



## Emerging issues

*Lastly, across our discussions we can see several issues that are fast emerging on to the radar. While not yet equally visible, nor having the same significance, in every location, there are nevertheless topics over which there is increasingly hot debate. They are issues where there is yet to be clear consensus on the challenge and some may have very different political and commercial implications in the future. They are however also topics that could have manifest impact on how the future of patient data actually plays out, how and where greatest benefit can be achieved and who may gain the most. These are matters about which many organisations will need to both understand the core drivers and develop a firm point of view on so that, as we move forward, collaboration can occur between the key parties – those who can deliver the ambitions around a more patient centric approach to healthcare and its intrinsic use of data.*

These four areas are:

**Data Sovereignty** – More nations seek to restrict the sharing of health data beyond their borders. This is driven by concerns around national security, the desire to protect commercial interest and the different cultural attitudes to privacy. Consequently, there is a corresponding push-back against some global ambitions with India and China potentially gaining the upper hand.

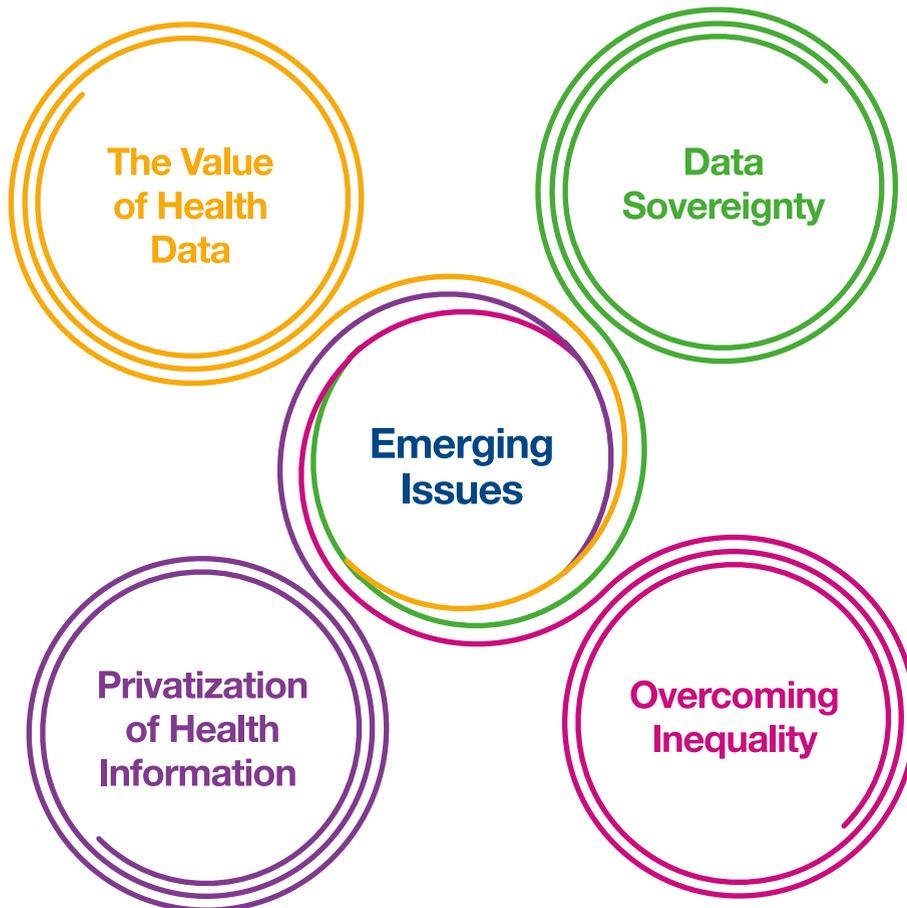
**Digital Inequality** – As advances roll out, there is growing concern around those who are not included in the “system”. Several hope that, with more and better data, health inequality can be reduced but others see a widening divide between those with access to technology and those without. Adapting to change is a real challenge for healthcare workers and patients alike. To help drive progress, many want outcome-based measures to be standardised, but many regulators are

behind the curve. How countries deal with these is as much political and commercial as it is technological.

**Privatisation of Health Information** - The privatisation of medical knowledge and the increased use of new ‘secret software’ challenges the potential for healthcare data to be more open source or, at least, shared within an agreed governance system.

**The Value of Health Data** – It is clear that patient data can be used to drive both social and economic benefit. As public understanding grows so will consensus about its worth. As this shift happens, those who can best grasp its multiple roles in, and value to, society, and render these things comprehensible to others, will likely have the more powerful voice.

Each are explored in the following pages.





## Data sovereignty

*More nations seek to restrict the sharing of health data beyond their borders. This is driven by concerns around national security, the desire to protect commercial interest and the different cultural attitudes to privacy. Consequently, there is a corresponding push-back against some global ambitions with India and China potentially gaining the upper hand..*

Data sovereignty refers to the fact that data in a cloud service provider may well be subject to the jurisdiction of more than one country.<sup>193</sup> This has specific implications for the health sector. As more organisations seek to integrate multiple patient data sources from around the world, accommodating local and regional rules is a growing concern. In parallel, as more data moves to the cloud, traditional geopolitical boundaries are being challenged and questions are increasingly being raised about where exactly it is being stored, and under what jurisdictions it lies.

From a health research perspective many believe that access to global databases could have the potential to transform real-world evidence in medicine and healthcare. For example, terabytes of unstructured data from many different, real-world data sources ranging from EMRs, genetic profiles, phenotypic data and mHealth devices could be explored in order to find unexpected patterns and identify possible new solutions. Genetic data in particular can provide deeper insights into the nature and size of the sub-population groups who could be served by new treatments. Many new healthcare innovators, from Alphabet and Amazon to DigiMe and iCarbonX, are keen to exploit this

global data opportunity. By definition they all assume they will operate in multiple markets. However, this is not a given. As one expert noted *“the internationalisation of data is not guaranteed.”* To be effective in the future organisations should be cognisant of, and sensitive to, the sovereign requirements of other countries. In a world of rising nationalism and increasing scepticism about the benefits of globalisation, much of which is negatively associated with companies based on the west coast of the US, this is no easy task.

Although open to the benefits of big data sharing in healthcare, many experts are also cautious about its implications and agree that in many regions *“we will increasingly have to consider the issue of data sovereignty.”* Certainly, several governments are deploying a variety of discourses, policies and practices in order to constrain what many wish to be global to the local level. More nation states are claiming sovereignty over both the technological architecture that enables transnational information flows, and the communications themselves. Academic literature and public policy refer to these claims of *“supreme authority”* over ICT and its content respectively as technological sovereignty and information sovereignty. These can often overlap since the differences between them are not clear-cut.<sup>194</sup>

In its 2018 Tech Trends report, Deloitte highlights data sovereignty as a key issue for the future and suggest why different regions are taking alternative views.<sup>195</sup> “In Northern Europe historical context related to civil liberties, privacy, and nation-state data collection may make the topic of data sovereignty particularly sensitive and highly politicized. Across the Americas, Europe, and Asia Pacific, active discussions are under way between the government and private sectors to shape regulation. In all corners of the world - including South Africa, Italy, Brazil, and China - public providers are racing to build ‘national’ clouds in advance of evolving privacy laws. Region-specific timeframes and barriers reflect these considerations, indicating either the expected window for

investments and policies to mature or a cautious buffer due to the complexities involved.”

