

In symposium: **Schooling, identity and social connectivity: Sustainable futures for young people with chronic health conditions**

Research Design and the *Keeping Connected* Project

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Abstract

The initiative to develop a new approach to researching young people involved with the Education Institute of the Royal Children's Hospital in Melbourne came both from the Director of the Institute and from a number of the researchers who are now involved in the project. Those involved shared an interest in the perspectives of the young people themselves, and an interest in understanding how the different professional agendas and practices that they were subject to affected (or failed to affect or support) those young people. The 'industry partner' and the researchers were agreed on the need for a project that took continued connection to school and community rather than the health issue as its research focus. This paper discusses some issues of design and methodology relating to the project. One set of these are what might be considered pragmatic framing effects from external or contingent sources: how the shape of the project we designed is affected by politics of funding, institutional ethics processes, and strategic agendas of researchers working in different institutional contexts. A second discussion elaborates some of the methodological questions we face and debate in the process of the longitudinal qualitative case-study work: issues related to the appropriateness of different steps or techniques to the intent of the project and the possibility of producing good insights and evidence from it. Here the different research histories, interests and theoretical commitments of the large team of researchers, together with our experience of the first wave of the longitudinal case-study work itself, has produced an ongoing dialogue between us about the specific setting up of interviews and the use and limitations of different kinds of visual technologies and other narrative methods for the purpose of this project.

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The website for the Keeping Connected project is:
<http://www.education.unimelb.edu.au/keepingconnected/index.html>

Research Design and the *Keeping Connected* Project

This paper is intended as an introduction to the symposium **Schooling, Identity and Social Connectivity: sustainable futures for young people with chronic health conditions**. The symposium focuses on an ARC Linkage Project² that began in 2007, and which brought together a team of researchers from education and health settings together with a collaborative partner, the Royal Children's Hospital Education Institute. The aim was to develop a project that would give a more central attention to young people's own perspectives on who they were and what they needed than the kinds of research that framed them primarily through professional discourses of health and education. It also was intended to focus in the project on the maintenance and disruption of their connection to education and social activity and relationships. Issues relating to their illness (the group we were researching have in common that they have experienced hospitalization at the RCH, and had been registered with the Education Institute of the hospital) were to a background to the study, but not its own main focus. In this paper I will discuss a little of the background of the project, and some of the continuing effects of developing a project of this kind through a Linkage grant; and then I want to talk a bit more about some design issues at the heart of the project.

Our aim was to work in this project with visual and narrative methods, and to hear more of the voice and identity of the young people themselves. Giving cameras or video cameras to young people is one way of requesting their story, and their perspectives, and of producing artefacts or evidence that might carry that story powerfully in other contexts. But how that 'voice' is produced; whose voice it represents; and how the product of that research is used and interpreted are all contentious issues for researchers working in this area, and ones that we have continued to grapple with not just in the initial design but as the project has proceeded.

The project

The project discussed in this paper is *Keeping Connected: young people, identity and schooling*, a Linkage Project funded by the Australian Research Council in

² <http://www.education.unimelb.edu.au/keepingconnected/index.html>

partnership with the Education Institute of the Royal Children's Hospital in Melbourne, and originally titled *A Multi-Disciplinary Investigation Of How Trauma And Chronic Illness Impact On Schooling, Identity And Social Connectivity*.

The research team was initially built from a collaboration of seven researchers from the faculty of Education of the University of Melbourne, two researchers from that university's Centre for Adolescent Health (which is a Centre within the faculty of medicine), and professional support and research involvement from the Director and Education Advisors of the Education Institute. (Further details about the project and research team are given in the end acknowledgements of this paper)

The researchers (and the funding partner) who have come together to work on this project broadly share ethical commitments to giving higher priority to the voices and interests of the young people than has been common in previous research related to them; and also have a high degree of goodwill towards each other. The group came together voluntarily and spent a year working on the initial application, and many of the group had been meeting regularly for over a year prior to the year in which the design of the project and the grant application was finally submitted. The Director of the Education Institute was committed to building stronger relationships with the faculty of education, and a number of those now involved in this project had previously done some reciprocal services for each other.

