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**ETHICAL DILEMMAS AROUND ANONYMITY AND CONFIDENTIALITY IN LONGITUDINAL RESEARCH DATA SHARING: THE CASE OF DAN[[1]](#footnote-1)**

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**Introduction**

This chapter is concerned with ethical practice around anonymity and confidentiality in the specific context of data sharing and secondary use of longitudinal research data in the United Kingdom (UK). With respect to data sharing for secondary use, all publicly-funded research data is regarded as a public good, produced in the public interest, and therefore to be made as openly available as possible.[[2]](#footnote-2) In this context, the concepts of anonymity and confidentiality usually occur in tandem in ethics guidelines produced by funding bodies and disciplinary associations. They are concerned with disguising the identity of people who have taken part in research from secondary users of data sets (outside of the original researcher or research team), whether quantitative or qualitiative, and thus protecting the information that participants have disclosed from being associated with them (see e.g. section 4.7 of the Social Research Association’s and sections 35-38 of the British Sociological Association’s ethical guidelines.[[3]](#footnote-3) We explore these concerns through a particular focus on a piece of qualitative longitudinal work that we have been conducting, tracking the lives of around 50 young people in Great Britain for around a decade. We will look at the issues that arose for us following the death of one of our participants who was killed in a road traffic accident, which involved not only the sharing of his research material through archiving for re-use by secondary analysts, but also dilemmas of sharing some of his data with his family.

Some of the dilemmas around anonymity and privacy in family and secondary analyst data sharing that we faced were amplified by the long term nature of our study, as we experienced a growing sense of interest in, emotional connection with and obligation towards our project participants and their families. Indeed, this chapter fills a gap where we consider some of the implications for anonymity and confidentiality of producing data for reuse from the perspective of the original researchers. We also raise the issue of anonymity and confidentiality in the context of discussing our research experiences, a form of auto-ethnography.

We begin our discussion with a brief consideration of what we mean by anonymity and confidentiality, particularly in the context of debates about sharing research data for reuse.

**Anonymity and Confidentiality in Data Sharing**

Ethical conduct refers to moral values and behaviour; it is a foundation on which the legitimacy of social research rests. Keystones of ethical consideration in all research contexts include issues of anonymity and confidentiality, both in the creation and use of primary data, and when it comes to data sharing and secondary use of that data. Anonymity and confidentiality are often run together as if they were the same or interchangeable ethical issues, but they are distinct concepts and practices (Sieber and Tolich 2013; Wiles 2013). Nonetheless, as we discuss, they tend to be bound up with each other in UK discussions, including in relation to qualitative social research, as well as in the case of sharing longitudinal data. Largely, they are not concerned with the relationship of the original researchers to the data in addressing anonymity and confidentiality but with the potential relationship of third parties.

Anonymity refers to the protection of the identity of participants in research. For UK institutional review boards or ethics committees, it is an accepted ethical principle that the data collected should not be identifiable as related to a particular person, so readers of the outputs of a piece of research cannot identify a participant or setting.[[4]](#footnote-4) Qualitative researchers pursue various means to achieve this, notably using pseudonyms rather than the real names of participants, organisations or places (although there are challenges made to this practice: Hammersley and Traianou 2012). In some settings identities can be recognised from distinct characteristics, such as an unusual occupation, when a distinctive event took place, or other contextual details, and these may need to be changed in ways that do not affect the integrity or accuracy of the data or withheld. The more detailed the descriptions of the research process, the data and the sample, the more difficult maintaining anonymity can be. (In some cases it is impossible: for example, a study of women leaders of nation states that included interview material from a UK prime minister[[5]](#footnote-5).) Yet holistic ‘thick description’ and richness of detail are hallmarks of qualitative research.

Confidentiality, in contrast, refers to what can be disclosed about the data and who to and in what circumstances. Researchers usually assure participants that only they and members of their team will have direct access to the records of the data collected about them, and that their particular actions or words will not be disclosed to others in the field such as a family member, work colleague or service providers. (Again, sometimes this is impossible: for example if a court subpoenas interview transcripts as part of a police enquiry.) Conventionally research participants are asked to consent to researchers using their data for particular purposes without identifying them, and this is where anonymity and confidentiality are bound together. Anonymity is one means of achieving confidentiality when it comes to writing up and dissemination of research – no-one will know that a specific person disclosed a particular piece of information to the researcher because no-one can find out that that specific person took part in the research.

