

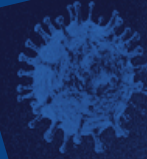


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MELBOURNE

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

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PLATFORM**

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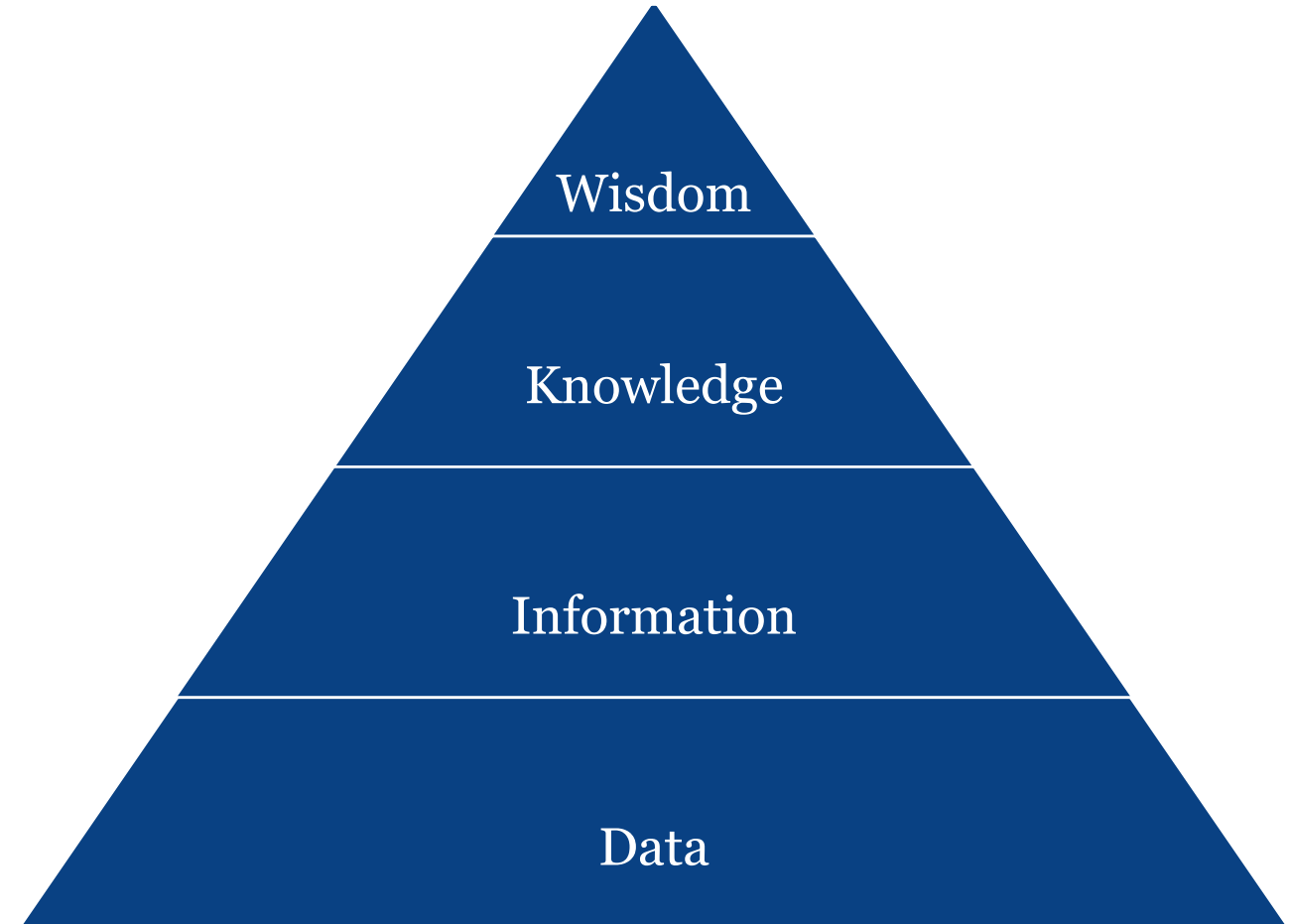
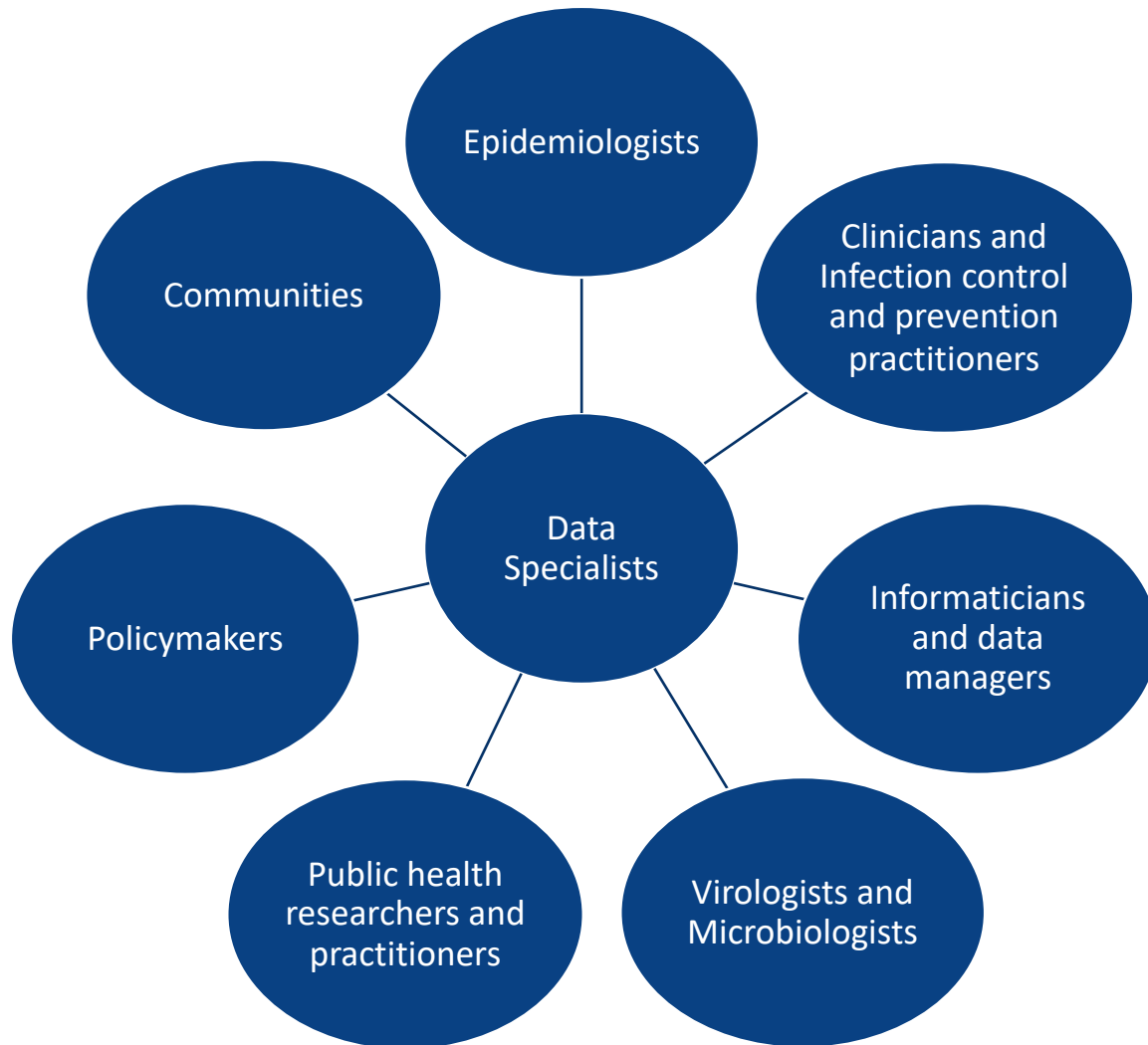
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2. Infectious diseases data ecosystem (APPRISE CRE)
3. Types of data and how they inform outbreak investigation and response
4. Barriers and enablers to data sharing/usage
5. COVID-19 investigation through open data access and analytics
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1.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

