‘Ensuring prevention is effective because it is ethical: a social science perspective on new HIV Prevention options’

Paper presented by Marsha Rosengarten, Department of Sociology, Goldsmiths, University of London, United Kingdom m.rosengarten@gold.ac.uk

New Perspectives on HIV Prevention – Opportunities and Challenges for Peru Public Forum and Stakeholder Consultation, organized by Unit of Health, Sexuality and Human Development/UPCH; UNAIDS and co-sponsors, HIV Knowledge Management Network (CVCC), Ministry of Health and National Institute of Health of Peru, CONAMUSA (Peruvian CCM, including community representatives), Lima, Peru, 2-4 Nov 2011.

I would like to begin by thanking the organizers for inviting me to participate in this important meeting on New Perspectives on HIV Prevention held here in Peru, and especially Carlos Carceres.

My paper is based on my research as a sociologist of HIV, hence you will see it is rather conceptual in orientation. But to begin, I shall provide a little bit of background to my involvement in the epidemic. This should also give you some idea of the sort of ethics I propose. I sincerely hope that what I have to offer will be helpful for going forward in evaluating and planning for new interventions.

In the late 1990s/early 2000 I worked with Kane Race (here) and Susan Kippax to investigate the relationship between antiretroviral treatments and unprotected anal intercourse amongst self-identified gay men in Australia– a topic of immediate relevance to the strategy of Treatment as Prevention. The research brought me to the view that although antiretrovirals have turned an almost inevitable terminal disease into a chronic infection, there remains a need for HIV positive people to be able to envisage a life where they do not always have to use a condom (Rosengarten, Race & Kippax, 2000). I think this is a key point in thinking about prevention – not only how people without HIV are protected but how people *with* HIV can live in the best possible way.

The notion of what is meant by 'best' takes me immediately to the topic of ethics and whether it is possible to talk about what is 'best' without imposing some sort of normative notion of how people should conduct themselves. Although this might seem inevitable and might well be argued as desirable given we are in the business of HIV prevention, I'm not convinced that 'we' (as in here) need decide or defer to a norm. And I hope the reasons why I want to avoid imposing a normative approach will become clear, although this particular point will not feature in what I mainly want to discuss.

Since 2007 I've been following the development of PrEP (oral HIV pre-exposure prophylaxis), intrigued by the opportunities but also the challenges that it poses. With my colleague Mike Michael, Professor of Science and Technology Studies at Goldsmiths, I have co-authored as series of articles focused mainly on PrEP trials, including on bioethics that accompany such trials (Michael and Rosengarten, in press; Michael and Rosengarten, forthcoming; Rosengarten and Michael, 2010; 2009a; 2009b). Here I will propose that it may be valuable to rethink both interventions of PrEP and Treatment as Prevention (TaP) with the aim of achieving prevention that is effective *because* it is ethical. Ethics—as I am situating it—is thus about practice and this includes the practice of how we think or conceive of intervention. It can be characterized as a pragmatic ethics in contrast to what may be a more familiar ethics derived from moral philosophy.

For the chemist-come-social-theorist-of-science and ethics, Isabelle Stengers (1997), the 'AIDS Event,' as she terms the period prior to antiretrovirals, was characterized by the choice

of not yielding to the urgency of the strictly medical problem, of resisting demagogic and security-seeking temptations, in other words of trying to pose the problem clearly.' Posing the problem clearly was made possible by the inclusion of not only the usual 'experts' of science but also, as she puts this: 'those who represent what we know about the manner in which individuals, groups, and societies invent themselves by way of rules, laws and technical apparatuses' (1997:217.8). Prevention has not worked by imposing obligatory testing or forced disclosure but by designing programmes that enlist people to adopt practices in their perceived interests (Kippax & Holt, 2009;Kippax, 2010).

Following the argument of Isabelle Stengers (1997), I want to attempt a shift from thinking prevention according to what is 'technically' proficient—as, for example, we see in with randomized clinical trials testing for drug 'efficacy'—to intervention that incorporates, within it, strategies that enhance the lives of those affected by HIV. Without proceeding to rehearse the vast range of contributions from the social and biomedical sciences—including the psycho-social which seems to predominate—I'm going to suggest that prevention work relies on the presupposition of an 'HIV prevention user' who exists as pretty much 'given' and is distinct from the means of prevention. Always already conceived as independent of the means of prevention, 'he' or 'she' is assessed according to whether 'he/she' does or does not utilize prevention. If not, it is because:

1) He/she is deficient in knowledge or understanding that leaves him or her unable to act safely.
2) He/she is deficient due to asymmetries in power and situated in a deficit manner to what others may have ready access, for example, housing, food, education, safe forms of employment without discrimination and, again, leaving him or her unable to act safely.
3) He/she is deficient in responsibility causing him or her to be unable to act safely.

