

# Foreword

It is clear that we are witnessing a growing revolution around the provision of healthcare. In the main this is being driven by the proliferation of medical data and the technology that supports this. As the pressures on existing healthcare providers continue to escalate, the better collection, management and use of more patient-specific information provides a significant opportunity for innovation and change. In the winter of 2017/18 the Future Agenda team made this the focus of our latest Open Foresight project and this led us to hold 12 discussions across 11 countries and gather outlooks from over 300 experts.

During these discussions there was near universal agreement that there are significant opportunities to be explored and, within this, few are blind to the challenges ahead. Better diagnosis, the ability to manage or delay the onset of chronic conditions, driving cost reductions and enabling greater, more personalised patient focus are just some examples of the upsides. However, at the same time, concerns were raised around the difficulty of integration of multiple datasets, the need to improve trust amongst all parties, the complexities of data ownership and in ensuring the overall security of personal information.



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It is also noticeable that there are several important emerging issues that are the source of major differences of opinion around the world. How to best accommodate rising data sovereignty concerns, the privatization of health information and the growing value of health data are just three examples.

Some of the challenges and opportunities are technical in nature, but many are concerned with different ethical, philosophical and cultural approaches to health and how we treat the sick in society. We suggest that these, in particular, can best be solved through the provocation of thoughtful debate and by the collaborative sharing of views across multiple regions and sectors.

As with all Future Agenda projects we have done our best to engage with many different and alternative voices in different geographies and are delighted that so many leading organisations have supported this approach. We hope that this document is an accurate reflection of what we heard and, that by sharing the observations, it generates new ideas and inspires different approaches to solve some of the future challenges and so improve healthcare.



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# Acknowledgements

The insights upon which this report is based were gained via multiple discussions with over 300 experts around the world. We would also like to thank all those who have spared their time to join in these events and share their perspectives.

We hope that this report provides an accurate reflection of your views. In addition, we would like to thank the generosity of the forward-looking organisations that have supported the varied events.

Future of Patient Data

Insights from Multiple Expert Discussions Around the World



UiO : University of Oslo



# Introduction

The world's healthcare systems are experiencing significant change. We are at a point, or more accurately multiple points, of major transition around the ways we can improve access, manage and transform how to control and treat disease. The expectation is that over the next few years we will see a sizeable shift in the effectiveness of healthcare.

As the impact of rising public expectation around better wellness and health, the effect of increasingly sedentary lifestyles and progressively aging populations all converge, some fear that, in many nations, we will be unable to find the necessary funds for high quality healthcare. Others are more hopeful that with the adoption of new technologies, particularly associated with a more patient-centric approach to both health and sick care, we are on the cusp of a significant step forward in the efficiency, efficacy and effectiveness of how we diagnose, treat, manage and, ideally, prevent chronic and acute disease. Indeed, a commonly shared ambition is that a more information-rich, digital approach to healthcare over the next decade will inherently be more effective and patient focussed.

Some key advances that are seen to have already had substantial effect include:

- Wider adoption of smartphones which are able to sense as well as diagnose,
- More empowered patients equipped with a burgeoning volume of information about their condition,
- Tangible advances in machine learning, cognitive computing and wider AI,

- Increasing automation across healthcare – from chat-bots to surgery,
- The expansion of wearables, providing access to new aspects of personal health data and
- A steady decrease in the cost of, and an increase in, the access to genetic profiling.

Within this context, there are however many differences of opinion and perspectives on how these and other shifts will actually play out over the next decade. What will drive them? Who will pay? Who will benefit the most? How quickly will transformation occur? What will be the catalysts for change? Where specifically will be the greatest impact and why? These are all key questions that many organisations around the world and across multiple sectors are asking. As many governments, companies and communities all seek to make the right moves and investments, a good number are keen to see the global, cross-functional context within which the possible change is occurring. In a sector where fragmentation is sometimes extreme, where funding is often challenging and where local or regional regulations can frequently influence the market, many are keen to gain the broader perspective and then see how, where and why their individual areas of focus can have the greatest impact.

# Approach

In order to provide a global view of the patient data arena, over a six-month period the Future Agenda team undertook a major multi-country project to explore the key changes on the horizon. A series of 12 events took place around the world from September 2017 to the end of January 2018 providing the opportunity to discuss the major shifts with multiple experts from across a wide range of industries, providers, researchers, governments and start-ups.