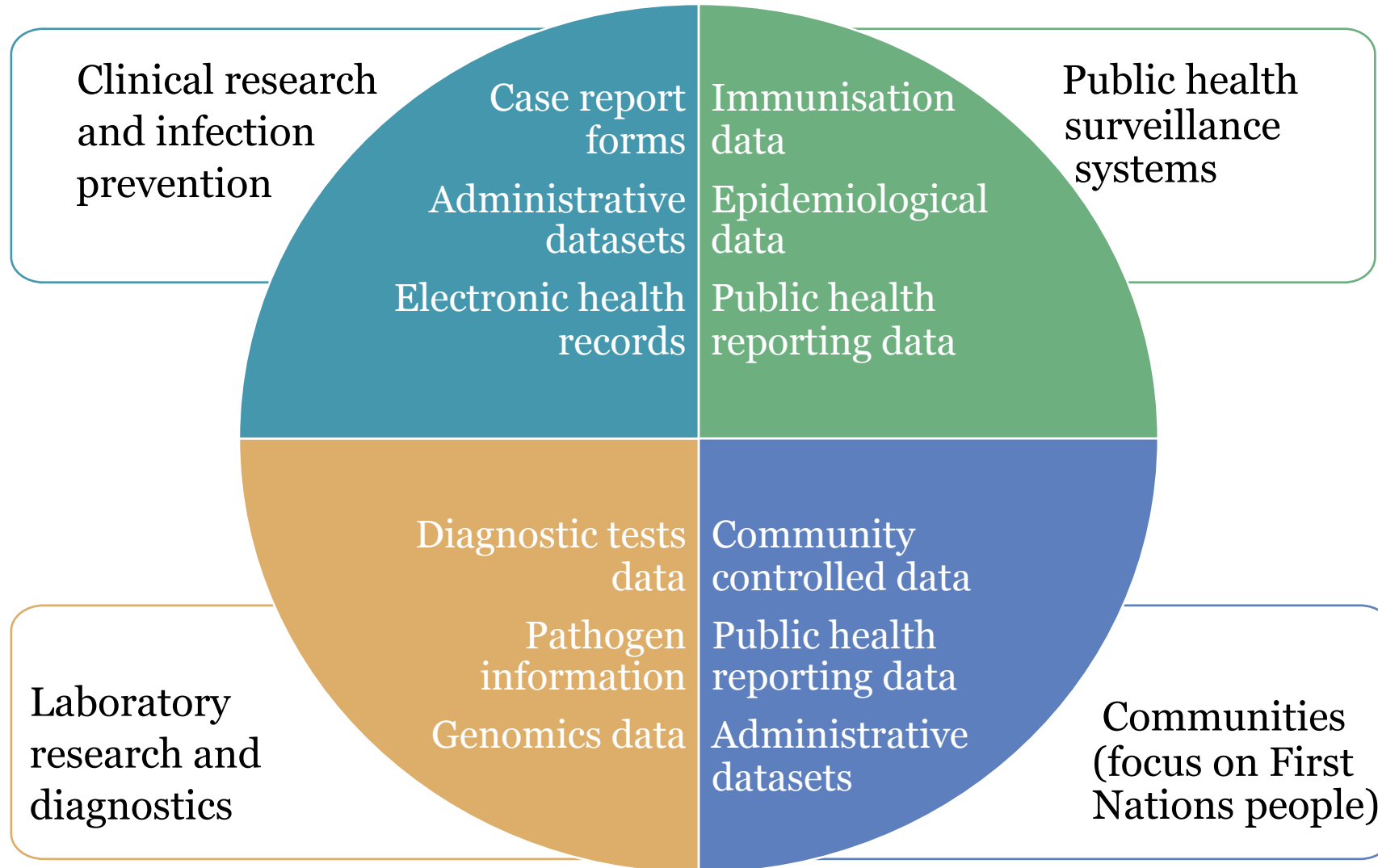
Role of a data specialist





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)



