



## BHIVA Satellite Symposium

*Tougher Times: Adapting to Increasing Demand with Declining Resources*

Monday 24 July 2017



# Miss Angelina Namiba

Salamander Trust

Speaker Name	Disclosure Statement
Miss Angelina Namiba	
Date	

# **Tougher Times: Adapting to Increasing Demand with Declining Resources: The Patient Perspective**



**British HIV Association Satellite Symposium**

IAS. Paris. 25<sup>th</sup> July 2017

# **Salamander Trust**

Small, young with a global reach

## **Aims:**

- Protect, Promote & Enhance the health and rights of people particularly, but not exclusively, marginalised as a result of their Gender, HIV status or Sexual & Reproductive health

## **Through:**

- Training, Global Advocacy & Research

# What can patients do/how can we adapt?



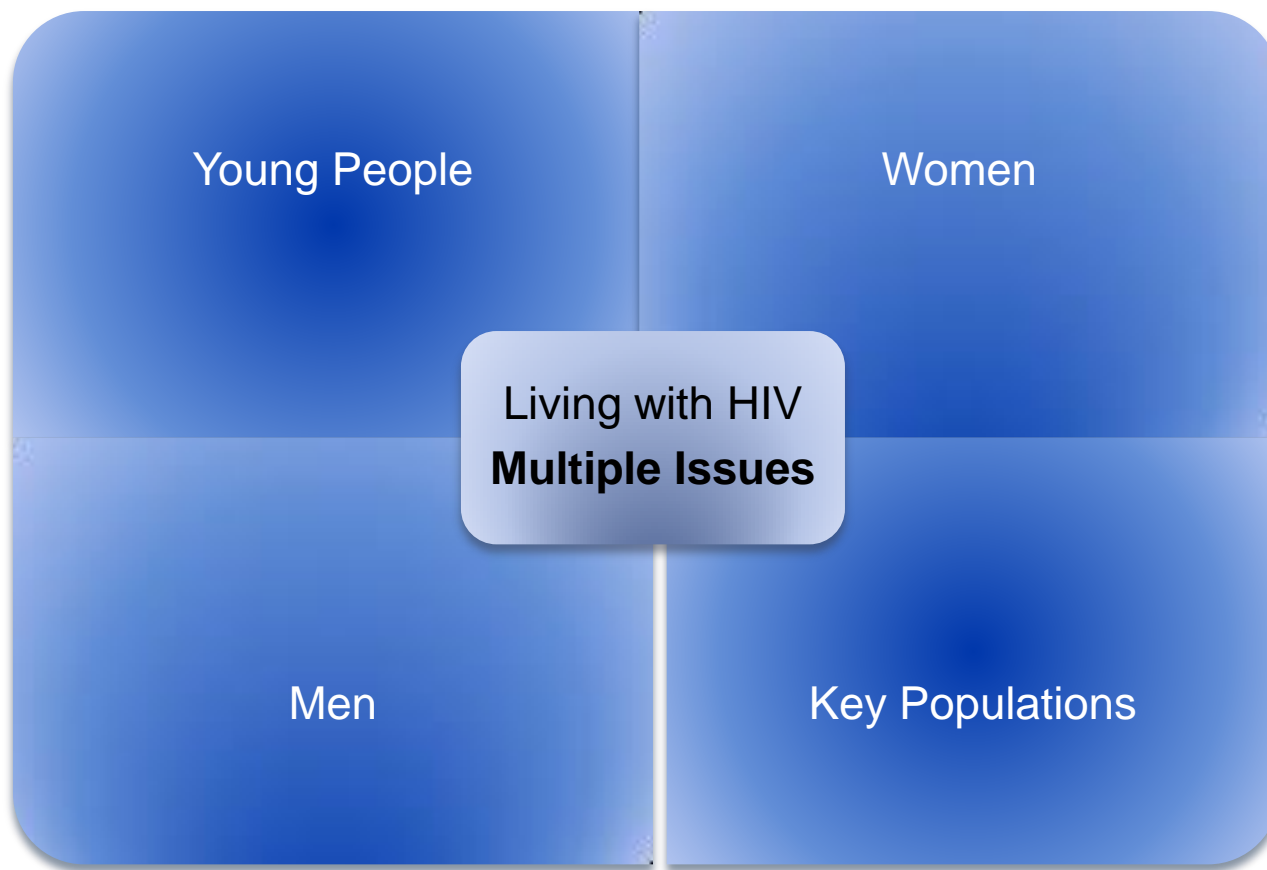
I asked a group of women living with HIV & Members of the [www.ukcab.net](http://www.ukcab.net) To inform this presentation.

