



European African HIV/AIDS & hepatitis C Community Summit Report

AIDS 2018
Affiliated Independent Event
21-22 July 2018
Amsterdam Netherlands



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BACKGROUND

European African Treatment Advocates Network (EATAN) is a community network of HIV and hepatitis treatment advocates for the migrant communities living in Europe.

EATAN was founded in 2012 with the aim to empower migrant communities in Europe to advocate for access to quality HIV prevention and inclusive care services in fulfilment with their health and treatment rights. Secondary, EATAN sought to develop a network of advocates to provide peer support and advocacy services.

Treatment Action Group (TAG) is an independent, activist and community-based research and policy think tank fighting for better treatment, prevention, a vaccine, and a cure for HIV, tuberculosis, and hepatitis C virus (HCV). TAG formed out of the AIDS Coalition to Unleash Power (ACT UP) in New York City and was founded in 1992. TAG works to ensure that all people with HIV, TB, or HCV receive lifesaving treatment, care, and information. TAG consists of science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions. TAG catalyzes open collective action by all affected communities, scientists, and policy makers to end HIV, TB, and HCV.

87 delegates from 12 European countries attended the summit. The goal was not solely to share experiences of advocacy initiatives from their respective countries, but to also develop ways in which the campaign could lobby the objectives of EATAN, with respect to migrant

health priorities and HIV/HCV elimination, to national governments and a worldwide civil society.

Delegates visited from the following European countries;

- | | |
|------------|-----------------|
| 1. Belgium | 7. Italy |
| 2. Denmark | 8. Norway |
| 3. England | 9. Portugal |
| 4. France | 10. Scotland |
| 5. Germany | 11. Sweden |
| 6. Holland | 12. Switzerland |

This report captures the two-day programme of deliberations, panel discussions, and interactive dialogues during the 21-22 July, 2018 European African HIV/AIDS & hepatitis C, Community Summit in Amsterdam, Netherlands.

The European African Treatment Advocates Network (EATAN) hosted the summit, in partnership with Treatment Action Group (TAG) and other migrant-focused organizations. It brought together delegates from across the EU, with technical experts from the EU and North America, who sought to develop enduring plans for cooperation and commitment towards the elimination of HIV and hepatitis C. The Summit provided a platform for the initiation of a campaign designed to develop a European African consensus statement on migrant communities' inclusion in decision-making processes. With novel treatment regimens that treat all genotypes, or genetic variations, of the hepatitis C virus, an opportunity exists to make HCV elimination a reality. To fast-track elimination, the Summit considered the diverse healthcare policy landscape among EU states, patient education and empowerment practices, barriers to accessing affordable diagnostics, treatment, and care for migrants, and treatment advocacy strategies needed to catalyze policy changes.

The summit was attended by professionals from the European Commission, European Centre for Disease Prevention and Control (ECDC), European HIV and hepatitis Specialist Consultants,

European Law society and HIV and hepatitis activists from within the migrant community programs and communities in Europe.

The summit allowed various international actors to interact on a shared platform.

There were a total of nine presentations by professionals on a variety of topics surrounding HIV/AIDS and hepatitis C. It is hoped that the outcomes of this summit will enable EATAN and partners to strengthen advocacy efforts for HIV/AIDS and hepatitis C care and treatment for migrant communities in both Eastern and Western Europe.



OVERVIEW

European African Treatment Advocates Network (EATAN) is a European initiative that aims to enhance the quality of life of black and minority ethnic (BME) people, particularly African migrants at risk of or living with HIV, viral hepatitis and other chronic conditions.

EATAN is committed to addressing the lack of voice and participation that African migrants have in the decision-making process for screening and treatment. Additionally, it collaborates with key stakeholders across Europe to influence policy, best practice and to empower individuals with information, skills and resources to access relevant services.

In July 2018, EATAN organised a summit in order to launch a campaign for a European African statement on immigrant community's inclusion. With new medications readily available, an opportunity exists to completely eradicate hepatitis C. To achieve this, pharmaceutical companies, governments, doctors, and health care purchasers need to invest in raising awareness and support the affected communities.

The summit partially highlighted the epidemiological data on affected communities, the factors that contribute to the risk of acquiring the infections and potential solutions. Additionally, it highlighted the role that trained advocates can have in addressing the risks.

It was expected that the development of an evaluation framework would be achieved in order to understand future trends in epidemics.

The deliberations incorporated surveys, focus groups discussions and a visit of 2 follow up projects that are funded for early this year. This enabled the EATAN and TAG team to understand how activities being delivered are impacting the lives of the target beneficiaries.

The first treatment advocates summit which was held in Brussels, included 30 previously trained and potential new advocates. This summit focused on sharing experiences and procuring recommendations for future work.

The summit planning committee received 98 applications. Selection criteria were based on how active the advocate was. These applications were evaluated by the extent to which the

advocate would improve access to services and contribution to advocacy for the immigrant communities. Other considerations included applicants' project location, topic, and leadership. 35 participants from immigrant and migrant communities, with 87 delegates representing other stakeholders, represented varying projects focused on immigrant communities.

The summit programme included projects and presentations from professionals of varying backgrounds. Following presentations, the participants engaged in discussion. Each presentation concluded by identifying a message that the participants would use to foster their advocacy efforts. The presentations focused on sharing experiences, case studies, epidemiology, advocacy tools, treatment guidelines, situation analysis and best practice. A number of presentations included research studies on HIV/AIDS and hepatitis C. Following the presentations, interactive discussions, participatory learning, and question-answer sessions took place, thus enabling each participant to actively contribute to the discussions.

Specific objectives of the summit:

1. To raise awareness on assessing the risk of acquiring these infections
2. To encourage affected communities to seek screening for infections
3. To involve advocates from affected communities to provide peer support
4. To develop reader friendly content targeting to enhance prevention programmes
5. To inform civil society and leadership about the importance of community health care support systems

Topics of discussion:

1. Epidemiological and evidence-based statistics updates
2. Disease knowledge and awareness
3. Existing health care systems and access to these systems
4. Effective prevention programmes
5. Support needed to deliver effective prevention and care
6. The role of advocates

DAY ONE

SESSION 1: KEYNOTE

BY DR IRIS SHIRIPINDA

Dr Iris Shiripinda , the Secretary of EATAN gave a welcome and opening statement. She highlighted the concern of gender imbalance between women and men in addressing access to care and treatment, citing the summit attendance, which had more men attendees than women. This was in contrast with the fact that women who more affected than men. Dr Iris lamented that in many cases migrants from countries such as Ghana, Nigeria, Cameroon, Ethiopia have been deported from Europe, arriving in their home countries where they end up succumbing to death due to such diseases. The chairperson of EATAN noted that advocates could play a key role in potentially influencing decision-makers to decrease deportation rates on the grounds of "Human Rights". An account on research conducted by UNAIDS in the fight against AIDS was given by Dr Iris. The findings of the research can be used to advocate for migrants to avoid deportation. Dr Iris was motivated by the fact that the research findings were used to push the Netherlands Government to listen and act. As a result, the number of deportations of such vulnerable people declined.

Citing the above example, Dr Iris rallied summit participants to stand together, speak with one voice and advocate for the recommendations from the research. There is a need to advocate for change in the way diagnoses and access to care and treatment is conducted in Europe and countries of origin for migrants. Dr Iris challenged the summit to address self-stigma on communities, corruption in the healthcare field and caring for youth and young women. She found the interactions with participants from various countries valuable and she hoped that this would give the call a strong voice to proceed forward.

