



# **SHE: Strong, HIV positive Empowered Women**

**Launch Meeting and Workshops**

**Saturday, 16 July 2011**

# Welcome

Silvia Petretti, MSc

Positively UK

SHE Programme Co-Chair

# Today's Agenda

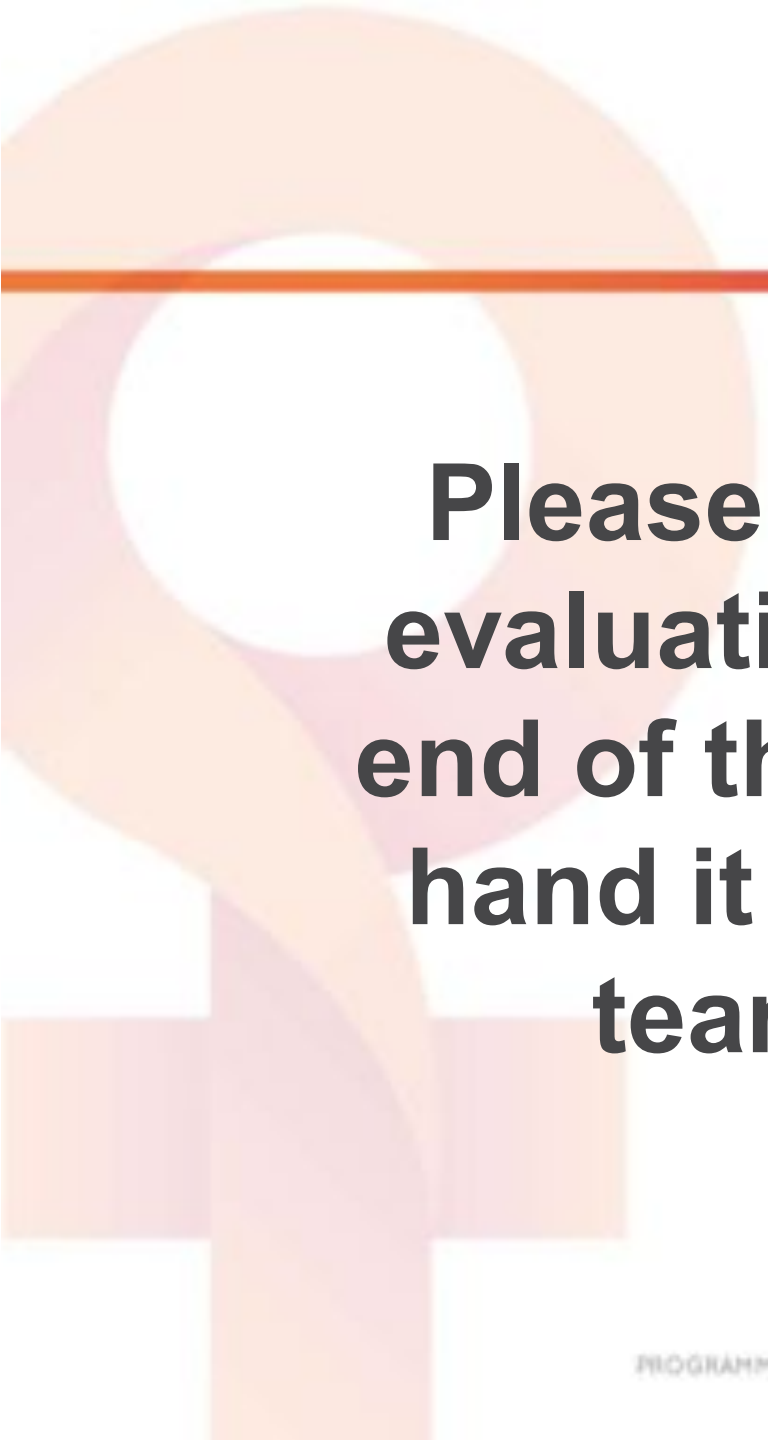


- **Introduction to the SHE Programme**
- **Programme Materials & Roll-Out**
- **Call for Action: Policymakers' Involvement**
- **Interactive Sessions**
- **Local Breakout Sessions**
- **Close**


# Please Turn Off Your Phone

**Thank you!**





**Please complete the  
evaluation form at the  
end of the meeting and  
hand it to a TogoRun  
team member**



**For how many years  
have you been affected  
or involved with HIV?**

The logo for SHE (Strong, HIV positive, Empowered Women) features the letters 'SHE' in a bold, sans-serif font with a red-to-orange gradient. To the right of the letters is a red awareness ribbon.

♀ Strong, HIV positive, Empowered Women

# Introduction to the SHE Programme

Alice Welbourn, PhD  
Salamander Trust

# Understanding the Visions of Women Living with HIV

Alice Welbourn, PhD  
Salamander Trust



# What We Know: Women and HIV



- Across Europe and Central Asia, it is estimated that nearly 2.2 million people are living with HIV
  - Approximately 930,000 (42%) are women<sup>1</sup>
- HIV is rising at a faster rate among women than men<sup>2</sup>

1. UNAIDS: "Global Report on the AIDS Epidemic 2010." Available at [http://www.unaids.org/globalreport/documents/20101123\\_GlobalReport\\_full\\_en.pdf](http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf). Accessed July 2011.

2. UNAIDS, UNFPA, UNIFEM: "Women and HIV/AIDS: Confronting the Crisis," 2004. Available at <http://www.unfpa.org/hiv/women/report/chapter1.html>. Accessed June 2011.

# Gender Inequalities Drive the HIV Epidemic

**There is an increased vulnerability of women to HIV transmission due to<sup>1</sup>:**

**Biology**

**Social,  
economic,  
legal and  
cultural  
issues**

**Unbalanced  
power  
relations**

**Burden of  
HIV -related  
violence  
against  
women**

**Sexual  
coercion**

1. UNAIDS. "Agenda for Accelerated Country Action for Women, Girls, Gender Equality and HIV." Available at [www.unaids.org/.../20100226\\_jc1794\\_agenda\\_for\\_accelerated\\_country\\_action\\_en.pdf](http://www.unaids.org/.../20100226_jc1794_agenda_for_accelerated_country_action_en.pdf). Accessed in June 2011.

