

Institution: University of Sussex
Unit of Assessment: UoA 32 Philosophy
Title of case study: Improving understanding of the ethics of sexual health and disease
<p>1. Summary of the impact</p> <p>This case study focuses on impact that has occurred because of the research of faculty member Lucy Allais in the areas of disease and sexual health. Impact includes:</p> <ul style="list-style-type: none"> • Influencing the ethical outlook of HIV health-workers and policy-makers on issues surrounding HIV testing and transmission • Influencing the design of a cholera drug trial • Influencing public opinion, through the medical and general media, on TV, in newspapers and blogs, on philosophical questions to do with HIV and sexual health.
<p>2. Underpinning research</p> <p>Allais is an internationally-recognised Kant scholar who has worked at Sussex since 2004. In connection with her Kantian background, she has developed an interest in ethics [see Section 3, R1], and particularly matters related to notions of personal autonomy, personhood, and rights, as they pertain to healthcare and disease transmission. Her work on the sexual ethics of disease transmission and of mandatory testing stems from this interest, since each raises questions about its relationship to the infringement of one's own and others' rights, and the exercise of personal autonomy. With Dr Francois Venter, a former President for the Southern African HIV Clinicians' Society, she has co-authored two articles, which are the underpinning research for this study. [R2, R3]</p> <p>In 'HIV, logic and sex' [R2], Allais and Venter identify two problems with the widely accepted explanation of the dramatically high rates of HIV infection in sub-Saharan Africa: that HIV prevalence is due to a supposedly distinct model of sexual partnering referred to as 'multiple concurrent partnerships' or 'concurrency', common in the region. They argue that the 'concurrency' explanation does not contribute to understanding the unusual rates of HIV infection in the region; that there is no single 'concurrency hypothesis', and that the term 'concurrency' is imprecise and does not pick out one distinct form of sexual behaviour, so is not explanatorily useful.</p> <p>In 'Exposure ethics: does HIV pre-exposure prophylaxis raise ethical problems for the health care provider and policy maker?' [R3], Allais and Venter argue that, contrary to widespread opinion within the medical profession, the development of HIV pre-exposure prophylaxis (PrEP) does not raise new ethical concerns. They suggest that some of the questions posed by PrEP are not specific to HIV prophylaxis, but are simply standard public-health considerations about resource allocation and striking a balance between individual benefit and public good. They consider sexual disinhibition in the context of private prescriptions, and conclude that only unjustified HIV-exceptionalism (treating HIV as different, in moral terms, from other infectious diseases) or inappropriate moralism about sex supports the thinking that PrEP raises new ethical problems. This negative conclusion is significant in a context where supposedly ethical concerns about PrEP have been raised, and in the context of HIV exceptionalism.</p>
<p>3. References to the research</p> <p>R1 Allais, L. (2008) 'Wiping the slate clean: the heart of forgiveness', <i>Philosophy and Public</i></p>

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Affairs, 36(1): 33–68.

R2 Allais, L. and Venter, W.D. (2012) 'HIV, logic and sex in Africa', *Preventative Medicine*, 55(5):401–404.

R3 Allais, L. and Venter, W.D. (2013) 'Exposure ethics: does HIV pre-exposure prophylaxis raise ethical problems for the health care provider and policy maker?', *Bioethics*, 2013 Jun 24. doi: 10.1111/bioe.12021. [Epub]

Outputs can be supplied by the University on request

4. Details of the impact

The impact of this research takes three main forms.

- **Increasing the ethical understanding of HIV health-workers and policy-makers**

As a result of their publications, and presentations to exclusively medical audiences (e.g. 5th International AIDs Conference, Durban, South Africa, 2011), Allais and Venter's work has enhanced the ethical understanding of HIV health-workers and policy-makers. Evidence of this takes two forms.

- First, Allais was invited to participate in a closed World Health Organisation meeting on HIV self-testing ('The Legal, Ethical, Gender, Human Rights and Public Health Implications of HIV Self-Testing Scale-up, Brocher Foundation, Geneva, 8–9 April 2013). The aim was to see whether there is a broad consensus about going forward with developing self-testing and scaling it up, and to identify research questions, including ethical concerns, which need to be addressed. Fifty doctors and academics, of whom Allais was the only philosopher, were invited to develop ideas in discussion (rather than via papers). The meeting jointly produced a consensus statement on the legal, ethical, gender, human rights, and public health implications of HIV Self-Testing scale-up, published in the wider 'Report on the First International Symposium on Self-Testing for HIV: The Legal, Ethical, Gender, Human Rights and Public Health Implications' [see Section 5, C1], now available on the WHO website. Following the meeting, Allais was invited to submit for consideration to the journal *AIDS and Behavior*, an abstract entitled 'An evaluation of the ethical and human rights considerations of HIV self-testing'. She was then invited to develop the abstract into an article for publication as part of the March 2014 special edition of the journal on HIV self-testing. In addition, the review panel suggested by email [C2] that she and Professor Anne Scott (Head of the School of Nursing, Dublin City University) collaborate in further bringing to light the ethical and human rights issues addressed by the abstract.
- Second, positive influence is attested in communications to the Philosophy Department, following presentations of Allais and Venter's work both on HIV status-ignorance (presented by Allais), and the 'concurrency' explanation (presented by Venter), at the Royal Sussex County Hospital in Brighton in December 2012 [C3]. Several participants commented on how what they had heard had informed them and caused them to think differently about the issues. For instance: 'It made me think differently about a question that arose more than once afterwards, which was whether some form of "compulsory" testing might compensate for the increasing rates of STIs, HIV and unprotected sex. My immediate response would have been negative, but especially the philosophical presentation/discussion and the narrative on the South African experience made me think twice' (Chief Executive of HIV Scotland until October 2011); and 'What I found particularly useful was the integration of philosophical considerations with multidisciplinary clinical research disciplines... Particularly for me it brought to the fore the importance of philosophical and ethical considerations' (Reader in Palliative Care, King's College London). A researcher from the Tuke Institute attended the event, and in October 2013 Dr Rupert Whitaker, co-founder of the Terrence Higgins Trust and founder of the Tuke Institute, approached Kathleen Stock with a view to

