

# Awareness, understanding and impact of U=U: views from patients and staff

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# Overview

- Rationale / context for survey
- Survey results
  - Patients
  - Staff
- Conclusions

# U=U Timeline...

July 2016	PARTNER study published
July 2017	BHIVA endorses Undetectable = Untransmittable consensus statement
April 2018	BHIVA workshop
June / July 2018	Bloomsbury clinic survey
October 2018	Prevention Access website qualification
October 2018	BHIVA members survey

# Survey Monkey questionnaires June / July 2018

## Patient Survey

- N=74 online
- N= 7 in clinic
- 86% male, 72% gay, 100% on Tx and undetectable

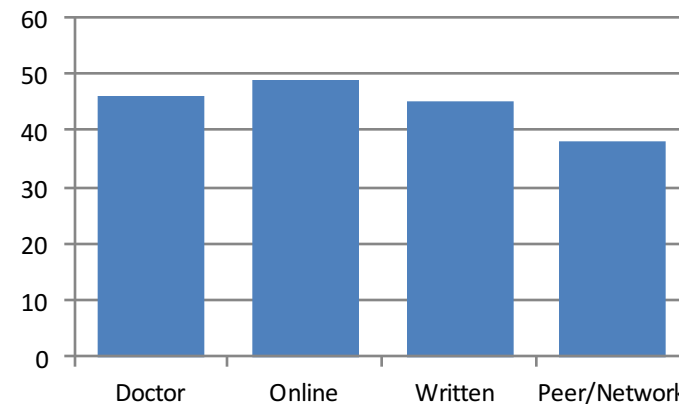
## Clinician Survey

- N=31 online
- 15 doctors, 5 nurses, 6 health advisors, 4 psychologists, 1 patient rep

# Patient Responses

- Heard of “U=U” 68%
- Heard from clinic 30%
- Agreed with the statement “being undetectable for six months means no sexual transmission” 80%
- Agreed with the statement “being undetectable for six months means HIV can’t be passed to a baby, **including breastfeeding**” 58%

- “U=U has had a positive impact on how you feel about your HIV”  
79%
  - MSM – disclosure, sexual choices and confidence 52-56%
  - Heterosexuals – starting / taking meds 47%
- Described negative effects, related to both side-effects and a lack of confidence in the U=U message 14%
- Wanted more information 42%



# Patient comments...

“Still can't quite believe it – probably HIV–ve people find it hard to believe too“

“Can I have sex with my negative partner and not transmit the virus to him?”

“(My) negative partner still worries about having sex with me”

“I want more information about breastfeeding, pregnancy”

“I would like there to be workshops where we can bring neg friends / family / partners / others, basically people in our lives who need to hear the news from the professionals.”

“This needs to be more widely advertised, the way the terrible AIDS tombstone was spread everywhere in the 80s. U=U needs to be on television sets and on the internet.”

“Why is it being peddled as truth when it is not: tell the truth no matter how small the risk is”

“...this U-U has bring back my happiness”

# Staff Responses

- Discussing U=U with all or most patients 87%
- Felt that all or most of their patients knew about U=U 35%
- U=U explanations varied significantly
- Reported reactions from patients included relief 70%, disbelief 33%, confusion 37% and anger 3%
- Clinician perception of positive impact of U=U on patient feelings 77%
  - over-estimated in other areas (disclosure / sexual choices and confidence)
- Clinician perception of negative impact of U=U 14%



- Reported barriers to discussing U=U:

- time 31%

- only if asks 29%

- assumption of knowledge 18%

- assumption of no transmission risk 6%

- Requested:

- more training 62%

- more information in our newly diagnosed packs 72%

- U=U artwork in the clinic and written information in the waiting area 72% - in different languages 66%

# Conclusions

- Mixed level of understanding
- Staff U=U explanations varied
- Staff training requested (can be complex)
- U=U can have a positive impact in multiple areas (disclosure, sex and medication)
- Staff are mostly aware of these positives, but may under-estimate complexities, or incorrectly assume knowledge / relevance

⇒ **U=U can have a positive impact on both individuals and prevention**

⇒ **HIV clinics are well placed to proactively check and promote understanding,**

⇒ **Information must be clear, consistent and accessible.**

# BHIVA Position Nov 2018

“We urge health care professionals to **discuss U=U proactively** with all people living with HIV at appropriate points during care including, but not limited to:- at diagnosis, when initiating treatment, to encourage adherence, when undetectable, and if planning to conceive.”

“We recommend consistent and unambiguous terminology when discussing U=U such as **"no risk" or "zero risk"** of sexual transmission of HIV, avoiding terms like "negligible risk" and "minimal risk.”

“We encourage clinics to **display and provide information** on the use of ART to maintain an undetectable viral load as a highly effective strategy to prevent the sexual transmission of HIV. We also advise explaining the scientific evidence behind U=U, emphasising the importance of excellent adherence to ART and highlighting that U=U is dependent on maintaining a sustained undetectable viral load.”

# With thanks to...

- Patients and staff at the Mortimer Market Centre
- Judy Murrill, Trainee Clinical Psychologist
- Fiona Rooney, Trainee Clinical Psychologist
- Bloomsbury Patient Reps
- Dr Al Teague, Consultant HIV Physician
- Dr Laura Waters, Lead HIV Consultant