

Data for international health emergencies: governance, operations and skills

This Statement has been created by the Science Academies of the Group of Seven (G7) nations. It represents the Academies' view on the need for the G7 countries to realise a better level of 'data readiness' for future health emergencies.

Data is the currency for exchanging information, building knowledge and driving action in health. Amid the disastrous loss of health and life to Covid-19, people around the world have engaged with data and information more intensively than ever. As the pandemic is brought under control, the G7 should champion the cause of establishing health data as a global public good. To achieve this, the nations of the G7 and beyond should work together to: adopt principle-based governance systems for securing safe sharing and use of data for health emergencies; build and implement the operational systems, infrastructures and technologies for implementing a principle-based and privacy-preserving approach to equitable use of data for health emergencies; and foster the skills and capabilities at all levels – from the general public to health professionals – needed for trusted and accurate use of data. There is an opportunity now to learn from international responses to Covid-19, and the G7 should capture this moment to help build a trustworthy and trusted international data system for health emergencies. The Governments of the G7 should establish a commission on data for health emergencies to agree on how to achieve this. The initial aim of this commission could be to identify procedures for data sharing that were used in response to Covid-19, which might be adopted for longer-term use in G7 and other nations. The commission should involve meaningful public dialogue to build trusted systems that can support the global health beyond the G7, and beyond health emergencies.

1. Data for health emergencies: what is needed for a data-informed response?

Data is a fundamental resource for modern health and social care, and access to that data is a core utility for emergency preparedness and response. The production of data continues to grow rapidly, but the ability to analyse and draw insights from it has been hampered by the slow adoption of digital technologies, by inconsistencies in data types and definitions, by restrictions on access to the data held by public agencies and private businesses, and by political differences between nations. The case for building international data systems has been made clearly in the past, including by the Academies of the S7 in 2018¹, and

is embraced by international law², yet the pandemic has revealed that there are many obstacles to real-time data collection, distribution and use. The weaknesses in global data systems mean the world is operating, for example, with a pandemic alert system that is not fit for purpose³.

The value of data may have been more fully and rapidly realised if the pandemic had emerged in a context in which: Shared principles governing safe, ethical and timely use of data had been adopted and implemented;

- Standardised collection and access to appropriate data had been guided by an established international body such as WHO, so as to prepare for, and respond to, this and other emergencies;
- International databases of primary (raw, detailed and disaggregated) data were available to public health authorities and trusted researchers, under the direction of this body;
- Skills and capacity to collect, manage and analyse data were established across nations, including access to the technologies for enabling data analysis while ensuring security and protection of privacy;
- Policies were defined and implemented to engage the public in the collection, use and understanding of data, with due regard for the social and political differences between nations; and
- Incentives were in place to promote international action towards these objectives.

With such a system of principles, governance, skills and engagement in place, an earlier, better-informed, and more publicly acceptable pandemic response may have been possible. Issues such as gaps in data about sources of infection, who is affected (by age, sex, occupation, ethnicity etc) would be more easily avoided, enabling rapid and comprehensive learning about the pandemic and averting inequalities in its impact. Early availability of data relating to emerging challenges such as 'long Covid' would be available to researchers internationally.

The G7 countries should capture this moment to work together to achieve these outcomes globally, based on the actions set out below. They should establish a commission that will identify, join together and work with the systems, structures and organizations that have the technical expertise to implement them, the ethical and political understanding to appreciate the complexities of world health issues, and the political influence to ensure that they are delivered. These organizations include the African and European Unions, OECD, WHO, the World Bank and the Global Partnership on AI (including its working group on data governance). Succeeding in this end will enable rapid response to future health emergencies, create systems that also better support use of data for health outside periods of crisis, and set an example for the world to follow.

