Case Study

Case Study: Neglected Health Issues in Niger

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Abstract

The project "Problemes négligés du système de santé au Niger" focusses on a core set of often-neglected issues that nevertheless have an overall negative impact on health system effectiveness in Niger. For example, poor quality maternal health services result from challenges related to the midwifery profession and from pressures from addressing the effects of illegal termination of pregnancy. Overall health system governance is undermined by weak management of human resources and health information systems as well as problems related to decentralisation of health care provision and dependence on external funding for health projects. LASDEL applies a rapid assessment and qualitative research approach to working with patients and health care professionals to identify the scale and characteristics of these problems.

The project goal is to develop an evidence base to support tackling these neglected issues.

Développer des recherches sur les « problèmes négligés » dans la gouvernance de la santé, et sur cette base contribuer à des réformes des systèmes de santé permettant une meilleure qualité des soins pour les populations vulnérables.

"Develop research on "neglected problems" in the provision of health systems, and through this work, contribute to health system reforms, that provide better quality of care for vulnerable populations."

As can be seen above, many of these issues relate to reproductive health and more generally to health issues of disadvantaged groups. Some issues are neglected for political or social reasons meaning that they are not recognised or acknowledged and in some

cases are criminalised. Therefore there are profound issues of participant privacy, protection and even safety for this project. Data sharing therefore requires thoughtful anonymisation and selection.

The project group is Francophone with limited English language knowledge and the researchers and the context is largely in French. In common with much of Francophone Africa there has been limited development of Open Access to research outputs or Open Research Data agendas at governmental or funder levels. Outside of Canada and France there has been limited development of infrastructure, systems or policy relating to data sharing in the global francophonie specifically.

Keywords

health, neglected health issues, francophonie, language, research data, data management, data sharing, Niger

Main Findings

The main finding from this Case Study is the myriad ways in which English language hegemony creates challenges. This is not limited to infrastructure provision, or materials or resources, but includes fundamental assumptions of systems design that embed the assumptions of English language and Anglo-American culture deep within their working.

Secondary findings were that many online systems are not useable in the context of areas with limited internet bandwidth and high connectivity fees and that offline forms that can be sent by email are more appropriate. The issues of participant privacy, while serious, were possible to address in the production of aggregate anonymised data with appropriate support.

- The assumptions of English language and Anglo-American culture are deeply embedded in systems and policy design, and cultural assumptions that surround the Open Research agenda. These surface in, but are not limited to:
  - Challenges of communication with (generally English speaking) policy makers, implementers, infrastructures and trainers
  - Online systems, tools and training resources that are primarily English language
  - Deposition requirements for data infrastructures for English language metadata and description standards that privilege English expression
  - In some cases, concepts are deeply embedded within database schema and standards in ways which do not readily translate to French
- It is important to explain, as soon as possible, the issues of data management and data sharing to the researchers of the team involved and to gain sufficient support. In this case the project leader organized one informative workshop for developing a background knowledge in RDM.

- Guidelines and basic tools as data inventory are necessary.
- Good support and advice mitigates many of the challenges of appropriate anonymisation and participant protection, at least on a small scale
- Online systems, including DMP tools and standard video and audio call technologies are not sufficiently reliable to provide good support to many parts of the world where network bandwidth is insufficient or overly expensive.

Awareness and pre-existing capacity for managing and examining data

The project team and LASDEL had limited experience of data management planning and approaches for data sharing. LASDEL's team worked largely separately from each other, holding research materials individually until late in the process. It was noted that the training and workshops provided through the Pilot Project would have been valuable at the team level.

The development of data management plans

The development of the DMP was challenging and required substantial support. Multiple versions of the DMP can be found in the project data package (Neylon 2017). Technical issues with the online system are noted below. The lack of previous experience and language challenges meant that the iterative process of developing the DMP was dependent on the contribution of the Francophone advisor. This involved substantial effort and iterations to develop the final DMP.

Aside from the specific technical and language issues, the challenge of support materials in French, and relevant to the local context in Niger was an issue. In practice a high level of personal support was able to address this. However this is unlikely to be scalable to all projects, even in the context of a relatively small funder.

Tools and systems: Experience of use in developing world context

Online tools for data management planning were not appropriate given the reliability of network access for the LASDEL group. Document templates that could be emailed and worked on were much more appropriate. The existence of the French-language version DMP was of value.

Throughout the Pilot Project materials were provided in French translation. This created challenges both in terms of timelines and cost, but also challenges of ensuring correct and idiomatic translation. Without substantial support from Francophone expert advisors and program officers large parts of this interaction would not have been possible.

Translation from a specific English technical idiom into the equivalent specific French technical idiom is a highly specialised task. Automated tools are useful for general person to person communication but for either broadcast training materials and tools or wider dissemination of results much greater human intervention is required.

In addition to this, as the project engaged with DataFirst to explore data deposition a series of issues with data sharing platforms became evident, particularly the requirement for English-language metadata and description standards. This raised issues of costs but also of compatibility with the local context of data collection. Concerns of accurate translation into schema and standard descriptions derived from Anglo-American English language technical idioms that embed both English grammar and specific technical meanings that are not common to general use create substantial resource and user interface challenges.

Challenges of implementation and data sharing

The challenges of language are addressed above and issues of network availability were also touched on. If data sharing is intended beyond the local context then the challenges of network capacity also imply that the platforms used for data sharing will be outside the local context. In the case of the LASDEL project DataFirst (UCT, South Africa) was selected as an appropriate data platform. Questions of the balance between local provision, and the resourcing and capacity building that this implies, and shared provision away from the local context are challenging to resolve through any simple solutions and will likely need to be addressed on a case by case basis.

The potential challenges for anonymisation and research participant protection were addressed through focussing on the release of aggregate data and research protocols. For management and archive purposes raw data including anonymised interview transcripts is to be deposited at DataFirst under restricted access. DataFirst provides high levels of security appropriate to controlling access to these sensitive materials while simultaneously providing robust archiving for the future. However some data such as document protocols, survey methodologies, interviews canvas and results analysis will be available publicly.

Throughout there were challenges relating to the expertise with data sharing. It appears unlikely that the progress made could have been achieved without significant and ongoing support taking substantial resources in terms of time and expertise. In particular the challenges of understanding the issues in context, and therefore in French, combined with appropriate technical expertise places limits on the availability of people appropriate to provide this support.

Changing culture and the role of policy

The LASDEL group represents the Case Study in which the most significant change in practice was observed. In part this was related to their initial position, in which the idea of data sharing was relatively new, and in part down to the high level of support provided in

this case by the advisor. This demonstrates that it is feasible that where a funder provides policy direction alongside sufficient support a great deal of progress can be made.

It also aligns with emerging findings from other projects that Francophone regions may be well placed to make rapid progress by learning from the mistakes made in Anglophone (and to a lesser extent Latin American) areas and applying the benefits of those experiences directly. The language issues raise interesting questions for policy implementation and support provision. There are also questions about the distribution of research data sharing platforms, and the need for greater resources to be provided in French, and by extension in other languages.

The Pilot Project also helped to drive local conversations within LASDEL. Both practice and capacity were limited, with issues including a lack of group systems for sharing data. Challenges arose in finding common ground across the group. However it seems that the process was useful and made progress. The role of the funder in indicating direction here is extremely valuable. The flexibility to define how this was developed within the group was also important.

Grant title

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

References

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