

UK Data Archive Resources for Studying Older People and Ageing

Libby Bishop

Senior Research Archivist-Timescapes Project-University of Leeds

Research Liaison Officer-UK Data Archive-University of Essex

e.l.bishop@leeds.ac.uk

ebishop@essex.ac.uk

+44(0)1206 820 042

Abstract

There is a growing collection of data available on older people and ageing at the UK Data Archive. Collections include “On the Edge of Later Life”, a study that investigated the experiences of people in their 50’s, and “Older Men: Their Social Worlds and Healthy Lifestyles”, a study that investigated masculinity and ageing, with a focus on men living alone. Both qualitative and quantitative data are available. The UKDA wants to make data easily useable for research, teaching and policy purposes. To those ends, it provides access to data, additional resources and user support for those interested in using archived data. This paper describes the kinds of data and related materials that are available on ageing and later life and explains how they can be accessed and used.

Keywords: qualitative data, ageing, UK Data Archive, ESDS Qualidata, secondary analysis, data reuse; old age.

Acknowledgements: This paper draws extensively on content from ESDS Qualidata web pages (<http://www.esds.ac.uk/qualidata/> and also from Timescapes web pages <http://www.timescapes.leeds.ac.uk/>). I am grateful to Jack Kneeshaw at the UKDA who provided information about quantitative data collections on ageing. Richard Deswarte and Bethany Morgan at UKDA provided very useful feedback.

INTRODUCING ESDS QUALIDATA

ESDS Qualidata is a specialist service of the Economic and Social Data Service (ESDS) led by the UK Data Archive (UKDA) at the University of Essex. The service provides access and support for a range of social science qualitative datasets, promoting and facilitating increased and more effective use of data in research, learning and teaching.

The service's focus is on acquiring digital data collections from qualitative and mixed methods contemporary research and from UK-based classic studies. Data are typically acquired via the Economic and Social Research Centre Datasets Policy that requires all research grant award holders to offer data collected during the course of their research for preservation and sharing to the ESDS. ESDS Qualidata works closely with data creators to ensure that high quality and well-documented qualitative data are produced. General guidance and advice are offered for data creators and depositors on research project management, issues of confidentiality and consent, and data documentation.

RESOURCES ON AGEING AND LATER LIFE

ESDS Qualidata provides a wide range of resources ranging from data collections and documentation to user guides and materials specifically customised for teaching. A number of the data collections on ageing are described briefly below.

SN (Study Number) 4750 The Last Refuge, 1958-1959, Townsend, P.

This dataset consists of material generated by a national study in 1958-1959, which investigated the provision of long-stay institutional care for old people. Interviews were conducted with 67 local authority chief welfare officers and 173 institutions - local authority, voluntary and private. Additional material includes diaries kept by residents and professionals, and Townsend's accounts of two institutions where he stayed and worked.

SN 4878 Time Used in the Family Care of the Handicapped, Elderly and Children, 1980-1982, Nissel, M.

This study is concerned with the time spent by households in caring for dependent adults and for children. It covers the time allocated to caring, the particular times during the day when care is required, and their relationship to other support services available in the community. The study examines: the extent to which the caring function of the family constrains women's participation in the community; problems created by the mismatch between times when support services are available and the needs of the household.

SN 4934 On the Edge of Later Life, 1930-1990, Thompson, P.

The project was carried out between 1991 and 1993 to establish sources of self-identity and relate this to prospective ageing, and to consider how earlier life experiences contributed to adaptability to ageing. In-depth life history interviews were carried out with individuals aged 55 to 59 drawn from participants in the pilot study for the British Household Panel Study.

SN 4875 Impact of Family Change on Older People: the Case of Stepfamilies, 1994-1996, Bornat, J., Peace, S.

This project was concerned with the effects on the lives of older people of the changing structure of the family through separation/divorce and re-marriage. The main points of interest were: caring for older people; ties between the generations; grandparenting; and changes in the ways resources, e.g. property and money, are exchanged between family members.

SN 4840 Technology and Natural Death: a Study of Older People, 2001-2002, Seymour, J.

