



European
AIDS Treatment
Group

Annual Report / 2018

(January – December)

Catch up
with the evidence
Reach out
to communities
Integrate
services

‘We have the evidence and the tools to implement in order to improve the health of millions of people left behind in Europe and Central Asia. We now need the political determination to build and retain resilient and people-centered health systems. We all must catch up with existing evidence and commitments so the people and services that are lagging behind can catch up with us and our real needs’

Catch up

with the evidence and commitments

Reach out

to communities in law/policy making, programmes and research that affect their lives

Integrate

services to facilitate access and uptake of prevention, testing, treatment and care



Quotes (pages: 2, 7, 11, 19 and 24) from:

EATG AT THE 22ND INTERNATIONAL AIDS CONFERENCE:
CATCH UP WITH THE EVIDENCE AND GIVE OUR COMMUNITIES
THE SERVICES WE NEED

<http://www.eatg.org/news/22ndias-catch-up/>

Acronyms

ARV	Antiretroviral
AVAC	AIDS Vaccine Advocacy Coalition
CHIP	Centre of Excellence for Health, Immunity and Infections
CoPE	Continuous Patient Education
EU CSF	European Union Civil Society Forum
EC	European Commission
ECAB	European Community Advisory Board
ECDC	European Centre for Disease Prevention and Control
EFGCP	European Forum for Good Clinical Practice
EFOEUPATI	Ensuring the Future of EUPATI Beyond 2020
EFPIA	European Federation of Pharmaceutical Industries and Associations
EHVA	European HIV Vaccine Alliance
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EmERGE	Evaluating mHealth technology in HIV to improve Empowerment and Healthcare utilisation: Research and innovation to Generate Evidence for personalised care
EPF	European Patient Forum
EPHA	European Public Health Alliance
ESF+	European Social Fund Plus
ESTICOM	European Surveys and Trainings to Improve MSM Community Health
ETW	European Testing Week
EUPATI	European Patient Academy of Therapeutic Innovation
HAND	Hepatitis Access Needs
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIVACAR	Evaluating a Combination of Immune-Based Therapies to Achieve a Functional Cure of HIV Infection
HTA	Health Technology Assessment
ILGA Europe	International Lesbian, Gay, Bisexual, Trans and Intersex Association - Europe
IMI	Innovative Medicines Initiative
Metrodora	Meaningful Engagement of Women in HIV Treatment Research
MSM	Men who have Sex with Men
PARADIGM	Patients Active in Research and Dialogues for an Improved Generation of Medicines
PE	Patient Engagement
PICUM	Platform for International Cooperation on Undocumented Migrants
PLHIV	People Living with HIV
PrEP	Pre-exposure Prophylaxis
PROM	Patient Reported Outcome Measures
QoL	Quality of Life
R&D	Research and Development
SDG	Sustainable Development Goal
SPC	Supplementary Protection Certificates
TB	Tuberculosis
TB CAB	Global Tuberculosis Community Advisory Board
WHO	World Health Organisation

Achievements shown in numbers

Governance

- 1** General Assembly
- 7** Board of Directors Meetings (& **8** Teleconferences)
- 1** EATG Stakeholders' Meeting
- 3** Staff Strategic Meetings

Training

- 8** face-to-face trainings organized
- 63** people trained in face-to-face trainings
- 4** translations/new publications and a total of **2,200** printed copies were distributed through local organisations and HIV clinics
- 6** webinars conducted
- 3** advocacy and awareness raising campaigns, **1** position paper and research proposal and **312** people trained in the course of **7** follow-up projects implemented by participants of EATG trainings

Projects¹

- 14** projects of which:
 - 6** are initiated and/or led by the EATG: STEP-UP, CoPE, Ageing with HIV, Metrodora, HAND, HIV Long-Term Health Survey
 - 8** are in partnership with other organisations (not led by EATG): **HIVACAR, EHVA, EmERGE, ESTICOM, EUPATI, EFOEUPATI, PARADIGM², M-Care**
- 1** 'Ageing with HIV' conference with **97** participants from **28** countries
- 1** 'Metrodora' multi-stakeholder meeting with **40** participants from **15** countries

¹For more information please visit: eatg.org/projects

²These projects have received funding from the European Union 

Science

- 3** European Community Advisory Board (ECAB) meetings (**2** on HIV; **1** thematic meeting on viral hepatitis)
- 1** scientific meeting on diagnostics developments
- 1** workshop on long term remission from HIV infection
- 1** advocates' consultation on HIV vaccine trial
- 8** community reviews of protocols for clinical trials and document related to R&D

Policy, Advocacy and Political Mobilisation

- 15** events with public health policy makers in which EATG contributed speakers, advised the programme development and/or provided input to conferences' call for action/ outcome documents
- 4** strategy defining meetings of partners EATG engaged with (ILGA Europe, EPF, EPHA and PICUM)
- 1** stakeholders' session on women (AIDS 2018 conference)
- 2** co-organised, chaired and attended Civil Society Forums on HIV, viral hepatitis and TB and one Think Tank meeting in June and December
- 2** Civil Society Forums on Drugs attended
- 2** position papers (sex work & drug policy)
- 1** community research report with policy recommendations on prison health
- 15** initiated or signed-on letters statements (**3** TB, **1** HCV, **3** key populations, **1** HTA, **3** EU health agendas)
- 4** press releases (on data protection, on patents, addressing the AIDS 2018 conference, on seeking justice for a murder)
- 1** co-organised European NGOs booth showcasing community policy and advocacy work, bringing together policy-makers, influencers and community together for debates.

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1.1 OUR STRATEGIC GOALS AND OBJECTIVES (2016 – 2018)

1.1.1 TARGET RESOURCES ON ACCESS GAPS AND SPECIFIC KEY POPULATIONS



‘We cannot tolerate that 2 out of 3 PLHIV in Eastern Europe and Central Asia do not have access to ARV medication. We cannot tolerate the neglect and abuse of communities’ health caused by a punitive approach to substance use and sex work. We cannot tolerate the systemic stigma and discrimination based on sexual orientation, gender identity, ethnic origin or status of residence’

EATG organised and participated in a series of initiatives, activities and events focusing on **key populations** and prioritising **(sub-) regions, countries and cities with the greatest gaps to access** screening, prevention and affordable treatment.

Advocacy for policy frameworks at national and European levels to reach the Sustainable Developments Goals on HIV, TB and viral hepatitis

- EATG and partners have advocated for a **European Union Joint Action** -an initiative bringing EU member states to work together on a project- focused on **Gay men and other MSM to address HIV, viral hepatitis and other STIs**. Unfortunately, advocacy did not lead to the expected result. The topic was not considered a political priority for that year for EU funding.
- EATG provided input in the development of **EU and European level public health agencies policy documents**. EATG contributed to the expert panel of the ECDC testing guidance preparation. It contributed to the preparation of the **European Commission staff working document** on “Combating HIV/AIDS, viral hepatitis and tuberculosis in the European Union and neighbouring countries - State of play, policy instruments and good practices” published on 19 July 2018. The document -while it is not as political as civil society would have liked- can be used for local advocacy as it emphasises the need to address socio-economic determinants of health.

- In May, EATG, together with the EU Civil Society Forum (EU CSF) coordination team, organised the second meeting of the Forum, which examined **new developments, the issue of integrated services as well as explored joint advocacy**. At the same time, EATG jointly channeled EU CSF messages on **prevention** to EU member states institutions. There have been concerns about the **merging of the EU health programme into a larger single programme in the next EU Budget 2021-2027**. As the political profile of the current EU health agenda has already receded, **the EU Civil Society Forum reached out to the European Commission** leadership about this matter in March. The EC proposal for a “**European Social Fund Plus**” (**ESF+**) published in May suggests the merging of several programmes with social dimensions, including the EU public health programme. ESF+ would tackle health inequalities and support health policies and the response for cross-border health threats.
- EATG co-chaired the **EU-UNAIDS session with Ministers of Health** at the AIDS 2018 conference and took part in **the ECDC panel on the SDGs at the European Health Forum** in Gastein.
- EATG was selected to take part in the **EU Civil Society Forum on Drugs**, a European Commission experts’ group. It participated in its constitutional meeting in early July and in the November session in Brussels.
- EATG worked with partners to organise **a joint meeting of the EU CSF on drugs and EU CSF in HIV, TB and Viral Hepatitis in Brussels** in November that addressed policies that harm and those that enable prevention among **people who inject drugs**.
- EATG collaborated with both EU Civil Society Forums in **advocacy** towards the next **European Parliament and European Commission** (2019) to make the case for EU and member states leadership on health and addressing the needs of those communities that are inadequately served by the health systems.

