EATG
Projects
& Initiatives
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# Project/Initiative Summary

## Ongoing Projects

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## Initiatives EATG is Involved In

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1. Projects (ongoing)
HIV & Mental Health

EATG contact person(s): Marina Cognée - marina.cognee@eatg.org
Duration of the project/initiative: March 2020 to August 2021
Project/Initiative Leader: EATG
Project/initiative Main Partner(s): n/a
Budget: 206.175 €
Main Funding Sources: Gilead Sciences, Merck Sharp and Dohme (MSD), ViiV Healthcare Europe Ltd
Communication Disclaimer: The HIV & Mental health project has been developed by the EATG, and was made possible through a grant from Gilead Sciences, Merck Sharp and Dohme, and ViiV Healthcare Europe Ltd. EATG acknowledges that the sponsors had no control or input into the structure or the content of the initiative.

Why?
One of the main outcomes of the Ageing with HIV Project of the EATG (2016-2018, https://www.ageingwithhiv.com/) was the identification of mental health as a key neglected area, and its importance for the quality of life for PLHIV. This finding is also supported by scientific evidence, which suggests that mental health problems are one of the most significant areas of co-morbidity for people living with HIV worldwide and are more prevalent among PLHIV than the general population.

What?
The Mental Health, Well-being and HIV Project aims to explore the existing knowledge about the interplay of mental health, well-being and HIV and translate it into practical recommendations for both community organisations and healthcare professionals in the European context. The recommendations will advise on how to develop a supportive and integrated framework within the HIV care setting, which provides people living with HIV with
access to prevention, screening, treatment and care for mental health problems. This framework will take into consideration the specific needs of vulnerable populations and address the issue of substance use. A European network bringing together the different stakeholders in the field of mental health and HIV is formed and a platform for them to interact will be established.

With whom?
The project is mainly addressed to: 1) community, people living with HIV as well as persons working in community HIV organisations at the local, regional or international level in the European context and 2) healthcare professionals who provide prevention, treatment and care services for people living with HIV. Other key stakeholders are national/EU-level decision-makers and agencies in the health sector and international organisations working in the mental health field. Researchers/academia and industry working in HIV field will also be closely linked to during the project.

How?
The main activities of the project are:

- Literature review on HIV and mental health.
- Survey on community perspective on the role of mental health in HIV prevention, treatment adherence, quality of life and retention in care.
- Workshop to define recommendations for practical interventions in community and healthcare settings to improve access to and quality of HIV prevention, treatment and care services for people living with HIV who face mental health problems.
- Multi-stakeholder event to present findings and recommendations to community, healthcare sector, policy, industry, research and international organisations.
- Development of a briefing paper on mental health and promising approaches.
- Dialogue with EACS on better integration of the mental health dimension in the HIV guidelines.
- Meeting bringing together members of community and representatives of industry partners about mental health related endpoints in research and drug development.
- Dissemination of information via website and social media, webinars, publications, translated materials.
- Creating a European Platform to allow continuous and sustainable collaboration and experience exchange of the stakeholders involved in the project beyond the project duration.
- Development of concept for a reoccurring bi-annual European conference on interplay of mental health, well-being and HIV.

For what outcome?
The expected specific outcomes of the project are:

- Awareness on the interplay of mental health, well-being and HIV is created among community organizations, healthcare professionals and other stakeholders in the HIV
field at the European level through broad dissemination of the knowledge generated through this project.

- European stakeholders from community, healthcare sector, policy, industry, research and international organisations are considering the interplay of mental health, well-being and HIV in their respective areas of work, based on the findings and recommendations of the project.
STEP-UP: Skills Training to Empower Patients

EATG contact person(s): Marina Cognée - marina.cognee@eatg.org

Duration of the project/initiative: Started in 2007 - ongoing

Project/Initiative Leader: EATG

Project/initiative Main Partner(s): n/a

Budget: 185.400 €

Main Funding Sources: Gilead Sciences, ViV Healthcare Europe Ltd

Links: [https://www.eatgtrainingacademy.com/about-step-up](https://www.eatgtrainingacademy.com/about-step-up)

Communication Disclaimer: This initiative has been independently developed by EATG, and was made possible through sponsorship from Gilead Sciences Europe Ltd and ViV Healthcare Europe Ltd. EATG acknowledges that neither Gilead Sciences Europe Ltd nor ViV Healthcare Europe Ltd have had any control or input into the structure or content of the initiative.

What?

STEP-UP is a year-long bilingual (English-Russian) modular training programme for HIV activist/advocates in Europe and Central Asia to advance their knowledge and skills. By the end of the programme, trainees should be better equipped to:

- Confidently engage in dialogue with researchers, policy makers and industry to on projects, interventions, programmes, R&D, policies and regulations related to the prevention, treatment and care of HIV and related infections (mainly hepatitis B and C, TB and STIs) and morbidities, at local or international levels.
- Enhance treatment literacy and advocacy capacities of local and regional HIV community organisations
- Further promote the adherence to HIV treatment, care, support and prevention in Europe
- Fight stigma, health inequalities and discrimination towards people living with HIV

With whom?
The STEP-UP programme is designed for people living with HIV/AIDS, health care providers, civil society representatives and other professionals who work in service delivery and/or advocacy to ensure universal access to combination prevention, treatment and care. Trainees have prior knowledge of HIV and related infections prevention, treatment and care and aspire to expand their capacities. They should assume a leadership role in prevention, treatment and care advocacy, fighting stigma and discrimination, and in increasing understanding and acceptance of HIV in their country and at international level.

How?
The main activities of STEP-UP 2020/2021 are:

- Regular online training sessions (live), complemented by exercises and reading assignments
- 1 face-to-face summer weekend
- 5 local trainings organized by STEP-UP trainees themselves (“train the trainer”)
- 4 follow-up projects implemented via small grants

For what outcome?
The expected outcomes of the project are:

- 27 treatment advocates based in the WHO Europe region gain advanced knowledge and advocacy skills related to HIV.
- 27 treatment advocates from the WHO Europe region are empowered to initiate change at local level in collaboration with peers and partners.
- STEP-UP participants are linked to international networks.
CoPE – Continuous Patient Education

EATG contact person(s): Marina Cognée - marina.cognee@eatg.org
Duration of the project/initiative: Started in 2001 - ongoing
Project/Initiative Leader: EATG
Project/initiative Main Partner(s): n/a
Budget: Varies by year / call for applications
Main Funding Sources: Within various project budgets
Links: https://www.eatgtrainingacademy.com/cope
Communication Disclaimer: Depending on the funder

What?
The CoPE project is a funding mechanism 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 people living with HIV/AIDS and their advocates by providing access to the latest information about HIV/AIDS and co-infections in their local language. Being able to refer to up-to-date and reliable information adapted to the local situation is essential in the dialogue with clinicians, health administrators and policy makers.

With whom?
Any community-based organisation in the European and Central Asian region dealing with prevention and treatment of HIV/AIDS and co-infections can apply to CoPE.

How?
The production and printing of materials is coordinated by the local community organization that has received the CoPE grant. The resource is then distributed through different channels, nationally, regionally and locally, e.g., to hospitals and maternity services, NGOs, Opioid Substitution Therapy services, libraries, government agencies, HIV screening centres and clinics and prisons.
For what outcome?

CoPE supports publications which:

- Promote necessary, objective, reliable and up-to-date knowledge and skills about HIV/AIDS and co-infections among patients, patient groups, groups at-risk, and healthcare providers.
- Raise awareness and appreciation of facts and issues related to HIV/AIDS treatment among PLWH (such as women, men who have sex with men, injecting drug users, sex workers, migrant communities and other groups).
- Offer objective, scientifically accurate, high-quality, patient-focused and user-friendly overview and summary of relevant health and treatment information on specific and generic HIV-related topics and issues.
- Engage, support and empower local HIV-positive community for the preparation and development of necessary and relevant treatment materials.

An archive of the materials funded by CoPE is available:

https://www.eatgtrainingacademy.com/cope-publications
The European Community Advisory Board - ECAB

EATG contact person(s): Giorgio Barbareschi - giorgio.barbareschi@eatg.org
Duration of the project/initiative: 1997 - ongoing
Project/Initiative Leader: EATG
Project/initiative Main Partner(s): n/a
Budget: It varies by the year and type of event. It is part of EATG Scientific / core funding depending on the sponsors.
Main Funding Sources: Industry (Generally funded by Viiv, MSD, Gilead, Janssen)
Links: http://www.eatg.org/ecab/
Communication Disclaimer: This initiative has been independently developed by EATG and was made possible through sponsorships from the pharmaceutical partners engaging in R&D on HIV and related co-infections like viral hepatitis or tuberculosis.

Why?
The European Community Advisory Board - ECAB was created in 1997. At the time, patient advisory boards only existed on an ad-hoc basis and were convened by the pharmaceutical companies, a major limitation that ECAB successfully overcame by putting forward an innovative model for the patient community to provide meaningful, independent, and valued input in research on treatment, prevention and quality of life for HIV and its main co-infections and related medical conditions.

What?
ECAB is a high-level scientific platform that brings together civil society, scientific researchers, the pharmaceutical industry and international institutions to address key science and access issues related to HIV and its main co-infections like viral hepatitis or tuberculosis.
EATG, within the remit of the European Community Advisory Board (ECAB), addresses critical scientific questions around HIV drug-development and its main coinfections as well as access to treatment in the European region as defined by the World Health Organisation.

With whom?
ECAB is composed by expert patients and treatment advocates coming from the WHO European region continuously working together to end the epidemic by advancing research on HIV/AIDS and its main coinfections/conditions, broadening access to treatment, training/mentoring new HIV/AIDS advocates and ensuring that the patient Community is a permanent and highly-recognised voice in the research arena. It is a volunteer, community-based structure, also collaborating actively with national and regional Community Advisory Boards in Europe and other groups sharing the same philosophy in other geographical areas. Many ECAB participants are living with HIV. ECAB participants represent the diverse needs, interests, and concerns of the entire spectrum of the European HIV patient community (women, men, trans population, sex workers, drug users, ethnic minorities, people in detention, and other underrepresented or vulnerable populations).

