



Case Study 10

The Health and Human Rights Programme

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Contents

List of Figures	4
Acronyms and abbreviations	5
The Health and Human Rights Programme	6
Teaching	6
The 'Train the Trainer' course	6
Teaching modules at UCT	8
Research	9
The Rights of the Deaf in the Health Care System	9
Equinet	10
Conferences and presentations	11
Community projects and advocacy	11
Dopstop	11
Health and Human Rights Network	12
The People's Health Movement	12
Advocacy and policy submissions	13
Networking and links	14
Lessons learned and recommendations	14
Lesson 1: Research, teaching and community engagement activities are synergistically reinforcing each other	14
Lesson 2: The dissemination strategy appears to be largely ad hoc	15
Lesson 3: Most materials are not adequately protected in term of copyright	15
Lesson 4: Profiling could improve the visibility of the contribution made by the HHRP	15
Lesson 5: Time and expertise to keep information up-to-date	15
Lesson 6: Value of having an outsider review the HHRP communication strategy and current website	16
Conclusion	16
References	16

List of figures

Figure 1: Cover of the Training Trainers for Health and Human Rights manual	7
Figure 2: Copyright openness with Creative Commons licences	8
Figure 3: An Equinet publication	10
Figure 4: An Equinet parliamentary briefing pamphlet	11
Figure 5: Poster on individual and collective rights in public health	13

Acronyms and abbreviations

CET	Centre for Educational Technology
EQUINET	Regional Network for Equity in Health in East and Southern Africa
FAS	Foetal alcohol syndrome
HHR	Health and Human Rights
HHRP	Health and Human Rights Programme
ICTs	Information and Communication Technologies
LMS	Learning Management System
MPH	Masters Programme in Public Health (at UCT)
NGO	Non-governmental organisation
OER	Open education resources
OSS	Open source software
SADC	Southern African Development Community
SAMJ	South African Medical Journal
SASL	South African Sign Language
SEAPACoH	Southern and East African Parliamentary Alliance of Committees on Health
TARSC	Training and Research Support Centre
UCT	University of Cape Town

The Health and Human Rights Programme

From 1997 to 1999, the University of Cape Town's (UCT) School of Public Health and Family Medicine jointly established and ran the Health and Human Rights project (HHRP) with a human rights NGO, the Trauma Centre for Survivors of Violence and Torture, to devise a submission to the Truth and Reconciliation Commission on health-related issues.¹ The HHRP subsequently assisted the organisation of the commission's health-sector hearings. This collaboration resulted in the publication of a book based on the submissions and stimulated the inclusion of human rights in undergraduate teaching. After the project closed in 1999, the focus of the department shifted to research on human rights issues and the training of university educators of health professionals.² The HHRP provided the basis for the development of the Health and Human Rights Division within the School of Public Health and Family Medicine.³

Teaching

The teaching undertaken by the HHRP occurs within UCT and beyond in association with other partners. We discuss the latter first as it highlights both the use of ICTs and potential open dissemination models.

The 'Train the Trainer' course

Since 1998 the HHRP has run a 'Train the Trainer' course for academics who teach health professionals at higher education institutions in South Africa. In the past this course has drawn on contributions from UCT and other training institutions, related agencies (such as the Human Rights Commission, the Statutory Councils and professional associations), NGOs, and past participants of the course itself (UCT 2007:21). In 2009 the co-convenors of the course will be drawn from UCT Public Health and Family Medicine and Trinity College, Hartford, USA with a specialist contribution from a local advocate.

According to the Social Responsiveness report:

To date, approximately 200 staff have been trained [by the HHRP]. The programme provides them with the skills to implement curriculum change in their own institutions, skills related to teaching about human rights, and skills for promoting transformation. Trainees have included nurses, physiotherapists, doctors, community activists, NGO workers and lawyers, all involved in some way in the training of health professionals. More recently, participants from human rights networks of health professionals from Southern and East Africa have joined the programme. (UCT 2007: 21)

