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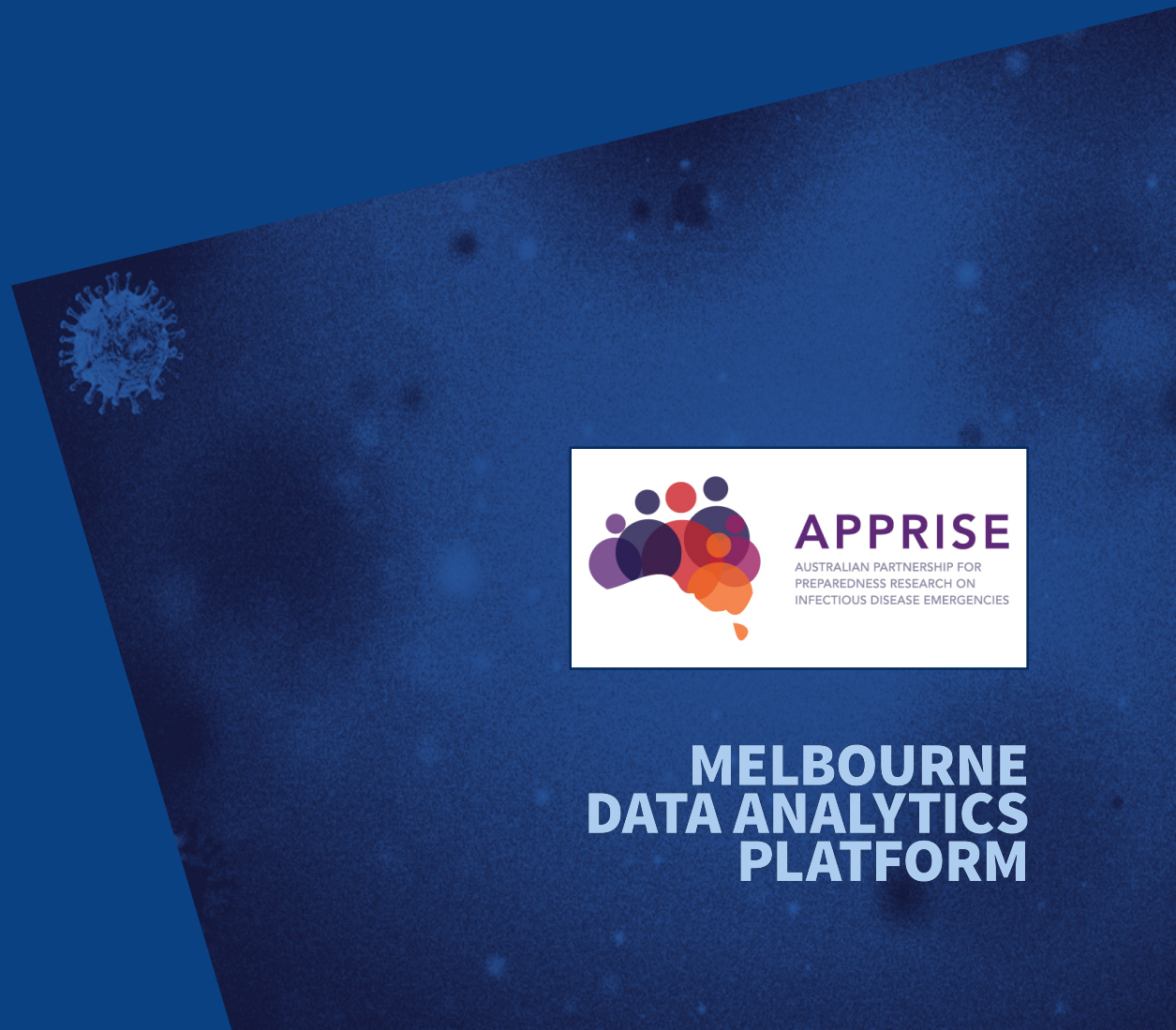
The role of data in a rapid and coordinated response to infectious disease outbreaks



