USING SCIENCE DIPLOMACY
FOR ADDRESSING GLOBAL CHALLENGES

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 770342.

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Science Diplomacy:

Global Health and Open Science Data Sharing in Global Health Emergencies

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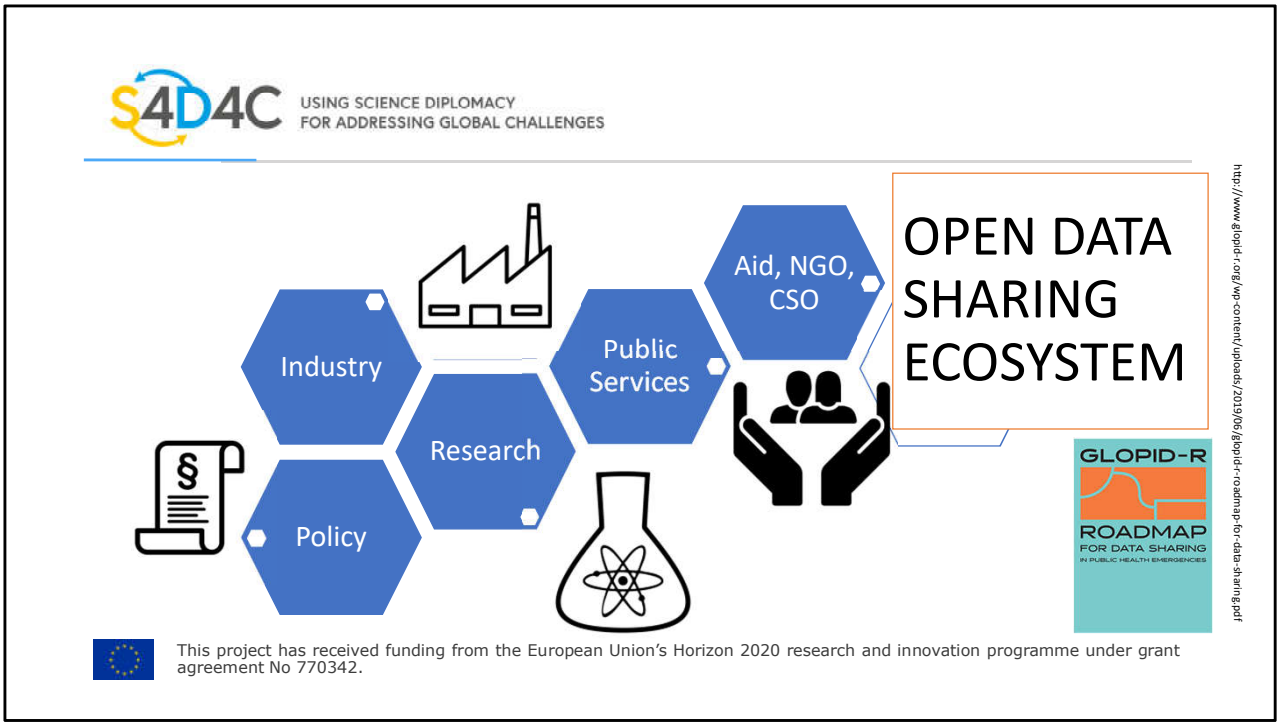
"The COVID-19 crisis has shown that cooperation at international level in research and innovation is more important than ever, including through open access to data and results. No nation, no country can tackle any of these global challenges alone. An important role for science diplomacy is to build bridges between science, technology and innovation practices, national interests, as well as global challenges."

Mariya Gabriel, Commissioner for Innovation, Research, Culture, Education and Youth



Enhanced public health and research data sharing during Public Health Emergencies (PHEs) can result in significant public health benefit. Data sharing during PHEs is not currently sufficiently effective, has many challenges and is dependent on the establishment of collaboration in advance of emergencies. The roadmap for data sharing aims to accelerate effective data sharing by highlighting measures GloPID-R research funders can take to improve research data sharing by their grantees and to advocate for increased research and public health data sharing more widely.