Key ways in which ICTs are being deployed within this course include the marketing of the course on the HHRP website;⁴ the use of the learning management system (LMS) at UCT which is a version of the open source software (OSS) platform Sakai called 'Vula' (which means 'open' in Xhosa) and the deliberate inclusion of a session where participants go online to identify resources for HHR teaching. The course coordinators also subscribe course alumni to the ETiHHRnet, a closed mailing list, after the course, to try to set up and broaden

1 <http://www.hhr.uct.ac.za/about/about.php> [accessed 30 October 2008]

2 http://www.uctsocialresponsiveness.org.za/Activities/detail.asp?prj_ID=56 [accessed 30 October 2008]

3 <http://www.hhr.uct.ac.za/about/about.php> [accessed 30 October 2008]

4 [Ibid.](#)

an electronic network. In particular, the course manual, *Training Trainers for Health and Human Rights*, is made available online. While not an online course, this 69-page freely downloadable manual covers:



- Human rights violations and the health worker
- The origins and underpinnings of human rights
- Claiming health rights: the South African situation
- Objectives-based health and human rights curricula
- Councils and professional associations
- Training institutions
- The relationship between bioethics and human rights: implications for teachers
- Resources for education and training in health and human rights
- Core competencies revisited
- Implementation issues
- Developing teaching materials
- Leadership and advocacy

Figure 1: Cover of the Training Trainers for Health and Human Rights manual

As no copyright is specified in this manual, it might be assumed by a reader to be in the public domain where no rights are reserved. If this were so, the publication would be available for others to use without any attribution to the original authors, and could be appropriated and reworked without penalty. However, the legal default is that nothing is in the public domain unless so stated explicitly, and any written resource is thus protected by copyright, with all rights reserved (until the copyright expires). Anyone wanting to copy or reuse the content must therefore apply for permission. As far as this manual is concerned, a protected, yet open, way would be to copyright it under an alternative licensing model such as Creative Commons (see below), where there is a range of six options to choose from.

A detailed explanation, with examples of each licence, is given on the Creative Commons website. These licences offer a spectrum of intellectual property rights that allows authors or lecturers to offer their work to others under certain specified conditions – from the most restrictive licence, which allows others to copy, distribute, display and perform the work only if it is unchanged, to the most accommodating, which allows others to copy, distribute, remix and extend the original work – even commercially – as long as the original author is acknowledged. A key condition for all these licences is ‘author attribution’ so that the originator’s contribution is always legally recognised (Figure 2).








Copy-right	Creative Commons Licences						Public domain
	All rights reserved	Attribution Non-commercial No derivatives	Attribution Non-commercial Share alike	Attribution Non-commercial	Attribution No derivatives	Attribution Share alike	
							
							
Most restrictive				Most accommodating			
<i>BY = Attribution</i>		<i>NC = Non-commercial</i>		<i>ND = No derivatives</i>		<i>SA = Share Alike</i>	

Figure 2: Copyright openness with Creative Commons licences

To ensure that these licences are applicable in various legal jurisdictions around the world, the Creative Commons site offers lecturers the option to choose a licence applicable in their own country. This licence is then made available in three forms:

- As a Commons Deed – a simply worded summary of the licence.
- As Legal Code – a more comprehensive document that ensures that the licence will stand up in court.
- As Digital Code – a machine-readable version of the licence that allows search engines to find materials with various licences.

The Training Trainers for Health and Human Rights manual is already a fully functional open educational resource (OER), but it does not as yet have the legal protection that is recommended. This is also true of the accompanying comprehensive 492-page resource manual to support trainers in running their own courses.

Teaching modules at UCT

The HHRP also offers two taught programmes:

- Special Study Modules in Health and Human Rights⁵
- MPH Module: Public Health and Human Rights (PPH 753S)⁶

The special study modules are compulsory four-week periods of supervised study which form an integral part of the new MB ChB curriculum at UCT. Students elect to do different modules offered on a rotational basis by departments.

