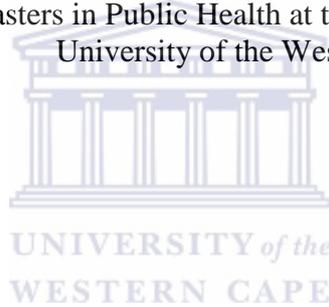


**The human rights-based approach to public health: An inquiry into  
the challenges of its adoption in Uganda**

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A mini-thesis submitted in partial fulfilment of the requirements for the degree for the  
degree of Masters in Public Health at the School of Public Health,  
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## ABBREVIATIONS

AGHA: Action Group for Health, Human Rights and HIV/AIDS

AIDS: Acquired Immunodeficiency Syndrome

AMREF: Africa Medical and Research Foundation - Uganda

ART: Anti-Retroviral Treatment

AHSPR: Annual Health Sector Performance Report

CEDAW: Committee on Elimination of Discrimination Against Women

CEHURD: Center for Health, Human Rights and Development

HEPS: Coalition for Health Promotion and Social Development

CHAIN: Community Health and Information Network

CPHC: Comprehensive Primary Health Care

CRC: Convention on Rights of a Child

CSO: Civil Society Organisations

DHO: District Health Officer

EM: Essential Medicines

FGDs: Focus Group Discussions

GoU: Government of Uganda

HB: Hospital Boards

HCT: HIV Counseling and Testing

HIV: Human Immunodeficiency Syndrome

HR: Human Rights

HRAPF: Human Rights Awareness and Promotion Forum

HRBA: Human Rights Based Approach

HSSIP: Health Sector Strategic and Investment Plan

HUMC: Health Unit Management Committees



ICESCR: International Covenant of Economic, Social and Cultural Rights

ITN: Insecticide Treated Net

KCCA: Kampala City Capital Authority

LGs: Local Governments

MoH: Ministry of Health

MoICT: Ministry of Information and Communication Technology

MUSPH: Makerere University School of Public Health

NCDs: Non- Communicable Diseases

NGO: Non-Government Organisations

NHP: National Health Policy

NODPSP: National Objectives and Directive Principles of State Policy

NTDs: Neglected Tropical Diseases

OHCHR: Office of the High Commissioner for Human Rights

PHAPC: Public Health Act and Patients Charter

PHC: Primary Health Care

PHC: Public Health Care

TASO: The Aids Support Organisation

UBOS: Uganda Bureau of Statistics

UHRC: Uganda Human Rights Commission

UNHCO: Uganda National Health Consumers Organisation

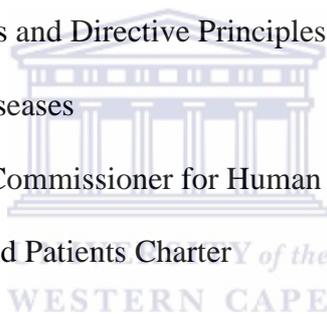
UN: United Nations Organisation

UNCT: United Nations Country Team

UNDAF: United Nations Development Assistance Framework

UNDG: United Nations Development Groups

UNDHR: Universal Declaration of Human Rights



UNDP: United Nations Development Programme

UNFPA: United Nations Population Fund

UWC: University of Western Cape

VHTs: Village Health Teams

WHO: World Health Organisation



## TEN KEYWORDS

- Human rights based approach
- public health
- right to health
- Comprehensive Primary Health Care
- Uganda Human Rights Commission
- social rights implementation
- progressive realization
- justiciability
- health promotion
- stakeholder perceptions



## DECLARATION

I declare that the work presented herein is original and that it has not been submitted for any degree or examination in any other university or institution for the award of a degree or certificate and that all sources of information and dates used or quoted have been duly acknowledged.

Full name: David Ouma Balikowa

Date: 22 December 2011

Signature: 



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## **ABSTRACT**

Knowledge about the challenges in adopting the Human Rights Based Approach (HRBA) to public health is still limited, necessitating an exploration into the subject. The purpose of this study is to contribute to strengthening the implementation of the HRBA to public health in Uganda. The aim was to explore challenges to the implementation of this approach. The objectives of this study were to examine whether there is a shared understanding and agreement among stakeholders about the meaning and potential value of the Human Rights Based Approach (HRBA) to public health, and to describe stakeholders' perceptions on the challenges to the adoption and implementation of the HRBA to public health.

**Methods:** The study employed a cross-sectional qualitative exploratory descriptive method including archival, legislation and strategy review, key informant interviews, and focus group discussions with a purposive sample of rights holders (Ugandans in urban and rural communities), duty bearers (health sector actors), and advocates (civil society and academic human rights organizations and activists). The data analysis was cumulative using analytical index categories. The study adhered to ethical principles of voluntary participation, protection of anonymity of participants and confidentiality of information.

**Findings:** There is lack of coherence between State commitments under International Covenant on Economic, Social and Cultural Rights (ICRSCR), National Health Policy, Health Sector Investment Plan (HSSIP) and the Constitution which impede the application of the HRBA to public health. The question of the labour rights of health workers also has to be addressed as an integral component of the HRBA to promote consensus and common understanding of the approach by stakeholders. Comprehensive Primary Health Care and Health Promotion as public health

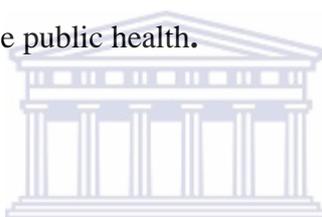
approaches are actually abundantly informed by the HRBA. But while they are appropriate in framing equity and health access issues among others, they are not sufficient as vehicles of the HRBA.

**Conclusion:** Lack of coherence between international obligations, health policy and sector strategic plans' provisions on the right to health, and the national Constitution is a key challenge to the adoption of the HRBA to health. This is compounded further by lack of prioritization of the health sector in resource allocation, limited knowledge, common understanding and consensus on the HRBA to public health among stakeholders, as well as lack of effective mechanisms for community involvement.



## **1. CHAPTER 1: INTRODUCTION**

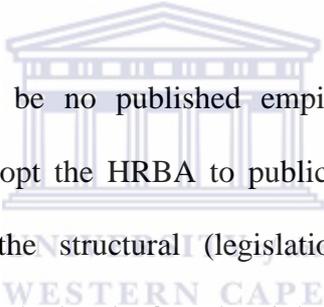
Uganda was one of the first countries to respond to the findings on the human rights dimensions of Neglected Tropical Diseases (NTDs) by the former United Nations Special Rapporteur on the right to health, Prof. Paul Hunt, by setting up a health rights desk at the Uganda Human Rights Commission (UHRC) in 2006 (Hunt, 2006 ). The initiative coincided with increased calls globally for the development process, especially the health sector, to adopt the Human Rights Based Approach as a means of ensuring that health interventions benefit most those in dire need of services (UN, 1997; UN, 2005; UNDG, 2003; &UNDAF, 2007). Half a decade later, it is important to explore and document what challenges – if any – the country has encountered in adopting the HRBA to improve public health.



### ***1.1 The HRBA to health***

The WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948). By implication, the right to health is the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (WHO, 2008: p5). Like other human rights, it is also universal, indivisible, inter-dependent and interrelated (UNDHR, 1948) and is assertable against duty bearers such as the state, and perhaps the entire world (Wasserstron, 1979). Its realization is, however, highly dependent not only on health services but on the underlying determinants of health such as safe and adequate drinking water, sanitation, food security, nutrition, housing, healthy working and living environmental conditions, education and information, and gender equality among others (ICESCR, 1966); as well as participation of communities at all levels (Balusubramaniam, 2009).

In practice, the right to health is usually operationalised in terms of availability, accessibility, acceptability and quality of health services to the rights bearers (WHO, undated). In essence, the HRBA presupposes the application of the human rights standards and principles. They include equality and non discrimination especially of the vulnerable and marginalised in the legal and policy framework as well as provision of health care services to progressively realize basic health standards; accountability of the duty bearer especially through legal recourse (justiciability), and; participation of rights bearers and communities in the planning and delivery of health services (London, 2008; Asher, 2004.).



In Uganda, there appear to be no published empirical studies of whether the declaration of principle to adopt the HRBA to public health has been matched by significant moves at both the structural (legislation and policy) and process (implementation) levels, and whether in fact the right to health is justiciable. Some health rights activists have intensified education of rights holders and health workers about the right to health (Musoba & Kalloch, 2009) but there are no studies yet on the impact of this intervention. For example, it is not clear whether the awareness drive is starting to translate into a common understanding and consensus between health sector actors and human rights activists on the mode of application of human rights principles.

The lack of common understanding could partly be resolved by looking at the approaches of new public health (Baum 1998) such as Comprehensive Primary Health Care (CPHC) and Health Promotion in their human rights aspects, and human rights

in its CPHC and Health Promotion aspects. It might be the case that the HRBA to public health is intrinsic to both CPHC and Health Promotion. Such possible approaches to building a shared understanding and common plan of action between human rights and public health actors have not, however, been empirically examined.

### ***1.2 Problem statement***

While a number of countries have responded to calls to adopt the HRBA to health and development in the last decade, the right to health is still far from being realized by the majority of populations in much of the developing world. Despite statements of commitment to the application of human rights principles, there is lack of empirical evidence on the perceptions and level of consensus among stakeholders on what a Human Rights Based Approach actually means, and the challenges faced by a developing country like Uganda in implementing the HRBA. Exploring these stakeholder perspectives may help to clarify whether indeed the HRBA offers anything new to the current public health approaches.

### ***1.3 Research question***

How do stakeholders perceive the meaning, potential value, and challenges for implementation of a Human Rights Based Approach to public health in Uganda?

### ***1.3 Study rationale***

Countries around the globe are being obliged by funders and urged by United Nations agencies such as the UNDP and WHO to base development programmes including health, on human rights principles (UN, 1997; UN, 2005; UNDG, 2003; &UNDAF, 2007). Unfortunately, knowledge about the adoption of the HRBA to public health in

the developing countries is still inadequate. By studying the level of consensus among stakeholders and the challenges to the adoption of the HRBA to public health in Uganda since 2006, it is hoped that critical issues underlying its adoption will be unmasked to form part of the much needed empirical evidence on the subject, and also help to determine whether it indeed offers new insights and opportunities complementary to public health approaches in improving public health.

#### ***1.4 Study context: Health and the Human Rights Based Approach in Uganda***

Uganda is located in East Africa and occupies 241,039 sq km. The country is predominantly agricultural with the majority of the population dependent on subsistence farming. The country's burden of disease is still very high. Malaria is the major communicable disease in Uganda and is largely responsible for the high infant mortality of 79 per 1,000 live births (UBOS, 2007). Maternal mortality stood at 435/100,000 births by 2010. The country is also greatly affected by HIV/AIDS. By 2009, up to 1,192,372 individuals had been affected with HIV while 64,016 people had died from HIV/Aids related causes (MoH, 2010). Furthermore, 32% of children below five years are stunted, while 6% are wasted due to malnutrition, exacerbating their vulnerability to disease (UBOS, 2007). Data on non-communicable diseases (NCDs) are scarce but there are concerns that NCDs are on the increase, as are deaths and disabilities due to injuries, mostly traffic accidents which doubled from 1993 to 2003 (UBOS, 2007).