Source: https://www.glopid-r.org/wp-content/uploads/2019/06/glopid-r-roadmap-for-data-sharing.pdf

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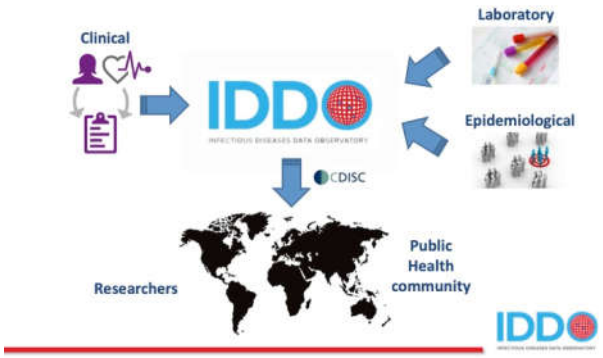
DATA SHARING IN GLOBAL HEALTH EMERGENCIES



Infectious Diseases Data Observatory, Oxford.

IDDO collects and integrates clinical, laboratory and epidemiological data relating to a number of infectious diseases.

Analysis of combined datasets increases the power to determine optimal treatments, identify the most effective intervention in outbreaks.

Slide Credit: Fernando Gouveia Reis and Laura Merson, IDDO

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The Infectious Diseases Data Observatory (IDDO) assembles clinical, laboratory and epidemiological data on a collaborative platform to be shared with the research and humanitarian communities. The data are analysed to generate reliable evidence and innovative resources that enable research-driven responses to the major challenges of emerging and neglected infections.

Source: https://www.iddo.org/

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West African Ebola Outbreak 2014-2016

Government-led response including many very different international organisations.

Only a selection of international responders is shown. There were many more.

Slide Credit: Laura Merson, IDDO, Simon Hodson CODATA

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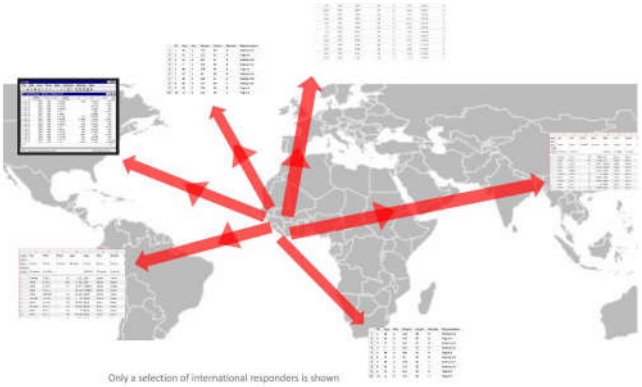
West African Ebola Outbreak, 2014-2016
When the outbreak ended and organisations left the region, important data was scattered globally, not accessible, findable, interoperable and re-usable.

Pisani et al. estimate that 65% of study data is not available, not shared.

Pisani E, Ghataure A, Merson L: Data sharing in public health emergencies: A study of current policies, practices and infrastructure supporting the sharing of data to prevent and respond to epidemic and pandemic threats. Wellcome Trust. 2018.



Slide Credit: Laura Merson, IDDO

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Data sharing in public health emergencies: A study of current policies, practices and infrastructure supporting the sharing of data to prevent and respond to epidemic and pandemic threats: https://wellcome.figshare.com/articles/Data_sharing_in_public_health_emergencies_A_study_of_current_policies_practices_and_infrastructure_supporting_the_sharing_of_data_to_prevent_and_respond_to_epidemic_and_pandemic_threats/5897608

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Data aggregation is essential for research and action.

Barriers to data aggregation impede research and action.