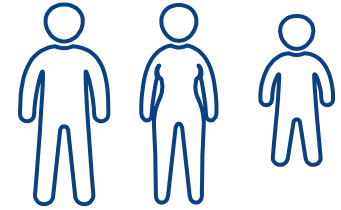
Public health surveillance systems

- 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

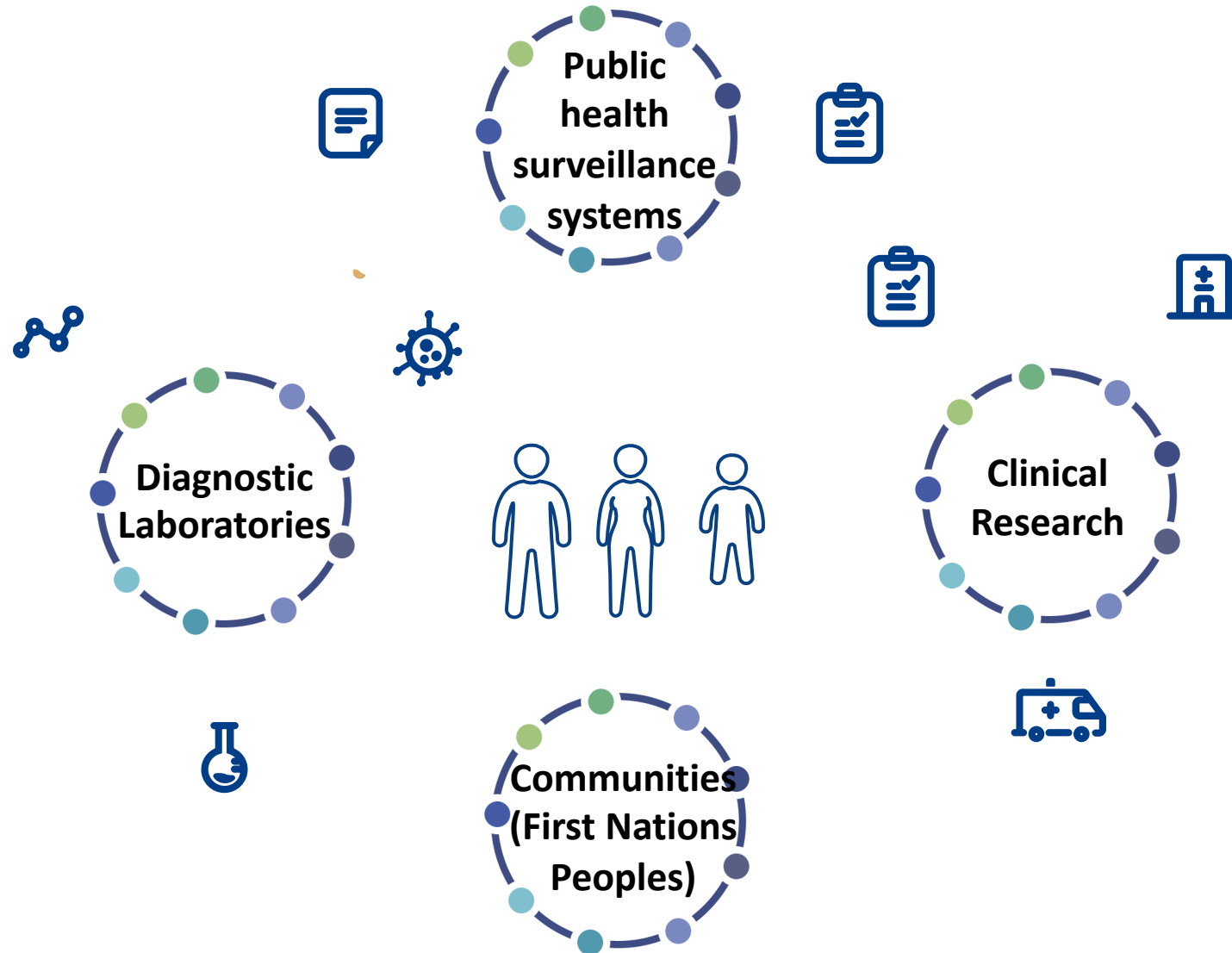


Communities (First Nations peoples)

