Blockchain and COVID19: the INATBA Experience

Mirko De Maldè – Co-Chair of the Healthcare WG

RDA Plenary Session – Blockchain for healthcare WG 09/11/2020

Healthcare

The Healthcare Working Group aims to identify stakeholders and their contributions in healthcare, establish communication with regulators and stakeholders, understand the potential of blockchain for healthcare innovation and outline regulatory elements.

Read More

DANNY VAN ROIJEN

in

MIRKO DE MALDE

in

International Association for Trusted Blockchain Applications

INATBA offers developers and users of DLT a global foru to interact with regulators and policy makers and bring blockchain technology to the next stage.

Search by Country, Territory, or Area

WHO Coronavirus Disease (COVID-19) Dashboard
Data last updated: 2020/11/9, 2:46pm CET

Overview   Data Table   Explore
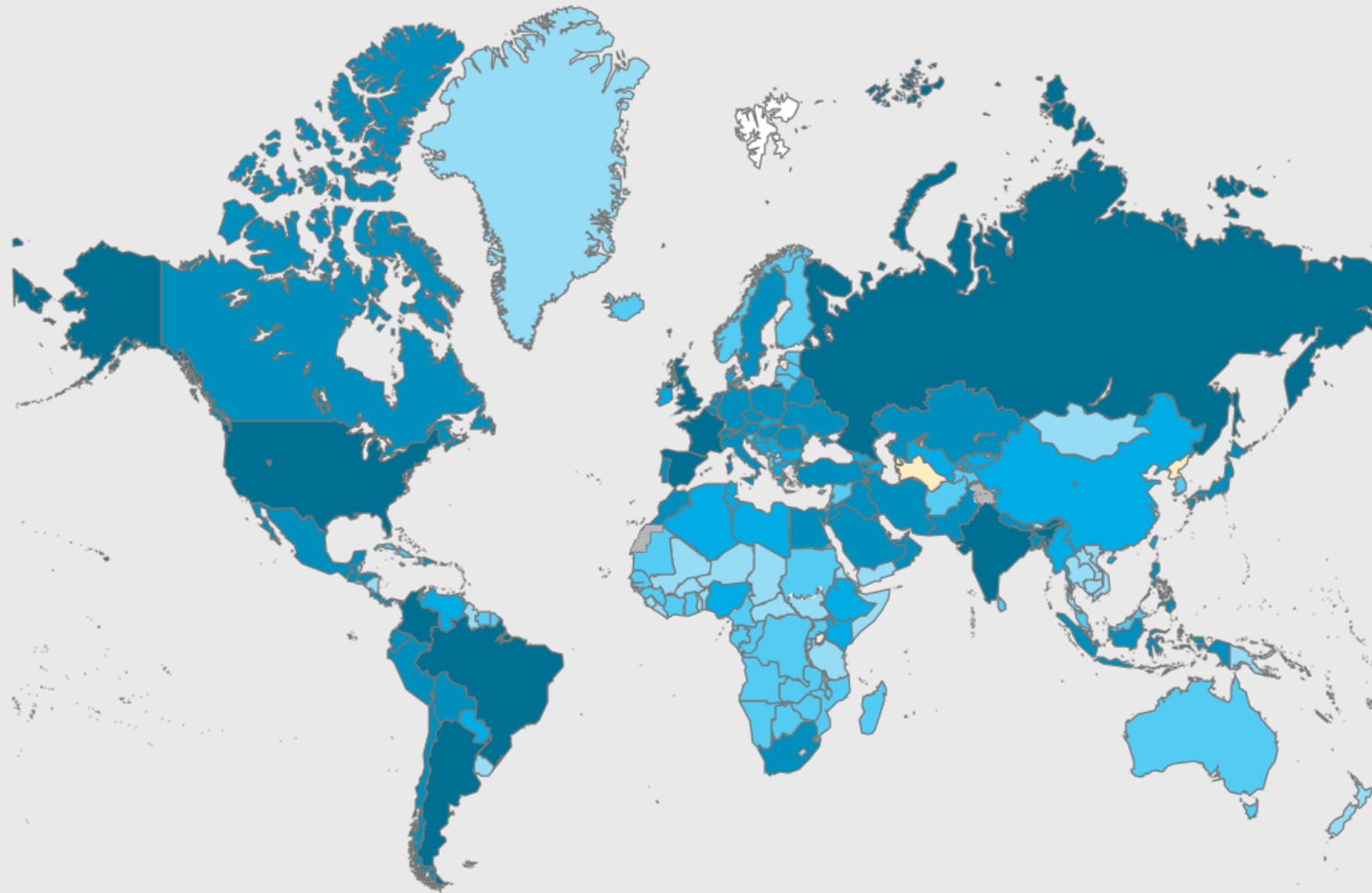
Choropleth Map   Bubble Map

Cases   Deaths

Total

677,806
new cases

50,266,033
confirmed cases

1,254,567
deaths

Globally, as of **2:46pm CET, 9 November 2020**, there have been **50.266.033 confirmed cases** of COVID-19, including **1.254.567 deaths**, reported to WHO.

