

Progress Report 2016



IN TOUCH

A pilot to assess effectiveness of mobile phones for follow-up and adherence to ART among people who inject drugs.

An innovative pilot by Nai Zindagi and Mainline

Acknowledgements

Nai Zindagi would like to thank Mainline, which supported the ART Adherence Unit (AAU) under the Bridging the Gaps initiative of the Dutch Ministry of Foreign Affairs from January 2014 to December 2015, and the Global Fund to Fight AIDS, Tuberculosis and Malaria, which began supporting the facility in 2016 in addition to providing support to CoPC+ sites.

We would also particularly like to thank Mainline, who supported the innovative pilot to assess effectiveness of mobile phones for adherence to ART among people who graduated from the ART Adherence Unit under the Bridging the Gaps initiative of the Dutch Ministry of Foreign Affairs.

A special thanks to the In Touch team and Mr Bilal Qureshi for the well conceptualised photographs.

A very special thank to all clients and their families who made this pilot possible.

Introduction

The ART Adherence Unit (AAU)

The ART Adherence Unit (AAU) is a residential rehabilitation facility for HIV positive persons who inject drugs (PWID) that combines 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.

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 is now secured further support from the Global Fund to continue its operation until the end of 2017 with double the capacity of 200 beds.

Detoxification and ART initiation support are provided at the AAU in a two month residential program. A client who has been tested HIV positive, and who has a CD4 count of 500 or below, will undergo residential detoxification for two weeks. After detoxification the client is then inducted in the AAU for a therapeutic community programme based on behaviour shaping strategies and tools.

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.

The facility is staffed by a mixed gender team of Medical Officers, Paramedics, Psychologists, Counsellors, and a compliment of administrators, with several of the counsellors themselves being ex-users. Medical services provided include basic health care, treatment of OIs (as recommended by the special clinics) STI treatment, ARV adherence monitoring, diagnosis and treatment of TB, and medical referrals.

AAU graduates on completion of the 8 week program return to their cities of origin, where the Social Mobilisers and Female out reach workers follow up on adherence related issues with clients, families and the Public sector ART clinics.

Background to In Touch

AAU residents are referred from 28 districts across 3 provinces of Pakistan. For the AAU staff to physically follow up clients due to distances, availability, travel, etc. would be not only difficult but extremely costly.

In September 2014, we carried out an assessment of mobile usage and knowledge of usage among one hundred PWID for ART adherence through mobile phones who were resident at the AAU.

The key findings and conclusions of this assessment revealed that a very large proportion (95%) of PWID have been using a mobile phone for over 5 years and know how to make and receive calls and 64% can also use SMS. Hence the mobile phone ARV reminder is a possibility to improve adherence and follow up clients who complete AAU.

Sixty two percent of those who owned a mobile set either lost it or sold it. This is

an element that will need to be catered to and may be is directly related to drug use/relapse.

Mostly prefer a weekly voice call reminder rather than a daily or weekly SMS. A combination of both may be deployed.

By law a SIM can only be allotted to a person with a National Identity Card, however 40% do not have one and cannot get a SIM.

Eighty five percent have family members who have a mobile phone. One or more family members could be included with consent to be part of the adherence tracking pilot.

Mainline as part of the BtG program supported a pilot in 2015 and two hundred AAU graduates were provided a set of simple, functional and inexpensive mobile phones.



In close consultation with AAU residents, staff and cell phone experts a process to initiate the pilot was outlined. The key elements were:

- Criteria: Two hundred PWID who complete two months of residential care at the AAU and have ever used and/or can be taught how to use a mobile phone; who have a SIM or can have a SIM on their CNIC or from a family member and consent to be part of the pilot.
- Staffing: A Call operator will be responsible for training the participant in the proper use of the phone while at AAU; he/she will also be responsible to contact as per the procedure study participants once they leave the AAU; contact the designated family member/s and remain in regular contact with the social mobiliser at the CoPc+ site of the participant; data entry operator: will be responsible to maintain hard and soft records of contacts made and generate a weekly report to inform management and the CoPc+ site of outcomes.
- The cell phone: Will be robust, basic with music, camera, reasonable display screen and an ability to

receive and send SMS. Both english and urdu software will be installed; every day the cell phone will initiate an audio alarm reminding to take ARVs twice a day at 09:00 and 21:00 hours. A button will have to be pressed to close the alarm.