SESSION 2: HCV & HIV TREATMENT UPDATE

BY DR RANJABABU KULASEGARAM – CONSULTANT PHYSICIAN ON HIV/HEPATITIS CO-INFECTION AT ST. THOMAS HOSPITAL

Dr. Kulasegaram's presentation focused on HIV and hepatitis C. Dr. Kulasegaram noted that HIV/AIDS and hepatitis used to be commonly understood as diseases found in special populations. He explained that it is important that individuals are conscious and aware of the diseases. If an individual believes that they could potentially be a carrier, that individual should test and, in the event, that they are infected, seek medical guidance from qualified professionals. "*Treat as soon as possible*" has become the standard of care for all HIV-infected individuals, pushing the idea that therapy should be initiated as soon as possible. Dr. Kulasegaram pointed out that testing-and-treating is now the primary HIV prevention strategy in the world of HIV/AIDS Care. Antiretroviral therapy (ART) can reduce individual-level morbidity and mortality for those affected, and has been demonstrated to significantly reduce transmission risk.

Dr. Kulasegaram explained the HIV Prevalence by Category with emphasis on the mother to child transmission. More details of Dr Ranjababu presentation can be found in his slides attached to this report.



SESSION 3: PREPARING TO START ART: INFORMATION AND READINESS

BY ROBERT FIELDHOUSE

The discussion brought out common thoughts regarding the start of ART such as uncertainty, anxiety and lacking confidence.

Potential barriers to starting treatment include finances, housing, childcare, fear and stigma. There are concerns around the tolerability of medicines, confidentiality/privacy concerns, as well as concerns around ease of access to treatment, care and support

What is needed to feel 'ready' to start?

- Information & Knowledge
- Communication & Involvement
- Access to care and support

There is a need to be well informed:

- Have a basic understanding of how drug resistance develops
- Feel more confident in the understanding of ART
- Feel more confident in decision making in relation to whether to start taking ART, and if not yet ready, to consider possible strategies needed for you to reach that point
- Know where to access the credible and accessible resources
- Translate materials for your audience

The presentation discussed Antiretroviral Therapy (ART) and the different drug classes as can be seen in the presentation attached to this report.

Six different types/classes of drugs that treat varying stages of the HIV life cycle:

- HIV treatment is often discussed as 'combination, triple or quadruple therapy' or 'HAART' (Highly Active Anti-Retroviral Therapy)
- These medicines are often referred to as 'ARVs' (Anti-Retroviral)
- Several recommended ART drug combinations are available combined as single tablets

Classes of Antiretroviral Drugs

- Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs); interfere with the action of an HIV protein called Reverse Transcriptase which the virus needs to make new copies of itself
- Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs); stop HIV from replicating within cells by inhibiting the reverse Transcriptase protein
- Protease Inhibitors (PIs); inhibit Protease, which is a protein involved in the HIV replication process
- Fusion Inhibitors; prevent HIV from binding to or entering human immune cells
- Integrase Inhibitors; interfere with Integrase enzymes, which HIV requires in order to insert its genetic material into human cells
- CCR5 Inhibitors; another type of entry inhibitor

More than 30 different ART drugs are now available, in several different & effective combinations:

Considerations for successful treatment

- Other current medications
- Own medical and family history, including co-existing conditions
- Risk of and/or planned pregnancy, contraception
- Individual 'readiness'
- Pill swallowing ability/ pill size and burden
- Lifestyle restrictions
- Social circumstances
- Sexual partnerships and partner transmission prevention
- Considerations for prescribers – e.g. cost, health insurance, local policy and drug availability
- Baseline tests and investigations

Starting ART /Clinical Preparation

- Blood chemistry (includes: liver, kidney, bone health markers)
- Full blood count (includes: white blood cells, haemoglobin and clotting ability)
- Blood tests for hepatitis, Cytomegalovirus, Toxoplasma and Sexual Health screens

- Viral load, CD4 count and CD4%
- Drug resistance and HLA B5701 test
- Cardio Vascular Disease risk assessment (includes; Body Mass Index, blood fats & blood pressure)
- Tropism testing may be considered

When is an individual ready to start ART?

- Many factors must be considered when deciding when to start ART
- Level of commitment, including motivation, incentives and personal goals, are major factors influencing treatment decisions
- Readiness depends on many factors, such as knowledge, your physical and mental health, previous HIV related illness, level of social support, etc.

Preparing to start ART

Before starting it is important to have:

- Basic knowledge of HIV transmission and prevention
- Basic understanding of ART & the possible side effects
- A belief that treatment is effective
- Anticipation that the benefits of ART will outweigh possible disadvantages
- Ability to understand, cope with, and adhere to the recommended treatments, as prescribed
- A supportive environment, including a good relationship with your clinic, to help you manage your treatment
- A willingness to address other possible obstacles to ART

Additional Benefits of Starting ART

- After starting ART, you will probably begin to develop:
- Increased knowledge that helps you cope with and manage your HIV status and treatment
- Increased confidence and skills in self-management

- An ability to recognise many treatment related side effects and/or HIV related infections
- Increased capacity to take action that promotes your health and well being
- A reassurance that comes with the knowledge that there is likely to be a reduced risk of transmitting the virus to others

Side Effects and What to Expect

- All medicines have the potential to cause unwanted effects
- Some side effects are to be expected, but they are not inevitable
- Most side effects are short term, mild and manageable
- Your health care team are experienced at giving clinical support and advice to help to relieve these effects
- Do not hesitate to seek advice on any new symptoms, especially possible (but uncommon) allergic responses including fever and rash symptoms

Tips for Effective Treatment Adherence

- Good preparation is vital
- Plan, especially for changes from your usual daily routine
- Devise systems to remind you of your dosing times
- Keep a diary of doses taken, any missed doses and any side effects
- Don't try to put up with side effects - seek advice as soon as possible



Session 4: RAISING AWARENESS OF TRANSMISSIBLE DISEASES AMONG MIGRANT COMMUNITIES: OPPORTUNITIES AND CHALLENGES: "A SWISS EXPERIENCE"

BY CELESTE UGOCHUKWU

Immigration statistics in Switzerland:

| |
|--|
| 2,053,589 foreigners, ¼ popu, 70% EU/EFTA, |
| 121,402 Asylum seekers, 18'088 in 2017 |
| 751'800 Swiss in abroad, 62% in Europe |
| Asylum seekers in 2017 |
| 78% of foreigners in 2017 came regular |

Examples of Raising Awareness with Migrants:

- Testing at registration camps for Asylum seekers
- Awareness raising and free condoms at Asylum camps
- Culturalization and intercultural competences
- Free intercultural translators for foreigners (4 official languages)
- Mobile info centers for sex workers
- Miss Africa (Swiss Aids Federation Ambassador) by African Mirror Foundation
- Awareness raising campaign at events and parties
- Current campaign in African community as pioneer 2017 (The Get Tested – Know Your HIV Status campaign)
- HIV tests during pregnancy

Recommendations:

- Empower migrants to seek out members of their communities to raise awareness in STD
- Adequate consultations of the most affected communities in policy formulation and implementation
- Communities are to encourage more of their affected members to reach out and take advantage of existing instruments
- Increase the finances of STD projects to engage more personal in the field
- Introduce more free treatment for disadvantaged victims
- Fight against marginalization syndrome in communities

Session 5: TREATMENT ACTIVISM AND ADVOCACY FOR HCV ELIMINATION – A FOCUS ON MIGRANT COMMUNITITES

**BY BRYN GAY AND ANNETTE GAUDINO – HCV PROJECT CO-DIRECTORS,
TREATMENT ACTION GROUP**

Bryn and Annette presented and exchanged ideas on treatment activism and advocacy for HCV elimination with a focus on migrant communities. In general, migrants have limited access to health care, and few know about their rights to health care in their host countries. Improving knowledge of their rights and access to health care requires a raising of awareness through public health campaigns and capacity building among peer educators, champion medical providers, and other advocates who directly engage with these communities.

