

# **The biopolitics of engagement and the HIV cascade of care: a synthesis of the literature on patient citizenship and antiretroviral therapy**

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## **ABSTRACT**

The 'cascade of care' construct is increasingly used in public health to map the trajectory of local HIV epidemics and of different HIV populations. The notion of 'patient engagement' is key to the progress of people living with HIV through the various 'steps' of the cascade as currently conceptualised. The public health literature on the definition, measurement, and interpretation of cascade of care frameworks is growing in parallel with critical social science literature analysing patient engagement through the lenses of 'patient citizenship' theories. In this paper, we review qualitative literature on HIV treatment, adherence to antiretroviral therapy, and care engagement that draws upon the interlinked concepts of *therapeutic* and *biological citizenship*. We aim to offer a critique of the cascade of care construct using empirical data from research studies published since 2005 that were influenced by these two concepts. In so doing, the paper places public health literature on the cascade of care in dialogue with in-depth qualitative and ethnographic approaches, to unpack the understandings and processes shaping patient engagement in HIV treatment and care in different settings. The paper also examines the contributions and limitations of the concepts of biological and therapeutic citizenship as argued by a number of scholars here reviewed.

## **KEYWORDS**

*HIV; engagement; adherence; cascade of care; citizenship.*

## INTRODUCTION

The HIV treatment ‘cascade of care’ envisages ‘treated HIV’ as the end point of a process of sequential care engagements – from HIV testing, to diagnosis, to linkage and access to antiretroviral treatment (ART), to retention in treatment – sufficient to bring about viral suppression (Mugavero, Amico, Horn and Thompson, 2013). The cascade creates a framework for generating step-wise estimates of intervention access, coverage, adherence, retention, and outcome at national and regional level (Kozak, Zinski, Leeper, Willig and Mugavero, 2013; MacCarthy et al., 2015). Such a framework provides an overview of key indicators (diagnosed and undiagnosed infections; numbers on or off treatment) and their public health implications, and offers a surveillance grid for monitoring patient dis/engagement through the pathways of care. The cascade construct thus tends to define HIV care (and its success or failure) narrowly in relation to the ultimate benchmark of viral suppression, resulting from patients being sufficiently and appropriately engaged through each of its steps.

With ‘treated HIV’ dependent upon patient engagement, HIV treatment is inevitably a *political* process. Discourses of the care cascade imply certain kinds of patient expectation and responsibility. An extensive body of extant literature accentuates how social and environmental factors shape HIV treatment provision and engagement (Gari et al., 2013; Merten et al., 2010; Underwood, Hendrickson, Van Lith, Kunda, and Mallalieu, 2014). Additionally, critical perspectives in the social sciences have reflected upon HIV and its care as constituted through situated health practices, identities and subjectivities, with implications for different social and political contexts (Doyal, 2013; Whyte, 2009).

Much of this empirical work is qualitative in orientation and has focused on: experiential accounts of life with HIV (often contrasted to ‘biomedical’ articulations) (e.g. Davis, Frankis and Flowers, 2006; Persson, 2013); the ‘identity’ work involved in reconstructing life around an HIV diagnosis and related treatment (e.g. Baumgartner and David, 2009; Flowers, Davis, Larkin, Church, and Marriott, 2011); the gendered dimensions of HIV and health-seeking behaviours (also in combination with other social categories) (e.g. Doyal, 2009); and the *biopolitical* aspects of HIV care and the ‘making’ of HIV patient citizenship. This latter domain is our primary concern here, and draws heavily upon the linked theoretical frameworks of *biological* and *therapeutic citizenship* (Nguyen, 2005; Rose and Novas, 2005).

Conscious of the parallel developments in HIV care literatures in public health and social science – which characterise HIV and its treatment as a biomedical product of the care cascade on the one hand, and critique how this politically constructs a certain patient citizenship and HIV identity on the other – we aim to track the use and development of notions of ‘biological’ and ‘therapeutic’ citizenship applied to the field of HIV treatment. In doing so, we will assess the relevance of these theoretical contributions to understanding current paradigms in HIV care, including in relation to the concept of the care cascade in the era of ‘treatment-as-prevention’ (Gardner, McLees, Steiner, Del Rio and Burman, 2011). By reflecting on the primarily epidemiological notion of the HIV care *cascade* through a synthesis of published social science studies investigating how the HIV care *process* shapes the making of patient-citizens, we hope to bridge these bodies of knowledge. In so doing, we aim to emphasise the particular contribution that critical, and in-depth qualitative, social research makes to the understanding of dynamics of HIV care engagement.

## **HIV treatment engagement and the ‘care cascade’**

An undetectable HIV viral load in the blood significantly reduces the chances of HIV being transmitted (Cohen et al., 2011; World Health Organisation [WHO], 2014). In the ‘treatment-as-prevention’ era, measuring HIV viral load to indicate ART impact is central to definitions of what constitutes ‘HIV health’ and also to projecting the trajectory of HIV epidemics (Gardner et al., 2011; Hull, Wu and Montaner, 2012; May et al., 2014). ‘HIV care’ itself is thus increasingly envisaged as this progressive continuum (De Cock, 2014; Mugavero et al., 2013; Nachega et al., 2014).

In the continuum, quantitative indicators monitor the number of people who are: living with HIV; HIV tested; linked into care post-diagnosis; started on ART; on treatment; and with an undetectable viral load (MacCarthy et al., 2013; Kozak et al., 2013). Patient engagement is key to the seamless progression through the cascade, from deciding to test, following up appointments, agreeing to start and adhering to ART until the virus is suppressed and undetectable in the blood. Patient engagement needs therefore to be ‘managed’ to minimise disruption to the care cascade, untreated infections and onward transmissions (Nachega et al., 2014). Progression to a state of ‘treated HIV’ pivots on the capacity of services to attract and retain patients, and on patients’ commitment to ‘actively’ access these in return.

However, there are three immediately visible limitations to the cascade concept. First, the narrow focus on viral load progression (from detectable to undetectable) detracts attention from the broader aspects of HIV as a health and social *condition*, and not only a virus. ‘Treated HIV’ represented as a product of the care cascade is blind to the complex of individual and social practices, which situate HIV and its care relative to wider definitions of ‘health’. Second, viral suppression is not a ‘goal’ that needs to be reached, but rather a ‘state’ that must be maintained over time via ongoing systemic care provision coupled with continuous patient re-engagement. System- and patient- components and relations are clearly susceptible to multiple changes. Third, by delineating the accomplishment of viral suppression *as* and *for* public health control, the cascade distinguishes success and failure, of services and patients alike, in stark biomedical terms.

Against an increasing shift towards ART envisaged as ‘prevention’, the concept of the care cascade may thus serve to accentuate further what some have termed the ‘re-medicalisation’ of HIV (de Wit, Aggleton, Myers and Crew, 2011; Nguyen, Bajos, Dubois-Arber, O’Malley and Pirkle, 2011). ‘HIV health’ is increasingly reduced to clinical markers of ART effect, whilst patient engagement in HIV care is reduced to specific measures of ART adherence. The discourse and practices of the care cascade thus underpin a very particular biomedical constitution of HIV patient-citizens.

## **Antiretroviral therapy and patient citizenship**

The history of the HIV/AIDS pandemic is inextricably linked to global activism from people living with HIV/AIDS and the deployment of large funding for a global humanitarian response through a complex apparatus of transnational and non-governmental organisations (Nguyen, 2009). Political and humanitarian movements have been built around the biological condition of HIV infection, and are implicated in radical transformations of the relationship between people living with HIV and the state. Key here, are developments in HIV medicine and antiretroviral treatments. Although historically accompanied by struggles for broader health, economic, social and legal rights, demands

for treatment development and access have increasingly taken centre-stage in what has been termed a 'political economy of pharmaceuticals' (Biehl, 2007, p. 10).

