



Open Research Online

The Open University's repository of research publications and other research outputs

Embodied, clinical and pharmaceutical uncertainty: people with HIV anticipate the feasibility of HIV treatment as prevention (TasP)

Journal Item

How to cite:

Keogh, Peter (2017). Embodied, clinical and pharmaceutical uncertainty: people with HIV anticipate the feasibility of HIV treatment as prevention (TasP). *Critical Public Health*, 27(1) pp. 63–74.

For guidance on citations see [FAQs](#).

© 2016 Taylor Francis

Version: Accepted Manuscript

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.1080/09581596.2016.1187261>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

Embodied, clinical and pharmaceutical uncertainty: people with HIV anticipate the feasibility of HIV treatment as prevention (TasP)

Abstract

Evidence of the efficacy of HIV treatment as prevention (TasP) precipitated a highly optimistic global response and a radical re-design of HIV policy. Sociologists and others have framed TasP within promissory or enterprising discourses which require HIV prevention planners and people with HIV to engage in anticipatory assessments of risk and uncertainty. In 2013, I conducted focus groups with people with HIV in London, UK to explore their understandings and anticipations of TasP.

An environment of economic constraint obliged participants to triage clinical need and presentation and they expressed scepticism about the sustainability of pharmaceutical investment in treatment innovation. These perceptions were informed by an embodied knowledge of HIV which implies a construction of health as a form of capital that is finite and must be conserved. This is contrasted with a bio-medical construction of health as a form of capital that can be exponentially generated through investment. The imperative of conservation entailed by people with HIV's anticipations contrasts with the speculative economy of biomedical production entailed in planners' anticipations of TasP.

Rather than researching 'TasP acceptability' and considering whether people with HIV's behaviours constitute an obstacle to TasP's effectiveness, we should recognise that people with HIV are already involved in shaping what TasP is, what it will be and ultimately how it 'works'.

Key Words: HIV/AIDS; People with HIV; Treatment as Prevention; Embodiment, Bio-medicalisation, Focus Groups.

Background

HIV Treatment as Prevention (TasP) refers to the redeployment of pre-existing pharmaceutical anti-retroviral treatments to prevent HIV transmission by reducing levels of the virus in blood, semen, vaginal and rectal fluids to undetectable levels, thus rendering the person with HIV functionally non-infectious. Evidence of the efficacy of TasP emerged in 2011 when the HPTN 052 study found that early initiation of anti-retroviral treatments reduced HIV transmission by 96 percent in trial conditions (Cohen, et al., 2011, 2012). These findings precipitated an unprecedented global response. TasP was hailed as a 'serious game changer [that] will drive the prevention revolution forward' by Michel Sidibé, Executive Director of UNAIDS in 2011, whilst Hilary Clinton used evidence on TasP's efficacy to announce the goal of an 'AIDS free generation' by 2030. This future-oriented and optimistic rhetoric endures: the 2015 Vancouver Consensus Statement from the International AIDS Society asserts that 'The strategic use of [antiretroviral treatments] – through treatment and other preventive uses – can save countless millions of lives and move us vastly closer to our goal of ending the epidemic. A new era of opportunity against this epidemic has dawned, and we must seize it' (International AIDS Society Conference, 2015).

TasP inaugurated a shift in global HIV prevention policy towards biomedical approaches to preventionⁱ which in turn entail changes in treatment guidelines. CD4 count is a measure of immune function which indicates the progression of the virus, allowing decisions to be made about commencing anti-retroviral treatments. Prior to evidence of TasP's efficacy, antiretroviral treatments were not generally recommended until CD4 count fell below 250-300. However, in response to TasP, the World Health Organisation changed guidance to recommend commencing antiretroviral treatments at 500 (World Health Organisation, 2013).

The British HIV Association (the professional body of HIV physicians responsible for developing clinical protocols and guidance around HIV treatment and care in the UK) had been cautious in implementing the World Health Organisation guidance, awaiting evidence on potential benefits or harms of early antiretroviral treatment initiation (British HIV Association, 2014). In 2015, however, they recommended that people with HIV start antiretroviral treatments at *any* CD4 count. This is in response to early results of research which found that the risk of developing serious non-AIDS events was reduced in those starting treatment early (The INSIGHT START Study Group, 2015). However, the 2015 British HIV Association guidance notes that at the time of writing, these findings had not been published or presented at any open scientific meeting and that data on virological efficacy, drug resistance and toxicity, and the results of sub-studies examining effects on bone, neurological function, lung function, cardiovascular risk and quality of life, had not yet been reported (British HIV Association, 2015). Thus, this guidance reverses the traditional relationship between evidence and policy production with policy now *anticipating* evidence of efficacy, effectiveness and patient acceptability.

The aspirational nature of the British HIV Association guidance can be further appreciated when we place it within the context of global economic crisis and austerity policies. The guidance was developed in the wake of the most severe cuts to public sector funding in a generation, accompanied by a massive overhaul of England's National Health Service (Health and Social Care Act 2012). Clinical HIV services are currently subject to unprecedented scrutiny with regard to rationalisation and cost-saving. This has resulted in pressure to transfer the care of 'stable' patients as much as possible to primary care (general practitioners) and the development of treatment protocols which recommend fewer direct clinical consultations and more 'arm's length' management of HIV (Keogh, et al., 2016). Recent controversy over the funding of another pharmaceutical HIV prevention technology (pre-exposure prophylaxes, or 'PrEP') (Pebody, 2016) illustrate the extent to which pharmaceutical HIV treatment costs are being monitored and the

unwillingness of the UK Department of Health to increase these costs. The British HIV Association guidance implies increased rather than decreased pharmaceutical treatment costs as well as more rather than less contact between patient and HIV clinician/physician, thus placing it in conflict with the austerity policies of successive UK governments.