# Gender Inequalities: Biology and Social Challenges

## Biology

- Women twice as likely as men to get HIV through unprotected heterosexual intercourse<sup>1</sup>
  - The structure of women's reproductive organs leaves us more exposed to the virus than men<sup>2</sup>
- Young women at higher risk of contracting HIV
  - Vaginas not as well lined with protective cells as those of mature women<sup>2</sup>

## Social, economic, legal and cultural issues

- Low social status and economic dependence on men prevent many women from controlling HIV risk<sup>1</sup>
- Women often have little access to health education and training<sup>1</sup>

# Gender Inequalities: Unbalanced Power Relations and Violence

**Unbalanced power relations**

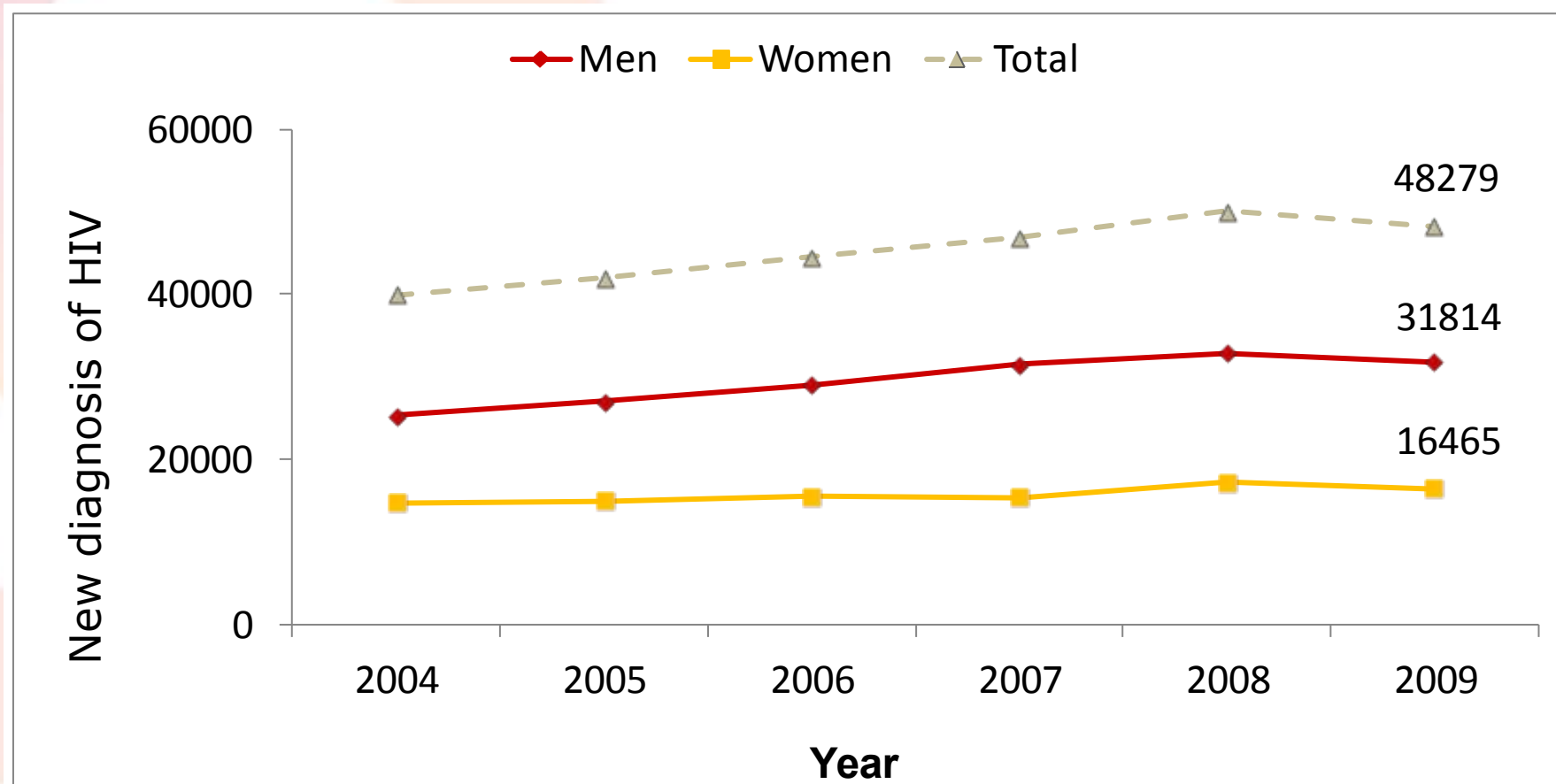
**Burden of HIV-related violence against women**

**Sexual coercion**

- 70% of women worldwide have been forced to have unprotected sex<sup>1</sup>
- Experiencing violence hampers women's ability to negotiate safe sex<sup>1</sup>
- Men are expected to control women's sexual relations in many societies<sup>2</sup>

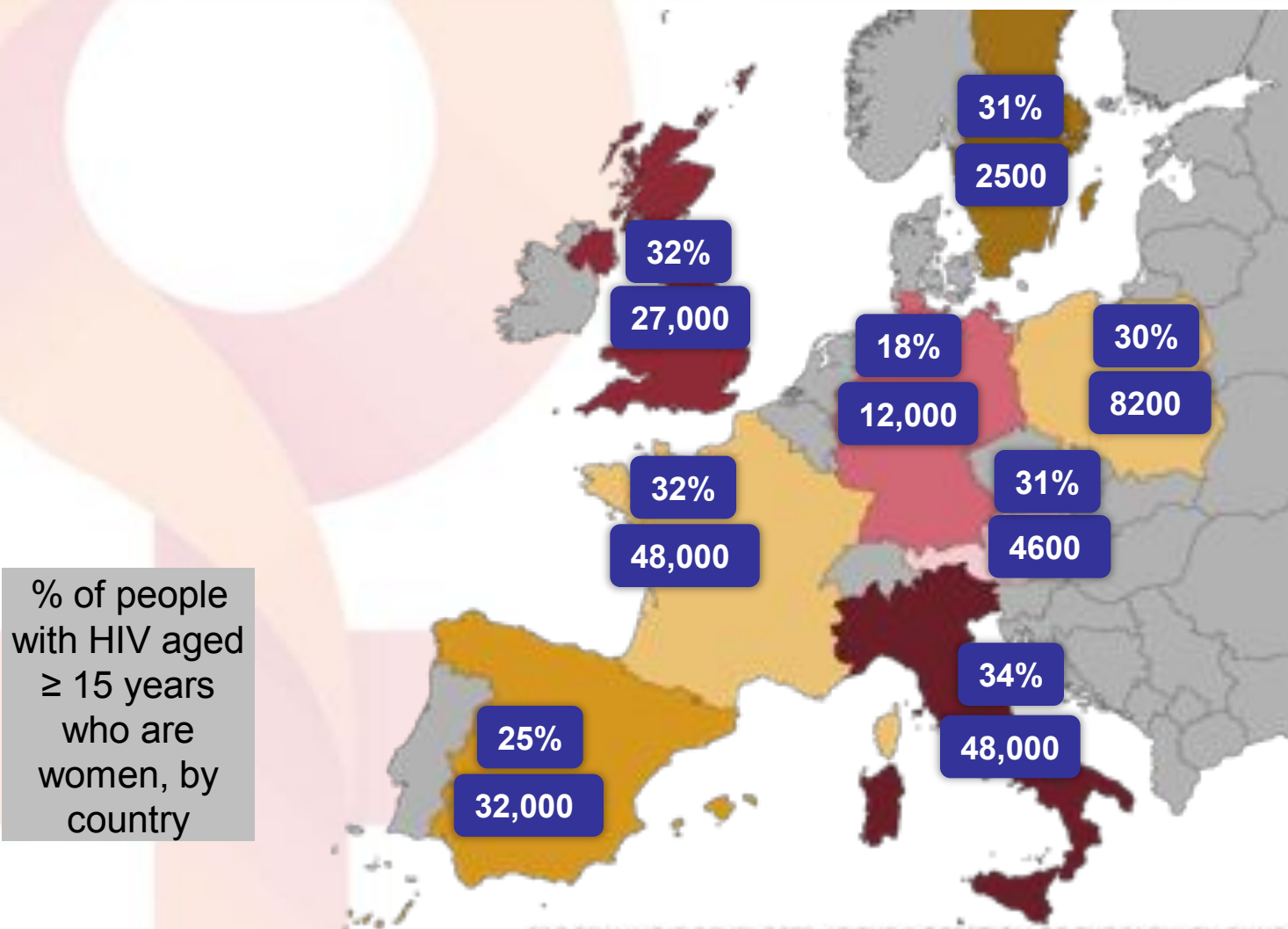
1. BBC News. "UN Warns HIV/AIDS Leading Cause of Death in Women." Available at <http://news.bbc.co.uk/2/hi/health/8546655.stm>. Accessed March 2010. 2. Facing the Challenges of HIV/AIDS/STDS: A gender-based response. Available at [http://data.unaids.org/Topics/Gender/FacingChallenges\\_en.pdf](http://data.unaids.org/Topics/Gender/FacingChallenges_en.pdf). Accessed June 2011.

