It’s just pixels, right?
Ethics in Global Health Data

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Ransomware attack on Hancock Health drives providers to pen and paper

The first reported hospital ransomware attack in 2018 was sophisticated – and not caused by an employee opening a malicious email.

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What MEASURE Evaluation does

Better systems
- HIS strategic plans
- HIS governance
- System interoperability

Better data
- Assess and improve data quality

Better decisions
- Equip personnel for data analysis
- Mechanisms to inform decision making

Better health care
- Resource allocation to greatest need
- Reaching key populations
- Train for evaluation of what works

Better health
Global footprint
More than 40 countries
Where LMIC HIS are now

- Many paper-based systems
- Fragmentation, duplication, non-standardized
- Attending to donors’ requirements
- Low data quality
Where LMIC HIS are headed

- Digitization
- Standardization
- Interoperability
Data power

• Quick and targeted action
Data power

- Quick and targeted action
- For better or for worse
Data power

“With great power comes great responsibility”
Data security in Kenya and Tanzania

• Identified HIS influencers
• Reviewed HIS-related documents for ethics policies and guidance
• Interviewed the influencers
Data security in Kenya and Tanzania

• Weak or non-existent legal frameworks for data protection
• Lack of a dedicated unit in ministries of health, with appropriately skilled staff
• Inadequate capacity to effectively implement secure information systems
Data security in Kenya and Tanzania

- Weak or non-existent legal frameworks for data protection
- Lack of a dedicated unit in ministries of health, with appropriately skilled staff
- Inadequate capacity to effectively implement secure information systems
- **Wanted**: an institutional framework for data governance to oversee digital health data ethics
Other ethical issues in HIS
Where LMIC HIS are headed (2)

- Use of existing data
- Machine learning
- Decisions by algorithm
Imagine a society in which you are rated by the government on your trustworthiness. Your “citizen score” follows you wherever you go. A high score allows you access to faster internet service or a fast-tracked visa to Europe. If you make political posts online without a permit, or question or contradict the government’s official narrative on current events, however, your score decreases. To calculate the score, private companies working with your government constantly trawl through vast amounts of your social media and online shopping data.
Trying to simplify complexity

1. Administrative ordering
2. Self-confidence about scientific and technical progress.
3. Coercive power
4. Passive civil society
Challenges to responding in academia

- Ethics research is not lucrative
- In most Schools of Public Health, ethics is not owned by any department
- Research ethics is perceived as a drag on research
- Advances in technology are outpacing our wisdom
- Digital advances are often seductive
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