



European
AIDS Treatment
Group

Annual Report 2021



Acronyms and Abbreviations

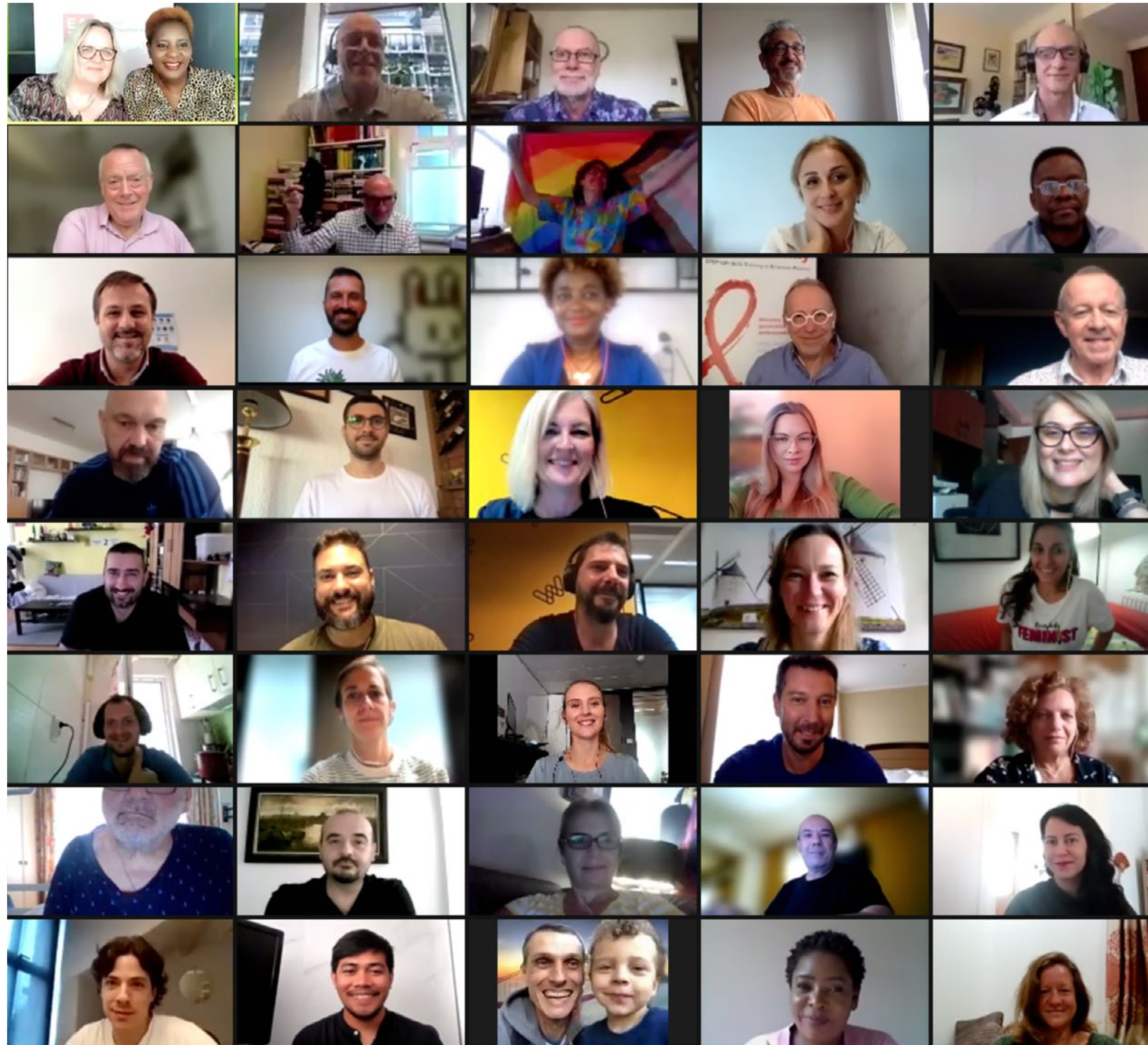
ACHIEVE	Associations Collaborating on Hepatitis to Immunise and Eliminate the Viruses in Europe	e-MPOWER	Partnership to Overcome Challenges of Online Learning and to Empower Youth Actors in the Field of Sexual Health Promotion in the COVID-19 Era
ARV	antiretroviral (drug)	EPF	European Patient Forum
AVAC	AIDS Vaccine Advocacy Coalition	EPHA	European Public Health Alliance
Co-Lead	Strengthening Community Leadership for Decentralised Access to HIV and HCV Testing	ESWA	European Sex Workers Rights Alliance
CoPE	Continuous Patient Education	EU CSF	European Union Civil Society Forum
COVID-19	Coronavirus Disease 2019	EUPATI	European Patient Academy of Therapeutic Innovation
CP	Combination Prevention	FIND	Foundation for Innovative New Diagnostics
DIAGNOSE	Diagnostics initiative for community-level service delivery	HBV	hepatitis B virus
EACS	European AIDS Clinical Society	HCV	hepatitis C virus
ECAB	European Community Advisory Board	HIV	human immunodeficiency virus
ECDC	European Centre for Disease Prevention and Control	HIVACAR	Evaluating a Combination of Immune-Based Therapies to Achieve a Functional Cure of HIV Infection
EECA	Eastern Europe and Central Asia	HRQoL	health-related quality of life
EFOEUPATI	Ensuring the Future of EUPATI Beyond 2020	ICRSE	International Committee on the Rights of Sex Workers in Europe
EHVA	European HIV Vaccine Alliance	IMI	Innovative Medicines Initiative
EMA	European Medicines Agency	LGBTIQ+	lesbian gay bisexual trans intersex queer
EmERGE	Evaluating mHealth technology in HIV to improve Empowerment and Healthcare utilisation: Research and innovation to Generate Evidence for personalised care	MSM	men who have sex with men
		NASH	non-alcoholic steatohepatitis
		PFMD	Patient Focused Medicine Development

PiS	Partners in Science
PrEP	pre-exposure prophylaxis of HIV
PROMs	patient reported outcome measures
QoL	Quality of Life
R&D	research and development
RBDCOV	RBD Dimer recombinant protein vaccine against SARSCoV2
SCOPE	Strategic Community HIV Prevention Empowerment
TB	Tuberculosis
TB CAB	Global Tuberculosis Community Advisory Board
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation

EATG aims to abide by the [UNAIDS terminology guidelines](#) to the greatest extent possible. According to the guidelines ‘people should never be referred to as an abbreviation, such as PLHIV, since this is dehumanising. Instead, the name or identity of the group should be written out in full. Abbreviations for population groups can, however, be used in charts or graphs where brevity is required.’ As many abbreviations referring to people are widely used, we include them in [EATG’s online glossary](#).

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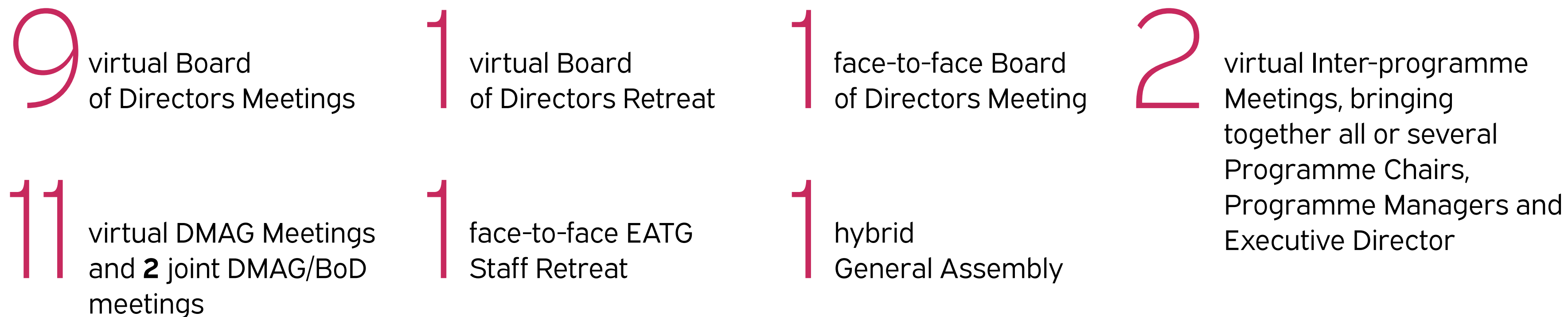
EATG would like to thank its members, partners, stakeholders, funders and other contributors for their continued support, collaboration and trust.

01

Achievements in Numbers

01 Achievements in Numbers

Governance



Projects



Programmes

Quality of Life | Combination Prevention | Partners in Science

Trainings:

28

online training sessions
(STEP-UP)

27

trainees of online training
sessions (STEP-UP)

1

face-to-face Training
Weekend (STEP-UP)

36

participants (including **19** trainees)
on face-to-face Training Weekend
(STEP-UP)

2

trainings on Patient Reported Outcomes Measures
(PROMs) **1** in Istanbul in November, **1** online webinar
in December

4

online train-the-trainer sessions to build capacity on
delivering peer-based, online sexual rights and health
education to youth activists (e-MPOWER)

Webinars / E-meetings:

1

meeting on the biomedical prevention pipeline for community workers and activists

4

community and stakeholders' meetings to advance decentralised testing and access to self-testing at community level

1

apero-science meeting to engage with new members in Partners in Science activities

1

series of Breakfast/Margarita community meetings for CROI 2021, co-organised with international community partners

3

Patient Engagement Open Forum sessions focusing on PROMs (led by EATG), integrated platform trials (presented by EPF) and inclusion in clinical trials (presented by ATAC)

28

online training sessions (STEP-UP)

1

online workshop (HIV & Mental Health)

1

online multi-stakeholder meeting (HIV & Mental Health)

Scientific Committees:

14 EATG members represented the community perspective in different projects and advisory boards of scientific projects and consortia

Protocol reviews:

16 — documents reviewed from stakeholders:

1 — clinical trial protocol from an industry partner,

14 — documents (guidelines, training and capacity building materials) for multi-stakeholder initiatives (PFMD, EUPATI)

1 — document for the EMA

Publications:

3

publications on HIV
and mental health

1

bilingual magazine
(EN/RUS) with stories from
STEP-UP graduates (digital
and printed)

3

publications on community
involvement in PROMs

1

podcast episode on PROMs
in the EPF EU Patient
Podcast series

1

rapid assessment bulletin
on the impact of the
COVID-19 crisis on people
living with or affected by HIV

1

scoping paper on HIV
and eHealth

1

diagnostics landscape
for self-testing of HIV, viral
hepatitis and STIs meeting report

1

HIV, viral hepatitis and
tuberculosis clinical trial
sites in Eastern Europe
and Central Asia
landscape review

1

advocacy toolbox
on sex work & HIV

1

long survey report (EN/RUS)
1 briefing paper (EN/RUS) **1** short
survey report in **7** languages on
HIV & mental health

Check out
our publications [online](#)

Conferences

4 conferences
(**CROI 2021, EACS 2021, HepHIV 2021, Fast-Track Cities 2021**)

Engagements in policy development and implementation

4 meetings as
co-coordinator
in EU Civil Society Forum
on HIV, Viral Hepatitis, and
Tuberculosis (TB)

10 as **contributor**:

1. EU Civil Society Forum on Drugs
2. WHO Regional Coordination Committee on HIV, TB and viral hepatitis
3. WHO Quality of HIV Care Technical Working Group
4. UNAIDS consultations in preparation of the 2021 UN High Level meeting on HIV/AIDS: EU Civil Society Forum on HIV
5. TB and Hepatitis, Platform for International Collaboration on Undocumented Migrants and HIV Outcomes
6. WHO consultation of Global Health Sector Strategy on HIV, viral hepatitis & STIs
7. WHO expert consultation for the European action plans
8. European Commission EU4Health work programme consultations
9. ECDC STIs Network meeting
10. Communities Delegation to the Board of GF around the new GF Strategy narrative

Engagements in policy development and implementation

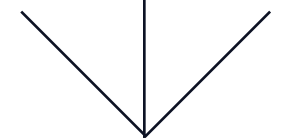
3 meetings **as observer** in UNAIDS Programme Coordinating Board meetings (on the Global AIDS Strategy, Unified Budget, Results and Accountability Framework (UBRAF) 2016-2021)

4 **long-term engagements** in policy multi-stakeholder initiatives:

1. EuroTEST
2. ACHIEVE
3. HIV Outcomes
4. Nobody Left Outside

3 **submissions** to consultations:

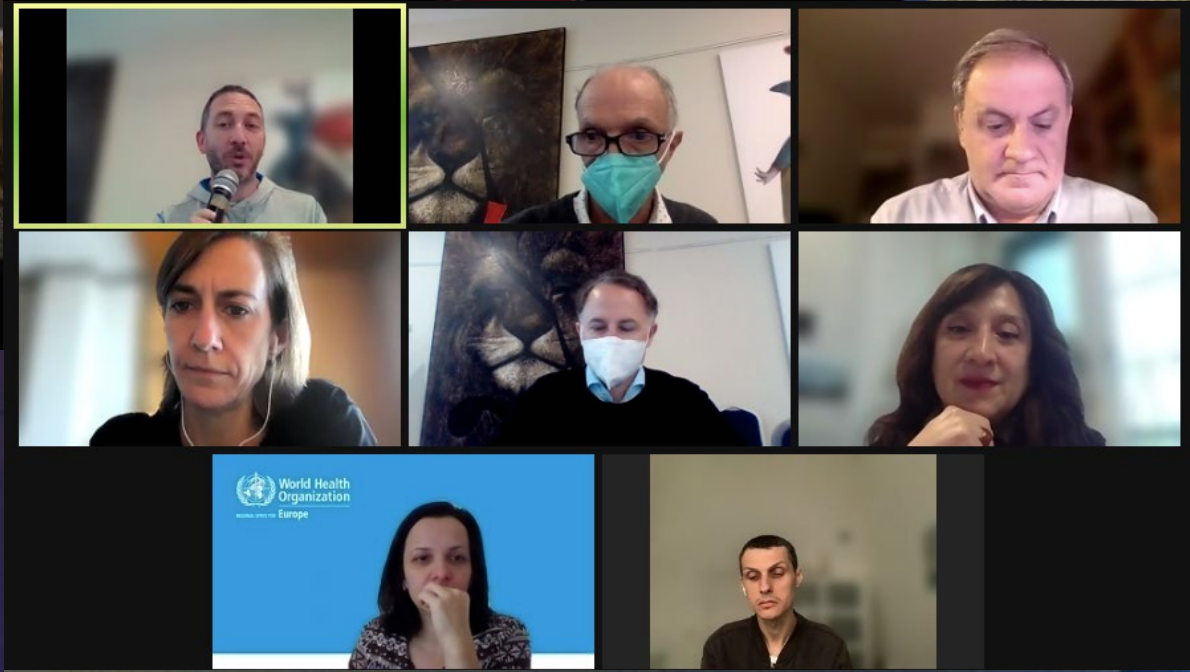
1. ECDC mandate extension
2. European Health Data Space
3. UNAIDS PCB



Engagements in policy development and implementation

- 9** **as contributor** in other policy meetings (speaking as panelist, agenda setting, endorsing event etc.):
1. EACS standard of care session
 2. EU Policy HCV Summit by Hepatitis B and C Public Policy Association
 3. IAS satellite on Health-Related Quality of Life
 4. ESWA stakeholders meeting on community leadership and policy
 5. European Testing Week webinar on self-testing
 6. Regional dialogue on Progressive Approaches to HIV Diagnostics and Treatment in Eastern Europe and Central Asia (EECA) and Balkan countries
 7. European Health Data Space (EHDS) From a Civil Society Perspective
 8. HIV 40 years on: Time to focus now on Health-Related Quality of Life EC webinar on Mental Health
 9. EATG multi-stakeholder meeting on mental health

- 56** **Letters and Endorsements** about:
- ECDC mandate extension
 - EC EU4Health programme
 - equity in SARS-CoV-2 vaccine access
 - kidney care
 - Global AIDS Strategy
 - shortages
 - access to PrEP
 - HCV elimination
 - The Global Fund
 - mental health
 - sex workers' health
 - Innovative Medicine Initiative
 - cancer care
 - exclusion of people living with HIV in clinical trials
 - drug policy and harm reduction funding



02

Foreword



02 Foreword

Another year in the merde... or not?

Dear friends of EATG!

Yes, it is true, we went through another “year in the merde”, to use the eloquence of Stephen Clarke. Again, it was not pretty: we spent most of the year in front of a computer screen, Zooming-Teamsing-Skyping-WebExing until our eyes hurt and until it was impossible to bring a smile to even the most optimistic staff member. Yes, again we had to cancel the face-to-face meetings we were looking forward to and adjust to sudden regulation changes in one country or another. Yes, again we saw colleagues and loved ones catching COVID or worse, we saw people in our environment passing away.

In the beginning of the year, there was so much hope. Vaccines would make 2020 seem like a bad dream and the Realm of Freedom would start again!

Yes, it is true... things did not turn out exactly the way we wanted them to in 2021. But other, more uplifting aspects deserve to be said and shared as well. Therefore, even if COVID-19 is mentioned here and there in this annual report, it should not cast a shadow over everything that was achieved in 2021.

And that is not minor. Thanks to the relentless efforts of EATG’s members, board, staff and friends, we can proudly look back on a year with some remarkable achievements.

