Recruiting and Retaining Participants in a Longitudinal Qualitative Study
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Case Title

Recruiting and Retaining Participants in a Longitudinal Qualitative Study

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Published Articles

More information and technical reports from the Longitudinal Transitions Study can be found at the project website:

http://www.birmingham.ac.uk/schools/education/research/victar/research/transitions-study.aspx

Hewett, R., Douglas, G., Keil, S. (2014) Post-16 transition experience of visually impaired young people in England and Wales: Early findings from a longitudinal study. *British Journal of Visual Impairment, Vol. 32* (3), pp. 211-222.

Douglas, G., Hewett, R. (2014) Views of independence and readiness for employment amongst young people with visual impairments in the UK. *The Australian Journal of Rehabilitation Counselling. Vol. 20* (2). pp 81 - 99.Inclusive Design

Hewett, R., and Douglas, G. (2015) Inclusive Design: It's impact on young people with vision impairment. *Journal on Technology& Persons with Disabilities. Vol 3. pp 277-290.*

Abstract

Since 2010 I have acted as the full-time researcher on a longitudinal qualitative study which has been following the transition experiences of over 80 young people in the UK who have a visual impairment. When I first started working with these participants they were aged 14-16, and I have now been working with them for 6 years. There are over 60 of the participants

who have remained active in the research study and contribute to two interviews per year. This is despite the changing environments they have experienced such as moving to university or starting their first job. The aim of the research has been to assess how prepared these young people were for employment and adulthood having left compulsory education by tracking their experiences through various pathways such as Further Education, Higher Education, apprenticeships and the labour market.

This case study explores firstly what exactly longitudinal qualitative studies are, including their strengths and weaknesses and their value in researching transition. It then discusses some of the techniques which are recommended by researchers for retaining and engaging participants in longitudinal studies, before examining the practical approaches which I took in order to retain these participants.

Learning Outcomes

By the end of this case students should be able to:

- Have a better understanding of what longitudinal qualitative studies are

- Understand the strengths and weaknesses of longitudinal qualitative studies

- Evaluate whether the use of a longitudinal qualitative study is an appropriate research design for their research problem

- Develop a strategy for retaining and engagement participants in a longitudinal qualitative study

Case Study

Project Overview and Context

The Longitudinal Transitions Study started in 2010 and has been following the experiences of over 80 young people with visual impairment in the UK since they have left compulsory education by tracking the various transitions that they have made (e.g. into further and higher education, apprenticeships and employment). The research came about as a result of concerns relating to the outcomes of young people with visual impairment in the labour market. Whilst research evidence shows that young people with visual impairment do well in compulsory education (Hewett et al, 2014), the proportion who successfully make the transition into employment is relatively low (Douglas et al, 2006; 2009; Clements and Douglas, 2011; Hewett, 2014). The aim of the research has been to ascertain what happens to these young people once they leave compulsory education and to establish how well prepared they are for the transitions they make and the environments they are in. This is particularly important in the context of young people with visual impairment as during their time in compulsory education they receive support from specialist teachers. This support may include teaching them how to get around independently, how to access information independently, how to use

specialist technology, and how to live independently (this all comes under the umbrella term of the 'additional curriculum'). These specialist teachers also provide guidance to schools on how to make the learning environment as inclusive as possible, and work alongside families in aiding their child's development. It is obviously important therefore that the support that these young people receive is evidence based so that they are receiving the best preparation possible for adult life.

The Longitudinal Transitions Study is now in its third phase. Phase one was funded by the UK charity Royal National Institute of Blind People, phrase two by the Nuffield Foundation and phase three is being funded by Thomas Pocklington Trust.

Research Design

The Transitions Study was always conceptualized to be a longitudinal study. Research literature identifies a longitudinal approach as particularly beneficial when looking to understand transition experiences. For example, Holland et al (2006) highlight several longitudinal studies which have investigated transition.

Our initial intention was to conduct a quantitative based study, collecting data from a large number of participants using repeated questionnaires. However, as visual impairment is low incidence among young people and we focused on a specific area of England and Wales we did not recruit sufficient participants for a quantitative study (our final sample was 88 young people). Instead we decided to adopt a qualitative approach.

Farrall (2006) defines longitudinal qualitative research as embodying "a range of mainly in-depth interview-based studies which involve returning to interviewees to measure and explore changes which occur over time and the processes associated with these changes". This has meant speaking with the participants regularly enough to be able to capture the changes which they have been going through. We started working with the young people when they were aged 14-16, a time in their lives when change happens rapidly as they move into further education and then make decisions about whether to go to university, whether to do additional training or to go straight into the labour market. Consequently we decided to speak with the young people twice a year – once in the summer (June-August) to find out how the previous year had gone for them and what their plans were next, and once in the autumn/winter (October-January) to find out what transitions they had made and how these had gone.

