

Dealing with sensitive data: managing ethics, data security, confidentiality and trust

24 July 2014

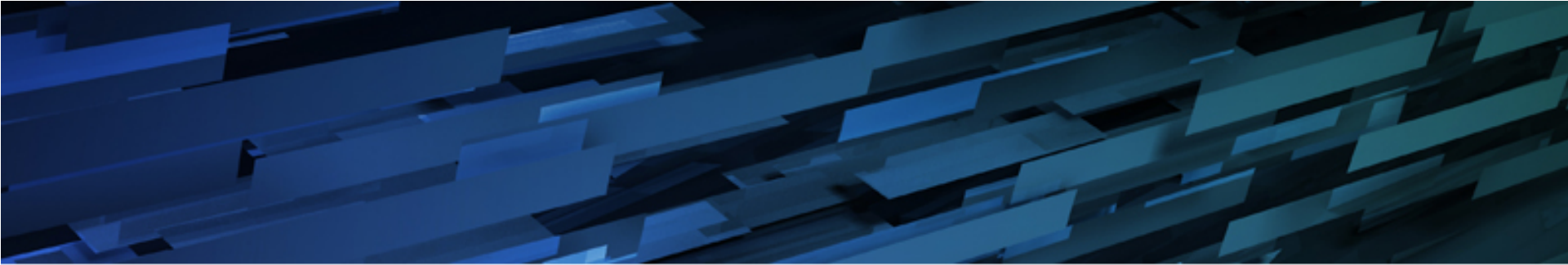
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Introduction

Facebook has betrayed us!

A new paper in the **Proceedings of the National Academy of Sciences** reveals that Facebook intentionally manipulated the news feeds of almost 700 000 users in order to study “emotional contagion through social networks”

http://www.slate.com/articles/health_and_science/science/2014/06/facebook_unethical_experiment_it_made_news_feeds_happier_or_sadder_to_manipulate.html#



Experimental evidence of massive-scale emotional contagion through social networks

Adam D. I. Kramer, Jamie E. Guillory, and Jeffrey T. Hancock

<http://www.pnas.org/content/111/24/8788.full.pdf>

- The paper published in the ***Proceedings of the National Academy*** reveals that Facebook intentionally manipulated the news feeds of almost 700 000 users in order to study “emotional contagion through social networks”
- The paper raises concerns about researchers’ ethical obligations in dealing with sensitive data, data security, confidentiality and trust
- Is our confidence shaken in FB or in Science?
- **What should guide researchers access, use and storage of sensitive data in a context of digitisation and the internationalisation of research?**

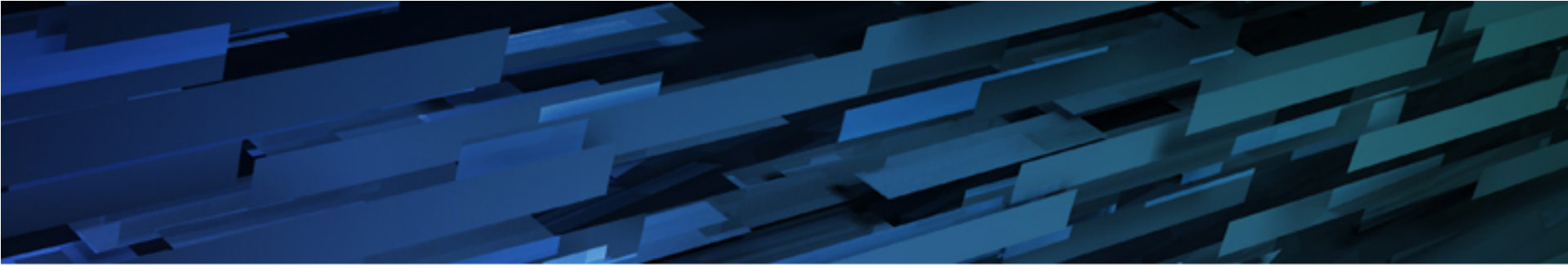


**“Trust me, I’m a scientist’ is not a
good enough answer”**

Sir Paul Nurse

Nobel Laureate and President of the Royal
Society, London 2011

(Slide adopted from Tony Mayer, National Research Foundation
Seminar, SA, 2011)

