Data ethics: Unashamedly ethical
Dr Retha Visagie, Manager: Research Integrity
NeDICC, CSIR
7 March 2018
“We are witnessing merely the latest stage of the Information Revolution that has transformed our society and our lives over the past half century”.

Potential for social change means that we are now at a critical moment

Data issues are “sticky” and challenge public and academic notions of what is "no big deal"

“Individuals have little idea concerning what data is being collected, let alone shared with third parties …”

Secondary use of data sets
What are we called to do against the backdrop of the emergence of a new digital society?

“... the values we build or fail to build into our new digital structures will define us. ... if we fail to balance the human values that we care about, like privacy, confidentiality, transparency, identity, and free choice, with the compelling uses of (big) data, our ... society risks abandoning these values for the sake of innovation and expediency.”

ETHICAL ISSUES …

- Protection of participant privacy & confidentiality (e.g. medical data, information on legal transgressions); Robust de-identification strategies
- Validity of consent – Broad consent
- Researcher ability to keep to commitments to participants & communities

ETHICAL ISSUES

- **Potential harm** to participants - Unintended uses of data; Discrimination & Stigmatisation
- **Moral distance** & Limited awareness of original data collection context
Data ethics decision framework

Access
Creation
Recording
Sharing

Embracing shared responsibility

Morality, Ethics & Law
Data ethics decision-making framework

- Ethical principles foundational to decision-making
- Guidelines – Global science forum of OECD
- International, National and Institutional regulations
- Vulnerability, methods procedures and contexts

Principles

Benchmarks

Statutory responsibilities

Special considerations
MORALITY?

Sum of moral values, norms & judgements that are shared & agreed upon (sometimes strongly) within a larger social framework (scholarly community, institution) …

BUT it differs between groups …

Slide: Prof WA Hoffmann, 5th Ethics Educator Course, Durban, October 2017 (Adapted)
“Common/Intuitive sense” beliefs of “right” & “wrong” … What we ought to do, even though the future is not absolute (Prof WA Hoffmann, 5th Ethics Educator Course, Durban, October 2017)
ETHICS?

• **Meta-level reflections** about morality ... using an argumentative system (critical thinking)
• **Analysis of fundamental reasons** for favouring or rejecting moral choices

Slide: Prof WA Hoffmann, 5th Ethics Educator Course, Durban, October 2017
RESEARCH ETHICS?

• “Research is finding out the things that we don’t know, while ethics is doing it in a way that does not hurt anyone.”

   Ann Robertson
   University of Toronto
The aim of research ethics is to ensure that participants are treated with dignity and respect while they contribute to the social good and research endeavours”

Prof Doug Wassenaar
Chair: HSRC REC
DATA?

• Observable facts, observations or experiences on which an argument, theory or test is based
• Records, files or other evidence, irrespective of their content or form (e.g. in print, digital, physical or other forms), that comprise research observations, findings or outcomes
• Biological data or samples
• Primary materials and secondary data
• Numerical, descriptive or visual
• Raw or analysed, experimental or observational
• Personal
DATA ETHICS?

Data access, creation, recording and sharing that do not hurt anyone.
MORALITY vs ETHICS

Morality – Derived from beliefs and personal values
Ethics - Derived from principles
The difference is not a function of what, but rather of how derived

Morality
Ethics
Law
Scientific community:

- Finds expression in the principles and responsibilities that are fundamental to the integrity of research wherever it is undertaken.
“Ethics … can and must be converted into tools for (future and current professionals) to construct a better and fairer world”

Volnei Garrafa
University of Brasilia, Brazil

Slide: Prof WA Hoffmann, 5th Ethics Educator Course, Durban, October 2017
• Statutory authority for governance of ‘health research’ & regulatory infrastructure
• Ethics review committees that review health research with humans must register with the National Health Research Ethics Council (s 73(1))
• REC's must review research proposals to ensure that they meet the accepted ethical norms and standards in accordance with the Ethics in Health Research guideline (DoH, 2015)
Protection of Personal Information Act no 4 of 2014

• Personal information
  “information relating to an identifiable, living, natural person, and where it is applicable, an identifiable, existing juristic person”
Purpose: Guidance on how the right to privacy regarding personal information is protected

Right to privacy includes – “protection against unlawful collection, retention, dissemination and use of personal information” (Preamble to Act)

Act does not appear to restrict research activities that record personal information

Provides stipulations for the protection of stored data (electronically and other) – unauthorized access, inadvertent or accidental dissemination and distribution in form of “data dump”
A participant should know & agree

- What information is being collected
- What will happen to it
- How long it will be retained
- Whether it will identify the person
- Whether it will be stored with others and why
- Whether it will be sent outside South Africa and why

(DoH, 2015)
Proposal should explain

- How data records (written, audio or visual) are to be secured
- Length of time they will be retained
- Who will be responsible for storage and/or final disposal
- Why specific identifying information is required that purports to select data anonymously
- Might notifiable activities occur – abuse of minors … Is this clearly explained in the proposal and explained in the consent documents
- Special precautions for focus groups – where are they planned, potential breach of potential confidentiality (is this explained in the consent documents), non-disclosure of personal sensitive information advised (DoH, 2015)
Specific stipulations?

