

Ethical issues during the Oldest Generation Project

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The Oldest Generation Project ((TOG) was one of the seven empirical projects making up the Timescapes programme. Our aim was to investigate the impact of family transitions on members of the oldest generation, how such transitions affected relationships between the generations, how older people made sense of these changes, and what key events mark the passage of time in later life. With these aims in mind our research design was inevitably going to be qualitative, generating experience of emerging ethical issues. And it was going to involve time as a factor in family lives and as an aspect of our project research methods.

With these aims and methods in mind we designed a project which, over the course of 18 months, allowed us to track twelve families from across the UK, in which there was one member over the age of 75. We recorded life history interviews with these twelve 'Seniors' on two occasions and drew on monthly diaries of key family events involving members of the oldest generation which were kept by twelve 'Recorders'. The Recorders were also given cameras to keep a photographic record as the project developed.

The Recorders were usually younger family members and, while they were given an induction about their role and its contribution to the project, they were also encouraged to feel unconstrained about what they included as content in the diaries. Similarly, while the interviews were presented as life histories and the Seniors were guided biographically to talk about their lives, participants were free to include and exclude experiences as they saw fit. Both sets of data were thus to an extent serendipitous in nature, as they included individual reflection and historical content as well as accounts of daily living. To some extent the freedom we allowed them regarding their accounts of family life eased some of the ethical issues that might have arisen. At the same time, it meant that we had to approach the analysis of these accounts critically, appreciating the fact that they were inevitably selective.

There is more information about the project with links to publications at: <http://www.timescapes.leeds.ac.uk/research/oldest-generation>

During the course of the project a number of specific ethical issues arose, some were generated by the project's design and were to an extent anticipated, but others were unexpected. In what follows we outline a number of these issues. In each case we highlight an on-going ethical dilemma which remains unresolved.

Ethical issues generated by the project design

We begin with those that we had anticipated or had at least discussed as being likely to raise ethical dilemmas for ourselves as researchers and for the participants.

Photographs and anonymity: A critical issue we faced in archiving our data concerned identity and photographs. Having painstakingly anonymised all our interviews and diaries, we realised that individual identities were still evident, not through names, but through photographic images. Many of these were captioned or, through dates, they could be collated with the diaries. The result was that in archiving the photographs, there remained the possibility that real identities would be revealed. The participants had given us permission to archive these photographs but it seemed likely that most had not appreciated how this would conflict with our assurances of confidentiality. Only one Recorder expressed any concern over our use of photographs when being inducted. Given that we had only included photographs in our methods as a supplement to information resulting from the interviews and diaries, we decided that all the photographs should be archived but only a limited number should be available for publication prior to the year 2040.

- For us the ethical issue remains that data which we and participants had generated is not available for publication now, although photographs can be viewed and described. That is, until such time has lapsed that their value may be greatly diminished. The ethical problem facing us as researchers was how to choose the limited number of photos which might be shown and published now.

Payments to participants: In planning the project we decided that we would offer £50 shopping vouchers in exchange for each interview and each monthly diary. We hoped that this would encourage a wider participation, thereby reducing the inevitable bias towards families with the time and inclination to take part.

Broadly speaking we felt this strategy worked, not least because we engaged in several exchanges with participants which indicated that, for them, the vouchers were more than just a token payment. Associated with this was a related issue regarding other 'expenses'. We agreed to cover these when they related to travel to meetings with us (e.g. to Recorders when they travelled for their induction) but we refused to cover other travel costs (e.g. for the Recorder to visit the Senior in order to take photographs). In at least one case, this led to some minor ill-feeling.

- Payments to research participants is a much contested issue amongst researchers. For some it raises the question of power relations between researcher and researched affecting the outcomes. For us, a small payment felt appropriate given that participants were being expected to make a continuing commitment to the project over a period of time.

Recruitment: We recruited families through the Open University network. This is extensive, covering the whole of the United Kingdom and including people employed in many different capacities. Initially we concentrated on the Regional Offices and only turned to staff based at the national headquarters in Milton Keynes when hoping to attract the interest of someone in a blue-collar occupation. One consequence of this strategy was that, being based ourselves in Milton Keynes, we reduced the risk of a familiar colleague offering to participate. Given the longitudinal nature of the project, we could foresee this might create real ethical problems. Nevertheless we did attract a colleague based in one of the regions with whom we had worked in another capacity, and we did decide to include her family in the project. No problems arose although her participation did possibly discourage us (and perhaps her too) from other forms of collaboration. Another family joined after we appealed for help in recruiting minority ethnic participants (see more below) and a colleague suggested that we contact her father-in-law who joined the project. Again we were aware that in the event of any difficulties arising, within the family or in our relationship with him, we were at risk of damaging working and even personal relationships with the colleague who had approached us.

