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In the Journals - December 2016, Part II

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By Anna Zogas

Here is the second part of our article roundup for December (find the first set of articles here). Happy reading, and happy new year!

New Genetics and Society

Redrawing the boundary of medical expertise: medically assisted reproduction and the debate on Italian bioconstitutionalism
Volha Parfenchyk

In 2004, the Italian Parliament passed a controversial law on medically assisted reproduction (Law 40/2004). The Law obliged clinicians to create a maximum of three embryos during one in vitro fertilization (IVF) cycle and transfer them simultaneously into the patient's uterus. With this "three embryo" standard, the Parliament sought to secure the realization of rights of IVF embryos. Drawing on the concepts of boundary-work and bioconstitutionalism, this article explores the role that the constitutional obligations of the Italian State towards its citizens, including IVF embryos as its new "citizen subjects," played in how it envisaged and demarcated the professional boundaries of medical expertise. It argues that the latter depended upon how it balanced its commitments to protect the rights of IVF embryos and those of adult citizens. As such, the demarcation of the jurisdictional boundaries of medical expertise, and the definition of constitutional rights, formed two sides of the same governing project.

Traveling questions: uncertainty and nonknowledge as vehicles of translation in genetic research participation
Klaus Hoeyer

In this paper, I argue that uncertainty and nonknowledge, and not just research results, can be important vehicles of translation through which genetic research participation comes to affect the lives of research participants. Based on interviews with participants in a genetic research project, I outline epistemic, emotional, relational and moral implications of research participation. Many of them resemble what the literature has described as the social implications of genetic counseling, but here they stem from interaction with knowledge-in-the-making or what I simply call nonknowledge. While policies aimed at stimulating translation from bench

to bedside tend to build on the assumption that research only works when knowledge translates into technological ability and creates utility, I suggest acknowledging that research has implications long before any clinical applications are at hand. Research questions, and not just results, may serve as a generative form of knowledge that can travel as fast as any answer.

Voluntary DNA-based information exchange and contact services following donor conception: an analysis of service users' needs
Marilyn Crawshaw, Lucy Frith, Olga van den Akker & Eric Blyth

Medical science has enabled the creation of families through the use of donor conception but some lifelong policy and practice implications are only recently being recognized. Research and practice have shown that donor conception can, for some, carry substantial long-term consequences. In this paper we present findings from a questionnaire-based study that sought to shed light on donor-conceived adults' and gamete donors' views on service and support needs when searching for genetic relatives with the aid of DNA testing. The findings demonstrate the complexity and sensitivity of providing services in this newly emerging area of need. Such provision requires collaboration between very different disciplines and agencies (scientific and psychosocial), introduces the potential for blurring of lines of accountability and responsibility, and highlights the challenges of identifying appropriate funding streams. In addition, the findings demonstrate the opportunities and limitations afforded by the use of DNA in identifying unknown genetic relatives.

In search of lost time: age and the promise of induced pluripotent stem cell models of the brain
Richard Milne

This paper explores the promise of induced pluripotent stem cells as a model system for the study of neurodegenerative diseases of Alzheimer's, Parkinson's and other diseases of the aging brain. Research in these areas, as in neuroscience more broadly, has struggled with the imperfect mapping between human and animal brains. The paper argues that the contemporary promise of induced pluripotent stem cells for research is established through their potential to resolve problems of translation, bridging laboratory and clinical contexts by acting as a model of "real" patient bodies. However, the paper shows how this promise is contested and renewed through a rearticulation of the relationship between neurodegeneration, aging and the qualities of "young" and "aged" bodies. This not only results in the introduction of new qualities and attributes to the model system, but also a re-imagining of how aging features within both late and early-onset neurological diseases.

