International Labour Organization

ACCESS to and EFFECTS of Social Protection on Workers living with HIV and their Households:

An analytical report

ACCESS TO AND EFFECTS OF SOCIAL PROTECTION ON WORKERS LIVING WITH HIV AND THEIR HOUSEHOLDS: AN ANALYTICAL REPORT

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FOREWORD

This report analyses research findings from four countries – Guatemala, Indonesia, Rwanda and Ukraine – on "*Access to and Effects of Social Protection on workers living with HIV and their households*". The report is the result of a process that included a global literature review, development of a research methodology guide through consultation with experts, and research in four countries. The report analyses the social protection policy environment through the lens of HIV. It highlights the challenges faced by workers living with HIV and their households in accessing social protection programmes; examines the effects of such programmes on their lives; and makes evidence-based recommendations.

HIV-sensitive social protection is increasingly recognized for its key role in reducing the disadvantages and inequalities that make people vulnerable to the HIV infection, helping overcome barriers in access to HIV treatment and mitigating the impact of HIV on households. The ILO Recommendation concerning HIV and AIDS and the world of work, 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*'. Social protection is also one of the ten goals of the Joint United Nations Programme on HIV/AIDS (UNAIDS) Strategy, which recognizes that investments in social protection are necessary to achieving the vision of zero new infections, zero discrimination and zero AIDS-related deaths.

Creating and extending social protection floors is one of the areas of critical importance identified by the ILO. Key principles of the ILO Social Protection Floors Recommendation (No. 202) include universality of coverage, non-discrimination and gender equality. Undertaking research to guide action is an important aspect of the ILO's work, and this research is our contribution to filling the existing knowledge gaps, to enable scaled-up HIV-sensitive social protection programmes in the world of work.

The report shows that even though policies do not exclude people living with HIV, they face challenges in accessing the existing social protection services; primarily a lack of adequate knowledge about the programmes, complicated procedures for accessing programmes, and stigma and discrimination. Workers in the informal economy, particularly women and key populations – sex workers, transgender people and men who have sex with men – face greater challenges, which must be addressed.

This report contributes to the body of knowledge on HIV and social protection, promotes HIV-sensitive social protection with gender equality at its centre and provide guidance to stakeholders in expanding the coverage of HIV-sensitive social protection programmes at the global, regional, country and local levels. As the development community prepares for the post-2015 era, it is important to invest in policies and programmes that leave no-one behind.

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- Ms Rosalia Rodriguez-Garcia wrote this report, after thoroughly reviewing the four country research studies. Rosalia was also engaged by ILOAIDS to develop the Research Methodology Guide, which was finalized after consultation with experts. Country research teams used the guide making necessary country-specific adaptations.
- Ms Anna McCord and Ms Carmen Leon Himmelstine from the Overseas Development Institute (ODI), UK. The ODI was engaged by the ILO to undertake a global literature review on social protection and HIV in 2013, which provided a synthesis of the available research and identified knowledge gaps.
- The research teams of the following institutions conducted the country research:
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– Members of various national networks of people living with HIV and key populations' networks, from each of these four countries contributed to the research design, data collection and analysis.

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- This report also benefited from national consultations in all four countries held between November 2013 and February 2014. The participants included national stakeholders such as ministries, ILO constituents (ministries of labour, employers' and workers' organizations), PLHIV organizations, national AIDS programme and national social protection administration, country research teams, civil society organizations, ILO specialists and Country Offices, UNAIDS and its cosponsors.
- A small task team within ILOAIDS worked on this research. It comprised Ms. Lee-Nah Hsu, Ms. Julia Fäldt Wahengo, Ms. Ingrid Sipi-Johnson, Mr. Kofi Amekudzi and Mr. Afsar Syed Mohammad, who led the team.

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LIST OF ABBREVIATIONS

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
ARV	Antiretroviral medication
BLT	Bantuan Langsung Tunai (= Direct cash transfer)
BLSM	Bantuan Langsung Sementara Masyarakat (= Temporary community direct assistance)
CBHI	community-based health insurance
CCT	conditional cash transfer
FARG	Genocide Survivors Support and Assistance Fund in Rwanda
FSW	female sex worker
HDI	human development index
HIV	human immunodeficiency virus
ID card	identification card
IDR	Indonesia Rupiah
IDU	injecting drug user
IGSS	Guatemalan Institute of Social Security
ILO	International Labour Organization
ILOAIDS	HIV/AIDS and the World of Work Branch
IAU	integrated AIDS service unit (in Guatemala)
MDGs	Millennium Development Goals
Minsa	Ministry of Health in Peru
MSM	men who have sex with men
NGO	non-governmental organization
OECD	Organisation for Economic Co-operation and Development
PAHO	Pan American Health Organization
PKH	Program Keluarga Harapan (=Family of Hope Programme)

PLHIV	people living with HIV
PPP	Purchasing Power Parity
RP-CI	Principal Recipient – international market prices (under Global Fund grant)
SPP	social protection programme
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
USA	United States of America
UN Women	United Nations Entity for Gender Equality and the Empowerment of Women
USD	United States Dollar
VCT	voluntary counselling and testing
VPP	Voluntary Pooled Procurement
VUP	Vision 2020 Umurenge Programme in Rwanda
WHO	World Health Organization

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EXECUTIVE SUMMARY[1]

Social protection has long been part of the socioeconomic policy landscape. As part of broader socioeconomic policies, countries use a variety of social protection schemes to alleviate poverty, protect the most vulnerable, and ensure that the benefits of economic growth reach poor and marginalized populations. Nowadays, there is a wider conceptualization of social protection as a response to a range of challenges countries face, including chronic poverty, high unemployment, gender-based and other inequalities, food insecurity and the effects of HIV.

The ILO HIV and AIDS Recommendation, 2010 (No. 200) *provides 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. (para. 3, j)*

Key principles of **the ILO Social Protection Floors Recommendation, 2012 (No. 202)** *include universality of access, non-discrimination and gender equality.*

The ILO's official engagement with HIV and AIDS, which began in 2001, is crystallized in two landmark recommendations: the ILO Recommendation concerning HIV and AIDS and the World of Work, 2010 (No. 200) and the Social Protection Floors Recommendation, 2012 (No. 202).

An ILO research report released on World AIDS Day 2013 -*The Impact of Employment on HIV Treatment Adherence*- revealed that people living with HIV who are employed are, on average, 39 percent more likely to persist with antiretroviral treatment than those who are unemployed. This is because employment ensures access to food and financial security during

[1] The main sources of data for this synthesis are the four country research reports: Guatemala, Indonesia, Rwanda and Ukraine. (See the Executive Summaries of country research in the Annex.) Except when otherwise indicated, country specific data and examples are based on information contained in these reports.

treatment. With earned income and access to social protection benefits, workers are more resilient and can continue lifelong treatment (ILO, 2013).

As stated by the ILO Director-General Guy Ryder:

"The message is clear: employment is not only a right – it is part of the treatment." (ILO, 2013a)

Social protection reduces the disadvantages and inequalities that make people vulnerable to HIV infection, helps overcome barriers in access to HIV prevention, treatment, and mitigates the impact of HIV on households. The HIV/AIDS and the World of Work branch of the ILO (ILOAIDS) undertook a global research in 2012-13 to gain knowledge on access to and effects of social protection policies and programmes on women and men workers affected by HIV or AIDS and their households. The research aimed to answer three main questions:

1. Does social protection cover men and women workers affected by HIV and AIDS, and their households?
2. How does social protection reduce the impact of HIV and AIDS on affected households?
3. How does social protection contribute to HIV prevention and reduce the vulnerability of the target population?

This research involved three steps[2]:

- A *global literature review* of existing social protection policies and schemes was undertaken.
- A *research methodology guide* was developed in consultation with a group of experts. The guide provided a conceptual framework, guidance on methodology and tools for undertaking this research at country level; and
- A *multi-country research* was conducted in four countries: Guatemala, Indonesia, Rwanda and Ukraine – one each from Americas, Asia, Africa and Eastern Europe and identified by UNAIDS as highly impacted by HIV.

[2] The executive summary of the Global Literature Review, the overview of the Methodological Guide and the executive summaries of the country research reports are in the annex.

This document provides an analytical synthesis of this research. It brings together the findings of the global literature review and those of the four country studies. These findings are revealing, both in their similarities and in their differences.

All countries have social protection programmes, but access to them is unequal… particularly for People Living with HIV, including key populations, for whom social protection programmes might be available but not necessarily accessible… thus, the barriers to accessing services encountered by PLHIV, including key populations, must be eliminated….in order to improve access to social protection and maximize its effects.*

All countries have social protection programmes, but access to them is unequal…

Like in most other countries in the world, social protection programmes in Guatemala, Indonesia, Rwanda and Ukraine are linked to the formal public or private sectors of the economy – sometimes covering only public servants and the military. Workers in the informal economy rely on programmes for the poor and vulnerable. Each country has laws and legislation aimed at supporting individuals and households to overcome social risks and vulnerability. For instance:

- Article 100 of the Constitution of the Republic of Guatemala establishes that "The State recognizes and guarantees the right to social security for the benefit of the citizens of the nation." lt further establishes that social security is a public function nationally. Since 1971, through the implementation of a series of National Development Plant, the State has continously aimed at improving the health, nutrition, basic education, employment opportunity and standard of living of its people, including increasing employment opportunities for women.

* "Key populations refer to those most likely to be exposed to HIV or to transmit it, including people living with HIV. Countries have their own definitions. In most settings, key polulations include men who have sex with men, transgender persons, people who inject drugs, sex workers and their clients, and seronegative partners in serodiscordant couples" (reference: UNAIDS Terminology Guidelines, 2011).

- The Indonesian government reformed its social protection system to implement the National Social Security System law, enacted in 2014, aiming for universal coverage for all Indonesian citizens with insurance for health, work injury, old age, pension and death.
- The Government of Rwanda prioritizes social protection for the poor in its economic development and poverty reduction strategy. A broad range of social protection programmes are in place under the umbrella of *Vision 2020.*
- In 1991, the Government of Ukraine began to review a long-established social protection system with the result that now all citizens, regardless of their employment status, have the right to request social assistance (e.g. allowances for low-income families) and social services (e.g. food products, health services, legal services).

In all countries respondents have some degree of access to health/medical insurance and/or services, but these services are not fully free as there are often hidden costs. Although the written social policies might indicate that medical services are free, the reality is different. Access to medical tests and to some medicines depends, to a large extent, on individuals' ability to pay; this increases individual and household out-of-pocket expenses and vulnerability.

Access to social protection by the population at large is linked to working in the formal sector. In reality, only about 6 per cent of the labour force in Rwanda, 30 per cent in Indonesia, 31 per cent in Guatemala and 77 per cent in Ukraine[3] has access to formal social security, leaving a significant proportion of the general population relying on social assistance. Except in Ukraine, access to social security is curtailed for those working in the informal economy; they therefore rely heavily on social assistance.

…particularly for PLHIV, including key populations, for whom social protection programmes might be available but not necessarily accessible…

None of the social protection programmes in the four countries explicitly excludes HIV or AIDS, but only Guatemala and Ukraine explicitly mention them. Guatemala has a rich social policy and legal framework for HIV

[3] See World Bank, 2014, in references.

and AIDS framed around human rights, as well as an active civil society, both of which help to keep important self-identity issues on the national agenda and in national HIV and AIDS decrees and programmes. Ukraine has a different approach. In 2011, the Ukrainian Government, along with employers' organizations and trade unions, adopted a national tripartite strategy to respond to HIV and AIDS in the workplace. Together with the national programme (2009-2013) for HIV prevention, treatment, care and support, this means that, theoretically, PLHIV are covered both through work and by individual healthcare programmes.

In Indonesia and Rwanda PLHIV rely on national social assistance programmes for the poor. If PLHIV meet the poverty criteria in these countries, they can, theoretically, access several schemes targeting vulnerable groups. In 2012, the Indonesian Ministry of Manpower and Transmigration adopted a policy that mandates the state programme *Jamsostek* to provide health insurance to PLHIV, which give assistance in paying for medical care costs to those employed in the private sector. This policy, however, covers only those working in the formal economy. Those who work in the informal economy, but do not meet 'poor status' criteria, are not eligible for any social protection programme. Thus, even when specific social programmes exist to address HIV and AIDS, there are critical gaps and barriers – especially related to poverty levels, but also to gender-based inequalities. In Guatemala and Indonesia national programmes only recognize biological sex, leaving people with other gender identities, especially transgender individuals, underserved.

In all countries social protection is closely tied to the formal economy, whereas PLHIV in these studies are more represented in the informal economy. This situation is made worse by the fact that workers with HIV might leave their jobs in the formal economy due to illness or hostile work environment, thereby increasing the number of PLHIV in the informal economy or under-employed. The majority of PLHIV in these studies, especially if they also belonged to a vulnerable group, worked in the informal economy (61 per cent of respondents – all four countries combined) or are under-employed or unemployed (7 per cent of respondents across the four countries).

The main opportunities for PLHIV and their households to access social assistance are through programmes for the poor. However, most respondents were unaware of the existence of these programmes, and access levels are low. This has created an ironical situation: on the one hand, some existing social protection programmes are underutilized, and on the other, PLHIV are left with little social protection. Low social protection access by key HIV populations in low-income countries was also found to be a problem by the global literature review of more than 100 studies commissioned by the ILO (ILOAIDS, 2013a). The social protection benefit that seems to be most readily available to PLHIV in all four countries is health insurance schemes and access to free medical care, including antiretroviral therapy (ART) and medicines for the treatment of opportunistic infections.

Uncovering barriers to access by PLHIV, including key populations

In all four countries accessing social protection is unduly convoluted:

First, many PLHIV, including key populations, are unaware of the social protection benefits they can apply for and of the application process. **Lack of information** was identified as one of the main factors limiting access to social protection in all countries. For instance, in Ukraine the principal problem respondents identified in accessing social services/assistance from state institutions (67 per cent) and from non-governmental organizations (51 per cent) was a lack of information about available types of social assistance or services. In Rwanda more than half of the respondents (59 per cent) indicated that they were eligible for social protection benefits, but that the application process was too complicated, while 47 per cent simply said that they did not know how to apply. In Guatemala a broader lack of information about PLHIVs' rights to certain services was identified as a key barrier, while in Indonesia many PLHIV heard about social assistance programmes for the first time through this research.

Second, when PLHIV do apply for social protection – often assisted by NGOs – they find the **procedures to access social protection** complicated

and unfriendly. Demonstrating that the applicant meets eligibility criteria is the first hurdle. In Indonesia, the requirement for an identification card and certificate of poverty is often an insurmountable barrier, leading to abandonment of the application process at its very first stage. Although these are universal requirements, they disproportionately hinder PLHIV, who tend to relocate more often than the general population, and are reluctant to disclose their HIV status to their community. This situation underscores the negative influence of discrimination – a problem identified by all the studies and by the global literature review.

Third, **discrimination, and self-stigma** in the form of poor self-image and low self-confidence, coupled with a lack of knowledge about their rights, often stop PLHIV from seeking social protection. When they do, discriminatory behaviour and poor treatment by service providers reinforces their self-doubt.

Discrimination is complex, with PLHIV being discriminated against more severely for different reasons in different countries. PLHIV, including key populations, are discriminated against for various reasons:

(i) they belong to HIV vulnerable groups (e.g. sex workers, Men who have Sex with Men (MSM), or Injecting Drug Users (IDU),

(ii) they are poor and disadvantaged (e.g. in Indonesia),

(iii) their work status (e.g. in Ukraine the unemployed experienced more discrimination than those working – both in the formal and informal economies), and/or

(iv) their HIV status (e.g. in Guatemala, Indonesia, Rwanda and Ukraine).

Any overlap of these deepens the experience of stigma and discrimination.

Discrimination by service providers cannot be overlooked. In Rwanda, 18 per cent of respondents identified providers of social, health and insurance services as the second largest source of discrimination (after discrimination by family and friends). In Ukraine the same was true for 31 per cent of respondents (29 per cent of men and 34 per cent of women), who faced

stigma and discrimination when receiving social and medical services. Although not quantified, in both Guatemala and Indonesia discrimination from service providers was likewise identified as a barrier to accessing services by focus group discussion participants.

In Guatemala and Indonesia transgender individuals suffered the most; discrimination often led them to sex work as the only option available to sustain themselves. One outreach worker in Bali, Indonesia put it this way:

"Some of our transgender friends are so afraid of being discriminated against by service providers, either at the hospital or at the social protection agencies, that they don't even bother to try accessing the services. They just know that they will be ill-treated by those people."

Many providers face challenges of their own: from fear of contagion to insufficient training, a lack of necessary supplies and limited overall capacity to provide services – often national hospitals and clinics are overburdened. The global shortage of healthcare providers is a challenge that has received increasing attention recently in the context of the push for universal access to healthcare. (World Bank, 2013)

Fourth, **the cost of living with HIV** can be prohibitive. In all countries, access to medical services and antiretroviral therapy (ART) is supposed to be free, but in reality this is not always the case. Respondents indicated that merely obtaining prescriptions for medicines to treat opportunistic infections medicines are not always available, results in out-of-pocket payment to purchase these medications from pharmacies, which few PLHIV can afford. This affects their health and their livelihood. In addition, PLHIV and their households must cover one or more care-related expenses:

(i) co-payments on insurance in Indonesia and Rwanda;

(ii) payments for hospital or clinic visits in Indonesia and Ukraine;

(iii) payments for transportation in Guatemala, Indonesia, Rwanda and Ukraine; and

(iv) payments for medicines, other than ART, in Guatemala and Ukraine.

These findings uncover some of the key barriers to accessing social protection, and thus fill the knowledge gap in the global literature. (ILOAIDS, 2013a)

… in order to improve access to social protection and maximize its effects.

PLHIV, including key populations, and their households, do have access to some social protection in these four countries, despite the challenges highlighted above. This includes health insurance, medical care and livelihood support. However, these are insufficient and not tailored to meet the needs of PLHIV. Findings from the four countries show that more PLHIV benefit from **health insurance** and **access to health and medical services** than any other forms of social protection.

In Rwanda 83 per cent of respondents had health insurance (82 per cent of women and 90 per cent of men). Among those with insurance, 94 per cent had access to community-based health insurance, and 93 per cent of them paid the small premiums themselves. However, very few received livelihood protection such as income support (8 per cent), child support (4 per cent) or cash transfers (4 per cent). The majority of respondents (95 per cent) received ART, mostly (92 per cent) free of cost; and 20 per cent received medicines to treat opportunistic infections (23 per cent of men and 17 per cent of women).

Access to health insurance by PLHIV in Indonesia mirrors that of the general Indonesian population as shown by the 2012 Indonesian Demographic and Health Survey: higher access by those working in the formal economy (71 per cent) than by those in the informal economy (53 per cent). Slightly more than half of the respondents in Indonesia (57 per cent) had health insurance, whether working in the formal, informal economies, or not working. This includes 61 per cent of women, 58 per cent of men and 34 per cent of transgender individuals. More women than men received government social protection due to their poverty status. This leaves almost half of the respondents of this study with limited or no access to social protection.

PLHIV who seek health care in Guatemala obtain services mainly from social security services (formal sector) or from AIDS clinics (informal economy), along with military services and hospices. Together these services cover 65 per cent of PLHIV in the country.[4] A high percentage (96 per cent) of respondents was taking ART and 72 per cent received medicines for the treatment of opportunistic infections.

In Ukraine, the majority (96 per cent) of respondents were registered at AIDS centres for medical consultations, ART and other needs. Of these, 82 per cent accessed services from national public health units and 24 per cent from public institutions of social protection. The majority of respondents (95 per cent) also had access to ART medicines (97 per cent of men and 93 per cent of women) although only 72 per cent needed and were receiving treatment at the time of the study. It is worth noting that the work status of PLHIV did not greatly affect their access to ART. The country study revealed that, despite a policy providing that all citizens should have access to social services, the reality is restrictive and people's needs are only partially met.