# People living with HIV:

- Living longer, thriving, surviving and ageing
- Newly diagnosed, long term diagnosed

Stable and living well

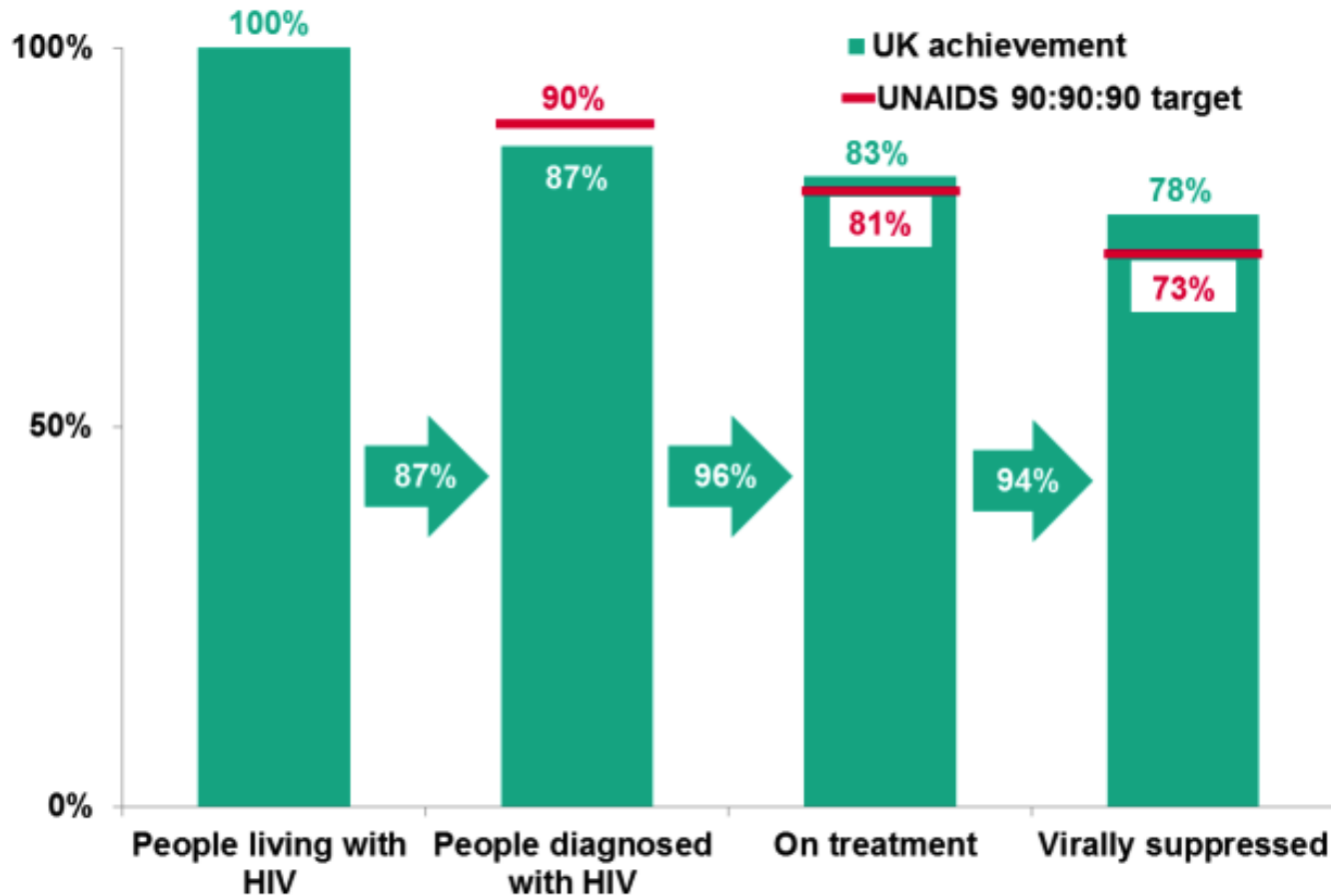
Have issues & challenges



**AND...ISSUES THAT COME WITH AGEING**



# UK HIV continuum of care: progress against UNAIDS targets



# UK HIV continuum of care...

## We need a 4<sup>th</sup> 90 in order to truly achieve a 360 degree view!

BMC Medicine

HOME	ABOUT	ARTICLES	SUBMISSION GUIDELINES
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OPINION | OPEN ACCESS

### Beyond viral suppression of HIV – the new quality of life frontier

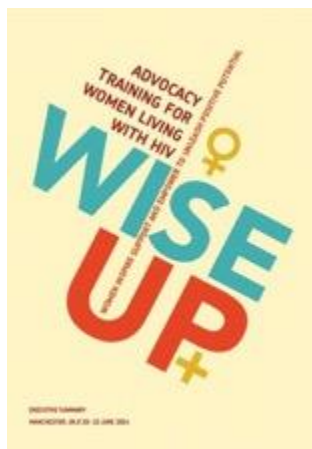
Jeffrey V. Lazarus , Kelly Safreed-Harmon, Simon E. Barton, Dominique Costagliola, Nikos Dedes, Julia del Amo Valero, Jose M. Gatell, Ricardo Baptista-Leite, Luís Mendão, Kholoud Porter, Stefano Vella and Jürgen Kurt Rockstroh

