Progress Report 2016

Self help groups for ART Adherence Unit graduates and their families

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, which supported the innovative pilot for self help groups of ART Adherence Unit graduates and their families under the Bridging the Gaps initiative of the Dutch Ministry of Foreign Affairs.

A special thanks to Ms Afroz Fatima, National Coordinator of the AGA and AFA groups 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

By the end of 2014 people who inject drugs (PWID) formed the single largest group of an estimated 91,340 people living with HIV (PLHIV) in Pakistan.

They also accounted for "the bulk of new infections." The most recent Global AIDS Response Progress (GARP) Report for the country declared that the HIV epidemic is "mainly driven by PWID," with the weighted national HIV prevalence among injecting drug users estimated to be 37.8%. The GARP report estimates less than 10% ART coverage of all eligible people by the end of 2014 in Pakistan.

This makes the issue of securing adequate coverage of Antiretroviral Treatment (ART) for this population critical to the control of what is still a growing epidemic. However, achieving adequate treatment coverage for PWID with HIV in Pakistan has proved particularly challenging.

To understand the challenge that Pakistan faces in addressing this problem it is important to break down "treatment coverage" into its constituent, and sequential, components of treatment initiation, retention in treatment, and adherence to treatment.

The aim should be to optimise all three by identifying and addressing barriers to initiation, understanding and addressing causes of loss to follow up (LTFU), and understanding and addressing causes of non-adherence.

Anticipated adverse treatment outcomes create a systemic caution around prescribing treatment. As one report puts it: it is *"pre-emptively assumed that PWID [will] not adhere to treatment and should not be initiated."* This assumption needs to be addressed if the treatment coverage problem is to be resolved.

There is no real analysis of the causes of the remarkably high loss to follow up rates. The author's suggestion that the solution is for NGOs to ensure "complete rehabilitation" indicates that they are perhaps aware of this and are inclined to attribute the cause to drug use itself, though this is not explicitly stated and would, in any case, have very weak explanatory value; drug users are lost to follow up because they are drug users.

Regardless of the explanation there is clearly a very significant problem with retaining PWID in ART treatment in Pakistan and adherence rates will not increase unless this retention problem is properly understood and addressed. This has fuelled concerns among clinicians about the potential emergence of treatment resistant strains.

During the development of Pakistan's recent HIV Concept Note in 2015 these concerns were one of the main reasons given by clinicians for still insisting that PWID undergo two weeks detoxification prior to ART initiation, despite the fact that national guidelines no longer require this.

Again, the implication is that drug use itself is perceived to be the main cause of loss to follow up and if we can convert a drug user into a ex-drug user we will stand a much better chance of retaining him in treatment. This is why "complete rehabilitation" is viewed as a solution.

The main problem with the "no initiation without rehabilitation" approach to treating HIV infected PWID in the Pakistan context is the limited availability of quality services for addressing opioid dependence.

With no OST programmes in place, this makes the coverage of treatment (at the initiation end of the continuum) totally dependent on the capacity and availability of quality detoxification services.

A collaborative, coordinated and fully integrated approach is required in order to boost treatment outcomes for this population. This might well mean a new level of on-going treatment access support to ensure that PWID initiating treatment stay adherent and make it back to their next appointment. Dispensing the medications and scheduling the next clinic appointment alone is unlikely to suffice. This is particularly so given that clinics are often situated a long way from the client's place of residence and multiple visits are often required.

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.

The original design of the AAU service was built around the ART treatment centres' requirement that PWID clients undergo a minimum of 2 weeks detoxification prior to treatment initiation. Detoxification and ART initiation support were initially provided in two separate residential facilities some distance apart. A client who had been tested HIV positive, and who had a CD4 count of 500 or below, would undergo residential detoxification for two weeks before being escorted to the clinic to initiate treatment. After treatment initiation the client would then be taken to the AAU for a therapeutic community programme based on behaviour shaping strategies and tools.

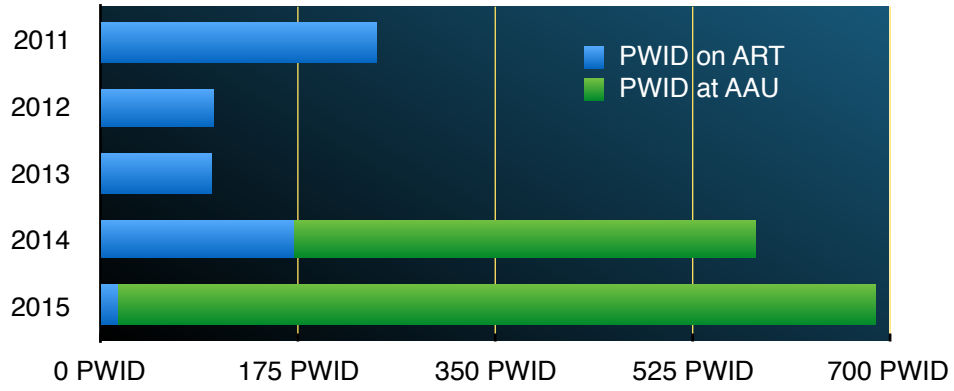
The overall objective of the AAU is primarily about supporting the client to reorient their life so that lifelong treatment with ART becomes a realistic and achievable proposition for them. The service model is designed in recognition of the fact that the transition from active opioid user to ex-drug 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.

From 2011 to 2013 PWID as a percentage of all PLHA on treatment remained relatively stable at a rate of 11-13%. After 2 years of operation for AAU, the absolute numbers of PWID on treatment increased 288% from 441 at the end of 2013 to 1710 at the end of 2015. People attending AAU represented 40% of all PWID on treatment in 2014 and 2015, or 85% of the growth in numbers of PWID on treatment in those two years. As a percentage of all PLHA on treatment PWID had doubled in these two years to 23%.

The service is consensual; a client is free to leave at any time. The approach is intended to be entirely non-coercive and founded on principles of mutual respect between staff and client.



The Rise in PWID on ART Coincides with the Operation of AAU

AAU Clients in a group session

An independent evaluation of the AAU - April 2016

Although Nai Zindagi's service data appeared to be showing favourable outcomes in terms of post-AAU, ART adherence there was a demand for an independent assessment of the model to better understand its impact on improving treatment outcomes for PWID. The evaluation study was commissioned in response to that demand.

The evaluation study detailed in this report was commissioned by Nai Zindagi to better understand the AAU's contribution to addressing the treatment coverage problem for PWID in Pakistan. It took place in the first quarter of 2016 and was designed and overseen by three independent consultants.

The study consisted of five separate methodological components including:

- a cross- sectional survey of ART-initiated PWID,
- a series of focus group discussions with ART clinic staff,
- PWID family members and spouses,
- a survey of the Nai Zindagi staff team, and
- an observational residency at the AAU conducted by an international harm reduction expert

A A U

ATTENDEES WERE

43-51

TIMES MORE LIKELY TO BE ADHERENT IN A PERIOD BETWEEN 7-19 MONTHS OF TREATMENT INITIATION

IN TERMS OF THE CASCADE OF SERVICES FROM PREVENTION THROUGH TO TREATMENT AND CARE, THE AAU SITS AT THE THRESHOLD OF TREATMENT INITIATION

BASIC FINDINGS

ADHERENCE RATES DECLINE OVER TIME MUCH FASTER

44.4%

FOR THOSE NOT ATTENDING AAU

VERSUS

1.7%

FOR THOSE ATTENDING AAU

60%

OF THOSE REPORTING RELAPSE ARE ALSO REPORTING ADHERENCE WITH HIGHER RATES AMONG CLIENTS OF AAU

Conclusions and recommendations leading to piloting self help groups for AAU graduates and their families.

- The results of our study show that AAU is having a strong impact on ART adherence for PWID when compared to the alternative of not attending AAU, exposure to other services being equal. A person attending AAU was between 43 and 51 times more likely to be adherent to ART than a person who did not attend AAU. Overall the adherence rate was 77.4% for those attending AAU versus 51.1% for those not attending. There is encouraging evidence that adherence can and is being maintained during relapse for a significant portion of those who relapse. The data suggests that the provision of on-going post-AAU support is an important enabling factor.
- The period immediately following AAU discharge is likely to be a risk point for potential LTFU. It is recommended that a coordinated schedule of short-term support over the months immediately following discharge is shared between clinic, AAU and CoPC+ site. All parties should be aware of the date of discharge, the date of the clients next clinic appointment and the length of time that the client's existing supply of medications will last for.
- There is a recognised need for more relapse prevention support with which the consultant team concurs. But there is also a need for relapse management support to ensure that when relapse does occur it does not result in non-adherence. There needs to be a shift in mind-set that accommodates relapse as a fact of life for a considerable population of PWID on treatment and adjusts services accordingly with a view to supporting adherence across the relapse cycle. In relation to this it is highly recommended that healthcare and related support workers at all stages in the cascade avoid perpetuating the myth that relapse + ARV = death.
- Given that clients need to be tracked from CoPC+, through AAU and back to CoPC+, with follow-up support from the In Touch programme and other soon-to-be-started support services it would be extremely useful to have a centralised data system that tracked an individual client's exposure to each service component with appropriate indicators for tracking significant outcomes.