As with all Future Agenda programmes, each event brought together a rich mix of informed people who could challenge existing assumptions, share new perspectives and build insightful pragmatic views of how change will most likely occur. Starting with an initial perspective drawn from existing research and previous discussions about the future of health, the future of ageing, the future of data and the future of privacy, this series of workshops progressively

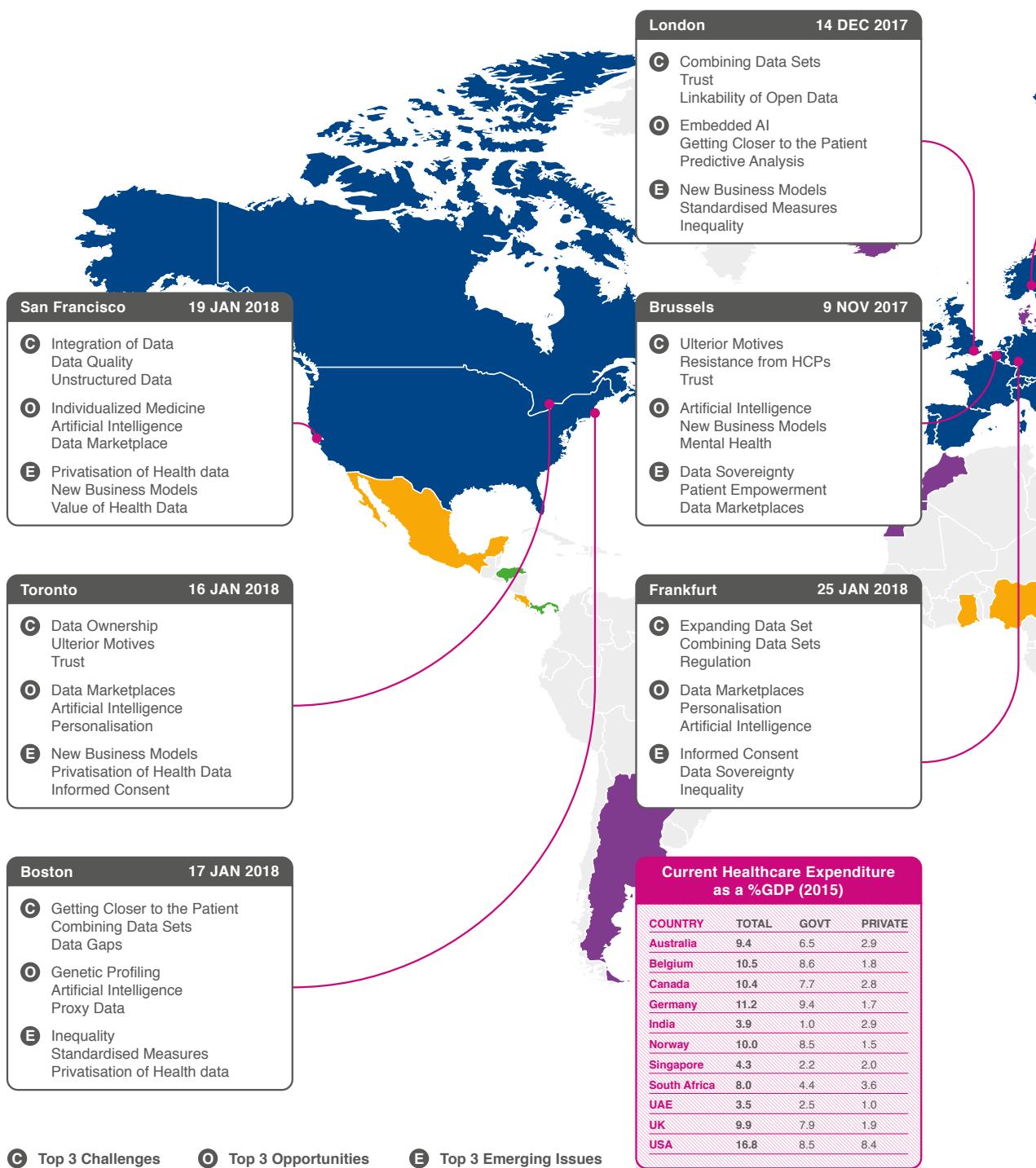
identified the key issues that matter, added in additional views and highlighted the pivotal areas for future innovation and the most significant shifts - both globally and locally. Each event was supported and hosted by different organisations from across the healthcare arena keen to collaborate and build the informed global view. This report is a synthesis of the insights gained from these discussions.