The unique and mutual constitution of transnational, biomedical and biopolitical claims based on an individual yet *shared* biological condition has meant that AIDS activism first, and HIV/AIDS humanitarian interventions later, have been positioned as new forms of citizenship, *biological* and *therapeutic* respectively (Nguyen, 2005; Rose and Novas, 2005). From the mid-2000s onwards, notions of citizenship have informed analyses of HIV and treatment engagement, as well as of other health conditions (Petersen, Davis, Fraser and Lindsay, 2010; Rhodes, Harris and Martin, 2013).

Drawing from Petryna's (2002) original research tracing how biology and illness were implicated in citizenship claims to compensation made by Chernobyl inhabitants, Rose and Novas (2005) propose 'biological citizenship' as the historical citizenship project of the contemporary era that "links conceptions of citizens to beliefs about the biological existence of human beings" (p. 440). In the biological citizenship project, the citizen holds specific individual rights and responsibilities towards his or her own health, and the health of society and future generations too. As a form of governing, biological citizenship is at once prescribed top-down from the state (and biomedicine) to citizens (and patients) *and* co-and-re- produced horizontally and relationally amongst citizens themselves, as they share a common biological trait or condition. Biological citizens are thus simultaneously governed subjects *and* active and engaged, including in forms of alliance with or resistance to biomedicine, science and state regulations as they pertain their health condition.

Expanding on the concept of biological citizenship to encompass the global health and humanitarian response to HIV/AIDS, Nguyen proposes the concept of 'therapeutic citizenship' as a series of "claims made on global social order on the basis of a therapeutic predicament" (2005, p. 126). Based on ethnographic work spanning the early days of the AIDS epidemic and the introduction of ARV programmes in West Africa, Nguyen argues that a global AIDS industry increasingly entangled with the development industry and with humanitarian intervention has effectively created new subjectivities and "life forms: AIDS activism, resistant viruses, and therapeutic citizens" (Nguyen, 2005, p. 126). The therapeutic citizenship project he describes in West Africa is supported by a 'vanguard' of local activists (Nguyen, 2005), fashioned through 'confessional technologies' in peer-support groups (Nguyen, 2010, pp. 35-50) modelled on early (US) gay activism, evangelical movements (Nguyen, Ako, Niamba, Sylla and Tiendrébéogo, 2007) and counselling techniques (Nguyen, 2013).

Through these and other 'technologies of the self' (Foucault, 1988) people living with HIV and AIDS in resource-scarce (and treatment-scarce) settings learn to tell a certain story, and those who succeed in performing their role are 'triaged' into ART as potentially more valuable members of an emerging HIV/AIDS community (Nguyen, 2010, pp. 80-110). Thus, ties originally intended to forge solidarity and support amongst positive members are changed by the (partial) arrival and (scarce) distribution of life-saving antiretroviral medicines through patchy services, interventions and small personal networks.

## **APPROACH**

Conscious of the growing body of literature investigating the social dynamics of HIV treatment engagement, we explore the use of frameworks of therapeutic and biological citizenship in qualitative social science studies of HIV, HIV care and patient citizenship. In doing so, we are particularly interested in considering how such work can contribute to situating HIV treatment engagement in relation to epidemiological notions of the HIV cascade of care. The context-specificity of in-depth social research does not reduce its capacity to illuminate *general* global health frameworks and to document their emergence and effect. A collective synthesis of critical case studies can provide a nuanced yet integrated understanding of the making and implications of particular ways of looking at and intervening in major health issues, such as the HIV pandemic.

Given that social science literature specifically focused on the cascade of care is nascent, we began by using 'adherence' as an initial proxy to inform our search of qualitative research on HIV care engagement. This yielded 222 article abstracts and 37 article reviews of qualitative studies published since 2005. Among these were studies which had a specific *interpretive* emphasis that tended to use in-depth methods (multiple qualitative methods or ethnography) to explore experiences of people living with HIV, including those related to different stages of the cascade of care, and that drew upon social theories, including those related to *citizenship*. A total of 82 article abstracts fell into this category, and these were the 'pool' for our initial review. Two seminal essays by Paul Rabinow (1992a, 1992b) were added early on as they provided the foundations of the concept of 'biosociality', which we were aware, from previous readings, would be at the core of biological and therapeutic citizenship theories.

Our review proceeded in two steps. First, we considered each of the 84 article abstracts for their relevance to three questions: 1) Does the article make explicit reference to concepts of biopolitics, biosociality, biological, therapeutic or health citizenship?; 2) Does the article focus on HIV treatment, adherence, care or care engagement?; and 3) Does the article use qualitative methodology empirically or offer a theoretical framework that can be used to inform such qualitative research? This led to us honing our selected articles for review to 22. Through an iterative process involving citation tracking in article bibliographies, additional searches of individual social science journals and of relevant social science books or monographs, we identified a further nine articles and book chapters meeting our criteria, for a total of 31 overall.

Second, we undertook an additional electronic search, using Medline, of journal articles published since 2005 and focused specifically on HIV and citizenship using the key words of: biological citizenship and HIV; therapeutic citizenship and HIV; health citizenship and HIV. After checking for duplicates, six were selected. Thus, a total of 37 articles and chapters (hereafter 'papers') were included.

Of the 37 papers in our review, nine were summarised, using a narrative approach, for their theoretical contribution to definitions of biological and therapeutic citizenship (Table 1). The remaining 28 (Table 2), largely empirical case studies, were synthesised using a structured approach to extract and distinguish content alongside original author interpretations. Having extracted key content and author interpretations of these 28 papers, we worked across them to produce a third level of abstraction focusing specifically on our key areas of analytical interest (engagement; adherence; patienthood; citizenship). Our summaries of content were thus coded, and re-coded,

through a process of iteration, enabling the identification of key themes, which formed the basis for our synthesis.

In our synthesis, empirical findings, and the ways authors presented them, were coded in place of original excerpts of data, as many of the reviewed papers tended not to emphasise low inference description and accordingly reported little direct quotation but instead emphasised theory-informed interpretation. Boxes 1-3 present some illustrative extracts and field observations from the reviewed literature across the core themes, which shape our synthesis.

In addition to these core papers forming the basis of our synthesis, we also draw upon wider published literature, especially where it has informed the studies reviewed in the synthesis, in order to illuminate the analyses we present. Where such additional references appear in the results section, they have been marked with *cf.* for readers' clarity.

### **Emerging themes**

We identified three primary thematic areas of study that form the basis of our synthesis: patient engagement (how people living with HIV engage with HIV-related knowledge and treatment intervention); therapies and politics (how HIV treatment engagements are contextualised politically, including in relation to the state); and biosociality and responsibility (how engagements with HIV and social identities and relations are mutually constituted).

## **PATIENT ENGAGEMENT**

Patient engagement in HIV care is situated in relation to its specific social context, which shapes the multiple and competing meanings of HIV intervention to would-be patients, including how biomedical treatment opportunities are negotiated in everyday social life. In addition, there is an emphasis on exploring notions of engagement through the ways in which people living with HIV interplay with biomedical expertise, and how this shapes HIV and health identity.

### **'Deflecting' biomedical knowledge and practice**

Side-effects linked to ART emerge as central elements of meanings of 'HIV health' and ART held by patients (Alcano, 2009; Cataldo, 2008; O'Daniel, 2014; Persson and Newman, 2006). Clinicians may tend to think of the immune system as the locus of the patient's health (Persson and Newman, 2006), and of ARVs as restoring and protecting the patients' strength, but side-effects of ARVs can compromise strength as experienced by the patient (Alcano, 2009; Cataldo, 2008; Box 1, extr.1). What clinicians might conceive of as 'tolerable' side-effects, and what patients might find difficult to manage day-to-day, may differ (Persson and Newman, 2006).

Ethnographic studies report that participants may find that ART side-effects render physically demanding jobs difficult (Alcano, 2009; Cataldo, 2008). Amongst residents of *favelas* in Rio de Janeiro precariously employed in manual labour ART is seen as a "luxury" because of the toll of side-effects (Cataldo, 2008, p. 905), whilst positive male construction workers in Milan comment that they cannot afford weakness or tiredness (Alcano, 2009) interfering with their work (Box 1, extr. 1-2).