2. Shared principles: a common basis for action on health for emergencies

Fundamental to enabling a data-informed response to health emergencies is commitment to shared, foundational principles for ethical and safe use of data, building on examples such as those adopted by WHO⁴, and incorporating the widely adopted FAIR principles⁵ – making data Findable, Accessible, Interoperable and Reusable. Each of the areas of action below is premised on a shared commitment to ensuring that data is accurate, representative, that any bias in the data is well understood and compensated for, and efforts are maintained to address any biases in data. That commitment requires using data in a way that is agreed through societal deliberation to be ethical, non-discriminatory and fair, which requires interdisciplinary collaboration between technological and social approaches and research to learn from the best models for public engagement. It involves understanding the health inequalities and systemic biases that create differential impact on different communities, including indigenous populations⁶, and commitment to minimising these inequalities. This means understanding the different needs of diverse communities within and across nations, and creating the agility in systems to adapt to those needs and the systems designed to meet them. It is to collect, share and use data in a transparent way, with oversight of and clarity on purposes of use. It is to use it in a secure and privacy-preserving way, to protect the rights and interests of individuals and organisations.

In short, data that informs preparation for, and response to, pandemics and other health emergencies should be viewed as a global public good. With these principles in place, built on the foundation of a shared commitment to democratic process, the appropriate governance mechanisms, operational systems and capabilities can be established.

3. Areas for action: Governance, operations and skills

3.1 Governance: Adopt principle-based governance mechanisms to enable safe data access and use for health emergencies

Data relevant to pandemic preparedness and response essentially includes data from medical, research, care, and public health sources but extends to social and commercial data such as information on income, location, mobility and occupation, which reflect and describe people's everyday behaviours and living conditions. Enabling privacy-preserving access to and use of these wide ranges of data, in order that they can inform policy and healthcare decisions, could be supported by establishing a set of common governance mechanisms, and harmonisation of regulatory approaches to data systems and the tools for data analysis.

An example of such a mechanism would be defining and requiring the adoption by public and private organisations of a duty to safely share data, where this is vital to crisis situations such as pandemics. Such a duty to encourage would put an obligation on public and private organisations – from hospitals to mobile phone providers – to be ready respond to an emergency, preparing their data systems to be able to share good quality data in a timely, yet secure and transparent manner.

Templates for data sharing agreements across public and private organisations can create mutually beneficial data access arrangements, and thereby underpin such a duty to share. These agreements would set out who can access the data and for what purposes, with clarity on how the rights and interests of those who hold the data assets, and the data subjects, are protected both legally and through secure use of data.

Promotion and use of the widely adopted FAIR principles should be encouraged. Agreements to share data should establish the importance of sharing detailed, primary data, capturing characteristics such as sex, ethnicity, age, language, location, and related socioeconomic factors, in order to identify and address disparities in health outcomes.

Governance mechanisms must set a framework for the appropriate use of technologies to support the safe use of data. Agreements should also recognise the need to use, wherever possible, approaches that enable privacy-preserving data analysis such as federated machine learning, which allows analysis across datasets without linking them; or trusted research environments to enable secure data analysis. Collaboration on research and development to deliver these tools, and the appropriate policy frameworks to guide their use, will be key for a trustworthy and societally acceptable use of data for health emergencies.

3.2 Operations and infrastructure: Build the operational systems, infrastructures and technologies for implementing a principle-based approach to use of data for health emergencies

A rapid, data-informed response to health emergencies requires common standards to enable interoperability between datasets and to ensure that good quality data can be accessed and used in a timely way. This starts with common health data descriptions and harmonisation of data documentation, so that different countries can align, compare and control the data they hold.

Creating a shared data infrastructure also involves cooperation on the algorithms and methods that extract knowledge and value from data. It requires shared standards and approaches for data security, anonymisation or pseudonymisation, and privacy protection, including the adoption of privacy-enhancing technologies, as set out above.

Establishing robust operational systems and infrastructure for data is a long-term programme. The G7 nations should support international bodies with responsibility for health data, and expertise in data analysis, in building improved data infrastructures, building on existing principles such as FAIR.

These bodies should advise on priority areas where common standards and data harmonisation are needed – in particular focusing on areas which would better address health inequalities.

The data needs in the context of an emergency depend on the nature of the crisis. Establishing international leadership ahead of a pandemic will enable rapid convening of experts to advise on and oversee the rapid construction of the specific data systems in the context of an emergency, operating with, and within, the principles and governance frameworks set out above.