- Recruitment of participants where there is some existing relationship, even through a third party, may raise ethical dilemmas for researchers. We were fortunate that in both cases there were no crises or changes within the two families (or at least none which were revealed to us) which could have meant that we were privy to situations which we might have chosen not to know about.

Achieving diversity: In order to ensure maximum diversity in our sample, we agreed that the twelve families should include a minimum number with specific characteristics. One of these was that there should be at least one family from a minority ethnic background. Meeting this objective proved to be more difficult than we had expected (for a detailed account, see Bytheway and Bornat, 2010). At various points in the process of trying to recruit a family that met this criterion we placed possibly excess pressure upon our contact, offering for example to relax some of our expectations regarding their participation. In retrospect we do not feel we overstepped any ethical threshold, but there was a serious risk we might have. In the end we were lucky in that the family that volunteered did not raise any serious difficulties. When, however, the nominated Senior indicated that he would prefer to keep the diary himself (and thereby be both Senior and Recorder) we readily agreed. Adjusting our methods in this way seemed a small price to pay. Two other criteria we set ourselves were that there should be at least one Senior who had no living children and at least one Senior who lived in a care home. One volunteer who offered his own family as participants mentioned that his wife had an aunt living in a care home whom she regularly visited. It also turned out that the aunt did not have any children. We had no other Senior who met these two criteria and so we were keen to select this family along with the volunteer's own family. Fortunately this was agreed by all concerned and, as a

result, unexpectedly, the twelve families included two in which the respective Recorders were married to each other.

- These two solutions to the problems we had in achieving the sample were unexpected, and they entailed risky adjustments to our recruitment plans which might have generated ethical problems, but fortunately nothing arose. Indeed by relaxing our approach we ended up with participants whose contributions greatly enriched the scope of the data we were able to collect: an ethical compromise perhaps.

Internal Confidentiality amongst participants. Our methods featured two people in each family: the Senior and the Recorder. As indicated there was one family in which this was one and the same person and, in another, the role of Recorder changed hands. In two other families, the person who first contacted us (the 'volunteer') was neither Senior nor Recorder. In all of the families there were other members who played important parts in family life who, undoubtedly, were aware of their involvement in the project. So, we appreciated that, throughout, there was the risk that someone would ask us if they might view the growing file we had on their family. For example and most obviously, the Recorder might ask us for a transcript of the interviews undertaken with the Senior, or the Senior might ask to see the diaries kept by their Recorder. At the project's end all interviewees were given copies of their interviews, both transcriptions and audio files.

- We did not receive requests for interviews or diaries; quite possibly this is because any such person had their curiosity satisfied through ordinary family exchanges. Most of the Recorders appeared to assume, and in some cases assured us in the case of the interviews, that the stories we would hear had been told many times before. Indeed some families offered to join the project because they were looking for ways to satisfy the need of members of the oldest generation to talk about the past. This was recognised by some of the older participants who, in turn, viewed the interviews and resulting transcripts as a family history resource which would be available to younger family members. To this extent, participating families resolved potential ethical conflicts themselves.

Internal confidentiality and researcher awareness: Though we felt confident that family members were aware of the existence of different accounts and appeared not to be concerned, we the researchers were in a more privileged position, potentially since we had access to both. This inequality did not always feel comfortable. For example, the diaries of one Recorder contained information about a key family commitment which was completely absent from the first interview with the Senior. Were we to follow up on this at the second interview, or should we wait to see if it was again not mentioned and draw conclusions from an apparent silence?

In another case, a Senior's daughter talked openly after the second interview about tensions in the family which she said were generated by the Senior's

presence. The Senior had only tangentially referred to this in the first interview. The Recorder's concerns, mainly expressed in a humorous way, were included in the field notes written up for that particular interview. Although her comments provided valuable insights into the situation in that particular family we were uncertain as to whether we could refer to them given that such comments were not covered by the terms of the consent form which family members had signed.

- It is our view that the whole area of internal confidentiality and researcher awareness is ethically unclear but that perhaps the best guidance is to pay careful attention to anonymisation in any discussion with other researchers and not to pass on information gained to research participants (See Hammersley & Traianou, 2012, pp 121-126 for a discussion of confidentiality and anonymity). In the end, the field notes were archived in two formats, anonymised and non-anonymised. Only the former are available for accredited researchers.

Unanticipated ethical issues

In this section we consider ethical issues which were unanticipated given that they occurred as a result of unexpected changes in the lives of participants. A project such as ours which engages directly with people might be expected to be able to manage such new challenges, however it is the very particular nature of certain types of event and how people cope with them which led to the ethical issues which we go on to outline here.

