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Report summary of the socio-economic impact of people living with HIV at the household level in Myanmar

1. Introduction

This study was designed and carried out with the following key objectives: (1) to establish scientific evidence and deepen understanding of the socio-economic impact of HIV at the individual and affected household levels in Myanmar; and (2) to develop recommendations on impact mitigation policies and programmes, to inform the national HIV/AIDS, poverty reduction and social protection strategies. The Burnet Institute and Sanigest Internacional carried out the work under the coordination of UNDP Myanmar.

Survey modules covered key socio-economic indicators affected by HIV: income, employment, revenues, expenses, consumption, education, health, family composition, gender considerations, stigma and discrimination. This broad purview provides multi-dimensional information that can aid in determining the epidemic's impact on households and how households respond to these social and economic challenges, analysing the broader impacts of HIV, and considering the policies and programs that best address these concerns.

This study explores differences in socio-economic costs between households affected by HIV and those affected by chronic diseases such as diabetes, hypertension and chronic cardiac conditions. Nationally representative data on the impacts of chronic diseases on households are lacking for Myanmar and are needed to inform the new strategic plan for national social protection.

In this context, the report aims to detail the socio-economic impact of HIV at the household level in Myanmar, to provide a basis upon which to design better mitigation strategies, and to inform policy dialogues on social protection of the marginalized population. The study was designed with a focus on greater engagement and empowerment of the community, with community member involvement occurring throughout the study, from inception, to design, and survey to finalization.

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Abbreviations

ART	Anti-retroviral therapy
HCT	HIV counselling and testing
HHs	Households
HIV-CD-HH	Household with [a member living with HIV + another with chronic disease] or [a single member with both HIV and another chronic disease]
HIV-HHs	HIV affected household (household with at least 1-member living with HIV)
HoH	Head of household
HoHWCD	Head of household without a chronic disease
NA-CD-HH	Non-affected household with a member living with a chronic disease
NA-HHs	Non-affected household (household with no members reported living with HIV)
PLCD	Person/people living with a chronic disease
PLHIV	Person/people living with HIV
PLNODX	People living with no diagnosis of HIV or a chronic disease
UNDP	United Nations Development Programme

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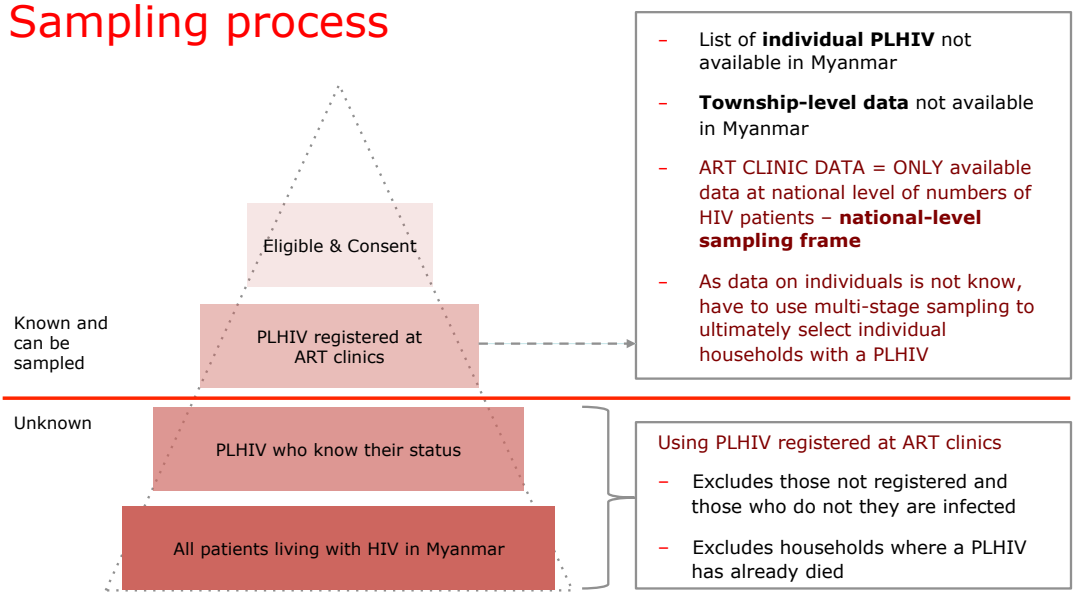
2. Methodology and data analysis

