

# **Health is a Human Right**

*An evaluation of a toolkit on the right to health  
in the Western Cape, South Africa*



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# Contents

Acknowledgements	pag. 4
Foreword	pag. 5
Abstract	pag. 6
1. Background	
1.1. Introduction	pag. 7
1.2. Human rights and the right to health	pag. 8
1.3. A brief history of South Africa	pag. 9
1.4. The influence of South Africa's history on the right to health	pag. 10
1.5. Health promotion and the Learning Network	pag. 12
1.6. Toolkit on the right to health	pag. 13
1.7. Research Aim	pag. 15
2. Conceptual Framework	
2.1. Framework for evaluation	pag. 16
2.2. Research question and sub-questions	pag. 20
3. Methodology	
3.1. Qualitative research	pag. 22
3.2. Research setting	pag. 22
3.3. Research population	pag. 22
3.4. Recruitment	pag. 24
3.5. Data collection	pag. 25
3.6. Data analysis	pag. 26
3.7. Methodological Limitations	pag. 26
4. Results	
4.1. Opinions of researchers of the Learning Network	pag. 27
4.2. Opinions of trainers and participants of the toolkit workshops	pag. 29
4.2.1. Experiences	pag. 29
4.2.2. Overall findings	pag. 31
4.2.3. Lay-out & language	pag. 32

4.2.4. Content of the toolkit	pag. 33
4.2.5. How the toolkit is used	pag. 35
4.3. Promotion of the toolkit	pag. 36
5. Discussion	
5.1. Summary of finding and take-home message	pag. 38
5.2. Comparison with previous studies	pag. 39
5.3. Limitations	pag. 40
6. Recommendations	
6.1. Recommendations for further research	pag. 42
6.2. Recommendations for the toolkit	pag. 42
7. Literature	pag. 44
Appendix I Ethics Approval	pag. 48
Appendix II Interview guides for interviews	pag. 49
Appendix III Information about the research project	pag. 52
Appendix IV Inform consent form	pag. 53

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## Foreword

Proudly I present to you my thesis with which I finalize my master study International Public Health (Health Sciences) at the Vrije Universiteit, Amsterdam. The subject of this thesis is health and human rights. I evaluated the toolkit on the Right to Health, developed by the Learning Network. It is an educational method which can be used to teach community members from low socioeconomic class in the Western Cape of South Africa about their right to health and what they can do when their rights are getting violated. A qualitative study design was chosen to study the experiences with and effectiveness of the toolkit, by interviewing participants who worked with this toolkit. This research has been done in commissioned by the Learning Network at the University of Cape Town in South Africa. With this thesis I hope I will contribute to optimize the effectiveness and applicability of the toolkit and thereby enhancing the understanding of the right to health among community people in the Western Cape, South Africa.

This report includes a theoretical background of the subject that has been researched, the conceptual frame and methodology that is used, the results of the research and the discussion and recommendations. There is also a chapter added which will give a brief impression of my own experiences during my stay in Cape Town, South Africa, due to the fact that it had a big influence on my personal development.

I hope you enjoy reading this thesis.

Marjan Heida

## Abstract

**Background** Partly due to the turbulent history of South Africa, the country still struggles with one of the highest levels of inequality in the world, also when it comes to health rights. The Learning Network developed a toolkit on the Right to Health to increase knowledge and awareness about health rights for people from the low socioeconomic class in South Africa. The toolkit has been in use for one year now, by 5 civil society organizations which are members of the Learning Network. With this study, an evaluation of the toolkit has been done to clarify how the toolkit is used, if it enhances the understanding of health rights and what recommendations can be made to optimize the effectiveness of the toolkit.

**Methodology** For this qualitative research study, 19 participants from 3 different target population groups have been recruited; 4 Learning Network researchers, 9 trainers of the workshops on the right to health and 6 participants of the workshops on the right to health. Semi-structured interviews have been chosen as a method for this research. Analyzing the data has been primarily done by thematic analysis.

**Results** The findings showed that the toolkit is used by civil society organizations to compose their own workshop on the right to health. The participants of the workshops have never seen the toolkit, but did however receive handouts. All participants of the workshops said their understanding about the right to health has improved after participation in the workshops. They also reported that they now have the strength to stand up for their rights in practice, because they have the knowledge about what their rights are and how they can protect their own rights. The participants mentioned several positive aspects of the toolkit; the handouts, case studies, definition list and activities are reported as valuable aspects of the toolkit. The section about the Violation of the Right to Health is by the majority of the participants seen as the most important part of the toolkit. Only one participant could mention a negative or less useful aspect of the toolkit; the legal articles. The majority of the participants could not mention a point of improvement for the toolkit. However, the subject promotion was discussed often in the interviews. Some participants mentioned that it is important to promote the toolkit and the associated workshops, in order to ensure more people will learn about the Right to Health.

**Conclusion** The understanding of health rights can be increased through increasing knowledge by giving workshops on the Right to Health, composed by civil society organisations with the use of the toolkit on the Right to Health. The toolkit on the Right to Health is seen as a useful, applicable education material to create awareness and to enhance the knowledge when it comes to the Right to Health of vulnerable groups in the Western Cape of South Africa.

**Key Words** South Africa, Human Rights, Health, Toolkit, The Learning Network, Health Promotion

# 1. Theoretical background

## 1.1. Introduction

*Wednesday, the 25th of July 2012; it is the official opening of the Fashion Week in Cape Town. The red carpet is rolled out and dozens of glamorous people with glasses of the finest champagne in their hands occupy the stair of the City Hall. The streets around the old city hall have been deposited, just like twenty-two years ago when the newly freed Nelson Mandela had his first speech. Renown people in the fashion industry who are enjoying the party, state how important it is for the country that Cape Town is voted Design Capital of the year 2014, while a black<sup>1</sup> waitress looks away and works hard to satisfy the guests.*

When hearing this story from a Dutch stylist who joined this luxury event, my thoughts wander to the 4 million people who live in the townships around Cape Town. According to the International Council of Societies of Industrial Design (ICSID) events like this will have a positive influence on the poverty, unemployment and the poorly functioning services in South Africa (Financieel Dagblad, 28 juli 2012). It is doubtful that events like this, which suppose to give the country a boost will really help the people with poor living conditions and lack of services. There have been made promises like this before, for instance with the World Cup which took place in South Africa in 2010. It has been said that this major sport event would change the lives of the inhabitants. Because of World Cup related investments, everybody in Cape Town and surrounding areas should for example have the possibility to travel safe from A to B (Financieel Dagblad, 28 juli 2012). Now, two years later, the city bowl has a MyCiti-busline which works most of the time, but millions of township inhabitants are still waiting for one of many promises that have been made, will be realised. They are still walking along the high way risking their lives and the lives of others.

The reason why this thesis starts with this story, is because it describes the unequal society of South Africa. While Cape Town is nowadays seen as the Los Angeles of Africa which attracts thousands of tourists who consume their 50 dollar steak in Camps Bay and shop in the most expensive shops at the Waterfront, there are still millions of people living in the townships that surround the city where some of the people not even have access to drinking water or proper sanitation, not to mention healthcare services.

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<sup>1</sup> In South Africa it is common and not derogatory to denote dark colored people 'blacks' and white people 'whites'. Despite of the fact it is rude to call people 'black' or 'white' in many countries and cultures, these terms will be used in this thesis, since it concerns a research which regards South Africa and has been performed in South Africa.

According to the World Bank (2010), South Africa is an upper middle income country and is one of only four countries in Africa who has this ranking. South Africa has the largest economy of whole Africa, due to a good infrastructure, a developed financial system and a many natural resources. It has a wide income gap between the wealthiest citizens and the poorest and research shows that South Africa has one of the widest gaps between GDP per capita versus its Human Development Index ranking (World Bank, 2004). Research based on National Income Dynamics Study (NIDS) done by Gumede (2010) suggests that 47% of South Africans live below the poverty line. 56% of blacks live in poverty compared to 2% of whites. So South Africa has not only a inequality in living conditions, but also inequality of income. This is inter alia a remnant from the Apartheid period, in which the society was divided according to race (Coovadia, 2009). There is not only an equality in income in South Africa but also in health rights, which is the subject of this thesis. To be more precisely, it has one of the highest levels of inequality of health rights (Foundation for Human Rights, 2009).

There are several organisations in South Africa trying to reduce this huge inequality, all having different kind of strategies. One of those organisations is the Learning Network (see paragraph 1.4.), that focuses on enhancing the understanding of the right to health for people from the low socioeconomic classes, mainly living in the poor areas or townships in and around Cape Town. This thesis is about the toolkit on the Right to Health which is developed by the Learning Network as educational material to teach community people about their rights to proper health services. Before the focus will be placed on the toolkit, a theoretical background will be provided about human rights in general and health and human rights in South Africa in particular.