*BMC Medicine* 2016 14:94 | DOI: 10.1186/s12916-016-0640-4 | © The Author(s). 2016

Received: 5 May 2016 | Accepted: 10 June 2016 | Published: 22 June 2016

 Open Peer Review reports

# Structured peer support works.



[My Health My Choice My Child My Life peer mentoring project with women living with HIV](#)

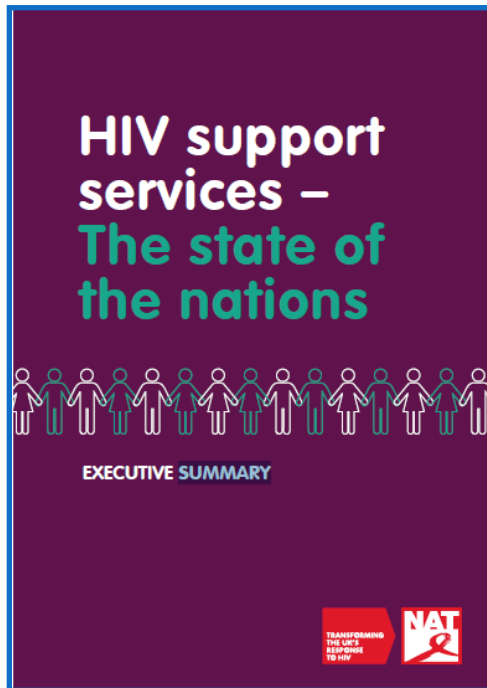


## Women's Room

Living with HIV isn't something you have to deal with on your own. Our Women's Room group for women living with HIV meets the **second Wednesday of every month.** [Read More](#)



**Now**



**Future?**



**Overthrow the Tory  
government, tax  
multinationals, get the  
resources to fund health  
and social care?**

# Investment in Peer Support

Go back to basics as in the beginning as and do something ourselves. With a small amount of money we can do wonders by using our empowerment training and some voluntary time to help newly diagnosed women. But that doesn't solve the funding crisis.....