Overview of study design

- The study employed a cross-sectional comparative design using a multi-stage cluster sampling methodology to randomly select households with a resident living with HIV (case household) and households where no resident had HIV (comparison households);
- Small clinics and insecure areas were excluded from selection; however, these represented <6% of all people living with HIV (PLHIV) registered at anti-retroviral therapy (ART) clinics in Myanmar;
- 30 urban and 30 rural townships throughout the country were surveyed; PLHIV (case households) were recruited as they attended ART clinics; comparison households were geographically matched to case households and recruited separately;
- Information about chronic diseases and disabilities were collected from comparison households to allow comparisons of socio-economic costs with households affected by HIV.
- The study design reflects a balance between recruiting a sample that best represents all PLHIV in Myanmar, minimises harms to participants, and allows comparisons with the other country studies in the region coordinated by UNDP

Details of sampling process

- The best (and only) available national list of PLHIV - the list of PLHIV registered at public and private ART clinics throughout Myanmar - was used to randomly select households with a person living with ART via three steps
- This list does not include PLHIV who do not know their HIV status, those who know their status but have not sought care or those who have already died



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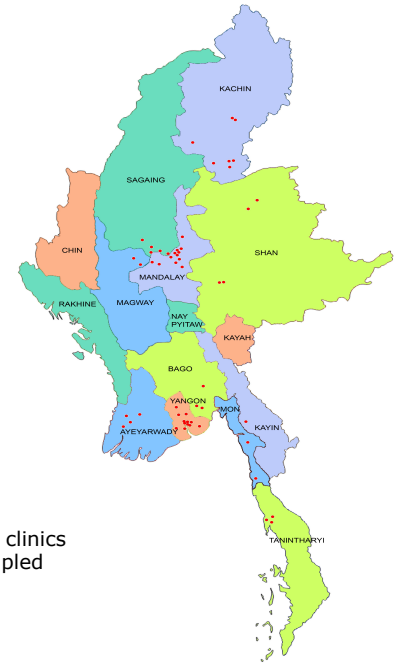
STEP 1:

- We excluded ART clinics that were inaccessible due to insecurity and those that had too few patients to recruit the required sample within the survey period. These exclusions amounted to just 5.7% of all PLHIV registered by ART clinics in Myanmar.
- From the remaining 67 ART clinics, we selected 26 "clusters" with a probability proportional to the number of patients registered at that clinic i.e. clinics with more registered patients were more likely to be selected than clinics with only a small number of registered patients, and very large clinics may even be allocated 2 or more "clusters"
- 4 additional clusters were purposely selected to improve the geographical coverage of the survey
- In all, 30 clusters were allocated to ART clinics situated throughout Myanmar



ART clinics sampled

Sampling process
STEP 1

Selection of ART clinics

- Total of 30 clusters allocated randomly to clinics proportional to the number of patients registered at each clinic
- x4 randomly selected clusters replaced with x4 purposely selected clusters to improve geographic representation

STEP 2:

- ART clinics record the township of residence for each registered PLHIV so the list of patients from a township is unique to each ART clinic
- We drew up lists of all the rural and all the urban townships served by an ART clinic and the number of registered PLHIV from each township
- We randomly selected at least one urban and one rural township from each of the clusters we had selected in Step 1 with a probability proportional to the number of registered PLHIV in each township i.e. townships with lots of registered PLHIV had a higher chance of being selected than those with few registered PLHIV
- Where more than one "cluster" had been allocated to an ART clinic we selected more than one urban and rural township e.g. the large MSF-Holland ART clinic in Kachin had 4 clusters allocated to it so 4 urban and 4 rural townships were randomly selected from that clinic
- In all, 60 urban and 60 rural townships were sampled

