

# Missing The Target

## Key Barriers in Accessing ART by HIV Positive PWIDs in Pakistan

QUALITATIVE ASSESSMENT BY **NAI ZINDAGI** IN COLLABORATION WITH  
**ITPC & MAINLINE**

### Introduction & Background

Nai Zindagi in collaboration with Mainline and the International Treatment Preparedness Coalition (ITPC) conducted the research on key barriers of access to services and treatment for HIV positive PWIDs. Part of the Missing the Target (MTT) report series, the research focuses on major implementation barriers that create obstacles for street based injecting drug users to access.

Mainline has worked extensively for over 25 years in Netherlands and their mission is to improve the health and rights of people who use drugs. Mainline shares their experiences with local organizations and have been providing health education, trainings and support for best practices across regions in collaboration with partner organizations, dedicated to the principle of harm reduction.

ITPC is a worldwide network of community activists united by a vision of a longer, healthier, more productive life for people living with HIV. ITPC's mission is to enable communities in need to access HIV treatment. ITPC's programs have evolved to focus on treatment gap issues at the global level, through direct grants and support to grassroots community organizations for activities related to treatment education, research and monitoring of treatment. ITPC contributes a unique perspective to global health advocacy through its Missing the Target (MTT) report series. The MTT model is unique in empowering communities affected by HIV to understand research methodology and undertake community-led research. Rather than waiting to get the attention of outside researchers or development institutions, the MTT model puts the power in the hands of affected communities to document their issues. As a result, critical gaps in the HIV response are exposed earlier and people empowered to advocate for relevant solutions.

Nai Zindagi Trust is non-governmental organisation established in Pakistan in 1989, which focuses on rights based health and social services for persons affected by drug use, HIV and AIDS. It works with people and communities affected by drug use, HIV and AIDS and empowers them to improve their knowledge, health, socio economic well-being and access to essential services.

The primary focus of the harm reduction services being provided by Nai Zindagi aims is to prevent, halt and reverse the transmission of HIV and Hepatitis B & C viruses among PWID and their sexual partners.

Transmission and prevalence rates of Hepatitis C (89%) and HIV (38.4%) among street based people who inject drugs in Pakistan and has reached pandemic proportions due to sharing of infected syringes/needles, lack of awareness on prevention and absence of quality HIV prevention services at scale. Nai Zindagi is the Principal Recipient for the Global Fund HIV Grant to Pakistan and provides comprehensive harm reduction, HIV prevention and access to treatment care and support services to PWID and their spouses in 30 districts of Pakistan.

The package of services for PWID include outreach-based Needle Syringe Exchange Program (NSEP), point of care HIV Testing and Counselling (HTC), Antiseptic dressing, condoms, personal hygiene services, point of care CD4 testing, referral for detoxification, ART and adherence

monitoring. The spouses of HIV positive PWID are also provided HIV prevention services along with point of care (POC) HTC services, linkages to PPTCT and other treatment, care and support services.

Continuum of care services encompasses the ART Adherence Unit (AAU), which is a residential rehabilitation facility for HIV positive persons who inject drugs that combine treatment for opioid dependence with HIV treatment adherence support. It aims at stabilising the client so that HIV treatment becomes a realistic and achievable proposition for them. It is a 4-6 week residential care program that is specifically designed to simultaneously address the opioid dependence and HIV treatment adherence support needs of HIV positive PWID.

Its clients have all been certified by clinics as eligible for ART and are just beginning their opioid-free treatment journey. Opening in January 2014, the facility is operated by Nai Zindagi, and was funded in its first two years by the Dutch Ministry of Affairs through the Mainline Foundation in the Netherlands. It has secured further support from the Global Fund to continue its operation.

The overall objective of the AAU is primarily about supporting the client to reorient their life so that lifelong treatment with ART becomes a realistic and achievable proposition for them. The service model is designed in recognition of the fact that the transition from active opioid user to ex-drug user is a process with many potential stumbling blocks and cycles of relapse along the way. It is based on principles of respect for the client's life choices and an understanding that the healing process that the client needs to go through in order to regain his sense of self-worth has only just begun. Structure and order are provided in the form of a fixed schedule of daily activities that include individual and group therapy sessions, lectures and presentations on various topics around HIV/AIDS (treatment adherence, safer behaviours, OIs,) sessions on psychosocial issues (goal setting, family reintegration, anger management, disclosure and risk, relapse prevention) and family call time and diary writing.

On completion of the program, AAU graduates return to their cities of origin, where social mobilisers and female outreach workers follow up on adherence related issues with clients, families and the Public sector ART clinics. IN TOUCH (IT) program continually follows the clients in their cities of origin. The call operator in IT Program aims for three calls a week to the participant on his designated cell phone. The calls are specifically to ask about ART adherence and in general related to health messages, drug use or other needs based counselling. He/she also speaks to the designated family member once a week directly or through the participant; data entry operator records the outcome of the call and issues/needs raised and counselling is provided weekly. Data is shared with the NZC management, CoPc+ staff and ART staff at NZT; the operator in addition may directly also contact the ART clinic providing ART if required.

## **Aims and Objectives**

The assessment focused on HIV positive PWIDs who complete/are in process of utilising complete continuum of services till the initiation and management of ART. It aims at highlighting major policy, structural and human rights related access issues that created hurdles in timely treatment preparedness and follow-up.

Following were the major objectives of the research study.

- Through a civil society and community led approach for HIV+ PWIDs, this research aims to understand and recognise the major implementation barriers.
- Focus on outcomes, identify specific barriers & be solution-oriented.
- Research based on confidential interviews with selection of three major cohorts using standardised questionnaires.

- Informed advocacy with objective research. Need to make government and networking agencies accountable for progress and identification of levels of advocacy to increase access to treatment barriers.

## **Strategy**

Missing the target –Framework Pakistan Workshop was arranged from November 26<sup>th</sup>-28<sup>th</sup> 2016 in which major goals, objectives and strategy of the study were outlined. A history of ITPC model and MTT success was a highlight to familiarise key staff with expected outcomes and advocacy actions with relevant stakeholders.

This workshop in November aimed at an introduction of the MTT model and made a start of the identification of scope, stages and level of advocacy needs. The need to remain focused on the need of involvement of relevant ART adherence unit staff being directly involved with HIV positive PWIDs was identified, CoPC+ site social mobilisers and relevant IT staff for the filling of questionnaires. An overview of the project and brief context of Pakistan was discussed and finalised. Workshop served as a pre-mapping exercise for identification of goals and objectives, roles and responsibilities as well as timeline of the MTT framework. All-encompassing and exclusive discussion resulted in variables identification as well as agreement on relevant information for the question.

## **Methodology**

### **1. Population**

The population consisted of HIV positive People who inject drugs (PWIDs) having accessed continuum of care services and registered clients of Nai Zindagi Trust.

### **2. Sample Size**

The cohorts were divided in two major cohorts. Cohort 1” 500 respondents who have completed two-week detoxification and are residing at the AAU, have undergone detoxification (interviews conducted after 1 week of completing detox), Initiated on ART and access AAU therapeutic & medical services. Respondents who had consented were the part of cohort 1. Psychological / Mental / Medical challenges that inhibit respondent ability to respond to questions were excluded from the study. Cohort 2 were 100 respondents who had completed residential AAU as regular discharge and at least were in 6 months of contact post AAU. IT Coordinator administered short interviews with AAU graduates.

Field-testing of the questionnaires was completed and all due suggestions incorporated. The questionnaires were filled as telephonic interviews for cohort 2. Every 3<sup>rd</sup> random was interviewed. Calls were recorded. Hard data files of both cohorts have been maintained.

