



Timescapes Project One: Ethical Dilemmas Correspondence

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The 'Your Space!' Timescapes project documents the meanings, experiences and flows of young people's prescribed (sibling) and chosen (friendship) relationships. The study builds on three previous projects conducted between 2002 and 2005. Over 50 young people, born between 1989 and 1996, from these three studies were re-interviewed in 2007 and 2009. Our sample is nationally distributed across England, Scotland and Wales.

This paper documents email exchanges about a set of ethical dilemmas that we (the Your Space! project team) felt that we faced because of the death of one of our sample. We emailed the advisory group for our project, and researchers working on other Timescapes projects, to ask for their advice – the text of this initial email is reproduced below. It is followed by the texts of the responses that we received. All are included with the permission of the senders, with all anonymised at the request of some of the respondents. We then provide the text of the email we sent letting our advisory group and Timescapes colleagues know how we decided to handle the ethical issues that we felt we confronted, and finally also provide a postscript about the result.

INITIAL EMAIL SENT FROM PROJECT TEAM 1.12.09

Dear Timescapes colleagues / Timescapes Project 1 advisory group

We would appreciate your advice concerning a sad and difficult issue that has arisen in our 'Siblings and Friends' study.

One of our sample, Dan, was recently killed in a traffic accident. Dan was 18 years old when he died and, as a member of our heritage sample, had been participating in our research since he was 11. We have felt shocked by his death, realising that we both know him and yet do not know him at the same time. We have sent a condolences card to his parents, sister and brothers (with whom he lived).

Dan's death raises some ethical and legal issues concerning the data we have collected from him so far. While Dan verbally agreed to all the data we have from his participation in our research being archived in our previous wave of interviews back in 2007 (a very general assertion which we recorded as part of that interview), we have been providing our participants with more detailed information about archiving and asking them to sign consent to archiving forms in this year's round. Unfortunately Dan died just before he was about to participate in the 2009 wave, and so he has not signed the form. The question here, therefore, is can we go ahead and archive the data anyway on the basis of his verbal consent two years ago?

An alternative is that we ask Dan's parents if they would sign the archiving consent form, as his next of kin. This, however, implies or suggests that they have some sort of ownership of the data. What is the legal situation here? Could Dan's parents demand their own copies of Dan's data, for example? Or they could refuse to give permission to archive the data, despite Dan's implied consent two years previously?

But perhaps there is also a moral dimension to the issue of the data and Dan's parents too. We both have a sense that we hold something material of Dan, while his parents and siblings have lost their son and brother. We have, for example, recordings of his voice. We are wondering whether we should offer to give Dan's parents in particular a sample of his voice identifying a non-sensitive part of the 2007 interview, such as Dan's discussion of his interests. There are several issues that we are thinking about in this respect. We did promise Dan confidentiality and anonymity when we collected the data from him, though of course we and he did not have such a situation in mind. Does that promise over-ride this situation? (Having said that, we never promise complete confidentiality – we say that if something worries or concerns us about what our interviewees say then may need to tell someone, but we will discuss it with them first.) If the confidentiality promise doesn't over-ride giving Dan's parents a sample of his voice, who are we to decide that they should not hear anything we consider sensitive? (The fact that Dan's parents may not want a recording of his voice is beside the point in our considerations at the moment.)

Do you know if anyone else has faced such a situation and how they dealt with it?

We would value your thoughts generally.

Ros and Susie

EMAIL RESPONSES

Sent: Tue 01/12/2009 11:47

Subject: RE: We would appreciate your advice - Timescapes Project 1

We have recently been facing a similar problem. One of our participants had a potentially life threatening illness throughout the study and died earlier in the year at 24. We discovered this recently when his brother answered a Facebook message on his behalf.

We have sent the family condolences via messages to him (do not have phone number for the family and had to gently request an address) and also sent them copies of the film we had taken as a memoriam. We gave them feedback in the accompanying letter on the impact his films have made on students, particularly their admiration for his positive outlook on life. The family have given us very positive feedback, again via the brother, on the value of our tributes.

We have also sent an adapted consent form and info sheet to the brother, as he said they would consider giving consent. We are unclear as to the legality of this and obviously need to discuss more at our team meeting on Thursday. Morally we feel that they share with us a positive feeling in this tragic situation that this young person lives on through the study.

The question of whether to give them a copy of his interviews has also occurred but not been discussed yet. Seems like an important discussion to be had between us all.