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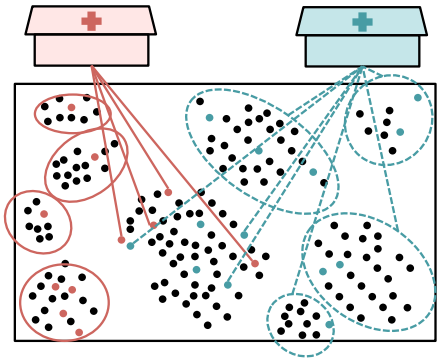
Sampling process
STEP 2

Selection of townships after stratifying into urban and rural

- ART clinics have data on township of residence for registered PLHIV
- Visit ART clinics to compile number of registered patients in each township – gives **township sampling frame**
- Impractical to visit multiple townships
- Townships can be classified as URBAN / RURAL
- Select 60 clusters [30 urban / 30 rural] with a probability proportional to the number of registered patients from each township



*The list of patients from a township is **unique** to each ART clinic*

STEP 3:

Cases – Households with a PLHIV

- PLHIV were recruited from ART clinics as they attended until at least 19 PLHIV had been recruited from the selected township
- It was not possible to randomly select PLHIV from the clinic list of patients because clinic rules forbid sharing even non-identifiable patient lists and residence data was not available for many registered patients
- Recruitment at the clinic was the safest way to recruit PLHIV and avoid inadvertent disclosure of their HIV status
- This sampling process enabled recruitment of a mixed group of PLHIV including those on ART, people eligible for ART but awaiting treatment, and people newly diagnosed with HIV
- ART clinic volunteers assessed whether PLHIV were eligible for the study with 3 questions: (i) are they from an eligible township; (ii) are they aged 18 years and over; (iii) are they interested in participating in the study
- Study team members then determined final eligibility with 3 additional questions: (iv) whether the patient was the head of their household; (v) whether they had disclosed their HIV status to their family; (vi) if anyone else in their household had also participated in the study
- The study questionnaire was administered in the clinic if the PLHIV was the head of the household or else plans were made to visit the head of household in their home at a later date

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Sampling process
STEP 3 – recruiting cases (PLHIV)

At the ART clinic, PLHIV (cases) were asked a series of 6 questions to determine eligibility – this aimed to minise inadvertent disclosure and potential harms of participation

Eligible township	≥18 years	Head of household	Disclosed to family	Eligible
no	.	.	.	NO
.	no	.	.	NO
yes	yes	no	no	NO
yes	yes	no	yes	YES
yes	yes	yes	no	YES
yes	yes	yes	yes	YES

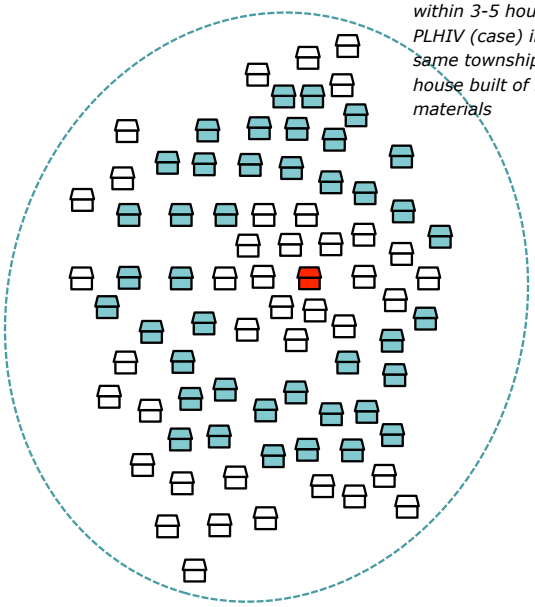
Comparisons – households without a PLHIV

- The study matched every case (household with a PLHIV) with a comparison
- Comparisons were matched to cases based on a crude geographical matching – households located 3-5 houses away from each case and made of similar materials were eligible for selection as a comparison and one was randomly selected
- Households were excluded as comparisons if they had a PLHIV or a family member with tuberculosis
- Heads of comparison households were interviewed in their home

Sampling process
STEP 3 – selection of controls

Recruitment of CONTROL household situated 5 houses away from PLHIV household

- MATCHED case-control study: x1 control for every x1 case
- **Crude geographic matching**
- Excluded households that had a family member with HIV or tuberculosis (= possible HIV infection)



Control households within 3-5 houses of PLHIV (case) in the same township AND house built of similar materials

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Myanmar study design compared to other Asian studies

On balance, the Myanmar study employed a cross-sectional comparative study design that was arguably the most sound of all of the six Asian studies coordinated by UNDP in terms of national representativeness and the quality of socio-economic data collected. The study provides high quality data for evidence-based policy development.