As I will show in this paper, these tensions and conflicts also play out in the experiences of patients. The UK has a socialised healthcare system that provides care and treatment free at the point of need. However, like most healthcare systems in post-industrial nations, the UK National Health Service has increasingly been the target of managerial and rationalising processes of economisation. Economisation implies the rationalisation of state resources and services according to over-arching cost-benefit criteria and cost-saving through homogenisation of treatment approaches. Inherent in economisation is the notion that resources are limited and hence need to be optimised or rationed (Kuhlmann & Saks 2008). Economisation also implies that the user of healthcare, the patient, becomes active in shaping their own healthcare use and provision (Bevir & Trentmann 2007; Clarke, et al 2007). Under economisation, the ideal patient becomes highly cost-aware and able to orient their use of healthcare services and treatments in ways that optimises health and minimises cost (Ewert 2009). This also implies that she develops an awareness of uncertainties or fluctuations in the market of healthcare and pharmaceutical provision and responds accordingly.

The British HIV Association guidance makes the role of the 'cost-conscious' patient somewhat more problematic in terms of how they are expected to engage with their treatment options. In the past, patients commenced antiretroviral treatments when health was compromised – as indicated by a clinical marker. Now, the guidance recommends that antiretroviral treatments should be commenced 'once [the patient is] ready to commit to taking therapy' (British HIV Association, 2015). Thus, rather than being faced with a choice of starting on anti-retroviral treatments or getting sick (an immediate embodied threat) the patient must now consider a more abstract future-oriented

equation: the future risk of deferring treatments versus the future benefits of starting immediately. The guidance further states that ‘the absolute risk of deferring [antiretroviral treatments] is one that an HIV positive individual might be reasonably, prepared to accept in the short term’ (British HIV Association, 2015). Thus, although the person with HIV always had to consider her future health and monitor it through biomarkers, this ‘future’ is now longer term, mediated and involves more abstract concepts such as relative infectiousness and the benefits of viral suppression on a population level. In effect, questions of enterprise and benefits beyond those that pertain immediately to the self enter into treatment decisions.

These changes can be seen as part of a process of *HIV biomedicalisation*. Re-framed by a promissory or enterprising language of expectation (Rosengarten & Michael, 2009), or ‘treatment possibility’ (Squire, 2012), antiretroviral treatments become less about treating current symptoms than reaping future health benefit (Clarke, et al., 2010). The imperative of living with HIV shifts from self-care in the face of illness to self-monitoring to maximise future health (Nguyen, et al., 2007; Squire, 2013). TasP extends this future-orientation by exhorting people with HIV to take treatments for their own future health *and* for the future health of their partner/s (in taking treatments to become less infectious) *and* for the population generally (by contributing to lowering the ‘population viral load’) (Nguyen, et al., 2011).

This future-orientation also entails questions of *uncertainty*, with much public health research focusing on factors likely to limit TasP implementation or effectiveness. However, as we have seen, people with HIV are also obliged to engage in anticipatory assessments of risk and uncertainty. This paper explores the futures that people with HIV anticipate for TasP and the uncertainties that inform these anticipations. In particular, I focus on anticipations of TasP’s *feasibility*. Such anticipations are not visible in the clinical, scientific and evaluative research and policy literatureⁱⁱ, but they are likely

to determine what TasP will be, whether (and how) it will be used and whether (and how) it will 'work'.

Methodology & Sample

Reviews have highlighted a lack of research into how people with HIV perceive TasP, with much research focusing on whether TasP is 'acceptable' to people with HIV (Young & McDaid, 2014). Acceptability studies often assume that a technology bears a fixed meaning with defined aims and a clear causative model to be 'tested for acceptability' on those who will use it. This approach casts 'producer' and 'user' in oppositional terms: the user being a group for whom the producer must make the product acceptable. In contrast, I assume that what a technology is, or will be, depends on how it is used and understood. TasP redeploys a pre-existing technology already imbued with manifold meanings and understandings. For example, many people with HIV will have considered their infectiousness in relation to their CD4 counts and viral load long before TasP was formalised. I therefore aimed to explore perceptions of TasP in relation to existing understandings and experiences of using, or not using, antiretroviral treatments.

I conducted focus groups of people with HIV to explore processes by which the group arrived at an understanding of TasP exploring tensions or disparities within these understandings. I also focused on experiential and embodied knowledge (understandings informed by bodily experiences and sensations) (Fainzang & Haxaire, 2010) by including prompts on the experience of taking treatments: on symptoms, side-effects and the clinical encounter. Forty-two people with HIV took part in six groups held at two HIV service agencies in South and East London. Service users in each agency were contacted through mailing lists and promotional posters telling them about the groups and encouraging them to tell others in their social networks. Participants had to pre-register for the group with a staff member of each agency. Participants received £10 cash to cover expenses. The

study received ethical approval from the University of Greenwich Research Ethics Committee and written consent was obtained from all participants. The composition of groups was as follows:

- 2 groups of gay/bisexual/men who have sex with men (MSM) (15 participants)
- 2 groups of African heterosexual men (13 participants)
- 2 groups African heterosexual women (14 participants).