The above brief discussion of anonymity and consent considerations has been framed implicitly in terms of the collection and use of primary data; that is, generated by a researcher or researchers for a research purpose, who then use it for that purpose. In recent years, as we have noted, data sharing is a requirement of research funding for publicly funded data gathering in the UK. This means that the data should be made available for others to use, which can be for a different purpose than originally intended (see Mauthner 2012 for discussion and critique). Archives have been established in the USA and Europe to enable such sharing and reuse (Corti 2012). Ethical issues of anonymity and hence confidentiality have their own concerns when it comes to data sharing.

In the case of qualitative research, ensuring confidentiality through processes of anonymisation that change or remove personal characteristics, location references or people’s roles and relationships to each other in a setting, notably, may undermine the integrity of the data and hence its utility for secondary researchers. How researchers may ensure confidentiality of participants’ disclosures while at the same time ensuring the data has analytic value for secondary use is a key tension. For large scale data sets, such as quantitative longitudinal cohort studies, removing all personal identifiers from the data set and aggregation (merging of individuals within a large data set) is regarded as ensuring that secondary users cannot link variable information back to particular individual participants. In other words, anonymity achieves confidentiality.

There has been a recent furore about this in the UK concerning confidential medical data (Bolten 2014; Goldacre 2014). In addition to data gathered by researchers funded from public money, government plans to make administrative data collected by itself, the health service, social security and so on publicly available for reuse. The UK Health and Social Care Information Centre revealed, however, that it had already made some health records available not only to academic researchers, who are subject to UK institutional Research Ethics Committee review[[6]](#footnote-6), but also to commercial companies who are using and selling it, for example for social marketing campaigns, or to make actuarial estimates for insurance purposes. The government and government agencies involved sought to downplay the issue by stating that the confidential medical data remained confidential because it was anonymised and aggregated. It was then revealed that a range of variables are included in the data sets, such as postcodes, that when put together mean that many people could be re-identified. In other words, anonymisation does not necessarily guarantee confidentiality.

In contrast to the statistical variables of quantitative research or medical data, qualitative data is very rich in detail and context, and problems of anonymisation and confidentiality of data reflect this. We now turn to a case study of the distinction and relationship between anonymity and confidentiality in the context of qualitative longitudinal data gathering and of data sharing of various forms.

**‘Your Space! Siblings and Friends’ Qualitative Longitudinal Research Study: The Case of Dan**

Over a period of around 10 years now, our ‘Your Space! Siblings and Friends’ study has documented the meanings, experiences and flows of young people’s prescribed (sibling) and chosen (friendship) relationships. We have explored how these connections relate to their sense of self as their individual and family biographies unfold (e.g. Edwards and Weller 2010, 2014; Edwards et al. 2012).

Our participants were born between 1989 and 1996 and come from a diversity of family, social class and ethnic backgrounds, and a range of locations across Great Britain (England, Scotland and Wales). To date the Your Space participants have been interviewed on four occasions or ‘Waves’ (2002/5, 2007, 2009 and 2013) using in-depth interviews and a variety of other interview tools. Participants have also taken part in a range of postal, email and internet-based activities between interviews, and have been sent regular project newsletters (see Weller et al. 2011). The funder of the research is a public body – the UK’s Economic and Social Research Council – that requires researchers to make the data from studies that they fund available for reuse. So, with participants’ permission, anonymised data from our study has been placed in an online Archive for use by other researchers, but not open to public access (http://www.timescapes.leeds.ac.uk/archive/). We adopted a ‘light-touch’ approach to anonymisation: disguising people, place names (with the exception of large places or countries) and institutions (such as schools and employers), whilst retaining all other contextual material.