The module in Public Health and Human Rights is part of the School’s Masters Programme in Public Health (MPH). It is run over a semester as a series of weekly or biweekly seminars, and is suited for part-time students resident in Cape Town. The MPH course website makes available the course objectives, content, module

⁵ <http://www.hhr.uct.ac.za/teaching/teaching.php#ssm> [accessed 30 October 2008]

⁶ <http://www.hhr.uct.ac.za/teaching/teaching.php#mph> [accessed 30 October 2008]

structure, readings, assessment strategy, evaluation strategy and the teaching strategy. The course syllabus alone can be considered as an OER, according to the OER Commons, which describes OER as:

teaching and learning materials that are freely available online for everyone to use, whether you are an instructor, student, or self-learner. OER may be either Course-Related Materials or Libraries and Collections items. Course-Related Materials include both Full Courses and Learning Modules. Components include syllabi, lectures, lesson plans, homework assignments, quizzes, lab activities, pedagogical materials, games, and simulations. Libraries and Collections items are resources from digital media collections or libraries of digitized primary sources.⁷

Research

The HHRP website⁸ lists four specific areas of research:

- Development of an Implementation Tool for the Patient Rights Charter.
- The Rights of the Deaf in the Health Care System.
- Equinet Research.
- Dual Loyalties.

Two of these areas of research, 'The Rights of the Deaf in the Health Care System' and 'Equinet Research', are discussed in more detail to highlight the use of ICTs and open dissemination models.

The Rights of the Deaf in the Health Care System

The Social Responsiveness report (UCT 2007) reports on a project, which aims to extend the right of access to health care of deaf people in Cape Town:

The deaf people who are the focus of the project are those who are born deaf or who become deaf as children and whose first language is South African Sign Language (SASL). The project aims to make professional SASL interpreting services an integral part of health care in Cape Town. The dire shortage of interpreting services and the often serious consequences for the health and human rights of deaf people emerged from a long-term social anthropological study. The work in public health and human rights has involved undergraduate health science students working alongside deaf research assistants and learning from them. Academic and advocacy outputs have been achieved, with the students and deaf people collaborating to produce a pamphlet of guidelines to assist health care staff. The work has also established interdisciplinary collaborations locally and internationally. (UCT 2007: 22, emphasis added)

It would be useful to have a link to a downloadable version of this 'pamphlet of guidelines' covered by a Creative Commons licence that could allow for re-working of the original material, yet with full acknowledgment of the original authors. It would also be interesting to have details about and links to some of the research work in this area, for example Marion Heap's 2006 article 'Sign-deaf spaces'.

7 <http://www.oercommons.org/help/learn-more-about/oer> [accessed 30 October 2008]

8 <http://www.hhr.uct.ac.za/research/research.php> [accessed 30 October 2008]

Equinet

Equinet is the Regional Network on Equity in Health in East and Southern Africa. Staff of the School of Public Health and Family Medicine are members of the steering committee of Equinet,⁹ and the staff in the HHRP contribute specially on the theme of Health Rights.

As a contribution to Equinet, staff in the HHRP produced a research report (London 2003) and a human rights audit for SADC countries (Kamupira and London 2005). In association with Equinet, the Southern and East African Parliamentary Alliance of Committees on Health (SEAPACoH), and the Training and Research Support Centre (TARSC) in Zimbabwe, the School of Public Health and Family Medicine produced a series of parliament briefing documents (Figure 3 and Figure 4).