Uneven diary keeping: Ethical issues arose from the submission of diaries. The agreed arrangement was that Recorders would be provided with blank monthly diaries and, when completed, they would submit these to the TOG project office at the end of each month. Apart from providing us with a constant supply of data, this arrangement ensured that we kept in touch with the participating families. Most Recorders had problems from time to time, but these were easily resolved. Three however fell behind with the monthly routine and never satisfactorily caught up. We realised they were busy people who perhaps had not fully appreciated what was involved in keeping to the monthly routine. We were also aware that the then economic situation was taking a heavy toll on one family with the result that the TOG diary was low in the list of the Recorder's priorities.

We were very concerned to keep the Recorders and their families involved since the last thing we wanted was for families that had to cope with conflicting pressures to be unrepresented. For this reason, we suggested ways in which we could help them catch up, and changes in how they might subsequently keep their dairies. Broadly speaking, we failed in these efforts and the three sets of diaries remained incomplete. All three Recorders promised they could and would catch up, but they never did. Paradoxically, however, we obtained much 'diary-like' information from the email correspondence we had with them, and relevant extracts from these emails have been included in the archived diaries. In this way, we were able to sustain a degree of continuing longitudinal participation.

- An ethical issue arose while we attempted to balance our desire to have as near complete diaries as possible with socially acceptable levels of pressure on the Recorders. The result was that we had incomplete data, however we felt that sensitivity to participants' circumstances should take priority in this situation. Moreover there was the risk that the family would drop out altogether, with the result that there would be no follow-up interview.

Family disputes: One unambiguous ethical issue that we faced concerned one particular family. A deep-seated conflict between the Recorder and his brother became evident following the death of their mother, the Senior. Essentially it related to complex long-term inter-personal histories and to some extent issues concerning their mother's care in her final year, rather than to matters of inheritance. The Recorder used his diary to express strong emotions, not just in relation to the conflict with his brother, but also his sense of loss following his mother's death. Tensions in other participating families were evident but nowhere near as starkly. In this particular case (as in another where the Senior died before the second interview), the Recorder was invited to be interviewed in the place of his mother, eighteen months after the first interview. He readily accepted and what followed was in part an explanation of events surrounding his mother's death but also an opportunity for him to reflect on how he was feeling and how he expected his relationship with his brother to develop over the coming years.

- We discussed whether the relevant diary entries should be included in the Timescapes Archive since it was clear that the conflict had been heightened by the Senior's death and, conceivably, the diary could be used in future legal proceedings. We decided they should be archived, but our intention is that access to them should be tightly controlled. Similarly, the second interview, while it included reflections and comments on the Senior's life, was more in the nature of a personal statement by the Recorder. Talking this through with the Recorder and between ourselves, we felt that the interview was, even so, highly valuable and relevant to this family's own story.

Pushing at boundaries: The first round of interviews with Seniors produced some wonderful accounts of growing up in various parts of the UK during the 1920s and 1930s. The life stories carried on into courting, getting work, marriage, parenting and grand-parenting and growing old, within the context of twentieth century history. In almost every case, the account that was presented, even where deaths, illnesses and disappointments were mentioned, was of a life fulfilled and the overall tone was happy and positive. It seemed that the emotional range was limited in ways that belied the nature of the events and experiences described. We wondered if this was the result of interviewer style or of the fact that the interviewees knew that their interview would become public within their family. They may thus have been guarded in their emotional

response. Noting this rather positive impression we considered ways to provoke a more in-depth reflection on the lives lived. However we felt that there were ethical limits to what we might seek to generate. To press interviewees to talk in greater depth about topics which interested us as these emerged in the interview might breach the understanding we felt we had, which was that there should be an element of control by the participants over what and how accounts should be related. We also felt that the tone of the interviews was in itself interesting evidentially. However, for the second interview we decided to add a question which introduced the possibility for reflection on a topic which is both individual and general: the future. This generated some insightful comments about future ageing and plans for coping with frailty and, in some cases, death.

- Dealing with difficult questions is a challenge to both researcher and researched. How far these should be pushed in an interview raises ethical issues which tend to be resolved through mutual understanding. To disturb that mutuality may risk the interview relationship and ultimately the whole project. We decided that the balance of emotions was for the participant to resolve but did introduce a question which had the potential to provoke less happy reflections but with enough scope to allow for more or less personal responses according to people's choices.

Bytheway, B. and Bornat, J. (2010) Recruitment for 'The Oldest Generation' project', in *Conducting Qualitative Longitudinal Research: Fieldwork Experiences* (eds. F. Shirani and S. Weller), Timescapes Working Paper Series No. 2, University of Leeds.

Hammersley, M and Traianou, A (2012) *Ethics in Qualitative Research: Controversies and Contexts*, London, Sage.