Globally, treatment side-effects, dietary requirements, the need to rest and to take treatments at set times of the day all create obstacles to working activities, especially for those employed in low-paid jobs requiring long hours of hard physical work, often at irregular times and with little flexibility (Doyal, 2013). ART can thus become financially non-viable, not only because of its cost but also because of its demands, and *adherence is adjusted* accordingly. ART is adapted to competing requirements made upon the body, with people balancing the preservation of a 'biomedical' (Persson and Newman, 2006) or 'pharmaceutical' (Biehl, 2007; Mattes, 2012) self against a 'side-effects free' self that is able to work (Alcano, 2009; Cataldo, 2008).

Studies thus point to a 'situated rationality' whereby the perceived health risks of 'non-compliance' to biomedical advice may be juggled alongside securing the welfare of self, children or other dependants, including protecting damage to reputation and social position through work (Alcano, 2009; Cataldo, 2008; Mattes, 2011). In the harsh contexts of daily survival, such as that described by Mattes in Tanzania (2011), ART adherence may become a measure of last resort to stay alive, rather than a form of proactive and ongoing self-care. Here then, people can be seen to 'manipulate' (Niehaus, 2014) or '*deflect*' (Alcano, 2009), rather than outright resist, biomedical knowledge and practice. Treatment engagement becomes a matter of *accommodation*, with the take-up of clinicians' guidance moderated according to situation (Box 1, extr.3).

In addition, O'Daniel's (2014) ethnography among poor African-American women in Midway (North Carolina, USA) shows that even in absence of side-effects, immediate problems of homelessness, destitution, and social isolation reduce space for attending to HIV health, and increase fear of stigma and of the loss of already scarce support networks. While interacting with HIV services and (mostly) adhering to HIV treatment, O'Daniel (2014) found that the most destitute amongst these women displayed little overt understanding of, or interest in, the progression of their HIV or their clinical outcomes (Box 1, extr. 4).

This might be described as a form of 'utilitarian' care engagement (cf. Rhodes et al., 2013). Practices of deflection, adaptation, and relative indifference, run counter to the clinical requirements of patient engagement characterised by exemplary adherence through the 'cascade of care'. Nonetheless, the very practices which deflect biomedical treatment expectations still serve to accommodate them, and many such participants collect, store and take their medicines whenever and as much as possible (Cataldo, 2008). Deflected biomedicine is not a challenge to it, and often preserves its idealisation, even in social conditions that mitigate against its immediate realisation. Indeed, deflection can be simultaneously reasoned as necessity *and* as personal failure as patients navigate their way through competing social, material, moral and therapeutic demands.

In contrast to the 'single rationality' of 'treated HIV' as synonymous with viral suppression brought about by patients' strict adherence and responsibility towards health (Beckmann, 2013; Niehaus, 2014; Thomas, Aggleton and Anderson, 2010), a 'situated rationality' of 'HIV health' envisages biomedical engagements as relational. To address what Mattes (in Tanzania) refers to as the "rationale of being problematic" (2011, p.170), patients' perspectives on ART may be appreciated as non-dichotomous, multiple and context-dependent (Box 1, extr. 5). Niehaus (in South Africa) likewise reminds us that "knowledge about sickness does not imply unswerving commitment to one set of beliefs" and "practical considerations often outweigh explanatory consistencies" (Niehaus,



2014, p. 362). Compliance to biomedicine, Niehaus argues, is *one* way people may comply with *one* form of ‘authority’, alongside that of priests, healers, and older family members.

Adherence is thus a form of ‘submission’ susceptible to change, and which can be modified in relation to other forms of authority. Equally, seemingly ‘irrational’ behaviours, such as interrupting treatment (Beckmann, 2013; Persson and Newman, 2006), sharing antiretrovirals with others (Cataldo, 2008), changing doses, or using alternative medicines and healing practices (explicitly or implicitly) against clinicians’ advice (Niehaus, 2014; Thomas, Aggleton and Anderson, 2010), are ways in which people enact agency in the context of their day-to-day needs.

Qualitative longitudinal research in Serbia, for instance, illustrates how patient narratives of ‘disengagement’ from treatment, and even of apparent ‘treatment resistance’, are ways in which people act to cope with and respond to treatment access insecurity or pervasive uncertainty (Bernays and Rhodes, 2009). At the same time, narratives of disengagement entertain the hope of a better treatment future, thus acting to deflect or defer rather than fundamentally resist engagement with biomedical practices.

### **Treatment literacy and expertise**

Uncertainty is also a feature of biomedical scientific knowledge *itself* that is made evident to people living with HIV in the context of side-effects, unexpected reactions to treatment, treatment changes, and the ‘failure’ of therapy to restore a sense of health that is compatible with the lives people try to live (Alcano, 2009; Davis, Frankis and Flowers, 2006; Flowers, 2010; Mazanderani and Papparini, 2015; Persson and Newman, 2006; Thomas, Aggleton and Anderson, 2010). Treatment engagement is thus not only an accommodation to the particularities and uncertainties of social situation but also of the ‘treatments’ themselves, and their multiple effects. As the above case example of Serbia illustrates (Bernays and Rhodes, 2009; cf. Rhodes, Bernays, and Terzić, 2009), ‘patient adherence’ to treatment is at least in part a structural effect of ‘state adherence’ to delivering secure and uninterrupted treatment, with engagements with biomedical expertise moderated in relation to a circulating culture of information scarcity.

Rose and Novas (2005) suggest that different technologies and practices actualise citizenship, including what they term *informational biological citizenship*, which refers to engagement with “specialized scientific and medical knowledge of one’s condition” (p. 442). This form of citizenship closely echoes the emphasis on treatment literacy and expertise characterising the rise of ‘expert’ (cf. Kielman and Cataldo, 2010) and ‘active’ (cf. Barbot, 2006) patienthood in contemporary public health. Here, gathering, sharing and debating biomedical information on HIV is both a process of ‘empowerment’ of the patient *vis-a-vis* the authority of clinicians, and of ‘responsibilisation’ of the patient-citizen in the context of their condition.

Emphasis on treatment expertise has ramifications for patient-clinician discussions and for how treatment literacy may be imparted. For example, concerns about appearing ‘foolish’ or causing ‘offense’ to the doctor may manifest in patients’ reticence to disclose their use of alternative medicines, as is reported to be the case with African men and women living with HIV and accessing UK national health services (Thomas, Aggleton and Anderson, 2010). Rather than experts on equal grounds with their care providers, patients may be informed just enough to know what not to say (Box 1, extr. 6).

Others too have observed how adherence discourse, as circulated in ART literacy sessions or other clinical encounters, can be *disempowering*. Here, competing forms of local knowledge can be discouraged, and everyday demands that affect treatment-taking discounted, often through the threat of treatment failure, and consequent sickness or death as a result of poor patient adherence (Beckmann, 2013; Mfecane, 2011).

### **The case of 'blood counts'**

Particular attention has been paid to the meanings assigned to blood tests or 'counts', and their role in monitoring CD4 counts and viral load and the progression of HIV infection. The ethnographic work of Meinert, Mogensen and Twebaze (2009) in Uganda, for instance, focuses on CD4 counts as the "technological hook that clients can hang their hopes on" (p. 203), whilst the qualitative research of Flowers (2010) in the UK suggests that 'health' among people living with HIV is increasingly being measured by blood counts alone, turning the body into a "mere setting for action" (p. 110). Most such studies frame blood counts as technologies of *discipline* (Alcano, 2009; Meinert et al., 2009; O'Daniel, 2014; cf. Foucault, 1978): while indicators of what the *virus* is doing, changes in HIV viral load can also reveal to the clinician what the *patient* might be doing. Holding the potential for unwanted disclosure and revelations about adherence, blood counts are clinical evidence indicating whether patients-clients are maintaining their part of a therapeutic deal (Meinert et al., 2009), acting as a kind of truth-telling device (O'Daniel, 2014; Box 1, extr.7).