Data sovereignty is generally allied to the principle that data stored in a country is subject to its laws and regulations. In Europe an additional layer of protection is added because the private data of citizens falls under the sovereignty of the EU as well as that of sovereignty of their individual nations. With its wide mandate, the European GDPR legislation, covering all EU data irrespective of location, is also setting a new benchmark for non-EU jurisdictions. This is particularly the case for several US based companies as, in the main, much European personal data is currently processed by US service providers such as Cisco, Google, Facebook and Microsoft. Some data sovereignty regulations, for instance Russia’s 2015 On Personal Data (OPD) law, go even further and not only specify who has power over data but also mandates that any data pertaining to a country’s citizens must physically reside in that country.

Throughout our conversations it became clear that geography and national identity are becoming of increasing significance when considering the sharing of data. In some areas, such as Singapore, the primary issue was around security and how to protect its citizens if personal data was housed outside the state. Indeed, Singapore offered perhaps our most extreme view in favour of maximising data sovereignty by arguing the case for limiting data sharing on the basis of national security: *“Our existing laws restrict the sharing of personal data (including health data) beyond the national boundary”* plus there is a potential risk that *“future warfare may use health data”* and as *“no-one has yet worked out the extent to which patient data can compromise government security”* so it cannot be shared.

By contrast, in South Africa data sovereignty was more a concern around “the risk of commercial exploitation.” Here, the government has restricted the sharing of blood samples with US based

companies for genetic profiling. The worry is that 'cheap' African data can be used as a valuable reference set that can then be exploited commercially. It was suggested that one reason for this may well be due to the US laws around privacy and genetic regulation. In Sydney, as a follow-on comment, it was observed "US privacy legislation only protects US residents' data and not that from other countries' citizens."

Elsewhere the argument for greater data sovereignty falls between these extremes but it is perhaps in India where the most significant actions are now having impact. There, the planned legislation around the use of personal data (best summarised in the India Stack<sup>196</sup> proposal - the ambitious and controversial project of creating a unified software platform to bring India's population into the digital age) sees the significant repatriation of Indian citizens' data taking effect in the next few years. This is similar to the Russian OPD legislation and current practice in China. If this goes ahead as expected, India may well also restrict personal data sharing to within its national boundaries, where it can then be managed and, as best suits, monetised by Indian, and not foreign, companies. The same principles will apply to financial and health data. In Europe questions around sovereignty are intrinsically tied up with the those around privacy. In the US, however, experts were more confident that this could be addressed and therefore supportive of the benefits of openly sharing health data globally.

Concern was specifically expressed in the UK which has the world's largest publicly funded health service and, as such, one of the most comprehensive health datasets. Its patient records are, maybe, uniquely suited for driving the development of powerful algorithms and, so, several felt they should be protected from commercial exploitation. *"What you don't want is somebody using NHS data as a learning set for the next generation of algorithms and then moving the algorithm to San Francisco and selling it, so all the profits come back to another jurisdiction."* To go some way to addressing this, NHS Digital has begun to provide guidance on how

care providers can best choose offshore public cloud services to store patient data.<sup>197</sup>

Some have also argued for a more equal geographic distribution of the value extracted from data. Currently, most big data refineries are based in America, or are controlled by US firms, and it is through them that a significant amount of innovation takes place. As the data economy progresses in other markets this may not continue. Europe has, for instance, proposed a digital tax. Others disagree. Some in our San Francisco discussion suggested that the fact that patients will increasingly own their own data is a major driver against greater data sovereignty. *"They, and not federal government can choose what happens to their data."* One view was *"this sounds a bit Big Brother and could limit cross country sharing and movement of data."* Moreover *"it seems as though other countries are using data sovereignty as an excuse for not making progress"* and *"we have bigger issues to address."* In addition, *"worrying about this is like moving the deckchairs on the Titanic – legislation is 5 years behind what is already happening."* The feeling was that while other countries may be concerned about data sovereignty, *"in the US we are moving ahead and are more focused on making better use of our healthcare information."*

Given the strong and varied views on this pivotal topic, it is clear that the ambitions for international companies to act as conduits for multinational, or even global, shifts towards more patient control may well need to be modified within more localised priorities. As trust between nations becomes increasingly challenged and fears of cyber-attacks are on the rise, perhaps it is unsurprising that data sovereignty has become a priority for some. Should the protectionist approach become more widely adopted it may well give highly populated countries such as India and China an advantage when it comes to medical research. Both countries have populations of over 1.2 billion, increasingly connected people. Access to their data will provide a wealth of information and understanding. Those in smaller markets may find it hard to challenge.





## Digital inequality

*As advances roll out, there is growing concern around those who are not included in the “system”. Several hope that, with more and better data, health inequality can be reduced but others see a widening divide between those with access to technology and those without. Adapting to change is a real challenge for healthcare workers and patients alike. To help drive progress, many want outcome-based measures to be standardised, but many regulators are behind the curve. How countries deal with these is as much political and commercial as it is technological..*

While greater use of more and better patient data is the global ambition for everyone, there are several issues which may well constrain adoption and impact. Although the ideal is that the better and more efficient use of patient data will benefit everyone, some indications suggest, in the next decade at least, its impact may well only benefit the few. Across all of our discussions, there were three key areas of concern – access, skills and standards.

### **ACCESS INEQUALITY**

Globally, there is great hope that a more digital approach to healthcare will both increase efficiency and increase access. Given that nearly 70% of the global population still does not yet receive decent healthcare, there is a strong belief that data-driven technology has the potential to transform the situation. The question is how much? Telemedicine is already having significant impact and seeding

wider change. Across Africa and Asia, the addition of more intelligent systems is expected to further improve remote access. At the same time, while the focus is often on developing economies, there may be just as many challenges in improving access in the ‘developed’ world.

