Health Research Ethics

Wits/Aberdeen University 2-day training

Mpumalanga Health Research Committee
Mpumalanga Department of Health

Module IV
Contemporary issues

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August 2022

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What does this training cover?

Module I: Health research, ethical principles

Module II: Norms, standards, and criteria

Module III: Research governance and RECs

Module IV: Contemporary issues

Module V: Monitoring research conduct

Not specifically covered: Biological materials/Human tissue; Clinical/medical ethics, therapeutics; Genetics/genomics research but principles apply



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Module IV

Contemporary issues: Who counts? Knowledge and power in global health; data and evidence systems; and the decolonisation imperative

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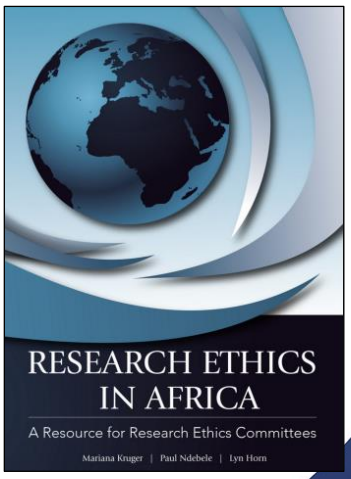
Module IV Learning Outcomes

a) Relate decolonialisation to research governance

b) Orient to emerging research paradigms

c) Familiarise with open science/open research

Plenary: Adaptive research governance in PHRC



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4a | Decolonising global health research

"ethical review originates in the US, …regulating medical doctors' research on their patients. Nowadays ethical review process acts as a safeguard against exploitation of research participants, determining what is acceptable behaviour or methodology …

Yet, there remains much work to be done to make the process suitable for non-medical and non-Western contexts…. While ethical review is needed … **we must also take seriously the research ethics framework's limitations"**

Chaurey, 2020



"Research and researcher increasingly require decolonization so that research can create a positive impact on the participants' community, and conduct research ethically" Datta, 2019



MOUNT ROYAL UNIVERSITY 1910

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Decolonisation, some terms

- **Colonisation/Colonialism**: taking over someone else's land, people and resources
- **Post-colonial:** effects profound, engaging with consequences of colonialism
- **Neo-colonialism**: continuation of structures/relations of **extraction, dispossession and imposition**
- **Decolonization**: fighting exploitation, extraction, dispossession, and imposition of one way of knowing/governing

"Colonization models are … perpetuated by fellow citizens, former colonizers, and other external actors, as well as through institutions of global governance"



"…reconnect with local configurations, … break with sterile imitation, … adapt science, technology and research to our context, … elaborate institutions on the basis of our specificities and our resources, .. adopt an inclusive governance framework and endogenous development, to create value in Africa ."

Source: Atuire & Rutazibwa 2021

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Who's values? Who's driving the agenda?
"An inclusive governance framework"

*…we need to think carefully about different interpretations of value concepts such as solidarity, and it's a good example of a relatively recent recognition in 'mainstream' academic bioethics that western analytic philosophy is **not the only source** for identifying and understanding value concepts and developing good ethical reasoning*

Entwistle 2021

Governance structures must be adaptive to embrace new developments in science. …Opportunities that accrue from collaborative research need to be seized through strong MoH leadership and clear partnership frameworks that guide negotiations *Nabyonga-Orem, 2021*

Nabyonga-Orem et al. Health Res Policy Sys (2021) 19:11
https://doi.org/10.1186/s12961-020-00676-9

Health Research Policy and Systems

RESEARCH Open Access

The state of health research governance in Africa: what do we know and how can we improve?

Juliet Nabyonga-Orem[1*], James Avoka Asamani[1] and Micheal Makanga[2]

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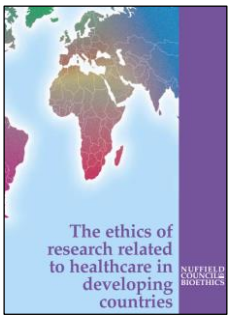
Driving the agenda 'adaptive governance'

- Provincial Research Committees
  - liaise with researchers
  - ensure greatest health needs of each province addressed
  - effect of research on services
  - Gate-keeping role in access to health facilities
- Consistent deliberative and decision-making about ethics
- Best ethical practices in research
- Compliance with national/international requirements
- Framework for South Africa-based research



NUFFIELD COUNCIL ON BIOETHICS

All countries should set **national priorities** for healthcare research. If external sponsors propose research which falls outside the national priorities, the research should be justified to the appropriate research ethics committees