[Social Science & Medicine](#)

[Social media as a space for support: Young adults' perspectives on producing and consuming user-generated content about diabetes and mental health](#) *(open access)*
Gillian Fergie, Kate Hunt, Shona Hilton

Social media offer opportunities to both produce and consume content related to health experiences. However, people's social media practices are likely to be influenced by a range of individual, social and environmental factors. The aim of this qualitative study was to explore how engagement with user-generated content can support people with long-term health conditions, and what limits users' adoption of these technologies in the everyday experience of their health condition. Forty semi-structured interviews were conducted with young adults, aged between 18 and 30 years, with experience of diabetes or a common mental health disorder (CMHD). We found that the online activities of these young adults were diverse; they ranged from regular production and consumption ('prosumption') of health-related user-generated content to no engagement with such content. Our analysis suggested three main types of users: 'prosumers'; 'tacit consumers' and 'non-engagers'. A key determinant of participants' engagement with resources related to diabetes and CMHDs in the online environment was their offline experiences of support. Barriers to young adults' participation in online interaction, and sharing of content related to their health experiences, included concerns about compromising their presentation of identity and adherence to conventions about what content is most appropriate for specific social media spaces. Based on our analysis, we suggest that social media do not provide an unproblematic environment for engagement with health content and the generation of supportive networks. Rather, producing and consuming user-generated content is an activity embedded within individuals' specific health experiences and is impacted by offline contexts, as well as their daily engagement with, and expectations, of different social media platforms.

[Social networks, social participation, and health among youth living in extreme poverty in rural Malawi](#)
Amelia Rock, Clare Barrington, Sara Abdoulayib, Maxton Tsoka, Peter Mvula, Sudhanshu Handa

Extensive research documents that social network characteristics affect health, but knowledge of peer networks of youth in Malawi and sub-Saharan Africa is limited. We examine the networks and social participation of youth living in extreme poverty in rural Malawi, using in-depth interviews with 32 youth and caregivers. We describe youth's peer networks and assess how gender and the context of extreme poverty

influence their networks and participation, and how their networks influence health. In-school youth had larger, more interactive, and more supportive networks than out-of-school youth, and girls described less social participation and more isolation than boys. Youth exchanged social support and influence within their networks that helped cope with poverty-induced stress and sadness, and encouraged protective sexual health practices. However, poverty hampered their involvement in school, religious schools, and community organizations, directly by denying them required material means, and indirectly by reducing time and emotional resources and creating shame and stigma. Poverty alleviation policy holds promise for improving youth's social wellbeing and mental and physical health by increasing their opportunities to form networks, receive social support, and experience positive influence.

[The Quality and Outcomes Framework: Body commodification in UK general practice](#)
Armando H. Norman, Andrew J. Russell, Claudia Merli

The UK's Quality and Outcomes Framework (QOF) is the largest pay-for-performance scheme in the world. This ethnographic study explored how QOF's monetary logic influences the approach to healthcare in UK general practice. From August 2013 to April 2014, we researched two UK general practice surgeries and one general practice training programme. These environments provided the opportunity for studying various spaces such as QOF meetings, consultation rooms, QOF recoding sessions, and the collection of computer-screen images depicting how patients' biomarkers are evaluated and costed through software systems. QOF as a biomedical technology has led to the commodification of patients and their bodies. This complex phenomenon breaks down into three main themes: commodification of patients, QOF as currency, and valuing commodities. Despite the ostensible aim of QOF being to improve healthcare in general practice, it is accompanied by a body commodification process. The interface between patients and care providers has been commodified, with QOF's pricing mechanism and fragmentation of care provision performing an important role in animating the UK economy.

[Everyday tactics in local moral worlds: E-cigarette practices in a working-class area of the UK](#) *(open access)*
Frances Thirlway

Research into e-cigarette use has largely focused on their health effects and efficacy for smoking cessation, with little attention given to their potential effect on health inequalities. Drawing on three years of ethnographic research between 2012 and 2015, I investigate the emerging e-cigarette practices of adult smokers and quitters in a working-class area