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organising a multi-disciplinary research group on Rights and Responsibilities in HIV at Sussex, including Philosophy.

- **Positively influencing the design of a cholera drug trial**

Allais's work has led to her involvement in the design of a cholera drug trial. Helen Rees, a doctor and vaccine expert at Witswaterand, recommended Allais to the organiser of the trial at the Center for Vaccine Ethics and Policy at NYU/Wistar Institute/CHOP on the basis of Allais' research. Allais was invited to comment on the trial and her comments are reproduced in their entirety (pp. 51–53) in the White Paper which followed [C4]. Her comments concerned the use of a placebo in the trial, whether informed consent would be achieved from socio-economically deprived participants, the compensation of any harm resulting from the trial, the need for community involvement in it, and the training that would be given to the research ethics committee. Correspondence from the Center's Director [C5] attests that 'This consultation was complex insofar as it was proposed to be conducted in a country where the vaccine in question was already licensed, and was already WHO pre-qualified as a two-dose regimen. Ms. Allais shared important insights and perspectives which assisted us in framing our final recommendations and the final white paper. We were please to include some of Professor Allais' direct comments in the appendix reserved for this purpose'.

- **Influencing public opinion, through the medical and general media, on TV, in newspapers and blogs, on philosophical questions to do with HIV and sexual health**

Allais and Venter's work has also caused follow-up articles in non-academic media, which have had the effect of informing public opinion:

- 'HIV, logic and sex' is referenced in an article 'Immune activation, inflammation, and HIV acquisition risk', on the medical blog of the Treatment Action Group's 'Michael Palm Basic Science, Vaccines and Prevention Project' [C6].
- Allais' work was discussed in a South African national newspaper – *Times Live* – blog article, 'Philosopher's view on HIV testing and human rights' (9 June 2011) [C7].
- In November 2012, given her expertise in sexual ethics as a result of her work on sexual health, Allais was a panellist in a public debate, 'Should consenting adults be allowed to pay and be paid for sex?'. Allais argued that sex work should be decriminalised. She was subsequently interviewed for radio and primetime TV news slots. According to media monitoring services at the University of Witswaterand, the debate generated exposure of about R 230,650 (£14,120) in Advertising Value Equivalency (AVE), and an estimated PR value of R 922,600 (£5,638,315). Her talk also was discussed in South African blog *The Daily Maverick* (21 November 2012) [C8].
- In April 2013, as a result of this exposure, Allais was invited as a guest on '3 Talk with Noeleen', a popular daily chat show on national television channel SABC3, to discuss the decriminalisation of sex work.

5. Sources to corroborate the impact

- C1** WHO (2013) *Report on the First International Symposium on Self-Testing for HIV: The Legal, Ethical, Gender, Human Rights and Public Health Implications*. Geneva: World Health Organisation.
- C2** Email from World Health Organisation, available for reference.
- C3** Emails from participants to Kathleen Stock, Head of Sussex Philosophy, available for reference.

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- C4** Center for Vaccine Ethics and Policy, VI-NICED OCV (Oral Cholera Vaccine) Trial Ethics Consultation White Paper/Project Summation, 2012.
- C5** Letter from Executive Director, Center for Vaccine Ethics and Policy, to Kathleen Stock, Head of Sussex Philosophy.
- C6** Link to article 'Immune activation, inflammation, and HIV acquisition risk' (21 August 2012) in the Treatment Action Group's 'Michael Palm Basic Science, Vaccines and Prevention Project' blog, http://tagbasicscienceproject.typepad.com/tags_basic_science_vaccin/2012/08/immune-activation-inflammation-and-hiv-acquisition-risk.html
- C7** Link to newspaper blog article 'Philosopher's view on HIV testing and human rights', by Claire Keeton, *The Times*, South Africa, 9 June 2011, on Allais' discussion of HIV testing and human rights: <http://blogs.timeslive.co.za/hiv/2011/06/refusing-to-find-out-your-hiv-status-is-not-a-human-right-philosopher/>
- C8** Link to article 'The hard sell in selling sex' by Nicola Fritz in *The Daily Maverick*, discussing Allais' talk 'Should consenting adults be allowed to pay and be paid for sex?' <http://dailymaverick.co.za/opinionista/2012-07-25-the-hard-sell-on-selling-sex>