

Key considerations for a two-year implementation plan on improving safe data access and use for health emergencies - advice to the G7

SUMMARY OF AN INTERNATIONAL ROUND-TABLE SUPPORTING THE G7

On 30th April 2021, The Trinity Challenge and co-hosts the Royal Society and the International Digital Health & AI Research Collaborative (I-DAIR), ran a roundtable on data access and use for health emergencies, to help the G7 under the UK's presidency drive global improvements in pandemic resilience. The roundtable was framed around a statement from the Science Academies of the G7 (the S7), which recommended developing **common governance principles, improved operational systems and infrastructure, and improved skills**. International leaders from industry, academia, non-profits, and governments suggested tangible actions in the context of a **2-year implementation plan led by the G7, working with WHO, the G20 and others**.

Delivery Priorities: Implementation should seek to inspire leaders and to drive incentives for people and organisations to commit to building safe data access and use capability to deliver three priorities:

- 1. **Developing a global disease surveillance and risk monitoring system -** to provide early warning signals of emerging infectious zoonoses with pandemic potential, using health and microbiology data as well as non-traditional insights (e.g., mobility & transaction data).
- 2. Building and promoting public health capacity to create the organisational infrastructure to improve global resilience, and to develop public awareness of and engagement with public health systems (including through behavioural insights to understand vaccine uptake and attitudes to non-pharmaceutical interventions such as social distancing).
- 3. Accelerating the development and delivery of diagnostics, vaccines, and therapeutics, by growing the scale of investment, the pace of innovation (for 100-day vaccine development), the scale of production and delivery capacity (including logistics infrastructure), and the prioritisation of these to optimise equitable benefits to humanity.

Priority Actors: the following key actors have central responsibilities.

- 1. Policymakers are both users of data, and shapers of the regulatory environment (including standards, IP, and privacy regimes). They should seek to understand optimal safe data access and use environments, the stakeholders involved in delivering these, and policy blockers and enablers. They should clearly define data and analysis needs and anticipate how these will differ for different emergencies. They should create a smart policy roadmap that supports all capacity levels, incentivises capacity building, is adaptive to technology change, and has the building of trust at its heart. Policymakers should explore incentives for safe data access and use from all actors, including citizens, institutions, and private sector organisations. A central goal for policymakers should be that safe data sharing regimes are in place and delivering positive public value for 'business as usual', in order that capacity to handle emergencies is already in place when the emergency arises.
- 2. **Data Users** include Governments, analysts, researchers, technology innovators, and commercial operators. This community needs awareness of current and future technologies and tools to enable trusted and privacy preserving use of data, and 'right-size' data requirements for timely effective end-user delivery.

- 3. Data Owners need the capacity to enable safe data access and use with the building of trust as a central priority. They need to understand the current and future public value of their data, and to have the competence (legal, technical, motivational) to deliver this public value whilst mitigating risks in doing so. They should anticipate public value demands for specific use cases, and work with stakeholders (e.g., shareholders) on the implications for this, including on motivations and incentives to realise public value. They should ensure that users and policymakers understand owners building blocks (e.g., data standards, data-sharing platforms, data use norms, skills and capabilities)
- 4. Communities and publics, especially those with greatest vulnerability to health emergencies, will be critical to engage throughout this process. Actors should seek out representative groups for deliberative engagement on use cases. Building sustainable trust will be central to such engagement, as will developing behavioural insights. Actors should engage with all perspectives to understand citizen concerns and policy trade-offs.

TWO YEAR IMPLEMENTATION PLAN - BUILDING BLOCKS

- For each priority (developing a global disease surveillance system, building public health capacity, accelerating development and delivery of diagnostics, therapeutics, and vaccines) specific priority use cases chosen for their ability to most advance the priority objectives should be chosen from which to assess current capabilities and best practice, identify desired outcomes, and work across actors on delivery roadmaps.
- Create a shared on-line living repository to catalog data, technologies, and use cases where updates and points of contact for new data sources, tools, etc. can continually be shared, to promote learning and enable scaling and sharing of systems.
- **Build on existing strengths –** exploit knowledge, partnerships, collaborations, and networks, data access and use platforms, that already exist.
- Inspire leadership and explore and develop incentives for priority actions, particularly the development of organisational capacity for safe and effective data access and use. This could include specific pledges and commitments.
- Technology leaders should make technology and tools available easily findable, and develop a playbook for leading-edge approaches (e.g., distributed learning, differential privacy, neutral consent managers) that address concerns around privacy, security, and IP. Minimum Viable Products should be defined for data and analytics infrastructure (e.g., data sources, analytics, platforms) for each priority use case at-scale.
- **Public Health actors** should set out frameworks for building international public health capacity that delivers clarity of responsibility, rules, obligations and operations, which is rooted in everyday public health practice and allows for change through advancing technology.
- Data assets should be defined for each use case. Roadmaps for access and use protocols should be developed for data beyond the traditional (e.g., telecoms, web scraping, financial transactions, mobility data, sewage testing, satellite images).
- A clear investment roadmap should be defined to build capacity and critical infrastructure at pace and scale for low to middle income countries.
- Current international agreements governing data access and use should be audited, and a policy roadmap created for updating these and developing any new agreements, building on existing and commonly agreed principles (e.g., FAIR+) and governance mechanisms.
- **Stress testing resilience** protocols should be developed for stress testing the international actions that would be most relied upon in a new pandemic or similar emergency.