Among people living with HIV interacting with public or welfare services, blood counts may be further seen as "gatekeepers" (Meinert et al., 2009, p. 206), or stand for "biolegitimacy" (Marsland, 2012, p.472; cf. Fassin, 2001), enabling access to additional forms of support, such as state benefits, housing, food staples and other goods. This system can work in opposing ways, however. In some settings, only those with very low CD4 counts (indicating advanced disease progression) may be eligible for welfare support, a potential disincentive to ART adherence in the context of otherwise scarce resources (cf. Leclerc-Madlala, 2006, in South Africa). Elsewhere, only those with a 'good' CD4 count can prove that they are engaged with health services and stable 'enough' to access additional resources such as housing support (O'Daniel, 2014, in the US).

In all cases, the meanings assigned to biomarkers – as vehicles or obstacles to other forms of support – exemplify how biomedicine is often able to shape specific subjectivities insofar as its promise stretches *beyond* clinical care itself (O'Daniel, 2014). In the absence of further incentives to 'achieve viral suppression', patient engagement, especially in the context of poverty, can alternatively be mitigated by practices of deflection or indifference towards HIV health and treatment.

Not only disciplinary tools, biomarkers also shape *interpretations of life and self* with HIV (Mazanderani and Papparini, 2015). Blood counts can be seen as forms of 'abstract knowledge' about HIV, functioning as 'maps': where they rise as a result of ART, they "give a sense of direction, and ability to have plans and make priorities", turning however into "uncertainties and disorientation" when they do not rise as fast as expected (Meinert, et al, 2009, p. 204). Yet, such maps of an 'inside' are always framed by an 'outside': the interpretation of bio-information is situated in everyday social relations, indicating life situation and social condition.

In this way, blood counts chart socio-economic trajectories in relation to food, work and immunity (Marsland, 2012). Food, for instance, is recommended for ARVs to work effectively and, in turn,

ARVs are perceived to cause hunger (cf. Hardon et al., 2007; cf. Kalichman et al, 2015; cf. Kalofonos, 2010). In the context of often otherwise rationed resources, CD4 counts do not drop when patients *fail* in their adherence, but when they are unable to purchase sufficient food to *sustain* adherence. Medical records thus tell stories of the alternate fortunes and misfortunes of those living with HIV, especially in precarious circumstances, just as they tell a story of the clinical and pharmaceutical care available to them at different times. In so doing, bio-information provides personal as well as political substantiation of the changing fate of people and their nations alike.

## **THERAPIES AND POLITICS**

The ways in which ART is provided to, fought for, and accessed by people living with HIV constitute new forms of therapeutic citizenship (Nguyen, 2010). These intersect with extant relationships between *self* and *state* prior to HIV and ARVs, whilst at the same time “the way a state deals with AIDS reveals its statecraft” (Biehl, 2007, p. 11).

### **ART as a link between body and state(s)**

The ethnographies of Cataldo (2008) and Biehl (2007) document an emphasis on social justice and the redistribution of resources through which grassroots organisations effectively articulated their demands for ARVs in the early days of the Brazilian epidemic. Similarly, earlier claims to the right to ART in South Africa were characterised by dramatic competition with a strong nationalist discourse about ‘authentic’ African citizenship, infamously expressed through President Mbeki’s AIDS denialism (Kagee, Swartz and Swartz, 2014; Robins, 2005). According to Kagee et al. (2014), the struggle for ARVs in South Africa signalled both the rise of an international therapeutic citizenship and an engagement with emerging national identity issues post-apartheid (see also Robins, 2005).

Yet studies reviewed here note that the quality of HIV care often surpasses other domains of state health and social care, particularly in lower income settings where ART provision is funded by an uneven mixture of agencies, a phenomenon described by Whyte, Whyte, Meinert and Twebaze, (2013) in Uganda as the “*projectified*” landscape of HIV care (p. 143). ART can frequently be distributed amidst a lack of other services, exposing a ‘state’ that is “pharmaceutically present but institutionally absent” (Biehl, 2007, p. 285). This paradox has multiple divergent ramifications for patient-citizens: further collective engagement and demands on the one hand, but also a divisive pressure in the competition for resources on the other, or else a kind of *apathy* as the “pharmaceutical wellbeing” (Biehl, 2007, p. 302) afforded by ART is not enough to give rise to a socio-political sense of possibility.

For example, in the *favelas* of Brazil’s Rio de Janeiro (Cataldo, 2008) and in Kenya’s national hospitals (Moyer, 2014), patients may respond to the variation in the quality of the health services provided by developing a stronger sense of entitlement to better care *beyond* HIV. In this sense, therapeutic citizenship is enacted when people become more “sensitive to their individual rights” (Cataldo, 2008, p. 907; see also Biehl, 2007) through ART provision and then seek to extend these to other areas of governmental services. Here, state provision of ARVs represents a link between individual ‘politicised bodies’ and the state, opening up the possibility of further interaction and involvement.

Free ART provision on the part of the state represents the inclusion of people otherwise socially and economically marginalised, for example those living in the South African townships (Robins, 2005), the patients of a non-governmental *house of support* in Brazil's Salvador de Bahia (Biehl, 2007), or the residents in Rio de Janeiro's *favelas* who feel "privileged" because their government is both manufacturing and providing their HIV medications (Cataldo, 2008, p. 906).

As people depend on governmental HIV programmes, however, their individual fate becomes inextricable from their national economy. A state of anxiety among people with no alternative means to HIV care can ensue (Box 2, extr.8). In the example of Serbia and Montenegro (Bernays and Rhodes, 2009), insecure availability of ART means patients worry daily about interruptions to their life-saving medications and the rumours circulating about ART rationing. Disengagement from the state and services, rather than the uptake of political action or engagement, manifests the anxiety produced by such uncertainty. Taking ART 'on' and 'off' is deemed more dangerous, and more difficult to cope with, than making a decision to avoid treatment altogether (Bernays and Rhodes, 2009; Box 2, extr.9).

### **ART and communities in the biomedicalisation of HIV**

The gathering of activist communities around a shared biological condition is a core feature of biological and therapeutic citizenship (Nguyen, 2005; Rose and Novas, 2005). Whilst the seminal ethnographies of Nguyen in West Africa (2010) and Biehl in Brazil (2007) documented the early days of treatment activism following the *development and distribution* of ARVs, recent studies framed by these concepts concentrate on the increasingly 'individualising' features of biological citizenship under the influence of biomedical understandings of HIV as a 'manageable' and 'normalised' chronic condition following the *scale-up* of ART (cf. Moyer and Hardon, 2014).

Studies we reviewed suggest that the accent placed on *individual responsibility* in the management of HIV is a prominent and consistent feature of current ART provision worldwide. Even where treatment activism was originally linked with rights-based discourses beyond healthcare (as in the case of South Africa), many observe a progressive reduction of the 'social problem' of HIV to an individualised concern (Biehl, 2007; Kagee et al., 2014; Mfecane, 2011; Robins, 2005). In high-income settings with free healthcare, such as the UK, neoliberal versions of HIV care are increasingly turned into a "depoliticised form of health consumerism" (Robins, 2005, p. 12).

Grassroots NGOs become larger institutions in partnership with the state, and are increasingly oriented towards providing healthcare services rather than mobilising political activism (Robins, 2005; Mfecane, 2011; cf. Seckinelgin, 2008). Bureaucratisation and the need to attract funding through complex donor schemes set up hierarchies and weaken ties within communities (Biehl, 2007; Robins, 2005). Yet community organisations continue to be tasked with supporting those who 'fall out' of the patient/provider contract premised on the individualised 'management' of HIV via ART. When such 'failed' patients cannot be accommodated by NGOs, they fall out of the picture altogether (Biehl, 2007; Kistner, 2009; Nguyen, 2010; Mazanderani and Papparini, 2015; Squire, 2010).

As the "master status" (Flowers, 2010) of HIV identity is diluted through a (chiefly biomedical) emphasis on the normalisation of HIV as 'just another' chronic condition, some reason that the very bases for HIV biological citizenship comes undone (Robins, 2005) and a fragile sense of HIV

community (Biehl, 2007) creates hurdles for NGOs' response. Without HIV community, it becomes challenging to engage with 'HIV identity', considered central to a collective and relational drive towards 'responsibility' and adherence (Robins, 2005). The dissolution of ties of solidarity in the face of the putative normalisation of HIV thus makes it easier for some to be 'left behind', in varying degrees of social and moral isolation (Squire, 2010).

