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PrEP: time to rethink prevention, effectiveness and ethics?

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One of the more controversial interventions proposed for HIV prevention in those who test HIV antibody negative and perceived to be at risk is pre-exposure prophylaxis (PrEP) – a daily pill comprising one or two antiretroviral drugs manufactured by Gilead Inc. Besides the mixed results from multi-site randomised controlled trials (RCTs) seeking to establish the efficacy of PrEP (see iPrEX versus Fem-PrEP), concerns have been raised about PrEP's potential to undermine condom use, its cost implications in locales where treatment provision is still lacking and elsewhere, its potential to cause unwanted drug side-effects as well as possible drug resistance in those it fails to protect.

Nevertheless, continuing new infections and evidence that high adherence produces a strong protective effect are mobilising many public health authorities to devise feasible implementation models.

Most remarkable about the growing interest in PrEP is the exclusion of the social sciences from major forums where this work is taking place. One such example is a two-day forum held in the UK by IAPAC on the dual topics of treatment as prevention (TasP) and PrEP. The only non-biomedical speakers listed on the programme were a psychologist (speaking on adherence), a bioethicist, activists and public health officials linked to various national epidemics.

Indeed it won't come as a surprise to many to know that despite the millions of dollars to support RCTs for PrEP, the Bill and Melinda Gates Foundation have so far declined to support a substantial programme of social research on PrEP. In fact if we consider the bioethical requirements imposed on the conduct of RCTs for PrEP and other biomedical interventions, there is no ethical requirement for research on the social dimensions of the intervention during or post RCTs. This applies even when RCTs demonstrate candidate efficacy.

The multiple ways in which PrEP will unfold across the epidemic and the

absence of social scientific approaches to grapple with this multiplicity is worrying. Without doubt it underscores the need for this particular blog and other forums designed to enliven the social science contribution and increase its visibility. But the absence of social science also raises the question of what sort of social research should be called upon in response to the biomedicalisation of the epidemic.

Although not wanting to diminish what has already been achieved to date by the social and biomedical sciences, it is worth pointing out that much of this work has relied on the presupposition of an 'HIV prevention user' who exists prior to and remains largely distinct from the means of prevention or RCT technology. Always already conceived as independent of the means of prevention, 'she' or 'he' is assessed according to whether 'she' or 'he' does or does not utilize prevention. If not, it is because:

i) She/he is deficient in knowledge or understanding necessary for adopting safe practices.

ii) She/he is deficient due to asymmetries in power and situated in such a way to be without services that help mitigate against unsafe practices, for example: housing, food, education, safe forms of employment without discrimination.

iii) She/he is deficient in responsibility causing her or him to be unable to act safely.

Leaving aside any preferences we may have for one or even two of these accounts of 'the user', all can be said to assume and, indeed, enact HIV risk as if consisting of 'stand-alone entities.' These entities— for example, users, bodies, knowledge, rights, HIV, condoms, drugs, routes of transmission and so on—are imagined as present in a stable form prior to the risk event and ontologically distinct. This thinking is especially prevalent in RCT design, sometimes even the explanation for failure. The MIRA trial (Methods for Improving Reproductive Health in Africa) found that women in the candidate arm who were asked to use a diaphragm with a condom in sexual intercourse were less likely to sustain condom use than women in the placebo arm who were recommended to use only condoms. In other words, the combining of presumed distinct prevention technologies gave rise to women in the candidate arm being more at risk of HIV infection than those in the placebo arm. Here the 'additional' object (the diaphragm) did not enhance but, instead, diminished the capacity of the more protective object (the condom).[1] In sum, a logic of 'stand-alone' entities undermined prevention in the candidate arm, rendered ineffectual the statistical calculations necessary to a worthwhile trial and, it can be argued, raises the question of whether the logic of

‘stand-alone’ entities leads to a practice devoid of satisfactory ethics.

Importantly, the women in the MIRA trial, like many others negotiating the demands of HIV in the midst of complex and sometimes competing social relations, remind us that ‘objects’ such as condoms, diaphragms, pills etc. are not stable and distinct but emerge with heterogeneous effects in their relations with other phenomena.

Ironically, biomedicine also offers a reminder of the dynamic co-affective nature of the epidemic, even if those practicing it fail to fully comprehend their objects in this way: 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. Similarly antiretroviral drugs are made effective in their use; or through the 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.

As a guide to how we might extend the social science of prevention, I want to propose a rethinking of *prevention as that which is effective because it is ethical*. By hinging effectiveness to ethics, the relational aspects of intervention come into view. Put simply, if prevention is to take place—in this instance through the uptake of PrEP—it must perform an aligning with the varying interests of those it is intended for and, at the same time, affecting. More specifically, it must weigh in on some affects—most likely those of pleasure although this is complex territory in itself —well over others—such as coercion and homophobia —and do so by appealing in such a way that the effective user is able to emerge as such.[2]

By anticipating ethics as immanent in the affective work of practice it also becomes possible to become sensitized to dynamics that work against prevention. Particularly pertinent here is the manner in which PrEP has emerged. Its controversial nature cannot be disentangled from the technology of the ‘efficacy’ testing RCT and the legitimation of this process by bioethics. The legitimizing of RCTs in their current form where only a delimited set of effects are of concern—those that may incur more risks than benefits within the parameters of the RCT—excludes precisely that which the more everyday use of the candidate may generate. Here I am thinking in particular of concerns that PrEP may give rise to what is termed ‘risk compensation’ or may alter gender relations in such a way that women take responsibility for prevention as has happened with the contraceptive pill.[3] Crudely put, how has it come to be ethically legitimate to spend millions of dollars on the efficacy testing of a biomedical agent[4] without providing research into how it will affect the epidemic? Or, to turn the gaze on those who would otherwise neglect us and, at the same time, open for consideration the achievement of biomedical prevention more

generally: has bioethics usurped the role of social science as such by granting biomedicine greater license for its activities but less viability for its products? These questions and a host of others could become part of a different approach to prevention, effectiveness and ethics. To reiterate, by conceiving of effectiveness as an achievement of ethical design it may be possible to shift the logic of the stand alone as evident in the deficit individual and as exemplified in the MIRA trial and begin to work *with* PrEP as a highly relational entity. Working *with* PrEP means attending to how it emerges, including how it does so through the design of RCTs *and,* possibly, as part of the everyday relations involved in its uptake.

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[1] Rosengarten M, Michael M, Mykhalovskiy E & Imrie J (2008)'The Challenges of Technological Innovation in HIV' *Lancet* Aug 2;372 (9636):357-8.

[2] See for example: Race, K (2009) *Pleasure Consuming Medicine: The Queer Politics of Drugs,* Duke University Press, Durham & London; Gomart, E. (2004) 'Surprised by Methadone: In Praise of Drug Substitution Treatment in a French Clinic', *Body & Society*, 10 (2–3): 85–110.

[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*, Volume 69, Issue 7, October: 1049-1055.

[4] Peters A JTP, Micevska-Scharf M, Van Driel FTM, Jansen WHM (2010) 'Where does public funding for HIV prevention go to? The case of condoms versus microbicides and vaccines' *Globalization and Health* 6, 23:1-10

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