FUTURE OF PATIENT DATA
Insights from Multiple Expert Discussions Around the World
Global Ambition

There are great expectations on the benefits from access to more and better patient data - A common aim is to ‘give health data back to the individual’ so the patient becomes the point of integration and control.
Improving Efficiency

Implicit within many healthcare systems is the need to use data to improve efficiency and reduce costs. Without a fundamental shift driven by enhanced information use, several care services may become stressed to breaking.
RESEARCH CONTEXT
Expert Insights | 12 Major Discussions Around the World (Sep 2017 to Jan 2018)
Location Criteria
These twelve events were held in a selection of countries with different levels of health spending and average life expectancy - as well as varied combinations of public and private healthcare systems.
The volume of health data is evidently growing rapidly.
Sources of Patient Data
Changing Definition of Patient Data

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

- External Innovators
- Patients
- Primary Care
- Secondary Care
- Marketplaces
- National Governments
- Payers
- Manufacturers
SHARED CHALLENGES

- Security and Privacy
- Integration
- Trust
- Ownership vs. Access
INTEGRATION
Gaps and Interoperability

Given the multiple data gaps in existing systems, the expectation is that technology will provide solutions that better bridge these and ensure interoperability. Common standards and cleaner data will be fundamental drivers of change.
Doctors with EHR and Multifunctional Health IT Capacity

Source: Commonwealth Fund 2014

EHR Integration | A core ambition in combining data sets
Increasing Control

The question of ownership of health data is in flux - especially on access vs. use. Patients may have increasing ‘control’ of their data, but whether they become ‘custodians’ depends on culture, regulation and need.
TRUST
Building Trust

In many regions, trust needs to (re)built between payers, providers and patients as well as with new entrants. New technology platforms and improving communication with the public both play a major role.
Managing Distrust

Concern about ulterior motives for the use of data is high and some see AI adding to the challenge. Many recognise the need for greater transparency on practice in some pivotal areas.
Consumers Willing To Share Health Data

Source: Rock Health 2016 Consumer Survey

Data Sharing | Who we trust with our health data is critical
SECURITY AND PRIVACY
Data Breaches | Health data breaches have been amongst the biggest globally
Enhanced Protection
Anonymized, aggregated data is more easily re-linked and sensitive health data is a target for cyber-attacks. Questions are raised around the benefits of centralized vs. decentralized data, encryption and the impact of localisation.
PERSONALISATION
Individualized Medicine
The prospect of more individualized ‘n=1’ healthcare is accelerating. Predictive analytics and genetic profiling transform medicine: But will the benefits be for all or just a lucky few?
Personal Data Stores

New platforms help patients and providers to manage and curate their data across multiple partners. Universally accepted credentials help to drive greater personalisation of health services.
DATA MARKETPLACES
Health Data Marketplaces
Embedded in the future of access to health data, is its value, exchange and what will be public commons vs. what is for commercial purposes. Personal and clinical data will increasingly be represented in healthcare data marketplaces.
The Initial Impact of AI

There are great expectations around AI. Initial advances from machine learning and pattern recognition will be most significant in enabling more efficient diagnosis and better prediction.
AI and Unstructured Patient Data

As deep, self and reinforced learning develop, the ability to deal with unstructured data delivers major improvements in diagnosis and treatment. AI agents learn by trial and error and AI is embedded into many clinical decisions.
AI and Mental Health

With voice and facial recognition increasingly analysing users’ patterns of behaviour, AI is applied to identify stress and anxiety. Some patients are more comfortable and honest talking to machines rather than humans in high-stress situations.
China is rapidly growing its AI capability in healthcare.
NEW MODELS
Re-engineering from Within

Change is coming from governments and major existing healthcare companies. More patient-focused and collaborative business models are targeted on changing reimbursement mechanisms and driving shared risk across the payers and providers.
India and China Setting Standards

Significant new approaches for global healthcare may emerge from India where the scale of Aadhaar and related platforms drives integration and innovation. China is also building momentum across surgery, AI and predictive analysis.
Big Tech Health

Led by Amazon, big tech will disrupt and reinvent some core elements and unify fragmented systems. All of the big 5 are investing heavily in major ‘special’ projects focused on the radical transformation of healthcare centred on the individual.
DATA SOVEREIGNTY
Data Localisation and Control

Driven by national security, commercial interest and privacy standards, more governments seek to restrict the sharing of health data beyond their borders - and so push-back against some global ambitions.
DIGITAL INEQUALITY
Access Inequality

As advances roll out, there is growing concern for those being left behind. Some hope that, with more and better data, health inequality can be reduced. Others see a widening divide between those with access and those without.
Ageing Populations | More remote and caregiver support is seen as critical
Digital Skills

Some healthcare professionals lack the skills for digital transformation. Whether we need to learn, unlearn and relearn new skills, or if new systems can evolve fast enough to provide seamless support for doctors, is a growing debate.
Agreed Standards
Many want standardisation of outcome-based measures. With regulators behind the curve, compliance, consent and privacy are shared concerns. How countries deal with these is as much political and commercial as it is technological.
PRIVATISATION OF HEALTH INFORMATION
Open vs. Private Knowledge

Escalating privatisation of medical knowledge and more ‘secret software’ challenge the view that healthcare information, especially concerning AI, should be open source or shared within agreed governance systems: Deep pockets have greatest impact.
THE VALUE OF HEALTH DATA
Value of Data | Health data is seen as being increasingly valuable
Financial vs Social Value

As organisations retain as much information as possible, health data has a price. It is increasingly prized and what may be public vs. commercial is a major debate. Many compete to prioritise the social value of health data over the financial.
CONCLUSION
Ensuring Impact

There is lots of potential, but also many challenges. Change may occur more at a regional than global level but, to have impact, it must deliver clear advantage for those who most need better healthcare – often the weakest and most vulnerable.
Thank You
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