

<b>Institution:</b> Goldsmiths, University of London
<b>Unit of Assessment:</b> Sociology
<b>Title of case study:</b> Building capacity for HIV prevention
<b>1. Summary of the impact</b> (indicative maximum 100 words)

Rosengarten's work during the past fourteen years has provided the HIV field with new ways of rethinking otherwise seemingly intractable problems of more effective prevention. Despite over 30 years of biomedical and social research, and policy and programme implementation, the HIV epidemic continues to grow. The efficacies of repurposing potentially toxic and partially effective antiretroviral drugs for prevention in those perceived at risk of infection has thus come under scrutiny. It is in this context that Rosengarten's work has intervened and introduced an alternative approach to prevention that directly scrutinises the social contexts in which people live and work with HIV. Through this approach and her active engagement with clinicians, policy makers, scientists and advocacy groups she has contributed critical insights that have been incorporated into approaches to HIV prevention in practice.

<b>2. Underpinning research</b> (indicative maximum 500 words)
--

Rosengarten was appointed at Goldsmiths as lecturer in September 2004; she is now Reader. Her collaborator, Mike Michael, was appointed at Goldsmiths as lecturer in April 1998 and is now Professor (0.2 FTE).

The design and delivery of HIV prevention interventions has traditionally relied on a deficit model of the knowledge and resources of individuals and populations. As a consequence, it has been unable to consider adequately the complex ways in which interventions affect but are also affected by the contexts in which they are delivered. Rosengarten's research since 1999 has worked towards a more comprehensive understanding of *how* these interventions work. In 1999, in collaboration with Race and Kippax, she showed how newly introduced antiretroviral drug treatments were altering conceptions of risk and risk minimisation practices. The collaboration identified a new sexual risk minimisation practice, later termed 'strategic positioning' and made apparent how clinical conceptions of reduced individual viral loads were fracturing a more homogeneous approach to risk otherwise reliant on condom use.

In 2009, Rosengarten published her monograph *HIV Interventions: The Traffic in Information and Flesh*, which expanded this work by drawing on feminist theories of materiality as well as Science and Technology Studies. It radically revised the bifurcation of thinking on HIV into the biological and the social, reconceptualising the work of HIV diagnostic technologies and other interventions. Interventions such as antiretroviral drugs and diagnostics (for example the HIV antibody test and the viral load test) as well as concepts of gender, ethnicity, race and sex, were shown to be active in shaping the changing HIV epidemic.

In 2008, Rosengarten began a highly productive and innovative collaboration with Mike Michael, Professor of Science and Technology Studies (STS), which has developed a process-oriented theoretical approach to HIV. The work has focussed primarily on the clinical trialling and recent US approval of PrEP, a pill-a-day pre-exposure prophylaxis intervention of antiretroviral drugs. The work offers new conceptual tools for conceiving of PrEP and, by implication, the epidemic. PrEP - not unlike what could be argued of other 'objects' - is presented as a multiple entity, emerging as such in relation to heterogeneous context specific phenomena. For instance, PrEP can be a prophylactic, a marker of international exploitation, and the occasion for the renegotiation of sexual practices. This way of viewing PrEP contrasts significantly with the current reliance on behavioural surveillance and structural analyses, allowing for a conception of the HIV epidemic affected by as well as affecting interventions.

Outputs from the collaboration include numerous invitations to participate in biomedical and policy oriented forums, keynote conference papers, journal articles, chapters and a book to reframe the 'goldstandard-ness' of randomised control trials, bioethics and evidence. With Michael, Rosengarten

**Impact case study (REF3b): GOLDSMITHS – HIV prevention**

has demonstrated that randomised control trials and bioethics close down understandings of the complex manner in which prevention - and notably, PrEP - does or does not emerge.

Rosengarten and Michael's timely work on the increasing predominance of biomedical approaches to prevention is now animating ideas across the HIV field. In particular, Rosengarten has drawn on this to found the Association for the Social Sciences and Humanities in HIV (ASSHH). This growing international organisation has been designed to achieve greater impact by the social sciences in the field of HIV, supporting multidisciplinary collaborations and new modes of thinking about HIV interventions.

Rosengarten's research is being further advanced through her establishment of a doctoral research group who are influencing understanding of how biomedical protocols are shaped by the challenge of dealing with stigma factors; how pregnant women with HIV do not necessarily share biomedical understandings of antiretroviral drugs for prevention of mother-to-child transmission; and how the history of the epidemic offers a space for those living and working with HIV to reflect on how HIV science is entangled with gay sexuality, activism, memory and loss, and specific clinical and research practices.

**3. References to the research** (indicative maximum of six references)

Evidence of the quality of the research: Reference 1 was accepted as a commentary piece in the high-ranking international medical journal, *The Lancet*. Reference 2 was awarded the BSA Sociology of Health and Illness book prize in 2010 as the book 'making the most significant contribution to medical sociology/sociology of health and illness.' A recognised and distinguished academic publisher also published it. Refs 3, 4 & 5 are articles published in refereed journals.