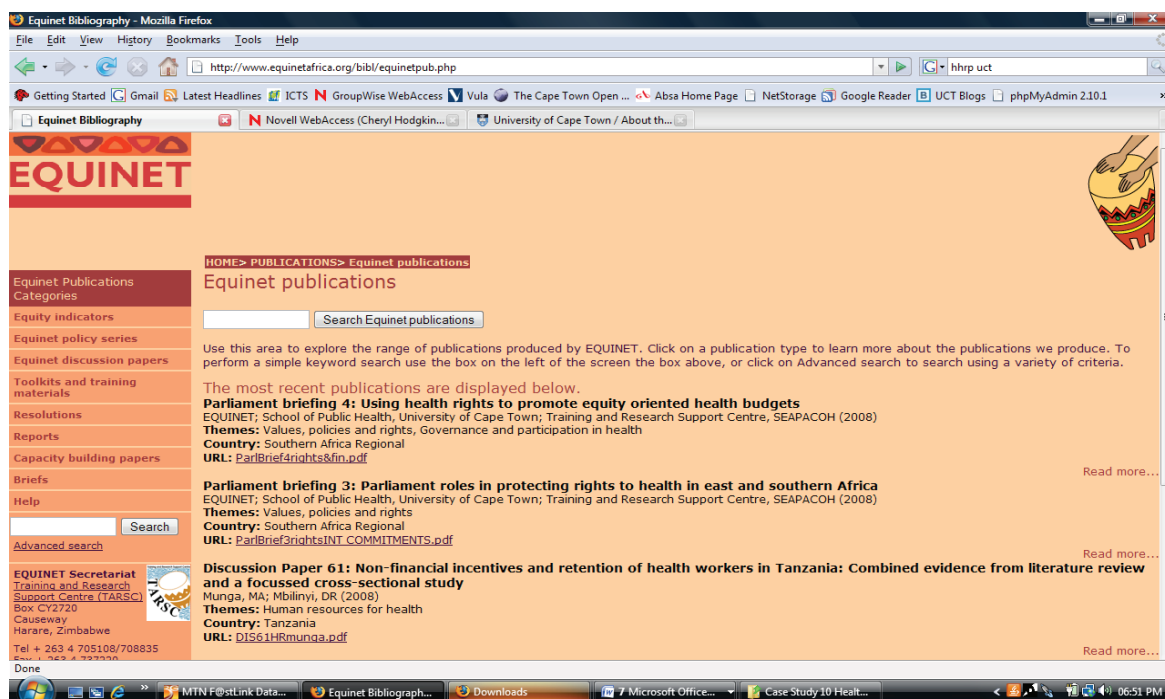


Figure 3: An Equinet publication¹⁰

Like the training manual discussed above, these parliament briefings are available online but without the licence that would make them freely available. They would benefit from a Creative Commons Attribution Share-Alike licence.

⁹ <http://www.equinet africa.org/> [accessed 30 October 2008]

¹⁰ <http://www.equinet africa.org/bibl/equin etpub.php> [accessed 30 October 2008]

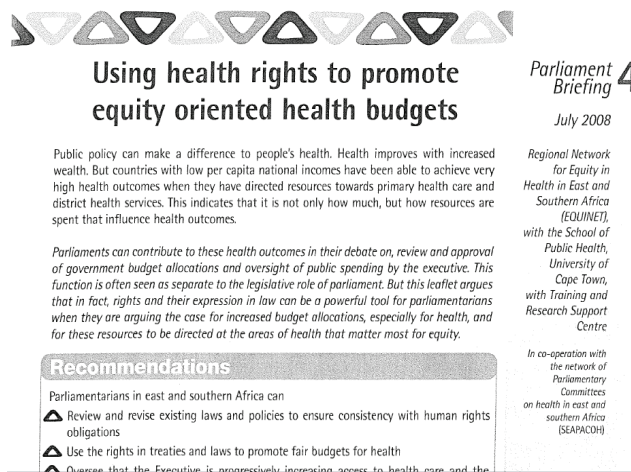


Figure 4: An Equinet parliamentary briefing pamphlet

Conferences and presentations

The 'Conference' section of the HHRP website currently lists only a 2006 conference, together with PowerPoint presentations from the speakers. Each of these presentations could act as an OER since they are accessible to anyone. Once again, as there is no copyright indicated, the authors of these presentations would be better served through the inclusion of an appropriate Creative Commons licence. In addition it would be helpful to have other such conference presentations made available on the website as these are often visually interesting and accessible to a broad audience.

Community projects and advocacy

Dopstop

Dopstop is a Western Cape NGO that started as a collaboration between UCT (Public Health), the University of the Western Cape (Public Health), Stellenbosch University (Social Work), the Centre for Rural Legal Studies, farmers, farm worker representatives, and public health services. It works towards the eradication of the 'dop' system¹¹ and its legacy among rural farming communities in the Western Cape, particularly through developmental approaches to address the excessive use of alcohol in rural communities.