How?
ECAB ‘s work includes:
- Reviewing clinical trial protocols giving the point of view of PLHIV community
- Promoting best practices procedures and ethics
- Promoting universal access to fair, sustainable, affordable drugs
- Promoting research developments improving the quality of life for PLHIV

ECAB meetings do not only focus on HIV/AIDS. Thematic ECAB meetings are also organised on important topics such as viral hepatitis, tuberculosis as co-infections, diagnostics, prevention, patient reported outcomes, gender representation in clinical trials, etc.

ECAB meetings are conducted under confidentiality.

For what outcome?
ECAB activities aims to promote the harmonisation of the best available clinical practices, standards of care and access to the latest and best available therapies and diagnostic tools throughout Europe, with a particular regard to Central and Eastern Europe. ECAB members meet regularly with the pharmaceutical industry and researchers to discuss, under confidentiality, the advances in HIV drug development and related co-infections, and access to treatment in the WHO European region.
PROMise

EATG contact person(s): Fiona Greenhalgh – fiona.greenhalgh@eatg.org
Duration of the project/initiative: February 2020 - ongoing
Project/Initiative Leader: EATG
Project/initiative Main Partner(s): n/a
Budget: 2020: 10,000 €, 2021: 50,000 €
Main Funding Sources: Merck Sharp and Dohme (MSD)
Links: n/a
Communication Disclaimer: This initiative has been independently developed by EATG and is supported by a grant from Merck, Sharp & Dohme.

Why?

Today, HIV is increasingly being considered as a chronic condition with near-normal life-expectancy. Consequently, the well-being and health-related quality of life of people living with HIV are gaining increasing importance. Evidence suggests that even with effective treatment, people living with HIV have a significantly lower quality of life than the general population.

Reasons for this are grounded in the physical, psychological and social domains that are likely to be overseen by traditional clinical measures focusing mainly on viral load suppression, that determine the choice of treatment and drive the development of new drugs. Patient Reported Outcomes (PROs) can be a tool to address this issue. Defined as “data reported directly by a patient on his or her own health condition, without interpretation by a doctor or anyone else”, PROs can help assessing the implications of a disease and the applied treatment on how the patient feels and functions and comparing the clinical outcome to what the patient expects from the treatment.

Therefore, PROs and the corresponding Patient Reported Outcome Measures (PROMs), usually in form of standardized questionnaires, constitute a unique means of capturing the personal and social context of the patient’s experience in terms of the disease and treatment that might not necessarily be captured by biomarker4 measures or adverse events.
Project/Initiative Summary

What?
The overall goal of the project is to establish a joint framework for the consideration of HIV-specific Patient Reported Outcome Measures (PROMs) in HIV R&D in collaboration with key stakeholders from community organizations, academia, industry, regulators and Health Technology Assessment (HTA) bodies. The framework will provide guidance to the stakeholders involved in the field of HIV R&D on to what extent the currently used PROMs reflect the quality of life related needs and priorities of people living with HIV and to what extent the development of new HIV-specific PROMs is necessary. Furthermore, the framework will provide guidance for the involvement of patient representatives in all stages of the development process of new HIV-specific PROMs.

With whom?
The project is mainly addressed to 1) community organizations and people living with HIV advocating for stronger consideration of quality of life aspects in HIV R&D, treatment and care; 2) industry, academia or research institutions working in the field of HIV R&D; 3) researchers and clinicians developing PROMs; 4) regulatory agencies in charge of drug approval and registration at European level (EMA) and at national level; 5) international organizations and institutions working in the HIV response in the WHO Europe region; 6) health policy decision-makers at EU level and national level; and 6) Health Technology Assessment bodies.

How?
Project activities include:

- Research to establish community recommendations based on a literature review, community survey, outreach and consultation interviews with key Informants from different stakeholders working in HIV R&D in industry, academia or research institutions, as well as clinicians working in research.
- Developing materials and training around basic literacy on PROMs within the context of improving quality of life to develop knowledge and awareness.
- Continued 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.

For what outcome?

- Awareness and knowledge are created among community in Europe on the relevance of Patient Reported Outcomes for quality of life of people living with HIV.
- Community advocates have knowledge on the different Patient Reported Outcome Measures that are being used in HIV R&D.
- Community advocates have assessed whether the current Patient Reported Outcome Measures are adequate to reflect the quality of life related needs of people living.
with HIV and are able to represent their interests on Patient Reported Outcome Measures towards the relevant stakeholders

- A set of recommendations that reflects community needs in the area of PROMs is agreed upon among key stakeholders in the field and guides the development, selection and implementation of HIV-specific PROMs in HIV R&D

- Community representatives are involved in all stages of the development of new HIV-specific PROMs according to the recommendations from this project
STEPS: HIV Cure Community Workshops

EATG contact person(s): Giorgio Barbareschi - giorgio.barbareschi@eatg.org
Duration of the project/initiative: November 2014 - ongoing
Project/Initiative Leader: EATG
Project/initiative Main Partner(s): Glasgow HIV Congress / EACS
Budget: Varies by year
Main Funding Sources: Industry partners
Links: n/a
Communication Disclaimer: Depending on the funder

Why?
In recent years, there has been a renewed scientific focus on therapeutic strategies for long term drug-free remission from HIV infection. This type of research is very important and is widely supported by both the scientific and advocacy communities. However, it raises critical issues such as minimizing risk for analytical treatment interruptions and restarting therapy, assessing benefit-risk balance, managing the expectations of the participants, providing update and reliable information accessible to the participants and the community at large.

What?
The STEPS workshop brings the discussion on the importance of patient involvement from the very earliest phases of the development of this innovative research. The objective is to improve participation, exchange of information and knowledge about research on therapeutic strategies for long term remission from HIV and the possible dissemination among the European activists and the community at large. The workshop presents an overview about investigational strategies used in the HIV cure and vaccines field, analyses in depth the mechanism of persistence and intervention to reduce the size or eradicate the HIV reservoirs, brings to the discussion psychosocial and ethical questions related to the participation to trials and to the potential achievement of a cure for HIV.
With whom?
The workshop is led by EATG and is primarily of interest for the community of people living with HIV, but aims to engage with a wide range of stakeholders including: peer educators, community journalists, advocates, industry partners, academic researchers and healthcare professionals with an interest in the scientific research for the long-term drug-free remission of HIV infection.

How?
Since 2014 a yearly workshop is organised by EATG ahead of or as part of the programme of the main European HIV scientific events (HIV Glasgow Congress and EACS Conference).

For what outcome?
The workshop is an opportunity to expand the dialogue among community members, researchers and other relevant stakeholders in order to promote the share of knowledge, information, experiences from different perspectives and promote community engagement in research on the HIV cure and related topics.
Project/Initiative Summary

Related Programme: Quality of Life / Combination Prevention

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

EATG contact person(s): Sarah North – sarah.north@eatg.org
Duration of the project/initiative: March 2021 - September 2022
Project/Initiative Leader: EATG
Project/initiative Main Partner(s): ICRSE - International Committee on the Rights of Sex Workers in Europe (https://www.sexworkeurope.org/)
LEGEBITRA - Association Cultural, Informational and Counseling Center Legebitra (https://legebitra.si/en/)
Budget: 78,398 €
Main Funding Sources: ERASMUS+
Links: n/a
Communication Disclaimer: n/a

Why?
The response to the COVID-19 pandemic around Europe has caused several NGO’s engaged in providing support to vulnerable groups to either completely stop, postpone or adapt their activities. Organisations working with vulnerable populations, have experienced extreme difficulties and pressure due to restrictions and sanitary emergencies causing severe limitations of resources to advocate for the needs and rights of those populations. This might have resulted in increased feelings of isolation, helplessness and risks for physical and mental health for their members and users. In these circumstances building the capacity of young advocates is of extreme urgency, and is challenged by the fact that the task has to be almost exclusively transferred online.

What?
The project will focus on an adapting training activity for young advocates/activists, offered by organisations working in the field of sexual health (HIV and coinfections, sex workers, LGBTI) to the new virtual reality (as a consequence of COVID-19). It will have a specific focus on mental health as the trainings are not only providing knowledge, online safety & digital rights’ (data protection, privacy issues, censorship) which can be relevant to young stigmatised or criminalised populations, but also personal growth. It will also create an online youth activist toolbox, which can be used by partners in the projects and by any other youth activist or organisation it may be relevant to. The project will develop an online platform that will act as an exchange of best practices for youth training programmes between organisations. Create online tools/trainings that would be useful for youth advocacy work in the field of human rights/organisations led by key populations.

**With whom?**

ICRSE- network of sex worker organisations and allies supporting the development of national and international law, policy and practice, which respects and upholds the human and labour rights of sex workers throughout Europe and Central Asia.

LEGBITRA- Local Slovenian LGBTI+ NGO, offering counselling (including online), active on HIV and sexual health, working with youth.

The project will target young advocates working or volunteering in the field of sexual health, to address the challenges of the key populations (sex workers, people living with HIV, and LGBTI persons).

**How?**

Through the project activities, and the following intellectual outputs (IOs), the project will result in a clear and implementable model of online training provision for young advocates with a focus on sexual health, as well as a freely accessible online toolbox of guidelines.

**IO 1: Needs assessment and recommendations.**

The project will conduct desk research and quantitative and qualitative research will be conducted to inform the design of future activities with the needs of the key populations.

**IO 2: Written recommendations.**

The needs assessment will provide a solid base for written recommendations. Following that, the project will conduct an online training for trainers to train them according to the written recommendations, which will be updated after the training. The written recommendations will serve as a guide for how to conduct trainings online for youth activists.

**IO 3: Training programme outline and training materials.**

Once the trainers are trained, the project team will conduct a pilot training to test the written recommendations in a real setting. The team will work together with the trainers to develop the training programme outline and training materials.

**IO 4: M&E Framework.**
In parallel, evaluation will be done with training participants before, during and after conducting the training. The project team will prepare an M&E framework to assess the impact of the training activities.

