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### ACADEMIC AND ETHICAL CHALLENGES IN PARTICIPATORY MODELS OF COMMUNITY RESEARCH

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# Tom Denison & Larry Stillman

## ACADEMIC AND ETHICAL CHALLENGES IN PARTICIPATORY MODELS OF COMMUNITY RESEARCH

*The purpose of this paper is to identify and explore academic and ethical challenges with Participatory Community Research (PCR) in the context where many universities and researchers are moving to embrace new e-Research infrastructure. A case study of a project focussing on developing electronic capacity in a deprived community in Africa is used to problematize issues. E-Research also brings its own challenges for PCR, such as: a need to clearly understand the dynamics of community-based research and ethics and ethical frameworks that are responsive to this; the development of new legal ownership and access rights; the need for appropriately sensitive institutional commitment to the long-term maintenance of repositories to support continued data storage and curation; and the formation of adaptive, inter-organizational research teams which are comfortable with community and electronic interactions.*

**Keywords** community informatics; research methodology;  
participatory community research

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### Introduction

Academic researchers are increasingly being encouraged to use data repositories and e-Research tools, in order to better manage their research data and, wherever possible, to make that data available for re-use (David 2004). E-Research tools include data repositories and tools to facilitate data access, storage, searching, and retrieval (David 2004) based on an integrated environment comprising hardware, data, networks and an interoperable suite of software and middleware services (National Science Foundation (NSF) 2006). Access is often provided via Wikis or similar collaborative spaces.

While, in fact, much e-Research activity occurs at a distance from the actual 'field' or source of data, it is important that e-Researchers develop an awareness of the issues that affect the setting in which data are collected from vulnerable communities, and the ethical challenges that are posed in such work. The degree to which ethical practice is conducted in turn affects the validity of the data and the understanding of the context in which it was created or collected.

Participatory Community Research (PCR) represents an approach to research that is popular in Community Informatics, one in which the traditional research subject becomes a research partner. Community Informatics is a field of research and practice concerned with community development in conjunction with Information and Communication Technologies, and the question of the validity of research methods and the use of data for different forms of memory production has been taken up on numerous occasions (for example, in Stillman & Johanson 2007). PCR has implications for all aspects of research, including methodology, analysis, interpretation and dissemination of results, the collection, and short and long-term storage of data. While issues associated with the legal, ethical and cultural frameworks within which research currently takes place have been recognized as having the potential to hinder the take-up of such e-Research infrastructure (Denison *et al.* 2007), the complexity of such issues is amplified in the conduct of PCR. The purpose of this paper is to identify and explore academic and ethical challenges that researchers engaged in PCR may encounter in adopting e-Research techniques.

## Participatory research and empowerment

According to Stoecker (2005) new models of PCR, such as community-based research (CBR), empowerment research, and participatory action research, possess a number of shared attributes. These include the acknowledgement of communities as equal partners, a focus on problems important to the community, and the production of outputs relevant to a community's needs. Many of the specific research methods used by PCR derive from other forms of qualitative research, and many of the issues raised here occur in the practice of those methods, but with PCR they unfold in a context in which community members have quite different functions and relationships to the researcher and the research from those in traditional expert-researcher managed and controlled research. With PCR, community members sit somewhere along the spectrum of: researcher, subject–researcher, consumer–researcher, stakeholder–researcher, and partner–collaborator. PCR can be powerful when working with marginalized groups or social inclusion research. It is also useful in drawing on other sources of knowledge that have previously been ignored or under-acknowledged.

With community engagement, PCR insists upon a process and outcome which lead to mutual understanding and articulation of values. With other research approaches, this process and outcome may be ignored, sidelined, or only marginally acknowledged. Consequently, PCR gives primacy to the role of research partners making sure that there is a common understanding of things such as research questions, the form of reporting, research methodologies, and level of participation in data collection, management, assessment, and the future use of data (Johanson *et al.* 2007). These things can only be achieved when trust has been established and the interests of all stakeholders have been well aired through the development of a common language (Stoecker 2005).

