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## In the Journals - June 2017, part two

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By Aaron Seaman

The first part of the In the Journals post for June 2017 can be found [here](#).  
And now, for part two...

### [Medical Humanities](#)

SPECIAL ISSUE: Communicating Mental Health

[Introduction: historical contexts to communicating mental health](#)

*Rebecca Wynter and Leonard Smith*

Contemporary discussions around language, stigma and care in mental health, the messages these elements transmit, and the means through which they have been conveyed, have a long and deep lineage. Recognition and exploration of this lineage can inform how we communicate about mental health going forward, as reflected by the 9 papers which make up this special issue. Our introduction provides some framework for the history of communicating mental health over the past 300 years. We will show that there have been diverse ways and means of describing, disseminating and discussing mental health, in relation both to therapeutic practices and between practitioners, patients and the public. Communicating about mental health, we argue, has been informed by the desire for positive change, as much as by developments in reporting, legislation and technology. However, while the modes of communication have developed, the issues involved remain essentially the same. Most practitioners have sought to understand and to innovate, though not always with positive results. Some lost sight of patients as people; patients have felt and have been ignored or silenced by doctors and carers. Money has always talked, for without adequate investment services and care have suffered, contributing to the stigma surrounding mental illness. While it is certainly 'time to talk' to improve experiences, it is also time to change the language that underpins cultural attitudes towards mental illness, time to listen to

people with mental health issues and, crucially, time to hear.

[The presentation of mental disturbance in modern Scottish literature](#) (open access)

*Allan Beveridge*

The subject of madness features throughout world literature, but the literature of modern Scotland appears to be especially preoccupied with it. This paper gives a brief overview of the ways in which madness is represented in modern Scottish literature and the different artistic functions it performs. It will consider the subject on a thematic basis. First, there are accounts by writers who have experienced mental turmoil themselves. Second, there is the theme of the 'Narrative of personal crisis' which depicts in fictional form an individual's journey through madness. Third, there is the theme of the 'Gothic or divided selves'. The fourth theme is that of the 'Female voice' and the last is that of 'Outsiders and holy fools', whose existence is to unsettle the beliefs of a wider society.

['Trapped in the labyrinth': exploring mental illness through devised theatrical performance](#)

*Paul Patterson and Persephone Sextou*

Mental health difficulties remain a major source of burden and distress for individuals, families, health and social care providers with stigma a key target for educational campaigns attempting to improve care pathways and access to support. Stigma is a multifaceted concept having a range of drivers including shame and is thought to act as a barrier to successful help seeking and engagement with support services. The current paper explores some of the salient themes that emerged from a British university drama project on the impact of symptoms and behaviours associated with a severe mental health condition on a young couple's relationship and reflects on the opportunities for connection with an audience provided by the medium and experience. It is suggested that enabling the impact of mental ill health to be explored in a protected environment such as theatre can allow for reflection and empathy to develop, with potential for positive impact on awareness understanding and stigma. Elements of the drama setting and narrative are explored, and analogies are made with the emerging literature on post-traumatic growth.

[Heritage and Stigma. Co-producing and communicating the histories of mental health and learning disability](#) (open access)

*Rob Ellis*

University engagement with mental health services has traditionally been informed by the vocational and pedagogical links between the two sectors. However, a growth in the interest in public history and in the history of mental healthcare has offered new opportunities for those in the humanities to engage new audiences and to challenge perceptions about care in the past. The introduction of the 'impact agenda' and related funding streams has further encouraged academics to contribute to historical debates, and to those concerning current services. One such example of this is the Arts and Humanities Research Council funded Heritage and Stigma project at the University of Huddersfield, which was conceived to support mental health and learning disability charities in the exploration and dissemination of their own histories. Using this project as a case study, this paper will draw on primary source material to reflect on the opportunities and challenges of working in partnership with such groups. In particular, it will consider the need to address issues of stigma and exclusion in tandem with a critical understanding of the moves to 'community care' instigated by landmark legislation in the form of the 1959 Mental Health Act. Overall, it provides evidence of an inclusive, coproductive model of design and highlights the positive contribution to communicating mental health made by those based in the humanities.

['She sits all day in the attitude depicted in the photo': photography and the psychiatric patient in the late nineteenth century](#)

*Katherine D.B. Rawling*

The links between mental state and art in all its various forms and media have long been of interest to historians, critics, artists, patients and doctors. Photographs of patients constitute an extensive but largely unexplored archive that can be used to recover patient experience in the late nineteenth and early twentieth century. The camera and the photograph became tools to communicate information about mental ill health between doctors, their patients and their colleagues. They were published in textbooks and journals, exhibited, exchanged and pasted into medical case books alongside case notes. But they were also used

by patients to communicate their own experiences, identity and sense of self. This article uses published and case book photographs from c. 1885–1910 to examine the networks of communication between different stakeholders and discourses.