- 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





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

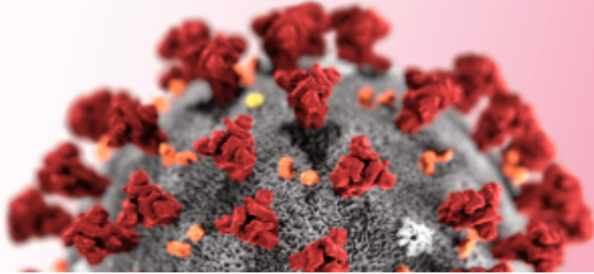


5. Exemplars of COVID-19 investigation through open data access and analytics



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)

Genomic epidemiology of novel coronavirus

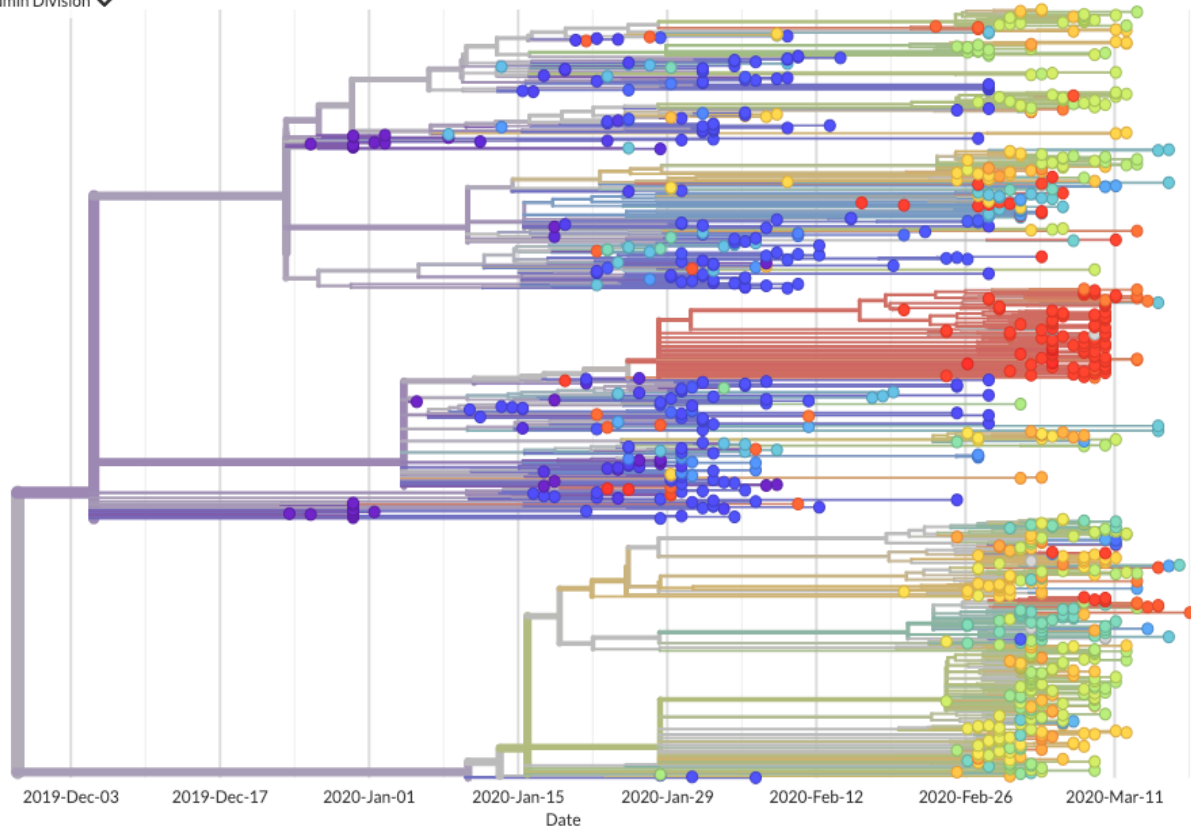
Maintained by the [Nextstrain team](#). Enabled by data from [GISAID](#)

