Historical Ontology and Infrastructure

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ABSTRACT
We explore the relationship between long-term scientific infrastructure and its changing objects of research. Specifically, we focus on the historical changes in HIV disease during the life of a longitudinal medical study investigating the disease for nearly thirty years. We ask, within the study of information infrastructure and research-based organizations, what are the things that inherently change, and how do such changes reverberate through the practice and organization of infrastructure? In applying the philosophical concept of *historical ontology* to cyberinfrastructure, we present the groundwork for a broader understanding of infrastructural sustainability within an environment inherently in flux.

Categories and Subject Descriptors
J.4 [**Computer Applications]**: Social and Behavioral Sciences – *sociology*.
K.4.3 **[Computers and Society]**: Organizational Impacts – *computer-supported collaborative work.*

General Terms
Management, Design, Human Factors, Theory.

Keywords
Infrastructure, sustainability, long-term, change, historical ontology, science and technology studies, ethnography.

1. INTRODUCTION
The title of this paper is decidedly philosophical and treacherously highfalutin. *Historical ontology* is "too self-important by half" notes Ian Hacking [1] and 'infrastructure,' departing from its humble beginnings, is approaching its own crescendo. And yet, this paper is about something decidedly direct: how does a long-term organization supporting medical science (an infrastructure) sustain itself while its core research objects fundamentally change over time (historical ontology). Why not then simply refer to this as a case of 'infrastructure meets change'— a worthy topic that has much to do with our research? The answer is that such a focus is just too broad. Our interest is far more specific: that the changes are to the objects and subjects of scientific research, and that these changes are brought about in an historical manner. Specifically, we examine the changing nature of HIV disease, those whose life work has been to study it and those individuals who have it; how this disease has changed over time, subsequently altering the lives of those living as HIV-positive, and most centrally to us, a medical study, the Multicenter AIDS Cohort Study (MACS) that has been investigating this dynamic disease for nearly thirty years.

Our research is ongoing, and as such, this paper is neither a report of findings nor a presentation of conclusions. Rather, it acts as an exercise in empirical philosophy. In broad strokes, we investigate how our particular case, and our focus on historical ontology, speaks to infrastructure studies. We seek to more precisely define the problem space: within the study of information infrastructure and research-based organizations, what are the things that are changing over time, and how do such changes reverberate through the practice and organization of infrastructure? How are facets of infrastructure transformed by, or molded to, the changing dynamics of things and people that in-themselves are central to an infrastructure's very purpose, existence and survival over the long-term?

Our contribution here is to the study of cyberinfrastructure [2]: large-scale and long-term ventures, ongoing in many sciences, tasked with developing information technologies (IT) that support research and facilitate knowledge creation. In this paper, the empirical focus is MACS, a medical research study that has been running for over a quarter of decade— an infrastructure in which the objects of study have been thoroughly transformed many times in its own history, and yet, it continues to remain 'the same study.' Generally speaking, our curiosity is rooted in the ways objects of research can play a role in reshaping cyberinfrastructure.

2. CASE: THE TRAJECTORY OF INVESTIGATION AND THE RECURRENCE OF SCIENTIFIC OBJECTS
The Multicenter AIDS Cohort Study (MACS), a longitudinal investigation of homosexual and bisexual men, was initially founded in 1983, and continues today in four large American cities. MACS is one of the longest running longitudinal studies of the 'natural history' of HIV disease. In 1983, the medical community had only just reached agreement on the name we use today for what at the time was a very poorly understood disease: Acquired Immune Deficiency Syndrome (AIDS). While in some circles this 'largely gay epidemic' was ignored— most notably, in political circles, such as Congress and the Reagan administration, as well as within the media— awareness and fear of the disease grew quickly and exponentially within certain spheres— including the gay community, amongst hemophiliacs, and within subsections of public health institutions. In 1983, AIDS was

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strongly suspected to be infectious, but no agent had been identified.

A common understanding of a scientific study is that it is centrally organized around the exploration of one research object (in our case, HIV), or an interrelated network of objects (e.g., *HIV disease*: the array of behavioral and physiological manifestations of HIV infection in a population). In such a formulation of research, the object is presumed to shift over time from that which is poorly understood to something that is increasingly well understood. Research in the area of HIV, for instance, has resulted in the generation of an increasingly larger body of scientific knowledge about the disease. From this perspective, we may be disappointed, but not altogether surprised, that the object remains ultimately recalcitrant— that is, we have yet to develop a cure or effective vaccines for HIV. But, even if we have thus far failed to 'win' over the disease, we have accomplished a great deal: we have rendered HIV comparatively docile. For many Americans, HIV has transitioned from being a terminal and acute syndrome to a more chronic and manageable disease. And so, to an extent, this *linear model of progress* remains true for this research program: certainty, HIV is a better understood disease than it was in the early 1980s.