## **1.2. Human rights and the right to health**

The foundational principle of human rights is that all human beings are equal in rights, dignity and worth (Universal Declaration of Human Rights, 1948). Health is a fundamental human right and it is indispensable for the exercise of other human rights (United Nation General Comment 14, 2000). Health as a human right, outlines explicitly the states' obligations in ensuring access to health for all, inclusive of availability, accessibility, acceptability and quality of health care (United Nations High Commissioner for Human Rights (UNHCHR, 2000). Nowadays, the right to health is in many countries recognized, but in constitutions, declarations and covenants, this recognition has taken a long time.

As stated in the Universal Declaration of Human Rights (1948), human rights are inherent to all individuals, regardless of their nationality, place of residence, gender, ethnicity, colour, religion,

language or any other status. According to the Office of the High Commissioner for Human Rights (OHCHR), there are two aspects why human rights differ from other rights:

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

Since 1946, the right to the highest attainable standard of health has been explored and recognized in a multitude of international fora. Health is defined by the World Health Organization (WHO, 1946, p. 100) as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. When looking at health from a international and public agenda and not only from a private and individual point of view, the WHO’s definition makes it possible to explore other factors influencing human well-being, like the physical and social surroundings. Over the years, several human rights instruments recognized health as a human right including the 1948 Universal Declaration of Human Rights, the 1976 International Covenant on Economic, Social and Cultural Rights, the 1978 Declaration of Alma-Ata on Primary Health Care and the 1981 African Charter on Human and People’s Rights.

Even though there are many human rights instruments and the Universal Declaration of Human Rights was unanimously proclaimed more than sixty years ago, the world is still ravaged by inequalities in power, money, and resources both within and between countries (Yamin, 2009). This creates implications for the distribution of population health and also the unequal enjoyment of economic and social rights. Even for human rights in general (Yamin, 2009).

### **1.3. A brief history of South Africa**

When the focus is led from general human rights and the right to health, to health and human rights in South Africa, a brief look at the turbulent history of this country is needed. For this thesis is it not relevant to discuss the history of South Africa extensively, but the Apartheid period is important to mention, while inter alia that period had a big influence on the human rights approach in South Africa as it is nowadays.

When the Union of South Africa was formed in 1910 under British dominion, an uneasy power-sharing between the two groups (the British and the Boers) held sway until 1948, when the Afrikaner National Party (ANP) was able to gain a strong majority. The ANP formalized an apartheid policy, which aimed to maintain white domination while extending racial separation. People were separated into different races (white, black, Indian and colored), by a system of

racial classification (Wilson, 2010). Race laws touched every aspect of social life and racial discrimination against all black people also affected people's health in many ways because of lack of social conditions, the segregation of health services and unequal spending on health services (Hassim, 2007).

Many international protests and boycotts and also national mobilization and opposition by several civil society organizations, led eventually to the end of the Apartheid and the first democratic elections in 1994 (South Africa History Online, 2012). The ANC was the winner of these elections with a large majority of the votes. Nelson Mandela became the first black president of South Africa and an icon of the anti-apartheid struggle. The international world immediately recognized the new government and made a formal end to the sanctions against South Africa (Wilson, 2010).

#### **1.4. The influence of South Africa's history on the right to health**

In the Apartheid period, major violations of human rights occurred in many ways and on different levels. Many rights of black and colored people have been infringed in that period, like the right to determination, freedom of movement, the right to non-discrimination and also the right to (proper) health services (Hassim, 2007). Several conventions and declarations on human rights were violated, like the Universal Declaration of Human Rights (ANC, 1996).

During the years of apartheid the ANC and other progressive organizations developed an alternative framework for providing health care in South Africa. This vision was based on racial equality and human rights and was named the Freedom Charter. In later years, the ANC embraced the principles of primary health care (PHC) as a way to realize this vision. When the ANC came to power in 1994, it intended to reduce the inequalities in the society and also the inequalities in health care provision (Hassim, 2007).

Nowadays, South Africa's health system consists of a large public sector and a smaller, but fast growing private sector. Health care varies from basic primary health care to highly specialized services available in the private sector for those who can afford it (South African Government, 2011). The public sector is under-resourced and over-used. It is under pressure to deliver services to about 80% of the South African population. (McIntyre, 2007). The private sector caters to middle- and high-income earners who tend to be members of medical schemes and to foreigners looking for top-quality surgical procedures at relatively affordable prices. Most health professionals, except nurses, work in private hospitals. With the public sector's shift in emphasis from acute to primary health care in recent years, private hospitals have begun to take over

many tertiary and specialist health services (Health Department of South Africa, 2012).

So it can be said that the Apartheid period has, just as imperialism and colonialism, still its effects on the health care provision in South Africa as it is nowadays, while the mix of a public and private health care system is considered as one of the greatest equality challenges in South Africa. The rich are covered by private schemes, but the poor are depending on under-resourced, tax funded public sector. South Africa does not have a mandatory health insurance (Health Department, 2012).

South Africa has still one of the highest levels of inequality in the world, also when it comes to health rights (Foundation for Human Rights, 2009). A report of the South African Human Rights Commission (SAHRC) indicates that many patients are not aware of their rights and that even those who are aware have difficulty asserting their rights (SAHRC, 2009). Civil society can play an important role in creating awareness of health rights (Hassim, 2007).

Active citizenship has been found as a key determinant in the implementation and promotion of the right to health such as access to HIV treatment in South Africa with the Treatment Action Campaign (TAC) (Heywood, 2009). The TAC brought people together to campaign for the right to health. A combination of human rights education, HIV treatment literacy and litigation was used. Results of this TAC were for example the reduction of the price of medicines and the prevention of many HIV-related deaths. Besides that, the TAC forced significant additional resources into the health system (Heywood, 2009).

For every human right, responsibility of the citizens is needed to ensure the highest attainment of human rights for all. However, this can only be achieved by the protection and promotion of human rights education. Creating awareness of peoples basic rights, promotes values and attitudes that encourage all individuals to take responsibility. Empowerment and knowledge about human rights and the right to health is needed for the vulnerable groups in South Africa, to change the conditions in which they live (London, 2008).

A pilot study done by Thomas & London (2006) showed that there was a need for practical support to civil society and that learning from other organizations through sharing information and experiences was a critical need. In response to this pilot, further research was done and the Learning Network was established in 2008.

### **1.5. Health Promotion and the Learning Network**

The Ottawa Charter for Health Promotion (1988) and the Jakarta Declaration on Leading Health Promotion (1997) into the 21st century defined five priority actions; inclusive of building healthy public policy, creating supportive environments for health, strengthening community action for health, developing personal skills and re-orienting health services (WHO, 1997). They particularly noted the role of participation in sustaining efforts: “people have to be at the centre of health promotion action and decision-making processes for them to be effective” (WHO, 1997, p. 19). Health promotion action should not only be on the policy agenda in all sectors, but also at all levels of government and society (WHO, 1998).

The objectives of the Learning Network (LN) follow the Ottawa and Jakarta priorities and its aim is to increase community capacity and to empower individuals to strengthen community action for health. Community action for health is defined by the WHO as “one in which individuals and organization apply their skills and resources in collective efforts to address health priorities and meet their health needs. Individuals and organizations within an empowered community provide social support for health, address conflicts within the community and gain increased influence and control over the determinants of health in their community” (WHO, 1998, p. 6).

The Learning Network (LN) is a project on Health and Human Rights based at the University of Cape Town. It includes six civil society organizations and four higher education institutions (University of Cape Town, University of Western Cape, Maastricht University and Warwick University), collaborating to explore how collective action and reflection can identify best practice with regard to using human rights to advance health. The Learning Network links research, training and advocacy to empower organizations and their members to claim health rights (University of Cape Town, 2010).

The following civil society organizations located around Cape Town, have been partners in the Learning Network since 2008:

- The Women’s Circle, based in Athlone, is a grassroots, community-based network of women operating primarily in the poorer areas of Cape Town. The TWC trains women in community development, local democracy and income-generation (Learning Network, 2012).
- Ikamva Labantu, is a large national South African NGO that seeks to create positive social change in disadvantaged communities by strengthening and supporting affiliated community based organizations, so that they become autonomous and proactive role players in their communities. The organization implements programmes providing four

core services of health, capacity-building, poverty alleviation, land and buildings (Learning Network, 2012).

- Ikhaya Labantu, located in Langa, provides shelter to anyone finding themselves in the traumatic position of being homeless. The shelter helps to rehabilitate people and gain skills in order to find a job and a place to live back in the community. Support is also provided to young people to help them further their education (Learning Network, 2012).
- Women on Farms, located in Stellenbosch, strives to strengthen the capacity of women who live and work on farms to claim their rights and fulfil their needs. This is done through socio-economic rights-based and gender education, advocacy and lobbying, case work and support for the building of social movements of farmwomen (Learning Network, 2012).
- Epilepsy South Africa, located in Lansdowne (Western Cape Branch), provides integrated services that are equitable, accessible, sustainable and people-centered with and for people with epilepsy and other disabilities and all people affected by epilepsy, to promote social justice. Their work is conducted through individual counselling, support groups, public education and advocacy action, youth development, community outreach services and workshops (Learning Network, 2012).
- Metro Health Care Forum, located in Cape Town, acts at the coordination structure for the Health For a and Health Committees for the Metro district of the Health Department in the Western Cape (Learning Network, 2012).