APPRISE
AUSTRALIAN PARTNERSHIP FOR PREPAREDNESS RESEARCH ON INFECTIOUS DISEASE EMERGENCIES

MELBOURNE DATA ANALYTICS PLATFORM

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

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https://www.apprise.org.au/

https://www.apprise.org.au/contact-us

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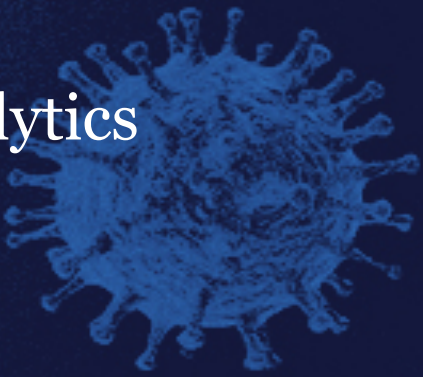
6. Discussion



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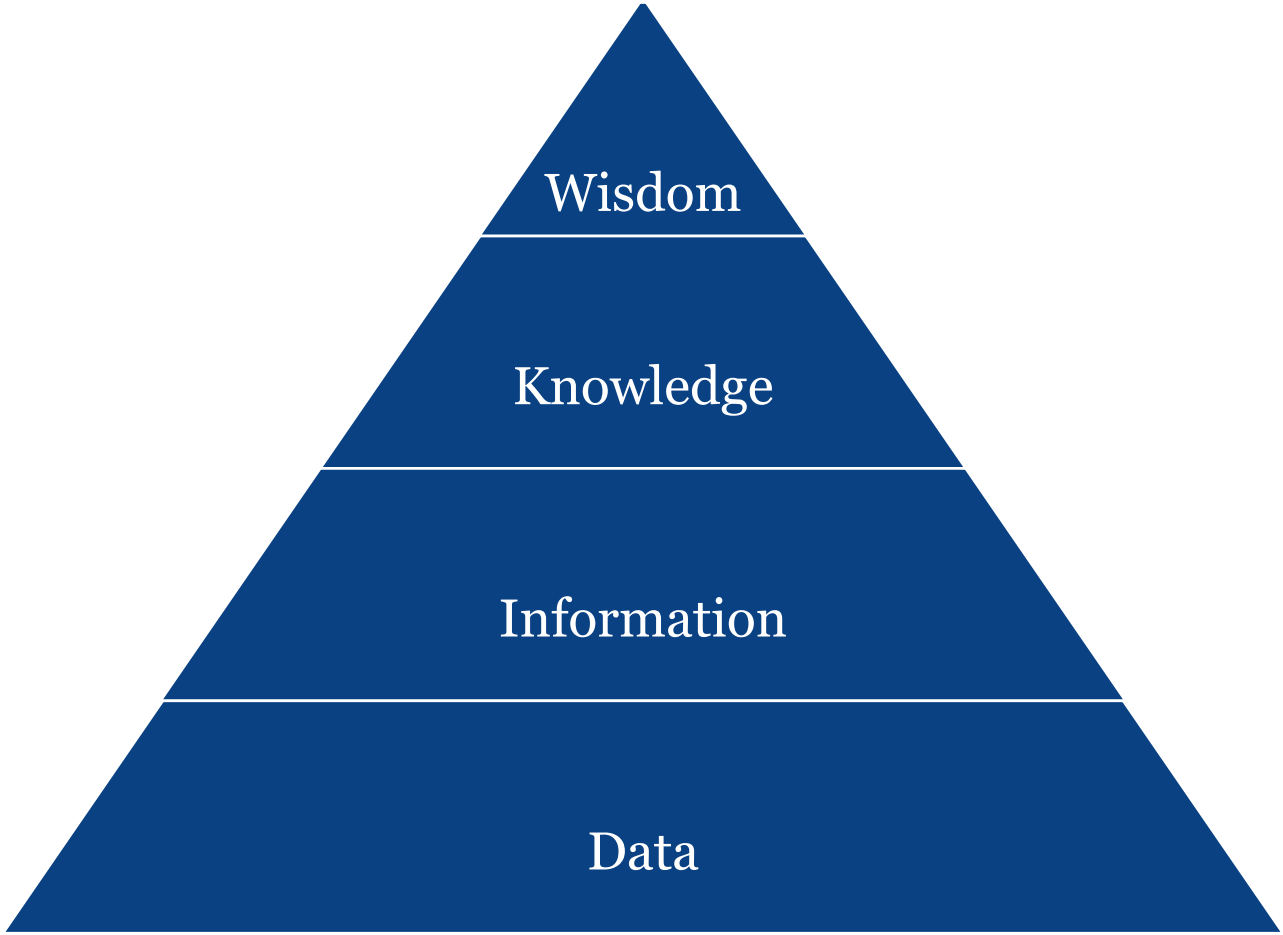
1. Role of a data specialist in infectious diseases data ecosystem

