Safeguards, Data-sharing and the Disclosure of Sensitive Results: An Educational Scenario by the EnTIRE project

Background

A group of researchers in the faculty of educational and social studies at the University of Burammas are conducting a large European study, the SCUSTEN study ('The impact of secondary School CUrriculum, STructure and ENvironment on academic achievement')[1], in order to investigate the impact of curriculum, school structure and environment, and individual student factors on academic achievement in core subjects in secondary schools. Nine European countries are participating; in each country, one higher education institution will take a lead role in coordinating the research in 50-70 of their own country's secondary schools. Each of those 'lead' institutions have applied for and been granted ethical approval as governed by their own relevant research ethics committees.

'Structure and environment' is evaluated by trained assessors using a standardised approach. The outcome measures for academic achievement are standardised national tests results. The study also uses an online mental health screening test that is completed by the schools' students. The project is planned to last three years with three rounds of data collection. The Principal Investigator, Deborah, has been granted ethics approval by the Research Ethics Committee at her home institution, the University of Burammas. She has also received assurances from the University of Burammas' information governance office that the study's plan for data sharing and processing is compliant with the EU General Data Protection Regulations ("GDPR").

Issue 1

During the first project meeting after the first round of data collection, one of the research partners, John, suggests that the results of each school-level analysis should be

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[1] This study and the scenario are purely fictional.

disseminated to the schools concerned, and that each school should also be provided with anonymised benchmarking information concerning the ten schools that are geographically closest to their own. He argues that sharing this data will increase buy-in to the project because each school will 'get something back'. He claims that the data really belongs to the schools involved in the study and could be useful to them.

The project group has a long discussion, eventually deciding to introduce a policy of disseminating school-level analyses to individual schools and supplying each school with anonymised benchmarking information.

1a. Questions for Researchers

1. By referring to The European Code of Conduct for Research Integrity's (ECCRI) principles of a) 'honesty' and b) 'respect', is John's suggestion to disseminate the results of the school-level analysis to individual schools along with anonymised benchmarking information an example of 'good research practice'? What are your reasons?

2. By referring to BERA's Ethical Guidelines for Educational Research (or similar codes of ethics for educational research in your country), why should we support, or reject, John's suggestion?

3. What are the key ethical and integrity issues when considering whether to share anonymised benchmarking data with other schools?

4. From whom should consent to share such data be sought? How should you go about obtaining consent?

5. From the schools' point of view: a) what are their rights in respect to their own data? b) why might schools object to sharing data with other schools and what assurances might they need from the project group?

6. If a school decides to opt out of the research project prior to its conclusion, then is it entitled to receive anonymised benchmarking data regarding the ten schools geographically closest to it? What are your reasons?

1b. Questions for Research Ethics Committees and Research Integrity Offices

1. Does a change in policy regarding the sharing of school-level data require the submission of a research ethics amendment? Should the REC/RIO (Research Ethics Committee / Research Integrity Office) accept and review an addition to the application for a policy? What considerations need to be taken if such an amendment is to be approved?

2. If the project group at the University of Burammas introduced school-level and benchmarking data-sharing without seeking an amendment from the research ethics committee, then a) would this be considered as research misconduct? What are your reasons? b) What steps could the REC take in terms of disciplinary action?

1c. Questions for Research Administrators

3. If the project group at the University of Burammas introduced school-level and benchmarking data-sharing without seeking an amendment to the research ethics approval from the research ethics committee, then what would be your institution's procedure for dealing with this omission?

4. In seeking an amendment to the research ethics approval, what information, documents and/or assurances should the research ethics committee request from the project group?

Issue 2

The project group submits a research ethics amendment and receives approval.

Sharing school-level data introduces additional costs, but the research funders are unwilling to provide extra funding. The funders insist that the project should be delivered in line with the budget that has already been provided.

Some of the project's partners have already begun to disseminate the results of the school-level analysis to individual schools in their country, but others have not yet started. Some of the schools' senior leadership teams are very dissatisfied with their 'structure and environment' evaluation; they maintain that the analysis of the results has not considered the data in a completely objective way, and that certain confounding variables have been left out thereby presenting an 'unjust' picture of their school. Collectively, they make a complaint about what they claim is clear bias in these evaluations to the Principal Investigator's university, the University of Burammas, using the research governance complaints procedure.

2a. Questions for Researchers

1. The project group insist that additional funding is necessary in order to fully anonymise the benchmarking data. By referring to the Economic and Social Research Council's first principle for ethical research (that is, 'research should aim to maximise benefit for individuals and society and minimise risk and harm'), describe a case that the project group could present to the funding organisation in order to justify the receipt of additional funding?

2. If the project group is unable to procure additional funding to ensure that all the benchmarking data is fully anonymised, how should it proceed with the task of sharing data with individual schools?

2b. Questions for Research Ethics Committees and Research Integrity Offices

1. Does the University of Burammas have an obligation to investigate the schools' collective complaint as, specifically, a research misconduct complaint? By referring to The European Code of Conduct for Research Integrity, what (if any) are the grounds for the complaint? What standards of good research practice has the project group violated (if any)?

2. If there are grounds for a case of research misconduct, what additional details would the university's research integrity office require in order to reach a conclusion?

3. Assuming you have all the necessary information relating to the complaint, what would be an appropriate verdict for your committee to come to? Why have you come to that conclusion?

2c. Questions for Research Administrators

1. Does the University of Burammas have an obligation to investigate the schools' collective complaint as, specifically, a research misconduct complaint? What are your reasons?

