

A CALL TO ACTION BY THE HIV OUTCOMES INITIATIVE

## Improving Outcomes for People Living with HIV

This is a call to action for European governments, international organisations, patient organisations, and the wider health community to align on a new HIV policy agenda that addresses the crucial unmet needs of people living with HIV (PLHIV) – to ensure they can live longer in good health, and participate fully in society and the economy.

Current HIV policy frameworks rightly focus on prevention, diagnosis and effective treatment (viral suppression). However, there are other important health and social challenges faced by PLHIV – from the moment of diagnosis and throughout their lives – that require attention and action by policy makers and healthcare providers.

An integrated approach is needed to improve:

- Health outcomes – by addressing the increased risk that PLHIV will develop other medical problems (co-morbidities) – including mental health issues
- Social outcomes – in particular by combatting stigma and discrimination, and ensuring that PLHIV are able to secure and retain employment and housing

Effective action to improve outcomes, and reduce the health burden and costs associated with HIV, can bring meaningful economic benefits and reduce demands on European healthcare systems.

We call on the EU and Member States to:

1. Revisit the **Dublin Declaration** on Partnership to Fight HIV/AIDS<sup>1</sup>, and ensure that its monitoring adopts a 'life-long' approach to the health and social inclusion of PLHIV.
2. Identify and agree on **policy indicators** necessary to monitor and assess country performance in improving health and social outcomes for PLHIV.
3. Adopt in 2017 an **integrated EU Policy Framework** on HIV/AIDS, viral hepatitis and TB – thereby extending the focus of the EU Action Plan on HIV/AIDS, which comes to an end in 2016.

<sup>1</sup> Signed during the Irish EU Presidency (2004), with UN engagement, on 24 February 2004 by government and state representatives of European and Central Asian countries.

## BACKGROUND

Whilst important progress has been made in the global response to HIV/AIDS, with the European Union (EU) playing an instrumental role, the European region – and in particular Eastern Europe – now has the fastest growing HIV epidemic globally. 29,992 people were diagnosed with HIV in the EU/EEA in 2014. At the same time, PLHIV are living longer, which has created new challenges relating to the prevention, treatment, and management of co-morbidities.

With the EU Action Plan on HIV/AIDS having expired at the end of 2016, and the Dublin Declaration on Partnership to fight HIV/AIDS now more than a decade old, European governments and the EU institutions have an opportunity to make progress on their political commitment to fighting both the transmission of HIV, as well as its health and social impacts – including the Sustainable Development Goals (SDGs).

Continuing challenges include the strengthening of prevention programmes, reducing late diagnoses, ensuring equity and universality of access, and the social consequences of HIV that stem from stigma and discrimination.

Governments and health systems must respond to the fact that PLHIV are living longer. We must ensure that PLHIV remain in good health as they grow older, and can lead successful, productive and rewarding lives. This aspiration should motivate the HIV response in all European countries – not only those that already perform well in relation to the UNAIDS targets for diagnosis, treatment and viral suppression.

## THE HIV OUTCOMES INITIATIVE

The HIV Outcomes initiative arises out of a shared recognition among leading HIV experts that there are crucially important issues relating to the health and social inclusion of PLHIV that have to date received insufficient attention from policy makers and healthcare providers, and which must now form part of our HIV response.

In an era when ageing populations and health system sustainability are central challenges for all European countries, the initiative will also aim to inform debates about cost-effective strategies for co-morbidity prevention and management, whilst ensuring patient-centred healthcare delivery. Our recommendations should therefore be of high relevance both to policy makers and the wider health community. The HIV Outcomes initiative complements the work of other initiatives focusing on HIV prevention, diagnosis, and access to high quality treatment and care.

**John Bowis OBE**, former UK Health Minister and MEP, and **Marc Danzon**, former Director of the WHO Regional Office for Europe are Presidents of the initiative. The steering group<sup>2</sup> is co-chaired by: **Nikos Dedes**, the Founder of Positive Voice (the Greek association for PLHIV) and a Board member of the European AIDS Treatment Group (EATG); Professor **Jane Anderson** of Homerton University Hospital NHS Foundation Trust in London; and Professor **Jeffrey Lazarus** of ISGlobal, Hospital Clínic at the University of Barcelona, and CHIP, Rigshospitalet, University of Copenhagen. The initiative is enabled by sponsorship provided by Gilead Sciences and ViiV Healthcare.

The initiative is developing a performance assessment of HIV services ‘beyond viral suppression’ – focusing on: i. access to appropriate health services; and ii. health outcomes – comorbidities and health-related quality of life.

A research team supported by a study group of leading academics<sup>3</sup> will seek to identify the policy indicators necessary to assess countries’ performance at improving access to services and health outcomes. This will provide a basis for the development of policy recommendations by all stakeholders participating in the HIV Outcomes initiative.

<sup>2</sup> The steering group is composed of:

- AIDS Action Europe: represented by Sini Pasanen
- AFEW International: represented by Anke van Dam
- East Europe & Central Asia Union of PLWH (ECUO): represented by Vladimir Zhovtyak
- European AIDS Treatment Group (EATG): represented by Jackie Morton
- Jane Anderson: Homerton University Hospital NHS Foundation Trust, London
- Nikos Dedes: Positive Voice
- Jeffrey Lazarus: ISGlobal, Hospital Clinic, University of Barcelona
- Richard Stranz: AIDES
- Industry represented by: Annick Manuel (Gilead Sciences) and Evelyn Schoedl (ViiV Healthcare)
- European Centre for Disease Prevention and Control (ECDC) (*observer*)

<sup>3</sup> Study group participants include Professor Jeffrey Lazarus (ISGlobal, University of Barcelona), Dr Julia del Amo (National Centre for Epidemiology, Spain), Professor Jane Anderson (Homerton University Hospital NHS Foundation Trust), Yusef Azad (UK National AIDS Trust), Dr Natasha Azzopardi Muscat (European Public Health Association and the University of Malta), Dr Udi Davidovich (Amsterdam Public Health Service), Nikos Dedes (European AIDS Treatment Group), Dr Josep Maria Gatell (University of Barcelona), Meaghan Kall (Public Health England), Konstantinos Lykopoulos (ViiV Healthcare), Dr Annick Manuel (Gilead Sciences), Dr Ellen Nolte (London School of Hygiene and Tropical Medicine), and Professor Kholoud Porter (University College London).