Self help groups for ART Adherence Unit graduates and their families.

In close consultation with Mainline, AAU staff and clients and key staff of Nai Zindagi Trust (the Global Fund PR) its was decided to initiate this pilot in 4 districts of Punjab with a high incidence of injecting, high prevalence of HIV and larger number of AAU graduates.

The districts of Rawalpindi, Gujrat, Toba Tek Singh and Rahim Yar Khan were selected based on the criteria mentioned above. It was decided to initiate two support groups in each city and scale up based on learning while implementing. Both groups are defined as under:

AGA

The "AAU Graduates Alumnae" – is a self-help fellowship of persons who have in the past/or are currently using drugs, are living with HIV and have completed the two month residential program at the AAU.

It is nonprofessional, self-supporting, multiracial, apolitical, non-religious and available to all members free of charge. There are no age or education requirements.

Membership is voluntary and open to all AGA members who wish to support and protect each other.

AFA

The "AAU Families Alumnae" – is a self-help fellowship of female family members of persons who have in the past/or are currently using drugs, are living with HIV and have completed the two month residential program at the AAU.

It is nonprofessional, self-supporting, multiracial, apolitical, non-religious and available to all female family members free of charge. There are no age or education requirements.

Membership is voluntary and open to all female family members who wish to support and protect their loved ones.

The AAU Graduates Alumni

Goals

- To establish contact and strengthen relationships among members of AGA
- Engage members of AGA to share, learn and equip themselves with practical solutions/ways to improve their and client's quality of life and well being.
- To empower members of AGA to access HIV and AIDS related diagnostics and treatment for themselves and their family members.

Specific Objectives

- To provide a platform for sharing common experiences, situations, problems, conflicts or conditions faced by members of AGA in supporting and protecting themselves and their family members.
- To inform each other on aspects related to psycho-social-emotional needs including relapse and relapse prevention.
- To bring members of AGA together in order to gain strength and address their own psycho-social-emotional needs and associated problems e.g drug use, treatment related issues, etc..
- To discuss importance of ART adherence, better nutrition, health care and safer sexual practices.
- Equip members of AGA to mitigate stigma and discrimination.

AGA members in a group

The Methodology

- To recruit no more than 30 AGA members on a voluntary basis per city.
- To provide AGA members on a weekly basis a secure and non-judgemental platform (venue) to engage and share.
- To provide AGA members on a weekly basis transport costs and refreshments.
- To support and encourage AGA members to attend weekly meetings and engage within the framework of the goals and specific objectives of AGA.

Structure of the Pilot

- To employ an AGA Country Coordinator who will be stationed in Islamabad to initiate four AGA city based self help groups. Detailed Job Description of the Coordinator is developed.
- Each city based AGA self help group will have a designated and paid post (stipend) of a AGA Secretary from within the AGA members. This position will rotate every three months through voting by AGA members. Detailed responsibilities of the AGA Secretary will be developed.
- Each city based AGA self help group will have a designated AGA Organizer and paid post (stipend) from within the AGA members. This position will rotate every three months through voting by AGA members. Detailed responsibilities of the AGA Organizer will be developed.
- Each city based AGA self help group will have a designated AGA Facilitator and paid post (stipend) from within the AGA members. This position will rotate every three months through voting by AGA members. Detailed responsibilities of the AGA Facilitator will be developed.
- Each city based AGA self help group will have a designated AGA Observer - Social Mobiliser of the CoPc+ site of the city if he is approved by AGA members. His/her role is purely to observe, record and report to the AGA Country Coordinator - he will not participate in discussions. Detailed responsibilities of the AGA Observer are attached as Annex.

Selection, qualities, disqualifications of the AGA Secretary

- The first AGA secretary will be appointment by the AGA coordinator in close consultation with the NZC and NZT relevant teams and coached by the AGA coordinator. Subsequent AGA secretaries will be selected with some influence of the AGA coordinator and in a year the selection will be only by the AGA members.
- **Acceptable Qualities:** Commitment, humility, good at establishing relationships, leadership, charisma, a fair person, living by example, ability to learn, non judgemental - genuinely accepts other people, good listening skills, honesty, adherent to ARVs & drug free, punctual, loyalty
- **Disqualification:** Drug use, pushing drugs, abusive (verbal, physical), non adherent on ARVs.

Roles and Responsibilities of the AGA Secretary

- **Acceptable Qualities:** Commitment, humility, good at establishing relationships, leadership, charisma, a fair person, living by example, ability to learn, non judgemental - genuinely accepts other people, good listening skills, honesty, adherent to ARVs & drug free, punctual, loyalty
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- The meeting will begin with reading the definition, goals and specific objectives of AGA.
- The AGA Secretary will introduce a speaker from among AGA members to share her experiences. From time to time a speaker can be invited to speak on specific issues e.g. ART, drug use, relapse prevention, etc..
- The speaker will speak for approx 30 minutes maximum. Post which AGA members can share, identify and ask clarifications for approx 30 minutes.
- Speaker for the next meeting will be appointed by the AGA Secretary and announced.
- The meeting will close with the serenity prayer, and refreshments offered by the AGA organiser and AGA monitor.
- Transport fares will be disbursed by the AGA secretary and AGA organiser and signatures/thumb impressions recorded.