IO 5: Guide for assuring psychosocial well-being during online trainings.
According to the chosen methodology, the psychosocial aspect will be measured during the pilot training. A guide for assuring psychosocial well-being during online trainings for youths with clear recommendations will be written after completion.

IO 6: Youth activist training materials online toolbox.
All partners together will select and review the materials, that are relevant for young activists working in the field of HIV, sex work or in the LGBTI field. The online toolbox will be freely accessible.

IO 7: Video presenting the toolbox and project outcomes.
The project will record a video that will be widely shared by project partners and their networks, to provide an introduction to the toolbox and further information on the project outcomes.

For what outcome?

- To develop an online platform that will act as an exchange of best practices for youth training programmes between organisations.
- To create online tools/trainings that would be useful for youth advocacy work in the field of human rights/organisations led by key populations.
HIVACAR – Evaluating a Combination of Immune-Based Therapies to Achieve a Functional Cure of HIV Infection

EATG contact person(s): Giorgio Barbareschi - giorgio.barbareschi@eatg.org
Duration of the project/initiative: January 2017 – Summer 2022
Project/Initiative Leader: Consorci Institut d’Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS), Spain
Project/initiative Main Partner(s): eTHERNA NV (eTheRNA), Belgium, Fundació Privada Institut de Recerca de La Sida-Caixa (IRSICAIXA), Spain, Aarhus University Hospital Skejby, Denmark Institute of Clinical Medicine, Aarhus University (AARHUS), Denmark, Vrije Universiteit Brussel (VUB), Belgium, Laboratory of Molecular Immunology, The Rockefeller University (LMI), US, Centro Nacional de Biotecnología, CSIC (CNB), Spain, Faculty of Health Sciences, Simon Fraser University, Burnaby, British Columbia Centre for Excellence in HIV/AIDS (SFU), Canada, EATG, Facultad de Ciencias Económicas y Empresariales. Universidad Complutense de Madrid (UCM), Spain, European Clinical Research Infrastructure Network- European Clinical Research Consortium (ECRIN-ERIC), France, Asphalion, S.L. (ASPHALION), Spain, Assistance Publique Hôpitaux de Paris (APHP), France, Zabala Innovation Consulting, S.A (ZABALA), Spain, Aelix Therapeutics, S.L. (AELIX), Spain
Budget: Total: 6.685.111 € / EATG: 150.000 €
Main Funding Sources: The European Commission - Horizon 2020 (Call H2020-SC1-2016-RTD)
Links: http://www.hivacar.org/
Communication Disclaimer: This Project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 731626

Why?
Currently, over 36 million people worldwide are infected with HIV, most of them living in developing countries1. In 2014, 1.2 million people died of AIDS-related illnesses. Combined
Project/Initiative Summary

antiretroviral therapy (cART) has proven to be highly effective to prevent clinical progression and death, but HIV-1 infection is considered a chronic disease and antiretroviral treatment on its own is unable to eradicate the infection. The patients hence necessitate therapy throughout their lives. Moreover, viral resistance development, adverse effects in the medium-long term, and its significant cost are important limitations for lifelong adherence to antiretroviral treatment and for widespread use mainly in developing countries, but also in the developed world. Therefore, for an effective control of the HIV epidemic new cost-effective and viable therapeutic strategies need to be evaluated. A safe, affordable and scalable cure could address both the individual and public health limitations that are associated with lifelong cART.

What?
HIVACAR aims to provide a new therapeutic alternative to “cART for life” (combined antiretroviral therapy) and will address the individual and public health limitations associated with this standard of care:

- Cost of the medication.
- Mandatory high adherence to medication for life.
- Side effects.
- Risk of resistances development.

An innovative strategy based on the patient’s immune system, safe, affordable and scalable to achieve the functional cure of HIV-1 infection will be tested in a Phase I / IIa clinical trial. In addition, the ethical, economic and psychosocial challenges associated with a functional HIV cure will be investigated to provide a complementary alternative to the current treatment standard.

With whom?
You can find the project partners here.

How?
The project has been divided into seven Work Packages that will lead to the achievement of the ambitious goals of HIVACAR:

1. Scientific coordination and project management
2. Design of a personalized mRNA vaccine
3. Clinical Trial Management and Development
4. Clinical Trial Phase IIa implementation
5. Data Analysis
6. Socio Economic and Psycho-Social Impact and Patient Engagement
7. Dissemination and exploitation

EATG is co-leading with the Computense University of Madrid (UCM), the research on economical and psychosocial challenges associated with a functional HIV. The project takes in account the view of the patient for the design of the clinical trial, the ethical problems raised
by a functional cure or the generation of false and high expectations but also the socio-economic consequences of the new approach compared with the traditional therapies. EATG is ensuring the real participation and engagement of patients and other stakeholders. EATG is also involved in the dissemination and communication of the project, the research and the concept to HIV community, policy makers and the general public in Europe.

**Involvement of EATG:** Leaders for WP6 (Socio-Economic and Psycho-Social Impact and Patient Engagement); Contribution for WP4: Clinical Trial phase I/IIa Implementation and WP7: Dissemination and Exploitation

**For what outcome?**

The main goal of HIVACAR is to change the current paradigm of HIV treatment by obtaining a functional cure for HIV by effectively targeting residual virus replication and viral reservoirs. In order to do so, the proposed novel strategy is to successfully combine immune-based therapies, including therapeutic vaccines and broadly neutralizing antibodies with latency reversing agents. HIVACAR project has been conceived under the framework of responsible research and innovation, so patients and other stakeholders will have a key role from the inception of the project until obtaining the results. Patients will be perfectly aware of how this therapy has been conceived and how it could impact and change their actual quality of life. They will also be informed of how the clinical trial has been designed and the consequences of participating in it. In addition, patients (and the general population) will tailor the project’s results dissemination and communication. This patient engagement will not be limited to the clinical trial but also to the rest of the activities of the project, so patients and the general society will be aware of how the research is developed and can include the patients’ point of view in the research activities. In addition, the socio-economic and psycho-social impact of the new treatment will also be analysed so that data on the benefits and impact of the new treatment will be obtained and made available to all the stakeholders.
EHVA – European HIV Vaccine Alliance, an EU Platform for the Discovery and Evaluation of Novel Prophylactic and Therapeutic Vaccine Candidates

EATG contact person(s): Giulio Maria Corbelli - giuliomariacorbelli@gmail.com
Giorgio Barbareschi (office) - giorgio.barbareschi@eatg.org

Duration of the project/initiative: January 2016 - December 2022

Project/Initiative Leader: Institut national de la santé et de la recherche médicale (INSERM)

Project/initiative Main Partner(s): Involves 39 institutions including Universities, Research Institutes, SMEs, and larger industries

Budget: 50,000 €

Main Funding Sources: EC Horizon 2020

Links: http://www.ehv-a.eu/

Communication Disclaimer: This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 681032

Why?
With 37 million people living with HIV worldwide, and over 2 million new infections diagnosed each year, an effective vaccine is regarded as the most potent public health strategy for addressing the pandemic. Despite the many advances in the understanding, treatment and prevention of HIV made over the past 30 years, the development of broadly effective HIV vaccine has remained unachievable.

What?
The European HIV Alliance (EHVA) is a project funded by the European Union’s Horizon 2020 Research and Innovation Programme designed to foster the development of an effective vaccine. The EHVA encompasses 41 partners, each with the expertise to promote a comprehensive approach to the development of an effective HIV vaccine. The international alliance, which includes academic and industrial research partners from all over Europe, as well
as sub-Saharan Africa and North America, will work to discover and progress novel vaccine candidates through the clinic.

**With whom?**

Drawing from 39 partner organizations, EHVA encompasses expertise in the fields of molecular biology, structural biology, vectorology, adjuvants delivery, immunology, clinical science, biostatics and social science. The alliance is devised to approach the challenges that have hindered the development of a broadly effective vaccine, to date, from all possible angles. The 39 partnering organisations are located in 16 different countries (11 in Europe, 4 in Sub-Saharan Africa and the US) and the alliance includes academic centres of excellence, leading pharmaceutical companies, start-up companies, a non-profit product-development partnership (the International AIDS Vaccine Initiative), and EATG as community and non-governmental organization.

**How?**

EHVA is structured into 12 work packages:

1. Coordination and Management
2. Vaccine Discovery – Novel Envelope Proteins
3. Vaccine Discovery – Non-viral and viral-vectors
4. Non-Human Primate Studies
5. Vaccine Development
6. Immune Profiling
7. Virological Monitoring
8. Prophylactic Vaccine Trials
9. Therapeutic Vaccine Trials
10. Data Integration and Down Selection
11. Dissemination and Exploitation
12. Partnership Building with EDCTP

**EATG is involved in** providing community input in the therapeutic vaccine trials, and in the scientific committee and the data and safety monitoring board (DSMB); EATG is also a community partner in ensuring community feedback to the scientific developments within the project.

**For what outcome?**

To develop a Multidisciplinary Vaccine Platform (MVP) in the fields of prophylactic and therapeutic HIV vaccines. The MVP includes four components: 1) Discovery, 2) Immune Profiling, 3) Data Management, Integration and Down-Selection, and 4) Clinical Trials.
EUPATI - European Patients’ Academy on Therapeutic Innovation

EATG contact person(s): Fiona Greenhalgh - fiona.greenhalgh@eatg.org
Duration of the project/initiative: Since 2012
Project/Initiative Leader: European Patients Forum (EPF)
Project/initiative Main Partner(s): EUPATI is a public-private partnership composed by a collaborative multi-stakeholder representing patient organisations, not-for-profit, pharmaceutical industry and academic institutions. The updated list of partners is available on https://eupati.eu/about-us/contributors/
Budget: In-kind contribution (staff time: 5,000 € in 2020)
Main Funding Sources: Industry, public partners and EIT
Links: https://www.eupati.eu/
Communication Disclaimer: n/a

What?
The European Patients’ Academy on Therapeutic Innovation (EUPATI) is a multi-stakeholder public-private partnership originally launched by the IMI-EUPATI project (2012-2017) and hosted by the European Patients’ Forum (EPF) from 2017 to 2020. EUPATI is today established as an independent Foundation in the Netherlands. It is a successful programme that provides education and training to increase the capacity and capability of patients and patient representatives to understand and meaningfully contribute to medicines research and development (R&D), and to improve the availability of medical information for patients and other stakeholders. It does so by conducting its established Patient Expert Training Course which has trained more than 150 patient experts (EUPATI Fellows), and with 60 more enrolled currently in the Course. In addition, EUPATI provides an open-access multilingual Toolbox that has served more than 4 million users around the world to date.

