

Institution: The University of Edinburgh
Unit of Assessment: Anthropology & Development Studies
Title of case study: 1: Tuberculosis Control in South Asia
<p>1. Summary of the impact</p> <p>Edinburgh research has played a central role in the development of Tuberculosis (TB) control policy in South Asia in general, and in Nepal in particular, with specific impact in placing patient-centred approaches at the heart of health policy. This has taken the following main forms:</p> <ul style="list-style-type: none"> • Development of desk manuals for health staff in the Nepal Tuberculosis Programme (NTP), recommending more flexible support for patients with TB. • Design and implementation of the Programme Management Unit (PMU) for the Nepal Tuberculosis Programme - enabling the release of \$3.5m for TB control, and setting in place national mechanisms for monitoring the effectiveness of TB control programmes. • Increasing the significance of, and capacity for qualitative research in TB prevention, both in South Asia and more globally. • Significant contributions to public debate on TB prevention in Nepal, and globally.
<p>2. Underpinning research</p> <p>Ian Harper has combined long-term research into TB control and community health, with direct engagement at the level of policy and practice in the National TB Programme in Nepal. This dual track approach has been at the core of all his research and engagement. Harper's research has highlighted the importance of context-specific social and political factors in understanding how the disease is controlled, how patients respond, and how drugs are made available. Whereas policy-makers and programme-implementers often think of TB as simply a technical or medical problem, Harper's research has provided strong empirical evidence for the importance of social context in influencing the ways in which TB control mechanisms are implemented and take effect.</p> <p>Since arriving in Edinburgh in 2004, Harper has worked on an ethnographic study of how the internationally recommended strategy for TB control, the Directly Observed Treatment Short course (DOTS) programme, was translated into local contexts. The research highlighted the importance of social relationships and cultural assumptions for the effective diagnosis and treatment of TB (2006, 2007). In doing so, one of the most significant implications of the research has been to stress the importance of qualitative methods in the assessment of TB programmes. The research argued that the use of rigid definitional categories in the monitoring of TB programmes marginalises some patients from treatment, and that randomised controlled trials have important limitations in the assessment of TB control effectiveness.</p> <p>In 2006-2009, Harper concentrated on issues around the production, marketing and distribution of anti-TB drugs, as part of a wider three-year ESRC/DfID multidisciplinary project on <i>Tracing Pharmaceuticals in South Asia</i>. The research highlighted the importance of local relationships of trust for the distribution of pharmaceuticals: trust of the companies that make the drugs, of the clinic spaces that provide the drugs, and of the relationships between pharmacists, retailers, wholesalers and others (2010, 2011a, 2011b). One of the most significant findings of the research was that any analysis of the potential effectiveness of TB control regimes needs to take into account the specific contexts of pharmaceutical production and distribution, especially the relationship between private and public sector providers on the ground.</p> <p>Harper started work as a PI on a Wellcome Trust Senior Investigator Grant in 2012. This is a 5-year research programme on <i>Understanding TB Control – Technologies, Ethics and Programmes</i>. This research focuses on the impact of the Global Fund on TB control and development aid, how drug resistant tuberculosis is managed, how new diagnostic technologies impact on health systems, and TB/HIV co-infection (from the perspective of those infected with HIV). This research has direct impact on policy and practice. The research has been designed with partners in Nepal</p>

specifically to develop their own capacity for operational research, and subsequent practical interventions.

3. References to the research

Brhlikova, P., I. Harper, R. Jeffery, et al. 2011b. 'Trust and the Regulation of Pharmaceuticals: South Asia in a Globalised World', *Globalisation and Health* 7 (10), DOI: [10.1186/1744-8603-7-10](https://doi.org/10.1186/1744-8603-7-10).

Ecks, S. and I. Harper. 2013. 'Public-Private Mixes: The Market: for Anti-Tuberculosis Drugs in India', In J. Biehl & A. Petryna (Eds). *When People Come First: Critical Studies in Global Health*. Princeton University Press, pp252-275, available via REF2.

Harper, I. 2006. 'Anthropology, DOTS and Understanding TB control in Nepal', *Journal of Biosocial Science* (2006) 38, 57-67, DOI: [10.1017/S0021932005000982](https://doi.org/10.1017/S0021932005000982)

Harper, I. 2007. 'Translating ethics: Researching public health and medical practices in Nepal', *Social Science & Medicine* 65: 2235-2247, DOI: [10.1016/j.socscimed.2007.08.007](https://doi.org/10.1016/j.socscimed.2007.08.007).