A G A

SELF HELP GROUPS INITIATED IN

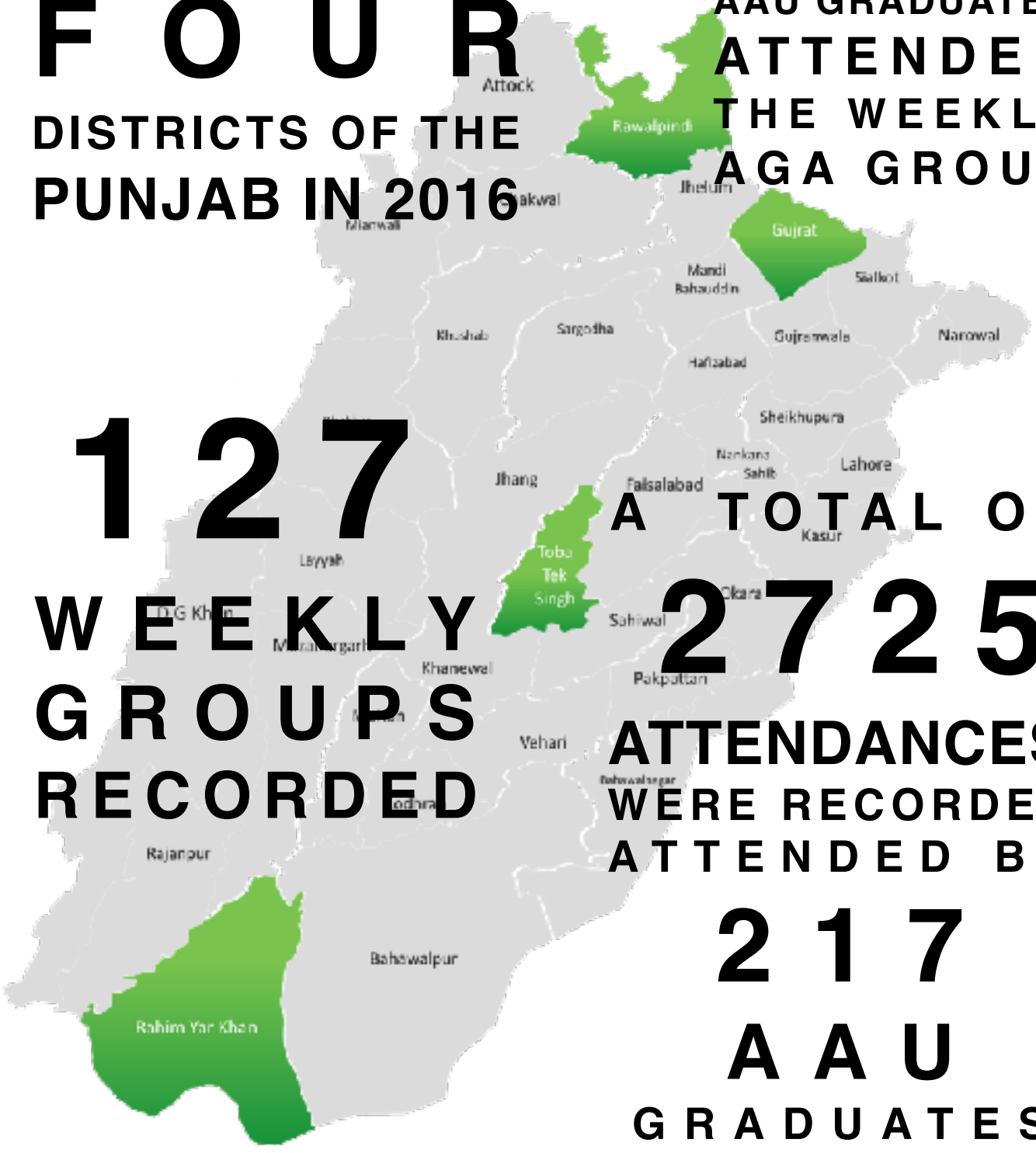
F O U R

DISTRICTS OF THE PUNJAB IN 2016

ON AN AVERAGE

2 0

AAU GRADUATES ATTENDED THE WEEKLY AGA GROUP



1 2 7

WEEKLY GROUPS RECORDED

A TOTAL OF

2 7 2 5

ATTENDANCES WERE RECORDED ATTENDED BY

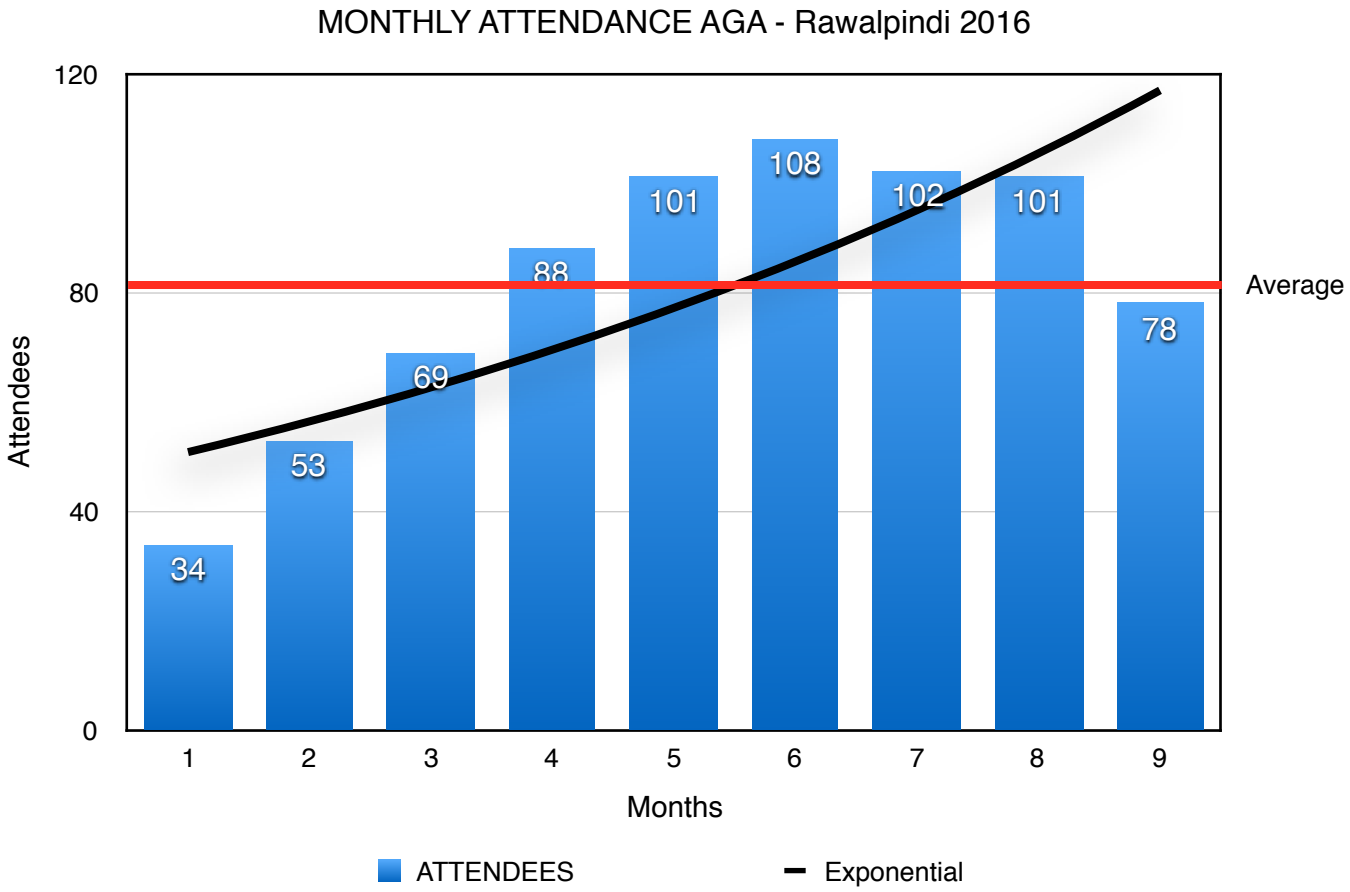
2 1 7

A A U

G R A D U A T E S

District wise AGA progress

RAWALPINDI DISTRICT



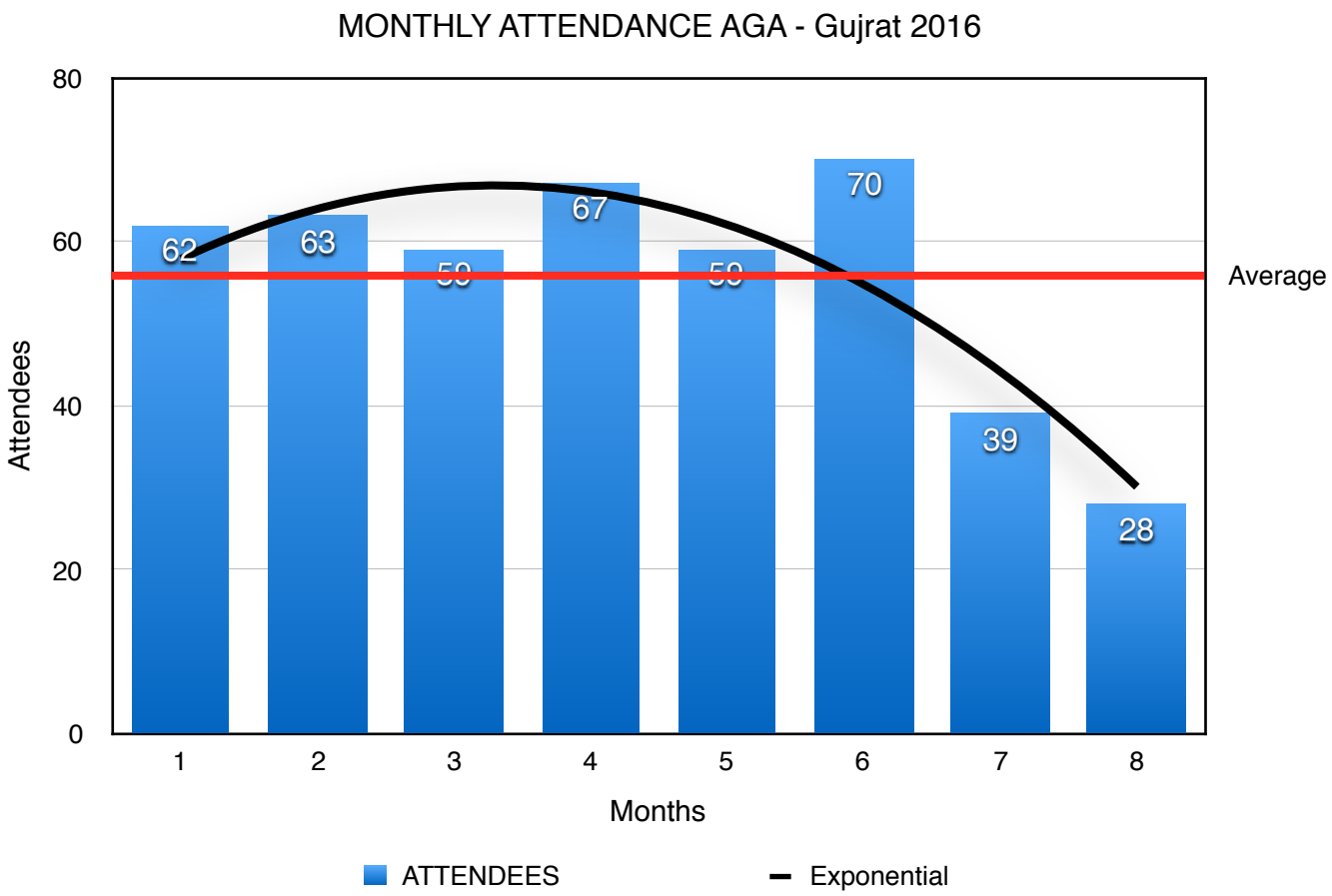
The first AGA self help group was held on 24 April 2016 in Rawalpindi after making the required arrangements which included orientation of CoPc+ staff were meetings would be held; allocation of space for meetings; explanation and clarity on rules & regulations etc..

