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Tensions between data sharing and data protection in research with people

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As the designated national centre for preservation and dissemination of research data arising from ESRC-funded research, with expertise in quantitative and qualitative social science data, the UK Data Archive (UKDA) is concerned about the number of research projects undertaken where consent agreements between researchers and research participants precludes any sharing of research data beyond the original research. Many researchers fail to take into account the potential longer-term use of their data by the wider research community when obtaining consent, and draw up agreements prohibiting data sharing. Examples range from consent forms or verbal agreements saying that the research data will only be seen and used by the principal investigator, to clauses stating that raw data will be destroyed upon project completion. In doing so, researchers restrict the wider use of research data and their preservation in digital archives like the UKDA, when there is no ethical or legal need to do so.

On one side, research funders such as ESRC, MRC, the British Academy, the Wellcome Trust and others increasingly require or encourage research data to be shared beyond the primary research. MRC and ESRC specifically advise researchers to take sharing and re-use of data into consideration when obtaining consent.

On the other side, researchers are bound by legislation like the Data Protection Act 1998 (DPA) and ethical duties towards participants. Research ethics committees, as

custodians of ethical standards in research and the safety and rights of participants, place a strong emphasis on data protection and the ethical use of data, and may well steer researchers away from data sharing.

At first sight, it may seem difficult to reconcile protecting the rights of participants, honouring a duty of confidentiality and obeying the DPA, with sharing research data, especially for sensitive or confidential research topics. Whilst the need to protect personal data and to honour confidentiality where this is explicitly required cannot be ignored, this does not mean that research data cannot be shared. The DPA principles apply to personal data, and should not be applied to all research data obtained from participants. Sensitive and confidential data can be shared ethically if researchers pay attention, from the planning stages of research, to three key aspects:

1. Obtaining informed consent for data sharing, besides consent for participation and other data uses
2. Protecting people's identities when needed, by anonymising research data
3. Deciding if access restrictions to all or part of the data may be needed

These measures should always be considered jointly – not in isolation – and discussed openly with participants.

Researchers and research ethics committees should inform themselves about these measures to enable ethical data sharing. Whilst the latter provide good guidance on data protection, they

should equally guide researchers on ethical sharing of research data and how to address this in consent discussions. Researchers themselves should ensure that consent agreements address the long-term use of research data and develop anonymisation and data access strategies where needed.

The UKDA is as concerned as research ethics committees and researchers are about research ethics, protecting participants and safeguarding personal data. UKDA takes its duty very seriously to make sure that archived materials are used only in appropriate and ethical ways. Archived data are anonymised where needed and data users do not have access to personal data. Archiving does not mean placing data in the public domain. The UKDA uses licences to control access to data and to make sure that only people who agree to use data ethically have access to them. Whilst most data are generally available for research and education purposes, with registered users required to sign an end use licence which details how the data can and cannot be used, confidential data may be further restricted, requiring special permission from the data creator prior to release, or being under embargo for a certain period.

If researchers, research ethics committees and data archives work together in dialogue, data sharing can be increased for the benefit of researchers and participants alike.

Detailed guidance on how research data can be shared ethically, how to

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1950s and 1960s. The role of individuals, social class, institutions and ideas are all explored through a series of in-depth examples of distinct cultural movements.

The structure of the book takes a chronological approach, with each chapter very unique in terms of its focus. Chapters include an examination of Edwardian cults of youth around the twentieth century, the role of Rolf Gardiner and the Flapper cult in inter-war Britain, through to the pop cultures of Beatlemania and the Rolling Stones.

The book uses original archive research of great value for scholars of cultural history and sociology, but the wide ranging scope and readable nature also make it accessible for the general reader. This book is particularly successful in its ability to place in an appropriate historical context, the influence upon youth of trends amongst the media and consumerism.

The reader is left with a convincing impression that twentieth century youth cultures were created through interactions within distinct communities, as opposed to a niche achievement of a homogenous mass culture. Challenges are also made to a number of orthodox interpretations, such as the 'classless' nature of 1960s youth culture.

However, there is little in the way of consistent narrative or focus running throughout the book, the effect being that it is difficult to be persuaded on some of the more general premises. Once the beginnings of youth culture are successfully challenged, it appears less convincing that we should begin our focus in the 1920s for example. But to seek to draw too many generalist conclusions from a concise book such as this would be a mistake. Rather, a principal strength should be seen as its ability to reveal an eclectic collection of insights throughout every chapter.

ITEMS FOR REVIEW

If you would like a copy of any of the following books, simply write a short review of about 300 words. In exchange, you get to keep the item. Contact Annie Irvine, book review editor: aj513@york.ac.uk

Towards a more equal society? Poverty, inequality and policy since 1997 Edited by John Hills, Tom Sefton and Kitty Stewart (2009, Policy Press)

Well-being of Older People in Ageing Societies Asghar Zaidi (2008, Ashgate)

Research Methods for Everyday Life: Blending Qualitative and Quantitative Approaches Scott W. VanderStoep and Deirdre D. Johnston (2009, Jossey-Bass)

Internet, Mail, and Mixed-Mode Surveys: The Tailored Design Method, 3rd Edition Don A. Dillman, Jolene D. Smyth, Leah Melani Christian (2009, Wiley & Sons)

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address data sharing in consent and how to anonymise qualitative and quantitative research data, as well as information on training workshops on these topics is available on the UKDA website at: www.data-archive.ac.uk/sharing/confidential.asp. A shortened brochure on data management and sharing is available at: www.data-archive.ac.uk/news/publications/managingsharing.pdf
 Advice on this topic can be provided by UKDA staff members Louise Corti, Libby Bishop and Veerle Van den Eynden via datasharing@essex.ac.uk.

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This seems to be somewhat of a grey area, but IES is deemed by HMRC not to be an eligible body, because, although a charity, it is also engaged in other activities (e.g. consultancy and a membership programme) which are not research. Given also that some of any surplus generated by a research project is ploughed back, not only into research and training activities (acceptable for VAT exemption purposes), but also into other activities of the institute, not falling into this exempt category, it is deemed that all of its activities are VATable, despite its charitable status.

Second, there is an issue of competitive equity among research organisations with different VAT status – e.g. an exempt charity/university vs a non-exempt charity (such as IES) vs a private research organisation. While VAT status should arguably make no difference, because the purchaser can reclaim VAT paid, in practice, different budget lines may be involved, with the research commissioned from one budget, and VAT reclaimed under another budget line.

From the perspective of the commissioning department, therefore, with a fixed research budget, there may, in practice, be a price advantage in commissioning a VAT-exempt supplier. Indeed, some public sector commissioners make it clear in tendering research projects that the fixed budget must include VAT if charged; hence organisations which charge VAT must have a lower effective price to compete with organisations which do not.

It would be interesting to hear from readers who have themselves come across these, or similar issues, as a problem and better still to learn of approaches to counteract the seeming inequality this creates.

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