The project has adopted the principles of the Ottawa Charter on Health Promotion, which include the reorientation of health services, policy interventions, advocacy, training, and the empowerment of communities most affected by alcohol. It helped pioneer the Farm Health Award, which acts as an incentive for farmers to improve the living and working conditions of their farm workers, and has implemented health and development programmes on farms, and in rural schools. The project has built partnerships among rural NGOs and between NGOs and government and industry organisations, and has provided a platform for research and training for interns and Masters students. It is a partner in a large collaborative prevention project on foetal alcohol

¹¹ The 'dop system' describes the remuneration system for some farm workers – particularly on the wine farms in the Western Cape – where a portion of their wages are "paid" in the form of alcohol. A 'dop' is Afrikaans for an alcoholic drink.

syndrome involving UCT, the Medical Research Council, the University of Pretoria and the Centre for Disease Control at Stellenbosch University. The project has also provided policy inputs to provincial and national government on alcohol policy. UCT played a founding role in the project, and since Dopstop has developed into an independent NGO with sustainable funding, UCT continues to be a partner in its development, research and advocacy work (UCT 2007: 21–22).

To market the fact that the UCT School of Public Health and Family Medicine is a partner in the Dopstop initiative, it would be valuable for there to be a link from the Dopstop website¹² to the HHRP website. Moreover, although staff members from the School were involved in the foetal alcohol syndrome presentation to the Parliamentary Portfolio Committee, there is currently no link to this presentation – something that might be a useful resource for others. It would also be helpful to list at least some of the academic articles that have been written in this area, for example, the 1998 South African Medical Journal (SAMJ) paper by London et al. and London's 1999 papers in Social Science and Medicine and in the Medical Research Council bulletin so that those interested know what information is available.

Health and Human Rights Network

The HHRNET mailing list was established in 1997 by the HHRP as part of the Health and Human Rights Division within the UCT School of Public Health and Family Medicine. According to the HHRP website, the

vision of the Project is the establishment of a culture of human rights in health, in a society where human rights are respected, and where the mutually reinforcing relationship between health and human rights is explicitly recognised.

In order to communicate with individuals and groups who wish to participate in the sharing of information and debates relating to health and human rights, interested parties can join the HHRNET¹³ which is hosted by the Health Systems Trust.

During the author's interview with him, the Director of the HHRP pointed out what a time-consuming, though valuable, process running a mailing list is. With their current complement of four staff – the director, a post-doc fellow, a research assistant and the deputy dean – it is difficult to maintain an up-to-date web presence.

The People's Health Movement

The People's Health Movement was established in 2005. According to the UCT Social responsiveness report:

[S]everal staff members in the department have joined the People's Health Movement as activists. They conduct research on the movement's methods, using ethnographic methods, and became involved in establishing a learning network of civil society groups in urban and rural Western Cape. This network has been established to help participants develop ways of accessing their rights in the health context. A pilot study, funded by the Centre for Civil Society at the University of KwaZulu-Natal, and the research on the People's Health Movement has influenced the way in which the network is being established. The process involves combining training and research in

12 <http://www.dopstop.org.za/> [accessed 30 October 2008]

13 Send email to: lyris@hst.org.za with the following text in the subject line of the email message: subscribe hhrnet (where you replace the part in <> with your name).

a dialectical relationship: the researchers participate in the network and research the process at the same time. (UCT 2007: 22)

One of the visible outputs of this movement is the production of various posters aimed at the public. For example, Poster 4, in the space of a double-sided A3 two-colour sheet (Figure 5), attempts to provide a simple answer to the question: What are individual and collective human rights?.

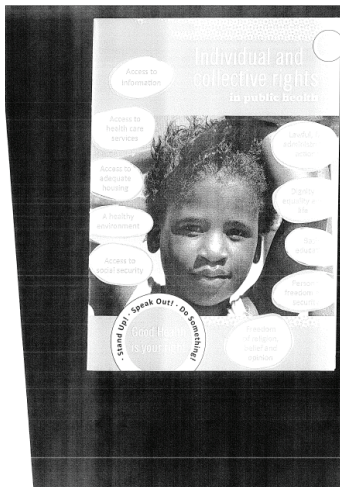


Figure 5: Poster on individual and collective rights in public health

As has happened with a number of the above-mentioned cases, the copyright on these posters is not specified. Again, as suggested previously, a protected, yet open way would be to copyright these posters under a Creative Commons licensing model.