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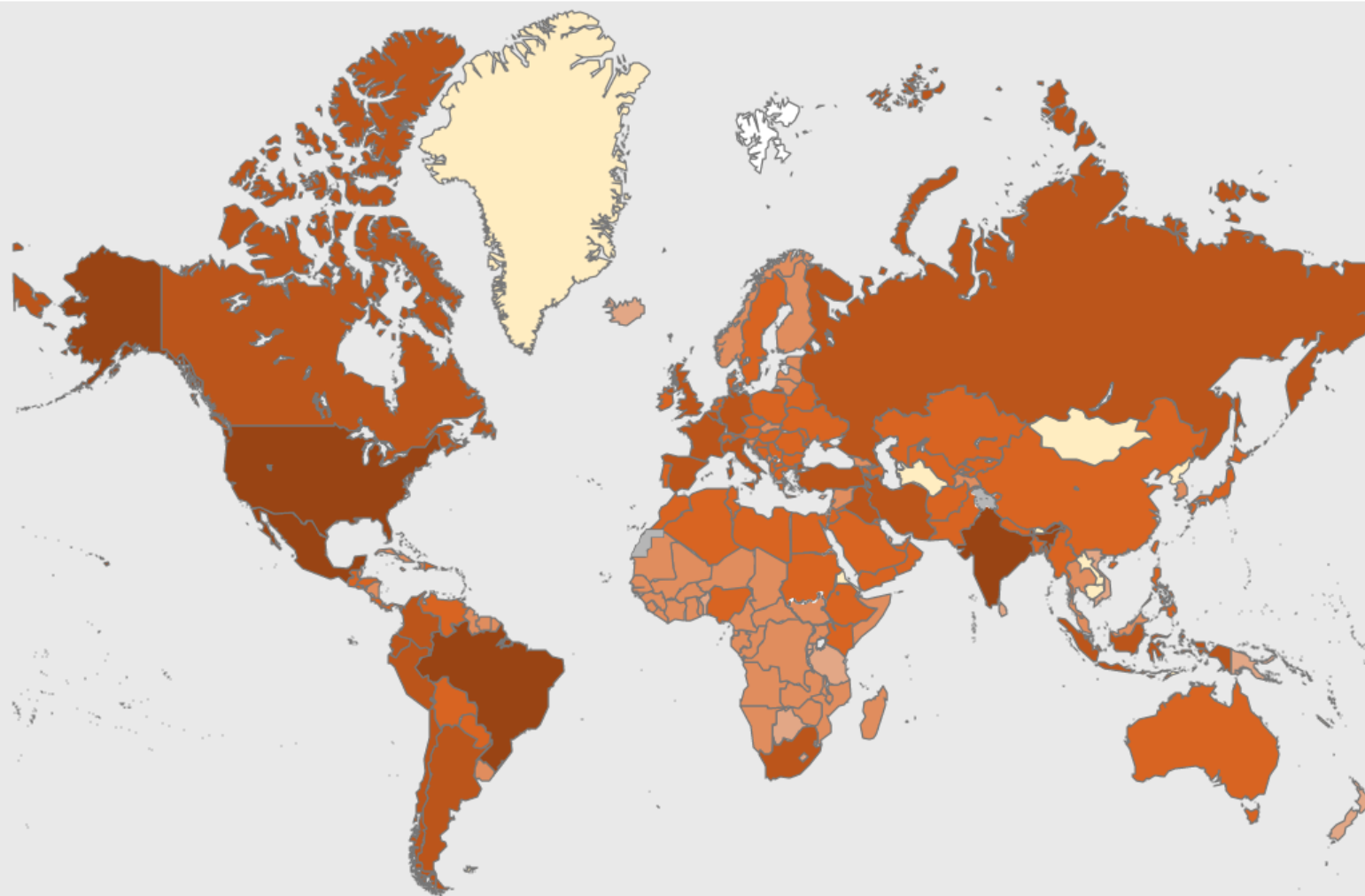
Total

8,311
new deaths

1,254,567
deaths

50,266,033
confirmed cases

Globally, as of **2:46pm CET, 9 November 2020**, there have been **50.266.033 confirmed cases** of COVID-19, including **1.254.567 deaths**, reported to WHO.

