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Kevin P. Corbett

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Multiplicity, Heterogeneity, and the Unintended Consequences of HIV-related Tests

Kevin P. Corbett
Independent Research Consultant

This article considers the experiences of health consumers who have undergone testing for human immunodeficiency virus (HIV) antibodies, T cells, and viral load. These HIV-related tests are deployed for the purposes of making definitive diagnoses; yet some test consumers experience ambiguous outcomes. Drawing on an analysis of differing end-user experiences of these tests, where consumers' knowledge reflected the multiplicity and heterogeneity in test design, the author explores how these experiences reflect particular knowledges about these tests. The article contributes to efforts analyzing how health consumers are active end users co-constructing the social meaning of technologies in mutual relationship with other users. The author discusses how this new knowledge can be used to delineate a greater role for consumer evaluation of medical testing within a broader understanding of test design and performance. Relevant links are made to issues such as genetic testing and assessing claims about the efficacy of medical tests.

Keywords: *health consumers; co-construction; HIV-related tests*

Introduction

The three tests currently deployed in medical testing for the human immunodeficiency virus (HIV) and in clinical monitoring of the progression of the acquired immunodeficiency syndrome (AIDS) were licensed in different eras. The first tests used were the antibody-tests from the mid-1980s onward (Epstein 1996). T cell counts were used from the late 1980s onward, and with antibody-tests, they defined subsequent global definitions of AIDS (Epstein 1996). The viral load/polymerase chain reaction (PCR) tests were

used from the mid-1990s to identify/quantify retroviral DNA/RNA (Rabinow 1996). These tests also give early knowledge of disease when no symptoms exist (Epstein 1996). They are used in routine laboratory surveillance of the following "surrogate" markers that respectively identify HIV antibodies (antibody testing), measure immune function (T cell testing, Epstein 1996), and calculate amounts of circulating virus (viral load/PCR testing, Rabinow 1996). These surrogate markers are used for regulating normality/pathology in biomedical platforms that encompass the test kits, test algorithms, and all end users (Keating and Cambrosio 2003, 9-10).

Medical testing[1] aims to unambiguously separate the normal from the pathological and increasingly enables the identification of early asymptomatic disease (National Screening Committee 1998). If health consumers' experience is the opposite—ambiguous diagnosis—reports suggest this may foster skepticism (AVERT 2007; Gallagher 2005). As national health agencies imply (National Screening Committee 1998), ambiguity arises due to medical tests' intrinsic designs, which all display biomedical multiplicity/heterogeneity. This may be defined as the many ways in which the same tests perform differently, thus causing dissimilar, interpretable, and contingent diagnoses shown in the reports on test technologies, practices, and experience (Ball 2000; Gigerenzer, Hoffrage, and Kleinbolting 1998; Mylonakis et al. 2000).[2] These phenomena are unintended or unanticipated consequences arising from the prospective use of a technology, and as such, they are also examples of "autonomous properties" (Brey 1997, 56). Currently, no published study has focused on this topic in respect to HIV-related tests (Corbett 2001b), which is of importance, as it causes abandonment of HIV tests (Buhl 2005), questioning of expertise (Maggiore 2000; Papadopulos-Eleopulos, Turner, and Papadimitriou 1993; Papadopulos-Eleopulos et al. 1995), and false positive diagnoses (AVERT 2007; Gallagher 2005; Gigerenzer, Hoffrage, and Kleinbolting 1998).

This article focuses on the experiences of health consumers (end users) with the autonomous properties of these tests, which encompass test

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technologies, practices, and experiences. The next section describes the overall approach developed for analyzing health consumers' experiences of these properties using a purposive sample of narratives on each of the above HIV-related tests derived from different end users (health consumers, manufacturers, regulators). In the following sections, these narratives are juxtaposed for each of the above HIV-related tests in turn so as to analyze how health consumers renegotiate and rework the meaning of these tests in relation to experience. The aim is to reveal how the reasoning of health consumers co-constructs the social meaning of these test phenomena through their relationships with other end users (Oudshoorn and Pinch 2003, 6-11). The final section discusses what is implied for consumer evaluation of medical testing in the context of test design and performance. The final discussion also describes the relevance of these issues to user experiences of genetic testing and assessing claims over the efficacy of medical tests.

Research Approach

The term *health consumer* in this article means those end users who undergo testing and receive diagnostic labels. They are one type of user positioned as test taker/test recipient downstream of the technology (Casper and Clarke 1998; Caron-Flinterman, Broerse, and Bunders 2007). As such, they resemble "implicated actors" in the technological design (Clarke 2005, 46) or "public downstream end users" (Lyall et al. 2004, 73). Conversely, licensed medical practitioners (another end user) are the only social group legally empowered to translate laboratory test readings into diagnostic labels (Her Majesty's Stationery Office 1992; Mensah 2000). These differences imply a particular set of relations between different end users of the same technologies.

