

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

Realizing the Right to Health through the use of health print materials in the Western Cape, South Africa

BY

MORGAN STRECKER

SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER IN PUBLIC HEALTH

IN THE FACULTY OF HEALTH SCIENCES

SCHOOL OF PUBLIC HEALTH AND FAMILY MEDICINE

UNIVERSITY OF CAPE TOWN

SUPERVISOR:

PROFESSOR LESLIE LONDON

FEBRUARY 2011

DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and has not previously in its entirety or in part been submitted at any other university for a degree

Signature:

Signed by candidate

Date: February 29th, 2011

University of Cape Town

ABSTRACT

This qualitative study was conducted in Cape Town, South Africa in 2010. It examines the effectiveness of promotional educational pamphlets on the awareness, understandings and practice of the right to health among eight civil society organizations and their constituents.

The purpose was to evaluate the pamphlets developed by the Learning Network and, in doing so, highlight the facilitators and barriers to accessing and understanding information on health rights as well as taking action towards strengthening the right to health. Understanding the various challenges to health literacy provides an opportunity for health and human rights practitioners to explore new ways of and for learning, new approaches as well as new vehicles to enhance community empowerment around health issues such as the right to health.

The literature review revealed that print materials alone are essential but not sufficient to increase knowledge and action around health rights. Moving towards collective agency on health rights is not a one-approach-fits-all but rather a consultative and participatory process carried by motivated individuals and organizations who see value in health rights. Therefore the theoretical and conceptual framework drew on a range of literature within the broader context of health promotion, inclusive of print materials, theories of behavior change, adult education and health literacy – all of which have links to health learning and, as a result, collective empowerment. Health learning among civil society organizations is an essential prerequisite to achieving the effective participation and empowerment of individuals and communities.

Active citizenship is a key determinant in the implementation and promotion of the right to health but can only be achieved through an informed demand by people for the protection and promotion of their rights. Print materials are one of the most effective channels for communicating information but require strategies to facilitate co-learning and organisational commitment. This qualitative study, combining semi-structured interviews and focus groups conducted with 59 participants including staff and constituents from eight civil society organizations (CSOs), focuses on what works to enhance awareness of health rights, and why it does or does not. Facilitating factors for effectiveness include the presence of committed and skilled individuals, existing material, a CSO commitment to health rights and being part of a collective. Co-learning and dissemination strategies are essential for pamphlets to work. The failure to reach constituents requires additional organizational and collective work.

ACKNOWLEDGEMENTS

I wish to express my sincere gratitude to the following people who contributed to this study and who made it possible through their continual support and understanding:

- ❖ My supervisor, Professor Leslie London, for his time, advice, guidance and support towards the completion of this mini-dissertation.
- ❖ Mr. Christopher Colvin, Professor and Senior Research Officer in Social Sciences and HIV/AIDS, TB and STIs for his continued support and advice.
- ❖ Ms. Nicole Fick, Research Coordinator for the Learning Network, for her advice and support during the initiation of the research.
- ❖ The following organizations, and most particularly the respondents, who participated in this study:
 - ❖ Epilepsy South Africa
 - ❖ Ikhaya Labantu
 - ❖ Ikamva Labantu
 - ❖ Metro Health Care Forum
 - ❖ The Women's Circle
 - ❖ The People's Health Movement
 - ❖ Women on Farms
- ❖ My partner, close friends and family for their patience and encouragement throughout the completion of the MPH programme and mini-dissertation.

Morgan Strecker
February 2011

Table of Contents

Part A – Protocol of the study	1
Abstract.....	1
Background	1
Research Questions.....	4
Study Methodology	5
Research Setting.....	5
Population & Sampling	6
Recruitment	7
Data Collection	8
Data Management.....	9
Data Analysis	10
Limitations.....	11
Logistics	12
Ethics	13
Write-up & Dissemination.....	14
Part B – Structured Literature Review	15
Information as a means to community empowerment.....	15
Human Rights and the right to health	16
The right to health in South Africa.....	18
Adult learning and community empowerment	19
The role of printed materials in promoting health-related information.....	21
Theories towards triggering change in health information & behavior	24
Evaluating the LN pamphlets.....	25
References	27
Part C – Journal Ready Manuscript	30
Abstract.....	
Setting the stage	
The current study	
Findings	
Discussions – Creating conditions for effectiveness	
Conclusion	
Acknowledgements.....	
Funding.....	
References	
Part D – Appendices	46
Appendix A – Timeline.....	46
Appendix B – Ethics Approval	47
Appendix C-1 – Topic Guide for Interviews	48
Appendix C-2 – Topic Guide for Focus Groups.....	49
Appendix D – Consent Form.....	50
Appendix E – Instructions for Authors (Health Promotion Int.).....	51
Appendix F – Examples of Community Empowerment.....	56
Appendix E – Recommendations for the Learning Network.....	57

RESEARCH PROTOCOL

Realizing the Right to Health through the use of health print materials in the Western Cape, South Africa

Morgan Strecker (STRMOR004)

Abstract

Findings from previous research indicate that while civil society organizations have a general sense of the types of rights which exist, they can not simply define a human right¹. One of the key outcomes of this research was the establishment of a Learning Network (LN) to advance health equity through human rights strategies. Among the various strategies of the LN was the development of communication tools around the right to health in the form of 6 pamphlets. The following qualitative research study seeks to assess the effectiveness of the Learning Network (LN) pamphlets developed around the right to health among 6 civil society organizations actively involved in the LN, their members and their constituents. Furthermore, the research will seek to understand the impact of the pamphlets on CSO, community and individual awareness and action around the right to health as well as provide suggestions for improvements

A combination of semi-structured interviews and focus groups conducted with eight CSOs, their members, beneficiaries and communities; and complemented with a literature review will seek to explore the effectiveness of the six LN pamphlets in enhancing community and individual awareness, as well as the understanding and practice of the right to health.

Background

Since 1946, the right to the highest attainable standard of health has been explored and recognized in a myriad of international fora. The World Health Organization (WHO) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”². Moving health away from the private sphere and onto the international and public agenda, the WHO’s definition

¹ Thomas J, London L. Towards establishing a learning network to advance health equity through human rights strategies. Report to the Centre for Civil Society, University of Kwazulu Natal, December 2006.

² World Health Organization. (1946). WHO Definition of Health. Retrieved September 2nd, 2010, from <http://www.who.int/about/definition/en/print.html>

opened the door to exploring other factors impacting human well-being such as physical and social surroundings. Ensuing international and regional human rights instruments recognizing health as a human right include the 1948 Universal Declaration of Human Rights (Article 25), the 1976 International Covenant on Economic, Social and Cultural Rights (Article 12), the 1978 Declaration of Alma-Ata on Primary Health Care, the 1981 African Charter on Human and People's Rights (Article 16). Additional international conferences such as the 1994 International Conference on Population and Development have focused on specific health issues such as reproductive health and family planning services. The 2000 UN General Comment 14 recognizes health as "a fundamental human right indispensable for the exercise of other human rights" and outlines explicitly the states' obligations in ensuring access to health for all, inclusive of availability, accessibility, acceptability and quality of health care³.

In the South African context, the 1994 elections provided the momentum for tremendous change to overcome the discrimination and segregation engrained throughout Apartheid. In light of national and international events, human rights (inclusive of political, civil and socio-economic rights) and gender issues were prioritized in the drafting of the 1996 Constitution. This resulted in a right to health encompassing not only access to healthcare but also the necessary protection of the social determinants of health such as the right to education, to housing, to a safe environment or to food and water as essential and indivisible to attaining the highest level of health. While heralded as one of the most advanced constitutions globally, the concept of *progressive realization* in which the "state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights"⁴ has probably contributed to the slow growth of healthcare access for all in South Africa.

Despite remarkable changes since 1994, South Africans still struggle to realize their health rights. South Africa remains a country with profound health inequalities in the distribution of resources and access to adequate and acceptable services. Districts with the highest burden of disease receive fewer health care resources than wealthier districts – a reality that both managers and policymakers acknowledge but find extremely hard to challenge.⁵ Compounding the lack of resources or inequitable resource allocations is the lack of knowledge or awareness of the right to health among individuals and communities. Furthermore, when there is a sense of awareness or knowledge, translating that into understanding and practice is filled with difficulties and obstacles.

³ United Nations High Commissioner for Human Rights. (2000) *General Comment 14*. Retrieved September 2nd, 2010, from [http://www.unhchr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En)

⁴ South Africa Constitution. (1996). Retrieved September 2nd, 2010, from <http://www.info.gov.za/documents/constitution/index.htm>

⁵ Victora, G. The challenge of reducing health inequalities. *American Journal of Public Health* January 2006; 96(1):10

Hence the need for sustainable advocacy and organized community demand in order to push for equitable access to care as has been the case in South Africa on a number of issues. South Africa's Treatment Action Campaign demonstrated the effectiveness of human rights litigation for socio-economic rights in creating the opportunity for effective civil society action as well as gaining legitimacy through a popular discourse framed in socio-economic rights terms⁶. Greater organized and informed community demand is necessary to redress South Africa's social inequalities and therefore, requires individuals and communities to have access to adequate information (the right to information). Empowerment through awareness-raising and knowledge must be given to those most vulnerable to enable them decision-making scope to change their conditions of vulnerability⁷. "Thus, individuals, groups, and communities whose rights have been or are likely to be violated have choices and capabilities, and the extent to which a human rights approach enables them to exercise their agency in such choices is critical"⁸.

Three studies laid the basis for the development of the Learning Network. First, research into case studies in the Southern African region provided a conceptual framework for the role of collective agency⁹ in realizing health rights¹⁰. A second study with three civil society organizations in the Western Cape identified the need to enhance CSOs capacities to realize health rights¹¹. A third study into the Patients Rights Charter identified the importance of changing the culture of health worker practice to create a climate of mutually shared respect for human rights between users and providers of health care¹². In response, the Learning Network was established involving 6 CSOs committed to exploring various strategies to strengthen civil society agency to realize health rights. Among the strategies used

⁶ L. London, "Can Human Rights Serve as a Tool for Equity?" Equinet Discussion Paper 14 (Harare, Zimbabwe: Regional Network for Equity in Health in Southern Africa [EQUINET] and University of Cape Town School of Public Health and Family Medicine, December 2003). Available at <http://www.equinetafrica.org/bibl/docs/POL14rights.pdf>; L. London, "Issues of Equity Are Also Issues of Rights': Lessons from Experiences in Southern Africa," *BMC Public Health* 7/14 (2007). Available at <http://www.biomedcentral.com/content/pdf/1471-2458-7-14.pdf>.

⁷ London, L. What is a human rights-based approach to health and does it matter? *Health and Human Rights – An International Journal* 2008. 10(1). Available at <http://hhrjournal.org/index.php/hhr/article/viewArticle/25/84>

⁸ Ibid

⁹ Agency refers to an individuals' ability to intentionally pursue interest and to have some effect on the social world, altering the rules or the distribution of resources (Scott, 2001). Collective agency refers to the process by which an individual or a community identifies its needs or objectives, develops the confidence and the will to work at these needs or objectives, finds the resources to deal with these needs or objectives, takes action in respect to them, and in so doing extends and develops co-operative and collaborative attitudes and practices in the community (Ross, 1955).

¹⁰ London L. 'Issues of equity are also issues of rights': Lessons from experiences in Southern Africa. *BMC Public Health* 2007, 7:14.

¹¹ Thomas J, London L. Towards establishing a learning network to advance health equity through human rights strategies. Report to the Centre for Civil Society, University of Kwazulu Natal, December 2006.

¹² London L, Holtman Z, Gilson L, Erasmus E, Khumalo G, Oyedele S, Ngoma B. Operationalising Health as a Human Right: Monitoring Tools to Support Implementation of the Patients' Rights Charter in the Health Sector. Report to the Health Systems Trust, April 2006. HST: Durban.

was the development and dissemination of six pamphlets providing information on various crucial aspects of health rights and their realization:

1. The overall right to health
2. Community involvement and the right to health
3. The Patients' Rights Charter
4. Individual and collective rights to public health
5. Access to information and the right to health and health care
6. Rights and resource allocation with regards to fulfilling the right to health.

Recent findings identify the key role of agency (empowerment of the individual and of the community) on the part of rights holders (community members) as critical for health equity. Human rights approaches coupled with community engagement succeed in achieving health equity and reinforcing community capacity, particularly when strengthening the collective agency of its most vulnerable groups¹³. The six LN pamphlets developed in 2008 aim to provide information on the right to health as well as supporting the development of a collective agency. Between 2008 and 2010, these pamphlets have been widely distributed to participating organizations and through them, to their members and communities, with the aim of encouraging collective agency in realizing their rights. However, the effectiveness of this tool has not yet been evaluated.

This project is a qualitative study that aims to evaluate the effectiveness of the six pamphlets developed by the LN and oriented to communities in promoting awareness and action related to the right to health.

Research Questions

How effective have the six Learning Network pamphlets been in enhancing the understanding, communication and practice of health rights?

Sub-Questions:

1. **Objective 1 - To describe how the pamphlets were used and disseminated**
 - a. How have the selected CSOs and its members come into contact with the LN pamphlets?
 - b. How have the pamphlets been disseminated within the various CSO communities?
 - c. To whom have the pamphlets been provided?
2. **Objective 2 - To describe changes in understanding and practice of health rights**
 - a. How did the LN pamphlets contribute to an understanding of the right to health among its various audiences/users?
 - b. How have the contents of the pamphlets been understood by its users?

¹³ London L. 'Issues of equity are also issues of rights': Lessons from experiences in Southern Africa. *BMC Public Health* 2007, 7:14.

- c. Has knowing about the right to health triggered any community action? If so, what kind of action?
3. **Objective 3 - To describe competing source of information accessed on the Right to Health**
- a. What other sources of information are used on the right to health and in which way?
 - b. How do the LN pamphlets compare to other sources of information?
4. **Objective 4 - To identify suggestions for improvement**
- a. How could the pamphlets distribution be improved to reach more people?
 - b. Are there other settings where the pamphlets should be distributed?