In settings where ART access is uneven or insecure, HIV care may become an outcome of competition between individuals in need rather than of collective actions (Bernays and Rhodes, 2009). Different examples of 'triage' into therapy (Nguyen, 2005) can be found in these studies: ART provided only to patients attending compulsory adherence-focused 'support' groups in South Africa (Mfecane, 2011); ART provided only to those people who inject drugs in Russia who can demonstrate sufficient efforts to stop using drugs (Rhodes and Sarang, 2012); or amongst Ugandan patients assessed for their potential compliance through educational sessions and pill counts at the time of refill (Whyte et al., 2013). When state offers of treatments are made contingent upon patients performing sufficient deservedness, a narrative of disempowered may be produced, far from the ideal of the 'engaged' and 'active' community of (biological) interest envisaged in citizenship claims (Mfecane, 2011; cf. Rhodes et al., 2013).

## **BIOSOCIALITY AND RESPONSIBILITY**

As mentioned early on, biological and therapeutic citizenship theories – and the studies they frame – are commonly connected to Paul Rabinow's conceptualisation of a nascent 'biosociality' (1992a, 1992b) pertaining new forms of interaction and "belonging" (Nguyen, 2010, p. 178) based on shared biological characteristics. Biosociality refers to a process whereby people gather via the shared learning and experience of specific health conditions related to newly-identified objects in the body, such as genes or viruses, otherwise devoid of socio-cultural contextualisation. Specific technological interventions pinpoint common biological traits, as in the case of drug treatments, drug regimens or clinical tests. HIV treatment, and not only HIV status, is thus productive of a new biosociality, as the practice of biomedicine and pharmaceutical technologies invite people to associate outside their everyday social relations and networks.

### **Going back to 'normal'? Returning to sociality from a new biology**

In his account of treatment activism in South Africa, Robins (2005) refers to a "new family" created through nascent biosocial communities linked to the experience of HIV positivity (p. 10), whilst Biehl (2007) describes the residents of a grassroots AIDS hospital in Salvador as a "biocommunity" (p. 324). Both authors note that biosociality emerges in the context of the stigmatisation of HIV, parallel to an observation made by Rose and Novas (2005) regarding biological citizenship as a project of *inclusion* in response to discrimination (pp. 448-451). Gay activism in the context of the early AIDS epidemics in the US and Europe is most often cited as an example of mobilisation against fear, negative propaganda, and political and therapeutic neglect (cf. Epstein, 1996; Rose and Novas, 2005).

Echoes can also be found in other literatures which frame HIV diagnosis as a 'turning point' through which people from marginalised groups find new meaning, direction and belonging. Although these

studies do not necessarily refer to Rabinow's idea of biosociality, and are articulated as individual journeys of identity reconstruction around a stigmatised condition, they nonetheless point to forms of sociality emerging from a new biological condition of HIV seropositivity, which help to frame new understandings of self and community (cf. Berger, 2010; cf. Watkins Hays, Pittman-Gay and Beaman, 2012).

Yet many studies reviewed here unpack and contest the idea that a new sociality can be forged via HIV and ART. HIV stigma is not seen as a cohesive force for the stigmatised but as an ostracism leading to self-silencing. New forms of HIV-related sociality are thus described as a product of the re-shaping of *existing social ties* rather than of biological connections.

For instance, Marsland (2012) argues that HIV and ARVs in Tanzania are insufficient to produce a new biosociality and that it is the shared experience of clinic and treatment practices that enables people with *pre-existing links* to gather under the recognised predicaments of HIV and ART. Similarly, Whyte et al. (2013) observe that social connections which pre-date HIV diagnosis provide an "already-existing personalised web of influence" that people living with HIV in Uganda perceive as more salient than HIV bio-status alone as networks that can "be set in motion to get things done" (p. 149). In both cases, study participants lived in households affected by HIV wherein family relations were among the primary 'ties' in relation to life with HIV. They were also weaved into healthcare via personal acquaintances, not as 'individual' HIV patients, which suggests resourcefulness but also an inherent "fragility" as different people have unequal access to influential 'actors' (Whyte et al., 2013, p. 147). In the creation of HIV-related sociality, pre-established social relationships may take precedence over new forms of 'bio'-social solidarity or connection.

Beckmann (2013) further explores how people in Tanzania wish to "return to a normal life" more than they wish to create new (bio)social networks (p. 166). Once health is 'restored' through ART, the main preoccupation is not to assume a new HIV identity or enter a new biosocial 'family', but rather to disclose one's status to as few people as possible, both to avoid stigmatisation and to attempt to seamlessly re-commence life post-HIV diagnosis (Box 3, extr.10). The quest for solidarity is thus overridden by the social risks involved in disclosure and, if ART produces any physical or visible side-effects, even treatment itself comes to be seen as threat to a return to normality.

People living with HIV in Tanzania express the desire first and foremost to develop ways to sustain a 'life worth living', embedded in social relations and exchange (Marsland, 2012). Other studies add weight to this observation: Levy and Storeng note the need for income among HIV positive women in South Africa before they can engage in any discourse of 'positive living' (2007); men engaged in peer-support in Cape Town want to work, earn money and resist the category of the "HIV vulnerable sufferer" (Colvin, Robins and Leavens, 2010, p. 1187); and Mattes finds that "dignity and social recognition" may constitute a core aspiration for some of his participants much more than the creation of a "pharmaceutical self" (2012, p. 81).

As engagement with biomedicine is 'deflected', HIV biosociality is edged to the periphery, only momentarily incorporated into primary forms of sociality. New forms of HIV sociality, although borne out of existing social ties rather than biology, nonetheless begin to modify existing social structures from the perspective of biology. Biosociality thus *progressively* intersects with, and might only *eventually* supersede, previous sociality over the long course, rather than in any immediate or automatic fashion (Rabinow, 1992a, 1992b).

## Adherence and responsibility: towards whom?

An emphasis on personal responsibility frames the moral expectations placed on the therapeutic citizen's health behaviours (Rose and Novas, 2005; Petersen et al., 2010). Social discourses of responsibility have also emerged from public health framings of the management of HIV risk, as moral counteraction to the negative sanctioning of people with HIV as 'deviant'. Biomedical responsibility especially is performed through adherence to ART, protecting the self through protecting immunity (Persson and Newman, 2006), reducing the risks of other illnesses, and minimising onward HIV transmission (cf. Persson, 2013).

Testing, or 'knowing one's status', begins the process for "responsible citizens who have taken action" (Russell, Namukwaya, Zalwango and Seeley, 2015, p. 5). Additional demonstrations of 'health-promoting' and responsible behaviours include abstaining from sex or using condoms, disclosing serostatus to partners, following guidance on 'positive living', advocating for those with the same condition, keeping informed, 'active' and engaged with healthcare and surrounding issues (Flowers, 2010; Levy and Storeng, 2007; Mazanderani and Papparini, 2015; Nguyen, 2010; Rose and Novas, 2005; Russell et al., 2015). Health workers are indeed often 'framing agents' instrumental in drawing the parameters of responsible citizenship (Russell et al., 2015).

Studies reviewed observe that responsibility is less an individual self-preserving endeavour than a "socio-moral phenomenon" (Mattes, 2012, p. 77) imbued with obligations towards the "hidden collective" of family, kin and community (Marsland, 2012, p. 474). Adherence to treatment expresses responsibility *as reciprocity* towards the "consistent good will of potential helpers... required for survival" (Ware et al., 2009, p. 45) and preserves physical health necessary to perform income-generating and caring activities for the collective (Colvin et al., 2010). Studies in South Africa cast adherence as a "pro-social behaviour furthering the common good" (Kagee et al., 2014, p. 107), with doing one's best to stay healthy and to 'self-improve' via ART (Colvin et al., 2010) enacting responsibility towards communities. Likewise in Uganda, a *collective* therapeutic citizenship is "socially fashioned" by people living with HIV, based on responsible condition management and allegiances to healthcare workers and other patients alike (Russell et al., 2015, p. 8).