An important part of the work of the Learning Network has been to use research results and practical information gathered by the members of the Learning Network, to develop training materials. An example of these training materials are the six pamphlets with educational information about the right to health. The pamphlets seem to be useful for building awareness of health rights in communities and encourage community people to assert their rights. Another example of a training material developed by the Learning Network is a Toolkit on the Right to Health.

#### **1.6. Toolkit on the Right to Health**

The South Africa Human Rights Commission (SAHRC) has identified ongoing violations of the right to access to health care services (SAHRC, 2009). Also the research data collected by the Learning Network state that community members experience violations of their health rights. Themes related to rights violations include: violations of access to care, violations of access to information, violations of confidentiality, poor quality of care and lack of access to complaint and

redress (London, 2004). Civil society members in the Learning Network indicated that there was a need for a practical tool to use to train communities on what the right to health means and how violations of the right to health can be identified. This led to the development of a toolkit on the Right to Health.

The first version of the toolkit (designed by Professor F. Coomans, Maastricht University and M. Stuttaford, Warwick University) was piloted in April 2009 with a group of women from The Women's Circle. The most important outcomes of this pilot were the need to think about the toolkit, as being structured to be a part of a training program and the need for additional practical information on how to complain about health rights violations. Another very important point of critic was the fact that the civil society organizations found the toolkit way to difficult. It was written at an academical level and many women struggled with the difficult language and the use of big words. The pilot group also indicated that it would be helpful to translate the toolkit in Xhosa and Afrikaans. After some further workshops with the Women's Circle and Ikamva Labantu to test out changes made to the toolkit, the development of the toolkit was continued (University of Cape Town, 2012).

The finalized toolkit, launched in May 2011, is a resource and training manual for civil society organizations and communities for creating awareness on right to health and on dealing with health rights violations. It can be used as a stand-alone source of information, but it is practically intended as training tool for workshops on the right to health. The toolkit is used by civil society organizations and community members to advocate for the realization of the right to health. This could lead to improvement of accessibility, affordability, acceptability and quality of health care and the conditions needed for health. These improvements could be reflected in improvements in the health status of communities most vulnerable in South Africa and the reduction of health inequalities (Fick et al., 2011)

The last version of the toolkit has been in use for more than one year now by the civil society organizations that are linked to the Learning Network, but also by other organizations and communities. Like it has been done with the first version of the toolkit, also this version has been evaluated to find out what the experiences are and if there are possible points of improvement.

### **1.7. Research Aim**

Therefore, the aim of this research project is to evaluate the toolkit on Health and Human Rights developed by the Learning Network, to make possible deficiencies transparent, to optimize the effectiveness of the toolkit and to inform the Learning Network about the implementation of the toolkit.

## 2. Conceptual Framework

### 2.1. Framework for evaluation

Worthen et al. (1997, p. 5) defined the term evaluation as judging the worth or merit of something. Evaluation of the toolkit and workshops is important to gain an understanding of program operation, to document program effectiveness enhancing understanding and practice of health rights and to examine strengths and weaknesses of the program (Owen, 2006).

A formative evaluation has been done, because the toolkit is still in use and the results from the evaluation initiate changes to produce better results in the future (Berg, 2009). While the evaluation of the toolkit and associated workshops concerns a program evaluation, the Recommended Framework for Program Evaluation of the Centers for Disease Control and Prevention (CDC) (1999) has been used. This is a practical tool designed to summarize and organize the essential elements of program evaluation (Milstein & Wetterhall, 1999). This framework is chosen for this evaluation research because it gives a clear and structured view of the steps that should be taken by an evaluation of a program. The framework can be used for nearly all programs, so it also fits the toolkit and associated workshops.

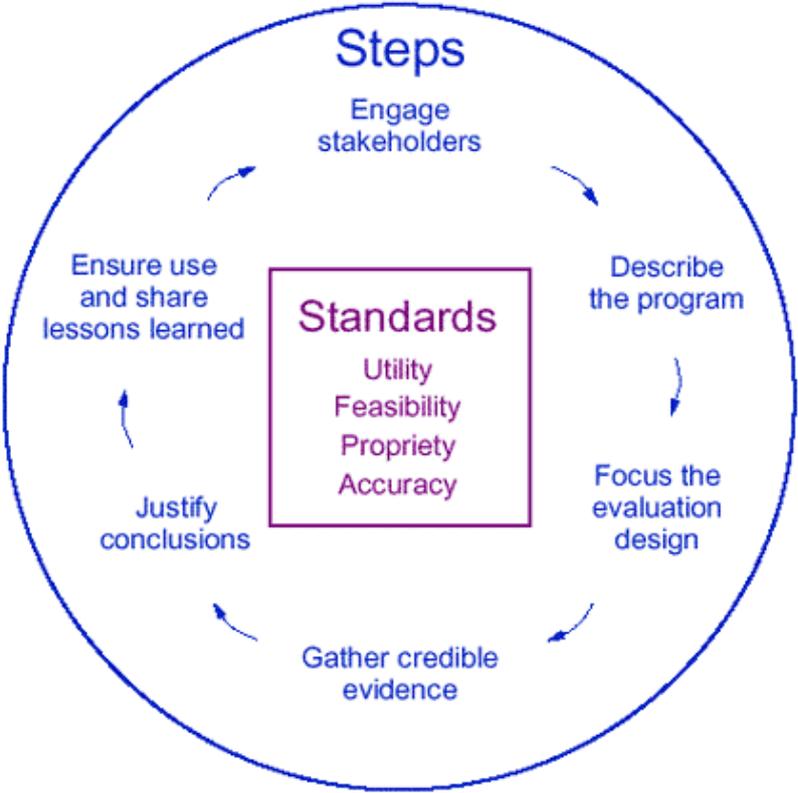


Figure 1. Recommended framework for program evaluation (CDC, 1999)

The framework includes 6 steps that must be taken in any evaluation and these steps are all interdependent, so they might be encountered in a nonlinear sequence. However, an order exists for fulfilling each. Earlier steps provide the foundation for subsequent progress (Milstein & Wetterhall, 1999). Therefore, it is important to not start a step, before the previous steps have been thoroughly addressed. The six steps will be explained in the following paragraphs.

### Step 1: Engage stakeholders

Stakeholders have been engaged, to be sure that the evaluation addressed important elements of the program's objectives, operations and outcomes. When stakeholders are not engaged, evaluation findings might be ignored or resisted because the evaluation does not address the stakeholders' concerns or values (JCSEE, 1994).

There are two groups of stakeholders that should be engaged:

1. *Those involved in the program operations*

This group consist of the people from the Learning Network (LN); so the people who play a role in the LN from the involved universities as well as the people from the involved civil society organizations.

2. *Those served or affected by the program*

This group consist of people who participated in the workshops about the toolkit and the trainers of the workshops.

### Step 2: Describe the program

A detailed description of the Learning Network and the toolkit was important to understand the goals and mission of the program. Before the evaluation research started, a clear view of the program had be formed to make sure the evaluation touches upon the right elements.

Consulting diverse stakeholders has helped by drawing a good description of the program (Milstein & Wetterhal, 1999). Therefore, researchers of the Learning Network have been interviewed.

### Step 3: Focus the evaluation design

After gathering information from the researchers from the Learning Network, a clear picture could be made about what the goals and mission of the program is and where the evaluation should focus on. A plan for the evaluation design have been made, while being useful, feasible, ethical and accurate (Milstein & Wetterhal, 1999). The evaluation design focuses on different kind of purposes; to gain insight, to asses effects and to make recommendations. The users and uses of the toolkit and workshop, the research questions and the methods are other things where the evaluation design is focused on.

#### Step 4: Gather credible evidence<sup>2</sup>

An evaluation should try to collect information that can make a well-rounded picture of the program so that the information is seen as credible by the evaluation's primary users (Milstein & Wetterhall, 1999). The credibility of information (which is called 'evidence' in this framework) can be improved by using multiple procedures for gathering, analyzing and interpreting the data. Aspects of evidence gathering that might affect the credibility include indicators, sources, quality, quantity and logistics.

#### *Indicators*

The indicators define the program attributes that pertain to the focus of the evaluation and the research questions (Milstein & Wetterhall, 1999). Indicators are a sort of concepts regarding the program and thereby they provide a basis for collecting information that is valid and reliable for the evaluation's intended uses. The indicators in this evaluation are:

- *Relevance*: Do the objectives and goals of the Learning Network match the problems or needs that are being addressed?
- *Effectiveness*: To what extent does the toolkit achieve its objectives? What are the supportive factors and obstacles encountered during the implementation? This may also include making valuable aspects and least useful aspects of the toolkit transparent.
- *Impact*: What happened as a result of the toolkit after the first year of implementation? This may include intended and unintended positive and negative effects, but also the use of gained knowledge by the participants in practice.
- *Sustainability*: Are there lasting benefits after the toolkit (and related workshops) is/are used?
- *Applicability*: The toolkit should be easy and handy to use. This may include (just as with the effectiveness) making valuable aspects and least useful aspects of the toolkit transparent. (Auger, 2007).