PCR is developing as an important research method in areas such as community informatics, and the investigation and community development of technology, especially in relation to Indigenous communities. Stillman believes PCR is significant because 'the richness of the processes that take place can best be captured through collaborative participative research that is valued by communities, rather than through less engaged approaches' (Stillman 2005, p. 77). PCR is also important because it can leave something of value behind to the community resulting in empowerment, something that is axiomatic in community development practice: increased skills in self-assessment, knowledge, research methods, and advocacy, resulting in less reliance on outsiders to 'present' the community.

PCR is also situated or embedded research that is based on mutual trust and respect that can only be achieved if concomitant ethics regimes are based on principles and guidelines that are adapted to meet community needs. Within Australia two influential sets of guidelines have been developed in an attempt to meet those concerns: the National Health and Medical Research Council (NHMRC) and the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). Both emphasize that any failure to understand differences in values and culture can weaken both the ethics and quality of research. As the NHMRC Guidelines state, such understandings require 'time, care, patience and the building of robust relationships' (NHMRC 2003, p. 3).

Oxfam Australia's Research Ethics Guidelines brochure, an example of ethics practice in the non-government aid sector in both Australia and developing countries, similarly emphasizes the need for ethical research with respect to vulnerable communities. Starting with the premise that doing research with people is a privilege, not a right, its key principles include:

- Respect
- Beneficence – that is that research has a benefit for those involved and that research participants are involved at all stages of the research process
- Integrity in research methods and processes, and
- Justice – ensuring 'that the benefits for participants are at least as great as the risks, and that the benefits and burdens are fairly distributed' and that

people's dignity and rights are protected, and that people are not marginalized. (Oxfam Australia 2009)

The practice of PCR raises a number of significant issues when applied to e-Research with communities, particularly in relation to the collaborative creation of data objects such as content and cultural records. Questions relating to the social and political context of research, participation and empowerment, ways of knowing, research design and funding, research outcomes and benefits, and ethical frameworks arise, as well as issues related to the creation, storage and use of data outside the community setting.

One of the major criticisms of PCR is that it has not been subject to sufficient critique. Hayward *et al.* (2004) argue that there has been 'a mythologising of the power of participatory methodologies to accomplish problem solving, emancipation or empowerment' (pp. 95–96). There exists a continuum of relationships that range between consensus and conflict that is axiomatic to all forms of social organization, and this must be recognized when engaged in PCR (Haugaard 2011). Consequently, ideals about the need for agreement, pluralism or democratic decision-making in conjunction with assumptions about the nature of 'community power' may also come into conflict in situations where the leader traditionally makes the decisions; or contra wise, in some communities, the desire for leaders or stakeholders to represent community interests may go against a tradition of consensus-making. And finally, the role accorded to women may widely differ in communities (Bamberger 1999), as does that of men or people from particular age groups, castes and so on.

The complexities of this issue can mean that researchers need to understand the cultural and power dynamics of the communities they wish to work with, and to think through their assumptions so that a balance is made between their interests and those of the communities they wish to work with. These issues are discussed in relation to a case study below.

## Case study

Monash University South Africa is engaged in social justice and community development work at Zandspruit, an informal settlement (shanty town) not far from its campus on the edge of Johannesburg, South Africa. The population of Zandspruit is about 60,000, and includes a high number of unemployed and very low-income unskilled people, and single parent householders (predominantly headed by women). The population comprises migrants from all parts of South Africa, looking for work in Johannesburg, and many undocumented migrants and refugees from other countries such as Zimbabwe or Mozambique, who are sometimes seen as not belonging to 'the community'. In addition, the settlement suffers from a number of infrastructure problems, with water,

sanitation and garbage collection, power, and even traversable roads lacking in many parts. Indeed, the fact that the Government classifies such areas as ‘informal settlements’ is indicative of ambiguous situation that such communities have in South Africa, as they struggle to be recognized as formal and legitimate places that deserve to be supported with adequate infrastructure.

The question should also be asked whether Zandspruit can be considered as a functioning *social* community, given that its social problems are so great and its level of intra-community social capital so dispersed, with the only strong ties apparently amongst family groups or gangs. This may affect the legitimacy of any research which is done with what is perceived to be ‘the community’ and how the ‘community’ is subsequently represented. Part of the problem is definitional: the term ‘community’ is heavily debated in sociology and places like Zandspruit appear to display more social deficits than obvious uniting or positive assets which are considered essential for a community (Clark 2001). Nonetheless, Zandspruit is a social fact, a physical setting with increasing permanency, in which many people live and try to make do. Similar places such as Alexandra, on the other side of Johannesburg, were in the same situation a century ago, but have now become large and thriving communities which, despite all their problems, are recognized as legitimate and which deserve support.

