



Data Saves Lives

DATA SAVES LIVES IN THE SPOTLIGHT



### Data Saves Lives Celebrates Five Years of Impact

On the 26th and 27th of November, we gathered in Brussels for a special in-person event to mark the 5th anniversary of the **Data Saves Lives** (DSL) initiative. It was a joy to reconnect with friends and partners whose invaluable contributions have shaped DSL's mission over the years.

The diverse Data Saves Lives community exchanged on pressing topics, such as AI literacy in healthcare, patient-centred care decisions informed by HTA, patient registries, and digital health education, while looking towards the future of transparent and ethical use of health data.

The future of Data Saves Lives is clear: we aim to empower even more communities with tools and knowledge, not just about health data but also about the broader digital

#UNDERSTANDINGAMR



**Patient organisations have a crucial role as partners and multipliers in Antimicrobial Resistance awareness campaigns.**

#UnderstandingAMR

### European Antibiotic Awareness Day

#### **Antimicrobial resistance (AMR): how serious is the current situation in Europe?**

This month was marked by European Antibiotic Awareness Day (18th November), an initiative coordinated by the **European Centre for Disease Prevention and Control** (ECDC) to promote the prudent use of antimicrobials. This is an opportunity to consult the latest reports and data from the ECDC, which assess the AMR situation in Europe and recommend key measures to be taken.

#### **The year 2023 was marked by little progress towards the EU's targets for antimicrobial consumption**

As a reminder, EU targets call for a 20% reduction in the total consumption of antibiotics in humans by 2030. According to the ECDC, there has been slow progress, and the latest data show regress in many areas. The EU population-weighted mean total consumption of antibiotics was 1% higher in 2023 compared to 2019 (baseline year).

After unprecedented reductions during 2020 and 2021, antimicrobial consumption across the EU/EEA rebounded in 2022 and 2023. The ECDC explains this increase over the last few years by the lower intensity of the COVID-19 pandemic. *"Patterns of communicable diseases, social contacts, hygiene habits and antibiotic-prescribing practices may now be closer to what they were before the COVID-19 pandemic"*.

#### **The high burden of healthcare-associated infections**

In particular, ECDC's report points out the role of infections that patients get while or soon after receiving health care. For instance, the ECDC estimates that 1 in 14 patients in hospitals in the EU/EEA have at least one healthcare-associated infection; and over 70% of

Half of these healthcare associated infections could be prevented through adequate infection prevention and control measures (hand hygiene, alcohol-based hand rub, adequate number of specialised infection control personnel and sufficient number of single rooms).

### Antibiotics consumption in outpatient setting

The high burden of healthcare-associated infections does not mean that the situation outside hospitals does not contribute to AMR. The ECDC estimates that 90% of total human consumption of antibiotics is in the community sector (or outpatient setting). To patients, the ECDC recommends to avoid antibiotics when they are not needed (such as viral illnesses) and reminds that *"many infections can be prevented through hand hygiene, vaccination and other measures such as respiratory etiquette and physical distancing"*.

The ECDC concludes its report by pointing out that, at the current rate of progress *"it is unlikely that the EU will reach all its AMR targets by 2030"*, which will result in *"an increased number of infections with antimicrobial-resistant bacteria that will be more difficult to treat, leading to increasing challenges for patients and AMR-related deaths"*, and reminding us of the importance of stepping up our efforts to raise awareness of AMR among patients and other stakeholders.

With the goal of improving awareness and understanding of AMR among patient communities. EPF has launched, earlier this year, the **AMR Info Point** is dedicated to providing extensive resources on the topic. This dedicated resource point provides comprehensive information on AMR, including EPF statements, summaries of AMR webinars, access to the AMR communications toolkit, and links to relevant external resources.

## SECRETARIAT NEWS

### EPF'S FEEDBACK ON JOINT SCIENTIFIC CONSULTATIONS ON MEDICAL DEVICES, UNDER THE EU HTA REGULATION

This month, EPF provided feedback on the European Commission's public consultation on joint scientific consultations on medical devices, under the upcoming EU Health Technology Assessment (HTA) Regulation. Read the feedback [here](#).

### EPF JOINS A STATEMENT IN SUPPORT OF THE NSA ENGAGEMENT PLAN

EPF, the **European Public Health Alliance**, and the co-signatories of this statement express our strong support for the Non-State Actors (NSA) Engagement Plan presented at the **74th Session of the WHO Regional Committee for Europe**. [Read our full statement](#).

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## REACTION TO THE DRAFT IMPLEMENTING ACT ON JOINT SCIENTIFIC CONSULTATIONS ON MEDICINES

EPF welcomes the publication of the draft Implementing Act on Joint Scientific Consultations (JSCs) on medicines as a critical step towards securing mandatory, meaningful patient participation in EU health technology assessments. Read the full feedback to the public consultation [here](#).



## ENSURING CONSISTENT AND COHERENT APPLICATION OF EU RULES ON MEDICINES' ADVERTISING

EPF raises its concern about the fragmented interpretation of the current rules on the advertising of medicines. Reports from multiple EPF member organisations point to this inconsistency leading to unequal access to information for patients across Europe and restricting the activities of patient organisations. Read more [here](#).