Role of a data specialist



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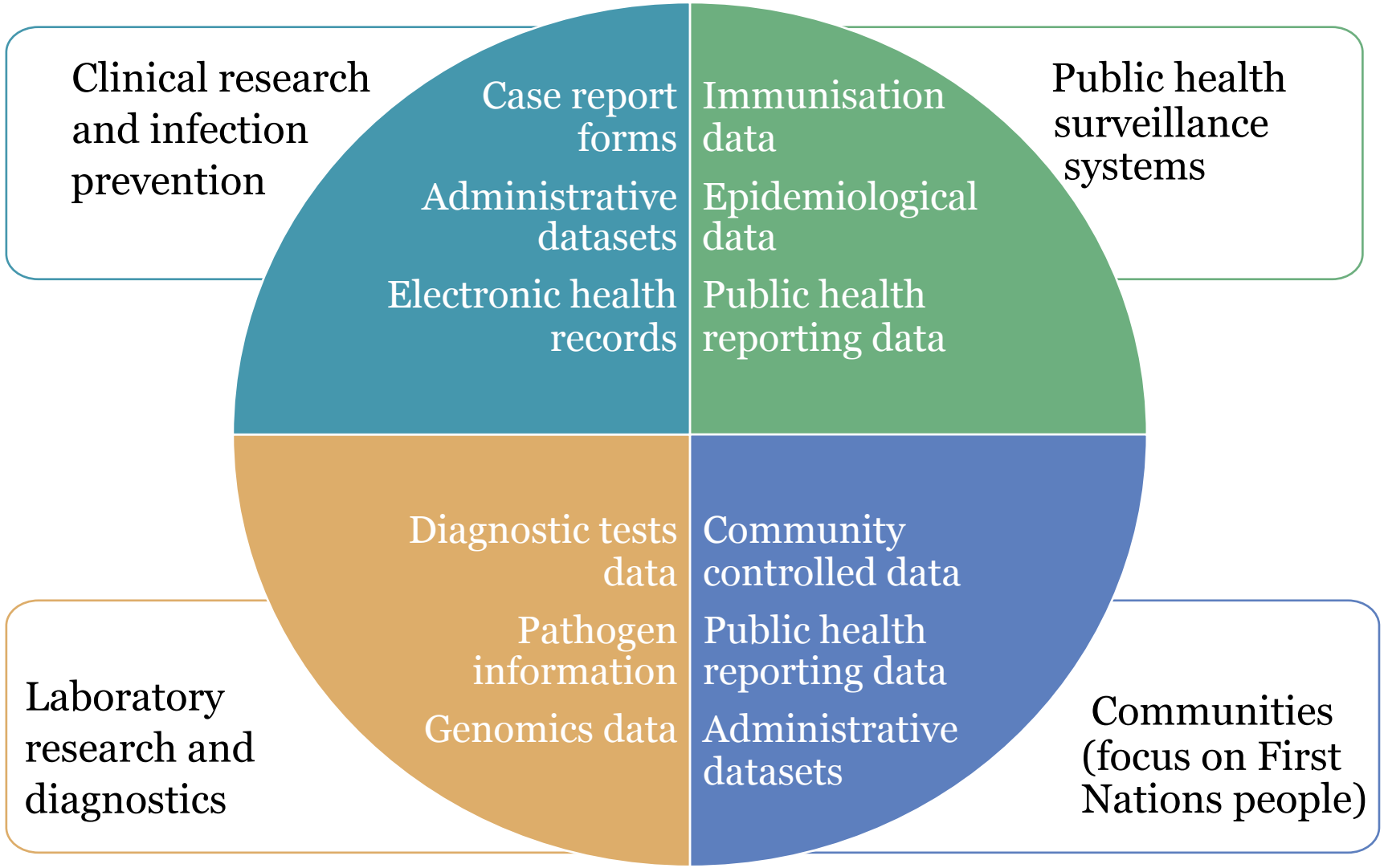
2. Infectious diseases data ecosystem (APPRISE CRE)