Between 42 per cent and 67 per cent of respondents across the four countries have lived with HIV for 5-9 years; this demonstrates that this population's access to **social health protection**, and specifically to medical services and medicines, is keeping them alive. However, only 20 per cent of respondents in Guatemala, 11 per cent in Indonesia, 25 per cent in Rwanda and 19 per cent in Ukraine have lived with HIV for more than 9 years. A plausible explanation is that medical services are necessary, but are not alone sufficient; other social benefits play a role in the longevity and quality of life of PLHIV.

Data from these studies suggest that a combination of income, livelihood and employment support is needed, in addition to health services, in order for social protection to have a bigger impact on key HIV populations. The global literature review supports this point, noting that having access to health social protection alone does not resolve the social protection needs of PLHIV and their households. (ILOAIDS, 2013a)

[4] Guatemala is one of the countries that has estimated the total population of PLHIV and can address issues of coverage.

In Ukraine, the share of PLHIV who received **social protection support** was small, although significantly larger than in other countries: 31 per cent of respondents received insurance benefits or assistance (e.g. unemployment and maternity benefits, paid sick-leave), while only 9 per cent received state social assistance (e.g. monthly allowances for children living with HIV, support for low-income families). It is worth noting that for 18 per cent of respondents in Ukraine, social protection contributions represented 50 per cent of total household income. This was not the case in the other countries. In Rwanda only 8 per cent received livelihood support and 4 per cent cash transfers, while in Guatemala about 15 per cent of respondents received social protection including food and cash transfers, and less than 3 per cent received a retirement pension.

In Guatemala, 60 per cent of lesbians, 56 per cent of transgender individuals and 40 per cent of heterosexual women were in the lowest income bracket. This finding is partially explained by the fact that these population groups have fewer options and depend on low-paid work such as subsistence-type occupations, domestic work or sex work.

This research shows that for the most part, with the possible exception of medical services, social protection access for PLHIV and key populations is wanting in the four countries. It is not only a matter of a sound combination of benefits, but of getting more benefits to reach more of the population in need. These findings are supported by the global literature review, which found little evidence of the impact of social protection on household vulnerabilities. (ILOAIDS, 2013a) This was probably because the amount of social protection support received by most PLHIV and their households is not significant enough to be measured at the population level. It is only worth measuring at the level of individual projects targeting specific communities with social protection interventions.

Thus, while the lack of adequate social protection keeps most PLHIV and their households vulnerable and poor, access to medical services is keeping them alive. Health insurance and **access to health and medical services**,

especially if they include access to medicines and treatment for HIV and other infections, are critical.

...When PLHIV can access social protection, the effects are felt.

The survey in four countries showed that 57 to 96 per cent of PLHIV had some kind of social health protection; 16 to 31 per cent of PLHIV received some form of non- health social protection benefit.

Despite the low coverage and challenges that PLHIV faced in accessing social protection, positive effects of social protection were highlighted by respondents.

Among those who received social protection support, 63 to 95 per cent of PLHIV were able to retain their jobs or some forms of productive activities, 49 to 99 per cent of their children could remain in school, and 72 to 96 per cent were able to access ART across four countries.

...What have we learned?

This research indicates that social protection could play an important role in reducing the vulnerability of PLHIV and their households. Most respondents were primarily able to access health insurance and/or medical services. Despite the uneven accessibility of health services and the barriers that obstruct access to broader social protection programmes, when PLHIV and their households were able to receive social benefits, especially free health and/or medical services, those benefits made a difference. The effects summarized in this section are tempered by the low incomes of most of the study population and the proportion of that income that goes to out-of-pocket expenses. Hence, we can say that people live with HIV for longer thanks to social health protection, but not whether they live better. No one should fall into poverty or be kept in poverty as a result of medical expenses, and yet, these remain one of the biggest expenses for PLHIV

and their households that are not mitigated by livelihood support or social assistance.

This research set out to answer three major questions, and in so doing it has provided important evidence. The findings, broadly, are as follows:

(Q1) Access to social protection by women and men workers affected by HIV and AIDS, and their households, is limited. There are gender-related differences in access, and these must be scrutinized further to bridge this gap. Further, transgender individuals are the worst off in relation to all key variables: social protection benefits, access to medical care, work opportunities and discrimination.

(Q2) Social protection in the form of health or medical insurance and/or access to health and medical services provides for free ART to those who need it and who do access the services, thus contribute to mitigating negative impact of HIV. Although ART is usually free, there are sometimes costs of medicines for opportunistic infections as well as medical tests. In addition, people incur out-of-pocket expenses related to transport or even lost wages.

(Q3) The contribution of social protection – other than its medical contribution – to reducing the vulnerability of the target population is very limited, given the low level of access to non-health social benefits.

The fundamental message that emerges is that although social health protection has positive effects, as respondents indicated, the number of PLHIV with access to broader social protection benefits, (except perhaps in Ukraine) was very small. This is due to the barriers that have been identified by respondents in all countries. It follows that the single most important challenge for decision makers and programme implementers is to determine how best to remove the barriers that are preventing PLHIV, including key populations, from accessing social protection.

The top three barriers emerging from the research are: prevailing stigma and discrimination, lack of knowledge amongst PLHIV about existing programmes, and the complicated procedures for accessing the existing schemes. A coordinated effort involving world of work actors (ministries of labour, employers/private sector and trade unions), ministries of health and gender, national AIDS programmes, social protection programmes, civil society organizations and PLHIV organizations, is called for, in order to address the existing barriers and increase the proportion of PLHIV, including key populations, who can access and benefit from social assistance and other forms of social protection.

INTRODUCTION

Over the past two years, the ILO has supported the development and implementation of research on access to, and the effects of, social protection on PLHIV, including key populations and their households. HIV and AIDS is an integral part of the ILO's Decent Work Agenda. Through activities such as this research, the ILO also contributes to the achievement of the United Nations Millennium Development Goals and to achieving full access to HIV prevention, treatment, care and support, as well as universal healthcare access.

This document synthesizes the major findings of four studies conducted in Guatemala, Indonesia, Rwanda and Ukraine, as reported by the country-specific research. It also incorporates findings from the global literature review commissioned by ILO in 2013. (ILOAIDS, 2013a) It does not aim to include every single indicator, rather it highlights the aggregate key findings from the four countries, as well as findings that appear more significant in one country than in others in order to underscore the uniqueness of each country's experience. Participants' voices, in the form of testimonials, complement the data.

The synthesis begins with brief sections on background, the problem, and the research approach used – based on the approach recommended in the Research Methodology Guide of the ILO (ILOAIDS, 2013b). The findings are presented as they pertain to five main areas: (i) profiles of the countries and study populations; (ii) the availability of social protection programmes in general; (iii) the social protection programmes available to PLHIV, including key populations, and their accessibility; (iv) the barriers to access to social protection experienced by PLHIV; and (v) the effects of social protection on workers living with HIV and their households. The Conclusion and Recommendations section highlights key evidence-informed messages supported by this research and the global literature.

BACKGROUND TO THE STUDY AND METHODOLOGY[5]

BACKGROUND TO THE STUDY

The Millennium Declaration, adopted in 2000, was a historic international compact to reduce inequality in human development and to achieve the Millennium Development Goals (MDGs). 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. Much of the acknowledged progress, however, is based on improvements of national averages, which can hide wide disparities among regions and within countries. (Bamberger and Segone, 2011) Inequality within countries is being addressed further in the context of universal healthcare access. A World Bank paper on poverty and health monitoring has noted this problem, indicating that progress towards the achievement of the MDGs is being measured by nation, despite the limitations of national health data with regard to inequalities associated with poverty. (Suzuki et al., 2012) The paper states 'the problem is, countries can show national progress toward these goals even if it is only their rich who benefit from health gains, with the result that the health disadvantage due to poverty does not receive the required attention'. (2012, p.1)

The ILO emphasizes that, despite some progress on HIV and AIDS and the world of work, there is still much work to be done to combat poverty and disadvantage: '870 million workers and their families live in poverty (based on the threshold of 2 US dollars per person per day), 400 million of those in extreme poverty; some 20.9 million people were in forced labour at any given point during the period between 2002 and 2011; and today there are still 168 million children in child labour, half of them in its worst forms'. (ILO, 2013b, p. 1)

In the field of HIV and AIDS, these disparities hamper progress towards the three zeros: zero new infections, zero discrimination and zero AIDS-

[5] This section borrows from the *Guide on Research Methodology for Undertaking Research at Country Level* by R. Rodriguez-García, with Syed Mohammad Afsar, Lee-Nah Hsu, Ingrid Sipi-Johnson and Julia Faldt. ILO, July 2013 (White Paper). See reference, ILOAIDS, 2013b.

related deaths (UNAIDS, 2012), and pose a significant obstacle to millions of people living with HIV, or affected by the epidemic, obtaining decent work and livelihoods. In fact, while in recent decades global attention to healthcare has oscillated between focussing on health system approaches and disease-specific programmes, the problem of inequality has remained a constant concern, one which has not yet been surmounted. (Bristol, 2014)

Article 23 of the Universal Declaration of Human Rights underscores the universal right to earn a living and to social participation through work. (UN, 1948) This right is a target of Millennium Development Goal #1 (1.B). (See Box 1) (UN, 2011) Yet, HIV remains a major obstacle to achieving this goal. Social protection in general contributes to preventing HIV and mitigating the impact of AIDS because it helps to prevent poverty, and to meet peoples' basic livelihood, education and health needs.

ILO Recommendation 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. (ILO, 2010, p.4)

This Recommendation emphasizes the importance of protecting workers in the formal and informal economies, and those whose occupations expose them to a high risk of HIV transmission, such as sex workers. 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, pp. 4-5) Furthermore, it encourages social dialogue between public and private employers and workers, stakeholders and relevant civil society organizations, especially those representing PLHIV. (ILO, 2010, pp. 8-9)

For PLHIV and their households, working in the informal economy is particularly challenging due to stigma and discrimination, and the sometimes episodic disabilities associated with HIV and AIDS. In addition, PLHIV in informal work settings lose their daily wages for the days they visit treatment

Box 1: Millennium Development Goal (MDG): Goal 1

Eradicate extreme poverty and hunger

Target 1.A: Halve, between 1990 and 2015, the proportion of people whose income is less than one dollar a day

1.1 Proportion of population below $1 (PPP) per day

1.2 Poverty gap ratio

1.3 Share of poorest quintile in national consumption

Target 1.B: *Achieve full and productive employment and decent work for all, including women and young people*

1.4 *Growth rate of GDP per person employed*

1.5 *Employment-to-population ratio*

1.6 *Proportion of employed people living below $1 (PPP) per day*

1.7 *Proportion of own-account and contributing family workers in total employment*

Target 1.C: Halve, between 1990 and 2015, the proportion of people who suffer from hunger

1.8 Prevalence of underweight children

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

This situation is not much easier for those working in the formal economy. Often, for PLHIV who are members of key population groups, the stigma and discrimination incurred by their HIV status is compounded by stigma and discrimination based on sexual orientation, gender identity, profession or drug use. PLHIV face problems in accessing treatment; healthcare and private insurance schemes; social, religious and family support; and in gaining financial security. Even in countries that provide free antiretroviral therapy (ART) to PLHIV, HIV-related stigma and discrimination – including self-discrimination – often prevent people from accessing or continuing with the treatment.

More recently, ILO member States adopted Recommendation No. 202, concerning national social protection floors. This reaffirms social security as a human right; as well as the principles of non-discrimination, social inclusion, gender equality and inclusion of people in the informal economy. It states that social security programmes should guarantee respect for people's rights and dignity. (ILO, 2012) Furthermore, it recognizes social protection as a key public policy instrument to tackle the socio-economic impacts of HIV, by mitigating poverty and enhancing access to services. Recommendation No. 202 provides guidance to member States on establishing or updating their national social security programmes. To prevent or alleviate, poverty, vulnerability and social exclusion, they should guarantee access to essential goods and services, such as healthcare and basic income security for children, people of working age and older people. (ILO, 2012, pp. 2-3) This Recommendation, together with Recommendation No. 200, is a critical tool for the implementation of social health protection.

Most social protection programmes aim to combine preventive, promotional and protective measures; however, social health protection in particular is one of the most important forms of social security for PLHIV and workers in occupations that particularly expose them to the risk of HIV transmission. (ILO, 2010, p. 4) The ILO recommends that States ensure that as many people as possible have effective access to health care; that is, access to affordable services of adequate quality, and financial protection in case of sickness. These commitments were reinforced in June 2013 when the ILO, and world of work actors launched the VCT@WORK Initiative – a bold rights-based global partnership that aims to increase voluntary and confidential counseling, testing and access to treatment. VCT@WORK involves governments, employers' and workers' organizations, the private sector, the international community and civil society, including people living with HIV – and aims to reach 5 million workers. (ILO, 2013a)

The adverse effects of denying access to social health protection cannot be overestimated. Besides causing poor health and poverty, the denial of access to livelihood support and healthcare affects economic growth because health status, the labour market and income generation are closely connected.

Healthier workers have higher productivity, which positively affects labour supply and thus economic growth and development.

Despite these ILO Recommendations and countries' efforts to improve access to social protection, the global literature review found important knowledge gaps in HIV-sensitive social protection, understanding the multiple barriers to accessing services, and the determinants of antiretroviral therapy uptake and continuation in different settings, despite the availability of services. (ILOAIDS, 2013a) This research helps fill some of these gaps.

STATEMENT OF THE PROBLEM

The social protection and HIV research referred to in this document aimed broadly to support the implementation of ILO Recommendations at country level through the generation of country-level data that would comprise the beginning of a knowledge base on access to and the effects of social protection policies and programmes on HIV-affected workers in the formal and informal economies.

This research looks explicitly at the HIV and AIDS dimension of social protection, social insurance and other social assistance and livelihood support schemes, and analyzes the effects of social benefits access on PLHIV. It is guided by ILO principles set out in Recommendations No. 200 and No. 202: universality of protection, non-discrimination, gender equality, social inclusion and realization of human rights. More particularly, this research was guided by the following two principles.

Principle 1: Meaningful involvement of people living with HIV – this includes men, women and transgender people living with HIV, and is underpinned by the principles of Greater Involvement of People Living with HIV (GIPA), which aims to realize the rights and responsibilities of PLHIV, including their right to self-determination and participation in decision-making processes that affect their lives. (UNAIDS, 2007)

Principle 2: Gender equality – ensuring an adequate level of social protection – especially social health protection; identifying gaps in and barriers to access to protection; and considering effective and efficient combinations of benefits and schemes in the national context to benefit all, regardless of sex or gender identity. (ILO, 2012)

OBJECTIVES OF THE STUDY

The ILO intends to generate knowledge from several countries on access to, and effects of, social protection policies and programmes on women and men workers in formal and informal economies living with HIV, and their households.

METHODOLOGICAL APPROACH

The methodology for this multi-country research involved:

1. A global literature review[6] of existing social protection policies and schemes;
2. A guide to research methodology[7] for in-depth country studies, informed by in-person and virtual consultation with experts; and
3. Four country-based studies on Guatemala, Indonesia, Rwanda and Ukraine.[8]

These products represent the main sources of information for this synthesis, and are complemented by sources cited in the literature review.

At the country level, researchers applied a cross-sectional design with a three-pronged methodology comprising a desk review of relevant documentation, a quantitative survey, and a qualitative component, which entailed

[6] ILO commissioned *Social Protection and HIV Global Literature Review: Access and Effects of Social Protection on People Living with and Affected by HIV and their Households by* A. McCord and C. Leon Himmelstine, ILOAIDS, March 2013 (White Paper).

[7] ILO commissioned *Guide on Research Methodology for Undertaking Research at Country Level* by R. Rodriguez-García, with Syed Mohammad Afsar, Lee-Nah Hsu, Ingrid Sipi-Johnson and Julia Faldt. ILOAIDS, July 2013 (White Paper).

[8] See Executive Summaries of *Country research* in the Annex.

interviews with key informants and focus group discussions. All studies met basic quality and ethical research standards, applied appropriate design and sampling methods, involved men and women workers living with HIV and working in the formal and informal economies, and engaged with national specialists and NGOs working to provide social and health services to key HIV populations.

COUNTRIES AND COUNTRY CONTEXT

The four countries where research was conducted were selected using the following criteria:

1. One country was chosen from each of four regions: Africa, Americas, Asia and Europe.
2. Each country is on the UNAIDS list of high HIV impact countries.
3. Each country is in the process of developing or updating its social security system.

Table 1 shows selected statistics for these four countries. Note the differences in their rankings according to the Human Development Index – from Ukraine, ranked 78th, to Rwanda, ranked 167th, out of 195 countries. Moreover, of the four, only one – Rwanda – is considered a low-income country. Guatemala, Indonesia and Ukraine are categorized as lower-middle income countries.[9]

COUNTRY-LEVEL RESEARCH IMPLEMENTATION

Each country established a research team to plan and conduct the research. The research team was also responsible for data validation with stakeholders and engagement with NGOs and PLHIV networks. A mixed method approach was applied in all four countries using a cross-sectional design. (see Table 2)

[9] The World Bank categorizes countries based on estimated income per capita: low-income=US$ 1,035 or less; lower middle-income=US$ 1,036-4,085.

Table 1: Selected statistics by country, 2012

	Guatemala	Indonesia	Rwanda	Ukraine
HIV prevalence in adults aged 15-49	0.7%	0.4%	2.9%	0.9%
Adults aged 15 and above living with HIV	53,000	590,000	180,000	230,000
Women aged 15 and above living with HIV	20,000	230,000	110,000	95,000
Proportion of women to men living with HIV	38%	39%	61%	41%
Deaths due to AIDS	3,400	27,000	5,600	18,000
Orphans due to AIDS aged 0-17	25,000	13,000 (2011)	120,000	26,000 (2011)
ART Access*	51%	17%	87%	41%
Number needing ART*	30,000	180,000	130,000	100,00
Estimated new infections	9,400 (2011)	76,000	7,800	11,000
Population (millions)**	15.08	246.9	11.46	45.59
Human Development Index[10] Ranking 1-195***	133	121	167	78

*Sources: Websites accessed March 14, 2014: UNAIDS; *WHO; **World Bank; and *** UNDP*

Table 2: Research design and methods

Design Type	Cross-sectional design	
Methods of Data Collection	**Quantitative**	**Qualitative**
	Survey	Document review
	Secondary data analysis	Semi-structured key informant interviews
		Semi-structured focus group discussions

Source: Rodriguez-García et al., ILOAIDS, 2013, p.39.

The specific characteristics of the studies in terms of sampling approach and sample size (formal/informal and quantitative/qualitative) are shown in Table 3.

[10] The Human Development Index (HDI) is a composite statistic of life expectancy, education, and income indices used to rank countries. It was created by Mahbub ul Haq and Amartya Sen in 1990 and has been applied by the United Nations Development Programme ever since. Source: UNDP web site, accessed March 14, 2014.

Table 3: Sample size for quantitative and qualitative components

	Guatemala	Indonesia	Rwanda	Ukraine	Total
Design: Sampling:	Cross-sectional Random sampling	Sequential, Explanatory, Snowballing	Cross-sectional Random sampling	Cross-sectional Targeted sampling	Study sample size by type of work
QUAN sample Total N=>	**380**	**300**	**481**	**800**	**1961 (100%)**
Formal economy	169	79	34	349	631 (32%)
Informal economy	211	221	416	349	1197 (61%)
Others			31	102	133 (7%)
QUAL Sample Total N=>	**79**	**100**	**96**	**59**	**334 (100%)**
Key informants interviewed	17	76	16	15	124
Focus group participants	62	24	80	44	210

Note: The category "Other" includes 3 retirees and 7 no-answer in Rwanda and 8 seasonal workers in Ukraine.
Source: Elaborated with data from the Country Research Reports by the Author.