In hindsight it proved very beneficial to be able to take a qualitative approach to the research, and thereby collect a richer set of data. The experiences of the young people have been vast due to their range of academic achievements, chosen pathways and also the spectrum of levels of visual impairment. Henwood and Lang (2003: 49) when reflecting on longitudinal studies observed that they "are highly sensitive to contextual issues, and can illuminate important micro-social processes, such as the ways in which people subjectively negotiate the changes that occur in their lives at times of personal life transition". This is illustrated well in a study by Brooks (2003) who investigated how friendships in school and college could influence young people when deciding which higher education courses to apply for. She

identified how previous quantitative studies found that young people spoke with friends with regards to the HE courses that they were going to apply for, and thus concluded that conversations with peers formed an important part of the decision making process. In contrast Brooks found with her longitudinal qualitative study that whilst the young people did have some conversations about HE, these were often limited, and for various reasons there was often some reluctance for the young people to have these discussions. When evaluating the difference between her studies findings and the findings of previous quantitative studies, she concludes that 'it would be difficult for a quantitative study to provide this level of detail'. This has certainly been something which I have observed. For example one large quantitative study which investigated satisfaction levels of students in higher education found that students with visual impairment rated their experiences very highly (Purcell et al, 2009).This appeared to contradict findings of our qualitative study which has found that students with visual impairment face a great range of challenges in this setting, with several participants having to repeat years or even leave their courses altogether. Having spoken in depth with over 30 young people who made the transition into higher education this apparent anomaly can be partly explained by the fact that these young people whilst experiencing challenging times also appreciated how complex the support they received can be, and were often, where appropriate, extremely grateful for the effort put in by their respective institutions.

Strengths and Weaknesses of Longitudinal Qualitative Studies

Researchers have identified various strengths and weaknesses of longitudinal qualitative studies. One of the main strengths is that these studies are prospective rather than retrospective, which reduces the barriers of participants not recalling events accurately. The design also allows participants to reflect on their experiences and therefore the accounts of the participants are not limited to a contextualised snapshot (Farrall, 2006). For example, in our recent interviews I have been asking the participants to reflect back on the support they received whilst in education and it has been interesting to hear how their views have changed over time. Longitudinal studies can also offer a more in-depth picture to help understand how and why things happen as they do (Molloy and Ritchie, 2000; Thomson, Henderson and Holland, 2003) and more time is available for ideas to 'come about', develop and emerge. (Hermanowicz, 2013). The studies also generate a lot of data - although the Longitudinal Transitions Study has been working with less than 100 participants due to the repeated data collections I have conducted over 800 interviews.

It is possible to analyse data both cross-sectionally and longitudinally allowing for innovative methods of data analysis and the ability to make comparison across a range of factors (Yates, 2003; Holland et al, 2006, Thomson et al, 2003). It is also a flexible approach which allows for changes to be made to the questions being investigated as the study progresses (Holland et al, 2006). Many of the questions we have asked have been in response to changing policies, such as the young people's experiences of changing from Disability Living Allowance to Personal Independence Payments and their knowledge of changing government policies such as the introduction of Educational Health and Care Plans.

Finally and importantly, by working with the same participants over a period of time the researcher can establish a trusting relationship with the participants, leading to more thorough and honest accounts of their experiences (Holland et al, 2006). I have certainly found this to be the case as the young people have felt more confident in sharing with me the challenges and frustrations that they have faced, and often shared things with me unprompted.

There are however some weaknesses of longitudinal qualitative studies which should be taken into account if you are considering using this approach. Firstly the studies are resource intensive, and due to their length there can be challenges in securing ongoing funding (Farrall, 2006; Holland et al, 2006). We have found this to be the case and did have a short gap in funding of five months, but have been fortunate enough to find funders who have shared our vision for the research and therefore have been able to keep the project running. Change can take time to emerge which means that some studies will need to be conducted over a long period of time. If you are considering a longitudinal design for your study, it is important to consider whether you have sufficient time to observe the change you are interested in within the timescales permitted (Farrall, 2006; Holland et al, 2004; Thomson et al, 2003). When considering my doctoral research for example, it would not have been possible to conduct a study of this kind if I were enrolled as a full-time PhD student. However as I have been writing my thesis part-time alongside full-time employment, this has given far more flexibility. This has proved particularly beneficial as when we first designed the study the objective was to follow the young people through to the point when they would enter the labour market. However in many cases this has taken longer than we initially anticipated. Several of the participants took longer to complete sixth form/college than the average student, others have taken gap years or go on to take Masters courses. This has meant that we have had to remain flexible in our study design, and we have been fortunate in being able to maintain the necessary resources to extend the research.

