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In the Journals -- September 2016, part II

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By Aaron Seaman

And, now, part two of September's journal posting! (Part one is [here](#).)

[Medical Anthropology Quarterly](#)

[“I Hope I Get Movie-star Teeth”: Doing the Exceptional Normal in Orthodontic Practice for Young People](#)

Anette Wickström

Orthodontics offer young people the chance to improve their bite and adjust their appearances. The most common reasons for orthodontic treatment concern general dentists', parents' or children's dissatisfaction with the esthetics of the bite. My aim is to analyze how esthetic norms are used during three activities preceding possible treatment with fixed appliances. The evaluation indexes signal definitiveness and are the essential grounds for decision-making. In parallel, practitioners and patients refer to self-perceived satisfaction with appearances. Visualizations of divergences and the improved future bite become part of an interactive process that upholds what I conceptualize as “the exceptional normal.” Insights into this process contribute to a better understanding of how medical practices intended to measure and safeguard children's and young people's health at the same time mobilize patients to look and feel better. The article is based on an ethnographic study at two orthodontic clinics.

[Huichol Migrant Laborers and Pesticides: Structural Violence and Cultural Confounders](#) (*open access*)

Jennie Gamlin

Every year, around two thousand Huichol families migrate from their homelands in the highlands of northwestern Mexico to the coastal region of Nayarit State, where they are employed on small plantations to pick and thread tobacco leaves. During their four-month stay, they live, work, eat, and sleep in the open air next

to the tobacco fields, exposing themselves to an unknown cocktail of pesticides all day, every day. In this article, I describe how these indigenous migrants are more at risk to pesticides because historical and contemporary structural factors ensure that they live and work in the way of harm. I discuss the economic, social, political, and racial inequalities that exist in their every-day environment and how these forms of structural violence are mitigated by their intersection with local cultural contexts and their specific indigenous lifeworld.

[The Global Context of Vaccine Refusal: Insights from a Systematic Comparative Ethnography of the Global Polio Eradication Initiative](#)

Svea Closser, Anat Rosenthal, Kenneth Maes, Judith Justice, Kelly Cox, Patricia A. Omidian, Ismalia Zango Mohammed, Aminu Mohammed Dukku, Adam D. Koon, and Laetitia Nyirazinyoye

Many of medical anthropology's most pressing research questions require an understanding how infections, money, and ideas move around the globe. The Global Polio Eradication Initiative (GPEI) is a \$9 billion project that has delivered 20 billion doses of oral polio vaccine in campaigns across the world. With its array of global activities, it cannot be comprehensively explored by the traditional anthropological method of research at one field site. This article describes an ethnographic study of the GPEI, a collaborative effort between researchers at eight sites in seven countries. We developed a methodology grounded in nuanced understandings of local context but structured to allow analysis of global trends. Here, we examine polio vaccine acceptance and refusal to understand how global phenomena—in this case, policy decisions by donors and global health organizations to support vaccination campaigns rather than building health systems—shape local behavior.

[Human Rights, Humanitarianism, and State Violence: Medical Documentation of Torture in Turkey](#)

Ba?ak Can

State authorities invested in developing official expert discourses and practices to deny torture in post-1980 coup d'état Turkey. Documentation of torture was therefore crucial for the incipient human rights movement there in the 1980s. Human rights physicians used their expertise not only to treat torture victims but also to document torture and eventually found the Human Rights

Foundation of Turkey (HRFT) in 1990. Drawing on an ethnographic and archival research at the HRFT, this article examines the genealogy of anti-torture struggles in Turkey and argues that locally mediated intimacies and/or hostilities between victims of state violence, human rights physicians, and official forensics reveal the limitations of certain universal humanitarian and human rights principles. It also shows that locally mediated long-term humanitarian encounters around the question of political violence challenge forensic denial of violence and remake the legitimate levels of state violence.

[On the Margins of Pharmaceutical Citizenship: Not Taking HIV Medication in the “Treatment Revolution” Era](#)

Asha Persson, Christy E. Newman, Limin Mao, and John de Wit

With the expanding pharmaceuticalization of public health, anthropologists have begun to examine how biomedicine’s promissory discourses of normalization and demarginalization give rise to new practices of and criteria for citizenship. Much of this work focuses on the biomedicine–citizenship nexus in less-developed, resource-poor contexts. But how do we understand this relationship in resource-rich settings where medicines are readily available, often affordable, and a highly commonplace response to illness? In particular, what does it mean to not use pharmaceuticals for a treatable infectious disease in this context? We are interested in these questions in relation to the recent push for early and universal treatment for HIV infection in Australia for the twin purposes of individual and community health. Drawing on Ecks’s concept of pharmaceutical citizenship, we examine the implications for citizenship among people with HIV who refuse or delay recommended medication. We find that moral and normative expectations emerging in the new HIV “treatment revolution” have the capacity to both demarginalize and marginalize people with HIV.