of the UK. I first use de Certeau's notion of 'tactics' to describe the informal economy of local e-cigarette use. Low-priced products were purchased through personal networks and informal sources for financial reasons, but also as a solution to the moral problems of addiction and expenditure on the self, particularly for older smokers. E-cigarette practices were produced in local moral worlds where smoking and cessation had a complex status mediated through norms of age and gender. For younger men, smoking cessation conflicted with an ethic of working-class hedonism but e-cigarette use allowed cessation to be incorporated into male sociality. Continued addiction had moral implications which older men addressed by constructing e-cigarette use as functional rather than pleasurable, drawing on a narrative of family responsibility. The low priority which older women with a relational sense of identity gave to their own health led to a lower tolerance for e-cigarette unreliability. I draw on Kleinman's local moral worlds to make sense of these findings, arguing that smoking cessation can be a risk to moral identity in violating local norms of age and gender performance. I conclude that e-cigarettes did have some potential to overcome normative barriers to smoking cessation and therefore to reduce health inequalities, at least in relation to male smoking. Further research which attends to local meanings of cessation in relation to age and gender will establish whether e-cigarettes have similar potential elsewhere.

[Realities of environmental toxicity and their ramifications for community engagement](#)
Justin T. Clapp, Jody A. Roberts, Britt Dahlberg, Lee Sullivan Berry, Lisa M. Jacobs, Edward A. Emmett, Frances K. Barg

Research on community responses to environmental toxicity has richly described the struggles of citizens to identify unrecognized toxins, collect their own environmental health facts, and use them to lobby authorities for recognition and remediation. Much of this literature is based on an empiricist premise: it is concerned with exploring differences in how laypeople and experts perceive what is presumed to be a singular toxic reality that preexists these varying perspectives. Here, we seek to reexamine this topic by shifting the focus from facts to facticity—that is, by exploring the many types of knowledge that communities develop about toxicity and how these knowledges articulate with the ideas of scientific and governmental authorities about what kinds of information are valid bases for policymaking. In making this shift, we are influenced by work in semiotic anthropology and science and technology studies (STS), which emphasizes that lived experience generates distinct realities rather than different perceptions of the same underlying state. Using this framework, we present an analysis of oral history interviews conducted in 2013–14 in the small American town of Ambler, Pennsylvania. Part of Ambler's legacy as a nineteenth- and twentieth-century center of asbestos

manufacture is that it is home to two massive asbestos-containing waste sites, one of which was being remediated by the Environmental Protection Agency (EPA) at the time of this study. Our interviews demonstrate that even asbestos, a toxin with a well-established public narrative, is a fundamentally different object for different members of the Ambler community. For many of these individuals, the epistemology and practices of the EPA are incongruent with or tangential to their toxicity-related experiences and their consequent concerns for the future. As such, our findings suggest caution in framing the community engagement efforts of environmental health agencies primarily as facilitations of citizen science; this approach does not acknowledge the multiplicity of toxic realities.

[Suffering and medicalization at the end of life: The case of physician-assisted dying](#) *(open access)*
Hadi Karsoho, Jennifer R. Fishman, David Kenneth Wright, Mary Ellen Macdonald

'Suffering' is a central discursive trope for the right-to-die movement. In this article, we ask how proponents of physician-assisted dying (PAD) articulate suffering with the role of medicine at the end of life within the context of a decriminalization and legalization debate. We draw upon empirical data from our study of Carter v. Canada, the landmark court case that decriminalized PAD in Canada in 2015. We conducted in-depth interviews with 42 key participants of the case and collected over 4000 pages of legal documents generated by the case. In our analysis of the data, we show the different ways proponents construct relationships between suffering, mainstream curative medicine, palliative care, and assisted dying. Proponents see curative medicine as complicit in the production of suffering at the end of life; they lament a cultural context wherein life-prolongation is the moral imperative of physicians who are paternalistic and death-denying. Proponents further limit palliative care's ability to alleviate suffering at the end of life and even go so far as to claim that in some instances, palliative care produces suffering. Proponents' articulation of suffering with both mainstream medicine and palliative care might suggest an outright rejection of a place for medicine at the end of life. We further find, however, that proponents insist on the involvement of physicians in assisted dying. Proponents emphasize how a request for PAD can set in motion an interactive therapeutic process that alleviates suffering at the end of life. We argue that the proponents' articulation of suffering with the role of medicine at the end of life should be understood as a discourse through which one configuration of end-of-life care comes to be accepted and another rejected, a discourse that ultimately does not challenge, but makes productive use of the larger framework of the medicalization of dying.