Akrich (1992) describes how actors can define their own roles for a technology contrary to those prescribed by the design. They do this through a process of *de-inscription*, going back and forth between the world *inscribed* by the object (artifact) and that *described* by its displacement. This means that the identity of tests and end users can be seen to emerge by a process of *reciprocal definition*, whereby test artifacts are defined by subjects and subjects by objects (pp. 208-9). In this article, to *de-inscribe* an HIV-related test means to interrogate the scripted meaning of the test by assessing how well or not it correlates with actual experience. End users may *de-inscribe* while simultaneously taking standard and non-standard positions (Oudshoorn and Pinch 2003, 11) on issues such as disease etiology.[3] Similarly, to *subscribe*

means to bolster the inscribed meaning of the test through explaining away its multiplicity/heterogeneity to underwrite its scripted meaning. End-user narratives on their experiences of testing may reveal *subscriptions* or de-inscriptions (Akrich and Latour 1992, 261), as they respectively react to the scripts of the HIV-related tests. These test scripts, which promise ideal functionality, certainty, and ease of use, are presented to health consumers on an either/or basis, depending on the presence/absence of detectable laboratory markers: either detectable (meaning sick) or undetected (meaning healthy); see Mensah (2000) and Patton (1990). Health authorities know that these scripts may actually predispose users to take tests through a tacit promise of gaining unambiguous knowledge (National Screening Committee 1998). This apparent clarity and ease of use belies the fact that by engaging with these tests, all types of end user are also engaging knowingly or unknowingly with the inherent multiplicity and heterogeneity in the essential design of these tests (Gigerenzer, Hoffrage, and Kleinbolting 1998; National Screening Committee 1998).

A literature search was conducted to identify published sources that (1) detailed health consumers' experiences of taking HIV-related tests and how the same tests were also described by test manufacturers and other scientific actors in health agencies, (2) covered a range of types of publications dating from 1985 up to 2004 (as tests were first licensed from 1985 onward [Epstein 1996]). This time frame allowed coverage of all test eras to better enable identifying a comprehensive range of sources. Using these criteria, a broad range of sources were identified and systematically collated within a bibliography (Corbett 2001b). This search also found that no previous study in the science and technology studies (STS) or other (e.g., Moore, Candlin, and Plum 2001; Race 2001; Rosengarten et al. 2004) literatures had explored these tests' autonomous properties or used the above (or any) STS perspective for analyzing users' HIV-related testing experiences or viewed autonomous properties as artifacts of known HIV-related test multiplicity/heterogeneity (Corbett 2001b). Codes were allocated to each source according to type of publication source (TPS) type of end user, de-inscriber or subscriber (TD/S), and user articulation of non-standard views on AIDS causation/etiology (see note to Table 1). Categories were subdivided and numbered for all sources, compiled into a spreadsheet (see excerpt, Table 1), and summarized (Table 2).

Purposive sampling was undertaken across this broad range of sources for narratives on autonomous properties. Using the above theoretical approach, narratives for each HIV-related test were selected as data for analysis, as original sources noted autonomous properties without analysis so warranting the approach taken below (Heaton 2004). Juxtaposing narratives from

Table 1
Excerpt from Spreadsheet of Data Sources (n = 127)

Documentary Sources (n = 127)	Type of Publication Source (TPS)						Type of De-inscriber/Subscriber (TD/S)					Non-standard (NS)
	TPS 1	TPS 2	TPS 3	TPS 4	TPS 5	TPS 6	TD/S 1	TD/S 2	TD/S 3	TD/S 4	TD/S 5	
1. Abbott Axsym System (1995, 1998)	0	1	0	0	0	0	0	0	0	1	0	0
2. Abbott Laboratories (1997)	0	1	0	0	0	0	0	1	0	0	0	0
126. Young (1995)	0	0	1	0	0	0	0	0	0	1	0	1
127. Wong-Wylie and Jevne (1997)	0	0	1	0	0	0	0	0	0	1	0	0

Note: Type of publication source (TPS): TPS 1 = national regulatory health authority; TPS 2 = commercial test design manufacturer; TPS 3 = academic peer reviewed medical/social science journal/textbook/dissertation/thesis; TPS 4 = autobiography; TPS 5 = community newspaper; TPS 6 = mass circulation daily. Type of de-inscriber/subscriber (TD/S): TD/S 1 = health agency scientific regulator; TD/S 2 = test kit manufacturer; TD/S 3 = health consumer/patient; TD/S 4 = medical/social scientist; TD/S 5 = investigative journalist. Non-standard (NS): NS = non-standard views on AIDS causation/etiology.
Documentary sources: Included in bibliography of Corbett (2001b).

Table 2
Summary of Data Sources (n = 127)

Number of Documentary Sources	Type of Publication Source (n = 6)						Type of De-inscriber/Subscriber (n = 5)					Non-standard (NS)
	TPS 1	TPS 2	TPS 3	TPS 4	TPS 5	TPS 6	TD/S 1	TD/S 2	TD/S 3	TD/S 4	TD/S 5	
127	6	5	101	1	13	1	6	5	31	81	4	18

Note: See note to Table 1 for definitions.
Documentary sources: Included in bibliography of Corbett (2001b).

regulators/manufacturers (TD/S 1, 2; see Tables 1 and 2) with those of health consumers (TD/S 3; see Tables 1 and 2) enabled analysis in relation to Akrich's theory of *user de-inscription* and *subscription* noted previously. Narratives were selected that typified the content of each subcategory (TD/S 1, 2, 3; see note to Table 1) and are cited below with respective coding. Validity was enhanced in several ways. First, only sources were selected that included users' experience of the above issues of heterogeneity/multiplicity associated with autonomous properties (the analytic topic). Second, narratives were only selected that included users talking of these topics and/or where researchers included such unprompted talk, thus orienting to its occurrence without analysis (Fielding 2004; Heaton 2004). Third, the context for the analysis below was health consumers' experiences of test taking matching those of original sources (Fielding 2004; Heaton 2004).