In the programme section of this report, you will see the exciting work done by our three programmes. First, **Quality of Life**, where the first phase of the HIV & Mental Health project was finalised and where 19 alumni from STEP-UP joined forces during a long weekend in Istanbul. Or the different projects to improve diagnostics and prevention tools by the **Combination Prevention** programme. And the valuable contributions of the **Partners in Science** programme to R&D through protocol reviews, European Community Advisory Boards and participation in high-level scientific projects.



Pieter Vanholder
Executive Director

As a window to the world, 2021 was the year in which EATG's new website saw daylight and our motto "**Diversity is Strength**" was presented. Diversity is a golden thread that runs through our membership and work, this is not just a slogan, it is continuously reflected in our focus on key populations in most of our projects and member activities. In the physical space, we kept the window to the world wide-open through our participation in the **EACS conference**, ensuring the Community Corner and organising much-welcomed scientific sessions on HIV cure, PROMs and Mental Health.

Finally, 2021 was also the year in which many collaborations blossomed, were created or renewed. With **Virology Education**, EATG co-organised a conference on Healthy Living with HIV. We joined the Strategic Advisory Board of **PFMD**. With **ECDC** and **AIDS Action Europe**, we launched a European-wide survey on Stigma and Discrimination. We intensified collaboration with **WHO Europe** and **WHO HQ**. And joint project proposals were submitted with a wide range of partner organisations: **Alliance for Public Health, European Sex Workers Rights Alliance, Africa Advocacy Foundation, Trans United Europe, AIDS Action Europe, Correlation-European Harm Reduction Network...** A huge thank you to all these brilliant people and organisations we were so lucky to work with.

So yes, it is true... Maybe 2021 was not that bad after all. All of the above inspires us to move forward and look ahead. We are ready to face 2022, the year in which a massive make-over of our IT set-up will take place, the year in which we will write a new 3-year Implementation Plan 2023-25, and above all, the year when we will celebrate our 30th Anniversary!

Happy reading!

Pieter Vanholder, Executive Director

P.S.

While editing this Annual Report for release, unfortunately the horrible events in Ukraine started to develop. It seems 2022 will be yet another challenging year for our friends in Ukraine and host communities throughout Europe. At the moment of publication, millions of people are fleeing the country. People in Ukraine and abroad have difficulties accessing life-saving commodities and services, including ART and OAT. Our love and solidarity go out to all people directly or indirectly affected by this catastrophe.

03

Programmes



03 Programmes

Quality of Life

In 2021, the Quality of Life (QoL) programme continued to engage, inform and empower all people living with and affected by HIV aiming to improve their health-related quality of life. The programme kept promoting and increasing the attention of stakeholders on HIV and mental health issues in the WHO European region, with a specific focus on Eastern Europe and Central Asia. Furthermore, it enhanced treatment literacy and the advocacy capacity of local and regional HIV community organisations. Finally, it kept fighting stigma, health inequalities and discrimination against people living with HIV.

Despite the challenges presented by COVID-19, the **HIV and Mental Health project** made meaningful progress. The main findings of a desk review and European-wide survey from 2020 were integrated in a survey report, which was launched during a first multi-stakeholder meeting in May 2021 and then published in autumn. The external evaluation of this project emphasises an increased focus on mental health within HIV prevention, support, treatment and care that did not exist before: the project has brought new assets to this underserved field and proved that further research is needed. In order to reach a more diverse group of stakeholders, a summary report was translated into 7 European languages. A briefing paper identifying specific recommendations for various stakeholder groups was pre-launched within the CSF on HIV, TB and viral hepatitis thematic meeting on mental health and officially launched on World Mental Health Day.

Due to the COVID-19 pandemic, the multi-stakeholder event was divided into two parts: (a) an online event in May 2021 and (b) a face-to-face event in November 2021. At the event in May, online participation was diverse, including representation from the community of people living with HIV, MSM, LGBTIQ+ and migrants organisations, as well as industry, WHO, the EU Parliament, health researchers/academics and clinicians. At the face-to-face meeting in November, there was representation from industry, research/academic and healthcare. The highlights of the meeting included a discussion about setting up a European Platform for different stakeholders involved in HIV and mental health and the fruitful exchange of ideas in the multi-stakeholder panel that included WHO and UNAIDS representatives.

In terms of expected outcomes, the project has indeed been effective in widening awareness and increasing stakeholder engagement on HIV and mental health among community, healthcare professionals, industry representatives, people living with HIV and English and Russian speakers from across the WHO European region. In line with the HIV and Mental Health Project, EATG launched a campaign in the context of World AIDS Day 2021, titled **40 years of HIV/AIDS: Stigma & Discrimination and the impact on Mental Health**, to raise awareness around persistent stigma and discrimination faced by people living with and communities affected by HIV/AIDS and the impact on their lives and mental health. With this campaign,



EATG presented stories of people from different communities and realities across Europe and Central Asia.

In 2021, EATG consolidated the **STEP-UP** online training format and organised 28 and training sessions that took place live on Zoom twice per week, in English and Russian, from January to April 2021. The online sessions of the training were attended by 36 participants, 19 of which were selected to join a face-to-face STEP-UP training and networking weekend in Istanbul. Each module organised within the STEP-UP 2020/2021 programme had a specific focus related to EATG's current programmatic strategy:

Module 1

Standard of care for HIV in 2021 and emerging issues for people living with HIV.

Module 2

Prevention and diagnostics existing and emerging tools.

Module 3

Community research and community mobilisation.

A bilingual magazine titled **Seven Stories of Success from Europe and Central Asia** was published this year as well, sharing personal stories about the activist lives of several STEP-UP alumni.

The STEP-UP programme proved to be a valuable educational and capacity building resource for HIV activists working in Europe and Central Asia. It continued to equip its participants with the most up-to-date knowledge on HIV and related issues,

developing the participants' advocacy and leadership potential. The distance learning format provided a good opportunity to educate more participants than usual. Despite their different levels of knowledge and length of experience, trainees were able to benefit from the training and enhance their capacity. Indeed, 85% of participants reported that their expectations from the training were fully met and 15% partially met. All the participants would recommend the STEP-UP programme to their colleagues.

In light of the COVID-19 pandemic, the European Sex Workers Rights Alliance (ESWA, formerly ICRSE) and EATG had to readapt their work to the circumstances created by the COVID-19 pandemic. It was the case of the **European Red Umbrella Training Academy** programme, a training project specifically targeted at sex workers. Within the frame of this project, a toolbox with resources on 'Sex Work and HIV Prevention' was published. This toolbox aims to provide key information to sex workers and HIV activists, as well as policy makers, and to re-affirm community and international recommendations.

Based on the recommendations and lessons learned from the **EmERGE** project, in July 2021 EATG submitted its views on the establishment of the European Health Data Space (EHDS) to the European Commission within the public consultation regarding a future legislative framework to address the issues related to the exchange of and access to health data and the use of digital services and products including artificial intelligence in health.

“It has been a fruitful year despite the ongoing limitations imposed by the COVID pandemic. In line with our Long-Term Strategy and thanks to the commitment of our programme staff and committee members, we have been able to successfully implement many activities and projects under the QoL programme. Our STEP-UP training, conducted for the first time online and our HIV & Mental Health project, has broadened our knowledge on how we can address this neglected area together. We have conducted relevant research work such as a survey on mental health and HIV and in collaboration with ECDC and AIDS Action Europe the first European-wide survey on stigma, which continues to affect the well-being and quality of life of people living with HIV. This survey will hopefully engender concrete policy changes and actions. New opportunities have arisen and new partnerships and collaborations have been established, as well as new ideas for future projects have been developed. Through our policy work we have contributed to highlighting the importance of health-related quality of life in HIV care. Finally, our engagement in the EECA region has been intensified and is reflected in all our activities.”

Mario Cascio,
Quality of Life Programme Chair



Mario Cascio

03 Programmes

Combination Prevention

EATG's Combination Prevention (CP) programme worked to empower communities in their efforts to ensure access to HIV, viral hepatitis, TB and STI prevention tools for most affected populations, those inadequately served by the health system.

In 2021, building off EATG's COVID-19 rapid assessment bulletins that highlighted the impact on testing service delivery, EATG's **DIAGNOSE** project assembled a Diagnostics Task Group of EATG members. It was decided to focus efforts on decentralised access to rapid diagnostic tests for self-testing of HIV and HCV across Europe and Central Asia. This resulted in 4 online multi-stakeholder meetings which highlighted community-level needs and efforts to advance access to self-testing diagnostics for HIV and HCV. An online survey in English and Russian was launched between July and September. It mapped out current pricing and availability of self-tests for HIV and HCV in the WHO region, as reported by individuals familiar with rapid diagnostic tests for self-testing. Key findings from the mapping survey and themes stemming from the online meetings went on to inform the **Co-Lead** project research priorities, carried out in collaboration with the Foundation for Innovative New Diagnostics (FIND). See policy section for advocacy work to increase access to self-testing as part of the basket of testing options.

In the frame of the **Co-Lead** project, EATG carried out qualitative research with key informants (in Armenia, Bosnia and Herzegovina, Kazakhstan, Kyrgyzstan, Poland, Slovenia and the Russian Federation) to identify the regulatory barriers and practical solutions to implementing self-testing diagnostics for HIV and HCV at community level. An online community health worker exchange workshop took place in December to share the findings from the qualitative research conducted by EATG, Alliance for Public Health and FIND as well as the WHO 2021 recommendations on HCV self-testing.

EATG is leading on the Erasmus+ funded project **e-MPOWER**, carried out in partnership with the European Sex Workers Rights Alliance (ESWA, formerly ICRSE) and Association Legebitra. In September, project partners recruited a team of 4 youth peer trainers to participate in 4 train-the-trainer sessions on good practices for delivering online sexual health and rights education to youth activists who are living with HIV, involved in sex work and/or identify as LGBTIQ+.



03 Programmes **Combination Prevention**

In 2021, EATG developed the **SCOPE** project to strengthen community capacity to address the needs of populations lacking adequate access to combination prevention programmes by facilitating peer-to-peer exchanges, clinical and implementation science updates, community research and advocacy for investment in combination prevention. The project will be implemented with partners in 2022 and 2023.

EATG also partnered with 20 European and local organisations for a project application to the European Commission's **EU4Health** programme. The aim of the project is a) to increase community health workers' capacity to promote and conduct community-led/community-based interventions for prevention, testing, and linkage to care with respect to HIV/AIDS, TB, viral hepatitis and STI, b) to expand the use of harmonised data collection and reporting tools and c) to promote policy updates to enable the delivery of community-based health services in the response to HIV/AIDS, TB, viral hepatitis and STI.

“Again, the COVID-19 crisis was a challenge for the work of the Combination Prevention (CP) programme in 2021. However, the CP programme continued its work with a lot of online meetings, calls and emails. Being Programme Chair since September, the programme's committee, the office and I have managed to sustain the running projects and started new ventures. All this to advance HIV prevention as an important component of promoting sexual health, also for people living with HIV.”

Harriet Langanke,
Combination Prevention
Programme Chair



Harriet Langanke

03 Programmes

Partners in Science

The Partners in Science (PiS) programme continued to have a strong focus on treatment advocacy and literacy. PiS addresses community engagement with industry and other stakeholders (regulators and academics) in the design and development of innovative therapeutic solutions and in other areas of research, with attention to the needs of the HIV Community in the WHO Europe region.

To harmonise the interactions and collaboration with industry partners, PiS developed a comprehensive **Modus Operandi** document, outlining the work and processes of PiS activities which is now in use, to guide programme activities and initiatives. Subsequently, PiS drafted a **Memorandum of Understanding** outlining its main principles of collaboration with industry. This draft MoU was presented to EATG's main industry partners and is currently under discussion.

In 2021, EATG conducted several activities on research and development (R&D) and science. It organised 6 online **European Community Advisory Boards (ECABs)** with four pharmaceutical companies to inform and engage the community members on the latest advancements within the HIV portfolio, such as PrEP, HIV treatment and other related topics. In addition to the ECAB meetings, EATG held 2 other **collaborative meetings with community and industry partners** on cure programmes and new scientific developments. EATG also created a pool of 50 members to encourage more members with scientific interests to attend the ECAB meetings.

Throughout the year, 10 EATG members provided **community input** into 17 documents including clinical trial protocols on new therapeutic strategies for HIV, as well as for the patient booklet for European Medicines Agency (EMA), training materials and guidelines for the European Patient Academy for Therapeutic Innovation (EUPATI) and guidelines for Patient Focused Medicines Development (PFMD). EATG also created a pool of 25 reviewers, including new members with scientific interest, to take part in its protocol review processes.

PiS held an **Apero-Science** event to encourage new members to get involved with the activities of the programme. The informal session was an opportunity to ask questions, get to know new members and was a success in bringing new EATG members on board with the programme committee and projects.

Throughout the year, 14 EATG members represented **the community perspective in different projects** and advisory boards of scientific projects and consortia (EHVA, EU-PEARL, RESPOND, EUPATI, pxROAR, IAS Cure, EACS, Viral Education, CROI Community Breakfast/Margarita Club).

EATG had several developments within the **PROMise** project in 2021. It published its preliminary research which established community recommendations for different stakeholders working in HIV R&D in industry, academia or research institutions, as well as clinicians, to ensure community involvement in the development of HIV-specific PROMs. Outcomes were presented at a Patient Engagement



Open Forum event, discussed in a European Patient Forum podcast episode and shared in a EUPATI webinar on patient preferences on PROMs. After presenting a poster and holding a community session at EACS 2021 under the scope of the project, EATG continued its consultation with a variety of relevant stakeholders to develop ways to implement the set of community recommendations. Towards the end of the year, EATG began developing materials and training around basic literacy on PROMs to enhance capacity at the community level.

Additionally, EATG began to address the issue of the exclusion of people living with HIV in non-HIV clinical trials. EATG began to map and contact potential community-based partners to collaborate on promoting advocacy around this topic.

To enhance the access to scientific research for communities in the EECA region, EATG published the Russian-translated version of the **HIV Pipeline Report**, in collaboration with HIV i-Base. The translated report aims to facilitate improved access to information and important updates for Russian speakers. EATG also updated and published the **Brief Landscape Review on HIV, Viral Hepatitis and TB Clinical Trial Sites in Eastern Europe and Central Asia**.

In the context of long-term remission from HIV, EATG organised the seventh **STEPS community-led workshop on HIV cure research**. The workshop brought contributions from prominent researchers in the field of HIV cure-related research in Europe to the community and other stakeholders collaborating in this area. This year the meeting focused on promising approaches

for potential cure applications and upcoming trials for therapeutic vaccines.

As partners in the EU-funded project **European HIV Alliance (EHVA)**, EATG continued to provide community input into clinical trials and in communication on project developments. The project is designed to foster the development of an effective vaccine for HIV.

In **HIVACAR**, another EU-funded project on functional cure for HIV, EATG relaunched part of the **psychosocial research** of the project in late 2021. The project has been extended to continue until 2022, after delays related to COVID-19.

In 2021, EATG continued to strengthen partnerships in multistakeholder consortia through projects and initiatives that focus on patient and community engagement. As 2021 was the first year of **EUPATI** functioning as a foundation, EATG supported the initiative by being a sustaining partner and by holding a seat on their Board. Additionally, EATG reviewed several training and capacity building materials from the community perspective.

EATG continued to move forward with the Horizon 2020-funded **EATRIS Plus** project, which aims to support the long-term sustainability strategy of EATRIS as one of Europe's key research infrastructures for personalised medicine. There, EATG has been coordinating the Patient Advisory Committee, ensuring that patient empowerment is at the heart of EATRIS operations.

03 Programmes Partners in Science

Within **EU PEARL**, an IMI-funded project focusing on building a patient-centred integrated research platform, EATG has been coordinating the Patients Advisory Group (PAG). In addition, EATG provided advice on the tuberculosis work package.

In other activities around co-infections, EATG continues to collaborate with the **Global TB CAB**, providing updates for the TB-Online website and newsletter. The newsletter is dedicated to increasing community involvement in TB research and advocacy.

Throughout the year, EATG has engaged with industry partners in the discussion on **treatments and vaccines for COVID-19** via the ECAB forum. In late 2021, EATG joined as a leading partner in the Horizon 2020 Europe-funded **RBDCOV project** that will test a new vaccine against different variants of COVID-19. One of the clinical trials will focus on immunocompromised participants, including people living with HIV with low CD4 count. EATG's role in the project is to provide community feedback on the design of the study and clinical protocols, to lead on the psychosocial assessment of the study and to support the communications around the trial and project.

“We have adapted to the COVID-19 circumstances and done our job online well. But it was also important that we met with the PiS Programme Committee in person to recognise our most important achievement in 2021: our PiS Modus Operandi and the start of negotiations with stakeholders towards a Memorandum of Understanding on Collaboration with Industry, during EACS 2021.”

Alex Schneider,
Partners in Science Programme Chair



Alex Schneider

04 Policy



04 Policy

In 2021, EATG engaged with United Nations agencies, WHO and European Union policy and programming processes, which we hope will steer the cross-sectoral response needed to reduce structural inequalities that feed the HIV/AIDS epidemic. A response that has been negatively impacted by the COVID-19 pandemic.

