FAST-TRACK
CITIES
LONDON

Reflections from the HIV Empowerment Programme

April 2023

ACKNOWLEDGEMENTS

A special thank you to all those who were involved in delivering the Fast-Track Cities London Empowerment Programme Framework to tackle internalised stigma in 2022-2023 and participating in the action learning sets to share their good practice and learning. We are thankful for their contribution in this reflections report.

The action learning sets were facilitated by:

CONTENTS

INTRODUCTION

Fast-Track Cities (FTC) is a global movement to end HIV by 2030. London is already leading the way in diagnosis and treatment but is now aiming to be the first city in the world to end new cases of HIV. London wants to get to zero new HIV infections, zero preventable deaths and zero stigma by 2030, making sure everyone with HIV is living well.

In 2020 a community of practice (COP) was formed by the Fast-Track Cities Stigma London Subgroup to come together to share best practice and develop an adaptable framework for an Empowerment Programme for people living with HIV (PLWHIV) who experience internalised/self-stigma. The COP comprised of eight organisations with specialist experience in supporting those living with HIV, facilitated by Healthy Dialogues. The resulting Fast-Track Cities London - A framework for empowerment programmes to tackle internalised stigma was published in October 2021.

In January 2021 the Stigma Sub-group commissioned six local organisations to deliver the Empowerment Programme Framework to support people living with HIV to develop resilience, confidence, and other skills to tackle self-stigma.

The key outcomes for individuals completing the Empowerment Programme were to:

- Develop a support network
- Understand internalised/self-stigma
- Understand what HIV is, U=U and living well with HIV
- Build self-acceptance, self-esteem, and an individual’s sense of power

Voluntary sector organisations were commissioned to deliver the programme targeting specific populations in London most in need of this type of support. The programme would have two key objectives:

1. Empowering the HIV community to tackle self-stigma through development and support:
    - Organisations will deliver their programmes (for a contract length of 1 year) aimed at the specific groups identified in stage 1 with a high level of need.
    - Programmes submit evaluation reports after their first cohort, and present their learning with the Community of Practice
    - Adjustments are made in a reviewed plan for the next cohort to continue to hone and improve.
2. Collaborate on the development and delivery of a training programme to support the development of a group of HIV ambassadors, to be hosted and managed by the London FTCI programme. The ambassadors would be visible voices, sharing their stories the HIV community and the wider public.

This report presents each of the empowerment programmes, reflections from their collective learning and case studies that emerged from them.

POSITIVE EAST

The target community was diverse including African communities, women and gay men.

Programme approach

Three courses were delivered, each running over five sessions targeting different cohorts. The aims of the courses were to:

- Give participants the opportunity to explore, address and reframe the negative and debilitating impact of internalised stigma.
- Reduce isolation and to seek ways to develop a support network.
- Regain power with understanding of U=U, and how to use it effectively in relationships with self and others.
- Build a positive relationship with self, increase self-esteem and develop new skills to live a life free of internalised stigma.

Evaluation surveys collated participants wellbeing, self-esteem and self-stigma before and after participants completed the empowerment programme to understand the impact of the programme.

Summary of programme year

1. Women
2. Online mixed group and African communities
3. Gay men

The first course targeted Women. It was delivered in-person from May 2022 over a series of half-days (10am-2pm) on Saturdays. Lunch, travel expenses and a creche were provided. A total of nine participants successfully completed the course.

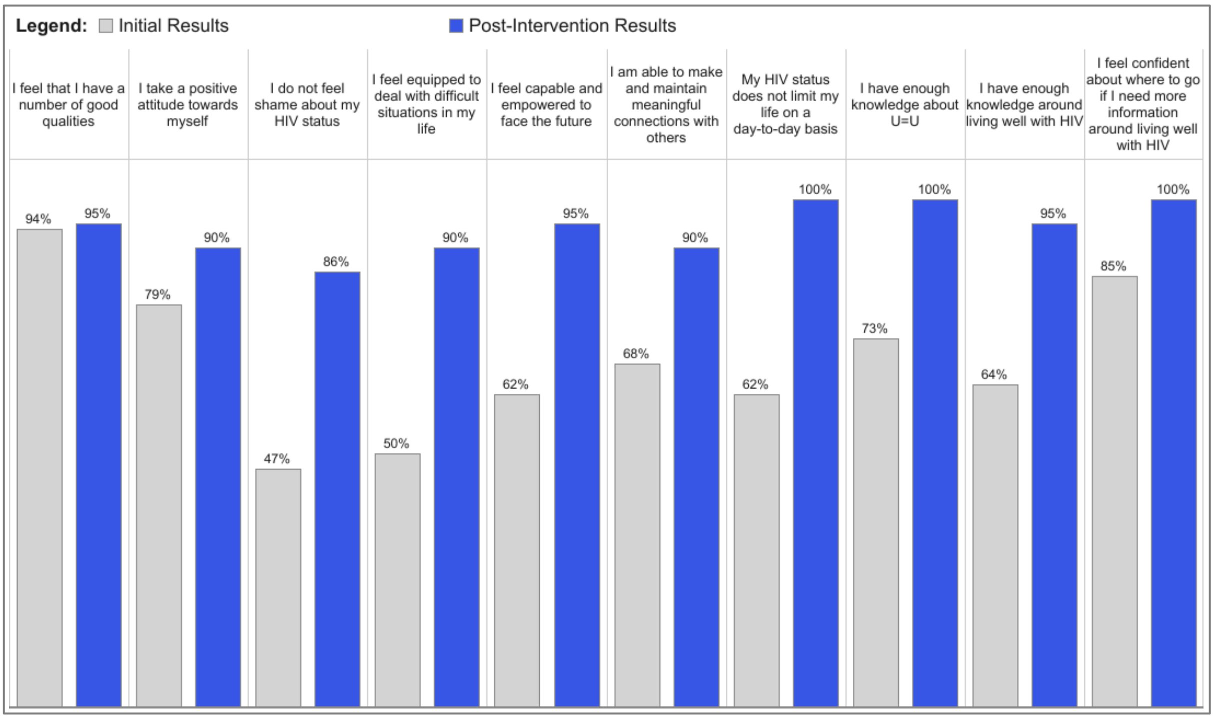
The second group targeted a mixed group of people from diverse and African communities. It was delivered online via zoom over a series of five half-days on (10am-2pm) Saturdays from September 2022. A total of nine participants successfully completed the course.

The third group targeted gay men. It was delivered in-person on Saturdays (10am-2pm) in January 2023 over five half days. Lunch and travel expenses were provided. A total of 11 participants successfully completed the course.

Handouts and a list of HIV services and resources were provided and all participants who completed the Empowerment and Stigma course received certificate of attendance.

The evaluation surveys of all courses showed a marked increase in all measures of wellbeing, self-esteem, and self-stigma following the course, except for on one statement: “I feel that I have a number of good qualities” where scores were already high (see figure 1).

Figure 1: Positive East Empowerment Programme pre-(initial) and post-intervention survey results for Cohort 3



Feedback from participants was very positive, with some mentioning that more of such empowerment groups were needed, and that “All the facilitators were amazing, very supportive and knowledgeable on the subjects discussed.”

When asked what they would take away from the training, participants mentioned a range of different topics including, U=U, self-advocacy, better connection with others, self-confidence, and medication.

A number of case studies were provided by participants that highlight the impact the programme had on them. They are presented in the Appendix: Positive East Empowerment Programme case studies

Feedback from participants

Feedback from participants on what they will do differently as a result of the programme:

> *“To love myself by having more confidence and believing in myself, try to forgive and stop the worrying and blaming myself.”*
>
> *“Appreciate myself and be more compassionate to myself.” “Try to love myself again, have me time, think of me again”*

“I learnt the importance of taking treatment at the same time everyday so that the treatment continues to work”

“Thank you! for today's seminar. I have never felt comfortable in a group of women, or speaking with group of strangers, period, - unlike today. So, Thank you for the epiphanies and smiles. I'm looking forward to the next week.”