HIV Antibody-Tests

There are two different types of HIV antibody-tests: the enzyme-linked immunosorbent assay (ELISA) and the Western blot (WB) (Bartlett 1998). They are different laboratory methods used to detect (often in asymptomatic users) antibody markers for HIV in human blood (Patton 1990). Both scripts are that of a test for HIV. ELISA reactions either give "detected" or "undetected." Manufacturers' subscriptions describe test multiplicity in terms of many causes for non-specific reactions, which then imply heterogeneity of diagnosis (false positive or indeterminate). For example, one ELISA test kit manufacturer's package insert states that

> ELISA was designed to be extremely sensitive. As a result non specific reactions may be seen in samples from some people who, due to prior pregnancy, blood transfusion, or other exposures, have antibodies to the human cells or media in which the HIV1 is grown for manufacture of the ELISA. (Abbott Laboratories 1997, 1) (TPS 2, TD/S 2; see note to Table 1)

Similar acknowledgement for the WB appears in another extract from a test manufacturer:[4]

> Persons, who have had no known exposure to HIV1, produce reactive results in the screening test for still unknown reasons . . . it is recommended additional testing be performed. (Organon Teknika Corporation, 1997, 2) (TPS 2, TD/S 2; see note to Table 1)

The WB has eight bands to identify each separate HIV protein, combinations of which must simultaneously react to constitute a positive result. Globally, different combinations of reactive bands are used to define a positive WB (Ball 2000; Genelabs Diagnostics 2004; Gigerenzer, Hoffrage, and Kleinbolting 1998). The above extracts also show how the manufacturers underwrite or subscribe to test inscriptions by reference to autonomous properties known in biomedicine (Blattner 1989; Mortimer 1988; Mylonakis et al. 2000). Any reactive or non-reactive WB/ELISA signal has multiple diagnostic translations depending on the heterogeneous sexual risk profile of the donor (Gigerenzer 2003; Gigerenzer, Hoffrage, and Kleinbolting 1998; Mensah 2000). The sexual risk profile must be established to interpret the ELISA/WB laboratory signals for diagnosing users as "sick" (reactive or detected meaning seropositive) or "healthy" (non-reactive or undetected meaning seronegative) (Mensah 2000), irrespective of whether the user has any symptoms. Therefore, multiplicity/heterogeneity underpins all ELISA/WB tests shown in the following subscription by Mortimer (1988), a scientific regulator in the United Kingdom's Health Protection Agency:

> [HIV diagnosis is] . . . based almost entirely on detection of antibodies to HIV . . . there can be misleading cross reactions between HIV1 antigens and antibodies formed against other antigens . . . these may lead to false positive reactions . . . it may be impossible to relate an antibody response specifically to HIV1 infection. (P. 2336) (TPS 3, TD/S 1; see note to Table 1)

Narratives from users implicitly or explicitly *de-inscribe* by reflecting on some of the above aspects of multiplicity/heterogeneity underwritten in the above *subscriptions*. For example, Siegel et al. (1989)'s study of users' motives for testing reported the following from one respondent who refused to test:

> So I get a negative? Great. Well, maybe it's a false negative. You know, who knows? Or then I have to go get tested again. If they come up with a sure fire test that says, "you are definitely. 100%." Until then I don't really think it would do that much for me. And I think getting a positive, which again could be false, is actually worse than not being sure and sort of assuming you have it. I think that would be, that would be worse. (P. 379) (TPS 3,TD/S 3; see note to Table 1)

This above extract shows that this user *de-inscribes* and renegotiates his or her intended role in test taking by reference to his or her knowledge of the autonomous properties of the test. The test/user emerges in the above

de-inscription in a reciprocal manner. The user reworks the inscription of the test based on knowledge of multiplicity/heterogeneity intrinsic to test design. The test's inscription of the user as a passive test taker—a "subject"—is reworked into that of one who will probably decline testing. This order of awareness is also evident in the following extract from a different respondent in the same Siegel et al. (1989) study:

> I have friends who have tested negative up to the day they died . . . I have heard it's as high as 40% false positive, false negative for example. 40% on the ELISA. The Western blot is 70%, fairly accurate . . . [My roommate's second lover] . . . one day his test result was positive the next day negative, right up until the end . . . Really, every couple of days it was "you've got it, you don't have it, you've got it, you don't have it," you know. (P. 379) (TPS 2, TD/S 3; see note to Table 1)

The above user *de-inscribes* contradictory test results in terms of their potential translation into vastly different medical diagnoses: "you've got it, you don't have it, you've got it, you don't have it." This extrapolation of diagnostic multiplicity/heterogeneity occurs in context of the user's own knowledge/experience about the test's autonomous properties. Their own knowledge itself appears multiple (cf. Barbot and Dodier 2002) being composed of received information and experience. Yet this extract also appears as a *subscription*: test accuracy is upheld and testing is not rejected per se. It implies that health consumers can also act to subscribe or bolster the inscribed meaning of the test. Other sources also focus on these autonomous phenomena. For example, the following extract from a California AIDS activist describes her experiences of undergoing WB testing before becoming skeptical of orthodox views on HIV/AIDS. It occurs in a non-standard source, an interview with the editor Gabrish-Conlan (1995) of *Zenger's*, a community newspaper in San Diego:

> This one [Western blot] had eight categories, and two of those eight categories were reactive. She [doctor] told me this meant I was HIV positive . . . I went to this other doctor. He . . . said, "I don't know what this means." Because there were eight categories, and only two were reactive. He . . . said, "We're going to have to do this over again. I don't know what to say. We'll do it over again at my lab." This [next] eight band test had suddenly become a four band test, and at his lab, all four bands were reactive, which meant that I definitely had HIV . . . [another doctor] took a look at [all the tests]. She took a look at my health profile, and said, "You know, this doesn't add up at all to me. . . I mean, you're just—you're not like the other people I see here. This first test

> is completely inconclusive. This second test—I mean, why four days later, completely reactive? This is very strange. I think you ought to retest" . . . we went to pick up the results of this test, and it was marked, "Indeterminate," by the laboratory. That threw me and the doctor and everybody through a loop: "What does this mean? Gee. She sort of had it; she kind of doesn't have it; she kind of doesn't have it anymore. (Pp. 8-13) (TPS 5, TD/S 3, NS; see note to Table 1)

The above occurs in a non-standard source and *de-inscribes* the test script based on user experience of autonomous properties. The extract refers to user receipt of contradictory reactive laboratory signals from several tests as well as lack of congruity between the user's profile (implying "well") and the tests' diagnostic implication ("ill"). Similar to the previous extract, the de-inscription occurs in relation to test multiplicity/heterogeneity and reveals the potential for vastly different diagnostic outcomes when those reactive laboratory signals are translated into actual medical diagnoses: "she sort of had it; she kind of doesn't have it; she kind of doesn't have it anymore." However, both of these above-mentioned similar extrapolations are found in two sources espousing different views on AIDS. Such consistency in user experience transcending personal belief increases the validity of these findings.

To summarize, narratives from various test eras reflect users' knowledge about the autonomous properties of HIV antibody-tests. There were resonances between the articulated themes from different end users in de-inscriptions and subscriptions, which referred to test multiplicity in reasoned narratives. Similarly, users articulating different views on AIDS could exhibit similar reasoning over multiplicity/heterogeneity and how contradictory laboratory results/signals translate to vastly differing medical diagnoses. It implies that different users at different times (and espousing different views on AIDS) articulated knowledge of the autonomous properties of these tests and their possible diagnostic meanings. The intention of some users may be to decline testing based on this knowledge, a knowledge also shared by users espousing non-standard views.

T Cell Tests

Once users are diagnosed HIV antibody-positive routinely, tests are undertaken for specific white blood cells called "T4" or "T" cells (Bartlett 1998) because the occurrence of AIDS-defining opportunistic infections

(OIs) is correlated in statistical epidemiology with declining numbers of these cells (Keating and Cambrosio 2003). This correlation has enabled the calculation of the average times for users to develop OIs before dying so that the trend in the count has become a script of impending illness/death (Epstein 1996). It is held to be a statistical/epidemiological marker of immune functioning implying either worsening health, if the trend is downward (with a zero count implying imminent death/dying) or if upward, improving health (Centers for Disease Control and Prevention 1993, 1997). Over time, activists and regulators all came to share these latter subscriptions (Centers for Disease Control and Prevention 1993, 1997; Epstein 1996, 280; Keating and Cambrosio 2003, 9-10). This script is illustrated in the following extract reported by a female respondent in Wong-Wylie and Jevne's (1997) U.S. study of communication between different end users:

> He [the doctor] drew a chart with a T4 cell count on the diagonal axis and a life line on the horizontal axis . . . the correlation illustrated that T4 cell count at zero meant death. (P. 53) (TPS 3, TD/S 3; see note to Table 1)

As with the antibody-tests, autonomous properties have emerged over time. Narrative extracts from users variously *de-inscribe* the scripted test resonating with aspects of the above activist/regulatory subscriptions. For example, the following extract *de-inscribes* this script in terms of such knowledge. It occurs in a non-standard source and is extracted from an article by Ratcliffe (1997), a female Shiatsu practitioner:

> The number of T-cells changes in response to many variables including time of day the blood was taken and your emotional state at that time. The same sample of blood tested at different laboratories can give a count differing up to 200. Yet it was and is presented as an absolute marker of immune functioning and serious treatment decisions are based on it. Discoveries such as this led me to a place of profound scepticism regarding the accepted views on HIV and AIDS. (Pp. 10-11) (TPS 4, TD/S 3, NS; see note to Table 1)

This above de-inscription resonates with the above activist/regulator subscriptions and biomedical de-inscriptions referring to multiplicity/heterogeneity and citing the phenomena of lowered numbers of cells occurring without HIV due to smoking, sunlight/solarium use, normal immune function, malaria, variations in laboratory practice, and for no known reason (e.g., Papadopulos-Eleopulos et al. 1995). The above extract explicitly articulates such knowledge of test multiplicity/heterogeneity and the user's view of its portrayal, as

certainty may have undermined the user's faith in the test and facilitated a more skeptical non-standard viewpoint. This points to the way in which multiplicity/heterogeneity is constructed within the relationships between different users (patient/physician) of the same technology. Given the non-standard nature of this source, the extract may be seen as illustrating user rejection of the biomedical platform, and by definition, rejecting all Western medicine for alternative medical cosmologies (Keating and Cambrosio 2003, 9-10). After Barbot and Dodier (2002), this extract can also be seen as an awareness of multiplicity/heterogeneity and an engagement with the script resonating with the above *subscriptions*. Therefore, the extract may also be viewed as illustrating a critical engagement with this part of the platform on its own terms, indicative of reworking the script using a different set of heuristics (Keating and Cambrosio 2003, 329).