Strategies adopted by Monash South Africa to support the Zandspruit community include supporting a Saturday School for children, a sports programme, and the installation of a Digital Doorway computer kiosk in the grounds of an old farmhouse belonging to a number of non-government organizations. The Digital Doorway, a robust public computer kiosk designed for tough conditions in South Africa, is intended to assist in informal learning and skilling of people who have little opportunity to use a computer. It is also intended as a ‘platform’ for researchers to develop new content and applications in conjunction with communities.

In the case of the Zandspruit initiative with Monash, the word ‘apathy’ has been used to describe attitudes towards residents’ engagement with each other, but this is an inadequate way of describing the fact that unity in the community is extremely difficult to achieve. As a community of migrants, people can choose to be disembedded from traditional relations in pursuit of their own opportunities, just as occurs in middle class suburbs (Putnam 2000).

However, even the right of outsiders to access and know about the needs of poor communities can be challenged. In a newspaper commentary about Harber’s (2011) book on Diepsloot, a larger settlement on the other side of Johannesburg, Harber was accused of being ‘motivated by the impulse to “civilize” – that colonial desire to study and save the native from himself’ (Mngxitama 2011). Mngxitama argued that Harber’s work could not truly reflect the nature of the community, because that could only be achieved through the work of a black African. A week later, another correspondent in the same newspaper responded: ‘Are we really still being subjected to that tired old lament

about white writers appropriating the black experience?' (Khan 2011). The debate highlights a wariness with regard to 'outsiders' from formerly dominant cultures who could potentially exploit communities and emphasizes the need for researchers to remain sensitized to issues of power, race and gender in theory and practice (Smith 1999).

Such sentiments have also been expressed by young residents of Zandspruit. For example, there is an active discussion group on Facebook. One of the topics under discussion has been the colonization of the community by churches, outside NGOs and researchers. Echoing the discussion on Harber's book, some of the discussion has called for a handing over or take-over of charitable NGO activity and assets in order that community, and African interests, rather than outsider interests are first and foremost.

As a consequence, Monash South Africa believes that it needs great care in the development of its relationship with Zandspruit, and is strongly concerned to protect Zandspruit from the intrusion of well-meaning researchers. As stated in its Community Engagement Strategy:

Monash South Africa is mindful of the mutual dependency which exists between itself and the broader society. The imperatives for community engagement lie in the responsibility of universities to develop critical citizens and to be socially accountable. Thus, Monash South Africa seeks to be critically responsive to society's expectations that higher education institutions should become an engine of development for people, communities, institutions and democracy. (Monash South Africa 2011)

The strategy to install the Digital Doorway is in partnership with the developers of the kiosk, the Meraka Institute of the South African Council for Scientific and Industrial Research. The intention of the project has been to engage the community through what is known as 'user-driven' CBR in the design of new content and innovative strategies for as many people as possible to use the Digital Doorway as a skills pathway (Stillman *et al.* 2010). The strategy is two-pronged, consisting of not just engagement, but research about what people in the community do with the Digital Doorway *in situ*. While the project is still in its early stages, and hampered by lack of resources, the relevance of the project as a case study for PCR, and particularly the complexities of ethics and protocols for research is immediate.

As part of the process of developing an appropriate research relationship, a workshop was held in October 2009, with Zandspruit stakeholders including residents, NGO workers, senior Monash South Africa staff, staff from Meraka, and Henry Atkinson, an Australian indigenous representative with considerable experience in protocol issues. The following key points were developed as a mission and values statement:



- CBR for Zandspruit is a collaborative co-creative journey between scholars (researchers, technologists, community members) and the people they serve.
- CBR for Zandspruit validates multiple sources of knowledge and promotes the use of multiple methods of discovery and implementation and of dissemination of the knowledge produced.
- CBR for Zandspruit has as its goal social action and social change for the purpose of achieving social justice and improving the human condition.