Overview of Project Design

The researchers involved in this project had previously not worked together as a group, and came from different kinds of backgrounds, but all had a commitment in this case to making more central the voice of the young people in this situation, and all had some enthusiasm about the possibilities of visual data as part of this. For about half the team the potential of visual methodologies was a specific ongoing focus of their ongoing research; for the other researchers (including myself) visual methods are one possible means that might be of use for a project of this kind. The team shared interests in identity and subjectivity, and a broad perspective on evidence as constructed and contextual, though our particular positions on this range from humanist qualitative orientations to poststructural ones; and our disciplinary and substantive research backgrounds varied, as did the extent to which visual methods

had been used in our previous work. From this we decided on an approach where each researcher working on the qualitative part of the study would take a limited number of participants and work with them in a two year longitudinal study, where there would be four ‘waves’ of visits in each of which participants would be invited to produce some visual or other accounts and discuss this at some length with the researcher in a subsequent visit. Reflexivity was to be a key part of the project: we would treat the (various disciplinary and other) perspectives we ourselves were bringing to our work and interpretation as ongoing objects of scrutiny and debate.

The components of the study are these:

- Around 30 qualitative longitudinal case-studies with young people where they would be invited to use some visual representations of who they are and what matters to them
- A review of the kinds of data-based evidence already kept on young people from the cohort is drawn, and analysis of the value and limitations of this for the work of the Education Institute
- A survey and follow-up survey a year later of the overall cohort to allow comparisons with other survey work carried out by the Centre for Adolescent Health
- Focus group or individual interviews with education and health personnel about the perspectives they bring to the group we are studying
- Interviews with parents about the perspectives they bring
- Retrospective interviews with a group who had been registered with the Education Institute at an earlier point, and who are now in their twenties
- An ongoing dialogue and reflexive attention to our own team meetings to try to examine the kinds of perspectives and assumptions we bring to this study

The epistemological perspective of the study, as explained in our application, sees qualitative evidence and methods as essential and important in their own right, not merely initial proxies for larger data; but it takes seriously too the issue of recording and testing larger patterns in an ongoing way, and that different types of research evidence are favoured by (and possibly needed by) different groups (eg. psychology and health compared with ethnography and education) and different parts of the system (eg. policy structural decision-making compared with practitioner training).

The more specific intention to invite visual representations using digital cameras and video, builds on an emerging body of work in this area (building on Prosser 1998, Moss 2002, Rich et.al.,1999, 2000, 2002). The aim is to produce young people's own representations of what was important, using narrative and visual technologies.

In the remaining sections of this paper, I will first discuss briefly some contextual 'pragmatics' that frame a project of this kind that is put together as a Linkage project; and then briefly some issues relating to methodological decisions and issues regarding the handling and interpretation of the case studies and visual data.

(1) Researching within institutional parameters: some pragmatic contextual impacts on design:

For all those involved in this project, securing grant funding through the Australian Research Council was desirable. It is one significant source of finance for a study that we believed is worth doing, and as well it is a signifier that has benefits for the different parties involved. Because ARC grants are both highly competitive and highly visible, and because Australian universities are moving towards a greater emphasis on 'measuring' research quality as part of a new research assessment exercise, individual researchers are under pressure to demonstrate achievements in terms of winning such grants. For the RCH Education Institute (which also is required to put in some matching funding), securing a large ARC grant brings further external resources to their research activity and self-scrutiny, and is a sign to external bodies such as their Board and the hospital of the status and quality of the work they are engaged in. So there was an imperative for all of us to work towards securing a grant in this way - but securing a grant in this way is not neutral in terms of the requirement to produce a certain kind of knowledge (or at least, to be able to describe the research and the knowledge it produces in certain ways). It is a context where applicants must attend to contribution to (academic) knowledge as well as to demonstrating benefit (of national significance) (Cheek 2005, Yates 2006).

