Epidemiology and omics – challenges and policy implications

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Enhancing access to research data during crises: lessons learned from the COVID-19 pandemic
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“Infectious disease surveillance is one of the most exciting opportunities created by big data, because these novel data streams can improve timeliness, and spatial and temporal resolution, and provide access to “hidden” populations. These streams can also go beyond disease surveillance and provide information on behaviours and outcomes related to vaccine or drug use. However, the promise of these big-data streams must be balanced by caution”

## TABLE OF CONTENT

| 01. | Challenges of multidisciplinary research |
| 02. | Omics and epidemiology data |
| 03. | What can be done better from the policy perspective? |
| 04. | Forming a Community of Practice (CoP) |
01. Challenges of multidisciplinary research
Value of multidisciplinary research

Clinical – Trials, observational and interventional studies, imaging, healthcare data

Omics – Rapid detection of pathogens and transmission

Epidemiology – Prevalence, risk factors, spread, severity and transmissibility

Social Sciences – Economic, social and political impact.

Evidence base
Challenges of multidisciplinary research

- Harmonisation across sophisticated yet diverse systems
- Minimum information dataset
- Integration of disparate sources of data for a complete picture
- Differences in maturity levels of data capturing systems
- Diversity in data models, definitions and standards
- Sensitivities about data linkage, accidental findings, miscalculations, etc
- Timeliness of accessing data across information systems
- Networked infrastructure and researchers who can integrate the resources
02. Omics and epidemiology data
Challenges in epidemiology data management

Minimum information dataset

Use and reuse

Interoperability
Challenging due to different standards, formats and definitions

Documentation
Lack of a rich knowledge base on data standards, data collections and sharing protocols, and metadata standards

Heterogeneity
In methods, tools, systems, analytics protocols...

The full picture
Linking epi data with clinical and genomics data
Challenges in omics data management

**Volume and diversity**
Lots of valuable sequencing data available openly but is it accessible for all?

**Inequity in capacity**
Not all regions have access to sequencing facilities

**Retention?**
Are we simultaneously building capacity to retain huge volumes of data?

**Reproducibility**
Complex pipelines, not enough skills to replicate those pipelines

**Increased demand for openness**
Linking epi data with clinical and genomics data

**The full picture**
Linking epi data with clinical and genomics data
03. What can be done better from the policy perspective?
Recommendations for policymakers

**Tools**
- Standardised tools, method and technology

**Global system**
- Combine genomics and epi for early detection and rapid response

**Knowledge base**
- Catalogue of resources, tools and repositories

**Harmonisation**
- Interoperable systems

**Promote openness where applicable**

Funding and partnerships will support all these recommendations…
04. Establishing a Community of Practice (CoP)
What will the Infectious Diseases Data CoP achieve?

People
Identify key international and local leaders and change agents

Priorities
Identify key priorities in the infectious diseases research community

Tools and technology
Scope data, definitions, systems, tools and analytical methods

Be an enabler
Build a global framework that can be adapted to localised settings
We need to make better decisions for data so the data can make better decisions for us....

- Break out of silos. There is immense value in combining information from different systems
- Acknowledging diversity of people that are centre of data...and the diversity they bring to the data as well
- Standardised and harmonised data fields, formats and definitions for consistent decision making
- Clear understanding of the value for collaborating and sharing data
- Build capacity (e.g., skills, people, methods, tools, platform, time, funding, collaborations) during preparedness stage for better response
THANKS!

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