Harper, I. 2010. 'Extreme condition, extreme measures? Compliance, drug resistance and the control of tuberculosis', *Anthropology & Medicine*, 17 (2): 201-214, DOI: [10.1080/13648470.2010.493606](https://doi.org/10.1080/13648470.2010.493606).

4. Details of the impact

TB is the second leading cause of death from infectious diseases worldwide, with 95% of deaths occurring in the developing world. Harper's research goes to the heart of the practical issues involved in the implementation of TB control, and its impediments in terms of health sector fragility, limited resources and vulnerable local populations. Impacts have been cumulative, and emerge from both an expanding research agenda, but also from a growing set of practice-based engagements with policy-makers and practitioners. Through placing patient centred approaches at the heart of *policy and practice* Harper's research has had impact in the *development of resources to enhance professional practice*, in particular by developing desk manuals. The research has also influenced *planning or management of services* through coordinating the Nepali government's Programme Management Unit, the central mechanism for the assessment of Nepal's TB programmes. More broadly Harper's research has been used by donors and governments *to define best practice*.

Desk manuals. Harper's research directly contributed to the content of the *Tuberculosis Case Management Guideline for Health Workers and Doctors* (Desk Manual), published in Nepal in 2009. The manual is the key reference for all health workers dealing with TB in Nepal and is used in all 4,251 health institutions in the country. This impact was facilitated by Harper's coordination of a 2007 review of the Nepal Tuberculosis Programme on behalf of the International Union Against Tuberculosis and Lung Disease and the WHO. Against this background, with colleagues from Leeds, Harper directly contributed to the writing of the 2009 manual (5.2). Two key recommendations from Harper's review were central to the manual. First, the manual followed a 'patient-centred' approach, taking into account how tuberculosis impacts on people's lives in diverse and complex ways. Second, the manual permitted health workers to adapt supervision and patient support to patients' circumstances. In particular, Harper's 2006 *JBS* piece was directly referenced in the manual's support of the recommendation that more flexible (rather than institutional) support be made available to TB patients (5.1). The former National Health Policy Advisor for the Department for International Development in Nepal, described Harper's work on this project as being a 'champion who successfully brought the... voices of thousands of people with tuberculosis, which were unheard, into the policy framework' (5.2).

Programme Management Unit. Harper's research has consistently argued that TB control interventions need to attend to local circumstances and qualitative evidence, if they aspire to be

effective. In 2008, the Global Fund to Fight AIDS, TB and Malaria (GFATM), which channels 82% of all global financing to TB control, offered support to the Nepal Government. One of the conditions of the grant was the creation of appropriate local structures for implementation and monitoring. On the basis of his earlier research into these local conditions, Harper was seconded as Start-up Coordinator in the Nepal NTP from August to December 2008 at the joint request of the Government of Nepal and the WHO. The Programme Management Unit is the central device for assessing the impact of TB control mechanisms in Nepal. Harper designed the structure, wrote the job descriptions, and created the assessment manuals. He was also directly involved in planning for the procurement of TB drugs for the Nepali national TB programme. The funding released as a consequence of these new forms of monitoring, eventually totalled over \$3.5m, and Harper received a certificate of appreciation from the Nepal Government in recognition of his contribution (5.3).

Harper's work with the Programme Management Unit in Nepal, led to him playing a similar role in India. In 2009 Harper acted as a consultant with Grant Management Solutions (GMS) working with the Indian Revised National TB Control Programme to strengthen their monitoring and evaluation plan, stressing the importance of qualitative context specific forms of assessment (5.4). This work was another prerequisite for the release of a \$90m GFATM grant.

Increasing capacity around qualitative research. Harper's work has played a central role in increasing capacity around the use of qualitative evidence in the assessment of TB prevention strategies, both in Nepal and more globally. On one level, this has meant producing qualitative evidence itself. For example, Harper conducted an ethnographic survey of TB services in Pokhara, Nepal for the NGO HERD in 2009. The survey allowed more responsive planning for targeted interventions, with stronger links between public and private sector, in the provision of TB medications and support.