Nuffield Council on Bioethics, 2002

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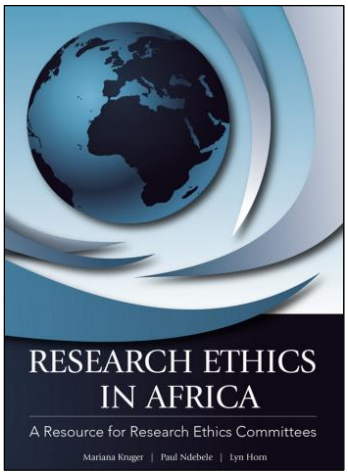
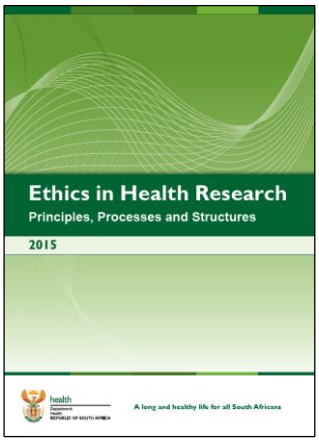
Urgent need for African ethics







Vaccine inequity and injustice is not just a moral failure. It is also a health and economic catastrophe [WHO 2022]

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Resources



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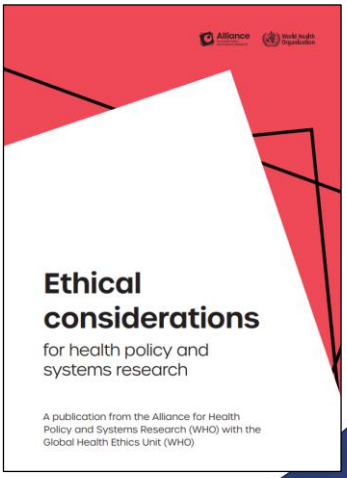
4b | Emerging paradigms: Health policy and systems research (HPSR)

- How societies organise in achieving health goals
- How actors interact in policy and implementation
- How health systems respond and adapt to health policies
- Research 'with' not 'on' stakeholders



Sources: Gilson, 2012; WHO 2019

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Embeddedness

- "…embedding of research in real world policy, practice and implementation is needed to strengthen health systems worldwide (Ghaffar et al 2017)
- "when embedding happens, researchers and decision makers are linked through a systems in which the need for evidence to inform policy is understood by decision makers" (WHO, 2012)

- Insider research: inside systems
- Changeable, flexible and adaptable process
- Interdisciplinary and intersectional
- Highly relational
- Aligned with local priorities
- Locally driven, locally owned
- Democratises research process

Source: Olivier 2017

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Participatory/cooperative

- Those affected are primary source of information & primary actors in generating, validating and using knowledge for action
- Process sensitive to context & shifts power towards those most directly affected
- Disrupts subject/object distinction
- Collective enquiry
- Organises experiential knowledge
- Transformative function



"Understand the world by trying to change it"

Source: Loewenson et al 2014

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Participatory research

- **Positioning of researchers:** Relationships with communities. Strong interpersonal +social competencies are necessary
- **Time/resource demands:** enabling context + communications skills for mutual understanding + trust to develop
- **Power and consequences:** whose interests drive the process; privacy and protecting information; risks in participating in action phases

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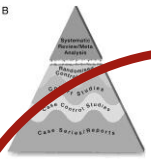
A continuum

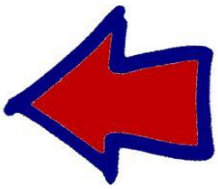




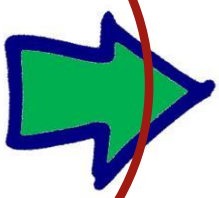


'Positivist'

'Interpretive'







Objective
Linear
Observations and measurements
Deductive
QUANTATIVE

bjectivity
Relativity
Contextualised interpretations
Inductive
QUALITATIVE

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4c | Open data


frontiers in Public Health

PERSPECTIVE

Who Owns the Data? Open Data for Healthcare

Patty Kostkova[1*], Helen Brewer[2], Simon de Lusignan[3], Edward Fottrell[4], Ben Goldacre[5], Graham Hart[6], Phil Koczan[6], Peter Knight[7], Corinne Marsolier[8], Rachel A. McKendry[9], Emma Ross[10], Angela Sasse[1], Ralph Sullivan[11], Sarah Chaytor[12], Olivia Stevenson[13], Raquel Velho[13] and John Tooke[14]

Developments, such as crowdsourcing, participatory surveillance, and individuals pledging to become "data donors" and the "quantified self" movement (where citizens share data through mobile device-connected technologies), have great potential to contribute to our knowledge of disease, improving diagnostics, and delivery of healthcare and treatment.

…also major concerns over privacy, confidentiality, and control of data about individuals once it is shared. Issues, such as user trust, data privacy, transparency over the control of data ownership, and the implications of data analytics for personal privacy with potentially intrusive inferences, are becoming increasingly scrutinized at national and international levels

Kostkova et al, 2016

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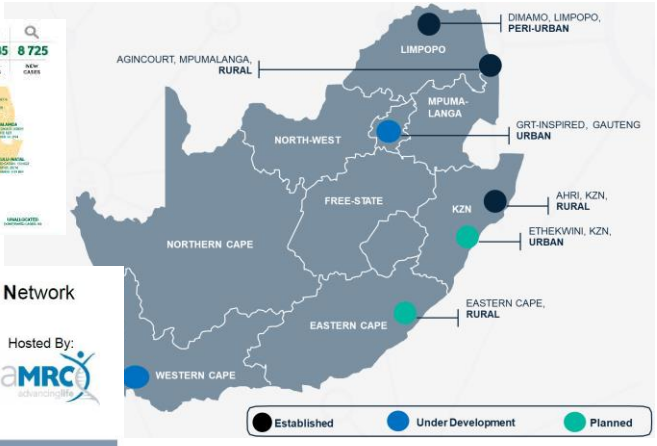
Big data