Together with AIDS Action Europe, Correlations-EHRN, TB Europe Coalition and Eurasian Harm Reduction Association, EATG organised **4 EU Civil Society Forum (CSF) on HIV, Viral Hepatitis and TB** with EU and UN agencies to discuss policy documents in progress and to exchange knowledge and good practice on testing access and uptake, on mental health and on access to COVID-19 vaccines. These organisations also held a civil society consultation meeting, submitted feedback to prepare for the **UN High-Level meeting on HIV/AIDS** and engaged with UNAIDS in the finalisation of the **Global AIDS Strategy**.

EATG, as observer and contributor, attended UNAIDS Programme Coordinating Board meetings regarding the Global AIDS Strategy and implementation of the global targets. EATG participated and spoke at the online consultations for the **WHO Global Health Sector Strategy** and **Action Plan** for the WHO Europe region to convey community perspectives.

EATG notices greater attention given to structural inequalities and key populations, stigma and discrimination, mental health, health related quality of life beyond viral suppression and integrated care and the role of community-based or -led

delivery of services by agencies. However, efforts are needed to fight the complacency or resistance at local level to some key evidence and rights-based approaches. In 2022, EATG will engage with the preparation of the WHO Europe action plan and raise community awareness in view of its implementation at local levels. It will also start monitoring the implementation of commitments.

In that regard, EATG partnered with AIDS Action Europe and ECDC to launch **the first ever pan-European HIV Stigma Survey** to address the data gap on this issue, as part of the ECDC Dublin reporting process. The results should be useful to local advocacy. It also started a dialogue with UNAIDS to encourage EU countries to join the Global Anti-Stigma Partnership.

EATG and partners advocated for the continued funding support (**EU4Health programme**) of the European Commission to countries and civil society to end the HIV, TB and viral hepatitis epidemics, to address the health needs of populations left behind and support the scale-up of integrated, person-centred community-based services. As a result, in October, the Commission launched a 5-million euro call for proposals along these lines. EATG contributed to the European Commission consultation processes regarding the EU4health programme for 2022 and **European Health Union** and **ECDC mandate extension**.

Building on the findings of the **e-health and HIV scoping paper** released in February and member consultation, EATG submitted a contribution to the **European Health Data Space** - regarding access and use of personal health data for healthcare, research and innovation, policy-making and regulatory decision-making, digital health services and products, rules for the development and deployment of Artificial Intelligence in healthcare.

EATG continued to advance its agenda via active participation in multi-stakeholder platforms. It contributed to the **EuroTEST initiative** and its self-testing working group, as well as the **European Testing Week** working group. It organised a side meeting at **HepHIV conference** on self-testing with community and manufacturers and presented self-testing research results at a European Testing Week webinar. EATG continued its collaboration with the **ACHIEVE coalition** for viral hepatitis elimination and its advocacy on European Commission funding programmes and cancer plan. It also collaborated with **HIV Outcomes** to get European Commission engagement to advance health related quality of life beyond viral suppression, by supporting projects to promote integrated interventions, mental health and well-being and PROMs. It also took part in the **Nobody Left Outside (NLO)** Initiative, including the NLO Voices sessions at the **European Health Policy Forum**.



05

Organisational Development



05 Organisational Development

This year EATG finalised a major organisational reform, which was started in 2019. New structures, like the Programme Chairs and Committees, the Ethics and Conflict Resolution Committee are fully operational. All existing bodies, like Internal Auditors and the Development and Membership Advisory Group (DMAG) now have their Terms of Reference revised and brought in line with new challenges. Old structures that had become superfluous were dismantled. New policies (Anti-corruption, COVID-policy, GDPR) and tools (Monitoring and Evaluation Framework) were put in place. EATG now has a paperless office, which also means all audits can be conducted remotely, a considerable advantage during COVID restrictions. In addition, online submission of all finance-related documentation is now possible.

EATG developed a new fundraising strategy for the period 2021-2022, with the focus on sustainability and diversification of funding sources. During 2021, the efforts focused on exploratory activities, development and implementation of structures and tools to support fundraising efforts and the development of new partnerships, becoming an affiliated partner of the **European Foundation Centre** (now **Philea**) and beneficiary of **Transnational Giving Europe Network**.

EATG receives multi-year funding from its two main funders, Gilead Sciences and ViiV Healthcare. Not only does this major achievement reduce the administrative burden of annual applications, but it also results in a more stable cash flow.

Also in 2021, EATG launched its new website, redesigned into an updated, simplified and user-friendly structure. This external website is to be complemented by an exclusive member area in 2022. In addition, EATG continued streamlining its communications in social media and adapting a more cohesive visual identity in digital media as well as free merchandising.

This year EATG redesigned and relaunched both the EATG newsletter and the regular daily and weekly HIV and co-infections news bulletins. It continued integrating digital e-meeting, creation, productivity and collaboration tools (i.e., Zoom, Canva) in its daily work.

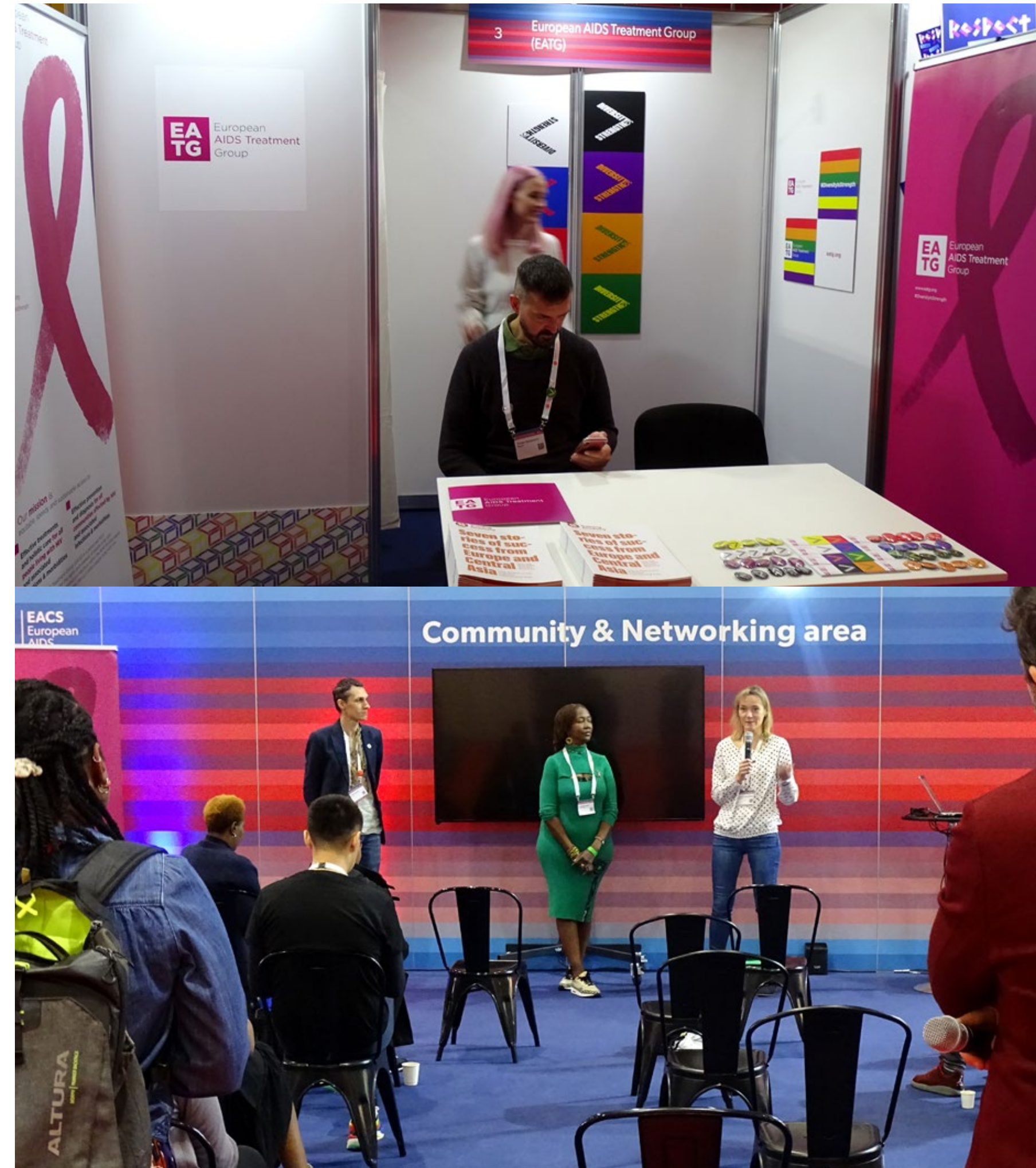
Finally, after more than a year of only virtual events, EATG succeeded in re-introducing live events, both internal and external, respecting all applicable COVID-safe standards.

Highlights

Highlights

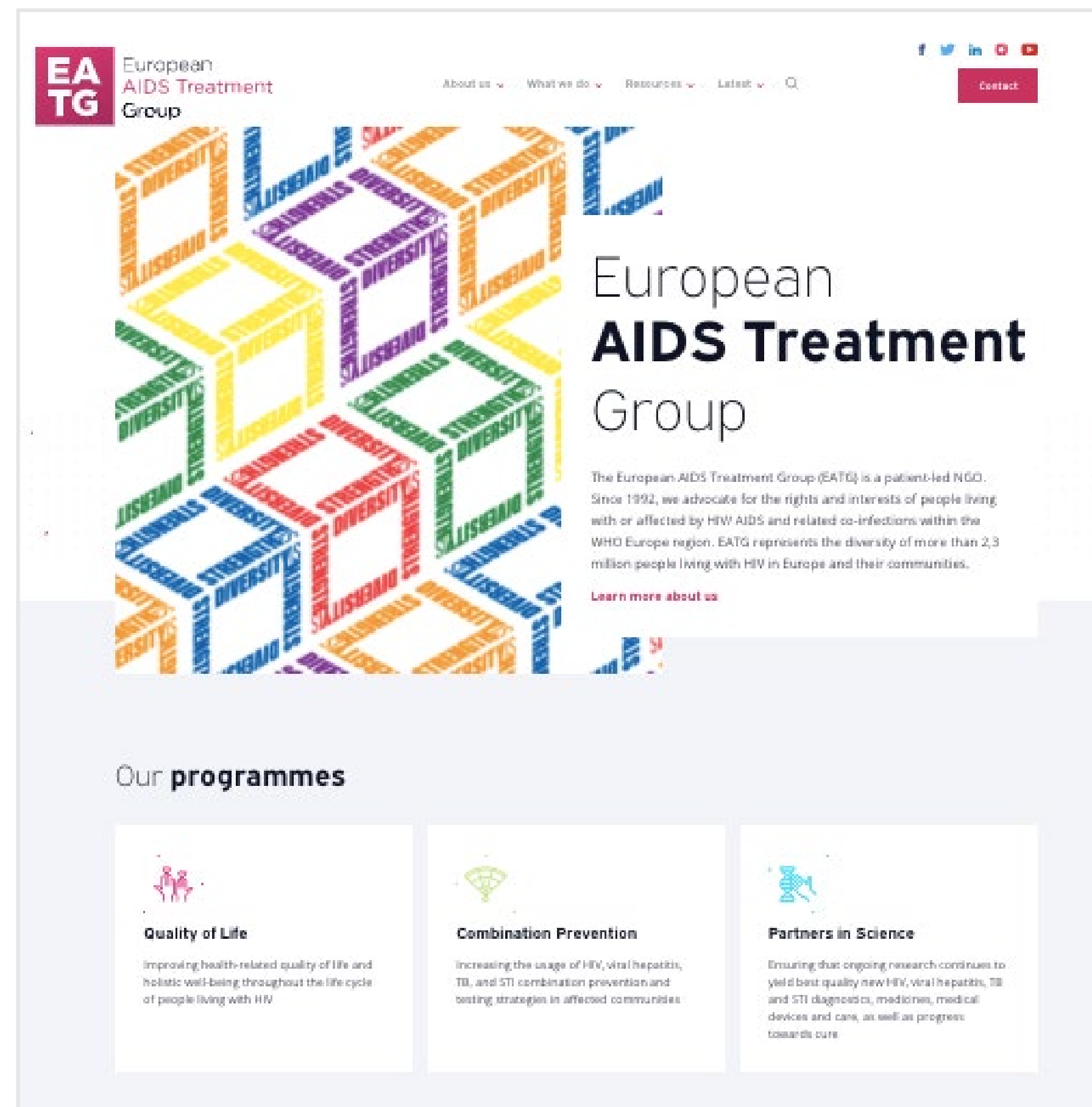
Back to live meetings: EATG at the EACS 2021 conference

The 2021 EACS Conference was the first international conference since the COVID-crisis where EATG ensured major physical presence of board, staff and members. It was an important event for networking, relation building and scientific work. EATG, together with UK CAB, was in charge of the EACS2021 Community Corner, organised a training on HIV cure, as well as two scientific sessions on mental health and PROMs. Through its “Diversity is Strength” booth it ensured its visibility to a wider audience.



New structure, new website, new era

A year after our lives turned increasingly more digital due to the ongoing COVID-19 pandemic, launching a new website seemed timely. In June, eatg.org was relaunched after more than a year of being offline. The website was built to reflect the new structure of EATG while presenting our strategy, identity and story: centred around three programmatic areas with a set of projects, initiatives, events, news and resources under each.



Go East: Race in support of children living with HIV in Eastern Europe and Central Asia

In collaboration with Life4me+, EATG organised a virtual race aiming to raise the level of public awareness and understanding around the problems faced by children and adolescents living with HIV in the countries of Eastern Europe and Central Asia as well as funds to support a camp for Russian-speaking children living with HIV.

The race kicked off at the EACS 2021 conference and the virtual finish line was reached one day before World AIDS Day. During the five weeks it was online 380 participants ran, walked or wheeled crossing borders and raising 10.000 euros for the summer camp for children and adolescents living with HIV held annually by the Svetlana Izambayeva Charitable Foundation. The upcoming 2022 camp will be held by the shores of Lake Issyk-Kul in Kyrgyzstan.



Back to live meetings: STEP-UP training and networking weekend in Istanbul

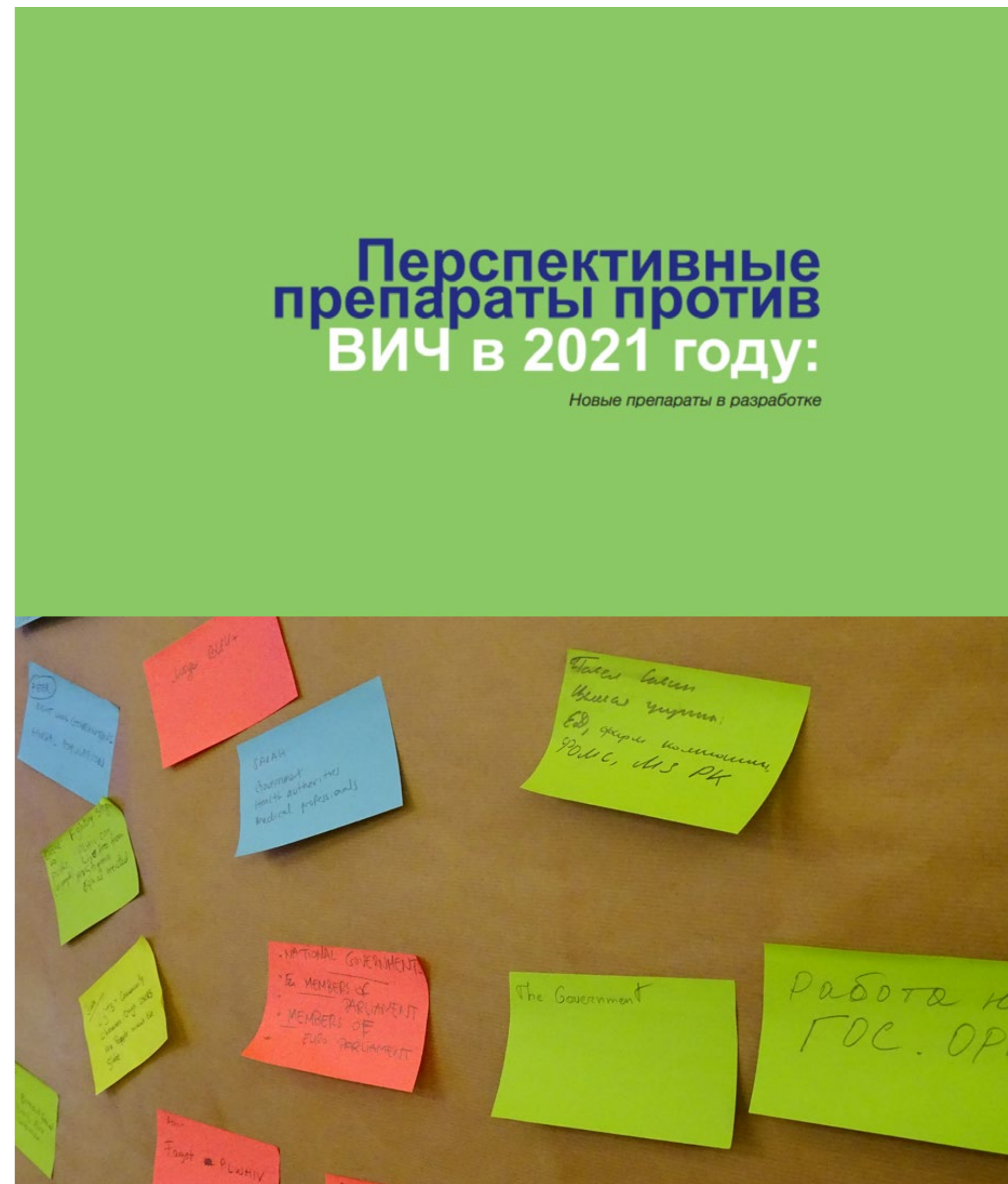
The latest cycle of STEP-UP was postponed in 2020 and had to be adapted to the virtual format due to the COVID-19 pandemic. In November, while activities were gradually returning to face-to-face settings, EATG organised an in-person training and networking weekend in Istanbul. The training gathered the prospective graduates of this cycle - HIV activists from all over Europe - for the concluding training modules focusing on advocacy and networking.