“I have realised that I have more of a voice then I thought and thought I had lost it but have it! Would like to work with young people to help bring change.”

“I have learnt to accept and talk about my HIV now and to go at my pace, it's my journey.”

“I gained more information on U=U, the concept gives me hope and freedom to have sex”

“Self-love and stop absorbing more negativity. I appreciate and grateful to be alive. Be happy, Kuma Tada”

“I am always ready to help in churches and to my community to raise awareness”

“A journey of self-discovery and more self-aware now of how I rely on others that influence how I feel and my emotions.”

“I am now going to stop thinking what others think about me and stop putting and caring for others first and forgetting about myself.”

“I know how to remove stigma from my life now. Before I was not able to understand stigma or able to remove it when I had psychological work with my therapist.”

4 M MENTOR MOTHERS NETWORK & NAM AIDS MAP

The target community was African/Afro-Caribbean and migrant women disproportionately affected by HIV who face multi-layered challenges and/or stigma.

Programme approach

The programmes incorporated ongoing inclusion of the women's voices, experiences, and expertise in addressing stigma. They utilised participatory, creative, person-centred approaches with a mixture of virtual and in-person interactive methods of training delivery.

The in-person programme was delivered by 4M Network of Mentor Mothers in St Lukes' Community Centre, London. It was delivered as a hybrid event as a 6-hour interactive workshop. The workshop included peer support, creative writing, mindfulness, information, dancing, exchange, group discussions and skills development.

Seventy women registered and 55 attended (30 face-to-face and 25 virtual). These included women who had previously attended virtual sessions and those who were attending for the first time.

Participants also provided and received peer support, shared information, related updates and creative writings via online support group hosted on the WhatsApp platform.

In addition, 4 M Mentor Mothers Network collaborated with NAM and the programme participants to create empowering videos that were shared on social media and in training throughout the duration of the project.

Topics of the videos included (follow the links):

- U=U featuring Dr Vanessa Apea
- HIV, sex & relationships featuring Dr Shema Tariq, Dr Naomi Sutton & Angelina Namiba.
- HIV & Pregnancy featuring Professor Yvonne Gilleece & Rebecca Mbewe.
- Making U=U t-shirts in conversation with Angelina Namiba & Susan Cole
- Quality of life by Estelle Ndungu & Rebecca Mbewe

Feedback from participants

Qualitative feedback of the programme was collated from participants by the programme facilitators. It captured what participants learned and enjoyed as well as what they will use from the programme. Some comments received from the feedback forms are presented below.

What I learned and enjoyed:

“Joy of sisterhood through dance”

“Life can be resilient”

“Sharing knowledge and experience”

“Laughter”

What I will use:

“Learning about adherence”

“Open to be more involved”

“Empathy”

“Freedom to get into relationships

A case study presenting this programme and evaluation findings are presented in the appendix:

4M Mentor Mothers Network CIC (4MNet) and NAM aidsmap Empowerment Programme Case Study.

Here is a creative writing piece created by one of the participants during the programme:

My journey
I rise from the ashes
I use them for grounding
I picked them up and made them sit

I'm still standing
Darts of life have made me multicolored Like a rainbow
In my surrender, it's only on the surface Inside it's me
I blow
The energy of challenge creates my experience Of growing my community

I've always had support
I belong to something bigger I have compassion for myself
What is life if I do not care for me?
Have faith, be brave

TERRENCE HIGGINS TRUST

The target community was a diverse group including: Gay, bisexual, and other men who have sex with men, and black African adults.

Programme approach

This programme was delivered to over four peer learning sessions to four cohort groups. The programme was available to any person living with HIV in London. Individuals were given the choice to attend in-person or online (via Zoom). They were also offered a one-to- one question and answer session prior to starting the programme.

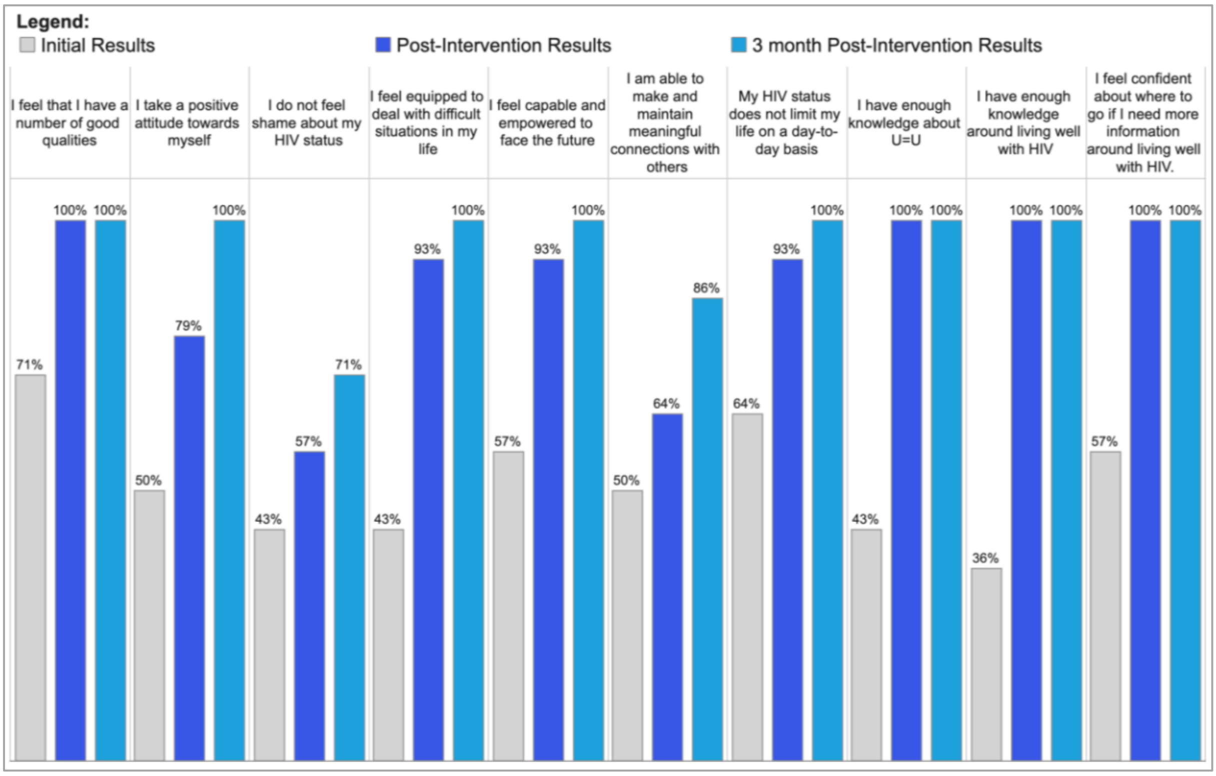
The sessions covered: understanding stigma and self–stigma, understanding HIV and U=U/can't pass it on, building confidence and self-esteem and building resilience for the future.

The sessions included interactive learning and video sharing, break out groups, sharing experiences and stories and fun and creative activities. A takeaway toolkit was provided to enable ongoing learning and reflection.

The programme also provided volunteer co-facilitating opportunities for participants from cohorts 1 and 2 to deliver cohorts 3 and 4.

Evaluation surveys collated participants wellbeing, self-esteem, and self-stigma before, after and three months after participants completed the empowerment programme. Fourteen participants completed both the pre-(initial) and post-intervention surveys and of those, seven completed the 3-month post intervention survey. The results are presented in Figure 2 below. They show that in all statements within the survey participants showed an improvement between pre-and post the programme, which was sustained or improved three months after the programme.

Figure 2: THT Empowerment Programme pre-(initial), post-intervention and 3-month post-intervention survey results.



The facilitator and two participants provided case studies to illustrate the delivery and impact of these empowerment programmes. They can be found in the appendix: Terence Higgins Trust Empowerment Programme Case Studies.