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- Research integrity
 - Responsible research conduct = making the right choices

Relationship between research integrity and ethical conduct

Research integrity (having strong moral principles)

The **trust** articulated by the scientific community and the public that research is above doubt – at the heart of research in higher education institutions

Scientific Misconduct (FFP) & questionable research practices (failure to keep records, authorship, acknowledgements)

- *An honest researcher that does not maintain good practices*
 - *Research is conducted in an irresponsible manner*

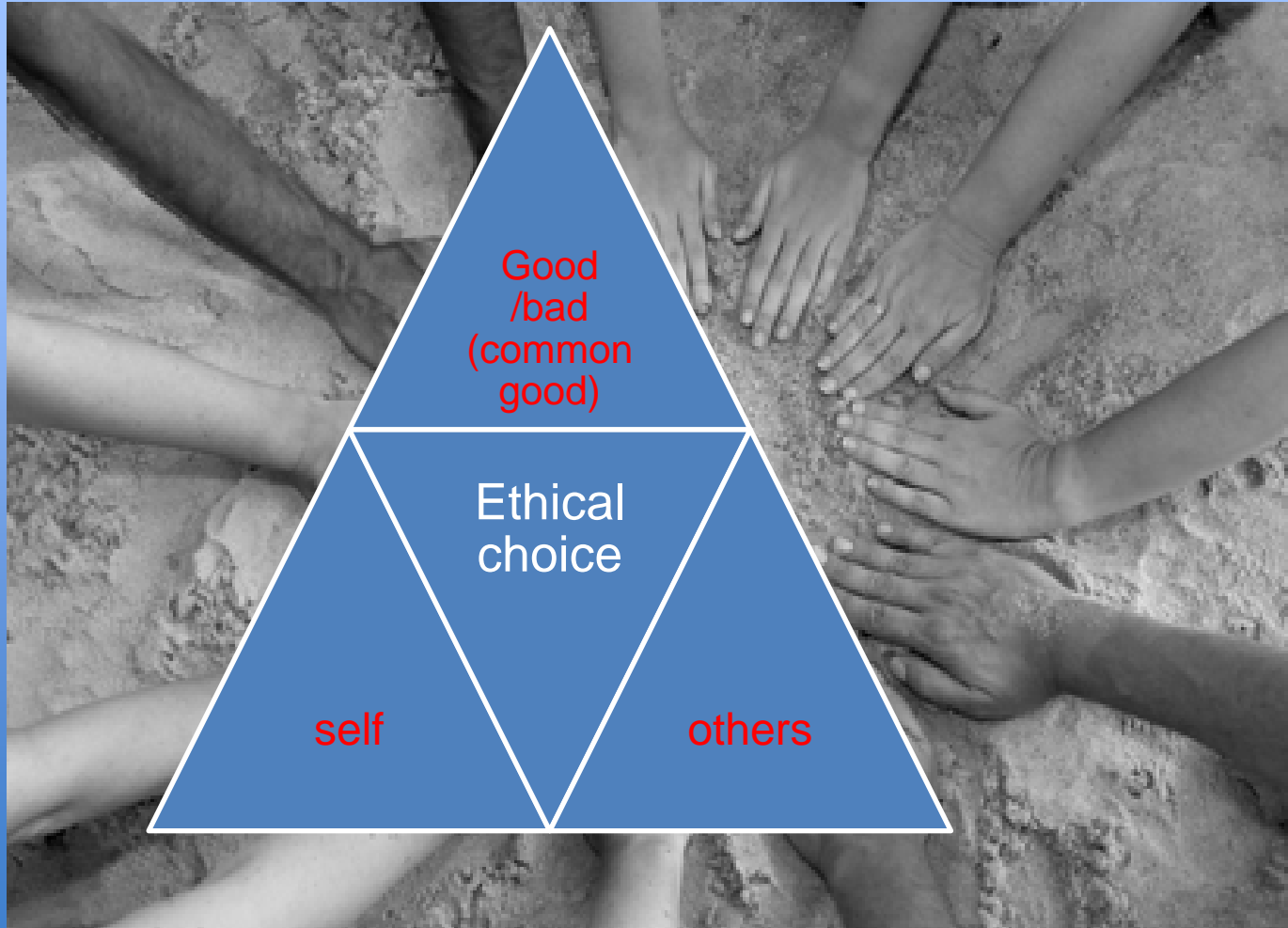
Responsible research conduct

A way of being – character/values driven

Exemplary – Good – Mediocre – Poor – Sloppy

Engaging in good research practice

Research ethics



Critical concerns

- 1) The potential use of previously collected **personal information** for selecting a sample of potential survey participants
- 2) The collection, use and disclosure of **personal information** from participants
 - Protection of Personal Information Act, 2013
 - “Section 14 of the Constitution of the Republic of South Africa, 1996, provides that everyone has the right to privacy”
 - “the right to privacy includes a right to protection against the unlawful collection, retention, dissemination and use of personal information”
- 3) Unauthorised access to data due to sound security measures

Personal information

- Personal information = “ ... information relating to an identifiable, living, natural person ...”, including information about:
 - race
 - gender
 - sex
 - pregnancy
 - marital status
 - national, ethnic or social origin
 - colour
 - sexual orientation
 - age
 - physical or mental health
 - well-being
 - disability (Protection of Personal Information Act, 2013)
 - religion
 - conscience
 - belief
 - culture
 - language
 - education
 - criminal or employment history
 - name if it appears with other identifying info
 - identifying number/symbol