[A crisis of meaning: can 'schizophrenia' survive in the 21st century?](#)

*Jerry Tew*

Both within clinical and wider societal discourses, the term 'schizophrenia' has achieved considerable potency as a signifier, privileging particular conceptual frames for understanding and responding to mental distress. However, its status has been subject to instability, as it has lacked indisputable biological correlates that would anchor its place within the canon of medical diagnosis. Informed by a semiotic perspective, this paper focuses on its recent history: how 'schizophrenia' has been claimed, appropriated and contested—and how this connects with its earlier history of signification. It also explores how the dominance of this signifier has influenced the ways in which people with the diagnosis may find themselves constructed in their interactions with professionals, family and wider society, and hence how they may come to see themselves. It is argued that, from a point in the 1990s when 'schizophrenia' had achieved an almost iconic status, the term is now subject to greater instability, with concerns and challenges being raised from both within and outside psychiatry. On the one hand, this uncertainty has triggered a 'calls to arms' from those within the psychiatric establishment who see diagnoses such as 'schizophrenia' as crucial to their professional identity and status. On the other hand, this has created spaces for new conversations and alliances between elements within neurology, psychiatry, social work and other professions, and between these and service users. Some of these conversations are casting doubt on the validity and utility of 'schizophrenia' as a construct, and are beginning to posit alternative regimes of signification.

[If psychosis were cancer: a speculative comparison](#) (open access)

*Michael Larkin, Zoë Boden, and Elizabeth Newton*

Recently, health policy in the UK has begun to engage with the concept of 'parity of esteem' between physical and mental healthcare. This has led one recent initiative to improve service

provision for first episode psychosis, which aims to bring it into line with some of the principles underpinning good practice in cancer care. In this paper, we consider some of the metaphorical consequences of likening psychosis to cancer. While we find the comparison unhelpful for clinical purposes, we argue that it can be a helpful lens through which to examine service provision for psychosis in young people. Through this lens, specialist community-based services would appear to compare reasonably well. Inpatient care for young people with psychosis, on the other hand, suffers very badly by comparison with inpatient facilities for teenage cancer care. We note some of the many positive features of inpatient cancer care for young adults, and—drawing upon previous research on inpatient psychiatric care—observe that many of these are usually absent from mental health facilities. We conclude that this metaphor may be a helpful rhetorical device for communicating the lack of ‘parity of esteem’ between mental and physical healthcare. This inequity must be made visible in health policy, in commissioning, and in service provision.

[Listen and learn: engaging young people, their families and schools in early intervention research](#) (open access)

*Charlotte Connor on behalf of Collaboration for Leadership in Applied Health Research and Care West Midlands (CLAHRC-WM) Youth Mental Health*

Recent policy guidelines highlight the importance of increasing the identification of young people at risk of developing mental health problems in order to prevent their transition to long-term problems, avoid crisis and remove the need for care through specialist mental health services or hospitalisation. Early awareness of the often insidious behavioural and cognitive changes associated with deteriorating mental well-being, however, is difficult, but it is vital if young people, their families and those who work with them are to be fully equipped with the skills to aid early help-seeking. Our early intervention research continues to highlight the necessity of engaging with and listening to the voices of young people, families and those who work with children and young people, in developing greater understanding of why some young people may be more at risk in terms of their mental health, and to provide children and young people with the best mental health support we can. Collaborative working with young people, their families and those who work with them has been an essential dimension of our youth mental health research in Birmingham, UK, enabling us to listen to the personal narratives of those with lived experience and to work

alongside them. This paper highlights some of our key studies and how we have endeavoured to make intra-agency working successful at each stage of the research process through increasing use of digital and youth-informed resources to engage young people: a methodology which continues to inform, guide and develop our early intervention research and implementation.

### [Identity, law, policy and Communicating Mental Health](#)

*Peter Bartlett*

This paper reflects on the special edition, *Communicating Mental Health*, from the perspective of a legal academic with an interest in the service user rights and in United Nations Convention on the Rights of Persons with Disabilities. It is argued that the special edition demonstrates the breadth of the medical model but also that the medical model remains firmly in place in academic understanding of mental disability. The paper questions what this means for identity formation of people with lived experience of mental disability and how we should conceptualise mental disability in the future.

### [New Genetics and Society](#)

#### [The politics of biomedical platforms: controversy around the molecularization of cytogenetics in prenatal diagnosis](#)

*Mauro Turrini*

The introduction of a new technique based on molecular cytogenetics (the comparative genomic hybridization microarray, Chromosomal Micro-Array) in prenatal diagnosis is here used as an occasion to politically elaborate Cambrosio's and Keating's framework of "biomedical platform." The uncertainty generated by molecularization leaves the field open for two different modalities of implementation: using targeted microarrays to completely replace traditional karyotyping versus using genome-wide analysis of chromosomal anomalies only in at-risk pregnancies. Retracing the global scientific controversy on this issue and, particularly, the heated debate that has taken place in Italy, the paper intends to analyze the rise of a biomedical platform in prenatal diagnosis as a multi-layered phenomenon. Diverging epistemological strategies to

deal with uncertainty, professional interests, relationship between medical practice, innovation and research, and patient subjectivities interact with each other, by shedding light on the inherent political dimension in the epistemological and material of an emerging biomedical platform.