THE LOVE TANK

Programme approach

The programme aimed to involved a seven-session life-coaching programme developed in partnership with Life Clubs CIC, followed by monthly facilitated workshops. In the structured workshops the men would also devise and develop six online editions of a peer-produced magazine, monthly online events, and regular social media content. The online magazine and events will provide the peers of the men with information about empowerment, challenging stigma, and self-stigma, as well as signposting to services and peer support for men with HIV.

The aim of the programme was to encourage men to ‘take-action’ rather than be passive recipients of self-stigma challenging approaches. This might include learning steps for challenging stigma; advocating for better sexual or mental health services; and fighting trans and homophobia, racism and anti-migrant sentiments that impact on the well-being of marginalised men with HIV, and their peers.

The programme had a two-fold impact: Firstly, directly impacting the men themselves, and their self-esteem, including by creating a ‘community’ of men to work on a specific short-term project. Secondly, on the men (and their peers) who engage with the online content and events created by the project.

Several attempts were made to recruit men to groups (online and in person). However, uptake was low, with not enough sign-ups to make the groups viable.

The Love Tank focused in producing the magazine. The Love Tank then recruited gay men living with HIV to be contributors and content creators. This included training on writing and editing.

The project leads and content designers were gay men living with HIV (either gay men of colour and/or migrants), with the key project lead being a skilled and experienced peer- based group work facilitator and trainer.

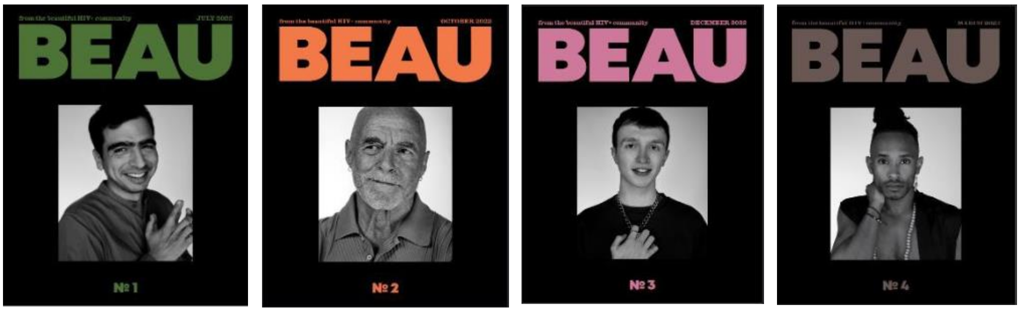
The result is a topical and beautifully presented magazine. The issues are focused on a range of topics including:

- Men under 25
- Men over 50
- Migrant men
- Black men
- The basics of HIV treatment and research
- Understanding CD4 + VL tests
- HIV + sex
- Chemsex

- MPox and HIV+ men
- Building resilience

By March 2023 there were 2,541 views of the magazine. Here are the numbers of downloads each magazine generated:

- Issue 3: 82
- Issue 2: 91
- Issue 1: 133



Beau Magazine is published online and can be viewed here.

POSITIVELY UK

The target community was a diverse group of people who experienced internalised stigma, to the extent that it negatively impacted engagement in medical care or confidence in accessing additional external HIV support. The participants were recruited within two HIV clinics, at North Middlesex & Homerton Hospitals.

Programme approach

The programme was delivered within the two clinics, as participants were unlikely to attend external workshops. The programme was developed to include seven workshops topics as stepping stones to dismantling stigma over seven weeks, with modules gradually building knowledge, confidence and connections. The seven topics were:

1. External perceptions and their role in shaping our own perceptions (negative media, etc.)
2. Exploring personal beliefs (understanding diversity/inequalities/privilege, window of the world/tree of life - how our background may shape our perceptions/responses)
3. Understanding HIV, transmission, U=U
4. Talking to others about HIV (who/why/what/when/how do we tell?)
5. Advocacy/assertiveness/effective communication (meeting our health/wellbeing needs, self-advocacy at workplace and intimate needs)
6. Developing pride and empowerment (creative tools to identify/explore personal strengths, community engagement opportunities)
7. Sharing our self-love with others (community building, empowerment connections)

The programme was continually adapted and improved in response to participants reactions and feedback, including reducing the number of workshops to six after the first cohort by merging sessions 6 and 7.

In our first cohort in North Middlesex, we had 20 referrals from healthcare team in Alexander Pringle Centre. 17 of these showed interest but only five attended, with most attending one or two sessions but not all. The main reason for not sustaining engagement was work shifts and not being able to take time off to attend. Socio-economic status of participants played a significant role in their attendance.

None of those referred had ever engaged with other people living with HIV or talked about their status with anyone but their clinicians. The planned seven-session programme wasn't fully delivered as intended, as we had to adapt based on the new and changing participants. The most frequently discussed topics were HIV facts, science and treatment and how to share our status with others. The post-workshop evaluations showed slight increases in all results but the largest was in knowledge about U=U and living well with HIV as well as dealing with difficult situations in their lives.

One participant quoted:

> *"I have been motivated by the sessions in the workshop but unfortunately attended only one. I still have a long way to compose myself and will be happy to continue with future sessions. The group was excellent. Thank you so much to everyone."*

At the end of the session all participants agreed to register with Positively UK services to get further support, which was a huge step forwards from their starting point.

Our second cohort was at Homerton Hospital, where we received 14 referrals from the peer navigators in the clinic. Twelve of these showed interest and seven participated. Given the integrated peer navigator service within the clinic, all had previously accessed one-to-one peer support but few had ever been in a group support setting.

In contrast to the first cohort in North Middlesex we had regular participants show up to all sessions, making it possible to deliver the programme as planned. Language barriers and learning difficulties made understanding and answering the pre-evaluation survey challenging and we received feedback regarding this. Even though we provided support to complete it, they found it hard to understand and answer the questions.

We paid special attention to base the sessions on life experiences and conversations and we didn't focus on HIV alone. Instead, we explored other challenges that participants went through in their lives and tried to help them understand their strengths and apply it to their life with HIV.

The last cohort of the programme returned to the North Middlesex Hospital. We received 16 referrals, eight showed interest, but only three participated. Again, work shifts, general health issues or self-stigma were the reasons for low attendance. Many of the referrals had past disengagement from care. Our main struggle within the cohort was language, since one participant was Turkish and didn't know English well. Luckily, our facilitator was Turkish, and so covered sessions in both languages, where ironically, low attendance was a benefit.

Adjusting sessions to a more conversational and Q&A style also helped us greatly.

All three cohorts were from very diverse backgrounds and demographics - the large majority being migrants to the UK. Our evaluation survey results showed an increase across all questions around wellbeing, self-esteem, and self-stigma. We also noted that people who are accessing integrated peer support already have greater confidence around living with HIV. However, their main challenge was stigma in the wider healthcare system and racism. Many had experienced and therefore expected stigma in healthcare and several spoke about changing GPs or not being supported by their dentists or GPs, due to their HIV status.

Feedback from participants

> *"I feel like I have gained a lot from the workshops and have much to take with me. I loved the pace and was given time to move at my own speed without ever feeling any pressure."*
>
> *"Found in my first time since being diagnosed I felt comfortable being around others who were also HIV+"*

> *Great information gained around being undetectable and finding put what if any I had to disclose my diagnosis legally or personally"*
>
> *"It's help me understand more about HIV. Make me feel bit better about knowledge of my treatment I have. I start feel bit easy in my mind about HIV"*

In the final round of workshops, a female participant who attended the first cohort in North Middlesex came back to share how empowered she felt after the workshops, which encouraged her to share her status with her partner. The participant said she is no longer "torturing herself" because our sessions made her understand how U=U is possible. She was able to answer all questions her partner raised and even brought him to the clinic so that he could speak to the HIV consultant. She shared that she was living her best life, not letting HIV stop her in any way. This was a great experience to have, and it was amazing to see the impact of the programme in real life.

