

**Complete list of resources referenced in the Chatham House Guide to Sharing the Data and Benefits of Public Health Surveillance**

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## **Model Agreement and Annexes**

Model Agreement for Sharing the Data and Benefits of Public Health Surveillance  
Author: Chatham House

Annotated Model Agreement for Sharing the Data and Benefits of Public Health Surveillance  
Author: Chatham House

Model Agreement Annex A: Initiating Public Health Surveillance Data Sharing Form  
Author: Chatham House

Model Agreement Annex B: Data Management Plan  
Author: Chatham House

Model Agreement Annex C: Intellectual Property Rights Management Plan  
Author: Chatham House

Model Agreement Annex D: Benefit Sharing Plan  
Author: Chatham House

## Agreements, Guides and Frameworks

### Agreements

Ensuring Citizens' Privacy: the European Data Protection Supervisor  
Author: European Parliament

International Covenant on Civil and Political Rights  
Author: United Nations

International Health Regulations (2005) - Third Edition  
Author: World Health Organization

Nagoya Protocol on Access and Benefit-Sharing  
Author: Convention on Biological Diversity

Sustainable Development Goal 3  
Author: United Nations

### Guides

A Guide to Confidentiality in Health and Social Care: Treating Confidential Information with Respect  
Author: NHS Digital

Communicable Disease Surveillance and Response  
Author: World Health Organization

Fair Research Contracting  
Author: Council on Health Research for Development

Frequently Asked Questions about the International Health Regulations (2005)  
Author: World Health Organization

General Data Protection Regulation  
Author: Information Commissioner's Office

Guide to Social Science Data Preparation and Archiving  
Author: Interuniversity Consortium for Political and Social Research

Guidelines for Evaluating Public Health Surveillance Systems  
Author: US Centers for Disease Control and Prevention

MRC Data Sharing Policy and Guidance

Author: MRC

NHS Digital Data Sharing Audits

Author: NHS Digital

NIH Data Sharing Policy and Implementation Guidance

Author: National Institutes of Health

Open Data Handbook

Author: Open Knowledge International

Research Data Management

Author: London School of Hygiene & Tropical Medicine

Research and Policy in Development Outcome Mapping Approach

Author: Overseas Development Institute

Sharing Social Data in Multidisciplinary, Multi-Stakeholder Research

Author: Ecosystem Services for Poverty Alleviation

Statistics Canada Quality Guidelines

Author: Statistics Canada

WorldWide Antimalarial Resistance Network Toolkit

Author: WWARN Toolkit for Data Collection

## **Frameworks**

African Union Convention on Cyber Security and Personal Data Protection

Author: African Union

Framework for Responsible Sharing of Genomic and Health-Related Data

Author: Global Alliance for Genomics & Health

Pandemic Influenza Preparedness (PIP) Framework

Author: World Health Organization

Public Health Outcomes Framework

Author: Public Health England

R&D Blueprint for Action to Prevent Epidemics

Author: World Health Organization

WHO Integrated Disease Surveillance

Author: World Health Organization

## **Data Management Resources**

Companion Material for Managing and Sharing Research Data Handbook

Author: UK Data Service

Create and Manage Data Guides

Author: UK Data Archive

EU Data Quality Monitoring and Surveillance System Evaluation

Author: European Centre for Disease Prevention and Control

FOSTER Open Science Resources

Author: Facilitate Open Science Training for European Research

International Household Survey Network Data Management Tools and Guides

Author: International Household Survey Network

NHS Digital Information Governance

Author: UK National Health Service

Open Government Licence for Public Sector Information

Author: UK Controller of Her Majesty's Stationery Office

Policy on Data Submission, Access, and Use of Data within TESSy

Author: European Centre for Disease Protection and Control

Reproducibility and Open Science

Author: eScience Reproducibility and Open Science Working Group

UK Anonymisation Network Resources

Author: UK Anonymisation Network

## **Technical Standards**

CDISC Foundational and Therapeutic Area Standards

Author: Clinical Data Interchange Standards Consortium

Data Citation Metadata Schema

Author: Data Cite

Data Documentation Initiative

Author: Data Documentation Initiative Alliance

Date and Time Format

Author: International Organization for Standardization

ECDC Case Definitions

Author: European Centre for Disease Prevention and Control

HL7 Clinical Document Architecture

Author: Health Level 7 International

International Statistical Classification of Diseases and Related Health Problems

Author: World Health Organization

Open Data Protocol

Author: Microsoft Corporation

Statistical Data and Metadata Exchange - Health Domain (SDMX-HD)