A total number of 35 AGA self help groups were held since, with an average of 21 AGA members attending each group. The number of attendees varied between 6 to 31. The numbers stabilised post the 9th AGA meeting and gradually increased. Of the 734 attendees 64 were distinct AAU graduates, of which 40% were married, 61% using drugs and 20% employed.

All AGA members were adherent at the time of attending the AGA groups. Major findings of all AGA meetings are clubbed together later in the report.

Kindly note that month 9 only represents three weeks

GUJRAT DISTRICT

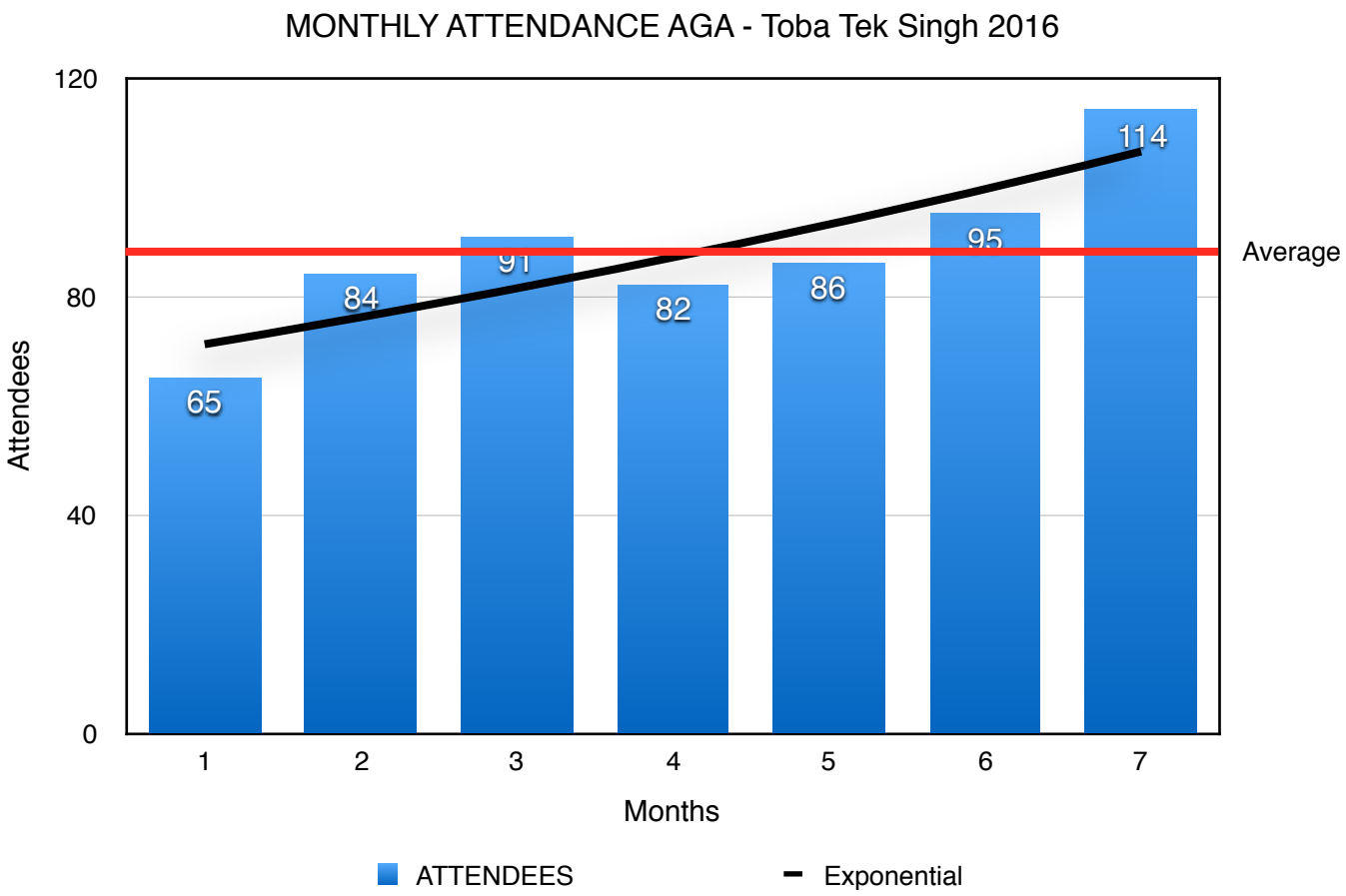


The second AGA self help group was started in Gujrat District on 21st May 2016 almost one month after Rawalpindi, under Nai Zindagi's Global Fund sub recipient namely Rutgers WPF.

A total number of 31 AGA self help groups were held since, with an average of approximately only 14 AGA members attending each group. The number of attendees varied between 7 to 21. Of the 447 attendees 46 were distinct AAU graduates, of which 47% were married, 47% using drugs and 36% employed.

Kindly note that month 8 only represents three weeks

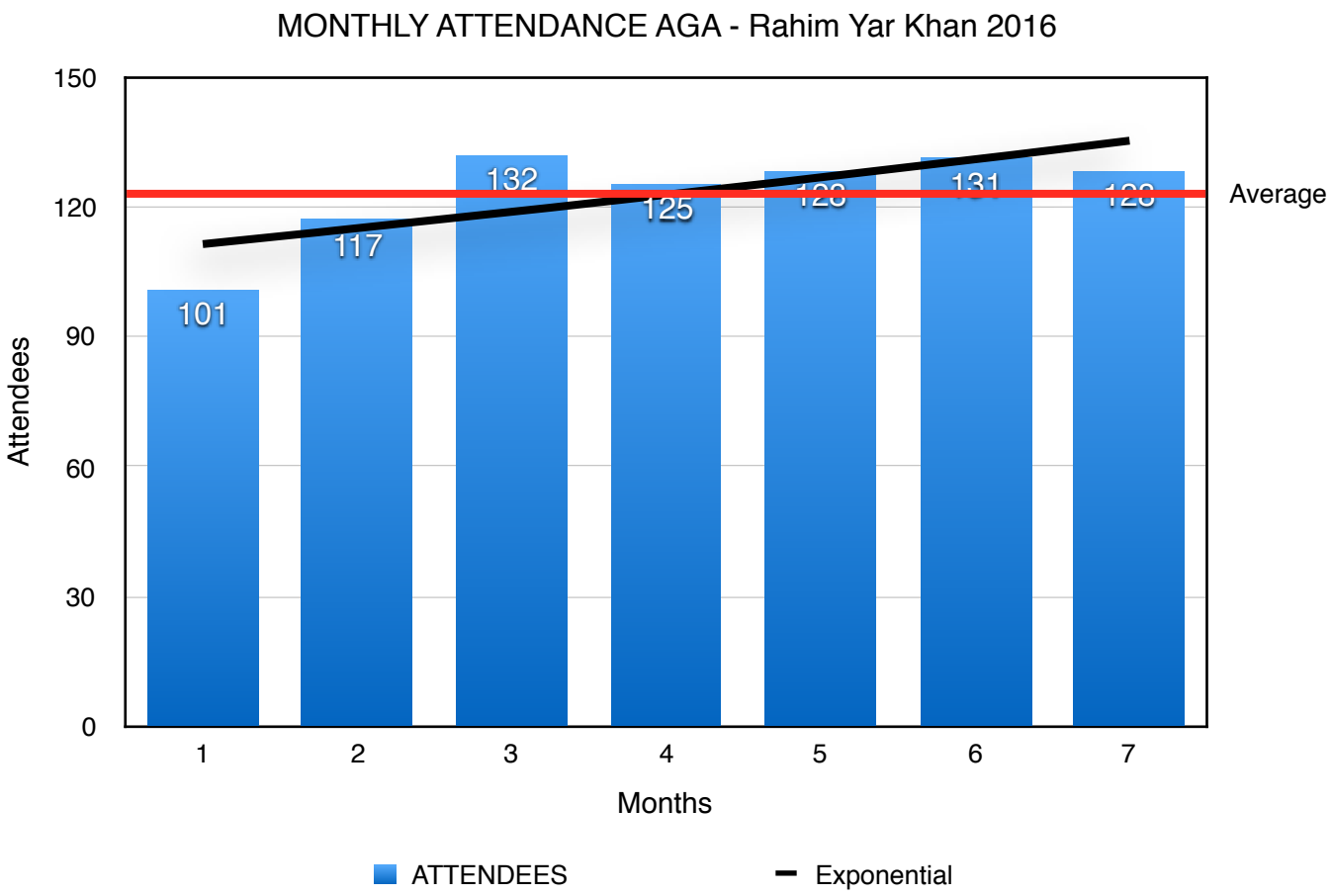
TOBA TEK SINGH DISTRICT



The third AGA self help group was started in Toba Tek Singh District on 6th June 2016.

A total number of 29 AGA self help groups were held since, with an average of approximately 30 AGA members attending each group. The number of attendees varied between 22 to 38. Of the 617 attendees 33 were distinct AAU graduates, of which 60% were married, 80% using drugs and 54% employed.