Conclusions

Across all three cohorts, improving understanding of HIV science/treatment was key, helping participants to better understand the condition and having this information delivered by peers empowered people in a different way. Although many had heard of U=U from their healthcare providers, few genuinely understood or believed it until our sessions, which acted as a myth busting opportunity, allowing us to answer participants' questions around HIV and address those that were incorrect or misunderstood.

By the end of the programme, we concluded that integrated in-clinic peer support is genuinely life-changing for people living with HIV in helping to combat self-stigma and address external stigma. The Homerton cohort was empowered enough to fight for their rights and feel more confident in sharing their status, making meaningful connections more easily. They could focus on other challenges of their lives such as racism, unemployment, cost of life. In contrast, the North Middlesex Cohorts were reluctant to engage because they were still in denial or unwilling to talk to others and it is our belief that a group environment is probably not the easiest way to begin. Their work-life balance was also a challenge as they were working long hours in difficult shifts. Childcare and taking time off/arranging shifts was difficult because they didn't want to share their status with their employers and would not be paid for any leave. While we did see a few participants who managed to share their status with their children or partners, they still needed help from their clinical team/therapists.

In further support of this conclusion, the medical team at North Middlesex were so happy with our workshops within the clinic and feedback from participants that they secured funding to bring our Youth Team into the clinic for monthly peer support sessions. They are also about to commission additional adult peer support services in a tender agreed with their local authority.

METRO AND NAZ

This programme targeted marginalised groups within Latin American communities.

Programme approach

After the success of the My Message to You, five short films featuring Latin Americans living with HIV, Naz and Metro Charity have collaborated again to deliver Invisible Stories – Latin Americans living with HIV tackle stigma. This is a creative project that zeroes in on the experiences of three marginalised groups within Latin American communities; Trans people, Latin American MSM and Latin American women.

There is a high and increasing rate of new HIV diagnoses among Latin Americans, partly due to high rates of HIV stigma that is driving transmission within Latin American communities.

The aims of this programme were to shine a light on the high rates of internalised HIV stigma developed in response to high levels of community stigma and examine the impact and explore ways to break the silence and develop activities of empowerment.

The objectives of the programme were to increase understanding of, and ability to respond to HIV stigma, and empower key underserved and rarely heard Latin American communities to speak out against and stand up to stigma.

The programme was rooted in creative and educational interventions that resulted in a series of podcasts to reduce HIV self and community stigma, which were shared on social media.

Programme summary

In October and November 2022, we facilitated creative sessions for two cohorts, one in Spanish and one in Portuguese. the numbers for this group were much lower than the first one. We believe that there was a lower engagement and attendance due to strikes.

In December we hosted a Christmas lunch for these cohorts. At these lunches we reflected on our achievements for the year. This was to focus on the positive outcomes of a year that was challenging for most of them. We were happy to hear that some of the participants said that the best achievement of 2022 was having joined this group, meeting the fellow participants and us.

We also asked them for their objectives for 2023 and all of them mentioned projects about being more positive or focused on themselves and their wellbeing. Some of them mentioned projects like "making their new house, a home", other participants mentioned, "exercise more and work on their English" and "finding a partner", which showed a different attitude towards dating from when we first met them.

As part of our Christmas lunch, we played Christmas crackers which was a new activity for all of our participants which they really enjoyed, particularly the Jokes, riddles and charades – We also had a surprise “Secret Santa”!

Podcasts

In December 2022 and January 2023, we recorded and edited six episodes of our podcast. We published them weekly from Friday the 20th February 2023 in blocks of 2 for 6 weeks.

We aim to continue with the podcast as a legacy of this programme. We have collaborated with people from other organisations working on HIV awareness with the Latin American community and there is definitely an interest in amplifying the voice of this community.

The podcasts can be listened to:
https://open.spotify.com/show/2unUhgWiHwOmDrxMsU936l?si=c8fccdf42cdb4be2 .

On March 16th we are hosting at Metro Charity’s HQ in New Cross a recap of the programme, a night to wrap up all the work, present the podcast to the community and have a live Q&A with some of the participants.

THE AMBASSADORS TRAINING

The organisations collaborated in developing and delivering an Ambassador's Training programme. The aim of the training programme was to develop a network of ambassadors to support the work of the FCTI HIV Friendly Charter and work with FTCI London to share their stories and reduce stigma.

The cohort of ambassadors recruited and trained five women and six men of different ages, sexualities, ethnicities and time diagnosed. These new voices will support the delivery of the anti-stigma work across London (and online to the public), to provide their lived experience to raise awareness of HIV and stigma.

The organisations developed a recruitment criteria guide and a training programme that would include:

- Introducing the FCTI HIV Friendly Charter and its work to address stigma
- Introducing the Ambassador role
- Exploration of the social, community and demographic issues surrounding stigma
- Providing updates on HIV treatment
- Exploring stigma, its impact and what tools we have to address it (within people and society)
- Building emotional wellbeing and support networks
- Building presentation skills on a range of mediums
- Developing public speaking skills and confidence
- Learning how to maintain personal boundaries and responding to challenging questions.

The programme was delivered over two Saturdays in February 2023, with a total of 11 participants completed the training, with the scores for the two day's training averaging out at

4.7 across all participants.

Some of the feedback from participants on key learning from the training included the following:

> *"Better understanding of the programme and my role. Better understanding of HIV treatment. Better ways and tools for speaking in public."*
>
> *"Dealing with challenging questions - how to manage without getting anxious."*
>
> *"Be yourself, share the information about U=U, Prep, Pep, HIV awareness. I'm committed to the goal of zero transmission by 2030."*
>
> *"That the topic of HIV doesn't need to be a complex one and that we can be effective by using the Coco Chanel method of 'less is more'."*
>
> *"Be yourself! Lean into our authentic approach. Specific, Personal stories have the most impact.*
>
> *Know boundaries, what we feel is appropriate to talk about, and also consideration of the effect on the wider community our words will have."*

REFLECTIONS

Representatives from each of the six programmes came together every two months for action learning sets facilitated by Healthy Dialogues. They discussed their different programmes, challenges, what was working well and what they have learned. Overall, the facilitators enjoyed delivering the programmes and felt they were making a positive difference in people's lives.

A number of key themes came out of the discussions at the action learning sets. These are presented below.

Key themes

Difficulties in recruitment and retention of participants

There were a number of challenges in recruiting and retaining participants, particularly those from more marginalised communities. Factors that hindered recruitment included:

- Gloomy Winter months
- Train strikes
- Zoom fatigue
- Participant work shift schedules

Positively UK found a substantial difference between cohorts that were recruited by a clinic that had integrated peer support than those from a clinic without peer support. Their course targeted those who had poor engagement with HIV care or hesitancy to access additional external HIV support. They found that those participants who accessed support through the clinic peer navigators had achieved a certain level of self-awareness and confidence and already seemed to take positive actions in their lives. Whereas those from the clinic that did not have peer support had lower confidence and did not engage well with their referral to the programme, even though they were regularly followed up with. Still, the results showed that both groups benefited from joining the sessions, as all, except one participant signed up for Positively UK's additional support services.

The different programmes trialled a range of options to improve participant attendance. They found that weekday courses excluded those who worked during the day. Weekend programmes had better attendance. However not everyone could attend all weekends either, including those who work on shift rotas. One programme found that running the course over fewer sessions enabled more participants to sign-up to the programme. A later start time on Saturdays was also more accessible for participants (a 10am start was found to be too early).

Some groups were delivered online, some in-person and some using a hybrid model, they found that different approaches appealed to different people.

For some there wasn’t much that could be done to improve attendance due to the participants own circumstances. For example, in the Metro programme, many participants were experiencing difficulties with their immigration status and financial insecurity. When they were able to attend, often they were expecting more practical help and support to address these issues.

Conversely, 4 M Mentor Mothers Network were able to run full courses. This is likely because they were reaching out to a larger pre-existing cohort and running shorter courses.