Key populations greatly overlap. The needs of key population people are diverse among the groups and within the groups. Access to services varies greatly, depending on the region and social setting in which a person affected by HIV is living. This year EATG work focused on:

Gay men and other MSM
LGBTI
Drug Users
Migrants
People in Detention
Sex Workers



ESTICOM - European Surveys and Trainings to Improve MSM Community Health

(Timeline: September 2016 – September 2019)
esticom.eu



ESTICOM aims to facilitate access to and to improve the quality of prevention, diagnosis of HIV/AIDS, STI and viral hepatitis and health care services for **men who have sex with men (MSM)**. Two large EU-wide surveys gathered important data about MSM behaviour (EMIS2017) and Community Health Workers (CHW) (ECHOES). Moreover, a European training programme for CHW was developed. **EATG is part of the project consortium and many EATG members have contributed to the preparation and translation of the surveys.**

In 2018, EATG:

- attended an Expert Workshop in April to discuss the preliminary results from the surveys and the design and structure of the final reports.
- co-chaired the symposium “European surveys and trainings to improve MSM community health (ESTICOM)” at AIDS2018 conference in July, and contributed to the **Community Report**.
- as part of the project deliverables, submitted a report about recommendations for CHW training, based on the ECHOES survey findings and a literature review.

Hepatitis Access Needs (HAND)

(Timeline: March 2017 – March 2018)

This EATG-led project aimed at obtaining knowledge about access to hepatitis prevention, testing, treatment and care services in the European Region within co-infected key populations, as well as addressing their specific needs. The focus was on people in detention and migrant communities.

- A literature review and a desk research focusing on **people in detention** and **migrant communities** were finalised in a selected number of countries in Europe. Based on the findings, key policy recommendations were developed addressing major barriers to access. EATG translated the report focusing on people in detention **into Russian** to reflect the relevance of this topic for Eastern Europe and Central Asia.
- The report was launched during Spring European Testing Week and coincided with the launch of EMCDDA and ECDC public health guidance on active case findings of communicable diseases in prison settings. The report was also presented in a side event at the AIDS 2018 conference with the participation of Correlations, EMCDDA and other stakeholders.
- This year the project provided grants to local community organizations in Armenia, Romania, Russia and Kazakhstan to foster community mobilisation at local level.

EUROPEAN TESTING WEEK (ETW)

testingweek.eu



EATG is involved in the European HIV-Hepatitis Testing Week working group. In 2018, EATG supported both the sixth edition of the campaign and the spring pilot. **It reached out actively to different networks and groups representing the most affected populations** to explore which ETW joint actions should be taken so that the campaign reflects issues that they face. EATG reported on HIV, viral hepatitis and TB for the ETW working group in the EU CSF.

ECDC - HIV Testing Guidance in the EU/EEA

(Timeline: 36 to 48 months starting November 2016)



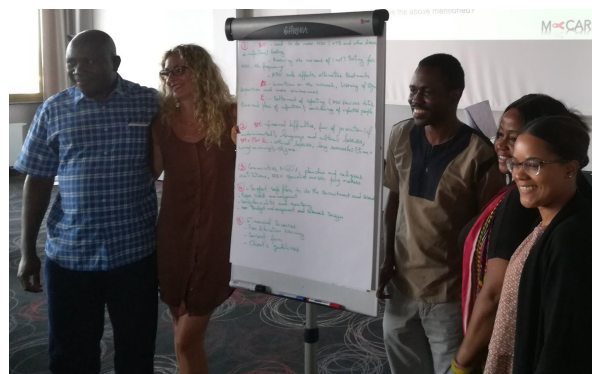
The ECDC guidance development process led by the CHIP programme in Copenhagen concluded and was released in November. EATG has supported outreach to identify possible case studies of innovative testing models through our networks. Two EATG members were engaged in the expert panel review of the guidance.

M-Care 2018



Together with Africa Advocacy Foundation (AAF), EATG has implemented the **M-Care 2018 training programme**, targeted to **migrant populations**. Between March and June 2018, over the course of three modules, a group of **twenty European migrant community advocates** facilitated by nine trainers created a network willing to empower and bring positive changes back to their communities. The trainings focused on:

- barriers migrants face with regard to access to prevention, testing and treatment services
- epidemiology and co-infections
- migrant community activism
- practical approaches, tools and advocacy instruments for the future work of the trainees.



Move to Action!

(capacity-building seminar on HIV and STIs)

In February, EATG co-organised the 'Move to Action!' seminar with ILGA-Europe. The seminar focused on **how LGBTI organisations can most effectively address HIV in their work** and what opportunities for collaboration and synergies exist between LGBTI activism and HIV activism. The seminar built on and followed-up on the discussions held during the first capacity-building seminar organised in 2017. Following that training, EATG took part in a brainstorming session organised by ILGA-Europe on addressing the HIV epidemic in **MSM and trans communities** to feed into its next long-term strategy. In October, EATG jointly organised a workshop on sexual health promotion in migrants' communities with Metro Charity and UK Lesbian and Gay Immigration Group at the ILGA-Europe Annual Conference in Brussels.

1.1.2 INCREASE COMMUNITY INFLUENCE IN RELEVANT BIOMEDICAL AND SOCIAL SCIENCE COMMUNITIES

‘Ensure early community involvement to research agenda setting, as well as designing patient-reported outcomes. This is essential for the development of relevant, safe and effective prevention, treatment and diagnostics tools to address unmet medical needs and improve quality of life’

Beyond the political agenda, EATG has been advocating for the **meaningful and early involvement of community in clinical research and social sciences**. EATG has been pioneering community inclusion in biomedical research through successful models such as the European Community Advisory Board (ECAB).

EATG experience in discussions with various stakeholders that design and implement programmes has shown that community is often considered as a needed, but not as an equal, partner.

Putting HIV and co-infections on the political and scientific agenda of relevant stakeholders

European Community Advisory Board (ECAB) meetings on HIV

During the two ECAB meetings on HIV (in April and November) members, other community representatives and allies from the WHO Europe region discussed the current R&D programmes and new strategies for HIV treatment with **Gilead** and **Merck Sharp & Dohme (MSD)**:

- **New medicines** entering the market
- **Safety, tolerability and clinical profile** of upcoming medicines
- **PrEP** and **biomedical prevention** programmes
- Potential strategies for **remission** of HIV or HIV **eradication**

A session of the ECAB meetings on HIV was dedicated to a thematic discussion on **Patient-Reported-Outcome-Measures (PROMs)**. EATG discussed with the companies on the following topics:

- Inclusion of PROMs in clinical studies
- Development and use of specific PROMs for PLHIV
- Involvement of community in the development of PROMs



Preparatory Webinars

As preparation for the discussions at the ECAB meeting in April, EATG organised two webinars:

- **What are patient-reported outcome measures and how are they used in medicines development?** led by Diana Barger, from the University of Bordeaux, and moderated by Giulio Maria Corbelli. The webinar provided participants with information on the concept, tools and application of **PROMs in R&D**.
- An internal webinar on the **most relevant advancements in medicines R&D** with a discussion about specific advocacy elements for the community. It was led by Simon Collins and moderated by Giulio Maria Corbelli.

Thematic ECAB on viral hepatitis

In December an ECAB meeting on **viral hepatitis** took place in Brussels with presentations by **Gilead**. The agenda included updates on **HCV programmes for key populations** (drug users, pregnant women, paediatric population) and **R&D plans for new HBV treatments and therapeutic solutions**. Dr. Stefan Dressler updated the participants on the HBV pipeline for new treatments.

Thematic meeting on diagnostics

In September a thematic meeting on **diagnostics for HIV and related co-infections** was organised in Berlin. Fifteen community representatives from various checkpoints and other community-testing initiatives around Europe met with **Cepheid, Abbott, Roche** and **AAZ self-test** to:

- Identify effective approaches for community testing in different settings and according to different targets.
- Investigate which products are marketed, which are in development and for which infections diagnostics tools need to be developed.
- Update the community on diagnostic tools- both approved and in development, pros and cons of point-of-care testing vs. laboratory testing.
- Review barriers -legal, regulatory, financial- to access of critical diagnostic tools in different European countries/regions and possible advocacy to address them.
- Foster understanding and collaboration between stakeholders.



Advocates' consultations on HIV vaccine trial

In September five EATG representatives participated in a consultation organised by AIDS Vaccine Advocacy Coalition (AVAC) in Amsterdam. The objective of the meeting was **to provide updates and obtain community feedback on Janssen's proposed HIV vaccine trial designs and possible trial participation**.

Community reviews of scientific material

EATG continuously advocates with industry, academia, regulatory bodies and other stakeholders involved in medicine process to integrate the perspective of PLHIV in R&D

for new medicines. From the beginning of 2018, ECAB members have been involved in the review of 8 scientific documents including protocols for clinical trials, clinical trial synopses, package leaflets and information material for medical products.