There was also a call for a high-level vision statement by Monash for ethical community engagement and CBR that could take into account the following principles as deemed relevant for Zandspruit:

- Monash and Meraka wish to work towards a joint impact for transformation in a partnership with the Zandspruit community.
- For Monash and Meraka the challenge is empowerment of the Zandspruit community in the context of a long-term trusting sustainable relationship.
- Monash and Meraka wish to establish a framework which can be adopted elsewhere to inform other community processes.

## Identifying community

As noted, the traditional role of communities in the Western research paradigm has been to treat individuals and communities as passive research subjects rather than active and conscious research partners who have world views that need to be considered as legitimate rather than somewhat inexperienced and underdeveloped in comparison to that of the researcher (Couzos *et al.* 2005; Cochran *et al.* 2008). PCR requires that communities and their representatives be treated on equal terms, and that all effort should be put into ensuring community participation. Typically, this requires working through community leaders and other networks, though it is often hard to know to what degree any group is representative of 'community'. Problems can arise, for example, when researchers are confronted by a lack of community representation, and resort to the use of surrogate means, for example, welfare or religious organizations working but not resident in the community, to claim a source of community interest or knowledge.

The use of such leadership, because of its convenient prominence though political, church or other affiliations, and the ready availability of its members as articulate stakeholders, may lead to the misrepresentation of the interests of others in the community and act to reinforce existing relationships and structures by furthering the interests of a dominant group (Hayward *et al.* 2004). In practice, however, researchers often have little choice to work with such groups, and indeed Monash is working with a local NGO as well as individual

community members. In this situation, care needs to be taken that other voices are not left out, or at least that there be an awareness of the difficulties of effective representation and gaining access to a fuller range of community 'voices' (Martin & Mathema 2006).

## Alternative ways of knowing

Bernal (1998) argues that the understanding of knowledge that a researcher adopts is strongly influenced by history and the researcher's social position, with the result that alternative values and knowledge may be discounted. Russell (2005) used the term 'irreconcilable ontologies' to reflect differences between Western and Indigenous Australian knowledge systems due to them being based on different world paradigms. The ontological problem affects academic ethics processes, which are based on Western concepts of privacy, informed consent, and the ownership and control of data by academics, and which focus on protecting the interests of the university rather than those of any community. Faulkhead *et al.* (2007) argue that:

although it is possible to vary the standard approaches to managing relationships with community partners and handling research data, the standard approaches reveal a lack of sensitivity to community protocols, with it being possible for community projects to gain ethics approval without adequate community consultation, or full compliance with community protocols. (p. 50)

However, the issue is not just one that affects Indigenous people. As we see from the situation in the above case study, the situation of (racially) outside researchers can be controversial, and the idea of 'community representation' or even discoverable 'community knowledge' that is applicable to all circumstances is contestable. Crude ideas about who or what constitutes a particular body of knowledge ('African', 'traditional', 'tribal') that is discoverable through adherence to a particular protocol can result in quite erroneous and potentially embarrassing situations. There may be no one authentic way to do discover the 'truth' or multiple 'truths'. Sub-Saharan Africa is many places and peoples with diverse beliefs, though there are recognized commonalities (Mbiti 1969) that are regarded by Africans themselves as distinguishing them from others (Appiah 1997; Dowden 2009). Despite this qualification, for example, in a traditional sub-Saharan African village, decisions were undertaken under a tree in the presence of a leading elder. When a white person calls a meeting 'under a tree' this can be perceived as an attempt to adopt the same role as an elder or leader. Yet this traditional view of leadership is not axiomatic. In the second author's experience with interviewees from Zandspruit, where people come from different parts of

Africa or are internal South African migrants, there is a recognition that such traditions are not salient in the life they lead in the city, in a geographic community that houses a multiplicity of different sub-communities or disaffiliated individuals. Indeed, one young person from Zandspruit said that the only difference between her and other South Africans, including white South Africans, was her poverty. Thus, one has to be guarded against making assumptions about any community or person's identity based on pre-conceived notions, or ideals about 'protocols'. The researcher has to be guided by careful awareness of 'cultural factors' without engaging in over-compensation, stereotyping or pandering to what is seen in some quarters as ethnic chauvinism and power plays rather than a genuine expression of local culture (Appiah 1997).