Vulnerable participants

Some of the programmes included participants who were particularly vulnerable and struggling with immigration and financial issues, mental health problems or were living with HIV for many years but had not yet engaged with any HIV support services before.

Retention was very low in these groups but the impact with those who stayed or at least came to 1-2 sessions was significant.

The facilitators found that vulnerable participants needed flexibility in the groups they attended, including the option of reengagement if they were not able to complete a previous course. They also found that these participants often shared deep hesitation to engage with non-HIV services, and in particular, found the idea of talking therapies very daunting. They were more comfortable with the idea of community orientated peer led support.

The facilitators agreed that it is important for groups to facilitate access to other services as psychological therapy. Participants who attended these groups were at the start of the healing journey, understanding the impact of HIV was only one aspect of that. They found that people felt they needed permission to access 1:1 support, and that the courses need to demystify exploring psychology, especially when they are tackling issues around HIV and other areas that were impacting participants such as social issues and trauma.

Impact of the programme on individuals living with HIV

The facilitators agreed that the psychology element was key to these programmes. The programmes enabled a personal development journey where participants could look at their own dialogue and their own story.

By exploring language, the programmes equipped participants, increased their resources and motivation and helped them to articulate what they were going through. By talking through their barriers with others, participants realise that others are going through barriers too, often similar barriers which helped to normalise their experiences.

Facilitators found that participants were going away from a session thinking about what was discussed and coming back to the next session with fresh ideas and thoughts they are keen to bring to the discussion. They valued that space to talk.

They found that exploring issues around adherence to treatment helped participants gain an appreciation of their healthcare routine. They found that the health educational element was very powerful.

Other key aspects that were considered to have a powerful impact on participants included:

- Peer support, as some participants had been very isolated. Some participants were interested in becoming activists themselves.
- Learning to have compassion for themselves.
- Positive role modelling
- Building a community of people with HIV, with connections with each other, resources and signposting support.

As a result of the programme facilitators found that participant's attitudes had shifted. Some had begun looking for a job, some had begun telling friends and family about their HIV status, some had begun seeking psychological help via talking therapies, and some felt they had permission to live again and plan for the future. Some participants had shown an interest in co-facilitating future programmes.

Collaboration

All organisations highlighted the value of working with each other, rather than competing with each other for recruiting participants. As a result, they were able to support each other by signposting people to the empowerment programmes that were most suitable for them.

Working collaboratively also allowed organisations to draw on each other's strengths. For example, 4 M Mentor Mothers collaborated with NAM to create videos with the participants to share on social media and raise awareness of empowerment.

Key learning points

There were several key learning points drawn from discussions with the facilitators regarding the adaptations they made to their training programmes in response to participant engagement and feedback. These are listed below:

- Facilitators closely identified activities that supported and encouraged discussions and moved away from activities that sometimes hindered discussions.
- One course increased the session time from two to three hours in response to the participant's enthusiasm to stay in discussion and keep learning.
- Facilitators agreed that was important to ensure that learning around HIV treatment and U=U was delivered conversationally, using simple language.
- They also agreed that more time and focus should be spent on topics about the social consideration of living with HIV such as telling new partners about HIV status.

Facilitators discussed the importance of having groups protected for certain cohorts such women’s groups or groups that are delivered in certain languages. However, others really saw the value in providing mixed groups (i.e. by religion, disabilities, race, LGBTQ, gender etc). They found that by delivering to diverse groups, participants were able to tackle their own unconscious bias, preconceptions or stereotypes. They found that through conversations with different participants they were able to explore what they have in common and realise they may have similar challenges and barriers.

Considerations for the future

The facilitators agreed the following should be considered when commissioning or delivering future empowerment programmes:

- The organisations would like to work more closely together as a cross-organisational partnership for recruitment to ensure those who are eligible for groups are signposted to the group most suited for them.
- The organisations have been developing their resources and building a resource library for their programmes which they would like to share with each other to continue the collaborative relationship.
- Consideration should be given to provision of women only spaces within these courses, to enable women to talk about family planning and safety.
- Organisations will continue to consider how they promote their programmes, including who they are attracting and how they are perceived. There is concern that some participants who attend expect help with wider social issues outside the remit of the empowerment programmes, such as immigration issues or financial hardships. The promotion should ensure to hit what people want to overcome in terms of empowerment, for example, managing conversations about HIV or addressing difficult questions, etc.
- Programmes should include links to financial support services so that people can be directed to the help they need outside of the course. Or perhaps have a core course plus additional modules for those who need extra topics, such as family planning, U=U.
- Supervision support is needed for facilitators while they are running programmes, particularly those working with vulnerable participants who are experiencing, for example, trauma or suicidal ideation.
- Help for transport costs should be offered to participants experiencing financial hardships.

CASE STUDIES

POSITIVE EAST

Case Study 1

40-year-old Portuguese, gay male. Diagnosed on March 2019.

Tell me about your HIV journey

I was diagnosed though a HIV home testing kit and then accessed the Royal London clinic who were an amazing team. The impact of the diagnosis led me not being able to sleep for two days and I began to isolate myself and was in denial and pretended that everything was normal and fine, but I was crying all the time and had suicidal thoughts. I met with Positive East staff member and then Covid-19 pandemic, and I did not access any services apart from my clinic.

How did you hear about the Empowerment Programme course?

I picked up an Empowerment and Stigma card poster from my local clinic- Graham Hayton Unit.

What made you decide to come on the course?

I listened to my intuition, and I also wanted to reconnect and learn more about with Positive East charity and services after the pandemic and the goals and the objectivities of the Empowerment course appeal to me towards understanding myself better living with HIV and to "get and give to others" and to contribute as a volunteer. So, I signed up to be a PE volunteer and to their newsletter. I also remember you calling me that reinforced me to come along on the online course, even though I had monkey pox at the time.

How did you feel about your HIV status before you attended the course?

When I was diagnosed, I read all the information about HIV, U=U and received leaflets from my HIV clinic. But I still felt emotionally vulnerable after having a negative experience of being rejected by a guy I really liked after sharing my status. I found it hard to talk and think about my HIV. I separated it out from my outside life and the clinic as a way to protect myself from it and avoid dealing with it my day-to-day life.

How has the Empowerment Programme course helped and benefited you?

I had no expectations from the course and went in with an open mind and an opportunity to meet others. What I realised is that irrespective of our differences and diverse cultural and sexual backgrounds, we all had similar experiences, issues and challenges around suffering the same kind of pain around self-shame, isolation, loosing ourselves to the diagnosis's and exploring the fears around telling.

The course has helped me gain a lot self-confidence and I'm more comfortable around the decision to tell others about my status. I am ready and planning to tell three important people in life, a friend, cousin and my brother over Christmas and New Year. It has also given me the confidence to give back and help others to feel better about their HIV and to know that you are not the only one, not matter your background and discovering self-acceptance and that is why I wanted to contribute as a case study for this programme.

I am now able to deal with my emotions better as before, I dealt with my emotions around HIV like opening and closing them in box and shutting them away. Now I feel more normal again, free and I feel I have integrated my HIV into my life and feel more open talking about my HIV and comfortable venturing into a sexual relationship with confidence. My attitude of doubt, self-rejection and behaviour of secrecy is gone and not hidden away anymore.

How do you feel about your HIV status after completing the EP course, has it changed your outlook or attitude around your HIV?

I have no fear about with HIV now as before the course, I thought I was going to live a short life the course allowed me to realise that I can have a normal and long-life expectancy and so I am now getting my future long-term plans in place. I have now started to live my life with hope and positive future again.

What has been the biggest impact or change/ difference has the course has made in your life?

I am going to tell me brother about my HIV as I feel it's important for one of my family members knows about my health condition, just in case in the future I become unwell. I feel a sense of liberty that is priceless, and I don't want it to be a taboo.

What would you like to see and get involved in the future?