Because of the use of panel members who come from outside the discipline of the application being assessed, and because applications are scored on 'national benefit'

as well as ‘significance’ (along with track record and methodology), there is an imperative to frame research in terms of its short-term instrumental (especially policy-related) benefits. In our short summary, we conformed to the implicit protocols of the funding program, by using instrumental and non-tentative promises about what this project would ‘deliver’:

School connectedness and retention is an established key to both immediate and long-term health, academic and life outcomes. Young people with chronic illness or accident trauma often miss schooling and get caught in a spiral of catching up and disconnection from important peer relationships and from school. This study investigates the experiences and perspectives of young people whose schooling is disrupted by illness and trauma. It will produce guidelines for better practice by health and schooling professionals and parents of such children, and provide better knowledge about the processes by which disconnection occurs.

(from our grant application, section A5.2 of the required form, where we are required to provide a ‘*Statement of National/Community Benefit (For Publicity Purposes)*’ and whose instruction reads as follows: “In no more than 750 characters (approx 100 words) of plain language, summarise the national/community benefits that are expected to arise from the research.”)

This instrumental framing of the research is not at odds with the ultimate or overall interests of the researchers involved in it, and is particularly useful for the ‘industry partner’ who must sell their own funding commitment to the board. However it does contribute to one of our ongoing tensions in the project: the distinction between seeing this as *a study which will show more about who the young people are* and have *implications* for the professional fields; and seeing this as a study in a professional context where we are expected to be producing *action implications* for the field even at a mid-point of the project (for example in a mid-year conference with a professional audience this year).

The concern about *identifiable uses* of the research as an important issue in selection of which grants would be funded did intrude in our discussions as we met monthly to

work up our research design. In particular, the project started out with a more open-ended intent to know more about and hear directly from the young people involved. Focusing on what would be changed as a result of the research (new protocols, or guidelines) kept drawing us back instead to the interests and needs of the professionals and others who are involved in this area. Going into a project with a strong framing of what you want to do with the knowledge that results can influence the questions that are asked and the steps that are taken.

A second way in which the issue of ‘what textual representations are needed to speak to grant bodies’ intrudes is on the epistemological and methodological foundations of what we are doing. There is an imperative here to speak of our research in terms of ‘evidence’ and ‘findings’ rather than as ‘ways of seeing’. In the grant application we argued for (made an explicit case about) the value of the interpretive methods, but we argued for it in terms that implicitly accepts that terms like ‘findings’ and ‘evidence’ speak quickly to readers who are outside these traditions. Similarly, we are aware of the value of justifying our approach with references whose status seems readily apparent (Rich’s study located in the Harvard Medical School, for example). These strategies work to legitimize a research project whose approach may be questioned as too small scale or questionable as ‘evidence’, but they simultaneously do so through reinforcing past ways of thinking about the more conservative existing standards and methodology by which we research is deemed as legitimate or important. To some extent this approach is inevitable, and in the project we attempt to maintain a self-consciousness about the pragmatics of what we are doing so these pragmatics do not simply continue as the framework by default.

We already have had to confront some problems related to the language we used in our initial application. The title for the project in that application was *A Multi-Disciplinary Investigation Of How Trauma And Chronic Illness Impact On Schooling, Identity And Social Connectivity*. That wording made the project recognizable as one that would ‘get at’ findings or causes (‘impact on’) rather than one that sounded like an exploratory investigation of ‘young people’s voices’. But when we represent our project to the young people themselves (or to researchers and the public more generally, via the website we will set up), we want the intended emphasis of our project to be clearer: it is about identity, schooling, connectivity. ‘Trauma and

chronic illness' is the short-hand for the group we are studying (the grounds on which they have come to be involved with the Education Institute, the grounds on which they pre-constitute a particular 'group') rather than the intended central concern of our study. We explicitly did not want this to be yet another study within a medical model of understanding more about illness and trauma, but wanted to be open about what mattered to these young people, and in our own focus to be more concerned with the non-health relationships and institutions involved. The point is that the naming, even in this short-hand way, feeds meanings that grant bodies, potential participants and others give to research and whether they will readily be involved with it.