Powerful associations between the need to be healthy and to care for others constitute a collective moral economy of adherence which, for Ware et al. (2009), explains how people in sub-Saharan Africa manage to adhere as well as – or better than – those in higher income settings, in spite of the multitude of barriers they face (cf. Hardon et al., 2007). Yet Beckmann (2013) argues that ART programmes (in Tanzania) "shift the burden of responsibility for success... onto the shoulders of patients" despite the limits to responsible adherence in the context of poverty and survival (p. 161). Adherence and the importance of keeping the virus suppressed (now and in future) are threatened by the lack of opportunity for social and economic lives in the present.

Adherence then, is seen as a social (as well as a biomedical) technology requiring collective practice and commitment (from patients, healthcare workers, peer mentors, family members) (Biehl, 2007; Moyer, 2014), and responsabilisation may be articulated as constituting a means to provide and care for others. Responsibilisation can thus incorporate adherence but it extends further, as its reason-to-be is the preservation of social ties, above and beyond the preservation of health.

## DISCUSSION

We have focused on social science studies that have engaged with ideas of biological and therapeutic citizenship in their accounts of HIV and its treatment. The literature reviewed is highly context-specific and grounded primarily in the global south (and Africa in particular), whilst in dialogue with discourses around global health. An overarching theme concerns the *limits to the actualisation of citizenship* in the context of competing social needs, alternative forms of knowledge and expertise, and structural relations, especially patterns of poverty and inequity.

Empirical case studies note tensions in the language and expectations of patient citizenship, the emphasis on individual responsabilisation, expertise, engagement and awareness of rights, in contrast with some of the situated experiences of HIV health and healthcare, particularly in lower income settings (Beckmann, 2013; Biehl, 2007; Cataldo, 2008; Levy and Storeng; Marsland, 2012; Mattes, 2011, 2012; Meinert et al., 2009; Mfecane, 2011; Niehaus, 2014). This has led to a questioning of the scope of the theoretical frameworks of biological and therapeutic citizenship (Kagee et al., 2014; Kistner, 2009; Meinert et al., 2009; Mfecane, 2011; Whyte et al., 2013), also in instances where these are applied to conditions other than HIV (cf. Rhodes et al., 2013).

### **The limits of HIV citizenship and the ‘health contract’**

Whyte et al. (2013) propose that the concept of ‘therapeutic clientship’ might more appropriately describe patron/client relations, embedded not only in funder/provider HIV-aid exchanges on a global scale, but also in provider/patient encounters in health systems characterised by scarcity, rationing, and conditional ART provision. Whilst a neoliberal reading of ‘clientship’ “suggests enlightened consumerism and user friendliness” (Whyte et al., 2013, p. 150), in Uganda the patronage system of therapeutic clientship casts treatment provision as a profoundly social, and often tenuous, form of healthcare where there is little room for negotiating inclusive citizenship through treatment. This contrasts with the purported, idealised ‘health contract’ (Robins, 2005; Kistner, 2009) between HIV patients and their clinicians, which hints at shared duties and reciprocal rights in a supposedly neutral context of equal political grounds.

Whether offered on condition of compulsory treatment education and attendance at peer group discussions (Mattes, 2011; Kistner, 2009), or whether non-coercive by emphasising “responsibilisation, consent and self-regulation” (Colvin et al., 2010, p. 1183), therapeutic clientship is implicitly unequal. Support group members can at times be treated as little more than “blank slates waiting to be filled with health and treatment information” (Mfecane, 2011, p. 133). ‘Reliable’ and ‘deviant’ patients are separated to maximise resource allocation through an array of social and ‘confessional’ technologies (Nguyen, 2010), and the performance of the patient-citizen “comes to include the conditions and means for survival” (Kistner, 2009, p. 4).

Therapeutic clientship reproduces a version of “healthcare as charity” in which “entitlements become concessions” (Biehl, 2007, p. 310) to those who display ‘deservedness’ (Rhodes and Sarang, 2012). Reciprocity is required from the side of the patient-receiver who must give back through adherence first and foremost, but also through openness, patience, clinic attendance, gratitude and allegiance to the biomedical rationalities of ART (cf. Bernays et al., 2010; Biehl, 2007; Whyte et al., 2013; Mazanderani and Papparini, 2015). Thus, as Kistner (2009) suggests, the only aspect of biological citizenship that is enacted in circumstances where people are entirely dependent on these



forms of unequal HIV care, is the way in which patient-citizens are actually governed through biomedicine and made responsible not only in relation to their health, but also in relation to the state as a whole, “under the threat of the withdrawal of the means of life” (p. 1). Biological citizens rally behind a biological condition to seek *re-inclusion* under the protection (and provision) of the state rather than to have their biological rights recognised and needs met. When the state is ‘absent’, claims are made on global humanitarian grounds (Nguyen, 2010).

People living with HIV in many settings access healthcare in the context of otherwise disappearing public services infrastructures (Biehl, 2007; Whyte et al., 2013). But Kistner (2009) argues that protection and improvement of health and social care systems cannot be actualised through biological citizenship projects: they require broader political and economic struggles that are often *beyond* the capacities of patient-citizens, precisely because they depend so heavily on state ART provision.

Furthermore, biological inclusion (or re-inclusion via responsabilisation and adherence) runs parallel to social exclusion (Kistner, 2009): the same people ‘failed’ by health and social care systems become those who cannot keep up their side of the new health contract. Examples of this abound in the studies reviewed, describing the conditions of those who are homeless (O’ Daniel, 2014), have substance use issues that preclude their access to ART (Rhodes and Sarang, 2012), are ‘troublesome’ in instances of communal institutional living (Biehl, 2007), or exist on the margins, in one way or another, to the extent that they ‘fall out’ of healthcare relations despite being in utmost need (Biehl, 2007; Mattes, 2011).

Perhaps the limits of citizenship frameworks for understanding ART and care engagement are to be found in the application of the theories to empirical contexts and examples other than those for whom they were originally conceived. For example, Rose’s and Novas’s (2005) concept of biological citizenship illuminates clearly the trajectory of early gay activism in relation to the US HIV/AIDS epidemic and successfully links this to the mobilisation of other, new, biosocial communities, for example around genetic conditions. It may lose some of its analytical power *vis-à-vis* landscapes where health systems and techno-science are barely visible.

Similarly, therapeutic citizenship might more accurately describe the biopolitical repercussions on local lives of the introduction of ARVs at a global scale. It addresses that very momentum in the shift in sovereignty beyond national health systems, tracking HIV and AIDS as an extraordinary global health experiment ushering in and transposing a whole apparatus across settings and health conditions. It may not stretch to encompass *all* forms of HIV and ART engagements and disengagements throughout the pandemic.

## CONCLUSION

Theories of patient citizenship both herald and critique the concept of ‘cascade of care’ and its components. The progression of the cascade of care can be seen to represent a clear pathway to HIV biological citizenship, with viral suppression projected as the objective measurement of success and hope of HIV citizens. Multiple constituents of biological citizenship are implicated in the care

engagement pivotal to the cascade, including informational citizenship, patient rights, and moral values surrounding responsabilisation.

Our synthesis suggests that further research about emerging forms of patient citizenship linked to care and pharmaceutical demands would be greatly relevant in the context of competition for public funding and expenditures. Citizenship theories may also need to be 'tested' with empirical studies regarding rationing and treatment reductions, at a time when engagement and retention in care is increasingly articulated along the lines of cost effectiveness debates in health systems (Nosyk et al., 2014; Stover et al., 2014). Furthermore, as well as their health benefits, the added prevention effects of HIV viral suppression also represent significant cost savings (Gupta, Williams and Montaner, 2014). Against this background, it will be important to analyse how biological citizens may be increasingly made individually responsible for more than their own health.