The burden of disease in Uganda is traced to socio-economic factors which do not enable the great majority of the population to live healthy lives. While the country's population grew from 4.9 million in 1948 to 24.2 million in 2002 (2011 estimates at

33.5 million), failure to maintain corresponding economic growth is accelerating poverty, exposing the poor majority to a host of preventable diseases (UBOS, 2007).

To deal with the disease burden, human rights groups have intensified the campaign for the country to start treating health as a fundamental human right. The Uganda Human Rights Commission (UHRC) was one of the first commissions in the developing world to set up a unit in 2006 to specifically handle the right to health. This was in response to a recommendation by the former United Nations Special Rapporteur on the right to health, Prof. Paul Hunt who visited the country in March 2005 to examine the human rights aspects of the Neglected Tropical Diseases (NTDs). The unit initially planned to start by dealing with NTDS, was extended to issues of accountability in the delivery of health rights by monitoring policies, programmes and project activities in the health sector. The activities included sensitizing health policy makers and workers on the HRBA and communities on the right to health plus investigating complaints on the right to health violations (Hunt, 2006).

The effort has been supplemented by Civil Society Organisations and Non Governmental Organisations. The Action Group for Health, Human Rights and HIV/AIDS (AGHA) Uganda has in the last five years tried to raise awareness among medical personnel and other stakeholders on health care rights with some success (Musoba & Kalloch, 2009).

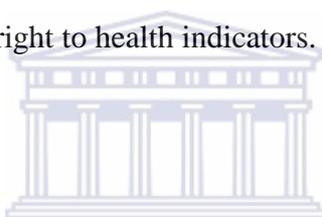
The specific setting of this study of the challenges to implementation of the HRBA in the context of Uganda's health and policy situation is rural, semi-urban and urban

slum communities in Uganda's Mayuge, Kamuli, Jinja and Kampala districts. It is described in more detail in the methodology chapter.



## 2. CHAPTER 2: LITERATURE REVIEW

This literature review focuses on challenges to the implementation of a human rights based approach to health,. The challenges to the actual implementation of HRBA can be examined at three levels; structural (legislation, policies and health sector strategic plan put in place by duty bearers to meet obligations of the right to health), process (implementation activities) and outcome (standard of health care realized by rights bearers) indicators (OHCHR 2006; Gruskin & Ferguson, 2009). The three also provide a measure of the level of stakeholder consensus. This study and literature review address structural and process challenges, including capacity. Conceptually, challenges at the structural and process or implementation levels result into negative outcomes in the form of poor right to health indicators.



### 2.1 Structural challenges

The right to health is universally recognized as contained in international instruments. Article 12 of the International Covenant of Economic, Social and Cultural Rights (ICESCR) states that member “State Parties recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (ICESCR, 1966). The Covenant obliges State Parties to take steps to reduce stillbirth and infant mortality rates and promote the healthy development of the child; improve environmental and industrial hygiene; prevent, treat and control diseases among others (ICESCR, 1966). There are, however, variations in the interpretation and level of domestication of international obligations by different jurisdictions, and consequently their implementation. Human rights writers like Steiner and Alston have attributed this to ideological, theoretical and legal divergences (Steiner and Alston, 2000).

The varied understanding and commitment to the ICESCR is mirrored in the varied levels of domestication of its provisions and implementation by the State Parties. The variations while reflecting the governmental ambivalence to the rights under this covenant, also offer pointers as to the challenges encountered as a result of the gaps in laws protecting the right to health among other positive rights. Positive rights impose an enormous obligation on the State as a duty bearer to provide physical services like drugs, hospitals, doctors, clean water in contrast to negative rights that merely require restraint, for example by the state or its agents from acts such as torture that compromise the good health of citizens (Steiner and Alston, 2000).

## ***2.2 Progressive realization and justiciability***

The issue of progressive realisation of the right to health as funds become available is highly contested. Beetham (1995) in an article examining the future of economic and social rights poses the question as to what level of deprivation of nutrition, sanitation or health care is sufficient to trigger legal redress. He also wonders whether the obligation on the state to deliver health services when they lack the capacity to do so simply pits them against an impossible mission. By implication, would it not be futile for citizens to bear a right to health without the prospect of ever enjoying good health? Steiner and Alston (2000) note that it is for reasons like these that the human rights approach to fundamental needs like health among the most vulnerable groups adds an “inspirational or promotion dimension” to provide both moral and legal ground for citizens to negotiate with the state to meet its international obligations. In effect, the progressive implementation mentioned by the ICESCR can only materialize if health rights holders stand up to claim their right.

The United Nations Committee on Economic, Social and Cultural Rights in General Comment 14 provides the standard for applying the Covenant's provision on the right to health by the State Parties to their health systems. It points out that the aspect of progressive realization as resources become available is, however, also associated with the obligation for states to take "deliberate and immediate" steps towards ensuring that realization occurs within "reasonable time" (UN, 2000). But while "reasonable time" in policy and legal documents diminishes prospects for successful litigation in case of denial of health rights, progressive jurisprudence on economic rights and the matching of the right with an obligation even when coined in the "progressive realization" fashion could be seen as a step in increasing its justiciability (Steiner & Alston, 2000).



Progressive jurisprudence in South Africa (*Minister of Health v. Treatment Action Campaign, 2002*) has demonstrated that courts can offer remedies in cases of denied rights to health under Section 27(3) of the constitution, again highlighting the importance of elaborate legal provisions coupled with positive obligations as pointed out in General Comment 14. But while there has been successful litigation in cases seeking medical treatment, it is yet to be seen if, given the resource implications, courts in resource-poor settings can – in response to litigation on behalf of the most vulnerable or marginalized – provide remedies where the determinants to health such as food, clean water and basic hygienic housing, or a healthy environment are lacking (Gloppen, 2008).

### ***2.3 Process challenges: Implementation, resources, participation and capacity***

Having the laws, policies or strategic plans in place spelling out the obligations of the state is not enough to ensure the realization of the right to health. Ecuador in 1998 promulgated a free maternity law guaranteeing health care to pregnant women, newborns and children below five, and family planning care to women of reproductive age. But seven years later, the law was yet to be fully implemented, making a case for the need of having in place redress mechanisms for implementing laws guaranteeing the right to health (UNFPA, 2009).

#### **2.3.1 Lack of resources or political will?**

But while the resource constraint to meet the right to health is well acknowledged, it masks lack of political will by some governments that instead spend heavily on the military or non priority items. This is despite commitments such as the Abuja Declaration for countries in Africa to ensure that by 2005, at least 60% of those affected by malaria have access to “correct, affordable and appropriate treatment in 24 hours after the onset of symptoms” (WHO, 2003). It is also the target of the Declaration to ensure that 60% of those at risk (pregnant and children below 5 years “benefits from community protective measures” against malaria. A study by London on how human rights approaches can promote health equity concluded that approaches that recognize the need to target vulnerable groups and their roles can help achieve this goal (London, L 2007).

Noting the social returns on the right to education of females in form of reduced infant and indeed maternal mortality, a UN human development report urges countries to “orient national priorities” to accommodate additional spending on

development and actualize rights such as health (UNDP, 1990). The HRBA would seem to have the distinctive character and mission of seeking to prioritize national resources in favour of the most vulnerable citizens, a process described by Frenk and Gomez-Dantes (2009) as the democratization of health— and by Kelly as the “expansion of democracy to social rights” through, among others, the introduction of a welfare system that seeks to redistribute resources by taxing the wealthy (Kelley 1998).

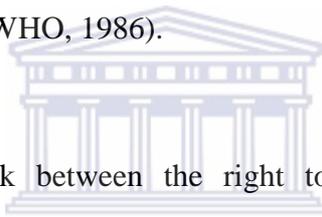
Also, the HRBA challenges the health sector to transcend accepting as given the assumption that resources are scarce and start to advocate for increased budgeting (Schuftan, 2010). It is for such reasons that Kelley (1998) argues that progressive legislation to increase the justiciability of the right to health could compel the governments to pursue welfare right based approach to providing basic needs that will promote fundamental rights such as health. But while governments have the political obligation to create an equitable society and support the right to health (Holmes & Sunstein, 1999), the challenge is how to compel them make legislative and budgetary adjustments.

### **2.3.2 Stakeholder consensus, participation and awareness**

In a study on whether the HRBA to health matters, London noted that evidence from South Africa had suggested that lack of a common perception on human rights to an extent influenced the way the State implemented the right to health (London, 2008).

Haigh (2002) notes that the interdisciplinary effort is often characterized by tension due to lack of a common perspective on the HRBA to health. Health policies and programmes may be viewed by human rights activists as being “population oriented”

(public health) instead of having the individual orientation often associated with human rights. This may however be a false dichotomy. There is a growing consensus on the need to broaden the definition of health beyond the individual-focused medical approach and include the social determinants of health that affect populations (WHO, 2005; Beaglehole & Bonnita, 1997; Baum, 1998). Asher (2004) notes that it is precisely for the very reason that public health is population focused that the health sector planning ought to take into account human rights principles such as equality, equity, justice so as to succeed. Indeed, the Alma Ata Declaration advocated for community involvement and a multi-sectoral approach in 1978, while the Ottawa Charter speaks of population based participation of communities in health care and personal skills (WHO, 1978; WHO, 1986).



Underscoring the strong link between the right to health and PHC, Schuftan advocates for wide discussion of this relationship and how for example community participation empowers rights holders and duty bearers (especially health workers) in PHC (Schuftan, 2010). For example, a pilot citizen card report project in Uganda in 2007 to strengthen providers' accountability to clients in 50 health facilities is reported to have resulted into improvements of both the quality and quantity of health care (WHO/OHCHR, 2007). Further on the lack of stakeholder consensus, Solomon (2009) notes that skepticism and financial constraints can be overcome as long as the approach identifies allies as entry points, aligns with existing efforts or initiatives, and impresses upon the policy makers the importance of communication and dissemination of information to the public. Explanation of human rights concepts in simple terms increases stakeholder participation. In addition to access to information by the rights bearers on entitlements and how to claim them, Frenk and Gomez-

Dantes (2009) and Schuftan (2010) argue that open evaluation, feedback, demand, dialogue and negotiation by rights holders are critical to the success of the HRBA in public health. Participation and training of stakeholders in HRBA is even more critical in settings where the subject of human rights is regarded as culturally and politically sensitive (UNCT Tunisia, 2007).