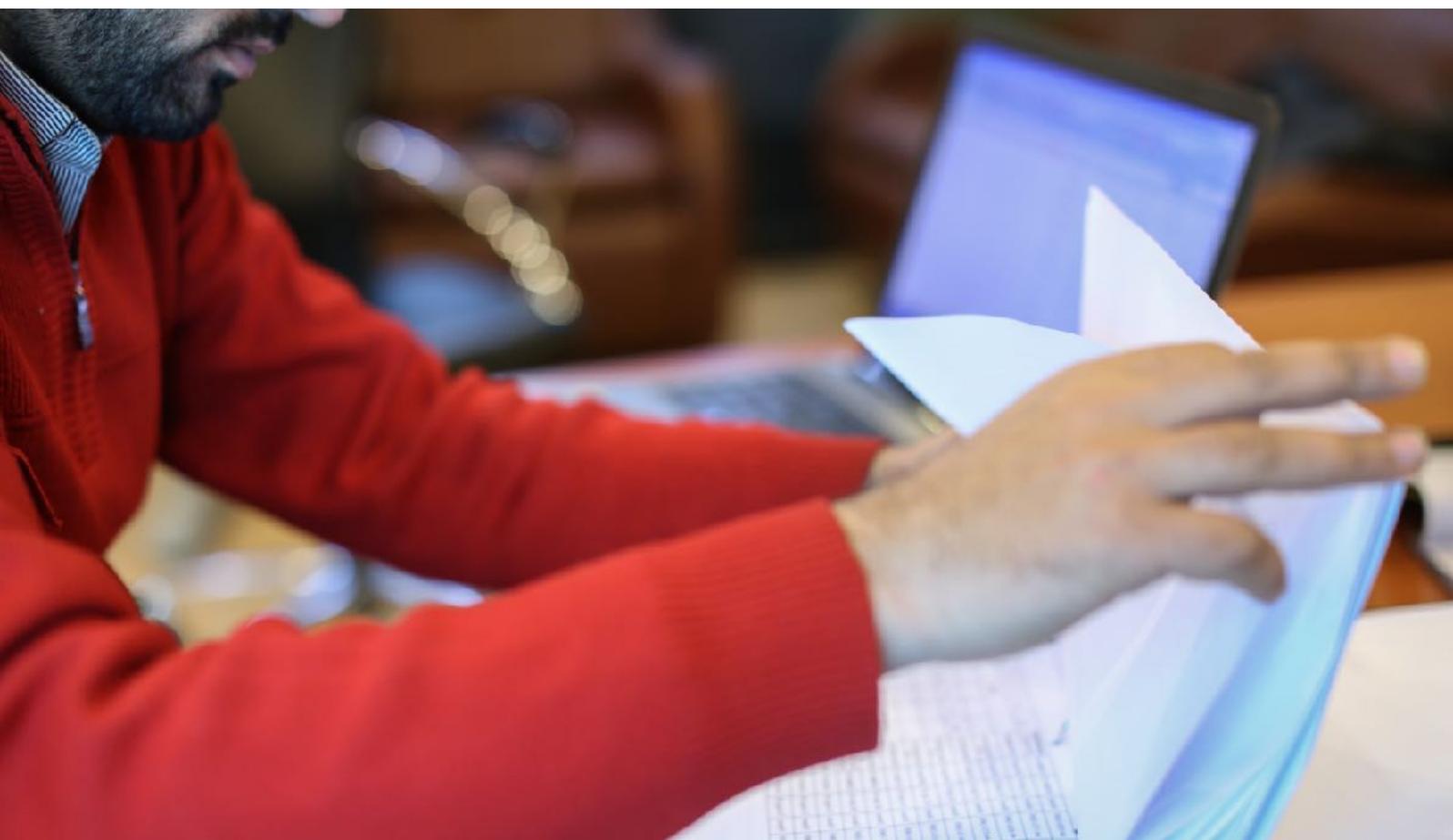
- Staying in touch: The call operator: will make aim for three calls a week to the participant on his designated cell phone. The calls will be specifically to ask about ART adherence and in general related to health messages, drug use or other needs based counselling. He/she will also speak to the designated family member once a week directly or through the participant; data entry operator will record the outcome of the call and issues/needs raised and counselling will be provided; weekly data will be 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.
- Incentive: Participants who comply to 3 weekly calls and one call with a family member will as an incentive get a weekly top up on their cell phone.