Although we may have a preference for one or even two of these, all can be said to assume and, indeed, enact HIV risk as comprised 'stand-alone entities,' that is, as if the epidemic consists of subjects and/or objects that are stable and distinct from one another. We imagine we are dealing with bodies, knowledge, rights, HIV, condoms, drugs, routes of transmission and so on that can be mixed and matched. Yet we know—intuitively and on the basis of evidence—that these 'objects' only have meaning in relation to each other and therefore are not so distinct or stable. Indeed we could say that they are not given but emerge to have particular effects only in association. The virus is of consequence when it is with the human body or in a laboratory study, not when it is independent of other phenomena. Antiretroviral drugs are made effective in their use or through monitoring of adherence or through their capacity to induce 'side effects' and so on. They, too, acquire their effect only in relation to other phenomena and, moreover, it is their effect that we are concerned with.

With PrEP, for instance, we assume we are faced with a finite pharmaceutical product and then ask what effect will it have? Will it cause 'disinhibition' or 'risk compensation,' where people are less concerned about HIV risk and are less vigilant in their sexual practice? But we

intuitively know and have the evidence to say that the effects of PrEP will be contingent on context specific phenomena.

There are many phenomena that might be considered to enter into making PrEP effective or not effective in some instances. I have compiled a rough and ready list of some that can be considered on an individual or on a population basis: access; cost; regular antibody testing; dosing adherence; metabolic absorption; route of transmission; seroconversion on PrEP – which means it is no longer PrEP but sub optimal therapy—and I will come back to this; assumption of negative status now on 'sub optimal therapy', high viral load due to process of seroconversion and having sex with HIV negative partner unknowing transmission while on PrEP, possible drug resistance while on 'PrEP-become (or slash)-sub-optimal therapy' (AVAC, 2008; Grant et al, 2005; Paxton et al, 2007).

The range of phenomena however need not or, as I am suggesting, should not be thought of as singular issues or events or activities. Important is how they affect each other. For example, metabolic absorption of the drugs needs to take place so that the drugs intercept with the route of transmission. For PrEP to be PrEP it will require antibody testing in order to ensure that it is not taken by someone who is already seropositive. Indeed if someone seroconverts while on PrEP, as I noted earlier, PrEP will no longer be PrEP. It will become 'sub-optimal therapy.'

The contingent nature of PrEP is a powerful example of how we are dealing with 'open' or 'fluid' objects that alter in effect and, consequently, we can say the object, itself, is no longer the same. Indeed, not only are these 'things' relational, their relational nature means that what we are dealing with is—as I'm sure you are well aware—an evolving dynamic. Moreover, it is a dynamic that is or can be directly affected by our interventions.

I now have another list. These are some of the 'things' that might emerge due to intervention: condom use by an individual and across a population; other sexually transmitted infections; more diversity in when condoms are or are not used; changes in sexual practice; new forms of sorting that are not necessarily serosorting; increased awareness of antiretroviral drugs and more engagement with health and medicine; shifts in appeal of PrEP; different attitudes and practices if PrEP and some form of Treatment as Prevention are introduced; more antibody testing; more engagement with HIV risk; reduced infections overall; more infections overall.

Although I would argue that the epidemic has always been driven by the relationality of different phenomena, the increasing biomedicalisation of the epidemic has brought new phenomena and, hence, has increased the relations or associations affecting what is taking place. If we consider both PrEP and Treatment as Prevention it would be stupid to not consider what they may do with each other. I purposely use the preposition 'with'—what they will do with each other—because it allows us to think about their capacity to co-affect each other. Will, for instance, both sexual partners in a regular serodiscordant relationship take antiretrovirals? On what basis will they make their decision? Could it be that the seropositive

partner will assert that it is better for his partner to take PrEP rather than he, himself, start treatment early because his partner will have protection in other sexual relations and he, himself, will be able to defer lifelong use of antiretrovirals?

While serodiscordant partners in a regular relationship may reach a decision on who takes antiretrovirals to prevent transmission, it is important to consider how the change in seropositive status—along the lines of variable and possible no infectivity—will affect sexual cultures and expectations. Will seropositive MSM introduce condoms because they are unsure about their viral load? Will seronegative men inquire not about status but about viral load? In other words, will HIV status become a variable entity that further fractures how people decide to have intercourse? Could we make this happen in place of a possible general assumption that treatments necessarily mean almost complete viral suppression? How can the introduction of one or both of these strategies be maximized to ensure living with HIV and risk of HIV is easier than at present and, in turn, makes the virus different to the threat it is with as well as without antiretrovirals?