### **2.3.3 Literature limitations**

The literature reviewed above exploring the challenges to the adoption of the HRBA is not based on field research. This is partly because the nature of empirical evidence tends to differ across health and legal disciplines. While public health gravitates towards field research for empirical evidence, in the legal discipline – which tends to dominate human rights discourse including the right to health – jurisprudence is relied on to test, form laws and gather knowledge and are often the focus of research. Unfortunately, except for two cases in South Africa on the right to treatment, jurisprudence on the right to health in the developing world is still very limited to offer meaningful insights more especially on the justiciability of the determinants to health. This study will provide some empirical evidence to guide further studies on the subject.

### 3. CHAPTER 3: METHODOLOGY

The study employed key informant interviews, Focus Group Discussions (FGDs), and document review.

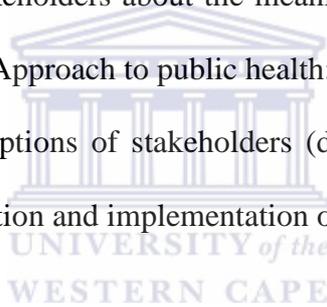
#### *3.4 Aims and objectives of study*

##### **2.4.1 Aim**

The aim of this study was to explore challenges to the implementation of the HRBA to public health in Uganda.

##### **2.4.1 Objectives**

1. To a) describe and b) examine whether there is a shared understanding and agreement among stakeholders about the meaning and potential value of the Human Rights Based Approach to public health;
2. To describe the perceptions of stakeholders (duty and right holders) on the challenges to the adoption and implementation of the HRBA to public health



#### *3.1 Study design*

The study employed a descriptive qualitative method to inquire into and describe the nature and extent of stakeholders' perceptions on the Human Rights Based Approach to public health, and the challenges to its adoption and implementation. The stakeholders included in this study were the **health rights holders** (communities), **duty bearers** (health service planners and providers) and **advocates of the right to health** (civil society and academic organizations). Qualitative data provide valuable insights into the “meanings, experience and views” of both the professional and lay stakeholders on the social phenomenon such as the challenges to the HRBA (Pope et al 2007). The case for the qualitative method was made stronger due to limited information on the subject (Chopra & Coveney, 2008), and the complexity of the

HRBA in public health as discussed in the literature review. In addition, the descriptive study design was feasible and affordable for an exploratory study of this nature.

### ***3.2 Study population***

The study population was composed of stakeholders in three fields: the health service delivery system, human rights organizations and actors, and communities. They included rights duty bearers (health service providers at national and district levels), right bearers (community members), and human right activists/advocates (CSO/NGO and academic institution members).

The study included poor urban, peri-urban, and rural communities and the health districts actors serving these communities, as well as stakeholders who are not linked to any particular geographic community of rights holders: academics, activists/NGOs working in various sites, and the Uganda Human Rights Commission.

### ***3.3 Sample size and sampling procedure***

The sample of information rich respondents was purposively selected to capture a range of perspectives across the salient categories among the duty and right holders with regard to the right to health so as to capture the variations in perceptions (Rice & Ezzy, 1999). The respondents and their roles in the study are described in more detail in section 3.4 below. A total of nine in-depth respondents were selected to capture a range of perspectives across gender, health service delivery at the national and district level, and human rights advocates.

A total of 33 participants (19 women and 14 men) aged between 18 and 60 years participated in the FGDs. The majority of the participants were peasant farmers and with primary education. There were a few with secondary education and diploma education who included teachers and readers. The participants in the Kifumbira city slum included casual workers and petty traders. The participants were recruited by convenience sampling from homes, at the market, churches and shops frequented by both men and women in the study communities.

**Table 1: Demographics of FGD participants**

No	Place of FGD	Rural/urban	Women	Men	Age/Yrs	Education
1	Wamulongo (Mayuge district)	Rural	5	4	22-60	Primary 4 - diploma
2	Bugewya (Kamuli district)	Rural	5	3	18 - 55	Primary 4 –Senior 4
3	Wabulenga (Jinja district)	Peri-urban	4	3	28 - 60	Primary 7 -senior 5
4	Kifumbira Kampala/capital city	Urban slum	5	4	20 -49	Primary 6 –Senior 6
<b>Total</b>	<b>4</b>		<b>19</b>	<b>14 = 33</b>		

### 3.4 Instrument development and data collection methods

As the empirical or field research base of the literature on the HRBA is underdeveloped, no existing validated instruments and tools were found. This project therefore used interview and discussion guides (instruments) which had been

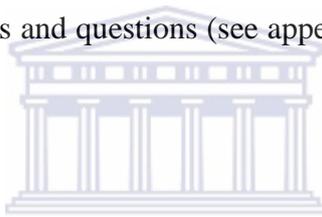
developed and pilot-tested before field implementation. The design of the instrument was informed by the literature review and sought to explore stakeholder perception of the meaning, potential value and challenges for implementing the HRBA. Open ended questions were used to permit respondents to formulate their own answers and arranged in sequence to flow from the general to specific questions. The interview guide was reviewed with two human rights advocates and a health worker in the capital city. The FGD guide was piloted with a convenience sample of community members in Kireka city suburb not involved in the study. The interviews and FGDs were recorded and transcribed for reference purposes. The interviews and FGDs were conducted by one trained research assistant and supervised by the researcher.

#### **3.4.1 Key informant in-depth interviews**

Key informant interviews were conducted with purposively selected respondents involved in the health and human rights sectors. They included human rights advocates at NGOs, the Uganda Human Rights Commission, and academic institutions. These provided information on legislative, policy and health strategy challenges. Other respondents included health sector actors (agents of duty bearers) in charge of developing and implementing the health sector strategy at national (MoH) and district level (district health offices and health centres) who provided information on structural and implementation process challenges and the level of consensus on the adoption of HRBA to health. During the interviews, probes and prompts were employed to bridge information gaps. The questions captured responses on perceptions on structural, process and capacity challenges (see appendix One). The interview instrument was pretested both at national and district level.

### **3.4.2 Focus Group Discussions (FGDs)**

FGDs were held with men and women (right bearers) in rural, semi-urban, and urban slum communities to capture their perceptions of the right to health, whether it was realized or not (outcome) and why. The objective was to explore the knowledge on the right to health (both in its duty and right bearer aspects) and perceptions on their level of participation (a critical component of the HRBA) as rights bearers in health service delivery. The candid exchange of ideas based on group dynamics provided stepping stones in data analysis (Kitzinger, 1995). The FGDs were conducted in both Lusoga and Luganda languages spoken in the communities. The FGD guide was translated into both languages and pretested. The FGDs were conducted along the proposed discussion guidelines and questions (see appendix One) and lasted one hour on average.



### **3.4.3 Legislation, policy and strategy review**

The above two methods were supplemented by a review of national legislation, health policy and strategic plans. The national Constitution was reviewed to establish if it had any express provision on the right to health; the Public Health Act and Patients Charter for legislation on the right to health; the Second National Health Policy and HSSIP for pronouncements on the right to health and the HRBA, and coverage of health care; Civil Society Organisation advocacy information materials on statistics, court petitions and analysis, negotiations, lobbying and petitions on the right to health. The legal, policy and sector strategic plans were purposively identified, while the advocacy papers were sourced directly from the CSOs and NGOs promoting the right to health and the websites. The review assessed the extent to which the above documents were guided by human rights principles or reflective of the requirement of

the duty bearer to take “deliberate and immediate steps” towards the realization of health rights and in “reasonable time.”

### **3.5 Credibility and trustworthiness**

The following validity procedures were used to enhance study credibility. Key informant interviewees familiar with the HRBA, human rights and public health were selected. Triangulation using the various data collection methods were relied on to get the different perceptions on the subject (Gifford, 1996). The approach to data analysis also sought to balance close adherence to the objectives with openness to new or unexpected findings.

### **3.6 Data analysis**

The data analysis was cumulative as the collection progressed and sought to maximize both reliability and validity by making sure that it was consistent with the research questions and study objectives but also take into account negative and exceptional cases (Pope et al., 2007). Information from the FGDs was also compared with that generated by informant interviews to establish the shared perceptions between the different categories of duty and rights bearers (Kitzinger, 1995).

The full recordings were listened to in their entirety. The descriptive records of the interviews and FGDs were carefully read repeatedly and cross-checked with the recordings. The content was indexed under thematic categories (clustering data of a similar nature or subject) on the major challenges to the adoption of the human rights approach. Analysis of frequency of issues as presented in the respondent perspectives

and document review generated six broad analytical index categories as discussed in Chapter 4, Findings.

After analysis of the interviews and documents in relation to the specific objectives of this study, the results were also interpreted in relation to the literature and the broader questions of whether an explicit HRBA to public health offers advantages beyond current public health framework such as CPHC and health promotion to advance the realization of health rights in Uganda, and the next steps that should be addressed in research and practice.

### ***3.7 Study limitations***

This is an exploratory study which sought to capture stakeholder perceptions of a broad range of issues related to the HRBA and health; it sought breadth rather than depth. Much of the information collected was therefore of a general nature and did not go into depth on specific issues. The sample size (nine interview respondents and four FGDs) was not large enough to reach an information saturation point and therefore presents an initial picture on this subject. A follow-up larger scale study would be required to explore the complex and emerging issues in more depth, and to apply and extend the initial findings of this exploratory study to be able to influence policy and practice in the application of human rights principles to public health.

### ***3.8 Ethical considerations***

Participants were given prior explanation as to the purpose, extent of the study and the eventual use of the findings. This enabled them to decide whether they wanted to participate or not. General terms such as “health sector actors” were used to describe interview respondents instead of specific offices to ensure non-disclosure of

respondents. Respondents were asked to disclose any competing interest in the study prior to participation to help the researcher determine their inclusion or exclusion. Lastly, besides holding some assumptions about the respondent perceptions, the researcher had no conflict of interest in the subject of this study. Ethical clearance was obtained from the UWC Senate Research Committee prior to beginning fieldwork.



#### **4. CHAPTER 4: FINDINGS**

This chapter presents results and findings in two sections. First, it reports on the results of the mapping of legislation and NGOs most relevant to the HRBA to health. Second, it presents the synthesized findings from the documentary analysis, key informant interviews and FGDs under the major thematic content index categories which emerged from the data. The document review, key informant interviews and FGDs about the perceptions on the challenges of adopting the HRBA to public health, and whether there was a shared understanding on the meaning and value of the approach suggest six key themes or content index categories to capture important dimensions of how the HRBA is understood and the challenges to its implementation. These are: guarantees of the right to health and other legislation; health policy and sector strategic plan; resource allocation and prioritisation; justiciability of the right to health; knowledge about the right to health and HRBA; and community involvement. The community/FGD perceptions were limited to community awareness about the right to health and involvement. There were no major variations in perception by gender of the FGD and interview respondents. This could be due to the fact that the sample of study was small.

##### ***4.1 Legislation and NGOs relevant to HRBA to health in Uganda***

Nine documents on legislation, policy, strategic planning and advocacy papers by the NGOs were found and reviewed. Three are legally binding documents (Constitution, Public Health Act, Patients; Charter and court petition, one policy and two health sector strategic plans (current and previous), and; two advocacy papers (see table 2 below).