Viral suppression and related biomarkers are a universally recognised language in biomedicine (Flowers, 2010), which lends this clinical information certain *capital* (Nguyen, 2005). The 'biological efficacy' of a clinic in retaining patient cohorts on treatment (Nguyen, 2005, p. 139) is intertwined with collective evidence of the functioning of national health systems. The notion of biological efficacy is thus useful and relevant to analyses of care cascade frameworks, since these are already in use to track and model national epidemics and to inform further investment in treatment-as-prevention strategies in different regions. The literature reviewed here cautions that steps in the cascade, which are becoming globally recognisable characteristics, can obfuscate stark structural inequalities, pay insufficient attention to local context, and describe little of the linkage between initiatives that can achieve potentially more *meaningful* health outcomes for people living with HIV *and* their broader health needs and rights.

## **ACKNOWLEDGEMENTS**

This research was funded by the National Institute for Health Research and undertaken by the National Institute for Health Research Health Protection Research Unit (NIHR HPRU) in Blood Borne and Sexually Transmitted Infections at University College London in partnership with Public Health England and in collaboration with the London School of Hygiene and Tropical Medicine. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research, the Department of Health or Public Health England. The authors would like to thank Steven Russell for providing us with a copy of Russell et al.'s (2015) paper ahead of publication. We would like to thank Sarah Bernays, Andy Guise and Pippa Grenfell for suggestions on how to approach the literature synthesis.

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<b>Table 1 Core theoretical papers</b>			
	<b>Authors</b>	<b>Year</b>	<b>Title</b>
1	Nguyen, V.-K.	2005	Antiretroviral globalism, biopolitics and therapeutic citizenship
2	Nguyen, V.-K.	2009	Government-by-exception: enrolment and experimentality in mass HIV treatment programmes in Africa
3	Nguyen, V.-K.	2010	The republic of therapy: triage and sovereignty in West Africa's time of AIDS
4	Nguyen, V.-K.	2013	Counselling against HIV in Africa: a genealogy of confessional technologies
5	Nguyen, et al.	2007	Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment
6	Rabinow, P.	1992a	Artificiality and enlightenment: from sociobiology to biosociality
7	Rabinow, P.	1992b	Studies in the anthropology of reason
8	Petersen, et al.	2010	Healthy living and citizenship: an overview
9	Rose, N. & Novas, C.	2005	Biological citizenship



<b>Table 2 Synthesised papers</b>				
	<b>Authors</b>	<b>Country</b>	<b>Aims</b>	<b>Participants</b>
1	Alcano, 2009	Italy	<ul style="list-style-type: none"> <li>Ethnography of HIV clinic in Milan (2007-2008);</li> <li>Examines relations between biotechnologies and work.</li> </ul>	7 male construction workers living with HIV ( <b>LWH</b> ) in Milan.
2	Biehl, 2007	Brazil	Ethnography of Brazilian AIDS policy, ART and survival amongst urban poor and marginalised populations.	Policymakers, clinicians, workers, patients and members of State and NGO treatment and support organisations.
3	Beckmann, 2013	Tanzania	<ul style="list-style-type: none"> <li>Ethnography of ARV roll-out in Tanzania and Zanzibar (2 years);</li> <li>Looks at the promotion of ideas of responsibility and self-care in donor AIDS intervention programmes.</li> </ul>	<ul style="list-style-type: none"> <li>People living with HIV (<b>PLWH</b>): in clinics; in support groups; at home;</li> <li>Life histories and observation of public discussions about HIV.</li> </ul>
4	Bernays and Rhodes, 2009	Serbia and Montenegro	<ul style="list-style-type: none"> <li>Qualitative study;</li> <li>Looks at the impact of fragile ART delivery in Serbia &amp; Montenegro.</li> </ul>	<ul style="list-style-type: none"> <li>41 PLWH in three waves of recruitment;</li> <li>18 service providers.</li> </ul>
5	Cataldo, 2008	Brazil	<ul style="list-style-type: none"> <li>Ethnography in Rio de Janeiro;</li> <li>Explores the 'public health rhetoric of universalism' from the perspective of the urban poor</li> </ul>	<i>Favela</i> inhabitants LWH; health care team at local health centre; two HIV NGOs.
6	Colvin et al., 2010	South Africa	<ul style="list-style-type: none"> <li>Ethnography of the Khululeka support group for men LWH;</li> <li>Explores citizenship, subjectivity and masculinity in the context of HIV</li> </ul>	<ul style="list-style-type: none"> <li>Group members and NGO workers in Gugulethu (Cape Town).</li> <li>No info on number of pts.</li> </ul>
7	Doyal, 2013	n/a	<ul style="list-style-type: none"> <li>Book focuses on commonalities, differences and inequalities in the pandemic using narratives of PLWH.</li> <li>Chapter charts issues related to treatment.</li> </ul>	n/a
8	Flowers, 2010	UK	Two qualitative studies re-focusing on the psychosocial issues of PLWH.	<ul style="list-style-type: none"> <li>Interviews with PLWH in the UK;</li> <li>In 2001 and 2006 using IPA;</li> <li>No detail on size of samples.</li> </ul>
9	Kagee et al., 2014	South Africa	Contextualises adherence in political and historical developments of resource-constrained countries.	<ul style="list-style-type: none"> <li>Historical and political examination of ART provision and adherence in SA.</li> <li>No empirical data.</li> </ul>
10	Kistner, 2009	South Africa	Discusses the limits and contradictions of biological citizenship analysis of SA treatment activism and HIV care systems.	n/a

11	Levy and Storeng, 2007	South Africa	<ul style="list-style-type: none"> <li>Ethnographic fieldwork in Cape Town and surrounding area;</li> <li>Explores the meaning of 'living positively' for women LWH.</li> </ul>	<ul style="list-style-type: none"> <li>12 women LWH; 11 HIV counsellors; 12 public health researchers; policy-makers and people involved in voluntary orgs; 2 healthcare providers;</li> <li>Observation in support group meetings; conferences; policy meetings.</li> </ul>
12	Marsland, 2012	Tanzania	Ethnography looking at experiences of living with HIV and ART with families in the district of Kyela.	12 families affected by HIV.
13	Mattes, 2011	Tanzania	<ul style="list-style-type: none"> <li>Ethnographic fieldwork (11 months) in Tanga;</li> <li>Investigates 'techniques used to produce treatment adherence during treatment preparation' in post ARV roll-out.</li> </ul>	<ul style="list-style-type: none"> <li>Main hospital, five health centres; observation in VCT settings, education sessions, clinic consultation and hospital floors;</li> <li>27 interviews with providers and 26 with patients;</li> <li>Observation in support groups, focus groups, and at home.</li> </ul>
14	Mattes, 2012	Tanzania	<ul style="list-style-type: none"> <li>(Study same as above);</li> <li>Discusses how 'patients' practices and ideas regarding ART are related to morality.</li> </ul>	(Same as above); focuses on the case study of one man and his family.
15	Mazanderani and Paparini, 2015	UK	<ul style="list-style-type: none"> <li>Joint re-analysis of two qualitative datasets;</li> <li>Focuses on questions of normalisation of HIV;</li> <li>And on the role of research interviews in this process.</li> </ul>	<ul style="list-style-type: none"> <li>One study with 35 PLWH;</li> <li>And the other with 41 African women LWH;</li> <li>Both in the UK</li> </ul>
16	Meinert et al., 2009	Uganda	<ul style="list-style-type: none"> <li>Ethnography in Kampala and South-eastern Uganda;</li> <li>Explores CD4 counts as a social technology, different ART provision and CD4 count services, and how people appropriate these.</li> </ul>	48 men and women LWH, accessing ART and HIV care through 7 different programmes.
17	Mfecane, 2011	South Africa	<ul style="list-style-type: none"> <li>Ethnography in Bushbuckridge;</li> <li>Explores the experience of ARV usage and support group attendance in a rural health facility.</li> </ul>	<ul style="list-style-type: none"> <li>25 men interviewed one-to-one;</li> <li>Attending support groups for 14 months;</li> <li>Engaging with public discussions about HIV.</li> </ul>
18	Moyer, 2014	Kenya	<ul style="list-style-type: none"> <li>Ethnography of Kenyatta National Hospital (2011-2014) in Nairobi;</li> <li>Focuses on peer mentors but as part of broader and longer-term ethnography in the country.</li> </ul>	<ul style="list-style-type: none"> <li>10 HIV peer mentors in daily clinical and peer-group practice;</li> <li>Nurses, social workers, administrators and doctors.</li> </ul>
19	Niehaus, 2014	South Africa	<ul style="list-style-type: none"> <li>Ethnography in Mpumalanga Province;</li> <li>Explores how ART intersects with broader national situation and history and local village factors in relation to uptake.</li> <li>Presents the in-depth case of one man LWH.</li> </ul>	<ul style="list-style-type: none"> <li>87 households;</li> <li>Individual interviews and biographies of 25 men (four LWH).</li> </ul>
20	O'Daniel, 2014	USA (North Carolina)	<ul style="list-style-type: none"> <li>Ethnography of a federally-funded HIV/AIDS service organisation in Midway;</li> <li>Explores how low-income African-American women LWH engage with laboratory results and clinical understandings of HIV.</li> </ul>	<ul style="list-style-type: none"> <li>40 African-American women LWH;</li> <li>And 11 providers.</li> </ul>