In its focus on older people's understanding of technologies used in end of life care, this study has developed new methodologies for social science in a demanding and ethically sensitive field. The study highlights: the role that older people have in caring for the dying and their needs for support and training; information needs about issues of ethics, clinical practice and advance care planning; and the willingness of older research participants to discuss these matters and to enjoy the process of so doing.

SN 4825 Generational Contract Between Care and Inheritance in Britain and Japan, 2002-2003, Izuhara, M.

This research examined the changing trends of exchanging care and inheritance between older parents and their adult children in the two ageing societies - Britain and Japan. Through a series of in-depth interviews, the distinct ways in which specific cultures, institutions, laws and housing markets combine to influence different 'generational contracts' were explored.

FINDING AND ACCESSING DATA

Qualitative (and other) data can be found at: <http://www.data-archive.ac.uk/search/searchStart.asp> using standard search options such as basic, free text and advanced search. Alternatively, the main UKDA Data Catalogue includes ESDS Qualidata collections as well as thousands of quantitative data sets. Terms such as "ageing" and "old age" will locate all relevant collections. There is also the support of an online social science thesaurus, called HASSET, to assist in finding key words useful for searching. It is also possible to browse the catalogue by collection and by subject area.

Registration is not required to access to the Data Catalogue, and many online materials including documentation such as questionnaires are also open access. However, to download the data, individual registration is required. Registration entails providing contact details and a description of the intended use of the data. Potential users are required to sign a legally binding End User Licence that lays out the terms and conditions of use. Key obligations of the licence include: to preserve confidentiality and not to identify persons, households or organisations in the data; not to share the data; to appropriately cite the data collection; and not to use the data for commercial purposes. The full text of the licence is available here, <http://www.esds.ac.uk/aandp/access/licence.asp>.

THEMATIC AND OTHER GUIDES

As well as the data itself, ESDS Qualidata provides access to a number of additional resources that are publicly available and require no registration. First, there are resources that are specific to each data set. Most collections have two kinds of documentation, a data list and a user guide. The data list is, typically, an inventory of all items in the collection. For an interview-based project, it will consist of a list of the people interviewed and key information about them, usually ID number or pseudonym, and any relevant personal details subject to confidentiality constraints. The user guide is a PDF document containing all documentation that ESDS Qualidata has been given by the depositor and collected through its own processing procedures. Most often this will contain the project proposal, the data collection instruments, and any end of project reports. Links to publications based on the data are provided in the catalogue record.

Other resources are classified as user guides – these can be by theme or by dataset, and there are also generic guides for accessing data, analysis, and other topics. ESDS Qualidata has compiled a thematic guide specific to ageing, called “[Later Life Studies](#)”. This guide (and other thematic guides) provides a brief overview of the subject area, a list of the most relevant collections held at UKDA, and a matrix that lays out key features of each collection in a manner that makes comparisons among studies clear and straightforward. These features are factors such as when the data were collected, sample size, geographical area covered, the type of data collected (interview, focus group, etc.) and the format (digital, paper).

Finally, ESDS Qualidata occasionally develops a guide specific to a single dataset. There are two such guides for ageing-related collections, ‘[Families, Social Mobility and Ageing, an Intergenerational Approach, 1900-1988](#)’ and ‘[Family Life and Work Experience Before 1918, 1870-1973](#)’ both deposited by Paul Thompson. Each guide provides an overview of the collection, background, methodology, relevant publications and other information:
<http://www.esds.ac.uk/support/datasetguides.asp#qual>.

REUSING QUALITATIVE DATA

The practice of reusing *quantitative* data is well-established and is, now, quite taken for granted. For *qualitative* data, the situation is more complicated and debates have been vigorous (Bishop 2005; Bishop 2007; Moore 2007; Mauthner and Doucet 2003; Parry and Mauthner 2005). The current debate has altered in character somewhat, to focus on actual cases and practices and the details of research practice.

What is particularly refreshing and useful about the articles contained in this special issue is the way that they push past the more moralistic overtones of the ‘re-use’ debate to focus instead on what happens, what is involved, what can and cannot be achieved, when sociologists get on and do it. In the process the articles give grounded and finely grained insights into the challenges but also the potential for qualitative ‘secondary’ analysis. In their different ways, the articles are qualitatively analytical about ‘re-use’ and they are engagingly reflexive in their arguments. They make the case for using any qualitative data carefully, revealingly, and reflexively, rather than arguing that a specific set of rules applies to so-called data re-use (Mason 2007).