**Table 2: List of documents reviewed**

1	Constitution of the Republic of Uganda, (1995).
2	Public Health Act 1935
3	Patients Charter 2009
4	Centre for Health, Human Rights and Development v Attorney General, 2011
5	Second National Health Policy
6	Health Service Sector Investment Plan (HSSIP) 2010/11 – 2015
7	Health Sector Strategic Plan II 2005/6 – 2009/10
8	Kiapi, S. (2010) Status of the right to health in Uganda in 2010. AGHA-U
9	Civil Society Organisations statement, 1 <sup>st</sup> April 2011. Government spending and budget allocations violate human rights and cause preventable deaths.

**Table 2: List of NGOs and CSOs involved in advocacy for the right to health**

1	Action Group for Health, Human Rights and HIV/AIDS
2	Africa Medical and Research Foundation (AMREF) Uganda
3	Center for Health, Human Rights and Development
4	Coalition for Health Promotion and Social Development
5	Community Health and Information Network
6	Foundation for Human Rights Initiative
7	Health Rights Action Group
8	Human Rights Network
9	Human Rights Awareness and Promotion Forum
10	Uganda National Health Consumers Organisation

## ***4.2 Emerging themes on perspectives on and challenges to the adoption of HRBA to health***

Six themes emerged on stakeholder perspectives on and challenges to the adoption of the HRBA to public health.

### **4.2.1 Guarantees of right to health: Human rights advocates' and health personnel perspectives, and legislative review**

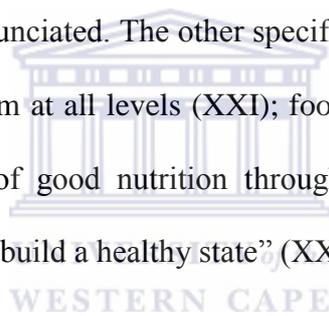
Overall, there was no outright shared understanding and agreement among key interview respondents and legislative and Health Sector Strategic Investment Plan (HSSIP) on the guarantee of the right to health. The review of the legislation and HSSIP showed a lack of consistency in the provisions on the right to health.

Human rights advocates were, more than health personnel respondents, of the view that the right to health is neither explicitly nor comprehensively guaranteed. A human rights advocate noted that *“The major problem is in the lack of a substantive article on the right to health. Right to health is only mentioned under the principles of state policy which are not legally binding. The HSSIP and the newly adopted National Health Policy are very pronounced on the rights based approach.”*

They said that besides being mentioned in the national Objectives and Directive principles, the 1995 Constitution does not have an express substantive right to health provision. This view was corroborated by the findings from the review of the national constitution and other statutory legislation. The National Objectives and Directive Principles of State Policy oblige the State to provide medical services and social determinants of the right to health but are neither specific nor binding.

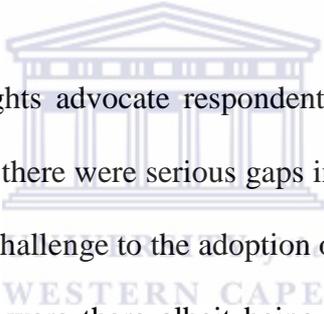
Provisions in the preamble of the constitution such the National Objectives and Directive Principles are not substantive (do not explicitly express rights) provisions and are not therefore legally binding much as they may aid the interpretation of any ambiguity in substantive and legally binding provisions. Policy documents are also not legally binding. Like the national objectives and directive principles, provisions on the right to health in policy documents are not easily justiciable.

Under the General Social and Economic Objectives (XIV)/b), the obligation to ensure that “all Ugandans enjoy the rights and opportunities and access to education, health services, clean and safe water, adequate clothing, food, security and pension and retirement benefits” is enunciated. The other specific objectives include clean and safe water management system at all levels (XXI); food security and nutrition (XXII i) including the promotion of good nutrition through “mass education and other appropriate means in order to build a healthy state” (XXII/c).



Although the 1995 Constitution does not have an express right to health provision, most of the human rights advocate respondents felt that some aspects of this right could be inferred from other substantive provisions. For instance, Article 39 which guarantees every Ugandan the right to a clean and healthy environment; Article 33(3) which obliges the State to protect women and their rights taking into account, among other things, their natural maternal functions; Article 34(3) which protects children against deprivation of medical treatment and education by “reason of religious or any other beliefs”; and Article 34(4) against activities that may be “hazardous or interfere with their education, or to be harmful to their health or physical, or moral or social development.”

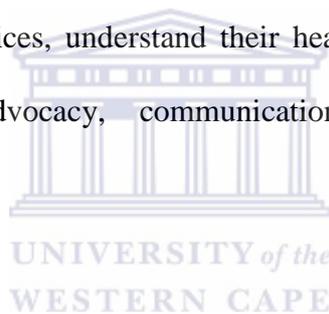
Even then, however, the advocate respondents noted that there was no specific legislation to give legal effect to, or operationalize, most of the above provisions in respect of the right to health. They pointed to the fact that the Public Health Act 1935 is archaic and outdated with many of its provisions being out of touch with current human rights principles such as non discrimination. For example, Part III Section 49 discriminates against people with venereal diseases from employment. The Patients' Charter is equally not legally binding much as Section 1 spells out the patient's right to medical care, prohibition against discrimination, participation in decision making, and a healthy and safe environment. (MoH, 2009).



While most of the human rights advocate respondents were more detailed in their responses and unanimous that there were serious gaps in the law on the right to health and saw this inadequacy as a challenge to the adoption of the HRBA, health personnel tended to think that the laws were there albeit being brief, silent on how the right should be operationalised and being poorly implemented. One responded that *“They (laws) seem to be well laid out, but implementation is another course all together,”* while another one noted that *“the laws, policies and health strategic plan all contain issues regarding HRBA. However, this is quite brief and very silent on how this can be integrated and operationalised. There is need to come out clearly on how this will be integrated into the health delivery system.”* Another health worker said she was *“not aware of any that hinder, but I know that there are some policies that promote HRBA.”*

#### **4.2.2 Health policy and sector strategic plan: Human rights advocates' and health personnel perspective and document analysis**

Both the human rights advocates and health personnel unanimously agreed that the national health policy and sector strategic plans are very pronounced on the HRBA. The shared perception was well elaborated by findings of the health sector policy and plan review. The Second National Health Policy promises the “right to the highest attainable level of health,” solidarity in the “social health protection of vulnerable groups” and accountability to the communities among the key social values (MoH, 2010). To ensure universal access to the proposed minimum health care package, the health policy obligates government to ensure that “all people in Uganda, both users and providers of health services, understand their health rights and responsibilities through comprehensive advocacy, communication and social mobilization programmes.”



The policy document lists levels of income and education, living conditions, access to safe water and sanitation, cultural beliefs, social behaviour and access to quality health services as the key social determinants of health in Uganda. The health policy vision, mission and goal all gravitate towards creating a good standard of health for the entire population through providing “the highest possible level ...of promotive, preventive, palliative and rehabilitative health services at all levels”. The national health policy is guided by principles including PHC, decentralisation, evidence-based strategies, gender-sensitive and responsive health care targeting the poor, and sustainability, and healthy policies (mainstreaming health in all policies).

The Health Sector Strategic Investment Plan (HSSIP) 2010/11-2014/15 states that its implementation will be guided by both international covenants and domestic laws and policies to “progressively realise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (MoH, 2010). The principles listed include: “equality and non-discrimination, participation and accountability, and the right to health elements of availability, accessibility, acceptability and quality.” The plan elaborates a dedication to reduce mortality and morbidity related to “sexual and reproductive health and rights.”

The review of the previous HSSP II 2005-2010 found that it recognised that ill-health is a major cause and result of poverty and hence requires much attention in poverty eradication initiatives (MoH, 2005). The HSSP II key target outputs included increasing the percentage of child immunisation rates from 80% to 90%, percentage of households with at least one Insecticide Treated Net (ITN) from 23% to 72%, percentage of households with latrines from 57% to 70%, percentage of deliveries taking place at health facilities from 25% to 50%, proportion of approved posts filled by trained health personnel from 68% to 100%, proportion of health facilities without any stock-outs of first line drugs such as anti-malarial from 35% to 100% (MoH 2005). These provisions demonstrate the perception that health sector policies and plans are cognizant of the need to attain equity in health care. The challenge as the review of the HSSP II found is low funding. Only 30% of the HSSP I was funded due to financial constraints, highlighting the challenge of underfunding (MoH, 2005).

Overall, both groups of stakeholders agreed that it was the low implementation of the provisions on the right to health in the national health policy and sector strategic plan

that is the major challenge to the application of the HRBA as it makes healthcare constantly inaccessible to rights bearers, especially the most vulnerable.

#### **4.2.3 Low resources not prioritised**

Both the human rights advocates and health personnel tended to agree that the resources allocated to the health sector were inadequate, a factor they attributed to lack of prioritization of the health sector and political will by government. They also shared the view that even the little resources made available to the health sector were not efficiently utilized. Human rights advocates noted that the budgetary allocation to health was often retrogressive even when the national resource base increased. The health personnel noted that the budgetary allocations to the health sector are very little compared to other sectors, yet health is a key component of national development. Even though the country as a whole is resource-constrained, there does not seem to be a deliberate effort to focus on key social service sectors such as health. Even the little that is given is sometimes “recalled” and diverted to other sectors. In addition, they noted that there seemed to be little effort to streamline the health delivery system.

The shared perception about the non-prioritization was corroborated by the findings of the review of the HSSP II 2005-2010, sector reports and advocacy position documents. The HSSP II cited underfunding as the major challenge, noting that only 30% of the preceding HSSP I (2000-2005) was funded (MoH, 2005). An advocacy paper on the status of the right to health in Uganda notes that whereas government spending on health has increased ((donor funding excluded), it has not been consistent and fluctuated between 8.6% and 9.6% of the budget between 2005 and 2010 (Kiapi, 2010). Nearly 40% of the health budget in that period was funded by donors. In April

2011, Civil Society Organisations (CSOs) working in the health sector issued a strong statement castigating government for spending US \$740 million to purchase military hardware (fighter jets), moreover without the requisite Parliamentary approval. The statement noted that the US \$740 million could “cover the total annual cost of medicines and related health commodities including scaling up ART to 100% for the next four years, and/or recruiting the desired number of health professionals in accordance with the Government Human Resources for Health Recruitment Plan” (CSOs, 2011).

The Annual Health Sector Performance Report shows the inequitable distribution of the health sector budget between the centre (MoH headquarters) and rural areas where 80% of the population is served by the Local District Health Services. In 2009/2010, government allocated Shs192.8 billion to Local Governments (LGs) representing 46% of the GoU health sector budget but even then only Shs183.3 billion was disbursed translating into Shs6274 or US \$3 per capita (AHSPR, p. 137).

