500 sexual partners this year

the essential involvement of people living with HIV in research

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Conflicts

I have no financial conflicts of interests relating to this talk.

Outline

- Community interest in modelling studies for healthcare?
- What is the development process?
- What assumptions are made?
- Eg: - Missed and/or inaccurate data.
  - Approaches that could help.
  - Use of appropriate language and assumptions.
- Transgender rights and missing data.

Gateways to our care

- Modelling studies are a gateway that enables access to treatment or a way to block that can restrict access.
- Modelling in cost effectiveness studies produces different results for commissioning (vaccines), prevention (PrEP), side effects (New-fill), new drugs (HCV DAAs) etc.
- Results depend on the questions asked, assumptions and quality of the data.
- Missing essential data will affect the outcome.
- Community knowledge can help at all stages.

Conflicting results: HPV for boys

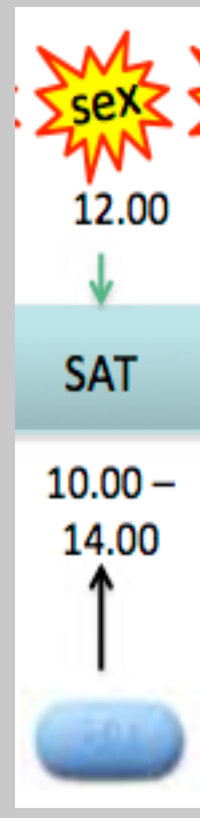
- UK JCVI modelling reported vaccination for boys was not cost effective in 2007, 2914 and 2017. *(JCVI interim statement. 2017).*
- Meta analysis of 9 studies showed gender-neutral programmes were cost effective in 4 studies, and only in alternative scenarios in another 4. *(Linertova R et al. 2021).*
- Dutch study reported cost effective in boys with an overall ICER estimated at €7310 per QALY gained. (*Simons JJM et al. 2020).*

Conflicting results: PrEP

- PrEP in MSM population costs less than $100,000 per QALY gained. (Jussola JL et al. 2012).
- PrEP costs $298,000 per QALY gained among high-risk MSM. (Paltiel et al. 2009).
- PrEP in high-risk men in New York City costs $32,000 per QALY gained. (Desai et al. 2008).

BUT

- No PrEP scenarios were cost-effective in heterosexual men in South Africa at a willingness-to-pay threshold of $1175/DALY averted. (Vogelzang M et al. 2020).



Data not collected?

- How to check various models when results can be complex and conflicting?
- *Impact of funder bias, political implications?*
- What happens with lack of data?
  - All health services for transgender people.
  - Support services for chemsex-linked mortality – still no simple answer on annual rates.
  - Still no data on PrEP in trans men.

Collecting data sexual health

A sexual behaviour survey partner number over 6 mo.

0	1	2-5	5-10	>10

- Why pick this upper limit?
- Why is partner number needed?
- Is risk more appropriate?
- How is risk defined?
- Was employment considered?

>10 vs 500 partners?

- Sex-on-premises venues easily enable contact with >10 people in a single visit.
- Does sexual contact = number of sexual partners?
- Is contact dependent on risk? Ie COVID? mpox? HIV?
- Is risk adjusted: 500 partners with U=U or PrEP or condoms vs 5 partners with none of the above protection?
- Is sex work considered?
- Would researchers know about chemsex and partner numbers and would this be asked? (possible surrogate).

Data collection and language

- Language and format can decide who continues with a survey or how representative the results are.
- Language sensitivity can either positively engage or negatively push people away.
- Using "HIV infected" will make an HIV survey unusable (peoplefirstcharter.org).
- Similar examples affect all populations:
  - 2-stage questions to include transgender data. (1) What is your gender? and (2) is this the same as your sex assigned at birth?

Suggested guidelines

- Actively engage with community and include input from the first stages - find out the gaps we have.
- Connect before you even have a research study.
- Encourage equal partnerships - in aims, enrolment and results.
- Prepare to listen and change even if this challenges your professional ideas. (Optima study and PROUD study).

Holodniy M et al. Plos ONE 2011.

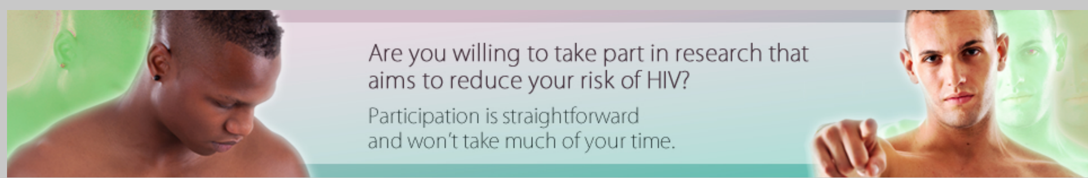
Example: Optima study

Optima
OPTIONS IN MANAGEMENT WITH ANTIRETROVIRALS

- Options in MDR HIV: >20 years ago
- 2x2 factorial randomisation:
  - (i) Fewer drugs vs mega-ART?
  - (ii) Direct switch or after 12 wk interruption.
- *Community feedback: equipoise on both questions was too complicated: just randomise to one.*
- Only enrolled 390/1700 over five years.
- UK study switched to single randomisation.

McCormack S et. Lancet 2016

Example: PROUD study



- Groundbreaking UK pilot study of PrEP in gay men.
- Radical design for UK data (FDA-approved in 2012): immediate vs deferred PrEP. *Community co-chair.*
- “placebo would be unethical, enable access for all, include any sex with men (not just passive), have a DSMB…”
- Community meetings and statements helped enrol.

Transgender rights

- Medicalised: doctors gatekeep access to gender affirming surgeries and hormones.
- Long waiting times: years for appointments and more years for surgery. Puberty blockers now illegal.
- Review of adult gender clinics could further restrict trans healthcare.
- Need to support/advocate for trans rights. For equity, to end discrimination.

Learn more, connect & support.

Learn more, connect & support

TransActual @TransActualCIC

https://x.com/transactualcic

Trans Safety Network @trans_safety

https://x.com/trans_safety

What The Trans @WhatTheTrans

https://x.com/whatthetrans

Thank you

Thanks for comments and support

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Additional slides