At another level, Harper has played a significant role providing training, advice and increasing the professional recognition given to qualitative research by practitioners. In 2012, for example, as part of the Wellcome programme of research, Harper ran a workshop (with Professor Roger Jeffery) with the NGO *HERD* on the use of qualitative research. Nine organisations participated, and Nepal's first *network* for qualitative research into the health sector was set up. In 2012 Harper facilitated a workshop in Kathmandu for policy-makers and academics on ethical review of health related research. He has also provided methodological advice for the Transcultural Psychosocial Organisation, Nepal (TPO) as they develop operational research into psychopharmaceutical markets in Nepal (5.10). More globally, through his role with the practitioner based *International Journal of TB and Lung Disease* he has also raised the profile on qualitative research in assessing the impact of TB control programmes, and set new guidelines for scientific standards in qualitative research into TB (5.5).

National and international development policy. Harper's insights are widely recognised as important for the development of international development policy. He has given talks on TB control to USAID and other donors in Nepal. In 2010 Harper participated in workshops developing policy paper positions on operational research in TB control for the WHO (5.6), and in implementing new diagnostic technologies for the *Gates Foundation* (5.7). In July 2012 he was invited to present a paper on the regulation of pharmaceutical marketing at the Logistics Management Division (LMD) in the Ministry of Health Nepal with participation from DfID, the German development agency GTZ and the Nepali Department of Drug Administration (DDA) (5.8). On the basis of Harper's research, DfID are currently considering further investment into the Nepal DDA to assist in the strengthening of their regulatory capacity (5.9).

Public debate. Harper has also made significant contributions to public debate about TB control and broader public health issues in Nepal. He was interviewed for Nepali TV in April 2009, has written comments and articles in newspapers, and magazines, and has given numerous local seminars in Nepal with local organisations (e.g., at Martin Chautari, a forum for public discussion and debate) on all aspects of his research (5.6).

5. Sources to corroborate the impact

PDFs of all web links are available at www.wiki.ed.ac.uk/display/REF2014REF3B/UoA+24

5.1 Tuberculosis Case Management Guideline for Health Workers and Doctors (Desk Manual), available from www.wiki.ed.ac.uk/display/REF2014REF3B/UoA+24.

5.2 Letter from Director of HERD. Corroborating Harper's influence on the NTP in developing patient-centred approaches to TB control, and Harper's involvement in workshop to rewrite the desk manuals. Provider is a reporter on the process of impact.

5.3. 'Certificate of Appreciation', from the Government of Nepal. Corroborating Harper's role in the Programme Management Unit, available at www.wiki.ed.ac.uk/display/REF2014REF3B/UoA+24.

5.4 Letter from Senior Associate, Grant Management Solutions. Corroborating Harper's role in the Indian Revised National TB Control Programme. Provider is a reporter on the impact process.

5.5 Evidence of working as an associate editor for the International Journal of Tuberculosis and Lung Disease (IJTLD), along with the co-written guidelines for submission and associated editorial: <http://www.theunion.org/index.php/en/journals/the-journal/about-the-journal/ijtld-editorial-board>; and http://www.theunion.org/images/stories/journal/IJTLDD_Guidelines_for_Qualitative_Research.pdf

5.6 Corroboration of examples of Harper's public presentations in *Martin Chautari*: <http://martinchautari.org.np/discuss/28-discussions/index.php>

5.7 Harper referenced as a contributor in WHO, 2010, 'Priorities in Operational Research to Improve Tuberculosis Care and Control': http://whqlibdoc.who.int/publications/2011/9789241548250_eng.pdf

5.8 Cobelens et. al. 2012. 'Which Diagnostics for Tuberculosis, and When?', *Journal of Infectious Diseases*, 205(s2). Corroborating evidence for Harper referenced as a member of the Gates Foundation 'Evidence for Scale-up Group', responsible for a policy statement on utilising new diagnostics for tuberculosis. DOI: [10.1093/infdis/jis188](https://doi.org/10.1093/infdis/jis188).

5.9 Evidence of presenting at the LMD Logistics Managements Division in the Ministry of Health Nepal, and impact on DfID funding considerations on DDA regulation. Letter from Health Policy Advisor, DfID, Nepal. Provider is a reporter on the process of impact.

5.10 Letter from Co-Founder of TPO Nepal. Corroborating Harper's impact on operational research. Provider is a reporter on the impact process.