RAHIM YAR KHAN DISTRICT



The fourth AGA self help group was started in Rahim Yar Khan District on 21st June 2016.

A total number of 26 AGA self help groups were held since, with an average of approximately 21 AGA members attending each group. The number of attendees varied between 14 to 26. Of the 862 attendees 73 were distinct AAU graduates, of which 50% were married, 50% using drugs and 45% employed.

The AAU Graduates Families Alumnae

Goals

- To establish contact and strengthen relationships among members of AFA
- Engage members of AFA to share, learn and equip themselves with practical solutions/ways to improve their and client's quality of life and well being.
- To empower members of AFA to access HIV and AIDS related diagnostics and treatment for themselves and their family members.

Specific Objectives

- To provide a platform for sharing common experiences, situations, problems, conflicts or conditions faced by members of AFA in supporting and protecting themselves and their family members.
- To inform members of AFA on aspects related to psycho-social-emotional needs of clients undergoing treatment.
- To bring members of AFA together in order to gain strength and address their own psycho-social-emotional needs and associated problems.
- To inform members of AFA about ART adherence, discordant couple information, reproductive health and safer sexual practices.
- Equip members of AFA to mitigate stigma and discrimination.

AFA members in a group

The Methodology

- To recruit no more than 30 AFA members on a voluntary basis per city.
- To provide AFA members on a weekly basis a secure and non-judgemental platform (venue) to engage and share.
- To provide AFA members on a weekly basis transport costs and refreshments.
- To support and encourage AFA members to attend weekly meetings and engage within the framework of the goals and specific objectives of AFA.Structure of the Pilot

Structure of the Pilot

- To employ an AFA Country Coordinator who will be stationed in Islamabad to initiate 4 AFA city based self help groups. Detailed Job Description of the Coordinator will be developed.
- Each city based AFA self help group will have a designated and paid post (Rs. 5000) of a AFA Secretary from within the AFA members. This position will rotate every three months through voting by AFA members. Detailed responsibilities of the AFA Secretary will be developed.
- Each city based AFA self help group will have a designated AFA Organizer from within the AFA members. This position will rotate every three months through voting by AFA members. Detailed responsibilities of the AFA Organizer will be developed.
- Each city based AFA self help group will have a designated AFA Facilitator from within the AFA members. This position will rotate every three months through voting by AFA members. Detailed responsibilities of the AFA Facilitator will be developed.
- Each city based AFA self help group will have a designated AFA Observer - FORW of the CoPc+ site of the city if she is approved by AFA members. Her role is purely to observe, record and report to the AFA Country Coordinator - she will not participate in discussions. Detailed responsibilities of the AFA Observer will be developed.

Structure for AFA weekly meetings

- The AFA members will decide the fixed day and fixed time to meet at the venue for the weekly basis.
- Ground rules will be decided by AFA members, documented and displayed during the meeting. Definition, goals and specific objectives of AFA will also be displayed during the course of the meeting.
- Each AFA meeting will be no longer than one hour followed by refreshments. Attendance will be recorded in the attendance register.
- The meeting will begin with reading the Definition, goals and specific objectives of AFA.
- The AFA Secretary will introduce a speaker from among AFA members to share her experiences. From time to time a speaker can be invited to speak on specific issues e.g. ART, drug use, relapse prevention, etc..
- The speaker will speak for approx 30 minutes maximum . Post which AFA members can share, identify and ask clarifications for approx 30 minutes.
- Speaker for the next meeting will be appointed by the AFA Secretary and announced.
- The meeting will close with the serenity prayer, and refreshments offered by the AFA organiser and AFA monitor.