With whom?
The Patients’ Academy was started, developed, and implemented as a flagship project of the Innovative Medicines Initiative, and continues to be led by the European Patients’ Forum. EUPATI has already trained over 150 patient experts on medicines development, clinical trials, medicines regulations, health technology assessment. Additionally, EUPATI offers and maintains the Toolbox on Medicine Development and coordinates a network of national platforms for patient advocates. 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 form of in-kind contribution.

How?
EUPATI focuses on education and training to increase the capacity and capability of patients to be valuable contributors to medicines research and development by working with patients and the stakeholders they collaborate with, and also improve the availability of objective, reliable, independent, patient-friendly information for the public. EUPATI does not educate about disease-specific issues or therapies, but about the process of medicines development in general. Indication-specific information or specific medicine interventions are beyond the scope of European Patients’ Academy and are the remit of health professionals as well as patient organisations.

For what outcome?
EUPATI focuses on education and training to increase the capacity and capability of patients to be valuable contributors to medicines research and development by working with patients and the stakeholders they collaborate with.
EU-PEARL – EU Patient-Centric Clinical Trial Platform

EATG contact person(s): Fiona Greenhalgh - fiona.greenhalgh@eatg.org
Duration of the project/initiative: 42 months (started in November 2019)
Project/Initiative Leader: VALL D’HEBRON - INSTITUT DE RECERCA (VHIR), Industry co-leader: Janssen and Novartis
Project/initiative Main Partner(s): 36 public and private partners
Budget: 26,000,000 €
Main Funding Sources: IMI (Innovative Medicines Initiative 2 programme): European Union and the European Federation of Pharmaceutical Industries Association (EFPIA)
Links: https://eu-pearl.eu/
Communication Disclaimer: EU-PEARL has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 853966-2. This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA

What?
EU-PEARL has the ambition of transforming the current approach of conducting single-compound clinical trials into the use of cross-company Integrated Research Platforms (IRPs), taking into consideration both patients’ interests and the opportunities from novel molecules for addressing medical needs. Patient-centric data and knowledge sharing have the potential to accelerate the development of new treatments and reduce the operational costs of clinical trials. EU-PEARL will improve clinical effectiveness, patients’ satisfaction and societal access to timely and affordable medicines and it will shape the clinical trials of the future. This will change the industry paradigm from competition to cooperation in four disease areas and provide the framework for designing IRPs in other disease areas.

With whom?
EU-PEARL is engaging with patients from the start to co-design the platform trial framework, and in that way, bring on board more patient-relevant outcomes. EATG’s role in the project is...
to coordinate the Patients Advisory Group (PAG) and monitor patients' involvement throughout various work packages.

**How?**

One of the ways we are ensuring that patients are real partners in the project is by inaugurating two consultative bodies – a Patient Advisory Group (PAG) and an Expert Advisory Group (EAG). The PAG is coordinated by the European AIDS Treatment Group (EATG), which is an external partner to the EU PEARL project, brought on board to support in coordinating the PAG. The PAG comprises representatives per EU PEARL disease area, and two additional representatives from patient organisations. The PAG will bring the patient perspective to the work of the project, and will consult on the work of EU PEARL and the design of the platform, ensuring these are as patient friendly as possible.

**For what outcome?**

The main objectives of EU-PEARL are: (1) To create a reusable, accessible and sustainable modular IRP for the design and execution of patient-centric, cross-company IRP in any disease area with unmet needs; (2) To set up the open, dynamic, patient inclusive IRP governance structure that will manage the appropriate regulatory, ethical, legal, statistical and data utilisation requirements of the IRP; (3) To disseminate and exploit the EU-PEARL paradigm through the provision of the necessary common tools, procedures, expertise and operational skills working to the highest scientific, regulatory and ethical standards and best practices, developed jointly by public and industry partners in a consensus-based approach; and (4) To create trial-ready IRP networks in the four disease areas of Major Depressive Disorder (MDD), Tuberculosis (TB), Non-Alcoholic Steatohepatitis (NASH) and Neurofibromatosis (NF).
EATRIS+ - Flagship in Personalised Medicines

EATG contact person(s): Karina Huberman - karina.huberman@eatg.org
Duration of the project/initiative: 48 months (started in January 2020)
Project/Initiative Leader: EATRIS
Project/initiative Main Partner(s): 19 partners including all current national nodes of the research infrastructure, academic representatives of new prospective member countries as well as umbrella organisations representing the patients’ voice and biotech companies
Budget: 4,900,000 €
Main Funding Sources: IMI
Links: https://eatris.eu/projects/eatris-plus/
Communication Disclaimer: This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 871096.

What?
In the first five years of operations, EATRIS has shown strong proof of concept of the value of the services portfolio, with users ranging from academia, SMEs, large pharma, to biotech and research funding organisations. The overarching aim of EATRIS-Plus is to support the long-term sustainability (LTS) of EATRIS by delivering innovative scientific tools to the research community, strengthening the infrastructure’s financial model and reinforcing EATRIS leadership in the European Research Area (ERA), particularly in the field of Personalised Medicine (PM) research and development.

With whom?
The project comprises 19 partners including all current national nodes of the research infrastructure, academic representatives of new prospective member countries as well as umbrella organisations representing the patients’ voice and biotech companies EATG’s role in the project is to coordinate the Patients Advisory Committee (PAC).
How?
The omic tools will be developed and tested with a real-setting demonstrator, an already established cohort of 1,000 healthy individuals in Czechia upon whom genomic sequencing has been already performed. Information available on this healthy individual cohort will be augmented during the project with transcriptomic, proteomic and metabolomic data.

For what outcome?
By providing such toolbox to the research community, EATRIS-Plus will be the engine to enable high-quality research in the context of patient stratification and accelerate the implementation of Personalised Medicine solutions. EATRIS is the European Infrastructure for Translational Medicine providing services for accelerating biomedical innovation.

The main goals of the EATRIS-Plus will be to:

- Consolidate EATRIS capacities in the field of Personalised Medicine (particularly omics technologies) to better serve academia and industry and augment the number of EATRIS Innovation Hubs with large pharma;
- Drive patient empowerment through active involvement in the infrastructure’s operations;
- Expand strategic partnerships with research infrastructures and other relevant stakeholders, and
- Further strengthen the long-term sustainability of the EATRIS financial model.
Testing and Diagnostics

EATG contact person(s): Ann Isabelle von Lingen -annisabelle.vonlingen@eatg.org
Sarah North – sarah.north@eatg.org

Duration of the project/initiative: 2021 - 2022

Project/Initiative Leader: EATG

Project/initiative Main Partner(s): Community (AIDS Action Europe, Checkpoints, harm reduction services, service providers for trans, women, sex workers)
European initiatives (EuroTEST, European HepHIV Testing Week, European projects -e.g. INTEGRATE)
Agencies (ECDC, EMCDDA, WHO Europe, EU CSF HIV, Hepatitis, TB)
Industry (Molecular, rapid and self-tests, Foundation for Innovative New Diagnostics [FIND])

Budget: TBD

Main Funding Sources: -

Links: -

Communication Disclaimer: -

What?
In 2021, EATG will hold a series of online community workshops and dialogues between diagnostic developers/manufacturers and civil society to support the scale up of proven and innovative HIV, TB, viral hepatitis and STI testing at community level. It will conduct focused research regarding practical challenges currently surrounding point of care and/or self -testing/ sampling at the community centre level (i.e. price, regulation, etc.) and ways in which these are being overcome in various locations.

Why?
In line with EATG’s long-term strategy to empower affected communities to work in collaboration and to access the HIV, viral hepatitis, TB and STI prevention tools they need for prevention, treatment and care. EATG will implement a project focused on access to affordable, timely and quality testing tools for use in community settings.

The landscape of HIV, viral hepatitis, TB, and STI testing service delivery models continue to evolve alongside the introduction of novel biomedical technologies and evidence-based testing guidelines. As a result, community level and civil society organizations have been equipped with the tools to implement innovative diagnostic tools via non-traditional service models (i.e. community-based HIV testing services, HIV self-testing, and the endorsement of approved rapid and/or dual diagnostics). By optimizing the use of existing tools and building off of novel testing technologies and approaches, key populations have been provided with testing offer and access.

COVID-19 brought about challenges for HIV, viral hepatitis, and sexually transmitted infections testing activities in Europe, and its impact on stakeholders continues to be documented. During this time, the pre-existing structural barriers regarding the accessibility and implementation of novel diagnostics at the community level were amplified. Advances in accessible diagnostics/testing have been previously hindered by cost - at the production, marketing, and service delivery/health system(s) levels. Community based organizations (CBOs) have been previously identified as key players in priority population testing access, early diagnosis and linkage to care. While COVID-19 may have disrupted the delivery of testing services at community centres in Europe, there is growing evidence demonstrating CBOs establishing and enhancing testing uptake by initiating service delivery options such as self-testing/sampling and task shifting.

How?
EATG will organise a community briefing on diagnostics to bring members and partners up to speed with latest research and regulatory issues. EATG will bring together members to discuss innovative practices, challenges and possible joint actions. Then, it will organise bilateral dialogues meetings with developers to discuss needs and challenges. Such activities will facilitate a knowledge transfer exchange between community centres on challenges and successes regarding financing (devices and service delivery), advocacy (regulatory barriers), and capacity building (adapting in response to COVID-19).

