International
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Organization

Research on “ACCESS” and “EFFECTS” of Social Protection Policies & Programmes on Women and Men Workers and their Households in the Informal & Formal Economy Affected by HIV and AIDS

A Guide on Research Methodology for Undertaking Research at Country Level

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INTRODUCTION

The Millennium Declaration adopted in 2000 produced a historic international compact to reduce inequalities in human development and to achieve the Millennium Development Goals (MDG). The past decade has witnessed considerable progress towards the goals of reducing poverty and hunger, combating disease and child mortality, promoting gender equality, expanding education and building global partnerships for development. Many of the achievements however, are based on improvements made in national averages which can hide wide disparities among regions and within countries (Bamberger and Segone, 2011). In HIV and AIDS these disparities hamper progress towards reaching the three zeros: zero new infections, zero discrimination and zero AIDS-related deaths (UNAIDS, 2012), and pose a significant obstacle to the attainment of decent work and livelihoods of millions of persons living with HIV or affected by the epidemic.

Since 2001, with the adoption of the code of practice on HIV and AIDS and the world of work, the International Labour Office (ILO) and its constituents have been committed to tap into the immense contribution that the world of work can make to ensuring universal access to HIV prevention, treatment, care and support. In 2010, Recommendation No. 200 concerning **HIV and AIDS and the World of Work** called for strengthening HIV prevention efforts at the workplace, the integration of workplace policies and programs on HIV and AIDS into national policies and programmes, respect of the fundamental human rights of all workers, gender equality, and the right of workers to be free from stigma and discrimination (ILO, 2010). In the International Labour Conference of 2012, the ILO reaffirmed these commitments in Recommendation No. 202 concerning **National Floors of Social Protection** defined as sets of basic social security guarantees which secure protection aimed at preventing or alleviating poverty, vulnerability and social exclusion (ILO, 2012a, p.2).

The social protection and HIV research referred to in this document aims broadly to support the implementation of these Recommendations at the country level through the generation of country-level data to begin building a knowledge base on the access and effects of social protection policies and programs on HIV affected workers in the formal and informal economy.

This document –a research guide - is divided into four main sections. The Introduction situates the research in its global context and describes the audience, purpose and uses of the document. Part One presents the rationale and context of the research. Part Two describes some of the key aspects of a research plan, including: planning the research, preparing the research protocol, designing and conducting the research and reporting on findings. Part Three includes core and illustrative research tools and sample data collection instruments. References can be found before the Appendices. The Appendices include the ILO HIV/AIDS Terms of References for this country-based research on social protection and HIV, the UNAIDS list of high impact countries, and a list of selected resources.

The preparation of this research protocol is the result of a process initiated recently by the ILO to encourage and support country-based research in the area of social protection and HIV in the world of work. The three major steps in this process are as follows:

1. Conduct a global literature review on existing social protection policies and schemes;
2. Develop a methodology for in-depth country study through in person and virtual expert consultation; and
3. Undertake research in selected countries.

Countries are proposed to be selected based on the following criteria:

1. Countries from each of four regions: Africa, Asia, Europe and the Americas.
2. Countries on the UNAIDS list of the HIV high-impact countries[1] from each of the four regions.
3. Countries that are developing or updating their social security system, whether they receive formal ILO technical cooperation or not.

WHAT DOES THIS RESEARCH PROTOCOL OFFER?

This **research protocol** is intended to provide a framework and overarching guidance to country-based researchers to carry out research related to social protection and HIV in response to the TOR prepared by the ILO HIV/AIDS Team (see Appendix 1). This document focuses on the core principles and core aspects of the research, including the research approach, core indicators and measures, and the sequence of research activities. In addition, the protocol details the data collection and data analysis procedures for each of the research components. It also discusses quality assurance and ethical considerations and provides illustrative tables and tools to support the successful implementation of the research. Instruments such as a sample informed consent form as well as data collection tools are included in Part Three. Guidance is also given on how to approach the engagement of national stakeholders and the PLHIV community.

However, this is not a normative how-to-do-research guide. It cannot be too prescriptive and cannot include a priori specific country characteristics of social protection programmes or epidemiological contexts, which, in many cases, will dictate what is possible or not for field work.

The main **audience** for this research protocol is experienced country-based researchers. However, the ILO plans to make available this methodology to other relevant stakeholders who may like to make use of this guide in their work, with necessary adaptations, to conduct

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[1] Note that this refers to “high impact” not to high prevalence countries. The list can be found in the Appendix.

research or to prepare research proposals. This protocol complements the range of relevant texts on research and evaluation that exist by providing a particular focus on social protection and HIV.

The **purpose** of the document is three-fold: one, it sets forward the scope of the research within the time and resource parameters described in the ILO Note/TOR (see Appendix 1); second, it identifies the principles that are fundamental to this research (gender equality and the engagement of the study population); third, it proposes data collection tools to gather standardized quality data on social protection and HIV in support of ILO's social protection and HIV and AIDS goals. This protocol **aims** at facilitating coherence and consistency among all the country studies, and by so doing, injecting robustness into the research effort.

This research is conceived as a retrospective study with a mixed-method design that integrates quantitative and qualitative data collection and triangulation as a powerful tool for deepening understanding of findings. However, the study also has a cross-sectional perspective; meaning, it seeks to explore, describe or explain the variables of interest at one particular moment in time.

The **time-frame** reflects ILO's commitment to move the research forward at good speed. Each of the country cases is expected to take up to **6 months** from planning to dissemination, including up to three-four months of field-based data gathering.

The **end result of this research** is an increased knowledge and understanding of the unique role that access to national social protection benefits can play in the lives of persons living with HIV and their households.

The primary **intended users** of this research are the ILO and its constituents but it can also be used by other development partners/ relevant stakeholders who can use the information to support national social protection initiatives and to advice national decision makers; networks of people living with and affected by HIV who can use the findings for advocacy and policy action; and donors, development agencies and implementing agencies who can use the information to adjust programming or to support follow-up actions based on the research findings.

While this protocol has been developed to help **standardize the research process** as well as the survey questions, it recognizes that all survey populations and site-specific realities that govern them are different. The application of the research protocol should be informed by the all-important knowledge and common sense that country-based researchers and stakeholders will bring to the research. This notwithstanding, researchers are expected to adopt the main principles, research questions and core indicators described in this protocol.

PART ONE:
RATIONALE AND CONTEXT

WHY IS SOCIAL PROTECTION AND HIV IMPORTANT?

Article 23 of the Universal Declaration of Human Rights underscores that all people have a right to earn a living and to social participation through work (UN, 1048). This right is recognized as a target of the Millennium Development Goal # 1(.B) (UN, 2011).[2] Yet, HIV remains a major obstacle to achieving this goal. Social protection contributes to preventing HIV and mitigating the impact of AIDS because it aims at preventing poverty and supports meeting peoples' basic livelihood, education and health needs. The ILO Recommendation No. 200 concerning HIV and AIDS in the world of work states that *measures to address HIV and AIDS in the world of work should be part of national development policies and programmes, including those related to labour, education,* ***social protection*** *and health* (ILO, 2010, p.4).

This Recommendation emphasizes the protection of workers in the formal and informal economies and in occupations that are particularly exposed to the risk of HIV transmission, such as sex work. It also stresses the importance of addressing the gender dimensions of the HIV epidemic, ensuring that gender equality and women's empowerment are key factors in the response to HIV and AIDS (ILO, 2010, p. 4-5). Furthermore, this Recommendation encourages social dialogue among public and private employers and workers, stakeholders and relevant civil society organizations, especially those representing persons living with HIV (ILO, 2010, p. 8-9).

Informal work is the norm in many countries. Workers in informal employment are a majority in low-income countries and most middle-income countries, and they are also sizeable in some high-income economies (see Figure 1). Informal employment in total non-agricultural employment ranges from 35 - 95% in Africa; 51 – 83% in Asia; 36 – 75% in the Americas; and 9 – 44% in East and Central Europe and Central Asia. The share of informal employment by women is of 77.1% in South Sahara Africa, 59.5% in Latin America and 35.4% in West Asia as compared to men in the same regions- 62.6%, 55.4% and 44.4% respectively (OECD, 2009).

Yet, the importance of formal employment must be addressed in the context of social protection provision and the barriers in access to health services posed by informality. Large informal sectors hamper collection of sufficient taxes, premiums and overall contributions for financing social health protection. Furthermore, individuals active in the informal economy

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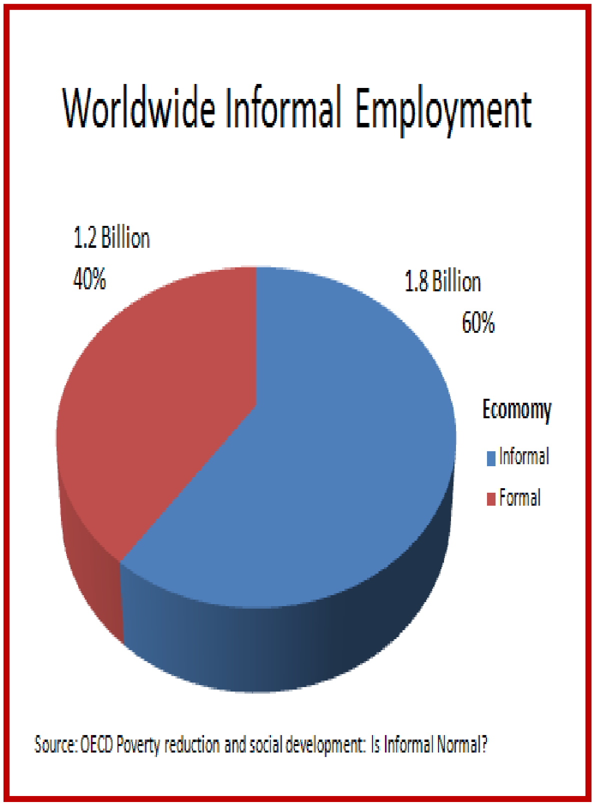
[2] Millennium Development Goal 1 aims to eradicate extreme poverty and hunger. Goal 1 includes three targets including target 1.B: 'Achieve full and productive employment and decent work for all, including women and young people'. United Nations, Millennium Development Goals Report, June 2011.

frequently are not affiliated to any health scheme or system, limiting their potential to make use of health services when in need.

Figure 1: Worldwide Formal and Informal Employment



Source: OECD Poverty reduction and social development: Is Informal Normal?

Extending social protection to workers in the informal economy has several challenges. Generally, informal workers earn less and their basic rights are more vulnerable and difficult to defend. Informality can be a major cause of poverty as most informal workers are insufficiently protected from illness or health problems, unsafe working conditions and possible loss of earnings due to sudden dismissal. This is particularly important for the poor, whose labour is their most significant asset. Persistently high levels of informal employment also reduce fiscal revenues and the state's ability to develop social security systems.

In the case of People Living with HIV (PLHIV) and their households, working in the informal economy becomes even more challenging due to stigma and discrimination and the sometimes episodic disabilities associated with HIV and AIDS. This situation is not much easier for those working in the formal economy. Often, for people living with HIV who are members of key population groups,[3] the stigma and discrimination due to HIV status is compounded by stigma and discrimination due to sexual orientation, profession, drug use and other social determinants. Likewise, many PLHIV face problems in accessing treatment, health care and private insurance schemes, social, religious and family support, and economic security. Even in countries providing free antiretroviral therapy to PLHIV, HIV-related stigma and discrimination – including self-discrimination- often prevent them from accessing or continuing with the treatment. In addition, PLHIV in informal work settings lose their daily wages for the days they

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[3] As defined in the UNAIDS 2011-2015 Strategy 'Getting to Zero', footnote n. 41: "Key populations, or key populations at higher risk, are groups of people who are more likely to be exposed to HIV or to transmit it and whose engagement is critical to a successful HIV response. In all countries, key populations include people living with HIV. In most settings, men who have sex with men, transgender people, people who inject drugs and sex workers and their clients are at higher risk of exposure to HIV than other groups. However, each country should define the specific populations that are relevant to their epidemic and response based on the epidemiological and social context".

visit the treatment centres and they often do not have social health protection to cover expenses for opportunistic infections associated with HIV and AIDS.

More recently, ILO member States adopted Recommendation No. 202 concerning **national floors of social protection** which reaffirms social security as a human right, and the principles of non-discrimination, gender equality, social inclusion, inclusion of persons in the informal economy, and respect for the rights and dignity of people covered by social security guarantees (ILO, 2012a). Recommendation No. 202 provides further guidance to member States to establish or update their national social security programmes to *prevent or alleviate poverty, vulnerability and social exclusion by providing access to at least essential goods and services, such as health care and basic income security for children, persons in active age and older people* (ILO, 2012a, p. 2-3). This Recommendation, together with Recommendation No. 200, is a critical tool for the implementation of social health protection.

While most social protection programs aim to combine preventive, promotional and active measures, social health protection is perhaps one of the most important forms of social security for PLHIV and the protection of workers in occupations that are particularly exposed to the risk of HIV transmission (ILO, 2010, p. 4). ILO recommends States to ensure that as many people as possible have effective access to health care; that is, effective access to affordable services of adequate quality and financial protection in case of sickness that is available.

Effective and equitable access to social protection is based on shared principles of social justice and is grounded in the Universal Declaration of Human Rights of 1948 (UDHR), the International Covenant on Economic, Social and Cultural Rights of 1966 (ICESCR), ILO Conventions on Social Security, the Convention on the Rights of the Child and other human rights instruments. This focus on effective and equitable access reflects the call of the UDHR for adequate life standards and access to health, education, food, housing and social security for all. Specifically, the ILO defines effective access to health care as *effective access to affordable services of adequate quality and financial protection in case of sickness*.

The right to social security in itself is recognized as a human right; for example, in article 22 and 25 of the UDHR and article 9 of ICESCR; and the ILO social protection floor concept enables the concrete realization of respective human rights in the workplace. Furthermore, social protection is recognized as a key public policy instrument to tackle the socio-economic impacts of HIV, as poverty mitigation and service access are enhanced.

Evidence also suggests that well targeted social transfers have direct relationship with reducing vulnerabilities related to sexual transmission of HIV and enables people to better withstand crisis (Miller and Samson, 2012). Cash transfers have become very common in general and are increasingly utilized in the AIDS response (ILO, 2013). However UNAIDS notes that many cash transfers are expanding but are often not embedded in the national social protection strategy or AIDS response thus challenging their long-term impact (UNAIDS, 2010).

Most countries have national social protection policies and strategies, but these are not always implemented efficiently or are reaching the people in need. Geographic, policy/legal and cultural barriers often maintain key populations outside the national social protection umbrella. Case in point: social health protection. It is available in most countries and encompasses all public and mandated private measures against the social distress and economic loss caused by the reduction of productivity, stoppage or reduction of earning or the cost of necessary treatment that can result from ill health. At the country level, however, much of social health protection favors facilities and the urban areas, creating significant imbalances of resource allocation (Scheil-Adlung and Kuhl, 2012).

In the case of eligible people living with HIV and their households, there are additional barriers linked to vulnerabilities that result in their facing additional problems in accessing social programs benefits, treatment, health care benefits and employment (UNAIDS, 2012). Moreover, those PLHIV in the informal economy can lose their daily wages for the days they seek services and they often do not have social health protection to cover expenses, as already mentioned. These barriers to accessing health care services, employment and social protection programmes are heightened for key populations living with HIV, and for women in an environment challenged by gender inequalities.

The adverse effects of denial of access to social health protection cannot be underestimated. Besides effects on health and poverty, the denial of access to health care affects economic growth due to the fact that health status, labour market and income generation are closely intertwined. Healthier workers have higher productivity, which positively affects labour supply and thus economic growth and development.

Despite major advances in the global HIV response, universal access to prevention, treatment, care, support and mitigation remains elusive. Discrimination (self and others) against PLHIV prevents many men, women and key populations from accessing social and health services. For instance, although the number of countries that reported having programs to reduce HIV-related stigma increased from 39% in 2006 to 92% in 2012, many of these programs lack adequate budgets, their activities were minimal and therefore had little impact (UNAIDS, 2012).

Evidence from the PLHIV Stigma Index (PSI)[4] found that in Rwanda, 53% of people living with HIV who participated in the study have been verbally abused and 33% of Zambian, 20% of Rwandan and 25% of Colombian study respondents have experienced physical violence (UNAIDS, 2012). Evidence from the PSI shows mixed results in terms of loss of employment due to HIV status as experienced by men and women. In some countries HIV status has triggered men's loss of employment (Nigeria) and in others (Mexico), women's loss of employment (PSI, 2012). (See Figure 2.)

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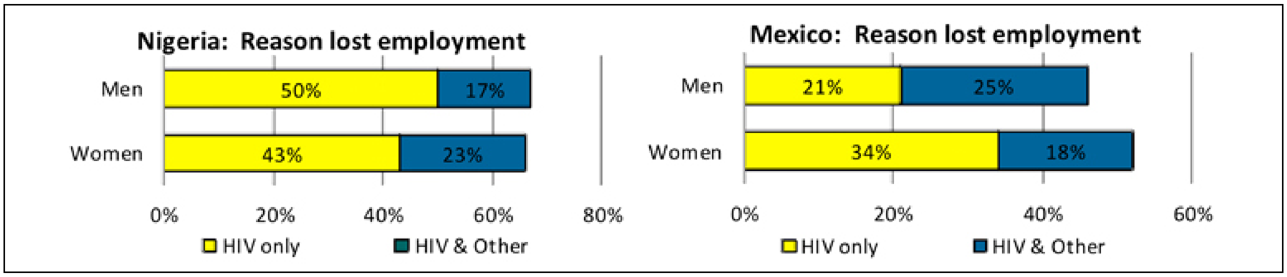
[4] The people living with HIV stigma index is a research tool that is used to capture data on HIV positive people's experiences and perceptions regarding stigma and discrimination. http://www.stigmanindex.org.

Figure 2: HIV Status and Lost Employment in Nigeria and Mexico by Sex, 2012.



Source: GNP+, ILO, The PLHIV Stigma Index. 2012. Evidence Brief: Stigma and Discrimination at Work. Findings from the PLHIV Stigma Index. Amsterdam, GNP+, p. 11.

However, data from the 2011 PLHIV Stigma Index in the Asia Pacific Region on loss of employment are staggering. In the nine countries of the study, stigma and discrimination were the key factor – or had played a part in – respondents' loss of employment or income (16–50%), being refused the opportunity to work (9–38%), and in being refused promotion or the nature of work changing (8–52%). Many respondents had also decided to stop work (3–38%) or decided not to apply for a job or promotion (10–31%) (UNAIDS-PSI, 2011b).

This report on the Asia Pacific Region also revealed that HIV had significantly affected people's ability to secure and retain employment, and their employment and career progression. Between 16% (Fiji) and 50% (Cambodia) of study respondents had lost their job or other form of income during the previous 12 months. Although many respondents attributed their loss of employment or income to poor health, according to the report, discrimination was the key factor or played a role in many other respondents' loss of income or employment. For instance in the Philippines 38 % of respondents identify HIV "discrimination" as the only cause of loss of employment, while 63% indicated a combination of discrimination and ill health (UNAIDS-PSI, 2011b).

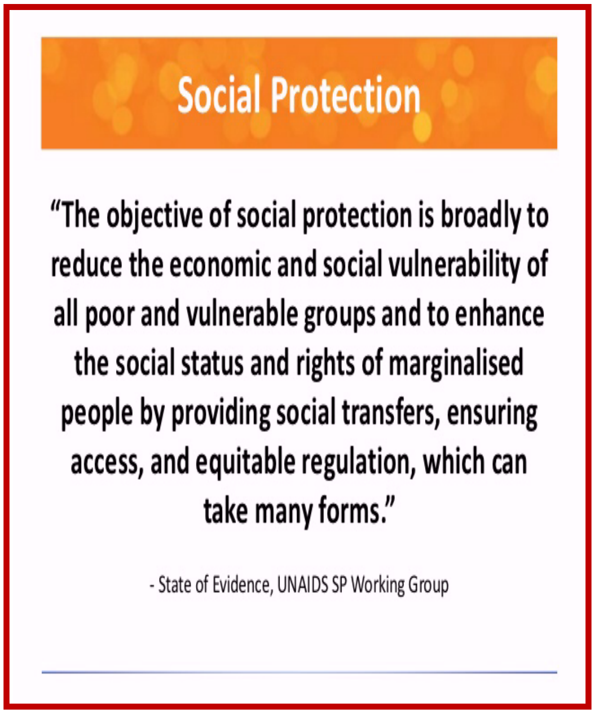
The higher the stigmatizing attitudes at the workplace and within the household, the less likely that an individual would seek the results of an HIV test and therefore less likely to be treated if needed (Rodriguez-García et al., 2013). Moreover, many people living with HIV manage their HIV infection in a context of insecure employment. Yet, understanding what is behind the numbers is critical to achieve change. Persons living with HIV and their families -often poor and sick- are particularly vulnerable, being typically more exposed to risk and less able to access opportunities, which in turn exacerbate the marginalization and vulnerability experienced by key populations at higher risk of HIV infection, including women and girls.

Social protection needs to be inclusive--a vehicle for persons living with and affected by HIV to access much needed services and benefits. Inclusive social protection (UNAIDS's HIV-sensitive rather than HIV-exclusive social protection) can be defined as the degree to which social protection instruments impact on HIV prevention, treatment and care outcomes. It lies within a broader range of concerns of inclusion such as gender, ethnicity, age, race, sexual identity, disability and any other form of social vulnerability. HIV-sensitive social protection programs are those which respond to both social exclusion and economic distress of people disproportionately impacted by the epidemic. These inclusive and HIV-sensitive programmes can help address the multiple social determinants of the epidemic – income inequalities, gender inequalities, social exclusion – and thus contribute to both a reduction in new infections as well as mitigation of the epidemic's impacts (Temin, 2010).