Digital health at the time of a global pandemic

- COVID-19 pandemic caused the sudden surge in both private and public interest in digital health all around the world
- Many organisations started experimenting on DLT-based solutions for facilitating data exchange and collaboration for fighting the pandemic, or improve the spread of trustful information about it
- At the same time, people started realising in a more direct way the importance of health data sharing, while also appreciating the relevant privacy concerns
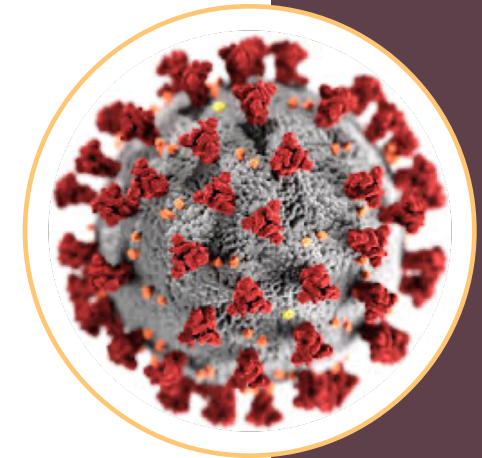
Covid-19 and Health Care's Digital Revolution

Sirina Keesara, M.D., Andrea Jonas, M.D., and Kevin Schulman, M.D.

As health care systems nationwide brace for a surge of Covid-19 cases, urgent action is required to transform health care delivery and to scale up our systems by unleashing the power of digital technologies.

How personal data could help contribute to a COVID-19 solution

In a scenario where certified applications are launched for these purposes, personal data from individuals' wearable devices or smartphones could automatically be transmitted.[…]It could then be enforced by blockchain smart-contracts that ensure that data cannot be used for other purposes. We could easily find ourselves in a scenario where individuals can opt in and provide anonymised data for free to accelerate a cure for certain diseases and then make some of our data accessible to businesses for a fee.

What Blockchain Could Mean for Your Health Data

by Don Tapscott and Alex Tapscott

June 12, 2020

It's time we started taking our personal data as seriously as the top tech firms do. We need to understand its real value to us in all aspects of our lives. Blockchain technology can help us do that, enabling us to use our data proactively and improve our well-being. And while there are many areas where taking control of our data might improve our lives, there is one particularly promising place to start: healthcare data.

09/11/2020 - Mirko De Maldè

IN/ AT BA\

RDA on COVID19

COVID-19 Recommendations and Guidelines for Data Sharing

The Challenge:

Under public health emergencies, particularly the COVID-19 pandemic, where the rapid pace of a disease and the immense and rapid mobilisation of resources could create an environment for inaccurate or low-quality data, sharing preliminary data and results in both a timely and accurate manner and harmonising the many diverse data infrastructures is crucial. The availability of research data is a key component of pandemic preparedness and response; the timeliness of accessing data and the harmonisation across information systems are currently major roadblocks.

Produced by: RDA COVID-19 Working Group

https://www.rd-alliance.org/groups/rda-covid19

What is the solution?

Develop a body of work that comprises how data from multiple disciplines inform response to a pandemic combined with guidelines and recommendations on data sharing under the COVID-19 circumstances. This extends to research software sharing, in recognition of the key role in software in analysing data. The work is divided into four research areas (Clinical, Omics, Epidemiology, Social Sciences) with four cross-cutting themes (Community Participation, Indigenous Data, Legal and Ethical Considerations, Research Software). The guidelines aim to help stakeholders follow best practices to maximise the efficiency of their work and to act as a blueprint for future emergencies. The recommendations aim to help policymakers and funders maximise timely, quality data sharing and appropriate responses in such health emergencies.

What is the impact?

A system for data sharing in public health emergencies that supports scientific research and policymaking, including an overarching framework, common tools and processes, and principles that can be embedded in research practice. Guidelines that address general aspects of data practice, for example the FAIR principles, or the adoption of research-domain community standards.

Find out More about the RDA COVID-19 Recommendations and Guidelines for Data Sharing

August 2020

COVID-19 TASK FORCE

Government Participants

Government participants will support the COVID Task Force by identifying their most important challenges caused by the COVID pandemic to the systems and services they provide their citizens.

JOIN

Academic Participants

Academic participants will support impartial research and analysis of blockchain-based projects identified by the Task Force.

JOIN

Industry Participants

Industry participants will support the COVID Task Force by submitting proposals for solutions that can solve the significant issues and challenges caused by the COVID pandemic.

JOIN

WHAT IS INATBA'S COVID TASK FORCE?

The INATBA COVID Task Force is convening key players in the global blockchain ecosystem to identify deployable technology solutions that address governmental, social and commercial challenges caused by COVID. Working on an expedited timetable, the Task Force will analyze, sort, package and present solutions to governments and organizations to deliver real value quickly.

For governments, the Task Force will leverage its expertise and neutrality to identify deployable solutions that are most applicable to their specific needs. For the private sector, the Task Force will serve as a curator of solutions, convening partners and managing relationships to adapt the solutions as needed and ensure that specific needs are being met.

The Task Force will build an intelligence engine that identifies and catalogues industry-wide blockchain-related solutions that can assist with the global challenge. The engine will establish the state of readiness of each solution, identify any additional work required to make the solutions ready for market or fit to solve the identified issues. The process will include the ability to curate collaborations between solution providers to deliver the best solutions.