# Project Summary

Future of Patient Data

Insights from Multiple Expert Discussions Around the World





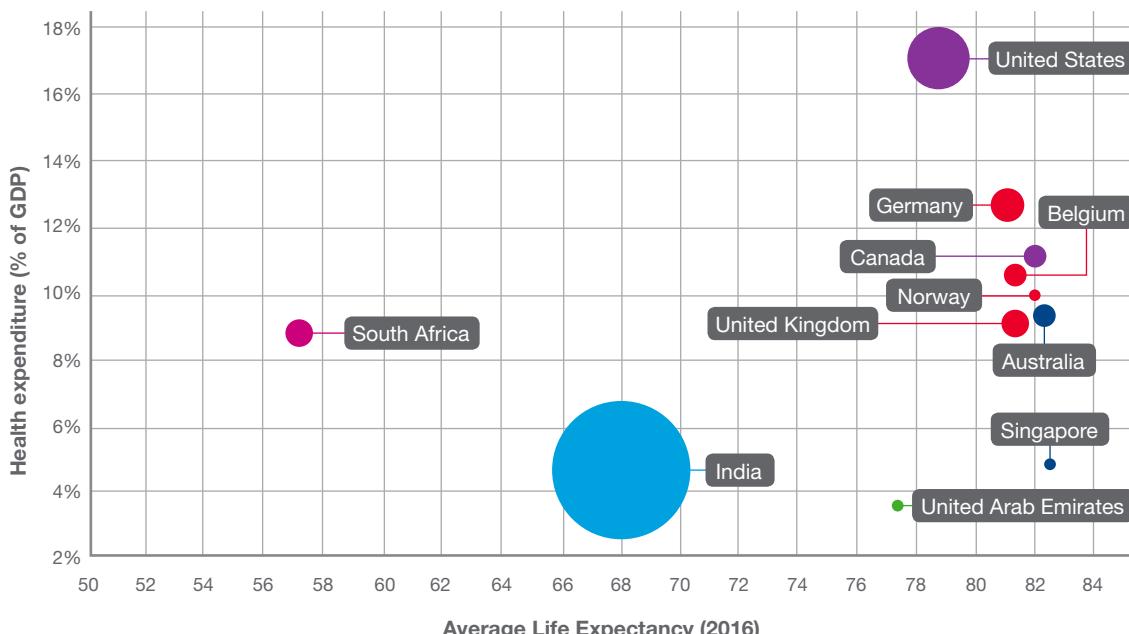
**Level of Privacy Regulation:**  
DLA Piper <https://www.dlapiperdataprotection.com>



# Locations and hosts

In order to gain a diverse range of perspectives we chose to hold the discussions in a variety of countries where healthcare is at different stages of evolution, where funding systems and access to funding vary and where regulation around privacy, and patient data in particular, is taking alternative paths. This is highlighted in the preceding Project Summary and in the Healthcare Spend vs Life Expectancy chart below.

## Healthcare Spend vs Life Expectancy



Size of dot represents size of the population

- East Asia & Pacific
- North America
- Europe & Central Asia
- South Asia
- Middle East & North Africa
- Sub-Saharan Africa

We kicked the project off in September 2017 in **Dubai** in the UAE, one of the wealthiest nations in the Middle East with a small population of 6.0 million and an average life expectancy of 77.7 years. It is also a country with high-levels of government control and significant inequality between the rich Emiratis, the wealthy ex-pats and the poorer migrant workers. It also has a relatively low overall healthcare spending of 3.5% of GDP but this figure does not include the informal care provided by domestic staff. This opening event was hosted by Herman Miller.

In early October we moved onto **Johannesburg** in South Africa, a far poorer country. It has 1/6th of the GDP per capita of the UAE and an average life expectancy of just 57 years. Its total healthcare spending of 8.0% of GDP is almost evenly split 55/45 between public and private systems but, according to the national government,<sup>1</sup> most of the private healthcare is focused on just 16% of the population. This event was hosted by Discovery Health.

Next, we went to **Oslo** in Norway, one of the wealthiest and, arguably, the healthiest country of all. With life expectancy of 82 years and healthcare spend running at 10% of GDP, Norwegians are also seen by many measures to be consistently among of the happiest and best educated in the world. Beyond this, Norway is in the top 5 most 'digital' nations. This workshop was the first of three supported by Accenture and took place at the University of Oslo.

In November, our focus shifted to **Brussels** to gain both the Belgian and the wider EU policy perspective. With an average life expectancy of 81 years and healthcare spend also of 10% GDP, Belgium is one of the wealthier European countries. Its GDP per capita is just over \$41,000 compared to the EU which collectively has a GDP per capita of around \$39,000 and average life expectancy of 80.2 years. The Brussels workshop was hosted by UCB.

Then, we moved to **Singapore**, another very wealthy, highly digital but relatively small 5.8m population nation with strong government influence over many aspects of life and the economy. With, at 83 years, the highest average life expectancy of all the countries we visited, official healthcare spend is relatively low, at 4.3%. However, as with the UAE, this does not include a significant proportion of the informal care provided by domestic staff. The event here was also hosted by Accenture.

**Sydney** was the next port of call. Despite the Australia's physical size, its total population is just over 24m. With an overall GDP per capita of \$50,000, similar to that of Singapore, and a healthcare spend of 9.5% of GDP split 2 to 1 between public and private systems, Australia is also one of the world's healthier nations with an average life expectancy just over 82 years. The Sydney workshop was jointly hosted by TAL and Pfizer.

The last event of November was held in **Mumbai**, one of India's largest cities. With a rapidly growing population now over 1.3bn, India is moving fast up many global rankings around technology and health. Although, on average, still a poor country with the lowest GDP per capita of the nations visited and average life expectancy of 68.3 years, healthcare spend is rising and is currently at 3.9% of GDP. While these figures may give a view of a poor country, it is important to remember that India also has some of the wealthiest people in the world and so, given the size of the population and economy overall, the 2.9% of GDP spend on private healthcare is globally significant.