In order to show how the increasingly biomedicalisation of the epidemic is giving rise to a more dynamic and open or fluid context, I think its worth reflecting on one of most power examples of a biomedical intervention that has affected all of us. The technology that I'm referring to is the contraceptive pill.

Without doubt, the contraceptive pill can be said to have altered just about every aspect of life or not life and irrespective of whether we, as individuals, have ever had occasion to use it. The contraceptive pill's entry into everyday life and even its prohibition in some places has affected not just reproductive practices and number of births but, moreover, femininity, masculinity, heterosexual sex, STIs, abortions and gender roles with follow on effects to the division of labour in the workplace and home.

What we don't usually think about is how 'it' – the Pill—has also been altered in the course of these changing dynamics. Since it was first introduced, the pharmacology of 'it' has been altered to reduce unpleasant side effects. It has also altered in form so that 'it' is not longer necessarily a daily pill but may be attached to the body in the form of a patch or it may be injected 3 monthly. Its use has also altered. Compared to its early popularity in countries such as the United States, knowledge of risks such as breast cancer or thrombosis and a more general skepticism about pharmaceuticals has led to a preference, amongst some, for other methods that initially declined with its introduction, including condoms (Edwards et al, 2000; Piccinino & Mosher, 1998).

Besides altering with time, it also performs differently in different contexts. I do not know the history of the contraceptive pill here in Peru but I feel fairly confident in saying it will not be identical to the Australian context. And I would not assume it performs in the UK, as it does in Australia. To put this succinctly, 'the pill' has changed through time and also within

space. Women, their male sexual partners, reproduction and contraception come together in different ways in different contexts to generate new contexts/new phenomena.

Not unlike the contraceptive pill, HIV prevention will continue to alter and so will those affected by HIV, as will the virus.

On the basis that we are dealing with an evolving epidemic, the task is then: how can we work with what is being generated rather than enacting the epidemic as comprising distinct stable objects?

Of course it may seem daunting to say that—as with the example of the contraceptive pill—the relations continue to widen. There is a multiplying effect with more and more and things to consider. But what I want to leave you with is a sense that, as much as the epidemic is increasingly complex and there are many things to consider, recognizing the complex and dynamic nature of an evolving epidemic opens up new possibilities.

In place of holding fast to the idea that there is a user whose 'lack' determines whether they will use a prevention technology correctly, I am proposing that we devise methods to study movement. If we want to find ways of utilizing antiretrovirals so that they achieve the prevention that is effective because it is ethical, we will need to investigate: what is enabling or disenabling prevention with antiretrovirals?

Some time ago, Robert Grant told me he saw the possibility for positive synergies between PrEP and testing, PrEP and treatment, PrEP and stigma, PrEP and counseling, and PrEP and complacency. PrEP could bring people into prevention care who had never been tested or counseled previously, and may help de-stigmatize testing and therapy. Although I have suggested we replace the preposition 'and' and use, instead, 'with'—for example, PrEP with testing, PrEP with treatment—if these sorts of outcomes are to be sought, we will need to reflect carefully on what we know and design more research that is more encompassing of the complexity that drives the epidemic.

Conclusion

I would like to finish by saying that I think this meeting is groundbreaking for a number of reasons. Most obviously because it brings such a diverse range of people together working across the epidemic and, therefore, transcends disciplinary boundaries as well as local/global and 'north/south' divides.

But it could also be groundbreaking for a further reason. The careful way that Carlos Carceres and his colleagues, here in Peru, have organized the meeting presents a unique or first of its kind opportunity to reflect on the question: What sort of research will enable the tailoring of programes that can enlist people to adopt practices in their perceived interests, including how antiretrovirals can be performed to achieve this?

To be effective, both PrEP and Treatment as Prevention require research programmes comprising novel methods that can move beyond a reliance on what I call 'the logic of the stand alone.' New methodologies and methods will be important if we are to effectively engage with the dynamic complexity of an evolving epidemic. The research will need to draw on the success stories that are too often overlooked in the pursuit of what Nancy Paidan et al (2008) have referred as a 'biomedical fix.' Indeed it will be important to recognize that there is, in fact, no such thing as a 'biomedical fix'! PrEP, Treatment as Prevention and other biomedical interventions do not and cannot stand apart from those they are intended for.

In sum, while the research programmes I am proposing will need to involve those at risk or living with HIV, the programme of inquiry needs to be much broader than a behavioural change model of 'a prevention user' or even a model that assumes different prevention technologies can simply be combined.