Participation in Clinical Trial Committees

EATG has been involved in the PARTNER study from its early stages, with EATG members sitting in the Executive Committee as well as co-authoring interim and the final results paper. The results of the second phase of the trial (PARTNER 2) were **presented in the AIDS 2018 conference**, attesting that the risk of HIV transmission through condomless sex in gay couples where one partner is HIV negative and the other HIV positive with undetectable viral load is zero.

PARADIGM - PATIENTS ACTIVE IN RESEARCH AND DIALOGUES FOR AN IMPROVED GENERATION OF MEDICINES

(Timeline: March 2018 – September 2020)

imi-paradigm.eu



PARADIGM is looking at providing a framework that allows structured, meaningful, sustainable and ethical **patient engagement (PE)**. It aims to demonstrate return on engagement for all players, through three key decision-making points of the development of medicinal products: **the research priority setting, the design of clinical trials and the early dialogue with regulators and HTA bodies**. PARADIGM's objective is to develop processes and tools for facilitating patient engagement in these three points in the medicine lifecycle, to develop a monitoring and evaluation framework and a sustainability roadmap for patient engagement. The Consortium is composed of 34 partners, including patient organisations, pharmaceutical companies, regulatory authorities and HTA bodies, universities and small and medium-sized enterprises (SMEs).

EATG co-leads the work package responsible for the **development of a set of recommendations on the required capabilities for patient engagement, a code of conduct and a set of guidance and tools for patient engagement in R&D**. EATG has an important role in different work packages.



In 2018, EATG contributed to the project through different means, namely:

- organising a webinar addressed to patients, community groups & patients organisations from all disease areas to inform about possibilities of engagement along the project and share the EATG experience
- contributing to the development of a survey to assess patient engagement needs and expectations of all stakeholders and a Delphi study to define priorities. These results will inform the work package co-led by EATG, to decide on the material to be developed for facilitating PE activities
- contributing to the development of recommendations on the required capabilities for patient engagement as part of the authoring group
- contributing to the project sharing our expertise with ECAB, providing it as a case study for further development of an M&E framework
- participating at project team and work packages meetings

EUPATI - European Patient Academy of Therapeutic Innovation

(Timeline: January 2017 - December 2019)

eupati.eu



EUPATI was a project funded by the Innovative Medicines Initiative (IMI) from 2012 to 2017, focusing on patients' involvement in medicines research and development across disease areas. In 2017, a 2-year follow-up project was created to ensure the promotion and sustainability of its deliverables. Currently, EUPATI operates as a public-private partnership led by the European Patients' Forum (EPF). EATG is part of the **Steering Group of EUPATI** and participates in the further **promotion and implementation of EUPATI training resources within its projects, membership and networks**.

- In 2018, EATG conducted a survey among its membership and STEP-UP participants about the use of EUPATI Toolbox in English and in Russian. The results show that **EUPATI is not widely known among the surveyed groups but those who had accessed the material had found it useful**. Further dissemination efforts are planned based on these findings.
- In April, a [webinar about the EUPATI toolbox](#) was conducted in Russian.
- A translation of an updated EUPATI brochure into Russian was completed in collaboration with EATG members.

EFOEUPATI - Ensuring the Future Of EUPATI

(Timeline: September 2018 - August 2020)

EFOEUPATI, was launched in September with the goal of ensuring the sustainability of the achievements of the EUPATI project: **the Patient Expert Training Course, the multilingual online Toolbox, and the EUPATI National Platforms Network**. The project is co-led by the European Patients' Forum (EPF) and Bayer and funded by the IMI. EATG acts as a **community partner** and participates in developing a sustainability/ business model for the EUPATI activities. EATG participated in the creation of a new Patient Education and Engagement Portal for information and resources for patients and other stakeholders aiming to ensure meaningful and value-adding patient engagement in medicines R&D. EATG participated in the kick-off workshop for the online portal development.

EHVA - European HIV Vaccine Alliance - an EU platform for the discovery and evaluation of novel prophylactic and therapeutic vaccine candidates

(Timeline: January 2016 - January 2021)

ehv-a.eu



EHVA is an EU-funded initiative designed **to foster the development of an effective HIV vaccine**. EATG is part of this large international consortium, providing **community input to the clinical trial protocol and procedures**, ensuring that participants are well informed about the risks associated with study procedures and that the language used is simple and understandable. EATG is also involved in the communications and dissemination of project information. In 2018, EATG:



- Contributed to the development and dissemination of two project newsletters.
- Was present at the project consortium meeting in June.
- Organised a meeting for members of HIV organisations from six European countries to discuss the launch of the EHVA clinical trial.

HIVACAR - Evaluating a Combination of Immune-Based Therapies to Achieve a Functional Cure of HIV Infection

(Timeline: January 2017 - January 2022)

hivacar.org

HIVACAR

The HIVACAR project aims at **obtaining a functional cure for HIV by effectively targeting residual virus replication and viral reservoirs**. EATG is providing **community input to the clinical trial** and also leading a **socio-economic study** on the ethical, economic, and psychosocial impact and expectations. EATG were also involved in the dissemination of the project information. In 2018, EATG:

- Participated in the consortium's general assembly meetings in March and October.
- Developed a **community page** on the project website, containing easily accessible information in local languages for people interested in participating in the study.
- Set up a peer-support group of community representatives in the sites of the clinical trial and organised a webinar to inform them about the trial and their role.
- Contributed to updating and translating project brochures and summaries.



EMERGE - Evaluating mHealth technology in HIV to improve Empowerment and Healthcare utilisation: Research and innovation to Generate Evidence for personalised care

(Timeline: May 2015 – May 2020)

emergeproject.eu



EmERGE is developing a mobile application to enable self-management of HIV in patients with stable disease. EATG acts as a community partner within this project and facilitates the interaction between patient representatives and clinicians at the five study sites in Belgium, Portugal, Spain, Croatia and the UK. It is also responsible for the project communications, website & social media. In 2018, EATG:

- Published the annual **newsletter**.
- The **project brochure** and a **slide-set** were updated.
- Facilitated the production of posters presented at BHIVA 2018 and AIDS 2018 conferences.
- Organised a meeting with representatives from EACS guidelines and conference committees in October 2018 to discuss integration of mHealth in the guidelines and in the upcoming EACS conference.
- Organised a **community meeting** for representatives of local HIV NGOs from the five study sites in November 2018.



Metrodora - Meaningful Engagement of Women in HIV Treatment Research

(Timeline: October 2017 - September 2018)



The goal of this EATG-led project was **to foster women's involvement and active participation in decision-making processes in R&D within the HIV field**. The project consisted of three main levels of activities: 1) Desk study: assessing the involvement of women in clinical trials in Europe; 2) Training: education of community advocates in HIV R&D as well as on barriers for women to get involved in research; and 3) Multi-stakeholders Meeting: enhancing collaborative efforts between key stakeholders to improve the involvement of women in HIV R&D. In 2018, EATG:



- Conducted a **desk study** about the participation of women living with HIV in HIV clinical trials between October 2017 and March 2018.
- Submitted an abstract about the desk study findings to the AIDS 2018 conference.
- Developed a **reading list** with informational material on the topic of clinical research in HIV, addressed to women advocates participating in the project.
- Organised three **webinars** about women's involvement in HIV R&D.
- Held a training workshop about women's involvement in HIV R&D in May 2018.
- Organised a **multistakeholders' meeting** in May, bringing together EATG members and other community representatives from a variety of NGOs, participants from pharmaceutical companies, researchers/ academics and agencies such as UNAIDS, EFGCP, EFPIA, EC and others from stakeholder groups across Europe.
- Organised a **side meeting** at the AIDS 2018 conference: Addressing research gaps identified by women living with HIV in Europe and Central Asia.

TB Online is a news website for activists, patients, health workers and researchers, which **disseminates knowledge and promotes advocacy to end the worldwide epidemic of tuberculosis**. It is run by the Global Tuberculosis Community Advisory Board (TB CAB). In 2018, EATG continued its contribution to TB Online, providing updates of content to the website and the regular newsletter.



1.1.3 ADVOCATE FOR AFFORDABLE TREATMENT AND EVIDENCE / RIGHTS-BASED POLICIES

‘Repeal punitive, restrictive and intrusive laws such as regulations criminalising sex workers or their clients, laws criminalising people using drugs, laws criminalising homosexuality, forcing mandatory and coercive testing, forcing registration, restricting access to health service for people without insurance or residence permit. These create barriers to access services for certain key populations because of the stigma and practical obstacles that they generate’

Putting affordability on the political agenda

Access to affordable medicines and diagnostics remain high on the EATG agenda. As evidence regarding the effectiveness of medicines as both treatment and prevention becomes more robust each year, **access is evidently the strategic path to ending the HIV/AIDS** epidemic and achieving SDG goal 3.3.