In December the final workshop of 2017 was in **London** where the dominant NHS single payer system is seen as one of the most efficient in the world. Although often portrayed in the media as being under stress, in a country of 70m, the UK is spending just under 10% of its GDP on a healthcare system, 80% of which is via the NHS, and is achieving average life expectancy of 81 years. This event was the third supported by Accenture and was hosted by the University of Warwick in London.

In January the focus moved to North America; first to **Toronto** in Canada. Another vast country with a population of only 36m, Canada is also seen to be one of the healthier global nations. Average life expectancy is just under 82 years and its healthcare spend is 10.5% GDP, of which over 70% is in the hands of the public sector. The Toronto event was hosted by York University.

Next, we moved to the US - first to **Boston** and then to **San Francisco**. With, at around 17% of GDP, the highest healthcare spending in the world, there is little doubt of the influence of the US market on global healthcare. However, with over 50% of this focused on the private system and over 12% of the total 325m population now without any insurance cover, there is also significant health inequality. The Boston workshop was supported by Amgen and hosted by Philips and the San Francisco event was hosted by Hanson Bridgett.

The final workshop of this project took place in **Frankfurt** in Germany. With one of Europe's most advanced healthcare systems, average life expectancy is currently 80.8 years and healthcare spend is over 11% of GDP with 84% of this provided from government. The home of many leading medical equipment and pharmaceutical companies, Germany also has a significant influence on the global market. This event was hosted by Cognizant.

# Report structure

*From these 12 discussions and additional dialogue in New York, Singapore and London, we have explored many points of view hearing different perspectives on some pivotal issues that may well have a major impact on how change will play out across healthcare in the next 10 years.*

There has also been clear areas of consensus around where and why we may see the greatest shifts in the use of patient data taking place. This document provides a summary of the insights and, at its core, is based on the views of over 300 experts, entrepreneurs and other informed individuals who attended our events. It is a playback of what we heard in the varied discussions with additional research and context added to help frame some of the primary points made.

We have structured this report into 5 sections:

- **Context** – addressing the growing sources and users of patient data as well as the global ambition
- **Shared Challenges** – that are seen as common issues to address across multiple locations
- **Future Opportunities** – highlighted as priority areas in the varied discussions
- **Emerging Issues** – that will become increasingly influential over the next few years
- **Conclusions and Questions** – points raised that may provoke further thinking

Lastly, in the appendix we have also included a summary of some of key insights gleaned from each workshop classified by location as well as associated rankings of many of the shared issues as judged by future potential impact.

As all our events are run under the Chatham House Rule,<sup>2</sup> we do not attribute quotes to any one individual or organisation. Instead we have sought to identify the discussions that insights were gleaned from. Therefore, throughout this document we have highlighted comments from the workshops in blue and also referenced key locations as appropriate.



# Context

Before delving into specific challenges and opportunities it is valuable to first replay views on some of the overall issues on both the future sources of patient data and some of the primary users of this information. In addition, we have highlighted the global ambitions for more and better use of patient data as an initial stake in the ground.

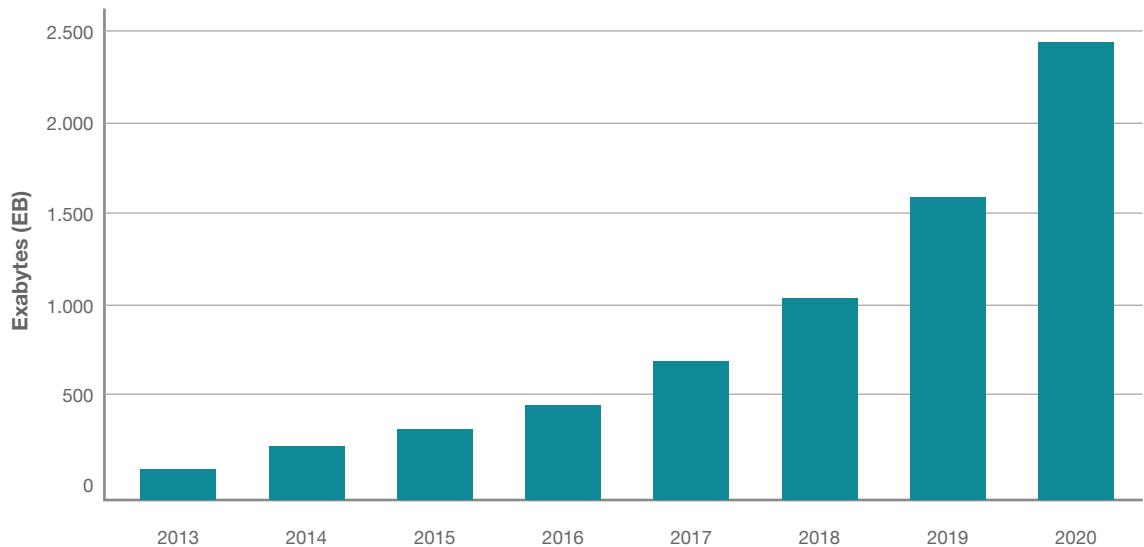
# Sources of patient data

*The patient data set is expanding: It includes high-quality clinical information, more personal data from apps and wearables, a broadening portfolio of proxy data as well as insights on the social determinants of health.*

The increasing breadth of information available about our health is leading many to wonder what will constitute patient data in the future. The growing use of personal technologies has opened the door to the convergence of medical data about patients generated by healthcare providers with a plethora of non-medical, lifestyle related data, much of which is generated by the patient.