- I would like to be the Ambassador training programme because I really want a make a positive difference in other people's lives.
- Access peer mentoring training and support gay men
- Break the language barriers and set up a Latin support group
- Be an Empowerment Champion volunteer with Positive East and would like to help out with Gay men's group in the new year.
- Volunteer as Receptionist and get involved with communications and social media.

Anything else you would like to say?

I would like to talk about my HIV story with others and have realised I have better choices, clarity and discernment with no self-judgement and shame. I discovered a clear filter of who I wish to tell and not share my status with: who should know, who must know, and who does not need to know.

Case Study 2

A 45 year old Latvian Female, age 45, married with two children. Diagnosed in February 2021.

Tell me about your HIV journey

In the middle of the Covid pandemic in 2020. I was misdiagnosed by my GP as I had been unwell with symptoms two years prior with rashes and breathing issues, tiredness, weight loss was tested negative for Covid. Eventually a blood test was done and I was hospitalised and isolated and was told about my HIV diagnosis in front of students at Royal London. I felt there was no privacy and my husband also tested positive. My husband informed his workplace and is now being discriminated against and has been dismissed from work. NAT provided information support.

How did you hear about the Empowerment Programme course?

Through my therapist at the Royal London who felt I could benefit from the course.

What made you decide to come on the course?

To be honest, I was feeling very low and suicidal and I was reaching out for something to keep me going**.**

How did you feel about your HIV status before you attended the course?

I felt like the HIV took away my future and everything that I had planned and hoped for in my life. I was also planning to move back to Latvia before my diagnosis. I felt very betrayed by my husband. I realised that in Latvia that HIV people hold secret meetings.

How has the Empowerment Programme course helped and benefited you?

I am grateful for the medical treatment and support from the NHS and became aware of my white privilege and realised the challenges of the African women from the course. It also gave me a women's shared experience of living with HIV. The course also helped me set boundaries in general and I am now able to say no. I felt the course gave me safe and non-judgemental space surrounded by women and an energy and vibe I absorbed was like getting a big hug by the other women and a sense empowerment. Before I felt lost, judged and left behind. I felt accepted and it did not matter whether you were white, we were all in it together.

How do you feel about your HIV status after completing the Empowerment Programme course, has it changed

I feel I have a future now and the possibility of finding new relationships with others.

What has been the biggest impact or change/ difference has the course has made in your life?

I have left my job and started a new job to have a better work life balance. I feel I don't have to be defined by my HIV since I've been on the course. I feel like I'm living again and have redecorated my home to make feel calmer, comforting and relaxing with my two cats.

What would you like to see and get involved in the future?

Become a Peer Supporter and help others change their lives and access counselling services.

Anything else you would like to say?

I want the human connection and to come together and I want something to fight for and volunteer with group work and take up yoga and Tai Chi.

Case Study 3

A 36 year old African, single Female, aged 36. Diagnosed July 2007.

Tell me about your HIV journey

I came to the UK in 2004 and was subjected to modern slavery and this led to my current leave to remain immigration status. I was diagnosed in 2007. I went to my GP as I had a lump on my and neck and had a biopsy and diagnosed with TB. The lump did not go away and then I was tested HIV positive 6 months later and hospitalised for 2 weeks. After my diagnosis, I did not want to associate myself with HIV services and I was in 100% denial. A friend supported and looked after me. At that time I did not share my status with her. I told her only last year, she suspected that it was HIV and has been very supportive.

How did you hear about the Empowerment Programme course?

Through Positive East who felt I could benefit from the course.

What made you decide to come on the course?

The need to connect and learn from others. I wanted to update myself on HIV information as well as to have some fun. It mentally helped me as I sometimes I get into my own thoughts and being with others helps me come out of my own thoughts and having to this knowledge so that I can apply and share with others, it gave me a positive mindset.

How did you feel about your HIV status before you attended the course?

It increased my creativity, and I was inspired to open up and express my creativity that I had known I had but had never used it. It was great to be inspired to write a poem whilst I attended the course. I feel more of an advocate and encouraged and feel my communication and language skills have improved and the changing language around HIV.

How has the Empowerment Programme course helped and benefited you?

It has given me a positive mindset and feel I can set goals and a confidence that helps me move forward and not dwell so much on the negative. That HIV does not have to define you and not take you away from your talent and creativity and to shine your light! To inspire others along the way and to look at what you have gained and not what you have lost along the way. This is my HIV family, and the support groups empower me and allow me to be more creative.

How do you feel about your HIV status after completing the Empowerment Programme course, has it changed

I feel more empowered to help others and feel I am allowed to be more creative and express myself through cooking, writing and dancing with the information I got from the course and Positive East.

What has been the biggest impact or change/ difference has the course has made in your life?

I took away developing my relationship skills and realised we are all leaders. Learning and the wisdom to share and guide others.

What would you like to see and get involved in the future?

Yes, get involved in other programmes that empower others. Get involved with creative workshops to bring out others hidden talents and get social support groups. I would like to get involved in peer support and ambassadors programme and video work. Interested in migration policy.

Anything else you would like to say?

I like to express creativity and like to attend knitting classes. I was interested in African women and hair loss during HIV diagnosis and began to collect hair and part of Women aids day I did a knitted hair art piece about weak and straight hair as a symptom of HIV.

Case Study 4

A 58-year-old single black British Male. Diagnosed June 2011.

Tell me about your HIV journey

I went to Newham General for blood test as my GP informed me about abnormal white blood cell count and was asked to go to Newham General to get my results. When I got there, they were not aware of my case. I then received another call from my GP to go to Greenway GUM clinic where they gave me my HIV results. I could not believe it and asked them to do the tests again and they came back positive. I felt at death's door and asked to repeat the test twice. I remember the nurse saying that I was not going to die from it and live to old age. It led to me to keep to myself and I took away all the HIV literacy and self-educated myself around it but did not speak to anybody else about it. I isolated myself and started the medication and took a week off work to manage the side effects but did not get any. I accessed Positive East and attend a Newly Diagnosed workshop involved in drug trials.

I was on my solo journey and did not tell my adult children. I felt the Newly Diagnosed group was more focused on gay men and the U=U message was a game changer for me and helped me relax and build my confidence and having sexual relationships again. But I still experienced dilemmas in telling and sharing my status to others.

How did you hear about Empowerment Programme course?

Positive East Newsletter and phone call from Mina

What made you decide to come on the course?

After Covid-19 to reconnect and get more knowledge and Understanding around HIV.

How did you feel about your HIV status before you attended the course?

Before I was a lone ranger and alone and after the course I did not feel alone and feel I was more aware about HIV information and what's its all about to share with the public without needing to sharing my status and volunteer to raise awareness in the public. Have the confidence to speak, inform and signpost about HIV services and support.

How has the Empowerment Programme course helped and benefited you?

It has built my confidence in building up relationships to others and knowing that telling world would not end the world and feel empowered. African communities still do not believe U=U. I feel ok about and know I can be of use and give support to others and speak to the public and get involved in peer mentoring and group work.

How do you feel about your HIV status after completing the Empowerment Programme course, has it changed

I feel less isolated and my attitude has change as now I see myself as anyone else. I feel I can get on with my life and have the skills on how respond and telling.

What has been the biggest impact or change/ difference has the course has made in your life?

I feel less isolated, and part of community and I also feel as a retired lawyer to offer volunteer support in HIV rights in the workplace and human rights. To have more social groups and mixed groups. Access Gym services. HIV hub – drop in.

What would you like to see and get involved in the future?

Yes, get involved with benefits advice,

Anything else you would like to say?

I like to express and say a big thank you to Mina who really engaged us in our hearts and Minds who brought a human face to the training and brought passion & warmth that you brought to the course, thank you!

Case Study 5

A 45 year old African, married Female, age 45 female with children. Diagnosed in May 2002.