Treatment activism involves understanding the basics of disease-relevant medicines and diagnostics currently available and in the pipeline, the immense treatment barriers that exist, while thinking through the enormous complexities of accessing health care for marginalized and at-risk populations. In translating the scientific evidence on HIV and HCV treatments and diagnostics, people living with and affected must have the educational tools and knowledge to empower their own advocacy for affordable treatment access.

Advocates from migrant communities can use data to dispel myths, understand political realities, and inform campaigns that could benefit overall migrant health. This approach can facilitate and guide progress towards developing a national elimination or micro-elimination strategy. This work must be developed in tandem with inclusion and consultation of affected communities, including migrants, so that elimination strategies are localized, tailored, accurate, and effective.

The session covered key issues:

- Treatment options in hepatitis C
- Evidence on effective treatment outcomes for people who inject or use drugs
- Examples of countries with and without viral hepatitis plans, as a call to action to demand that health systems incorporate migrant health concerns
- Review of treatment restrictions, intellectual property, licensing, and pricing barriers
- Drug criminalization and scarcity of harm reduction programs in numerous countries as driving the HIV/HCV epidemics

- Strengthening of treatment advocates' knowledge on HCV treatments
- Introducing concepts of HCV diagnostics in order to better raise awareness within their communities
- Engaging with policy-makers, and shape national and micro-elimination campaigns
- Including and amplifying migrant voices in EU policy debates
- Outlining of conditions and criteria for micro-elimination among migrant populations.



DAY 2

SESSION 1: HIV TREATMENT ADVOCACY FOR MIGRANT COMMUNITITES IN EUROPE BY BADRU MALE

Badru explained that there is a thin line between activism and advocacy.

Definition of advocacy

Advocacy is referring to support, argument for, calling for, pressing for, advising on, in favour of, pressing for, promotion and backing some action.

Badru gave a brief history of advocacy for migrant communities in Europe and how it has evolved. In the 1990's, HIV management was so poor that there were many HIV/AIDS related deaths. During this time, organizations started developing means of addressing the then devastating epidemic by providing support and advocacy to individuals living with HIV. Advocacy came in various forms as treatment was improved by various charities in the UK.

- Pre- combination therapy - (Treatment Action Taskforce, 1994)
- Era of combination therapy - (AIDS Treatment Project, 1996)
- Access to expanded treatment advocacy - (ATP, European AIDS Treatment Group, 1998)
- Civil society advocacy (UK Community Advisory Board, EATG 1998)
- Anti-stigma and discrimination advocacy (National AIDS Trust 2000)
- User Involvement advocacy (NAT, UKCAB 2004)
- No decisions about me without me (Positively UK,2006)
- PrEP (NAT, EATAN, UKCAB, THT, EATG , 2015)

As part of the presentation, participants were given information on EATAN and its' contribution to the field of advocacy in migrant communities in Europe. EATAN was born out of the need to advocate for access to treatment for migrant communities in Europe.

A combination of key advocacy skills have been used to achieve EATAN's aims and objectives including recruitment and training of advocates, and introducing prevention services to migrant communities. The participants were given additional details on the methodology and key advocacy skills that EATAN has used.

In so doing, EATAN expects to achieve efficient infection management, leading to reduction of onward transmission, and morbidity /mortality rates of People Living with HIV (PLH).

The network has registered steady progress in these initiatives. Advocates have been recruited and trained in Western Europe, and networking with major organizations like TAG, EATG has resulted in empowering migrant communities to access quality care and treatment services

Apart from the costs involved, the network has found it difficult to reach various communities, which need the services. In addition to being hard to reach, it has proved challenging to confront some of the health beliefs that some migrant communities hold. It is important to note that migrant communities come from varying cultural backgrounds with belief and value sets. There is the element of changing needs of the target communities, which calls for additional skills and resources.

Moving forward, EATAN will continue with the recruitment and training of advocates, working with existing statutory and non- statutory organizations, building capacity of the organizations and individuals, and advocating for quality care, support and treatment of HIV and hepatitis C.



SESSION 2: EUROPE'S "INTEGRITY" ON MIGRATION, HIV/AIDS AND THE BODY POLITIC

BY DR TODD SEKULE and SR AYATA DZIUBAN (Poland), University of Berlin

The "Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health" (EUROPACH) project, which is funded as part of the third joint research programme of the Humanities in the European Research Area (HERA), investigates how the past has shaped the current field of HIV policies, and the initiatives of the past that may have been forgotten in contemporary projects of health policy or activist commemoration.

Conceptually, the programme aims to understand how different forms of citizenship exist across Europe in relation to HIV. With the term citizenship, we refer to one's legal status as a citizen, but also to the terms that determine the relationship between a given state and its subjects. The materials gathered during EATAN's research is being compiled into a project referred to as a "European HIV/AIDS Archive". This will be made available through EATAN's website as the project progresses. Central to this archive is a European HIV/AIDS Oral History sub-archive that, to date, includes 85 interviews.

In this presentation, EATAN relies on proceedings from three European Court of Human Rights cases that pertain to the politics of migration in relation to HIV. These proceedings are used to argue that there is an unstable blending of humanitarianism and securitisation. They juxtapose a perception of undue suffering against a sense of mounting crisis, functioning through an appeal to compassion and insistence on an impending threat and danger. Moreover, EATAN suggests that embedded in each of these regulatory strategies are varying concepts of integrity. EATAN argues that the humanitarian side of this metaphorical pendulum functions through an investment in what we call the integrity of the body. By this, EATAN means that the body is imagined as somehow typically healthy and thus as "whole" or "complete", and that HIV poses exceptional harm to the health of the body, thereby provoking damage in that sense of wholeness and thus justifying exceptional measures in existing approach to migration.

Securitisation-driven decisions, alternatively, function through variously conceived notions of what we describe as territorial integrity. Through the policing of borders in the name of securing the lives of state subjects who exist within a territory, the terms of belonging to and conditions of exclusion from membership in that model of subjecthood produce a sense of

“wholeness”, a sense of integrity, albeit one that exists in states of multiplicity, ephemerality, and contestation. EATAN suggests that these two concepts of integrity lie at the heart of both methods for managing migration in relation to HIV.



Session 3:

ECDC: LATEST EPIDEMIOLOGY ON MIGRANTS IN THE EUROPEAN UNION

BY DR. TEYMUR NOORI (HIV EXPERT-ECDC)

ECDC Latest epidemiology on migrants in the EU (both mono and co-infection data)

- The burden of Infectious diseases
- Screening newly arrived migrants
- Countries should deliver training on HIV Care
- Evidence of screening is weak and limited
- Recommendations are weak.