Expected outcomes vs actual in - 2015

EXPECTED OUT COMES	ACTUAL OUTCOMES												
<p>Accessing PWID communities through cell phones for ART adherence and health related messages has never been piloted. This initiative will form a documented evidence of how this can be useful and scaled up.</p>	<p>The processes and methodology have been documented and its evident that cost effective and timely follow up to monitor adherence and post AAU issues related to counselling, drug use, etc. can be addressed. By the end of 2015 followup was scaled up from the initial 200 AAU graduates to approximately 600 plus across 28 districts.</p>												
<p>Although chaotic drug use can lead to a higher possibility of losing, selling, misplacing phones this risk will need to be taken.</p>	<div data-bbox="861 772 1181 1288" data-label="Figure"> <table border="1"> <caption>Phone Status Data</caption> <thead> <tr> <th>Status</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Reported Lost</td> <td>7%</td> </tr> <tr> <td>Reported Out of order</td> <td>37%</td> </tr> <tr> <td>Reported Sold</td> <td>19%</td> </tr> <tr> <td>No Contact, Status Not known</td> <td>9%</td> </tr> <tr> <td>In Order</td> <td>29%</td> </tr> </tbody> </table> </div> <p>By the end of December 2015 - only 29% of the 200 phones given to AAU graduates were functional. However as a result of this initiative the IT team managed to follow-up 600 graduates through cell phones that belonged to them and/or their family members. To initiate the pilot the 200 phones provided initially played an important role.</p>	Status	Percentage	Reported Lost	7%	Reported Out of order	37%	Reported Sold	19%	No Contact, Status Not known	9%	In Order	29%
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<p>The data reported weekly will show trends related to ART adherence or non adherence, issues clients face post AAU, drug use related information, etc. and can form the basis of improved follow up procedures.</p>	<p>All conversations are recorded and a manual register is maintained on a daily basis to inform relevant sections of the program for an urgent response/ intervention. For example if it is discovered that in a particular city a specific client is running out of ARVs, all relevant sections are promptly informed.</p>												

EXPECTED OUT COMES	ACTUAL OUTCOMES
<p>In the long run this can become a cost effective tracking mechanism across Pakistan.</p>	<p>A two person team manages the In Touch program centrally from the Islamabad office.</p> <p>In December 2016 approximately 613 clients were followed up across 28 districts at least once. The monthly budget for the program is approximately Euro 1900 per month, amounting to Euro 3 per follow up contact. This includes salaries, top up incentives, communication expenses, etc.. In December 2016 the same team reached 1238 clients hence Euro 1.5 per follow up.</p> <p>It would be impossible to follow up 1238 clients with a two member team and with such an immensely low cost.</p>
<p>The systems can after the completion of the pilot for the basis of a more sophisticated cell phone company based process.</p>	<p>We do not see the need for a sophisticated cell phone company based process e.g developing apps, etc..</p>



In Touch - 2016

The process of staying in touch through **In Touch** has been well rehearsed, adapted to follow up needs and embedded into the overall program - both with the AAU and the Global Fund supported interventions in 28 districts.

