

# Data Sharing and Ethics of Big Data

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IMED, Vienna, 6 November 2016

# Sharing data saves lives

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- Twenty-first century - several major global disease outbreaks (SARS, H1N1, Ebola, Zika ....)
- Common characteristic - sharing of public health surveillance data leads to improved public health action
- Failure to share - very real health consequences for individuals and communities (MERS-CoV).





# Essential for Sustainable Development Goals

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- Enables regional collaborations, capacity strengthening, insight into public health system performance
- Better public health outcomes - a global public good

# *Strengthening Data Sharing for Public Health*

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- Project started in 2014
- ‘How to create the right environment and achieve good practice’
- Iterative process - wide range of leading international experts and thematic and regional roundtables

## *Key points*

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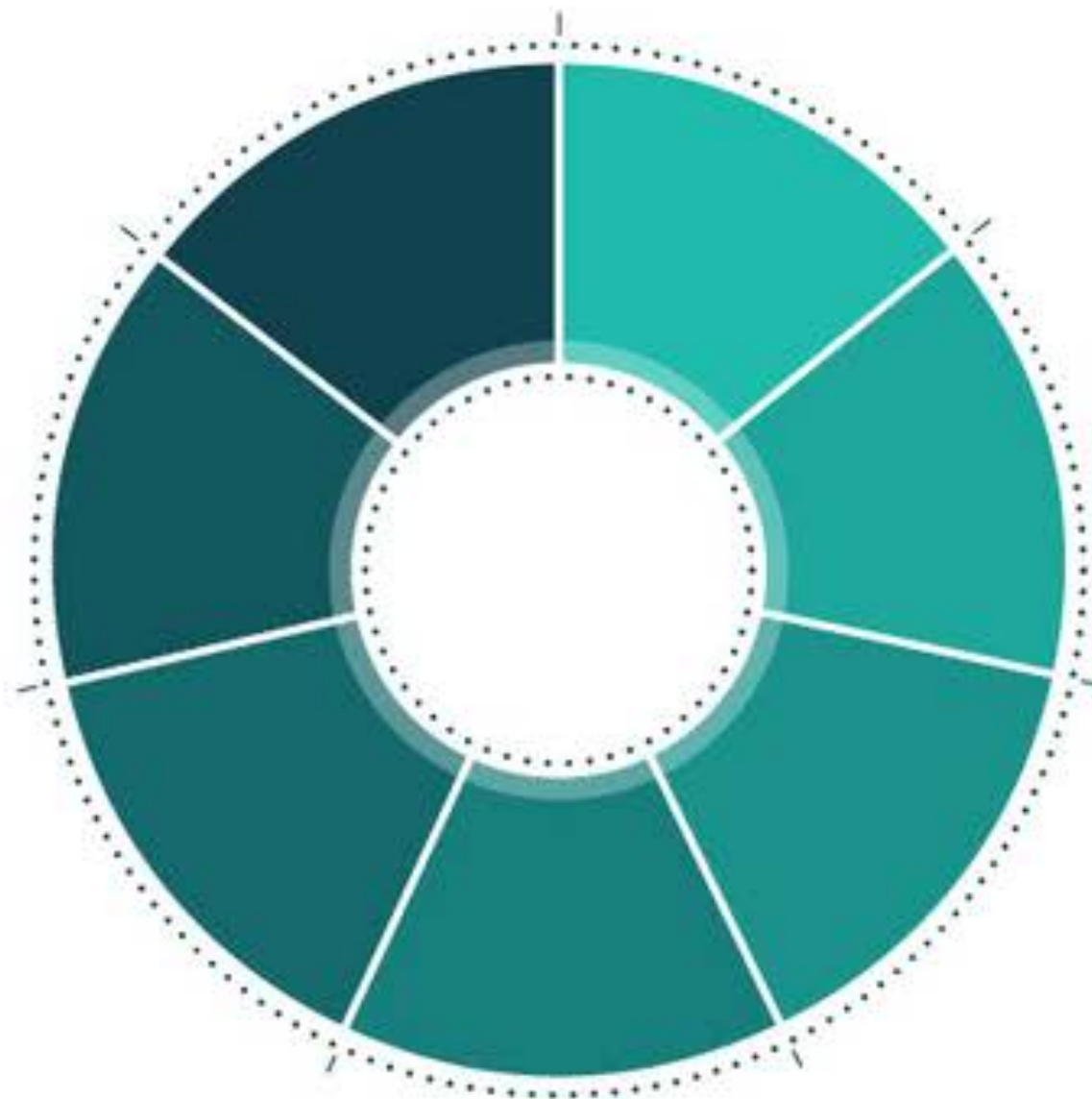
- *All* public health surveillance data should be shared as necessary to improve and protect public health
- Unacceptable to claim ownership of, or restrict access to, data if this decreases potential health benefits
- Commitment to principles of social beneficence, respect, justice and transparency is essential
- Norm - data to be accessible in timely manner for public health action while taking appropriate steps to safeguard the privacy of individuals and other legitimate public interests