Inclusive and HIV-sensitive social protection has been integrated into UNAIDS Unified Budget and Resource Allocation Framework (UBRAF) and UNAIDS Strategic Investment Approaches. Within the strategic investment approach, social protection can be seen as both a critical enabler as well as a development synergy because of its cross-sectoral linkages and its potential to influence socio-economic determinants of HIV (Schwartlander et al., 2011).

Although the investment framework does not address explicitly the biological vulnerabilities to infection that women face, this is a determinant of HIV infection for women that should be implicit in the concept of comprehensive social protection. Recent studies have underscored the potential of social protection in reducing an individual's chance of becoming infected with HIV (susceptibility), reducing the likelihood that HIV will have a damaging effect on individuals, households and communities (vulnerability) (UNAIDS, 2010; Miller and Samson, 2012), enabling universal access goals (UNAIDS, 2011a), and battling stigma and discrimination, which threaten fundamental rights at work and undermine opportunities for people living with HIV to obtain decent work and sustainable employment (ILO, 2013).

Lastly, evidence so far reinforces the understanding that social protection instruments such as cash transfers are necessary but not sufficient to tackle the underlying structural inequalities that fuel the HIV epidemic and create barriers to service access. Although evidence of linkages between different social protection instruments and HIV outcomes is surfacing very few studies have looked at how countries comprehensively addressed issues related to inclusive social assistance –formal and informal- for men and women living with and affected by HIV, or the roles that social protection can play in reducing risk of HIV or mitigating its effects (Temin, 2010; Miller and Samson, 2012; ILO, 2013).



Social Protection

"The objective of social protection is broadly to reduce the economic and social vulnerability of all poor and vulnerable groups and to enhance the social status and rights of marginalised people by providing social transfers, ensuring access, and equitable regulation, which can take many forms."

- State of Evidence, UNAIDS SP Working Group

WHY IS RESEARCH ON SOCIAL PROTECTION AND HIV NEEDED?

Research on social protection and HIV looks explicitly at the HIV and AIDS dimension of social protection, social insurances and other livelihood support schemes, going beyond more conventional mapping studies to the analysis of the effects of social benefits access on persons living with HIV. Specifically, the ILO Programme on HIV/AIDS intends to generate knowledge from several countries on the **"access to and effects of social protection programmes on women and men workers in formal and informal economies living with HIV and their households."** Table 1 shows HIV and AIDS statistics for the first cluster of countries being considered by the ILO for this research.

The knowledge generated through this research will:

- Support good governance of social protection policies and programs.
- Provide evidence for policy advocacy to ensure that current and future policies protect the rights of men and women living with HIV to retain their jobs, access goods and services, and enjoy income security.
- Disseminate information that has the potential to leverage partners' resources and political commitment to HIV-sensitive and gender-sensitive social protection.
- Contribute critical information for addressing gender-based and HIV-based discrimination.

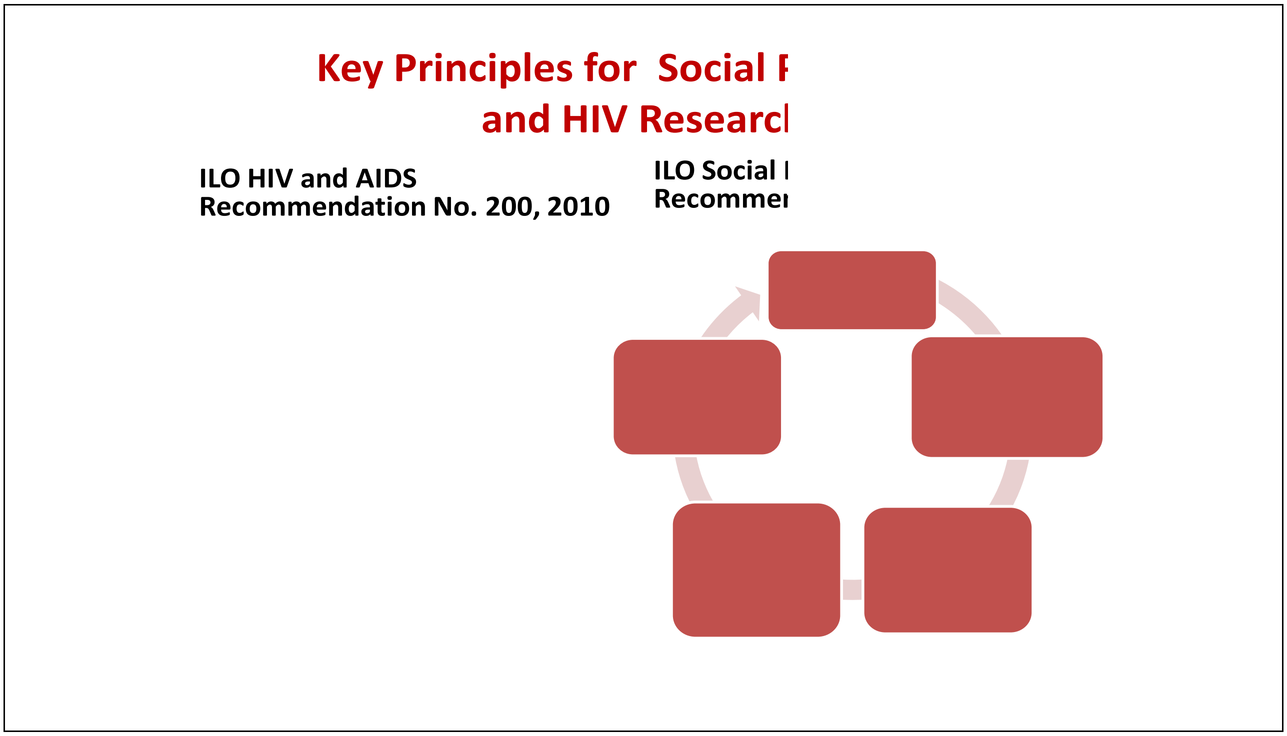
Table 1: HIV and AIDS Statistics in Five Countries, 2011

	Brazil	Guatemala	Indonesia	Rwanda	Ukraine
Adults aged 15-49 prevalence	0.30%	0.80%	0.30%	2.90%	0.80%
Adults aged 15 and above living with IV	470,000	62,000	380,000	210,000	230,000
Women aged 15 and above living with HIV	200,000	26,000	110,000	110,000	94,000
Proportion of women to men living with HIV	42%	41%	29%	52%	41%
Children aged 0 to 14 living with HIV	N/Av	N/Av	N/Av	27,000	N/Av
Deaths due to AIDS	15,000	2,500	15,000	6,400	22,000
Orphans due to AIDS aged 0-17	78,000	25,000	13,000	170,000	26,000
ART Coverage	71%	56%	24%	82%	22%
Estimated new infections	18,000	9,400	55,000	10,000	3,500
Population 2011*	196,655,014	14,757,316	242,325,638	10,942,950	45,706,100

Source: UNAIDS website, June 2013. * World Bank website, June 2013.

This research is guided by ILO principles put forward in Recommendations No. 200 and No. 202 as depicted below.

Figure 3: Key Principles for Social Protection and HIV Research



Key Principles for Social
and HIV Researc

ILO HIV and AIDS
Recommendation No. 200, 2010

ILO Social
Recomme

Source: Authors using several sources.

These principles shall apply to all actions involved in the research on social protection and HIV. Drawing inspiration from the principles of these two fundamental ILO Recommendations, this research will pay particular attention to the following two:

Principle 1: Meaningful involvement of people living with HIV

This study will meaningfully engage men and women and transgender people living with HIV and will follow the principles of the Greater Involvement of People Living with HIV (GIPA). As defined by UNAIDS, GIPA is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives (UNAIDS, 2007). By promoting and strengthening the involvement of PLHIV, the application of the GIPA principle enhances the quality and effectiveness of HIV responses, and shall equally improve the planning and implementation of this research. (See Part Two, section 1.) Below is an example of global PLHIV networks with substantial experience in country-based surveys involving PLHIV.

Table 2: Two Global Networks of People Living with HIV

GLOBAL NETWORKS OF PEOPLE LIVING WITH HIV	
The International Community of Women Living with HIV/AIDS (ICW)	**The Global Network of People Living with HIV/AIDS (GNP+)**
ICW is the only international network run for and by HIV-positive women, and its purpose is to promote the many voices of women living with HIV and advocate for changes that improve their lives. The work of ICW is framed by a human rights strategy that focuses on three areas: gender equity; access to care, treatment and support; and the right to meaningful involvement in all decisions that affect the lives of women living with HIV.	GNP+ is a global network run for and by people living with HIV. Its overall aim is to improve the quality of life of people living with HIV. GNP+ focuses on promoting global access to HIV care and treatment, ending stigma and discrimination against people living with HIV, and promoting the greater and more meaningful involvement of people living with HIV in the decisions that affect their lives and the lives of their communities.

Source: People Living with HIV Stigma Index User Guide. UK: International Planned Parenthood Federation. 2008, p. 5-6.

Principle 2: Paying attention to gender equality

No society can develop successfully without advancing equality between females and males, and empowering women and girls to participate fully in and benefit from the development of their societies. Accordingly, ILO Recommendation No. 200 (2010) provides guidance in this area. Ensuring gender equality and the empowerment of women, ensuring actions to prevent and prohibit violence and harassment in the workplace, promoting the protection of sexual and reproductive health, and sexual and reproductive rights of women and men are among key actions that can be taken in or through the workplace to reduce the transmission of HIV and its impact. Reducing the impact of HIV also involves ensuring an adequate level of social protection –especially social heath protection- identifying the gaps and barriers to protection, and considering effective and efficient combination of benefits and schemes in the national context to benefit all regardless of sex or gender (ILO, 2012).

Country-based researchers can apply this principle of gender equality in different ways, by:

- Promoting partnerships among stakeholders engaged in social protection and social assistance programmes to ensure that the benefits of social protection have a positive impact on key populations and men and women living with HIV and their households.
- Engaging World of Work actors (Ministry of Labour, employers and labour unions) to ensure that the findings of the research are taken forward.
- Identifying good practices to be collected and shared with other countries.

- Disaggregating data between men and women, boys and girls as well as by gender if data allow. This is one way in which research findings can contribute to our understanding of gender equality in HIV and AIDS and the world of work.

WHAT KEY CONCEPTS SHAPE THIS RESEARCH?

This section defines six key concepts: social protection, employment in the formal and informal economy, sex and gender in social protection, key populations, households, and care giving and caregivers.

Social protection

Social protection is defined by the ILO as sets of basic social security guarantees which secure protection aimed at preventing or alleviating poverty, vulnerability and social exclusion. In other words, it is programs and instruments that individually or collectively aim to be *protective* (providing relief) of the population, *preventive* (averting deprivation), *promotive* (enhancing incomes and capabilities) and/or *socially transformative* (addressing social equity and exclusion, which often underpin chronic poverty and vulnerability) (Devereux and Sabates-Wheeler, 2004). Vulnerability in the world of work means the "unequal opportunities, social exclusion, unemployment or precarious employment, resulting from the social, cultural, political and economic factors that make a person more susceptible to HIV infection and to developing AIDS (ILO, 2010, p.3).

Social protection is commonly understood as comprising of four major pillars[5]:

- **social assistance** (such as cash transfers, pensions, child grants, food aid, public works, assets transfers and subsidies);
- **social insurance** (such as old-age, survivorship, health insurance, disaster insurance, disability pensions, and unemployment insurance);
- **social services** (such as social welfare services- e.g. orphans and vulnerable children, home based care and support for households with chronic illness, shelters for women, rehabilitation services); and
- **policies, legislation and regulation** (such as equal rights and social justice legislation, minimum labour standards and affirmative action policies).

These pillars are reflected in UNAIDS's HIV-sensitive social protection approach which includes: (i) financial protection through predictable transfers of cash, food or others, (ii) access to affordable quality services, and (iii) policies, legislation and regulation that uphold the rights of the most vulnerable and excluded. Inclusive and HIV-sensitive social protection can help address the multiple social determinants of the epidemic – income inequalities, gender

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[5] Note: Researchers can use these categories to map the social protection programs at the country level. See Part Three, section 1 for details on ILO's social protection categories.

inequalities, social exclusion – and thus contribute to both a reduction in new infections as well as mitigation of the epidemic’s impacts (Temin, 2010; Miller and Samson, 2012).

Employment in the formal and informal economies

The formal economy includes all those types of employment that offer regular wages and hours, which carry with them employment rights and the responsibility to pay taxes. The informal economy encompasses all jobs that are not recognized as normal income sources, and on which taxes are not paid. It is broadly characterized as consisting of units engaged in the production of goods or services with the primary objective of generating employment and income to the persons concerned. This type of economic activity is often neither taxed nor monitored by a government.

According to the ILO-definition of informal employment, the following persons are informal workers:

- Own account workers and employers employed in their own informal sector enterprises.
- Contributing family workers, irrespective whether they work in formal or informal sector enterprises.
- Employees holding informal jobs, whether employed by formal sector enterprises, informal sector enterprises, or as paid domestic workers by households.
- Members of informal producers’ cooperatives’ account workers engages in the production of goods exclusively for own final use by their household (ICLS, 1993).

For this research, the indicators of employment in the informal economy are based on ILO’s typology and thus would include: (i) workers who are not employed by formal institutions, (ii) workers who are employed by formal institutions, but on contracts and frequently have no access to social or occupational insurance schemes, (iii) seasonal workers, (iv) workers with their own business, and (v) workers in the service sector. Workers refer to any persons working under any form of arrangement; while workplace refers to any place in which workers perform their activity (ILO, 2010, p.3). (See ILO’s categorization of Social Protection Programs in Part Three 1.)

Sex and gender in social protection

As previously mentioned, ILO Recommendation No. 202 concerning National Floors of Social Protection is based on the principle of gender equality. Men and women experience poverty and vulnerability in different ways. Women experience biological vulnerabilities throughout the course of their lives, and as Table 1 shows the proportion of women with HIV is high and, in many countries, there are more women than men affected by HIV. Yet, women are more deprived in access to social protection than men, including to social heath protection. The root causes for women vulnerability are diverse and are related to the socioeconomic status of women, the role of women in society, and inadequate social health protection coverage, resulting in barriers of accessibility to health care (Scheil-Adlung and Kuhl, 2012).

Location is also relevant to women's ability to access health and other services. The main financing mechanisms for health are based on taxes, payroll taxes or premiums. However, in almost all countries, there are out-of-pocket (OOP) payments (i.e., co-payments, user fees, other expenditures related to transport or that occur at the point of health service delivery), which many women and vulnerable populations cannot afford. This situation is even worse for women in the rural areas, who face important barriers to health services utilization frequently linked to eligibility criteria, lack of formal employment, deficits in financial protection, and loss of income due to sickness and maternity (Scheil-Adlung and Kuhl, 2012, p. 25).

Not only women in rural areas face additional barriers but such barriers are also encountered by women as well as vulnerable and marginalized populations living in poor neighborhoods and slums within cities, especially large and growing (mega) cities in low income countries.

Gender encompasses more than men and women, and in this research gender is defined broadly and it includes transgender individuals. When analyzing the formal and informal economy the statistics will be disaggregated by sex. Furthermore, when analyzing the quantitative and qualitative data collected through this research every attempt will be made to break down the data by gender and key-population categories as self-identified by the respondents. This would include the following categories:

1. Men who have sex with men
2. Gay or lesbian
3. Transgender
4. Sex worker
5. Injecting drug user
6. Refugee or asylum seeker
7. Internally displaced person
8. Member of an indigenous group
9. Migrant worker
10. Prisoner

Key populations

As defined by UNAIDS, key populations at higher HIV risk are groups of people who are more likely to be exposed to HIV or to transmit it and whose engagement is critical to a successful HIV response. In all countries, key populations include people living with HIV. In most settings, *men who have sex with men, transgender people, people who inject drugs and sex workers and their clients* are at higher risk of exposure to HIV than other groups. However, each country should define the specific populations that are relevant to their epidemics and response based on the epidemiological and social context (UNAIDS, 2011a).

Households

A typical household consists of a person or group of persons, related or unrelated, who live together in the same dwelling unit, who share the same living arrangements, and are considered as one unit. Households of PLHIV includes orphans whose parents died of AIDS, whether they are still living in the household or have been displaced because of the loss of the parents. Orphans are directly affected by HIV related deaths. Country-level research would be guided and adopt the country's definition of household as nationally-defined by the statistics bureau.

Care giving and caregivers

In many countries the proportion of women to men living with HIV is significant, from 29% in Indonesia to close to half in countries like Brazil (42%), Guatemala and Ukraine (41%) and Rwanda (52%) (see Table 1). Yet, women, irrespective of HIV status, are often the first (and sometimes only) providers of social support at the household, extended family and community levels, especially in terms of caring for chronically ill immediate family, relatives and AIDS-related orphans. Care giving at the household level is often uncompensated and undervalued. This situation underscores the need for better understanding of the benefits of women and girls' empowerment to improve household wellbeing and livelihood and contribute to economic growth (Holmes and Jones, 2010).

Caregivers in the HIV context are often referred to as lay or community caregivers. In terms of social protection, it is important to further define this group into primary and secondary caregivers. Primary caregivers are both adults and children who care for other family members in their homes. The majority of primary caregivers are women, often older women, but also young girls. Because this work takes place within the extended family, it is outside both the formal and informal economies, and therefore invisible. Secondary caregivers are community caregivers or other health workers who work as individuals or staff (paid or volunteer) of clinics, non-governmental organisations (NGOs) and faith based organisations (FBOs). Some secondary caregivers also self-organise into community-based organisations (CBOs) and networks. More often than not, secondary caregivers are not remunerated and often not compensated either (UK Consortium, 2012).

PART TWO:

PLANNING AND MANAGING THE RESEARCH

This section highlights the key steps involved in research planning and implementation specifically for this social protection and HIV research. Below is the research flowchart. It presents the **core components** and key principles of the research in a logical way. Researchers might order or cluster the key steps of the research in different ways. Particularly, they would want to add more detail and additional intermediate steps based on the country context. There are numerous research and evaluation guidelines in the research literature and by development agencies, think tanks and NGOs which researchers might like to consult. A list of a few recent works that might be particularly helpful is included in Appendix 3.

Section 1: Preparing the research

Engage stakeholders
Involve PLHIV networks
Select a multidisciplinary strong research team having expertise in research, gender, HIV, social protection and informal economy

Section 2: Preparing the research protocol

Address confidentiality
Prepare informed consent forms
Obtain research ethics committee clearances

Section 3: Designing the research

Clarify the research questions
Construe the research framework
Select the research design
Select the research methods and measures
Define the research population
Select data collection methods

Section 4: Collecting and analyzing data

Develop/adapt, translate and pilot test data collection forms
Pilot test the consent forms
Revise and finalize data collection tools
Document process of data collection, data management and data analysis

Section 5: Validating and reporting findings

Prepare preliminary report
Validate research findings with stakeholders
Finalize research report

SECTION 1: PREPARING THE RESEARCH

Strong pre-research preparations, administrative and stakeholders support are essential factors in carrying out a sound study. It also helps ensure that quality data will be collected in a manner that is beneficial to participating populations and stakeholders, who are the ultimate end-users of the information. This section discusses, albeit succinctly, the core activities in planning the research. One of the first planning activities researchers would want to engage in is the preparation of a time table. (An illustrative Research Management Plan and Time-Table is included in Part Three, 2.)

1.1 Engaging Stakeholders[6]

The research process begins by engaging stakeholders. Research is often a partnership between decision makers, researchers and stakeholders, with each group dependent on the other for its success. It is a balance between the technical expertise and independence brought to it by researchers, and the context and policy relevance brought by the stakeholders.

A fundamental principle of this research is to involve stakeholders who are in a position to inform the design, planning and implementation of the research, and/or can enhance the use and application of research findings; most particularly, people living with HIV. Stakeholders also include national decision makers, community leaders, implementing agencies, the ILO and other development partners. As appropriate, stakeholders should be involved in the research in the early stages of the research planning process and play an important role in the validation of findings.

Identifying and engaging the following three principal groups of stakeholders is critical:[7]

- ✓ those involved in program operations (e.g., sponsors, collaborators, coalition partners, funding officials, administrators, managers, and staff);
- ✓ those served or affected by the program (e.g., PLHIV, key affected populations, clients, family members, neighborhood organizations, academic institutions, elected officials, advocacy groups, professional associations, skeptics, opponents, and staff of related or competing organizations); and
- ✓ primary users of the evaluation.

Researchers will aim at the early identification of who the different stakeholder groups are, and how and when they should be included in the research process. Researchers will also need to

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[6] This section is informed by *How to design and manage equity-focused evaluations by M. Bamberger and M. Segone.* New York: UNICEF, 2011; and *Framework for Program Evaluation in Public Health*. Atlanta: CDC, 1999/48(RR11);1-40.

[7] CDC, 1999, p. 13.

weigh-up the level of stakeholders' participation against the benefits and constrains. However, stakeholder participation should be sought and ensured. Experience shows that stakeholders' participation contributes to accountability, builds credibility and enhances the use of research findings. Stakeholders are not, and should not be treated as uniform. There will be variations among the stakeholders and thus awareness of this diversity will be a critical factor in any process that is sensitive to HIV populations. Stakeholders should be involved as much as possible and as appropriate as possible within the local social cultural context.[8]

Selected questions to be considered when deciding the appropriate degree of participation by stakeholders:

1. How can stakeholders, including PLHIV, be involved in the research process with varying degree of intensity? What will be the implications in terms of effort, timeline and budget?

2. Should all stakeholders be involved together or separately? If involved together, what will be the process for ensuring all perspectives are fairly heard, avoiding bias because some may be more reticent that others to express their opinions, for a variety of reasons (literacy levels, power differences, confidence levels, confidentialities, etc.), build agreement or make decisions?