For whom?
- Primary audience/stakeholders: EATG members and AIDS Action Europe /COBATEST Network, Correlations- European Harm Reduction Network EuroTEST /European Testing Week
- Secondary audience: Diagnostics developers/companies, FIND, WHO, ECDC
To be determined: community and civil society organizations providing screening services, clinical societies, diagnostics companies, other national/international public health agencies.

With whom?

- Community: AIDS Action Europe, Checkpoints, harm reduction services, service providers for trans, women, sex workers.
- European initiatives: EuroTEST, European HepHIV Testing Week, European projects (e.g. INTEGRATE)
- Agencies: ECDC, EMCDDA and WHO Europe, CSF
- Industry: Molecular, rapid and self-tests, Foundation for Innovative New Diagnostics (FIND)

For what outcome?

- These activities are intended to equip EATG members and partners with up-to-date information, and to build on their experiences to inform planning of services.
- Activities should also advance community dialogue with and access to diagnostics manufacturers.
- This may act as a bridge for future collaboration and communication between community centres, policy makers/decision makers, and diagnostics companies.
- The ECAB activity strives to integrate community perspective needs in the research and development of user-friendly diagnostic tools and testing policy.
2. Projects (recently concluded)
EATG COVID-19 Community Response
Adjusting to COVID-19 to ensure access to needed services for PLHIV and communities most affected by HIV

EATG contact person(s): Ann Isabelle von Lingen - annisabelle.vonlingen@eatg.org
                       Bojan Cigan - bojan.cigan@eatg.org
                       Fiona Greenhalgh - fiona.greenhalgh@eatg.org

Duration of the project/initiative: June-December 2020

Project/Initiative Leader: EATG

Project/initiative Main Partner(s): n/a

Budget: 20,000 £

Main Funding Sources: ViiV Healthcare UK Ltd

Links: https://linktr.ee/eatgcovid19

Communication Disclaimer: This initiative has been independently developed by EATG and was made possible through funding from ViiV Healthcare Europe Ltd. EATG acknowledges that ViiV Healthcare Europe Ltd have had any control or input into the structure or content of the initiative.

What?
Due to a health emergency situation, the COVID-19 pandemic responses in different countries have so far largely been top-down with minimal community input. Yet, disruptions in critical services have been reported. Communities are able to and have already identified innovative and tailored solutions in some locations to mitigate the impact of the crisis on people living with or affected by HIV. This project intends to further strengthen communities’ capacity to respond to existing and emerging needs of people living with and affected by HIV in the short to medium term.

EATG will continue documenting, in a structured manner, concerns and experiences in the field to understand the impact of the COVID-19 epidemic on persons living with and affected
by HIV and to improve the capacity of local organisations to respond to emerging issues. It will engage with European agencies, as well as policy makers and other relevant bodies, NGOs or companies. The project has a specific focus on sharing of approaches and practical solutions (e.g. online peer support, self-testing, remote consultations) and knowledge on HIV and COVID-19 between community organisations.

With whom?
The project will be carried out with people living with HIV and most affected by it, as well as persons involved in related service provision at community level. The project will cover the World Health Organization Europe region.

How?
EATG will research for and issue four community bulletins in English and Russian. Two rapid assessment bulletins already having been released (April and May), the third bulletin will be based on a short follow up research activity to capture improvements and deterioration of the situation (July). The fourth bulletin (September) will focus on HIV (co-infections and morbidities) care delivery. The fifth bulletin (October) will focus on combination prevention. The sixth bulletin (December) will document innovative solutions including digital services at community health service levels. It has a specific focus on sharing of approaches (e.g. online peer support, self-testing, remote consultations). These bulletins will be based on a small mapping exercise identifying issues of concerns by the communities and opportunities. The information will be gathered via a limited set of structured interviews and desk research.

EATG will organise online mutual learning sessions drawing on the highlights of the bulletins. The format and the specific audience may vary according to the topic.

The findings of the community monitoring will be used for advocacy with relevant stakeholders, (i.e. communities, NGOs, policy makers, industry) directly and/or via our communication channels. This includes collaboration with the EU Civil Society Forum on HIV, TB and Hep, European Patient Forum, European Public Health Alliance and other disease-related organisations. EATG will use its different communication channels to disseminate project outputs and results.

EATG will continue moderating the public Facebook group ‘HIV/co-infections and COVID-19 Resources’ with scientific and policy updates; outputs and promotions for activities of the project, as well as community activities by third parties.
EMERGE – Evaluating mHealth Technology in HIV to Improve Empowerment and Healthcare Utilisation: Research and Innovation to generate Evidence for Personalised Care

EATG contact person(s): Brian West - brian.west@eatg.org
Ann Isabelle von Lingen -annisabelle.vonlingen@eatg.org

Duration of the project: May 2015 - September 2020

Project/Initiative Leader: University of Sussex (UOS)

Project/initiative Main Partner(s): University of Sussex (UOS) UK; European Aids Treatment Group (EATG) DE; University of Brighton (UOB) UK; Institute of Tropical Medicine Antwerp (ITM) BE; Podmedics (POD) UK; Fundacio Privida Clinic per a la Recerca Biomedica (FCRB) ES; Brighton and Sussex University Hospitals NHS Trust (BSUHT) UK; Centro Hospitalar Lisboa (CHLN) PT; Klinika za Infektivne Bolesti (KIB) HR; National Prospective Monitoring System (NPMH) UK; Universidad Politecnica de Madrid (UPM) ES; mHealth Futures SME (mHF).

Budget: Total: 5,457,483 € / EATG: 490,500 €

Main Funding Sources: EC Horizon 2020

Links: http://www.emergeproject.eu

Communication Disclaimer: The EmERGE Project has received funding from the European Union’s Horizon 2020. Research and Innovation Programme under Grant Agreement No:643736

Why?
The management of HIV and co-morbidities still requires regular clinical monitoring. Efforts are being made to reduce the impact of this in the everyday lives of People Living with HIV (PLHIV). eHealth tools have emerged as part of these efforts to support self-management and care by enabling remote access to health care providers.

What?
EmERGE has developed a mHealth platform to enable self-management of people living with stable HIV. The platform builds upon and integrates the existing mHealth solutions operated by pioneering healthcare providers in the UK and Spain and applies a rigorous co-design approach to ensure patient and clinician input to the solution.

With whom?
The platform provides users a mobile device application which interfaces securely with relevant medical data and facilitates remote access to key healthcare providers. EATG, the European HIV patient organisation, are providing a direct and deep interaction with representative patients and clinicians from 5 EU countries.

How?
EATG was the leader of WP8 – Dissemination and Popularisation. It has:

- established a website for EmERGE serving internal and external communication to interested parties
- provided regular updates and sharing of good practice and opportunity for discussion by beneficiaries during the EmERGE programme
- continued to disseminate study results to HIV patient community, the HIV scientific community and the mHealth technology communities.
- Initiated informing policy at national, European and wider international levels of the benefits of mHealth in HIV and potential extrapolation to other areas (geographical including developing countries, other chronic diseases).

EATG was also involved in WP2 - Co-Design and Sociotechnical Evaluation.

For what outcome?
Based on prior work showing a high uptake rate and use of mHealth in HIV patient populations, EmERGE demonstrated the benefits to patients and simultaneous increases in cost-effectiveness for healthcare providers by reducing face-to-face consultations, estimated at least 2,250 saved within this study alone.
PARADIGM - Patients Active in Research and Dialogues for an Improved Generation of medicines

EATG contact person(s): Karina Huberman - karina.huberman@eatg.org
Giorgio Barbareschi - giorgio.barbareschi@eatg.org

Duration of the project/initiative: March 2018 to November 2020

Project/Initiative Leader: European Patients’ Forum (EPF) and the European Federation of Pharmaceutical Industries and Associations (EFPIA)

Project/initiative Main Partner(s): Patient organisations (EPF, EURORDIS, EATG, Alzheimer Europe), Regulators/HTA/Payers (AIFA, HTAi), Academics (CASMI, INSTITUTO ARAGONES DE CIENCIAS DE LA SALUD, Athena Institute, FOUNDATION SAN JOAN DE DEU)
SMEs (SYNAPSE, SYNERGIST), EFPIA
Companies/corporate associations (BAYER, MSD, MERCK, UCB, AMGEN, GRÜNENTHAL, GSK, JANSSEN, LILLY, LUNDBECK, NOVO NORDISK, PFIZER, ROCHE, SERVIER, SANOFI, NOVARTIS, COVANCE, ALEXION, ABPI, VFA),
NGO (EFGCP)

Budget: Total: 4,498,931 € / EATG: 381,750 €

Main Funding Sources: Innovative Medicines Initiative (IMI)

Links: http://imi-paradigm.eu/

Communication Disclaimer: PARADIGM is receiving funding from the Innovative Medicines Initiative Joint Undertaking 2. This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA.

Why?
There is increasing consensus among stakeholders that patient engagement at different points of the medicine’s lifecycle is critical to fostering patient access to innovative therapeutic
solutions and delivering better health outcomes for patients. Despite such development, patients continue to be a largely underutilised resource in medicines development. While there are many initiatives emerging to involve and engage with patients, inconsistency and fragmentation remain the norm. For key stakeholders, such as researchers/drug developers, regulatory authorities, HTA bodies (reimbursement agencies), pertinent and basic issues across all groups are: who should be involved, how and when.

Meaningful patient engagement brings mutual benefit to the community of medicine developers (meaning all stakeholders involved from the patients, industry, regulators, HTA bodies to the payers), and requires inputs into decision-making, co-production and dissemination of knowledge.

What?
The overarching mission of PARADIGM was to develop a framework that allows structured, meaningful, sustainable and ethical patient engagement throughout three key decision-making points of the development of medicinal products (prioritisation of research, early dialogue between regulators and HTA and design of clinical trials).

The framework included consensus-based recommendations on processes, tools (with the creation of templates) and methods to measure and demonstrate the added value of innovative and effective approaches to patient engagement.