However, from the perspective of a well-functioning infrastructure, designed to support research, such a straightforward model can be highly misleading. The trajectory of HIV research— far from a tidy linear path— has presented many unexpected twists. Initially, MACS was established as an epidemiological study of AIDS. Researchers were tasked with understanding the disease's patterns of distribution and transmission throughout the US, and hopefully to help identify AIDS's etiology (the cause and mechanisms of the disease) [3]. Throughout its lifetime, MACS has experienced many significant changes in its organization and purpose, scientific focus and methods, researchers and subjects ("participants"), and in its data practices and technological infrastructure (to name only but a few).

For the purpose of this paper, we concentrate on one such change: the transition of AIDS as a death sentence to HIV disease as a long-term manageable condition. We characterize this evolution as an *historical ontological* change. However, before we can distinguish ontological change from other forms of change by elaborating our case study, we must first explore the concept of historical ontology and its relevance to infrastructure.

This project is based on ethnographic, interview and archival research. One author has become a working member of MACS, and both authors are conducting a study about the emergence of the Internet in the lives of MACS participants— over 10 years following its inception! That said, this paper is less an ethnographic endeavor aimed at constructing grounded theory (forthcoming), but an empirical-philosophical investigation with the goal of making sense and clarifying the tricky subject of historical ontology in the study of infrastructure.

3. HISTORICAL ONTOLOGY AND INFRASTRUCTURE

Scientific infrastructures are complex organizations, responsible for supporting a myriad of ever evolving research questions, participant needs, and collaborating networks of researchers that may spread across a nation or the globe. Scholars of infrastructure have studied the long-term of such organizations as a matter of changing technology [4], data [5], scale [6], practice [7], organization [8], rhythms of collaboration [9] or funding structures [10]. Such changes present challenges to infrastructure, which ultimately seeks to be a persistent set of resources that can also support the ongoing daily activities of heterogeneous actors [11]. Many questions remain, but the research program on infrastructure and sustainability is well under way.

What the field of infrastructure studies has not examined with care are the dynamic phenomena that these scientific infrastructures take as their research objects. We examine historical ontology so as to place it within the larger pantheon of 'change' an infrastructure may encounter: data, instruments, collaborative tools, funding arrangements and so on. In the tradition that has become central to the research program of Science and Technology Studies (STS) we seek to add *changing-things-in-the-world* to the mesh of activities of technological development, collaboration and scientific investigation.[1] We do so while placing such 'things' in a web of sociotechnical action. By no means does nature determine infrastructure; so, how are we to think of changing scientific objects and subjects as they participate in reshaping infrastructure over time?

Ian Hacking in his book of the same title provides a tidy summary of the three approaches scholars have taken to *historical ontology* [1], a concept that has been primarily rooted in recent history and philosophy of science. To his three approaches, we add a fourth that follows readily from a concern with historical ontology, but which has not yet been addressed in the literature.

The first approach is that of Michel Foucault, who innovated the term historical ontology [15]. He did not use the concept extensively; it appears only twice in a single text written in the early 1980s. The term emerges from his later research program— often characterized as the genealogical method— in which he examined the *historical conditions of possibility* for researchers to take interest in a 'thing'. In an example quite relevant to our case, Foucault unearthed the conditions of possibility that paved way for doctors, psychologists, sociologists and others in the 18th and 19th centuries to become interested in, and more importantly, concerned with, the health of the population. Sex, or rather the *regulation* of sexual acts, for instance, came to be a central concern in the 19th century when the healthy reproduction of the population became synonymous with a healthy economic and political environment; "There emerged the analysis of modes of sexual conduct, their determinations and their effects, at the boundary line of the biological and economic domains" [16]. At the risk of simplification, Foucault sought to understand why phenomena come to be the objects of research during a particular historical period, and in doing so, how do such investigations and interventions shape the phenomena themselves.

[1] There are many examples, but some that are closest to the study of infrastructure include Bowker's examination of the difficulties of biodiversity classification in the face of changing and often irreducible phenomena [12], Edwards' exquisitely detailed study of atmospheric science, climate change and its modeling [13], and Jackson, Ribes et al.'s study of temporal patterns of collaboration which points to 'phenomenal rhythms' such as the role of changing seasons in the ecosciences or the difference between Earth Time (24hrs per day) and Mars Time (24hrs and 37mins) as we send interplanetary probes across the solar system [14].