Study Methodology

Research Setting

The research will take place among six civil society organizations that have been partners in the Learning Network since 2008 and are located around Cape Town:

1. **The Women's Circle (TWC)**, based in Athlone, is a grassroots, community-based network of women operating primarily in the poorer areas of Cape Town. The TWC trains women in community development, local democracy and income-generation.
2. **Ikamva Labantu**¹⁴ is a large national South African NGO that seeks to create positive social change in disadvantaged communities by strengthening and supporting affiliated community based organizations, so that they become autonomous and proactive role players in their communities. The organization implements programmes providing four core services of health, capacity-building, poverty alleviation, land and buildings.
3. **Ikhaya Labantu**¹⁵, located in Langa, provides shelter to anyone finding themselves in the traumatic position of being homeless. The shelter helps to rehabilitate people and gain skills in order to find a job and a place to live back in the community. Support is also provided to young people to help them further their education.
4. **Women on Farms**¹⁶, located in Stellenbosch, strives to strengthen the capacity of women who live and work on farms to claim their rights and fulfill their needs. This is done through socio-economic rights-based and gender education, advocacy and lobbying, case work and support for the building of social movements of farmwomen.

¹⁴ For more information, please visit: <http://www.ikamva.com/>

¹⁵ For more information, please visit: http://www.myggsa.co.za/connect/receivers/ikhaya_labantu_homeless_shelter_and_eyabantu_educare/

¹⁶ For more information, please visit: <http://www.wfp.org.za/>

5. **Epilepsy South Africa**¹⁷, located in Lansdowne (Western Cape Branch), provides integrated services that are equitable, accessible, sustainable and people-centered with and for people with epilepsy and other disabilities and all people affected by epilepsy, to promote social justice. Their work is conducted through individual counseling, support groups, public education and advocacy action, youth development, community outreach services and workshops.
6. **Metro Health Care Forum**, located in Cape Town, acts at the coordination structure for the Health For a and Health Committees for the Metro district of the Health Department in the Western Cape.

Upon consultation with the initiators of the LN, it was recommended to also include a seventh organization that has been actively involved in the distribution of the LN pamphlets:

7. **People's Health Movement**¹⁸, located in Observatory, is a global network of civil society groups, researchers, trade unions, activists and workers involved in health. It seeks to provide a forum for networking and mobilization around key issues; to mobilize progressive health professionals to advocate for the Primary Health Care approach; to increase information flow and knowledge on global and local issues impacting on health; as well as to participate in and comment critically on health policies.

Population & Sampling

Findings from research conducted by Thomas and London (2006) indicate that civil society organizations have a general sense of the types of rights which exist but can not easily define a human right. Furthermore, the organizations involved in the study¹⁹ recognized the rights of vulnerable individuals and groups as is reflected in their target audiences (ie: the most vulnerable individuals and communities - women, children, farm workers, refugees, people with disability and the poor). The organizations also recognize the importance of collective agency as a key mechanism through which vulnerable people can take action to redress the challenges they face in enjoying the right to health²⁰.

One of the key outcomes was the need to build a firm knowledge base within civil society organizations around human rights and rights-based approaches. This led to the participatory development of six LN pamphlets covering various right to health aspects. Staff, members and constituents of the 6 CSOs mentioned in the Research Setting section were involved at various levels in the development, dissemination and use of the LN pamphlets. Hence the population for this study will be made up of

¹⁷ For more information, please visit: <http://www.epilepsy.org.za/wcape/index.php>

¹⁸ For more information, please visit: <http://asnahome.org/peopleshealth/>

¹⁹ Organizations involved in the 2006 study include: Epilepsy South Africa, Ikhaya Labantu, Women on Farms Project.

²⁰ Thomas J, London L. Towards establishing a learning network to advance health equity through human rights strategies. Report to the Centre for Civil Society, University of Kwazulu Natal, December 2006.

CSO staff and CSO members, as well as constituencies of CSOs to whom pamphlets were given or amongst whom pamphlets were used in the course of 2009 and 2010.

The target population of this study will include:

- Sample 1 – Key Informants (staff or office-bearers) from the target CSOs listed above who have used or disseminated the pamphlets during 2009 and 2010;
 - o If less than 5 staff in the organization, researcher will interview all staff.
 - o If between 6-10 staff in the organization, the researcher will purposively sample 5 staff from various areas of work (ie: 1 administrator, 4 field workers, 1 manager)
 - o If more than 10 staff in the organization, the researcher will sample 5-10 staff members (ie: 8 field workers, 1 administrator, 1 manager).
- Sample 2 - A sample of members of the CSOs who have used or disseminated the pamphlets during 2009 and 2010;
 - o If less than 5 CSO members in the organization, the researcher will interview all five.
 - o If between 6-10 CSO members in the organization, the researcher will purposively sample 5 CSO members from various areas of work or target audiences.
 - o If more than 10 CSO members in the organization, the researcher will purposively sample 10 CSO members
- Sample 3 - A sample of 30 community members/leaders who comprise the constituency of LN CSOs and who have come into contact with the LN pamphlets. For each CSO, an analysis will be undertaken to identify community members/leaders who comprise the CSO constituency.

These three sample groups allow for an examination of the various understandings and uses of the pamphlets, the dissemination and outreach strategies used in distributing the pamphlets and the relative efficacy of these strategies in triggering community action around the right to health.

The study population will be sampled through snowballing sampling (the researcher will ask the LN members/respondents to give referrals to other possible respondents) in order to select those participants best suited for the needs of this research. The researcher will first identify, in cooperation with Nicole Fick and Leslie London from the Learning Network, key informants for the first sample group (CSO staff). These initial key informants will then be contacted for an interview and also asked for recommendations for additional respondents from sample groups 2 & 3 (CSO members and community members) relevant for this research. Participants in sample group 2 & 3 will also be identified through attendance registries of meetings where pamphlets were distributed; and from organizational membership lists.

Recruitment

Recruitment will commence once the Faculty Postgraduate Programmes Committee has provided approval for the protocol. Ethics approval for the study has already been granted by the Ethics Committee (**Appendix B**).

In all sites, the researcher will implement the study as well as recruit and follow-up participants. the researcher will work in close cooperation with Professor Leslie London, Head of Department and Head of Health and Human Rights Project, and Ms. Nicole Fick, research co-ordinator for the Health and Human Rights Project. the researcher will also work together, in consultation with CSO leaders and staff to identify and recruit respondents from each site. The researcher will collaborate with student assistants and from the Health and Human Rights Project whenever translation in Afrikaans and Xhosa is required as some respondents do not speak English. When translation is required, the translator and the researcher will go through the data collection tools and expectations prior to meeting with participants to clarify any potential confusion or problems.

Data Collection

Two topic interview guides (**Appendix C-1 and C-2**) have been developed and will be used during the data collection to gather qualitative data regarding the use of the LN pamphlets, understanding of the right to health, and accessibility to other forms of media on the right to health. These guides will be pre-tested among LN members. Respondents will also be asked to report suggestions for any changes and improvements in the pamphlets.

Data collection tools used will be interviews and focus groups that include a mix of qualitative and quantitative questions (with a balance leaning towards qualitative responses). It must be clear that the researcher is not trying to generate a representative sample through the quantitative work.

Interviews with Key Informants

These interviews will focus on the first sample set of staff members from the 6 CSOs as well as from staff from the People's Health Movement who have piloted and used the pamphlets in their work. Some of the respondents partook in the piloting of the pamphlets, others will have used them during workshops/activities while others in their daily work to provide information to patients or community members. As these respondents are actively involved in the LN, it will be important to gather their experiences and suggestions. Open-ended questions will include information on where the pamphlets were first piloted (for those involved in the piloting phase), where used and how, which pamphlet most often used, in which settings, usefulness of the information, how could the pamphlets provide more support, what other media of information on the right to health are being used, etc.

Important in the interview process is the creation of a trusting space where participants can feel free to bring up any issues they feel important. The interviewer will have a topic interview guide (**Appendix C-1**) and probes available containing

the main research questions but with the understanding that it is not a rigid structure and can welcome additional information. The interviewer engages with participants by posing questions in a neutral manner, listening attentively to participants' responses, and asking follow-up questions based on the responses. The researcher will not encourage participants to provide particular answers by expressing approval or disapproval of what they say. If issues not addressed in the interview guide repeatedly come up during the interviews, the guide will be amended to include questions around these particular issues. The interviews will be recorded with permission from the respondents.

Interview data will consist of tape recordings, typed transcripts of tape recordings, and the interviewer's notes. Notes may document observations about the interview content, the participant, his or her behavior and body language as well as the context. Documenting the discussions will include tape recordings (to later be transcribed) and writing of notes. The researcher will be obligated to expand my notes within 24 hours of the interview.

All transcripts and notes from interviews will be identified in case there is a need to re-contact a respondent. However, respondents' identities will be completely removed in the report. Language challenges will be worked out prior to the interviews and focus groups to ensure that a Xhosa or Afrikaans translator is available for the interview if needed.

Focus Group Discussions

Focus group discussions will allow the obtention of a range of health and human rights perspectives within each CSO's respective community and will further allow the understanding and use of the pamphlets among a sample set of the broader public. Focus groups will be held with both CSO members and community members from each of the CSOs. Overall, 6 to 10 focus groups are expected to be carried out.

During focus group discussions, I will guide the discussion with the interview guide (**Appendix C-2**), take minimal notes and make use of the audio recording equipment. The purpose of these focus groups is to better understand the contexts within which the pamphlets were first seen, how they were/are used, what impact they have had, and whether there are other sources of information on the right to health. The discussions will also seek to gather any inputs for improving the outreach and content of the LN pamphlets. The focus groups also seek to generate discussion so that participants can openly discuss their experiences with individuals who have also used the pamphlets, possibly generating new avenues for dissemination and cooperation.

Documenting the discussions will include tape recordings (to later be transcribed) and writing of notes. The researcher will be obligated to expand my notes (to

include contextual information as well as personal sentiments after the focus group) within 24 hours of the focus group.

All transcripts and notes from focus groups will be identified in case there is a need to re-contact respondents. However, the identity of respondents will be completely removed in the report.

Language challenges will be worked out prior to the focus group to ensure that a Xhosa or Afrikaans translator is available for the discussion if needed. As translation will slow down the discussion, the researcher will work closely with the translator prior to the focus group to go over the interview guide and ensure a common understanding of our objectives during the focus groups.

Data Management

Prior to data collection, the researcher will create packets of all necessary forms for each data collection event using large envelopes. Each of these envelopes will contain the necessary materials: interview guides, notetaker forms, informed consent forms, a list of audio equipment needed and any other materials necessary. For easy tracking, each data collection event will be assigned a number (unique identifier) to be recorded in a log. This number can also be used as the computer file name for the interview transcript.

During all the interviews and focus groups notes shall be taken and responses recorded on tape with respondents consent and managed by the researcher and a student assistant to ensure that all data (field notes, tape recordings, transcripts and other additional materials) is carefully stored after each focus group and/or interview.

To minimize memory lapses and avoid the accumulation of collected data, the researcher will expand my notes within 24 hours of the interview or focus group sessions. All documents related to a given data collection event will be locked in a cupboard at the UCT School of Public Health and Family Medicine (Nicole Fick's Office) in one large archival envelope per event with an archival information sheet. The contents of the envelope will include typed transcripts, expanded field notes, handwritten versions of the notes (notes taken simultaneously during the interview) and audio tapes.

Data Analysis

It is important to note that the majority of the data collected in the study involves the subjective views and experiences of the participants selected. Though the sampling strategies will aid in the generalizability of the findings, the researcher understands that these conclusions may not represent the whole truth.

All data will require the analysis of:

1. Semi-structured interviews

2. Focus group discussions
3. Any additional data that may have emerged through the implementation of the study.

Thematic Analysis

Transcribed data from both interviews and focus group discussions (including observational data) will be analyzed primarily by *thematic analysis*. This type of analysis will allow the researcher to familiarize herself with the content and begin to identify regular recurring experiences, uses and perceptions described by the respondents.

Analysis of the data will be largely descriptive, seeking to characterize the various uses of the LN pamphlets, the other types of information available around the right to health and the range of knowledge of the respondents.

The thematic analysis will therefore necessitate the completion of the following phases

1. Data familiarization is key to thematic analysis and requires that the researcher carry out both the data collection and data transcription.
2. Data coding – the researcher will apply brief verbal descriptions to various portions of the data. The detail of this process will vary according to circumstances including the researcher’s expectations about the direction in which the analysis will proceed.
3. At every stage of the analysis, the researcher will alter and modify the coding in light of input from participants and as ideas develop. Thus the researcher may adjust earlier codings in the light of the full picture of the data.
4. The researcher will identify examples of each theme (a theme describes an integrating, relational idea from the data) to illustrate what the analysis has achieved. The researcher will also provide numerical indications of the incidence and prevalence of each theme in the data.

Limitations

The methodological limitations within this study will mainly stem from language barriers as the researcher does not speak Xhosa or Afrikaans. However, there are student assistants available for Xhosa and Afrikaans translations and transcriptions in the LN, partner CSOs may be able to help and there is funding available for translation hires. Other factors such as participants' concerns about confidentiality; misinformation, lack of information, fear of participating in a study will also impose some restrictions.

It will be key to understand the socio-cultural and economic realities and hardships of the CSOs and the communities they serve as it will aid in producing data and conclusions of high integrity regarding the pamphlets.

There may also be conflict of interest issues as this evaluation study is a component of a larger Learning Network project, the researcher is receiving assistance from the Learning Network and I am being supervised by the principal investigator of the overall project. In managing this, the researcher will clearly explain her role as an external researcher not involved in the Learning Network. the researcher will also keep the principal investigator blinded during the initial analysis and will request and gather feedback/comments on the draft report from a range of members in the Learning Network.

Respondent bias may also impact the results of the study as they could answer questions according to what they think the researcher or the Learning Network wants them to answer. To manage this, the researcher will probe with participants with further concrete questions such as asking for examples of their application/use of the pamphlets, practical recommendations for strengthening the outreach of the pamphlets, etc. the researcher will seek to gather as much in-depth information as possible to minimize this bias.