# Women Represent One Third of New Diagnoses of HIV in Europe



PROGRAMME IS DEVELOPED AT THE DISCRETION OF THE FACULTY, FUNDED BY BRISTOL-MYERS SQUIBB

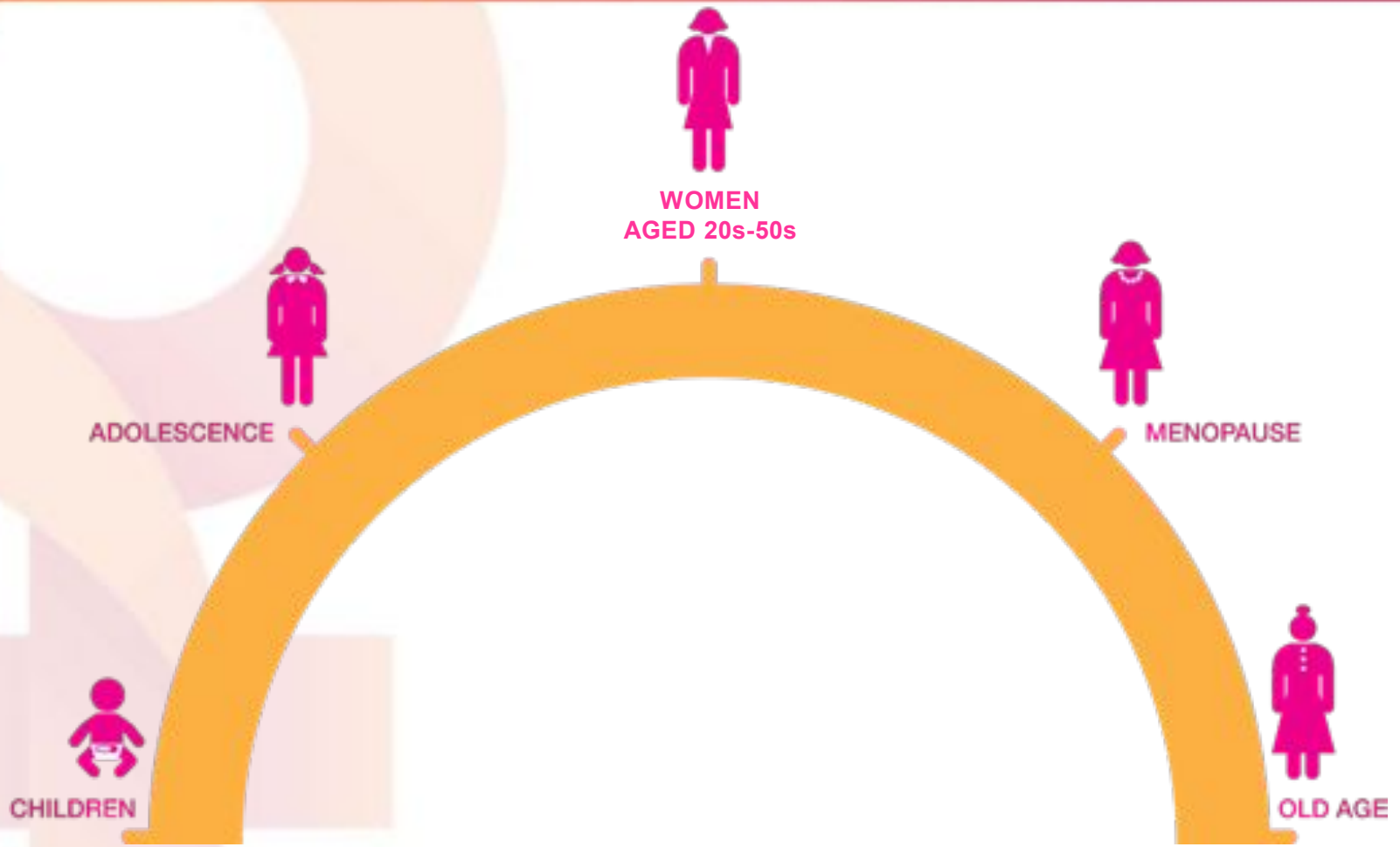
# Epidemiology of Women with HIV in Europe in 2009