The risk of a widening healthcare divide was highlighted as a major concern in several locations.<sup>198</sup> Take South Africa for example. It has one of most advanced private healthcare systems on the continent and yet many believe that the public health service is unfit for purpose with a doctor-patient ratio of 0.8 per 1,000, lower than Brazil, Russia, India and China. In Johannesburg the view was that *“ineffective government support and inadequate investment in the public sector means that the majority will remain without access to health data that is only available through private healthcare systems.”* Priority investment by the private sector and poor management from government result in some feeling that that access to new technologies and services for the masses may well be 5 to 10 years behind the leaders. Elsewhere, others added that for many *“economic and social challenges are leading to more inequality of outcomes.”*<sup>199</sup> Participants in Dubai also recognised the challenge of extending healthcare reach beyond the private sector seeing that *“we have lots of new technology solutions which are designed to improve patient care, but many are in their infancy. They are not reaching those who most need them, and the cost of supply is a major issue.”*

Another view was that many developing countries have less data silos than in Europe and the US and so, as with mobile payments a decade ago, they have the opportunity to leap-frog legacy systems. The rising penetration of smartphones is having particular impact as shown in the graph below. Several see that developing countries will *“go mobile first and challenge existing models.”* Clearly issues around literacy and numeracy add an additional layer of complexity but in India there was great optimism that healthcare is on the cusp of change. Again, much hope is being placed on

India’s centralised data system, Aadhaar. In London, it was proposed that *“Africa can teach the West a lot about health care”* as mobile data access in key groups (e.g. refugees, migrants etc.) has been shown to deliver significant benefit: *“Mobile platforms will increase accessibility.”*

Richer economies also have challenges. An important early US-focused insight was that *“while many health apps are used by the healthy and the worried well, reaching the 5% of patients that incur 50% of healthcare costs remains a major challenge: Comorbidity will continue to drive the greatest spend.”* In Sydney, it was suggested that there is no lack of data on the 5% with comorbidity who suffer from multiple conditions today. The question going forward is whether more information will enable us to take better care of them or indeed enable patients to take more care of themselves? If the answer is no, should we consider a different approach? As highlighted in the map below, there are many countries where there are a large number of adults with three or more chronic conditions which drive compound impact – both on the ability to treat and the costs of doing so. While the US has over a third of its adult population in this category, across many OECD nations the average is 1 in 5. As a response to this, in Brussels it was suggested that *“maybe we need to change the narrative around digital health and provide more incentives to use technology at key points”* – with the ambition of *“better managing (and preventing) the transition from healthy to ill.”*

## DRUG PRICING

Several experts see that more transparent data across healthcare could have a major impact on pricing and therefore access to important drugs. If we can all see the price of drugs in different markets, will the advent of ‘international prescriptions’ make purchasing easier – and what role will technology companies like Amazon (again) play here? What happens when there is total transparency of cost to the patient and they can choose to buy from anywhere?

Moreover, given that over-prescription, especially of antibiotics, is such a problem today, if healthcare is rewarded more on outcomes, as is the case in some instances in China, will doctors and providers including pharma be paid when their treatment works but not when it does not? *“If only 40% of cancer drugs work – why charge if they don’t bring benefit? How can this be arbitrated? Will greater transparency of impact (and so reimbursement) change GP prescription behaviours?”*

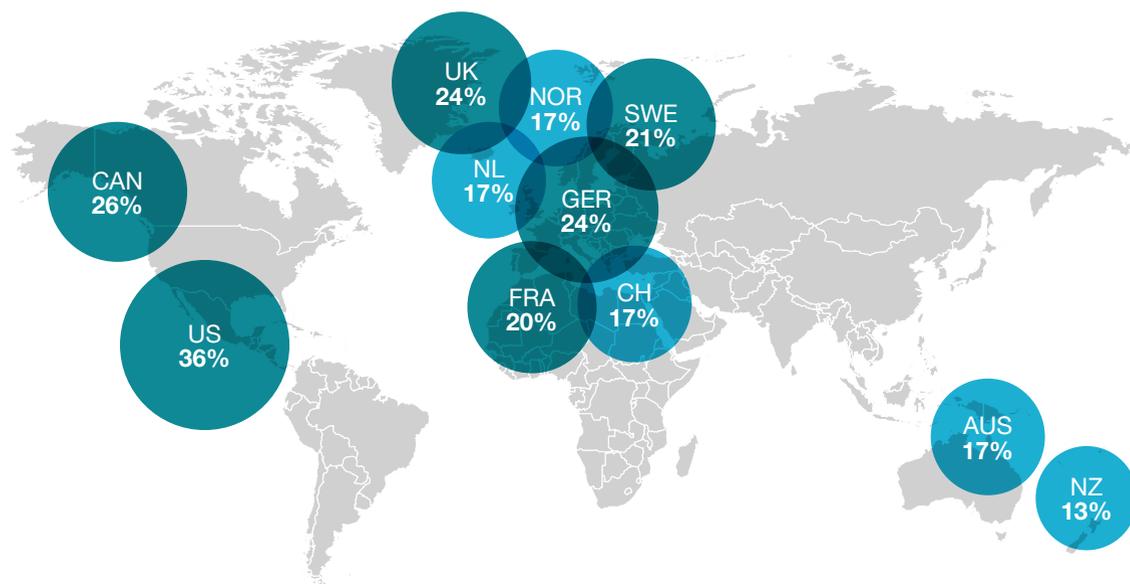
## AGEING

A specific focus in Boston was on how to give more support to the ageing population and enhance care in the home. There is a *“growing ‘isolation epidemic’ of people living on their own with no social infrastructure and little understanding of technology.”* Maybe *“over the next decade this will change with the wide-scale adoption of more monitoring, more in-home sensing and a broader range of*

*technology enabled human support. As a result, the care-giver will be able to better understand the healthcare needs of a patient before they even walk into the room.”* Greater understanding of an individual’s health and lifestyle gleaned through regular monitoring and data collection at home will provide context and richness that in theory should allow more focused treatment. In addition, *“there will be greater transparency of needs, a rise in care coordination and navigation and more care delivered in the home than in medical sites.”* Key enablers here include *“information integration between community and medical providers, a rise in co-living and co-habitation, better resource reallocation and more risk-sharing.”*

No one expects technology to deliver the solution to what is the cultural problem around how richer societies in particular treat the old. That said, many felt at least it could in some way assist by relieving some of the difficulties of isolated living.

## Older Adults With Three Or More Chronic Conditions



**Source:** 2017 Commonwealth Fund International Health Policy Survey of Older Adults

## LITERACY AND UNDERSTANDING

However, underpinning much of the potential benefits of increased use of data in the delivery of healthcare are other concerns about the level of public understanding of health issues and how best to communicate in order to influence positive behaviour. For example, some in our workshops wondered how literate you need to be to understand how to manage your health? In Oslo, the question was raised as to whether *“the typical citizen understands the concept of probability”*, while in San Francisco it was highlighted that the average US citizen has a reading level of grade 5 or 6. Indeed, over 20% of Americans are *‘not able to locate information in text’* or *‘integrate easily identifiable pieces of information’* and only 7 in 10 read books.<sup>200</sup> A core request therefore is how best to communicate with patients and how much information should be shared so that they can reasonably be expected to make choices. Some wondered what should be filtered. Everyone agreed that if patients are going to be given more access to their own health data, we still need to work out who is going to explain what it actually means.