[“Make Sure Somebody Will Survive from This”: Transformative Practices of Hope among Danish Organ Donor Families](#)

Anja M.B. Jensen

Based on anthropological fieldwork among Danish organ donor families and hospital staff in neurointensive care units, this article explores the transformative practices of hope in Danish organ

donation. Focusing on various phases of the organ donation process, I demonstrate how families and professionals practice hope in astounding ways: when hoping for organs, when hoping for the end of patient suffering, when hoping for the usability of the donor body, and when hoping to help future donor families by sharing painful experiences. By focusing on such practices and transformations of hope, this article sheds light on the social negotiations of life and death among families and staffs in medical contexts and describes how the dignity of the deceased donor and the usability of the donor body are closely connected in family attempts to make donation decisions meaningful during and after a tragic death.

["No One Ever Even Asked Me that Before": Autobiographical Power, Social Defeat, and Recovery among African Americans with Lived Experiences of Psychosis](#)

Neely Anne Laurenzo Myers and Tali Ziv

Our article draws on ethnographic research with African American males diagnosed with a psychotic disorder in a high-poverty urban area of the northeastern United States. Our participants frequently described the ways public mental health services led them to experience a paralyzing erosion of autobiographical power, which we define as the ability to tell one's own story and be the editor of one's own life. We identified three important points when the loss of autobiographical power seemed to perpetuate social defeat or a sense of social powerlessness (Luhmann 2007) for our participants during their interactions with public mental health care. We invite further inquiry into the loss of autobiographical power in settings of public mental health care, the sense of social defeat it seems to perpetuate, and the impact of these on mental health recovery, especially for people living in contexts of persistent social adversity.

[Dying for Money: The Effects of Global Health Initiatives on NGOs Working with Gay Men and HIV/AIDS in Northwest China](#)

Casey James Miller

Drawing on 17 months of ethnographic fieldwork (2007–2011), this article critically examines the consequences of two global health initiatives (GHIs), the Global Fund and the Gates Foundation, on NGOs engaged in HIV/AIDS prevention and treatment among gay

men in northwest China. I argue that a short-term surge in funding provided by GHIs between 2008 and 2010 exacerbated preexisting conflicts between NGOs by promoting a neoliberal process in which the state outsourced public health services to civil society organizations, deliberately encouraging a climate of competition among NGOs. I also show how GHIs encouraged the bureaucratization and medicalization of one grassroots gay NGO, channeling its activities away from broader political and social objectives and compelling the group to develop a narrower and more entrepreneurial emphasis on HIV testing and treatment. This article contributes to a deeper ethnographic understanding of the complex and perhaps unintended consequences of GHIs.

[Medicine Anthropology Theory \(open access\)](#)

[Affect, Infrastructure, and Vulnerability: Making and Breaking Japanese Eldercare](#)

Jason Danely

Care work requires a vulnerability and ethical responsiveness towards the cared-for, including an openness to ebbs and flows of affective intensity. For care workers, affective vulnerability is not only a precondition for good care but can also precipitate exhaustion, neglect, and even violence under precarious political and economic conditions. I argue that the concept of vulnerability allows us to trouble the distinction between the supposed oppositional forces of care and violence, allowing us to imagine other possible ways of being in the world with others. Drawing on ten months of fieldwork in Kyoto, Japan, I describe how care workers constitute a human infrastructure whose vulnerability facilitates flows of compassion and cruelty, erotic intensity and heavy fatigue. Care workers' narratives reveal a process of striving to embody vulnerability and sustain moral selfhood without breaking down.

['My Friends Look Just Like You': Research Encounters and Imaginaries in Vancouver's Urban Drug Scene](#)

Danya Fast

Drawing on eight years of research with young people who inhabit the margins of Vancouver, in this article I bring into view some of the 'frictions' that can arise when conducting anthropological

research at home, across vast differences in power and privilege. I argue that our research subjects can also be deeply concerned with how to position themselves in relation to researchers and research studies, and with navigating the various forms of social and geographical distance and proximity that are embedded in anthropological encounters across time. Paying attention to how our research subjects position themselves in research encounters may force us to problematize tidy boundaries between ‘us’ and ‘them’.