# PROJECTS PORTAL



November is Lung Cancer Awareness Month and, to mark it, we are bringing under the spotlight the work conducted by project researchers at the ImmuneLandscape Laboratory (CHUV - Lausanne University Hospital) Stephanie Tissot-Renaud, Sylvie Rusakiewicz, Despland Lucie, Preethi Devanand and Abdelkader Benyagoub.

Their contribution consists in developing three 7-plex immunofluorescence panels, which enable in-depth analysis of the immune system in patients with lung cancer. These panels provide a comprehensive overview of the immune response, with a particular focus on T cells, specifically examining the polyfunctionality of CD8 T cells.

This approach helps us better understand the complexity of immune responses and identify potential biomarkers for personalised treatments.

Moreover, they have collected samples collected from three distinct cohorts of patients with non-small cell lung cancer (NSCLC):

- ◆ NSCLC1: patients with confirmed advanced or metastatic NSCLC (stages 3b and 4) who have not received any prior local or systemic cancer treatment.
- ◆ NSCLC2: the SPECTA Lung cohort, comprising treatment-naïve patients from stage 1 to

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peramivir, exploring whether lower dosages can be effective while allowing for more personalised treatment approaches.

Multiple research groups have already started to work on the rich dataset we have generated. These collaborations are key to uncovering new insights and accelerating progress in lung cancer treatment.

## MEMBER FOCUS

### EFA launched a new report to raise standards of COPD care in Europe

EFA launched 'Raising Standards of Care for COPD,' a new report shedding light on critical gaps in care for 36 million COPD patients in Europe. Despite being the third leading cause of death worldwide, COPD remains underdiagnosed and poorly managed, costing the EU €38.6 billion annually.



The report outlines persistent issues, including delayed diagnosis, limited prevention, and stark disparities in access to care. To address these, EFA outlines clear **policy recommendations** to improve early detection, expand access to multidisciplinary care and ensure equitable treatment across Europe.

This report is the result of a collective effort. We thank the EFA Community of patients and the COPD Working Group for their invaluable contributions, from national data to patient stories. Their insights highlight the challenges and progress in COPD care, putting patient realities front and center.

How can you make a difference? Help raise awareness by sharing the report and using #COPDStandardsOfCare on social media. Tag EFA on [LinkedIn](#), [Instagram](#) and [Facebook](#) to spread the message. Your support is essential in advocating for stronger care standards!

[Read the full report](#) and learn more about EFA's work [on their website](#).

### News from Europa Donna

**OCTOBER BREAST HEALTH DAY** - This initiative is aligned with the European Union's mission to improve the member states' ability to address cancer. This includes Europe's Beating Cancer Plan, which has prevention as its first pillar and outlines key strategies to tackle the 40% of cancer cases in Europe that are preventable.

[See the campaign.](#)



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from Stella Kyriakides, European Commissioner for Health and Food Safety, stressing the critical importance of continued breast cancer advocacy at the European level.

The conference provided specialised training for breast cancer advocates, with exceptional speakers sharing the latest insights and advancements.

**NOVEMBER – EUROPEAN CANCER SUMMIT:** Policy Officer, Martina Fontana, and Board Member, Ellen Verschuur, attended the European Cancer Summit for the final speech by Commissioner Stella Kyriakides.



### 7 MEPs participate in meeting of the MEP Interest Group on Brain Health & Neurological Conditions!

On 12th November 2024, the first post-election meeting of the MEP Interest Group on Brain Health and Neurological Conditions took place, hosted by Co-Chair MEP Romana Jerković (S&D, Croatia) at the European Parliament, Brussels. Titled '*Invisible Issues: Bridging the gap between the perception of neurological conditions and their true impact*', the event's main objective was to discuss the challenges of living with a neurological condition, the impact this has on the individuals and families affected, the impact on education and employment and to highlight where we need to do better in terms of policy development and implementation.

[Click here to read the meeting report.](#)

### Join EFNA's Community Advisory Board!

The European Federation of Neurological Associations (EFNA) is now accepting applications from those interested in joining their 2025 Community Advisory Board (CAB). The CAB is a group comprised of up to 12 dedicated patient advocates who will receive specialised advocacy training. Together with the core EFNA team, they will have the opportunity to engage with stakeholders such as policymakers, researchers and clinicians, representing the needs and priorities of people with neurological conditions. [Learn more and apply here.](#)