As we have indicated, archiving research data for the purpose of sharing it brings about additional ethical considerations, on top of those arising from the data collection and writing up process. Because detail and context are so important in qualitative research, these considerations include balancing obligations to participants in relation to obligations to data quality for the Archive in the negotiation of confidentiality through anonymity. In addition, another sort of data sharing issue involving confidentiality but not anonymity was also thrown up for us following the death of one of our participants, who chose his own pseudonym of Dan.

Dan was a working-class, White-British young man. Dan first took part in the project in March 2003. He was 11 years-old and lived with his parents, an older brother and sister and two younger brothers, in a small village in the South-East of England. Dan was then re-interviewed in November 2007, aged 16. At this time he was attending a school for young people with additional educational needs. Some months later he completed one of our interim postal activities, in which he indicated that he wanted to follow in the footsteps of relatives and have a career in agriculture, as well as his hopes that he would have his own family by the age of 25. By 18, Dan was working in his chosen career, and we were in the process of organising a third interview with him shortly before his death, which was in late autumn 2009. After several unsuccessful attempts to reach Dan on his mobile phone we rang the family home and learnt of his recent death in an accident. We were stunned by his death and the circumstances surrounding it. We sent a condolences card to his parents and siblings. We then gave some time to reflecting on two key ethical (and indeed legal) issues concerning the data we had gathered from Dan in Waves 1 and 2 of the Your Space! project.

***Ethical issue 1:***

One ethical issue brought our longstanding moral and professional commitment to Dan to ensure the confidentiality of his data up against our sense of moral responsibility to his parents and siblings brought about by his death. We had spoken to Dan’s parents over the telephone to gain their agreement to and set up interviews with Dan for Waves 1 and 2 – this was in the days before UK University ethics committees required all projects to have ethical approval and signed consent forms. We negotiated consent both with them and with Dan in these early stages of the project. We had not had much by way of face-to-face contact with Dan’s family beyond seeing them in passing when visiting to interview him; nonetheless his family had been part of the research process for as long as he had. For us, some of our emotional connection to Dan, intrinsic to a professional commitment built up over years, became extended to his family upon his death. We felt that we ‘held something’ material of Dan, while his parents and siblings had lost their son and brother. We pondered whether or not to offer his family a selection of ‘non-sensitive’ audio extracts from his interviews, such as a sample of him discussing his interests. Indeed, it was the sound of his voice rather than what he said that felt more significant to give them.

A dilemma here was whether our sense of moral obligation to Dan’s family overrode the promise of confidentiality we had made to him for his Wave 1 and 2 interviews, or did Dan’s death change the context and standing of the promise? Perhaps a ‘let-out’ for upholding confidentiality was provided because we never offered any of our participants absolute confidentiality. Rather, we had told all our participants that if they raised something that concerned or worried us during the interviews, we would discuss with them whether we needed to tell someone else. If we did feel that it was acceptable ethically to share aspects of Dan’s data with his family, we then faced a further dilemma about what constituted ‘non-sensitive’ material. For instance, Dan had voiced negative as well as positive thoughts about his family life and relationships. We imagined listening to the more sensitive disclosures could be distressing for his family. Might other material also upset them further, which we could not anticipate? At the same time to offer nothing seemed uncaring. Dan’s family were aware that his invite to take part in Wave 3 arrived at the family home around the time of his death, and his father said that he had intended to contact and inform us.

***Ethical issue 2:***

Another ethical issue related to the nature and standing of Dan’s consent to archive his interview material for data sharing. The need for ‘informed consent’ is a keystone of the ethical guidelines of professional bodies and the practice of most researchers. Negotiating informed consent is not a straightforward or one-off process however, and this is especially the case in longitudinal work. It was our practice in the Your Space! study to send out an information leaflet explaining the aims, processes and potential outcomes of the research before each interview: to participants and their parent/s for Waves 1 and 2. In the Wave 2 leaflet we included a reference to depositing the interview material in an archive[[7]](#footnote-7). We discussed and answered questions about the study at the start of each interview, after which we asked our participants if they would consent to taking part. At the end of the interview we asked participants if they consented to us using their material in our research. Before we embarked on Wave 3 of data gathering, we provided a detailed information leaflet explaining the purpose and process of archiving project data to our participants, and at the end of the interview itself we discussed the leaflet with them and asked them for written consent to anonymised versions of their material being deposited in the Archive for use by other, registered researchers. We did not prepare a participant’s data for deposit prior to receiving signed consent at the end of the Wave 3 interview.