It shows the design and sampling approach for the research in the four countries. The combined four-country total sample size for the quantitative component is 1961, while for the qualitative component is 334. About one in three respondents worked in the formal economy and 61 per cent worked in the informal economy. However, these figures are skewed towards the formal sector due to targeted sampling in Ukraine, where there were equal numbers of respondents from the formal and informal economies. If we removed Ukraine, the distribution of study respondents by employment category would be about 73 per cent in the informal economy (the majority of them in Rwanda) and 24 per cent in the formal economy (the majority in Guatemala). The percentage of respondents in the informal economy is higher than 60 per cent – the per cent of worldwide employment that occurs in the informal economy, according to global statistics. (OECD, 2009) However, this is to be expected; PLHIV are more likely to work in the informal economy than the general population, or be unemployed or underemployed. Guatemala offers a case in point.

POPULATION CHARACTERISTICS

The population of interest for this study was people living with HIV, and, secondarily, their households. In addition, key populations and key inform-

ants participated in focus group discussions, regardless of their HIV status. Social protection and health service providers were selected, alongside other key informants, for the qualitative component.

Inclusion criteria. The study respondents were: (1) people living with HIV who were employed, unemployed or not working; and (2) priority populations, regardless of HIV status, for qualitative data collection.

Exclusion criteria. Potential respondents were disqualified if they: (1) declined to participate in the study; (2) were younger than 15; (3) were ill; (4) had already been interviewed for the same study; or (5) had participated in the testing of the survey.

Table 4 shows respondents' sex and gender identity. More women (54 per cent) than men (46 per cent) participated in the study. Rwanda had the highest proportion of female respondents (67 per cent) and Ukraine the highest proportion of male respondents (52 per cent). Gay men (self-identified) in Guatemala, Indonesia and Ukraine were 8 per cent, 13 per cent and 4 per cent of their country's sample population respectively. Respondents identified themselves as lesbians primarily in Guatemala (4 per cent of the country sample); only one person self-identified as a lesbian in Ukraine, and in Indonesia and Rwanda none did. The highest proportion of respondents self-identified as sex workers was in Indonesia (10 per cent). Transgender individuals participated mainly in Guatemala (6 per cent) and Indonesia (5 per cent) – with only three transgender persons in Rwanda and one in Ukraine. Only the population samples in Indonesia and Ukraine included injecting drug users (22 per cent and 24 per cent respectively), which reflects the HIV epidemic in these countries. Note that close to half the respondents in Rwanda and Ukraine said that they did not belong to any of the pre-identified groups (41 per cent and 46 per cent respectively); while 38 per cent of respondents in Indonesia self-identified as belonging to multiple groups, and 37 per cent of the Rwandan sample considered themselves 'poor'.

Table 4: Study population by sex, gender identity, sexual orientation and others (self-identified); by country

	Study population by sex and gender identity (self-identified)							
Sex	Guatemala N=380		Indonesia N=300		Rwanda N= 481		Ukraine N= 800	
Male	168	44.2%	126	42%	157	32.6%	416	52%
Female	145	38.2%	145	48%	324	67.4%	384	48%
Identifying as:								
Gay	31	8.1 %	(38)	12.6%	–		(32)	4%
Transgender	22	5.8%	29	4.7%	(3)		(1)	
Lesbian	14	3.7%	–		–		(1)	
Sex worker	–		(31)	10.3%	(4)		(8)	
Injecting drug users	–		(66)	22%	–		(192)	24%
Multi groups	–		(113)	37.6%	–		–	
Poor/Ubedehe	–		–		(179)	37%	–	
Indigenous group	–		–		–		(176)	22%
Refugee	–		–		(1)		–	
None	–		(38)	12.6%	(202)	41%	(368)	46%
No-response	–		–		(92)		–	
TOTAL	380	100%	300	100%	481		800	

Note: Values between parentheses are subsumed in the male/female categories.
Source: Elaborated with data from the Country Research Reports by Synthesis Author.

TOOLS AND INSTRUMENTS

The survey questionnaire and semi-structured interview guidelines for use with informants and focus group discussions were adapted from those developed with the country teams, and tested and included in the Guide on Research Methodology. (ILOAIDS, 2013b)

ANALYSIS AND REPORTING

Researchers used triangulation, analyzing information of different types and from different sources: desk reviews of the characteristics of the social protection programmes, the quantitative survey data, the qualitative focus group discussions and key informant interviews – to increase the studies' validity. Data were analyzed to identify the relationship between the variables of interest and access to social protection by men and women living

with HIV and working in the formal and informal economies. The data were validated at country level through seminars with stakeholders, and the final research reports were peer-reviewed. (The Executive Summary of each Country Research is included in the Annex of this Analytical Report.)

LIMITATIONS AND CONSTRAINTS

Like all research, this multi-country study has its limitations. Key among them is the one-shot nature of cross-sectional design, which provide information only on one point in time. This constraint is addressed in this synthesis by the use of findings from the global literature review and from other publications; these provide proxy data points against which to compare the results of the country studies. Cross tabulations could not always be run as the values by cell of different variables were small. However, the triangulation of quantitative and qualitative data helped solidify some of the key findings; while findings of a similar nature in all studies point to possible associations among the variables of interest.

All countries made an effort to engage PLHIV in a meaningful way in the research, not only as subjects, but as advisors to the research team, interviewers, and in other roles. This was valuable, although in a small number of cases unclear expectations had to be addressed to strengthen the collaboration.

The main limitation of this synthesis is that it relies on data and findings as reported in the four country research reports, and thus cannot be said to be a comprehensive global report.

OVERVIEW OF KEY FINDINGS

STUDY POPULATION PROFILE

In all four countries, three out of four respondents were between ages 25 and 49. The majority of the sample population in Guatemala, Indonesia and Ukraine lived in urban areas; in Rwanda the sample was split almost equally between urban and rural dwellers. More than half of the respondents were women (54 per cent); the country with the highest proportion of men was Ukraine (52 per cent) and that with the highest proportion of women was Rwanda (67 per cent). (Refer to Table 4 for gender identity details.)

Ukraine's respondents had the highest level of education. More than half of the sample had attended vocational school or higher. Forty per cent of respondents had completed vocational school (43 per cent of men and 27 per cent of women), 27 per cent had completed high school and 17 per cent had completed higher education (21 per cent of women and 13 per cent of men).

Indonesia came second after Ukraine, with 59 per cent of its respondents having completed high school – more women (75 per cent) than men (45 per cent) or transgender individuals (28 per cent). Only 8 per cent had completed vocational school or higher education.

Significant proportions of the respondents in Guatemala (45 per cent) and Rwanda (55 per cent) had only completed primary education (in Rwanda this breaks down as 57 per cent of men and 54 per cent of women). In Rwanda 21 per cent of respondents had completed high school, but only 8 per cent of respondents had completed vocational school or higher. In Guatemala 14 per cent of respondents had not attended any school. This value is 16 per cent for Rwanda, comprising 20 per cent of female respondents and 10 per cent of male respondents.

It is worth noting that despite the differences in education, all respondents identified lack of knowledge of social protection programmes as a barrier to access. However, respondents in Ukraine, which had the most educated population, benefited more from social protection and social assistance than respondents in other countries. In Guatemala, the low education level might help explain the higher number of respondents, especially women and transgender individuals, who were in low-earning jobs such as domestic or sex work.

Civil status varied: around 40 per cent of respondents in Rwanda and 46 per cent in Indonesia were married, while only 30 per cent in Ukraine indicated that they were officially married (with 17 per cent more in civil marriages). Seventeen per cent of the sample in Indonesia and 23 per cent in Rwanda were widows, while Ukraine had a higher rate of divorce, at 21 per cent, than any other country. A proportion of respondents in Indonesia (43 per cent) and Ukraine (23 per cent) lived with parents, while in Rwanda almost half of the respondents (47 per cent) lived with a spouse and children in their own home.

Respondents turned first to family and then to friends when they were in need of care and/or support – including psychological or financial support, and help with logistics or access to goods and services. Respondents in Rwanda also went to state medical institutions for medical information. Some respondents (3 per cent in Ukraine, 21 per cent in Guatemala and 56 per cent in Rwanda) recognized that they needed a considerable amount of help, but the overwhelming majority of the caregivers were close family members, and for that reason, never paid. Eighty per cent of caregivers in Guatemala were women.

Eight per cent of respondents in Ukraine, 16 per cent in Rwanda and 98 per cent in Indonesia said they had faced discrimination in the previous 12 months. In Guatemala 5 per cent of respondents indicated that they had experienced discrimination in the workplace. Slightly more women (17 per cent) then men (13 per cent) in Rwanda and more men (9 per cent) than women (7 per cent) in Ukraine had experienced discrimination.

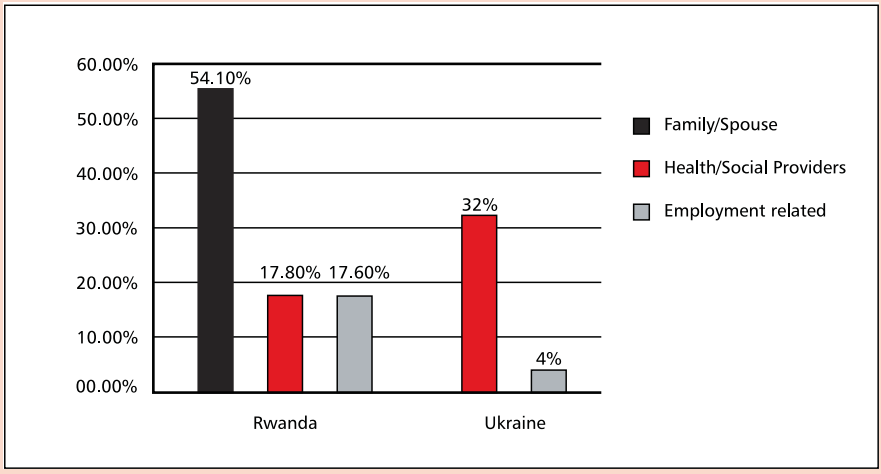
Spouses, partners or family members were identified as the top source of discrimination by more than half of the respondents in Rwanda (54 per cent), followed by medical/social service providers (18 per cent of respondents). Medical providers were identified by 15 per cent of Ukraine's respondents as their top source of discrimination. Discrimination suffered when seeking social or health services did not appear to be related to employment status in Ukraine. Among the 31 per cent who encountered discrimination, 29 per cent worked in the formal economy, 30 per cent in the informal economy and 40 per cent were unemployed. However, across the three categories, more women (34 per cent) than men (28 per cent) experienced discrimination. Qualitative data from Guatemala and Indonesia also point to respondents having experienced discrimination by health and social service providers.

Figure 1 shows the top sources of discrimination in Rwanda and Ukraine according to the respondents. (Quantitative data from Guatemala and Indonesia on these variables are not available.)

In terms of **type of work**, out of the total sample 32 per cent of respondents worked in the formal economy, 61 per cent in the informal economy and about 7 per cent were unemployed. (Refer to Table 3) There are country differences. Of the respondents in the informal economy, 44 per cent were Rwandan, 18 per cent were Indonesian and 18 per cent Guatemalan. Note that the sample in Ukraine, uniquely, was drawn evenly between workers in the formal and informal economies, making Ukrainians 56 per cent of respondents in the formal and 44 per cent of respondents in the informal economies overall.

Country-specific examples are provided below. Table 5 shows the type of employment for women, men and transgender individuals in Indonesia, and Figure 2 depicts the proportion of respondents in Guatemala working in the formal and informal economies and in sex work, disaggregated by self-declared gender identity. As background to the study, it is relevant to note that the overall unemployment level in Guatemala, Indonesia and Rwanda is quite high, with a large percentage of the general population

Figure 1: Top sources of discrimination in Rwanda and Ukraine in previous 12 months (by percentage of respondents)



Source: Elaborated with data from the Country Research Reports by the Author.

working in the informal economy. For instance, in Guatemala in 2012, only 30 per cent of the population were formally employed, 17 per cent were underemployed, and about 69 per cent worked in the informal economy. (National Employment and Income Survey, as mentioned in the Guatemala Research Report)

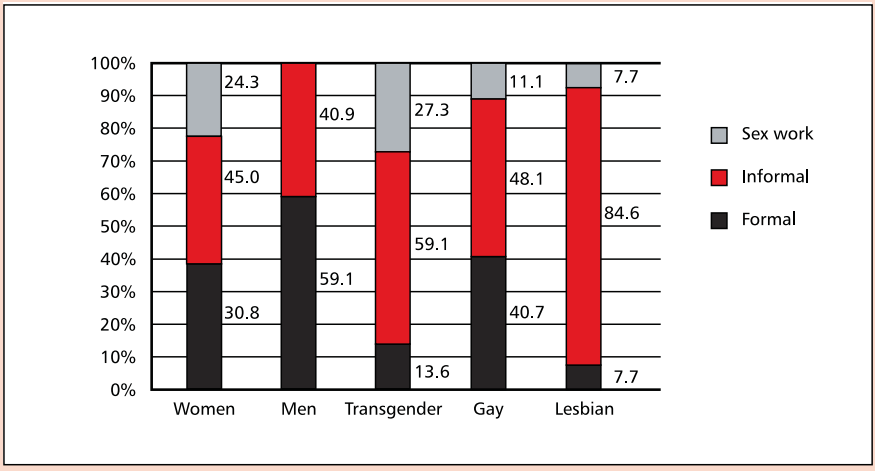
Figure 2 shows that most heterosexual men worked in the formal sector (59 per cent), while larger percentages of lesbians (84 per cent), transgender individuals (59 per cent), and heterosexual women (45 per cent) worked in the informal economy.

With regard to **discrimination at work,** the data must be interpreted only as indicative since the majority of the respondents worked in the informal economy, where employment relations differ from the formal economy. For instance, only 14 per cent of respondents in Rwanda indicated that their employer knew of their HIV status. Of those, 10 per cent had experienced discrimination from their employer and 8 per cent from co-workers.

Table 5: Type of employment of study respondents in Indonesia by sex (per cent of total) N=300

Type of employment	Sex			Total
	Male	Female	Transgender	
Formal	21.19	33.33	10.34	26.33
Informal	68.64	52.29	86.21	62.00
Other	10.17	14.38	3.45	11.67
Total	100%	100%	100%	100%

Figure 2: Type of employment by sex and sexual orientations among respondents in Guatemala (%) N=380



However, in Guatemala, the effects of discrimination on the individual are more pronounced. Almost half of the respondents (48 per cent), were not able to continue working as before due to their HIV status – and 85 per cent of those, perhaps as a consequence, could not afford to buy medicines or pay for tests that are not covered by national health services.

Table 6 shows the reasons for respondents in Ukraine leaving or changing their jobs. A smaller percentage (16 per cent) of formally-employed respondents

Table 6: Reasons for changing job by type of employment and sex in Ukraine N = 69 (8.6% of total respondents)

«If you changed or lost your job, what was the reason?"	Working in the formal economy (%)	Working in the informal economy (%)	Un-employed (%)	Total for each response (%)	Disaggregated	
					Men (%)	Women (%)
I decided to quit the job	16	20	6	42	55	45
I was too sick to continue working	10	13	1	25	47	53
I felt discriminated against by co-workers	14,5	9	0	23	31	69
I was asked to quit my job	6	6	1	13	56	44

made the decision to leave their job, compared to those who worked in the informal economy (20 per cent). Note that some workers in both the formal (10 per cent) and informal (13 per cent) economies responded as 'being too sick to continue'. People living with HIV need care, rest and good nutrition so they could remain productive in the labour force. Social protection is critical, to reduce their vulnerability and maintain their health. Table 6 reveals gender-based difference in Ukraine. A respondent could choose more than one of the options. More women (53 per cent) than men (47 per cent) were too sick to continue performing their duties; more women (69 per cent) than men (31 per cent) faced discrimination from co-workers. More men (55 per cent) than women (45 per cent) decided to quit their jobs; and more men (56 per cent) than women (44 per cen) said they were asked to quit the job.

The population covered in this research is largely vulnerable – whether economically, socially, culturally and/or physically – although this is truer in some countries than others. For example, despite its classification as a lower-middle income country, Guatemala has a low ranking in the human development index (133rd of 195) and experiences one of the highest levels of HIV vulnerability in the region. Every day 25 individuals become infected with HIV, which is 9,000 infections per year, with men who have sex with men, and sex workers, the worst affected. (Guatemala Research Report, 2014)

In Indonesia, a Ministry of Health survey conducted in 2007 highlighted the vulnerability of key HIV populations, as follows: 'Injecting drug users (IDU) are at the greatest risk of HIV – about 50 per cent of IDU participating in

the study were HIV-positive, 28 per cent were married and 47 per cent had multiple sexual partners. This shows that IDUs do not constitute a single entity but have multiple partners, thereby increasing the risk of getting infected with HIV and STIs, and of infecting others. The Indonesia country study also found that the second most vulnerable population were transvestites and transgender individuals, between 14-34 per cent of whom live with HIV, followed by female sex workers (6-16 per cent living with HIV), and men who have sex with men (2-8 per cent living with HIV)' (Indonesia Research Report, 2014).

AVAILABILITY AND TYPE OF SOCIAL PROTECTION PROGRAMMES

Like in most other countries, social protection programmes in Guatemala, Indonesia, Rwanda and Ukraine are linked to the formal public or private sector of the economy – sometimes covering only public servants and the military – thus largely fail to provide for those working in the informal economy. However, these populations are not fully deprived of benefits, as each country has enacted laws and legislation aimed at supporting individuals or households facing social risks and vulnerability.

Types of social protection programmes

- **social assistance** (such as cash transfers, pensions, child grants, food aid, public works, assets transfers and subsidies);
- **social insurance** (such as old-age pensions, survivorship, health insurance, disaster insurance, disability pensions, and unemployment insurance);
- **social services** (such as social welfare services – e.g. for 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).

Since 1998 the Government of Indonesia has provided social protection to the poor, the majority of whom work in the informal economy or are self-employed, through several programmes. (See Table 7) According to a World Bank report on universal health access, access for the poor and near-poor to *Jamkesmas* is subsidized by general revenue. Means testing and local eligibility criteria are used to determine who qualifies as poor or near-poor. The high proportion (>50 per cent) of mis-targeting and leakages to the non-poor, stem from variable eligibility criteria and lack of validated targeting methods. Another programme, *Jampersal*, provides free maternity services to all pregnant women, regardless of income. (World Bank, 2013, p.34)

Table 7: Types of social protection programmes for the poor in Indonesia

Name	Transfer type	Target group	2010 recipient number	2010 access	2010 benefit level	Total 2010 budgeted spending (IDR Billion)	Key executing agency
Raskin	Subsidized rice	Poor and near-poor households	17.5 million households	National	15 kg rice per month	13,925	Bulog
BLT*	Cash	Poor and near-poor households	18.7 million households	National	IDR 100,000 per month for 9 months	17,700 – 23,100**	Ministry of Social Affairs
PKH	Cash on conditions	Very poor households	810,000 households	Pilot	IDR 1,287,000 per year	1,300	Ministry of Social Affairs
Jamkesmas	Health service fees waived	Poor and near-poor households	18.2 million households	National	Varies depending on utilization	5,022	Ministry of Health
BSM	Cash on conditions	Students from poor households	4.6 million students	National but not full scale	IDR 561,759 per year	2,904	Ministry of National Education and Ministry of Religious Affairs

** During the last funding release in 2008-2009.*
*** Total expenditure for twelve months of BLT programme (2005-2006): IDR 23,100 billion and for nine months of BLT programme (2008-2009): IDR 17,700 billion.*
Source: World Bank 2012, as shown in the Indonesia Research Report 2014.

In Rwanda, the Government made social protection for the poor a priority in its economic development and poverty reduction strategy. A broad range of social protection programmes for vulnerable groups are in place under the umbrella of *Vision 2020* (Rwanda Research Report, 2014).