[“Participating means accepting”: debating and contesting synthetic biology](#)

*Morgan Meyer*

This article analyses opposition to public debates. In doing so, the article builds upon the tradition of analyzing controversies by symmetrically describing the advocates and the opponents of public debates. First, the public debates on synthetic biology will be placed in their wider political and institutional context. The call for a “serene” debate by the French public authorities will be retraced and its genealogy vis-à-vis previous controversies (i.e. on genetically modified organisms (GMOs) and nanotechnology) will be elucidated. The article then describes how the group *Pièces et main d’œuvre* (PMO) obstructed a public debate on synthetic biology, an obstruction that will be analyzed by mobilizing and extending the notion of divisible versus indivisible conflicts. But the article will also move beyond the symmetrical analysis of a controversy by discussing one of the criticisms raised by PMO, that some researchers are “sociologists of acceptability.” The notions of divisibility, indivisibility and what I call “inversibility” will be used to reflect upon the positionality of social scientists and to offer a constructive view for a sociology of acceptability.

[Pride and concern: differences between sperm and egg donors with respect to responsibility for their donor-conceived offspring](#)

*Margaret K. Nelson and Rosanna Hertz*

Comparative research on sperm donors and egg donors in the United States suggests that while men view themselves as fathers of their offspring, women do not view themselves as mothers. Comparative research suggests as well that men and women are equally interested in contact with offspring, equally curious about them, and equally likely to hold themselves responsible for those offspring. This paper re-examines these differences and similarities using data from a survey of donors who registered on a third-party website with hopes of having some contact with their genetic

offspring. Our findings suggest that women and men offer similar reasons for donating and similar assessments of the experience. Yet, the two groups have developed quite different patterns of interest in their offspring. The men create a sense of “prideful lineage” rather than fatherhood. The women create a pattern of feeling that involves “concerned responsibility” rather than motherhood.

### [Spitting images: remaking saliva as a promissory substance](#)

*Mette Kragh-Furbo and Richard Tutton*

Of the bodily substances in which STS scholars, anthropologists, sociologists, and medical historians have been interested, saliva has arguably been overlooked. Yet, in the past 20 years, saliva has become important to the development of consumer genetic tests. Historically, expectoration has been associated with the spread of disease and social indecency, but when the personal genomics company 23andMe began hosting spit parties in 2007, the act of spitting was transformed into an act of self-empowerment through which the individual gained new health information and saliva turned into a new biological source for measuring health and illness. Attending to saliva’s social meanings over time, and by analyzing 23andMe “unboxing” YouTube videos, we argue that saliva has become a promissory substance whose place is no longer reserved only for the inner spaces of the body, but circulates outside the body, forming an important part of the contemporary bioeconomy.

### [Science as Culture](#)

#### [Problematisations of Complexity: On the Notion and Production of Diverse Complexities in Healthcare Interventions and Evaluations](#) (open access)

*Tineke Broer, Roland Bal, and Martyn Pickersgill*

Within the literature on the evaluation of health (policy) interventions, complexity is a much-debated issue. In particular, many claim that so-called ‘complex interventions’ pose different challenges to evaluation studies than apparently ‘simple interventions’ do. Distinct ways of doing evaluation entail particular ontologies and epistemologies of complexity. They differ

in terms of whether they define complexity as a quantitative trait of interventions, whether they see evaluation as part of or outside the intervention, and whether complexity can be regarded as an emergent property of the intervention and its evaluation. In practice, evaluators and commissioners of large health care improvement programmes rely on different, sometimes contradictory, repertoires about what it means to conduct a 'good' evaluation. This is an ongoing matter negotiated between and among commissioners, researchers, and—sometimes—programme managers. In particular, notions of evaluability, usefulness and distance/independence are problematised in different ways and with diverse consequences, which, in turn, produce other notions and layers of complexity such as temporal, institutional and affective complexities. When (social science) researchers claim that one method or another is better able to grasp complexity, they elide the issue that any methodological choice emphasises some complexities and lets others fade into the background. Analysing the practicalities and emotions involved in evaluation studies opens up the notion of complexity to analytical scrutiny, and suggests a basis for co-theorising between biomedical, public health and social scientists (including Science and Technology Studies scholars).

