



# **Medical Sociology Study Group**

## **Annual Conference Programme Important Information**

**14 – 16 September 2022**

**University of Lancaster**



# Day 2 Morning Abstract Book

Thursday 15 September  
09:00-09:30

NB - Virtual presentations are highlighted in blue

## **Lifecourse - Reproductive Health; Chronic Conditions; Ageing: Death and Dying**

### **Bodies and Medicines: The materiality of 'good care' in care homes**

**Jane Dickson**

(University of Dundee)

A substantial part of the daily work for senior staff in nursing and residential care home settings involves the administration of medications. This is a specialized job, requiring certification by training and includes ordering, reviewing, recording and reconciliation as well as administration. Care home residents, who often have multiple, complex conditions, frequently take a large number of medications, multiple times a day and can also lack the capacity to assess or communicate their own feelings and needs. The production of good care through medication administration is not, therefore, a simple matter of following the instructions on the packet, but a complex process, involving the negotiation of different capabilities, moods and materialities.

This paper draws on ethnographic data from 80 interviews with care staff, prescribers and pharmacists, residents and their families across seven care homes and non-participant observation across six care homes gathered during the Antibiotic Research in Care Homes (ARCH) study, pre and during the COVID-19 pandemic.

The paper considers the materiality of medications and how this is negotiated within ongoing decision making processes which are as simultaneously social and legal as they are medical.

Daily engagements enable staff in care homes to examine and interpret the complex interactions between bodies and medications, in order to assess the ongoing needs of their residents. Staff come to know and understand residents through these negotiated materialities and this is vital to resident health and wellbeing. A knowledge of these 'body-drug assemblages' become one of the unspoken keys to 'good care'.

## **Pedagogy and Methods**

### **Fidelity in Video Reflexive Ethnography - a review of the evidence**

**Tom Furniss**

(Dept. of Health Sciences, University of Leicester)

Video reflexive ethnography (VRE) involves videoing patient care and sharing clips of the footage with staff, to prompt reflection and discussion to promote improvement. VRE is a relatively new approach for quality improvement (QI), evidence is lacking to inform learning about how best to use VRE

effectively for QI in healthcare.

A systematic review was conducted of the use of VRE as a QI method. Medline, Cinahl, Web of science core, and Scopus were searched using the term: reflexiv\* AND video. Inclusion criteria: empirical studies using VRE as a QI method, in a healthcare setting. Papers not in English were excluded. 75 articles met the search terms, post-screening 18 remained. These included the use of VRE to improve communication and handovers, address infection control issues, and examine how staff use space. The TIDieR checklist was used to assess how VRE QI projects reported their methods and findings. Reporting lacked relevant details – none of the 18 articles reported on all areas of the TIDieR checklist. Characterising VRE as an intervention in the QI sense is problematic – VRE projects have variability built into their design, are context specific, and are not designed to be replicated exactly, creating an issue around reporting ‘fidelity’. There are epistemic difference between QI’s medical-scientific and VREs contextual-participative approaches to learning and development. Rather than replicating the methods used in VRE QI interventions to date, effective use of VRE in QI instead requires an understanding of, and adherence to, the underpinning principles of this methodological approach.

## **Inequalities and Intersectionality**

### **Reproductive health in times of crisis: A critical analysis of abortion portrayals in local news during the onset of the COVID-19 pandemic**

**Anna Theresa Schmid, Avery Veldhouse, Shahin Dr. Payam**

(Technical University of Munich)

Access to safe abortion is an important aspect of reproductive health. Abortion stigma and impeded abortion access, for instance, are known to adversely impact on women’s health, especially affecting minority women. Nevertheless, several states in the US—including those in the American South known for a large non-white population—attempted to suspend abortions within their COVID-19 public health emergency declarations. Although these restrictions were successfully challenged, it sparked discussions about abortion in local news.

This study aims to explore the framing of abortion in local newspapers during the onset of the pandemic, in order to assess possible implications for public understandings of the topic. For data collection, articles on abortion published in three top circulated local newspapers from Alabama, Louisiana, and Mississippi, respectively, were identified. These States were selected for their high non-white populations. Using a critical thematic analysis, four themes were identified: individual-centric, public health risk, interplay with Inequalities and Intersectionality and hierarchical health care.

The analysis demonstrates how stigma is recreated within public narratives by shifting the blame on women or abortion providers and thereby justifying restrictions by the state. The findings suggest that different sides of the abortion debate used pandemic-related arguments to expand on previously existing narratives. These could reinforce power differences and abortion stigma, which might be particularly affecting minority women. However, the pandemic also seemed to heighten health-related narratives, holding the potential to raise awareness for the need of structural change.

## **Health Policy**

### **Nucleic Acid Censorship: Reconstructing Social Order and Daily Routine in China**

**Jian Meng**

(Minzu University of China)

This paper proposes the concept of Nucleic Acid Censorship (NAC) to understand the current anti-epidemic policy in China, where the widespread dissemination of Covid-19 has changed the perception of health by the central government. Health is no longer a positive description of an individual’s long-term status, but rather a transient status judged by the technology nucleic acid testing. The only way to stay “healthy” is to keep proving through the test that one is not diagnosed. Given the nature of enforcement and its broad social implications, this paper refers to it as NAC. Through in-depth interviews with residents in the control areas and textual analysis of official policies, this study reveals

that, as a nationwide system, NAC is deeply embedded in community governance, transportation, and health system, and gradually interferes with their original modes of operation; on the other hand, the incessancy of NAC has led to a gradual shift in individual perceptions of testing, initially as an important means of defense against unknown enemies, but later as a routine part of life.

## **Diagnosis, Screening and Treatment**

### **"Just suck it up": dealing with side-effects of vaccines on menstrual cycles**

**Meghna Roy**

(Jawaharlal Nehru University)

Following Mildred Blaxter I look at diagnosis as a category and process in the case of recognising the side-effects of COVID-19 vaccines on menstrual cycles. While in the UK there is a Yellow Card system to record the side-effects of the vaccine, there is no comparable system of self-reporting in India. Even in the UK menstruators often shy away from reporting their symptoms owing to the stigma associated with menstruation as well as the lack of medical knowledge about the same. I ask: how do patients and physicians navigate the uncertainty of science during crisis? My paper is at an intersection between sociology of diagnosis and sociology of ignorance. It uses the framework of sociology of diagnosis to demonstrate how an everyday illness does not become a disease in the absence of advocacy. I use a combination of tweets, and interviews with doctors and menstruators in India and the UK to understand what it means to be at the liminal zone between: a. disease and illness, and b. knowledge and ignorance. I also look at how science travels transnationally in a situation where diagnosis and cure are uncertain. This is where I use the lens of ignorance studies to explain what I have observed during my research - women become bearers of the burden of risk and uncertainty. As a result of systemic ignorance, biomedicine lacks classificatory categories to adequately capture the emergent experiences of illness among people who menstruate.

## **Professions**

### **Not task and finish: the work of patient and public involvement leads and the temporalities of care labour in health research ecologies**

**Stan Papoulias**

(King's College London)

Evidencing meaningful involvement of patients, public members and communities (PPI) is currently deemed essential for funding and undertaking health research in the UK. Yet while there is a developing investment in evaluating the quality and impact of PPI, the work of those responsible for embedding involvement has received scant attention to date. This paper presents findings from a participatory empirical study which brings together interviews, guided diaries and workshops to better understand the labour of this new cadre of professionals variously termed PPI leads, co-ordinators and managers. It focuses on PPI workers employed on research programmes funded by the National Institute for Health and Care Research (NIHR) - a key actor in the operationalisation of PPI - and tasked with aligning research team objectives with patient/public concerns. It asks what is at stake in these workers' oft repeated plaint that they feel undervalued and that their efforts are undercut by a lack of resources. It argues that PPI leads are not only tasked with reconciling and harmonising potentially conflicting values and priorities but, additionally, with negotiating the disjunctive temporalities of ongoing care and relational labour on the one hand (PPI time) and project management and strategy building on the other (deadlines and deliverables). This demand that PPI leads work both within and against the organisational logic of the institution cannot simply be met through better resourcing. Rather, the irreconcilable aspects of this demand testify to some of the paradoxes animating the collaborative rationales and labour ecologies constituting health research.

## **Experiences of Health and Illness**

## **“Working out the maths”: making sense of risk in inherited motor neurone disease**

**Jade Howard**

(University of Aberdeen)

Motor neurone disease (MND) is a neurodegenerative condition that in a minority of cases is passed down in families. With research scrutiny, the complex genetic architecture of inherited MND is becoming better understood. To date, over two thirds of the gene variants linked to the disease have been identified, with implications for asymptomatic family members. How people with a family history of MND make sense of genetic risk is the focus of this presentation. Based on an interview study with 35 individuals from across the UK (including people living with inherited MND, family members at risk, and partners/ family caregivers), this PhD research draws on a thematic analysis using a method of constant comparison. It unpacks how people translate an initial awareness of MND in the family into an understanding of personal risk. It highlights that calculating, quantifying, and feeling risk is a varied process. It explores how interpretations are brought to bear on Mendelian genetics, as concepts like inheritance, penetrance and age of onset are intertwined with the observable pattern of the disease, gut feelings and other characteristics in this sense-making process, revealing constructions of risk as grounded in a complex logic. This is not about (mis)understanding but rather reveals an intricate interweaving and weighting of different forms of knowledge. This study contributes to literature on the lived experience of risk in this timely research area that has previously been given little attention. Findings from the wider study have been used to develop a resource on the website [healthtalk.org](http://healthtalk.org).

## **Politics and Ethics of Health**

### **Zero-COVID Policy and Shanghai’s Lockdown: How Does China Exercise Biopower in a State of Exception**

**Xu Liu**

(Goldsmiths, University of London)

This paper analyses the implementation of the Zero-COVID Policy in China through the case of Shanghai’s lockdown in 2022. Through discourse analysis and online ethnography, I investigate how the Zero-COVID policy emerges and evolves while the ruling party continuously regards COVID-19 as the most significant problem of its governance and how the government carries out the enforcement with extreme measures. In the governmental strategies and policies on health-related topics, China’s ruling party always legitimates its governance by dominating the knowledge production of population health. The government establishes its governmentality for “conducting, shaping and steering the ways in which human individuals and groups act”. During the COVID-19 outbreaks, this idea of governmentality authorises various public sectors to implement mandatory PCR tests, quarantine and lockdown. Reflecting on Shanghai’s lockdown, I suggest that the ruling party utilises the securitisation of the COVID-19 topic in China to create a state of exception for its authoritarian exercise of biopower. Through the discursive practices, the ruling party of China justifies its dominant exercise of biopower by regarding strict enforcement as the protection of the public good. In the name of population health, fighting COVID-19 infections becomes the only overwhelming target for any governmental techniques. However, according to the existing laws, the biopower in China’s Zero-COVID policy has transcended the institutionalised scope of the state power. Meanwhile, the emerging civil resistance demonstrates that the government is losing the legitimacy of maintaining the state of exception.

## **Mental Health**

## **S136 Detentions: The criminalisation of mental distress**

**Jayne Erlam**

(Liverpool John Moores University)

To explore the personal impact and the processes involved in the increasing rates (Home Office, 2019, 2020) of police-invoked Section 136 (S136) detentions under the Mental Health Act, my research analysed an NHS Trust's administrative dataset and interviewed front-line police officers (n=12) and adults with experience of S136 detention (n=5). This mixed-methods approach positioned findings against criminal, medical and social models of mental distress (MD).

Over a 40-month period (December 2017 to April 2021), from one constabulary in the North of England there were 4,211 S136 detentions, 300 of which were of children and young people (CYP) aged from 9 years. 50% of detentions were of people who had previous S136 detentions. 70% of detained persons were taken to Accident and Emergency (A&E) departments rather than to an S136 suite, which is the preferred place of safety. In A&E departments, detained people, under police supervision and control, remained under the public's gaze.

Police officers were found to play a significant role in the care of persons experiencing MD which is perceived and experienced as criminalising. The lack of available inpatient beds is key: correlation is found between discharge after a bed request fails to result in admission and repeated detention, and S136 suites are rendered inaccessible due to detainees awaiting admission which results in an overuse of A&E departments.

There is no parity of service provision for CYP. Proportionally, CYP have less access to S136 suites, experience more repeated detentions and spend longer under police supervision and control than adults.