Advocacy and policy submissions

The HHRP website helpfully differentiates advocacy activities and policy submissions from its other work, but regrettably merely lists the various resources. These need to be hyperlinked to the primary source documents for readers wanting more detail. The documents listed are:

- AIDS and HIV – letter to the President and Minister of Health – see London *et al.*, SAMJ (2000) 90: 444.
- COIDA and the Public Protector – see Onwuchekwa *et al.* Occupational Health Southern Africa (2002); 8: 8-11.
- SAMDC legislation - presentation to the Parliamentary Portfolio Committee.
- Dopstop presentation on foetal alcohol syndrome to the Parliamentary Portfolio Committee.
- HIV Notification.
- HIV Code of Conduct for Department of Labour.
- Department of Health Ethics Codes for Research.

Neither of the two articles above from scholarly journals is directly available online. It might be worthwhile for the HHRP to contact the SAMJ¹⁴ and the project coordinator of the South African Society of Occupational Medicine to request that these be made available online. As already suggested, there should, ideally, also be electronic links to all these documents from the HHRP website.

Networking and links

The HHRP website has a 'Links' item that provides – with many electronic links – an extensive list of human rights network and discussion groups including:

- Email bulletins.
- Health and human rights internet guides, databases and search engines.
- Academic centres for health and human rights.
- Health and human rights journals and journal alerts.
- Health and human rights organisations.
- Human rights education.
- Research and public health ethics.

This is a very useful list, but as the director points out, the challenge is to keep it up-to-date.

Lessons learned and recommendations

The HHRP showcases possible synergies between research and teaching and learning, but also highlights the necessity of using ICTs strategically to promote its work and maximise the use of the various resources that they have produced over the years.

The key lessons learned and key recommendations are as follows:

Lesson 1: Research, teaching and community engagement activities are synergistically reinforcing each other

The various research activities are feeding into teaching and training both within the university, as modules within traditional courses, and in the broader community with open resources such as the trainers' manuals, pamphlets, posters, and presentations.

Potential ways forward

The affordances of ICTs can be used to enhance and extend this synergistic relationship by reconfiguring the HHRP website and creating additional electronic links.

¹⁴ <http://www.samj.org.za/index.php/samj> [accessed 30 October 2008]

Lesson 2: The dissemination strategy appears to be largely ad hoc

The strategy behind the use of ICTs – and also of paper-based materials – is mostly implicit and therefore appears to be largely ad hoc. This should not be seen as a criticism, since many departments at UCT would do well to emulate what the HHRP has already achieved. It is rather a plea to make the useful resources developed by the HHRP more readily available to the broader public.

Potential ways forward

Deliberately plan the dissemination strategy to optimise the use of ICTs and paper-based resources.

Lesson 3: Most materials are not adequately protected in term of copyright

Although the copyright is not specified in most of the resources that the HHRP produces, these resources are not – contrary to popular opinion – in the public domain with no rights reserved. The legal default is that nothing is in the public domain unless so stated explicitly, and any written resource is thus protected by copyright, with all rights reserved. Anyone wanting to copy or reuse the content must therefore apply for permission.

Potential ways forward

A protected, yet open, way of making materials available would be to copyright the resources under an alternative licensing model such as Creative Commons, where there are six options to choose from. Depending on the purpose and the specific content of each resource, at least one of the Creative Commons licences should be suitable.

Lesson 4: Profiling could improve the visibility of the contribution made by the HHRP

Unfortunately, much of what the HHRP and the academics involved contribute is unseen and difficult to find, as inadequate attention has been given to the profiling of the project and individual academics. This makes it difficult for various stakeholders – including the general public, donors, university agencies and government – to make optimal use of the work undertaken by HHRP or to note the contributions of individual academics. The HHRP could be a very useful platform for showcasing what the various academics have done, both for university purposes and for interested donor agencies.

Potential ways forward

Investigate the current profiling of the HHRP and the individual academics contributing to the programme and use ICTs more strategically to make the HHRP's contribution more visible and easily accessible.