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<sup>2</sup> Evidence is a word that is used in this framework. The expression evidence is according the researcher tricky to use, but because it is a term that is part of the framework the word evidence will be used in this chapter to clarify the framework.

### *Sources*

Sources of evidence in this evaluation are the persons that have been interviewed, the documents that are have been used and observations (during interviews) that have been done.

### *Quality*

Quality refers to the appropriateness and integrity of the information that have been used in this evaluation (Milstein & Wetterhall, 1999). The quality of the data determined by the reliability and validity.

### *Quantity*

Quantity refers to the amount of information gathered in this evaluation. Quantity affects the potential level of confidence or precision of the evaluation's conclusions (Milstein & Wetterhall, 1999).

### *Logistics*

Logistics refers to the methods and timing for gathering and handling the information. This will be explained in the following chapter (Methodology).

### Step 5: Justify conclusions

Conclusions of the evaluation are justified when they are linked to the evidence that is gathered and judged against the standards set by the research team and stakeholders (see below). Justifying conclusions on the basis of evidence includes standards, analysis and synthesis, interpretation, judgment and recommendations (Milstein & Wetterhall, 1999).

### Step 6: Ensure use and share lessons learned

The recommendation as an outcome of the evaluation does not automatically lead to changes and appropriate action. Effort is needed to make sure that the evaluation processes and findings are used appropriately. The results of this evaluation research might lead to recommendations for adjustments and/or changes in the toolkit and workshops. The results of the evaluation will be discussed with the stakeholders and a plan for possible adjustments in the program will be made. A follow up is needed to see what has been done with the recommendations and how the program is functioning after the evaluation. This will be done by another research team.

Besides these six steps, there is a second element of the framework which consists of a set of standards, divided in 4 groups for assessing the quality of evaluation activities (Milstein & Wetterhall, 1999):

### Standard 1: Utility

The evaluation will serve the information needs of the users of the toolkit, including those who organize the workshops and those participating in them. This standard addresses items such as the type of information that has been collected and the values used in interpreting evaluation findings.

### Standard 2: Feasibility

The evaluation should be realistic, prudent and frugal. The evaluation should employ practical procedures and the different interests of those involved should be anticipated and acknowledged. The use of resources in conducting the evaluation should produce valuable findings.

### Standard 3: Propriety

The evaluation should be conducted legally, ethnically and with respect to those involved in the evaluation as well as those affected by the results.

### Standard 4: Accuracy

The evaluation should reveal information sufficient to determine the merit of the toolkit being evaluated. This standard ensures that the evaluation produces findings that are considered correct.

These standards, from the Joint Committee on Standards for Educational Evaluation (2012), will make sure that the evaluation is effective. The standards are recommended as criteria for judging the quality of program evaluation efforts (Joint Committee on Standards for Educational Evaluation, 2012).

## **2.2. Research question and sub-questions**

The central question of this research project reads as follow:

*In what waysp is the toolkit on the Right to Health used, how does it enhance the understanding of health rights and what recommendations can be made to optimize the effectiveness of the toolkit?*

In order to answer the central question, sub-questions are derived from the central question and read as follows:

1. *How and by whom has the toolkit been used?*
2. *What are valuable aspects and least useful aspects of the toolkit and the workshops?*
3. *Did the toolkit contribute to a better understanding of the right to health among the participants of the workshops? If yes, how did it contribute to a better understanding of the right to health?*
4. *Are there suggestions from the participants of the evaluation research for improvement of the toolkit and/or workshop?*

## **3. Methodology**

### **3.1. Qualitative research**

In order to answer the central- and sub-questions, qualitative research has been performed. Qualitative research is chosen as a method for this research. Behavior and attitude of the participants can be observed when using qualitative research and this can be an important aspect when analyzing and interpret the data (Berg, 2009). The method that has been used for data collection are semi-structured interviews. Furthermore, an extensive literature review has been done in the preparation phase of the research and during the data collection and data analysis phases.

### **3.2. Research setting**

The research has taken place among the members of the Learning Network. This includes several researchers from the universities which are involved in the Learning Network:

- The University of Cape Town, which has a health and human rights program that does research exploring the role of civil society agency in realizing health rights (University of Cape Town, 2012).
- Maastricht University's Centre for Human Rights encompasses research activities in the field of human rights (Maastricht University, 2012).
- Warwick University's Health and Human Rights Research Group, within the Institute of Health, which supports the development of multi-disciplinary research in the field of health and human rights (Warwick University, 2012).

Five of the six civil society organizations that are members of the Learning Network since 2008 are also a part of the research setting:

- The Women's Circle
- Ikamva Labantu
- Women on Farms
- Epilepsy South Africa
- Metro Health Care Forum

Ikhaya Labantu is a civil society organization that is also a partner in the Learning Network, but which is not included in the research because they have not used the toolkit yet.

### **3.3. Research population**

The toolkit is developed by researchers from the universities which are involved in the Learning

Network. Several health workers from the civil society organizations which are members of the Learning Network got a “train the trainer” workshop from a researcher of the Learning Network to get familiar with the toolkit and to be able to teach other about the right to health and how the toolkit can be used. The civil society organizations give workshops to society members about the right to health. Hence the population for this study are made up of Learning Network researchers, trainers of the workshops and participants of the workshops.

The target population of this study included:

- Sample 1: Learning Network researchers.  
Researchers who played a role in the development of the toolkit on the right to health have been interviewed to gather more background information about the Learning Network and the toolkit. Two researchers of the University of Cape Town have been interviewed, one from the Maastricht University and one researcher from Warwick University. The researchers from the University of Cape Town have been interviewed in person and the other two researchers have been interviewed by using Skype because of the distance. Two male and two female researchers have been interviewed.
- Sample 2: Trainers of the workshops on the right to health.  
This sample group consisted of people working at the civil society organizations which are members of the Learning Network, who attend the “train the trainer workshop” and/or who are leading workshops on the right to health using the toolkit. Nine trainers have been interviewed, who were all women; 3 trainers from Ikamva Labantu, 2 trainers from Epilepsy South Africa and 2 trainers from Women’s on Farms. The other 2 trainers are not working or volunteering for one of the civil society organizations which are involved in the Learning Network. These 2 trainers were health workers at an organization that works with deaf people, who recently participated in the “train the trainer” workshop.
- Sample 3: Participants of the workshops on the right to health.  
This group consisted of six society members who participated in the workshop on the right to health organized by civil society organization Ikamva Labantu. The participants were all women from the working class, with a low social economic status. They were all living in the township Khayelitsha. All participants participated the workshops at least 6 months before the interview. This was an important inclusion criteria to ask the participants about using the gained knowledge in practice. (See Appendix 1: Interview Guides)

These three sample groups allow for an examination of the various understandings, experiences

and uses of the toolkit. A translator was available, but all participants of the research project could speak and understand English.

### **3.4. Recruitment**

Before participants could be recruited, ethics approval for the research study had to be granted by the Ethics Committee of the University of Cape Town (See Appendix I).

The study population has been sampled through get in contact with the contact person of each civil society organization by email or phone. The contact person is the one who knows her organization very well and who also stays in touch with the researchers of the Learning Network. The contact persons of the five civil society organization have been approached. Unfortunately only three of these five civil society organizations responded and were able to help with the recruitment of trainers and participants of the workshops at their organization. The three civil society organizations that did participate in this research project were:

- Ikamva Labantu
- Epilepsy South Africa
- Women on Farms

The other two civil society organizations (The Women's Circle and Metro Health Care Forum) unfortunately did not respond to any kind of approach to get into contact. The reason they did not respond is beyond the scope of this research question, but it concerns possibly the priorities of the civil society organizations. Many civil society organizations are poorly staffed, so they are busy enough with their own activities and might not be able or not willing to spend time on a research like this, while it is not their priority.

The researchers of the Learning Network were recruited in person (researchers at the University of Cape Town) or by email (researchers at Maastricht University and Warwick University).

All participants have been informed about the aim of the research before the interviews started. They have been asked to read the informed consent form and to sign it (Berg, 2009). The participants that have been interviewed by using Skype could not sign the informed consent form. So before the interview started, the information on this form has been discussed and the researchers have given their oral consent to participate in the research. This has also been recorded.

### 3.5. Data collection

Semi-structured interviews are chosen as a method for this research, to give participants space for their adjustments. With the research questions in mind, it is important to have a more or less structured interview, but with space for the interviewees to add or delete probes and information to the interview between the subsequent subjects (Berg, 2009). Following Boyce & Neale (2006, p. 3) interviews *“are useful when you want detailed information about a person’s thoughts and behaviors or want to explore new issues in dept”*. Due to the fact that there was a tight time schedule and just one none experienced researcher, it cannot be said that those interviews really explore issues and information in dept, but by using interviews, the researcher tried to gather as much detailed information as possible about the toolkit and the experiences with the toolkit.