# Thursday 15 September

## 09:35-10:05

### **Lifecourse - Reproductive Health; Chronic Conditions; Ageing: Death and Dying**

**“Late” motherhood and reproductive exclusion. Cross-border reproductive journeys of French women and couples to Barcelona**

**Alexandra Desy**

(Universitat Autònoma de Barcelona - AFIN Research Group)

Europe’s dense reprocscap (Inhorn, 2015) is where the highest mobility can be observed in terms of reproductive travels, a process which the ESHRE Task Force on Ethics and Law (2008) termed Cross-Border Reproductive Care. Indeed, the extremely diverse European regulations concerning Assisted Reproductive Technologies (ART) -in terms of accessibility, affordability, cost, and reimbursements (Chambers et al., 2014; Präg & Mills, 2017)- have forced but also allowed many people to seek ART outside their home countries.

Since 2016, Spain has been known as the number one destination country for cross-border reproductive care (Desy & Marre, 2022; Marre et al, 2018; Wyns et al, 2020), thanks to its prestige in reproductive medicine and its high availability of donated oocytes, but also because of a particularly flexible and inclusive framework surrounding access to medically assisted reproduction. Over the years, Spain has become the principal destination for French women and couples accessing ART treatments outside their country of origin, known for its particularly restrictive legal reproductive framework. Although the law has recently been revised (2021), the reproductive exclusion of women who are seeking to become mothers in their 40s has been maintained, condemning them to travel abroad to fulfil their reproductive desire. Based on ethnographic work of participant observation in various assisted reproduction clinics in Barcelona and in-depth interviews with their patients from France, this presentation deals with the exclusion of maternity considered as "late", one of the reasons for many of the cross-border reproductive journeys.

### **Pedagogy and Methods**

**Enabling the authentic voice: generating ethnographies of women with cerebral palsy**

**Sonali Shah**

(University of Nottingham)

Historically, research has been undertaken using methods that have restricted the participation of disabled women with speech impairments. Metaphorically and literally, their voices have not been heard. Facing barriers to speak for themselves makes it difficult for women to challenge disabling narratives, including those of asexuality. The result is increased marginalisation, inequality and simultaneous oppression across different spheres of public and private life. In this paper, we reflect on our experiences of undertaking two qualitative studies that explored experiences of sexual and reproductive healthcare for women with cerebral palsy (CP), using internet-based methods such as Facebook and email. We offer reflective insights regarding the core issues for researchers when conducting research about sensitive topics with women with CP in particular, and disabled women in general. Specifically: 1) An enabling research environment; 2) Interpersonal relationships and identity. Overall, we argue that using digital and flexible research approaches not only enables disabled women to be involved in research about issues that concern them, but also provides an enabling context in

which their authentic voices can be heard.

## **Inequalities and Intersectionality**

### **Trustworthy Medicine: Perspectives from the Race-Disability Intersection**

**Mary Crossley**

(University of Pittsburgh School of Law/ St. Louis University School of Law)

Black people and people with disabilities in the United States are distinctively disadvantaged in their encounters with the health care system. These groups also share harsh histories of medical devaluation and experimentation, eugenic sterilizations, and health care discrimination. Yet the similarities in health inequities experienced by Black people and disabled people and the harms endured by people who are both Black and disabled remain largely unexplored. Moreover, the relationship between racial justice activists and disability rights advocates at times reflects tensions around movement aims and personal identity. Drawing from my book *Embodied Injustice: Race, Disability, and Health* (to be published August 2022 by Cambridge University Press), this paper adopts an interdisciplinary approach, weaving health research with social science, critical approaches, and personal stories, to examine how understanding historical and contemporary health inequities can inform the narrative around trust in medicine and science. The focus of discussions about trust is shifting from steps to increase the trust felt by persons from medically marginalized communities (as if low trust levels were like a vitamin deficiency) to efforts to make medicine demonstrably more trustworthy for members of those communities. Histories of untrustworthiness reverberate today in choices by Black and disabled patients (and their families) about medicine's role at life's end. Specifically, the paper asserts that shared reluctance relating to physician aid in dying, hospice care, and organ donation are traceable in part to shared experiences of injustice. The paper concludes with suggestions for increasing trustworthiness.

## **Health Policy**

### **Perceptions of place in health and social care**

**Melissa Surgey, Katherine Checkland, Jonathan Stokes, Lynsey Warwick-Giles**

(The University of Manchester)

"Place" is a key pillar of integrated health and care reform internationally and in the UK. However, definitions of place in English health policy are ambiguous, over-simplified and lack the clarity needed to operationalise policy initiatives locally. The complexities of reconciling the heterogeneous perceptions and experiences of multiple health and care organisations and the public are underestimated, and due consideration is not given to the sociological, historical and political context within which health and care partners and local people connect to and identify with place.

In this paper I present initial findings from my PhD study in which I am taking an ethnographic case study approach to examining how health care is organised around place in two Integrated Care Systems (ICSs) in the English NHS. Data has been gathered from 50 semi-structured interviews with local health and care leaders and observing place and ICS meetings over the last four months. These case studies are supplemented by eight interviews with national leaders and policymakers to compare how place is conceptualised nationally and locally.

I examine the factors which influence how place is defined and implemented in health and care and how this relates to organisational, individual and community identity and culture. I consider the strengths and limitations of presenting place as a technical construct purely for the purposes of delivering public services, and if developing truly joined up place-based health and care necessitates deeper consideration of what place means for and to health and care systems and the people they serve.



## **Diagnosis, Screening and Treatment**

### **“Anticipatory biomedicine” in the “family we live by”: reproductive preservation and Turner Syndrome**

**Kriss Fearon**

(Centre for Reproduction Research, DMU)

Social imaginaries (Jasanoff, 2015) play a key role in shaping reproductive choices about whether, when and how to have a child, expressing social norms of fertility, maternity and family relationships which inform people's family-building preferences. This paper explores how women in families affected by Turner Syndrome (TS) deployed imaginaries to navigate and re-frame their choices when considering the use of reproductive technologies.

TS is a chromosome disorder in which 90% of girls are infertile, while coexisting conditions mean pregnancy is often high risk. A diagnosis in childhood raises the question of future reproductive desires and options; consequently, some mothers have frozen their eggs for their daughter to use in later life, while ovarian tissue freezing can preserve potential fertility for some girls with TS. Both options are uncertain and emotionally complex.

Reproductive preservation (RP) is an anticipatory technology (Bach and Krolokke, 2019), mobilising both hope (Franklin, 1997) for a desired future pregnancy, and fear (Tymstra, 2007) that, without taking action, hope will never be achieved. The timing of RP treatment means girls with TS are too young to make an informed choice, yet decisions need to be made on their behalf as to what they might wish in the future.

Based on qualitative interviews with 30 UK-based women with TS and mothers of girls with TS, this paper shows how women deploy maternal, kinship and reproductive imaginaries, and demonstrates how imaginaries and future-focused thinking are entwined in their reproductive decision making.

## **Professions**

### **Patient and public involvement/engagement in medical research in Japan: Learning from the UK and exploration for the unique future**

**Kaori Muto, Jin Higashijima, Saori Watanabe, Kumiko Fujisawa, Izen Ri, Yukitaka Kiya**

(The University of Tokyo)

This paper aims to discuss the characteristics of the patient and public involvement/engagement (PPI/E) initiative in Japan, which is strongly influenced by preceding policies of the United Kingdom. Although its origins are difficult to trace, PPI/E in Japan has been conducted spontaneously and sporadically in various medical research settings, with no clear concept or rules, and handled on a case basis. Classical examples can be observed in research on rare diseases and supporting care on cancer. Since the late 2010s, there has been increased focus on PPI/E, including the government's strategic plans for genomic medicine (2015), cancer (2017) and immunological allergic diseases (2019); publication of a report on 'Patient Centricity' by Japan Pharmaceutical Manufacturers Association, a counterpart of the European Federation of Pharmaceutical Industries and Associations (2018); a working group on Pharmaceuticals and Medical Devices Agency, an organisation similar to European Medicines Agency (2019); and the first guidebook published by The Japan Agency for Medical Research and Development (2019), an equivalent organisation to the National Institute for Health and Care Research. These activities are spontaneous and not organised by the government, due to the lack of a Patient's Charter and national strategic plans on PPI/E in research and development. Our online surveys on PPI/E towards patients and researchers conducted between 2017 and 2022 indicate that increases in the percentages of degree of recognition, supporting attitudes to promote and willingness to contribute are good signs ensuring diversity and inclusion. More cases and experiences should be shared among researchers and patients.

## **Experiences of Health and Illness**

### **Navigating Diabetes: An Anthropological Study of the Everyday Experiences of Chronic Illness and Healthcare in India**

**Avilasha Ghosh**

(Indian Institute of Technology Delhi)

India is considered to be the "diabetes capital of the world" (Mendenhall 2019). Yet, very few studies have focused on understanding the medical and social implications of diabetes in the country. My proposed paper will explore the plural medical landscape (biomedicine, homoeopathy, Ayurveda) and patients' experiences of diabetes management in India. Drawing from qualitative interviews with patients, their families and medical professionals, and a multi-sited ethnography including hospitals, private clinics and patients' homes in Delhi, the paper highlights the everyday experiences of patients and their families with chronic illnesses (diabetes) and Indian healthcare. Additionally, it charts the social and financial challenges that patients from various socio-economic backgrounds (class, gender, religion, class, region) face with access to quality care services, medical counselling, and affordable health facilities for the management of diabetes in India. The onset of the Covid-19 has radically shifted popular understandings of and the care practices around diabetes. My paper will briefly address these shifts (if any) in India's healthcare model and patient's disease perceptions in the pre- and post-pandemic period. In so doing, the paper seeks to interrogate the importance of categories like kinship, gender, class and State in patients' health-seeking behaviours and practices, while proposing the urgency of an anthropological assessment of chronic illness experiences and the healthcare system in India.

## **Politics and Ethics of Health**

### **Government guidance and citizen responses during the COVID-19 pandemic: a cross-country analysis**

**Cervantee Wild, Sasha Lewis-Jackson, Tanvi Rai, Anna Dowrick, Kaveri Qureshi, Sue Ziebland**

(University of Oxford)

The perception of public health guidance has played an important role in citizen responses to the COVID-19 pandemic. Although the state and associated health institutions are intended to be sources of epistemic authority, the pandemic tested their legitimacy as anti-science rhetoric proliferated and 'fake news' spread rapidly. We present a comparative analysis of interviews with citizens in the UK, Spain, Brazil and Japan who had Covid in 2020/21 to explore how perceptions of inconsistency and lack of clarity in public health guidance led to the polarisation in public perceptions and mixed understandings of the pandemic. This resulted in a proliferation of a disparate set of definitions regarding what constitutes 'good' citizenship responsibilities and behaviours, including (e.g. adherence to public health guidance, level of individual decision-making and navigation).

We use a cross country comparative thematic analysis to explore differences in the perceived degree of state responsibility towards citizens in terms of preventing Covid infection, and the extent to which state governments were perceived as epistemic authorities through managing the pandemic. We examine the tensions between personal responsibility and collective or state responsibility for health. Participants grappled with decisions about how far to trust government guidelines, manage infection risk, self-medication, and debates around whether to get vaccinated.

## **Mental Health**

### **'We're welcomed into people's homes every day' versus 'we're the people that come and arrest you': The relational production of masculinities and vulnerabilities among male first-responders**

**Damien Ridge, Skaiste Linceviciute, Skaiste Linceviciute, Chantal Gautier, Alex Broom, John Oliffe, Coral Dando**

(University of Westminster)

Encouraging men to open-up about their feelings is a new cultural directive, yet little is known about how this works in practice, including to promote mental health. Ideals of hegemonic masculinity are increasingly tolerating expressions of vulnerability in some areas of social life. However, the expression of vulnerability in paid work and/or career situations is regulated by organisational ideals and circumstances that may also produce distress. We investigated the experiences of men in traditionally male dominated professions, namely first responders (police, paramedics, and firefighters/rescue), asking the research question: Relationally, among male first responders, how do vulnerabilities develop, organise and mend in connection to workplaces, public incidents, homelife and hegemonic masculinity? Twenty-one UK based men of diverse ranks and experience currently working within the first responder services participated in semi-structured interviews. Distress was positioned as an inevitable part of the work. Yet, striking differences in institutionalised ways of expressing vulnerabilities differentiated the experiences of frontline workers, contributing to a wide spectrum of men's silence right through to relative openness about vulnerability, both in the workplace and domestic spheres. The findings provide important insights into how vulnerability is institutionally regulated, illuminating and contrasting how the possibilities for male vulnerabilities are produced.

