'Connectedness' and the hospital/schooling interface: evidentiary and ethical issues in a collaborative research project using visual and narrative methods

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Issues of methodology and ethics are often discussed as a series of questions about epistemology or best practice or ethical dilemmas relating to theoretical or political frameworks within which a researcher is working. But in the world of funded projects the methodological choices, ethical steps and justifications and the language we draw on to defend these are all contextually located. The issue of credibility of the approach is not simply a matter of technical epistemological arguments, but is contextual, related to the history, networks and institutional arrangements of those who will judge the grant application or the research outcomes (Yates 2004, Cheek 2005). Framing the ethics of a project is not simply a matter of working through appropriate ways to defend or advance the interests of those who will be researched, but is also a matter of negotiating the history and assumptions of Institutional Review Boards or Ethics committees, and the historically constituted legal processes that have set up some procedural taken-for-granteds about what ethical procedures look like. And the issue of an appropriate approach is further complicated where researchers from different disciplinary and methodological foundations attempt to work together. This paper discusses a project which is attempting to negotiate these various issues. It is in its early stages, so the focus of this paper is on the issues and tensions that are evident at the point of designing a project for the purpose of a grant application; and at the point of negotiating ethics committee approvals prior to the actual conduct of research.

The project
The project I will discuss in this paper is one intending to study the experiences and perspectives of young people whose lives and schooling are disrupted by serious illness or accident, and who are required to spend time in hospital and continuing their education using the support and liaison activities of the Education Institute of the Royal Children's Hospital in Melbourne. Our interest is in their trajectories and perspectives over two years from when they first register with the institute, and in particular on their identities in this time, their experiences of connection and disconnection from their previous education, and their perspectives on the approaches of the various school and health professionals who work with them. It is a project which will use some mixed methods, but in which longitudinal qualitative research which foregrounds the voices of the young people themselves is intended to be central, and in which education and social relationships and concerns, not discourses of illness and health are intended to frame the study design. The project will involve visual and narrative evidence from around 30 young people, and also other evidence

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from and about data-bases kept on the cohorts who experience this situation; and focus group interviews with teachers, health professionals, education advisers and parent. The research team was 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 associated within the faculty of medicine), and professional support and research involvement from the Director and Education Advisors of the Education Institute, and two research fellows employed to work on the project, one of whom has a background in sociology, and the other in adolescent health. (Further details about the project and research team are given in the end acknowledgements of this paper)

The politics of collaborative work:
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 has come together voluntarily over time, 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 (which is usually seen as part of the hospital, though it is separately governed by its own board) 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. The issues I want to discuss in this section are not about individual goodwill but about the way the politics of funding, and of different institutional contexts impact on research design, and particularly on collaborative activity.

Funding programs and their effects:
For all those involved in this project, securing grant funding through the Australian Research Council was desirable. The ARC grant program is the main open funding source for non-medical research in Australia, and it is valuable both materially (in terms of the money it brings) and in terms of status. Because ARC grants are both highly competitive and highly visible (publicly announced and outcomes compared between universities and between fields when they are announced) , and because Australian universities are moving towards a greater emphasis on research quality as part of a new research assessment exercise (RQF), individual researchers are under pressure to demonstrate achievements in terms of winning such grants. For our partner, 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).

I have written in detail elsewhere about the particular form of the Australian context and mechanisms for assessing grants (Yates, 2004, 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. As well, although currently these panels are not technically constrained to a US version of 'scientifically-based research' as the only appropriate model of research, my experience working in a situation where I was able to read many hundreds of assessors' comments on applications led me to this conclusion

A number of elements of the 'evidence-based' movement have taken a stronghold because they *are* close to a contemporary commonsense about what makes research trustworthy and important: that it sets up careful selection and controls and that it is of a scale that matters; that in principle the 'results' should not be dependent on the say-so of the researcher who did it. And it is still more common for these issues about method to be posed to education researchers than for economists or psychologists to be asked to demonstrate that their findings, no matter how controlled or rigorous, will make a difference to teaching and learning in ordinary school contexts. A second point is that the textual task of establishing 'significance' and adequacy of methods is a simpler task when working with that established commonsense than when challenging it. (Yates 2006)

Qualitative and poststructural research does get funded (and track record as well as 'innovativeness' of the project are also important) but it is common for assessors to raise questions about scale and selection even for qualitative studies. In the case of this project, the Education Institute sees some 1500 young people a year, and these come from many different backgrounds, with different illnesses, ages, types of schooling experience. Even with our large team of researchers (though all except two have many other teaching, administrative and research commitments), for the central qualitative longitudinal case-studies, using visual and narrative methods, we can only follow about 30 individuals over the two years, so we had to spend a relatively large part of the application explaining why this might nevertheless produce some new and 'general' insights into the experiences of the young people in this situation, and we included a survey of the entire cohort in our study, in part as a way of demonstrating the limited nature of such evidence compared with the narrative and visual and longitudinal methods for the questions we wanted to address. As well, 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 influence how research needs to be described, and this in turn can influence what, effectively, the research becomes. 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'. Our research team includes a range of disciplinary perspectives among its members, including a number of researchers with poststructural perspectives and more interested in how truths are constructed than in claiming these as findings, and others comfortable with quantitative ways of establishing causal influences. 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.

 In our project we have tried to maintain a vigorous discussion about these issues, and a self-reflexivity about what approaches we take up and what interests dominate. As part of the project we are taping and transcribing our own team meetings to look at these questions, and the ways different disciplinary and institutional locations of the research team generate particular types of questions and interpretations. However the issue of how research outcomes and findings and interpretations are represented to various groups is one that will continue to be an issue as we continue with the project.