As already noted, these types of studies generate a lot of data as data is collected over multiple waves. This can prove overwhelming and complex to analyse (Yates, 2003, Thomson et al, 2003). To date most of our analysis has been cross-sectional as we have observed the participants experiences at a set time-point. Longer term we will make greater use of the longitudinal nature of the data. Due to the length of the studies there is also a challenge in maintaining the commitment of participants (Thomson et al, 2003). Sullivan et al (1996) identify this as one of the most daunting challenges of conducting a longitudinal study and this is something which I will discuss further in the next section. One suggested way in which to maintain the commitment of participants is by maintaining the same research team (as we have done) and developing a relationship with those participants. However as Farrall (2006) notes, by having the same research team this can lead to a loss of objectivity, and also there is potential of researcher effect (where the researcher influences participant outcomes) in working with the participants over a long period of time (Yates and McLeod, 1996; Thomson et al, 2003). We have sought to overcome this challenge by having a large steering group who give us advice on the direction of the study.

Recruitment and retention of participants

Central to the success of a longitudinal qualitative study is the retention and engagement of the participants. High levels of attrition can lead to bias in the study's findings (Sullivan et al, 1996), particularly as qualitative studies tend to be based around smaller sample sizes (Hermanowicz, 2013). Hermanowicz also argues that whilst longitudinal qualitative studies can elicit more detailed accounts of the participant's experiences as the participant-researcher relationship has a chance to develop over time (I have definitely found this to be the case); such benefits are obviously lost in the event of participant leaving the study. Maintaining contact with participants is identified as one of 'most intimidating and difficult obstacles' in conducting a longitudinal qualitative study by Sullivan et al (1996) who suggests that there is a gap in literature in which researchers share the strategies that they have used successfully or otherwise in retaining research participants. Taylor (2009) in working with young people identified that it is inevitable that there will be challenges in retaining youths in longitudinal studies due to the changes that are happening in their lives. Below I present some strategies which were suggested by Taylor and other researchers who have conducted longitudinal qualitative studies, and in the following section I explain how I took responsibility for retaining and engaging the participants in the study.

Firstly, it has been found to be important to establish multiple ways of communicating with the participant at the time of recruitment, for example multiple phone numbers, email addresses and the contact details of close family members. It is also suggested that participants should be contacted regularly to remind them of the research and to keep an up to date record of where they are. This has the additional benefit of providing an opportunity to establish the best time at which to contact the participant (Taylor, 2009; Sullivan et al, 1996). As well as communicating with participants prior to new periods of data collection it has been found to be helpful to maintain regular contact and keep participants updated on the research through other forms of communication such as Christmas cards, newsletters and a project website ((Sullivan et al, 1996; Thomson et al, 2003). In the event of a participant being difficult to reach, Sullivan et al (1996) emphasised that it is important to make multiple attempts to re-establish communication with that participant and found in their study that it sometimes required multiple attempts. Thomson and Holland (2003) expressed how important it is to value each individual's contribution to the research and to use 'every conceivable strategy' to reconnect with that individual, but recognised that this requires commitment from the research team. They also suggested that whilst participants may have declined to participate in one wave of data collection, it was also important to give that participant the opportunity to re-join the longitudinal study at a later date. A further important approach is to compensate for the participants time, for example by giving them a voucher (Taylor, 2009; Sullivan et al, 1996), although Hermanowicz (2013) stresses the importance of the participant knowing that accepting compensation of this form does not affect their ability to withdraw from the study at any time. Finally Sullivan et al (1996) recommends that the procedures used for retaining participants are written down in a Retention Plan which is evaluated over the course of the study, and that the necessary resources are given to fulfil the content of this plan.