# Thursday 15 September

## 10:10-10:40

### **Lifecourse - Reproductive Health; Chronic Conditions; Ageing: Death and Dying**

#### **Death, Grief and Social Justice: Does Working Class Bereavement Present a Challenge to Neoliberalism?**

**Stephanie Mulrine**

(Newcastle University)

Sociology has long studied, highlighted and, more recently, advocated against the deleterious consequences of social inequalities on those least equipped to challenge them and prosper. This has given voice to particular groups and deepened understanding of the issues at differing life course transitions. Yet the warning of Howarth (2007) is over a decade old but increasingly relevant, that to make assumptions of the working-class experience of death and bereavement is deeply problematic. Drawing on interviews with bereaved carers in the North East of England this paper seeks to restate the importance of inequality and the end-of-life as an area of research.

Society oriented to a neoliberal economy renders grief as problematic in two ways. Firstly, it is unproductive (Harris, 2017). The social expectations of the bereaved are both overt (e.g. workplace bereavement leave policy) and tacit (e.g. informal time limitations for which grief is acceptably manifest). For those who do not conform, their status as a dutiful consuming citizen is insolent. Secondly, grief is shameful insofar as it represents a threat to, and a loss of, a social bond (Peacock, Bissell and Owen, 2014). Findings from interviews suggest a desire to return to 'normality' in emotional state, however this was frustrated by complex circumstances (unemployment, criminality, mental health issues) and a perception that grief required justification against a prevailing discourse of achieving acceptance and 'moving on'. Working class grief challenges neoliberal ideals of bereavement and so is stigmatised, but, it is concluded, this challenge can show pathways to collective resistance.

### **Citizenship and Health**

#### **Neither compliant citizens nor defiant rebels: Exploring the Covid-19 vaccine hesitancy/acceptance continuum**

**Bridget Lockyer, Laura Sheard**

(Bradford Teaching Hospitals Foundation Trust)

The public discourse around Covid-19, and vaccines in particular, has often felt polarised. There has been an assumption that people have either been compliant citizens or defiant rebels, assumptions which often have classist and racist undertones. This paper asks us to consider the feelings and behaviours of the vast majority of the population who are neither. The findings are based on two interview studies with the same West Yorkshire participants which aimed to understand health experiences and health beliefs during the pandemic. The first study conducted in 2020, encountered participants' anticipated vaccine intentions, the follow up study conducted in 2021/22 was able to capture their decisions. By following up with the same group of people from a largely deprived and multi-ethnic city, we could appreciate, in context, how and why they made their decisions and more deeply explore the complex influences of family and peers, health (mis)information and (mis)trust in institutions. The majority of the participants had chosen to be vaccinated, but this was not without some uneasiness and their narratives still contained threads of misinformation and mistrust. This paper re-emphasises vaccine hesitancy/acceptance as a continuum, rather than as a binary. In doing so we hope to contribute to a greater and more empathetic understanding of what shapes the health beliefs and behaviours of

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all those on the continuum.

## **Inequalities and Intersectionality**

**Exploring access to yoga and its health and wellbeing benefits for people with marginalised identities.**

**Sally SJ Brown**

(Leeds Beckett University)

Yoga offers increasingly well-documented physical and mental health and wellbeing benefits (Büssing et al., 2012; Cramer et al., 2016). However, in Britain and other developed countries, groups marginalised in society are severely under-represented in yoga (Cartwright, 2021).

This study of people with marginalised identities in four northern British cities is the first to explore yoga accessibility for the broad range of groups under-represented in yoga and marginalised in the United Kingdom (UK). The origins of this study lie in a community initiative in a northern UK city which offered free yoga to people living in some of the 10% most deprived neighbourhoods in the country. The researcher taught one of these classes for 18 months over 2019/20.

Using qualitative methodology, the study employs semi-structured, 1-1 interviews to explore the lived experience of 17 diverse yoga participants from four different cities. Sampling uses eight categories of marginalisation identified with reference to anti-discrimination legislation: Ethnicity, Sexuality, Gender, Disability, Body type, Socioeconomic status, Religion and Age.

Emerging findings identify factors affecting yoga accessibility for marginalised groups, confirming and expanding on the literature. Thematic analysis identifies twelve themes affecting yoga access, including “Makes me feel uncomfortable” and “People who do yoga”. Analysis of data through the lenses of Critical Disability and Race Theory and Social Capital indicates impacts on accessibility arising from behavioural and attitudinal norms within the yoga field.

This study’s findings add to the knowledge and provide insight to help increase diversity and accessibility in yoga.

## **Health Service Delivery**

**'Why Doesn't Our Baby Count?' Clinical thresholds and the ascription of value in the investigation of incidents in NHS maternity care**

**Mary Adams, Julie Hartley, Natalie Sanford, Jane Sandall**

(King's College London)

A succession of damning reports on some NHS maternity services highlight the need for families' concerns about the limited, defensive local investigations of infant deaths and serious incidents to be heard. These reports imply a powerful confluence of the interests of injured families to avoid similar events happening in the future and national ambitions to improve maternity safety through investigation and learning programmes. However, in practice, these relationships are far less straightforward.

This paper considers findings from a 3-year NIHR HS&DR study examining approaches to the improvement of disclosure and discussion with families after incidents of harm in NHS maternity care. Data collected included national stakeholder and HCP interviews (n=111); family interviews (n=24) and in-depth ethnographic research in 3 NHS maternity services. Drawing on sociologies of diagnosis, we examine the enrolment of injured families in different incident investigation systems. Our findings identify the consequences of enrolment and its determination by clinical thresholds designed to maximise organisational learning within the constraints of service resourcing. We also identify the compensatory approaches of HCPs, national stakeholders, and families themselves as they question or manipulate the construction of investigation cohorts and reconfigure individual risk trajectories to align with classificatory requirements - practices that contribute to a wider debate over the relevance of

safety improvement projects to meet a family's interests 'in the here and now'. We highlight the shifting ascription of value of, and by, injured families as they are positioned in populations of organisational relevance or as individuals with limited recourse to assistance.

## **Diagnosis, Screening and Treatment**

### **Why don't people take part in atrial fibrillation screening? Findings from the SAFER study**

**Sarah Hoare, Gwilym Thomas, Alison Powell, Rakesh Modi, Jonathan Mant, Jenni Burt**

(University of Cambridge)

The perceived obligation to attend national screening programmes, to demonstrate 'good patient' status and responsibility for one's health, is well documented in medical sociology. Whilst screening uptake by individuals is in practice variable, those decisions to attend or not are made against a broad clinical and societal presumption that taking part in screening is the 'right' choice. The strength of the perceived obligation may be affected by factors like public understanding of the screened diseases and the 'official' status of the screening programme.

In this presentation, we explore the limits of this screening obligation through interviews with those invited to take part in SAFER, an atrial fibrillation (AF) screening study. AF is a common, often asymptomatic, heart arrhythmia which increases in prevalence with age and increases the risk of stroke. We report interview findings about why participants chose not to take part in the SAFER study as a whole or chose to decline the invitation for AF screening. We found that beyond practical reasons for non-participation, participant accounts were underlined by a presumption that participation was optional. Participants did not always recognise a clinical necessity for AF screening and often perceived that the screening was voluntary because it was offered as part of a research study as opposed to an official national programme. Significantly, this framing influenced how they evaluated the benefit (and cost) of participating, and disrupted a well-rehearsed presumption that screening was something one 'ought' to do.

## **Professions**

### **Working well with others? The childbirth ideologies and interactions of NHS midwives and private maternity care providers**

**Georgia Clancy**

(University of Nottingham)

**Aim:** To compare the childbirth ideologies of NHS midwives, independent midwives, doulas and antenatal educators, and consider the consequences this has for interactions between these professional groups.

**Background:** For most women, NHS midwives are the main point of contact and care during pregnancy and childbirth. However, in recent years, dissatisfaction and distrust of NHS maternity care services has led to increasing numbers of women seeking support from non-NHS providers such as independent midwives and doulas, bringing multiple perspectives into the birth room. Previous research has identified tensions between various professional groups, in particular between midwives and doulas.

**Methods:** 13 semi-structured interviews with a range of maternity care professionals working for the NHS or privately.

**Findings:** The greatest differences in the childbirth ideologies of maternity professionals did not occur between NHS providers and private providers, but between those who worked inside the labour ward and those who worked outside the labour ward (whether NHS or private). Tensions between different professional groups were most likely to arise when the status quo (i.e. medicalised birth) was challenged, regardless of whether this challenge came from an NHS or private provider.

Conclusion: Whilst this research highlights ideological differences and tensions between maternity care providers, it also demonstrates the points of convergence which could facilitate a range of professionals working well together. This is pertinent amidst calls for greater 'multi-professional working' and reports of growing demand for doulas, especially from women who do not trust NHS care.

## **Experiences of Health and Illness**

**Adolescents' autonomy transition from parental to self-management of Type 1 diabetes (T1D): a phenomenological study.**

**Carol Kelleher, Eluska Fernandez, Paula Leocadio**

(University College Cork)

Type 1 diabetes (T1D) is a childhood-onset chronic disease, which results in a lifelong dependence on exogenous insulin. T1D is more prevalent in adolescents than in adults, and the self-management of insulin-dependent diabetes is extremely complex and difficult, as it involves injecting with insulin, self-management of blood testing, regular physical activity and diet monitoring (Yang et al. 2018). Transitioning autonomy from parental to self-management of diabetes within and beyond the family are not well understood, in particular from the phenomenological perspective of teenagers, despite being frequently accompanied by worsening diabetic health. While existing research, primarily from the medical and psychology domains, has focused on medical case analysis and outcomes, the complex lived experience, and social and family contexts which impact adolescents' autonomy transition have been neglected (Wu et al. 2014, Yang et al. 2018). Diabetes control is not just the outcome of medical interventions, adherence with this burdensome disease is influenced by psycho-social factors (Lipman and Hawkes, 2021). Here we present findings from a qualitative phenomenological study which explores the process of autonomy transition from parental to self-management of T1D and how this is experienced by the adolescents and their parents/guardians. Data was collected from interviews with 12 adolescents (16-18 years old) and 24 parents/guardians. Findings reveal the importance of understanding adolescents' conception of autonomy and self-management, characterized by the pulls of desire for autonomy and the need of support from others, and the complexities of responsibility-sharing between the adolescent and their caregivers.

## **Politics and Ethics of Health**

**The politics of assisted and unassisted suicide in the UK: pain, prevention and porous boundaries.**

**Hazel Marzetti, Amy Chandler, Alex Oaten, Ana Jordan**

(University of Edinburgh)

The distinction between assisted and unassisted suicide is rigidly constructed and fiercely defended in policy, parliamentary debates, and public discourses. Suicide was decriminalised in England and Wales in 1961 and in Northern Ireland in 1966 through the Suicide Acts of the respective countries (in Scotland suicide was not illegal). It was also these acts that precluded the encouragement of, or assistance with, suicide; preventing assisted suicide across the UK. In this paper, we draw on a qualitative analysis of records from UK parliamentary debates (2009-19) to explore the ways in which pain and suffering, vulnerability, and the right to life and death are employed in order to question the rigidity of the distinction between un/assisted suicides. Our analysis underlines the relevance of sociological theorisation of pain, and the intractable challenges of mind/body dualism and other binary imaginaries. Throughout the debates we analysed, MPs grappled with what we call 'porous boundaries' between emotional and physical pain and the extent to which either may be understood as in/tolerable to bear. In doing so, they appeared to consider, contest and construct a rationality to the resulting deaths. The construction of these rigid binaries then formed the foundations of decision making with regard to complex ethical questions around the imperative to prevent both assisted and unassisted suicides which we will explore in this paper.

## **Mental Health**

### **Developing bespoke models of care: Examining how young people provide informal support to each other during tough times**

**Benjamin Hanckel, Jasbeer Musthafa Mamalipurath**

(Western Sydney University)

Mental health and help-seeking activities are often framed through the provision of services to support people into pathways of care. This includes formalised peer-based models, however there is less research on informal help-seeking and support between friends. This work-in-progress paper draws on focus group data with a diverse sample of young people (16-25) across two urban settings to explore the ways that care is produced and enacted between friends, and how support is provided for those experiencing mental ill-health. Our findings point to the varied and multiple ways that care enters into friendships, and the complex ways that support sits intentionally outside of and/or in parallel with formal based care provision. The young people in our study spoke about care as an identity and a one-on-one interaction between friends, which requires emotional labour in its identification and production, and is regulated according to the temporal capacities of young people. The support work produced through these encounters provides a sense of agency to young people in a system that often positions them at deficit and/or does not recognise their capabilities. This support is enacted across on-/offline contexts and made possible through the affordances of spaces, where institutional and digital infrastructures complicate and support care practices. Within these narratives bespoke models of care emerge. These sit in parallel to the formalised pathways to help-seeking and mental health care that exist. We conclude by considering the implications this has for how we think about youth mental health care and trajectories of help-seeking.