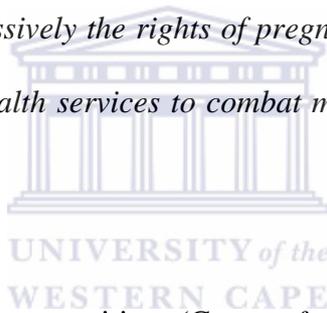
#### **4.2.4 Justiciability of right to health**

While human rights advocates overwhelmingly believed in court action against the State where it has failed to progressively meet its health obligations, there were variations in perceptions among health professionals. One said *“Taking the state to court would probably be the last resort and may not necessarily provide solutions to the problem. One option would be to empower the communities to an extent that they can look at health as fundamental human right and be able to demand for it.”* Another one noted that *“It may be challenging to take the state to court because strategies have been put in place to address accessibility to affordable health care.*

*There may be some factors that hinder implementation of these strategies that one should find out. Otherwise the state has put in place affordable health care.” One health worker agreed – though hypothetically –with the human rights advocates that “If it’s the state’s obligation to provide care, then citizens have a right to care and should seek remedy in court to get the government to provide this right.”*

Unlike the health professionals, human rights advocates dwelt more on the question of justiciability of the right to health in Uganda. They noted that justiciability of the right to health had not been tested in Uganda because of the presumed absence of a substantive constitutional provision on the right to health. One advocate observed that *“This is an area which has not been tested in Uganda and the reasoning could probably be the absence of a substantive constitutional provision on the same. However claims on the right to health could be linked to other rights such as the right to life, rights of women etc. The state’s defense has always been the fact that right to health is progressively realized and therefore a state cannot be compelled when it does not have resources.”* It was, however, perceived by human rights advocates as worth trying since the right to health was linked to the substantive right to life, a clean and healthy environment and natural maternal functions of women. Government, they argued, can be challenged in court where measures are retrogressive i.e. taking steps backwards on health funding and services. They made reference to an ongoing petition in the High Court relating to the State’s failure to fulfill the right to health with respect to maternal health (*Centre for Health, Human Rights and Development v Attorney General, 2011*).

One human rights advocate noted that ‘*There is an ongoing petition that in the High Court relating to the states’ failure to fulfill the right to health with respect to maternal health. Since the 1995 Constitution does not have an express right to health provision, it is difficult to say what the Court will decide. However, Uganda has signed onto international treaties such as ICESCRs, CRC, CEDAW etc which have not been domesticated. We shall see what the Court says. In the South African case of Minister of Health and others v Treatment Action Campaign and others (2002), where the government had failed to set out a timeframe for a national programme to prevent mother-to-child transmission of HIV, the court ordered the government to devise and implement, within its available resources, a comprehensive and co-ordinated programme to realise progressively the rights of pregnant women and their newborn children to have access to health services to combat mother-to-child transmission of HIV.*”



A review of the Uganda court petition (Centre for Health, Human Rights and Development v Attorney General, 2011) and State’s response reveals some marked differences in perspectives on the matter between human rights advocates and the duty bearer (State). The petition citing constitutional Objectives I (i), XIV (b), XXVIII (b), Articles 33(2) & (3), 20(1) & (2), 22(1) &(2), 24, 34(1), seek, among others, a declaration that the omissions of the MoH, and health workers contravention of women’s rights amount to a violation of their rights. The petition also seeks that the families of mothers who had died during child birth be compensated because of the said rights violations.

The State, in response, argues that; there were competing interests and priorities to be catered for from meager national resources; and the treaties and conventions the State had signed were “not self executing but their provisions must be incorporated in our domestic laws.”

#### **4.2.5 Knowledge about HRBA**

The findings on whether there was a common understanding and agreement on stakeholder knowledge of the right to health, and what they perceive as the challenge to the adoption of the HRBA was reported under two major content index content sub-categories: health workers, and community awareness. The latter is again subdivided into two sub-content categories used to gauge right holder awareness: unfulfilled obligations, and possible measures to compel the State to protect, promote and fulfill the right to health. The findings here represent the perspectives of the interview informants on knowledge of health workers and, community awareness on the right to health and the HRBA and involvement. Findings on the FGDs perceptions on the components of the right to health (including community involvement) are presented as their level of awareness.

##### **4.2.5.1 Health workers**

Both the human rights advocates and health personnel respondents agreed that knowledge about the HRBA to public health was still a major challenge for health professionals, especially among the community health workers. They reported that this could be responsible for lack of a common understanding between the two and affecting the implementation of the HRBA to health.

Health personnel noted that while some health workers do understand and appreciate HRBA to public health, the awareness is still very limited. Some attributed this to the fact that some health workers are yet to view the HRBA as part of their required knowledge content. A health worker academic said *“May be they do. But they need further sensitization to better appreciate these issues. Sometimes they may be ignorant especially the lower level cadre health workers.”* Another health worker and academic said *“Certainly there is. The health workers may have less knowledge like I said compared to the advocates primarily because this is not their key area of concern in the health sector. Also because they may lack sensitization to full appreciate.”*

Some interview informants reported that the few health workers that seemed to appreciate HRBA had been sensitized or had been exposed to it in foreign work contexts where the HRBA is widely embraced in health delivery. One health worker said *“health workers do understand and appreciate HRBA to public health. However, the numbers are very few and this is on individual basis. The few that seem to appreciate HRBA have had a chance to practice in countries where health is looked as a human right and not a favour and can appreciate its benefits.”*

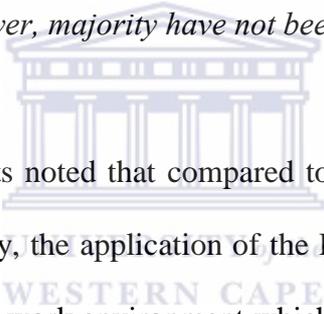
Both the health workers and human rights advocates reported that health workers tend to fear the HRBA as they associate it with court action and see themselves as the target in cases of deaths or injuries resulting from medical shortcomings. A human rights advocate made this observation about lack of understanding of the HRBA: *“This is still a major challenge for health professionals, there is a fear within the professionals because of the legal proceedings etc which are involved in the*

*enforcement of rights. There are however a number of trainings going on to ensure that a HRBA is adopted in public health.”*

Community awareness of the HRBA and involvement in health management is also not well appreciated by health workers because they are not used to it or prepared in their training to deal with it. A health worker and academic explaining the challenge of lack of a common understanding on this said that *“Many health care professionals may view HRBA as a way of raising issues of litigation against them. They are probably used to the traditional way of doing things the “I know it all style”. They have probably not discovered the strengths associated with the dealing with an informed community, so they tend to shun things to do with HRBA. In addition, they probably are not very well versed with the HRBA hence the fear. On the other-hand, human rights advocates are well informed about HRBA and tend to be very aggressive when agitating for it, many times putting blame on the providers and systems without studying the challenges therein.”*

Fear was not limited to the claims by patients in cases of injuries or deaths at health facilities. Further to the potential value of the HRBA to a health worker not being appreciated, health workers respondents reported that health professionals are less inclined to raise issues related to their labour rights due to fear of being victimized by the state which is their employer. One health worker asked about the understanding of health of the HRBA said *“Some not all health workers understand and appreciate the importance of HRBA. Some of them are cowards. They fear being identified as culprits if they strictly scrutinize issues that affect their rights, for example, working conditions, compensation for heavy workload etc.”*

Health respondents attributed limited knowledge of the HRBA among health professionals to its omission in the curriculum at the medical and health training institutions. A human rights advocate and academic said *“Except for very specific modules in certain courses at the MU School of Public Health, the formal training of the majority of health workers does not include/integrate HRBA. However, their education includes some training on Ethics which to some degree overlap with human rights principles ie confidentiality and privacy of patient information. Some health workers I know have received some level of training outside of their formal education on health and human rights and have applied it practically ie former DHO Lyantonde initiated HCT among sex workers during the night in bars in order to address the epidemic in his district. However, majority have not been able to apply it practically.”*



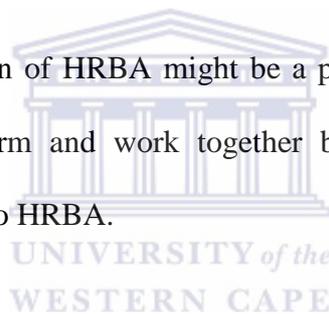
Both categories of respondents noted that compared to human rights advocates who acted on behalf of civil society, the application of the HRBA by health professionals was highly dependent on their work environment which, besides being determined by the State and the fears mentioned above, may not be always conducive due to resource constraints. A human rights advocate and academic observed *“Health professionals tend to apply RBA within their work environment bearing in mind the limitations of their workplace. Health professionals operate in resource constrained settings eg. lack of Essential Medicines, work overload, lack of room/adequate space for privacy and therefore may violated patients rights owing to resource constraints. And because they largely work for Government, they are afraid to challenge acts/omissions of their colleagues that lead to human rights violations.”*

This was compounded by the lack of a discussion about responsibilities in the implementation of the HRBA and answers to how the rights of health workers are

protected. A human rights advocate who saw this this as a major challenge said: *“I don’t think it’s the differences in the understanding; the challenge is in the approach to of talking and implementation of the HRBA which seems to lack the component of talking about responsibilities. The major question always is ‘what are our rights as health professionals?’”*

There was also the feeling among some health personnel respondents that even when health professionals are sensitised about the right to health and the HRBA for which they could be good advocates, they lack a good platform to do this. Apart from the right to health and the HRBA being pronounced in the national health policy and HSSIP, its advocacy was not structured into the activities of health workers.

Therefore, the implementation of HRBA might be a problem if both parties are not brought on the same platform and work together because of the differences in understanding and approach to HRBA.

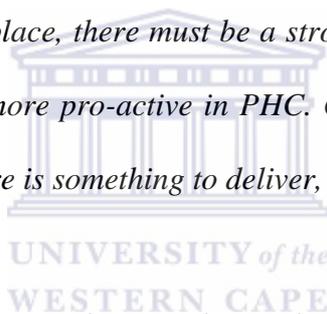


A health worker respondent noted that this difference in the level of knowledge affects the level implementation of the HRBA to health: *“Because then you are emphasizing something or advocating for something that the health workers may not fully comprehend”* while another health worker said *“Ideally there should not be a difference. Health professionals should ideally be HR advocates, given a good platform.”*

However, some respondents felt that it was not so much the lack of understanding as failure to implement that is the challenge to the adoption of the HRBA to public health. An advocate was of the view that *“I don’t think it’s the differences in the understanding; the challenge is in the approach of talking and implementation of the*

*HRBA which seems to lack the component of talking about responsibilities. The major question always is: What is our right as health professional?"*

There was also a consensus between the human rights advocates and health workers that the HRBA had something in common with PHC and health promotion frameworks. They explained that .the HRBA is increasingly looking at the other social determinants of health which are actually addressed under PHC and health promotion. *"It allows Government to put focus on the marginalized and disadvantaged,"* observed one human rights advocate. A health worker and academic summed it up this way: *"I think the two complement each other. In order for comprehensive PHC to take place, there must be a strong HRBA component because this makes the communities more pro-active in PHC. On the other-hand, HRBA can only be operationalised if there is something to deliver, that is, PHC."*



Initially, the study was structured to understand the challenge of community awareness among the others to the adoption of the HRBA to health. But analysis of perspectives of health respondents revealed an equally important and competing challenge of knowledge about health workers' rights as a critical component of the HRBA framework. Further studies are required to increase understanding of the position of health worker rights in the HRBA to health

#### **4.2.5.2 Community awareness: Human rights advocates', health Personnel, and Community perspectives**

The fifth theme on community awareness is sub-divided into: health worker and human rights advocates' perspectives, and community perspectives on community

awareness. The later is further split into community perspectives on unfulfilled obligations, and possible actions to compel the State to meet its obligations.