3.3 Foster data skills and capabilities at all levels for data management, data analysis, data-informed decision making and public deliberation

G7 nations should work together to develop greater levels of data literacy, statistics, privacy awareness and cybersecurity skills so that public and private sectors, academia and civic society can all make use of data for benefits of society, while protecting against risks of misusing data.

This involves political and research leaders learning from best international practice for data collection, use and governance to help build systems to collect, store, curate, analyse, disseminate and use data appropriately, evaluating and learning from the benefits of data use. A number of examples of good practice can be replicated internationally, such as the Health Data Hub⁷ in France; OpenSafely⁸ in the UK, which enables safe use of patient health records; the European Health Data Space⁹, the Covid-19 Genomics Consortium UK (COGUK), which combines virus genome data with clinical and epidemiological datasets¹⁰. Lessons should also be drawn from examples of misuse of data, and from the history of failed international co-operation, to work towards trustworthy and trusted use of data. It involves investment in the skills to collect, clean and manage data, and to analyse and draw insights from it. It includes ensuring these skills are available across sectors so that they can be used to support the use of data for health.

Creating these skills and systems globally is essential to early detection and containment of emerging health crises.

Recommendations

The G7 nations working together can help to develop the principles, systems and skills to safely and rapidly share data in health emergencies. This will ensure improved health outcomes beyond emergency response, as we recover from the pandemic and for future generations.

RECOMMENDATION 1

Governance: Adopt principle-based governance mechanisms to enable safe data access and use for health emergencies.

- Governments of the G7 nations should work together to adopt foundational principles and frameworks that underpin agreements to share data to respond to health emergencies.
- The health, business, legal and policy communities across G7 nations and beyond should collaborate to define an obligatory duty to safely share data for health emergencies that will stimulate data use for a common social benefit.
- Legal communities across the G7 should collaborate on governance mechanisms for data access, such as template agreements to share data, within the context of data governance regimes such as the General Data Protection Regulations (GDPR) and International Health Regulations (IHR)¹¹.
- International research endeavours should be funded to further the development of technologies that can help improve the reliability and accessibility of data for better health and health care, while protecting sensitive data.

RECOMMENDATION 2

Operations and infrastructure: Build the operational systems, infrastructures and technologies for implementing a principle-based approach to use of data for health emergencies.

- G7 nations should set in place a network of expert bodies to advise on and act to enable the use of data for health emergencies.
- The aim of this network should be to work towards an international, interoperable, data infrastructure for health emergency response, enabling the rapid convening of specialist expertise to agree the details of the data needed when emergencies arise.
- The network should be established to enable international cooperation on data for health that can both improve healthcare outside of emergencies, and work towards better data use for other critical areas such as climate change and biodiversity loss – ensuring that data is used to support the ‘one health’ approach^{12,13}.

RECOMMENDATION 3

Skills: Foster data skills and capabilities at all levels for data management, data analysis, data-informed decision making and public deliberation.

- Individual nations should invest in the skills needed for data literacy and for skilled data use, including skills to ensure data use is ethical, privacy-preserving and supported by public engagement. Means to achieve this include ensuring that accessible online resources, translatable into multiple languages, are available, with international reach and benefit beyond G7 countries.
- Leaders across G7 nations should make a coordinated effort to share and learn from best practice in using data in the pandemic response.
- G7 nations should support low-resource countries in developing and using examples of best practice, including through grant aid and technological cooperation.

RECOMMENDATION 4

Establish a commission to agree on the mechanisms to achieve these recommendations.

The Governments of the G7 should establish a commission on data for health emergencies. The initial aim of this commission could be to identify procedures for data sharing that were used in response to Covid-19, which might be adopted for longer-term use in G7 and other nations to enable response to and recovery from health emergencies. The commission should involve meaningful public dialogue to build trusted systems that can support global health beyond the G7 and beyond health emergencies. Progress of this commission should be reported on and reviewed at the next meeting of the G7 in Germany.



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