Sent: Tue 01/12/2009 13:17

Subject: RE: We would appreciate your advice - Timescapes Project 1

I am very sorry to hear about this, I imagine it's upsetting for you both. I've never had an experience like this so cannot advise on either a formal ethical or legal basis.

My instinct though is that you ought to contact Dan's next of kin given the reasons you mention (that you hold something material of his) and that he was only 16 when he consented. It may be that you need to remind them (I'm assuming they know he was taking part) that you have the data and offer a chance for them to consent to archive, or request that Dan's data is withdrawn and destroyed. This need not mean handing it to them but you will have a second chance to consider this point if they request it (rather than you offering it). It may be worth mentioning in this contact the confidentiality that was promised to Dan - they may well wish to respect that too.

If they do request Dan's data, that's the bit I find very difficult to make a judgement on, so I won't attempt it.

You don't mention timing - obviously they will need time to deal with the immediate horrors of this tragic event though I wouldn't leave it too long if you do decide to write to them, given they may know you have this data.

Again, I just offer these thoughts in helpful spirit and expect you may be guided by more expert others.

Sent: Tue 01/12/2009 16:26

Subject: Re: We would appreciate your advice - Timescapes Project 1

This is very sad and I think you raise some really important issues about the special value some of our data can come to have. The issues you face seem to underline how important and potentially difficult it can be to treat our data with due care and attention; also how it brings into the frame the various people who become connected in some way to our studies - even if they are not main participants.

I am sending you my first response; no doubt more thought and discussion would be beneficial. But I have in my mind how strange it would seem in these circumstances for the archive to potentially be in a position to preserve Dan's words - & especially his voice - while his parents might not have access to it. I think considering offering his parents a sample of his voice would be to consider their feelings in the circumstances, rather than necessarily infringing Dan's privacy.

I think it could become much more difficult to decide what to do if the sample of his voice made his parents want to have what one might consider, as researchers, private and sensitive data. One way of proceeding might be to try to find out if/how/how far his parents would wish to become involved in deciding what the best way of proceeding with the archiving might be (without assuming at the outset that they will necessarily want to be highly involved, or when/whether it will become clear in their own minds).

I'm not sure that the main thing is to get the parents to sign the form on Dan's behalf - they might welcome this as a sign that they were his parents or they might they see it as mercenary researchers wanting the data. But I agree with you that you may not be able to work out what to do for best without taking some small steps to talk to his parents and find out how they see things.

I hope these immediate reactions are of some value.

I should mention how to deal with traumatic events is something we have been dealing with with two of our heritage participants. We raised it a few weeks ago at our advisory panel, and it has demanded quite a lot of thinking through.

Good luck with it all.

Sent: Tue 01/12/2009 19:06

Subject: Re: We would appreciate your advice - Timescapes Project 1

How very sad for everyone, his family of course but you two as you say, who both knew and yet did not know him.

We can't give you much that's useful in the way of advice or suggestions, but can say something about how deaths affected us and what we've done since.

Three of our participants have died, none as young as Dan of course and again unlike Dan we'd only known them for months rather than years. Two died of cancer, the other of being 101 and all that that entails. Even though they were all over 75 their deaths came as a blow to us, especially the two younger ones who were both in their 80s, since their deaths seemed to us to come suddenly. All of us on the project felt the deaths very strongly. Like you we felt we'd got to know the people in various ways, through interviews, diaries and photographs.

The two younger people I had only interviewed once and had been looking forward to going back to talk to them again. Both had signed consent forms for their first interview. The issues relating to consent and signing off don't apply in our situation, however what you say about ownership and confidentiality did apply. In both cases my feeling was that I needed to replace the follow-up interview, in part to complete the process but also to get a sense of how that person was now remembered, how they survived in the family. I've since discovered that in bereavement counselling the idea of continuity, once controversial, is now accepted. I offered an interview at which we would talk about the deaths, what followed and how these two parents are remembered and recalled in the families. Both family members accepted and I interviewed them this summer. In both cases this was some months after the deaths and we waited a while before asking.