As shown in the graph below, some are predicting a 300% growth in healthcare data between 2017 and 2020. It is clear that Electronic Health Records (EHR) are no longer the only point of reference and we are entering a new era of health monitoring. However moving forward it will be important to clearly define who will have access to what information, when and how.

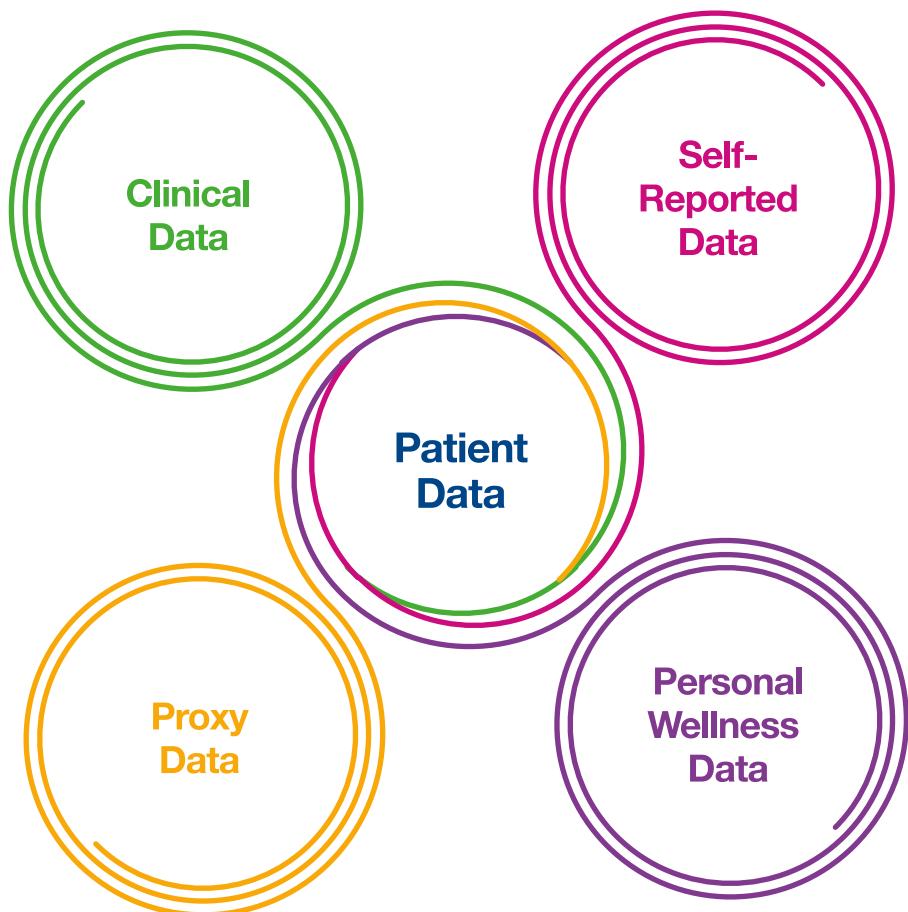
## Growth In Healthcare Data



Source: EMC Digital Universe / IDC

To see the bigger picture about individuals' health we have to ensure that all data sources are recognized appropriately. While some medical data will remain rigorous and so potentially more reliable, many other sources of information could be useful if accessed, assessed and used in the right context. If an holistic approach is agreed, this allows a shift

away from today's largely scientific / medically-oriented focus on illness towards one more concerned with staying well and which can include patient-generated, lifestyle related content. This approach will allow increased patient involvement in making informed decisions around the management of their own personal health care.



Alongside traditional data sets (e.g. clinical medical quality data typically found on the EHR; administrative data; claims information; health surveys; clinical trial results) we will expect to access other sources. These include:

- **Self-reported data** – such as blood pressure, heart rate, glucose levels, temperature, weight and in-home remote monitoring,
- **Personal wellness data** – such as feeds available from wearables, smart watches, fitness machines and numerous diet, exercise and social apps, and
- **Proxy data** – ranging from Facebook likes and Instagram comments to location and environmental data, resident post codes and even bathroom and fridge access