**viral
hepatitis
2030**



SESSION 4:

COMBATING HIV/AIDS, VIRAL HEPATITIS AND TB IN THE EUROPEAN UNION AND NEIGHBORING COUNTRIES, POLICY INSTRUMENTS AND GOOD PRACTICES

BY JEAN LUC

Jean Luc presented the "Staff Working Document Combatting HIV/AIDS, Viral hepatitis and Tuberculosis", which highlighted the frameworks, approaches, guidance, experiences, and best practices that were used, transposed and adapted to help Member States improve their response and reach the Sustainable Development Goals.

The working document supports decision makers, stakeholders, and interested citizens with an overview of policies, approaches, guidance, experiences and best practices that have proven to generate impact on HIV/AIDS, viral hepatitis and tuberculosis prevention, control and treat

For this discussion, focus was placed on Sustainable Development Goal 3.3, which is related to good health and well-being.

There are several EU policy instruments, which can be mobilized to combat HIV/AIDS, viral hepatitis and tuberculosis:

- Public Health
- EU Drugs Strategy and Programme
- Research Programmes
- Development Cooperation Policy which covers support to Global fund to fight HIV/AIDS, tuberculosis and malaria and advocates for Universal Health Coverage among others.
- EU Structural and Investment Funds (ESIF)
- Instrument for Pre-accession Assistance (IPA)
- European Neighbourhood Policy (ENP)
- The Northern Dimension (EEAS)

Several types of actions have contributed to the tackling of HIV/AIDS, viral hepatitis and tuberculosis:

- Technical guidance to tackle the epidemics by ECDC and EMCDDA
- HIV and STI prevention among men who have sex with men
- Systematic review on the diagnosis, treatment, care and prevention of tuberculosis in prison settings
- Prevention and control of infectious diseases among people who inject drugs
- Early diagnoses of HIV, viral hepatitis and tuberculosis
- Integration of treatment and care
- Civil society involvement in the response
- Early diagnoses of HIV, viral hepatitis and tuberculosis
- Integration of treatment and care
- Civil society involvement in the response

Jean Luc went on to provide a link where additional information on the topic can be found:

https://ec.europa.eu/health/sites/health/files/communicable_diseases/docs/swd_2018_387_en.pdf



SESSION 5: PANEL DISCUSSIONS AND WAY FORWARD

The panel discussions highlighted the following themes and participants had the opportunity to exchange ideas and brainstorm on how to address them:

- Importance of disclosure to partners
- Fighting stigma
- Patients asking for Rx in the community
- Stigma on evidence-based models
- Space for community development



SESSION 6:

A QUALITATIVE STUDY EXPLORING COMMUNITY CHARITY WORKERS' PERSPECTIVES ON MEDICATION ADHERENCE AMONG AFRICAN MEN ON LONG TERM HIV TREATMENT IN SOUTH EAST LONDON

BY BONIFACE OBURU

Boniface Oburu presented findings of a qualitative study that explored community charity workers' perspectives on HIV medication adherence. This study was conducted in order to recommend adherence improvement strategies for African men on long-term HIV treatment in South East London, to public health stakeholders.

The study sought to understand community charity workers' perspectives on African men HIV medication adherence. Despite constituting only 5.5% of London's population, Africans are the second largest group using HIV services. African men present late to HIV services and poorly adhere to medication. Non-adherence denies optimal treatment benefits, does not suppress onward HIV transmission, and may precipitate drug resistance and treatment failures. It is a public health problem costing the NHS £4 billion yearly. The study uncovered issues specific to South East London African men's adherence to ARVs.

Boniface presented in detail the finding of the study, which included the following:

Barriers to HIV medication adherence

- Living & working conditions (shared housing, nature of work, lifestyle, side effects)
- Psychosocial stress factors (immigration status)
- Gender & cultural socialization barriers (equating illness to weakness, "feel good" paradox versus adherence)
- Individual motivations, attitudes & knowledge (denial, treatment literacy, forgetfulness)
- Interaction with health system (time, patient/doctor power imbalance)

Facilitators of medication adherence

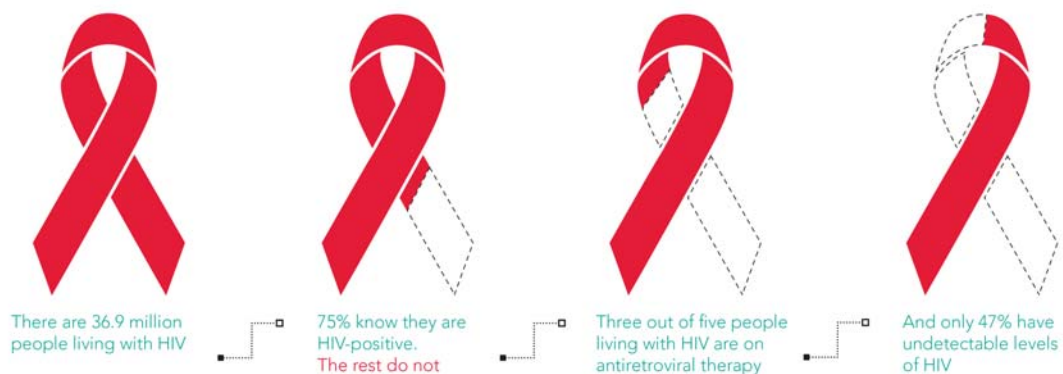
- Peer support sessions
- Disclosure/ friends & family support
- Health care support (Health professional, HIV consultants)

- Knowledge levels (treatment literacy, side effects management/reminders /pill dosage boxes/associations with daily routines)

The study had recommendations as follows:

- Strengthening linkages between Gento-urinary medicine (GUM) clinics & community groups
- Upscale community organizations peer support sessions
- Further reductions on ARV's pill frequency, pill numbers, sizes.
- One tablet a month/ a week

90-90-90: Treatment for all



90-90-90 HIV treatment targets

30 million people on treatment by 2020

90% of people living with HIV know their status

90% of people who know their status are on antiretroviral therapy

90% of people on antiretroviral therapy achieve viral suppression

SESSION 7: USER/PATIENT DRIVEN MEDICAL CLINIC FOR PLWHIV IN NORWAY

BY MARIAN SAID

Vision: Promoting optimal health through a holistic treatment approach and empowering the individual patient.

The presentation outlined the process of developing and implementing user-driven care at Sørlandet Hospital in Kristiansand, Norway. The vision of healthcare should be approached holistically – it is not solely physical health that is important. In tandem, there are the considerations of the psychological, social and spiritual well being of the individual.

Transitioning to user-driven care was initiated by the head of infectious diseases, who oversaw the HIV clinic. Participants living with HIV were invited to brainstorm about the question, “How would you run the clinic differently?”

This resulted in a “patient order” that outlined the necessary components for better care as defined by the patients themselves, including:

- Creating the position of “HIV Coordinator” to have oversight of aspects of a user’s care
- Initiating interdisciplinary team meetings and individual patient plans
- Developing comprehensive checklists to ensure that all aspects of the user’s care is addressed and monitored
- Developing and implementing the learning and mastering courses for all users to give them the knowledge and skills they need to participate in their own care
- Systematic use of peer support
- Secure communications via a mini-journal
- Clinic needs to follow national guidelines
- Psychosocial measures integrated into services
- Need for management and responsibility for the project

The initiative started as a pilot project and has since been applied to 133 patients. The project has proven successful.

One of the key concepts of user-driven care at the Sørlandet Hospital is the function of the HIV coordinator, who is a nurse. This position is a link between the patient, specialist health services, the GP and other services. The HIV coordinator assists the users in ensuring that aspects of their care needs are addressed appropriately. The HIV coordinator also helps to develop and manage the individual plan with the user and to identify health outcomes and the services required to achieve them.