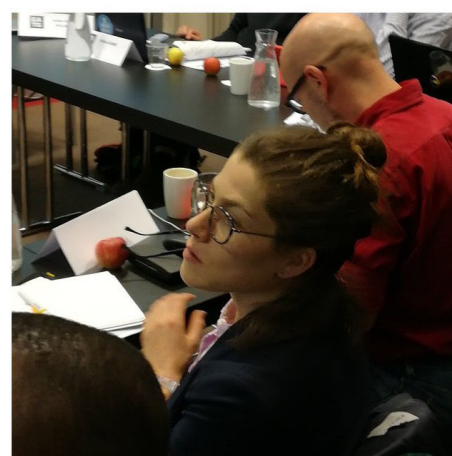
Through membership of and contribution to the European Patients’ Forum, the European Public Health Alliance, the European Alliance on Affordable Medicine and Responsible R&D and the EU Civil Society Forum and Think Tank, EATG works to address structural barriers to access such as **obsolete policies, abuse of the intellectual property systems, stigma and discrimination** etc.

Furthermore, in the European NGOs booth at the AIDS 2018 conference EATG co-hosted a discussion about the views and actions undertaken by Civil Society on **overcoming EU IP barriers, focusing on the example of Supplementary Protection Certificates (SPCs) and access to generic PrEP**.

Fighting stigma and discrimination

EATG continues to foster the exchange of best practices on the subject of stigma and discrimination via the **EU Civil Society Forum** meetings and input into the **EU Think Tank**. EATG representatives who were invited to speak at conferences highlighted the issue during the **European Health Forum** in Gastein and the EATG-chaired **EU-UNAIDS session at the AIDS 2018** conference.

The **European NGOs booth co-organised by EATG and AIDS Action Europe at the AIDS 2018 Global Village** also provided a space for community to share knowledge and best practice to tackle enduring stigma and discrimination.



#JusticeForZak

On 21 September, HIV activist Zak Kostopoulos, died as a consequence of brutal beatings in Athens Greece. EATG initiated a **campaign** and a **petition** calling all relevant Greek authorities for a swift, thorough, independent and impartial investigation into the events so that the perpetrators of the violence are brought to justice. Members of the European Parliament as well as key stakeholders from the Civil Society supported EATG's campaign.



The campaign contributed to the local communities' effort to raise the issue towards the Greek authorities. An investigation was initiated and is still ongoing. Zak had been an EATG member.



On 6 November, EATG published a **position paper** on the **impact of drug policies on human rights, public health and the prevention, treatment and care of HIV and other blood-borne infections**. In doing so, EATG aimed to clearly stand by people using drugs and advocate for a syndemic approach in improving health outcomes. In particular, EATG called for key principles to be adhered to by all in order to improve the prevention, treatment and care of HIV and other bloodborne infections. Those principles include **1) the meaningful involvement of communities at programme planning, implementation and evaluation processes; 2) ending the criminalisation of drug use; 3) the harm reduction approach as the most effective, costeffective and humane response to the negative health consequences of problematic drug use and 4) considering gender related aspects in programmes and funding for equitable, sustainable evidence-based services for people who inject drugs.**

On 17 December, on **International Day to End Violence Against Sex Workers**, EATG published its **position paper** on **the impact of punitive sex work laws and regulations on human rights and public health**. EATG considers that the ongoing and increasing criminalisation of sex work across WHO Europe has a negative impact on sex workers' health and human rights. In particular, EATG stresses the following principles to be adhered by all: **1) decriminalisation of sex work, including sex workers, clients and third parties; 2) establishment of anti-discrimination, hate crime and other rights-respecting laws to protect against discrimination and violence, and other rights violations, faced by sex workers; 3) stand in solidarity with the sex workers and their fight for self-determination, self-organisation and the pursuit of human and labour rights; 4) meaningful involvement of sex workers in their diversity in developing, implementing and evaluating laws, policies, programmes, services and research that affect them and to collaborate in research and; 5) to offer relevant resources, advice and expertise where possible.**







Follow-Up projects

In 2018, some EATG trainees completed follow-up projects for which they have received funding in the context of the trainings organised by EATG. Many of them come from the EECA region.

In **Poland**, a STEP-UP trainee implemented activities and events directed at **facilitating the linkage, involvement and active participation of people living with HIV in the work of the NGOs**.

In **Russia**, a series of trainings on **HIV prevention and treatment in prisons** were organised. The trainings targeted both prisoners and staff that works in prisons.

In **Belarus**, a **permanent photo exhibition with the title 'We among you'** was launched. The photo exhibition hosts portraits of representatives from key population groups and is directed as an advocacy instrument towards decision makers to make sure that funding for community-based services will be continued by the government after the Global Fund withdraws from the country.

In Spain, the awareness and information online campaign **PrEP UP** was implemented. The campaign is targeting **young people from Spain and Europe from the most affected communities** and provides information about Pre-Exposure Prophylaxis (PrEP) and also about sexual and health rights.

1.1.5 MAXIMISE IMPACT THROUGH MULTI-STAKEHOLDER STRATEGIC PARTNERSHIPS

'Reach out for partnerships across sectors, communities and countries across Europe to capitalise on innovative, promising and successful interventions'

Ensuring sustained external communication and visibility

In 2018, EATG co-signed **14 joint letters**, statements and declarations along with many Civil Society Organisations across Europe and other allies.

EATG was active in the preparation of the **AIDS 2018 Conference** in Amsterdam in July. EATG co-hosted a number of discussions with the participation of diverse stakeholders in the European NGOs booth.

Fostering and harnessing new collaborations in the 'Ageing' field and further promoting this agenda

AGEING WITH HIV - A Lifecycle Approach

(Timeline: October 2015 – March 2019)

ageingwithhiv.org



The overall goal of this large EATG-led project is **to better understand and address the challenges and unmet needs of PLHIV in a life cycle perspective**. The project aims to increase the patient community's, healthcare providers' and other key stakeholders' knowledge on HIV and ageing, to identify and raise awareness regarding unmet care needs for PLHIV/AIDS in a lifecycle perspective and to provide networking opportunities for establishing collaborative efforts to advocate for priorities in this domain.



- The third-phase conference of the project, focusing **on the Quality of Life and Preventive Healthcare of people between 18 and 50**, and was held in May 2018. The conference welcomed 97 participants from 28 countries in Europe and East Asia. It also reached a wide external audience, with over 5,000 related posts and mentions on social media during the event.
- Two **webinars**/video recordings were organised related to the conference.
- The last phase of the project was launched in July 2018, focusing on **dissemination of the project outcomes and evaluation**.
- The project outcomes were presented at the **HIV Drug Therapy Conference**, in October. The session titled '**Quality of Life Across Different Age Groups of People Living with HIV**' summarised **key outcomes** of the project by age-group.
- In December, EATG was invited to present findings in a seminar on ageing with HIV organised by Belgian partners. The event brought together civil society, community, doctors, researchers, nurse training coordinators and elderly care actors.

HIV long-term health survey

(Timeline: 2015 – 2018)

The **results on HIV long-term health survey**, conducted **in eight European countries** in 2016, were presented in June 2018. The online survey reached **1,342 respondents** via national or regional organisations of people living with HIV. The results were also presented at the **Ageing with HIV conference** in May 2018 and at the **AIDS 2018 conference**. The survey was implemented in collaboration with **Volle Maan Communicatie Bureau**.

HIV in Europe

In 2018, EATG continued to engage with **HIV in Europe**. The initiative seeks **to ensure earlier diagnosis** for people living with HIV, viral hepatitis, STIs or TB and **better linkage to care** than is currently the case. It provides a platform for independent experts from civil society, policy institutions, health care and European public health institutions to share knowledge, develop tools and influence policy based on evidence. **EATG is the policy and advocacy secretariat of the initiative.**

HIV Outcomes



EATG has been involved in the **HIV Outcomes Initiative Steering Committee**, a multi-stakeholder initiative **to improve long-term health and well-being of people living with HIV**. In November, EATG took part in a panel held in the European Parliament organised by the initiative. During the event good practices from across EU Member States were presented. Challenges in the broader European and international context were also addressed.



1.1.6 ENSURE INTERNAL STRUCTURES ARE 'FIT FOR PURPOSE'

An efficient system and structure that enables the implementation of our work plan and strategy

EATG appointed a consultant to develop a new Long-Term Strategy (2019-2021) with the intention to have a finalised version at the end of 2018. As there was no draft version available for the 2018 General Assembly, the process of development was continued in 2019.

A system that enables reporting on achievements to external stakeholders

EATG installed **a system of continued monitoring and evaluation of the work plan**, with an 18-month planning horizon. Twice a year the plan gets revised to enable adjustments as well as to monitor and evaluate milestones and indicators.