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. So for 'plain language' purposes, we now name the project as *Keeping connected: young people, identity and schooling* – together with naming this as a partnership project of the Education Institute, the Education Faculty and the Centre

for Adolescent Health. 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' in part to try to woo a potential partner to feeling that their interests were being highlighted, and in part 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 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.

I have discussed above how, at least from the perspective of academic researchers, the emphasis on 'significance' and 'national significance' produces a certain instrumental imperative to research framing for the purposes of winning a grant. (The program is known as Linkage Grants, and was previously named more explicitly as SPIRT projects 'strategic partnerships with industry'). The program is promoted by a government which wants research to have clear commercial or social benefit, and which has been differentially shifting its funding to research that includes industry partner funding commitment rather than the more open 'Discovery' program that does not require such contribution. Nevertheless the 'Linkage' program is intended to support 'research' as distinct from 'consultancy'. That is, the proposals need to make a 'contribution to knowledge' and not simply answer questions that are specific to the partner; and the assessment process is a lengthy review involving multiple academic assessors, which takes about 9 months from an application being submitted until funding is made available to successful applicants. For many 'industry' potential partners, this still looks far too 'academic' in its form. In the project we describe here, we had a further potential partner working with us through the year of the project design, but, in the late stages before submission, the board of that partner refused to sign off on their own commitment, judging the project to be insufficiently tied to direct outcomes for that partner.

Politics of institutional location:
Across many fields today, there is an expressed enthusiasm for new cross-disciplinary and cross-institutional collaborations, to build bigger research programs and new perspectives and theories and ways of seeing. However, as Gaskell and McLeod (2005) noted in one of the few 'insider' discussions of a major cross-disciplinary collaborations in Canada, these collaborations can founder not because of the researchers' failure to be capable of working together well or communicating with each other, but because of pragmatic demands on their respective conditions of work, and what they need to demonstrate for their own institutional context. In the Canadian collaboration, researchers from Economics were discouraged from developing work and publishing in journals of interdisciplinary studies, because these were considered to have less status than 'pure' journals of their own field (including in the ways

researchers are assessed for employment, promotion, tenure). For individual researchers, the research that they are engaged in has to be represented in ways that meet demands of their current institutional role and criteria, as well as extending over time appropriately for their research career.

Research is not an activity that takes place in the ether[2], but is built on human practices located in institutional settings, and its representation matters to those institutions in their competitive relationships to demonstrate productivity and status and public presence. Issues of this pragmatic institutional kind are already impacting on our collaborative work together in this project. To date, we have had to negotiate decisions about which (that is, whose) computer server will host the project (as the Faculty of Education, the hospital and the Centre for Adolescent Health each have different protocols and templates about design, intended to develop a consistent image to enhance the profile and visibility of that body, so choosing one, is to not choose the other); which names and logos will be represented on website and brochures and in what order and prominence; protocols for writing and authorship (how do we decide who can take lead authorship on a paper; what right do others have to be included, etc)[3]. Everyone faces particular imperatives here, but, given the different location and agendas of the Faculty of Education, the Centre for Adolescent Health and the RCH Education Institute, the ways we resolve these issues potentially also impacts on what is constructed as 'knowledge' from this project.

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 Australia, the main protocols that currently govern institutional ethical processes are the National Health and Medical Research Council ethics guidelines. These protocols derive from research that usually involves giving treatments of some kind, and where the emphasis is on detailed information about the treatments and possible side-effects, and on a requirement of the researcher to justify the steps they have taken to avoid unnecessary harm

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[2] I probably should say '*not only* takes place in abstracted form'. It is important to recognize in terms of the current SBR debate and protocols that research *is* about *a field of inquiry extending discursively over time*, and the appropriateness of methodology of a particular project is judged not just according to its techniques but according to what has been previously accepted or rejected in the field. (cf Yates 2003, 2004). But the discussion here is drawing attention to research as a set of practices conducted by people, and the need to attend to the location of those people.
[3] This is the first paper relating to the project, and the issue of authorship will be revisited before it takes any published form.

and to ensure that research subjects have legally agreed to the treatment. When these guidelines are adapted to social science and qualitative studies, many issues arise about this approach to deciding what is 'ethical' , and different universities in Australia have developed different cultures of assessing the non-medical disciplines. For example, in some cases, ethics boards still assume that research design should normally include a control group, and have quite prescriptive views of what research designs are acceptable; and they make it hard to submit applications that are not prepared to outline in detail what questions will be asked in an interview or period of fieldwork. In other words, they make ethnographic styles of research almost impossible.

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 in fact undermines the ethical approach to this with young people. The current approach 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. (We are at present considering whether we can apply to modify the detailed statement further.) 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 pro-active 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.

A third issue that is arising concerns the use of visual data and requirements or appropriateness of anonymity. With digital technology, faces can be pixillated, but we are too early in the project to have some sense of whether doing this will be appropriate in terms of use of this data for reporting or other purposes. From other projects we have worked on, we know that often young people who participate do not want to be anonymous; they want to have their contribution recognized. At the same time, they may not be aware of how others may see them, or of how they may feel in the future about having this data available and readily identifiable. At this point in the project we have said only that we will not use data in identifiable form without further specific permission in relation to that; and that we will be discussing permissions and use of the data both in seeking initial agreement to take part in the study, and at the end of the two year longitudinal case-study with each young person.

In this paper I have discussed a research project in its earliest stages, prior to any entry to the field or relationship with participants. What I want to draw attention to here is that these framing pragmatics themselves begin to impact on the ways we in fact develop the research design, the ways we collaborate or identify questions and intended outcomes, the public representation of what questions matter and whose questions matter, and what knowledge the project generates. In the project we are beginning we want to keep some scrutiny on ourselves and these pressures so that they do not crowd out the original intentions of the project, to make some space for the perspectives and experiences of the young people themselves to be heard.

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