To facilitate the individual plan, quality of life checklists have been developed, which are available to the user and to the healthcare providers. The checklist is used throughout the lives of the patients. That way, even if one of the points on the list are not relevant at that time, you can still look back on it later. For new patients, low threshold testing is key.

Another important component of the clinic care is the intensive training that users undergo to ensure that they understand their role in user-driven care. These courses are mandatory to ensure that the interaction between service providers (including the HIV coordinator) and the user are productive.

User involvement in care has increased significantly. Before 2012, there was minimal user input and now there is active engagement between users and service providers.

Today, there is increase adherence, improved quality of life and improved cost efficiency.

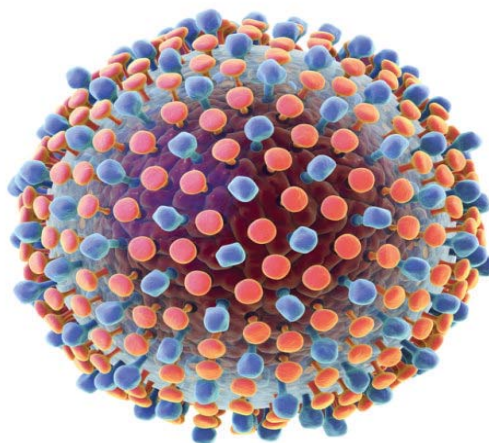
Questions still remain. Is there true power sharing and influence on all levels regarding diagnosis, prevention, treatment and care? Although a formalized user forum comprising patients are given formalized decision-making at the institutional level, does that mean that the goal should be absolute equality? Is user governance a means to get there?

The Sørlandet Hospital experience is almost ideal: those in power were ready to accept user influence; there was money and willingness to hire people to manage the new processes; and the Norway is a country where the laws and budgets allow for this kind of change.

FEEDBACK

Issues Raised in Discussion:

- Participants were concerned about ways of reaching out to some communities that seem to be hard to reach.
- It was noted that there was a need for EATAN to develop a living website with resources that are specifically intended to target migrant communities.
- Participants agreed to develop activist and political education skills which will enhance their capacity to lobby the relevant sectors for services for migrant communities
- There was intense discussion on coordination of the network and a campaign going forward - map policies in EU and involvement of migrant communities
- The need to develop the necessary tools that would be useful when meeting with policy makers. The summit report is one of such tools that will be very useful for this. Once the report has been prepared, efforts should be made to disseminate it using all avenues like radio and other media
- The participants felt that they were empowered, but they still felt the need for more capacity building and training on HIV/HCV treatment and diagnostics
- TAG pledged commitment to continue working with EATAN and to support EATAN priorities. TAG committed to dissemination through social media, sharing information of funding opportunities and providing consultation and capacity building for EATAN when their services are required.



CONCLUSION

The summit was attended by a spectrum of professionals and community representatives from different organizations that address the health issues of migrant communities.

The presentations and discussions were rich with research regarding the concern for migrants' access to care and treatment for HIV and hepatitis C. The summit highlighted the extent of the epidemic and the affected communities by professional epidemiologists, the risk factors that contribute some people being exposed to these viruses, and potential solutions to the problems.

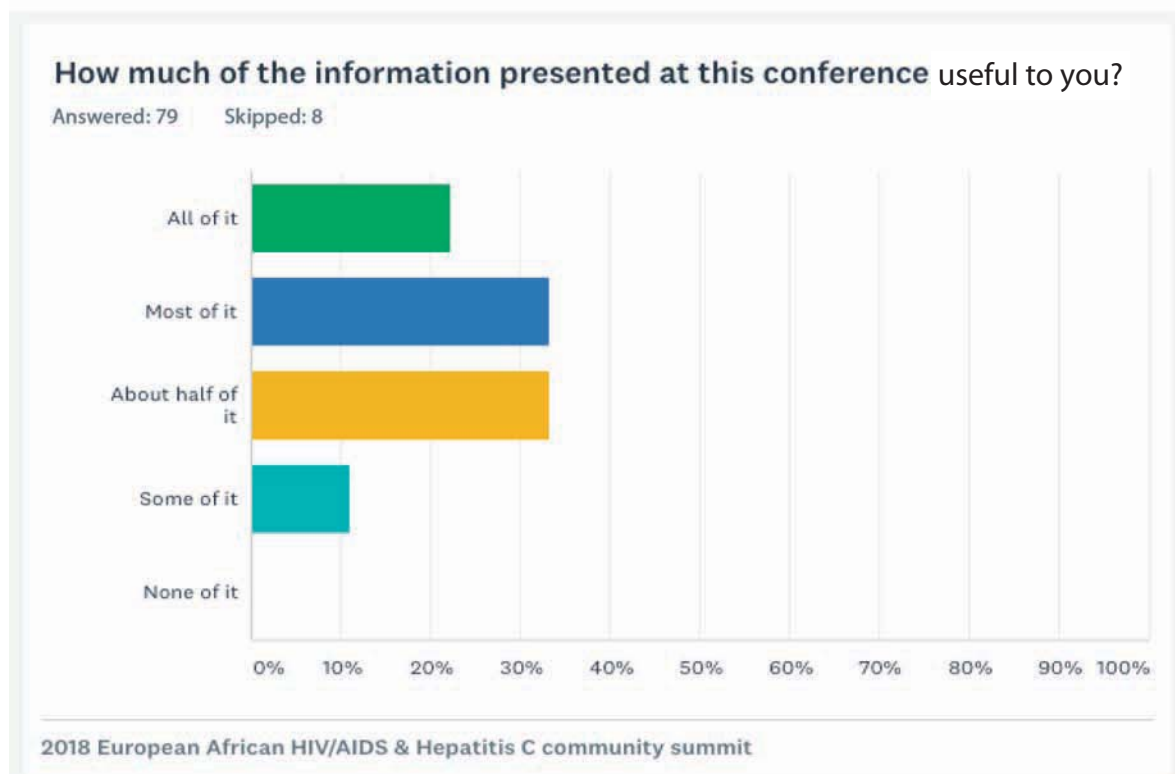
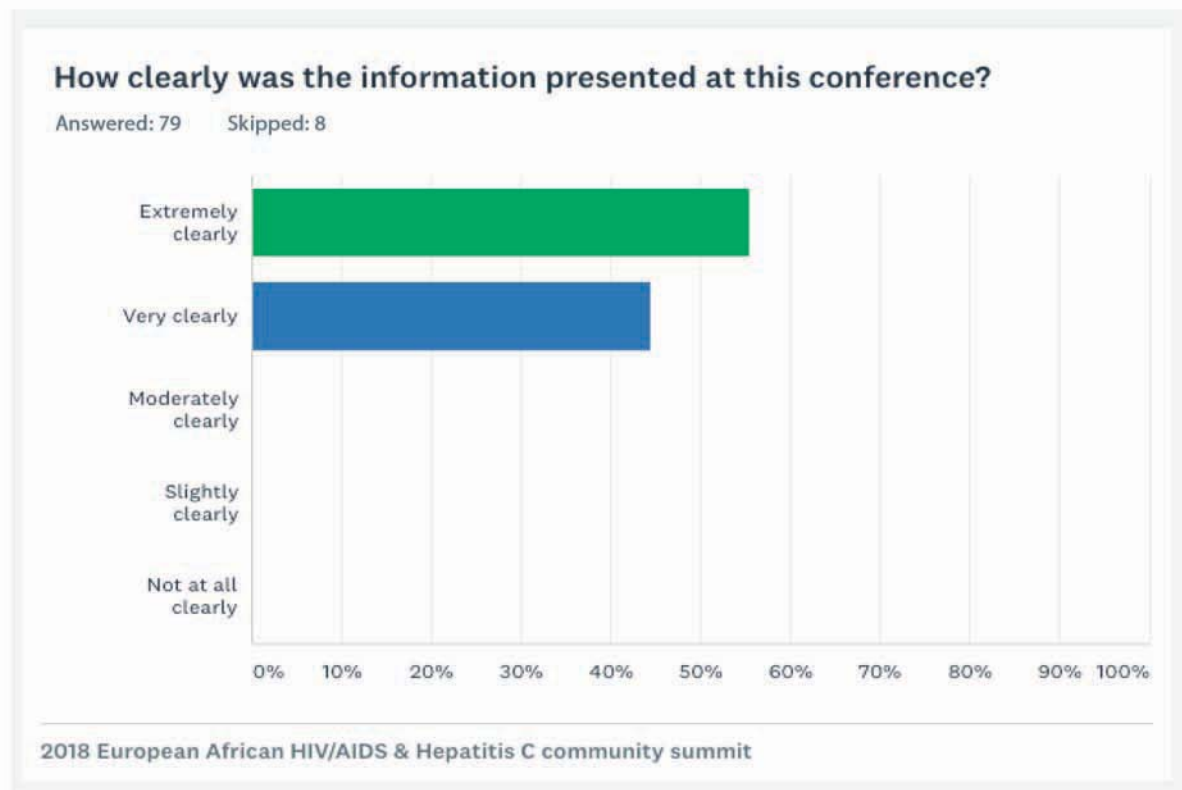
The summit highlighted the role of trained advocates in addressing the risks associated with limited provisions to care and treatment for both people living with HIV and/or HCV and communities affected by these infectious diseases. Participants developed an evaluation framework to understand the impact of the summit and to review future programmers. (Highlights of the evaluation are included in the Annex of this report).