Go East: EATG science in Eastern Europe and Central Asia

EATG increased its efforts to reach out to the EECA region and support local communities by addressing their needs. Under the lead of the Partners in Science programme, EATG developed two advocacy tools to enhance access to scientific research developments for advocates in the EECA region. EATG translated into Russian the *annual HIV Pipeline* Report regularly published by i-Base to promote these updates amongst Russian-speaking HIV activists.

To support medicine developers in bringing more research to the region, EATG also updated and published the *Brief Landscape Review on HIV, Viral Hepatitis and TB Clinic Trial Sites in Eastern Europe and Central Asia* and disseminated it to key stakeholders.



The first ever European-wide HIV stigma survey

ECDC, EATG and AIDS Action Europe - following the strong push of the EU CSF on HIV, TB and viral hepatitis - launched the first ever Europe and Central Asia-wide HIV stigma survey to fill the data gap on stigma and discrimination. It will be a great advocacy tool to push for evolution in local policies and practices. Its results, expected to be published in spring 2022, will inform the ECDC-led Dublin monitoring process and contribute to the monitoring of the Global AIDS Strategy.



HIV and HCV self-testing strategies during the COVID-19 pandemic

Following the significant disruptions in testing caused by the COVID-19 crisis, EATG prioritised access to self-testing for HIV and HCV as a topic for community exchanges and engagement with policy makers and industry.

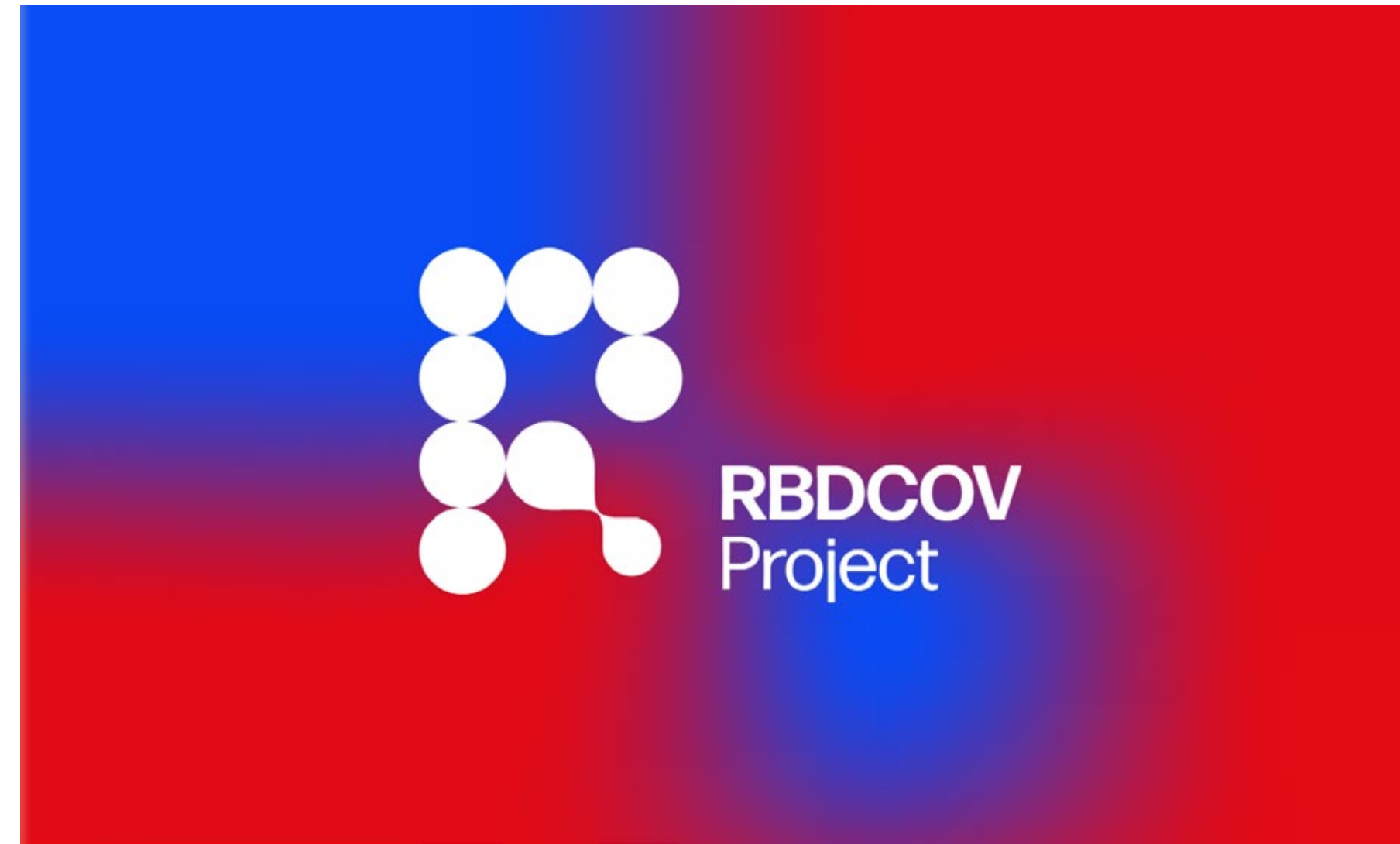
EATG partnered with FIND and built on the recently released WHO guidelines on HCV self-testing. The Co-Lead project research and workshop conclusions clearly pointed to three strands of actions to ensure access to HIV and HCV test kits to those who would benefit the most, namely addressing: 1) the absence of legal framework for HIV and HCV self-testing or its poor implementation on the ground 2) lack of funding to implement self-testing with the full-service cycle and/or needed treatment and high cost of kits 3) insufficient understanding of the self-testing concept and advantages of self-testing among key populations, local authorities and healthcare providers. Further dialogue is to be had with governments, manufacturers, wholesalers, pharmacists' associations, and community centres.



EATG representing community in a study for a new COVID-19 vaccine

EATG was invited to join the RBDCOV project as a leading partner, due to its historic experience and long-standing commitment to community engagement in treatment advocacy and representation in research and development.

The project tests a new vaccine against different variants of COVID-19, with one of the clinical trials focusing on immunocompromised participants, including people living with HIV with low CD4 count. The main task of EATG will be to lead the community advisory panel, providing feedback on the design of the study and clinical protocols. EATG will also lead the psychosocial assessment of the study and will support the communications around the trial and the project.



06

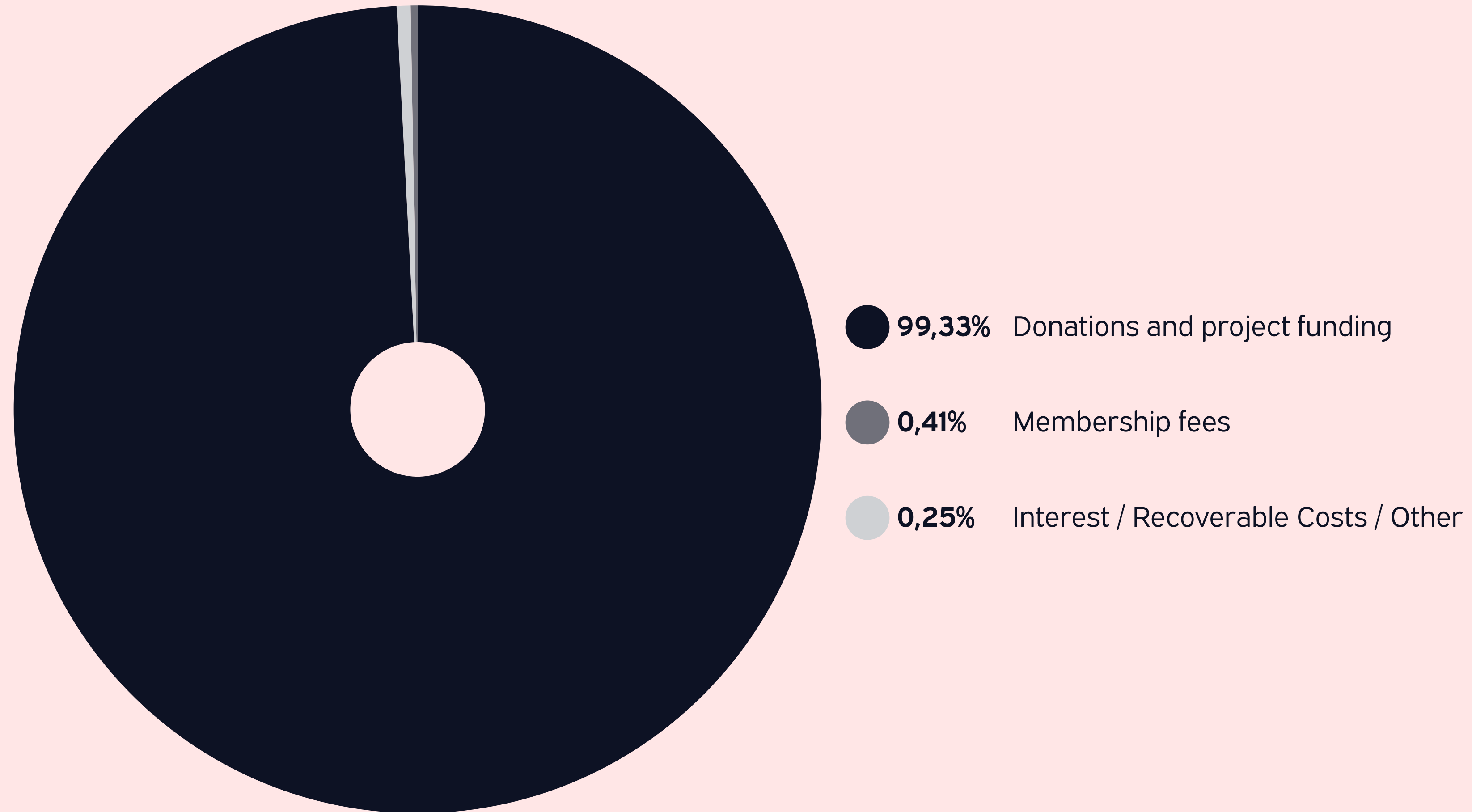
Finances



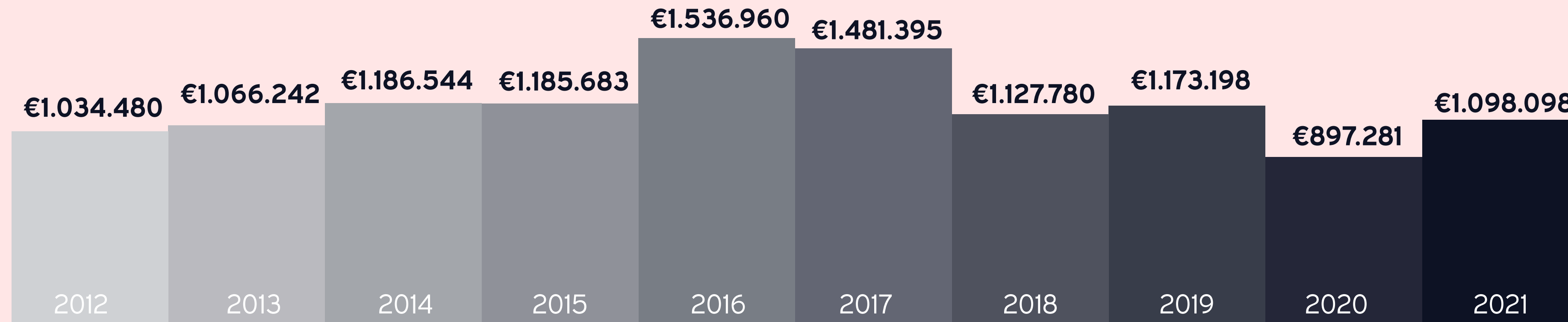
Income

€1.098.098

The distribution **by sources** of EATG income is shown here.



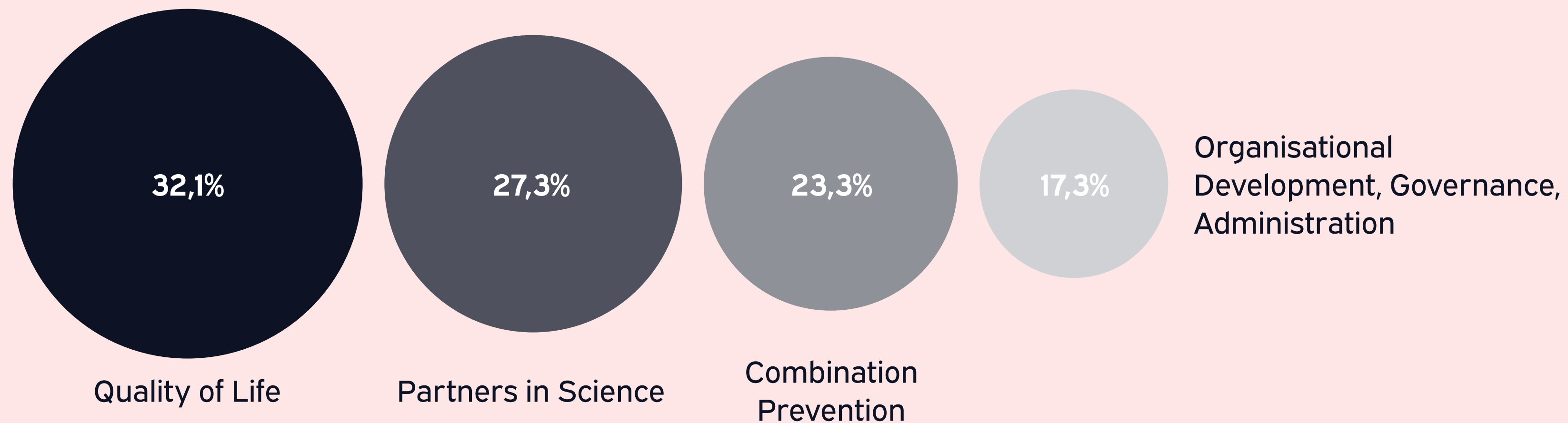
Income development



Expenditure

As in 2020, the total expenditure of **€1.092.643** was spent in a less diverse manner than before the COVID-19 pandemic due to the reduction of face-to-face events and therefore keeping all related costs to a minimum.

Breakdown according to programmes

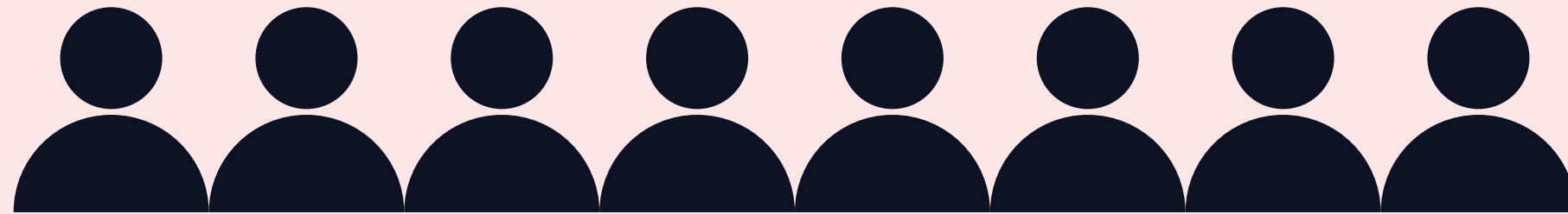


EATG Volunteer time

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 that the in-kind contribution in volunteer time in 2021 amounts to be at least:

Approximately 14.000 hours, equivalent to 8 full-time staff.