## DIGITAL SKILLS

The ability to understand and communicate the meaning of large amounts of data is just one of the skills needed in the future provision of healthcare. As our discussions revealed there are several emerging areas of concern. Many expect the way doctors and other healthcare professionals care for their patients will change over the next decade. There will be *“job transformation in every aspect of healthcare. In the future, there will be fewer higher paid clinicians per capita but maybe more nurse practitioners. There will be clearer standards for care and better training programs for care givers.”* As more information is made available to augment individual knowledge, some propose that doctors will become more focused on the softer skills, caring for the psychological effects of illness rather than the disease itself. Others consider that healthcare will become even more business focused – one hospital manager highlighted that *“we are increasingly recruiting business analysts rather than tech expertise*

*as the skills we need are in joining together issues and looking at workflows.”*

This could all significantly impact the amount and type of training required. Diagnostics for example is a major area for tech innovation especially in countries such as India where there’s just one doctor for every 1,700 people. In specialist care, that gets even more compounded. Cloud based analytics is one way around the problem and companies like Tricog (INSERT TRICOG CASE STUDY) are making a real difference in this area. The company uses advances in computer science, communication, algorithms, and the cloud to amplify the work of specialists. In the US neurosurgeons are already talking about halving the time to qualify by focusing earlier on key specialisms. *“How many fully trained (over trained?) HCPs do we actually need? If we can work that out, then we can significant lower the cost of health care”* was an opinion in Dubai. *“In Ethiopia healthcare officers can undertake surgery after only 4 years of training.”* As appendicitis is such a leading cause of death in some parts of Africa, having someone able to perform just an appendix operation (and nothing else) could have considerable impact. So, does more personalized medicine mean more specialized doctors? In India, Narayana Healthcare surgeons perform hundreds of cardiac surgery operations each week (compared to tens in many facilities in the West) and so they can specialize within cardiac surgery to a greater degree – focusing on performing multiple identical operations.

From the discussions around AI, the short-term view is very much about augmentation and clinical decision support but, in the longer-term, jobs may well be replaced. This may be very dependent on geography: In South Africa, where there is a huge scarcity of trained doctors, the view was that *“AI would not replace the GP rather it will support them.”* In San Francisco it was pointed out that *“AI will have a role to play in helping to overcome physical burnout of clinicians – and much of this burnout is currently coming from excessive documentation.”* In Boston, one point was there will be an ongoing shortage of care-givers so can AI help to upskill them?

Long-term there is concern about what happens when machines are more effective than humans in fields such as radiology, pathology, pharmacy and even oncology. In Frankfurt, it was suggested that *“there is a risk that doctors will become too dependent on AI and will lose necessary skills to act without the robot – an unlearning of basic physician’s skills.”* There was also expectation around the potential of AI to “augment the process of hiring and training people, as it will create a supportive ‘infrastructure’ providing on-demand, on-time training and support.

Despite this optimism, many expressed concerns about how medical education is falling behind medical technology. In Oslo, it was pointed out that students are still being trained to hand-write prescriptions (or recipes) even though the system has gone digital – so there is already a disconnect. In addition, it was felt by some that *“doctors are not being asked to be part of IT projects – they are not invited and are also too busy keeping up with the day-to-day to be able to spare much bandwidth”* as such, in some key areas a digital skills gap is building up. In Brussels, a view was that *“digital literacy is*

*an ongoing problem and currently the curriculum does not accommodate data understanding.”*

This skills gap may well delay the adoption of new approaches. As such, as was agreed in several locations, *“re-skilling and up-skilling may become a priority focus for many systems.”* Healthcare professionals need to have a willingness to *“learn, unlearn and relearn”*. Ultimately most agreed that the problem is short term, *“the next generation will be more technically literate”*.

In Boston, significant change is expected as the US caregiver to senior ratio seeks to change from 1:7 (now) to 1:3 over next 20 years. There will be new innovation opportunities and business models. Similarly, *“the US crisis may be eased when job roles are separated out more cleanly so that CNAs (Certified Nursing Assistants) are supplemented by lower skill substitutes.”* Here ‘social prescribing’ is also expected to become more prevalent, with medical providers being able to prescribe and then deliver non-medical interventions. However, maybe, as shown by the ‘community coach’ model,<sup>201</sup> the most valuable role for care workers will be how to deliver behaviour change.



## AGREED STANDARDS

As one means to help bridge the gaps, many highlight the role of digital standards. There is universal agreement that effective multi-sector and ideally multi-national (if not global) standards are a key requirement for the changes taking place around the use of patient data to have lasting impact. Public concerns around the unregulated use of data are growing and, unless controlled successfully, fears concerning how personal data is gathered, stored used and shared will become more pointed. Within this, the two primary areas of focus have been the need for standard measures and the importance of informed consent.

Improved, shared standards to measure health outcomes are believed to be a fundamental need in all locations. In part, this is driven by the predicted shift from payment for intervention (e.g. pills and the 'Rx based revenue model' for pharmaceutical firms) to payment-on-results: *"The healthcare market is evolving from a utilization marketplace to an impact marketplace."* Funders, providers, insurers, regulators and data platforms all agree that as momentum grows so does the need for standardisation of health outcomes. *"We will have to work out a new normal."*<sup>202</sup> Agreeing both what this should be as well as some broader digital standards, is, however, not easy. There are major commercial implications that may impact future business models.

The rapid adoption of new technologies has meant that current regulation is fragmented so needs to be consolidated and, as far as possible, future-proofed. Many agree on the requirement for a convening body to show leadership either on a regional basis (e.g. the EC) or from a global perspective (e.g. WHO). However, there are fundamental differences between European and US regulation on issues such as privacy, data protection and citizen's data rights. Most consider that regulators, almost across the board, have reached a bit of a stalemate. To address this, one suggestion was to encourage self-regulation using different industry bodies to gain consensus and then seek alignment across the

sector. Singapore is already taking action but, while the models that are being adopted are proactive and ambitious, many felt it was unlikely that they will be accepted as a global standard.

Some advocate a cross-sector body which includes wellness in addition to sick care in its remit. Others fear that too much regulation early on could inhibit innovation – after all, look what happened to driverless cars. It will be slow work. In a 2016 UK discussion, it was acknowledged that *"legislators and funders of healthcare tend to be risk averse, there is a regulatory desire for certainty with a continuous concern about unintended consequences of change."* In South Africa, the Protection of Personal Information (POPI or POPIA) regulations were highlighted.<sup>203</sup> *"Anyone who processes health information has been invited to comment on whether the regulator should prescribe rules and what those rules should be."* In Germany, the view was that "we need networks, vocabulary and common standards to make sharing possible: We need open standards." Toronto added the requirement for *"greater evidence-based guidelines tied to clear outcomes."*

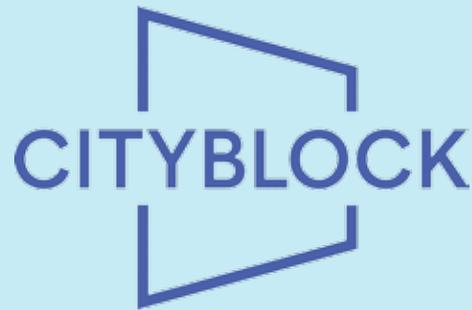
## INFORMED CONSENT

Given the complex data flows, clearly articulating what is meant by informed consent is also challenging – so some see that an alternative is needed: An accountability governance model incorporating ethics and respectful data use is considered by some as a compelling substitute or complement. In Mumbai, the view was that *"if we make the end-user the custodian of data, there may be a trip wire in place."* But a key question is the extent to which poorly-educated, or extremely ill people, will really be able to understand what they are being asked to permit? The India Stack proposals<sup>204</sup> include at their heart a consent layer *"which allows data to move freely and securely to democratize the market for data."* Concerns were raised that, with over 1.2bn Indians coming into this framework, there will be a significant number who may not be aware what they are giving consent to.