Comparison with other Asian studies

	Myanmar	Cambodia	China	India	Indonesia	Viet Nam
Probability sampling strategy used	YES ✓	YES	UNCLEAR	UNCLEAR	NO	NO
Nationally representative sample	YES ✓	YES	NO	NO	NO	NO
Sampling frame for HIV affected HHs	ART clinic lists All registered patients ✓	Home-based care lists of PLHIV within 20km of an ART site				
Interviews for HIV affected HHs	PLHIV + Head of Household ✓	PLHIV				
Non affected HHs	Within 3-5 HHs of case HH	Within 3 HHs of case HH				
Non-response PLHIV	7.8% ✗	2.9%				

Myanmar study is likely the most representative sample for HIV affected households

Myanmar study likely has better quality of household level data e.g. economic data

Lower response rate of Myanmar study likely due to recruitment at clinics rather than through home-based care networks

3. Profile of Sample Households and PLHIV

This section of the report provides a profile of the surveyed households (HH), highlighting the principal socio-economic and demographic differences between case and comparison households.

- There was no difference in the urban / rural distribution of HIV affected households (HIV-HHs) and non-affected households (NA-HHs) (49.4% for both)
- HIV-HHs were smaller in size on average (3.9 HH members) than NA-HHs (4.8 HH members) as well as the national average of 5 HH members.
- HIV-HHs were more likely to have migrated within the previous 5 years than NA-HHs (34.2% vs. 23.1%)
- There was no significant difference in the gender distribution of the households' members (males represent 46.3% of HIV-HH members and 46.6% of NA-HHs)
- There was no significant difference in the mean age of household members (30.9 years in HIV-HHs versus 31.5 years in NA-HHs)
- A significantly larger proportion of HIV-HHs contained a person living with a chronic disease (PLCD) than NA-HHs (30.7% of HIV-HHs versus 26.4% of NA-HHs)

- HIV-HH Head of Households (HoH) were more likely to be female than in NA-HHs (33.1% versus 25.7%)
- HIV-HH HoHs were more likely to be currently widowed, separated, divorced, or abandoned than those in NA-HHs (30.1% versus 17.0%)
- 38.9% of HoHs in HIV-HHs are either PLHIV or PLCD while PLCD represent only 14.4% of HoHs in NA-HHs
- A greater proportion of HIV-HHs were in the lowest quintile than in the highest (23% versus 17%) while the reverse proportions was true for NA-HHs
- There were no significant differences in the distribution of households across quintiles of socio-economic status based on the gender of the head of household for either NA-HHs or HIV-HHs (i.e. male headed households were not more likely to be in the highest socio-economic status (SES) quintiles than female headed households)
- HIV-HHs were less likely to own their place of residence (64.0%) compared to NA-HHs (79.9%), but ownership within type of household did not vary by the gender of the head of household, nor based on whether a member was living with a chronic disease
- HIV-HHs were more than twice as likely to pay rent as non-affected households (20.2% versus 8.8%)
- HIV-HHs suffer from reduced asset accumulation, and owned less of almost every item than non-affected households
- For NA-HHs, the only significant difference in asset ownership between households with a member living with a chronic disease compared to those without was for radios - those with a PLCD were more likely to own a radio (31.1% of households without a PLCD compared to 38.4% of households with a PLCD owned a radio)
- For both HIV-HHs and NA-HHs, male-headed HHs reported owning more basic assets than female-headed HHs

4. Impact of HIV on Economic Factors

In this section, specific differences between the economic circumstances of HIV-HHs and NAHHs are explored in detail. In addition, the economic impacts of HIV and chronic diseases are compared.