Poverty and extreme poverty, concomitant with widespread inequality, have made social protection and social security a Government priority in Guatemala since 1971, when, for the first time, the national development plan (1971-1975) set the goals of fostering employment, decreasing unemployment, increasing labour opportunities for women, and improving health. (Guatemala Research report, 2014)

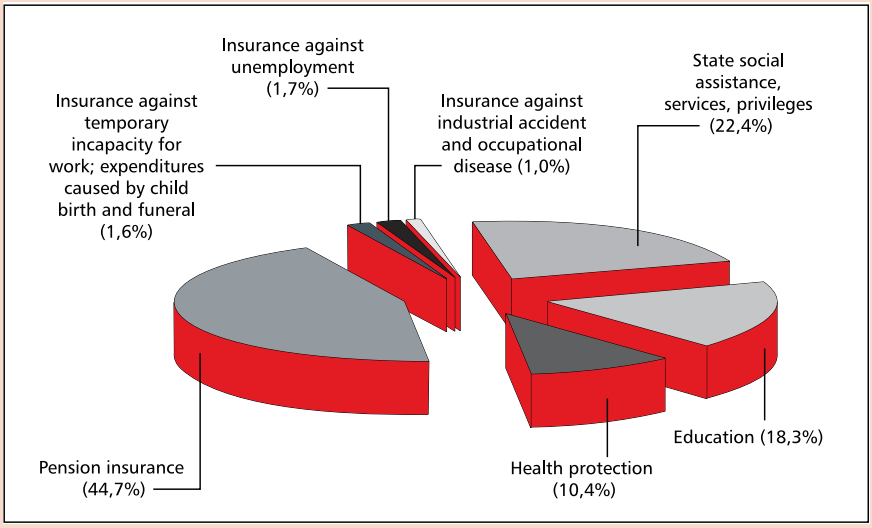
In 1991 the Government of Ukraine began to review a long-established social protection system inherited from the Soviet Union. Its efforts are undermined by the increasing number of persons entitled to benefits due to the economic crisis, which has created a major budgetary hurdle for the Government as it attempts to support socially vulnerable groups.

Social security in Ukraine is financed by mandatory contributions from citizens, enterprises, organizations and institutions, as well as public funds and other sources of financing. It is guaranteed by the network of state, communal and private institutions charged with providing assistance to persons lacking the capacity to work. Figure 3 depicts the structure of the social budget of Ukraine for 2011.[11] There are four mandatory insurance contributions: the Pension Fund, the Unemployment Fund, the Temporary Incapacity to Work Fund, and the Industrial Accidents and Occupational Diseases Fund.

Current Ukrainian social security legislation guarantees that requirements and regulations ensure equal treatment for all, and its constitution guarantees basic social rights related to social security for all, including for PLHIV. PLHIV have the same rights to social benefits as other working men and women. (Ukraine Research Report, 2014, p.21)

[11] Ukraine, with support from ILO, developed an economic-mathematical simulation model of the social budget to analyse, forecast and calculate national expenditures on social security.

Figure 3: Structure of social budget expenditures in Ukraine in 2011



Source: Ukraine Research Report, 2014.

While in Guatemala, Indonesia and Rwanda, social protection is linked to employment in the formal economy, in Ukraine all citizens, regardless of employment status, have the right to request social assistance (e.g. allowances for low-income families) and social services (e.g. food products, preventative health services, legal services, and general health services).

All four countries have social programmes for the poor and do make health services available. However, medical services are not always free and there are often hidden costs. This is the case in Ukraine, Indonesia and Guatemala. Even though the written social protection policies might indicate free medical services provisions, the reality is different. Access to medical tests and medicines (although usually not to ART), depends to a large extent upon individuals' ability to pay; this increases individual and household out-of-pocket expenses and vulnerability. In Rwanda, health services were available through community-based insurance schemes aimed at reaching as many poor and vulnerable people as possible, and, according to the respondents,

services and medicines are free. However, there is a small co-payment, which respondents must pay themselves.

➔ **Interpretation:** In all countries social protection for the general population is linked to working in the formal sector. This means that only about 6 per cent of the active workforce in Rwanda, 30 per cent in Indonesia, 31 per cent in Guatemala and 77 per cent in Ukraine[12] are covered, leaving a significant proportion of the general population in each country relying on social assistance. Since key HIV populations and PLHIV are unduly represented in the informal economy, their degree of reliance on social assistance and social insurance is much greater than that of the general population. Equally, the negative effects of a lack of access to social protection are much more severe for this population.

ACCESS TO SOCIAL PROTECTION PROGRAMMES

As stated in the Introduction, this research shows that in all four countries social protection is heavily weighted towards the formal economy, whereas PLHIV in these studies are more represented in the informal economy. This situation is made worse by the fact that workers with HIV might leave their jobs in the formal economy due to illness or an unwelcoming work environment, thereby increasing the number of PLHIV in the informal economy or underemployed. The majority of PLHIV in these studies (61 per cent with all four countries combined), especially if they also belong to a vulnerable group, work in the informal economy, are under-employed or unemployed (7 per cent of respondents in the four countries).

Programmes for the poor provide the vast majority of opportunities for PLHIV and their households to access social protection. However, many of the respondents had not heard of these programmes; thus, while availability might be high, access is not. This has created a double burden: on the one hand, some existing social protection programmes are underutilized, and on the other, PLHIV are left with inadequate social protection. This situation is compounded for many workers in the informal economy who are low income

[12] See World Bank, 2014 in references.

earners, but not poor – or not poor enough to meet poverty criteria to qualify for certain social programmes, and are left with limited, if any, protection.

Focus group discussion participants in these countries indicated that low-income workers in the informal economy are vulnerable, but would be willing to contribute to social security in order to be protected. It follows that there need to be better mechanisms at country level for this to happen; that is, for workers in the informal economy to be able to contribute to national social security schemes. This is one way PLHIV with low incomes, and their households, could improve their livelihoods and overcome their vulnerability.

None of the four countries' social protection programmes explicitly exclude HIV or AIDS, but only Guatemala's and Ukraine's programmes explicitly cover them – particularly through their national HIV and AIDS strategies. This cover is essentially healthcare-related. In Indonesia and Rwanda PLHIV are covered by these countries' social assistance to the poor, as previously indicated. To the extent that PLHIV meet the poverty criteria in these countries, they can, at least in theory, access several schemes targeting vulnerable groups. In Rwanda and Ukraine PLHIV theoretically have access to the same social protection programmes that are available to the poor and vulnerable populations. In all countries, except possibly in Ukraine, the research shows that workers in the informal economy, especially PLHIV, do not have the same access to social protection as workers in the formal economy.

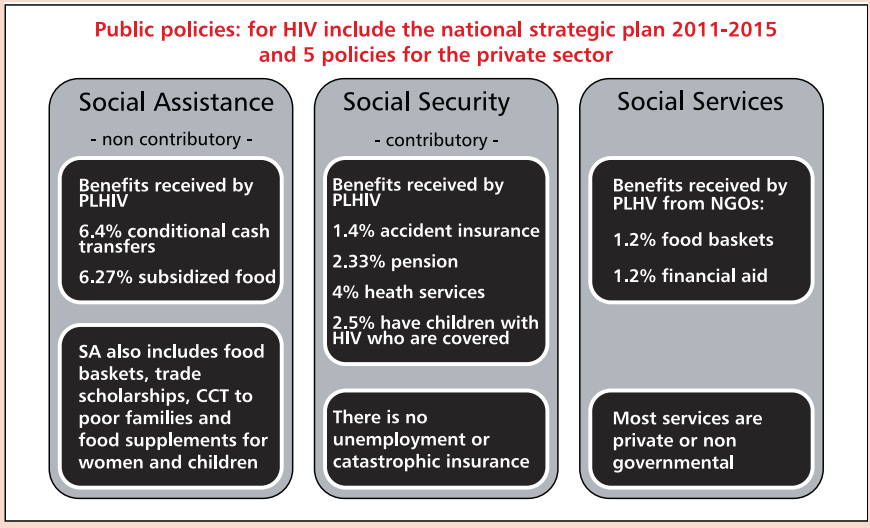
In response to ILO Recommendation N° 200 (2010), in 2011 the Ukrainian Government, along with employers' organizations and trade unions, adopted a national tripartite strategy to combat HIV and AIDS in the workplace. Together with the national programme (2009-2013) for HIV prevention, treatment, care and support, this means that, theoretically, PLHIV are covered both through work and by personal healthcare programmes.

Guatemala has rich social policy and legal frameworks for HIV and AIDS. In 2000 the Government adopted a decree to respond to HIV and AIDS

and to promote and protect the human rights of PLHIV. This was followed in 2005 by a policy designed to address sexually transmitted infections and AIDS, and, in 2008, by a pivotal decree against *femalicide* and violence against women. Figure 4 shows the social protection system in Guatemala and selected benefits.

Even when there are specific programmes to address HIV and AIDS, there are critical gaps, especially related to gender. For instance, although Guatemala seems to have the strongest sense of the importance of addressing gender issues in national HIV and AIDS decrees and programmes, its national AIDS programme only recognizes biological sex, leaving other gender identities unacknowledged. Because of this, transgender individuals

Figure 4: Social Protection System in Guatemala



Source: Adapted from the Guatemala Research Report, 2014.

in Guatemala are often underserved by social programmes, as they are in Indonesia.

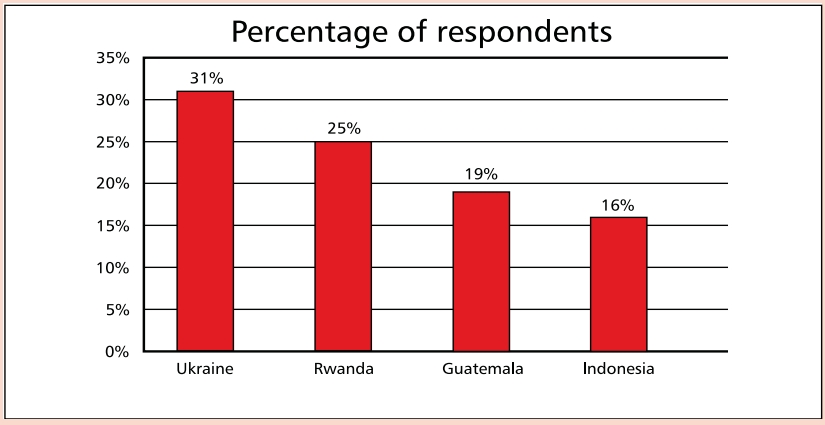
One of the main reasons why transgender individuals have problems accessing health insurance is the incongruency between their sex as stated on their identity cards, and their gender identity and physical appearance. One health worker in Malang, Indonesia said:

"We don't discriminate against transgender. We just want them to state their gender as either male or female. They can't say that they are in between male and female. Everyone has to say whether they are male or female when they apply for an ID card, right? Why should we do things differently?"

The percentage of respondents who benefit from social protection is small. Respondents in countries that receive support from the Global Fund (Guatemala, Indonesia, Rwanda and Ukraine) and/or PEPFAR (Indonesia) or other donors, have been able to participate in programmes targeting PLHIV. These programmes organize projects such as income-generation schemes, often in collaboration with local NGOs. Figure 5 shows estimated aggregate levels of social protection access by country.

These findings are supported by the global literature review of more than 100 studies, which likewise found that key HIV populations in low-income countries had low levels of access to social protection. The review noted that this was often aggravated by policy – for example, the exclusion of households with working-age members from certain schemes (e.g. cash transfers), further constraining the livelihood of PLHIV and their households. In this four-country research, PLHIVs' lack of knowledge about the programmes led to continuous low levels of access to social protection. Inadequate dissemination of information regarding social protection programmes, coupled with complicated access processes, becomes more limiting to a population whose educational level is largely basic (except in Ukraine) and who might, in addition, feel physically and emotionally ill. In countries such as Guatemala and Indonesia NGOs play an important role informing PLHIV

Figure 5: Estimated Access to Social Protection / Social Assistance (excludes health)



Source: Elaborated with data from the research reports by the author.

of their rights, and act as intermediaries between PLHIV and a daunting social protection system.

In Indonesia, less than 16 per cent of respondents received non-health related social protection benefits whereas 32 per cent received local government health insurance (Jamkesda). In Guatemala, 41 per cent accessed health or medical services through national HIV clinics and 34 per cent accessed services through the Guatemalan Institute of Social Security, which only covers workers in the formal economy.

In Ukraine the share of PLHIV who received social insurance (31 per cent) was significantly greater than those receiving state social assistance (8.5 per cent). Social insurance can be largely broken down as follows: a large proportion of respondents received a disability pension (18 per cent); this was followed by paid sick leave (6 per cent), unemployment benefits (3 per cent), and assistance in connection with pregnancy and childbirth (2.5 per cent). In most cases 'benefits to families with children' were paid to women. Moreover, more men than women do not receive benefits or assistance despite being entitled to them.

This reveals a unique situation where entitlements and social payments are the predominant forms of social protection. While this is not intrinsically negative, it raises questions as to how well-suited this type of assistance is for PLHIV, whose own social support priority might be their health needs.

Box 2 shows the percentages of respondents in Ukraine who benefit from social protection and where they obtain services. The share of women who use state social assistance for medical consultations is almost double that of men (11 per cent and 6 per cent respectively), and women's use of social assistance from communal services is also higher than men's (24 per cent and 19 per cent respectively) as is their utilization of subsidized food (30 per cent and 26 per cent respectively).

The situation in Rwanda is similar to the situation in the other countries: respondents' access to social protection is low, even though on paper

Box 2: Sources of social protection in Ukraine and their access

- Public health organizations (82 per cent)
- Ukrainian NGDs (26%)
- State social protection institutions (24%)
- International organizations (15.5%)
- Communal sources (housing management units, transport facilities, etc.) (4%)

Note: Percentages not mutually exclusive
Source: Elaborated with data from the Ukraine Research Report, 2014.

PLHIV could potentially access public works programmes for the poor, direct support, and financial support (a cash transfer for the extremely poor, the elderly and people with disabilities) through the *Vision 2020 Umurenge Programme* (VUP) – a social protection programme aimed at reducing extreme poverty through direct, targeted support of the most vulnerable. In reality, few PLHIV and key populations benefit from these schemes. Table 8 shows that only 25 per cent of respondents received social security and that small proportions of respondents benefited from livelihood support (8 per cent), credit support (7 per cent), pension (6 per cent) or cash transfers (4 per cent). However, 83 per cent of respondents had access to health insurance (mainly through the national community-based health insurance scheme).

One participant in the focus group discussion in Rwanda shared her experience as follows:

"I am a widower, my husband died of AIDS and I am one of the beneficiaries of the VUP programme. I am enjoying the benefit of the programme because I can cover most of the basic needs of my household. Before joining the programme I was living in a thatch-roofed house and now my house has an iron-sheet roof. My children are going to school; the Government and I are paying the community health insurance premium for everyone in my household."

Participants in focus groups in Rwanda highlighted the challenges faced by workers in the informal economy, especially PLHIV, in terms of accessing social security services. As mentioned above, only workers in the formal economy are part of the Social Security Fund, while those in the informal economy have access to several national social protection programmes only if they meet poverty criteria.

Focus group participants in Rwanda asked for mechanisms that would enable workers in the informal economy to contribute to the Social Security Fund. This is worth noting: a failure to address the gaps in access to social protection could worsen inequality and threaten the social and political conditions that are conducive to economic growth.

Table 8: Access to social protection by type of programme and sex in Rwanda

Type of social protection programme	Female		Male		Total	
	N	%	N	%	N	%
Are you covered by:						
Social security system	59	24	32	27.4	91	25.1
Public Service Pension scheme	5	2	17	13.3	22	5.8
Ubudehe credit scheme	22	7.7	9	6.7	31	7.4
Vision 2020 Umurenge programme	12	4.2	3	2.2	15	3.6
VUP loans & employment	5	1.8	3	2.3	8	1.9
FARG	14	5.6	6	4.8	20	5.3
Social Welfare services provided publicly	19	6.6	4	2.9	23	5.4
Social Welfare services provided by NGOs	17	5.9	4	2.9	21	5
Medical care supported by an employer	2	0.8	2	1.5	4	1
Wages through participation in public works	7	2.5	5	3.7	12	2.9
Child/family benefits	14	4.9	4	2.9	18	4.3
Food support	7	2.4	4	2.9	11	2.6

Source: Rwanda Research Report, 2014.

Although respondents appear to receive little in the way of direct family benefits, Rwanda has implemented a free, compulsory, universal nine-year basic education programme (6 years of primary education and 3 years of secondary school). According to the Ministry of Education Statistics Yearbook of 2012, the programme has contributed to the increase of primary school enrolment rates for both boys and girls, and the country is on track to achieve universal access to primary education by 2015. Gender parity at primary level has been achieved. Girls' net enrolment rate (98 per cent) is higher than boys' (95 per cent); the overall completion rate at primary level was 72.7 per cent in 2012 (a dramatic increase from 52.5 per cent in 2008), with girls' completion rates at 77.7 per cent. (Rwanda Research report, 2014)

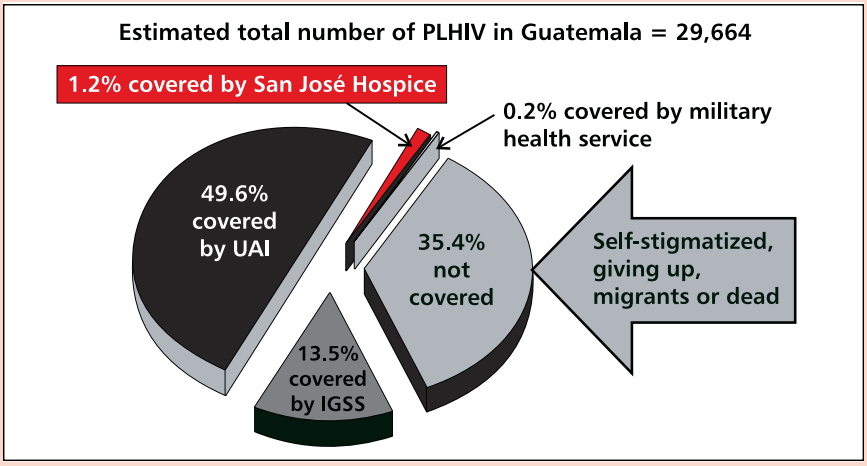
This research shows that the most accessed social services in all four countries were related to heath or medical care, including medical consultations for prevention, treatment and therapeutic measures; medical and social

support services related to ART; treatment of opportunistic infections; and medicines.

Guatemala is the only one of the four countries for which the approximate number of PLHIV is known, and where, therefore, the extent of health/medical coverage of PLHIV can be measured with some accuracy. Figure 6 shows the distribution of care services accessed by the Guatemalan PLHIV overall. The providers are the Guatemalan Institute of Social Security (IGSS), which covers workers in the formal economy (13.5 per cent), the Integrated AIDS Units (UAI) (50 per cent), the Saint Joseph Hospice (1.2 per cent) and the military health system (0.2 per cent).

Table 9 illustrates gender differences in access to health insurance in Indonesia. A slightly higher percentage of women (61 per cent) than men

Figure 6: PLHIV coverage by type of health services



Source: Adapted from Guatemala Research Report, 2014.

Table 9: Access to health insurance in Indonesia

Do you have access to health insurance?	Female	Male	Transgender	Total
Yes	61%	58%	34%	57%
No	39%	42%	66%	43%
Total	100%	100%	100%	100%

(58 per cent) had access to health insurance. Only a third of transgender individuals had access to health insurance. Forty-three per cent of the respondents went without health benefits.

➔ **Interpretation:** The data presented above, gathered from more than 2000 respondents, reveal an alarming picture. Despite differences in socio-economic levels and social protection policy between countries, the findings of this research lead to four conclusions with regard to social protection and HIV:

(1) Among PLHIV social protection access is low or very low.

(2) PLHIV have access to health insurance and medical services.

(3) PLHIV have access to little else: only a very small number of them receive livelihood support, with minor gender-based differences.[13]

(4) Workers in the informal economy who are not poor are frequently excluded from access to social protection because they do not meet the eligibility criteria.