The test's inscription is further *de-inscribed* in several extracts. For example, an autobiographical extract from Moore (1996), a U.K. male seropositive journalist and novelist, follows:

> At a recent seminar on new treatments, one speaker blithely noted that everything he said applied only to people with lower [T cell] count of more than fifty, because people with lower cell counts than fifty had a life expectancy of only five to seven months. This was a matter of fact. Fatigue, shock and an uncertainty that if I stood up I wouldn't fall over prevented me from pointing out that, by his logic, I had been technically dead for eighteen months having had a cell count of zero for two years. . . . (P. 163) (TPS 4, TD/S 3; see note to Table 1)

The above extract dramatizes the script's implication of death/dying. This extract can be seen as a de-inscription because it renegotiates this fatal script, which is based on statistical/epidemiological reasoning (Keating and Cambrosio 2003, 334). This extract also reflects on a user's dissonance between the script and the user's actual experience, problematizing the above subscription of fatality. It illustrates how multiplicity/heterogeneity may be constructed within the relationships between different end users of the same technology. It also emphasizes two divergent forms of reasoning—statistical/epidemiological and lay. However, it further echoes Keating and Cambrosio's (2003, 334) portrayal of both of the latter as "branches" of the same "biomedical enterprise" that promotes and critiques biomedicine, respectively. Other extracts similarly rework the above activist/regulator subscriptions interrogating the script based on actual experiences of users. For example, see the following extract from a male respondent reported in

Crossley's (1998) U.K. study of life after serodiagnosis, where re-inscription makes the script redundant:

> Theoretically my T4 cell count is low but that seems to have no basis in real life, in the real world . . . they say that if your T4 count is below a level, then you are ill, you know, the Americans set up the control definition of AIDS as a T4 cell count below 300 . . . I don't think it makes a great deal of difference . . . it's a nominal thing. (P. 507) (TPS 3, TD/S 3; see note to Table 1)

In summary and similar to the previous analysis of antibody-test scripts, similar themes emerged from the experiences of the T cell test. Different users *de-inscribed* and re-inscribed the test's script. End users could perceive a dissonance between the theoretical application of the fatal script (derived from statistical/epidemiological reasoning) and their own experiences. Presenting test multiplicity/heterogeneity as certainty was cited as a factor in the development of skeptical reasoning. Several of these findings point to the way in which multiplicity/heterogeneity may be socially constructed within the relationships between different users of the same technology.

Viral Load/PCR Test

The viral load test was developed from PCR technology (Rabinow 1996). It is licensed as an aid for identifying (not diagnosing) HIV, for measuring disease progression in those diagnosed with HIV disease (AIDS), and for calculating amounts of circulating HIV (Roche Diagnostic Systems 1996; Bartlett 1998). Viral loads are quoted on logarithmic scales of copies per milliliter of blood. Readings of $>10^6$ (100,000) mean "high" and of $<10^4$ (10,000) mean "low" viral loads, respectively. Anti-HIV therapy aims to make viral load undetectable (National AIDS Manual Publications 1997, 47). This statistical and epidemiological reasoning informs the prescribed script for users; for example,

> Viral load is the amount of HIV in the blood. The more HIV you have in your blood, the faster your T cell count will fall, and the greater your risk of developing symptoms of HIV infection or AIDS-defining illnesses. People taking anti-HIV drugs normally see an increase in their T cell count as viral load falls. If you're taking treatment, monitoring your viral load gives an indication of how well your treatments are working. (National AIDS Manual Publications 2007) (TPS 5, TD/S 3; see note to Table 1)

As with the other HIV-related tests, autonomous properties have prospectively emerged. Manufacturers/regulators subscribe to the test script, for example, the following extract from Roche Diagnostic Systems (1996):

> [PCR] is intended for use in conjunction with clinical presentation and other laboratory markers as an indicator of disease prognosis. The test has also been used as an aid in assessing viral response to antiretroviral treatment as measured by changes in plasma HIV1 RNA levels. The clinical significance of changes in HIV RNA measurements has not been fully established . . . The utility of plasma HIV1 RNA in surrogate endpoint determinations has not been fully established . . . [PCR] is not intended to be used as a screening test for HIV or as a diagnostic test to confirm the presence of HIV infection. (P. 1) (TPS 2,TD/S 2; see note to Table 1)

Test multiplicity/heterogeneity is shown by the test's poor correlation with immune markers (e.g., T cell test), HIV/AIDS symptoms, and the reported incidence of false positives (Rabinow 1996; Teo and Shaunak 1995). The above manufacturer subscriptions resonate with some aspects of users' de-inscriptions, as, for example, in the following extract from a community newspaper espousing non-standard views describing the script's limitations:

> Although PCR viral load tests are unable to distinguish infectious virus from bits of non infectious genetic fragments, they are incapable of measuring actual virus, and are not approved for diagnostic use, the tests are being used every day to diagnose infection with HIV and as a basis for prescribing long term treatment with protease inhibitors, chemotherapy compounds like AZT, powerful antibiotics and other drugs. PCR is routinely used to diagnose HIV infection in newborns, and as a justification to treat infants with AZT, Bactrim [Septrin] and other potent chemicals. (Maggiore 2000, p. 38) (TPS 5, TD/S 3, NS; see note to Table 1)

The above extract *de-inscribes* in exactly the same terms (treatment potential, diagnostic utility) that the above Roche subscription underwrites test utility. In this way, the extract resonates with the multiplicity/heterogeneity cited in the above subscriptions engaging with the script on its own terms. This is contrary to any expectation of wholesale rejection of the biomedical platform by non-standard sources (Keating and Cambrosio 2003, 9-10). Of course, this engagement may be political for the purposes of knowledgeably critiquing the script to show up its inherent contradictions and limitations. Yet this does not devalue the nature and terms of that engagement. The following extract from Gabrish-Conlan (1995) also features diagnostic multiplicity, heterogeneity, and indeterminacy:

> . . . [a friend] called me up and said . . . "There's an article you ought to see in *Bio/Technology* magazine that talks about how unreliable these tests are, including the viral load test." I thought, "Oh, my God!" This was just incredible! *So I figured, "Well, I've got nothing to lose here. I'm just going to go in and take another test, and see what happens to the 'detected' virus that was 'indeterminate' a few weeks ago*. Let me take another antibody-test." I take another viral load test and, lo and behold, I'm "non reactive!" So the virus that they "detected" suddenly, a few weeks later, was non reactive to the viral load test. (Pp. 10-11; italics in original) (TPS 5, TD/S 3, NS; see note to Table 1)

The above non-standard source *de-inscribes* the script based on successive inconsistent laboratory readings. These readings translate into vastly contradictory medical diagnoses of positive, indeterminate, and negative, respectively, recalling the earlier extract recounting the diagnostic conundrum of "she sort of had it; she kind of doesn't have it; she kind of doesn't have it anymore." Given the test script's promise of certainty, it is unsurprising that this user further explores script inconsistencies through serial retesting and triangulation of results from the same type of test. As with the other HIV-related tests, this shows how end users can redefine new roles to those inscribed, based on experiential dissonance between script/experience. Another example of experiential dissonance is shown in the following extract about anti-HIV therapy from Flynn (1998), a male seropositive, occurring in a U.K. self-help community newspaper, *Body Positive Newsletter*:

> . . . [the] medical view of treatment "failure" is defined as not getting viral load down to undetectable . . . This is called "virological failure". It also includes patients whose viral load was undetectable but has rebounded to a measurable quantity. This definition makes no distinction between patients who have had their viral load go down to a few hundred copies and those whose viral load has rebounded to millions of copies . . . [people] have achieved and maintained substantial and sustainable viral load reductions and have at least some immune restoration and consequent CD4 count increases. So it may be virological failure but it is not immunological failure. So whilst reaching undetectable levels of viral load remains the so-called "gold standard" of anti-HIV therapy, this may be unobtainable. (P. 5) (TPS 5, TD/S 3; see note to Table 1)

This extract *de-inscribes* the script of "undetectable" and "virological success" experienced as setting up unobtainable goals and devaluing the immune response. As such, it is a critical engagement with the script on its own terms, a de-inscription from a standard source. Dissonance emerges

between trying to achieve the scripted statistical/epidemiological goal ("reaching undetectable levels of viral load") and actual experiences ("not getting viral load down"). This is caused by the biomedical application of the script, suggesting it is constructed as such with the relations between users (physician/ patient). Therefore, the inscription (part of viral load/PCR platform) seems amenable to negotiation, renegotiation and reworking, contrary to the claims of Keating and Cambrosio (2003, 333).

Different users may view both the script and experience as mutually beneficial. This is shown in the next extracted interaction reported in Moore, Candlin, and Plum's (2001) U.K. study of lay expertise. It features an audiotaped dialogue between different end users, a seropositive male patient (P) and his doctor (D):

D: Now once I've done this I'll look up your old viral load.
P: 30,000.
D: Ah thanks.
P: But I feel all right, so y'know that's the main thing isn't it?
D: Yes . . . that's half way there.
P: Yeah well this is only half of the picture isn't it?
D: Exactly.
P: If I was feeling lousy I'd be concerned but since I don't . . .
D: Yeah I was going to say even if your results were fantastic but you were still . . .
P: Yeah.
D: . . . feeling lousy and sleeping all day, um, I'd want to do something about the pills and change it anyway.
P: Mmm.
D: Okay thank you . . . now 30,000. All right then Phil, ultimately if it's less than 10 I'm going to be . . . happy. Less than 5 would be ideal. (P. 433) (TPS 3, TD/S 3; see note to Table 1)

The above includes the prescribed script and the health consumer's subjective knowledge based on experience. Both are viewed by each user (D and P above) as indicating health, so much so that because the script does not equate with experience, so it cannot be the sole determinant of decision making. This points back to the above subscriptions and the limits of the script (correlation of symptoms with test logarithmic values). It also reflects mutual acceptance from different end users of the mutual relevance of script/ experience (implied by D: "half way"; P: "half the picture"). It is a further example of Keating and Cambrosio's (2003, 334) vision of epistemological unity within the "biomedical enterprise" through heuristic or "rule of thumb"

practices (p. 329). Yet this contradicts the script, which *a priori* does not require dialogue with experience. The extract shows how the identity of test/end users emerges through dialogue, as test multiplicity/heterogeneity is co-constructed within the relations between different users of the same technology.