[Occupational citizenship: Practice, routine, and bureaucracy among nurses and midwives in rural Burkina Faso](#)

Lise Rosendal Østergaard

Health workers are an overlooked category in the growing literature on health and citizenship. In this article I describe a 2012–2013 nationwide conflict in the public health care sector in Burkina Faso to explore how ideas about citizenship were mobilized in a situation of political agitation. I examine how public health care is done in a context of material deprivation, technological shortage, and great demand from the population. Three distinct repertoires of practice, routine, and bureaucracy are identified, through which health workers strive to make meaning of their work and engage in the practice of public health care. Drawing on these findings, I argue that adopting a citizenship framework offers an opportunity to improve our understanding of the multiple ways in which health workers manage the difficulties related to being (health professionals) and doing (professional health care) in rural Burkina Faso.

Special Section: *Ethnomedicine and medical anthropology today, in the case of Tibet*

[Introduction](#)

Vincanne Adams

This collection of essays brings to light important themes in medical anthropology that have been eclipsed in recent years by theoretical turns toward problems of suffering, experience, and ontology (among others). Namely, they remind us of the importance of what was once popularly called the study of ‘ethnomedicine’.

[The recognition of Sowa Rigpa in India: How Tibetan medicine became an Indian medical system](#)

Stephan Kloos

In 2010, the Government of India officially recognized Tibetan medicine as an 'Indian system of medicine' called 'Sowa Rigpa'. This article documents the processes that led to Sowa Rigpa's recognition, and situates them at the confluence of economic interests and political strategies within a larger historical and cultural context. Recognition emerges here as a twofold process that makes Sowa Rigpa legible to the state while simultaneously facilitating its incorporation into the market as capital. Previously an inalienable part of Tibetan and Buddhist Himalayan cultural heritage, Sowa Rigpa could now be legitimately claimed or appropriated as cultural, political, or economic capital, giving rise to tensions over ownership and control. Tracing how Sowa Rigpa's recognition transformed from an initial struggle for protection to one over control, this article offers a critical new perspective on the recognition of cultural heritage, India's pluralistic health care system, and the Asian traditional pharmaceutical industry.

[Positioning Sowa Rigpa in India: Coalition and antagonism in the quest for recognition](#)

Calum Blaikie

The years leading up to the recognition of Sowa Rigpa (Tibetan medicine) by the Government of India in 2010 saw unprecedented interaction between various branches of the tradition and the state apparatus. These interactions grew particularly intense during March 2008, when two conferences focusing on related issues took place. The first referred to 'Tibetan medicine' and was organised by Tibetan exile institutions, while the second spoke of 'Sowa Rigpa' and was hosted by a coalition of Himalayan Indian associations. Through detailed ethnography of these events, this article examines the way in which a medical system was discursively constructed and positioned on the brink of state enfranchisement. It shows how 'discourse coalitions' and antagonisms formed during these events, and enquires as to the implications of these for the balance of power in Sowa Rigpa and for its positioning in relation to the Indian state, technoscience, and the growing market for traditional medicines.

[Naming and forgetting: Sowa Rigpa and the territory of Asian medical systems](#)

Sienna R. Craig and Barbara Gerke

Sowa Rigpa is generally translated as ‘the science of healing’ and often used synonymously for ‘Tibetan medicine’. Historically, Sowa Rigpa can be considered a borrowed term from Sanskrit, accompanied by an adopted sense of ‘science’, which initially signified all forms of medicine known to the Tibetan world, regardless of their place of origin. Over the centuries, Sowa Rigpa became linked to local, indigenous, and ‘enskilld’ practices; later, to nationalist political sensibilities; and of late to cultural belonging. The term evokes territoriality, claims to ownership of knowledge, concerns over sustaining national identities, and considerations about how place-based healing practices and material resources relate to the globalizing ideas about traditional Asian medicines. Textual and ethnographic analyses and interviews with practitioners from China, India, and Nepal show how Sowa Rigpa exists at once as a marker of shared intellectual and cultural histories and forms of medical practice and as a label for a globally circulating medical system with distinct interpretations. Looking at Sowa Rigpa as operating in de- and reterritorialized global spaces makes visible how, why, and to what end modernity forgets (Connerton 2009), thereby allowing for broader conclusions applicable to other medical contexts.

Special Section: *Think Pieces on Critical Global Health*

[The work of evidence in critical global health](#)

Vincanne Adams and João Biehl

This special section critically examines the paradigms and values that undergird the ever-expanding field of global health. The richly textured ethnographic think pieces presented here tackle problems of evidence and efficacy as complex forms of ethical and theoretical engagement in contexts of neoliberalism, war, technological innovation, inequality, and structural violence. These works seek to contribute to a people-centered and politically relevant social theory for the twenty-first century.

