

# U=U

## Perspectives from people with HIV

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Positively UK

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# This presentation:

- Consulting with People with HIV
- Spreading the message
- U=U as a tool for changing attitudes and overcoming stigma
- Conclusions



# Ask a friend....

Survey Monkey

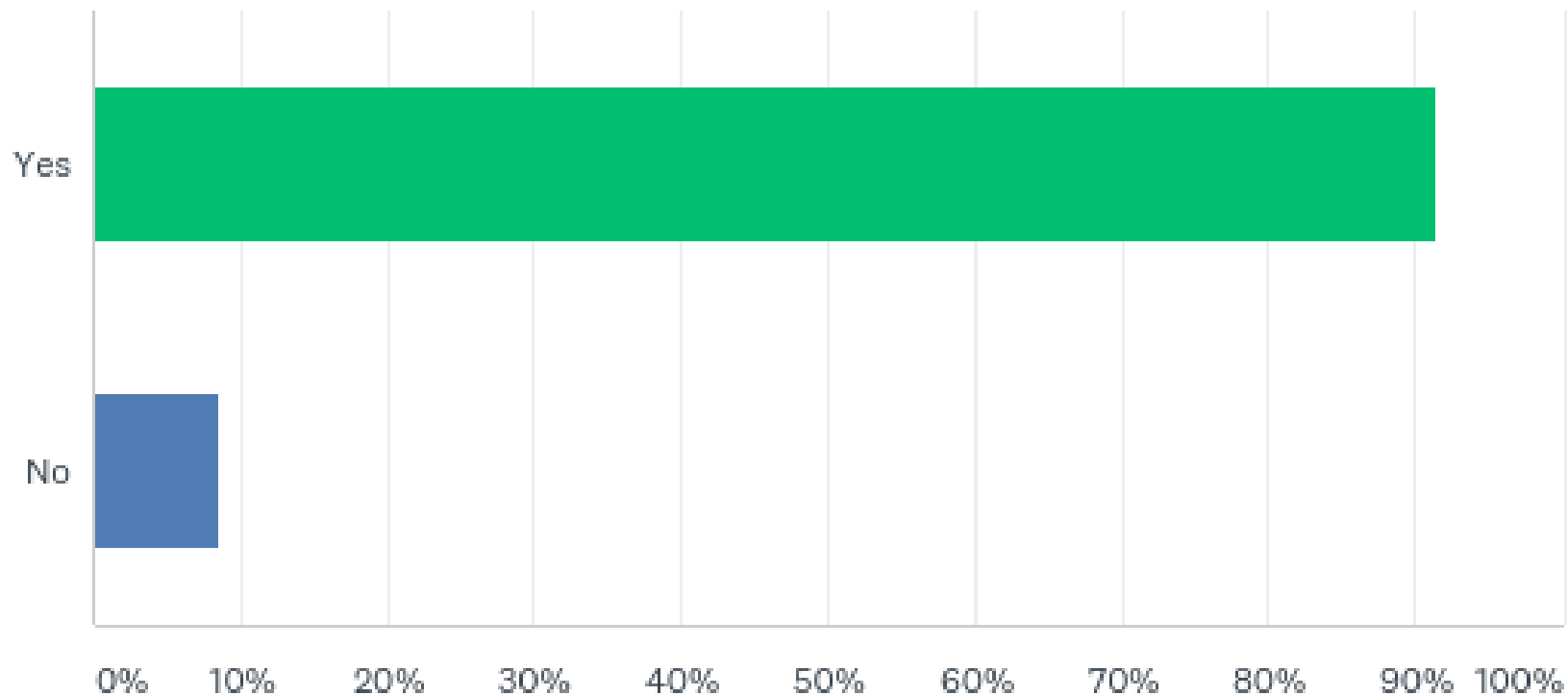
98 respondents in one week

Positively UK service users, staff and volunteers

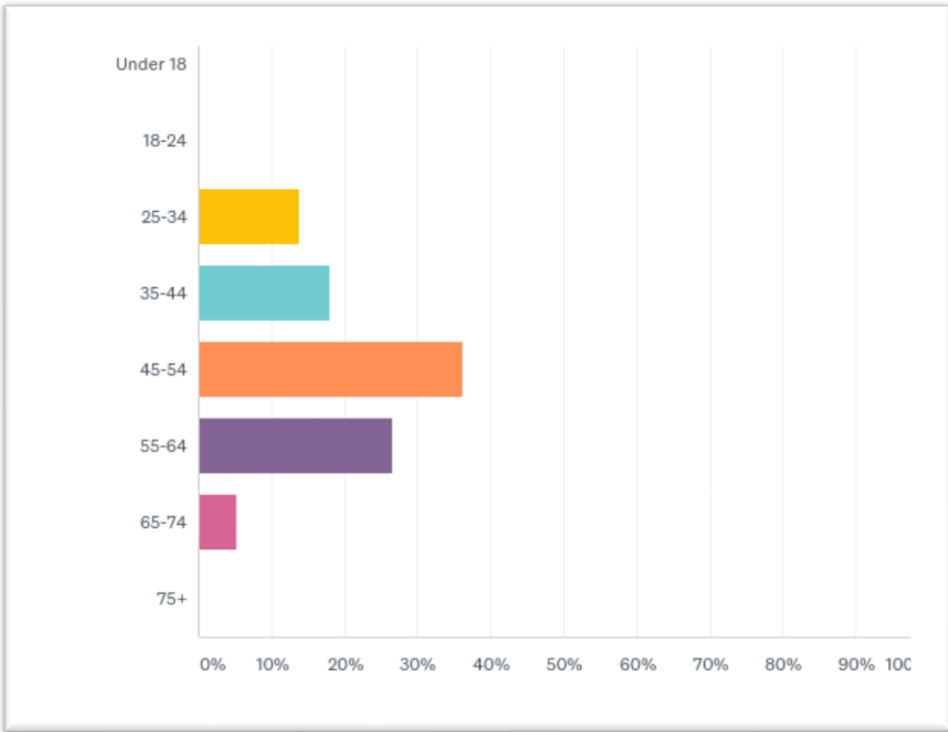
UK –CAB



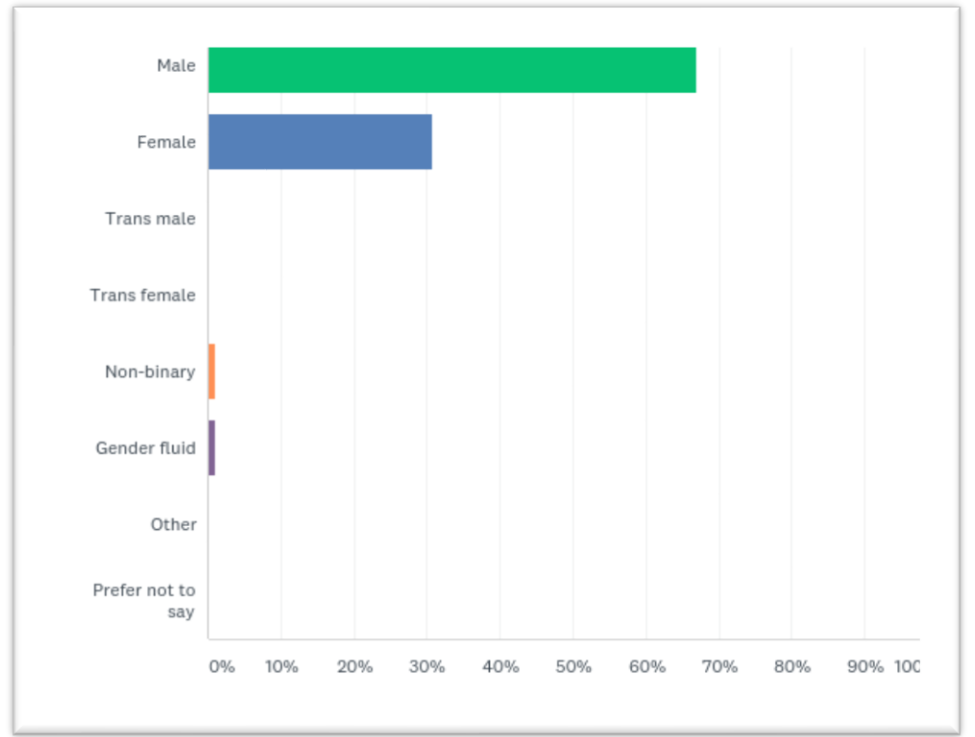
# Have you heard of U=U?