A further problem we had here was the use of the word 'trauma'. This was used because at an early stage the Transport Accident Commission was also going to be a partner in the research and 'trauma' was the accepted professional term used for those whose accidents resulted in longer-term medical needs of the kind that they might be part of our study (it does not imply mental trauma in that context). We used the term 'trauma and chronic illness' because of that potential association and because titles of grant applications need to be succinct but descriptive, and we could not think of an alternative brief way of saying who our study would be dealing with ('those who experience some kind of health or accident issue sufficient to have them spend enough time at the Royal Children's Hospital to require support from the Education Institute'). Unfortunately, in most other contexts, when people read that initial title, 'trauma' is not only incorrectly understood as emotional trauma, but it is the term that seems to be most noticed in the title. When we advertised a PhD scholarship, for example, even though we emphasized that we were looking for someone with a sociology, anthropology or education background, we got far more enquiries from psychology and health students.

Ethics Approval:

In the past decade, the issue of ethics has become more fraught, both within the research literature, and in terms of university processes and regulations. In the literature there has been a heightened concern about the ways in which powerless or subordinate groups (including young people, indigenous groups, those living in poor circumstances, or who are illiterate) might be appropriately involved, and have some control over what is done and said about them, rather than simply used as research

subjects. (Bogdan & Biklen 2007; Halse & Honey 2005; Bibby 1997) In universities and hospitals, there has been a growing use of detailed regulation via university committees or review boards to require approval of very detailed descriptions of the research, justification of what will be done, informed consent protocols before research can proceed. In some cases, as with this project, the regulatory form of ethics approval can not only direct the methodological and interpretive work of a project along particular lines, but can work against some important threads of ethics as understood by the research literature, and this is already an issue that is affecting the project discussed in this paper.

In the case of this project, because it would be drawing on young people who are patients at the hospital, the project requires ethics clearance from the hospital ethics board as well as the university, and we have been faced with the problem of being expected to set out *in detail prior to any contact with participants* what we would say to them, what questions would be asked of them, etc.

The formal institutional role of ethics committees and processes is to ensure good research practice and build attention to potential ethical issues prior to the research being carried out. The legal function of institutional ethics boards is to make sure that correct processes have been followed, and required consents obtained, so that the institution is protected from legal action by disaffected participants or harm that results from research that has been inadequately considered such issues as conflicts of interest, emotional distress, unintended effects. But this legalistic mind-set has developed expectations about the textual requirements of 'informed consent' that requires pages of detail about the project, institutional contacts if complaints are to be made etc. The language and length of this has no regard to either the language competency of different ages (or social classes – it does require translators for those of non-English language background): nor of what representation of the research would be meaningful to those being asked whether they wish to participate in it. The protocols are part of the research tradition which the project is seeking to change, where the overwhelming emphasis has been on the parents or adult professionals as the proxy voice of the child. The tradition of considering what is 'ethical' here is heavily weighted to dis-allowing what might be harmful (or worse, dis-allowing research that does not fit a particular template regarding what is not harmful). It does

not consider an alternative conception, that ‘ethical’ research might need to have proactive regard to making sure those whose interests are involved (in this case the young people whose schooling has been disrupted) were fully represented and given an opportunity to be a voice in this project.

(2) Visual and narrative methods: some methodological points at issue

Visual methods are not always being used in the same ways or for the same purpose (Moss 2008; Thomson & Gunter, 2007; Piper and Frankham 2007; Chalfen 2007). Sometimes (for example, Clarke et.al.2006), their intention is about capturing reality – that is, to actually get a different kind of objective evidence than a survey, so that we can stand back and analyse what is there in a way that we might not have noticed when we were actually there. Sometimes (for example, in Moss 2008) it is about a way that people are able to tell their own story in a form that they choose – they are given time and make choices about how to represent something that gives new insight about it. Sometimes the use of visual data is very explicitly for the purpose of producing a certain kind of action with a certain audience or setting. Sometimes the visual is a tool used within an action research frame, so that participants themselves revisit and use those initial photographs to consider next steps.