[How food insecurity contributes to poor HIV health outcomes: Qualitative](#)

[evidence from the San Francisco Bay Area](#)
Henry J. Whittle, Kartika Palar, Hilary K. Seligman, Tessa Napoles, Edward A. Frongillo, Sheri D. Weiser

Rationale: Food-insecure people living with HIV/AIDS (PLHIV) consistently exhibit worse clinical outcomes than their food-secure counterparts. This relationship is mediated in part through non-adherence to antiretroviral therapy (ART), sub-optimal engagement in HIV care, and poor mental health. An in-depth understanding of how these pathways operate in resource-rich settings, however, remains elusive.

Objective: We aimed to understand the relationship between food insecurity and HIV health among low-income individuals in the San Francisco Bay Area using qualitative methods.

Methods: Semi-structured in-depth interviews were conducted with 34 low-income PLHIV receiving food assistance from a non-profit organization. Interviews explored experiences with food insecurity and its perceived effects on HIV-related health, mental health, and health behaviors including taking ART and attending clinics. Thematic content analysis of transcripts followed an integrative inductive-deductive approach.

Results: Food insecurity was reported to contribute to poor ART adherence and missing scheduled clinic visits through various mechanisms, including exacerbated ART side effects in the absence of food, physical feelings of hunger and fatigue, and HIV stigma at public free-meal sites. Food insecurity led to depressive symptoms among participants by producing physical feelings of hunger, aggravating pre-existing struggles with depression, and nurturing a chronic self-perception of social failure. Participants further explained how food insecurity, depression, and ART non-adherence could reinforce each other in complex interactions.

Conclusion: Our study demonstrates how food insecurity detrimentally shapes HIV health behavior and outcomes through complex and interacting mechanisms, acting via multiple socio-ecological levels of influence in this setting. The findings emphasize the need for broad, multisectoral approaches to tackling food insecurity among urban poor PLHIV in the United States.

[Culture: The missing link in health research](#)
M. Kagawa Singer, W. Dressler, S. George, The NIH Expert Panel

Culture is essential for humans to exist. Yet surprisingly little attention has been paid to identifying how culture works or developing standards to

guide the application of this concept in health research. This paper describes a multidisciplinary effort to find consensus on essential elements of a definition of culture to guide researchers in studying how cultural processes influence health and health behaviors. We first highlight the lack of progress made in the health sciences to explain differences between population groups, and then identify 10 key barriers in research impeding progress in more effectively and rapidly realizing equity in health outcomes. Second, we highlight the primarily mono-cultural lens through which health behavior is currently conceptualized, third, we present a consensus definition of culture as an integrating framework, and last, we provide guidelines to more effectively operationalize the concept of culture for health research. We hope this effort will be useful to researchers, reviewers, and funders alike.

First depressed, then discriminated against?
Stijn Baert, Sarah De Visschere, Koen Schoors, Désirée Vandenberghe, Eddy Omey

Each year a substantial share of the European population suffers from major depression. This mental illness may affect individuals' later life outcomes indirectly by the stigma it inflicts. The present study assesses hiring discrimination based on disclosed depression. To this end, between May 2015 and July 2015, we sent out 288 trios of job applications from fictitious candidates to real vacancies in Belgium. Within each trio, one candidate claimed to have become unemployed only recently, whereas the other two candidates revealed former depression or no reason at all for their unemployment during a full year. Disclosing a year of inactivity due to former depression decreases the probability of getting a job interview invitation by about 34% when compared with candidates who just became unemployed, but the stigma effect of a year of depression is not significantly higher than the stigma effect of a year of unexplained unemployment. In addition, we found that these stigmas of depression and unemployment were driven by our male trios of fictitious candidates. As a consequence, our results are in favour of further research on gender heterogeneity in the stigma of depression and other health impairments.