A study such as this is more than an agency with an idea and a team of researchers. This study can provide much needed information for the local community on social protection, HIV vulnerabilities and health services. But if not carefully planned it can also be disruptive for both the people who are asked to participate in the research and their communities.

Researchers will reach out to community leaders and community-based organizations to generate ideas especially around survey implementation. Meeting with community representatives is recommended to make sure the objectives of the research and the survey are clearly understood and to ensure that communities are committed to participating.

1.2 Involving PLHIV Networks

The Greater Involvement of People Living with HIV and AIDS (GIPA) is a principle that aims to realise the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. In these efforts, GIPA also aims to enhance the quality and effectiveness of the AIDS response. UNAIDS asserts that the engagement of people living with HIV is all the more urgent as countries scale up their national AIDS responses to achieve the goal of universal access to prevention, treatment, care and support services (UNAIDS, 2007).

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[8] Bamberger and Segone, 2011, p. 26.

Depending upon the country situation and consultation with stakeholders, the engagement of PLHIV may take different forms. The following are examples of different ways in which country-based research can engage with PLHIV:

- Consultation with the most representative networks of PLHIV in the country at the research planning stage to identify how this study can best serve PLHIV and how the networks can best support the research.
- Getting an endorsement of the key questions and the methodology to be applied in the study.
- Getting suggestions from PLHIV networks as to the possible ways to reach the study population.
- Pre-testing the draft tools.
- Engaging relevant PLHIV networks in training of investigators to ensure that investigators are oriented to the sensitivities involved in this research and that the necessary ethical procedures are followed.
- Engaging experienced PLHIV networks in data collection and validation wherever possible depending upon the existing capacities.
- Partnering with PLHIV networks to organize focus groups discussions with key populations and/or participate in other parts of the study.
- Sharing results and identifying issues for advocacy - so that research findings feed into the advocacy agenda of the PLHIV networks.

1.3 Selecting a Strong Multidisciplinary Research Team

The composition of the research team is important in any research. In this study of social protection and HIV a strong research team will possess the cultural sensitivity needed to work effectively with stakeholders, including men and women living with HIV. Although each research is different, the research team should have members having expertise in multidisciplinary areas of research (qualitative and quantitative), gender, HIV, social protection and informal economy.

Team members should come from diverse backgrounds and it is important to invest time and resources in team building around issues such as respect from different viewpoints and diverging opinions. They could be PLHIV.

SECTION 2: PREPARING THE RESEARCH PROTOCOL

This entire publication provides a template for the preparation of the research protocol, research plan and/or technical research proposal. This section focuses on two core activities that need to be completed early on to ensure that the research can take place. These are: obtaining ethical clearances and approval of the informed consent statement or form. Confidentially is important throughout the research process, although some researchers use a confidentiality agreement form that data gatherers are asked to sign. The mandatory informed consent form is for the survey and it needs to be included as part of the protocol that is submitted for ethical clearance. The consent form will be pre-tested later. It can be done at the time when the survey questionnaire is tested. Once the ethical clearance is obtained, the proof becomes part of the research documentation.

2.1 Ethical Clearances

In many countries, international institutions and academic centers review boards or ethics committees have been set up to regulate research involving human subjects. These boards are charged with assessing, approving and monitoring research studies, with the primary goal of protecting the rights and promoting the welfare of all subjects. Although social research does not involve clinical interventions, it does involve human subjects and should adhere to research guidelines for human subjects. Countries and institutions vary as to the requirements, but most countries do require a research protocol to be reviewed by national ethical review boards before the research can begin. Researchers should allow time for this process to go through as ethical review board requirements and processes might be complex and time consuming.

The basic principles pertaining to the protection of human subject include ensuring that:[9]

- Selection of subjects is equitable.
- Risks to subjects are minimized.
- Risks to subjects are reasonable in relation to anticipated benefits.
- Informed consent is sought from each prospective subject or his/her legal representative.
- Adequate provisions are in place to protect the privacy of subjects and maintain confidentiality.
- Additional safeguards are included to protect more vulnerable subjects such as children, prisoners, and the disadvantaged.
- Relevant information relating to the research, such as available resources in the communities for obtaining additional information or counseling relating to HIV or provision of a list of social protection programme service centres, should be provided to those who have consented to participate in this research, upon completion of their interviews or focus group discussions. This way, there is some minimal information and benefit to those who participate.

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[9] Gertler et al., 2011, p. 154.

2.2 Confidentiality[10]

Confidentiality is concerned with the issue of who has the right to access data provided by the participants of a research study. When conducting research, one should always ensure that appropriate measures are put in place so as to make absolutely certain that the information participants have disclosed and their identity are kept in confidence.

Data gathering and analysis will be done in a way that will protect the confidentiality of respondents and responses. During training, interviewers and data collectors will be instructed to:

- Conduct interviews in private with no other adults present, unless specifically requested by the respondent.
- Ensure the respondent is fully informed about the goals of the research and signs willingly the informed consent form prior to administering the questionnaire. However, in view of the need for confidentiality, when seeking informed consent by PLHIV, alternatively, one could ensure the respondent gives willingly his/her consent that is then recorded on the form by the interviewer, without the person having to sign his or her name. Or, the person could write on the form that "I agree to be interviewed".
- Explain to the interviewee that they are free to refuse to be interviewed, to withdraw from the interview at any time, or to refuse to fill in a particular question or set of questions.
- Keep all answers strictly confidential.
- Allow respondents to ask questions of their own and clarify any issues they may have.

Researchers will make every effort to ensure that:

- Confidentiality is maintained during the implementation of fieldwork.
- Tables and reports show only data in the aggregate so that it will not be possible to identify localities or individuals who were interviewed.
- Responses are reported only down to the study variables level, which will not allow the identification of sites, households, or individuals.

2.3 Informed Consent

Informed consent in ethics refers to the idea that a person must be fully informed about and understand the potential benefits and risks of his/her choice of treatment. In cases of social

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[10] Partially adapted from The People Living with HIV Stigma Index User Guide. 2008. UK: The International Planned Parenthood Federation.

research with no treatment, informed consent refers to the need for a person to be fully informed about and understand the potential benefits and risks of his/her participation in a given study.

Four principles form a commonly held set of ethical behavior that underscore the ethical approach in social studies that involve human subjects.[11] Table 3 describes each of the four principles.

Table 3: Principles of Ethical Behavior

Principles	Description
Respect for a person's 'autonomy	Acknowledge a person's right to make choices, to hold views, and to take actions based on personal values and beliefs.
Justice	Treat others equitably, distribute benefits or burdens fairly.
Non-maleficence (do no harm)	Obligation not to inflict harm intentionally. In medical ethics, the physician's guiding maxim is "First, do no harm."
Beneficence (do good)	Provide benefits to persons and contribute to their welfare. Refers to an action done for the benefit of others.

Source: Authors based on reference. See footnote #11.

Informed consent forms such as those used by the research team in other similar studies may be adapted for use in this study, provided it meets the basic information requirements as shown below. Researches can also consult the literature for other examples; for instance, the consent form used by the PLHIV Stigma Index. A sample Consent Form for this research is included in Part Three, 3 of this document.

The informed consent statement will be read to each respondent prior to beginning the interview. If the respondent agrees to be interviewed, the interviewer will sign a statement that "he/she has read the informed consent statement to the respondent and that the respondent has agreed to participate in the survey." In addition, respondents will be given an opportunity to ask any questions about the survey that will help them decide whether or not they want to participate.

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[11] http://nwabr.org/sites/default/files/Principles.pdf. [May 2013].

The informed consent statement or form contains all of the information the respondent would need in order to make an informed decision about whether or not to participate in the study. This information usually includes the following language:

- The survey provides some indirect benefits to respondents.
- There are no direct benefits to individual study respondents; however, respondents may gain a better understanding of their own, their households, or their organizations circumstances as a result of responding to interview questions.
- The risk to respondents from participating in this study is minimal.
- The findings of this study have great potential for gaining a better understanding of the access to social protection programs by people living with HIV and their households.

The information needed in an informed consent form or statement is typically the following:[12]

❶ **Inform Consent Part I**:
Information Sheet: Introduction - Purpose of the research - Type of Research Intervention - Participant Selection - Voluntary participation

Procedures: (a) a brief introduction to the format of the research study and (b) explanation of the type of questions that the participant is likely to be asked in the focus group, the interviews, or the survey

Duration - Confidentiality - Risks – Benefits – Sharing the results

Right to Refuse or Withdraw

Who to Contact

❷ **Inform Consent Part II:**
Certificate of Consent where the subject signs or indicates his/her consent, or alternatively, where the interviewer indicates the verbal consent of the respondent.

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[12] http://www.who.int/rpc/research_ethics/informed_consent/en/ [May 2013].

SECTION 3: DESIGNING THE RESEARCH

This section highlights the importance of selecting appropriate methods to ensure that the variables of interest are measured and analyzed during the research. It is important at this stage to make sure that the objectives and scope of the research are clear, paying attention to keeping both the scope and the purpose focused.

This research would be limited in scope as a function of given parameters-- timeframe (six months) and resources. Furthermore, in order to capture as many of the study population as possible the study may need to focus on sites with high epidemiological HIV concentrations based on institutional location or geography.

This study will:

1. Focus on the inclusion of people living with HIV, and their households,[13] in social protection programmes.
2. Include men, women and transgender people as well as key populations living with HIV working in the formal and informal economy.
3. Examine the degree of awareness and utilization of social protection programs by people living with HIV.
4. Identify the factors that influence access and utilization of services, and coverage, if possible.
5. Assess the nature and extent of any effect of social protection programs or interventions on people living with HIV and their households related to HIV, particularly adherence to treatment.

3.1. Research Questions, Indicators and Effects Measures

The overarching objective of this research is to examine the tenet that a national response to HIV and AIDS necessitates the implementation of social protection programs that are HIV-sensitive, gender-sensitive and inclusive of people living with HIV. Social protection programmes and schemes at the country level would vary. They may include:

- Public sector-government national social protection programs for people in the formal and informal economies, including PLHIV.
- Private sector insurances schemes for people in the formal and informal economy, including PLHIV.

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[13] Note: Households of PLHIV includes orphans whose parents died of AIDS, whether they are still living in the household or have been displaced because of the loss of the parents. Orphans are directly affected by HIV related deaths.

- Non-government sector social assistance schemes for people in the informal economy, vulnerable men, women and key populations, including PLHIV.

The results of the research will help respond to the following guiding questions from the ILO Note/Terms of Reference (see Appendix 1):

1. Does social protection in the country cover men and women workers affected by HIV and AIDS, and their households? If so, under which contingencies of social protection, for example: social health protection, livelihood/income support, cash transfers, etc.? What is the coverage, key gaps and challenges in enhancing social protection coverage to them?

2. How does the social protection coverage contribute to reducing the impact of HIV and AIDS on vulnerable or HIV-affected households? To what extend does the employment status, whether formal or informal, (e.g. self-employed, casual employee or day-labourer, etc.) influence the access to both public, private; national or community based social protection coverage?

3. How does social protection contribute to prevent new HIV infections and reduce the vulnerability of the target population?

These guiding questions are operationalized into the six clusters of more specific research questions shown below. Furthermore, a **Core Research Elements and Menu of Indicators** matrix is included in Part Three, section 4. This is an important Table that captures and summarizes four core elements of this research: (1) research questions, (2) indicators and measures, (3) data collection method and sources, and (4) basic analysis of findings. It shows a total of 20 core indicators and 7 effects measures. In addition, it identifies 18 optional indicators. Country-based researchers can choose from these optional indicators or add new ones as relevant in their country context.

Six clusters with 20 specific research questions. ***Effects*** **questions are shown in *italics*.**

Q1. Availability: Type of Social Protection Policies, Programs and schemes (SPP) in the country
1.1. What are the main types of social protection programs (SPP), schemes and benefits in the country?
1.2. Are there stand alone SPP that explicitly target a disease whether HIV or any other acute or chronic condition?
1.3. Are there stand alone SPP that explicitly target specific population groups?
Q2. Access: Type of Social Protection Programs in the country for PLHIV
2.1. Do social protection programs cover workers living with HIV?
2.2. Do social protection programs explicitly include benefits for PLHIV?
2.3. Do social protection programs explicitly exclude benefits for PLHIV?

2.4. Do social protection programs exclude any population group?[14]

Q3. Social Protection Programs benefits and PLHIV employment status

Access

3.1. Does HIV status exclude workers from accessing national SPP benefits?

(i) when employed in the formal or informal economy?
(ii) when unemployed and looking for a job?
(iii) when not-working and not looking for a job?

3.2. Does HIV status exclude workers from accessing SPP benefits from private or community based social protection schemes?

Effects

3.3. Does receiving social protection enable PLHIV to improve their ability to:

(i) work (e.g., retain their jobs or return to their productive activities) or

(ii) not work (remain not-working), and

(iii) social health protection coverage including access to health care benefits and medical care?

Q4. Barriers to social protection benefits for PLHIV

4.1. What are the barriers for PLHIV to access social protection benefits?

4.2. What are the challenges in providing/delivering social protection benefits to the PLHIV population?

4.3. Is access to and delivery of social protection benefits equitable along gender and key population groups?

Q5. Social protection programs and household vulnerabilities

Access

5.1. Does access to social protection benefits contribute to reducing the vulnerabilities of PLHIV and their households?

Effects

5.2. Are PLHIV and their households who are receiving social protection benefits better off than those not receiving benefits?

(i) children remain at school?
(ii) members of the household retain their jobs or productive activities?
(iii) care giving does not increase?

5.3. Since receiving social protection benefits has there been any increase in the number of people living in the household?

Q6. *Effects* of social protection benefits on PLHIV HIV-related health status

6.1. Do social protection benefits improve PLHIV's ability to utilize health and social services for HIV-related screening, treatment and care?

6.2. Do social protection benefits contribute to PLHIV's ability to utilize health services equally by gender or membership to a particular population group?

6.3. Do social protection benefits affect ARV therapy adherence?

6.4. Do social protection benefits affect HIV-Tuberculosis co-infection treatment adherence?

6.5. Do social protection benefits affect STIs or opportunistic infections treatment adherence?

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[14] Population groups may include sex workers (female and males), men who have sex with men, transgender individuals, intravenous drug users, inter-gender (neither men nor women), gays, bisexual, men and women in prison or migrants.

3.2. Conceptual Framework

This research entails examining social protection policies and programs and their effects related to PLHIV. Commonly, public policies are understood as the formal, written documents, rules and guidelines that present policy makers' decisions about what actions are deemed legitimate and necessary to strengthen the social protection system in a country, and the political, management, financial, and administrative mechanisms that are arranged to achieve explicit goals (Geurts, 2011; Gilson, 2012). These are decisions made by the State to reduce poverty and vulnerability not only among individuals, households and communities facing absolute deprivation but also among the currently non-poor in the event of risks/shocks due to unemployment, illness, permanent disability, ageing and so on. These written policies are then translated by policy actors (i.e., middle managers, social workers, health workers, citizens) into their daily practices and by so doing these intermediaries become pivotal players in the implementation of public policies. In dispensing services, these players -teachers, police officers, social workers, health workers- exercise a large amount of influence over how public policy is actually carried out (Lipsky, 1980). Ultimately these daily practices become policy as it is experienced, which may differ from the intentions of the formal documents (Gilson, 2012).

This theoretical construct -policy as written and policy as experienced- is relevant to this research as the phenomena being investigated –access and effects of social protection policies and programmes on PLHIV- are produced through interaction among social actors; that is, the phenomena of interest does not exist independently of these actors. The central task of research grounded in this tradition (relativism) is not to explain cause and effects, but rather to understand providers and beneficiaries' intentions, behaviors, experiences and the meanings they give to social phenomena. In the case of PLHIV, this may encompass their experience in accessing social protection, their capacity to keep their jobs, or their ability to access medical/health services.

This conceptual approach views social protection policies not only as the formal statements of intent but also as the informal unwritten practices that follow (Buse, Mays and Walt, 2005). It facilitates the study of phenomena such as stigma and discrimination, which affect the interaction among social actors (e.g., in accessing and delivering social protection benefits), in order to assist in the process of understating and promoting change. It also facilitates the analysis of implementation gaps; that is, the difference between what the policy architects intended and stated and the end result of the policy, affected by the intermediary actors.

3.2.1 Program Theory of Change

There are a number of frameworks and designs that exist, which researchers can choose to guide this research. The nature and context of the research as well as its scope and purpose should be taken into consideration when making the final decision. Social protection policies achieve its objectives through the promotion of behavioural changes involving a complex set of interventions and multiple actors that cannot be examined through conventional pre-post test comparisons.

The program theory of change captures complex initiatives to explain how the desired change is expected to come about. It is a description of how a program is supposed to deliver the desired results. The program theory is also a valuable tool in the interpretation of the research findings and provides a framework for identifying unanticipated outcomes (positive and negative; intended and unintended). Ideally, the programme theory of change will be developed at the policy design stage. However, this is seldom the case and the researchers would need to construct or reconstruct the implicit theory on which the policies are based. This is best done at the county level in consultation with stakeholders (Bamberger and Segone, 2011).

The process of policy implementation, the implementing actors and the context within which implementation takes place have a significant impact on the accessibility of social protection programs and benefits by key population groups and PLHIV. For these reasons, it is important to base the research on a theory of change that can depict the main pathway to results. Given the complex reality within which social protection policies and programs operate, a program theory of change in the context of this research provides only broad parameters for understanding the expected results. One key reason is that "complex interventions present the greatest challenge for research and for the utilization of findings because the path to success is so variable and it cannot be articulated in advance" (Rogers, 2008, p. 31).

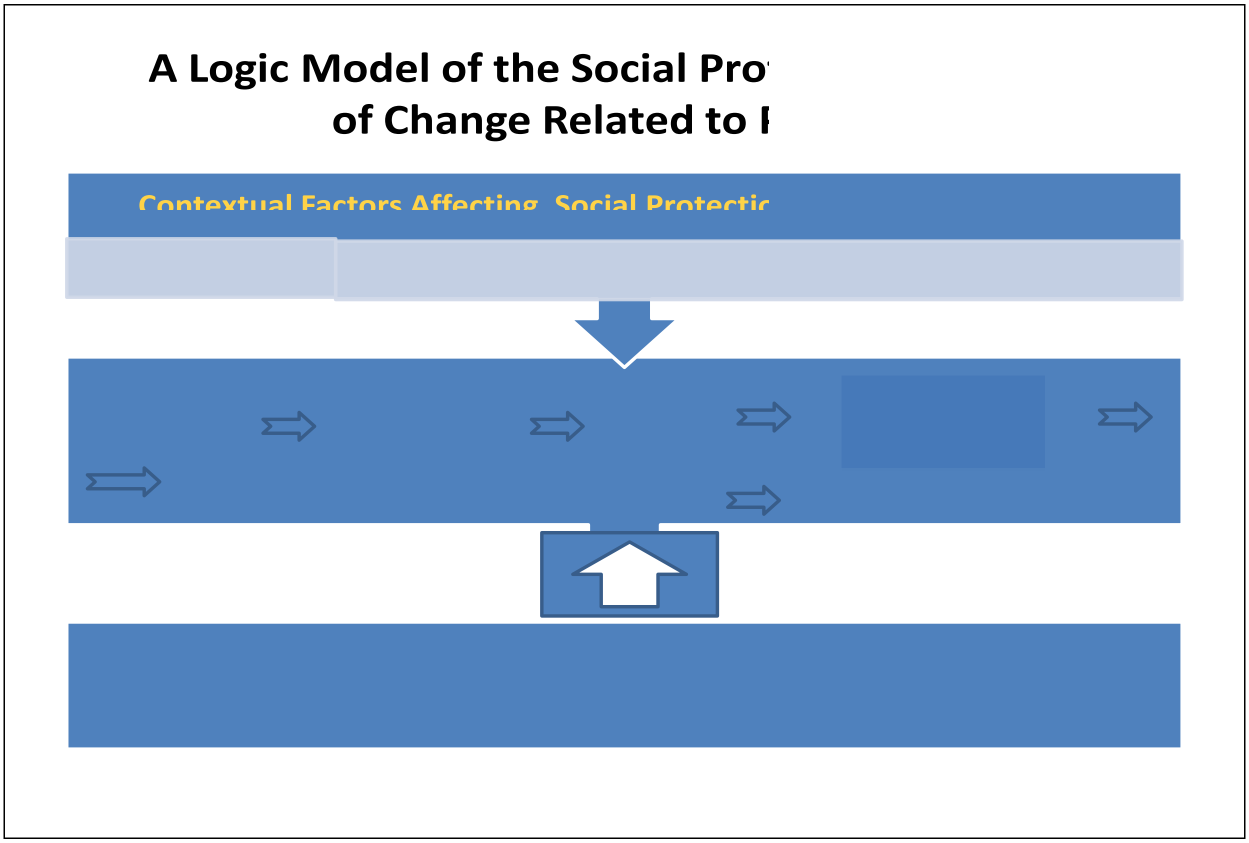
Program theories of change are often represented graphically through a logic model. The results logic model is widely used because researchers and evaluators find that "it is the simplest and clearest model to outline the theory of change in the operational context of development programs" (Gertler et al. 2011, p. 25). Figure 4 presents a simplified logic model describing a pathway of social protection towards results, at the macro level. At the country level, researchers may add more specificity in each category based on the realities of the country context.

The logic model includes three main components:

1. The major phases in the **program cycle** (inputs, processes, outputs, outcomes (shorter-term and longer-terms, and impacts) defining the major social protection elements at each stage.

2. The **contextual factors** (socio-political, economic, institutional/operational and the natural environment) that affect implementation.
3. The **socio-cultural characteristics** of the target populations (PLHIV) that affect implementation and outcomes.