The mean age of participants was 34 with a range of 22-68 years. The mean time since HIV diagnosis was 6 years with a range of <1-16 years. Thirteen of the 15 gay/bisexual/MSM and all of the African men and women were on anti-retroviral treatments.

This brief description belies the diversity of the sample in terms of ethnicity, migration status and sexuality. For example, over half of the MSM participants and all but one of the African participants were adult migrants and five of the MSM participants came from Black Caribbean or South Asian backgrounds. Moreover, although all the African participants identified as heterosexual and the vast majority of MSM participants identified as gay on their monitoring forms, discussion within all groups hinted at a more complex or fluid picture of sexual experience and identity. As such, this diversity – gender, age, ethnicity and residency status – shaped many of the experiences recounted within the groups. However, this paper presents just one part of the analysis which looked at anticipations of TasP for the self; and one's management of and expectations of one's health in relation to the imperatives brought to bear by TasP. What is noteworthy here is the uniformity of responses despite this diversity.

The groups explored factors mediating how TasP might be understood and used by people with HIV. I defined engagement with TasP as bringing an awareness of one's viral load (viral load measures how active HIV is in someone's body: the higher the viral load, the more infectious someone would

be) under treatment to bear on one's intimate and sexual life. Engaging with TasP thus implies attending to infectiousness or viral load through tests and diagnostics or considering going on treatments in order to control one's infectiousness.

In each group, the term 'Treatment as Prevention' was introduced and participants were prompted to discuss their understandings of the term. After this, participants were given a brief presentation which included a description and definition of TasP and findings from the HTPN 052 trial. This was followed by information about then current treatment guidelines from the World Health Organisation and the British HIV Association and a brief discussion about how these guidelines were predicted to change in the light of evidence of TasP's efficacyⁱⁱⁱ. Subsequent discussion focused on initial responses to TasP and factors likely to mediate engagement with it. As mentioned, I included prompts on taking treatments, embodied health, symptoms, side-effects and encounters with clinical specialists.

With participants' permission, groups were audio-recorded. Recordings were transcribed with any identifying features removed. Data were analysed thematically. Emerging themes were identified through detailed reading of transcripts and refined by comparing themes arising in one group to those arising across all groups. In this way, a final analytic framework was developed and data were then coded and entered onto this framework (Gale, et al., 2013) allowing for analysis of variation within themes and across groups (Silverman, 2000).

The groups were conducted during the summer of 2013. As discussed, this was a period of uncertainty in relation to the organisation of healthcare generally and of HIV care in particular. The global financial crisis was at its peak and the UK had endured severe cuts to public sector funding

accompanied by a massive overhaul of England's National Health Service (Health and Social Care Act, 2012). Clinical HIV services in London were under scrutiny with the aim of rationalising clinical services city-wide. There had also been controversy with regard to new block purchasing arrangements of HIV pharmaceuticals, raising the possibility that patients might be asked to switch to cheaper regimens of antiretroviral treatments (Weatherburn, et al., 2013). As we will see, discussion of economic factors and questions of austerity emerged spontaneously within and tended to dominate large sections of each group.

Findings

Findings are presented as two thematic categories: clinical uncertainty and pharmaceutical uncertainty. Clinical uncertainty is concerned with the effects on the clinical encounter, and, in turn, the feasibility of TasP in relation to the service rationalisations wrought by government austerity policies. Pharmaceutical uncertainty describes concerns about the future significance of HIV in terms of ongoing investment and innovation in pharmaceutical treatments.

Clinical Uncertainty

In light of the logic of economisation within the overarching context of austerity policies and cost-scrutiny of HIV clinical services, there was protracted discussion in all groups around clinical uncertainty: that is, concerns about the financial stability of HIV clinical services as currently provided in London and scepticism about the clinical feasibility of TasP.

Participants in all groups described busier clinics; in particular, physician consultations were becoming less frequent and were of a shorter duration.

Participant 1: *I've noticed more and more glancing at the clock when I see my consultant [HIV physician]. I understand he's a busy man and that we're all busy, but they may be asking us to go over to just one longer consultation per year.*

Facilitator: *What's that about do you think?*

Participant 1: *Cost saving, pure and simple. I understand that though, the money is tighter and the clinic is busier than ever [others agree].*
(MSM Group)

The notion that 'we are all busy' aligned the patient with the clinician as being equally effected by constraints and equally implicated in the management of scarce resources. The logistical concept of 'task-shifting' was employed when describing clinical consultations. Participants triaged their needs, sometimes consulting with HIV specialist nurses rather than HIV consultant physicians.

Participant 1: *The length of time between [physician] visits is getting longer. At other times, in between, I talk to the nurse. It depends on what you want to talk about.*

Participant 2: *Some things the nurse can do better than the doctor and the nurse can spend more time with you and make sure it's done right.*
(African women's group).

This clinical uncertainty influenced participants' perceptions of the feasibility of TasP. The first factor to emerge was that using treatments to prevent sexual HIV transmission implies a personal relationship between patient and doctor where sexual risk and infectiousness can be discussed, necessitating more rather than less contact with an HIV physician.

The doctors are busy so the patient needs to build the relationship too and that takes time. So it would take time for me to look at him and say: 'What can I tell him and what can I leave out?' (African men's group)

Sexual risk and infectiousness is a matter for discussion between clinician and patient within the context of a personalised relationship built up over time. The imperative to manage scarce clinical resources was seen as at odds with the imperative to build such a relationship: in short there was neither the time nor the money to do so.