INATBA Convenes Global Conversation on Standards, Governance and Interoperability

✉ News

June 3, 2020

READ MORE

by Sofie Peeters

💬 0 Comments   🕐 16 Minutes

The INTABA COVID Task force

- Convening key players in the global blockchain ecosystem

- Identify deployable technology solutions that address governmental, social and commercial challenges caused by COVID19

- Analyze, sort, package and present the solutions to governments and organizations to deliver real value quickly

- INATBA has already secured commitments from the European Commission and the University College London (UCL) to participate in the Task Force
  - UCL's analysis seeks to establish the closest fit between the requirements identified by the Government of Spain and the 20+ private sector solutions submitted

- INATBA also joined the World Economic Forum's COVID Action Platform
  - The WEF platform brings together the World Health Organization, corporate CEOs and top experts from leading global organisations to coordinate multi-stakeholder contributions into the fight to combat the global spread of coronavirus

The categories of solutions submitted to the WG

- A variety of solutions have been submitted for evaluation to the healthcare WG:
    - Digital identity systems
    - Secure health record sharing (e.g., provenance, integrity)
    - Verifiable tests results
    - Clinical trial data integrity, auditability, and system integration
    - Traceability of financial and in-kind donations and social impact reporting during Covid-19 crisis
    - Pharma supply chain and anticounterfeiting for covid-19 related drugs
    - Ecosystem for managing subsidy programs, automatically distribute them, and allow private actors to collect donation or pre-sell vouchers for good and services
    - Tackle misinformation

The INTABA Healthcare WG - Objectives

- **Mapping the blockchain landscape in the healthcare sector**, identifying key stakeholders, use cases, success factors, legal and other challenges in uptake

- As a solid basis to **structurally engage with relevant bodies and governments**

- While interacting with the broader healthcare community with a view to **educate and establish a bi-directional learning process**

Some specific objectives

- Increase the clarity on how Blockchain operates in Healthcare, also and address technical, organizational, and behavioural economics challenges related to uptake

- Enhance clarity on the stakeholder's landscape

- Increase clarity on the legislative and regulatory landscape (we are currently working on a comprehensive list of current regulations and existing gaps)

- Improve interaction with the stakeholders in the healthcare domain (i.e. healthcare providers and professionals) to clarify the potential of blockchain in different potential use case scenarios, via a two-way learning process

INATBA and the EU Blockchain Observatory and Forum

- The Healthcare WG has established a cooperation with the European Blockchain Observatory and Forum (EUBOF)

- This collaboration will also include INATBA's contribution to the forthcoming EUBOF Report on blockchain in healthcare

INATBA and RDA

The INATBA healthcare WG and RDA could cooperate in:

- Organisation of roundtables on specific topics of common interes
- Collaboration in the standardisation effort
- COVID 19 – blockchain-based solutions, in cooperation with relevant RDA working groups

Thanks!

But it is not just about COVID-19

- A profound rethininking of health services delivery is a mandatory step for ensuring long-term sustainability of health services all around the wolrd
- We also need digital tools for achieving the UN Sustainable development Goal no. 3: Good Health and Well-Being
- Prevention, personalisation, risk assessment, participation of citizens in the care process, are all fundamental aspects of this process

But how digital health tools and DLT-based tools can help?

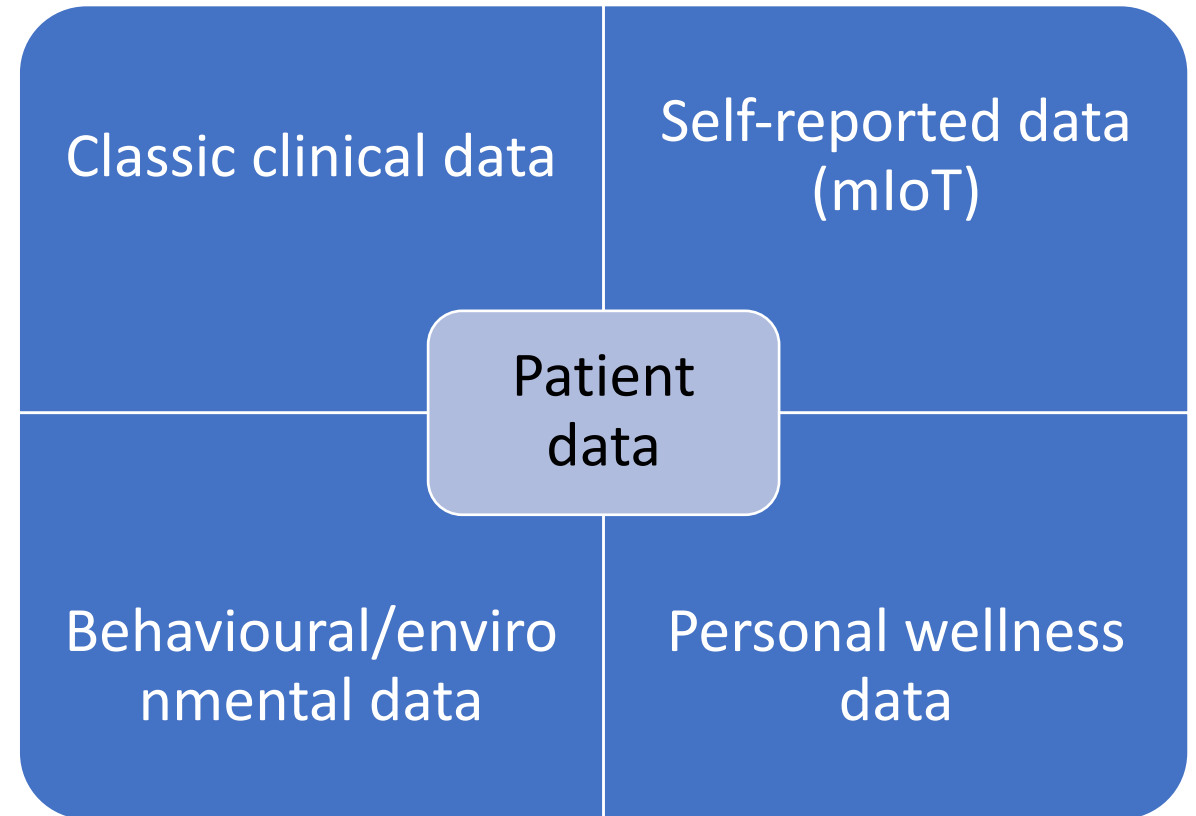# Data: a key element for the transformation of medicine