The In Touch team is in regular contact with the following sections and persons:

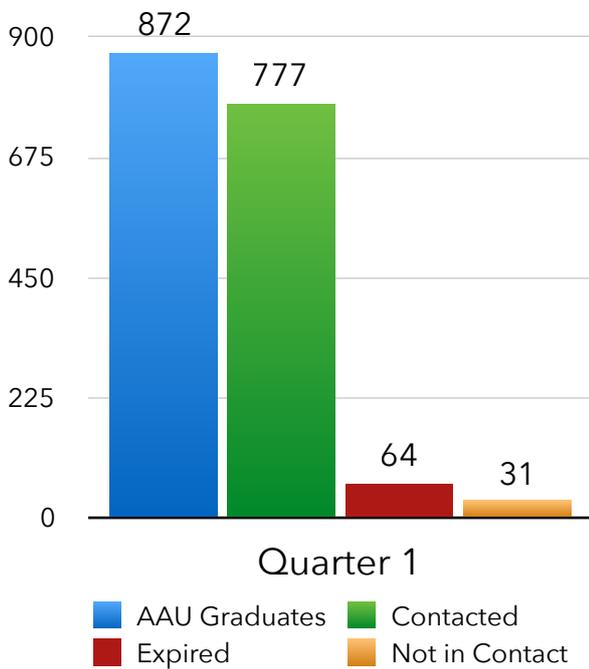
- MIS Team - the overall Management Information System that keeps track of the status of all AAU graduates when they return to their cities of origin. For example during follow up if its confirmed by the family and the district level teams that the client has expired, the In Touch team will confirm from the MIS is he has been coming for services or has been absent/disappeared.
- AAU Team - to update the list of graduates who return to their cities of origin that need to be followed up and for any other related matters.
- In Districts of origin: with the AAU graduates, their designated family members selected during their stay at the AAU, the Social Mobilisers, the Female out reach workers and the Management of the CoPc+ sites.
- Designated ART Centres: in regular contact with the ART centres/clinics in the Public sector where the follow up client accesses ARVs for confirmation or in case there is a short supply.
- Nai Zindagi Management: to regularly update management on follow up related matters and issues for advice and consultation when needed.

The following indicators are reported on a daily, weekly and monthly basis:

- AAU Graduates to be followed up
- Clients not in contact
- Clients who have expired
- Clients available for follow up
- Clients who are Adherent
- Clients who are Non Adherent
- Clients who are Drug Free
- Clients who are have Relapsed
- Clients who are Adherent and have Relapsed

These are the basic indicators that are reported, however numerous other factors related to follow up are recorded and reported to the relevant department/s or section/s within the program.

In Touch - Quarterly Outputs

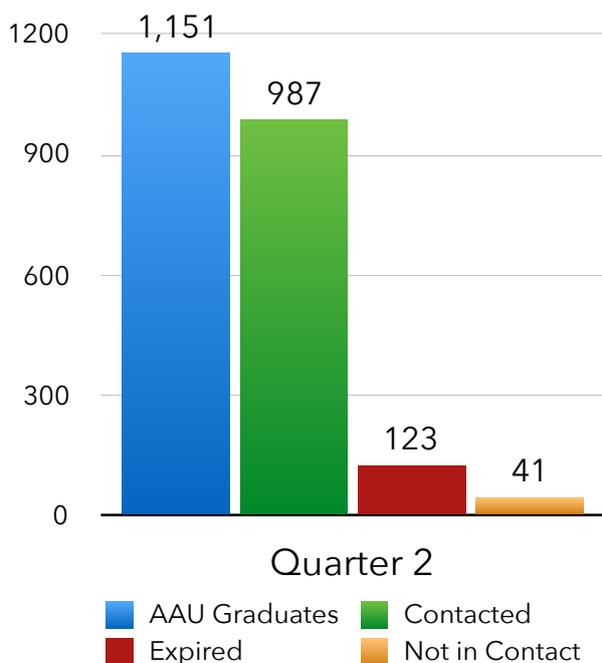


By the end of March 2016, a total of 872 clients graduated from the AAU and returned to their cities of origin.

During this quarter approximately an additional 200 new AAU graduates were added to the In Touch follow up.

On an average 70-90 calls were made every day with a connecting/success rate of approximately between 40-50%.

Seven percent of the AAU graduates had expired, however this is a cumulative figure from January 2014 when the AAU was initiated.