# Thursday 15 September

## 10:45-11:15

### **Citizenship and Health**

**“The beautiful thing was I made a lot of sweets and cooked for my family during the pandemic. We all used to eat together...” The Effects of the COVID-19 Pandemic Among Undocumented Migrants in the UK: findings from the CICADA study**

**Kusha Anand, Amanda Moore, Victoria Redcliff, Carol Rivas**  
(UCL Institute of Education)

According to the Pew Research Centre, undocumented migrants are estimated at between 800,000 and 1.2 million people in the UK. These individuals face multiple structural and social challenges when attempting to access social services. One area of concern is how undocumented migrants negotiate access to health care services. The CICADA study has explored disabled undocumented migrants' experiences of the pandemic through an intersectional lens. We used online semi-structured interviews to collect experiences of undocumented migrants. Data were analysed by looking for common patterns and themes in the transcripts and guided by Critical Race Theory and Undocumented Critical Theory. The undocumented migrants shared narratives on fear, survival, and community as these relate to negotiating health and well-being.

Psychological distress is common not only for undocumented people but also for their loved ones who are not undocumented. Family was extremely valued in this community, however, some participants specified that they felt disconnected from their families post-covid. In terms of strengths, findings exposed that problem solving is a chief coping strategy, and many participants reported using religion to remain hopeful and optimistic about their future.

This study is funded by the National Institute for Health and Care Research (NIHR) [NIHR132914, HS&DR]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

<https://www.pewresearch.org/global/fact-sheet/authorized-immigrants-in-the-united-kingdom/>

### **Inequalities and Intersectionality**

#### **The Digital Health needs of a deprived community**

**Chris Yuill, Scott Mcvean**  
(Robert Gordon University)

This research explored the digital health needs of a deprived community as defined by residents of the community. The estate in which we conducted the research is marked by high levels of deprivation, unemployment and levels of health and wellbeing that are much worse than national and local averages.

Through a series of focus groups, we asked them to define what they saw as the causes of poor health and wellbeing that faced the wider community, and what digital health and digital health technologies may make a difference to their health and wellbeing.

The findings indicated that participants understood that unemployment and low-paying jobs were the root causes of poor health and wellbeing, and that digital approaches to health were unlikely to tackle systemic and structural Inequalities and Intersectionality. Indeed, digital health approaches were not liked by many participants, who lacked either the necessary digital skills or lacked the necessary infrastructure of smartphones, computers or internet supply.

The need for community physical spaces was advanced by the participants as being a more pressing need to tackle health and wellbeing, as was the provision of a cheap (if not free) public transport system to allow access to healthcare and GP Surgeries that lay outside their locality.

Overall, older forms of technology and non-digital solutions were seen as being necessary to counter health problems in the community.

## **Health Service Delivery**

### **Ambivalence in safeguarding practices when primary care pivoted to remote consulting during the COVID-19 pandemic.**

**Sharon Dixon, Lucy Frost, Sue Ziebland, Cathy Pope**

(Nuffield Department of Primary Care Health Sciences, University of Oxford)

Before the COVID-19 pandemic, the uptake of remote consulting in primary care was low. Typically remote consultations were utilised by enthusiastic GPs or for selected patients. The pandemic required a rapid shift to remote care delivery for all patients as part of policies designed to 'protect the NHS' and limit spread of the virus. Concerns were voiced about adverse impacts of this 'remote by default' mode of delivery, notably in relation to patient safety, equity of access and the quality of therapeutic relationships.

Ambivalence as a sociological construct has been used to explore sociotechnical change and digital health interventions. Here we enrol ambivalence in a reflexive consideration of nuance and complexity surrounding the use of remote consulting in a discrete area of general practice work namely safeguarding. We conducted qualitative interviews with 18 GPs in England to examine how they accomplished safeguarding during the COVID-19 pandemic. GPs held seemingly opposing perspectives and described how remote consulting simultaneously promoted safety (reduced infection) and increased clinical risk (missed physical signs, more transactional encounters). Remote consulting increased Inequalities and Intersectionality and reduced equity of access – but conversely it offered flexibility that could be actively harnessed to create equity. GPs also described their work consulting remotely as adaptive and responsible, yet they also felt also hindered by the technology, and somehow simultaneously they became more approachable and less accessible. We use the notion of ambivalence to explore these contradictions and explain why, when, and for whom remote consulting works – and when it might not.

## **Diagnosis, Screening and Treatment**

### **Frailty and the becoming-aged body: a more-than-human analysis**

**Nick Fox, Victoria Cluley**

(University of Huddersfield)

'Frailty' is increasingly used as a clinical term to refer and respond to a particular bodily presentation, with numerous scores and measures to support its determination. While these tools are typically quantitative in nature and based primarily on physical capacity, qualitative research has revealed that frailty is also associated with a range of social, economic and environmental factors, and is generally considered to be a stigmatising term that older people resist. We apply a relational and more-than-human perspective to re-think these biomedical and sociological understandings of frailty. We conduct a materialist synthesis of recent qualitative studies of ageing and frailty, to explore the material assemblages and affects that this perspective reveals.

This analysis leads us to replace a biomedicalised and essentialist conception of frailty as bodily attribute with a relational understanding of a 'frailty assemblage'. Within this more-than-human assemblage, materialities establish the on-going 'becoming' of the ageing body. We suggest that what clinicians refer to as 'frailty' is one becoming among many, produced during the daily activities and interactions of older people. We conclude that clinical and sociological perspectives on ageing need to

acknowledge the complexity of these more-than-human becomings; to move beyond biomedical conceptions of 'frail bodies'; and to support and enhance the lives and rights of older people.

## **Experiences of Health and Illness**

### **Vulnerability and epistemic injustice following post-surgical complications: An in-depth qualitative study**

**Liz Sutton, Lesley Booth, Mudathir Ibrahim, Peter McCulloch, Mark Sujan, Janet Willars, Nicola Mackintosh**  
(University of Leicester)

Clinical deterioration following abdominal surgery is both a medical emergency as well as a very personal crisis for patients. Drawing on in-depth interviews with seven abdominal surgery survivors, we present an idiographic account of participants' experiences, situating their contribution to safety within their personal lived experiences and meaning-making of these episodes of deterioration. We draw on epistemic injustice as an analytical frame (Fricker, 2007) to understand the role of embodied knowledge in terms of whose knowledge counts within escalation of care practices within the hospital context. Our analysis reveals the overarching meta-theme of vulnerability in relation to participants' experiences of complications after abdominal surgery. This encapsulates the uncertainty of the situation all the participants found themselves in, and the nature and seriousness of their health conditions. We see elements of both testimonial injustice as some of our participants' embodied knowledge is dismissed or seen as less valuable, and hermeneutic injustice as lack of information and interpretative resources negatively affect participants' ability to articulate and give meaning to their experiences. Our insights are timely given recent high profile cases of families who have suffered harm after their concerns about care were disregarded. Our work has implications for designing strategies to enable escalation of care, both in terms of supporting staff to deliver compassionate care, and in strengthening patient and family involvement in rescue processes.

#### References

Fricker, M. (2007). *Epistemic Injustice: Power and the Ethics of Knowing*. Clarendon Press.

## **Politics and Ethics of Health**

### **The politics of problematic polypharmacy. Whose knowledge counts? An ethnographic study.**

**Deborah Swinglehurst, Nina Fudge**  
(Queen Mary University of London)

Polypharmacy - multiple medicines used by one person - is a global safety concern. Growing recognition of the scale of the phenomenon and the potential dangers of overtreatment has culminated in recent changes in NHS policy demanding structured medication reviews in primary care.

Polypharmacy is a 'wicked problem' emerging within a complex system of interconnected people, practices, norms and conditions. Tackling polypharmacy is likely to require significant collaborative effort within the health system.

We present findings from an in-depth ethnographic study of polypharmacy across general practice, community pharmacy and patients' homes. We focused on older patients prescribed 10+ medications ('higher risk' polypharmacy). Adopting a range of qualitative methods including observation, interviews, cultural probes, and video-reflexive ethnography we studied the experiences and practices of professionals and patients and their interactions.

Drawing on Fricker's concept of epistemic injustice – both testimonial injustice and hermeneutical injustice - we illuminate the politics of polypharmacy by considering knowledge practices at three key interfaces: patient-general practitioner (GP); pharmacist-GP; GP-specialist. Despite recognition within all groups that polypharmacy presents a problem that warrants action, the circulation of epistemic injustice serves to sustain inertia. Patients and professionals find themselves unable to act because of how they are positioned, and how they position themselves with respects to the kinds of knowledge or expertise they lay claim to. Polypharmacy emerges as an 'inarticulate' conundrum characterised by a

gap in the collective shared hermeneutical resources available to doctors, pharmacists and patients. Without such resources, the paralysis of polypharmacy is likely to persist.

## **Mental Health**

### **Transitioning to working from unemployment and social security benefits. A qualitative exploration of the experiences of people with the diagnosis of depression in England**

**Krisztina Nemeth**

(University of Essex)

Introduction: Mental health problems have been the single biggest cause for disability benefit claims in the UK for a decade. Welfare reforms (e.g., welfare activation) have been increasingly focused on supporting disabled people into employment, with questionable outcomes.

Aim: To qualitatively explore how people who have the label of depression experience the transition back to the labour market from being unemployed and receiving social security benefits.

Method: Qualitative method was used with elements of participatory study design, convenience and snowball sampling, and thematic analysis. Participants: All interviewees (5 males, 3 females; age range: 25–51) had worked in paid jobs and most had had several periods of unemployment. All had tried medication for depression, had received at least one psychologically informed intervention, and had experience of the new and/or old social security benefits.

Results: Six main themes were constructed: (1) Communicating confusion, (2) Managing in hardship, (3) Managing mental health, (4) Considering the consequences of working, (5) Questioning volunteering, and (6) Facing discrimination. Two overarching themes (i.e., Interacting barriers and Counteracting the barriers) emphasise the interconnectedness of the six main themes.

Discussion: Participants' experiences of navigating the welfare systems (i.e., benefits and health care) are considered within the social model of disability and comparisons are drawn to a VUCA environment. This research highlights the importance for policy makers that evaluating the combined effect of social policies across health care and welfare is essential in order to prevent avoidable harm to those in need of mental health and/or financial state support.

# Thursday 15 September

## 11:20-11:50

### Citizenship and Health

#### Bridging the Gap between Patients and Migrant Doctors

**Hande Guzel**  
(University of Cambridge)

Migrant bodies are sites of struggle and contention at social and individual levels. These bodies become more vulnerable and open to scrutiny through their movement and/or the impossibility thereof. Sitting at the intersection of sociology of migration and medical sociology; this paper will explore the relationship between migrant doctors and their (potential) patients, by focusing on (i)migrant doctors' experiences of working in Turkey, and (ii)the experiences and views of patients in Turkey in their interactions with migrant doctors. I am interested in understanding to what extent (potential) patients perceive their interactions with migrant doctors to be different from those with doctors of Turkish nationality, and how migrant doctors experience and make sense of this difference, if it exists.

This paper aims to bridge the gap between patients and migrant doctors. Increasingly more doctors are migrating to Turkey (Erdogan 2015), with more than 4000 migrant doctors currently working in general practices, in private clinics, and private or city hospitals (Danyildiz 2021). While there is increasingly more literature on refugees' access to healthcare, experiences of migrant doctors are largely ignored, especially in Turkey. How patients view migrant doctors, and how doctors' experiences at medical institutions and how the doctor-patient relationship are moulded through doctors' migrant status have been under-researched, a gap that this paper will aim to fill. Through the analysis of online forums and semi-structured in-depth interviews, this paper will unpack the discourses surrounding the intersubjective relations between migrant doctors and their (potential) patients.

### Inequalities and Intersectionality

**"More than living healthy, it's living with what you have": The collide among medicalized health practices and children and mother's daily routines to reduce overweight. A qualitative study in Santiago, Chile.**

**Cecilia Prieto, Linda Bauld, Nicola Boydell, Jeni Harden**  
(University of Edinburgh)

Introduction: In Chile, 54.1% of children are classified as higher weight. However, there is limited understanding of children's experiences with weight and health-related practices and how these experiences might inform public health policy in Chile.