 - physical address, online identifier
 - biometric information (DNA, voice recognition, ...)
 - personal opinions
 - correspondence or private nature
 - views of opinions of other
 - email address, telephone #
 - medical history
 - financial history

Principle, human dignity based framework

- Human dignity is an end in itself
- Equality in dignity of all human beings
- Respect and care
- The interests and welfare of the individual are prior to the sole interest of society

Belmont report: Ethical principles guiding ethical decision-making in research

- Respect for persons

Protect the rights of self-determination, privacy, confidentiality and well-being of research participants, including vulnerable populations

Obtain informed consent, consider consent monitors, support measures

- Beneficence and non-maleficence

Protect the well-being of research participants, including vulnerable populations

Favourable risk/benefit analysis; protection against harm

- Justice

Minimise the burden of the study participation to the greatest extent possible

Respecting human dignity: dealing with sensitive data

- Ensure competence in research ethics, research methodology and scientific rigour (researcher(s), field workers and others)
- Adhere to scientific standards in research design, data collection and data processing (data management)
- Evaluate the risk of breach of confidentiality and implement appropriate techniques to protect the data confidentiality (de-identification)
- Ensure sound consent protocols

Respecting human: dealing with sensitive data

- Evaluate the risk of breach of confidentiality and implement appropriate techniques to protect the data confidentiality (de-identification)
- Translate and adapt consent protocols and forms according to best practices
- Obtain and securely store signed pledges of confidentiality and consent forms
- Employ appropriate recruitment methods, respecting privacy
- Review data collection methods to assure adherence to informed consent procedures