Dan had given verbal agreement for us to use his material in our research in Wave 1 (when he was 11) and Wave 2 (when he was 16). Additionally, he made an audio-recorded general assertion in the Wave 2 interview that we could archive his data. Dan had died before he was about to participate in Wave 3, though, and so had not been able to consider giving written consent. This raised the question as to whether or not we could archive his data on the basis of the loose verbal consent we recorded two years previously, or should we exclude Dan’s data from the Archive? Perhaps we could seek consent from Dan’s next of kin given that they had originally given consent for us to interview him? What would we do if his parents denied permission though, given we had recorded Dan’s verbal consent? And would the implication of asking Dan’s parents be that they ‘owned’ his data and could demand their own copies?

**Consulting the Your Space! Reference Group**

Throughout the Your Space! study, consultation has been a consistent feature of our working process. We have an Advisory Group made up of national and international academics, and of practitioners working in a range of youth and family-oriented organisations. In the face of the ethical dilemmas surrounding Dan’s data we conducted an email consultation of our Advisory Group along with other academic colleagues who had particular expertise in qualitative longitudinal research, together comprising a wider reference group. We laid out the dilemmas and concerns described above and asked for their comments and advice. With their permission, we review the responses that we received, discussing the two key ethical considerations and consequences that our colleagues drew to our attention.

***Ethical dilemma 1:***

Our first dilemma concerned the tension between our promise of confidentiality to Dan and our feeling that his family should be offered a copy of the sound of his voice. This seemed to be a moral obligation that many understood. Our colleagues took into account the context of the Archive, where Dan’s interviews would be lodged and available to others, as a warrant for setting aside the principle of confidentiality in this particular instance. For example, one of them remarked that it would be strange to preserve Dan’s voice and words in an Archive to which registered researchers but not his parents would have access. Two colleagues who were conducting qualitative longitudinal research themselves recounted their own actions following the death of a (adult) participant in each of their studies. In both cases, they had contacted the family concerned and provided them with some or all of the material that they had collected. Beyond that, our colleagues often left the selection and nature of the material from Dan’s interviews that we might offer his parents with us. They felt that our situated knowledge meant that we were best placed to judge what might or might not be too sensitive to hand over. One colleague, however, felt that while providing interview material to Dan’s parents may be ethical, making judgements about what should or should not be included was not. This person made the point that we could not possibly know what would or would not upset Dan’s parents. They might be well aware of his feelings that he had not been the favoured son for example.

A provocative challenge from one colleague was to our entire notion of a dilemma created by a moral responsibility to a young person’s bereaved parents because we held his interview material:

In this case, Dan’s withdrawal from the study has been caused by his tragic death, but if he had withdrawn for any other reason … and not be in contact with his family or the research team … this could be just as upsetting for his family and yet his confidentiality be maintained … I’d also encourage you to look more closely at the notion that you ‘have’ something that they don’t. Dan will have had all sorts of relationships that excluded his parents and in that sense, they never did have all of him. You may want to offer them extracts from the data ... but again, would you want to do this for parents whose son had left home and cut off all contact with him because of irreconcilable conflicts? Parents in this situation may also long to hear their lost child’s voice, but would you be willing to do this?

This colleague’s challenge to our assumptions also raised the issue that we might be more preoccupied with our own need to reach out to Dan’s parents than with any need on their part.