Objective: To explore children's and caregivers' accounts of their health-related practices (purchases, diet, exercise) and weight in their daily lives.

Methods: 34 online semi-structured interviews were conducted with children between 10-12 years classified as overweight or obese at ANCORA UC clinics and their mothers. A Reflexive Thematic approach to analysis has been adopted (ongoing PhD studies).

Findings: Health-related practices (HRP) on weight in their daily lives are experienced from notions of risk, weight stigma and medicalization, provided by the expert knowledge that encourages children to

increase exercise and modify diet. These HRP are experienced as family tension, and it does not necessarily improve children's health or weight status. HRP are associated with socioeconomic circumstances, time, and family compositions. The notions of care and nurturing are highly shouldering on mothers.

Conclusion: Children and mothers feel individually responsible for the overweight condition, and the discourses from experts collide with family compositions, socioeconomic circumstances and daily routines. These findings are relevant because this might explain the unintended consequences that the current Chilean policies and primary care to reduce overweight have on children and carers, focusing mainly on behavioural changes and reinforcing weight stigma without improving health conditions.

## **Health Service Delivery**

### **Terms of Endearment Used Towards People Living With Dementia In The Acute Hospital Environment.**

**Lauren Bridgstock**  
(University of Nottingham)

The acute hospital setting is an environment which is known to be difficult for people living with dementia (PLWD); dementia can be invisible and poorly understood, and healthcare staff often view communication with this group as challenging. Elderspeak is a type of communication used specifically towards older people, particularly PLWD. It involves features such as high pitch/ tone of voice, simplified sentences/grammar, and terms of endearment. Terms of endearment in particular are typically advised against in training and guidelines for healthcare staff, yet as this paper shows, they still occur within practice. Despite this, there is mixed evidence regarding how individuals may receive and respond to these terms of endearment and elderspeak more generally. This paper uses conversation analysis to begin to examine the occurrence and function of terms of endearment within a collection of video data recorded on a UK hospital ward. The data shows routine healthcare interactions between PLWD and a range of healthcare professionals. This is part of a wider PhD project entitled: "Is elderspeak always inappropriate? An empirical investigation into the use of elderspeak in dementia care," supervised by Dr Alison Pilnick, Dr Sarah Goldberg and Dr Rowan Harwood. The analysis within this paper will contribute to the empirical literature and may aid the development of future training resources, leading to improvements in the quality of care given to PLWD in hospital environments.

## **Diagnosis, Screening and Treatment**

### **Metrification: Exploring the Case of Pain Scales**

**Jaya Mathur**  
(Jawaharlal Nehru)

In the history of pain medicine, several techniques of measuring pain have been experimented upon, from the dolorimeter to the pain scale — in order to facilitate diagnosis and treatment. The metrification of pain which involves translating felt pain into measurable categories has been oft-criticized by medical practitioners, bio-statisticians, and even social science scholars for several reasons and on several registers. However, it is interesting to note how all strands of criticism coalesce around the same theme — how the metrification is not accurate enough — in doing this, they effectively do not offer criticism of metrification itself, rather suggestions on how it could be done in a more exact, clinical manner. The usage of various pain scales and suggestions for making them more accurate are made claiming that these instruments need to be invariably resorted to as long as any better or alternate ways of measuring pain come about. Such claims are in ignorance of the fact that qualitative modes of collecting information on pain could be developed and sophisticated in order to be deployed in a clinical context. For instance, both public health and medical practice stand to benefit greatly from the ethnographic method.

I intend to argue, that such tendencies might be understood as an indication of how metrics, in having

penetrated and gained preponderance even in the realm of a phenomenon as complex as pain, have subsumed most other ways of apprehending the world.

## **Experiences of Health and Illness**

### **The impact of culture and religion on the experience of dementia in Southwestern Nigeria**

**Elizabeth Onyedikachi George, Ruth Bartlett**

(VID Specialized University, Oslo, Norway)

Dementia has been designated a public health crisis by the World Health Organisation and other leading health organisations around the world. To date, much of the research on people's experiences of living with a dementia has been situated in the Global North, even though countries in the South account for two-thirds of dementia cases worldwide. This paper reports findings from an ethnographic study, which sought to explore the everyday experiences of people with dementia in a Nigerian community and contribute an in-depth Nigerian – and African – perspective to the literature on dementia experiences. The ethnographic fieldwork was conducted in Southwestern Nigeria and involved 35 conversational interviews with people with dementia, their families/neighbours, and members of their community, and detailed observations of the environment. The concepts of citizenship and disability informed the study to advance sociological knowledge of this health condition in a Nigerian context. Data were analysed abductively using thematic analysis. Analysis revealed that the culture of the community promotes communal care for older people, including people with dementia. However, some participants still experience neglect and of exclusion owing to widespread poverty in the community and accessibility issues. Further, the study shows that aspects of the Islamic religion, such as the call to prayers, communal prayers and visitations, and personal daily prayers can create spaces of inclusion, hope, and meaning making for people with dementia. The main recommendation from the study is better utilisation of religious and cultural resources in dementia care planning in all countries.

## **Politics and Ethics of Health**

### **Health Campaigning in the UK (1930-1974)**

**Martina Topic, Ralph Tench**

(Leeds Beckett University)

During the current COVID-19 pandemic, some commentators argued that the economy is prioritised over the health of the population with measures either not being introduced on time or lifted prematurely. In this paper, we are arguing that historically the UK's health campaigning was always grounded in the British libertarianism tradition, which up to today underpins British health politics. To that end, we are analysing 'coughs and sneezes' TV adverts from the 1930s and 1940s as well as campaign posters that were disseminated to the British public in the period from 1930 until 1974, which changed the health behaviour of the country and stabilised the economy.

The UK launched a 'coughs and sneezes' campaign during the 1930s after the country experienced grave consequences of the so-called Spanish flu pandemic during WWI. The initial 'coughs and sneezes' campaigns targeted behavioural change and asked people to change their behaviour when coughing and sneezing by using a handkerchief. These campaigns were launched through advertising posters as well as health promotion TV adverts. Throughout the period from the early 1930s until 1974, the UK Governments had campaigned on coughs and sneezes and these Governments came from Liberal, Conservative and Labour parties, as well as national and coalition governments during war periods, and the priority throughout this period, irrespective of who was governing the country, was to protect the economy and the workplaces.

The research is ongoing but we confirm that we will have a paper to present at the conference.

## **Mental Health**

### **Living with the spectre of combat: Non-serving military partners' narratives of deployments and mental health outcomes**

**Emma Long**

(University of East Anglia)

The impact of war upon the mental health of UK service personnel attracted significant political, cultural and academic interest during the height of the deployments to Iraq and Afghanistan in the 2000's and beyond. Whilst much of the current research portfolio focuses on quantifying mental health outcomes among military populations, this presentation is concerned with how partners of (ex)service personnel narrate and thus live with the possibility of combat trauma. It focuses on how they construct narratives through imaginings of their (ex)service partners' previous combat experiences, watching for signs of trauma, and anticipating unknown futures (and future deployments). Through doing so, it shows how they live with the spectre of war and its affects, often long after the return of their partner, regardless of whether they have received a diagnosis. These findings have implications for how we understand the impact of mental health outcomes from war upon families, showing how they can be haunted by possibility. Understanding this experience as haunting blurs the commonly demarcated boundaries between battlefield/homefront and war/peace. This presentation is based upon the findings from three phases of my qualitative research programme: (1) PhD involving semi-structured in-depth interviews with 26 non-serving female partners, exploring their experiences of supporting their male partners' reintegration post combat-related deployment, (2) pilot study exploring the life-courses of 6 female partners of male veterans, and (3) an autoethnography as I grew up in a military family and am now a military partner.



# Thursday 15 September

## 11:55-12:25

### **Inequalities and Intersectionality**

#### **“Dystopian Eugenics and Mestizo Futurisms in Eduardo Urzaiz’s Eugenia”**

**R Sanchez-Rivera**

(University of Cambridge)

Set in 2218, *Eugenia*, the first science fiction novel about eugenics in Latin America, envisions a contradictory utopian and dystopian future premised upon eugenical engineering. Telling the story of Villautopia, this novel was published by Eduardo Urzaiz—medical doctor and teacher—in 1919, preceding the institutionalisation of eugenic societies in Mexico. In this presentation, I analyse Urzaiz’s vision of the beginnings of eugenics in Mexico, through the framework of Hooker’s (2017) concept of mestizo futurisms. Ultimately, I argue that *Villautopia* is presented as ever-vigilant and always responding to threats of degeneracy and social disorder, which accurately reflect eugenicist underpinnings of Urzaiz’s time.

### **Health Service Delivery**

#### **Who is left behind? Access to remote antenatal care through the lens of candidacy**

**Lisa Hinton, Karoline Kuberska**

(University of Cambridge)

Remote appointments, delivered via telephone or video, became a standard feature of antenatal care pathways in response to the COVID-19 pandemic. This paper explores the impact of remote provision of antenatal care on access to care through analysis of in-depth interviews with pregnant people, healthcare professionals, managers and system-level stakeholders who received, delivered, and organised antenatal care. We found that remote provision of antenatal care had far-reaching effects on access when understood through the lens of candidacy (Dixon- Woods 2006). It altered pregnant women’s own identification of themselves and their babies as eligible for antenatal care. Navigating services became more challenging, often requiring considerable digital literacy and sociocultural capital. Services became less permeable, meaning that they were more difficult to use and demanding of the personal resources of users. Remote consultations were experienced as more transactional in character. They were limited by lack of face-to-face contact and safe spaces, making it more difficult for women to make their needs – both clinical and psychosocial – known, and for professionals to assess them reliably. Operational and institutional challenges, including problems in sharing of antenatal records, were influential. There were strong suggestions that a shift to remote provision of antenatal care may increase risks of inequities in access to care in relation to every feature of candidacy we characterised. A shift to remote delivery is not a simple swap: it restructures many aspects of candidacy for care in ways that pose risks of amplifying existing intersectional Inequalities and Intersectionality that lead to poorer outcomes.

## **Diagnosis, Screening and Treatment**

**“Adding meaning to medicine”?: An exploration into the affective practices of men who engage in social prescribing.**

**Adam Mars**

(Lancaster University)

In recent decades, many health policy makers, across the political spectrum, have argued that the NHS is in need of reform. A central thrust of this critique is focused upon the lack of democratic participation on the demand side of the service, either stressing the increasing need for patient choice as quasi market mechanism or other pedagogical mechanisms that look to increase patient involvement and move away from a paternalistic ethos of professional care. Social prescribing is a policy agenda that looks to transition from consultations on “what’s the matter with you?” to conversations on “what matters to you?”, connecting patients up with surrounding community assets that can provide novel engagement with new practices and social capital. As a “sub clinical” policy, social prescribing seems to be well positioned to attract men, many of whom prefer “informal” conversations about mental health than those driven by professionalism.

My paper will present findings from working class men who have engaged with social prescribing in the north of England. The men interviewed often reflected upon “ultimate concerns” of life, helping them to critically interrogate their earlier relationship to “hegemonic masculinity”. The paper will examine how they made sense of this through “affective practices” and through the lens of classical sociological theory, re-enchantment, drawing conclusions on what health policy makers will need to take into account if they are serious about revitalising democratic involvement in the NHS.

## **Experiences of Health and Illness**

**Harmony from cacophony? Influence, autonomy and interdependence in the construction of ‘the voice of local people’ in health and care systems in England**

**Graham Martin**

(University of Cambridge)

The question of how to ensure that patient and public voice feeds into decisions about the planning, delivery and improvement of healthcare has long vexed policymakers in the UK and elsewhere. Following a rapid succession of new organisations responsible for public voice, local Healthwatch were introduced in 2013 as part of reforms to the organisation of healthcare in England. Drawing on a national study of Healthwatch, this paper uses institutional sociological theory, and particularly Bourdieu’s (1981) conceptualisation of the political field, to examine how Healthwatch bodies seek to realise their mandate to act as a ‘voice of local people’ in changing local health and care landscapes. Using an extensive empirical dataset comprising ethnographic and interview data from five Healthwatch case studies (collected 08/2019– 01/2021), sampled for their diversity of organisational form and context, we illustrate the range of publics and approaches to voice covered by Healthwatch. The underspecified remit for local Healthwatch organisations appeared to allow them significant latitude in determining priorities and in their approach to representing the public. However, pressures common to all case-study sites led to a preoccupation with demonstrating activity and influence, and a convergence towards an enactment of voice that emphasised ‘insider’ status, sympathetic critique, and usefulness. This conception of Healthwatch, as a constructive, collaborative partner at the table rather than a more independent source of challenge, might be understood as a faithful realisation of its role in the system as designed. However, it has important implications for both the issues and the publics prioritised.

