Open Access of Health Research Data: Free Trade or Fair Trade?

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Compelling Arguments

- Growing research and technological advancement
- Funders – Maximize the use of research findings through data use
- Journals – Mandatory or voluntary provision to share original data
- Research Participants – Expect to use research result to improve health for them and their community

Benefits: Economic & Academic Valise

- Justice to information funded by taxpayers' money
- Useful when large studies are economically and technically compromising
- Dataset arising from large studies are useful for size and cost – Epidemiological research question specially in disease genetic
- Opportunity to investigate rare epidemiological phenomena

Benefits: Economic & Academic Valise

- Infrastructure development and scholarly quality
  - E.g.: NHS and Welcome Trust invested in data cleaning for Human Genome Study with the condition to make the raw data publicly available (Pisani and AbouZahr, 2010)
- Answer new research questions far beyond the original research studies.
  - E.g.: Time series analysis of routine data to guide policy makers on historical development of an issue (Pisani and AbouZahr, 2010)

Differing Views

- Ownership: Open access data underestimate efforts and integrity of primary researchers

  o E.g.: Primary researchers has to cross the ethic huddle which is a benefit for secondary researchers

- Insecurity: hostile agencies or researchers may access data to deliberately criticize researchers

  o E.g.: pharmaceutical/chemical industries hire epidemiologist to criticize independent research into side effects of drugs/chemical to label the original research as a junk science.

Challenges- Methodological

- Possibilities for ambitious request beyond the capacity of an entity. E.g.: X Ray image rather than coded data
- Reanalysis is not a mere calculation but is understanding substantive context, the weakness and strength of data
  - E.g.: certain variable collected in Epidemiological studies in UK and Ireland were never cleaned resulting limited analyzability by primary researchers and secondary (Pisani and AbouZahr, 2010).

Challenges: Technical/ Resource

- Few competent data managers in the public health field have realized the value of secondary raw data.
- Lack of institutional incentives for data preparation, annotation and communication
- Research from LMIC will lose out to resourceful researchers from developed countries with advance tool

Challenges: Ethical/Legal

- Personal information and geographic location are sufficient to reveal personal identity

- Provision of privacy law, copy right and intellectual property right

- Lack of institutional policy and operational guidelines

Existing Practices

- No ongoing discussion and specific policy in developing countries

- Donors and Research Council from Global North oblige researchers to share data in public domain.

  - E.g.: UK Medical Research Council requires all applicants to indicate data archiving and sharing plan in its funding application, Similar Case for Welcome Trust applicants (Rani and Buckley, 2012)

Effectiveness Evidence?

- Little evaluation of effectiveness of data sharing policies.

- Publicly shared database has large impact on research and policy

  - E.g. : Secondary analysis of NDHS data has significantly increases over the past decade, which has influenced health policy in many countries (Fabic et al., 2012).

Principles

- Equitable: Data sharing should recognize the need of researchers generate and use data and those who wants to reuse those data.

- Ethical: Data sharing should protect privacy of individuals, dignity of community and should respect the scholarly work of primary researchers.

- Efficiency: Data sharing approach should improve the quality and value of research, and increase its contribution to improve public health

Possible Approach

#1 Regular deposit of data into archive for free access

#2 Researchers can request data access on ad hoc basis

#2 Establish Network with researchers to conduct focus analysis in specific areas

#3 Sharing unaltered data with silence agreement with legitimate researchers

#4 Obliging researchers to conduct analysis in controlled environment and submit report

Ways Foreword- Top 10 Questions

1. When, where and which data should be archived?
2. What ethical considerations should be in placed?
3. What are quality control measures to ensure the quality of dataset?
4. What are the archiving and sharing methods?
5. What mechanisms are needed to overcome researchers' reluctance?

Ways Foreword- Top 10 Questions

6. Does the existing institutional capacity address the resource need for data sharing?

7. Does the exiting capacity development programs address the competency need for data sharing?

8. Who will access the data and how?

9. Which data to be shared? What criteria will define the priority?

10. What are the mechanism to monitor compliance with the data sharing policies?

Do we want a freed trade or a fair trade policy?

Further Readings

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