# Home page



## SHARING PUBLIC HEALTH SURVEILLANCE DATA



Sharing public health surveillance data leads to better control of infectious diseases and is essential for the achievement of the Sustainable Development Goals. This guide aims to help facilitate sharing of public health surveillance data across borders and provide answers to any technical, political, ethical, economic and legal concerns that may arise.

[OPEN THE GUIDE](#)

# Home page (scrolling down)

The image shows a home page layout. At the top is a teal navigation bar with four columns. Each column contains an icon, a question, and a red plus button. Below the navigation bar is a dark grey footer containing a mailing list sign-up form and contact information.


WHAT	WHO	WHEN	HOW
is this guidance?	is this guidance for?	to use this guidance?	to use this guidance?
+	+	+	+

**SIGN UP TO OUR MAILING LIST**

First name	Last name	Email address	<b>SUBMIT</b>
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**Contact us**  
email@xxxxxxxxxxxxxxxxxxxx.co.uk

**Find out more**  
Strengthening Data Sharing for Public Health project page

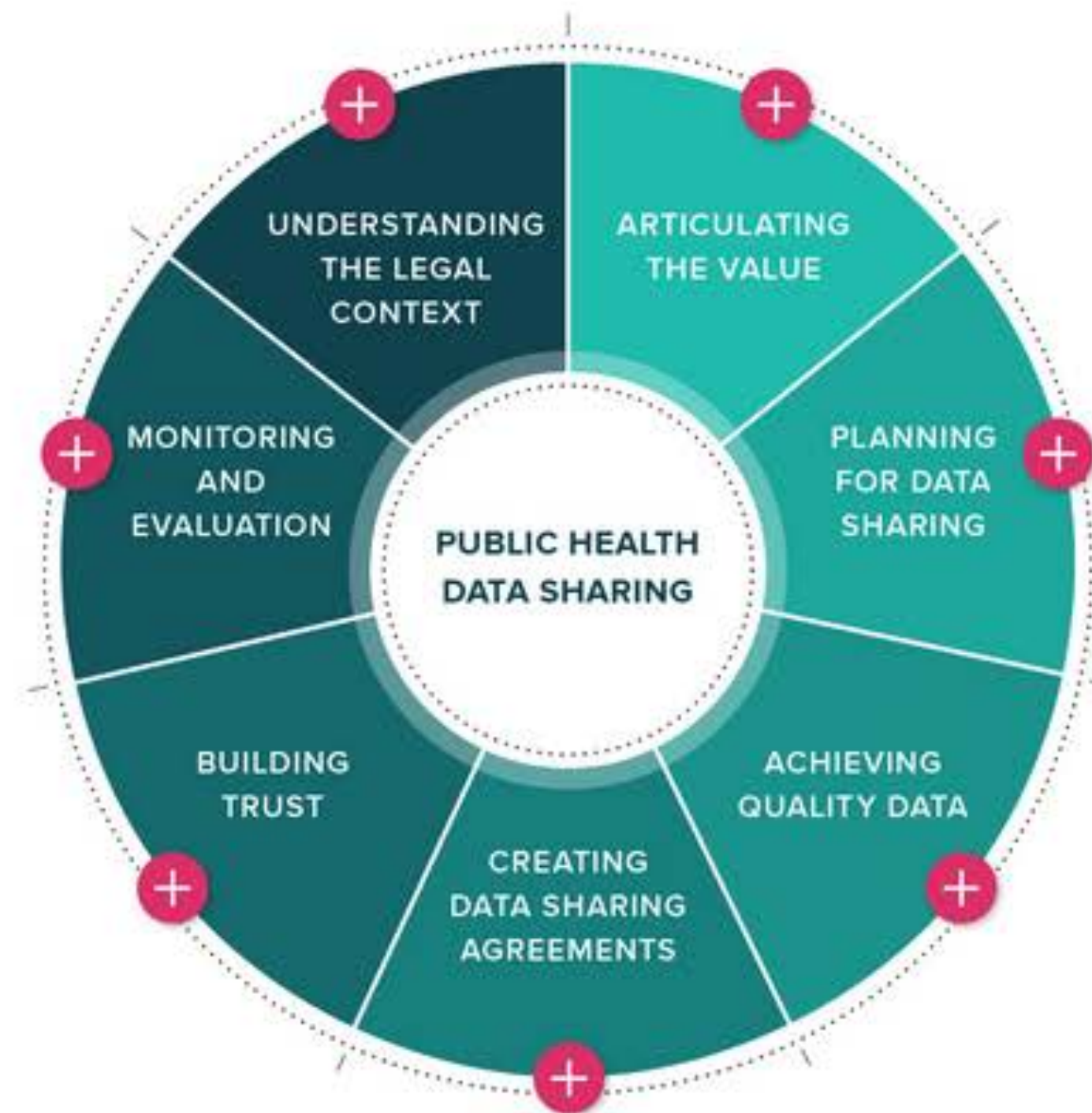
 **Join the conversation**  
#publichealth #datasharing