In contrast to Foucault, historian Lorraine Daston (and colleagues) have focused on the ways in which objects enter and exit the scientific gaze [17]. Her insight is that things do not simply become objects of scientific concern, thereafter 'linearly' explored by scientists, forever more becoming better understood; but rather, that certain objects can also cease to be of interest to science altogether. Thus, for Daston the focus is not the things in-themselves, but instead, their social life within the sciences, and then without. For example, "where have all the 'monsters' gone?" Daston asks in her exploration of the rise and fall of 'preternatural philosophy' [17]. Objects of natural anomaly and wonder— such as the Medusa or two-headed cats— once concerned the likes of Pietro Pomponazzi and Francis Bacon in the 16th century. However, these vanished as valid scientific objects in the wake of an 18th century focus on utility and order.

Ian Hacking contributes a third approach to historical ontology, focusing on those things that come to be in the world through the very activities of scientists. In other words, his interest is in how objects are constituted by science: things that had no existence whatsoever before they were the objects of scientific activity. His most notable contribution is *making up people*, where he has focused on the ways the human sciences have constituted new human kinds. This process occurs through law and medicine, but also very often mundanely, through categories, classification systems, and paperwork. These new kinds take on a reality in the world through human action. The most renowned example is still Foucault's examination of the medical constitution of the homosexual in the early 18th century: whereas before there were only homosexual *acts*, thereafter, the homosexual became a *human kind*.

These three approaches to historical ontology have proven invaluable in our study of MACS— all apply in their own ways, and we return to each in the next section. But, the particular form that interests us most, a fourth approach, has yet to be discussed as a matter of historical ontology.

The approach we contribute to historical ontology is a focus on objects of scientific research that *themselves* fundamentally change over the course of being studied. These objects display what Gaston Bachelard has called a *recurrence*— appearing to the scientific gaze first in one form, and then later returning as the 'same phenomenon,' yet in quite a different form. As objects are transformed, a consequent shift can be observed in the scientific practices, methods, instruments and social organization oriented toward those phenomena. The relationship is not one of linear causality, e.g., change in phenomena leads to change in science and infrastructure. Rather, many surprising factors and reversals can play a role in the recurrence of objects. For example, in our case, scientific interventions are the very reason for the phenomenon's transformation.

HIV disease went through a distinct change since its public emergence in the early-1980s: what was once an acute and terminal disease became a manageable and chronic condition by the mid-1990s. Medical interventions in the form of surveillance and treatment played a significant role in this transformation. Following from Hacking's making up people, not only did the objects of science (HIV disease) go through an ontological change, but so too did the 'subjects' of research: first, as people who were *dying from*, and later, *living with* HIV.

If these four forms are proper to historical ontology, let us also clarify that which is not. Historical ontology should not be conflated with the study of change in general. In thinking about the long-term of infrastructure, there are many ongoing transformations: organizational and institutional changes; practical and methodological shifts; or transitions in the specializations and foci of its members. These facets are of interest for a paper on infrastructure and change, but not for an analysis of historical ontology. In this context, we view historical ontology to be concerned specifically with the objects and subjects of science that *change-in-and-of-themselves*. Moreover, following Foucault, ontological changes are those that broadly reconfigure axes of knowledge, power and ethics. Not any new or changing object is historically ontological, it must be consequential in reconfiguring a social order [18].

This said, in exploring our case, we cannot but acknowledge that MACS's organization, funding, practices and so on, were thoroughly transformed over time as HIV disease itself transformed. In fact, we will argue in the discussion section that understanding how MACS became a larger and more general infrastructure for the study of HIV disease is in large part due to the ontological changes in the disease itself. In the study of infrastructure, changes in the objects of study cannot be cleanly distinguished from changes in the scientific method, instruments used, data collected, and overall organization.

4. PLACING THE RESEARCH OBJECTS OF INFRASTRUCTURE IN HISTORY

In order to differentiate historical ontology from other forms of change let us begin by delving into the relationship between the history of HIV and the evolution of MACS as an organization.

MACS was formally funded in 1983 through the National Institutes of Health (NIH) in response to the emerging threat of a spreading epidemic. The first signs had come in 1981, with "15 cases of *Pneumocystic carinii* pneumonia and 26 cases of Kaposi's sarcoma (KS) found among homosexual men in New York City and California" [19]. By the beginning of the MACS project, just two years later from the initial outbreak, over 2,000 cases had been tracked, with more than 700 related deaths [19].

At the time, this disease was called neither AIDS nor HIV— it eventually came to be so:

> *Prior to the MACS actually enrolling study subjects, resources were needed from the NIH system while the condition was still being named. There was a pre-AIDS condition known as Lymphadenopathy Syndrome (LAS). As a name, GRID (Gay-Related Immune Deficiency) became popular for a while, especially in Congress for some reason. Finally, 'AIDS' gained ground both at CDC and NIH and stuck nationally.* (former MACS investigator, *MACS 25th Anniversary*, 2009).