Logistics

Job Allocations & Requirements

The researcher will be the principle researcher and will get support from two students assistants within the Health and Human Rights Unit. The student assistants will facilitate translation in Xhosa and Afrikaans. If student assistants are not available, research staff from will be able to help with translation needs. The researcher will also liaise with other researchers within the Health and Human Rights Unit throughout the duration of the data collection and data analysis. Other researchers within this unit have already had experience working with the 6 CSOs at hand and will be able to provide tips and recommendations throughout my research process.

Job Title	Job Description
1 researcher - Morgan Strecker	Development of research protocol; engagement of partners, collaborators and local community leaders; recruitment of participants, implementation of data collection, perform data analysis and report writing. Disseminate findings to appropriate bodies in cooperation with the LN. Qualified experience - the researcher has experience conducting qualitative research having

most recently partaken in the development, implementation and analysis of the UN Environment Programme Global Survey on Sustainable Lifestyles at both the international and South African levels. Additionally, the coursework involved in pursuing a master in Public Health at the University of Cape Town has provided with extensive knowledge and awareness of the challenges and needs surrounding the right to health in the South African context.

**2 Translators
(1 Xhosa, 1 Afrikaans)**

Translation of consent agreements, questionnaires, focus group and interview questions, health and education records and of all findings.

**1 or 2 Transcribers
(1 Xhosa, 1 Afrikaans)**

Transcription of data derived from focus groups & interviews.

Budget

Budget has already been approved and provided by a National Research Foundation grant 2010 to 2012.

Logistical Challenges

Challenges in this study will mainly stem from language barriers as the researcher does not speak Xhosa or Afrikaans. However, there will be student assistants and translators available in the LN and partner CSOs to help as well as funding available for translation hires.

With regards to travel, the researcher will make use of my own personal vehicle and reimbursements costs are included within the budget. Costs for the travel of participants are also covered in the budget. If participants do not show up to the confirmed interview or focus group location, the researcher will organize a second meeting time. However, if they do not show up for the second meeting, the researcher will pursue another participant.

Task Identification & Prioritization

In order to successfully implement the methodology of this study, there are several specific phases and operational tasks which must occur. Proposed timeframes are detailed in Appendix A.

Ethics

Ethics for this project has already been approved – **Appendix B**

Informed consent (**Appendix D**) will be obtained from participants with the use of thorough consent forms and an oral presentation of the research project, with a translator when necessary. Participants will be fully informed about the study design and the purpose of the study before the research activities. In addition, the researcher will encourage them to ask any remaining questions relating to the study before starting the interview and focus group discussion. Due to possible illiteracy and language challenges, the consent form will be read and translated when needed, and the study clearly explained to the participants prior to their signing the form.

Along with informed consent comes the crucial role of confidentiality and anonymity. All transcripts and notes from interviews and focus groups will be identified in case there is a need to re-contact a respondent. However, the identity of respondents will be completely removed in the report. Furthermore, prior to placing the data on the LN Vula website in order to share data with other researchers and project, as per the LN policy, all identity of respondents' will be removed.

In all the interviews and focus groups, notes shall be taken and responses recorded on tape with respondents consent and managed by the researchers to ensure that all data (field notes, tape recordings, transcripts and other additional materials) is carefully stored. If respondents do not want the conversations recorded on tape, the researcher will take detailed notes and ask them to repeat their responses when necessary. Discussions from both interviews and focus groups will be transcribed and will not be shared with respondents. Any personal information obtained through the research will only be used for the study and all data will be entered anonymously by the researchers in order to maintain participants' confidentiality. Photographs and video material will not be used. If any sensitive material is to be shared, the researcher will ensure that its source cannot be traced.

All notes and records will be securely stored in a locked cabinet at UCT School of Public Health and Family Medicine (Nicole Fick's Office) in one large archival envelope per event with an archival information sheet; and only accessed by authorized individuals. Notes will be encrypted to conceal identities and careful consideration will be given to the implications of sharing any information that may have been offered privately.

Write up and Dissemination

This research will inform LN members and donors as well as stimulate further discussion and developments around human rights and health communication materials. The outcome of this work will therefore be of relevance to a number of different stakeholders ranging from academics to international, national and community civil society organizations working on health and human rights-related issues, as well as communication agencies. Information on the relative effectiveness of pamphlets will provide a useful basis for the coordinators of the LN and those

using the pamphlets to assess the next steps in communicating about health and human rights.

The presentation and dissemination of results from this research will be adapted to suit the various target audiences. Though the entire result will be codified into a single research report, other forms of audience specific presentations can be made available such as executive briefs, feedback sessions, community presentations, etc.

University of Cape Town

Realizing the Right to Health through the use of health print materials in the Western Cape, South Africa – a literature review

Introduction

Information as a means for community empowerment

Recent findings identify the key role of agency²¹ on the part of rights holders as critical for health equity. Human rights approaches coupled with community engagement can succeed in achieving health equity and reinforcing community capacity, particularly when strengthening the collective agency²² of its most vulnerable groups (London, 2007). The six Learning Network (LN) pamphlets developed in 2008 aim to provide information on the right to health as well as support the development of collective agency.

The research study attempts to understand the impact of promotional educational pamphlets on the right to health on people's awareness and community empowerment around the right to health. The literature review provides background information on community empowerment and health literacy as well as an overview of various studies assessing the impact of health promotion through print materials. The review assesses:

1. The right to health and how it is conceptualized,
2. The various mechanisms in place advocating for the right to health;
3. The extent to which health promotion and health literacy play a role in improving the health and empowerment of individuals and communities
4. A range of studies on the effectiveness of print materials on health-related issues. In light of these studies, the paper draws from the field of health and rights communications to identify the most important elements for a study on the effectiveness of materials for communication on the Right to Health.

For the literature search strategy, a targeted review of journals and studies linked to human rights, rights literacy, health promotion, health literacy and education was carried out. Articles were found through the UCT Health Science library database, Google Scholar and specific searches through:

- the World Health Organization (WHO) Health Promotion Website
- the International Union for Health Promotion and Educations Website
- the following journals:
 - o Health Promotion International,
 - o Global Health Promotion,

²¹ Agency refers to an individuals' ability to intentionally pursue interest and to have some effect on the social world, altering the rules or the distribution of resources (Scott, 2001).

²² Collective agency refers to the process by which an individual or a community identifies its needs or objectives, develops the confidence and the will to work at these needs or objectives, finds the resources to deal with these needs or objectives, takes action in respect to them, and in so doing extends and develops co-operative and collaborative attitudes and practices in the community (Ross, 1955).

- Critical Public Health,
- Health Promotion Practice,
- Health and Human Rights International Journal,
- the British Medical Journal and Health Education Research.

In line with the research objectives, keywords were combined to find relevant literature. Such combinations included:

- print materials and health,
- human rights and education,
- health literacy and health promotion,
- brochures and health behavior,
- communication campaign and health behavior,
- evaluation and print materials,
- empowerment and health literacy,
- community action and health education,
- print materials and life skills,
- effectiveness and public campaigns,
- right to health in South Africa,
- South Africa and health literacy.

While there is an abundance of studies done on the effectiveness of public health communication campaigns with the use of TV and radio advertisements, billboards, presentations, workshops, etc., few focus solely on the effectiveness of print materials in increasing people's knowledge of health-related issues and enhancing community empowerment. Furthermore, most relevant studies found on print materials date from the mid to late 1990s. The articles for this review were therefore selected based on the following inclusion criteria:

- ❖ Relevance – studies reported results on relevant topics: print materials, health promotion, health education/literacy, individual/community empowerment.
- ❖ Studies that evaluated the differences between various forms of health promotional materials: brochures, television advertisements, radio, etc.
- ❖ Quality of the article – publication in a renown journal or on a well-referenced website: ie the WHO or United Nations (UN).
- ❖ Accessibility – available through the UCT libraries server or for free online.
- ❖ Availability in the French and English language
- ❖ Published after the year 1980.

The following topics were developed in the literature review:

- ❖ Human Rights and the Right to Health
- ❖ The Right to Health in South Africa
- ❖ Adult Learning and Community Empowerment
- ❖ The role of printed materials in promoting health-related information
- ❖ Theories towards triggering change in health information and behavior
- ❖ Evaluating the LN pamphlets

Human Rights and the Right to Health

The 2000 UN General Comment 14 recognizes health as “a fundamental human right indispensable for the exercise of other human rights” and outlines explicitly the states’ obligations in ensuring access to health for all, inclusive of availability, accessibility, acceptability and quality of health care (UNHCHR, 2000). As recognized as the right to health is today - in constitutions, declarations or covenants - such recognition has taken more than half a decade to be recognized.

Formalized in 1948 in the form of the Universal Declaration of Human Rights, human rights are inherent to all individuals, regardless of their nationality, place of residence, gender, ethnicity, color, religion, language or any other status. According to the Office of the High Commissioner for Human Rights (2002), the concept of human rights differs from other rights with regards to two aspects:

1. Human rights are characterized as inherent to all human beings by virtue of their humanity alone; they are inalienable; and equally applicable to all.
2. The obligations and duties deriving from human rights fall upon the states and on states and their authorities, not on individuals (OHCHR, 2011).

Since 1946, the right to the highest attainable standard of health has been explored and recognized in a myriad of international fora. WHO (1946) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Moving health away from the private sphere into the international and public agenda, WHO’s definition opened the door to exploring other factors impacting human well-being such as the physical and social surroundings. Ensuing human rights instruments recognizing health as a human right include the 1948 Universal Declaration of Human Rights (Article 25), the 1976 International Covenant on Economic, Social and Cultural Rights (Article 12), the 1978 Declaration of Alma-Ata on Primary Health Care, and the 1981 African Charter on Human and People’s Rights (Article 16).

Further anchoring health as a right, the 1988 Ottawa Charter for Health Promotion distinguished between *health policy* and *healthy public policy*. The former focuses on health services and programmes whereas the latter is much broader, recognizing the need to create a supportive environment in which people can lead healthy lives (WHO, 1998). Health promotion action goes beyond the health care sector in stating that health should be on the policy agenda in all sectors, and at all levels of government and society.

The Ottawa Charter and the 1997 Jakarta Declaration on Leading Health Promotion into the 21st Century defined five priority actions, inclusive of building healthy public policy, creating supportive environments for health, *strengthening community action for health*, *developing personal skills*, and re-orienting health services (WHO, 1997). They particularly noted the role of participation in sustaining efforts – “people have to be at the centre of health promotion action and decision-making processes for them to be effective” (WHO, 1997). To foster participation, health literacy and health learning are essential prerequisites as access to education and

information is essential to “achieve effective participation and the empowerment of people and communities” (WHO, 1997).

As per the Ottawa and Jakarta priorities, the objectives of the LN and the use of the pamphlets had the aim of increasing community capacity and empowering individuals to strengthen community action for health. Table 1 presents clear definitions of some of the terms used in the area of Health Promotion and are relevant for this research.

Life skills	Abilities for adaptive and positive behavior - enabling individuals to deal effectively with the demands and challenges of daily life. Consists of personal, inter-personal, cognitive and physical skills enabling people to control and direct their lives, and produce changes in their environment.
Health literacy	Represents the cognitive and social skills determining the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.
Community Action for Health	One in which individuals and organizations apply their skills and resources in collective efforts to address health priorities and meet their health needs. Individuals and organizations within an empowered community provide social support for health, address conflicts within the community, and gain increased influence and control over the determinants of health in their community

The right to health “places an obligation on governments to address discrimination and inequality. The right to the highest attainable standard of health requires governments to increase access for disadvantaged individuals, communities and populations; in other words, it has a social justice component. It also requires governments to put in place arrangements that facilitate the active and informed participation of those affected by health-related policies, programmes and practices. Crucially, the right to the highest attainable standard of health is subject to progressive realization²³” (Hunt, 2009).

The Right to Health in South Africa

In the South African context, the 1994 elections provided the momentum for tremendous change to overcome the discrimination and segregation engrained during Apartheid. In light of national and international events, human rights (inclusive of political, civil, socio-economic and cultural rights) and gender issues were prioritized in the drafting of the 1996 Constitution. This resulted in the introduction of a range of health policy reforms to ensure the provision of safe,

²³ *Progressive realization* as defined by the International Covenant on Economic, Social and Cultural Rights (Article 2.1) - “Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures” (OHCHR, 1966).

effective, affordable and acceptable health care. Such changes included, for example, the 1994 Reconstruction and Development Programme (redressing past inequities and inequalities), the National Health Plan (outlining national health priorities), the 1996 Choice on Termination of Pregnancy Act, the 1997 White paper for the Transformation of the Health system in South Africa and the 1999 Patients Rights Charter (guaranteeing the realization of patients rights of access to quality health care services) (Van Rensburg & Pelsler, 2004).

Despite remarkable changes since 1994, ordinary South Africans still struggle to realize their health rights. South Africa remains a country with profound health inequalities in the distribution of resources and access to adequate and acceptable services. Districts with the highest burden of disease receive fewer health care resources than wealthier districts (Victoria, 2006). Compounding the lack or inequitable distribution of resources is the lack of awareness of the right to health among individuals and communities further complicated by the socio-cultural context of public health care facilities (Victoria, 2006). Thomas (2008) found that through health learning, women experienced an increased positive self-image and awareness about health rights. However, these same women struggled to assert their health claims within health facilities because of fear of being scolded or denied access to the services (Thomas, 2008). While there is a sense of awareness about rights, translating that into understanding and practice is filled with difficulties and obstacles.

Alongside state obligations and existing legislation, active citizenship has been a key determinant in the implementation and promotion of the right to health such as access to HIV treatment in South Africa. Hence, for every human right, there is a necessary responsibility on the part of its citizens to ensure the highest attainment of human rights for all. However, this can only be achieved through the informed and continued demand for the protection and promotion of human rights education. Rendering people aware of their basic rights promotes values and attitudes that encourage all individuals to take responsibility. Empowerment and knowledge is needed for those most vulnerable to enable them decision-making scope to change their conditions in which they live (London, 2008). "Thus, individuals, groups, and communities whose rights have been or are likely to be violated have choices and capabilities, and the extent to which a human rights approach enables them to exercise their agency in such choices is critical" (London, 2008).

