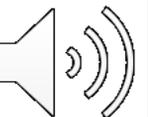


Global Health Research: Challenges with Data Management and Data Sharing across Continents

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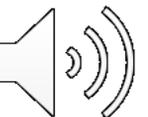


Importance of research data sharing



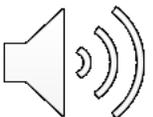
Wikipedia

- ▶ Data is the lifeblood of the modern global economy.
- ▶ Much of the data collection that could improve public health research is expensive and time-consuming.
- ▶ making research data sets available to investigators beyond the original research team in a timely and responsible manner, subject to appropriate safeguards, will generate three key benefits:
 - ▶ faster progress in improving health
 - ▶ better value for money
 - ▶ higher quality science.

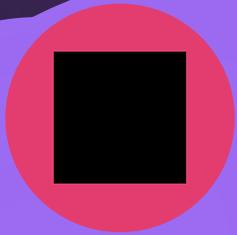


Data management challenges

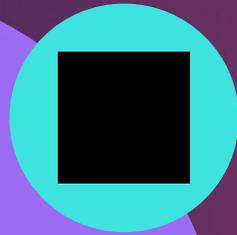
- ▶ Sheer volume of data
- ▶ Lack of processes and systems
- ▶ Fragmented data ownership
- ▶ Optimal database performance at o
- ▶ Data Governance
- ▶ Data protection
- ▶ Many languages of data reports
- ▶ Heterogenous format



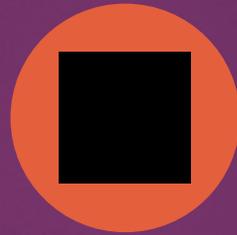
Extended consequences



WHEN IT IS NOT POSSIBLE TO CREATE A PUBLIC-USE FILE BECAUSE THE ANALYTIC POTENTIAL OF THE DATA SET WILL BE COMPROMISED,



SPECTRUM OF SOLUTIONS FROM SECURE DATA DOWNLOAD WITH A LEGAL AGREEMENT ON DATA USE TO ANALYSIS IN A VIRTUAL DATA ENCLAVE TO HIGHLY RESTRICTED ACCESS IN AN ON-SITE PHYSICAL DATA ENCLAVE



THE IMPORTANT THING IS FOR THE LEVEL OF DATA SENSITIVITY TO BE MATCHED WITH THE APPROPRIATE DISSEMINATION MECHANISM

4

COMMON CONCERNS

ABOUT OPEN ACCESS DATA SHARING

1 COMPETITIVE ADVANTAGE

- Fear of being 'scooped' by other researchers
- Need to protect intellectual capital

2 NATURE OF DATASET

- Dynamic dataset
- Large dataset
- Data in non-digital form

3 CONFIDENTIALITY

- Personal Data Protection Act (PDPA)

4 LEGAL & IP RIGHTS

- Using a derived dataset
- Data has a commercial application

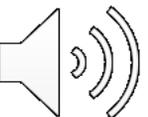


How the COVID-19 pandemic is shining a light on the importance of robust and timely data management and data sharing

- ▶ In the first few weeks of the pandemic, knowledge about the disease and its treatment was generated from sharing of anecdotal observations and small case series.
- ▶ Lessons Learned on Data Sharing in COVID-19 Pandemic Can Inform Future Outbreak Preparedness and Response
- ▶ Many journals have lowered their paywalls on COVID-19 papers in accordance with WHO guidelines for sharing data in public health emergencies. Lowering of paywall for publications.....22k papers on COVID published just in 3-4months time.



Opendatawatch

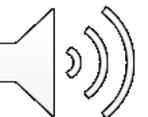


Contd.



Biomed central

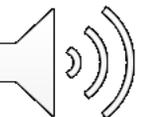
- ▶ A robust system now exists for the rapid sharing of viral genome sequence data
- ▶ Clinical and research data are often siloed, requiring further efforts to join them
- ▶ Healthcare Data Sharing Connects the Dots for COVID-19 and Beyond
- ▶ Centralized healthcare data available for the country which helps in policy and decisions



Examples from India



- ▶ Details led to lots of discrimination against Covid -19 patients
- ▶ Personal data safety of COVID patientsa lot of such instances were noted like publicising individuals of a certain community who had gathered for a religious convention in New Delhi and then spread to the rest of the country.
- ▶ Arogyasetu app.... privacy still a concern.... accessible to many ...



Decoding the data protection bill

WHAT IT MEANS FOR CONSUMERS

- **DATA** can be processed or shared by any entity only after consent.
- **SAFEGUARDS**, including penalties, introduced to prevent misuse of personal data.
- **ALL** data to be categorized under three heads—general, sensitive and critical.

THE GOVERNMENT & REGULATORY ROLE

- **GOVT** will have the power to obtain any user's non-personal data from companies.
- **THE** bill mandates that all financial and critical data has to be stored in India.
- **SENSITIVE** data has to be stored in India but can be processed outside with consent.

WHAT COMPANIES HAVE TO DO

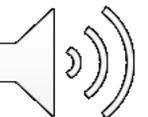
- **SOCIAL** media firms to formulate a voluntary verification process for users.
- **SHARING** data without consent will entail a fine of ₹15 crore or 4% of global turnover.
- **DATA** breach or inaction will entail a fine of ₹5 crore or 2% of global turnover.

Source: Mint research



Personal Data Protection bill 2019

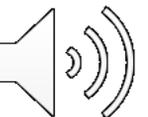
The Hindu



Tips for data sharing



- ▶ Anonymize personal information
- ▶ Take care when using data
- ▶ Statistical ability
- ▶ Be aware of legal obligations
- ▶ Acknowledge the data generators



Solutions

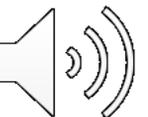
Treating data sets as first-class intellectual objects, akin to articles in peer-reviewed journals, is a relatively new idea

Incentivizing data sharing

The key to providing recognition to data producers is citation.

Recommendations and guidelines on data sharing

Split up guidelines for four research areas (clinical, omics, epidemiology, social sciences)



Thank you for your kind attention



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