At the risk of greatly oversimplifying, the current state of data sharing in the UK is an uneasy tension between pressures to share data countered by requirements to protect data and confidentiality. While it remains legitimate (essential even) to protect data either fully or partially (e.g. by anonymising) because it is sensitive or confidential, it is no longer seen as legitimate to protect it because the original researchers wish to have exclusive use of it. In brief, there is a strong move toward data sharing with key factors including: transparency, accountability, open access movements, the needs of service providers (law, health), and not least the “value for money” argument. Equally important are the concerns for protection, codified in the UK Data Protection Act 1998 (and international laws) which intend, rightly, to assure that all data sharing is done ethically (RIN 2008; Walport and Thomas 2007).

In spite of this difficult environment, sharing and reuse of data is growing. ESDS Qualidata supports these activities by making data available, enhancing data by various means such as digitising paper collections and adding documentation, by providing “early access” in selected cases when data are not ready for publication, and by connecting data depositors (with their permission) with data reusers. One of the best known examples of reusing qualitative data on ageing has been done by Julia Johnson and Sheena Rolph. They have been successful in securing an ESRC grant to undertake a study of continuity and change in residential care for older people. Their work is based on Peter Townsend’s 1962 study of residential care, *The Last Refuge*, based on fieldwork undertaken in the late 1950s. Drawing on these data, as well as the published book, Johnson and Rolph have done two connected studies. The first was a tracing study to find out and document what happened to the 173 homes visited in the Townsend study. The second study was of the 20-25 homes that are currently registered with the Commissions for Social Care Inspection in England or Wales as care homes. This follow-up study broadly replicates Townsend's method and will allow for direct comparison of the situation in 2005 with the detailed information on the individual homes contained in the archive. Before his death, Professor Townsend lent his active support to the project. Xx add ref if Julia J provides one.

Reusing data for research can have multiple motivations – methodological enhancement, restudies, reducing burdens on elderly populations, and more. As reuse become more taken for granted, research on ageing and later life benefits from the overall trend.

REUSING DATA FOR TEACHING

As well as encouraging the use of data for research, ESDS Qualidata also supports and promotes reusing data for teaching. The diversity of themes covered makes the materials suitable for various topics, but one of the most common ways of reusing data for teaching is in methods instruction. To that end, ESDS Qualidata has developed a “teaching pack” on interviewing. This teaching pack provides instructors and students with materials designed to assist in teaching qualitative interviewing. ESDS Qualidata's aim in creating this pack was to illustrate interview methods using its extensive data collection and, in particular, to assist instructors who have limited research materials of their own. The pack provides brief summaries of several

different interviewing techniques and each summary is accompanied by full transcripts or excerpts and the interview schedule (or guidance notes). It concludes with selected references and practical suggestions and classroom activities for how to use the materials for teaching. One of these interview extracts is an oral history interview conducted with a man born in 1895. While not all of the interview concerns ageing, the interview does exemplify the oral history method and as the interview was done when the man was in his 70s, some of the content is relevant to his reflection on ageing and his later years. Because special consent has been obtained for these data examples, the materials have been made public and do not require registration to use.

ESDS Qualidata has presented this resource to lecturers in several workshops in the past year and it has been very warmly received. More generally, the reports collected from people reusing data suggests that approximately half intend to use the data for teaching purposes.

ETHICAL REUSE OF DATA

Concerns about ethics and confidentiality are probably the most frequently encountered objections to reusing and sharing data. There is no doubt that there are very real challenges here, and protecting participants (and researchers) is a paramount concern of the UKDA. However, with care and diligence, even complex data can be archived and shared. There are three tools or strategies for doing so. The first is consent. That is, while getting consent for participation and publishing, researchers can also get consent for subsequent sharing of data. In fact, ESRC now requires that sharing be taken into account in consent.

www.esrcsocietytoday.ac.uk/ESRCInfoCentre/opportunities/research_ethics_framework/. The second strategy is data alteration to mask identities. All manner of techniques of anonymisation and aggregation are possible here. Data vary in how suitable they are for these procedures. Much longitudinal data is harder to anonymise, and visual data can be altered, but at a high cost to integrity and quality. The final tool is controlling and restricting access. Most data archives do not provide public (open)access, and this is one of the primary reasons. Data archives require users to register, give details, state reasons for using data, and to sign a licence specifying these and other terms and conditions. In the majority of cases, some combination of these tools can enable data to be shared ethically.