## Research design and funding

Funding bodies for academic research generally require that applications go into great detail as to the research questions to be addressed and the methodologies to be adopted, before funding is awarded. Communities can and should be involved in the preparation of these submissions, but such work has the potential to consume significant resources and to raise expectations among whatever stakeholder or representative groups are identified. Given the previous discussion, the capacity of a community to devote itself to such efforts needs to be carefully considered. The effort is often not justified as there is no guarantee of success in seeking funding, and such failures can lead to disappointment and a reluctance to engage in future attempts.

The approach taken by Monash when working with the Zandspruit community and with Australian indigenous communities is to attempt to develop long-term relationships that are based on realizing mutual benefits from a series of research projects and other activities rather than one-off or opportunistic interventions. This approach facilitates community consultation, the identification of needs, and a focus on finding funding specifically to meet those needs rather than trying to manipulate needs to meet the criteria of more targeted funding sources.

Even so, the time and the cost required to plan and implement research must be realistic and it is not unreasonable to expect that community members and stakeholders should be funded for their work, particularly if the requirements of the project impact on their substantive roles (Cochran *et al.* 2008). In addition, payment made to community researchers and the sense of being part of a team can be important in helping develop job skills to escape poverty. Of course, there is the potential danger that paying people for their time and effort may lead to a skewing of results. Researchers should be alert to this possibility, just as they should be in the situation where people are not paid for their participation. Anecdotal evidence from Zandspruit and other research strongly suggests that people in the community perceive that they are 'doing a job' and deserve recompense for it.

Whether or not research participation is paid for, consultation fatigue can result from too frequent demands for information or participation and may limit the willingness of the community, or key community members, to participate in future research. For this reason Monash South Africa limits the number of research projects undertaken with the Zandspruit community. The community (inchoate or developing as it is) needs to live and breathe its own life and engender its own structures and capacity to call the shots with researchers.

## Outcomes and benefits

PCR requires that the benefits and outcomes of research have value for all participants, although those benefits and outcomes may be different for the various stakeholders. For example, in Australia the NHMRC guidelines are based on the principle of reciprocity, which is intended to cover not just participation and the recognition of partners' contributions, but the recognition that research outcomes are of value to Aboriginal and Torres Strait Islander communities or individuals as well as the academic community or the broader community at large. This benefit is generally expected to contribute to the cohesion and survival of the community, but it recognizes that Aboriginal and Torres Strait Islander communities 'have the right to define the benefits according to their own values and priorities' (NHMRC 2003). Similarly, Monash wishes that in every way possible that all research which engages impoverished communities, such as Zandspruit, results in long term social or economic good for the people there.

However, it must also be acknowledged that academic researchers have needs and priorities which may be quite different from those of the community. These can include: a desire for original research findings free of external filtering of controversial findings by community participants or funders; the desire to secure job tenure or promotion, which requires demonstrating the value or impact of the research they have undertaken; more intangible benefits, such as a sense of contributing to social good or to social justice; and, different priorities attached to timeliness whether it involves grant submissions, meetings, activity, or reporting.

A key task of PCR is the reconciliation, in an ethical manner, of the often competing priorities of all participants.

## Ethics

The preceding discussion has implications for the ways in which ethics should be approached in any given project, and also serves to highlight that it must be an ongoing process. An additional consideration that must be taken into account is that academic ethics frameworks are concerned with the obtaining of informed

consent by those in a position to make a voluntary choice to participate. This requires that participants be provided with sufficient information, in language that they comprehend, describing the purpose, methods, demands, risks, inconveniences, discomforts and possible outcomes of the research to be undertaken. Depending on the nature of the community involved, this may mean not only obtaining an individual's consent, but also that of the organization, or the community or collectivity, to which they belong.

Even if such procedures have been adhered to, most of the issues raised in this paper have the potential to raise questions about the ethics of research undertaken because, as the NHMRC (2003) guidelines note:

Unethical behaviour need not always be a glaring act or infraction. It often includes subtle or only sub-consciously intended encroachments on values and principles. (p. 15)

Researchers need to be aware that such infractions may do irreparable damage to their relationships with community partners or at the very least engender an atmosphere of distrust that will be detrimental to their research. Consequently, ethical behaviour requires ongoing attention to detail, and regular self-reflection about the effect of action.