A F A

SELF HELP GROUPS INITIATED IN

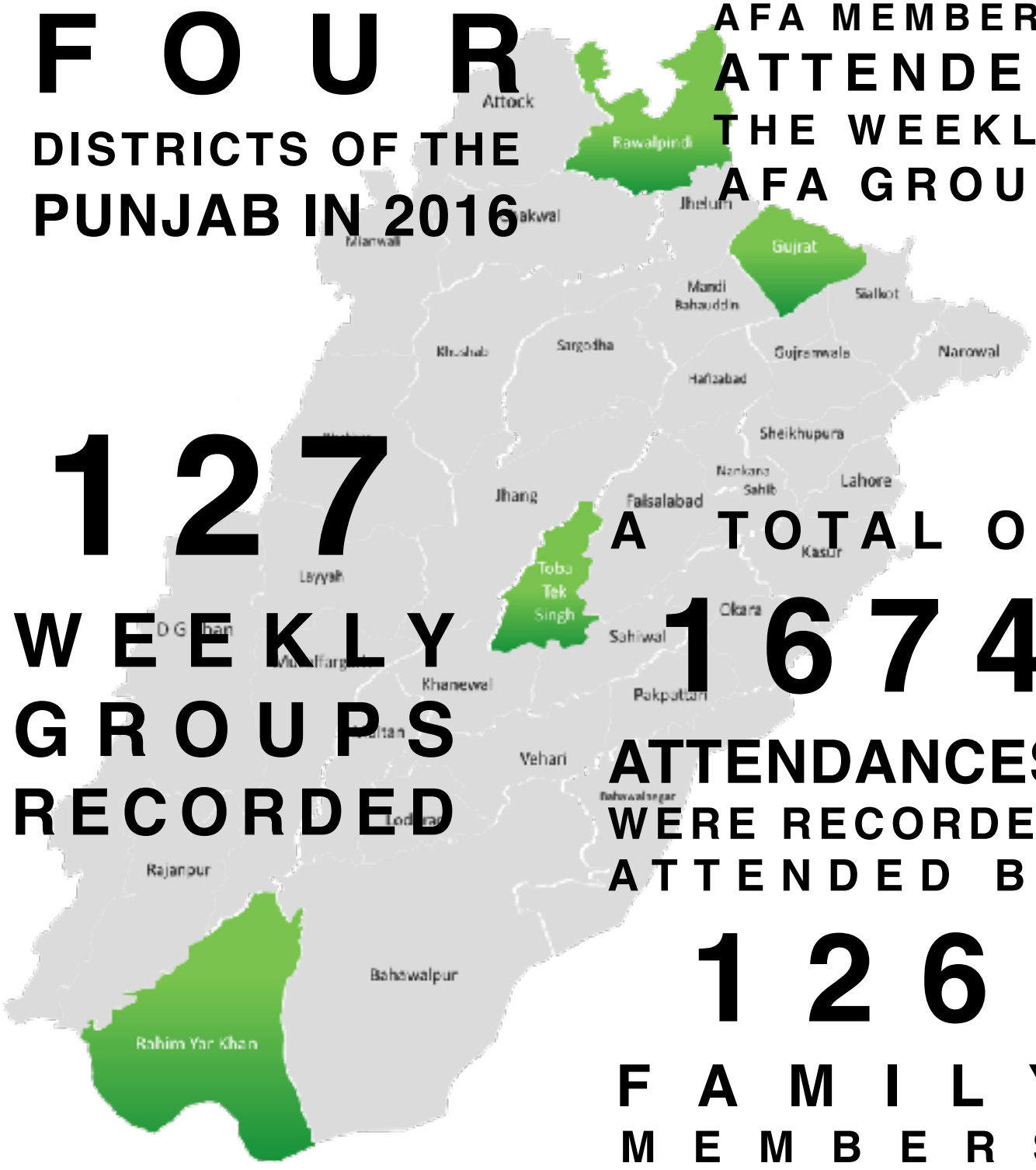
F O U R

DISTRICTS OF THE PUNJAB IN 2016

ON AN AVERAGE

1 3

AFA MEMBERS ATTENDED THE WEEKLY AFA GROUP



1 2 7

WEEKLY GROUPS RECORDED

A TOTAL OF

1 6 7 4

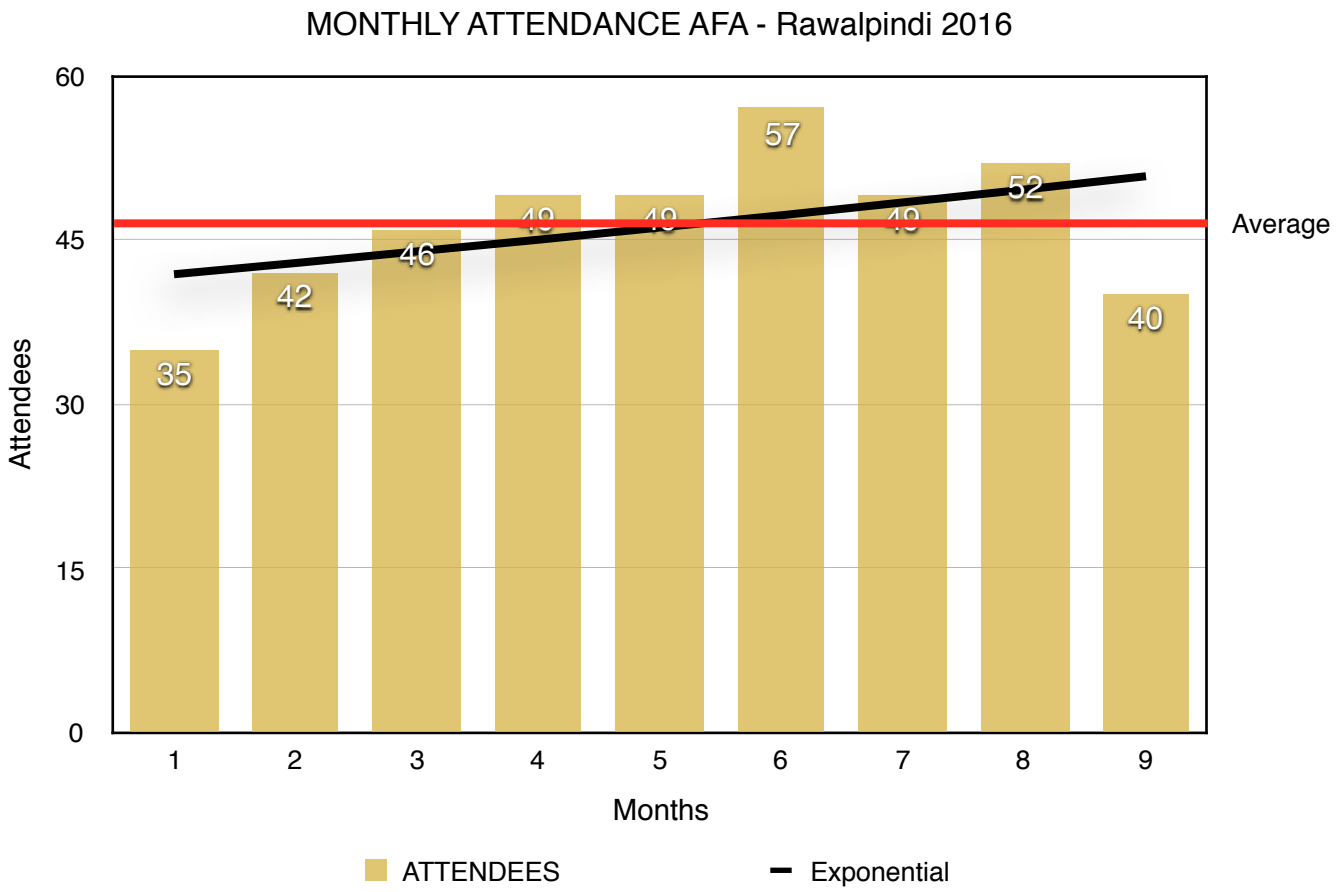
ATTENDANCES WERE RECORDED ATTENDED BY

1 2 6

F A M I L Y M E M B E R S

District wise AFA progress

RAWALPINDI DISTRICT



The first AFA self help group was held on 25 April 2016 in Rawalpindi after visiting and debriefing the relevant staff at the CoPc+ site office. Space within the CoPc+ was designated to hold the AFA group meeting.

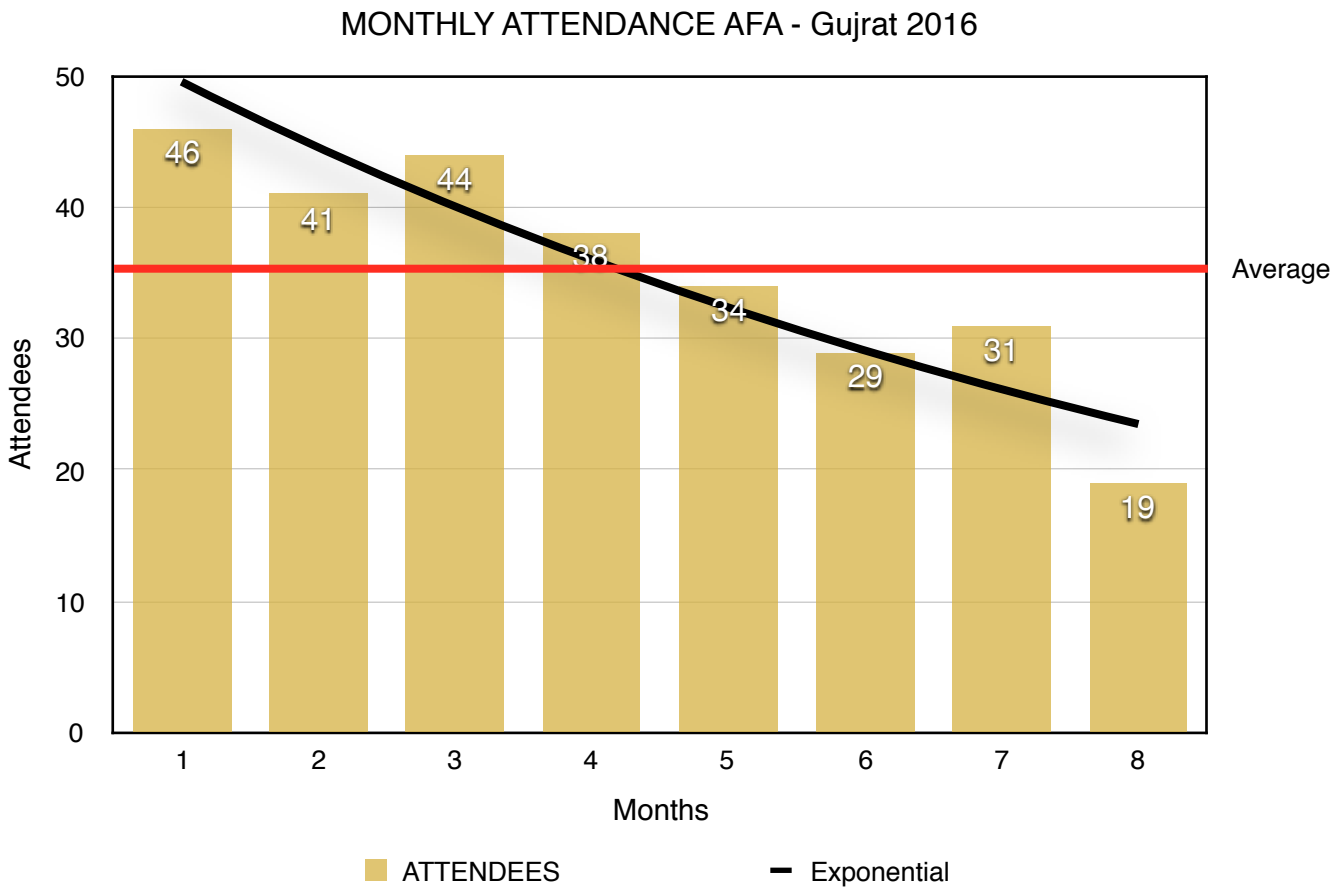
Goals, objectives, rules, regulations, roles and responsibilities of group secretary and facilitators were discussed, finalised and translated for ease and consistency to explain to AGA members.

A total number of 35 AFA self help groups were held since, with an average of 13 AFA members attending each group. The number of attendees varied between 8 to 17. Of the 441 attendees 41 were distinct AFA members, of which 42% were wives of AGA members and the rest mothers.