EATG continued to invest in communication towards stakeholders. The annual **stakeholders meeting**, as well as bilateral discussions with funders and stakeholders are central. This year the stakeholders meeting in January focused on the meaningful involvement of PLHIV in different ways within the organisation. Regular meetings were held with funders and stakeholders, often linked to events such as conferences.

Apart from face-to-face communication our **digital communications** have been upgraded, by introducing a revamped newsletter and enhancing presence across social media.

EATG presented outcomes of projects and hosted discussions at the AIDS 2018 conference, where we had the opportunity to collaborate with a variety of external stakeholders.

Transparency and privacy policy

EATG applies transparency standards as required by the EU **transparency register**, which guarantees full transparency in financial data, not only towards its members but also towards external stakeholders.

This year EATG adapted its mailing lists, policies for the use of audiovisual materials, and **privacy policy** across all the platforms used in accordance to the GDPR.

Diversifying sources of project funding

EATG made an effort to secure non-pharma income, mainly via the application for project funding at EU level. Throughout the years, the percentage of non-pharma project funds has increased considerably. In 2018, the share of income coming from the industry receded to 74% (2017: 86%)

EATG applied for some projects, not all of them successfully. However, efforts resulted in some project confirmations. Two grants were approved from **Innovative Medicines Initiative (IMI) (PARADIGM, EFOEUPATI)**.

In addition, amongst others, EATG collaborated with PrEP in Europe Initiative, HIV in Europe Initiative, Deutsche AIDS-Hilfe e.V. (EU Civil Society Forum) and Africa Advocacy Foundation.



1.1.7 ENSURE ACTIVE & REPRESENTATIVE MEMBERSHIP

Development and Membership Advisory Group (DMAG): Welcoming and supporting EATG members

The **mentorship project** within our **DMAG** continues. This process brings together new members with their mentors to optimise integration to the organisation. The Terms of Reference for mentors have been clarified.

One of the challenges of a growing organisation, is to find a good balance between the available resources -that limit certain ways of involvement- and the available capacity of membership. As part of the governance review, EATG looked into ways to make the induction of new members better and to allow them to be actively involved.

Ensuring that the diversity of the HIV-affected population is optimally reflected with the membership

The BoD, DMAG and others have been working on **an optimised membership recruitment strategy**. This did lead towards a temporary stop of membership recruitment, allowing the BoD to reflect on a new membership strategy -as approved by the General Assembly. After adoption by the BoD, DMAG started reviewing new applications again- as decided by the General Assembly.



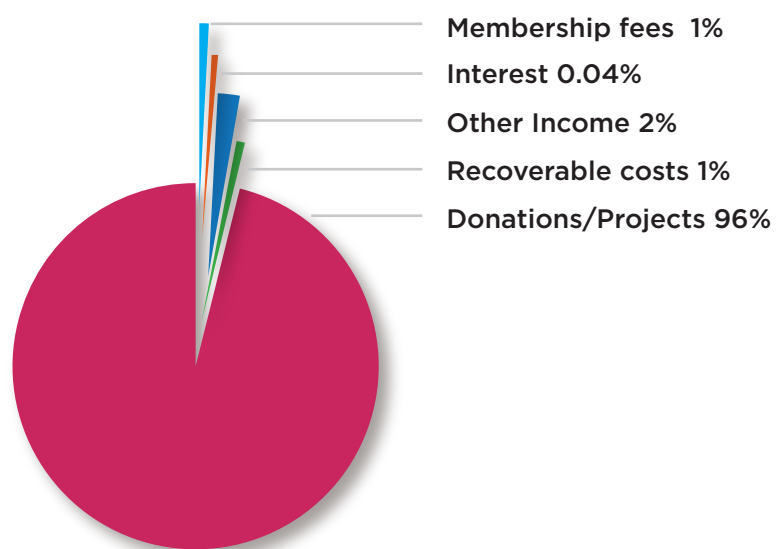


1.2 FINANCES

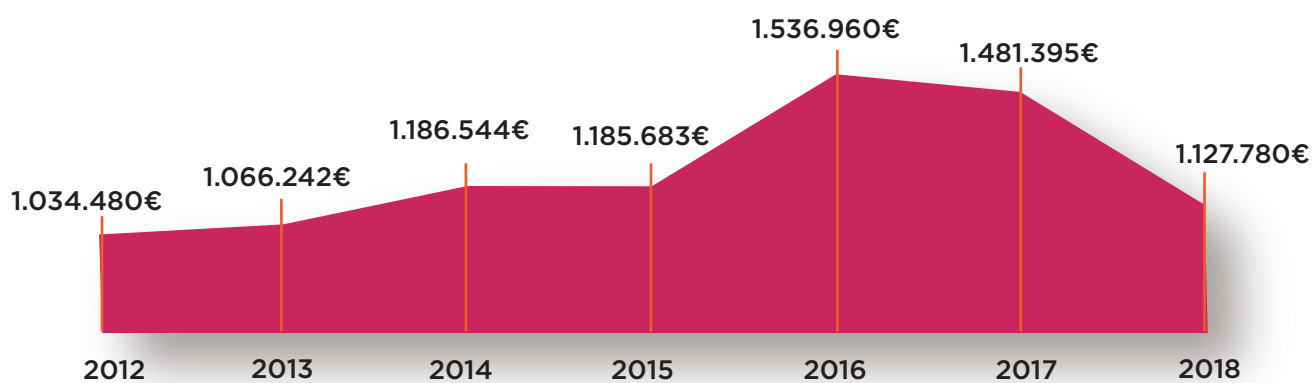
INCOME

€ 1.13 million

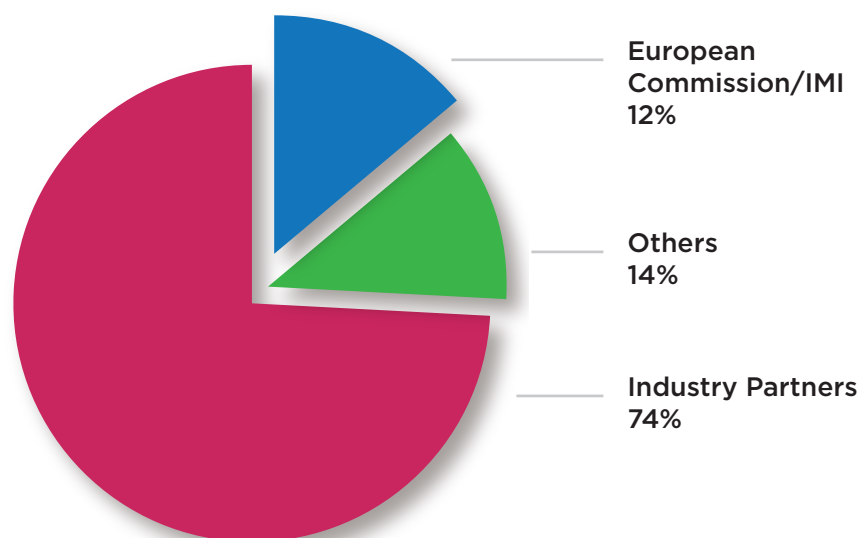
The distribution **by sources** of EATG income is shown below