% of people with HIV aged ≥ 15 years who are women, by country

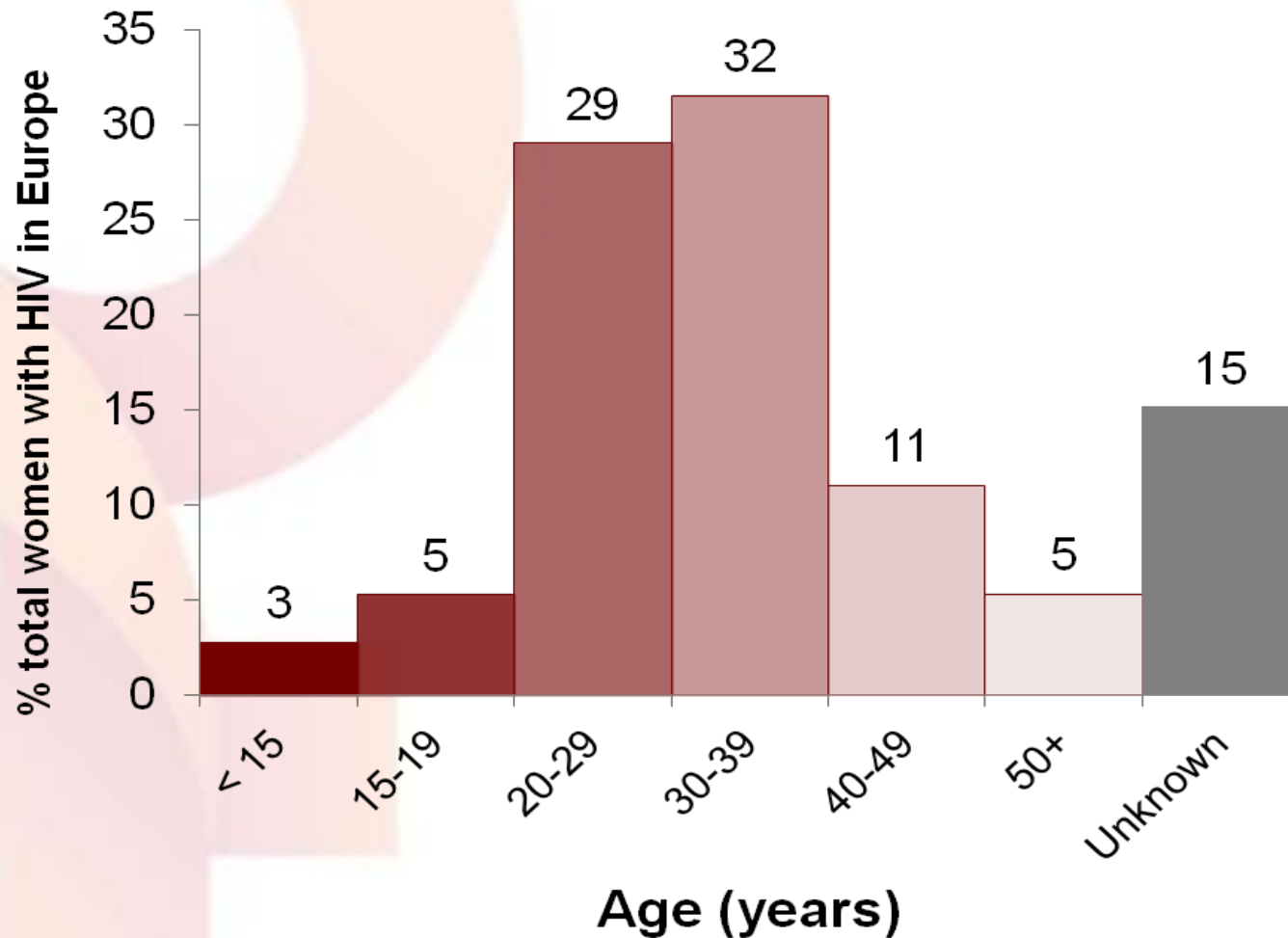
PROGRAMME IS DEVELOPED AT THE DISCRETION OF THE FACULTY, FUNDED BY BRISTOL-MYERS SQUIBB

# HIV Affects Women Throughout Our Lives



PROGRAMME IS DEVELOPED AT THE DISCRETION OF THE FACULTY, FUNDED BY BRISTOL-MYERS SQUIBB

# Most Women with HIV in Europe are Between 20 and 39 Years Old<sup>1,2</sup>



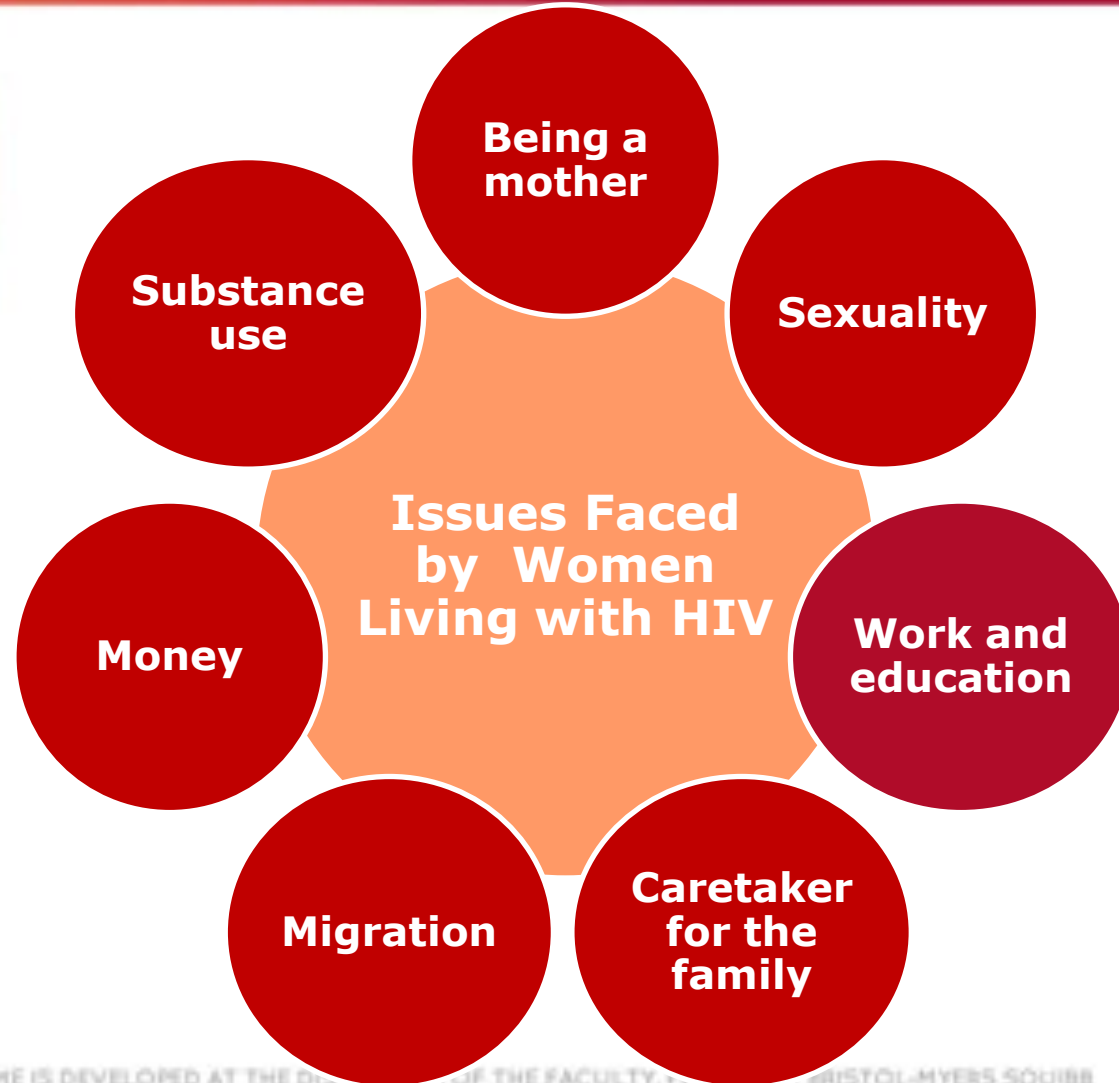
1. ECDC/WHO. HIV/AIDS Surveillance in Europe, 2009, available online: <http://www.ecdc.europa.eu/> [accessed May 2011].

