

Research Ethics and New Forms of Data

OECD GSF Expert Group

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Recommendation made in 'New Data for Understanding the Human Condition: International perspectives' OECD, February 2013

'Research funding agencies should collaborate to develop a framework code of conduct covering the use of new forms of personal data, particularly those generated via network communication. This framework, built on best practice procedures for consent from data subjects, data sharing and re-use, anonymisation methods, etc. could be adapted as necessary for specific national circumstances.'

Terms of Reference for the Expert Group

- identify and analyse ethical issues that may arise from research use of various new forms of data..., with particular reference to the balance between the social value of research utilizing such data and the protection of the well-being and rights, including privacy rights, of individuals;
- conduct a review of activities, practice and problems across a range of countries... regarding the ethical use of new forms of data for research;
- convene an international conference to identify best practice regarding the ethics of using new forms of data... to address research issues in the social sciences and at the boundary with other scientific disciplines;
- draft internationally acceptable guidelines, suitable for adoption by research funding agencies..., for an ethical approach to the use of new forms of data for research.

Membership of the Expert Group

Australia	Gemma van Halderen
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France	Pascal Buleon
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Norway	Hallvard Fossheim (Vice Chair)
South Africa	'Maseka Lesaoana Christa van Zyl
United Kingdom	Matthew Woollard Peter Elias (Chair) Vanessa Cuthill
United States	Peter Muhlberger Charlie Catlett Robert Goerge Kate Cagney
Invited expert	Charles 'Chuck' Humphrey

Timetable and deliverables

- Finalize a report containing a draft set of guidelines covering ethical issues around from the use of new forms of data for research (by end November 2015).
- Publish report in February 2016
- Undertake a major international conference, showcasing the ways in which countries are making use of new forms of data for policy-relevant research in the social sciences (by April 2016).

New forms of data and research ethics

- Ability to link between and process large volumes of data has heightened the risk of disclosing identities of individuals and organizations
- Standard consent processes have become less workable as way of insuring ethical standards of research are sustained
- Private sector organizations are already exploiting new forms of data for profitable ends – creates a dynamic which could be dangerous for publicly funded research to follow
- No clear guidance on the ethics associated with the curation and reuse of new forms of data

Draft Recommendations

- Recognition that all new forms of data with research value which relate to discrete individuals present ethical issues – checklist of issues to be addressed by researchers
- All countries need to promote formal mechanisms through which this checklist of ethical issues can be taken up
- In those countries where IRBs/RECs exist, need to ensure that they all operate within a common framework and to a consistent standard
- Data holders/owners should have ethics bodies which can advise on ethical research use of their data.
- Data holders/owners and research funders need to cooperate to ensure that resources exist for the curation and ethical reuse of new forms of data

Personal Concern: A Need to Consider the Ethics of Research Findings **Use**

- Current ethics guidelines say nothing about considering how research might be used
- Big data social research may prove, for various reasons, to have rather immediate applicability by large organizations
- Some uses may have societally harmful effects: technologies of manipulation
 - Facebook emotion manipulation
- Need for an authoritative organization to identify potential societal harms of big data social research, publicize these harms, seek means of counteracting them