The Summit was able to launch a campaign for a European African consensus statement on migrant communities' inclusion in decision-making processes and to develop enduring cooperation and commitment towards HIV and hepatitis C elimination. With new treatment regimens that treat all genotypes, or all genetic variations, of the hepatitis C virus, an opportunity exists to make HCV elimination a reality. To fast-track elimination, the Summit considered the diverse healthcare policy landscape among EU states, patient education and empowerment practices, barriers to accessing affordable diagnostics, care for migrants, and treatment advocacy and activism strategies needed to catalyze policy changes.

At the end of the summit, organisers launched a press release (included in the Appendix).

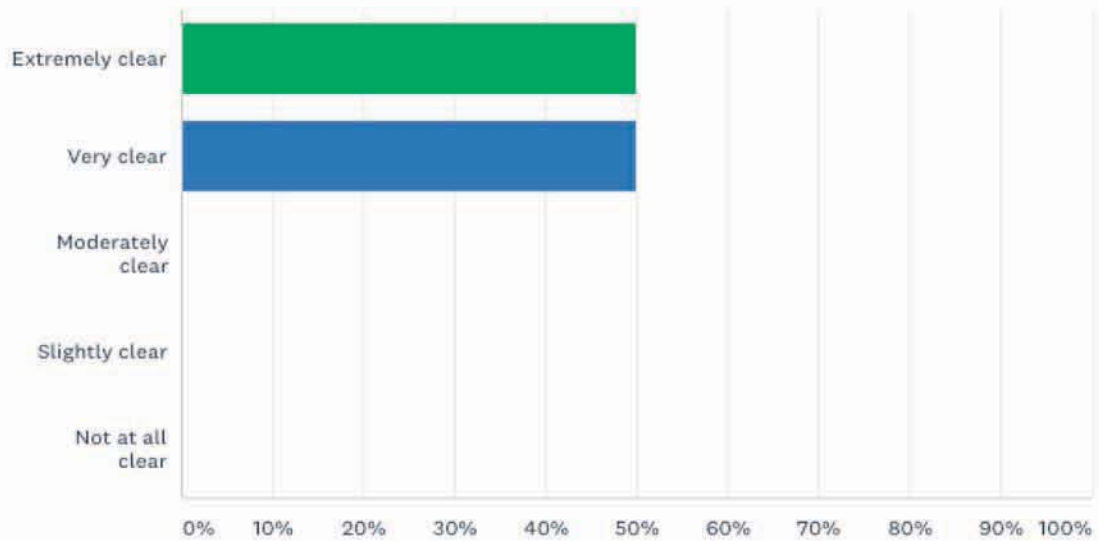
EVALUATION

Following the conference, a survey was sent to participants in order to gauge satisfaction and overall success of the event. The survey allowed for participants to select areas that could be improved for future conferences.



How clear were the objectives of this conference?

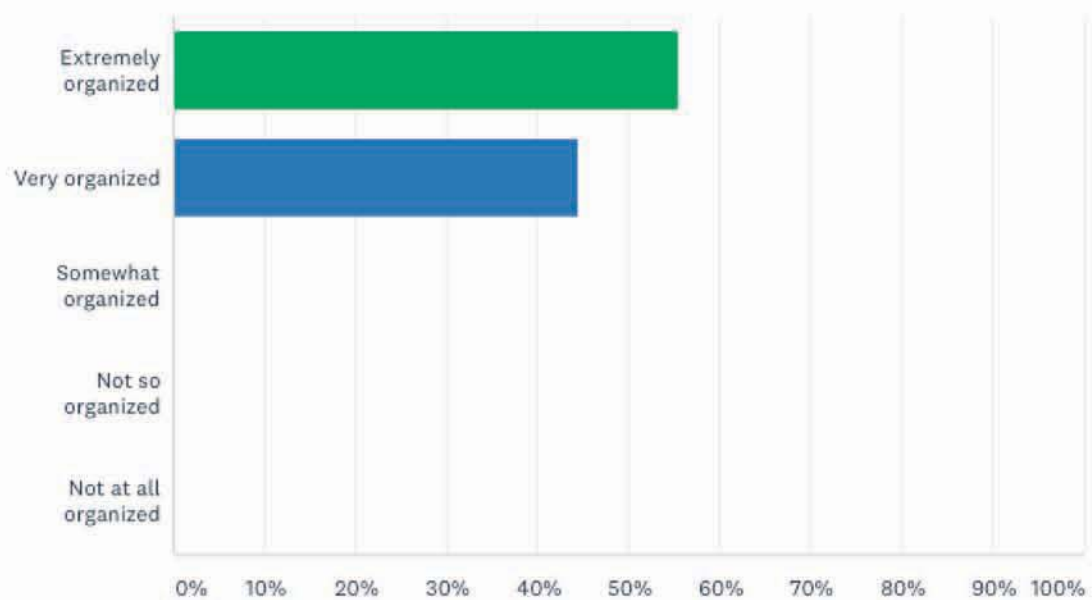
Answered: 79 Skipped: 8



2018 European African HIV/AIDS & Hepatitis C community summit

How organized was the event?