Adult Learning & Community Empowerment

Having policies in place that promote and protect the right to health for all is essential but not sufficient to ensure its progressive realization. Recent evidence demonstrates the importance of agency on the part of those communities most vulnerable to the violation of their rights as key to redress social inequalities (London, 2007, Thomas and London, 2006). In a background paper presented during the 7th Global Conference on Health Promotion (2009), Laverack (2009) defined community empowerment as including "personal empowerment, organizational empowerment and broader social and political actions". Labonte

(1990) and Laverack (2009) expand community empowerment to comprise: personal action; the development of small interest groups; community organisations; partnerships; and social and political action. “This continuum has been used by health promotion practitioners to explain how community empowerment can potentially be maximized to close the implementation gap of public health priorities as people progress from individual to collective action” (Laverack, 2009).

However, before personal action can occur, individuals need to be literate. Education is recognized as a key predictor of health and “literacy is a fundamental right and a springboard not only for achieving Education For All but also for eradicating poverty and broadening participation in society” (UNESCO, 2010). A systematic review of the relationship between literacy and health outcomes concluded that “patients with low literacy have poorer health outcomes, including knowledge, measures of morbidity, general health status, and use of health resources” (DeWalt et al, 2004).

Improving health literacy is critical to tackling health inequalities, as it is fundamental to patient engagement. If people cannot obtain, process and understand basic health information, they are unable to look after themselves well or make sound health-related decisions. “Health Literacy has been defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (WHO, 1998). This requires improving people's access to health information and their capacity to use it effectively. Nielson-Bohlman et al. (2004) take the definition of health literacy a step further by stating that such literacy is also dependent “upon the skills, preferences, and expectations of health information and care providers: our doctors; nurses; administrators; home health workers; the media; and many others”.

Recent UNESCO statistics reveal the challenges that lie ahead with regards to achieving better literacy rates, let alone health literacy. “In 2008, 796 million adults worldwide (15 years and older) reported not being able to read and write and two-thirds of them (64%) were women. More than half of those unable to read and write lived in Southern Asia and 176 million adults were in sub-Saharan Africa. Together, these two regions account for 74% of adults unable to read and write worldwide” (UNESCO, 2010). Low literacy rates among young people also concentrate in these regions - home to 86% of all youths unable to read and write worldwide (UNESCO, 2010).

People are increasingly exposed to health information from a variety of sources with different motivations and varying levels of credibility (Green, 2008). In order to make sense of it all and gain some form of personal control, they require the combination of knowledge and skills to facilitate health literacy or empowerment.

Nutbeam (2000) distinguishes health literacy at three levels:

- ❖ Functional literacy: basic literacy skills enabling individuals to read, understand

- and perform written and oral health-related information;
- ❖ Interactive literacy: skills/competencies developed over time enabling individuals to seek out, comprehend and use health information to make informed choices and enhance their quality of life. Individuals at this level demonstrate improved motivation and self-confidence.
- ❖ Critical literacy: analysis skills allow individual and group empowerment which in turn supports social action and participation in health-related issues.

Understanding the various challenges to health literacy provides an opportunity for health and human rights practitioners to explore new ways of learning, new approaches, as well as new vehicles to enhance community empowerment around health issues such as the right to health. Kickbush (2003) noted that participatory learning through the settings approach may be one such novelty as it locates public health action in the social, cultural and physical places in which people live, learn and work. Hence, such an approach makes use of the available communications media, community radio, health on the internet, creating alliances with civil society organizations, with researchers, social marketing, etc.

The next section of the literature review explores the role of print materials in communicating health information.

The role of printed materials in promoting health-related information

According to Allensworth and Luther (1986) and Paul and Redman (2004), printed materials are among the most popular and effective media for communicating health messages. However, Allensworth and Luther (1986) recognize the limitations of such materials such as the appropriateness of the material in accomplishing the learning objectives. If the desired learning objective is directed towards performing a skilled perceptual motor act (the acquisition of a skill in which movement is an important part), printed texts and still pictures are not very effective. If the goal is to trigger behavioral change, still pictures are given a low rating whereas printed texts are given a medium rating (Allensworth & Luther, 1986). A second limitation stems from the readability of the material – in other words: is the printed material properly communicating the desired message? To maximize effectiveness, the authors suggest analyzing the legibility, learnability (reader's ability to retain and recall information), usability (how current, unbiased, appropriate and comprehensive the material is), motivation (why reader picks up a certain pamphlet), ease of reading and ease of comprehension of the printed material (Allensworth & Luther, 1986).

In an extensive literature review to explore the effectiveness of print material, Paul and Redman (1997) found that pamphlets were more effective in changing knowledge and attitudes than behavior when used for patient education rather than public education and as a complement to another form of intervention. In a later study, Paul & Redman (2004) found that the inclusion of behavioral and social marketing strategies increased the effectiveness of pamphlets. Hence, "the inclusion of behavioral strategies is likely to be a cost-effective approach to the development

of printed health education materials” (Paul & Redman, 2004).

Little et al (1998) conducted a study to assess whether the provision of educational leaflets or questions on contraception improved the knowledge of women taking the combined contraceptive pill. The researchers concluded that “women attending check ups for repeat prescriptions of the contraceptive pill should be provided with educational leaflets on contraception or asked relevant questions to help improve their knowledge of contraception. Interaction with women in combination with providing a leaflet may have been more time consuming but resulted in knowledge gain (Little et al, 1998). Atkinson (2003) in a literature review of 25 articles, noted that many people cannot understand print materials alone and therefore, more interaction is essential.

A survey conducted in Canada evaluated the effectiveness of promotional materials used during a measles immunization campaign. Various information materials were developed and distributed at the local, provincial and federal levels, inclusive of TV advertisements, newspaper articles, information from health personnel and leaflets sent to all parents of school-age children. According to respondents (parents of school-aged children), leaflets turned out to be the most useful source of information (for an average of 70% of the parents reached), followed by newspaper articles and information obtained through health staff (Pelletier et al, 1998). Pelletier et al (1998) also noted a notable increase in the proportion of parents who believed measles immunization was important after the campaign. Despite the results, the authors concluded that while information leaflets are a cheap and easy information delivery mechanism; they are more likely to reach a wider audience more effectively if developed in combination with other promotional materials (newspapers, websites, interactions, etc.) (Pelletier et al, 1998).

In the South African print materials context, the National AIDS Coordinating Committee of South Africa ran a *Beyond Awareness Campaign* from 1997 to 2000. The campaign focused on: advertising, materials development, training and research to intensify communication, and distribution of key resources around HIV/AIDS; promoting social action, building capacity among HIV/AIDS communicators; and conducting research related to communications and evaluating various aspects of the campaign (Hurt, 2000). Eleven leaflets on various HIV/AIDS aspects were developed and translated into all official South African languages. Twenty-seven users of the Aids Action Office - social workers, liaison officers of provincial departments of health, health promotion coordinators, district health services, professional health bodies, local AIDS centers and NGOs - were selected for interviews. (Hurt, 2000). The findings revealed that the leaflets “provided basic and valuable information, explained things well, helped as stand-alone information resources, were written in an easily understandable way, helped people negotiate and cope in whatever environment they were in” (Hurt, 2000).

A further study was conducted in 2003 to assess the effectiveness of one of the above eleven leaflets, ‘HIV/AIDS Counseling’, among low literate South Africans.

This time, interviews were conducted with twenty-seven visitors in health clinics from previously disadvantaged areas. Respondents came from lower-income groups with literacy levels ranging between grade 5-10 (Carstens & Snyman, 2003). Results showed that people picked up the leaflet and took it home because of the “visual-perceptual stimuli (headings, AIDS logo, color) and a need for information” (Carstens & Snyman, 2003). However, few participants were able to summarize the key points of the leaflet (Carstens & Snyman, 2003). This lack of comprehension was linked to the level of difficulty of the text or the inclusion of too much information for a low-literate audience (Carstens & Snyman, 2003). “Appreciation for visuals and other layout characteristics is not enough to substantiate their effectiveness in health communication documents” (Carstens & Snyman, 2003). The message intended by the authors of the pamphlet was not understood as such by the users of the pamphlet. Health promotion interventions involving print materials therefore need to take this into account and develop mechanisms to ensure that the information is pretested with the intended audiences and correctly understood.

Another study conducted in 2005 investigated the effectiveness of print materials compared to that of audiocassettes in communicating information about HIV AIDS to patients at health clinics in South Africa (Veldsman et al., 2005). Due to the semi to low-literacy rates of people in South Africa and the existing strong oral culture, the authors hypothesized that an audio-delivery of information would be more effective than a written one (Veldsman et al., 2005). Findings revealed little difference between the two media with regards to information delivery but recommended the use of both print and audio materials to ensure comprehension of the material.

In 2005, Soul City (SC)– a non-governmental organization (NGO) using mass media to promote health and development to reach previously disadvantaged South Africans – launched a campaign (Series 7) focusing on antiretroviral treatment, volunteering, health equity and gender issues. Alongside television episodes and radio series, SC developed and distributed HIV//AIDS treatment information booklets through a variety of channels – door-to-door, inserts in newspapers, resource centers, and training programmes in conjunction with 18 NGO partners (Soul City, 2007). Amid the evaluation highlights of SC (2007), the following, concerning print materials, were relevant to the literature:

- ❖ 87% of the total adult population was reached by one or more of the SC programming components in 2006;
- ❖ SC print materials had content specifically focusing on reducing behaviors putting people at high risk for HIV and consequently showed impacts across all dimensions of condom use. SC print was responsible for a significant 21% increase in condom use with a regular partner.
- ❖ SC was highly successful in increasing community empowerment around addressing HIV prevention. SC television and print materials were associated with a 15% and 13% improvement on this measure respectively.
- ❖ SC print and multi-media were successful in increasing the percent of people

participating in community actions to support people living with HIV/AIDS. However, SC (2007) recognized the difficulty in isolating the effects of the print media alone as some of the mentioned impacts may be a result of the distribution channel utilized (ie: face-to-face communication or household visits), rather than the print material itself. Hence, the delivery method of print materials plays a role in people's understanding and use of the content.

Comprehension has also proven to be more successful when facilitated by co-learning strategies to facilitate the appropriation of information. In an unpublished working paper, Stuttaford et al (2011) point out that the involvement of CSOs in the development of the content of the six LN pamphlets provided an additional learning opportunity and strengthened the use and dissemination of the pamphlets. The other studies covered in this literature review demonstrate that information conveyed through print materials is important and has proven to work but needs to be properly designed, pretested, distributed and supported with a range of dissemination strategies to ensure readers' understanding of the content and to maximize behavioral change.

The following section briefly looks at theories of behavior change and their relation to the effectiveness of print materials.

Theories towards triggering change in health information and behavior

Health promotion programs, such as the one developed through the LN pamphlets, employ a range of strategies and operate on multiple levels to reach target audiences. Social cognitive theory (SCT - Table 3) and community level theory (COT - Table 2) come into play when designing and analyzing the effects of the LN pamphlets on people's awareness and community empowerment.

COT recognizes multiple levels of a health problem and seeks not only to address individual health issues, but also group, institutional and community health issues. Applicable to the overarching objectives of the LN pamphlets, the social action component of COT seeks to increase a community's capacity to solve problems and achieve concrete changes that redress social injustice. It differs from other forms of community intervention in that it is grassroots based, conflict oriented, and geared to mobilizing disadvantaged people to act on their own behalf (Rothman, 2001). Self-interest is seen as a key motivator for action – people and communities become involved when the perceived benefits are understood. It focuses on building power and encouraging community members to develop their capacities as active citizens (Rothman, 2001). COT and SCT theories work hand in hand as both aim to have individuals play an active role in shaping the future of their communities.

However, prior to community empowerment comes individual empowerment – creating a sense of personal agency in which individuals are empowered through gain in awareness to make informed decisions. SCT theory asserts that behavior is a product of the interaction between individual and environmental factors, and requires supportive beliefs, training, skills, incentives, reinforcements, and social

and physical environments (Baranowski et al, 2002). Three factors affect the likelihood that a person will change a health behavior: self-efficacy, goals and outcome expectancies (Glanz et al, 2005). The interactions surrounding the delivery of print materials can contribute to shift a person's readiness to change or increase their self-efficacy.

Table 2: Community Organization (Glanz et al, 2005)

<i>Term</i>	<i>Definition</i>	<i>Potential Change Strategies</i>
Empowerment	A social action process through which people gain mastery over their lives and their communities	Community members assume greater power, or expand their power from within, to create desired changes
Community capacity	Characteristics of a community that affect its ability to identify, mobilize around, and address problems	Community members participate actively in community life, gaining leadership skills, social networks, and access to power
Participation	Engagement of community members as equal partners	Community members develop leadership skills, knowledge, and resources through their involvement
Relevance	Community organizing that “starts where the people are”	Community members create their own agenda based on felt needs, shared power, and awareness of resources
Issue selection	Identifying immediate, specific, and realizable targets for change that unify and build community strength	Community members participate in identifying issues; targets are chosen as part of a larger strategy
Critical consciousness	Awareness of social, political, and economic forces that contribute to social problems	Community members discuss the root causes of problems and plan actions to address them

Table 3: Social Cognitive Theory (Glanz et al, 2005)

<i>Concept</i>	<i>Definition</i>	<i>Potential Change Strategies</i>
Reciprocal determinism	The dynamic interaction of the person, behavior, and the environment in which the behavior is performed	Consider multiple ways to promote behavior change, including making adjustments to the environment or influencing personal attitudes
Behavioral capability	Knowledge and skills to perform a given behavior	Promote mastery learning through skills training
Expectations	Anticipated outcomes of a behavior	Model positive outcomes of healthful behavior
Self-efficacy	Confidence in one's ability to take action and overcome barriers	Approach behavior change in small steps to ensure success;

		be specific about the desired change
Observational learning (modeling)	Behavioral acquisition that occurs by watching the actions and outcomes of others' behavior	Offer credible role models who perform the targeted behavior
Reinforcements	Responses to a person's behavior that increase or decrease the likelihood of reoccurrence	Promote self-initiated rewards and incentives

Evaluating the LN pamphlets

“Contemporary health promotion involves more than simply educating individuals about healthy practices. It includes efforts to change organizational behavior, as well as the physical and social environment of communities (Glanz et al, 2005). With regards to public health messages, the effectiveness of a pamphlet is the result of various elements, some of which include self-interest, usability, comprehension, literacy and interactions. Print materials can indeed be effective but often their effectiveness is contingent on the context in which they are used, their legibility and the various delivery methods used.