2. Thorne et al. AIDS Care 1996;8:33-42.



# Women with HIV in Europe are Diverse

- HIV remains complex, imposing **unique challenges** for women<sup>1</sup>
- Women are particularly vulnerable to HIV, yet there is a **lack of HIV/AIDS programmes** and resources that address our specific needs and visions
- **Many women are left with an unaddressed gap** between diagnosis and effective, informed health care<sup>1</sup>



# UNAIDS Goal

“Gender equality must be at the core of all of our actions. Together we must energize the global response to AIDS, while vigorously advancing gender equality.<sup>1</sup>”

Michel Sidibé  
UNAIDS Executive  
Director



UNAIDS. “Women and girls.” Available at <http://www.unaids.org/en/strategygoalsby2015/womenandgirls/>. Accessed June 2011.

# Overview, Mission and Objectives of the SHE Programme

Silvia Petretti, MSc

Positively UK

SHE Programme Co-Chair

# Overview of the SHE Programme



**SHE = Strong, HIV positive, Empowered Women**

An European programme for women with HIV designed to:

Empower women  
living with HIV

Address the unmet  
needs we face

- Developed at the discretion of the faculty (independent advisory board)
  - In close collaboration with the SHE Scientific Committee
  - Funded by Bristol-Myers Squibb
- Designed to bridge the knowledge gap between physicians and women living with HIV
- Will function as a long-term programme with actions for beyond this meeting

# Outcomes of the SHE Programme

Peer support in clinics

Comprehensive toolkit

Website

## Local rollout in 7 European countries

UK

France\*

Spain

Germany

Italy

Portugal

Poland

*Getting endorsement and support from clinical teams will be **essential** to the successful widespread roll-out of this initiative*

# Mission Statement, Objectives and Resources



*'Support women living with HIV to feel empowered to improve the quality of our lives, including getting the most out of our healthcare services.'*

**Enable healthcare providers (HCPs) and women living with HIV to create an effective dialogue with each other**

**Deliver a toolkit to enable women living with HIV to provide peer support in a clinical setting with strong clinical engagement**

**Provide materials and support that facilitate HCP understanding of the initiative and secure their buy-in for a successful rollout in clinics**

**Develop a website to help expand the programme's online presence and maximise the reach of the materials (i.e. toolkit)**

# SHE Community and Medical Advisory Boards Members



- The SHE Community Programme is running in parallel to the SHE Scientific Advisory Board of European healthcare professionals committed to developing best practices regarding the management and treatment of women living with HIV

Scientific  
Advisory  
Board

A Venn diagram consisting of two overlapping red circles. The left circle is labeled 'Scientific Advisory Board' and the right circle is labeled 'Community Advisory Board'. The circles overlap in the center.

Community  
Advisory  
Board

# Advisory Board Members



## Community Advisory Board

- Silvia Petretti, MSc – SHE Programme Co-Chair (UK)
- Prof Jane Anderson – SHE Programme Co-Chair (UK)
- Magdalena Ankiersztejn-Bartczak (Poland)
- Juliet Bennett (UK)
- Stefania Doglioli (Italy)
- Antonella D'Arminio Monforte, MD (Italy)
- Robert Fieldhouse (UK)
- H el ene Freundlich (France)
- Mar a Jos e Fuster Ruiz de Apodaca (Spain)
- Annette Haberl, MD (Germany)
- Thandi Haruperi, BSc, PgD (Pan-EU)
- Karine Lacombe, MD (France)
- Peggy Maguire (Pan-EU)
- Celia Miralles, MD (Spain)
- Nicky Perry (UK)
- Annette Piecha (Germany)
- Alice Welbourn, PhD (Pan-EU)
- Brian West (UK)

## Scientific Advisory Board

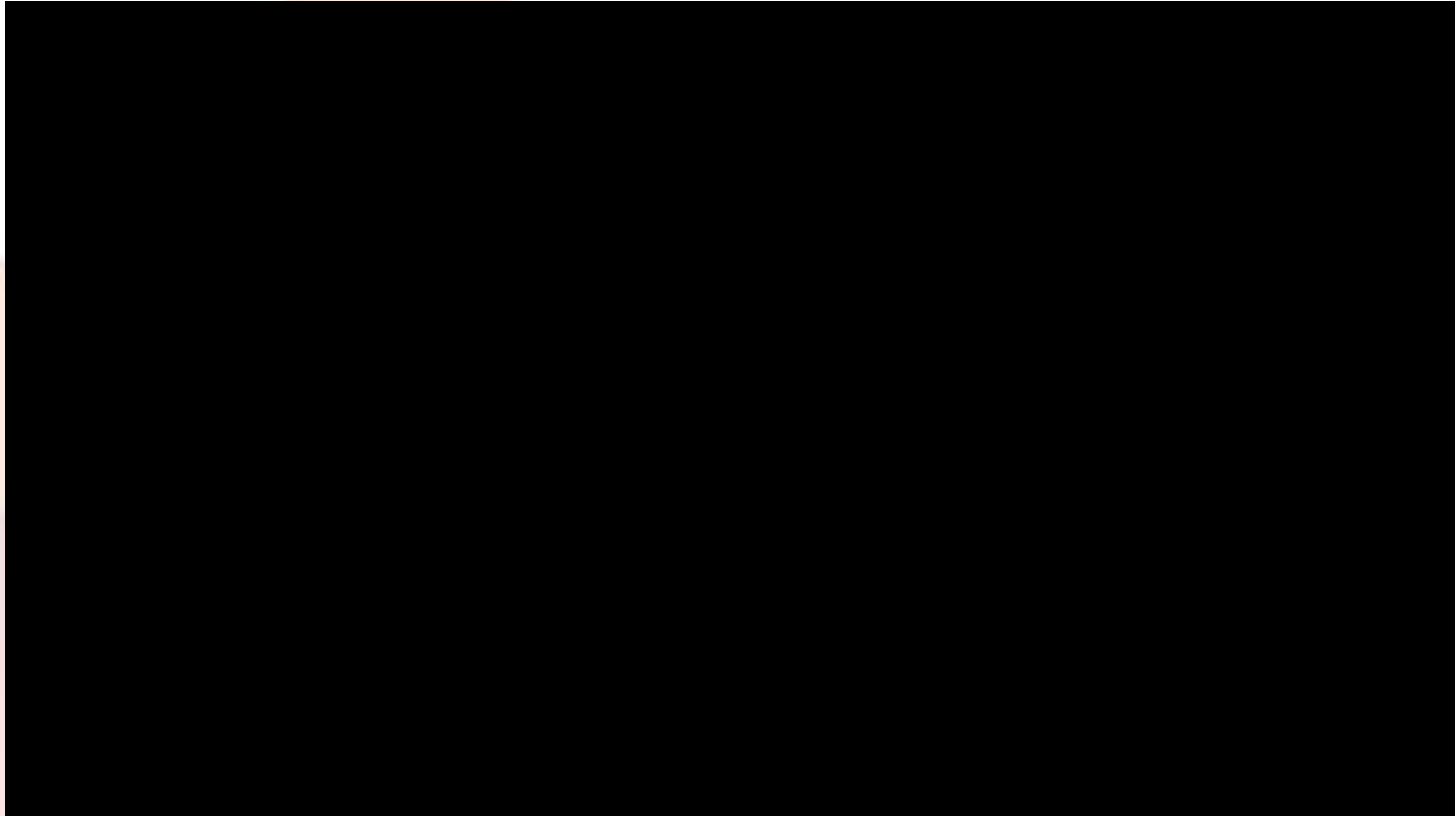
- Margaret Johnson – UK Topic Leader
- Annette Haberl, MD – Germany Topic Leader
- Stephanie Dominguez – France Topic Leader
- Antonella D'Arminio Montforte – Italy Topic Leader
- Celia Miralles – Spain Topic Leader
- Anke Reitter (Germany)
- Ophelia Orum-Haanyama (Sweden)
- Thandi Haruperi, BSc, PgD (Pan-EU)
- Lorraine Sherr (UK)
- Mariana Mardarescu (Romania)
- Larissa Afronina (Russia)
- Anita Olczak (Poland)
- Prof Jane Anderson, PhD (UK)
- Teresa Branco (Portugal)