Clinical resource concerns also animated discussion informed by contrasting knowledges of symptoms and antiretroviral treatments. Some participants questioned their physician's judgement

with regard to their symptoms, pitting their embodied knowledge – their sense or concern that they may be developing symptoms – against their physician’s clinical expertise.

These days they don’t even give you the proper test. Now I am on tenofavir and some other drug that affects the bone [density] and I ask can I have a test for the bones and [physician] says, ‘You don’t need it, I can see’. How can he see? I can feel it! (African women’s group)

Concerns over the cost and availability of diagnostic procedures were also taken into account when considering TasP. Many participants saw the viral load test as an indication of their infectiousness and therefore considered it as potentially a vital tool in sexual risk management. However, the current frequency of testing (every 3-4 months) was seen as insufficiently regular to operationalise within a personal risk management approach.

We get our bloods tested every 4 months and each time they say to you that it is undetectable. But how do you know it is undetectable in the times between? [...] It is good that we get that result every four months because it means that our treatments are going well and that we are healthy but it’s not enough to tell you that you are not infectious and you can do what you like. (African men’s group)

Thus, different types of knowledge come into play when considering TasP: the patient’s embodied knowledge in terms of how they feel and clinical diagnostic knowledge which is ascribed value but is not wholly reliable because it cannot be affirmed with sufficient frequency (Persson, 2012).

Concerns around the cost and quality of generic drug regimens informed participants’ anticipation of TasP. Participants were concerned about having to change combinations because of cost concerns, whilst TasP implied far greater numbers on treatment than at present.

Participant 1: *We are now getting cheap drugs because they are trying to save money so you have to think twice about what kinds of drugs you are being given and if they are working. Are the cheap ones going to disorient my system?*

Participant 2: *So they are talking about increasing the numbers of people on drugs and trying to reduce the cost^{iv}.*

A picture thus emerges of patients managing uncertainty around clinical provision connected in turn to over-arching economic uncertainty. The patient is active within the clinical context, engaged in a process of biomedical surveillance, scrutinising apparent and possible symptoms and taking part in a process of self-triage. The clinical encounter is not one where the patient approaches the physician with an undifferentiated set of symptoms, but engages with the clinician in making sense of symptoms, mobilising and questioning various forms of knowledge from embodied knowledge to clinical or diagnostic knowledge.

Cost and quality concerns inform patients' considerations of their treatment generally and TasP in particular. Participants perceived that the implementation of TasP required a frequency of consultation and diagnostic procedures that is currently unfeasible. Moreover, other UK-based research on TasP has revealed very similar cost-related concerns about the availability of such pharmaceutical HIV prevention technologies on the National Health Service (Young, et al., 2016). What these concerns illustrate is that, rather than being the passive recipient of TasP or demanding greater choice of treatments or care regimes to enable TasP implementation, participants questioned the feasibility and hence the future of TasP precisely because it mobilised questions of uncertainty in their current health care.

Pharmaceutical uncertainty

The second category, pharmaceutical uncertainty, speaks to a different set of economic relations. In particular it highlights the relationship between the patient and the industry that produces the pharmaceuticals she relies upon to treat her condition. The capacity of the pharmaceutical industry to innovate depends on revenue which, in turn, depends on more distant and unstable factors such as share prices and market performance. Discussions around the feasibility of TasP mobilised pre-

existing concerns around this 'pharmaceutical uncertainty' which in turn informed participants' anticipation of TasP as a biomedical prevention approach.

In the UK, biomedical monitoring ensures that people with HIV who are in care are now less likely to experience symptomatic HIV than previously; their experience of their prognosis and state of health is increasingly indicated by biomarkers such as viral load tests and CD4 cell counts. Such biomarkers establish a distance between the embodied experience – how HIV disease is *felt* – and the treatment response. That is, antiretroviral treatments are not commenced when the patient experiences symptoms, but prior to this based on a trigger removed from the patient's embodied experience. This reflects a tendency of biomedical technology to make the detection of illness the preserve of the diagnostician rather than the patient. In turn, this requires the patient to engage in ongoing clinical monitoring to ascertain how well her condition is responding to treatment rather than, or in addition to, attending to her embodied sensations and symptoms – how she feels (Rose, 2007).

Moreover, the use of biomarkers also allows for their recalibration in response to public health imperatives not necessarily connected to the patient's own health, for example the imperative of reducing population infectiousness to prevent HIV transmission. Thus, the implementation of TasP as a prevention approach and the recommendation that treatments are commenced at *any* CD4 count now implies that biomarkers such as CD4 and viral load counts are used simultaneously as indicators of the health of the individual patient and the health or otherwise of population level pharmaceutical HIV prevention (through the notion of 'population viral load').

In contrast to the bio-medical tendencies just described, embodied experience predominated in group exchanges about early commencement of treatments. These exchanges focused on the

perceived costs and benefits of antiretroviral treatments in relation to embodied health and symptomology. The perceived benefits of taking antiretroviral treatments are an absence of symptoms and increased life expectancy. However, perceived costs included actual or anticipated long-term side effects, in particular the potential impact of antiretroviral treatments on the liver, kidneys, bones or possible neurological damage.

Those of us who are on medications for 10 years, the results of that puts a completely different perspective on whether we would choose [TasP] or not. On the one hand, they kept us alive. On the other hand, we all now have serious side effects which might be worse than the HIV itself. (MSM Group)^v

Such concerns were also expressed by those diagnosed more recently, with some considering delaying treatment initiation to minimise the longer-term cost to health.