### **3. Study Sites**

ART adherence unit (AAU) was used for collection of data from the referral of the sites. AAU staff (4 Psychologists) administered questionnaire for Cohort 1. Survey and filling of tool was during the third week at the AAU according to the intake process and was dependent upon stability of the clients. Most of the withdrawals and ART side effects were dealt by 3<sup>rd</sup> week during their stay at AAU. IT site office was used for recording of data for cohort 2 and IT coordinator administered the interviews.

### **4. Data Tools**

Trained interviewers using structured questionnaires collected data. The questionnaires were in English and for both cohorts the clients were retrospectively taken through the journey to record series of events and issues of access. Questionnaires included questions on socio-demographic

and personal characteristics, as well as a core set of disclosure and processes involved in getting anti retroviral treatment. Standardised questionnaires were developed for each of the cohort on identified variables. Research question focused on the key barriers in PWID PLHIV accessing ART timely, since diagnosis for Cohort 1 and viral load as well as access to general healthcare for Cohort 2. Following were the variables for selected cohorts;

### **Cohort 1**

#### **Demographic**

Registration Number, age (at the time of interview), current marital status, education (number of years of schooling), current living status, professional skills, source of Income, disability, prison history, drug use and drug treatment information.

#### **Access to services along the HIV cascade**

Length of time from HIV diagnosis to receiving CD4 test, reasons for delay if any in receiving CD4, problems faced if any, while accessing this service, frequency of CD4 test since diagnosis point of care or facility based CD4 tests.

#### **Logistics to access ART**

Travel distance/traffic/time required, transportation type, health condition/ management of clinical withdrawal, hours of operation of the ART clinic, costs involved to access, weather conditions that may impact travel to health facility and emergency handling/ accidents that impact on travel to health facility.

#### **Baseline Investigations**

Length of time from CD4 test (below CD4 500) to completion of baseline investigation, reasons of delay in linkages to care, problems faced while accessing this service, types of baseline tests, number of repeated visits for baseline investigations, time spent at health care facility for receiving baseline investigations, length of time to receive results of baseline investigations and health condition of client.

#### **Linkage to care (ART Registration)**

Length of time from CD4 test (below CD4 500) to ART registration, reasons for delay in linkages to care, problems faced while accessing this service, frequency of visits to health facilities before ART registration and referral to parallel services (clinical management of OIs & Co-infections)

#### **ART issuance**

Length of time from ART registration to ART Issuance, delay time definition (more than 30 days), reasons for delay in linkages to care and problems faced while accessing this service

### **Cohort 2**

#### **ART Management**

Adherence Status, reasons for non- adherence, factors that support Adherence, identify problems faced with monthly ART refills and 3-month Consultation, frequency of visits to ART centres, problems faced in travelling to ART centres, side effects of ARVs, expressed need to access general health care services, types of services sought and problems faced in accessing services as a PLHIV.

Determine if RVLТ is done, if results of RVLТ communicated to client and if the RVLТ results are used for ART management. Is the client his viral status.

#### **5. Field test questionnaire**

Tools were field tested for both cohorts at AAU (ART adherence unit) after formal training of the staff involved in data collection as well as at IT site office for 1 & 2 respectively

#### **6. Ethical Clearance requirements**

The study protocol was designed to meet international ethical protocols by taking effective measures to avoid risk, protect individuals' rights, and ensure safety of all study participants. Protecting the rights of clients was integral. All efforts were made to follow the research protocol to ensure harm minimisation and that all those involved in the data collection were appropriately trained and familiar with the study protocol and monitoring measures were in place for quality control.

#### **7. Confidentiality of responses**

Strict measures were taken to ensure and maintain participants' confidentiality. No false information was required or used for any part research process. Written consent was sought. A unique identifier coding system for questionnaires with following pattern was adopted.

#### **8. Informed Consent**

It was very important to obtain informed and voluntary consent from the respondents before proceeding. The consent form helped educate the respondents on the purpose of study, its benefits and risks, its confidentiality, and what participation will bring about. Recruitment of participants was conducted only after describing the study procedures and obtaining informed consent. During the process of obtaining informed consent, participants were clearly informed of their participation as voluntary and that non-participation would have no negative consequences in terms of access to programs or services.

#### **9. Numbering questionnaires and methodology**

The methodology for numbering of questionnaires for cohort 1 was mutually agreed upon during the field-testing of the questionnaires. Psychologists will daily be completing forms and numbering to be allotted at the end of the day for recording purposes.

#### **10. Record Keeping**

All research related materials (e.g., completed questionnaires, etc.) was kept in a secure field office, which was accessible only to the study lead and staff. NZMIS Electronic data is password protected and will be kept confidential for study purposes only. For record keeping box files were used, separate sections were marked in files and were prepared. All interviewers had to file their respective filled questionnaire in assigned section and at the end of month, proper receiving method PR was assigned to related staff to receive hard data.

#### **11. Training on data collection process and tools**

Selected staff (Psychologists) from AAU and IT coordinator were trained at Nai Zindagi PR office from 15<sup>th</sup>-17<sup>th</sup> august 2017. Agenda is attached as Annex 1. Some of the additional suggestions were also incorporated in the study tool. It was decided that every selected interviewer will be conducting at least one interview per day dependent on availability and stability of clients, deliverables and timelines were decided. As per client turnover, MIS generated list by PR staff were provided to ITPC selected interviewers for their comfort and convenience. PR provided stationary items to selected psychologists for the filling of questionnaires.

As per decided plan, it was PR responsibility to provide set of questionnaire every month to selected interviewers for data collection. Distance of COPC+ sites to ART Centre and details of ART Centre's Matrix were provided to interviewers for better understanding of the national treatment centre response and average time and travel calculations

### **12. Data Collection – Process, Procedure, Data Flow**

Data from the questionnaires was added into a purposely-designed Access database before being uploaded into SPSS for analysis. An extensive data cleaning process took place for final analysis. MIS team at Nai Zindagi PR Office developed a database for the data entry. Data collected, was given to data operator at AAU to be entered. Frequency of data entry was immediate / as soon as information is received. Data verification routinely occurred between the AAU staff, then NZ conducted random data audits.

### **13. Quality Assurance and Monitoring**

For Cohort – 1, the chief psychologist at AAU and for Cohort – 2, the head of IT was the in charge of data collection and ensured eligibility, completeness and consistency of the completed questionnaires. The verified questionnaires were entered in database by the data entry operator (DEO) and sent to Nai Zindagi Head Office on a fortnightly basis.

All filled hard copies of questionnaires after data entry were compiled and sent to Nai Zindagi Head Office at the end of every month.

Data quality assurance was ensured via a data audit at the Nai Zindagi Head Office whereby 10% of questionnaires were selected on a random basis and were routinely cross checked with data entered in NZMIS.

Any discrepancies were removed through data cleaning. Additionally, every month Nai Zindagi Head Office staff member(s) visited AAU/IT for one day to physically review the interview process and ensure quality of data collection process.

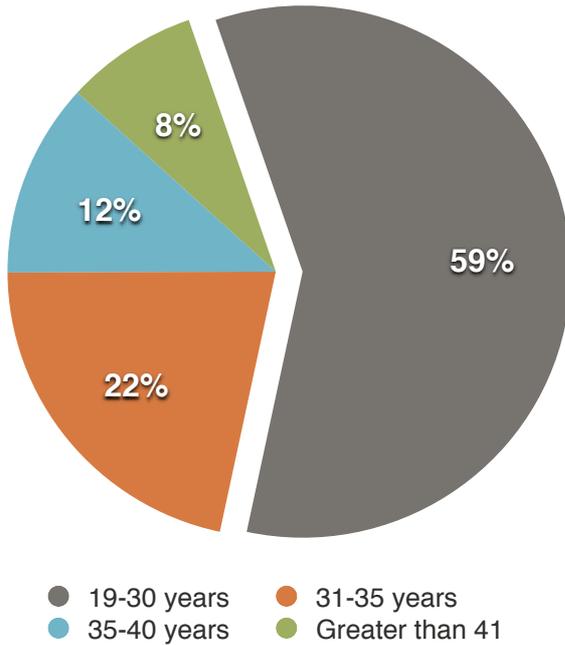


# Findings

## Cohort 1

Five hundred respondents who have completed two-weeks detoxification and have been residing at the AAU for at least three weeks and were assessed stable for being part of this assessment.