In summary, irrespective of health consumers' positions on AIDS and similar to the two other HIV-related tests, these different users show knowledge about the autonomous properties of the viral load/PCR tests. As in the case of the T cell count, users may refer explicitly to aspects of the subscriptions of other users within their own reasoned accounts. In the case of indeterminacy, this engenders new roles for users such as serial retesting and triangulating the results of serial tests. The scripted goals of undetectability and virological success were seen as unobtainable and as devaluing bodily responses. As with the T cell count, a dissonance is then perceived between the application of the test script (based on statistical/epidemiological reasoning) and contradictions to this script informed by experience. However, processes of co-constructing shared meanings based on giving equal weight to user experience and test inscription seem to be heuristic yet somewhat contradictory practices.

Conclusions and Recommendations

This article seems to be the first to have developed a perspective from within STS (Akrich 1992) to conceptualize the autonomous properties of the HIV antibody-tests, T cell tests, and viral load/PCR tests as well as to analyze how health consumers co-construct the meaning of these tests. While a paucity of literature exists on this topic (Corbett 2001a, 2001b), the above analysis uniquely shows how published sources reflect user experiences of these properties. This analysis was delimited by the available sources; yet a varied collection of relevant sources (n = 127) was found: six types of publication and five types of *de-inscribers/subscribers* (Tables 1 and 2). Published narratives from the latter were used for purposes similar to the original sources (experiences of testing), thus validating the above analysis (Fielding 2004; Heaton 2004).

The above findings contribute additionally to the existing STS literature in terms of uniquely illustrating how users can rework the meanings of HIV-related tests resonating with statements on these tests from manufacturers/regulators. Users were shown to occupy variable positions in relation to other

users of the same technology and to disparate/multiple forms of knowledge (Barbot and Dodier 2002); and to tests located within different biomedical platforms (Keating and Cambrosio 2003). Health consumers undergoing HIV-related testing are here found to reject, rework and/or renegotiate the scripts of these tests within their relations with other users. As these scripts were also found to influence relations between different users (those deploying tests/consumers) therefore, it is now shown that these parts of the platforms are amenable to social construction, contrary to claims by Keating and Cambrosio (2003, 333). The analysis additionally illustrated aspects previously only alluded to (Keating and Cambrosio 2003, 329-330), such as health consumers' decision-making and users' heuristic practices. The term *implicated actor* (meaning one silenced by technology) seems problematic from the above findings because users are found to actively co-construct and so do not lack voice (Clarke 2005).

Users' experience of the T cell and viral load/PCR tests could contradict test inscriptions, which derive from statistical and epidemiological reasoning (Keating and Cambrosio 2003, 334), as test predictions of death, illness, and undetectable viral load engendered by inscriptions were not fulfilled. This knowledge was derived from experience and affected intentions and viewpoints. This perception of dissonance underlined the manner whereby heterogeneity/multiplicity was constructed within the mutual relations of users of the same technology. Users who espoused non-standard views did not reject any consideration of the epistemology of these tests (Keating and Cambrosio 2003, 9-10). Further illustrating the findings of Barbot and Dodier (2002), these particular users engaged with the multiplicity/heterogeneity of the tests/platforms to rework/renegotiate scripts. From this analysis, autonomous properties appear like logical (if unintended) consequences of test design, as they reflect intrinsic design features known to manufacturers/regulators. This was confirmed by the above finding that similar experiences were evident for a diverse range of users. Yet such consequences are not necessarily unanticipated, as knowledge of these intrinsic design features is already known to manufacturers/regulators.

Irrespective of users' views on AIDS, the above users were found to operate within particular sets of relations with other users of the same technology, and on different terms; for example, only certain users can legally formulate diagnoses. The findings also point to the relations between different users and the tests within respective platforms, originally portrayed as health consumers either rejecting or accepting the epistemic basis of tests/platforms and thereby all biomedicine (Keating and Cambrosio 2003, 9-10). This reductive categorization seems deficient in several respects, as the above findings

show users' routine experience of tests invokes different knowledge/expertise (Latimer et al. 2006, 607). First, this categorization fails to capture the range of approaches shown by health consumers to test multiplicity/heterogeneity. Following the logic of Keating and Cambrosio (2003, 9-10) non-standard sources, by definition, should reject, not critically engage as seen above, with test epistemology. Second, an either/or categorization collapses the dialectical nature of the relations between different users of the same technology, whereby test multiplicity/heterogeneity are co-constructed; and in the case of antibody-tests, for a diagnostic label to be imparted by one group of users for and on behalf of another.