Author: UN Statistics

WHO Recommended Surveillance Standards

Author: World Health Organization

## **Project Resources**

A Guide to Sharing the Data and Benefits of Public Health Surveillance

Author: Chatham House

Complete List of Key Points to Consider

Author: Chatham House

Complete List of Resources

Author: Chatham House

## **Statements on Data Sharing**

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

Author: World Health Organization

Policy Statement on Data Sharing by the World Health Organization in the Context of Public Health Emergencies

Author: World Health Organization

Public Health Surveillance: A Call to Share Data

Author: International Association of National Public Health Institutes

Sharing Research Data to Improve Public Health: Full Joint Statement by Funders of Health Research

Author: Wellcome Trust et al.

Toronto Statement on Prepublication Data Sharing

Author: Toronto International Data Release Workshop Authors

## **Project Research**

Data Sharing for Public Health: Key Lessons from Other Sectors

Authors: Matthew Brack and Tito Castillo

Digital Disease Detection

Authors: Michael Edelstein and David R Harper

Overcoming Barriers to Data Sharing in Public Health: A Global Perspective

Authors: Michael Edelstein and Jussi Sane

Perspectives on Data Sharing in Disease Surveillance

Author: Emma Ross



Sharing Surveillance Data for Global Health: Seeking Much-Needed Improvements  
Author: Matthew Brack, et al.

## **External Resources**

A Systematic Review of Barriers to Data Sharing in Public Health  
Author: Willem Van Panhuis, et al.

A World That Counts: Mobilising the Data Revolution for Sustainable Development  
Author: UN Data Revolution Group

African Health Observatory  
Author: WHO Regional Office for Africa

Ben Goldacre on Open Data  
Author: Ben Goldacre

Data for Health and Sustainable Development  
Author: Health Data Collaborative

Digital Disease Detection – Harnessing the Web for Public Health Surveillance  
Author: John Brownstein, et al.

Ethical Justification for Conducting Public Health Surveillance Without Patient Consent  
Author: Lisa M Lee, et al.

Ethics and Best Practices in Sharing Individual-Level Research Data  
Author: Global Health Network

Global Health Network Methodology Projects  
Author: Global Health Network

Global Healthcare Innovation Alliance Accelerator  
Author: Global Healthcare Innovation Alliance Accelerator

GloPID-R Principles for Data Sharing during Emergencies  
Author: Wellcome Trust

GloPID-R Data Sharing in Public Health Emergencies  
Author: GloPID-R

Information: To Share or Not to Share? The Information Governance Review  
Author: UK National Data Guardian

Public Health Research Data Forum  
Author: Wellcome Trust

Sharing All Types of Clinical Data and Harmonizing Journal Standards  
Author: Corrado Barbui

Sharing Data: What to do with your Processed Data  
Author: Responsible Data Forum

Sharing Health Data: Developing Country Perspectives  
Author: Viroj Tangcharoensathien, et al.

The Practice of Reproducible Research  
Author: Justin Kitzes, et al.

Wellcome Trust Policy on Data Sharing  
Author: Wellcome Trust

Wellcome Trust Research  
Author: Wellcome Trust

What Incentives Increase Data Sharing in Health and Medical Research? A Systematic Review  
Author: Anisa Rowhani-Farid, et al.

What is Fair and Equitable Benefit-Sharing?  
Author: Bram de Jonge

WHO Consultation on Data and Results Sharing During Public Health Emergencies  
Author: Ben Goldacre, et al.

## **Additional Resources**

Acknowledgements  
Author: Chatham House

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