### Age of respondents (n=500)



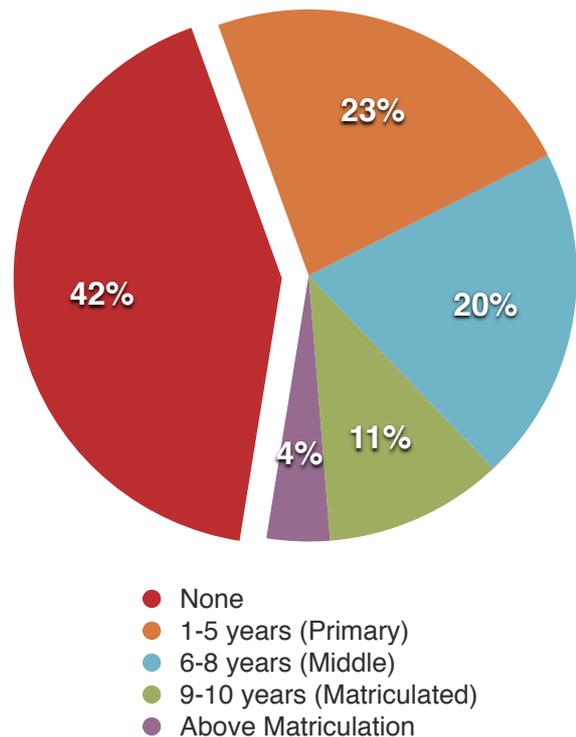
Fifty nine percent of the respondents of Cohort 1 were between 19-30 years of age. Twenty eight percent were between 19-25 years of age. This indicates a high burden of disease (HIV) among young PWID.

The younger HIV positive PWID are also sexually more active and chances of sexual transmission to their sexual partners is likely to happen.

Forty two percent of the respondents of had no formal education (could not read or write). Fifty four percent only had schooling up to 10 years.

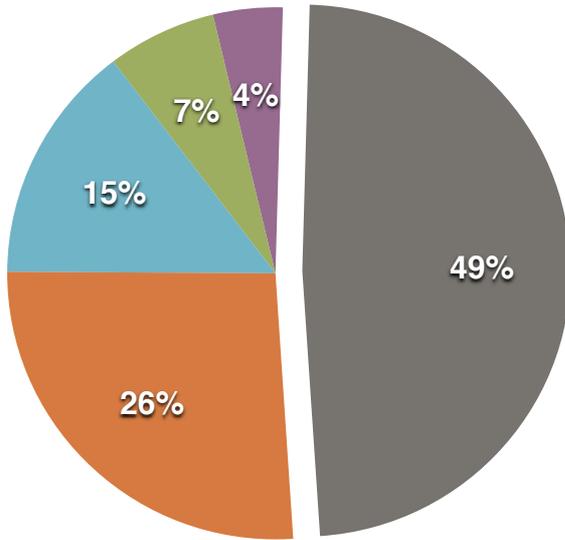
Lack of education often results in poor access to information related to HIV, AIDS and other blood borne diseases. Information is best provided in this case through inter personal contact and communication, rather than written materials.

### Education (n=500)



- None
- 1-5 years (Primary)
- 6-8 years (Middle)
- 9-10 years (Matriculated)
- Above Matriculation

### Current source of income (n=500)



- Daily wages
- Personal business(self employment)
- Salary
- Financial support by others
- Others (Begging)

Forty nine percent were daily wagers. These were hawkers, loaders, field work, etc.. This is in most cases not a regular income and depends on demand and supply for labor on a given day.

Fifteen percent only had a regular job (salaried).

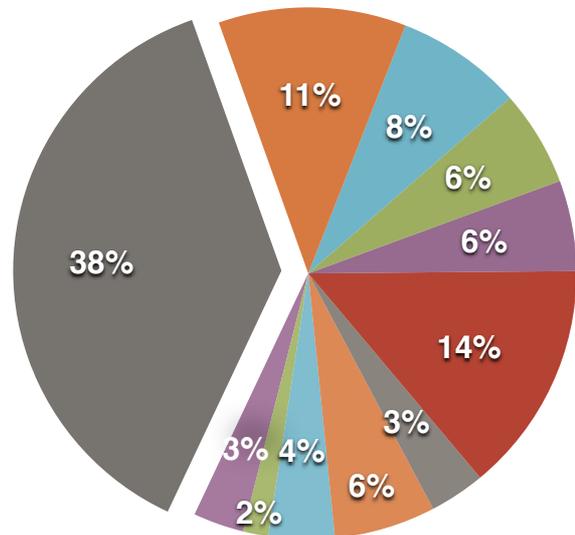
Forty seven percent of the 500 respondents had no professional skills. Of the 265 who had some professional skills there were multiple responses.

Of those who had skills driving (38%) was the most popular skill reported, followed by masonry work.

Comparing current source of income and professional skills, its obvious that they don't match.

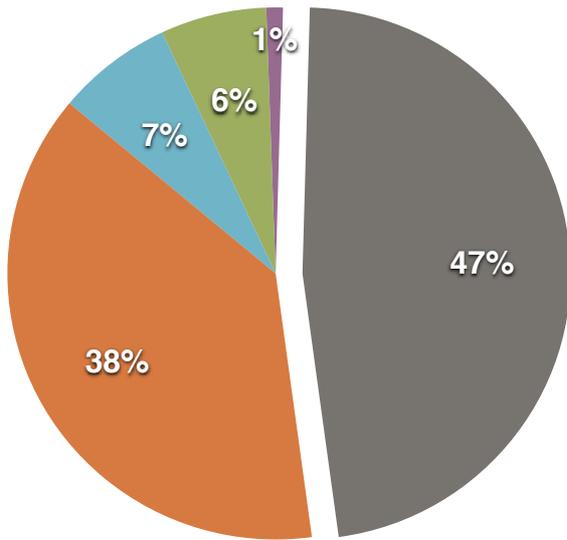
This could be due to drug use or poor health conditions.

### Professional skills (n=265)



- Driving
- Electrician
- Carpentry
- Tinter/dyer
- Agriculture
- Othe (Fisher Man, Cook, Butcher)
- Mason
- Plumber
- Mechanic
- Parget (whitewash)
- Cobbler

### Marital status (n=500)



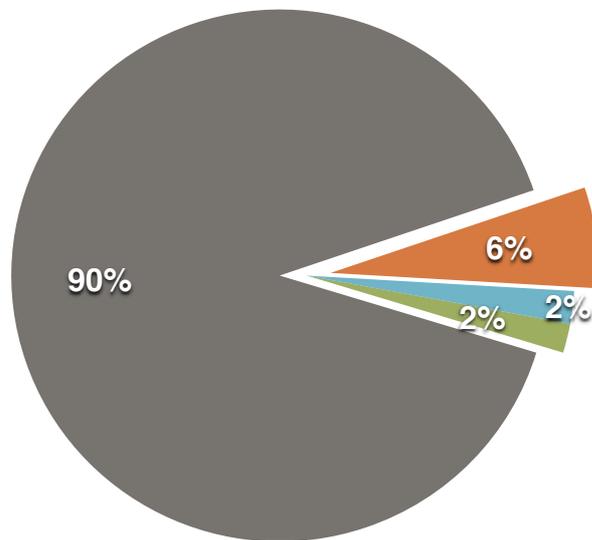
- Un-married
- Married
- Divorced
- Separated
- Widowed

Forty seven percent were not married. Thirteen percent were either divorced or separated.