Showing 955 of 955 genomes sampled between Dec 2019 and Mar 2020.

Phylogeny

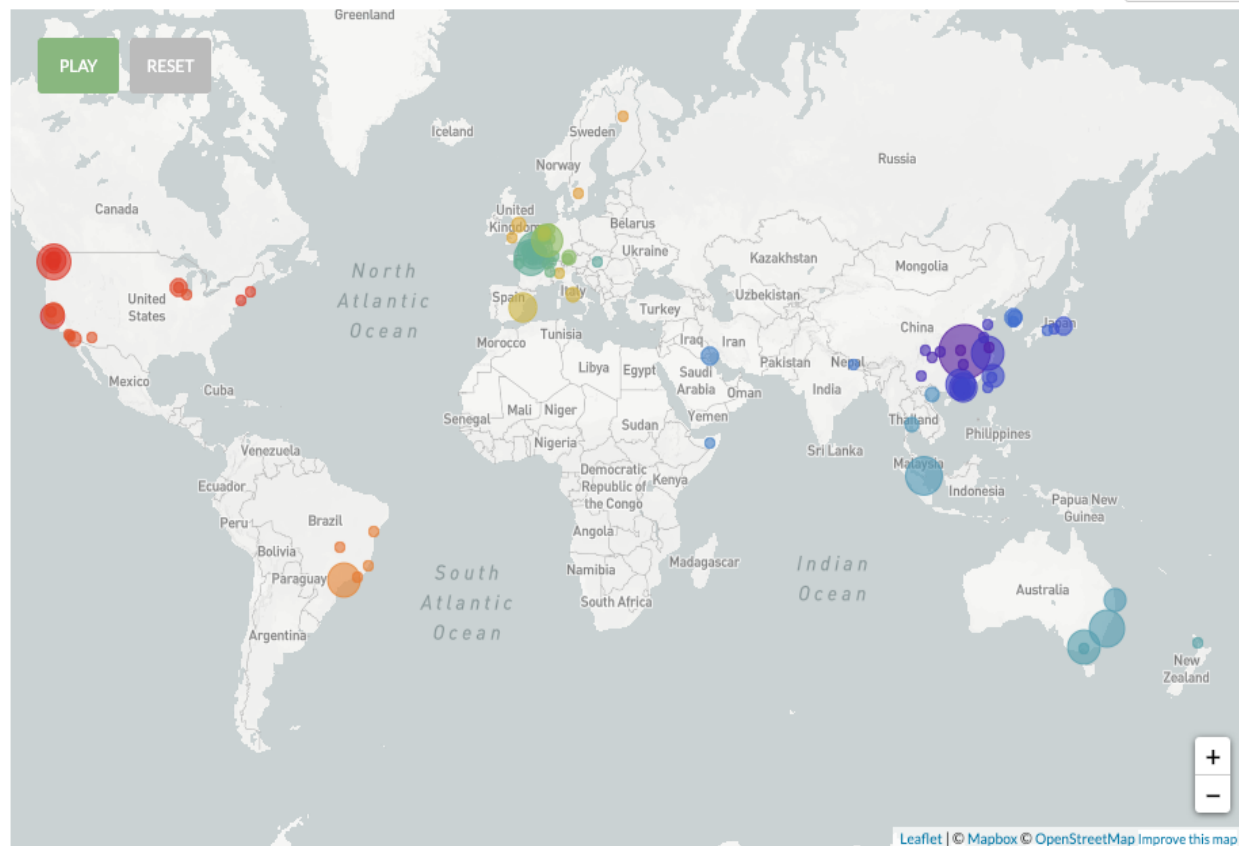
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Geography