The situation in Ukraine is somewhat better. The social protection system fulfils its basic function – to provide people with subsistence levels of support. However, it does not significantly improve their living standards. Thirty-four per cent of Ukraine's respondents lived at, or below, the minimum subsistence threshold.

Participants in focus group discussions in all countries shared the same concern: there were limited financial protection or financial assistance services available to PLHIV that provided predictable transfers of cash, food or other benefits. Where there were donors working at country level there seemed to

[13] Note: 67% of the respondents in Rwanda were women.

be some initiatives in place that supported income-generation activities and provided livelihood support for PLHIV and affected communities. Some PLHIV suggested that households' ability to pay out-of-pocket expenses and to ensure food security had been reduced because of limited financial assistance they could receive.

The most significant social benefit PLHIV receive is health insurance and medical care. There is also evidence that PLHIV access health insurance and/or medical services that are officially free or largely subsidized. Often, however, this is not what happens in practice: in many cases the user of the services needs to pay for clinical visits, tests and/or medicines – this is due in large part to shortcomings in the supply chain or in the implementation of social protection programmes; ARV are the exception, and are usually free. According to the findings from these country research, PLHIV's access to health insurance and medical services is highest in Ukraine (96 per cent), followed by Rwanda (83 per cent) and Guatemala (65 per cent), with the lowest level of access in Indonesia (57 per cent). Nonetheless, this level of access to health and medical services is not without constraints, mainly in the form of out-of-pocket payments by the user. Access to medical care has likely contributed to PLHIV living longer; however, the lack of meaningful livelihood support hampers their ability to maintain basic living standards for themselves and their households. Thus, with the current level of access to social protection, PLHIV might live longer, but not necessarily better.

BARRIERS TO SOCIAL PROTECTION ACCESS

In all countries the processes for accessing social protection resemble obstacle courses and are unduly convoluted:

1 Insufficient information about social protection. Dissemination of information about social protection programmes is inadequate: many PLHIV, including key populations, were aware neither of the benefits for which they could apply, nor of the application process. In Ukraine, for instance, respondents identified a lack of information about the type of

assistance available as the main impediment to accessing social services or assistance from state institutions (67 per cent) and non-governmental organizations (51 per cent). In Rwanda, more than half of the respondents (59 per cent) indicated that they were eligible for social protection benefits, but that the process for requesting support is too complicated; 47 per cent simply said that they did not know how to apply. (See Table 10) In Guatemala a broad lack of information about PLHIV's rights to certain services was identified as a key barrier, while in Indonesia many PLHIV heard about social assistance programmes for the first time through this research.

Table 10: Livelihood support in Rwanda

	Benefits from any livelihood support scheme	
	N	%
Have you or your spouse/partner benefited from any livelihood support?		
Yes	83	19.5
No	341	80.0
I don't need such support	2	0.5
Total	426	100
Reasons, if not getting support you need		
I am not eligible	53	15.7
I am eligible but the procedures to request support services are too complicated	212	59.4
I don't work in a company and I have no access to insurance	58	17.3
I work in a company, but I don't receive insurance or other social benefits	14	4.2
I don't know how to apply	171	46.6
I know where the services are, but they are too far from where I live	11	3.3
Transportation is expensive	12	3.6
I don't like how I am treated	36	10.8
I need to pay for services	9	2.7
Other	33	10.6

Source: Rwanda Research Report, 2014.

Sometimes, when governments do make an effort to inform the population about social protection programmes, PLHIV decide not to use the services for fear of retaliation by their communities or employers. The *Jamsostek* programme in Indonesia is a case in point. *Jamsostek* is a social protection programme that is open to workers in the informal economy. However, PLHIV have been reluctant to access health insurance through it, because of fears of employers becoming aware of their HIV status and firing them as a consequence. A staff member of the Malang Labour Union said that he had never heard of any PLHIV workers in Malang having been fired, and the *Jamsostek* programme staff said that they had not received applications for *Jamsostek* insurance from PLHIV workers. A *Jamsostek* programme staff member said:

"….as long as they pay the premium they can be members. Yet, the participation of workers in the informal economy is still very low… Jamsostek [programme staff] collaborate with the Labour Office and local government to conduct awareness-raising activities for workers both in the formal and informal economies. Together with local government representatives, Jamsostek programme staff go to villages to visit traditional markets, and we offer different schemes to those available to workers in the formal sector. They [workers in the informal economy] can choose from different packages: pension, accident and death insurance, or health insurance."

What this particular case illustrates is the extent of the misinformation, miscommunication and overall distrust that seems to exist between the key players. NGOs could be useful partners to governments at the country level – and in many instances they are – to support access by PLHIV and key populations to social protection. It is worth noting that in Indonesia, donors such as the Global Fund and PEPFAR support the national and local governments and NGOs by enabling them to improve social services for PLHIV and key populations.

2 Complexity of gaining access to services, and services' limited capacity. Even when PLHIV apply for social protection – often assisted by NGOs – the road to accessing services and benefits is tortuous at best, and

demeaning at its worst. Demonstrating that the applicant meets eligibility criteria is the first hurdle in Indonesia. The requirement for an identification card soon cuts the process towards social benefits short. A permanent address must be provided, and this is the basic requirement for obtaining not only an individual identification card, but also a family card and a 'poor status' letter. The poverty criteria stipulate that people need to obtain a letter from the leader of their community stating that they are poor, and hence eligible for locally-run health assistance. However, PLHIV do not always have a permanent address, which means that they are not known by the local leader; and when they are known in their community, PLHIV might not want to divulge their HIV status.

In all four countries, availability of services for PLHIV and key populations is critical, and yet, most respondents encountered challenges when they tried to access social protection, particularly health or medical services (although to a lesser degree in Rwanda). In Indonesia and Guatemala, the supply side of health and medical services is not always fully functional. Lack of institutional capacity, inadequate stocks of medicines and few hospital beds make it difficult for the population at large to access services. In some health centres in Bali, Indonesia only 30 per cent of the staff have received training on managing HIV. People are sometimes denied services in Indonesia because there are no hospital rooms available. To fully comprehend the situation of providers in Indonesia and elsewhere, it is helpful to look at the broader context of health service provision. The World Health Organization (WHO) estimates that the minimum number of skilled health professionals[14] needed per 10,000 people is 22.8. In Indonesia there are 16.1 per 10,000 people. Furthermore, to achieve universal healthcare access, Indonesia would have to increase its skilled health workforce by 78 per cent – a formidable task. (World Bank, 2013, p.21) The shortage of health service providers is a global challenge, which is being revisited in the context of an international push to achieve universal healthcare access.[15] In absolute terms, the greatest shortage occurs in South-East Asia, which is dominated by the needs of Bangladesh, India and Indonesia. The largest relative need exists in sub-Saharan Africa. (WHO, 2006, p.12)

[14] Skilled health professionals refer to doctors, nurses and midwives.

[15] This method of defining a shortage is driven partly by the decision to set the minimum desired level of universal access at 80% and partly by the empirical identification of health worker density associated with that level of access (WHO, 2006, p.11).

PLHIV seeking services face additional challenges – there is no single place they can go for all the services they need. Some sites in Indonesia offer only Voluntary Counselling and Testing (VCT), while antiretroviral drugs (ARV) are only stocked in hospitals. This necessitates considerable to-ing and fro-ing between centres, which makes getting medical care daunting. There are similar difficulties for PLHIV in Guatemala. The Integrated AIDS Units are not really integrated. Due to frequent stock-out of medicines or lack of institutional capacity, PLHIV spend much of their time seeking the care they need from different sites. In focus group discussions PLHIV often said that what they needed was a 'one-stop service' that would eliminate the need for them to travel to and from different institutions just to access necessary medical treatment.

As Table 10 shows, 59.4 per cent of Rwandan respondents indicated that they were eligible for social protection, but that the procedures for requesting support services were too complicated. Even in Ukraine, where the social protection sector is more established, only one out of every three or four respondents knew about the different social protection programmes available. Twenty-six per cent of respondents in Ukraine working in the formal economy and 26.5 per cent of the unemployed knew about eligibility for insurance benefits, as compared to 22 per cent of respondents working in the informal economy. While 31 per cent of respondents knew about eligibility for state social assistance, only one in four (25 per cent) knew whom to contact in order to apply. Those working in the informal economy were better informed about state social assistance than those working in the formal sector or the unemployed (with 33 per cent of respondents in the informal economy aware of eligibility, compared to 29 per cent – formal economy, and 31 per cent – unemployed). Women were slightly better informed about both insurance benefits and state social assistance than men.

3 Discrimination, stigma and self-stigma. Stigma, manifested in poor self-image and low self-confidence, coupled with a lack of knowledge of their rights, often stops PLHIV from seeking social protection. When they do, poor treatment by service providers often reinforces their self-doubt. Discrimination by social and health service providers cannot be overlooked.

In Rwanda, 18 per cent of respondents identified social/heath/insurance providers as the second largest source of discrimination (after discrimination by family and friends), while in Ukraine this was true for 31 per cent of respondents (28.5 per cent of men and 34 per cent of women). Although not quantified, in both Guatemala and Indonesia discrimination from service providers was identified by focus group discussion participants as a barrier to accessing services.

It is worth noting that while 43 per cent of respondents in Rwanda identified themselves as 'poor' and 48 per cent selected 'don't belong to any category', none identified themselves as belonging to 'men who have sex with men (MSM)', 'transgender', 'IDU' or other key populations, despite these populations being represented in the focus groups.

Discrimination against vulnerable populations and PLHIV is well documented in Guatemala. In spite of the Government's efforts to address HIV and AIDS as a human rights issue, society is slow to recognize the rights of these groups. Along with an increase in HIV cases, this research found an alarming 23 per cent increase in the number of formal legal complaints filed in 2012 in relation to 2011. The majority of the 280 claims filed in Guatemala related to violations of the rights of PLHIV to health, to non-discrimination, and to access to work.

The issue of discrimination has many facets. PLHIV and key populations suffer discrimination sometimes because they belong to less socially acceptable groups (e.g. IDU or sex workers), because they are poor and disadvantaged (e.g. in Indonesia), due to their work status (e.g. in Ukraine the unemployed encountered more discrimination than those working in the formal or informal economies) and lastly because of their HIV status (in Guatemala, Indonesia, Rwanda and Ukraine).

In Ukraine more women (34 per cent) encountered discrimination than men (28.5 per cent) due to their HIV status. Transgender individuals in Guatemala and Indonesia suffered the most from discrimination, which often lead to sex work being the only way they could sustain themselves.

Of the different types of discrimination suffered by PLHIV, perhaps the most pernicious is discrimination by those who these populations should be able to trust: family, friends, health and social service providers. Discrimination by family and friends cannot be underestimated; it was the principal source of discrimination for more than half of respondents in Rwanda, and a significant proportion in Indonesia. A man living with HIV in Surabaya, Indonesia shared his experience:

"Disclosing my status to my family was very difficult. My father turned against me. He burned my clothes, threw away my eating utensils. Thankfully my brother is a medical student. He took my side, and helped me a great deal to explain my situation to my father and my other family members. After six years, six long and tortuous years, my father is finally able to accept me as I am. The memory is still painful, but it's okay, because now he is willing to help me out not only financially, but also emotionally."

As mentioned above, many providers also face challenges: from fear of contagion to lack of adequate training, insufficient supplies and limited capacity to provide services, as national hospitals are often overburdened (in Indonesia and Guatemala in particular).

This research coincides with the world witnessing, astounded, countries such as Nigeria and Uganda adopting new legislation against homosexuality. Homosexuality was already illegal in Uganda, but the new legislation threatens to usher in an era of harsh treatment of offenders and makes it a crime to fail to report anyone who breaks the law, which could lead to widespread oppression and the institutionalization of discrimination. (Raghavan, 2014) The bill also has public health implications. Studies show that when gay people face discrimination including abuse, incarceration and prosecution, they are less likely to seek HIV testing, prevention and treatment services. (UNAIDS, 2014) Furthermore, such a law places social and health services providers in an untenable situation where at times they might have to choose between caring for those with HIV and reporting them.

These instances of discrimination are not isolated occurrences: 83 countries in the world outlaw homosexuality; more than 100 countries legally discriminate against women; and even more have laws that discriminate against minority groups. Institutionalized discrimination is bad for people, for societies and for economies. (Kim, 2014)[16]

Social networking site Facebook's decision to allow users to customize how they identify themselves is a breath of fresh air. Facebook users can choose 'female', 'male' or 'custom' – a 'customizable' gender option. (Dewey, 2014) Brielle Harrison, a Facebook engineer who identifies as 'transwoman', said:

"There's going to be a lot of people for whom this is going to mean nothing, but for the few it does impact, it means the world."

4 HIV is expensive. The cost of living with HIV can be prohibitive, especially in those countries where the costs of antiretroviral therapy (ART) are high. Among the six Central American countries, ART medicines in Guatemala are the priciest – five times more than in the second most expensive country in the sub-region. (See Table 11)

Although in most cases ART is free, PLHIV and their households have four major household expenditures: (i) co-payments on insurance (Indonesia and Rwanda), (ii) transportation for medical appointments (Guatemala, Indonesia, Rwanda and Ukraine), (iii) payments for medicines (Guatemala and Ukraine), and (iv) payments for hospital, clinic visits, or tests (Guatemala, Indonesia and Ukraine). A medical doctor working in a hospital in Surabaya, Indonesia said:

"The Government still provides free ART for PLHIV, but laboratory tests and supporting vitamins are not free."

In Rwanda PLHIV received medicines from national medical services, therefore transport was most commonly cited as the most important out-of-pocket expense (26 per cent of respondents) followed by medicines (14.6 per cent). In Ukraine 72 per cent of respondents identified medicines as their principal health expense (71 per cent of men and 67 per cent of women), followed

[16] The World Bank has historically shied away from intervening in its client's politics, however, on Thursday (February 27, 2014) the Bank Group announced that it would indefinitely delay $90 million worth of loans to Uganda for further review of the project to ensure that the development objectives would not be adversely affected by the enactment of the new law.

Table 11: Prices of antiretroviral therapy medicines in six Central American countries

Prices in US Dollars (US $)

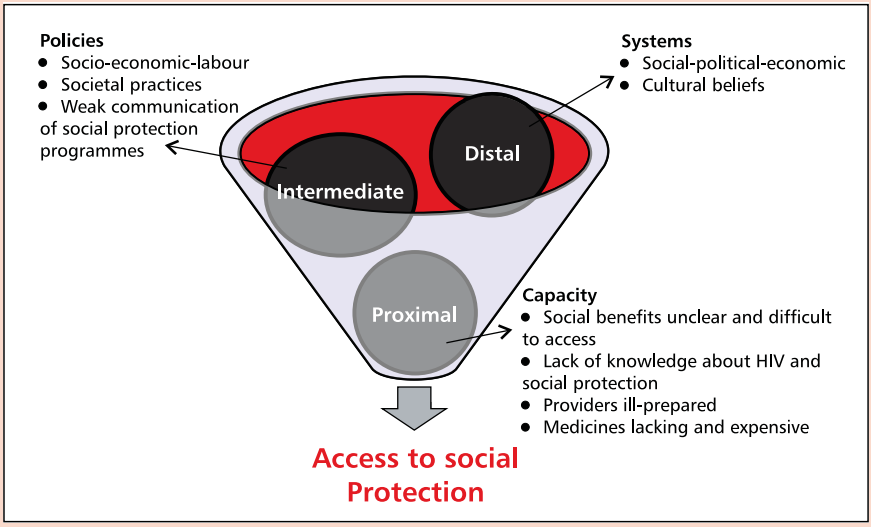
PRODUCT	NICARAGUA VPP	HONDURAS VPP (Local)	GUATEMALA Local Market	BOLIVIA (RP-CI)	PERU	ECUADOR
Abacavir 300mg	210	180.68	1923.40	175.80	235.52 (Social Security) 241.01 (Minsa)	624 (Local market) 186.60 (PAHO/ WHO)
Efavirenz 600mg	51.12	51.60	639.81	56.88	95.02 (Minsa)	264 (Local market)
Emtricitavina 200 mg + **Tenofovir** 300 mg	130.56	138	656.87	No data	No data	621 (Local market)
Lopinavir 200 mg + **Ritonavir** 50 mg	437.52	420	1315.75	No data	528.06 (Minsa)	772.80 (Local market) 415.32 (PAHO/ WHO)

Note: VPP=Global Fund prices. RP-CI=Principal Recipient-International market prices. Minsa=Ministry of Health
Source: Guatemala Research Report, 2014.

by transport. More workers in the informal economy cited both medicine and transport as their biggest out-of–pocket expense than formal-economy workers: for medicine it was 80 per cent and 71 per cent respectively and for transport 61 per cent and 46 per cent respectively. In Indonesia, three out of four respondents indicated that they paid for healthcare themselves. In Guatemala, 96 per cent of respondents said that they received the medications they needed (in 3-month supplies) from social security facilities (IGSS), while only 61 per cent said that they received the medicines they needed from the Ministry of Health's integrated AIDS service units (UAI). Fewer respondents received medications for opportunistic infections (72 per cent received them from social security facilities and only 14 per cent were able to obtain from the integrated AIDS service units). When medications are not available through the national health system, PLHIV receive prescriptions, which they have to get filled at private pharmacies – a daunting task for the many respondents who cannot afford to pay.

These findings provide more information about some of the key barriers to social protection experienced by people living with HIV, including key populations; and by so doing fill a void in the global literature review regarding these barriers. Figure 7 depicts the interrelation of the different barriers.

Figure 7: **Barriers to Social Protection for People Living with HIV**



Source: Elaborated with data from the Country Research Reports by the Author.

➔ **Interpretation:** In all countries barriers to social protection are surprisingly similar, although different barriers are more significant in different countries. PLHIV are often unaware of the social protection benefits they might be eligible for. While this might be partly due to the fact that the majority of respondents worked in the informal economy, information on social protection does not seem to be readily available even to PLHIV employed in the formal economy. When PLHIV attempt to apply for services, they encounter a series of obstacles that soon curtail their progress towards accessing services, often fueled by discrimination at all levels. As a result, few participants in this research enjoyed the most basic livelihood support – with the notable exception of Ukraine (and even in Ukraine one in three respondents remained poor). (Ukraine Research Report, 2014)

The most accessible type of social protection benefit people living with HIV receive is health insurance and/or medical services. However, access to health and medical services is not without costs. PLHIV have to pay for transport

as part of getting their treatment, or cover a portion of the costs of tests or medicines. Given that this population does not receive significant livelihood support for themselves or their families in the countries researched, in most cases the living standards of people living with HIV are low.