"big-data_conew1" (CC BY-SA 2.0) by luckey_sun

- With **its 150 exabytes of stored data worldwide per year**, Healthcare is a bright example of **"data explosion"** phenomenon

- Within 2020 – **40% of IoT technologies will be healthcare-related**

- This will be the basis of hte "Internet of Medical Thing" (IoMT), or **medical Internet of Thing (mIoT)**

The explosion of patient-generated data

- Patient datasets are expanding, thanks to genomic data and patient-generated data
  - 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.
  - Some analysis have seen a **300% growth** in healthcare data between 2017 and 2020.
- Improved patient engagement and self-management will occur as a result

Classic clinical data	Self-reported data (mIoT)
Behavioural/environmental data	Personal wellness data

Patient data

TIME

Google's Health Care Ambitions Now Involve Thousands of Patient Records

THE WALL STREET JOURNAL.

Google's 'Project Nightingale' Gathers Personal Health Data on Millions of Americans

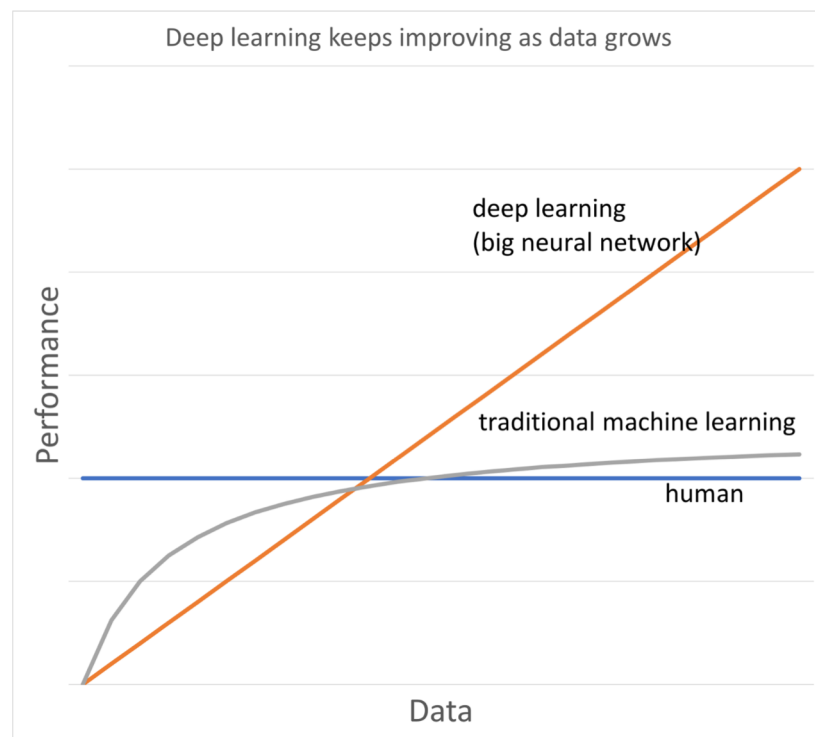Search giant is amassing health records from Ascension facilities in 21 states; patients not yet informed

GOOGLE · **Published** 2 days ago

Google defends amassing health data on millions of people

CONNECT UNIVERSITY – 29/09/2020 - Mirko De Maldè

INATBA

Data and AI

Deep learning keeps improving as data grows

deep learning
(big neural network)

traditional machine learning

human

Performance

Data

Kevin Dewalt, "Deep Learning Matters for One Simple Reason –
Prolego Blog." Prolego Blog, Prolego Blog, 12 Apr. 2017,
blog.prolego.io/deep-learning-matters-for-one-simple-reason-
3cf51e25937d