## **Politics and Ethics of Health**

### **The 'ethical way' to do health business? Moral economies of UK-India public sector exports in health worker training and education**

**Sibille Merz, Benjamin Hunter, Ramila Bisht. Susan Fairley Murray**

(King's College London)

As government pressure is growing for public healthcare organisations, including NHS Trusts in England, to become more entrepreneurial, many are pursuing income through the provision of transnational services for health worker training and education. The Indian healthcare system, with its rapidly expanding training and provision industries, is being targeted as a potential market for these services. Using a moral economies framework (Sayer, 2015), this paper examines attempts to realise cross-border markets in a postcolonial context, focusing on the thriving UK-India trade in health education. Drawing on qualitative data derived from publicly available documents and semi-structured interviews with 67 representatives from different organisations in the UK and India, it explores how these activities are legitimised and negotiated by the actors involved. It finds that UK-based respondents navigate a complex terrain where the new expectation of a transnationally commercial NHS generating extra funds to support local activity exists alongside motivations framed around philanthropy and diasporic links; motivations that in turn are being challenged by growing awareness of the coloniality of 'global health'. Expanding opportunities in health worker training and education provides an opportunity to address these multiple obligations, casting it as 'the ethical way' to do health business. Indian respondents frame their engagement in these markets as meeting individual career objectives and also contributing to the collective wellbeing of the population, carrying forward the common narrative of serving the nation through corporate healthcare.

## **Mental Health**

### **The medicalisation of memory and age through the diagnosis of Mild Cognitive Impairment**

**Christine Carter**

(UCL)

Mild Cognitive Impairment (MCI) is a diagnostic category describing cognitive concerns inconsistent with age and is viewed as not being dementia. For older people living with MCI this leads to uncertainty and confusion with defining conditions presented as both illness and as risk conditions that are not illnesses. Identifying and diagnosing MCI is difficult given a lack of standardised criteria (Schweda et al 2018). This paper explores the role of MCI as a diagnosis and discusses how older people with MCI navigate the complexity that goes with the condition.

It is widely accepted that dementia is a preventable condition; with a range of risk factors recognized as being potentially modifiable, (Livingstone 2021). Additionally, narratives of healthy ageing are projected onto older people with memory impairments. This compounds individuals need to navigate a sense of identity and affirm that identity alongside the perceived moral responsibility to take action to prevent dementia, I discuss this as a liminal experience which is fluid rather than static and which involves broader social and individual responses that encompass negotiating relationships and identity. I conclude that the increased medicalisation of memory impairment and diagnosis of MCI needs to be situated within the social context of disruptions to 'normal' ageing, whereby the disruptions to everyday life caused by MCI leads to an increase in perceptions of personal responsibility for memory deterioration. This can be arduous and difficult for the individual as well as prompting a too early acceptance of memory disruption.

# Day 2 Afternoon Abstract Book

NB - Virtual presentations are highlighted in blue

## Thursday 15 September 14:00-14:30

### Patient - Professional Interaction

**What's wrong with patient centred care?: autonomy, abandonment and expertise**

**Alison Pilnick**

(University of Nottingham)

PCC is typically framed as a moral imperative, necessary to prevent a return to the unacceptable medical paternalism of the past. However, empirical research repeatedly fails to show a clear link between the adoption of PCC and improvement in health outcomes. These results are largely considered as professional failings, to be remediated through 'better' training in PCC: as a result empirical research is largely focused on the extent to which practice does not live up to PCC checklists. At last year's Medsoc I presented preliminary work from a British Academy funded project to critically re-examine the concept of PCC. The project was delayed by Covid-19 but is now completed. Drawing on a large corpus of healthcare interactions collected from a range of settings over a 25 year period, and analysed using conversation analysis, I will consider some of the reasons why the enactment of PCC is more complex than is typically acknowledged. I will argue that this is grounded in the way that the operationalization of PCC can problematize medical expertise. This problematization is a result of the conflation of two different kinds of authority: epistemic authority (put simply, the right to know something) and deontic authority (the right to decide what happens as a result). In rejecting the deontic authority that was the hallmark of medical paternalism, PCC can also sideline professionals' epistemic resources. Reform may therefore be better directed at considering how this expertise can be more productively enacted for a 21st century public.

### Mental Health

**Older men, masculinities and mental wellbeing: Initial findings from a study exploring older men's help seeking and use of community support groups for mental health and wellbeing.**

**Alex Vickery**

(University of Bristol)

Historically men have lower levels of help seeking for mental health difficulties than women (Olliffe et al., 2019) due to barriers related to dominant masculine norms (Seidler et al., 2020), stigma, and lack of available and engaging services accessible to men (Seidler et al., 2018). Although men's mental health has received greater academic attention in recent years, there are few studies that have explored use of support services by older males whose needs are different to younger males (Meyer, 2019). Mental health in older people is a social care area that requires more attention as there is still an existing long-held assumption that mental ill-health is an inevitable consequence of 'old age' (Milne, 2020). For

men, experiencing ageing and mental distress can be difficult to navigate because of the impact on their social life, self-identity and (re)construction of the masculine self (Apesona-Varano et al., 2015). Older men may try to avoid any forms of subordinate reliance on others which can lead to a delay in seeking help for mental health concerns (Griffith et al., 2017). This paper will examine some preliminary findings from an ongoing post-doctoral study that is exploring older men's mental health and emotional wellbeing, help seeking and specifically their use of community support groups. It will consider older men's mental health experiences and their use of support groups in relation to (multiple) masculinities, also acknowledging the importance of age relations in understanding older men's experiences of mental and emotional difficulties.

## **Experiences of Health and Illness**

**Working it out: will the improved management of leaky bodies in the workplace create a dialogue between medical sociology and disability studies?**

**Jennifer Remnant, Katherine Sang, Katriona Myhill, Thomas Calvard, James Richards, Sushila Chowdhry**

(University of Strathclyde)

This paper focuses on the workplace as a significant site of convergence between the disciplines of medical sociology and disability studies. As disability remains on the margins of sociological exploration and theorising relating to health and work, disabled workers remain on the margins of the workforce, subject to disproportionate rates of unemployment, under employment and workplace mistreatment.

The paper focuses on the experiences of people with 'leaky bodies,' focusing specifically on employees who experience troubling menstruation and/or have gynaecological health conditions. It brings together data from three studies conducted between 2017 and 2020; interviews with disabled academics (n=75), key stakeholders in universities (n=35) (including university executives, line managers and human resources staff) and university staff with gynaecological health conditions (n=23). Drawing on the social model of disability and theories of embodiment, we explore the experiences and management of workers with leaky bodies in UK University workplaces.

Data illustrates how workplace practices undermine embodied experiences of workers with 'leaky' bodies by maintaining workplaces which ignore the materiality of bodies. We highlight that, in addressing embodied needs alongside acknowledging disabled people as an oppressed political category, represents a theoretical meeting point for disability studies and medical sociology.

## **Experiences of Health and Illness 2**

**Gynae Cancer Narratives: Micro-Infringements of Dignity During Radiotherapy Treatment for Gynaecological Cancer**

**Lisa Ashmore, Vicky Singleton, Mette Kragh-Furbo, Hilary Stewart, Hutton Daniel, Lorraine Salisbury, Corinne Singleton**

(Lancaster University)

This paper is concerned with dignity in care during radiotherapy. It describes how, as part of a project collecting narratives from people having radiotherapy treatment for gynaecological cancer, patients reported micro-infringements of dignity.

Dignity, the state of being worthy of respect, is understood to be a fundamental human right. Providing care and treatment that ensures people's dignity is legislated in the UK (Regulation 10, The Health and Social Care Act 2008, 2014) and the Radiographers' Code of Conduct and Ethics stresses respecting individual dignity, to prevent behaviour that causes physical, emotional, or psychological distress or damage to anyone. Yet patient narratives revealed subtle lapses that undermined patient dignity: forgetful moments, mundane practices, environmental characteristics, intentional and unintentional incidents.

We explore how the context of radiotherapy, with high precision accuracy and rigid treatment

preparation regimes, is experienced as chaos by some and how treatment demands that patients expect the unexpected and rapidly absorb change. It is a delicate act of balancing potentially conflicting values and engaging in intricate ethics (Pols, 2015). We present data that describes how micro-infringements of patient dignity, experienced as fleeting or mundane lapses in provision of respectful care, can become embedded into structures and routines of practice.

By throwing a light on patient narratives about micro-infringements of dignity, we reveal how dignity can be threatened by demands of the system and environment of radiotherapy treatment, and present a means through which we can use patient voices to be hopeful about better care in the future.

## **Pedagogy and Methods**

### **Developing Problem Based Learning for Sociology undergraduate teaching**

**Kate Stewart, Emma Long, Tom Porter**  
(University of East Anglia)

Problem Based Learning (PBL) has become commonplace in undergraduate curricula in certain subjects including medicine, and sociologists teaching in this context have become familiar with this format and its potential for student learning.

However, PBL is not widely used in UG Sociology programmes, despite it being consistent with fostering innovative thinking about social issues and social change (Eglitis et al 2016). Given that sociology is described in the QAA Benchmark Statement as a reflexive discipline aimed at developing critical awareness of and engagement with the social world (QAA 2019), the use of PBL offers a pedagogical approach that coheres with this disciplinary vision.

This paper outlines the development and introduction of a PBL design for the delivery of a second year UG option module 'Social Policy and Social Justice' which is offered as part of the new BA Sociology programme at the University of East Anglia. It is co-delivered by a team of 3 sociology lecturers, 2 of whom have experience delivering PBL in medical school contexts and who felt that the approach would work successfully on a BA Sociology programme.

In developing the teaching, we drew on the wealth of literature and resources on PBL teaching, the vast majority of which is framed for teaching of that narrow range of (mostly vocational) subjects where PBL is commonly used. Our experience has shown the transferability of models of PBL development to sociology, and highlights the suitability, challenges, and opportunities of using PBL for teaching sociology.

# Thursday 15 September

## 14:00-14:30

### **Patient - Professional Interaction**

#### **Stakeholder involvement and engagement in the development and implementation of Artificial Intelligence technologies in healthcare: A scoping review**

**Beverley Yamamoto, Nisha Shah, Seongeun Kang, Amelia Katirai, Sarah Coy, Kazuto Kato**  
(Osaka University and the University of Oxford)

Artificial Intelligence (AI) technologies are expected to improve and make efficiencies in healthcare delivery, and reduce burden on health systems and clinical stakeholders. However, the impact of healthcare AI is also expected to be disruptive. Therefore, robust stakeholder involvement and engagement activities to guide the roll out and regulation of these technologies are important. This paper reports on a scoping review of stakeholder involvement and engagement around AI in healthcare focusing on English and Japanese-language literature published in or after 2010. The primary inclusion criterion was that stakeholder involvement or engagement around healthcare AI was the main topic of the publication. As a result, 27 papers of 1775 were extracted and analysed. Our aim was to discover who is facilitating any involvement, which stakeholders are being targeted, what methods have been used and what are the outcomes. We found several types of facilitators of involvement/ engagement including efforts from the technology industry, academia, professional and regulatory organizations, and international policy-related organisations. Healthcare professionals (HCP) were more likely to be the targets of activities, rather than patients and the public. Methods of involvement/engagement of stakeholders that we defined as low intensity were the most common mechanisms employed, with little high-level and sustained involvement being facilitated. Recommendations were a frequent outcome of the reported activities. We conclude that, given the complexity of the ethical, social and regulatory concerns, as well as diversify the stakeholder base, there is a need to increase the scope and intensity of engagement about AI technologies in healthcare.