Infectious diseases data ecosystem (APPRISE CRE)



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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

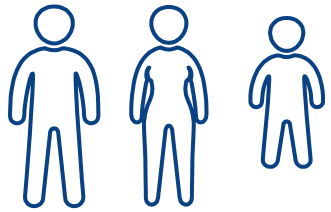
- Timely diagnostics
- Testing capabilities
- Specialised reference laboratories
- Pathogen (bacterium, virus, or other microorganism that can cause disease) characteristics
  (Genomics)

Public health surveillance systems

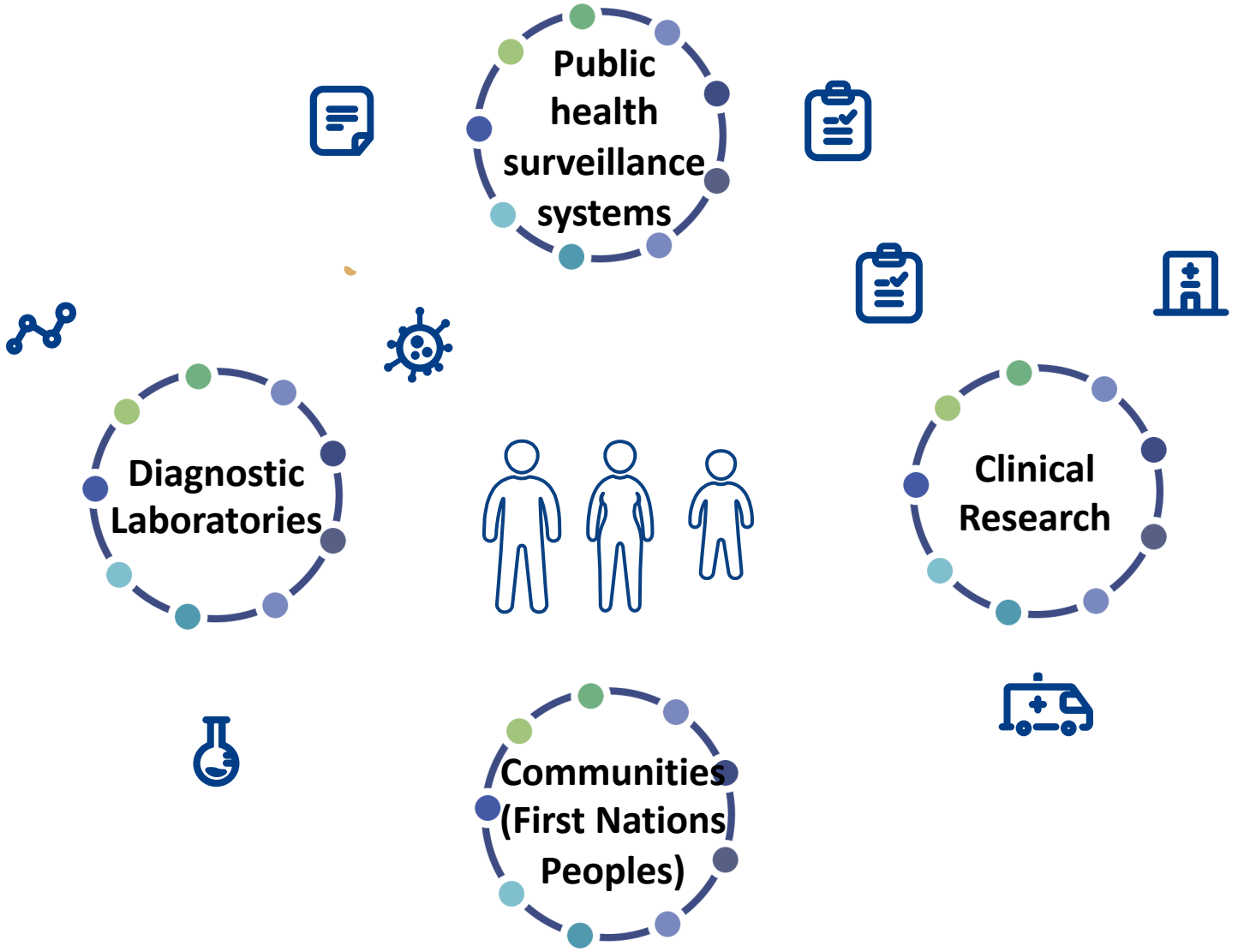
- Impact assessment
- Severity and transmissibility
- Pathogen-based (bacterium, virus, or other microorganism that can cause disease) surveillance system
- Syndrome-oriented (set of medical signs and symptoms) surveillance systems