### [Contesting a Pandemic: The WHO and the Council of Europe](#)

*Sudeepa Abeysinghe*

Contemporary risks are often understood as fundamentally uncertain. This uncertain status can be mobilized within political debates surrounding risks. Such a challenge serves to destabilize scientific claims. The World Health Organization's (WHO) management of the 2009/10 spread of the H1N1 virus became a site of one such contestation. Debate within the Council of Europe particularly served to criticize the action of the WHO. This resulted in a definitional and policy contestation between the two institutions. The WHO accounted for its actions through allusions to (seemingly stable) scientific facts, using epidemiological evidence of influenza and its management based on normal science. In contrast, in criticizing public expenditure and panic, the Council of Europe critics problematized the stability of the science employed by the WHO. This included fundamental aspects of scientific knowledge such as the measurability of morbidity and mortality caused by H1N1 and the effect of vaccination against influenza viruses. This criticism relied upon the ability to destabilize the WHO's scientific knowledge, a process made possible through

understandings of the uncertain nature of the science of risk (post-normal science). The case study illustrates that potential for previous-established and seemingly stable scientific facts to become destabilized and problematized during contestations of risk management.

[The Genealogy of “Empirical Post-structuralist” STS, Retold in Two Conjunctures: The Legacy of Hegel and Althusser](#)

*Johan Söderberg*

Recent discussions in science and technology studies (STS) about the risks of science and technology have led to political economy occupying centre stage. Closely related to political economy as a field of investigation are a number of overarching concepts, such as class, capitalism and interest. However, reliance on such concepts is rejected in post-Actor Network Theory STS. This stand-off over overarching categories can be traced back to two conjunctures in the genealogy of STS. First, the influence of Hegel and his concept of “totality”; and second, the influence from anti-hegelian French epistemology with its celebration of the opposite concept, that of “multiplicity”.

[Autistic Heterogeneity: Linking Uncertainties and Indeterminacies](#) (*open access*)

*Gregory Hollin*

Autism is a highly uncertain entity and little is said about it with any degree of certainty. Scientists must, and do, work through these uncertainties in the course of their work. Scientists explain uncertainty in autism research through discussion of *epistemological uncertainties* which suggest that diverse methods and techniques make results hard to reconcile, *ontological uncertainties* which suggest doubt over taxonomic coherence, but also through reference to autism’s *indeterminacy* which suggests that the condition is inherently heterogeneous. Indeed, indeterminacy takes two forms—an inter-personal form which suggests that there are fundamental differences between individuals with autism and an intra-personal form which suggests that no one factor is able to explain all features of autism within a given individual. What is apparent in the case of autism is that scientists put uncertainty and indeterminacy into discussion with one another and, rather than a well-policed epistemic-ontic

boundary, there is a movement between, and an entwinement of, the two. Understanding scientists' dialogue concerning uncertainty and indeterminacy is of importance for understanding autism and autistic heterogeneity but also for understanding uncertainty and 'uncertainty work' within science more generally.

### [From Standardization to Adaptation: Clinical Trials and the Moral Economy of Anticipation](#)

Catherine M. Montgomery

Hailed as the gold standard, the randomized controlled trial (RCT) occupies a hegemonic position at the top of evidence-based medicine's hierarchy of knowledge. It is testament to the methodology's capacity for standardization that it can so readily be spoken of in the singular: the RCT. Under what conditions, then, is it possible to speak of change in the gold standard? Since the 1950s, alternative versions of the RCT have been advocated for under the banner of 'adaptive design'. Adaptive designs allow investigators to make pre-planned changes to a trial on the basis of accruing information while the experiment is ongoing. Initially a niche topic of methodological debate among biostatisticians, the approach is becoming widespread in mainstream drug development. A genealogical analysis exposes the discursive moves used to justify and popularize adaptation, from a focus on patient well-being and the greater good in the 1960s and 1970s, to efficiency and virtualism in the 1990s and 2000s. Changing discourses of time and patienthood have facilitated a move away from standardization as the singular logic of trials towards an appreciation of flexibility, undergirded by probabilistic methodologies. Adams *et al.*'s [(2009). Anticipation: Technoscience, life, affect, temporality, *Subjectivity*, 28, pp. 246–265] conceptual framework of anticipation illuminates this evolving moral economy of medical research, in which modes of knowledge production which claim to know the future are supplanting the traditional certainties of fixed and standardized experimental designs. Predictable uncertainty is the currency of this emerging economy, which capitalizes on computer simulation and ever more sophisticated tools of prediction to leverage credibility.