To return to Isabelle Stengers and my pragmatic concept of ethics where effects may be the guide, our aim over the next couple of days could be framed by the question: What will enhance prevention that is effective because it is ethical? Along these lines we would need to consider—as Kane Race (2009) has done in his extraordinary book *Pleasure Consuming Medicine*—the importance of pleasure in the achievement. Central to achieving effective prevention is its willing adoption by those for whom it is intended.

I know that the sort of rethinking I have proposed may seem to demand more of all of us and I think this is the case. But it also opens up new possibilities, possibilities that can and need to be utilised in association with what could otherwise remain controversial and challenging biomedical contributions.

References:

AVAC (2008) *Anticipating the Results of PrEP Trials: A powerful new HIV prevention tool may be on the horizon*. A publication from AVAC's Anticipating and Understanding Results series August 2008.

Edwards, J.E., Oldman, A., Smith, L., McQuay, H.J., & Moore, R.A. (2000) 'Women's knowledge of, and attitudes to, contraceptive effectiveness and adverse health effects' *British Journal of Family Planning* 26:73-80.

Grant, R. M., Buchbinder, S., Cates, W., Clarke, E., Coates, T., Cohen, M. S., Delaney, M., Flores, G., Goicochea, P., Gonsalves, G., Harrington, M., Lama, J. R., MacQueen, K. M., Moore, J. P., Peterson, L., Sanchez, J., Thompson, M., Wainberg, M. A. (2005) 'AIDS: Promote HIV Chemoprophylaxis Research, Don't Prevent It', *Science*, 30, September: 2170–1.

Kippax, S. & Holt, M. (2009) *The State of Social and Political Science Research Related to HIV*: a Report for the International AIDS Society.

Kippax, S. (2010) 'HIV-treatment as prevention: the exclusion of the social', invited paper at the HIV and Social Exclusion seminar at the Institute for Medical Anthropology and Medical History, University of Oslo in collaboration with the Norwegian Directorate of Health, Oslo: 18th June.

Michael, M. and Rosengarten, M. (forthcoming) 'HIV, Globalization and Topology: Of Prepositions and Propositions.' *Theory, Culture and Society*.

Michael, M & Rosengarten, M (in press) 'Quantitative Objects and Qualitative Things: Ethics and HIV Biomedical Prevention' in *Objects and Materials.* Penelope Harvey, Eleanor Casella, Gillian Evans, Hannah Knox, Christine McLean, Elizabeth Silva, Nicolas Thoburn and Kath Woodward. A Routledge Companion.

Paidan, N.S, Buvé, A., Balkus, J., Serwadda, D. & Cates, W. (2008) Biomedical interventions to prevent HIV infection: evidence, challenges, and way forward. www.thelancet.com Vol372 August16.

Paxton, L.A. et al, (2007) 'Pre-exposure prophylaxis for HIV infection: what if it works?' *Lancet*, 370: 89-93.

Piccinino, L.J. and Mosher, W.D. (1998)'Trends in Contraceptive Use in the United States: 1982-1995' *Family Planning Perspectives*, Vol. 30, No. 1: 4-10+46

Race, K. (2009) *Pleasure Consuming Medicine: The Queer Politics of Drugs*, published by Duke University Press

Rosengarten, M. Race, K. & Kippax, S. "Touch Wood, Everything Will Be Ok": Gay Men's Understandings Of Clinical Markers In Sexual Practise, Monograph 7/2000 Sydney: National Centre In HIV Social Research, 2000.

Rosengarten, M. & Michael, M. (2009a) 'Rethinking the bioethical enactment of drugged bodies: On the paradoxes of using anti-HIV drug therapy as a technology for prevention' Special Issue on 'Living Drugs' *Science as Culture.* Guest editors: Suzanne Fraser, Celia Roberts and Kylie Valentine.18,2:183-199.

Rosengarten, M. & Michael, M. (2009b) 'The performative function of expectations in translating treatment to prevention: the case of HIV pre-exposure prophylaxis or PrEP' *Social Science & Medicine*, 69, 7:1049-1055.

Rosengarten, M & Michael, M. (2010) 'HIV: pre-exposure prophylaxis or PrEP and the complexities of biomedical prevention' *HIV Treatment and Prevention Technologies in International Perspective* (eds.) Mark D M Davis and Corinne Squire, Palgrave.

Stengers, I (1997) 'Drugs: Ethical Choice or Moral Consensus' in *Power and Invention: Situating Science* University of Minnesota Press: Minneapolis & London.