14.000hrs



You can find more financial information
on our website via the following link: [Financial compliance](#)

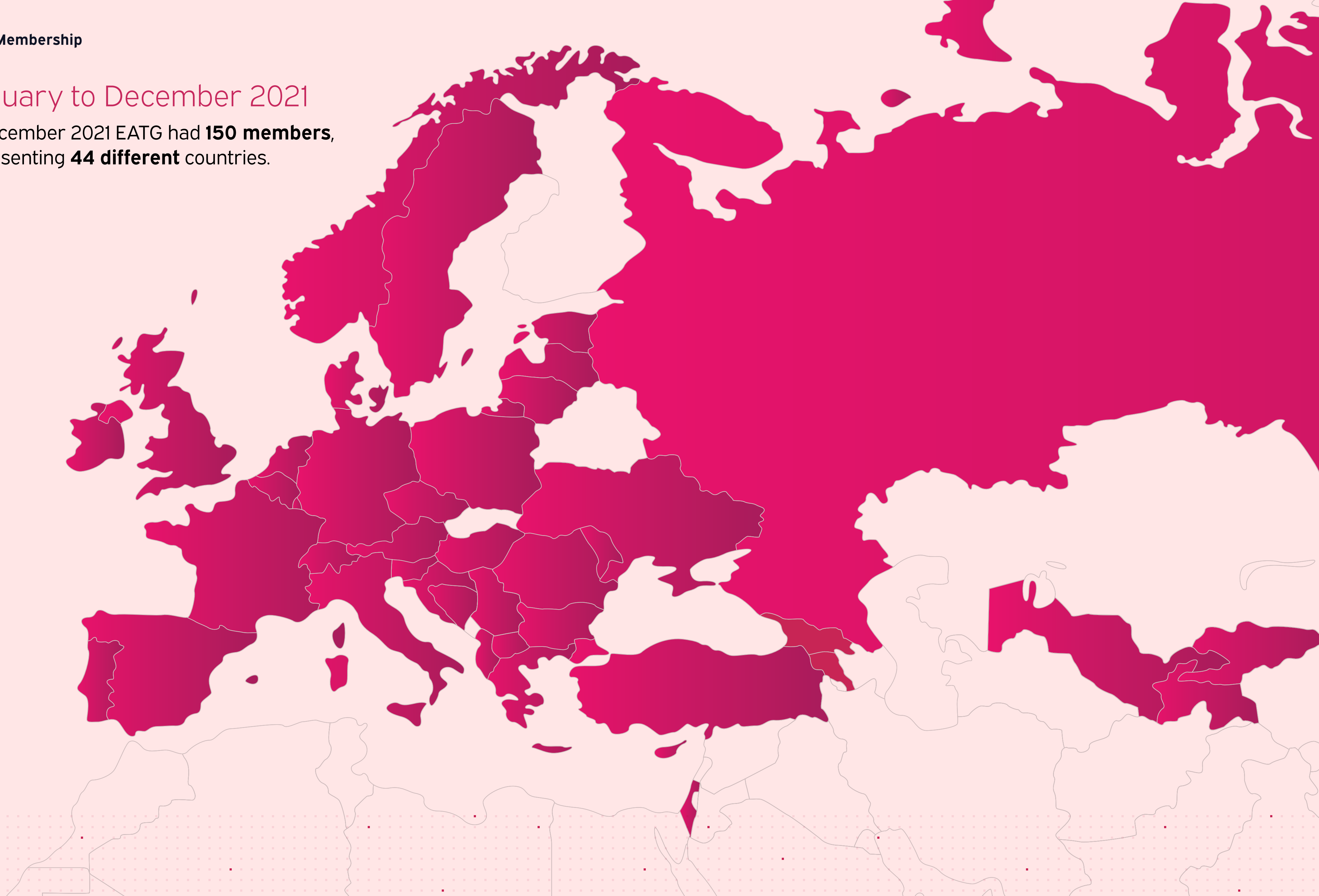
07

Membership



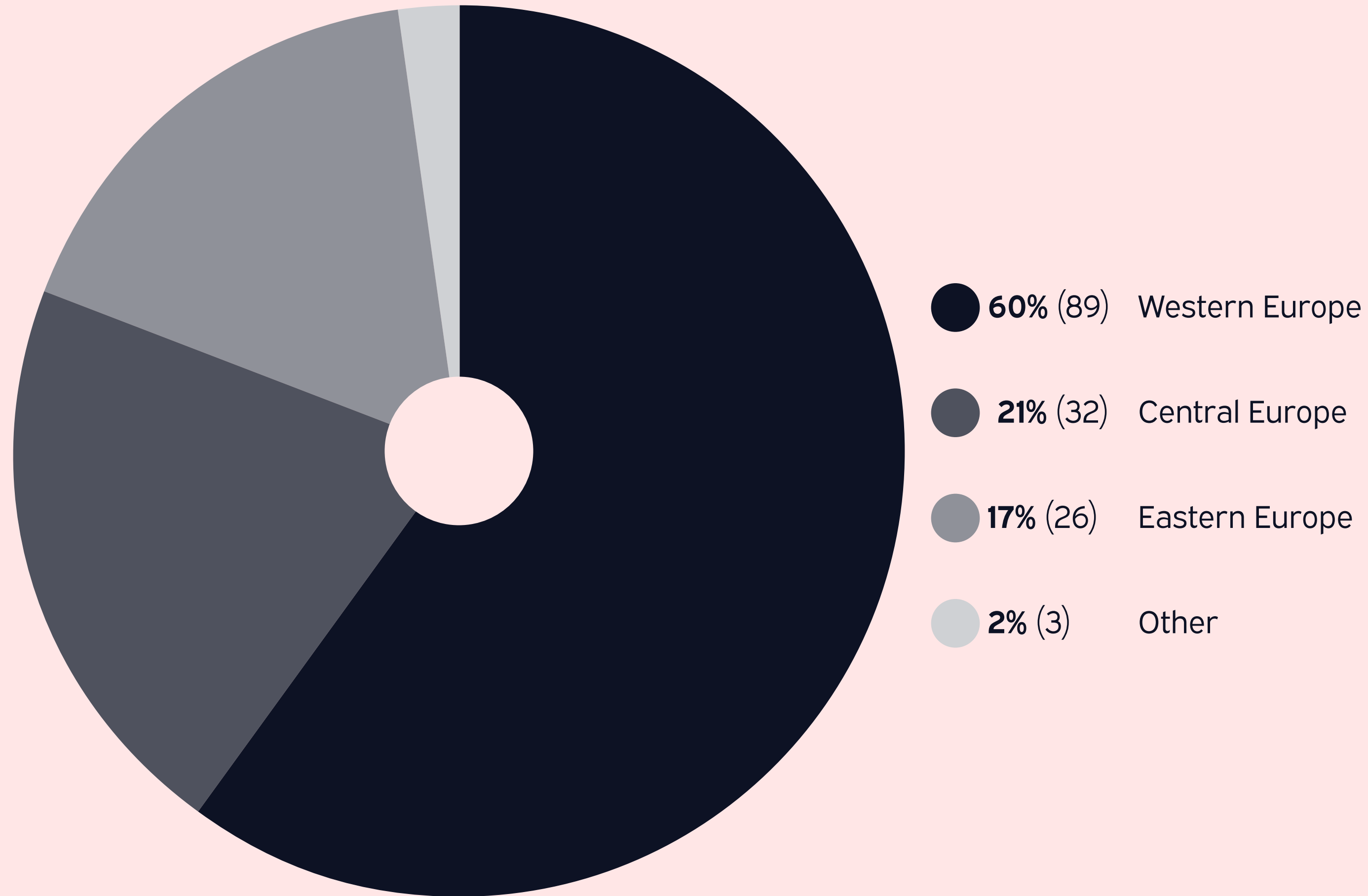
January to December 2021

In December 2021 EATG had **150 members**,
representing **44 different** countries.

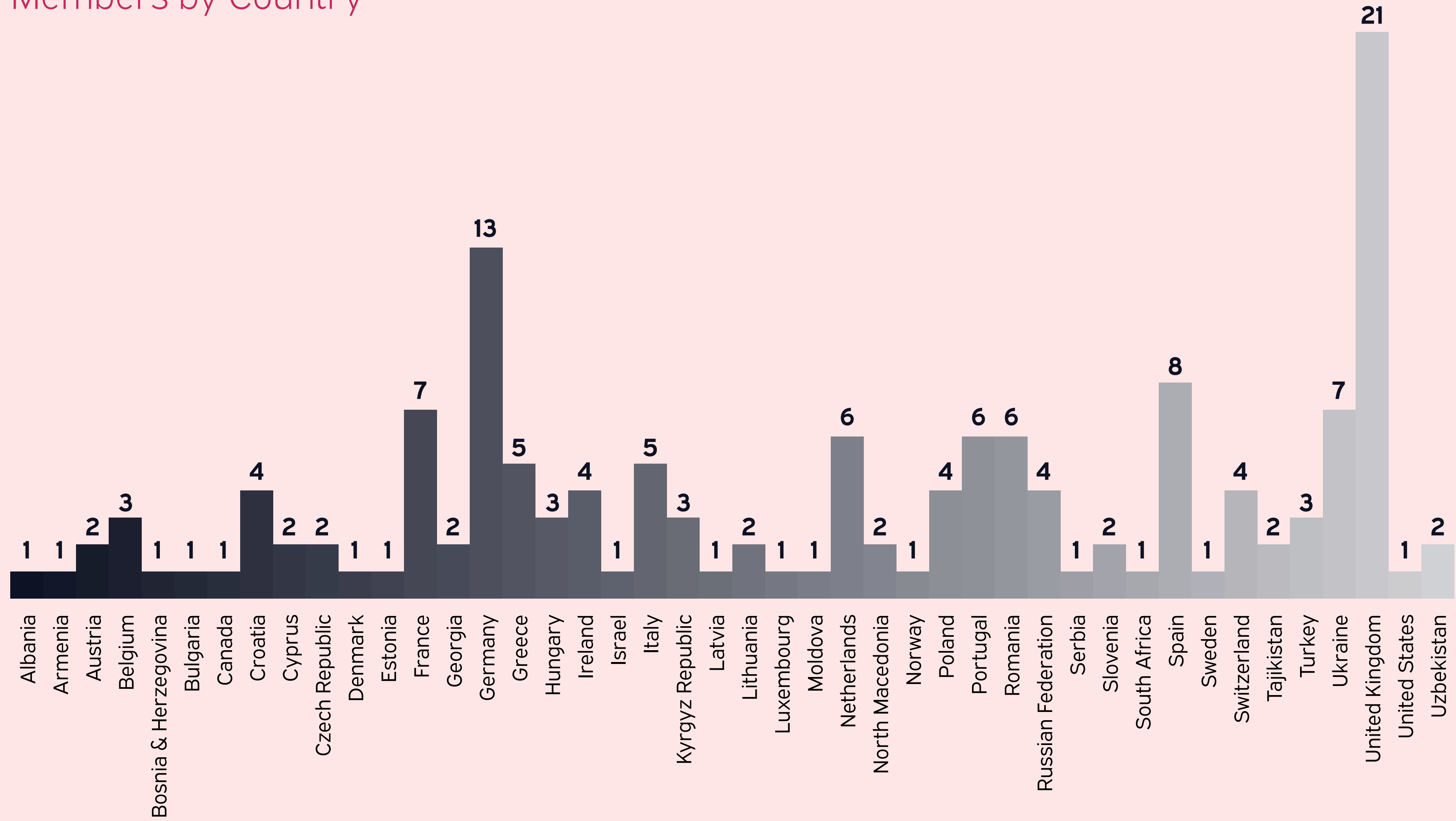


Regions (as defined by WHO)

More than half of EATG members (89 members - 60%) come from **Western Europe**. **32 members** (21%) are from **Central Europe** and **26 members** (17%) come from **Eastern Europe and Central Asia**. Three (supporting) members (2%) were located outside of the WHO Europe Region.

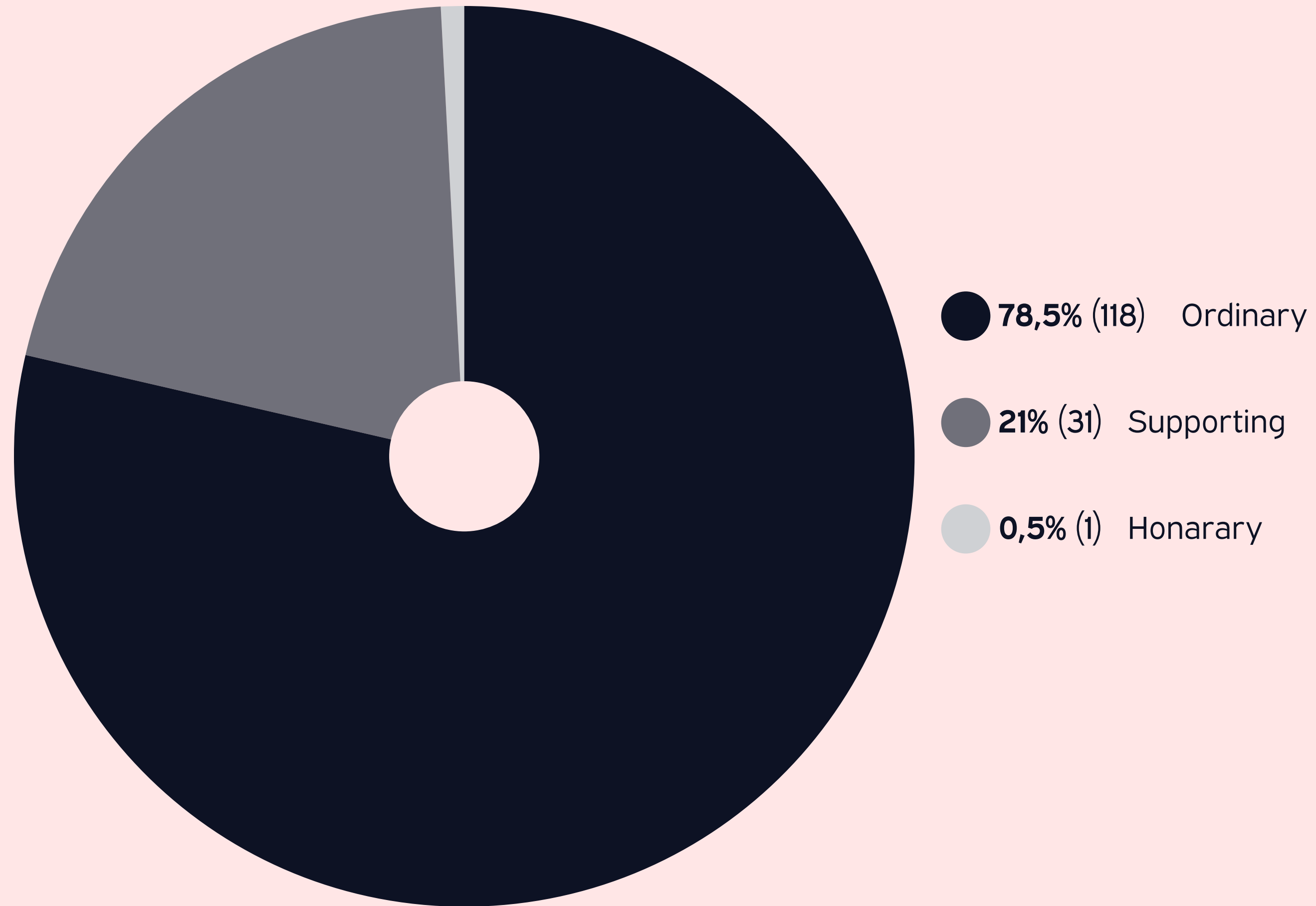


Members by Country



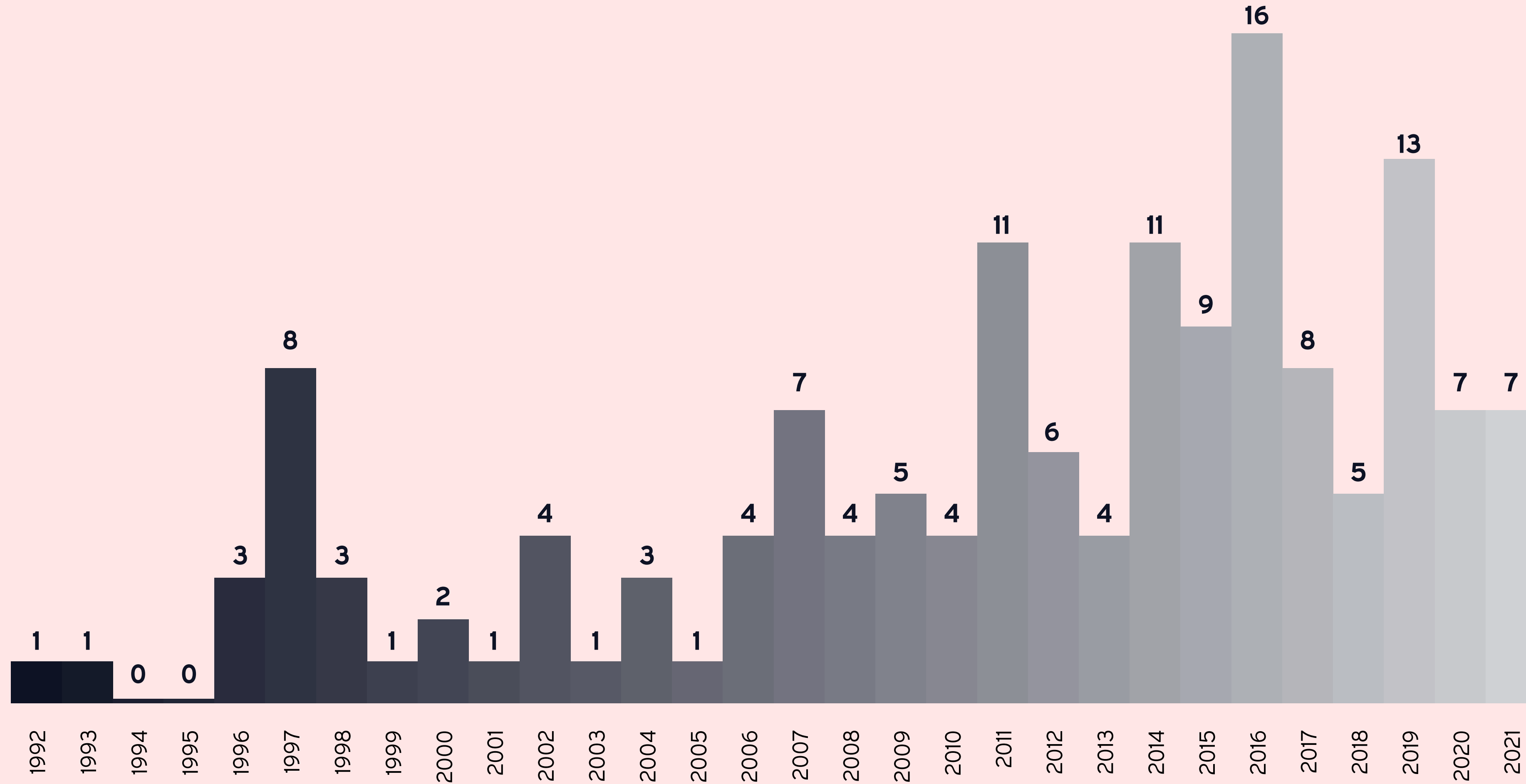
Supporting, ordinary and honorary members

At the end of 2021, EATG had **118 ordinary members** (members with voting rights), **31 supporting members** and **1 honorary member**.