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

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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

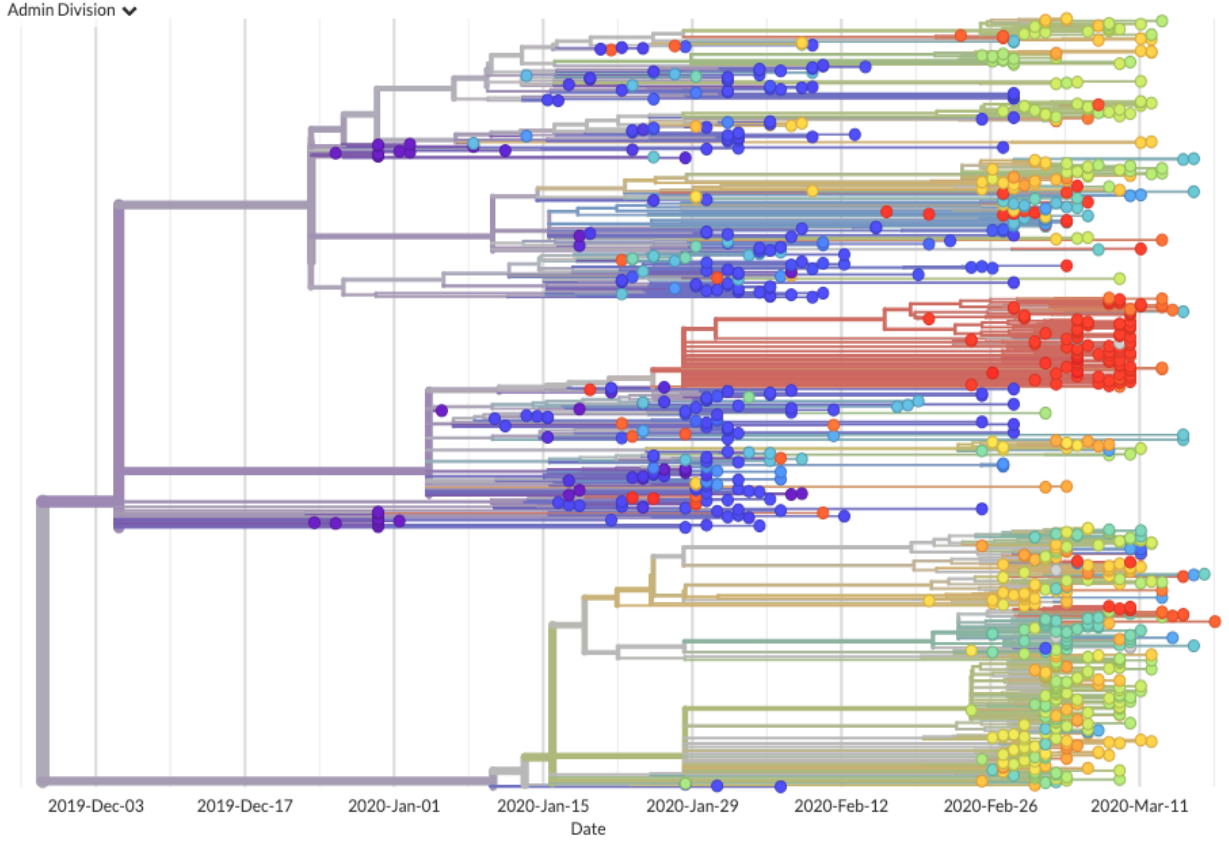
Maintained by the Nextstrain team. Enabled by data from GISAID