The above findings show how some users may experience vastly different diagnoses. Yet diagnostic certainty (not multiplicity/heterogeneity) has been the overarching public perception of HIV-related tests since the dawn of the HIV/AIDS era (Fauvel 1986). This is in contrast to the situation in the social science literature on genetic testing, which includes reference to autonomous properties suggesting patterns of user *subscription/de-inscription* similar to those cited above. North American breast cancer activists are acutely aware of these properties in genetic testing, especially in regard to asymptomatic users and on that basis argue for cautionary approaches to commercially led testing and the claims made for these emerging technologies (Parthasarathy 2003). This early awareness may partly explain why these issues in genetic testing are mainstream within the social science literature (e.g., Bouchard et al. 2004, 1087) and are actually cited as "key aspects" for research (e.g., Cho, Arruda, and Holtzman 1997, 316). Yet comparatively few reports in the biomedical literature cite the autonomous properties of HIV-related tests (Corbett 2001a, 2001b), which are also absent as a research topic in the social science literature (Corbett 2001a, 2001b). This recalls earlier disquiet over the lack of critical awareness about the limits of HIV tests and the claims originally made for these technologies (Fauvel 1986, 53).

The above experiences of autonomous properties may be unintended yet their occurrence across different eras/sources may appear, as in the above analysis, to qualify the promised inscription of diagnostic certainty and to add potential for dissonance between the script and experience. It is this dissonance between the promise and the actual experience that further enables experiential understanding on behalf of users about autonomous properties known to regulators/manufacturers. This is not to argue that medical testing is only valid in research settings, such as the U.S. breast cancer lobby arguing for genetic testing (National Breast Cancer Coalition 2006). However, it is an argument for a further reappraisal of user experiences and understandings by health agencies and regulators, as is implied within their own policy

statements (e.g., National Screening Committee 1998, 9) and in the findings from their quality assurance research (e.g., Balmer et al. 2000, 7).

One concern over developing a more considered view of medical testing may be the effects on public confidence and utilization (Houston et al. 2001). However, to oppose transparency about the actual limitations of tests (and users' experiences of these) contradicts not only recent quality assurance findings (Balmer et al. 2000) but also upstream modes of socio-technical user engagement (Wilsdon and Willis 2004). A need for better information on the "expectation gap" between the above test limitations and how these are experienced by users has already been established (Balmer et al. 2000, 7). Concern over public portrayal of test limitations may be offset by experience of medical testing programs where deficits were publicized (e.g., U.K. cervical testing) but failed to negatively affect user confidence or utilization (Houston et al. 2001). The worst outcome in testing is for users to be falsely diagnosed and receive unnecessary intervention and conversely, for those falsely undiagnosed not to receive any necessary intervention (National Screening Committee 1998). A more upstream mode of public engagement could address these issues by widening the scope of user evaluation (Wilsdon and Willis 2004). Further research could empirically analyze these phenomena in a structured qualitative manner (Rowe and Frewer 2004), further adding to our empirical knowledge of the actual/potential roles played by health consumers in co-constructing medical technologies.

The above findings also point to an issue about how multiplicity/heterogeneity is co-constructed within the relations of different end users of the same technology. By convincing health consumers that their real experiences of test multiplicity/heterogeneity are just remarkable anomalies (National Health Service Litigation Authority 2005), health agencies/regulators may actually cause the public to lose faith in testing if or when health consumers realize the likelihood of such experiences (Gallagher 2005, Maggiore 2000).[5] A credibility gap (Wynne 1996) may then emerge about testing if consumers realize they were uninformed about these possibilities already known by manufacturers and regulators (Gigerenzer, Hoffrage, and Kleinbolting 1998, Maggiore 2000). Given that multiplicity and heterogeneity are intrinsic to test design (National Screening Committee 1998), it seems somewhat predictable (not unanticipated) that such outcomes will be experienced by a percentage of users undergoing testing. This is also clear in professional exhortations to physicians on HIV-test multiplicity/heterogeneity (Ball 2000). On this basis, it seems reasonable for regulators to involve users upstream in any reviews of current test designs, licensing, quality assurance programs, and assessments of the claims made for newly emerging tests.

Notes

1. This use of the term *testing* adapts Hanson's (1993, 19) definition: a representational technique applied by a medical end user on behalf of a health consumer end user for purposes of information gathering.

2. The balancing of sensitivity/specificity of tests in testing algorithms/protocols limits heterogeneity and multiplicity; yet the latter persist, as they are intrinsic to test design (see Gigerenzer, Hoffrage, and Kleinbolting 1998, 199; National Screening Committee 1998, 9).

3. These user positions are noted here, but they are not the focus of this article. See Epstein (1996).

4. Research suggests data published by test manufacturers included within their test kits are not routinely given to health consumers (Gigerenzer et al. 1998).

5. Gallagher (2005) describes how one male U.K. health consumer was diagnosed HIV positive and then later judged to be HIV negative after subsequent and successive negative test results. Although available data suggest the initial diagnosis was a false positive (AVERT 2007), U.K. regulators informed the user that this was not so. Indeed, by declaring his experience "exceptional" and also by implying that he had "recovered" from HIV infection (National Health Service Litigation Authority 2005)—which is an oxymoron in respect to any orthodox concept of HIV as a lifelong retroviral infection—regulators were apparently contradictory in their responses. This had the effect of deflecting public attention away from the reality of there being false positive diagnoses created by the national screening program, with media coverage concentrating on the "inexplicable" recovery from HIV infection instead.

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Kevin P. Corbett is an independent research consultant, educator, and nurse clinician with extensive experience of the networks/groups involved in debates on HIV/AIDS science and technology. His research focuses on user experiences of the organization and/or delivery of health and social care services. He has recently completed a research fellowship in health and social care at Liverpool John Moores University, United Kingdom.