These are clearly not just patient-generated health data but also include a growing range of social-determinant information. As we gain access to additional contextual insight, there are a range of signals that can help build an accurate picture of the patient and his/her health.<sup>3</sup> However, having access to biometric, nutritional, clinical, fitness and even psychological information does not necessarily make it comprehensible. As was stated in Mumbai “*we are already data-rich but information-poor. Currently the data we have is not leveraged enough to help providers help patients.*” It is clear we will also need better analytical tools to help make sense of the masses of additional material heading our way. “*Big data needs to be unlocked – the more organized we can get it, the more preventative we can be.*”

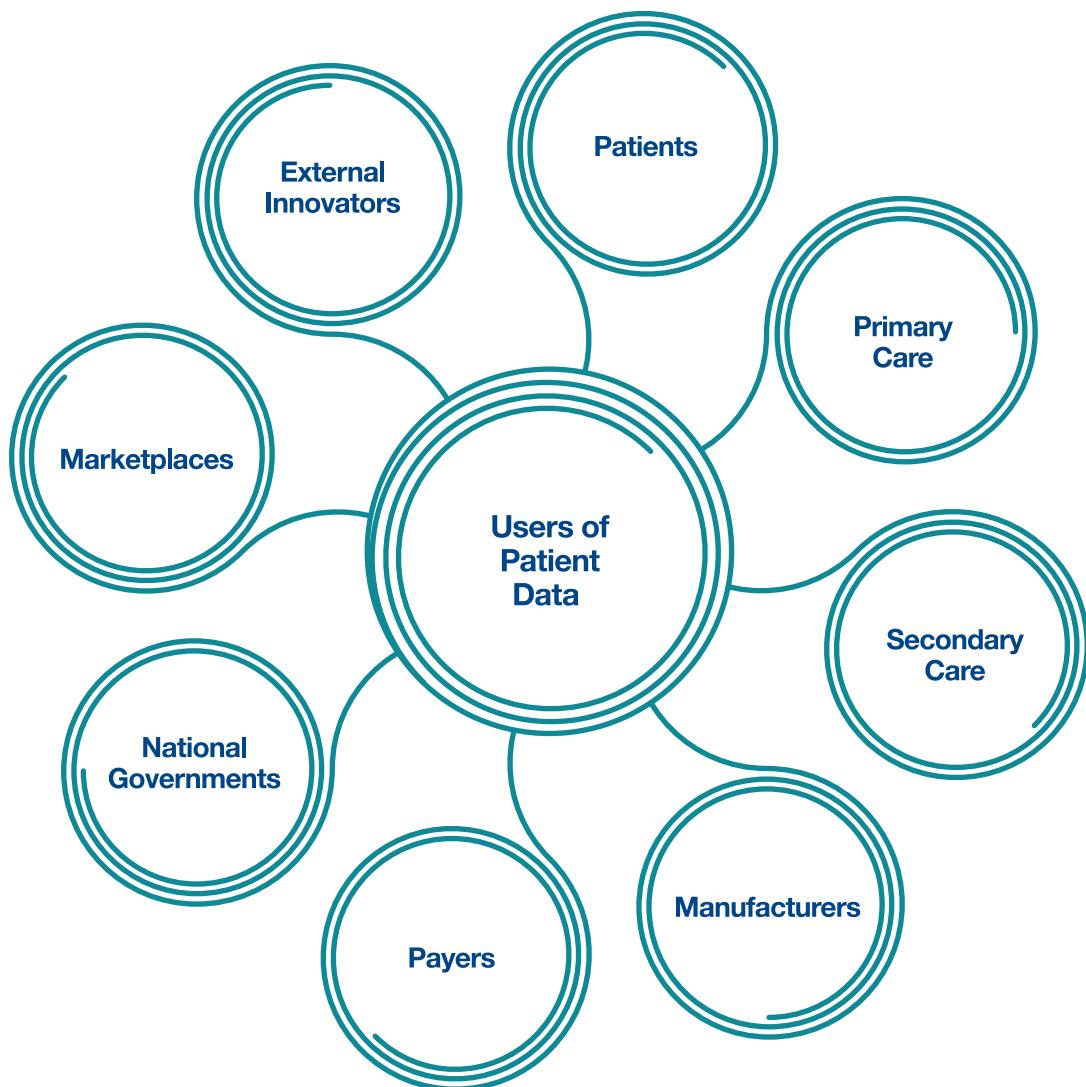
There were several discussions around how proxy data is already providing additional insights on the social determinants of health. Lifestyle data is readily available through social media plus any number of fitness apps and devices. But there are many other opportunities to gather data which could be facilitated by technology and are currently available and under-utilized; for example, enabling delivery personnel to monitor and, importantly, report on any concerns they may have for the elderly or infirm they encounter as they carry out their rounds. In Boston the consensus was that new, efficient ways to collect data will change how ongoing healthcare support is provided. Different ways to observe eating habits were also discussed, such as by tracking when a fridge or oven door is opened. Equally ‘gate detection’ for repeated night-time bathroom access could act as an early warning signal for possible UTI and so the need for increased care.

