The role of data in a rapid and coordinated response to infectious disease outbreaks

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1. Role of a data specialist in infectious diseases data ecosystem
2. Infectious diseases data ecosystem (APPRISE CRE)
3. Types of data and how they inform outbreak investigation and response
4. Barriers and enablers to data sharing/usage
5. COVID-19 investigation through open data access and analytics
6. Discussion
1. Role of a data specialist in infectious diseases data ecosystem
Role of a data specialist

- Epidemiologists
- Clinicians and Infection control and prevention practitioners
- Informaticians and data managers
- Virologists and Microbiologists
- Public health researchers and practitioners
- Policymakers
- Communities

Hierarchy:

- Wisdom
- Knowledge
- Information
- Data
2. Infectious diseases data ecosystem (APPRISE CRE)
Infectious diseases data ecosystem (APPRISE CRE)
3. Types of data and how they inform outbreak investigation and response
Clinical research and infection prevention

- Clinical data in prior pandemics
- Collect data from hospitals, clinical care and ambulatory settings
- Observational studies
Laboratory research and diagnostics

- Timely diagnostics
- Testing capabilities
- Specialised reference laboratories
- Pathogen (bacterium, virus, or other microorganism that can cause disease) characteristics (Genomics)
Public health surveillance systems

- Impact assessment
- Severity and transmissibility
- Pathogen-based (bacterium, virus, or other microorganism that can cause disease) surveillance system
- Syndrome-oriented (set of medical signs and symptoms) surveillance systems
Communities (First Nations peoples)

- Information on risk factors
- More severely affected during past pandemics
- Respectful and ethical engagement with First Nations peoples
- Integrate into clinical, laboratory and public health information systems.
Information hubs

- Public health surveillance systems
- Diagnostic Laboratories
- Clinical Research
- Communities (First Nations Peoples)
4. Barriers and enablers to data sharing and usage
Clinical research and infection prevention

Barriers to sharing and using data
• Platform to collect multi-site data
• Other syndromic presentations
• Rapid data dissemination

Enablers for sharing and using data
• Harmonised protocols
• Multi-site implementation capacity
• Comprehensive information
Laboratory research and diagnostics

**Barriers to sharing and using data**
- Jurisdictional material/data governance
- Computational and analytical capacity for genomics
- Lengthy approval processes

**Enablers for sharing and using data**
- Model for cross-jurisdictional information sharing
- Genomics capacity
- Laboratory network of experts
- Research and surveillance capacity
Public health surveillance systems

Barriers to sharing and using data

- Trigger data for public health response
- Comparability to non-epidemic data
- Synthesis across health and community settings

Enablers for sharing and using data

- National level information gathering
- Collaborative working relationships
- Data is routinely shared
- Existing systems leveraged for emerging infections
Communities (First Nations peoples)

Barriers to sharing and using data

- Data sovereignty
- Retrospective data completeness
- Past experiences and mistrust of health services
- Ethical sensitivities
- Orphaned datasets

Enablers for sharing and using data

- Research capacity
- Respectful community engagement
- Ongoing process of changing the way administrative datasets collect data on identities
5. Exemplars of COVID-19 investigation through open data access and analytics
ISARIC — International Severe Acute Respiratory And Emerging Infection Consortium
COVID-19 Clinical Research Resources

In response to the outbreak of novel coronavirus (COVID-19), ISARIC has developed a portfolio of clinical research resources. This is an international resource for facilitating the collection of standardised clinical data on patients hospitalised with suspected or confirmed infection with COVID-19. The tools have undergone extensive review and validation by international clinical experts.

To access the tools, please click on the links below:

1. ISARIC/WHO Case Record Form (CRF) for prospective or retrospective standardised clinical data collection to inform patient care and public health responses.

2. Clinical Characterisation Protocol (CCP) to enable clinical data and biological samples to be collected in a globally harmonised manner.

The resources are free to use and investigators retain full control of all data and samples.

You will retain full ownership and access to your data and it will not be used or shared in any way without your permission.

Below, a COVID-19 map with data collected from publicly available news and media.
Open genomics data access and analytics
Open genomics data access and analytics
GISAID (Global Initiative on Sharing All Influenza Data)
Coronavirus COVID-19 Global Cases by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU)
Coronavirus COVID-19 Global Cases by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU)

Total Confirmed: 378,547

Confirmed Cases by Country/Region/Sovereignty:
- China: 81,498
- Italy: 63,927
- US: 43,847
- Spain: 35,136
- Germany: 29,056
- Iran: 23,049
- France: 20,123
- Korea, South: 8,938
- Switzerland: 7,995
- United Kingdom: 6,726
- Netherlands: 4,764
- Austria: 4,478
- Belgium: 3,748
- Norway: 2,621
- Canada: 2,087
- Portugal: 2,048
- Sweden: 2,048
- Brazil: 1,928
- Australia: 1,682
- Denmark: 1,572
- Turkey: 1,529

168 countries/regions

Total Deaths: 16,505

- Total Deaths by Country:
  - Italy: 6,077
  - China: 3,153
  - Spain: 2,311
  - Iran: 1,812
  - France: 880
  - United Kingdom: 335
  - Netherlands: 213
  - Germany: 153
  - Switzerland: 120
  - South Korea: 111
  - China: 99
  - Hong Kong, China: 86

Total Recovered: 100,958

- Total Recovered by Country:
  - China: 59,882
  - Italy: 5,376
  - Iran: 3,256
  - Spain: 3,183
  - Korea, South: 2,000
  - French Polynesia: 1,322
  - Guangdong China: 1,268
  - Human: 1,231
  - Zhejiang China: 1,014
  - India: 984

Last Updated at (M/D/YYYY): 3/24/2020, 11:24:12 AM
Key messages

How do we make better “Decisions for Data” to improve the “Data for Decisions”?

• Break out of silos. There is immense value in combining information from different systems
• Standardised and harmonised data fields, formats and definitions for consistent decision making
• Clear understanding of the value for synthesising and aggregating data
• Build capacity (e.g. infrastructure, skills, people, time, funding, collaborations) during preparedness stage for better response
Acknowledgements

Professor Jodie McVernon
Dr Miranda Smith
A/Prof Douglas Boyle
Dr Dieter Bulach
Professor Ross Andrews
Professor Angus Dawson
Dr Teresa Wozniak

Professor Bart Currie
Kylie Carville
Dr Julian Druce
Dr Neil Killeen
A/Prof Sheena Sullivan
Professor Steve Webb

(and many more experts)
Thank you