Alongside a shortage of evaluations of print materials on the right to health, specifically in South Africa, there is also a need to understand the role of CSOs in strengthening the use and comprehension of print material. The development and dissemination of the six Learning Network pamphlets provide an opportunity to evaluate not only the effect of the pamphlets, but also the role CSOs have played in strengthening individual and collective empowerment. This research is therefore two-fold as it seeks to understand how print materials can enhance individuals' knowledge of the right to health and, as a result, trigger a sense of collective agency; as well as understand the role of CSOs in making use of and making the content of the print materials effective to change its constituents' behavior.

References – Literature Review

Allensworth, D and Luther, C. (1986) Evaluating printed Materials. *Nurse Educator*, **11**, 18-22.

Atkinson, T. (2003) Plain language and patient education: a summary of current research. *The Centre for Literacy - Research Briefs on Health Communications*, 1, 1-4 – Available at: <http://www.centreforliteracy.qc.ca/health/briefs/no1/no1.pdf>. Accessed on February 7th, 2010.

Baranowski, T., Perry, C. L., & Parcel, G. S. (2002) How individuals, environments, and health behavior interact: Social cognitive theory. In K. Glanz, B. K. Rimer, & F. M. Lewis (Eds.), *Health behavior and health education: Theory, research and practice* San Francisco: Jossey-Bass, 165-184.

Carstens, A. and Snyman, M. (2003) How effective is the Department of Health's leaflet on HIV/AIDS Counselling for low literate South Africans? *Tydskrif vir Nederlands en Afrikaans*, **10**(1), 112-136.

Claasen-Veldsman, R. & Snyman, M.E. (2005) Health communication in South Africa – evaluating audiocassettes as a medium to communicate HIV/AIDS information. World Congress on Health Information and Libraries Working Document. Available at: <http://www.icml9.org/program/track6/activity.php?lang=pt&id=6>. Accessed February 2nd, 2011.

DeWalt D.A., Berkman N.D., Sheridan S., Lohr K.N. and Pignone M.P. (2004) Literacy and health outcomes. *Journal of General Internal Medicine*, **19**, 1228–1233.

Glanz, K., Rimer, B and Su, S. (2005) Theory at a glance: a guide for health promotion practice. United States National Cancer Institute

Green, J. (2008) Health education – the case for rehabilitation. *Critical Public Health*. **18**(4), 447-456.

Hunt, P. (2009) Missed opportunities: human rights and the Commission on Social Determinants of Health. *Global Health Promotion*, **16**, 36-41.

Hurt, K. (2000) *Tools for action. An evaluation of the Beyond Awareness Campaign's AIDS Action Office*. Pretoria: HIV/AIDS and STD Directorate, Department of Health.

Kickbush, I. (2003) Think health: what makes the difference? *Health Promotion International*, **12**(4), 265-272.

Labonte, R. (1990) 'Empowerment: notes on professional and community dimensions'. *Canadian Review of Social Policy*, **26**, 64-75.

Laverack, G. (2009) Promoting Health and Development - Community

Empowerment. World Health Organization (WHO) Conference Working Document. Available at: http://www.who.int/healthpromotion/conferences/7gchp/Track2_Inner.pdf. Accessed on February 7th, 2011.

Little, P., Griffin, S., Kelly, J., Dickson, N. and Sadler, C. (1998) Effect of educational leaflets and questions on knowledge of contraception in women taking the combined contraceptive pill: randomised controlled trial. *British Medical Journal*, **316**, 1948 – 1955.

London, L. (2008) What is a human rights-based approach to health and does it matter? *Health and Human Rights – An International Journal*, **10**(1). Available at <http://hhrjournal.org/index.php/hhr/article/viewArticle/25/84>

London L. (2007) 'Issues of equity are also issues of rights': Lessons from experiences in Southern Africa. *BMC Public Health*, **7**, 14. First published on January 26, 2007: doi:10.1186/1471-2458-7-14

Nielson-Bohlman, L., Panzer, A. and Kindig, D. (2004) *Health Literacy: A Prescription to End Confusion*. National Academy of Sciences, Washington, D.C.

Nutbeam, D. (2000) Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, **15**(3), 259-267.

Office of the High Commissioner for Human Rights (OHCHR). (2011). *What are Human Rights?* Available at: <http://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx>. Accessed February 4th, 2011.

Paul, C.L. and Redman, S. (1997) A review of the effectiveness of print material in changing health related knowledge, attitudes and behaviour. *Health Promotion Journal of Australia*, **7**(2), 91-99.

Paul, C.L. and Redman, S. (2004) A cost-effective approach to the development of printed materials: a randomized controlled trial of three strategies. *Health Education Research*, **19**(6), 698-706

Pelletier, L., Duclos, P., Daly, P. and Kerbel, D. (1998) Evaluation of the promotion materials used during the measles mass immunization campaign in Ontario and British Columbia. *Canadian Journal of Public Health*, **89**(5): 329-332.

Ross, M. G. (1967) *Community Organization. Theory, Principle and Practice*, New York: Harper & Row.

Rothman J. (2001) Approaches to Community Intervention. In Rothman J, Erlich JL, Tropman JE (Eds.), *Strategies of Community Intervention*. Itasca, Ill.: Peacock Publishers, 364-379.

- Scott, W. R. (2001) *Institutions and Organizations*. Thousands Oaks, CA: Sage.
- Soul City Institute for Health and Development Communication (Soul City). (2007) *Evaluation Report Series 7*. Available at: <http://www.soulcity.org.za/research/evaluations/soul-city-its-real-evaluation-report-2007>. Accessed February 16th, 2011.
- Stuttaford, M., London, L., and Glattstein-Young, G. (2011) Dialogue and co-learning on the right to health: reflections from the Learning Network, Cape Town, South Africa. Unpublished paper, University of Cape Town & University of Warwick.
- Thomas, J. and London, L. (2006). Towards establishing a Learning Network to advance health equity through human rights strategy. *Final project report to the Center for Civil Society*, University of Cape Town, South Africa.
- Thomas, J. (2008). Is knowing that you have rights enough? Exploring marginalized women's experiences of the right to health. *Master of Education Mini-Dissertation*, University of Cape Town, South Africa.
- UNESCO Institute for Statistics. (2010) Adult and Youth Literacy: Global Trends in Gender Parity. *UIS Factsheet*, 3, 1-4.
- United Nations High Commissioner for Human Rights. (2000) *General Comment 14*. Available at [http://www.unhcr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En). Accessed September 2nd, 2010.
- Van Rensburg HCJ and Pelsers AJ. (2004) The transformation of the South African health system. In Van Rensburg HCJ (ed.) *Health and Health Care in South Africa*. Pretoria: Van Schaik, 109-170.
- Victoria, G. (2006) The challenge of reducing health inequalities. *American Journal of Public Health*, 96(1), 10.
- World Health Organization. (1998) Health Promotion Glossary. Available at: http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf. Accessed February 3rd, 2011.
- World Health Organization. (1997) Jakarta Declaration on Leading Health Promotion into the 21st Century. Available at: http://www.who.int/hpr/NPH/docs/jakarta_declaration_en.pdf. Accessed February 3rd, 2011.
- World Health Organization. (1946). WHO Definition of Health. Available at: <http://www.who.int/about/definition/en/print.html>. Accessed September 2nd, 2010.

Realizing the right to health through health print materials in the Western Cape, South Africa.

MORGAN H. STRECKER

School of Public Health and Family Medicine, University of Cape Town, Cape Town, South Africa

Abstract*

Active citizenship is a key determinant in the implementation and promotion of the right to health, but can only be achieved through an informed demand by people for the protection and promotion of their rights. Print materials are one of the most effective media for communicating information, but require strategies to facilitate co-learning and organisational commitment. This qualitative study, combining semi-structured interviews and focus groups conducted with 59 participants including staff and constituents from eight civil society organizations (CSOs), focuses on what works to enhance awareness of health rights, and why it does or does not. Facilitating factors for effectiveness include the commitment and skills of individuals, the existing materials, a CSO commitment to health rights and being part of a collective of CSOs. Co-learning and dissemination strategies are key for pamphlets to work. The failure to reach constituents calls for additional organizational and collective work.

*Keywords: *the right to health, pamphlets, community empowerment, effectiveness, health promotion

Setting the stage

Since 1946, the right to the highest attainable standard of health has been explored and recognized in a myriad of international fora. Health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1946). This definition opened the door to exploring other factors impacting human well-being such as the physical and social surroundings. Numerous human rights instruments have since recognized health as a human right. Since 2000, the UN General Comment 14, which elaborates on the interpretation of the right to health contained in international human rights law, recognizes health as “a fundamental human right indispensable for the exercise of other human rights”, outlining explicitly the states’ obligations in ensuring access to health for all (UNHCR, 2000).

Advancing health as a human right means making people conscious of both their challenges and the possibilities for change (WHO, 2002). Despite remarkable changes since 1994, South Africa remains a country with profound health inequalities in the distribution of resources and access to adequate services and ordinary South Africans still struggle to realize their health rights. Compounding the lack or inequitable distribution of resources is the lack of awareness of the right to health among individuals and communities. While awareness about rights exists, translating awareness into understanding and practice is challenging.

Clearly, active citizenship is a key determinant in the implementation and promotion of the right to health which can be achieved through informed demands by people for the protection and promotion of their rights (Robins, 2004, Jones, 2005). Empowering those who are vulnerable with knowledge and enabling them with decision-making power to change their conditions of vulnerability is essential (London, 2008).

The role of agency in realizing the right to health

Human rights approaches coupled with community engagement succeed in achieving health equity and reinforcing community capacity, particularly when strengthening the the most vulnerable (London, 2007). Laverack (2009) defined community empowerment as including personal empowerment, organizational empowerment and broader social and political actions. “This continuum has been used to explain how community empowerment can potentially be maximized to close the implementation gap of public health priorities as people progress from individual to collective action” (Laverack, 2009).

The 1988 Ottawa Charter for Health Promotion defined five priority actions: building healthy public policy, creating supportive environments for health, strengthening community action for health, developing personal skills, and re-orienting health services (WHO, 1997). It particularly emphasized the role of participation – “people have to be at the centre of health promotion action and decision-making processes for them to be effective” (WHO, 1997). To foster participation, health literacy and learning are prerequisites as access to education and information is essential to achieve effective participation and the empowerment of people and communities (WHO, 1997).

Print materials – a means to collective agency

According to Allensworth and Luther (1986), Paul and Redman (2004), and Pelletier et al (1998), printed materials are among the most popular and effective channels for communicating health messages. To maximize effectiveness, the authors suggest

analyzing the legibility, learnability, usability, motivation, ease of comprehension of the printed material (Allensworth & Luther, 1986). In 2004, Paul & Redman found that the inclusion of behavioral and social marketing strategies increased the effectiveness of pamphlets while Little et al. (2008) found that interacting with patients alongside leaflets may be more time consuming, but resulted in greater knowledge gain. Atkinson (2003) noted that print materials alone are not easily understood and require a co-learning strategy.

In South Africa, Hurt (2000) and Carstens and Snyman (2003) found leaflets helpful in providing health information. People picked up leaflets due to visual-perceptual stimuli or need for information but few were able to summarize the key points of the leaflet. Appreciation for visuals and other layout characteristics is not enough to confirm the effectiveness in health leaflets. (Carstens & Snyman, 2003). Health promotion interventions involving print materials need to take into account existing literacy and develop mechanisms to ensure correct understanding of the information.

The Soul City (SC) Series 7 campaign evaluation revealed that print materials were responsible for a significant 21% increase in condom use with a regular partner. SC television and print were associated with a 15% and 13% improvement in the sense of community empowerment as communities came together to address HIV prevention issues; and SC print and multi-media were successful in increasing the percent of people who participated in community actions to support people living with HIV/AIDS (Soul City, 2007). However, SC (2007) recognized the difficulty in isolating the effects of print media alone as some of the mentioned impacts may have resulted from the delivery method used (i.e.: face-to-face communication).

Comprehension and appropriation of print material has proven to be more successful when facilitated by co-learning strategies. Stuttaford et al (2011) point out that the involvement of civil-society organizations in the development of the 6 LN pamphlets provided an additional learning opportunity and strengthened the use and dissemination of the pamphlets. Information conveyed through print materials has proven to work but needs to be properly designed, distributed and supported to ensure readers' understanding of the content so as to maximize behavioral change.

Theories of Behavior Change

Health promotion programs employ a range of strategies and operate on multiple levels to educate the individual, change organizational behavior, and the physical and social environment of communities (Glanz et al, 2005). The social action model is grassroots-based, conflict-oriented, and geared to mobilizing disadvantaged people to act on their own behalf (Rothman, 1996). It focuses on building power and encouraging community members to develop their capacities as active citizens; and self-interest is seen as one of the key motivators for action (Rothman, 1996).

Prior to community comes individual empowerment – creating a sense of personal agency in which individuals are empowered through gain in awareness to make informed decisions. Social Cognitive Theory describes behavior as a product of the interaction between individual and environmental factors, and requires supportive beliefs, training, incentives and social and physical environments (Baranowski et al, 2002). The interactions surrounding the delivery of print materials can contribute to shift a person's readiness of change and/or increase their self-efficacy.

The current study

Three studies laid the basis for the development of the Learning Network (LN). Research in the Southern African region provided a conceptual framework for the role of collective agency in realizing health rights (London, 2007). A pilot study with 3 CSOs in the Western Cape identified the need to enhance CSOs capacities to realize health rights (Thomas and London, 2006). A third study into the Patients Rights Charter identified the importance of changing the culture of health workers practice to create a climate of mutually shared respect for human rights between users and providers of health (London et al, 2006). In response, the LN was established involving six CSOs, academics and health sector practitioners committed to exploring various strategies to strengthen civil society agency to realize health rights.