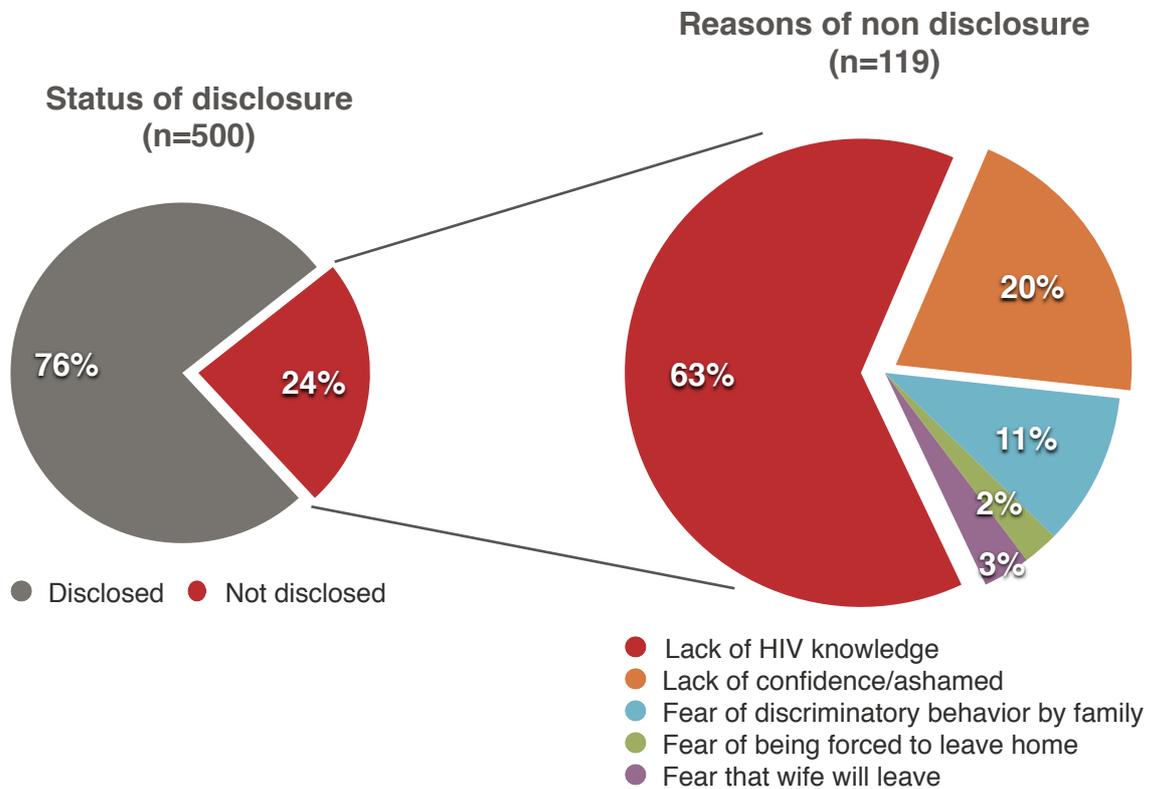
### Living status before coming to AAU (n=500)

Ninety percent of the 500 respondents were living at home with family or parents. This is a trend that has changed over the last decade. For PWID to reside on the streets in major cities is difficult due to strict law enforcement actions and security issues.

In smaller cities, PWID prefer not being seen living on the streets as the general community is smaller and people tend to know each other. To avoid stigma of living on the streets they tend to return home after scoring and using on the streets.



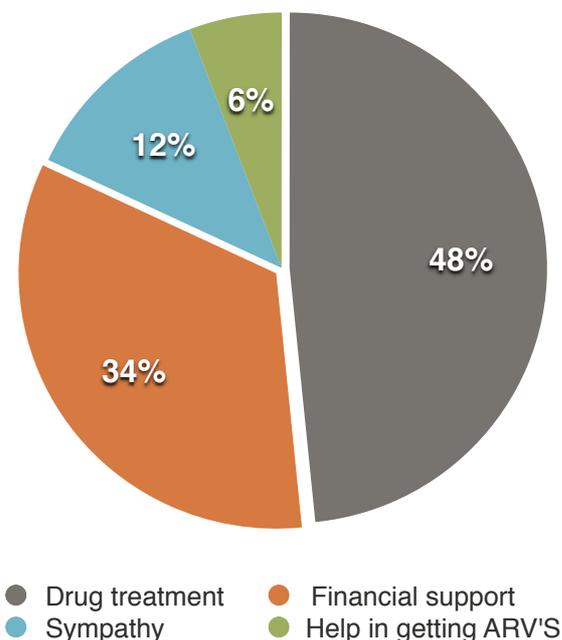
- At home (family/parents)
- On street
- With Friends
- Others



Sixty three percent of those (24%) who had not disclosed their HIV status mentioned 'lack of knowledge of HIV' as being the main reason for non disclosure. Further probing this response it was reported that although out reach workers and social mobilisers and related staff did provide information, however due to their state of chaotic drug use they could not either retain this information or did not understand its importance. Field staff has been informed to further strengthen this area.

Reasons for non disclosure by thirty seven percent was primarily associated with fear, stigma, discriminatory behaviour and probably violence as a reaction to disclosure. This area needs to be further strengthened in the program.

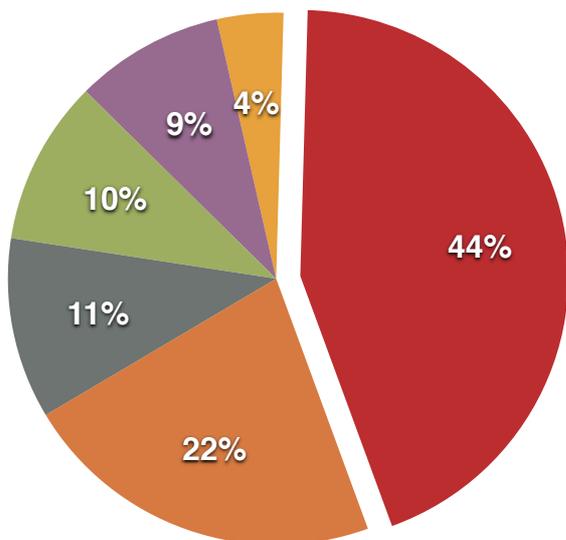
**Positive reactions after disclosure (n=155)**



Seventy six percent had disclosed their status. Forty one percent (155) of those who disclosed reported a positive reaction.

Forty eight per percent of the 155 mentioned resources provided by the family for drug treatment (48%) as a positive reaction; thirty four percent got financial support from their families.

### Negative reactions after disclosure (n=100)



- Physical Abuse
- Forced out of home
- Discriminatory Behaviour
- Others (anxious, anger, scared)
- Forced Admission at rehab program
- Confined at Home/Prison

Twenty six percent of those (381) who had disclosed their status had negative reactions.

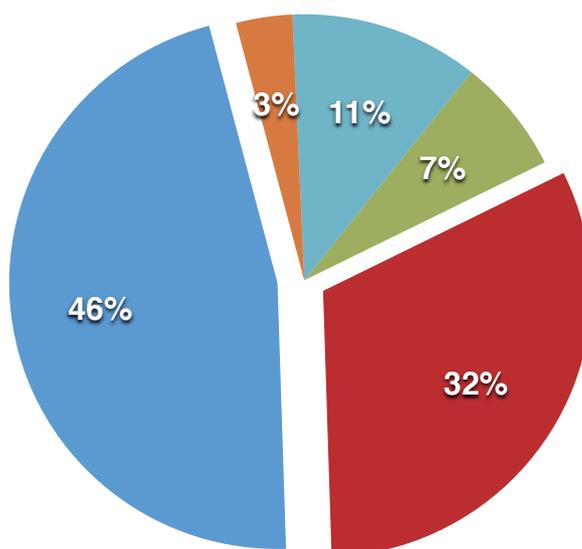
Physical abuse remains the main negative reaction on disclosure, followed by being forced to leave home.