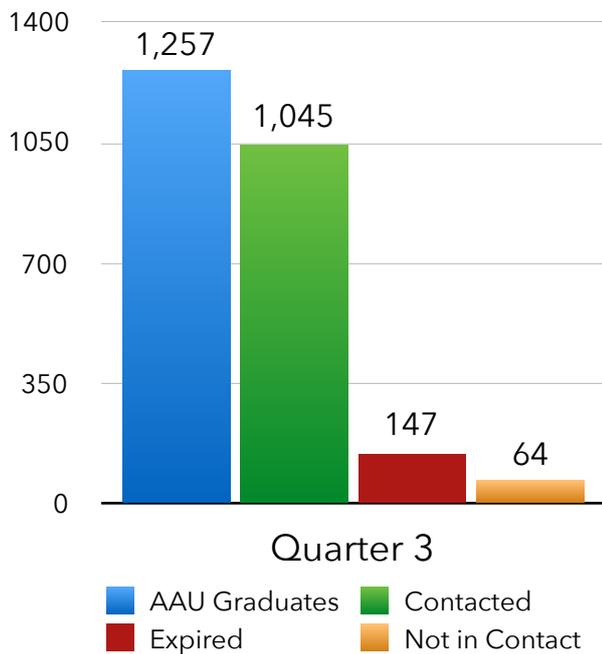
By the end of June 2016, a total of 1,151 clients graduated from the AAU and returned to their cities of origin.

During this quarter approximately an additional 279 new AAU graduates were added to the In Touch follow up.

On an average 80-100 calls were made every day with a connecting/success rate of approximately between 45-50%.

Ten percent of the AAU graduates had expired. In this quarter 59 AAU graduates were reported expired.

In Touch - Quarterly Outputs

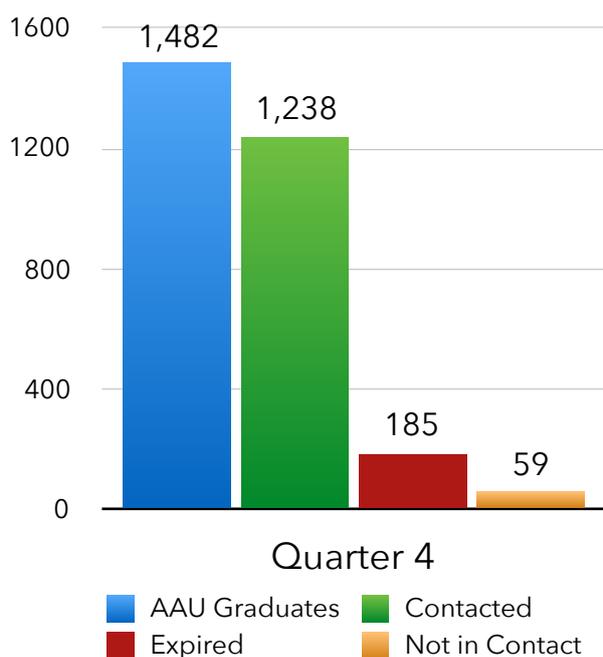


By the end of September 2016, a total of 1,257 clients graduated from the AAU and returned to their cities of origin.

During this quarter approximately an additional 106 new AAU graduates were added to the In Touch follow up.

On an average 90-110 calls were made every day with a connecting/success rate of approximately between 45-50%.

Twelve percent of the AAU graduates had expired. In this quarter 24 AAU graduates were reported expired.