- **65% of data was not shared, made available** (finding in E. Pisani *et al*. Data sharing in public health emergencies. Wellcome Trust, 2018.)
- Most data **cannot be accessed directly at the record level** (e.g. summarised in studies and not shared).
- Most clinical records from the outbreak are **pdf scans**.
- **Lack of metadata** (data / information about the data which allows the data to be discovered, aggregated, integrated).
- **Lack of a data dictionary** (a set of definitions that allows the variables in the data to be understood).
- **Technically challenging to integrate and analyse trials data and clinical data; and other relevant data (e.g. genomic data, vector data, transport and environmental data etc).**

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Slide Credit: Fernando Gouveia Reis and Laura Merson, IDDO
Simon Hodson, CODATA

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Data aggregation is essential for research and action.

- Data that characterise many of the factors influencing the progression of an outbreak are available but **remain isolated in siloes** within the various domain- specific communities, often with their own domain-specific formats, vocabularies and ontologies.
- Availability of datasets from **industry, the research community, national public health surveillance, climate and environmental monitoring systems, health systems administration, social media feeds, and animal health services** will then be sought in order to understand how their integration can fill critical knowledge gaps across disciplines.
- Reports and lessons learned from previous infectious disease outbreaks have identified **clinical, genomic, demographic, pathogen and vector surveillance, communications, land-use, health administration, and environmental data** as powerful inputs to support planning and operationalising outbreak response.

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Slide Credit: Fernando Gouveia Reis and Laura Merson, IDDO
Simon Hodson, CODATA

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Data sharing: Make outbreak research open access

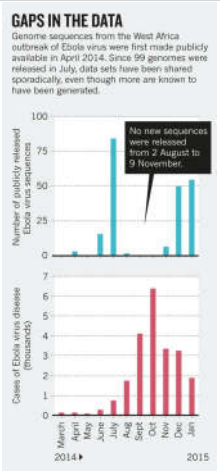
Nathan L. Yozwiak, Stephen F. Schaffner & Pardis C. Sabeti

25 February 2015

Establish principles for rapid and responsible data sharing in epidemics, urge Nathan L. Yozwiak, Stephen F. Schaffner and Pardis C. Sabeti.

PDF Rights & Permissions

Subject terms: Diseases · Genetics · Virology · Ebola virus



"As a first step, we call on health agencies such as the World Health Organization, the US Centers for Disease Control and Prevention and Médecins Sans Frontières, as well as genome-sequencing centres and other research institutions, to convene a meeting this year — similar to that held in Bermuda in 1996. Attendees must include scientists, funders, ethicists, biosecurity experts, social scientists and journal editors.

We urge researchers working on outbreaks to embrace a culture of openness. For our part, we have released all our sequence data as soon as it has been generated, including that from several hundred more Ebola samples we recently received from Kenema. We have listed the research questions that we are pursuing at virological.org and through GenBank, and we plan to present our results at virological.org as we generate them, for others to weigh in on. We invite people either to join our publication, or to prepare their own while openly laying out their intentions online. We have also made clinical data for 100 patients publicly available and have incorporated these into a user-friendly data-visualization tool, Mirador, to allow others to explore the data and uncover new insights."

https://www.nature.com/news/data-sharing-make-outbreak-research-open-access-1.16966

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In an increasingly connected world, rapid sequencing, combined with new ways to collect clinical and epidemiological data, could transform our response to outbreaks. But the power of these potentially massive data sets to combat epidemics will be realized only if the data are shared as widely and as quickly as possible.

Source: https://www.nature.com/news/data-sharing-make-outbreak-research-open-access-1.16966

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Global Health and Open Science: Data Sharing in Global Health Emergencies

Promotion and fostering of effective, ethical, and equitable data sharing across geo-political and disciplinary boundaries during Global Health Emergencies is crucial.

Core principles for rapid responses:

- Preparedness: better learning from existing failures, challenges and best practices
- Transparency and accessible documentation
- Governance: strong institutional networks across geopolitical borders with broad stakeholder inclusion
- Robust infrastructures for data exchange, data curation and aggregation/syndication
- Legal frameworks and international consensus for reciprocal openness
- Communication and expectation management

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This slide was adapted in Jan 2021
Further reading: https://osf.io/preprints/metaarxiv/axy84/

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