[Theorizing Global Health](#)

João Biehl

Reflecting on the recent West African Ebola outbreak, this piece advocates for a critical and people-centered approach both to and within global health. I discuss the current state of the field as well as critical theoretical responses to it, arguing that an ethnographic focus on evidence and efficacy at the local level raises rather than lowers the bar for thoughtful inquiry and action. The current moment calls less for the all-knowing hubris of totalizing analytical schemes than for a human science (and politics) of the uncertain and unknown. It is the immanent negotiations of people, institutions, technologies, evidence, social forms, ecosystems, health, efficacy, and ethics – in their temporary stabilization, production, excess, and creation – that animate the unfinishedness of ethnography and critical global health.

[Ordinary Medicine: The power and confusion of evidence](#)

Sharon Kaufman

Medicine in the twenty-first century is constituted and propelled by the production of evidence. Once produced, the use of that evidence is complicated by features inherent in the American and global biomedical economy itself. With the exponential rise in the use of cardiac devices as my case study, this think piece traces the links among evidence-based medicine, insurance reimbursement policies, and clinical trial outcomes to reveal how evidence produced by trial findings creates treatment standards. Those standards, in turn, expand what is thought to be 'treatable' by reconceptualizing risk as a condition that deserves intervention. Such standards affect what physicians recommend and what patients decide to do. The essay emphasizes that evidence-based medicine can be a source of anxiety that patients and families feel when considering how to proceed. It highlights the debates, increasingly common both within and beyond the health professions, about what is actually best as we grow older. It provides an example of how, today, most deaths, even among the very old, are considered premature. In an aging society, the treatment protocols that fall under the evidence-based medicine umbrella constitute an enormous truth-making regime that determines the goals of medicine and shapes health care consumers' quandaries about medical intervention, and especially the quandary, for those in later life, about crossing the line of too much treatment.

[Ecologies of Evidence in a Mysterious Epidemic](#)

Charles L. Briggs

An epidemic in a Venezuelan rainforest in 2007-2008 killed 38 children and young adults, puzzling clinicians, epidemiologists, and healers alike for over a year. This essay traces the way each contribution to knowledge production formed part of a larger ecology of evidence. Focusing on how the parents' knowledge was exploited and denigrated by clinicians, epidemiologists, and healers alike points to the health/communicative inequities—grossly unequal distributions of access to the production and circulation of evidence—that structured ecologies of evidence in ways that thwarted diagnosis. Recruiting a nurse, a healer, a physician, and an anthropologist, two indigenous leaders launched an investigation that juxtaposed parents' narratives, vernacular healing, epidemiology, and clinical medicine, resulting in a clinical diagnosis of bat-transmitted rabies. This case suggests that perspectives in global health will fail to become fully critical unless they attend to health/communicative inequities, how they structure ecologies of evidence, and strategies for transforming them.

[addicted.pregnant.poor](#)

Kelly Ray Knight

[addicted.pregnant.poor](#) is an ethnography addressing the biomedical, social, political, and ethical dimensions of ongoing illicit drug use during pregnancy. A result of four years of fieldwork in daily-rent hotels – privately owned buildings in which the exploitation of women's sex work and on-going poor health was normative – the book follows nineteen women who had twenty-three pregnancies. To answer the question 'What forms of life are possible here?' I engaged with the social actors who are called upon to produce knowledge about addicted pregnancy, including addicted, pregnant women; an anthropologist; public health epidemiologists; advocates; social policymakers; treatment professionals; bureaucrats; and scientists. In this essay, I describe the relationship between the scientific contours of reproductive health and the personal and social consequences of pregnancy in the context of addiction and housing instability. Pregnant women in the daily-rent hotels existed within multiple temporalities. Here I explore what an ethnographic understanding of memorial time and biomedical time can teach us about the vital politics of viability at work in addicted pregnancy.

[Lower Extremities](#)

Harris Solomon

How might global health evidence waste away? The thing that generates evidence in this case, the metabolism, offers some possible answers to this question. But it does so, sometimes, only when things devolve. This essay takes up the case of amputation in the case of diabetes. The ethnography of atrophy highlights how knowing and embodiment wither, all while the thing that is supposed to absorb the world – the metabolism – offers less and less return on such a promise.

[After war](#)

Zoë H. Wool

In the United States – as in other places in the ambit of biomedicine – the efforts exerted on and by injured soldiers' bodies in the aftermath of war are generally understood under the familiar medical rubric of 'rehabilitation'. This reflection troubles that term by moving away from the medical logic of rehabilitation and its telos of injury and healing, and the logics that see injured soldiers as promising bodies. Instead, the think piece explores a wider range of practices of attention to injured soldiers' bodies that emerge ethnographically, and traces embodied forms of being made within unsteady temporalities of life, health, and death after war, forms that call the temporality of rehabilitation into question and highlight care's collateral affects. I reflect on the phenomenon of heterotopic ossification – bone growth at the site of injury that is a sign of healing that is also itself a form of injury – to think through the confounding analytical, ethical, political, and corporeal implications of such a space.