The cause of AIDS was identified as a virus in 1983: first, as LAV (Lymphadenopathy-Associated Virus) by Dr. Luc Montagnier in Paris and HTLV-III by Dr. Bob Gallo in the US, and then combined under the single header of HIV by 1986.

Thus far we are primarily describing *epistemological transformations* in the terminologies of the disease. This should be thought of as including the novel techniques and technologies by which scientists came to know the disease, e.g., narrowing in on the early signs of AIDS, such as off balance ratios of 'T-helper' and 'T-suppressor' white blood cells, to the identification of HIV antibodies through the commercial licensing of diagnostic tests in 1985. Such changes are fascinating and each worthy of

study, but in most senses, it is within the purview of normal science to redefine and elaborate the categories of its knowledge [12] and to produce novel inscription techniques [20].

Returning to the beginnings of MACS: in 1983 an AIDS diagnosis was a death sentence. There were no available treatments demonstrating results. Doctors could attend to the rare systematic cancers (Kaposi's Sarcoma) and inexplicable pneumonias (pneumocystis), but thereafter infections would inevitably return and patients painfully wasted in the face of new illnesses.

What was being witnessed was the decimation of a generation of young gay men in America. By 1986, the US had over 16,000 cases of AIDS and experienced more than 8,000 AIDS-related deaths [19]. And the disease was demographically spreading— with the CDC reporting "the cumulative incidence of AIDS among blacks and Hispanics [to be] more than three times the rate of whites" [19].

For its study, MACS initially recruited over 4,000 men who "did not have signs or symptoms of AIDS at baseline" [21]. Because no agent had been discovered and thus no test available, subjects were recruited based on a lack of physically manifested symptoms and through an *ad hoc* test measuring the balance of t-cells. It was soon discovered, however, that AIDS has a surprisingly long latency— often well over a year before observable symptoms began displaying themselves in patients. What this meant for MACS was that in 1985, when the first antibody tests became available, researchers were able to uncover that 30% of the subject population were in fact HIV-positive— and had likely already been so prior to these diagnostic measures [22].

As with the epistemological changes described above, this tragedy is a not a matter of historical ontology. It presented itself as misery and suffering for those who were ill and their loved ones who had to stand by and watch. To a striving study of AIDS it was a logistical challenge as the number of positive and negative participants shifted. Partially in response to this numerical imbalance in participants, MACS recruited a second cohort in 1987. Recruiting new subjects is an organizational endeavor, requiring changes to the study protocol, but again this is not ontological.

So, what *is* ontological?

In 1987 the first treatment for HIV came to market. Azidothymidine (AZT), used as a treatment for cancer since the 1970's, and then suspected to help with AIDS by 1983, did not complete clinical trials until four years later when the FDA finally approved its use in AIDS patients. This four-year gap, from 1983 to 1987, in approving the only known treatment to a fatal disease prompted waves of inventive activism that culminated in new rules for clinical trials [23].

Despite its promise, AZT on its own probably did not greatly extend the lives of those with HIV. The second generation of drugs, nucleotide reverse transcriptase inhibitors (NRTI), proved more effective, but still only pushed back an inevitable AIDS diagnosis. The third generation of drugs, protease inhibitors, in combination with NRTIs, resulted in Highly Active Antiretroviral Therapy (HAART)—what we now refer to as 'the cocktail.'

This is an historical ontological change in HIV disease: reconfiguring the knowledge, power and ethical axes of the sciences and individuals involved. With the first HAART treatments, the entire HIV landscape in America transformed: "it proved to significantly delay the onset of AIDS, and the life expectancy of HIV-positive people was greatly increased. *HIV infection was no longer thought of as a death sentence, but a manageable condition*" [24]. However, it had come too late for many, and for those who had been living with HIV for some time,

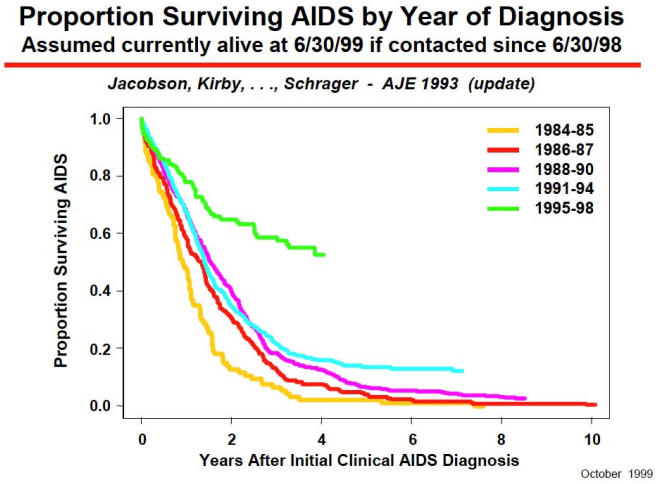

Figure 1. MACS Dossier, May 2009
http://www.statepi.jhsp.edu/macs/html

HAART would prove less effective. For MACS, it presented a change in their central research phenomenon. Those participants diagnosed as HIV-positive during a time when HAART was available developed AIDS at a slower rate: living with the disease for longer periods of time as compared to those who had AIDS prior to the development of such treatments [25]. As Figure 1 illustrates, the proportion of those MACS participants surviving four years post-AIDS-diagnosis (top line), are those diagnosed after HAART became readily available.