1. Rosengarten M, Michael M, Mykhalovskiy E, Imrie J (2008) 'Dealing with the challenges of technological innovation in HIV prevention and treatment.' *The Lancet*, 372 (9636): 357 – 358. DOI: 10.1016/S0140-6736(08)61140-X
2. Rosengarten M (2009) *HIV Interventions: Biomedicine and the Traffic in Information and Flesh*. University of Washington Press. (REF output)
3. Rosengarten M, Michael, M (2009) 'The performative function of expectations in translating treatment to prevention: the case of HIV pre-exposure prophylaxis or PrEP.' *Social Science & Medicine*, 69: 1049-1055. (REF output)
4. Rosengarten M, Michael M (2009) 'Rethinking the bioethical enactment of drugged bodies: On the paradoxes of using anti-HIV drug therapy as a technology for prevention.' *Science as Culture*, 18: 183–99. DOI:10.1080/09505430902885565
5. Holt M, Murphy DA, Callender D, Ellard J, Rosengarten M, Kippax S, de Wit JBF (2012) 'Willingness to use HIV pre-exposure prophylaxis and the likelihood of decreased condom use are both associated with unprotected anal intercourse and the perceived likelihood of becoming HIV positive among Australian gay and bisexual men.' *Sexually Transmitted Infections* 88(4): 258-63. doi:10.1136/sextrans-2011-050312.
6. Michael M, Rosengarten M (2013) *Innovation and Biomedicine: Ethics, Evidence and Expectation in HIV*. Palgrave Macmillan. (REF output)

**4. Details of the impact** (indicative maximum 750 words)

Rosengarten's Australian-based research provided the HIV field with an awareness of how the introduction of antiretroviral drugs changed conceptions of risk and risk minimisation practices. It has directly informed policy and prevention education by the Australian Federation of AIDS Organisations<sup>[7]</sup> and has gone on to influence understandings of HIV prevention including randomised trials for HIV prevention in a number of other countries including Canada, Peru, South Africa, Thailand, the United Kingdom and the United States.

Rosengarten's more recent research is now providing the international HIV field with insights into devising more ethical and effective prevention interventions.<sup>[8][9]</sup> Her work on PrEP provides a radical

**Impact case study (REF3b): GOLDSMITHS – HIV prevention**

rethinking of this drug, showing that new forms of interdisciplinary collaboration are needed for more user-friendly and effective interventions.<sup>[10][11]</sup> It has provided new ways of thinking and working that allow scientists, clinicians, policy makers, implementers and social researchers to develop new ways of conducting effective randomised control trials, demonstration studies, and prevention policies.

She has responded to many invitations to address clinical trialists, epidemiologists, clinicians, policy makers, implementers and user advocates;<sup>[12][13][14][15]</sup> to act as co-principal investigator on randomized control trials;<sup>[7]</sup> and she has attracted the participation of those advising on medical guidelines and policy in international forums.<sup>[9][15]</sup>

Rosengarten has led actors within the HIV field to devise new approaches to user interventions such as condoms, pills and needles. It is this activity from which the Association for the Social Sciences and Humanities in HIV (ASSHH) emerged in 2009. ASSHH (Rosengarten founder and Chair 2011-2013) has attracted the interest of biomedical researchers, policy analysts, implementers and advocacy organisations.<sup>[16]</sup> Non-academic participants which represent people living with HIV include the International AIDS Society (IAS), The Global Fund to Fight AIDS and Tuberculosis and Malaria, International HIV/AIDS Alliance; Australian Federation of AIDS Organisations (AFAO); The Zambia AIDS Related Tuberculosis (ZAMBART), Zambia; British HIV Association (BHIVA); Joint United Nations Programme on AIDS (UNAIDS); World Health Organisation (WHO); and AIDS Vaccine Advocacy Coalition (AVAC).

Through her publications and all of these activities and direct engagements with clinicians, policy makers, scientists and advocacy groups, at a global level and at a number of national levels including the United Kingdom, the following groups of people have benefited from her work: people living with HIV; people at risk of contracting HIV; people targeted as 'experimental subjects' in 'offshore biomedical trials'; HIV specialist clinicians; HIV scientists; HIV international policy analysts and programmers; HIV advocacy organisations; and, HIV prevention educators.

How have they benefited? People living with HIV, people at risk of contracting HIV, advocacy groups, clinicians, scientists, public health policy analysts and programmers and prevention educators have benefitted as a consequence of Rosengarten's attention to the dynamic processual and increasingly heterogeneous area of HIV prevention. She has reconceptualised and extended understandings of antiretroviral drugs as agents affecting risk perceptions and practices, thereby explaining and offering new ways of intercepting modes of HIV transmission.