***Ethical dilemma 2:***

Our second dilemma focused on the standing of Dan’s consent to his data being archived for sharing, and whether or not his family should be involved. There was a strong consensus that Dan’s verbal consent was sufficient and should stand. A typical response was that if Dan had had a problem with us using the information he would not have agreed verbally to participate in the study. Perhaps this is not an unexpected conclusion from consultation with a reference group mainly made up of social researchers! Having said that, the consequences for our treatment of Dan’s parents that stemmed from this ethical resolution were not so clear-cut. For some colleagues, they had no role to play in the face of Dan’s autonomous action; it was not their decision to say whether Dan’s data could be archived because it was an agreement that we had entered into with Dan, not his parents. While there was no reference to Dan’s parents having agreed to him participating in the research in the first place, our colleagues discussed the legal as well as ethical standing of Dan’s consent and the position of his parents. For example some drew a parallel with next of kin having no rights to know about a patient’s medical information. (This statement now seems ironic given the subsequent data sharing furore referred to earlier.)

For other colleagues though, while Dan’s consent stood and his parents may not have the moral or legal right to demand that his material should not be deposited in the Archive for data sharing, an ethical way forward was to negotiate carefully the archiving of his data with them. Colleagues suggested that we could ensure that Dan’s family understood that the data did not belong to them through explaining that Dan had consented to his interview material being archived and that we had promised him confidentiality. Some proposed that we interview Dan’s family members and archive these interviews alongside his own, so that they had the knowledge that their version of Dan was represented in the Archive, and which could also serve as contextual background to his interview material for secondary researchers.

The reference group responses to our consultation were invaluable in our considerations and decisions about how to negotiate our two dilemmas. The variety of thoughtful responses from experienced researchers and practitioners made it clear that an obvious single solution to the issues that we felt that we faced was a chimera. We thus decided to take the course of action that felt morally caring to us based on a feminist ethics of care that emphasises care and responsibility situated in context, and admits emotion into the ethical process (Edwards and Mauthner 2012). Our considerations led us to place any abstract rights to confidentiality or to information, the standing of informed consent and so on, within the specific circumstances of our qualitative longitudinal study. The Your Space! study involved us in a set of relationships. As researchers with obligations to professional practice and to archiving our data, we had initiated and listened to accounts of his life from a young man as he moved from childhood into adulthood. This young man was firmly embedded in a set of loving, and at times troubled, family relationships that he valued. We also considered these circumstances within the practical and emotional context of the end of the young man’s life, where we felt a loss to our longitudinal research knowledge generation and empathy with parents who had lost their son and whose relationship with him now existed through memories.

**What Did We Do?**

The result of our deliberations around relationships and obligations in the particular case of Dan was as follows. We waited until after the Christmas and New Year period subsequent to his death on the assumption that this time of year would be particularly difficult for them, and then wrote to his parents. In our letter, we offered Dan’s parents and siblings the opportunity to archive any memories of him alongside his research data if they so wished. This offer effectively informed them that Dan’s interview material was being archived. We felt that this course of action at least allowed us to work with the tensions and ambivalences around our separate and overlapping obligations to, respectively, the archive, Dan, and his family. Additionally, we offered Dan’s family a sample of his voice. In an attempt to balance offering them involvement with respecting their privacy, we signed off our letter by saying that if they did not contact us we would understand that they preferred not to be involved in these ways.

After some time Dan’s mother responded to say that the family would like a DVD of extracts from his interviews, and also wanted to have their memories recorded for deposit in the Archive. In putting the DVD together, we did maintain a form of confidentiality. We excluded any passages where Dan discussed family members and friends. Instead, we identified an extract where Susie explained the research to Dan for context, followed by some extracts from his Wave 2 interview, age 16, where he discussed his interests and career aims. Susie then arranged to deliver the DVD to Dan’s mother personally, and to audio record a discussion with her if she still wanted to do this.