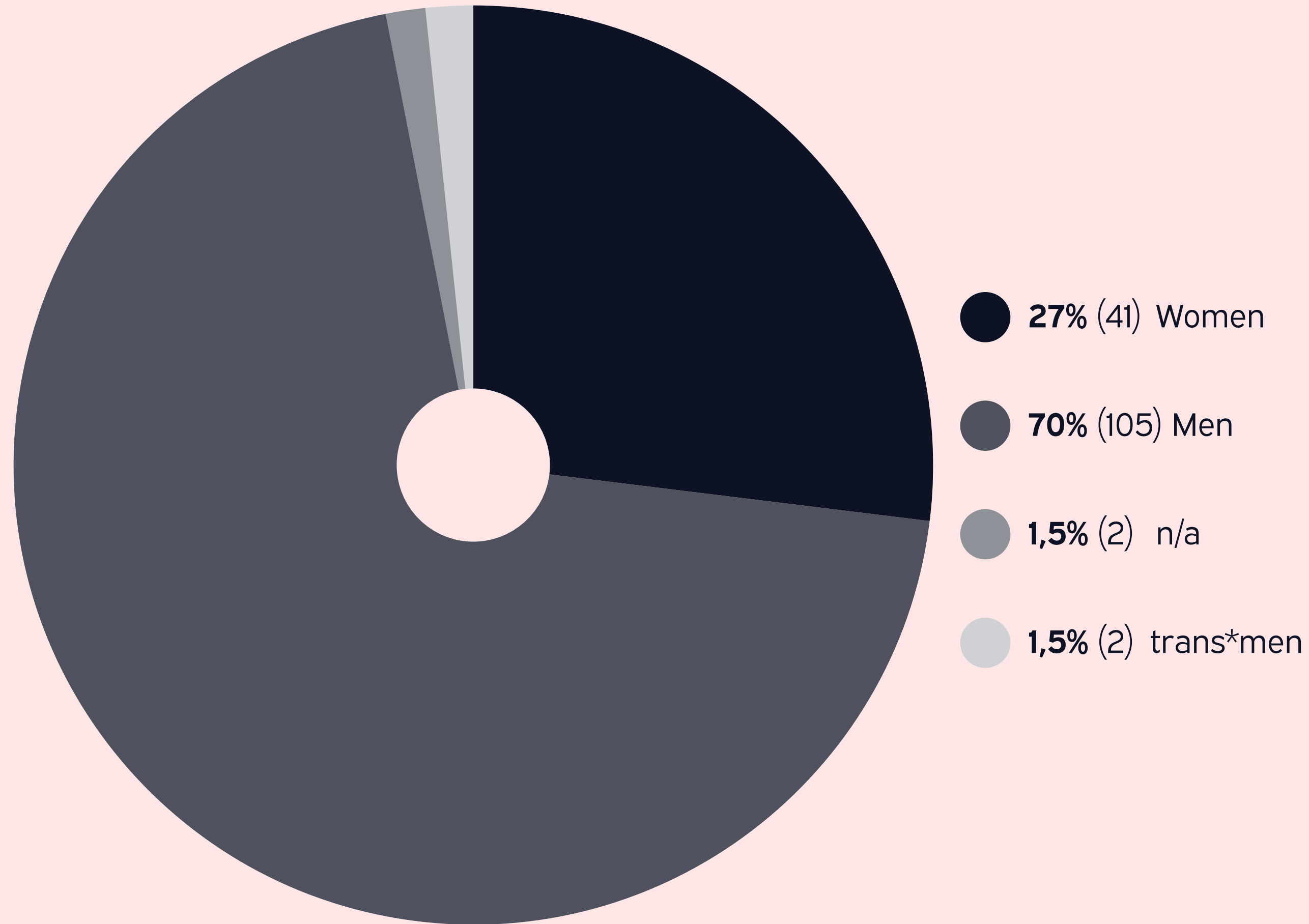
Recruitment

More than **half** of the current membership joined EATG during the past eight years. **7 members were recruited in 2021.**



Gender

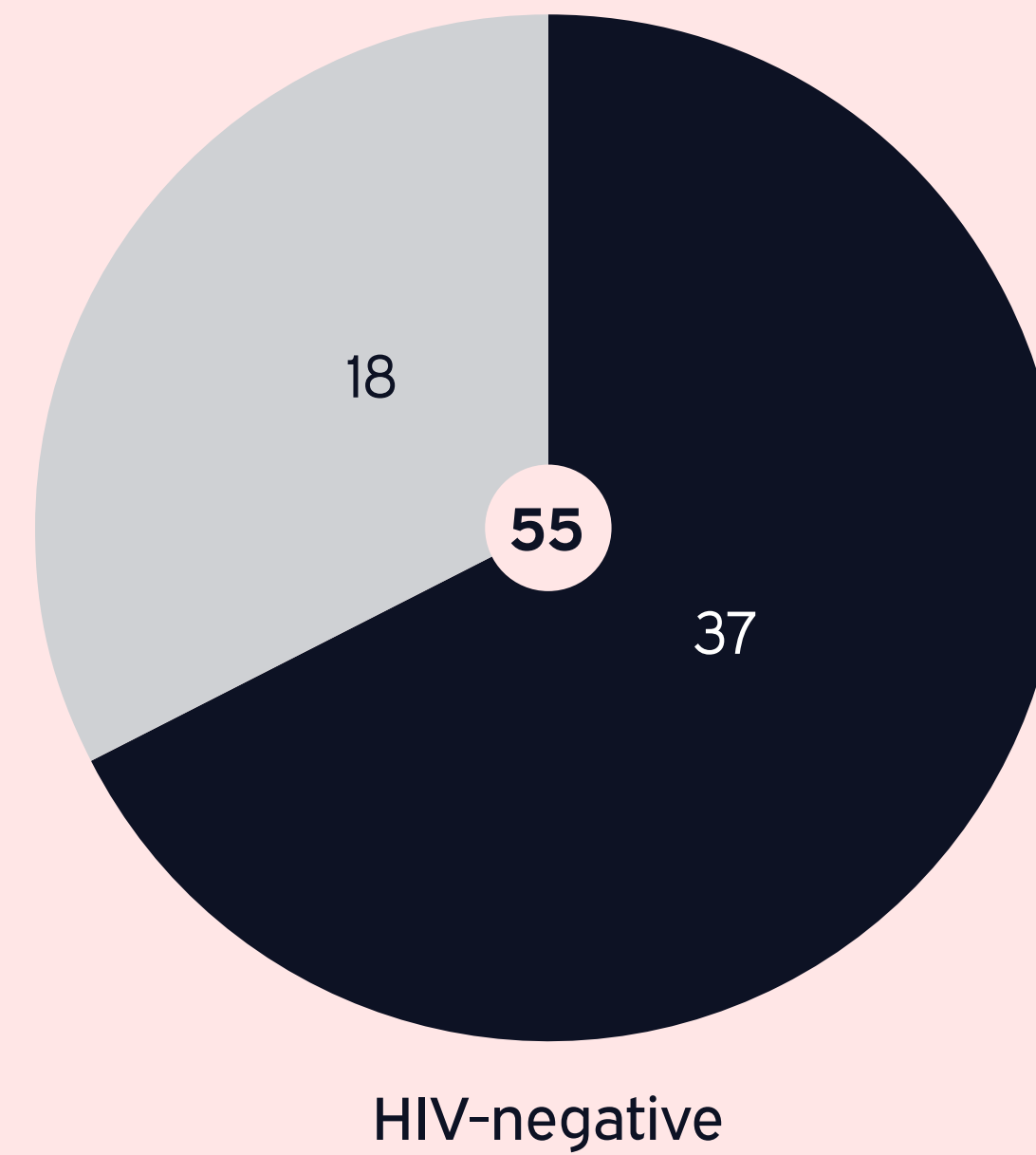
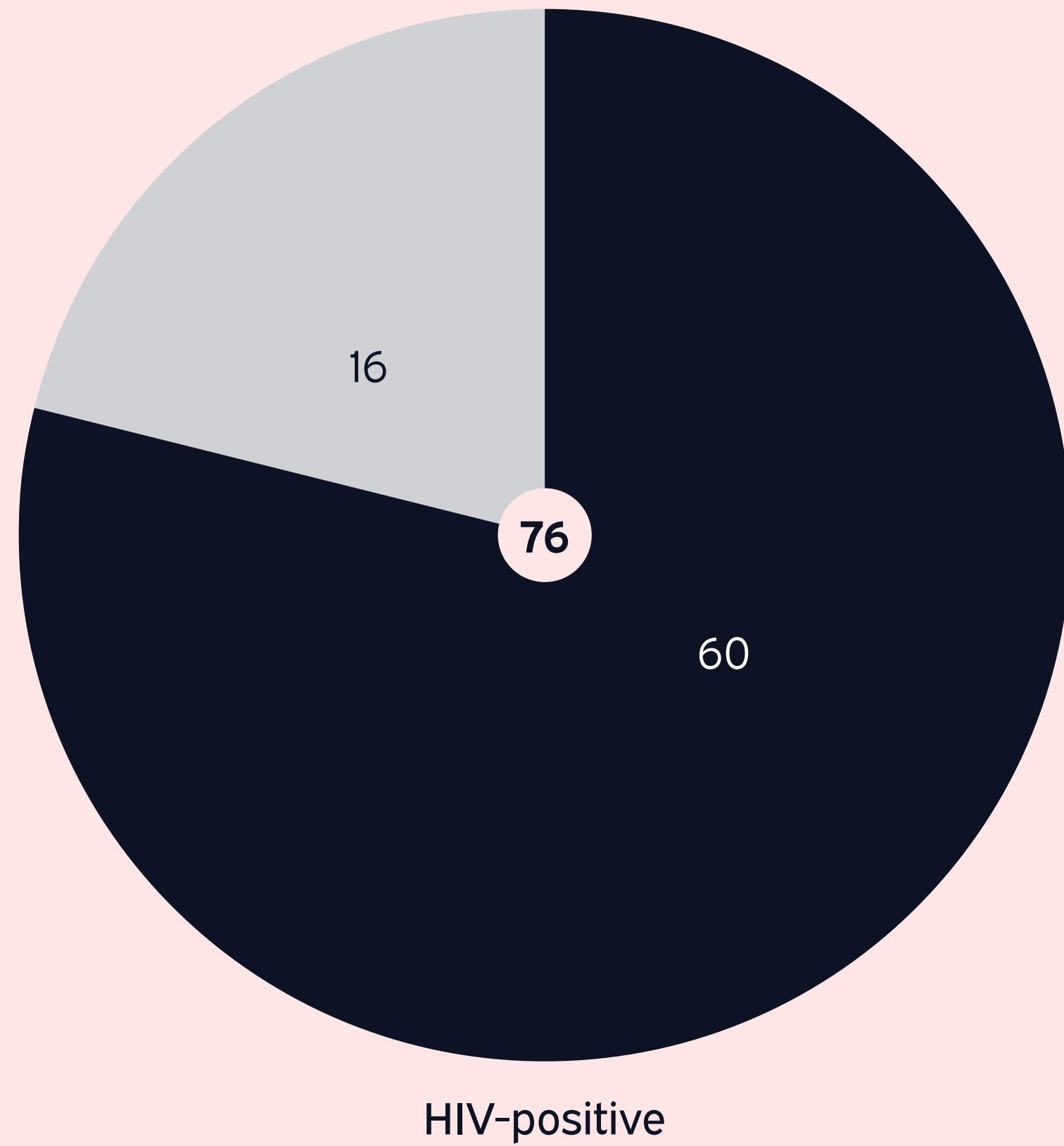
The gender balance is relatively uneven with **70% men (105) compared to 27% women (41)**. Two members are trans*men and two members prefer not to say.



HIV Status

At the end of 2021, EATG had **76 HIV-positive** members (51%); **55** members (36%) identified themselves as HIV-negative. **19** (13%) members said their status is unknown or preferred not to say.

- HIV status women: **16** (+), **18** (-), **7** (unknown)
- HIV status men: **60** (+), **37** (-), **12** (unknown)



08

Online Communication

EATG Website

On **June 1, 2021**, EATG's new website was launched. Its format reflects the renewed EATG programme structure and aims to present EATG's identity, updates and resources in a user-friendly way.

Within its first **seven months** of operation (June - December 2021):

- The site was visited by approximately 29.000 users, viewing more than 60.000 pages in about 35.000 sessions.
- Most users were from the USA, Belgium, Germany, Ireland, Netherlands, United Kingdom, Switzerland and France.
- Almost half of the users were between 25 and 44 years old. 6 in 10 were women and 8 in 10 visited the website from a desktop.
- 2 in 10 users acquired access through search engines or social media.

www.eatg.org

29.000

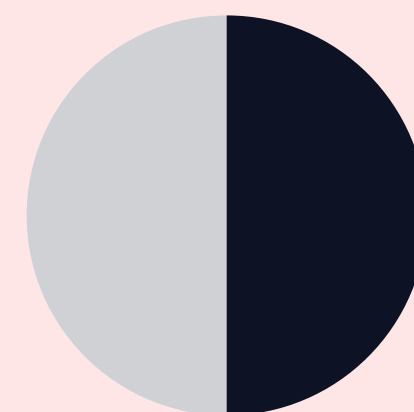
Users

60.000

Pageviews

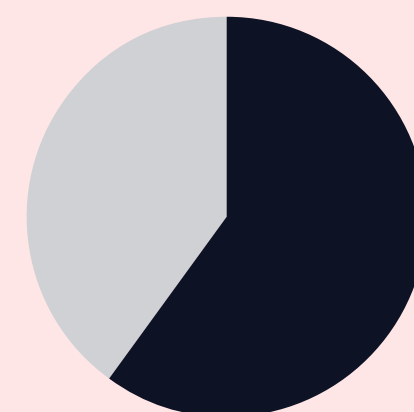
35.000

Sessions



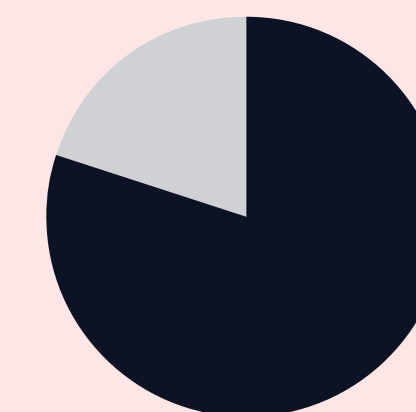
5/10

25-44 years old



6/10

Women



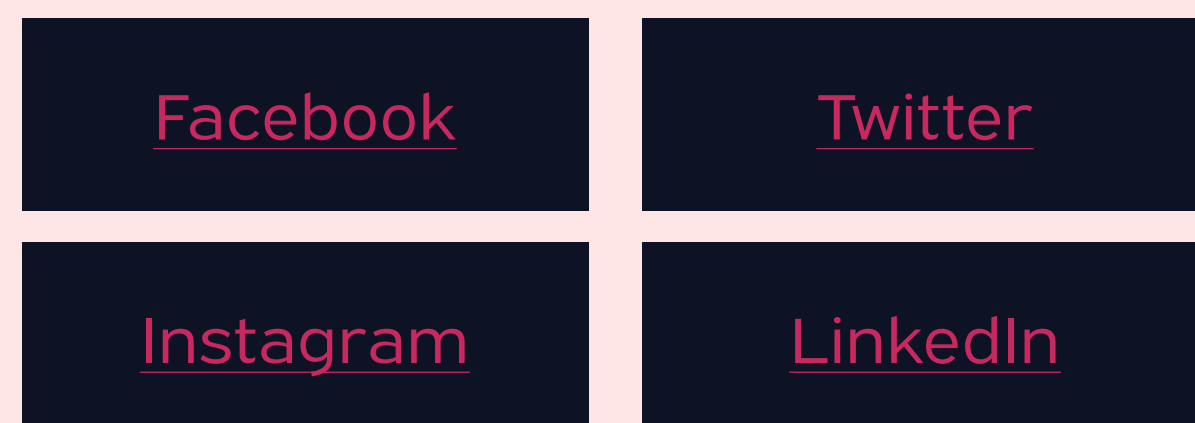
8/10

Desktop

EATG Social Media

As social media platforms are becoming more commercialised, organic (non-paid) reach declines for civil society organisations media that do not invest in sponsored content. In addition, virtual meetings and conferences in the COVID-19 context have a negative impact on the engagement of participants as creators and consumers of content.