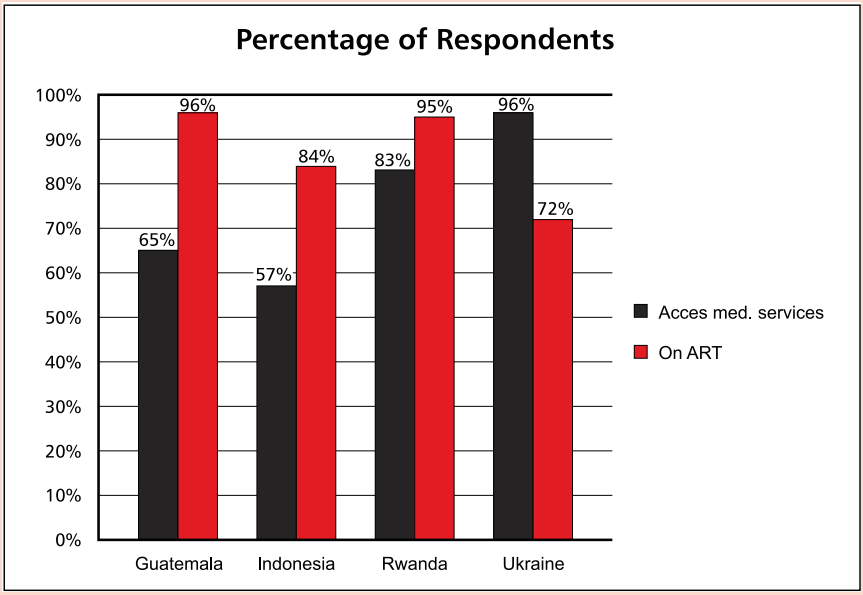
EFFECTS OF ACCESS TO SOCIAL PROTECTION

Despite the challenges highlighted above, many respondents and their households in these four countries have access to some sort of social protection and social assistance, mainly to health insurance and health or medical services – although not to the extent they require nor in the most appropriate form. As the social protection received is not significant enough, this research cannot say whether PLHIV who receive it are better off than those who do not. What this research does make clear, however, is the critical importance for this population of health insurance and access to health and medical services and treatment for HIV and opportunistic infections. (See Figure 8)

The importance of such insurance and access is reflected by the percentage of respondents on treatment for HIV and other infections. Nevertheless, because PLHIV and their households do not sufficiently benefit from broader social assistance schemes, only a small proportion of respondents live with HIV for longer than 9 years. Even though medicines and health and medical services keep people with HIV alive, they and their households remain vulnerable, and poor households are not lifted out of poverty.

With regard to **work status and social protection**, civil servants and formal private sector employees are covered by national social and health insurance in all countries, but, as previously mentioned, they are a small percentage of the population, and an even smaller percentage of the HIV population – with the noted exception of Ukraine. Access to social protection by those not working in the formal economy differs from country to country, as described below.

Figure 8: Access to Medical Services and ART



Source: Elaborated with data from the Country Research Reports by the Author.

When the respondents had access to services and did receive benefits, there were positive effects.

➢ **Effects: Few PLHIV who participated in this research accessed social protection at a high enough level for it to make a difference to their households – except in Ukraine.**

In Rwanda PLHIV and their households have access, at least in theory, to several social security programmes, provided that they meet poverty criteria (such assistance might include a cow per family, micro-credit, direct support for the poorest and most vulnerable households, and the chance to participate in public works programmes which allow people to buy small household items); but very few respondents received livelihood protection such as income support (8 per cent), child support (4 per cent) or cash transfers (4 per cent). Gaps exist, primarily with regard to predictable transfers of

cash or food to those who are too ill to participate in programmes such as public works. Still, of the 83 per cent of respondents with access to health insurance, 94 per cent had access to community-based health insurance, although 93 per cent paid the small premiums themselves.

The situation in Indonesia is similar to that in Rwanda only in that PLHIV have access to social protection if they meet poverty criteria, and in that health services are easier to access than other social protection services. The situation differs in important ways: in Rwanda there is a high degree of health service access by PLHIV and access to medicines is generally free, but in Indonesia this is not the case.

Access to social protection in Indonesia is limited and the process for accessing it is riddled with difficulties for PLHIV, as explained previously. Only one in three respondents (32.3 per cent) was covered by *Jamkesda*, a local government health insurance scheme with user fees. Respondents received additional social protection as follows: subsidized rice (16.3 per cent), community-based free health services for the poor (15 per cent), assistance to the poor (13.3 per cent) and private health insurance (10 per cent). Very few received cash transfers (9 per cent) or a pension (0.67 per cent).

Guatemala and Ukraine have legal frameworks that support social protection, including for PLHIV. Since 2005 Guatemala has had a social protection policy for HIV and sexually transmitted infections (STIs) based on respect for human rights. In 2006 HIV was categorized as a chronic disease; this was an official recognition that PLHIV could continue to work thanks to ART. A decree stipulated that PLHIV working in the formal economy would enjoy the same benefits as other workers. However, informal economy workers and the unemployed are not covered by any social security benefit, as Guatemala does not provide unemployment insurance, nor formal cash or food transfers. This leaves many PLHIV who work in the informal economy without essential services. Less than 22 per cent of the respondents received livelihood benefits. However, 64.5 per cent of respondents had access to health/medical services (14 per cent through social security –formal sector, and 50.5 per cent through integrated AIDS clinics and hospices).

Specifically, in Guatemala, social protection programmes meant that 68 per cent of respondents' partners kept the same job, and those with children (37 per cent) indicated that their children were attending school and, if HIV-positive, receiving medical services. More than half the respondents said that they had access to good nutrition – a key factor in HIV treatment adherence.

In Indonesia, respondents were positive about the effects of social protection: 'We can keep our jobs or at least continue working, access medical services when we need them and continue ART, and pay out-of-pocket expenses; while our partners are able to continue their economic activity, and our children continue school, and if they are HIV-positive, they can get treatment while going to school'. (Indonesia Research Report)

In terms of livelihood support, in Ukraine the share of PLHIV as recipients is small, although significantly larger than in other countries: 31 per cent of respondents received insurance benefits or assistance (e.g. unemployment or maternity benefits, or paid sick-leave) – although only 8.5 per cent received state social assistance (e.g. monthly allowances for children living with HIV or support for low-income families). It is worth noting that for 18 per cent of respondents in Ukraine, social protection contributions represented 50 per cent of the total household income. This was not the case in the other countries. In Rwanda only 8 per cent received livelihood support and an additional 4 per cent cash transfers, while in Guatemala only two per cent received a social security pension and one per cent monetary support from NGOs.

These findings are supported by the global literature review, which found little evidence of the impact of social protection on household vulnerabilities. (ILOAIDS, 2013a) One plausible explanation is that the level of support received by most households is not significant enough to be measured at the national level; its impact is only noticeable in the context of the specific communities and population groups targeted by social protection interventions.

➢ **Effects: Health insurance and/or health or medical services were the most important, and sometimes the only significant, social protection benefit that PLHIV in this study received**

As the data show, most respondents had access to health insurance or health/medical services. Access to medical services and medicines could account for the fact that 63 per cent to 89 per cent of respondents across the four countries had lived with HIV for between 1 to 9 years. However, only 20 per cent of respondents in Guatemala, 11 per cent in Indonesia, 25 per cent in Rwanda and 19 per cent in Ukraine had lived with HIV for more than 9 years.

It appears that medical services, while necessary, are not enough to keep PLHIV alive. Other social benefits play a role in longevity, and in quality of life. The global literature review notes that income support alone cannot address all the needs of PLHIV and their households. Livelihood, employment and health support are equally important, and a combination of the three is needed.

In Guatemala, all PLHIV who seek healthcare receive services, mainly through social security health facilities (for those in the formal economy) or the integrated AIDS service units (for those in the informal economy), together with military services and hospices – in total these cover about 65 per cent of PLHIV. The vast majority of respondents registered with the Social Security Institute indicated that they received 3-month supplies of ART medicines (96 per cent), while only 61 per cent of those using the integrated AIDS service units did. Similarly, 72 per cent of those with the Social Security Institute indicated that they received medicines for the treatment of opportunistic infections, while only 14 per cent of those using the integrated AIDS service units did. The integrated AIDS service units were more likely to give out prescriptions (42 per cent of respondents had been given prescriptions by these clinical units), which create treatment-adherence problems – as many as 78 per cent of those who received prescriptions said that they could not always afford to buy the medicines.

Access to health insurance by PLHIV in Indonesia mirrors that of the rest of the population, as measured by the 2012 Indonesian Demographic and Health Survey: higher access by those working in the formal economy (71 per cent) than by those in the informal economy (53 per cent). Slightly more than half of the respondents (57 per cent) had health insurance. Sixty-one per cent of women had health insurance, 58 per cent of men and 34 per cent of transgender individuals. More women than men received government social protection due to their poverty status. Almost half of the Indonesian respondents had limited or no access to health insurance. In the region of Surabaya, 86 per cent of respondents had access to free ART (although the discontinuation rate was high, mostly due to fear of side effects).

In Rwanda the majority of the respondents (95 per cent) received ART medicines; these were free for most of them (92 per cent); however only 18 per cent received medicines for the treatment of opportunistic infections. The benefit of access to health insurance in Rwanda extends beyond curative care; access promotes proactive behaviour to improve health. According to the Ministry of Health, 91 per cent of the population is covered, and this has contributed to health protection by increasing the utilization of health services. According to community health workers, people now go to health centres before they are seriously ill because they are insured. Seeking medical services earlier often leads to quicker recovery. Service users living with HIV in Rwanda acknowledged the importance of health insurance. One respondent, the head of a household, said:

"Health-seeking behaviour upon sickness changed among households with the expansion of health insurance. Nobody who has subscribed to CBHI(community-based health insurane) is afraid of seeking treatment at a health facility."

The higher number of people insured means that utilization of health services has substantially increased, resulting in a significant reduction of illness and also the costs associated with more complex medical cases. Community-based health insurance in Rwanda also contributes to protecting households against financial risk. Being insured has helped people save money by reduc-

ing health-related out-of-pocket payments. Moreover, participants in focus groups pointed out that, as people living with or affected by HIV have equal access to care and treatment through the community-based health insurance, it has led to a significant reduction in morbidity and mortality among PLHIV. (Qualitative data, Rwanda Research Report)

Some respondents expressed a different view of the system, however, in light of its treatment of marginalized populations such as men who have sex with men (MSM) and sex workers. These groups are not recognized, either by the legal-policy framework or the cultural environment in Rwanda, which creates barriers to their accessing services. Participants in two focus groups (one with sex workers and another with MSM) stressed the significant vulnerability to HIV they faced as a result of high-risk behaviour, punitive environments, social marginalization and continuing stigma and discrimination. All these factors contribute to poor social protection and health access for MSM and female sex workers (FSWs).

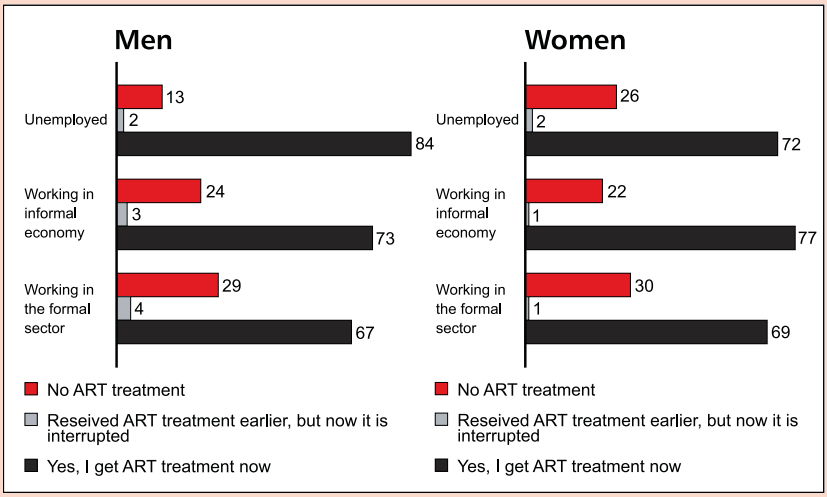
In Ukraine the majority of respondents (96 per cent) were registered with AIDS centres and used health services – for medical consultations, ART and other needs. Eighty-two per cent of those accessed services provided by national public health units, and 24 per cent accessed services provided by public social protection institutions. The majority of respondents (95 per cent) had access to ART (97 per cent of men and 93 per cent of women), although only 72 per cent needed and were receiving treatment at the time of the study. It is worth noting that access to ART did not appear to depend greatly on the employment status of PLHIV: 75 per cent of those in the formal economy had access, 77 per cent of those in the informal economy and 72 per cent of those who were unemployed. Despite a policy that provides for universal access to health services, the reality is that people's needs are only partially met. More than half of Ukraine's respondents paid for medicines and one third paid for hospital visits. Figure 9 shows that, among the unemployed, more men than women were receiving ART (84 per cent and 72 per cent respectively); while more women than men in the informal (77 per cent and 73 per cent) and formal (69 per cent and 67 per cent) economies received ART.

Table 12 shows that at the time of the study a high percentage of respondents were taking ART and medicines for opportunistic infections. What is less clear is the proportion of PLHIV who needed treatment and received it. The country research reports indicated that all who needed them received ART and other treatments in Guatemala, Rwanda and Ukraine. In Indonesia, some respondents said that they did not like the side effects of ART, and this was a reason for delaying or abandoning treatment. This could explain why only 11 per cent of respondents in Indonesia had lived with HIV for more than 9 years.

Although access to health and medical services by PLHIV is higher in Guatemala, Rwanda and Ukraine than in Indonesia, out-of pocket payments often remain an obstacle to utilization of services in all countries and to reducing economic vulnerability. Type of work is linked to the amount PLHIV spend. For example, as mentioned above, in Ukraine workers in the informal economy spend, proportional to their overall income, more than those in the formal economy on medicines and transport to get medical services.

Despite the low coverage and challenges that PLHIV faced in accessing social protection, positive effects of social protection were highlighted by respondents. As shown in Table 14, among those receiving social protection supports, 49 to 99 per cent of their children could remain in school, 63 to 95 per cent of PLHIV were able to retain their jobs or some forms of productive activities, and 72 to 96 per cent were able to access ART across four countries.

Figure 9: Percentage of respondents receiving antiretroviral therapy – 95% reported having access



Source: Ukraine Research Report, 2014.

Table 12: Respondents who received ART, treatment for opportunistic infections and have lived for more than 9 Years with HIV by country

Effects	Guatemala	Indonesia	Rwanda	Ukraine
ARV Therapy	96%	84%	95%	72%
Opport. Infect. Treat.	86%	9%	18%	20%
> 9 Years Living with HIV*	20%	11%	25%	19%

* Proxy indicator of ART adherence and retention
Source: Elaborated with data from the Country Research Reports by the Author.

Table 13: Summary of effects of social protection on key indicators, by country

Effects	Guatemala	Indonesia	Rwanda	Ukraine
Were able to keep their jobs or productive activities	63%	69%	95%	91%
Children retained in school	Yes Did not provide specific data	49%	99%	99%
Were able to access to **ART**	96%	84%	95%	72%

Source: Elaborated with data from the Country Research Reports by the Author.

CONCLUSIONS

To end poverty and contribute to shared prosperity, all countries need to build on human capital investments in health, education, and social protection for all, through sustainable and inclusive development strategies. (World Bank, 2013) The research conducted in Guatemala, Indonesia, Rwanda and Ukraine underscores the importance of the above statement. Countries face unique and complex challenges as they attempt to provide social protection services and benefits to the people who most need them and who tend to have the least access to them: the poor, vulnerable and marginalized. The challenges of improving the access PLHIV have to social protection echoes the challenges of universal health access, as these populations have the worst access to health services, often pay for services directly at the time of care and are the most likely both to go without care that they need, or be impoverished if they do seek it. (Bristol, 2014, 12)

This research aimed to find out more about:

"access to, and effects of, social protection policies and programmes, particularly social health protection and income support, on women and men workers in formal and informal economies living with HIV, and their households".

The main **messages** that the data from this research support are:

1. All countries have social protection programmes that HIV key populations can access – their HIV status or poverty status making them eligible. However, existing social protection schemes are underutilized owing to various barriers on both the supply and demand sides, and many people who need protection fall in the cracks between different systems and programmes because of the complex bureaucratic procedures involved in demonstrating that they meet poverty criteria.
2. There are access and eligibility problems with existing social protection programmes, and they fail to meet some of the specific needs of PLHIV and their households.
3. The public sector plays a dominant role in social protection, but the majority of PLHIV are not reached as they are more likely to work in the informal economy (women or transgendered person in particular) or be unemployed. In some countries NGOs and donors provide medical care and some types of social support.

4. Access to social protection by men and women workers affected by HIV and AIDS, and their households, is limited. There are gender-related differences in terms of access. In particular, women are more likely to work in the informal economy, to undertake work that is not formally recognized, or to be employed in sectors that are poorly protected by labour and social security legislation – all of which constitute barriers to accessing social protection.
5. The single social protection benefit that most PLHIV who participated in this research received was health insurance/medical services, thus, they accessed health and medical services more than any other form of social protection.
6. When PLHIV access medical services, a significant percentage can and do get treatment, regardless of employment status.
7. The effects of social protection and social assistance are less clear, as the proportion of the study population who received this type of support was small. Although in Ukraine one in three respondents enjoyed social protection benefits, these were not enough to lift them out of poverty and out of vulnerability.
8. Although the work status of many respondents changed – particularly in the formal sector – very few reported that their children had to leave school, or that their partners had to change jobs, due to their HIV status.
9. Transgender individuals are systematically the worst off in relation to all key variables: social protection benefits, access to medical care, work opportunities, and discrimination.

This research indicates that social protection could play an important role in reducing the vulnerability of PLHIV and their households. Most respondents were able to access primarily health insurance and/or medical services, and, to a much lesser extent, social assistance. Despite the unequal accessibility of health services and the barriers – including gender inequalities – that obstruct access to broader social protection programmes, when PLHIV and their households were able to access social benefits, especially free health and/or medical services, those benefits made a difference. The effects summarized in this section are tempered by the low incomes of most of the study population and the proportion of that income that goes to out-of-pocket medical expenses. Hence, we can say that people live with HIV for longer, but not whether they live better. No one should fall into poverty or be kept in poverty as a result of healthcare expenses, and yet, this remain one of the major expenditures for PLHIV and their households that are not mitigated by livelihood support.

RECOMMENDATIONS

Several courses of action should be considered based on the evidence presented in this synthesis.

National decision-makers

- Positive effects of existing social protection programmes could be maximized if PLHIV and key populations experienced less discrimination and were more readily eligible for livelihood, income and/or employment support. Some changes are imperative:
  - ✓ On the demand side, (i) reach out to PLHIV – perhaps through collaboration with NGOs and trade unions – to increase the number of PLHIV and key populations who have access to and use social protection; and (ii) provide information on the social protection programmes available to them and how to access them.
  - ✓ On the supply side, (i) help the population be better informed about social protection, e.g. through demand-creation campaigns that target women and PLHIV specifically, as well as vulnerable and disadvantaged populations more generally; (ii) develop a better understanding of the bottlenecks that make access difficult; and (iii) make programmes more user-friendly by simplifying and streamlining the processes people have to go through to reach benefits.
- Increase the involvement of PLHIV and key populations in developing social protection programmes as well as in governance and monitoring mechanisms of existing social protection programmes, to better reflect their needs, in other words, to improve HIV-sensitivity of these programmes.
- Discrimination remains a major challenge that must be addressed at the institutional and societal levels. Countries need to show that the agreements they sign at the global level to uphold respect for human rights for all, including for PLHIV; as well as workplace polices at national, sectoral and enterprise levels; gender-sensitive social protection policies; and others; are relevant and meaningful at the country level, and are implemented.

- Devise mechanisms for low-income workers in the informal economy who do not meet poverty criteria, but who cannot afford private insurance, to benefit from national social assistance schemes. For instance, as focus group participants in Rwanda proposed, allow low-middle income informal economy workers to pay a small premium to have access to national social protection programmes.
- Maximize coordination at country level among stakeholders (Government – national and local, national AIDS authorities, national social protection programmes, employers, the private sector, workers' trade unions, NGOs and PLHIV associations) to address the economic and gender aspects of social protection issues.

International partners

- Social protection is one of the ILO's Areas of Critical Importance. The ILO could play a key role in helping countries streamline the processes by which workers access social protection benefits, by liaising with workplaces, as they bring large numbers of people together. This research demonstrates unequivocally that this area needs special attention.
- The UNAIDS secretariat, its cosponsors and other international partners, should support national stakeholders in scaling up efforts to eliminate discrimination against PLHIV and key populations by social and medical service providers.
- The ILO and UN Women should focus on the gender-related risks of women workers, and women domestic and sex workers of diverse gender-identities in particular. Social protection should include the economic empowerment of women living with HIV.
- The ILO must scale up efforts to address issues of social exclusion related to PLHIV and key populations in the context of employment and job opportunities.
- International efforts to achieve universal access to healthcare may provide an opportunity to scale up social protection services to PLHIV and key populations, especially those services related to prevention and treatment of HIV and opportunistic infections. Better health is one of the most valuable investments for development.