Kindly note that month 9 only represents three weeks

District wise AFA progress

GUJRAT DISTRICT



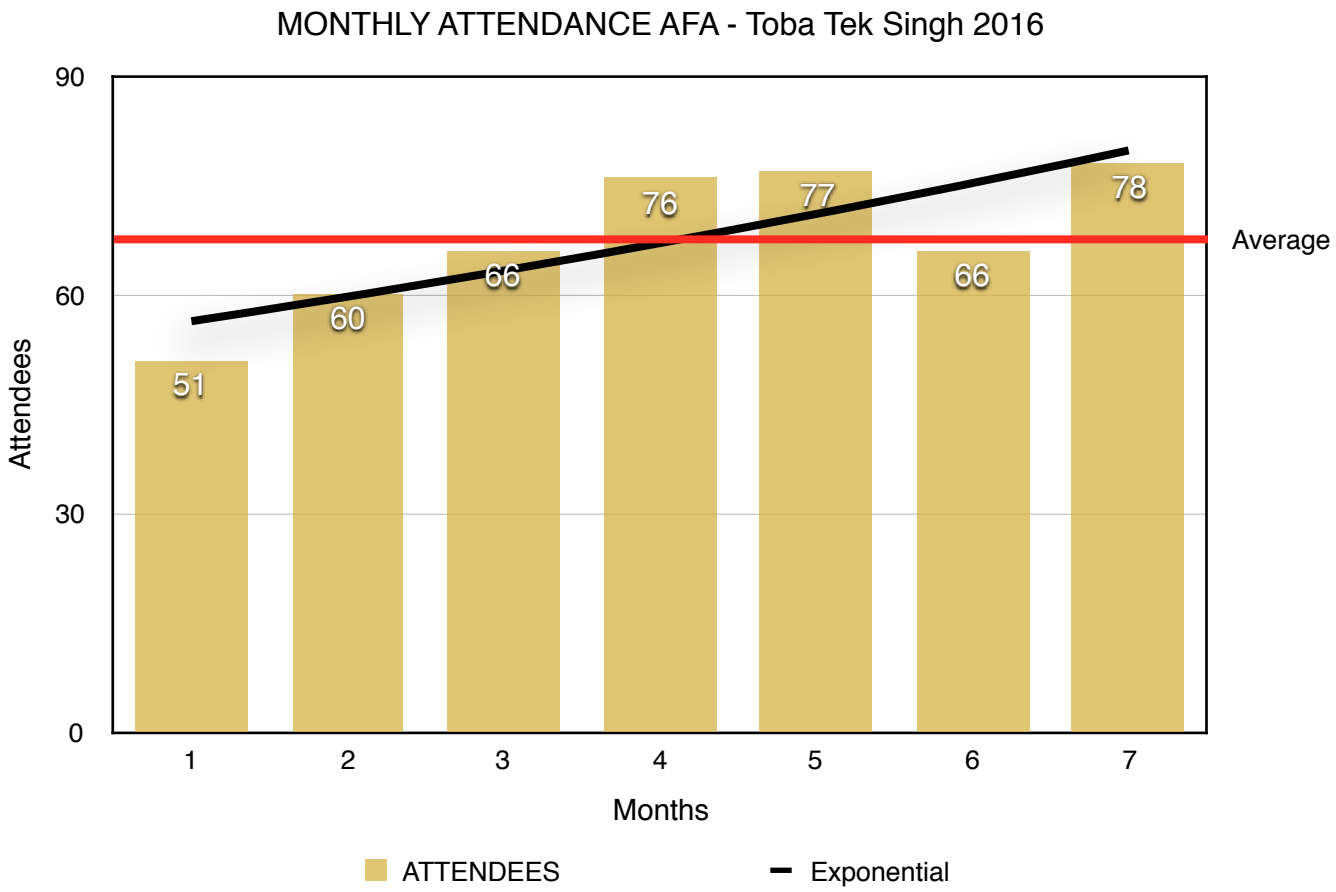
The second AFA self help group was held on 22nd May 2016 in Gujrat.

A total number of 31 AFA self help groups were held since, with an average of 9 AFA members attending each group. The number of attendees varied between 5 to 17. Of the 282 attendees 23 were distinct AFA members, of which 74% were wives of AGA members and the rest mothers.

Kindly note that month 8 only represents three weeks

District wise AFA progress

TOBA TEK SINGH DISTRICT

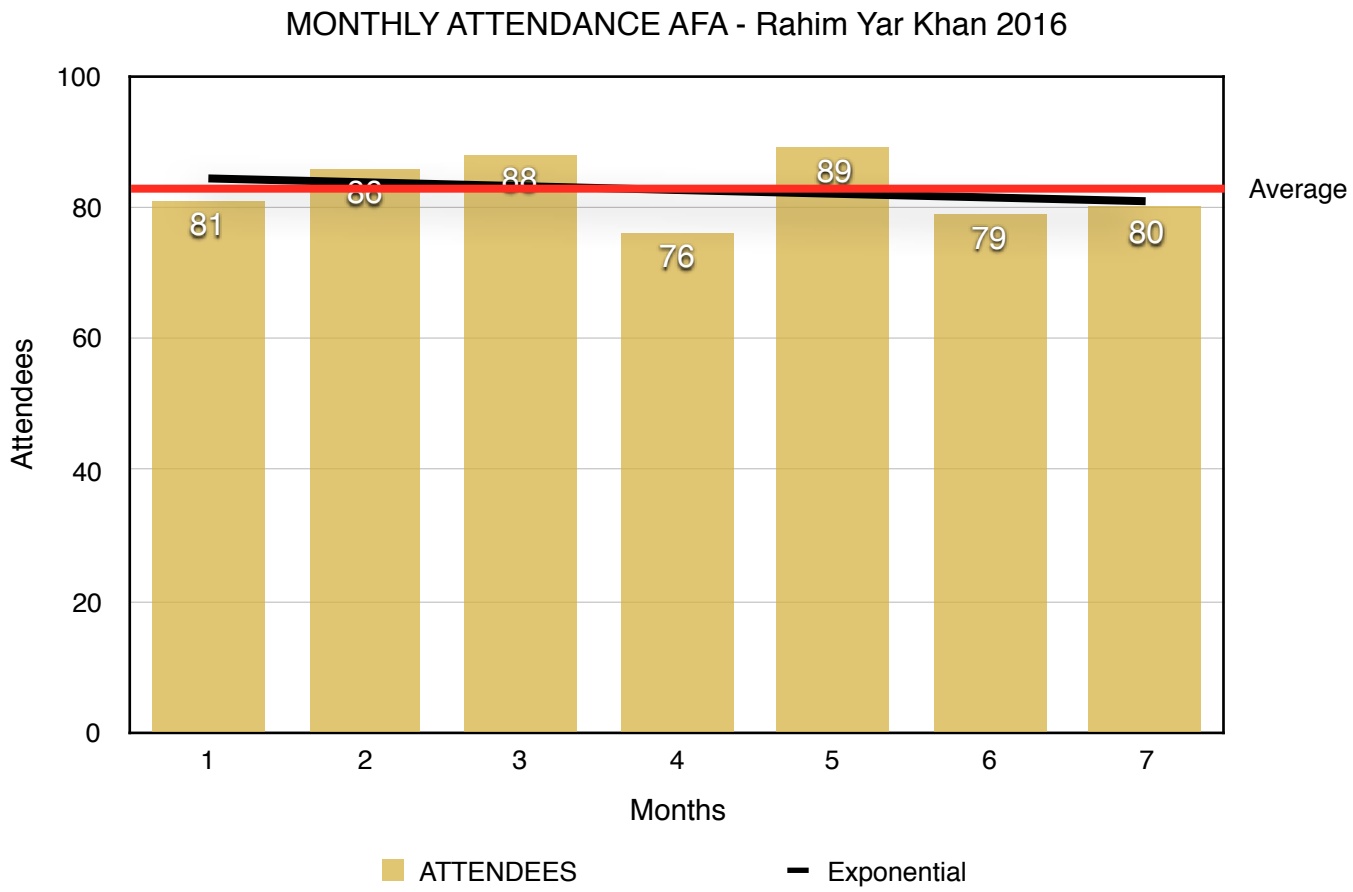


The third AFA self help group was held on 22nd May 2016 in Toba Tek Singh.

A total number of 29 AFA self help groups were held since, with an average of 16 AFA members attending each group. The number of attendees varied between 11 to 22. Of the 474 attendees 30 were distinct AFA members, of which 63% were wives of AGA members and the 17% mothers, while rest were other family members.

District wise AFA progress

RAHIM YAR KHAN DISTRICT



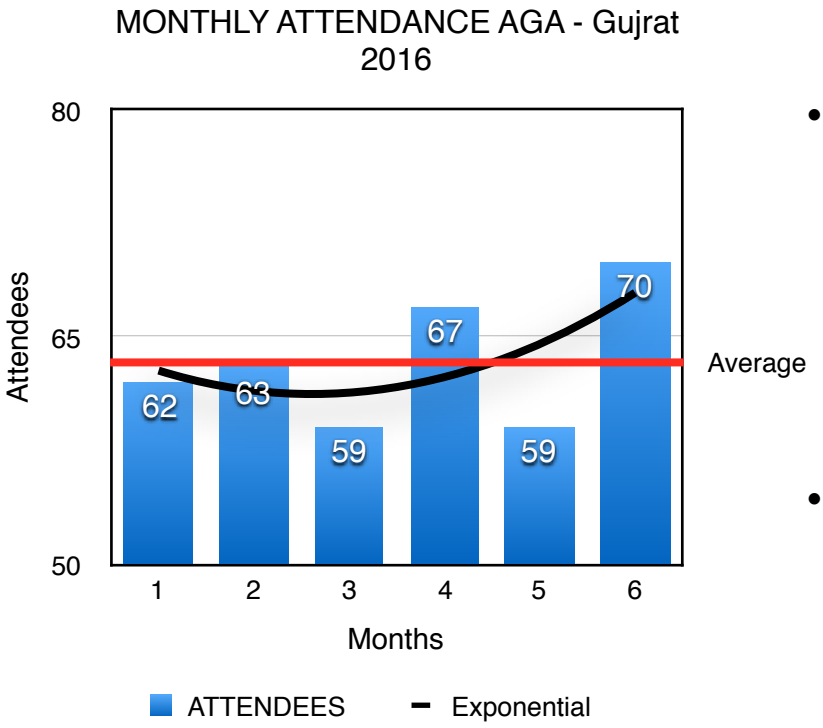
The fourth AFA self help group was held on 21st June 2016 in Rahim Yar Khan

A total number of 26 AFA self help groups were held since, with an average of 21 AFA members attending each group. The number of attendees varied between 16 to 28. Of the 579 attendees 28 were distinct AFA members, of which 85% were wives of AGA members and the rest mothers.