This topic was also explored in depth in Sydney. *“The current consent system does not work given the growing predominance of technology. The existing regulation is not fit for purpose.”* In addition, *“in Australia the current privacy act<sup>205</sup> and state legislation is very fragmented.”* Moreover *“there is little consumer understanding of consent – particularly around the use of secondary data and the difference between opt-in an opt-out.”* Looking ahead it was proposed that *“new regulation will be influenced by others including the EU’s GDPR highly granular approach<sup>206</sup> versus the US which is more hands-off.”* The view was that the EU approach and its wider global influence could well prevail in most countries (beyond the US, India and China).

While some put faith in the ability of new privacy-enhancing technologies to address some of the core requirements, and so move ahead of regulation, by and large, the need for more proactive regulation around patient data is a common request and so one that should be central to many future strategies. In the US, *“to provide better services while dealing with the challenges of privacy and cross border differences in regulation and operating models”* is seen as no easy task.

## CASE STUDY:



*“We believe health happens locally, so we put individuals and their communities at the centre of what we do.”*

*One of the most recent Alphabet spin-outs, Citiblock Health is focused on the poorest city dwellers – initially with a US remit. It is building a personalized health system concentrated on local communities and is seeking to more effectively provide health services to those on Medicaid or Medicare who have either fallen through the gaps in the system or are ‘frequent travellers’ to hospital which, on average, cost \$10,000 per stay.*

Aiming to send its own health-care professionals into people’s homes and so avoid the need for early hospital admission, its core capability is the potential to mine data to identify and direct where care is most needed.<sup>207</sup> Linking together caregivers and clinicians with social services all within the day-to-day life of the city block, the core aim is to address medical, behavioural and socio-economic factors in an integrated manner and shift the care balance to prevention and community support.

Adopting shared-profit partnerships with payers and hospital systems, by redirecting spending towards prevention at the local, neighbourhood level, Cityblock’s primary focus is on the 20% of Americans at the bottom of healthcare access and especially those that have complex and costly health needs.<sup>208</sup>

Launched in 2018 in Brooklyn, to support its model of developing personalized plans with which clinical teams can better engage with patients, it is building ‘Commons’ – a digital care management platform that collects structured data on medical, behavioural and social needs. Mixing a broad set of real-world data with the latest in predictive analytics technology, Cityblock Health is taking a bold approach to improving impact in one of the world’s most complex health systems “improving the health of urban communities, one block at a time.”

## CASE STUDY:



*5 million Indians suffered a heart attack every year. India is one of many countries where it has been impossible to offer advanced heart treatment in poor villages, and, even if you could get an ECG, the local physician was not in a position to interpret it. Bengaluru based Tricog has fundamentally changed this and is now providing high quality analysis remotely. The company has built a cloud-based ECG machine and built a team of doctors providing 24/7 support from a centrally-located hub. Now any doctor at any remote location can take the ECG data of the patient and share it via the cloud to the Tricog team and receive expert advice within six minutes.<sup>209</sup>*

Coronary heart disease is increasingly prevalent in India, having escalated from causing 26 percent of adult deaths in 2003 to 32 percent in 2013. In a nation where the doctor-to-patient ratio is one of the worst in the world with just 0.2 doctors per 1000 population (five times fewer than the US), delivering accurate diagnosis is therefore a major bonus. By adding a simple 3G communicator to a standard low-cost GE ECG machine, the company's platform collects physiological data and ECGs from medical devices in the field and then uses a specialized AI engine to process the data in real time and give the cardiologist an initial diagnosis. The cardiologist reviews the diagnosis and recommends next steps to the GP or nurse in the field instantaneously using the associated mobile app. A few specialists in Bengaluru can diagnose over 20,000 patients per day and provide the fastest and most-real time ECG analysis globally.<sup>210</sup>

Tricog was the first start-up selected for GE's Healthcare accelerator in 2016 and launched the same year. Coverage started locally in Karnataka and quickly expanded to Andhra Pradesh, Telangana, Tamil Nadu, Kerala, Maharashtra, and Delhi.<sup>211</sup> With product and the services offered on a pay-per-use model, so it also solves affordability issues for even small general practitioners, Tricog now provides access in 340 cities in 23 states, including in some of the most remote locations in India. It has changed the 80% chance that a heart attack will take a life to an 80% chance that the patient survives.<sup>212</sup> One of several Indian start-ups significantly improving access and highlighting how in partnership with human expertise, AI can become a 'force multiplier' in bringing preventative health care to everyone, rather than just the affluent few.<sup>213</sup>



## The privatisation of health information

*The privatisation of medical knowledge and the increased use of new ‘secret software’ challenges the potential for healthcare data to be more open source or, at least, shared within an agreed governance system.*

Many believe that more ‘open’ sharing of patient data has the potential to transform healthcare. But few seem to consider that it is a realistic possibility – there are just too many political and commercial interests at stake. Despite this, the ability to give a wide range of different organisations access to health information is an important element in many new models. Inevitably much could be available from a range of sources. Public healthcare providers often share data. It is also gathered by pharma companies from years of clinical observations and trials; some is controlled by the patient or an agent representative - social media and the app economy makes up most of the rest.

In general, however, there is little commercial appetite to share and most data is consequently stuck in some sort of silo. It hasn’t helped that key regulations to set the standards for wider sharing have yet to be agreed. Despite the obvious benefits to society perhaps all this is unsurprising as, at a more mundane level, many established organisations are increasingly being threatened by newcomers from the world of technology. With deep pockets and huge ambition, they look set to challenge existing practises. In fact, they are already upping the ante by attracting significant numbers of experienced, data-savvy healthcare professionals - many of whom have cut their teeth in the public sector. Looking ahead, increased competition,

certainly in the short term, looks likely to limit the amount of data sharing still further. Despite the hopes, some important health information may be increasingly protected and ring-fenced.