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Coronavirus COVID-19 Global Cases by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU)

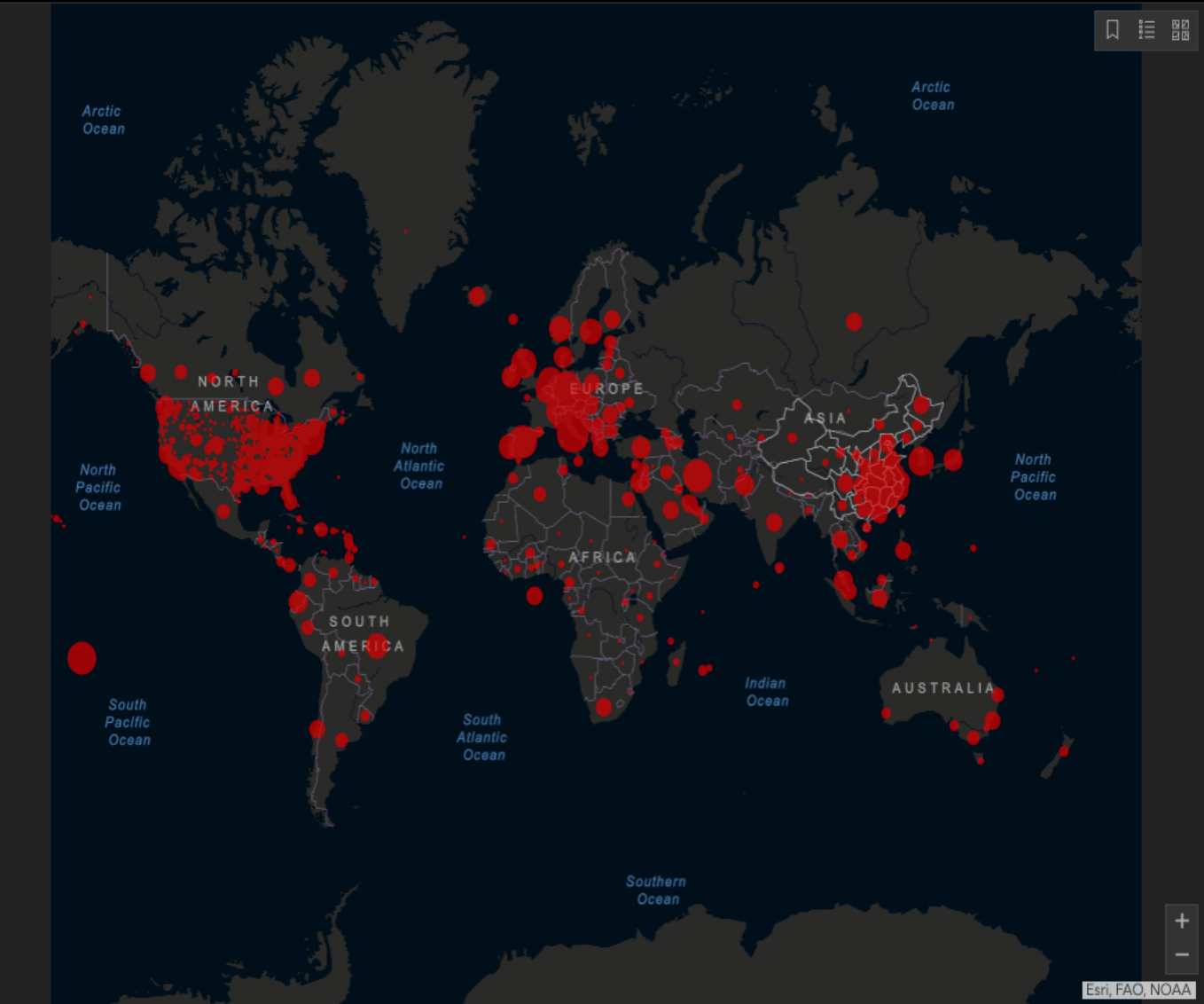
Total Confirmed
378,547

Confirmed Cases by Country/Region/Sovereignty

81,498	China
63,927	Italy
43,847	US
35,136	Spain
29,056	Germany
23,049	Iran
20,123	France
8,961	Korea, South
8,795	Switzerland
6,726	United Kingdom
4,764	Netherlands
4,474	Austria
3,743	Belgium
2,621	Norway
2,088	Canada
2,060	Portugal
2,046	Sweden
1,924	Brazil
1,682	Australia
1,572	Denmark
1,529	Turkey

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



Cumulative Confirmed Cases Active Cases

168
countries/regions

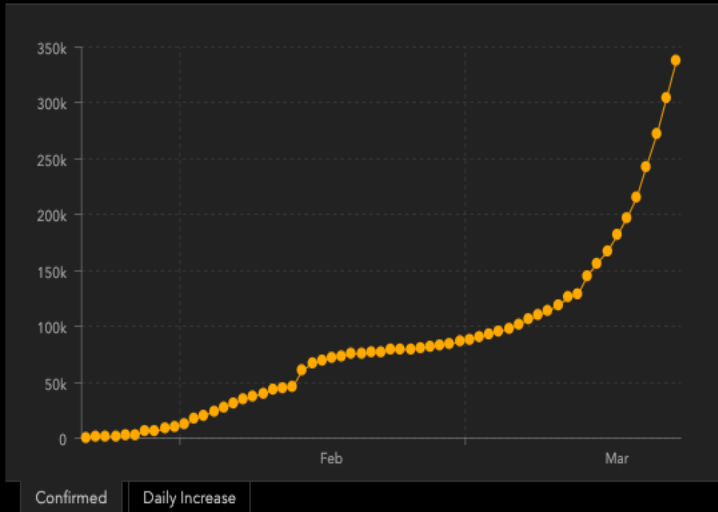
Lancet Inf Dis Article: [Here](#). Mobile Version: [Here](#). Visualization: JHU CSSE. Automation Support: [Esri Living Atlas team](#) and [JHU APL](#). [Contact US](#). [FAQ](#). Data sources: [WHO](#), [CDC](#), [ECDC](#), [NHC](#), [DXY](#), [1point3acres](#), [Worldometers.info](#), [BNO](#), state and national government health departments, and local media reports. Read more in this [blog](#). Downloadable database: GitHub: [Here](#). Feature layer: [Here](#). Confirmed cases include presumptive positive cases. Recovered cases outside China are estimates based on local media reports, and may be substantially lower than the true number.

Total Deaths

16,505
6,077 deaths Italy
3,153 deaths Hubei China
2,311 deaths Spain
1,812 deaths Iran
860 deaths France
335 deaths United Kingdom
213 deaths Netherlands
123 deaths Germany
120 deaths Switzerland
111 deaths Korea, South
99 deaths New York City, New York, US

Total Recovered

100,958
59,882 recovered Hubei China
8,376 recovered Iran
7,432 recovered Italy
3,355 recovered Spain
3,166 recovered Korea, South
2,200 recovered French Polynesia France
1,332 recovered Guangdong China
1,250 recovered Henan China
1,221 recovered Zhejiang China
1,014 recovered Hunan China
984 recovered Anhui China



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

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Dr Neil Killeen

A/Prof Sheena Sullivan

Professor Steve Webb

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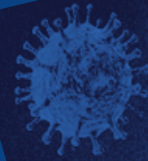


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Thank you

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APPRISE

AUSTRALIAN PARTNERSHIP FOR
PREPAREDNESS RESEARCH ON
INFECTIOUS DISEASE EMERGENCIES

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