve **Singular Medicine**.

Real-world data has clinical and scientific value, largely ignored in professional healthcare delivery

Singular medicine

We believe the logical conclusion to future healthcare delivery is the inclusion of all these data source layers into the delivery of care for an individual. The use of combined genomic, clinical and real-world data in a clinical setting is what we term **Singular medicine**. This is based on the belief that real world patient generated data has both **clinical and scientific value** (currently largely ignored in professional healthcare delivery). These real-world data sources will be the most valuable for the goal of truly person-centric care.

At the very least singular medicine could provide:

- Extreme **care pathway optimisation** for particular diseases. Giving an efficiency gain to current healthcare systems. This addresses the fact that while most diseases present differently across patients (even within a particular cohort), their care pathway is far more rigid and possibly not optimal for an individual.
- Enrich many phases of **clinical trials**. The 21st Century Cures Act[11,12] which is part of the FDA's legislative framework for drug approval, acknowledges the value of real-world evidence (patient generated data). The systematic collection and processing of this data can give internet scale observational studies. This could not only improve clinical trials, but itself lead to clinical practice improvement.
- Assist with the **re-purposing of drugs** for other conditions via at-scale observational studies. This has a direct impact on rare-disease suffers in particular.
- Move medical care from a reactive discipline to a more **preventative** one, fulfilling the primary goal of public health organisations worldwide. This would of course rely on both systematic collection of data and robust AI[13] in accurately detecting leading indicators for particular condition exacerbations.

Further reading:

[1] - https://www.noink.me/cws/news/insights_press.php. Article entitled ***The problem with mHealth***
[2] - https://en.wikipedia.org/wiki/Gene_therapy
[3] - Human DNA is very similar across all populations. At a genomic level you are 99.9% the same as every other human, 99% Chimpanzee or 60% banana
[4] As the data is static, even with a high volume the throughput of processing can be high. Latency can be considered the amount of time for a data item to be processed. Throughput is the amount of processing possible. It is possible to have very high throughput data processing even with high latency data types.
[5] - **EHR** (Electronic Health Record), are digital systems used by care providers to collect and store patient and population health information see https://en.wikipedia.org/wiki/Electronic_health_record
[6] - https://medlineplus.gov/genetics/understanding/precisionmedicine/definition/
[7] - https://en.wikipedia.org/wiki/Precision_medicine
[8] - https://en.wikipedia.org/wiki/Quantified_self
[9] - https://en.wikipedia.org/wiki/Internet_of_things
[10] - https://www.noink.me/cws/news/insights_press.php. Article entitled ***Move fast and don't break things***
[11] - https://www.fda.gov/regulatory-information/selected-amendments-fdc-act/21st-century-cures-act
[12] - https://www.congress.gov/114/plaws/publ255/PLAW-114publ255.pdf
[13] - https://www.linkedin.com/pulse/ai-stars-health-data-tomatoes-liam-holohan/