### [Social Science and Medicine](#)

["I started working because I was hungry": The consequences of food insecurity for children's well-being in rural Ethiopia](#)

*Virginia Morrow, Yisak Tafere, Nardos Chuta, and Ina Zharkevich*

Food insecurity, the state of being without reliable access to a sufficient quantity of safe, nutritious food, is a persistent problem in rural Ethiopia. However, little qualitative research has explored how food insecurity affects children over time, from their point of view. What are the effects of economic 'shocks' such as illness, death, loss of livestock, drought and inflation on availability of food, and children's well-being? To what extent do social protection schemes (in this case, the Productive Safety Net Programme) mitigate the long-term effects of food insecurity for children? The paper uses a life-course approach, drawing on analysis of four rounds of qualitative longitudinal research conducted in 2007, 2008, 2011 and 2014, with eight case study children, as part of Young Lives, an ongoing cohort study. Children's descriptions of the importance of food and a varied diet (dietary diversity) in everyday life were expressed in a range of qualitative methods, including interviews, group discussions and creative methods. The paper suggests that while the overall picture of food security in Ethiopia has improved in the past decade, for the poorest rural families, food insecurity remains a major factor influencing decisions about a range of matters – children's time allocation, whether to continue in school, whether to migrate for work, and whether they marry. The paper argues that experiences of food insecurity need to be understood holistically, in relation to other aspects of children's lives, at differing stages of the life-course during childhood. The paper concludes that nutritional support beyond early childhood needs to be a focus of policy and programming.

[Performing boundary work: The emergence of a new practice in a hybrid operating room](#)

*Kajsa Lindberg, Lars Walter, and Elena Raviola*

This paper addresses the processes of boundary work, in relation to the introduction of new technology, unfolding during the emergence of new medical practices. Inspired by Gieryn's fluid and practical view of boundaries and boundary work, and by Actor-Network Theory's description of scripting processes, we study the processes of negotiating and (re-)constructing boundaries in order to reveal both the interactions between

different kinds of boundary work and their situatedness in the context of the emerging practice. We conducted a longitudinal and qualitative study of a generic Hybrid Operating Room at a Swedish university hospital, where sophisticated imaging devices are combined with open surgery procedures in a single room; consequently, medical requirements regarding radiology, surgery and anesthesia, as well as the specificities of the new technology, all need to be met at the same time. The study shows how the visibility of boundaries is a result of as well as a condition for boundary work, how boundary work is a dynamic and iterative process, and how it unfolds in a recursive relationship between practice and boundaries.

[Health policy in the concertación era \(1990–2010\): Reforms the chilean way](#)

*María Soledad Martínez-Gutiérrez, and Cristóbal Cuadrado*

The Chilean health system has experienced important transformations in the last decades with a neoliberal turn to privatization of the health insurance and healthcare market since the Pinochet reforms of the 1980s. During 20 years of center-left political coalition governments several reforms were attempted to regulate and reform such markets. This paper analyzes regulatory policies for the private health insurance and health care delivery market, adopted during the 1990–2010 period. A framework of variation in market types developed by Gingrich is adopted as analytical perspective. The set of policies advanced in this period could be expected to shift the responsibility of access to care from individuals to the collective and give control to the State or the consumers *vis a vis* producers. Nevertheless, the effect of the implemented reforms has been mixed. Regulations on private health insurers were ineffective in terms of shifting power to the consumer or the state. In contrast, the healthcare delivery market showed a trend of increasing payers' and consumers' control and the set of implemented reforms partially steered the market toward collective responsibility of access by creating a submarket of guaranteed services (AUGE) with lower copayments and fully funded services. Emerging unintended consequences of the adopted policies and potential explanations are discussed. In sum, attempts to use regulation to improve the collective dimension of the Chilean health system has enabled some progress, but several challenges had persisted.

[Culture and depression in global mental health: An ecosocial approach to the phenomenology of psychiatric disorders](#)

*Laurence J. Kirmayer, Ana Gomez-Carrillo, and Samuel Veissière*

Depression is a major focus of concern in global mental health, with epidemiological surveys indicating high prevalence rates worldwide (Ferrari et al., 2013a). Estimates of the global burden of depression in terms of disability, quality of life, and economic impact have been used to argue for scaling up the detection and treatment of depression as a public health and development priority in low and middle-income countries (Chisholm et al., 2016; Patel, 2017). These projections, however, are based on limited data and make many assumptions about the generalizability of findings across populations. While epidemiological research suggests there is substantial cross-cultural variation in the prevalence and symptomatology of depression (Ferrari et al., 2013b; Kessler and Bromet, 2013), there is evidence that a syndrome similar to major depressive disorder can be identified across diverse cultural contexts (Kleinman and Good, 1985; Kirmayer and Jarvis, 2006; Steel et al., 2014).

In a useful contribution, Haroz and colleagues (Haroz et al., 2017) reviewed the qualitative literature on cultural variations in depression to gauge the extent to which current diagnostic criteria fit the experience of people in diverse contexts. They found significant cultural variation and call for an expanded research program to explore the meaning and significance of these cultural differences for our understanding of mental health. This is crucial for current efforts to address global inequities in mental health and to make sense of claims of a global “epidemic” of depression (Baxter et al., 2014).

In this commentary, we examine the methods and findings of Haroz and colleagues’ study and discuss implications for future research on depression and the development of interventions in global mental health.