Standardizing psycho-medical torture during the War on Terror: Why it happened, how it happened, and why it didn't work
Myles Balfe

After 9/11/2001 the United States launched a global War on Terror. As part of this War, terrorism suspects were detained by the U.S. military and by the C.I.A. It is now widely recognized that the United States tortured a number of these detainees in the context of its 'enhanced interrogation' programme. This article examines how and why U.S. organizations developed standards that allowed healthcare professionals to become

involved in torture; why the standards developed by U.S. security institutions failed to control the actions of enhanced interrogation personnel on the ground; and what the role of standards were in stopping the enhanced interrogation initiative. The article concludes by discussing the general lessons that the enhanced interrogation programme has for social science research on standards, namely that individuals can experience ambivalence when caught between competing organizational and professional standards and that it might be inherently difficult to successfully enact certain protocols when these relate to deviant or destructive acts.

[Increased drug use and the timing of social assistance receipt among people who use illicit drugs](#)
Emanuel Krebs, Linwei Wang, Michelle Olding, Kora DeBeck, Kanna Hayashi, M.-J. Milloy, Evan Wood, Bohdan Nosyk, Lindsey Richardson

Background: The monthly disbursement of social assistance (SA) payments to people who use illicit drugs (PWUD) has been temporally associated with increases in drug-related harm. Yet, whether SA receipt changes drug use intensity compared to levels of use at other times in the month has not been established. We therefore examined this relationship among PWUD in Vancouver, Canada (2005–2013).

Methods: Data were derived from prospective cohorts of HIV-positive and HIV-negative PWUD. Every six months, participants were asked about their illicit drug use during the last 180 days and the past week. We determined whether SA receipt occurred within the assessment's one-week recall period. We employed generalized estimating equations controlling for confounders to examine the relationship between SA receipt and the change in drug use intensity, defined as a 100% increase in the average times per day a given drug was used in the last week compared to the previous 6 months. We tested the robustness of this relationship by stratifying analyses by whether individuals primarily used stimulants, illicit opioids or engaged in polydrug use and examining the timing of SA receipt relative to date of assessment.

Results: Our study included 2661 individuals (median age 36, 32% female) with 1415 (53.2%) reporting SA receipt occurring within the one-week recall period of the assessment at least once. SA receipt was independently associated with intensified drug use (Adjusted Odds Ratio [AOR]: 1.79; 95% Confidence Interval [CI]: 1.53, 2.09), and remained significant when stratified by primary use of stimulants (AOR: 1.87; 95% CI: 1.54, 2.26), opioids (AOR: 1.96; 95% CI: 1.23, 3.13) and polydrug use (AOR: 1.53; 95% CI: 1.11, 2.10).

Conclusion: We found a temporal association between SA receipt and

drug use intensification. While the health and social benefits of SA are significant, these findings suggest that alternative disbursement strategies, such as staggered or smaller and more frequent SA payments may be able to mitigate drug-related harm. Alternatives should be tested rigorously.

Social Studies of Science

A home for science: The life and times of Tropical and Polar field stations
(open access)
P Wenzel Geissler, Ann H Kelly

A 'halfway house' between the generic, purified space of the laboratory and the varied and particular spaces of the field, the field station is a controlled yet uncontained setting from which nature can be accessed and anchored. As living quarters for visiting scientists, field stations are also enmeshed in the routine and rhythms of everyday domestic life, and in longer cycles of habitation, wear, and repair. This introduction considers the empirical and conceptual significance of Polar and Tropical field stations as homes for scientific work and scientific lives. The field station's extra-territorial yet intimate character affects the credibility and circulation of knowledge along science's frontiers. The challenge of making a home in the (non-temperate) field and the mundane experiences of expatriation and appropriation establish particular political dynamics of knowledge-making in these locations. They bring into focus the imaginaries of nature and science that drive transnational research and put into relief the aesthetic and affective dimensions of work and life in these distant homes for science. All these themes are pursued and amplified in a different medium by the artists who contributed to our research and are also featured in this special issue.