## **PCR, data management and e-Research**

The issues raised by the Zandspruit project have implications for the conduct of e-Research. For instance, consider the Zandspruit Facebook social networking group. On the one hand, the site is an open public group and anyone in the world can view its content, however it is likely that members of the Zandspruit group assume that they are talking among themselves, and are not visible world-wide. If there was a desire to directly use the site by quoting postings, or to take part in it, an ethical procedure might be to alert members of the group that a researcher wishes to use the information on the site with their permission. However, it is an informal group of about 100 people and obtaining consent to use everyone's data – because it is so linked and threaded through the discussion and activity – would be an almost impossible task. Furthermore, alerting the group of researcher interest might act to dampen the important discussion and community-building that go on through the group. It could also inhibit the development of relationships beyond the social networking site. The long-term ethical judgement in this case would be to develop a relationship with members of the online community such that they are prepared for their data to be openly used and acknowledged. Otherwise, researchers run the risk of mining the information developed by the community and exploiting it for their own benefit without leaving anything of benefit behind. The same issues

could arise in a discussion group established specifically to support an e-Research project or projects.

The projects based on the Digital Doorway and envisaged by Monash University include a number of elements, starting with the use of the basic Digital Doorway and the development of applications specifically for the community, for example, the development of information services or applications to assist with the teaching of specific skills, or the creation or publication of local information or cultural outputs. There needs to be an evaluation of the ways in which such applications and services are used, and this would involve techniques such as data mining of log files, or focus groups and interviews with community members. Data from these activities can take a variety of formats, including text, audio and video. Datasets produced may also have value beyond the life of the specific project for which they were created, both for researchers and the community itself. Future use would not only necessitate the creation of adequate contextual and providential metadata, but would also require provision for ongoing access to the data and the negotiation of terms of access, or protocols to secure permission to use the data.

The use of collaborative tools such as Wikis and annotation software, which may involve the shared creation of data or other research outputs, can also obscure the ownership of research outputs because the original source of data or values attributed to it – as a community product – can become obscured as layers of conversation or interpretation or metadata are added by researchers. In addition to the community issues identified above, if researchers believe that they are going to lose recognition for their work, or ownership of intellectual property, they may also withhold material, or refuse to contribute to online resources such as Wikis or annotations software (Denison *et al.* 2007).

A further impediment to community use is that e-Research environments typically provide access to collaborative virtual environments for geographically distributed researchers, whether they are members of a lead institution, CBRs or interested stakeholders. Collaborative systems, for example, those based on the Sakai or Confluence packages which have been implemented at Monash University, are primarily geared to providing access to data storage facilities, and have interfaces that are challenging, even to many academic researchers. If these are to be made available to all participants in a way that actually facilitates use by the community, more attention needs to be given to the interface design and the type of functionality supported (Denison *et al.* 2007).

## Data ownership and access rights

The *Australian Code for the Responsible Conduct of Research* includes several provisions relating to the preservation and accessibility of research data. It recommends that research institutions must have policies ‘that address the

ownership of research materials and data, their storage, their retention beyond the end of the project, and appropriate access to them by the research community' and that, while specific questions of ownership and questions of retention are determined by law or the funding agency, where possible 'the period for which data should be retained should be determined by the specific type of research' (NHMRC 2007, p. 2.1). However, where the work has community or heritage value, the code states that the aim should be to keep data permanently, preferably within a national collection and, 'research data should be made available for use by other researchers unless specifically prevented by ethical, privacy or confidentiality matters' (NHMRC 2007, p. 2.3).

Denison and Johanson found that researchers engaged in participatory research argued that any data collected needed to be regarded as the joint property of the participants and the researchers, with the knowledge and opinions expressed clearly acknowledged as those of the participants. However, in most cases the University and ethics documents required that the researchers, or the University, be specified as the owners, and that the participants' knowledge be considered in terms of pre-existing intellectual property (Denison & Johanson 2010). This may not appear a significant difference in attitudes, however the consequences are that it is the University that controls what can be done with the data, who has access to it, and when it must be disposed of.

More generally, previous research has found a lack of clarity about data ownership (Denison *et al.* 2007; Henty *et al.* 2008), which also may have repercussions when assessing what access rights can be assigned to data and at what stage. These problems are very real in terms of e-Research practice and if there is a lack of clarity researchers and their community partners may choose not to deposit at all, or may choose to place tighter restrictions on the data than is actually necessary. At the very least, repositories will need to include metadata that describes a range of options relating to ownership, and the specific rights of users in relation to the data held.