Lesson 5: Time and expertise to keep information up-to-date

Material on some parts of the website is slightly out of date. It was evident from the interview with the Director of the HHRP that the tasks of keeping information current and responding to individual requests falls on the shoulders of very few staff members.

Potential ways forward

The website is the HHRP's main window to the rest of the world, showing what it does and how it contributes to social development. So it could be helpful to allocate the updating of the website to specific people for specific periods (it does not necessarily have to be one person's job, but it does need to be clear who is responsible for what and for how long). To expedite this strategy it would be useful to identify the skills required and assess to what extent these already exist within the department, and where further training might be necessary. Alternatively, outsourcing could be considered, but it needs to be borne in mind that this would still require input regarding content and linkages from the HHRP staff.

Lesson 6: Value of having an outsider review the HHRP communication strategy and current website

The HHRP have, in their self-proclaimed ad hoc way, still managed to use the web quite well for marketing what they do and disseminating their materials. What was interesting to note was how, both in the interview and in the subsequent review of this report, the staff members were able to re-appraise their own communication strategy – seen through the eyes of others – and note areas where they are doing far more than they are reflecting publicly. For example, one person commented: '[t]his makes me realise that we are doing more current FAS [foetal alcohol syndrome] work (co-convoked a symposium on FAS research at the MRC in Sept) but haven't thought to put that on the website', highlighting that an outsider view could spark additional ideas.

Potential ways forward

Discuss the communication strategy with a specialist in the area and debate ways forward for the HHRP with staff and possibly the Dean or Deputy Dean.

Conclusion

This HHRP case study clearly illustrates how research, teaching and community engagement activities can exist symbiotically and how ICTs, to some extent, are already extending the reach of what this project is doing. More deliberate and strategic planning of the use of ICTs to profile the project and the academics is recommended as well as the use of more open dissemination models to distribute existing and future resources.

References

- Córcoles, C Hornung-Prähauser, V Kalz, M Minguillón, J Ferran Ferrer, N Naust-Schulz, V & Schaffert S (2007) Introduction: PLAN of the use of Open Educational Resources (OER). http://www.olcos.org/cms/upload/docs/Introduction_en.pdf [accessed 30 October 2008].
- Geser G, Salzburg Research and EduMedia Group (2007) Open educational practices and resources: OLCOS Roadmap 2012. Open eLearning Content Observatory Services. http://www.olcos.org/cms/upload/docs/olcos_roadmap.pdf [accessed 30 October 2008].

- Heap, M (2006) Sign-deaf spaces: The deaf in Cape Town creating community, crossing boundaries, constructing identity. *Anthropology Southern Africa*, 29 (1&2): 35–44.
- Kamupira, M and London, L (2005) An audit of human rights commitments relevant to health [sic] made by member states of the Southern African Development Community (SADC): Implications for advocacy for health equity and the realisation of the right to health. The Regional Network for Equity in Health in Southern Africa (EQUINET). Harare. <http://www.equinetafrica.org/bibl/docs/DIS25rights.pdf> [accessed 30 October 2008].
- London, L (1999a) Addressing the legacy of the Dop System: Tackling alcohol abuse among South African farm workers. *Urban Health and Development Bulletin*, 2(1). Cape Town: Medical Research Council.
- London, L (1999b) The 'dop' system, alcohol abuse and social control amongst farm workers in South Africa: a public health challenge. *Social Science and Medicine*, 48(10): 1407–1414.
- London, L (2003) Can human rights serve as a tool for equity? Equinet Discussion Paper 14. Co-published by the Regional Network for Equity in Health in Southern Africa (EQUINET) and the University of Cape Town School of Public Health and Family Medicine, December. Harare. <http://www.equinetafrica.org/bibl/docs/POL14rights.pdf> [accessed 30 October 2008].
- London, L Sanders, D Te Water Naude, J (1998) Farm workers in South Africa – the challenge of eradicating alcohol abuse and the legacy of the 'dop' system. *South African Medical Journal*, 88. Cape Town.
- Robson, C (1993) *Real World Research*. Oxford: Blackwell.
- University of Cape Town (2007) *Social Responsiveness Report: Portraits of Practice 2007*. University of Cape Town.