When we embarked on this project, a number of us had previously used qualitative, narrative and visual approaches in different ways; and we also were building on some other related research both at the Boston Children’s Hospital (Rich and Chalfen 1991; Rich et al 2000), in the Faculty of Education (for example, Clarke et al 2006 is doing using detailed video research on classrooms) and in the Centre for Adolescent Health (eg Sawyer et.al. 2007) which potentially might be models for our choices about hardware and software as well as protocols. Exploring these other approaches made it clear that the purposes of this project and epistemological assumptions of the team required a different approach to those we were reviewing elsewhere. In particular we were more interested in visual as a means of accessing who these young people were, and what mattered to them, than how they spend their day. Our focus was not simply on what happens at a particular point in time. And we knew that what was produced would require interpretation, not simply factual coding.

So our central approach was to treat each involvement as a case-study that would be interpreted initially by the researcher involved in that case-study. Any ‘objective’

cross-coding was to be a minor and subsidiary element of the project. In the first round of encounters with the young person for example, we gave each of them a digital camera, and invited them to take whatever photographs they liked to show who they were and what mattered to them. Following that, a discussion between researchers not only about the photographs that their collaboration has produced, but about the meanings they are making of those, is intended to elicit assumptions we bring to the research, and to challenge and expand these (cf Yates 2003).

But this initial agreement about our approach by no means disposes of the kinds of issues we have to go on considering as the project continues. For example, a central feature of the approach was that we wanted this to be the young person's own account of what mattered. But there isn't only one such account, and there is no neutral or context-free account. In the first stage we spent a lot of time discussing how we would approach the first meeting with each person and what kind of instruction or suggestion or invitation we would give in terms of using the camera. We were trying to balance here our understanding that some kind of relationship between researcher and participant needed to be built for the study to engage the participant over the two years, and our wish to be as non-leading as possible about the kinds of photographs they took. But a very open approach can become boring for the participant if it continues into the second round, as well as, for our purposes, can have the danger of simply repeating what already took place in the first wave. So the issue of the relationship, the meaning and the co-construction continues to be an issue of scrutiny as we continue.

A second issue here was an initial intention to emphasize to the young person that we wanted *their* perspective, not that of their parents or others. We had intended to keep their parents out of the picture as much as possible (after initial meetings and agreement with the parents for the research to proceed). We have found that in very many of the situations here, that has not been possible nor apparently desired by the young person themselves. They do not speak less freely in the presence of their mother, though potentially they may speak about different things. The point again is that there is no neutral 'elicitation' of a story: what we see are accounts that we can return to and challenge and deepen.

Acknowledgement and note about the Project:

The project being discussed is *Keeping Connected: young people identity and schooling*. It is a Linkage Project funded by the Australian Research Council in conjunction with the Education Institute of the Royal Children's Hospital, Melbourne, for the period 2006-2009. The research team consists of Lyn Yates, Julianne Moss, Trevor Hay, Peter Ferguson and Pam St Leger all of the Faculty of Education and Melbourne Education Research Institute, University of Melbourne; Sarah Drew of the Centre for Adolescent Health of the University of Melbourne and Royal Children's Hospital; Lyndal Bond of the Social and Public Health Sciences Unit (Glasgow); Julie White of Faculty of Education, La Trobe University, Mary Dixon of the National Institute of Education (Singapore) and Ria Hanewald (MGSE, University of Melbourne) and Amy Basile (Centre for Adolescent Health) who have been newly appointed to work on the project. In addition Margaret Robertson, recently retired Executive Director of the Education Institute, Tony Potas, Executive Officer of the Education Institute and more recently Julie Green, Research Director of the Education Institute are involved in all regular team meetings and planning; and other members of the Institute we will be involved as the project progresses. Further information about the project can be obtained from Ria Hanewald, the Project Officer for this project: riah@unimelb.edu.au or via the project website (<http://www.edfac.unimelb.edu.au/keepingconnected/index.html>).

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