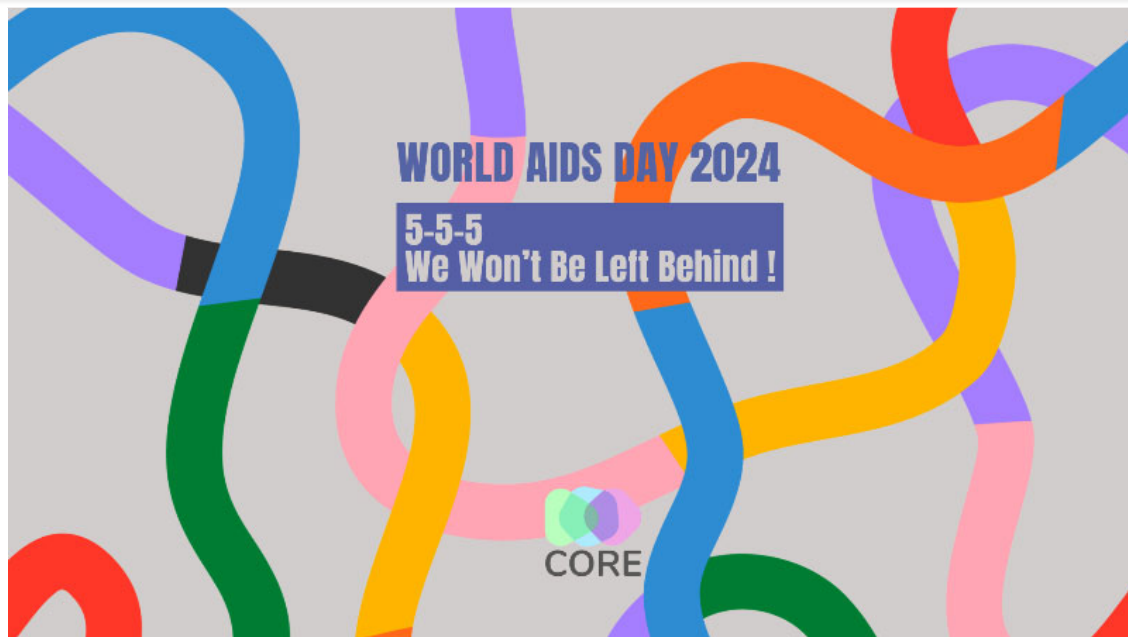
### New podcast episode looks at patient involvement in neuroscience research

In recent years, there has been growing recognition of the crucial role that patient organisations play in driving advancements in medical research and healthcare. In the [latest episode of the Brain Health Matters podcast](#), by the European Federation of Neurological Associations (EFNA), you'll hear why this is especially true in the field of neurology, where patients and their families face complex conditions that require innovative approaches to care. Listen to the episode at [www.efna.net/podcast-episode-research/](http://www.efna.net/podcast-episode-research/), or search for 'The Brain Health Matters Podcast' on [Spotify](#), [Apple Podcasts](#), or wherever you get your podcasts!

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## World AIDS Day 2024 | 5-5-5 – We Won't Be Left Behind

On this year's World AIDS Day, the European AIDS Treatment Group (EATG), Correlation – European Harm Reduction Network (C-EHRN) and Fundacja Edukacji Społecznej (FES) are organising a face-to-face roundtable in Warsaw (Poland). The roundtable takes place in the frame of CORE – COmmunity REsponse to End Inequalities. They aim to bring together policymakers, healthcare professionals, community leaders, civil society organisations, and international partners to discuss gaps, barriers, and potential solutions to achieving the 95-95-95 targets set by the UNAIDS by 2030 in Poland and in the region. Leading up to the 1st of December, we blast community messages from across Europe, reflecting on how no one is left behind in the fight to end HIV/AIDS and inequalities. Learn more about **5-5-5 – We Won't Be Left Behind – A national and regional roundtable**

### EATG at HIV Glasgow 2024

EATG was present at the **HIV Glasgow** congress in Glasgow, Scotland from 10th until 13th November 2024. EATG hosted a booth as well as co-organised a session on *Emerging Ethical and Participation Challenges in HIV Research and Development*. In addition, the workshop **STEPS 10: A Community**

## EATG calls for unified actions to address the interconnected crises of gender-based violence and HIV/AIDS

For the global campaign "16 Days of Activism Against Gender-Based Violence" (GBV) from 25th November to 10th December, the European AIDS Treatment Group (EATG) calls for immediate, unified actions to address the interconnected crises of gender-based violence and HIV/AIDS. This year's campaign theme, **"Towards Beijing +30: UNiTE to End Violence Against Women and Girls"**, underscores the urgency to eradicate all forms of gender-based violence towards the Sustainable Development Goals (SDGs). The campaign concludes on International Human Rights Day, a poignant reminder of the fundamental rights violated by both gender-based violence and the HIV/AIDS epidemic. For EATG, this period also includes World AIDS Day on December 1, providing a critical opportunity to highlight the intersecting impacts of GBV on HIV/AIDS.

### EU Civil Society Forum on HIV/AIDS, HEP and TB | Ageing and HIV – Webinar

The **CSF** organised a webinar to examine the specificities of older age for people living with HIV, what can be done to

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**Direction** took place prior to the official opening of the conference.

promising practices for integrated care. During the webinar, insights and perspectives are shared by representatives from various populations, including gay and other men having sex with men, people who use drugs, women cis and trans, transgender and gender-diverse populations. The expected outcome of the webinar is to identify and share innovative good practices in integrated care for older people living with HIV.

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