



**SIDE SESSION**

**Addressing research gaps identified by women  
living with HIV in Europe and Central Asia**

**Tuesday 24 July (14:00 – 16:00)**  
**UNAIDS Room 2**



European  
AIDS Treatment  
Group

# Addressing research gaps identified by women living with HIV in Europe and Central Asia

24 July 2018

AIDS2018 Conference, Amsterdam, Netherlands

[www.eatg.org](http://www.eatg.org) | [www.eatg4women.com](http://www.eatg4women.com) | [www.ageingwithhiv.com](http://www.ageingwithhiv.com)

Moderator: Fungai Murau, International HIV/AIDS Alliance

Time	Presentation	Speaker
14:00-14:05	Introduction	EATG & UNAIDS (tbc)
14:05-14:30	METRODORA & Ageing with HIV projects	Christina Antoniadis, EATG, Greece/UK Harriet Langanke, EATG, Germany
14:30-14:40	Q&A	
14:40-15:30	Panel discussion <ul style="list-style-type: none"> <li>• Meaningful engagement of women in research</li> <li>• Use and strengthening of surveillance and pharmacovigilance systems</li> <li>• Addressing data gaps</li> </ul>	<ul style="list-style-type: none"> <li>• Maryan Said, NYE PLUSS, Norway</li> <li>• Chubukova Lyubov, ALE "Kazakhs Union of People Living with HIV"</li> <li>• Maria Jesús Pérez Elías, Hospital Ramón y Cajal/ EACS WAVE, Spain</li> <li>• Natella Rakhmanina, Elizabeth Glaser Pediatric AIDS Foundation</li> </ul>
15:30-15:50	Q&A, discussion	
15:50-16:00	Wrap up	

Video

from METRODORA Multi-Stakeholder's Meeting,  
16 May 2018,  
Brussels, Belgium

## METRODORA project:

- Strengthening women's involvement in HIV research and clinical trials
- Optimising women's engagement in clinical decision-making processes
- Promoting collaborative efforts with key stakeholders for meaningful involvement of women in HIV research
  
- **Activities:** Desk research, training & webinars, online resources, multi-stakeholder meeting & dialogue
- **Target audience:** Patient community, researchers, pharmaceutical industry, policy makers, international agencies and other key stakeholders

# METRODORA - background

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- Globally, women are disproportionately affected by HIV, and constitute more than half of all people living with HIV.
- Young women and adolescent girls: 46% of new infections in Eastern Europe and Central Asia & 29% in Western and Central Europe [UNWOMEN].
- Women are **underrepresented in HIV treatment research**
- Lack of guidelines, limited evidence on treatment and care of WLHIV.

- Project proposal developed by:** Aisuluu Bolotbaeva, women’s coordinator, and steering committee: Jackie Morton, Sanja Belak – Skugor, Rebekah Webb, Silvia Petretti, Maria Xanthaki, Yulia Raskevich, Marine Gogia, Ivana Benkovic
- Project coordinator:** Mariana Vicente, Maria Duterte
- Advisory Committee:** Christina Antoniadis, Damian Kelly, Lucia Trasca, Marine Gogia, Rebekah Webb, Julia Dragunova, Ian Hodgson, Deniz Uyanik
- Desk research:** Mark Rapa
- Training:** Jackie Morton, Liza Hamza, Kristjan Jachnowitsch (coordinator)
- Webinars:** Shema Tariq, Tamas Bereczky, Giulio Maria Corbelli, Mark Rapa
- Training + meeting participants:** 15 women living with or affected by HIV
- Meeting Stakeholders:** Research Community, Industry, Regulatory bodies, International Organizations, Politicians.

# METRODORA – preliminary outcomes

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Desk research: in UK, Spain and France the overall average percentage of the participation of women living with HIV in clinical trials was 25.90%.