QUANTITATIVE DATA ON AGEING

The key UKDA resource on ageing is the English Longitudinal Study of Ageing (ELSA). ELSA follows a sample of people over the age of 50 every two years in order to see how people's health, economic and social circumstances change over time. The study is modelled on the US Health and Retirement Study and further cross-national comparisons are possible through projects such as the Survey of Health, Aging and Retirement in Europe (SHARE).

Increasingly, another longitudinal study, the National Child Development Study (NCDS), will become an important comparator for ELSA. The NCDS is a cohort study of people born in 1958 and thus cohort members have now entered their 50s.

Like ELSA, the NCDS will follow a set of respondents through the ageing process but, in contrast, the NCDS already provides very rich detail on the early and middle stages of the respondents' lives as this information has been collected concurrently; for ELSA, piecing together life history data has necessarily been a retrospective process.

For obvious reasons, longitudinal studies provide the best design for studying ageing as it is a process. Other longitudinal studies available via the ESDS that have been used for researching ageing are the British Household Panel Survey (BHPS) which followed a cross-section of the UK households on an annual basis; the Health and Lifestyle Survey (HALS) which followed up a sample of respondents from the mid-eighties after seven years and now provides cancer and death registration data updates on the respondents; and the (rarely used) Southampton Ageing Project, 1977-1998.

ESDS also makes available a large number of cross-sectional studies, especially repeated cross-sections, that include respondents aged 50 and over. These large sample, nationally representative studies can be used to explore health, consumption, labour market activity, time use, victimisation etc. among a sub-set older of respondents. Though the cross-sectional design of these studies precludes researchers from modelling the process of ageing, the studies are especially useful for tracking aggregate-level patterns of behaviour.

A small number of 'stand-alone' survey datasets relate to particular aspects of ageing; for example, the Life Before (After a) Death studies from the 1970s and 1980s or the Quality of Life of the Healthy Elderly study from the early 2000s.

RECENTLY PUBLISHED AND FORTHCOMING DATA SOURCES

As noted above, some of the richest data on later life available at ESDS Qualidata was deposited by Peter Townsend, who died earlier this year. This data was successfully deposited as part of the Pioneers Project, <http://www.esds.ac.uk/qualidata/pioneers/about/>, an initiative of the ESRC Qualidata Centre (the predecessor to ESDS Qualidata) to seek out surviving research data from pioneering examples of social research. In addition, a series of interviews were carried out with the pioneering researchers themselves. These interviews were conducted by the oral historian Paul Thompson. They are very detailed interviews, covering each individual's family, social background, intellectual development and key influences. Generally there is also a detailed account of the major research projects associated with that researcher. The first interview, now available online in both transcript and audio, is with Peter Townsend and is a tribute to his long and rich research career.

ESDS Qualidata also enables access to data through collaborations with major ESRC research programmes. Through a collaboration with one such programme, Timescapes, ESDS Qualidata will enable access to an extremely rich, qualitative longitudinal data collection in which themes of ageing are investigated. The Timescapes programme explores how personal and family relationships develop and change over time. Timescapes is based on seven empirical projects that span the life course: two on young lives, three on mid lives and two on older lives. The first of the older life projects is called Intergenerational Exchange: Grandparents, Social

Exclusion and Health. It will include life history interviews with grandparents in eight families. The second project, The Oldest Generation: Events, Relationships and Identities in Later Life, is concerned with the dynamic nature of older people's relationships and identities in the context of these changing structures of family life and service provision. Some materials from these studies will be available after the launch of the Timescapes Archive on 16 October 2009 from LUDOS, the digital repository at Leeds University where Timescapes is based. (An early version of the repository is here:

https://ludos.leeds.ac.uk/R/EP8IXA3G813TN2PUIM5IYQSK6GY3PCLXCFXP4PHI9HDSMCQSL8-01056?func=search-simple&local_base=gen01-tsc01. At various points in the programme, the Timescapes data will also be deposited and made available from the UKDA.