Figure 4: Logic Model of the Programme Theory of Change

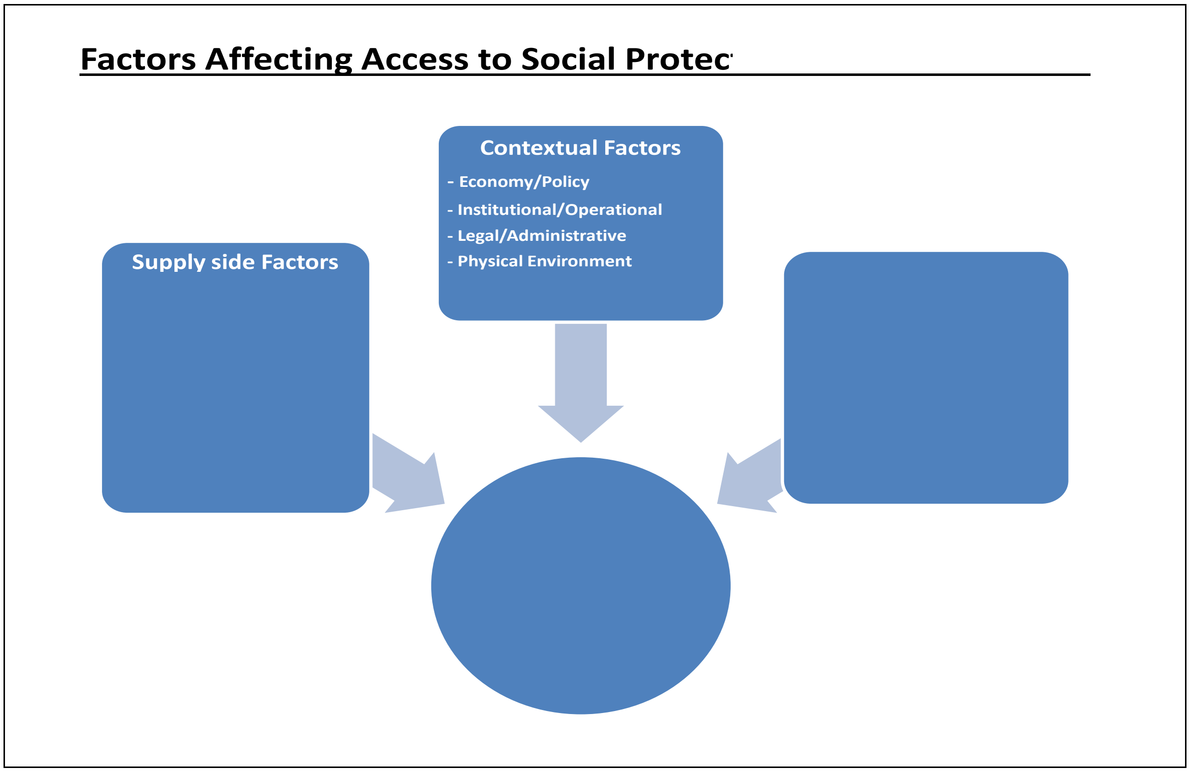


Source: Authors using several sources.

3.2.2 Supply and Demand Analysis

In addition to the program theory of change, this research will adapt elements of the supply and demand analysis framework to describe the contextual and the supply and demand factors involved in the access of social protection services by PLHIV. Supply and demand analysis has been used effectively to describe and analyze the factors affecting the delivery and utilization of services, especially in the health sector. Figure 5 identifies key factors that affect access to services by PLHIV. The Core Research Elements and Menu of Indicators matrix (Part Three, 4) includes indicators that measure the demand-supply variables identified in this figure Driven by the core principles grounding this research, every effort will be made to assess barriers to access and utilization of services by gender, participation in the formal and informal economy, and other variables.

Figure 5: Supply and Demand Analysis Framework



Source: Authors using several sources.

3.3 Research Design

This social sciences research asks two fundamental types of questions:

1. What is going on (descriptive research)?

2. Why is it going on (explanatory research)?

To answer these types of questions the researchers can select a simple-cross-sectional design. Cross-sectional perspectives seek to explore, describe or explain a phenomenon at a point in time (Gilson, 2012). This type of design is appropriate to study subgroups responses within the overall sample. The subgroups will be based on subgroup characteristics such as age, gender, income, employment status, or whether they work in the formal or informal economy. The point of this design is to systematically disaggregate the subgroups within the sample so they can be examined in detail against the outcome of interest: access and effects of social protection programs by PLHIV. The descriptive component of the research will describe the phenomena as they exist. The explanatory component adds rigor by attempting to explain- not only to describe- the phenomena studied. Cross-sectional design is often used along with a survey in a mixed method design (Morra Imas and Rist, 2009).

Table 4: Research Design and Methods

Research Design and Methods		
Design Type →	Cross-sectional design	
Design Notation →	[X O_1; O_2; O_3; etc.]	
Methods of Data Collection →	**Quantitative**	**Qualitative**
	Survey	Documents review
	Secondary data analysis	Semi-structured key informant interviews
		Semi-structured focus groups

Source: Authors.

3.4 Research Methods

This research applies a mixed method approach. Mixed-method designs combine the strength of quantitative and qualitative methods. Quantitative data is more structured and easier to analyze. It permits more precise analysis of differences among subgroups. Qualitative data is less structured but demands more labor intensity in the analysis. It provides "rich-data" specific to each subgroup being studied (Morra Imas and Rist, 2009). By using several methods, the limitations of any particular method are mitigated, and each method provides more value when used in a mixed approach design providing information that is more coherent, reliable and useful than those from single method studies (Adato, 2012). Mixed-method designs are gaining increased recognition in development research and evaluation, especially when it is used as a systematic approach throughout the research.[15]

Researches will need to decide the most appropriate **implementation sequence** of data collection and what type of method takes priority during data collection and analysis by responding to one fundamental question: *Does the country context permits an explanatory study or an exploratory study?* Researchers shall document their decision. Using a systematic approach and documenting the decisions made and the reasons, adds to the robustness of the research.

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[15] A mixed method approach was applied to the recent 17-study evaluation of the community response to HIV/AIDS led by the World Bank (see Rodriguez-García et al., 2013). UNICEF is proposing a mixed-method approach for equity-focused evaluations (see Bamberger and Segone, 2011).

There are three possible implementation sequence options in this research (Creswell, 2003; Bamberger and Segone, 2011). This topic is further developed in Section 4.3.1: Triangulation.

Data collection and analysis sequence:

1. Sequential Explanatory. Characterized by collection and analysis of quantitative data followed by a collection and analysis of qualitative data.

Purpose: To use qualitative results to assist in explaining and interpreting the findings of a quantitative study.

2. Sequential Exploratory. Characterized by an initial phase of qualitative data collection and analysis followed by a phase of quantitative data collection and analysis.

Purpose: To explore a phenomenon. This strategy may also be useful when developing and testing a new instrument

3. Parallel or Concurrent. Characterized by collection and analysis of either quantitative or qualitative data first. The results are integrated in the interpretation phase.

Purpose: To employ the methods that best serve a theoretical perspective.

3.5 Study Population

The population of interest for this study is people living with HIV, and secondarily, their households. In addition, priority populations (as previously defined) will participate in focus groups discussions, regardless of their HIV status. Social protection and health service providers will be targeted along other key informants for the qualitative component of the research.

To ensure access to the study population, country-based researchers will work in close collaboration with national and other informal networks of people living with HIV and PLHIV enrolled in treatment, care and support programmes. This is one way to ensure that the largest possible number of potential respondents is reached and when reached that they agree to participate in the research. Researchers will make every effort to incorporate special protections for vulnerable populations into the protocol and the data collection process.

Inclusion criteria. The characteristics that the study population must have if they are to be included in the study are: (1) people living with HIV, (2) priority populations regardless of HIV status for qualitative data collection, and (3) PLHIV who are employed, unemployed or not working.

Exclusion criteria. The characteristics that disqualify the prospective subjects from inclusion in the study are: (1) the person declines to participate in the study, (2) the person is younger than 15 years old, (3) the person is ill, (4) the person has been interviewed already for the same study, and (5) the person participated in the testing of the questionnaire.

3.6 Sampling Approach

Defining a sampling approach for this type of study is not easy. Researchers will aim at choosing the best method or combination of methods that would add the maximum rigor to the study and make the findings and conclusions reflect the real situation and phenomena that is being studied. The study can apply both nonrandom and random sampling techniques[16] as shown below. As a minimum a combination of both is recommended.

Option 1: No-probability-based sampling

- **Purposeful sampling** where the selections are based on predetermined criteria (see inclusion criteria), especially (i) *maximum variation sample* where units are drawn to represent the full range of the characteristics of interest (i.e., sex, gender, formal/informal economy), and *quota sample* where units are drawn so that there are equal number of an equal proportion from each stratum.

- **Snowball sampling** is useful when the boundaries of the population are unknown. A challenge of this sampling technique is the potential for overrepresentation of certain subjects within the universe of the population of interest.

Main limitation: Findings cannot be generalized to the entire population. However, sampling techniques such as purposeful and snowball sampling are used often in HIV and AIDS research to study sex workers (SW), injection drug users (IDU) and in any research that involves marginalized populations (Kral et al., 2010) and vulnerable populations such as child labour (ILO/UNICEF, 2005). The sample size is determined by the maximum number of HIV positive people that interviewers can reach.

Option 2: Probability-based sampling

- **Defined-population random sampling** may be possible by considering networks, physical facilities (i.e., service delivery sites) and other organized groups as a sampling unit. Assuming these groups have lists of members or clients, a sample can be drawn applying a probability-based method. Researchers can identify a large number of testing and services delivery point sites, informal peer-support and women groups, hospitals and AIDS services institutions and organizations to capture as many HIV positive people as possible, representing national and local levels.

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[16] This section is informed by The People living with HIV Index. The Index has an approach to sampling that is relevant to this research as it involves the same population. Consult PLHIV Index User Guide, p. 14-16 for more details. Also by ILO/UNICEF Manual on child labour rapid assessment methodology. 2005.

Main limitation: Organized groups might not include all possible variations of PLHIV. Members are self-selected into membership and their level of knowledge and experiences might be different from other PLHIV who are not in groups. There is also the multiplicity factor to be taken into consideration –a person belonging to more than one group. On the other hand, this approach presents an opportunity to ensure that certain groups are included. Furthermore when presenting the findings researchers will need to indicate that findings are based on a sample from a specific organization or facility.

Option 3: A combination of probability-based and non-probability sampling, including

- The square root allocation method could also be used to allocate the sample across the sub-groups (stratum) of interest representing men and women in the formal and in the informal economy, or unemployed. In *square root allocation* the sample is allocated proportionally to the square root of the stratum size. The square root allocation might be a choice as it would allocate relatively less sample units to the informal economy where sampling is more difficult and more expensive.

Main limitation: Although these techniques allow researchers only limited ability to generalize findings to the larger population, they are appropriate for this research given the objectives and population of interest.

Sampling size is a function of the size of the population of interest, the desired confidence level and the desired level of precision. Samples are used to ensure that those actually interviewed are in some definable way representative of the target group or the universe being researched (ILO/UNICEF, 2005). The appropriate sample size can be determined in two ways. The first is to use a formula, such as the square-root sample allocation. The second is to use a table that shows the sample size needed for a certain level of confidence-the smaller the population, the larger the sample relative to the population as a whole. For instance Table 5 shows that if the population of PLHIV is 500, a minimum sample size of 217 is needed to obtain a confidence level of 95 percent-almost half of the population. A population of 1000 would require a minimum sample size of 278 - less than a third of the population.

A final decision of sample size will take into consideration the features of the population and the number of variables of interest. The sample size needs to be large enough to capture the variability among them – to have enough observations in each data cell for comparison and correlations. Researchers will consider recruiting 10 to 15 percent more subjects than the number needed, so as to make up for those subjects who withdraw from the study. Depending on the country context the sample size may vary anywhere between 150 and 400.

Table 5: Minimum Sample Size Needed at the 95 Percent Confidence Level

with a 5 Percent Point Margin of Error

Population size	Sample size	Population size	Sample size
100	80	600	234
150	108	700	248
200	132	800	260
250	152	900	269
300	169	1,000	278
350	184	1,500	306
400	296	3,000	341
450	207	6,000	361
500	217	9,000	368
550	226	50,000	381

Source: Morra Imas and Rist, 2009, p. 365

If researchers are able to use randomized sampling techniques, then power calculations are important to determine how large a sample is required to avoid concluding that a program has had no impact, when it has in fact had one. To finalize the research design, the researchers will work with a statistician.

Power calculations are usually conducted for power of 0.9 or 0.8. Researchers will make decisions on the level of power taking into consideration other realities (i.e., context, population, resources, time-frame) while keeping in mind that the higher the power the largest the sample size that is needed. Table 6 illustrates one example of social protection effects on household out of pocket health expenditures. The table shows the reduction of household out-of-pocket health expenditures (minimum detectable effect) to be detected by the research of $1, $2, and $3. Thus, if the researchers accept a power level = 0.8 to detect a $2 reduction in households out of pocket health expenditures a total sample or at least 502 units would be sufficient (Gertler et al., 2011). In the Table, the minimum detectable effect describes the minimum reduction of household out-of-pocket health expenditures to be detected.

Table 6: Sample Size Required to Detect Decreases in Household Health Expenditures, Power = 0.9 and 0.8. (illustrative)

Minimum detectable effect	Total sample Power=0.9	Total sample Power=0.8
$1	2,688	2,008
$2	672	502
$3	300	224

Source: Authors from Gertler et al., 2011, p. 190-191.

SECTION 4: CONDUCTING THE RESEARCH

This section describes the main elements of this research and the data collection and data analysis approach, beginning with a brief discussion of population recruitment procedures.

First, a word about process: Researchers are expected to have established a **process of stakeholders' consultation** (see section 1) that includes the target populations and PLHIV in ways that are suitable to the country context. Meetings with community leaders and CBOs representatives where data collection will take place are encouraged. These meetings shall be open and inclusive, enabling both sides to (i) explain the research, (ii) spread the word about the research, (iii) increase the researchers' knowledge of important program and behavioral issues related to the variables and the population of interest, and (iv) reveal other issues that warrant further action. Although community meetings have pitfalls as well (i.e., may not represent all of the groups; those who attend might have strong opinions -positive and negative- about social protection, medical HIV services or about the HIV priority population) in most cases the benefits surpass the risks (Bamberger and Segone, 2011).

4.1 Population Recruitment Procedures

Recruitment methods will ensure that the incursion on individual privacy, necessary to determine a potential subject's eligibility, is minimized and that all private information collected at that stage is kept confidential until destroyed. Researchers will select the method(s) of recruitment that is/are most suitable to reach study subjects in sufficient numbers (recruitment feasibility) and that take into consideration the characteristics of the study population (recruitment appropriateness).

There are several options for recruiting respondents. Each has its strengths and weakness. A combination of all can be applied.

Option 1: Going through networks of PLHIV. This involves identifying networks on the assumption that they group large(r) numbers of the population of interest, and then use their list of members (identification numbers only) to select the sample size for each network. The networks facilitate access to the individuals.

Weakness: Going through these networks may create an over-representation of certain groups of people living with HIV. Groups such as women, migrants, truck drivers might not be as well represented if they do not organise themselves into formal groups.

Option 2: Going through health-HIV services provision facilities. This involves using medical records identification numbers (without access to actual medical records) to select the sample size. Potential respondents are recruited and interviewed by trained data-gatherers (not by service providers) as they appear at the sites.

Weakness: Going through health-HIV facilities may create the impression that respondents are obligated to participate in the study. It may also skew the research towards those PLHIV who are already accessing social/health protection services.

Option 3: Going through, NGOs or national service facilities working with priority populations such as sex workers, drug users or migrants. This involves using their list of members (identification numbers only) to select the sample size for each NGO or facility. Potential respondents are recruited by trained data-gatherers (not service providers) as they appear at the sites. It may include a larger representation of key populations at the poorest income level living with HIV, who may not necessarily be captured in some of the other NGOs or networks.

Weakness: Going through these venues may create a bias by focusing on people who are already linked into the social protection system in some way or that already receive some sort of benefits.

There might be other ways and means to recruit respondents for the study, such as going through labour unions, trade associations (i.e., truck drivers), programs that target PLHIV, sex workers or migrant workers, and others. These populations are not necessarily HIV infected, but they are disproportionately at risk. Researchers would consider the advantages and disadvantage of all options and decide on the best one or the best combination of procedures within the country context. Also researchers will keep in mind that the recruitment procedure(s) should never sacrifice the rights, confidentiality, security and the wellbeing of people, irrespective of HIV status, gender or membership to a key population.

This is an area –recruiting population for the study- where the meaningful engagement of PLHIV and PLHIV networks would be appropriate and mutually beneficial.

4.2 Data Collection Plan

According to the Terms of Reference for this research prepared by the ILO Programme on HIV/AIDS, the scope of the research includes three main components or methods of data collection. These are:

- **Desk review**: Qualitative data compilation for development of social protection programs mapping. If data are available, the desk review will include a secondary analysis of quantitative national survey and/or services data and costs/spending data on social protection coverage and use.
- **Primary qualitative** data collection through interviews of key informants and focus groups.
- **Primary quantitative** data collection through a survey of people living with HIV.

These three components will allow triangulation of data collection methods and sources in order to provide a more complete picture of the relevant social protection programs and their effects on the outcomes of interest. Particularly, data and findings from other studies will be examined and triangulated to determine changes and trends. Table 7 summarizes the research components, data collection methods and sample sizes for each component.

Table 7: Summary of Research Components, Methods and Sample Size (estimations)

Research Component	Data collection Method	Estimated Sample Size
Desk review	- Documentary review - Secondary analysis of existing data including programs costs, spending and service statistics	N/A
Qualitative		
- Stakeholders analysis	- Key informants interviews	30
- Beneficiaries analysis	- Focus groups with men or women or mix sex and key populations participants (10-12 per focus group)	6-8 (groups) (60-96)
Quantitative-Survey	- Survey questionnaire	150-400

Source: Authors

Desk Review

4.2.1 Desk Review

The collection of relevant information is a continuous task during the research process. The systematic, yet selective, gathering of information from documentary sources is particularly relevant in the early stages of any study in order to examine existing data that can inform the research and the field work. The desk review may also raise new questions about the overall scope of the research allowing time for adjustments as needed (UNODC, undated). Above all, a desk review should be credible, objective, transparent, and systematic following a logical and rigorous procedural method (Rodriguez-García and White, 2005). The **desk review** is also an important element in the triangulation of methods and sources that is a critical part of a mixed-method research design. In this research, the desk review will have two main components: (1) a documents review, and (2) a secondary analysis of existing data, if possible.

While the desk review can help answer all three ILO/HIV guiding questions, it would be particularly useful for question one and part of question two as follows:

1. Does social protection in the country cover men and women workers affected by HIV and AIDS, and their households? If so, under which contingencies of social protection, for example: health care, livelihood/income support, cash transfers, etc.? What are the coverage, key gaps and challenges in enhancing social protection coverage to them? What are good practices?

2. To what extend does the employment status, whether formal or informal, (e.g. self-employed, casual employee or day-labourer, etc.) influence the access to both public, private; national or community based social protection coverage?

The desk review consists of two main activities: a documentary review and a secondary analysis of data.

1. **The document review** will help determine which documents are critical to understanding social protection in the country, which literature makes a significant contribution to the understanding of the topic -what is known already- and what new data is required. It will also inform the research design and data analysis. (A full citation of original sources, in the form of a complete listing or annotated listing will be included in the final research report.)

The desk review will include at least four main documentary sources related to the area of research and the study population:

1. National policies and strategies on social protection including social health protection, costs and coverage.

2. National social protection, labour and HIV-health services and costing statistics.

3. NGOs reports, research reports and other pertinent documents from national or global sources.

4. Relevant published materials from peer review journals and from the gray literature, and technical reports.

Documentary items will differ in many aspects. As a quality control mechanism, in reviewing each piece, researchers may take into consideration the following criteria:[17]

Provenance—what are the author's or source's credentials? Are the arguments supported by evidence (e.g. primary historical material, case studies, narratives, statistics, recent scientific findings)?

Objectivity—is the paper's or author's perspective even-handed or prejudicial? Is contrary data considered or is certain pertinent information ignored to prove the author's point?

Persuasiveness—which of the author's theses are most/least convincing?

Value—is the paper's or author's arguments and conclusions convincing? Does the work ultimately contribute in any significant way to an understanding of the subject?

The output of the desk review is expected in the form of a "resource mapping or matrix" -a mechanism that allows plotting information in a succinct, synthesized way.

Suggested criteria for **documenting the modalities of social protection**:

- The types of **agencies, organizations and structures** implementing the programs.
- The types of **instruments or services** implemented and the **beneficiaries** of these.
- The **actors** involved in making social protection **available and accessible.**
- The **contextual factors** that influence the **utilization** of those goods and services.
- The extent of **population coverage** by the different social protection programs.

2. The secondary analysis of existing data. When possible the researchers will conduct a secondary analysis of survey, service statistics or spending data to determine trends in issues such as eligibility, coverage, costs, and national spending. For instance, researchers may examine the existing cost structure of the social security system that affect PLHIV and those most at risk. Depending on the data, the analysis may yield information on the HIV-related costs that are covered by the health system or the social protection system, the costs that are covered by different sources (i.e., government, donors such as GFATM, private sector, community schemes, charity organizations, and others), and the percentage of costs cover by the individual out-of-pocket.

The output(s) of the desk review-secondary analysis of data is expected to be synthesized in the form of tables or figures. (See illustrations with selected information from Indonesia, Rwanda and Ukraine and at the end of this section.)