## THE TALENT GRAB

Looking first at expertise, we see a growing anxiety about the wholesale acquisition of talent by technology companies. This was specifically highlighted as an issue in Singapore. Allegedly (according to Linked-In analysis) over 2000 leaders in healthcare research have moved over to big tech in the last year or so to work on the varied associated 'special projects'. Whether recruited by Amazon, Alphabet, Apple, Facebook, Microsoft or others, the concern expressed was that *"so much talent is being bought wholesale by big-tech that the implications for the wider healthcare systems are substantial. Hospitals and even pharmaceutical companies cannot compete."* Even if, in the unlikely scenario, big-tech's moves into healthcare do not deliver on their ambitions, the downside for healthcare generally could be significant. Parallels have been drawn to the *"wholesale recruitment by Uber of Carnegie-Mellon's autonomous vehicle expertise"* in 2014 and 2015. Carnegie had spent 30 years and many millions of public research dollars building world-leading expertise – think of Mars Curiosity Rover navigating its way around a planet on average 200m km away from ground control. *"Within one fell swoop Uber took the majority of this knowledge private and, even though paying super-high wages, in doing so arguably gained from decade of public research at a discount. The same may now be taking place in healthcare."*

In a 2016 Nature article<sup>214</sup> Eric Topol, author of 'The Patient will see You Now', voiced several concerns. Although recognising that *"migration of clinical scientists into technology corporations that are focused on gathering, analysing and storing information is long overdue,"* he and co-author, John Willbanks, also see a shortcoming. With large organisations like Google and smaller firms such as 23andMe owning the talent and also controlling the data as well as the methods to match this to

the individual, there could be a *"fundamental shift in biomedical research and health care."* The problem, they argue, is that if undisclosed algorithmic decision-making, traditionally used by the tech companies, starts to incorporate health data, the ability of black-box calculations to accentuate pre-existing biases in society could greatly increase. There is a huge downside to this for *"if the citizens being profiled are not given their data and allowed to share the information with others, they will not know about incorrect or discriminatory health actions – much less be able to challenge them."* The recent shenanigans of companies like Cambridge Analytica have already shown the potential costs to individuals and society of the mis-management of data.

## PRIVATE INFORMATION

Many we spoke to were also concerned about the harvesting of information – both indiscriminate and focused. Many have their hats in the ring. For example, Apple's ResearchKit allows anyone who want to use it to design data collecting apps and is consequently already gathering data from millions of people, while IBM Watson, and similar organisations, are sifting through petabytes of data and building up unique insights on the health of individuals. Moreover, 23andMe is now the holder of the world's largest repository of genomic data and companies like ancestry.com entice the public to buy an analysis of their DNA on the cheap but the company gets to own a record of it too – that it can then monetise. Others have highlighted more *"secret software"* that may be in development: interrogating health information in similar ways to others like Cambridge Analytica have been doing with personal data. Palantir Technologies<sup>215</sup> is just one of those now working on health data *"revolutionising how your organisation manages, analyses, and shares data, irrespective of scale, format, or federation."*

Meantime pharmaceutical firms have been acquiring and retaining clinical data for many years. Although many of them see that they are now 'losing' their lead as new tech gains the upper hand in more personal and contextual information. Topol and Willbanks believe that *"closer-data and closed-*

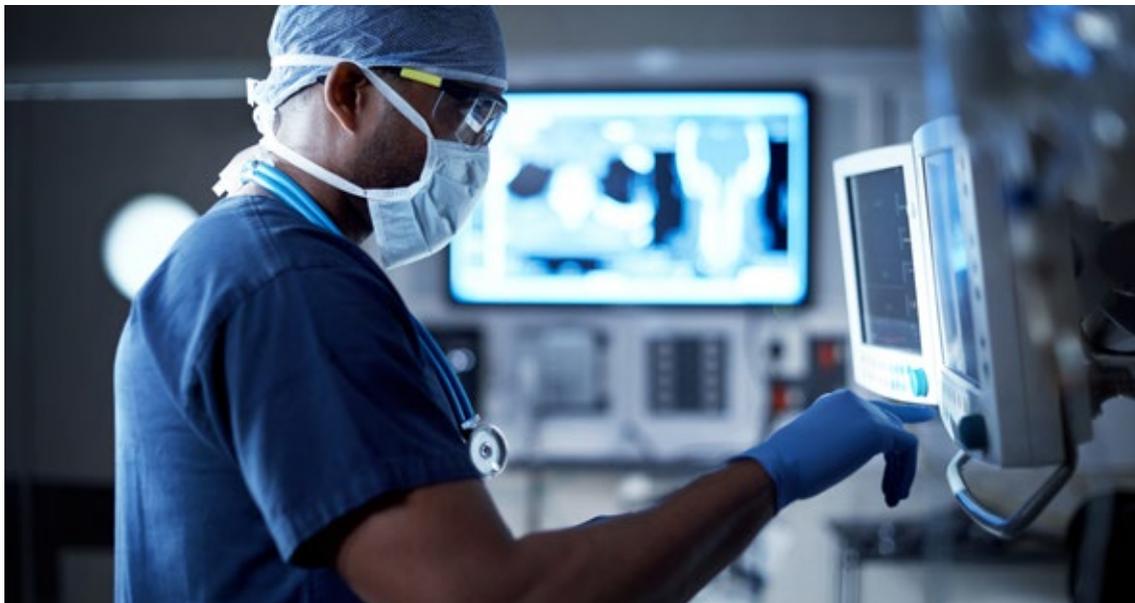
*algorithm business models will hamper scientific progress by blocking the discovery of diverse ways to examine and interpret health data.”* Private capital and public good may be at odds: As of Dec 2017, Apple, Alphabet, Amazon and Microsoft alone had over \$500bn of cash in the bank.<sup>216</sup> Their ability to privatise health is considerable. As highlighted in one discussion, in 2016, *“23andMe’s fundraising of \$115m was, for example, equivalent to more than 70% of the entire US federal investment in the Precision Medicine Initiative.”*

In other discussions several healthcare providers, hospitals and insurers reinforced that they *“would not be willingly sharing patient data with competitors any time soon.”* Even though big tech is seeking partnerships, many established payers and players are holding firm and seeking to protect unique information and insights. Indeed, some are becoming more protective and see building competitive advantage in keeping hold of healthcare information – further increasing privatisation in silos. Others see that this may be a red-line in the control of individual data. With GDPR in the EU and similar regulations elsewhere all coming into force, many see future friction between the public and private data and knowledge pools.

## OPEN AI

In our Boston event there was a fervent debate about how this impacts the next generation of AI – especially in terms of what may or may not be open source. Some see that *“there are uncertainties such as the privatisation of medical knowledge as more investment in genomics and AI mean that it is no longer open source.”* Within this, some assumptions are being made on the *“key characteristics of future AI in healthcare will be that it is ambient, global, open-source, patient-focused and include humans in the loop.”* In the follow-on discussion, the challenges about whether or not AI knowledge will be open source and what the governance model for this should be was explored in more depth.