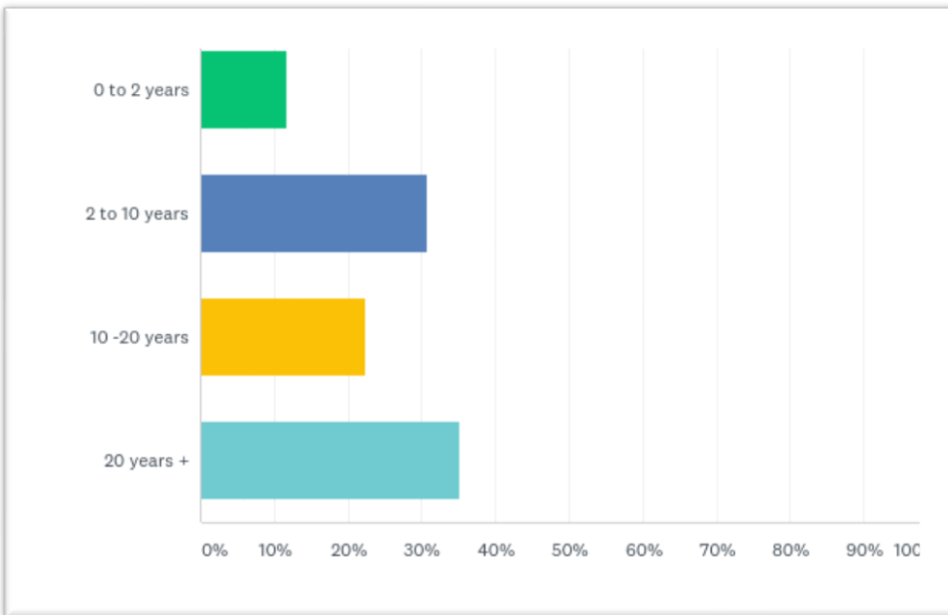
## Age



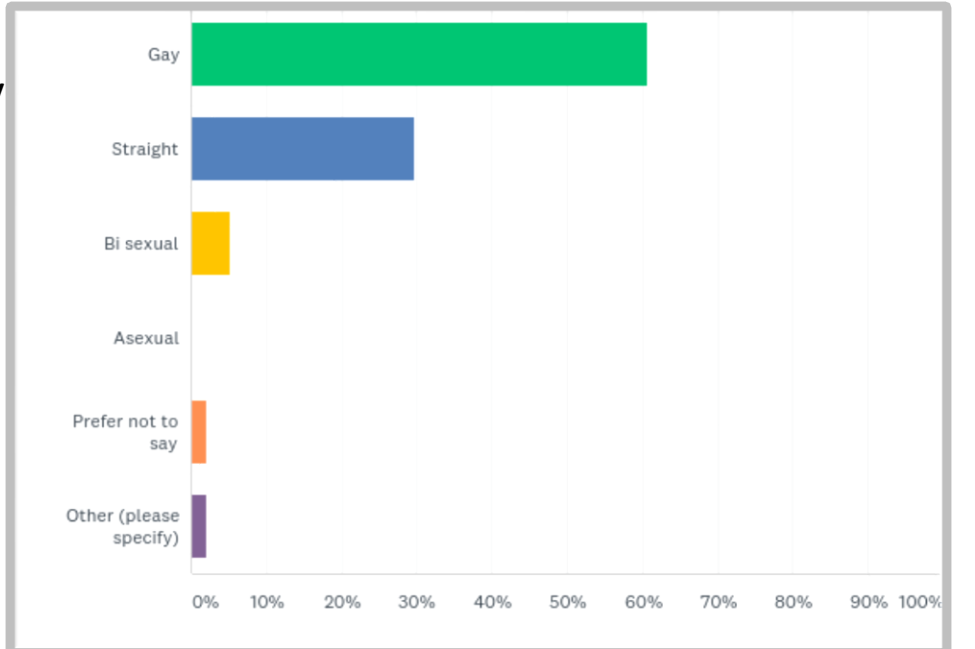
## Gender



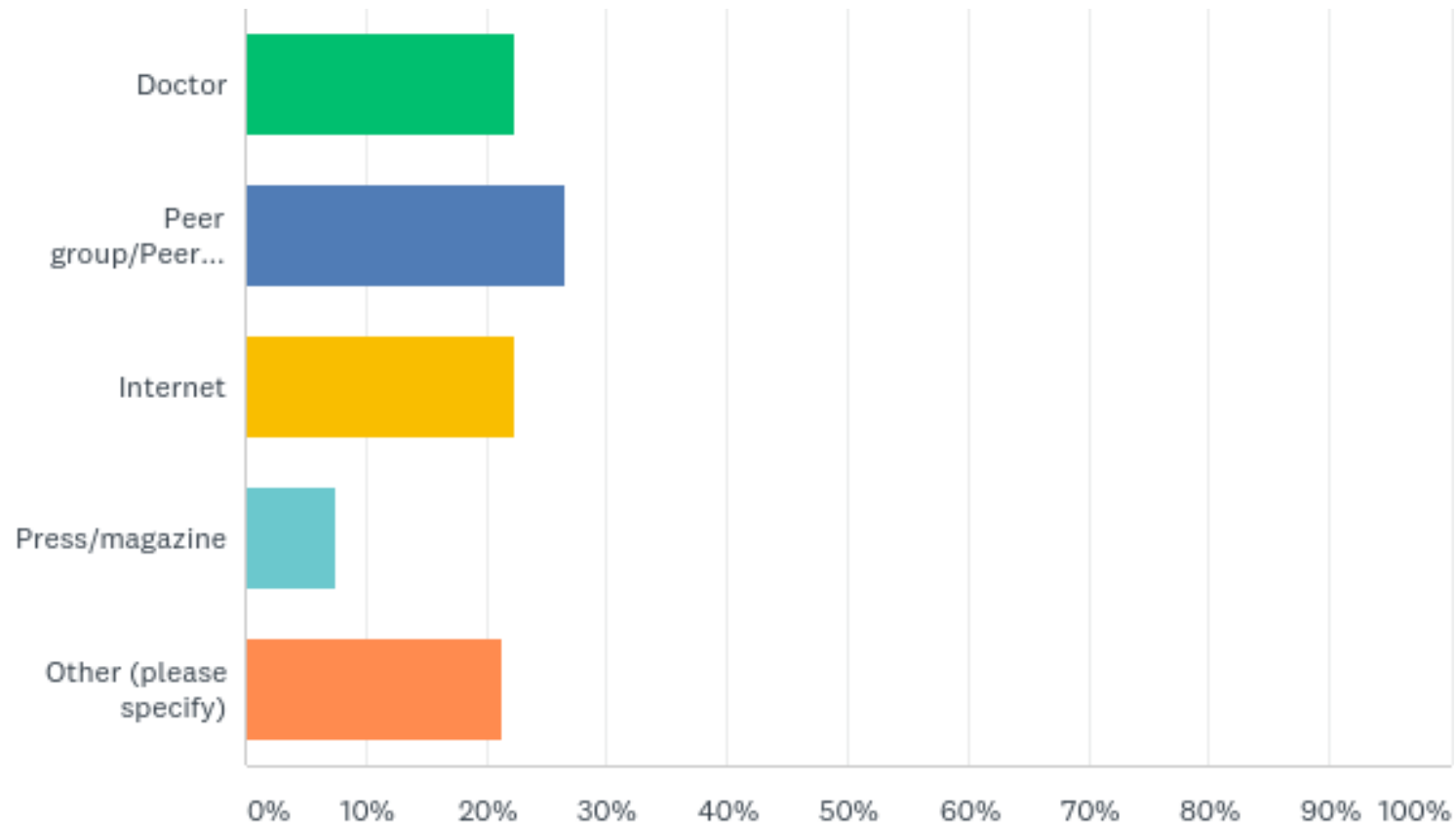
## Time of Diagnosis



## Sexuality



# Where did you learn about U=U?



# How do you feel about U=U?

....**Free of fear** of transmission to HIV negative fiancé and he understands and knows there is no risk. Biggest impact on my HIV life since diagnosis in 1991.