2. Having received the complaint, what would be your next steps in managing the complaint as an administrator for a research ethics committee or research integrity office?

Issue 3

When analysing the school-level results, the researchers notice two issues that give them cause for concern. The first is that the mental health screening test results show that there are some individual students who are likely to have clinically-significant mental health problems, possibly requiring treatment. Secondly, the analysis shows that there are a

number of schools in a particular country (Country X) which seem to be performing particularly badly. Further analysis shows that these schools have a very high proportion of students from a particular ethnic minority. Furthermore, these schools seem to be funded at a much lower level compared with similar schools in the same country.

When informed of these results by her junior colleagues, Deborah, as the Principal Investigator, decides to raise these issues at the next project meeting in order to determine what should be done.

3a. Questions for Researchers

1. By referring to the four principles of The European Code of Conduct for Research Integrity, your country's/institution's relevant codes as well any codes and guidelines listed in the resources section below, where do researchers stand in terms of their a) rights and b) responsibilities to disclose the clinically-significant mental health problems they have discovered?

2. [Paragraph 53 of the BERA guidelines](#) state: *At all times, the decision to override agreements on confidentiality and anonymity should be taken after careful and thorough deliberation. In such circumstances, it is in the researcher's interests to make contemporaneous notes on decisions and the reasoning behind them, in case a misconduct complaint or other serious consequence arises. The researcher should also consider very carefully whether overriding confidentiality and anonymity compromises the integrity and/or usefulness of data, and withdraw any compromised data from the study*. In light of paragraph 53, would the disclosure of clinically-significant mental health problems constitute research misconduct? If so, under what conditions? Would the disclosure of this information compromise the integrity of the entire data set? What are your reasons?

3. Thinking in terms of the research participants, their schools, their families, the funders, the research institution, health care providers and professional bodies, to whom should the clinically-significant mental health problems be disclosed in the first instance? What are your reasons?

4. The European Code of Conduct for Research Integrity (ECCRI) suggests that '*Research protocols [should] take account of, and are sensitive to, relevant differences in age, gender, culture, religion, ethnic origin and social class*'. Referring to the ECCRI, should the project disclose the results that suggest causal links between school performance, the ethnic backgrounds of its students and the funding it receives from the State? To whom should the results be disclosed? What are the risks in disclosing these results? How could the project group protect itself, its members and its research participants and partners from these risks? What are your reasons?

3b. Questions for Research Ethics Committees and Research Integrity Offices

1. By referring to the European Code of Conduct for Research Integrity, your country's/institution's relevant codes as well any codes and guidelines listed in the resources section below, should the project disclose the results that suggest causal links between school performance, the ethnic backgrounds of its students and the funding it receives from the State? What are your reasons?

2. Would your committee determine that the research project should disclose the results to the schools concerned? What are the risks associated with the disclosure of these results? How could the project group protect itself, its members and its research participants and partners from these risks? What steps need to be taken by the project group when disclosing these results?

3. Despite the fact that the project group did not propose to investigate mental health issues amongst the research participants, should the project group and/or the relevant research ethics committee have considered the possibility of discovering significant mental health problems prior to seeking/granting ethics approval for the project? In the case that the research ethics committee had foreseen such a possibility, what details should it have requested from the project group and what would it require the project group to do in order to grant ethics approval?

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Suggested Resources

For Researchers:

ECCRI: <u>The European Code of Conduct for Research Integrity</u>.

ERIC: <u>Ethical Research Involving Children</u>.

APA: American Psychological Association: <u>Ethical Principles of Psychologists & Code of Conduct</u>

BERA: British Educational Research Association. <u>Ethical Guidelines for Educational Research</u>.

NSPCC: <u>Research with children: ethics, safety and avoiding harm</u>.

Matt Barnard, Nick Drey, and Caroline Bryson (2012) <u>NSPCC Research Ethics Committee: Guidance for applicants</u>.

ESRC: <u>Economic and Social Research Council: Research with children and young people</u>.

For Research Ethics Committees, Research Integrity Offices and Research Administrators:

ECCRI: <u>The European Code of Conduct for Research Integrity</u>.

ESRC: <u>Economic and Social Research Council: Criteria for research ethics committee review</u>.

Related Scenarios

ERIC 'Ethical Research Involving Children: Child protection and confidentiality: Surveying children's experiences of violence, abuse and neglect'. (Contributed by: Lorraine Radford, Professor of Social Policy and Social Work, University of Central Lancashire, Preston, UK.) Accessed Nov 2019.

ERIC 'Finding the balance between protection and participation: What do you do when follow-up services are not readily available?' (Contributed by: Mónica Ruiz-Casares, Division of Social and Transcultural Psychiatry, McGill University, Canada) Accessed Nov 2019.

ESRC: Economic and Social Research Council: Case study: longitudinal research in developing countries.

ESRC: Economic and Social Research Council: Case study: working with disabled young people - Embodied selves in transition: Disabled young bodies.

Felzmann, H. (2009). Ethical Issues in School-Based Research. *Research Ethics* 5.3, 104–109. https://journals.sagepub.com/doi/pdf/10.1177/174701610900500304

Hemmings, A. (2009). Ethnographic Research with Adolescent Students: Situated Fieldwork Ethics and Ethical Principles Governing Human Research. *Journal of Empirical Research on Human Research Ethics*, *4*(4),27-38. https://doi.org/10.1525/jer.2009.4.4.27

ESRC: Economic and Social Research Council: Case study: data sharing and informants' safety. The social life of achievement and competitiveness in Vietnam and Indonesia.