

Case Study

Case Study: Indigenous Knowledge and Data Sharing

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Abstract

The IDRC-funded project 'Empowering Indigenous Peoples and Knowledge Systems Related to Climate Change and Intellectual Property Rights' is part of the Open and Collaborative Science in Development Network (OCSDNet). The project "examiners processes of open and collaborative science related to indigenous peoples' knowledge, climate change and intellectual property rights". Natural Justice, the lead organisation has a strong ethical stance on the agency and control over knowledge being vested with the contributing project participants, communities of the Nama and Griqua peoples of the Western Cape of South Africa.

The project focuses on questions of how climate change is affecting these communities, how do they produce and maintain knowledge relating to climate change, how that knowledge is characterised and shared (or not) with wider publics, and how legal frameworks promote or hinder the agenda of these indigenous communities and their choices to communicate and collaborate with wider publics.

Indigenous Knowledge is an area where ethical issues of informed consent, historical injustice, non-compatible epistemologies and political, legal, and economic issues all collide in ways that challenge western and Anglo-American assumptions about data sharing. The group seeks to strongly model and internally critique their own ethical stance in the process of their research, through for instance, using community contracts and questioning institutional informed consent systems.

Keywords

data sharing, data management, indigenous knowledge, intellectual property, ethics, case study

Main Findings

There are two main strands of findings from this case study. One set are logistical and management issues that arise where conflicting policy and compliance requirements are imposed on projects that already have many requirements in tension. The second is a fundamental question of whether the concept of "data" can be applied to projects where there is a strong driver in principle to ensure that the objects arising from the project are maintained in context.

- Particularly when dealing with historically disadvantaged communities but also in many cases where there are strong ethical and legal obligations in play, hard policy requirements can lead to deadlock and conflicts of interest for researchers and other stakeholders
- Many of the issues could be mitigated by surfacing and addressing all the issues in tension in advance. However actually achieving this in practice is very challenging. New issues almost always arise.
- Even where data is not shared, the process of data management planning can be valuable in providing a framework for surfacing and where possible, resolving issues.
- Research with a strong commitment to retaining the connection between research outputs and the context in which they are found raise deep questions of what should be counted as data. This issue can be avoided within policy implementation via exceptions but directly engaging with these challenging issues may have real value for policy design, particularly in a development research context.

Awareness and pre-existing capacity for managing and

examining data

The BVH project was recruited from the <u>Open and Collaborative Science in Development</u> <u>Network</u> (OCSDNet, Chan et al. 2015).The project team had a well developed concern for the management and control of access to the outputs of their work. In common with many qualitative projects the question of what is "data" and what is "research record" was less clear. In common with many of the other contributing projects there was a realisation, once the digital outputs of the project were catalogued, that there was much more to consider than what had previously been thought of as data.

Concerns over control and access were paramount for the project and less attention had been paid initially to back up and management. Formats and software choices were driven

largely by convenience and limited attention had initially been paid to the use of open and archive-suitable formats. Nonetheless the strong focus on care of the digital assets of the project and a responsibility to the contributing participants aligned well with the value of a coherent and well thought out management plan.

The development of data management plans

Data Management Planning was a complex process and a lot of focus was applied to issue of what could (not) be shared. Once it was clear that it was legitimate to state that objects would not be shared the process was found quite useful. In response to the planning process the project developed more robust file naming procedures as well as backup and archiving processes.

For this project we have three versions of the DMP available, one prepared in early 2016 a revised version from June (available in the project data package, Neylon 2017) and the final published version (Traynor 2017). The updates reflect some developments in awareness and changes that occurred throughout the project. The main change is a shift from individual named persons to roles, reflecting the possibility of changing personnel (see also Derechos Digitales project).

The project found the DMP process mostly useful as a structured means of working through the issues. It also provided a prompt for the project lead partner, a legal NGO, to work through the issues specific to data management with the academic partner based at Indiana University. Another key benefit was thinking about longer term preservation. In common with other projects it was noted that benefits would have been greater had the DMP process been carried out at the beginning of the project.