HIV international policy analysts and programmers, HIV activist organisations, and HIV social scientists have benefited through the rethinking of Pre-Exposure Prophylaxis as a multiple entity, contingent on the context of its use and immensely complex in its generative effects. This has enabled the HIV field to reassess intervention, moving beyond arguments for or against particular drugs in order to attend more closely to *how* context informs effectiveness and that context is itself open to transformation. For example, HIV policy and programming has benefited from acceptability studies conducted with Holt et al., which has been cited in scientific journals that promote the uptake of research findings into routine healthcare in clinical, organisational or policy contexts.<sup>[17]</sup>

People targeted as 'experimental subjects' in 'offshore biomedical trials' in Africa, South America and South East Asia have benefitted by inviting the attention of trialists, ethicists and social scientists to the performative and exclusionary effects of bioethics, thereby making possible broader consideration of the complex ways in which 'experimental subjects' are affected by trial participation and, in turn, affect trial enrolment, trial retention and trial outcomes. This has also been important to explaining why costly randomised controlled trials may achieve unexpected results.<sup>[7][9][11][14]</sup>

HIV specialist clinicians in the UK have benefitted through the articulation of how their concerns and experiences altered from a focus on palliative care to a biotechnology informed practice (e.g., viral RNA testing) with the introduction of antiretroviral drugs, reflecting an entirely different medical practice.<sup>[12]</sup> Furthermore, the doctoral research group that she established links Goldsmiths researchers with medical professionals at the Homerton, Middlesex and Royal Free hospitals in London and in 2013 will extend to clinics in Poland.

<b>5. Sources to corroborate the impact</b> (indicative maximum of 10 references)
---

All the material below is available in hard/electronic form from Goldsmiths Research Office on request.

7. Corroboration of Rosengarten's role as Co-investigator can be provided by a representative of the Victorian PrEP demonstration project at Monash University, Australia. [contact details provided separately]
8. Cited in an International AIDS Society report by [Kippax S & Holt, M \(2009\)](#): 'The State of Social and Political Science Research Related to HIV'. Rosengarten's main contribution was a new conceptual approach to understanding the experience of living with HIV and being at risk of HIV.
9. Invited presentation: Rosengarten (2011) '*Ensuring prevention is effective because it is ethical: a social science perspective on new HIV Prevention options.*' [Foro Prevencion VIH](#) (p.5).  
 This was a public forum and stakeholder consultation event, "[New Perspectives on HIV Prevention: Opportunities and Challenges for Peru](#)" (organized by Unit of Health, Sexuality and Human Development/UPCH; UNAIDS and co-sponsors, HIV Knowledge Management Network, Ministry of Health and National Institute of Health of Peru, CONAMUSA. Lima, Peru, 2-4 Nov 11.
10. Invited presentation at *Controlling the HIV Epidemic with Antiretrovirals: From Consensus to Implementation* ([Plenary 6: The Social Science Perspective on TasP - Challenges and Opportunities](#)). International Association of Providers of AIDS Care (IAPAC), in partnership with the British HIV Association. Queen Elizabeth II Conference Centre, 23/09/13.
11. Invited presentation to the PrEP symposium at the [International Microbicide Conference](#) (Sydney Convention and Exhibition Centre, Australia, 15-18 April 2012). Attended by community advocates/people living with HIV, policy analysts, scientists, implementers, and clinicians.
12. Invited presentation to '[Making Sense of HIV at 30](#)' (Cumberland College, 12-14 June 2013). Participants included HIV specialist clinicians, Terrence Higgins Trust, Public Health England, and community organisations.
13. Invited presentation to '[HIV and biomedical prevention: re-framing the social science agenda](#)'. (workshop funded by Foundation for the Sociology of Health and Illness, convened by London School of Hygiene and Tropical Medicine; 17/12/12). Attended by HIV scientists, clinicians, policy advisors, National AIDS Trust.
14. Invited presentation to '[What has feminism done for global health?](#)' Chaired by Martin McKee, LSHTM, Richard Horton, Editor of The Lancet; John Snow Lecture Theatre, LSHTM, 24/01/12. Attended by public health advisors, policy analysts, implementers, advocates/people living with HIV.
15. Invited presentation to 'What is a Pill?' iPrEx (Chemoprophylaxis for HIV Prevention in Men Phase III clinical study) - Trial Investigators Meeting, Rome, Italy, 21-23 July 2011. Corroboration of Rosengarten's invitation and role at this event from the organiser can be provided on request to Goldsmiths Research Office.
16. Association for the Social Sciences and Humanities in HIV (ASSHH): see [History of the Association](#)' webpage which refers to Rosengarten's work.
17. Holt M, Murphy DA, Callender D, Ellard J, Rosengarten M, Kippax S, de Wit, J (2012)<sup>[5]</sup> cited by:
  - Hankins CA, Dybul MR (2013) 'The promise of pre-exposure prophylaxis with antiretroviral drugs to prevent HIV transmission: a review.' *Current Opinion in HIV & AIDS*, 8(1): 51-58. DOI: 10.1097/COH.0b013e32835b809d.
  - Galindo G et al (2012) Community member perspectives from transgender women and men who have sex with men on pre-exposure prophylaxis as an HIV prevention strategy: implications for implementation. *Implementation Science*, 7:116. DOI: 10.1186/1748-5908-7-116.
  - Wheelock A et al (2013) Are Thai MSM Willing to Take PrEP for HIV Prevention? An Analysis of Attitudes, Preferences and Acceptance. *PLoS ONE*, 8(1): e54288. DOI: 10.1371/journal.pone.0054288.