

Data Sharing in Public Health Emergencies

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APPRISE Annual Conference, 15th August 2017



A joint venture between The University of Melbourne and The Royal Melbourne Hospital

Data sharing as a cross-cutting platform

- Why, and with whom, will information be shared?
- How will information be shared?
- How will information be used to inform emergency response?

Why will information be shared?

- Data sharing in public health emergencies is needed
 - To permit analyses that allow the fullest possible understanding of the emergency, and to ensure that decisions are based on the best available evidence (WHO data sharing policy)
 - To enable national and international effective, rapid, co-ordinated and co-operative health sector responses, and comply with IHR responsibilities (National Health Security Act 2007)
- APPRISE focus on making key *research* data elements and insights accessible to/usable by decision makers and clinicians

With whom will information be shared?

- We will prioritise timely exchange, synthesis, interpretation and reporting of emerging data with
 - Advisory committees – AHPPC, CDNA
 - Australian Government Office of Health Protection
 - Jurisdictional public health units
 - Research community
 - Clinicians
 - Wider community of stakeholders
 - International partners

How will information be shared?

- GLOPID-R Action Plan: design a system for data sharing in public health emergencies to support research response
- Key areas
 - Define the data – decision tree tool to identify questions and data needs
 - Map the environment – defining data and metadata (permissions, outputs)
 - Develop policy and a framework – timely, ethical, equitable access
 - Focus on implementation of data sharing policy and practice – build trust relationships, confidence in the process
 - Roadmap for collaboration

Data domains

- Different considerations for data sharing in domains of
 - Surveillance and epidemiological data – ‘opt-out’
 - Observational studies and clinical trials – reporting timelines
 - Genetic sequences – unified approach to analysis

Overarching themes to be considered

- Risks of sharing
- Benefits of sharing
- Standards and harmonisation
- Stakeholders and their concerns
- Identifying and accessing existing repositories

Implementation challenges

- Incentives and recognition
 - Promote sharing, but not at the expense of competition
 - Accountability for data misuse
- Infrastructure and tools development
 - Best practice for repositories
 - Tools for pre-publication data sharing
- Ethical, legal and governance issues
 - Benefit sharing and reciprocity
 - Safeguarding individuals, building trust

How will information be used to inform emergency response?

- Which measures should be implemented?
 - Scenario analysis for proportionate response
- For whom should they be implemented?
 - Risk assessment
 - Spatio-temporal spread
- When should measures be started and stopped?
 - Algorithmic outbreak detection
 - Prediction of peak timing and burden

With thanks

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