CONCLUSION

The practice of reusing qualitative data is growing, though rigorous measurement is very difficult to do. One measure is the number of datasets downloaded from ESDS; ESDS Annual Reports indicate that nearly 3000 downloads have taken place from 2005-2008 (<http://www.esds.ac.uk/news/publications.asp>). Additional indirect measures include articles and special issues published on secondary analysis (Barbour and Eley 2007; Witzel et al. 2008). Another important metric has been the willingness of funders to underwrite projects all, or partially, engaged in advancing data sharing. The most obvious is, of course, the continuing support for the UKDA and ESDS. In addition to these core commitments, a number of projects specific to sharing qualitative data have also been funded, with Timescapes being the largest recent investment. Finally, new depositors, especially major research centres, are also an important signal about attitudes toward data sharing. The National Centre for Social Research (NatCen) is the largest independent social research institute in Britain. Later in 2009, it will begin depositing qualitative data that meet consent requirements with ESDS.

Some of this growth of reuse of data is no doubt explained by the diverse benefits of reusing data. Some of the most frequently cited are for methods study and advancement and for teaching. Two further benefits may be particularly relevant to the study of older people. First, reusing data can help to prevent unnecessary and repetitive data collection. Avoiding burdensome data collection is important under any circumstances, but especially relevant when dealing with vulnerable populations. Of course, is it not the case that all older people are vulnerable – far from it – yet some are, and if existing data can answer important research questions that might improve policies affecting their lives, that is a very significant benefit. Finally, reusing data can extend the voices of research participants beyond the original project. The Family Life and Work Experience collection at ESDS Qualidata is a heavily used resource, with dozens of researchers having used some or all of the 450+ interviews for projects on topics as diverse as smoking, food, war, free trade and more. The voices of those participants, born in the Edwardian era, are still heard in research today because of the improving infrastructure and changing norms that enable sharing and reuse of qualitative research data.

REFERENCES

- Barbour, S., and Eley, S. (eds.) (2007) Refereed special section: reusing qualitative data, *Sociological Research Online* [Online journal], 12(3).
- Bishop, L. (2007) A Reflexive Account of Reusing Qualitative Data: Beyond primary/secondary dualism, *Sociological Research Online* [Online], Special Section on Reusing Qualitative Data, 12(3). Accessed 25 July 2009: <http://www.socresonline.org.uk/12/3/2.html>.
- Bishop, L. (2005) Protecting Respondents and Enabling Data Sharing: Reply to Parry and Mauthner, *Sociology*, (39,2), 333-336.
- Mason, J. (2007) Re-Using' Qualitative Data: on the Merits of an Investigative Epistemology, *Sociological Research Online*, (12)3. Accessed 25 July 2009: <http://www.socresonline.org.uk/12/3/3.html>.
- Mauthner, N. S. and A. Doucet (2003) Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis, *Sociology*, (37)3, 413-431.
- Moore, N. (2007) (Re)Using Qualitative Data?, *Sociological Research Online*, (12)3. Accessed 25 July 2009: <http://www.socresonline.org.uk/12/3/1.html>.
- Parry, O. and N. Mauthner (2005) Back to Basics: Who Re-uses Qualitative Data and Why?, *Sociology*, (39),2, 337-342.
- Research Information Network (2008), To Share or not to Share: Publication and Quality Assurance of Research Data Outputs. Accessed 25 July 2009: <http://www.rin.ac.uk/files/Data%20publication%20report,%20main%20-%20final.pdf>.
- Savage, M. (2007) Changing Social Class Identities in Post-War Britain: Perspectives from Mass-Observation, *Sociological Research Online*, (12)3. Accessed 25 July 2009: <http://www.socresonline.org.uk/12/3/6.html>.
- Walport, M. and Thomas, R. (2007) Data Sharing Review Report. Accessed 25 July 2009: <http://www.justice.gov.uk/reviews/datasharing-intro.htm>.
- Witzel, A., Medjedovic, I. and Kretzer, S. (2008) Focus: Secondary Analysis of Qualitative Data, *Historical Social Research*, 33(3).