Governance of confidential research data in low- and middle-income countries

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Background

• 2021 – The present and future of confidential microdata access
• Summer school
• Gap in research (as far as we know)
Unresolved questions

• What are the attitudes towards data sharing in LMICs?
• What are the challenges in using confidential data in LMICs?
• What is used as a guide for the governance of confidential data in LMICs?
• What happened in LMICs during the COVID-19 pandemic?
• How can we develop support networks?
The workshop

• Some 40 attendees. Mainly from Africa, Latin America, and West and South Asia.

• Pre-workshop survey

• Three sessions over a week
  • Discussion on attitudes, main challenges and what happened during COVID.
  • Discussion of what is working well and what isn’t.
  • Ways forward for data governance in LMICs.
Establishing the current state of play

- Technology
- Organisations
- Societal context
Establishing the current state of play

Technology

• Data availability and quality is a challenge
• Low bandwidth is common
• Paper-based data collection and physical storage.
• Research data centres/data enclaves are rare
• Remote access to data has increased, but there are issues.
• Most researchers are unfamiliar with SDC and PETs.
Establishing the current state of play

Organisation

• Guidelines and training are needed.
• Training designed in HICs is sometimes less adequate in LMICs.
• Approval processes are commonly designed in HICs.
• Low funding and short-termism limits long-term capacity building.
• LMIC data is sometimes managed in HICs.
Establishing the current state of play

Societal context

- Data sharing competes with other priorities.
- Limited communication and collaboration between agencies.
- Low trust between (and within) organisations.
- Governments and key institutions are often unaware of importance of data access.
- Governments are less involved in data governance policy.
- Less public awareness and engagement limits support for initiatives.
Ways forward

• Training and information resources
• Accreditation and auditing
• Changes in attitudes
• Knowledge exchange networks
Ways forward

Training and information resources

• Accessible guidance across the range of data governance activities, including templates for best practice.

• High-level principles-based guidelines on data governance

• LMIC input for workshops developing good data governance principles – ensuring guidelines are relevant

• Specific case studies and examples reflecting the likely needs of LMIC users

• Support for hierarchical training models including training for champions and train-the-trainer materials.
Ways forward

Accreditation and auditing

• Models of accreditation that can be adapted and adopted
• Accreditation provides a link between principles-based planning and implementation.
• Potentially based around the Five Safes.
• Should have validity outside of local contexts.
Ways forward

Knowledge exchange networks

• Almost no experts in policy design in LMICs.
• LMICs should be included in existing networks
• LMIC specific networks should be developed
• Regional, national and sectoral champions have a key role here
• Engagement with non-obvious events can also help.
Ways forward

Changes in attitudes

• Data owners’ attitudes
• Data users' attitudes
• Government institutions’ attitudes
• Funding agencies’ attitudes
• Public attitudes and engagement
Who can do what?

• International agencies and NGOs
• NSIs, local research institutions and public health bodies in LMICs
• National and regional champions
• IRBs and other actors
• Professional practice and research associations
• Academia
Let’s stay in connected

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