First the Learning Network researchers have been interviewed to gather more information about the Learning Network, the toolkit and what the aim of the toolkit is. The researchers of the Learning Network were involved in the development of the toolkit, so they could give useful information what was good to know before starting the evaluation. It was also good to gather their experiences, opinions and suggestions about the toolkit. The interviews have taken about 30 minutes each.

After gathering more background information about the Learning Network and the toolkit, interviews were held with trainers and participants of the toolkit. The interviewer has traveled several times to the offices or meeting place of the five participating civil society organizations to interview trainers and participants. It was often a surprise how many people were there at those moments, because the civil society organizations did not really stick closely to the agreements that have been made with the researcher. The interviews with the trainers and participants took approximately 30 minutes each.

The interviewer had a semi-structured interview question guide (Appendix II) and probed available containing the main research questions but with the understanding that it was not a rigid structure and could welcome additional information. The interviewer engages with participants by listened attentively to participants’ responses and asking follow-up questions based on the responses. The interviewer did not encouraged participants to provide particular answers by expressing approval or disapproval of what they said.

The interviews have been recorded with a dictaphone with permission from the participants. Interview data consists of tape recordings, typed transcripts of the tape recordings and the interviewers’ notes.

### **3.6. Data analysis**

The majority of the data that have been collected involves subjective views and experiences of the participants. The collected data have been analyzed with the use of transcripts and coding. Repeatedly listening to the tape recordings and making notes was also an important part of the data analysis.

Because there were not many data, the coding process have been done by the researcher by creating a coding matrix and without the use of any computer program. Analyzing the data has been primarily done by thematic analysis (Howitt & Cramer, 2005). This type of analysis allowed the researcher to familiarize herself with the content and begin to identify regular recurring experiences and opinions described by the participants that have been interviewed.

### **3.7. Methodological Limitations**

Respondent bias might had an impact on the results of this research study, as the participant could have answered questions according to what they think the researcher or the Learning Network wants them to answer. Furthermore, participants could have been afraid to speak negative about the toolkit, because they get services from their civil society organization or the Learning Network. The trainers and participants are very thankful for the effort the Learning Network puts into the civil society organizations, so it could have been that they did not want to fall off the toolkit and the Learning Network. This could be an methodological limitation within this research study. This will further be discussed in Chapter 5.

## 4. Results

When writing the proposal of this research project, it was unclear what to expect from the collaboration within Learning Network and the use of the toolkit. When arriving in Cape Town and having the first meeting at the University of Cape Town (UCT), it became clear that also the researchers from the UCT who are involved in the Learning Network and the development of the toolkit did not really have a clue about which of the civil society organisations uses the toolkit and how they use it. From that first day in Cape Town on, the concrete and strict plan and time schedule as described in the proposal was flushed down the drain. This study, what was planned to be a concrete evaluation, suddenly had much more background information that needed to be researched. Therefore, the data collection is not only focused on the toolkit itself, but also on the aim of the Learning Network and the toolkit, which of the organisations use the toolkit and how the toolkit is used.

The sample size that has eventually been obtained is nineteen (N=19); four researchers from the Learning Network, nine trainers of the workshops associated with the toolkit and six participants of the workshops associated with the toolkit. Because the interviews with the researchers were meant to obtain more background information, those findings will be presented separate from the findings of the interviews with the trainers and participants of the workshops.

### 4.1. Opinions of researchers of the Learning Network

Firstly, four researchers who were involved in the development of the toolkit were interviewed to gain more background information about the aim of the Learning Network and the toolkit. All researchers agreed on the fact that the Learning Network is there to explore what the right to health means and how the right to health can be implemented.

*“..it aims to basically identify what the right to health is and the best practice or good practice for realising the right to health”* (Participant 3).

It is set up to bring civil society organisations in the Western Cape and university researchers on Human Rights together, although other civil society organisations cannot apply to be a member of the Learning Network.

*“We don’t want to make it bigger...we feel like we all know and trust each other... bringing in new members would bring in a new sort of dynamic and people did not feel like they wanted to do that, yet”* (Participant 2).

The Learning Network gives the involved organisations and universities the opportunity to share their experiences and to learn from each other, to create a space where learning around human rights could be translated into action.

*“... and it is about learning from each other. So the universities are learning from the experiences of the civil society organisations and the civil society organisations are learning from the universities and their researchers.”* (Participant 1)

The question if they were satisfied with the collaboration within the Learning Network between the researchers and the civil society organisations made all researchers laugh and looking for the right answer. *“Uhhhh (laughs) well, that is a big question!”* (Participant 4).

Three of the four researchers mentioned that the Learning Network is not the number one priority of the civil society organisations and that this makes it sometimes difficult to work together.

*“..sometimes there is sort of barriers with getting to participate because also, the network is not their core work, the NGO has it's own core mission. So it is an extra additional thing”* (Participant 1).

They all agreed on the fact that the collaboration within the Learning Network could be improved, but that this will be difficult to achieve.

*“It could definitely be improved.. everyone is busy and we don't want the learning network to go away, so we take the sort cuts ..we should take it more slowly, to make things happen differently but it is hard to find the time and space”* (Participant 3).

*“It is hard to get a sort of common agenda”* (Participant 4).

But on the same hand, the researchers are glad that even if all the civil society organisations and researchers are busy with their own work and missions, the Learning Network still exists and the organisations take work on the right to health.

*“If you look at the time and resources we have and what we do, I think we achieve uh, I think we do quite well”* (Participant 1).

The opinions about the aim of the toolkit on the right to health is in general with all four researchers the same. The toolkit is a guide organisations can use to train people about the implementation of the right to health and what to do when their rights are getting violated.

*“The aim of the toolkit is really to provide a kind of practical guide for mainly civil society organisations on what they can do to improve the implementation of the right to health. Another is about redressing violations on rights”* (Participant 1).

*“...it was designed to be a tool that we could give to NGO's and say: this is something you can use to give training about the right to health”* (Participant 4).

They all specifically focus on the fact that the toolkit is not just a book to read about the right to health, but that it is very closely linked to training and that people cannot really use it on its one.

That is also the reason why the first version of the toolkit which has been piloted in 2009 has been adapted.

*"We first designed it a little bit to academically, so it was not really useful for training people.... that is why we piloted it and revise it and we think it works better now"* (Participant 1).

*"The toolkit is meant to be uhh, a resource that allows people to be able to do training on the right to health"* (Participant 2).

All four researchers have been asked what they think that should be accomplished to consider the toolkit a successful. Also on this topic, the answers of all the researchers were similar. They think the most important thing is that individuals and civil society organisation are able to take action for the right to health after participating in the workshops where the toolkit is used.

*"... if organisations and individuals come back to the Learning Network and say: we have experienced a violation of our health and because of the toolkit we have been able to address that violation"* (Participant 1).

*"If organisations are able to report that they have changed their practice in a way they feel more capable of defending the members rights or training people or taking action"*(Participant 3).

But for two of the four researchers it was also very important that the civil society organisations that use the toolkit are satisfied with the toolkit as a training material itself.

*".. if organisations are using it and finding it an useful tool, uhh that then, I would feel that it was accomplishing what we set out.."*(Participant 2).

*"...when people come back to use and say: we been using the toolkit but we think this, this and this needs to change.... Then I guess that is an indication that they are using it, uhh in an active way. And that is a matter of success"* (Participant 4).

## **4.2. Opinions of trainers and participants of the toolkit workshops**

To evaluate the toolkit six participants and nine trainers of the workshops on the Right to Health in which the toolkit is used, have been interviewed. Using the interview guides (Appendix ???) as a guidance, the most important results of these fifteen interviews will be presented below in five main themes; *experiences, overall results, lay-out & languages, content of the toolkit and how the toolkit is used.*

### **4.2.1. Experiences**

When interviewing the trainers and participants of the workshops on the right to health, it became clear why it is so important for them to learn about their rights and what they can do when their rights are getting violated. Because mainly, most participants of the workshop wanted just to talk about their experiences when it comes to the right to health. Most of the

participants have had bad experiences with hospitals and clinics and their rights (or the rights of a family member) have been violated.

*“I took my daughter to the clinic. I was like, I went to the toilet because we had to wait so long, but I told this to the woman at the reception and gave her my card. But then the doctor called my name when I was not there. When I came back from the toilet, I was waiting and waiting and waiting you know. The doctor kept on coming calling people, but not me. So I went to him and gave him my card and I said: I am waiting so long, but you have not called my name and stuff. And then he was like, where were you?! I told him I went to the toilet and told this to the woman. He said that he did not care and that I should come back tomorrow and wait again all day, because my chance has passed. That is how they treat people like us in a clinic... the doctors have all the power”* (Participant 14).

*“When my mother finally could see the doctor, he was really rude to her... he wanted to give her an injection, without telling her what the medicine is for”* (Participant 17).

*“Nurses at the local clinic are shouting at patients.... so some people who live just in the community (township Khayelitsha) go near their working place to a hospital to get their treatments. But then they sometimes get sent away, because the nurses there say uhh you know, you don't belong here”* (Participant 8).