In addition to these practical steps to maintain contact with participants, researchers have identified a number of ways in which the underlying philosophy used in the study can help engage the participants, and ensure they remain committed to the research. Firstly it is important to establish the trust of the participant, and maintain their confidence (Taylor, 2009; Sullivan et al, 1996). An important starting place for this is the researcher being clear with the participant with regards to what they are committing to, and to begin building a rapport with them. Examples of ways in which to do this include by taking an interest in them as an individual (Hermanowicz, 2013) and by maintaining the same research team so that the participant and researcher have the opportunity to get to know one another (Thomson and Holland, 2003; Holland et al, 2006). As identified by Denzin (2001), it is important to always recognise the contribution of the individual and not take their participation for granted. In qualitative social research it is common for participants to share stories of difficult experiences which they have faced which can make them vulnerable. Taylor (2009) reminds researchers that it is important to treat such stories with sensitivity. Taylor also found that participants in longitudinal research will engage more if the interview schedules are less structured giving them more opportunity to share what is important to them, whilst Holland et al (2006) suggest it is beneficial to use personalised interview schedules which build upon previous conversations. Finally, Thomas and Holland (2003) found that it was helpful to allow the participant to talk about the impact that the research had had upon them.

"Method" in Action: Retaining participants in the Longitudinal Transitions Study

The participants in the Longitudinal Transitions Study were identified through Local Authority Sensory Support services and specialist schools in the England Midlands and Wales. These services and schools provided anonymised details of the young people in schools years 9 and 11 that they were supporting for their visual impairment. A number of steps were taken to try to engage with as many potential participants as possible. Firstly, the recruitment packs were prepared in the participants preferred format, including Braille copies. Participants who used Braille or large print above font size pt20 were also supplied with a CD-Rom which contained electronic and audio versions of the recruitment pack. In a small number of cases the Local Authority services identified that the participant's parents/guardians would require a recruitment pack in a different language, and therefore we arranged for these materials to be translated. The recruitment packs were designed to help the participants understand the purpose of the research and the way in which we were hoping they would be able to contribute to the study – i.e. that we were intending to conduct a longitudinal study which would investigate their transition experience from school through to employment, that we were recruiting them into the study for five years at the first instance, but that they would be free to withdraw from the study at any time. We also prepared information packs for the parents and asked for their consent. At the early stages of the research this was helpful as phone conversations demonstrated that parents were also engaged with the study, and encouraging their son/daughter to remain involved in the research.

One additional benefit of recruiting the young people whilst they were still in compulsory education was being able to identify potential participants through local authority services. As visual impairment at a young age is very low incidence, it would have been very difficult

to recruit the numbers we have done once they had left education, and even more challenging to have recruited a representative sample.

At the start of the study, participants were informed that they would be compensated with a £10 gift voucher for completing an introductory questionnaire and for each additional wave of data collection. The purpose for this voucher was to both provide an incentive for them to participate, and also to compensate them for the time they would be investing in the research. The gift vouchers have been sent out along with a project newsletter designed to inform the participants of recent developments in the study, such as news on funding, what we had been doing with the research findings, and what our future plans are. We also have used the newsletter as an opportunity to address matters of discussion which had come about through the previous wave of interviews. For example, we found that some of the participants were unaware of some important changes to a benefit which they were entitled to, and in the newsletter we provided details of a website where they could access further information. The newsletters were personally addressed to the participants, and also made available to them in their preferred format, with the intention of communicating to them that their individual contribution was valued.

Whilst no formal retention plan was written (as was suggested by Sullivan et al 1996), a consistent process was used to re-establish contact with the participants to conduct the next interview. Firstly I used the given telephone numbers (usually a landline number and a parent/guardians mobile number) to try and make contact with the participant. If successful I would then remind them of the study, and ask whether they would be happy to take part in another interview. Quite often the young person would be willing to speak to me at that time, otherwise a mutually convenient time would be arranged. Frequently I spoke with a family member who then advised me of a suitable time to phone the participant. This process could sometimes be a time consuming one, as on occasions the participant would forget the scheduled interview and an alternative time would have be arranged at a later date.

Sometimes it was not possible to contact the participant by their given telephone number as either the number was no longer registered or despite frequent attempts at different times of day no answer was made. I then used a given email addresses to contact them (or their parents) to advise that I had been seeking to make contact and to request an alternative telephone number to make contact. If no response was made to this email (or an email address was not available), a final attempt to contact the participant was made by sending a letter in their preferred format to their given address, along with a form to complete with their updated contact details and a pre-paid envelope to return the completed form.