***(a) Health worker and human rights advocates' perspectives on community awareness***

Almost all health and human rights informants felt that the communities lacked understanding of the right to health and saw this as both a constraint to having effective demand from the rights bearers and communities, and a challenge to the adoption of the HRBA to public health.

The human rights advocates noted that the Patients Charter had not been popularised. People see health services not as a right but as a privilege. They beg and sometimes bribe to see health personnel. They attribute this to lack of public sensitisation on human rights and its non inclusion in lower school syllabus. Remedial actions suggested include human rights awareness campaigns to help demystify and explain the State's obligations. However, some of the human rights advocates felt that community awareness of the right to health is increasingly becoming possible. Civil society organisations and the Uganda Human Rights Commission have actually put more emphasis on this.

The health personnel informants said that the average Ugandan has been programmed (at all levels from household to the state) to look at health as a privilege and ready to take whatever is given in whatever form and ask no questions. The few that may come up to demand for the right to health let it go for fear of the repercussion. Official policy stipulates that communities should participate in decisions affecting their own health. Were it to occur, such participation could act as starting point to recognize

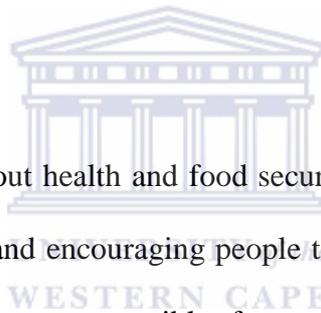
health as a human right; however, participation rarely occurs. Like the human right advocates, some health personnel informants noted that while the majority in the communities may not actually comprehend the right to health fully, some understand it in different ways. They may know the State is obliged to provide services, but when they are denied health care because of, for example, drug stock-outs, they do not seek redress due to either lack of awareness of how to seek remedies or fear of repercussion. In one of the FGD reported on below, discussants said that *“It was reported that sometimes, health workers remove labels from the drugs but “when you report such matters to police, they blacklist you at the health facility. This hatred affects your family since police takes your details in the process”*.

***(b) Community perspectives on community awareness***

Findings from the FGDs differed in some ways from the perspectives of key informants above. Community awareness was gauged on FGD participant perspectives on State obligation, what it can do to meet its obligation, whether it was being fulfilled, and possible measures to compel the State in case of violations. Overall, participants in all the FGDs named Government as the obligation bearer with the responsibility to provide healthcare as well as attending to the social determinants of health such as widespread poverty, lack of education, water and food security. Government was considered to consist of the president, ministers, members of parliament, and all local councils from the village to the district level. The FGDs at Wamulongo in rural Mayuge district noted that *“they had a responsibility to elect the best leaders to present their problems at the different levels of government”*. NGOs like The Aids Support Organisation (TASO) were also mentioned as some of the

organisations with the responsibility to provide specialised health services to people with specific diseases such as HIV/AIDS.

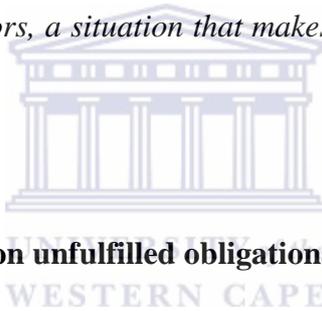
On what government could do to tackle the disease burden, FGD respondents listed provision of medicines in all health facilities, immunisation (as it was done in the past), clean water, food, measures to ensure food security such as ensuring a granary for each homestead be enforced, and production of long storage crops. One even suggested that *“If the government became serious, they can immunise people against curable diseases like malaria and then concentrate on incurable ones like HIV. This will enable us contribute to the economy since it only a healthy person who can work”*.



The need to teach people about health and food security, bring health centres closer to communities, counselling and encouraging people to test for HIV while educating them about what practices are responsible for particular diseases were raised. However, the FGD discussants said that the duty of ensuring the presence of latrines in every household ought not to be left to local councillors who fear that if they were strict they could lose votes in elections. In one rural FGD in Mayuge district, the discussants were of the view that *“Implementation of health standards should not be left to local councillors who fear doing so lest they lose votes in elections.”* Also notable, were: enforce general hygiene in homes such as clean floors and reduce corruption where health enforcers take bribes from errant homesteads, make health personnel easily accessible, reduce poverty which has increased food theft by educating people on how it can be eradicated, and provide education for children. They also noted that lack of education leads to poor feeding. The FGD in semi-urban

Wabulenga in Jinja district said. *“Malnourished children are likely to skip school and their parents are more likely not to provide scholastic materials”*.

The FGD participants in the urban city slum added the following: provision of mosquito nets to prevent malaria; collection of garbage regularly since garbage sites are breeding areas for disease-causing vectors; stop people from building in wetlands since this raises the water level hence floods and related diseases, widen and repair roads to prevent accidents, adding that wounds from accidents can provide entry points for other disease-causing organisms. The FGD in urban capital city slum (kifumbira) said that *“the government should build clean markets to stop vendors from selling food on dirty floors, a situation that makes buyers compete for food with flies”*.

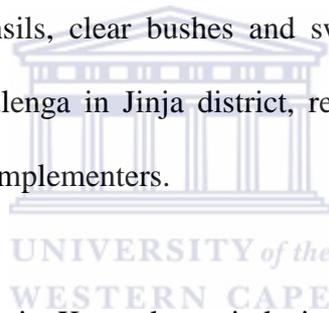


**c) Community perspectives on unfulfilled obligations**

There was a strong perception that government is not fulfilling its obligations in regard to the right to health. The FGD respondents said people were not satisfied with the public health services the government was offering. Patients are made to buy exercise books which serve as medical forms. They also buy drugs and blood when the need for transfusion arises. It is very common for patients to be given prescriptions and directed to specific drug shops to buy them. Health workers were said to be arrogant and were accused of attending to private issues on the phone for many minutes while patients were kept waiting. In all places, it was reported that other than immunisation, the information on health was not adequate. Some areas no longer had health educators to pass on information about health. In all FGDs, it was acknowledged that Local Council leaders, radio and occasionally posters were major

sources of information, especially regarding immunisation. Posters are only accessed at Health Centres hence those who don't visit health centres cannot access such information. The illiterate, too, cannot understand messages on the posters.

The discussions on obligations to ensure good health did not put full responsibility on the State. Some respondents in the FGDs said the households had a responsibility to keep their homes healthy by but cited poverty as a major constraint. They also said health providers should sensitise people about health issues such as home hygiene as the case is during immunization campaigns. In rural Bugeywa in Kamuli district, FGD respondents reported to have improved sanitation in their homes by encouraging their children to bathe, wash utensils, clear bushes and sweep inside and outside their houses. In semi urban Wabulenga in Jinja district, respondents said they observed sanitation but were not strict implementers.



In the urban Kifumbira slum in Kampala capital city, one person reported getting involved in clearing the spring every time there is a water shortage. Another reported to have seen some people picking garbage from the community but never personally got involved. The group noted that women normally collect and burn the garbage. Sometimes, they said, when it accumulates, people collect the garbage, keep it and wait for rain to come and runoff with it. One respondent noted, *“Those of us whose residences cannot be accessed by KCCA (Kampala City Capital Authority) use the opportunity of being near the streams to pour garbage into the water source”*.

#### **d) Community perspectives on possible actions to compel state**

The rural FGDs blamed themselves for being illiterate and not knowing who and where to report when they encountered problems in the process of accessing health services. Measures they said communities could use to compel government to provide health services were: start up institutions that report to the president directly where local leaders fail to monitor the implementation of health programmes; form pressure groups and meet the president; all sick people should pile up at the health centres and not go to private clinics and create ugly scenes as a way of drawing attention to their plight which would compel the government to improve health service delivery; call journalists to publicise their plight. The FGD in the urban slum added staging of demonstrations involving dumping garbage into roads that would draw attention to the health problems they face.



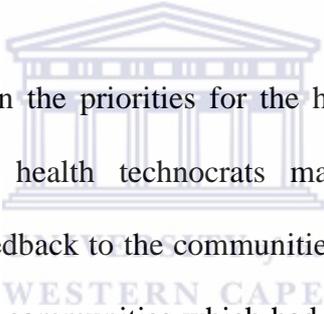
#### **4.6 Community involvement**

Almost all respondents (key informants and FGDs) expressed the view that communities are not involved effectively in health care planning and delivery. In rural Wamulongo, a FGD discussant said in their community they are involved only when it comes to immunisation because there is no personal gain for the health personnel. Unlike other drugs, vaccines cannot be easily sold off by errant health workers and would therefore have no problem in letting the community get involved in the accountability process.

Respondents reported that communities are involved to a small extent mostly in Village Health Teams. Both the key informants and FGDs reported that health centre management committee membership is influenced by politics which undermines

accountability. A human rights advocate and academic said *“Health Unit Management Committees/Hospital Boards which represent communities are non functional/ nonexistent and where they exist, they are political appointees and do not serve interests of the communities. People are poor and busy looking for means of survival rather than monitoring Government services.”*

Participants in the Wamulongo FGD suggested that government should *“appoint committees that must not be political to avoid stigmatising others on the basis of the parties they belong to”*. They added that *“participation can only work if the process is not politicised. We want committees with people not involved in politics.”*



Healthcare workers decide on the priorities for the health facilities based on their professional judgment. The health technocrats many times do not take the responsibility of providing feedback to the communities. In some of the FGD, it was reported that there were some communities which had taken a keen interest in issues concerning their health and participated in the planning process. But overall, rights bearers were poor and busy looking for means of survival rather than monitoring government services. The communities hardly got to know about the planning and how funds were disbursed; did not even know they were entitled to information about health financing; cited long distances from health centres, working for no pay (volunteerism) as constraints to their participation even when given the opportunity. The FGD in rural Wamulongo reported that *“Involvement can only work if the health centres are near for effective participation in planning and monitoring (nearest is 6km and 7kms).”* This would require them to spend own money on transport yet *“one is not paid for the work.”*

Other reasons included: inability to participate effectively and track the running of health facilities due to lack of skills in management and monitoring; political differences which in some instances resulted in discrimination of some people, say, when distributing mosquito nets or access to drugs at VHTs and water points. In a rural FGD, one respondent who was involved on Health centre committee said there is a lot of falsification of records by health officials because most of the villagers on the committees are illiterate or not well prepared to police the health centres. The respondents said community members cannot feel involved if they cannot track what the health centre does



## **5. CHAPTER 5: DISCUSSION**

The findings are discussed under two general parts; structural and process challenges, and stakeholder knowledge and consensus of the HRBA. Structural challenges include laws and policies. Process challenges include stakeholder knowledge, consensus (common understanding and agreement), and community involvement.