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[17] Adapted from: http://guides.library.ucsc.edu/write-a-literature-review [June 2013].

Finally, the desk review will attempt to place social protection in the country in its (i) legal, (ii) economic, (iii) HIV epidemiological, and (iv) socio cultural context, in order to achieve a better understanding of program offerings and programs gaps as they relate to the population of interest. More specifically, the desk review will:

- Capture the policy and legal environment and how it enables or handicaps PLHIV access to benefits and services; and how it may differ by gender and key HIV populations.
- Provide up to date information on HIV trends and capture the socio cultural environment that supports PLHIV and at risk populations (i.e., anti-discrimination legislation) which, in turn, influence the demand and supply of services.
- Capture the range of national social protection programs and other schemes available in the country, which would include those for people living with HIV, and in particular to draw up a typology according to which actors are delivering which types of services to whom.
- Determine social protection coverage and utilization, and if possible national and personal spending levels and costs. This approach would take advantage of existing national level data to provide points for comparison between PLHIV and the non PLHIV population, and to examine trends.
- Provide contextual information on social protection inputs that will be utilized to inform study implementation, as well as contribute to the explanation and interpretation of study findings.

The desk review is the first stage of a triangulation process which serves to independently assess the research topic(s) from at least three different sources of information or methods of information collection. (Triangulation is discussed in section 4.3.1 below.)

Table 8: Desk Review Results

Illustrations

Indonesia	Ukraine
Labour and Social Trends in Indonesia 2012 An ILO 2012 presentation on Labour and Social Trends in Indonesia 2012[18] is a useful source of current information on several fronts. One learns that in 2012 between 60 to 63 per cent of all those employed could be considered “vulnerable workers” --typically working in the informal economy, with inadequate earnings, low productivity and poor working	**Social Protection Policies and Programs in Ukraine** In Ukraine the social insurance scheme is composed by four types of compulsory state social Insurance: 1) against industrial accidents and occupational diseases; 2) against unemployment; 3) against temporal disability; and 4) pension insurance. Non-contributory social benefits and services schemes include: social assistance (e.g., assistance to low-

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[18] http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---ilo-jakarta/documents/presentation/wcms_210095.pdf.

conditions. Furthermore, one can learn that women are paid between 25% to 35% less than men, and are three times more likely than men to be considered vulnerable workers due to their status as "family workers", while men are more likely to be vulnerable workers due to their employment status as a "casual" or "own-account workers".

Regarding the formal and informal economies, between 2001 and 2009 the share of employment that was in the informal economy was between 61 to 66 per cent. Trends over the last three years have shown a substantial shift towards formality. In 2012 it was estimated that 53.6 per cent of employed people were working in the informal economy.

Source: ILO, 2012b. Labour and Social Trends in Indonesia 2012: Working for a sustainable and equitable economy. A presentation by Emma Allen, ILO Country Office of Indonesia and Timor-Leste. Jakarta, Indonesia, 2012.

income families, disability), subsidies (e.g., veterans, workers, housing), and social services (e.g., persons with disability living alone). While Rwanda's (GOR, 2011) national social protection strategy defines social protection across two main dimensions: social protection and access to public services. The country's social protection floor for the most vulnerable households and individuals, comprises: (1) cash transfers, providing a minimum income and livelihood security, (2) continuing extension of access to core essential services for poor and vulnerable households, in particular health, education, shelter, water and sanitation; and (3) Increased participation of the informal economy in the contributory social security system, with more people enjoying the benefits of labour legislation.

Source: Social Protection and Social Inclusion in Ukraine. European Commission. Directorate-General for Employment, Social Affairs and Equal Opportunities. 2009.

National AIDS Spending Accounts

In many countries, national AIDS spending accounts (NASA) supported by UNAIDS provides information on social protection and/or care and support spending. National AIDS Spending Accounts reports are available for Guatemala (2004-2005) and Indonesia (2006-2007); two of the countries of interest for this research. However, this type of information is also available in the countries UNGASS report. For instance, Rwanda reported its 2006 HIV spending as shown in the Table. 8.

Source: UNGASS Country Progress Report. Republic of Rwanda. January 2006 - December 2007, p. 19.

Rwanda

Spending category	Amount spent 2006
Prevention programmes	11,519,430,542
Treatment and care components	14,975,375,517
Programme management and administration strengthening	14,250,590,951
Incentives for human resources	229,596,813
Social protection and social services excluding OVC	3,108,734,148
Orphans and vulnerable children	3,880,904,328
Enabling environment and community development	108,173,109
HIV- and AIDS-related research (excluding operations research)	267,783,872
TOTAL	**48,340,589,281**

Source: UNGASS report 2006, Expenditure records e.g. Ministry of Finance execution report, CEPEX, annual and audit reports from CNLS,TRAC, GF, PEPFAR, WB/MAP project and NHA data. Exchange rate 2006: 1$ = 551.74 RwF.

4.2.2 Qualitative Data Collection

In this study, researchers will seek to understand the context and factors that affect accessibility of social protection by PLHIV and HIV priority groups as well as the views and attitudes of service providers and provider agencies in regard to the availability and access of services by these populations. This is best achieved through the collection and analysis of qualitative data.

The objective in designing the qualitative research component is to reduce the chances of discovery failure; that is, the chances of missing a potentially important perception. The qualitative sample size will be big enough to assure that most or all of the perceptions that might be important can surface. It is not the intention of informants' interviews or focus group approaches to produce conclusions that can be generalized beyond the context in which they are conducted. The value of qualitative approaches is that they can help to confirm facts and generate recommendations.

Qualitative data will be collected by qualified, experienced fieldworkers, men and women who will be trained prior to the beginning of data collection, and may include representatives of the key populations and PLHIV. (See section 1, and section 4 below.)

This research will focus on two methods of qualitative data collection: Key informants interviews and focus groups. Below is a description of some of the major steps in data collection for each method.

Key informants interviews

The purpose of this data collection method is to explore in depth how social protection programs, procedures and benefits work and how PLHIV can access them. It will capture mostly the perspectives of the suppliers. Key informants for this research are those who are in position to describe the characteristics of social protection policies and programs, and/or who are involved in deciding benefits qualification, or are program implementers (managers and providers). Because informants present information from one particular viewpoint, it is important to select a sample of informants that is varied and invites different points of view to surface and counterbalance each other. Interview data will be validated against the relevant documentary evidence as encountered and collected during the desk review or the survey. Additional pertinent documents will be collected from each organization at the time of the interviews and shall be used to improve the literature review report. Researchers will use triangulation to reconcile information obtained from different informants (Bamberger and Segone, 2011).

Informants will represent the groups shown below. These are core groups, except when noted. Researchers can add more groups as relevant to the country context.

Key informants will include these categories:

National Agencies and Institutions:

- ✓ Ministry of Health, National HIV/AIDS Commission, Ministry of Social Affairs, Department of Social Protection, Department of Labour, and Department of Gender/Women's Affaires/Child Welfare.
- ✓ Private sector insurances, private social security systems.
- ✓ Labour and Trade Unions, Employees associations, including women or gender focal points.
- ✓ Non-governmental organizations: Representatives of women's rights groups, and organizations engaged in treatment, care and support programmes for PLHIV and key populations.
- ✓ Optional: Media representatives and relevant opinion leaders, including faith leaders and parliamentarians; national think-tanks, academic or other specialists such as in social protection, gender or HIV and AIDS (where present).

Development Agencies and Donors:

- ✓ Donors and development agencies: ILO, UNAIDS, WHO, UN Women, UNDP, UNICEF, World Bank, DFID, USG and others (as relevant).

Health/Medical/Social Service Providers:

- ✓ Services Providers in social protection programmes, HIV service or treatment centres, medical institutions, NGOs.

PLHIV Networks and NGOs working with PLHIV:

- ✓ National networks and organizations of people living with HIV, including associations of women living with HIV (where present).
- ✓ Different key population networks (where present)
- ✓ Non-governmental organizations: organizations engaged in prevention, treatment, care and support programmes for PLHIV and key populations

The **data collection process** will be systematic. The sample size may vary, given the different categories of informants that exist in the country. A number of studies show that for in-depth interviews (stakeholders/informants) a sample of 30 respondents is a reasonable starting point for a sample size that can reveal a full range of perceptions.[19] The study sample will be reached with informants at the central and local levels. Key informants should include an adequate number of women. Each interview may take about one hour.

The instrument: The researchers will develop or adapt a semi-structured interview guide that is gender-responsive. The interview guide will be translated and tested as needed, and finalized before the interviews begin. The instrument would include **open-ended questions to a**llow the respondents to answer in their own words. Probing by the interviewer will elicit more specific details in the areas of interest to this study. (A sample instrument is provided in Part Three section 5).

The following is a menu of some of the areas researchers will seek to cover through qualitative data collection, especially from key informants:

- What are the opinions of different respondents about the most important characteristics of the social protection system; what have the social protection programs accomplished; and what they have not?
- What needs exist that the social protection programs should address?
- How does social protection programmes cater to PLHIV in the informal economy?
- Which groups are most affected by the gaps in the social protection program? Are PLHIV or priority groups included? Is any population group excluded?
- What are the reasons for lack of access to social protection benefits by the population that need them?
- What are the challenges key populations encounter in accessing and continuing the use of medical/health services?
- What are the opinions of respondents concerning social and health services? Who use the services and who does not; what challenges do providers face in providing services?
- What are the opinions of respondents about ways for people who are self-employed, daily laborers or those who are unemployed to gain access to social protection benefits, health insurances and other benefits and services?
- Has social protection for PLHIV ever been raised by national organisations (NGOs, social movements etc) or international groups as part of policy discussions?

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[19] http://www.uniteforsight.org/global-health-university/importance-of-quality-sample-size.

- How do you think these groups could be best covered through special targeted policies or within general programmes?
- Are there any cultural practices or views that affect access to services especially by PLHIV, women and key populations?

Focus groups

The focus group data collection method involves a discussion with a small group of people who are brought together to discuss specific topics under the guidance of a moderator. Researchers will use a script to generate verbal data via group interaction. Focus groups are particularly relevant to this study to explore answers to 'what' (content) and 'how' and 'why' (process) questions, as well as the contextual aspects of accessing social protection, the intensity of opinions, and the views on sensitive topics. Information gathered though focus groups will point towards the degree of implementation and implementation fidelity of social protection programs.

Participants in focus groups shall include any of these categories:

- ✓ men, women, transgender
- ✓ sex workers (male and female)
- ✓ injecting drug users
- ✓ migrant workers
- ✓ employed men, women and transgender
- ✓ unemployed men, women and transgender
- ✓ not working men, women and transgender
- ✓ primary and secondary caregivers
- ✓ PLHIV residing in urban, peri-urban and rural areas
- ✓ Members of indigenous groups
- ✓ Members of different faith groups
- ✓ Other groups as relevant in the country context (ie., migrants)

Focus groups participants will represent primarily beneficiaries or potential beneficiaries of social protection. However, researchers may choose to collect data from other groups such as health service providers or social workers through focus groups instead of or in addition to including a number of service providers as key informants.

People living with HIV, key populations and other people whose HIV status is not known but who's experience in accessing –or not- social and medical services may be deemed to represent an important contribution to the discussion will be included in focus groups. There are several possible ways to segment the populations of interest for focus groups to ensure that there is inclusivity and a culturally appropriate mix. Researchers will apply a gender lens to focus groups participants and discussion moderators to ensure that key HIV populations and women are included. To maximize the discussion of sensitive issues and to ensure that diverse opinions are heard in all focus groups, no category of potential participants will be overlooked. Researchers will select (i) participants from similar population categories, status and/or sex for some focus groups, and (ii) a combination of different kind of participants for other focus groups. Researchers will uphold the principle that the selection of participants must not bias the research results in any predictable way.

The following is a menu of some of the areas researchers will seek to cover through qualitative data collection, especially from focus groups:

- Experience in accessing social protection programs in general: Which features or components are most useful? Who provide the services (agencies, organizations?
- Social insurance benefits participants are enjoying. Which programmes are most used? What is best about these programmes? What are the biggest problems? How significant is the problem? Please give an example.
- Social insurances benefits participants think they should be able to enjoy. How does HIV qualify or disqualify someone from social insurance coverage. Does having a pre-existing condition affect access, are benefits capped – which can create challenges for chronic care. Are there other chronic conditions which should be considered in similar way to HIV? (Avoid giving the impression privileged access to services for HIV infected if others are equally vulnerable.)
- Health and other medical or social services: What types of services are being used? How was the experience? What problems were encountered in accessing health services? Please give an example. What causes the problem? How did it happen? What did you do? Are you using medications? Do women with HIV encounter special problems in accessing social protection despite having many points of entry into the health system, related to maternity and child care?

The **data collection process** will be structured and follow a script. The recommended sample size (number of groups) varies. Some researchers have noted that the data generated after about 10 sessions are largely redundant (Millward, 2012). The final **sample size of focus groups** for this study will be chosen to reflect the segments of the population who will provide the most meaningful information in relation to the research objectives as well as considerations of cost in terms of time and resources. The sample size is estimated at 6-8 focus groups total. The **group size** would be of about 10 participants per focus group-a range of 8-12 participants. The total number of participants could be in the range of 48-96. Experience shows that focus groups should be as small as possible while still being able to elicit the breadth of responses required.

The choice of **location and setting** will be based on convenience and accessibility for participants, including considerations of mobility constrains especially for women or those in ill health who might not be able to travel alone. Focus group meetings will take place in a neutral site.

The instrument: A script will be translated as needed, tested and finalized prior to starting the focus groups. The script will allow the moderator latitude to improvise fruitful questions and pursue unanticipated lines of inquiry. (See instrument in Part Three, section 6.)

Quantitative Data Collection – The Survey

4.2.3 Quantitative Data Collection

The survey is a critical part of this research. It will be used to elicit information regarding respondents' knowledge, attitudes, opinions, perceptions and experiences. It is also useful, although less accurate, in measuring behaviour because what people say they do may not reflect what they actually do.

While the preparation of the actual questionnaire is an iterative process that takes time and effort, this is not the only important aspect of the survey. This section describes albeit succinctly some of the key steps in carrying out the survey. At this stage researchers will have had the research protocol approved by the relevant ethical committees at the country level, which included the informed consent form and the data collection tools. The study population has been defined, the sampling approach decided, and the research questions, indicators and outcomes measures selected. [20]

Four key actions are critical in planning out the survey:

1. **Community meetings.** Researchers will want to meet with community leaders and key stakeholders as a way to launch the survey. The purpose of these meetings will be to confirm their agreement and seek their guidance with regard to any changes –political, economic, safety-related- that might have occurred, which may affect the sites where the survey is to take place.

2. **Translating and testing the questionnaire**. The survey questionnaire needs to be translated from English into the language in which the interviews will be conducted, and finalized afterwards. Researchers will review the translation and may need to do a rapid-translation-back to make sure that the basic concepts are correctly translated and are clear for the research team. Translations will be done directly into the master questionnaire shell so the

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[20] Many technical documents and academic publications exist that explain in detailed how to conduct surveys even with vulnerable populations. The purpose of this section is to briefly highlight those aspects which are critical. Researchers may also consult the User Guide for the PLHIV Stigma Index, which provides a good description of how to plan and conduct surveys with PLHIV.

questionnaire format is the same for all languages. Reformatting creates confusion and can lead to missed questions and mistakes in skip patterns.

The **field testing of the questionnaire** should be done before the questionnaire is finalized and before the interviewers are trained. Adequate time will be allocated for the translation and testing processes. Then, the research team will test the questionnaire with a cross section of the survey population, representing different sexes, gender, employed, unemployed and other social factors and variables. The interviews will be conducted in the same manner as a formal interview. The information generated during field testing of the questionnaires should not be included as part of the study data. Those who participated in the field testing of the study questionnaires shall be excluded from the actual study participants.

The informed consent form can also be tested at this point if not already done. These tools are later used in the training of interviewers.

3. **Training of interviewers.** Training is an essential activity to complete before the data collection can begin. This training shall focus not only on understanding the data collection tool, and coding system; but most importantly it should address basic HIV, social protection terminologies and concepts, how to deal with sensitive issues, and the process of interviewing. The training also includes going over the data collection tool and the procedures and mechanisms of data collection to ensure confidentiality.

A training outline:

Objective of research

Concepts of stigma, discrimination and human rights and basic knowledge on HIV

Orientation to tools

Interviewing techniques, particularly sensitizing interviewers on how to deal with potentially difficult emotional situations

Practicing interviewing
logistics of data collection.

4. **Scheduling the interviews**. During the planning phase of the research the researchers would have (1) compiled a list of names and agencies that were suitable for key informants interviews, as well as (2) a list of agencies and organizations and informal groups that covers the majority of the target population. They would have also contacted the selected subjects and ascertain their interest and availability to participate in the survey. At this stage, these lists are used to begin scheduling the interviews. The interviews should be conducted in private with enough time to collect all the necessary data. At least two interviewers should be present having agreed on who would be the note taker and who the interviewer. Researchers shall decide if the use of tape recorders is culturally acceptable.

The **data collection process** will begin once the sample has been drawn, the instruments have been designed and piloted, and the teams have been trained. Attrition and non-response rates provide a good indicator of survey quality. The researchers will conduct quality checks during field work to ensure the completeness of questionnaires, appropriate data entry and relevant data outputs.

The instrument. This is a structured survey administered in person by trained interviewers. It will be conducted in a private setting. A mix of interviewers will be chosen to respect gender sensitivities and cultural knowledge. A core instrument is included in Part Three section 6.

The survey instrument includes the following clusters of questions:

Section 1: **Demographic characteristics of respondents**

Section 2: **Social protection programs and employment status**

Section 3: **HIV status, stigma and discrimination**

Section 4: **Effects of social protection benefits on access to HIV-related medical and health services**

Section 5: **Access to and effects of social protection benefits**

Section 6: **Care giving and caregivers**

4.2.4 Quality Control

The **implementation** of this study is the responsibility of the research team led by the principal investigator or research manager in accordance with the parameters and conditions agreed upon with the agency which has commissioned the research. . The principal investigator will provide research oversight. The research team will share responsibility for technical quality on the overall study design, sampling and methods selection; questionnaire design or adaptation, translation and field-testing; interviewer training and supervision; fieldwork logistics; data quality checks, processing and analysis; findings verification and report production; and research findings dissemination--the latter in collaboration with the ILO.

Data collection involves a **complex sequence of operations.**[21] First, the researchers select the indicators that need to be measured and the measurements using local and international best practice. (A matrix with the core indicators and measures for this research is in Part Three, section 4.) Being selective helps to limit data collection costs, simplifies the task of data collection and improves the data collected by minimizing demands on the respondent’s time. Second, the final survey instrument will be formatted with codes so that it is ready for data

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[21] For more detail information consult Chapter 12 of Gertler et al. 2011.

entry. Different ways of asking the same questions can yield different answers; thus, both the framing and the format of the questions should be the same for all units to prevent any respondent or enumerator bias. This is particularly relevant after the survey questionnaire has been translated into local languages.

After the data have been collected, data entry and data management, including "data cleaning" becomes the focus of quality control. This process continues up to the preparation of the research report.

The United Nations (Glewwe, 2005) specific recommendations regarding the formatting of questionnaires for household surveys are presented below. These recommendations apply equally to most other data collection instruments.

BOX 1: United Nations Recommendations for Formatting Questionnaires

1. Each question should be written out in full on the questionnaire, so that the interviewer can conduct the interview by reading each question word for word.
2. The questionnaire should include precise definitions of all of the key concepts used in the survey, so that the interviewer can refer to the definition during the interview if necessary.
3. Each question should be as short and simple as possible and should use common, everyday terms or in specific situations, the specific terms used in a country.
4. The questionnaires should be designed so that the answers to almost all questions are pre-coded.
5. The coding scheme for answers should be consistent across all questions.
6. The survey should include skip codes, which indicate which questions are not to be asked based on the answers given to the previous questions.

Quality control in research takes many forms and is applied at all levels of the process. Four important elements of quality control related to data collection and field work are:

- ✓ thorough training of data gatherers,
- ✓ close supervision of field work,
- ✓ checking and verifying the correct completion of questionnaires by data gatherers, and
- ✓ verification of correct data entry by computer data clerks.

Another important aspect of quality control is **thorough documentation** - from the moment the research protocol is completed and cleared by the appropriate ethical committees to the safe keeping of data and consent forms to the confidentiality of the data and of the interviewees.

4.3 Analysis of Data

This section suggests approaches to data analysis based on the data collection methods selected for this research.

Desk review analysis. For the analysis of desk review documentation, researchers may apply a modified policy gap analysis approach. **Policy gap analysis** identifies specific programs priorities and target beneficiaries and assess if the policies or programs address these priorities for the target populations. The analysis relies on secondary data from surveys, service statistics and agency records and assesses “desired” or “optimal” performance against the current situation. It does imply that one knows what the “optimal performance benchmarks” are, which is not always the case. The depth of the analysis depends in great measure on the quality of documentary sources or the quality of existing statistical or financial data.

Qualitative analysis. Upon completion of qualitative interviews, the interviewer(s) will review and refine notes and check materials collected during the interview for completeness. Researchers will review all the notes for quality control. Any notes, materials and tapes of interviews will be turned in as a package to be used for transcription and data analysis. Backups of materials will be prepared for safe storage. Audio tapes of interviews, if used, will be transcribed, and transcriptions along with other materials will be analyzed.

Content analysis will be used to classify findings. The content analysis will analyze the text (interview transcripts, documents check lists, and other identified documentary sources) in order to identify consistencies and meanings. The data’s meanings will be gauged by identifying patterns and themes. A process of inductive analysis will be used to identify these patterns and themes and therefore, unlike deductive analysis, a specific framework for data analyses does not need to be developed prior to data collection. A similar analysis strategy will be used with focus group data.