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

Phylogeny

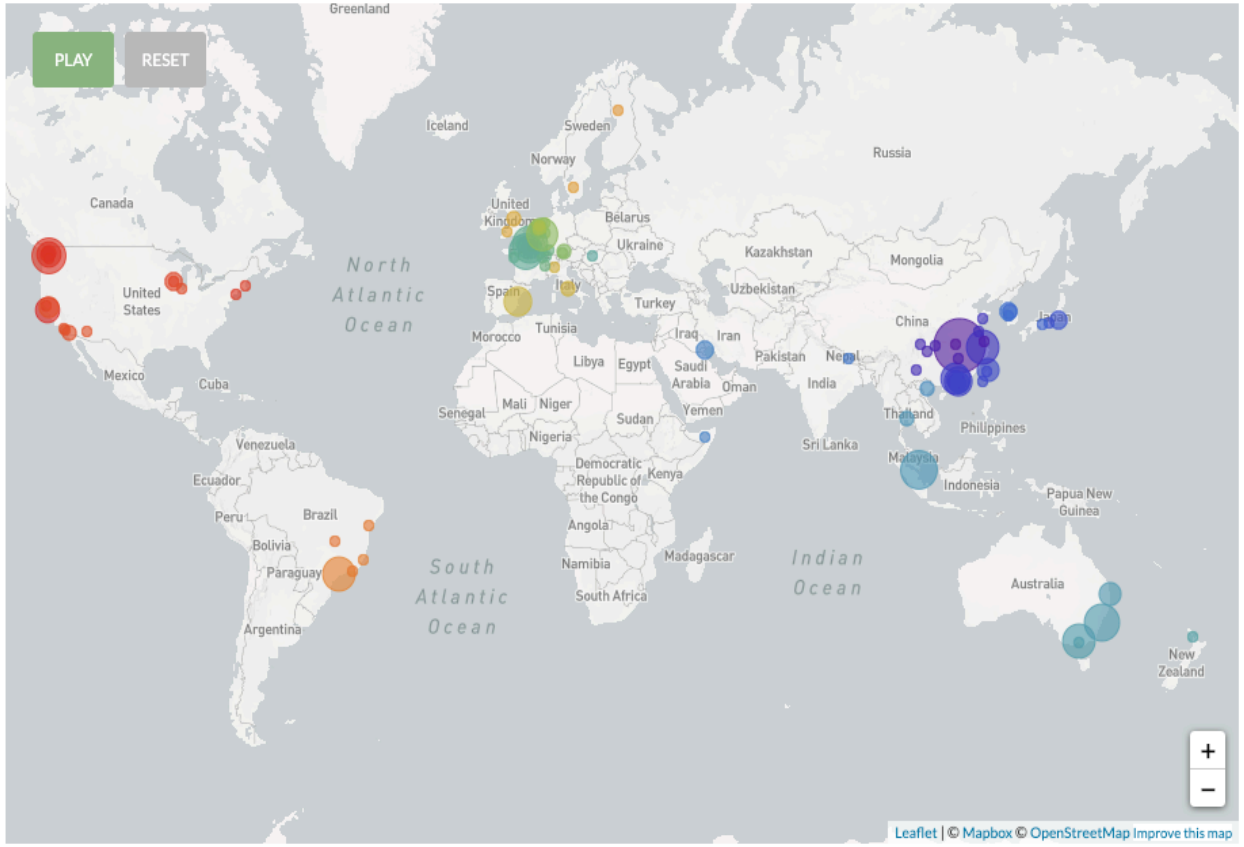
RESET LAYOUT

Admin Division



Geography

RESET ZOOM



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)