[What Is Critical Global Health?](#)

Vincanne Adams

[Review of Disability Studies: An International Journal](#)

Special Issue: *Forum on Disability and Aging*

[Old and Disabled: Disabled and Old](#)

Megan Conway

This editorial proceeds the Forum on Disability and Aging and discusses some personal reflections on the relationship between aging and disability.

[Disability & Aging: International Perspectives](#)

Katie Aubrecht, Tamara Krawchenko

This issue of *RDS* features eight original articles and art which analyze how disability and aging appear in research, policy and everyday life. Contributors to this international collection use interdisciplinary perspectives to explore the complex relationship between disability and aging, and challenge disability and age related myths and misconceptions.

[Aging and Disability: The Paradoxical Positions of the Chronological Life Course](#)

Amanda Grenier, Meredith Griffin, Colleen McGrath

This paper explores aging and disability, problematizing the paradoxical tendency to separate and conflate these social locations in chronological understandings of the life course. Exploring how such thinking has shaped assumptions, responses, knowledge, policy and practice, we conclude with suggestions to reconsider disability across the life course and into late life.

[Securing Personal Input from Individuals Aging with Intellectual Disability: Do Differing Methodologies Produce Equivalent information?](#)

Stuart Wark, Miranda Cannon-Vanry, Marie Knox, Marie Parmenter, Rafat Hussain, Matthew Janicki, Chez Leggatt-Cook, Meaghan Edwards, Trevor Parmenter

Research is limited on whether differing methodologies for facilitating personal contributions from individuals aging with intellectual disability produce equivalent knowledge outcomes. Two matched purpose-developed tools examined five quality-of-life domains. Results showed substantial variance between qualitative

interview responses and Likert-scale data, and indicate validity concerns for using either methodology in isolation.

[To Include or Not to Include Them? Realities, Challenges and Resistance to the Participation of People with Disabilities in Seniors' Organizations](#)

Emilie Raymond, Nadine Lacroix

People with disabilities are often excluded from mainstream seniors' organizations. A participatory action research project was undertaken in a seniors' leisure association to better include members with disabilities. Results underline the importance of understanding the interaction of individual and environmental factors when looking to support the participation of seniors with disabilities.

[Compulsory Youthfulness: Intersections of Ableism and Ageism in "Successful Aging" Discourses](#)

Hailee M. Gibbons

This article forwards the theory of compulsory youthfulness as a way to explore how ableism, ageism, and other systems of oppression intersect to produce the societal mandate that people must remain youthful and non-disabled throughout the life course, particularly in a cultural context that holds successful aging as an ideal.

[Coverage of Aging Well of Individuals Aging with a Disability in Canadian Newspapers: A Content Analysis](#)

Gregor Wolbring, Bushra Abdullah

We ascertained how disability and disabled people were framed within the 4899 articles covering *aging well*, *active aging*, *healthy aging*, *natural aging* and *successful aging* in the 300 Canadian newspapers of the *Canadian newsstand complete* database. The framing was mostly medical. Problems faced by individuals aging with a disability were mostly ignored.

['My Body Feels Old': Seniors' Discursive Constructions of Aging-as-Disabling](#)

Yvonne R. Teems

Social gerontology and disability studies have made similar but separate arguments for ways to study aging and disability, respectively. This study of interviews with seniors finds that seniors characterize aging as disabling and position both identity constructions as negative. The article argues for the use of disability theory and discourse to examine seniors' lived experiences.

['No Longer Disabled' – Reflections on a Transitional Process Between Disability and Aging in Switzerland](#)

Francesca Rickli

Switzerland's social security system categorizes seniors with disabilities according to the onset of the disability. The transitional point between the disability insurance and the old age insurance is retirement. The paper describes the underlying assumptions leading to this transition as well as the ways in which seniors with mobility disabilities deal with its effects.

[The Becoming Subject of Dementia](#)

Katie Aubrecht, Janice Keefe

In this paper we analyse the becoming subject of dementia, as it is made to appear within the contexts of nation-building and everyday life. Insights yielded from this analysis suggest the importance of time to recognition of normalcy, and to the meaning of being a person.