Tell me about your HIV journey

I was dating by husband, my then boyfriend and I had some lumps and bumps around my body. We both decided to go for a sexual health check and have all the STI checks done, and we were both diagnosed HIV positive. I was also experiencing migration issues and challenges and no family support. I accessed support but put it on hold as it was triggering me, knowing that my boyfriend had given it to me. I felt angry and panicked while my partner was in denial about it all. I married my partner in 2004 and had 2 children and the babies helped us pushed through together. My first birth was a C-section and for my second I opted for a natural birth and did not breast feed them. My babies had to have HIV treatment after birth which was really difficult for me.

I was depressed as I felt helpless having uncertainty around my migration status and felt like I was in an open prison. In 2007 my migration issues was finally resolved.

I joined Body and Soul and Positively Women at the time, but I stop going as I was young, and I felt I could not fit in. So, I created my own support network and got my own information and treatment on HIV which was a lifeline for me.

How did you hear about the Empowerment Programme course?

Through UK CAB.

What made you decide to come on the course?

Having completed the Grows training. I also thought about how I can contribute in the HIV field and receive support from HIV services as well as increase my knowledge. It was nice to be part of mixed group and have different dynamics and enhance shared, understanding, knowledge and experience. The concept of the Empowerment Community Champions appealed to me and the course information.

How did you feel about your HIV status before you attended the course?

I feel it gave me a sense of purpose again in my life and I feel my depression had lifted and I don't need psychotherapy. It helped decide to do my social work degree which I was undecided about before the course. It also gave me clarity and I want to help others and get paid. I have an interest in supported housing for HIV.

How has the Empowerment Programme course helped and benefited you?

Having the course on the weekend 10am to 2pm was good as it was something I looked forward to and it was fun and informative and made me feel relaxed.

How do you feel about your HIV status after completing the Empowerment Programme course, has it changed?

I feel the course has allowed me to continue to shift my attitude around my HIV and allowed me to process feelings that I had not delt with and had hang ups about it. I spoke to my children about my status and did not want to keep it a secret anymore and not get emotional. I wanted to talk about it with emotional balance. Exploring and gaining a good understanding of U=U and the benefits that comes from it and the fact it's a game changer in managing rejection and able to explore in detail that you are no longer the victim and have choice and knowing your sense of self-worth and value was covered very well.

Also hearing other people's experiences, perceptions and different journeys help put things in context and help me be mindful and respect the different HIV experiences and in how to help different people in peer mentoring. How the type of support has changed and where to get information and a lot more resources now. I now recognise the importance of networking and making private connects and cultivating peer support. HIV is unique and learning different perspectives.

What has been the biggest impact or change/ difference has the course has made in your life?

I can now speak more openly and live more openly with my HIV and I am at ease with it and talk and laugh with my children. Freedom from the shackles and become the best version of myself. My life was on hold before. Everyone was able to share stories and vulnerability that I was able to relate to. Gained information and skills around U=U, adherence and psychological wellbeing. Having a week to reflect on the learning was good to apply the leaning and new ways of thinking.

The impact the course is that it has given me the confidence and clarity from the information, knowledge and perspectives on knowing how to take care of myself, not be the victim and how to tell others. Having a purpose in life and that I cannot empower others if I cannot feel empowered. It helped me make the decision to do a degree and living a life with ease and freedom and not let my children to be the victim and permission to be honest. I was working on my depression, and it has freed me from it. I would like to attend more groups in the future.

What would you like to see and get involved in the future?

Yes, get involved in peer mentoring and the train the trainer course. The Ambassadors Programme and creative writing. I am currently a training and development lead and would like to build the confidence and talents of other people.

Anything else you would like to say?

Thank you!

4M MENTOR MOTHERS NETWORK CIC (4MNET) AND NAM AIDSMAP

Programme overview

February 2022-February 2023

4MNet: Unique peer-led organisation, training women living with HIV across the UK to become Mentor Mothers (MMs) and provide psychosocial peer support to other women living with HIV going through the pregnancy journey and beyond, addressing quality of life.

NAM aidsmap: World's leading source of HIV information providing clear, accurate & reliable information since the beginning of the HIV pandemic.

Please describe your empowerment program

The programme was delivered by peer Mentor Mothers (Trained women living with HIV who provide support to other women living with HIV going through a pregnancy journey and beyond). It was for mainly African/Afro-Caribbean/Black British and migrant women disproportionately affected by HIV who face multi-layered challenges/stigma. However, it was open to all women living with HIV.

The purpose of the programme was to adapt the Stigma Empowerment Framework and develop training for black African/British women living with HIV and other experts to discuss and address internalised stigma.

What activities did you include?

We included participatory, creative, person-centred approaches with a mixture of virtual and face-to-face interactive training delivery methods, we ran a series of Interactive workshops including peer support, creative writing, mindfulness, information, dancing, digital outputs, exchange, group discussions and skill development. working collaboratively with NAM aidsmap and relevant experts.

We facilitated professional and personal development for women through involvement as participants, ambassadors, co-facilitators and expert speakers.

We also included powerful creative writing exercises served as a form of self-expression and catharsis for women. The outputs that were produced in training are a vital resource to inspire others on their journey.

How was it delivered?

We delivered four virtual sessions every other month. The programmes were delivered as six-hour interactive workshops over two days (3 hrs per day) including creative writing, mindfulness, webinars/information, group discussions and skill development.

Our virtual sessions improved accessibility and data bundles were provided to facilitate participation.

The final programme was a face-to-face hybrid event. It brought together all participants from the four virtual training sessions and other women who were interested in attending the training. It was delivered as a six-hour interactive workshop including peer support, creative writing, mindfulness, information, dancing, exchange, group discussions and skills development. This aim of the programme was to strengthen the network and consolidate learning. In total, 70 women registered, and 55 attended.

In addition, a taster session of the training was facilitated at the annual Children and HIV Association Family conference in May 2022. This was held in London and attended by approximately 65 parents/carers and young people living with HIV.

The session covered:

- What is Stigma and it’s definition
- Myths & Misconceptions
- Experiencing Stigma
- What is Self Stigma and it’s definition
- Dealing with stigma

What (if any) barriers did you come across and how did you overcome them?

Participants requested longer training time/training events. Our plan is to fundraise for a follow up.

Attrition rate for evaluation forms were low with less forms returned in comparison to participant numbers. We sent additional reminders, and provided time as we do at the start and end of the session so that they can be completed in training. The evaluation form was reviewed to make it more suitable.

Participant feedback throughout the program was noted and incorporated with flexibility and pragmatism.

Overall, if you could sum up the benefits in one sentence what would you say?

Awareness, Information, empowerment, connection in safe spaces, partnership, advocacy, capacity building and funding for self and community is power

A peer-led flexible, innovative, and holistic quality of life approach is essential to focus on what the priorities are.

TERENCE HIGGINS TRUST

Programme overview

Terrence Higgins Trust aimed to maintain a peer led approach throughout the delivery of this programme. The Empowerment Workshops were delivered by the Stigma Empowerment Programme coordinator. The programme coordinator was a person living with HIV (PLWH) with experience working with other PLWH to overcome the psychological difficulties related to self-stigma.

In addition to the primary facilitator, each cohort of the Empowerment workshops had two co-facilitators. Co-facilitators were also people living with HIV from diverse backgrounds. The aim of the co-facilitators was to represent the wide range of experiences that service users brought to the Empowerment Workshops. Co-facilitators utilised their own stories to provide attendees with examples of how to overcome the difficulties associated with living with HIV.

Who was the empowerment programme for?

With the Empowerment Workshops, Terrence Higgins Trust aimed to engage a population of people living with HIV who experience high levels of self-stigma. Among this population, experiences of high levels of stigma manifest as shame, social isolation, low self-confidence, poor treatment adherence, or the general challenges of trying to live well with HIV.

A key aspect of this population is their poor engagement with services. A number of service users who attended the Empowerment Workshops had either no or poor experiences of previously engaging with support services. This presented unique challenges in recruiting and delivering these workshops.

What was the purpose of the programme, based on your service/organisation?