This transformation echoed throughout the entire MACS study. In 1999, MACS's funding was renewed, this time formally adding two new objects to its concerns: the effects of treatment, and the techniques of disease management. As Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases (NIAID) stated: "In coming years, we are confident that MACS will keep providing critical information as we pursue the best ways to treat, manage or prevent HIV" [26].

HIV disease's transition from terminal and acute to a condition more chromic and manageable opened novel vistas of research for MACS. Today, MACS often defines itself as a study of HIV disease and aging:

> The disease is no longer new, and great advances in treatment mean diagnosis is no longer a death knell. But that does not mean the research has stopped – it's only changed…now that researchers know how to treat the virus, they're faced with a question that wasn't a possibility three decades ago. 'Now what does the virus do on top of the aging process?' asked Charles Rinaldo, chairman of infectious diseases and microbiology at Pitt's Graduate School of Public Health [as well as the principle investigator of the Pittsburgh MACS site] [27].

Before the advent of the cocktail, HIV and aging were rarely thought of together; this new angle of study for MACS emerged as HIV became chronic and patients increasingly surviving longer periods of time.

But, what makes *this* a matter of historical ontology? It is ontological because the very nature of the 'same' scientific object (HIV) was transformed through the proliferation of many new research objects, e.g., aging with HIV; livers with long-term exposure to HAART; hearing and balance loss at the intersection of HIV, aging and the cocktail. The disease was still caused by HIV and transmitted through bodily fluids, such as semen and blood, but infection would no longer inevitably result in AIDS. From the perspective of MACS, their participants had shifted from quickly dying subjects to an aging population living with a chronic disease. The same cohorts could now be tracked for decades rather than years. It is an historical change because this transformation occurs within the domain of history; in fact, it is the scientific interventions and medical treatments, HAART, that lead directly to the ontological transformations.

There is a second, albeit subtler, historical ontological change here as well: what Ian Hacking calls *making up new people*, and in our case, the making of 'people with HIV/AIDS.' This change is society-wide, far broader than the domain of a research infrastructure, but MACS activities played a role in making and remaking new kinds of people— subsequently shifting individuals from one set of categories, identities and ways of being to another.

Making up people is not simply a matter of naming, but of classification and systematic placement within institutional routines. For example, MACS researchers were central in determining that a CD4 count greater than 200 indicated an AIDS diagnosis [28]. Afterwards, the general category that had been used to describe the disease, AIDS, became a particularly severe instantiation of HIV infection. Being HIV-positive was no longer the same as having AIDS. As research of the disease continued, MACS protocols became more precise, resulting in new ways of identifying its participants.

Institutions and experts ensure cases of HIV are *accounted for* by making the process of (ac)counting easy [29]. HIV became a measurable and diagnosable state and "HIV-positive" a line item in, for example, sexual health surveys. This process resulted in an understanding, knowledge and acceptance of HIV-positive as "a way to be a person" [30]. It is not that being HIV-positive did not exist prior to HIV being named as such; rather, in the case of HIV/AIDS, one became what one *had* and what one *lived with*.

Jumping back to our case, let us look at the journey of making-up a new *kind* of person from the perspective of several HIV-positive MACS participants. These quotes are based on our interviews and focus groups with participants who will remain anonymous. Our first respondent is from the initial MACS cohort, recruited in the early 1980s prior to the identification of the HIV agent, or a diagnostic test:

> *[A]t the time, the circle of my friends started to die…And I just said there's something here obviously…My first [MACS] visit, it was a [physician's assistant] or maybe a [registered nurse]…she was doing the physical part. She said, 'Oh, you have enlarged lymph nodes under your arm.' That was one of the tell tale signs. It's the only time I've ever broken out in a cold sweat. Only time and that's when I knew (Participant 1)*

In referencing his first MACS study visit in 1984, this participant remembered the very moment— the "cold sweat"— of being made *into* something else. At the time, to *have*, or rather to be made aware of *having* "one of the tell tale signs" of AIDS was to become a dying patient.