As far as internal confidentiality was concerned, I don't think it occurred to us not to offer the transcripts and the audio file to the children of the people who died. The families were interested in both, though I think they might take time to listen to the audios. Hearing voices is so different to looking at photographs of course. I think the moral dimension was quite different to your situation. This is partly because the original contact with our project was made with the children and not with the parents who were, in a way, offered to us though obviously as willing participants. However, I think there's another difference and that is that in the families we've been in contact with the interview with the older person tends to be seen as a perspective on family history by the interviewee as much as an individual's life story. Thus it felt as if the life story was created as a resource for the whole family. I wonder if this may be as much to do with motives for telling in late life as the way in which people were recruited.

Of course it could be that the children's generation may hear things they've not heard, or hear things articulated in a different way. They may also be disappointed not to hear more than they already knew. The thing is we can't know whether either is likely to be the case so I'd be unwilling to make a decision to withhold access. I think our motive in making the material available was based more in the assumption that the least we could do was to provide the younger generation with ways of knowing and thinking about their parents which we had had access to and they hadn't. I guess if either of the older generation had expressly said that the interview was not to be shared, then we might have thought again, but since they were willing for it to go into an archive which non family members might ultimately have access to, we didn't think it was fair to exclude them.

I'm not sure how sound our thinking has been and I'm also not sure, as I said, how well our experience and actions would be helpful to you. I just offer an account as a response to your query.

Sent: Wed 02/12/2009 01:26

Subject: RE: We would appreciate your advice - Timescapes Project 1

So sorry to hear of this and I appreciate how upsetting it is for you and Susie; a very real moral dilemma that needs careful thought and with no easy answers. I have faced the question of how to represent young peoples' accounts of parental and sibling oppression and protect these accounts from identification by the parents and sibs, who were also part of the research. But i haven't faced anything like this, so what follows may not be particularly helpful in this case.

i know from my own experience of bereavement that when people die who are close to you, you want to know anything and everything about them from other people. Sometimes you glow with pride at what people tell you, e.g .when people write to tell you about acts of kindness or integrity that you were previously unaware of. But sometimes bits of the knowledge you gain are painful - especially if they reveal problematic relationships or anything that might question their moral integrity or undermine their moral reputation - and you may want to discard these bits and tear up the evidence. You want to create a version of them to hang on to and remember that may not entirely accord with the reality of their lives.

You both know a version of Dan that might enable you to gauge whether his parents and sibs would be able to respect and indeed value his involvement in the project and his agreement to be represented in the archive (for it seems he has given consent). If that were the case, the way forward would be much clearer. But you might need to work this out, perhaps obliquely, in conversation with his family members so that a solution gradually emerges. For example, the parents may really want to be able to talk about him and have their version of Dan represented in the archive too. The only thing that seems clear is that you two are in the best position to decide on how or in what ways or whether to represent Dan, both within the archive and to his parents.

I hope others have more concrete advice or suggestions.

Sent: Wed 02/12/2009 13:30

Subject: Fw: We would appreciate your advice - Timescapes Project 1

I think there are some really challenging ethical and moral issues to be addressed. In my opinion, I think having gained Dan's verbal consent for you to use the data is sufficient under the circumstances to archive his data and to use to write reports etc. My undertaking is that gaining written consent was in addition to verbal consent and (if I remember correctly) sought permission to archive the information. If Dan had a problem with you using this information I think he would not have verbally agreed to participate in the study in the first place. Given that these are exceptional circumstances I do not think it would be unethical to retain his information without a signed consent form.

I do however think the issue of sharing voice recording with his parents is a more pressing and delicate matter especially as this raises lots of moral and ethical issues. I think that if you did approach his parents you would need to agree beforehand what information you feel as researchers it is ethical to share. I feel that it is not their decision to refuse whether Dan's data can be archived as this was an agreement which you entered into with Dan - not his parents. Therefore, I would not get them to sign the archive consent form as I agree with you that this could give them some form of ownership over the data which is not there's to own.

Giving his parents a non-sensitive extract of the 2007 recording I think seems reasonable and fair. Given the circumstances I think (if his parents want a recording) that the right to anonymity and confidentiality can be overridden in this respect in so far as the researcher will be still be able to choose which extracts can be shared with his parents. However, I think choosing these extracts and the reasons for taking this approach need to be discussed delicately and sensitively with his parents (if, in fact, they want a recording of his voice).