I was diagnosed with low CD4 which means I was infected a long time before. See thing is we don't know what the longer-term side effects are. If I had started taking treatments in my early 20s rather than having delayed them, I wouldn't know what state my liver would be in, so I'm glad I delayed. (MSM group)

Thus, many talked about the need for conservancy with regard to antiretroviral treatments: they were to be used in moderation – and preferably not at all – to mitigate the payback of side effects.

Understandings of the promissory nature of pharmaceutical production were rehearsed in the groups. Biomedicalisation is predicated on a logic of pharmaceutical advance that presupposes that treatments will become less toxic, easier to tolerate and that new treatments will combat the side effects of the old.

I remember a time when taking your pills was a full-time job. You had so many to take, things you could and couldn't eat and most of us felt like death warmed up the whole time. They were nearly worse than HIV! You put up with the pain because they were going to keep you alive until a time when they had better treatments. And that's what happened in the end. [...] Now you take them, and you don't feel anything but you worry about the long-term effects on your body, but it's the same thing. They're keeping you alive. You can't worry about the side effects until you have them and then you cross that bridge when you come to it. (MSM group).

However, this understanding of pharmaceutical treatments as promissory also engendered more sceptical responses.

Participant 1: *The thing with what you are saying [referring to TasP] is that we all go on treatments as early as possible and we all take as many treatments as we can so that we don't give it to anyone else and, you know, don't worry about the side effects or having all your bones breaking and no liver by the time you are fifty because by then, there'll be a pill for that too. But that's like saying, 'Oh just invest in my pension scheme and by the time you're sixty, we'll have made enough money for everyone to retire'. But what if there are no advances? What if the money dries up or the pharma companies lose their interest and stop making the drugs we need for the side effects? Then we're all high and dry*

Participant 2, 4 and 5: *That's it, that's the trouble. I agree.*

Participant 1: *I get the infectiousness thing, but it's not that simple. You're looking for us to take a risk with our future health and if you've survived once, you think about that twice. (MSM Group)*

Thus, tensions between embodied experience and biomedical practice inform uncertainty about the feasibility of TasP. This uncertainty coalesces around the potential for long-term embodied 'health' (the absence of disability) balanced with questions about continued investment in pharmaceutical innovation. Again, embodied and material concerns mediate constructions of TasP, which in turn entangles the person with HIV in negotiations and decisions – the parameters of which are profoundly future-oriented or promissory in nature.

Discussion

This research is situated within a body of work which describes the potential for pharmaceutical HIV prevention to generate complexity, uncertainty and risk in the lives of people with HIV. This complexity generates new sites and moments of resistance, novel subject positions and identities and new experiential knowledges of HIV (Adam, et al., 2003; Adam, 2011; Davis & Squire, 2010; Doyal, 2013; Flowers & Davis, 2012; Kippax & Stephenson, 2012; Keogh & Dodds, 2015;

Mykhalovskiy & Rosengarten, 2009; Nguyen, et al., 2007, 2011; Persson, 2012; Rosengarten, et al., 2004; Squire, 2012, 2013).

More recently, researchers have been investigating the various ways in which TasP as a biomedical technology and a technology of biomedicalisation is playing out in the intimate and social lives of people with HIV: that is, investigating the emerging social and intimate uses of TasP beyond reductions in HIV transmission on a population level (Davis, 2015; Grace, et al., 2015; Persson, 2016). In a recent paper, Perrson describes the ways in which TasP impacts the intimate lives of sero-discordant couples (where one partner is HIV positive and the other is not); on how such couples perceive their relationship; and how they represent their sero-discordancy to others (Persson, 2016). Grace has reported on the integration of norms around infectiousness (or non-infectiousness) associated with HIV treatments into identity formation and sexual practices of those recently diagnosed (Grace, et al., 2015). These researchers are addressing vital questions about the extent to which TasP is a disciplining and/or liberating technology and how it might be being used in novel ways by those engaging with it. This paper differs inasmuch as it remains within the clinical and health systems context, considering how people with HIV anticipate the feasibility of TasP both for themselves and for the healthcare system they use

Anticipating TasP: Public health perspectives vs. those of people living with HIV

TasP has been ascribed the potential to radically alter the course of the HIV epidemic. The various pronouncements of global policy agencies and key players described in the introduction to this paper serve to inscribe TasP within promissory or speculative discourses that emphasise the need for investment to reap exponential health benefit. Such anticipations also raise uncertainties about factors likely to impede TasP's feasibility. Although there are concerns about the infrastructure and resource implications of 'scale up' and 'roll-out' of TasP (Mayer & Krakower, 2012) most uncertainty focuses on people with HIV. Concerns abound about who is or is not testing for HIV, whether

individuals can access and comply with drug regimens (Diamond, et al., 2005; Kalichman, 2008)and the potential for 'compensatory' sexual risk-taking (Crepaz, et al., 2004; Eaton & Kalichman, 2007). Thus, we witness a tendency to locate uncertainties associated with TasP within HIV positive subjects and people with HIV are seen as generating uncertainties for public health rather than public health generating new uncertainties in the lives of people with HIV.

People with HIV have always lived with profound uncertainty; however, its content, degree and consequences have altered as the epidemic has unfolded. Prior to the advent of antiretroviral treatments, uncertainty was associated with the potential onset of debilitating illness or death (Weitz, 1989; Brown & Powell-Cope, 1990; Pierret, 1992, 2000). The advent of antiretroviral treatments replaced these uncertainties with contingencies associated with the prospect of a longer and relatively healthy life with HIV. This was sometimes experienced as debilitating, especially for those who had already experienced ill health (Barroso, 1997; Sowell, et al., 1998; Brashers, et al., 1999; Anderson, et al., 2000; Pierret, 2007). The imperative to manage uncertainty and risk also became part of the work of forging new HIV positive identities (Green & Sobo, 2000; Halkitis, et al., 2005; Flowers, et al., 2006; Baumgartner, 2007) and this imperative is operationalised within regulatory regimes for people with HIV (Kinsman, 1996; Lupton, 1999; Adam, 2005; Keogh, 2008; Patton, 2011).