Woman

Our strength is that our community is diverse, and so are our skills. We are all good at providing information, but in different ways and for different needs.

Man

I agree wholeheartedly that peer support is one of the best ways forward. But what about support for the mentor? It's all very well saying you'll mentor people. But, what about when it's you that need the support too? Also I think it's a joke that the UN etc go on about 90-90-90 and yet governments don't even have correct structure in place. Gov'ts need to get it together!

Young woman

# Investment in Peer Support



We need effective peer support strategies that will not only seek to provide the necessary support. (We do not need further proof that this works). Strategies that will also encourage, support and recognize the givers of this support because I feel there is a sense that these can be given freely. We lose good support as a consequence.

We also need to continue making noise to commissioners about the importance of these!

Woman

One practical point about peer support is that while some health workers are great at referring to peer mentors, some health workers see this as a threat (to their own work). **Hospitals need to smooth these fears by making sure everyone who is newly diagnosed (perhaps everyone who is positive) gets information about peer support.**

Man

# Patients recommend **DIY**



I think there is a need to re-evaluate the support aspect & I feel a lot more can be done by ourselves with regard to our own care. It's sad that a lot of people struggle to come to terms with HIV. Having been diagnosed 14 years now, I feel that I have outgrown support groups...

Woman

More needs to be done to make people not feel so reliant on the system. I visit my consultant every 4 to 6 months and discuss things with her if I have issues. I feel that we need to become more reliant on ourselves and not the system. I try to live my life everyday as normal and make HIV a small side issue.

Woman

I am with doing things for ourselves. We need to carry out a needs assessment of what our immediate & near future needs are, do a skills audit to see what we can offer then research into starting some sort of social enterprise to provide these services for ourselves.

Woman



## Patients recommend: **DIY**

Fundamental is that we keep empowering each other and those who just don't know how to navigate the system.

Our rights are at the heart of ensuring that we get the care and support we need.

Woman

# Patients recommend: **Organizational Collaboration**

I think partnership with organisations is hugely important, but what about the fact that those are struggling too?



Young woman

Working collaboratively within HIV organisations as well as those organisations that deal with mental health and other areas that affect people living with HIV.

Woman

Continued partnering with organisations like diabetes, the liver trust and all that fit co-morbidities. Further pushing on health and wellbeing from charity perspective. Definitely approaching commissioners relentlessly where necessary, if misused funding.

Woman



# Patients recommend: Effective use of technology

We can make more effective use of our HIV consultant's time. For stable patients who are responding well to ARVs and have no health issues, then would it be possible to really streamline the visits to the consultant? I'd be happy to go to my GP to get blood samples taken, which can then be sent to the hospital. Once results are in I'd be happy with an email, or face-time meeting. I would though, want there to be very open communication lines with my consultant (email, text or phone) so that any problems issues can be resolved quickly.

Ben, living with HIV long term



# Summary

## A few words of caution

- All services/initiatives need to be **embedded** in and **informed** by community
  - Caution around the message 'we can do it all ourselves', as it **washes responsibility** off the government's hands
- Community based services & mobilization are **most effective** as part of :
  - A well funded NHS
  - A good education system
  - A compassionate society

# Acknowledgments

Thank you, **Asante sana**, Mazvita, **Mille grazie**  
Twalumba, **Zikomo**, **Plang des**

**Women living with HIV in all your diversity:**

Silvia, Linda, Sophie, Leigh, Rebecca, Alice,  
Mercy, Charity, Matilda & Longret

**Members of the UK Community Advisory Board:**

Robert, Johnson, Jane, Simon, Kathleen, Roy & Ben