### **Mental Health**

#### **Professional Trajectories of Psychiatrists and Clinical Psychologists in Turkey: In Case of Depression**

**Betul Babacan Sevim**  
(Turkish-German University)

Studies on the approach of healthcare professionals to psychiatric patients have an important place in medical anthropology and medical sociology literature. In Turkey, most of the studies handle the attitudes of healthcare professionals towards patients in the context of stigmatization or exclusion. It is rarely the work that led to the discussion of the effects of specialization education on practical diagnosis and treatment of psychiatric disorders. Patients treated with the principles of diagnosis and treatment of psychiatric institutions show a parallel shift in the world and Turkey. The process of mental health professionals defining people with mental problems as sick or healthy creates a biopower mechanism on individuals by sharpening the distinction between normal and pathological. This mechanism affects the whole society by going beyond individuals. In this study, common psychiatric practices in Turkey are discussed in relation to the professionalization process of psychiatrists and clinical psychologists. It is analyzed in the contexts of biopolitics and biopower conceptualized by Foucault, and the explanations of Goffman's dramaturgical analysis and framework theory. In this context, qualitative data were collected through semi-structured in-depth interviews with psychiatrists and clinical psychologists. The recording of the interviews with 6 psychiatrists and 5 clinical psychologists was included in the

discussion by making text analysis. Finally, this study aims to contribute to the literature on depression studies in Turkey with an emphasis on role, authority, and mental healthcare policies.

## **Experiences of Health and Illness**

**“It’s being believed!” Attempting to resist the medical discourse and advocating for oneself in the narratives of fat body positive individuals.**

**Rachele Salvatelli**

(University of York)

The impact of the medical discourse in framing issues concerning “obesity” has been widely discussed both in medical sociology (Lupton, 2013; Throsby, 2009; Tischen and Malson, 2008) and fat studies (Farrell, 2011; Murray, 2008; Oliver, 2006). However, these works have not fully addressed personal accounts of medical experiences within the fat community. In this paper, I analyse health stories of fat body positive individuals. My findings suggest that adopting a positive outlook on one’s fat embodiment does not wash away the intricate web of meanings and attributes attached to fatness. The complexities, contradictions and ambiguities presented in fat body positive individuals’ health stories display the extent to which the medical discourse is difficult to resist, but also it shows an overall messiness when dealing with health experiences. This paper, by closely examining health stories, sheds new light on the rarely acknowledged issue of fat individuals and their attempts to resist the medical discourse.

## **STS and Medicine**

**Neurodiversity and brain plasticity**

**Tomoko Tamari**

(Goldsmiths, University of London)

The paper discusses the brain as an interdisciplinary research topic which creates the opportunity to understand the significance of neurocultural intervention not only for contemporary medicine, but also for medical discourse.

The brain is plastic, as Catherine Malabou (2008) writes, ‘it designates suppleness, a faculty for adaptation, the ability to evolve.’ The plastic brain can be continuously modified itself and modify its environment. The environment here includes the biological, the social, the cultural and the political fields. Hence, the notion of plasticity challenges biological reductionism and neurological determinism and brings up the view of socio-political constructionism into the brain discourse. Recently, neurointelligence research has played an important role to better understand the discourse of the diversity and plasticity of the brain. Although this approach seeks to investigate the neural basis of cognitive development and intelligence, their analytical theory closely resonates with Malabou’s notion of the plastic brain. They examine how ‘the brain updates its internal models or alters the environment by active inference’ (Nagai 2021), in order to understand the neurodiversity of the brain, such as autistic brains. How complex information about the socio-cultural ‘environment’ can be translated into neurological mechanism is an open question. Exploring how brain plasticity works in neuroscience can still bring significant medical advances for understanding both physical brain damage, and those who have atypical information processing mechanism (e.g. autism spectrum disorder or ‘prodigious savants’). In this sense, understanding the neurodiversity of the brain embraces the diversity of the neuronal discourses.



## **Experiences of Health and Illness 2**

### **The Impact of COVID on a Rural Community: Access, Cohesion and Wellbeing**

**Jennifer Deane, Sara Macdonald, Gregory Rubin, Peter Murchie, Lorraine Angell, Christina Dobson**

(Newcastle University)

#### Introduction -

COVID presented specific challenges for rural populations; difficulties accessing healthcare services due to distance and a lack of public transport, poor internet infrastructure, isolation impacting mental health, and a loss of community interaction.

#### Methods -

This case study population comprised of patients registered at one rural Yorkshire, serving a population within a remote rural area of approximately 200 square miles.

Fourteen respondents to a survey exploring attitudes to help-seeking in primary care were purposively sampled for interview, to discuss experiences of accessing health care after the pandemic and the impact of Covid-19 on their community. One-to-one interviews were conducted remotely, audio-recorded and transcribed. An inductive analytical approach was undertaken as this is a novel topic.

#### Results -

Five themes were derived from the data.

Theme 1; Healthcare interaction emphasised the importance of trust between the GP Practice and the community. Theme 2 covered perceptions of health and wellbeing. Theme 3 considered the impact of Covid-19 on the rural economy, and the tensions created by the communities' differing economic needs.

Theme 4; Community Interaction and Protection highlighted how the community came together to protect itself whilst also dealing with threat of "outsiders". Finally theme 5; the environment, showed how behaviour and feelings about Covid-19 were shaped by their physical environment.

#### Discussion -

The impact of the pandemic on rural communities was evident in the changes to community interaction and support systems, mental health impacts of loneliness and isolation and worries about financial security for those whose income was grounded in rural tourist economies.

## **Theory**

### **Bodies, machines and much, much more: a post-human understanding of haemodialysis**

**Victoria Cluley, Helen Eborall, James Burton**

(University of Leicester)

The haemodialysis machine is pivotal to the life-giving process of haemodialysis. However, little research has explored the relational aspects of this machine and its wider role in the haemodialysis process. While care offered to haemodialysis patients follows a generally similar pattern it is argued here that haemodialysis is far from homogenous and requires a relational approach to care that accepts and embraces difference and extends beyond biomedical understandings of bodies and treatments. The findings presented are taken from an ongoing process evaluation of a clinical trial to explore differences between daytime and night-time haemodialysis. We draw upon findings from photovoice work and qualitative interviews conducted with 30 haemodialysis patients to consider the relational assemblage that is haemodialysis and explore the differences and similarities between instances of effective haemodialysis care. The participants' talk about the relationship between the body, the dialysis machine, and everything else that supports this life-giving interaction is explored through the lens of new materialist, post-human theory, specifically drawing on the work of Deleuze and Guattari and Rossi

Braidotti. The findings are considered specifically in terms of a relational, more than human assemblage, that while outwardly homogeneous, is fundamentally heterogeneous. We propose, here, that the acknowledgement and acceptance of difference in this complicated, rhizomatic process is essential to the delivery and receipt of effective post-human care.

## **Pedagogy and Methods**

**Whose line by line coding is it anyway? Generating conceptual themes based on researchers top down impressions from the field rather than forensic bottom up coding**

**Laura Sheard, Helen Smith**

(University of York)

Analysis in qualitative health research is increasingly stuck in a quagmire of procedure. Notions of replicability, reliability, impartiality and 'bias' coupled with checklists seem to have displaced what is in essence a creative endeavour. Correspondingly, there seems to be a cultural turn towards the descriptive and the banal being privileged over and above conceptual ideas drawing on empirical data combined with the broader corpus of sociological theory and wider societal debates. Inherent in this is the well-entrenched ritual of forensic line by line coding of fragments of speech in transcripts rather than themes being initially generated by researcher's overall fieldwork impressions.

We put forward two recent case studies of qualitative health research where overarching themes were derived by group discussion among the research team and then tested on the empirical data. Both are three wave, longitudinal interview studies about Covid-19. Study A looked at 18 women's experiences of pregnancy and childbirth during 2020/21. Study B is exploring 80 patient's experiences of living with long-Covid until 2023. The most powerful themes to arise from both studies were sometimes difficult to articulate from line by line coding of transcripts, including themes regarding what was not said. We will compare the different types of findings that arose when line by line coding was undertaken as compared to high level group thematic generation, using Study A. We show the potential for moving away from a traditional 'coding first' approach by reflecting on our analytic experience whilst balancing this with points of caution.

# Thursday 15 September

## 15:10-15:40

### **Patient - Professional Interaction**

**The Palliativisation of dying: A conceptualisation of how palliative care is problematising and transforming dying**

**John MacArtney**  
(University of Warwick)

First founded as a speciality in the UK in 1987, palliative care is a relatively new discipline in biomedicine. The many benefits to those with life-limiting conditions of having specialist pain and symptom clinicians attending to them at the end-of-life are well established. However, palliative care's prominent position in the social organisation of dying is under conceptualised. In this paper I outline an agenda for critically reflecting on the difference that the palliative approach is making to how dying is understood.

I start by identifying the breadth of palliative knowledge and its expansion beyond healthcare contexts. To do this I describe a productive ambivalence I argue drives much of (specialist) palliative care's expansion into contemporary understanding and managing the dying: the paradox of early intervention.

Second, I argue that we need to develop novel conceptualisations of the emerging practices and discourses of dying. To contribute to this, I outline three contemporary features of palliativisation: (1) Qualification of dying (cf Moreira et al, 2020; Wahlberg, 2018); (2) Palliative care as an imagined community; and (3) Dying as a discursive-empowerment problem.

I close by providing some ways to problematise these developments to understanding dying - and reflect on the potential of Covid-19 to act as an accelerant - so to guard against the dangers, and be more aware of the distribution of (dis)advantages, that the palliativisation of dying brings.

### **Mental Health**

**Redefining mental health: Marginalisation and the impact of the Covid-19 pandemic on understandings of mental disorders**

**Richard Jia**  
(Westlake Boys High School and Cambridge Centre for International Research)

Mental health awareness has seeped into mainstream discussions in the past half-century. (Farreras, 2022) The Covid-19 pandemic has accelerated the attention given to mental well-being, as the social restrictions during the lockdown have caused levels of stress, anxiety and depression to increase (Ni et al., 2020). Various governments and organisations have attempted to combat this surge by increasing social awareness of mental disorders relevant to the pandemic, such as anxiety, depression, and stress. These started to be discussed more often, changing definitions of mental health and normality. Within this framework, this research explores the impact of the Covid-19 pandemic on the (re)definition of mental health disorders in New Zealand and worldwide. New Zealand presents a unique case with indigenous cultures' emphasis on well-being, and the government's increased attempts to raise mental health awareness. To study the impact of the pandemic on mental health definitions, I analysed social media content posted during the mental health awareness week in New Zealand and the mental health awareness day around the world, over a period of four years, two before the pandemic (2018 and 2019) and two after (2020 and 2021). 10 most liked and/or viewed posts per year on Instagram with the

hashtags #mhawnz for New Zealand, and #worldmentalhealthday globally have been analysed. Preliminary findings suggest that there is a significant increase in the engagement with mental health related social media content during the pandemic, while marginalising disorders that are regarded as less relevant to the pandemic, such as bipolar disorder and schizophrenia.

## **Embodiment and Emotion**

### **Mad, Bad, and Beautiful: How Women's Accounts of Psychiatric Institutions Create Narratives of Abjection and Discipline**

**Phoebe Greenwood**  
(University of Warwick)

While Barbara Creed revolutionised abject theory in *The Monstrous Feminine*, very little research has since been conducted considering how the abject intersects with the daily life of mentally ill women. Further, as Kristeva herself recognises the innate connection between the feminine and the abject, there is a clear lack in scholarship exploring the intersections between women and the abjected subject. Having conducted a digital ethnography of female psychiatric patients on TikTok, I examine the extent to which: 1) mentally ill women within psychiatric institutions are forced into the role of the abject woman; 2) instances of abjection that arise within psychiatric institutions consequently result in strained patient-staff member relationships; and 3) these instances of abjection consequently result in increased discipline and ultimately hinder patients' treatment. These findings indicate that instances of the abject that occur within female patients often result in increased use of restraints and sedatives, and similarly that the abjected woman's autonomy within the psychiatric institution is always at threat. Ultimately, these findings illuminate women's mistreatment within psychiatry, highlighting the possible misogynistic thought that continues to permeate such institutions and practices.

## **STS and Medicine**

### **How do scientists define humanness? A qualitative study of human organoid model systems in biomedical research.**

**Sara Bea, Amy Hinterberger**  
(King's College London (KCL))

In this presentation we examine how biotechnology reframes notions of humanness and we consider the implications for human health applications. We do this by examining the scientific practices and promises of a stem cell-based biotechnological innovation poised to revolutionise the study of human disease and development. That is, organoids which are three-dimensional multicellular living systems, made with human stem cells, that recapitulate in vitro the form and function of the corresponding human organ in vivo. Organoids offer human-specific models considered more physiologically relevant than animal models and more accurate than two-dimensional cell lines. To unpack the crucial notion of humanness that underpins the prominent scientific purchase garnered by organoids, we turn our analytic attention to the accounts and experiences of biomedical researchers working with organoids. Through multi-sited ethnographic research in organoid labs and 22 semi-structured interviews we explore how biomedical researchers model, enact, and accomplish humanness within organoid model systems. In doing that, we identify four themes that characterise researchers' enactments of humanness: approximation, substitution, simplification, and diversification. Drawing on our findings, we explain that organoids are transforming the pursuit and delineation of human-specific models of disease and development, and we unpack the many ways that humanness comes to be modelled, approximated and acted upon in biomedicine. We argue that the humanness of organoid models is neither a given nor a generic category. Rather, the human privileges of organoids are built-in and accomplished in culture at the lab site and hinge upon many critical decisions that require sociological scrutiny.