*“One day I was in a hospital in Khayelitsha and we were sitting down and then the nurse came out and started to say, all those who came to fetch the ARV's [HIV medication, MH] must come to this side of the waiting room... where is our privacy?”* (Participant 12).

By hearing different stories and experiences of the participants about hospital or clinic visits, it becomes clear that most participants have not much trust and believe in hospitals, clinics, doctors, nurses and even not in the government when it comes to Health Rights.

*“... you never get feedback in terms of what happens with the person you complained about. Because the lady [health worker at a civil society organisation, MH] phoned to the department, because she knew someone in the department. That guy (the doctor) was removed from the clinic. He is working in another clinic now!! Which is going to mess another clinic instead of putting him down. And telling him: this is how you have to work with people and that stuff”* (Participant 14).

Because rights are getting violated so often in the Western Cape area of South Africa (SAHRC, 2009), all participants agree that it is very important to know your rights and to stand up for your rights. That is also the reason why they all showed that they are very eager to learn.

*“Here in South Africa, there are so many things happening. And if you don’t know your rights, you’re out!!!”* (Participant 16).

#### **4.2.2. Overall results**

None of the fifteen trainers and participants of the workshops on the Right to Health was negative about the toolkit and/or the associated workshops. The trainers were all very grateful to the Learning Network for having this toolkit. For the trainers as well as the participants of the workshops associated with the toolkit, the toolkit is very important. They see it as an opportunity to learn about rights that they can use in practice, for example in the clinics, to stand up for themselves. Despite the fact that Human Rights and the Right to Health are a big issue in South Africa and rights are getting violated often (SAHRC, 2009) all trainers and participants of the workshop on the right to health admit that they had little to no knowledge about the right to health before they acquainted with the toolkit. Even the trainers of the workshop associated with the toolkit, gained most of their knowledge by participating in the “train the trainer” workshop, which is giving by one of the researchers of the Learning Network. In this workshop, all the sections of the toolkit are being discussed. The trainers are very happy with the toolkit, not only because they have new gained knowledge about the right to health for themselves, but also because they now have a tool with which they can teach others about the right to health.

*“First we had nothing and now we have this! It is great.”* (Participant 10)

*“When I saw it [the toolkit, MH] for the first time, it was amazing, because I never thought I could have something like this... everything you should know about your right to health is in there”* (Participant 11).

The participants who knew the first version of the toolkit said it improved a lot. The first version which was launched in 2009 was written on an academic level, which was too difficult for the trainers and participants of the workshops. They were not able to use this toolkit to train community members about the right to health.

*“I said no, this is not going to work. It was so up there! It was too legalistic and the language was so high”* (Participant 10).

All the trainers who knew the first toolkit are very positive about the changed that have been made. The renewed toolkit is user-friendly and applicable for the workshops.

*“Now that they have brought it down to case studies, exercises and all that and they have improving it and make it simpler it really works!”* (Participant 8).

All participants of the workshops associated with the toolkit mentioned that their understanding about the right to health has improved after participating in the workshops. Some participants

do admit that this was not difficult to achieve, because before they participated in the workshop, they had little to no knowledge about human rights at all.

*“All the information was useful you know.. Because we just sit there and we know nothing. We want to learn, so all the information is important for us”* (Participant 19).

To the question if the workshop gave the participants more strength and knowledge to stand up and fight for their rights, they all answered yes. Some participants said that the information from the workshop and toolkit learned them what to do when your rights are getting violated and they can use this knowledge in practice.

*“Now I know more about my rights, I can protect myself. I know I can ask the doctor what the injection is for, because it is my right to know that”* (Participant 17).

#### **4.2.3. Lay-out & Language**

The toolkit is a manual of 194 pages. In all the interviews the amount of pages was discussed and the opinions about this differ. Participants of the workshops did not have a opinion about this, because none of them saw or have read the toolkit. The majority of the other participants (nine trainers) said that the toolkit is too big and therefore not attractive to read. They said that probably more people would take (or download) the toolkit and read it, if it was more compact with less pages.

*“The size of the book scared me a bit, it is so big!”*(Participant 16)

*“I think it is simple to make it a bit smaller, so you look at it and you get interested to reading it”* (Participant 11).

*“It is a big book now, it is too big... maybe you could make it a bit smaller? I think it could be smaller, because sometimes they repeat things”* (Participant 7).

One of the participants who also said the toolkit has too many pages, made a suggestion about designing additional pamphlets or posters on which the most important information from the toolkit is briefly shown. These pamphlets or posters could be spread among different clinics and hospitals, so the patients can read the pamphlets and poster and get maybe interested in reading the whole toolkit.

*“That is way maybe they can also make pamphlets or posters... so when you go to the clinic, you can read about human rights.... it could also trigger them to read more about it”* (Participant 8).

Some participants said that the amount of text is fine the way it is. They admit that it is a big book, but that it is pleasant to have all the important information about the right to health together in one manual.

*“... it is a lot of important information.... but otherwise without the toolkit, it's scattered all over the place. With the toolkit it's everything in here”* (Participant 10).

The level of language that is used in the toolkit is easy and clear enough for all participants. The participants of the workshops did not have an opinion about the whole toolkit, but they have seen the handouts which are a part of the toolkit. Some participants mentioned the definition list of difficult words at the beginning of each section to be very helpful enhancing the understanding of the information.

*"... with legal terms there is a limit in terms of how simple you can make it without losing the meaning... but even for community people that are not educated it is easy to read and understand"* (Participant 15).

*"For us (participants of the workshop) it is important to understand the text on the handouts, but that is no problem"* (Participant 9).

When the level of the language was being discussed, seven of the nine trainers mentioned that they would like to see the toolkit translated into Afrikaans or Xhosa (depending on the organisation). Some community members don't understand English, meaning that the trainers have to translate the information from the toolkit for some target groups, which is time consuming for them. Especially the handouts should be translated according to the majority of the trainers, because those handouts are distributed to the participants during the workshops.

*"When you train people here, you have to translate everything whatever topic to Xhosa, so they will be able to read it in their own language at home..... yes, so it will be better to have it already translated, then we don't have to do that ourselves"* (Participant 10).

All participants have been asked what they think is the most valuable aspect of the toolkit and the majority of the participants mentioned the handouts that are attached at the end of every section of the toolkit. Those handouts are used in the workshops to hand out to the participants and they are allowed to take it home.

*"The handouts are very useful. I took it home and now still use it for my sisters... some of the handouts I use to teach them now. So it was very useful for me. I now also teach others about what I learned"* (Participant 15).

#### **4.2.4. Content of the toolkit**

Participants have been asked what they think is the most valuable and most important aspect of the toolkit regarding the content. Again, participants of the workshops could not answer this question, because they have not seen the toolkit. The several case studies which are in every section of the toolkit are seen as a valuable aspect of the toolkit, while they can delineate a situation in which the participants can identify themselves in.

*"It is very practical and easy to explain to others, to visualize what you are actually talking about"* (Participant 13).

The definition list at the beginning of each section, makes it for the participants easier to understand the information in the toolkit. Several participants mentioned this definition list as a essential part of the toolkit.

*"... but even if I don't understand it, I can look it up in the list with difficult words and then I understand"* (Participant 15).

*"I find that list very useful..."* (Participant 14).

Each section of the toolkit has several exercises, which are designed for participants to do practical tasks or to answer series of questions during workshops. Trainers as well as participants of the workshop are very positive about those exercises.

*"It made the workshop really fun. She gave us exercises and it was really nice, cause we had the chance to discuss everything and everyone go and present and then the other would do something... It made it fun"* (Participant 11).

*"The activities are a good thing. There is a lot information we are giving... by doing activities with the participants, they don't have to sit and only listen to use. It is more interactive"* (Participant 9).

The nine trainers have been asked which part of the toolkit they think is the most important. Almost all trainers said that the section about 'what to do when your rights are getting violated' is the most important. All participants are aware of the fact that rights are getting violated very often in South Africa (BRON!!!!), so they believe that is the most important to know what you should do when this happens. Also five of the six participants of the workshops reported the part of the workshop about violations of rights as the most important.

*"I would say the part about violations... Being aware of your rights is one thing, but knowing what to do when rights are violated is at least just as that important"* (Participant 17).

The participants have been asked what they think is the least useful or least important aspect of the toolkit. Also this question could not been answered by the six participants of the workshops. Only one of the nine participants could mention an aspect of this toolkit that was not useful for her. In her opinion the sections of the law that are mentioned in the toolkit are not necessary. She said: *"I think nobody will really learn or remember those sentences [legal articles, MH], so I don't think you have to put them into the toolkit"* (Participant 14).

All the other eight participants said that all the information in the toolkit is beneficial and that they could not mentioned one thing that was not useful for them. Again, the participants of the workshops who had not seen the toolkit, were talking about the handouts they received.