Knowledge-building and utilization

This research has led to significant findings regarding access to, and effects of, social protection. Further research involving more countries would add weight to these findings, and would provide us with specific approaches to address the challenges identified. While the obstacles to access by PLHIV have been examined, there is less information on the supply-side. The ILO, with partners and country teams, might consider conduct selected in-depth studies on how and what actions could help remove existing supply-side bottlenecks.

This research has demonstrated that reducing economic and social inequalities and discrimination, and increasing access to social protection benefits for PLHIV and their households, would pave the way for a lasting improvement of the lives of men and women workers living with HIV; but obstacles are on both the supply and demand sides. Both sets of difficulties need to be addressed in order to find effective solutions.

To conclude, decision-makers must take note that *social protection programmes as in written policy*, and the *reality of social protection* experienced by PLHIV, including key populations, and by service providers, can diverge significantly. It is the reality of social protection access that needs to be targeted to pave the way for lasting effects on the lives of those individuals living with, or affected by, HIV.

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ANNEXE 1: EXECUTIVE SUMMARY OF GLOBAL LITERATURE REVIEW

ACCESS AND EFFECTS OF SOCIAL PROTECTION ON PEOPLE LIVING WITH AND AFFECTED BY HIV AND THEIR HOUSEHOLDS

Anna McCord and Carmen Leon Himmelstine, ODI

March 2013

This report offers a review of the international literature on the access to and impact of social protection programming on people living with HIV (PLHIV) in low and middle income countries. Impact is examined in relation to prevention, treatment and care.

The review identified 104 relevant studies, 35 of which were found to be methodologically rigorous and in many instances innovative, offering strong evidence on impacts or access, and methodologies which would be potentially replicable, in full or in part. These 35 high quality studies are discussed in detail and for each the key issues of relevance to the review are extracted, namely; the geographical location, the issues explored (access or impact, impact on what outcome(s)), and the research methodologies and relevant indicators are presented and critically discussed together with the main findings which are of relevance. Key gender insights from each study are also summarized.

Three main areas of impact were examined; prevention, treatment, and care. The literature identified offers a partial evidence base for each of these three outcome areas, being constrained both by the methodological approaches adopted, many of which do not provide robust or readily comparable analyses, and data limitations which are in part linked to the sensitivities surrounding HIV and the resulting adoption of either process or proximate, rather than outcome indicators. The limited adoption of RCT or other similarly robust approaches has limited the opportunity for the implementation of systematic reviews or other forms of met-analysis in this area.

The evidence on the impact of social protection on care and support, primarily through cash transfer provision, is stronger than for impacts on prevention or treatment outcomes, while analysis of impacts on prevention and treatment are in some measure reliant on proximate rather than ultimate indicators and hypothesized impacts on health outcomes.

Little material was identified on the nexus between complementary livelihoods interventions, HIV and social protection provision, or the extent to which such complementary interventions improve the sustainability of the social protection system or improve prospects for the graduation of beneficiaries of these schemes.

The limitations of social protection provision in many low income countries in terms of low coverage, and the exclusion of households with working age members from cash transfer eligibility was recognized as a significant constraint to access among many vulnerable households, including those living with HIV or AIDS.

Full report of the Global Literature Review can be seen at:
http://www.ilo.org/aids/Publications/WCMS_217664/lang--en/index.htm

ANNEXE 2: AN OVERVIEW OF RESEARCH METHODOLOGICAL GUIDE AND SURVEY INSTRUMENT

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

July, 2013
by
R. Rodriguez-García, MSc, PhD
with Syed Mohammad Afsar, Lee-Nah Hsu, Ingrid Sipi-Johnson and Julia Faldt Wahengo

ILOAIDS developed this Research Methodology Guide to guide the country research through a consultation with experts in May 2013.

This research guide provides 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 ILOAIDS.

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.

This 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 I presents the rationale and context of the research. Part II describes some of the key aspects of a research plan, includ-

ing: planning the research, preparing the research protocol, designing and conducting the research and reporting on findings. Part III includes core and illustrative research tools and sample data collection instruments. References can be found before the Appendices. The Appendices include the ILO 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.

This is not a normative how-to-do-research guide. It is not prescriptive and it encourages researchers to adapt it to specific country characteristics of social protection programmes or epidemiological contexts.

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 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.

The Research Methodology Guide can be seen at: http://www.ilo.org/aids/Publications/WCMS_248600/lang--en/index.htm

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.

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?	<u>Categories</u> 1. Children aged 0-14 years 2. Orphaned Children (if any, due to AIDS) 3. Youth aged 15-24 years 4. Adults aged 25-49 years 5. Adults aged 50-59 year 6. Adults 60 years and older	Number 1. 2. 3. 4. 5. 6.	<u>Sex</u> 1. 2. 3. 4. 5. 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

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

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 (Mark all that apply)	1. From Spouse/partner 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	In past 12 months	Not in past 12 months	Never happened

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

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

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……..)						

	Source of Regular In-Kind Income	SAME QUESTION AS ABOVE				PAYMENTS IN KIND			
		1. YES 2. NO (>>NEXT ROW)	MEMBER›S ID CODE			FORM: WHEAT…1 RICE…2 MEALS…3	QUANTITY	UNITS: KGS…1 LITRES…2	Number of Months Received
			1	2	3				
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 benefits? (Mark all that apply)	Health insurance 1. Government 2. Private 3. Non-government organization 4. Other. Specify _____ 99 = Don't know	Unemployment insurance 1. Government 2. Private 3. Non-government organization 4. Other. Specify _____ 99 = Don't know
505. Have you or your spouse/ partner benefited 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[17]

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

[17] 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.

ANNEXE 3: EXECUTIVE SUMMARY – GUATEMALA COUNTRY RESEARCH

Belejeb' Q'anil and the North West University Centre, Guatemala

Guatemala is the country from Americas participated in the ILO multi-country global research on the *"Access to and effects of social protection policies and programmes on women and men workers affected by HIV or AIDS and their households"*.

The **objectives** of this research are as follows:

1. To determine whether workers living with HIV, in both formal and informal economies, are covered by existing social protection policies and programs.
2. To analyze whether social protection policies and programmes contribute positively to the life of workers living with HIV and their households.

This research was conducted by the Belejeb'Q'anil organization and the North West University Centre of Guatemala, in collaboration with People Living with HIV (PLHIV).

METHODOLOGY

This retrospective study followed the ILO research methods guide and applied a mixed-method to collect both quantitative and qualitative data, in addition to reviewing the country's social protection policies and programs and existing social protection literatures.

The ***qualitative data*** was collected through ***13*** semi-structured, ***key informant interviews*** with representatives of relevant governmental and non-governmental organizations (NGOs); and ***six focus group discussions*** with a total of ***52*** members of PLHIV associations.

A ***quantitative survey*** was conducted with ***380 PLHIV*** using a standard questionnaire developed by the ILO and adapted to the Guatemalan con-

text. Among the PLHIV, 210 were receiving services from four hospitals: The Roosevelt Hospital, Guatemala city; National Hospital of San Benito Petén, Petén; National Hospital of Escuintla, and the Regional Hospital of Coatepeque. The remaining 170 PLHIV were beneficiaries of the social security institute of Guatemala City (IGSS).

The research followed human research ethics procedures. All study respondents gave their informed consent to participate in this research. The following people were excluded from the sample:

- Those who declined to participate in the study
- Those under 15 years old
- Those who were ill or unavailable
- Those who have already been interviewed in the same study
- Those who have participated in pilot testing of the study questionnaire.

SPSS Data Entry Builder (version 4.0) was used for data processing and analysis in addition to triangulate the information between literature review, the quantitative and qualitative data.

RESEARCH FINDINGS

1. Non-health Social Protection

Guatemala social protection programmes consist of a non-contributory programme covering poor people, whose members are either unemployed or workers in informal economy; and a contributory program for formal economy workers.

The ***non-contributory*** social protection program, since 2008, has established conditional transfer programs covering health care services, food and school grants for poor households or those in extreme poverty, including guaranteed Bonus, Food Package, Meals, and Grants with varied rural and urban eligibility and targeting. Key beneficiaries are households with boys and girls under 15 years of age, pregnant or breastfeeding mothers, senior citizens, disabled

or chronically ill persons, or households in a crisis or emergency situation. HIV is not an explicit criterion for targeting, however, PLHIV who are poor or extremely poor may qualify as a beneficiary of these programmes.

The IGSS, founded in 1946, manages the ***mandatory, contributory insurance*** for workers in the formal economy including the public sector. There are two programmes under IGSS: (1) A disability, old age, and death benefit programme; and (2) An illness, maternity, and accident protection programme.

There is also the Civil Service Pension and the Military Pension Institute. In addition, there are other complementary and voluntary contributory schemes providing marginal coverage.

In 2012, 25 per cent of economically active population (about 2.4 million people) were covered by the IGSS; and 16 per cent of the poor or extreme poor were covered by the non-contributory social protection programmes. Despite governments' effort to increase social protection coverage, it remains a challenge as 67 per cent of Guatemalans live in poverty or extreme poverty.

2. Social Health Protection

The Ministry for Public Health and Social Welfare (MSPAS) is responsible for public health and provides primary, secondary and tertiary care to about 47 per cent of the population directly: Another 23 per cent is served by NGOs who are under contract of the Ministry of Health. All citizens can access MSPAS services for free, even if they are covered by other insurance. The MSPAS has 13 comprehensive AIDS care units (UAIs) to provide antiretroviral therapy (ART) for PLHIV.

The IGSS also provides preventive, curative and rehabilitative health services. Members' wives and their children less than seven-year-old are also covered (maternity and accidents). However, once a child reaches the age of seven, he/she is no longer covered. The Infectious Disease Unit of IGSS provides ART to members and their families. There is also private health insurance, which does not cover HIV.

As of 2012, 65 per cent (19,152) PLHIV were covered by the social health system, of which nearly 50 per cent were served by UAI, 13.5 per cent by the IGSS, 1.2 per cent by NGOs.

3. Profile of respondents

Of the 380 PLHIV surveyed 48% were women, of which 80 per cent considered themselves as heterosexuals, 12 per cent transgender, and 8 per cent lesbians. Among the men, 15 per cent declared themselves as gay. About 86 per cent of the respondents were economically active, with 42 per cent in the formal economy, 46 per cent in informal economy, twelve per cent in sex work and there were seven respondents in prison. Up to 45 per cent had primary education and 14 per cent had no formal education.

4. Access to social protection programmes

Proper nutrition is important for ART adherence. Among 43 per cent of PLHIV surveyed indicated that they were unable to have proper nutrition. Only six per cent of the respondents received conditional transfer and only seven per cent received Food Package-the only nutrition support programme.

Despite 22 per cent of respondents expressing a need of HIV related care there is no home care services under the existing social protection programmes. Consequently, the burden of care falls entirely on family members, with a direct repercussion on household finance, as family members dropped out of paid employment to care for ill members.

Most (90 per cent) of the IGSS members had access to free ARV and associated laboratory tests, but only 60 to 70 per cent of the UAI clients did. While 50 to 70 per cent of the IGSS members could obtain free treatment for opportunistic infections and testing, only 10 to 13 per cent of the UAI clients could avail of these. Most UAI clients instead, received a prescription, resulting in an over 50 per cent increase in their out-of-pocket medical expenses. In such case, 36 to 42 per cent of them could not afford to buy the required medications.

Both IGSS and UAI services are available mainly in capital cities, 55 per cent of the PLHIV respondents reported a heavy burden of transportation costs to reach needed medical services. Some PLHIV, in order to reduce stigma and discrimination in their own communities, also opted to travel to other regions for treatment. As for prisoners, the difficulty to coordinate transportation to reach designated HIV treatment services is a key barrier to treatment. To date, there is no service that is sensitive to the special needs of the transgender community. However, a care guide and protocol is being developed at present to fill this gap.

About 35 per cent of PLHIV reported being discriminated at work due to their HIV status resulting in their changing jobs or losing formal employment. An additional 25 per cent stopped working upon HIV diagnosis due to fear of stigma and discrimination at work. Women, transgendered people and gays were the most affected. In particular, transgendered people were forced to enter sex work as the last resort to earn income. Although progress has been made in adopting HIV work place policies, their implementation has not been monitored properly.

5. Effects of social protection

Among the PLHIV surveyed who received some form of social protection benefits, 63 per cent were able to retain their existing employment or continued their engagement in productive activities, and partners of 68 per cent of the respondents were able to retain their gainful employment. About 57 per cent of the respondents were able to obtain the needed nutritional food; and 58 per cent have lived with HIV for more than five years (ranging from 5 to 15 or more years).

CONCLUSIONS AND RECOMMENDATIONS

The study found that the PLHIV employed in formal economy have benefitted from the IGSS' medical and non-medical social protection services. They have better access to health care services than the PLHIV in informal economy, who mainly received ART through the Ministry of Health's com-

prehensive care units. The cost of out-of-pocket payment of medications, laboratory tests, transport and food are major financial burden. Overall, transgendered population are most affected by stigma, discrimination and barriers to services. However, PLHIV covered under social protection programmes have benefited from improved nutrition, access to medical services, have less dependency on family members for care and support; and majority of them and their partners were able to retain their jobs.

Key recommendations from this research are as follows:

- Engage with workers' unions and employers, including the private sector, to advocate for revision of the Public Policy 638-2005 on social protection, such as inclusion of vocational training, income generation support, formalization of informal economy, inclusion of people of divers gender orientation, in the coverage.
- Create a partnership among the Ministry of Social Development, the MSPAS, the IGSS, the Ministry of Labour and Social Welfare, representative of PLHIV, and NGOs to participate in the social protection governance committee to set national quality assurance standards for health services, including HIV, of the social protection services and in general.
- Revise the IGSS eligibility policy so that children living with HIV are able to continue their social health protection beyond seven years of age.

ANNEXE 4: EXECUTIVE SUMMARY – INDONESIA COUNTRY RESEARCH

Centre for Population and Policy Studies, Gadjah Mada University

Indonesia from Asia, participated in the ILO multi-country research on the *"Access to and effects of social protection policies and programme on women and men workers affected by HIV or AIDS and their households".*

The **purpose** of this research was as follows:

1. To find out whether existing social protection policies and programmes, particularly social health protection and livelihood support, cover men and women workers, in both formal and informal economies, affected by HIV and AIDS and their households.
2. To assess how social protection coverage contribute to prevent HIV and reduce vulnerabilities of PLHIV and other HIV-vulnerable key populations, such as transgendered people, sex workers, and drug users.

The **geographic scope** of this research, within the time and resource constraints, covered Malang and Surabaya in East Java, Denpasar in Bali, and Jakarta. Bali has one of the highest HIV prevalence in the country. ILO Indonesia plans to conduct a pilot on single-window social protection service in Malang to enable PLHIV access to a variety of services by using a single entry point. This study finding will feed directly into this pilot. Surabaya, with similar HIV prevalence as Bali, is near Malang geographically.

METHODOLOGY

The study employed a ***mixed methods*** using ***sequential exploratory design***. Extensive ***literature review*** of social protection policies, assessments on national and local social protection floors and HIV-sensitivity of existing social protection programmes, was conducted first, to identify the scope of existing social protection programmes in Indonesia.

Quantitative data were collected using a standardized survey questionnaire. The standard questionnaire was adapted, based on local culture, system and structures, from a generic ILO research methodology guide, developed through an expert consultation which the Indonesian research team participated. The adapted questionnaire was *field- tested* and adjusted, to ensure suitability for Indonesia.

Qualitative data were collected through in-depth key informant interviews and focus group discussions using purposive sampling in order to reach the intended key informants. This data were used to elaborate and complement the quantitative data.

The entire research protocol was reviewed and cleared by human subject review committee of the Gadjah Mada University. This research was conducted with PLHIV based on the GIPA[18] principle, the team engaged PLHIV from local NGOs in each of the three research sites. They were involved in the adaptation of the survey protocols, data collection and analysis.

The **data** were **collected** at national, provincial and individual levels. At both national and provincial levels, key informant interviews were conducted with policy makers in Health Ministry, social protection agencies, labour unions, workers' associations, NGOs working on HIV responses and key populations' networks including that of PLHIV, sex workers, trans-gender and drug users. In addition, ***300 PLHIV,*** upon their *informed consent*, ***were surveyed*** voluntarily through ***snow-ball sampling*** applying the standard questionnaire (100 PLHIV in each of the three sites). Additional PLHIV, with their informed consents, participated in local focus group discussions.

The following people were *excluded* from this research:

1. Those who declined to participate in this study
2. Those younger than 15 years of age who do not have legal status for informed consent
3. Those who are too ill to participate, and
4. Those who participated in pilot testing of the proposed questionnaire.

[18] GIPA: Greater involvement of people living with AIDS.

Key informant interviews captured relevant officers of both national and provincial levels, with ten key informants per site, for a total of ***30 key informants*** from:

- Commission on AIDS Eradication, Department of Health, Health Insurance, Community Social Health Protection, Regional Social Health Protection, members of medical institutions serving PLHIV
- Ministry of Social Affairs, Department of Social Affairs, National Team for the Acceleration of Poverty Reduction, Board of National Planning, Savings and Pension
- Ministry of Manpower and Transmigration, Social Protection for Labour Force, and Labour Unions

A total of ***30 people***, mostly NGOs and key populations' network members, participated in ***focus group discussions*** with ten people per site.

Data analysis: Quantitative data were analysed using statistical programme STATA. Qualitative data were transcribed, categorized by theme and sequences. Finally, triangulation of quantitative, qualitative data and secondary document review findings, were conducted to cross-validate the findings and draw inferences.

RESEARCH FINDINGS

1. Social protection programmes in Indonesia

There is one programme for workers in formal economy and one for those in informal economy. For the **informal economy workers**, there is coverage ***for poor households*** as part of the social safety net programme (JPS). The JPS covers health, labour-intensive programme in public works, school scholarships, block grant assistance, special market operations to control prices, and local empowerment programme to deal with economic crisis impact. These programmes are grouped into six clusters:

Rice subsidy for poor households, covering 16 per cent of PLHIV respondents

- Direct cash transfer programme
- Family of hope programme, covering 2 per cent of PHIV respondents
- School operational cost programme
- Scholarship for poor students programme
- Community health insurance programme

Informal economy workers living ***above poverty line*** have no ***social protection*** coverage. For the **formal economy workforce**, it includes programme for public versus ***private sectors*** (Jamsostek) which covers health, work injury, old age and death. For those in ***public sector***, there is programme for *civil servants* health insurance (Askes) and old age pension (Taspen) plus old age insurance; and for *military personnel* health service (ABRI) and pension (Asabri).

In 2012, the Minister of Manpower and Transmigration ratified a ministerial regulation which extends social protection coverage for workers living with HIV in the formal economic sectors with HIV and AIDS treatment medications. The Indonesian is reforming its social protection system to implement the National Social Security System law (UU SJSN). This law aims to institutionalize a social security system with universal social protection coverage for all Indonesian citizens under insurance for health, work injury, old age, pension and death. In theory, under the UU SJSN, PLHIV, working in informal economy and live above poverty line, would also be eligible for these different forms of insurance coverage.

2. Profile of PLHIV and key populations

The 300 PLHIV surveyed were in the 15 to 59 age group (48 per cent women, 42 per cent men, and 10 per cent transgender). Most (78 per cent) of the PLHIV surveyed had middle school or above level of education. Most (70 per cent) were living in rural area, and 62 per cent were engaged in informal economy. About 83 per cent of them self-identified as sex workers, drug users, gay, transgender, or a mixture of these groups. Forty-one per cent of them have lived with HIV for over five years, 39 per cent for one to four years, and 19 per cent under one year.

3. Access to social protection programmes

Whereas 71 per cent of those PLHIV working in formal economy has access to health insurance, only 53 per cent in the informal economy have such access. Such access for PLHIV in informal economy is due to their poverty status and not their HIV status.