## **Experiences of Health and Illness 2**

### **A UK-Japan comparison of the gendered care burden of children with complex medical needs during COVID-19 pandemic**

**Ikuko Tomomatsu, Beverley Anne Yamamoto, Carol Rivas**

(Osaka University and University College London)

Many actors are involved in ensuring that children with complex medical care needs (C-CMCN) enjoy the highest possible quality of life. This study sought to understand how the COVID-19 pandemic had impacted the care burden for the parents of C-CMCN in Japan and the UK, two countries very differently positioned in relation to gender equality indices. This paper reports on interview and digital ethnographic data collected from 7 family carers of C-CMCN in Tokyo and 3 family carers in London, with 2 children also interviewed about family relationships. The data was collected between February and May, 2021. Of the six Japanese families, the mother was the primary carer for five of the children. Only two of the mothers had been able to continue their careers. Schools closures during the pandemic led to greater use of remote learning, which reduced some of the physical burden of going to school, but increased their responsibilities for overseeing their child's learning, play and stress management. Emergency measures increased their sense of isolation. In the UK, the key differences were that fathers played an important role and that both parents reported struggling between having time to attend to the child's needs and at the same time keeping their jobs. Bonds between fathers and children were strengthened. This small study suggests differences in the gendered division of labour for the care of C-CMCN between the two countries and that the pandemic shifted the nature of the burden for carers.

## **Theory**

### **Understanding safety as a fluid accomplishment of situated practice: perspectives from Social Practice Theory**

**Sarah Chew, Elizabeth Sutton, Nici Mackintosh**

(Sapphire research group: University of Leicester)

Following recent 'scandals' within healthcare settings, efforts have been made to improve safety and 'Safety Culture'. Many interventions have been delineated and implemented, but evidence for their efficacy remains patchy: sometimes they work and sometimes they don't. Failure is often seen as a function of contextual lack, e.g. of; fidelity, capacity, engagement, expertise, time, resources etc. Implicitly, interventions are neutral and can work anywhere as long as local lacunae are remedied and fidelity is maintained, but filling the gaps does not always prove effective either, resulting in wasted time, resources and goodwill.

Here, we argue that to understand how safety works and how to improve it, we may need to step back from traditional process orientated perspectives that focus on safety as a stable state that can be achieved by engineering interventions into context. Instead, we may gain a better understanding of safety as a fluid accomplishment of situated practice. To do so, we propose that Social Practice Theory (SPT), which has already been shown to be analytically fruitful in the context of environment and risk studies, can bridge the conceptual gap between intervention and context by framing 'safety', 'safety culture' and improvement interventions as connected 'arrays of human activity'. Thus, our mode of enquiry become holistic and ethnographic, sensitive to the meanings, materials and competencies that make up safety-in-action. We explore this theoretical framing using qualitative data from a safety cultures in maternity project to highlight utilities and contradictions (theoretically, empirically and practically) for safety culture research.

## **Pedagogy and Methods**

### **Medical imperialism, sociological imperialism? The politics of reporting guidelines**

**Judith Green, Sara Papparini, Sara Shaw**

(University of Exeter)

Biomedical journals typically require submissions to conform to reporting guidelines for the type of study (qualitative, systematic review, survey, etc). Such guidelines – which we term here ‘reporting technologies’ - have proliferated in recent years, along with increased standardisation of academic research processes. Debates in sociology of health have typically focused on these as examples of the hyper-bureaucratisation of research, and on the awkwardness of aligning diverse approaches, thick description and theoretical insights to checklists. However, taking Susan Leigh Star’s insight that infrastructure is both ‘transparent and opaque’, we argue that, like any infrastructure, the ‘work’ that guidelines do is both explicit (in prioritising, for instance, the publication of certain kinds of research within the health evidence base) and also implicit, in the ways in which norms become sedimented and black-boxed in reporting technologies. Reporting guidelines are therefore not simply an instance of ‘medical imperialism’ in their work in prioritising particular designs, or shoehorning ethnographic or qualitative work into a medicalised model of evidence production. They can also be objects of ‘sociological imperialism’ (Strong 1979), including overt political moves to legitimate particular designs and extend professional reach into health and medicine: through developing a guideline, for instance, or contributing to revisions such that the use of social science is highlighted. Reflecting on our experiences of developing guidelines (for Case Study research and for Natural Experiment Evaluations), we point to the politics of mundane research infrastructure, and the ways in which these can be sites of resistance as well as co-option.

# Thursday 15 September

## 15:45-16:15

### **Patient - Professional Interaction**

**Medical mediators, brokers of knowledge or commercial actors? Mapping intermediaries in the new oocyte economy**

**Nicky Hudson**  
(De Montfort University)

Whilst there is a growing scholarship that explores third party involvement in the brokerage of medical travel, less attention has been paid to other forms of commercial medical facilitation. In the context of egg donation, what work does exist comes from the US where it is argued market forces shape practice. More recently, a range of intermediaries has begun to emerge in the European context; offering new forms of mediation between egg providers, clinics and egg recipients, and giving rise to a more diverse and increasingly commercialised geography of provision. Since these intermediaries often operate outside the medical field, they pose pressing questions related to their governance and oversight.

This paper considers the reasons for these developments in the European context and maps the new configurations of mediation and exchange they represent. Taking three national case studies – the UK, Spain and Belgium – it examines how the traditional link between the donor and the recipient that underpins most of the existing national regulations in Europe, is being disrupted. Drawing on policy mapping, online marketing analysis and interview data from across the three national study sites, we illustrate how these developments have significant implications for egg donation policy and egg provider welfare, as well as for wider understandings of the fragmentation of traditional healthcare pathways and their co-ordination by a range of commercial and non-commercial actors.

### **Mental Health**

**Sharing the Narrative - Resistance, Resilience and Anger.**

**Chantelle Taylor**  
(Loughborough University)

This paper is a resistance of the current motherhood ideology. Drawing on feminist theory to underpin the lived experiences of the researcher, this paper illustrates how I, a mother of three, have suffered and continue to live with depression and anxiety. In order to contribute to the vital work in medical sociology on motherhood and mental health, this paper will use autoethnography to emphasise and validate my own subjective experiences of maternal mental health (MMH) issues to create a counternarrative to the dominant societal discourse on good motherhood. This paper uses a feminist methodology to empower women and aims to create much needed social change.

Habitually academics hide away their personal lives, in order to appear objective and scientific. Through rigorous analysis of my own lived experiences of MMH issues I explore how MMH struggles can be a reaction to the overlapping pressures of modern womanhood and idealised good motherhood. By placing women's experiences and voices at the centre of the research, I embrace the resistance, the resilience, and the anger of women.

Bringing together literature in medical sociology on motherhood and mental health, I argue that through reflecting on and sharing our narratives, we can resist the common-knowledge and the disparaging discourses that keep us, mothers, oppressed. Further, rooted in my anger and dissatisfaction of what

is deemed good scholarly work, this paper will also challenge the 'good researcher' discourse, using matricentric feminist autoethnography as a resistance to both the institution of motherhood and the ivory tower of academia.

## **Inequalities and Intersectionality**

### **Black Voice on Contraception Choices and Access to Sexual Health Services**

**Shardia Briscoe-Palmer, Julia Baily, Annabel Sowemimo**

(University of Nottingham)

There have been racial disparities within sexual and reproductive health (SRH) amongst Black, Asian, Minority and Ethnic (BAME) groups living in the UK for several decades. Whilst we must acknowledge that there are significant differences within this umbrella; being racially marginalised plays a significant role in how groups experience SRH. Black people experience some of the worst sexual and reproductive health outcomes in the UK, and Inequalities and Intersectionality have widened during the Coronavirus pandemic. Accessing healthcare is increasingly difficult, and there are extra barriers for Black people because of structural, institutional and interpersonal racism. The Black Voices project highlights ways that the NHS (National Health Service) can fail Black people.

We held online interviews and focus groups with Black people and have produced short videos which highlight their experiences of contraception and of sexual health services in England. The videos feature Black voices on contraception choice (including the pros and cons of different contraception methods) and Black voices on experiences in sexual health services. Participants in the Black Voices project described a lack of appropriate treatment, inaction or poor-quality care, disrespect, discrimination, stereotyping, and lack of appropriate 'cultural' awareness. Participants described experiences of racist assumptions, stereotypes and judgmental attitudes within sexual and reproductive healthcare. These kinds of experiences make people less likely to trust healthcare services, and less likely to engage with testing, screening, and treatment.

## **Embodiment and Emotion**

### **Can a public health perspective on place of trauma in functional seizures and related conditions help to answer the question, "Why women"?**

**Marian Peacock**

(Edge Hill University)

Studies consistently show that women make up the majority of those diagnosed with medically unexplained symptoms and functional conditions with this gender divide being most marked in functional seizures (also known as Non-Epileptic Attack Disorder- NEAD) where over 75% of those so diagnosed are female. Functional seizures present as embodied experiences often appearing similar to epilepsy, but when further investigated, there are none of the bodily changes associated with epilepsy. Given how strong the association is, there is a surprising gap in the literature where this link with female gender is explored in non-biomedical ways. Whilst the connection with sexual trauma arguably goes back to Freud, its centrality and salience as an explanator in functional conditions has waxed and waned. More recently the DSM-5 has moved to remove traumatic precipitants from its definition of functional or conversion disorders with a recent review apparently evidencing this (Ludwig et al 2018).

Drawing on data from a small explanatory study using narrative methods as well as the wider contemporary literature, we look at the place of trauma (and where trauma may well be absent) and specifically at sexual trauma in both childhood and adult life and what its place might be in understanding functional seizures. We also begin to grapple with why so little interest has been paid to this link in mainstream functional neurological research and propose some future directions to better understand this.



## **Experiences of Health and Illness 2**

### **In the (Dog) House of Care: Navigating self-management of long-term conditions/disabilities with the use of assistance dogs as guides**

**Grainne O'connor**

(The Open University)

The use of specially trained assistance dogs (ADs) by people living with a wide range of physical, psychological, sensory and mental conditions/disabilities (PWDs), is a culturally situated and rapidly expanding phenomenon. However, research in the field of Human-Animal Interactions in Disability (HAI-D) is beset with issues around methodological rigour and interdisciplinary confusion. In the UK there are more than 7,000 AD/Human partnerships accredited by ADUK - a coalition of ten non-profit assistance dog organisations, who train and provide ADs to PWDs for free. Membership of ADUK denotes high standards of assistance dog training, welfare and appropriate use of funds donated by the general public. An imbalance between the supply of ADs and demand from PWDs has resulted in a large increase of for-profit AD training organisations and owner trained ADs. Some of these have negatively impacted on the welfare of the dogs and the loss of vulnerable families' money. Equally, the use of 'fake' assistance dogs undermines public confidence in those who use ADs creating hostility and potentially limiting public access to services by PWDs. In this paper the following interrelated, interdisciplinary and interspecies questions are explored drawing on the author's own qualitative, insider research with participants from ADUK charities and research from medical sociology, HAI-D studies and critical disability studies. Why are PWDs turning in increasing numbers to assistance dogs to help self-manage their long-term conditions/disabilities? Are PWDs experiences of psycho-emotional disablism in our society indicative of the need to have a dog to be seen as a human?

## **Theory**

### **Place, health and dis/advantage: a posthuman analysis**

**Katie Powell, Nick Fox**

(University of Sheffield)

This paper presents a novel approach and method for researching 'places' (in relation to health Inequalities and Intersectionality) not simply as physical localities, but as sociomaterial assemblages of diverse human and non-human matter, imbued with social and power relations. We begin by offering a typology of the literature on place and health in terms of a material/social dualism. We critique this dualism and develop a new materialist and more-than-human alternative to understand 'place', 'health' and 'social position'. We use this framework to establish a methodological approach, and then apply this to a dataset of in-depth qualitative interviews, from which we draw out three illustrative place-assemblages, and explore the human capacities that place-assemblages produce. We conclude by discussing the implications of this approach for the study of place, health and dis/advantage.