### SHE Extended Faculty

- Maria Jose Galindo (Spain)
- Maria Jesus P erez El as (Spain)
- Anne-Mette Kj ær Lebech (Denmark)
- Christina Mussini, MD (Italy)
- Philip Hay (UK)
- Leo Flamholz (Sweden)
- Katja Roemer (Germany)



# Voices of SHE: The SHE Advisory Board



**Alice Welbourn, PhD**

PROGRAMME IS DEVELOPED AT THE DISCRETION OF THE FACULTY, FUNDED BY BRISTOL-MYERS SQUIBB

# The Importance of Peer Support for Women Living with HIV

Thandi Haruperi, BSc, PgD  
European AIDS Treatment Group (EATG)  
RestorEgo

# Using Peer Support to Create Change

## **Empowered!**

Create an enabling environment for us to feel empowered and take better control of our lives

## **Prepared!**

Prepare us for the formal consultation with our doctor

## **Confident!**

Increase confidence and self-esteem<sup>1</sup>

## **Healthier!**

Help improve our physical and mental health<sup>1</sup>

*Peer support may help us women living with HIV to be:*

## **Engaged!**

Help us overcome isolation and be heard, with a stronger voice as part of a group

## **More knowledgeable!**

Enhance our understanding of HIV and related issues, increasing our knowledge of treatments and adherence to them<sup>3</sup>