DSI-MRC South African Population Research Infrastructure Network

Funded

science & innovation
Department:
Science and Innovation
REPUBLIC OF SOUTH AFRICA

SAPRIN
POPULATION-BASED SCIENCE

Hosted By:

saMRC

Health and Demographic Surveillance System (HDSS) Nodes:

Partner Universities:

stats sa
Department:
Statistics South Africa
REPUBLIC OF SOUTH AFRICA

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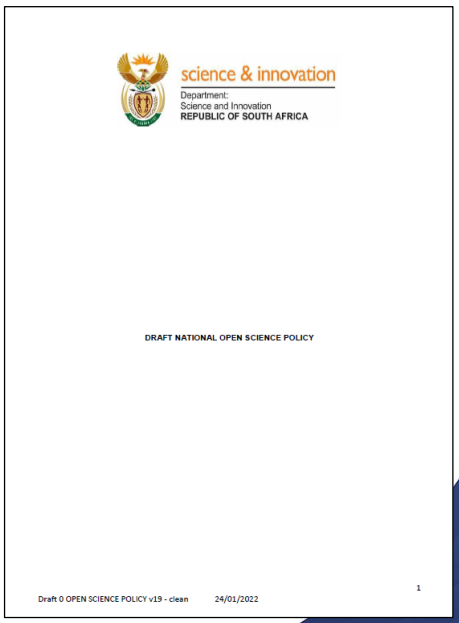
Open research

Open research is research that is openly accessible and modifiable by others. Much like open-source schemes that are built around a source code that is made public, the central theme of open research is to make clear accounts of the methodology freely available via the internet, along with any data or results extracted or derived from them. This permits a massively distributed collaboration, and one in which anyone may participate at any level of the project (Wiki)



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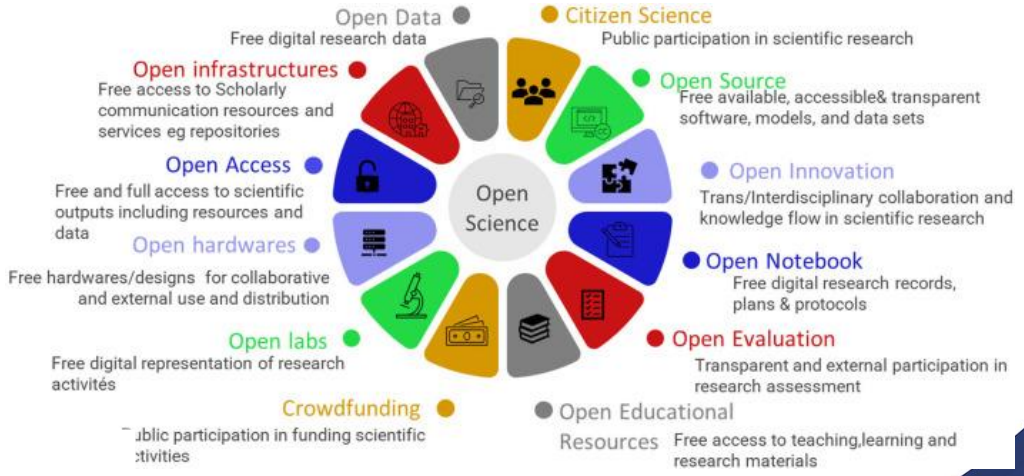
Elements of open science
(and why we need adaptive governance)



Adapted from UNESCO recommendation 2021

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Plenary: Decolonising research governance Adaptive governance in PHRC (30 mins)

1. How does one decolonize and reclaim the meanings of research and researcher?

2. Indigenous communities have long experienced oppression by Western researchers. Is it possible to build a collaborative research knowledge that is culturally appropriate, respectful, honouring, and careful of the Indigenous community?

3. What are the challenges in Western research, researchers, and Western university methodology research training?

4. How have 'studies' – critical anti-racist theory and practice, cross-cultural research methodology, critical perspectives on environmental justice, and land-based education – been incorporated into the [university] to disallow dissent? What can be done against this disallowance?

Source: Datta (2017)

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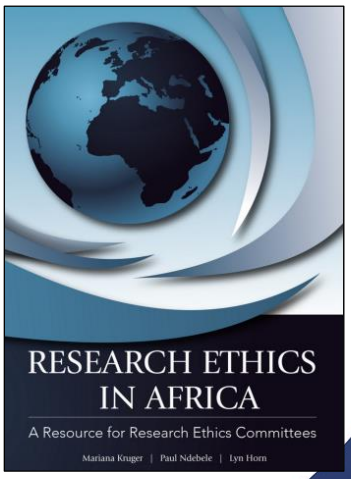

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