[Science as Culture](#)

[Promise and Ontological Ambiguity in the *In vitro* Meat Imagescape: From Laboratory Myotubes to the Cultured Burger](#)

Neil Stephens and Martin Ruivenkamp

In vitro meat (IVM), also known as cultured meat, involves growing cells into muscle tissue to be eaten as food. The technology had its most high-profile moment in 2013 when a cultured burger was cooked and tasted in a press conference. Images of the burger

featured in the international media and were circulated across the Internet. These images—literally marks on a two-dimensional surface—do important work in establishing what IVM is and what it can do. A combination of visual semiotics and narrative analysis shows that images of IVM afford readings of their story that are co-created by the viewer. Before the cultured burger, during 2011, images of IVM fell into four distinct categories: cell images, tissue images, flowcharts, and meat in a dish images. The narrative infrastructure of each image type affords different interpretations of what IVM can accomplish and what it is. The 2013 cultured burger images both draw upon and depart from these image types in an attempt to present IVM as a normal food stuff, and as ‘matter in place’ when placed on the plate. The analysis of individual images and the collection of images about a certain object or subject—known as the imagescape—is a productive approach to understanding the ontology and promise of IVM and is applicable to other areas of social life.

[Science, Technology, & Human Values](#)

[The Vulnerability of Cyborgs: The Case of ICD Shocks](#)

Nelly Oudshoorn

This article contributes to Science and Technology Studies on vulnerability by putting cyborgs at center stage. What vulnerabilities emerge when technologies move under the skin? I argue that cyborgs face new forms of vulnerability because they have to live with a continuous, inextricable intertwinement of technologies and their bodies. Inspired by recent feminist studies on the lived intimate relationships between bodies and technologies, I suggest that sensory experiences, material practices, and cartographies of power are important heuristic tools to understand the vulnerabilities of hybrid bodies. Based on an analysis of how patients in the Netherlands and the United States cope with appropriate and inappropriate implantable cardioverter defibrillator shocks, I describe how defibrillators introduce two new kinds of vulnerabilities: vulnerability as an internal rather than an external threat, and as harm you may try to anticipate but can never escape. Despite these vulnerabilities, some heart patients don't position themselves as passive victims of faulty machines. They actively engage in material practices of resilience by using magnets to stop inappropriate shocks. I conclude that anticipating and taming the improper working of technologies inside bodies constitutes a new form of invisible labor that is crucial to

diminishing the existential uncertainties of cyborgs.

[Bioinformatics and the Politics of Innovation in the Life Sciences: Science and the State in the United Kingdom, China, and India](#) (*open access*)

Brian Salter, Yinhua Zhou, Saheli Datta, and Charlotte Salter

The governments of China, India, and the United Kingdom are unanimous in their belief that bioinformatics should supply the link between basic life sciences research and its translation into health benefits for the population and the economy. Yet at the same time, as ambitious states vying for position in the future global bioeconomy they differ considerably in the strategies adopted in pursuit of this goal. At the heart of these differences lies the interaction between epistemic change within the scientific community itself and the apparatus of the state. Drawing on desk-based research and thirty-two interviews with scientists and policy makers in the three countries, this article analyzes the politics that shape this interaction. From this analysis emerges an understanding of the variable capacities of different kinds of states and political systems to work with science in harnessing the potential of new epistemic territories in global life sciences innovation.

[Toxic Lunch in Bhopal and Chemical Publics](#)

Rahul Mukherjee

On November 28, 2009, as part of events marking the twenty-fifth anniversary of the disaster at the Union Carbide plant in Bhopal, gas survivors protested the contents of the report prepared by government scientists that mocked their complaints about contamination. The survivors shifted from the scientific document to a mediated lunch invitation performance, purporting to serve the same chemicals as food that the report had categorized as having no toxic effects. I argue that the lunch spread, consisting of soil and water from the pesticide plant, explicitly front-staged and highlighted the survivor's forced intimate relationship with such chemicals, in order to reshape public perception of risks from toxins. Chemical matter like sevin tar and naphthol tar bound politicians, scientists, corporations, affected communities, and activists together, as these stakeholders debated the potential effects of toxic substances. This gave rise to an issue-based "chemical public." Borrowing from such theoretical concepts as

“ontologically heterogeneous publics” and “agential realism,” I track the existing and emerging publics related to the disaster and the campaigns led by the *International Campaign for Justice in Bhopal* advocacy group.