Income Development



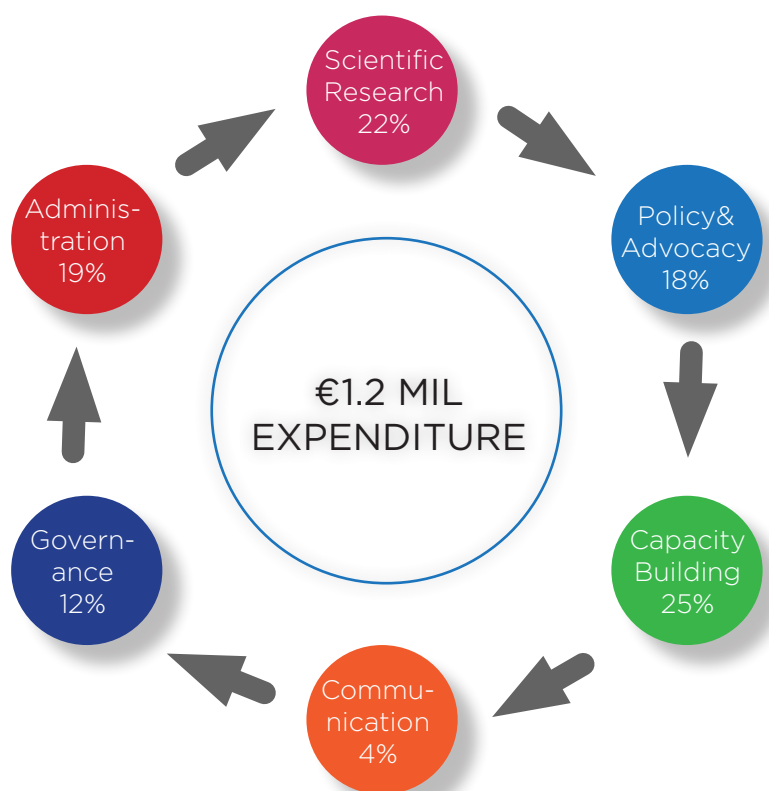
FUNDERS



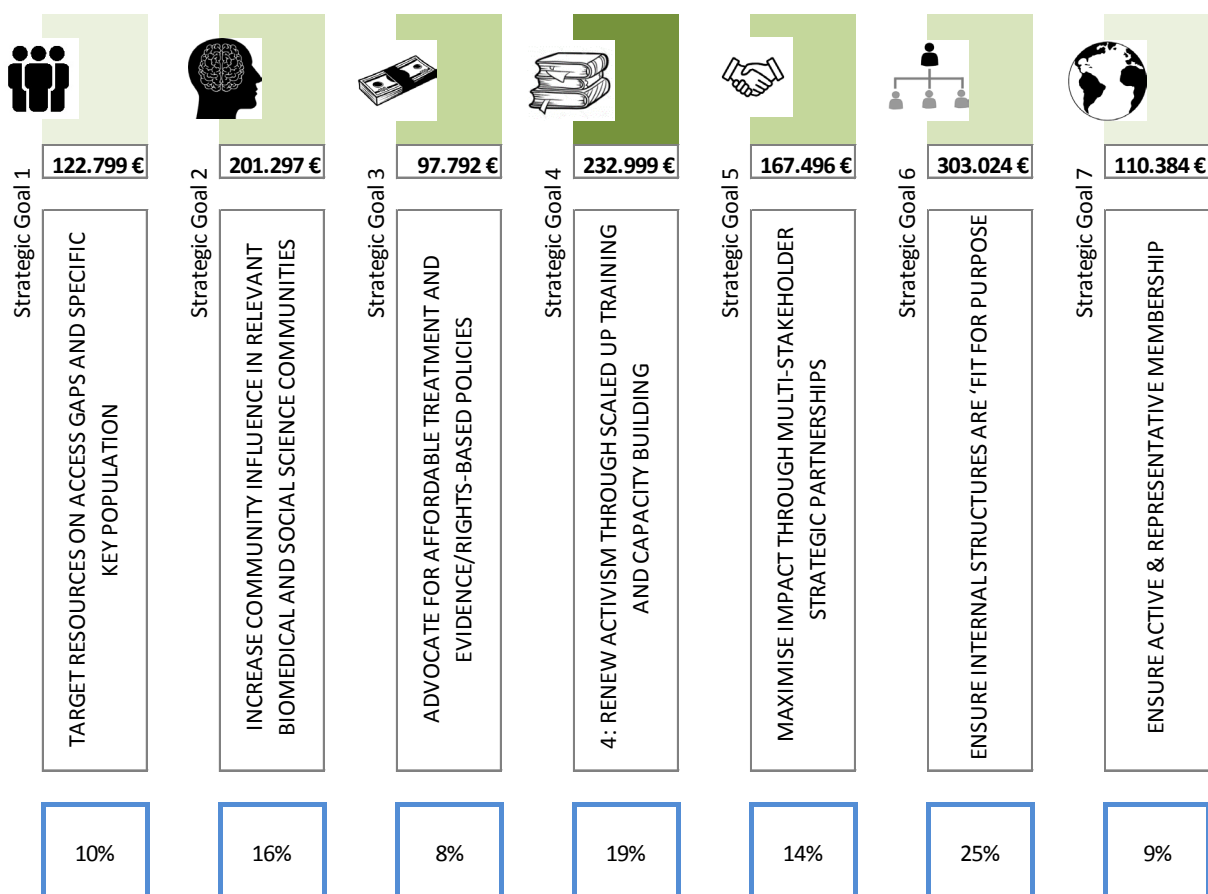
EXPENDITURE

In 2018, EATG invested **€1.235.790** in numerous ways, including projects, trainings and activities, as well as representation, staff salaries and office operations.

Below is the distribution of the expenditure by function:



2018 EXPENDITURE ACCORDING TO BUDGET LINES



2018 EXPENDITURE ACCORDING TO BUDGET LINES

VOLUNTEER TIME

EATG is a **membership-led and membership-driven organisation**. The work of EATG members is vital and many are very active. The estimated volunteer time in 2018 amounts to be at least:

14,000 hrs

equivalent to
8
full-time staff

You can find more financial information on the EATG website:
eatg.org/financial-compliance/

1.3 ONLINE COMMUNICATION

EATG Websites

eatg.org

eatgtrainingacademy.com



For the period between the 1st of January and 31st of December 2018 both EATG websites were

visited by approximately **63.000 users**

amounting to **84.000 sessions**



During these sessions **140.000 pages** were accessed

Visitors **stayed** in the websites for almost **2 minutes** per session.

Audience



On average, **2.000 users** visited our websites every week



4 in 10 users were based in **Europe** while **3 out of 10** accessed our pages from **Americas**

Of the European audience, **32%** were from **Northern Europe**, **30%** from **Southern Europe**, **28%** from **Western Europe** and **10%** from **Eastern Europe**



6 in 10 users were **women**

4 in 10 users were between **25 and 34 years old**



Acquisition

Half of the users used their **mobile device** to access our webpages

Of the traffic, **46%** was **organic**, **33%** **direct** and **15%** from **social media**. Of the social media traffic, **86%** were directed to the websites by **Facebook** and **12%** by **Twitter**. Paid publicity was not used³

The two most read stories were about **Chechnya's concentration camp for homosexuals** and **the murder of Zak Kostopoulos**



³ Organic: Traffic from search engine results that is earned, not paid
Direct: Any traffic where the visitor did not click a link to get to your website
Social: Traffic from a social network, such as Facebook, LinkedIn, Twitter, or Instagram

EATG Social Media

Facebook: @EuropeanAIDSTreatmentGroup

Twitter: @EATGx

Instagram: europeanaidstreatmentgroup

In 2018, EATG's social media have grown in numbers of **followers** and **engagement** by the audience. Along with **Facebook** and **Twitter**, we introduced an **Instagram** account.

EATG's

Facebook page



received more than **250 new likes/followers** (2017: 1567, 2018: 1823).

Of the **160 status updates** posted,

81 managed an **engagement rate greater than 10%**⁴.

A Facebook page for the AIDS 2018 conference was set up (@eatgataids2018)

attracting **160 followers** with **145 status updates**.

1 in 10 posts managed to **engage more than 30% of the users**.

EATG's **Twitter**



attracted **264 new followers** (2017: 1311, 2018: 1575).

Twitter **impressions** reached 165.000 (2017: 148.000)⁵.

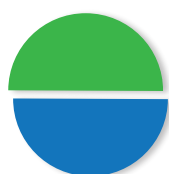
The **average engagement rate** was boosted by **20%** (2017: 1.02%, 2018: 1.23%).

EATG newsletter

HIV and co-infections news bulletin

In May, in line with **GDPR** provisions, EATG restructured the mailing lists receiving the **EATG newsletter** as well as the daily, weekly and monthly **HIV and co-infections news bulletins**. The newsletter is now disseminated to **300 subscribers**, while **260 subscribers** receive the news bulletin. Both editions are sent via Mailchimp and one can subscribe via EATG's website.

The average of people actually **opening** the newsletter campaigns they receive in their e-mails is **42%** for the EATG newsletter and **35%** for the HIV and co-infections news bulletin.



1 in 2 users
access websites
via **mobile**



3 in 4 of the readers
access the newsletters
via **desktop**

TB Online

tbonline.info

Facebook: @TBonlineTBCAB

For the period between the 1st of January and 31st of December 2018 the TB online website was visited by approximately **183.000 users**, amounting to **218.000 sessions**. During these sessions **278.000 pages** were accessed.

61% of the visitors were **younger than 34 years old** and **54%** were **men**. Users located in **India** and the **USA** constitute **half** of the site's visitors.

TB online's **Facebook** page had more than **1200 likes**.

TB online's **newsletter** had more than **700 subscribers** - including individuals from the World Health Organization, the Stop TB Partnership, Unitaids, universities, pharmaceutical companies, NGOs, researchers, medical doctors and activists.

⁴ Engagement rate shows how much people interact with the content. Factors that influence engagement include users' comments, shares, likes, and more.

⁵ Twitter impressions are the number of times a tweet shows up in somebody's timeline.



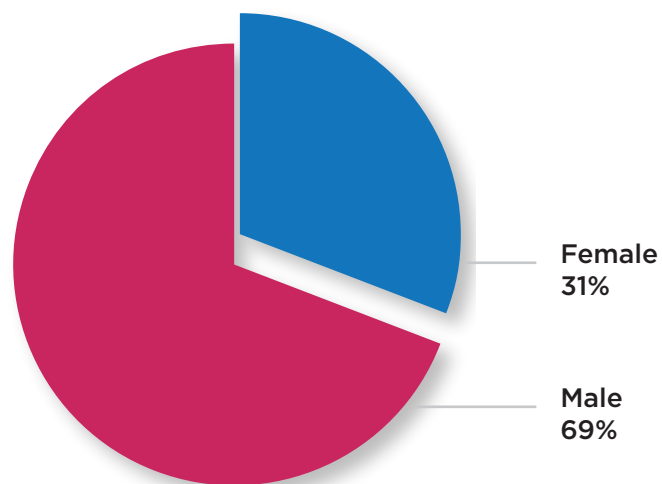
1.4 MEMBERSHIP

January - December 2018

EATG had **176** members at the beginning of the year, coming from **48** countries (including US, South Africa and Canada). **7** new members were approved in 2018. **13** members left the organisation during the year. By the end of the year EATG had **171** members.

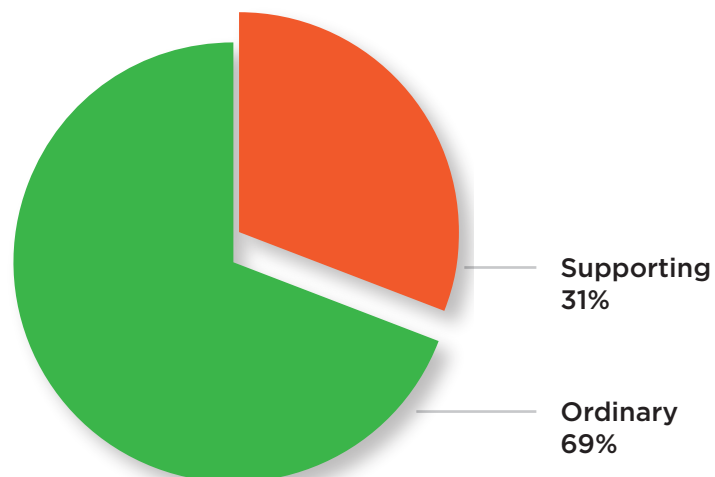
Gender

The gender balance has remained relatively stable during the past years with now **69% men (116) compared to 31% women (51)**. Unfortunately, trans people are not represented in EATG membership.



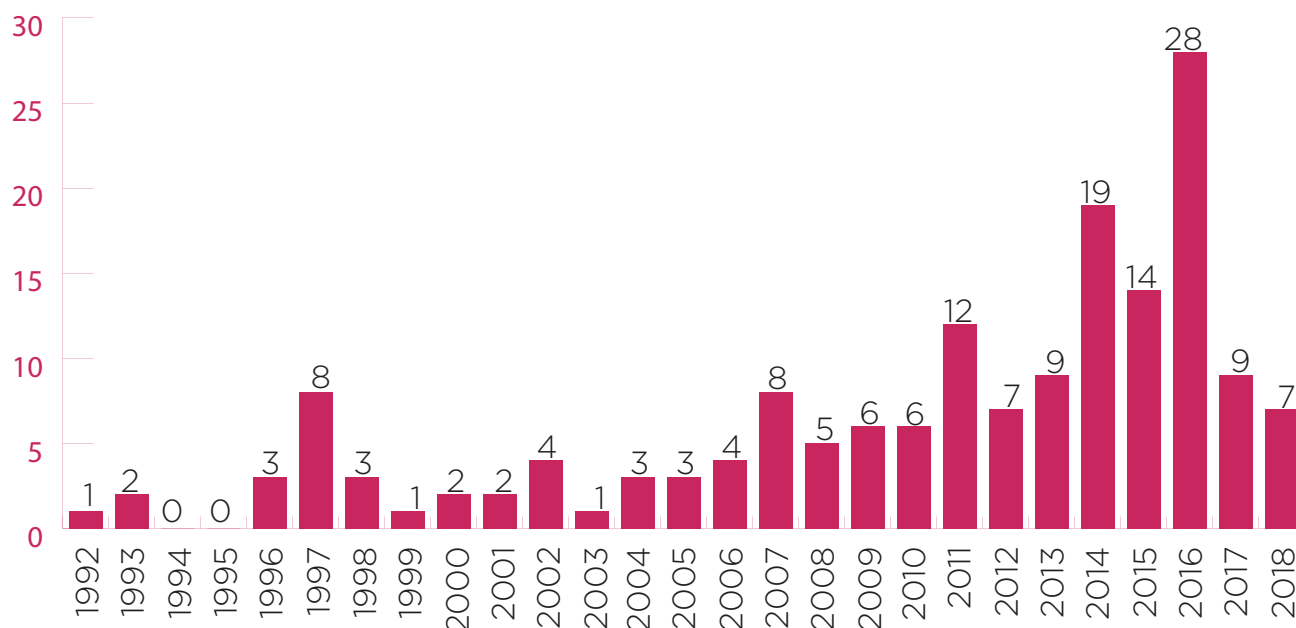
Supporting and ordinary members

At the end of 2018 EATG had **116 ordinary** members (members with voting rights) and **51 supporting** members.



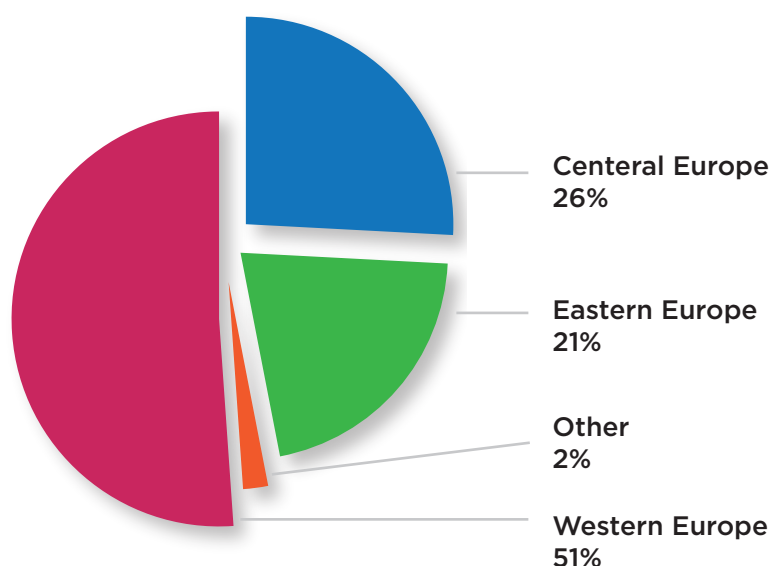
Recruitment by year

Working towards an optimised membership recruitment strategy during 2018, the number of new members has receded in comparison to recent years' trend. **Almost half of the membership joined the organization in the past 5 years.**



Regions

Half of EATG members come from **Western Europe** (as defined by WHO). By the end of 2018, **86** members (51%) came from this region. **43** members (26%) were from **Central Europe** and **35** members (21%) came from **Eastern Europe**. EATG clearly see increases in membership coming from Central and Eastern Europe within the past years.



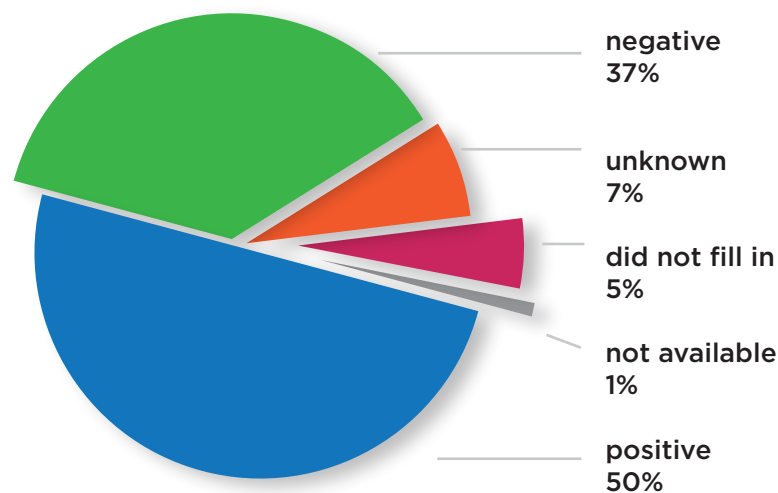
WHO definition of Western Europe (24 countries): Andorra, Austria*, Belgium*, Denmark*, Finland*, France*, Germany*, Greece*, Iceland, Ireland*, Israel, Italy*, Liechtenstein, Luxembourg*, Malta*, Monaco, Netherlands*, Norway, Portugal*, San Marino, Spain*, Sweden*, Switzerland, United Kingdom*;

Central Europe (15 countries): Albania, Bosnia and Herzegovina, Bulgaria*, Croatia, Cyprus*, Czech Republic*, Hungary*, Montenegro, Northern Macedonia, Poland*, Romania*, Serbia, Slovakia*, Slovenia*, Turkey;

Eastern Europe (15 countries): Armenia, Azerbaijan, Belarus, Estonia*, Georgia, Kazakhstan, Kyrgyzstan, Latvia*, Lithuania*, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, Uzbekistan.

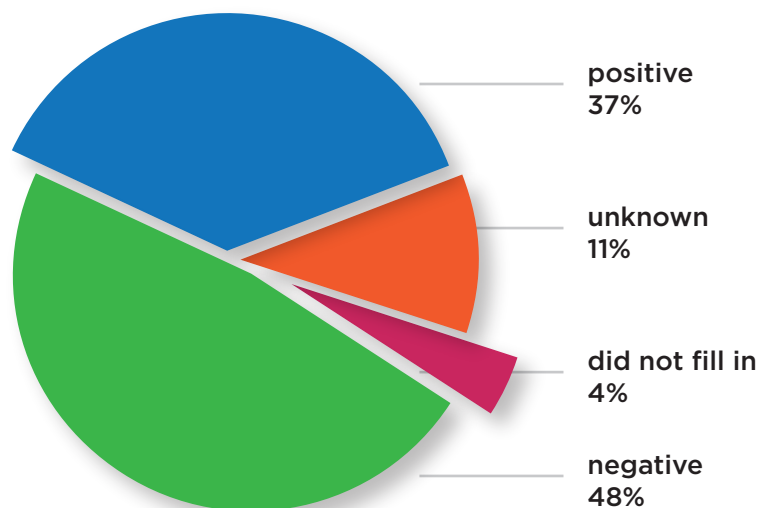
HIV status

At the end of 2018 EATG had **84 HIV-positive** members (50%); **61** members (37%) identified themselves as **HIV-negative**. **11** members said their status is **unknown**. No information was available for **11** members.



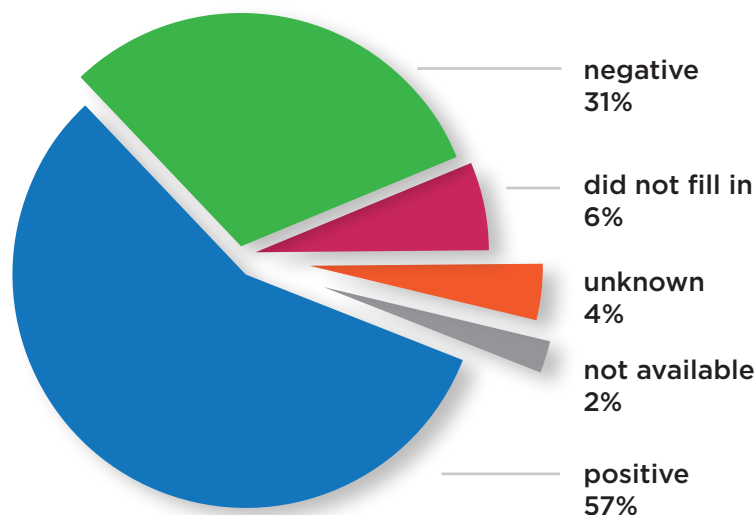
HIV status of women

Almost half (48%) of the women within the organisation identified themselves as **HIV-negative** (25) at the end of 2018 and **19** as **HIV-positive** (37%). **11%** of women said their status is unknown.



HIV status of men

57% of the men in the organisation identified themselves as **HIV-positive** (65) at the end of 2018 and **36** as **HIV-negative** (31%). Only **4%** of men said their status is unknown.





1.5 GOVERNANCE

The Board of Directors

The EATG General Assembly elects the Board of Directors (2-year term).

Nikos Dedes (chair) – Bryan Teixeira (secretary) – Brian West (treasurer) – Mario Cascio (director) – Esther Dixon-Williams (director)

As from the General Assembly in September 2018 in Vilnius the board included: Nikos Dedes (chair) – Mario Cascio (vice chair) – Andrej Senih (secretary) – Esther Dixon-Williams (Treasurer) – Aisuluu Bolotbaeva (director)

The EATG External Advisory Board

Lella Cosmaro - Michel Kazatchkine - Jürgen Rockstroh - Matthew Weait- Sini Pasanen - Ricardo Baptista Leite

The Development and Membership Advisory Group (DMAG)

The Development Membership Advisory Group DMAG is the internal group dealing with membership issues and internal working mechanisms.

DMAG chairs: Memory Sachikonye & Ferenc Bagyinszky

Working Group Chairs

(as from the General Assembly in September 2018)

The Policy Working Group: Frank M. Amort

European Community Advisory Board: Luis Mendaõ

The Training and Capacity Building Working Group: Ian Hodgson

The Staff Members

Executive Director, Koen Block - Policy Officer, Ann-Isabelle von Lingen - Scientific Officer, Giorgio Barbareschi - Trainings Coordinator, Kristjan Jachnowitsch - Project Manager, Maria Duterte - Project Manager, Karina Huberman - Communications Coordinator, Apostolos Kalogiannis - Financial Manager, Marie McLeod - Events Coordinator, Nadiia Gaidak - Events Coordinator, Bojan Cigan - Project & Administration Intern, Fiona Greenhalgh - News Bulletin Editor, Ana Balkandijeva - IT and Design advisor, Deniz Uyanik

The Funders

European Commission
IMI Innovative Medicines Initiative
Janssen Pharmaceutica NV
Gilead Sciences Europe Ltd
Merck Sharp & Dohme Ltd
Roche Diagnostics Corporation
ViiV Healthcare UK Ltd
Deutsche AIDS-Hilfe e.V. (CSF)
PrEP in Europe Initiative
HIV in Europe Initiative
Others

Long Term Strategy (2016-2018): Strategic Goals and Objectives

GOAL 1: TARGET RESOURCES ON ACCESS GAPS AND SPECIFIC KEY POPULATIONS

Objective 1.1 **Prioritise (sub-) regions, countries, and cities** with the greatest gaps in access to screening, prevention, and affordable treatment as well as inequities in protection from stigma and discrimination

Objective 1.2a **Prioritise key populations** with the greatest gaps in access to screening, prevention, and affordable treatment as well as inequities in protection from stigma and discrimination

GOAL 2: INCREASE COMMUNITY INFLUENCE IN RELEVANT BIOMEDICAL AND SOCIAL SCIENCE COMMUNITIES

Objective 2.1 Improve effectiveness and efficiency of members' and **community involvement** in HIV-related social and clinical research

GOAL 3: ADVOCATE FOR AFFORDABLE TREATMENT AND EVIDENCE/RIGHTS-BASED POLICIES

Objective 3.1 Expand community involvements in the promotion of **affordable and innovative treatment** and services for HIV and co-infections

Objective 3.2 Promote enabling socio-economic and legal environments to **fight stigma and discrimination** as well as human rights violations

GOAL 4: RENEW ACTIVISM THROUGH SCALED UP TRAINING AND CAPACITY BUILDING

Objective 4.1 Build-up **capacity on cascades of care** and "Knowing your epidemic" especially on key population access gaps

Objective 4.2 Provide **training and capacity building** using face-to-face as well as distance learning technologies

GOAL 5: MAXIMISE IMPACT THROUGH MULTI-STAKEHOLDER STRATEGIC PARTNERSHIPS

Objective 5.1 Confirm **key strategic partners** and develop working agreements with them, including community representation within their structure

Objective 5.2 Pursue **work on co-infections, co-morbidities, well-being and ageing** through collaborative arrangements with pre-existing specialist organisations

GOAL 6: ENSURE INTERNAL STRUCTURES ARE 'FIT FOR PURPOSE'

Objective 6.1 Ensure that **all levels of EATG are working collaboratively** towards achieving the goals of the LTS

Objective 6.2 Establish **a strong fundraising capacity** to build sustainability and a diversified funding base in terms of the needs of the LTS and beyond

Objective 6.3 **Establish an M&E system** that demonstrates the difference EATG makes to the quality of life of PLHIV and other at-risk communities across Europe

GOAL 7: ENSURE ACTIVE AND REPRESENTATIVE MEMBERSHIP

Objective 7.1 **Enhance member engagement** in all activities of EATG

Objective 7.2 Establish a system of **strategic recruitment with focus on diversity and representation**



***EATG would like to thank
its members, partners, stakeholders,
funders and other contributors
for their continued support,
collaboration and trust.***