Tools and systems: Experience of use in developing world context

The project team used the DMPAssistant tool online with reasonable ease. Network Access is not always consistent in South Africa, however the service was usable. Questions were raised about the intent of questions. As a first time user many of the queries were unclear and the guidance was not considered helpful in many cases.

Challenges of implementation and data sharing

Complexities of overlapping ethical and contractual requirements

The project had developed "community contracts" as a key part of their methodology (Traynor 2017b), focussing on ensuring that the contributing communities had control over the choices to share or distribute outputs, particularly those relating directly to the recording of knowledge. In addition the informed consent process required by two participating

institutions added complexity. Finally legal frameworks for indigenous knowledge, both locally in South Africa and in international treaties added further complexity with respect to disclosure (Foster 2014).

Layering funder requirements, even with allowance for exceptions on top of this creates a very complex ethical and legal situation. The project notes in its response to the interim report that a researcher can be in a legal conflict of interest with respect to their contracts with their employing institution, with the funder, and in this case with the communities. In this case the project had specifically not sought consent from contributing communities to share the records of interviews. Institutional and funder policy could impose requirements that make this difficult and the legal standing of materials held in institutional resources further complicates this.

From a pragmatic perspective the key is that these interacting requirements need to be surfaced early on. In this case some issues may have been avoided by seeking broader consent at the beginning of the project. However this was not clear until the varying requirements were actually encountered. Bureaucratic systems are generally poorly equipped to deal with these interacting requirements. In this case an effort to challenge the assumptions of institutional informed consent processes, through including the partner communities as investigators, was made difficult or impossible due to rigidity of these systems (Traynor et al. 2015).

Should digital objects to be kept in context be considered data?

This project raises a much more challenging question with respect to policy design and implementation. Policy on data sharing and implementation generally avoids defining exactly what is meant by "data" in too much detail, allowing flexibility for both funders and researchers. Nonetheless the digital objects generated through the research project that are not narrative documents are generally included in this set.

This project raises a challenge to this through its commitment to maintain the knowledge objects generated through the project within the context that they were collected. Arguably the intent behind data sharing and management policy is directly opposed to this. The claims around sharing data are that there is value in maximising the useability of digital objects away from the context in which they were created. Standardised metadata and formats are designed so as to minimise what is special and unusual about the context in which data is collected.

This is in direct opposition to the ethos of the Natural Justice project and arguably raises profound issues around what can ethically be considered data in a development research context. It also speaks to some of the challenges around objections to data sharing more generally from humanities disciplines and the claim that they "don't have data". Again as development research often navigates the boundaries between humanistic and social science approaches this is likely to be more relevant in a development research context.

Changing culture and the role of policy

The project, while situated around questions of knowledge sharing was unusual within the pilot as it started from a strong perspective that much of the relevant outputs should not be shared, or that at the very least the subjects (who were described throughout as partners) of the study should have the final say over what is shared. In this sense the cultural change targeted within this project was directed outwards, at institutional systems, including consent and ethical review, towards the project team itself and more generally towards the academy and society.

These efforts to raise issues relating to consent, agency, and historical injustice are difficult to assess. The interaction of the project with the Indiana IRB was not productive in the surface sense that challenging aspects - project subjects being included as investigators - of the original submission were ultimately removed prior to approval (Traynor et al. 2015). Nonetheless it is to be expected that this intervention does have an effect on these systems.

Policy directed at the project would be likely to be similarly unproductive on the surface for similar reasons. Like the Institutional Review Board the project has many competing obligations. Imposing a one-size-fits-all policy over the top of this is unlikely to be helpful. Considering how the motivations behind the project, and the obligations it has voluntarily and non-voluntarily entered into align with those of a data sharing and management policy will likely be more productive.

In practical terms such a project would generally seek an exemption from comprehensive data sharing obligations under a funder policy, or that policy might have blanket exceptions for personally identifiable information or Indigenous Knowledge. However the more productive approach would be for policy to be able to learn from projects such as this one which challenge the underlying motivations and their framing. This is beyond the scope of the current project but merits further study.

Grant title

Exploring the opportunities and challenges of implementing open research strategies within development institutions (Neylon and Chan 2016).

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