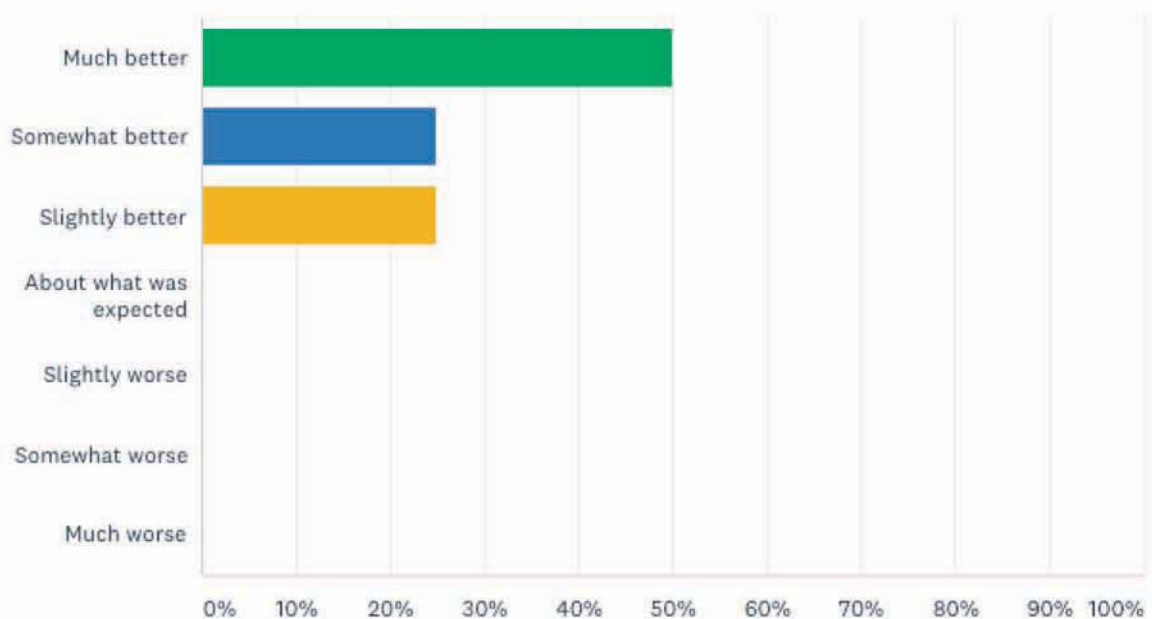
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2018 European African HIV/AIDS & Hepatitis C community summit

Was the conference better than what you expected ?

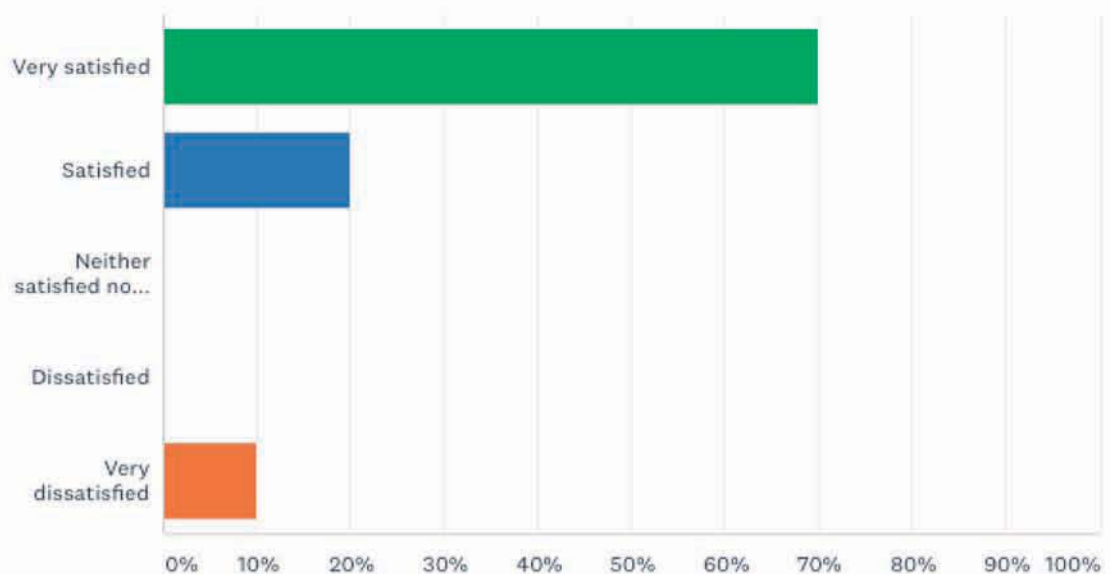
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2018 European African HIV/AIDS & Hepatitis C community summit

Overall, were you satisfied or dissatisfied with the conference?

Answered: 79 Skipped: 8

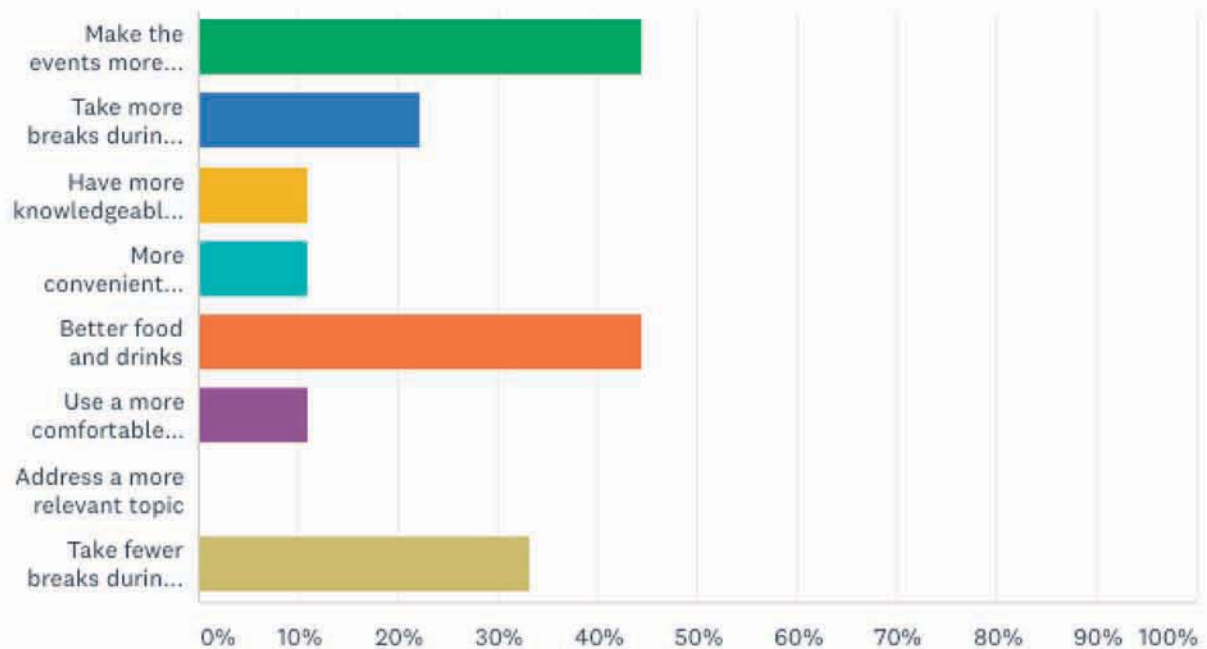


2018 European African HIV/AIDS & Hepatitis C community summit

How could future events be improved? Select all that apply.