- In 2021, EATG's **Facebook** page received **112 new likes**.
- In 2021, EATG's **Twitter** profile attracted **131 new followers**. For 2021, **Twitter impressions** reached **176.000**.
- By the end of 2021, EATG's **LinkedIn** profile had **324 followers**, gaining **174 new followers** during this year.
- Three years after its soft launch (October 2018), EATG's **Instagram** profile has **319 followers**, attracting **87 new followers** in 2021.



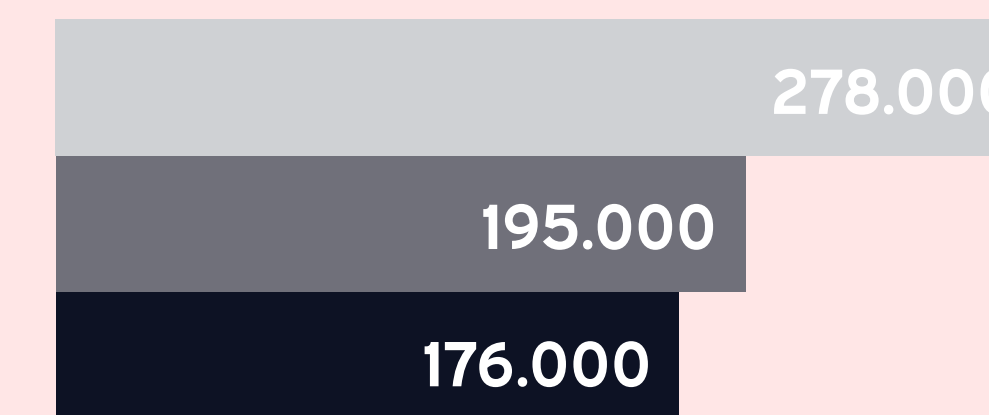
Facebook Page Likes



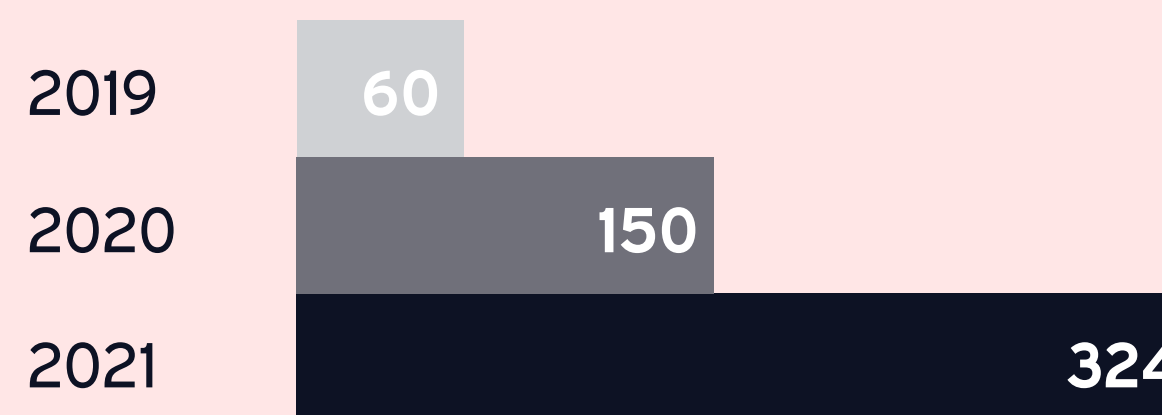
Twitter Followers



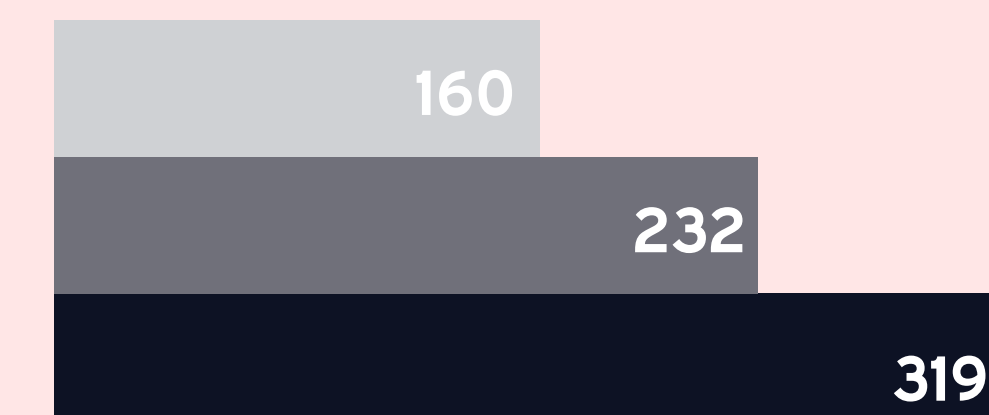
Twitter Impressions



LinkedIn Followers



Instagram Followers



EATG newsletter & HIV and co-infections news bulletin

The EATG newsletter was disseminated to **390 subscribers**, while **275 subscribers** received the news bulletin. Both editions were sent via Mailchimp and one can subscribe on EATG's website. In 2021, a total of **7 periodic and thematic** EATG newsletters were disseminated.

The regular daily and weekly **HIV and co-infections news bulletins** were redesigned and reinstated with the new website in June. There were also **18 weekly bulletin issues** from January until June.

390

Subscribers EATG Newsletter

7

Periodic and thematic issues

275

Subscribers HIV and co-infections
News Bulletin

18

Weekly bulletin issues

Campaigns

WAD 2021

40 years of HIV/AIDS: Stigma & Discrimination and the impact on Mental Health

On 2021 World AIDS Day, EATG launched a campaign to raise awareness around persistent stigma and discrimination faced by people living with and communities affected by HIV/AIDS and the impact on their lives and mental health.



Campaigns

Race in Support of Children Living with HIV

The race to support children living with HIV - co-organised by Life4me+ and EATG - aimed to raise the level of public awareness and understanding around the problems faced by children and adolescents living with HIV in the countries of Eastern Europe and Central Asia. Funds raised will also help to provide support for a camp for Russian-speaking children living with HIV.



Campaigns

Diversity is Strength

EATG is led by people living with or affected by HIV and associated infections (mainly hepatitis B and C, TB and STIs) and morbidities. We are a diverse group of people from across the WHO European region. We value our diversity in nationalities or countries of residence, languages, sexes, genders, ages, beliefs and ethnicities.

This diversity in who we are is our strength.

#DiversityIsStrength is EATG's motto attached to its Long-Term Strategy 2020-2025



09

Governance



The Board of Directors

Since the 2020 virtual General Assembly, the composition of the Board is as follows:

Ricardo Fernandes (*Chair*)*

Maka Gogia (*Vice-Chair*)*

Ian Hodgson (*Secretary*)*

Ben Collins (*Treasurer*)

Nyambe Mukelabai (*Director*)

*Re-elected by the 2021 General Assembly

Internal Auditors

Harriet Langanke

Fatih Egelioglu

Brian West*

Tomislav Vurušić*

*From September 2021

Ethics and Conflicts Resolution Committee

Julian Hows (*Chair*)

Rosaline M'Bayo

Koen Block

Mike Hiiza



The Development and Membership Advisory Group (DMAG)

Ann Piercy (*Chair*)

Memory Sachikonye

David Haerry

Dimitris Nastos

Sanja Belak Kovačević

Tomislav Vurušić

Lisa Power (*Interim Chair* until August 2021)

Programme Chairs

Mario Cascio

Quality of Life Programme Chair

Harriet Langanke (Frank Amort: until September 2021)

Combination Prevention Programme Chair

Alex Schneider (until October 2021)

Partners in Science Programme Chair

The Staff Members

Pieter Vanholder
Executive Director

Ann Isabelle von Lingen
Programme Manager (Combination Prevention)

Giorgio Barbareschi
Programme Manager (Partners in Science)

Anton Basenko
Programme Manager (Quality of Life)

Nadiia Gaidak
Events Coordinator and Data Protection Officer

Fiona Greenhalgh
Project Officer

Bojan Cigan
Project Officer

Sarah North
Project Officer

Marina Cogneé
Project Officer

Eleonora Tillich
Accounts Assistant

Silvian Ngefor and Rocco Pignata
Project & Administration Interns

Jean Claude Cagas
Communications Intern

External Consultants

Karina Huberman
Fundraising and Membership

Apostolos Kalogiannis
Communications

Marie McLeod
Finances, Accounting and Human Resources



Funders

Gilead Sciences

ViiV Healthcare

Merck Sharp & Dohme

Janssen Pharmaceutica NV

European Commission

EmH Initiative

Virology Education

Life4Me+

Foundation for Innovative New Diagnostics

Deutsche AIDS Hilfe

(Civil Society Forum on HIV, hepatitis and TB)



10

Annex Implementation Plan 2020-2022 Progress Report

Implementation Plan 2020-2022 Progress Report

Reporting period: 1 January - 31 December 2021

Outcomes 2022

Evolutions

Quality of Life

1
New and integrated models of care are identified, designed, developed, and promoted with community involvement

The first phase of the HIV & Mental Health project was finalised. Survey reports (full and summary) were produced based on the research. Multi-stakeholder meetings took place online in May and a hybrid one in November in Sitges (Spain). A briefing paper with clear recommendations to different stakeholders was launched. Both the survey results and the briefing paper with recommendations were presented at several international conferences (including during a session at the EACS conference) and disseminated at a national event in Belgium.

A total of 28 STEP-UP online training sessions (joined by 36 participants) were successfully completed. A face-to-face training weekend took place in Istanbul in November 2021 and focused on regional advocacy and networking. The STEP-UP training programme consists of 3 modules, of which one is traditionally focused on Standard of Care for HIV and emerging issues for people living with HIV, where trainers bring new approaches and promote integration. 5 sub-grants were issued to STEP-UP trainees, who successfully implemented follow-up projects.

In the framework of the European Red Umbrella Training Academy project, a series of resources was published on 'Sex Work and HIV Prevention'. These resources, available as a tool kit, aim to provide key information to sex workers and HIV activists as well as policy makers, and to re-affirm community and international recommendations, including promotion of new and integrated models of care.

EATG successfully conducted thematic sessions on mental health at the EU Civil Society Forum (CSF) on HIV/AIDS, Hepatitis and TB and advocated mental health issues, which contributed to the promotion of integrated mental health and well-being services into the models of care.

The membership, advocacy and partnership of EATG with initiatives such as HIV Outcomes and Nobody Left Outside, allowed EATG to advocate health-related quality of life and mental health as a priority of the EU in 2022 directly with the EU Health Commissioner Stella Kyriakides. EATG continued to contribute to advocacy activities via other third-party collaborations (e.g., European Public Health Alliance, European Patient Forum, EuroTEST).

Outcomes 2022	Evolutions
Quality of Life	
<p>2</p> <p>Healthcare service providers' awareness is increased about HIV-related stigma and discrimination and is acted upon</p>	<p>EATG launched a campaign on World AIDS Day (1 Dec 2021) with the title "40 years of HIV/AIDS: Stigma & Discrimination and the Impact on Mental Health" to raise awareness about persistent stigma and discrimination faced by people living with and communities affected by HIV/AIDS and its impact on their lives and mental health.</p> <p>HIV & Mental Health project activities such as two multi-stakeholder events, survey report data promotion (i.e. during EACS2021 special session) and briefing paper recommendations addressed to healthcare providers meaningfully contributed to the increase of their awareness about HIV-related stigma and discrimination. The QoL Programme contributed to the European Stigma Survey.</p> <p>In order to overcome the lack of knowledge and to promote awareness and better understanding of U=U, EATG conducted a mapping initiative that aimed to collect and report on U=U awareness-raising initiatives in HIV care services/settings in four EECA countries: Belarus, Kazakhstan, the Russian Federation and Ukraine. In late 2021, the mapping was finalised.</p>
<p>3</p> <p>Community influences the development and implementation of digital solutions at local, national and regional level</p>	<p>On the basis of the lessons learned from the EmERGE project, EATG contributed to the European Commission within the public consultation regarding a future legislative framework to address the issues related to the exchange of and access to health data and the use of digital services and products including artificial intelligence in health.</p> <p>EATG published a scoping paper on HIV and e-health. It served as a basis for EATG engagement (submission and speaker intervention) throughout EC policy plans regarding the European Health Data Space.</p>

Outcomes 2022	Evolutions
Quality of Life	
<p>4</p> <p>Rights violations in specific countries or sub-regions are monitored and reported</p>	<p>Human rights violations in specific countries and sub-regions were monitored and reported in the concluding issue of Rapid Assessment Bulletins: EATG COVID-19 Community Response.</p> <p>The QoL Programme has contributed to European Stigma Survey. The results of the survey will provide data to help monitor rights violations to be addressed through relevant human rights mechanisms.</p>
<p>5</p> <p>Good practices on Health Technology Assessment (HTA) and community engagement are identified and promoted</p>	<p>This year, EATG did not make any progress in this domain. It would be needed to further explore if and how EATG can play a more strategic role with regard to HTA.</p>

Outcomes 2022	Evolutions
Quality of Life	
6 Community members are equipped to influence pricing negotiations/ engage on medicines shortages	<p>36 trainees followed the STEP-UP 2020/2021 online training cycle, and 19 trainees attended the STEP-UP weekend in Istanbul in November. Amongst many other things, they were equipped with the knowledge and skills to influence price negotiations.</p> <p>Through its network, staff relations and linkages with regional stakeholders, EATG was involved and contributed to several cases of ARV shortages.</p>

Outcomes 2022	Evolutions
Partners in Science	
<p>1</p> <p>Community is engaged in the design, development and implementation of research/programmes for new therapeutic solutions</p>	<p>The PiS programme organised 6 online ECABs with four pharmaceutical companies (ViiV, MSD, Gilead and Janssen) to inform and engage the community members on the latest advancements within the HIV portfolio and related topics, such as PrEP, HIV and COVID-19 vaccine. EATG created a pool of and encouraged new members with scientific interest to attend the ECAB meetings.</p> <p>Throughout the year, 10 EATG members and staff provided community input into 17 documents including clinical trial protocols on new therapeutic strategies for HIV, as well as for the patient booklet for European Medicine Agency (EMA), training materials and guidelines for the European Patient Academy for Therapeutic Innovation (EUPATI) and guidelines for Patients Focused Medicines Development (PFMD). EATG created a pool of members and encouraged new members with scientific interest to take part in the protocol reviews.</p> <p>In collaboration with HIV i-Base, EATG published the Russian-translated version of the HIV Pipeline Report to facilitate improved access to information and important updates for Russian speakers. EATG also updated and published the Brief Landscape Review on HIV, Viral Hepatitis and TB Clinic Trial Sites in Eastern Europe and Central Asia.</p> <p>EATG updated the monitoring tool for clinical trial sites in the EECA region and updated its report on this which was published and made available on the EATG website.</p> <p>EATG had several developments within the PROMise project. It published its preliminary research which established community recommendations based on a literature review, community survey, outreach and consultation interviews with key informants from different stakeholders working in HIV R&D. Towards the end of the year, EATG began developing materials and training around basic literacy on PROMs within the context of improving quality of life, to develop knowledge and awareness. EATG then continued its consultation with a variety of relevant stakeholders to discuss and develop ways to implement the set of recommendations to improve community involvement in PROMs development and use.</p> <p>14 EATG members represented the community perspective in different projects and advisory boards of scientific projects and consortia (EHVA, EU Pearl, RESPOND, EUPATI, pxROAR, IAS Cure, EACS, Viral Education, Community Breakfast/Margarita Club).</p> <p>PiS developed a comprehensive Modus Operandi document, outlining the work and processes of PiS activities. It also drafted a Memorandum of Understanding document which aims to harmonise the interactions and collaboration with industry partners.</p>

Outcomes 2022	Evolutions
Partners in Science	
<p>2</p> <p>Community needs, priorities and strategies for viral hepatitis, TB, and STI co-infection with HIV are defined with key stakeholders</p>	<p>In collaboration with the Global TB CAB, EATG has continued to provide updates for the TB-Online website/newsletter. TB-Online is an initiative dedicated to increasing community involvement in TB research and to mobilising political will to develop and make available TB diagnostics, treatments and preventive technologies.</p> <p>EATG takes part in the EU PEARL project that aims to improve health outcomes for patients by transforming the way clinical trials are conducted. It focuses on four disease areas: major depressive disorder, tuberculosis, non-alcoholic steatohepatitis (NASH), and neuro-fibromatosis. EATG coordinated the Patients Advisory Group (PAG), provided advice on the TB work package and on the development of a patient engagement platform.</p> <p>In response to Covid-19 developments, EATG has engaged with industry partners in the discussion on treatments and vaccines for COVID-19 via the ECAB forum.</p> <p>In late 2021, EATG joined as a leading partner in the Horizon Europe funded RBDCOV project, to test a new vaccine against different variants of COVID-19. One of the clinical trials will focus on immunocompromised participants, including people living with HIV. EATG's role in the project is to provide community feedback on the design of the study and clinical protocols, lead on the psychosocial assessment of the study and support the communications around the trial and project.</p>
<p>3</p> <p>Community members have increased scientific knowledge on HIV and relevant co-infections</p>	<p>EATG held training and community-led sessions to build capacity amongst community members, for example a face to face and online training on PROMs, an online training on HIV Cure under the STEPS initiative and a community session on PROMs which took place during the EACS 2021 conference. Internally, EATG organised an informal Apero-Science event to engage with new members on scientific activities under the PiS programme.</p> <p>2021 was the first year of the European Patients' Academy on Therapeutic Innovation (EUPATI), as a foundation. EATG was a sustaining partner and held a seat as a member of the Board. EATG reviewed several training and capacity building materials from the community perspective.</p>