[Patient engagement at the margins: Health care providers’ assessments of engagement and the structural determinants of health in the safety-net](#)

*Mark D. Fleming, Janet K. Shim, Irene H. Yen, Ariana Thompson-Lastad, Sara Rubin, Meredith Van Natta, and Nancy J. Burke*

Increasing “patient engagement” has become a priority for health

care organizations and policy-makers seeking to reduce cost and improve the quality of care. While concepts of patient engagement have proliferated rapidly across health care settings, little is known about how health care providers make use of these concepts in clinical practice. This paper uses 20 months of ethnographic and interview research carried out from 2015 to 2016 to explore how health care providers working at two public, urban, safety-net hospitals in the United States define, discuss, and assess patient engagement. We investigate how health care providers describe engagement for high cost patients—the “super-utilizers” of the health care system—who often face complex challenges related to socioeconomic marginalization including poverty, housing insecurity, exposure to violence and trauma, cognitive and mental health issues, and substance use. The health care providers in our study faced institutional pressure to assess patient engagement and to direct care towards engaged patients. However, providers considered such assessments to be highly challenging and oftentimes inaccurate, particularly because they understood low patient engagement to be the result of difficult socioeconomic conditions. Providers tried to navigate the demand to assess patient engagement in care by looking for explicit positive and negative indicators of engagement, while also being sensitive to more subtle and intuitive signs of engagement for marginalized patients.

### [Sadness or depression: Making sense of low mood and the medicalization of everyday life](#)

*Christian Bröer and Broos Besseling*

This research focusses on low mood as a generic category in everyday social interactions, outside the clinical realm and among non-patients. We examine if and how a clinical depression label and treatment are employed when low mood occurs in everyday life, which enables us to analyze the extent and content of medicalization and brings to the fore the interactional mechanisms and cultural concerns that potentially drive medicalization. The analysis is based on 316 observations of everyday life in the Netherlands. We observed and recorded interactions in which low mood was spontaneously expressed.

Our paper shows that the clinical depression label resonates widely even if low mood is not fully medicalized. People de-medicalize low mood, and low mood can be un-medicalized. Our analysis thus suggests that dominance is not achieved, which

nuances Horwitz and Wakefield's claim that the clinical category of depression has come to encompass all forms of low mood. Moreover, uncertainties about the meaning of low mood *and* about the depression label remain pragmatic concerns of everyday life.

The cultural norm of happiness and active citizenship are very prominent in everyday life across medicalized and un-medicalized interactions. These norms thus seem to be a necessary but insufficient condition for medicalization. While pragmatic concerns do not seem to trigger medicalization either, one specific type of concern is consistently related to medicalization: relational conflicts.

In sum, the cultural construction of low mood is not dominated by a single medical approach; however, it mirrors the diversity and uncertainties within and around the medical field.

[Controversies about cervical cancer screening: A qualitative study of Roma women's \(non\)participation in cervical cancer screening in Romania \(open access\)](#)

*Trude Andreassen, Elisabete Weiderpass, Florian Nicula, Ofelia Suteu, Andreea Itu, Minodora Bumbu, Aida Tincu, Giske Ursin, and Kåre Moen*

Romania has Europe's highest incidence and mortality of cervical cancer. While a free national cervical cancer-screening programme has been in operation since 2012, participation in the programme is low, particularly in minority populations. The aim of this study was to explore Roma women's (non)participation in the programme from women's own perspectives and those of healthcare providers and policy makers. We carried out fieldwork for a period of 125 days in 2015/16 involving 144 study participants in Cluj and Bucharest counties. Fieldwork entailed participant observation, qualitative interviewing and focus group discussions. A striking finding was that screening providers and Roma women had highly different takes on the national screening programme. We identified four fundamental questions about which there was considerable disagreement between them: whether a free national screening programme existed in the first place, whether Roma women were meant to be included in the programme if it did, whether Roma women *wanted* to take part in screening, and to what degree screening participation would really benefit women's health. On the background of insights from actor-network theory, the article discusses to what degree the programme could be said to speak to the interest of its intended Roma public, and considers

the controversies in light of the literature on patient centred care and user involvement in health care. The paper contributes to the understanding of the health and health-related circumstances of the largest minority in Europe. It also problematizes the use of the concept of “barriers” in research into participation in cancer screening, and exemplifies how user involvement can potentially help transform and improve screening programmes.

[“How can anybody be representative for those kind of people?” Forms of patient representation in health research, and why it is always contestable](#)

*Kath Maguire and Nicky Britten*

Different discourses that co-exist within the world of patient and public involvement in health and social care mirror a tangle of historical, social, political and theoretical roots. These range from the radical activism, born of civil rights movements, to a more passive model in which patients are the recipients of information. This paper explores the concept of ‘representation’ and the ways the concept is used by people serving as ‘patient’ or ‘lay’ representatives in a range of roles within research projects, funding bodies and academic institutions. We address the issue of why the representativeness of those involved is contestable. Drawing on qualitative research and engaged practice as well as on literature from social and political sciences we question how people conceptualise their own and their fellows’ acts of representation. In doing this we identify nine different conceptualisations of what it is to represent and use these to explore how judgements are made about what can count as legitimate forms of representation.