- There was no difference in levels of unemployment between PLHIV and PLCD, but unemployment was significantly higher than among both groups than for people living with no diagnosis of HIV or a chronic disease (PLNODX)
- PLHIV were significantly more likely than PLCD and PLNODX to report having missed a day of work
- PLHIV and PLCD were both more likely to report being sick as reason for missing work than PLNODX
- Average per capita income in HIV-HHs was lower than in NA-HHs
- More PLHIV needed care (14.3%) than were receiving it (7.9%)
- The majority of caregivers (77.0%) for PLHIV were unpaid household members
- HIV-HHs reported more deaths than NA-HHs
- HIV-HHs reported slightly less household consumption overall than NA-HHs;

however, they had higher per capita medical care consumption than NA-HHs

- 56.5% of HIV-HHs reported they had reduced household consumption due to HIV, with the main reductions occurring for food consumption
- Over 20% of HIV-HHs and NACD-HHs indicated they reduced their savings to finance the costs associated with their illness
- HIV-HHs were more likely to be in debt compared to NA-HHs (32.6% vs. 23.6%)
- HIV-HHs were more likely to report paying higher monthly interest rates (10.3%) than NA-HHs (8.8%)

5. Impact of HIV on Education

Beyond reducing the immediate economic capacity of the household, diseases can influence the human capital accumulation of the household and, therefore, may have long-term impacts by negatively affecting the education of children.

- Children living in HIV-HHs reported lower attendance rates than those in NA-HHs but had similar primary school Net Attendance Rates
- There was a difference in attendance rate between HIV-HHs and NA-HHs for girls 10-13 years (91.1% in HIV-HHs versus 96.0% in NA-HHs)
- Children in HIV-HHs were more than twice as likely as those in NA-HHs to have missed school because they had to contribute to the household income or help with household chores
- Children in HIV-HHs were more likely to have missed more than 10 days of school in the past year than those in NA-HHs, especially for young children and those in rural areas
- There were no differences in the proportion of children who had repeated a grade by type of household.

6. Impact of HIV on Health

This section examined the impact of HIV and chronic diseases on self-reported health status, behaviours, utilisation of health services, out-of-pocket and catastrophic health expenditures.

- Members of HIV-affected households were reported to be in worse health status than those in NA-HHs. However, PLCD self-reported having lower health status than PLHIV
- Members of poorer households (both HIV-affected and non-affected) were reported to be in worse health status than those in wealthier households
- PLHIV utilised significantly more ambulatory and inpatient health services, and were significantly more likely to seek care in the public sector than those in NA-HHs
- PLHIV were more likely to use tobacco or betel nut than those not living with HIV (regardless of their chronic disease status)
- PLHIV had similar levels of heavy drinking patterns to PLCD and PLNODX,
- Among PLHIV, those who reported heavy drinking were more likely to have missed ART in the previous week than those who did not report heavy drinking

- Individuals living with a chronic disease (excluding HIV) were more likely to state they rarely or never performed physical activities than individuals not diagnosed with a chronic disease
- Non-affected household members were less than half as likely as HIV-affected household members to indicate they did not seek care due to insufficient money.
- Almost five times as many PLHIV were hospitalised in the previous year compared to individuals living in NA-HHs (14.1% vs. 2.9%)
- PLHIV were significantly more satisfied with their access to health services than survey respondents in NA-HHs
- Charges for health care services reported by members of HIV-affected households were significantly lower than those reported by members of NA-HHs, except for female-headed HIV-HHs, which had higher charges than their NA-HH female-headed counterparts
- PLHIV were more likely to have healthcare charges exempted than members of NA-HHs
- PLHIV reported selling land and other assets, cutting into savings and taking on debt, in order to cover costs associated with prolonged illness prior to diagnosis. However, the amounts were lower than those of NA-HHs
- ART utilisation is increasing among all PLHIV. However, utilisation of medications to prevent or treat opportunistic infections is lower for PLHIV living in rural areas
- There was a slight difference between the proportion of HIV-affected and NA-HHs who had incurred catastrophic health expenditures, with HIV households only spending 1.5 times more than NA-HHs

7. Impact of HIV on Food Security

The nutritional status of a population is critical to a country's economic progress and numerous studies have linked individual caloric intake to productivity and income later in life. The high prevalence of poverty in Myanmar is one reason that nearly three million people are classified as food poor and 35% of children aged under 5 years are stunted. HIV is an additional factor that impacts on individual nutrition and household food security. "The relationship between HIV/AIDS and malnutrition is a particularly extreme example of the vicious cycle of immune dysfunction, infectious disease and malnutrition". This section examines the effect of HIV on household food security and the impact of food assistance programs currently in place.