And then, this same respondent speaks of becoming something new, yet again:

> *Then when the first meds started coming out, the AZT, which I took for a little while. I tolerated it, but it was an awful drug. You know, but that's when I said, maybe there is hope. And then ten years ago, I guess when the HAARTs started coming in, I remember going to the main announcement…the main doctor…up in New York…He said we're on the verge of what became the cocktail. And then we all started hearing, at least among those of us who were positive, it will be someday, just like diabetes. Chronic. Chronic.*

The moment the virus came to be HIV was the moment being "positive" came to mean something very distinct: first, as a dying patient, then to a hopeful participant (in an uncertain treatment regime), and eventually to a positive person, living a life comparable to a diabetic. However, as HIV and AIDS became more and more understood, *making-up* the positive person became more and more complicated:

> *Participant2: You know, HIV/AIDS and really they are two different things. Because, you know, I have been living as an HIV-positive person for 30 years or more and I consider that very different, maybe I'm paranoid or something. I don't have AIDS, I am HIV-positive (FG2 Transcripts, pp.28)*

> *Participant3: I take a slightly different view of that because years ago when my T-cell count I think, went down to below maybe it went below maybe 200 and then I went on meds and then, so technically when it went below 200, I was said to have AIDS, no one really said it, but in my mind, I knew that that was the cutoff. But I just sort of lump them together now because when it's convenient for me, like, when there was something I wanted, I would say 'Oh, I'm an AIDS victim can you give me that car?' But, normally, 99.9% of my life, I have never thought of myself as a person living with AIDS…So, I see it a little differently. I see a reason to lump them together. I didn't always feel that way, but I feel that way now (Focus Group 2).*

As the dialogue between these two MACS participants shows, to be "an HIV-positive person" in 2010 can mean a myriad of things. The definition of a positive person can mean, for instance, to be: (a) optimistic, (b) HIV-seropositive, (c) living with AIDS, or (d) all of the above. Positive people existed prior to the identification of HIV. In fact, HIV existed prior to being HIV. It is simply that pre-HIV those infected did not experience themselves as such. And more importantly, they did not live within MACS's distinct medical regime for its HIV-positive subjects; their own personal medical treatments as HIV-positive patients; and a broader social world with, on the one hand, support groups, HIV-positive communities and events, and on the other hand, a plethora of institutionalized discrimination and more casual stigmas. With

each moment in the history of understanding HIV, new kinds of people were being made.

The changes described above are relevant to historical ontology and infrastructure because participants are the lifeblood of MACS— figuratively, and also literally. Without an ongoing population of participating subjects there simply is no longitudinal study of HIV disease, a continuing collection of specimens, a database of CD4 counts, or a consistent pool of participants over time.

More than just a conduit for examining how the disease manifests itself, the participant— a human individual with routines and everyday behaviors— is also an object of research for MACS. As participants were first *made into* people with AIDS, infectious and threatening to unprotected sexual partners, on a quick route themselves to death, and then later *into* people living with a manageably chronic disease, able to have safe sexual encounters, the living patterns of these people inevitably changed. It is a basic tenet of epidemiology that such life changes result in new vectors and pathways of disease transmission, new forms of community formation, and new ways to share information— all changing objects of investigation.

Even beyond their everyday routines and behaviors, some MACS participants helped to make the study itself. As they themselves took on the role of "expert consultants" and "representatives of the [participant] cohort" within locally established Community Advisory Boards (CABs) at each of the four MACS sites. Today, as members of these boards, participants are given the opportunity to review study instruments prior to implementation, partake in the approval and rejection of newly proposed sub-studies, actively help in recruitment processes, and recommend topics worthy of study [31, 32].

MACS epidemiologists continuously probe participants for new trending behaviors, including: drug use, new places for sexual encounters, treatment compliance, as well as the attitudes of younger generations towards safe sex and other potential factors that could lead to new dangers of transmission. In fact, the author's of this paper were first brought into MACS to help determine and understand new and emerging ways in which gay and bisexual men build community, share information or meet sexual partners through the Internet (as with the currently popular *Manhunt*) or mobile devices (through apps like *Grindr*). Such forms are themselves novel ontological entities in the world, reshaping the nature of the social link [33]. But that is another paper…

5. DISCUSSION: ORGANIZING FOR ONTOLOGICAL CHANGE

The 'so what' of this philosophical exercise is quite direct: within the history of an infrastructure it may experience forms of ontological change in its research objects. Those shifting objects— phenomena— may in turn play a role in reshaping the very organizations dedicated to their study. For those *studying infrastructure*, this is compelling in and of itself. In our case, ontological transformations go a long way toward explaining how MACS became a long-term endeavor— placing historical ontology in the broader pantheon of change an infrastructure may encounter. For those concerned with the *development of infrastructure,* this paper may serve as a 'heads up' that infrastructure will encounter fundamental changes in its research objects. More practically, we have observed within MACS several strategies for developing infrastructure that seek to make ontological change both visible and manageable. *Organizing for ontological change* is a feature of infrastructure design. In this section we will treat these topics in turn.