Paradigm addressed the current situation by delivering:

- Tools and practices: a set of comprehensive tools and practices, that was built upon, and aligned with, amongst others existing EUPATI and PFMD platforms, in order to support mainstreaming the integration of patient perspectives and experiences while enhancing mutual trust among the different stakeholders in the patient engagement process
- Metrics for impact: developed agreed patient engagement metrics with validated tools to increase evidence demonstrating the impact of patient engagement practices

With whom?
The consortium Is composed by 34 partners: 4 European patient organisations; 2 Competent authorities; 3 Academic teams; 1 Non-profit organisation; 2 SMEs; 1 Hospital; 21 Industry partners: 3 associations, 17 bio-pharmaceutical companies, 1 contract research organisation.

How?
EATG was co-leader of WP4 (Co-designed recommendations and resources for patient engagement) and involved in all the other work packages as well.

1. WP1: Defining stakeholders’ preferences, needs and expectations
2. WP2: Assessment of practices and processes
3. WP3: Development of metrics for monitoring and evaluation
4. WP4: Co-designed recommendations and resources for patient engagement
5. WP5: Dissemination and engagement
For what outcome?

The main outcome of the PARADIGM project is the Patient Engagement Toolbox created under the co-leadership of EATG. The Patient Engagement toolbox centralises all PARADIGM’s co-created recommendations, tools and relevant background information to make patient engagement in medicines development easier for all. The material is organized under three layers:

1. Planning Patient Engagement
2. Conducting Patient Engagement
3. Reporting and Evaluation

Browse from the link below for the tools you might need, on the page of each tool you can find a version of the document in Russian:

https://imi-paradigm.eu/petoolbox/
EFOEUPATI - Ensuring the future of EUPATI beyond 2020

EATG contact person(s): Giorgio Barbareschi - giorgio.barbareschi@eatg.org
Duration of the project/initiative: September 2018 - September 2020
Project/Initiative Leader: European Patients Forum (EPF)
Project/initiative Main Partner(s): Irish Platform for Patients’ Organisations Science and Industry Limited by Guarantee (IPPOSI), European AIDS Treatment Group, European Forum for Good Clinical Practice (EFGCP), Kobenhavns Universitet (UCPH), AbbVie, Bayer, GSK, Novo Nordisk, Novartis, Pfizer, UCB
Budget: 31.487,50 €
Main Funding Sources: Innovative Medicines Initiative (IMI)
Links: https://www.eupati.eu/efoeupati/
Communication Disclaimer: This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 806995. The JU receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA.

Why?
IMI’s EUPATI project delivered a wealth of resources to support and educate patients who wish to become more involved in medical research and drug development. These include the patient expert training course, the online multilingual toolbox, and the network of national platforms. The goal of EFOEUPATI was to develop a viable business model to ensure the viability of these resources in the medium to long term. Among other things, the project created a patient education and engagement portal that will hosts relevant information and resources for patients and other stakeholders. This has ultimately replaced the current EUPATI website. EFOEUPATI has also strengthened the coordination and impact of the existing EUPATI national platform network by promoting collaboration and knowledge exchange.

What?
EFOEUPATI sought 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 was co-led by the European Patients’ Forum (EPF) and Bayer and funded by the Innovative Medicines Initiative (IMI). EATG was one of the community partner and participated in developing a sustainability/ business model for the EUPATI activities.

With whom?
The Patients’ Academy was started, developed, and implemented as a flagship project of the Innovative Medicines Initiative, and continues to be led by the European Patients’ Forum. EUPATI has already trained over 150 patient experts on medicines development, clinical trials, medicines regulations, health technology assessment. Additionally, EUPATI offers and maintains the Toolbox on Medicine Development, and coordinates a network of national platforms for patient advocates.

How?
The project was organised in four work packages:

1. Project Coordination: it provided coordination between the different Work Packages and took decision that govern the direction of the project.
2. Sustainability: it developed a viable sustainability / business model for the medium – long-term future of EUPATI activities and objectives in the form of the European Patients’ Academy by identifying new funding sources and creating the necessary plans to exploit and implement them.
4. European National Platform: it strengthened the coordination of the existing network.

EATG participation: Project partner, co-leader of WP2 (sustainability).

For what outcome?
EFOEUPATI ensured the sustainability of the results of the EUPATI project, developed sustainable models of collaboration to ensure this, and put into place the infrastructure required for these to work, building on those already established under IMI-EUPATI.
Why?

Sex Workers remain a vulnerable population group that is difficult to reach by HIV prevention and treatment services. At local and national level there are only few Sex Work activists willing to assume a leading activist role. HIV activists on the other hand often lack the understanding of the specific vulnerabilities, needs and barriers that might prevent sex workers from accessing HIV services. Often sex workers are not connected to or represented in local HIV organizations which makes collaboration difficult. Current priorities of the HIV movement such as stigma and discrimination, access to services or PrEP are also rarely discussed in collaboration between Sex Work and HIV activists. Regional consultations on such topics are rare or inexistent.

What?
The aim of the project is to foster collaboration between sex work activists and HIV activists through two means. 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.

With whom?
Main target groups of the project:
- Sex workers
- Sex work advocates
- People living with HIV
- HIV advocates

How?
The project is an initiative of ICRSE and EATG and is implemented in partnership. Its first edition consists of a regional sex work and HIV activists training, bringing together 24 activists from 8 countries. The training is followed by national one-day trainings for local sex worker communities on topics related to HIV. Furthermore, the project includes the development of briefing papers on topics identified by the participants for advocacy and education purposes.

The training will cover the following topics:
- Introduction to HIV: HIV life cycle, transmission, treatment options, history of HIV
- HIV combination prevention
- Realities of sex work in Europe
- Needs and barriers of different groups of sex workers with regards to access to HIV services
- Specific vulnerabilities: stigma and discrimination, criminalization
- Collaboration possibilities between sex workers and HIV activists

For what outcome?
- An international network of Sex Work activists and HIV activists is created through the training that will support each other and assume a leading role in promoting the collaboration of sex workers and HIV activists.
- In 8 countries specific collaboration formats between sex workers and HIV activists are discussed and agreed upon to make HIV services more accessible to sex workers.
- Sex Work activism is strengthened and sex workers in 8 countries are empowered to take practical actions to make HIV services more accessible within their communities.
- HIV organizations in 8 countries sensitized about the specific vulnerabilities, barriers and needs of the local sex worker community.
- The project will directly reach 220 Sex Work activists and HIV activists.
- Three position papers are developed and presented at key conferences and events.
3. Initiatives EATG is involved in
ACHIEVE Coalition - Associations Collaborating on Hepatitis to Immunise and Eliminate the Viruses in Europe

Why?
The elimination of viral hepatitis B and C is amongst the stated goals of the UN and the WHO. However, Europe is yet to make significant progress. These viruses affect 28 million people in the WHO Europe region, most of whom are living without visible symptoms for decades before disease progression. As many as 171,000 deaths annually in the WHO Europe region are caused by two infections – hepatitis B virus and hepatitis C virus. Experts warn that the number of individuals affected will continue to increase in many countries across Europe over the next 15 years unless action is taken to prevent, detect, and cure these diseases. Countries must move to prevent infection, improve diagnosis across the spectrum of risk groups and ensure that direct acting antiviral treatment is affordable and accessible. Spending money today to control viral hepatitis will reduce costs later from its complications.
What?
This coalition of patients, community actors, clinicians and researchers has come together to mobilise European policymakers for eliminating viral hepatitis throughout the European neighbourhood, improving both patient outcomes and health systems’ sustainability (the implementation of the WHO Global Strategy, the WHO Europe Action for viral hepatitis elimination and the UN SDG, by means of a new Declaration, and adoption of an EU Policy Framework for Communicable Diseases.

How?
The coalition implements activities supporting the achievement of its objectives, including a political statement, published in a relevant; gather, interpret and leverage existing evidence to support the “case for viral hepatitis” and to provide guidance to policymakers; engage with and raise awareness among policymakers at European level and national level. The initiative organizes policy roundtable seminars, high-level discussion meetings with policymakers and various stakeholder events targeting decision-makers.

For what outcome?
- A declaration that sets policy expectations as regards prevention, screening, and detection, linkage to care, evaluation and surveillance of viral hepatitis and a monitoring framework.
- Active EU support to governments in achieving viral hepatitis elimination goals.
The Civil Society Forum on Drugs (CSFD)

EATG contact person(s): Marios Atzemis (member representing EATG)
Ann Isabelle von Lingen - annisabelle.vonlingen@eatg.org

Duration of the project/initiative: 2018 - 2020

Project/Initiative Leader: The CSFD is governed by a core group of 4 CSFD members


Why and What?
The Civil Society Forum on Drugs (CSFD) is an expert group of the European Commission that was created in 2007 on the basis of the Commission Green Paper on the role of civil society in drugs policy in the EU. Its purpose is to provide a broad platform for a structured dialogue between the Commission and the European civil society which supports drug policy formulation and implementation through practical advice. The CSFD is consistent with the EU Strategy on Drugs 2013-2020 and the new Action Plan on Drugs 2017-2020 both of which require the active and meaningful participation and involvement of civil society organisations (CSOs) in the development and implementation of drug policies, at national, EU and international level.

With whom?
CSFD membership comprises 45 CSOs from across Europe and representing a variety of fields of drug policy, and a variety of stances within those fields. Membership is renewed every three years, and the last call was in March 2018.