When you have this conversation will also be critical as it may be best not to approval this subject in the immediate aftermath of the accident. I have never had to deal with such a situation but I would imagine that being sensitive to their needs and having your own parameters about what information you think it may be appropriate to share would helped both parties reach a compromise

The more I think about these issues the more I think they raise critical ethical dilemmas which are often overlooked in the research community. Perhaps you could send out your request for advice to the children's participation network as this is a fascinating dilemma and other may have more knowledge about the legal position in regards to the issues you raise.

I hope this helps.

Sent: Wed 02/12/2009 18:43

Subject: RE: We would appreciate your advice - Timescapes Project 1

This is an awful situation. As I understand it there are indeed clear legal issues – I spoke briefly (and vaguely) to a colleague who works on copyright, privacy, intellectual copyright etc.

I didn't mention the verbal consent though – is that recorded and if so could it constitute formal consent? This would need to be checked with a lawyer. Depending on that it would then answer the question about the archive.

His parents may not automatically 'inherit' the right to know what he had decided was confidential. I don't think the next of kin would automatically 'own' data – in the same way that although you 'own' the recordings it doesn't give you the right to reveal content. There are precedents in relation to medical information e.g. where next of kin may not have rights to knowledge despite wanting them

And I think that his agreement to anonymity and confidentiality still stands, he hasn't revoked it – and - honestly, ethically, I am not sure you can speculate on what he may or may not have wanted and how that may or may not have changed over time or with circumstances.

It's a really really sad case with no good outcome but this is my view for what its worth.

Sent: Sun 06/12/2009 21:44

Subject: RE: We would appreciate your advice - Timescapes Project 1

what a tragic situation - hopefully no one has had to face a similar one

in terms of the purely legal situation I am sorry I am not qualified to comment - perhaps you could get in touch with the Children's Legal Centre who may be able to advise, and/or the Children's Commissioner.

One of the first questions I have been considering since your email is: what is 'confidentiality' about, whom or what does and should it protect, and what damage would the selected disclosure have on/for whom.

I think that you have enough evidence to decide to use Dan's material.

I presume that Dan's parents knew about his involvement in the project as you say he has been a participant since he was 11. When the pain of his death has receded somewhat, perhaps you could talk sensitively with his parents and ask whether they would like to have extracts of his recordings; if there are any critical comments about his siblings or parents, you could tell them that you'd rather edit them out as he believed he was guaranteed

confidentiality? Depending on their situation, they may have lots of videos etc and may not want/need this but if not, it may be a very sad but permanent reminder of their son.

But let's see what the strictly legal situation is. It may be of broader interest and include multi-media recordings children and young people produce and file-share without their parents necessarily knowing about it.

Please do keep us updated with developments.

Sent: Tue 01/12/2009 11:42

Subject: Re: We would appreciate your advice - Timescapes Project1

My first thoughts are about how very sensitive your consideration of these extremely complex and sad issues already is. I can't really think of how to respond to your questions right now - that will take me a bit of time. But what I thought would be helpful is if I talked to people here in Psychology who've done research with people who have subsequently died. There's quite a lot of health research going on here, but in particular the researchers in one of our Centres could cast some light on your ethical and moral situation.

I'll get back to you in due course.

Sent: Mon 07/12/2009 11:34

Subject: RE: We would appreciate your advice - Timescapes Project 1

I've had some more thoughts about your situation. I've also spoken to someone from the Centre here and some interesting points were raised which might be helpful.

One set of questions arises in relation to the use of data from participants who leave a study for one reason or another. 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, you probably wouldn't be considering whether to offer his parents samples of the data or not. He could have withdrawn because of other, painful and difficult reasons, and not be in contact with his family or the research team. This could be just as upsetting for the family and yet his confidentiality would be maintained.

It's usual for people to consent to the use of their interview and other material up until the point at which they withdraw from a study. Most often, this means that the data collected up until that point can be included in the analysis and published, unless the participant explicitly asks that their data be withdrawn from the study. I think this stands in Dan's case.

In relation to consent: I would have thought that verbal consent from Dan is enough to give you ownership of the data and permission for it to be archived. But I was also wondering, did you seek consent from his parents for Dan to take part?

The family are likely to have lots of objects, including images and recordings, that will remind them of Dan. 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 later on, but again, would you want to do this for parents whose son had left home and cut off all contact with them 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?

Clearly something like this also has a big impact on a research team and it's very important to critically reflect on the situation and your own responses, thoughts and feelings to it. This will help you maintain the kind of empathy and sensitivity that you are showing, but also help you to think about your own motives for wanting to act in certain ways - and sometimes question them. More academically, it's also important for us to seriously consider

the ethical and moral dimensions of such a situation, which, although tragic and shocking, may be statistically likely to happen in longitudinal studies.