The ontological change we have described in this paper— HIV disease's shift from a deadly to chronic illness in the developed world— is a significant facet in MACS's institutional transformation from project to facility [34]. In other words, MACS shifted from a bounded study with specific aims and a definitive end-date to an ongoing infrastructure supporting the heterogeneous research of many scientists, largely because HIV disease itself became a long-term (and heterogeneous) phenomenon.

In 1983, MACS was funded for four years to study the etiology and epidemiology of AIDS. At the time, doctors were only beginning to grasp the scope of the problem, but were already estimating 75 to 100% fatalities within a few years of manifestation. A truly devastating prospect. With such a high a rate of fatality in such a short window of time, few were expecting a cohort study to continue for decades. Perhaps, more importantly, at the time there was a continuing hope for a cure and vaccines: recent successes with Polio in the 1950s to Hepatitis B in the 1980's had left the medical community with great hubris. But this was not to be.

The four centers were awarded a total of 3.2 million dollars to execute their ambitious longitudinal study (a tiny sum for the goal of the project). Without delving into the arcane details of funding arrangements, this first award was a contract, with a finite time frame, and no structured avenues for renewal. In 1987, MACS became a cooperative agreement, a line item program, with five-year windows for review and renewal. In 1995, it was renewed again, this time with redefined research goals— essentially, a long-term research institution.

As a finite research project, the first iterations of MACS had targeted research goals: 1) to account for the early symptoms leading up to "AIDS-related conditions," as well as AIDS itself; 2) to identify the avenues of transmission of AIDS; and 3) to gather specimens that may help in identifying an agent of infection [3]. From inception, the project had been interdisciplinary— drawing together oncologists, epidemiologists, and molecular biologists, to name a few. In this sense, MACS was 'always already an infrastructure,' supporting the research and collaboration of many specialists. However, following HIV's transformation into a chronic illness, it became 'far more of an infrastructure.' We have noted, for example, that aging-with-HIV became a research object following the disease's transition from terminal to chronic. Along with this transition, a plethora of new scientific researchers joined MACS: for example, extensive mental health research. Managing a chronic disease is a matter of body and mind over time. New kinds of researchers also meant new kinds of research protocols, and new forms of data to collect and manage. HIV disease's transition meant transitions throughout all aspects of MACS's organization.

Our actors are not naïve. There is very little we have discussed in this paper that they themselves have not first discussed with us, or that they have not captured in their own retrospective pamphlets celebrating MACS's accomplishments. For instance, the transition we have focused on in this paper is reflected in the taglines MACS uses to describe itself: whereas in its early years MACS identified itself as studying the 'natural history' of AIDS, today,

the phrase 'natural and treated history of HIV' is used instead— reflecting the drastically changing nature of the phenomenon itself. The continuance of infrastructure is not an academic matter for scholars alone; it is also a practical everyday concern for members of an organization.

Infrastructural actors looking to sustain the long-term must act reflexively and prospectively, asking themselves: what are we today and what might we look like tomorrow? Ribes and Finholt [34] have observed that challenges of the long-term are sometimes articulated as *tensions*, and that such articulations can serve as sources of insight for infrastructure studies. It is for this reason that in this paper we turn our attention to a research infrastructure that has successfully *gone on* in the face of fundamental transformations in its scientific objects.

We have much to learn from the outcomes of such negotiations. As a taste of our research to come, we have found that MACS has shaped itself to expect changes in its objects of research. Members of MACS have not simply reacted to ontological changes, they have built an organization precisely to seek out and manage such transformations. In other words, they have *organized for ontological change* by developing an infrastructure attuned to such changes.

Consider three actual potentialities for the HIV virus itself: diverging strains; mutations; and resistance to treatment. MACS scientists and the broader HIV research community are perpetually scouring their data and subjects for these terrifying possibilities. The potential of a 'super-AIDS' has occasionally made headlines in newspapers. This could manifest in many ways, but one possibility is a mutated strain of HIV that is highly infectious— most terrifyingly if it is transmitted despite what we have come to think of as safe sex practices. MACS epidemiologists are on the frontlines of detection should such a disaster occur. The change with the greatest immediacy (though it still cannot be predicted in any precise manner) is the possibility that current strains of HIV will become resistant to the various cocktails— reversing the ontological change outlined in this paper, and once again, threatening the lives of over one million Americans living with HIV, and many more millions around the world. MACS researchers are also working to identify such changes in HIV disease. These organizational practices are not about *predicting* the specific trajectory of change. Instead, longitudinal studies are designed with *an expectation of change* in its objects: it is the purpose of research in such projects to make visible and then investigate these changes in an ongoing fashion.