Looking ahead, many expect the increase in sensory monitoring to massively improve information capture from across the eco-system.<sup>4</sup> This is based on the assumption not only that the public will become less sensitive about sharing personal data but there will also be better analysis once more data is gathered. It also means we need to accommodate multi-dimensional data outside hospitals and so some big challenges will include managing not just the sheer volume of information but also identifying ‘signal / noise ratios’ that help us work out what is really important. Traditional population benchmarks, such as average life expectancy, may have to make way for new baselines for comparison; these could include a greater focus on years of active healthy ageing.

# Users of patient data

*The users and uses of the patient data set is broadening:  
Alongside the patient and traditional payers and providers it  
increasingly includes multiple new entrants seeking to disrupt and  
improve healthcare.*

As well as a wider selection of sources of patient data, there is a correspondingly growing diversity amongst those who use, or plan to use, newly available individualized health information.



We have rapidly moved beyond just the traditional payer / provider portfolio to encompass a wider user-group, with new communities which, importantly, more frequently now include the patients themselves.<sup>5</sup> Across our global discussions, experts highlighted that going forward we should probably consider eight key user groups in terms of patient data access and use:

**Patients** – who are increasingly becoming better informed about their own health and fitness, as well as whether appropriate providers are accessing their data, when and why.

**Primary Care** - including GP practices, social care, pharmacies and community support all of whom want as much contextual insight as possible as well as quality health data to enable effective diagnosis and prescription.

**Secondary Care** – hospitals and clinics receiving patient metrics, scheduling appointments, providing remote support and running analytics on patient treatment and outcomes as well as integrating data within the EHR.

**Manufacturers** - such as medical device and pharmaceutical companies alongside associated service providers that want real-time analysis of performance, the ability to interrogate information to learn and refine their products.

**Payers** - including insurers, third-parties and health plan sponsors as well as, in many countries, government keen to track patient health, monitor interventions and reward successful outcomes.

**National Governments** – whether or not in single payer systems, national governments increasingly want to track individual and population wellness, so they can identify and manage risks to public health and national security.

**Marketplaces** – as health data is increasingly monetized and traded via new marketplaces, these markets themselves will need to be confident of the provenance and quality of the information as well as permissions to trade - even if the data is aggregated and anonymized.

**External Innovators** – big tech, start-ups and established IT companies all keen to improve the patient experience also require good-quality anonymized and aggregated data sets from patients to build, test and develop new services.

Recognizing not only these different potential users of patient data as groups, but also understanding their requirements for and use of data is critical. Although not all needs will be aligned all the time, harmonization and standardization of data to ensure high levels of use by all is clearly desirable.



## The global ambition

### BENEFITS FOR THE PATIENT

Across all our discussions there was great anticipation of the benefits to be gained from access to more and better patient data. At its core, one common ambition is to ‘give health data back to the individual’ so that the patient becomes the point of integration and control. Patients will thus become more ‘empowered’ by having greater access to more information about their health and so will be able to make more informed decisions about their lifestyle choices. As more personal data will, in turn, enable more personalised healthcare so, the argument goes, this healthcare can become increasingly tailored to the individual – addressing their behavioural needs as well as their genetic predispositions. In this way there can be more accurate interventions and patients can be healthier for longer – a key benefit for an ageing population.

Richer data will open the door to more targeted responses facilitating predictive, personalized and effective healthcare. The advantage of this for a patient is that they can more easily see the potential benefit of preventative measures and therefore have a

greater incentive to make timely behaviour changes. It could also mean that it will be easier to test and support more hypotheses prior to diagnosis.

If used in the right way data can also be a great communications tool and, as we collect more of it, it will become more precise in its ability to deliver relevant and targeted messages. There are already a number of successful initiatives including ‘Stickk’ for goal setting;<sup>6</sup> peer-based education, for instance NHS MMR vaccination stories; and agewell global<sup>7</sup> and Swordhealth<sup>8</sup> in Portugal where 3D sensors are providing real time feedback.

Most of those we consulted agreed that, if we are going to encourage people to more proactively engage in their health and related decisions, then more attention has to be focused on communicating the right information effectively and ensuring healthcare systems incorporate faster feedback from patients’ data:<sup>ix</sup> “*We will need to have more compelling narratives to deliver and support*

*behavioral and societal change.*" We may, for example, seek to make more of positive feedback, such as Walgreen's success with using points as payback for drug compliance<sup>10</sup>, rather than encourage negative pressures such as are generated by exercise monitors which highlight failure to meet set goals.<sup>11</sup> That said, in San Francisco it was pointed out that, we should be careful not to confuse consumers with patients. They are very different - "*consumers are increasingly digitally dependent, but patients are often digitally desperate.*"

## BENEFITS FOR THE SYSTEM

There are also wider benefits of access to better data – primarily for healthcare providers and payers who see the opportunity for far greater efficiency - especially in reducing complexity and improving compliance. At an industry level, richer data offers the opportunity for more experimentation to test then scale. More and better data about patient health will not only improve the effectiveness of individual healthcare but, by implication, at a population level enhance that of the whole health infrastructure. This is welcome news at a time when many healthcare systems are under increasing stress and ensuring that the benefits of this flow through is a priority for many. A recent Willis Towers Watson study found that U.S. employers expect their health care costs to increase by 5.5% in 2018, up from a 4.6% increase in 2017. The study projects an average national cost per employee of \$12,850.<sup>12</sup> Getting this spend under better control is clearly a priority concern.

