Towards fair and sustainable real-time sharing of data during emergencies

Sequence data sharing through GISAID
A move to open science for COVID-19 vaccine trials in France

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Experience during SARS, H1N1 influenza pandemic and Ebola

• Data sharing was slow and inconsistent
• Some samples were exported without proper Material Transfer agreement
• Concerns about ownership
• Concerns about Intellectual Property Rights
• Concerns about possibility to publish data already publicly released
• Lack of trust
• Others...
Data/information sharing during outbreaks/epidemics: what is needed?

- Epidemiological
- Surveillance (clinical, laboratory)
- Emergency response
- Health facility data
- Research data including surveys, observational studies, clinical trials of diagnostics, therapeutics and preventives
- QC’d interim results
- Final research results
- Ancillary research results
- ‘Negative’ and inconclusive results
Genomic sequence data
Development of the GISAID data sharing principles

• GISAID sharing agreement developed with WHO MS Support (DAA) as a response to many countries refusing to share sequence data
• Open Access Data sharing platform since 2008
• Essential for the Global Influenza Surveillance and Response System (GISRS)
• Real-time progress in the understanding of the new COVID-19 disease and in the research and development of candidate medical countermeasures
• March 2020:
  o 2,500 institutions entrust data to GISAID
  o 34,000 participating researchers
Publicly-accessible data during the COVID-19 Pandemic

Data Submitters can choose between GISAID transparent sharing mechanism or anonymous access

On 20 Mar 2021 all 830,013 publicly available genomes and associated data submitted to GISAID

Today, more than 1.2 million sequences
Timecourse of clade distribution in collected sequences 2021-04-23

Given the widespread appearance and large numbers of B.1.1.7 genomes globally surpassing numbers of other existing clades, we have elevated the B.1.1.7 lineage (GR/501Y.V1) to its own clade GRY for simple reporting purposes, descending from clade GR with addition of spike markers including N501Y.

We gratefully acknowledge the Authors from Originating and Submitting laboratories of sequence data on which the analysis is based.

RBDx: Relevant changes near receptor and antibody binding sites (relative to clade reference)
GISAID enables real-time virus tracking and analysis

Enabling impact through analysis reports and connected tools

Summary reports of large trends
Interactive genomic epidemiology
Global phylogeny
Variant tracking

Primer checks
Spike changes

gisaid.org/variants
gisaid.org/spike
Clinical trial data
Delayed / non-reporting of pandemic vaccine trials: reporting bias a major issue
CoviCompare: a project based on the French Covireivac COVID-19 vaccine clinical trials

• The CoviCompare project consists of in depth *in vitro* and *ex vivo* tests for systematically assessing humoral and cellular as well as mucosal immunity over time following COVID-19 vaccination

• CoviCompare will analyze any difference of immune responses across age groups, including in the elderly (18-45y, over 65, over 75)

• CoviCompare will analyse differences across vaccine platforms: mRNA vaccines, Ad-vectored vaccines, sub-unit vaccines, inactivated COVID-19 vaccines
Open access and Global Public Good principles of the CoviCompare project

In order to allow the greatest number of people to have access to scientific advances in the field of vaccination against COVID-19, the support provided by the French Government to the CoviCompare is based on the following crucial pillar: the **societal valorization of the data and scientific results**

Where vaccine manufacturers collaborate with CoviCompare, they have to abide by the same principles
Consequences of the policies agreed for the CoviCompare project

CoviCompare results will be published as soon as possible, firstly in the form of preprints, secondly in peer-reviewed journals, in order to advance science towards safe and effective COVID-19 vaccines.

Access right, the right of use and to disseminate the protocol, the raw data and the results will be provided free of charge to any third party under the same conditions.
Towards a new norm on rapid data sharing in emergencies?

Developing Global Norms for Sharing Data and Results during Public Health Emergencies

Kayvon Modjarrad, Yasee S. Moorthy, Piers Millett, Pierre-Stéphane Gsell, Cathy Roth, Marie-Paule Kieny
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A worthwhile policy undertaking for OECD...