# Principles

I am a state organization, my role is data producer,  
sharing is taking place between state and multilateral, my context is emergency.

EDIT

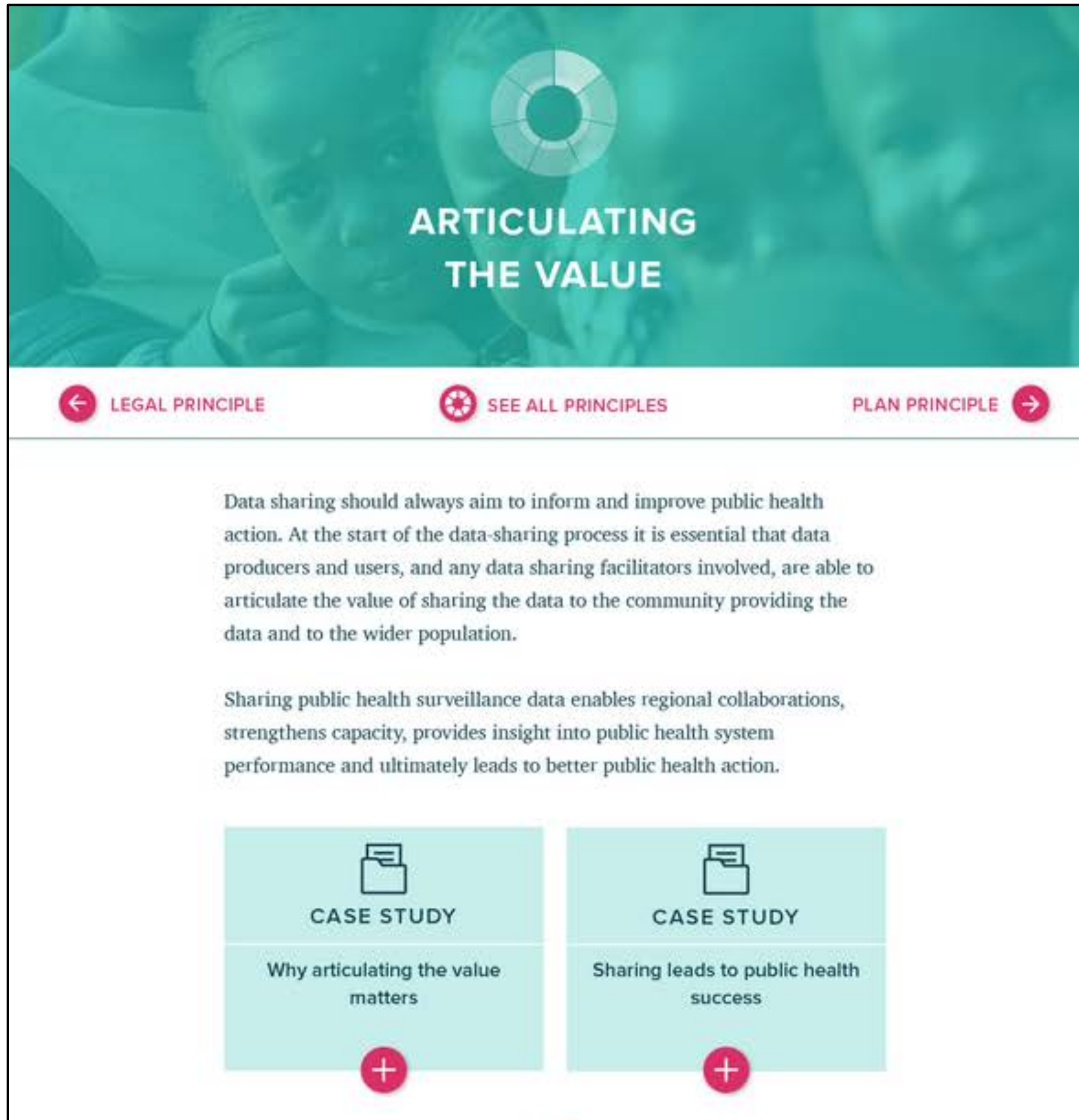


The seven principles above enable to create an environment conducive to data sharing and achieve good data sharing practice. They also ensure data sharing is conducted in a fair and ethical manner for all parties, and contribute to building surveillance capacity for those involved.