This research describes a further realm of uncertainty associated with antiretroviral treatments which informs people with HIV's understandings and anticipations of TasP. Participants considered economic and managerial factors when seeking healthcare, triaging their clinical presentation in response to cutbacks in clinical services. As such, they were engaged in the production of their care within overarching austerity conditions. In a recent paper, Young *et al.* point to the various ways in which the perceived 'commodification' of pharmaceutical HIV prevention technologies such as TasP

shape how they are anticipated and experienced by people with HIV and those at risk of contracting the virus (Young et al, 2016) . Similarly, participation in an economised health system operating within austerity conditions informed how the participants in this study understood, anticipated and ultimately how they would 'co-produce' TasP as a risk reduction approach. Various forms of knowledge were at play. The first was the patient's embodied knowledge – how they felt – and their concerns about their future physical response to the treatments they are obliged to take. This is placed alongside the presence or absence of diagnostic knowledge: knowledge gained from biomarkers such as viral load testing. Participants were also considering pharmaceutical uncertainty. Put simply, they were not convinced that current treatment regimens would be continued nor pharmaceutical interest and investment be sustained. Thus, they saw themselves as conserving increasingly scarce health care resources. This awareness of scarcity also informed their understandings of pharmaceutical production and TasP.

We can discern contrasting conceptions of health in the two anticipations of TasP I have described. TasP as a biomedical public health intervention constructs health as a form of capital that can be exponentially generated through investment. Thus, it espouses an economic logic of speculation, accumulation and promissory return. TasP, as anticipated by people with HIV, constructs health as an *embodied* capital which is finite and can therefore be depleted by mis-timed treatment decisions generally and by decisions around TasP in particular. Thus, under this conception, health needs to be conserved.

We can also discern contrasting conceptions of uncertainty. TasP as biomedical public health intervention is certainly concerned with material factors, but it also constructs people with HIV as uncertain in terms of their ability to adhere to regimens and regulate their risk behaviours. For people with HIV, uncertainty resides in the capacity of governments to deliver sufficient healthcare

and of markets to deliver treatment innovations. Although questions around adherence and risk are germane, they occlude uncertainties introduced into the lives of people with HIV by TasP and the investment that people with HIV have in ensuring that treatments are sustainable and effective.

The participants in this study were enmeshed in a complex and future-oriented relationship with clinical provision, diagnostic technologies, and techno-scientific practices. However, the imperative of conservation that informed their anticipations of future health in relation to antiretroviral treatments and TasP contrasts with the speculative economy of biomedical production entailed in public health anticipations of TasP. Moreover, the biomedical project *vis-a-vis* TasP is not the application of a pharmaceutical technology to a passive population of people with HIV. Rather, it is a negotiation involving many players including scientists, public health implementers and people with HIV. In conclusion, there are manifold anticipations of TasP and what TasP will be, or what TasP is, is by no means straightforward.

This has implications for how we evaluate the impact of TasP. Our current conception of TasP as a pre-defined intervention constrains us to ask certain questions or ask our questions in certain ways. Attenuating the idea that TasP has already been defined allows more speculative investigations of its possible effects. Thus, by eschewing 'acceptability research' and the instrumental constructions of 'producer' and 'user' it entails we can bypass the question of whether the attitudes and behaviours of people with HIV constitute an obstacle or facilitator to TasP's feasibility and effectiveness. Thus we can perhaps achieve a modest epistemic shift in the way we consider its impact.

Notes

ⁱ The World Health Organisation's 'Treatment 2.0' document (World Health Organisation, 2013) and 90-90-90 policy initiative seeks to ensure that by 2020, 90% of all people with HIV will know their HIV status, of whom 90% will be on sustained antiretroviral therapy, of whom 90% will have the virus in their blood suppressed, whilst the UNAIDS 'fast-track' initiative seeks to end the AIDS epidemic by 2030 (UNAIDS, 2014).

ⁱⁱ Although see my overview of the social science literature on TasP in the discussion section.

ⁱⁱⁱ The groups took place just before the publication of new WHO guidance on commencing treatments in June 2013 and there was much anticipation of a radical change in this guidance, which is indeed what happened when it was published (World Health Organisation, 2013).

^{iv} This statement speaks to a common misconception regarding the impact of TasP implementation on the overall percentage of people diagnosed with HIV who are on treatment in the UK. In fact, the percentage of those linked to care and on treatment is currently already very high (90% overall or roughly 85% of those diagnosed) (Public Health England, 2014)

^v All of the quotations in this section come from the MSM groups. The notion of pharmaceutical uncertainty emerged in all of the African groups as well and the analysis presented here is derived from all six groups. However, the quotations that most clearly and neatly encapsulate meaning all emerged from the MSM group. In view of space and word limit, these are the quotations that are presented here.