[Ignoring Complexity: Epistemic Wagers and Knowledge Practices among Synthetic Biologists](#)

Talia Dan-Cohen

This paper links two domains of recent interest in science and technology studies, complexity and ignorance, in the context of knowledge practices observed among synthetic biologists. Synthetic biologists are recruiting concepts and methods from computer science and electrical engineering in order to design and construct novel organisms in the lab. Their field has taken shape amidst revised assessments of life’s complexity in the aftermath of the Human Genome Project. While this complexity is commonly taken to be an immanent property of biological systems, this article presents an epistemological view of complexity according to which complexity relates to a specific scientific theory or model and refers to that which exceeds the theory or model’s explanatory power. This epistemological view allows us to narrate a particular story about the changing relationship between biology and synthetic biology in the last decade and accounts for early knowledge practices in synthetic biology that “ignored” biology. This article further argues that while the failure of ignorance to produce clear-cut results for synthetic biologists has led practitioners back to biology, the entanglements between different pragmatic orientations and ways of knowing trouble the implications of this return for assessments of the complexity of biological systems.

[Variants of Epistemic Capitalism: Knowledge Production and the Accumulation of Worth in Commercial Biotechnology and the Academic Life Sciences](#)

Maximilian Fochler

Capitalist dynamics in knowledge production are not limited to situations in which economic interests influence researchers’ practices. Building on laboratory studies and the French “pragmatic” tradition in sociology, this article proposes an approach to tackle more pervasive capitalist logics at work in contemporary research and their consequences. It uses the term

epistemic capitalism to denote the accumulation of capital, as worth made durable, through the act of doing research, in and beyond academia. In doing so, it conceptualizes capitalism primarily not as a system of circulation and accumulation of monetary value but rather as a cultural way of producing, attributing, and accumulating specific forms of worth, which need not be monetary. Empirically, the article studies variants in epistemic capitalism by addressing the differing role of the accumulation of different forms of capital and the regimes connected to it in two institutional settings in Austria, academic life science laboratories and biotechnology start-up companies. Concluding, it argues that analytically dissociating the concept of capitalism from its link to economic value allows a finer-grained cultural analysis of the importance and effects of processes of accumulation in contemporary research. It ends with discussing the normative implications of these findings for debates about the commercialization of academia.

[Social Science & Medicine](#)

[Visualising uncertainty: Examining women's views on the role of Magnetic Resonance Imaging \(MRI\) in late pregnancy](#)

Kate Reed, Inna Kochetkova, and Elspeth Whitby

Prenatal screening occupies a prominent role within sociological debates on medical uncertainty. A particular issue concerns the limitations of routine screening which tends to be based on risk prediction. Computer assisted visual technologies such as Magnetic Resonance Imaging (MRI) are now starting to be applied to the prenatal realm to assist in the diagnosis of a range of fetal and maternal disorders (from problems with the fetal brain to the placenta). MRI is often perceived in popular and medical discourse as a technology of certainty and truth. However, little is known about the use of MRI as a tool to confirm or refute the diagnosis of a range of disorders in pregnancy. Drawing on qualitative research with pregnant women attending a fetal medicine clinic in the North of England this paper examines the potential role that MRI can play in mediating pregnancy uncertainty. The paper will argue that MRI can create and manage women's feelings of uncertainty during pregnancy. However, while MRI may not always provide women with unequivocal answers, the detailed information provided by MR images combined with the interpretation and communication skills of the radiologist in many ways enables women to navigate the issue. Our analysis of empirical data

therefore highlights the value of this novel technological application for women and their partners. It also seeks to stress the merit of taking a productive approach to the study of diagnostic uncertainty, an approach which recognises the concepts dual nature.

[Understanding HIV-related stigma in older age in rural Malawi](#)

Emily Freeman

The combination of HIV- and age-related stigma exacerbates prevalence of HIV infection and late diagnosis and initiation of anti-retroviral therapy among older populations. Interventions to address these stigmas must be grounded in understanding of situated systems of beliefs about illness and older age. This study analyses constructions of HIV and older age that underpinned the stigmatisation of older adults with HIV in rural Balaka, Malawi. It draws on data from a series of in-depth interviews (N = 135) with adults aged 50–90 (N = 43) in 2008–2010. Around 40% (n = 18) of the sample had HIV.

Dominant understandings of HIV in Balaka pertained to the sexual transmission of the virus and poor prognosis of those infected. They intersected with understandings of ageing. Narratives about older age and HIV in older age both centred on the importance of having bodily, moral and social power to perform broadly-defined “work”. Those who could not work were physically and socially excluded from the social world. This status, labelled as “child-like”, was feared by all participants.

In participants’ narratives, growing old involves a gradual decline in the power required to produce one’s membership of the social world through work. HIV infection in old age is understood to accelerate this decline. Understandings of the sexual transmission of HIV, in older age, imply the absence of moral power and in turn, loss of social power. The prognosis of those with HIV, in older age, reflects and causes amplified loss of bodily power. In generating dependency, this loss of bodily power infantilises older care recipients and jeopardises their family’s survival, resulting in further loss of social power. This age-and HIV-related loss of power to produce social membership through work is the discrediting attribute at the heart of the stigmatisation of older people with HIV.