In summer 2012 the interviews focused on the participant's use of social networking websites and mobile phones. We established that almost all of the participants were using the popular social networking website Facebook to communicate with their friends. Consequently I decided to experiment by setting up a Facebook group for the project to see whether this would be a helpful way of maintaining contact with the participants and keeping them engaged in the study. I set up a project-specific profile on Facebook, and created a private group on Facebook. During the next round of interviews I asked the participants if they

would be interested in joining this group, and whether they would be happy if I sent an electronic invite. I later reminded the participants of the group in a project newsletter, and advised them of how to connect with the group if this was something they would be interested in doing. The Facebook group has since been used as a way of alerting the participants of developments in the project, sharing reports, and linking them to dissemination work that they may have been interested in and generally keeping them engaged in the study and its findings. However, it has also proved an extremely valuable tool for making contact with the participants. For example, prior to each data collection period I have sent each participant a private message reminding them of the study, establishing whether they were still willing to take part, and asking when would be a convenient time to speak with them. This has generally resulted in very prompt replies and enabled us to go back and forth to establish a time suitable for both parties. Additionally some participants have used this as a means for updating me, for example if they had a new phone number or email address, and even on one occasion to explain to me what had happened when their phone had run out of battery in the middle of an interview! Understandably not all participants agreed to connect via Facebook, but this proved an excellent way of supplementing the existing methods of communication.

The way in which I sought to contact the participants also evolved as the young people got older and left compulsory education. For example after sixth form/college many participants moved away to university at which point it became necessary to communicate directly with them, rather than relying on their parents/guardians to help facilitate in setting up an interview time. I therefore asked the participants if they would be willing to share their mobile phone number and university email address, to which all but one participant agreed. By also considering the pathway the participant was currently taking, this helped direct the time and day of the week I sought to make contact with that individual. For example I have prioritised contacting students in FE during their half term breaks and school holidays, students in HE I have contacted during their holiday periods, and participants in employment I have contacted during evenings and weekends. This strategy has helped maximise the number of participants I have been able to speak with at each wave of data collection, and also in using my time more efficiently.

Consideration has also been given to how best to communicate to the participants that we valued their individual contribution, and that we were interested in their unique story. As well as thanking the participant at the end of each interview and reassuring them that what they had shared was interesting and valuable to us, I also started the next interview by summarising what they had been doing at the last time at interview. These individualised interview schedules also, where appropriate, drew upon previous responses. For example in a recent interview I discussed with the participants the way in which they access information. Beforehand I took note of whether they had previously told us they had learned to read Braille, if they used specialist software, and whether they had used low vision aids. Whilst it was more time consuming to prepare individualised schedules it communicated to the participant that we had taken note of what they had shared with us previously and avoided awkward repetition.

I have also found that by starting the interview by recapping to the participant what they had been doing at the time of previous interview and asking for them to provide an update on where they were currently, it has helped to re-establish rapport between us. I also have chosen to use this time to have more casual conversation with the participants to help ease them into the interview and to feel more comfortable before we moved onto more personal (and sometimes difficult) discussions.

By spring 2016 after six years of the study sixteen of the eighty-eight participants who had consented to take part in the study were considered to have withdrawn from the project. Only seven of the sixteen specifically requested to withdraw – five because they were no longer interested in participating and two because they felt they no longer had the time to participate. Two participants did not complete the initial baseline questionnaire – one because they did not provide their contact details when returning the consent form making it impossible to contact them, and one who did not respond to multiple invitations to do so. In seven cases the participants were considered as 'withdrawn' as it was not possible to make contact with them, despite using all the methods described. It is interesting to note that 11 of the 23 participants who are no longer part of the research (after six years of the study) all withdrew in 2012. This coincides with a funding gap in the study when the participants were not surveyed for over a year. During this time the contact details of several of the participants changed and it was not possible to reestablish contact with them, and others lost interest in the study. This emphasizes the importance of ensuring that sufficient resources are in place prior to starting a longitudinal study, in order to be able to observe the changes you are interested in and to retain participants.

Conclusions and Practical Lessons Learned

My time in working on this study has shown to me how beneficial longitudinal qualitative studies can be as a research design. It is an extremely valuable way for researchers to observe change and once trust is established between the researcher and participant over time this can enable the researcher to elicit very rich data from the participant which would not be possible with shorter studies. I would like to conclude by highlighting some of the practical things I have learned during this process:

- It is vital to be realistic about the timeframe required to observe the change you are interested in so that you have sufficient resources and can meet your deadlines

- Investment needs to be given to establishing rapport with the participants, and ensuring they know that their contribution is valued

- Longitudinal studies elicit large amounts of data which can be analysed cross-sectionally and longitudinally. It is important to make sure you have sufficient resource to devote to this

- The way in which you communicate with your participants may evolve over time. This is particularly true when working with young people who move between settings. Adopting a communication method which is the norm to your

participants (e.g. in the case of young people social media) can be extremely helpful in maintaining contact

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