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
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
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

Image Credits
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