### ***5.1 Structural challenges: legal guarantees and justiciability***

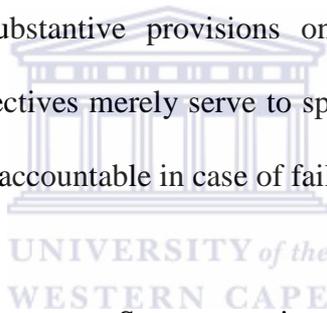
The finding that there is no coherence between State commitments under ICESCR, the Constitution, National Health Policy, and HSSIP suggests that there are serious structural impediments to the implementation of the HRBA to public health. Treatment of health as a human right as opposed to a need presupposes that the claim for the service by individuals or groups and its delivery by the State is law-governed. The absence of an express provision in the Ugandan Constitution guaranteeing the right to health diminishes the prospects for it to be law-governed. There is no explicit directive to the State and commitment in the supreme law to provide accessible, affordable, acceptable and equitable health services. Because the right to health is not enforceable, the courts find it difficult to protect it or make or order that it be fulfilled. This makes it difficult for the citizens to legally hold government accountable. Litigation as a vital HRBA advocacy tool is, as such, rendered speculative as long as the State is not explicitly committed to the right to health by the Constitution (Tomasevski, K. 2005). The pronouncement by the High Court in the petition on the States' failure to fulfill the right to health with respect to maternal health will help clarify on the justiciability of the right to health (*Centre for Health, Human Rights and Development v Attorney General, 2011*).

In the *South African case, Minister of Health and others v Treatment Action Campaign and Others 2002*, the petition was bolstered by Section 27(1) in that country's Constitution which sets out the express right of access to health care services, including reproductive health care, sufficient food and water, as well as emergency medical treatment. The South African Constitution is also explicit on the State obligation to take reasonable legislation plus other measures "within available resources, to achieve the progressive realisation" of the right to health (*The Constitution of South Africa, 1996*).

Progressive jurisprudence in South Africa and other developing countries is increasingly rejecting the State's perpetual excuse of "competing interests and priorities amid meagre resources" as not strong enough excuse to delay the "progressive realisation" of the right to social and economic rights as provided for in the ICESCR (*The Government of the Republic of South Africa v Grootboom, 2000; Van Biljon v Minister of Correctional Services, 1997; Residents of Bon Vista Mansions v Southern Metropolitan Local Council, 2002*). Fluctuations in health spending amid GDP expansion violate the principle of "progressive realisation". Having signed the ICESCR, the object and purpose of the arising obligations are defeated if the State which was supposed to domesticate the provisions in the ICESCR, can, decades later, still turn around to argue that the covenant is not "self executing" but that the "provisions must be incorporated in our domestic laws." Rather, the State should instead be explaining why decades later they have not domesticated the international obligations with regard to the right to health. Until the authorities offer better explanations, the fact that those obligations are clearly domesticated in the Second National Health Policy but not in the Constitution, suggests a deliberate move by the

authorities to limit legal exposure by distancing the State from any legally enforceable claims by right to health bearers.

Findings from the review of the National Health Policy and HSSIP showed that both documents have over the last decade had consistent pronouncements on the right to health. The pronouncements however merely reflect the abstract declarations in the National Objectives and Directive Principles of State Policy to ensure provision of health services, clean and safe water, adequate clothing, and food among other social and economic rights. As some key informants stated, policies and objectives are not judiciary enforceable. They can only guide the courts in interpreting laws based on them. In the absence of substantive provisions on the right to health in the constitution, these policy objectives merely serve to spell out societal goals to which the authorities cannot be held accountable in case of failure to deliver on them.



Clearly, lack of coherence between State commitments under ICESCR, national health sector policies and strategies, and the Constitution with respect to the right to health constitute major structural challenges which impede the implementation of the HRBA to public health. This is partly attributed to lack of a consensus between the State and the rest of the stakeholders on having the right to health to be law-governed.

## ***5.2 Process challenges***

Despite the right to health being well pronounced both in the National Health Policy and HSSIP as findings from the document review and interview respondents have shown, the health system is still not well positioned to provide adequate healthcare for the vulnerable groups (the poor, women and children). The findings from the

interviews and review of advocacy documents attributed this to the failure to match increases in health spending with national earnings. Health facilities remain poorly equipped, workers poorly facilitated and motivated. The issue is not so much whether there are competing interests and priorities to be catered for from meagre resources as the lack of prioritisation of the health sector. High spending on military hardware such as fighter jets as raised by key informants reinforce perceptions that even the few available national resources are not being prioritised on bringing down the high infant and maternal mortality rates or provision of safe drinking water and nutrition. Continued failure to prioritise and step up investment in the health sector perpetuates the vicious circle of poverty, low national economic growth and development.

### **5.2.1 Knowledge about right to health**

The finding that rights bearers are starting to comprehend the obligation of the State in providing health services suggests that universal awareness is increasingly becoming possible and, therefore, less of a challenge by itself. In tandem with new public health, the FGDs listed both diseases and determinants of health as their major health problems where the State was failing in its obligation. The high proliferation of FM radio and TV stations in the country which have increased the level of open discourse of public affairs could be partly responsible for the rising awareness. By 2011, a total of 264 radio stations and 56 TV stations have been licensed (MoICT 2011). Whether this perceived obligation is triggered by an understood need or right is unclear, but what might be critical is how the passion and frustrations around deep-seated expectations from the State with regard to health service provision can be harnessed and steered to reinforce the HRBA.

Low knowledge about the HRBA among health workers is blamed on the absence of human rights in the training curriculum and lack of sensitization. The findings above suggest that slightly different imperatives may influence knowledge of, or lack thereof, about health human rights amongst health workers and rights bearers. In the communities, unmet needs invariably breed demands for the right to health care which are often expressed with emotion. Not surprisingly, the options the FGDs listed to compel the State included resort to political petition and demonstrations.

The question of knowledge of health workers about HRBA arises out of their role as agents of the duty bearer. But as findings have shown, it is related to the question about their occupational rights. It also raises the suggestion to start treating health workers rights and the right to health as twin rights in both the discourse about and practice of the HRBA. But even as the health professionals become knowledgeable on the HRBA to health, the lack of consistent progressive spending and prioritisation of the health sector will continue to undermine the effectiveness of that gain. The frontline role in a poorly financed health system characterized by endemic shortages constantly places health workers in the firing line. So while awareness campaigns among both rights-holders and health workers have the object of empowering communities, equal efforts ought to be put into finding the answer to the question health worker raise; “what are our rights as health professionals?” They raise this question in the knowledge that despite increases in health budget and major donor investments in health the front lines are still far from adequate. In the circumstances, health workers feel dis-empowered in scenarios where criminal negligence suits are made more likely by lack of medicine and medical equipment. Elaborating answers to this question through dialogue ought to be a key component of the knowledge

building process for the health workers on the HRBA. Delinking discussion of the right to health from the labour rights of health workers is less likely to achieve a common understanding on the values and practicability of the HRBA. A poorly motivated and facilitated health work force can neither deliver affordable, acceptable and accessible health care nor be a defender of the right to health. The question health workers ask serves indirectly the object and purpose of the HRBA. Knowledge therefore ought to address the rights of communities without forgetting that health workers are an integral and interrelated component of the HRBA to health. A common understanding will depend on how the lines of responsibility are drawn between the State, health workers and communities. Awareness building campaigns to enable rights-holders claim the right to health ought to be matched with capacity building of the MoH as a duty bearer to meet its obligation. The HRBA require in its application a strong component of “institutional accountability” to avoid “shifting responsibility solely onto the health professional” and increase consensus between stakeholders especially between communities and health workers (London, 2008)

### **5.2.3 Community involvement**

Universal awareness of the right to health is becoming increasingly possible. However, the often romanticized community involvement in the realisation of the right to health faces major challenges. The Village Health Teams, where they have not been fractured by politics as reported by the FGDs or worn down by tiring volunteerism, operate in a top-bottom approach with political appointees on the Boards and are not about to be the sound platforms for compelling the State to fulfill its obligations in respect of the right to health. There is still a challenge of how to erect democratic structures that would permit a bottom-up community involvement

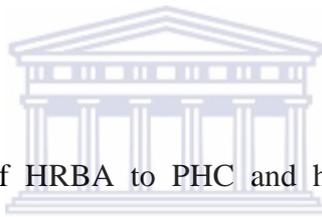
both in Village Health Teams and through other channels. The lack of such structures is reflected in the suggestions by the FGDs to try, in addition to protests, to meet the President in the efforts to compel the State to fulfill its obligations.

#### **5.2.4 HRBA consensus and responsibilities**

Human rights groups try to use every possible forum to advocate on behalf of civil society for the right to health. On the other hand, health workers being agents of the State – the target of the advocacy – tend to be less enthusiastic about the HRBA, even when they start to appreciate its likely impact in bettering their working environment. This could be wrongly interpreted as lack of consensus on the HRBA approach between health rights advocates and health workers. Discussion of the HRBA has tended to revolve around treatment and patient-health worker relationship at the expense of the preventive and promotive aspects as well as determinants of health and the multi-sectoral aspects of the right to health. As a result, patient and health worker rights tend to be discussed as if they are parallel, yet they are correlated. Inevitably, to win the support of health workers, the question of their occupational rights has to be addressed as an integral component of the HRBA.

Some health professionals accustomed to Primary Health Care and Health Promotion would be right to ask whether the HRBA offers anything new in the framing of equity and access issues in public health. Health promotion strategies (healthy public policy, appropriate environment, community action, re-orientation of health services); and PHC principles (equitable distribution of services, community involvement, preventive and promotive services, multi-sectoral approaches) are actually abundantly informed by the HRBA. But while they are appropriate in framing equity and health

access issues among others, they are not sufficient as vehicles of the HRBA. The health sector as a technical arm is politically weak to lead the advocacy for progressive realization of the right to health even when it is pronounced in the national health policy and HSSIP. In fact, the Second Health Policy and HSSIP do provide for both PHC and health promotion the same way they make pronouncements on the right to health. However, while they are limited to statements on paper, they are nothing but abstract declarations of principle that are not, in the State's words, "self executing". They require parallel language in the Constitution, strong and consistent claims by rights bearers, and advocacy, negotiation and even litigation by civil society to compel the State machinery into progressively implementing them and realise the right to health.



The potential added value of HRBA to PHC and health promotion is, however, dependent on overcoming the following challenges: closing the loopholes in the legal framework on the right to health to make it justiciable; turning the increasing knowledge about the right to health within communities into effective claims for the right to health; creating platforms for technical and often politically weak health sector and its workers to use acquired knowledge on the right to health aid advocacy for improved health services; stakeholder consensus between a purely technocratic health service approach on the one hand, and one complemented by an advocacy and legally oriented HRBA.