Most PLHIV under-utilize available social protection services due to lack of the requisite identification card (ID) or the complexity of the application procedures. To obtain an ID, one has to link to a family, have a local residential address, or have a clear sexual orientation. Some PLHIV has been dis-owned by their families due to their sexual orientation, HIV status, or both. It was found that transgender people have the least access to social protection, when compared to male or female PLHIV, because they do not present the same sexual appearance as reflected in their ID, resulting in them being rejected by the social protection administration staff.

NGOs working with Gay, MSM, transgender sex workers and drug users have facilitated as bridge between supply and demand thus resulting in better health insurance access for these groups compared to female sex workers or transgender who are not sex workers as they do not have such strong NGO network support.

Barriers to access, aside from gender identity, include self-stigmatization, societal discrimination, lacking requisite ID, local address, or a letter from local leader certifying their poverty status. About 98 per cent of PLHIV respondents stated experiencing some sort of stigmatization regardless of the duration of their HIV status.

Most PLHIV, for fear of being stigmatized by others, do not try to obtain the poverty certification because they do not wish to disclose their HIV status despite of being poor. In addition, the lack of knowledge of available social protection services, the complexity of the application procedures and requirements, form additional barriers. Finally, to access the services, one

still need to pay out-of-pocket the cost of hospital registration fees, transportation to clinics, or non-ARV medication.

Another barrier is the portability of available social protection services. Under a decentralized system, each city operates its own programme of social assistance for the poor and one of the eligibility criteria is proof of local residence. Most PLHIV do not wish to be identified for fear of being discriminated against, shun services close to home. Some of the key HIV vulnerable populations are very mobile. It further hindered their access to available services.

4. Effect of social protection on PLHIV households beneficiaries

The good news is, based on this Indonesia research findings, when a PLHIV could access some sort of social protection services, nearly 70 per cent of them could retain their employment, 76 per cent continue to engage in productive work for a living, 81 per cent could access health services when needed, 84 per cent are able to continue their ARV treatment, 50 per cent of their children stay HIV-free, 50 per cent continued their schooling, 43 per cent of their partner continue to engage in their own economic activities, 32 per cent of their partners stay HIV-free. However, only 17 per cent of their HIV-positive children continued their schooling and on treatment.

LIMITATIONS

The findings are based on data from the samples of this research. Due to limited geographic location and sample size, it could not be generalized nationally. Although the data provided an overview of access and effect of social protection for these 300 PLHIV, it is not possible to break-down into sufficient details about the complexity of the tension between supply and demand of social protection at the local level. To gain a sense of local success and challenges, in-depth case studies were conducted in each of these three research sites.

Denpasar, Bali, specifically developed social protection programme tailored to the needs of PLHIV. This is because it has a mature government institution, which developed partnership with community actors and stakeholders

to build a participatory, grass-root attempt to prevent HIV and limit the negative impact of AIDS.

RECOMMENDATIONS

A national stakeholder consultation was held in November 2013 to review the findings of this research. It involved representatives from National AIDS Commission, social protection entities, Ministry of Manpower and Transmigration, employers' and workers' organizations,, PLHIV and key populations networks, in addition to ILO, UNAIDS Secretariat, UNICEF and UNDP. The Stakeholders reviewed the findings and made the following recommendations:

- To the ***Government of Indonesia***:

Establish a legal umbrella on the provision of social protection for PLHIV under BPJS I and II as part of the UU SJSN to reduce barriers of access and to ensure universal coverage. Strengthen partnership with other actors particularly NGOs and engage them in governance of the reformed social protection system.

- To ***Ministry of Health***:

Develop a monitoring mechanism to ensure PLHIV who holds private insurance actually receive coverage of part or all medications and health treatment costs.

- To ***Local governments***:

Strengthen collaboration between the local, provincial and national government and make local social protection HIV-sensitive. Award good practices and share them with other provinces for replication.

- To ***local NGOs***:

Strengthen collaboration with government, and strengthen resource mobilization capabilities, in view of the imminent withdrawal of GFATM from Indonesia, in order to ensure sustainability.

- To ***ILO tripartite constituents*** (Ministry of Manpower and Transmigration, Employers' organization, workers' trade union):
  - ➢ For ***future research***: Future social protection research should continue to fully engage PLHIV and key populations as part of the research team thus enrich future research.
  - ➢ For ***advocacy***: Findings from this research should be packaged for targeted advocacy
    - To improve PLHIV and key populations' social protection literacy so that they are able to have improved access.
    - To social protection administration (BPJS I and II) in order to include the participation of PLHIV as part of their governance mechanism to monitor its development and implementation thus ensuring universality of coverage.
    - To social protection administration and civil society organizations so as to enhance a collaborative partnership while continue to identify, award and promote good practices, including HIV-sensitive practices.

ANNEXE 5: EXECUTIVE SUMMARY – RWANDA COUNTRY RESEARCH

The University of Rwanda College of Medicine and Health Sciences School of Public Health

Social protection plays a very important role in preventing HIV and mitigating the impact of AIDS because it supports basic livelihood, education and health needs of the poor and vulnerable populations. The ILO Recommendation concerning HIV and AIDS and the World of Work, 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 ILO National Social Protection Floors Recommendation, 2012 (No. 202), guides member States on how to update their national social security programmes in order to prevent poverty, vulnerability and social exclusion through essential health care and basic income security for the population.

Extending social protection to workers, particularly to those in the informal economy, has several challenges. persons Living With HIV (PLHIV) face stigma and discrimination that prevent access to treatment, health insurance and employment. Even in countries where free treatment is provided, these barriers still exist and severely impact the quality of life of PLHIV.

The HIV/AIDS and the World of Work Branch of the ILO (ILOAIDS) undertook a global research in 2012-13 to gain knowledge on access to and effects of social protection policies and programmes on women and men workers affected by HIV or AIDS and their households.

Rwanda was one of the four countries covered under this global research, which explored the following questions:

1. Does social protection in the country cover women and men workers living with HIV and their households?
2. How does the social protection coverage contribute to reducing the impact of HIV and AIDS on vulnerable or HIV- affected households?

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

The research in Rwanda was carried out by the University of Rwanda College of Medicine and Health Sciences, School of Public Health with support from ILOAIDS. The research was conducted in consultation with and engagement of the Rwandan Network of People living with HIV and AIDS (RFP+).

Methodology

The research team developed its methodology making adaptations to the research methodology guide, developed by ILOAIDS, in consultation with an expert group, which was also attended by the research team from Rwanda. The guide provided a conceptual framework, guidance on methodology and tools for undertaking this research at country level.

A cross-sectional design involving both quantitative and qualitative methods was adopted for the research. It included:

– A desk review of existing literature;
– Interviews with key informants and focus group discussions with people living with HIV and key populations; and
– A survey using a standardised questionnaire.

The desk review included policy documents and key materials including past research and studies on social protection programmes in Rwanda.

Sixteen key informant interviews were conducted at the central and local levels. A list of key informants from the national social protection programme, the national AIDS programme, relevant ministries including the ministry of labour, employers' and workers' organizations, people living with HIV and other important actors was made using purposive sampling techniques. These contacts were supplemented through snow-balling. Key informants were asked to provide names of potential respondents who could provide complementary information.

Eight focus group discussions were held involving PLHIV working in the formal and informal economy, including people who were not working, as well as key populations, particularly sex workers and men who have sex with men.

A sample of **481** PLHIV (67.4 per cent women and 32.6 per cent men) was interviewed between November and December 2013, following a detailed questionnaire. Six health facilities supporting a large number of PLHIV and PLHIV associations in the country were engaged to select the respondents.

Results

The Government of Rwanda has made social protection for the poor a priority in its economic development and poverty reduction strategy. A broad range of social protection programmes are in place under the umbrella of Vision 2020. Social protection exists mainly in two parts in Rwanda: social security and social assistance. Social security includes schemes for the formal economy and private insurers; and social assistance targets all vulnerable populations. These programmes do not exclude people living with HIV.

Access to health care is different based on the sector in which people work. Formal economy workers are covered by different health-care schemes based on their occupation. The Rwanda Health Insurance Scheme covers all services and include civil servants and public sector employees. The armed forces and their families are covered by Military Medical Insurance. Laws on insurance regulate the coverage of other formal economy workers by private insurance companies.

The informal economy is covered by a Community Based Health Insurance (Mutuelles de Santé), which extends coverage to rural populations. Prepayment and risk pooling are used to provide access to health services for this segment of the population fairly and equitably.

There are challenges that PLHIV face in accessing social protection services. More than half of the respondents (59.4 per cent) indicated that they are eligible for benefits but the process to request support is too complicated; whereas 47 per cent said that they simply do not know how to apply.

Sex workers and men who have sex with men (MSM), are not recognised by the cultural environment in Rwanda. While they are not discriminated against in the social protection schemes available, the cultural barriers create obstacles in terms of delivering services and hence MSM and sex workers access to relevant services become limited.

Highlights of the research include:

- 81.9 per cent of the respondents were between the ages of 25 and 54, showing that HIV is impacting the prime working-age population.
- Only 7.6 per cent of respondents (6 per cent of women and 11 per cent of men) were engaged in formal employment; 44.3 per cent of respondents (43.3 per cent of women and 46.5 per cent of men) were engaged in the informal economy.
- Overall, 55 per cent of respondents had completed primary education; 19.6 per cent of the women and 10 per cent of the men said they had never attended school.
- Around 34 per cent of respondents reported to have faced stigma and discrimination. More women (17.2 per cent) reported to have faced discrimination than men (13.2 per cent) in the past year. The source of discrimination originated from partners (15.8 per cent); family members (38.3 per cent); employers (9 per cent); coworkers (7.8 per cent); health care facilities (6.6 per cent); social services (5.9 per cent); and insurance providers (5.3 per cent). Significant variables were seen in the case of gender: 42.7 per cent of women faced discrimination from family members whereas only 28 per cent of men reported to have faced discrimination from family members.
- 59.4 per cent of women and 50.3 per cent of men reported needing someone to take care of them during the past twelve months. For 86.4 per cent of men, their primary caregiver was their spouse/partner. For women, 49.3 per cent reported that it was their spouse/partner and 41.5 per cent reported it was their children. It reinforces the notion that women have a much greater role in care giving than men.

- 94.6 per cent of respondents (evenly spread between men and women) are accessing antiretroviral treatment (ART), a majority of respondents getting it free of change from the Government; 89 per cent of respondents, more men (93.8 per cent), than women (86.6 per cent), reported that they go for medical care every time they have a need. The major out of pocket expense related to health care is transport (26 per cent) and a majority (69 per cent) of respondents pay it themselves.
- Overall 82.8 per cent of respondents reported to have access to medical insurance with women reporting lesser access (80 per cent) than men (89 per cent); 93.9 per cent of respondents, split evenly between men and women, reported that they were covered by Mutelle de Santé, the community-based health insurance scheme. Only 5 per cent have access to the health insurance for civil servants. The majority (93 per cent) pay the premium of health insurance themselves.
- About 45.7 per cent of respondents find the insurance coverage not adequate for their needs.
- An overall 94 per cent (95 per cent of women, 93 per cent of men) mentioned that social protection has a positive impact on their lives. While the maximum benefit was from health insurance, 25.1 per cent (27.4 per cent of men and 24 per cent of women) respondents mentioned to have benefitted from different social security schemes.
- Only 20 per cent of respondents reported to have benefited from livelihood support schemes, interestingly more women (22 per cent) than men (15 per cent).

Conclusions & Recommendations

The social protection system is well established in Rwanda. PLHIV are not excluded, and they can access it if they meet the criteria often based on their economic status. Overall the research showed that when PLHIV can access social protection, it makes a positive contribution in their lives. Three key barriers that affect access to social protection include: complicated procedures for applications; lack of knowledge about existing social protection schemes amongst PLHIV; and prevailing stigma and discrimination. PLHIV are benefitting from the free ART provided by the government. The social protection programmes are not reaching men and women equitably. Health insurance

benefited a large number of PLHIV but when it comes to other social assistance schemes, particularly employment support schemes, the coverage of PLHIV is very limited. Majority of PLHIV are in the most productive age group, engaged in the informal economy, unpaid work as well as unemployed. It is, therefore, necessary to address the existing barriers and make efforts to expand the coverage of social protection in the world of work.

Key recommendations include:

- There is a need to strengthen the implementation of existing social protection programmes in order to enhance its coverage, with a particular focus on people in the informal economy.
- Efforts must be made to make the existing programme gender-responsive.
- The procedures of different schemes need to be reviewed from the perspective of PLHIV and key populations (MSM and sex workers). Necessary changes should be made to simplify the procedures and remove bottlenecks to access.
- As PLHIV lack information about social protection schemes, there is a need to undertake campaigns for PLHIV informing them about existing schemes.
- There is a need to strengthen efforts to reduce stigma and discrimination associated with HIV and AIDS.
- Service providers engaged in delivering social protection need to be sensitized about HIV and AIDS and should be trained in developing a non-discriminatory attitude.
- Collaboration between social protection programmes, PLHIV networks, national AIDS programmes and the world of work actors (ministry of labour, employers and unions) needs to be strengthened.

ANNEXE 6: EXECUTIVE SUMMARY – UKRAINE COUNTRY RESEARCH

The Centre of Social Expertise, Institute of Sociology, National Academy of Sciences of Ukraine

The HIV/AIDS and the World of Work branch of the ILO (ILOAIDS) undertook a global research in 2012-13 to gain knowledge on "access" to and "effects" of social protection policies and programmes on women and men workers affected by HIV or AIDS and their households.

Ukraine was one of the four countries covered under this global research, which explored the following questions:

1. Does social protection in the country cover women and men workers living with HIV and their households?
2. How does the social protection coverage contribute to reducing the impact of HIV and AIDS on vulnerable or HIV – affected households?
3. How does social protection contribute to prevent new HIV infections and reduce the vulnerability of the target population?

The research in Ukraine was carried out by the the Center of Social Expertise, Institute of Sociology of the National Academy of Sciences (NAS), Ukraine, with financial and technical support from ILOAIDS. The research was conducted in consultation with and engagement of the ***All-Ukrainian Network of People living with HIV***.

Methodology

The research team developed its methodology making adaptations in the research methodology guide, developed by ILOAIDS, in consultation with an expert group, which was also attended by the research team from Ukraine. The guide provided a conceptual framework, guidance on methodology and tools for undertaking this research at the country level.

The research design involved three components:

1. **A desk review of** published literature on laws, policies, programmes on social protection and HIV.
2. **Qualitative study:** This involved interviews with key stakeholders and focus groups, including relevant officials responsible for the public and private social security systems, the national AIDS programme, ILO constituents, UNAIDS, the national and community-based social protection schemes, including social health protection programmes, relevant civil society organizations and organizations of PLHIV. In all, 15 key stakeholder interviews and five focus group discussions were conducted. The focus groups included PLHIV and representatives of key populations, including injecting drug users, men who have sex with men and sex workers.
3. **Quantitative study:** A survey was carried out with **800 PLHIV** (52 per cent were men, 48 per cent were women). It included 349 people working in the formal economy, 349 people working in the informal economy and 102 unemployed people. The survey was conducted between August and October 2013 in five administrative and territorial units of Ukraine (Donetsk, Lvov, Odessa, Kyiv regions, the Autonomous Republic of Crimea and the city of Kyiv).

Results

The social protection system in Ukraine is very comprehensive. Different privileges, social benefits and social services are available, regulated by 58 laws and over 120 by-laws. Universal health care is provided to all Ukrainians under the Act 280 I-XII (1992).

Social protection equally covers all citizens in Ukraine, including men and women living with HIV.

The Act of 1991 (amended in 2010) provides for prevention, treatment care and support for HIV-associated diseases and ensures legal and social protection for PLHIV. The Act ensures the right to information, and the right to work for PLHIV, free ART as well as free treatment for opportunistic infections.

Medical assistance seems to be the most important aspect of social protection, playing an important role in HIV prevention and reducing the vulnerability of the target group. Medical assistance is provided by the health institutions of the Ministry of Health of Ukraine, AIDS centres, and by non-governmental HIV-service organizations. The majority (95 per cent) of all respondents, irrespective of their employment status, reported to having access to ART (97 per cent of men and 93 per cent of women), even though they might not currently use them.

The survey revealed that 82 per cent of PLHIV received assistance from public health organizations, 26 per cent from Ukrainian NGOs, 24 per cent from institutions of social protection, 15.5 per cent from international organizations, 4 per cent from municipal institutions (housing services, transport, etc.), 2 per cent from employers and 0.6 per cent from trade unions.

The proportion of PLHIV who received social insurance benefits is significantly greater (31 per cent), compared to 8.5 per cent who received state provided social assistance. State social assistance contributions received by PLHIV are mainly spent on food, payment of daily expenses, utility services, transportation and payments for medical consultation and medication.

The Ukrainian legislation also provides for wide use of substitution therapy (ST) to reduce the risk of HIV-infection and enhance favourable attitude to ST among injecting drug users (IDUs).

Key findings include:

- 86.5 per cent of respondents (almost equal between men and women) were between 25 and 49 years of age. This shows that HIV is impacting the working-age population the most.
- Overall, the share of women is higher among those employed in the formal sector (44.6 per cent) compared to men (42.7 per cent.) But women also make up a higher share of those unemployed, 14.9 per cent of women were unemployed, compared with 10.8 per cent of men.

- More men (38 per cent), were living with HIV in a household as compared to women (29 per cent). In 29 per cent of cases, both partners in the household were living with HIV, and 9 per cent reported that other family members in the household were also living with HIV.
- About 42 per cent of respondents did not receive any insurance benefits/assistance or state social assistance, although they were eligible. The main obstacle to access was the lack of information: 67 per cent of the respondents lacked information about state institutions schemes and 51 per cent about NGO schemes. The second-biggest obstacle, indicated by 25 per cent of respondents, was that the procedure for application which was too complicated.
- Stigma and discrimination is another barrier faced by PLHIV in accessing social protection. About 15 per cent of respondents (split evenly between the sexes) reported abuse by medical personnel in the process of obtaining social and health care services. PLHIV also faced discrimination at their workplaces. While 6 per cent of respondents reported job loss during the past twelve months, another 9 per cent (12 per cent of women and 7 per cent of men) reported that they had to change their jobs due to HIV status. Sex workers reported to have faced double discrimination, one due to their HIV status, and the other due to the fact that they were engaged in sex work.

Conclusions and Recommendations

Social protection in Ukraine is well established and it is inclusive of PLHIV. The research indicated that the majority of PLHIV are accessing medical services and treatment at little to no cost through government and non-government service providers. The major barriers that are affecting access to social protection include a lack of knowledge about available services; complicated procedures and stigma and discrimination, both in the workplace and in the process of receiving services.

A large majority of PLHIV is of working-age but very few workplaces have policies and programmmes on HIV and AIDS. Social protection ensures the minimum subsistence level for PLHIV but it can get better in order to make a difference in quality of life.

Key recommendations include:

- PLHIV need to be made aware of existing social protection programmes. A focused communication effort, involving unions and PLHIV organizations, should be made to raise awareness among PLHIV about existing policies and programmes, including how to access them.
- Efforts should be made to look into the procedures of accessing current schemes and simplify them to address the bottlenecks faced by PLHIV.
- Greater attention must be paid to reducing the stigma and discrimination associated with HIV and AIDS, including stigma faced by key populations (men who have sex with men, sex workers and injecting drug users).
- Enterprises should develop and implement HIV and AIDS workplace policies and programmes in line with the Tripartite National Strategy on HIV and AIDS and the world of work.
- Service providers, including medical service providers, should be trained to develop non-discriminatory attitude towards PLHIV and key populations.
- A strategy should be developed to expand the coverage of the social protection for people in the informal economy.
- Collaboration between PLHIV networks, social protection programmes, non-governmental organizations, national AIDS programme, ministry of labour, employers and workers' organizations needs to be strengthened.

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