Habituating field scientists *(open access)*
Lys Alcayna-Stevens

This article explores the sensory dimensions of scientific field research in the only region in the world where free-ranging bonobos (Pan paniscus) can be studied in their natural environment; the equatorial rainforest of the Democratic Republic of Congo. If, as sensory anthropologists have argued, the senses are developed, grown and honed in a given cultural and environmental milieu, how is it that field scientists come to dwell among familiarity in a world which is, at first, unfamiliar? This article builds upon previous anthropological and philosophical engagements with habituation that have critically examined primatologists' attempts to become 'neutral objects in the environment' in order to habituate wild apes to their presence. It does so by tracing the somatic modes of attention developed by European and North American researchers as they

follow bonobos in these forests. The argument is that as environments, beings and their elements become familiar, they do not become 'neutral', but rather, suffused with meaning.

Field station as stage: Re-enacting scientific work and life in Amani, Tanzania *(open access)*
P Wenzel Geissler, Ann H Kelly

Located high in Tanzania's Usambara Mountains, Amani Hill Station has been a site of progressive scientific endeavours for over a century, pushing the boundaries of botanical, zoological and medical knowledge, and providing expertise for imperial expansion, colonial welfare, national progress and international development efforts. The station's heyday was from the 1950s to the 1970s, a period of global disease eradication campaigns and the 'Africanization' of science. Today, Amani lies in a state of suspended motion. Officially part of a national network of medical research stations, its buildings and vegetation are only minimally maintained, and although some staff report for duty, scientific work has ceased. Neither ruin nor time capsule, Amani has become a quiet site of remains and material traces. This article examines the methodological potentials of re-enactment – on-site performances of past research practices – to engage ethnographically with the distinct temporalities and affective registers of life at the station. The heuristic power of re-enactment resides in its anachronicity, the tensions it introduces between immediacy and theatricality, authenticity and artifice, fidelity and futility. We suggest that re-enacting early post-colonial science as events unfolding in the present disrupts straightforward narratives about the promises and shortfalls of scientific progress, raising provocative questions about the sentiments and stakes of research in 'the tropics'.

The hospital and the hospital: Infrastructure, human tissue, labour and the scientific production of relational value *(open access)*
Alice Street

How does science make a home for itself in a public hospital? This article explores how scientists working in 'resource poor' contexts of global health negotiate relationships with their hosts, in this case the doctors, nurses and patients who already inhabit a provincial-level hospital. Taking its lead from recent works on science, ethics and development, this article seeks to 'provincialize the laboratory' by focussing on the scientific tropics as a space of productive encounter and engagement. A view from the hospital reveals the tenuous process of 'setting up' a place for science, in a world that does not immediately recognize its value. The article examines the material exchanges of infrastructure, bodily tissues and labour that enable one young scientist to establish a scientific life for himself. The success of those transactions, it argues, ultimately derives

from their objectification of scientific vulnerability and their enactment of relationships of mutual recognition. As opposed to asking how scientific knowledge is produced in the tropics, the view from the hospital challenges us to focus on the establishment of relationships between scientists and their hosts as a productive endeavour in its own right.

[Science, ethnography, art](#) *(open access)*

Excerpt from the introduction by P Wenzel Geissler and Ann H Kelly: The conference 'A Home for Science' from which this special issue originated, and the larger project of which the conference was part, sought to combine anthropological and historical studies of science, and contemporary artists' engagements with scientific practice, to jointly interrogate scientific work in marginal places (Geissler et al., 2016). Collaborations between ethnography and conceptual art have evolved in recent decades, drawing on older convergences between anthropology and art practice (Gell, 1998). Conceptual artists entered into broadly ethnographic terrains and found inspiration in ethnographic methods, while social and cultural anthropologists and archaeologists pursued experimental methods beyond social scientific realism, gesturing towards or learning from conceptual art – variously contriving social situations and observing their unfolding, studying the social by way of material objects and forms, or emphasizing performative and playful dimensions of fieldwork, seeking poesis and surprise rather than 'data' (Marcus, 2010; Pearson, 2004; Schneider and Wright, 2013; Ssorin-Chaikov, 2013) … What follows are samples of the art presented at the 'A Home for Science' conference, along with excerpts from the statements that artists made about their work.

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