Answered: 79

Skipped: 8



2018 European African HIV/AIDS & Hepatitis C community summit

Appendix



2018 European African HIV/AIDS & Hepatitis C Community Summit
"Our Voices Matter for a lasting solution!!"

PRESS RELEASE

Migrants' Inclusion Central to Achieving HIV and Hepatitis C Targets by 2030

Press Release No. 18/01126/ 06, 2018

26 July, 2018, Amsterdam, The Netherlands — The European African Treatment Advocates Network (EATAN), in partnership with Treatment Action Group (TAG) and other migrant-focused organisations, hosted the European African HIV & Hepatitis C Virus (HCV) Community Summit 2018. The Summit was organised as an AIDS 2018 Pre-Independent Affiliated event, taking place on 21-22 July 2018 in Amsterdam, and attended by 87 delegates from across the EU, and with 10 technical experts from the EU and North America.

The Summit aimed to launch a campaign for a European African consensus statement on migrant communities' inclusion in decision-making processes and to develop enduring cooperation and commitment towards HIV and hepatitis C elimination. With new treatment regimens that treat all genotypes, or all genetic variations, of the hepatitis C virus, an opportunity exists to make HCV elimination a reality. To fast-track elimination, the Summit considered the diverse healthcare policy landscape among EU states, patient education and empowerment practices, barriers to accessing affordable diagnostics, treatment, and care for migrants, and treatment advocacy and activism strategies needed to catalyse policy changes.

"There should be a policy and clear protocol on people living with HIV and hepatitis C. Lack of this is a pointer to discrimination and exclusion of these people from essential services...HIV/HCV is not only a threat to the lives of those living with these conditions but to the public, in general," said Dr. Iris Shiripinda, Secretary General at EATAN.

Koen Block, Executive Director at the European AIDS Treatment Group, said, "More than ever this conference has shown how important it is to reach out to – and collaborate with – key populations such as migrants to effectively fight HIV and other infections, such as hepatitis C. Including the community can really make a difference."

The Summit delegates also learned about the role of community involvement in impacting HIV/HCV policies and micro-elimination processes. The network has the potential to influence policies aimed at affordable, equitable, and effective treatment and diagnoses for this key population and the myriad structural barriers and social injustices they face.

"Marginalisation and criminalisation of migrant communities is not a public health policy. The voices of migrant communities, particularly people living with hepatitis C and people who use drugs, must be centred in national viral hepatitis plans and in developing strategies to ensure the most optimal, affordable treatments and diagnostics are available for everyone who needs them," said Bryn Gay, HCV Project Co-Director at Treatment Action Group (TAG). "The community summit was an essential step in strengthening the technical knowledge of treatment advocates and ensuring the latest scientific research could be translated and utilised by treatment advocates, migrant community members, and people living with HIV/HCV to affect policy changes needed for eliminating hepatitis C in this overlooked, marginalised population."

Delegates had the opportunity to share ideas with experts from the European Union, the European Centre for Disease Prevention and Control, National Health Service in England, among others.

“[There] was a unified voice of immigrants, asylum seekers and refugees at the summit. This summit came at the right time when advocates in the UK are dealing with the hostile environment created by the UK government against the above-mentioned groups of people. There can never be progress in health care in Europe when migrants, asylum seekers, and refugees are being stigmatised, scapegoated, and denied access to basic health care,” stated Edwin Sesange, Director at the African Equality Foundation.

Participants agreed that pharmaceutical companies, governments, health care professionals, and health care purchasers must commit to opportunities that ensure that HIV and HCV medicines are immediately available and accessible to all.

The sponsorship from ViiV Healthcare Europe Ltd, Gilead Sciences Europe Ltd, the Ganda Foundation, Radio Kyeyo Amsterdam, and Hotel Aalsmeer is acknowledged by EATAN for convening the community summit.

About EATAN

European African Treatment Advocates Network (EATAN) is an exciting Europe-wide initiative founded in 2012 by a team of treatment advocates passionate about improving the health and social care outcomes of Africans living in Europe who are affected by HIV, viral Hepatitis and TB. We are motivated to promote patient involvement, reduce stigma and discrimination and enhance access to culturally sensitive health and social care professionals; through developing and implementing a range of innovative policies and practices that ensure Africans living in Europe achieve empowerment, the ability to make informed choices, an unrestricted attainment of health and social care and an improvement of physical and emotional well-being.

Contact

UK office
3rd Floor
207 Regent Street London
W1B 3HH London United Kingdom Tel: +44 203 0265826 Hotline +44 747 544 6182

About Treatment Action Group

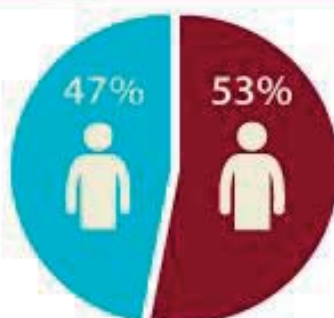
Treatment Action Group (TAG) is an independent, activist and community-based research and policy think tank fighting for better treatment, prevention, a vaccine, and a cure for HIV, tuberculosis, and hepatitis C virus. TAG works to ensure that all people with HIV, TB, or HCV receive lifesaving treatment, care, and information. We are science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions. TAG catalyses open collective action by all affected communities, scientists, and policy makers to end HIV, TB, and HCV.

Contact

Treatment Action Group
90 Broad St, Suite 2503
New York, NY 10004
Tel: 212.253.7922
Fax: 212.253.7923
tag@treatmentactiongroup.org

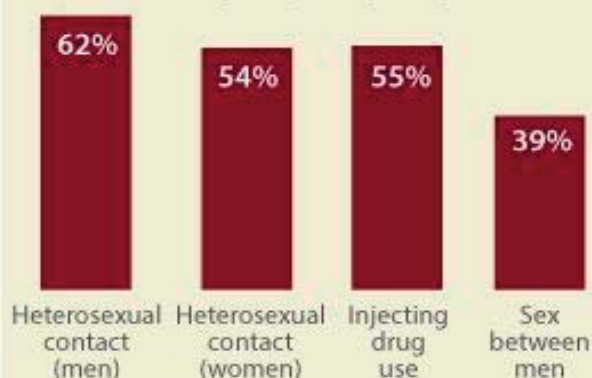
Half of people with HIV in the WHO European Region are diagnosed late.

Early diagnosis
results in longer and
healthier lives and
reduces transmission.

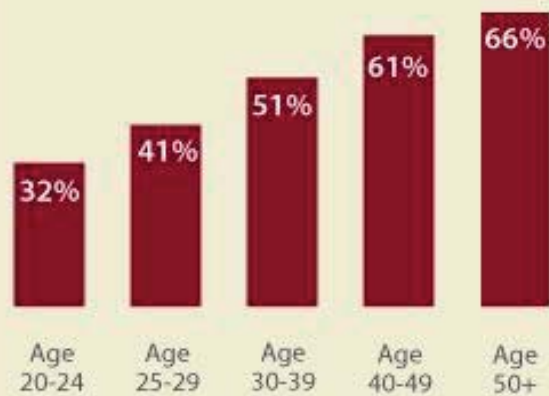


Late diagnosis
delays treatment and
increases the risk of
AIDS and death.

Percentage of people with HIV
diagnosed late is higher among those
infected **heterosexually**, particularly men,
or through **injecting drug use**.



Percentage of people with HIV
diagnosed late increases with age
and is highest in people **over age 50**.



**Make HIV testing
free and easy to
access**



**Ensure rapid
HIV treatment
and care**



Based on data from 40 of 53 WHO European Member States. Source: European Centre for Disease Prevention and Control, WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2018 – 2017 data. Copenhagen: WHO Regional Office for Europe; 2018.

Test earlier. Treat all.

www.euro.who.int/aids

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