- In case of a child, a parent or guardian must give permission for the information to be collected (s 35 (1)(a))

- If the information is to be sent outside South Africa, the recipient must assure that the level of protection afforded in that country is commensurate with that expected in South Africa (s 18 (1)(g))

- Information about a person’s race or ethnic origin must be necessary (s 29(a)) or for affirmative action purposes (s 29(b))

- Information about a person’s health or sex life must be necessary for the research activity (s 27 (1)(d))

- Biometric information about a person must be necessary for the research activity (s 27(1)(d))

(DoH, 2015: 23 - 24)
Privacy, confidentiality and autonomy

Privacy
“… a person’s interest in controlling access to his/her personal information” (DoH, 2015)

Confidentiality
“… whether and how research data might be disclosed carelessly or inadvertently, thus revealing the participant’s identity …, making him vulnerable to harm.” (DoH, 2015)

Autonomy
(autonomy (self-determination - research should respect the autonomy, rights and dignity of research participants) (DoH, 2015)
Statement on Open Access to Research Publications from the National Research Foundation (NRF)-Funded Research (2015)

https://lh3.googleusercontent.com/Kb9dFlqXtVCBuUBNSw3auwWcYcNpnEmADBaql64wyutoSA0bNvmgzyRWi1Uo4yn39u7ZS=s630-fcrop64=1,5d940000f532ffff (19 Sep 2012)
“From 01 March 2015, authors of research papers generated from research either fully or partially funded by NRF ... the data supporting the publication should be deposited in an accredited Open Access repository ...
DATA SHARING

• The sharing of individual-level data from research for use/analysis by others …
• in open-access repositories …
• mandated by large funding bodies and regulatory agencies

http://gking.harvard.edu/files/gking/files/dataandcloudcomputing.jpg?m=1430186249  (19 Sep 2016)
SCIENTIFIC BENEFITS …

• Improves the evidence base for policies, funding & applications – Maximisation of participants’ contribution to research (fairness & reciprocity)

• Avoids unnecessary replication of risky research

SCIENTIFIC BENEFITS …

- Establish **reference datasets** in different contexts & locations
- Allows **meta-analyses** – Maximise utility of datasets; ↓ Duplication (avoid risks to participants)
- Allows novel & innovative **statistical analyses**

SCIENTIFIC BENEFITS

- Allows **independent scrutiny / verification** of research results (i.e. novel findings with widespread impact) – Data reliability, Transparency & Researcher accountability (↓ bias, ↓ dishonesty)
- Identify **gaps** in research – Future research priorities & research design
Primary researcher - Reputational harm of critical secondary analyses; ↓ Publications; “Pirating” of data from developing country researchers by developed country researchers (↓ resources to access / analyse shared data)

Free-riding secondary analysers – Fewer primary studies; ↑ Publications; ↑ Reputation; Failure to acknowledge primary researcher

Scientific consequences of flawed secondary analyses – Poor analysis design, Bias & Misinterpretation
SCIENTIFIC CONCERNS

• **Ownership** – IP & Innovation products (fair practices); Commercialisation of datasets (exploitation)
• **Costs** – Curation & sharing infrastructure

ETHICAL SUPPORT

• Maximises scientific value of research; making best use of data & limited resources
• Demonstrates respect for research participants (no undue replication)
• Promotes public good

http://2s7gjr373w3x22jf92z99mgm5w-wpengine.netdna-ssl.com/wp-content/uploads/2012/02/worldpic.jpg  (19 Sep 2016)
WAY FORWARD …

• **Institutional Policies** – Data Management Regulations (non-sharing & restricted access to selected datasets); Exclusive fair use periods; Facilitate international co-operation

WAY FORWARD

• **Researchers** – Consent content; Data management & Data analysis training (capacity development)

• **REC** - Awareness of ethical challenges; Ethics advice

https://sylvaniadigitallearning.files.wordpress.com/2016/03/data-analysis-image-for-blip.jpg (19 Sep 2016)
Data ethics decision-making framework

- Ethical principles foundational to decision-making
- Guidelines – Global science forum of OECD
- International, National and Institutional regulations
- Statutory responsibility
- Vulnerability, methods, procedures, and contexts
- Principles
  - Ethical principles foundational to decision-making
  - Guidelines – Global science forum of OECD
- Benchmarks
- Special considerations
- Statutory responsibility
  - International, National and Institutional regulations
  - Vulnerability, methods, procedures, and contexts
SAVE THIS DATE

6TH INTERNATIONAL CONFERENCE ON ETHICS EDUCATION
A LONG WALK TO ETHICS EDUCATION

3-5 OCTOBER 2018
STELLENBOSCH
SOUTH AFRICA
Training – TRREE (Module 1, 2 & 3)

Joining the discourse – Research Ethics Committee Association of Southern Africa (REASA)

ARESA & REASA – 23 – 25 May 2018

3 – 5 October 2018 – IAEE conference, SPIER
Acknowledgement:

Partly based on a presentation made by Prof Braam Hoffman, TUT, New Trends in Research Ethics
REFERENCE