Among the strategies was the development of six pamphlets, in cooperation with CSOs, providing information on various crucial aspects of health rights and their realization²⁴. Between 2008 and 2010, these pamphlets were widely distributed to participating members of the LN, to CSO staff, members and constituents and to a partner organization with the aim of encouraging action around health rights. The present study assesses the effectiveness of the pamphlets among CSOs actively involved in the LN, their members and their constituents. It aims to understand the impact of the pamphlets on CSOs, community and individual awareness and on their actions around health rights.

Additionally, print materials' effectiveness is often contingent on the context in which they are used and the delivery methods used. The evaluation of the LN pamphlets, therefore, provides an opportunity to examine the role CSOs may have played in strengthening individual and collective empowerment through increased knowledge on health rights.

Methods

The design of the study was informed by the research objectives, and hence chose a qualitative approach to gain a better understanding of the following areas of interest: the use of the LN pamphlets, understanding of health rights, and access to other forms of media on health rights.

Through a snowballing sampling technique among the six CSOs and two organizations associated with the LN, fifty-nine respondents participated in the research – ranging from those who worked or were closely connected to CSOs and those whom the CSOs sought to reach secondarily. Thirty-four respondents were staff or trained volunteers from the 6 LN CSOs and the 2 associated CSOs who had made use of LN pamphlets, defined as F or M-CSO, F or M-TV (F referring to female and M to male). Twenty-five respondents came from the target beneficiaries of the CSOs, known as constituents and defined as F or M-CTT. The majority of participants were female (51 females and 8 males) and, consistent with these CSOs beneficiaries, came predominantly from disadvantaged areas. A total of 18 interviews with conducted with staff and volunteers - sixteen interviews in-person and two over the phone (two participants asked for phone interviews due to busy schedules). Based on availability and willingness to participate, forty-one respondents (volunteers and constituents) took part in eight focus group discussions.

All participants, having read and signed a consent form were interviewed. All

²⁴ The pamphlets are available at: <http://www.hhr.uct.ac.za/about/about.php>

exchanges were recorded and lasted between 20 and 35 minutes. Open-ended semi-structured questions were used flexibly, being omitted, adapted or elaborated upon accordingly and appropriate probes were used. The questions were used to promote a two-way dialogue in which to explore key themes. All interviews and focus groups were transcribed for data analysis.

The exchanges were thematically analyzed – taking one piece of information and comparing it with all others, similar or different, in order to develop conceptualizations of the possible relations within the data (Thorne, 2000). Such a process of data analysis is a systematic taxonomic one of sorting and classifying the collected data (Braun & Clarke, 2006). Braun and Clarke (2006) outline the following key thematic analysis steps: immersion in the data, generating initial codes, creating categories and the identification of themes. The data was revisited to view how links could be made between the codes, thereby creating coherent categories. Finally, the generation of themes that reflected the participants' experiences with the LN pamphlets required testing the explanation both with the data and with the literature (Willis & al, 2007).

Findings

As presented below, four main themes presented below emerged from the data. All CSOs disseminated pamphlets to their constituents; in numbers ranging from 300 to 3,000 pamphlets disseminated depending on the organization. All CSOs made use of the pamphlets in training or communication campaigns.

“We used 1,200 pamphlets during our campaign. Additionally, approximately 1,800-2,400 pamphlets are used throughout the year for any awareness day, during workshops, in clinics, schools and libraries.” (F-CSO)

Understanding and awareness of health rights – as knowledge for action?

The idea that for every right, there is a correlative duty for both the government and the individual was expressed by numerous respondents. With the health system depicted as understaffed and overcrowded; responsibility increasingly lies on the individual and its community to know and demand changes.

“It’s important that we know we have a right to health, including all the services the government must provide. We (the rights holders) also need to know that we have a responsibility and duty to respect these rights.” (F-TV)

Repeatedly, participants commented on the lack of awareness of health rights among their constituents and also among providers. That is not to say that people do not know when they are being wronged, but rather that specifying a particular right and knowing how to claim a right is the main challenge. The Right to Health (1) and the Patients' Rights Charter (PRC) (3) pamphlets were unanimously voted as the most useful pamphlets, while the remaining four were useful depending upon each respondent's personal and professional needs.

“People are generally aware about their rights but more concerned about the wrongs. Pamphlets (1) and (3) make them aware that they have rights. Pamphlet (3) gives them some guidelines on what they can demand.” (F-CSO)

When asked which additional tools respondents used to run discussions or workshops around health issues, only four respondents mentioned creating homemade materials due to limited easily legible information available. The majority of respondents had either learned about or worked on health rights with existing South African policy tools - the

Constitution and the Bill of Rights to cite a few. The pamphlets filled a gap left by policy documents difficult to comprehend by a layperson and even harder to relate to one's own context. Foremost, the pamphlets created a link between the conditions which people experience and the social determinants of health and the collective versus individual roles in addressing these determinants so that good health is no longer merely the absence of disease, but instead, the conjunction of a myriad of elements.

"Before, I didn't address health rights specifically but human rights in general and used the Bill of Rights and the Patients Rights Charter. The LN pamphlets are more specific and provide concrete information to people. (F-CSO).

"The pamphlets help establish the links between other factors that make us unwell as a society, as an individual, as a household." (M-CSO).

"We first saw the pamphlets in a media training with the People's Health Movement. The training was informative because it triggered discussions and enabled us to see how all community issues are interlinked and have an impact on health. It created a platform to understand, because sometimes written information, like the pamphlets, is hard to understand." (M-TV)

The majority of CSO staff and trained volunteers had seen and used the pamphlets, describing them as a useful resource. Human rights are not a new concept and having a right to a healthy life was mentioned often. The LN filled a gap related to knowledge for redress and created an opportunity for growth around information on the right to health among CSOs and eventually, their constituents.

"I find the pamphlets very useful and necessary for the work of my organization." (F-CSO)

Those who had either never seen or read the pamphlets were mainly constituents and they mentioned needing motivation to engage with the material.

"We've seen the pamphlets as someone brought them to a meeting, but we never read them or took them home. It would be nice to have someone present them to us or do a training." (M & F - CTT)

Understanding of health rights has been a driver for public events which, in turn, have been strategic for disseminating the pamphlets. CSOs reported using the pamphlets in diverse public campaigns – ranging from 'community blitzing' (described as going into a community and informing people of their rights through pamphlets, in presentations/training, foras, posters, etc.), exhibitions on Women's Day or Human Rights Campaign, public radio shows and public hearings. Such events increased the visibility and outreach, demonstrating a commitment to health rights by CSOs, but were not sufficient alone in ensuring people's understanding of the pamphlets. Requests were made to further popularize the materials in the public domain and to seek opportunities to address the topic.

"We use the pamphlets in community 'blitzing' – this entails going into a community and informing people of their rights." (F-CSO)

"One of our community members lost her child due to bad birthing medical support. This provided a timely opportunity to move people in her community on health rights and create some awareness and action." (M-CSO)

The role of organizing action and using print materials in fostering the right to health

A clear difference emerged in exposure to, relevance to and interaction with the LN pamphlets among respondents who were CSO staff or trained volunteers versus constituents. The former had, to varying degrees, taken part in the development, piloting and dissemination of the pamphlets. They expressed more interest in an understanding of health rights and, as a result, in using the pamphlets. Experience with human rights work varied, yet prior to joining the collective and the development of the LN pamphlets, most respondents did not specifically address health rights in their work. The advent of the LN and the pamphlets facilitated CSOs understanding of health rights and empowered make use of their rights for themselves and their families, as well as for in their work and with their beneficiaries.

“I didn’t really focus on health rights, though I had knowledge of them through Batho Pele, the PRC and the Constitution. I only started including health rights in my work after joining the LN.” (F-CSO)

“The pamphlets themselves helped deepen my understanding of health rights. But it’s only when I started joining the LN that my understanding of them changed a lot. I started looking at pamphlets differently.” (F-CSO)

“The pamphlets have acted as catalysts to talk about health issues and do more research on specific issues mentioned by community members.” (M-CSO)

The degree of separation from and involvement in the CSOs or LN impacts the interest in and use of the pamphlets. Those who had partaken in workshops or trainings through their organizations or the LN were keen users of the pamphlets. Those who had seen the pamphlets in meetings or conferences (mostly constituents) but had never received formal training were less likely to go beyond the front cover of the pamphlets.

“We did not know much about the right to health but through our organization, we’ve become aware of rights generally and the pamphlets reinforced our understanding of the right to health.” (F-TV)

“The pamphlets are in our packet for the workshop. I’ve looked at the pictures but I didn’t read them. I’ll wait for the trainer to explain them to us.” (F-CTT)

Several methods are used among organizations to teach about health rights – community-blitzing, participatory Reflect²⁵ approach, public hearings, community mapping or face-to-face interventions. Despite the diversity, the overarching concern across organizations is that effectiveness of print materials needs to be supported by informed individuals - particularly in light of the low-literacy challenge.

“When I give out pamphlets, I always explain the content. Otherwise, people take them and don’t really understand the purpose.” (F-CSO)

“In our workshops, we used community mapping to identify the problems and the facilities in our area. After, with the information in the pamphlets, we tried to figure out what we could do.” (F-CTT)

Stuttaford et al (2011) reported that the LN CSOs had requested specific training on health rights. Two years later, these CSOs demonstrate not only an ascending learning curve on health rights, but also a commitment to use it in their daily work with their constituents.

“Prior to the LN Pamphlets, our organization did not focus on the broader theme of health but rather on the problems facing people with disabilities. Since, staff

²⁵ Reflect refers to Regenerated Freirian Literacy through Community Empowerment Techniques.

are aware of issues surrounding health rights and are developing a programme on disabilities and the right to health.” (F-CSO)

“I first saw the pamphlets during the Right to Health Campaign in 2009. They’ve now become one of the key materials for one of the organization’s programmes.” (F-CSO)

Community Empowerment is ‘a process’

Concurring with Laverack’s (2009) continuum, most CSO members see community empowerment as a process – one that requires knowledge, partnerships and individual empowerment prior to reaching community empowerment. Print materials alone are not always sufficient to raise awareness or produce behavior change. For a majority, the reinforcement of information through co-learning strategies was essential towards increasing their knowledge and empowering them to take action in their field of work. All but one respondent felt that health learning through the pamphlets was essential to ensure that staff convey appropriate information to their audiences. However, learning of human rights was never done alone, but through various co-learning efforts such as workshops.

“Our organization had a workshop on health rights through the LN and the pamphlets were a great deal for those who attended. It gave them ideas on what was the right to health and the PRC... It created a ripple effect among the women in the organization as they passed information to one another.” (F-CSO)

While CSO members have demonstrated an increase in knowledge and commitment towards health rights, this has only partially trickled down to constituents.

“I am surprised by how little our people know about their rights, let alone their right to health.” (F-CSO)

The passive dissemination of print material does not acknowledge the diversity of constituents’ learning needs and must therefore be accompanied by appropriate tools for the various audiences.

“The pamphlets have empowered individuals and can enable community action but not in isolation. The lead to community action is associated with a variety of tools and needs to be linked to the reality and felt emotions of people.” (M-CSO)

“It is difficult to say that the pamphlets alone have empowered community action. Rather it is a process of various steps, including community meetings, public hearings, workshops on issues raised by the community, pamphlets that eventually provide communities with enough strength to gather and assert their rights.” (M-CSO)

A multitude of individual and community empowerment examples were found in the data (**Appendix F**). Staff increased their work around health rights, organizations included or developed programmes on health rights, information was diffused to individuals and communities and was linked to action by groups most in need.

“Through the work of my organization and the pamphlets, I no longer just complain about rights violations, I take action. A man in my community had chest pains because he was exposed to pesticides. I gave him the pamphlet on the Right to Health and explained the rights he had with his employer. He now receives medical treatment.” (F-TV)

Agency applies not just within the health sector but across sectors. Mapping of existing community infrastructures and community leaders is essential and youth must also participate in creating their healthy future.

“Use pamphlets in schools, with children, churches, health committees, libraries, in supermarkets and in the line at health facilities... This knowledge must filter down to schools and teachers to develop a new era of children who know and stand for their rights, and are no longer victimized because they don’t know.” (F-CSO)

Facilitators and Barriers to realizing the right to health

In light of the above, the presence of committed and skilled people, availability of material, organizational commitment in relation to health rights and being part of a collective are the main factors ensuring the implementation of the right to health in the work of CSOs.

The visual attractiveness, color-coding, relevance and adaptability of the print materials also played a prominent role in the dissemination of the pamphlets. Motivation on the part of the reader – whether because of work purposes or self-interest can also render the pamphlets more effective.

“Adults and children are attracted to the color of the pamphlets. With our organization’s pamphlets, people usually take one. With these, people take all of the pamphlets because the different colors indicate different topics.” (F-CSO)

Only one organization noted that funds and human capacity impeded their use of the pamphlets despite a need and interest. Low-literacy, while not noticed by the researcher, was claimed by several respondents to be a barrier for CSO constituents to understand the pamphlets. For some, the huge inadequacy of health services weakened their trust in the possibility of changing the health system and even more so in their power to bring about changes.

“It is useless to know about our rights since people do not listen to us in the clinics. When we do assert our rights, we are told we are being ‘too clever’.” (F-TV)

“I’ve never seen the pamphlets. I speak to the doctor, read the newspaper or listen to the radio for information. Put the pamphlets in supermarkets, local convenience stores and libraries – places where we go often and where people are nicer than here (clinic).” (F-CTT).

Discussion – Creating conditions for effectiveness

The objective of the study was to evaluate the effectiveness of the pamphlets; and examine the role CSOs played in strengthening individual and collective empowerment through increased knowledge of health rights. With regards to outreach, the pamphlets were extensively and actively disseminated by CSOs. The experiences and perspectives of the researcher and respondents helped to identify which factors play a greater role in effectively communicating and promoting health rights.