Staff that is directly in contact with families, needs to further sensitise families to mitigate negative reactions on disclosure.

### Gap between HIV diagnosis and ARV initiation (n=500)

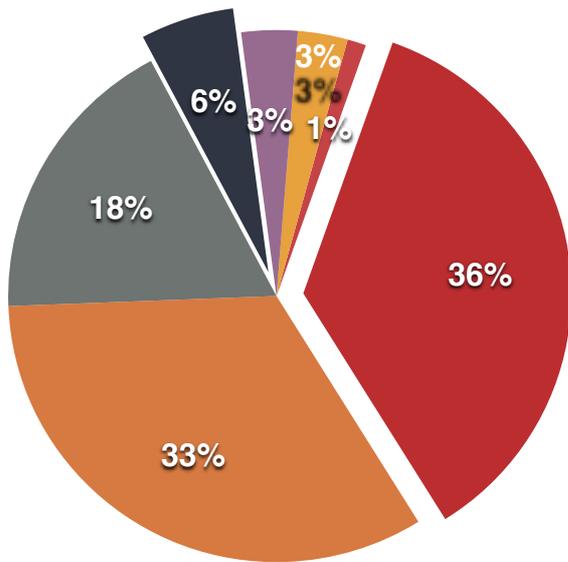
Treatment for all was initiated as a National Policy since January 2018. This has drastically reduced the gap between HIV diagnosis and initiation of ARVs.

A majority of the 32% who had to wait for more than 4 months from diagnosis of HIV to initiation of ARVs, were either those who could not have access to CD4 or did not have a CD4 below 500 which was a pre requisite for initiation of ARVs as a National Policy at that point in time.



- Less than 30 days
- 30 to 60 days
- 61 to 90 days
- 91 to 120 days
- More than 121 days

**Reasons for gaps between HIV diagnosis and ARV initiation (n=500)**



- Lack of awareness about possible harms of HIV
- Drug use
- Incomplete information by CoPc+ staff
- Imprisonment
- Non supportive behavior of family
- Abscess/Health related
- Family Boycott

These are multiple responses.

Chronic drug use has been given as major reason by respondents for not accessing services timely or promptly, in addition to what has been mentioned earlier.

We also need to further explore lack of awareness of HIV and incomplete information provided by CoPc+ staff as reasons and improve it.

Six percent were imprisoned after being diagnosed as HIV positive.

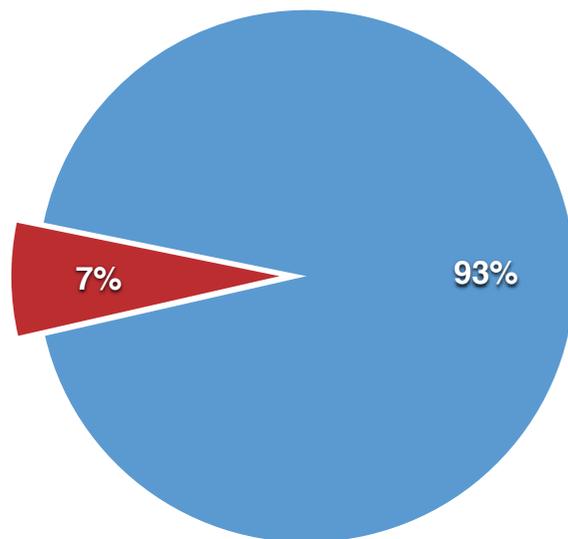
Other reasons that could delay initiation of ARVs were: migrated to another city (8%); forcefully admitted in drug rehab. (6%); imprisoned (6%).

**Difficulties faced while receiving ARVs (n=249)**

Seven percent (17) faced difficulties while getting their ARVS.

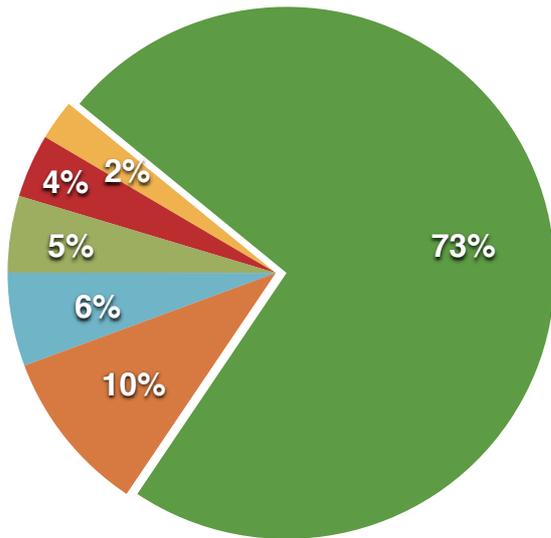
Forty one percent reported travel distances to another city for ARVs as a major difficulty followed by 38% who had to wait to meet ART staff.

Fifteen percent experienced drug withdrawals and ten percent who had to pay to travel to ART centres.



- No
- Yes

### Baseline tests (n=500)



Seventy three percent got baseline tests done at the ART associated Public Sector Laboratory.

Of the 362 respondents who got baselines from the ART associated Public Sector Laboratory 13% (49) had problems of which most common was travel distances, drug withdrawal and interference by law enforcement agency during travelling to the ART clinics.

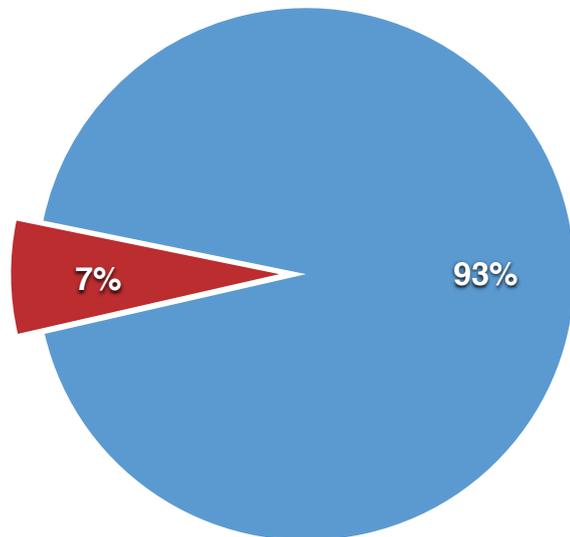
- ART associated Public Sector Laboratory
- From local private laboratory with the help of COPC+ staff.
- From Local Public hospital's laboratory.
- Details are not remembered
- Not Done
- From any other hospital/ organization

### Difficulties faced while registration at ART centres (n=249)

Seven percent (17) faced difficulties while getting registered at the ART centres.

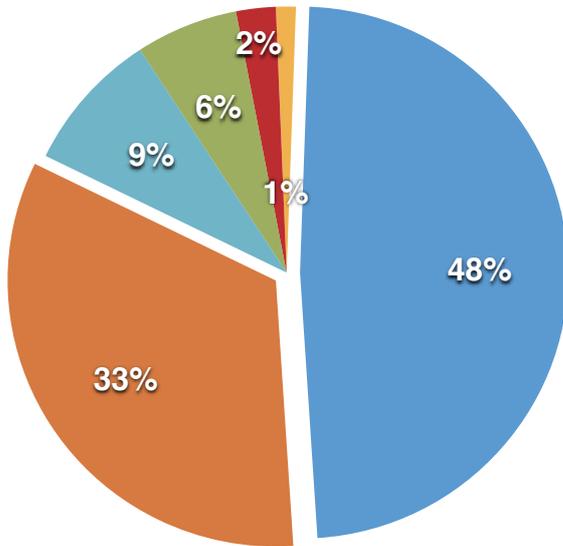
These again were long distance travel, drug withdrawals and waiting time at the ART centres.