[Finding joy in poor health: The leisure-scapes of chronic illness](#)

*Julia McQuoid*

Globally, increasing numbers of people face the challenge of enjoying life while living with long-term illness. Little research addresses leisure participation for people with chronic illness despite its links with mental and physical health and self-rated quality of life. I use a space-time geographical approach to explore experiences with leisure in everyday life for 26 individuals with chronic kidney disease (CKD) in Australia. I examine ways in which the spatial and temporal characteristics of illness management and symptoms shape where, when, and how participants can enjoy

leisure, focusing on: 1) logistical conflicts between illness and leisure; 2) rhythmic interferences with the force of habit in skilful leisure performance; and 3) absorbing experiences of encounter with self and place through leisure. Data were collected from 2013 to 2014. Participants kept diaries over two sample days and then participated in semi-structured interviews. Findings show that the voluntary nature of leisure offered participants important benefits in coping with and managing illness over the long-term, including opportunities to experience greater sense of control, an alternative experience of one's body to the 'sick body', and knowledge creation that supports adaptation to the uncertainties of illness trajectories. The ability to engage in meaningful leisure was constrained by the shaping forces of illness symptoms and management on participants' leisure-scapes. Illness treatment regimens should therefore be adapted to better accommodate leisure participation for chronically ill patients, and leisure should be explicitly incorporated into illness management plans negotiated between patients and health practitioners. Finally, greater understanding of the transformative capacity of habit in activities of experimentation and play may have wider-reaching implications for leisure's potential applications in public health. Leisure should be taken seriously as a vehicle for enhancing wellbeing and adaptation to life with long-term illness.

### [Social Studies of Science](#)

SPECIAL ISSUE: Breaking Scientific Networks

#### [A long history of breakdowns: A historiographical review](#)

*Dániel Margócsy*

The introduction to this special issue argues that network breakdowns play an important and unacknowledged role in the shaping and emergence of scientific knowledge. It focuses on transnational scientific networks from the early modern Republic of Letters to 21st-century globalized science. It attempts to unite the disparate historiography of the early modern Republic of Letters, the literature on 20th-century globalization, and the scholarship on Actor-Network Theory. We can perceive two, seemingly contradictory, changes to scientific networks over the past four hundred years. At the level of individuals, networks have become increasingly fragile, as developments in communication and

transportation technologies, and the emergence of regimes of standardization and instrumentation, have made it easier both to create new constellations of people and materials, and to replace and rearrange them. But at the level of institutions, collaborations have become much more extensive and long-lived, with single projects routinely outlasting even the arc of a full scientific career. In the modern world, the strength of institutions and macro-networks often relies on ideological regimes of standardization and instrumentation that can flexibly replace elements and individuals at will.

### [A fragile assemblage: Mutant bird flu and the limits of risk assessment](#)

*Andrew Lakoff*

This paper examines the recent public controversy sparked by the laboratory creation of a strain of highly pathogenic avian influenza transmissible among mammals. The contours of the controversy can be understood by tracking the assemblage of actors, institutions and devices gathered together in response to the governmental problem of how to manage emerging diseases. The grouping is tenuously held together by a shared commitment to the project of 'pandemic preparedness'. However, as the controversy unfolds, it becomes clear that the main actors involved do not share a common understanding of the problem to be addressed by pandemic preparedness, and the assemblage threatens to decompose. At the center of the dispute is the question of how to assess the risks and benefits of research in a field characterized by urgency and uncertainty.

### [The missing, the martyred and the disappeared: Global networks, technical intensification and the end of human rights genetics](#)

*Lindsay A. Smith*

In 1984, a group of Argentine students, trained by US academics, formed the Argentine Forensic Anthropology Team to apply the latest scientific techniques to the excavation of mass graves and identification of the dead, and to work toward transitional justice. This inaugurated a new era in global forensic science, as groups of scientists in the Global South worked outside of and often against local governments to document war crimes in post-conflict settings. After 2001, however, with the inauguration of the war on terror following the September 11<sup>th</sup> attacks on the World Trade Center in

New York, global forensic science was again remade through US and European investment to increase preparedness in the face of potential terrorist attacks. In this paper, I trace this shift from human rights to humanitarian forensics through a focus on three moments in the history of post-conflict identification science. Through a close attention to the material semiotic networks of forensic science in post-conflict settings, I examine the shifting ground between non-governmental human rights forensics and an emerging security- and disaster-focused identification grounded in global law enforcement. I argue that these transformations are aligned with a scientific shift towards mechanized, routinized, and corporate-owned DNA identification and a legal privileging of the right to truth circumscribed by narrow articulations of kinship and the body.