Respecting human dignity: dealing with sensitive data

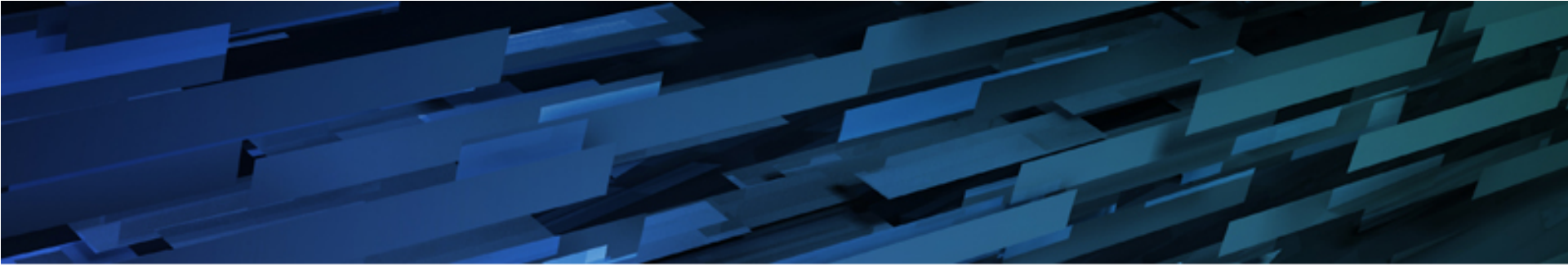
- Interpretations should be made consistent with the data
- Honesty about confidence in the conclusions drawn from the data
- Report research findings, including findings that are not in line with the researcher's hypothesis (academic reporting)
- Be sensitive to ethics violations/misconduct during all phases of the survey, including plagiarism, falsification and fabrication
- Reporting to relevant research stakeholders (participants, institutions, communities) – report findings as completely and objective as possible, while protecting participants confidentiality
- Consider negative impact of reporting on unfavourable findings about a specific ethnic, religious or other social group
- Keep a solid audit trail – study's methods, results, raw data – in order to permit peer evaluation and allow for replication, while considering participant's confidentiality

Respecting human dignity: dealing with sensitive data

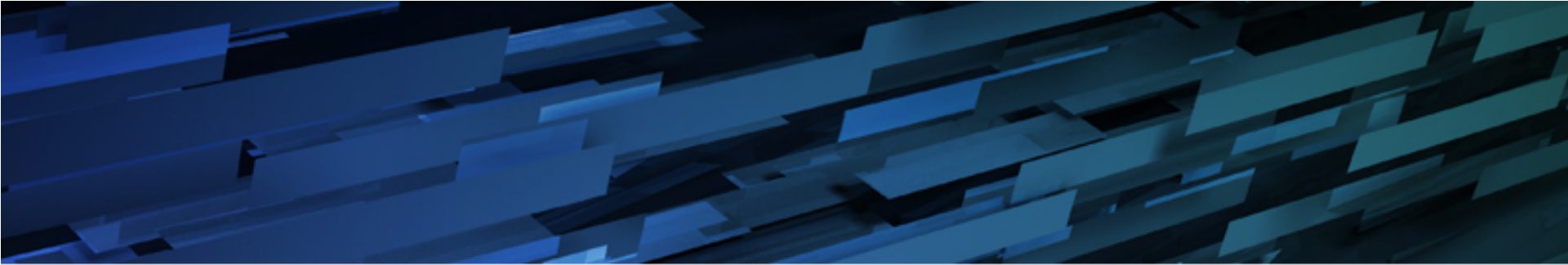
- Provide a copy of the de-identified dataset(s) and documentation to international data repositories (e.g. UK data archive, European Social Survey website) or the South African Data Archive (SADA)
 - serves as a broker between data providers (academic institutions, statistical agencies, government departments, etc.) and the research community
 - preserves data for future use, safeguards data sets and make it accessible for researchers and education purposes
 - sada@nrf.ac.za
- Provide safe, sustainable storage of the raw and de-identified data sets
- Adhere to minimum storage period
- Adhere to government laws and agreements that address disclosure of survey data

Conclusion

- Ethical considerations in research play a key role in ensuring research integrity
- Research integrity and research ethics are complementary, but not identical
- Scholarship is in essence about relationships of trust
- Researchers need a framework for decision-making when dealing with sensitive data, thus optimising data security, confidentiality and trust within research
- Education is critical ...



“... If it seems to us that we know everything, we can easily think that we can do everything, and then we are going to believe that we may do everything. And that is how we find ourselves in front of a question: are we permitted to do everything we can?” (Ivo Šlaus)



Thank you