Nine percent of the respondents had to have a HIV re confirmatory test, more than once for registration at ART centres and 5.6% had to have ELISA. This did result in additional visits and similar issues as mentioned above.



- No
- Yes

### CD4 tests (n=490)



- From CoPC+ site - NZ
- From ART Center
- Not done
- Details not remembered
- From any other hospital/ organization
- From any other hospital/Organization

Forty eight percent of the respondents got their CD4 from NZ's Point of Care CD4 services.

These were done in the community (on street) and at the CoPc+ site offices.

Ninety nine percent of the respondents did not face any problems in accessing CD4 tests.

After January 2018, CD4 is no longer a pre-requisite for ART initiation.

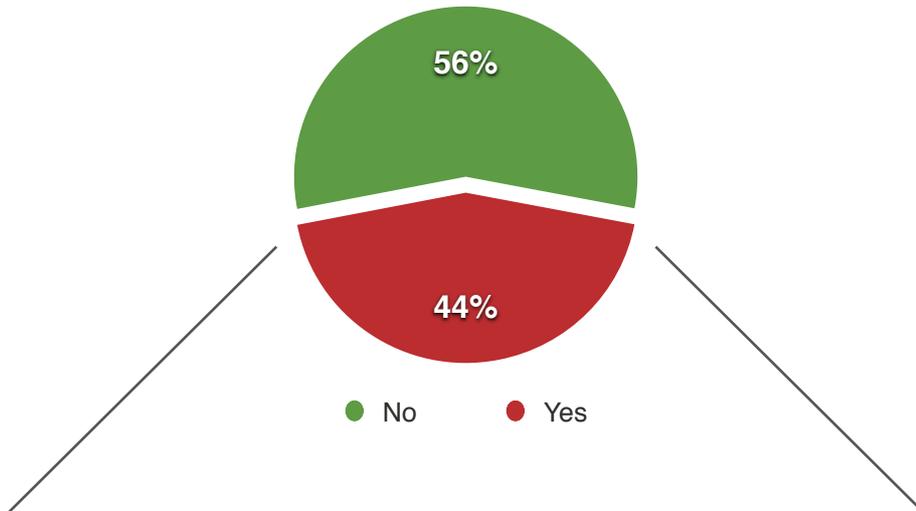


# Findings

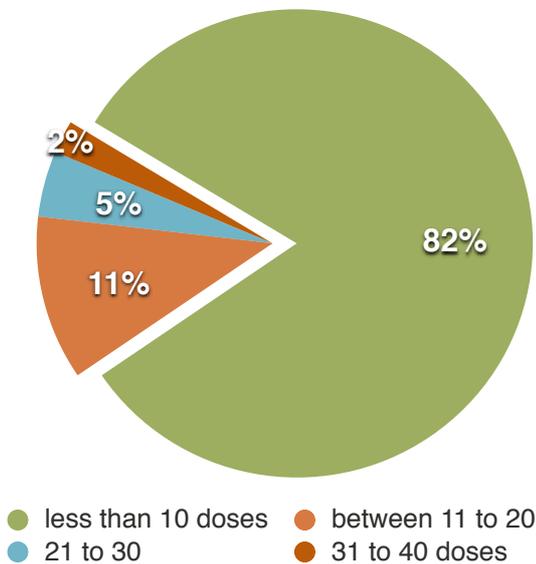
## Cohort 2

One hundred respondents who had completed the residential program and returned to their cities of origin, at AAU at least 6 months ago.

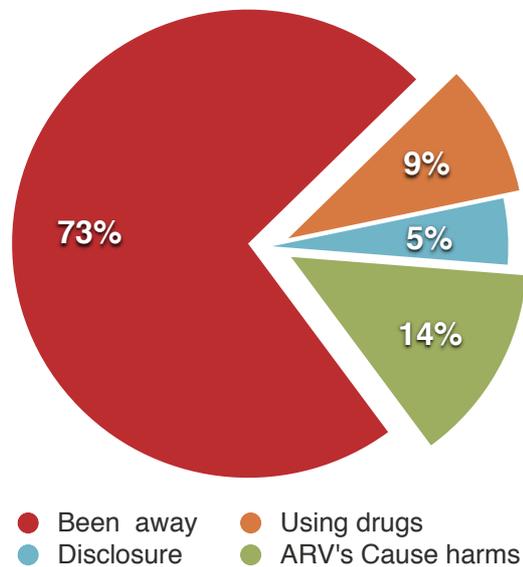
### Missed ARV doses in last three months



### Number of missed doses (n=44)



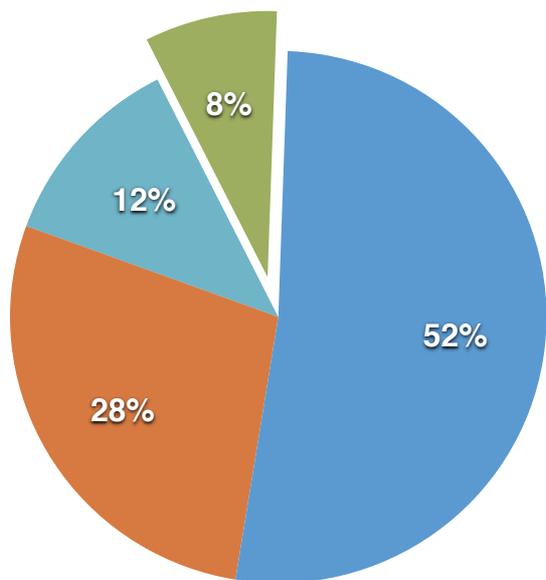
### Reasons for missing doses (n=44)



Eighty-two percent of the 44 respondents had missed less than 10 doses in the last three months. Major reasons were being away from home (73%). Fifty-three percent who had missed doses because they were away from city of origin were away to look for employment or nature of employment followed by moving away due to family matters and imprisonment.

Fourteen percent reported that using drugs with ARVs may cause harm/death and hence missed and restarted later.

**Where do you get your ARVs? (n=100)**



- From NZ-SMZ at home
- Directly from ART Centre
- NZ's Outreach Teams
- From CoPC+site

Seventy two percent of the 100 respondents got their ARVs through NZ's services and programs and 28% were escorted to the ART centres to collect ARVs.

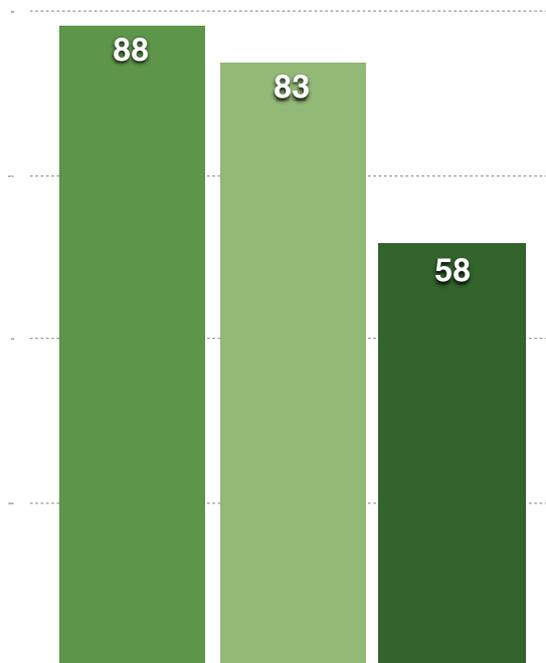
**Factors supporting adherence in last three months post AAU (n=100)**

Post residential care at the AAU sensitisation and knowledge of HIV and importance of adherence to ARVs is the main factor supporting adherence, followed by in city follow up support from the CoPC+ staff.