### [Sociology of Health and Illness](#)

#### [A day in the life of a Ménière's patient: understanding the lived experiences and mental health impacts of Ménière's disease](#)

*Sarah L. Bell, Jessica Tyrrell, and Cassandra Phoenix*

Concepts of social practice are increasingly being used to understand experiences of everyday life, particularly in relation to consumption and healthy lifestyles. This article builds on this in the context of lives disrupted and reshaped by chronic illness. It uses social practice theory to examine the lived experiences of individuals with Ménière's disease; a long-term progressive vestibular disorder, defined by episodes of severe and debilitating vertigo, aural fullness, tinnitus and sensorineural hearing loss. Drawing on the findings of 20 in-depth narrative interviews with Ménière's patients, and eight spousal/partner interviews, we explore the impacts of the condition on sensory, temporal, spatial and social dimensions of the body. In doing so, we highlight the intensely embodied sensory and emotional work required to maintain connections between the 'competences', 'materials' and 'meanings' that constitute and sustain the performance of both mundane and meaningful social practices over time. As connections between these elements of social practice are disrupted during more active phases of the condition, affected individuals may be deflected from old practices and recruited to new ones, often requiring both time and social support to find meaning or pleasure in these alternative ways of being in the

world.

### [Might constraint be compatible with care? Home care as a situational ethics](#)

*Antoine Hennion and Pierre A. Vidal-Naquet*

Respecting the autonomy and will of people has legitimately led to strictly control the use of constraint in care activities, and promote a care ethics centred around people's needs and wills. But constraint is underlying in any action aiming at making people do something, even with their consent, especially when their ability to evaluate what is best for them may be altered. Ceaselessly present in care, this ordinary, silent constraint should not be only deemed as a necessary evil to be prevented. In contrast with this legally-based view, the paper adopts a pragmatic perspective. Leaning on minute case studies carried out at disabled people's homes, the empirical section takes up some key troubling moments between caregivers and patients as trials capable of revealing 'constraint in practice': a situation of uncertainty, doubt, hesitations on the appraisal of what is happening and how to deal with it, banning any clear-cut distinction between technical gestures and moral values. Having outlined the characters of such a 'situational ethics', the authors argue in conclusion that, provided caregivers are never quits with its use, constraint is compatible with care, and assume that care theories could fruitfully support this advocacy to 'maintaining the trouble' in care practices.

### [The concept of medicalisation reassessed](#)

*Joan Busfield*

Medicalisation has been an important concept in sociological discussions of medicine since its adoption by medical sociologists in the early 1970s. Yet it has been criticised by some sociologists, in part because it seems too negative about medicine, and modified or replaced by others with concepts deemed more relevant like biomedicalisation and pharmaceuticalisation. My aim in this paper is to reassess the concept and consider whether it still has value in exploring significant aspects of the role of medicine in present-day society. I start with an archaeology of the concept's development and the different ways it has been used. This covers some familiar ground but is essential to the main task: examining

criticisms of the concept and assessing its value. I conclude that the concept continues to have a crucial and productive place in sociological analyses of medicine and that the process of medicalisation is still a key feature of late-modern social life and culture.

[The concept of medicalisation reassessed: a response to Joan Busfield](#)

*Simon J. Williams, Catherine Coveney and Jonathan Gabe*

[The concept of medicalisation reassessed: a rejoinder](#)

*Joan Busfield*

[Transcultural Psychiatry](#)

[“In our community, a friend is a psychologist”: An ethnographic study of informal care in two Bhutanese refugee communities](#)

*Liana Chase and Ram P. Sapkota*

The recent rise in suicide among Bhutanese refugees has been linked to the erosion of social networks and community supports in the ongoing resettlement process. This paper presents ethnographic findings on the role of informal care practiced by relatives, friends, and neighbors in the prevention and alleviation of mental distress in two Bhutanese refugee communities: the refugee camps of eastern Nepal and the resettled community of Burlington, Vermont, US. Data gathered through interviews ( $n = 40$ , camp community;  $n = 22$ , resettled community), focus groups (four, camp community), and participant observation (both sites) suggest that family members, friends, and neighbors were intimately involved in the recognition and management of individual distress, often responding proactively to perceived vulnerability rather than reactively to help-seeking. They engaged practices of care that attended to the root causes of distress, including pragmatic, social, and spiritual interventions, alongside those which targeted feelings in the “heart-mind” and behavior. In line with other studies, we found that the possibilities for care in this domain had been substantially constrained by resettlement. Initiatives that create opportunities for strengthening or extending social networks or provide direct support in meeting perceived needs may represent fruitful starting points for suicide prevention

and mental health promotion in this population. We close by offering some reflections on how to better understand and account for informal care systems in the growing area of research concerned with identifying and addressing disparities in mental health resources across diverse contexts.

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