**Ethics Upon Ethics**

The ‘resolution’ of our two ethical dilemmas through our decisions about how to act are not actual resolutions. Rather, further ethical considerations were consequent upon them. Ethical conduct was to the fore in Susie’s mind when she visited Dan’s mother, as this extract from her fieldnotes makes clear:

… visiting the family felt very different; the boundaries and purpose of our discussion was less clear. I was concerned about long silences, upsetting Dan’s mother further and about explaining that his interviews were confidential for fear that she might wish me to divulge all that he had said … Despite my anxieties the visit went as well as could be expected given the circumstances … At no point did she enquire what Dan had discussed and completely respected the confidentiality of his interviews. Occasionally she broke the conversation to show me photographs, sharing all they had done to keep his memory alive. She also took me to the area in the house dedicated to his memory, where his ashes stood on a small table surrounded by photographs and candles … After almost an hour we moved on to talk about ways in which she could record memories of Dan for the Timescapes Archive. She was unsure how best to do this and did not feel confident in talking in an unstructured way or in writing her thoughts. Instead she suggested I ask her questions … on leaving [I] agreed to send her a copy of the transcript of her memories before depositing them in the Archive. She also gave me a photograph, which she felt best represented her son … I wholeheartedly believe that it was the right thing to do and that Dan’s mother appreciated the opportunity to share her memories. It appeared to be part of a series of activities she and her family had done to pay tribute to her son and ensure his memory lived on.

Clearly, identifying a course of action for dealing with an ethical dilemma is not necessarily a final resolution. Ethical resolution is a contingent process in which the actions to address one ethical dilemma can create and raise other, subsequent ethical issues. In our case, one of these was Dan’s mother’s needed to consent to her memories of Dan being archived, and her material then had to be anonymised in an effort to preserve confidentiality, not just for herself but also for Dan. This raises a question about confidentiality and thus anonymity. Rather like the fitting together of various variables that could re-identify people in the supposedly confidential medical statistics dataset referred to earlier, the details of Dan’s life as he recounted it and in his mother’s memories, brought together with the fact that he died in a particular way at a particular age at a particular time, could reveal who he was to third parties. Some dedicated time with a search engine might do it, despite our efforts at anonymisation in this chapter and elsewhere. And yet it is exactly these sorts of details and context that are necessary for case studies to be the rich, informative and illuminating processes that qualitative researchers value.

We appreciate that the ways of dealing with the dilemmas posed by Dan’s death that we have described will not necessarily be judged by others as ‘the right thing to do’. Indeed, another ethical issue concerning confidentiality is raised by the fieldnotes extract that we have presented above. If this material is viewed as a piece of auto-ethnographic practice, there are several confidentiality issues raised.

**Confidentiality and Auto-ethnography**

The meaning, form and epistemological status of auto-ethnography is subject to lively debate. It is broadly understood, though, as an approach to research and writing where, through a process of rigorous, multi-layered reflexivity, a researcher aims to analyse their own personal and/or professional life, and emotional and sensory experiences, in order to situate them within and throw light on broader social, cultural and political processes (Grant et al. 2013). Some consider that this approach does not raise ethical issues because researcher and researched are the same; since an auto-ethnographic piece is about the researcher and their own life, confidentiality issues will not be raised because it is a person sharing their own life material. As others have pointed out, however, auto-ethnography nearly always implicates other people and their lives in the researcher’s story about themselves – parents, siblings, friends, work colleagues and so on. This raises a host of complex and challenging ethical dilemmas around the ethical boundaries between Self and Other that involve the status of knowledge and are not necessarily amenable to clear-cut stipulations about ethical practice (Turner 2013).

Focusing in particular on issues of anonymity and confidentiality, and continuing our discussion of the relationship between the two, it is the case that if the researcher’s identity is known, then the relationship between researcher and implicated person can mean that it may be difficult to hide the identity of others in the auto-ethnographic account, dependent on their relationship. An auto-ethnographer may refer to an encounter with a shop assistant in a generalised way that maintains anonymity, but if the person or setting invoked and discussed in an auto-ethnography is specific rather than general, then others who know the auto-ethnographer or the implicated person or setting are likely to be able to identify them even if they have been given a pseudonym and some details are changed. Anonymisation will not mean that the aspect of their lives discussed will be confidential.

In our case, the extract from Susie’s fieldnotes make reference to Dan’s mum. Dan’s mum consented for us to lodge her memories of Dan in the archive for other researchers to access, but it is a moot point as to whether or not that would extend to writing up and making public through a discussion of the research process. And what about this chapter and other contexts where we talk or write about the dilemmas created for us by Dan’s death? What if members of his family hear or read them? The supposed anonymity provided by a pseudonym will not hide Dan’s real identity from them. They would then know that Dan had talked about the pains and pleasures of his family relationships. The issues about anonymity and confidentiality and their relationship are far from straightforward.