In principle creating and providing more health value for patients has always been both the ultimate goal and an increasingly critical competitive advantage for health care payers and providers worldwide. It is a continuous challenge, particularly when payer organisations are having to manage funding gaps and improve the care of members within a changing regulatory environment. Such are the growing pressures that many healthcare providers must transform their business models to deliver cost-competitive services that not only improve patient outcomes but are also expected to deliver sustainable growth for the organisation.<sup>13</sup> In many

regions achieving this is about improving access. However, in nations where there is already pervasive healthcare, there are still constant demands for greater efficiency. Budgets are always tight and so any opportunity to improve efficiency is welcome.

The German and Swiss healthcare systems are often seen as the world's best<sup>14</sup> with the French method often in close contention.<sup>15</sup> However when "*value for money*" is considered, across Western nations, studies frequently identify the UK's NHS as the most efficient.<sup>16</sup> The US-based, Commonwealth Fund<sup>17</sup> analysis of healthcare systems in 11 nations finds NHS is the best, safest and most affordable.<sup>18</sup> Within this context, it was notable that in our London workshop it was suggested that "*many Western healthcare systems are on the verge of failing and without significant improvements in efficiency or major increases in funding they may collapse.*" Better use of data is going to be pivotal. In US discussions the response was more prosaic, pointing out that healthcare systems have allegedly been on the edge of failure for decades, but they never do as 'customers' keep paying more. Indeed, in a New York discussion it was highlighted that, despite spending around 17% of GDP on healthcare, all expectations are that the money flow will continue to grow. That said, not everyone was optimistic, and another US opinion in Boston was that "*global healthcare is on the brink of a series of multiple systemic shocks that will force a rethink to a more efficient model – and this will apply across many nations - including the US.*"

In Brussels, the assessment was that "*healthcare is struggling to manage budgets, but digitization provides an opportunity to identify the low-hanging fruit.*" In London, it was seen that AI could be a key enabler of greater efficiency, while in Dubai it was envisaged that both AI and robotics will drive down healthcare costs: "*To deliver the envisioned change, massive parallel processing needs to take place - and this has to be aligned with much lower cost diagnostics across data sets. Only then can we achieve large-scale implementation that will provide cheaper, better diagnosis and start to have a positive impact on patients globally.*"

The potential for greater efficiency was also highlighted elsewhere: “*Innovation happens when there are gaps and there are lots of gaps in India - so lots of opportunity.*”<sup>19</sup> In South Africa, a major focus is the need to bridge the divide between the public and private systems. In Singapore, where there is increasing collaboration across multiple areas of activity, greater efficiency remains a core objective.

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. Comparing the cost of prostate cancer treatment in Canada vs. the US was a frequent reference point; in Canada it is limited to \$6,500 per patient but in the US, it is much higher – over \$30,000 in some cases. Another common issue raised in Europe is the need to improve end of life support.<sup>20</sup> Whether by more open discussion of palliative care, more data-enabled ‘in-home’ support or more transparent options for intensive care, refining the financial and social dimensions, is a growing priority.



# Unexpected outcomes

*A number of experts also highlighted that there may also be a negative impact from too much data. A frequent concern in many foresight projects is that we do not think enough about the unexpected outcomes and unintended consequences of our well-intentioned actions.*

In a previous programme exploring the future of food, a New York conversation highlighted the introduction of calories alongside prices on all restaurant menus. While designed to provide individuals with better information about the possible food options and so help people to make choices that improve their diet, this was not a universal outcome. Notably, for a good number of the urban poor, seeking to get value for money, the new menus allowed them to choose food options that provided the most calories per dollar. As such their behaviour was the opposite of what was intended.

Several experts in our discussions saw that there is often a downside about the growing dependence on technology. A question to consider therefore is what will be the unexpected outcome of all the new, more personalised information that is being generated, shared and analysed? For example, in the US and South Africa events there were comments from doctors about too much tech meaning that, “*we spend too much time looking at screens rather than patients' faces.*”<sup>21</sup>

More accessible data, more accurate information and better analysis will, as we will see later, provide the opportunity for all to be healthier and receive better healthcare support – but it may, for instance, also result in the identification and exclusion from systems of those with very high or expensive health risks. As we embrace new technology and develop new models we should be cognizant of both risk and opportunity.

This will, we hope, help to support and validate many of the assumptions that you are making about how healthcare will improve over the next ten years. In addition, as it shares a broad range of views drawn from many different expert voices around the world, it may also challenge some of your current perspectives and lead to new opportunities for innovation in and around patient data. We hope that it is a useful addition to your library.