Quantitative analysis. Researchers would use descriptive statistics to summarise data. The measures of central tendency, which describe a group of data to indicate the central point, most commonly used are the mean, median and mode. The measures of dispersion, which describe a group of data to indicate how spread-out the data are, most commonly used are the range, frequency distribution and the standard deviation (see Box 2). The standard deviation measures how closely the data cluster around the mean. In addition, percentages, rates, ratios, trends and rates of change can be used, as well as other statistical means of presenting the data.

Whereas the frequency distribution and standard deviation provides the distribution for one variable, cross tabulations display the joint distribution of two or more variables simultaneously, usually presented in a matrix from. Each cell shows the percentage and the number of respondents who give a specific combination of responses. Additionally, correlations among relevant issues, such as sex and SP coverage, will be relevant to detect associations.

BOX 2: Calculating the Standard Deviation

The standard deviation of a distribution is calculated as follows:

1. Calculate the mean for the data.
2. Subtract the mean from each data point to find the deviation.
3. Square each of the deviation scores.
4. Sum all of the squares of deviations.

5. Subtract 1 from the number of data points.
6. Divide the sum of all the squares of deviations by the result of step five (number of items in the list minus 1).
7. Take the square root of the result of step 6.

The formula for calculating standard deviation is as follows:

$$S=\sqrt{\frac{\sum(X-M)^2}{n-1}}$$

(where **S** = standard deviation, Σ = the sum of, M = the mean, and N = the number of values)
Most statistical programs, including Excel and SPSS can make the calculations.

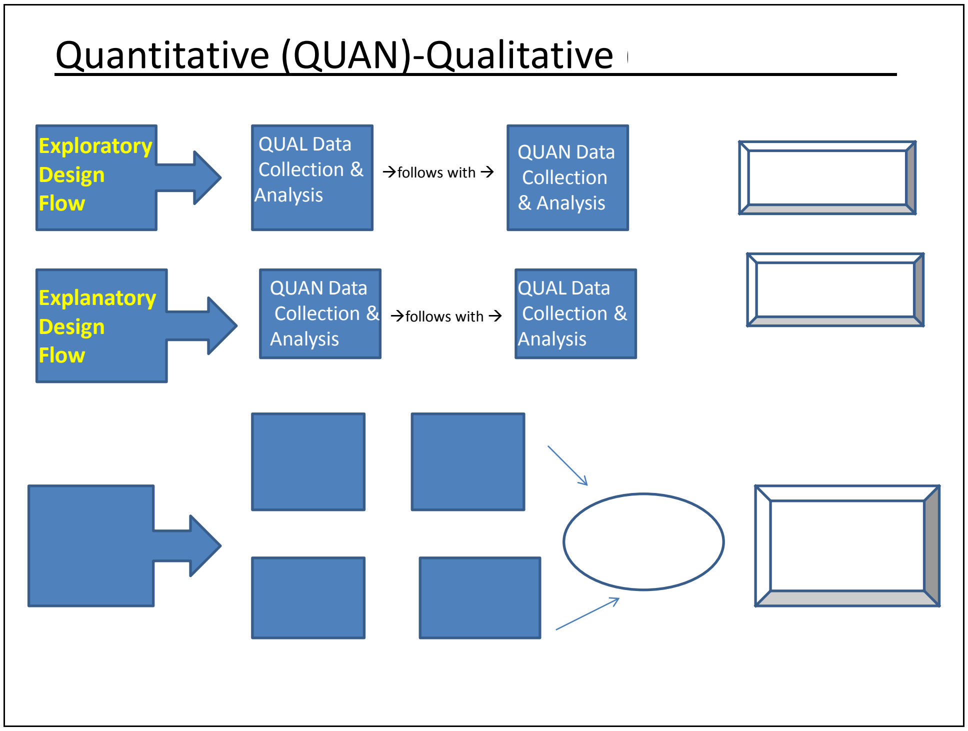
Source: Adapted from Morra Imas and Rist 2011, p. 395.

4.3.1 Triangulation

An important aspect of the mixed method approach is triangulation --a method used by researchers to check and establish studies validity by analyzing a research question from multiple perspectives. Data triangulation involves using different sources of information and different type of data in order to increase the validity of a study.

The data obtained from multiple sources --desk reviews on the characteristics of the social protection program, the quantitative survey data, the qualitative focus groups and key informants interviews-- will be examined in relation to each other to provide the most complete picture of the relationship between the variables of interest and access to social protection by men and women living with HIV in the formal and informal economy. Figure 6 shows three different scenarios for data analysis that can guide the triangulation approach of this study. At this stage, the researchers would have decided the sequence of the data collection method: quantitative-qualitative; qualitative-quantitative; or both in parallel, described in Past Two, section 3.4.

Figure 6: Approaches to Quantitative-Qualitative Analysis in Mixed-Methods Design



Source: Authors based on a presentation on Designing and conducting mixed methods studies by Beth Angell and Lisa Townsend. Workshop for the 2011 Society for Social Work.

Triangulation is a valuable and feasible approach to understand some of the important questions countries wish to answer related to various aspects of outcome and impact of programmes. It is used to answer different questions, ranging from exploring programmes effects, to explaining trends, to assessing the impact of programmes (WHO-EURO, 2011).

The goal of triangulation is not to arrive at consistency across data sources or approaches. Inconsistencies may be likely given the relative strengths of the different approaches proposed in this research. But these inconsistencies do not necessarily weaken the evidence; rather, they present an opportunity to uncover deeper meaning in the data (Patton, 2002).

4.4 Limitations

All studies, regardless of the approach taken have limitations whether related to the questions, the study population, the design, the sampling or the methods chosen. In this research the main limitations are related to the design and the sampling; themselves related to the study population.

Cross-sectional Design. The main limitation of this type of designs is that they can demonstrate associations, but they cannot identify cause-and-effect relationships. The limitations will be addressed by a careful selection process to minimize and document populations' similarities and differences, and by careful analysis and review of findings for identification of possible issues. Findings will be reviewed by individuals familiar with the context, the social protection programs and the circumstances of PLHIV in the particular country. A "findings validation" exercise with stakeholders is planned for each country in order to strengthen the validity of research findings.

Non-probabilistic sampling. Although sampling techniques such as targeted, purposeful and square-root sampling are appropriate in this research, there is no way of knowing whether the samples chosen this way are representative of the target population as a whole. Response bias is a limitation of all surveys, regardless of sampling methods. Given that it is not always feasible to carry out population-based randomized sampling of PLHIV, it is important to choose methods that are most likely to fit the geographic, social, and political characteristics of the country or region and the epidemiology of the epidemic. Randomized sampling of the PLHIV population is not always feasible or advisable. The statistical generalizability of findings will be limited to the populations participating in the study.

Theory of change. The increased availability and access to services does not automatically lead to an increase in utilization, neither does increased coverage automatically lead to a transformed social environment.

SECTION 5: VALIDATION AND REPORTING OF FINDINGS

5.1 Validation

The key output of this research will be a research report with the key findings. However, one critical action at this stage will be the **validation of findings** with stakeholders. Once the data have been analyzed and the preliminary findings known, researchers will plan a meeting with stakeholders in collaboration with the ILO. A brief summary of findings or a power point presentation will be prepared for purposes of validating the findings with stakeholders at the country level. Sharing this information with stakeholders in written form will help maintain the discussion focused. Feedback from the stakeholders would be compared with the findings to determine areas of agreement as well as areas of divergence, and the reasons will be discussed. This information will enrich the final report. Stakeholders can also be helpful in identifying gaps in knowledge, trends and good practices. Most importantly, stakeholders can help formulate recommendations that are relevant --actionable and/or aspirational-- in the country context.

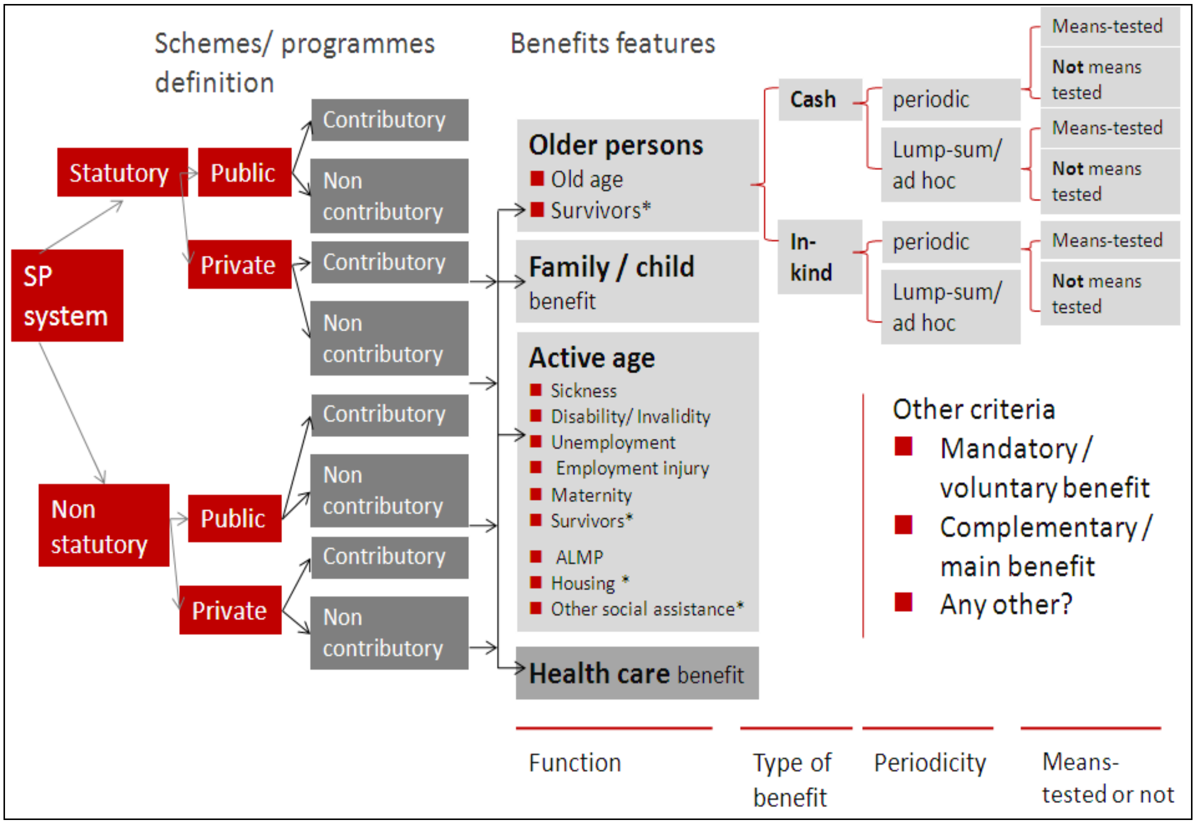
5.2 Reporting

The purpose of a research report is to communicate with readers. A **draft research report** will be prepared first for ILO review and comments. Once the comments on the draft report have been incorporated, the researchers will prepare a final report. An important aspect of preparing the research report is the identification and documentation of good practices and lessons learned. However, the ultimate goal of this research is to make the information widely available so that it can be used. Therefore, the researchers will work with ILO to identify other platforms where the findings can be disseminated orally, virtually or in written form. (See a suggested Final Report Outline in Part Three, section7.)

PART THREE:
TOOLS AND INSTRUMENTS

This section includes the core tools and instruments suggested for this research.

1. ILO Social Protection Categories



2. Research Management Plan and Time-table

A brief overview of the key actions and expected timing of project activities is shown below. This table identifies key steps, products, and timeline. It assumes a time period of 6 month or 24 weeks to carry out the research. The Table is provided as an illustration.

Activity	Product/Activity	Estimated Time	Person
Planning phase Complete protocol and submit Obtain ethical clearance Define geographic areas Establish contact with stockholders Build partnerships with the PLHIV Compile list of possible informants Compile list of organizations/facilities/PLHIV groups Sensitize the community Finalize staff roles and responsibilities	Protocol Revised timeline Selection of sites Selection of populations Interviews schedule Stakeholders meetings Community meetings	Weeks 1-3	
Desk review Compile documentary sources Review relevant materials Compile/select secondary data sources Review/analyse data	Mapping of social protection programs and schemes Tables and figures	Weeks 3-7	
Data collection tools Translate data collection tools and consent form Field test questionnaire (back translate) Finalize and print forms Develop operational manual Finalize sampling frame & plan to access study popul. Finalize field and training materials	Final Consent form Final data collection tools and questionnaire Operational manual Training materials	Weeks 2-5	
Training and logistics Recruit interviewers (and supervisors) Organize training (3-days?) Train field workers	Final list of interviewers Final training manual	Weeks 4-6	
Data collection Finalize logistics for field work Schedule meetings with Key informants Prepare for and schedule focus groups meetings	Final list of key informants Final list of focus groups mix and locations	Weeks 8-12	
Data management Data entry by clerks Data entry reviewed by supervisor Data cleaning	Preliminary computer data print outs	Weeks 10-16	
Data analysis Final cleaning and coding Data analysis Preliminary research report Validation of findings with stakeholders	Preliminary draft research report Brief summary or power point presentation to share with stakeholders	Weeks 17-20	
Reporting Prepare research report for review Incorporate comments Disseminate findings in accordance to funding agency requirements	Draft report for review by ILO Final report	Weeks 21-24	

Source: Authors using several sources.

3. Sample Informed Consent Form

Site ------------------------------- [__]

District/Ward ---------------------------------- [__]

IDENTIFICATION CODE [__][__][__][__][__]

Researchers/ field assistants Names ____

Date___________

INSTRUCTION: Seek and obtain individual informed consent from participant before commencing the interview session

Introductory Remarks

Good morning /afternoon, my name is ....*(interviewer*). I am working for *Name of Research Institution* on a study on social protection and people with and affected by HIV in your community. You have been chosen as a key informant for this project. We are here to exchange ideas with you on issues related social protection programs and benefits and HIV and AIDS services/interventions/programmes being implemented in your community; your experience of social protection; your relation with services providers; your involvement in the implementation of social security, your major concerns about health and social protection programmes and how to address them. Your participation to the discussion is very valuable if you are willing to be involved. All information will be used without mentioning your names. However for practical reasons, we will like to record the discussion so that we could capture all the ideas expressed. We'll be discussing for a maximum of one hour.

Do you have any questions or comments before we proceed?

Interviewer: In case of any questions, please try to address them before proceeding.

I also wish to kindly request you to allow me tape record this discussion so that I can capture everything we discuss.

a. Statement that the study involves research

This project in which we want you to participate in is a research project.

b. Explanation of the purposes of the research

There are many organizations that would like to have people with and affected by HIV able to access social protection programs. We are collecting information on people's experiences to help us to strengthen social and health care activities for this population.

c. Description of the procedures to be followed

We will ask questions about many aspects of life of this population. We want to learn more about you and your social system and health care experience. We will talk with leaders like you in this institution/agency/state/community. Some of the conversations may be tape-recorded, so that we do not miss out some of the important things that are said.

d. Expected duration of participation in the research

This study is expected to last about eight months. If you choose to be in this study, we will ask you questions about your personal experiences. The questions are general but if you find that some questions are not going well with you, please do not feel compelled to answer any of them for any reason. We will talk to you for about 45 -60 minutes.

e. Disclosure of appropriate alternative to participation

You can decide if you want to take part in this study. Taking part in this study will not cost you anything. You may also leave the study at any time. You can leave for any reason without any problems.

f. Description of any benefits to the subject or to others, which may reasonably be expected from the research

You may not get any direct benefits from being in this study but what you tell us will help us better develop a strategy for strengthening social protection and health care activities and thus improve the health and living conditions of people with and affected by HIV.

g. Risk involved

The risk involved in this research is minimal. However, there may be inconveniences with regards to privacy and confidentiality.

h. Confidentiality of records

Your name and what you say to us for this study will be kept private as much as the law allows. The information you provide shall remain confidential. The tapes, notes and transcripts shall be stored in a place where only the research team will have access. This will be for a period of 3 years after completing the study, after which they will be destroyed. For monitoring and evaluation purposes, the sponsors or the national social protection agency regulatory organs may review the documents.

i. Questions about research

If you have any questions about this study, you may contact Dr. XXXX, Research Project Director (full address) during the study and in the future. If you have concerns about human rights, ethics and welfare issues contact Dr. XXX (full address).

If you agree to answer our questions, you can tell us that you agree by repeating these words and then putting your name and signature in the space below.

Certificate of Consent by Respondent
I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant___________________

Signature of Participant ____________________

Date ____________________________

Day/month/year

If illiterate, a literate witness selected by the participant without connection to the research team must sign. Participants who are illiterate should thumb print as well. Alternatively, one of the data gatherer can sign as witness of consent.

Certificate of Consent by Witness
I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness____________

Signature of witness _____________

Date _________________________

Day/month/year

Thumb print of participant

Certificate of Consent by Witness the researcher, data gatherer or person taking the consent
I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what is involved.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my *ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.*

A copy of this Inform Consent Form has been provided to the participant.

Print Name of Researcher/person taking the consent_________________________

Signature of Researcher /person taking the consent___________________________

Date ____________________________

Day/month/year

4. Core Research Elements and Menu of Indicators

ILO SOCIAL PROTECTION AND HIV RESEARCH **Core Research Elements and Menu of Indicators**			
Research Clusters and Questions	**Core and Optional Indicators and Measures**	**Data collection Method and Data Sources**	**Basic Analysis and Presentation of Findings**
Q1. Availability: Type of SPP in the country 1.1. What are the main types of social protection policy & programmes (SPP), schemes and benefits in the country? 1.2. Are there SPP that explicitly target a disease whether HIV or any other acute or chronic condition? 1.3. Are there SPP that explicitly target specific population groups? Such as PLHIV, disabled, etc. *Note: SPP is meant to include policies, strategies, programmes, schemes and contingencies, including income generation/livelihood*	**Core Indicators** 1. Types of SPP(Criteria: specify the kind of SPP, beneficiaries, eligibility, inclusion, exclusion criteria) 2. Accessibility of these SPP (Criteria: affordability, availability, financial protection, quality) **Core Measures** 1. Absolute numbers of beneficiaries in the different schemes. 2.Absolute numbers and % of beneficiaries that are men/women, boys/girls **Optional Indicators and Measures if data allow** 1. SPP coverage rate as % of eligible 2. National spending on SPP and amount/source (external/domestic) 3. Total spending including private and NGO sectors	**Methods** 1. Desk review 2. Secondary analysis of existing data 3. Services statistics analysis 4. Labour statistics analysis **Sources** 1. National SPP administrative reports and documents 2. Related surveys 3. Private sector insurances documents 4. NGO and/or community based schemes documents 5. ILO national social protection floor assessment and Social Security inquiries 6. ILO SSPTW documents 7. National social protection accons 8. National AIDS Programmes reports and statistics 9. Networks of people Living with HIV	1. Categorize SPP, schemes and benefits statutory/not statutory, public/private (contributory or not) 2. Categorize benefit features as per ILO criteria in terms of function, type of benefit (cash/ in kind), periodicity (periodic/lump sum), mandatory/voluntary, complementary/main benefit, and others 3. Illustrate the evidence 4. Identify gaps 5. Identify good practices

Core Research Elements and Menu of Indicators			
Research Questions	**Core and Optional Indicators and Measures**	**Data collection Method and Data Sources**	**Basic Analysis and Presentation of Findings**
Q2. Access: Type of SPP in the country for PLHIV 2.1. Do SPP cover workers living with HIV? If so, under which contingencies of social protection (e.g., health or unemployment insurance, livelihood/income support, cash transfers, etc.)? 2.2. Do SPP explicitly include benefits for PLHIV? 2.3. Do SPP explicitly exclude benefits for PLHIV? 2.4. Do SPP explicitly exclude any population group (e.g., sex workers (female and males), men who have sex with men, transgender individuals, intravenous drug users, inter-gender (neither men nor women), gays, bisexual, men and women in prison or migrants)?	**Core Indicators** 1. Types of HIV-targeted SPP (Criteria: beneficiaries, eligibility, inclusion, exclusión) 2. Accessibility of these SPP (Criteria: affordability, availability, financial protection, quality) 3. HIV-specific SP benefits (e.g., free ARV, free Tuberculosis medication, health insurance for PLHIV, livelihood support programmes for PLHIV, transport support to enable PLHIV access ART, etc.) and inclusion criteria **Core Measures** 1. Absolute numbers of HIV-targeted SPP Programs and PLHIV beneficiaries in the different schemes, if available. 2. Absolute numbers and % of PLHIV beneficiaries that are men/women, boys/girls **Optional Indicators and Measures if data allow** 1. Coverage rate of SPP (as % of eligible) 2. Absolute numbers and % of PLHIV beneficiaries 3. National SPP and health spending on PLHIV 4. Total spending including private and NGO sectors 5. Budget provisions (amount and %) for (i) HIV-sensitive & (ii) gender-sensitive programs (unemployment and health insurances)	**Methods** 1. Desk review 2. Secondary analysis of existing SPP data 3. Service statistics analysis 4. Research survey 5. Informants interviews 6. Focus groups **Sources** 1. National SPP administrative reports and documents 2. Private insurances documents and policies 3. NGO and/or community based schemes documents 4. ILO national surveys/studies 5. ILO SSPTW documents 6. National social protection accounts 7. National AIDS Spending Accounts (NASA) UNAIDS 8. Country UNGASS reports 9. National Demographic Health Survey (DHS)	As above, plus 1. specify SPP that are HIV-sensitive, HIV inclusive and/or which exclude HIV 2. Specify SPP that are gender-sensitive, gender-inclusive and/or gender not-exclusive 3.Illustrate the evidence 4. Correlation of findings among key variables 5. Identify gaps 6. Identify good practices