Ideally, guidelines or rules should be associated with permissions relating to management of resources by authorized users, including disposition (that is, the right to delete information, retain for a set time or indefinitely, or transfer ownership), specified or negotiated conditions of use, rights management (including rights of access, confidentiality and privacy, ownership including copyright and moral rights), and information security safeguards, in particular audit trails which capture and maintain information about the movement and use of the resources (ACLS 2006).

Questions of ownership require further attention to ensure that such guidelines can be properly implemented. For example, negotiations between research partners in relation to the ownership of the data produced during a study may need to include a broad range of stakeholders. As can be seen from the Zandspruit Case Study, this can be a difficult process. It becomes more complicated when working with Indigenous communities and notions of collective ownership,

but in any case shared information with multiple contributors and owners does not fit neatly into existing personal property law (Iacovino 2006).

Finally, if researchers are to be able to re-use data, they must be able to find data via some standard search and discovery mechanism, understand the provenance of the data and its meaning, and have a clear understanding of the ways in which it is permissible to use the data. Anderson and Carlson (2006) drew particular attention to the difficulty of preserving the meaning of data once it has been detached from its source. Henty *et al.* (2008) found that many researchers considered their data would be meaningless to others because they would not have sufficient context to interpret it. This is particularly true of data collected in the course of participatory projects because the situated nature of those projects is key to their success. Different types or levels of metadata are required depending on the roles of those involved. Those creating or depositing the data need to add metadata related to provenance and meaning, and a key challenge for those engaged in PCR is how to capture the richness of the context in which the data was collected. As the Zandspruit Case Study demonstrates, this may include contested meanings.

## Conclusions

The purpose of this article has been to explore the relationship between the practice of PCR, the ethical issues that arise in that practice, and the implications for e-Research practice. While communications networks hold much potential in this field, two significant shifts in approach are required. First, the community must be able to fully interact with the information and community technologies in place, and have meaningful input into their design and deployment. Second, as Stoecker notes, although the research community is empowered to create, collate, disseminate and control its own products, and to effect change, it will only occur if it conforms to an overall community development strategy (Stoecker 2005).

As Byrne put it, 'participation creates memories, individual and community, and is shaped by memory, manifesting public and private textures of experience and reference, the textures which are refracted through memory institutions' (Byrne 2007, p. xxi). It is all too easy to forget that people who create electronic records in and about communities – whether they are drawings on a Digital Doorway, or musings about service delivery on a social network – are demonstrating their agency and skill. They are not passive subjects who should not be engaged in research, but have the capacity to contribute to much richer forms of e-Research.

The challenges of conducting effective PCR have implications for data management and the take-up of e-Research infrastructure in partnership with communities. With respect to data preservation, clear ownership of information



resources in e-Research communities, including ownership of intellectual property is critical for accountability, long-term storage, accessibility and archiving. Within the social sciences and the humanities, particularly when dealing with communities and individuals in ethnographic work, there may be broader questions about who actually owns the research – the researcher, the community, or the group – as well as exactly what it is that comprises the research content, and what can be done with it. Such questions need negotiation, and that negotiation can be more complex than what existing frameworks currently provide for. It is clear that such guidelines as do exist, for example, the AIATSIS protocols for conducting research with Indigenous communities (AIATSIS 2002), are not well served by current arrangements, and that more work needs to be undertaken in the areas of:

1. Allowance for joint ownership of data,
2. More flexible rules regarding retention of data,
3. Greater recognition of specific community ethics frameworks,
4. Recognition of prior community ownership of knowledge, and
5. Protocols for re-use.

It is also clear that the assignment of metadata which adequately captures the context within which the data was collected, and which consequently reflects its meaning, is difficult but essential for any future interpretation or use of that data.

In conclusion, while the physical location of electronic resources is of decreasing importance, control and ownership, as reflected in intellectual property policies and ethical requirements, have become highly contested. Current research suggests that such problems will be particularly acute in relation to new models of participatory research involving vulnerable communities and that due care needs to be taken in maintaining ethical relationships, so that data created is not misinterpreted or misused.

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