How?
The CSFD is governed by a core group, comprising the four Chairs of the working groups, along with a Chair and Vice-Chair of the forum itself, again elected by the members of the forum at the plenary.
The CSFD operates via four working groups:
- EU Strategy and Action plan on Drugs: A survey of the EU action plan from the perspective of civil society; a report; a resources section.
- Relations with International Institutions: policy papers and advocacy notes targeted at (primarily) EU actors; policy meetings.
- Civil Society Engagement with National Drug Policies: e.g. A survey and report on CSO engagement; Development of a database of CSOs involved in drug policy; Members have participated in the Pompidou Group and contributed to its paper on CSI
- Minimum Quality Standards in Drug Policy: an assessment tool which can be used by stakeholders to assess the extent to which the council conclusions are being implemented in their locality, and the production of a report based on the application of the assessment too.
The EU Civil Society Forum on HIV, TB and viral Hepatitis

EATG contact person(s): Frank Amort - frank.amort@eatg.org
Ann Isabelle von Lingen - annisabelle.vonlingen@eatg.org

Duration of the initiative: July 2020 - ongoing

Coordination: Correlation, Eurasian Harm Reduction Association, European AIDS Treatment Group, AIDS Action Europe, TB Europe Coalition/Global Health Advocates (transition coordination team)

Main Partner(s): 61 NGOs, 2 Parliamentarian Networks: UNITE, Global TB Caucus European Commission Agencies: ECDC, EMCDDA, UNAIDS, WHO

Main Funding Sources: Secretariat work funded by AAE via operating grant from EC

Links: https://www.csfhivheptb.eu/

Why?
Since its creation in 2005, the EU Civil Society Forum on HIV/AIDS and since 2017, the EU Civil Society Forum on HIV, viral hepatitis and tuberculosis (CSF), has been instrumental in providing and sharing critical information and evidence, in undertaking joint actions and creating synergies between its members. These activities have advanced policies and interventions improving the health and well-being of communities that are most affected by HIV, viral hepatitis and tuberculosis.

What?
The CSF is a body originally supported by the European Commission DG SANTE to facilitate the involvement of civil society in policy development and programme implementation. It seeks to provide a platform for mutual learning and strategic thinking to improve policies and their implementation; to strengthen advocacy for the rights of key communities living or affected by these infections; to contribute to the empowerment of community groups.
With whom?
Until 2019, the CSF was hosted at the EC Health directorate, which selected members, financed and facilitated bi-annual face-to-face meetings. In September 2019, the European Commission decided to close down the CSF as an expert group along with the EU Think Tank on HIV, viral hepatitis and tuberculosis, which brought together government representatives and health agencies.

In July 2020, the CSF coordination team re-launched the group via a call for applications, with an updated structure, operating mode and agenda to advance policies improving the health and well-being of the communities that its members serve. It will continue to work closely with the European Commission. Its members are not-for-profit organisations that are based in the WHO European region and whose main activities are related to the prevention, outreach and awareness raising, health support services, community services and/or other similar activities aimed at reducing the transmission or improving the quality of life of people living with HIV/AIDS, viral hepatitis (B and/or C) and/or tuberculosis are called to apply.

How?
EATG is one of the members of the CSF transition coordination team and EATG is supporting the secretariat functions.
The European Alliance for Responsible R&D and affordable Medicines

EATG contact person(s): Ann Isabelle von Lingen - annisabelle.vonlingen@eatg.org (several EATG members connected to the alliance)

Duration of the initiative: 2018 - ongoing

Coordination: European Public Health Alliance

Main Partner(s): More than 60 European NGOs

Main Funding Sources: Open Society Foundations and European Public Health Alliance

Links: https://medicinesalliance.eu

Why?
"In Europe and worldwide, the price of new medicines is rising year on year, especially where there is no therapeutic alternative. As a result, treatment for life-threatening infections and diseases, like HIV/AIDS, cancer and hepatitis C, are increasingly unaffordable for both individuals and national health systems. This is the result of an ineffective and costly research and development (R&D) system that rewards new medicines with fixed-term monopolies (patents) and encourages unaffordable price setting. This patent-based system grants pharmaceutical companies’ monopolies, which allow them to charge exorbitant prices totally unconnected to the cost of developing and manufacturing the medicines. Urgent measures must be taken to ensure that people can afford the medicines they need. At the same time, new models of R&D must be engaged to meet therapeutic needs."

What?
Started in 2014, “The European Alliance for Responsible R&D and Affordable Medicines is a civil society coalition gathering consumer, patient and public health organisations calling for the creation of an R&D system that is driven by public health needs and delivers medicines that are universally accessible and affordable. Read the Alliance Joint Declaration

With whom?
The Alliance consists of European and national consumer, patient and public health organisations. "The Alliance is supported by the work of its members as well as by the financial contributions from the Open Society Foundations and the European Public Health Alliance."
How?
Members exchange information on policy developments, advocacy approaches and join forces in joint statements and letters.

For what outcome?

- "New medicines that are safe, effective and offer real therapeutic progress.
- Relevant data is available in the public domain so it can be independently and transparently assessed.
- Pharmaceutical R&D is not be driven by monopoly protection, which results in high medicine prices.
- Pharmaceutical R&D results in public goods and medicines that are needed and affordable.
- The pharmaceutical policy process is transparent and developed in consultation with independent stakeholders to avoid conflicts of interest."
EuroTEST – Working Together for Optimal Testing and Earlier Care

EATG contact person(s): Ann Isabelle von Lingen - annisabelle.vonlinger@eatg.org

Duration of the project/initiative: Started in 2007 - ongoing

Secretariat: Rigshospitalet – University of Copenhagen - CHIP Department of Infectious Diseases, (Coordinating Secretariat); European AIDS Treatment Group (Advocacy Secretariat)

Steering Committee: The Steering committee is an independent group of HIV, viral hepatitis and sexually transmitted infections experts and is instrumental in helping achieve the aims and objectives of EuroTEST (formerly HIV in Europe).

Funding Sources: Gilead Sciences, ViiV Healthcare, Janssen, Merck/MSD, AbbVie, AAZ, Cepheid, InTec, OraSure and the European Commission under the 3rd and 2nd Health Programmes and European Centre for Disease Prevention and Control (ECDC).

Links: https://www.eurotest.org/

Why?
Even though combination therapy had been making an enormous difference for patients for more than a decade, HIV research in 2007 was still focused on what to do with people once they entered the clinic – not on getting them there. Therefore, that year, a group of clinicians, community activists, and other HIV organisations started a collaboration to barriers to testing, ensure early diagnosis and linkage to care on the policy agenda. It was called HIV in Europe.

What?
EuroTEST is a pan-European multi-stakeholder initiative that provides a platform for information exchange and activities to improve early diagnosis and care of HIV, viral hepatitis, sexually transmitted infections and tuberculosis. It aims to inform policy processes, share knowledge and improve the evidence base around important issues of earlier testing and care.
With whom?
The initiative is led by an independent group of experts from civil society, policy makers, health professionals and European public health institutions.

How?
The initiative implements projects. Current ones include:

**European Testing Week:** European Testing Week is a European campaign that encourages partner organisations—in community, health care and policy institutions—throughout Europe to unite for one week twice a year to increase testing efforts and promote awareness on the benefits of earlier hepatitis and HIV testing. [http://www.testingweek.eu/](http://www.testingweek.eu/)

**INTEGRATE Joint Action:** The INTEGRATE Joint Action seeks to increase integrated early diagnosis and linkage to prevention and care of HIV, viral hepatitis, TB and STIs in EU Member States by 2020. Integrate offers a platform to disseminate and exchange best practices among Member States and facilitate the discussions on innovations and emerging issues within these four diseases. Existing tools for prevention, testing and linkage to care for HIV, viral hepatitis, TB and STIs will be evaluated, adapted, extended and implemented for one or more of the four diseases in selected pilot countries. It is a shared European effort that aspires to extend beyond the partners to create important synergies across European stakeholders, projects and initiatives. [https://integrateja.eu/](https://integrateja.eu/)

**HepHIV conference:** these are biennial conferences on optimal testing and earlier care. The conferences bring together civil society, policymakers, health professionals and European public health institutions and provide these stakeholders with the opportunity to learn from each other and to reflect on experiences, achievements and challenges. The conference format includes a mix of plenary sessions, expert panel and roundtable discussions and moderated parallel sessions driven by submitted abstracts selected by the Conference Organising Committee based on a thorough review process. The next HepHIV Conference will take place in Lisbon, Portugal in 2021.

For previous projects of the initiative, see [here](#).

For what outcome?
The overall objective of EuroTEST is to ensure that people living with HIV, viral hepatitis, STIs or TB have access to testing and 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.
HIV OUTCOMES – Beyond Viral Suppression

EATG contact person(s): Mario Cascio - mario.cascio@eatg.org
Ann Isabelle von Lingen - annisabelle.vonlingen@eatg.org

Duration of the initiative: Started in 2017 - ongoing

Secretariat: Foresight International Policy and Regulatory Advisers (FIPRA)

Main Partner(s): Members of the Steering Group: AIDS Action Europe, AFEW International, East Europe & Central Asia Union of PLWH (ECUO), European AIDS Treatment Group (EATG), Homerton University Hospital NHS Foundation Trust, Positive Voice (Greek association for PLHIV), ISGlobal - Hospital Clinic - University of Barcelona, AIDES, Hannover Medical School, University of Milan, Gilead Sciences, ViiV Healthcare

Main Funding Sources: Gilead Sciences, ViiV Healthcare

Links: https://hivoutcomes.eu/

Why?
While important progress has been made in the global response to HIV/AIDS in Europe, the WHO European region – and in particular, Eastern Europe – now has the fastest growing HIV epidemic globally. At the same time, people living with HIV are living longer, it has created new challenges relating to the prevention, treatment, and management of comorbidities (co-existing medical conditions) as well as health-related quality of life. In an era when ageing populations and health system sustainability are central challenges for all European countries, HIV Outcomes also aims to promote innovative approaches to improve long-term health and quality of care in a sustainable manner, whilst ensuring patient-centred healthcare delivery. Governments and health systems must respond to the fact that people are living longer and ensure that they remain in good health as they grow older and can lead successful, productive, and rewarding lives.

What?
HIV Outcomes aims to address the needs generated by increased life expectancy, by looking to improve health outcomes and quality of life of people living with HIV in the long-term. It
does so by sharing evidence-based best practices and innovative approaches to care, while implementing policy and clinical changes in European countries.

**With whom?**

HIV Outcomes brings together patient organisations, medical professionals, academics, public institutions, and the private sector to mobilise the policy and clinical agenda to ensure that long-term health and wellbeing of people living with HIV is addressed beyond viral suppression. You can find the list of members here.