Click on the principles above for more information.



# Content: principle and case studies




The image shows a digital interface with a teal header. At the top center, there is a circular icon with a grid pattern. Below it, the text "ARTICULATING THE VALUE" is displayed in white. A navigation bar below the header contains three items: a left arrow, "LEGAL PRINCIPLE", a gear icon, "SEE ALL PRINCIPLES", and "PLAN PRINCIPLE" with a right arrow. The main content area has two paragraphs of text. Below the text are two teal case study cards, each with a folder icon, the text "CASE STUDY", a title, and a red plus icon at the bottom.


## ARTICULATING THE VALUE

[← LEGAL PRINCIPLE](#) [SEE ALL PRINCIPLES](#) [PLAN PRINCIPLE →](#)

Data sharing should always aim to inform and improve public health action. At the start of the data-sharing process it is essential that data producers and users, and any data sharing facilitators involved, are able to articulate the value of sharing the data to the community providing the data and to the wider population.

Sharing public health surveillance data enables regional collaborations, strengthens capacity, provides insight into public health system performance and ultimately leads to better public health action.

  
CASE STUDY  
Why articulating the value matters  
[+](#)

  
CASE STUDY  
Sharing leads to public health success  
[+](#)

# Content: points to consider and resources

The infographic is divided into two main sections. The top section, 'KEY THINGS TO CONSIDER', has a teal background and a checklist icon. It lists five questions, each with a red plus icon to its right. The bottom section, 'RELATED RESOURCES', has a light teal background and a wrench and screwdriver icon. It contains three white boxes with resource information, each with a red download or link icon at the bottom right.

## KEY THINGS TO CONSIDER

- How can data sharing agreements contribute to the development of surveillance capacity? +
- How can a data sharing agreement address legal concerns such as data protection? +
- Have all parties had an equal say in the development of a data sharing agreement? +
- How can a data sharing agreement increase data quality? +
- Have mechanisms been put in place for ongoing discussions and trust-building exercises between data sharing parties? +

## RELATED RESOURCES

Template	Guidance	Comment
Chatham House Centre on Global Health Security <b>Model agreement for the sharing of public health surveillance data beyond national borders</b>	Council on Health Research for Development <b>Fair Research Contracting</b>	Matthew Brack et al. <b>Sharing Surveillance Data for Global Health: Seeking Much-Needed Improvements</b>
.DOC file   345KB		



# Resource portal



## RESOURCES

### GLOSSARY

A glossary of terms used throughout this guidance.

[VIEW GLOSSARY](#)

### ETHICAL PRINCIPLES UNDERLYING THE

Four ethical principles underlie each of the data-sharing principles detailed in this guidance.

[VIEW ETHICAL PRINCIPLES](#)

### OPERATIONAL GUIDES AND TEMPLATES

Templates and explanatory documents that have been designed to for those wishing to enter into data-sharing agreements.

[VIEW RESOURCES](#)

### EXTERNAL RESOURCES

A series of external tools and other guidance that present a critical resource for data sharing and have informed the work of this project.

[VIEW RESOURCES](#)

### BACKGROUND RESEARCH AND

Project research documents and key external research on issues surrounding the sharing of public health surveillance data.

[VIEW RESOURCES](#)

# Digital Disease Detection

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# *Where are we now?*

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- ‘Traditional’ public health surveillance
  - Largely ‘government-owned’
  - Formal, structured, validated, quantitative
  - Laboratory reports etc
  - Public health professionals
  - Can be slow.....

# *Where are we now?*

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- Digital Disease Detection
  - Generally not ‘government-owned’
  - Informal, unstructured, not validated, potentially inaccurate, biases?
  - Multiple sources
  - Often unconfirmed
  - Can be rapid.....



# *Where are we heading?*

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- New technology?
- Synergy between DDD data sources?
- Legal issues?
- Ethics framework – privacy etc?
- Move from informal to formal?
- Standards?
- Government traction?

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‘We are drowning in information but starved  
for knowledge.’

John Naisbitt (author)



# Thank you

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## **Strengthening data sharing for public health**

### **Centre on Global Health Security**

- Dr David Heymann
- Dr Michael Edelstein
- Matthew Brack
- Asha Herten-Crabb

### **Bill & Melinda Gates Foundation**

- Dr Scott Dowell
- Dr Kendall Krause