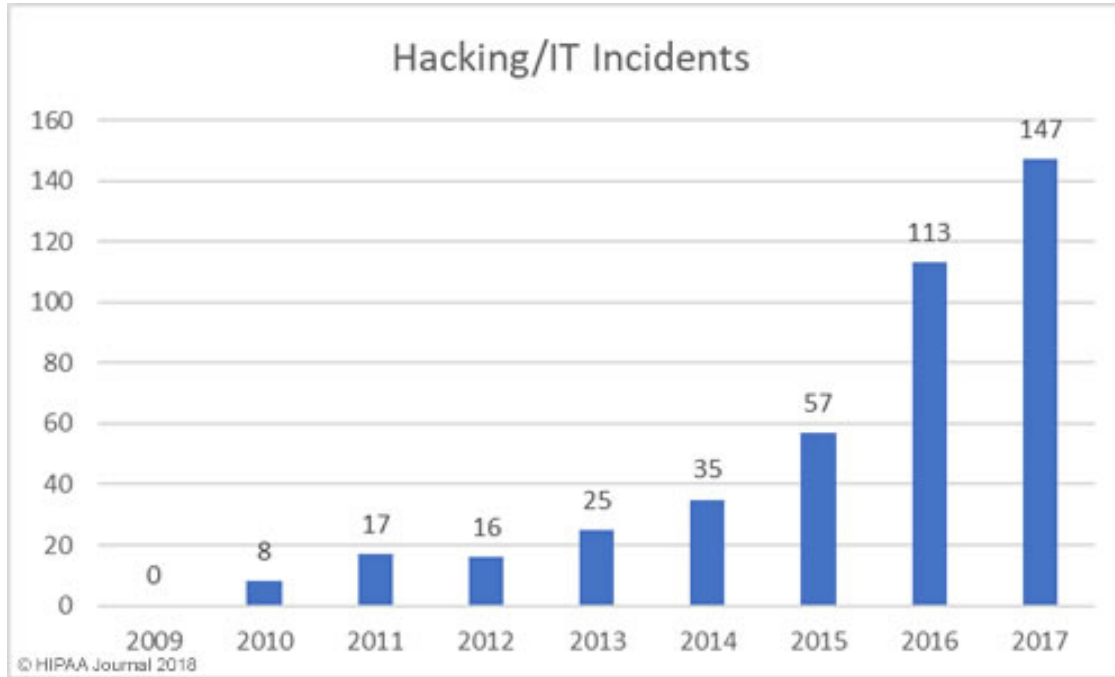## FORTUNE

Unmasking A.I.'s Bias Problem

Artificial intelligence can imitate and enhance human decision-making -- and amplify human prejudices. Can Big Tech tackle A.I.'s discrimination problem?

By Jonathan Vanian

June 25, 2018

- AI algorhitms are known to be extremely data hungry, and their effectiveness depends on quality and quantity of data used for their trianing
- Also due to the fact that data for training are in siloded database, AI alogrhitms have alreadyw showed to be biased, and not able to provide proper answer to questions in regard to specific diseaseas/populations
- In order to overcome this issue, open distributed databases could be a solution, provided that they ensure:
  - Data integrity
  - Interoperability
  - Lawfull data access, security and privacy

The issue of security

Hacking/IT Incidents

Year	Incidents
2009	0
2010	8
2011	17
2012	16
2013	25
2014	35
2015	57
2016	113
2017	147

© HIPAA Journal 2018

"Healthcare Data Breach Statistics." *HIPAA Journal*, HIPAA Journal, www.hipaajournal.com/healthcare-data-breach-statistics/. Visitato il giorno 9/11/2018

Q2 2018 PROTENUS BREACH BAROMETER

3.14M Patient Records Breached As Patients Are Increasingly Anxious About Health Data Security

Protenus, Inc. in Collaboration with DataBreaches.net

Q2 2018 PROTENUS BREACH BAROMETER

The General Data Protection Regulation (GDPR)

- ***Data access*:** "A data subject should have the right of access to personal data which have been collected concerning him or her"

- ***Right* to *data portability*:** receive personal data in a **structured, commonly used, machine-readable and interoperable format**"

- **Consent**
  - **Freely given**, **informed**, and **specific**
  - **Easily readable**, and in **plain language**
  - Data Controller will have to **demonstrate consent**

Increasing awareness and concerns over personal data is of particular interest…

- "Soon after you tell your doctor about an intimate medical problem, data about your condition are sold commercially to companies that have nothing to do with your treatment or billing"