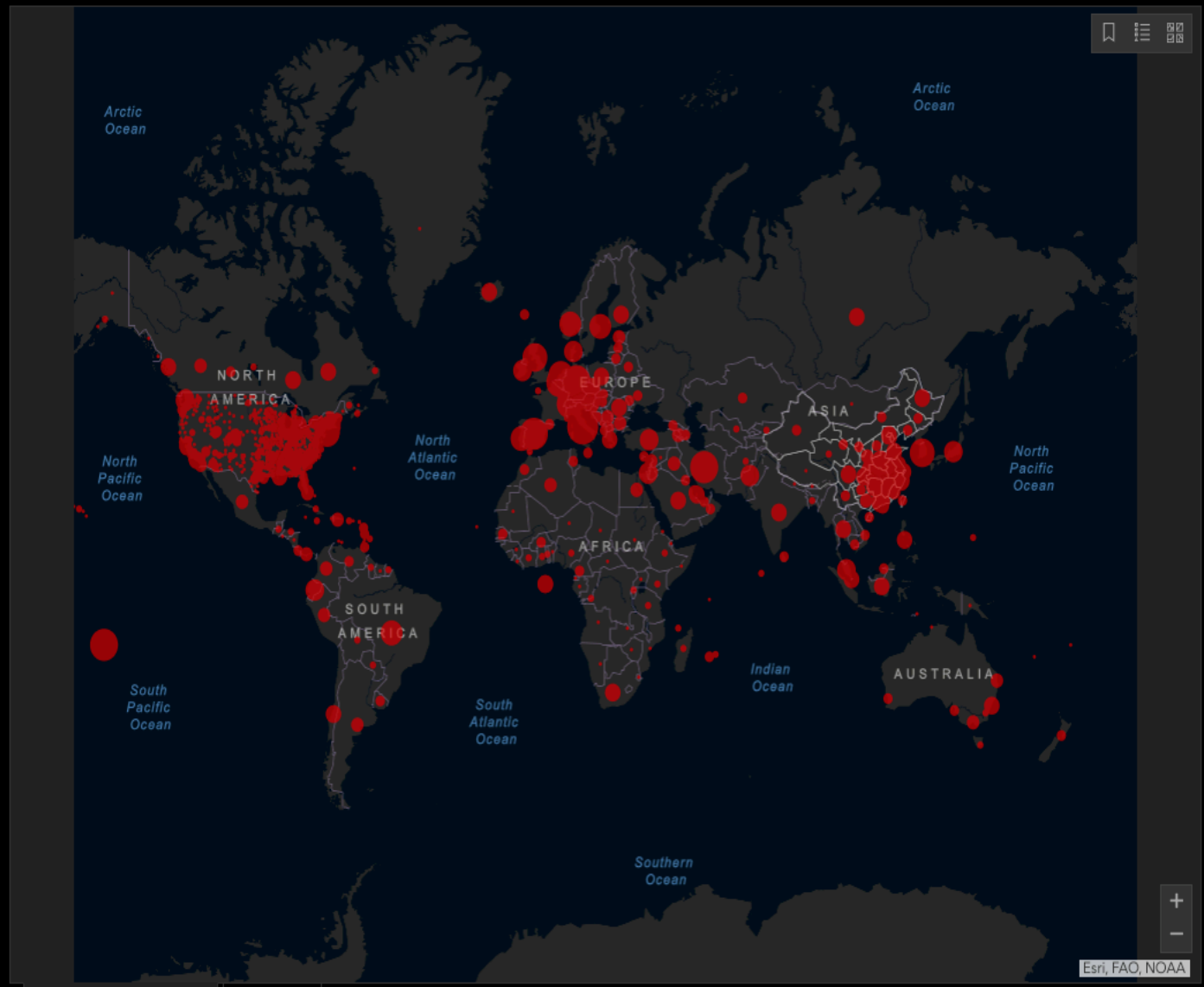
Total Confirmed
378,547

Confirmed Cases by Country/Region/Sovereignty

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

Admin1 | Admin2 | Admin3

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



Cumulative Confirmed Cases | Active Cases

168
countries/regions

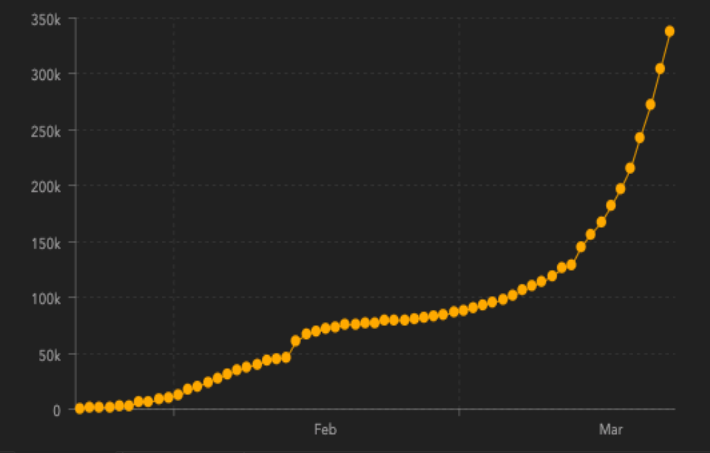
Lancet Inf Dis Article: Here. Mobile Version: Here. Visualization: JHU CSSE. Automation Support: Esri Living Atlas team and JHU APL. Contact US. FAQ.
Data sources: WHO, CDC, ECDC, NHC, DXY, 1point3acres, Worldometers.info, BNO, state and national government health departments, and local media reports. 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