While the relevance of the right to health was probably recognized by the LN members at LN’s inception, the inclusion of this right in many of the CSOs programmes of work in line with target audiences’ needs reflects the development of their critical consciousness. Consistent with theories of behavior change, the health literacy of individuals was strengthened first, increasing their understanding of the right to health

and empowering them to engage in the next step of promoting collective agency. Throughout the interviews, they displayed confidence in taking action to support health rights, by advocating for their personal or family rights when at health clinics and providing information to their beneficiaries when at work. This, in turn, strengthened the action of their organizations in tackling health rights. The existence of comprehensive and visually attractive print materials combined with motivated individuals, participation in a collective and diverse delivery mechanisms appear as key drivers towards enhancing the effectiveness of print materials.

Emerging as a relatively new approach in South Africa, the right to health framework requires the underlying support of a collective of both individuals and resources, experts in this right and knowledgeable of their communities needs and capabilities. The active participation of organizations has facilitated individual capacities in terms of health rights literacy and skills. Such improvement is critical to tackling health inequalities, as it is fundamental to beneficiaries engagement. If CSO staff, volunteers and the broader general public cannot obtain, process and understand basic health information, they are unable to look after themselves or make sound health-related decisions; let alone convey that information to their constituents.

Characteristics of communities, community leaders, needs and priorities as well as trends in the health and social policy environment all influence health promotion efforts (Green & Kreuter, 2005). Partnerships among CSO-LN members proved to be important for support, information and exchanges of best practices. Such a model needs to be expanded across sectors – not solely for organizations working on human rights or health-related issues, but across sectors to create a supportive environment in which people can lead healthy lives (WHO, 1998). According to Riley (2003), partnerships between agencies, community groups and health departments are important external influences for effective health promotion. Lack of trust in health services is another potential negative influence to be redressed by organizations acting as disseminators and validators. Robinson et al. (2006) support “the role of organizational and/or community buy-ins and interest and partnerships and/or relationships or the lack of these, as facilitators and barriers to health promotion capacity building, implementation and evaluation and/or research”. Hence, community empowerment is a process in which the most vulnerable require consultation.

However, there are some limitations to the study as it was not possible to assess the veritable challenge posed by varying literacy levels, a critical issue in South Africa, nor was it possible to access sufficient information to assess whether the pamphlets have had any effects among every day citizens and most importantly, the most vulnerable. While some pre-testing of the topic interview guides was done prior to gathering data, time limitations did not allow for an extensive pre-testing phase.

Moving towards collective agency on health rights is not a one-approach-fits-all but rather a consultative and participatory process carried by motivated individuals and organizations who see value in this right. A call echoed throughout the research: creating a collection of organizations, committed to and trained on health rights made a difference. The collective has a responsibility to enhance the awareness on health rights of its various constituents and assuring their voices are heard. Through community mapping and involvement of existing infrastructures, the right to health can become the

responsibility of all. With the roll-out of co-learning strategies among constituents, the understanding and knowledge of health rights can provide the foundation for action.

Conclusion

The current study documents opportunities to increase the effectiveness of print materials through increasing knowledge and empowerment of a collective of 'right to health champions'. Facilitating factors include the presence of committed and skilled individuals, existing material and being part of a collective. The role of supportive and stable structures must be recognized as essential. Co-learning strategies and dissemination strategies are essential for pamphlets to work. The failure to reach constituents requires additional organizational and collective work.

University of Cape Town

Acknowledgments

This evaluation was developed as part of the Health and Human Rights Division in the School of Public Health and Family Medicine at the University of Cape Town, South

Africa.

I thank Leslie London, Professor and Director of the School of Public Health & Family Medicine, Head of the Health and Human Rights Division, University of Cape for his support and ongoing contributions to this research; Christopher Colvin, Professor and Senior Research Officer in Social Sciences and HIV/AIDS, TB and STIs for his continued support and advice; Nicole Fick, Research Coordinator for the Learning Network, for her guidance during the development and initial contact phase with the participants; the civil society organizations and their constituents for their invaluable feedback that made this research possible.

Funding

Funding for this research was provided by the South African Netherlands Programme for Alternative Development (SANPAD), the National Research Foundation and the Rotary Clubs of Cape Town and Paris Ouest, France.

University of Cape Town

References

Allensworth, D and Luther, C. (1986) Evaluating printed Materials. *Nurse Educator*, **11**, 18-22.

Atkinson, T. (2003) Plain language and patient education: a summary of current research. *The Centre for Literacy - Research Briefs on Health Communications*, 1, 1-4 – Available at: <http://www.centreforliteracy.qc.ca/health/briefs/no1/no1.pdf>. Accessed on February 7th, 2010.

Baranowski, T., Perry, C. L., & Parcel, G. S. (2002) How individuals, environments, and health behavior interact: Social cognitive theory. In K. Glanz, B. K. Rimer, & F. M. Lewis (Eds.), *Health behavior and health education: Theory, research and practice* San Francisco: Jossey-Bass, 165-184.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**, 77-101

Carstens, A. and Snyman, M. (2003) How effective is the Department of Health's leaflet on HIV/AIDS Counselling for low literate South Africans? *Tydskrif vir Nederlands en Afrikaans*, **10**, 112-136.

Glanz, K., Rimer, B and Su, S. (2005) Theory at a glance: a guide for health promotion practice. United States National Cancer Institute

Green, L. W., & Kreuter, M. W. (2005). *Health promotion planning: An educational and ecological approach* (4th ed.). New York: McGraw-Hill.

Hurt, K. (2000) *Tools for action. An evaluation of the Beyond Awareness Campaign's AIDS Action Office*. Pretoria: HIV/AIDS and STD Directorate, Department of Health.

Jones, P. (2005) "A Test of Governance": rights-based struggles and the politics of HIV/AIDS policy in South Africa. *Political Geography*, **24**, 419-447

Laverack, G. (2009) Promoting Health and Development - Community Empowerment. World Health Organization (WHO) Conference Working Document. Available at: http://www.who.int/healthpromotion/conferences/7gchp/Track2_Inner.pdf. Accessed on February 7th, 2011.

Little, P., Griffin, S., Kelly, J., Dickson, N. and Sadler, C. (1998) Effect of educational leaflets and questions on knowledge of contraception in women taking the combined contraceptive pill: randomized controlled trial. *British Medical Journal*, **316**, 1948 – 1955.

London, L. (2008) What is a human rights-based approach to health and does it matter? *Health and Human Rights – An International Journal*, **10**. Available at <http://hhrjournal.org/index.php/hhr/article/viewArticle/25/84>

London L. (2007) 'Issues of equity are also issues of rights': Lessons from experiences in Southern Africa. *BMC Public Health*, **7**, 14. First published on January 26, 2007: doi:10.1186/1471-2458-7-14

London, L., Holtman, Z., Gilson, L., Erasmus, E., Khumalo, G., Oyedele, S and Ngoma, B. (2006) Operationalising Health as a Human Right: Monitoring Tools to Support Implementation of the Patients' Rights Charter in the Health Sector. *Report to the Health Systems Trust*, Health Systems Trust, Durban.

Nutbeam, D. (1994) Intersectoral action for health: making it work. *Health Promotion International*, **9**, 143–144.

Paul, C.L. and Redman, S. (1997) A review of the effectiveness of print material in changing health related knowledge, attitudes and behaviour. *Health Promotion Journal of Australia*, **7**, 91-99.

Paul, C.L. and Redman, S. (2004) A cost-effective approach to the development of printed materials: a randomized controlled trial of three strategies. *Health Education Research*, **19**, 698-706

Pelletier, L., Duclos, P., Daly, P. and Kerbel, D. (1998) Evaluation of the promotion materials used during the measles mass immunization campaign in Ontario and British Columbia. *Canadian Journal of Public Health*, **89**, 329-332.

Riley, B. L. (2003) Dissemination of heart health promotion in the Ontario Public Health System: 1989-1999. *Health Education Research*, **18**, 15-31.

Robins, S. (2004) 'Long live Zackie, long live': AIDS activism, science and citizenship after apartheid. *Journal of Southern African Studies*, **30**, 651-672

Robinson, K., Driedger, S., Elliott, S. and Eyles J. (2006) Understanding facilitators of and barriers to health promotion practice. *Health Promotion Practice*, **7**, 467-476.

Rothman J. (2001) Approaches to Community Intervention. In Rothman J, Erlich JL, Tropman JE (eds.), *Strategies of Community Intervention*. Itasca, Ill.: Peacock Publishers, 364-379.

Soul City Institute for Health and Development Communication (Soul City). (2007) *Evaluation Report Series 7*. Available at: <http://www.soulcity.org.za/research/evaluations/soul-city-its-real-evaluation-report-2007>. Accessed February 16th, 2011.

Stuttaford, M., London, L., and Glattstein-Young, G. (2011) Dialogue and co-learning on the right to health: reflections from the Learning Network, Cape Town, South Africa. Unpublished paper, University of Cape Town & University of Warwick.

Thomas, J. and London, L. (2006). Towards establishing a Learning Network to advance health equity through human rights strategy. *Final project report to the Center for Civil Society*, University of Cape Town, South Africa.

Thomas, J. (2008). Is knowing that you have rights enough? Exploring marginalized women's experiences of the right to health. *Master of Education Mini-Dissertation*, University of Cape Town, South Africa.

Thorne, S. (2000) Data analysis in qualitative research. *Evidence-Based Nursing*, **3**, 68-70.

United Nations High Commissioner for Human Rights. (2000) *General Comment 14*. Available at [http://www.unhcr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En). Accessed September 2nd, 2010.

World Health Organization. (2002) Linkages between health and human rights. Available at: <http://www.who.int/hhr/HHR%20linkages.pdf>

World Health Organization. (2002) 25 questions and answers on health and human rights. *Health & Human Rights Publication Series*, **1**, 1-35. Available at: <http://www.who.int/hhr/information/25%20Questions%20and%20Answers%20on%20Health%20and%20Human%20Rights.pdf>. Accessed February 6th, 2011.

World Health Organization. (1997) Jakarta Declaration on Leading Health Promotion into the 21st Century. Available at: http://www.who.int/hpr/NPH/docs/jakarta_declaration_en.pdf. Accessed February 3rd, 2011.

World Health Organization. (1946). WHO Definition of Health. Available at: <http://www.who.int/about/definition/en/print.html>. Accessed September 2nd, 2010.

Willis K, Daly J, Kealy M, Small R, et al. (2007) The essential role of social theory in qualitative public health research. *Australian New Zealand Journal of Public Health*, **31**, 438-43.

Appendices

Appendix A: Timeline

	2010				2010		
	September	October	November	December	January	February	March
Protocol submission and approval							
Engagement of CSOs and recruitment of participants							
Data collection							
Data analysis							
Write-up							
Dissemination							

University of Cape Town

Appendix B: Ethics approval



UNIVERSITY OF CAPE TOWN

**Health Sciences Faculty
Research Ethics Committee
Room E52-24 Grootte Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: lamees.emjedi@uct.ac.za**

22 May 2007

REC REF: 179/2007

Prof L London
Public Health & Family Medicine

Dear Prof London

PROJECT TITLE: LEARNING BY DOING AND DOING BY LEARNING: A CIVIL SOCIETY NETWORK TO REALISE THE RIGHT TO HEALTH

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

lemjedi

Appendix C-1: Topic Guide – Interviews

Name:

Organization/Community:

Part 1 – Use and Dissemination of Pamphlets

1. When you used the LN Pamphlets:
 - ❖ How did you use the LN pamphlets?
 - i. Probes: during activities, conferences, meetings, presentations, as displays, etc
 - ❖ How did you disseminate them?
 - ❖ Who was/were your target audience(s)
 - ❖ How many have you used?
2. How did people react to the pamphlets?
3. Of these pamphlets, which received the most interest? And why do you think that is the case?
4. Which has been most useful for your work? Can you give an example?
5. *Having discussed the most useful pamphlet* – Which other LN pamphlets have been useful? Can you give an example?

Part 2 – Awareness of Health Rights

6. Did the LN pamphlets change your understanding of the right to health? If so, can you give an example of how?
7. What is the key lesson or lessons you have learned from using the LN Pamphlets?
8. Have the LN pamphlets or your knowledge of the pamphlets empowered community action around the right to health? Can you give an example?

Part 3 – Accessing information on the Right to Health

9. Prior to the LN pamphlets, what media/tools did you use to access and provide information on the right to health?
10. Do you currently use any other communication media on health and human rights to provide information on the right to health?
 - ❖ If yes, how do the LN pamphlets compare to these other sources of information?
11. Where else do you get information on the right to health? *(Use if need more depth to answer to previous question).*

Part 4 – Suggestions for improvement

12. What improvements would you suggest for the LN pamphlets?
13. To who and where else could the pamphlets be sent to?
 - ❖ Who else would find them useful?
14. What would you suggest for improving the outreach and use of the LN Pamphlets?

Appendix C-2: Topic Guide – Focus Groups

Name:

Organization/Community:

Part 1 – Use and Dissemination of Pamphlets

1. I have 6 pamphlets here (showing them), have you seen them before?
 - a. Where did you first see them?
 - i. Prompts: at a conference, workshop, meeting, from a friend, community leader, community organization, local health facility, Learning Network, other.
 - b. How many did you take?
 - c. What have you used them for?
2. Of these pamphlets, which have you found most informative?
 - a. Which has been most useful for you? Can you give an example?
 - b. Which has been most useful for your organization? Can you give an example?
3. *Having discussed the most useful pamphlet* - Have you found any other LN pamphlets useful? Can you give an example?

Part 2 – Awareness of Health Rights

4. Prior to the LN pamphlets, did you know about your health rights?
5. Did the LN pamphlets change your understanding of your right to health? If so, can you give an example of how?
6. What is the key lesson or lessons you have learned from the LN Pamphlets?
7. Have the LN pamphlets or your knowledge of the pamphlets empowered community action around the right to health? Can you give an example?

Part 3 – Accessing information on the Right to Health

8. Have you used any other sources of information on health and human rights to know more about the right to health?
 - a. If yes, how do the LN pamphlets compare? (more or less useful, in which way, etc)
9. Have you used these pamphlets in your own work/community/family?
 - a. If yes, in what way?
10. Where else do you get information on the right to health? How do the pamphlets compare to these other sources of info?