One standpoint was *“AI has to inherit policy from communities of interest such as patient groups - people you can trust, and so open source is key.”* An alternative perspective considered if the AI data had been developed privately – *“why should it be made open? Several companies do not see how to shift AI to an open source model.”* Within this some commented that *“the (US) Health Information Exchange model<sup>217</sup> is not working – maybe because it was constrained to just Google and Microsoft?”*



and asked whether or not *“HIPAA will continue to restrict data sharing between organisations and so limit the more open ideal here?”* Many recognize the need for greater collaboration and data sharing (or even data philanthropy) but point out that HIPAA is currently preventing this. One key difference highlighted in an AI discussion in Boston was the approaches that have taken by Apple vs. Amazon. *“Apple with its ‘we will not see your data’ (differential privacy) has had many benefits over Amazon which is listening and using your personal information. However, given there is a great incentive by AI teams to access and use more information, it may be that the Amazon approach wins out.”* Apple’s recent switch of policy on health data access may however change this.

There is clearly a divergence of views. Some companies who have made significant investments over the years in developing machine learning, cognitive computing and now deep learning believe that the hardware and software advances are their intellectual property and a source of competitive advantage - and so should not be openly shared. Others have either been open source from the start or have joined new open collaborations. Open source AI tools include Caffe at UC Berkley and Google’s TensorFlow as well as Microsoft’s CTNK and DMTK.<sup>218</sup> DeepMind regularly release open source environments, datasets and code to support and accelerate research in the wider AI community.<sup>219</sup>

One potentially significant collaboration here is the ‘Partnership on AI’ whose mission is ‘to benefit people and society’. Founded by Apple, Amazon, DeepMind, Facebook, Google, IBM and Microsoft, part of its remit is to formulate best practices on AI technologies, to advance the public’s understanding of AI, and to serve as an open platform for discussion and engagement about AI and its influences on people and society.<sup>220</sup> Widely praised as a welcome cross-sector collaboration at the early stage of a new industry’s development, this may well emerge as a mechanism for more open sharing of health information. How far it will enable more data sharing is however challenged by some.

## HOSPITAL DATA

One final notable view from Singapore was that, as global tech firms become more data-rich and influential in healthcare, *“hospitals will themselves want to develop / gain their own algorithms to use with their own data (that is not shared with others).”* This will then potentially enable them to be more accurate than the general AI systems developed by others. The high-quality, clinical data in hospitals will *“give them the advantage allowing them to provide better assessment (and prediction).”*

It appears as though the ownership and access to AI technology and specific algorithms may be influenced by just as many perspectives as the wider patient data arena.

As Topol noted<sup>221</sup> “during the 1990s, IBM abandoned its proprietary web server software in favour of selling services based around open source software.” At around the same “open source Netscape prevented Microsoft gaining monopoly with Internet Explorer.” Will we see a replay in the world of health data? Maybe? Maybe not?



## The value of health data

*It is clear that patient data can be used to drive both social and economic benefit. As public understanding grows so will consensus about its worth. As this shift happens, those who can best grasp its multiple roles in, and value to, society, and render these things comprehensible to others, will likely have the more powerful voice.*

Lastly, throughout our discussions, there has been an implicit view that patient data has value. As covered in the chapter on security and privacy, even at a mass level, hacked health data is worth more than financial data and can also be leveraged in more ways. The going price for a single record of financial information on a user that includes name, social security number, birth date, account information such as payment card number can range from \$14 to \$25 per record.<sup>222</sup>

With a reported street value of over \$1000<sup>223</sup> the average US EHR is certainly a focus for hackers and, as we have seen, a legitimate, holistic, personalised health data set at an individual level is already worth

more than that to interested parties. It is little surprise therefore that targeting US healthcare providers data is the top priority for many cyber-criminals. Equally, as addressed in the previous section, given this, there are many organisations increasingly seeking to privatise as much of it as possible.

More practically keeping patients in hospital is expensive and if data can be used to reduce these costs then many organisations are keen to explore its benefits. Some of the discussions in Boston focused on the potential changes that could be considered. *"It currently costs a hospital \$2600 a day to provide a bed, and, in some cases, we are seeing hospitals pay care homes \$500 a day to take*

*patients out of hospitals. This is not the way the system is meant to work and shows why alternative reimbursement models must be explored.*" But is the discussion of value all about the money?

### WHY THE CONCERN?

Within the current landscape, the advent of 'big' has changed our relationship with data. In particular, the meteoric rise of the so-called 'tech titans' whose business models rely on the collection, creation and monetisation of huge data sets, has thrust data to the forefront of social and political discourses around the world. These companies, whose products are now woven into the very fabric of our existence, have shown us what data can do and how it can transform our lives, but perhaps unwittingly, they have also pushed a topic once the preserve of 'nerds' and 'wonks' into the mainstream. Global public debates around everything from growing inequalities, to political freedoms and human rights, and the very future of economic and social progress, all now involve heady proclamations about the use, abuse, power and possibility of big data.

With the arrival of mass collection of 'personal' data, data *politics* is inevitable. It is the movement of data collection and analysis, experiment and discovery from remote processes, to the most intimate and fundamental parts of *everyone's* personal, social and economic lives, that has driven the idea of it into the heart of contemporary social and political conversation. Right now, debate about privacy is at the forefront of global discussion, but there are also those who are seeking to understand how new kinds of data might be used to address some of the biggest challenges in society.

No one doubts that patient data has economic value, the question is rather around how that value is exchanged and shared. But we should also consider the potential social value of health data, and how it might change the nature of the society's in which we live. *"Patient data has both commercial and competitive value – the principle of sharing this more freely is not going to be an easy conversation to have."*

The optimists see that *"new platforms will seek to help individuals not only manage their personal information but also extract the best value from it – whether that be social, economic or health related."*

In Dubai, one negative future scenario saw that *"data mining and analysis will become expensive and data itself will become hard to access with less sharing than is really required for significant impact."* Moreover *"in this world, only data that has monetary value will be of interest and hence supported."* So, therefore *"we will focus on only the few, targeted conditions where impact can be made, or those for which the rich are willing to pay."*

If we are going to better manage the value of health data, then maybe we need a better shared understanding of what it actually is?

### A CURRENCY?

To many of those we have talked to across multiple regions and topics *"data is a currency, it has a value and a price, and requires a marketplace."* But others are not so confident in this definition? Data can certainly serve as a medium for exchange, as it does when a consumer, for example, shares their personal data in exchange for so-called 'free' services. It can also be used as a store of value, even in quite a literal (albeit unstable) sense when it comes to crypto-currencies. So yes, data is like currency. But describing data as currency really doesn't tell us much. It just tells us that data has exchangeable value in certain contexts. In that sense, many things operate like currency. The economic value of health data might have risen in recent times, and more people might be aware of that value, but the same might also be said of quinoa. Describing data as currency simply edits out its myriad other features.