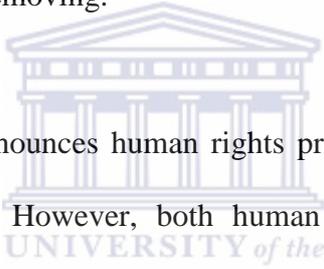
In addition, to make a difference on the ground, the HRBA to health will have to broaden its scope of the health agenda beyond diseases and treatment and start framing it into a social goal that addresses the underlying social determinants to

health such as education, poverty eradication, information, shelter, food security, safe and clean water, which as rights, are interdependent and interrelated to the right to health. This way, the right to health would transform public health as the cohesive factor to join-up government service delivery. Tackling these challenges would enable the HRBA create power balance among stakeholders and ultimately the strengthening of human rights and public health in Uganda.



## **6. CHAPTER 6: CONCLUSION AND RECOMMENDATIONS**

The major finding of this study is that the declaration of principle to adopt the HRBA to public health in Uganda is yet to be matched by significant moves at both the structural (legislation and policy) and process (implementation) levels. There is a strong perception among human rights advocates and to an extent the health workers that the claim by bearers of the right to health against the State which is the obligation and duty bearer is ideally supposed to be law-governed. However this prospect is made untenable by structural impediments to the implementation of the HRBA to public health. The major challenge the study identified is the lack of coherence between State commitments under ICESCR, National Health Policy, HSSIP and the Constitution with the aim of removing.



The health sector readily pronounces human rights principles in the national health policies and strategic plans. However, both human rights advocates and health workers agree that the sector remains politically weak to be able to negotiate for increased spending and progressive realisation of the right to health. The situation is compounded by the uncertainty surrounding the justiciability of the right to health which the study also found to be a challenge to the implementation of the HRBA.

Over and above dealing with the structural challenges, the process or implementation emerged in the study as a major challenge. The HSSIP still requires sustained campaigns to ensure that adequate resources are progressively allocated to the health sector and efficiently utilised. This includes the other challenge which emerged in the findings of how to harness and channel the increasing knowledge of both communities and health workers about the right to health as well as erecting effective mechanisms to ensure their involvement in realising the right to health and enhance

understanding and a common agreement among shareholders about the potential of the HRBA to health. To increase a common understanding among stakeholders on the application of the HRBA, the study suggests that the right to health should not be treated and promoted as if it were parallel and not cognizant of the occupational rights of health workers. The two are integral and correlated, a fact that should be emphasized in knowledge building on the right to health and the HRBA.

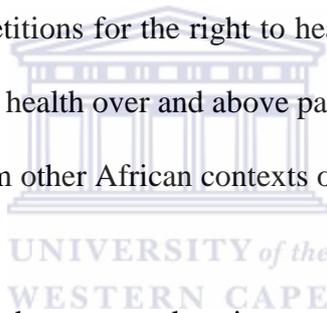
Finally, the finding that universal awareness by rights holders of the State's obligation on health is becoming increasingly possible; plus their broad take on health problems to include social determinants, necessitate the broadening of the focus and application of the HRBA beyond the medical and treatment perspective and tackle the social determinants to health. Broadening the health agenda, the study found, would help to make it a social goal instead of placing unrealistic expectations on a purely technical and politically weak health sector. Health as a right is interdependent and interrelated to the other determinants such as food, water, a healthy environment, poverty and education.

### ***6.1 Recommendations***

This is a critical inquiry, so the recommendations emerge from but go beyond the specific data. The study has found fertile ground to move ahead and increase understanding on this subject. It therefore makes the following recommendations:

1. A negotiated consensus should be sought to enhance coherence between State commitments under ICESCR, National Health Policy, HSSIP and the Constitution with the aim of removing structural impediments to the implementation of the HRBA to public health.

2. Advocates of the right to health should use international human rights commitments to which Uganda is a Party to pressure government to remove the structural impediments to realizing the right to health
3. Advocacy should be stepped up to ensure that the health budget progressively matches increases in national earnings well knowing that the health sector is politically weak to negotiate by itself for prioritization of the sector.
4. Knowledge building activities on the right to health and the HRBA by the various stakeholders should be harmonized to clarify and highlight the occupational rights of health worker as an integral and not parallel component of the right to health and HRBA.
5. Negotiations, lobbying and petitions for the right to health should widen the scope to include social determinants of health over and above patient treatment rights.
6. Lessons should be sought from other African contexts on the best strategies to harness the HRBA
7. More studies should be carried out to explore improved mechanisms of community involvement in healthcare so as to realistically benefit the HRBA.



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## 8. APPENDEXES

### 8.1 0 Research Instruments

#### 8.1.1 In-depth interview guide

**Note:** HRBA is the abbreviation for Human Rights Based Approach. Skip questions you do not have immediate answers to.

1. What gaps – if any – in laws, policies and health sector strategic plan are you aware of that might affect the implication of the HRBA to health?
2. Tell us what you think about taking the State to court to seek remedies to health problems such as lack of access to affordable health care (e.g. treatment, immunization, health education)?
3. What about the determinants of health such as provision of clean water, food, shelter or healthy environment?
4. Is it the lack of funds OR prioritization of health that is constraining the delivery of health services by the state? Explain your answer?
5. Do you think health workers understand and appreciate the importance of the Human Rights Based Approach to public health? (Give reasons why you think so)
6. Do you think there is a difference between health professionals and human rights advocates in the way they understand the HRBA to health? (Give reasons for your answer).
7. Could this (if there is a difference) be a problem to the implementation of the HRBA to health?
8. Based on what you know about Comprehensive Primary Health Care and Health Promotion, would you say the two add anything or have anything in common with the HRBA?
9. In your view is the average person in Uganda aware of their right to health and the obligation of the state to respect, protect and fulfill this right? Give reasons for your answer.
10. To what extent do you think communities are getting involved in the planning, implementation and monitoring of health service?

11. Are there some other challenges to the adoption of the HRBA that you are aware of besides those you have mentioned above?

### **8.1.2 FGDs guide**

1. Whose responsibility it is to provide us health care? (prompt and probe to see if they recognize state obligation)
2. What can government do for us when we fall sick or to protect us from catching avoidable diseases, accidents etc?
3. What about provision of clean water, sanitation and food?
4. Is government fulfilling its obligations named above? If yes, how and if no, why?
5. What do you think you can do as a community to compel the State to provide you with better health services?
6. Has any of us (or anyone we know) in the recent past been involved in any activity aimed at improving health services in our community? (Attending meeting on health in community, serving on health centre committee, monitoring health centre services?)
7. What do you think about the idea that if government involved us in planning, implementation and monitoring of health services at the health centres, the services would improve?
8. What kind of information do you get about how to safeguard and improve your health? From who? Is it adequate?

## 8.2 PARTICIPANT INFORMATION SHEET

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### UNIVERSITY OF THE WESTERN CAPE School of Public Health

Private Bag X17 • **BELLVILLE** • 7535 • South Africa  
Tel: 021-959 2809, Fax: 021 -959-2872

May 2011

Dear Participant

Thank you for agreeing to be a respondent in the study I am undertaking in partial fulfilment for the award of a Masters Degree in Public Health at the University of the Western Cape, Republic of South Africa.

The study is looking at challenges to the adoption of the Human Rights Based Approach to public health in Uganda. This is an exploratory study is aimed at gathering information to contribute to strengthening the implementation of the Human Rights Based Approach to public health in Uganda

Your confidentiality is guaranteed and under no circumstances will your identity or recorded responses be disclosed or put to any other purpose other than that to which it is sought as stated above. In this respect, there are no adverse consequences to your person or reputation.

Your participation is voluntary and you have every right to withdraw from the study without any adverse effect to your person. You are also at liberty not to disclose any information while responding to the questions put to you.

Kindly consent to this interview or discussion by signing the consent form provided. Feel free to contact any of the under-mentioned in case of any questions.

Researcher:  
David O. Balikowa  
Timeline Communication

P.O Box 70624 Kampala, UGANDA  
Tel. 256 77 2200572  
e-mail: [dbalikowa@yahoo.com](mailto:dbalikowa@yahoo.com)

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University of the Western Cape  
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Website: <http://www.uwc.ac.za/>



### 8.3 INFORMED CONSENT FORM



## UNIVERSITY OF THE WESTERN CAPE School of Public Health

Private Bag X17 • BELLVILLE • 7535 • South Africa  
Tel: 021-959 2809, Fax: 021 -959-2872

### INFORMED CONSENT FORM

Date: May 2011

Interviewer: David Balikowa

UWC Student no: 2831831

Tel: 256 77 2200572

E-mail: [dbalikowa@yahoo.com](mailto:dbalikowa@yahoo.com)

Institution:

Interviewee's pseudonym:

Place at which the interview was conducted:



Thank you for accepting to be a respondent in this study. Kindly give your consent after reading the brief about the study below to participate and being recorded on tape.

#### **1. Information about the interviewer**

I am David Balikowa a student at the School of Public Health (SOPH), University of the Western Cape. As part of my Masters in Public Health, I am required to submit a mini-thesis on an area of Public Health interest. I will be focusing on the challenges to the adoption of the Human Rights based Approach to Public Health in Uganda. I am accountable to Christina Zarowsky who is contactable at c/o SOPH Fax: 021 959 2872 or by e-mail: [czarowsky@uwc.ac.za](mailto:czarowsky@uwc.ac.za)

Here is some information to explain the purpose and usage of my interview.

#### **2. Purpose and contents of interview**

The purpose of this study is to contribute to strengthening the implementation of the Human Rights Based Approach to public health in Uganda

#### **3. The interview process**

The study will employ key informant interviews and Focus Group Discussions (FGDs). The Key informant in-depth interviews will be conducted with purposively selected respondents in the health and human rights sectors. They will include human rights advocates and public health personnel at national and district levels. The FGDs will be conducted in the capital city and two rural districts.

#### **4. Anonymity of contributors**

At all times, I will keep the source of the information confidential and refer to you or your words by a pseudonym or invented name which I would like you to choose. (See name above). I shall keep any other records of your participation locked away at all times, and destroy them after the data has been collected.

### **5. Things that may affect your willingness to participate**

The interview may touch on issues which you consider personal or confidential. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

### **6. Agreement**

#### **6.1 Interviewee's agreement**

The purpose of this study has been explained to me by the interviewer in addition to reading the participant information sheet. The interviewer has given me the opportunity to ask any questions and satisfactory answers have been given.

I voluntarily consent to participate in this study. I am aware that I can end my participation at anytime or even not answer particular questions that I may deem inappropriate.

I agree to keep the information discussed in the focus groups as well as the identities of the other participants confidential.

#### **6.2 Interviewer's agreement**

I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred to above, but may be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you.

Signed by interviewer:

Signed by participant:

Date:

