



European
AIDS Treatment
Group

20 19

**ANNUAL
REPORT
European
AIDS Treatment
Group**



Acronyms

ARV	Anti-retroviral
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
EMA	European Medicines Agency
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
GA	General Assembly

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
MSM	Men who have Sex with Men
NASH	Non-Alcoholic Steatohepatitis
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
TasP	Treatment as Prevention
TB	Tuberculosis
TB CAB	Global Tuberculosis Community Advisory Board
WHO	World Health Organisation

Table of Contents

ACRONYMS	2
ACHIEVEMENTS SHOWN IN NUMBERS	5
EATG INVOLVEMENT IN PROJECTS AND INITIATIVES	10
MESSAGES FROM THE WORKING GROUP CHAIRS	11
LUIS MENDAO (ECAB/Science Working Group Chair)	11
FRANK AMORT (Policy Working Group Chair)	13
IAN HODGSON (Training & Capacity Building Working Group Chair)	14
1. OUR STRATEGIC GOALS AND OBJECTIVES 2016 - 2018 (EXTENDED TO 2019)	16
1.1 TARGET RESOURCES ON ACCESS GAPS AND SPECIFIC KEY POPULATIONS	16
1.2 INCREASE COMMUNITY INFLUENCE IN RELEVANT BIOMEDICAL AND SOCIAL SCIENCE COMMUNITIES	21
1.3 ADVOCATE FOR AFFORDABLE TREATMENT AND EVIDENCE / RIGHTS-BASED POLICIES	37
1.4 RENEW ACTIVISM THROUGH SCALED-UP TRAINING AND CAPACITY BUILDING	39
1.5 MAXIMISE IMPACT THROUGH MULTI-STAKEHOLDER STRATEGIC PARTNERSHIPS	43
1.6 ENSURE INTERNAL STRUCTURES ARE 'FIT FOR PURPOSE'	49
1.7 ENSURE ACTIVE & REPRESENTATIVE MEMBERSHIP	51
2. FINANCES	52
2.1 INCOME	52
2.2 FUNDERS	53
2.3 EXPENDITURE	53
2.4 VOLUNTEER TIME	54
3. MEMBERSHIP	55
4. ONLINE COMMUNICATION	60
5. GOVERNANCE	63
ANNEX: LONG TERM STRATEGY (2016-2018 [EXTENDED TO 2019]): STRATEGIC GOALS AND OBJECTIVES	66

Achievements shown in numbers

GOVERNANCE

5

Board of Directors Meetings (& 5 Teleconferences)

1

EATG Long-Term Strategy Meeting

1

Governance Meeting

2

DMAG Meetings

2

EATG Staff Retreats



Achievements shown in numbers

PROJECTS

12

projects of which:

7

are EU or IMI-funded:
HIVACAR, EHVA, EmERGE, ESTICOM, EUPATI,
EFOEUPATI, PARADIGM

3

are initiated and/or led by the EATG:
STEP-UP, CoPE, Ageing with HIV

2

as implementing partner:
M-Care, European Red Umbrella Academy



Achievements shown in numbers

TRAINING

2

STEP-UP face-to-face trainings organised

19

new STEP-UP graduates

1

face-to-face training in Russian (STEPru) attended by 15 participants

1

face-to-face pre-GA science training attended by 35 participants

2

M-Care face-to-face trainings organised

16

M-Care graduates

85

participants in total trained in face-to-face trainings

3

webinars conducted

Achievements shown in numbers

SCIENCE

2

European Community Advisory Board (ECAB) meetings on HIV

1

European Community Advisory Board (ECAB) meeting on viral hepatitis

1

European Community Advisory Board (ECAB) on diagnostics

13

community reviews of protocols for clinical trials and documents related to R&D



Achievements shown in numbers

POLICY / ADVOCACY

14

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

6

engagements through meetings or documents providing input to strategies of EATG partners (ECDC, EACS, AAE, PICUM, EPHA, CSF on Drugs, EU CSF on HIV, TB and Hepatitis)

1

co-organised and chaired EU Civil Society Forum on HIV, viral hepatitis and TB and 1 Think Tank meeting

1

policy recommendations document (Ageing with HIV)

1

policy brief: Advocating for the EU uptake of the HIV, viral hepatitis, and TB elimination agenda 2019-2024

27

initiated or signed-on statement letters (main issues: HIV, key populations, EU health agenda, medicines shortages, tuberculosis)

What is the impact of the first comprehensive continuous education programme for activists in the field of HIV?

















EATG Involvement in Projects and Initiatives

The EATG has been working towards achieving the goals and objectives set by the **Long-Term Strategy (2016-2019)**, along the following **thematic areas**:

- Prevention
- Community Involvement in HIV & co-infections R&D
- Availability & Affordability of Medicines and Diagnostics
- Equal Access to HIV Services for All: Key Populations
- Quality of Life for PLHIV
- Empowerment & Literacy

Here is an overview of projects and initiatives we were involved in during 2019 **by thematic area**:

Prevention	HIV and co-infections R&D	Availability and Affordability	Equal Access & Key Populations	Quality of Life	Empowerment and Literacy
<p>PrEP in EUROPE</p> 	<p>EHVA European HIV Vaccine Alliance</p> 	<p>European Alliance for Responsible R&D and Affordable Medicines</p>	<p>ACHIEVE Associations Collaborating on Hepatitis to Immunise and Eliminate the Viruses in Europe</p> 	<p>EmERGE Evaluating M-health Technology in HIV to Improve Empowerment and Healthcare Utilisation</p> 	<p>EUPATI European Patients Academy on Therapeutic Research</p> 
	<p>HIVACAR Evaluating a Combination of Immune-Based Therapies to Achieve a Functional Cure of HIV Infection</p> 	<p>COST Action Establishing a Research Network for Medicines Shortages</p> 	<p>EuroTEST Working together for integrated testing and earlier care Addressing Hepatitis, HIV, STIs and TB</p> 	<p>HIV OUTCOMES Beyond Viral Suppression</p> 	<p>EFOEUPATI Ensuring the future of EUPATI beyond 2020</p>
			<p>European HIV-Hepatitis Testing Week</p> 		<p>PARADIGM Patients Active in Research and Dialogues for an Improved Generation of Medicines</p> 
			<p>ESTICOM European Surveys and Trainings to Improve MSM Community Health</p>		<p>STEP-UP Skills Training to Empower Patients</p> 
			<p>ECDC HIV Testing Guidelines in the EU/EEA</p>		<p>CoPE Continuous Patient Education</p> 
			<p>M-CARE Mobilizing Migrant Communities via Capacity and Access Resource Development</p> 		
<p>EU HIV/AIDS, Hepatitis and Tuberculosis Civil Society Forum</p>					
<p>EU Civil Society Forum on Drugs</p>					

Updated: July 2019

MESSAGES FROM THE WORKING GROUP CHAIRS

This year's General Assembly decided to restructure the way EATG will operate in the coming years, moving from a Working Groups model (Science, Policy, Training & Capacity Building) into a programmatic structure. This will include three Programme Areas: Quality of Life, Combination Prevention and Partners in Science.

We asked the last Working Group Chairs to share their thoughts and impressions from 2019.



LUIS MENDAO
(ECAB/Science Working Group Chair)

From 2018, **ECAB** has introduced a **thematic approach** to working with companies and research bodies to enable members to be involved in areas that are most important for the community. This has not always been successful but has helped ECAB to move away from a repetitive module and refocus on emerging priorities.

In addition to the standard community advisory boards other thematic areas were included into 2019 advisory board activities such as **ageing** (March 21), **diagnostics** (September 20-22), **viral hepatitis and related liver conditions** (October 18-20) as well as **cure and vaccines** (November 6 at the EACS 2019 conference).

A strong feature of ECAB is the **review of protocols and documents related to research and development processes**. Small and focused teams of members with advanced expertise in treatment advocacy have provided input on protocols and design of clinical trials in HIV and related therapeutic areas. Similarly, this year EATG has provided input on regulatory issues in two EMA consultations (one on the role of big data for the evaluation and supervision of medicines in the EU and one on regulatory strategy 2025) and numerous documents for the regulatory agency.

On top of working directly with companies, ECAB members also provide **input in EU-funded academia-led research projects** to help them design focussed trials and think through ethics issues related to cure and vaccine research.

Behind clinical trials ECAB has been **collaborating with other patient's organisations and stakeholders** to improve community participation in medicine development. In March, an ECAB was organised to meet with researchers from the University of Amsterdam, who are EATG partners in the PARADIGM consortium, to develop a framework to measure patient engagement in the interaction with the industry and other stakeholders, based on the ECAB experience. A follow up interactive session took place in November's HIV ECAB meeting.

Capacity building is key to empowering members in order to ensure proper interaction within the ECAB forum. ECAB, in collaboration with TCWG, successfully carried out a training on understanding science for advocacy purposes just before our 2019 GA in Sofia.



FRANK AMORT (Policy Working Group Chair)

After numerous months without a Policy Working Group (PWG) Chair, I was appointed in summer 2018, aware of the fact that this would be a transitory task due to the organisations restructuring process. In my personal opinion, this fact together with the continuous engagement of the PWG steering committee (Tomislav Beganovic, Zoran Dominkovic, Harriet Langanke, Nyambe Mukelabai, Daniel Simões, Andrej Senih), the highly motivated staff members, the nomination of a new executive director as well as a staff member for communication helped to stabilise EATG’s policy efforts.

Working Group members provided active contribution to the **new Long-Term Strategy (2020 - 2025)** rethinking policy work and helping to implement **a more horizontal and intersectoral approach** more suited to fit the policy priorities in the new context of HIV.

This year we published an **EU-Briefing document** on occasion of the elections of the EU Parliament in 2019. This document highlights the current challenges regarding HIV in the EU, as well the importance of EU actions in this area for the wider European region.

Numerous **collaborations with other organisations and networks**, as well as **representation**, play an important role in EATG’s policy work and as PWG chair I have asked for **a structured evaluation and improved management system** to make better use of this resource for the organisation’s policy work.



IAN HODGSON
(Training & Capacity Building Working
Group Chair)

Highlights

2019 has been an exciting year for EATG's training and capacity building activities, and I'd like to highlight three achievements. We've seen the successful completion of the 5th cycle of **STEP-UP**, and with the assistance of Shona Schonning and Raminta Stuikyte an extremely valuable evaluation of STEP-UP since its launch in 2013. Lots of useful insights and information was gathered to feed into future iterations. This systematic approach to exploring the actual impact of EATG's capacity building is going to be a core part of our M&E in the future. An abstract based on the evaluation was presented at AIDS Impact 2019 and an article was approved for publication by the AIDS Care review.

Connected with this was an **event held in Russia** earlier in 2019. STEPru was an initiative supported by EATG, where a 'training of trainers' event was held in Rostov, Russia. This two-day training of trainers was led by a local organisation, Kovceg AntiAIDS, and aimed to improve activists' knowledge of HIV, treatment, and advocacy.

Another initiative to highlight is a new **partnership developed between EATG and the International Committee on the Rights of Sex Workers in Europe (ICRSE)**. This involves a training event bringing together sex workers and HIV activists to cover topics such as PrEP, service access, stigma, and discrimination.



The aim of the project is to bring together sex workers and HIV activists from 8 countries for a three-day training followed by small national workshop, and the development of position papers on key issues relating to sex work and HIV.

Other things have been going on of course, including the successful implementation of the second **M-Care** course in collaboration with Africa Advocacy Foundation and EATG's ongoing commitment to **EUPATI** and **CoPE**.

Challenges / expectations

For the TCWG, one of the ongoing challenges is to deliver on our commitment to **strengthen targeted capacity building** for EATG members, especially those new to the organisation. Following discussions earlier in 2019 with the Chairs of ECAB and the Policy working groups, two **advisory groups** were established to help steer the development of two important areas: **the review of clinical trial protocols; and treatment advocacy**, specifically understanding, monitoring and discussing scientific data for advocacy purposes. The training day prior to 2019's GA was one of the outcomes of these discussions.

1. OUR STRATEGIC GOALS AND OBJECTIVES 2016 – 2018 (extended to 2019)

1.1 TARGET RESOURCES ON ACCESS GAPS AND SPECIFIC KEY POPULATIONS

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

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

In June, **EATG, together with the EU CSF coordination team, organised the third meeting of the Forum.** The group discussed policy and technical work with the European Commission, EU and international agencies. The EU CSF structured itself into 4 working groups: **EU advocacy and funding; stigma and discrimination; access to medicines and implementation of combination prevention.** The attendees discussed the work until the end of the year. This included outreach to the new MEPs and the new Commissioner, initiating a survey on stigma and discrimination and a survey on shortages, working on two statements around condom use, TasP and PrEP, and combination prevention at large. It also discussed developments on the abolishment of mandatory HIV-status disclosure, removal of testing consent from guidelines and legislation in Czech Republic, e-prescriptions in Latvia and a U=U campaign in Poland. Finally, there was a session with different Commission services on EECA.

EATG collaborated with both the EU CSF on HIV, hepatitis and TB and the EU CSF on Drugs 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.

EATG also sought to ensure that partners integrate HIV, TB and hepatitis concerns in their advocacy (2.1.5 EU4Health, EPHA) towards EU actors. It spoke at **two multi-stakeholder meetings** on the future of the EU health agenda.

In October, **the European Commission announced the closure of the EU CSF and the Think Tank on HIV, hepatitis and TB.** The work of the Think Tank was transferred to the EU Health Security Committee. EATG and partners continue to advocating for the preservation of these strategic information and experience exchanging platforms.

In October, EATG and MSD co-hosted a session at the **European Health Forum Gastein** on **'Transforming HIV responses in Europe: Focus on disruptive community actions'**.

In December, EATG published **an EU Policy Brief** with an agenda for cross-sectoral EU action for 2019-2024. In addition, EATG **called on the EU Fundamental Rights Agency** to produce an opinion on legal and regulatory reforms needed to ensure that the fundamental rights of people living with HIV and other populations at risk are fully respected, protected, promoted and fulfilled.



WORKSHOP ON EATG'S INVOLVEMENT IN EASTERN EUROPE & CENTRAL ASIA (EECA) REGION

On Friday 25 October 2019, prior to its General Assembly, EATG used the opportunity of the presence of members and finalisation of the Long-Term Strategy 2020-2025 (LTS), to examine **EATG's engagement in the South Eastern, Eastern Europe and Central Asia region (EECA)**. Led by a presentation from **Prof. Michel Kazatchkine**, the workshop addressed countries and regions that share some heritage and similar systems: EECA, the Baltic states and South Eastern Europe.

The EECA region is where more than half of HIV-positive Europeans and Central Asians live and where the epidemic continues to expand in contrast with most of the rest of the world. The session explored the realities of communities most affected by the HIV - and TB and viral hepatitis - epidemics in the EECA region and relevant interventions for EATG in that context.

The session also addressed the challenges faced and opportunities for EATG in **South-Eastern Europe (SEE)**.



ESTICOM - EUROPEAN SURVEYS AND TRAININGS TO IMPROVE MSM COMMUNITY HEALTH (Timeline: September 2016 - August 2019)

esticom.eu

ESTICOM aimed to facilitate access to and 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 was part of the project consortium and many EATG members contributed to the preparation and translation of the surveys as well as developing the training programme.**

The EMIS 2017 survey report is available [here](#) and ECHOES survey report [here](#). The training materials are available [here](#) in 10 European languages.

In 2019, EATG:

- attended a Final dissemination meeting in June to discuss the outcome of the EMIS and ECHOES surveys, as well as the recommendations
- attended the final consortium meeting in July and contributed to the final technical report as part of the project deliverables, revised a previously submitted report about recommendations for CHW training, based on the ECHOES survey findings and a literature review
- contributed to the finalisation of the ECHOES report

M-CARE 2019 (Timeline: July 2019 – December 2019)

eatgtrainingacademy.com/m-care-2019

Together with the Africa Advocacy Foundation (AAF), EATG conducted the M-Care 2019 training programme, targeted to **migrant populations**. The call for applications was announced in July and the selection of participants finalised in August. Over two modules, in September and December 2019, a group of 16 European migrant community advocates received training 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



1.2 INCREASE COMMUNITY INFLUENCE IN RELEVANT BIOMEDICAL AND SOCIAL SCIENCE COMMUNITIES

EATG continued playing a pivotal role in ensuring that the HIV community perspective is reflected in current biomedical and social research, by organising **Community Advisory Boards** and engaging in **multi-stakeholder initiatives**

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

Community discussion on the development of a framework to measure patient input's impact based on the Sitges and ECAB observation:

Academic researchers involved in the PARADIGM project, of which EATG is a partner, gathered feedback from ECAB members to develop a framework that would help measure and monitor patient engagement in the interaction with industry partners and other stakeholders involved in medicine research and development processes. The **Sitges meeting series 2007-2017 was considered together with the ECAB observations presented in the ECAB session above.** For the Sitges case study feedback was provided via online surveys or recorded discussions and submitted to the task leaders. EATG will continue the collaboration for the development of the framework until the conclusion of PARADIGM in 2020.

Community reviews of scientific material: A strong feature of ECAB is the review of protocols and documents related to research and development processes. From the beginning of 2019 10 members, organised in small and focused teams, have provided community input on:

- **8 protocols and designs of clinical trials for HIV treatment** and prevention and related therapeutic areas
- **2 consultations** launched by the EMA
- **3 package leaflets** for the EMA

Advocacy with Gilead: As a result of the latest discussion with industry within the ECAB forum, EATG has sent **two letters to Gilead** requesting **a) a stronger involvement of EATG in R&D, including submission of protocols for community reviews and community participation in investigators' meetings** and **b) the implementation of a policy for the production of stand-alone key medicines** to respond to the needs of the entire community of people living with HIV.

Consultation and advocacy with EMA: EMA EATG has also responded to an **EMA consultation** on the regulatory science strategy 2025. Wide availability of stand-alone compounds is important for expanded access and combinations tailored to patients' needs. Thus, EATG asked the agency **not to grant marketing authorisation to products which are only available in fixed-dose combination**, unless there is a clear, established futility in their availability as stand-alone compounds. Furthermore, EATG continues to insist on EMA to bring clarity to **indications** for ARV medicines regarding the notion that **sustained, undetectable levels of HIV in the blood cannot result in HIV transmission in sexual partners.**

EATG and HIV Cure research project proposals: EATG participated as a community partner in **three Horizon 2020 proposals on research for innovative** solutions submitted to the European Commission in April. Unfortunately, all three proposals were rejected in August.



EUROPEAN COMMUNITY ADVISORY BOARD (ECAB) MEETINGS ON HIV

ECAB has introduced a thematic approach working with companies and research bodies to enable members to be involved in R&D areas that are most important for the community and to advocate for the specific needs and promote access to treatment for the HIV community with attention to vulnerable/underrepresented groups. In the past this has not always been successful but has helped ECAB to move from a repetitive module and refocus on emerging priorities.



First meeting

During the ECAB meeting on HIV (March 22-24, Frankfurt) 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 meeting on HIV was dedicated to a thematic discussion on **women's participation in clinical trials**. EATG discussed the following topics with the companies:

- Promotion of developers' policies to facilitate women's inclusion in clinical research
- Creation of favourable conditions for participants with children
- Possibilities to expand research to Eastern Europe and Central Asia in order to increase access to care



Second meeting

During the ECAB meeting on HIV (November 22-24, Berlin), activists from across Europe, as well as a community representative for the USA, met with **Gilead, Janssen** and **ViiV** to discuss:

- HIV medicines **pipelines**
- R&D on **vaccines**
- new methods of **medicines administration**
- **implementation science**

The meeting also addressed participation of the transgender community in trials. EATG engaged with an advocate of GATE and a training session was offered to the participants on the importance of addressing trans issues in HIV research. During the meeting the following points of advocacy have been raised:

- Specific plans to reach out/recruit from the trans community
- Specific data/studies supporting the use of ARVs among trans people
- Active engagement with the trans community to ensure that the language and materials used in the studies are (trans)gender inclusive

A community training on **trans men and sexual health** was offered at the conclusion of the meeting.

Both ECAB meetings on HIV were followed by an interactive session as part of a participatory observation exercise in the development of a framework to measure the impact of patient engagement. These activities are part of the PARADIGM project. Prior to the meetings, participants were invited to attend preparatory webinars.





EUROPEAN COMMUNITY ADVISORY BOARD (ECAB) MEETINGS ON HEPATITIS

An advisory board on viral hepatitis was held first in Brussels, and continued in Leuven over the weekend of October 18-19. A group of 17 advocates with expertise on viral hepatitis engaged with **Gilead** representatives to discuss:

- the pipeline for **hepatitis B (HBV)** and **Non-Alcoholic SteatoHepatitis (NASH)**
- post-marketing trials for **hepatitis C (HCV)**
- **access** and HCV **elimination** efforts
- community involvement in **protocol reviews**

The meeting was followed by a training on HBV by [Sanjay Bhagani MD](#) (EACS - Vice President)

EUROPEAN COMMUNITY ADVISORY BOARD (ECAB) MEETINGS ON DIAGNOSTICS

A community advisory board on diagnostics was organised by EATG and hosted by GAT in Lisbon (20-22 September). During the meeting EATG facilitated the discussion between 15 community members from different checkpoint initiatives around WHO Europe region and three diagnostics producers (**Cepheid, Abbott, Owen Mumford**).

The discussion highlighted community needs that were shared with producers:

- Need to focus on the advancement of the **pipeline** of the producers (what is new and useful for community testing)
- Need to develop diagnostic devices for advancing **community service on PrEP** (HIV test for acute infections, Point-of-Care creatinine measurement etc.)
- Need to reprioritise specific tests (such as technologies for **latent TB** and **active syphilis**)



STEPS VI: A COMMUNITY INITIATIVE TO DESIGN THE PATHWAY TO A LONG-TERM REMISSION OF HIV INFECTION

On November 6th at EACS 2019 conference in Basel, EATG organised the sixth edition of the STEPS workshop focused on **scientific research to reach a long-term medicine-free remission of HIV infection**. The workshop is dedicated to community advocates working in the HIV field in Europe interested in the advancement of research for a “functional cure” or long-term medicine-free remission of HIV infection.

In 2019, the workshop was integrated within the EACS programme and was held just before the opening session of the conference. It covered two major aspects related to HIV cure research:

- the **London & Dusseldorf patients** that apparently seem “cured” from HIV -after the Berlin patient- and the **ethical challenges related to these and other cases of HIV remission**
- the use of **broadly neutralising antibodies (bNAbs)** within HIV cure research: introduction and ongoing studies

The meeting was largely attended (more than 40 people attended the meeting and the room ended up overcrowded) and a lively dialogue was held between community members, researchers and clinicians.



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 2019, **EATG** contributed to the project through different means, namely by:

- participating and contributing to **2 workshops**, the first on the development of a tool for assessing existing Patient engagement initiatives and the second for the development of a monitoring and evaluation framework on PE
- contributing to the **development of recommendations** on the required capabilities for patient engagement as part of the authoring group
- co-organising **a workshop** to discuss the developed recommendations on patient engagement and the material needed to be created for facilitating PE
- contributing to the **assessment of existing initiatives on patient engagement**, for further analysis on the existing gaps
- contributing to the development of **a framework for monitoring and evaluation of PE initiatives**, bringing the community perspective
- facilitating **access to the ECAB model** for testing the framework and further identification of relevant indicators
- organising a **webinar** addressed to EATG members for presentation of the monitoring and evaluation framework, and how it can be used for ECAB meetings
- contributing to the development of materials on **CABs, Conflict of Interest** and **complementary material to the EUPATI industry guidance**, as well as PE Code of conduct and preparatory work for the development of additional resources on the areas of identification of patient representatives, report and dissemination of PE activities and lay language of legal agreements, which will be publicly available at the end of the project in the summer 2020
- contributing **an article on ECAB**, published in the PARADIGM blog in September
- contributing to the organisation of the **Open Patient Forum on Patient Engagement** in Brussels in September 2019, where **EATG co-organised a session**
- contributing to the development of the **sustainability framework** to enable the continuation of sustainable and meaningful patient engagement after the end of the project
- participating at project team and work package meetings

EUPATI - EUROPEAN PATIENT ACADEMY OF THERAPEUTIC INNOVATION

(Timeline: ongoing, started in 2012)

eupati.eu

EUPATI was a project funded by the Innovative Medicines Initiative (IMI) from 2012 to 2017, focussing on patients' involvement in medicines research and development across disease areas. In 2017, a 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 a project partner and 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 the form of in-kind contribution.**

In 2019, EATG:

- published an **article** about the synergies between EUPATI and the STEP-UP training programme
- conducted a member survey about the use of EUPATI Toolbox among Russian-speaking community of people living with or affected by HIV in EECA
- conducted a needs assessment exercise among EATG members and other patient representatives to assist in the continuous updating of EUPATI training modules and toolbox
- attended the annual **Sustaining Partners Meeting** in June and regular Steering Committee teleconferences

EFOEUPATI - ENSURING THE FUTURE OF EUPATI

(Timeline: September 2018 - August 2020)

eupati.eu/efoeupati

EFOEUPATI seeks to ensure the sustainability of the achievements of the EUPATI project: **the Patient Expert Training Course, the multilingual online Toolbox, and the EUPATI National Platforms (ENP) Network**. The project is co-led by the European Patients' Forum (EPF) and Bayer and funded by the Innovative Medicines Initiative (IMI). EATG acts as a community partner and participates in developing a sustainability/business model for the EUPATI activities.

In 2019, EATG:

- contributed to the activities of the sustainability work package by supporting the organisation of **three face-to-face meetings** (May, July and November) and the drafting and submission of the first deliverable, **a sustainability business model for EUPATI**
- produced a news **article** for the EATG website
- continued to provide feedback for 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

EHVA - EUROPEAN HIV VACCINE ALLIANCE - AN EU PLATFORM FOR THE DISCOVERY AND EVALUATION OF NOVEL PROPHYLACTIC AND THERAPEUTIC VACCINE CANDIDATES

(Timeline: January 2016 - December 2020)

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 2019, due to a bankruptcy filed from a former partner (and consequently the unavailability of one of the study products), **the therapeutic trial was redesigned with a different product and the opportunity was taken to adjust the design. A new protocol for the study was drafted.**

In 2019, EATG:

- continued to provide **community feedback** to the clinical trial protocol
- contributed to the development and dissemination of two **project newsletters** (July, December)
- contributed to the dissemination of project information at international conferences (AIDSImpact 2019, EACS 2019)



HIVACAR - EVALUATING A COMBINATION OF IMMUNE-BASED THERAPIES TO ACHIEVE A FUNCTIONAL CURE OF HIV INFECTION

(Timeline: January 2017 - December 2021)

hivacar.org

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 2019, **the project was on hold due to the departure of one key partner from the consortium**.

In 2019, EATG:

- participated in the consortium's general assembly and steering committee **meetings**
- contributed to the financial and technical periodic **reporting**
- continued preparations to conduct **a psychosocial survey about HIV cure among clinical trial participants and PLHIV community at large** in the countries included in the study.

EMERGE - EVALUATING MHEALTH TECHNOLOGY IN HIV TO IMPROVE EMPOWERMENT AND HEALTHCARE UTILISATION: RESEARCH AND INNOVATION TO GENERATE EVIDENCE FOR PERSONALISED CARE

(Timeline: May 2015 – April 2020)

emergeproject.eu

EmERGE is developing a **mobile application to enable self-management of people living with stable HIV**. 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 2019, EATG:

- published the annual **newsletter** (April)
- revised the **Project Publication Strategy** document, coordinated regular Publication Management Team meetings and tracked project publications



- updated and produced the **project brochure** and other promotional materials
- started working on video materials for app users and the general public
- organised two **community meetings** for representatives of local HIV NGOs from the five study sites in June and October
- attended the Consortium meetings (April and October) and the European Commission Project Review meeting (July)
- coordinated the project information booths at **AIDSImpact conference** (July) and **EACS 2019** (November)
- coordinated a presentation at a community session at EACS2019 (November)
- conducted a survey among community about visits to HIV clinics
- lead a dialogue with the EACS Guidelines Committee about inclusion of virtual visits in the EACS 2019 guidelines
- launched work on a policy brief about barriers for implementing mHealth in the EU

TB ONLINE

tbonline.info

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 2019, EATG continued its contribution to TB Online, providing **updates of content to the website and the regular newsletter**.

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

EATG focussed on advocating for policies to overcome barriers impeding access to medicines and healthcare services for people living with and affected by HIV

Addressing access to medicines and continuity of access

EATG joined a coalition of national and European patient, public health, medical professional and pharmacist organisations calling the European Commission to collaborate with member states in improving **reporting on shortage situations**. The European Commission staff and Health Commissioner have been receptive though the decision on next steps will be taken by the new Commission. The group is following up with the **European Parliament Committee** responsible for health to advocate a hearing on the subject.

Regarding medicines shortages, the EU CSF on HIV, Hepatitis and TB working group on access to medicines coordinated **a short survey on medicines shortages for the treatment of hepatitis B and C, HIV and TB as well as Opioid Substitution Therapy (OST)**. The data collected and summarised are used to advocate for a comprehensive investigation into the causes of shortages in order to improve understanding of the situations and seek possible solutions.

#MedicinesShortages

Fighting stigma and discrimination

EATG continues to foster the exchange of best practices on the subject of stigma and discrimination via the **EU CSF meetings** and **input into the EU Think Tank**.

Via the **Ageing with HIV** project, EATG held a small storytelling activity presenting **testimonials by community members** on discrimination in healthcare services provision other than HIV care (such as dental care, among others). The aim was to raise awareness around the issue. The topic is also one of the points addressed by the **HIV Outcomes** Initiative (see 1.1.5).



1.4 RENEW ACTIVISM THROUGH SCALED-UP TRAINING AND CAPACITY BUILDING

EATG invested in capacity building and knowledge sharing initiatives to empower HIV advocates from across Europe and Central Asia with diverse background and level of experience

Empowering community to engage in designing and implementation of national plans

COPE - CONTINUOUS PATIENT EDUCATION

(Timeline: continuous, 1-2 calls for applications per year)

eatgtrainingacademy.com/cope

The CoPE project is a funding mechanism, initiated and coordinated by EATG, that **enables the production and translation of patient education materials**, brochures and other resources related to HIV/AIDS & co-infections in multiple languages. The project aims at **empowering PLHIV and their advocates by providing access to the latest information about HIV/AIDS and co-infections in their local language**. Community-based organisations in the European and Central Asian region working on prevention and treatment of HIV/AIDS and co-infections are eligible to apply.

A call for applications **was launched in December 2018 and closed in February 2019**, focusing on HIV and co-infection, but also encouraging applicants to address the following aspects:

- the capacity of community to understand the **treatment cascade** in their country and to use treatment cascades as a tool for advocacy
- the capacity of community to engage in **data collection and community research, monitoring and reporting**
- the capacity of **migrant communities in Europe** to get involved in the provision of healthcare services, research, access programmes, and early testing initiatives; as well as to fight HIV, HCV, and TB related stigma and discrimination towards and within their community

9 publication projects were selected in Czech Republic, Poland, Greece (2), Slovenia, Latvia (2), Portugal and Tajikistan. These publications represent a total of 12,800 printed copies distributed through local organisations and HIV clinics. The format of funded publications is developing and diversifying. One of the selected projects produced a website in Polish for information about sex and drugs for gay and bisexual men.

STEP-UP - SKILLS TRAINING TO EMPOWER PATIENTS

(Timeline: ongoing, started in 2013)

eatgtrainingacademy.com/about-step-up

In January and March, EATG implemented the two concluding modules of the STEP-UP 2018-2019 programme. A new cohort of young HIV activists was empowered to assume a leading role in advocating for the needs of people living with HIV through 40 hours of in-depth training – a total of 100 hours since the first module in June 2018. The fifth edition of STEP-UP enrolled 19 participants from Ukraine, Kyrgyzstan, Tajikistan, Russia, Kazakhstan, Croatia, Turkey, Belgium, Scotland, Greece, North Macedonia, Romania, Germany, Ireland, Belarus, and Portugal. The following modules have been organised:

- Module 4 (Warsaw, Poland | 18-20 January 2019) focusing on patient engagement in R&D and stigma & discrimination
- Module 5 (Brussels, Belgium | 01-03 March 2019) focusing on HIV criminalisation and issues around HIV treatment and cure research

All materials of the training are accessible at the EATG Training Academy website.



In April 2019, EATG published a report assessing the impact of the first four cycles of STEP-UP on its participants, their work and their communities. While recognising the value these early Step-Up cycles had, the assessment highlights a number of areas for improvement.

STEPRU: TRAINING IN COLLABORATION WITH RUSSIAN COMMUNITY ORGANIZATION “КОВЧЕГ АНТИСПИД”

In April 2019, EATG initiated a training in Russia, in collaboration with the local community organisation **Kovceg AntiAIDS (Ковчег Антиспид)**. Fifteen activists from Rostov-on-Don and other nearby cities attended the two-day training., where participants discussed topics such as **HIV treatment literacy, co-infections and counselling**. The training focused further on providing trainees with hands-on skills on how to organise trainings and moderate groups in resource-limited settings. Through this initiative, EATG contributed directly **to community education and mobilisation at a local level**.



EUROPEAN RED UMBRELLA ACADEMY (ERUA)

(Timeline: November 2019 - October 2020)

eatgtrainingacademy.com/about-european-red-umbrella-academy

The project is an initiative of the International Committee on the Rights of Sex Workers in Europe (ICRSE) and is implemented in partnership with EATG.

The aim of the project is to foster **collaboration between sex work activists and HIV activists**. On the one hand, it aims to enhance the understanding of HIV among sex work activists as well as of the realities faced by sex workers among HIV activists. On the other hand, it aims to develop practical models for collaboration at local level. Another aim is to produce position papers on topics identified by sex work and HIV activists to be used for education and advocacy purposes at national, regional and global level.

In 2019, ERUA began to implement the first stages of the project by engaging a consultant to draft three position papers on sex work and HIV policy issues and a call for two trainers for the face-to-face module.

COMMUNITY TRAINING ON BASIC HIV SCIENCE FOR ADVOCACY PURPOSES

On October 24, before the beginning of the General Assembly in Sofia, EATG offered the new and less experienced members the opportunity to attend a training **on how to translate science into advocacy**. The idea behind this initiative: **a passionate EATG advocate who wants to share the enthusiasm for HIV advocacy with other members and support them in becoming stronger treatment activists**.

The training was organised in response to an internal assessment which highlighted the need of less experienced members to acquire new knowledge to advocate during HIV conferences, community advisory boards and other scientific meetings. The training was conducted in an interactive fashion and was based on real cases (sharing a streaming presentation from CROI and explaining the slides step-by-step). The focus was on **how to identify the relevant information and translate it in an understandable way**. The participation was higher than in usual training modules (35 participants and a very lively discussion) and the response from the participants was very positive.

1.5 MAXIMISE IMPACT THROUGH MULTI-STAKEHOLDER STRATEGIC PARTNERSHIPS

EATG continued being actively present in **key events** and engaging with a variety of partners within **multi-stakeholder initiatives** and its **own projects**

Ensuring sustained external visibility and fostering collaborations in the area of Quality of Life of PLHIV

In 2019, EATG co-signed **27 joint letters, statements and declarations** along with many Civil Society Organisations across Europe and other allies.



In 2019, EATG participated in:

CROI 2019 (Conference on Retroviruses and Opportunistic Infections – 4-7 March 2019, Seattle), reporting back updates from the sessions as well as from the community breakfast meetings.

AIDSImpact 2019 (29-31 July 2019, London), where EATG hosted a booth and presented in sessions and in the poster exhibition.

EACS 2019 (6-9 November 2019, Basel), hosting a booth and two sessions on **HIV Cure research** and **HIV and migrants**.

EUROPEAN PUBLIC HEALTH ALLIANCE

EATG was **elected as member to the European Public Health Alliance (EPHA) Board of Trustees**. EPHA is an organisation made up of European public health NGOs, patient groups and health professionals working together to improve health and strengthen the voice of public health in Europe. EPHA is embarking on the development of **a new long-term strategy** and the agenda regarding the new European Commission and European Parliament is being developed. Moreover, 2019 and 2020 are important years on health policy with the new European Parliament and European Commission starting agreement.

EU4HEALTH ALLIANCE

EATG joined the EU4Health alliance of European, national and grassroots level health organisations, coordinated by a group of European level health umbrella NGOs. This core group is – currently – composed of 21 organisations: The campaign is supported by 241 NGOs.

The alliance seeks to ensure that **the European institutions will continue to work on health protection and promotion**. EATG seeks to ensure that **HIV, TB, viral hepatitis and STIs are in that agenda**.

EUROTEST (formerly HIV IN EUROPE)

EATG is part of the EuroTEST initiative **steering committee** and **advocacy secretariat**. A pan-European multi-stakeholder initiative that works to ensure that **people living with HIV and viral hepatitis enter care earlier in the course of their infection than is currently the case**, as well as to study the decrease in the proportion **presenting late for care**. It aims to inform policy processes, share knowledge and improve the evidence base around important issues of earlier testing and care. The initiative is led by an independent group of experts from civil society, policy makers, health professionals and European public health institutions.

In January 2019, **EATG and EuroTEST organised a stakeholders meeting on the side of the HepHIV conference** (28-30 January, Bucharest) to discuss what needs to be done to **implement guidelines in the real world**. The meeting increased understanding of the new ECDC testing guidance, ways to foster implementation at the local level from the perspectives of different actors, as well as indications of further “game-changing” screening approaches to improve the health outcomes of key affected populations.

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**. HIV Outcomes is a multi-stakeholder initiative developing and communicating expert, evidence-based recommendations for policy makers about the delivery of high-quality care for people living with HIV (PLHIV).

In 2019, HIV Outcomes has promoted debate at national level on the implementation of relevant HIV Outcomes recommendations in Italy and Sweden and investigated the possibility to adapt recommendations in other countries. It continued to advocate for the HIV response and the consideration of enhanced quality of life in long-term HIV care to be included on the EU political agenda. Moreover, it has been sharing learnings and good practices as well as building bridges with other disease areas.

In November 2019, the initiative launched a Call to Action urging European policymakers to ensure that long-term health outcomes and the quality of life of people with HIV are high on the political agenda. At a roundtable event in the European Parliament, Members of the European Parliament, the European Commission, European experts, patients and clinicians discussed key findings from a new report, which highlights the unaddressed long-term needs of people living with HIV in Europe.

NOBODY LEFT OUTSIDE (NLO)

EATG contributed to the Nobody Left Outside initiative strategy and the dissemination of **health service checklist**. NLO includes organisations working with people using drugs, undocumented migrants, other migrants, LGBTBI communities, sex workers, homeless people. These have come together to identify common issues and develop a set of principles – the checklist – as a tool for advocacy **to improve the delivery of health care to inadequately served populations**. The initiative has since created the “Nobody Left Outside” (NLO) Thematic Network at the EU health policy platform to identify common challenges, share best practices, shape guidance and try approaches to improve delivery of care for groups with sub-optimal access to health related services.

In October 2019, the initiative presented the Joint Statement on ‘Improving healthcare Access for Marginalised People’ at the EU Health Policy Platform.

THE PATIENT ACCESS PARTNERSHIP (PACT)

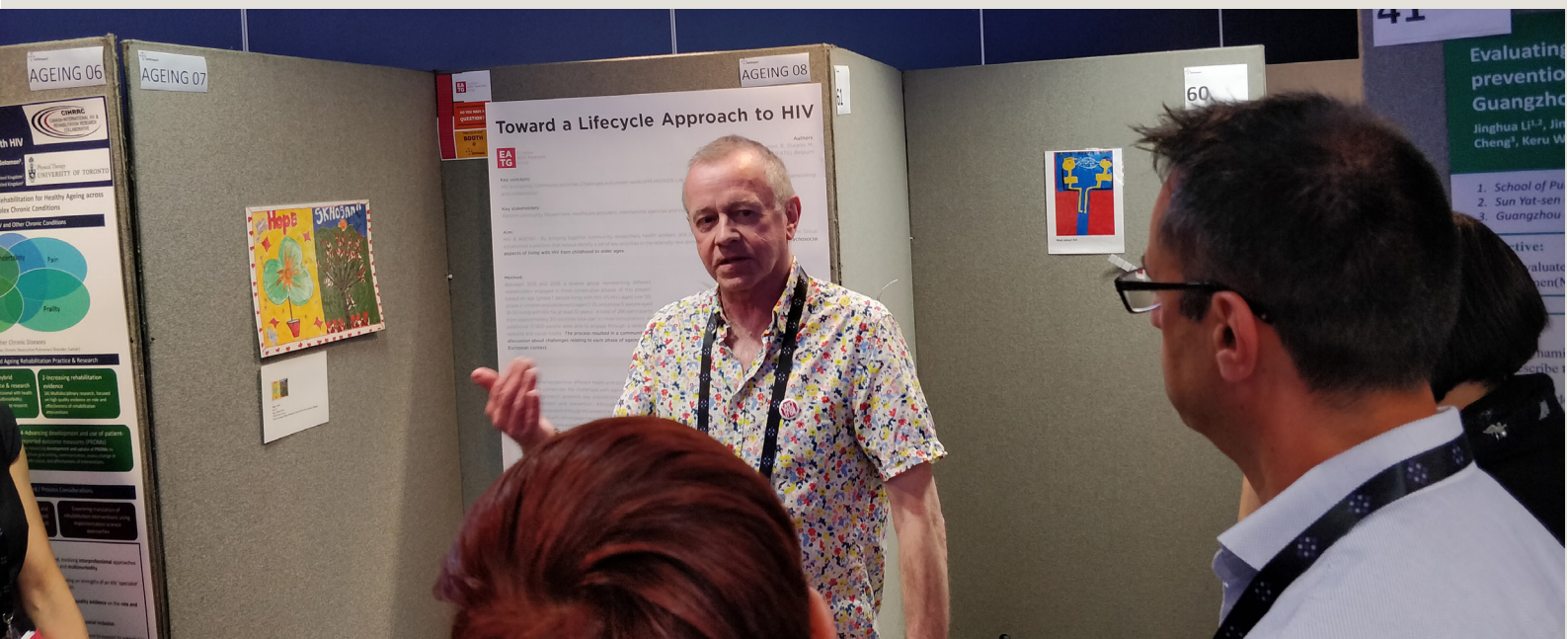
EATG contributed as speaker to **two high-level policy meetings** on the future of EU health policy organised by the Patient Access Partnership. PACT is a multi-stakeholder network bringing together patients, the medical and public health community, industry and European and member states policy makers and institutions, in order to develop and move forward on innovative solutions to reduce inequities in access to quality healthcare in the EU.

AGEING WITH HIV - A LIFECYCLE APPROACH

(Timeline: October 2015 – March 2019)

ageingwithhiv.org

The overall goal of this large EATG-led project was **to better understand and address the challenges and unmet needs of PLHIV in a life cycle perspective**. The project aimed 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 last phase of the project focused on the **dissemination** of the project **findings and evaluation**.

In 2019, the EATG:

- summarised the key outcomes and recommendations of the three phases of the project
- submitted abstracts to **IAS2019** and **AIDSImpact2019** conferences. The latter was accepted for oral poster discussion session
- finalised a **project evaluation report**
- organised a Taskforce meeting: *Operationalising Ageing with HIV project R&D Outcomes* and identified research gaps, in March

- conducted an **awareness-raising storytelling activity** about stigma and discrimination in healthcare services provision (other than HIV care)
- produced a special project newsletter, where the final reports and deliverables are showcased
- presented the project outcomes at the **BREACH (BELGIUM)** Spring Symposium 'Beyond viral suppression' in May
- **conceptualised several new project proposals based on the recommendations.** Separate initiatives on mental health & well-being, patient reported outcome measures (PROMs) as well as healthcare worker-patient collaboration have been developed and are being funded or fundraised for



1.6 ENSURE INTERNAL STRUCTURES ARE ‘FIT FOR PURPOSE’

2019 was a year of formative changes for EATG, finalising a new **long-term strategy** and a novel **transversal structure**, under the direction of a new **Executive Director**

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



In **March 2019**, Pieter Vanholder started his term as the Executive Director of EATG.

EATG appointed Bryan Teixeira as a consultant to develop a new **Long-Term Strategy** with a **6-year scope (2020-2025)**. The process kicked off in January. Several online and face-to-face consultations were carried out as well as a face-to-face meeting in June. In **October 2019**, the finalised version was presented to the General Assembly and approved.

In continuation from previous years' efforts to move towards a **renewed and transversal structure**, the Secretariat worked on a plan for the restructuring of EATG. The proposed plan introduces **three programmatic areas** (Quality of Life, Combination Prevention and Partners in Science) replacing Working Groups as well as upgraded and flexible roles for members participating in a model of Programme Chairs, Programme Committees and think tanks. In October 2019, the plan was presented to the General Assembly and approved.

A flexible, sustainable and easily accessible workplace that fosters collaboration

In **October 2019**, the EATG Secretariat moved to Interoffices co-working space. Centrally located in Brussels, near Trône/Troon metro station, one can work either in the designated area of our office or in a variety of shared space corners. We have the opportunity to hold in-house meetings in bigger meeting rooms, such as part of the ECAB meeting on hepatitis which we hosted in October.



Towards a monitoring and evaluation (M&E) framework

The office has continued working on **an M&E framework** that was discussed by the entire staff at a full-day staff meeting in September 2019. The framework may be used for monitoring the progress towards set objectives, on both process and outcome levels, for the Long-Term Strategy, mid-term and short-term workplans as well as for projects. The same framework can also be used when conceptualising project proposals submitted to funders. The work on **operationalising the Long-Term Strategy into concrete objectives for the mid-term and short-term workplans** continued at the staff retreat in November 2019 and onwards.

A system that enables reporting on achievements to external stakeholders

EATG continue to invest in communication towards stakeholders. Bilateral discussions with funders and stakeholders are central. Regular meetings were held with funders and stakeholders, often linked to events such as conferences.

Apart from face-to-face communication we continued to enhance our **digital communications** by setting up a LinkedIn page and with streamlined presence across social media.

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.

In 2019, EATG updated and fine-tuned its **privacy policy** in accordance with the GDPR.



1.7 ENSURE ACTIVE & REPRESENTATIVE MEMBERSHIP

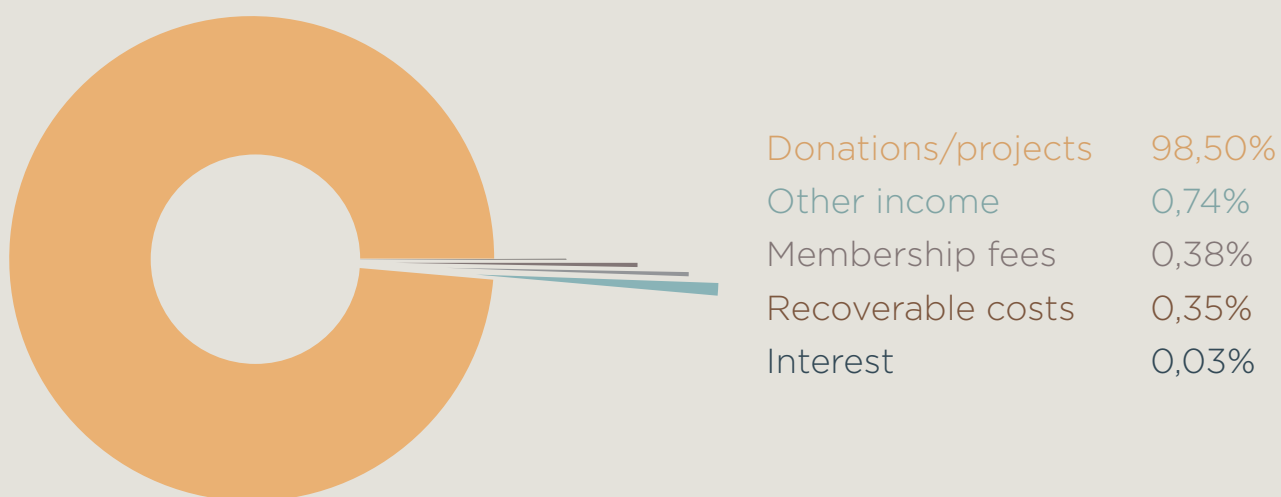
For this strategic goal, please see [3.MEMBERSHIP](#)

2. FINANCES

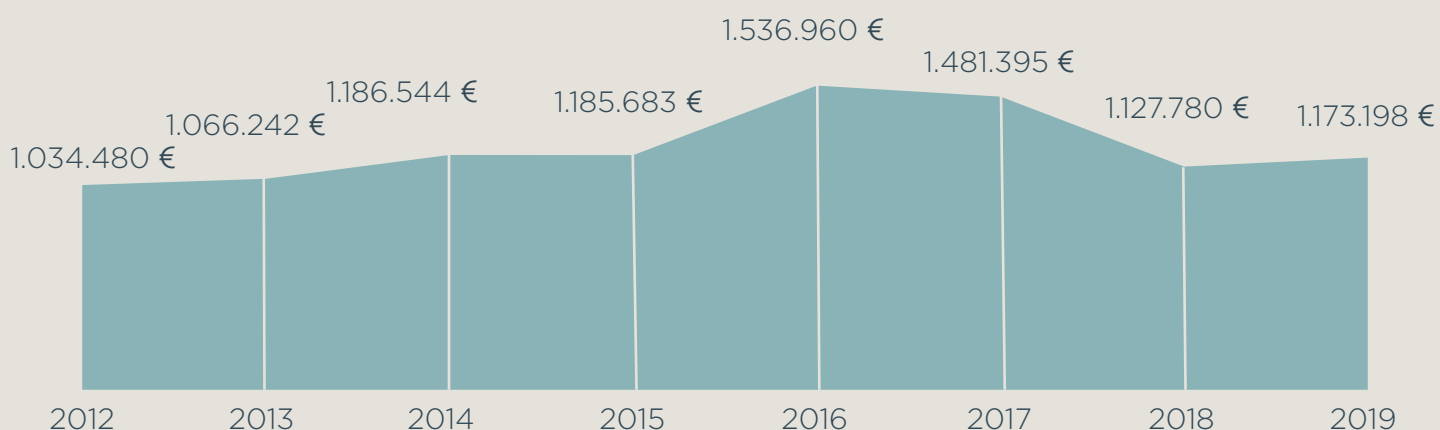
2.1 INCOME

€1.17 million

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

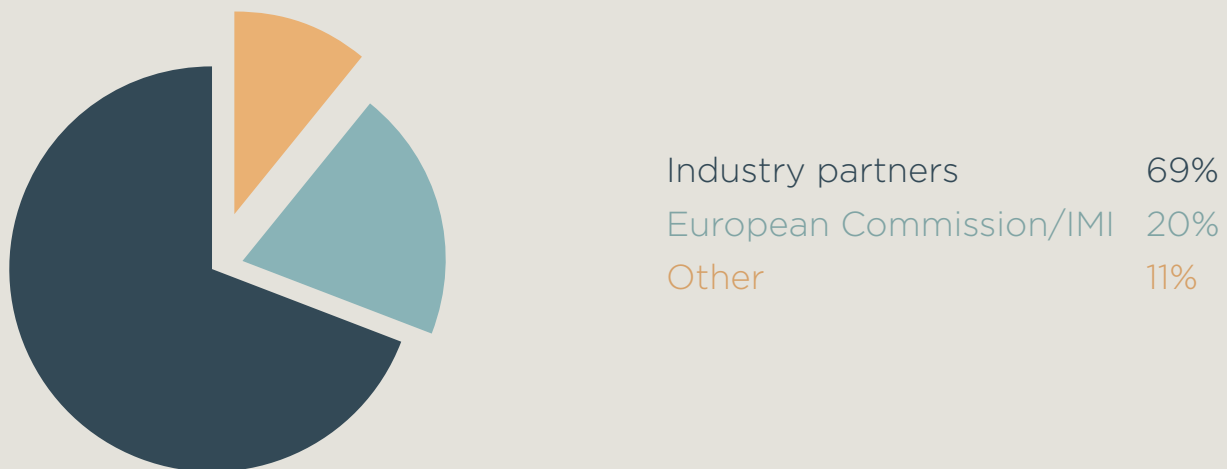


INCOME DEVELOPEMENT



2.2 FUNDERS

The distribution **by sources** of funding and grants is shown below

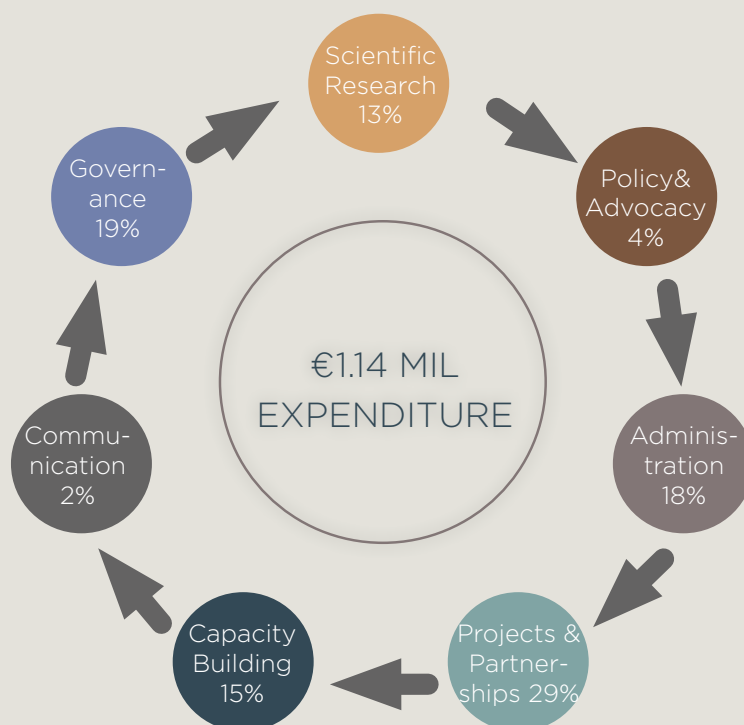


2.3 EXPENDITURE

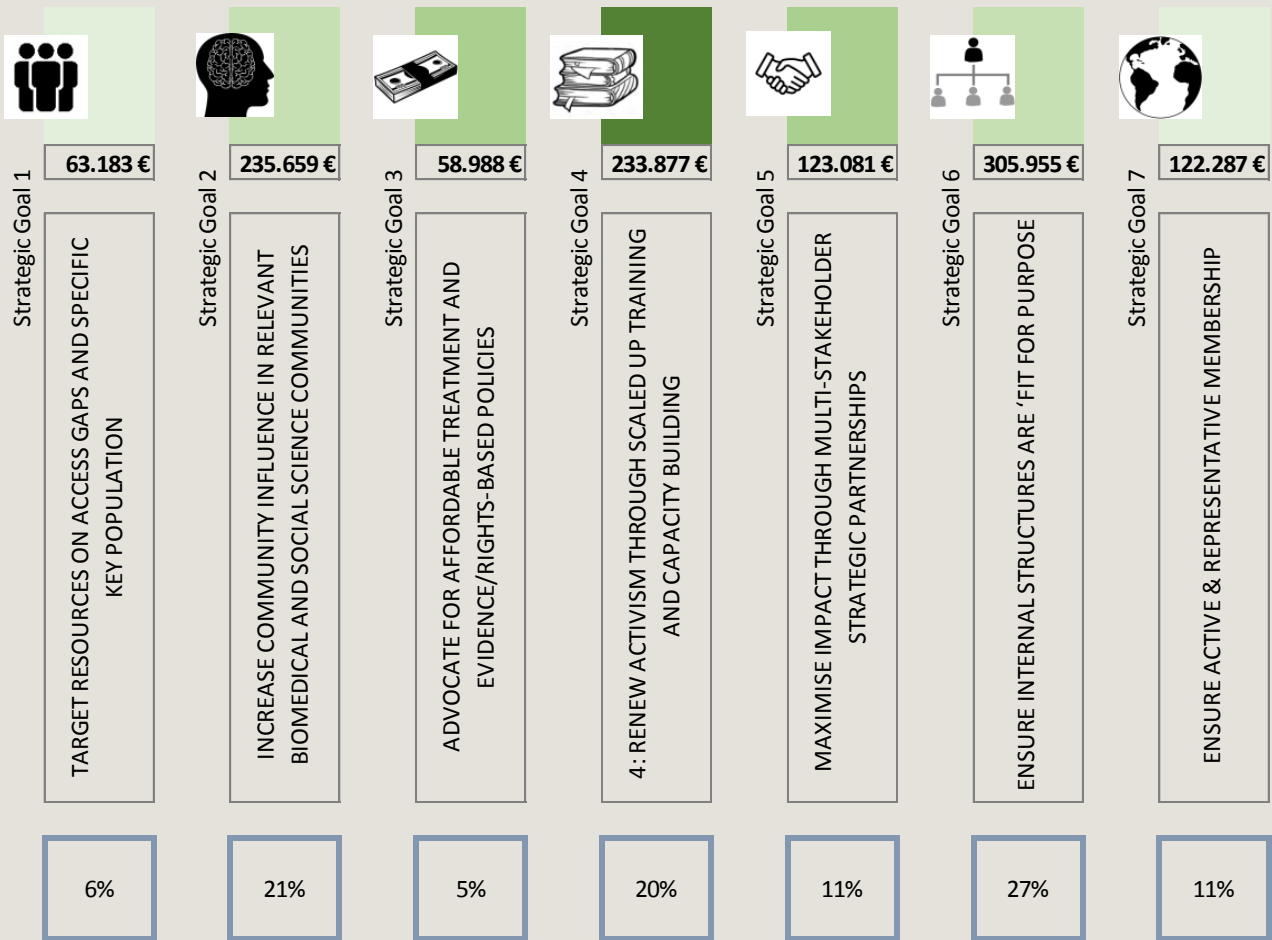
In 2019, EATG invested **€1.143.031** in numerous ways, including projects, trainings and activities, as well as representation, staff salaries and office operations.

Below is the distribution of the expenditure by function

EXPENDITURE ACCORDING TO BUDGET LINES



EXPENDITURE ACCORDING TO STRATEGIC GOALS



2.4 VOLUNTEER TIME

EATG is a membership-led and membership-driven organisation. The work of EATG members is vital and many of our members are very active. We estimate the volunteer time in 2019 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/

3. MEMBERSHIP



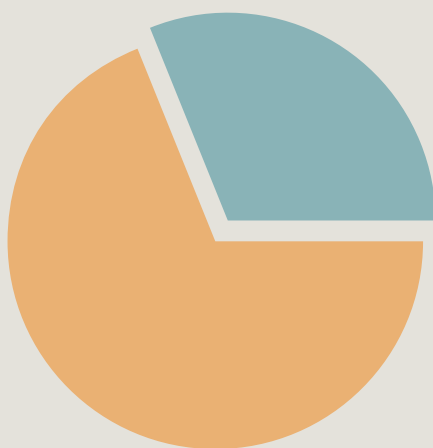
January - June 2019

At the end of 2019, EATG had 178 members representing 48 countries.

Gender

The gender balance has remained relatively stable during the past years with **69% men (123) compared to 31% women (55)**. Unfortunately, **trans people** are not represented in EATG membership.

Members by Gender

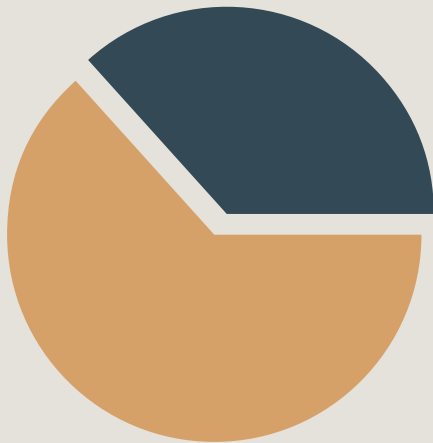


Men	123 ; 69%
Women	55 ; 31%

Supporting and ordinary members

At the end of 2019, EATG had **113 ordinary** members (members with voting rights) and **65 supporting** members.

Members by Status

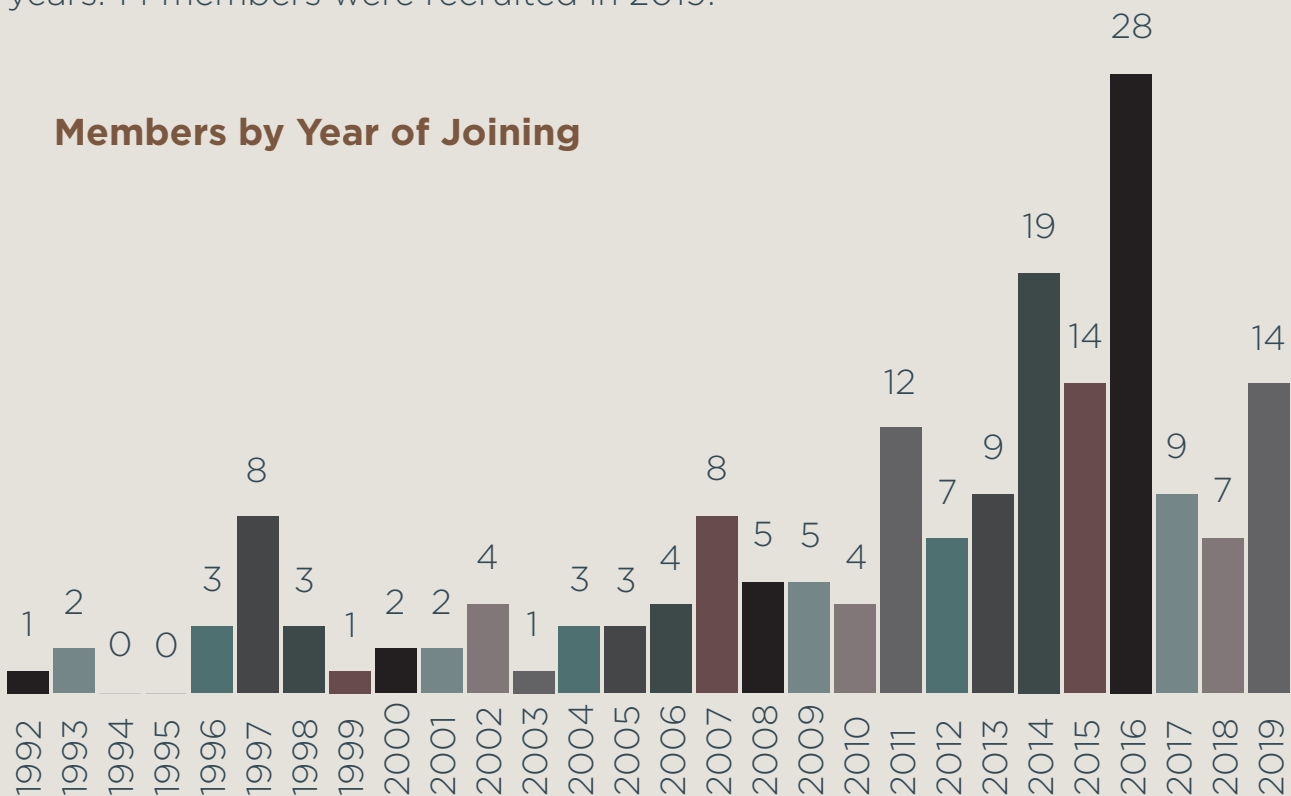


Ordinary	113 ; 63%
Supporting	65 ; 37%

Recruitment

More than half of the current membership joined EATG during the past six years. 14 members were recruited in 2019.

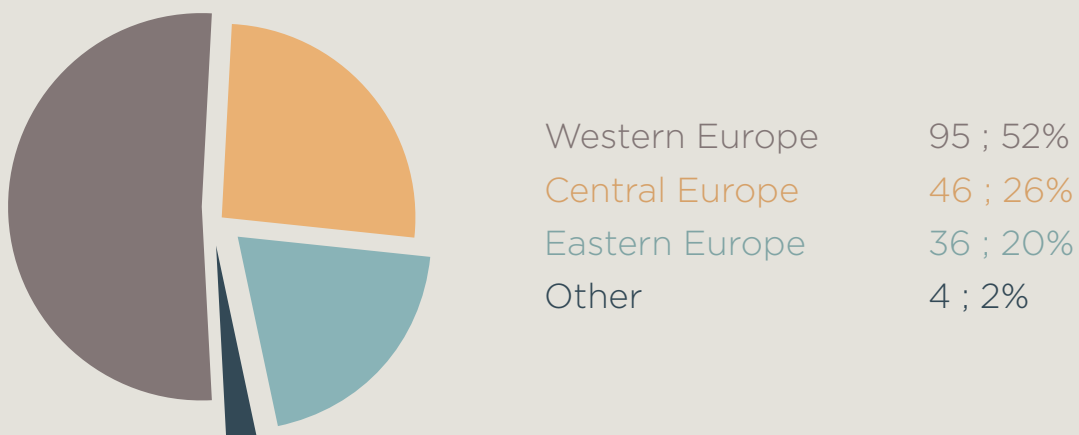
Members by Year of Joining



Region

More than **half** of EATG members come from **Western Europe** (as defined by WHO). At the end of 2019, **92** members (52%) came from this region. **46** members (26%) were from **Central Europe** and **36** members (20%) came from **Eastern Europe and Central Asia**. EATG sees increases in membership coming from Central and Eastern Europe and Central Asia within the past years. 4 members (2%) were formerly living in Europe and now are in other continents.

Members by Region



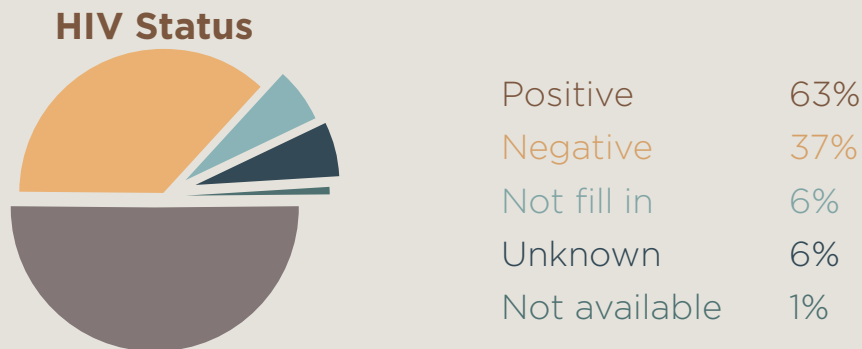
WHO definition of Western Europe (23 countries): Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom;

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

Eastern Europe and Central Asia (15 countries): Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russian Republic, Tajikistan, Turkmenistan, Ukraine, Uzbekistan.

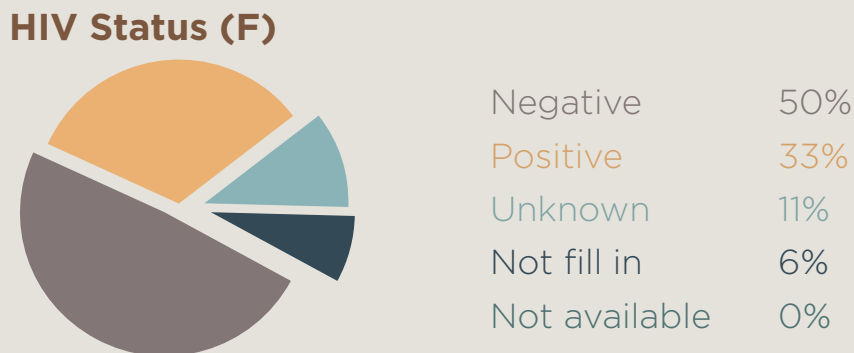
HIV status

At the end of 2019, EATG had **89 HIV-positive** members (50%); **65** members (37%) identified themselves as **HIV-negative**. 11 (6%) members said their status is **unknown**.



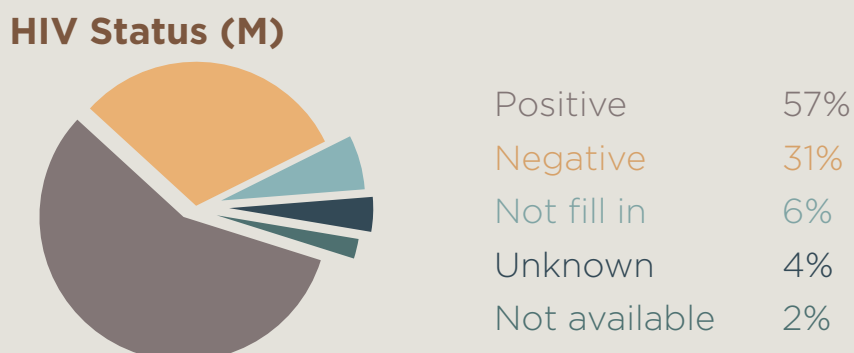
HIV status of women

Half (50%) of the women within the organisation identified themselves as **HIV-negative** (27) and **18** as HIV-positive (33%). **6** (11%) women said their status is unknown.

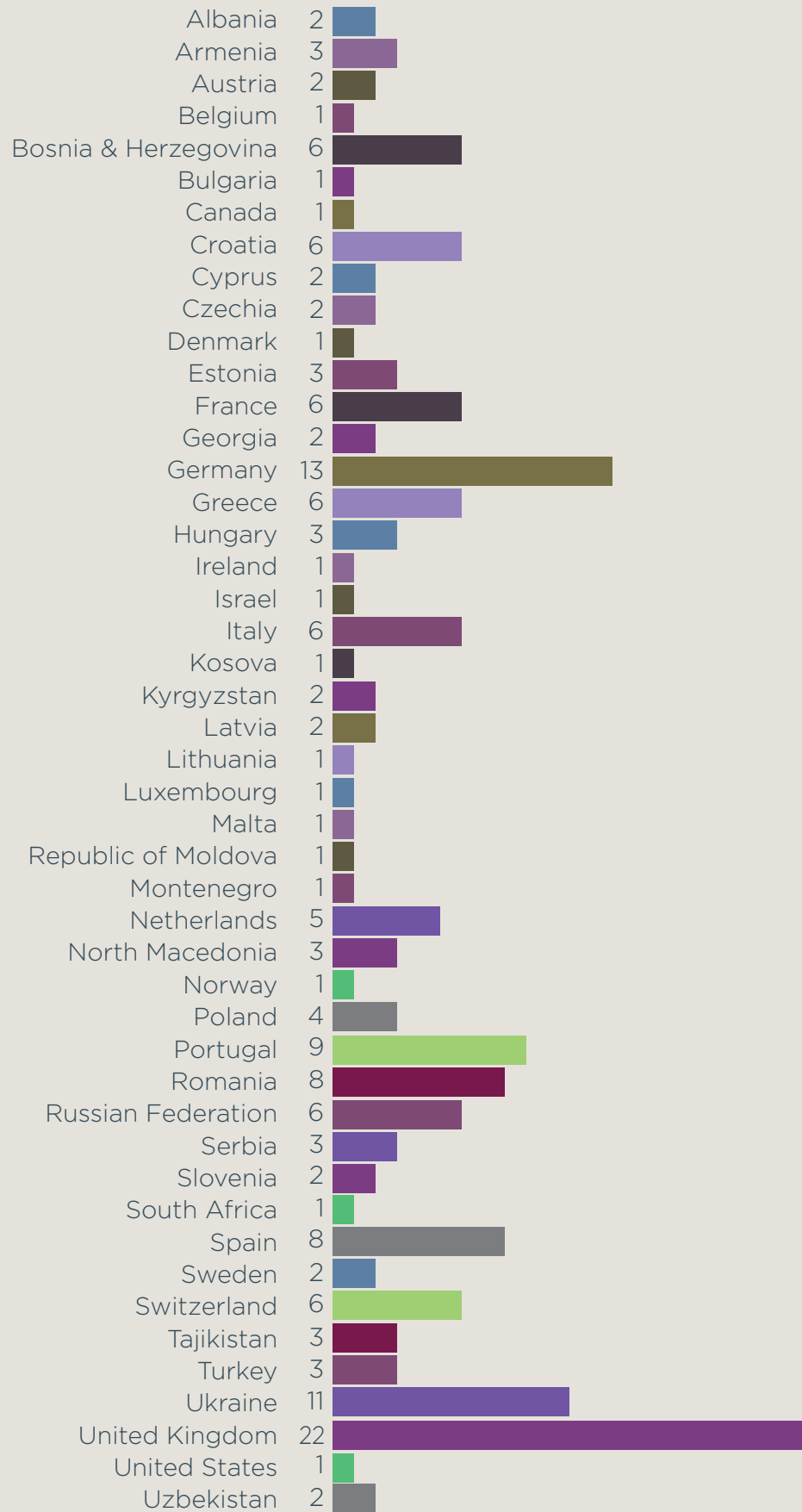


HIV status of men

70 men in the organisation identified themselves as **HIV-positive** (57%) at the end of 2019 and **38** as HIV-negative (31%). **5** (4%) men said their status is unknown.



Members by Country



4. ONLINE COMMUNICATION

EATG Website

eatg.org

EATG's website has been offline since August 1st 2019, due to mismanagement from the hosting service providers and a string of related incidents that kept us from having access to a back-up. EATG employed all means available – including legal aid from the provider – to regain access with no result. In December 2019, positive feedback was received from the insurance agency and EATG will be building a new website during 2020.

A mock-up site with extremely limited functionalities has been online since September 2019. The use of our social media and newsletters has been scaled-up to fill the gap.

For the period between the 1st of January and 31st of July 2019, EATG's website was visited by approximately **38.000 users**, amounting to **48.000 sessions**. During these sessions **74.000 pages** were accessed. Visitors stayed in the website for almost 80 seconds per session.

Audience

On average, **1.500 users** visited the EATG website every week.

5 in 10 users were between **25 and 34 years old**.

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

Of the European audience, **2 in 3** users were based in **Northern Europe** and **Western Europe**.

Acquisition

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

Of the traffic, **57%** was **organic (traffic from search engine results that is earned, not paid)** **33% direct (any traffic where the referrer or source is unknown)** and **6%** from **social media**.

EATG Social Media

Facebook: [@EuropeanAIDSTreatmentGroup](https://www.facebook.com/EuropeanAIDSTreatmentGroup)

Twitter: [@EATGx](https://twitter.com/EATGx)

Instagram: [@europeanaidstreatmentgroup](https://www.instagram.com/europeanaidstreatmentgroup)

LinkedIn: [linkedin.com/company/european-aids-treatment-group](https://www.linkedin.com/company/european-aids-treatment-group)

In 2019, EATG's **Facebook page** received **219 new likes** (2018: 1823, 2019: 2042).

In 2019, EATG's **Twitter** account attracted **280 new followers** (2018: 1575, 2019: 1855).

For the same period Twitter **impressions** reached 278.000 (2018: 165.000), increased by almost 70%.

In July 2019, EATG launched its LinkedIn account. In six months, the account's updates earned 2000 impressions.

EATG newsletter

HIV and co-infections news bulletin

The EATG newsletter is disseminated to **330 subscribers** (2018: 300), while **270 subscribers** receive the news bulletin (2018: 260). Both editions are sent via Mailchimp and one can subscribe on 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.

63% of all the subscribers are **highly engaged and often open and click e-mails they receive from EATG.**

Since August, the creation and dissemination of the HIV and co-infections news bulletin has been affected by the website's malfunctioning. Temporarily, we are sending out a weekly version with links to the news from their original sources.

In 2019, there were **13** periodic and thematic EATG newsletters disseminated.



5. GOVERNANCE

The Board of Directors

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

As from the 2019 General Assembly in Sofia, the composition of the Board is as follows: Ricardo Fernandes **(Chair)** – Andrej Senih **(Vice-Chair)** – Ian Hodgson **(Secretary)** – Aisuloo Bolotbaeva **(Treasurer)** – Maka Gogia **(Director)**



The EATG External Advisory Board

Lella Cosmaro - Michel Kazatchkine - Jürgen Rockstroh - 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: Ben Collins & Dimitris Nastos

Working Group Chairs

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, Pieter Vanholder - **Policy Officer**, Ann-Isabelle von Lingen
- **Scientific Officer**, Giorgio Barbareschi - **Events Coordinator**, Nadiia Gaidak
- **Events Coordinator/Project Officer**, Bojan Cigan - **Finance Assistant**, Nora
Tillich - **Project & Administration Intern**, Fiona Greenhalgh (until November
2019)

External Consultants

Projects, Maria Dutarte - Karina Huberman - **Training & Capacity Building**,
Kristjan Jachnowitsch (until 30 June 2019) - **Communication**, Apostolos
Kalogiannis - **Finances and Accounts**, Marie McLeod

The Funders

European Commission

IMI Innovative Medicines Initiative

Janssen Pharmaceutica NV

Gilead Sciences Europe Ltd

Merck Sharp & Dohme Ltd

ViiV Healthcare UK Ltd

Alere International Limited

Owen Mumford Limited

Contributing Partners

Africa Advocacy Foundation (M-Care Training Programme)

Deutsche AIDS-Hilfe e.V. (EU Civil Society Forum)

International Committee on the Rights of Sex Workers in Europe (European Red Umbrella Academy)

PrEP in Europe Initiative

ANNEX: Long Term Strategy (2016-2018 [extended to 2019]): 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.

Design by:

Freepik

Deniz Uyanik

Apostolos Kalogiannis

68

European AIDS Treatment Group (EATG)

Telephone +322 626 96 40 | **Twitter** @EATGx

Secretariat Interoffices | Avenue des Arts 56 -4c, 1000 Brussels, Belgium | www.eatg.org

Mettmanner Str. 24-26, 40233 Düsseldorf, Germany | German Charity no. VR8542 |

Belgian reg. no. 0877.686.583

© EATG Annual Report 2020