

# How should we share?

[https://dqbasmyouzti2.cloudfront.net/assets/content/cache/made/content/images/articles/BigData\\_Wormhole\\_XL\\_721\\_420\\_80\\_s\\_c1.jpg](https://dqbasmyouzti2.cloudfront.net/assets/content/cache/made/content/images/articles/BigData_Wormhole_XL_721_420_80_s_c1.jpg)

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# Acknowledgements



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# Overview

- **Why share?**
- Issues and challenges
  - Respecting participants and communities
  - Equitable sharing
- Governance and ways forward

# Practical justifications



Improve **science**:

- Enable verification, replication and expansion of results
- Address biases, deficiencies and dishonesty
- Address novel research questions
- Inform research design and research funding
- Promote education
- Increase primary data producers' profiles and opportunities for collaboration



# Practical justifications

Translational benefits in **health** by increasing the evidence base to inform:

- Policy design
- Healthcare allocation
- Regulatory review
- Clinical care



# Ethics

- Utility, cost-effectiveness
- Respect for participants
- Promote scientific values
- Promote best practices
- Promote the public good



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- Why share?
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  - Equitable sharing
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# Respecting participants and communities

- Preserving privacy
- Consent and control
- Engagement and governance

# Preserving privacy

- Practical challenges
  - Effective de-identification
  - Combining datasets
- Ethical issues
  - Tensions between preserving privacy and promoting utility
  - Implications of de-identifying samples and data

<https://schoolsweek.co.uk/government-halts-data-sharing-on-pupils/>

# Respecting participants and communities

- Preserving privacy
- **Consent and control**
- Engagement and governance

# Consent and control

- What kind of consent should be sought and how?
- What are the limitations of consent in this context?
- How should we respond to these limits?
- What should we do when consent cannot be sought?

Cheah et al. *BMC Medical Ethics* (2018) 19:86  
<https://doi.org/10.1186/s12910-018-0326-x>

BMC Medical Ethics

RESEARCH ARTICLE

Open Access



# Challenges arising when seeking broad consent for health research data sharing: a qualitative study of perspectives in Thailand

Phaik Yeong Cheah<sup>1,2,3\*</sup>, Nattapat Jatupornpimol<sup>1</sup>, Borimas Hanboonkunupakarn<sup>4</sup>, Napat Khirikoekong<sup>1,5</sup>, Podjanee Jittamala<sup>6</sup>, Sasithon Pukrittayakamee<sup>4</sup>, Nicholas P. J. Day<sup>1,2</sup>, Michael Parker<sup>3,7</sup> and Susan Bull<sup>3,7</sup>



SMRU – Shoklo  
Malaria Research  
Unit



MORU –  
Mahidol Oxford  
Tropical Medicine  
Research Unit

# Respecting participants and communities

- Preserving privacy
- Promoting choice
- Engagement and governance



# Engagement and governance

## Nothing about us, without us

*We currently have a system in which power over the judicious and ethical use of data is overwhelmingly concentrated among white men.  
(Arvanitakis, Francis et al. 2018)*

# Overview

- Why share?
- Issues
  - Respecting participants and communities
  - **Equitable sharing**
- Ways forward

- What is equitable sharing?
- How equitable do we need to be?



DATA AND DEVELOPMENT

## *Open data sharing and the Global South—Who benefits?*

Limited capacity, deep mistrust pose challenges to sharing

(Serwadda, Ndebele et al. 2018)

# Respecting participants and communities

- Preserving privacy
- Consent and control
- Engagement and governance
- Prioritisation of secondary research that is responsive to their health needs
- Access to benefits of secondary research

# Promoting primary data producers' interests

- Interests
  - Receive appropriate recognition in secondary use
- Resources and capacity to:
  - Identify and access relevant datasets
  - Conduct secondary analyses to address research priorities, including promoting collaborations where appropriate
  - Participate in the development of relevant standards for data curation and sharing

## Policy responses

*Some policies include aspirational statements about equity, but few provide guidance on how to operationalize them. For interviewees, especially in research-poor settings, this is the biggest obstacle to sharing. In those policies that mention it, 'equity' is often reduced to norms for citation and authorship. (Pisani, Ghataure et al. 2018)*

# Overview

- Why share data?
- Issues and challenges
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  - Equitable sharing
- Ways forward

# Recent developments



**wellcome**  
**centre**  
**ethics+**  
**humanities**



# GDPR

General  
Data  
Protection  
Regulation



GL  PID-R  
Global Research Collaboration for Infectious Disease Preparedness

Principles of data sharing in  
public health emergencies

June 2018

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## NIH Seeks Public Comment on Proposed Provisions for a Future Draft Data Management and Sharing Policy



# Governance priorities



- Respect participants and communities
  - Minimise harms and promote benefits
  - Appropriately responsive to stakeholder interests
  - Promote equitable sharing
- 
- Trustworthy
  - Fair and transparent
  - Proportionate
  - Contextually relevant

Ways forward...