I hope this is useful.

Sent: Tue 15/12/2009 17:27

Subject: RE: We would appreciate your advice - Timescapes Project 1

Sorry for the delay in replying but I've been away on fieldwork. A very difficult issue although if Dan gave previous verbal consent to archiving I'd be inclined to think that is ok even though he did not sign the form. For me, the alternative would be to just not include his data in the archiving and explain that to the archivers. I think either that or take his verbal agreement rather than involve his parents, but I'm just basing this on my instinct rather than any prior experience of such an issue. I do not have very strong views about what is 'right' (and ethical dilemmas rarely have one 'right' answer) so if you have decided to involve the parents, I would not object.

Sorry not to be more helpful as I'm really not sure what's best for you to do in this situation.

Sent: 17 December 2009 13:21

Subject: RE: We would appreciate your advice - Timescapes Project 1

Sorry for a delayed response here, but this is not something to be done without much considered reflection.

First to the particular questions:

1. The question here, therefore, is can we go ahead and archive the data anyway on the basis of his verbal consent two years ago?

Yes, verbal consent is fine. It is made better by you created a written record of what was agreed, even if not verbatim, capturing as best you can what you communicated and what Dan agreed to. So, no need to deal with the family re consent.

2. Making materials available to the family.

I think it is appropriate to do so. If there are some sections you think Dan would NOT want shared, then it seems necessary to exclude those. If the family knows Dan spoke in confidence, they may well wish to respect that (that is, they would not ask for everything). I think offering extracts of non-sensitive content would be welcomed.

3. Could the family demand the data?

If Dan spoke to you with an understanding of confidentiality, and that is certainly the case from what you have said here, then I don't think such a claim would stand up. But I think the offer of non-sensitive content would be best and very likely forestall them even making such a request.

The key issue seems, to me, to be balancing your responsibility to Dan (confidentiality) with the new and unanticipated sense of responsibility to the family due to Dan's death. The form of sharing you have outlined would seem to negotiate that successfully.

Much depends, as always, on context and the nature of family relationships. If you want to discuss further and share more particulars, I will be happy to talk with you more.

EMAIL FROM PROJECT TEAM SENT 22.1.2010

Dear colleagues

We would like to thank those of you who gave us such thoughtful responses to our email about the death of one of the sample for our Timescapes Your Space project: Dan, and also to let everyone we contacted know what we have decided to do.

As you will recall, as well as sadness at Dan's death, we were in a dilemma about two main issues that were moral as much as legal: whether we could archive his data on the basis of his verbal consent two years ago, or whether we should approach Dan's parents to give written consent as his next of kin? and whether we should offer Dan's parents a sample of his recorded voice or whether this broke confidentiality?

We found all the responses to these issues that we received really helpful in thinking about what to do. Reading through them, we came to the conclusion that there was no, one, solution to the ethical dilemmas, and we would do what felt comfortable for us. Other researchers may have settled on other courses of action in the same situation, but we decided to do the following because it feels morally caring to us.

We have followed up our condolences card by writing to Dan's parents after Christmas and New Year was over, on the assumption that this period would be particularly difficult for them. We offered them and/or Dan's siblings the opportunity to archive any memories of Dan alongside his research data if they wanted to (this offer was in effect informing them that the material was being archived). We also offered them a sample of Dan's voice. We left it that if they did not contact us we would understand that they would prefer not to be involved in these ways.

Finally, it has been suggested that it might be a good idea to deposit our email request and the responses we received in the Timescapes archive, so that they are accessible to secondary analysts. If you send us a reply, we would like your opinion about this and to know whether or not you would be prepared to have your email stored in this way (identified or anonymised).

Thanks once again for your support, which we both really value.

Ros and Susie

POSTSCRIPT

Dan's parents responded to say that they would like a DVD of extracts from his interview, and also to have their memories of Dan recorded for the archive.

In a visit to Dan's mother in May 2010, Susie gave his mother a DVD recording of her explaining the research to Dan (for context) and then some extracts from his last interview where he discussed his likes and his career aims. Susie then recorded a discussion with Dan's mother in which she spoke about Dan. The recollections have been transcribed, anonymised and archived with Dan's own interviews.