Organizing for ontological change is a strategy of the long-term. Arguably, it is a feature of good design. Computer scientists have developed a robust vocabulary for the kinds of technological changes they have come to expect in cyberinfrastructure: systems are designed for the growth of users, storage or network capacity (known as *extensibility*), or for the easy replacement of outdated technologies with novel ones (called *modularity*). A similar vocabulary is necessary for ontological changes and the sociotechnical solutions available. Consider ecoscientists, who during the 20th century went through a comparable transition to the one discussed in this paper: from a 'natural history' of the environment to one that is 'anthropogenically transformed.' One would expect cyberinfrastructure for the environmental sciences to be attuned to the emerging features of human-caused climate change, that tools to detect and interpret such ontological transformations would be part of design. This is certainly the case, but we do not yet have a systematic language and knowledge base within infrastructure studies to speak of it. This paper is a contribution to making sense of such ontological changes, and our future research will continue this trajectory with a more elaborated exploration of organizing for this specific type of change.

6. CONCLUSION

We have spilt a great deal of ink in this paper distinguishing historical ontology from other forms of change infrastructure may encounter over time. By bracketing out dynamic phenomena, we engaged in a project of philosophical clarification, allowing us to elaborate the complex concept of ontology. We have done so with the hope of adding to the theoretical and methodological toolset of infrastructure studies.

Our overarching critique is of the claim (or assumption) that research infrastructure can be general with respect to its phenomena of study; in making this assumption we are in danger of ignoring the research objects of infrastructure. The field of infrastructure studies is successfully *sociotechnical* in its approach. That is, careful attention is paid to the mesh of technology, design, users, practice and information. Scholars have effectively demonstrated that infrastructure must be tailored to many things: to the specific structures and kinds of data, to the patterns of communication and collaboration of its users, to the everyday practices of its scientists, and to the epistemic criteria of the community. In this sense, infrastructure scholars have not made the mistake of the naïve *social constructivist* that ignores materiality: technology and practice are central.

But what of the objects of study and their role in shaping research infrastructure? We have largely ignored the X in the formulation "cyberinfrastructure for the study of X," whether the X is 'for' the earth, the environment, physics or genetics. In doing so, scholars of infrastructure are at risk of 'going native,' of drinking the Kool-Aid of the *myth of information*: the assumption that information is universal, that it is general, and that its IT tools can travel from one object of study to another as easily as water through the pipelines of the nation.

Some *caveats*: While this paper has focused on dynamic phenomena within research infrastructure, we do not argue that this should be a privileged object of research. Our goal has not been to define strict criteria distinguishing ontology from epistemology, practice, or instruments. Ontological change cannot be understood as 'impacting upon' a research organization in any linear fashion. Nature does not determine infrastructure. Such a project of demarcation is doomed from the start. In our case, we have shown how HIV's transformation to a manageable disease is itself because of the medical interventions that were, in part, due to the science conducted by MACS researchers. Such complex causal loops are not surprising.

Our boundaries between ontology, epistemology, instruments and practice serve an analytic purpose rather than being realist in some static manner. They are specific to particular circumstances, demanding attentive empirical investigation. And, over time, they shift in surprising ways. Ontological change must be investigated as part of the broader mesh that includes scientific investigation, social organization, networks of collaboration and so on. Following from Bachelard, we argue that in addition to being *sociotechnical* in our studies of infrastructure we must also be *phenomenotechnical*.

We are also not proposing that adapting to ontological change is a necessary feature in the long-term success of infrastructure. In some circumstances, the reverse may be true. MACS proves remarkably agile in the face of *some* transformations in its research objects, but it has intentionally ignored others. Arguably, such exclusions are a benefit to its longevity. For example, a feature of AIDS is that it manifests itself very differently in the US than in developing nations. In West Africa, for instance, the most common form of infection is HIV-2, a subtype that displays lower virulence, e.g., infection from mother to child is less likely. Following the identification of HIV-2, MACS explicitly identified itself as studying HIV-1, the most common species within the US. Similarly, MACS has from its inception, and then following two further rounds of subject recruiting, renewed its decision to exclude heterosexual men or women. MACS then can be characterized as 'inflexible' in the face of certain changing aspects and manifestations of HIV disease. A refusal to spread itself too thin, with the goal of concentrating resources and creating a focused base of expertise, may go a long way towards explaining its success over time.

This leads us directly to our future topics of research. A common trope in explaining the success of long-term infrastructure is to claim that infrastructure must remain 'flexible.' And yet, while MACS in its nearly three decades has clearly reshaped itself to a changing and emerging disease, it has also steadfastly redefined its research agenda in ways that exclude other facets of the changing phenomenon. Such exclusions may also help us understand its longevity. In our future research, we will investigate such decisions and strategies of inclusion and exclusion in order to ask, *what is flexibility?*

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