Additional support includes self help groups and In Touch program's regular contact and reminders.

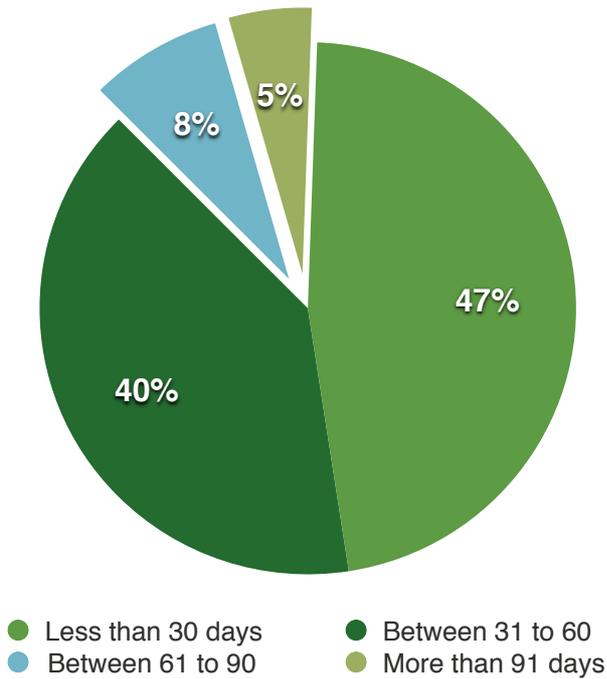
Lack of knowledge of HIV remained a main barrier in Cohort 1, which is not the case anymore in Cohort 2, post AAU exposure.

These are multiple answers.



- Sensitization and HIV knowledge
- Availability of social support
- Availability of additional support

**Frequency of getting ARVs in last three months post AAU (n=100)**



All of the respondents are on first line and majority on single dose ARVs.

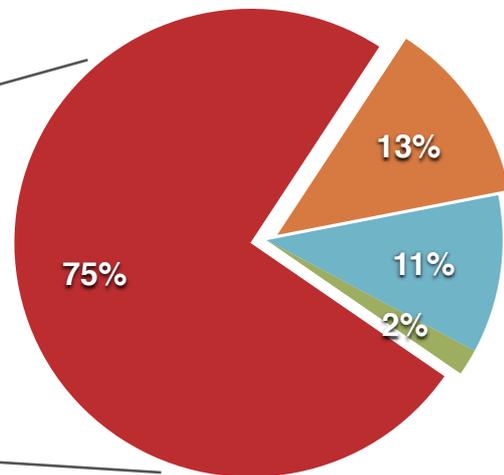
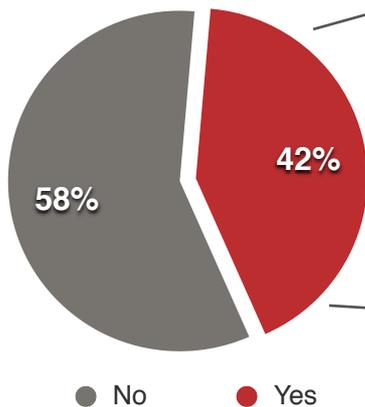
Ideally respondents should have a refill in two months and currently 87% are on this frequency.

Few respondents are on quarterly ARVs.

Eighty four percent of the respondents had visited the ART clinic for ARVs ever. The major issues they faced were long travel distances, drug withdrawals and weather extremities.

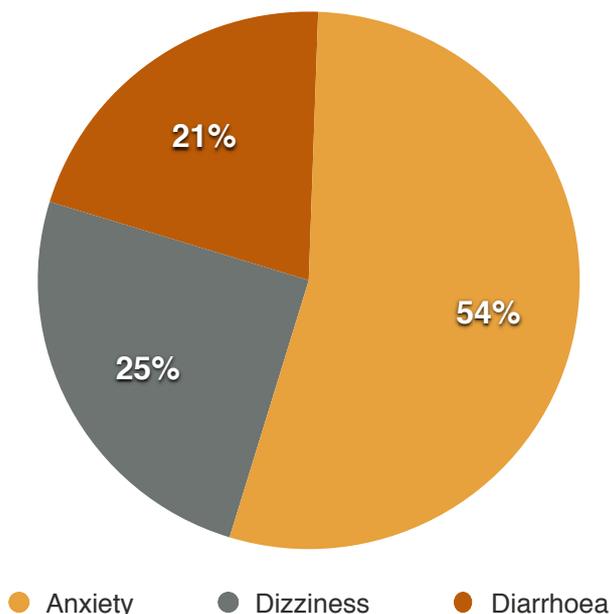
**What problems did you face? (n=42)**

**Did you face problems in accessing ARVs in the last 3 months (n=100)**



Long travel distances, weather conditions and quality of logistics remain a major problem to access ARVs followed by drug withdrawal particularly in longer travel distances.

### Ever experienced side effects of ARVs (n=38)

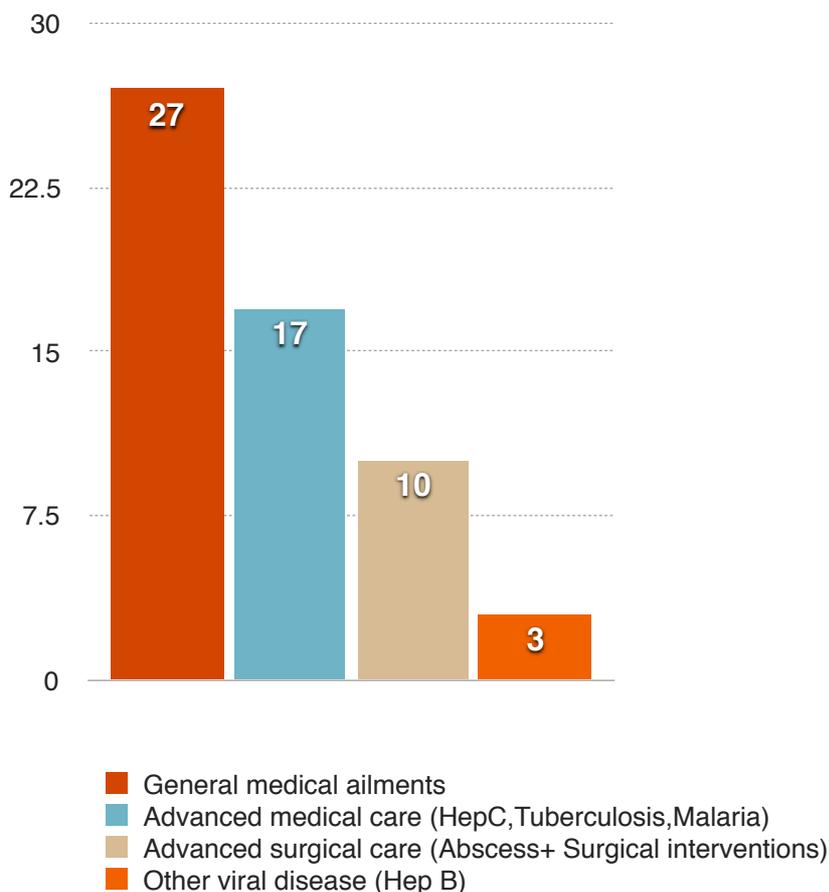


Thirty eight percent reported having side affects after initiating ARVs.

Anxiety was the most common reported symptom, followed by dizziness and diarrhoea.

Few respondents mentioned loss of appetite and insomnia.

### Have you ever availed any other medical service after initiation of ARVs? (n=47)



Of the 100 respondents only 47 had availed some medical care while on ARVs.