- Only small differences exist in the reported number of daily meals between the members of HIV-affected and non-affected households
- However, members of HIV-HHs were significantly more likely to report being hungry but not eating due to lack of food, than members of NA-HHs
- Female-headed HIV-HHs were almost 10 times more likely to go hungry than male-headed NA-HHs (10% compared to 1.5%)
- HIV-affected households received food support at significantly higher levels than non-affected households, and a greater percentage of poor HIV-households received food support than wealthier household

8. Impact of HIV on Stigma, Discrimination and Quality of Life

HIV can have a traumatic impact on an individual's sense of self-worth, personal security and social standing within the household and community. Emotional, mental and sometimes physical manifestations of stigma and discrimination can further reduce an individual's capacity to engage in productive economic activities. Stigma and discrimination may deter people from accessing HIV testing and treatment, sharing their diagnosis and taking action to protect PLHIV.

- PLCD experience higher percentages of stigma compared to PLHIV
- PLHIV were more likely to avoid getting married because of their health status, and to avoid going to local clinics or hospitals when they needed to
- The majority of married PLHIV and PLCD reported disclosing their status to their spouse or partner immediately after diagnosis
- Discrimination from healthcare workers was higher for PLHIV than PLCD, yet still remained relatively low compared to historical levels and neighbouring countries (5.8%)
- 6.0% of PLHIV and 8.6% PLCD reported to have lost their job or been refused employment because of their disease
- PLHIV were more likely to rate their quality of life as poor or very poor compared to PLCD and Heads of household without a chronic disease - HoHWCD (26.8% PLHIV vs. 20.7% PLCD vs. 12.7% HoHWCD)
- Higher levels of depression and anxiety were seen in PLHIV than PLCD or HoHWCD
- PLHIV were much more likely to report not having sufficient money to meet their needs
- PLHIV reported higher levels of satisfaction with healthcare services compared to both PLCD and HoHWCD
- Higher levels of self-reported disability were seen in PLCD than in PLHIV

9. Impact of HIV: Special Considerations

This study also examined some particular aspects of the impact of HIV on households:

- All of the widows surveyed in NA-HHs and HIV-HHs are female due to an increased likelihood for widows to be females
- Widowed HoHs are seen more commonly in HIV-HHs than in NA-HHs
- Widows in HIV-HHs were less likely to receive their deceased husband's assets than widows in NA-HHs
- HIV-HHs were much more likely to have migrated in the previous five years (34.2%) compared to NA-HHs (23.1%)
- The majority of HIV-HH's moved to a different village within the same township (34.9%).
- HIV-HHs were more likely to report migrating because they had been evicted, and in order to seek medical treatment than NA-HHs

- HIV-affected households cited the need to seek medical treatment as responsible for 7.2% of moves, while non-affected households stated this reason for only 2.1% of moves
- HIV-affected households gave discrimination as a reason for migration more often than non-affected households (1.9% vs. 0.7%),

10. Knowledge and Awareness of HIV

Analysing levels of HIV awareness and understanding is important when determining the best policies and programs to reduce transmission, improve treatment and prevention, care and support services, and address stigma and discrimination.

- Levels of knowledge of HIV were high for both HIV-HHs and NA-HHs
- 99% of survey respondents from HIV-HHs reported being tested for HIV, while only 51.4% of respondents from NA-HHs had been tested
- 80% of HIV-HHs were aware of a location where they could be tested for HIV compared to only 55.2% of NA-HHs
- HIV-HHs were much more likely to have received their testing from INGO's/NGO's compared to NA-HHs
- A much greater percentage of people in richer quintiles from NA-HHs had been tested for HIV compared to those in poorer quintiles, however no difference existed in testing behaviour for HIV-HHs based on wealth
- A high number of respondents indicated that they did not know that HIV is a preventable disease (10% in affected households; 39% in non-affected)
- Knowledge of condom use as a method of prevention was quite low, with 79.0% of people in HIV-HHs being aware of condoms as a prevention method, and only 41.5% awareness in NA-HHs. Notable gender differences existed, with lower levels of knowledge seen in females.
- 13.2% of people living in HIV-HHs, and 41.2% of people in NA-HHs did not know that the disease could be transmitted through unprotected sex, with lower levels of knowledge seen in females
- 71.3% of people in HIV-HHs and 92.8% of people in NA-HHs were not aware that HIV could be transmitted through mother-to-child transmission