Key barriers for women's involvement in clinical trials include:

- Ethical issues
- Regulatory barriers
- Protectionist and paternalistic attitudes
- Real (or perceived) increased cost
- Problems with retention
- Lack of knowledge among women about participating in trials



# METRODORA – conclusions

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- Sex- and age- disaggregated data is often missing in clinical trial reporting
- Regulatory, legal, financial barriers and practical adversities prevent women from participating in clinical research
- Lack of knowledge about education & awareness-building about clinical trials among WLHIV
- Clinical research is only conducted in specific countries, hospitals, centres. What about the rest?

# Ageing with HIV Project - introduction

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Project presented by: Harriet Langanke, Cologne, Germany

- journalist and sexologist
- editor of Germany's magazine DHIVA – Women, Sexuality and Health
- Co-founder of Germany's national Network Women and AIDS (1992)
- Disclosures: no funding; but: EATG member

Contents of presentation:

- Overview of the EATG Ageing with HIV Project
- Highlighting the identified research gaps related to women's needs

# Ageing with HIV Project - concept

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The project is built on a **life cycle perspective**:

Three phases & conferences:

- ❖ **Children and adolescents**
- ❖ **18-50 years, living with HIV/AIDS for at least 10 years**
- ❖ **50+ years**

**Target audience:** Patient community, researchers, healthcare providers and other key stakeholders

**Activities:** Conferences, webinars and online resources

Duration: 2015-2018

# Ageing with HIV Project - concept

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## Conferences:

1. New challenges and unmet needs of people living with HIV/AIDS aged **50+**, Berlin, Germany, 31 March – 3 April 2016
  2. New challenges and unmet needs of children and adolescents living and ageing with HIV/AIDS (aged **0-25**), Bucharest, Romania, 19 - 22 January 2017
  3. New challenges and unmet needs of people living and ageing with HIV/AIDS aged **18-50** - Quality of Life and Preventive Healthcare. Kyiv, Ukraine, 3-6 May 2018
- 286 participants in total (45% women)
  - Over 250 have accessed webinars online + many more on social media (up to 5,000 posts for each conference)

# Ageing with HIV – background

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What is meant by 'ageing' in this context?

- Advancement in treatment → HIV considered now a **chronic condition** with higher life expectancy
- However, HIV still poses very specific **challenges to health and well-being** : biological (co-morbidities, side-effects of long-term treatment) , psycho-social (stigma & discrimination etc.) which effect each other
- Therefore: important to explore the **quality of life** of PLHIV, including social, psychological, physical and functional well-being

# Ageing with HIV Project - goals

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The Ageing with HIV project focuses on the **unmet needs and challenges** of PLHIV/AIDS:

- To **increase knowledge** on HIV and ageing
- To **raise awareness** regarding the clinical and psychosocial needs of PLHIV/AIDS at different stages in their lives
- To provide **networking opportunities** for establishing collaborative efforts to address and advocate for priorities in the HIV and ageing domain

# Ageing with HIV – women's needs

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Key research gaps identified during the three Ageing with HIV conferences:

- Contraception & drug-drug interaction
- Pregnancy (information needs and support during pregnancy), drug-drug interactions
- Breastfeeding
- U = U (re sexuality, pregnancy, birth, breastfeeding...)
- Menopause
- Sexual and reproductive health

# Way forward

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- **Build synergies with researchers, industry, regulatory bodies**
- **Advocate for the removal of regulatory barriers** : Women and men are equal in rights and dignity, and therefore have an equal claim to concern (= prevention, treatment, care)
- **Advocate for transparency in research**: share freely disaggregated data
- **Advocate for women inclusion from the start**: design, clinical trial board, ethics committees, as researchers, as staff, as participants
- **Education for women on research and HIV**
- **Informed consent and peer support** to improve retention





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## PANEL DISCUSSION

- Meaningful engagement of women in research
- Use and strengthening of surveillance and pharmacovigilance systems
- Addressing data gaps

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