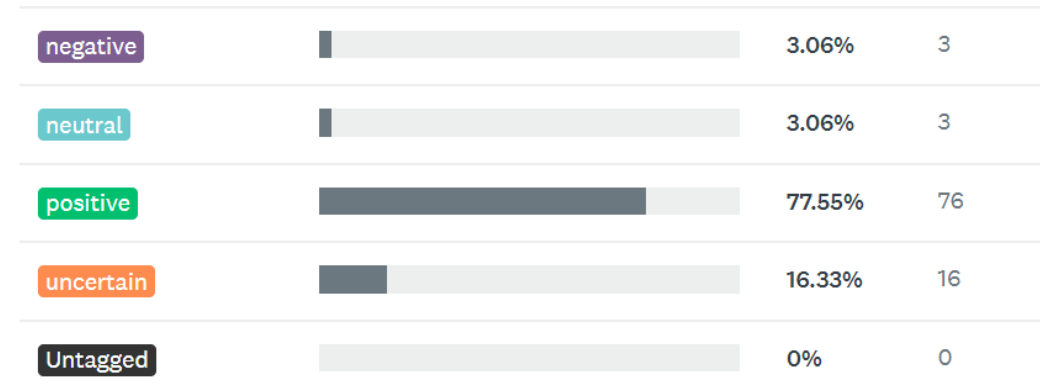
I think it's important to know that you cannot pass on HIV and it is great **peace of mind** also to ensure that you on the right treatment no just to prevent you and people around from being ill.

It has given me a feeling of **liberation**.

It's fantastic! A real **game-changer**

It **makes me more confident** and I am more in peace with my HIV status

it made me realise that **I can have a normal life**.



# Uncertainty

**Uncertain.** Disbelief

I still have **doubts** about how safe it is for a HIV - person to have unprotected sex with someone who is HIV +. ...(.)that is based on a blood test that that is done every 6 months. Is there a possibility for: VL to vary within that period? For HIV + person to become resistant to HIV meds due to having unprotected sex with an individual who is resistant to said person's meds?

I feel positive about **it I'm not hundred percent sure Whether to believe it or not**

**Wouldn't rely on it** alone (viral load measured less frequently these days; what about blips?; trust issues similar to contraceptive pill) but it does add an extra layer of reassurance





# Spreading the message

- Get it outside HIV community, like in **GP surgeries** etc
- What I'd like to see is all **non-hiv health professionals being aware** of this.
- Lobby **Government** to put some resources into an **up to date campaign about HIV** as it is today rather than as it was in the 80's.
- Mass **mail out** like the tomb stone aids campaign to **every household**
- Honestly do believe that Support Organisations are very good at letting people who have HIV know about U=U. The struggle is the people that don't have it. **SCHOOLS** is a good start
- It's essential that **all of us living with HIV** are aware of this, and able to inform others. But we also need to tell the rest of the world, not just PLWH. So getting the word out in as many ways as possible is key - but we also need to **look beyond those we normally support**