[Agroecology and sustainable food systems: Participatory research to](#)

[improve food security among HIV-affected households in northern Malawi](#)

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This article shares results from a long-term participatory agroecological research project in northern Malawi. Drawing upon a political ecology of health conceptual framework, the paper explores whether and how participatory agroecological farming can improve food security and nutrition among HIV-affected households. In-depth interviews were conducted with 27 farmers in HIV-affected households in the area near Ekwendeni Trading Centre in northern Malawi. The results show that participatory agroecological farming has a strong potential to meet the food, dietary, labour and income needs of HIV-affected households, whilst helping them to manage natural resources sustainably. As well, the findings reveal that place-based politics, especially gendered power imbalances, are imperative for understanding the human impacts of the HIV/AIDS epidemic. Overall, the study adds valuable insights into the literature on the human-environment dimensions of health. It demonstrates that the onset of disease can radically transform the social relations governing access to and control over resources (e.g., land, labour, and capital), and that these altered social relations in turn affect sustainable disease management. The conclusion highlights how the promotion of sustainable agroecology could help to partly address the socio-ecological challenges associated with HIV/AIDS.

[Collaboration and entanglement: An actor-network theory analysis of team-based intraprofessional care for patients with advanced heart failure](#)

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Despite calls for more interprofessional and intraprofessional team-based approaches in healthcare, we lack sufficient understanding of how this happens in the context of patient care teams. This multi-perspective, team-based interview study examined how medical teams negotiated collaborative tensions. From 2011 to 2013, 50 patients across five sites in three Canadian provinces were interviewed about their care experiences and were asked to identify members of their health care teams. Patient-identified team members were subsequently interviewed to form 50 “Team Sampling Units” (TSUs), consisting of 209 interviews with patients, caregivers and healthcare providers. Results are gathered from a focused analysis of 13 TSUs where

intraprofessional collaborative tensions involved treating fluid overload, or edema, a common HF symptom. Drawing on actor-network theory (ANT), the analysis focused on intraprofessional collaboration between specialty care teams in cardiology and nephrology. The study found that despite a shared narrative of common purpose between cardiology teams and nephrology teams, fluid management tools and techniques formed sites of collaborative tension. In particular, care activities involved asynchronous clinical interpretations, geographically distributed specialist care, fragmented forms of communication, and uncertainty due to clinical complexity. Teams 'disentangled' fluid in order to focus on its physiological function and mobilisation. Teams also used distinct 'framings' of fluid management that created perceived collaborative tensions. This study advances *collaborative entanglement* as a conceptual framework for understanding, teaching, and potentially ameliorating some of the tensions that manifest during intraprofessional care for patients with complex, chronic disease.

[Truth and lies: Disclosure and the power of diagnosis](#)

Annemarie Jutel

The moment at which a diagnosis is delivered to a patient, particularly when it is serious, is an important social moment. It not only dictates the clinical pathway, it also rewrites the patient narrative, shifts their identity, predicts potential outcomes, and foregrounds mortality. It may provide a sense of relief, or one of despair. Over time, and across cultures, there have been many different approaches used to palliate the potential impact of the diagnostic utterance on the patient. France, as one example, provides an interesting case study. Until the turn of the century, cancer diagnoses were often concealed from patients. However, recent legislation now requires full diagnostic disclosure according to prescribed protocols. Using Zerubavel's social patterning methodology, and transcultural historical methods, I seek to understand beliefs about the potential impact of the diagnostic moment by identifying common features across cultural and historical social contexts. I examine writings of French oncologists, and physicians in related fields, from the pre- and post-legislation era who discuss if and how a cancer diagnosis should be disclosed to the patient. While the approach to diagnostic disclosure has changed significantly, medical representations of diagnostic power have not. The diagnostic utterance is still cast by medical professionals as a terrifying and life-disrupting moment.

["I have to constantly prove to myself, to people, that I fit the bill":
Perspectives on weight and shape control behaviors among low-income,
ethnically diverse young transgender women](#)

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The impact of societal femininity ideals on disordered eating behaviors in non-transgender women has been well described, but scant research has explored these processes among transgender women. The present study explored weight and shape control behaviors among low-income, ethnically diverse young transgender women at high risk for HIV or living with HIV in a Northeastern metropolitan area. Semi-structured in-depth interviews were conducted with 21 participants (ages 18–31 years; mean annual income