Adam Tanner, "Our Bodies, Our Data"
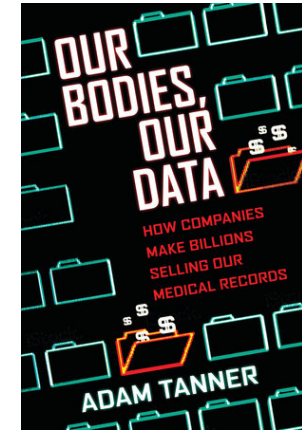
The New York Times
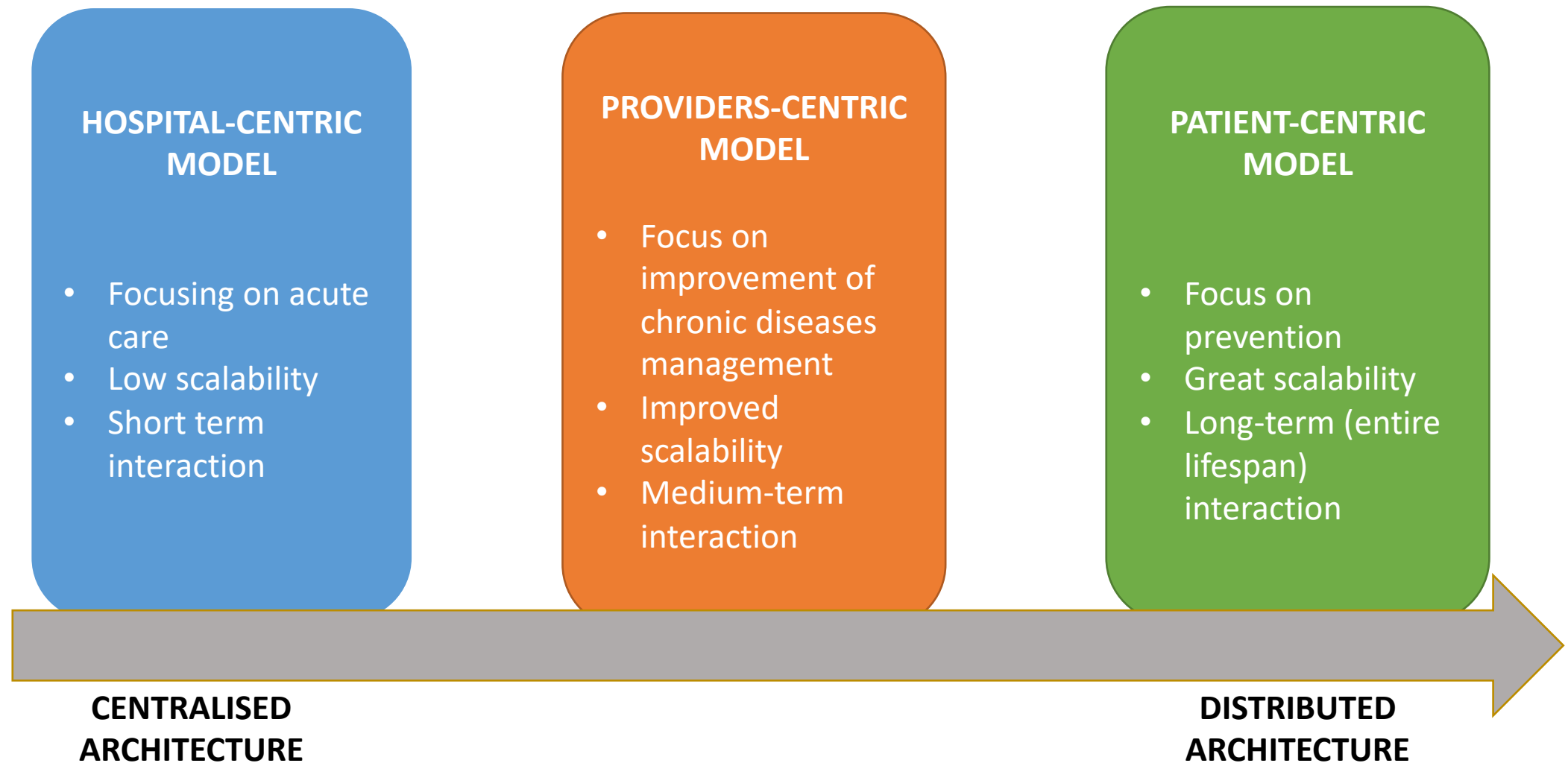
The Opinion Pages | OP-ED CONTRIBUTORS

The Health Data Conundrum

By KATHRYN HAUN and ERIC J. TOPOL   JAN. 2, 2017

"[We shall overcome] the old, paternalistic model in medicine in which the data is generated and owned by doctors and hospitals"…

"*Patients should be the owners of their own medical data. It's an entitlement and civil right that should be recognized*".