1. Positively UK. Peer Support Model. 2010.
2. Broadhead et al. Soc Sci Med 2002;55(2):235-46.

# Peer Support is Important in a Clinical Setting



## Peer Support Can Help Clinicians By:

**Complementing formal clinical support**

**Improving quality of care for women**

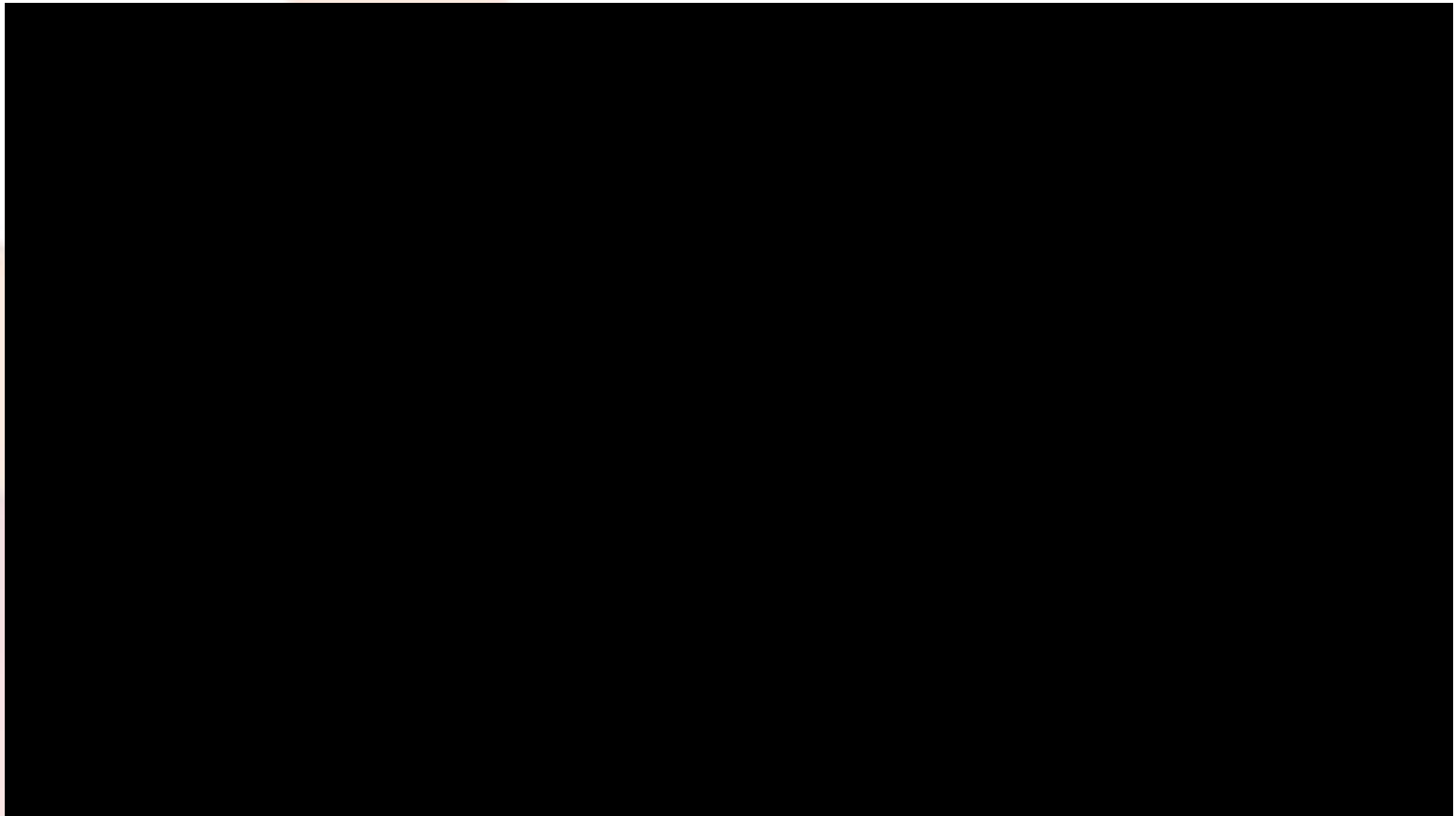
**Optimising financial resources**

**Creating an environment in which women feel safe and better able to take control**

**Helping to improve and support adherence**

**Increasing women's confidence about treatment**

# Voices of SHE: Peer Support



**Charity**

PROGRAMME IS DEVELOPED AT THE DISCRETION OF THE FACULTY, FUNDED BY BRISTOL-MYERS SQUIBB



# **SHE Programme Materials & Roll-Out**

**Prof Jane Anderson  
Homerton University Hospital  
NHS Foundation Trust, SHE  
Programme Co-Chair**

# How the SHE Programme Will Run

Prof Jane Anderson

Homerton University Hospital, NHS Foundation Trust

SHE Programme Co-Chair

# Why Develop the SHE Programme?

The SHE Programme addresses the information needs of women living with HIV, complementing healthcare resources.

- Women with HIV need relevant information

- HIV affects women in ways that are sex and gender specific

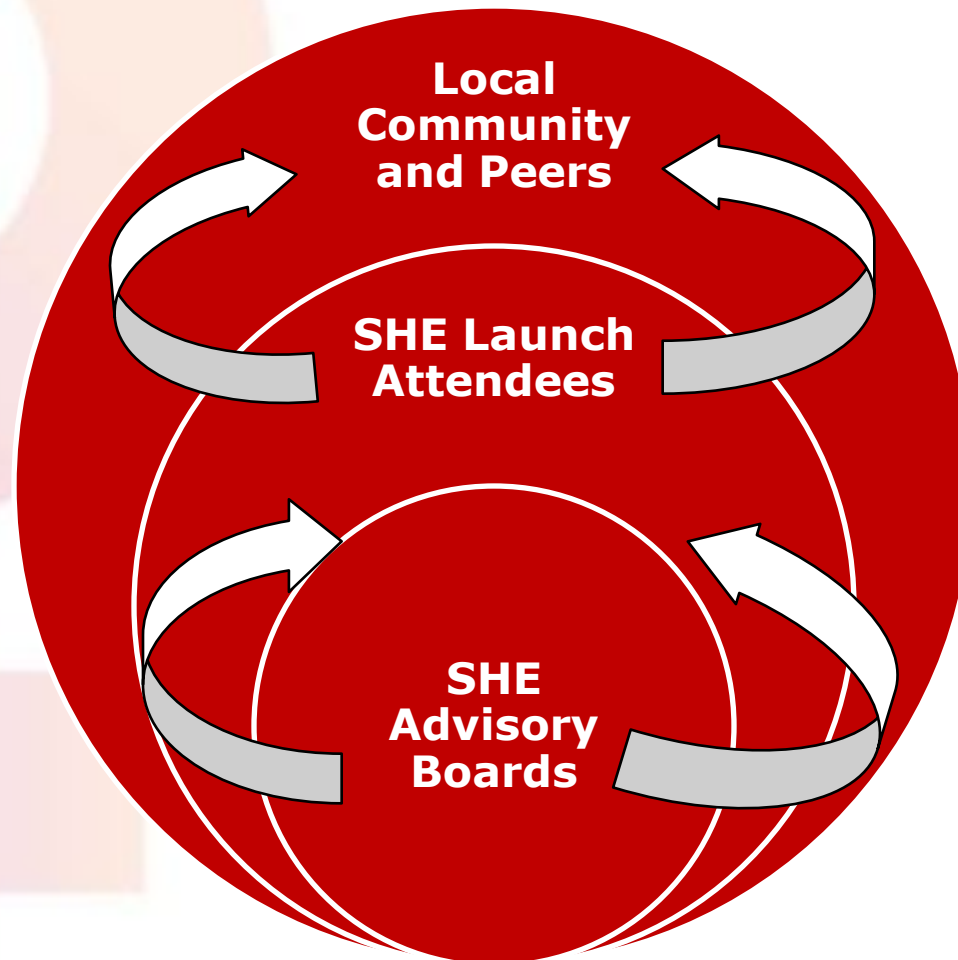
- Few resources exist that specifically address the information needs of women with HIV



# How Will the SHE Peer Support Programme Work?



# Building the SHE Network



# Role of the Clinic

The SHE Programme is designed for use in a clinical setting:

**Briefing staff on the role and goals of the programme**

Keeps the staff and peer support advisors informed



**Acting as a liaison and resource to the peer support facilitator**

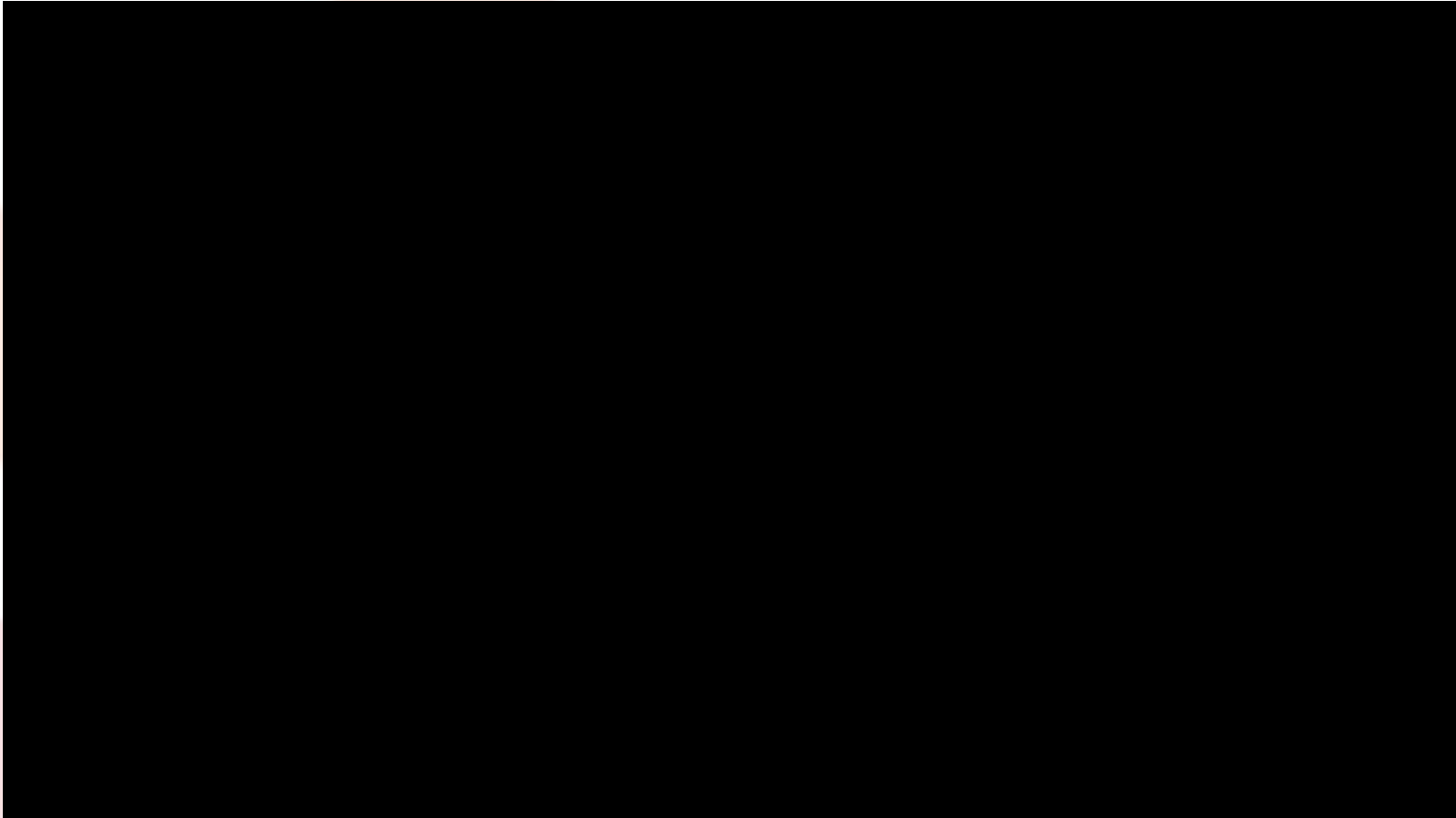
Ensures any questions or concerns can be handled promptly