Confirmed | Daily Increase

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

(and many more experts)

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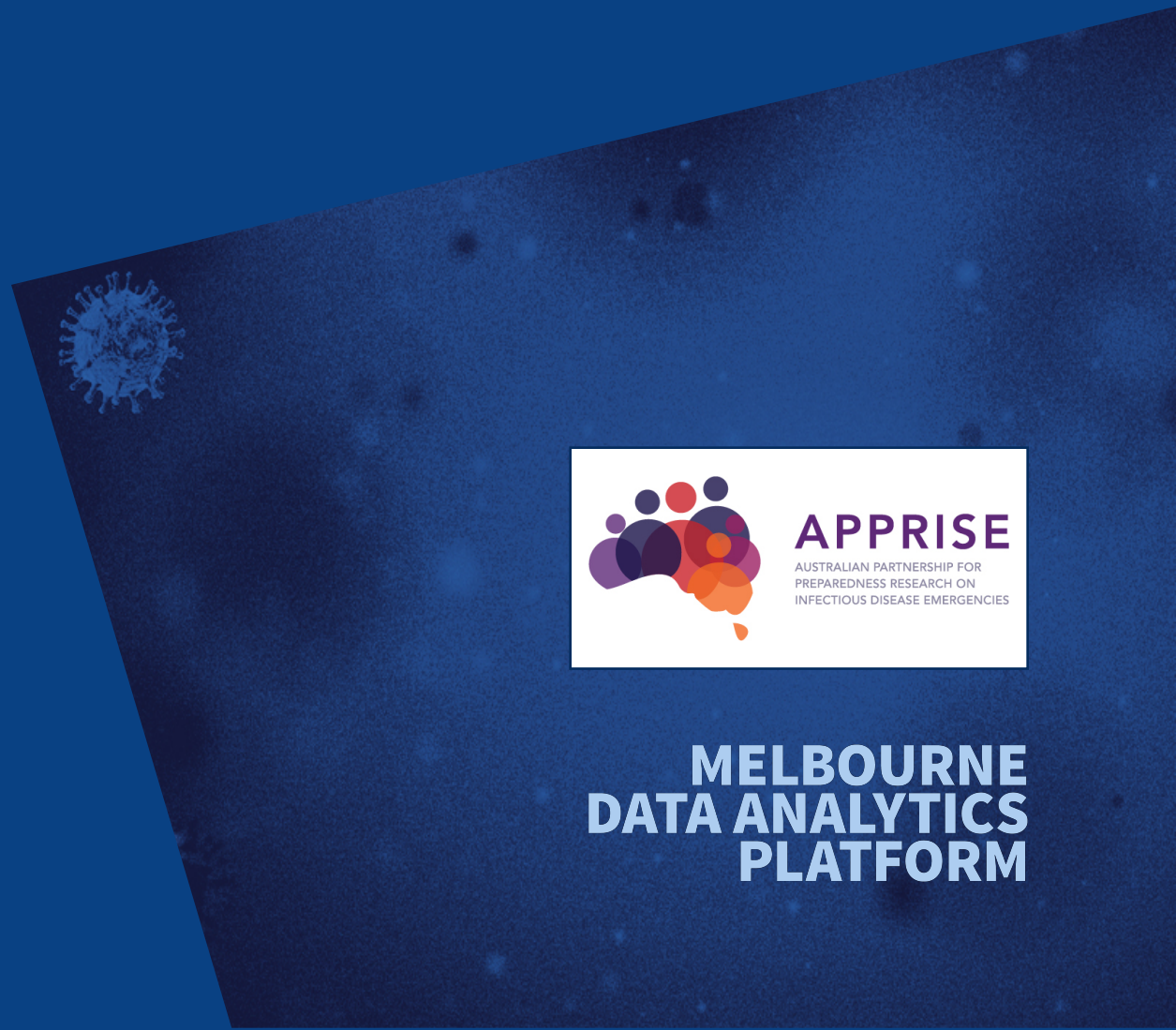
Thank you



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