Core Research Elements and Menu of Indicators			
Research Clusters and Questions	**Core and Optional Indicators and Measures**	**Data collection Method and Data Sources**	**Basic Analysis and Presentation of Findings**
Q3. SPP benefits and PLHIV employment status **Access** 3.1. Does HIV status exclude workers from accessing national SPP benefits? - when employed in the formal or informal economy? - when unemployed and looking for a job? - when not-working and not looking for a job? 3.2. Does HIV status exclude workers from accessing SPP benefits from private or community based social protection schemes? **Effects** 3.3. Does receiving social protection enables PLHIV to improve their ability to (i) work (e.g., retain their jobs or return to their productive activities) or (ii) to not work (remain not-working), and (iii) to access health care benefits and medical care?	**Core Indicators** 1. Access to SPP for respondents in formal and informal economy, analysed by gender 2. Job loss due to HIV 3. Income loss due to HIV or seeking care 4. Frequency/duration of work absenteeism 5. Family income and sources (e.g., person with HIV, retired person, others) 6.Out of pocket expenditures in medical care, medications, transport, children education or food **Core Measures** 1. Absolute numbers and relative amounts (income, absenteeism, out of pocket spending, hours in care giving, etc.) 2. Percentages (income sources by household member, among difference sources of income, other) 3. Disaggregation by category as relevant **Optional Indicators and Measures if data allow** 1. Respondent/household out of pocket payments as % of total individual and/or household health expenditures 2. % increase in care giving, income generating tasks, unpaid household or family-related work, due to HIV by men/women, boys/girls	**Methods** 1. Desk review 2. Secondary analysis of existing data 3. Research survey 4. Informants interviews 5. Focus groups **Sources** 1. National SPP documents 2. National labor strategy, administrative reports and documents 3. Labor statistics 4. Unemployment regulatory framework 5. Related surveys 6. ILO national surveys/studies 7. ILO SSPTW documents 8. National social protection/social insurance system accounts 9. National DHS	1. Frequency, trends, proportions, correlations of key variables. 2. Show type of program, coverage, source of funds, qualifying conditions unemployment benefits 3. Show programmes that are HIV-sensitive/HIV inclusive and those which are HIV exclusive? 4. Show programs that are gender-sensitive, gender-inclusive and/or gender not-exclusive 5. Cross tabulate key variables 6. Show the evidence, including costs associated with covering HIV prevention, HIV treatment, HIV care, HIV support (livelihood) 7. Identify gaps 8. Identify unexpected effects (positive and negative) 9. Identify good practices related to workers with HIV

Core Research Elements and Menu of Indicators			
Research Clusters and Questions	**Core and Optional Indicators and Measures**	**Data collection Method and Data Sources**	**Basic Analysis and Presentation of Findings**
Q4. Barriers to SPP benefits for PLHIV 4.1. What are the barriers for PLHIV to access social protection benefits? 4.2. What are the challenges in providing/delivering social protection benefits to the PLHIV population? 4.3. Is access to and delivery of SPP benefits equitable along gender and key population groups?	**Core Indicators** 1. Supply side. Programs that exclude PLHIV; programs for which PLHIV are not eligible. 2. Demand side. Out-of-pocket costs of accessing services by place of residence; self-stigmatization; economic or physical dependency on others for clinic visits or payments **Core Measures** 1. List of Barriers 2. Absolute numbers 3. % of men/women, MSM, sex workers, transgender, IDUs, workers, unemployed, and other disaggregation as relevant	**Methods** 1. Secondary analysis of existing data (i.e., community surveys, providers surveys) 2. Research Survey 3. Informants interviews 4. Focus groups **Sources** 1. NGO and/or community documents 2. Labor studies and documents 3. ILO national surveys/studies 4. Labor services statistics 5. Stigma Index national report 6. Country UNGASS reports 7. National DHS 8. Informants 9. Respondents	1. Compare outcomes for each variable of interest 2. Show frequency, distribution and correlations for key variables 3. Cross tabulate by gender, work status, others 4. Determine trends 5. Compare findings with previous studies 6. Show how SPP caters to PLHIV in the informal economy 7. Show how SPP caters to PLHIV who are unemployed 8. Illustrate with examples given by respondents if possible 9. Identify unexpected effects (positive and negative) 10. identify good practices related to access, and enabling factors

Core Research Elements and Menu of Indicators

Research Clusters and Questions	Core and Optional Indicators and Measures	Data collection Method and Data Sources	Basic Analysis and Presentation of Findings
Q5. SPP benefits and household vulnerabilities Access 5.1. Does access to SPP benefits contribute to reducing the vulnerabilities of PLHIV and their households? Effects 5.2. Are PLHIV and their households receiving SPP benefits better off than those PLHIV or non-PLHIV not receiving benefits? **-**children remain at school? -members of the household retain their jobs or productive activities? -Care giving does not increase? 5.3. Since receiving SPP benefits has there been any increase in the number of people living in the household?	**Core Indicators** 1. Amount of work-related income by household member 2. Amount and periodicity of assets received 3. Type of benefits (cash/in-kind) received (food, school supplies, old age, survivor or disability pension, medical benefits, family allowances, livelihood support, others) and household source (person with HIV or other members of the household) 4. Household savings and household spending **Core Measures** 1. Absolute amount, number and % 2. Disaggregation by all relevant categories **Optional Indicators and Measures if data allow** 1. Income and assets pre-post HIV positive status (increased, decreased, stable) 2. National spending in care and support 3. School attendance (age and % of boys/girls) 4. Care and support received and given by men /women, boy/girls)	**Methods** 1. Secondary analysis of existing data 2. Research survey 3. Informants interviews 4. Focus groups **Sources** 1. National SPP administrative reports and documents 2. Related surveys 3. Private sector insurances documents 4.NGO and/or community based schemes documents 5. ILO national surveys/studies 6. ILO SSPTW documents 7. National social protection accounts 8. National DHS 9. Stigma Index national report 10. Country UNGASS reports 11. National AIDS Spending Accounts (NASA) UNAIDS	1. Compare outcomes for each variable of interest 2. Show hours expended by men and women in paid and unpaid household or family-related work and on care giving 3. Show correlations by gender, work status, site of residence, benefits received, others 4. Determine trends if possible 5. Compare findings with previous studies 6.Illustrate with real examples given by respondents if possible 7. Identify unexpected effects (positive and negative) 8. Describe good practices related to effects of SPP access

Core Research Elements and Menu of Indicators			
Research Clusters and Questions	**Core and Optional Indicators and Measures**	**Data collection Method and Data Sources**	**Basic Analysis and Presentation of Findings**
Q6. Effects of SPP benefits on PLHIV HIV-related health status 6.1. Do SPP benefits improve PLHIV's ability to utilize health and social services for HIV related screening, treatment and care? 6.2. Do SPP benefits contribute to PLHIV's ability to utilize health services equally despite of group membership e.g., sex workers (female and males), men who have sex with men, transgender individuals, intravenous drug users, inter-gender (neither men nor women), gays, bisexual, men and women in prison or migrants 6.3. Do SPP benefits affect ARV Therapy adherence? 6.4. Do SPP benefits affect treatment adherence for opportunistic infections such as TB, and others.	**Core Indicators** 1. PLHIV who report treatment adherence as a result of access to SPP 2. PLHIV who report completion of TB treatment as a result of access to SPP, 3. Hospitalizations (frequency, length of stay, costs, reasons) –as a proxy for broader HIV-related health status **Core Measures** 1. Absolute numbers and % 2. Absolute numbers and % of PLHIV seeking care or not seeking care although in need 3. Absolute numbers and % of PLHIV not fulfilling prescriptions and reasons 4. Absolute amount and % of total HIV-related medical payments **Optional Indicators and Measures if data allow** 1. ARV Therapy coverage and adherence 2. Opportunistic infections coverage and adherence 3. National spending in medical care for PLHIV 4. Reasons for clinic visits: diagnostic, follow-up, ARV therapy, STI, other opportunistic infections and tuberculosis treatment, emergency, others.)	**Methods** 1. Secondary analysis of existing health services and HIV statistics 2. Research survey 3. Informants interviews 3. Focus groups This one finds out from treatment providers but may need to correlate with PLHIV's own reporting to check for discrepancies or consistency **Sources** 1. MOH services statistics 2. National HIV/AIDS statistics 2. Country UNGASS reports 3. Country MOH reports 4. National AIDS Spending Accounts (NASA) UNAIDS 5. National DHS 6. Stigma Index national report	1. Compare outcomes for each variable of interest 2. Show correlations among variables 3. Cross tabulate by gender, work status, others 4. Assess trends if possible 5. Compare findings with previous studies 6. Illustrate with real examples given by respondent if possible 7. Identify unexpected effects (positive and negative) 8. Identify good practices related to effects of SPP on access and utilization of health/medical services by PLHIV

5. Semi-structured Interview Guide for Key Informants

Note to Interviewer: First, introduce yourself, then thank him/her/them for their participation and explain the reason for the meeting and the expectations.

1. Fill out the first section. It is shaded.

2. Read all the questions one by one out loud as they are written. After listening carefully, probe each answer with follow up questions such as: "Can you please explain why? Could you give me an example?

3. The instructions that are underlined and italicized in the text *like this* are for the interviewer only and are not to be read out loud during the interview.

At the end of the interview, thank the respondents and don't forget to ask if the respondents have any questions.

Identification

Name of Informant _______________________ Man___ Woman____

Title and Institutional Affiliation ____

Name of Interviewer _____________________________ Man____ Woman_____

IDENTIFICATION CODE [__][__][__][__][__] Date of Interview (Day, Month, Year)

MENU OF QUESTIONS

Core Questions to all key informants

1. What is your general view of the social protection programmes and benefits in the country? (do they work, are they funded, are they successful or not)

2. What in your opinion are the most important features of the social protection system?

3. Are these programs available only to those who work in the formal economy?

4. How can people who are self-employed, day laborers, those who work in the informal economic or those who are employed gain access to social protection benefits, health insurances and other benefits and services?

5. Which population groups are targeted by these programs? Women, youth, children, migrants? How about for women living with HIV?

6. How easy is for different population groups to access social protection benefits? (migrant workers, sex workers, IDUs, MSM, women, the disable, the poor?)

7. Do you think the social protection program covers all the population groups equitably? (different gender groups, key populations, geographic differences, the poorest, prisoners, others.)

8. What about groups such as PLHIV. Are there programs that specifically target this population group? How can social protection programmes respond to PLHIV in the informal economy?

9. What is the role of your organisation/section/department in the social protection system of the country? (policy making, managing benefits, funding, providing services, advocating for programmes, regulating programs, reporting, etc)

10. How, in your opinion, does social protection programme assist PLHIV with regard to gender equity and with regard to employment?

Additional Questions for Government Agencies

In your opinion:

1. What is the most important role of the government in social protection?

2. What is the role of the private sector in social protection in the country?

3. What is the role of the civil society sector in social protection in the country?

4. What are the most important gaps that exist in the present social protection system?

5. What services or benefits would you add or remove from the social protections system to make it more efficient and more equitable?

6. Have you ever considered PLHIV in the design of social protection instruments?

7. Has social protection for PLHIV ever been raised by national organisations (NGOs, social movements etc) or international groups as part of policy discussions?
8. How do you think these groups could be best covered through special targeted policies or within general programmes?

Additional Questions for Development Agencies and Donors

In your opinion:

1. What are the most important gaps that exist in the present social protection system?
2. Are the key vulnerable populations protected by the current social protection system? Women, children, the disable? The PLHIV, for instance? PLHIV who are of different gender? Those living in rural areas? Those groups that are marginalized? The poor? Prisoners?
3. Where any of these groups engaged in the policy making process? What about PLHIV?
4. What are the main barriers to accessing social protection benefits? How could these barriers be overcome?
5. Who pays for social protection?
6. What services or benefits would you add or remove from the social protections system to make it more efficient and more equitable?
7. What are some examples of programmes that worked and programmes that did not work well?

Additional Questions for Heath/Medical/Social Service Providers

What services do you provide related to HIV and AIDS?

1. Prevention (e.g. education/ information campaign, voluntary counselling and testing, condom distribution)?
2. Provision of medication (e.g. ART, medication for opportunistic infections)?
3. Follow-up for treatment adherence?
4. Support for PLHIV (e.g. peer support, financial assistance, in kind support, home care)?
5. Activities involving orphans and vulnerable children (scholarships, help buying school supplies, running an orphanage)?
6. Other activities related to social protection of PLHIV?
7. Other activities related to medical aspects of HIV/AIDS?
8. Other activities unrelated to HIV/AIDS?

In your opinion:

1. What are some of the factors that have helped you in serving the key populations of PLHIV?
2. What are some of the main obstacles you encounter in providing services?
3. Has your department/agency influence how people of different gender are treated? If so, how?
4. Do all people who need services seek services? If not, why?
5. Do all people who seek services receive services? If not, why?
6. Are you aware of any PLHIV in the community in which you are operating?
7. Are there specific provisions in the programme that you administer for PLHIV?
8. In practice does this social protection programme meet the needs of the PLHIV that you know?
9. How are PLHIV perceived in your country, culture or religion?

Additional Questions for PLHIV Networks and NGOs Working with PLHIV

What is the role and responsibility of your organization in regard to PLHIV?

1. Prevention (e.g. education/ information campaign, voluntary counseling and testing, condom distribution)?
2. Provision of medication (e.g. ART, medication for opportunistic infections)?
3. Follow-up for treatment adherence?
4. Support for PLHIV (e.g. peer support, financial assistance, in kind support, home care)?
5. Activities involving orphans and vulnerable children (scholarships, help buying school supplies, running an orphanage)?
6. Other activities related to social protection of PLHIV?
7. Other activities related to medical aspects of HIV/AIDS?
8. Other activities unrelated to HIV/AIDS?
9. Who is the main target/audience of your organization?
10. How many clients are you currently reaching (within the past 6 months or one year)?
11. How is the community / and or beneficiaries involved?
12. Do you report the outcomes/progress of your activities to anyone? If so, to whom?

In your opinion:

1. Are there any activities/initiatives that you would like to carry out with PLHIV but have not been able to do so? If so, what are those activities/initiatives? Why haven't you been able to carry them out?

2. Has the work of your organization affected how people of different gender are treated? If so, how?

3. What is your experience with government and local authorities' response to the social protection needs of people with HIV?

4. In what way, if any, does your organization interact with the government? (*Probe for activities related to social protection and HIV/AIDS*)

5. What other organizations or institutions in your community provide HIV social protection related services? What serviced do they provide? (*Probe: treatment, prevention, care & support, impact mitigation and networking & advocacy; health insurances, cash transfers, food aid*)

6. In what way, if any, does your organization interact with other organizations working with people with and affected by HIV? (*Probe for other NGOs, private sector, government agencies*)

7. In practice does this social protection programme meet the needs of the PLHIV that you know?

8. How are PLHIV perceived in your country, culture or religion?

6. Interview Script for Focus Groups

Introduction

Focus group discussions will be conducted with both PLHIV who are accessing benefits and those who are not accessing benefits as well as people from key populations whose HIV status is unknown. There should be gender diversity in the groups.

Researchers may choose to conduct additional focus groups with employers and workers' organizations and with service providers, or may include these individuals for interviews as key informants.

Note to Interviewer:

First, introduce yourself, then welcome the participants and explain the reason for the group meeting. Introduce the data recorders and explain their role. Thank the group for their cooperation and begin.

Each answer to a specific question can be followed by probing questions asking for clarification. You can also paraphrase to make sure you understood a particular point. Be careful not to digress or to ask leading questions.

Name of and location ____

Number of participants __________ Men ______ Women _______

Name of Interviewer _______________________

IDENTIFICATION CODE [__][__][__][__][__] Date (Day, Month, Year) _____

MENU OF QUESTIONS

1. Are any of you receiving social protection benefits? Which benefits? Which ones are the most useful? Why?
2. If receiving benefits, what do you like best about this program? What are the biggest problems? Please give an example.
3. If not receiving benefits, do you know where you can go to access social protection programs? Do you encounter any barriers in accessing benefits? Are you afraid or

uncomfortable asking for services? Why? How are you treated when you do go for services? Is a friendly way? In a formal way?

4. Are there programs/benefits you need since you are HIV positive that you are not receiving? If so, why?
5. Do you have health insurance? Or unemployment insurance? If yes, for how long, If not, why?
6. What health and social protection benefits do you think you should receive?
7. Have you changed your living arrangements after being diagnosed with HIV?
8. Is anyone in your household receiving any form of social protection benefits? Who? What type of benefits?
9. Since you were diagnosed with HIV, has the number of people in your household increase or decreased? Why?
10. What type of work or income generating activity are you doing right now? For how long have you been doing this activity or held this job?
11. Who in your household contributes to generating income? How? Who are they (spouse, partner, parents, siblings, brothers/sisters, others)?
12. What type of medical or community services are you using? How was your experience? Did you encounter any problems accessing the services? Please give an example. What causes the problem? How did it happen? What did you do?
13. If you could access any social protection program/services, what would it be? What program(s) will be most useful to you? Why?

7. Survey Instrument

Before starting the interview:

1. Ask the respondent if he/she has been interviewed before for this study. If yes, do not interview. If possible double-check against the Respondents Identification number list or the Questionnaire Serial number. If the person has not been interviewed for this study, please continue.
2. Complete the Identification box. Note that the name of the respondent is not needed and should not be recorded in the questionnaire to maintain confidentiality.
3. Explain the purpose of the study and the objective of the interview. Give and read the informed consent form to the interviewee and seek his/her consent. If he/she agrees to participate in the study, please proceed and ask questions.

Questionnaire Serial Number [__][__][__][__][__]

Identification				
01. Location ID	1. Number	2. Name		
02. Respondent ID	#			
03. Gender of Respondent	1. Female	2. Male	3. Transgender	4. Other
04. Interviewer ID	#			
05. Name of Interviewer				
06. Gender of Interviewer	1. Female	2. Male	3. Transgender	4. Other
07. Respondent is:	1. Interviewed	2. Refuses to be interviewed	3. Already interviewed	
08. Date of Interview	Day/	Month/	Year/	

Control	**Name**	**Date (Day/Month/Year)**
1. Field Level		
2. Central Office		
3. Data Entry Clerk		
4. Researcher(s)		

Notes:
Mark only one answer for each question except when otherwise noted.
Recall time is 12 months except when otherwise noted

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SECTION 1: DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

101. How old are you?	1. Yrs. _____ 2. 15-24 years 3. 25-49 years 4. 50-59 years 5. 60 years old or more 99 = Don't Know		
102. What is the highest level of schooling you have completed?	1. Have never attended school 2. Primary school up to______(year) 3. Secondary school up to ____ (year) 4. Technical/Vocational college 5. University or higher 98 = No answer 99 = Don't know		
103. Where do you live? (Location, not address)	1. City (urban) 2. Village (rural) 3. Outside the city (peri-urban)		
104. What is your current **main** job or occupation? (**Countries may use their national classification categories to collect the data for formal and informal employment)** (Mark two responses maximum)	1. Working in formal employment (full time) 2. Working in formal employment (part time) 3. Working in informal employment (full time) 4. Working in informal employment (part time/seasonal) 5. Self-employed 6. Engaged in Household/ family work (unpaid) 7. Unemployed but looking for employment 8. Unemployed and not seeking employment 9. Retired 10.Others Specify _____________ 98 = No answer		
105. What is your current relationship status?	1. Single, never married 2. Currently married 3. Divorced/ separated 4. Widow/widower 5. In a committed relationship 98 = No answer		
106. What is your current living arrangement	1. Living alone 2. Living in parents household 3. Living in own household with spouse/partner and children 4. Living in own household **but** spouse/partner lives/works away from the household. Specify for how long _____ and how often______ 5. Other. Specify _____________ 98 = No answer		
107. How many people currently live in your household in each of these categories?	Categories	Number	Sex
	1. Children aged 0-14 years	1.	1.
	2. Orphaned Children (if any, due to AIDS)	2.	2.
	3. Youth aged 15-24 years	3.	3.
	4. Adults aged 25-49 years	4.	4.
	5. Adults aged 50-59 year	5.	5.
	6. Adults 60 years and older	6.	6.