**Providing a quiet meeting space for peer support groups**

Peer support groups will meet at the clinic

# Voices of SHE: Relationships with HCPs



**Memory Sachikonye**

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# **SHE Resources: Toolkit and Website**

Silvia Petretti, MSc

Positively UK

SHE Programme Co-Chair

# SHE Resources: Toolkit



Introduction

Why Peer Support is Good for HCPs

Diagnosis

Accessing and Using Healthcare Services

Sex and Relationships

General and Reproductive Health

Living Well with HIV

Women and ART

Women Living with HIV and Human Rights



- Practical, information-based toolkit for use by peer support facilitators in clinical settings
- Divided into nine sections
- Separate document for HCPs covering
  - Value of the programme
  - Why use a peer support model
  - Benefits of this approach
- English version to premier at IAS; local versions to follow

# SHE Resources: Website



Comprehensive resource meeting the unmet needs and visions of women living with HIV seeking out information online

The website will help expand the programme's online presence and maximise the reach of the toolkit content



# SHE Resource: Website



Broadens access and allows for individual and anonymous use

English version ([www.SHEtoSHE.org](http://www.SHEtoSHE.org)) to be launched in September

Other language versions to follow

The screenshot shows the SHE website interface. At the top right, there are navigation links for Home, About SHE, Contact, and a Language dropdown menu. Below the navigation is a search bar. The main header features the SHE logo and tagline, followed by a navigation menu with items: About SHE, Just Diagnosed with HIV, Living Well with HIV, Treatment, Care & Support, Helping Each Other, and Know Your Rights. The hero section displays three women's portraits with a 'Personalise Your Own Toolkit' button that says 'Add only the information you want and create a toolkit personalized just for you' and a '+ Create' button. Below the hero section, the text reads 'We are here to help, browse our resources.' The content is organized into several sections: 'Just Diagnosed' (with sub-points: Coming to Terms with Diagnosis, The Emotional Impact), 'Your Sexual Health & Family Planning' (with sub-points: Sexuality and HIV, Trying to Conceive, Raising a Family), 'Learning about the Treatment Options' (with sub-points: Medical Treatment, Importance of Staying Healthy, Accessing Health Services), 'About Peer Support' (with sub-points: Why Peer Support is Important, How it Works), 'We understand your situation' (with a search bar and a 'Remember, you are not alone.' message), and 'Find Support Groups' (with a 'Read More' link).



# Local Roll-Out

Thandi Haruperi, BSc, PgD  
European AIDS Treatment Group (EATG)  
RestorEgo

# Local Roll-Out

- The UK version of SHE programme will be modified for other countries and launched at a country level in:



**United Kingdom**



**Germany**



**Italy**



**Poland**



**Portugal**



**Spain**



**France\***



**SHEA**

♀ Strong, HIV positive, Empowered Women

## **Call for Action: Policymakers' Involvement**

**Alice Welbourn, PhD**  
Salamander Trust

# SHE in the Political Context

- WECARe+ survey conducted by and for women living with HIV
- On a voluntary basis
- The big issues for women living in Europe and Central Asia were:

**Concerns  
about  
criminalisation  
of HIV  
transmission**

**Migration**

**Gender  
equality**

**Gender  
violence**

**Imprisonment**

# Engaging Policymakers



The SHE programme aims to engage European policymakers to consider the special issues confronting women living with HIV:

## **Creating awareness:**

- the unmet need and visions of women with HIV in Europe
- the SHE programme addresses these issues

**Advocate for change amongst policymakers, donors and practitioners**

# Meeting with Member of European Parliament



## Letter of support from Marina Yannakoudakis, Member of European Parliament

- SHE Co-Chairs, Silvia Petretti and Jane Anderson discussed the SHE programme with Marina Yannakoudakis, Member of European Parliament, and member of the Committee on Women's Rights and Gender Equality





**SHEA** 

 **Strong, HIV positive, Empowered Women**

## **Interactive Sessions**

**Thandi Haruperi, BSc,  
PgD**

**European AIDS  
Treatment Group  
(EATG)**

**RestorEgo**

**15:20-17:10**

# Toolkit Showcase



*At this time, SHE representatives will rotate around the tables to discuss the sections of the toolkit and peer support.*

*We encourage you to contribute to the discussion and provide your feedback!*





**SHEA**

♀ Strong, HIV positive, Empowered Women

# Local Breakout Sessions and Discussion

Thandi Haruperi, BSc, PgD  
European AIDS Treatment Group (EATG)  
RestorEgo

**17:20-18:30**

# Local Breakout Sessions

- Discuss adapting the programme to fit the needs of your country and next steps for local roll-out
- To be held in the following rooms:
  - Viminale – France
  - Quirinale – Germany
  - Parlamento – Italy
  - Montecitorio – Portugal
  - Borghese – Spain
  - Barberini – Poland
  - Trinita` dei Monti A+B – UK and Eastern European countries
- Please appoint one person from your group to provide an update on your local roll-out activities to the larger group

# Highlights from Each Country

## Session: 18:00-18:30





# SHE

 Strong, HIV positive, Empowered Women

## Close

**Silvia Petretti, MSc**  
**Positively UK**  
**SHE Programme Co-Chair**

## 18:30

# THANK YOU!

*Please remember to complete an evaluation form  
and return to a TogoRun member*