*“All the information is useful, definitely!” (Participant 17).*

*“No! Everything is useful, because I don’t know what is coming. But if it is a new thing, I want to learn” (Participant 16).*

*“All the information was useful you know.. Because we just sit there and we know nothing. We want to learn, so all the information is important for us” (Participant 19).*

The majority of the participants did not had any suggestions regarding the content of the toolkit for improvement. According to them, the toolkit is perfect the way is it.

*“There is nothing I want to change. This new toolkit is very good and useful” (Participant 11).*

One participant made the suggestion to include less legislation in the toolkit (see above). Another participant suggested to focus more on how to cope with personnel in a hospital or clinic, because in her opinion most people struggle with rights violations and rude behaviour of personnel in these settings.

*“...more about what to do in a hospital or so. What are your rights as a patient. What can you do when a doctor gives you medication or operations without explaining you why. What can you say, so the doctor will explain everything to you” (Participant 5).*

#### **4.2.5. How the toolkit is used**

It is a remarkable finding that during the interviewing with the nine trainers who use the toolkit for their workshops on the right to health, it seemed that no one uses the whole toolkit. The trainers take parts out of the toolkit and use that information to compose their own workshop. Each organisations has a different target group and the trainers pick out the information of which they think is important for their target groups. Besides that, all of the trainers reported that there is not enough time scheduled for the workshops to discuss every section and/or all the information that is in the toolkit.

*“The toolkit couldn’t be used just like that. We had to change it and take certain aspects of it.” (Participant 7).*

*“We don’t use the toolkit just like it is. We take things out of it and change it a bit... I think everybody has it’s own way of teaching, but the toolkit is a very good basis to work from.... I don’t think it is possible for any organisation to discuss the toolkit from the first to the last page, but that is fine” (Participant 13).*

Because of the fact that the trainers can take parts out of the toolkit which they find important and the information lends itself well to compose different workshops for different target groups, all of the trainers said that the toolkit is applicable.

*“Yes, it is very applicable... it is a manual and you can use it the way you want... all the information*

*is in it and it is up to the trainer to make a workshop out of it. The trainers can use the case studies that are in it and the exercises, but they can decide what they want to discuss.” (Participant 5).*

The trainers that participated in the “train the trainer” workshop which was given by a researcher of the Learning Network, said they take that training as an example for their own workshop. Their workshop have the same structure as the “train the trainer” workshop. The trainers said the “train the trainer” workshop was very useful and that after participating in this workshop they feel skilled enough to teach others about the right to health.

*“I do it the way she (the researcher of the Learning Network who gave the “train the trainer” workshop) did it... It is not only sit there and listen, but they (the participants of the workshops) really participate and discuss the information” (Participant 13).*

*“Yes, I feel skilled enough, because we learned a lot in that training... and sometimes I read the toolkit again if I want information about it” (Participant 9).*

None of the participants of the workshop on the right to health have seen the toolkit. So the trainers use the toolkit to gather information and compose their own workshop. The participants of the workshops, did however all received handouts during the workshops which they could take home.

*“No I never saw it [the toolkit, MH], but we did got papers with information [the handouts, MH]. Those are useful” (Participant 18).*

#### **4.3. Promotion of the toolkit**

Promotion is a subject that was not included in the interview guide, but it was mentioned by a majority of the fifteen participants during interviewing. Almost none of the participants could say something negative about the toolkit, but most of them did however suggest to promote the toolkit, so more people will read it or will participate in the workshops associated with the toolkit. The participants reported that too few people know their rights when it comes to health care and that it would be useful for them to receive education on the right to health by reading the toolkit or participating in the workshops.

*“It would be very good if more people know their rights... so it would be very useful to spread it [the toolkit, MH] everywhere” (Participant 12).*

*“You know, there are so many people out there [in the townships, MH], they don’t know... I don’t know how to reach them, but they need to know.. they should also get this training and learn about their rights!” (Participant 16).*

*“So those posters and pamphlets I talked about (see quote in paragraph 4.2.3.), that you can spread, it will also promote the toolkit.... so people will go to the website and take it from the internet” (Participant 8).*

Two of the nine trainers reported that they promote the toolkit to other organisations in Khayelitsha like the Medical Knowledge Institute.

*“We have a network of NGO’s... and we are sharing skills. So I tell them about the toolkit... I gave them the website link of the toolkit” (Participant 10).*

A participant of the workshop associated with the toolkit made a suggest to promote the toolkit and the workshops in Khayelitsha through the use of the local radio.

*“There are a lot of people in the shelters we can’t reach, but they also have to learn about this (the right to health).... we have got a radio station here (in Khayelitsha)... so maybe do promotion on the radio, tell the people they have to come here (to the Ikamva Labantu center) to get the workshops” (Participant 17).*

So even though promotion was not a subject which was included in the interview guide, many participants wanted to talk about it and suggested that promotion of the toolkit would be beneficial for the community members to increase their knowledge about the right to health.

In order to answer the research question of this study, results specified in this section of the thesis will be summarized and discussed in the following chapter.

## 5. Conclusion & Discussion

### 5.1. Summary of findings and take-home message

The aim of this research was to evaluate the toolkit on the Right to Health, developed by the Learning Network, to make possible deficiencies transparent, to optimize the effectiveness of the toolkit and to inform the Learning Network about the implementation of the toolkit. Therefore, the following research question has been formulated: *In what way is the toolkit on the Right to Health used, how does it enhance the understanding of health rights and what recommendations can be made to optimize the effectiveness of the toolkit?* The designed sub-questions (see paragraph 2.2.) and thereby this research question will be answered by presenting a summary of the key findings below.

- Findings show that the toolkit is used by the civil society organisations to compose their own workshop on the right to health. All of the trainers who participated in the “train the trainer” workshop of the Learning Network, take this training as an example for their own composed workshops. None of the trainers use the whole toolkit and none of the participants of the workshops have seen the toolkit. The participants did however received handouts of the toolkit.
- All participants of the research study reported that it is important for them to learn about the right to health, because there are so many violations going on in the area where they are living (Western Cape). All participants of the workshops said their understanding about the right to health has improved after participation in the workshops. Also, all trainers stated that their understanding about the right to health has improved after participating in the “train the trainer” workshop and after reading the whole toolkit.
- Due to the fact that the toolkit and associated workshops are an education method that brings all the important information about the right to health together in a compact and clearly to follow way, the toolkit contributed to a better understanding of the right to health among the participants (trainers as well as the participants of the workshops). Participants of the research study stated that before reading the toolkit or participating in the workshops, they had little to no knowledge about the right to health. After reading the toolkit or participation in the workshops, they reported that they have the strength to stand up for their rights in practice, because now they have the knowledge about what their rights are and how they can protect their own rights.

- The participants mentioned several positive aspects of the toolkit. So are the handouts, case studies, definition list and activities reported as valuable aspects of the toolkit. The section about the Violation of the Right to Health is by the majority of the participants seen as the most important part of the toolkit. Only one participant could mention a negative or less useful aspect of the toolkit; the legal articles. All the other participants could not name a negative element. The amount of text is a matter of which the opinions of the participants differ. Some participants stated that the toolkit has too many pages and that it would be more attractive to read if the book was smaller. Other participants said the toolkit is fine as it is, because it has all the important information together in one book.
- The majority of the participants could not mention a point of improvement for the toolkit. However, the subject promotion was discussed often in the interviews. Some participants mentioned that it is important to promote the toolkit and the associated workshops, in order to ensure more people will learn about the Right to Health. Recommendations that can be made for the Learning Network to possibly adjust the toolkit to optimize the effectiveness of the toolkit on the Right to Health are based on the findings and suggestions made by the participants of this research study and will be presented in the following chapter (Chapter 6. Recommendations).

When recapitulate the key findings mentioned above, the following take-home messages can be formulated:

<b>Take-home messages</b>
None of the trainer use the whole toolkit, but they use parts of it to compose their own workshop.
The understanding of the right to health of all participants has been improved after participating in the workshop on the Right to Health.
All participants were very positive about the toolkit and almost none of the participants could mention a negative aspect.
Some participants mentioned it is important to promote the toolkit, to make sure more people will increase their knowledge about the Right to Health.

## **5.2. Comparison with previous studies**

In the studied literature is found that many patients in South Africa are not aware of their rights and that even those who are aware have difficulty asserting their rights (SAHRC, 2009). This

statement can be endorsed when it comes to Health Rights, when looking at the findings of interviews with the different members of civil society organisations. All of them reported that their knowledge about the Right to Health and how to stand for their rights was little to none, before they read the toolkit or participated in the workshops on the Right to Health. It is also been stated that the rights of many participants are being violated in healthcare services. Previous studies, done by the SAHRC (2009) and the Learning Network reported the ongoing violations of the right to access to health care services and thereby, show similar outcomes. Results of the evaluation of the toolkit show that the toolkit on the Right to Health and the associated workshops made the participants aware of what their rights are when it comes to healthcare and after participation in the workshops, their knowledge about the right to health has been improved. All participants mentioned the importance of improving their knowledge and to spread this knowledge. This result can be backed up by research done by London (2008) that stated that knowledge about human rights and the right to health is needed for the vulnerable groups in South Africa. London (2008) also reported that human rights education is important to create awareness of peoples basic rights and that to ensure the highest attainment of human rights for all, promotion of human rights education is needed.