21	Persson and Newman, 2006	Australia	<ul style="list-style-type: none"> <li>• Qualitative study on side effects of ART;</li> <li>• Explores how self is constituted in the context of strength and immunity;</li> <li>• Focuses on efavirenz.</li> </ul>	40 PLWH with past/present ART and past/present side-effects.
22	Rhodes and Sarang, 2012	Russia	<ul style="list-style-type: none"> <li>• Qualitative study;</li> <li>• Explores factors that impact conditional access to ART among people who inject drugs in a city with high HIV prevalence.</li> </ul>	<ul style="list-style-type: none"> <li>• 42 people who inject drugs who are LWH;</li> <li>• And 11 health practitioners.</li> </ul>
23	Robins, 2005	UK and South Africa	<ul style="list-style-type: none"> <li>• Compares the relationship between the advent of ART and activism in the UK and South Africa;</li> <li>• and how new social movements shape identities.</li> </ul>	<ul style="list-style-type: none"> <li>• Limited information;</li> <li>• Observation and interviews with positive activists and organisation members in UK and South Africa.</li> </ul>
24	Russell et al., 2015	Uganda	<ul style="list-style-type: none"> <li>• Qualitative study;</li> <li>• Explores ideas of self-management, and the role of healthcare workers and peer support groups in shaping treatment experience</li> </ul>	Two waves of interviews with 38 participants LWH.
25	Squire, 2010	UK and South Africa	<ul style="list-style-type: none"> <li>• Two qualitative studies;</li> <li>• Explores the 'naturalization' of HIV through medicalisation, normalisation and marketization processes in different local epidemics.</li> </ul>	<ul style="list-style-type: none"> <li>• In the UK (with 55 PLWH);</li> <li>• And South Africa (with 37 PLWH).</li> </ul>
26	Thomas, Aggleton and Anderson, 2010	UK	<ul style="list-style-type: none"> <li>• Part of qualitative study on use of alternative medicines by PLWH;</li> <li>• Explores communication and meaning-making in the clinic.</li> </ul>	<ul style="list-style-type: none"> <li>• 79 PLWH focus groups;</li> <li>• And 20 interviews;</li> <li>• All with migrants from Southern Africa LWH.</li> </ul>
27	Whyte et al., 2013	Uganda	Ethnography of the experiences of people on ART from the first generation of ARV roll-out in Kampala and Eastern Uganda (2005-2007).	48 PLWH from 7 health centres.
28	Ware et al., 2009	Nigeria, Tanzania and Uganda	<ul style="list-style-type: none"> <li>• Ethnographic study in three countries;</li> <li>• Explores views on adherence from perspective of patients, treatment partners and health care providers;</li> <li>• With particular attention to obstacles and facilitators of adherence.</li> </ul>	<ul style="list-style-type: none"> <li>• 158 PLWH</li> <li>• 45 treatment partners (TPs)</li> <li>• 49 health care providers across three hospital sites in the three countries (for a total of 414 interviews);</li> <li>• 136 sessions of observations in the field (clinic visits, counselling sessions, health education sessions, medication dispensing).</li> </ul>

## **BOX 1**

### ***Deflecting biomedicine***

(1) One of the HIV doctors in Alcano's ethnography in Milan says: *'a strong patient' is 'a patient who complies with prescriptions, who takes the medicines methodically'* (2009, p. 121). One of his patients, a positive male construction worker, asserts instead: *'My doctor always repeats that I have to stay strong and take the medicine. I tried to explain to him that what makes me strong kind of kills me at work'* (Alcano, 2009, p. 125).

### ***Situated rationality of ART and adherence***

(2) As the primary provider of the household, Paolo – a construction worker from Milan – feels that ART side-effects clash with his primary necessities: *'I have a family to support and my wife does not have a job. I need to go to work and provide for basically everything. And when you are in my situation your arms better be strong and working, otherwise you're in trouble'* (Alcano, 2009, p. 127).

(3) Leo – another construction worker in Alcano's ethnography in Milan – describes his 'steering' strategies about treatment-taking as: *'getting comfortable in the space between myself and my doctors'* (Alcano, 2009, p. 124).

### ***Non-engagement***

(4) When asked what their latest blood tests say, participants in O'Daniel's ethnography with African-American women living with HIV in the US reply: *'I don't know as far as number wise';* or: *'she checked my levels but I don't really know where they are now'*, adding that: *'On the weekend I really don't [take ARVs], but Monday through Friday I usually get up and pop them. But as long as I feel good and I'm taking my medicine most of the time, I know that it can't be that bad'* (O'Daniel, 2014, p. 331).

### ***Case study of competing priorities***

(5) Mattes' (2011) case study is the story of Haruna, an HIV positive male construction worker in Tanga (Tanzania) recently widowed. He is concerned his in-laws will refuse to contribute to the medical care of his new-born son if he discloses the mother's death due to HIV and his own HIV status. Haruna's need for both treatment and support is impossibly balanced, he cannot "harmonize the rigid treatment regime with his working conditions" (p. 170) but also has to disclose and "risk his relatives' solidarity... to ensure adequate medical care for his new-born son" (p. 171).

### ***Treatment literacy and expertise***

(6) *'I believe that if you are talking to someone who is educated medically, they won't understand – you are using herbs, what do you need to use herbs for?' So I thought they wouldn't understand why I wanted to use the herbs... So that's why I didn't tell them'* (Zimbabwean participant in Thomas, Aggleton and Anderson, 2010, p. 740).

### ***Blood counts as truth telling***

(7) As Lady E, one of the positive African American women in O'Daniel's ethnography in North Carolina (US), explains: *'That's on you to care about taking those meds. Let's keep it real. Just call it whatever the hell it really is – 'lazy' or 'don't give a damn'. This is the truth of your life. Take the medication or don't... they'll know because they [doctors'] read it [the truth] in your blood'* (2014, p. 328).

## **BOX 2**

### ***Insecurity and disengagement***

**(8)** As expressed here by Edilson, one of Cataldo's (2008) Brazilian participants: *'I am afraid that we could be in a situation where treatment is not available any more, and if there is a lack of treatment it would be fatal, death would be the only outcome . . . I'm scared, because I have seen many weaknesses in the government, and I'm scared that it could be another failure'* (p. 908).

**(9)** Insecure availability of ART means participants in Bernays and Rhodes' (2009) qualitative study in Serbia and Montenegro discuss how they *'have constantly the worry about what happens today and after today', 'live from one day to another'*, and complain that: *'the talk with people and in the media is always these terrifying headlines, like: 'there won't be any medicines'; or 'there won't be enough money for HIV treatment'* (p. 317).

### **BOX 3**

#### ***Returning to sociality***

(10) Maria, a participant in Marsland's (2012) ethnography in rural Tanzania, states: '*until there is some kind of profit in living openly with HIV, I am going to keep it a secret*' (2012, p. 470; also echoed by participants in Mfecane, 2011 in South Africa).

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