Outcomes 2022	Evolutions
Partners in Science	
<p>4</p> <p>Community understands and is engaged in cure and vaccine research</p>	<p>EATG led the seventh STEPS community-led workshop on HIV cure research. The workshop brought forward contributions of prominent researchers in the field of HIV cure-related research in Europe to the community and other stakeholders collaborating in this area. This year, the meeting focused on promising approaches for potential cure applications and upcoming trials for therapeutic vaccines.</p> <p>EATG takes part in European HIV Alliance (EHVA). This is an EU-funded project designed to foster the development of an effective vaccine for HIV. EATG provided community input into clinical trials and in project communication.</p> <p>The EU-funded project HIVACAR aims to change the current paradigm of HIV treatment by obtaining a functional cure for HIV. The EATG activities, which mainly focus on psychosocial research, were relaunched in late 2021 after being put on hold due to limitations of resources within the clinical trial centres and in recruiting participants following the COVID-19 pandemic. The project has been extended to continue until 2022.</p>
<p>5</p> <p>HIV Community is actively engaged in improving and promoting Patient Engagement in several disease areas</p>	<p>EATG takes part in EATRIS-Plus, a Horizon 2020 project aiming to support the long-term sustainability of EATRIS by delivering innovative scientific tools to the research community, strengthening the EATRIS financial model, and reinforcing EATRIS' leadership in the European Research Area, particularly in the field of Personalised Medicine research and development. The project drives patient empowerment through active involvement in EATRIS operations. EATG coordinates the Patient Advisory Committee, ensuring that patient empowerment is at the heart of EATRIS operations.</p> <p>EATG began to address the issue of the exclusion of people living with HIV in non-HIV clinical trials. EATG started mapping and contacting potential community-based partners to collaborate on promoting advocacy for this topic.</p> <p>RESPOND is a consortium of several cohorts and a flexible organisation, with several independent sub-studies operating under one shared governance. An EATG representative is part of the scientific committee of the consortium and provided feedback from community.</p>

Outcomes 2022	Evolutions
Combination Prevention	
<p>1</p> <p>Increased community involvement in the development and promotion of innovative, sensitive, user-friendly diagnostics tools</p>	<p>EATG developed the DIAGNOSE project to help strengthen communities' capacity to access and use of affordable, sensitive and user-friendly testing tools for prevention, testing and care. EATG held 3 online stakeholder meetings with community service providers, manufacturers, WHO and FIND on advancing the roll-out and uptake of self-testing diagnostics for HIV and HCV as part of the testing offer at local level. EATG launched an online survey between July-September 2021 to map out the current pricing and availability of self-test diagnostics for HIV and HCV in the WHO European region. Results were presented at a European Testing Week webinar on HCV self-testing together with WHO and FIND.</p> <p>EATG further focused on access to HIV and HCV self-test tools in Europe and Central Asia via the Co-Lead project, a collaboration with the Foundation for Innovative New Diagnostics (FIND). The project equipped community members involved in HIV and HCV related services delivery with up-to-date information about rapid diagnostic tests for self-testing, regulatory issues and good/promising practices to inform planning of testing at community level. EATG undertook qualitative research to identify factors enabling/hindering the roll-out and uptake of self-testing for HIV and HCV at community level and promising practices. A research report of the findings was drafted, in addition to a policy and operational briefing with specific recommendations. The report and briefing are to be published early 2022.</p>

Outcomes 2022	Evolutions
Combination Prevention	
<p>2</p> <p>Community is involved in the development and implementation of innovative (biomedical) prevention technologies and programmes and their delivery models</p>	<p>See PiS Programme (above) for ECABs with MSD, Gilead and ViiV covering PreP and Janssen regarding vaccines.</p> <p>EATG left the PrEP in Europe initiative steering committee together with other steering committee members and is looking to collaborate with partners on a project basis.</p> <p>In collaboration with AVAC, PrEPster, and AIDS Action Europe, EATG organised a web meeting for community educators and advocates on the biomedical HIV prevention pipeline.</p> <p>Together with AVAC, PrEPster, AIDS Action Europe and AIDES, EATG started drafting a community manifesto on combination prevention, with a focus on PrEP.</p> <p>EATG submitted a funding application for the Strategic Community HIV Prevention Empowerment (SCOPE) two-year project, which aims to reduce the gap in access and use of HIV combination prevention interventions by populations that are most affected by HIV, but remain inadequately served by the health system and which are underrepresented in policy and public debate. The application was approved in late 2021/early 2022. During 2022/2023 SCOPE will equip communities with enhanced scientific and technical knowledge and data for advocacy. Research will be carried out on community interest, acceptability, usability and acceptability of selected combination prevention tools and approaches.</p>

Outcomes 2022	Evolutions
Combination Prevention	
<p>3 Community's capacity to respond to the needs of inadequately served populations is increased, by identifying and promoting evidence based combination prevention programmes</p>	<p>EATG published the last bulletin of the COVID-19 Community Response project, which reflected on the lessons learned of the pandemic response for community actors and provided recommendations on measures to be taken by policy-makers, healthcare providers, industry and community services. Findings from the project were presented at community sessions on the side of the EACS conference.</p> <p>ESWA and EATG launched an Advocacy Tool Kit on Sex Work and HIV in Europe. These were presented at a HIV and Sex Work workshop with stakeholders in April and at the EU Civil Society Forum (CSF) on HIV/AIDS, Hepatitis and TB in June.</p> <p>Via STEP-UP, EATG delivered trainings on combination prevention, including 1 online sessions on harm reduction (in English) and 2 on-line sessions on specific key populations (in English and Russian). The STEP-UP face-to-face training in Istanbul included sessions on harm reduction specifically for people who use drugs, decriminalisation for sex workers and using gay apps for prevention (all bilingual).</p> <p>EATG organised 2 combination prevention and PrEP think tanks with interested EATG members.</p> <p>EATG submitted a funding application for the Strategic Community HIV Prevention Empowerment (SCOPE) project (see above). 2022/2023 activities will include an online meeting, translation/development of new community-informed information materials, activist health worker study trips, and reporting/dissemination on SCOPE research findings.</p> <p>In partnership with the European Sex Workers Rights Alliance and Association Legebitra, EATG rolled out 4 online e-MPOWER train-the-trainer sessions, to build capacity of youth peer trainers to deliver online sexual rights and health education to youth activists (aged 18-30 years).</p>

Outcomes 2022	Evolutions
Combination Prevention	
<p>4</p> <p>Community concerns on the enabling legal environment, investment and implementation of combination prevention are reflected by international/regional policies and programmes</p>	<p>EATG continued to engage with the EU Civil Society Forum on Drugs.</p> <p>EATG co-organised 4 EU Civil Society Forums (CSF) on HIV/AIDS, Hepatitis and TB including EU and UN agencies addressing: testing, sex workers, access to COVID-19 vaccination and prioritisation, mental health, harm reduction funding.</p> <p>EATG provided input into the drafting of the UN Global HIV/AIDS Strategy, the drafting of the WHO global health sector strategy on HIV/Viral Hepatitis/STIs and the action plan for the WHO Europe region on the drafting of the UNAIDS strategy 2021-2026, and the development of the EU4Health programme 2022.</p> <p>EATG collaborated with several multi-stakeholder initiatives to advance this agenda, including ACHIEVE (viral hepatitis), EuroTEST, Nobody Left Outside, the European Public Health Alliance, and the Platform for Collaboration on Undocumented Migrants (PICUM).</p> <p>EATG's World AIDS Day action was a campaign highlighting the enduring stigmatisation of people living with and affected by HIV and its impact on mental health.</p> <p>EATG provided support to strategic litigation by French sex workers organisation with a letter of intent in support of the case together with AIDS Action Europe and Correlations-EHRN.</p> <p>EATG is co-secretariat for the EU Civil Society Forum (CSF) on HIV/AIDS, Hepatitis and TB. 4 meetings took place in 2021.</p> <p>EATG supported advocacy efforts via EU4Health Coalition, ACHIEVE, HIV Outcomes, ECDC, MEPs, CSF for investment of EU4Health in areas of concerns.</p> <p>EATG contributed directly in the finalisation of the UNAIDS Global AIDS Strategy and the UN High-Level meeting on HIV/AIDS written input and the organisation of civil society consultation meeting as EU Civil Society Forum (CSF) on HIV/AIDS, Hepatitis and TB co-coordinator.</p>

Outcomes 2022	Evolutions
Combination Prevention	
<p>4</p>	<p>EATG provided input on the development of the European Health Data Space (EHDS) via its mapping paper on digitalisation and HIV, a submission to the EC consultation and EPHA policy meeting on the EHDS.</p> <p>EATG took part in the UN Programme Coordinating Board meeting as observer and submitted a written statement at the June meeting.</p> <p>EATG provided a community perspective on STIs prevention, testing and care at the ECDC network meeting on STIs.</p> <p>EATG is represented on the EPHA and EPF Board of Directors, whose advocacy reach goes beyond the HIV sector.</p> <p>EATG engaged with the EU4health civil society coalition in the development of the European Health Union and programming of the EU-4health programme to restoring core funding for health-related NGOs. It joined forces with ACHIEVE regarding funding for projects addressing viral hepatitis/tackling cancers caused by viral infections.</p>
<p>5</p> <p>Community is involved in the monitoring and reporting of treatment shortages as part of the Treatment as Prevention, PreP and harm reduction agenda</p>	<p>While EATG is still reflecting on how it can play a more systematic, strategic role, it continues to advocate for access and against shortages on an ad hoc basis, mobilising its pharmaceutical partners, its network and national/European authorities.</p>

Outcomes 2022	Evolutions
Organisational Development	
<p>1</p> <p>EATG is restructured following the Programme Structure of its LTS</p>	<p>All new/renewed bodies are in place and functioning: Board of Directors, Programme Chairs and Programme Committees, ECRC, DMAG, Internal Auditors. Evaluation of programme structure to take place during first half of 2022. Older, less productive structures have been dismantled (External Advisory Board; Finance Committee).</p> <p>In 2021, the 2-year mandate of the first EATG Programme Chairs since the organisational reform came to an end. Three new Chairs were elected for the programmes “Combination Prevention”, “Partners in Science” and “Quality of Life”. New Programme Committees were created for each programme. In line with the revision of EATG's internal procedures, both chairs and committees were now elected for a three-year period.</p>
<p>2</p> <p>EATG has proper tools, policies and procedures in place that allow for professionalism and transparency</p>	<p>EATG developed and continuously updated COVID-19 policy.</p> <p>EATG operates in full respect with its Data Protection policy and regularly reviews it.</p> <p>In 2021, EATG started implementing an entirely new Monitoring and Evaluation system. On a three-monthly basis, all staff members come together to monitor the progress of their activities against pre-set targets and outcomes.</p> <p>EATG now uses an online timesheet system.</p> <p>Terms of Reference for staff/consultancy positions are updated.</p> <p>EATG has a paperless office.</p> <p>EATG has an anti-corruption policy, which is annexed to the Operating Guidelines.</p> <p>At the 2021 General Assembly, new Terms of Reference were approved for Member Recruitment. This will serve as a basis for a more elaborate strategy to be developed in the coming years.</p>

Outcomes 2022	Evolutions
Organisational Development	
<p>3</p> <p>EATG has a sustainable and diversified income stream</p>	<p>Reviewed key operating documents, to make the organisation more modern and efficient, were adopted into the Operating Guidelines and Constitution.</p> <p>EATG's two major donors, Gilead Sciences and ViiV Healthcare, now provide multi-year funding to EATG.</p> <p>EATG has a fundraising strategy for 2021 - 2022.</p> <p>EATG identified potential new donors.</p> <p>EATG put in place the structure and tools to support fundraising efforts.</p> <p>In the ongoing quest to diversify income streams, EATG developed several project proposals in collaboration with other organisations. e.g. eMPOWER (approved by Erasmus+); RBDCOV (Approved by EC); Co-Lead (approved by FIND); PARTNER (submitted to RCF).</p> <p>EATG became affiliate partner of the European Foundation Centre (now Philea).</p> <p>EATG initiated the process for enabling tax deductible international donations (and become a beneficiary of Transnational Giving Europe Network).</p>

Outcomes 2022	Evolutions
Organisational Development	
<p>4</p> <p>EATG members in all their diversity have increased knowledge and capacities for patient engagement, science and HIV related advocacy and activism</p>	<p>All membership applications are up to date and a new membership application form is now online.</p> <p>All events organised by EATG promote diversity in participation, with special attention to age, experience, gender, geography, and key populations.</p> <p>Since 2020, EATG office systematically translates all communication on the members list into Russian. Translated forms for member administration were updated in Russian.</p> <p>Almost all project proposals that were developed in 2021 had a focus on key populations: STEP-UP; Frailty; PARTNER; DIAGNOSE, Co-Lead, SCOPE.</p> <p>EATG has developed a pool system for protocol reviews and ECABs. Through this pool system, EATG makes sure that less experienced members can be involved in order to gain knowledge and experience.</p>

Outcomes 2022

Evolutions

Organisational Development

5

EATG pays specific attention on domains and geographical areas where the HIV/Hep/TB epidemic is most severe

EATG's new STEP-UP project proposal was submitted to donors, which has a 50%-focus on EECA. This proposal was submitted in collaboration with Alliance for Public Health from Ukraine. EATG's Co-Lead project was implemented in 2021, with focus on EECA region (bilingual project). EATG's SCOPE project was submitted and approved, which includes EECA and translations in Russian.

EATG hired a new Programme Manager from EECA region, who can help to keep/increase the focus on that region.

Many of EATG's online meetings, research and policy documents published in 2021 were translated into Russian: COVID-19 response bulletin #6; online briefing meetings (and their report) on the Biomedical Prevention Pipeline, Diagnostics Self-Testing of HIV, Viral Hepatitis and STIs workshop on self-testing; self-testing research report and policy brief.

Since 2020, EATG office systematically translates all communication on the members list into Russian. Translated forms for member administration were updated in Russian.

EATG organised an informative brainstorming session for all its members to explain EATG's existing focus on the EECA region, as well to explore possible ways of engaging members from EECA region and how EATG can be more involved in the region.

Outcomes 2022

Evolutions

Organisational Development

6

EATG's internal and external communications are effective and efficient

EATG's new website was launched on June 1 2021.

EATG established collaborations with new IT partners and administrator of its eatg.org domain. Consultations for the simplification of EATG's IT set-up were completed and the intranet platforms were prepared for launch early in 2022.

Going Virtual: EATG's investment on digital platforms and integrated tools for internal and external collaboration, meetings, webinars and design continued (Zoom, Teams, O365, Canva etc.). EATG limited printing materials, focusing on digital visuals and publishing for the new website as well as targeted free merchandising for members and outreach.

Events: EATG hosted a booth, sessions and community corner events at EACS 2021 conference - the first face-to-face conference after 2019.

Main Publications / Campaigns: 1) EATG Annual Report 2020 2) PROMS in HIV research reports and podcast 3) HIV, Viral Hepatitis and Tuberculosis Clinical Trial Sites in Eastern Europe and Central Asia: Brief Landscape Review 4) HIV and Mental Health reports 5) STEP-UP: Seven stories of Success (digital and printed) 6) HIV and eHealth scoping paper 7) ERUA: Sex Work and HIV in Europe advocacy toolkit 8) WAD2021: 40 years of HIV/AIDS: Stigma & Discrimination and the impact on Mental Health campaign (webpage, videos) 9) HIV Run: Race to Support Children Living with HIV.

There has been a stable growth of audience across all EATG social media:

Facebook: 112 new page likes (+6%), Twitter: 131 new followers (+7%), In December 2021, EATG LinkedIn account had 324 followers (December 2020: 150). There were 7 EATG newsletters sent out in 2021.

The regular daily and weekly HIV and co-infections news bulletins were redesigned and reinstated with the new website in June.

There were also 18 weekly bulletin issues from January until June.

EATG continues to provide content and administer TB online; website (<https://www.tbonline.info/>).

Outcomes 2022	Evolutions
Organisational Development	
<p>8</p> <p>EATG concerns are reflected in regional policy and guideline documents</p>	<p>EATG contributed to and influenced the key UN and WHO policy processes relevant to HIV. It was also involved in policy processes pertaining to the development of EC cancer actions, European Health Data Space, European Health Union, ECDC monitoring, programming of EU4Health funding, mental health.</p>
<p>9</p> <p>EATG concerns are reflected in regional policy and guideline documents</p>	<p>In order to provide adequate trainings/education, EATG has Individual Development Plans for each staff member with an annual training budget.</p> <p>EATG allows homeworking and flexible working hours, which have a positive impact on work-life balance.</p> <p>EATG continues to ensure extras and benefits are in line or above standards as compared to the sector. Further investigation and the creation of more streamlined salary scales is foreseen for 2022.</p> <p>EATG has introduced a system of weekly team calls during the COVID-19 Pandemic; there are yearly retreats for the whole team; regular team building activities are organised.</p>

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