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11. Policy Conclusions

The scope of services for PLHIV should be expanded to ensure integrated social protection strategies address the myriad challenges of HIV-affected households. In this regard, based on the findings in the previous chapters, the study points to the areas that need to be further addressed through HIV sensitive strategies. The main recommendations are:

- Use key study findings to strengthen the equity and effectiveness of national social protection efforts including universal health coverage.
- Integrate targeted HIV impact mitigation programming into "HIV Sensitive" social protection strategies: poverty reduction and income subsidy approaches.
- The National Strategic Plan for HIV should include lifestyle issues related to chronic diseases and alcohol and tobacco cessation strategies as well as incorporating chronic disease prevention and management programmes into the care management for PLHIV.
- Develop targeted interventions to address negative self-esteem and psychosocial challenges faced by PLHIV and their family members.
- Adherence strategies should take into account the broader social risks, e.g. alcoholism, and develop "predictive" models toward case management.
- Ensure asset protection strategies for widows through legal and support strategies.
- Develop targeted policies for boys aimed at reducing human capital 'wastage' – for example, conditional cash transfers might be targeted to boy's permanence in school.

Many of the current interventions for PLHIV are focused on basic prevention or ART treatment. The study shows the full range of challenges for PLHIV extends well beyond the biological aspects and requires greater depth in the care provided. The main changes proposed are:

- Accelerate community-based rapid testing and self-testing to further strengthen decentralization of HCT.
- Increase the use of community health workers to provide a higher level of social care for PLHIV, as well as increasing the reach of the health system to increase testing, counselling and adherence for ART.
- Increase activities for knowledge awareness of HIV, prevention and testing, as well as programmes to reduce the stigma of HIV.
- Develop targeted approaches to address the challenges of the poorest households in everything from knowledge and awareness to risk mitigation strategies.
- Increase emergency food support to all HIV-affected households, with special attention to female-headed HIV-HHs and low-income households. Integrate with social protection measures.
- Strengthen mental health and psychosocial support services for PLHIV and PLCD. Training for social workers to diagnose and address basic mental health issues with basic checklist approaches or even the use of technology.
- Improved legal protection strategies including legal literary and access to justice for PLHIV to mitigate the study's result showing high eviction rates for HIV-HHs.

- Strengthen TB/HIV minimum package to improve coverage.
- Expand standardized and online reporting tools to and improve real-time analysis of data from ART and HCT at decentralized sites.

The ambitious goals of the UNAIDS 90/90/90 strategy will require changes in the Breadth of Services offered to the population. The main recommendations to support this are:

- Support the scale up of ART coverage to achieve the goal of 90 percent ART coverage and the goal of 90 percent viral suppression by 2020.
- Scale up HIV counselling and testing (HCT) services with focus on increasing yield (e.g. positives/ 100 tests) in support of the goal of 90% awareness among PLHIV regarding their HIV status.
- Build more flexibility into HCT services and create demand for early testing, especially amongst lower income more vulnerable populations.
- Expand the definition of vulnerable groups in the Social Protection Strategy to include PLHIV specifically.
- Increase the coverage of chronic disease management programmes for PLHIV and access to the necessary diagnostic, medicines and care to minimise disability.
- Strengthen HIV education, along with targeted behavioural and mass communications to "normalize" condom use and increase HCT usage.
- Strengthen coordination with the private sector to maximize inclusion of the population that seeks HCT and other services in the private sector.
- PLHIV networks must be technically and financially supported and fit for purpose and effectively managed to deliver strategic results for the PLHIV community.