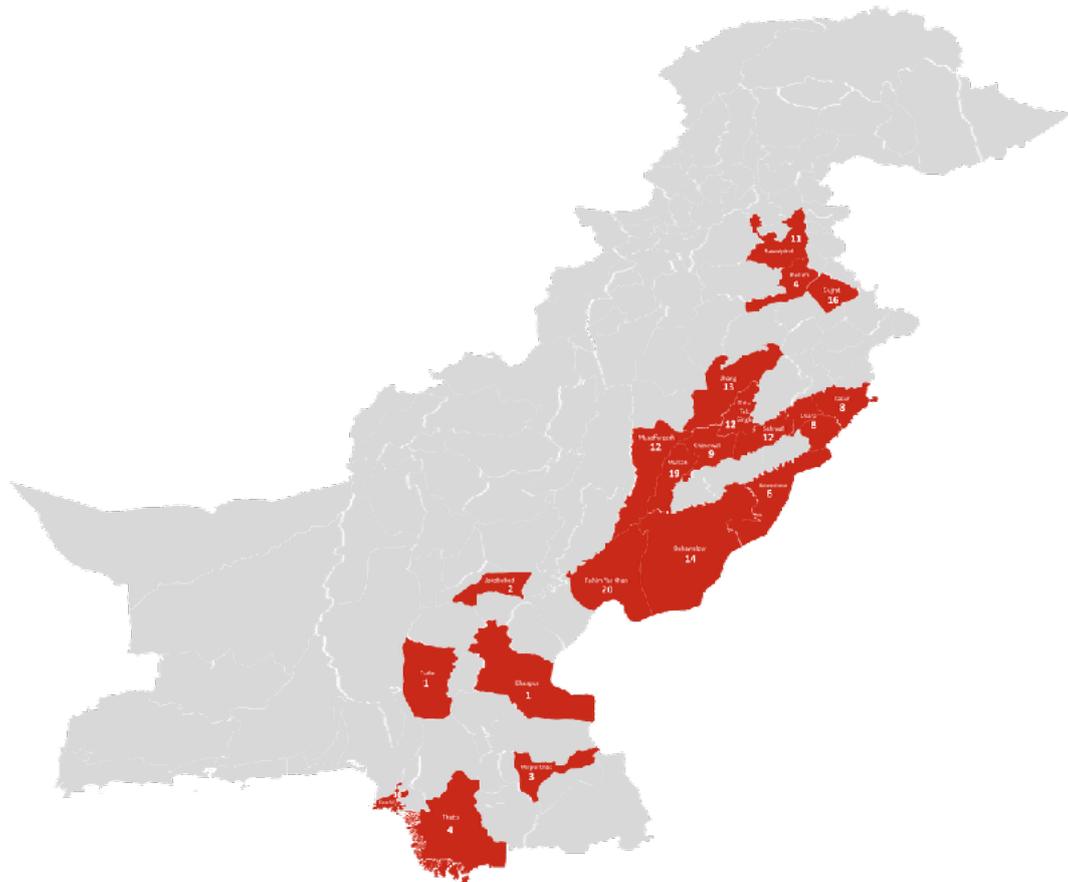
By the end of December 2016, a total of 1,482 clients graduated from the AAU and returned to their cities of origin.

During this quarter approximately an additional 225 new AAU graduates were added to the In Touch follow up.

On an average 90-120 calls were made every day with a connecting/success rate of approximately between 50-55%.

Twelve percent of the AAU graduates had expired. In this quarter 38 AAU graduates were reported expired.

AAU graduates reported expired



The map above gives the cumulative figures of AAU graduates who are reported - expired since January 2014. This is confirmed from families, staff on ground in the districts and through the MIS records of service attendance.

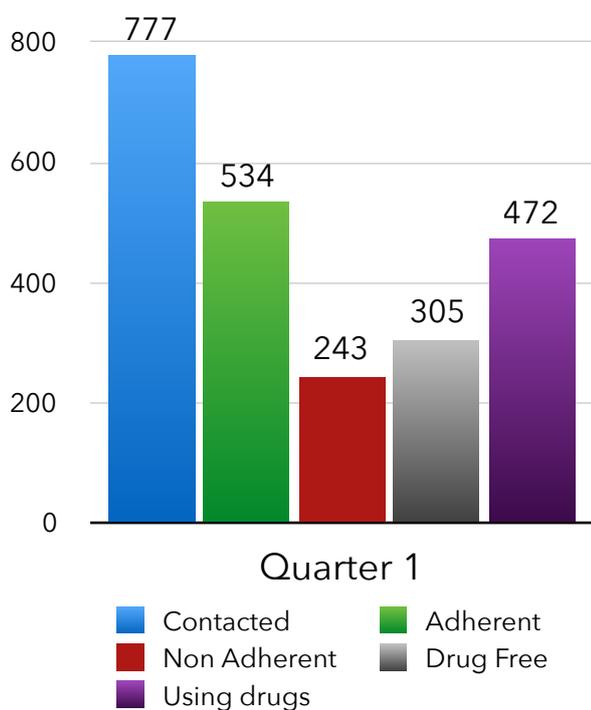
The highest numbers were in Rahim Yar Khan (20), followed by Multan (19), Gujrat (16), Bahawalpur (14), Jhang (13) and Sahiwal (12). In rest of the cities it varied between (11-2).