### THE NEW OIL?

To others, there is another view that data is the new oil. As the Economist, for one, recently highlighted,<sup>224</sup> *"data is to this century what oil was to the last*



*one: a driver of growth and change. Flows of data have created new infrastructure, new businesses, new monopolies, new politics and – crucially – new economics.*” Bloomberg and IDC have forecast the amount of data in the world to reach 45 Zettabytes by 2020 and 180 by 2025. The data majors of Apple, Amazon, Facebook, Google and Microsoft are now more valuable than the 20th century oil majors of Exxon, Shell, Chevron, Total and BP.

But again, is data like oil? Well, data is mined and refined, like oil. Vast hordes of it can make its owners (or ‘controllers’) very wealthy and powerful, like oil. We might even go to war over it, like oil. But there are also many ways in which data is not like oil. Data is not a finite, exhaustible resource, unlike oil. In many cases data is replicable or reproducible, unlike oil. The material costs of extraction, collection and movement of data are not high, unlike oil. The risks of data collection and use to society are real but not inherent to it, as they are with oil. In addition, as we have seen, data ownership is also not particularly easily defined, unlike oil.

These differences are important since they point to a completely different set of end-points for the data economy than there have been for the oil economy, and so demand a different set of societal responses. This metaphor blinds us, in fact, to the different options we have around how we, as a society, might *benefit* from data and avoid the calamitous potentials of its use, in ways that are simply not possible when it comes to oil.

The world’s wealthiest companies are almost all now data-driven, or data-rich and the future of government looks set to be defined by ‘smart’ uses of large data sets. Great social value is also being created by the institutions of civil society, and a new breed of ethics-driven start-ups. Consumers and citizens are also now beginning to understand this landscape. Increasingly they are grasping the fact that what they once thought of as inconsequential personal data points, are actually being used to shape and define their lives at the very largest scales and are increasingly seeking ways to derive value for themselves from them.

As the volume multiplies and its quality improves, patient data is certainly going to become even more valuable in the next ten years. Healthcare organisations are already sitting on large stores of data that have significant value beyond the primary clinical use for which they were collected. Some are however reluctant to share what they have because they feel its value can be better used within their own ecosystems than by making it more widely available. They are also wary of exploitation by some of the larger, wealthier technology companies, hungry to enter the market. Others are, by contrast, still struggling to define what the value of their data really is, and are trying to understand which data-enabled outcomes to measure, and how to collect, analyse and share their findings.<sup>225</sup> McKinsey is not alone when it suggests that big data could transform the health-care sector, and many acknowledge that the industry must undergo fundamental changes before its full value can really be captured.<sup>226</sup> Lessons can of course be learned from any number of other data-driven revolutions where, all too often, players have taken advantage of data transparency by pursuing objectives that create value only for themselves and to the detriment of society as a whole. Given the global need for wider and more effective health care it would be a great loss to society if the industry did not learn from the mistakes of others.

Several of our experts felt that there is *“increasing honesty about the economics and value of healthcare and significant digital capability is being built within pharma.”* But should we just be looking at health data’s value through a financial lens? Isn’t there *“a bigger picture view that should be driving our approach to the new world of more and better patient data?”* Moreover, are there not more enlightened ways to see value from data? Maybe more democratic perspectives? In Singapore, one view was that *“if the data value extraction can be democratised then this will open the door to information sharing at an extraordinary scale.”* Our Toronto discussions highlighted the success of a system that *“has embraced evidence-based medicine where the focus is on the ‘long run value’ of healthcare.”* Elsewhere the underlying sense that

data has an inherent value (like oil) was challenged by the idea that *“health data itself is not interesting without context. More (like water) it can be valuable if it is in the right place at the right time.”* Better patient data classification may be one solution providing insight between high value, low value and peripheral information.

Several organisations are now seeking to change the way we treat the value of patient data. For instance, Nebula Genomics’ goal is to get the price of sequencing below \$1,000 by working with biotech and pharma companies, which will subsidize a large share of the cost. In addition, users will be able to earn cryptocurrency in exchange for letting pharma companies use their data.<sup>227</sup> People who want to get their genomes sequenced through Nebula will pay with tokens, which will also be used by researchers and companies wanting to acquire that data. Initial modelling proposes that an individual could earn up to 50 times the cost of sequencing their genome – taking into account both what could be made from a lifetime of renting out their genetic data, and reductions in medical bills if the results throw up a potentially preventable disease.

## THE SOLUTION?

It is clear that data can be used to drive both social and economic value. And, without getting lost in a metaphysical discussion about the concept of value, it seems safe to say that therefore the value of data lies in the uses to which it is put. Some of those uses seem to provide unequivocally *positive* value, such as searching for new cures for diseases. Similarly, there are some uses of data which seem to generate unequivocally *negative* value like identity theft, cyber-attack and data blackmail. Other uses seem to allow for the generation of both positive *and* negative value, at the same time.

Patient data, shared responsibly, can be used to help solve some of healthcare’s most challenging problems. It can allow ideas to flourish and play a critical role in driving innovative research, deriving key

insights and gaining new knowledge that can lead to faster and better treatments and cures for a wide range of health conditions and diseases.<sup>228</sup>

Similarly, whilst some argue that the principle of open data (particularly open government data) offers the best chance of unlocking the potential to solve societal challenges and bring collective benefit, others describe the exact same effort as giving away our most valuable assets to those with the best means to exploit it, whether or not they have the means to properly determine the best outcomes for society. The recent and controversial collaboration between the UK's National Health Service and Google's Deep Mind is a case in point. The partnership seemed to point towards exactly the kinds of optimistic hopes for big data sets and machine learning to help solve collective problems, whilst simultaneously sparking all of the worries around the potential harms of big data sets of personal information being collected and used by powerful stakeholders with inscrutable long-term interests<sup>1</sup>.

## THE FUTURE?

As many have stated "*data sets that contain information about human health are evidently hugely valuable.*" At a time when health-care budgets around the world are stretched, payers are desperate for insights that might enable them to cut costs while maintaining quality.

Patient data and the uses to which it is put are set to define the future for societies and economies. We are going to see more data-driven companies, more data-driven social innovations, more cyber-security incidents, more breaches of privacy, more artificial intelligences, more miraculous transformations of the ways we live, and more dramatic consequences of that transformation.

In the short term, properly or improperly, many of the *mysteries* around data and its role in societal and economic change are going to disappear. Citizens,

service users, consumers... people... *are* going to find a way to understand the value of their data (including their health data) to different organisations, and the different uses to which their data is put. This will happen regardless of debates about whether the way they understand it is technically correct or incorrect. This de-mystification is sometimes portrayed as a shift in power to the consumer, but it is really about a simple conveyance of understanding of big data from the few to the many, and it may happen regardless of where power or wealth ultimately comes to rest.

As this shift happens, those who can best grasp health data's multiple possibilities and realities, it's multiple roles in, and value to, society, and render these things comprehensible to others, will likely have the more powerful voice.

<sup>1</sup><https://link.springer.com/article/10.1007%2Fs12553-017-0179-1>