### **5.3. Limitations**

Based on the fact that despite the great effort that has been made, it was not possible to get in contact with all the participating civil society organisations of the Learning Network, only three of the five civil society organisations have participated in this study. Also the recruitment of participants was extremely difficult and time consuming, so the actual sample size of this research is nineteen participants, of which fifteen members of civil society organisations (trainers and participants of the workshops) that work with the toolkit or the information in the toolkit. The participant group is therefore much smaller in size than originally intended. For the reason that there was a strict time limit for the data collection, while this part of the research necessarily had to take place in South Africa, the researcher decided to base the analysis on this limited sample size. Results of this study might be unique to the relatively few people that were included in this research study. It is crucial to keep in mind that it could have an influence on the reliability of the data and therefore be a limitation of this study.

Fifteen of the nineteen participants which formed a part of the sample size of this study, were members of civil society organisations linked to the Learning Network. The fact that most of those people receive services from the civil society organisations, could have an influence on answers to the interview questions, regardless of the fact that in the inform consent form the participants had to sign was pointed out that nothing what they would say would be hold against

them or would have in an influence on the services they received from their organisation. All participants were very grateful for the help and the collaboration with the Learning Network. It is doubtful that the participants did not want to speak negative about the toolkit and/or the Learning Network, because they were afraid it would affect their relationship with the civil society organisation and/or the Learning Network in a negative way. Within the realm of possibility, participants therefore gave socially desirable answers and have not given their full opinion. Notwithstanding the fact that there is not much to do about this limitation, it must be kept in mind that it could be a bias and have an influence on the validity of this study.

## **6. Recommendations**

### **6.1. Recommendations for further research**

To continue on the limitations of this study mentioned in the preceding chapter, some recommendations can be made for further research.

- It is recommended to perform another evaluation of the toolkit on the Right to Health in one year. It is preferred that this evaluation research will be performed by at least two researchers to minimize the change of personal bias and enlarge the reliability of the research. Furthermore, it is advisable to schedule a longer study period than with the current study, while data collection can be very time consuming within in this study population. Especially accounted for the fact it is recommended to recruit a bigger sample size for the following evaluation research of the toolkit, to enlarge the reliability of the study.
- Furthermore, it would be of great theoretical and practical importance to evaluate the toolkit anyway every one or two years for a following period of time, while it concerns a education method which requires frequent evaluation to optimize effectiveness. Besides that, the information of the toolkit needs to be updated on regular basis, due to the fact that it includes details on the South African health system and government which might change sooner or later.
- Based on the fact that promotion of the toolkit and associated workshops was mentioned several times during the interviews with the fifteen participants from the civil society organisations, it could be taken in consideration to investigate whether this is desirable and useful. The Learning Network could for example have an intern looking into this subject and start a research to figure out if it is feasible en effective to promote the toolkit and in what ways the potential promotion can take place.

### **6.2. Recommendations for the toolkit**

- When looking at the results of this study it is apparent that all the participants are very positive about the toolkit. In spite of the fact that almost none of the participants could mention a negative aspect of the toolkit, some recommendations can be made to improve the effectiveness and applicability of the toolkit.
- It is recommended to translate the toolkit in Afrikaans and Xhosa. The participated civil society organisations indicate that it would be very helpful for them to have the toolkit

also in Afrikaans and Xhosa. Currently, quite a large quantity of the trainers translate some parts of the toolkit and the handouts to Afrikaans or Xhosa themselves, because many society members do not understand English very well. Translation of the information is time consuming for the trainers and therefore they would like to have the toolkit also in Afrikaans and Xhosa for those who do not understand English.

- Even though the opinions about the amount of text of the toolkit differed among the participants, it could be recommended to look into the possibilities to reduce the number of pages. Most of the trainers have no difficulty with the fact that the toolkit is a big book because they use it to compose their own workshops, but they indicated the possibility that it would not be attractive to read for community people who want to download it from the internet and read it without participating in the associated workshops. Therefore, it could be a suggestion to create additional pamphlets with the most important information from the toolkit. Those pamphlets can be spread in clinics, hospitals and civil society centres, so the ones who don't want to read the whole toolkit or who cannot or will not participate in the workshop, still can be reached. The pamphlets can also function as a kind of promotion of the toolkit and the associated workshops.

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## **Appendix I      Ethics Approval**

## **Appendix I      Interview Guides for interviews**

### **Interview Guide for the Learning Network professionals**

1. Can you tell something about the aim of the Learning Network?
2. Can you tell something about the collaboration between the different members of the Learning Network (Universities, CSOs etc.)?
3. Can you explain the aim/the objective of the toolkit?
4. What do you see as the key lessons that should be learned after participating in the workshops?
5. Have you already seen or heard about the effects of the toolkit/workshops? Can you give an example?
6. What do you think that should be accomplished to consider the toolkit as successful?
7. What do you find important to be evaluated?
8. What improvements would you suggest for the toolkit?
9. Do you think there is more I need to know about the toolkit before I start this research project?

## **Interview Guide for the educators of the workshop**

1. Of what Civil Society Organization are you a member? Can you tell something about this organization? What is your role as a member?
2. When did you start leading the workshops associated with the toolkit on the right to health?
3. What is your profession?
4. Have you had training or a course before you started leading the workshops?
5. How did you gain your knowledge about human rights and the right to health?
6. Do you feel you are skilled enough to lead the workshops?
7. What do you think about a potential training for the educators?
8. Can you tell what you think the aim/the objective of the toolkit and workshops is? Do you think this aim/objective is achieved?
9. Do you find the toolkit applicable? Can you explain why?
10. What is the most valuable and least useful aspect of the toolkit according to you?
11. What improvements would you suggest for the toolkit?

## **Interview Guide for the participants of the workshop**

1. Of what Civil Society Organization are you a member? Can you tell something about this organization? What is your role as a member?
2. When did you participate in the workshops?
3. Can you tell something about how the workshops were educated? Do you have suggestions for improvement on this?
4. Do you find the toolkit applicable? Can you explain why?
5. What do you find to be the most valuable and the least useful aspect of the toolkit?
6. Did the toolkit and associated workshops change your understanding of the right to health? If so, can you give an example of how?
7. What is the key lesson or key lessons you have learned from the toolkit and workshops?
8. Have you already used your gained knowledge from the toolkit in practice? Can you explain how?
9. Would you recommend someone to participate in the workshops? Can you explain why or why not?
10. What improvement would you suggest for the toolkit?

## **Appendix III      Information about the research project**

### **Summary of the research project**

South Africa is known for its rich, but turbulent and dramatic history. Events that have occurred in the past had a big influence on the society as it is nowadays, especially the Apartheid period. Although South Africa is renowned to be one of the most rights-oriented constitutions in the world, the practical realization of socio-economic rights remains slow and uneven. Despite all efforts, South Africa has still one of the highest levels of inequality in the world, also when it comes to health rights. The South African Human Rights Commission (SAHRC) indicates that many patients are not aware of their rights and that even those who are aware have difficulty asserting their rights. The SAHRC also found evidence of numerous ongoing violations of the right to access to health care.

Civil society plays an important role in mobilizing communities around the right to health. They can do this by creating awareness of health rights. The Learning Network is a project on Health and Human rights based at the University of Cape Town. Six civil society organizations (CSO) are involved in this project and so are 2 other universities. Together they explore what can be done to make people aware of their health rights and how they can use their rights to advance health.

Civil society members of the Learning Network indicated that there was a need for a practical tool to use to train communities on what the right to health means and how violations of the right to health can be identified. This led to the development of a toolkit on the right to health. The toolkit is a guide, written in understandable English, which can be used in workshops for improving human rights and right to health awareness.

The toolkit has been in use for almost one year now and the aim of this research is to evaluate the effectiveness (enhancing the understanding and practice of health rights) of the toolkit. Valuable and least useful aspects of the toolkit will be made transparent and recommendation for achieving better results in the future will be made. It will also be researched by whom the toolkit is used and how it contributes to a better understanding of health rights.

The research team will collect data by interviewing and leading focus groups among three different groups: LN professionals who contribute in the development of the toolkit, educators of the workshops and participants of the workshops. The outcomes of these interviews and focus groups will be analyzed and this will result in a report and recommendations for a renewed toolkit.

## Appendix IV Consent Form Interviews & Focus Groups

### Consent Form

We are doing a study to evaluate the effectiveness of the toolkit on the Right to Health developed by the Learning Network. This evaluation will be done by the 6 civil society organizations that are involved in the Learning Network. You have already read the information about this research and we would now like you to ask you to participate in our study.

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

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

You will not be paid for being involved in this research.

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

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

If you have any questions about the research, please contact:  
Nicole Fick, School of Public Health and Family Medicine, UCT  
[Nicole.fick@uct.ac.za](mailto:Nicole.fick@uct.ac.za)

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

Participant (name and surname): .....Signature: .....  
Researcher: .....Date .....