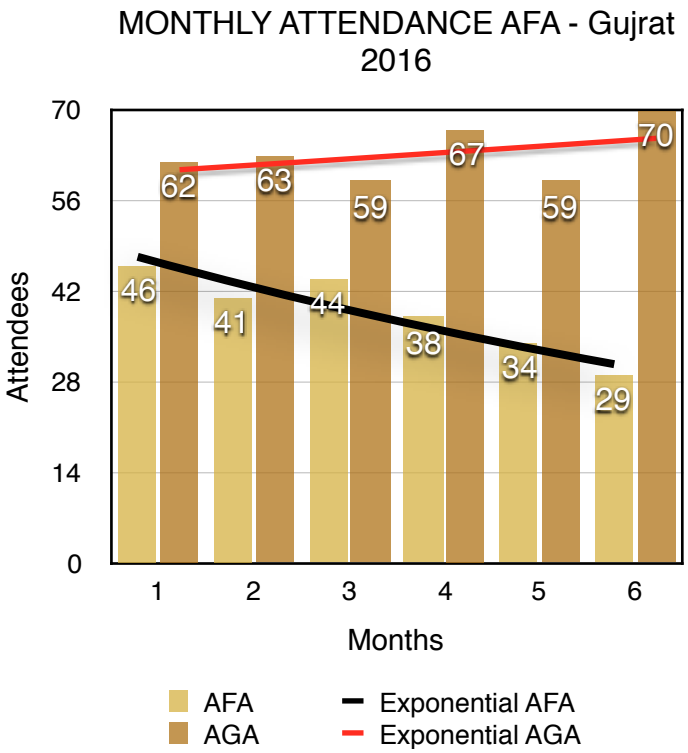
Additional information

GUJRAT DISTRICT

Attendance in the Gujrat District has seen a decline of both AGA and AFA members. To better understand this decline kindly note the following:



- If we remove the last two months the scenario in terms of attendance in Gujrat changes. On inquiry it was discovered that Rutgers re-allocated space where AGA and AFA groups were held to other activities which resulted in declining attendance, due to privacy related issues.
- Distance from Copc+ site, high staff turnover in Gujrat (resulting in loss of contact of clients and families with previous social mobiliser) is one of the major reasons as well.



- Even by removing the last two months there still is a decrease in the attendance of the AFA members.
- It was also observed that in Gujrat almost **50% of AGA members were non-adherent** where as in other cities almost 100% were adherent.
- The complexity of Gujrat District will need to be further explored and understood.

OVERALL AVERAGE WEEKLY ATTENDANCE

- The average attendance of AGA and AFA members was the highest in Rahim Yet Khan district and lowest in Gujrat.
- In Rahim Yar Khan the weekly attendance of AGA members exceeded 40 attendees and that of AFA members approximately 20 attendees.
- There are definitely lessons to be learnt from Rahim Yar Khan and shared among other sites.

NATURE OF AFA FAMILY MEMBERS

- Of the 126 distinct family members who attended the AFA meetings 64% (81) were wives; the highest percentage of wives attending the AFA meetings were in Rahim Yar Khan, followed by Gujrat, Toba Tek Singh and Rawalpindi.
- Other distinct AFA attendees 32% (40) were mothers of AGA members and 4% family members (sister, aunt, etc..)

DRUG USE AMONG AGA MEMBERS

- Highest drug use among AGA members was in Toba Tek Singh (65%), followed by Rawalpindi (60%); Gujrat (58%) and Rahim Yar Khan (45%).
- Although with over 50% drug use among AGA members, adherence was almost 100% except for Gujrat where 50% were non adherent.

EMPLOYMENT STATUS OF AGA MEMBERS

- Highest employment among AGA members was in Rahim Yar Khan (50%), followed by Toba Tek Singh (43%); Gujrat 35% and Rawalpindi (20%)
- Overall 37% of AGA members in all districts were employed.

KEY POSITIONS

- Three key positions by rotation were allocated to each AGA and AFA group. The positions in each group were that of the group secretary, group organiser and group facilitator. These positions were elected by the group and were paid a stipend during their tenures.
- Group secretaries rotated during this period (AGA -12; AFA 13)
- Group organisers rotated during this period (AGA12; AFA 13)
- Group facilitators rotated during this period (AGA 12; AFA 14)

Additional Outcomes

The AGA and AFA meetings resulted in additional outcomes as a result of a structured, well defined and organised structure of the self help groups. Main areas are mentioned below:

- **An improved family support system:** Importance of disclosure; improved family re-integration; an increased sense of responsibility; families developed a support system for improved ARTs adherence; positive relationships among group members led to a better understanding of problems, issues and realities; generally a more positive and less blaming and mistrusting environment; a general sense of belonging and not in isolation any longer.
- **Improved knowledge:** improved knowledge about ARVs; improved knowledge about dosage of ARVS; demystify myths around ARVs; safer sexual practices; improved knowledge about STIs; knowing their rights to cope with stigma and discrimination.
- **Coping with relapse and relapse prevention:** motivation for self detoxification; coping with drug use (understanding chaotic use to function use); identifying triggers that lead to relapse and how to mitigate relapse; importance of ART adherence during relapse.
- **Leadership and financial support:** holding key positions in groups resulted in confidence building and improved financial status; encouragement to seek employment for an improved quality of life.

Conclusions

- In line with the **goals** and **specific objectives** of the AGA and AFA self help groups this pilot managed to establish contact and strengthen relationships among members; engage members to share, learn solutions/ways to improve their quality of life and well being; provide support for psycho-social-emotional needs including managing relapse; understand the importance of ART adherence, better nutrition, health care and safer sexual practices.
- **Adherence** among AGA members in 3 cities of Rahim Yar Khan, Toba Tek Singh and Rawalpindi remained 100% - whereas if we combine Gujrat (with 50% non adherent members) - the overall adherence remains 90%, which is by far the highest so far experienced or recorded. (The In Touch program and the AAU Evaluation mention adherence rates between (65-75%)).
- Although **drug use** among AGA members varies between 65-45% adherence rates are substantially high (90%). The AGA and AFA support groups provide a regular, consistent and on going platform that does not judge drug use - and instead provides practical tools to cope and remain functional.
- The combination of AGA and AFA groups meeting regularly also results in a better understanding of drug use and related family dynamics. Families do not remain isolated and in fear, but are able to correlate and share feelings and emotions. A better home environment of increasing trust has also resulted in **higher employment** rates (37%) among AGA members.

Conclusions

- **Wives** of AGA members represented 65% of the AFA group. The AFA groups have provided them with a platform to engage, share, understand and gradually move from the position of an 'isolated victim'.
- **Crisis management** among AFA members due to the AFA groups has been a key achievement. AFA members stay in contact beyond the AFA meetings and support each other in crisis related to drug use, relapse and/or dealing with issues with law enforcement.
- Most AFA members have expressed that the self help groups provide them with a **space away** from their daily routines where they can learn and also have moments of fun and laughter. The burden of having a husband or a son who is using drugs and HIV positive is often lightened when they witness other AFA members who are living normal happy lives and coping with reality.
- **Guilt** has been a major factor that has often blocked AFA members to act and has often resulted in **mis directed anger** or **depression**. The catharsis that takes place during the AFA meetings helps AFA members to off-load past and re-load positive thoughts of understanding, forgiving, letting go and moving on with life.
- The AFA groups have **empowered** wives and mothers of AGA members to better relate to the AGA members and draw **boundaries** as far as expectations from each other are concerned. This has resulted in less conflict, and if it does arise the AFA and AGA groups provide that platform for conflict resolution.

Recommendations

It is essential to understand that the first AGA and AFA groups started in April 2016 and have been expanded to other districts over the next 9 months. The pilot is still in its infancy and will evolve organically over 2017, with expansion to two new districts in collaboration with support from Mainline. The following recommendations will help further improve outcomes of the AGA and AFA support groups:

- **Leadership:** To identify leaders in the AGA and AFA groups and link them to the District AIDS Councils (where they exist) to voice their concerns and needs. After identifying leaders to first conduct a basic leadership training course for those identified.
- **Report and record human rights violations:** This has been a weak area and a system could be proposed to record human rights violations, stigma and discrimination that members come across and report it to relevant persons/authorities to mitigate such instances.
- **Networking:** Plan and implement inter district exchanges between AGA and AFA groups/members to further exchange ideas, information and extended support.
- **Non adherent AGA members:** To investigate reasons for non adherence among AGA members (particularly in Gujrat at this point) and develop a plan to further reduce non adherence. The goal should be 100% adherence.
- **Handbook:** Based on two years (2016-2017) of the pilot develop a handbook of how to initiate similar self help groups with specific focus for specific communities among key populations.