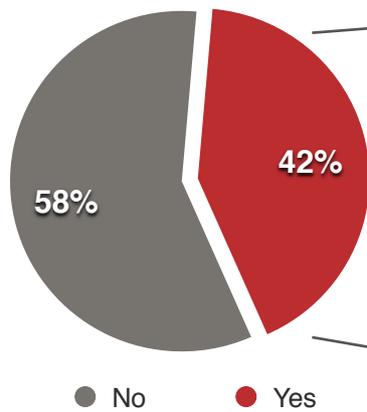
Advanced medical care includes Hep C treatment, malaria (dengue) and TB.

Abscess and wound management is mainly the advanced surgical care.

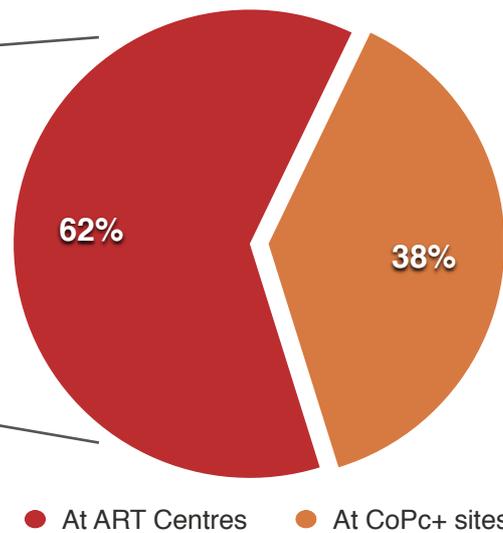
Of the 47 who received medical care 51% had experienced problems and reported: drug use and followed by discriminatory attitude of medical staff, including refusal to treatment.

Respondents mentioned that stigma of being a drug user and HIV positive person is the major reason for discrimination.

Did you ever face problems in follow up consultations (n=100)



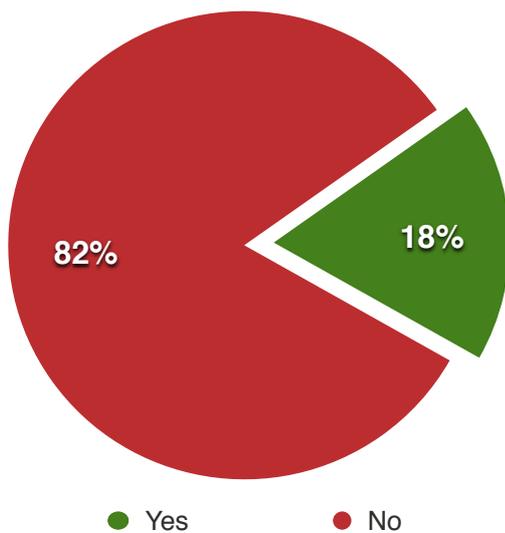
Where did you encounter this problem (n=42)



Problems encountered at the CoPc+ sites were: offensive and discriminatory behaviour of staff.

At the ART centres the main problems were: discriminatory behaviour, non supportive, large number of clients and shortage of staff.

Ever tested for viral load (n=200)



All 18 respondents who had a viral load test, were tested post completion of AAU.

Of the 18 who had a viral load test 3 (16%) were informed of their results.

Forty four percent knew the importance of viral load tests and mentioned: to monitor ARVs effectiveness (54%); it is a marker for HIV suppression level (30%); its a routine medical test (16%).

## **CONCLUSIONS AND RECOMMENDATIONS**

### **“KEY BARRIERS IN ACCESSING ART BY HIV POSITIVE PWIDs IN PAKISTAN”**

Six hundred respondents in two cohorts were enrolled in the study. The conclusions and recommendations are as follows:

- Fifty nine percent of the cohort 1 (n=500) was between 19-30 years of age, suggesting a younger population at risk and 38% percent of the respondents are married.

*There is need to further explore specific HIV prevention and treatment needs of younger PWIDs by gathering evidence through research. Based on findings programs may need to be tailored if the current National response is currently inadequate for this particular population.*

- Forty two percent had no formal education and 49% of the respondents are daily wagers.

*Information sharing and communication related to behavior change will largely remain through interpersonal communication between clients and staff. Economic rehabilitation through access to skills training can improve the socio economic status of clients, however these opportunities are currently almost negligible.*

- Ninety percent of the 500 respondents were living at home with family or parents. Twenty four percent had not disclosed their HIV status. Reasons of non-disclosure by 37% were primarily associated with fear, stigma, discriminatory behavior and violence as a reaction to disclosure. Twenty six percent of those (381) who had disclosed their status had negative reactions.

*Laws and national policies that effectively address stigma and discrimination need to be implemented. Service providers need to further intensify the process of disclosure and facilitate staff through training in order to have more disclosure and reduced negative reactions from family and/or community.*

- The gap between ARVs initiation and registration has been reduced after the treatment for all initiative. A majority of the 32% who had to wait for more than 4 months from diagnosis of HIV to initiation of ARVs, were either those who could not have access to CD4 or did not have a CD4 below 500 which was a pre requisite for initiation of ARVs as a national policy at that point of time. Only 7% faced difficulties while getting ARVs.

Chronic drug use has been given as major reason by respondents for not accessing services timely or promptly. Lack of OST and detoxification remains the key challenge and is identified as an access barrier to treatment. Efforts through advocacy and dialogue for OST needs to be intensified.

- Six percent were forcefully admitted in commercial drug rehabilitation centers and 6 % reported imprisonment.

Forced drug treatment by private commercial drug treatment centers remains the most common approach. Unfortunately in the absence of voluntary treatment this is the only option available. Civil Society should advocate for voluntary drug treatment instead of compulsory detention centers. Service providers need to increase capacity to provide ART in collaboration with District Jail Authorities for those who are incarcerated due to drug related offences.

- Forty one percent reported travel distances to another city for getting treatment as a major difficulty followed by 38% who had to wait to meet ART staff. Eight percent of the clients had migrated to another city and required re-registration with ART center that increased the gap between ART registration and in accessing ARVs.

Number of ART centers should be increased to reduce travel distances and new approaches (like the mobile ARV Roll out by Nai ZIndagi) should be explored, piloted, assessed and deployed. Processes of re-registration or transfer of clients files should be simplified.

- Thirty six percent reported lack of HIV knowledge and incomplete information by the CopC+ site as a reason of delay in ARVs initiation.

We need to further explore lack of awareness of HIV and incomplete information provided by CoPC+ staff and we are currently looking at city wise details to address the issue.

- Seventy three percent got baseline tests from ART associated public sector laboratory. Of the 362, 13% (49) had problems of which most common was travel distances, drug withdrawal and interference by law enforcement agency during traveling to the ART clinics. Nine percent of the respondents had to have a HIV re confirmatory test, and 5.6% had to have ELISA.

Law enforcement agencies need to be sensitized to the issue of drug use, HIV and AIDS in order to mitigate interference in the treatment process. Furthermore there is scope to increase the number of people accessing various services in the Public sector hospitals.

- Thirty eight percent reported having side effects after initiating ARVs. Anxiety was the most common reported symptom, followed by dizziness and diarrhea. Few respondents mentioned loss of appetite and insomnia.

*Consistent and on going dialogue with the ART clinic staff is important to address the side effects for those who return to the city of origin post AAU.*

- Of the 18(cohort 2) who had a viral load test 3(16%) were informed of their results. Only forty four percent knew the importance of viral load tests.

*Only few treatment centers are equipped with facilities to provide VL testing and this remains a challenge. Consistent and on going dialogue with the National and Provincial AIDS Programs and ART clinic staff is important to address this.*

- Fourteen percent reported that using drugs with ARVs may cause harm/death and hence missed their treatment and restarted later. Seventy two percent of the 100 respondents got their ARVs through NZ's services and programs and 28% were escorted to the ART centers to collect ARVs by NZ staff.

*The myth that using drugs with ARVs may cause death/harm needs to be demystified and clarified at all levels of staff that interacts with clients on ARVs.*