References

- International AIDS Society Conference, 2015. *The Vancouver Consensus*. [Online]
Available at: <http://vancouverconsensus.org/>
[Accessed 02 August 2015].
- Adam, B., 2005. Constructing the neoliberal sexual actor: Responsibility and care of the self in the discourse of barebackers. *Culture, Health & Sexuality*, 7(4), pp. 333-346.
- Adam, B., 2011. Epistemic fault lines in the biomedical and social approaches to HIV prevention. *Journal of the international AIDS society*, 14(Suppl 2).
- Adam, B., Maticka-Tyndale, J. & Cohen, J., 2003. Adherence practices among people living with HIV. *AIDS Care: Psychological and Sociological Aspects of AIDS/HIV*, 15(2), pp. 263-74.
- Anderson, W., Weatherburn, P., Keogh, P. & Henderson, L., 2000. *Proceeding with care. Phase 3 of an on-going study of the impact of combination therapies on the needs of people with HIV..* London, Sigma Research.
- Barroso, J., 1997. Reconstructing my life: becoming a long-term survivor of AIDS. *Qualitative Health Research*, Volume 7, pp. 57-74.
- Baumgartner, L., 2007. The Incorporation of the HIV/AIDS Identity Into the Self Over Time. *Qualitative Health Research*, 17(7), pp. 919-931.
- Bevir, M. & Trentmann, F., 2007. *Governance, consumers and citizens*. New York: Palgrave Macmillan.
- Brashers, D. et al., 1999. In an important way, I did die: uncertainty and revival in persons living with HIV or AIDS.. *AIDSCare: psychological and socio-medical aspects of AIDS/HIV*, 11(2), pp. 201-219.
- British HIV Association, 2014. British HIV Association guidelines for the treatment of HIV-1-positive adults with antiretroviral therapy 2012. *HIV Medicine*, Volume Suppl 1, pp. 1-85.
- British HIV Association, 2015. *Treatment of HIV-1 positive adults with antiretroviral therapy Consultation Draft 2015*. [Online]
Available at: <http://www.bhiva.org/treatment-guidelines-consultation.aspx>
[Accessed 15 July 2015].
- Brown, M. & Powell-Cope, G., 1990. AIDS family caregiving: transitions through uncertainty. *Nursing Research*, 40(6), pp. 338-345.
- Clarke, A. et al., 2010. *Biomedicalization: Technoscience, Health, and Illness in the U.S.*. s.l.:Duke University Press.
- Clarke, J., Newman, J. & Westmarland, L., 2007. The antagonisms of choice: new labour and the reform of public services. *Social policy & Society*, 7(2), pp. 97-117.
- Cohen, M. et al., 2011. *Antiretroviral treatment to prevent the sexual transmission of HIV-1: results from the HPTN 052 multinational randomized controlled trial..* Rome, Sixth International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention.

- Cohen, M., McCauley, M. & Gamble, T., 2012b. HIV treatment as prevention and HPTN052. *Curr Opin HIV AIDS*, 7(2), pp. 99-105.
- Crepaz, N., Hart, T. & Marks, G., 2004. Highly active antiretroviral therapy and sexual behavior: a met-analytic review. *JAMA*, 292(2), pp. 224-236.
- Davis, M., 2015. After the clinic? Researching sexual health technology in context. *Culture, health & sexuality*, 17(4), pp. 398-411.
- Davis, M. & Squire, C., 2010. *HIV technologies in international perspective*. 1st ed. London: Palgrave.
- Diamond, C., Richardson, J. & Milan, J., 2005. Use of and adherence to antiretroviral therapy is associated with decreased sexual risk behavior in HIV clinic patients.. *J Acquir Immune Defic Syndr*, 39(2), p. 211–218.
- Doyal, L., 2013. *Living with HIV and Dying with AIDS: Diversity, Inequality and Human Rights in the Global Pandemic*. 1st ed. London: Ashgate.
- Eaton, L. & Kalichman, S., 2007. Risk compensation in HIV prevention: implications for vaccines, microbicides, and other biomedical HIV prevention technologies.. *Curr HIV/AIDS Rep.*, 4(4), p. 165–172.
- Ewert, B., 2009. Economization and marketization in the German healthcare system: How do users respond?. *German Policy Studies*, 5(1), pp. 21-44.
- Fainzang, S. & Haxaire, C., 2010. Introduction. In: S. Fainzang & C. Haxaire, eds. *Of bodies and symptoms: anthropological perspectives on their social and medical treatment*. Tarragona: URV Publications, pp. 1-7.
- Flowers, P. & Davis, M., 2012. Obscure essentialism: identity transformation among gay men living with HIV. *Psychology & Sexuality Online*, 4(3), pp. 283-295..
- Flowers, P. et al., 2006. Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychology & Health*, 21(1).
- Gale, N. et al., 2013. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, Volume 13, p. 117.
- Grace, D. et al., 2015. Becoming “Undetectable”: Longitudinal Narratives of Gay Men's Sex Lives After a Recent HIV Diagnosis. *AIDS Education & Prevention*, 27(4), pp. 333-349.
- Green, G. & Sobo, E., 2000. *The Endangered Self: Managing the Social Risk of HIV*. London: Routledge.
- Halkitis, P. et al., 2005. Barebacking identity among HIV positive gay and bisexual men: demographic, psychological and behavioural correlates. *AIDS*, 19(suppl 1), pp. S27-S35.
- Health and Social Care Act, 2012. *Health and Social Care Act*. London: Stationary Office.
- Kalichman, S., 2008 . Co-occurrence of treatment nonadherence and continued HIV transmission risk behaviors: implications for positive prevention interventions.. *Psychosom Med.* , 70(5), p. 593–597.
- Keogh, P., 2008. How to be a healthy homosexual: HIV health promotion and the social regulation of gay men in the UK. *Journal of Homosexuality*, 55(4), pp. 581-605.