**Conclusion**

In this chapter we have drawn on our experience of conducting a qualitative longitudinal study with young people to be archived for reuse, to explore the relationship between issues of anonymity and confidentiality in social research. We have shown how these two key elements of ethical practice -- anonymity and confidentiality -- were amplified in this case because of the long term nature of the study.

We have outlined two key ethical issues and their implications for anonymity and confidentiality arising from the death of a young man, Dan, participating in our 10-year study. The first dilemma concerned the predicament we faced in balancing our long-standing promises of confidentiality to Dan (with some limitations) against our sense of moral obligation and responsibility to his family in light of his death. The second issue centred on the status and validity of Dan’s (verbal) consent to archive his materials for future reuse given that he had died prior to the formalisation of the consent process, as well as our deliberations about involving his family in this process. The issues were also heightened by our commitment to making our research materials available for future re-use, primarily the tensions between upholding our promises to Dan to assure confidentiality through anonymity, and to ensuring the rich, detailed material had analytic value to secondary users after it had been anonymised.

In this discussion, one of our aims has been to disentangle the conflation between anonymity and confidentiality, demonstrating the distinction between the concepts. This is evident in our account of providing Dan’s family with voice samples from his interviews, which involved considerations around confidentiality but not anonymity. But another aim has been to illustrate some of the complex inter-connections between anonymity and confidentiality as concepts and practices in the UK context and concerns about data sharing with third parties. We have shown how anonymisation may be one means of achieving confidentiality, and how a breakdown or lack of anonymity then is likely to lead to the breaking of confidentiality. This was evident through our discussion of the medical data furore in the UK, and also of auto-ethnography in the form of publishing one of our research fieldnotes.

We have also demonstrated that there was and is no single resolution to a confidentiality dilemma, in particular for us in the case of the implications of Dan’s death. Framed by an ethic of care, and drawing on the experiences and expertise of other researchers and practitioners, our course of action in relation to the maintenance or breaking of confidentiality was shaped by what we considered morally caring at the time and our situated knowledge of Dan, his life and family relationships. We cut across the confidentiality that we promised Dan, while retaining his anonymity as part of an archived study. We have also noted that while one ethical dilemma around confidentiality may have been resolved, yet another opened up through the way that we resolved it – in relation to his mother’s participation in our research and archiving endeavour. Thus we hope that we have demonstrated the complex distinctions and inter-weavings of ethical issues of anonymity and confidentiality in various forms of data sharing.

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1. This chapter draws on and substantially reworks material from Edwards, R. and Weller, S. (2013) ‘The death of a participant: moral obligation, consent and care in qualitative longitudinal research’ (pp.125-136), in K. te Riele and R. Brooks (eds) *Negotiating Ethical Challenges in Youth Research*, Abingdon: Routledge. Our thanks to the editors and publisher for their agreement to this reuse. Ros Edwards is also grateful to The Leverhulme Trust for funding a three-month International Academic Fellowship spent at the University of Otago, which stimulated a rethinking of the original published material from a different angle. [↑](#footnote-ref-1)
2. See, for example, the Research Data Policy of the Economic and Social Research Council (ESRC), which funded the research project that we discuss in this chapter. [↑](#footnote-ref-2)
3. See <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf> and <http://www.britsoc.co.uk/media/27107/StatementofEthicalPractice.pdf>. [↑](#footnote-ref-3)
4. This approach may be challenged, for example in the field of Oral History. [↑](#footnote-ref-4)
5. Margaret Thatcher has been the UK’s only woman prime minister so far. [↑](#footnote-ref-5)
6. Equivalent to IRBs. [↑](#footnote-ref-6)
7. At Wave 1 of data collection we had not planned for the study to become longitudinal and funding bodies in the UK had not implemented data sharing requirements at that point. [↑](#footnote-ref-7)