A shift from hospitals to patients

HOSPITAL-CENTRIC MODEL

- Focusing on acute care
- Low scalability
- Short term interaction

PROVIDERS-CENTRIC MODEL

- Focus on improvement of chronic diseases management
- Improved scalability
- Medium-term interaction

PATIENT-CENTRIC MODEL

- Focus on prevention
- Great scalability
- Long-term (entire lifespan) interaction

CENTRALISED ARCHITECTURE

DISTRIBUTED ARCHITECTURE

Healthcare data – some key needs

- New ways of mobilising data and allow trusted usage
- New ways of integrating data from various sources for meaningul use (in particular patient-generated data from mIoT and mobile apps)
- New consent management and direct data access and control tools for enabling individuals engagement

Why blockchain is relevant for health data management

- Overcoming issues associated with **centralized healthcare data management**

- Enabling individual **data self-sovereignity and patient-centric healthcare** (also through direct control of data by patients)

- Facilitating health data exchange for research, care, and new developments

- Facilitating tracing and certification of a variety of process (from pharma supply chain to clinical trial protocols' management)

- Creating new economy and market around patient data

- Improving economic incentive schemes and provide individuals with additional motivations for engaging with their health

Blockchain can mean different things for different actors:

- For **hospitals** it might be a way to solve data insecurity and interoperability;
- For **doctors** it might help manage professional identity and simplify payments;
- For **pharma** and **medical device companies** distributed ledgers can assist in supply chain, inventory management and fraud detection.
- For **patients** it can provide the opportunity to control and own their data, their insights and their health, also via advanced consent mechanisms

Data Access and exchange	• Improved access to data, facilitate privacy management, consent management • Identity management tools • Longitudinal health record
Drugs authenticity	• Supply chain transparency • Provenance tracking • Reduce drugs counterfeiting
Clinical trials	• Improve transparency and auditing • Improve relationship management among stakeholders • Facilitate protocol and consent management and updates
Epidemiology and public health	• Improve data flow on the spread of contagious diseases
Medical IoT	• Encrypt and share securely patient generated data • Ensure privacy and security and identity of the medical device
Improved service management	• Improved control and transparency over access to health services by individuals, including visit to GPs, drugs consumption, access to Emergency rooms • Certification of medical professionals • Compliance
Introduce reward system of service tokenisation	• Improve engagement of individuals, encouraging healthy behaviours or facilitating access to specific services
Blockchain-based claims billing management / health insurance	Improve health insurance services providing , tamper-proof claim management and fraud reduction, reduction of administrative burdens, as well as enabling personalised services, dynamic pricing, improved access

What role blockchain can play?

- Act as a **orchestration layer** in charge for managing and authorising data exchange and access

- **Regulate data access** on the basis of user-defined permission/consent settings

- Provide full **traceability and auditability** of data access and exchange

- **Automate data "sanitisation"** and data provision thanks to smart contracts

- Implement **GDPR compliance** in particular in regard to right to erasure/correction

Blockchain-enabled convergence…

- Blockchain can interact and orchestrate the usage of a variety of tools for both data gatherting, data protection, and data analysis
- It can coordinate IoT devices over a network, providing trust via authentication of devices and data streams
- It can orchestrate the adoption of privacy-preserving data analysis tools and federated learning processes

- The **MHMD project**, which we just saw, is a bright example of how blockchain can be used as orchestrator for the application of multiple tools for data clearance and certify data handling procedures

Recent trends in the industry

- According to the most recent Deloitte report on Trends in blockchain:
  - The industry passed the hype phase
  - Many industries are focusing on robust and enterprise-ready solutions, in particular in the area of identity protection, data access and data validation
  - Most of the solutions are adopting private permissioned DLTs solutions, due to high scalability and stronger governance, with pre-authorisation for all participants

Some challenges

- Awareness and education about the potential of the technology in the healthcare domain
- Cultural resistance in the adoption of novel IT tools and in the adoption of different data management modalities
- Interoperability with legacy IT systems
- Performances and DLT-based solutions interoperability
- Regulatory constraints
- Awarness about vendors and available solutions on the market
- Patients and citizens awareness in regard to data and lack of honest data stewardship

Some near-future predictions

BLOCKCHAIN IN HEALTHCARE TODAY

Top 10 Blockchain Predictions for the (Near) Future of Healthcare

John D. Halamka,[1] Gil Alterovitz,[2] William J. Buchanan,[3] Tory Cenaj,[4] Kevin A. Clauson,[5] Vikram Dhillon,[6] Florence D. Hudson,[7] Manouchehr (Mitch) Mokhtari,[8] Dennis A. Porto,[9] Ana Santos Rutschman,[10] Anh L. Ngo[11]

Table . Ten major themes for the near-term future of blockchain in healthcare

Predictions
#1. Blockchain will become an essential part of consent management in healthcare
#2. Remittance and micropayments will increasingly migrate to blockchain
#3. Non-cash assets including outcomes will be tokenized
#4. Providers will be credentialed on chain
#5. Improvements to blockchain infrastructure will reduce electricity requirements and enhance speed/scalability
#6. Supply chain integrity will be tracked on blockchain
#7. Education of stakeholders will refine use cases for blockchain and accelerate adoption
#8. Opportunities for monetization of data, including the genome, will be enhanced by blockchain
#9. Integrity of medical records will be an essential use case for blockchain
#10. Existing blockchain in healthcare startups will be acquired and we will see substantial consolidation of blockchain in healthcare offerings