U=U The Seeds Project says it with flowers



POSITIVELY UK

# The role of U=U in addressing Stigma

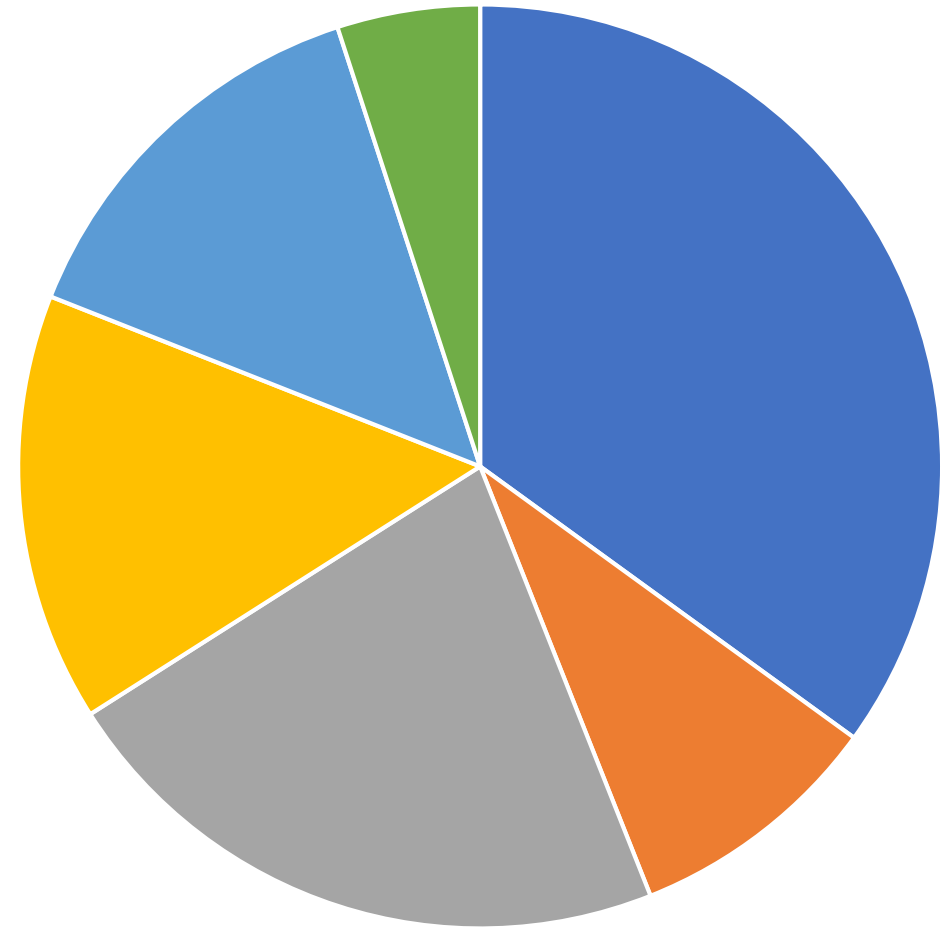
“It is part of the answer to reducing stigma but not the entire answer”

“It's an important part of challenging stigma, as the fear of HIV is based on a fear of transmission”

“I think it's already changed things. The past 7-10 years things have changed exponentially”



Role of U=U addressing Stigma



■ Very Important role ■ No Role ■ Partly ■ Long way to go ■ Great Start ■ not sure

# Proudly Undetectable



Positively UK marching at Pride 2018

# Layers of Stigma

“...But much of the stigma is around behaviour and U=U doesn't remove that. Talking about sex, being more positive about sex, less judgemental and open, our sexual rights. Challenging social norms that try to shame and label us. U=U might help us to overcome self-stigma and that has a knock on effect = more people openly talking about it and challenging harmful attitudes. This means future role of U=U work is to empower people with HIV to talk about more than just being uninfected....”

“**HIV stigma intersects with other layers of stigma**, one reinforces another. So work on HIV stigma has to be holistic and challenge all harmful attitudes. Empower us with correct knowledge, work on building our resilience, politicise us to see stigma in the wider context....”



# Catwalk4Power

Women with HIV  
challenging attitudes through  
empowerment, creativity and collective  
action

“I've learnt lots about “undetectable” and what that means. I'm not scared anymore. It's not enough to read it once. It's about being here with the community... I feel fully confident about “undetectable”

*Catwalk Participant*



# Conclusions

- U=U message has a huge positive impact on the lives of people with HIV.
- Much more needs to be done to spread the message (NHS, media, government campaign, general public, education/schools)
- People with HIV need support in dispelling uncertainties around U=U from a variety of sources/methodologies
- U=U plays an important role in a multi-layered approach to changing attitudes towards HIV