Our four workshop programmes aimed to address the unique needs of our particularly vulnerable target population. We addressed these needs by providing information about navigating HIV care, understanding HIV treatment and how to address these topics with healthcare providers. We also explored HIV stigma by defining it and breaking it down into understandable social concepts. This allowed attendees to understand how stigma impacts their lives and how they can begin to overcome it.

The second goal of our programme was very future orientated. A key aspect of empowerment is instilling the belief that people living with HIV are both capable and valuable. Therefore, we focused a large portion of the programme on building skills with service users that would enable them to shift their self-image, grow their self-confidence and build upon their resilience for the future.

What activities did you include?

The sessions included interactive learning and videos, break-out groups, sharing experiences and stories, and creative activities. A takeaway toolkit was provided to enable ongoing learning and reflection.

The Empowerment Workshops integrated Cognitive Behavioural Therapy (CBT) techniques throughout the programme. This CBT approach is particularly advantageous when attempting to make sustainable behaviour changes in short periods of time. Experiences of stigma that manifested in negative thought processes were addressed by identifying thought errors and engaging in cognitive restructuring.

What were your evaluation results, pre vs post questionnaire?

All attendees saw an improvement on the Stigma Empowerment Scale and at least one of the key outcomes.

- 80% of participants reported an increase in self-esteem and confidence
- 95% of participants have felt better equipped to deal with difficult situations in their life.
- 100% of participants have increased their knowledge about U=U and living well with HIV
- 80% of participants saw a decrease in the limitations HIV places on their life on a day-to-day basis.
- 100% of participants agreed that they felt safe and able to contribute freely to the discussions.

What (if any) barriers did you come across and how did you overcome them?

Terrence Higgins Trust experienced two significant challenges in delivering this Empowerment programme, recruitment and the pronounced vulnerability of our target population.

As previously mentioned, Terrence Higgins Trust aimed to engage a population of people living with HIV who experience high levels of self-stigma. The majority of attendees had no or poor experiences of previously engaging with HIV care and other support services. This presented unique challenges in recruiting and engaging this population. In order to recruit services users for our group substantial work was undertaken to engage this population, e.g., regular phone and email contact, providing phone data and meeting travel expenses. Even with these measures, it was quite common for service users to not consistently attend sessions, We took a number of measures in an attempt to improve the engagement among service users. In line with recommendations from the Fast Track Cities Initiative Action Learning group and service user feedback, we changed the name of the group by removing the word stigma. It was observed that there was a poor understanding of stigma among PLWH accessing our service. Therefore, we amended the name of the programme to increase the appeal and accessibility of the group. This change was received well by attendees.

Our second challenge falls in line with the previous issues explored. Service users presented to Terrence Higgins Trust's Empowerment workshops with pronounced needs and unique vulnerabilities. While it was expected that attendees experienced problems related to their HIV care and manifestations of self-stigma, we initially underestimated the issues that extended beyond their HIV status. Service users vocalised concerns around co-morbid mental health issues, financial struggles, employment difficulties, domestic abuse, sexual violence and chemsex. Fortunately, with the wide range of resources available within Terrence Higgins Trust, we were able to effectively internally refer service users to counselling, work and skills and Chemsex support. When service users presented with issues outside of the service offer at Terrence Higgins Trust, we signposted and supported them accessing support elsewhere.

What was the impact of the programme on the participants?

We thought that it would be best to illustrate the impact of the Empowerment Workshops through two case studies. These case studies have been anonymised.

Case study 1

James is a 30yr-old man who has sex with men based in South West London. He had been diagnosed with HIV 9 months before accessing support through Terrence Higgins Trust.

James initially had major concerns about confidentiality and joining the Empowerment Workshop group. He had a girlfriend for a few years and their relationship ended when he told her that he was living with HIV. James' HIV diagnosis had a massive impact on his confidence and he was extremely worried about other people discovering his status. DC also engaged in problematic patterns of chemsex in an attempt to cope with his diagnosis.

James heard of The Empowerment Workshops through accessing Chemsex support at Terrence Higgins Trust. James joined the group to learn more about how to cope with his HIV self-stigma and better navigate this in his relationships. James also had challenges understanding HIV treatment and had genuine concerns about long-term side-effects.

Worried about confidentiality, James initially struggled to share and engage in the workshops. However, as he progressed through the workshops, James began to not only contribute to the discussions on self-stigma but actively engaged in peer-to-peer support with other members of the group. James benefited from not only the information provided aimed at increasing HIV literacy, but also hearing the wide range of advice from other service users and the group facilitators.

While the Empowerment Workshops are no “quick fix” for overcoming self-stigma, James highlighted the new perspective on HIV the programme had to offer in his feedback survey, saying:

> *“When I was diagnosed with HIV, my consultant told me it was all going to be okay. I thought that was a load of crap. I have carried that attitude with me until now. This group has actually showed me that it will be okay”*

Upon checking in with James a few months after the programme, he reported being able to build on the progress made during the workshops, even going so far as to share his HIV status with his new girlfriend. This was received very well by the girlfriend who was non-judgemental and understanding.

Case study 2

Rachel is a 54 year old straight women based in North West London. She has been living with HIV for over 30 years. Having lived through the early HIV/ AIDS epidemic, she expressed how deeply traumatic this time was for her. Being a woman diagnosed with HIV in the early nineties was extremely isolating. This was isolation was further exacerbated after disclosing to her family who reacted negatively. Rachel went on to live her life only disclosing her HIV status to only a very few people, such as her husband of 10 years. In this relationship GS experience domestic violence which she linked with her HIV status.

Rachel discovered the Empowerment Workshops online and was eager to join. Before accessing support with Terrence Higgins Trust she had not met another person living with HIV. Her main goal of joining the group was to meet other people living with HIV. In tandem,at the time of accessing the group, Rachel had stopped taking her HIV treatment, citing long- term side effects as her primary motivation to stopping.

Rachel responded extremely well to attending the workshops and consistently attended all of the sessions. She said

> *“This is the first time I have been in a space like this. I have never been able to openly discuss being HIV positive without fear of judgement”. This non-judgemental environment was particularly important for Rachel when talking about their relationship with HIV medication, something she felt doctors and other healthcare professionals didn’t understand. In having these open conversations we were able to figure out some next steps and solutions for Rachel.*

Overall, Rachel expressed that her involvement in the Empowerment Workshops was very beneficial. She felt the group had armed her with the knowledge and skills that she could now "*stand in her truth*". GS was also referred onto counselling support for comorbid mental health issues and has joined the Common Bond women's group.

Feedback

Personal comments/ quotes from participants:

We received some **qualitative feedback** which highlighted some of the positive aspects of the programme:

> *"I have been speaking to my mum about what information I learnt and also the stupid practices I used to do and she feels happy for me, she said I seem happier… but I also feel the message is getting through to me, I don't feel so burdened in my mind"*
>
> *"I certainly enjoyed the workshop and those stories from other participants are truly inspiring."*
>
> *"Very well structured program- well designed - Comprehensive coverage of topics - Very powerful story sharing - Facilitated growth mindset - Michael and his colleague held a safe, no-judgmental space"*
>
> *"I liked the fact the people running the course were also HIV positive so can really connect with the message they are putting out. The people presenting and sharing their stories was a big deal as it was so relatable"*
>
> *"This is the future- Hybrid The sessions were conducted very well - didnt feel the gap at all"*

We also received some **valuable criticism** on the programme. This largely focused on operational issues around tech and facilities:

> *"It was tricky to hear because of the Hybrid nature of the sessions.*
>
> *Sometimes very echoey."*
>
> *"Being rushed at the end of session due to having to close the office and cleaners needing to do their job - felt there should be at least 15-20mins spillover period to accommodate for this"*

Recommendations or advice for other services who may be trying a similar approach

Despite the major advancements we have made in the treatment of HIV, there is still a population of PLWH who struggle to cope with their status on a psychosocial level. It is paramount that we continue to create spaces that empower these people to live fulfilled lives.