- Keogh, P. & Dodds, C., 2015. Pharmaceutical HIV prevention technologies in the UK: six domains for social science research. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 27(6), pp. 796-803.
- Keogh, P., Weatherburn, P. & Reid, D., 2016. Learning from the experiences of people with HIV using general practitioner services in London: a qualitative study.. *Primary Healthcare Research & Development*, Volume 15, pp. 1-10.
- Kinsman, G., 1996. Responsibility" as a strategy of governance: regulating people living with AIDS and lesbians and gay men in Ontario. *Economy and Society*, 25(3), pp. 393-409.
- Kippax, S. & Stephenson, N., 2012. Beyond the distinction between biomedical and social dimensions of HIV. *American Journal of Public Health*, 102(5), pp. 789-99.
- Kuhlmann, E. & Saks, 2008. *Rethinking professional governance: international directions in health care*. Bristol: Polliicy Press.
- Lupton, D., 1999. *Risk*. London: Routledge.
- Mayer, K. & Krakower, D., 2012. Antiretroviral Medication and HIV Prevention: New Steps Forward and New Questions.. *Annals of Internal Medicine*, Volume 156, pp. 312-314.
- Mykhalovskiy, E. & Rosengarten, M., 2009. HIV/AIDS in its third decade: renewed critique in social and cultural analysis.. *Social Theory and Health*, 7(3), pp. 187-95.
- Nguyen, V. et al., 2011. Remedicalizing an epidemic: from HIV treatment as prevention to treatment is prevention. *AIDS*, 25(3), pp. 291-293.
- Nguyen, V., Yapo Ako, C. & Niamba, P., 2007. Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS*, 21(suppl 5), pp. S31-S35.
- Patton, C., 2011. Rights language and HIV treatment: universal care or population control. *Rhetoric Quarterly*, 41(3), pp. 250-66.
- Pebody, R., 2016. *England's PrEP policy in disarray after NHS U-turn*. [Online] Available at: <http://www.aidsmap.com/Englands-PrEP-policy-in-disarray-after-NHS-U-turn/page/3045613/> [Accessed 15 April 2016].
- Persson, A., 2012. Non/infectious corporealities: tensions in the biomedical era of 'HIV normalisation'. *Sociology of Health and Illness*, 35(7), p. 1065–1079.
- Persson, A., 2016. 'The world has changed': pharmaceutical citizenship and the reimagining of serodiscordant sexuality among couples with mixed HIV status in Australia. *Sociology of Health & Illness*, 38(3), pp. 380-295.
- Pierret, J., 1992. Coping with AIDS in everyday life. In: *AIDS: A Problem for Sociological Research*. London: Sage, p. 66–84.
- Pierret, J., 2000. Everyday life with AIDS/HIV: surveys in the social sciences.. *Social Science & Medicine*, 50(11), p. 1589–1598.
- Pierret, J., 2007. An analysis over time (1990–2000) of the experiences of living with HIV. *Social Science & Medicine*, 65(8), p. 1595–1605.

Public Health England, 2014. *HIV in the United Kingdom: 2014 Report*, London: Public Health England.

Rose, N., 2007. *The politics of life itself: biomedicine, power and subjectivity in the twenty-first century*. New Jersey: Princeton University Press.

Rosengarten, M. et al., 2004. After the euphoria: HIV medical technologies from the perspective of their prescribers. *Sociology of health and illness*, 26(5), pp. 575-96.

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(7), pp. 1049-1055.

Silverman, D., 2000. *Doing Qualitative Research: A Practical Handbook*. London: Sage.

Sowell, R. L., Phillips, K. D. & Grier, J., 1998. Reconstructing life to face the future: the perspective of men after a positive response to protease inhibitor therapy.. *AIDS Patient Care and STDs*, 12(1), pp. 33-42.

Squire, C., 2012. Being naturalised, being left behind: the HIV citizen in the era of treatment possibility. *Critical public health*, 20(4), pp. 401-27.

Squire, C., 2013. *Living with HIV and ARVs: three letter lives*. Basingstoke: Palgrave Macmillan.

The INSIGHT START Study Group, 2015. Initiation of Antiretroviral Therapy in Early Asymptomatic HIV Infection. *The New England Journal of Medicine*, 20 July.p. DOI: 10.1056/NEJMoa1506816.

UNAIDS, 2014. *Fast-Track: ending the AIDS epidemic by 2030*, Geneva: Joint United Nations Programme on HIV/AIDS (UNAIDS).

Weatherburn, P. et al., 2013. *My care, I care: a study of what people with HIV value about NHS services across London*, London: Sigma Research.

Weitz, R., 1989. Uncertainty and the lives of persons with AIDS.. *Journal of Health and Social Behavior*, Volume 30, pp. 270-281.

World Health Organisation, 2013. *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection*, Geneva: World Health Organisation.

World Health Organisation, 2014. *Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations*, Geneva: WHO.

Young, I., Flowers, P. & McDaid, L., 2016. Can a pill prevent HIV? Negotiating the biomedicalisation of HIV prevention. *Sociology of Health & illness*, 38(3), pp. 411-425.

Young, I. & McDaid, L., 2014. How Acceptable are Antiretrovirals for the Prevention of Sexually Transmitted HIV?: A Review of Research on the Acceptability of Oral Pre-exposure Prophylaxis and Treatment as Prevention. *AIDS and Behavior*, 18(2), pp. 195-216.