**How?**

In 2017, HIV Outcomes issued recommendations in the European Parliament on the long-term health, well-being and chronic care of people living with HIV with cross-party support. It has issued a compendium of best practices. In 2018, and call to action to European and national policy makers. In 2019, the initiative collaborates with actors at national level to facilitate local multi-stakeholder dialogue on the topic. In 2020, the Initiative will increase its focus on mental health and stigma discrimination. In 2020, it organized a webinar on the Health Policy Platform to discuss the key learnings from The Lancet HIV Series on HIV Outcomes: Beyond Viral Suppression, and explore their policy implications for the EU.

**For what outcome?**

The initiative seeks to help achieve long-term health and well-being of all people living with HIV across Europe – and thereby contribute to the sustainability of European healthcare systems.
**PREP IN EUROPE**

**EATG contact person(s):** Frank Amort - frank.amort@eatg.org

**Duration of the project/initiative:** Started in 2016 - ongoing

**Project/Initiative Leader:** NAM/Aidsmap

**Project/initiative Main Partner(s):** AIDES, AIDS Action Europe, AVAC, the European AIDS Treatment Group and NAM/Aidsmap


**Why?**
The PrEP in Europe Initiative was set up to fill a gap in campaigning and policy around HIV pre-exposure prophylaxis (PrEP) in Europe.

**What?**
The PrEP in Europe Initiative is a partnership of eight HIV prevention and policy organisations that work in Europe: AIDES, AIDS Action Europe, AVAC, the Eurasian Coalition on Male Health (ECOM), the European AIDS Treatment Group (EATG), NAM/Aidsmap, the National AIDS Trust and PrEPster

**With whom?**
PrEP in Europe is community partnership that also consult with advisors drawn from organisations such as the World Health Organization, UNAIDS, and The European Centre for Disease Control and Prevention (ECDC).

**How?**
It operates at four levels:
- **Information:** provision on information the science, provision, cost and usage of PrEP throughout Europe. As well as providing content itself it also supports “knowledge exchange” on PrEP.
- **Advocacy:** Build the skills and knowledge of advocates by providing advocacy materials and helping people in national campaigns to exchange ideas.
• Policy: challenge the institutional division between healthcare and public health seen in many health systems, and challenges received wisdom that influencing risk behaviour is the only effective and ethical way of prevention HIV.
• Networking: a centralised site where people involved in advocating for the wider availability of PrEP can meet, exchange ideas, and gain strength from each other’s good examples.

For what outcome?
The PrEP in Europe Initiative dedicated to increasing access to pre-exposure prophylaxis (PrEP) throughout the European region.
Nobody Left Outside - NLO
IMPROVING HEALTHCARE ACCESS FOR MARGINALISED PEOPLE

EATG contact person(s): Alina Dumitriu (member representing EATG)
Ann Isabelle von Lingen - annisabelle.vonlingen@eatg.org

Duration of the project/initiative: 2017 - ongoing

Initiative secretariat coordinator: INTEREL

Main partner(s): AAF, Correlations, EATG, FEANTSA, Hep C Trust, ICRSE, ILGA-Europe, ISGlobal, NPS Italia Onlus, PICUM

Budget: N/A

Main funding sources: MSD

Links: https://nobodyleftoutside.eu/

What?
The Nobody Left Outside (NLO) initiative is a collective of organisations representing people in some of the most marginalised communities in Europe, who are underserved with respect to healthcare. These communities include homeless people, LGTBI people, people who use drugs, prisoners, sex workers and undocumented migrants.

The NLO initiative provides a European-level platform for organisations to collaborate to identify shared challenges, exchange lessons and good practice, seek innovative solutions, and speak with a unified voice to offer guidance to improve healthcare access for the communities of people they represent – on the basis that nobody should be left outside

Why?
Some populations including homeless people, LGTBI people, people who use drugs, prisoners, sex workers and undocumented migrants, minorities at a significantly higher risk of poor health than the general population and are often in highly vulnerable situations. At the same time, they face significant challenges in accessing healthcare systems. Underserved groups are often described as ‘hard to reach’, whereas, from the perspective of users, it is frequently the services that are hard to reach. Pockets of best practice across the European
region show us that inequalities in service access are not inevitable and can be addressed. Successful models of community-based care are ripe for replication. Such innovative pilots prove what can be achieved with community engagement, in spite of limited resources. Coupled with political will, they could be used to inform service redesign and spark a paradigm shift towards more integrated, people-centred, and equity-based health care services.

How?
Activities to date include: NLO Platform meetings to identify common barriers and identify best practices; Health service redesign checklist; Policy incubation workshops; awareness-raising; Communication through journal articles and blogs; Advocacy through open letters signed by all NLO organizations and awareness-raising communications campaign; participation and presentation at policy meetings.

For what outcome?
Common challenges and promising practices to address them are identified, shared and promoted via evidenced-based recommendations for policies and guidance. These will inform services redesign and support the transformation of current health systems towards people-centred, efficient care including community-based care.
EmH Ltd. - EmERGE mHealth Ltd

EATG contact person(s): Marina Cognée - marina.cognee@eatg.org
Duration of the project/initiative: October 2020 – April 2021
Project/Initiative Leader: EmERGE mHealth Ltd
Project/initiative Main Partner(s): EATG
Budget: 7,200 €/year
Main Funding Sources: EmH Ltd.
Links https://www.emergemhealth.com/

What?
Building on the EmERGE project, a not-for-profit company, EmH Ltd. was created to bring forward the commercialisation and further development of the platform. The EmERGE project has developed a mHealth platform to enable self-management of people living with stable HIV. The platform provides users a mobile device application which interfaces securely with relevant medical data and facilitates remote access to key healthcare providers. The platform development has applied a rigorous co-design approach to ensure patient and clinician input to the solution. EmH is set to sustain co-design with the support of EATG.

With whom?
EATG will work with clinical sites and local organisations to support co-design in local update of the platform.

How?
EATG assists EmH to deliver and support the EmH Platform at clinical sites via different forms of support:

- Support for the clinic at each side and those community user groups who are working collaboratively to reach, where possible, agreed decisions about how the EmH platform is implemented and used locally
• Support for at least one representative of the local community groups per site to participate in an annual EmH user group meeting
• Encouraging EmH platform users at each site to give EATG feedback on the EmH platform, and then to share such feedback with EmH

For what outcome?
Based on prior work showing a high uptake rate and use of mHealth in HIV patient populations, EmERGE demonstrated the benefits to patients and simultaneous increases in cost-effectiveness for healthcare providers by reducing face-to-face consultations, estimated at least 2,250 saved within this study alone.
Project/Initiative Summary

Related Programme: Partners in Science

RESPOND

EATG contact person(s): Alain Volny-Anne (member representing EATG)
Giorgio Barbareschi – giorgio.barbareschi@eatg.org

Duration of the project/initiative: 2017 - ongoing

Initiative secretariat coordinator: CHIP (Centre for Excellence for Health, Immunity and Infections)

Main partner(s): AIDS Therapy Evaluation in the Netherlands Cohort (ATHENA); The Australian HIV Observational Database (AHOD); Austrian HIV Cohort Study (AHIVCOS); CHU Saint-Pierre (Belgium); EuroSIDA Cohort (Denmark); Frankfurt HIV Cohort Study (Germany); Georgian National AIDS Health Information System (AIDS HIS); Italian Cohort Naive Antiretrovirals (ICONA); Modena HIV Cohort (Italy); Nice HIV Cohort (France); PISCIS Cohort Study (Spain)

Budget: n/a

Main funding sources: The International Cohort Consortium of Infectious Disease (RESPOND) has received funding from ViiV Healthcare LLC and Gilead Sciences. Additional support has been provided by participating cohorts contributing data in-kind and/or statistical support: Austrian HIV Cohort Study (AHIVCOS), The Australian HIV Observational Database (AHOD), CHU Saint-Pierre, University Hospital Cologne, EuroSIDA, Frankfurt HIV Cohort Study, Georgian National AIDS Health Information System (AIDS HIS), Modena HIV Cohort, San Raffaele Scientific Institute, Swiss HIV Cohort Study (SHCS), AIDS Therapy Evaluation in the Netherlands Cohort (ATHENA), Royal Free HIV Cohort Study.

Links: https://chip.dk/Research/Studies/RESPOND/Study-group

Why?
RESPOND offers a research framework with a flexible organization, applying a common data model across different substudies, utilizing one shared data pool. Additionally, all involved in RESPOND can contribute to the ongoing scientific agendas. Together, these dynamic features facilitate responses to a broad range of unmet research needs.

What?
The International Cohort Consortium of Infectious Disease (RESPOND) was formed in 2017 as a prospective, multi-cohort collaboration for the study of infectious diseases, with a special focus on people living with HIV. RESPOND was founded upon the groundwork laid by outstanding European HIV cohort collaborations such as EuroSIDA, the Collaboration of Observational HIV Epidemiological Research Europe (COHERE) and Data Collection on Adverse events of Anti-HIV Drugs (D:A:D) studies, and utilizes a similar, well-established infrastructure.

How?
The large size of RESPOND consortium and a heterogeneous study population with participants from across the whole of Europe and Australia and a high degree of data quality ensure that the results are reliable and applicable to a broader population of people living with HIV. 17 cohorts are currently involved in the RESPOND consortium with over 30,000 individuals are under active follow up.

For what outcome?
RESPOND aims to address clinically relevant research questions, including the risk and outcomes of non-AIDS comorbidities and the possible relationship to long-term ART exposure; to the outcomes and treatment of viral hepatitis B (HBV), hepatitis C (HCV), and tuberculosis (TB) co-infections; and to support public health initiatives.
About the European AIDS Treatment Group:
The European AIDS Treatment Group (EATG) is a patient-led NGO that advocates for the rights and interests of people living with or affected by HIV/AIDS and related co-infections within the WHO Europe region. Founded in 1992, the EATG is a network of more than 150 members from 45 countries in Europe. Our members are PLHIV and representatives of different communities affected by HIV/AIDS and co-infections. EATG represents the diversity of more than 2.3 million people living with HIV (PLHIV) in Europe as well as those affected by HIV/AIDS and co-infections. For more information, please visit www.eatg.org