The highest number of deaths also correspond to a higher number of AAU graduates from a particular city.

However it is important to note that in Southern Punjab (Rahim Yar Khan, Multan and Bahawalpur) due to poverty, extreme weather and high prevalence of HIV (an older epidemic) the deaths are relatively higher.

We do not know the reasons for the deaths which could be over dose, Hepatitis B or C, accidents, injuries, etc..

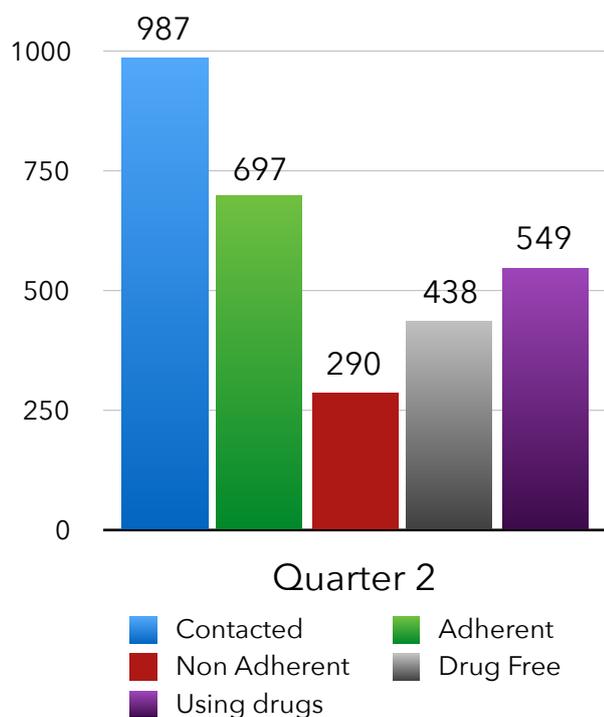
In Touch - Quarterly Outputs



By the end of March 2016, a total of 777 clients who graduated from the AAU and returned to their cities of origin were contacted at least once during this month.

During this month 68% of those contacted were adherent. This was reconfirmed from various sources: client self reported, families, social mobilisers, MIS - ART data and from the special clinics providing ARVs.

Of those contacted 60% reported using drugs, this too was confirmed from the MIS service delivery data.



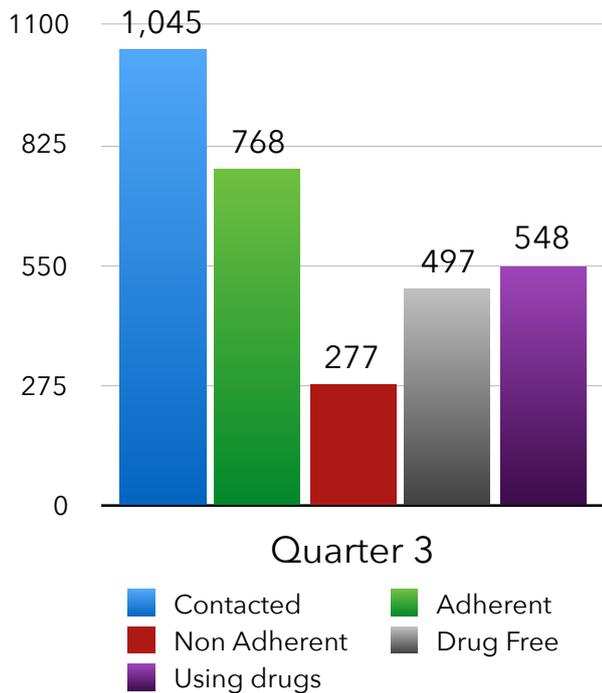
By the end of June 2016, a total of 987 clients who graduated from the AAU and returned to their cities of origin were contacted at least once during this month.

During this month 70% of those contacted were adherent.

Of those contacted 55% reported using drugs.

Among the adherent AAU graduates 42% reported using drugs.