108. Do you belong to any of the following categories? (Mark all that apply)	1. Gay/Men who have sex with men 2. Lesbian 3. Transgender 4. Sex worker 5. Injecting drug user 6. Refugee or asylum seeker 7. Internally displaced person 8. Member of an indigenous group 9. Migrant worker 10. Prisoner 11. I don't belong to, and have not in the past belonged to, any of these categories 98 = No answer

SECTION 2: SOCIAL PROTECTION PROGRAMS AND EMPLOYMENT STATUS

(Corresponds mainly but not exclusively to Q3 research questions in the Core Elements Table)

201. Has your monthly income changed due to your HIV status	increased	decreased	Main Reasons for decrease	Pl. mention the average amount of increase or decrease
202. Have your household monthly expenses changed due to your HIV status? (Mark responses for each category)	1. Food 2. Clothing 3. School supplies 4. School fees 5. Transport 7. Medicines 8. Medical care 9. Other. Specify ________________	Increased (pl. mention average amount) 1. 2. 3. 4. 5. 6. 7. 8.	The same 1. 2. 3. 4. 5. 6. 7. 8.	Decreased (pl. mention average amount) 1. 2. 3. 4. 5. 6. 7. 8.
203. Did any member of your household quit their employment or change the type of employment due to your HIV status? (Mark all that apply)	1. Yes 2. NO 3. My spouse/partner 4. My mother 5. My father 6. My sister 7. My brother 8. Other _____ 98 = No answer 99 = Don't know	Quit job 3. 4. 5. 6. Job/school 7. Job/school 8.	Changed work 3. 4. 5. 6. 7. 8.	Decreased hours worked 3. 4. 5. 6. 7. 8.
204. Did the children in the household drop from school due to your HIV status?	1. Yes 2. No 3. Yes my son. Age _____ 4. Yes my daughter. Age _____ 5. Other. Specify ______ 6. Why? ______________________			

205. Does your employer know about your HIV status?	1. Yes 2.No 3. Self-employed 99 = Don't Know			
206. If yes, have you been able to retain the same job?	1. Yes 2. No 3. If no, why? Specify ______________			
207. In the last 12 months, did you face any of these situations due to your HIV status?	Loss of job 1. Never 2. Once 3. A few times 98 = No answer	job description or the nature of your work changed,	by-passed for promotion,	I had to change my jobs
208. If you have lost or changed jobs, what was the reason? (Mark all that apply)	1. I was asked to quit job 2. I felt discriminated by co-workers 3. I was told to leave 4. I decided to quit 5. I was too sick to continue working 6. Other, specify_______________________			
209. Have you been refused employment benefits, available to other employees due to your HIV status?	1. Yes 2. No 3. If yes, why? Specify __________________			
210. In past 12 months, how many times and days were you absent from work due to ill health as a result of your HIV status?	1. Number of times __________ 2. Number of days each time________ 99 = Don't know			
211. In past 12 months, did you lose wages/income due to being absent from work due to HIV?	1. Yes 2. No 3. If yes, how much _____________ 99 = Don't know			
212. Does your workplace have a policy on HIV and AIDS?	1. Yes 2. No 98 = No answer 99 = Don't know			

SECTION 3: HIV STATUS, STIGMA AND DISCRIMINATION

(Corresponds mainly but not exclusively to Q3 research questions in the Core Elements Table)

A. HIV Status				
301. For how long have you been living with HIV?	1. Less than 4 months 2. Less than 1 year 3. 1-4 years 4. 5-9 years 5. 10-14 years 6. More than 15 years			
302. Is there anyone else in your family whom you know is HIV positive?	1. Yes 2. No 3. Yes, spouse/partner 4. Yes, sibling 5. Yes, children 6. Number of HIV positives in the household ____________ 98 = No answer 99 = Don't know	Age	Sex	
B. Stigma and Discrimination				
303. Have you faced stigma and discrimination due to your HIV status, please indicate the sources where you faced discrimination	1. From Spouse/partner	In past 12 months	Not in past 12 months	Never happened

(Mark all that apply)	2. From other family members 3. From employers 4. From co-workers 5. From health care facilities/providers 6. From social services 7. From insurance provider 8. Any other source 98 = No answer			

SECTION 4: EFFECTS OF SOCIAL PROTECTION BENEFITS ON ACCESS TO HIV-RELATED MEDICAL AND HEALTH SERVICES

(Corresponds mainly but not exclusively to Q4 and Q6 research questions in the Core Elements Table)

401. Are you currently taking antiretroviral (ART) therapy?	1. Yes 2. No 3. If yes, for how long? ____________ 4. If no, why? Specify___________
402. Do you have *access* to antiretroviral treatment, even if you are not currently taking it?	1. Yes 2. No 98 = Don't know
403. Have you ever stopped taking antiretroviral medication?	1. If yes, how many times? _____ 2. If yes, for how long each time? ________________ 3. Why did you stop? Specify__________
404. Have your expenses for antiretroviral treatment increased in the last year?	1. Yes Amount _________________ 2. No. HIV treatment medication is free to me 98 = No answer
405. Are you currently taking any medication to prevent or to treat opportunistic infections like TB, pneumonia etc.?	1. Yes 2. No 3. if yes, please specify the treatment you are taking 4. who is paying for the treatment 98 = No answer
406. Do you go for medical care every time you need it?	1. Yes 2. No. Explain why not _______________________
407. What are your major Out of Pocket Expenses related to your health care (ART/ treatment of Opportunistic infections	1. transport 2. consultation fee 3. purchase of medicines 4. Opportunity costs such as loss of wages/earning due to hospital visits
408. Who pays for your Out of Pocket Expenses at the moment?	1. you yourself out of your income 2. An existing scheme/benefit (pl. specify________________________) 3. Your employer 4. Others, please specify ___________________________________
409. Do you have access to health insurance	1. Yes 2. No
410. Who pays the premium for your health insurance	1. Self 2. Employer 2. Government 4. Contributory (you pay part and the other part is paid by others, pl.

	specify_________________)
411. Do you find the coverage of your health insurance adequate to your needs	1. yes 2. No. 3. Pl specify reasons in case of no

SECTION 5: ACCESS TO AND EFFECTS OF SOCIAL PROTECTION BENEFITS

(Corresponds mainly but not exclusively to Q4 and Q5 research questions in the Core Elements Table)

Please classify national social protection schemes/ other schemes private or community available to people under the broad ILO categories shown in the tables below. (2) DK = Don't know. It has a code of 777 instead of 99 as in the rest of the questionnaire. Adapt coding at the country level as needed. 3. NA = Not applicable.

501 Are you yourself covered by any of the following schemes? Read out (these are examples) (Mark all that apply)	501 a. Coverage of *respondent*				502 b. If yes in 501a, are you directly or indirectly covered?			
	Yes	No	DK	NA	Direct	Indirect	DK	NA
1. Social security system (general)*	1	2	777	999	1	2	777	999
2. Public Service Pension scheme	1	2	777	999	1	2	777	999
3. Workmen's Compensation	1	2	777	999	1	2	777	999
4.Social Welfare (assistance) services (including health/Medical assistance) provided publicly	1	2	777	999	1	2	777	999
5.Social Welfare (assistance) services (including health/ medical assistance) provided by NGOs or other private organizations	1	2	777	999	1	2	777	999
6. Medical care supported by an employer	1	2	777	999	1	2	777	999
7. Wages through participation in public works programmes	1	2	777	999	1	2	777	999
8. Child/ family benefits	1	2	777	999	1	2	777	999
9. Food supports	1	2	777	999	1	2	777	999
10. Community based insurance schemes	1	2	777	999	1	2	777	999

*** Social security system** refers to the general statutory existing social security scheme(s) in the country providing long term and short benefits (old pension, disability, survivors) and short term benefits (unemployment, sickness and health, maternity).*

	502 In the last 12 months have you [has any member of you household*] received regular benefits in cash or in-kind?	Received payment from this source	Which household members received the payment?*	How much was received in total from this source last month?	How much was received in total from this source in the last 12 months?

	Regular cash benefit	1. YES 2. No (>>NEXT ROW)	1	2	3	PAYMENTS IN CASH AMOUNT (CURRENCY UNITS)	PAYMENTS IN CASH AMOUNT (CURRENCY UNITS)
1	Old age pension						
2	Disability pension						
3	Survivor's benefit						
4	Unemployment benefit						
5	Sickness benefit						
6	Maternity benefit						
7	Child Benefit						
8	Work injury/ occupational disease benefits						
9	Social assistance						
10	Public works						
11	Other regular cash payments (specify……...)						

		SAME QUESTION AS ABOVE				PAYMENTS IN KIND			
			MEMBER'S ID CODE						
	Source of Regular In-Kind Income	1. YES 2. NO (>>NEXT ROW)	1	2	3	FORM: WHEAT…1 RICE…2 MEALS…3	QUANTITY	UNITS: KGS…1 LITRES…2	Number of Months Received
12	In-School Feeding								
13	Food for Work								
14	Education for family members								
15	Other regular payment in kind (specify………………)								

* If respondent is head of household

503 If you are in need, where do you go for help? (Mark all that apply)	1 – Psychological support	2 –Financial support	3–Information or advise	4–goods/ services support	5 –Logistical support (transport, social services, etc.)	6 –Other (specify, please)	7 –did not get any support
1. From family	1	2	3	4	5	6______	7
2. From friends	1	2	3	4	5	6______	7
3. From the employer	1	2	3	4	5	6_____	7
4. From trade-union	1	2	3	4	5	6_____	7
5. From social security institutions	1	2	3	4	5	6________ _____	7
6. From international organizations	1	2	3	4	5	6________ _____	7
7. From NGOs	1	2	3	4	5	6________ _____	7
8. From state medical institutions	1	2	3	4	5	6________ _____	7
9. From state non-medical institutions	1	2	3	4	5	6________ _____	7
10. From others______	1	2	3	4	5	6________ _____	7

504. Do you know where to apply for social security or social insurance	<u>Health insurance</u> 1. Government	<u>Unemployment insurance</u> 1. Government

benefits? (Mark all that apply)	2. Private 3. Non-government organization 4. Other. Specify ___________ 99 = Don't know	2. Private 3. Non-government organization 4. Other. Specify ___________ 99 = Don't know
505. Have you or your spouse/partner benefitted from any livelihood support scheme such as income generation, vocational training etc.	1. Yes (Please specify ____________________ 2. No. 3. I don't need such support	
506. Have your social benefits changed due to your HIV status?	1. Yes 2. No If yes, 1.a I receive **more** benefits. Specify_____ 1-b I receive **fewer** benefits. Specify _____ 99 = Don't know	
507. How do you use the social protection benefits you receive? (Mark all that apply)	1.To pay for daily expenses 2.Pay for medical consultations 3. To pay for medication 4. To pay for hospitalizations 5. To pay for food 6. To pay for transport cost related to hospital visits 7. To pay for my children's schooling 8. To pay a loan 9. Other. Specify _____ 98 = No answer	
508. Please respond Yes or No to the following statements. Since receiving social protection benefits : (Mark all that apply)	Yes No 1.I have been able to retain your job 2. I have been able to continue earning income 3. I am able to get the medical care when I need it 4. I am able to continue my ART 5. I am able to pay for the cost of my medications (out of pocket expenses) 7. My partner/spouse has been able to keep his/her jobs or economic activity 8. My spouse/partner has been able to stay HIV negative 9. My Children are able to stay HIV negative 10. My HIV positive child (if any) has been able to continue education and treatment 11. My children can continue to attend school 10. Other. Specify _____	
509. If you are not getting the kind of support you need, what are the reasons? (Mark all that apply)	1. I am not eligible 2. I am eligible but the procedures to request support/services are too complicated. 3. I don't work in a company and I have no access to insurance. 4. I work in a company but I don't receive insurances or other social benefits 5. I don't know how to apply 6. I know where the services are but they are too far from where I live. 7. Transportation is expensive 8. I don't like how I am treated 10. I need to pay for services 11. Other. Specify _______________ 98 = No answer 99 = Don't know	

SECTION 6: CARE GIVING AND CAREGIVERS[22]

(Corresponds mainly but not exclusively to Q3 and Q5 research questions in the Core Elements Table)

		In last 12 months	Not in last 12 months (years before)
601. Have you needed anyone to take care of you, due to your HIV status?	1. Yes 2. No		

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[22] Questions informed by "Past due: Remuneration and social protection for caregivers in the context of HIV and AIDS". Policy Briefing March 202. UK: The UK Consortium on AIDS and International Development.

602. If yes, who is your primary caregiver? And how many hours per day he/she provides care? (Mark all that apply)	Primary Caregiver is 1. Spouse/Partner Male_______ Female____ 2. Children Boy_______ Girl_____ 3. Parents Father_____ Mother ______ 4. Siblings Brother _____ Sister_________ 5. Friend Male_______ Female______ 6. Other. Specify _______		Hours per day in care giving
603. In addition to providing care is your primary caregiver employed?	1. Yes 2. No 3. If yes, what is the occupation? Specify_______________ 4. Is he/she employed 4.1. full time _________ or 4.2. part time_____ 4. If not employed, why not? Specify _________________		
604. Dou you have to compensate your caregiver? How much per day worked?	 1. Salary 2. Stipend 3. Transportation only 4. Food and other in-kind 5. No compensation 6. Other ____________ 98 = No answer	Pr. Caregiver Amount 1. 2. 3. 4. 5. 6.	Sec. caregiver Amount 1. 2. 3. 4. 5. 6.

At the end of the Interview.

1. Ask the respondent if they would like to add any comments or whether they have any questions:

____

____

____

2. If the respondent is interested in knowing more about social protection benefits and services, please refer the respondent to the appropriate agency or NGO which might be able to help or direct the person to the right agency.

1. Did the interviewee need a referral?	1. Yes 2. No
2. If Yes, what kind of referral(s)?	1. Social services 2. Health services 3. Support group 4. Counselling 5. Legal 6. Other. Specify_________________

8. Research Report Outline

FRONT PAGES

Inside Tile Page: Authors, Date and Abstract

Table of Contents

Preface or Foreword

Executive Summary (A short summary of the report that includes the research questions and the methodology used, and summarizes the report's findings, conclusions, recommendations, good practices and lessons learned)

Acknowledgements (this section can go at the end)

Abbreviations and Acronyms

BODY OF THE REPORT

Introduction

Purpose of the research

Background and context information

Research questions

Study population

People involved: PLHIV, stakeholders, national agencies, others.

Description of the research

Purpose

Scope

Questions

Methodology

Limitations

Findings

Highlight the most important findings or gaps

Organize the findings around research question and major themes and issues

Use graphics, charts and tables to highlight major points.

Conclusion

Provide a professional assessment of the findings as related to the research questions

Select good practices. Provide respondents’ worlds as illustration if possible

Identify lesson learned in the process of conducting the research

Recommendations

Indicate a few selected actions –policy programme or advocacy related – that could be taken on the basis of the findings, given the researchers knowledge of the country situation

References

Appendices

Research instruments

Others

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APPENDICES

Appendix 1

Terms of Reference
Social Protection and HIV Research

Guidance note to ILO country office regarding the country research on:
"The access to and effect of social protection programmes on women and men workers in formal and informal economies living with HIV and their households"

The ILO proposes to undertake research in **………** country to gain knowledge on *access to* and *effect of* social protection policies and programmes, particularly on social health protection and income support, on women and men workers in the formal and informal economies affected by HIV or AIDS and their households

Background

Established in 2001, the ILO Programme on HIV/AIDS and the world of work (ILO/AIDS), in collaboration with partners, has supported countries to implement innovative HIV workplace initiatives aimed at increasing access to HIV prevention, treatment, care and support services to vulnerable men and women workers. These initiatives have been implemented in the public and private sectors as well as the formal and informal economies. The ILO Code of Practice on HIV/AIDS and the ILO Recommendation concerning HIV and AIDS in the world of work, 2010 (No. 200) provide the framework for ILO's support to member States. More information on ILO/AIDS can be seen at www.ilo.org/aids.

Social protection contributes to preventing HIV and mitigating its impact because it aims at preventing or reducing poverty and supports meeting peoples' basic livelihood, education and health needs. The ILO HIV and AIDS Recommendation, 2010 (No.200) states that *measures to address HIV and AIDS in the world of work should be part of national development policies and programmes, including those related to labour, education,* ***social protection*** *and health.*

The *National Social Protection Floors Recommendation, 2012 (No. 202)* provides guidance to member States to establish or update their national social security programmes to prevent or alleviate poverty, vulnerability and social exclusion. They comprise essential health care and basic income security for children, persons in active age and older people.

Workers in informal economy are the majority in many developing countries. Extending social protection to workers in the informal economy has several challenges. In case of persons living with HIV (PLHIV) and their households, there are additional barriers such as stigma and discrimination. Consequently, PLHIV face specific problems in accessing treatment, health insurance and employment.

Even in countries providing free antiretroviral treatment to PLHIV, HIV-related stigma and discrimination often prevent them from accessing or continuing with treatment. In addition, PLHIV in informal economy can lose their daily wages for the days they visit the treatment services and they often do not have health insurance to cover expenses on other recurrent illnesses.

Scope of the country research

The proposed research aims to provide comprehensive gender-responsive answers to the following three key questions in the country:

1. Does social protection in the country cover men and women workers affected by HIV and AIDS, and their households? If so, under which contingencies of social protection, for example: health insurance,

livelihood/income support, cash transfers, etc.? What is the coverage, key gaps and challenges in enhancing social protection coverage to them?

2. How does the social protection coverage contribute to reducing the impact of HIV and AIDS on vulnerable or HIV-affected households? To what extend does the employment status, whether formal or informal, (e.g. self-employed, casual employee or day-labourer, etc.) influence the access to both public, private; national or community based social protection coverage?

3. How does social protection contribute to prevent new HIV infections and reduce the vulnerability of the target population?

The in-depth country research shall have the following components:

1. A desk review of existing published literature about the country, policies, documents, and costing information on social protection programmes as well as HIV treatment, care and support services.

2. Key stakeholder interviews including with relevant officials responsible for the public and private social security systems, national AIDS programme, ILO constituents, UNAIDS, national and community-based social protection including social health protection programmes, relevant civil society organizations and organizations of PLHIV.

3. Specifically focused research data collection, on the reach, level of coverage and effect of social protection programmes using a mix of qualitative and quantitative techniques, from PLHIV and their households to get the perspective from the beneficiaries in both formal and informal economy.

- **Extensive literature review and collection of costing data**

A review of existing published literature about the country, laws, policies, documents relating to social security/social protection systems and programmes with clear information of the eligibility criteria and enrolment process, with particular reference to inclusion or exclusion of PLHIV.

- **A combination of quantitative and qualitative studies**

The literature review shall be complemented by primary data collection, both quantitative (costing and others) as well as qualitative, such as (but not limited to) key informant interviews with relevant officials responsible for the social security systems, collection of data from social security system, health services facilities that deal with PLHIV, national AIDS programme, employers, workers trade unions (including both formal and informal economy) and the Ministry responsible for Labour and for social welfares, Ministry responsible for financing social security systems in the country, public and private health insurance entities, UNAIDS, community based social protection programmes and livelihood and employment generation/support for those in informal economy (for example, cooperatives, micro-insurance, micro-financing entities), relevant civil society organizations and organizations of PLHIV, as well as PLHIV and their household members.

- **Social protection and health service data and costing relating to PLHIV and similar vulnerabilities (informal economy)**

Collection, review and analysis of costing information on health service and social protection programmes, public, private, national or community-based and estimate the marginal costs in coverage of PLHIV, particularly pertaining to social health insurance and livelihood support including employment promotion and support.

- **Indicators and measures**

Devise indicators on access and effect of social protection on the target populations.

- **Good practice documentation**

Identify, document and analyse good practice examples.

- **Confidentiality protection**

It is critical to ensure strict confidentiality be maintained throughout the study as well as due respect for privacy of the PLHIV and their families. This safe-guard procedure shall be clearly described in the study protocol and reporting.

- **Informed consent**

Specific informed consent procedure shall be provided and records maintained. All necessary ethical procedures should be kept in mind and followed, including approvals as may be required.

- **Detailed study protocol and instruments**

The research institution is expected to provide a detailed study protocol (proposed methodology, time frame, work plan and research team and costing) to form the basis for a service agreement with the ILO.

Potential collaborating entities with the research institute could include the following:

a) Local organizations of PLHIV;
b) PLHIV enrolled in the national anti-retroviral treatment programme;
c) Government, private and community-based organizations engaged in social protection schemes and other community entities that provide HIV treatment, care and support to PLHIV and their families;
d) Trade unions and associations, including women's association and informal economy workers; and
e) Health or social insurance organizations and microfinance institutions.

- **Time Frame** of the proposed research and expected deliverables
- **Estimated Budget**

Appendix 2

UNAIDS List of High Impact Countries

AFRICA

1 Nigeria*
2 Ethiopia*
3 Mozambique*
4 Uganda*
5 Kenya*
6 Tanzania*
7 Zambia*
8 Malawi*
9 Zimbabwe*
10 Cameroon*
11 Dem. Rep. Congo*
12 Djibouti
13 South Africa*
14 Lesotho*
15 Rwanda
16 Namibia*
17 Botswana*
18 Swaziland*
19 Angola
20 South Sudan
21 Central African Republic
22 Burundi
23 Côte d’Ivoire
24 Ghana
25 Tchad

ASIA

1 Cambodia
2 China
3 India*
4 Indonesia
5 Iran
6 Myanmar
7 Thailand

AMERICA

1 Brazil
2 Guatemala
3 Haiti
4 Jamaica

EUROPE

1 Russian Federation
2 Ukraine

Appendix 3

Selected Resources for this Research

This final section of the document aims to stimulate broader thinking about methodological issues related to social protection and HIV research. Some of these recommended readings relate to concepts, others to methods and others to results of research. These are some of the seminal or most recent works in this area. The literature review commissioned by the ILO HIV/AIDS Team includes many additional sources of information, and of course, UNAIDS and co-sponsors, as well as other development and implementing agencies are good sources of normative and experiential readings.

International Labour Office

ILO. 2013. **Social Protection and HIV Global Literature Review** by A. McCord and C. Leon-Himmelstine . This document offers a review of the international literature related to the access and impact of social protection programs on people living with HIV.

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Scheil-Adlung, X.; Kuhl, C. 2012. **Evidence on gender inequities in social health protection**: the case of women living in rural areas. Geneva: International Labour Office, Social Security Department.

International Social Security Association

International Social Security Association, US Social Security Administration and the International Labour Office. **Social Security Programs Throughout the World**. This publication highlights the principal features of social security programs in more than 170 countries. One of four regional volumes is issued every six months.

Non-Governmental Organizations and Academic Institutions

Gilson, L. (ed.) 2012. **Health policy and systems research**: A methodology reader. Alliance for Health Policy Systems Research, Word Health Organization.

Maillot. M.; Sipi-Johnson, S. 2013. "**Les personnes vivant avec le HIV et le SIDA**" in "Droit International Social-droits économiques, sociaux et culturels" by J.M. Thouvenin et A. Trebilcock (eds). Brussels: Bruylant. (French only.) This chapter provides a thorough overview of global laws related to HIV.

PSI. 2008. **The People Living with HIV Stigma Index (PSI) User Guide**. UK: The International Planned Parenthood Federation. http://www.stigmanindex.org. This publication offers a useful and comprehensive approach to conducting surveys with PLHIV.

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