Part 4 – Suggestions for improvement

11. What improvements would you suggest for the LN pamphlets?
12. To who and where else could the pamphlets be sent to?
 - a. Who else would find them useful?
13. What would you suggest for improving the outreach and use of the LN Pamphlets?

Appendix D: Consent Form – Interviews & Focus Groups

Learning by Doing and Doing by Learning: A Civil Society Network to Realize the Right to Health

Consent Form

We are doing a study to evaluate the effectiveness of the Learning Network pamphlets in providing information on the right to health. We will be doing our evaluation with 6 civil society organizations actively involved in the LN as well as the People's Health Movement. You have already seen a copy of the information sheet and we would now like to ask you to participate in our study.

You do not have to participate in our study if you do not want to. You can stop participating any time you like (during the interviews, discussions or during the time of the research project). If you decide not to participate in the study or decide to stop participating, this will not affect the services you receive from NGOs or any other service providers.

Any information you give us will be anonymized. This means that only the research team will have access to your name and any recordings we might make. It means that in the report your name will be not be given and nothing will be said that can link what is reported on to you.

You will not be paid for being involved in the research. We will cover costs transportation costs for your participation.

You will be told about the findings from our research as they become available. This might be directly from a research team member, or it might be from other participants at Learning Network events.

We do not believe there are any risks in you participating in the research. However, you may want to talk to someone after being interviewed or speaking to the research team. We suggest that you contact the organization that put us in touch with you if you would like to talk to anyone.

If you have any questions about any part of the research, please contact:
Nicolé Fick, School of Public Health and Family Medicine, UCT
Nicole.Fick@uct.ac.za or 021 406 6978.2

I have read the information sheet and consent form and any questions I have, have been answered	Yes	No
I agree that a recording can be made	Yes	No
I agree that notes can be taken	Yes	No
I agree to take part in the research	Yes	No

Participant: _____
(Name and Surname) (Signature)

Researcher: _____ (Signature) Date: _____

Journal – Health Promotion International

INFORMATION FOR AUTHORS

OPEN ACCESS OPTION FOR AUTHORS

New for 2010 – Please note that the journal now encourages authors to complete their copyright licence to publish form online.

SUBMISSION OF MANUSCRIPTS

Please see the online submission instructions [here](#).

Articles must be submitted in English. The total word count should not be over 4500 words (including abstract but excluding tables, figures and references), together with no more than four 'key' words to aid literature searching. Where relevant, the country where the research was undertaken should be included in the title of the manuscript. Please state clearly on the article the total word count; the word count should include the summary but not the references or tables/figures. Over-length articles will not be considered.

The Editorial Office will correspond directly with authors on the acceptability of their papers. Authors may not submit manuscripts that are under consideration for publication elsewhere.

Manuscripts must be submitted online via <http://mc.manuscriptcentral.com/hpi>

Manuscripts must be clearly and concisely written in English. The Editors reserve the right to reject without review those that cannot adequately be assessed because of a poor standard of English. Authors whose first language is not English are encouraged to have their manuscript checked by a native English speaker. If you have difficulty with this you can obtain further help and information [here](#).

REFERENCES

Reference list: References should be listed at the end of the main text and reference citations should be inserted in the text using the author-date system described below. The list of references should be in alphabetical order of surnames. References by the same author(s) should be in chronological order. The normal form of listed references is author's surname, initials; year in parenthesis; article title; journal name in full, volume number and page numbers. For example: Bunton, R. and Macdonald, G. (eds) (1992) *Health Promotion: Disciplines and Diversity*. Routledge, London.

Author-date citations: References should be cited in the text using the author-date system, whereby the surname of the author and year of publication of the reference are used in the text. For example: 'Reports by Author (Author, 1989) have confirmed...' or '...as reported earlier (Author and Author, 1985; Author *et al.*, 1998)'. *Do not* place text other than the author and date within the parentheses.

Online references should be cited as in example 1, below. Please see examples 2 and 3 for papers that have been published online in more than one version. The initial version

of a paper published in this way can be cited by the Digital Object Identifier (doi) but, if available, the reference should also include the citation of the final version. Authors should check all references carefully, and in particular ensure that all references in the Reference section are cited in the text. Note that multiple references or page spans under one number are not allowed. Personal communications, unpublished results, manuscripts submitted or in preparation, statistical packages, computer programs and web sites should be cited in the text only, NOT included in the References section. Accession numbers may be cited either within the text or in the form of a reference.

Xu, L. S., Pan, B. J., Lin, J. X., Chen L. P., Yu, S. H. and Jones, J. (2000) Creating health-promoting schools in rural China: A project started from deworming. *Health Promotion International*, **15**, 197-206.

Salmon, J., Ball, K., Crawford, D., Booth, M., Telford, A., Hume, C., Jolley, D. and Worsley, A. (2005) Reducing sedentary behaviour and increasing physical activity among 10-year-old children: overview and process evaluation of the 'Switch-Play' intervention. *Health Promotion International*, January 24, 2005: 10.1093/heapro/dah502.

Messerlian, C., Derevensky, J. and Gupta, R. (2005) Youth gambling problems: a public health perspective. *Health Promotion International*, **20**, 69-79. First published on January 28, 2005: 10.1093/heapro/dah509.

PROOFS

Authors are sent page proofs. Please provide an e-mail address to enable page proofs to be sent as PDF files via e-mail. To avoid delays in publication, proofs should be checked immediately for typographical errors.

OPEN ACCESS OPTION FOR AUTHORS

Health Promotion International authors have the option to publish their paper under the Oxford Open initiative; whereby, for a charge, their paper will be made freely available online immediately upon publication. After your manuscript is accepted the corresponding author will be required to accept a mandatory licence to publish agreement. As part of the licensing process you will be asked to indicate whether or not you wish to pay for open access. If you do not select the open access option, your paper will be published with standard subscription-based access and you will not be charged.

If you choose the open access option you will be asked to complete an open access charge form online. Open access charges can be viewed here in detail; discounted rates are available for authors based in some developing countries (click here for a list of qualifying countries). Please note that these charges are in addition to any color charges that may apply.

Orders from the UK will be subject to the current UK VAT charge. For orders from the rest of the European Union, OUP will assume that the service is provided for business purposes. Please provide a VAT number for yourself or your institution and ensure you account for your own local VAT correctly.

LICENCE TO PUBLISH/OFFPRINTS

Upon receipt of accepted manuscripts at Oxford Journals authors will be invited to complete an online copyright licence to publish form.

This ensures that requests from third parties to reproduce articles are handled efficiently and consistently and will also allow the article to be as widely disseminated as possible. In granting an exclusive licence, authors may use their own material in publications provided that the Journal is acknowledged as the original place of publication, and Oxford University Press is notified in writing and in advance. In consideration for granting an exclusive licence, the publisher will provide free online access to your article. Printed offprints may be ordered at extra cost at the proof stage.

To download the offprint form, please click [here](#).

Orders from the UK will be subject to the current UK VAT charge. For orders from elsewhere in the EU you or your institution should account for VAT by way of a reverse charge. Please provide us with your or your institution's VAT number.

Please note that by submitting an article for publication you confirm that you are the corresponding/submitting author and that Oxford University Press ("OUP") may retain your email address for the purpose of communicating with you about the article. You agree to notify OUP immediately if your details change. If your article is accepted for publication OUP will contact you using the email address you have used in the registration process. Please note that OUP does not retain copies of rejected articles.

COMMUNICATIONS

Editorial Office contact information:

Ms Robyn Perlstein BSc (hons); Grad Dip Diet; APD
Health Promotion International Journal Administrator
Faculty of Health, Medicine, Nursing and Behavioural Sciences
Room ad2.211, Denny Lascelles Building
Deakin University
Geelong Waterfront Campus
Victoria, Australia 3220

Phone + 61 3 52 278724
<http://heapro.oxfordjournals.org/>
Email: hpij@deakin.edu.au

FUNDING

Please submit a separate title page (to be designated as "Title Page") with author address and contact details, funding sources, word count and any acknowledgements.

For the funding statement the following rules should be followed:

- ❖ The sentence should begin: 'This work was supported by ...'
- ❖ The full official funding agency name should be given, i.e. 'the National Cancer Institute at the National Institutes of Health' or simply 'National Institutes of Health' not 'NCI' (one of the 27 subinstitutions) or 'NCI at NIH' ([full RIN-](#)

- approved list of UK funding agencies) Grant numbers should be complete and accurate and provided in brackets as follows: '[grant number ABX CDXXXXXX]'
- ❖ Multiple grant numbers should be separated by a comma as follows: '[grant numbers ABX CDXXXXXX, EFX GHXXXXXX]'
 - ❖ Agencies should be separated by a semi-colon (plus 'and' before the last funding agency)
 - ❖ Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number 'to [author initials]'.

An example is given here: 'This work was supported by the National Institutes of Health [AA123456 to C.S., BB765432 to M.H.]; and the Alcohol & Education Research Council [P50 CA098252 and CA118790 to R.B.S.R.]'

Oxford Journals will deposit all NIH-funded articles in PubMed Central. See http://www.oxfordjournals.org/for_authors/repositories.html for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above.

AUTHOR SELF-ARCHIVING/PUBLIC ACCESS POLICY

Author Self-Archiving/Public Access policy from May 2005

For information about this journal's policy, please visit our [Author Self-Archiving policy page](#).

GUIDE FOR AUTHORS PREPARING DOCUMENTS FOR SUBMITTAL

DO

Enter text in the style and order of the Journal.

Insert figure captions and tables at the end of the file.

Save any tables, diagrams, figures, graphs or illustrations generated electronically as separate files and not embedded into the text file.

Type references in the correct order and style of the Journal.

Type unjustified, without hyphenation, except for compound words.

Type headings in the style of the Journal.

Use the TAB key once for paragraph indents.

Where possible use Times for the text font and Symbol for the Greek and special characters.

Use the word processing formatting features to indicate **Bold**, *Italic*, Greek, Maths, ^{Superscript} and _{Subscript} characters.

Indicate clearly any special characters or accents for which you have used alternative key/characters.

DO NOT

Enter carriage returns to obtain spacing between lines, paragraphs, references etc. The space required is generated automatically by the typesetters.

Use double spaces after each sentence within a paragraph.

Use the automatic page numbering (number the hard copies by hand at the bottom of the page), running titles and footnote features of your word processing program.

Leave blank spaces if special characters or accents are not available from your word processing package. **These should be substituted by alternative key/characters.**

Include any copyright material (e.g. word processor software or operating system files).

FIGURE SUBMISSION

Images on disk can be accepted in Adobe PhotoShop compatible formats. Images should be saved in TIFF format.

Image resolution should be a *minimum* of 300 dpi.

University of Cape Town

Examples of Community Empowerment around the Right to Health

“Community members and patients wanted to be a part of the discussion and planning of the health budget. The Rights and Resource Allocation (6) pamphlet created awareness as well as a sense of responsibility among people as to what their rights and responsibilities are. This has contributed to participation of health committees, for the last two years, in the provincial planning of the health budget.” (A-1)

“In the Limpopo province, where our organization held a workshop on the right to health, the health committee did not wait for the pamphlets to be translated. They translated them themselves into Sesotho.” (A-1)

“One of our communities will be holding a health summit and their focus is on the right to health and the social determinants of health. The summit is organized by the people and community, taking responsibility to draft the agenda, choose the topics and invite partners.” (A-1)

“I led a training on breast wellness and used the pamphlets to encourage young women to go for check-ups and get tested for breast cancer. Fortunately they all came out clear but this was possible as a result of these young women understanding their right to health.” (C-8)

“My husband is a tractor driver and he sprays pesticides. As a community health worker, I am aware of his right to health and worried. I informed him that he has the right to protective clothing when working with pesticides. He developed asthma so I encourage him to demand the gear. If he didn't demand it, I would! Now he wears protective gear and has an enclosed tractor to limit exposure to pesticides. I didn't know this before the training with these pamphlets.” (C-8)

*“Pamphlets have empowered community action or rather strengthened, because even before the pamphlets, women knew their rights and were taking action. For example, one of the health teams became aware of a lack of markings on the doors at the local health clinic. But everyone knew that the door on the left was people coming for HIV testing, medication, treatment or support. Due to the stigma this generated, people started staying from the clinic. The health team had a conversation with the clinic management which resulted in the use of both rooms for **all** patients in order to minimize stigma.” (A-14)*

Appendix E: Recommendations for the Learning Network

- Combine the LN pamphlets with the LN Health and Human Rights Toolkit during training and workshops;
- Increase and diversify members of the LN;
- As literacy is a problem in South Africa, pamphlets need to be made legible to the greater public and may require the use of images such as cartoons for people to understand more easily. Ensure the active participation of expected target beneficiaries in the design of these ‘user-friendly’ pamphlets.
- It is unclear from the research and findings whether the ultimate beneficiaries of the pamphlets actually understand the contents of the pamphlets. CSOs with their staff and volunteers prove to be a more effective dissemination mechanism and therefore should be the primary target audience of the LN pamphlets. Hence, more guidance on how to realize health rights and how to impart information from the pamphlets must be provided to CSOs and other community-related organizations.
- In cooperation with LN members and respective community leaders, identify, through community mapping, existing infrastructures and organizations that can facilitate the transfer of health rights information.
- Development of a two-fold dissemination strategy for the LN pamphlets:
 - o Broad outreach – through existing media such as community radios, public forums, community meetings, posters in health, education and community spaces (clinics, schools, vocational training, churches, etc.);
 - o Targeted outreach - staff and volunteers from organizations working directly with communities on a wide range of issues (not solely health and/or human rights) should receive training on the right to health, carried out by LN staff and members as well as complemented by the pamphlets.
- In cooperation with LN members, perform a baseline study in several different communities focusing on what existing knowledge people have about the right to health as well as existing actions around the right to health. After the baseline study, partner with community-related organizations (schools, churches, CSOs, etc) to disseminate information on the right to health through workshops for example. Perform a second study to assess whether the target beneficiaries of the pamphlets (individuals) were reached properly and gauge knowledge change due to pamphlets.