In Touch - Quarterly Outputs

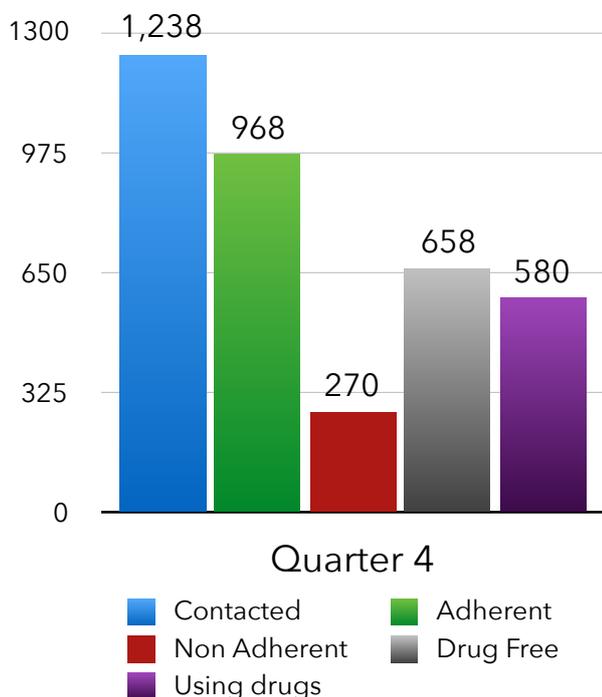


By the end of September 2016, a total of 1,045 clients who graduated from the AAU and returned to their cities of origin were contacted at least once during this month.

During this month 73% of those contacted were adherent.

Of those contacted 52% reported using drugs.

Among the adherent AAU graduates 40% reported using drugs.



By the end of December 2016, a total of 1,238 clients who graduated from the AAU and returned to their cities of origin were contacted at least once during this month.

During this month 78% of those contacted were adherent.

Of those contacted 47% reported using drugs.

Since March 2016 adherence rates have increased from 68% to 78% in December 2016. These rates are similar to what was informed by the AAU's evaluation commissioned by the Global Fund and conducted by independent consultants in 2016.

Drug use has also reduced from 60% to 54% in December 2016. This could be because of the revised AAU program that focuses on relapse prevention and tools like TBT (Trauma Buster Technique tools), AGA and AFA (support groups).

Conclusions



- The pilot to assess effectiveness of mobile phones for follow-up and adherence to ART among people who inject drugs has been successful.
- In Touch is a cost efficient and effective intervention to follow up clients over a large geographical spread. Mobile phone technology is now available even in the remotest areas and with time its usage, accessibility and availability will only increase, hence making it even more effective.
- It is a very low cost follow up system compared to physically reaching people for follow up. The human resource requirements, the travel and logistics costs, the board and lodging of people who follow up, would far exceed the benefit of following up.
- In Pakistan, PWID either have their own cell phones or those of family members - hence the need to provide phones is not necessary. Initially to for trials handing over phones was required, but no longer essential.
- AAU residents are briefed about the In Touch program while at the AAU which prepares them and their families member for follow up.
- Because the In Touch program addresses immediate needs of clients efficiently, they prefer being contacted regularly. The counselling sessions during the phone calls also plays an important role in addressing the psycho social and emotional needs of clients and their families.
- The In Touch data has been verified independently through physical verification (which was a very costly procedure) and the data is similar.
- Indicators of adherence and non drug use have improved over the period.

Recommendations



- **Review of collected data:** An audio and written log is maintained of all phone calls since 2014 to date. It is highly recommended that a team is put together locally to analyse these calls and identify main areas that have come up and addressed during this period. This analysis could become a hand book to prepare AAU residents what they may face once they return to their cities of origin and how to cope.
- **Report and record human rights violations:** Another indicator that is essential and can be easily incorporated is the reporting and recording of human rights violations and taking matters up with relevant partners or organisations.
- **Expansion:** With the passage of time the burden of follow up will increase and similarly the IT team should be expanded to meet the desired follow up protocols and quality.
- **Quality assurance:** It is advised that 10% of those reached through IT in the last month, be contacted independently to evaluate the quality of IT follow up and how it can be improved.
- **Beyond PWID:** The principles of mobile phone based follow up and counselling can be adapted and deployed in other similar situations and key populations.